Meeting The Needs of Minnesotans with HIV Disease

The Report from the HIV Services Planning Project

A project of the
Minnesota Department of Health
AIDS/STD Prevention Services Section

1991

Funded in part by the Health Resources and Services Adminstration

Meeting the Needs of Minnesotans with HIV Disease

Report from the HIV Services Planning Project

HIV Services and Planning Unit

AIDS/STD Prevention Services Section

Minnesota Department of Health

717 S.E. Delaware Street
Minneapolis, Minnesota 55440

1991

Printed on recycled paper

RAMSEY COUNTY
PUBLIC HEALTH DEPARTMENT
150 E. Kellogg Blvd., Suite 610
St. Paul, Minnesota 55101

298-5971

Rob Fulton, *Director*

RAMSEY COUNTY

April 23, 1991

Mary Jo O'Brien, Acting Commissioner
Minnesota Department of Health

Dear Acting Commissioner O'Brien:

As Chair, I am pleased to deliver this report of the Commissioner's Task Force on AIDS for the HIV Services Planning Project. This Task Force, and its supporting subcommittees, began work in January of 1990, and developed our final recommendations in the Spring of 1991.

The report details the current experience of Minnesotans affected by HIV disease, and makes recommendations for public and private agencies which, if enacted, will improve the system of care and service delivery for these citizens.

The analysis and recommendations contained in this report resulted from extensive review and data collection with broad community-based participation. Over 120 community members representing state and local agencies, persons with HIV disease, care and service providers and community health professionals first reviewed current services for Minnesotans with HIV disease. This analysis was combined with a uniquely comprehensive data collection effort involving an additional 339 persons with HIV and their caregivers. The recommendations set forth in this document are the result of this information and represents a collective plan by providers and consumers for improving care and services to this growing population.

The Task Force recognizes that these recommendations are very comprehensive. They ask for the commitment of state and local government, the support of private agencies and foundations, the participation of persons with HIV infection, and the collective will of our citizens. Enacting these recommendations, however, will help assure that the future for Minnesotans with HIV infection is one which provides quality health care, access to needed social services, and the attention of a compassionate society.

This document represents hours of hard work from hundreds of Minnesotans drawn together with common goals and commitment: to create a just and caring response to AIDS here in Minnesota. The recommendations in this document are reasonable, responsible and achievable.

The volunteer membership of the HIV Services Planning Project and the hundreds of persons with HIV infection who shared their experiences join with me in thanking you for the opportunity to serve the state, and look forward to working with you to implement this plan of action. The thousands of Minnesotans facing HIV, and the thousands yet to come, deserve our commitment to enacting this plan.

Sincerely,

Rob Fulton, Chair
Commissioner's Task Force on AIDS

TABLE OF CONTENTS

Executive Summary

EXECUTIVE SUMMARY

This section contains an overview of the HIV epidemic in Minnesota, a summary of the HIV Services Planning Project and its activities, and priority recommendations for improving the lives of Minnesotans with HIV disease developed by the Minnesota Department of Health's Commissioner's Task Force on AIDS.

The Continuing Challenge:
HIV in Minnesota

Since the first recorded cases of AIDS in Minnesota nine short years ago, agencies and individuals across our state have been actively reaching out to, loving, caring for, and treating persons with HIV disease. Minnesota's models for care are seen nationally as innovative, high quality, and cost effective, and Minnesotans are among the nation's leaders in speaking for the rights and needs of persons with HIV and AIDS.

Yet Minnesota as a whole has not fully accepted persons with HIV infection into our society. Citizens with HIV disease continue to face discrimination in all areas of life. Some members of our community continue to advocate that persons with HIV be quarantined, treated less than equally, loved and cared for less than others facing a terrible illness. This fear and discrimination must end before our state can fully address the crisis of HIV and AIDS.

Some persons in Minnesota ask why HIV/AIDS is treated "differently" from other chronic or terminal diseases and why a plan for meeting the service needs of this population is called for. The answers to these questions include both how HIV is transmitted and the unique needs of persons with this debilitating illness.

HIV transmission occurs primarily through sexual activity and the sharing of needles during drug use. These activities generate emotional responses from society which have too often resulted in the rejection of individuals with HIV/AIDS and the creation of barriers that impede their interaction in society and thus affecting their use of services.

Persons with HIV disease require not only traditional medical care and services, but assistance in learning to live with a disease that is both chronic and communicable. HIV disease causes debilitating infections which can interfere with the ability to be self supporting, necessitating the use of supportive services from housing, to personal care, to financial assistance. The epidemic has affected persons from communities of color, gay men, the poor, and the noninsured at a greater rate than in the general population. Many persons with AIDS struggle with their illness as they also struggle with homophobia, racism, sexism, classism, and poverty. These barriers make accessing and using health and social services more difficult for persons with HIV, and require assistance from society to see that the needs of persons with HIV are met.

Across the United States, as in Minnesota, AIDS has served to underline the weaknesses in our social service and health care systems. The recommendations contained in this report -- though specific to the needs of Minnesotans with HIV disease -- are applicable in many ways to all populations facing chronic and life threatening acute diseases. Changes which help HIV-infected persons access needed care and services will help all Minnesotans by improving the health of thousands of citizens, reducing the costs of caring for persons with HIV disease, and decreasing the spread of the epidemic.

Persons living with HIV in Minnesota tell us that they are fortunate to live in a state willing and able to meet their needs. Our challenge is to improve and maintain this level of care in times of declining funding and increased needs -- and to support the individuals and organizations who provide that care as their work grows even more difficult.

Although this Planning Project and its recommendations focus solely on the service needs of persons with HIV disease, the Task Force wishes to make clear its conviction that a variety of public health strategies to prevent the further spread of HIV must be continued, and that programs to meet the health and social service needs of Minnesotans with HIV should neither take precedence over prevention, nor be carried out with dollars earmarked for education.

The HIV Services Planning Project: *Methods for Community Involvement and Input*

In October of 1989, the Minnesota Department of Health (MDH) received funding from the federal Health Resources and Services Administration (HRSA) to conduct a year-long planning project designed to help Minnesota plan for HIV service needs through 1993.

This planning has taken place in a truly community-based forum, involving over 100 individuals from community based organizations, state agencies, caring professions and persons living with HIV. These volunteers, organized into four subcommittees (maternal and child, adolescents, adult and greater Minnesota issues) and guided by a Task Force appointed by the State Commissioner of Health, began their planning process by conducting a statewide needs assessment of HIV services.

Although Minnesota's professionals have a great deal of information about HIV services, it is people with HIV disease and their caregivers who have the most intimate and immediate experience of living with HIV in our communities. The second phase of the planning project involved gathering these voices and documenting the opinions of 238 adult Minnesotans with HIV disease, 59 of their caregivers, ten parents of HIV-infected youth, and three adolescents. Their assessment of services, conducted through a three-part study, formed a second layer of the planning process, and tested the assumptions of the subcommittees.

Armed with data from these studies, members of the subcommittees then drafted recommendations for the Commissioner of Health's Task Force on AIDS. This Task Force of diverse leaders working in -- and affected by -- HIV formed the final recommendations contained in this document.

This plan is, therefore, significant in two ways. First, it documents for the first time the experience of living with HIV in Minnesota through the voices and experiences of our citizens. Second, it represents a plan achieved by many segments of the AIDS community developed through difficult discussions, careful analysis, and compromise.

The Changing Epidemic In Minnesota: *Preparing for the Future*

To best understand the Task Force's recommendations for HIV services, it is important to note three changes in the epidemic which impact this report.

First, the face of the epidemic is changing. Through 1986, 82 percent of the persons with AIDS in Minnesota were gay men. Today, that percentage has decreased to 77 percent. Rising in number are individuals from communities of color, particularly the African American community, women and intravenous drug users (IVDUs).

Second, new medications now allow physicians to successfully treat or prevent a number of HIV-related infections, and FDA approved and non-approved treatments (such as AZT) may deter replication of the human immunodeficiency virus. Because of these interventions and other advances in treatment, persons with HIV infection are able to live more productive -- and longer -- lives. The availability of these new options for care also raises the issue of early testing for exposure to HIV, and the importance of early referral and access to appropriate health care.

Finally, Minnesota faces a change in the way AIDS activities have been funded. In 1990, Congress passed the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. This Act authorizes grants to improve the quality, availability, and organization of health care and support services for individuals and families with HIV disease. Although not fully funded at the level authorized, this Act represents the first block grant funding to states to provide care to persons with HIV/AIDS. These funds can be used for such essential health and supportive services as medical treatments, home care, and others. States are required to maintain the level of funding for persons with HIV/AIDS that was in place prior to the passage of this Act. The ongoing funding level for this Act is uncertain, making it difficult to plan for services long range.

Minnesota also has recently instituted a state funded pilot program for low income persons with HIV disease to pay health care insurance premiums if they need to terminate their employment because of illness. This program delays entry in to the Medical Assistance program, and this shift in payment coverage may affect access or delivery of care for persons with HIV.

Recommendations for Improving Services for HIV-Infected Minnesotans: *A Blue Print for Change*

1. *Minnesota should fully accept persons with HIV disease.*

The HIV epidemic offers an opportunity for Minnesotans to examine their personal and collective understanding not only of persons with HIV disease but also of those communities most affected by this devastating illness. By learning about the needs of persons with HIV, Minnesota can better understand the experience, cultures and barriers facing gay men, the African American, Native American and Hispanic communities, and drug users.

Paramount to creating this acceptance is interaction with individuals facing HIV disease. Employers, schools, religious organizations and mainstream social service agencies should create opportunities to learn from individuals and families living with HIV. Discrimination against persons with HIV disease in all areas of society must come to an end.

For individuals with HIV, greater acceptance by Minnesotans and their institutions will increase their personal ability to speak about their needs, ask for services and care, and begin or maintain behaviors which protect the public health. Acceptance by society is vital to creating a safe environment for persons with HIV disease; it is a cornerstone to empowering people with HIV in all areas of their lives.

The Commissioner's Task Force on AIDS recommends that all areas of society, including individuals with HIV disease, work to increase acceptance of persons with HIV and to eliminate discrimination against those individuals and communities affected by this epidemic.

2. *Minnesota should address the stresses the HIV epidemic places on the state's health and social services system.*

Although Minnesota has done a good job of responding to the AIDS crisis to date, the HIV epidemic serves as an early warning sign of impending problems in Minnesota's health and social service delivery system. The experiences of persons with HIV disease are a sentinel example of the fragility of health care for all Minnesotans, especially those with chronic diseases. Lack of insurance, the high cost of health care, the reliance on a handful of specialized physicians, and the enormous social costs of living with HIV disease contribute to this fragile state.

Changes in funding for HIV services which may increase reliance on state rather than federal funds also places stress on a system already scrambling to maintain quality levels of care. A reduction in funds during periods of increasing need may well decrease Minnesota's ability to meet the health and social service needs of persons with HIV disease.

Enhancing and maintaining the current level of care in the face of increasing need and tightening budgets will involve the cooperation and energies of many of the state's public and private agencies. A parallel concern is maintaining the energy and commitment of those workers who have brought the state through its first decade in the epidemic. Supporting their commitment and finding new workers is vital to maintaining our state's response.

As the second decade of living with HIV begins, the Commissioner's Task Force on AIDS recommends that government, non-profit organizations, third party payers, the legislature, private businesses, foundations, and the health care industry work together to strengthen the system of health and social services available to persons with HIV.

3. Dental and other health care should be made more available to persons with HIV disease.

Nine years into this epidemic, over 20% of HIV-infected Minnesotans surveyed as a part of the HIV Services Planning Project could not find a dentist willing to treat them. This lack of access to a basic health care service raises questions about training, understanding and application of infection control procedures, and reimbursement for health care providers.

Although dentists could be singled out for their continued inability to respond to the needs of persons with HIV, other health and social services also continue to deny persons with HIV infection the quality of care they need and deserve.

The Commissioner's Task Force on AIDS recommends that education for health care professionals be strengthened to ensure that providers are able to deliver the care they are legally and ethically bound to provide. Providers, consumers and society should increase efforts to identify and prohibit discrimination by any service provider.

4. Safe and appropriate housing should be available to all HIV-infected individuals and families in need.

No Minnesotan should be without a safe and secure home. But for Minnesotans with HIV disease, housing is crucial. The interviews conducted with homeless individuals with HIV illustrate the worst case scenario of life with this disease, but all persons with HIV are at risk of losing their home because of reduced income and safety concerns. Homelessness creates barriers to accessing even the most basic of health and social services, and places people under increased stress, causes deterioration of their mental and physical health, and increases their risk for behaviors which endanger the public health.

Providing decent housing, on the other hand, enables individuals with HIV disease to access health services such as home-based care, which reduce reliance on emergency and institutional care. Other social and supportive services, such as home delivered meals, transportation, case management, mental health services and chemical dependency programs, are difficult if not impossible to access if one has no permanent address.

The Commissioner's Task Force on AIDS recommends that a range of housing options be made available to all persons living with HIV infection.

5. Mental health and chemical dependency services should be available to all HIV infected individuals and their caregivers on an ongoing basis.

HIV infection places persons under incredible duress. Enormous physical, mental, and financial changes challenge the chemical and mental health of many Minnesotans affected by HIV -- persons living with the disease and the people who provide their care and support.

Current systems of payment for mental health and chemical dependency services often allow only a limited number of visits. Chemical dependency services in particular often have a long waiting period for certain kinds of treatment, and may be unavailable for certain populations.

Although mental health and sobriety are important components of physical health and quality of life for all Minnesotans, support of this type is more vital for persons with HIV because of the risk of transmission. Without access to needed chemical dependency treatment, chemically dependent persons with HIV are more likely to continue drug use behaviors which transmit the virus. Mental health services are also important to supporting behavior change.

The Commissioner's Task Force on AIDS recommends that early and ongoing access to chemical dependency and mental health services be made available to all persons affected by HIV.

6. Support for persons with HIV disease should be based on their level of physical and financial need rather than a diagnosis of AIDS.

Current definitions for financial and medical assistance are often based on a narrow definition of AIDS. This distinction means that very sick persons living with HIV disease can be prohibited from accessing needed health and social services.

Health care providers who serve persons with HIV sustain a broad range of physical, emotional, educational, referral and advocacy services. To maintain this level of support, providers should receive adequate compensation for this work.

Persons with HIV disease face financial devastation early in their working lives. They often suffer the loss of their job and income at the same time that they face enormous medical care costs and an increase in their cost of living while trying to manage the symptoms of their disease. For these citizens, the current level of financial support does not meet the basic needs of living with HIV. Services such as food programs, credit and legal assistance, transportation, housing and financial assistance programs need to be modified to better meet the needs of persons with HIV. Persons with HIV have the right to remain employed, and employers must improve their ability to accommodate these citizens in the work force.

The Commissioners Task Force on AIDS recommends that providers who serve persons with HIV assess the physical and financial need of the individual when determining eligibility for services and assistance, and modify their policies to ensure access to persons with HIV. The Task Force also recommends that third party payors compensate health and social service providers for the full range of services they provide.

Implementation of the Plan: *Changing Systems, Changing Attitudes*

The Commissioner's Task Force on AIDS recommends that the Minnesota Department of Health use the plan outlined in this document to stimulate change in the health care and social services system to help improve care and services for persons with HIV infection and their caregivers. As a first step, the Department of Health should coordinate efforts to bring together parties affected by these recommendations to work toward implementation of specific actions. Because many of the areas discussed in this plan are complex and may result in legislative or policy changes, MDH should initiate the creation of more detailed proposals for action which achieve the results desired by the Task Force.

Although the task of monitoring progress on these recommendations falls to the Department of Health, responsibility for implementing the proposed changes belong to many agencies and individuals, as well as to Minnesota as a whole.

The HIV Issues Team - State Agencies whose members are representatives from the state Departments of Finance, Human Services, Corrections, Planning, Housing Finance, Human Rights and Commerce, share responsibility to assure that persons with HIV receive adequate care and services. Many recommendations involve the assistance of the larger AIDS community -- persons with HIV infection, and the agencies and individuals who seek to support them. These organizations and individuals should continue to work together to assure the most effective use of resources, and to continue to speak out for the needs of all Minnesotans facing HIV disease.

Professional associations and general health care providers should be approached to improve their ability to serve persons with AIDS, and to increase their understanding of the unique needs of communities devastated by this epidemic. Foundations and third party payors who help fund prevention, services and health care are called upon to help improve access to care for persons with HIV infection. Finally, Minnesota's churches and synagogues, civic organizations, community-based organizations, schools and elected officials must strive to acknowledge the presence, contributions, and needs of Minnesotans with HIV.

Creating a caring environment for Minnesotans with HIV disease continues to call upon our collective energies. The readers of this report are invited to participate in this work, no matter their profession or community.

Background

BACKGROUND

This section contains a discussion of:

A. Current and projected cases of HIV infection and AIDS and trends in the epidemic
B. An Introduction to the HIV Services Planning Project
C. Results of the community-based HIV services needs assessment

I. Overview of the Current and Projected HIV/AIDS Epidemic in Minnesota

> In May 1982, the first case of AIDS was diagnosed in Minnesota. By January, 1991 over 800 cases of AIDS and almost 1,600 persons who are HIV-infected had been reported to the MDH. At least three hundred and forty-two (342) persons with AIDS and 1,590 persons with HIV are currently living in Minnesota. These numbers do not include the individuals who have moved to Minnesota since diagnosis, or non-documented persons living in Minnesota.

Summary of the Current HIV Epidemic in Minnesota:

In Minnesota most AIDS cases have occurred among men who have sex with men (81%). The majority of these individuals are less than 50 years of age (91%), and there is a disproportionate case-rate among African Americans and persons of Hispanic origin as compared to whites (167 and 81 versus 18 cases per 100,000 respectively). Few of Minnesota's AIDS cases have occurred in women (4%) or children (1%).

Although HIV infection and AIDS continue to be found overwhelmingly in the gay male community, examining cases of HIV infection compared to AIDS reveals changes in the course of this epidemic. Cases of HIV infection are more likely to be female (9% of HIV infection versus 4% of AIDS cases), younger (45% of HIV infection occurred in persons under 30, versus 22% of AIDS cases), intravenous drug users (15 % of HIV infection versus 3% of AIDS cases), and from communities of color (25% of HIV infection versus 15% of AIDS cases).

HIV as well as AIDS are reportable diseases in Minnesota. Persons who seek HIV testing and counseling at sites contracted by the Department of Health are requested to provide their name and identifying information. No person is denied services because of refusal to supply this information. Information about diagnosed cases of AIDS as well as HIV infection are also reported to the state by private physicians offices, hospital and clinics.

The MDH Acute Disease Epidemiology Section, AIDS Epidemiology Unit, described several consistencies and trends regarding AIDS cases, non-AIDS cases of HIV infection, and HIV seroprevalence in Minnesota in its report "Acquired Immunodeficiency Syndrome and Human Immunodeficiency Virus Infection in Minnesota: Update and Projections of AIDS Cases Through 1992".

First, Minnesota has relatively low rates of HIV infection for all of the population subgroups which have been tested. Furthermore, the incidence rate for AIDS cases in Minnesota in 1990 is relatively low when compared to national data.

Second, homosexual and bisexual men in Minnesota are consistently at highest risk across all studies. Most AIDS cases in Minnesota have occurred in homosexual/bisexual men and that trend will continue for some time with only a gradual decrease over time and a concurrent increase in the proportion of AIDS cases among IVDUs.

Third, a relatively low HIV seroprevalence appears to exist among Minnesota IVDUs; however, several conflicting pieces of evidence make it difficult to estimate actual seroprevalence. If available data from seroprevalence studies are representative for all users and if there are not major behavioral changes toward more risky behavior in the immediate future, it is likely that HIV prevalence and incidence will remain relatively low among IVDUs in Minnesota.

Fourth, all of the data indicate that relatively few women in Minnesota are infected. The low number of female IVDUs coupled with the low HIV seroprevalence in IVDUs results in this phenomenon. Additionally, since there are relatively few male IVDUs, there has been relatively little heterosexual transmission of HIV to female partners.

Fifth, because of the low number of HIV-infected women of childbearing age, there is reduced perinatal transmission occurring in Minnesota. Based on data collected from the seroprevalence studies, we estimate that four or five HIV-infected babies are born each year in Minnesota.

Sixth, while Minnesota's black and Hispanic populations are relatively small, the HIV epidemic has disproportionately affected them. Black and Hispanic cases of AIDS and HIV infection are increased in relation to their distribution in the population; Minnesota's black and Hispanic communities are, and will continue to be, adversely affected.

Summary of Projections for the HIV/AIDS Epidemic in Minnesota:

Projections of AIDS cases can serve to predict the future course of the epidemic by helping plan for the health and social services which will be needed by the persons who develop HIV disease.

The MDH AIDS Epidemiology Unit used three methods to determine a range of projections for a cumulative number of AIDS cases through 1992 from a low of 1,238 to a high of 1,611 cases.

These projections are based on historical Minnesota AIDS incidence data or assumptions regarding HIV incidence in Minnesota. The projected numbers do not include persons who migrate to Minnesota after being diagnosed with AIDS elsewhere. Additionally, two trends are not accounted for by these projections. First, behavioral changes in persons at risk for HIV infection are not accounted for, and these changes may not be reflected in the historical AIDS incidence data to date. Second, the long-term effects of preventive therapy are largely unknown; they may significantly affect future AIDS incidence. Therefore, the actual number of AIDS cases reported through 1992 could potentially be lower than the numbers projected. For a full discussion of the proportionate, regression and infection progression methods used to develop these projections, please refer to "Acquired Immunodeficiency Syndrome and Human Immunodeficiency Virus Infection in Minnesota: Update and Projections of AIDS Cases Through 1992".

The MDH AIDS Epidemiology Unit has also estimated the number of persons in each transmission category who may be infected with HIV.

They estimate that between 4,409 and 17,742 Minnesotans may be infected with HIV. These estimates are contained in Table 1.

TABLE 1

Estimated Number of HIV-Infected Persons in Minnesota By Transmission Category

Estimated Transmission Category	Estimated Size	Total Infected
Homosexual/Bisexual	45,227-125,260	3,618-15,031
Intravenous Drug Users	3,000-4,500	300-2,200
Hemophilia	275	110 -130
Heterosexuals Without Identified Risk (15-59 years)		
Males	1,020,967	
Females	1,149,112	171
SUBTOTAL		4,199-17,532
Other (Heterosexual Partners of Persons at High Risk, Transfusion, Perinatal, Occupational)	—	210
TOTAL	**2,218,581- 2,300,114**	**4,409- 17,742**

II. An Introduction to the HIV Services Planning Project

In October 1989, Minnesota was one of 22 states and cities to be awarded funding from the federal Health Resources and Services Administration (HRSA) to conduct a year-long project to plan for the needs of its citizens affected by HIV through the year 1993.

During the past year, the HIV Services Planning Project has grown from the cooperative vision of a handful of individuals active in AIDS services and education to a community-wide effort involving over 100 representatives of the diverse communities working in -- and affected by -- HIV. These peer-nominated community members have joined with the MDH AIDS/STD Prevention Services Section to develop recommendations to improve care and services for Minnesotans with HIV disease.

Goals of the HIV Services Planning Project: *Understanding the Present to Plan for the Future*

Minnesota has a strong tradition of planning for and meeting human needs, and HIV/AIDS is no exception. And while it is true that compared to other states and regions in the country, Minnesotans can turn to supportive organizations, access quality health care, and receive assistance from a variety of state and local agencies, important questions remain:

- Are programs and services truly accessible to all those in need?
- Are these services provided in a planned continuum of care, or in a fragmented manner?
- What barriers exist for individuals and families seeking assistance -- or for the agencies seeking to provide services?
- What services need to be developed, improved, or altered to meet the changing face of the HIV epidemic in Minnesota?
- How can agencies cooperate to provide needed care without costly duplication of services?
- How can Minnesota best prepare for changes in local, state, and federal funding?

The HIV Services Planning Project sought to answer these questions by:

- Conducting an inventory of current services that describe gaps in care and service delivery;

- Describing the experience of Minnesotans living with HIV through a series of user-based studies conducted in cooperation with a spectrum of care providers; and

- Developing recommendations to improve access to services and the continuum of care for persons with HIV infection.

The Project has been a forum to raise these and other issues in a supportive working environment, affording the AIDS community its first opportunity to come together and honestly assess current programs and services while planning to meet future needs.

The HIV Services Planning Project is a vital step in developing a quality, cost effective, and accessible continuum of care for all HIV-infected individuals -- regardless of their age, race, sexual identity, economic circumstance, or location within the state.

The Planning Structure of the HIV Services Planning Project: *Building Community Collaboration*

People living with HIV infection, and those individuals and agencies dedicated to meeting their needs, have the greatest understanding of HIV services and needs in Minnesota.

The Project provided for input from these groups in several ways: a comprehensive study of persons with HIV infection and their informal caregivers called the User-Based Study, focus groups and targeted surveys with more hard-to-reach populations, and the Project's Task Force and Subcommittees.

The Commissioner's Task Force:

A 16-member task force was appointed by the Commissioner of Health and charged with compiling recommendations made by subcommittees working on HIV issues specific to four populations: mothers and infants, adolescents, adults, and persons in Greater Minnesota.

The Task Force was chaired by Rob Fulton, Director of the Ramsey County Public Health Department. Members included representatives of Minnesota's communities of color; public health nursing; community-based AIDS service organizations; third party payors, mental health and chemical dependency; AIDS/HIV research; clinics and hospitals; community health services in the metro and Greater Minnesota areas; the Minnesota Department of Human Services; foundations; the religious community; and persons living with HIV disease. A full membership listing is in the Appendix .

Subcommittees:

Over 100 individuals participated in the four subcommittees: Maternal and Child, Adolescent, Adult and Greater Minnesota Issues. Membership included AIDS volunteers, physicians and nurses, chemical dependency and mental health professionals, educators, foster parents to HIV-infected children, persons working in and living with AIDS from Greater Minnesota, AIDS activists and outreach workers, members of the religious community, social workers, AIDS case managers, and persons living with HIV disease.

A Technical Advisory Workgroup of representatives from sites where persons with HIV infection were recruited for interviews, provided assistance in developing and analyzing the results of the User-Based Study. A full membership listing is contained in the Appendix .

Charge to the Commissioner's Task Force

The Commissioner's Task Force on AIDS will be composed of consumers, providers, and funders to oversee activities of the HIV Services Planning Project and recommend service development priorities. The Task Force should answer the following questions:

- What is the projected scope of the HIV/AIDS epidemic in Minnesota?
- What are the current service levels, funding sources and resources for infected persons and their significant others?
- How have services been coordinated or designed to facilitate a comprehensive program of services?
- What are the problems in accessing services, paying for services, maintaining services, individualizing services, evaluating services?
- What are ways to improve the delivery of existing services?
- Which services are currently unavailable? How should they be designed and delivered?
- What financial resources are needed to implement the recommendations for improving service delivery?

III. A Community-Based Assessment of HIV Services

As a first step to planning for the future, Task Force and Subcommittee members faced an enormous task: assessing the current service system for Minnesotans with HIV disease.

This assessment encompassed an examination of the health and medical care delivery system, public and private social, legal, and supportive services, employment options for persons with HIV, mental health and chemical dependency services - and how these health and social services are paid for. A more detailed accounting of this assessment is contained in "Report: Services Inventory Assessment Planning Forum, June 28, 1990"

Step One:
An Inventory of HIV Services:

To facilitate the assessment process, an inventory of currently available services was compiled. AIDS resource directories developed by community-based organizations, government agencies, and community health services formed the basis of the inventory.

Methodology of The Assessment Process:
Identifying Community Needs

Members of the AIDS community were asked to serve on a HIV Services Planning Subcommittee because of their specific expertise and experience. This experience formed the basis of each individual's assessment. Subcommittee members shared their individual findings and assessed 55 services used by persons with HIV disease and their families.

The subcommittees reached consensus on a composite score for each service using a common rating system. First, members determined if the service was a high, moderate or low ***need*** of the population studied by their subcommittee. Next, members assessed the ***adequacy*** of the service by evaluating three areas: ***access, quality and quantity***. The subcommittees were thus able to not simply count the number of any one type of service provider, but to judge the ability of persons with HIV infection to receive quality care in a service area.

In this manner, each subcommittee developed a list of priority services areas - those determined to be highly needed by their population, and which were also deemed inadequate in each of the three areas assessed. A listing of each subcommittee's assessment is in the Appendix.

Subcommittee Priority Service Areas

- *Health and Medical Services:*
  Primary care, including physicians, clinics, and outpatient treatment;
  Pharmaceutical services;
  Home health, personal care, and housekeeping services;
  HIV counseling and testing; and
  Education about HIV for health professionals, families and persons with HIV.
- *Chemical Dependency, Mental Health, Emotional Support Services:*
  Chemical dependency programs; and
  Mental health services and support groups.
- *Housing, Supportive Services, Case Management:*
  Housing programs;
  Transportation services;
  Legal services; and
  Case management services.
- *Financial Assistance, Payment for Services, Employment:*
  Government entitlement programs;
  Insurance and HMO coverage;
  Medical Assistance and General Assistance Medical Care; and
  Employment issues.

Results of the Assessment:
Setting Priorities for Change:

The next step was to reach community consensus about the overriding gaps in services or problem areas affecting *all* populations. This consensus building was accomplished at a joint planning forum involving all subcommittees and Task Force members held in June 1990. Priority service areas are listed in the box on page 14 and in the Appendix.

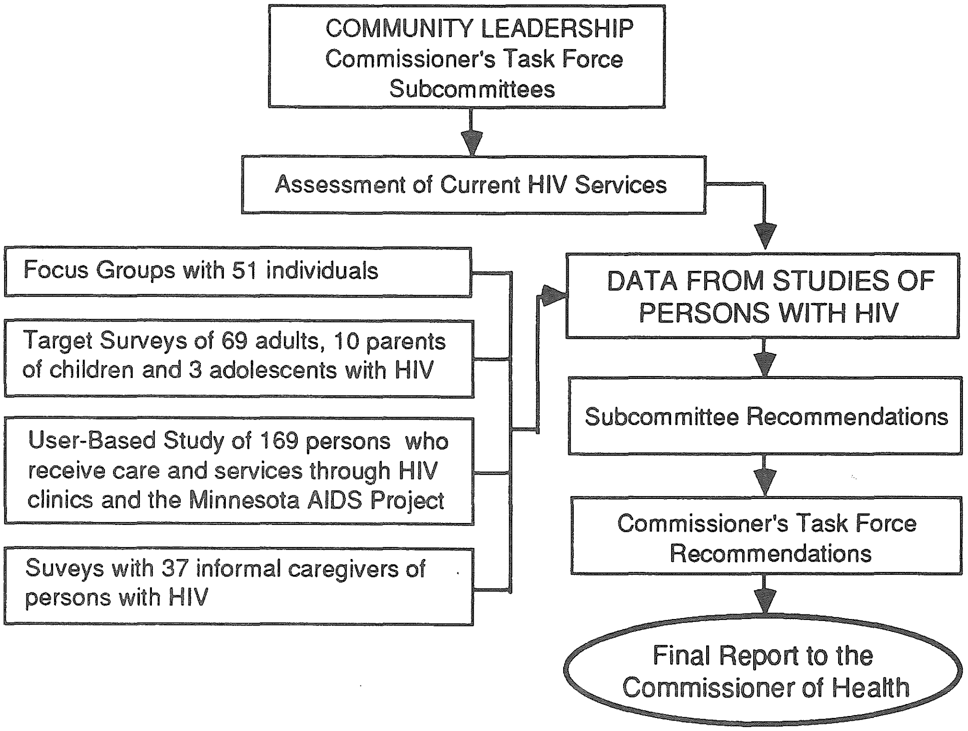
The Next Step:
Hearing the Voices of Persons Living with HIV

The completion of the community-based services assessment process was only the first step in Minnesota's HIV services assessment. The assessment completed by the subcommittees and the Planning Forum was conducted primarily through the eyes of professionals and the experience of a small number of persons facing HIV disease. Before completing recommendations to improve services, HIV Services Planning Project members would learn about the other -- and perhaps more personal -- part of the services assessment process: results from the User-Based Study of Minnesotans living with HIV disease.

The HIV Services Planning Project's methodology allowed for information from professionals to be compared to the experiences of those living with HIV infection. The information from these surveys and focus groups gave a more personal picture of the problems faced by persons with HIV disease.

This methodology -- though time consuming -- gave the subcommittees and Task Force a uniquely comprehensive look at what Minnesota is doing well and could do better to meet the needs of persons with HIV disease.

Methodology for Determining
The Needs of HIV-Infected Minnesotans and
Developing Recommendations to Meet Those Needs



The Study of Minnesotans with HIV Disease and Their Informal Caregivers

THE STUDY OF MINNESOTANS WITH HIV DISEASE AND THEIR INFORMAL CAREGIVERS

This section presents:

A. The methodology used in the HIV Services Planning Project data collection; and
B. Results of the focus groups, target survey efforts, User-Based Study and Caregiver Study.

I. Study Methodology, Design and Protocol: *Assuring the Quality of Data*

> The HIV Services Planning Project had at its core a commitment to bring the voice of persons living with HIV and AIDS into the planning process. The Task Force and Technical Advisory Workgroup developed three avenues to assure that the experience of those in the community living with HIV was a cornerstone to the community-based planning effort.
>
> First, a series of focus groups was conducted to allow for specific populations to share their experiences. Second, hard-to-reach populations were targeted for a special survey effort. Third, a survey of systematically-selected persons with HIV and AIDS involving 169 clients of the primary health and service providers in the seven-county metropolitan area, and an additional 37 of their caregivers was conducted.

Background:

As described previously, information about the current level and gaps in services was initially outlined in an assessment conducted by members of the HIV Services Planning Project. To supplement that assessment, a study of HIV-infected Minnesotans was designed with the assistance of a Technical Advisory Workgroup.

The Commissioner's Task Force and Technical Advisory Workgroup early on recognized two difficulties in designing the study. First, the support of communities affected by HIV needed to be gained, and their ideas and concerns about the survey instrument addressed, before the study began in earnest. Second, those HIV-infected individuals most likely to be without services were those most likely to fall out of any random sample. To compensate for these potential biases a three-pronged study was designed,

Goals of the Study of Persons with HIV and Their Caregivers

- Determine the health and social service needs of persons with HIV;
- Document the experience accessing and using a variety of health and social services;
- Examine the strategies persons with HIV use to cope with their illness;
- Learn about the role informal caregivers play in the lives of those affected; and
- Gather suggestions from persons with HIV for improving their care.

consisting of a large random sample to obtain information as unbiased as possible, focus groups and a targeted survey effort aimed at persons not likely to be represented in the larger study.

Focus Group Methodology:

Members of the Commissioners Task Force on AIDS and subcommittees were asked to identify those populations most likely to be missed in the random sample and who would be willing to share their experiences, concerns and needs in a focus group discussion. The following eight populations were proposed: African Americans, American Indians, adolescents, persons in recovery, women, caregivers of persons who have died, and partners of persons who have died. A focus group of gay men was also held to receive feedback about the pilot survey instrument.

The focus groups were set up to gain an understanding of the experience of specific populations affected by HIV; to allow for discussion around specific service related topics including suggestions for improvement; to reach targeted populations under-represented in the survey; and to pilot a short version of the survey instrument.

While attempts were made to bring together individuals in all targeted populations, focus groups were conducted for the African American, gay men, persons in recovery and caregivers communities only. American Indians, and women were later reached through the targeted survey effort. The majority of participants were not individuals with HIV, but their caregivers.

In all focus groups, cosponsorships by agencies and organizations with a strong history of trust with the target population proved to be beneficial in creating a responsive climate. Ann DeGroot, Executive Director of the Gay and Lesbian Community Action Council, facilitated all but the African American focus group, which was arranged with and facilitated by individuals working with HIV-infected people in that community.

Focus Group Topics

- What has been the one most helpful thing in your life since you've tested positive?
- What has been the most difficult part of your life since you've tested positive?
- What has been the most helpful service or assistance you have received from a formal provider, friends or family, your community, and/or your religious or spiritual community?
- What kind of problems have you had in getting formal health or social services from an agency or service provider?
- Have you ever felt you were discriminated against or mistreated in any way since you were told of your HIV infection or illness? Why do you feel you were discriminated against? What did you do?
- What are your suggestions for improving care for people living with HIV and AIDS?

Focus groups were held during May and June, 1990. Anonymity was assured for each focus group participant and each received $20.00 to cover expenses for their participation. Participants self reported having HIV infection. A short pilot of the User-Based Survey instrument was administered at the end of each focus group.

Fifty-one (51) individuals attended the focus groups. Focus groups provided an opportunity to speak directly with those who have tested positive and their caregivers. In addition, they provided a place for those individuals to interact with each other regarding quality of service issues and barriers to obtaining service. Modifications were made to the survey instrument based on information received from the focus groups.

The focus group component of the study held a number of potential biases. First, the focus group participants were self-selected, and were individuals who were willing to come forward and describe their experience in a group setting. Second, because focus groups were recruited through community-based organizations, participants, especially those from the African American community, may over represent members of those populations connected to HIV services.

Target Survey Methodology:

Target surveys were used to reach an additional 82 persons whose experience might not be fully represented by the larger study. As with the focus groups, this effort was conducted with the assistance of volunteers from community-based organizations with a strong history within the targeted community. Volunteers from these agencies conducted the interviews, and modified the instrument to meet their needs, sometimes translating the questionnaire into Spanish. The agencies and individuals who made this effort possible are listed in the Appendix.

Of the populations targeted for this phase of the study, only nonhemophiliac HIV-infected adolescents were not successfully surveyed. *Because those adolescents were also not reached in the focus groups or through the larger study, the lack of data from HIV-infected adolescents is a noted limitation of this study.*

As with the focus groups, participants were paid $20.00, the information was anonymous, HIV infection was self reported, and a consent form was obtained. The volunteers who spoke with the participants were not compensated for their time. The targeted survey also provided a second pilot of the User-Based Study instrument.

Planning Project members were asked to identify populations who would be most likely to share their experiences through an anonymous survey conducted by known volunteers or staff persons. Targeted for this outreach were HIV-infected members of the American Indian and Hispanic communities, HIV-infected homeless persons, women, adolescents, persons living in Greater Minnesota, parents of children with HIV infection, and HIV positive adolescents with hemophilia.

Eighty-two (82) individuals were surveyed through this targeted method between May and September 1990. Of those surveyed, 69 were HIV-infected adults, ten were parents of children with HIV and three were HIV-infected adolescents with hemophilia. Of the adults, nine were African American, 14 were Hispanic, nine were American Indian, 17 were women, and ten were from Greater Minnesota.

The protocol designed for this study attempted to reduce potential bias by requiring participating agencies to either survey all HIV-infected individuals identified or to select participants at random. Although this procedure reduced potential biases, several limitations of these data should be acknowledged. First, as with the focus groups, because participants were known to a staff person or volunteer from a community-based organization they were more likely to be connected to a level of HIV-related services. Second, the members of the American Indian community surveyed were primarily women (6 of 9 individuals). Third, the homeless persons studied were primarily from the Hispanic community (56%) and also represented a large percentage of nondocumented Hispanics. Finally, only one Asian was reached in any of the studies. At the time, twelve cases of HIV infection or AIDS were reported in that community.

User-Based Study Methodology:

This study was a systematic random sampling of clients from the metropolitan areas largest HIV clinics and the states largest AIDS Service Organization. Participating sites were: the Minnesota AIDS Project, Metropolitan Mt. Sinai Medical Center, the University of Minnesota AIDS/HIV Clinic, the Veterans Administration Medical Center AIDS/HIV Clinic, Hennepin County Medical Center AIDS/HIV Clinic, and the AIDS/HIV Clinic at St. Paul-Ramsey Medical Center.

The protocol for this study required that sites generate a list of all current HIV-infected patients seen in the last year. Clinics then divided those individuals into three groups based on degree of illness (non-symptomatic HIV, symptomatic HIV and AIDS diagnosis). The Minnesota AIDS Project divided its list of individuals into AIDS and non-AIDS. Potential participants were given a code number, and were then randomly selected, removing the potential for selecting only those clients known or liked by the clinic staff. Those individuals were then contacted by site staff and asked to participate. As with the other surveys, participants were paid $20, the information was anonymous, and a consent form was signed by all participants. Individuals who refused or were unable to participate were asked to complete a brief refusal sheet to determine any bias in the sample.

Summary of Participation in the Study of HIV-Infected Minnesotans and Their Caregivers

Focus Groups: 51 participants
9 HIV infected persons; 21 caregivers;
21 participants did not disclose their HIV status

Target Surveys: 82 participants
69 adults:
9 African Americans; 14 Hispanics;
9 American Indians; 17 women; and
10 persons from Greater Minnesota.
10 Parents of children with HIV; and
3 HIV-infected adolescents with hemophilia.

User-Based Study: 169 participants
48 from the Minnesota AIDS Project;
25 from Metropolitan Mt. Sinai Medical Center;
25 from the University of Minnesota;
25 from the V.A. Medical Center;
25 from Hennepin County Medical Center; and
21 from St. Paul-Ramsey Medical Center.

Caregiver Study: 37 participants
19 spouse or partner; 9 friends;
5 parents; 2 siblings; and
2 volunteer buddies.

Total Participation: 339 participants

Surveys were conducted by staff of the University of Minnesota Center for Survey Research. The survey staff were trained on AIDS issues by Dr. Kris MacDonald, Assistant State Epidemiologist, Derric Fields, an individual living with AIDS, Lydia Pizel, the mother of a person who died of AIDS, and Sister Joanne Lucid of the Archdiocesan AIDS Ministry. Survey staff were trained on the instrument by staff from MDH. Interviews took place between August 14 and November 2, 1990.

The survey instrument was piloted through both the targeted study and the focus groups. The Task Force and selected members of the Planning Project and members of the Technical Advisory Workgroup also reviewed and assisted in the instrument design. The survey primarily asked about experiences in the past three months. This time frame was chosen to document *current* problems in services, and to limit the time frame participants needed to remember.

One-hundred-sixty-nine (169) HIV-infected individuals took part in the User-Based study: 48 from the Minnesota AIDS Project, 25 from Metropolitan Mount Sinai Medical Center, 25 from the University of Minnesota Hospital and Clinic, 25 from the Veterans Administration Medical Center, 25 from Hennepin County Medical Center, and 21 from St. Paul-Ramsey Medical Center.

Several limitations exist in these data as well. First, the population surveyed was only from the metropolitan area and does not represent the experience of 13 percent of HIV-infected persons living in Greater Minnesota. Second, the persons interviewed at these clinics and the AIDS service organization are predominately gay white men. However, 81 percent of all AIDS cases and 63 percent of reported HIV are found in that community. Third, no individuals residing in institutional settings such as correctional or treatment facilities or nursing homes were interviewed. Fourth, and perhaps most importantly, because the sample was drawn from HIV clinics and an AIDS service organization, these data represent the experience of persons likely to be receiving at least some degree of health and social services related to their HIV infection.

Caregivers Study Methodology:

Once User-Based Study participants agreed to participate in a personal interview, they were asked to identify an informal caregiver or significant other. If they identified someone, the participants were asked for permission to contact the caregiver and ask them to participate in the caregivers' study. As with the other surveys, participants were paid $20.00, the information was anonymous, and a consent form was signed. A code number was assigned to the instruments so that the survey could be linked to the person with HIV.

Limitations of the data from the caregivers study are a result of the relatively low number of persons who were interviewed and that caregivers were likely to be identified by a person with HIV disease who had more physical care needs and periods of illness. Caregivers are more likely to be partners or spouses of the individual and may under-represent other family, friends and volunteers who also provide assistance.

II. Living with HIV Disease in Minnesota: *Results of the Studies*

Learning from Minnesotans with HIV Disease: *Results of the Focus Groups*

> Focus groups were designed to gain an understanding of the experience of specific populations affected by HIV; to allow for discussion around specific service related topics including suggestions for improvement; and to reach targeted populations under-represented in the survey. Focus groups involved 51 members of the African American, gay male, persons in recovery, and informal caregiver communities. Although the communities involved were very different, common experiences and concerns emerged. For a more detailed description, "Report of the HIV Services Planning Project Focus Groups", written by facilitator Ann DeGroot is available.

The Importance of Supportive Services and Community:

Open and comfortable support groups which help individuals in dealing with coming out as gay and /or HIV positive and in finding out how to access the system were reported by participants as the most helpful services. Community based organizations were reported often as valuable resources. A perspective of HIV infection as a "chronic illness, not a terminal illness", and "the faith that something good can come out of this", were cited as central to living with HIV infection.

Families and friends who provided care reported that the AIDSLine (an information and referral line), buddy training, teamwork, concrete and written information, open attitudes of medical personnel, and a flexible work situation played a critical role in their ability to provide adequate care and to feel support and confidence in their efforts.

The Hardships of Living with HIV Disease:

The emotional aspects of coping with HIV infection were reported most often across the board as the most difficult parts of life since testing positive. Getting sick or being hospitalized for the first time, the death of the first close friend, and grieving were mentioned often. Finally, counteracting the message that HIV is a death sentence, telling family and friends, and accepting that you are going to die sooner than you thought, and feeling like there is little you can do about it were described as difficult for persons with HIV. A major obstacle for caregivers was the lack of regular, trained volunteer assistance.

Difficulties Accessing Resources:

Lack of information by health professionals, loss of privacy, loss of decision making authority, and difficulty in accessing resources were all problems reported in focus groups.

The loss of privacy and dignity was felt by all focus groups, and experienced in a variety of settings.

Participants reported a number of incidents where physicians and medical staff lacked sensitivity. One caregiver asked "Is AIDS being taught in medical schools?". Maintaining financial resources to pay for the costs of being sick was a major factor in accessing resources recounted by members of focus groups across the board. Only one individual said that he had adequate health insurance and disability insurance to cover costs of the disease.

"People who become ill, who do not have resources, can get ill by trying to get them". The paperwork required to receive government assistance was overwhelming to many; "it's like having a part time job." They asked the question, "Why wait until AIDS or ARC to get help?"

Facing Discrimination:

"It is hard to get people to think of AIDS as a disease. Homophobia and AIDSphobia are two issues which are difficult to deal with."

HIV status complicates the impact of discrimination due to race, class, sexual orientation and/or age. Respondents summed it up this way, "insured, white, middle class professionals who speak English do better" in the system, and "If you have money and you look right, you get services." Many individuals reported they are unable to get health insurance. A black gay man said "it is not easy to be picked out as a gay, PWA, Jew - they are all so assimilated. But as an African American, I can't hide."

A mother who was also a caregiver for her son with AIDS realized that in dealing with his illness, she had to come out also. Caregivers reported they feel the impact of sexual orientation discrimination. They are often treated the same as people living with AIDS and people fear they are contagious, illegal, and immoral.

Suggestions for Improving Care for People Living with HIV and AIDS in Minnesota:

Caregiving organizations should *" stop fighting with each other. It takes a lot of energy and is too destructive."*

"Stop duplication of services and the battles for turf and money."

Persons with HIV infection had a wide ranging list of suggestions for improving care for themselves and future Minnesotans facing HIV. Comprehensive, accessible medical care was suggested most often and most strongly. Individuals also expressed the need for an up-to-date accessible clearinghouse which would include information on available services and how to access services. Others suggested that training should occur on all levels and in all places where people living with AIDS have interaction, and stressed the need for a reduction in red tape and bureaucracy.

Finally, individuals suggested that we take time to celebrate the victories and work together to fight the fear of AIDS.

Understanding the Needs of Hard-to-Reach Populations: *Results of the Target Surveys*

Although the target populations were diverse in race, sexual orientation, and cultural experience, many common elements were revealed by the interviews. In spite of their degree of education (over half said they had more than a high school education and 22 percent were college graduates), respondents had limited financial resources. More than two-thirds reported incomes of less than $10,000 annually.

Respondents had limited access to private health care coverage. Of the 69 adults interviewed, 44 (63 percent) said they had no insurance at the time of their diagnosis of HIV infection or AIDS. Ten (10) additional individuals said they had lost their insurance since learning of their infection.

The individuals also shared common concerns. First, 68 percent of respondents reported they were concerned about their health. Nearly as often - 65 percent of respondents - said that in the last three months they had been very worried about their financial status.

Results from target population surveys are summarized below. A more detailed examination of the survey results is available in the third edition of the Planning Project newsletter (Sept., 1990).

Hispanics:

Fourteen (14) persons of Hispanic origin with HIV disease were interviewed. Ninety-three (93) percent of respondents said they were heterosexual men. One quarter stated that they were either homeless or living in a halfway house. At the time of the study, 21 cases of AIDS had been reported in the Hispanic community, and an additional 51 persons had been identified as HIV-infected.

Lack of Health Care and Social Services:

Half of the Hispanics interviewed said they had yet to seek social or supportive services. Ninety-three percent (93%) said they did not have health insurance at the time they learned of their infection. Fifty-seven percent (57%) said they had not received any medical services for their HIV infection. The source of primary health care was split between reliance on an emergency room (43%) or a community-based clinic (43%). A total of eighty-six percent reported not taking any medications for their HIV infection.

21% of Hispanics interviewed were drinking or using drugs more often since learning of their HIV infection;

36% said chemical dependency services were the most difficult for them to find.

Struggling to Change Behavior:

Chemical dependency services were reported as the most difficult health care service to access (36%). One-third of individuals said they had made no changes in their chemical use, and 21 percent said they were drinking and using drugs more often. When asked about barriers to making healthy behavior change, drug and alcohol use was reported by over one-third of respondents as their biggest challenge.

For this group, making positive sexual changes had been even more difficult. Thirty-six percent (36%) said they had made no changes in their sexual behaviors. Here the use of drugs and alcohol presented an even greater challenge to change, with 57 percent of Hispanics citing their use as a barrier.

To cope with HIV-related stresses, 50 percent reported use of drugs or alcohol. No Hispanic person interviewed reported attending a support group.

African Americans:

> Nine (9) African Americans with HIV disease were interviewed by volunteers. At the time of the study 71 cases of AIDS had been reported and an additional 254 African Americans had been reported to MDH as having HIV infection.

Access to Health Care:

For this group of African Americans, medical care was received in a clinic setting. Seven respondents said they paid out of pocket for part of their hospital or physician services. Four said they participated in a government program that paid for their health care.

Poverty and Discrimination:

The most difficult social service for African Americans to locate was financial assistance. 6 persons said they had been discriminated against in this area, while 3 respondents said they had been discriminated against in employment.

The African Americans interviewed illustrate the pervasive poverty faced by persons with HIV.

Nearly all African Americans with HIV surveyed reported limited income. Eight respondents stated they were 'very worried' about their economic situation. More than half of respondents said they had no insurance at the time they learned of their infection.

The Importance of Spirituality:

Spirituality played the largest role in respondents' ability to cope with HIV infection and make positive changes in lifestyle. Six of the nine persons interviewed cited spirituality as their primary coping tool.

Positive Changes:

For this group of African Americans, the most prevalent changes in lifestyle since learning of their HIV infection came in the area of chemical and alcohol use. Six respondents had stopped using drugs, 5 said they had stopped drinking, and 4 said they had been in a chemical dependency treatment program.

Seven of the nine respondents stated that they began practicing safer sex after learning of their infection. Counseling, supportive family and friends and willpower were the main supports for these changes.

Homeless Persons:

> Nine (9) persons with HIV disease living in shelters or on the street were interviewed by volunteers. Five (5) respondents were Hispanic, three (3) were white, and one (1) person was an American Indian.

Unmet Needs:

The majority of homeless persons had never sought or received any form of HIV-related supportive services.

Although the majority of the homeless persons interviewed had known of their infection for several years, few had received any HIV-related services. Nearly half stated they have never received care for their HIV infection, and six said they receive their medical care through emergency rooms. Two persons said they had been released from a hospital to a shelter. Seven were currently not taking any form of medication. None of the respondents reported health insurance at the time of diagnosis.

The Role of Drugs and Alcohol:

The use of drugs and alcohol was the overwhelming issue for homeless persons struggling with HIV. Nearly half said they found chemical dependency programs the most difficult health or medical service to access and two said they were discriminated against when trying to get help.

Four of the respondents stated that they used drugs and alcohol *more* since learning of their infection, and 4 said they had made no changes in their chemical use or sexual behaviors. Seven stated that they used drugs and alcohol to cope with stress and worries. Reflecting the difficulty this group has had accessing treatment, respondents stated their primary barrier to making changes in their chemical and sexual behaviors is the use of drugs and alcohol. Professional counseling and chemical dependency treatment was cited as most helpful to those homeless individuals who had been able to make positive behavior changes.

Women:

> Seventeen (17) women with HIV disease were interviewed by HIV Services Planning Project volunteers. A total of 26 adult or adolescent cases of AIDS had been reported among women at the time of the study, and an additional 121 women were known to be HIV-infected.

Family and Friends:

One common thread identified from the surveys with women was the importance of family and friends. Whether discussing supportive influences in changing behaviors, coping strategies, help caring for themselves and their family, or finding services, these women said they relied on and received support from their social networks.

Women relied most heavily on their family members and friends for a variety of support and assistance.

Accessing Services:

The majority of women said they sought medical and support services within six months after learning of their infection. Women were also more likely to report they had insurance and are cared for by a private physician. Nearly half stated they are not taking any medications. The hardest service for women to find was reported to be support groups (29%). One quarter of women interviewed said they had been discriminated against in medical care.

Sex Roles and Safer Sex:

Women reported that talking about sex, and early training and taboos was a barrier for practicing safer sex (47%). Twelve percent (12%) of women said they faced resistance from their partners. Women were also more likely to state that education had helped them make changes in behavior. Again, supportive family and friends were cited as making the difference in this area for 76 percent of women in the survey.

Greater Minnesota:

> Ten persons from Greater Minnesota living with HIV infection and AIDS spoke with volunteers. Respondents in the survey were recruited from Duluth and northern Minnesota. At the time of the data collection, 88 cases of AIDS and approximately 255 cases of HIV infection had been reported among residents of Greater Minnesota.

Connected to the System:

Persons from Greater Minnesota were well connected to the health and social services system. Eight of the ten said they received their primary health care from a private physician. Like other groups, they stated that finding financial assistance (4 respondents) was difficult, and four stated that they had difficulty finding alternative medical services.

Although 80% said they practiced safer sex, difficulties talking about sex was cited as a barrier by persons in Greater Minnesota.

Living with AIDS:

Two of the ten persons from Greater Minnesota said they had ended the use of alcohol and drugs, and 8 of 10 reported practicing safer sex. Asked what helped them make and support these changes, respondents cited family, friends, willpower and spirituality. Most of those interviewed said they attended a support group, and 4 credited participation with their ability to make changes. However, 3 said that support groups were the most difficult service for them to locate.

When asked which barriers they faced in making these behavior changes, half of the persons from Greater Minnesota cited early training and taboos and a reluctance to talk about sex. Peer pressure was named by four individuals.

American Indians:

> Nine American Indians with HIV disease - three men and six women - were surveyed by volunteers. At the time of the study, 5 cases of AIDS were reported among American Indians, and an additional 35 cases of HIV infection had been reported in this population.

Health Care Issues:

Six of nine American Indians with HIV disease surveyed said that their heath care provider suggested that they be tested for HIV. Perhaps for this reason, seven persons said they were able to receive medical care within six months of learning of their infection. Seven of the nine persons interviewed said they were uninsured at the time they learned of their infection.

Low Use of Social Services -- High Use of Social Supports:

This population was most successful in making changes in their sexual behaviors. Nearly all those surveyed said they had made substantial changes, and none said they had made no changes. Five said they practiced safer sex, two said they had reduced the number of their partners, and three said they no longer had sex. Supportive partners, families, and friends were cited as important supports by six of the respondents.

An American Indian HIV educator described the experience of surveyed HIV-infected American Indians as a 'broken circle'.

What made these changes more difficult for American Indians? Four persons reported that talking about sex and early training or taboos had created barriers. Two of the respondents reported that the use of alcohol and drugs had caused problems.

Living With HIV in Minnesota: *Results of the User-Based Study*

The survey focused on the experiences and needs of persons with HIV as they accessed Minnesota's health and social services. The study documents, validates, and increases understanding of the experience of persons entering emergency rooms and hospitals, seeking primary physician care, and using home care, dental, and other medical services. Social service areas explored included housing, financial and emergency assistance, and volunteer-provided services such as transportation, practical, and emotional support.

This study also added significantly to the body of research conducted on the impact of informal social support on the lives of persons facing HIV disease. Besides assessing the formal health, social, and mental health services they received, participants were asked the importance of informal support they receive from family and friends — or how the lack of this support has affected their health. Perhaps most importantly, the survey participants shared their advice and suggestions for living well with HIV.

Highlights of the survey are presented below, and an expanded discussion of the results is part of the recommendations in this document. The data cited in the recommendations section includes both the results of the target and User-Based studies. Sometimes data from these two sources are reported in a combined fashion. A full report of the study results will be available in 1991.

Survey Respondents Were Primarily Gay White Males:

Of the 169 persons with HIV disease interviewed, over 93 percent were between the ages of 20 and 50, 86 percent were white, 86 percent said they were gay, lesbian, or bisexual, and 95 percent were men. Most were well educated with 67 percent saying they had more than a high school education while 66 percent said they made less than $12,000 per year. Thirteen percent reported living in Minnesota less than two years. All respondents were from the Twin Cities metro area.

Problems Accessing and Using Services:

Forty-eight respondents (28%) said they had visited the emergency room in the last three months and 40 (24%) had been hospitalized in the same time period. One-fifth of those who needed dental care in the last six months said they could not get this care. Fifty-three persons (31%) said they received mental health counseling in the past three months. Of the 36 persons who were medically indicated as appropriate for pentamidine (a medication to prevent HIV-related pneumonia), 29 (81%) said they weren't taking it because it was not prescribed for them. Forty percent (24 of 60) of the persons medically indicated for taking ziduvodine (AZT) also said they did not have a prescription for this medication.

Nearly half the respondents said they had recently needed financial or legal advice for will preparation, credit problems, power of attorney, or discrimination issues. Only half of those who needed this assistance reported they were able to get the help they required.

Fifty six (33%) of respondents said they had problems finding and getting the services they needed. Difficulties encountered with the health and social support services system reported by respondents included problems of not liking to ask for help, finding it complicated to get services, having to go from one agency to another, and bad past experiences with the system.

Behavior Change Successes and Failures:

Sixty-six percent (66%) of respondents reported using alcohol at the time they learned of their HIV status and 31 percent said they were using street or illegal drugs. More than two-thirds said they use alcohol and drugs less often now.

Although 14 persons said they needed chemical dependency services in the past three months, only ten said were able to get the services they needed. Of the ten in a chemical dependency program, only three reported that AIDS education was part of their treatment. Supports for changes in use of alcohol and drugs cited by all respondents included physicians and nurses, family and friends, and spirituality. Barriers identified included being hard to break old habits and liking to get high.

Sixty percent (60%) of respondents said they had engaged in anal or vaginal intercourse since learning of their HIV infection. Almost 60 percent of this group said they used condoms all the time, 92 percent said they have fewer sexual partners now, and 61 percent said they had told all their sexual partners about their HIV status. Supports for behavior change cited by respondents included safer sex education, physicians and nurses, and that sex partners want safer sex. Barriers identified by almost 31 percent were not wanting others to know, with 24 percent not wanting sexual partners to know of their HIV status.

Barriers to maintaining all healthy behaviors in the last three months (including chemical use and sexual activity) were rejection by family or friends, death of family members or friends, and inability to get needed emotional support. For persons who had known of their HIV infection for more than three years, almost one-third (28 of 100) said they had sometimes had problems maintaining sobriety.

Poverty, Insurance, and Employment Issues:

Ninety-four respondents (56%) said they had health insurance at the time they learned of their HIV infection. Of this group, 31 (33%) had lost insurance since that time. Primary reasons stated for losing insurance included: losing their job, being dropped by insurance, no longer able to afford premiums, and a new job that doesn't provide benefits.

Seventy-seven respondents (46%) said they were currently employed and worked an average of 37 hours weekly. Almost half the employed respondents said they had not missed any work days in the last three months. Less than half of the employed respondents (45%) said their employer knew of their HIV.

Caring for Those With HIV:
Results of the Caregiver Study

> The role informal caregivers to persons with HIV play in their ability to stay well and access services was documented in the second part of study. The survey explored the unique needs of those individuals who provide physical and emotional support to a person living with HIV disease.

Characteristics of the Caregivers Interviewed:

Fifty-two percent (52%) of caregivers said they were a spouse or partner, 19 percent said they were a parent or sibling, and 29 percent said they were friends. Caregivers covered many age groups, from 20 to 74 years, although 59 percent were under the age of 40. Seventy-eight percent (78%) of caregivers were white. Seventy-three percent (73%) said they lived in the same house or apartment, and 14 percent said they lived more than six miles away. Sixty-eight percent of the caregivers were male. Nineteen percent (19%) of caregivers identified a health condition that makes it more difficult for them to provide assistance. Twenty-seven percent (27%) of the interviewed caregivers said they had power of attorney over their family member/friend.

Caregiving Experiences:

Twenty-two percent (22%) said they were the only ones assisting with HIV-related problems or needs. Of those who identified others helping, the most common responses were: case manager (49%); friends (46%); parent (43%); and sibling (38%). Fifty-nine percent (59%) said they had provided care for more than a year, and 35 percent said it has been more than two years.

Sixty-five percent (65%) said they had helped their family member/friend with medications through activities such as going to the drug store, giving medications at the appropriate time, and helping to get medications ready. Fifty-one percent (51%) said they had helped give rides to physician's office, grocery shopping, and recreational activities, with almost one-half of caregivers giving rides at least weekly.

Thirty percent (30%) said they had helped with personal care such as bathing and dressing in the last three months. Caregivers stated the hardest parts of giving personal care were the emotional aspects and that it takes a lot of time to do. Twenty-seven (27%) of those who had helped with personal care reported assistance from others in giving this care in the last three months, mostly from other family members/friends.

All caregivers reported they provided emotional support to their family member/friend. Eight-four percent (84%) said it was hard to watch someone get sick, 62 percent said it was hard to be with someone who is dying, and 57 percent said it was depressing to talk about. An equal number of 35 percent each said they can't talk about their situation with friends, at work, or with people at church.

Fifty-seven percent (57%) said they had concerns about the safety of their family member/friend when left alone with the primary reasons being emotional depression, poor judgement or memory problems, and being too weak or sick to care for themselves in an emergency. Almost one-third of this group reported being afraid to leave their family member/friend because of suicide attempts or thoughts.

All caregivers had talked with their family member/friend about living well with HIV or AIDS, 89 percent said they had helped plan for the future, 86 percent said they had talked about death, 65 percent said they had helped their family member/friend talk with other family members/friends, and 59 percent said they had provided support in making changes in sexual behavior.

Fifty-nine percent (59%) said they had helped financially in the last three months. Twenty-five percent (25%) of caregivers reported helping with moving and in finding housing or information about housing.

How Caregivers Reported the Use of Services:

All but one said their family member/friend had a regular doctor. Seventy-eight percent (78%) said they had contacted the doctor or nurse; primarily to ask about symptoms or illnesses, to ask about how to give care, and to get a prescription refilled. Twenty-two percent (22%) of all caregivers said they had called the physician for emotional support.

Seventy-three percent (73%) said their family member/friend had a case manager and with half of the caregivers said the case manager helped with the caregivers' questions and needs.

Thirty percent (30%) said financial help was the most difficult service to locate, followed by alternative therapies (16%), and medications and counseling (11% each).

Support for the Caregiver:

Thirty-eight percent (38%) said they had participated in the past or are currently a member of a support group. The most helpful aspects of the support groups reported were the opportunities to meet others with similar problems, and being able to share frustrations and concerns. People no longer attended the support groups because the times weren't convenient or they had learned what they needed.

Thirty-five percent (35%) said there is no one they can go to for emotional support. Of those that had support, reported help comes from friends (57%), spouse or partners (43%), siblings (32%), other family members of persons with HIV (27%).

All caregivers cited a need for more information, with most requests for problems and solutions from others like themselves (92%); services available to the caregiver (84%); services available to their family member/friend (75%); and learning to live with a chronic disease (73%).

Recommendations

RECOMMENDATIONS

I. Health and Medical Services

V. Supportive Services

VII. Financial Issues

VIII. Special Populations

I. HEALTH AND MEDICAL SERVICES

The health and medical services examined by the Task Force include:

A. HIV Counseling and Testing;
B. Health Care, including primary care from physicians and clinics, pharmaceutical services, alternative therapies, and home health care; and
C. Dental Care

A. HIV Counseling and Testing and Early Intervention

> Testing for HIV infection which includes informed consent, information about the implication of the test result, counseling regarding risk reduction and pregnancy, and related services such as partner notification, referrals for appropriate medical, psychosocial, contraceptive services and follow-up.
>
> This section discusses the Task Force's desired outcome for HIV counseling and testing and early health and social service intervention for HIV infected individuals, the current status and experience of individuals seeking these services in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

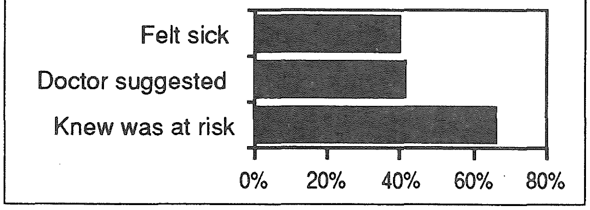
HIV counseling and testing is a vital step toward early medical and psychosocial intervention in HIV disease and prevention of further HIV transmission, and confidential testing should be available and accessible to all Minnesotans.

Current Status:

Over 37,000 Minnesotans have been tested for HIV infection at counseling and testing sites funded by the Minnesota Department of Health, and countless more have been tested at hospitals, clinics, and physicians' offices. Still more are tested routinely in the state's correctional facilities, or as a requirement to participate in the armed services or federal programs such as Job Corps.

- 58% of all persons interviewed said they sought an HIV antibody test because they knew they were at risk;
- 37% said their physician suggested the test to them.

Reasons Site-Based Survey Respondents Were Tested for HIV



Of the respondents who continued to be sexually active after learning of their HIV status, 61 percent of the site-based study, and 28 percent of the target study respondents said they have told their sexual partners about their HIV status.

Data from the HIV Services Planning Project and other studies show that counseling and testing services at the counseling and testing site programs and from HIV specialists are comprehensive and of

> "I applied for an insurance policy. I didn't know I was being tested."

high quality. Testing at other locations, however, varies in quality and is frequently done without the consent of the patient:

- 6% of all respondents reported they were tested without their knowledge or consent.

Assessment of health status, referral and follow up services were not in place for many respondents:

- 21% of all interviewed respondents said they did not look for medical services; and
- 47% said they did not look for social or supportive services until more than six months after learning of their HIV infection.

An overriding theme throughout the interviews conducted with HIV infected Minnesotans was the concern about confidentiality for the information that one was infected with HIV. In focus group and subcommittee discussions, concerns were raised about the need for an anonymous alternative for HIV testing. Other concerns centered around the need for more culturally-appropriate counseling and testing, and the availability of counseling and testing services for the non-English speaking and hearing impaired communities. The Greater Minnesota subcommittee identified a need for increased access to counseling and testing in Greater Minnesota.

Survey participants expressed concern for confidentiality in other areas, including telling their sexual partners about their HIV status.

- 31% said they didn't want others to know their status;
- 24% of respondents to the site-based survey said they didn't want their sexual partners to know they are HIV positive; and
- 18% of all respondents said it was hard for them to talk about sex, making it more difficult for them to discuss their status with past and future partners and to make changes in sexual behaviors.

Discussion and Implications:

When HIV testing is accompanied by quality counseling and referral to appropriate psychosocial and health care services, persons with HIV can begin to take the next steps to meeting their health and social service needs. This early intervention is the most important element of screening for HIV, and is even more vital as new therapies are developed which can improve and prolong health.

An HIV-infected person who has a negative experience with HIV counseling and testing, may not seek out social or health care services that can preserve and promote health. HIV-infected persons report guilt and concern for exposing others to HIV, but also report having difficulties in notifying sexual partners and others of their infection.

If persons who are HIV-infected do not learn of their HIV status, society can expect increased costs for care caused by otherwise preventable opportunistic infections, a decrease in overall health status and a shortened length of working capability. Persons who have been partners of persons with HIV have a right to know of that exposure whenever possible.

Unless persons with HIV infection know of their status and are supported in making behavior changes, HIV transmission will continue to occur. Studies have shown behavior change to be enhanced by knowing one's status (McKusick, Coates et al, 1989). Assistance with partner notification continues to be needed for persons who, for whatever reason, are unable to notify past partners of their HIV status.

Counseling, testing and referral to appropriate health and psychosocial care and services offers an opportunity for early intervention which can improve physical and mental health and decrease behaviors which can transmit HIV.

HIV Counseling and Testing Recommendations:

To further enhance the early intervention opportunities made possible by counseling and testing for HIV, the Task Force recommends:

1. That the Department of Health propose legislation that would require all providers of HIV counseling and testing services to provide written informed consent and, directly or through arrangements, comprehensive pre- and post-test counseling services, assessment of health status, and referral to needed services.*
2. That the Department of Health call together representatives of third party reimbursement services to develop methods to assure that reimbursement for HIV testing occurs only when accompanied by adequate counseling which includes a mechanism for informed consent and referral to needed health and social services.*
3. That the Department of Health develop strategies to assist all HIV service providers in helping HIV-infected persons to develop a range of strategies to inform their past and current sexual and/or needlesharing partners of possible exposure to HIV.
4. HIV-infected persons should be encouraged and supported in developing strategies to notify their past and current sexual and/or needlesharing partners of possible exposure to HIV, by counseling and testing providers in conjunction with the state's partner notification program.
5. It is the majority opinion of the Task Force that Minnesotans should have access to an anonymous testing option. The Commissioner of Health should establish a broad-based task force to develop recommendations about how such a service might be provided in Minnesota. Additionally, the task force should review current strategies and develop recommendations for providing education and intervention strategies, especially for people who are involved in high-risk behaviors, that encourage them to seek testing, ensures that they are fully informed of their rights, and encourages responsibility towards sexual and drug using partners.

To improve the quality of counseling and testing services, the Task Force recommends:

6. That support to HIV counseling and testing providers be increased statewide, targeting professional staff in private physicians offices, acute care facilities, and agencies providing health care services to communities at risk.
    a. The Department of Health should take a lead role in developing a network of experienced counseling and testing providers who can support less HIV experienced providers in counseling and working with newly identified HIV positive persons, and develop a counseling and testing training manual and video specific to Minnesota which includes specific skills in the area of cultural sensitivity and issues of concern to women, children, families, adolescents, IV drug users, gay men, and communities of color.

* Definitions of adequate counseling and referral are contained in the Appendix.

B. HEALTH CARE

Primary medical care which includes: monitoring and treatment of health, referral to specialists, and drug therapy received through a private physician's office, clinic, or hospital outpatient setting.

This section discusses the Task Force's desired outcome for health care services for HIV infected individuals, the current status and experience of individuals seeking primary physician care, institutional health care, home health care, pharmaceutical and alternative therapies in Minnesota, a summary discussion of the data, and recommendations for achieving the desired outcome.

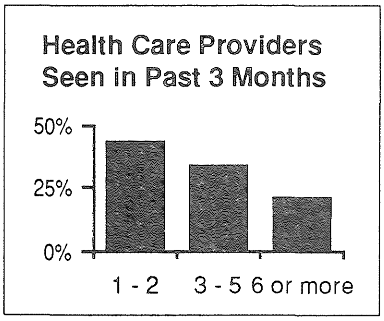
Desired Outcome:

For infected individuals, health and medical care should support a client-directed process of planning for current and future needs. Home and community-based services that prevent the use of unnecessary, more high cost institutional services while maintaining high quality health care should be a cornerstone of this plan.

Current Status:

Physicians, Clinics and Hospitals:

The study of Minnesotans infected with HIV showed that persons with HIV disease have difficulty accessing a range of home and community-based care, and are relying on higher-cost institutionalized services for their health care:



- 22% of all individuals interviewed said they had been hospitalized in the past three months, while only 9% had used home health care services;
- 28% of site-based respondents said they had used an emergency room in the past three months; and
- 14% of the target study group said they relied on the emergency room for primary medical care.

The study also illustrated how access to primary health care is based largely on access to health insurance and income level:

- 74% of target survey respondents reported having some form of private or government health care coverage compared to 98% of the site-based study respondents.
- 21% of site-based respondents cited cost as a barrier to accessing health care
- 59% said they paid out-of-pocket for some portion of their medications and 48% said they paid some portion of physician bills.

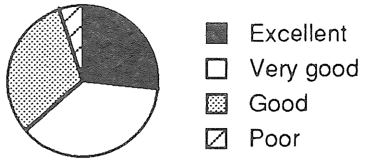
The important role medical staff play in supporting behavior change and providing referrals to HIV resources was documented:

> *"Last time I was there they looked at me for every different reason. They never consulted me about anything. They talked to themselves."*

- 68% said medical staff played an important role in supporting sexual behavior change;
- 57% said medical staff played an important role in supporting chemical use behavior change;

- 33% of respondents said they visited their physician for emotional support; and
- 89% said they learned about HIV services from their medical team.

Minnesotans With HIV Rate the Health Care System



Target surveys raised special concerns about access to primary health care services for the HIV-infected homeless and for Hispanics:

- 2 of 9 homeless persons interviewed said they had never sought medical care for their HIV infection;
- 5 of 9 said they were unaware of their CD4 count;
- 6 of 9 said they were not taking medications; and,
- 6 of 9 said they relied on the emergency room for their medical care.

- 57% of the 14 HIV-infected Hispanics interviewed said they had yet to seek medical services for their HIV infection;
- 50% said they had received no social services related to their HIV infection;
- 86% said they were not taking any medications for their illness; and
- 79% said they did not know their CD4 count.

Information from the target survey and subcommittees confirm that persons with HIV disease living in Greater Minnesota face a lack of experienced providers and concerns around confidentiality, difficulties finding transportation, and difficulty accessing HIV drugs and experimental treatments locally.

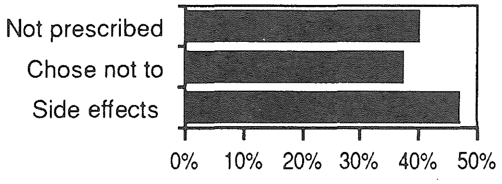
Pharmaceutical Services:

The study also illustrates that problems in accessing pharmaceutical services exist in both the metropolitan area and in Greater Minnesota. Although side effects and choice were factors in not taking drugs that prevent opportunistic infections, cost and the drugs not being prescribed caused access problems:

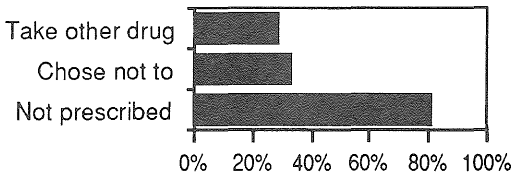
> ***" Find us drugs that make us live longer - or find a cure. "***

- 81% of the 36 individuals who were eligible for and *not* taking pentamidine treatments to combat development of pneumonia stated they had not been prescribed the drug, and 8% said it was too expensive;
- 40% of the 60 individuals eligible and not taking AZT said the drug was not prescribed;
- 28% of persons interviewed said they were unaware of AIDS Clinical Trail programs, and 12% stated they tried to enroll and could not;
- 17% of those persons currently taking AZT were receiving their medication through the AZT reimbursement program; and
- 32% said they received the drug through private insurance, which usually does not cover the full cost of drugs.

Reasons Persons With CD4 Counts <500 Are Not Taking AZT



Reasons Persons with CD4 Counts <200 Are Not Taking Pentamidine



Alternative Therapies:

Persons with HIV infection use a wide variety of alternative methods of wellness and healing, although few third party payors allow for reimbursement for these services. The site-based study revealed the extent to which treatments like acupuncture, vitamin therapy, nutritional education, and stress management are being used by Minnesotans with HIV:

- 64% of site-based respondents said they had made dietary changes;
- 62% said they regularly used meditation, imagery or prayer;
- 34% said they used vitamins and 15% use herbal therapy;
- 28% used massage;
- 15% said they used gems and/or crystals;
- 11% said they received homeopathy or holistic medical care;
- 8% said they used acupressure or acupuncture; and
- 8% said they consulted a medicine man or traditional healer.

> ***"Traditional Native American ceremonies."***
> ***"Champagne and chocolate."***
> ***"Gardening."***
> ***"Shopping."***
> ***"Listening to my music."***
> ***"Yoga."***
> ***"Writing in my journal."***

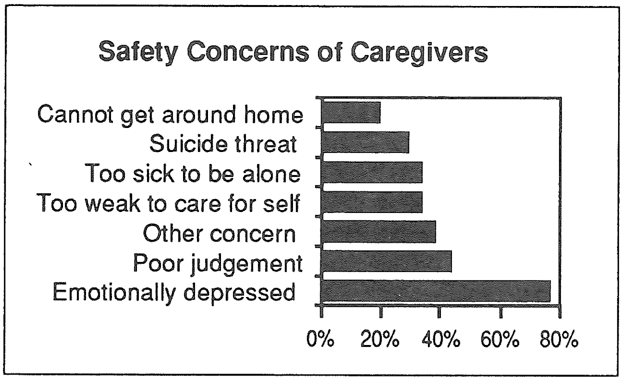
Home Care:

As noted earlier, only 19 persons (9%) of site-based, and 2 of 69 target respondents had used home health care services in the past three months. However, the study also indicated that persons in need of care had difficulties accessing services:

> **11% of site-based respondents needed home health care in the past 3 months.**

- 3 persons who needed attendant care were unable to receive the care they needed;
- 3 said they were unable to afford the care they needed;
- 3 said they were concerned about the confidentiality of the services they received; and
- 3 said they were treated poorly by the home health care agency staff because of their HIV.

An additional indication of the importance of home care comes from interviews with caregivers, who have concerns about the safety of persons with HIV:


Safety Concerns of Caregivers

- 57% of caregivers surveyed said they had concerns about leaving their loved one alone;
- 76% of those said they were concerned because the individual was emotionally depressed;
- 43% said the individual had poor judgement and trouble remembering;
- 33% said their loved one was too weak to care for themselves in an emergency; and
- 29% said they were reluctant to leave their loved one alone because of threatened or attempted suicide.

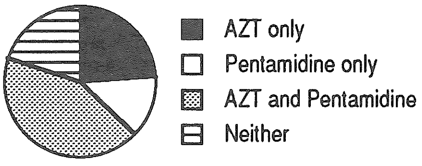
Discussion and Implications:

Current systems of care and reimbursement policies are focused on inpatient, medically-directed, procedure-oriented services, and crisis intervention services. Although medical staff are cited by respondents as the primary source of referral to HIV-related services and as a primary source of corresponding emotional support, costs to provide these services are largely nonreimbursed.

The majority of persons with HIV disease living in Minnesota are seen at a handful of HIV clinics in the metropolitan area. This fragile coalition of providers is under increasing strain. Loss of one physician or clinic would result in greatly decreased options for the individual, and increased stress on the remaining providers.

For the infected individual, primary health care can help prevent increased illness by monitoring health status, and intervening with timely medications and medical treatments. The data also shows that the health care team is a vital intervention point for emotional and behavioral change support, and for referral to other services.

HIV Therapies Taken by Site-Based Respondents



Without medical care and treatment to prevent opportunistic infections, hospitalization, and health status deterioration; society can expect health care costs for persons with HIV infection or AIDS to steadily increase. The creative use of community- and home-based services, such as personal care attendants and in-home therapies, can provide safe, effective care and treatment usually at a much lower cost than institution-based services.

The needs of special populations affected by HIV -- including the homeless, communities of color, non-English speaking, adolescents and families, and those in poverty -- have resulted in less access to primary care.

Health care for persons with HIV infection includes an assessment of behaviors that can transmit HIV, and the development of individually tailored strategies to help the individual change those behaviors. This component is a unique feature of HIV disease and requires both an expertise in HIV, and sensitivity to the unique behavioral and emotional issues inherent to this disease. The health care team can both support changes and make referrals to behavior change programs or individual counseling as needed. The primary team was identified by large numbers of respondents as important in assisting in needed behavior change to prevent further HIV transmission, and as an important emotional support.

> ***"My home health care nurse is a major resource to the medical system – the most important link to my medical care."***

Home health care can meet several needs of HIV-infected persons. First, home health care can decrease reliance on institutional care, a desire expressed by many individuals with HIV. Second, having a professional care provider at home can relieve stress on the informal caregivers, and help assure the safety of their loved one. Third, home health care providers can provide a wide range of supportive services including health education, and assistance with accessing needed services.

Assuring access to primary health care for persons with HIV infection will help improve and prolong the health of HIV-infected Minnesotans. Increased services from a health care team and community-based care may substantially decrease cost of care by reducing reliance on emergency room and hospital care. Sexual and chemical use behavior change support given by medical providers improves the public health by helping to reduce rates of HIV transmission.

Health Care Recommendations:

To decrease costs of care received in institutional settings by increasing reliance on community or home based services where appropriate, the Task Force recommends:

7. That the Department of Human Services examine Medical Assistance (MA) to increase reimbursement rates for HIV-related outpatient, home and community-based health care, including consideration of a waiver program for HIV infection.

8. That the Department of Commerce review minimum coverage requirements for HIV-related services to stimulate reliance on referral and support services designed to prevent unnecessary placement in a health care facility over the course of HIV disease.

9. That the Department of Commerce examine coverage for HIV diagnostic codes to enhance payments for assessment, support, and referral services provided to HIV-infected clients.

To better prepare for the diversity of individuals affected by HIV/AIDS, the Task Force recommends:

10. That the Department of Health work with community-based organizations, counseling and testing sites, and clinics to improve access to health care services for the homeless, American Indians, Hispanics, African Americans, non-English speaking persons, gays and lesbians, adolescents, women, and individuals in Greater Minnesota.

11. That the Department of Health encourage AIDS service providers, the Minnesota Medical Association, and Community Health Boards to work cooperatively to identify HIV sensitive and knowledgeable medical providers in rural communities, and create linkages between those providers and HIV specialists and community resources.

12. That strategies to increase reliance on home health care and services be developed:

    a. The Department of Health should encourage primary care providers to assess the need for home-based care for persons with HIV infection and make referrals to those services early in the disease process.

    b. The Department of Health should bring together funders and providers of home care services to develop strategies to improve access to home care by improving reimbursement for services, availability of 24-hour care providers, and continuity and quality of services provided to persons with HIV.

    c. The Department of Human Services should continue the current home health program and evaluate its effect on services for persons with HIV infection.

13. That the Department of Human Services consider establishing a waiver for persons with HIV disease.

To improve access to health care for persons with HIV disease, the Task Force recommends:

14. That discrimination by health care providers against persons with HIV infection be documented and reported and that laws prohibiting discrimination be enforced.

    a. The Department of Human Rights increase its role in ending health care discrimination by publicizing, and increasing enforcement of laws prohibiting refusal of services to HIV-infected individuals by health care providers.

    b. That the Minnesota professional boards determine the extent of denial of services to HIV- infected persons by health care providers, and develop training and sanctions for all members with the goal of increasing the number of providers willing to serve persons with HIV

To maintain and improve access to HIV-related drugs, the Task Force recommends:

15. That the Department of Human Services continue the drug reimbursement program and expand to meet increasing needs. Any reduction in federal funding for this program be made up by an increase in state dollars.

16. That AIDS service organizations and providers in Greater Minnesota work to increase access to HIV therapies in rural areas through promoting use of Buyers clubs and mail order services, and through cooperation with local pharmacies.

17. That the Department of Health and the Department of Human Services bring together a group of health care providers, third party payors, and consumers to discuss advances and research on alternative therapies to advocate for those which should qualify for third party reimbursement and which should be more widely available to persons with HIV disease.

C. DENTAL CARE

Routine dental care and more complex procedures associated with HIV disease.

This section discusses the Task Force's desired outcome for dental care services for HIV-infected individuals, the current status and experience of individuals seeking dental care in Minnesota, a summary discussion of the data, and recommendations for achieving the desired outcome.

Desired Outcome:

Persons with HIV disease should be able to receive routine dental care from any provider in the state, and should not be denied services because of their health or source of payment.

Current Status:

Persons with HIV infection are subject to a variety of oral infections and dental complications which can be recognized and treated by dental professionals usually without referral to specialists. Still, persons with HIV infection throughout the state cite difficulties accessing even the most routine dental services.

Although 69% of individuals surveyed said they needed dental care in the past six months:

- 21% said they could not find a dentist willing to treat them; and
- 22% said they could not afford the care they needed.

69% of site-based respondents needed dental care.

22% said they could not afford the care they needed.
21% could not find a dentist willing to treat them.

The 1990 resource directory developed by the Minnesota AIDS Project lists only 9 dentists willing to treat HIV-infected persons in the entire state. Subcommittee members noted that independent dental practitioners in particular find Medical Assistance (MA) reimbursement a difficult process, and an increased unwillingness to serve MA clients.

Discussion and Implications:

Denial of routine dental care creates increased physical risk for persons with HIV infection and their dental care provider, and adds to the atmosphere of discrimination against persons with HIV disease in the state of Minnesota.

For persons with HIV infection, dental services are among the most difficult health care to access. Yet persons with HIV are subject to a number of oral infections which, if left untreated, can result in severe illness and physical deterioration. The physical and emotional stress of being denied care - in spite of laws prohibiting the denial of service - can also reduce health status.

Persons with HIV infection are encouraged to tell their health care providers, including dentists, of their infection. This disclosure can protect the individual and the health care worker. The continuation of discrimination by dental providers against persons with HIV infection results in a reluctance to tell providers.

"My dentist of 25 years denied me care. That hurt."

Assuring access to dental services for persons with HIV infection will help improve and prolong the health of the individual by decreasing opportunistic infections. Supporting the ability of persons with HIV infection to inform their dental provider that they are infected could decrease occupational risk of transmission.

Dental Services Recommendations:

To improve access to dental care for persons with HIV disease, the Task Force recommends:

18. That the Department of Health encourage the Minnesota Dental Association and Community Health Boards to work cooperatively to identify HIV sensitive and knowledgeable dental providers in communities, and create linkages between those providers and HIV specialists and community resources.

19. That discrimination by dental providers against persons with HIV infection be documented and reported and that laws prohibiting discrimination be enforced.

    a. The Minnesota Department of Human Rights increase its role in ending dental care discrimination by publicizing and increasing enforcement of laws prohibiting refusal of services to HIV-infected individuals by dental care providers.

    b. That the Minnesota Board of Dentistry determine the extent of denial of services to HIV-infected persons by dentists, and develop training and sanctions for all members with the goal of increasing the number of providers.

To improve the ability of dental care practitioners to provide care to persons with HIV disease, the Task Force recommends:

20. That the Department of Human Services evaluate and revise MA forms to ease the reimbursement process for small and independent practitioners.

21. That the Department of Health and dental care providers meet to explore infection control and public concerns as they impact dental services.

22. That the Minnesota Board of Dentistry require all dental care providers to be trained and equipped to provide care to HIV-infected individuals.

II. CHEMICAL DEPENDENCY SERVICES

Assessment includes information and referral, diagnostic and identification services for chemically dependent individuals. Detox programs stabilize chemically dependent and currently using individuals in crisis, and refer them to an appropriate longer term program. Chemical dependency treatment programs involve residential, outpatient, halfway house, or other transitional program to prepare chemically dependent persons to re-enter the world. After care programs are primarily 12-step (Alcoholics [AA] and Narcotics [NA] Anonymous) or other ongoing sobriety programs for chemically dependent persons.

This section discusses the Task Force's desired outcome for a range of chemical dependency services for HIV-infected individuals, the current status and experience of individuals seeking assistance with chemical dependency in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

A range of chemical dependency treatment options able to meet their needs should be available and accessible to all HIV-infected persons living in Minnesota, including nondocumented and foreign nationals. Persons with HIV infection who choose to continue to use alcohol or drugs should receive education about the consequences of continued use.

Current Status:

The site-based study showed the degree to which chemical use and chemical dependency is a factor in the health of Minnesotans with HIV disease:

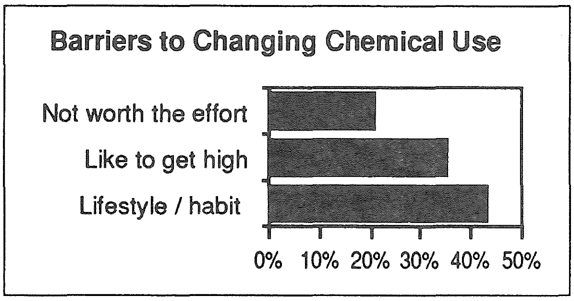
66% of site-based respondents were using alcohol at the time they learned of their HIV status 31% were using street or illegal drugs.

- 7% of respondents said they decided to be tested for HIV because a needlesharing partner tested positive;
- 66% of persons surveyed said they were using alcohol at the time they learned of their HIV infection;
- 31% said they were using street or illegal drugs;
- 28% said they used drugs and alcohol to cope with stress and worries;
- 9% said they drink and/or use drugs more often since learning of their infection; and
- 37% of persons using chemicals when they learned of their infection reported they had stopped using alcohol and/or drugs

The study also indicated the difficulty these individuals had in receiving chemical dependency services and education within those treatment settings:

Of the 10 people who received C.D. services in the past 3 months, *7 did not* receive any AIDS education as part of the program.

- 14 persons reported they needed chemical dependency treatment in the last three months; and
- 10 said they were able to get assistance, but only two individuals in treatment were given information on safer sex and safer needle use.


Barriers to Changing Chemical Use

Focus group members and survey participants spoke often of the importance of sobriety in maintaining health, and of the new incentive diagnosis with HIV gave to their sobriety. For those persons who were making changes in their chemical behaviors, the ability to discuss their HIV and chemical issues with family, friends, and health care professionals was an important factor in achieving change:

- 42% said family and friends were supportive in their behavior change;
- 40% said a physician had helped them make and support healthy chemical behaviors; and
- 36% said their spouse or partner was an important factor in making changes.

Barriers to change in chemical use reported by respondents included:

- 43% said using chemicals is a hard habit to change;
- 35% said they liked feeling high;
- 17% said changes did not seem worth the effort;
- 15% reported pressure from peers to continue using;
- 12% said use of drugs or alcohol made it difficult to change sexual behavior; and
- 21% said rejection by family members or friends had made it more difficult to maintain healthy sexual or drug use behavior in the past three months.

Almost one-third of persons who have had HIV infection for more than three years said that maintaining sobriety has been a concern for them.

Data from the target surveys showed even higher risks for alcohol and drug use, especially for the HIV-infected homeless and Hispanic individuals surveyed:

7 of the 9
HIV-infected homeless persons
interviewed
used alcohol or drugs
to cope with stress.

- 7 of the 9 HIV-infected homeless persons interviewed said they used alcohol or drugs to cope with stress.
- 4 of the 9 homeless individuals surveyed said they used drugs and alcohol more often since learning of their HIV status
- 4 of the 9 homeless stated they had made no changes in their use since diagnosis; and
- 36% of Hispanics interviewed said chemical dependency services were most difficult to find.

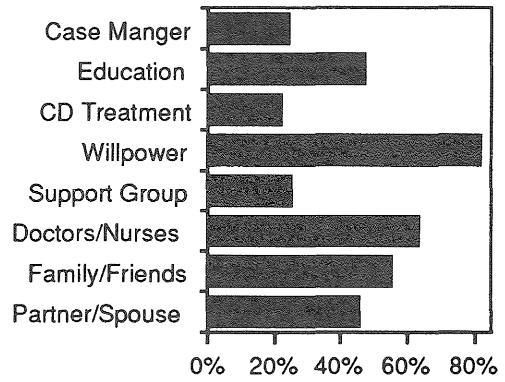
Focus groups raised additional issues of the increased risk of unsafe sex for the chemically dependent, and the conflict in use of prescription medications for HIV-infected persons in recovery. Focus group members felt these complex issues could best be addressed in a structured, supervised, and AIDS-specific setting.

Subcommittees identified additional barriers to chemical dependency programs for HIV-infected non-English speaking persons, and HIV-infected persons who struggle with additional disabilities such as mental illness, developmental difficulties, or hearing impairment.

Discussion and Implications:

Chemical dependency services are of special importance to the prevention and treatment of HIV services because: 1) national and Minnesota studies show that persons with HIV infection are likely to be at risk for chemical abuse, (Friedman, 1988; and Tilleraas, 1990); 2) use of alcohol and drugs increases the severity and progression of HIV disease, (Siegel, 1986); and 3) continued use of chemicals increases risk for activities which can cause transmission of HIV.

Helpful to Making Changes in Chemical Use



For the individual, chemical dependency causes deterioration in health status and decreased ability to fight off opportunistic infections. Chemical dependency can also mean denial by some services, such as housing, or difficulty using other services, such as support groups. The emotional stress of HIV infection has been shown to increase use of chemicals as a coping strategy for some persons.

The lack of access to chemical dependency treatment and ongoing support services can result in increased medical care needs and costs to society. For persons using drugs or alcohol, prevention is not a priority, therefore health care is more often sought in times of crisis.

For all HIV-infected persons, the use of alcohol or drugs places them at increased risk for unsafe sexual and needlesharing behavior, increasing the possibility for transmission of HIV. Excessive use of chemicals can impair judgement and limit one's ability to maintain a commitment to behavior change. Nationally, as well as in Minnesota, the sexual partners of intravenous drug users are at increased risk for infection.

Increasing access to appropriate chemical dependency services for persons with HIV infection may have a positive impact on the health of the individual by slowing progress of the disease. Increased access to treatment programs may decrease the need for high cost medical care. Effective chemical dependency programs may decrease rates of HIV infection in Minnesota.

> ***"I've become sober - no alcohol, no marijuana, no cocaine."***

Chemical Dependency Recommendations:

To safeguard the health of persons with HIV disease who choose to continue the use of alcohol and drugs, the Task Force recommends:

23. That community-based organizations such as the Recovery Alliance, health care providers and AIDS service organizations provide persons with HIV information regarding the physical and transmission risks associated with continued use of chemicals.

To increase access to chemical dependency services for persons with HIV disease, the Task Force recommends:

24. That the Department of Human Services develop a system for quick access to chemical dependency treatment services for HIV-infected individuals.
25. That the Department of Human Services and counties develop flexible alternatives for chemical dependency assessments of HIV-infected persons conducted by individuals sensitive to the needs of persons with HIV.

To increase referral capacity of AIDS service organizations and medical staff to chemical dependency services, the Task Force recommends:

26. That chemical dependency treatment programs, medical providers, and AIDS service organizations, through the leadership ofthe Department of Human Services, assess the current models of treatment and the efficacy of those programs in meeting the needs of persons with HIV disease.
27. That the Department of Health and the Department of Human Services investigate the establishment of a demonstration project to develop a model to serve persons with issues of a diagnosis of HIV, and additional issues of mental health and/or chemical dependency.
28. That community-based organizations work with chemical dependency programs to develop strategies to meet the needs of non-English speaking and/or undocumented persons.

III. MENTAL HEALTH AND EMOTIONAL SUPPORT SERVICES

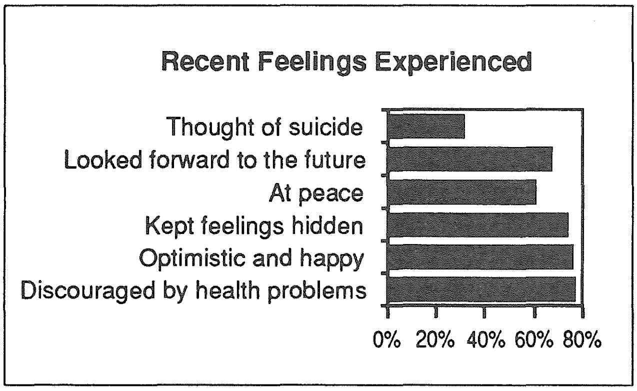
> Counselors and therapists who work with HIV issues who can be reimbursed by third party insurance. Sliding fee scale community-based mental health counseling services and county social services providers, including crisis and emergency counseling services. Support groups attended by persons with HIV disease.
>
> This section discusses the Task Force's desired outcome for mental health and emotional support services for HIV-infected individuals, the current status and experience of persons seeking those services in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Mental health services should be available to all persons with HIV infection throughout the course of their experience with the disease to support coping with the emotional stress and physiological complications of HIV disease.

Current Status:

The studies illustrated the emotional effect of HIV disease on the infected individual. A general theme throughout all discussions and interviews with HIV infected persons is the fear they have of being rejected when people or service providers learn of their HIV infection. Examples of emotional stress include:

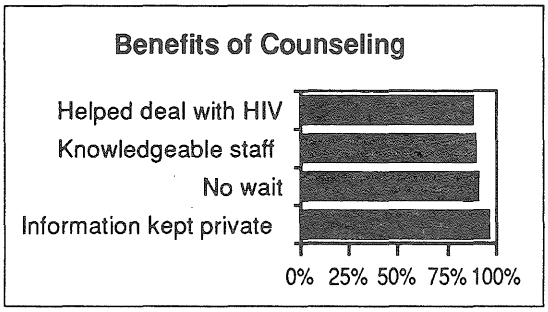

Recent Feelings Experienced

- 31% of the site-based study respondents said they had thought of suicide in the past three months;
- 28% of all respondents said they used drugs or alcohol;
- 27% said they engaged in sexual intercourse as a coping strategy during periods of stress;
- 28% of all respondents reported having concerns about being rejected by their family members or friends because of their HIV status; and
- 67% of those who have had HIV disease for three years or more said they have had to cope with the loss of many friends to AIDS.

One manifestation of HIV disease is AIDS-related dementia. Studies indicate that at the time of initial diagnosis, 25% of persons with AIDS may suffer from subclinical dementia or other neuropsychiatric disorders. As many as 90% of persons with AIDS will suffer from a degree of mental disability at the end stages of illness. (Boccellari, A. et al, 1990; and R.W. Price, et al, 1988.) The neurological complications of this disease were also evident in the study of Minnesotans with HIV disease:

- 41% of the targeted survey respondents said they had worried about losing their mental ability in the past three months; and
- 49% of site-based respondents and 28% of the target survey respondents said they had trouble with thinking, concentrating, or memory in the past three months.

Individual, one-on-one mental health services were seen by HIV-infected individuals to be valuable in coping with the stresses, fears, and life changing adjustments inherent in a diagnosis of HIV infection:


Benefits of Counseling

- 30% of all interviewed persons said they had received mental health counseling in the past three months;
- 96% of the 53 site-based respondents who had counseling said this relationship offered a safe place to discuss concerns, (this was the only service area studied where confidentiality was not a concern of respondents); and
- 81% said it was an important factor in their ability to adjust to their HIV status.

Accessing mental health counseling, however, has not been easy for many persons with HIV disease:

30% of all respondents received counseling in the past 3 months.

Of site-based respondents:

25% could not afford counseling.
15% attend a support group.
34% have attended previously.

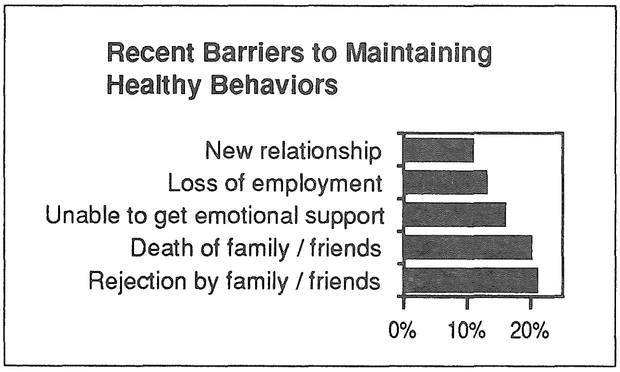
- 21% of all respondents who had received counseling said they could not afford the counseling they needed;
- 23% reported paying for counseling themselves; and
- 18% of all respondents who received counseling said their mental health provider was not knowledgeable about HIV issues.

Support groups are also an important emotional support to Minnesotans with HIV disease:

- 43% of all respondents said they had attended in the past or were currently attending a support group for persons with HIV.

Over 50% of HIV-infected support group participants said the support group has helped in learning about living with HIV and staying well, reduced stress, and provided a means of meeting other persons with HIV.

Focus group and subcommittee members expressed concerns that support groups are not able to meet the individual counseling and therapy needs of persons with HIV disease, especially for persons with chronic mental illness, chemical dependency, and neurological complications. This concern was also documented by the studies:


Recent Barriers to Maintaining Healthy Behaviors

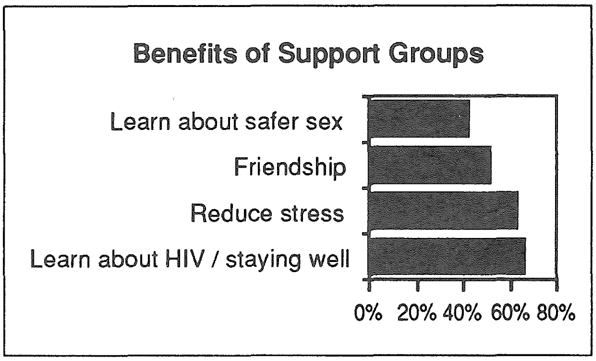
- 66% of past support group participants said they no longer attended because the group did not meet their needs; and
- 59% no longer attending said it was more depressing than helpful.

Discussion and Implications:

Many persons with HIV infection need assistance in coping with the emotional stress and physical changes resulting from the disease. Some individuals who face neurological impairment from HIV are in need of professional assessment and assistance. Although community-based support groups have been of benefit to many individuals, one-on-one counseling and therapy is sometimes needed by persons with HIV disease.

For the individual, diagnosis with HIV infection means a variety of intense and complex adjustments, frequently resulting in mental duress. The socially isolating diagnosis of HIV infection means possible rejection by society and fear of using services and telling others.

Professional mental health therapy and support groups can prevent debilitation from stress and its accompanying depression, isolation, irrational behavior, and mental deterioration. Therapists can help distinguish between AIDS-related dementia and stress-related symptoms, and intervene when needed to manage symptoms.


Benefits of Support Groups

Individual mental health services and support groups assist persons in making needed sexual and chemical use behavior changes to prevent further transmission of HIV. Without this support and intervention, infected persons may be at increased risk for transmitting HIV. Persons who have had HIV disease for longer periods of time continue to need assistance in maintaining behavior changes.

Improving access to mental health services for persons with HIV infection will increase their ability to manage the emotional and behavioral changes required by infection. Mental health services focused on early identification and treatment of mental health problems can prevent deterioration and the need for more intensive care. Effective mental health intervention has implications for decreasing rates of HIV infection in Minnesota. Support groups offer a peer-based means of providing emotional support and encouragement in a variety of settings and formats.

"We need to talk more about AIDS."

"It would be nice
if people in support groups
didn't die."

"Lighten up.
Maybe they need
one-to-one counseling
instead of whining."

"Have more social events.
Let's go to Valley Fair!"

Mental Health and Emotional Support Recommendations:

To increase access to mental health services by persons with HIV disease, the Task Force recommends:

29. That the Department of Commerce review minimum coverage requirements and make changes to assure persons with HIV disease have expanded and ongoing access to mental health services, including counseling, individual and group therapy, and psychiatric consultation.

30. That Boards which license mental health providers explore methods to develop a competency in HIV services.

31. That the Department of Health encourage AIDS service providers, the Mental Health Association, and Community Health Boards to work cooperatively to develop and maintain a referral list of HIV sensitive and knowledgeable mental health care providers, including psychiatrists.

To improve access to and quality of support groups for persons with HIV infection, the Task Force recommends:

32. That community-based organizations such as the Minnesota AIDS Project develop a time-limited education and support group led by a team of professionals for newly diagnosed HIV-infected individuals.

33. That AIDS service organizations develop a decentralized support system for persons in Greater Minnesota and those unable to attend support groups. Components of this system could include a computerized bulletin board/information bank, and a telephone support system.

IV. HOUSING SERVICES

Referral and advocacy for emergency and temporary shelter or long-term housing. Emergency shelters provide a place to stay for one or two nights with little or no ongoing social support. Transitional housing provides a place to stay for more than 30 days and is accompanied by supportive services aimed at providing the resident with an independent, long-term solution to their housing needs. Foster care takes place within a subsidized home setting. Independent housing is provided with a degree of social support and subsidy for an indefinite length of stay.

This section discusses the Task Force's desired outcome for a range of housing services for HIV-infected individuals, the current status and experience of persons seeking housing services in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

The goal of housing for persons with HIV disease is to allow the family unit, as defined by the individuals, to live in safe, secure, adequate, and appropriate housing.

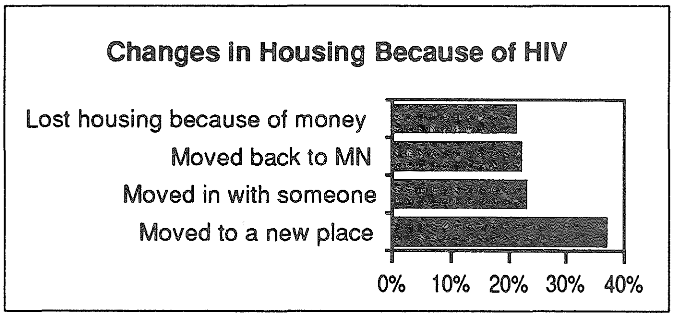
Current Status:

Maintaining a suitable independent living situation is a difficulty for many persons with HIV infection. Poverty, illness, the need to be cared for, discrimination and racism, isolation, and the lack of available suitable housing all contribute to this difficulty.

10% of site-based respondents said they lost their housing because of discrimination.

- 59% of site-based survey participants said they agreed that finding appropriate housing is a problem for many persons with HIV infection in Minnesota;
- 37% said they had moved because of their illness;
- 10% said they lost their housing because of discrimination;
- 21% said they lost their housing because of poverty;
- 15% of all respondents said they had difficulty finding a place to live because of their HIV infection;
- 57% of those respondents said they had a hard time finding assistance to locate a suitable home, and 54% reported they experienced discrimination when looking for housing.

Almost one-third of site-based respondents said they have moved in with someone or had someone move in with them because of their HIV.


Changes in Housing Because of HIV

Focus group and subcommittee members also spoke about the need for more safe, adequate, and independent housing.

Although limited transitional housing and adult foster care for persons with HIV infection is available in the metropolitan area, demand is greater than current services, and a continual waiting list exists for transitional and foster care beds.

Housing is tied to income and employment. Of all persons interviewed:

- 66% said they made less than $12,000 per year with over one-third of the site-based survey respondents said they made less than $6,000 per year;
- 14% of survey respondents said they stayed with family and friends for several weeks; and
- 23% said they stayed for several days in the past three months.

The data from nine HIV-infected individuals surveyed living on the street or in emergency shelters, illustrates the increased health risk and loss of housing places for persons with HIV:

9 homeless persons with HIV infection were interviewed by volunteers from Catholic Charities.

Their stories illustrate the dangers persons with HIV face when living without a safe and secure home.

- 5 of the 9 homeless persons with HIV surveyed said they did not know their CD4 count;
- 6 of the 9 said they were not taking any medications for their HIV infection;
- 4 of the 9 said they had never received medical care since learning of their HIV infection and 6 had never sought social services;
- 4 of the 9 said they had spent the night in a hospital in the past three months and 2 individuals were released from a hospital to the street; and
- 6 of the 9 homeless individuals said they relied solely on the emergency room for their medical care.

Homelessness also places persons with HIV infection at increased risk for behaviors which can transmit the virus:

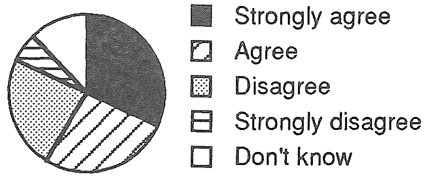
- 4 of the 9 homeless individuals interviewed said they use alcohol or drugs more often since learning of their HIV status;
- 7 of the 9 said they use drugs or alcohol to cope with stress; and
- 21% of the site-based respondents who had lost their housing said this loss made it more difficult for them to maintain healthy sexual or drug use behaviors.

Subcommittee and focus group members expressed concerns that shelters are not safe alternatives for families, individuals, or children with HIV infection because of increased risk for infection.

Subcommittee members who work with HIV-infected homeless individuals are concerned that these persons may trade sex for housing and/or drugs.

Subcommittee members from the Minnesota AIDS Project, which provides limited transitional housing for persons with HIV expressed concern that their service is being used more frequently by persons in crisis, and by the chronically mentally ill or retarded, increasing stressors on that system and the individuals living in those facilities:

"Finding Appropriate Housing is a Problem for Many Minnesotans with HIV"



- 36% of persons living in Minnesota AIDS Project transitional housing are considered "high risk" by the Project (persons struggling with chemical dependency, mental illness or mental retardation, as well as HIV).

The average length of stay in the Minnesota AIDS Project's transitional housing is seven months.

Discussion and Implications:

Housing for persons with HIV infection or AIDS requires assistance in locating and paying for housing and supportive services during times of illness.

Because HIV compromises the immune system, being without a home means living in constant danger of worsening disease and death for a person living with HIV infection. Home-delivered meals, home health care, and other supportive services are not available to those without a permanent address.

Safe, secure housing for persons with HIV disease also makes good fiscal sense. Homeless persons with HIV are more likely than others to use the emergency room for their routine medical care and are, as noted, at increased risk for complications. The homeless persons with HIV that were interviewed were also less connected to a medical and social support network, not taking medications which can prevent acute illness, and are more likely to be at risk for chronic chemical dependency.

"Create a place for in-between care for people who can leave the hospital, but who can't stay home alone."

Safe, secure, and appropriate housing is a prevention strategy. Persons who are homeless have little power and are concerned about the more central issues of warmth and safety than more abstract concerns about transmission or health care. Homeless HIV-infected persons may have difficulties maintaining safe sex and drug-use behavior, thus leading to increasing rates of HIV transmission.

Providing safe, appropriate housing for persons with HIV disease reduces the physical risk to persons with HIV by reducing the risk of infection. Coupling housing with supportive services helps to reduce cost of institutional medical care. Housing is a prevention strategy for reducing transmission of HIV infection in Minnesota.

"Housing is critical to each of us."

Housing Recommendations:

To improve housing options for persons with HIV disease, the Task Force recommends:

34. That the Housing Finance Agency and other agencies which provide housing, utilize HIV infection as a priority for determining eligibility for their housing assistance programs.

35. That the Housing Finance Agency request that housing for HIV-infected persons be addressed by all housing programs statewide.

    a. Bring together housing funders, administrators, related housing programs, and persons with HIV infection to explore a range of alternative housing options for persons with HIV.

36. That the Departments of Health, Human Services and Corrections and the Housing Finance Agency conduct a feasibility study for a pilot home-based facility, such as adult foster care, for housing hard-to-place homeless persons who are HIV-infected.

37. That HIV service providers and the Housing Finance Agency develop strategies to prevent homelessness among HIV-infected persons including: priority access to low income housing, assistance in locating alternative housing, moving assistance, and crisis prevention.

    a. A listing of housing options and programs be developed and widely distributed, and housing information and referral services at community-based organizations such as the Minnesota AIDS Project be supported.

    b. All HIV service providers assess the housing needs of their clients, including safety, costs, access, and security of the living situation; and provide referrals to programs that offer assistance in locating appropriate housing.

38. That in Greater Minnesota, discharge planning from institutions should include the assessment of housing and supportive services, and assistance in locating short- or long-term housing for persons with HIV infection. As needed, alternative community housing options should be explored and developed; for example, use of hospital or nursing home beds for transitional housing.

V. SUPPORTIVE SERVICES

The supportive services examined by the Task Force include:

A. Informal Caregivers
B. Transportation Services
C. Legal and Financial Services and Discrimination

A. Informal Caregivers

Family, friends, and volunteers who provide assistance with physical, emotional and service needs of persons with HIV.

This section discusses the Task Force's desired outcome for support and services to the informal caregivers of persons with HIV disease, the current status and experience of those citizens, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

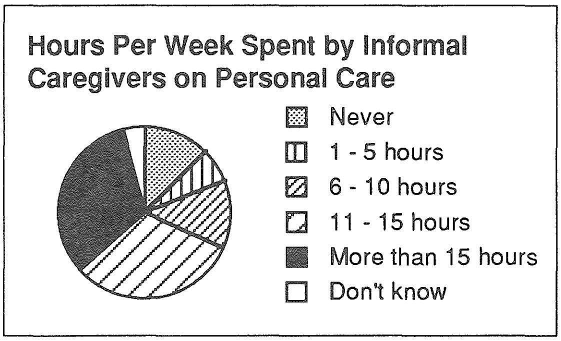
Caregivers should have access to training and ongoing support in order to enable them to meet the physical and emotional needs of their loved ones, and to enhance the use of social and health care systems.

Current Status:

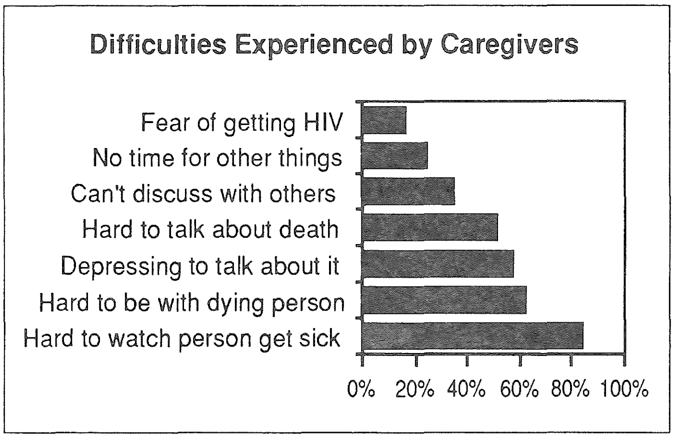
Community-based volunteers, friends, and family are providing an array of services which place complex and taxing demands on nonprofessionals. The intensity of the experience has highlighted specialized education needs documented in interviews with current caregivers.

The informal caregivers interviewed spent hours providing physical care to their loved ones, many on a daily basis:

- 49% of caregivers reported assisting with personal care;
- 57% of the 37 site-based caregiver respondents reported concerns about leaving their family member/friend alone, over 75% said it was because of depression and concerns about suicide attempts;
- 63% reported their family member/friend had problems with thinking, concentrating, or memory;
- 62% of the 29 caregivers who helped with personal care (bathing, meal preparation, and feeding) reported that the emotional stress was the most difficult part of providing that care; and
- 49% of site-based caregivers said they have helped give medications to their family member/ friend in the last three months.


Hours Per Week Spent by Informal Caregivers on Personal Care

Family and friends provide a great deal of emotional support and are themselves in need of assistance in coping with the strain of providing this care. Of the 59 caregivers interviewed:



- All caregivers reported providing emotional support, and 80% said they became emotionally drained themselves caring for their family member/friend;
- 85% of caregivers said they had talked with their loved one about death;
- 71% said they had helped them tell other family members and friends about their illness;
- 38% of site-based caregivers said they have no one they can go to for emotional support;
- 75% said they needed more information about HIV-related services; and
- 70% said they had helped their family member/friend make healthy changes in sexual and chemical use.

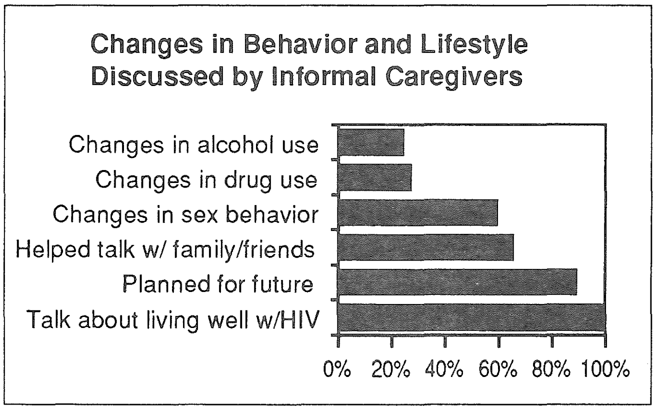
The study and surveillance data also uncovered the unique problems of family members caring for more than one member with this disease:

- 33% of gay men with HIV surveyed said their partner was also HIV-infected; and
- 55% of the state's 22 pediatric cases of HIV are due to perinatal transmission, indicating that the mothers and perhaps fathers of the children are themselves infected.

Subcommittee members and African American caregivers who attended a focus group were concerned about a lack of volunteers from the African American community, the need for more culturally sensitive caregivers, and the increasing "burn-out" among volunteers from the gay community. Subcommittee and focus group members also noted the unique difficulties associated with caring for persons with advanced stages of AIDS. Caregivers need additional training around care issues for women, pediatric HIV, and adolescents.

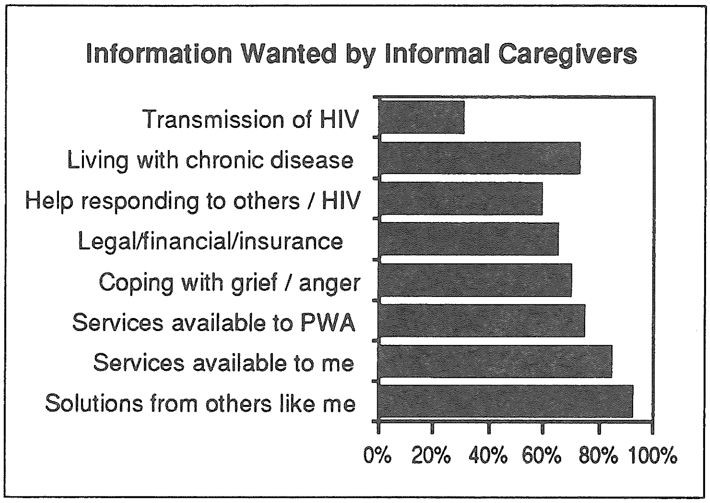
Discussion and Implications:

Persons with HIV, and the health and social services systems, have relied on volunteers and family members to provide a wide array of personal care and supportive services, including transportation, physical care, emotional support, and assistance in making changes involving sexual and chemical use behaviors. These family members and community volunteers are also called upon to assist in educating their loved one about the medical aspects of HIV, and in locating appropriate social and medical services to meet their needs.



Costs of caring for persons with HIV infection would be far greater without the assistance of uncompensated informal caregivers. These members of the community fill the gaps in transportation, home health and personal care, meals preparation, and a host of other services. They often fill a case management role, helping loved ones find and keep needed social and medical services. For many individuals, caregivers act as a link between the medical care team and the person with

HIV, by assisting with medications, consulting the nurse or physician by phone, and attending medical appointments with their loved ones. The costs of these services are not calculated when determining the costs of care associated with HIV.



Besides the physical aspect of providing support and care, family members, friends, and volunteers are a vital emotional support for many persons with HIV. Caregivers help persons with HIV make needed changes in lifestyle; changes which can improve the health of the individual, such as improved diet; and changes which can reduce transmission of the virus, such as locating a treatment center and encouraging safer sexual practices.

The services caregivers provide are complex, time consuming, physically tiring, and emotionally exhausting. More volunteers are needed to meet the increasing numbers of individuals with HIV who have little or no family support, and from communities who are seeing an increasing number of their members in need, especially the African American community.

Assistance from informal caregivers increases the ability of persons with HIV infection to live safely within a home setting and decreases reliance on high cost institutional care. Caregivers provide important physical and emotional support; and support to make behavioral changes which can decrease transmission of HIV, and enhance the physical and mental health of the individual. Services need to be in place which support the ability of these informal caregivers to assist persons with HIV disease.

> ***"I'm rewarded by giving help,***
> ***it's personally satisfactory.***
> ***Nurses that come by reassure me***
> ***that everything is okay.***
> ***That makes me feel better."***

Informal Caregivers Recommendations:

To enhance the ability of informal caregivers to meet unmet needs of family members and friends with HIV disease, the Task Force recommends:

39. That the informal caregivers to persons with HIV infection have access to comprehensive training on issues of health care, emotional support, legal rights, financial concerns, and community resources.

    a. Encourage community-based organizations with established volunteer training programs such as the Red Cross and Minnesota AIDS Project to expand training for family caregivers and community volunteers, especially in communities of color and other hard-to-reach populations.

    b. Encourage public health nurses, Community Health Boards, and home health care agencies to provide enhanced training on health care issues to family caregivers.

    c. Encourage physicians, health care staff, and case managers to refer and encourage caregivers to attend training programs and support groups specifically for caregivers of persons with HIV.

40. That the Department of Human Services explore methods to reimburse family caregivers who provide full-time care to persons with HIV infection for the in-home care they provide.

41. That the Department of Human Services explore methods to expand in-home and community-based respite care options and funding for persons with HIV infection.

42. That the Department of Commerce examine minimum coverage requirements to assure that caregivers of persons with HIV have unlimited and ongoing access to individual and group therapy during times of caregiving, and in the bereavement process.

B. Transportation Services

> Low-cost or volunteer-provided transportation to medical appointments, recreational programs, and support groups.
>
> This section discusses the Task Force's desired outcome for transportation services for persons with HIV disease, the current status and experience of those citizens, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Persons with HIV infection should have access to transportation programs that enable them to fully participate in medical care, support groups, and recreational activities.

Current Status:

The financial and physical toll of HIV infection makes transportation a problem for many Minnesotans with HIV disease. The study of Minnesotans infected with HIV showed:

- 29% of all persons interviewed said they needed help with transportation in the past three months;
- 62% of them said money is a barrier in obtaining transportation; and
- 29% said physical reasons prevent them from driving.

29% of those surveyed needed help with transportation.

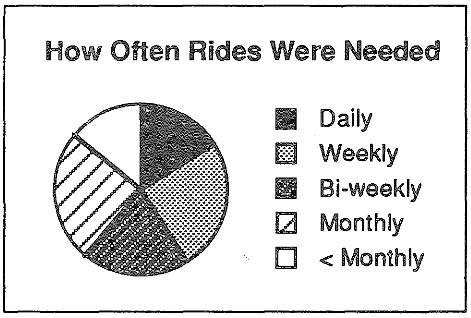
73% relied on family and friends for assistance .

Transportation is a fundamental need for many individuals, and it is a need met most often by informal caregivers:

- 40% of those who needed help with transportation said they needed a ride weekly or more often;
- 73% of site-based survey respondents said they received rides from family or friends;
- 40% said they had a ride from an AIDS service organization during this time period;
- 63% of all caregivers said they had helped with rides to appointments; with both financial and physical reasons cited as reasons for providing assistance; and
- 32% of all caregivers said they had made trips to the pharmacy to obtain medications.

A ramification of a lack of transportation assistance is the loss of other needed care and services:

- 32% of all respondents who needed transportation said they had trouble getting rides at the times needed;
- For persons in the site-based survey, 84% of those who needed transportation said it was for a medical appointment;
- 60% said it was for grocery shopping or laundry needs.
- 7 persons (4%) in the site-based survey said they had missed a medical appointment in the last three months because they were unable to get transportation; and
- Of the 58 persons who said they no longer attended a support group, 22% said it was because it was too hard to get to the meeting.



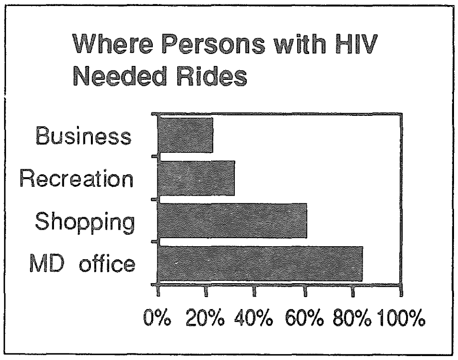
HIV-related symptoms also play a part in transportation difficulties:

- 71% of all respondents said they had problems with fatigue in the last three months;
- 49% said they had problems with thinking, concentrating, or memory; and
- 26% said they had eye trouble, including pain or change in vision in the last three months.

Discussion and Implications:

As a person with HIV becomes more debilitated, their ability to complete normal activities of daily living, including driving or using public transportation, is decreased. For those interviewed in the studies, transportation problems were the result of the two intertwined issues of physical health problems and lack of money.

The primary need for transportation was for medical care appointments and other HIV-related service needs with many persons needing rides on a frequent basis. Family and friends provide a great deal of assistance in this area, but without the availability of additional resources, persons with HIV have difficulty keeping necessary appointments thus jeopardizing their health.


Where Persons with HIV Needed Rides

Persons living in Greater Minnesota travel long distances to receive medical care and to attend support groups, even without traveling to the metropolitan area. Unique difficulties for these persons include: finding volunteer drivers who can take time off from work and the occasional need to spend the night in other cities. In the metro area, services between St. Paul and Minneapolis are also hard to access.

An HIV-infected person who is unable to keep medical appointments, attend support groups, and get groceries will more likely have decreased health status; requiring more intensive health and medical care at an earlier stage than someone who is better supported. Access to reliable transportation also assures better compliance with medical treatment.

Behavior change that prevents transmission of HIV is both complex and long-term. Frustrations raised by the inability to have needs met, such as transportation to medical appointments, add to the emotional stress of persons living with HIV. Maintaining sobriety and safer sex changes is strained by these frustrations.

Persons with HIV infection have a range of transportation needs. To maintain physical health, they need rides to medical appointments and pharmacies. Of equal importance to maintaining wellness is the ability to participate in chemical dependency programs, recreational events; and support groups. Without transportation assistance, persons with HIV infection may become more isolated and unable to independently care for themselves.

> *"Anything over a block, I need help getting to - no matter what it is."*

Transportation Services Recommendations:

To increase the ability of persons with HIV disease to receive health and social services by increasing access to transportation, the Task Force recommends:

43. That the Department of Health work with community-based organizations, government programs, and social service agencies which provide transportation services to increase collaboration to improve and expand services for persons with HIV disease.

    a. Ask groups such as the St. Paul Red Cross AIDS Transportation Working Group and AIDS service organizations to compile and publicize eligibility and access information for existing transportation services through Medical Assistance, Metro-Mobility, Limited Mobility, AIDS service organizations, Red Cross, and other related transportation programs to persons living with HIV infection, caregivers, and providers.

    b. Evaluate the transportation system for gaps in the above system in providing rides for medical, social, support, and recreational transportation needs.

    c. Encourage existing transportation services to expand their services to meet the medical, social, support, and recreational transportation needs of persons with HIV disease; and encourage financial support to organizations to provide those transportation services.

    d. Examine and distribute results of the Ramsey County pilot programs of Medical Assistance transportation and the St. Paul - Ramsey Medical Center Nurse Line on transportation needs of persons with HIV in Ramsey County for possible application to other areas of the state.

    e. Encourage the American Cancer Society to investigate the possibility of expanding its transportation model to persons with HIV disease.

    f. Encourage religious groups such as the Minnesota Council of Churches to encourage its members' transportation committees to provide services to persons with HIV infection.

C. Legal Services, Financial Planning and Discrimination:

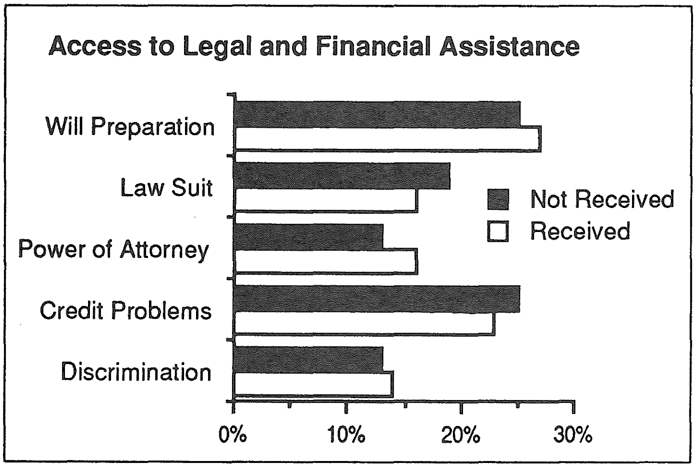
> Assistance with will and estate preparation, power of attorney, family law, financial planning, and discrimination issues.
>
> This section discusses the Task Force's desired outcome for legal and financial planning services for persons with HIV disease, a discussion of discrimination against persons with HIV, the current status and experience of citizens seeking these services, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

To successfully deal with the complex legal, financial, and discrimination issues surrounding AIDS, persons with HIV should have access to ongoing financial and legal advice.

Current Status:

Many Minnesotans living with HIV infection have a high need for legal and financial advice, but are often unable to receive the assistance they need:


Access to Legal and Financial Assistance

- 46% of the site-based survey respondents said they needed legal or financial advice in the last three months but had difficulty getting such assistance;
- Of the 40 persons who needed help with will preparation, only 21 said they were able to get help;
- Of the 22 who needed help with power of attorney, only 12 said they were able to get help; and
- Of the 37 who needed assistance with credit or bill problems, only 18 said they were able to get help.

Difficulties accessing government programs and problems with insurance claims were also described by respondents:

- Of the 119 respondents to both surveys who had private health insurance at the time of diagnosis, 40 (34%) said they had since lost this coverage;
- 8 individuals said their insurance company dropped them;
- 10% of site-based respondents said they had applied for social security but their application was denied; and
- 20% of site-based respondents said they had to fight to get medications or medical procedures covered by their insurance company.

22% of site-based respondents felt they had been discriminated against by being denied the quality of care they deserved.

The survey of HIV-infected Minnesotans also uncovered a pattern of discrimination, based on both the HIV status of the respondents and on sexual orientation.

"When I first moved into a building, the residents started a petition against persons with AIDS living there."

Individuals in the study were often unable to distinguish if the discrimination they faced was based on their sexual orientation or their HIV status:

- 22% of site-based respondents said they had problems with discrimination, particularly in access to services, housing issues, and financial programs;
- 87% of these persons said they believed discrimination resulted from HIV status; and
- 55% said they believed sexual orientation was also a factor.

Continued institutional and societal discrimination against gay and lesbian people also influenced the ability of HIV-infected individuals to seek out needed medical and social services or support from family and friends. Focus group members who were heterosexual noted that they were afraid to seek services for fear of being labeled as homosexual. For caregivers, disclosing their association with someone with HIV also meant risking judgement and discrimination.

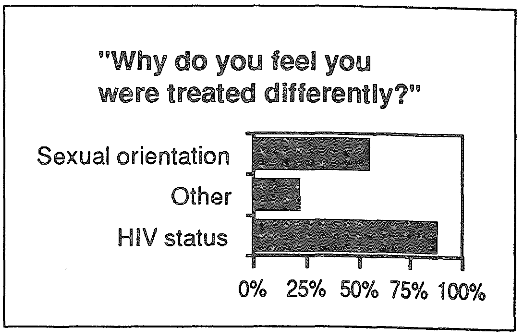
Subcommittees and focus group members noted that, for families, legal services are an increasing need, and may include such complex areas as guardianship and child custody.

"In dealing with my son's illness I had to 'come out' too."

Discussion and Implications:

Minnesotans with HIV infection need professional financial and legal advice to cope with the changes in their income caused by living with a devastating illness, the unique legal aspects of AIDS, such as wills and power of attorney, and with discrimination which still faces persons with HIV disease.

Stigma associated with HIV/AIDS prevents persons from asking for assistance and providers from freely offering services in the same way as for other diseases. Gay men, who remain the majority of AIDS and HIV cases reported in the state, face an additional barrier to services based on their sexual orientation. The data, as well as comments from focus group members, indicate that discrimination against HIV-infected persons is based on sexual orientation as well as disability. Persons with HIV are protected from discrimination by the Americans with Disabilities Act. Gay men and lesbians, however, have no similar level of protection under state or federal law. For this reason it is impossible in many cases to distinguish among causes of discrimination. Discrimination against HIV-infected individuals because they are gay or lesbian negatively impacts their health because it decreases the ability of HIV-infected individuals to access needed services.


"Why do you feel you were treated differently?"

Persons with HIV also have unique life planning and decision making issues. Living wills, will preparation, and power of attorney, are not usually dealt with by someone who is in their twenties or thirties. With the recent Supreme Court decisions regarding termination of life support, and under Minnesota's current system persons with HIV infection need a living will to provide guidance about their wishes to their providers. Persons suffering from AIDS-related dementia need power of attorney. Estate planning and will preparation are also common service needs which are currently not being met, and are made more important if the individual in question is a gay man or lesbian in a committed partnership. Unless available and accessible financial and legal advice is provided to persons with HIV, society will face difficult ethical decisions about the care and needs of persons with AIDS.

"It's not easy to be picked out as Gay, a PWA, Jewish - they are all so assimilated. But as an African American, I can't hide."

By virtue of declining health and changes in employment and income, persons with HIV also face problems with creditors.

Persons with HIV infection in Minnesota continue to face discrimination and continue to be denied access to chemical dependency programs, housing, dental care, and a variety of other services. Denial of these services has severe consequences in terms of the health of the individual and the cost to society.

If an individual cannot access chemical dependency treatment, they are at risk for continuing behaviors which can transmit HIV. If they lose their housing, illustrated by the experience of homeless persons with HIV, they likewise face increased risk for illness, and difficulty with behavior change. The atmosphere of discrimination has made it more difficult for HIV-infected persons to confide in their health care providers, employers, and family members. The stress of revealing or hiding their HIV status places individuals at increased risk for mental health problems.

Changes in HIV transmission behavior is more difficult to initiate and maintain if stress and worries are not reduced. Most respondents indicate a high level of stress and financial pressures. Access to comprehensive legal financial services is needed to support complex lifestyle changes.

Persons with HIV infection need ongoing access to professional legal and financial services, which can assist them in decision making and planning. Access to these services can forestall financial crisis, assist with accessing and successfully working with the disability application process and claims processing by private insurance, and decrease discrimination against persons with HIV.

"If you have money, and you look right, you get services."

"Insured, white, middle class professionals who speak English do better."

Legal Services, Financial Planning, and Discrimination Recommendations:

To enhance the ability of persons with HIV disease to meet their need for legal and financial management, the Task Force recommends:

44. That the legal foundations and private legal sector fund legal services for persons with HIV disease.

45. That community-based organizations strengthen relationships with the legal community to increase statewide access to legal services and advocacy for families and individuals dealing with AIDS including: assistance with entitlement and insurance appeals, immigration law, discrimination, and credit problems.

    a. Support the continuation of the volunteer attorney programs of community-based organizations such as the Minnesota AIDS Project and Chrysalis, and encourage lawyers to participate in the program.

    b. Encourage legal assistance programs such as Legal Services, Legal Aid, the State Bar, mediation programs, county attorneys, and County Attorney Associations statewide to conduct updated training on HIV issues including: legal rights and issues for persons with HIV, local resources for referral, and cultural and psychosocial issues.

46. That financial planning assistance programs be developed at community-based organizations which serve persons with HIV disease.

To reduce discrimination against persons with HIV disease in Minnesota, and to reduce the barriers for persons with HIV disease seeking support and health services, the Task Force recommends:

47. That the Department of Health support the repeal of laws which encourage an atmosphere of discrimination based on sexual orientation.

    a. Applaud Governor Carlson for renewing the Executive Order protecting state employees on the basis of sexual orientation.

    b. Amend Minnesota's human rights statute to include sexual orientation as a protected class.

48. That the Department of Human Rights increase its activities to protect and further the rights of Minnesotans with HIV infection.

    a. Work in concert with community-based organizations to repeal Minnesota statutes which criminalize adult consensual sexual activity.

    b. Work in concert with community-based organizations to assist persons with HIV infection in knowing and asserting their legal rights in the workplace and in society.

    c. Increase public awareness of federal and state antidiscrimination laws and procedures for recourse, and provide information on how to make a discrimination claim to all persons with HIV infection and all persons seeking services. Non-discrimination disclaimers should include the words "HIV disease or AIDS and sexual orientation" where enforceable.

VI. CASE MANAGEMENT SERVICES

Coordination, monitoring, and advocacy services designed to provide the most optimal use of social, nursing, and medical and support services by a person with HIV disease. Information about HIV disease and services, referral and follow-up to needed services and programs.

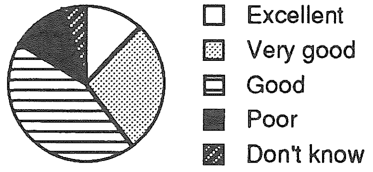
This section discusses the Task Force's desired outcome for case management services for persons with HIV disease, the current status and experience of persons seeking and receiving those services, a summary statement of need, and recommendations to achieve the desired outcome.

Desired Outcome:

Persons with HIV infection should be offered assistance in identifying their health, social, and emotional needs and be supported in accessing, using, and coordinating appropriate, community-based services.

Current Status:

The study of Minnesotans showed that, for some Minnesotans with HIV, the physical effects of the disease has a direct effect on their ability to locate, access, and coordinate needed health and social services:



Minnesotans with HIV Rate the Social Services System

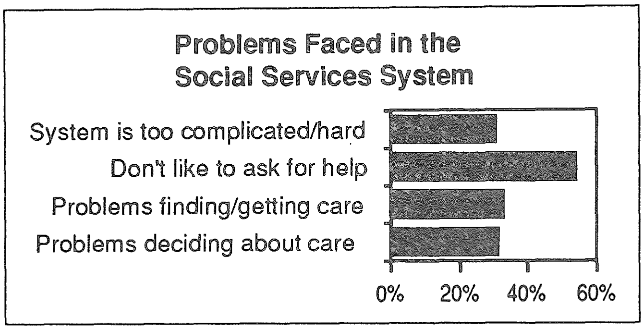
- 75% of site-based respondents and 61% of target survey respondents sad fatigue has been a problem in the last three months;
- 49% of site-based respondents and 28% of target survey respondents said they have had trouble with thinking, concentrating, or memory in the last three months; and
- 16% of site-based respondents said they have missed a scheduled health care appointment in the last three months because they forgot about the appointment.

Adjusting to a chronic illness also means learning to access a complex system of care:

- 31% of site-based respondents said they had problems deciding about the services they need; and
- 33% reported problems finding and getting the services they need.

In response to a general question about services, 31% said they agree or strongly agree with the statement that most people with HIV in Minnesota have trouble getting the medical or health care services they need. Among those services most difficult for site-based respondents to locate or access were:

- 31% of site-based respondents said the forms for insurance or paying for their medical care are hard to understand and take too much time to complete;
- 4 of the 14 site-based persons who needed chemical dependency services in the last three months said they were unable to get assistance;
- 20 of the 37 who said they had trouble finding a place to live said they had trouble getting help to find a place to live; and
- Half of the 77 persons who said they needed legal or financial advice in the last three months said they were unable to get the help they needed.


Problems Faced in the Social Services System

For target populations (communities of color, women and the homeless), primary health care and mental health services were among the most difficult to find:

- 6 of the 60 target respondents said chemical dependency services were difficult for them to locate; and
- 10 of the 69 target respondents said both physician visits and counseling services have been difficult to obtain.

Persons with HIV have to confront a range of barriers when accessing services, from a reluctance to ask for assistance to fear of being identified as a person with HIV:

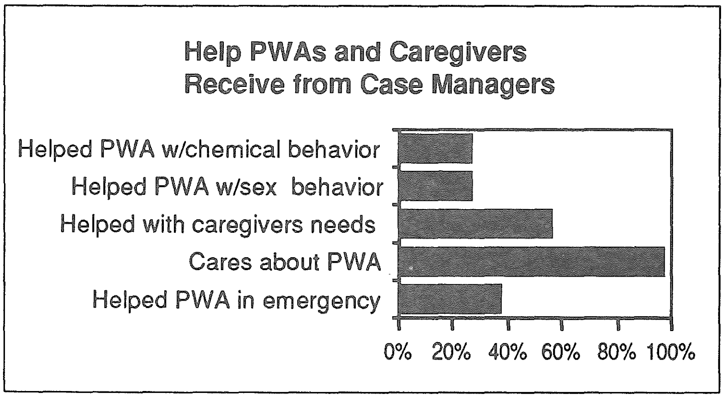
- 54% of site-based respondents said they don't like to ask for help;
- 30% said the system is too complicated and it is hard to get help;
- 28% said they have had to go from one agency to another to get help;
- 28% said they have tried to get help in the past, but it didn't work; and
- 20% said they were reluctant to seek help because of confidentiality.

> *"I've learned a lot about accessing service systems. They are out there, but you have to know how to utilize them."*

The study also indicated that some individuals have difficulties planning for their needs after discharge from the hospital. Of the 40 site-based respondents who were hospitalized in the last three months, six said the hospital did not help them plan for their needs upon discharge, and two others said they don't know if they got this help. Of the 13 target survey respondents who were hospitalized during this time period, 6 said the hospital did not help plan for needs when discharged and two said they went to a temporary shelter when released.

For the majority of persons living with HIV infection, case management is an integral part of their care and is seen as very helpful. Characteristics and assistance provided by the case manager for site-based respondents include the following:

- 70% said they had at least one case manager or advocate; 86% of which are HIV specific case managers;
- 69% of those who have a case manager said they see that person monthly or more often;
- 85% said the case manager cares about them;
- 77% said the case manager knows about all the services being received;
- 68% said the case manager has helped a lot to get benefits and services; and
- 50% said the case manager has helped in an emergency.


Help PWAs and Caregivers Receive from Case Managers

Case managers also assist persons in making needed behavioral changes:

- 22% of those using drugs and/or alcohol said their case manager has been helpful to them as they've thought about making changes in their chemical use; and
- 23% of site-based respondents said their case manager was helpful in making sexual behavior changes.

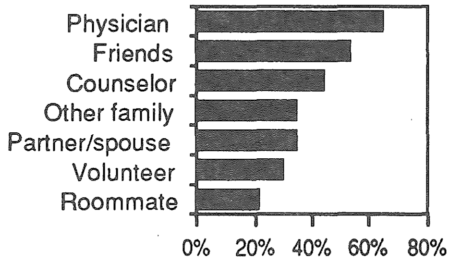
Beside formal case managers, most persons with HIV also receive informal assistance in finding services from a variety of professionals, friends, and family:

- 64% said their physician has helped;
- 53% said friends have helped;
- 44% said a counselor or therapist have helped; and
- 34% said family members have helped find services.

Coordination of the individuals involved in assisting persons with HIV find and access services, however, is a problem:

- 40% of those who have assistance of one or more helpers said they don't think the different persons are talking with each other about coordinating care and services.

Others Helping to Find and Get Services



Some persons with HIV infection reported they have little or no support system:

- 7% of site-based respondents said they have no family members or friends they can talk to about their personal feelings and problems; and
- 28% of respondents said they talked to these family members or friends less than twice in the last month.

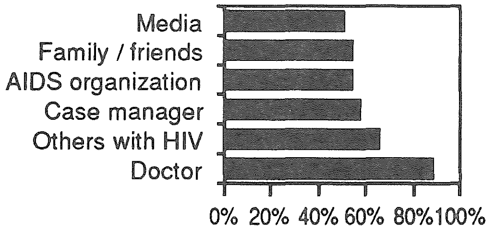
For individuals without a strong informal support system, the support of a volunteer may be crucial:

- 28 respondents said they have a buddy; and
- 82% said this person is somewhat or very important to their quality of life.

Persons with HIV receive information about HIV services from a variety of sources:

- 66% said they learn about HIV services from other persons with HIV;
- 57% said a case manager provides information about services;
- 54% said friends or family are helpful in this area; and
- 54% said an AIDS service organization has given them information.

Where Respondents Learn About HIV Services



Caregivers to persons with HIV also report needs for finding and coordinating services, the importance of assistance provided by professionals, and the need for more information about services available both to them and to their loved one:

- 41% of caregivers said they had called the physician to get help in arranging for services;
- 56% of caregivers of persons with a case manager said the case manager has helped meet their needs too;
- 75% of site-based caregivers and 45% of focus group caregivers said they wanted to learn more about services available to their family member or friend; and
- 84% of site-based caregivers and 36% of focus group caregivers said they wanted to know more about services available to them.

18% of site-based respondents said they know little or nothing about services available to them.

> *"I wish there was more help out there to help people find day care. If I don't tell anyone, and something happens to my son, am I going to be legally liable? It is just one big vicious circle."*

Many caregivers, however, struggled to provide emotional and physical support to their loved one in isolation, and may have health problems themselves:

- 35% of site-based caregivers said they have no one providing emotional support to them as they care for their family member/friend; and
- 32% of caregivers said their health problems included chronic fatigue or weakness.

As noted previously, the study showed that information about available services does not always reach those who need it, with one third of respondents saying they had problems finding and getting the services they needed. In addition:

- 36% of site-based respondents said they have little or no interaction with other persons with HIV infection, cited as a primary source of information about HIV services by survey respondents; and
- 18% of site-based respondents said they know nothing or not very much about services available to them, with an additional 43% saying they know only some about services.

Focus group members in particular spoke of the need for a single referral source, able to give information on medical and social services, alternative therapies and care, support groups, available financial assistance programs, and help with red tape.

Discussion and Implications:

Minnesota's health and social service system is complex, making locating and accessing appropriate assistance frustrating and difficult. Without the assistance of a case manager or access to an information and referral system, persons with HIV disease will be unable to maximize their use of services which can improve their health and well-being.

Providers who have no means of communicating effectively with each other are more likely to provide uncoordinated and overlapping care. Without assistance, persons with HIV are placed in the position of coordinating their own care while coping with symptoms of their disease including fatigue and memory problems. A case manager can reduce frustrations, help the client develop a coordinated system of care, and address problems of duplication and gaps in services.

A person who has to spend a disproportionate amount of time finding and coordinating services will not be able to spend that time learning new behaviors and lifestyles. Preventing HIV transmission is a lifelong effort that needs many levels of support, including that of the case manager.

As HIV-related services in Minnesota expand to meet growing needs and changing populations, the information and referral system in place must expand as well. Increasing medical and alternative care options; services geared to specific age, geographic, and ethnic groups; and changes in program personnel strain the current system. Information and referral needs of adolescents stretch beyond the specific concerns around HIV. Finally, care providers in Greater Minnesota are in need of a service which provides confidential support and information. Gay men and lesbians need referral to gay-sensitive services.

Case management is particularly applicable to persons with HIV infection, whose needs change often, and whose support systems and living situations are likely to be inadequate or stressed. When provided in a coordinated manner, case management allows for the optimal use of community-based, public and private services in a nonduplicated and cost-effective manner. Access to training and a comprehensive resource and referral source can assist persons with HIV infection to better manage their own care.

Case Management Recommendations:

To improve the ability of persons with HIV disease and HIV-related providers to access services, the Task Force recommends:

49. That community-based organizations and providers strengthen programs which enable persons with HIV disease to coordinate their own care and services while providing individual health care management, education, and advocacy.

50. That the Department of Health oversee efforts to evaluate and strengthen the information and referral component of the AIDSLine to provide regularly updated information on medical treatments for HIV, clinical trials, and alternative services; resources specific to the needs of persons of color, different age groups, and geographic locations; and a system to provide follow-up.

To strengthen and better coordinate the case management services available to persons with HIV disease in Minnesota, the Task Force recommends:

51. That the Department of Health, Department of Human Services, and agencies which provide HIV case management services develop and distribute a comprehensive guide to HIV case management services which includes: informed consent and materials describing the range of case management alternatives available in Minnesota to all current and potential case management clients.

52. That the Department of Health and the Department of Human Services develop guidelines for the coordination of their programs that describe: point of entry for case management and methods for coordination of multiple case managers for individuals and families.

53. That Department of Health and the Department of Human Services work together toward a goal of consolidating their HIV case management programs.

54. That Department of Health and the Department of Human Services convene all providers of case management programs to increase cooperation and coordination, emphasizing coordination of strategies, consensus building, development and sharing of resources, and the special needs of unique communities.

VII. FINANCIAL ISSUES

The financial issues examined by the Task Force include:

A. Financial Assistance Programs, including government and community-based financial aid, emergency needs, or entitlement programs; and
B. Payment for Services, including insurance, HMO coverage, and Medical Assistance.

A. Financial Assistance Programs

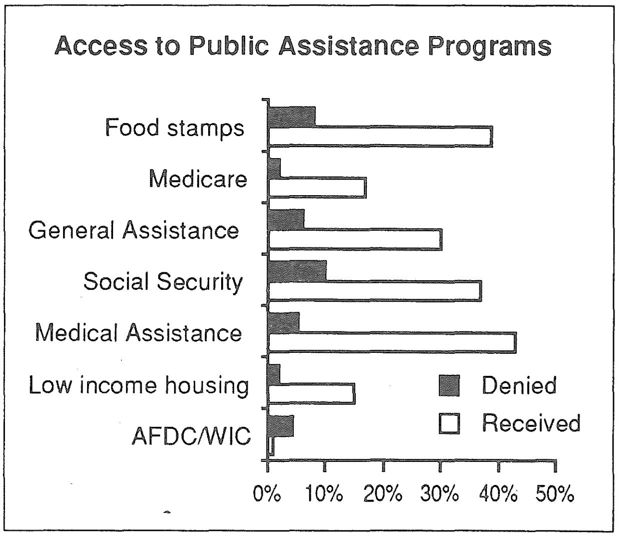
> Government financial assistance programs such as Food Stamps, Social Security Disability Insurance, General Assistance, WIC, AFDC, and Social Security Supplemental Income. Private assistance programs such as food shelves and emergency financial or material assistance programs.
>
> This section discusses the Task Force's desired outcome for government and private financial and emergency assistance for persons with HIV infection, the current status and experience of citizens with HIV seeking these services in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Because of the debilitating effects of HIV/AIDS, many infected persons will not be able to provide financially for themselves. Persons with HIV infection should have easy access to programs which support the health and welfare of the individual.

Current Status:

The study of Minnesotans with HIV disease illustrated the degree of poverty faced by persons living with this disease. Of the site-based respondents:



- 50% said they were not currently working;
- 38% made less than $500 per month ($6,000 per year before taxes);
- 51% said they made between $500 and $2,000 per month ($6,000 - $24,000 per year); and
- 11% said they made more than $2,000 per month.

The majority of these individuals said they were *not* able to rely on a partner or spouse for financial support, as 68% do not have an employed partner or spouse.

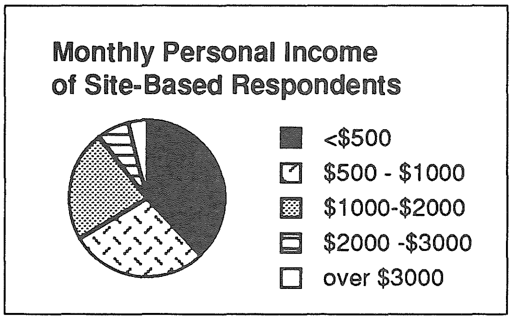
To survive, these individuals relied on family, friends, public, and volunteer assistance programs:

> *"We need a program so people can get enough money to survive."*

- 99% said they regularly get food, clothes, or other necessities from family, friends, or a volunteer agency;
- 20% said they had received more than $100 from family or friends in the past three months;
- 37% said they said they received social security benefits; 10% had been denied;
- 30% said they said they had received General Assistance; 6% had been denied; and
- 15% said they live in low income housing.

Poverty has had a direct effect on the ability of Minnesotans with HIV disease to access services:

- 21% of site-based respondents said they had lost housing because of money;
- 9 of 20 persons who had trouble finding a place to live said they could not afford a place to live;
- 32 of the 49 (65%) persons who needed help with transportation said it was because they can no longer afford a car;
- 9 of the 40 (23%) persons who needed housekeeping could not afford the help needed; and
- 21% of respondents had used a food shelf.


Monthly Personal Income of Site-Based Respondents

Persons reached through the target survey reported even greater financial difficulties:

- 65% reported a yearly gross income of less than $10,000;
- 29% reported a yearly gross income of between $10,000 and $25,000;
- 20% of respondents said medications were too expensive;
- 9 of respondents said they were homeless; and
- 10 of 17 said they had trouble finding housing because of cost.

Caregivers have been providing a safety net for their loved ones, supporting them financially, and meeting their transportation and service needs. Caregivers, however, said they need more information about programs which can help them provide for their family members/friends, and more than one-third said helping out has placed a financial strain on their lives:

- 38% of caregivers said they had loaned or given more than $100;
- 46% said they had paid for bills with their money;
- 16% said they had helped pay for medications;
- 14% said they had helped financially with housing in the past three months;
- 36% of those who had helped said they can't really afford to help out;
- 30% said financial help was hard to find or get for their family member/friend; and
- 65% of caregivers said they would like information about legal, financial, or insurance issues.

Caregivers who participated in a focus group had similar concerns for their family member/friend and for themselves:

- 8 of 22 (36%) said the medicine was too expensive;
- 15 of 22 (68%) said financial help has been difficult to obtain;
- 11 of 22 (50%) said they wanted information about legal, financial, and/or insurance issues;
- 6 of 22 (27%) said they had loaned more than $100; and
- 8 of 22 (36%) said providing assistance to their family member/friend cost a lot of money.

> *"I have so little money for gas that I have to choose between going to a doctor's appointment and going to a support group."*

Focus group members spoke often of the difficulty of surviving on General Assistance, the exhausting and frustrating degree of paperwork required by government programs, and the debilitating effect the stress of poverty had on their physical and mental health.

Discussion and Implications:

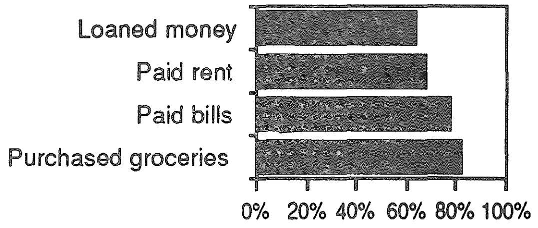
HIV disease presents unique challenges to the welfare delivery system. HIV financially devastates nearly all it touches. It is an unpredictable disease, making an individual's ability to work fluctuate over time. People living with HIV infection may be more debilitated than those persons who have been diagnosed with AIDS, and yet be unable to qualify for many assistance programs. Public assistance programs only provide for a minimal income, requiring persons with HIV to rely on family, friends, and community-based organizations for survival. Finally, HIV disease causes physical and neurological complications, which make paperwork and the complexity of the system even more difficult to negotiate.

For those receiving assistance, the amount of financial aid is making it difficult to manage their care. The wait between application and arrival of support can cause a delay in services. Food stamps and WIC do not meet the needs of a special high protein diet required by persons with HIV.

Without access to financial assistance and other support programs, persons with HIV infection will suffer from greater levels of disease, spend more time in acute care facilities, suffer greater mental anguish, and will be at increased risk for chemical dependency.

The poverty of persons with HIV also impacts the financial health of the state. Without access to financial and material support, persons with HIV infection can be expected to rely more on emergency services, require a greater degree of institutional care, and more emergency financial assistance.

Financial Assistance Received from Informal Caregivers



Finally, improving the financial status and thus access to health care can be expected to have a positive effect on rates of HIV transmission in Minnesota. Individuals without access to financial assistance are also unlikely to access programs and professionals which can help them with needed changes in their sexual and drug use behaviors. By supporting the health of persons with HIV infection, Minnesota supports their ability to change behaviors.

The financial and physical devastation facing Minnesotans with HIV requires an increased public response. Financial assistance programs, community-based organizations, churches, food shelves, and government all share in a responsibility to provide a standard of care and support for those suffering from this disease, and the poverty it so often brings. Providing financial and material supports will improve the health and welfare of Minnesotans with HIV disease.

> ***"I wouldn't create a new service -***
> ***I would just make what is current here more efficient to the client.***
> ***There's massive amounts of red tape.***
> ***The guy's half dead as it is and has to run around getting papers."***

Financial Assistance Program Recommendations:

To improve awareness of, and access to, publicly-funded assistance programs by persons with HIV disease, the Task Force recommends:

55. That the Department of Human Services and county social service agencies work with HIV-infected individuals, staff, caregivers, and volunteers of agencies serving communities affected by HIV to improve their ability to successfully access and negotiate the public welfare system.

    a. Recruit volunteers who are able to assist persons with HIV to access the system; offer an "application class" for persons with HIV and their caregivers entering the government entitlement and eligibility system.

    b. Ask the Department of Human Services and county social service offices to fund and provide outreach efforts consistent with the Budget Reconciliation Act, Section 4602, which calls for improved and expanded outreach for financial assistance programs.

    c. Ask the Department of Human Services and the Department of Corrections to investigate methods to improve the financial application process for HIV-infected individuals leaving corrections facilities.

56. That the Department of Human Services study and document the need for improved access to Social Security Administration benefits; devise innovative methods to improve access to those programs by documenting the need for and encouraging the SSA to expand benefits to include persons with disabling HIV illness; to expedite handling of claims by persons with AIDS; and to accelerate the review process by removing the reconsideration phase.

57. That the Department of Human Services encourage the Social Security Administration to waive the two-year waiting period for Medicare benefits for persons with AIDS.

To encourage persons with HIV disease to return or remain in the work force while maintaining health care coverage, the Task Force recommends:

58. That the Department of Human Services develop a pilot program which allows persons to receive a greater degree of outside earned income while preserving Medical Assistance benefits, and encourage the Social Security Administration to allow persons with HIV to earn a degree of outside income without jeopardizing their benefits.

To increase the ability of persons with HIV disease to meet their financial and material needs, the Task Force recommends:

59. That private foundations, nonprofit organizations, churches, civic groups, and businesses encourage financial and volunteer donations to assistance programs which meet the needs of persons with HIV, including emergency financial programs, food shelves, meal programs, and volunteer programs.

60. That the Department of Human Services increase the food stamp subsidy to a level which is responsive to the high nutritional needs of persons with HIV.

B. Payment for Health Care Services

Private insurance coverage, including health maintenance organizations (HMO), Medical Assistance, and assistance with paying premiums for health care coverage.

This section discusses the Task Force's desired outcome for payment and coverage for the health care services used by persons with HIV infection, the current status and experience of citizens with HIV seeking health care coverage in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Insured Minnesotans with HIV infection should continue to have access to insurance coverage and Medical Assistance which fully meets their ongoing needs for complete physical and mental health care and chemical dependency service needs.

Current Status:

The study of HIV-infected Minnesotans illustrated the importance of health care coverage to persons with HIV, and the problems persons with HIV have in accessing and maintaining insurance coverage:

- 56% of site-based respondents said they had insurance at the time they learned of their infection; and
- 31 of 94 (33%) of those who had insurance said they have lost it since they found out they were infected, primarily because they lost their job and thus their insurance coverage.

The physical complications of HIV and continued discrimination against persons with HIV disease, however, leads to access problems even for those with third party coverage:

56% of respondents had health insurance at the time of their diagnosis.

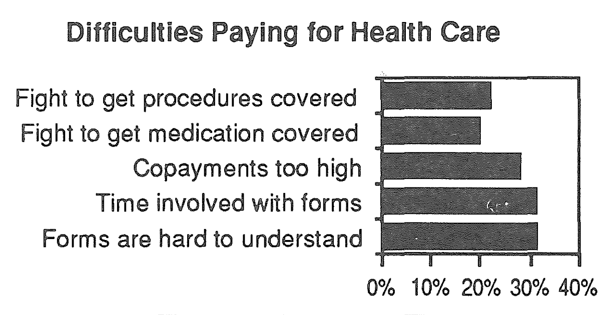
33% have lost their coverage since learning of their HIV infection

- 45% said they currently have coverage from private insurance or an HMO;
- 53% reported a government-paid health care plan including Medical Assistance, Medicare, General Assistance Medical Care, or Veteran's benefits;
- 31% said the forms for applying for assistance or insurance coverage are hard to understand or take too much time to complete; and
- 37% of those who have insurance coverage said they are afraid to make an AIDS-related claim on their insurance.

Focus group members stated that the paperwork required to receive Medical Assistance and other forms of government assistance is overwhelming to many.

For individuals with insurance policies, those on Medical Assistance, and persons who are uninsured, cost remains a factor in accessing needed care:

- 21% said medical care is hard to afford;
- 7% said they are not taking AZT because it is too expensive;
- 7% said they are not taking pentamidine because it is too expensive;
- 16% of those who needed home health care said it is too expensive;


Difficulties Paying for Health Care

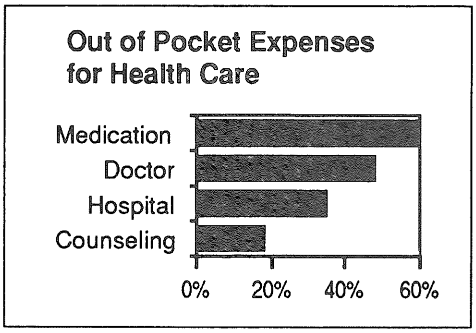
37% of those with health insurance are afraid to make HIV-related claims on their coverage.

- 28% of those who needed and got dental care said it is too expensive;
- 1 of the 4 persons who was not able to get chemical dependency treatment said it was because they could not afford the help; and
- 25% of those who have had counseling in the last three months said they could not afford the counseling.

Persons with HIV infection are also paying for a percentage of their medical care out of pocket:

- 59% said they often paid out-of-pocket for prescription drugs;
- 35% said they pay for a percentage of their hospital care; and
- 48% said they have paid for doctor's bills.

A lack of insurance of any kind leads to an increase in use of emergency room care:



- 43% of all respondents said they did *not* have health insurance at the time they learned of their HIV status;
- 64% of hard-to-reach persons surveyed said they had no form of health insurance at the time of diagnosis;
- 13% of the persons who used the emergency room for care in the last three months said it was because they did not have insurance; and
- 14% said that the emergency room is their primary source of medical care.

Of special concern to the subcommittees were the needs of nondocumented HIV-infected individuals who have no access to medical coverage. Current immigration law, which calls for deportation of HIV-infected persons who are not citizens, adds to the inability of these persons to seek medical care.

"I have to set aside one day of the week to fill out forms. It's like having a part-time job!"

Subcommittee members also noted that HMOs are geared primarily to well persons and health maintenance. For Minnesotans living with HIV disease, this has resulted in an inability to access providers of choice, those with the most experience treating HIV. This access problem is of special concern in Greater Minnesota where knowledgeable providers are extremely limited.

"My insurance company is withholding a group plan at work due to my HIV."

For focus group participants, problems with health insurance had most to do with the complexity of forms, the time and energy it takes to complete the required paperwork, and the high cost of co-payments. Several focus group members and survey participants spoke of problems their employers have had in gaining coverage for the group after insurance companies learned of an HIV-infected employee.

Discussion and Implications:

Persons with HIV disease have a compelling need for access to insurance coverage for their physical and mental health care needs. The unique qualities of this disease, including its communicability, call for a health care plan for persons with HIV to include enhanced mental and physical health care coverage, and an assurance that coverage will not be denied or terminated because of their disease or use of the coverage.

Minnesota has been among the first states to recognize the importance of providing adequate medical coverage and services to all its citizens. In 1989, the Governor's Health Care Access Commission was appointed and charged to recommend to the Legislature a plan by 1991 to provide health care access to all Minnesotans. Until there is a change in the manner in which Minnesotans access health care insurance, employers who offer health care coverage are required to provide nondiscriminatory coverage to persons with HIV disease.

Without adequate coverage, persons with HIV infection are likely to suffer a more rapid deterioration of health, and rely more heavily on expensive institutional and emergency health care services. Without coverage that provides access to mental health and chemical dependency services to the full extent that this care is needed, HIV-infected persons will be unable to confront behavioral issues which place their health -- and potentially the health of others -- at greater risk.

Cost savings achieved by adequately insuring this population are also substantial. The state's new HIV Insurance Program, which pays insurance premiums under the COBRA provision, has surpassed its initial goals for participation, and anticipates an increasing need for this service. By increasing access to health care coverage and by assuring that current policies provide coverage for needed care, Minnesota's health care costs for persons with HIV disease can be contained.

Data from the study of HIV-infected Minnesotans shows repeatedly that access to health care services, physicians, chemical dependency programs and mental health services are vital to reducing behaviors which transmit the virus. Providing health insurance which allows access to those services to the degree which they are needed is a important element in protecting the public health.

Access to physical, mental, and chemical health care through insurance coverage is fundamental to maintaining and improving the health of persons with HIV disease. Insurance coverage decreases costs of care by allowing for preventive services and decreasing reliance on higher cost care, and helps to assure the public health by providing access to services which assist persons with HIV in making needed behavioral change.

> ***"Convince insurance companies it would be to their benefit to pay for care for people now than the expense later."***

Payment for Health Care Services Recommendations:

To create a system of health care coverage that will meet the needs of persons with HIV disease, the Task Force recommends:

61. That any state program designed to assure access to health care through insurance for all Minnesotans include the following coverage: chemical dependency, mental health, and all HIV-related care regardless of pre-existing conditions.

To improve the current system of private health care coverage, the Task Force recommends:

62. That Minnesota's program which covers insurance premium costs under the COBRA provision be continued and expanded to meet the increasing need.
63. That the Department of Health, the Department of Commerce and third party payors work cooperatively to improve access to health care coverage and payment of health care services related to HIV disease, including: implementing a community-based rate for both individual and family coverage; reimbursing all HIV-related services and care, including those which enhance and support the immune system; removing the six-month precondition requirement for persons with HIV infection; and monitoring the needs of persons with HIV disease in HMOs to assure they are not denied services.
64. That the Comprehensive Health Association create a sliding fee scale premium until the enactment of a state insurance program.
65. That the Department of Human Services examine managed care organizations to determine if they are able to meet the needs of persons with HIV disease.

To improve access to health care services for Minnesotans receiving Medical Assistance, the Task Force recommends:

66. That the Department of Human Services examine the barriers faced by health care providers in accepting individuals on Medical Assistance, including reimbursement policies, training, and procedures.

VIII. SPECIAL POPULATIONS

The special populations examined by the Task Force are:

A. Adolescents
B. Families, women, and children
C. Employers and workplaces
D. HIV-related care providers
E. Persons with HIV disease

A. Adolescents

> Services for HIV-infected Minnesotans between the ages of 13 and 19.
>
> This section discusses the Task Force's desired outcome for care and services for HIV-infected adolescents, the current status of HIV-infected youth and their experience as they seek care and services in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

To assure that the physical and mental health needs of HIV-infected youth are met, the current barriers which limit access of HIV-infected adolescents to health and social services should be identified, and methods to reduce those barriers should be implemented.

Current Status:

Planning for the needs of HIV-infected adolescents is a unique and difficult challenge for a number of reasons important to understanding the recommendations of this report.

First, adolescents affected by HIV fall into three broad categories:

- Hemophiliacs, many with supportive parents, who have had a history of successfully accessing medical services;
- Adolescents who are gay or bisexual, or drug using, but who live with their family, and may have a regular physician; and
- Adolescents who are disenfranchised, gay or bisexual, chemically dependent, in the sex trade industries, or homeless, and who are not connected to a primary health care provider.

Second, surveillance data show that nonhemophiliac HIV-infected adolescents are learning of their status through medically necessary visits to STD clinics, community clinics, emergency rooms and hospitals. The majority of these HIV-infected adolescents are lost to medical follow-up, and are not currently receiving case management services or being or followed by a medical provider. In fact, although focus groups and targeted surveys were attempted, only three adolescents were successfully interviewed for the purposes of this project.

49% of adolescent HIV infection is due to sexual transmission.

"To cope with stress, I go hunting."

- an adolescent hemophiliac with HIV

Third, the subcommittee shared a lack of experience working with HIV-infected adolescents other than young hemophiliacs. There is little information about the experience of these HIV-infected adolescents, making planning for their needs difficult.

Fourth, the subcommittee identified an overall lack of youth-specific services in all service categories, and few services geared to HIV-infected adolescents in particular.

Finally, in Minnesota the number of HIV-infected adolescents remains small:

- As of January 1991, 40 males and 6 females between the ages of 13 and 19 have been reported as infected with HIV;
- 33% of transmission is due to hemophilia or other blood transfusion;
- 44% to homosexual activity;
- 10% to IV drug use; and
- 5% to heterosexual transmission. Transmission is missing or pending for 10 adolescents.

Discussion and Implications:

Although the experience of nonhemophiliac HIV-infected adolescents has yet to be documented, the Adolescent Subcommittee identified unique circumstances and barriers influencing health and social services access for adolescents.

Because adolescents usually access medical care through the health care plan of their parents, HIV-infected adolescents who are not hemophiliacs (and are more likely to be living on their own without support or supervision) are likely to be uninsured. Second, as the majority of adolescents living with HIV infection are minors who may be estranged from their families, these teens may not be able to receive HIV-related medical care without parental consent. Third, adolescents who are not mothers cannot independently apply for or receive Medical Assistance. Finally, adolescents are highly distrustful of social workers and social systems.

There are also unique challenges inherent to providing HIV-infected adolescents with social services. Adolescents are most likely to access social and health care services through the family structure. This system has worked well for adolescents with hemophilia. An increasing number of adolescents with HIV, however, live without parents and face a lack of access to basic social services, such as entitlement programs. In practical terms, this means that when a homeless or otherwise needy adolescent seeks assistance from a social service agency, they are likely to be turned over to authorities, such as child protection services or a foster care system, or returned to their parents. As a result, disenfranchised youth who are seeking to live independently from their family choose to avoid the social and financial assistance system.

"More people should talk in the schools about AIDS."

Housing is likewise a challenge, as current law prohibits public-supported housing for independent adolescents under the age of eighteen. Although most adolescents who are HIV-infected are without strong family support, they, like other populations with HIV disease, should be maintained in a home-like setting.

HIV-infected adolescents also have unique advocacy needs, due in part to a high level of distrust for persons wanting to help, especially those wanting to "manage their case." Advocacy is sometimes required for adolescents who need protection from agencies. The information and referral needs of adolescents stretch beyond the specific concerns around HIV. Professionals, caregivers, and HIV-infected youth need more complete information on a variety of concerns, from health, social or mental health care services available, to questions about sexual abuse, sexual orientation, drugs, and alcohol.

The Adolescent Subcommittee stressed that services for HIV-infected adolescents should be provided in a continuum of care in settings that are nonthreatening, innovative, and accessible to all adolescents. The guiding principles which should be used to design this continuum are:

1. Access for the least enfranchised assures access for main stream adolescents.
2. Medical and health services should be coupled with social services .
3. Home-based medical services and others requiring parental and/or social support are meaningless to an adolescent without a stable home.
4. Access includes assuring that the services are sensitive to communities of color, gay, lesbian, and bisexual youth, and those who live independently.
5. Youth should be included in planning for services.
6. Poverty, unstable housing, and lack of empowerment have a negative impact on access to services.
7. Adolescents need case managers or advocates to help them access and use health and social services systems.

Adolescent Recommendations:

To better understand the needs of adolescents with HIV disease, the Task Force recommends:

67. That the Office of the Attorney General commission a study of HIV-infected adolescents to determine the impact of the current legal status of adolescents and the effects an emancipation provision would have on access to health care, social services, housing, and public assistance programs.

To improve access to health and social services for adolescents with HIV disease, the Task Force recommends:

68. That the Department of Human Services and the Department of Commerce examine methods to ensure access to health care coverage or Medical Assistance for all noninsured HIV-infected minors, regardless of parental income; and alternative means for providing insurance coverage for youth who are not covered by parent's insurance plan, for example: the Children's Health Plan, group plans through schools, churches, or clinics.

69. That early intervention strategies at counseling and testing sites, emergency rooms, and other locations where adolescents learn of their HIV status, be developed and improved.

    a. Ask agencies which serve HIV-infected adolescents to create a system of adolescent advocates for emergency rooms, following the model of advocates for victims of rape, to assist HIV-infected adolescents entering the hospital.

70. That adolescents and providers of services to adolescents develop strategies to reach and provide ongoing support and services to meet the needs of HIV-infected adolescents.

    a. Create a pilot program to expand services at a teen medical clinic to include mental health, chemical dependency, and social service advocacy such as a mobile van service to provide health care, outreach, and social service advocacy to homeless youth.

To improve housing for adolescents with HIV diesease, the Task Force recommends:

71. That county social service agencies recruit gay and lesbian families to provide foster care to HIV-infected gay adolescents, and provide training on gay and lesbian issues to existing providers.

To improve chemical dependency services for adolescents with HIV disease, the Task Force recommends:

72. That the Department of Human Services work with existing chemical dependency providers to design programs to meet the needs of HIV-infected chemically dependent youth.

To expand the ability of support community volunteers and case managers to meet the needs of adolescents with HIV disease, the Task Force recommends:

73. That a program be designed and implemented to recruit and train volunteer caregivers and adolescent advocates for adolescents affected by HIV.

74. Enhance the ability of youth hotlines such as YES NEON to respond to concerns about HIV, and encourage the service to refer HIV-infected or at-risk youth to health and social service resources. Distribute a pocket-sized referral directory .

B. Families

> Family units, as defined by the members, which include one or more person infected with HIV. Special concern is given in this section to the issues of women and children.
>
> This section discusses the Task Force's desired outcome for care and services for families which include persons with HIV infection, the current status and experience of these families as they seek care and services in Minnesota, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Families where an adult or child is living with HIV have unique needs which can most effectively be met by assessing the family as a unit, working to keep the family together and supported, and by assisting the family in making long term plans for the care and support of all family members, whether or not they HIV-infected.

Current Status:

Data from target surveys of parents whose children are HIV-infected illustrates problems some women and families have had accessing health care services:

- 2 of the 7 parents interviewed said they did not receive medical care for more than six months after they knew their child was infected;
- 4 of 8 women in the site-based study said they did not know their CD4 count, 41% of the target group said they were unaware of their count; and
- 53% of women in the target group said they had no health insurance at the time they learned of their HIV infection.

53% of women in the target survey group had no health insurance at the time they learned of their HIV infection.

The data also documented a number of special health care concerns for women, including higher rates of herpes and yeast infections. Health care issues are different for children and include: concerns about development, the need for speech and physical therapy, and the different course HIV disease takes in young children.

Subcommittee members identified the different needs of families where one or more adults and children may be living with HIV. For women, the effects of additional caregiving duties within the home is evident in the current health of the women surveyed:

- 56% of women in the target surveys, and 7 of 8 in the site-based group complained of chronic fatigue;
- 22% said they had trouble with thinking or memory; and
- 3 of 8 women in the site-based study said they had been in the hospital in the past three months, a higher percentage than reported by the men surveyed.

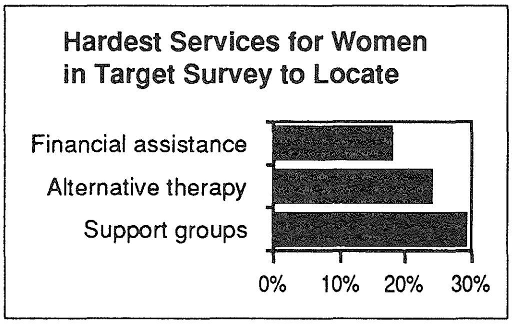
Families affected by HIV may need extended hours of home care, especially if both the mother and child are HIV-infected. Concerns regarding the care of children include: special needs of high tech care, and the need for extended hours of care and child care for HIV-infected children.

An additional barrier for parents who are caring for HIV-infected children and even more so for those who are also themselves HIV-infected is transportation. First, parents may have to find rides to their own appointments, as well as to the child's. Subcommittee members noted that in some cases, parents take care of the child's needs rather than their own. Second, there are problems of managing a sick child on public transportation.

Mental health services are another area where the needs of families and women are highlighted:

- 7 of the 8 HIV-infected women in the site-based study and 82% of the target group expressed fears related to the loss of their health;
- 4 of 8 site-based participants expressed fears for the future of their family and children;
- 65% of the target group reported worrying about the health or death of a loved one; and
- 53% of the target study group said they were afraid of being rejected by family and friends.

The study also illustrated the difficulties women experienced accessing mental health services:



Hardest Services for Women in Target Survey to Locate

- 29% of women in the target survey said both counseling and support groups were the most difficult services for them to find; and
- 7 of 8 women in the site-based study said they had received no mental health services in the past three months.

Subcommittee members noted a lack of mental health care providers able to meet the needs of HIV-infected children, or children in families where a parent is infected.

Although support groups were difficult for women in the target group to access, the experience of women in the site-based study illustrates their value:

- 5 of 8 women in the site-based study said they had attended a support group; and
- 6 of 8 women said a support group was helpful to making changes in sexual behavior.

Also important for support in changing behaviors related to sexual activity and chemical use were family members, partners, physicians, and education:

- 7 of 8 women in the site-based study and 29% of the target group cited education as important in changing sexual behaviors;
- 6 of 8 site-based women said a physician has helped them make changes in their sexual behavior; and
- 6 of 8 site-based women, but only 41% of the target group, said their partner has been supportive of changes they have made in their sexual behavior.

Being successful in making changes in sexual behavior was especially important for the site-based group, as 4 of the 8 women surveyed had regular partners who were negative for the virus; and 4 of 8 site-based women said they have sex to cope with stress.

3% of respondents needed child care in the past 3 months.

Chemical dependency services are also a high need because HIV-infected women who have unmet chemical dependency treatment needs are at increased risk of pregnancy and giving birth to an HIV-infected child.

Subcommittee members noted that for families with children who are HIV-infected as well as suffering from hemophilia, the financial demands of two diseases -- and the likelihood that more than one family member is ill -- can be overwhelming. Similar stresses occur in families where either or both parents are infected. AIDS surveillance data as of January, 1991 showed that:

- 54% of pediatric cases of HIV and AIDS are related to perinatal transmission; and
- 4% of all cases of HIV and AIDS is related to hemophilia.

Families with children who are HIV-infected also present unique and challenging needs regarding housing. Subcommittee and focus group members expressed concerns that shelters are not safe alternatives for families, individuals, or children with HIV infection because of increased risk for infection. Currently there are no options for housing these families as a unit outside of the shelter program.

Subcommittee members noted that because children and families access so many care networks, there are special needs for coordination of their case management services. Women are the primary health educators and consumers in the family, and are often providing care to both HIV-infected children and partners. There is a lack of supportive educational services for women and children, especially for those from communities of color.

Discussion and Implications:

Because families affected by HIV disease have different needs from individuals, they need to be assessed as family units, and services should be designed which meet the needs of all individuals in the family, whether or not they are HIV-infected. Women and children with HIV should have access to programs and services designed to meet their specific needs.

Women, families, and their children have health care needs which must be addressed in a holistic manner. Without this coordination, stress to the family member and the chance that appointments will be missed increases, resulting in a deterioration in health for the individuals.

Women and families facing the HIV-related illness of their child are at increased need for highly skilled professional therapy around issues of guilt, fear, and adjustment to lifestyle changes. HIV-infected women need chemical dependency programs which stress healthy sexual choices and pregnancy prevention, and which are able to meet the needs of women with children.

Families affected by HIV face complex and sensitive issues surrounding long-term care of their children after they die. Unless available, accessible financial and legal advice is provided to persons with HIV, society will be left with making difficult ethical decisions about care and needs of persons with AIDS rather than having directives or power of family/friends to make these difficult decisions.

The needs of families and children with HIV infection cannot be assessed outside the context of their families. Without assessing the family as a whole, care providers may miss the complexity of the health care and social service needs of the family, increasing duplication of service and overlooking needed services.

> ***"I'm worried that if I can't find child care***
> ***I will have to lose my job***
> ***and my health care."***

Families Recommendations:

To improve access of women and families to health care services, the Task Force recommends:

75. That the Department of Health respond to the specific testing and counseling issues facing women and children by increasing HIV counseling and testing in agencies which provide health service to women, and by developing a training manual and video specific to Minnesota and the gender, pregnancy, and cultural issues of concern to women and children.

76. That the Department of Health encourage health care providers serving families with more than one HIV-infected individual to provide health care services, including doctor's visits, treatment, and home health care services, in a coordinated manner.

77. That the Department of Health and the Department of Human Services work cooperatively to develop a comprehensive system of home-based care for families with HIV that includes pediatric care, respite and homemaker services, and a resource for consultation to providers.

78. That providers assess client need for and assist clients to obtain child car seats from existing programs.

To increase access of women to chemical dependency services, the Task Force recommends:

79. That the Department of Human Services Chemical Dependency Programs Division address the needs of HIV-infected women by encouraging their priority placement in treatment programs; and by increasing options for HIV-infected women with children by developing treatment programs which emphasize empowerment; and a pilot program which offers creative options for child care, such as placement of children in foster care during treatment, and housing women and children cooperatively during treatment.

To expand and support community volunteers to meet the needs of families and individuals living with HIV, the Task Force recommends:

80. That a program to recruit and train volunteer caregivers for families affected by HIV, especially from communities of color be designed and implemented:

    a. Expand caregiver training programs to include a section on care for children with HIV.

    b. Ask community-based organizations with access to families and children with HIV to develop a volunteer-based baby sitting list to provide care for children in and outside of the home.

C. Employers and Workplaces

> Education and support to employers regarding HIV, accommodations for HIV-affected employees, and discrimination.
>
> This section discusses the Task Force's desired outcome for programs for HIV-infected employees, and educational efforts to be made by Minnesota employers, the experience of employed HIV-infected individuals and the status of educational programs in the workplace, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

As increasing numbers of persons living with HIV infection continue to work in our society, employers should become more familiar with the effects of HIV on both individual employees and on Minnesota's work force as a whole, and become more able to respond to the challenge HIV presents to employers.

Current Status:

Many individuals with HIV infection continue to contribute to the work force for years after infection:

- 46% of the individuals surveyed said they were employed, and worked an average of 37 hours a week; with 69% working full-time.

Besides wages, employment also offers other financial benefits:

- 52% of persons with health coverage said their employer pays the premiums for that coverage.

46% of site-based respondents are employed and work an average of 37 hours a week.

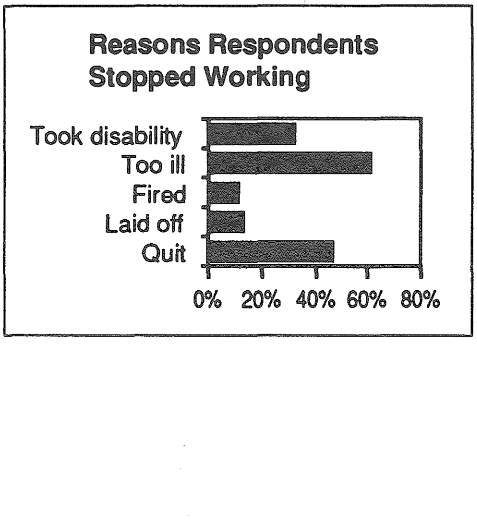
47% had not missed any days of work during the past 3 months.

For those persons who have stopped working, HIV was a major factor in their decision to stop working:

- 73% said their last regular job required physical exertion or strenuous activity;
- 61% said they stopped working because they were too ill to work;
- 13% said they were laid off;
- 8% said they moved; and
- 22% cited other reasons, including uncomfortable working conditions because of their HIV status.

The nature of HIV disease causes changes in health status on a recurrent basis that has implications for working conditions and which may require accommodation:

- 71% of those currently working said their job requires physical exertion or strenuous activity;
- 40% said they had missed one to seven days of work;
- 13% said they had missed more than seven days of work; and
- 47% said they had not missed any days of work in the last three months due to illness or injury.



The study shows that, in fact, working Minnesotans with HIV have made changes in their employment conditions to accommodate their changing health needs:

55% of working respondents
have not
told their employer
that they are HIV-infected.

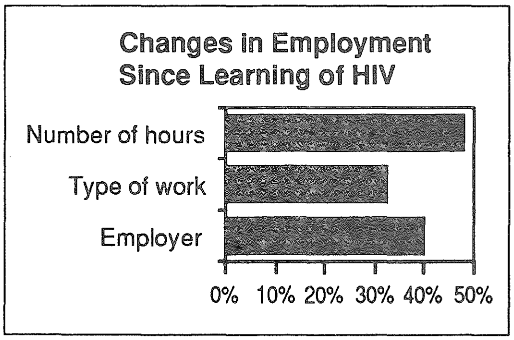
- 40% reported changing employers;
- 32% reported changing the type of work they do;
- 48% reported changing the number of hours of work; and
- 55% of those currently working said their employer does not know of their HIV status.

Employer and employee training programs have been developed in some industries and locations around the state. Community Health Services Agency HIV Resource Persons and AIDS services organizations provide some assistance to employers. As reported by respondents to the survey, however, some employers have not had HIV education programs or access to knowledgeable consultation causing anxiety for employees who are not able to share concerns about their illness.

Discussion and Implications:

Persons with HIV infection are often able to work even after receiving a diagnosis of AIDS. For these individuals, vocational rehabilitation is an increasing need. However, people with AIDS may need enhanced services, including assistance with changes in work responsibilities and increased flexibility for hours of work. Current financial assistance program regulations prevent persons from working and earning income during periods of good health because of losing eligibility for Medical Assistance.

Employers need assistance to provide appropriate support to their infected employers while considering the needs of their work force. Information about the implications of the Americans with Disabilities Act is needed by employers as well as HIV service providers.



Working is important to persons with HIV for many reasons: it often assures health coverage, it provides income, and it provides interaction with society.

Employers should help create a supportive environment for their employees with HIV. The initial corporate response which occurred at the beginning of the AIDS epidemic in Minnesota has waned, and currently there is not visible leadership in this important area. Corporations need access to AIDS education to support a compassionate, knowledgeable response to employees with HIV.

Persons with HIV infection have the ability and the right to contribute to Minnesota's work force. In order to continue in employment they, like other employees with disabilities, may need accommodations which are outlined and protected under federal law. Employers may need assistance in developing strategies to support their employees with HIV.

> *'"When you're on social security, you can't work.*
> *Basically you're no good...*
> *at times when a person feels good*
> *they need to know they are wanted.*
> *Don't just stick them in a corner*
> *and throw a check at them."*

Employer and Workplace Recommendations:

To enhance the ability of Minnesotans with HIV disease to remain as productive members of the work force, the Task Force recommends:

81. That the Department of Human Services and the Department of Jobs and Training investigate employment options for persons with HIV disease which will allow for work and income without reducing needed government entitlement, especially health care coverage. (*See Recommendation number 58*).

82. That employers create a supportive environment for employees with HIV disease.

    a. Developing flexible benefit plans for persons with HIV disease, and creative and flexible working hours and options for HIV-infected employees and for employees caring for ill partners, parents or children.

To increase the ability of Minnesota's business community to understand and deal productively with the challenges the HIV epidemic brings to the workplace, the Task Force recommends:

83. That employers and employer associations provide training regarding the impact of HIV on the work force which goes beyond issues of work-related transmission to include a discussion of HIV policies, reasonable accommodation, disability, and discrimination law.

    a. Develop a certification process for worksite training on HIV issues to be overseen by the Department of Human Rights and the Department of Jobs and Training in consultation with the Department of Health and AIDS service organizations.

    b. Encourage private foundations to support industry-specific organizations such as "Arts Over AIDS" which support efforts to develop AIDS policies and education.

D. HIV-Related Care Providers:

Professional, technical, and paraprofessional providers of care services in all care settings.

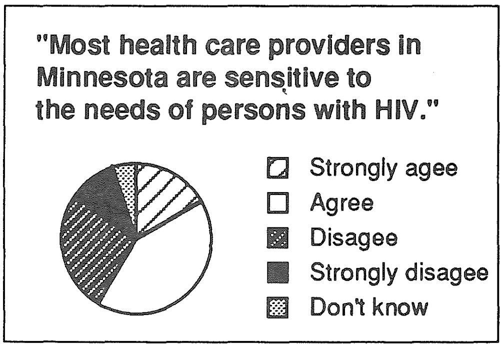
This section discusses the Task Force's desired outcome for education and support to HIV-related service and care providers, the current status and experience of these providers as they seek to serve HIV-infected Minnesotans, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Because HIV infection and AIDS has thus far affected persons from communities of color, gay and bisexual persons out of proportion to their numbers in Minnesota's general population, it is especially important that professionals understand the cultural beliefs, values, needs, and strengths of the persons they serve.

The site-based study showed most persons with HIV infection see their health care providers as important to their lives:

- All participants in the site-based study were active with a primary health care provider at the time of the study.
- 95% reported the staff at their medical provider's office was knowledgeable about HIV;
- 57% either agreed or strongly agreed that health care providers in Minnesota are sensitive to the needs of persons with HIV;
- 64% said the health and medical service system in Minnesota is either excellent or very good; and
- 33% of persons in the site-based study said emotional support is a main reason they see their physician.



"Most health care providers in Minnesota are sensitive to the needs of persons with HIV."

Although persons with HIV infection are generally pleased with the health and social services they receive, some areas of concerns remain. The most commonly identified problems cited by site-based respondents were:

- 21% said agencies were judgmental;
- 20% reported a reluctance to seek services because they feel confidentiality would be a problem; and
- 22% said they had been denied or refused the quality of care they deserved; with 87% of them stating it was because of their HIV status.

Surveillance data shows that communities of color are disproportionately affected by the HIV epidemic. AIDS surveillance data as of January 7, 1991 shows:

- African Americans accounted for 10% of all cases of AIDS, Hispanics for 3%, and Asians for 1% and American Indians for 1%.

The disproportionate effect of HIV is even more pronounced. HIV surveillance data as of January 1, 1991:

- African Americans accounted for 18% of all cases of HIV, Hispanics for 4%, Asians for 1% and American Indians for 2%, for a total of 25% of all cases. Only 5% of Minnesota's population is from communities of color.

Echoing the surveillance data, the target surveys and focus groups, which had larger representation from communities of color, had a different response to the health care system:

- 43% said they had been discriminated against in getting the care they needed;
- 14% said they do not have a primary health care provider; and
- 2 of the 7 parents interviewed said they have been discriminated against because of their child's HIV status.

"Is AIDS taught in medical schools?"
- a caregiver

Focus group participants told of feelings they were stereotyped as drug users or gay, and being treated as though they deserved their illness. Caregivers of persons with HIV who participated in a focus group said they too felt that they were discriminated against because of their association with someone with HIV disease.

Discussion and Implications:

Persons who have HIV infection are less likely to seek out health care if they feel threatened, afraid of being embarrassed, or find services not applicable to their needs. These persons are less likely to follow through on health care treatments and medications, resulting in a more rapid deterioration in health status.

An overriding concern of all communities involved in the HIV Services Planning Project was the need for an increase in our society's sensitivity toward persons with HIV disease, and toward the communities they come from. If care services are provided within an atmosphere of safety and understanding toward an individual's culture and/or sexual orientation, it is more likely that HIV-infected individuals will be able to feel safe in our world. Persons who provide services are, in essence, society's front line. If this interaction is not positive and supportive, it is likely that the individual will not continue to seek care and services.

Minnesota is a state primarily populated by persons of European descent. Many individuals in the caring professional received their training before the recent influx of persons from Central America, Mexico, and Asia, and may have had little interaction with persons of African American decent. The AIDS epidemic has, perhaps above all, increased our awareness of the gay men and lesbians in our community raising, for many persons, issues of sexual preference for the first time.

Caring professionals of all areas need training and assistance to become more fully aware of, and sensitive to, the uniqueness of the cultures in our community in order to more fully and effectively help those facing the HIV epidemic.

Unless persons with HIV infection have access to culturally-sensitive services, they are less likely to follow through with prevention-based care that will prevent the need for more expensive intervention during a crisis. It is in society's interest that persons with HIV infection feel comfortable with their care providers.

Persons with HIV infection who do not follow through with health care appointments because of a concern about sensitive and relevant care, are also less likely to be supported in their efforts to maintain safe sexual and chemical use behavior. Transmission of HIV will increase if these individuals are not receiving appropriate care.

Knowledge of community and family values, family structures and lifestyles, relationship issues, and other culturally-related aspects of life will enable program staff to reach out to persons from backgrounds other than their own, to deliver effective services in nontraditional ways.

HIV-Related Care Provider Recommendations:

To enhance the ability of health care providers to provide sensitive, effective care, the Task Force recommends:

84. That providers of HIV-related services be encouraged to recruit and hire staff from the communities which they serve including Spanish-speaking, African American, American Indian, Asian, Gay, Lesbian, and Bisexual communities.

85. That any state-funded program for HIV infection prevention or care services require staff orientation and periodic training in psychosocial referrals, medical issues, issues of concern to women, adolescents, communities of color, gay, lesbian and bisexual persons, and chemical use as it relates to HIV infection.

86. That all employers of health care providers, health care professional organizations, and schools preparing health care professionals, be encouraged to incorporate training about HIV-related services and medical issues, and issues of concern to women, adolescents, communities of color, gay, lesbian, and bisexual persons, and chemical use as it relates to HIV infection.

87. That the Department of Health develop a model HIV services training program for state agency employees including: infection control, issues of concern to women, adolescents, communities of color, gay, lesbian and bisexual persons, and the Americans with Disabilitites Act.

E. Persons with HIV Disease

> Persons with HIV infection or AIDS.
>
> This section discusses the Task Force's desired outcome for education and support to HIV-infected Minnesotans, shares the experience described by study participants and gives a summary statement of need and recommendations for achieving the desired outcome.

Desired Outcome:

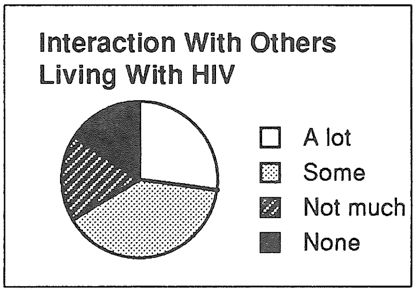
Persons with HIV infection should have information about HIV disease, nutrition, traditional and alternative therapies; access to others with HIV disease; a full range of services; and hope for the future.

Current Status:

The study of persons with HIV included a number of questions which illustrate the varied things persons with HIV infection have discovered and their ability to live well with their families. As indicated previously, the majority of individuals are taking advantage of methods to reduce stress and improve healing such as imagery, acupuncture, massage, and support groups.

Also important for many individuals was interaction with others facing HIV:

- 66% of site-based respondents said they learned about HIV services through others with HIV;
- 66% said they feel that they are part of a community;
- 51% said they enjoy support groups for the friendship and companionship they found there;
- 29% of site-based respondents said they have a lot of interaction with others infected with HIV; and
- 34% said they have some interaction.



Interaction With Others Living With HIV

That support and interaction has not been easy for all HIV-infected persons to find:

- 19% said they have little interaction; and
- 17% said they have no interaction with others facing HIV.

The consequences of not being a part of that community can be negative:

- 57% of site-based respondents said they have felt isolated;
- 18% said they know little or nothing about services available to persons with HIV;
- 28% of site-based respondents reported use of alcohol or drugs to reduce stress; and
- 31% said they had thoughts about suicide in the past three months.

The hopelessness that can result from isolation and fear were apparent in many of the interviews:

- "I feel dirty and sometimes I feel lonely because I don't think people understand."
- "I feel like I am a germ."
- "I feel useless, like I'm a burden to my family."

> ***"Start believing in yourself, knowing that there are tomorrows and years ahead of you."***

"Sometimes it is important to remember that we each have a contribution to make."

When asked what one attitude or activity has been most helpful in learning to live with HIV, many respondents spoke of the importance of getting involved with others with HIV, and reaching out for help and support:

- "Get involved."
- "I would create a service where a lot of AIDS patients could come together and talk...so they wouldn't feel like they were the only people out there, that there were others like them."
- "Get a good support system--parents, friends, loved ones. Talk about it, don't deny it."
  "If you find yourself getting depressed because of HIV, remember that there are others out there like you. You are not alone."

Changes in lifestyle and attitude were also encouraged by many:

- "Stay away from stress ... turn it into positive energy."
- "Stop smoking."
- "Affirmations ... Acupuncture...Find a quiet place, and find one-on-one with your own being."
- "Dreams don't die. You have to focus outside of being ill and it will make it so much easier. HIV status will never go away, but the survivors have learned not to be preoccupied with it."
- "Just have fun. Do stupid things."
- "Have safe sex or none at all."
- "Get connected with God."

Information about HIV disease and being involved in the decisions about one's care were also seen as vital to maintaining a positive attitude in the face of HIV:

48% of persons interviewed had volunteered during the past year.

- 88% said they felt involved in making decisions about their care; and
- 81% said they felt respected by the agencies they approach for assistance.

- "Read. Get as much information as you can, and don't limit it to AIDS."

Discussion and Implications:

For many persons with HIV, a positive attitude toward living with HIV was key to their ability to face a life affected by the uncertainty of disease. Achieving that understanding, however, is extremely difficult. For those persons who have learned how to live well with HIV, the importance of interaction with others and a sense of control over their care is vital.

Recommendations for Persons with HIV Disease:

To improve the ability of persons with HIV disease to live well with HIV, the Task Force recommends:

88. That all providers who work with HIV-infected persons continually assess the needs of their clients for support from others with HIV infection, and make referrals to community-based organizations and support groups which can provide that interaction.

89. That providers of support services to persons with HIV infection continually assess their outreach and barriers to accessing those services while working to develop a sense of safety and trust, openness to all cultures, and an ability to hear the needs of those they serve.

90. That persons with HIV infection look for ways to interact with others with HIV, and seek out information about their illness from a variety of sources and perspectives.

91. That community-based organizations of all types work to increase volunteer opportunities for persons with HIV infection, and to welcome and acknowledge the contributions of Minnesotans with HIV disease.

IX. SOCIETY

Minnesota's reaction to persons with HIV-infection.

This section discusses the Task Force's desired outcome for societal support to persons with HIV disease living in Minnesota, the current experience of HIV-infected Minnesotans, a summary statement of need, and recommendations for achieving the desired outcome.

Desired Outcome:

Minnesotans with HIV infection should be accepted fully by society.

Current Status:

The study of Minnesotans with HIV infection illustrates the importance of reaching out to others in order to live successfully with HIV disease. For HIV-infected citizens to feel safe to do that, however, a great deal still needs to change. As discussed previously, HIV-infected individuals continue to face discrimination in many areas of their lives *(See the Legal Services, Financial Planning and Discrimination section, page 64).* This lack of acceptance is in large part based on fear -- fear of contagion, of death, of difference, and of homosexuality.

Persons with HIV infection had suggestions for how to create this acceptance, and are also aware of the consequences of feeling unwanted:

- "Massive education, beginning in the 6th grade. Many people have not met a person with HIV."
- "Let them know that they are not less of a person because they are sick. It's not their fault."
- "Have a little more compassion for persons with HIV."
- "Very broad acceptance by the broad population of various sexual orientations and the victims of sexuality transmitted diseases. That's really it."
- "Helping people to increase their feelings of self esteem and self respect leads to people having safer sex, making nutritional changes and changes in drug and alcohol use."

Discussion and Implications:

Just as the AIDS epidemic makes apparent the failures of our health and social services system, so too it brings to light the underlying prejudices and fears in our society.

These fears and hatreds have been focused on a number of communities, creating divisions in our society which only serve to increase the incidence of HIV. The recent 133 percent rise in hate crimes against gay men and lesbians reported by the Gay and Lesbian Community Action Council is evidence of this fear. A general lack of understanding for those addicted to drugs -- especially compared to our state's well known environment of support for alcoholics -- is another indication of the fears that rise when society comes face-to-face with AIDS. We still hear the term "innocent victim of AIDS", making the delineation between "us and them" clear.

> *"We can't make the distinction between innocent victims and non-innocent victims. Are the innocent victims more deserving of compassion than the non-innocent?"*

Removing those distinctions -- as we have begun to do for persons with cancer, mental retardation, and mental illness -- will allow persons with AIDS to live in our society without fear of rejection, mistreatment, or prejudice. Allowing those fears to continue will only serve to drive persons with HIV infection away from the very services and care which can check the spread of this disease, and reduce suffering for those individuals facing HIV.

Recommendations for Minnesota:

To increase acceptance of persons with HIV disease in Minnesota, the Task Force recommends:

92. That mainstream organizations such as schools, churches, synagogues, and civic and community-based organizations create opportunities to interact and learn from persons with HIV and communities affected by this disease.

93. That the Department of Health continue to participate in activities such as mass media campaigns, World AIDS Day and National AIDS Awareness Month, and encourage statewide involvement in these events.

94. That Minnesota schools provide sexuality education and education about AIDS, including information about the communities affected by this disease and the positive contributions made to society by persons with HIV disease.

95. That organizations and agencies of all types and levels listen to the voices and needs of persons with HIV infection, and include them in planning for services and programs.

96. That Minnesotans give their time and money to programs which serve persons with HIV disease.

97. That foundations and corporations assume a greater role in responding to the HIV epidemic by increasing levels of contributed support, particularly in the following service areas: legal, transportation, housing, training for informal care providers, and worksite education, and that they work to increase awareness of HIV and the needs of persons with HIV in all aspects of their activities.

Appendix

APPENDIX

A. Membership of the HIV Services Planning Project

The Commissioner's Task Force on AIDS

Grace Arrington
Minneapolis Urban League
Vidal Castaneda
CLUES - Chicanos and Latinos Unidos en Servicio
Carol Fielders, R.N., M.P.H.
St. Louis County Health Department
Jerry Fruetel
Blue Cross/Blue Shield
Rob Fulton, *Chair*
Ramsey County Public Health
John Gonsiorek, Ph. D. *(former member)*
Therapist in Private Practice
Keith Henry, M.D.
St. Paul - Ramsey Medical Center
Clyde Holmes, M.Ed.
Duluth Community Health Clinic
Ron Hook *(former member)*
Department of Human Services
Jim Kurowski, M.D.
Olmsted County Community Health
Sister Joanne Lucid
Archdiocesan AIDS Ministry
Rhonda Lundquist, M.A.
Minnesota AIDS Project
Mary Alice Mowry, M.S.S.W.
Minnesota Department of Human Services
Health Care Management
JoAnne Stately
Indian Affairs Council
Karen Swanson, R.N., M.P.H.
Metropolitan Visiting Nurses Association
Bob Tracy
The St. Paul Foundation
Frezghi Tzeggai
Citizen
Stella Whitney-West *(former member)*
Minneapolis Urban League
Sue Zuidema
Hennepin County Community Health

Maternal and Child Issues Subcommittee

Carol Anderson, R.N.
Minnesota AIDS Project
Elizabeth Andres
Foster Mother
Kiran Belani, M.D.
Minneapolis Children's Hospital
Margie Clay, C.C.P.D.
Turning Point, Inc.
Jean Cornish, N.S.W.
Minnesota Human Services Association
Clare Edgar, R.N.
University of Minnesota AIDS Clinical Trials Unit
Mary Ellison, M.S.
Cornerhouse
Stacie Emberley, R.N.
Minnesota Department of Health
Emma Eskelson
Catholic Charities
Carolee Dodge Francis
Minnesota American Indian AIDS Task Force
Mary Ho, R.N.
Rice County Health Services Agency
Barbara Leone, M.D.
Model Cities Health Clinic
Ruth E. Luehr, R.N.
Minnesota Department of Education
Jeanie Morrison, R.N.
Minneapolis Health Department
Helen Reed, R.N.
Coalition of People of Color / AIDS
Jennifer Reinhart
Chrysalis East, A Center for Women
Patty Rezabek, M.A., P.H.N.
School Nurse, Wayzeta
Ann Ricketts
Face-to-Face Counseling Service
Patsy Stinchfield, R.N., P.N.P., *Chair*
St. Paul Children's Hospital
Vicki Thelen
Hennepin County Community Health Department
Estrella Urbi, R.N.
Fillipino and American Women Networking

Adolescent Issues Subcommittee

Roxanna Boelsen, R.N.
University of Minnesota Hemophilia Center
Kevin Cwayna, M.D.
University of Minnesota Youth and AIDS Project
Suzanne Douglas
Hennepin County Family Foster Care
Frank Guzman
Catholic Charities
Frank Hosch
Boys Totem Town
Mary Lou Jirik, R.N.
Carver County Community Health Services
Doug Kress
Minneapolis Health Department
Peg LaBore
Family Tree
Don LeTourneau, M.S.W.
Lutheran Social Services
David Lindahl
AIDS Interfaith Council
Steve Moore
Wilder Foundation
Diane O'Conner, R.N.
West Suburban Teen Clinic
Nancy Reed, N.P., M.P.H.
Health Start, Inc.
Anne St. Germain, Ph.D.
Minneapolis Public Schools
Mary Sonnen, R.N., B.S.N.
St. Paul Public Health Department
Charlie Tamble
Project Offstreets
Pat Thayer, *Chair*
Minnesota Department of Education
Leo Treadway, M.Ed.
St. Paul Reformation Lutheran Church
Renee Whiterabbit
Minneapolis Indian Health Board

Greater Minnesota Issues Subcommittee

Barb Anderson, R.N., M.S.
St. Joseph's Medical Center, Brainerd
Martha Arnold, R.N.
School Nurse, North Branch
Vanessa Bruggeman
West Central AIDS Project, Alexandria
Mary Carlsen, M.S.W.
St. Olaf College, Northfield
Beverly Chace, R.N.
University of Minnesota Hemophilia Center
Carolee Dodge Francis
Minnesota American Indian AIDS Task Force
Renee Frauendiest, R.N.
Stearns Co. Community Health Services, St. Cloud
Jane Hendricks, J.D.
Minnesota Department of Education
Clyde Holmes, M.Ed.
Duluth Community Health Center, Duluth
Mary Johnson, M.A.
Southeast Minnesota AIDS Project, Rochester
Wende Nelson
Arrowhead Alternative Services, Eveleth
Diane O'Brien
Minnesota AIDS Project
Ray Olsen, M.P.H.
Minnesota AIDS Project, Statewide Programs
Amon Petersen, *Chair*
Citizen, Fergus Falls
Cindy Skalsky
West Central ESCU, Fergus Falls
Lynn Theuer, R.N., M.S.C.S.
Winona Co. Community Health Services, Winona
Iva Thielges
Clay-Wilkin Community Health Services, Moorhead
John Yoakam, M.Div.
University of Minnesota Adolescent Health

Adult Issues Subcommittee

Pat Adams, A.D.A., M.S.
Dakota County Public Health Department
Dana Baumgartner, M.S.H.S.A.
Minnesota Department of Corrections
Rhoda Becklund, R.N.
Becklund Home Health Care, Inc.
Kathy Briggs, M.A.
Metropolitan - Mount Sinai Medical Center
Dan Capouch, M.S.W., J.D.
Hennepin County Services to the Disabled
Albert de Leon, Ph.D.
Council on Asian - Pacific Minnesotans
Carol Falkowski
Minnesota Department of Human Services
Chemical Dependency
Gerard Fergerson
Minneapolis Chapter of the American Red Cross

Jack Hunt
  Hunt Funeral Home
Randy Jenkins, Ph.D.
  Carver County Mental Health
Susan Kundel
  Catholic Charities
Steven Katz
  The Aliveness Project
Bill Kummer
  PWAlive
Frank Lamendola, R.N.-C., M.S.N.
  Journey Well
Sister Joanne Lucid
  Archdiocesan AIDS Ministry
James Maurer, M.Div.
  Grace House of Minneapolis
Mary May, R.N., B.S.N.
  North Country Hospital
Theresa Pesch, P.H.N.
  Meeker/McLeod/Sibley Community Health Services
Mary Rosch
  Bryn Mawr Health Care Center
Gaynell Schandel, *Chair*
  Minneapolis Health Department
Audrey Suker
  Minnesota Deptartment of Jobs and Training
Leslie Thompson, B.S.N.
  Veterans Administration Medical Center
Sally Todd
  Citizen
Bob Tracy
  The St. Paul Foundation

Technical Advisory Workgroup

Keith Henry, M.D.
  St. Paul Ramey Medical Center
Rhonda Lundquist, M.A.
  Minnesota AIDS Project
Kris MacDonald, M.D.
  Minnesota Department of Health
Mary Alice Mowry, M.S.S.W.
  Minnesota Department of Human Services
Claire Pomeroy, M.D.
  Veterans Administration Medical Center
Frank Rhame, M.D.
  University of Minnesota HIV Clinic
Hannan Rosenstein, M.D.
  Clinic 42
Margaret Simpson, M.D.
  Hennepin County Medical Center
Patsy Stinchfield, R.N., P.N.P.
  St. Paul Children's Hospital

Focus Group Sponsors

Facillitator
Ann DeGroot
  Gay and Lesbian Community Action Council

African Americans

American Red Cross, Minneapolis
Coalition for People of Color/AIDS
Hallie Q. Brown Community Center
Minneapolis Urban League
Minnesota AIDS Project
Pilot City Health Center
Turning Point

Caregivers and Care Partners

The Aliveness Project
Archdiocesan AIDS Ministry
AIDS Interfaith Council
Gay and Lesbian Community Action Council
Minnesota AIDS Project
Family, Friends and Lovers

Gay and Bisexual Men

Act Up
Aliveness Project
Bisexual Connection
The Gay and Bisexual Father's Group
Gay and Lesbian Community Action Council
Minnesota AIDS Project

Persons in Recovery

Affirmation Place
Chrysalis, a Center for Women
Eden House
Minnesota AIDS Project
Pride Institute
Recovery Alliance
Turning Point, Inc.
Wayside House

Target Survey Volunteers

Elizabeth Andres
  Foster Mother
Frances Benjamin, L.P.N.
  Minneapolis Indian Health Board

Roxanna Boelsen, R.N.
  University of Minnesota Hemophilia Center
German A. Carmona
  Catholic Charities
Vidal A. Castaneda
  CLUES - Chicanos and Latinos Unidos en Servicio
Frank Guzman
  Catholic Charities
Clyde Holmes, M.Ed.
  Duluth Community Health Center
Susan Kundel
  Catholic Charities
Don LeTourneau, M.S.W.
  Lutheran Social Services
Amon Peterson
  Fergus Falls
Molly Richey
  Casa De Esperansa
Patsy Stinchfield, R.N., P.N.P.
  St. Paul Children's Hospital
Rene Whiterabbit
  Minneapolis Indian Health Board
Cynthia Zegers, M.H.S.
  Chrysalis, a Center for Women

Site-Based Study Participant Sites

Veterans Administration Medical Center
Carole Hutchinson, R.N. Site Coordinator
Claire Pomeroy, M.D.
Joe Thurn, M.D.

Hennepin County Medical Center
Gen DuPlessis, R.N.Site Coordinator
Margaret Simpson, M.D.

Metropolitan-Mount Sinai Medical Center
Barb Carlson, R.N. Site Coordinator
Hanan Rosenstein, M.D.

University of Minnesota Hospital and Clinic
Jocelyn Archer, R.N. Site Coordinator
Frank Rhame, M.D.

St. Paul Ramsey Medical Center
Phyllis Collier, Site Coordinator
Keith Henry, M.D.

Minnesota AIDS Project
Eli Stein, R.N. Site Coordinator
Rhonda Lundquist, M.A.

Site-Based Study Survey Staff

University of Minnesota
Center for Survey Research

Kurt Alferness
Michaele Caron
Claudia Gietzen
Deidra Gorgos
Sharon Osborn
Valerie Richmond
Brent Whitmore
Chris Uting, Project Manager
Scott Berry
Doreen Caruth
Sarah Gilman
Carol Harrington
Jane Rehfuss
Vianne Verrecchi

Department of Administration
Intertechnologies Group

Elaine Kohoutek
Juanita Peuse
Data Entry Staff

Minnesota Department of Health Staff

AIDS / STD Prevention Services Section:

Judy Beniak, R.N., M.P.H.
  Section Chief
Bob Gillespie, M.S. (former staff)
  Research Scientist
Aggie Leitheiser, R.N., M.P.H.
  HIV Services and Planning Coordinator
Camilla Mateka-Lundberg
  Secretary
Fraser Nelson
  HIV Services Planner

Acute Disease Epidemiology:

Richard N. Danilla, Ph.D., M.P.H.
  Supervisor, AIDS Epidemiology Section
Kris MacDonald, M.D.
  Assistant State Epidemiologist
Karen White, M.P.H.
  Epidemiologist

Division of Disease Prevention and Control:

Michael E. Moen, M.P.H.
  Director

B. Materials Cited in the Report:

Background:

Acquired Immunodeficiency Syndrome and Human Immunodeficiency Virus Infection in Minnesota: Update and Projections of AIDS Cases Through 1992, AIDS Epidemiology Unit, Acute Disease Epidemiology Section, Minnesota Department of Health, September 1990.

HIV Services Planning Project: Report from Focus Groups of Persons Affected by HIV, AIDS/STD Prevention Services Section, Minnesota Department of Health, September 1990.

HIV Services Planning Project: Report from the Services Inventory Assessment Planning Forum, AIDS/STD Prevention Services Section, Minnesota Department of Health, June 1990.

Health and Medical Services:

McKusick, et al., "Longitudinal Predictors of Reducation in Unprotected Anal Intercourse among Gay Men in San Francisco: The AIDS Behavioral Research Project," American Journal of Public Health, Vol. 80, No. 8, August, 1990, pp. 978-983.

Chemical Dependency Services:

Freidman, H. et al., "Drugs of Abuse and Virus Susceptibility," Psychological, Neuropsychiatric, and Substance Abuse Aspects of AIDS, T. Peter Bridge, et. al., eds., Raven Press, New York, 1988, p. 125.

Siegel, L., M.D.,"AIDS: Relationship to Alcohol and Other Drugs," Journal of Substance Abuse and Treatment, Vol. 3, No. 27, 1986, p. 271.

Tilleraas, Perry, Circle of Hope: Our Stories of AIDS, Addition, and Recovery, Hazelden Press, Center City, MN, 1990.

Mental Health and Emotional Support Services:

Boccellari, A., et al., "Neuropsychologic Assessment in HIV-related Disorders," The AIDS Knowledge Base, Cohen, P.T., et al, eds., Medical Publishing Group, Waltham, MA, Vol. 5, No. 13, 1990, pp. 1-4

Price, R.W., et al., "The Brain in AIDS: Central Nervous System HIV-1 Infection and AIDS Dementia Complex", Science, Vol. 239, p. 568-92.

For more information about the HIV Services Planning Project, please contact:

Fraser Nelson, HIV Services Planner
Minnesota Department of Health
AIDS / STD Prevention Services Section
P.O. Box 9441
717 S.E. Delaware Street
Minneapolis, MN 55440

or call (612) 623-5721.

C. Definitions of Appropriate Counseling and Testing

From the Ryan White Comprehensive AIDS Resources Emergency Act of 1990

SUBPART III--GENERAL PROVISIONS

SEC. 2661. CONFIDENTIALITY AND INFORMED CONSENT

(a) CONFIDENTIALITY -- The Secretary may not make a grant under this part unless--

(1) in the case of any State applying for a grant under section 2641, the State agrees to ensure that information regarding the receipt of early intervention services is maintained confidentially pursuant to law or regulations in a manner not inconsistent with applicable law; and

(2) in the case of any entity applying for a grant under section 2651, the entity agrees to ensure that information regarding the receipt of early intervention services pursuant to the grant is maintained confidentially in a manner not inconsistent with applicable law.

(b) INFORMED CONSENT --

(1) IN GENERAL --The Secretary may not make a grant under this part unless the applicant for the grant agrees that, in testing an individual for HIV disease, the applicant will test an individual only after obtaining from the individual a statement, made in writing and signed by the individual, declaring that the individual has undergone the counseling described in section 2662(a) and that the decision of the individual with respect to undergoing such testing is voluntarily made.

(2) PROVISION REGARDING ANONYMOUS TESTING --

(A) If, pursuant to section 2664(b), an individual will undergo testing pursuant to this part through the use of a pseudonym, a grantee under such section shall be considered to be in compliance with the agreement made under paragraph (1) if the individual signs the statement described in such subsection using the pseudonym.

(B) If, pursuant to section 2664(b), an individual will undergo testing pursuant to this part without providing any information relating to the identity of the individual, a grantee under such section shall be considered to be in compliance with the agreement made under paragraph (1) if the individual orally provides the declaration described in such paragraph.

SEC. 2662. PROVISION OF CERTAIN COUNSELING SERVICES

(a) COUNSELING BEFORE TESTING -- The Secretary may not make a grant under this part unless the applicant for the grant agrees that, before testing an individual for HIV disease, the applicant will provide to the individual appropriate counseling regarding the disease (based on the most recently available scientific data), including counseling on:

(1) measures for the prevention of exposure to, and the transmission of, HIV;
(2) the accuracy and reliability of the results of testing for HIV disease;
(3) the significance of the results of such testing, including the potential for developing acquired immune deficiency syndrome;
(4) encouraging the individual, as appropriate, to undergo such testing;
(5) the benefits of such testing, including the medical benefits of diagnosing HIV disease in the early stages and the medical benefits of receiving early intervention services during such stages;
(6) provisions of law relating to the confidentiality of the process of receiving such services, including information regarding any disclosures that may be authorized under applicable law and information regarding the availability of anonymous counseling and testing pursuant to section 2664(b); and
(7) provisions of applicable law relating to discrimination against individuals with HIV disease.

(b) COUNSELING OF INDIVIDUALS WITH NEGATIVE TEST RESULTS -- The Secretary may not make a grant under this part unless the applicant for the grant agrees that, if the results of testing conducted for HIV disease indicate that an individual does not have the disease, the applicant will review for the individual the information provided pursuant to subsection (a), including--

(1) the information described in paragraph (1) through (3) of such subsection; and
(2) the appropriateness of further counseling, testing, and education of the individual regarding such disease.

(c) COUNSELING OF INDIVIDUALS WITH POSITIVE TEST RESULTS -- The Secretary may not make a grant under this part unless the applicant for the grant agrees that, if the results of testing for HIV disease indicate that the individual has the disease, the applicant will provide to the individual appropriate counseling regarding such disease, including--

(1) reviewing the formation described in paragraphs (1) through (3) of subsection (a);
(2) reviewing the appropriateness of further counseling, testing, and education of the individual regarding such disease; and
(3) providing counseling on--
    (A) the availability, through the applicant, of early intervention services;
    (B) the availability in the geographic area of appropriate health care, mental health care, and social and support services, including providing referrals for such services, as appropriate;
(C) the benefits of locating and counseling any individual by whom the infected individual may have been exposed to HIV; and
(D) the availability of the services of public health authorities with respect to locating and counseling any individual described in subparagraph (C)."

Guidelines for the Use of HIV Antibody Testing in Public Health From the Minnesota Department of Health, May 1989

III. RECOMMENDATIONS

A. General Recommendations:

Testing for HIV-1 by any health-care provider or organization should only occur when the following four procedures are followed:

1. The HIV-1 antibody test should only be performed after the patient or person designated to be responsible for the patient's medical decisions is consulted and permission obtained to have HIV-1 antibody testing done. The patient should be informed of the implications of test results. In addition, each person should be informed of how the results will be recorded, and that the positive results will be reported to the MDH. If the patient or person responsible for the patient's medical decisions declines HIV-1 antibody testing, it is recommended that the testing not be done.

2 All persons who are HIV-1 antibody positive should be counseled regarding specific health risk reduction behavior, such as safer sex practices. In addition, such persons need to be provided with appropriate psychosocial referral. If HIV-1 antibody testing is done for screening purposes, persons who are determined to be antibody positive should receive appropriate medical evaluation and follow-up. (The only exception to this is testing performed within the context of double-blinded seroprevalence studies, where identifying information is removed before testing is performed.)

3. Records and materials should be handled in the most protected way possible so as to respect the patient's rights of privacy.

4. HIV-1 antibody tests should not routinely be used for involuntary screening of any individual or group. Use of serologic testing is not appropriate, for example, as a precondition for employment, admission to hospitals, or admission to schools.

B. Public Health Issues

1. *Screening of blood and blood components, organs, tissues and semen donors:*

   The MDH recommends that all donors of blood and blood components, organs, tissues, breast milk, and semen be screened for the presence of HIV-1 antibody. The procedure is essential in protecting persons who receive blood, blood components, organs, breast milk or semen. In addition, collection facilities should provide educational materials to potential donors to assure that persons who are at risk of developing HIV-1 infection voluntarily exclude themselves from the donor pool.

2. *Screening of persons at risk:*

   Persons who have engaged in high-risk activities should be encouraged to learn of their HIV-1 antibody status. In addition to HIV-1 antibody testing, such persons need to be provided with risk reduction information and with appropriate emotional support. Although learning results of HIV-1 antibody serology may lead to emotional and psychological trauma for the individual patient, the potential public health benefits in limiting transmission are of highest priority at this time. For example, by testing persons who have engaged in high-risk activities and providing education and counseling, some of these persons may modify their behavior in ways that limit transmission. Also, some persons at high-risk, particularly bisexual men, persons with hemophilia and intravenous drug users, should be counseled about the risk of transmitting infection to their heterosexual sexual contacts, many of whom may not appreciate that they are at increased risk for acquiring HIV-1 infection.

   Counseling and testing are also particularly important for high-risk women of childbearing age, since infected women may transmit the virus to their offspring in utero or in the perinatal period.

3. *Maintaining counseling and testing sites:*

   Maintaining counseling and testing sites is important to help assure safety of the state's blood supply. In addition, such sites aid in limiting transmission by facilitating testing and providing counseling and education to persons who engage in high-risk behaviors. Existing sites have been well attended since they opened in July 1985. These sites should be maintained in Minnesota with test sites added or closed according to need.

4. *The use of screening in health care for purposes of infection control:*

   To date, epidemiologic data do not support routine screening of any admitted patients or presurgical patients for the purpose of infection control. Recent data suggests that health-care personnel are at low risk for acquiring HIV-1 infection, even following documented exposures to patients with AIDS. Also, in rare instances, patients have been identified who do not have detectable HIV-1 antibody but have had the virus cultured from their blood. Thus, health-care personnel should consider all patients as potentially infectious, regardless of HIV-1 serology test results, and should follow appropriate infection control guidelines when dealing with AIDS patients.

   All hospitals and other health-care providers should currently have infection control guidelines for limiting transmission of viral hepatitis, type B. Since HIV-1 transmission is similar to that of hepatitis B, such infection control procedures are adequate to protect health care personnel and others from acquiring HIV-1 infection.

5. *Screening of selected occupational groups:*

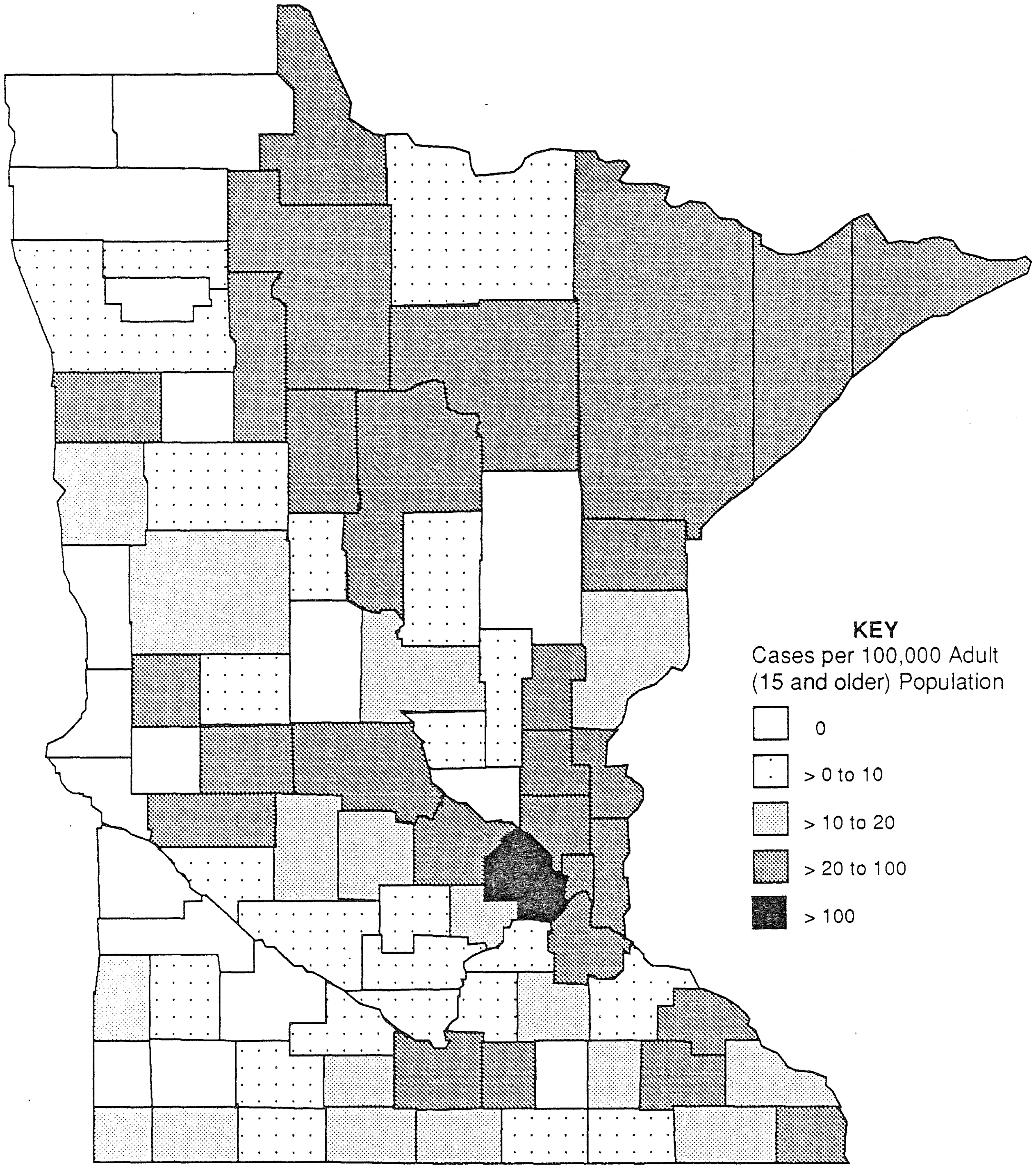
   HIV-1 antibody screening has been considered for certain occupational groups, such as foodhandlers, teachers and day care providers. Available epidemiologic data do not provide evidence of transmission of HIV-1 in such occupational settings. Transmission of HIV-1 to date has been limited to sexual contact, artificial insemination, shared needle usage, prior parenteral exposure to blood or blood products, transmission to infants born of infected mothers (either in utero, perinatally, or from infected breast milk) and, in rare instances, to contact with blood and body fluids from infected patients in the health-care setting. Since the mechanisms of transmission of HIV-1 are similar to those of viral hepatitis, type B, current recommendations for the prevention and control of hepatitis B should be followed. Therefore, based on existing epidemiologic data, routine screening of employees does not serve to limit HIV-1 transmission in the workplace.

6. *The use of HIV testing for on-going evaluation of disease trends:*

   Currently, the MDH is conducting annual HIV-1 seroprevalence studies in selected sites to follow trends in the epidemic. Data generated will be used to determine public health control strategies and evaluate the efficacy of prevention programs.

D. Cumulative Prevalence Rates of Reported Cases of AIDS and HIV Infection by County of Residence

January 1, 1991



E. HIV Services Assessment Summary from Subcommittees

Health and Medical Services	M/C	Adol	Adult	G Mn	Priority
Primary Physician Care	**H 3**	**H 3**	H 2	**H 3**	*
Ambulatory/Outpatient Treatment	**H 3**	**H 3**	**H 3**	H 1	*
Pharmacutical Services	H 1	**H 3**	H 2	**H 3**	*
Hospital Care	**H 3**	**H 3**	H 1	H 1	*
Home Health Care	**H 3**	M	**H 3**	**H Varies**	*
Personal Care Services	H	H 2	H 2	H 2	*
Volunteer Provided Personal Care	H 1	L	H 1	M Varies	
Skilled Nursing & Intermediate Care Facility	M/L	L	M 1	M 1	
Education about HIV	**H 3**	**H Varies**	H 2	**H 3**	*
Alternative Therapies	M	M/L	H 2	M	
Hospice	H	M/L	H 2	**H Varies**	
Mortuary Services	H	M/L	H 2	H	
Dental Services	H	H 2	**H 3**	**H 3**	
HIV Counseling and Testing	**H 3**	**H 3**	**H 3**	H 2	*

Chemical Dependency	**M/C**	**Adol**	**Adult**	**G Mn**	**Priority**
Assessment	**H 3**	**H 3**	H 1	H 1	*
Detox Programs	**H 3**	M	**H 3**	**H Varies**	
Residential Programs	H 2	M 3	H 1	**H Varies**	
Non - Residential Outpatient Programs	H 2	**H 3**	H 1	**H Varies**	
Intermediate & Extended Care Residential Programs	**H 3**	**H 3**	H 1	Inadequate Info Avail	*
Ongoing Support Programs	**H 3**	**H 3**	**H 3**	**H 3**	*

Mental Health & Emotional Support

Support Groups	H 2	**H 3**	**H 3**	H 2	
Volunteer-Based Emotional Support	M 2	**H 3**	H 2	H 2	
Wellness & Recreational Programs	M 3	**H 3**	H 2	H 2	
Spiritual Support Services	M/L	L	**H Varies**	**H Varies**	
Private Individual and Family Therapy	**H 3**	M 3	H 2	H 2	
Public Sector & Sliding Fee Mental Health Services	**H 3**	**H 3**	**H 3**	**H 3**	*
Inpatient Psychiatric Services	L	L	M 2	H 1	

Housing Services	M/C	Adol	Adult	G Mn	Priority
Referral & Advocacy	H	**H 3**	H 2	M 3	
Emergency Shelter	L	**H 3**	**H 3**	**H 3**	*
Transitional Housing	M	**H 3**	**H 3**	**H 3**	*
Foster and Group Homes	**H 3**	**H 3**	H 1	L	*
Independent and Long Term Housing	**H 3**	**H 3**	H 2	M 3	*
Temporary Lodging During Medical Visits	M	**H 3**	L	L	

Supportive Services					
Homemaker Services	H/M 3	L	M	H 2	
Respite Care	**H 3**	M1	H?	M1	
Child Care	**H 3**	M1	M 3	L	
Transportation	**H 3**	**H 3**	H 2	H 2	*
Transportation from Greater MN to Twin Cities	H	**H 3**	H 2	**H 3**	

Case Management	**M/C**	**Adol**	**Adult**	**G Mn**	**Priority**
Case Management Services	**H 3**	**H 3**	**H 3**	**H 3**	*
Information and Referral	**H 3**	**H 3**	H 1	**H 3**	
Training for Informal Caregivers	**H 3**	**H 3**	**H 3**	?	
Financial Assistance					
Community Emergency Financial Assistance	H 2	**H 3**	H 2	**H 3**	
Community Emergency Needs Assistance	H 2	**H 3**	H 2	**H 3**	
Government Assistance Programs	**H 3**	**not available**	**H 3**	**H 3**	*
Employment					
Employers	M	**H 3**	**H 3**	M	*
Vocational Rehabilitation	M	**H 3**	H 2/3	L Varies	
Sheltered Work	M	**H 3**	need info	?	
Employee Assistance Programs	L	L	need info	M 3	

Payment for Services	**M/C**	**Adol**	**Adult**	**G Mn**	**Priority**
Insurance Company Coverage	**H 3**	**H 3**	H 2	**H 3**	*
Health Maintenance Organizations	**H 3**	**H 3**	**H 3**	**not preferred**	*
Private Pay for Health Care	**Inappro-priate**	L	H 2	**H 3**	
Medical Assistance	**H 3**	**H 3**	H 2	**H 3**	
General Assistance Medical Care	M	**H 3**	**H 3**	M 3	*
MN Comprehensive Health Association	M 1	L	**H 3**	**H 3**	

Legal Services	**H 3**	**H 3**	H 2	H 2	*