AIDS IN TEXAS:

FACING THE CRISIS

LEGISLATIVE TASK FORCE ON AIDS

REPORT TO THE SEVENTY-FIRST LEGISLATURE

JANUARY 1989

ACKNOWLEDGEMENTS

The Legislative Task Force on AIDS expresses appreciation for the contributions of countless citizens, associations, state agencies, and organizations. In particular, the Task Force is indebted to:

- The courageous and dedicated people who publicly testified about the impact of HIV infection on their lives, many of whom died during our year-long study.

- Members of the Presidential Commission on the Human Immunodeficiency Virus Epidemic, especially Ms. Kristine Gebbie and Dr. Burton Lee, for their invaluable insights and suggestions.

- Dr. Palmer Beasley, Dean, and the faculty and staff of the University of Texas School of Public Health at Houston for their tremendous assistance with the Task Force's surveys, epidemiologic analysis, and cost projections.

- The Texas Hospital Association, the Texas Association of Public and Nonprofit Hospitals, the Texas Department of Health, and the Texas Department of Human Services for their assistance with the survey of Texas hospitals.

- The State Board of Insurance for their survey of health insurance carriers and health maintenance organizations.

- Southwest Texas State University for their assistance with the statewide survey of Texans with HIV infection.

- Members of the Dallas County AIDS Planning Commission for their comprehensive assessment of policy and service delivery needs.

- The numerous Texans with HIV, hospitals, community service providers, insurance companies, health maintenance organizations, and state agencies that responded to the Task Force's surveys and inquiries.

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". . . I had not thought death had undone so many."

T.S. Eliot
The Wasteland

Legislative Task Force on AIDS

The Honorable William P. Hobby, Jr.,
Lieutenant Governor

The Honorable Gibson D. (Gib) Lewis,
Speaker of the House

Dear Governor Hobby and Speaker Lewis:

On behalf of all of the members of the Legislative Task Force on AIDS, I hereby submit our Final Report.

Just over one year ago, you appointed the 19-member Task Force and directed it to recommend to the 71st Legislative Session public policies needed to reduce dramatically the current and projected impact of AIDS and HIV infection upon Texas' population and resources. In so doing, you required that special attention be given to the economic burden incurred by the HIV epidemic; the health and human service needs of people with HIV infection; the development of human and institutional resources for the provision of adequate care; the State's role in financing the cost of HIV-related services; and the study of alternative methods of financing by which needed services may be made available, accessible, and cost-effective. This Final Report is believed by all members to have fulfilled the responsibilities outlined in your charge to the Task Force.

It has taken more than 12 months of extensive research, analysis, public testimony, first-hand observation, and deliberation for the Task Force to develop the findings and recommendations detailed herein. In the course of its efforts, the Task Force directly benefitted from the timely release of a number of authoritative statements and actions on AIDS and HIV by our national leadership.

These include the Surgeon General's Report (1987), the Report of the Presidential Commission on the Human Immunodeficiency Virus (June 1988), the HIV policy of the American Medical Association (1988), the Report of the National Institute of Medicine (1988), and, most recently, the passage of the Omnibus Health Act by Congress (October 1988). While these documents differ in emphasis

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and focus, together they constitute the best of all medical, scientific, public health, and public policy expertise in our nation. We of the Task Force are confident that our report and the measures it recommends on every front are squarely placed in the mainstream of the soundest wisdom and guidance available. On the other hand, the uniqueness and diversity of Texas and the peculiar epidemiology of HIV in our state suggest that not all answers can be found at the national level.

In many instances, Texas must forge its own solutions, drawing on the abundance of skill, knowledge, resources, and initiative which so aptly characterize our state's history. Today, with the full force of the HIV epidemic positioned against us, Texas must again fight for the welfare of its people and the common good. Among the most profound lessons the epidemic would teach our society is that when we cannot cure, the mandate to care is all the more imperative. This mandate made itself relentlessly known in the faces and heartrending stories of Texans who took the courage to witness publicly to the ravaging impact of this epidemic and its consequences on their lives. Many of these citizens, or those on whose behalf they spoke, have since died.

Neither the darkness of human tragedy and loss nor the insidiousness of a fatal virus can obscure the spark of hope and human goodness manifest in the heroic struggles and achievements of those who are engaged in the battle against AIDS and HIV. Throughout the state, scientists, local health officials, service providers, volunteers, and religious communities are working in concert to shoulder the largest burden of treatment and services for people with HIV. Typically, these efforts are poorly sustained, if at all, by state resources. Without assistance, such private initiatives will soon be exhausted, leaving no other programs in their stead.

The steady and alarming rate by which the HIV epidemic continues to increase in our state has been described by a leading public health expert as the Tsunami, or tidal wave, of the future.[1] The prospect of 45,000 Texans dead or dying from AIDS within four years is terrible to contemplate in itself. In the absence of effective and far-reaching education about prevention, there is nothing to counter the likelihood of further increases in 1993 and beyond.

The HIV epidemic has provided Texas' leadership with the unsolicited opportunity to rediscover what is our State's role in the protection of public health, and to rededicate ourselves to that end.

Respectfully,

Chris C. Steele

The Rev. Chris C. Steele

Legislative Task Force on AIDS

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> AIDS demonstrates how economics and politics cannot be separated from disease; indeed, these forces shape our response in powerful ways. In the years ahead we will, no doubt, learn a great deal more about AIDS and how to control it. We will also learn a great deal about the nature of our society from the manner in which we address the disease. AIDS will be a measure upon which we may calibrate not only our medical and scientific skill but our capacity for justice and compassion.
>
> No Magic Bullet[2]

Acquired immunodeficiency syndrome (AIDS) constitutes a public health crisis in the State of Texas. In a competition no one wants to win, Texas is fifth among all states in the number of people reported to have AIDS. To put that national ranking into perspective, consider the following statistics:

- Houston leads 45 states in the number of people with AIDS.
- Dallas surpasses 42 states in the number of people with AIDS.
- Since 1986, AIDS has been the leading cause of death for men between the ages of 25 and 44 in the Houston area.
- The AIDS epidemic, however, is not just an urban problem. More than half of Texas' 254 counties, the majority of them rural, have reported cases of AIDS.

More than 2,500 Texans have been diagnosed with AIDS since the 70th Texas Legislature convened in January 1987. In the next four years the number of Texans who become ill or die from AIDS will continue to increase dramatically. By the end of 1992, one in 10 Americans with AIDS will be a Texan. By then, 45,000 men, women, and children in our state are expected to be diagnosed

with the disease. This number is comparable to the total battle deaths of American forces in Vietnam. The number of Texans infected with HIV but not yet diagnosed with AIDS is far greater and represents the real extent of the epidemic. An estimated 100,000 Texans are infected with HIV. Many, if not all of them, will develop severe illnesses and disabilities and ultimately will die from complications of HIV infection. The devastating toll of this epidemic is exacerbated by the tragic fact that a cure for HIV infection has not been discovered.

The 120 recommendations contained in this report cover a wide range of issues which together constitute the HIV crisis in Texas: treatment and services, financing, education and prevention, legal issues, coordination and planning, workplace issues, and research. The recommendations are based on 12 months and hundreds of hours of research, public testimony, site visits, interviews, and deliberation. Given the diversity of viewpoints and expertise among the Task Force members, it is noteworthy that nearly all of the recommendations contained herein received the unanimous endorsement of members.

The charge given to the 19-member Task Force by Lieutenant Governor Hobby and Speaker Lewis called for special attention to the economic, health care, and human service problems imposed by this epidemic on our state's resources and population. In addressing these areas of concern, the Task Force discovered that Texas' traditionally underfunded and poorly structured public health and human service system has directly interfered with a swift and ef-

fective response to the epidemic. The myriad of HIV-related needs in Texas cannot be addressed apart from the serious funding and service delivery problems inherent to our state's health and human service system. AIDS and HIV should be regarded no differently than other serious health and human service problems. But because of the social stigma unfortunately associated with HIV infection and the geometric rise in the number of people with HIV-related illnesses, extraordinary measures and immediate action are imperative. The foundations for a successful state strategy must be laid before the end of the 71st Legislative Session. In two years, when the Texas Legislature convenes again, the number of Texans diagnosed with AIDS will have increased at least four times.

The HIV epidemic imposes an economic burden on the State of Texas, on health care providers, and on individuals with HIV infection.

- State and local tax revenue lost due to premature deaths from AIDS alone was $110 million to $170 million in 1988. By 1992, the tax loss is expected to more than triple, ranging between $370 million and $615 million.
- In 1987, Texas hospitals averaged a net daily loss of $137 for people with AIDS. Hospital costs for AIDS care will increase from the range of $88.5 million to $102.7 million in 1988 to between $380 million and $530 million in 1992.
- The median annual income of Texans with AIDS who were surveyed by the Task Force declined from $20,000 to $6,000. Over half of the survey respondents with AIDS also reported spending their entire savings to pay for their illness. The proportion of those dependent upon county indigent health care facilities rose from 8 percent to 33 percent.

The recommendations of the Legislative Task Force on AIDS provide an initial strategy with which to battle this epidemic. This report does not claim to offer exhaustive analyses of all HIV policy and funding issues facing the State of Texas. There remain numerous other issues that go beyond the scope of the Task Force's charge but which must be addressed. These include, for example, a comprehensive analysis of legal issues, the evolving effects of dementia on health care and social services, and the impact of federal funding and other regulations on our state.

Generally, the Task Force's recommendations encompass three overall objectives:

1. to halt or slow the spread of HIV.
2. to provide appropriate and cost-effective care for those infected with HIV.
3. to protect the rights of infected and non-infected people.

PRIORITY RECOMMENDATIONS

The following is an overview of the major recommendations contained in subsequent chapters of this report.

The health, productivity, and self-sufficiency of people with HIV should be promoted by:

- Eliminating discrimination against people with HIV and their caregivers.

- Improving access to health and social support services, especially those that provide cost-effective alternatives to hospitalization.

- Increasing the scope of services available through Medicaid and broadening eligibility criteria for Medicaid services.

- Improving the availability and scope of private health insurance.

- Implementing a high-risk health insurance pool for people with catastrophic illnesses.

- Expanding the availability of experimental therapies for HIV-related conditions and other progressively fatal illnesses for which there are no known cures, such as through the enactment of legislation that would enable the testing and use of drugs manufactured in Texas.

- Expanding funding for the state grant program for HIV services under the Texas Department of Health.

<u>HIV education and prevention activities should be improved by:</u>

- Expanding the availability and quality of HIV counseling and testing services.

- Expanding the availability of substance abuse intervention programs.

- Promoting and funding HIV education programs, with attention to the sociocultural, behavioral, language, age, and financial characteristics of the intended audiences.

- Requiring comprehensive health education in kindergarten through the 12th grade.

Coordination and planning of HIV services should be improved by:

- Promoting consistency of state policies regarding HIV.

- Promoting regional planning and development of HIV services.

- Establishing a follow-up effort to the Legislative Task Force on AIDS to monitor implementation of the Task Force's recommendations, to maximize the availability of federal funds for HIV services, and to promote effective, broad-based planning of HIV education, prevention, treatment, social support, and research programs.

ACTIVITIES OF THE TASK FORCE

In response to the rising impact of AIDS on the State of Texas, Lieutenant Governor William P. Hobby, Jr. and Speaker of the House Gibson D. (Gib) Lewis appointed the Legislative Task Force on AIDS in the fall of 1987. The Task Force was directed to recommend to the 71st Legislature public policies needed to reduce dramatically the current and projected impact of AIDS on Texas. The charge to the Task Force called for special attention to:

- The current and anticipated economic burden of AIDS in Texas.
- The current and future health care and social service needs of people with AIDS and HIV infection.
- The development of human and institutional resources needed to care for people with AIDS and HIV infection.
- The State's role in financing the care of AIDS patients.
- The study of alternative financing to increase the availability, accessibility, and cost-effectiveness of services.

In addition to numerous site visits, presentations, interviews, and state agency surveys, the Task Force conducted regional public hearings in Arlington, Lubbock, Houston, Austin, El Paso, Lufkin, Weslaco, and San Antonio. Additionally, the Task Force conducted two special public hearings on substance abuse and on HIV-related concerns of ethnic and racial minorities and people with disabilities. The abundance of testimony presented by nearly 300 witnesses is central to the findings and recommendations contained in this report.

To assess the effect of the HIV epidemic on the state's resources and to determine what services are available and needed, the Task Force initiated the following research projects:

- All Texas hospitals were surveyed to document the extent of third-party reimbursement and the cost of caring for people with HIV infection. The project was conducted with the assistance of the Texas Hospital Association, Texas Association of Public and Nonprofit Hospitals, University of Texas School of Public Health, Texas Department of Health, and Texas Department of Human Services.

- On behalf of the Task Force, the State Board of Insurance surveyed Health Maintenance Organizations and major carriers of individual and group health insurance policies in Texas to document the availability of coverage and the claims being made for HIV-related services.

- With assistance from the University of Texas School of Public Health, providers of community-based health and social support services were surveyed to document the availability and cost of HIV-related services.

- People with HIV infection were surveyed to document the effect the virus has had on their lives and to identify needed services. The survey was conducted with assistance from the University of Texas School of Public Health and Southwest Texas State University.

A synopsis of the methodology used for each survey is included in the appendices of this report.

BRIEF MEDICAL OVERVIEW OF HIV AND AIDS

Description of HIV Infection

The human immunodeficiency virus (HIV) is the third member of a recently discovered family of RNA viruses, also known as retroviruses. First identified in the early 1980s, HIV is the cause of Acquired Immunodeficiency Syndrome.

HIV is capable of infecting humans and slowly destroying a person's immune system. The immune system normally protects people against micro-organisms that cause disease. As HIV attacks white blood cells and other essential components of the immune system, an infected person's ability to fight disease is severely diminished.

The HIV-infected person becomes vulnerable to infections that are otherwise easily suppressed by a well-functioning immune system. These "opportunistic" infections can be caused by bacteria, protozoa, and viruses. Additionally, there is a high occurrence of "opportunistic" malignancies that can occur separately or in conjunction with opportunistic infections.

There are other debilitating diseases that can accompany these two major sets of complications in people with HIV. One of the most devastating is dementia and other neurological problems that occur when HIV infects the central and peripheral nervous systems.

Definition of AIDS

The ultimate consequence of HIV infection and a weakened immune system is Acquired Immunodeficiency Syndrome. "Acquired" means the disease is not inherited, but rather is transmitted. "Immuno" refers to the body's immune system which protects an individual from disease. "Deficiency" signifies that the body's defense system is impaired. "Syndrome" refers to a particular set of symptoms which, when occurring together, indicates a disease that has a standardized definition.

The U.S. Centers for Disease Control (CDC) have classified the disorders caused by HIV and have carefully defined the specific criteria for the diagnosis of AIDS. As the epidemic of HIV progresses, the list of disorders associated with HIV infection is expected to expand. The current CDC definition of AIDS appears in the appendices of this report.

Transmission of HIV

Transmission of HIV is possible in only three ways:

1. Sexual intercourse between an infected person and a non-infected person.

2. Transmission of blood from an infected person to a non-infected person, as between people who share hypodermic needles and syringes or through transfusion of infected blood or blood products.

3. Between an infected mother and her infant during pregnancy, delivery or, less frequently, nursing.

HIV is a fragile virus, easily destroyed by such common disinfectants as household bleach. There is no evidence that the

virus is spread by casual contact, that is, sharing food, cups, or clothing; through coughing or sneezing; or by insects.[3]

After exposure to HIV, it can take up to six months for commonly used tests to determine the presence of antibodies to HIV. However, most people infected with HIV will develop antibodies between four to six weeks after exposure to the virus. Even before a test can detect the presence of HIV antibodies, the virus can still be transmitted. Research indicates that the incubation period (the period between infection and the development of symptoms) may be as long as five years or more. Once people are infected with HIV, they are infected for the rest of their lives and remain capable of infecting others.

Stages of HIV Infection

The stages of HIV infection are classified as:

- Acute onset of infection, sometimes accompanied by temporary mononucleosis-like symptoms.

- HIV asymptomatic infection or HIV seropositivity, which denotes infection with an absence of symptoms.

- HIV infection and related disorders, which describes a wide range of symptoms, some of which are very severe and disabling, that do not meet the diagnostic criteria for AIDS established by the CDC. This stage of infection is sometimes classified as AIDS-Related Complex (ARC).

- AIDS.

A recent study in San Francisco indicates that up to 75 percent of people with HIV infection will develop AIDS.[4] These results,

in conjunction with other research, support the prediction that the majority of people infected with HIV will eventually develop AIDS.

Symptoms of HIV Infection

Frequent symptoms related to HIV infection typically include persistent fevers, chronic fatigue, diarrhea, swollen lymph nodes, night sweats, skin rashes, significant weight loss, and fungal infections of the mouth and throat. People infected with HIV may show no symptoms for months or even years. Furthermore, an infected person may show symptoms of illness, yet not exhibit the specific disorders required for a diagnosis of AIDS.

Opportunistic diseases in people with AIDS are difficult to treat, often recur, and frequently require repeated hospitalizations. The most common causes of death for people with AIDS are opportunistic infections; one of the most frequent is Pneumocystis carinii pneumonia. Kaposi's sarcoma and non-Hodgkin's lymphoma are the two opportunistic malignancies most frequently associated with AIDS.

Treatment Issues

The diagnosis of AIDS is a virtual death sentence. More than 95 percent of all people in the United States who have been diagnosed with AIDS for two years or more have died. For adults in Houston alone, the median length of survival from diagnosis to death is less than nine months.[5]

At the present time, there is no cure or vaccine for AIDS or HIV infection. However, recent advances in the treatment of opportunistic infections and in the development of drugs with anti-HIV activity, such as AZT (zidovudine or Retrovir), are prolonging some lives. Early detection of HIV infection, in conjunction with preventive therapies and an emphasis on healthy lifestyles, appears to delay the onset of opportunistic infections.

Since no therapies exist that eliminate the virus or completely reverse the damage HIV causes to the immune system, people with AIDS develop repeated -- and ultimately fatal -- opportunistic infections and malignancies. It is expected that as scientific advances occur which will improve the treatment of HIV, people infected with HIV will be diagnosed earlier and live longer.

EXTENT OF THE EPIDEMIC

> People have AIDS. Statistics about cases are people.... We must not lose sight of the fact that all the numbers, all the programs, and all the issues really are about people.
>
> Chair, City/county AIDS panel
> Houston hearing

The rapidly increasing number of people with AIDS is what identifies this public health problem as an epidemic. AIDS statistics change daily. Consequently, the information contained in this chapter will be out of date by the time this report is published. Before quoting epidemiologic data contained in this report, readers are advised to obtain current national and state statistics from the AIDS Division of the Texas Department of Health.

National Statistics

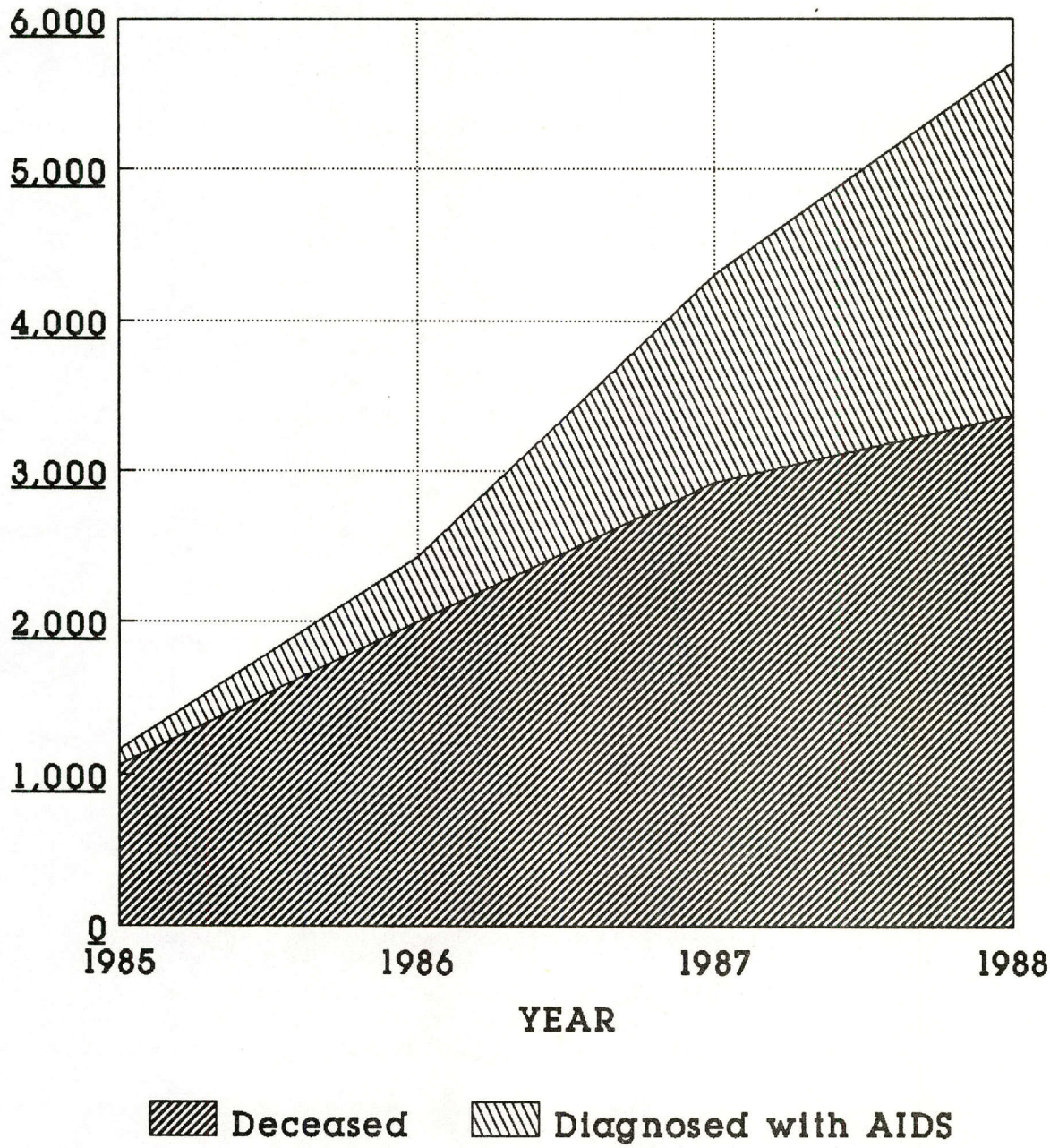
AIDS was first recognized in the United States in 1981. By January 1989, more than 82,700 Americans were reported to have AIDS. By 1992, a cumulative total of more than 300,000 Americans will be diagnosed with AIDS, according to the U.S. Public Health Service. The U.S. Centers for Disease Control estimates that up to 1.5 million Americans are infected with HIV. Most are unaware that they have the virus.

Texas Statistics

Since 1981, more than 5,800 Texans have been diagnosed with AIDS. Nearly 60 percent of those reported to have AIDS have died (Figure 1). In the 12 months of the Task Force's study, more than 2,000 Texans were diagnosed with AIDS. Texas now has more deaths

Figure 1

TEXANS WITH AIDS



Source: Texas Department of Health
Weekly Surveillance Reports

from AIDS than it had reported cases during the last legislative session. Since 1986, AIDS has been the leading cause of death in 25- to 44-year old males in Houston.[6]

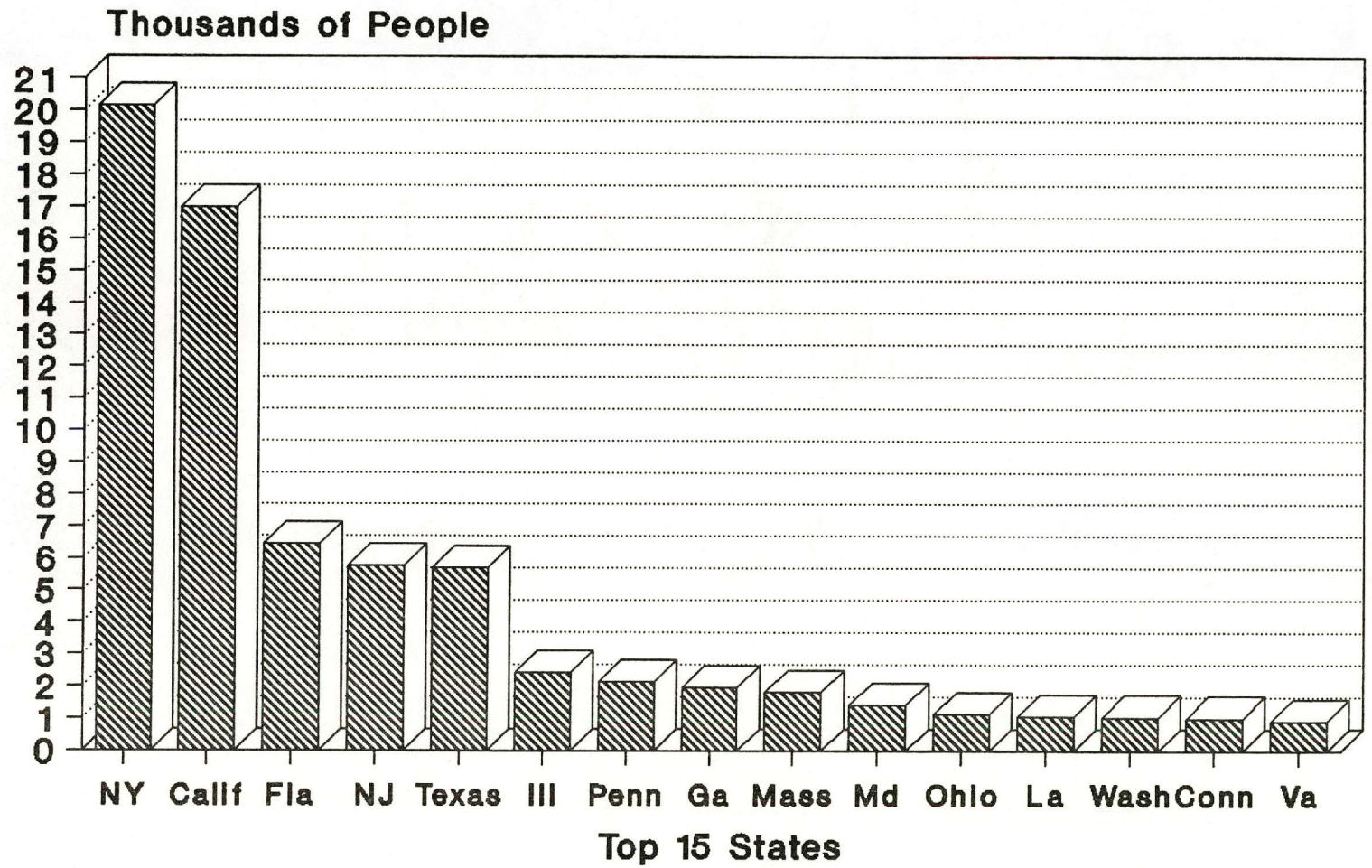
Using data from the Texas Department of Health and epidemiologic models from the CDC, the University of Texas School of Public Health predicts that by the end of 1991 as many as 30,000 cases of AIDS may be reported in Texas. By the end of 1992, a total of 45,000 cases are anticipated. One in 10 Americans with AIDS will be a Texan in 1992.[7]

As of January 9, 1989, Texas ranks fifth nationally in the number of people with AIDS, following New York, California, Florida, and New Jersey (Figure 2). Harris County (Houston) leads 45 states in the number of people reported to have AIDS. Dallas County has more people with AIDS than 41 states. Even Travis County (Austin) surpasses 20 states in the number of people with AIDS.[8]

More than three-quarters of all Texas cases are reported from Houston, Dallas, Fort Worth, Austin, and San Antonio. However, rural Texas is increasingly affected by the HIV epidemic. More than half of the state's 254 counties, most of them rural, have reported residents with AIDS. Figure 3 shows the dramatic increase in the number of counties that have reported cases of AIDS during the last seven years. Given the five-to seven-year lag time between initial HIV infection and diagnosis of AIDS, the statistics are expected to rise steadily in rural Texas.

Figure 2

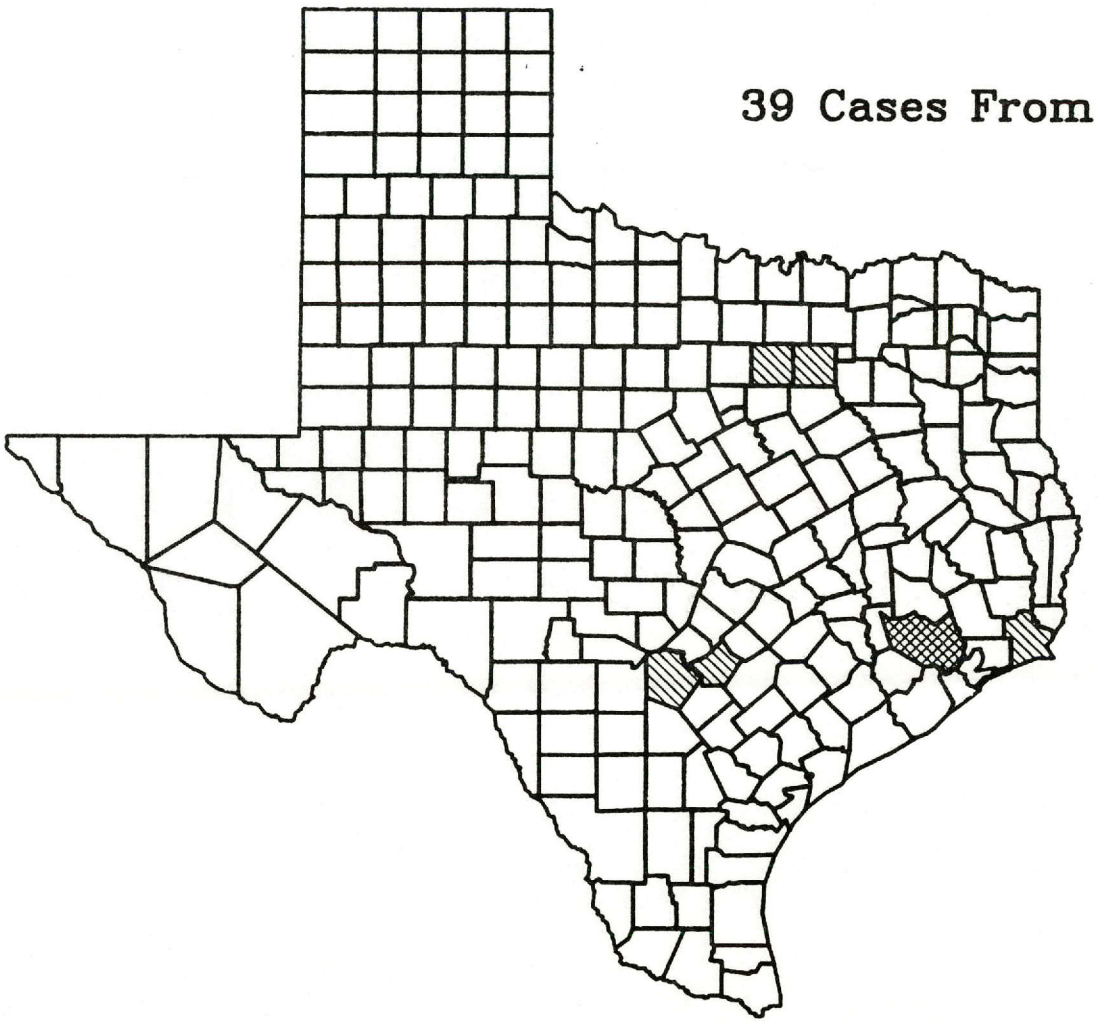
REPORTED AIDS CASES



Source: U.S. Centers for Disease Control
Weekly Surveillance Report 01-09-89

(Figure 3-A)

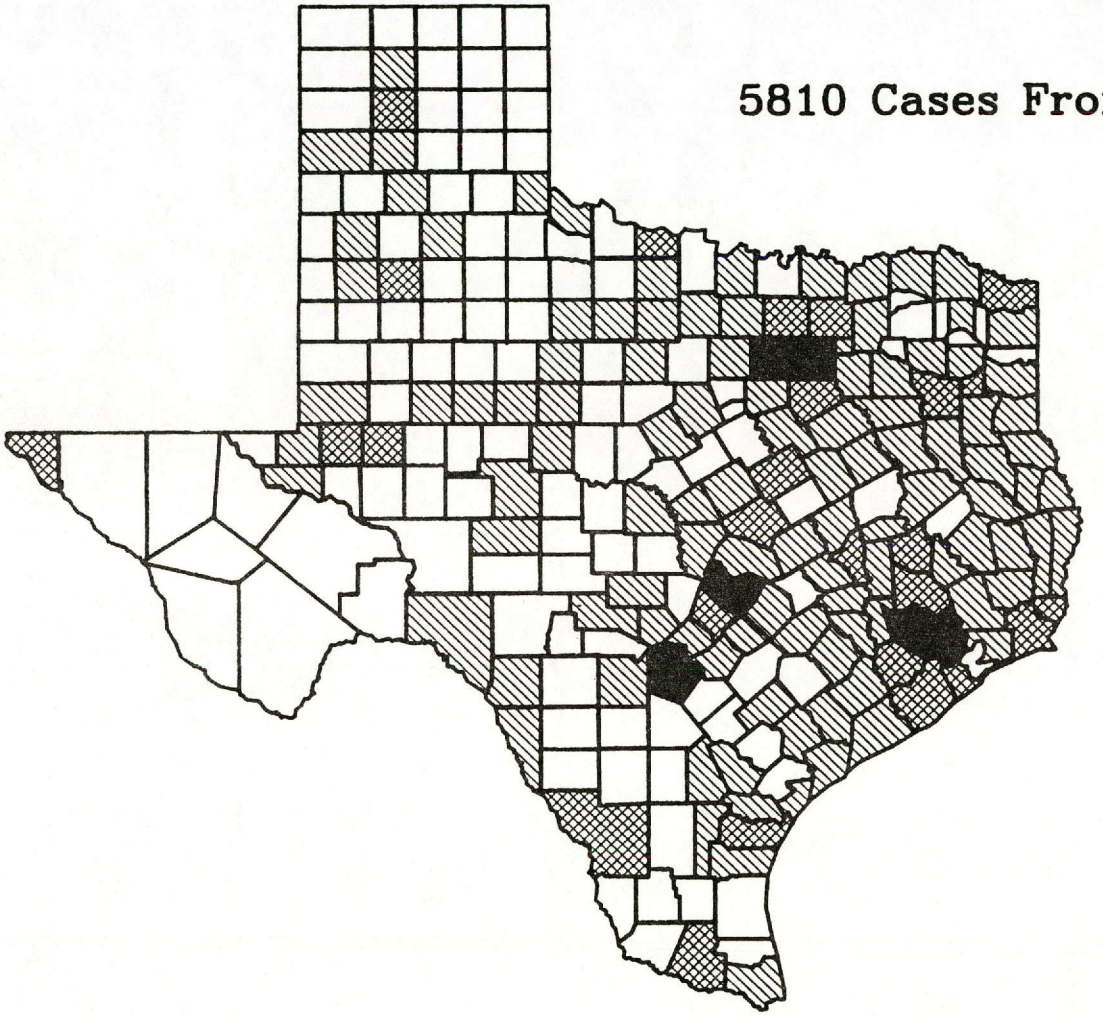
Reported Cases of AIDS by County of Residence At Time of Diagnosis, Texas 1980–1982



Texas Department of Health
Cases reported as of January 9, 1989

(Figure 3-B)

Reported Cases of AIDS by County of Residence At Time of Diagnosis, Texas 1980–1988



Texas Department of Health
Cases reported as of January 9, 1989

The nature of AIDS statistics is somewhat different in Texas than the entire United States. National statistics are significantly influenced by the large number of cases in New York and New Jersey that are attributed to intravenous drug use. In comparison, Texas has a higher percentage of AIDS cases among homosexual and bisexual men. A relatively lower incidence among intravenous drug users and heterosexuals does not mean, however, that these groups are not at risk in Texas. Because of the long incubation period of the virus, AIDS statistics can only provide a snapshot of what has taken five or more years to develop.

Limitations of AIDS Statistics

Statistics about AIDS reflect only those people reported to have "full-blown" AIDS. They are merely a fraction of a much larger number of HIV-infected people who currently are asymptomatic. The Texas Department of Health estimates that 100,000 Texans are infected with HIV. Most, if not all, of them will ultimately develop medical problems as a result of having the virus.

The method of collecting AIDS statistics provides uniformity and allows comparisons over time and between regions of the state. However, it does not measure the full impact of the HIV epidemic on any community at any point in time. AIDS statistics only indicate where people were living when they were diagnosed. They do not represent the actual number or distribution of cases in a locality. AIDS statistics do not include people who were diagnosed in other states and subsequently moved to Texas. Nor do these statistics account for people who were diagnosed in cities

and returned to their rural hometowns to receive care from their families. Furthermore, AIDS statistics do not include people with HIV-related illnesses which do not meet the clinical diagnosis of AIDS. These Texans often have health, financial, and social support needs that are just as great as those of people with AIDS.

AIDS statistics can give a false impression about the extent of infection in certain populations. The distribution of cases among men and women, racial groups, age groups, and those with high-risk behaviors will continue to change for years. Recent data from the U.S. military, for example, indicate that the rate of HIV infection among Blacks applying for acceptance into the military in Texas was 3.3 times higher than White applicants in Texas.[9] However, to date, the number of Black Texans reported to have AIDS currently is only one-sixth that of Whites.

By every indication, the number of infants born with HIV is much higher than that represented by current AIDS statistics. Two unique factors greatly affect the accuracy of AIDS statistics among infants. First, since an infant carries its mother's antibodies for up to 15 months, routinely available HIV screening tests cannot determine if the antibodies are the mother's or the infant's. Second, many infants with HIV infection die before a diagnosis of AIDS can be made. Current HIV seroprevalence studies on newborns and the availability of new diagnostic tools will provide more accurate data about the number of HIV-infected infants.

THE ECONOMICS OF HIV IN TEXAS

Attempts to estimate the cost of HIV and AIDS only suggest the magnitude of the economic burden of this epidemic. Problems estimating the costs mirror difficulties with estimating the extent of the epidemic. Most information is limited to people with AIDS; little is known about HIV and HIV-related illness.

The dollar cost of this epidemic includes education, research, testing and counseling, provision of health care and social services, and the loss of productivity because of illness and premature death. Although the responsibility for many of these functions is shouldered by the State of Texas, few state funds have been earmarked specifically for HIV services.

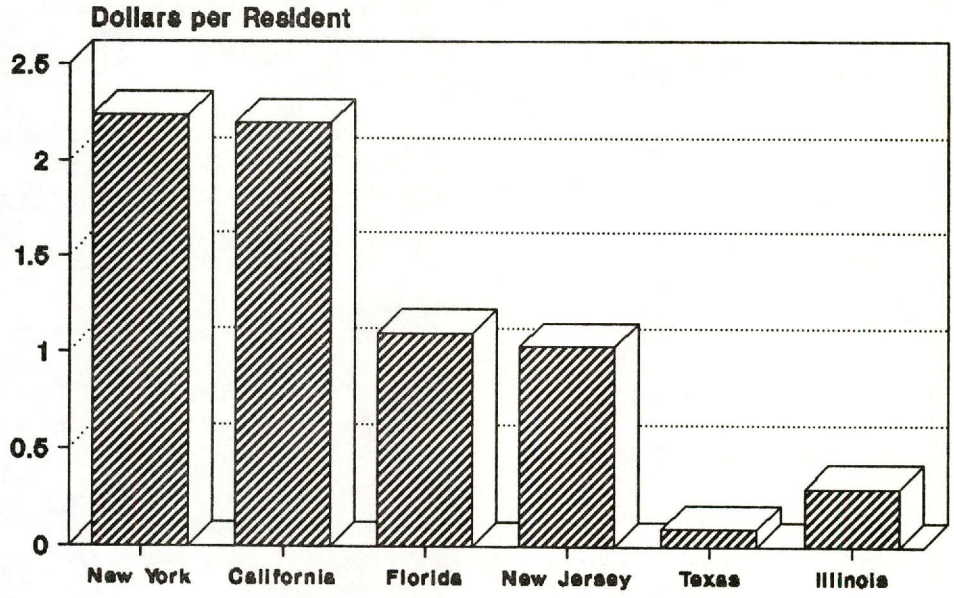
Although Texas ranks fifth in the number of reported AIDS cases, it ranks near the bottom in the amount of state funds expended on HIV or AIDS. Out of 37 states surveyed in 1988, the national average for per capita spending was 65 cents; Texas averaged 9 cents per capita. Nationally, the median expenditure per diagnosed AIDS case was $2,747. Texas averaged $473 per case (Figure 4).[10]

The actual amount spent in Texas on HIV services is far greater than these figures demonstrate. Services and programs are also offered by city and county governments, health care providers, and community service organizations. Through local health departments, some city and county governments supplement federally

Figure 4

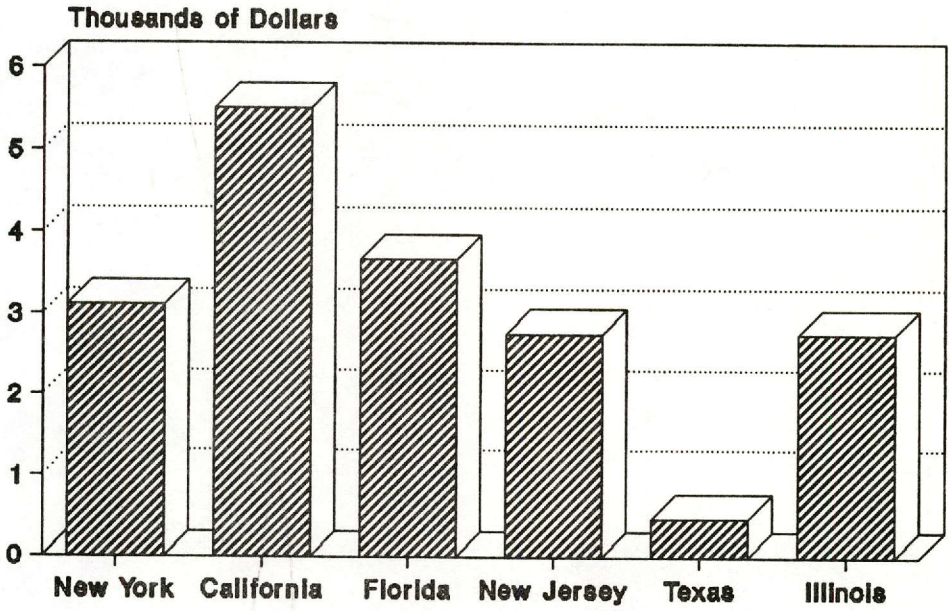
State Funding for AIDS Services/FY 1988

Per Capita Expenditures



State Funding for AIDS Services/FY 1988

Expenditures per Diagnosed AIDS Case



Excludes Medicaid Funding
Data source: Rowe and Caitlin

funded HIV prevention, counseling, and testing activities. Others provide some support to community organizations and local HIV planning efforts. Many providers offer substantial amounts of uncompensated care. The survey of Texas hospitals on AIDS-related costs in 1987 indicated that 34 percent of all admissions were "self-pay," i.e., had no public or private health insurance coverage. Community service providers, especially AIDS service organizations, have provided extensive social support, health care, and prevention services either at a reduced rate or at no charge. Most of these services are provided through volunteer labor. Both the extent and the value of services provided by these organizations are incalculable.

The State of Texas has been slow to recognize its implicit responsibilities for HIV education and services. HIV-related issues must be considered in state policies as diverse as public education, education of health care providers, indigent health care, regulation of foster care and day care, and the criminal justice system. Many state agencies provide important services to people with HIV but are unable to identify specific costs associated with these programs. Some state agencies are attempting to increase HIV-related services, but the lack of resources hinders their efforts. Few state agencies, however, have requested specific funding to increase HIV-related services and programs. Without funding allocated for HIV-related services, agencies cannot implement services without diverting dollars from other essential state programs. As a result, most HIV programs at the state level are inadequately funded and implemented.

Direct costs associated with AIDS include personal health care and non-personal costs. Personal health care costs include hospital services, physician charges, outpatient services, home care, pharmaceutical costs, nursing home and hospice care, and mental health counseling. Non-personal expenditures include health education and promotion campaigns, blood screening, counseling, testing, and research. None of these categories is easily quantified.

The charge to the Task Force called for an assessment of the economic burden of AIDS in Texas. While recognizing the above constraints, the Task Force compiled available information to estimate the current economic burden of HIV on the State. To identify Texas-specific data on the economic burden of AIDS, the Task Force commissioned a variety of surveys:

Survey of Texas Health Insurers and Health Maintenance Organizations: The State Board of Insurance survey focused on health insurance availability and scope of benefits, claims experience, and conversion/continuation benefits in Texas. Insurance companies participating in the survey included those that write individual accident and health policies and those that write group accident and health policies. All health maintenance organizations (HMOs) licensed in the state were surveyed. Of 169 HMOs and insurers surveyed, all but one responded.

Although the response rate was exceptional, the survey provided minimal data on the precise extent of insurance coverage for

Texans with AIDS. It also provided little information on the number of AIDS claims or the cost of AIDS care. Insurers providing group and/or individual coverage reported that AIDS/ARC claimants represent less than 1 percent of their total insured population. The AIDS/ARC claims reported among group insurers ranged from $346 to $130,284. Of the 20 carriers reporting claims data from group policies, 85 percent reported claims between $10,000 and $50,000. Of those carriers that write individual accident and health insurance, the AIDS/ARC claims ranged from $541 to $88,912. The majority of claims also ranged from $10,000 to $50,000. Because of inconsistencies among insurers in calculating average claim costs, the State Board of Insurance concluded that the survey results do not enable statistically valid comparisons among the insurers' average costs.[11]

The Survey of Texans with HIV Infection: Medical, Social Service and Financial Needs: This survey was conducted by two teams of researchers. One team was based at the University of Texas School of Public Health in Houston and surveyed people in the Houston area. The other team, from Southwest Texas State University, analyzed survey responses from clients of AIDS service organizations in Abilene, Austin, Bryan/College Station, Corpus Christi, Dallas, El Paso, Fort Worth, Longview, Lubbock, and San Antonio.

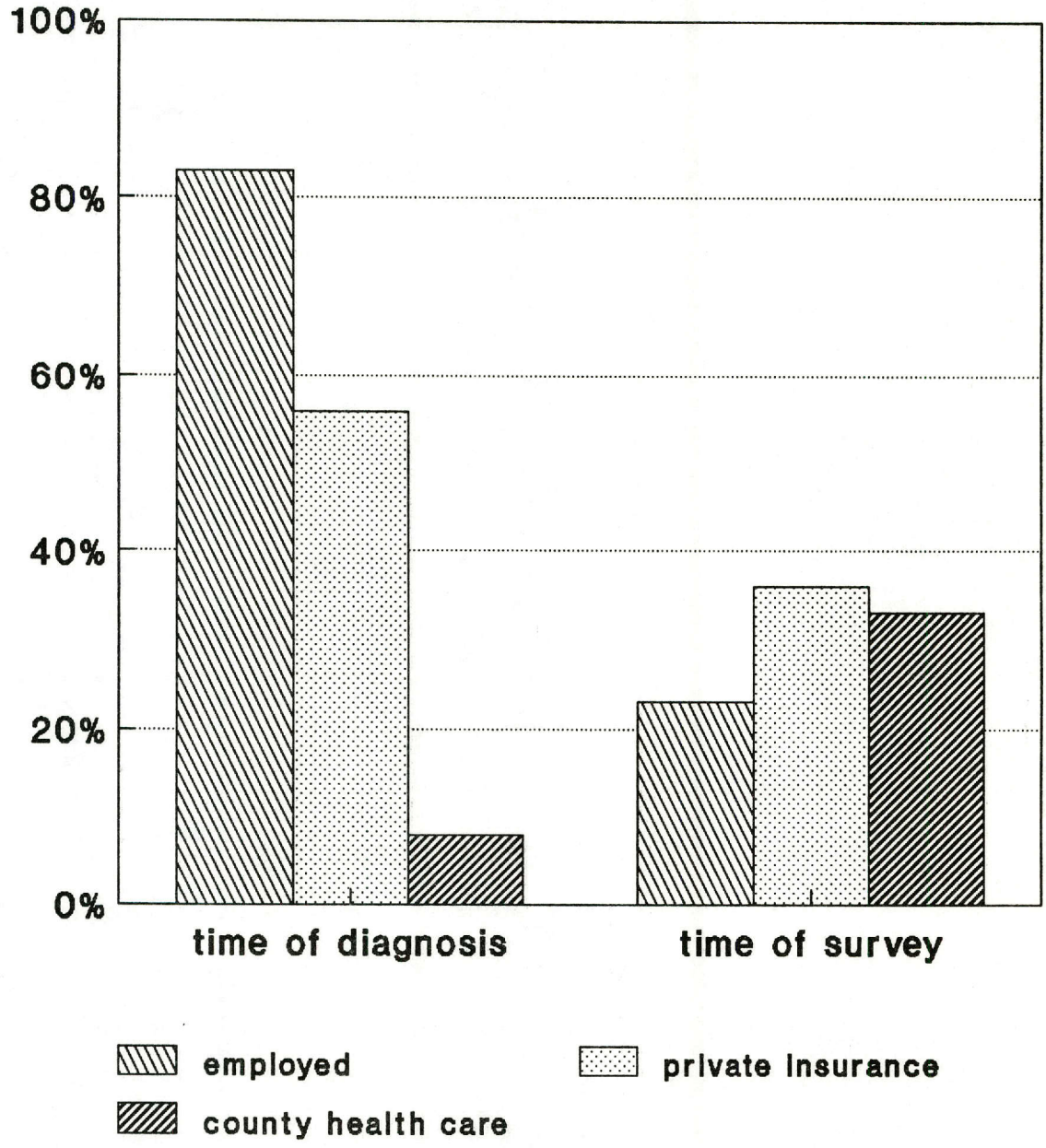
Of the 1,083 surveys distributed, 434 (40 percent) were returned -- 16 percent from asymptomatic individuals, 19 percent from people with HIV-related illness and 65 percent from people with

AIDS. Survey participants with AIDS were similar demographically to those in the statewide registry maintained by the Texas Department of Health, with the exception that Blacks and women were slightly under-represented. Because of the method of survey distribution, the researchers concluded that the survey respondents were probably better educated, healthier, and more likely to be from an urban area than the total group of Texans with HIV.

The devastating financial impact of HIV on those infected is clearly documented in this survey. Over one-half (54 percent) of the respondents with AIDS stated that they had spent all of their savings to pay for their illness. Forty-four percent indicated they were unable to pay for prescription medications. The majority (83 percent) of respondents with AIDS were employed at the time of their first HIV-related diagnosis. By the time of the survey, only 23 percent were still employed. The proportion of people with private insurance fell from 56 to 36 percent, and the proportion of respondents with AIDS who use county indigent facilities rose from 8 to 33 percent (Figure 5). Their median annual income fell from $20,000 to $6,000. Since nearly three-quarters of the 280 respondents with AIDS were under the age of 40, loss of employment represents a profound loss of income and economic productivity to the people infected, their dependents, and society at large.

Figure 5

Change in Employment and Health Coverage
Survey Respondents with AIDS



Source: *Survey of Texans with HIV*

The 1987 Hospital AIDS Survey: A statewide hospital survey was conducted from May through August 1988 by the Texas Hospital Association, the Texas Association of Public and Nonprofit Hospitals, the National Public Health and Hospitals Institute, and the University of Texas School of Public Health. The questionnaire was mailed to 588 Texas hospitals; 189 hospitals responded, representing a response rate of 32 percent.

The number of AIDS patients treated by the hospitals responding to the survey represents a majority of the AIDS cases reported in Texas during 1987. The demographic characteristics of the survey patients and the distribution of admissions by hospital type and location were also similar to those of reported cases.

This survey provided the most detailed data on AIDS- related costs. On a per day or per visit basis, the average inpatient and outpatient cost of treating AIDS patients was similar to general medical/surgical patients. However, the average length of stay and number of admissions required per AIDS patient make their hospital care more expensive. The estimate of the annual inpatient cost per AIDS patient was $15,713. The annual cost of outpatient care per patient was estimated at $1,903. Combining inpatient and outpatient costs adds to a total cost per AIDS case for hospital-based treatment of $17,616. This estimate does not include the cost of infection control, or the cost of treating HIV-related illnesses other than AIDS. These figures are consistent with claims reported in the insurance survey.

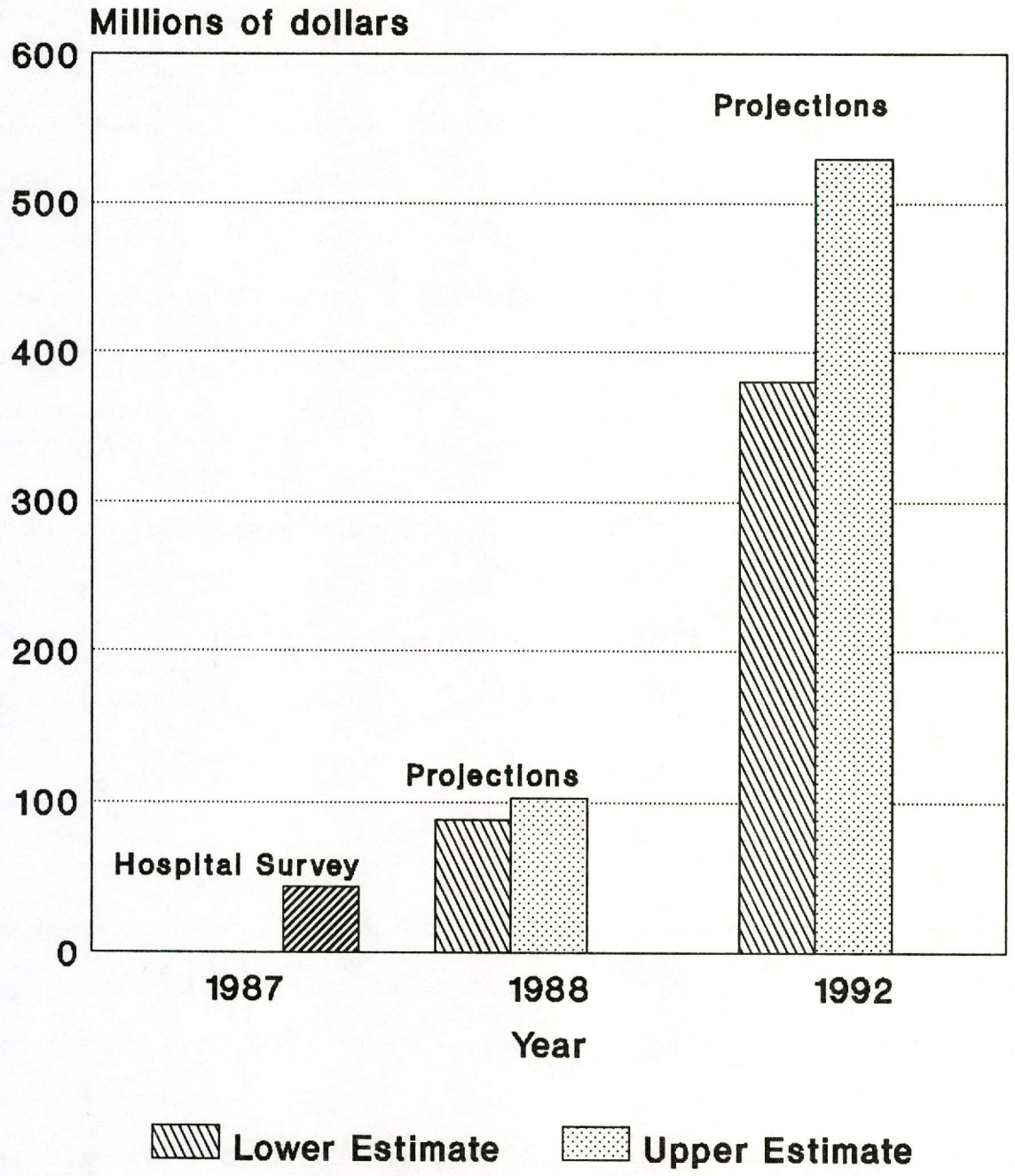
To estimate total hospital costs of AIDS patients, the survey estimate of cost per case was multiplied by the number of Texans with AIDS who are alive. Calculations indicate that the cost of inpatient and outpatient AIDS care in 1987 was $44 million. Based on these costs, over the next few years, hospital costs for AIDS will dramatically increase from the range of $88.5 million to $102.7 million estimated for 1988 to between $380 million and $530 million in 1992 (Figure 6).[12] The 1992 projections are staggering by themselves, but viewed in perspective, they are even more significant. Projected AIDS-related costs for 1992 exceed the total resources required by hospital districts in Dallas, Houston, and San Antonio to meet all other needs.

The survey also documents the burden placed on many health care providers by the current financing system. Hospitals were paid significantly less than the cost of care provided. The average payment per day of $485 was only 77 percent of the cost of inpatient care, resulting in a net daily loss of $137 for people with AIDS. This is more than twice that for general medical-surgical patients, which had a net daily loss of $67. The net loss for outpatient care for AIDS patients was even higher, with payments covering only 14 percent of the cost of care.

Several factors that are difficult to predict or control can affect projections relating to hospital-based care. First, the constant development of new information about the treatment of HIV can alter the cost of care. Further, treatment advances can

Figure 6

Cost of AIDS Care in Texas Hospitals



Data Source: UT School of Public Health

significantly prolong survival, which may increase the need for additional treatment for other HIV-related conditions. As a rule, however, treatment advances reduce the total costs due to fewer medical complications and hospitalizations and the increased capacity of those infected to continue working.

The treatment patterns for AIDS and HIV-related care have changed significantly in recent years. Changes in clinical management and the availability of home-based care have decreased reliance on hospital care. The medical costs for AIDS patients can be significantly reduced when there are community support systems available to provide home health services and hospice care.[13] However, care provided by community-based organizations has depended largely on unpaid labor. As the epidemic grows, it is unlikely the volunteer pool will grow commensurately. Therefore, the ability of community-based organizations to provide care is dependent on increasing third-party reimbursement or finding new funding sources.

Indirect Costs

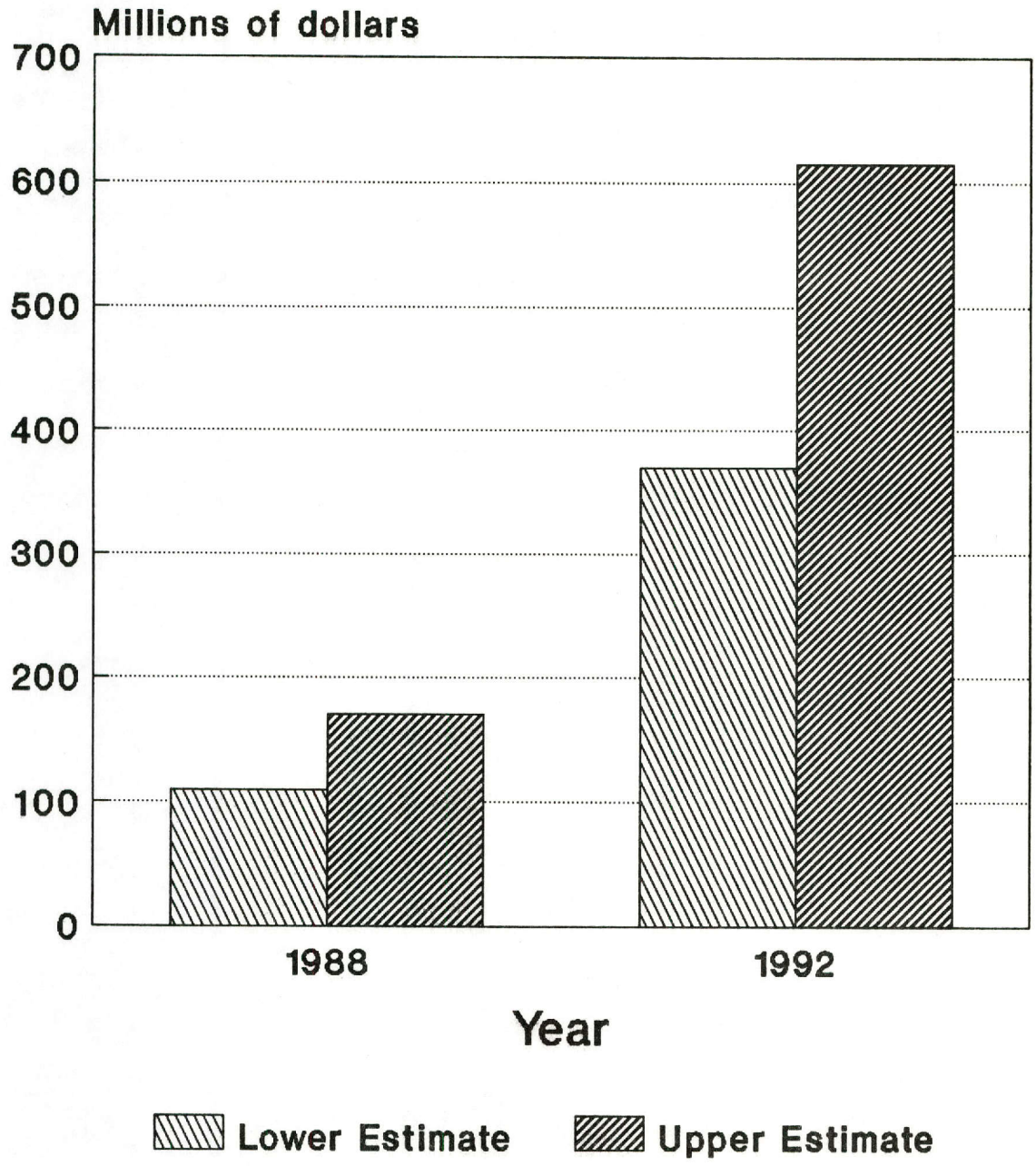
Estimates of the economic burden of the HIV epidemic must include indirect costs. Indirect costs are based on the loss of wages as a result of illness and disability and the loss of future earnings as a result of premature death. Researchers at the University of Texas School of Public Health attempted to calculate the indirect costs of AIDS in Texas. These estimates reflect only premature death due to AIDS, not to HIV-related illness and, therefore, are very conservative.

To estimate lost future earnings, the incomes of a sample of 100 AIDS patients who died in July 1988 were projected forward. These figures were then applied to all deaths estimated from 1988 to 1992. Calculation of future earnings was based on the identification of the occupational status from the death certificates of the sample patients, and their associated annual income data as reported by the U.S. Bureau of the Census. The estimates were based on the assumption that: 1) most people who died (average age of death was 35 years) lost about 30 years of employment, and 2) the labor force participation, occupational distribution, associated incomes, and the case fatality ratio are representative of all Texans who died from AIDS during the projection period. The value of earnings lost due to AIDS deaths is estimated at between $930 million and $1.4 billion in 1988. By 1992, it will range from $3.1 billion to $5.2 billion.

State and local tax revenues lost due to premature deaths from AIDS will be between $110 million and $170 million in 1988. The range of potential tax loss in 1992 will be between $370 million and $615 million (Figure 7).

Figure 7

Cost of Premature Death from AIDS
Lost State and Local Tax Revenues



Data Source: UT School of Public Health

The indirect costs of the HIV epidemic are substantially higher than direct costs. Taken together, they pose a significant economic burden to the state. Despite the difficulty of estimating all costs relating to HIV in Texas, it is clear that the costs of HIV in Texas are substantial and growing. The State has the opportunity to decrease the potential impact of AIDS and HIV-related costs by expanding prevention efforts and providing more cost-effective care in its programs and services.

FINDINGS AND RECOMMENDATIONS

TREATMENT AND SERVICES

> The HIV epidemic is placing an increasing strain on segments of our health care system, particularly our municipal and voluntary hospitals. This strain is illuminating many of the flaws in our health care system that have been present for a long time. As we try to address these flaws and the variety of possible solutions, we hopefully will end up with a better system which will be more responsive, more humane, and more able to direct its manifest strengths quickly and efficiently to where they are most needed.
>
> Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic [14]

One of the greatest challenges posed by the HIV epidemic is providing and financing health and social services. People with HIV need access to a full range of these services. But the majority of Texans with HIV have trouble obtaining services.

The current system of providing and financing health and human services adversely affects both people needing assistance and health care providers. In general, problems in obtaining HIV-related services in Texas are the same as those encountered by anyone with a catastrophic illness. These problems include:

- Inconsistent and restrictive eligibility requirements for public health care programs.
- Limited scope of benefits from both public and private third-party payors.
- Limited availability of community-based services, such as respite care, home health care, and hospice.

- Lack of coverage for preventive education and experimental therapies.

The unique characteristics of the HIV disease process and the groups currently diagnosed magnify these problems to an alarming extent. Early and prompt treatment of HIV and related conditions, and access to preventive education and experimental therapies can reduce hospitalization costs and illness. Although funding of early intervention programs and access to most experimental therapies are outside the scope of traditional insurance or public assistance programs, increasing coverage for these areas can prevent or delay the need for more costly services.

Reliance on public health care programs was clearly documented in the survey of Texans with HIV infection and the survey of AIDS-related costs in Texas hospitals. The survey of Texans with HIV infection showed that 43 percent of respondents with AIDS were using publicly funded insurance such as Medicaid (16 percent), Medicare (1 percent), Veterans benefits (5 percent) or indigent health care programs (21 percent). Data from the survey of AIDS-related hospital costs were similar. Eleven percent of all AIDS admissions were covered by Medicaid, 3 percent were covered by Medicare, and 34 percent were self pay, i.e., had no public or private third-party coverage.

The survey of AIDS-related hospital costs also documented the unfair burden placed on many health care providers by the current financing system. Hospitals were paid significantly less than the cost of care provided. The average payment per day of $485

was only 77 percent of the cost of inpatient care, resulting in a net loss for the hospital per day of $137 for a person with AIDS. The net loss for outpatient care for AIDS patients was even higher, with payments covering only 14 percent of the cost of care.

Every Texan should have adequate access to basic health care services. For people with HIV, services should:

- Stress early intervention in the disease process.
- Ensure timely and equitable access to needed care.
- Facilitate access to a continuum of care.
- Offer low-cost care alternatives.

Services most often needed by people with HIV include hospital, outpatient, home health, homemaker, hospice, nursing home, respite, and day care. Dental care and access to mental health services are also vital. Case management services and expanded coverage of outpatient and home-based care can significantly reduce the cost of health care services.

Developing an equitable and accessible health care system for people with HIV will require collaboration between the public and private sectors. There is no single solution to the complex problems of providing and financing health care services. Both public and private coverage systems must be expanded and refined to provide the most humane and cost-effective care possible.

ACCESS TO CARE

> I'm so tired of having to give up everything -- home, personal belongings, dignity, self respect, and a sense of decency -- to try to make it to the next day. Until this happened, I never had to ask for help from anyone. Now I wonder who I'm going to have to beg to next.
>
> Survey of Texans with HIV Infection

> When you choose to keep people in hospital beds that cost $520 a day...and sometimes keep them in those hospitals week after week without providing housing, which would cost a fraction of keeping them in the hospital, you choose to pay top dollars for the treatment of AIDS.
>
> HIV service provider
> Houston hearing

People with HIV can require a wide range of medical care and social support, including hospitalization, ambulatory outpatient care, and home health services. Without exception, health and social services for Texans with HIV are severely lacking, especially those that are alternatives to hospitalization. Several key factors contribute to the inadequate availability of such services -- notably, the lack of financial resources and third-party reimbursement, agencies' minimal experience with HIV-infected clients, and inappropriate fear of and discrimination against people with HIV.

It is significantly less expensive to care for people in their own homes than to keep them in hospitals for prolonged periods.

Unfortunately, because of the lack of community health and social support services, many people with HIV must remain in the hospital unnecessarily. During the course of its study, the Task Force learned of hospital care costs that could have been avoided if appropriate community services had been available. For example, the Task Force received a call about a middle-aged man with AIDS from a rural, North Texas county who had to remain in the hospital three extra weeks. He had no home, no caregivers, and no resources. Ultimately, the hospital transferred him to a charity hospice in Houston, more than 200 miles away, where he died.

The health care and social service needs of HIV-infected people vary according to their medical conditions, financial and social support resources, and personal preferences. Some HIV-infected Texans are relatively healthy and able to work. Others have severe neurological conditions, dementia, blindness, or mobility problems and require constant supervision and assistance. Some have caregivers and enough income to remain at home during the terminal stages of illness. Others are homeless and have no support system. Outpatient clinic and physician services, home health care, homemaker services, respite care, day care, foster care, case management, and residential services are among the programs most seriously needed by Texans with HIV. Figure 8 provides an overview of these services.

Figure 8

Array of Services Needed by People with HIV

HIV TEST?

Pre-Test Counseling
Education
Information and Referral

POSITIVE HIV TEST?

Post-Test Counseling
Education
Information and referral

GENERAL HEALTH CARE NEEDS?

Physician Services
Dental Care
Nutrition Counseling
Family Planning Services
Laboratory Services
Pharmaceutical Services

SUBSTANCE ABUSE?

Substance Abuse Treatment
Counseling
Education
Follow-up Services
Case Management

EMOTIONAL NEEDS?

Mental Health Counseling
Support Groups
Pastoral Care
Case Management

SYMPTOMS OF DISEASE?

Physician Services
Laboratory Services
Hospital Services
Outpatient/Clinic Services
Home-Health Care
Pharmaceutical Services
Case Management

FINANCIAL PROBLEMS?

Assistance with Housing
Assistance with Medications
Assistance with Utilities
Food Pantries
Employment Counseling
Legal Assistance
Public Assistance Programs
(SSI/AFDC/Food Stamps)
Case Management

OTHER SOCIAL SERVICE NEEDS?

Housing
Respite Care
Day Care
Foster Care
Transportation
Homemaker/Chore Assistance
Legal Assistance
Attendant Care
Case Management

SEVERE ILLNESS?

Physician Services
Hospital Services
Emergency Care
Laboratory Services
Pharmaceutical Services
Home-Health Care
Medical Equipment
Nursing Home Care
Case Management

DYING?

In-facility Hospice Care
Home-based Hospice Care
Legal Assistance
Pastoral Care
Support in Preparation for Death

The Task Force heard repeated testimony on the pressing need for housing. In the survey of people with HIV, 30 percent of respondents with AIDS indicated they had lost their housing because of a loss of income. Nine percent stated they had lost their housing because of discrimination. HIV-infected people who lose their homes due to poverty or discrimination must obtain residential programs or face homelessness. A wide range of housing alternatives, including emergency shelters and shared housing arrangements, is needed.

But few residential programs exist. Only 2 percent of the community service organizations surveyed by the Task Force provide low-cost housing to people with HIV. The handful of facilities that do exist can house very few people, and in no way are able to meet the growing demand for services. For example, McAdory House, operated by AIDS Foundation/Houston, can serve only 10 residents at a time, yet claims there are at least 100 people in need of their services. Bryan's House in Dallas, one of the few residential facilities available to infants and children with HIV, is receiving requests from all over the state.

Hospice care is often a suitable and cost-effective alternative to health and residential care for people in the terminal stages of HIV infection. Both in-facility and in-home hospice programs are severely limited. Lack of third-party reimbursement has contributed to their scarcity. The Texas Department of Human Services recently authorized Medicaid reimbursement for hospice

services, which should greatly increase their availability for impoverished Texans.

Nursing home services for people with HIV-related illnesses are also inadequate. Some of the major reasons cited are the potential costs and inadequate Medicaid reimbursement for HIV-related care and the fear and misunderstanding about HIV transmission. In rural areas, where there are few AIDS service or other community-based organizations, nursing homes are often the only long-term health care option. As the number of Texans with HIV escalates and more rural communities are affected, the demand for nursing home services is likely to increase.

Texas is poorly prepared to meet the projected increase in infants and children with HIV, who often have unique service delivery needs. Frequently one or both parents are infected with HIV, are in varying stages of illness, or have already died. Therefore, these children often do not have their parents available to attend to their health, emotional, and social support needs. Referred to as "boarder babies", some HIV-infected children face prolonged and costly hospitalizations when home health, foster care, day care, and hospice services are not available. The circumstances of a 4-year old girl at the University of Texas Medical Branch at Galveston exemplify the difficulties faced by some children with HIV. Born with multiple birth defects, the young patient was infected with HIV through a blood transfusion. Although she needs constant supervision, her medical condition does not require hospitalization. Nevertheless, she has lived in her

hospital room for over a year, at a daily cost of $244 to the State. After 18 admissions, her hospital bill totals $775,000. Medicaid has paid for a fraction of the hospital care. The majority of her bills are absorbed by the hospital, a state-operated, tax-funded institution.[15]

There is insufficient information about the fiscal effect of HIV upon the State's health and human service programs. The Commissioner of the Texas Department of Human Services has stated that obtaining such data "cannot happen overnight and (it) takes time to write programs, test, and produce computer reports that will assist in assessing the impact on the various programs."[16] To better prepare for HIV-related service needs and to target limited state funds, a thorough assessment of the health and human service costs and needs of people with HIV must be conducted.

CONCERNS/PROBLEMS IDENTIFIED

- Most public health and social service programs have restrictive eligibility requirements that limit the availability of essential services for people with HIV.

- People with HIV need access to a wide range of community-based services, among them housing, hospices, home health care, respite care, case management, and nursing homes. Such services are often cost-effective alternatives to hospitalizations. However, access to these services is lim-

ited by the lack of third party coverage and the lack of expertise in caring for people with HIV.

- Foster care and day care services for HIV-infected children are not adequately available. The lack of these services increases the financial burden on hospitals.

- Families with one or more members with HIV have special needs for assistance. However, few services are available to support these families.

RECOMMENDATIONS

1. The Legislature should establish programs that provide adequate health care coverage for all state residents whose income is at or below 200 percent of poverty. Thus, the Legislature should consider expansion of the Medicaid program (see page 67), establishment of the high-risk pool (see page 76), and/or establishment of other mechanisms that would be payor of last resort to supplement other existing benefit programs.

2. Since the care and treatment of HIV-infected persons should be provided in the least intense and most effective setting, all state funded health care programs should cover and/or provide referrals to a continuum of services, including ambulatory care, case management, home based care, inpatient care, and hospice-type terminal care as necessary. Additionally, the Legislature should develop incentives to encourage private third party coverage of preventive care, case management, home-based care, and hospice-type terminal care. Incentives may include, but should not be limited to, premium tax credits.

3. The Legislature should fund a program to provide information for health care providers regarding the most effective treatment of HIV-related conditions with emphasis on regional HIV-related health care service development.

4. The Department of Health, the Department of Human Services, and other appropriate agencies should encourage case management services by state funded community-based organizations that provide HIV-related services. The agencies should cooperate in promulgating standards for the establishment, funding, and evaluation of case management services.

5. The Texas Department of Human Services should implement regional demonstration projects to obtain cost data needed to determine appropriate levels of Medicaid reimbursement for HIV-infected nursing home residents.

6. The Texas Department of Health should assist nursing homes in designing and implementing effective HIV-related education programs for their staff, residents, and residents' families. The Department also should make appropriate education materials available for staff and resident training.

7. The Texas Department of Health should continue to monitor the delivery and quality of services to HIV-infected persons housed in smaller, special care facilities.

8. The Texas Department of Human Services should continue to monitor the Medicaid regulations adopted for hospices to ensure the regulations do not impede the quality or accessibility of hospice services for HIV-infected persons.

9. The Texas Department of Human Services should immediately take steps to make available foster care and day care services for HIV-infected children. At a minimum, the Department should assess whether state regulations impede the availability of services, explore the possibility of new classification categories for children with HIV infection, and evaluate the feasibility of new reimbursement levels for HIV-infected children. The Department should submit a comprehensive report of its findings to the 71st Legislature by January 1990.

10. The Texas Department of Human Services should evaluate the availability of services to families in which more than one member is infected with HIV. The study should explore the adequacy of respite, home health, and other social support services that help support and maintain families as intact units. The Department should submit a comprehensive report of its findings to the 71st Legislature by January 1990.

11. The Legislature should designate an agency to conduct an ongoing study to monitor the health and human service costs and needs created by the HIV epidemic. The study should maintain information necessary to identify critical services or programs and to assess the ability of state health and human service programs to meet the needs of persons with HIV and AIDS. Included in this effort should be:

- Analyses of economic trends and the assessment of the effectiveness of program development.

- Statistical data within each program related to the medical and financial profiles of persons with HIV-related illnesses.

- An evaluation of the availability and accessibility of non- acute care services to persons with HIV-related illness, such as adult day care, home health care, and respite services.

- An assessment of the housing needs of persons with HIV.

The study also should include an examination of possible regulatory barriers; incentive funding and demonstration projects; and state, federal, and local funding opportunities. A comprehensive report should be submitted to the 72nd Legislature when it convenes in January 1991.

EARLY INTERVENTION/EXPERIMENTAL THERAPIES

> By the time a person has full-blown AIDS, it is too late. By all means, science should continue caring and providing for these people, ensuring that they fulfill their remaining time with dignity, comfort and possible hope. But why isn't science concentrating on the seropositive person? Trying to stop the eventual progression of the disease?
>
> Survey of Texans with HIV Infection

> My (insurance) plan covers hospitalization, not drugs. I have a $1,000 per month drug bill for AZT and pentamidine. Help!
>
> Survey of Texans with HIV Infection

Early identification of HIV infection is essential. Not only does an early diagnosis help prevent further transmission of HIV, but it also can prompt those infected to seek proper medical treatment and to adopt behaviors that can maximize their health status. Many health care providers have found that the adoption of a healthy lifestyle and appropriate medical treatments can ensure a longer, better life for those infected.

Early diagnosis allows people with HIV to take precautions to protect their immune systems and to seek the most appropriate treatment of HIV-related illnesses. Most medical treatments relating to HIV are initiated at the onset of opportunistic infections when the immune system is sufficiently impaired to leave the infected person susceptible to illness. Current research is largely focused on protecting and strengthening the immune sys-

tem. Specialists now stress earlier treatment, or "intervention." In the absence of a known cure, aggressive use of new, experimental drugs and therapies are often appropriate. Early medical intervention can prolong the ability of HIV-infected Texans to work and remain financially independent and, therefore, has economic benefits for the state as a whole.

Information about the benefits of early intervention, lifestyle changes, and the use of experimental therapies is not widely available. Although community service providers in areas of high HIV incidence have supplied extensive education on these issues, in other areas of the state it is not routinely available. People with HIV should be educated about the importance and benefits of healthy lifestyle changes and the need for preventive care. For example, HIV post-test counseling sessions should include information about the benefits of early intervention in delaying and mitigating the effects of opportunistic infections.

The Task Force heard much public testimony on the need for greater access to experimental drug trials and therapies. Additionally, respondents to the survey of Texans with HIV infection overwhelmingly identified access to experimental therapies as their most important need.

Access to new therapies is among the greatest needs of people with HIV. However, it is not uncommon for the federal drug approval process to take eight years or more. Regulated by the Food and Drug Administration (FDA), the federal drug approval

process requires extensive laboratory and animal studies, followed by a three- and sometimes four-phase series of clinical (human) trials to prove drug safety and efficacy. Drugs are approved by the FDA only for a specific use. For example, the FDA has approved the intravenous administration of pentamidine for the treatment of Pneumocystis carinii pneumonia, the most common cause of death for people with AIDS. However, the use of pentamidine in an aerosol form is not an FDA-approved route of administration even though it has been shown to be effective in preventing recurrences of Pneumocystis carinii pneumonia with fewer side effects than when administered intravenously. Lack of FDA approval for the specific use of a drug limits the availability and coverage by third-party health insurance programs.

Access to experimental therapies and treatments is very limited in Texas. Most health care providers have little information on the use of experimental or alternative therapies or on participation in clinical drug trials. Treatment protocols for experimental therapies are not readily available to practitioners who infrequently care for HIV-infected people. Furthermore, most public and private third-party health insurance programs do not cover experimental or alternative drugs and therapies. Without insurance, a person's ability to pay for needed therapies determines access.

The cost of new treatments can be high. For example, the drug zidovudine (AZT) can lessen the severity of Pneumocystis carinii pneumonia and the cost and need for frequent or prolonged

hospitalization. However, the annual cost of AZT per patient is between $ 8,000 to $ 10,000. In Fiscal Year 1988, the federal government appropriated $2.1 million to Texas to cover the cost of AZT for people ineligible for Medicaid or without any other access to the drug. More than 800 Texans have benefitted from the funding. Although additional federal funds for Fiscal Year 1989 are forthcoming, future availability of federal funding is uncertain and may be insufficient to continue the current level of coverage. The survey of Texans with HIV infection indicated that most people taking AZT rely almost exclusively on governmental assistance. Only one-fifth of the respondents taking AZT were covered by private insurance.

Experimental drugs and therapies are critical for people with progressive fatal diseases for which there are no known cures. As with all other endeavors to increase access to services for people with HIV, an aggressive public/private sector collaboration is required.

Establishment of Community Research Initiative (CRI) programs can increase access to experimental therapies and, if properly supervised and funded, can provide valuable information about the effectiveness of specific therapies. The CRI program recently established by the PWA Coalition of Austin and the Central Texas Medical Foundation, for example, will increase HIV treatment options by: (1) giving area physicians information on experimental drug trials; (2) making available standardized treatment protocols for use with experimental drugs; and (3) facilitating

more patient participation in Phase II and Phase III experimental drug trials.

Another mechanism to facilitate the availability of experimental therapies is legislation that would allow the use, marketing, and testing of drugs and therapies that may not have received FDA approval. Drug testing without FDA approval was legal in Texas until 1985. The law was amended to omit such authority because of the administrative burden on the Department of Health and the lack of consistency with FDA regulations. The new law could be structured in accordance with federal standards and could reduce the administrative burden by limiting testing to new therapies for progressive and fatal diseases that have no known cure. This legislative change could encourage economic development, attract additional medical research, and promote pharmaceutical industries in Texas.

CONCERNS/PROBLEMS IDENTIFIED

- Delayed identification of HIV infection can impede early medical intervention, adoption of healthy lifestyle changes, and informed choices regarding medical treatments that may ensure a longer, higher quality of life for those infected.

- Most health providers have limited, sporadic information on the benefits or administration of experimental and/or alter-

native therapies, thereby limiting the availability of these therapies for people with HIV.

- The lengthy federal drug approval process impedes the availability of new therapies.

- Access to new drugs and treatments is limited by an individual's ability to pay and by restrictions in third-party coverage.

- Future federal funding of AZT for people without Medicaid or other resources is uncertain. No state funds have been allocated to increase availability of AZT.

RECOMMENDATIONS

12. The efficacy and cost of early intervention and various experimental therapies should be researched and standards for treatment adopted in all state-funded medical schools. These standards should be incorporated into continuing education programs for health care professionals on the care and management of persons with HIV infection.

13. The Legislature should appropriate funds necessary to provide AZT and other effective treatments to persons with HIV or AIDS who do not qualify for Medicaid and have no other way to pay for life-sustaining drugs.

14. The Texas Department of Health and the Texas Department of Human Services should continue cost effective approaches to purchasing AZT. Further, the Texas Department of Health should explore the feasibility of assisting local health care programs with bulk purchasing of AZT.

15. The Legislature should enact a law allowing testing, manufacturing, and use within the State of

Texas of any drug manufactured in Texas and designed to treat or prevent progressive fatal diseases for which there are no known cures. The Texas Department of Health should by rule define parameters of the testing and approval process that are consistent with Federal Drug Administration regulations. Such parameters also should include the list of diseases and disorders by which drug testing applications could be approved, methods for reviewing applications, and time frames for approving or denying applications.

16. The Texas Medical Association should work with local medical societies, AIDS service organizations, and persons with HIV infection to implement Community Research Initiatives programs. Such programs would increase HIV treatment options by providing physicians and persons with HIV infection with information on experimental drug trials; making available standardized protocols for use with experimental drugs; and expanding access to participation in experimental drug trials. This information should be routinely disseminated to community service providers, medical schools, and health care professionals.

17. State-funded universities should establish a partnership between private and public hospitals and medical schools for the administration and management of clinical patient trials involving experimental drugs for the treatment of HIV-related illnesses. Such collaborative efforts should seek federal funding whenever possible.

18. Sources for funding and access to experimental drugs of widely recognized potential value should be expanded. The Texas Department of Health should work with business coalitions and philanthropic groups in establishing a 501(c)3 corporation to facilitate access to experimental drugs. The Department should also research the feasibility of purchasing experimental drugs on a bulk basis which would then be sold on a sliding fee scale by either the 501(c)3 corporation or community service providers.

19. Public and private health agencies and institutions should develop and actively promote education programs targeted to persons who are infected with HIV, beginning at the earliest possible time. Such programs should include information on: prevention of HIV transmission, adoption and maintenance of healthful behavior, current medical treatments, the use and advisability of alternative treatments, and prompt identification of symptoms requiring medical intervention. The programs

should be designed in close consultation with members of the intended audiences and should address the diverse cultural, age, education, financial, and developmental considerations of persons with HIV infection. The Texas Department of Health should disseminate information about such programs to HIV counseling and testing sites and relevant community service providers.

MEDICAID/MEDICARE PROGRAM CHANGES

> There are people out there falling through the cracks, they need AZT and they aren't getting it, need health care and are not getting it.... There are people out there dying and they are dying alone and they are dying without care.
>
> Home health agency administrator
> Arlington hearing

> I need to get my diagnosis straight so I can get my SSI started before I starve to death.
>
> Survey of Texans with HIV infection

Medicaid is the major source of state-funded public health care in Texas. However, the design of the Medicaid program in Texas reduces the availability of timely, cost-effective care to people with HIV. At best, Medicaid provides limited coverage of health care services and access to AZT for those few Texans who are ill and poor enough to qualify for coverage.

The Medicaid program is jointly funded by the state and federal governments and is administered by the Texas Department of Human Services. For every dollar of Medicaid money spent in Texas, the federal government contributes 57 cents and Texas pays 43 cents. Federal regulations require that certain groups of people, such as those who are aged, blind, or disabled, be covered and that specific services, such as inpatient and outpatient care, be provided. Federal regulations allow states considerable latitude in designing and implementing their own Medicaid programs. States may choose to limit certain services or to expand others. In general, federal regulations require that a state's Medicaid program be "disease neutral." In other words, the same level of services must be available to all people statewide. Some optional coverages, such as expanding home and community services for people with a certain illness, require a waiver from the federal government.

People who qualify for one of the cash assistance programs established by the Social Security Act are automatically eligible for Medicaid. There are three main ways people qualify for Medicaid:

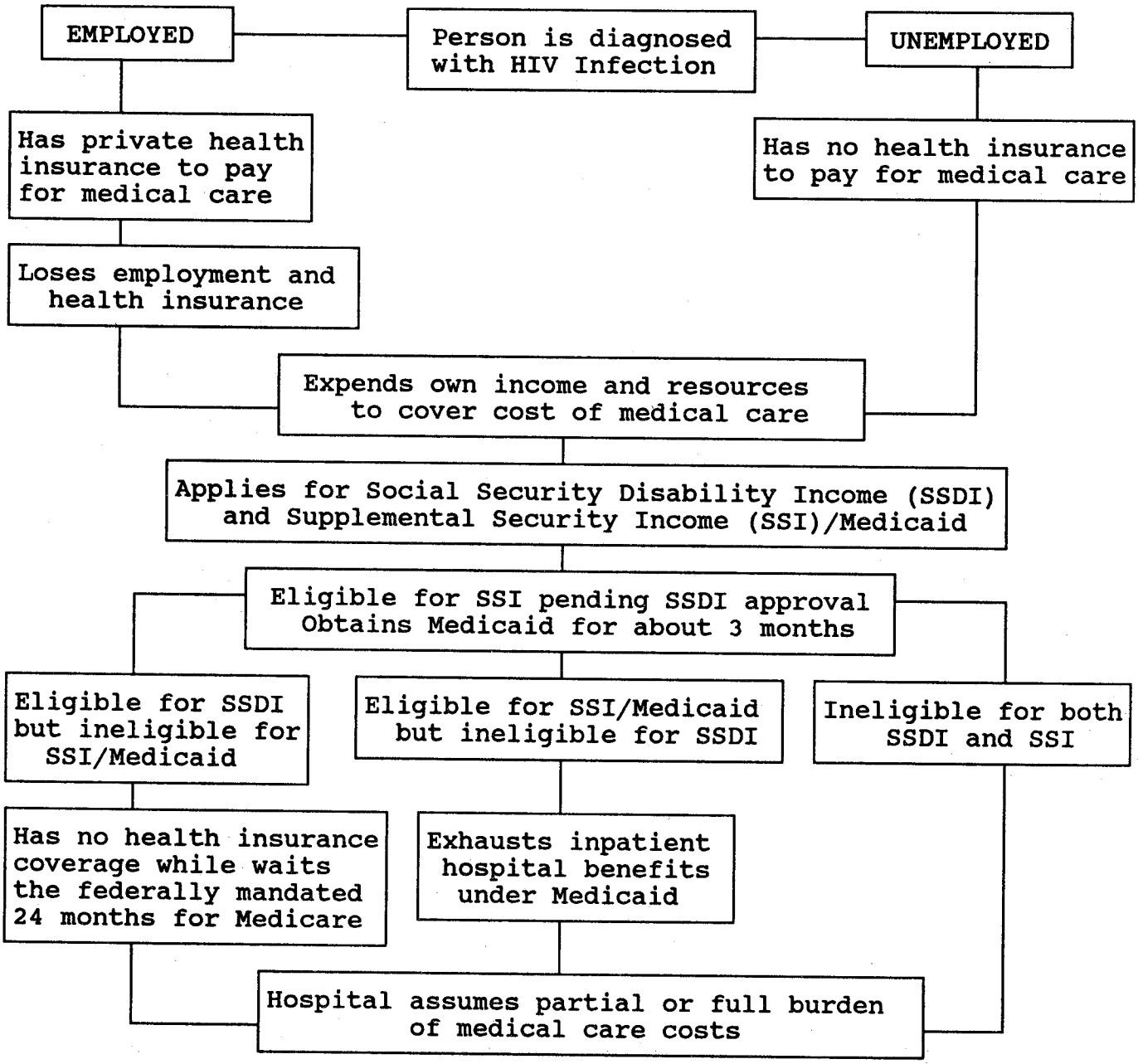
- Aid to Families With Dependent Children (AFDC) is available to children in one-parent families in Texas whose income does not exceed 24 percent of the 1988 federal poverty level.
- Supplemental Security Income (SSI) is available to those who meet disability criteria and have an income less than 77 percent of the federal poverty level.
- The Children and Pregnant Women (CPW) Program covers most pregnant women and children up to age 2 with income below 100 percent of the poverty threshold, and children to age 19 in two-parent households with income up to 24 percent of the federal poverty level.

A study by the Texas Department of Human Services of Medicaid recipients who are known to have AIDS indicated that most qualified through eligibility for SSI.[17] People with AIDS are automatically eligible for SSI if they meet the financial eligibility criteria. Although HIV-related illness can be as devastating and debilitating as AIDS, it currently is not a "recognized" disability. In addition to meeting the financial eligibility criteria, people with HIV-related illnesses must document that they are disabled to qualify for SSI. The additional disability determination process is often complex and time-consuming.

A "Catch-22" situation severely limits the length of time most people with AIDS in Texas have Medicaid coverage (Figure 9). People who apply for SSI are automatically given Medicaid coverage for three months while their applications for Social Security Disability Insurance (SSDI) are being evaluated. SSDI is a federal cash benefit program in which eligibility depends on the applicant's recent employment history. The amount of cash assistance a person receives is determined by the amount of Social Security tax paid. SSDI benefits are usually greater than income allowed for SSI/Medicaid coverage in Texas. Thus, most people who are eligible for SSDI lose their Medicaid coverage. According to the Department of Human Services, the average length of Medicaid coverage for people known to have AIDS is less than 6 months. In the survey of Texans with HIV infection, 98 percent of the respondents with AIDS who had lost their Medicaid coverage stated their coverage ended because their SSDI benefits were too high.

Figure 9

Typical Third Party Coverage Scenario for Texans with HIV Infection



Source: Legislative Task Force on AIDS

Under federal law, SSDI recipients must wait 24 months before they can obtain Medicare coverage, the health insurance provided by the SSDI program. Most people with AIDS die before the end of the 24-month waiting period and, thus, never receive Medicare coverage. The Task Force's survey of people with HIV showed that only 1 percent of the respondents with AIDS had Medicare coverage. The survey of AIDS-related hospital costs showed that only 3 percent of all AIDS admissions were covered by Medicare in 1987.

Although the state Medicaid program covers inpatient and outpatient care, physician services, home health care, and prescriptions, limitations on the amount of services provided prevent people from receiving the most cost-effective care. For example, home health care is limited to 50 visits per year and only three prescriptions per month are covered. The State of Texas also imposes a 30-day limit on inpatient care and requires an individual to be out of the hospital 60 days before coverage can resume.

Reimbursement for Medicaid-approved services is made directly to the provider. In most cases, payment is made according to a formula that does not necessarily reflect the actual cost of services. For example, hospitals are reimbursed for care on the basis of "diagnostic-related groups" (DRGs) that provide estimates of the usual cost for certain illnesses and procedures. In Texas, there are no AIDS-specific DRGs. Hospitals are reimbursed according to payment categories for other DRGs. For example,

there is no specific DRG for Pneumocystis carinii pneumonia. Hospitals are reimbursed according to the DRG for pneumonia. This causes a two-fold difficulty for hospitals. First, the DRG system, in general, reimburses hospitals for only a portion of the cost of care, regardless of the services provided or the length of hospitalization. Second, this system does not accommodate the fact that the cost and length of hospitalization are greater for people with HIV. The survey of Texas hospitals indicated that the average length of stay for people with AIDS is 12 days, nearly double that of most hospitalized patients.

Recognizing the need to expand coverage for people with AIDS, the Texas Department of Human Services in 1988 initiated a Home and Community Services Waiver application. If approved by the federal government, the program would cover Medicaid services for more people with HIV-related illnesses. The increased income threshold would reduce the loss of Medicaid coverage that occurs when people begin to receive SSDI cash assistance. However, the waiver program has additional eligibility requirements. Applicants must meet intermediate care facility or skilled nursing facility level-of-care criteria established by the Texas Department of Health. The waiver would provide a "plan of care" that includes regular Medicaid coverage, and special waiver and volunteer services. The following services would be available: case management, homemaker, hospice, skilled nursing, outpatient narcotic and drug abuse treatment, and some private insurance payments available under COBRA.

The potential availability of matching federal funds makes expansion and revision of the Medicaid program advantageous. Texas has the option to include, as part of its matching share, local funds spent on health care services. Local funds support hospital district services, public hospital services, and county indigent health care services. If these local funds were used as part of the state's matching share, Texas could maximize the availability of federal funds and have more state funds available to support additional expansion.

Any of the following options would further increase federal assistance for expanding eligibility of services: (1) supplementation of the SSI cash assistance grant;(2) expansion of eligibility criteria to 100 percent of poverty for people who are aged, blind, or disabled; (3) expansion of the Medically Needy program; and (4) implementation of AIDS-specific DRGs. As administrator of the major funding source of public health care for people with AIDS, the Texas Department of Human Services has the responsibility to research aggressively and implement needed program expansions and improvements.

CONCERNS/PROBLEMS IDENTIFIED

- The Texas Medicaid program's restrictive financial and categorical eligibility requirements have severely limited access to care.

- The fragmented public health care system in Texas fails to incorporate all state and local services which meet Medicaid program criteria. Costs of providing those services could be incorporated into the state's Medicaid program and would then be eligible for federal matching funds. The failure to pursue federal funds results in a loss of millions of dollars for the State of Texas.

- For the few people covered under Medicaid, coverage typically lasts less than six months when individuals become eligible for financial assistance through the SSDI program. The SSDI assistance received usually renders people financially ineligible for continued Medicaid coverage. The waiting period for Medicare coverage associated with the SSDI program is 24 months.

- The Department of Human Services has applied for a federal Home and Community Services Waiver which could increase the scope of services available and the amount of allowable income for people with AIDS. However, the waiver has not yet been approved by the federal government. Also, the waiver program would be operative in only six pilot sites.

- Medicaid reimbursement for HIV-related care does not cover the costs of care.

- The Medicaid program's current limit of three prescriptions per month severely limits access to needed drug therapies.

People with HIV are subject to various acute illnesses and their prescription needs may change frequently.

RECOMMENDATIONS

20. The Legislature and state agencies should develop and implement a Medicaid program that will effectively and efficiently maximize available federal Medicaid dollars for all services meeting Medicaid program criteria. This program should encourage a coordinated indigent health care system that maximizes federal Medicaid matching dollars and should clearly recognize the needs of the localities that generate the indigent care or Medicaid program funding. Funds gained from a maximized Medicaid program and coordinated indigent health care program will significantly contribute to the State's ability to provide HIV-related services and other services required by persons lacking the means to pay.

21. The State's Medicaid Program should be expanded by increasing eligibility criteria. The Texas Department of Human Services should extend Medicaid coverage to persons with disabilities whose incomes range from 74 to 100 percent of the federal poverty threshold as allowed by the federal Omnibus Reconciliation Act of 1986.

22. The Texas Department of Human Services should complete and submit the waiver for Home and Community-based Services as soon as possible. The waiver should extend eligibility to the institutional Medical Assistance Only unit and should provide case management services, expanded primary home care, continuous private duty nursing, outpatient drug abuse treatments, and payment of private health insurance as allowed under COBRA or state continuation/conversion laws. Upon approval and implementation of the waiver, the Department should closely monitor the effectiveness of the waiver program, make needed adjustments, and when possible, expand eligibility statewide.

23. The Texas Department of Human Services should research and implement a freedom of choice waiver for HIV-related services on a pilot project basis. The freedom of choice waiver could be used to establish a capitated system based on managed care and provide a wide scope of services, including

home based care, homemaker/custodial care, respite care, and all other services available under the Home and Community-based Services Waiver. Once implemented, the Department should conduct a cost-benefit analysis of both waiver programs.

24. The Texas Department of Human Services should research the possibility of exempting SSDI income from calculation of income for eligibility determination for Medicaid coverage. If federal legislation is needed to affect this change, the Legislature should encourage Congress to pass legislation so that SSDI income is exempted from the calculation of income for eligibility determination for Medicaid coverage.

25. The Texas Department of Human Services should evaluate the feasibility and potential benefits of providing SSI supplements as a way to increase financial and medical support of persons with HIV.

26. The Texas Department of Human Services should evaluate the option of enabling disabled individuals who cannot obtain or afford health insurance to buy coverage on a sliding fee scale basis as an adjunct to the state's Medicaid Program.

27. The Texas Department of Human Services should develop and implement a program to pay COBRA and state continuation/conversion premiums for those eligible but unable to pay these costs.

28. The Texas Rehabilitation Commission and the Social Security Administration should actively work to reduce the number of inappropriate SSI/SSDI eligibility denials of persons with HIV-related illnesses.

29. The Texas Rehabilitation Commission should conduct special training for both SSI/SSDI eligibility workers and physicians to ensure accurate and timely application decisions for persons with HIV-related illness.

30. The Texas Department of Human Services should research and implement AIDS-specific Diagnostic-Related Groups (DRGs) for hospital inpatient care and appropriate Texas Index Level of Effort (TILE) levels in the nursing home case mix program. These should be based on the full costs of caring for persons with HIV-related disorders.

31. The Texas Department of Human Services should ensure that all DRG and TILE payments are increased to include the cost of implementing universal infection control precautions.

32. The Texas Department of Human Services should increase coverage of prescription drugs required by patients who are enrolled in the Medicaid Program.

PRIVATE/COMMERCIAL HEALTH INSURANCE CHANGES

> I am on a leave of absence from work, after which, if I terminate employment, the company is only obligated to keep me on the group insurance policy for 18 months. I don't know if I'll be able to keep the insurance, how much the cost will rise, or if I'll be eligible to get more insurance.
>
> Survey of Texans with HIV Infection

The availability and extent of health benefits through private or commercial health insurance vary greatly. The majority of private health insurance in Texas is provided through some type of employment-related group plan. Group health insurance may be provided through commercial insurance carriers, health maintenance organizations, or self-insurance.

Group health insurance provided through a commercial carrier is a negotiated contract between the policy holder (usually the employer) and an insurance carrier. Premiums and benefits provided are determined by the size of the group, its industry affiliation, and claims experience. In small groups, insurers may require medical underwriting. The primary goal of underwriting is

to determine the potential risk of insuring an applicant and generally includes screening tests such as blood analysis and electrocardiograms.

Most group insurance is "experience rated," which means that premiums are based on actual costs previously incurred by the covered employees. Except for very large groups, one or two expensive cases in one year can result in higher premiums for the entire group the following year. In order to avoid increases in premium costs, the policy holder may limit or exclude coverage of certain "expensive" illnesses, such as AIDS.

In Texas, group health benefits are provided increasingly through self-insurance. The employer accepts liability for all or part of the insurance claim. Instead of paying premiums, an actuarially determined amount is placed into a fund on which the company earns interest. Claims are paid from this fund. For purposes of regulation, under the Employees Retirement Income Security Act (ERISA) passed by Congress in 1974, self-insuring firms are not considered insurance companies and, thus, are exempt from state insurance laws. Self-insured firms avoid state premium taxes, do not have to provide state-required benefits, and are generally outside the scope of state regulation.

Some people who lose their group health insurance may be able to continue their insurance through continuation privileges provided under the federal Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) or through conversion or continuation privileges

provided under the Texas Insurance Code. COBRA requires, with minor exceptions, that all employers with 20 or more employees continue health coverage for up to 18 months after a worker loses benefits because of reduced work hours or through loss of employment. People eligible for continuation of benefits under COBRA are responsible for paying the premium, which is capped at 102 percent of the group rate. Because COBRA is directed toward employers, it affects both self-insured and commercially insured groups. The individuals covered through the COBRA continuation option are part of the covered group. The cost of their care will be considered in the experience rating of the insurance policy and the individuals are subject to all the restrictions, exclusions, and limitations of that policy.

Conversion or continuation privileges provided under the Texas Insurance Code are part of the benefit package negotiated between the policy holder and the insurance carrier. If a conversion option is selected, premiums for the new policy are usually more expensive and benefits are not as comprehensive as those available under the group plan.

For people who are self-employed or not eligible for group coverage, the only option for coverage is through individual health insurance policies. These refer to policies which insure one person and to those which insure members of one family. Medical underwriting is usually required for anyone applying for individual insurance. In general, coverage by individual policies is

more expensive and less comprehensive than those available through group plans.

In Texas, individual health policies are subject to more statutory requirements than group plans. The State Board of Insurance has established minimum standards for benefits under several categories of coverage. Under an individual policy, the insurance carrier may not add limitations or exclusions after the issuance of the policy if its renewal is guaranteed. If the policy is renewable at the option of the carrier, carriers can inform policy holders, with 31 days notice, that they will no longer renew that type of policy. Other policies then made available may include disease-specific limitations if the person has pre-existing conditions.

To make availabile health insurance for people considered uninsurable because of pre-existing medical conditions, 15 states have implemented high-risk pools. Risk-pools provide health insurance that is comprehensive, although costly, to people who can afford but have difficulty obtaining private health insurance. Risk pool insurance covers a broad range of health services generally comparable to group health insurance plans. Eligibility for pooled coverage usually requires documented rejection for health insurance by one or more insurance carriers. Some states allow enrollment when existing policies exclude coverage of certain conditions or cost more than comparable coverage under the pool.

Due to health characteristics of those covered, pool losses usually exceed premium income. To ensure that coverage is as affordable as possible, premium levels are usually capped at between 125 and 200 percent of comparable coverage. States with operating risk pools use a variety of mechanisms to offset pool losses. Most allocate pool losses among insurers licensed within the state in proportion to their share of total premium income. Most states using this approach allow the insurers to credit their assessment against their state premium tax, such as through a premium tax credit. Other mechanisms to offset pool operating losses include use of general revenue and a tax on gross revenue from patient services.

Health Insurance and HIV

The Task Force heard considerable testimony on loss of health insurance, problems with denials of coverage, and the many difficulties in obtaining individual policies. The survey of Texans with HIV infection showed that many lose their medical insurance when they end their jobs. At the time of initial diagnosis, the majority (83 percent) of respondents with AIDS were employed and had private health insurance (56 percent). By the time of the survey, only 23 percent were still employed. The proportion of patients with private insurance fell to 36 percent.

The survey of Texas hospitals clearly documents that private or commercial insurance most often covers HIV-related claims. Private insurance was the predominant source of payment (40 percent) for all AIDS admissions reported. Furthermore, private insurance

was the only payor source that adequately covered the cost of care.

The State Board of Insurance survey of insurance carriers and health maintenance organizations documents that health insurance is not available for applicants with HIV. The survey also documents that the status of group health insurance is affected when one member in that group tests positive for HIV. In some instances, only that member is denied coverage; in others, the entire group is denied.

People with HIV and many advocacy groups across the state urged the Task Force to recommend that coverage of HIV or AIDS be required by the State Board of Insurance. Only the Legislature has the power to require insurance carriers to cover certain conditions. However, caution should be taken when considering mandated insurance benefits. The movement toward self-insurance has been prompted, in part, by the fact that the Legislature mandated benefits in the past. In addition, some mandated benefits can increase policy holders' premium costs.[18]

The Task Force received testimony about the difficulty HIV service providers have in obtaining health, disability, or liability insurance for their employees and volunteers. The lack of such insurance coverage discourages people from providing HIV services, thereby further restricting the availability of needed services.

CONCERNS/PROBLEMS IDENTIFIED

- People with HIV who would otherwise be covered by group insurance often find their health care coverage restricted or eliminated.

- As long as self-insured groups that qualify under ERISA are outside the scope of state law and the regulation of the State Board of Insurance, groups that self-insure their health benefit programs avoid state regulation.

- People with HIV who have been covered by group policies may not have access to comparable benefits at an affordable premium under conversion if they are part of a group that is not subject to COBRA.

- People who are self-employed or who do not have access to group coverage must apply for individual policies which are subject to medical underwriting. HIV-infected people are generally considered uninsurable and, thus, unable to purchase individual health insurance policies.

- Small groups that include one or more people with HIV infection or other catastrophic illness may have trouble purchasing comprehensive health insurance for all members of that group.

- HIV service providers report difficulty in obtaining health, disability, and liability insurance. Without such coverage, individuals and organizations will be reluctant to provide care to persons with HIV infection.

- The scope of benefits included in an individual's health insurance program will directly affect the availability of different types of care.

RECOMMENDATIONS

33. The State of Texas should enact legislation to establish a Texas Health Insurance Pool to provide health insurance coverage to persons generally considered uninsurable.

The design of the Texas Health Insurance Pool should include the following:

- The scope of benefits should emphasize the use of home health care services and outpatient services as much as possible. The pool should provide appropriate coverage for inpatient services if needed. Use of alternative management structures, such as a health maintenance organization or a preferred provider organization, should be carefully evaluated as possible cost containment measures.

- Eligibility criteria should be broadly constructed so that persons with a wide range of medical conditions that have rendered them uninsurable are eligible for pool coverage. Eligibility should also allow coverage of groups and organizations. Eligibility for group coverage should include, but not be limited to, rejection of coverage by two insurers. A separate premium structure for group coverage should be established.

- While recognizing the need to control for adverse selection, waiting periods, and other restrictions relating to pre-existing condition limitations should allow access to needed health care services as soon as possible. These periods should not exceed 6 months.

- Premium costs, deductible levels, and maximum out-of-pocket costs should be structured to be as affordable as possible. Premium levels should be no less than 125 percent and no greater than 200 percent of the average group premium cost in Texas for comparable coverage.

- The financing mechanism to subsidize the operating losses of the insurance pools should be as broad-based as possible.

- A premium subsidy program should be developed on a sliding fee scale to increase the affordability of pool coverage.

34. In lieu of mandating insurance coverage for the treatment of HIV and AIDS, the Legislature should prohibit insurers or employers from amending or renegotiating group health insurance contracts in a manner that would result in discontinuation or limitation of insurance benefits for an individual receiving benefits for a condition or injury under the existing contract, subject to any amended or renegotiated durational limits, dollar limits, deductibles, or coinsurance factors for all physical illnesses generally.

35. The State Board of Insurance should continue to monitor closely the number of group health policies filed with exclusions or limitations of coverage of HIV-related conditions.

36. The Legislature should amend the Insurance Code to direct the State Board of Insurance to establish standards guaranteeing the availability of conversion policies that provide a comparable scope of benefits to the previously held group policy at an equitable cost.

37. The Legislature should require employers to notify eligible employees of their rights to purchase insurance coverage under conversion policies.

38. The State Board of Insurance should establish a market assistance program to assist providers of HIV-related services in obtaining affordable health, disability, and liability insurance coverage.

OTHER PUBLIC HEALTH CARE PROGRAMS

> There is too much red tape to go through. A lot of us are not healthy enough to stand in long lines or mentally alert enough to fill out mountains of paperwork.
>
> Survey of Texans with HIV Infection

Texas' health and human service system is fragmented and poorly coordinated. State programs, county programs, and hospital district services use different financial and categorical eligibility criteria and provide different levels of services. The best ways to address the underlying deficiencies in the health and human service system -- short of a thorough restructuring -- are to integrate eligibility requirements and to provide a comprehensive spectrum of services. Changes can be made to existing programs to improve the availability of essential services.

Indigent Health Care

People ineligible for Medicaid coverage who do not have comprehensive private health insurance must rely on county programs, hospital district services, or public hospitals. However, there is substantial variation in eligibility criteria and services provided by these programs.

Texas law requires that all counties not fully covered by public hospitals or hospital districts provide health care services to eligible residents. Required services include inpatient and outpatient hospital services, clinic and physician services, labora-

tory and x-ray services, pharmacy, family planning, and skilled facility services. Minimum eligibility standards are based on Texas AFDC income (24 percent of federal poverty guidelines) and resource requirements. The restrictive eligibility standards ensure that only the poorest of the poor are covered.

Each county is liable for spending up to 10 percent of its annual county revenue tax levy on health care services. After that, the Texas Department of Human Services will reimburse 80 percent of the cost of additional services if state funds are available. If funds are not available, the county is not liable for expenditures above 10 percent of its general tax revenue and is no longer obligated to provide indigent health care.

Some counties with large indigent populations reach their liability threshold early in the year. Other counties have been slow to implement programs. There is no way to ensure that counties comply with the indigent health care requirements.

Uncompensated Hospital Care

People ineligible for county and state programs must rely on hospital districts or public hospitals for health care. The burden of care for persons who cannot pay on hospitals in Texas is substantial and growing. In 1986, Texas hospitals provided $1.4 billion in care for which they were not compensated -- the highest level in the nation. Based on reports to the Texas Department of Health, this total was $200 million more than 1985.[19] In recognition of the burden associated with uncompensated care, the

69th Legislature, in 1985, established a Disproportionate Share Fund Program to provide financial assistance to hospitals which provide a large volume of uncompensated care. The responsibility for this program was assigned to the Texas Department of Human Services. The Disproportionate Share Fund is operated in conjunction with the state Medicaid program, which allows matching of state funds with federal dollars (40 TAC 29.609).

Other State Programs

People with HIV can obtain health care coverage through other state programs, such as Maternal and Infant Health Improvement Services, the Primary Health Care program, and the Chronically Ill and Disabled Children's Services program, if they meet the eligibility criteria. Only one program, however, specifically lists HIV or AIDS as a covered condition. The Chronically Ill and Disabled Children's Services program provides health care coverage for children with HIV infection, but only if the condition was diagnosed after a blood transfusion or treatment for hemophilia.

CONCERNS/PROBLEMS IDENTIFIED

- Indigent health care services are limited. Once a county expends 10 percent of its general tax levy on indigent care and if state assistance funds are not available to support further provision of services, counties are no longer obligated to provide indigent health care services.

- Uncompensated care for people with HIV places an increasing financial burden upon Texas hospitals.

- There is no state program designed to cover the care of HIV illnesses. Services provided through other state programs to people with HIV may not be the most cost-effective mechanism to cover needed services.

- The Chronically Ill and Disabled Children's Services program provides coverage of HIV only under limited conditions and certain diagnoses.

RECOMMENDATIONS

39. The Legislature should increase the Texas Department of Human Services' State Assistance Fund to increase funding support for counties that expend 10 percent of their general tax levy for indigent health care programs.

40. The Legislature should increase funding for the Disproportionate Share Fund administered by the Texas Department of Human Services to assist hospitals that provide substantial amounts of uncompensated care. The Texas Department of Human Services should analyze the amount of uncompensated care provided to persons with HIV-related illnesses and evaluate the availability of funding through the current Disproportionate Share Fund.

41. The Legislature should direct and fund the Texas Department of Health to establish an HIV Health Services Program that would provide coverage for health care services on a sliding fee scale. The program should be a payor of last resort and cover both ambulatory and inpatient health care services.
(Dissenting vote: Rep. Billy Clemons)

42. The Chronically Ill and Disabled Children's Services program should cover HIV infection and related disorders as a primary covered condition regardless of the mode of transmission.

CRIMINAL JUSTICE SYSTEM

> The HIV epidemic places enormous stress on already overburdened correctional systems. Current and accurate information can place corrections officials in a stronger position to address the problem of AIDS, provide sound education and training, ensure equitable delivery of services, and develop reasoned and effective management policies.
>
> AIDS in Correctional Facilities: Issues and Options [20]

HIV poses numerous problems for our state's criminal justice system. These are often inter-related and include testing, confidentiality, discrimination, housing, and access to care.

In the absence of statewide standards, individual criminal justice agencies have dealt with HIV in a wide variety of ways. Some agencies have not adopted any policy. Others rely only upon informal guidelines. Inconsistent or unwarranted policies may unfairly stigmatize individuals with HIV or AIDS or deprive them of access to needed treatment and services. Such policies may

also needlessly increase the cost of incarceration and exacerbate jail and prison overcrowding problems.

Discrimination against people with HIV and AIDS occurs within Texas' criminal justice system. For example, in San Antonio, a seropositive individual held in county jail before trial complained that her HIV status was loudly announced as she was brought into court, ostracizing her from other inmates and possibly prejudicing her trial.[21]

Similarly, although the Texas Department of Corrections has adopted policies for dealing with HIV-infected inmates, some inmates still complain of institutional discrimination. One inmate recently sued the Department, charging he was unfairly transferred from a pre-release program after his HIV status was disclosed.[22]

Closely related to discrimination are the issues of testing and the confidentiality of medical records. Although state law, (Art. 4419b-1, VTCS), allows the Texas Department of Corrections to require inmates to take an HIV test, the Department has done so selectively. Inmates who believe they may be infected are allowed to take a voluntary test.

Although state law and Texas Department of Corrections policy require that all test results be treated as confidential medical records, many inmates charge that breaches of confidentiality are commonplace. Texas Department of Corrections and Board of Par-

dons and Paroles policies that allow the release of inmate and parolee medical records to operators of halfway houses or pre-release facilities also have raised difficulties. Operators have refused to accept inmates with HIV, even those who show no symptoms of disease. Probationers with HIV infection face similar problems.

A related issue is that of mandatory HIV testing of people charged with or convicted of crimes possibly connected with HIV transmission. State law allows judges to order individuals indicted for certain sex crimes to be tested (Art. 21.31, Code of Criminal Procedure). However, the law is very narrowly defined and does not include people who may be charged with intravenous drug crimes.

As discrimination and inappropriate disclosure of medical records continue, and as the number of those with HIV increases, parole and probation authorities may find it difficult to secure residential facilities and rehabilitation and training programs for their HIV-infected clients. In the absence of alternative placements, people with HIV who are otherwise eligible for lower cost probation or restitution programs may be incarcerated instead, contributing to existing overcrowding and the costs of prison housing and medical care. Similarly, if inmates are denied parole or are transferred to pre-release facilities solely because of their HIV status, they may be required to serve longer sentences than non-infected inmates. This would further limit the availability of space urgently needed to incarcerate those

sentenced for more serious crimes. It could also invite potentially costly lawsuits charging illegal discrimination.

The HIV epidemic inevitably affects all individuals identified with a correctional program. As in other areas that involve direct client contact, criminal justice employees must have ongoing training and education about HIV. Employees with accurate and adequate information are more likely to better protect themselves and to respond appropriately to inmates, parolees, and probationers with HIV. Since many inmates have a history of high-risk behaviors, they clearly need education and prevention programs. Using condoms is one way to reduce the risk of HIV transmission. However, the Texas Department of Corrections has not made condoms available, despite the Department's acknowledgement that sexual activity occurs among inmates.

All inmates, probationers, and parolees should receive prompt and adequate health services. Probation and parole agencies should help ensure that their clients with HIV infection are referred to local community service providers. Within the Texas Department of Corrections, inmates should receive prompt and accessible medical care. Currently, inmates must travel to the Texas Department of Corrections hospital in Galveston for specialized medical treatment. Sometimes this requires a round-trip bus ride of more than 400 miles. The Department should seek to minimize the length of time inmates must travel to receive medical care.

CONCERNS/PROBLEMS IDENTIFIED

- Criminal justice agencies do not have consistent policies or training programs addressing HIV-related education, prevention, treatment, or service issues.

- State law regarding mandatory HIV testing of people indicted for certain sex crimes only address those who may transmit the virus through sexual contact. It does not address intravenous drug-related crimes.

- While the Texas Department of Corrections acknowledges that sexual activity occurs in Texas prisons, the Department has not made condoms available to inmates.

RECOMMENDATIONS

43. The Legislature should require state, county, and local criminal justice agencies, including the Texas Department of Corrections, Board of Pardons and Paroles, Adult Probation Commission, Juvenile Probation Commission, and the Texas Youth Commission, to develop and adopt uniform policies to deal with persons with AIDS or HIV infection who are in their custody. These policies should apply to agency contractors and subcontractors, as well as to the agencies themselves, and must provide ongoing education of staff; infection control training and materials as appropriate; and education of inmates, probationers, and parolees. Policies also should prohibit discrimination based on HIV status, ensure access to all appropriate services, and protect the confidentiality of medical records relating to HIV status.
(Dissenting vote: Rep. Billy Clemons)

44. There should be mandatory HIV counseling and testing of people who are finally convicted of sexual assault or intravenous drug crimes. There should be criminal and civil sanctions for such persons who knowingly transmit the virus after being informed of being seropositive.

45. While not condoning illegal activity in adult correctional settings, the appropriate agency should allow condoms to be available to its clients at cost.

LEGAL ISSUES

DISCRIMINATION

> The most difficult part of this problem is being unable to tell anyone about it. I am afraid of the consequences of anyone knowing that I might have AIDS. We have already had a problem within our family where a misunderstanding of AIDS caused fear and prejudice. I'm afraid if that can happen within a family, there's no telling what may happen with strangers.
>
> Hemophiliac with HIV

> Discrimination shifts the financial burden.... People who lose their jobs cannot pay for their own care. People who lose their homes become burdens on the community. People who lose their health insurance become bad debts for hospitals and physicians.
>
> Local health department director
> Lubbock hearing

The Task Force was confronted time and again with the realities of discrimination against people with HIV. A broad range of violations is evident in the areas of employment, insurance, housing, education, and health care. Stemming from fear and misunderstanding about AIDS and HIV infection, discrimination lies at the root of many of the obstacles associated with the epidemic. It directly contributes to the economic burden of the HIV epidemic. Discrimination also impairs the State's ability to mount an effective and swift attack against the spread of HIV. Discrimination against people with HIV, or their caregivers, is unjustified and has no public health basis.

The following are examples of HIV-related discrimination occurring in Texas:

- A grandmother lost her job when her employer learned she was the sole caregiver of her 3 year old granddaughter with AIDS. She was unable to find a day care center that would care for the child.

- The wife of a hemophiliac with HIV was fired from her job when she told her employer she had AIDS.

- The HIV status of a professional employed by a major corporation caused his employers to force his early retirement, even though he was fully capable of working.

The cost of HIV prevention and care pales in comparison to the economic consequences of discrimination. The stigma that so often accompanies an HIV-related diagnosis directly effects the earning power and economic productivity of Texans with HIV.

In the survey of people with HIV infection, the Task Force found that 15 percent of the 434 respondents lost their jobs due to discrimination. Nine percent lost their housing due to discrimination. One-third of the respondents were rejected by family members.

Discrimination is expensive. It often leads to indigency and the subsequent need for public assistance. When people lose their income and resources, they lose their financial independence. Ultimately, discrimination results in increased economic burdens and loss of revenue for local taxpayers.

Discrimination also has direct public health consequences. Fear of discrimination causes many people to avoid HIV counseling and testing and, therefore, early medical treatment that could prolong their productivity and life. Furthermore, as long as HIV-related discrimination occurs, people will refuse to participate in epidemiologic studies necessary to document the spread of the virus.

Texas law does not prohibit discrimination against people with HIV. The Texas Human Rights Commission Act (Art. 5221k, VTCS) prohibits employment discrimination on the basis of race, color, handicap, religion, sex, national origin, and age. However, the Act does not clearly protect people with HIV infection or their caregivers. The Human Resources Code (Title 8, Section 121.002 and 121.003) prohibits discrimination in housing and public facilities for people with mental or physical handicaps. The law does not explicity protect people with HIV or AIDS, or their caregivers. Furthermore, the law does not include any enforcement provisions and a recent Supreme Court case, (Redmon v. Chevron), has limited the application of this statute to only the most severe disabilities.

Under federal law, facilities that receive federal funding cannot discriminate against people with disabilities. Through legislative and court decisions it is now clear that Section 504 of the Rehabilitation Act of 1973 covers the range of HIV-related impairments, including HIV infection. This federal law, however, only applies to situations where federal funding is involved.

The State of Texas should enact legislation that would provide anti-discrimination protections for the full range of HIV-related impairments.

Even with statutory safeguards, legal remedies can be illusory. People with HIV infection rarely survive to complete legal steps against discrimination complaints. Even when illegality and damages are proven, HIV-infected plaintiffs rarely live long enough to see the conclusion of legal proceedings. While awaiting court decisions, their productivity and medical needs may be threatened and they may become more reliant on public welfare systems.

Fear of potential liability under the Deceptive Trade Practices Act has caused Texas real estate agents to breach confidentiality about people with HIV. Such actions are clearly rooted in misunderstanding about HIV transmission. The HIV status of the owner or occupant of a commercial or residential property cannot in any way pose a public health threat. Nevertheless, demands for such information present an awkward business situation for real estate agents. By prohibiting such disclosure, agents would be legally protected from divulging the HIV status of property owners or occupants.

Alleviating discrimination will require the commitment of individuals and organizations at every level and in both the private and public sectors of Texas. Strong anti-discrimination laws are needed to establish a standard of behavior and to remedy individual cases. In addition, because discrimination occurs in common

daily interactions and attitudes, its eradication depends upon truly effective HIV educational efforts. Through a combination of laws and educational programs and policies, the State of Texas can progress toward the creation of a society in which discrimination against those infected with HIV, as well as those with other handicapping conditions, is unacceptable.

CONCERNS/PROBLEMS IDENTIFIED

- Discrimination against people with HIV and their caregivers has serious fiscal implications for the State of Texas. It also hampers an effective response to the HIV epidemic.

- Texas law does not adequately protect the legal rights of people with HIV and their caregivers.

- Court procedures are often too lengthy to be of any help to HIV-infected Texans.

RECOMMENDATIONS

46. The Legislature should enact legislation prohibiting discrimination against persons with handicapping conditions, including HIV and AIDS, and their caregivers, friends, and families. The legislation should address employment, housing, health care services, education, and public accommodations.
(Dissenting vote: Rep. Billy Clemons)

47. The definition of handicap in the Texas Commission on Human Rights Act should be patterned after the language used in the Federal Rehabilitation Act of 1973. Under this definition, a handicapped person is one who:

- Has a physical or mental impairment substantially limiting one or more of the person's major life activities.

- Has a record of such impairment.

- Or is regarded as having such an impairment. (Dissenting vote: Rep. Billy Clemons)

48. The Legislature should encourage and support development of mediation programs to expedite out-of-court resolution of HIV discrimination complaints. Such programs should be clearly designed to expedite complaints and should not be used by any party to a dispute in any manner that would delay pending litigation.

49. The Legislature should enact legislation to bar disclosure of information regarding the HIV status of an owner, occupant, or former owner or occupant, of any residential or commercial property.

CONFIDENTIALITY OF MEDICAL INFORMATION

> To encourage individuals to come forward voluntarily for necessary testing, counseling, and treatment, our health care system must be viewed with confidence and trust by those in need of its services.
>
> Presidential Commission [23]

Closely linked to the problem of discrimination is that of confidentiality of medical information. Breaches of confidentiality about a person's HIV status or AIDS diagnosis are

often the impetus for discrimination in health care, education, employment, housing, and other settings. As long as discrimination remains a valid concern, the need to maintain the confidentiality of HIV information is critical.

Confidentiality of medical information is required in several sections of Texas law. First, the Texas Medical Practice Act states that medical information between a physician and a patient is "confidential and privileged." Medical records that contain the identity, diagnosis, evaluation, or treatment of a patient can only be disclosed in specified circumstances (Sec.5.08, Art. 4495b, VTCS). Second, the Communicable Disease Prevention and Control Act states that information regarding a person's HIV status is confidential and can only be released to listed individuals and entities (Sec. 9.03, Art. 4419b-1, VTCS). Civil liabilities are specified for breaches of confidentiality in both statutes.

Despite these prohibitions, breaches of confidentiality occur. Within a variety of employment, school, health care, and residential settings, people often express a "need" or desire to know the HIV status of their employees, students, patients, or clients. In most cases, violations of confidentiality are unnecessary. Education about HIV transmission usually alleviates most concerns that lead to requests for HIV information.

State-funded programs should prohibit unauthorized release of HIV-related medical information. However, few agencies have im-

plemented such policies. All state agencies and the entities with which they contract should adopt guidelines that protect the confidentiality of HIV-related medical information.

Disclosure of HIV information by insurance companies is frequently voiced as a concern of people with HIV. In fact, many are reluctant to submit insurance claims because they fear that their employers will learn of their HIV status. They also are concerned that, once computerized, their HIV status and medical information will not be adequately safeguarded. Currently, no state standards exist for protecting the confidentiality of medical information obtained in insurance transactions.

CONCERNS/PROBLEMS IDENTIFIED

- Despite prohibitions in state law, unauthorized disclosure of HIV-related medical information does occur. Breaches in confidentiality often lead to discrimination against people with HIV.

RECOMMENDATIONS

50. By the end of Fiscal Year 1990, all state agencies should have developed and implemented guidelines regarding confidentiality of AIDS and HIV-related medical information for employees, clients, inmates, and/or residents, as appropriate. The policies should be consistent with guidelines published by the U.S. Centers for Disease Control and state and federal laws and regulations.
(Dissenting vote: Rep. Billy Clemons)

51. By Fiscal Year 1991, all entities receiving funds through contracts or arrangements with state agencies for residential or direct client services or programs should have developed and implemented guidelines regarding the confidentiality of AIDS and HIV-related medical information of employees, clients, inmates, and/or residents, as appropriate. Such policies should be required for continued funding and consistent with guidelines published by the U.S. Centers for Disease Control and state and federal laws and regulations.
(Dissenting vote: Rep. Billy Clemons)

52. The State Board of Insurance should establish standards for the collection, use, and disclosure by insurance institutions, insurance agents, and insurance support organizations of personal information gathered in connection with an insurance transaction or application for coverage. Such standards should stress the confidentiality of medical information while balancing the need for information by those conducting the business of insurance with the public's need for fair insurance information practices.
(Dissenting vote: Rep. Billy Clemons)

53. The Legislature should ensure that state law provides for the confidentiality of a diagnosis of AIDS or an HIV-related condition.
(Dissenting vote: Rep. Billy Clemons)

EDUCATION AND PREVENTION SERVICES

> Total community education must...reach out to every individual in the community in a clear and coordinated way and be sustained until every employer has educated his or her employees, every school child understands the risk of sexual activity and needle sharing with infected partners, until every taxpayer understands the crushing burden of not preventing the spread of AIDS, and until every church reaches out in compassion to those affected by the epidemic.
>
> Health education professor
> Houston hearing

> Persons from all walks and stations of life, from many belief and value systems, from a broad section of professional life can unite to be effective forces in AIDS education and prevention.
>
> HIV service provider
> Minorities hearing

In the absence of a cure or vaccine, the most cost-effective way to curb the HIV epidemic is prevention. HIV is transmitted almost exclusively by behaviors that can be modified. Thus, educational programs that help people change high-risk behaviors minimize the spread of the virus.

HIV education programs must be comprehensive, factual, and understandable. Their messages should be consistent and reinforced. HIV education programs also need to be designed to address the age, ethnic, educational, cultural, and socioeconomic characteristics of their audiences. To assess and maximize the effectiveness of these programs, constant evaluation is necessary.

HIV counseling and testing are key components of prevention. Knowledge of HIV status, combined with professional counseling about the meaning of the test and necessary behavior changes, can limit the spread of the virus. Counseling and testing also can help encourage early medical intervention and adoption of behaviors that prolong a person's health.

Substance abuse, especially with intravenous drugs, is a major route of HIV transmission. To curb the long-term growth of the epidemic, substance abuse education, treatment, and intervention programs must be readily accessible.

GENERAL EDUCATION

> There is no lack of information about AIDS -- what is lacking is effective coordination, targeting, and distribution of information.
>
> Report of the Dallas County AIDS Planning Commission [24]

The HIV epidemic affects all of society. Every citizen, regardless of age, gender, ethnicity, or geographic location needs a basic understanding of HIV and AIDS. Education programs aimed at the general public have two primary purposes: (1) to encourage people to adopt or maintain behaviors that prevent HIV transmission; and (2) to convey accurate information about how HIV is

spread, thereby correcting misconceptions and allaying unwarranted fears.

Despite the national household mailing on AIDS by the federal government and the frequent mention of AIDS by the media, misinformation persists. A recent survey conducted by the University of Texas at Austin found that 34 percent of those surveyed believed they could "get the AIDS virus" from an insect. More than one-fifth of the respondents believed they could become infected by handling food, sitting on a toilet, donating blood, or being coughed or sneezed on.[25]

The education of all Texans about HIV will require a multifaceted approach. HIV education must be a shared responsibility. Community leaders should be knowledgeable about HIV and AIDS and take a prominent role in educating the general public. Business leaders should ensure that accurate HIV-related information is available in their worksites and communities. Religious leaders should encourage compassion, care, and understanding of people with HIV and their caregivers. Professional and provider associations, especially those involved with health and social services, should help design and implement HIV education programs. Radio, television, and print media should present accurate HIV educational messages in ways that will reach large numbers of citizens within targeted audiences. Public officials should make an effort to understand the scope and complexity of issues related to the HIV epidemic and to formulate public policies based on medical and scientific knowledge.

Texas lacks a comprehensive and systematic approach to HIV education. Many community-based organizations provide basic information and written materials about HIV. However, there is no consistent mechanism for monitoring the accuracy of HIV information or establishing programs where none exist. To protect public health, the State, through the Texas Department of Health, has a clear responsibility to help communities design and implement HIV education programs. Such assistance is especially needed in rural areas, where fewer resources exist.

CONCERNS/PROBLEMS IDENTIFIED

- HIV education programs are needed to restrain the HIV epidemic and to foster appropriate public response.

- Texas does not have a well-organized or comprehensive approach to educating the public about HIV. State-level leadership and guidance on the availability, content, and design of HIV education programs have been limited.

RECOMMENDATIONS

54. All HIV education programs in Texas, including those funded or promoted by state agencies, should:

- be accurate, consistent and complete;

- be up-to-date information from the U.S. Centers for Disease Control;

- contain, at a minimum, factual information about basic routes of HIV transmission and ways to avoid such transmission;

- encourage compassionate and medically sound policies regarding persons with HIV infection.

55. The Texas Department of Health should have the primary responsibility for ensuring that sufficient and appropriate HIV education and prevention programs are available for the general public throughout the state. Activities necessary to fulfill this responsibility include, but are not limited to:

- Expanding and administering state-funded grants to community-based organizations for HIV education and risk reduction programs. The Department should ensure timely contract agreements and funding, ongoing monitoring of and assistance to grantees, and careful standardized evaluation of grantees.

- Assisting communities and organizations in identifying local HIV education needs; designing and implementing effective, targeted education programs; providing training for community educators; and assisting with media relations and public promotions.

- Serving as the primary resource for HIV education and risk reduction materials within the state.

- Determining where HIV education efforts are needed in Texas; initiating programs in those areas by identifying local resources; and helping communities, especially those in rural areas, establish self-sustaining private/public collaborative education programs.

DISTINCT POPULATION TARGETING

> There has been very little education to those individuals at greatest risk for this disease...we can anticipate transmission to still be occurring.
>
> HIV service provider
> Houston hearing

> Slowly and steadily the color of AIDS is changing. Texas will need innovative programs designed and implemented by persons from the Black and Hispanic communities who can best reach this population through on-the-street education, church groups, and existing role models in the minority community.
>
> Local health department director
> Minorities hearing

To be effective, HIV education efforts must address the diverse cultural, educational, socioeconomic, and behavioral characteristics of the people who live in Texas. As with all health education, HIV information must be targeted to specific groups and presented in ways that will help people adopt and maintain low-risk behaviors. Control of the spread of HIV will largely depend on the availability and effectiveness of education and prevention programs.

About 90 percent of the Texans diagnosed with AIDS have been homosexual or bisexual men. Educating these men about how to halt HIV transmission must be among the State's highest public health priorities. Important studies in San Francisco and other major cities clearly demonstrate that HIV education programs have directly contributed to slowing the rate of transmission among

homosexual and bisexual men.[26] In Texas, gay community-based organizations have taken the lead in organizing and funding education and behavior modification programs. Their efforts should be acknowledged and supported by the State.

Reported AIDS cases among ethnic and racial minorities in Texas do not mirror national trends. Nationally, more than 40 percent of AIDS cases among minorities is due to intravenous drug use. In Texas, only about 20 percent result from intravenous drug use. Attempts to reduce HIV infection among ethnic and racial minorities in Texas must reflect the specific transmission patterns occurring in our state. Furthermore, HIV education programs must take into account the language and cultural characteristics of Texas' ethnic and racial minorities. They also should be designed and administered by people with direct knowledge and experience with such communities.

The comparatively low number of AIDS cases in Texas among women and ethnic or racial minorities must not be taken as cause for complacency about the need for education programs among such communities. AIDS statistics do not provide a reliable picture of how many Texans are currently infected with HIV or may become infected during the next few years.

There are few HIV education programs for Texans with physical, mental, or learning disabilities. For example, few HIV education programs offer interpreters or captioned visual media resources, limiting the availability of information to people with hearing

impairments. Similarly, HIV information is rarely available in Braille for people with visual impairments. Few, if any, programs exist for people with other physical handicaps or learning disabilities.

Thirty-three percent of all adult Texans are functionally illiterate.[27] This fact, combined with the language and cultural diversity of Texas residents, necessitates the development of specialized HIV educational materials for people who may be illiterate or not fluent in English.

CONCERNS/PROBLEMS IDENTIFIED

- Special emphasis must be given to educating people whose behaviors might place them at high risk for acquiring or transmitting HIV infection.

- HIV education programs must address the specific sociocultural, behavioral, language, and learning characteristics of targeted populations and be readily available and accessible throughout the state.

RECOMMENDATIONS

56. The State of Texas should actively promote and fund effective HIV education and prevention programs targeted to persons whose behaviors place them at high risk for HIV transmission. To maximize the potential for behavior changes, programs should be targeted to distinct populations, designed in close consultation with members of the intended audience and tailored to the specific language, cultural, financial, educational, age, and developmental characteristics of the intended audience.

57. To meet the primary goal of reducing HIV transmission, it may be necessary, in some cases, to discuss and promote the effective use of condoms and the use of bleach to clean IV drug needles and syringes. It may also be necessary to develop and distribute explicit materials about sexual activity and IV drug use for use in counseling or in small group sessions with targeted populations.
(Dissenting vote: Rep. Billy Clemons)

58. All state-funded health clinics and substance abuse treatment and prevention programs should make HIV prevention information and materials, including condoms and bleach if appropriate, available to their patients and clients. HIV information should be routinely incorporated into patient education and counseling in clinics for substance abuse, family planning, sexually transmitted diseases, and women's reproductive health.
(Dissenting vote: Rep. Billy Clemons)

59. Inmates, staff, and clients of treatment, educational, correctional or residential facilities under the jurisdiction of the following state entities should routinely be provided with HIV education targeted to their cultural, educational, language, and developmental needs: Adult Probation Commission, Board of Pardons and Paroles, Commission on Alcohol and Drug Abuse, Commission on Jail Standards, Department of Corrections, Department of Health, Department of Human Services, Department of Mental Health and Mental Retardation, Juvenile Probation Commission, local jails, School for the Blind, School for the Deaf, Texas Rehabilitation Commission, and the Texas Youth Commission.

60. The Texas Department of Health should fund and aggressively promote HIV education and prevention programs targeted to homosexual and bisexual men.

61. The Texas Department of Health should fund and aggressively promote HIV education and prevention programs targeted to racial, ethnic, and language minorities.

62. The Texas Department of Health should encourage health care providers to promptly and accurately report AIDS diagnoses in racial and ethnic populations.

63. The Texas Department of Health, in formulating HIV reduction policies for ethnic minorities and assisting local community-based organizations in this attempt, should ensure that such policies and campaigns reflect the nature and spread of infection within ethnic minorities in Texas.

64. If Texas is to ensure that the spread of HIV infection among ethnic minorities does not accelerate to national rates, efforts must be made to ensure that transmission categories under-represented in this state among this group do not increase. This can be done by ensuring that ethnic minority populations are included in campaigns aimed at substance abuse, women, and prenatal counseling.

65. The State of Texas should promote or develop HIV education and prevention programs specifically designed to address the concerns of persons with physical and/or mental disabilities. Programs should be developed in consultation with persons with disabilities or experts in the appropriate fields.

66. To the maximum extent possible, state-funded HIV education and prevention programs should be accessible to persons with physical disabilities.

67. The Texas Commission for the Deaf, in conjunction with the Texas Department of Health, should continue to promote and support the TDD statewide HIV information and referral hotline and to develop and distribute educational materials specifically designed for persons with hearing impairments.

68. The Texas Commission for the Blind, in conjunction with the Texas Department of Health, should develop and distribute HIV education materials in Braille and on audiotapes throughout the state.

69. The Texas Department of Mental Health and Mental Retardation, in conjunction with the Texas Department of Health, should develop and distribute HIV education materials for persons with mental disabilities for inclusion in training and education programming.

70. The School for the Deaf and the School for the Blind should integrate appropriate HIV education into staff training and student programs.

71. The Texas Department of Health, in conjunction with the Texas Education Agency and appropriate public and private sector agencies, should design and distribute HIV educational materials targeted to persons with no or low reading comprehension levels.

PUBLIC SCHOOL EDUCATION

> If one student...were to contract AIDS because we did not give the information necessary to learn about the disease, to prevent it, then I would feel...that I had failed at my job.
>
> High School Principal
> El Paso hearing

> The AIDS epidemic has presented the American people with a terrible dilemma. It requires us to provide information to young people that we may not feel comfortable discussing in the classroom -- or even at home. But while we agonize about talking frankly about how the disease is transmitted and can be prevented, more young adults are becoming infected with a virus that may kill them.
>
> Effective AIDS Education: A Policymaker's Guide [28]

Educating Texas youth about HIV is the best way to reduce the long-term impact of the epidemic. Classroom materials are avail-

able from federal authorities like the U.S. Centers for Disease Control and most of the Texas regional Education Service Centers. However, model curricula have not been disseminated for use in Texas public schools and HIV education efforts have been implemented only at local discretion. There is no mechanism to track the number or types of programs across the state or to ensure that materials are accurate, consistent, and uniformly available.

This situation reflects the tradition of a decentralized public education system in Texas. Typically, the Texas Education Agency and the State Board of Education work together to set general policy and curriculum guidelines, leaving local districts a considerable degree of autonomy and control over specific areas of concern. Presently, decisions about HIV-related education are left to local districts. Many school administrators are working to overcome obstacles to effective instruction, including the lack of resources, concerns about repercussions from discussing sex or drugs in the schools, and a lack of understanding or confidence about teaching HIV-related curricula. Texas' nearly 1,100 independent school districts have varying needs, interests, and financial resources available to implement HIV-related education. None are required by state authorities to undertake HIV programs.

HIV education efforts also have been hampered by the lack of mandatory, comprehensive health education in Texas. Under State Board of Education rules, health information must be taught in kindergarten through grade seven. In high school, only one se-

mester of health education is required. Without the foundation provided by broad health education, students have inadequate knowledge and understanding of the concepts necessary to assimilate new, HIV-specific information. The effectiveness and appropriateness of HIV-related information are diminished when material is presented sporadically or not integrated into other coursework.

Two recently developed programs address some of the HIV-related needs in public schools. Education for Self Responsibility, which provides a model for coordinating instruction across subject areas, has been expanded by the Texas Education Agency to include AIDS. Once completed, this integrated approach to teaching HIV-related material will be promoted in a federally funded curriculum development and teacher training program targeting five regions of the state. These efforts, however, may not be implemented statewide for several years.

HIV education efforts in public schools must be expanded. According to a recent statewide poll, 98 percent of those surveyed agreed that AIDS education should be taught in the public schools. Sixty-three percent believed that AIDS education should begin before grade six.[29]

It is neither necessary nor desirable for HIV education programs to be identical. However, all public school education efforts should contain the following elements:

1. Age/developmental appropriateness. HIV-related information should be presented in a manner appropriate to students' ages and developmental levels. Educators, with advice from parents, are best equipped to determine at what level various topics are appropriate for children in Texas schools.

2. Full and accurate information. At the appropriate developmental level, HIV education programs should provide students with full and accurate information on HIV transmission routes and on methods to avoid or reduce transmission. This information should be presented in a manner that emphasizes abstinence from substance abuse and sexual behavior and thoroughly discusses those behaviors as they affect HIV transmission. Educators can provide needed information about sex and drug abuse behaviors without promoting those behaviors.

3. Local participation. In keeping with the tradition of local initiative and control, school districts must assume the primary responsibility for planning curricula and methodology for HIV-related education. Parents should have the opportunity to participate in program planning. They should be adequately informed about HIV and have access to all the information provided to students.

Teachers play an essential role in addressing HIV in the schools. There are no state-sponsored training programs to provide comprehensive, up-to-date, and accurate HIV information for teachers. Consequently, teachers may not fully understand the transmission

of HIV or policy considerations. This can, in turn, impede their ability to respond to students' questions or to respond appropriately to an HIV-infected student or colleague. Although Texas teachers must attend four days of in-service training each year, the content of the programs is not specified. To learn more about HIV, many teachers must do so on their own time. For those with the responsibility to teach HIV-related courses, the in-service training that does exist may not be adequate.

CONCERNS/PROBLEMS IDENTIFIED

- Texas public schools have not uniformly or consistently undertaken HIV-related education programs. No statewide mechanism exists to track such programs in the public schools or to assure that accurate and up-to-date materials are used.

- The lack of comprehensive health education in the schools leaves students without the foundation or preparation to integrate HIV-related information.

- Although curriculum development and teacher training programs have recently been undertaken by the Texas Education Agency with federal funds, these efforts may take years to implement statewide.

- Many public school teachers, staff, and administrators are not given adequate training in the areas of HIV transmission,

prevention, and policy. As a result, teachers may be ill-prepared to address HIV-related concerns.

RECOMMENDATIONS

72. The Texas Education Agency should have primary responsibility for ensuring that public school instruction includes accurate, comprehensive, and consistent information about HIV and ways to prevent its transmission. All HIV programs and materials developed or supported by the Texas Education Agency should be consistent with up-to-date findings of the U.S. Centers for Disease Control.
(Dissenting vote: Rep. Billy Clemons)

73. The Legislature should require all independent school districts to implement, in kindergarten through the 12th grade, comprehensive school health programs that emphasize health promotion and disease prevention by the Fall of 1990. The programs should include family life education encompassing age-appropriate information about decisionmaking skills, family and interpersonal relationships, and the value of abstinence from sexual intercourse until adulthood. Such curriculum should also include, but not necessarily be limited to, age-appropriate instruction on: (1) the definition, symptoms and prognosis of HIV infection and AIDS; (2) routes of HIV transmission; and (3) ways to prevent HIV transmission, including, but not limited to, abstinence from sexual relations and substance abuse.
(Dissenting vote: Rep. Billy Clemons)

74. Before implementing a new HIV-related curriculum, independent school districts should make the curriculum and associated educational materials available to students' parents and guardians for their review.

75. The Texas Education Agency should serve as the primary state resource for educational approaches and materials and assist independent school districts in developing HIV-related curricula. As part of this responsibility, the agency should gather and disseminate effective HIV curricula and materials and conduct educational seminars for school district personnel.

76. The Texas Education Agency should survey all independent school districts to assess the extent and educational context of HIV-related instruction throughout Texas and the level of training of HIV curriculum instructors. The agency should issue a comprehensive report of its findings to the 72nd Legislature when it convenes in January 1991.

77. A tiered system of mandatory in-service training on HIV should be instituted for all employees and volunteers in all independent school districts by the Fall of 1990. Such training should include, at a minimum:

- Basic information about the virus, routes of HIV transmission, and infection control measures.

- Relevant federal, state, local, and district laws and regulations regarding the rights of persons with HIV, including, but not limited to, release of medical information, confidentiality, and anti-discrimination.

- Resources within the community providing further HIV education and services.

More detailed instruction should be required for teachers, staff, and administrators in health or related fields, according to guidelines developed by the Texas Education Agency.

78. The Texas Education Agency should prepare and disseminate an information guide to all public school administrators, teachers, and personnel that includes accurate and up-to-date facts on HIV policies, relevant state and federal laws, and basic information about HIV transmission and infection control procedures. The guide should be prepared in conjunction with the Texas Department of Health and updated annually.

79. Schools of education should incorporate into existing courses the information and training needed to teach an HIV curriculum.

COLLEGES AND UNIVERSITIES

College and university campuses can serve as an important environment for HIV education of young adults. In many cases, campuses are relatively self-contained communities and are the only source of health care information available to their students. The effective implementation of HIV educational programs in institutions of higher education is among the stated objectives of the American College Health Association[30] and should be a leading priority for Texas colleges and universities.

The desire for HIV education is strong among Texas' student populations. Between 92 and 95 percent of college students recently surveyed expressed an interest in obtaining more information about HIV transmission, AIDS symptoms, and treatments, and risk-reduction behaviors.[31]

Texas colleges and universities are multipurpose communities. They provide a wide spectrum of services from teaching to residential facilities and medical care. Additionally, they serve as major employers. Controversy has occurred within some Texas institutions of higher education regarding the provision of family planning services -- including the distribution of condoms -- and policies concerning students, faculty, and staff with HIV infection. HIV prevention activities, as well as legal concerns, are best addressed when policies are carefully formulated, adopted, and based on reliable medical information.

With respect to HIV education, prevention, and policy, Texas colleges and universities have a unique opportunity and responsibility to provide important leadership. As visible public entities with broad roles, their actions will be widely recognized as models for other employers and for society at large.

CONCERNS/PROBLEMS IDENTIFIED

- College and university students need to have access to information about HIV and referrals to HIV service providers and testing sites.

RECOMMENDATIONS

80. All publicly funded institutions of higher education should make educational materials about HIV available to every student. This material should address, at a minimum, basic information about HIV, including routes of transmission and ways to prevent transmission, and referrals to local HIV service providers and anonymous HIV testing sites.

81. Student health centers should take a prominent role in providing clear, accurate information on how to prevent HIV transmission, including discussion and distribution of condoms; offering or referring to anonymous HIV counseling and testing services; and facilitating effective campus-wide, ongoing HIV education programs.
(Dissenting vote: Rep. Billy Clemons)

82. Boards of Regents, administrators and faculty of all colleges and universities should make a conscientious effort to have a thorough understanding of HIV transmission; federal, state and local laws and regulations pertaining to HIV; and effective HIV education and pertinent behavior change strategies aimed at young adults.

HEALTH CARE PROFESSIONALS

> There is a lot of ignorance and a lot of misconceptions among practicing physicians about the risks they incur in treating patients that are infected with this virus.
>
> Hospital administrator
> Lubbock hearing

> I had to close the door. I quit taking HIV-positive patients three months ago. We turn away three to four calls a day of individuals who have HIV disease in my office alone.... The system that doesn't provide for its providers is going to fall apart.
>
> Private physician
> Austin hearing

Education of health care professionals is critically important in increasing the quality and availability of care for people with HIV and in disseminating reliable information about this disease. The Task Force received extensive public testimony on the lack of HIV knowledge among health care providers. HIV information is not uniformly available in health care education programs. Coverage of HIV in continuing education programs also has been sporadic. Inadequate knowledge and expertise about HIV can result in inappropriate treatment of HIV-infected patients and prolonged or unnecessary hospitalization.

Recent federal funding of an AIDS Education and Training Center at the University of Texas School of Public Health in Houston will provide the first coordinated statewide mechanism to educate

and assist those who treat HIV patients. The center will provide:

- An administrative infrastructure to educate health care professionals about HIV.
- Educational programs, materials, workshops, and seminars to meet specific regional needs.
- An extensive literature review and bibliography.
- An AIDS hotline to answer general and specialized treatment questions.

The Center is an important model and first step in the education of health care practitioners. Additional mechanisms, however, are needed. Federal funding will end in 1991. Also, it is not yet clear how well the Center will reach small providers in rural areas or if the materials developed will be widely available.

Ensuring adequate education of health care professionals will necessitate collaboration among educational facilities, health care providers, and provider and professional organizations. The curricula of educational facilities must include a comprehensive overview of the diagnosis, prevention, and treatment of HIV and AIDS and infection control measures. Materials developed by the Education and Training Center should be made available to educational facilities and provider and professional organizations. Educational facilities, especially state-supported health science centers, should work with other providers and professional organizations in developing continuing education programs and materials. Provider and professional organizations are important vehicles for continuing education programs for their members and staff. Their involvement will reinforce their ethical commitment

to the provision of services regardless of patient diagnosis or lifestyle.

Continuing education programs are important for two reasons. First, they can provide comprehensive information on HIV to people whose health training was completed before the disease was discovered. Secondly, education about HIV improves providers' understanding of the disease, alleviates unnecessary fears about serving HIV-infected patients, and expands the availability of services. Continuing education programs can also provide information on recent developments in HIV diagnosis and treatment. As research continues, knowledge about HIV and its most effective treatment will change rapidly. It is important that a mechanism be in place to disseminate that information quickly.

All health care providers should be fully educated about HIV and infection control measures. Those who work closely with HIV patients must receive additional training. Many health care providers are not prepared to help meet the psychosocial needs associated with either human sexuality or death and dying. The development of educational and support resources for professionals who care for HIV patients will help prevent "burnout" of skilled personnel and will attract more professionals to this specialization. As the demand for HIV-related services grows, the demand for skilled professionals will substantially increase. Effective HIV training for these professionals, especially in rural areas where fewer resources exist, must be steadily pursued and closely monitored over the next several years.

CONCERNS/PROBLEMS IDENTIFIED

- Statewide efforts to educate health care professionals and students about HIV are limited.

- Health care professionals often have limited access to up-to-date information on treatments and protocols necessary to provide appropriate care to people with HIV infection.

- Increasing numbers of adequately trained health professionals will be needed to meet expected HIV-related treatment needs.

- Continuing education programs and educational materials for providers are not widely available.

RECOMMENDATIONS

83. The Legislature should develop incentives to ensure that sufficient numbers of adequately trained medical, dental, nursing, allied health, and mental health professionals are available to meet the treatment and service needs of persons with HIV infection.

84. The Legislature should require state-funded medical, dental, nursing, allied health, counseling and social work degree programs to include in their curricula information about HIV transmission and prevention and federal and state laws pertaining to HIV. Further, such programs should give special attention to professional stresses associated with the care of patients with terminal illnesses.

85. The Legislature should encourage medical, dental, nursing, allied health, social work, and mental health professional and provider associations to include in continuing education requirements and curricula information about: HIV

transmission and prevention, infection control practices, the importance of early intervention programs, and state and federal laws and regulations regarding confidentiality, release of medical information, and discrimination. Such associations also should provide their members with information, training, and supportive services on HIV.

86. Nursing home administrators, nurses aides, home health aides, homemakers, and other persons providing primary home care and residential services should be adequately educated about HIV infection, including routes of transmission, infection control practices, and state and federal laws and regulations regarding release of medical information, confidentiality, and anti-discrimination.

HIV COUNSELING AND TESTING

> Because of the important medical, psychological, ethical, and social implications of HIV antibody testing, providing adequate counseling and education is imperative.
>
> AMA Physician Guidelines[32]

Testing for HIV is a vital public health tool. However, the effectiveness and appropriateness of HIV testing are limited by the nature of the test and by some unique characteristics of the epidemic. Both pre-test and post-test counseling are essential to sound HIV testing policies.

When referring to the "HIV test," most people mean the enzyme-linked immunosorbent assay (ELISA), a blood test that detects

antibodies to HIV. Developed as a way to screen the blood supply, the ELISA neither confirms the actual presence of HIV nor provides a firm diagnosis of HIV infection or AIDS. It is a highly sensitive test that is designed to indicate the presence of HIV antibodies. The ELISA is so sensitive that it can produce a significant number of false positive results, especially among people at low risk for HIV. In HIV testing protocols, a positive ELISA is generally repeated and a confirmatory test, like the Western Blot, is conducted to verify the presence of HIV antibodies.

Among the most important uses of HIV tests are:

- To help diagnose individuals who have HIV-related symptoms.

- To screen blood, blood products, bodily fluids, organs or tissues for donation.

- To determine the incidence of HIV in a specific population.

To the maximum extent possible, all HIV tests should be confidential. Because of the stigma attached to AIDS and the discrimination against people who are HIV-infected or who are perceived to be infected, public health officials have developed systems for anonymous testing, known as "alternate test sites." These facilities allow people to use a pseudonym or identification number in order to assure an extra measure of confidentiality. Assurance of confidentiality encourages voluntary testing among

those most in need of HIV testing -- people with behaviors that might place them at high risk for HIV. The anonymity provided at these sites has dramatically increased the demand for testing, especially among high-risk populations.[33]

Federal funds have enabled to the State of Texas to offer anonymous testing since 1985. Federal funding regulations require that anonymous testing be accompanied by detailed pre- and post-test counseling, the component of HIV testing that is most likely to encourage the behavior changes needed to prevent HIV transmission. As of November 1988, the Texas Department of Health contracted with 35 organizations across the state to provide anonymous HIV testing.

The availability and accessibility of anonymous test sites, as well as facilities that offer confidential testing, are inadequate to serve all Texans who want to be tested. In some areas, there are not enough personnel and other resources to meet the demand, and people must wait several weeks to be tested. In other areas, people must travel 100 miles or more to be tested. Those who are concerned about their HIV status should have prompt access to testing. The State of Texas should remove all barriers that inhibit or delay people with high-risk behaviors from being voluntarily tested.

HIV test results have serious medical and social implications. Although all federally funded anonymous test sites provide pre- and post-test counseling, in other settings people are sometimes

tested without a full understanding of the test and its implications. They also may not obtain counseling on the appropriate actions to take following a positive test result, such as the need to change high-risk behavior, the desirability of notifying sex or needle-sharing partners, referrals to health or social service providers, and the benefits of early intervention.

Because of the sensitive and critical nature of HIV counseling sessions, counselors must be appropriately trained. But, because of the relatively recent development of the HIV epidemic and the rapid increase in demand for testing, counseling may not always be provided by well-trained personnel.

The laboratory procedures used to conduct an HIV test are also critical components of effective testing. Faulty testing can occur in home testing or in facilities that do not meet the laboratory standards of a clinic, hospital, or anonymous test site. Home test kits or mobile or storefront "labs" do not adequately address the sensitive nature of the test and the need for pre- and post-counseling.

HIV antibody testing continues to be a topic of controversy, confusion, and sometimes heated debate. Unfounded fears, misunderstanding, and even well-intended concerns to "do something about AIDS" can lead decision-makers to advocate testing without consideration of the benefits or limitations of the tests, HIV transmission, the cost-benefits of testing, or applicable federal, state, and local laws. For example, mandatory HIV testing

for marriage license applicants has been a very expensive and ineffective HIV prevention strategy.[34] Also, in health care settings, HIV testing is often proposed for situations in which possible HIV transmission could be averted through routine infection control procedures. Texas law, (Art. 4419b-1, VTCS), generally prohibits mandatory testing and provides for confidentiality.

Testing for HIV should be treated as any other important medical procedure. Concepts like confidentiality and consent are not new to medical practice and should be applied in the case of HIV testing. However, because of the implications of the test, the documented evidence of discrimination, and the unique nature of the currently available testing mechanisms, special actions are needed to ensure appropriate testing. HIV testing programs, practices, or policies should:

- Be based on medical and scientific evidence.
- Be consistent with state, federal, and local laws and rules and with generally accepted medical practice.
- Consider evidence on the most effective use of the test.
- Consider the costs and benefits of testing.
- Identify reasonable goals or objectives of testing.

Against these criteria, most mandatory HIV testing is unjustifiable. When people come forward voluntarily, the effectiveness and cost-efficiency of the testing are greatly increased. Those who

voluntarily seek HIV testing may be more motivated to alter behavior.

CONCERNS/PROBLEMS IDENTIFIED

- Anonymous counseling and testing sites provide important education and prevention services to many people whose behavior may place them at risk for HIV. However, these services are not readily available.

- All publicly funded HIV counseling and testing facilities in Texas are financed by the federal government. Current funding is insufficient to provide services throughout the state.

- A positive HIV test has critical health implications and, because of the discrimination associated with AIDS, often has social and economic consequences as well. Nevertheless, people have been tested for HIV antibodies without their knowledge or without an understanding of the test and its implications. Confidentiality regarding the test results also has been breached.

- Testing alone is an ineffective prevention tool. Without appropriate counseling, behavior modification to reduce HIV transmission is less likely.

RECOMMENDATIONS

87. The Texas Department of Health should ensure that affordable, voluntary, anonymous, and/or confidential HIV counseling and testing services or referrals to such services are routinely available in all state-funded clinics, such as those dealing with sexually transmitted diseases, women's reproductive health, tuberculosis and primary care.
(Dissenting vote: Rep. Billy Clemons)

88. The Texas Department of Health should ensure that affordable, voluntary and anonymous HIV testing and counseling are available within each public health region and that communities are aware of these test sites. Counseling and testing facilities should be readily accessible to those at high risk of HIV infection.
(Dissenting vote: Rep. Billy Clemons)

89. The Texas Department of Health should ensure that HIV counseling and testing facilities in each public health region adhere to the U. S. Centers for Disease Control guidelines regarding partner notification services.

90. The Texas Commission on Alcohol and Drug Abuse should ensure that voluntary, affordable, and anonymous HIV counseling and testing services are routinely available at all contracted alcohol and drug treatment facilities. The Commission also should ensure that HIV counseling and testing services are available and accessible to substance abusers not currently in treatment.
(Dissenting vote: Rep. Billy Clemons)

91. All HIV tests conducted in Texas should be accompanied by pre-test and post-test counseling and be consented to voluntarily, except as specified by existing law. HIV counseling should include a thorough explanation of the test, including its purposes, potential uses, limitations, and interpretations.

92. The Texas Department of Health should continue to offer a training course for persons conducting HIV counseling and should continue to maintain a registry of counselors successfully completing the course.

93. The Legislature should require the Texas Department of Health to promulgate rules that will ensure the quality and accuracy of HIV testing in laboratories and other sites.

94. The Legislature should prohibit the sale, delivery, or offering for sale of any self-testing kits designed to inform persons of their status concerning HIV infection or AIDS.

SUBSTANCE ABUSE INTERVENTION

> Education for the drug abuser will have to be close to the streets and will have to address subjects which many people will try to describe as promoting drug use.... But they do not promote drug use. They are viable options that must be considered if we are to limit the spread of AIDS.
>
> HIV service provider
> Austin hearing

The sharing of needles and syringes among intravenous drug abusers is a major cause of HIV transmission. Intravenous drug use is a factor in more than 27 percent of all AIDS cases in the United States. Currently, it is the leading cause of HIV infection among women and infants. Nationally, 70 percent of all heterosexually transmitted AIDS cases are due to sexual contacts among intravenous drug abusers. Similarly, the majority of children born with HIV are offspring of women who use intravenous drugs or who are sexual partners of those who do.

Alcohol and other judgment-impairing substances are also clearly implicated in HIV transmission. Several studies indicate that people who abuse alcohol and drugs may tend to engage in high-

risk sexual and substance abuse behaviors conducive to HIV transmission. Additionally, alcoholism and drug addiction weaken the abuser's immunological system, which can hasten the progression of disease from HIV infection to AIDS.[35]

Little is known about the extent of HIV infection among Texas' drug using population. Approximately 14 percent of all AIDS cases in Texas resulted from intravenous drug use, as compared with 27 percent nationally. Important federally funded research on the extent of HIV infection among substance abusers is presently under way in Texas. Results of this study should provide additional data and yield important information for developing education, prevention, and treatment strategies.

The relatively lower statistics do not mean that substance abuse is less prevalent in Texas. More than 900,000 Texans are in need of drug abuse treatment. Many are likely to use drugs intravenously. More than half of the clients in Texas' publicly funded treatment facilities are intravenous drug users.[36] The most direct way to halt HIV transmission through drug use is by interrupting the cycle of addictive behavior that puts the drug user at risk for HIV infection. While enabling people to stop using drugs, treatment programs can also serve as important opportunities for educating users and former users about HIV and ways to prevent its spread.

But there are not enough drug treatment programs in Texas. The state relies almost exclusively on federal funds for drug treat-

ment programs. Thus, many drug users who do seek treatment are turned away. The Texas Commission on Alcohol and Drug Abuse estimates that less than 5 percent of the state's drug-dependent population will obtain treatment and prevention services. Where treatment programs are available, they often lack sufficient follow-up and rehabilitative services necessary to reinforce initial treatment and to reduce possibilities for relapse.

With regard to potential HIV transmission, at least three categories of drug abusers can be identified: those in treatment, those turned away from treatment, and those who do not seek treatment. Some people question the wisdom and value of investing HIV prevention efforts in a population which already engages in the unhealthy practices of substance abuse. It is well documented, however, that people who suffer from addiction are concerned about HIV transmission. This is particularly true when they understand that they may be subjecting not only themselves but also their partners and offspring to HIV.[37] There is every indication that, once provided with HIV information and risk-reduction materials, drug users often change at least those habits that place them at risk for HIV infection, such as the sharing of contaminated paraphernalia.

For users who seek drug treatment, programs can offer prevention and education programs, including voluntary HIV testing and counseling. For users who do not seek treatment, outreach programs can help to reduce the behaviors that most cause HIV transmission. For example, model programs in San Francisco,

Baltimore, and Newark report success when drug users are approached in their own environment by trained local residents. Outreach workers can discuss HIV prevention methods regarding sex and drug precautions and be viewed with credibility by users.[38] Federal funds now support a handful of outreach demonstration projects in Texas. However, the drug using population and the need for additional outreach programs extend to many more areas of the state.

CONCERNS/PROBLEMS IDENTIFIED

- Drug and alcohol abuse impairs judgment and can lead to behavior that increases the risk of HIV transmission.

- Nationally, intravenous drug use accounts for 27 percent of AIDS cases. In Texas, 14 percent of reported AIDS cases are related to intravenous drug use. With increased education and prevention efforts, Texas may be able to reduce the spread of HIV into this population.

- The best way to reduce drug-related HIV transmission is to halt substance abusing behavior and provide those in treatment with HIV education and prevention services. Unfortunately, treatment programs are very scarce in Texas.

- Even with increased treatment capacity, only a fraction of the estimated 900,000 substance abusers in Texas are likely

to have access to treatment services. Outreach programs, which initiate direct contact with substance abusers, can effectively reach those not in treatment. However, such programs are not sufficiently available.

RECOMMENDATIONS

95. The Texas Commission on Alcohol and Drug Abuse should substantially increase the availability of publicly funded substance abuse treatment services, including detoxification, methadone, outpatient, residential, vocational rehabilitation, and aftercare.

96. The Texas Department of Corrections should contract with the Texas Commission on Alcohol and Drug Abuse and other appropriate service providers, including volunteer organizations, to increase the availability of substance abuse treatment and HIV prevention, counseling, and follow-up services to inmates.

97. The Texas Commission on Alcohol and Drug Abuse should require that all licensed substance abuse treatment programs provide HIV education to their clients and staff. Substance abuse staff should become skilled in counseling clients regarding abstinence from chemical use as well as reduced risk methods of chemical use and sexual contact. Standardized curricula for the education of staff, counselors, and clients should be established.

98. The Legislature should encourage and fund, through the Texas Commission on Alcohol and Drug Abuse, community outreach programs that initiate direct contact with intravenous drug users. The purpose of such outreach programs should be to provide HIV education, to distribute, as appropriate, HIV risk reduction materials, including bleach, needles, and condoms, and to encourage behavior changes in ways which can reduce HIV transmission.

COORDINATION AND PLANNING

> The effort to combat AIDS must not be, or appear to be, fragmented and divisive.... It requires a climate of expectation that individuals and organizations will become involved -- involved with one another against AIDS.
>
> Dallas County AIDS Planning Commission [39]

> Without accurate information on the size of the problem, we are just simply whistling in the dark. How can we possibly have any idea what resources we are going to need in the future if we don't know what we've got today?
>
> Health care worker
> Lufkin hearing

Texas' approach to the HIV epidemic has been one of crisis intervention. Inadequate attention has been given to the long-term coordination and planning of HIV services -- among service providers, within communities, and among state agencies. Without more forethought about the financial and service issues arising out of the epidemic, the problems and needs will only intensify. The number of Texans with AIDS will increase dramatically over the next few years, causing an even greater strain on limited resources and services. The State of Texas must make immediate efforts to implement a planned response to the HIV epidemic.

Texas has a very fragmented health and human service delivery system, both at the local and state level. Although the State provides some services and funding, most of the delivery and fi-

nancing of health care, education, and social services rests at the local level. City/county health departments, community mental health and mental retardation centers, and school districts all report to local governing bodies and are partly supported by local tax dollars. Except for Medicaid, financing of health care services for low-income Texans also rests primarily at the local level, either through hospital districts or county governments.

As evidenced by the Task Force's hearings and survey of community resources, coordination among local community agencies providing HIV services also is fragmented and sporadic. Without good working relationships, agencies compete for limited resources and unnecessarily duplicate or reinforce gaps in available services. Fragmentation among community-based organizations also thwart their ability to receive funding. Increasingly, major federal and private funding sources for HIV services require applicants to demonstrate coordination among community service providers. The absence of community coalitions and a smooth process for client referrals have caused grant applications to be denied. For example, the lack of congruence among community agencies in Houston contributed to grant applications being denied by the Robert Wood Johnson Foundation and, until recently, the U.S. Health Resources and Services Administration.

At the state level, nearly 50 state agencies, with separate boards, budgets, and policy-making authority, participate in the delivery of Texas' education, health, and human services. As explained in the Task Force's recommendations on workplace issues,

the HIV epidemic touches more than those agencies with direct responsibility for the state's education, health, and human services. All state agencies should implement sound HIV-related workplace policies and programs.

Texas' response to the HIV epidemic has been further encumbered by the fragmented and overlapping responsibilities of state agencies. No single agency oversees the full spectrum of program, funding, and policy issues that relate to HIV. There is no state plan that systematically maps out solutions to the array of economic and societal problems that must be addressed. Furthermore, there is no mechanism for ensuring the appropriateness, consistency, or cost-effectiveness of state-level HIV policies.

Texas lacks a system for encouraging local planning and development of HIV services and incorporating community needs into state-level plans and funding proposals. To be most effective, planning must occur at the regional level. Not only are there strong cultural variances across Texas, there are also geographic differences in the incidence of HIV and the level of resources and services. As the HIV epidemic escalates, an array of community-based organizations must be involved in providing the education, treatment, and social support services needed by HIV-infected Texans. A process must be developed to foster local and private funding partnerships and to expand the pool of community-based organizations offering HIV-related services.

Dollars for HIV services will continue to be available to Texas through various federal agencies. A mechanism must be established by which the legislative and executive branches of Texas government can appropriately distribute and administer federal HIV funding. Every effort must be made to ensure that Texas obtains maximum federal and private funding for HIV services.

The State of Texas must end its erratic approach to the epidemic and immediately initiate farsighted and broad-based planning. The only comprehensive evaluation of the HIV epidemic has been conducted by the Legislative Task Force on AIDS. Because the Task Force disbanded in January 1989, a process must be established to continue assessing, implementing, and strengthening the state's response to the epidemic.

A key component of HIV-related planning is epidemiologic analysis. The Texas Department of Health lacks the resources to conduct important analytical studies, especially those that would discern early patterns of change in HIV transmission. Such information is essential not only for state policy-makers but also for local public health officials. Without a sophisticated understanding of the patterns of HIV in Texas, it is impossible to target prevention activities toward the areas of greatest need.

CONCERNS/PROBLEMS IDENTIFIED

- Planning and coordination of HIV-related services and policies is inadequate, resulting in the possible loss of funding opportunities, fragmentation and unnecessary duplication of services, and inconsistent state agency policies.

- To maximize limited dollars for HIV-related activities, more epidemiologic analyses are needed.

RECOMMENDATIONS

99. The Legislature should designate an entity and establish a process for conducting the following functions after the Legislative Task Force on AIDS concludes its activities:

- Oversee implementation of the recommendations of the Legislative Task Force on AIDS.

- Facilitate cooperation and communication among state agencies and promote consistency of state policies regarding HIV.

- Work toward maximizing the availability of federal funds for HIV-related services.

- Help determine the effective distribution of federal funds for HIV-related services.

- Stimulate private sector involvement in HIV-related education, prevention, treatment, social support, and research programs.

- Promote effective, broad-based state and regional planning of HIV education, prevention, treatment, social support, and research programs.

- Propose policy and funding recommendations to the 72nd Legislature.

100. To stimulate and strengthen planning, development, and coordination of community-based prevention, treatment, and social support services throughout Texas, the Legislature should encourage and support the establishment of Regional HIV Planning Councils within the 24 state health planning regions. Activities of the Regional HIV Planning Councils should include:

- Identifying local HIV-related education, prevention, treatment, and social support needs.

- Developing regional plans that will be submitted for inclusion in state plans for HIV services.

- Developing cost-effective approaches to the delivery of health care services to persons with HIV infection.

- Promoting the development and funding of programs and policies that are tailored to meet local communities' and at-risk communities' needs.

- Serving as a forum for broadening public and private sector involvement in HIV-related services and improving communication and cooperation among local service providers.

- Seeking to improve the continuity of care provided to persons with HIV infection.

101. The Texas Department of Health should ensure timely and accurate reporting of HIV and AIDS data required by law. The Department should thoroughly analyze this data on an ongoing basis to determine trends in incidence and prevalence of HIV and AIDS by region, age, race/ethnicity, gender, transmission category, and other subgroups as appropriate. Annually, the Department should project the number of AIDS cases expected in Texas based on this data. Projections and other analysis, including comparisons of Texas and national trends, should be provided to state and local agencies on an ongoing basis for use in planning, developing, and evaluating HIV-related programs and services.

102. Local, state, and federal agencies and researchers should collaborate on incidence and prevalence studies within Texas to gain information about the extent of HIV infection and AIDS within various regions and subgroups. The Texas Department of Health should make every effort to aid these studies and to accommodate reasonable requests for data while ensuring the confidentiality

of medical information as required by law. To the maximum extent possible, the Department should maintain information about the results of these epidemiologic studies and should make such studies available to the public on request. If federal funds are insufficient to meet these needs in a timely manner, the Legislature should provide adequate funding for research, analysis, and dissemination of findings.

COMMUNITY-BASED ORGANIZATIONS

> The development and response of community-based organizations is an example of how even the worst of times can bring out the best in people.
>
> Presidential Commission[40]

Community-based organizations have marshalled Texas' response to the HIV epidemic. These private, non-profit organizations have helped fill the void of education, social support, and health services needed by HIV-infected Texans and local communities. However, the few services available are provided by a handful of agencies.

Most social support and education services are provided by AIDS service organizations. These groups developed primarily out of the gay community in direct response to the HIV epidemic. In the first seven years of the epidemic, the gay community initiated and funded nearly all of the social support services available to Texans with HIV. As the epidemic has extended its reach, so have AIDS service organizations, which have broadened their local support and representation. AIDS service organizations in Texas are truly community-based. Their continued existence depends upon their ability to raise funds and recruit a steady corps of local volunteers.

From the Task Force's community resources survey, it is clear that AIDS service organizations make greater use of volunteers

than other community groups. Their volunteers have helped relieve the overwhelming service demands and costs associated with the care of HIV-infected clients. The pool of volunteers willing to donate their time, energy, and resources to local HIV-related activities must be replenished as the epidemic accelerates.

One tragic consequence of the HIV epidemic is the number of early founders, volunteers, and leaders of AIDS service organizations who, themselves, have died from AIDS. Their death leaves a vacuum of historical understanding and expertise that can never be replaced. Many of these Texans were veterans of the struggle against the epidemic and knew first-hand the enormous problems faced by people with HIV.

AIDS service organizations, which exist primarily in larger cities, are the newest community-based organizations in Texas. They also tend to have fewer staff members and smaller budgets than other community-based groups, according to the Task Force's community resources survey. Nearly all AIDS service organizations reported fewer than 10 full-time employees. In contrast, a majority of all other community-based organizations reported having more than 10 full-time employees. Most AIDS service organizations have annual budgets of less than $50,000, an amount that is much smaller than other community-based organizations responding to the survey.

The majority of funding for AIDS service organizations is from private donations. Little state or local government funding has

been allocated for HIV services. Some community-based organizations have been able to expand HIV services with the minimal state funding appropriated for Fiscal Years 1988-1989. However, only a handful of organizations received the state dollars. Local government funding for HIV-related activities has been even more limited. The few dollars appropriated by city councils and county commissions have been given primarily to local health departments.

The type and extent of HIV services provided through local health departments vary greatly. Most provide basic public information, epidemiologic surveillance, and federally funded HIV counseling and testing. Some, as in Lubbock, have spearheaded local coalitions and helped broaden support and involvement in HIV services. The Austin-Travis County Health Department, which administers the county's indigent health care program, is one of the few to contract with an AIDS service organization for HIV education and social support services.

To keep pace with the escalating number of HIV-infected Texans, more than health departments and AIDS service organizations must be involved. A wide range of community-based organizations should expand their existing programs to provide HIV-related services. Family planning clinics and substance abuse treatment facilities must be active participants in education and prevention activities. Nursing homes, home health agencies, and hospices should provide health and residential services to people with HIV. Mental health centers and religious organizations should

provide emotional support and counseling. A mechanism must be established to assist community-based organizations in developing and implementing these needed HIV services.

STATE GRANT PROGRAM FOR HIV SERVICES

In 1987, the Texas Legislature appropriated $3.4 million to the Texas Department of Health for HIV education and direct service grants for Fiscal Years 1988 and 1989. The funding, targeted for community-based organizations, represented the first and only legislative appropriation specifically for HIV services. For each Fiscal Year, 18 organizations received funds to increase public awareness about HIV and to reduce behaviors that transmit the virus. Fifteen grants in 1988 and 16 in 1989 were awarded to organizations seeking to minimize high medical costs of HIV-infected Texans. The funding has improved the availability of services throughout the state; however, it is far short of the amount needed. For the first grant cycle the Health Department received proposals totaling $7 million, yet had less than $1.5 million to appropriate.

A variety of important services have been funded through the new program. For example:

- AIDS Services of Austin initiated an in-home nursing and respite care program and expanded the telephone information service to people with hearing impairments.

- Bering Center/Houston established a day care center for AIDS patients.
- Centro de Salud Familiar La Fe/El Paso initiated a street education program to high-risk individuals in the barrios.
- Fort Worth Health Department established a clinic for HIV-infected people who do not yet have symptoms of illness.
- PWA Coalition/Dallas expanded housing for people with HIV-related illnesses.
- San Antonio Tavern Guild expanded its housing and food pantry services.
- Triangle AIDS Network/Beaumont initiated a variety of HIV education programs.
- Valley AIDS Council developed a media campaign and trained people to provide HIV education.

The Texas Department of Health is not authorized to spend state funds to administer the new grant program. As a result, the Department uses existing resources, such as replicating federal budget forms in the grant application packages. The lack of administrative funds for staff caused grant awards to be delayed and limited the Department's ability to monitor and provide technical assistance to the grantees. To ensure that the program is of the highest quality, the Department must have sufficient administrative support to issue and monitor the grant awards and to help grantees implement their projects.

Enabling legislation for the grant program did not authorize the Department to carry over unexpended balances between fiscal years. Since most AIDS service organizations are small, young, and volunteer-based, it is difficult for new programs to be implemented promptly. As a result, $138,000 of awarded monies were not spent before the end of Fiscal Year 1988; the money was auto-

matically returned to the General Revenue Fund. Because of the scarcity of dollars for HIV services and the slowness in initiating new programs, the Health Department must have authority to carry unexpended balances into subsequent budget periods.

The new state grant program provides an excellent source of data about the effectiveness and comparative costs of different HIV service models; however, few of the grantees have the staff or computer resources to collect such data. This omission has been magnified by the Department's inability to provide the technical support and guidance needed to assure proper evaluation of the programs.

CONCERNS/PROBLEMS IDENTIFIED

- The state grant program for HIV services has been instrumental in improving Texas' response to the education, health, and social support needs arising out of the HIV epidemic. However, the funding is inadequate.

- The Texas Department of Health needs to monitor more closely the funded programs and promote better data collection.

RECOMMENDATIONS

103. The Legislature should re-authorize and significantly expand the Texas Department of Health

grant program to community organizations for education and direct services and grant the Department authority to carry over funds for these programs between fiscal years. In determining the distribution of these funds, the Department should seek to complement available federal funds and address the most pressing HIV education and service delivery needs in Texas.

104. The Legislature should appropriate funds to the Texas Department of Health to ensure that sufficient staff are available to review and process grant applications, monitor and evaluate the effectiveness of funded programs, and provide technical assistance to grantees.

105. The Texas Department of Health should establish state-specific and less complex application procedures for the state grants for HIV services, rather than using federal budget guidelines for the applications.

106. The Department of Health should develop evaluation criteria aimed at documenting the cost-effectiveness, unit of service costs, and extent of volunteerism of funded programs and should require all grantees to maintain relevant statistics as a condition of their contracts. The Department should provide prompt assistance to grantees in obtaining materials and skills necessary to collect such data.

TECHNICAL ASSISTANCE

> There have been times when there are federal sources of funding available, we have not been notified, and no one else has taken the initiative to apply for those funds. Consequently, we have had to work with a very, very short deadline.... That is one of the most grievous tragedies of all -- no one coordinating identification of those resources.
>
> HIV service provider
> Houston hearing

To maximize the availability of quality programs, Texas must implement a system for helping community-based organizations design, fund, and implement HIV-related programs. The HIV epidemic is too pressing to waste limited resources on poorly designed programs. It also is highly inefficient for local communities and service providers to struggle with structural concerns common to all new initiatives across the state. Many AIDS service organizations need assistance in establishing boards of directors and volunteer training programs, writing grants, and designing and evaluating programs. All can benefit from information on developing housing, day care, respite care, and other social support services for people with HIV.

Established AIDS service organizations face a double burden -- meeting their growing caseloads with limited resources and providing technical assistance to new groups throughout the state and even the nation. Repeatedly, the Task Force learned of new AIDS service groups turning to providers in Houston, Dallas, San Antonio, and Austin for basic program development. These organ-

izations cannot continue to respond to such requests without compensation, especially when their caseloads are growing disproportionately to their resources. Their expertise, however, is invaluable. A mechanism should be developed for using such agencies in state-sponsored technical assistance programs.

In the Task Force's community resources survey, the majority of AIDS service organizations indicated the need for help with program development, knowledge of funding sources and grant cycles, early notification of funding opportunities, and staff resources to prepare funding proposals. Other community-based organizations would benefit from such assistance, as well. For example, local health departments, key providers of HIV prevention services, expressed a strong need for technical assistance in developing grant proposals.

Increasingly, federal and private funds are available for HIV-related services. It is in the best interest of the State of Texas to strengthen the ability of community-based organizations to broaden their funding bases and services.

CONCERNS/PROBLEMS IDENTIFIED

- Community-based organizations, especially newly established HIV service providers, need assistance in developing, funding, implementing, and evaluating HIV services. However, Texas lacks a systematic vehicle for providing such help.

- Limited state and local resources for HIV services would be maximized if the State of Texas offered program development assistance to community groups.

RECOMMENDATIONS

107. To maximize the use of limited resources and volunteer efforts and to expand the availability of community-based health care, education, prevention and social support services needed to address the HIV epidemic, the State of Texas should support and provide technical assistance to community-based organizations. Among the issues that should be addressed through state-supported technical assistance programs are:

- Recruitment, training, and effective use of volunteers in the delivery of HIV-related services.

- Implementation of effective administrative policies and procedures, and Boards of Directors within community-based organizations.

- Identification of and application for funding opportunities and sources, including information on how to develop sound grant proposals.

- Development and implementation of proven, operable service delivery approaches for community-based health care, social support, education and prevention services pertaining to HIV.

To the maximum extent possible, such technical assistance efforts should be provided through contractual agreements with AIDS service and other community-based organizations with knowledge and expertise about volunteer services, delivery of HIV-related programs, and organizational structures of non-profit organizations.

108. The Texas Department of Health and the Texas Department of Human Services should jointly conduct educational programs and develop materials on residential, home health care, respite, day care, and homemaker services for community-based organizations serving persons with HIV infection. Information to be covered should include licensing regulations and application procedures, funding al-

ternatives, and model programs. These agencies should also establish an ongoing mechanism for providing technical assistance on such topics to community-based organizations.

109. The Legislature should establish and fund a mechanism to maintain current information on private and public funding sources for HIV-related prevention, education, treatment, and social support services. The information should be forwarded as soon as possible to public and private agencies likely to be eligible for funding.

WORKPLACE ISSUES

> Workplaces must be prepared to accept and protect persons with HIV infection. Each and every government body and public agency will become part of the solution or will remain part of the problem.
>
> Regional health department director
> Austin hearing

> If my employer finds out, I'm a month away from being homeless.
>
> Survey of Texans with HIV Infection

The HIV epidemic affects virtually every workplace and every employer whether directly, because of an employee, dependent, client or patient with HIV, or indirectly through increased taxes or health care costs. HIV has presented some workplace issues not generally associated with other life-threatening diseases. Because legal and medical knowledge has evolved rapidly for HIV, employers must maintain current information on relevant findings and laws. In addition, it appears that more widespread firings, demotions, breaches of medical confidentiality, and refusals to render service occur with HIV than with other diseases.

These adverse workplace responses contribute to misunderstanding about HIV, increase costs, lower productivity, and leave employers vulnerable to litigation. People with HIV become more reliant on public support systems when they are fired because of irrational fears about contagion in the workplace. Legal battles

may ensue if employer practices are inconsistent with current law or medical evidence.

If HIV-related issues are confronted early -- before the first employee, dependent or client has HIV-related illnesses -- employers can protect those who may be ill, retain productive employees, alleviate co-worker fears, and help contain costs. Education is the most effective tool for addressing HIV in the workplace, and offers three important benefits: limiting the spread of HIV through awareness of transmission routes, calming unwarranted fears, and promoting the retention of valuable and productive employees.[41] By providing facts and emphasizing that HIV is not spread through casual contact, employers can often allay concerns that may otherwise lead to inappropriate or illegal actions.

Although HIV is a concern for every workplace, the needs and issues raised by the epidemic vary according to the type and location of employment. The most effective programs and policies will be tailored to meet the needs of each workplace while protecting the legal rights of those who may be ill, preventing costly litigation, and educating and comforting anxious co-workers. In some settings, a simple review of policies regarding life-threatening illnesses and an effort to ensure that employees are knowledgeable about HIV are all that may be required. Levi-Strauss and Chevron, for example, have participated in HIV education programs but have no specific HIV "policy." Both companies

simply say that HIV will be treated like other catastrophic, life-threatening illnesses.[42]

In health care settings, on the other hand, where there may be a risk of HIV transmission, detailed staff training, infection control practices, and HIV testing policies should be implemented. Similarly, client education and prevention programs should be a vital component of HIV-related practices among service providers, particularly those with clients at high risk for HIV.

How public employers respond to HIV is important. The public sector can be a model for private employers and may be most vulnerable to legal challenges if policies, programs, and practices are inconsistent or medically or legally unsound. Public employers have a special responsibility to protect against further spread of HIV, reduce costs, and avoid litigation. In particular, those agencies, including health, human service, or correctional entities that provide or contract for direct client services must ensure that people with HIV receive appropriate care; infection control procedures are implemented where there is a risk of HIV transmission; staff is kept up to date on HIV-related matters; and clients at risk of HIV are provided with education and prevention programs.

Several major private employers, including Levi-Strauss, BankAmerica, Chevron, and the National Leadership Coalition on AIDS, a group of private employers, have developed exemplary approaches to HIV in the workplace. Through the Occupational

Safety and Health Administration, the Office of Personnel Management and the Centers for Disease Control, the federal government has developed detailed guidelines for a variety of workplace settings. A number of Texas state agencies have also addressed HIV-related concerns. The Department of Human Services, for example, published workplace guidelines in November, 1987.

Despite these standards and models, some employers and employees continue to respond inappropriately to HIV-related concerns. Many employers have not incorporated education or policies into the workplace, resulting in misconceptions about HIV transmission and undue fears of exposure to the virus. At the state level, policies and programs have not been widely adopted. Although the Texas Department of Health has helped some agencies address HIV-related concerns, there is no mechanism to ensure that public agencies receive such assistance, adopt uniform or consistent policies or practices or even consider HIV workplace issues.

CONCERNS/PROBLEMS IDENTIFIED

- Employers' programs, policies, and decisions regarding people with HIV may be subject to costly legal challenges if they are not consistent with state, federal, and local laws and rules or are not based on up-to-date scientific and epidemiologic evidence.

- If effective education programs and guidelines are not available, costly and inappropriate personnel decisions and major workplace disruptions can occur when co-workers realize that an employee is infected with HIV.

- People who are inappropriately fired because they have HIV become more reliant on public systems of care.

- Despite the availability of education and policy guidelines and models from a variety of sources, many Texas employers have not addressed HIV-related workplace issues.

- Public agencies have a special responsibility to address HIV-related concerns in a consistent, legal, and medically sound manner. However, no mechanism exists to ensure that state agencies address these issues or implement consistent, sound programs or practices.

- Public agencies with law enforcement, public safety, correctional, health care, education, and other direct client responsibilities have not adequately or uniformly addressed HIV issues.

RECOMMENDATIONS

110. To ensure consistent public policy, the Texas Department of Health should work with appropriate state and local agencies to develop HIV education programs and model workplace guidelines.

At a minimum, such programs and guidelines should address the following principles:

- All employees should receive some education regarding HIV.

- Persons with HIV infection do not pose a risk of transmitting the virus to co-workers through ordinary workplace contact.

- Persons with HIV infection are entitled to the same rights and opportunities as persons with other serious or life-threatening diseases. Accommodation should be made to keep persons with HIV employed and productive for as long as possible.

- The confidentiality of employee medical records should be protected.

- HIV-related policies should be based on information from public health authorities such as the U.S. Centers for Disease Control.

In businesses with medical, educational, correctional, health, or other social service responsibilities that entail direct client contact the programs should also address the following issues:

- Appropriate HIV-related education and training for staff, clients, students, or inmates.

- Prohibition on denial of services to persons with HIV infection and on the inappropriate use of HIV status as a criteria in program or service delivery decisions.

- Assurance that employees in settings where there may be a significant risk of exposure to HIV are provided with ongoing education and training and, where applicable, the necessary equipment to implement needed infection control procedures.

- Assurance that confidentiality of clients' HIV-related medical information will be protected to the fullest extent of the law.

111. By the end of Fiscal Year 1990, state agencies should implement an HIV education program and adopt an approach to HIV-related workplace concerns that incorporates the principles and guidelines outlined above. By the end of Fiscal Year 1991, all entities contracting with or funded through the following state agencies to provide direct client

services should also implement HIV education programs and adopt policies or guidelines consistent with outlined principles: Texas Commission on Alcohol and Drug Abuse, Texas Commission for the Blind, Texas Adult Probation Commission, Juvenile Probation Commission, Texas Department of Corrections, Texas Youth Commission, Texas Board of Pardons and Paroles, Texas Department of Health, Texas Department of Human Services, Texas Department of Mental Health and Mental Retardation, and the Texas Rehabilitation Commission.

112. As part of state policy regarding HIV in the workplace, thorough and confidential HIV counseling and testing should be provided on the request of any state employee who, through blood or other body fluid contact, may have been legitimately exposed to HIV while performing the duties of his or her job. The State should pay the cost of the counseling and testing. No state employee who may have been exposed to the HIV while performing the duties of his or her job should be required to be tested.

113. By the end of Fiscal Year 1989, each state agency should provide all new state employees with an informational pamphlet explaining the nature and extent of HIV and AIDS, methods of HIV transmission and prevention, and where further information and resources can be obtained. Annually, all state agencies should distribute the informational pamphlet in all state employees' pay warrants. The Texas Department of Health should distribute an appropriate pamphlet to state agencies to be copied and disseminated to state employees.

114. Private employers and local governments should be encouraged to adopt HIV education programs and to implement appropriate workplace policies. The Texas Department of Health should make resource materials available to assist employers with their HIV educational and policy efforts.

115. To reinforce workplace principles, state employees should not be allowed to refuse services to an individual with HIV infection.

RESEARCH

> There is a longstanding and understandable rivalry between universities which preclude any collaborative effort. I believe very strongly that if a concerted effort were made in Texas and presented to the federal government ... funding would be available throughout the state to take care of the needs of investigators and of the populations which they seek to serve. Certainly it is true that competition is a good thing in some areas, but in the face of a catastrophe such as threatens us now, it is divisive and destructive.
>
> AIDS physician and researcher
> Houston hearing

The HIV epidemic poses important biological and medical questions while offering basic and applied research challenges to the scientific community. Basic research important to HIV includes investigations into the ways viruses operate, the functions of the body's immune system, and factors that influence individual susceptibility to viral infections. Basic HIV research has already provided hopeful results in what is an otherwise disastrous epidemic -- valuable new information about viruses and the body's immune system, with potential applications for many other diseases and conditions. For HIV illnesses specifically, these studies represent important inroads for the development of such major clinical objectives as a vaccine or long-term treatment for HIV infection. Applied research aims to evaluate drugs or methods of treatment for AIDS or HIV illness. Emphasizing patient care, applied research can offer new hope for many with HIV ill-

ness by giving them access to otherwise unavailable experimental treatments.

Beyond the benefits offered to patients, HIV-related research can yield direct economic benefits and provide incentives that may attract and help retain professionals in state institutions of higher education. Texas' public universities and health science centers received $600 million in research funds from a variety of sources in 1987, creating nearly 29,000 jobs and adding approximately $1.4 billion to the state's economy.[43] Recognizing the economic benefits of both applied and basic research, the 70th Legislature established the Advanced Research and Advanced Technology programs to fund projects in Texas schools. These funds could be allocated to projects relevant to the HIV epidemic.

Funds are increasingly available from private companies and the federal government. Federal appropriations for HIV-related research, through the National Institutes of Health, have grown from $3.5 million in 1982 to approximately $468 million in 1988. Most of these funds are available to institutions and individuals through grants or contracts. In early 1988, the University of Texas System reported to the Task Force that it had received over $5.6 million in federal research funds for HIV-related projects.

With its medical research centers and many other resources, Texas has the capacity to conduct important investigative efforts that could directly contribute to national and international HIV research. In particular, Texas institutions could make valuable

contributions in applied research directed at patient care, thereby benefitting Texans with HIV as well as researchers, institutions, and the state in general.

Texas is not receiving grants and contracts commensurate with either the state's AIDS caseload or its research capacity. Among the problems often cited as impediments to additional, high-quality Texas-based HIV research are lack of timely access to information about funding sources; inadequate efforts at cooperative research among state researchers and institutions; and the lack of a mechanism to compile, evaluate, and exchange information about studies or resources.

CONCERNS/PROBLEMS IDENTIFIED

- There is little centralized information available on the extent and types of HIV-related research conducted in the state.

- Applied research that investigates experimental treatments through patient trials represents a major hope for people with HIV.

- Funding opportunities may be lost and important achievements never realized if researchers do not participate in cooperative ventures and if valuable information identifying fund-

ing sources, new research findings, or patients who medically qualify as subjects for clinical trials are not available.

RECOMMENDATIONS

116. Comprehensive information on the number and types of HIV-related research projects undertaken by public and private providers and organizations should be maintained at the state level, including data on the level and sources of funding. This information should form the basis for ongoing analysis of and reporting on Texas' HIV research efforts.

117. Scientists seeking to provide patient care in their research activities should be assisted by the State in the identification of patients appropriate for HIV-related projects.

118. The State should maintain current information on sources of private and public funding for HIV-related research, with an emphasis on research involving direct patient care. This information should be made available as soon as possible to public and private providers and organizations that may be eligible to submit research proposals.

119. The Texas Higher Education Coordinating Board should encourage all Texas institutions of higher education and their faculties to undertake and collaborate on HIV-related research efforts and should recognize their achievements in both basic and applied HIV-related research.

120. The Texas Higher Education Coordinating Board should encourage and fund applied and basic HIV-related research efforts through its ongoing programs, including the Advanced Technology and Advanced Research Programs. Special consideration should be given to research emphasizing clinical, patient care, and medical management of persons with HIV infection.

APPENDICES

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GLOSSARY

AIDS: Acquired Immunodeficiency Syndrome.

ALTERNATIVE THERAPIES: programs to provide holistic medical approaches to the management of AIDS such as acupuncture, massage, or nutrition.

ANTIBODY: a molecule produced by the immune system of the body in response to an antigen and which has the particular property of combining specifically with the antigen that induced its formation.

ANTIGEN: a molecule that induces the formation of an antibody.

ATTENDANT CARE: programs to provide eligible individuals with HIV/AIDS with non-medical, personal health and hygiene care such as preparing meals, bathing, going to the bathroom, getting in and out of bed, and walking.

BASIC RESEARCH: research in the basic or pure sciences. Not product-oriented.

CASE MANAGEMENT: an administrative mechanism for locating, coordinating, referring, and monitoring all health care and social services support necessary to meet the complex medical, psychosocial, and basic needs of individuals with HIV/AIDS.

CLINICAL TRIAL: studies with human subjects.

CO-FACTORS: those factors that can influence an individual's likelihood of becoming ill or influence the progression of disease. Commonly cited HIV-related co-factors include a history of intravenous drug use and a history of sexually transmitted diseases or other immunocompromising conditions.

COBRA: Consolidated Omnibus Budget Reconciliation Act of 1985. Federal legislation that requires, with minor exceptions, that all employers with 20 or more employees continue health coverage for up to 18 months after a worker loses benefits due to reduced work hours or loss of employment.

COHORT STUDIES: studies that follow groups of similar individuals over time, noting who develops a disease and who does not, and comparing these two groups to determine co-factors and other elements that may influence outcome. Cohort studies of gay men in San Francisco have determined that behavior modification can influence incidence of HIV infection and reduce the number of new cases.

DAY CARE FOR ADULTS: programs to provide substitute, non-medical caregiving in an adult group facility or adult family day care home for some portion of a 24-hour day for adults with HIV/AIDS whose caregivers are at work or away from the home for other reasons.

DAY CARE FOR CHILDREN: programs to provide substitute parental care in a group facility or in family day care homes for children with HIV/AIDS and for children of parents with HIV/AIDS while the parents or caregivers are at work or away from the home.

DEMENTIA: general designation for mental deterioration.

DNA (deoxyribonucleic acid): basic genetic material. A nucleic acid found chiefly in the nucleus of living cells that is responsible for transmitting hereditary characteristics.

ELISA: acronym for "enzyme-linked immunosorbent assay," a test used to detect antibodies against HIV.

EPIDEMIOLOGY: study of the relationships of the various factors determining the frequency and distribution of diseases in a human environment.

ERISA: Employees Retirement Income Security Act, a federal act passed by Congress in 1974, that defines requirements and exemptions for self-insuring firms.

ETIOLOGY: study of the factors that cause disease.

FOOD PANTRIES: programs to help people to meet their nutritional needs through the direct distribution of food items to eligible persons and their families who lack sufficient resources to purchase basic food items.

FOSTER CARE FOR CHILDREN: programs to provide a substitute family life experience in an agency-supervised home to children with HIV/AIDS or the children of parents with HIV/AIDS who need care for a temporary or an extended period during which the normal family environment is either non-existent or greatly hampered because of some social, emotional, or physical reason.

GRIEF AND BEREAVEMENT COUNSELING programs to provide counseling and emotional support to terminally ill people and to their families, friends, and caregivers to help those persons in dealing with the impending death and bereavement.

HIV: Human Immunodeficiency Virus.

HIV TESTING (CONFIRMATORY): programs to provide a confirmatory test, principally the Western Blot, to individuals who have two positive ELISA results.

HIV TESTING (ELISA): programs to provide for HIV testing by means of the screening test (ELISA) to preliminarily determine the presence of HIV antibodies.

HOME HEALTH CARE: programs to provide, under a physician's orders, medical, nursing, rehabilitation, and social services to eligible individuals with HIV/AIDS in their own homes and who require intermittent care without hospitalization.

HOMEMAKER SERVICES: programs to help eligible individuals handle household chores such as cleaning, laundry, bathing, and simple maintenance.

HOSPICE: facility or program which provides palliative care, primarily medical relief of pain and symptom management, and support services to terminally ill people and grief and bereavement counseling for their families. Can be provided either in a facility or the patient's home.

HTLV: human T-cell lymphotropic virus. This is the family of viruses to which HIV belongs.

IMMUNOLOGY: the medical study of the immune system.

INFORMATION AND REFERRAL LINE: telephone programs to link individuals in need of information or referral for services with the appropriate agency and/or to provide immediate factual information to questions about HIV/AIDS.

INTERVENTION (in behavior modification research): those techniques or devices by which one behavior is interrupted and another, presumably healthier, behavior is instituted.

KAPOSI'S SARCOMA: a cancer or tumor of the blood and/or lymphatic vessel cells. It is the most common opportunistic malignancy associated with HIV infection.

LOW-COST HOUSING: programs for direct provision of low-cost housing for eligible people either in government-owned facilities or in facilities owned and operated by private, non-profit agencies.

LYMPHADENOPATHY: disease of the lymph nodes.

LYMPHOCYTE: a particular type of white blood cells which are involved in the immune response.

LYMPHOMA: any of the various forms of cancers of the lymphoid tissue.

MEDICAL REFERRAL: referral of newly diagnosed people with HIV to a physician for assessment of general physical condition and overall immunological status.

MORBIDITY: frequency of disease occurrence in proportion to the population.

MORTALITY: frequency of number of deaths in proportion to the population.

OPPORTUNISTIC INFECTION: an infection caused by an organism that rarely causes disease in people with normal immune systems but attacks immunosuppressed patients. Infections common in people

with HIV include toxoplasmosis, Pneumocystis carinii pneumonia, cytomegalovirus, and tuberculosis.

PARTNER NOTIFICATION: programs to contact and educate sexual partners and needle-sharing partners of individuals with HIV/AIDS as to their own HIV risk status. Model program guidelines are available from the U.S. Centers for Disease Control.

PNEUMOCYSTIS CARINII PNEUMONIA: opportunistic infection most frequently diagnosed in patients with AIDS. Caused by a parasite commonly present in the normal population, Pneumocystis carinii infection is life-threatening in immunosuppressed patients.

POSTTEST COUNSELING: programs which provide individual counseling following HIV testing and which include the results, whether positive or negative, the implications of an individual's HIV status, and any necessary referrals for additional counseling or medical assessment.

PRETEST COUNSELING: programs to provide individual counseling before HIV testing which details the reasons for, possible risks of, and implications of possible results of HIV testing.

PSYCHOSOCIAL: associated with the systems of psychological support services.

RESPITE CARE: programs to provide on an intermittent basis a brief period of relief or rest to individuals who are the caregivers of individuals with HIV/AIDS. Respite care can be offered in the individual's home or in a separate facility.

RETROVIRUS: one of a group of viruses that have RNA as their genetic code and have the ability to copy that RNA into DNA and incorporate it into an infected cell.

RISK ASSESSMENT: programs to enable individuals to determine by means of oral or written questionnaires if they are or have been engaging in activities which may have exposed them to HIV.

RISK REDUCTION EDUCATION: programs to educate groups or individuals on methods of preventing the spread of HIV.

RNA (ribonucleic acid): basic genetic material. A nucleic acid associated with the control of chemical activities inside a cell.

SERO-: prefix referring to blood serum.

SEROCONVERSION: the initial development of antibodies specific to a particular antigen.

SEROLOGIC: pertaining to blood serum.

SEROPOSITIVE: condition in which antibodies to a specific antigen are found in the blood.

SEROPREVALENCE: prevalence based on blood serum tests.

SUPPORT GROUPS: programs to provide emotional support to persons with HIV/AIDS and their families, friends or caregivers through group meetings and discussions led by paid staff or trained volunteers.

SURVEILLANCE: process of monitoring public health conditions such as epidemics. Passive surveillance monitors conditions through the receipt of reports; active surveillance employs investigative techniques.

SYNDROME: pattern of symptoms and signs, appearing one by one or simultaneously that together characterize a particular disease or disorder.

T-CELL: cell that matures in the thymus gland. T-lymphocytes are found primarily in the blood, lymph, and lymphoid organs. Subsets of T-cells have a variety of specialized functions within the immune system.

T4 CELL COUNT: measure of the state of the immune system based on the number of T4 lymphocytes present in the blood.

WESTERN BLOT: blood test that involves the identification of antibodies against specific protein molecules. This test is more specific than the ELISA test in detecting antibodies to HIV in blood samples. It is used as a confirmatory test for positive ELISA samples. The Western blot requires more sophisticated lab technique than the ELISA and is more expensive.

Most of the above definitions were taken from the Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic and the Task Force's community resources survey.

CDC SURVEILLANCE CASE DEFINITION FOR AIDS

CENTERS FOR DISEASE CONTROL

August 14, 1987 / Vol. 36 / No. 1S

MMWR

Supplement

MORBIDITY AND MORTALITY WEEKLY REPORT

Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome

AIDS Program
Center for Infectious Diseases
Centers for Disease Control
Atlanta, Georgia 30333

Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome

Reported by
Council of State and Territorial Epidemiologists;
AIDS Program, Center for Infectious Diseases, CDC

INTRODUCTION

The following revised case definition for surveillance of acquired immunodeficiency syndrome (AIDS) was developed by CDC in collaboration with public health and clinical specialists. The Council of State and Territorial Epidemiologists (CSTE) has officially recommended adoption of the revised definition for national reporting of AIDS. The objectives of the revision are a) to track more effectively the severe disabling morbidity associated with infection with human immunodeficiency virus (HIV) (including HIV-1 and HIV-2); b) to simplify reporting of AIDS cases; c) to increase the sensitivity and specificity of the definition through greater diagnostic application of laboratory evidence for HIV infection; and d) to be consistent with current diagnostic practice, which in some cases includes presumptive, i.e., without confirmatory laboratory evidence, diagnosis of AIDS-indicative diseases (e.g., *Pneumocystis carinii* pneumonia, Kaposi's sarcoma).

The definition is organized into three sections that depend on the status of laboratory evidence of HIV infection (e.g., HIV antibody) (Figure 1). The major proposed changes apply to patients with laboratory evidence for HIV infection: a) inclusion of HIV encephalopathy, HIV wasting syndrome, and a broader range of specific AIDS-indicative diseases (Section II.A); b) inclusion of AIDS patients whose indicator diseases are diagnosed presumptively (Section II.B); and c) elimination of exclusions due to other causes of immunodeficiency (Section I.A).

Application of the definition for children differs from that for adults in two ways. First, multiple or recurrent serious bacterial infections and lymphoid interstitial pneumonia/pulmonary lymphoid hyperplasia are accepted as indicative of AIDS among children but not among adults. Second, for children<15 months of age whose mothers are thought to have had HIV infection during the child's perinatal period, the laboratory criteria for HIV infection are more stringent, since the presence of HIV antibody in the child is, by itself, insufficient evidence for HIV infection because of the persistence of passively acquired maternal antibodies < 15 months after birth.

The new definition is effective immediately. State and local health departments are requested to apply the new definition henceforth to patients reported to them. The initiation of the actual reporting of cases that meet the new definition is targeted for September 1, 1987, when modified computer software and report forms should be in place to accommodate the changes. CSTE has recommended retrospective application of the revised definition to patients already reported to health departments. The new definition follows:

1987 REVISION OF CASE DEFINITION FOR AIDS FOR SURVEILLANCE PURPOSES

For national reporting, a case of AIDS is defined as an illness characterized by one or more of the following "indicator" diseases, depending on the status of laboratory evidence of HIV infection, as shown below.

I. Without Laboratory Evidence Regarding HIV Infection

If laboratory tests for HIV were not performed or gave inconclusive results (*See* Appendix I) and the patient had no other cause of immunodeficiency listed in Section I.A below, then any disease listed in Section I.B indicates AIDS if it was diagnosed by a definitive method (*See* Appendix II).

A. Causes of immunodeficiency that disqualify diseases as indicators of AIDS in the absence of laboratory evidence for HIV infection

1. high-dose or long-term systemic corticosteroid therapy or other immunosuppressive/cytotoxic therapy ≤3 months before the onset of the indicator disease
2. any of the following diseases diagnosed ≤3 months after diagnosis of the indicator disease: Hodgkin's disease, non-Hodgkin's lymphoma (other than primary brain lymphoma), lymphocytic leukemia, multiple myeloma, any other cancer of lymphoreticular or histiocytic tissue, or angioimmunoblastic lymphadenopathy
3. a genetic (congenital) immunodeficiency syndrome or an acquired immunodeficiency syndrome atypical of HIV infection, such as one involving hypogammaglobulinemia

B. Indicator diseases diagnosed definitively (*See* Appendix II)

1. candidiasis of the esophagus, trachea, bronchi, or lungs
2. cryptococcosis, extrapulmonary
3. cryptosporidiosis with diarrhea persisting >1 month
4. cytomegalovirus disease of an organ other than liver, spleen, or lymph nodes in a patient >1 month of age
5. herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than 1 month; or bronchitis, pneumonitis, or esophagitis for any duration affecting a patient >1 month of age
6. Kaposi's sarcoma affecting a patient < 60 years of age
7. lymphoma of the brain (primary) affecting a patient < 60 years of age
8. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
9. *Mycobacterium avium* complex or *M. kansasii* disease, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. *Pneumocystis carinii* pneumonia
11. progressive multifocal leukoencephalopathy
12. toxoplasmosis of the brain affecting a patient >1 month of age

II. With Laboratory Evidence for HIV Infection

Regardless of the presence of other causes of immunodeficiency (I.A), in the presence of laboratory evidence for HIV infection (*See* Appendix I), any disease listed above (I.B) or below (II.A or II.B) indicates a diagnosis of AIDS.

A. Indicator diseases diagnosed definitively (*See* Appendix II)

1. bacterial infections, multiple or recurrent (any combination of at least two within a 2-year period), of the following types affecting a child < 13 years of age:
   septicemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses), caused by *Haemophilus, Streptococcus* (including pneumococcus), or other pyogenic bacteria
2. coccidioidomycosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
3. HIV encephalopathy (also called "HIV dementia," "AIDS dementia," or "subacute encephalitis due to HIV") (*See* Appendix II for description)
4. histoplasmosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
5. isosporiasis with diarrhea persisting >1 month
6. Kaposi's sarcoma at any age
7. lymphoma of the brain (primary) at any age
8. other non-Hodgkin's lymphoma of B-cell or unknown immunologic phenotype and the following histologic types:
   a. small noncleaved lymphoma (either Burkitt or non-Burkitt type) (*See* Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases,* Ninth Revision, Clinical Modification)
   b. immunoblastic sarcoma (equivalent to any of the following, although not necessarily all in combination: immunoblastic lymphoma, large-cell lymphoma, diffuse histiocytic lymphoma, diffuse undifferentiated lymphoma, or high-grade lymphoma) (*See* Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases,* Ninth Revision, Clinical Modification)

   Note: Lymphomas are not included here if they are of T-cell immunologic phenotype or their histologic type is not described or is described as "lymphocytic," "lymphoblastic," "small cleaved," or "plasmacytoid lymphocytic"
9. any mycobacterial disease caused by mycobacteria other than *M. tuberculosis,* disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. disease caused by *M. tuberculosis,* extrapulmonary (involving at least one site outside the lungs, regardless of whether there is concurrent pulmonary involvement)
11. *Salmonella* (nontyphoid) septicemia, recurrent
12. HIV wasting syndrome (emaciation, "slim disease") (*See* Appendix II for description)

B. Indicator diseases diagnosed presumptively (by a method other than those in Appendix II)

Note: Given the seriousness of diseases indicative of AIDS, it is generally important to diagnose them definitively, especially when therapy that would be used may have serious side effects or when definitive diagnosis is needed

for eligibility for antiretroviral therapy. Nonetheless, in some situations, a patient's condition will not permit the performance of definitive tests. In other situations, accepted clinical practice may be to diagnose presumptively based on the presence of characteristic clinical and laboratory abnormalities. Guidelines for presumptive diagnoses are suggested in Appendix III.

1. candidiasis of the esophagus
2. cytomegalovirus retinitis with loss of vision
3. Kaposi's sarcoma
4. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
5. mycobacterial disease (acid-fast bacilli with species not identified by culture), disseminated (involving at least one site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
6. *Pneumocystis carinii* pneumonia
7. toxoplasmosis of the brain affecting a patient >1 month of age

III. With Laboratory Evidence Against HIV Infection

With laboratory test results negative for HIV infection (*See* Appendix I), a diagnosis of AIDS for surveillance purposes is ruled out *unless*:

A. all the other causes of immunodeficiency listed above in Section I.A are excluded; **AND**
B. the patient has had either:
   1. *Pneumocystis carinii* pneumonia diagnosed by a definitive method (*See* Appendix II); **OR**
   2. a. any of the other diseases indicative of AIDS listed above in Section I.B diagnosed by a definitive method (*See* Appendix II); **AND**
      b. a T-helper/inducer (CD4) lymphocyte count <400/mm^3.

COMMENTARY

The surveillance of severe disease associated with HIV infection remains an essential, though not the only, indicator of the course of the HIV epidemic. The number of AIDS cases and the relative distribution of cases by demographic, geographic, and behavioral risk variables are the oldest indices of the epidemic, which began in 1981 and for which data are available retrospectively back to 1978. The original surveillance case definition, based on then-available knowledge, provided useful epidemiologic data on severe HIV disease (*1*). To ensure a reasonable predictive value for underlying immunodeficiency caused by what was then an unknown agent, the indicators of AIDS in the old case definition were restricted to particular opportunistic diseases diagnosed by reliable methods in patients without specific known causes of immunodeficiency. After HIV was discovered to be the cause of AIDS, however, and highly sensitive and specific HIV-antibody tests became available, the spectrum of manifestations of HIV infection became better defined, and classification systems for HIV infection were developed (*2-5*). It became apparent that some progressive, seriously disabling, and even fatal conditions (e.g., encephalopathy, wasting syndrome) affecting a substantial number of HIV-infected patients were not subject to epidemiologic surveillance, as they were not included in the AIDS

case definition. For reporting purposes, the revision adds to the definition most of those severe non-infectious, non-cancerous HIV-associated conditions that are categorized in the CDC clinical classification systems for HIV infection among adults and children (*4,5*).

Another limitation of the old definition was that AIDS-indicative diseases are diagnosed presumptively (i.e., without confirmation by methods required by the old definition) in 10%-15% of patients diagnosed with such diseases; thus, an appreciable proportion of AIDS cases were missed for reporting purposes (*6,7*). This proportion may be increasing, which would compromise the old case definition's usefulness as a tool for monitoring trends. The revised case definition permits the reporting of these clinically diagnosed cases as long as there is laboratory evidence of HIV infection.

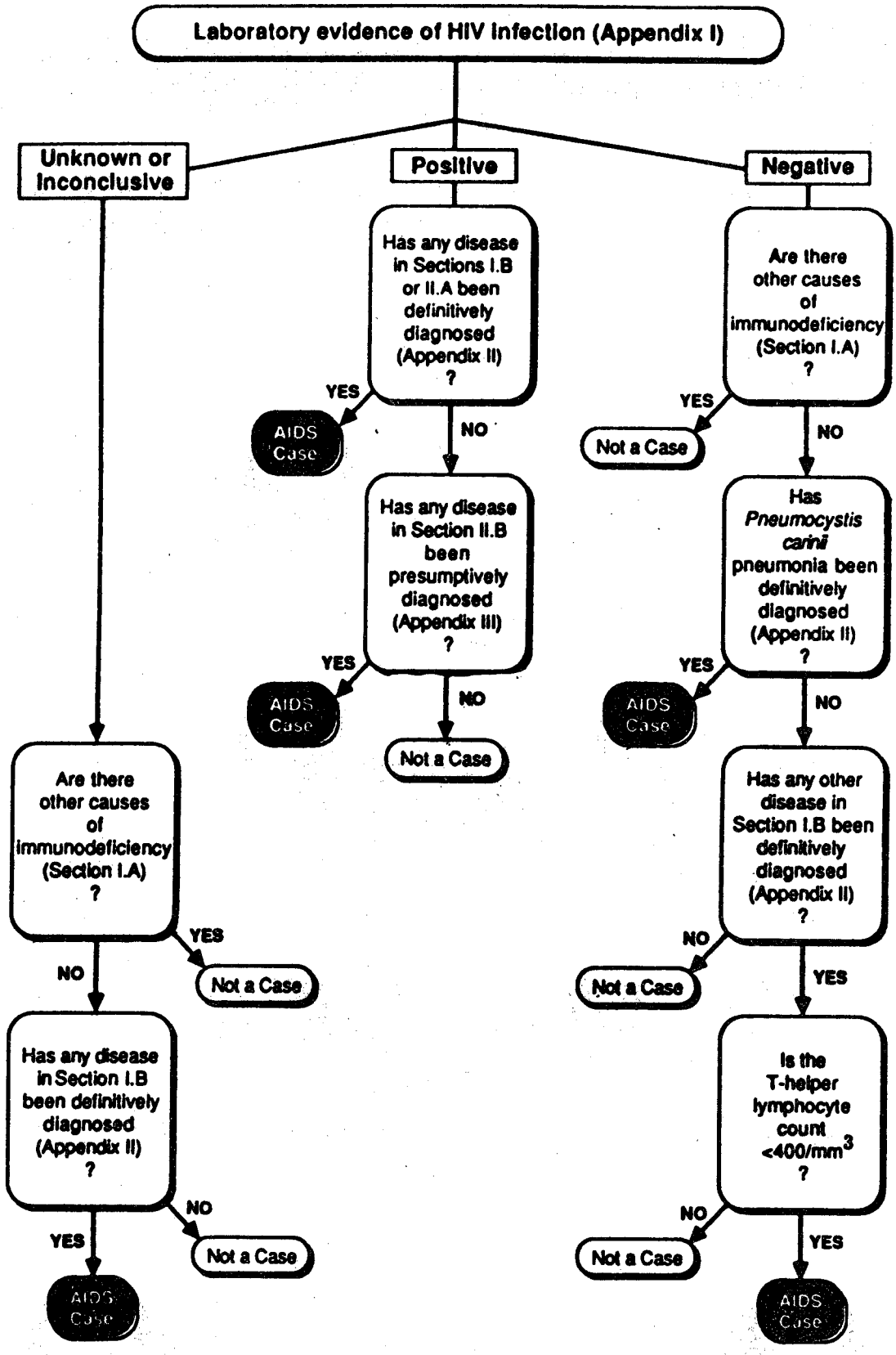
The effectiveness of the revision will depend on how extensively HIV-antibody tests are used. Approximately one third of AIDS patients in the United States have been from New York City and San Francisco, where, since 1985, < 7% have been reported with HIV-antibody test results, compared with > 60% in other areas. The impact of the revision on the reported numbers of AIDS cases will also depend on the proportion of AIDS patients in whom indicator diseases are diagnosed presumptively rather than definitively. The use of presumptive diagnostic criteria varies geographically, being more common in certain rural areas and in urban areas with many indigent AIDS patients.

To avoid confusion about what should be reported to health departments, the term "AIDS" should refer only to conditions meeting the surveillance definition. This definition is intended only to provide consistent statistical data for public health purposes. Clinicians will not rely on this definition alone to diagnose serious disease caused by HIV infection in individual patients because there may be additional information that would lead to a more accurate diagnosis. For example, patients who are not reportable under the definition because they have either a negative HIV-antibody test or, in the presence of HIV antibody, an opportunistic disease not listed in the definition as an indicator of AIDS nonetheless may be diagnosed as having serious HIV disease on consideration of other clinical or laboratory characteristics of HIV infection or a history of exposure to HIV.

Conversely, the AIDS surveillance definition may rarely misclassify other patients as having serious HIV disease if they have no HIV-antibody test but have an AIDS-indicative disease with a background incidence unrelated to HIV infection, such as cryptococcal meningitis.

The diagnostic criteria accepted by the AIDS surveillance case definition should not be interpreted as the standard of good medical practice. Presumptive diagnoses are accepted in the definition because not to count them would be to ignore substantial morbidity resulting from HIV infection. Likewise, the definition accepts a reactive screening test for HIV antibody without confirmation by a supplemental test because a repeatedly reactive screening test result, in combination with an indicator disease, is highly indicative of true HIV disease. For national surveillance purposes, the tiny proportion of possibly false-positive screening tests in persons with AIDS-indicative diseases is of little consequence. For the individual patient, however, a correct diagnosis is critically important. The use of supplemental tests is, therefore, strongly endorsed. An increase in the diagnostic use of HIV-antibody tests could improve both the quality of medical care and the function of the new case definition, as well as assist in providing counselling to prevent transmission of HIV.

FIGURE I. Flow diagram for revised CDC case definition of AIDS, September 1, 1987



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APPENDIX I

Laboratory Evidence For or Against HIV Infection

1. **For Infection:**
   When a patient has disease consistent with AIDS:
   a. a serum specimen from a patient ≥15 months of age, or from a child <15 months of age whose mother is not thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., enzyme-linked immunosorbent assay [ELISA]), as long as subsequent HIV-antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; **OR**
   b. a serum specimen from a child < 15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test (e.g., ELISA), plus increased serum immunoglobulin levels and at least one of the following abnormal immunologic test results: reduced absolute lymphocyte count, depressed CD4 (T-helper) lymphocyte count, or decreased CD4/CD8 (helper/suppressor) ratio, as long as subsequent antibody tests (e.g., Western blot, immunofluorescence assay), if done, are positive; **OR**
   c. a positive test for HIV serum antigen; **OR**
   d. a positive HIV culture confirmed by both reverse transcriptase detection and a specific HIV-antigen test or in situ hybridization using a nucleic acid probe; **OR**
   e. a positive result on any other highly specific test for HIV (e.g., nucleic acid probe of peripheral blood lymphocytes).

2. **Against Infection:**
   A nonreactive screening test for serum antibody to HIV (e.g., ELISA) without a reactive or positive result on any other test for HIV infection (e.g., antibody, antigen, culture), if done.

3. **Inconclusive (Neither For nor Against Infection):**
   a. a repeatedly reactive screening test for serum antibody to HIV (e.g., ELISA) followed by a negative or inconclusive supplemental test (e.g., Western blot, immunofluorescence assay) without a positive HIV culture or serum antigen test, if done; **OR**
   b. a serum specimen from a child < 15 months of age, whose mother is thought to have had HIV infection during the child's perinatal period, that is repeatedly reactive for HIV antibody by a screening test, even if positive by a supplemental test, without additional evidence for immunodeficiency as described above (in 1.b) and without a positive HIV culture or serum antigen test, if done.

APPENDIX II

Definitive Diagnostic Methods for Diseases Indicative of AIDS

Diseases	Definitive Diagnostic Methods
cryptosporidiosis cytomegalovirus isosporiasis Kaposi's sarcoma lymphoma lymphoid pneumonia or hyperplasia *Pneumocystis carinii* pneumonia progressive multifocal leukoencephalopathy toxoplasmosis	microscopy (histology or cytology).
candidiasis	gross inspection by endoscopy or autopsy or by microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface), not from a culture.
coccidioidomycosis cryptococcosis herpes simplex virus histoplasmosis	microscopy (histology or cytology), culture, or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.
tuberculosis other mycobacteriosis salmonellosis other bacterial infection	culture.

HIV encephalopathy* (dementia)	clinical findings of disabling cognitive and/or motor dysfunction interfering with occupation or activities of daily living, or loss of behavioral developmental milestones affecting a child, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Methods to rule out such concurrent illnesses and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.
HIV wasting syndrome*	findings of profound involuntary weight loss >10% of baseline body weight plus either chronic diarrhea (at least two loose stools per day for ≥ 30 days) or chronic weakness and documented fever (for ≥ 30 days, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that could explain the findings (e.g., cancer, tuberculosis, cryptosporidiosis, or other specific enteritis).

*For HIV encephalopathy and HIV wasting syndrome, the methods of diagnosis described here are not truly definitive, but are sufficiently rigorous for surveillance purposes.

APPENDIX III

Suggested Guidelines for Presumptive Diagnosis of Diseases Indicative of AIDS

Diseases	Presumptive Diagnostic Criteria
candidiasis of esophagus	a. recent onset of retrosternal pain on swallowing; **AND** b. oral candidiasis diagnosed by the gross appearance of white patches or plaques on an erythematous base or by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.
cytomegalovirus retinitis	a characteristic appearance on serial ophthalmoscopic examinations (e.g., discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner, following blood vessels, progressing over several months, frequently associated with retinal vasculitis, hemorrhage, and necrosis). Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.
mycobacteriosis	microscopy of a specimen from stool or normally sterile body fluids or tissue from a site other than lungs, skin, or cervical or hilar lymph nodes, showing acid-fast bacilli of a species not identified by culture.
Kaposi's sarcoma	a characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane. **(Note:** Presumptive diagnosis of Kaposi's sarcoma should not be made by clinicians who have seen few cases of it.)
lymphoid interstitial pneumonia	bilateral reticulonodular interstitial pulmonary infiltrates present on chest X ray for ≥2 months with no pathogen identified and no response to antibiotic treatment.
Pneumocystis carinii pneumonia	a. a history of dyspnea on exertion or nonproductive cough of recent onset (within the past 3 months); **AND** b. chest X-ray evidence of diffuse bilateral interstitial infiltrates or gallium scan evidence of diffuse bilateral pulmonary disease; **AND** c. arterial blood gas analysis showing an arterial pO_2 of <70 mm Hg or a low respiratory diffusing capacity (<80% of predicted values) or an increase in the alveolar-arterial oxygen tension gradient; **AND** d. no evidence of a bacterial pneumonia.

toxoplasmosis of the brain

a. recent onset of a focal neurologic abnormality consistent with intracranial disease or a reduced level of consciousness; AND
b. brain imaging evidence of a lesion having a mass effect (on computed tomography or nuclear magnetic resonance) or the radiographic appearance of which is enhanced by injection of contrast medium; AND
c. serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.

SUMMARY: SURVEY OF TEXANS WITH HIV INFECTION

A. Executive Summary

A survey in selected areas of Texas involving persons infected with the Human Immunodeficiency Virus (HIV) was undertaken over the summer of 1988 at the request of the State of Texas Legislative Task Force on AIDS. The objectives of the survey were to: (1) determine what kinds of medical and social services patients with HIV infection consume and how they pay for these services; (2) identify needs and problems in health and social services delivery and in financing of care for HIV-infected individuals; and (3) describe the economic and personal impact of infection with HIV.

Of the 1083 surveys that were distributed, 434 (40%) were returned, 16% from asymptomatic individuals, 19% from persons with pre-AIDS conditions and 65% from persons with full-blown AIDS. The AIDS respondents were similar demographically to those in the registry maintained by the Texas Department of Health with the exception that Blacks and women were underrepresented. It is believed by the authors that the survey population is healthier, better educated and more urban than the general population of AIDS patients

Respondents had consumed a wide variety of health care resources and the intensity of use increased with severity of disease. Whereas only 28% of pre-AIDS respondents reported having ever been hospitalized, 73% of AIDS patients did so (average number of hospitalizations = 1.7; average length of stay = 16 days). Fifty-five percent of respondents reported periodontal problems in the course of their illness and just under 40%

had visited a dentist during the 3 months prior to the survey. Virtually all respondents had visited a physician within the three months prior to the survey and 44% of the AIDS patients had been hospitalized over the same period. The psychosocial burden of HIV infection is enormous as evidenced by the fact that one-third of the respondents had seen a counselor or therapist in the three months prior to the survey, one-fifth had seen a pastoral counselor and 40% had attended a support group.

A major shift in income and financing of care was seen in AIDS respondents between the time they were first diagnosed and the time of the survey. Eighty-three (83) percent of the AIDS respondents were employed at the time of their first HIV diagnosis (median income = $20,000) and 60% had private insurance coverage. By the time of the survey, only 23% were still employed and the proportion with private insurance had fallen to 41% and most (65%) were living off or expecting to receive Social Security Disability Insurance (SSDI). The median income had fallen to $6,000. At the time of the survey, 47% of AIDS respondents were using publically-funded insurance such as Medicaid (16%), Medicare (1%) or Veteran's benefits (5%) and 21% relied on indigent care. Loss of employment not only carried with it loss of private insurance coverage and increased use of publically-funded programs but also a complex of other problems such as loss of housing, difficulty in paying for prescription drugs and depletion of savings.

Almost two-thirds (64%) of the respondents were taking Azidothymidine (AZT) at the time of the survey. Only 22% of these individuals paid for the drug with the help of private

insurance; the remainder relied almost exclusively on publically-funded programs. A common concern was the continued public funding of AZT therapy. Other problems identified by respondents included (1) cancellation of Medicaid benefits after receipt of SSDI over the minimum required income, (2) delays in receiving SSDI and (3) a reluctance to file HIV-related private insurance claims. Thirty-one percent of respondents indicated that there was medical care they were unable to obtain for financial reasons. Types of care that was unaffordable ranged from medications (45% of those with problems) to laboratory tests (5%).

When asked to rank various service and health care needs or improvements, the survey population overwhelmingly chose access to experimental drug therapies as the most important choice. Ranked second was an "AIDS hospital" but conversations wtih participants indicated that such a facility was perceived as increasing access to experimental therapies and was, in effect, measuring the same need.

Discrimination in employment (15%), loss of housing due to discrimination (8%), depletion of savings (47%), rejection by some family members (33%) and inability to pay for prescription drugs (39%) were not uncommon in the survey respondents. The most commonly cited unmet needs were inadequate income and lack of employment (53% of the 172 AIDS patients who had lost their jobs since being diagnosed expressed the desire to return to work).

Limitations of the study including representativeness

of the sample, difficulties in interpreting cross-sectional survey data and lack of independent verification of some of the information of the data are discussed at in the report. Conclusions include the following:

1. Patients with HIV infection consume a variety of medical, dental and other health and social services. Many of these services may not be covered by third party payments and are currently provided by "grassroots" or other service providers. The intensity of utilization increases with severity of illness but is substantial at all stages of disease.

Financing of these services with private insurance and other third party sources is limited. Fifty-four (54) percent of asymptomatic patients, 36% of pre-AIDS and 41% of AIDS patients had private insurance coverage at the time of the survey. Sixteen percent of the AIDS patients had Medicaid alone or in combination with another public form of insurance. Only 1% of AIDS patients had Medicare. The remaining patients had no insurance or relied on indigent health care services.

2. Loss of employment is a key event in ability to finance care. The majority (83%) of AIDS patients in the study were employed and 73% had some form of medical insurance at the time of first diagnosis. By the time of the survey, only 23% were still employed. The proportion of patients with private insurance fell from 56% to 36%, and the proportion of patients using County indigent facilities rose from 8% to 33%. These changes were due to loss of insurance by many of the formerly employed patients and the necessity for patients with no insurance to seek

care at indigent care facilities.

3. A high proportion (36% of AIDS; 44% of pre-AIDS respondents) were unable to pay all the costs associated with their illness in 1987. This was probably due to loss of employment, loss of insurance, depletion of financial resources or a combination of these factors.

4. Specific problems in providing care that were identified included loss of Medicaid coverage due to Social Security Disability Insurance (SSDI) or Veteran's Administration benefits above the maximum permitted income level, delays in obtaining SSDI, unwillingness to file HIV-related claims with private insurance companies and cost of medications. Of respondents taking AZT, only one-fifth were financing the cost with private insurance; the remainder relied almost exclusively on public sources of financing.

5. Just under one-third of respondents reported that they had been unable to obtain some kinds of medical care due to financial problems. The kinds of care, in descending order, included: (1) medications-- especially AZT and aerosolized pentamidine-- (14%), (2) medical or dental services (4%), (3) laboratory tests (2%), and (4) various miscellaneous services (11%).

6. The indirect economic and social impact of this infection is substantial. The majority of AIDS respondents were employed at the time of diagnosis (median income = $20,000) and most held professional, technical or managerial positions. Since three-quarters of the respondents were under the age of 39, this represents a profound loss of income and economic productivity to the patients and to society.

7. There was evidence that discrimination played a role in loss of employment for a substantial minority of pre-AIDS and AIDS respondents who lost their jobs. A significant number of the 34 pre-AIDS and 172 AIDS respondents who lost their jobs between the time of their first HIV-related diagnosis and the time of the survey were fired (39% and 23% respectively) either because of poor performance owing to their illness (9% and 7%), discrimination (15% and 11%) or other reasons (15% and 5% respectively).

8. The most preferred improvement to current health care delivery selected by participants was access to clinical trials involving experimental treatments and drugs. The second most frequently chosen item was establishment of an "AIDS hospital" but interviews with respondents indicated that such a facility was seen as providing access to experimental treatments.

9. Seventy-one percent (71%) of the pre-AIDS and 53% of the AIDS respondents expressed a willingness to work if employment was available.

10. Just under 80% of the 333 respondents who answered the question indicated they would be willing to pay for insurance were such insurance available. The median amount was $50.00 per month (range 0 to $500); this represented approximately 6% of the respondents' gross income at the time of the survey (range, 0 to 80%).

11. Approximately 5% of survey respondents had been diagnosed outside of Texas and subsequently moved here. The methods used in this study do not permit an estimate of outmigration. There

was considerable migration within Texas, with 18% of participants having done so, but there was no discernible pattern to this activity such as, for example, movement from rural to urban areas to seek better medical care. A variety of reasons were cited by patients for moving.

12. Respondents in this survey endured a variety of personal and financial difficulties including loss of friends (39%), rejection by some family members (33%), death of a spouse or partner (12%), inability to pay for prescription medications (39%), loss of job due to discrimination (15%), loss of housing due to loss of income (27%) and depletion of savings (47%).

13. The financial and emotional burden of HIV infection, as with any progressive illness, is incalculable.

SUMMARY: SURVEY OF TEXAS HOSPITALS

THE COST OF AIDS IN TEXAS:
1987 HOSPITAL AIDS SURVEY AND HOSPITAL COST PROJECTIONS

Executive Summary

Estimates of the cost of providing hospital inpatient and outpatient care to AIDS patients are presented in this summary. The first part summarizes information from a statewide hospital survey on 1987 per patient utilization, cost, and financing. The second provides estimates of the total cost of hospital care for all AIDS patients treated in 1987, and forecasts hospital care costs for AIDS patients through 1992.

I. The 1987 Hospital AIDS Survey

Survey Methods and Limitations: A statewide hospital survey was conducted during May through August 1988 by the Texas Hospital Association, the Texas Association of Public and Nonprofit Hospitals, the National Public Health and Hospital Institute (NPHHI), the University of Texas School of Public Health (UTSPH), and the Legislative Task Force on AIDS. A questionnaire requesting 1987 information was developed based on an existing instrument used by NPHHI in its national survey. The questionnaire was mailed to 588 Texas hospitals in late May and early June, allowing six weeks for responses. In June and July, follow-up contacts were made to a group of 43 target hospitals, located in 18 cities that were believed to represent the diversity of facilities treating AIDS patients. The cutoff date for the survey was September 2, 1988. When necessary, respondents were telephoned to clarify reported information and to request missing data.

One hundred eighty-nine hospitals responded, representing an overall response rate of 32%. Thirty-four out of the 43 targeted hospitals responded, representing a 79% response rate of those hospitals believed to be treating a number of AIDS patients. The number of distinct AIDS patients treated by responding hospitals represents almost half of the alive AIDS cases in 1987.

For the purpose of estimating the average use, cost, and financing of AIDS patients, 19 speciality hospitals that responded to the survey were eliminated from the sample. The response group upon which the analysis is based was 170 general acute care hospitals, of which 75 reported treating 1,146 distinct inpatients and 920 distinct outpatients with AIDS.

The cost estimates requested from hospitals do not include the cost of professional services provided in the hospital. Nor do they include the cost of infection control and other AIDS-related costs not directly attributable to patient care. Finally, they do not include the cost of treating patients with HIV-related illnesses other than AIDS.

Survey results: AIDS patients accounted for 2,404 admissions, 28,753 inpatient days, and 10,082 outpatient visits at the 75 hospitals included in the sample. Eight-nine percent of all inpatient days were in general acute care beds, 8% were in intensive care, and 3% other types of beds. The number of admissions per patient was 2.1 and the average length of stay per admission was 12.0 days. Total inpatient days per patient per year averaged 25.1 and total outpatient visits per patient per year averaged 11.5.

The average inpatient and outpatient cost of treating AIDS patients was similar to general medical/surgical patients on a per day and per visit basis. However, the length of stay per admission and the number of admissions required for AIDS patients makes them expensive to treat. The estimate of inpatient cost per patient per year was $15,713, derived from the survey by multiplying the cost per day ($626) by the average number of days per patient (25.1). The cost of outpatient care per patient was $1,903, calculated as the product of the cost per visit ($173) times the average number of visits per patient (8.2). Combining outpatient with inpatient cost leads to a total hospital cost estimate of $17,616 per AIDS case.

The payment hospitals received for AIDS treatment was significantly less than cost. Average revenue per day of $485 was only 77% of per day cost, resulting in a net loss of $137 per day. The net loss for outpatients was even greater, with revenues covering only 14% of costs. Based on the per day and per visit loss, net losses were estimated to be: $1,644 per AIDS admission, $3,439 per AIDS inpatient, and $1,628 per AIDS outpatient.

II. HOSPITAL COST PROJECTIONS

Projection Methods and Limitations: To estimate total annual hospital costs of AIDS patients, the estimate of cost per case obtained from the hospital survey was multiplied by the estimated number of living cases in a given year. The cost projections do not include the cost of nonhospital based tratment costs and they are limited to HIV patients with AIDS.

The total number of cases of AIDS alive during a year includes both the number of AIDS patients diagnosed in previous years who are alive during the year plus all new cases diagnosed during that year. To estimate these numbers for 1987, researchers relied on Texas Department of Health surveillance data on reported cases and deaths as of September 1988. An adjustment of 10% was made to account for underreporting, based on hospital validation studies.

To project the future number of alive cases in each of the years 1988 through 1992, a number of statistical extrapolation models were developed. Two models were selected based upon the closeness of fit with observed data. Least squares estimates of the parameters of each model were made using quarterly cumulative cases diagnosed from the first quarter of 1983 through the second

quarter of 1987. Cumulative cases were those reported as of July 31, 1988.

Cost Projection Results: Total annual direct treatment costs for hospital inpatient and outpatient care are estimated to be approximately $44.0 million in 1987. Hospital costs for AIDS will fall within a range of $88.5 million to $102.7 million in 1988, increasing to between $380 million and $530 million by 1992. The 1992 figures represent a four-to-five-fold increase over 1988.

SUMMARY: COMMUNITY RESOURCES SURVEY

A. BACKGROUND

The goal of the Community Resources Committee of the Legislative Task Force on AIDS was to develop recommendations which would assure the sufficient availability, accessibility, and cost effectiveness of community-based health and social services for persons with AIDS/HIV infection throughout the state. The present survey was undertaken to assist the Task Force in this effort.

The kind of survey that is reported on here is known as "a survey of the availability of resources." Studies of the availability of resources may be contrasted with those that examine a person with AIDS use of resources. When a person's use of a resource is being studied one may speak of a "study of utilization." Generally, a study of availability focuses upon the agencies and facilities that supply as service, while a study of utilization focuses upon those who use it.

B. SURVEY OBJECTIVES AND PROCEDURES

The Community Resources Survey had several objectives.

SURVEY OBJECTIVES

-- DEVELOP AN INVENTORY OF HIV/AIDS RELEVANT COMMUNITY SERVICE AGENCIES
-- DEVELOP A LIST OF HEALTH AND SUPPORTIVE SOCIAL SERVICES
-- ARRAY THESE SERVICES ALONG A CONTINUUM OF CARE
-- DETERMINE THE KINDS OF SERVICES OFFERED BY THE AGENCIES
-- OBTAIN HIV/AIDS BUDGET AND GRANT DATA

Community-based health and social services agencies were defined as those agencies providing services to the civilian, non-institutionalized population of their respective communities. This definition excludes hospital-based services, services offered by private practitioners of medicine, services to military personnel, and services offered to institutionalized populations.

The nucleus for the inventory of agencies was composed of the community-based health and social service agencies whose representatives testified before the Texas Legislative Task Force on AIDS during its state-wide hearings. This core list of agencies was augmented by the Task Force from directories and lists of service providers that it had available. In addition, local resource listings and conversations with knowledge community members were used to augment the AIDS-Related or Community Based Organizations.

The initial list consisted of 555 different agencies. Subsequent to the first mailing, extensive follow-up activities were undertaken to trim the list of (1) organizations that did not fit the definition of community service agencies, (2) agencies that had gone out of business, and (3) duplicate listings of agencies. This activity eliminated 56 agencies. The 499 agencies included a number of different types. The types of agencies surveyed and the number for each type are shown in Table 1.

TABLE 1
TYPE OF AGENCIES SURVEYED AND RESPONSE RATES *

	NUMBER IN GROUP	NUMBER RETURNED	PERCENT RETURNED
MARCH OF DIMES CANCER SOCIETIES LUNG ASSOCIATION SICKLE CELL ANEMIA ASSOCIATIONS HEMOPHILIA CENTERS/FOUNDATIONS AMERICAN RED CROSS	58	48	83%
COMMUNITY MENTAL HEALTH AND MENTAL RETARDATION CENTERS	31	29	94%
DRUG REHABILITATION CENTERS*	20	16	80%
COUNCILS OF GOVERNMENT*	4	3	75%
PUBLIC HEALTH REGIONS	8	8	100%
CITY/COUNTY HEALTH DEPARTMENTS	68	62	91%
AIDS-RELATED AGENCIES	59	51	86%
HOME HEALTH SERVICES*	39	24	62%
HOSPICES*	38	29	76%
SOCIAL SERVICES AGENCIES*	13	9	69%
PLANNED PARENTHOOD	14	12	86%
FAMILY PLANNING CENTERS*	11	7	64%
RELIGIOUS	26	17	65%
COMMUNITY ACTION PROGRAMS*	14	13	93%
STUDENT HEALTH CENTERS	35	34	97%
CLINICAL SERVICES* RESEARCH FACILITIES* UNCLASSIFIED OTHER	61	36	59%
Total	499	398	80%

*NOTE: An asterisk by an agency type means that no attempt was made to make the list of agencies on the inventory comprehensive.

For a number of the agency types no attempt was made to make the inventory complete. These incomplete agency types are indicated in Table 1 with an asterisk.

C. QUESTIONNAIRE DESIGN

Several steps were taken in designing the questionnaire. First a focus group was convened to suggest areas of content, design and to provide an assessment of agency capacity to provide the information requested. Participants represented a variety of agencies, including a local county health department, visiting

nurses association, AIDS Foundation, neighborhood services, religious, planned parenthood and an AIDS-related counseling center. The advice and opinions of the focus group were incorporated into a preliminary draft of the questionnaire.

The draft was then pretest among a selected group of service providers in the Houston community. Substantial changes were made in content and format. With a final review by representatives of the Community Resources Committee, the questionnaire was ready for the field.

D. FOLLOW-UP ON NONRESPONDENTS

The questionnaire was mailed by the Task Force from Austin on June 6, 1988. Follow-up procedures were initiated in the fourth week of the survey period. A telephone list was compiled to reflect all agencies included on the state mailing list but for which a completed survey form had not been received by OHSRA. These agencies were then contacted and their participation in the survey encouraged.

E. RESPONSE RATE

Returned surveys were entered into the data base through September, 1988. Out of a total of 499 agencies, 398 returned completed and useable questionnaires for a response rate of 80%. The response rate varied by the type of agency. Table 1 shows a breakdown of the response rate by agency type. A complete response from all eight Public Health Regions was obtained. The lowest reponse rate for known agency types was for the group of family planning centers. These varying response rates should be considered in interpreting the analysis.

F. DATA CODING AND ENTRY

Upon receipt of a questionnaire, it was reviewed for completeness and clarity and the agency was recontacted if necessary. Most of the coding was already formatted on the questionnaires. Codes had to be developed for the sources to which grants had been made and the purpose of the grant. Once editing and coding had been completed the data were entered into the data base and the entry verified.

The response to items in the questionnaire was generally high with a minimum amount of missing data. The only exception to this was for the cost/expenditure/revenue data for the detailed services. Many agencies apparently do not have this level of information readily available.

G. LIMITATIONS

The study was designed to provide information on the availability of community resources. This scope of the survey purposely excluded assistance provided by family and other informal

efforts. In addition, hospital and hospital affiliated services and physician practices were not surveyed. Conclusions on availability can only be drawn about community service agencies.

Within this limiting scope, the completeness of inventory varied by the specific type of agency surveyed. Public health departments, more established disease oriented agencies, and AIDS-related agencies were relatively completely covered, while family planning programs, drug rehabilitation centers, hospices and home health services were not.

All data were obtained by self-reports with a glossary of major service terms included to establish comparable reporting standards. The response was relatively high, but varied by the different types of organizations. No attempt was made to adjust for nonresponse or for an agency's failure to respond to a specific question. In addition, nonresponse varied by region of the state and should be considered if these data are used to do regional studies.

Many of the community service agencies and the reported data are organized around service areas, e.g., Planned Parenthood of Houston and Southeast Texas. Others reports are state-wide such as the American Cancer Society. The specific service area of agencies needs to be considered in other than state-wide tabulations.

Seven months have passed since the list of agencies was compiled and the survey designed and mailed. Community response to the AIDS epidemic in Texas is a dynamic process. Changes have no doubt already occurred since these data were collected.

SUMMARY: STATE BOARD OF INSURANCE SURVEY

INTRODUCTION

In 1987, the Texas Legislature passed a resolution directing that a special task force be appointed to study the problem of Acquired Immunodeficiency Syndrome (AIDS) and AIDS-related illness in Texas. The Legislative Task Force on AIDS was subsequently appointed and charged with the responsibility of developing recommendations needed to reduce the impact of AIDS in Texas, with particular attention being given to the need for social and medical services, and methods of financing the care of people with AIDS.

During the first part of 1988, the Task Force held numerous public hearings across the state in order to identify the particular problems and special needs of people with AIDS. One issue that was repeatedly raised was the underwriting practices of insurance companies and how the requirements practices affect people with AIDS, AIDS Related Complex (ARC), or HIV infection.

In response to a request from the Task Force, the State Board of Insurance (SBI) agreed to conduct a survey of Texas insurers and Health Maintenance Organizations (HMOs). The survey form was developed by the SBI in cooperation with the Task Force and insurance industry representatives. Though the content is basically the same, three separate survey forms were used to adapt the surveys to the variances in practices and terminology of HMOs, individual health insurance writers, and group insurers.

Insurance company survey participants were selected from two separate SBI lists of insurance companies licensed to write individual and group accident and health insurance. Fifty-six companies with 77 percent of the 1986 premiums written for group health insurance policies were selected, including the 25 largest insurers plus a random selection of 31 smaller companies. Seventy-two insurers writing 57 percent of the 1986 individual insurance premiums were chosen, including the 25 largest insurers and 47 smaller companies. All 41 HMOs (not including single service plans) were surveyed.

Of the 169 HMOs and insurers surveyed, all but one responded. However, 42 companies writing individual insurance and 22 companies writing group coverage no longer issue major medical policies, or have ceased writing health insurance entirely. One HMO survey was received too late to be included in the survey results. These companies represent only a small percentage of the survey sample. The usable survey participants represent approximately 68 percent of the insured Texas population, based on 1986 premiums written and 1988 HMO enrollment figures (Table A).

Table A: Survey Participation		
Insurers:	Group Survey Participants	Individual Survey Participants
Total Written Premiums 1986 (All licensed companies)	$3,165,459,598	$760,370,840
# of Cos. Surveyed	56	72
# of Usable Surveys Received	33(a)	30
Total Written Premiums of Usable Surveys	$2,097,640,553	$337,692,597
% of Total Written Premiums	66%	44%
HMOs:		
Total # of Eligible HMO participants(b)		41
# of Surveys Returned		41
# of Usable Surveys		40
% of Total HMO Enrollment represented by 40 survey participants		95%

(a) Two companies each returned one survey representing the response of two separate insurers. Therefore, although 33 companies responded, the data for group insurers will be based on a total of 31 actually entered in the data base.

(b) Four HMOs are single-service dental plans and were not included in the survey.

The survey is divided into two general sections. The first half ask insurers and HMOs about underwriting practices and includes questions on AIDS testing requirements for new insurance applicants. The second part of the survey requests information on insurers' claims experience for persons with AIDS. Group insurers and HMOs were also asked to provide information on continuation and conversion policies. The questions were designed to provide the Task Force with information which will best assist them in determining recommendations to the 71st Legislature in 1989.

SUMMARY

Three different survey forms were developed for companies answering questions about individual insurance, those answering questions on group insurance, and HMOs. The survey results are based on responses received from 33 insurers writing 66 percent of the Texas group premium volume, 30 companies with 44 percent of the individual accident and health premium volume, and 40 HMOs with 95 percent of the HMO members in Texas. The surveys were divided into two separate sections: 1) underwriting practices and 2) claims experience.

Medical Underwriting Prevalence

Applicants for individual and small group policies are much more likely to be asked to provide evidence of insurability than are group applicants. More than three quarters of the group insurers never underwrite groups with more than 25 employees, and none of the HMOs underwrite group applicants. However, group applicants with 10 or less employees/lives are required to be underwritten by 20 group insurers with 90 percent of the surveyed group market.

In determining whether an applicant is accepted or declined for insurance, survey respondents use health related questions on application forms, attending physician statements (APS), physical exams, and medical testing. Small group applicants are more likely than large group applicants to be asked to submit this information. Twenty-six insurers require all employees of underwritten groups to complete a health questionnaire, and 25 also require health questionnaires from dependents. None of the HMOs require group members to complete a health application unless they are a late entrant. Eighteen HMOs require late group applicants to submit health applications, and the five HMOs who accept individual members all require health applications.

Twenty-four insurers with 59 percent of the survey participants' market may request an APS from individually underwritten group members. Twelve of the insurers estimate that no more than 20 percent of the underwritten applicants are asked to provide an APS, while eleven request an APS from 21 - 50 percent of their applicants.

The number of insurers which request an APS from applicants for individual A&H policies ranges from as few as .005 percent of their applicants to as many as 80 percent. Only three HMOs request an APS from no more than five percent of the individual applicants, while 18 may ask late enrollees to provide an APS.

Physical exams are rarely required of either group or individual applicants. Thirteen companies responding to the individual survey and six companies responding to the group survey reported that they never use physical exams. Of the 15 individual and 19 group survey participants who do sometimes request physicals, the majority estimate that less than two percent of their applicants take physicals. Nine HMOs report that physicals are occasionally requested for individual applicants or late enrollees.

Medical Testing is also infrequently used by insurers. Nineteen group survey participants and 18 companies responding to the individual survey never use medical tests. Eleven companies report that no more than 10% of their group applicants require medical testing on the basis of their health history. Ten individual survey participants test between one and ten percent of their applicants, with one company performing blood chemistry analysis, blood pressure and urinalysis tests on all applicants. Three HMOs test late enrollees, and two HMOs test between two and ten percent of their individual applicants.

AIDS Testing

Twenty-six of the group survey participants attempt to identify applicants with AIDS or ARC, and 15 attempt to identify HIV infected applicants. Only nine insurers actually test applicants for AIDS, and seven for HIV infection. The remainder of the 26 respondents all include AIDS related questions in the health history questionnaire submitted by the prospective insured.

Insurers report a slightly higher frequency of testing of applicants for individual health insurance. Three insurers test all individual applicants for AIDS/ARC, and two for HIV infection. Another six test applicants if indicated by information in the health history questionnaire. Another 14 companies do not test applicants, but indicate they do try to identify infected applicants. Only two HMOs try to identify infected individual applicants and late enrollees, and three others do so with late enrollees only. All five HMOs include questions on the health history questionnaire rather than require testing of the applicant. Of the estimated 3,053 applicants tested so far by all survey respondents, no more than seventeen positive tests were reported.

Risk Classification

If it is determined that a group applicant tests positive for AIDS, 11 respondents will decline the entire group and 16 will accept the group with an exclusion for the infected applicant. Persons testing HIV positive are individually excluded from group coverage by 13 insurers, and 10 insurers decline coverage for the entire group. All 24 individual survey respondents report that the applicant would be denied coverage.

The survey respondents report few actual policies which exclude or limit benefits for AIDS/ARC. Twenty-six companies answering the individual survey and 24 group survey participants report that they have no policies with limited benefits or exclusions for AIDS-related treatment. One individual insurer said all policies issued since December 1, 1987 limit benefits for AIDS, and two

companies report that less than one percent of their policies cover family members with an exclusion for a member who tested positive for AIDS. Seven insurers have issued group policies excluding an applicant with AIDS, and three companies (with less than one percent of the survey participants' premium volume) report issuing policies which exclude or limit benefits for AIDS, but could not provide an estimate of the number of policies involved.

Insurance Availability - Pre-existing Conditions

To determine the availability of insurance for individuals with a pre-existing medical condition, insurers were asked to indicate whether applicants with particular disorders would be declined for coverage, if limited coverage would be available, or if an increase in premium would be applied. Fifty-five insurers of group and individual companies responded. The illnesses most likely to always result in declination of insurance include AIDS (54 companies), HIV infection (51), leukemia (48), severe mental illness (45), cystic fibrosis (44), and uncontrolled hypertension (41). The majority of insurers also report "always" or "sometimes" declining coverage for persons with spina bifida (53 insurers), neoplasms (51), multiple sclerosis (50), downs syndrome (48), or coronary artery disease (47).

Claims Experience

Of the 101 survey participants, 56 reported claims for the treatment of AIDS or ARC. (Time periods used in determining the number of AIDS/ARC cases and AIDS related claims varied, with some companies reporting claims for 1987 only and others reporting claims during 1986 through 1987.) Another ten reported that the number of claims was unknown. Twenty insurers identified a total of 1,004 insureds with AIDS or ARC under group policies. More than half (68%) of the reported AIDS/ARC group cases are insured by only three companies with678 identified cases. Seventeen insurers report a total of 54 claimants with AIDS or ARC under individual policies, with 19 of those insured by one company. Twenty-four HMOs report a total of 188 members diagnosed with AIDS, 41 members with ARC, and 159 members who have tested HIV positive. One HMO has identified an additional 113 members with either AIDS, ARC or HIV infection, but does not distinguish between AIDS, ARC or HIV infection.

When considered as a percentage of the total insured population, all survey respondents reported that the number of persons with AIDS, ARC, or HIV infection represents less than one percent of their insureds. However, many respondents stressed that the actual number of insureds with AIDS or ARC is believed to be higher than reported.

Information on the cost of AIDS-related claims is sketchy. Twenty group insurers estimated a total of $23,567,646 in claims for Texans with AIDS/ARC. Sixteen individual companies had paid a total of $3,057,326 for known AIDS/ARC claims.

Medical Case Management

Medical case management is used by 28 of the 31 companies writing group insurance and 10 companies responding to the individual survey. Twenty-two HMOs use case management for members with AIDS. Though the details of management plans differ, all are aimed at providing cost effective care in a variety of alternative settings that are desirable to the patient.

Policy Benefits

Nearly all survey respondents report their policies "commonly provide" outpatient hospital services. Twenty-six companies responding to the group survey and 23 individual survey respondents provide outpatient care, and 36 HMOs do so. AZT medication is covered by 27 insurers. Hospice care is most frequently offered by HMOs (26) followed by group survey respondents (14) and individual survey respondents (7). Nursing home care is included in individual policies provided by nine companies, 10 companies' most common group policies, and 28 HMOs. Home health care is offered by 14 group and 11 individual insurers. (Federally qualified HMOs are required to provide home health care.) Finally, mental health counseling is provided by 34 HMOs and 28 group insurers. Five individual insurers estimate that one percent of their policies provide mental health counseling.

SECTION 9, ARTICLE 4419b-1, VTCS

Sec. 8.43. NO EFFECT ON GUARDIANSHIP. No action taken or determination made under this Act and no provision of this Act shall affect any guardianship established in accordance with law.

Sec. 8.44. WRIT OF HABEAS CORPUS. This Act may not be construed to abridge the right of any person to a writ of habeas corpus.

Sec. 8.45. PHYSICAL RESTRAINTS. Physical restraint may not be applied to the body of a person unless prescribed by a physician, and if applied, the restraint shall be removed as soon as possible. Every use of physical restraint and the reasons for the use shall be made a part of the clinical record of the patient under the signature of the physician who prescribed the restraint.

Sec. 8.46. DISCLOSURE OF INFORMATION. Health care facility records that directly or indirectly identify a patient, former patient, or proposed patient are confidential unless disclosure is permitted by this Act or other state law.

ARTICLE 9. TESTS FOR ACQUIRED IMMUNE DEFICIENCY SYNDROME AND RELATED DISORDERS

Sec. 9.01. DEFINITIONS. In this Act:

(1) "AIDS" means acquired immune deficiency syndrome as defined by the Centers for Disease Control of the United States Public Health Service.

(2) "HIV" means human immunodeficiency virus.

(3) "Bona fide occupational qualification" means a qualification:

(A) that is reasonably related to the satisfactory performance of the duties of a job; and

(B) for which there is a reasonable cause for believing that a person of the excluded group would be unable to perform satisfactorily the duties of the job with safety.

(4) "Blood bank" means a blood bank, blood center, regional collection center, tissue bank, transfusion service, or other similar facility licensed by the Bureau of Biologics of the United States Food and Drug Administration, accredited for membership in the American Association of Blood Banks, or qualified for membership in the American Association of Tissue Banks.

(5) "Test result" means any statement or assertion that any identifiable individual is positive, negative, at risk, has or does not have a certain level of antigen or antibody, or any other statement that indicates that an identifiable individual has or has not been tested for AIDS or HIV infection, antibodies to HIV, or infection with any other probable causative agent of AIDS.

Sec. 9.02. TESTS FOR AIDS AND RELATED DISORDERS. (a) A person or entity may not require another person to undergo any medical procedure or test designed to show or help show whether a person has AIDS or HIV infection, antibodies to HIV, or infection with any other probable causative agent of AIDS unless required under Subsection (c) or (g) of this section or under Article 21.31, Code of Criminal Procedure, or unless the medical procedure or test is necessary:

(1) as a bona fide occupational qualification and there exists no less discriminatory means of satisfying the occupational qualification;

(2) to screen blood, blood products, bodily fluids, organs, or tissues for the purpose of determining suitability for donation;

(3) in relation to a particular person under this Act;

(4) to test residents and clients of residential facilities of the Texas Department of Mental Health and Mental Retardation, but only if:

(A) the test result would change the medical or social management of the person tested or others who associate with that person; and

(B) the test is conducted in accordance with guidelines that have been adopted by the residential facility or the Texas Department of Mental Health and Mental Retardation, and approved by the department; or

(5) to manage accidental exposure to blood or other bodily fluids but only if the test is conducted in accordance with written infectious disease control protocols adopted by the health care agency or facility and is conducted in accordance with Subsection (d) of this section.

(b) An employer who alleges that a test is necessary as a bona fide occupational qualification has the burden of proving the allegation.

(c) The board may adopt emergency rules for mandatory testing for HIV infection if the commissioner files a certificate of necessity with the board that contains supportive findings of medical and scientific fact and that declares a sudden and imminent threat to public health. Rules adopted under this subsection must:

(1) provide for the narrowest application of HIV testing necessary for the protection of public health;

(2) provide procedures and guidelines to be followed by affected entities and state agencies that clearly specify the need and justification for the testing, specify methods to be used to assure confidentiality, and delineate responsibility and authority for carrying out the recommended actions;

(3) provide for counseling of persons with seropositive test results; and

(4) provide for confidentiality regarding persons tested and their test results.

(d) Protocols adopted under Subsection (a)(5) of this section must clearly establish procedural guidelines that provide criteria for testing and that respect the rights of the person with the infection and the person who may be exposed to that infection. The protocols may not require the person who may have been exposed to be tested and must ensure the confidentiality of the person with the infection in accordance with this Act.

(e) When the prevalence rate of confirmed positive HIV infection is 0.83 percent, as reported under the Communicable Disease Prevention and Control Act (Article 4419b-1, Vernon's Texas Civil Statutes), the Texas Board of Health shall promulgate emergency rules for mandatory testing for HIV infection as a condition for obtaining a marriage license.

(f) This section does not provide a duty to test for AIDS and related disorders, and a cause of action does not arise under this section for the failure to test for AIDS and related disorders.

(g) A patient may be required to be tested for AIDS or HIV infection, antibodies to HIV, or infection with any other probable causative agent of AIDS if a medical procedure is to be performed on the patient that could expose health care personnel to AIDS or HIV infection, according to Texas Board of Health guidelines defining the conditions that constitute possible exposure to AIDS or HIV infection, and if there is sufficient time to receive the test result before the procedure is conducted.

Sec. 9.03. CONFIDENTIALITY AND DISCLOSURE OF TEST RESULTS. (a) A test result is confidential. Except as provided by this section, any person, firm, corporation, physician, hospital, blood center, blood bank, laboratory, or other entity that possesses or has knowledge of the test result may not release or disclose a test result or allow a test result to become known.

(b) A test result may be released only to:

(1) the department under this Act;

(2) a local health authority if reporting is required under this Act;

(3) the Centers for Disease Control of the United States Public Health Service if reporting is required by federal law or regulation;

(4) the physician or other person authorized by law who ordered the test;

(5) a physician, nurse, or other health care personnel who have a legitimate need to know the test result in order to provide for their protection and to provide for the patient's health and welfare;

(6) the person tested or a person legally authorized to consent to the test on the person's behalf;

(7) the spouse of the person tested if the person tests positive for AIDS or HIV infection, antibodies to HIV, or infection with any other probable causative agent of AIDS and the physician who ordered the test makes the notification. This subdivision does not provide a duty to notify the spouse, and a cause of action does not arise under this subdivision for the failure to make that notification; and

(8) if the person is tested as required by Article 21.31, Code of Criminal Procedure, the victim of an alleged offense listed in that article committed by the person tested. The court shall notify the victim of the alleged offense of the requirements of this Act under this section.

(c) This section does not prohibit the person tested or a person legally authorized to consent to the test on the person's behalf from:

(1) voluntarily releasing or disclosing that person's test results to persons or entities other than those provided by this section; or

(2) authorizing the release or disclosure of that person's test results to persons or entities other than those provided by this section.

(d) The authorization prescribed by Subsection (c)(2) of this section must be in writing and signed by the person tested or a person legally authorized to consent to the test on the person's behalf and must state the persons or entities or classification of persons or entities to whom the test results may be released or disclosed.

(e) If a report of a test result is used for statistical summary purposes only, the person or entity releasing or disclosing the test result may disclose or release the information without the written consent of the person tested only after any information that could identify the person is removed from the report.

(f) A blood bank may report positive blood test results indicating the name of a donor with a possible infectious disease to other blood banks. A blood bank that reports a donor's name to other blood banks under this subsection may not disclose the infectious disease that the donor has or is suspected of having. A blood bank making a report as provided by this subsection is not considered to have breached a confidence arising out of any confidential relationship.

(g) A blood bank may provide blood samples to hospitals, laboratories, and other blood banks for additional, repetitive, or different testing.

(h) A blood bank may report blood test results to the hospitals where the blood was transfused, to the physician who transfused the infected blood, and to the recipient of the blood. A blood bank may also report blood test results for statistical purposes. A blood bank that reports test results under this subsection may not disclose the name of the donor or person tested or any other information that could result in disclosure of the donor's or person's name, including addresses, social security number, designated recipients, or replacement information.

(i) This section does not prohibit an employee of a health care facility from viewing test results while performing the employee's duties if the employee's job requires the employee to deal with permanent medical records and the employee learns of test results during reasonable health care facility practices. Test results that may be viewed under this subsection are confidential as provided by this Act.

Sec. 9.04 CIVIL LIABILITY. (a) Any person who is injured by a violation of Section 9.02 or 9.03 of this Act may bring a civil action for damages. In addition, any person may bring an action to restrain a violation or threatened violation of those sections.

(b) If it is found in a civil action that a person or entity has violated Section 9.02 of this Act, the person or entity is liable for:

(1) actual damages;

(2) a civil penalty of not more than $1,000; and

(3) court costs and reasonable attorney's fees incurred by the person bringing the action.

(c) If it is found in a civil action that a person or entity has negligently released or disclosed a test result or allowed a test result to become known in violation of Section 9.03 of this Act, the person or entity is liable for:

(1) actual damages;

(2) a civil penalty of not more than $1,000; and

(3) court costs and reasonable attorney's fees incurred by the person bringing the action.

(d) If it is found in a civil action that a person or entity has wilfully released or disclosed a test result or allowed a test result to become known in violation of Section 9.03 of this Act, the person or entity is liable for:

(1) actual damages;

(2) a civil penalty of not less than $1,000 nor more than $5,000; and

(3) court costs and reasonable attorney's fees incurred by the person bringing the action.

(e) Each release or disclosure made, or allowance of a test result to become known, in violation of this Act constitutes a separate offense.

(f) A defendant in a civil action brought under this section is not entitled to claim any privilege as a defense to the action.

Sec. 9.05. TESTS FOR AIDS AND RELATED DISORDERS; PENALTY. (a) A person or entity that requires a medical procedure or test in violation of Section 9.02 of this Act commits an offense.

(b) An offense under this section is a Class A misdemeanor.

Sec. 9.06. RELEASING OR DISCLOSING TEST RESULTS; PENALTY. (a) A person or entity that, with criminal negligence, releases or discloses a test result or other information or that allows a test result or other information to become known in violation of Section 9.03 of this Act commits an offense.

(b) An offense under this section is a Class A misdemeanor.

Added by Acts 1983, 68th Leg., p. 1116, ch. 255, 1, eff. Sept. 1, 1983; Sec. 1.02 amended by Act, 1987, 70th Leg., ch. 543, 1, eff. Sept. 1, 1987; Sec. 1.04 amended by Act, 1987, 70th Leg., ch. 543, 2, eff. Sept. 1, 1987; Sec. 2.02(c) amended by Acts, 1987, 70th Leg., ch. 543, 3, eff. Sept. 1, 1987; Sec. 2.03(b) amended by Acts, 1987, 70th Leg., ch. 543, 4, eff. Sept. 1, 1987; Sec. 3.01(a)-(d) amended and Sec. 3.01(e) added by Acts, 1987, 70th Leg., ch. 543, 5, eff. Sept. 1, 1987; Sec. 3.02(b) amended and 3.02(c)-(d) added by Acts, 1987, 70th Leg., ch. 543, 6, eff. Sept. 1, 1987; Sec. 3.03 amended by Acts, 1987, 70th Leg., ch. 543, 7, eff. Sept. 1, 1987; Sec. 3.04(a) amended and Sec. 3.04(b) and (c) added by Acts, 1987, 70th Leg., ch. 543, 8, eff. Sept. 1, 1987; Sec. 3.05 amended by Acts, 1987, 70th Leg., ch. 543, 9, eff. Sept. 1, 1987; Sec. 3.06 amended by Acts, 1987, 70th Leg., ch. 543, 10, eff. Sept. 1, 1987; Sec. 3.07 amended by Acts, 1987, 70th Leg., ch. 543, 11, eff. Sept. 1, 1987; Sec. 3.08 added by Acts, 1987, 70th Leg., ch. 543, 12, eff. Sept. 1, 1987; Sec. 4.01(c) amended by Acts, 1987, 70th Leg., ch. 543, 13, eff. Sept. 1, 1987; Sec. 4.02 amended by Acts, 1987, 70th Leg., ch. 543, 14, eff. Sept. 1, 1987; Sec. 4.06(f) amended by Acts, 1987, 70th Leg., ch.543, 15, eff. Sept. 1, 1987; Sec. 6.01(b) amended by Acts, 1987, 70th Leg., ch. 543, 16, eff. Sept. 1, 1987; Sec. 6.02(b) amended by Acts, 1987, 70th Leg., ch. 543, 17, eff. Sept. 1, 1987; Sec. 6.04 amended by Acts, 1987, 70th Leg., ch. 543, 18, eff. Sept. 1, 1987; Sec. 6.09 and Sec. 6.10 added by Acts, 1987, 70th Leg., ch. 543, 19, eff. Sept. 1, 1987; Art. 7 added by Acts, 1987, 70th Leg., ch. 543, 20, eff. Sept. 1, 1987; Art. 8 added by Acts, 1987, 70th Leg., ch. 543, 21, eff. Sept. 1, 1987; Art. 9 added by Acts, 1987, 70th Leg., ch. 543, 22, eff. Sept. 1, 1987; Sec. 9.03 amended by Act, 1987, 70th Leg., 2nd Called Session, ch. _____, 4, eff. , 1987; Sec. 9.03 amended by Acts, 1987, 70th Leg., 2nd Called Session, ch. _____, 5, eff. , 1987.

Other Provisions from Chapter 543, Acts of the 70th Legislature,
Regular Session, 1987 (HB 1839, McDonald)

Sec. 23. Section 35.03(a), Family Code, is amended to read as follows:

(a) A minor may consent to the furnishing of hospital, medical, surgical, and dental care by a licensed physician or dentist if the minor:

(1) is on active duty with the armed services of the United States of America;

(2) is 16 years of age or older and resides separate and apart from his parents, managing conservator, or guardian, whether with or without the consent of the parents, managing conservator, or guardian and regardless of the duration of such residence, and is managing his own financial affairs, regardless of the source of the income;

(3) consents to the diagnosis and treatment of any infectious, contagious or communicable disease which is required by law or regulation adopted pursuant to law to be reported by the licensed physician or dentist to a local health officer or the Texas Department of Health and including all sexually transmitted diseases [within the scope by law or regulation of Section 1.03, Article 4445d, Vernon's Texas Civil Statutes];

(4) is unmarried and pregnant, and consents to hospital, medical, or surgical treatment, other than abortion, related to her pregnancy;

(5) is 18 years of age or older and consents to the donation of his blood and the penetration of tissue necessary to accomplish the donation; or

(6) consents to examination and treatment for drug addiction, drug dependency, or any other condition directly related to drug use.

Sec. 24. The following laws are repealed:

(1) Texas Venereal Disease Act (Article 4445d, Vernon's Texas Civil Statutes);

(2) Sections 4, 4A, 5, 6, and 7, Texas Tuberculosis Code (Article 4477-11, Vernon's Texas Civil Statutes);

(3) Sections 3, 4, 5, 6, 7, 9, and 10, Chapter 51, Acts of the 59th Legislature, Regular Session, 1965 (Article 4477-12, Vernon's Texas Civil Statutes); and

(4) Section 6.05, Communicable Disease Prevention and Control Act (Article 4419b-1, Vernon's Texas Civil Statutes).

Sec. 25. An offense committed before the effective date of this Act under a law that is repealed by this Act is governed by the law in effect when the offense occurred, and the former law is continued in effect for that purpose.

Sec. 26. Subsection (d), Section 3.06, Medical Practice Act (Article 4495b, Vernon's Texas Civil Statutes), is amended by adding Subdivision (7) to read as follows:

(7)(A) It is the policy of this state that the prevention of ophthalmia neonatorum in newborn infants is of paramount importance for the protection of the health of Texas children.

(B) Authority to delegate medical acts to a lay midwife registered under Chapter 365, Acts of the 68th Legislature, Regular Session, 1983 (Article 4512i, Vernon's Texas Civil Statutes), is recognized as applicable to the possession of the administration of eye prophylaxis for the prevention of ophthalmia neonatorum.

(C) A physician who has issued such a standing delegation order is immune from liability in connection with acts performed pursuant to the standing delegation order as long as a lay midwife has provided proof of compliance with Chapter 365, Acts of the 68th Legislature, Regular Session, 1983 (Article 4512i, Vernon's Texas Civil Statutes), prior to the issuance of the order.

Sec. 27. Title 108, Revised Statutes, is amended by adding Article 6203c-12 to read as follows:

Art. 6203c-12. TESTING FOR COMMUNICABLE DISEASES. The Texas Department of Corrections is authorized to test inmates of correctional facilities for human immunodeficiency virus. If the department determines that an inmate has a positive test result, the inmate may be segregated from other inmates.

Sec. 28. This Act takes effect September 1, 1987.

Sec. 29. The importance of this legislation and the crowded condition of the calendars in both houses create an emergency and an imperative public necessity that the constitutional rule requiring bills to be read on three several days in each house be suspended, and this rule is hereby suspended.

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