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Maine AIDS Plan : A Blueprint for Action

Maine AIDS Plan Coordinating Committee

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The graphic features the text 'Maine AIDS Plan' in a bold, sans-serif font. 'Maine' is in white, while 'AIDS' and 'Plan' are in black. The background is a grayscale image of a blueprint, showing architectural lines and dimensions. The phrase 'A Blueprint for Action' is written in a script font, slanted upwards from left to right, in the upper right portion of the graphic.

Maine AIDS Plan

A Blueprint for Action

**a statewide and local action plan
to improve the lives of Maine people
living with HIV/AIDS and prevent the
spread of the disease in our state**

September, 1995

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Acknowledgments

The *Maine AIDS Plan* has been a true community effort. We are deeply indebted to the many volunteers who contributed their time and expertise. (A list is included in the back.) Thank you.

The Maine AIDS Alliance has played a crucial role in the inception and administration of this project. The *Maine AIDS Plan* was supported through a grant from the U.S. Centers for Disease Control and Prevention administered by the HIV/STD Program, Bureau of Health, Maine Department of Human Services. Additional funding was provided by the Maine AIDS Alliance, the Maine Department of Education, and private donations. We sincerely appreciate their support.

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Introduction

A Blueprint for Action

AIDS, Acquired Immune Deficiency Syndrome, was first recorded in the United States in 1981. Since then, over 270,000 people in this country have died from the epidemic. In Maine, more than 200 people have died of AIDS, and another 2,000 are estimated to be living with HIV (Human Immunodeficiency Virus), the virus that leads to AIDS.

Economically, the cost of this disease is staggering: an estimated \$102,000 for each individual diagnosed with AIDS. Taking into consideration the number of Mainers believed to be infected today, a minimum of 204 million dollars will be required over the next decade for care and treatment alone.

And those are only the financial costs. The life costs are far greater: the loss of loved ones, family members, friends, relatives and co-workers.

For those who become ill, the costs are unthinkable. This virus has caused many to live and die in isolation and poverty. Thousands have had to suffer through stiff barriers of oppression just to get treatment. Thousands more have been so afraid of losing their jobs, their insurance, their homes and the love of friends and family, that they have literally wasted away without care.

The great tragedy of this disease is that it's almost completely preventable. In medical terms, we have the knowledge and the technology to stop the spread of HIV in Maine.

But HIV is not simply a medical issue. Our fear of this disease and denial of those who have contracted it have forced HIV to become an issue of basic human rights. In fact, this disease would never have progressed as far as it has if it weren't for discrimination.

With some irony perhaps, HIV has been referred to as "the equal opportunity disease." The virus has not discriminated; men, women and children from all walks of life have been infected. And even though HIV is not particularly vigorous as viruses go, it has thrived in an atmosphere of stigma, fear and misinformation.

The *Maine AIDS Plan* begins with the plain facts, such as how HIV transmission occurs and how to prevent it. In practical terms, such issues are easy to talk about and easy to understand. In fact, our society is already well aware of how to prevent HIV.

In social terms, however, we're still far behind. As a country, we have been unable to address this epidemic effectively. Yet one of the most powerful ways we can prevent HIV is by ending discrimination; by respecting people whose lives may be different from our own; and by standing together as a community in times of crisis, such as this.

These actions require more than knowledge. They take courage and commitment.

In the summer of 1992, responding to the lack of activity from our state leadership, 25 people gathered together to think about Maine's future and AIDS. Among them were health care practitioners, educators, service providers, bureaucrats, legislators, activists and people living with the disease. For four days, they shared their ideas and formulated a strategy. When the

"Every new case of AIDS could have been prevented."

—Dr. June Osborn,
former chair
of the National
Commission on AIDS
(now defunded)

conference ended, they had resolved to construct a specific, five-year course of action addressing HIV treatment, prevention and policy. This was the foundation for the *Maine AIDS Plan*.

As the Plan project developed over the next three years, eventually 200 people had come forward from all over the state. Organized into committees of shared expertise, they dedicated many hours to conduct interviews and research, and develop strategies for action as they meticulously constructed each small part of the whole. It wasn't long before volunteer and staff editors became as valuable as committee members poring over the wealth of material generated and paring it down to make the *Plan* as efficient and accessible as possible.

As the Plan project has progressed, so has Maine progressed. The HIV Advisory Committee, which provides guidance to state government, is active and proactive once again. A new resource for funds has emerged in the Maine Community AIDS Partnership, which distributed \$150,000 this year to local organizations.

Also, the statewide consumer-based HIV Prevention Community Planning Group sprang up in tandem with the Plan project, to analyze HIV prevention needs and prioritize effective strategies. Their recommendations determine how federal HIV prevention dollars will be spent in Maine. And in 1995 the Centers for Disease Control and Prevention, the federal agency overseeing treatment and prevention, renewed its commitment to HIV prevention by increasing its funding, at least temporarily, and allocating over \$600,000 to Maine for HIV prevention, more than ever before.

And the *Maine AIDS Plan*, with its many facets, is now ready to use.

The *Maine AIDS Plan* lays out a dynamic strategy for local and statewide HIV prevention, education, treatment, funding priorities and AIDS policy, targeted specifically to community leaders, administrators, health care providers, educators, employers, social service providers, and state government.

The *Maine AIDS Plan* is a resource guide with basic information, statistics and personal observations about how HIV affects different populations throughout the state, and how each sector of society can enlist its best resources to meet the challenge.

The *Maine AIDS Plan* is a profile—of courageous, caring individuals, each of whom, in his or her own way, has made us all stronger. And this *Plan* can help every one of us make a small but crucial difference in our homes, community or workplace.

The *Maine AIDS Plan* is a blueprint for action.

The *Plan* is a grassroots, community effort written by and for Maine people all across the state:

- those affected by HIV, directly and indirectly
- those working to help them
- those wanting to help
- those wanting to prevent HIV from infecting others

The *Plan* is user-friendly:

- free
- easy to use
- very readable
- divided into short sections, removable for photocopying

- includes real-life stories of what some Mainers are already doing about HIV and AIDS.

The *Plan* is a tool:

- up-to-date facts and resources
- concrete steps for action
- local, state and national resources

The *Maine AIDS Plan* is, in the end, a process.

From the beginning we made a commitment to create a Plan that would breathe and grow, not one that would sit on a shelf. We envisioned a Plan not made of pages, but of people, joining together in their communities, in their homes, in their schools, in their churches and in the places where they work.

But developing the *Plan* is only one step in the five-year strategy designed to effectively end HIV and AIDS in Maine, while ensuring dignity for those living with the disease.

As we have seen time and again through history, any group of people committed to a task can do amazing things. So far 200 Maine people have joined—and this is only the beginning. For the next year, we who have developed the *Plan* will do our best to make it known and available throughout the state.

Maine is off to a good start, as you will learn when you look through these pages. But right now we need you to join us, and take your next step. Use this “Blueprint for Action” to help stop HIV and AIDS in Maine.

The lives of people you love may depend on it.

Executive Summary

Nobody needs to be told that HIV/AIDS is a problem in America. We all know that people are becoming infected with HIV and dying of AIDS at a terrifying rate. In a state like Maine, where social problems are relatively mild, it may be easy to disregard our own struggle with this disease. But our own numbers give cause for alarm. The Division of Disease Control at the Maine Bureau of Health estimates that 1500–2500 persons in the state currently have HIV infection. Another 650 have AIDS.

Government has been reluctant to fully address HIV and AIDS. So have many social services, health insurance providers, and even some providers of health care. Trying to mount a defense against an incurable disease, and caring for all those who need treatment (including providing housing, heat, food, and the other necessities of life), is a very expensive prospect. Not to mention the enormous expense of compiling the research and organization necessary to generate a large, statewide response.

The *Maine AIDS Plan* is just such an undertaking.

After three years of committed and arduous research by an army of more than 200 volunteers from all segments of Maine society, including people living with HIV and AIDS, we are proud to have completed the most comprehensive set of strategies on HIV and AIDS the State of Maine has seen.

Through observational studies of Maine's various populations, as well as research into many public, private and professional settings that serve Maine people, we have compiled this Plan which 1) offers praise and support to those entities already meeting the challenge, 2) points out inefficiencies and potential action steps for all settings, and 3) provides pages of information and resources to facilitate action responding to this disease.

In its several parts, the *Maine AIDS Plan* offers practical and efficient steps that often require little more than a commitment to face this challenge. In its entirety, however, this document represents a powerful, well-organized, local and statewide response to this crisis. When the *Plan* is implemented fully, Maine will be well on its way to creating a compassionate world without HIV or AIDS.

HIV/AIDS in Maine: Who Is At Risk?

Anyone who engages in unprotected sex or who shares needles for injecting drugs (or otherwise piercing the skin) may be at risk for HIV, the virus that causes AIDS.

Even though HIV/AIDS has affected all segments of Maine's populations, since the late 1980s three significant epidemiologic trends have become evident:

Rural

The increasingly rural character of HIV/AIDS:

Recent AIDS diagnoses are more likely to have occurred among residents of non-metropolitan and rural communities in the central and northern areas of the state.

Women

The slow but persistent increase in the number and proportion of women with HIV and AIDS:

From one woman in 1988 to 11% of all Maine AIDS cases in 1993.

Presently, close to 40 Maine women have AIDS, and many more are HIV-infected. Because some women have such little knowledge of (or control over) their partners' habits, they may be at risk unknowingly.

Male-to-Male Transmission

The majority of recently diagnosed cases of AIDS in Maine (73%) are among men who have sex with other men:

Because HIV/AIDS is so closely associated with sex and with gay men, people living with HIV/AIDS have been shunned, discriminated against by all segments of society, and denied necessary services.

Because of society's wavering response to this disease, America's gay community itself has organized against this disease: from education and treatment efforts to the formation of service organizations and actually changing the way society treats all terminal illnesses.

HIV Affects Other Populations

Hemophiliacs

Although hemophiliacs have proportionally suffered the greatest infection rate from HIV and AIDS, since 1985 the blood products used to treat hemophilia have been tested and treated to eliminate the risk of HIV and other diseases. Still, from prior dependency on the blood supply, it is estimated that 70% of all hemophiliacs nationally are infected with HIV.

Maine Youth

Twenty-three percent of Maine persons living with AIDS are between the ages of 20 to 29; most of them probably became infected in their teens.

According to a survey conducted by the Department of Education, of the 54% of high school students who have had sexual intercourse, only 50% indicated that they (or their partner) had used a condom during the three months prior to the survey.

Fifty-six percent of high school seniors and 51% of juniors reported at least one drink of alcohol on one or more of the 30 days prior to the survey. In a separate survey, up to 46% of college students said that their having sex was due directly to alcohol use.

Approximately 25-30% of children born to HIV-infected mothers will have HIV infection.

Injection Drug Users

Sharing needles for injecting drugs accounts for 14% of AIDS cases in Maine.

Over 22% of positive HIV antibody tests in 1993 were attributed to injecting drug use.

Sex Industry Workers

In 1991, 47 Maine women and 61 Maine men were arrested for “prostitution and commercialized vice.” Risk for HIV infection is high because many are paid or forced to have unprotected sex with clients.

People of Color

Although non-white and Latino residents make up only 1.6% of Maine’s population, that same group comprises 5% of Maine’s HIV+ population.

Homeless People

On any given night, there may be 3,500-10,000 homeless people in Maine. Maine’s shelter capacity is 650 beds. Mental illness, substance abuse, and using sex to obtain food, shelter, or drugs are common issues for homeless people, thus increasing their risk for HIV.

In 1993, 16% of people testing positive for HIV antibodies were homeless.



Issues and Action Steps for Maine Settings

People with HIV, those who care about them, and those who have yet to pay much attention to HIV/AIDS can be found in all settings throughout Maine. For the sake of organization, the framers of this *Plan* arranged these settings into seven distinct categories, and then proceeded to explore ways in which HIV prevention and treatment could be most effectively carried out in each of them. It is important to realize that there is room in all Maine settings for appropriate and effective HIV awareness building, and that every effort will help. In addition, all settings can benefit by connecting with their national associations and local AIDS service organizations (ASO's). Staff of ASOs can provide a wide range of excellent resources, training, materials, speakers and model policies.

Workplaces

Nationally, 1 in 10 employers with fewer than 500 employees already has an employee with HIV infection or AIDS.

In Maine, as more persons test positive for HIV each year, the impact will increase—on employers, workers, worksites and the overall economy.

HIV affects short- and long-term disability costs, life insurance and pension plan payouts, as well as recruitment, hiring and training costs.

Violations of the rights of HIV+ persons can further reduce employee productivity and lead to lawsuits.

ACTION STEPS

- All workplace settings:
 - Implement HIV education program for employees.
 - Develop comprehensive HIV policies concerning employment and disability. Policies should address:
 - confidentiality
 - infection control
 - support services and benefits for all chronically ill employees

Educational Institutions

Adolescents and young adults are contracting HIV at higher rates than other age groups.

Lack of information does not seem to be the main problem. The Department of Education estimates show that 98% of in-school teens are aware of HIV and how to prevent it.

The challenge is getting teens to change their sexual behavior. Even though 98% of high schools and 94% of middle schools offer basic HIV education, too few HIV programs progress beyond basic information.

School communities may be unaware of the rights of an infected employee or student—or their responsibilities to them.

ACTION STEPS

- Maine Department of Education (Division of Instruction):
 - Require all education settings to have HIV policy and education programs for both staff and students.
 - Encourage education programs to promote respect for diversity and debunk HIV myths and misinformation.
- Maine Department of Education (Division of Certification):
 - Teach all candidates how to integrate HIV into the curriculum;
 - Require specialized HIV prevention training for health educators.
- All educational settings:
 - Develop a written policy concerning:
 - HIV safety procedures;
 - confidentiality for students and staff living with HIV.
 - Implement health education curricula for all grade levels that include values clarification, sexuality information and specific behavior skills for HIV prevention.
- All adults and youth in educational settings:
 - Learn and use basic universal precautions.

- Local leaders, school board members, parents, faculty, staff and students:
 - Support school health clinic services in providing sexual health screening and treatment and prevention services, including condom availability.

Physical Health Care Sites

While the health care sector has been among the most active in dealing with the prevention and treatment of HIV/AIDS, few primary care practitioners in Maine have treated a patient with HIV/AIDS. Residents in rural areas may have to travel long distances to obtain anonymous testing and counseling, or other HIV treatment.

Local health care facilities need to assume responsibility for HIV/AIDS care, from testing and counseling to end-stage nursing home or hospice care. Breaches in confidentiality are of utmost concern in rural areas, where disclosure of someone's HIV status can lead to loss of employment and insurance, and estrangement from family, friends and community.

Many health care providers need to broaden their level of comfort with gays/bisexuals and their issues.

- All health care sites and their staffs:
 - Provide risk assessment and counseling;
 - Make condoms available to the public on-site;
 - Care for persons with HIV/AIDS in your facilities.
- All health care sites are workplaces:
 - Have a comprehensive, written HIV policy in place that:
 - maintains confidentiality of employee medical records;
 - observes non-discriminatory policies for HIV+ employees; and
 - provides employees with education programs about personal and occupational exposures.
- Health care providers and third party payers:
 - Encourage home-based patient care for persons with HIV/AIDS.



Public Places

Malls, stores, barber shops, restaurants, bars, hotels, airports, beaches, civic centers, theaters, festivals, concerts are all public places.

Maine's thousands of public places represent a vast potential to focus people's attention on HIV issues through subtle and direct messages, activities, and interventions. Most public places are underused for HIV-awareness and prevention. Some public proprietors resist HIV-related programming because of fear of negative community response, or bias against homosexuality, drug use, or sexuality in general.

Public sex environments, where people meet to have casual sex—public bathrooms, adult book/video stores, bars, etc.—are important locations for HIV prevention outreach activities.

Presently such activities are carried out by AIDS organizations, and are not part of any statewide or local law enforcement program.

ACTION STEPS

- Business people, civic organizations, religious groups, AIDS service organizations (ASOs), municipal government, law enforcement, and other entities:
 - Develop HIV policies specific to your setting, and provide HIV prevention programming appropriate to the people using each setting.
 - Promote positive public relations. Projects should be creative and reflect cooperative effort.

Residential Settings

Shelters, correctional facilities, substance abuse treatment facilities, group care and foster homes, mental institutions are examples of residential settings.

People in these facilities are often at higher-than-average risk for HIV due to behavior related to substance abuse, street survival or diminished decision-making capacity. HIV-related policies and practices vary tremendously from agency to agency.

The state has not provided or clarified HIV-related policies and programs for these settings.

ACTION STEPS

- State agencies responsible for each setting (Department of Corrections, Bureau of Mental Health and Retardation, Department of Human Services, etc.):
 - Advocate for resources from the legislature and allocate the funding necessary to carry out policy and program mandates to all settings.
- All Residential Settings:
 - Work with the Bureau of Health (and other state offices responsible for HIV policy development) to institute policies for uniform treatment of residents, employees and guests who are infected with HIV.
 - Secure state funding for comprehensive HIV education and training for management, staff and clients.
 - Make sexuality education available to all clients, and condoms available to all potentially sexually-active clients in all state-funded residential programs.

Social Services, Mental Health Practitioners and Substance Abuse Treatment Providers

Service providers and counselors are in good positions to assess an individual's risk for HIV and then direct them to further assistance.

On the whole, Maine's mental health, social support services and substance abuse treatment are not uniform in terms of awareness and response to HIV.

- Legislators and government officials; mental health/social service/substance abuse treatment officials; management; workers and union leadership:
 - Provide uniform, up-to-date HIV policies for all settings.
 - Policies should address:
 - confidentiality;
 - prevention education;
 - discrimination;
 - infection control;
 - care of HIV-infected staff and clients.
 - Provide all personnel with comprehensive training on HIV, including client risk assessment.
- All state-funded and licensed facilities and practitioners:
 - Incorporate HIV risk assessment in client services.
 - Seek help from local AIDS service organizations (ASOs) to provide services more effectively.



Civic and Social Organizations and Communities of Faith

Examples of such groups are Rotary Clubs, League of Women Voters, Chambers of Commerce, Franco-American groups, Native American Nations, and state and local religious communities.

These community oriented organizations can lead the way in encouraging widespread understanding of HIV, educating people on how to prevent it, and helping those who have been infected.

Many organizations have yet to see how HIV prevention and support services relate to their mission, or how they as individuals can help.

All Civic and Social Organizations and Communities of Faith:

- Educate membership
- Explore ways to educate members of the broader community
 - Show visible support for local school sexuality/HIV education programs;
 - Sponsor public service announcements or media campaigns designed to educate the general community about HIV;
- Develop a volunteer system
 - Provide transportation for those with HIV;
 - Provide respite care service (such as housework)
 - Coordinate a volunteer workday at a local ASO or other support organization;
- Develop a community service project
 - Raise funds to help ASOs, and to help HIV victims with rent, fuel, groceries, etc.;
- Establish permanent service
 - Work toward establishing a support group and/or year-round residence for people living with HIV.



The Future

To some, HIV/AIDS may not appear to affect this northern rural state very much. Yet soon every Mainer will know someone infected with the virus or a person who has died of AIDS. We can prepare ourselves and possibly even turn this epidemic around. Each of us has a role to play. As Dr. June Osborn, former chair of the National Commission on AIDS, has said, "Every new case of AIDS could have been prevented." Implementing even a small piece of the *Maine AIDS Plan* is a step in that direction.

Facts about HIV/AIDS in Maine



Facts about HIV/AIDS in Maine



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What is AIDS?

AIDS, or Acquired Immune Deficiency Syndrome, is the advanced stage of a usually fatal illness caused by a virus. This virus is known as Human Immunodeficiency Virus, or HIV.

HIV attacks certain white blood cells that are part of the body's immune system. When the immune system is weakened by HIV, cancers, rare infections and other diseases occur, eventually causing death in most people. Approximately 5% of HIV+ people who have been infected are able to maintain their health for many years. They are referred to as long-term survivors or "non-progressors."

Not everyone who is infected with HIV develops AIDS. Some people develop chronic symptoms that vary from mild to severe. Other people who are living with HIV appear to be in good health. Some people may be unaware of their infection because they have no symptoms.

How Does AIDS Spread?

HIV, the virus associated with HIV infection, is found in certain body fluids—blood, semen (including pre-ejaculatory fluid) and vaginal secretions—in amounts that can cause infection. For infection to be transmitted, the infected body fluids of one person must enter the body of someone else. However, the virus cannot transmit through casual physical contact such as a handshake, a hug or social kiss, sneezing, or sharing a glass or bathroom.

HIV is Spread By:

Unprotected vaginal, anal and oral sex; that is, sex without using a latex condom or "dental dam" (flat latex square) correctly (preferably with a spermicide), from start to finish.

Shared use of needles for injection-drug use (of steroids, insulin, illegal drugs, etc.), tattooing or ear-piercing.

Maternal transfer to fetus or infant during pregnancy, delivery and breastfeeding.

Who is at Risk?

Anyone who engages in unprotected sex, or who shares needles for injecting drugs or otherwise piercing the skin is at risk of contracting HIV.

Protect Yourself and Others:

Protect yourself and others when engaging in oral, anal and vaginal sex. Condoms and dental dams (flat latex squares), when used properly (preferably with a spermicide), reduce the spread of HIV. It's crucial to prevent internal bodily contact with another's semen (including pre-ejaculatory fluid), blood, and vaginal secretions.

Use of drugs greatly increases the possibility of HIV infection.

Use of drugs greatly increases the possibility of HIV infection. Not only does sharing needles spread HIV, but alcohol and other drugs impair judgment and increase the chance of engaging in risky sex.

If you must inject drugs, always use a sterile needle. If you must share needles, learn how to clean them with bleach and water.

If you need help stopping your drug or alcohol use, seek treatment.

In Other Words:

Avoid blood, semen and vaginal fluid on open sores and broken skin.

Never take someone's blood, semen, or vaginal secretions into your mouth, rectum or vagina. Avoid blood, semen and vaginal fluid on open sores and broken skin.

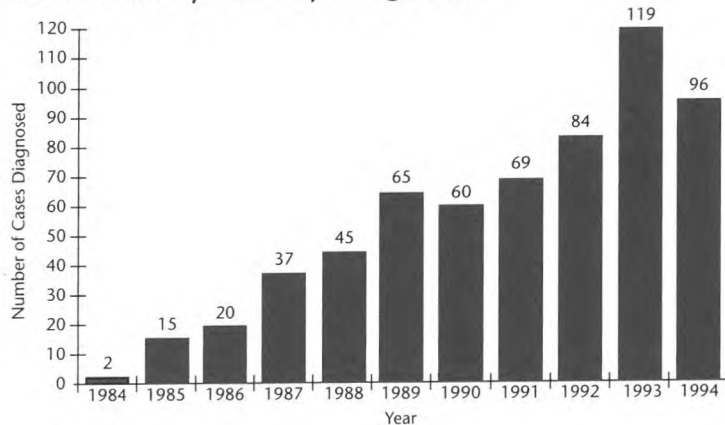
The Maine AIDS Hotline—1-800-851-AIDS—has lots of information on a variety of HIV-related concerns. Call them with questions.

Or contact:

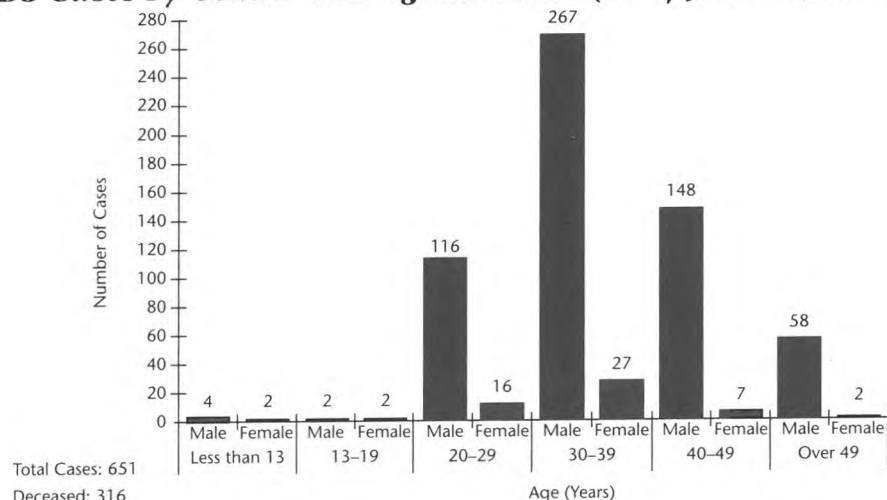
HIV/STD Programs
Maine Bureau of Health
State House Station #11
Augusta, ME 04333
(207) 287-3747

HIV/AIDS in Maine: A Statistical Summary

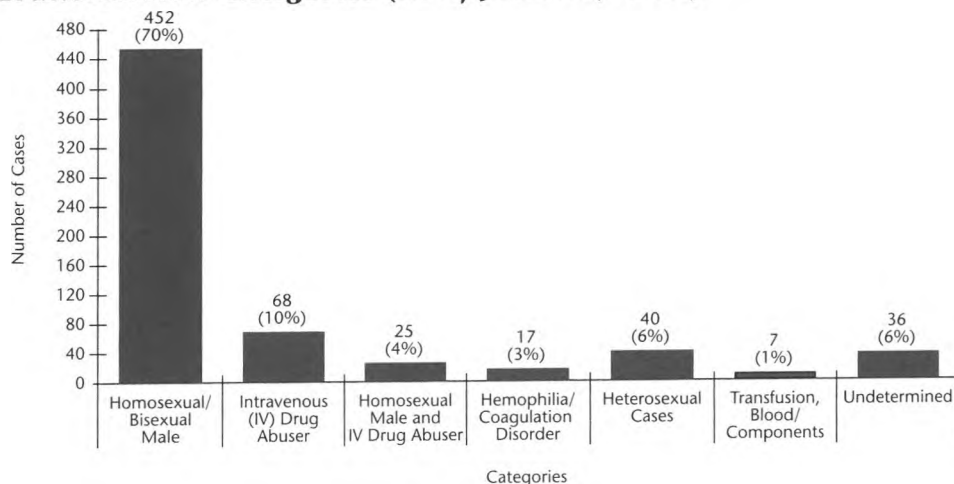
Maine AIDS Cases by Year of Diagnosis



AIDS Cases by Gender and Age in Maine (as of June 30, 1995)



Transmission Categories (as of June 30, 1995)



HIV/AIDS in Maine: What the Numbers Mean

The data summarized in these statistics is derived from AIDS case reports which physicians are required to submit to the Bureau of Health when a case of AIDS is diagnosed. The statistics do not include data on:

- Persons currently living in Maine but who were diagnosed with AIDS while living in another state;
- Persons with HIV infection who have not yet been diagnosed with AIDS.

The trend of reported AIDS cases shows that while the percentage of change from year to year may be increasing more slowly (and actually decreased in 1990 and 1994), overall the numbers are climbing.

From 1984 through June 1995, 651 Maine residents were diagnosed with AIDS. Over 315 of them have died. The Division of Disease Control at the Maine Bureau of Health estimates that 2,000 persons in the state have HIV infection. The median age at AIDS-diagnosis is 37. Two-thirds of AIDS cases reflect people who were between the ages of 20 and 39 at the time of diagnosis. This indicates that most of these people were infected in their teens and twenties, due to the long incubation period of HIV before symptoms surface.

Trends

Since the late 1980s three significant trends of HIV transmission in Maine have become evident:

Rural

There is an increasingly rural character of HIV/AIDS in Maine. Recent AIDS diagnoses are more likely to have occurred among residents of non-metropolitan and rural communities in the central and northern areas of the State. In Maine and nationally, men who have sex with other men and who live in rural areas, represent an increasing proportion of AIDS diagnoses.

Women

There is a slow but persistent increase in the number and proportion of women among the total of AIDS cases in Maine. Prior to 1988, only one case of AIDS in a woman had been reported. In 1993, 11% of Maine AIDS cases were female. Among persons testing HIV+, over 15% were female. More than 50% of women with AIDS became infected with HIV through heterosexual sex (in most cases from a male with an injection-drug history). The majority of Maine women with AIDS/HIV live outside of metropolitan areas.

Male-Male

The majority of recently diagnosed cases of AIDS in Maine (73%) are among men who have sex with other men. This trend exists in most non-urbanized areas of the U.S. where levels of injection-drug use are relatively low. In Maine, of the 651 adult cases of AIDS reported to date, 452 (77%) have had male-male sexual risk.

Prevention and Universal Precautions

Prevention:

Education, more than myth and medicine, is the most efficient protection against HIV.

Understanding that HIV can only be transmitted in one of four ways prevents hysterical and ineffective reactions to the disease:

1. HIV is transmitted by sexual contact, in semen, vaginal secretions, and blood.
2. HIV is transmitted through the sharing of needles during intravenous drug use.
3. HIV can be transmitted through contact with contaminated blood products.
4. HIV transmission can occur from mother to unborn child or through the birth process.

Universal Precautions:

Because ANYONE MAY BE INFECTED WITH HIV, universal precautions should be taken in all situations in which transmission can occur. Because any individual may transmit HIV for up to six months before they test positive for the disease, the Center for Disease Control states that precautions should be used with everyone at all times:

1. It is appropriate to wear latex gloves when contact with blood or body fluids is anticipated, and to wear gowns and masks when splashing of blood is expected. Washing hands frequently and well is important when contact with body fluids has occurred.
2. Condoms, dental dams and cellophane shields, used in conjunction with spermicide are 99% effective in preventing the transmission of HIV through sexual contact; monogamy and abstinence are 100% effective.
3. Unused needles within needle exchange programs have been an effective method of preventing the transmission of HIV among IV drug users.

HIV and Discrimination

Not many people would deny that homophobia—the irrational fear and hatred of people perceived to be gay or lesbian—is a significant feature of this country's social structure.

Although animosity toward gays is most prevalent among males, homophobia is present among males and females of all ages, and saturated into our institutions: religions, schools, government, business, military, entertainment, sports. In fact, homophobia itself seems to be one of our institutions, and along with it, the systemic sanctioning of widespread and blatant discrimination.

Such a license to discriminate means denying whole communities access to family life, religion, housing, and equal legal protection. Discrimination means oppressing individuals with threats and acts of violence that go unheeded and unpunished; discrimination can mean keeping people from working where they are most qualified.

Homophobia also impacts heavily on people who do not identify as gay or lesbian. As a social institution, homophobia maintains a very narrow definition of what is acceptable behavior. Anyone expanding their self-expression, such as wearing an earring or different clothes, or their ways of connecting with others, such as hugging friends of the same gender, does so at the risk of being labeled homosexual and perhaps shunned as a result.

By fostering acceptance of various lifestyles, gay and lesbian people could become more fully involved in their communities, and others might enjoy a broader range of self-expression, too.

In terms of this country's struggle with HIV and AIDS, the pervasive effects of homophobia have created huge barriers to HIV prevention and progress. Yet, despite such discrimination, the gay community, including many lesbians and bisexual women, was the first to respond to the AIDS epidemic, and has continued leading the way with strength, courage and compassion.

Homophobia, coupled with the American perception that HIV/AIDS is a "gay disease," may contribute to the lack of widespread HIV/AIDS education, and to the misperception that straight people don't get AIDS.

1. Basic civil rights protections must be extended to all Mainers.
2. Public information campaigns, using respected role models, should target heterosexual males and motivate them to use condoms.
3. Prevention programs among gay and bisexual men must be increased, and must address the root causes of risk behavior, such as the effects of living under oppression.
4. Non-gay groups can seek out ways to support gay/lesbian/bisexual communities.

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Confidentiality

Although not explicit in the Constitution, the Supreme Court has recognized that the right to privacy is fundamental to our concept of liberty. Implicit throughout the Bill of Rights is protection from governmental invasions into our homes, our letters and our affairs. It establishes our right to decide when, and to whom, we would like to disclose personal, confidential, and private aspects of our lives.

A medical record is exactly the type of information protected by this right to privacy. The Supreme Court recognized that individuals alone must estimate the effects of disseminating personal information about themselves, and that the government can play no role but to protect the confidential records of its citizens.

This right to privacy allows an individual to disseminate information about his/her HIV status, only when s/he feels comfortable doing so.

Even negligible, seemingly unimportant information may be kept confidential, and courts continue to try and “make whole again” those individuals whose rights to privacy have been violated. However, because of the effects of involuntary disclosure, the dissemination of highly personal information—such as an individual’s HIV status—receives even greater court protection. In *Woods v. White*, the court made clear that a person’s HIV status was exactly the type of information protected under the right to privacy, in part because of the widespread belief about how and to whom HIV is transmitted, and the way society feels about “those people”.

Confidentiality of HIV status must be the keystone of every educational, treatment and prevention program. As a philosophic, scientific and practical matter, individuals with HIV must maintain the right to decide if, when and to whom they disseminate their medical histories.

Democracy is founded upon certain ideals; freedom from governmental intrusion into the personal lives of its citizens is one of those ideals. As a practical matter, if individuals are no longer able to keep their medical records private, they may refuse testing and treatment for HIV, accepting ignorance of their HIV status over the involuntary disclosure of it.

Condom Availability in Youth-Serving Agencies

The Maine HIV Advisory Committee was created by the Legislature with 36 members appointed by the Governor from various constituencies' nominations. The Committee advises all departments and agencies of state government on prevention of HIV; services to persons with HIV, HIV-related policy, planning, rules or legislation and all fiscal matters related to HIV.

Recommendation

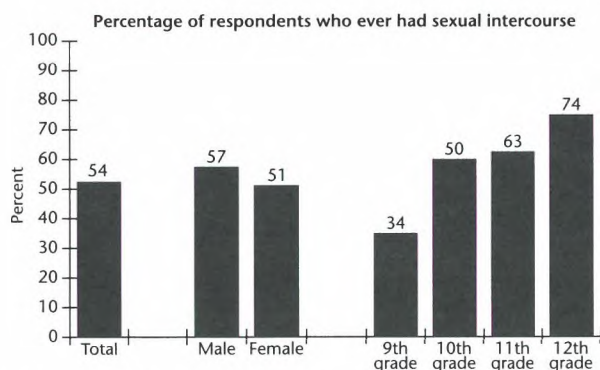
The Maine HIV Advisory Committee recently adopted the following recommendation regarding comprehensive sexuality education in youth-serving agencies and schools including condom availability:

"The ME HIV Advisory Committee recognizes that access to condoms for sexually active youth is essential to reducing the risk of HIV. The Committee recommends that youth-serving agencies including schools, should make condoms available along with comprehensive education, counseling and referral."

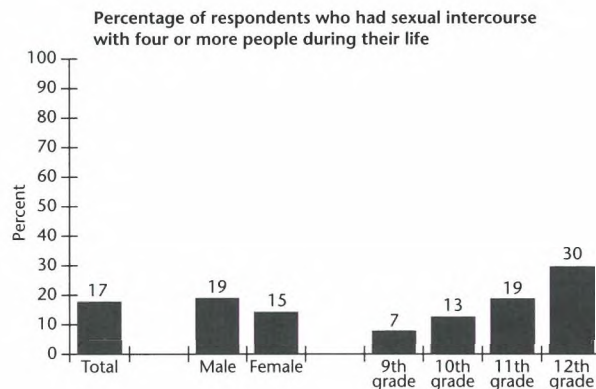
Rationale

The Committee was asked to take up the issue of condom availability in youth-serving agencies and did so as a logical follow-up to previous discussion of HIV Education and Prevention concerns. The Education and Prevention Subcommittee was charged to develop a policy to be recommended to school systems and other youth-serving agencies on condom availability for youth.

Good comprehensive education on sexuality and HIV is not consistently being provided to Maine's youth by schools. It must be. This knowledge is critical to their lives. It will empower youth and help to create a social norm of responsibility for self action and behavior. Abstinence from sexual intercourse is the safest option for Maine's youth. However, it is the shared responsibility of parents, families, and communities to provide HIV prevention information, skills and services to all youth.



1993 Maine YRBS Results



(continued)

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Condom Availability in Youth-Serving Agencies (continued)

Findings from the 1993 ME Youth Risk Behavior Study indicates that 74 percent of high school seniors are sexually active and 30 percent of this group have had four or more partners. The survey forms were completed by 2,421 Maine students in English classes in grades 9–12 in 24 cooperating public high schools. The ME HIV Advisory Committee recognizes that access to condoms for sexually active youth is essential to reducing the risk of HIV. The Committee recommends that youth-serving agencies, including schools, make condoms available along with comprehensive education and counseling.

There are several schools in Maine that have already implemented condom availability policies or are currently in the process of initiating such a policy. These school systems are to be commended for their proactive stance and should be considered a resource to school systems beginning to start the process.

A confidential survey of 350 of the 450 students enrolled at one of the school systems indicated that less than 1% of the students thought that having condoms available would increase their sexual activity.

AIDS is now the leading cause of death in men and women in the 25–44 age group. Because the average length of time before symptoms appear may be ten or more years, this means that many people are becoming infected while in their teens. In Maine, one in four people with an AIDS diagnosis is infected while in their teen years.

For more information about researched, skills-based HIV/AIDS programs please contact:

Joni Foster
State of Maine Dept. of Education
State House Station #23
Augusta, Maine 04333
207-287-5930

Personal Risk Assessment for HIV/AIDS

This questionnaire is for your information only. You do not need to write anything down unless you want to. You may want to share it with a friend or partner. These questions are to let you know what kinds of activities might have exposed you to HIV, the virus which causes AIDS.

All of the questions relate to behaviors that have occurred since 1977. You may answer "yes", "no", or "I don't know." If you have engaged in any of these high-risk behaviors even once, you should answer "yes."

SINCE 1977:

- _____ 1. Have I had anal intercourse without using a condom (rubber)?
- _____ 2. Have I had vaginal intercourse without using a condom?
- _____ 3. Have I had oral sex (mouth-penis, mouth-vagina, or mouth-anus) without protection (condom, dental dam, Saran Wrap, etc.)?
- _____ 4. Have I had more than one sexual partner?
- _____ 5. Have I had sex with anyone without knowing their past sexual behavior?
- _____ 6. Have I had a sexual partner who has had several sexual partners?
- _____ 7. Have I had sex with a man who has had sex with another man?
- _____ 8. Have I had sex with anyone who has AIDS or who has tested positive for the AIDS virus?
- _____ 9. Have I or any of my sexual partners been diagnosed with a sexually transmitted disease?
- _____ 10. Have I or any of my sexual partners shared needles or works to shoot drugs or for any other purpose?
- _____ 11. Did I or any of my sexual partners have a blood transfusion or receive blood products (example: Factor VIII for hemophilia) between 1977 and 1985?
- _____ 12. Have I or any of my sexual partners been artificially inseminated using untested semen?

If you answered "yes" or "I don't know" to any of the questions, you have engaged in risky behavior and might want to consider having an HIV Antibody Test (test for the AIDS virus). Feel free to contact the AIDS HOTLINE, your local AIDS service organization, an anonymous test site, or your personal health care provider with any questions.

Modified from *AIDS/HIV Information and Counseling in Family Planning Practice*
Planned Parenthood of Metropolitan Washington, DC 7/89

Testing for HIV

Due to new drug treatments, early diagnosis of HIV can make a significant difference in the life expectancy of an HIV+ individual. People involved in unsafe activities are encouraged by the Center for Disease Control (CDC) to stop engaging in those activities.

Everyone should also consider the benefits and detriments of taking an HIV test. Maine law requires that pre- and post-counseling be offered whenever an HIV test is administered. This counseling includes, without limitation, education on ways to prevent the transmission of HIV, information on the physical, physiological and societal effects associated with the virus, a referral network for additional services, and immediate psychological counseling and support.

There are two significantly different kinds of tests available to people who are interested in their HIV status:

Confidential Tests

Confidential tests are provided in the hospital, your doctor's office, or at your HMO. While they are called "confidential," the results of the test will be included in your official medical record and may be disclosed to a myriad of individuals:

1. your health care provider, an organization providing health care, and other health care providers whom your physician feels would benefit from the disclosure;
2. employees of the Department of Human Services, Mental Health and Mental Retardation, and the Department of Corrections if they may be responsible for your care;
3. people who see your medical record unless you state that only the portion of your medical record which does not contain your HIV infection status is authorized to be released.

However, Maine State law (5 M.R.S. @ 19203-d(5)) does state that at minimum, violations of a confidentiality policy shall result in termination of employment by the offending personnel.

Anonymous Testing

Anonymous testing occurs in one of the ten state sites established by law 5 M.R.S. 19203-b (1994). Anonymous testing means that your name is not linked to an HIV status, test result, or the fact that you have taken a test. It cannot be performed by your doctor or at an HMO. Anonymous testing prevents employers and insurers from determining whether you have had an HIV test, which may indicate to them that you feel you are participating in unsafe behaviors. Although it is illegal, potential discrimination may result from the disclosure of an HIV test. Insurance companies may limit your coverage merely because they find that a "confidential" HIV test occurred.

Employers under the ADA may require applicants to submit to a physical exam, and may include an HIV test as part of that physical. While these employers must keep the results of the test confidential, and may not legally discriminate upon the basis of that test, individuals should understand the potential impact of such a requirement.

If you have not engaged in high-risk behaviors, and continue to protect yourself from HIV infection, an HIV test is not necessary.

Statewide Organizations with an AIDS Focus

People With AIDS Coalition of Maine 696 Congress St. Portland, ME 04102 207-773-8500	Offers support, information, drop-in space, meals, and other services to people with AIDS. Volunteer-based.
Maine AIDS Alliance 112 State St. Augusta, ME 04330 207-621-2924	Consortium of the State's local community-based HIV/AIDS service organizations. Provides support, technical assistance, and coordination for member groups, advocates for HIV/AIDS issues at the state level.
HIV/STD Program, Maine Bureau of Health State House Station #11 Augusta, ME 04333 207-287-3747	Lead agency for State's public health response to HIV/AIDS. Develops, implements, and administers state and federal funds for HIV prevention activities.
Maine HIV Advisory Committee 524 Forest Avenue c/o American Red Cross Portland, ME 04101 207-874-1192	Broad-based membership committee charged with advising all departments and agencies of the State on HIV/AIDS matters. Meets monthly, open to the public.
Maine HIV Prevention Community Planning Group 112 State St. Augusta, ME 04330 207-622-2962	Consumer-based membership committee reflecting constituencies affected by the disease. Assesses HIV prevention needs, prioritizes strategies. Recommendations influence direction of federal HIV prevention funds in Maine. Meets monthly, open to the public.
Maine Community AIDS Partnership PO Box 15200 Portland, ME 04112-5200 207-874-1000	Grantmaking and fundraising partnership among the corporate sector, private foundations, and the AIDS service community to increase statewide capacity to meet demonstrated HIV/AIDS needs in Maine. Offers grants annually.
AIDS Consultation Service, Maine Medical Center 22 Bramhall St. Portland, ME 04102 207-871-2099	Provides consultation and education to health care providers throughout Maine on HIV/AIDS. Offers newsletter, consultation hotline, residencies, drug trials, program development, trainings, patient care, referrals, and resource directory.
Maine AIDS Plan 112 State St. Augusta, ME 04330 207-622-2962	Produces and promotes implementation of Maine AIDS Plan, publicizes HIV/AIDS information, fosters community activity.
The Names Project/Maine PO Box 10248 Portland, ME 04104 207-774-2198	Coordinates public showings of and Maine additions to the AIDS Memorial Quilt, an international collection of quilt panels commemorating individuals who have died of HIV disease.

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Maine Populations and HIV: A Closer Look



Maine Populations and HIV: A Closer Look



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MAINE POPULATIONS AND HIV: A CLOSER LOOK

People with HIV/AIDS

Because of the often lengthy period (8–10 years) between the time of HIV infection and the time of AIDS diagnosis, people with HIV generally experience years of good health before symptoms surface. As a result, they function in the world just like everyone else, even while carrying the virus.

Still, having a life-threatening illness usually means fear, confusion and huge medical bills. Sickness changes relations between spouses or lovers. These changes may be upsetting as people struggle to adjust to the disease process and various emotional and physical demands. Most people have to give up their jobs and other activities. The idea of leaving children and partners is very painful, adding to the burden of the illness.

Other unique problems arise. Since the development of antibacterial drugs in the 1940s, we have not had to worry about catching fatal infectious diseases. But HIV has changed that sense of security, both for the infected person and for those in contact with him or her. Because we still have no medical treatment to defeat this virus, unaware people may shy away from a person known to be HIV+. On the other hand, because a person with HIV cannot fight off infections like everyone else, he or she may choose to avoid people with colds and other diseases.



As of 1993, 85% of adults and adolescents with AIDS in the U.S. became infected through homosexual contact or from shared needle use. Seven percent were infected through heterosexual contact.

Because of our society's negative feelings about homosexuals and injection-drug users, people with HIV are sometimes as hated and feared as the disease itself. People may lose their jobs, not because they are too sick to work, but because of discrimination. Landlords have evicted tenants for having HIV.

The Americans with Disabilities Act (ADA) of 1990 now makes it unlawful to discriminate against people with disabilities—including people with HIV—in employment, education and access to public and private services (*please see Appendix*). The Fair Housing Act of 1989 prohibits discrimination in housing.





Still, prejudice has taken its toll. Even family and friends sometimes abandon people with AIDS as they discover that their loved one is gay or a drug user, as well as sick. Infected people and their families often try to keep HIV a secret for fear they will be shunned by co-workers, neighbors and friends. Medical treatment for people with HIV has been largely ineffective. A cure still appears to be a long way off. Even treatments which help people stay healthier or live longer are often experimental. When opportunistic infections eventually begin attacking an AIDS patient's weak immune system, medical interventions may also be experimental and can actually make an AIDS patient feel worse.

People with HIV may have problems obtaining adequate health care, similar to the problems experienced by many low-income, poor and uninsured people. They may be discriminated against by physicians, nurses or hospitals because of their disease, or because they are gay. Sometimes medical care providers have not been well-educated about HIV and do not know how to help.

In spite of all the difficulties and sadness that accompany HIV, some positive things can happen. Many individuals respond to this crisis by making personal changes, such as entering recovery programs, making amends with estranged family members, discovering their spiritual natures or accomplishing things they always wanted to do. Some become outspoken advocates for people with HIV or begin volunteering to help others. As in any human crisis, generous and compassionate people everywhere help in any way they can. Many communities have come together to support those with HIV in their neighborhoods, schools and churches.

The Impact of HIV/AIDS: Groups Hardest Hit

Because AIDS is determined by what you do, not who you are, anyone can potentially get HIV. However, the disease has affected specific communities at higher rates than others. Some infected populations have special issues worth noting. Later sections address the special HIV-related concerns for most Maine people. Here, however, we will discuss the special problems facing the groups hardest hit by the HIV epidemic:

- men who have sex with men;
- hemophiliacs; and
- injection-drug users.

Men Who Have Sex with Men

Worldwide, the vast majority of HIV/AIDS cases have been transmitted through heterosexual contact. But in Maine, as in the rest of the United States, gay and bisexual males have borne the brunt of this disease. Of the 651 known cases of AIDS in Maine (as of June 1995), 452 (70%) have been either gay or bisexual male and another 25 (4%) have also been gay or bisexual men who also used injection drugs.

Primarily, HIV/AIDS hits men hardest in their 20s through 40s, the years of peak sexual activity. Because these figures (from the Bureau of Health's *Maine Quarterly AIDS Update*) indicate the age when HIV/AIDS was diagnosed (rather than the age of infection), we can assume that high rates of infection actually

Because AIDS is determined by what you do, not who you are, anyone can potentially get HIV.

begin as early as the mid- to late teens. Because HIV/AIDS is so closely associated with sex and with gay men, it has been a disease unlike any other in American experience. In the first few years of the epidemic, while gay men across the country were becoming terribly ill and dying, American society, almost as a whole, chose to ignore them.

Part of society's inaction is undoubtedly due to homophobia—the irrational fear and/or hatred of homosexuality. But the greater blame probably lies less with malice than with our society's discomfort with sexuality in general. This is a country that does not know how to talk about sex. Certainly the sexual context of HIV discussions has never been part of our acceptable dialogue. Even the word “condom” is still struggling to gain acceptance—and condoms have been known, from the start, to be among the best preventions against HIV.

For gay men with HIV or AIDS, the repercussions of the disease have been doubled. Rather than receiving compassion from families and communities, state-of-the-art treatment from the medical field, and hope that researchers are uniting to find a cure, men with HIV and AIDS have been shunned, discriminated against by all segments of society, and forgotten.

Because of society's inability to respond, the United States gay community itself has mobilized against this disease. From massive education and treatment efforts to the formation of service organizations and the transformation of the way society treats all terminal illnesses, the gay community has paved the way for a global fight against this disease.

Hemophiliacs

Hemophilia is a rare, life-threatening blood coagulation disorder predominantly affecting males. The blood lacks the ability to clot, so bleeding is uncontrollable. The condition requires transfusions of blood-clotting factors pooled from multiple blood donors.

Since 1985 the blood products used to treat hemophilia have been tested for HIV and heat-treated to eliminate the risk of HIV and other diseases. As a result, HIV infection through clotting-factor transfusion has been almost completely eliminated. But in the very early days of the HIV epidemic, before an HIV blood test had been developed, some hemophiliacs were forced to choose between dying of untreated hemophilia or using possibly HIV-contaminated blood products. The legacy of those days is with us today. It is estimated that 70% of all hemophiliacs nationally are infected with HIV. In Maine, hemophiliacs constitute 3% (18) of AIDS cases.

While some hemophiliacs are gay, the majority are heterosexual men and boys, many of whom have girlfriends, wives and children to whom they have unknowingly passed the virus. When HIV was first recognized in the early 1980s, many hemophiliacs with HIV were afraid to disclose their illness for fear that people would think they were gay.

At the time, even hemophilia advocates and physicians did not publicly discuss HIV infection issues. As a result, many of these men and their families became even more isolated than they already were. They were not benefiting from the education and support services being offered by the active supporters of gay men with HIV.

Of course, many hemophiliacs with HIV are boys who attend public school. Over the past several years we have seen their stories in newspapers or on national television. The most well-known was Ryan White. Many of these



Even the word “condom” is still struggling to gain acceptance—and condoms have been known, from the start, to be among the best preventions against HIV.

It is estimated that 70% of all hemophiliacs nationally are infected with HIV.

children have suffered severe discrimination in their communities and were forced from schools and home towns.

Thankfully, the epidemic of HIV infection through blood transfusion has passed. Hemophiliac families continue to address issues such as living with two life-threatening diseases, physicians' past accountability, and practicing safer sex to prevent transmitting HIV infection.

Intravenous Drug Users

The majority of injection-drug users live in large urban areas in the Northeast, such as New York, Newark, Philadelphia and Boston. Groups of injection-drug users also live in areas such as Portland, Lewiston, Bangor, the St. John Valley and coastal communities, although efforts to establish how many have been largely unsuccessful.

As of 1993, 25% (81,000) of all AIDS cases in the U.S. were caused by sharing HIV-contaminated needles. In Maine 45 cases have been documented.

Many HIV and drug-use prevention strategies have been tried: needle cleaning, needle exchange, needle prescription, drug and HIV prevention education in schools, and drug-rehabilitation programs. Maine is one of the many states which allows for non-prescription purchase, by adults, of IV needles. Areas with this type of policy show a reduction in needle-sharing, which lessens the risk of HIV through drug injections. Still, new U.S. cases of AIDS related to injection-drug use rose over 26,000 in 1993.

Because the use of certain drugs is both illegal and socially unacceptable, many users become estranged from their families. The often destructive results of drug use, such as criminal activity, loss of employment and personality changes, may make the isolation even worse. Many users live in extreme poverty and support themselves and their habit as best they can through theft, drug dealing, prostitution and exchanging sex for drugs. Some are homeless, and all are at risk not only for arrest and incarceration but for HIV.

There are, of course, injection-drug users who do not fit this description. They may have responsible jobs and lead otherwise exemplary lives. If injection-drug users are cleaning their works correctly, or if they are not sharing needles, then there is little or no risk of acquiring HIV and other infectious diseases (they may, however, be at risk for abscesses and other diseases caused by the injection process).

Users often don't discover they are HIV+ until they end up in federal prison. Medical care for prisoners in general is not of high quality. For those with HIV it can be abusive or nonexistent. Stories abound about HIV+ people who have died in prison much sooner than necessary because they were deprived of even basic care. In addition, prisoners with HIV may be in danger of violence at the hands of other prisoners.

HIV+ prisoners who are drug addicts must also cope with unmonitored detoxification. While many an ex-user attributes his or her recovery to having been imprisoned, the withdrawal and recovery process can be very difficult.

HIV prevention information and education for injection-drug users probably is most effectively delivered by those who have been involved in drug use themselves.

Some are homeless, and all are at risk not only for arrest and incarceration but for HIV.

Resources for People with HIV/AIDS

American Civil Liberties Union AIDS Project
132 West 43rd St., Box ADA
New York, NY 10036

Maine AIDS Alliance
112 State Street
Augusta, ME 04330
207-621-2924

Maine AIDS Hotline
1-800-851-AIDS

Maine Hemophilia Treatment Center
Maine Medical Center
Portland, ME 04101
207-871-2871

Office on Substance Abuse
State House Station # 159
Augusta, ME 04333
207-287-2595

NAPWA News
National Association of People with AIDS
PO Box 18345
Washington D.C. 20036

People with AIDS Coalition National Hotline
1-800-828-3280

People with AIDS Coalition of Maine
696 Congress St.
Portland, ME 04102
207-773-8500

Positively Aware
Test Positive Aware Network
1258 West Belmont Ave.
Chicago, IL 60657-3292
312-472-6397

PI Perspective

Project Inform
1965 Market St, #220
San Francisco, CA 94103
1-800-822-7422

The AIDS Project Street Outreach Program
22 Monument Square, 5th Floor
Portland, ME 04101
207-774-6877

Understanding HIV: Consumer Guide
CDC National AIDS Clearinghouse
1-800-458-5231



Local AIDS service organizations are listed on page 261.

Co-workers, Caregivers, Family, Friends

Of the 362,000 women, children and men infected with HIV in the United States as of 1993, over 60% have died. Alongside these many thousands are even more lovers, family members, friends and professionals who have cared for and suffered the loss of their loved ones and clients. Since the early days of the AIDS epidemic it has been said that someday everyone will know someone with HIV or AIDS. With cases increasing each year, this prediction is fast becoming a reality. It seems important, therefore, to understand some of the issues related to living with and helping someone who is living with HIV.



Helping the person with AIDS or HIV

Facing the long term illness and probable death of a loved one can be frightening and emotionally overwhelming. Parents of a person with AIDS may have lost their own parents, but most are quite unprepared to lose a child, even if that child is an adult. For many young people who have a friend with AIDS, it may be the first time knowing someone who is very sick or dying.

Even adults may not know how to help a close friend or lover who is faced with dying. Here are a few suggestions, many excerpted from some of the resources listed at the end of this section:

1. Don't avoid your friend Be the friend or loved one you've always been, especially now when it is most important.
2. Call before you visit. Your friend may not be up to a visitor that day. Don't be afraid to phone again and visit on another day
3. Tell your friend what you'd like to do to help. If he or she agrees, do it. Keep any promises you make.
4. If your friend is a parent, ask about and offer to help care for any children.
5. If your friend wants to talk about death, allow this, even if it is hard for you. It will be very important to her/him.
6. Protect your friend from infection. If you have a cold or another infectious condition, stay away from your friend, or take measures to prevent passing it on.

Taking care of yourself

1. Know your limits. Decide how much you can reasonably give of yourself, and try to stick to it. This advice might not work for everyone. It may not be possible for some caregivers, especially parents and spouses/partners, to limit their involvement. They may not want to be away from their loved one.
2. Ask for help. Sometimes you may feel overwhelmed or just unsure how to handle some problems or situations. Ask friends, professionals or volunteers for assistance.
3. Take some time off. Again, this may be easier for some than others. Remember that if you are worn out you may not be able to help as well as you want to.
4. Join a support group or get some counseling. Sometimes just talking with others can be a relief. If you're having a problem, or if you are depressed or angry, often a professional counselor can help.
5. Protect yourself from infection. Learn universal precautions. A person with AIDS can develop diseases, like tuberculosis, that can be passed along to others without direct contact.

Nurses, Social Workers, Volunteers, Doctors

The overwhelming nature of HIV has made it very hard for providers of social service and health care. In addition to seeing so much human misery, socioeconomic factors and society's sometimes heartless response to the illness can leave caregivers feeling powerless and depressed. Many professionals and volunteers have burned out as a result of their HIV-related work.

From the start, there has never been adequate knowledge about this disease, nor enough money for research, social services, financial assistance, education or medical care. Professionals and volunteers have felt unprepared personally and in their work to provide the best care to persons with AIDS.

To some, HIV and the people who have it represent a lifestyle that is distasteful. To others, the disease represents a looming danger that medicine and technology cannot fix.

As providers become increasingly involved with HIV/AIDS in both medical and emotional ways, it is important to maintain a healthy perspective about one's relationship to the disease.

Helping the person with AIDS

1. Keep informed about HIV. While it's impossible for providers to know everything about HIV, several data bases are available for little or no cost. Consult with the experts, including the AIDS Consultation Service at Maine Medical Center, the State Bureau of Health, and your local AIDS service organizations (*see Resources*).
2. Be as non-judgmental as possible. Sometimes patients/clients may engage in behaviors or may have gotten their infections in ways you disapprove of. It's important not to let your negative feelings prevent you from helping; keep them to yourself. If you can't, refer your client/patient to another provider.
3. Be a good listener. It's easy to get caught up in the technology of medical and nursing care. Sometimes your patient just needs you to listen, or to answer questions and be caring.
4. Make your relationship with your client/patient a partnership. Many patients, if given the chance, want to help plan their own care and treatments. Others want decisions made for them. Take your cue from them. Share your information, thoughts and feelings together.
5. Protect the person with HIV/AIDS from infection. Follow universal precautions and other infection-control procedures.
6. Make yourself aware of other community resources available to the person with HIV/AIDS in your care. While personalized health care is crucial, many additional services can tremendously improve the quality of life for someone who is ill, while lessening the load on the primary health care provider.

Taking care of yourself

1. Recognize your limits. Professional knowledge and technology can't fix everything.
2. Know when and how to ask for help. Consult with other professionals. Sometimes your client/patient will offer you direction.
3. Vary your practice. Sometimes this may not be possible or appropriate. Some practitioners, however, have found that if they also see patients with problems other than HIV, they may feel less overwhelmed.
4. Join a support group, or start one. Many professionals who are strongly affected by the deaths and the frustration that go along with HIV work have found help in the group support of co-workers.
5. Take time off. It may seem impossible to find time for a vacation or to use some of your accumulated "comp" time. But for your own sake and that of your patients and family, make the time to get away from your work.
6. Protect yourself from infection. Follow universal precautions and other infection control procedures.

Resources for Co-workers, Caregivers, Family, Friends

Materials

Caring for Someone With AIDS: Information for Friends, Relatives, Household Members, and Others
Who Care for a Person With AIDS at Home
 CDC National AIDS Clearinghouse
 1-800-458-5231

HIV and the Health-Care Worker
 Service Employees International Union, AFL-CIO
 1313 L Street N.W.
 Washington, DC 20005
 202-898-3200

Kairos—magazine for caregivers
 114 Douglass St. San Francisco, CA 94114-1921

National Network of Libraries of Medicine/NE
 Region—offers 3 medical AIDS data bases free of charge (must have "Grateful Med" software)
 University of Connecticut Health Center
 263 Farmington Ave
 Farmington, CT 06030-5370
 203-679-4500

OSHA Bloodborne Pathogens Standard
OSHA Proposed Airborne Pathogens Standard
 available through:
 Bureau of Health
 Augusta, ME 04333
 207-287-3747

When a Friend Has AIDS.
 Chelsea Psychotherapy Associates
 80 Eighth Avenue, Suite 1305
 New York, NY 10011

Organizations

Maine Council of Churches
 Interfaith Council on AIDS
 15 Pleasant Avenue Portland, ME 04103
 207-772-1918

AIDS Consultation Service, ODP
 Maine Medical Center
 22 Bramhall Street
 Portland, ME 04102
 207-871-2099

American Red Cross—Portland Chapter
 524 Forest Avenue
 Portland, ME 04101
 207-874-1192

Center for Grieving Children
 PO Box 1438
 Portland, ME 04104
 207-799-1112

Men and HIV

In Maine, as in the rest of the United States, males are affected by HIV/AIDS to a far greater degree than are females.



As a rule, most men know little about sexuality. Consequently, they have limited experience discussing sexuality, either theoretically or practically, as it relates to their own lives. Even male health care providers sometimes have little educational background in human sexuality, and may be uncomfortable discussing related subjects with patients.

Male socialization in America rewards aggression, competition, courage and strength. Contrarily, traits that are seen as more feminine—sensitivity, compassion, passivity, openness—are condemned. Consequently, boys and men who are perceived as gay, bisexual or effeminate will probably suffer verbal or physical abuse, often inflicted by other males who might be schoolmates, teammates, family members, and even teachers and spiritual leaders. Homophobia, the irrational fear and/or hatred of people who are perceived as homosexual, is a common feature in American society.

Clearly, gay and bisexual men are rarely valued in the United States. More often, the lives of gay males involve fear of discrimination and physical violence, as well as fear of discovery by family, friends and employers. In fact, so pervasive is homophobia in American life, that gay and bisexual men often incorporate hostile societal attitudes into their feelings about themselves.

Men and HIV: The Facts

HIV/AIDS is a leading killer of Maine men:

- Since 1991 AIDS has been the fifth leading cause of death among young adult men in Maine.
- In Maine, adult men (over 18) constitute 40% of the population.
- Ninety-three percent of adult Mainers with AIDS are male.
- Eighty-five percent of positive HIV antibody tests (1993) were among men.

Gay and bisexual Maine men have borne the brunt of this epidemic:

- Estimates of the gay/bisexual male population range from 5% (30,000) to 10% (60,000) of adult men in Maine.
- Approximately 80% of AIDS cases have been among men who have sex with other men. This includes a small number (4%) of gay/bisexual men with both sexual and injection drug-related risk.

Straight men are also at risk:

- Heterosexual male drug use accounts for 7% of AIDS cases among Maine men.
- One percent of male AIDS cases is attributed to female-to-male sexual transmission.
- Both straight and gay/bisexual men have also been infected through infected blood and blood products (approximately 5% of AIDS cases).

Sexual Practices and Attitudes

When many men think of sex, they think of oral, vaginal and anal intercourse. Lower-risk sexual activities that do not involve intercourse may be less appealing, or may be unfamiliar. Many men report difficulties with condom use due to decreased sensation, loss of erection, or loss of spontaneity. Because correct and consistent condom use is one of the primary means of reducing the risk of HIV transmission among sex partners, condom use must be promoted heavily for all men, as both expected and erotic.

Condom use must be promoted heavily for all men, as both expected and erotic.

Labels: Gay, Straight, Bisexual

Most men identify themselves as gay, straight or bisexual. We often make assumptions about sexual behavior based on these labels. In practice, however, behavior may be inconsistent with labels. For example, some married or self-identified “straight” men engage in sex with other men. A man who identifies as “gay” may have sex with women. It’s important for health care providers and counselors doing risk assessment to look beyond labels, or they might miss important information regarding the client’s sexual practices, which may involve other male or female partners.

Some married or self-identified “straight” men engage in sex with other men.

Men Who Have Sex with Women

The majority of men in Maine self-identify as straight, and if sexually active they have female partners. Although AIDS has hit America hardest in its gay populations, the vast majority of HIV/AIDS cases worldwide are the result of heterosexual transmission. Because many heterosexual men perceive themselves to be at low risk, they may not have learned basic information on HIV/AIDS, and they may not be using safer sex methods.

Men Who Have Sex with Both Men and Women

Some men experience an erotic and affectional orientation to both men and women. They may engage in sexual activity with men only, women only, both or neither. They may have male and female sex partners concurrently, or alternately.

Men who have sex with both men and women may identify as gay, straight or bisexual. They may not classify themselves at all, perhaps in response to the inadequacies of these labels in describing the depth or variety of their feelings, or because of the prejudices that self-identified bisexual people may face.

One specific prejudice concerning HIV/AIDS is that bisexual men are responsible for spreading HIV from gay men to straight women. While it is true that women have become infected from unprotected sex with bisexual men, the majority have been infected from sharing injection-drug needles or from having unprotected sex with straight men who share needles.

Self-identified bisexual men may also face prejudice from others who identify as gay. Bisexuality may be viewed as a cop-out, as an attempt to seem “straight,” or as a phase.

Some men who self-identify as straight, but who sometimes have sex with other men, may be ashamed of their sexual behavior to the point of not acknowledging it, even to themselves—or of feeling that HIV would be more

Although AIDS has hit America hardest in its gay populations, the vast majority of HIV/AIDS cases worldwide are the result of heterosexual transmission.

or less what they deserve. It may be as difficult to convince these men that they are at risk as it is to convince them to protect themselves.

Men who have sex with both men and women, and who have developed a positive self-identity, are most likely to protect themselves and their partners.

There is a growing movement of self-identified bisexual men and women in Maine. This open acknowledgement offers hope for the associated positive impact on self-esteem and HIV risk reduction.

Men Who Have Sex with Men

By far, the majority of AIDS cases and HIV infection in Maine are found among men who have sex with men—most of whom self-identify as gay. Over a decade of infection, illness, grief and loss has devastated gay communities nationwide. This trauma may affect risk behavior. With such unremitting tragedy in so many lives, infection may be perceived as inevitable.

In cities like New York and San Francisco, during the 1980s, comprehensive HIV prevention programs among gay men resulted in safer sexual behavior. However, few prevention efforts have been made in Maine, and there is no data suggesting that Maine gay men have made and sustained the behavior changes necessary to reduce their risk. Contrarily, recent data from the cities suggest that younger gay men may be engaging in risk behaviors in large numbers, and that older gay men who had once changed their behavior may not have sustained those changes.

One of the keys to risk reduction is the development of a positive self-identity as gay, straight or bisexual. However, in Maine, many gay men are “closeted” and virtually invisible. The rural nature of Maine, combined with the hidden population of closeted gay men, and the limited venues for social and political gatherings, creates a challenge for HIV prevention and education among gay men. Studies have demonstrated that participation in organized community activities with other gay and bisexual men—whether singing in a chorus, demonstrating at the State house or bowling—has a positive impact on self-identity.

One of the keys to risk reduction is the development of a positive self-identity as gay, straight or bisexual.

HIV Information

Because few males in our society have had experience discussing homosexuality in an unemotional, straightforward way, homosexuality is, for many men, a very uncomfortable topic. Such discomfort may heighten barriers to education and prevention.

Health care providers, therapists and educators need to become better informed of the various social and cultural implications of sexuality. At the same time, these service providers need to be more comfortable with gay and bisexual men and their particular issues.

AIDS service organizations can work to help all gay and bisexual men, by taking advantage of their organizational capacities to foster more open and visible community activities for this population.

Prevention programs among all gay and bisexual men need to be increased and address the systemic issues at the roots of risk behavior. At all levels, gay and bisexual men should receive the message: “Your lives are worthwhile. You have an important role in Maine’s future.”

Heterosexual males need to understand their own risk. Public information campaigns, using respected role models, should target and motivate them to use condoms. Other public service campaigns could begin talking about the destructive effects of homophobia on the whole of our society.

Homophobia as a Barrier to HIV Prevention and Education

Because of the pervasive effects of homophobia throughout society, HIV-prevention programs for gay and bisexual men in Maine (which have been deemed "controversial") are woefully inadequate. These effects also contribute to the lack of widespread HIV/AIDS education, and to the misperception that straight men don't get AIDS.

Risk reduction practices may have become stigmatized: "If I use a condom, my partner will think I'm at risk (gay)." Some men may even erroneously believe that it is impossible to become infected from a female partner.

Some straight men who are living with HIV/AIDS may feel uncomfortable with HIV-related services (for example, support groups), which at this time serve mostly gay and bisexual clients. This may reflect both discomfort with homosexuality and/or the fear of being perceived as gay. Straight men with HIV/AIDS have experienced discrimination because they have been assumed to be infected with a "gay disease" and mistreated accordingly.

Some men may even erroneously believe that it is impossible to become infected from a female partner.

Resources for Men and HIV

Men Who Have Sex With Men

APEX

PO Box 4743
Portland, ME 04112
207-282-8091

Community Pride Reporter

142 High St.
Portland, ME 04101
207-879-1342

HIV Prevention and Men Who Have Sex With Men

CDC National AIDS Clearinghouse
1-800-458-5231

Maine Lesbian Gay Political Alliance
1-800-55-MLGPA

Maine Bisexual People's Network

PO Box 10818
Portland, ME 04104

Northern Lambda Nord

Social and educational programs serving lesbian, gay and bisexual people in northern Maine
207-498-2088

General

HIV/STD Programs, ME Bureau of Health

State House Station # 11
Augusta, ME 04333
207-287-3747

Women and HIV



Because they have been raised to go along with what men want, women may be unable to demand, or even to ask, that their partners practice safer sex.

HIV does not impact on women the same as it does for men. The differences have a lot to do with the ways women and men are treated in American society. For example, we know that girls are treated differently from boys in public schools. Women still earn much less than men do. Despite increasing numbers of women in certain professions, the highest levels of those professions remain reserved for men. Even in jobs where women are well-paid professionals, they are sometimes subjected to sexual harassment by male bosses and co-workers.

In a similar vein, women do not have the same sexual choices as men. They may be sexually abused by husbands, brothers or other males. They may be physically assaulted. Or they may have husbands or boyfriends who refuse to use condoms. Women may not even be able to choose whether to have children, when to have children or how many to have.

Sexual Risks

All of these factors make it more difficult for women to protect themselves from getting HIV. Because they have been raised to go along with what men want, women may be unable to demand, or even to ask, that their partners practice safer sex.

This kind of relationship can be hazardous when a man is sharing needles for injection drugs and then having unprotected sex with his wife or girlfriend. These women are in great danger of getting HIV.

Other women, whether they know it or not, may be with men who are bisexual. If these men have unprotected sex with other men and then have unprotected sex with their female partners, then these women are at a high risk for HIV infection.

For many years, HIV experts said that lesbians were not at risk for HIV. This is not true. If a woman is an injection-drug user sharing needles, or has had unprotected sex with an infected male partner or received a contaminated blood transfusion, she can get HIV whether she is a lesbian or straight. Lesbians who do not practice safer sex with their female partners are also at risk for HIV.

Sexual Abuse

Women raped or sexually assaulted by men are at risk for HIV. Girls and women of all ages may be sexually abused by strangers or by men they know, including family members. Sometimes these men may be at high risk for HIV and sometimes not. In these situations the women have little or no chance to protect themselves from getting sexually transmitted diseases from these men. Because they may be afraid to tell someone what is happening to them, especially in the case of child sexual abuse, they may be raped over and over again, greatly increasing the chance of infection.

Occupational Risks

Nurses, surgeons, laboratory workers, dental hygienists, some prison or police employees and emergency medical workers are viewed as having some risk of getting HIV from others' blood while at work. A disproportionate number of nurses and dental hygienists are women. The Centers for Disease Control reports that 42 workers in the U.S. (.01% of AIDS cases) have contracted HIV through occupational exposure. Generally, however, people are probably at higher risk of infection by not practicing safer sex with their partners than they are by being exposed at work.

People are probably at higher risk of infection by not practicing safer sex with their partners than they are by being exposed at work.

Ethnic and religious influences on women's risks

Some religious and ethnic groups hold strict beliefs that include a very narrow view of women's roles and activities. Many regard the man as the absolute head of the household and the woman as subordinate, with duties related to home, children and worship. Even birth control, abortion and sexual practices are matters that, in many traditions, are decided by men. Women often may not work outside the home, and girls are not encouraged toward higher education or careers. In some cases, women may not even allow themselves to be examined by health care professionals, especially males. Women who live with these religious and cultural rules have little say in protecting themselves against getting HIV from their men, who may not be bound by the same customs.

Health Care

Three major areas related to women and HIV have been neglected by health professionals:

- Identification of women who are at risk for HIV;
- Medical treatment of women who are infected with HIV;
- Research into both prevention and treatment.

For many years, health care providers were not well-informed about HIV. They often thought that only gay men and male injection-drug users contracted AIDS. Even if they had known the typical manifestations of the disease, at times the symptoms of HIV in women are different from those in men. In addition:

- Not all doctors considered sexual abuse of girls and women a risk factor;
- Sexually-active older women were not considered to be at risk for HIV because of their age;
- Teenage girls were thought not to be at risk because of their age; and
- Married women were not seen as being at risk because they were married.

Because of this lack of knowledge, the HIV status of many women who were infected or actually sick with HIV was not discovered. Also, some doctors did not educate their female patients about their risks or about safer sex. Some did not know how to bring up the topic of sex, or they were afraid to offend their patients.

Treatment of women is not as well understood as the treatment of men. Until a few years ago, there was no research into the medical aspects of HIV

or into drug treatments that are helpful to women. Now more experiments are being conducted to find treatments for women and children, as well as for men. Similarly, most education programs and materials have been directed at gay men and male injection-drug users. Some of these, especially those for gay men, have proved to be at least somewhat helpful. Much more research needs to be done to find effective ways to educate women about HIV.

Women and HIV: The Facts

HIV is increasing among Maine women:

Up from a total of two AIDS cases among Maine women in 1989, now close to 40 Maine women have AIDS, and many more are HIV-infected.

- Over 10% of Maine AIDS cases reported in 1993 were among women.
- In 1993, over 15% of positive HIV antibody tests were among women.

HIV affects both rural and urban women:

- More than 50% of women diagnosed with AIDS in Maine live outside Maine's three metropolitan areas. HIV infects young women.
- Maine women with AIDS tend to be younger at the time of diagnosis (median age=29) than do men (median age=35). This difference may reflect a younger age at the time of acquiring HIV infection, a more rapid disease progression, or both.

HIV affects childbearing women and children:

- Each year approximately 16,000 women give birth in Maine hospitals. Over the past five years, an average of four childbearing women per year have had HIV infection.
- Approximately 25-30% of children born to HIV-infected mothers will have HIV infection.

Primary modes of transportation:

- HIV is transmitted sexually (60% of cases).
- HIV is transmitted by sharing needles for injection-drug use (33% of cases).

HIV Information

Information and education for women and girls must take into account the many difficult issues facing women in our culture. In addition to addressing the concerns described above, an important part of HIV education must relate to helping women gain the self-confidence and economic independence necessary to take greater control of their lives.

Resources for Women and HIV

*Athena: a newsletter for women affected and infected
by HIV in Maine*

The AIDS Project
PO Box 5305
Portland, ME 04101
207-774-6877

Center for Women Policy Studies,
National Resource Center on Women and AIDS
2000 P St. NW, Ste. 508
Washington, DC 20036
202-872-1770

ME First! Medical Manifestations of HIV in Women
New Jersey Women and AIDS Network
5 Elm Row
New Brunswick, NJ 08901
908-846-4462

*The Invisible Epidemic: The Story of Women and
AIDS* by Gena Corea, Harper Perennial. 1992

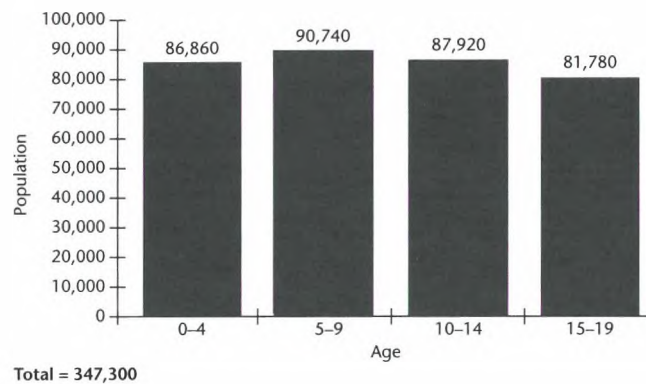
Women and AIDS Clinical Research Guide
San Francisco AIDS Foundation
333 Valencia, 4th Floor
San Francisco, CA 94103
415-864-4376

Women and AIDS Resource Network
P.O. Box 02025 Brooklyn, NY 11202
718-596-6007

WORLD: Women Organized to Respond to Life-
Threatening Diseases
PO Box 11535
Oakland, CA 94611
510-658-6930

Young People: Infants, Children, and Adolescents

In 1991, the Maine Office of Vital Statistics estimated that 347,300 children and youth up to age 19 lived in Maine, representing the following age groups:



As of July 1995, six children and four adolescents were diagnosed with AIDS in Maine. Many more may be living with HIV infection.

Infants

Up until a few years ago, almost all HIV-related research was directed toward white adult males. Few women and children were admitted to research projects before 1990. Even now, many doctors remain uninformed about pediatric AIDS treatment, and HIV+ children who live in Maine frequently travel to Boston or Washington, DC, for their medical care.

Although there are exceptions, infants generally acquire HIV in one of two ways: either from their infected mothers during birth or breast feeding; or from transfusions of HIV-contaminated blood or blood products. Because blood has been tested for HIV since 1985, nowadays transfusions rarely cause HIV.

Nationally, as of 1993, 4,900 cases of AIDS had been diagnosed in people under the age of 13. Eighty-eight percent were babies born to infected mothers; 11% were recipients of contaminated blood transfusions (4% hemophiliac). In Maine, there have been two hemophiliac cases and four infected infants born of HIV+ mothers.

Children who are infected with HIV face special problems that are made even worse if their parents are also HIV+. (This is often the case when children are born to parents who are injection-drug users.) These parents may not be able to care for their children. Some of them may require considerable medical care themselves or may die of AIDS (or for reasons connected with their drug use).

Only about 25-30% of babies born to infected mothers will themselves be HIV infected. Still, hospital wards in large cities are full of HIV+ babies who remain there for years in the care of nurses and volunteers.

For those children with HIV who survive until school age, and for boys at risk because of hemophilia, school presents additional challenges. School

employees, neighbors and parents may be overly concerned about their contagiousness. HIV+ students and their families may be shunned or harassed as a result of ignorance. It takes special attention on the part of schools and towns to respond with care to HIV-infected children and their parents. So far in Maine, children and families have been embraced by their communities.

Children

Some aspects of young people's activities, their position in society, and how they are treated by adults can put them at risk for HIV.

Although children are constantly involved in the process of learning, their reading, writing and other communication skills are still in the beginning stages. Their inherent curiosity may lead them to question certain things, like HIV, and adults may not provide adequate answers. Young children have little or no control over some aspects of their lives. For example, they may be sexually abused by adults, and not know what to do about it.

Adolescents

A quarter of the people with AIDS in Maine may have been infected in their teens. Some young people become infected through sexual abuse, injection-drug use or, more likely, through voluntary sexual activity as teenagers. Some young people will become infected because of trading sex for drugs, shelter or money.

In addition to the factors described above, adolescents have some other new experiences to address. As they move closer to adulthood, they are beginning to separate from their families. They may be experimenting with alcohol, drugs and sex, or they may have friends who are. Intense peer pressure causes most teenagers to go to great lengths to gain the approval of their friends, including taking ill-considered risks. In short, they believe that nothing can happen to them.

During adolescence girls begin to realize that, in our society, women are not treated as well as men. This knowledge can sometimes make them feel powerless and unvalued, especially if they are not encouraged by their families. These feelings can contribute to the inability to take responsibility for sexual decision-making, or to the need for attention through risk-taking behavior.



Twenty-three percent of Maine persons living with AIDS are between the ages 20 and 29; many of them became infected in their teens.

Infants, Children, Adolescents and HIV: The Facts

HIV Is Present Among Maine Children and Youth:

- Of approximately 15,000 live births per year in Maine, two to four babies are born to women with HIV infection. Because the rate of perinatal transmission is between 25 and 30%, the Maine Bureau of Health estimates that four to five HIV-infected infants were born in Maine between 1988 and 1993.
- Twenty-three percent of Maine persons living with AIDS are between the ages 20 and 29; many of them became infected in their teens.

Maine Youth Are Sexually Active:

- According to a survey commissioned by the Department of Education, 54% of high school students have had sexual intercourse, including 74% of seniors and 63% of juniors. Thirty percent of seniors reported four or more partners.
- In 1991, 5,234 adolescent females (through age 19) became pregnant.
- Seventy percent of school-aged but out-of-school youth indicated they had had more than three sex partners in the 12 months prior to the survey; 48% reported more than five partners.

Maine Youth Are Having Unprotected Sex:

- Ninety-three percent of the out-of-school youth surveyed indicated that they'd had sexual intercourse. Forty-nine percent used condoms "rarely" or "never."
- Only 50% of respondents who had sexual intercourse during the three months prior to survey indicated that they (or partner) had used a condom.
- In 1993 the incidence of chlamydia in females aged 15-19 was six-times higher than the statewide rate for all females (533 cases).

Maine Youth Are Using Alcohol and Other Drugs:

- Fifty-six percent of seniors and 51% of juniors reported at least one drink of alcohol on one or more of the 30 days prior to the survey; 34% of seniors and juniors reported five or more drinks on one or more of those days.
- There were 2,812 alcohol-related arrests among Maine teens in 1990 (including OUI, liquor law violations and drunkenness).
- Over 1,600 teens admitted to substance abuse treatment between October 1989 and June 1992, with alcohol abuse identified as the primary problem.

While knowledge is a necessary first step in changing behavior, we must realize it is only a first step.

HIV Information

Researchers have found that most children and adolescents understand the basic facts about HIV/AIDS. But like many adults, they do not translate what they know into safer sex practices. While knowledge is a necessary first step in changing behavior, we must realize it is only a first step.

A risky situation—such as whether to have sex or not—shouldn't be the first big decision young people have to make on their own. Prevention programs should help young people learn the skills they need to make good decisions about when, how and with whom to have sex. It is also important to develop the self-confidence necessary to handle difficult or risky situations.

Effective education should be right for the age of the young person. The presentation needs to be clear, direct and understandable, and it should relate to the lives of children and youth. It ought to contain positive messages about sexuality and not depend on scare tactics. Educators should be aware of emotional and age-related needs of young people. Sex, race and sexual orientation differences must be part of education for people of all ages.

We know that many of our young people are having sex. In order to make their sexual experiences as safe as possible, we must begin making condoms widely and easily accessible to them (for instance, in schools) and make sure they are taught how to use them correctly.

A risky situation—such as whether to have sex or not—shouldn't be the first big decision young people have to make on their own.

Resources for Young People and HIV

Advocates for Youth, Teens for AIDS Prevention Program

1025 Vermont Ave, NW, Ste. 210
Washington, DC 20005
202-347-5700

Camp Chrysalis
c/o Waldo-Knox AIDS Coalition
P.O. Box 956
Belfast, ME 04915
207-338-1427

Facts About Adolescents and HIV/AIDS
CDC National AIDS Clearinghouse
1-800-458-5231

Hetrick-Martin Institute
401 West St.
New York, NY 10014
212-633-8920

HIV Prevention Education Programs
Department of Education
State House Station #23
Augusta, ME 04333
207-287-5930

Listen to the Students:

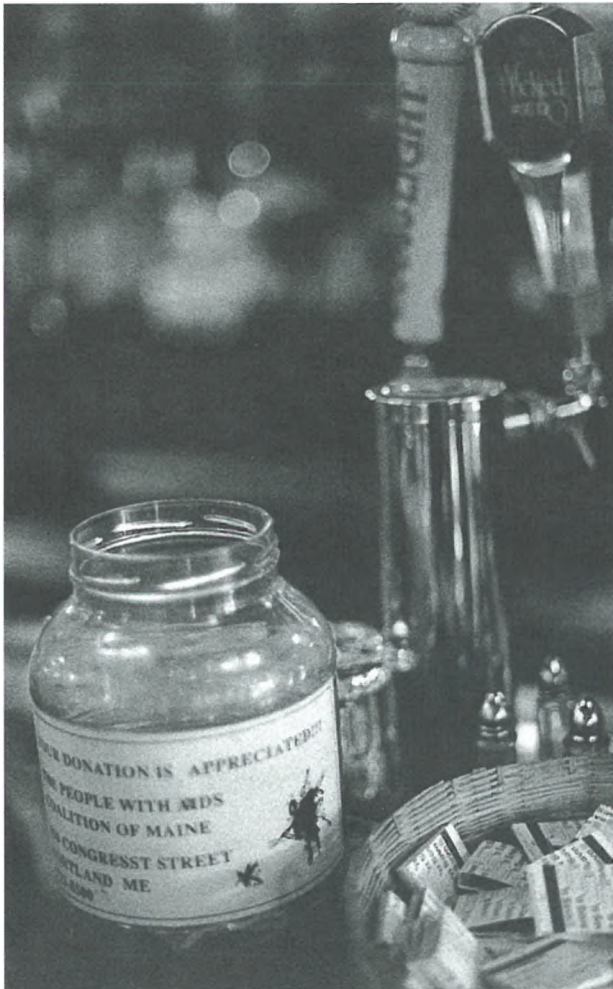
The AIDS Education Research Project
Family Planning Association of Maine
P.O. Box 587
Augusta, ME 04332-0587
207-622-7524

Maine College Health Association
c/o Chris Lyman
University of Southern Maine
96 Falmouth St.
Portland, ME 04103
207-780-5164

Teaching Your Children About Sexuality
The American College of Obstetricians and Gynecologists
409 12th St., NW
Washington, DC 20024-2188
202-638-5577

Substance Abuse

Alcohol use is widespread in Maine, and there is a significant population of injection-drug users. Injection-drug use is associated with a growing number of cases of AIDS and HIV infection in this state. And, quite clearly, many other cases of HIV/AIDS are attributable to drug and alcohol, which impairs judgment, resulting in increased risk of HIV infection from unprotected sex and needle-sharing. In fact, one reason that drinking and drug use may be appealing is that they do impair judgment and loosen inhibitions about sex and sexuality.



Injection Drugs

Sharing needles for injecting cocaine, heroin, amphetamines and other drugs results directly in the continued spread of HIV infection in Maine. Naturally, drug treatment should be a top priority; likewise the availability of sterile needles and hypodermic apparatus. At a minimum, all injection-drug users should have the knowledge and means necessary to disinfect shared needles with bleach and water prior to use. This can be accomplished through street outreach in Maine's urban areas; via interventions among those receiving treatment for substance abuse; or, among those arrested for related matters.

Social Drinking and Drug Use

Social or recreational users are not chronic abusers of alcohol and other drugs. Rather, they are people who use substances moderately or who may occasionally lapse into excessive use. This large group of Mainers may not recognize their risk of HIV infection—because they are not “abusers,” they may think they are not at risk. But the fact is, even moderate use of alcohol/drugs loosens inhibitions and increases risk-taking. The relationship between drinking and teen pregnancy (like drinking and car accidents) is well-documented. Another possible outcome of the risk of unprotected sex is HIV infection.

Adolescents and Substance Abuse

The search for independence by children and adolescents is often complicated by experimentation with drugs and alcohol. One researcher describes alcohol as a “facilitator of a young person’s sexuality. It is used as a vehicle to attain sexual encounters.”

In a recent survey done on three Maine college campuses, up to 46% of students responding said that their having sex was due directly to alcohol use. Twenty percent of these students reported not using safer sex practices after drinking, even though they were well-informed about safer sex. Eleven

percent of sexually-active Maine adolescents report using drugs or alcohol at their last sexual intercourse.

A focus group of high school students conducted by the Family Planning Association of Maine found that students were having “one night stands,” which typically involved alcohol and sometimes drug use, followed by sexual intercourse. Condoms were rarely used, and some teens engaged in sexual activities with multiple partners. These surveys were conducted with teenagers who were attending school. For students who have prematurely left school, risks are higher.

“Alcohol is the drug of ‘yes.’”

— Substance Abuse Researcher

Gay Men, Lesbians, Bisexuals and Transgenders

Historically for people in these categories, the use of alcohol and drugs has functioned as an escape mechanism from pervasive negative social attitudes. Bars have served as one of the few gathering places for gay and bisexual people, further fostering a connection to alcohol and drug use. For some, this connection may result in substance dependency. While there is a heightened awareness about safer sex practices in the gay community, HIV prevention messages must emphasize the link between higher risk of substance use and abuse and higher risk of infection.

Substance Abuse and HIV: The Facts

- There may be as many as 4,800 injection-drug users in Maine (Office of Substance Abuse, 1992).

Drug injection transmits HIV infection:

- Sharing needles for injection drugs accounts for 14% of AIDS cases in Maine (3/94), BOH).
- Over 22% of positive HIV antibody tests in 1993 were attributed to injection drug use.

Alcohol abuse is a major problem in Maine:

- Nine percent of adults surveyed reported five or more drinks on one occasion, one or more times in 30 days prior to the survey. (Maine Risk Behavior Survey, 1992) the percentage was much higher among males 25 to 34 (24.8%) and 18 to 24 (17.1%) than for other adults.
- There were 9,354 arrests for O.U.I. in 1991 (Maine Dept. of Public Safety).
- Of 17,059 admissions to substance abuse treatment programs from 10/89 to 6/92, 13,960 (82%) were for alcohol abuse. (MSATS)

Alcohol and other non-injected drugs are linked to HIV infection:

- Drugs impair judgment and inhibitions, resulting in increased risk of HIV infection from unprotected sex.
- Forty-six percent of college students attributed their sexual activity to alcohol abuse (Maine College Health Association).
- Fifty percent of pregnant women reported drug/alcohol use prior to intercourse leading to pregnancy (Advocates for Youth).

Resources on Substance Abuse and HIV/AIDS

HIV/AIDS and Substance Abuse,
Educational Materials
CDC AIDS Clearinghouse
1-800-458-5231

Maine HIV Prevention Community Planning
Group
112 State St.
Augusta, ME 04330
207-622-2962

National Association of State Alcohol and Drug
Abuse Directors, AIDS Policy Project
444 N. Capitol St., NW, Ste. 642
Washington, DC 20001
202-783-6868

Office of Substance Abuse
Information/Resource Center
Stevens School Complex
State House Station #57
Augusta, ME 04333
207-287-6330
TDD: 207-287-4475

Maine College Health Association
c/o Chris Lyman
University of Southern Maine
96 Falmouth St.
Portland, ME 04103
207-780-5164

Sex Industry Workers

The United States has a burgeoning sex industry, and Maine is no exception. Child abuse, sexual abuse, homelessness, poverty, drug addiction and other social ills all contribute to a socioeconomic phenomenon that has been rapidly increasing in recent years.

Traditionally, we have thought of prostitution simply as a woman selling sexual services to men in exchange for money. Today, thousands of women, children and men are putting themselves at extraordinary risk for HIV infection because of their reliance upon trading sex for money, drugs or actual survival.

Various studies have found that "hidden" sex workers (those who work for call services, escort services and massage parlors) have a lower rate of HIV than public sex workers. Their participation in the sex industry is not always the result of extreme circumstances as is often the case with those working the streets, parks and rest stops. Because of this relative degree of freedom, they may have more choices in choosing their customers and practicing safer sex.

However, public sex workers, including youth living on the street and those who trade sex for drugs, are more vulnerable to the wishes and demands of their customers. There may be requests for unsafe sex practices with promises of greater fees. There may also be sexual assault. The acquisition or actual use of drugs may lead to impaired judgment and rash, high-risk behavior. And a sex worker's customers are at increased risk too.

In addition to being at risk for HIV because of sex practices and lack of good judgment, some sex workers may be at risk for HIV because of injection-drug use with shared needles.

Nationally, thousands of women, children and men put themselves at extraordinary risk for HIV infection trading sex for money, drugs or actual survival.



Information Booth for Sex Industry Workers at the 1994 International AIDS Conference in Japan.

Sex Industry Workers: The Facts

Note: Accurate statistical data concerning sex industry workers is not available. This is an illegal activity that takes place in a covert manner. The arrest data used here from the Bureau of Public Safety represent only a portion of activity.

Women, men and young people are sex industry workers in Maine:

- Sex industry workers trade sex for money and/or drugs.
- In 1991, 47 Maine women and 61 Maine men were arrested for “prostitution and commercialized vice.”
- In 1992, 27 women and 83 men were arrested for same.

Sex workers may be “visible” to the experienced eye:

- On streets, in parks, rest areas, truck stops and elsewhere.

Sex workers may be hidden:

- Employed by escort services and massage parlors.

Sex workers may be at increased risk of HIV/AIDS:

- HIV is transmitted through unprotected oral, anal and vaginal intercourse. Sex workers who do not use condoms for these activities are at increased risk of receiving and transmitting HIV.
- Sex workers may receive a higher fee if they agree to have unprotected sex with clients.
- Sex workers may be forced to engage in unprotected sex.
- Sex workers may be sharing needles to inject drugs and may be using other drugs and alcohol. These behaviors may result in a higher risk for HIV.

Resources for Sex Industry Workers and HIV

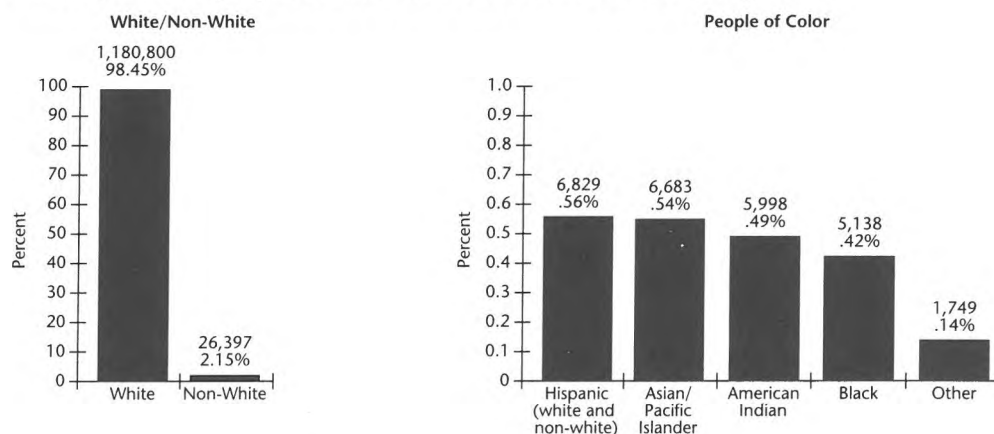
National Task Force on Prostitution
PO Box 2113
New York, NY 10025-2834
212-866-8854

Supports rights of sex workers and provides
education on sex workers' issues.

YWCA Street Outreach Program
87 Spring Street
Portland, ME 04101
207-874-1130

People of Color, Ethnic and Linguistic Minorities

Racial/ethnic populations in Maine (1990 Census)



Total residents approximately 1.2 million (1,199,369)

Although Maine's population is predominantly white, over 26,000 people of various other racial and ethnic origins live here.

Six thousand Native Americans live in Maine, about 30% of them on reservations. These include the Aroostook Micmac Council, the Houlton Band of Maliseets, the Passamaquoddy Tribe, and the Penobscot Indian Nation.

Refugees from many countries have come to Maine over the last 20 years. The Refugee Resettlement Program in Portland is constantly resettling people from around the world in the greater Portland area. Over 25 languages and dialects are spoken by students in the city's schools. Immigrants and migrant workers are moving into all parts of the state to live and work.

Franco-Americans were perhaps the first ethnic minority to settle in Maine in large numbers. Towns throughout Maine, such as St. Agatha and Biddeford, still host thriving bilingual communities. Over 5,000 African-Americans make Maine their home as well.

Members of refugee, immigrant, migrant worker and other minority groups struggle daily with poverty. Financial, health and family crises occur frequently. Creating even a minimally comfortable life can take all of a family's or individual's financial, emotional and physical resources. In those cases, preventative health care (including HIV prevention) is generally not an option. Young adults often use drugs, alcohol and sex to relieve the pressures of racism and poverty and to ease the process of acculturation. These activities can increase the risk of HIV and other health problems.



People of Color and Ethnic and Linguistic Minorities: The Facts

HIV Affects People of Color at a Higher Rate:

- Non-white and Latino residents make up 1.6% of Maine's general population.
- Non-white and Latino residents make up 5% of Maine's HIV+ population.
- This disproportionate incidence of HIV reflects a national pattern. Despite Maine's small minority population, there is still a greater incidence of HIV among people of color.

["Non-white" includes Asian/Pacific Islanders, American Indians, African-Americans and some people of mixed racial origins.

Latinos are regarded as white but of a distinct ethnic/linguistic group. This particular classification does not account for Asian/Hispanics or Black/Hispanics.]

■ *Non-white and Latino residents make up 1.6% of Maine's population.*

■ *Non-white and Latino residents make up 5% of Maine's HIV+ population.*

Says a Penobscot woman, "When one person on the reservation has HIV, it's everyone's issue."

HIV and a Small Community

Because of the relatively small numbers of people of color in Maine, large racial or ethnic communities are not often found here. Many minority individuals or families live quite separately from such communities.

A few exceptions to this dispersion are the Indian reservations in northern Maine, Franco-American neighborhoods in certain cities and towns, pockets of refugees in southern Maine and migrant workers in most parts of the state.

The Native American reservations (on Indian Island, Pleasant Point and Indian Township) and certain groups of refugees and migrant workers make up somewhat closed, isolated communities. In some cases, the isolation is cultural or religious; in others it is geographic. Within these close communities, one person's affairs are often known by everyone else.

Says a Penobscot woman, "When one person on the reservation has HIV, it's everyone's issue."

AIDS Awareness

Many refugees have escaped from their native countries with their lives, having lost everything else, including their families. Sometimes they come from cultures that isolate women and deprive them of autonomy, or cultures that do not discuss sexual issues, especially with outsiders. In comparison to the hardships these people have suffered and the challenges of learning English while working at one or two jobs, learning about HIV may not seem very important.

Social attitudes about sexuality, morality, and HIV/AIDS vary tremendously among all Mainers, and people of ethnic or racial minorities are no exception. It's a mistake to assume that everyone of a certain constituency has the same knowledge and beliefs about anything, particularly HIV. They may even deny that HIV is an issue for their people, regardless of the statistics.

Members of minority groups, especially those who may be uninformed about HIV, may believe that this has nothing to do with them. They may believe that AIDS is a "gay disease" or a "white man's disease," or that it affects only those in other parts of the country, but not people from Maine.

Some African-Americans and Latinos may firmly believe that there are very few black or Latino gay men, and so sexually-transmitted HIV is not a problem for their communities.

Cultural Isolation

Growing up and living in Maine for people of color is the same as for anyone else, with an added set of challenges. Pressures that hit everyone—economic hardship, family tensions, the draw of addictions—can be more destructive to people of color because such problems are compounded by subtle or blatant discrimination.

In an effort to maintain their dignity through cultural practices, some communities of color isolate themselves from mainstream society. For members of a minority community, it can allow a respite from mainstream messages that may not include them, and time to practice and develop their own heritage and cultural activities.

But isolation is a double-edged sword. Separation can also cut off communities of color from useful information disseminated through mainstream media. Less access may be compounded by a language barrier, so individuals in an isolated community—even in downtown Portland—may have little or inaccurate information about the AIDS epidemic. Current, accurate, culturally-relevant information about the spread of HIV is essential.

They may believe that AIDS is a “gay disease” or a “white man’s disease,” or that it affects only those in other parts of the country, but not people from Maine.

HIV Information

Culturally-significant approaches must be made. HIV education for linguistic, ethnic and racial minorities should, whenever possible, be planned and carried out by trained peer educators. Peer education programs around the United States (and one in Portland, Maine) have demonstrated repeatedly that “insiders” are effective as educators in ways that “outsiders” can never be.

It is important for administrators to remember, when developing HIV education programs for refugees and immigrants, that many are not able to read and write even in their own languages. Printed materials may be of little value, but videotapes in the appropriate language (and with actors of the audience’s race or ethnicity) are much appreciated.

The literacy level of printed materials is always a matter of concern for designers; it may be especially important in the development of HIV education brochures or posters intended for people of minority status.

Focusing on the health and education of children is often a key to the HIV education of adults as well. Regardless of their needs or risks, parents will often listen to HIV information that has been thoughtfully prepared and presented, if they believe it will help their children.

Resources for People of Color and Ethnic and Linguistic Minorities

Asian AIDS Project
300 4th St, Suite 401
San Francisco, CA 94107
415-227-0946

LLEGO
National Latino/a Lesbian and
Gay Organization
703 "G" St. SE
Washington, DC 20003
202-544-0092

National Association for the Advancement of
Colored People—Portland Chapter
P.O. Box 3631
Portland, ME 04101

National Minority AIDS Council
1931 13th St, NW
Washington, DC 20009-4432
202-483-6622

National Native American AIDS Prevention Center
6239 College Ave., Suite 201
Oakland, CA 94618
415-658-2051

National Task Force on AIDS Prevention
944 Market St, #210
San Francisco, CA 94102
415-403-3800

Refugee Resettlement Program
Catholic Charities Maine
107 Elm Street
Portland, ME 04101
207-871-7437

Umoja Sas Prevention Marketing Group
Unity Now! Protect The Blood
P.O. Box 41401
Baltimore, MD 21203
410-576-8688

People with Disabilities

According to the Maine Bureau of Rehabilitation, in 1993 over 73,000 people in Maine were living with a variety of disabilities:

- Mental Retardation
- Mental Illness
- Blind/Sight Impaired
- Deaf/Hearing Impaired
- Mobility Impaired
- Hidden or Internal Disabilities

Besides the basic human requirements for a safe and stable life, people with disabilities have a variety of additional needs, depending on their particular limitations. Many people who are technically in this category do not consider themselves disabled. These may include people with chronic back pain, severe arthritis, or a limp caused by a past injury. At least half of the 73,000 people identified as disabled are completely independent, perhaps fully employed, with little or no need for a modified lifestyle.

However, often people with greater disabilities are ignored by and isolated from the rest of society. This marginalization does not prevent these individuals from being at risk for the same illnesses as the rest of society though, and that includes HIV. The physical, emotional and intellectual vulnerability of many in this population may, in fact, place them at an increased risk for HIV infection.

Poverty and Disabilities

Financial security is practically non-existent among people with disabilities. Generally, any income is quickly spent on medical or therapeutic services to maintain even a manageable existence. Most people are unable to work because of a lack of society support or because of their health problems. Others work at part-time or entry-level positions. Fixed incomes are frequently subsidized by the Social Security Disability system. Because owning a reliable vehicle is not possible for many persons with physical, intellectual or emotional disabilities—even if they could afford it—their mobility is greatly restricted. They may be greatly dependent on friends, family or inadequate public transportation.

Caregivers

It is crucial that those who provide services recognize the potential risk of HIV infection for disabled people in their care. Prevention efforts, whether professional or volunteer, should be sensitively and knowledgeably prepared and presented. Teachers, social workers, friends and family should all learn about HIV and the most effective way of delivering HIV prevention information.



Barriers to Service

In spite of the Americans with Disabilities Act of 1990 (*ADA, see Appendix*), people who are disabled still lack access to many venues and services that are readily available to others. Some HIV service providers, for example, have not yet made their facilities accessible to people with disabilities. Lack of wheelchair ramps, TTY machines (which allow for hearing-impaired people to communicate over the phone), large-print materials and other resources and equipment impedes access to services (anonymous testing, case management, medical providers, etc.).

People with disabilities face more than just physical barriers to HIV information and services. Agencies that serve the disabled often have staff who are uninformed about HIV and thus fail to recognize the need to provide risk reduction and other information to their clients. AIDS service organizations (ASOs) could make it a priority to connect with those who offer services to disabled populations.

People with Disabilities: The Facts

People living with HIV/AIDS have a disabling condition:

- According to the Americans with Disabilities Act and the Maine Human Rights Act, HIV/AIDS is a disability. Therefore, people with HIV/AIDS are protected from discrimination in employment, education, housing and business services, and in state and local government programs (*see Appendix*).

People with disabilities may be at increased risk of HIV/AIDS:

- False assumptions by service providers concerning lack of sexuality in people with disabilities may result in inadequate prevention education.
- Vulnerability of some populations to sexual abuse may result in increased risk.
- There is a lack of readily available prevention materials and curricula suited to all needs.

Resources for People with Disabilities and HIV

AIDS Hotline for the Deaf
1-800-293-7889

Disabled People International
101-7 Evergreen Place
Winnipeg, Manitoba R3L2T3
Canada 204-453-1367
TTY 204-284-2598
Fax 204-453-1367

HIV/AIDS and Disabilities Access and
Information Project
c/o Latino Health Institute
95 Berkeley St.
Boston, MA 02116
617-350-6900

Maine Advocacy Services
P.O. Box 2007
Augusta, ME 04338
1-800-452-1948
207-626-2774

Maine Civil Liberties Union
97A Exchange Street
Portland, ME 04101
207-774-5444

Maine Independent Living Services
331 State Street
Augusta, ME 04330
207-622-5434

The Disability Rag ReSource
Box 145
Louisville, KY 40201

The Project on Women and Disability
1 Ashburton Place, Room 1305
Boston, MA 02108
617-727-7440 voice/TTY

Survivors and Victims of Sexual Abuse

Sexual abuse of all types occurs everywhere in the United States. Victims and survivors are found in all income groups, races, ethnic groups, sexual orientations, ages, and in both sexes. Experts estimate that 25-50% of women and 20-30% of men are sexually abused at some time in their lives.

Some experts define sexual abuse as only oral, anal, or vaginal penetration. Others define it more broadly: physical, emotional, or verbal. For example, rape, "date rape", wife- or child-beating, sexual assault, sexual harassment in the workplace, incest and sexual molestation are all sometimes seen as types of sexual abuse.

Abuse in any form can result in anger, distrust and difficulty in forming close relationships. Some who have been sexually abused may do things that place them in risky situations, due to low self-esteem and/or sexual dysfunction. Alcohol and drug abuse and careless sexual behavior, which have been linked to victims and survivors of sexual abuse, are high-risk activities for HIV transmission.

Survivors and Victims of Sexual Abuse: The Facts

Sexual abuse is prevalent in Maine:

- There were 298 rapes reported in 1992 (Department of Public Safety).
- There were 6,675 "appropriate referrals" (familial abuse) made to Child Protective Services. Of that number, 647 involved sexual abuse/exploitation.
- The Department of Human Services found 498 of those cases to warrant state action (such as removal of the child).

HIV Information

It is important for HIV prevention or treatment providers to understand the issues of those who have been sexually abused. Of course, victims of sexual abuse may be at risk for HIV as a result of forced unprotected sex. But survivors may also be at increased risk due to their own behavior.

These victims and survivors need:

- Good information on HIV transmission;
- Medical services from doctors, nurses and other practitioners who know about sexual abuse;
- HIV counseling and testing from counselors who are sensitive to the experience of victims and understand that not all people have sex because they want to;
- Support for partners and family members for those who have been abused, including those of survivors who are HIV+;
- HIV educators who understand that survivors may have a harder time than most listening to information about sex and carrying out safer sex practices;

- Service providers who know that survivors often engage in high-risk activities;
- HIV workers who are aware that HIV+ survivors may have difficulty carrying out plans to see physicians and take medication.

Resources for Survivors/Victims of Sexual Abuse and HIV

Ingraham Volunteers, Inc.—general crisis hotline
207-774-4357, 1-800-870-9998

Maine Department of Health and Human Services
Adult and Children's 24-Hour Emergency Service
1-800-452-1999

Maine Coalition Against Sexual Assault
PO Box 5326
Augusta, ME 04332-5326

Local Sexual Assault Services:

Augusta Area Rape Crisis Center
3 Mulliken Court
Augusta, ME 04330
hotline 207-626-0660
bus. 207-626-3425

Downeast Sexual Assault Crisis Hotline
PO Box 1087
Ellsworth, ME 04605
hotline 1-800-228-2470
bus. 1-800-492-5550

Midcoast Sexual Assault Support Center
PO Box 990
Brunswick, ME 04011
hotline 1-800-822-5999
bus. 207-725-2181

Rape Crisis Assistance
PO Box 924
Waterville, ME 04901
hotline 1-800-525-4441
bus. 207-872-0601

Rape Crisis Center
P.O. Box 1371
Portland, ME
207-774-3613 (accepts collect calls)

REACH Medical Arts Building
17 Winter St.
Norway, ME 04268
hotline 1-800-622-2365
bus. 207-743-9777

Rape Response Services of Bangor
PO Box 2516
Bangor, ME 04401
hotline 207-989-5678
bus. 207-945-5597

Sexual Assault Crisis Center
PO Box 6
Auburn, ME 04212
hotline 1-800-371-0000 or 207-795-2211
bus. 207-784-5272

SAVES
PO Box 349
Farmington, ME 04938
hotline 1-800-221-9191
bus. 207-778-9522

Homeless People

In Maine, between 3,500 and 10,000 individuals are without homes on any given night.

The largest segment of the shelter population, 30%, are youth under 18.

A homeless person is someone who lacks a fixed, regular and adequate nighttime residence. This definition includes those whose primary night residence is a supervised shelter designed to provide temporary living accommodations. Others who fit the homeless definition are those who sleep in:

- welfare hotels;
- single resident occupancies (SRO);
- congregate shelters and transitional housing for the mentally ill;
- an institution that provides a temporary residence for individuals intended to be institutionalized; or
- a public or private location improvised as a sleeping accommodation.

In Maine, between 3,500 and 10,000 individuals are without homes on any given night. Last year, 7,000 men, women and children stayed in emergency shelters throughout the state. Many more homeless individuals never use free shelter services.

Two major theories have been put forth to account for homelessness. Some say people are homeless because of a situation, such as losing a job, which has put them on the street. Others state that it is homelessness itself that creates unemployability, mental illness and other problems. Probably both of these theories are true, depending on individual circumstances.

Regardless of how people become homeless, the demographic groups are identifiable: families, "street kids," substance abusers of any age, the mentally ill and mentally retarded, and those who choose to be homeless for a number of reasons. Any of these people may be at increased risk for HIV depending on their methods of survival, their sex practices, possible drug use behaviors, or other factors.



Statistics show that homelessness and HIV infection are linked:

- In 1992, 7% of people testing positive for HIV antibody were homeless.
- In 1993, 16% of people testing positive for HIV antibody were homeless.

In 1993, 16% of people testing positive for HIV antibody were homeless.

Hopelessness and depression affect many of the homeless. Because access to stable shelter, food, and medical care is often difficult, sickness can seem normal to a homeless person. Research shows that people who are most sick are least likely to seek medical attention. If a chronic health problem is currently showing no symptoms (such as early HIV infection), it may seem a lower priority than daily survival needs. For most homeless individuals, it may be very difficult to sustain long term treatments such as those necessary for tuberculosis or HIV.

Homeless people are often coping with poverty, unemployment, violence, substance abuse, and mental or physical disabilities. When people don't know where they will sleep each night and have little access to, or information about, health care and other resources, concern over "a square and a bed" takes precedence over other problems. Unfortunately, these circumstances may contribute to increased risk of HIV infection.

Homeless People and HIV: The Facts

Homelessness is an increasing problem in Maine:

- 6,885 homeless people were served by shelters in 1992, an increase over previous years.
- There were 13,931 shelter admissions in 1992, up from 10,000 in 1990.
- On any given night there may be 1,500 or more homeless people in Maine.
- Statewide shelter capacity is 650 beds.

Homelessness may increase risk of HIV infection and AIDS:

- Extreme demoralization, depression and low self-esteem are widespread among the homeless. These conditions may impair the ability to act in one's self-interest.
- A disproportionate number of homeless people have serious functional disabilities—chemical dependency, cognitive delay or impairment, or mental illness.
- Illness may be perceived as normal.
- Illiteracy and lack of education may be linked to health-related misunderstandings.
- Homeless people suffer a serious lack of access to health care. Besides, daily survival takes priority.
- Violence on the streets and in some shelters is a fact of life for the homeless, especially for women and children.

HIV Information

Most of Maine's homeless shelters that were contacted for this survey reported some form of HIV prevention education services for clients, offered individually or in groups. Five of the eight programs have condoms available for clients on-site. But only one shelter program provides regular prevention information, counseling and support for HIV antibody testing.

Barriers to providing regular HIV prevention education at all sites include lack of time, money and adequately-trained personnel. The multitude of special problems of a transient population who are in crisis also complicate matters for these providers.

Shelters and AIDS service organizations (ASOs) need to begin coordinating with one another to provide condoms and HIV-related services and referrals in all facilities. All shelters must also begin providing access to free health care, which includes nursing care and basic health education.

Resources for Homeless People and HIV

Checkerboard Square: Culture and Resistance in a Homeless Community
by David Wagner. Westview Press, Inc. Boulder,
CO 1993 (The homeless population studied is in
Portland, ME)

Maine Coalition for the Homeless
P.O. Box 415
Augusta, ME 04332-0415
207-626-3567

National Network of Runaway and Youth Services,
Safe Choices Project
1319 F St., Ste. 401
Washington, DC 20004
1-800-878-2437

Pine Tree Legal Assistance
P.O. Box 547 DTS
Portland, ME 04112
207-774-4753

Portland Homeless Health Program
389 Congress St., #305
Portland, ME 04101
207-874-8449

Stand Up For Kids, National Office
PO Box 461292
Aurora, CO 80046-1292
1-800-365-4KID

Maine Settings and HIV: Steps for Action



Maine Settings and HIV: Steps for Action



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MAINE SETTINGS AND HIV: STEPS FOR ACTION

Workplaces

- Public and Private Sites
- Union and Non-union Companies
- Large and Small Businesses
- Self-employed

The Centers for Disease Control and Prevention (CDC) reports that AIDS is now the leading cause of death in men and women age 25-44. This age group represents America's and Maine's present and future workforce. In fact, 50% of our nation's 121 million workers are in this age group, and they are at risk.

The data also tells us that one in every 250 people in the United States is infected with HIV—and that the virus now exists in most Maine communities. Nationally, one in ten employers with fewer than 500 employees already has an employee with HIV infection or AIDS.

Almost everyone must work. With 58% of women and 74% of men in Maine over age 16 in the labor force—and most working outside the home—the worksite is a major focus in peoples' lives. The worksite is a place of professional affiliation and camaraderie. Co-workers frequently become friends and have social interaction outside the work environment. What happens to one member of a workplace community can have a profound effect on others.

HIV affects companies of all sizes. The impact can be direct, such as an employee living with HIV, or indirect—employees whose loved ones have HIV, for example. In Maine, as more persons test positive for HIV each year, the impact will increase—on employers, workers, worksites and the overall economy.

Background

HIV is an expensive disease. According to the U.S. Department of Health and Human Services, the average lifetime cost of treating a person with HIV is \$102,000. In addition to short and long-term disability costs, chronic illnesses such as HIV affect life insurance and pension plan pay-outs, as well as recruitment, hiring and training costs.

In Maine, the average age at death of people with AIDS is approximately 40. The premature death of individuals who may be performing key roles in

"... The economic impact of HIV and AIDS is staggering . . . By 1995, an estimated cumulative \$13.5 billion will have been spent on treatment."

—U.S. Dept. of Health
& Human Services,
Centers for Disease
Control

AIDS is now the leading cause of death in men and women age 25-44.

According to the U.S. Department of Health and Human Services, the average lifetime cost of treating a person with HIV is \$102,000.

business (and in whom the business may have invested heavily), results in an average of 25 years of lost productivity per person. These costs are measurable; others are not.

Violations of the rights of HIV+ persons can further reduce employee productivity and often lead to lawsuits. Furthermore, as treatment improves and HIV+ people are able to live longer with their disease, the cost of their health care will continue to increase.

For all of these reasons, every Maine employer has a vested interest in promoting HIV prevention and nondiscrimination practices.

Business leaders speaking at the 1994 USM conference on HIV noted that many employers waited to develop HIV policies and educational programs until the company became aware of employees who were living with HIV. The speakers recommended that employers prepare themselves by developing policies and programs before they have their first experience with an HIV+ employee. That way, management will know its legal responsibilities, the worker can continue working alongside co-workers without experiencing discrimination and fear, and production can continue without interruption or incidents.

General Recommendations

All Workplaces:

1. Develop HIV policies concerning employment and disability.
2. Educate staff to abide by the policies.
3. Implement HIV education program for employees.

HIV Policy for the Workplace

When a company has a clear HIV policy, an employee knows how the employer will respond to his/her HIV status. When such a policy is in place—and employees are familiar with the policy—there is also a reduced likelihood of discrimination and harassment.

In addition, a good HIV policy promotes good public relations: a workplace that is responsive to employee needs is likely to be perceived as a good place to work. This encourages employee loyalty and retention.

Several Maine companies have instituted exemplary HIV policies and education programs. However, the majority of worksites in Maine have no policies whatsoever, or have instituted only those programs that are required by law (such as the Occupational Health and Safety Administration (OSHA) bloodborne pathogens standard and the Americans With Disabilities Act (ADA) (*see Appendix*)). For many companies, these official mandates can provide a useful base from which to develop a more complete HIV policy.

Companies of more than 1,000 employees appear more likely than smaller companies to offer comprehensive HIV policies and employee education programs. For example, Konica Quality Photo, Hannaford Brothers, Blue Cross and Blue Shield of Maine, and UNUM all have strong, written policies on HIV and provide company-wide HIV education programs that could be modeled by other Maine companies, big and small.

Konica Quality Photo, Hannaford Brothers, Blue Cross and Blue Shield of Maine, and UNUM all have strong, written policies on HIV and provide company-wide HIV education programs that could be modeled by other Maine companies, big and small.

An Insurance Company Takes Lead

As a disability insurance company, UNUM was aware of HIV early on. "It was not hidden," says Ann Houser, second vice president of UNUM's human resource development. "We were faced with it as a business. Since we work with other businesses on disability issues, we needed to keep our house in order. 'How can we be a premier workplace for people with disabilities?'"

In 1988 UNUM, one of Maine's largest employers (with 2900 employees), issued a two-page position statement on their response to HIV in the workplace. (See appendix) "It's important that we had the written word," Houser says, referring to the statement. "But I'm happy to say, it's not just the written word." They distributed the policy and informational materials to all employees, brought in speakers who were living with HIV, and sponsored a display at the worksite of the AIDS Memorial Quilt, large handmade cloth panels which commemorate individual lives of people lost to AIDS.

Putting the policy into action has gone smoothly so far, Houser says. "One person approached me and asked, 'Is what's in writing real?' He had discovered he was HIV+ and needed to decide whether to tell his supervisor."

As with other employee issues that affect the workplace, UNUM takes a team approach, customizing it to the individual. Houser recalls two employees who handled the situation very differently. "One

held a meeting for his whole work unit and told them of his HIV status. Another person preferred to disclose his status to his co-workers one-on-one. They both were absolutely dumbfounded by the level of support we provided. They were so surprised they weren't treated like lepers."

UNUM offers many services to its employees through this process. Medical professionals make presentations, alternate work schedules are incorporated for those who need them, and individual and group counseling is available for the HIV+ person and co-workers alike. Houser explains, "When you know someone, and then they get sick and you didn't know they were positive—it's hard. Relationships are tight at work—we'll bring in counselors if someone dies. I don't know of any situation where that support was not available.

"UNUM is very committed to employee policies which promote a healthy, respectful environment. I wouldn't work here if we didn't."



Food Service

HIV cannot be transmitted in food products. Food service workers with HIV need not be restricted from handling food. Individuals with other infections, for which any food service worker should be restricted, should not prepare or serve food while they are contagious. For example, individuals with abscesses on their hands or with tuberculosis should not handle foods, whether they are HIV+ or not.

All food workers should follow universal precautions when an accident occurs, and avoid contact with another worker's blood. Work surfaces should always be cleaned frequently; in the case of spilled blood, they should be cleaned with a bleach and water mixture. Hands should also be well-washed after dealing with an accident.

Discomfort with HIV Issues

HIV is often closely associated with sexual activity, drug use, illness and death. These are topics that make many people uncomfortable, possibly enough to hinder clear policy development and implementation. Failure to face up to these issues, however, may exacerbate the existing workplace problems and affect productivity. By the same token, employees' discomfort with HIV issues might keep them from attending voluntary HIV education program. That's why many experts recommend that, to maximize effectiveness, HIV education programs should be mandatory for all employees.

Company owners and managers can go a long way toward setting a climate of comfort and reason with these issues by modeling leadership behavior. In other words, don't avoid HIV issues. Rather, engage others in conversations about HIV issues, and do so in a straightforward, matter-of-fact manner.

A Paper Mill Runs Successful Training

When you think of the small western hills town of Jay, you think of International Paper Company (IP) employing almost 1400 people. But thanks to the efforts of Lois Feith, the manager of health services at the mill there, IP is now also known in some circles for its HIV prevention education. "I said to myself," Feith recalls, "we have a moral and ethical obligation to train our workers. There is not an employee here who wouldn't go to the aid of another in the case of an accident. This means there is not one employee here who is not at risk."

The OSHA standard issued in the early 1990s offered the mill an opportunity to provide in-depth training on HIV. Three years ago Feith presented the OSHA recommendations and her arguments to the mill manager, who authorized a one hour, mill-wide mandatory training on bloodborne pathogens. AIDS is one of the most significant health problems we've had to deal with, and I've been a nurse for 30 years. We had to get out there and educate, and provide resources for our people.

"It's very expensive to take workers off their jobs for even an hour," Feith says. "But this is one of our most successful education programs. You'd be amazed at the outpouring of gratitude from employees." Bloodborne pathogens is now the topic of one of three annual hourlong trainings all workers must receive, along with heat stress and hearing conservation. After one training session, Feith recalls emotionally, "One woman came into my office and broke right down. She just put her head down on the desk. She'd lost a brother to AIDS and had no one to talk to."

"We know HIV infection is remote here at the plant, but it's in people's lives. We have an obligation."



The trainings go beyond the OSHA standards, says Sharon Chaplin, a nurse on the health education team. "We have to use basic terms, relate it to people's lives. For instance, I talk about how 20 years ago we lost classmates to Vietnam. Current graduating classes will lose 10-20% of graduates to AIDS. We'll focus the prevention stuff on their kids, rather than for adults, since most of them are parents or grandparents. We get some good discussions going about condoms, and how to talk to kids."

"I tell our employees," adds Feith in her up-front style, "that they're driving a nail into their kids' coffins if they shy away from their sexuality questions."

IP has made a real commitment to this effort, Feith reports she is available for consultation and trainings with other companies interested in HIV/bloodborne training. She can be reached at 897-1436, Androscoggin Mill, Jay, Maine 04239.

Migrant Workers

Migrant workers are brought into rural Maine to assist in the harvest of potatoes, blueberries, apples and other agricultural products. These laborers generally come from urban areas or the southern U.S., often having left poor homes in other countries to find work here. Most are originally from Latin America or the Caribbean and many have difficulty communicating in English.

For a number of cultural and circumstantial reasons, migrant and seasonal farmworkers present a very high risk population for HIV and other serious diseases such as tuberculosis, Hepatitis B and other STDs.

- A 1990 South Carolina study found a 13% seropositivity among 198 migrant workers tested for HIV and syphilis at migrant labor camps.
- In the summers of 1990 and 1991, a study was undertaken of farmworkers in New Jersey. They were tested for HIV after attending an hourlong AIDS prevention program. The study found a 3.2% positive rate among the 558 workers tested, a rate 8 times that of the national seroprevalence of .04%.
- People of color are 1.6% of Maine's population, yet constitute 5% of people diagnosed with AIDS in the state. This reflects national trends. AIDS cases occur nearly three times as often among Black and Hispanic men as among white men. Among women and children with AIDS, 73% of the women and 79% of the children are African-American or Latino.

Despite the overwhelming evidence, effective educational initiatives aimed at reducing at-risk behaviors among this population face many barriers.

- Respondents in a 1988 study of migrant and seasonal farmworkers in Georgia had a low level of accurate knowledge about the AIDS virus. Over 78% of the Hispanic respondents in this study had never used a condom.
- A high incidence of both prostitution and intravenous drug use has been observed within some farmworkers communities, especially in the east coast stream.
- Presently, there are no consistent formal education or HIV testing and counseling services being provided in the migrant worker communities in Androscoggin, Aroostook or Washington Counties.
- There are many barriers to the acceptance of the HIV message. Language and cultural barriers combined with a low perception of "risk" hamper patient education efforts in this population. Condom use is heavily influenced by Hispanic religious and cultural practices. Not only are Catholics banned from using condoms because of the contraception issue but there is also a subtle association between condoms and extramarital sex and prostitution. Issues such as fear of authority, suspicion of western education and medicine as well as discrimination blend to create barriers to receiving the message.

Quality health care is often unavailable for migrant workers who lack the financial resources, English-language skills, and transportation to seek out health care when needed. Access to their camps or living quarters is often limited for outsiders, and training in basic accident protocol or universal precautions is rare.

Still in Maine a few programs exist. The Pine Tree Chapter of the American Red Cross in Bangor has a migrant health initiative. And through a mixture of direct care and voucher models, Rural Health Centers of Maine currently provides primary care to the migrant community in each of the high impact harvests.

Components of an HIV Policy

A comprehensive HIV policy should address:

1. basic HIV education,
2. infection control, and universal precautions.
3. support services and benefits that provide flexibility for all chronically ill employees, such as:
 - part-time/flex-time hours,
 - job sharing, and
 - sick leave bank.

Blueprint for an HIV Company Policy

Responding to AIDS: 10 Principles for the Workplace

1. People with AIDS or HIV (Human Immunodeficiency Virus) infection are entitled to the same rights and opportunities as people with other serious or life-threatening illnesses. This is clearly codified in the Maine Human Rights Act and the Americans with Disabilities Act, both of which protect people living with HIV infection (as well as those who are perceived to have HIV) from discrimination in the workplace (*see Appendix*).
2. Employment policies must, at a minimum, comply with federal, state and local laws and regulations.
3. Employment policies should be based on the scientific and epidemiologic evidence that people with HIV infection do not pose a risk of transmission of the virus to coworkers through ordinary workplace contact.
4. Discrimination in employment practices based on actual or perceived sexual orientation should be actively eliminated. Because people with HIV and their significant others may fear discrimination based on their sexual orientation—or perceived sexual orientation—and may be reluctant to use existing benefits or programs for fear of jeopardizing their jobs, the highest levels of management and union leadership should unequivocally endorse nondiscriminatory employment policies (including health benefits) and educational programs about HIV and AIDS.
5. Employers and unions should communicate their support of these policies to workers in simple, clear and unambiguous terms. It is not sufficient to simply develop and implement a policy. The best policy can be meaningless if it is not clearly communicated and unequivocally supported by management and union leadership.

6. Employers should provide employees with sensitive, accurate and up-to-date education about risk reduction in their personal lives. Employee Assistance Programs and other sources of employee support should be resources for employees who need help with HIV-related issues.
7. Employers have a duty to protect the confidentiality of employees' medical information. Confidentiality requirements concerning HIV-antibody test results are established in Maine statute (*see Information Sheet "HIV Testing" and Appendix*). Workplace policies should outline disciplinary actions to be taken when confidentiality is breached by the employer or any employee.
8. To prevent work disruption and rejection by co-workers of an employee with AIDS or HIV infection, employers and unions should undertake education for all employees before such an incident occurs, and as needed thereafter. Family and medical leave policies should acknowledge the diversity of family structures that exist in the work force.
9. Employers cannot require HIV screening as part of pre-employment or general workplace physical examinations. This data, if collected, may be used to influence decisions only inasmuch as a person living with HIV is considered to have a physical handicap under the ADA (*see Appendix*).
10. In those special occupational settings where there may be a potential risk of exposure to HIV (for example, in health care, where workers may be exposed to blood or blood products), employers should provide specific, ongoing education and training, as well as the necessary equipment, to reinforce appropriate infection control procedures and ensure that they are implemented. According to the OSHA bloodborne pathogen standard, all employers must evaluate their workplaces for situations in which occupational exposure to potentially infectious blood and bodily fluids may be reasonably expected to occur, and should provide such protections to employees as training, vaccination (for Hepatitis B), exposure-control plan, and protective equipment.

Of the 450,000 individuals who have been infected with HIV in the U.S., fewer than 50 are known to have contracted the virus through occupational exposure.

Adapted from documents of the Citizens Commission on AIDS for the New York City/Northern New Jersey Region in 1988.

Your Job and HIV: Are There Risks?

Of the 450,000 individuals who have been infected with HIV in the U.S., fewer than 50 are known to have contracted the virus through occupational exposure. Health care workers who care for people with AIDS have been studied for years. Studies in this country, England and Canada show that less than one percent of these workers who were stuck accidentally by infected needles and sharp objects became infected with HIV. Even though the risk is low, health care workers who come into contact with blood every day should wear latex or vinyl gloves . . .

Scientific studies do not indicate any risk of HIV infection from contact with body fluids or waste: feces, nasal fluid, saliva, sweat, tears, urine or vomit . . . You will not become infected with HIV from everyday work activities that do not involve contact with blood, semen or vaginal fluids . . .

. . . For customer and personal safety, a personal service worker with an open sore or broken skin on the hands should wear latex or vinyl gloves during contact with customers until the wound has healed . . .

Instruments that can penetrate the skin or become contaminated with blood—such as ear-piercing devices; needles used for electrolysis, tattooing and acupuncture; razors, cuticle scissors and tweezers—should be sterilized or thrown away after one use . . .”

*excerpted from “Your Job and HIV: Are There Risks?”
published by the American Red Cross, 1992*

“Employee evaluations of worksite HIV education programs frequently noted that the information helped them feel more comfortable around HIV+ colleagues.”

—speaker at USM
Conference on AIDS,
1994.

HIV Education Programs

Employee education programs have a pronounced positive impact on employers, employees and their families. Among the costs associated with HIV illness are reduced co-worker productivity and morale, which occur when a workforce is uneducated about HIV and related issues. For example, fear of HIV transmission—which is often far out of proportion to the actual risk—may cause workers to waste time avoiding (or otherwise discriminating against) an HIV+ co-worker.

Bath Iron Works Responds to AIDS

"When Billy told me he had AIDS, I had no idea what to do," recalls Kevin Gildart, formerly the vice president of human resources at Bath Iron Works, Maine's largest private employer. "We'd never had a situation like this. For us, it was sort of a baptism by fire." Bill Vincent, who worked in the shipyard's engineering division, was a hemophiliac who had contracted HIV from a blood transfusion. Although at first he kept his HIV condition from his co-workers and from management at the shipyard, he did disclose his illness to his union leadership, who encouraged him to inform Gildart.

"As he was becoming ill with the disease and missing more and more work," Gildart explains, "some of the people in the division started to question why he was out so much. Here the poor guy has a fatal disease, and he's afraid to tell anyone, and some people he's working with are calling him a sandbagger and questioning why he's not being disciplined. I couldn't tell anyone because of confidentiality laws.

"Eventually Bill came to me and asked me to help. 'I need to tell them what I have,' he told me, 'so I can face them.'

"I promised him we'd do whatever we could. But I was thinking, who the hell can help me? We'd never gone through this before. I asked his permission to spend some time with the nurses who were treating him, and that's when I started learning about the disease and about the social issues that come with it. Because I needed to get educated myself.

"One of the reasons I wanted to be prepared is because I knew it would be a very emotional issue, and I thought that when Bill addresses all these guys,



he might not be able to get through it. I wanted to be ready to help him explain his situation. Eventually we met with 25 or 30 people in a small auditorium and spent about two hours walking everyone through Billy's problem. We had our medical people there to tell them they weren't at risk, and that they had no reason to be afraid. We also told them that Bill had a right to stay on the job.

"It was a difficult process, but we went through it. Here they are looking at a guy who is dying. Some of them cried. Some were afraid and didn't want to work in that area anymore. So we spent more time educating them. All in all, he had a lot of support.

"But it wasn't long before he started to have more medical problems and he was only able to come in to work two or three days a week. Eventually he and I had a chat. It was obvious that trying to come in to work was taking too much out of him. So we agreed it was best for him to stay home and take care of himself. It wasn't long after that he passed away.

"Now we have a policy on communicable diseases, and HIV is in that area. We don't have a specific HIV/AIDS policy. It's our feeling that people with any form of communicable disease have the same rights."

For the HIV+ worker who is fearful of potential workplace response to his/her HIV status, energy may be spent hiding the illness or seeking protection from recriminations—rather than working. To the extent that HIV education reduces stress and makes the work environment more productive, HIV education can effect real cost savings.

Health benefits to dependents is another area where HIV affects employers—and where employee education can have a benefit. Business owners and human resource managers interviewed by the Maine Community AIDS Partnership suggest that for some employers, dependent care constitutes as much as 75% of employee health-benefit costs. Interviewees who had participated in HIV education programs noted that their increased knowledge prompted discussions with their children and others at home, thus passing on to their families valuable knowledge about HIV prevention.

Blueprint for an HIV Education Program

1. Teaching Methods

- workshops
- small and large group presentations
- peer educators
- individual and group counseling
- videotapes
- written materials
- bulletin board displays
- inserts placed in paycheck envelopes
- computer network HIV updates

2. Nature of Presentation

- required for all employees
- open to participant expression of thoughts and feelings
- conducted in a safe, comfortable setting with plain, unembarrassed language and established guidelines for conduct
- designed with age, ethnicity, language, and other similar factors in mind for optimum accessibility
- tailored to the needs of workplace and employees
- related to job requirements
- conducted company-wide at least every two years
- supplemented with additional, voluntary sessions (for example, a "Lunch and Learn" workshop, with related topics like "Talking to Your Children About Sexuality and HIV")

3. Topics

- transmission and prevention information
- disease progression
- anonymous and confidential HIV antibody testing and counseling
- universal precautions
- review of workplace policies and protocols
- legal obligations of management and workers
- legal protections for employees
- sexual contact and HIV infection
- blood contact and HIV infection
- substance abuse and HIV infection
- living with HIV
- needs of workers with HIV
- needs of customers with HIV
- needs of employees living with HIV+ persons
- application of knowledge to the job and to personal life

4. Educators

- employees from home office
- motivated, knowledgeable employees
- trade associations members and leadership
- Employee Assistance Program staff

- outside sources, such as AIDS service organizations (ASOs) or the Red Cross, who are trained specifically to conduct workplace HIV education.

Cutting Hair for a Good Cause

"There was no one particular person [with HIV] that I was close to," reflects Linda Hollis, owner of Belfast hair salon The Upper Cut. "In my profession, there's a lot of awareness." And holding a cut-a-thon to raise money for the local AIDS organization just seemed like a good idea. "I wanted to do this because the money we raise stays right here in the community, impacting people that I come in contact with.

"It has to start on a small scale. Each community has to depend on itself," she says. "At first we seem so isolated here, and stuff from urban areas doesn't seem to affect us. But AIDS is something that could happen to you very easily."

Hollis says that at first, other stylists thought giving haircuts for free all day would be like a busman's holiday. The \$6 charged goes directly to the Waldo-Knox AIDS Coalition, as does the proceeds from any products sold that day. "A lot of them didn't realize how much fun it would be."

Hollis invited other stylists from the area to come and cut hair for two hours at a time. Begun in 1989, the annual cut-a-thon has raised almost \$1,200 for the Coalition. "It's like a party, with refreshments. Last



time we cut over 70 people's hair in just the afternoon." By the end of the day, the stylists had pooled their tips as a contribution to the effort, as well.

"It's important as a business to support those who live here," states Hollis matter-of-factly. "And I met a lot of new people. One woman was in the Rotary, and she mentioned it at a meeting. As a result, a lot of Rotarians came. In a roundabout way, it does increase clientele, though that wasn't the intention. People like to support businesses that support issues they care about."

ACTION STEPS

A Blueprint for Action

Business Owners, Managers and Human Resource Directors:

- Contact local AIDS service organizations (ASOs) for assistance with designing and implementing HIV education programs (*see Resources*).
- Call the Centers for Disease Control National AIDS Clearinghouse (1-800-458-5231) for a policy-oriented technical assistance package. Then develop your policy and educational programs.
- Solicit participation from employees in organizing and designing HIV educational programs. For example, ask if anyone who has been directly or indirectly affected by HIV would like to help.
- Evaluate and update your policy and program on a regular basis.

- Give financial and voluntary support to your local ASO.

Employees:

- Ask your employers if an HIV policy exists. Request that the company make their policy clear to all employees, including how an employee with HIV can be expected to be treated by co-workers.
- Ask your employer for worksite HIV education programming to educate yourself and your coworkers.
- Develop philanthropic enterprises to assist employees, family members and community members struggling to live with HIV.

Union Members:

- Contact your local for information on the contractual rights of persons with HIV in your company.
- Include establishment of HIV policy and employee education in contract agreement.

ASOs, American Red Cross Chapters, and Community-based Organizations with HIV Education Programs:

- Survey local businesses for HIV policy and education needs; offer support and technical assistance in program development.

Workplace Resources:

The Centers for Disease Control and Prevention (CDC) has initiated a program, "Business Responds to AIDS," which addresses such problems as "How to get started" and provides examples of model policies from a wide variety of businesses. Call: the National AIDS Clearinghouse (1-800-458-5231).

Technical assistance with policy and program development is also available from the Maine HIV/STD Prevention Program, the American Red Cross, the Maine AIDS Alliance and its member organizations. (*See Resources*)

Speakers

Many of the Maine AIDS Alliance member organizations offer AIDS education training sessions for companies. Trained educators, accompanied by speakers living with HIV/AIDS, not only present information but give a personal perspective into the disease. (*See Resources*)

The American Red Cross offers a Workplace HIV/AIDS Program designed to meet the needs of a variety of workplaces. Trained instructors teach in a series of five modules, covering topics such as confidentiality, disclosure, employee and employer rights and responsibilities. (*See Resources*)

Videos

"A Time to Know" (about Maine women with HIV)

Eastern Maine AIDS Network
207-990-3626

"Living and Working with AIDS"
Contact the AIDS Action Committee
617-437-6200 ext. 335

"The Next Step: HIV in the '90s" (1989)
Contact IMPACT AIDS
415-861-3397

"America at Work: Living with HIV"
Contact the American Red Cross
1-800-422-0743

"Talk About AIDS"
Contact the San Francisco AIDS Foundation
415-864-4376

"Changing Attitudes" (Union members talk about AIDS, 1991)

Contact the Maine AFL-CIO
207-945-3776

Many of these and other books and videos are available on loan from local Maine AIDS Alliance organizations (207-621-2924), or from the Maine HIV/STD Programs, 207-287-3747.

Books/Brochures

The following resources are available from IMPACT AIDS
415-861-3397.

"AIDS in the Workplace," a guide for employees

"An Educational Guide for Managers," a model for educating employees and themselves about AIDS

"The Next Step Manual," based on interviews with corporations nationwide, helping senior managers and human resources staff prepare for and manage HIV-infected employees and their co-workers. (1991)

"A Benefits Counselor's Guide"

"Strategy Manual," based on the experience of corporations that have dealt successfully with AIDS in the workplace; provides suggestions for the development of policies and guidelines.

HIV/AIDS in the Workplace: What Employers Need to Know and Do!

Summarizes the proceedings of a 1992 conference covering workplace AIDS policies, costs, benefits, disability, legal and personnel issues, and discrimination. \$15 for a single copy, +\$2.50 shipping and handling. Available from: the New York Business Group on Health, Inc., 622 Third Avenue, 34th floor, New York, NY 10017-6572.

Additionally, many fine materials are available for free or at low cost from the National AIDS Clearinghouse. Call 1-800-458-5231 for a free catalog.

(continued on next page)

Resources (continued from previous page)**Other Resources**

"Your Job and HIV: Are There Risks?" Pamphlet available from the American Red Cross
1-800-422-0743

"A Guide to Selected Workplace Resources," available through the Centers for Disease Control
"Business Responds to AIDS" Resource Service to assist professionals in choosing materials appropriate for training, education and awareness.
1-800-458-5231

"AIDS Reference Guide: A Source Book for Planners and Decision Makers," revised monthly by the Atlantic Information Services, Inc.
1-800-521-4323; 202-775-9008.

The HIV/AIDS Book: Information for Workers, produced by the Service Employees International Union, Occupational Safety and Health Department (1991); to order, write 1313 L Street NW, Washington, D.C. 20005
202-898-3443

Employer and Employee Packets and Programs

Contact Levi Strauss & Company's Corporation Communications Department
415-544-7220.

Contact the AIDS Action Committee, Workplace Education Program
617-437-6200 Ext. 335.

Contact the Service Employees International Union, Health and Safety Office, 145 Tremont Street, Suite 202, Boston, Massachusetts 02111
617-482-4471, FAX 617-482-6521.

"Business Responds to AIDS"—Manager's Kit, Labor Leader's Kit. Includes information on policy development, leadership training, employee education, community involvement, volunteerism, etc.
Call the National AIDS Clearinghouse,
1-800-458-5231.

Policy and Procedure Development

Many agencies, including the Maine AIDS Alliance, the State HIV/STD Program, and the National AIDS Information Clearinghouse, can provide models and technical assistance for writing policies and establishing procedures concerning HIV/AIDS.

Equal Employment Opportunity Commission
1801 L Street, NW
Washington, DC 20507
202-663-4900

National Leadership Coalition on AIDS. Sample policies from Bank of America, RJR Nabisco and various other large and small workplaces. Contact National AIDS Clearinghouse, 800-458-5231.

U.S. Dept. of Labor. *OSHA Bloodborne Pathogens Standard*.
207-622-8417

Maine Organizations

Maine Chamber of Commerce and Industry
7 Community Drive
Augusta, ME 04330
207-623-4568

Maine Labor Group on Health
PO Box V
Augusta, ME 04332-1042
207-622-7823

Rural Health Centers of Maine, Inc.
address migrant worker issues
Route 202
Manchester, ME 04351
207-622-9252

American Red Cross
Pine Tree Chapter
provides migrant workers with health and HIV prevention education
33 Mildred Street
Bangor, ME 04401-4305
207-941-2903

Education Settings

- Daycare/Head Start Programs
- Public/private schools: K-12
- Alternative education: school settings, independent programs
- Teen parenting programs
- Post-secondary education

Teens take risks. We know that the highest proportion of HIV+ people alive today were infected in their teens or early 20s. We also know that many STDs that are currently more prevalent than HIV, such as chlamydia and gonorrhea, are spreading through our teen population at epidemic levels—in 1993 the incidence of chlamydia in females aged 15-19 was six times higher than the statewide rate for all females (533 cases).

"This is a life and death issue. We have to do it."

—High School Superintendent

AIDS is now the leading cause of death among Americans age 25-44. The lengthy incubation period of HIV means many were infected in their teens and early 20's.

Maine teenagers are having sex. The latest studies by the State show that 54% of high school students have had sexual intercourse, including 24% of those aged 14 and under and 63% of those 17 years old.

The same research found that only 55% of high school students reported using a condom the first time they had intercourse. Approximately 25% of in-school teens and 35% of teens no longer in school reported using a condom last time they had intercourse. While those who did not use a condom may have used another form of birth control, such as pills or withdrawal, those methods do nothing to prevent someone from getting a sexually transmitted disease (STD), such as HIV. We must also note that these statistics reflect questions about heterosexual intercourse only, not about oral or anal sex, or other sexual practices in which STDs can spread.

Even teens with good intentions sometimes make bad decisions.

It is clear that far too many teens are having sex without protecting themselves. However, lack of information is not the main problem. Department of Education data shows that 98% of in-school teens are aware of HIV and how to prevent it. The challenge, then, is getting teens to change their sexual behavior. And that's not easily done. Even teens with good intentions sometimes make bad decisions. With high numbers of youth using alcohol and other drugs (approximately half of all Maine high school students had a drink in the past month—for out-of-school youth, alcohol and drug use is much higher) decision-making suffers markedly.

School is the one social structure common to the most young people—and therefore, the best chance we have to reach them en masse. Classrooms and other school settings provide a safe opportunity to reach students of all ages about HIV. Children can be educated early with age-appropriate messages about HIV routes of infection. Teens and pre-teens need to learn and practice their skills of communication, negotiation, and avoiding and managing risk behaviors.

There are many kinds of schools. For the purposes of this report we have categorized these settings as:

- Head Start and Daycare,
- K-12,
- Alternative Schools,
- Teen Parent Programs, and
- Post-secondary.

Some programs are subject to strict federal regulations while others operate with little oversight. Most formal education settings are recognized by the state or federal government. In these settings education and services are provided by licensed, certified or approved staff.

HIV needs to be addressed in all educational settings. But simply addressing HIV will not change behavior. For that to occur requires the active participation of entire communities—parents, students, school administrations and staff, local businesses, clergy, and other interested taxpayers. Every one of us has a role in helping to ensure that one of our children or students will not be the next young person to become infected with HIV.

To help find legislative solutions to HIV/AIDS, in 1986 Maine's governor and legislature created the Maine HIV Advisory Committee, a 36-member council whose mission is to advise all departments and agencies of state government on HIV-related matters. Among its recommendations, the group advised in May 1995:

"Schools, should make condoms available along with comprehensive education, counseling and referral."

"The Maine HIV Advisory Committee recognizes that access to condoms for sexually active youth is essential to reducing the risk of HIV. The Committee recommends that youth-serving agencies, including schools, should make condoms available along with comprehensive education, counseling and referral." (See *Information Sheet on page 10 for full statement.*)

General Recommendations

1. All organizations working with children and youth: Have a written policy identifying:
 - safety procedures concerning HIV;
 - ways in which the organization will maintain confidentiality for the young persons in their care and the adults on staff who are living with HIV.
2. All persons working with children and youth, from daycare providers to college professors and school janitors: Participate in Occupational Safety and Health Administration (OSHA) bloodborne pathogen standards training, with an annual update.
3. All schools: Provide ongoing and age-appropriate HIV prevention education programs for all grade levels.

Background

There is no state law that forces Maine schools to teach about HIV. However, most schools in Maine that are subject to Chapter 127, the School Reform Act of 1985, do offer HIV education as part of the mandatory health curriculum. Unfortunately, consistency is nonexistent within or between schools which offer HIV programming, despite several high quality curricula

that are available. So far, these curricula (e.g., Listen to the Students, Reducing the Risk, WEDGE, etc.) are used in only a few schools.

Licensing

Licensing requirements for the programs where education is provided to children vary greatly, depending on the setting and types of services provided. Daycare centers must meet a certain set of guidelines established by several state and federal agencies, while residential programs for youth adhere to other guidelines. Yet none of the policies that do exist require (or even describe) HIV education for staff or students.

Training

Ninety percent of the educational settings discussed here report that they have instructed staff on handling blood and body fluids (OSHA standards). It is difficult to know how prepared teachers are to address other, HIV-specific issues, because HIV/AIDS is not addressed in existing professional standards. In addition, there do not appear to be HIV-related requirements for teacher training or continuing education programs. Although the State Department of Education and the State Bureau of Health jointly offer annual HIV-education training sessions for K-12 school personnel and others, attendance is voluntary. Not even health educators are required to study human sexuality, family life education or HIV/AIDS prevention.

Policy

All of the education settings described here are required to be in compliance with the OSHA bloodborne pathogens standards, the Americans with Disabilities Act, the Maine Human Rights Act, and the Medical Conditions Law (Chapter 501) (*see Appendix*), all of which serve to protect students and staff. If teachers believe that they have been discriminated against on the basis of an HIV infection, they may get help through their collective bargaining agreement or, in certain circumstances, the Maine Civil Liberties Union.

Beyond these basic laws and regulations which govern infection control (i.e., caution when handling blood), discrimination (i.e., job security must be unaffected by real or presumed HIV status) and confidentiality (no one may reveal another's HIV status without that person's consent), schools are at liberty to develop policies or not, as they choose. The content of those that are developed is determined by local school systems.

In 1992, only 52% of school administrative districts had established written guidelines for HIV as a staff issue. In the districts with no HIV policy, faculty and staff may be unaware of relevant laws, protocol and appropriate behavior related to HIV on the job.

Issues

Although the state makes laws concerning confidentiality of HIV status for all people including school faculty, staff and students, few people are aware of the law and how it relates to them.

Provisions of the federal Americans with Disabilities Act and the state Human Rights Act (*see Appendix*) suggest appropriate behavior toward an

infected co-worker or student. School communities may be unaware of these rights—or their responsibilities to students or co-workers with HIV.

When accidents happen in school, faculty and staff need to know how to respond in a way that does not endanger themselves or the child. Once staff and students are trained in universal precautions, and strategies are in place (similar to fire drills), incidents involving bleeding can be addressed effectively and safely. This role modeling will enhance students' understanding of blood safety issues in their own lives.



Immediate

Parents, faculty, staff and students: Actively support your public high school's health clinic services in providing sexual health screening and treatment and prevention services, including condom availability.

- Department of Education: Look into all state-funded or recognized education settings for HIV policy and programs (for both staff and students). Surveys should include management, faculty, union leadership, administrators, staff and students.
- All adults and youth in educational settings: Learn and use basic universal precautions.
- All adults working in education, from daycare providers to college professors and school janitors: Participate in OSHA bloodborne pathogen standards training, with an annual update. Administrators should provide staff with appropriate materials and devices for implementing the OSHA standards.
- State Legislature and State Department of Education: Require that all employees of publicly-funded education programs participate in training that promotes respect for diversity, reduces fear of people perceived as "different," counteracts fears associated with HIV, and debunks HIV myths and misinformation.
- Parents, faculty, staff and students: Actively support your public high school's health clinic services in providing sexual health screening and treatment and prevention services, including condom availability.
- Local leaders, school board members, parents, faculty, and local ASOs (AIDS service organizations):
 - Initiate comprehensive, up-to-date HIV policies and programs in all state funded or recognized education settings. These efforts should educate and draw support from legislators and other elected representatives, government officials, education officials, management, workers, union leadership and the media;
 - Include parents in the educational process by developing companion programs for parents and their children to learn separately and together about HIV and sexuality.

Intermediate term

- All organizations working with children and youth:
 - Make sure you have a written HIV policy (the Department of Education has model policies available (*see Resources*)).
 - Any HIV policy, at a minimum, should explain:
 - safety procedures;
 - referral options for support or educational services;
 - guidelines on maintaining confidentiality for the young persons in your care, as well as for the adults on staff who are living with HIV.
- All education settings: Design and implement comprehensive, up-to-date HIV education programs for all employees in state funded or recognized education settings.
- Local leaders, school board members, parents, faculty and community-based HIV organizations: At election time, support candidates who advocate compassionate HIV laws, regulations and other public policy.
- All school administrators and teachers: Implement an ongoing, age-appropriate skill-based HIV prevention curriculum for all grade levels, K-12 and beyond.

Long-term

- Local leaders, school board members, parents, faculty and community-based HIV organizations: Fully implement and continually look to improve your HIV policies and programs as new information and teaching methods become available.
- Local leaders, school board members, parents, faculty and community-based HIV organizations: Follow the strong advice of the Maine HIV Advisory Committee—work to make condoms available (as well as counseling and education about their appropriate use) to students over the age of 13 in all state-funded or recognized education settings.
- Maine Department of Education teaching-certificate programs:
 - Teach all candidates how to integrate HIV into the curriculum;
 - Require sexuality and specialized HIV prevention training for health teachers.

Head Start and Daycare Programs

Since 1992 all of Maine's nursery schools and Head Start programs have been subject to daycare licensing requirements by Maine's Department of Human Services, Division of Licensing and Registration for Child Care.

Today more than 2,700 licensed, independent and school-based daycare centers operate in Maine, serving approximately 39,000 children. Among that number are 100 Head Start sites and more than 350 nursery schools, defined as those institutions providing care to children under age seven for up to 3½ hours a day.

In 1994 more than 3,200 children in 145 classrooms received Head Start services. Each of the state's 13 Head Start programs has its own operating budget. Nearly 75% of those budget funds come from the federal government; the balance comes from the state and other sources. Licensing laws require that all Head Start staff be trained in first aid and CPR, and that each program comply with OSHA bloodborne pathogens standards.

In addition, each Head Start site has a Health Coordinator who conducts federally-mandated health education and training for children, staff and parent groups. All Head Start employees interviewed for this report said that HIV education was included in their health education and training programs.

Licensed daycare centers that are not Head Start programs are not required to provide health education to staff or children. However, all licensed daycare centers must be compliant with OSHA bloodborne pathogens standards. No other HIV-related activity is expected or required.



Immediate

- DHS, Division of Licensing and Registration for Child Care, and state legislators: Require the staffs of daycare centers to receive HIV education and training.
- All parents of children enrolled in daycare: Ask to see your daycare provider's HIV policy and OSHA certification.
- Parents and Daycare Providers: Participate in HIV education and training.

Education K-12

Traditional Schools

Maine has 188 school systems comprising 284 local school units. There are 739 public schools and 98 private schools, 27 vocational schools and 20 special education facilities (9 public and 11 private). In all, 226,000 school-aged children live in the state. Of that number, more than 500 attend private, non-approved schools, and another 3,000 are home-schooled.

[Note: The State Department of Education does not monitor home schools or private, non-approved schools. The state's role in home-schooling is only to process home school applications and see that parents sign an agreement that they will meet the School Reform Act regulations; no curriculum description is required.]

Mostly, however, the lack of consistency in HIV education—in all schools, traditional and otherwise—results from the absence of any national or statewide educational standard.

The School Reform Act of 1985 requires that all Maine high school students earn a half credit in “comprehensive health education,” which consists of 10 health content areas. The Act recommends that HIV education be included in the curriculum, but it is not mandated.

The 1993-94 School Administrative Unit Survey of AIDS/HIV Education (commissioned by the Maine Department of Education) found that 98% of high schools and 94% of middle schools offer basic HIV education, and 57% of high schools require HIV education for graduation. Since 1991, 66% of upper elementary school grades have been teaching their students something about HIV/AIDS. While these figures show an increase in the number of HIV education programs in schools, they do not reveal anything about the quality of the programs.

98% of high schools and 94% of middle schools offer basic HIV education.

An area of particular concern is the distinction between HIV information and HIV prevention education. What we know about this aspect of HIV curricula is pieced together from our observations and from interviews with educators who specialize in sexuality and HIV education. At present, HIV education programs seem to range from those in which there is little mention of HIV/AIDS to others that include values clarification and specific behavior skills for HIV prevention (condom use negotiations, for example). During the last seven years much has been done to improve HIV education in Maine, but too few HIV programs progress beyond basic information.

Psychological and public health research shows that information alone does not lead to behavior change. Surveys of Maine youth have demonstrated similar results; while 93% of high school students who responded knew that condoms can offer protection from HIV infection, only 50% of those who had sexual intercourse during the previous three months reported using a condom the last time they had sex (According to the Maine Youth Risk Behavior Survey, 1993). If respondents had been questioned about consistent condom use, the percentage probably would have been much lower.

“Education doesn’t necessarily mean the end of confusion.”

—a teen speaking
in a discussion
about sexuality

To effect behavior changes in teens, some programs have enlisted teens themselves as educators. “Listen to the Students,” an HIV education and prevention curriculum for high schools, is the result of a three-year research project conducted by Family Planning Association of Maine, in which high school students were involved in designing, implementing and evaluating the program. Two high schools took part in the initial research, conducted from 1990 to 1992. Because of the program’s popularity and apparent success, at least 18 more Maine schools implemented “Listen to the Students.”

Students Put the Show on the Road

Three years ago, when Mount Desert Island High School nurse Nina "Cookie" Horner noticed some students offering information about HIV and sexuality, she decided to take them to the Student Leadership Conference on HIV, sponsored annually by the Department of Education (DOE). There they heard and saw college students doing some AIDS prevention skits.

"They came back wound up like tops," Horner recalls, "and they organized a group. Around 20 to 25 students showed up for the first meeting and that was the start of the Student AIDS Committee (SAC)."

The first agenda item was to make condoms available to high school students who were sexually active. "At first I panicked," Horner says, "but then we got to work. We started by training ten volunteer teachers, people the kids felt comfortable going to if they wanted condoms or if they just wanted to talk. Six months later we put in condom machines. Today it's divided pretty evenly—about half the kids go to a teacher, the other half use the machine."

SAC has presented for three years at the DOE's HIV Prevention Education Conference and at other conferences. And every spring they visit the eighth grades on Mount Desert, talking and putting on skits related to HIV, sexuality and relationships—whether it's male-female, male-male, or female-female—to show people that HIV is not a gay disease. Some skits are serious, some are candid. They write some of their own, as well as perform skits they've seen other AIDS groups do. They've even made a video, which Horner sends out



to other schools with an information packet, responding to up to three requests a week.

On September 25, 1994, the Family Planning Association of Maine awarded them the first David and Sherry Huber Award for Outstanding Contributions to Family Planning and Reproductive Health. Along with the award, the group received \$5,000 to help with their mission.

"Ultimately," says Horner, "we want to make life safer for gay, lesbian and bisexual youth. What we're doing now is trying to educate the people who walk down the hall calling their friends 'faggot' or 'homo.' Our kids will stop someone who says this and tell them, 'You know, there might be someone in the hall who's questioning, and you've just ruined their day—maybe their year.'"

"These kids are wonderful, and they've done it all.

"Probably the most gratifying thing I've ever seen was in this year's yearbook, on a page called 'What's Hot—What's Not.' Unprotected sex was listed as 'What's Not.'"

"I thought, 'They're getting it!'"

Listen to the Students

"Listen to the Students' came out of the recognition that even with our progress in sexuality education, we hadn't done a very good job in our schools preventing pregnancy," explains Mary Madden, who provides teacher training for the program.

This sexuality curriculum began as a project developed by Cathy Bradeen Knox in 1989, for the Family Planning Association of Maine, where she was Director of Training and Education. Together with Chuck Rhoades, who was experienced in adolescent sexuality education, and with assistance from the Muskie Institute and the UNUM Charitable Foundation, they set out to put together a pilot program.

They took a marketing approach, which meant they went to the people they were creating the product for—a focus group made up of students from Skowhegan and Waterville high schools—and they asked, "What can we give you that will enable you to change your behavior?" The answer, especially from the 11th and 12th graders, was, "We don't need any more information. We already know the facts. What we need are ways to use the information in our relationships."

In designing their ideal learning environment," according to Madden, "the kids described a classroom that was small, that was led by an adult who was comfortable with sexuality and who would let them talk about real stuff."

At first the students wanted adults who were young, but they refined that to mean someone with a young attitude—who wouldn't preach or be judgmental. "So Cathy and Chuck began training a small group of teachers—teachers from any field, as long as they were the type of people the kids had good relationships with." They ran the first pilot program in 1991-



92, and the Muskie Institute did an evaluation. They found that the students who participated demonstrated increased communication with their partners and parents, and an increase in their knowledge and attitudes about the risks of teens being infected with sexually transmitted diseases (STDs).

Other results that teachers reported were that students from the program seemed more comfortable communicating with adults around the school. Interested in these results, the CDC (Centers for Disease Control) began providing funds for technical assistance and further evaluation. The next year eight more schools were added. Now about 20 high schools are using Listen to the Students.

"And the students are just amazing. Each year we do an information session for new schools that have expressed interest in the program. At these sessions we bring kids who have been through the program, and they answer questions and do some exercises from the curriculum. The teachers are totally amazed. Here are kids from three different schools having an honest, straightforward dialogue about sexual behaviors. Afterwards, the teachers admit that they couldn't have done that themselves."

Alternative Education Schools

In Maine, an Alternative Education School (AES) is defined as “an education program that embraces subject matter and/or teaching methodology that is not generally offered to students of the same age or grade level in traditional school settings, which offers a range of educational options and includes the student as an integral part of the planning team.”

Currently 73 public and two private Alternative Education Schools operate in Maine, offering programs from K-12 (though the majority of sites focus on grades 9-12). Some are housed within a traditional school setting; others are free-standing. All must meet the requirements of the Maine Department of Education.

Many AES students have been labeled as “at-risk” because in traditional schools they exhibited one or more of the following behaviors or traits: unexcused absences, tardiness, dropping out, truancy, academic failure, detention, disciplinary problems, psychological withdrawal, etc.

With such a student population, HIV education takes on heightened importance—yet it also presents a number of opportunities. Because parents of students in alternative schools generally allow teachers greater latitude in trying to reach the students, topics such as safer sex and HIV prevention do not result in the same level of controversy as they might in traditional educational settings. This allows AES teachers flexibility in creating dynamic HIV education programs designed specifically for the personalities involved.

The downside is that this same flexibility can lead to inconsistency in HIV education from school to school (and within schools, from classroom to classroom), due to differing comfort levels teachers have with HIV and sexuality issues. Mostly, however, the lack of consistency in HIV education—in all schools, traditional and otherwise—results from the absence of any national or statewide educational standard.

Alternative Education Schools have high levels of flexibility and autonomy necessary to meet the needs of troubled youths—and that makes it easier to try new HIV prevention strategies.

Real Learning at the REAL School

The Regional Educational Alternative Learning (REAL) School in Windham is an example of an AES that has embraced the opportunity to create new HIV education while maintaining its goals of supporting its students and helping them remain in school.

Many of the students enrolled in the REAL School need special education for learning disabilities. The program consists of three teams, each led by a special education teacher and one or two aides. The teachers tailor individual education programs to each student's needs, his/her ability to approach particular subjects, and the school's curriculum requirements.

The teams approach HIV education differently. Two of the classes (14 students each) share a joint four-week concentration in HIV education integrated into the health curriculum.

The other class (11 students) takes a different approach. At the beginning of the year the teacher begins by introducing self-esteem issues and uses this topic to initiate discussions of feelings, sexual identity, gender, and sexually transmitted diseases. The HIV program is largely student-driven, and the teacher strives to fully integrate HIV into both science and human sexuality lessons.



In recent years students have generated a variety of projects, including a one-hour teen sexuality videotape, some public service announcements and an HIV photo exhibit—the Vincent Boulanger Memorial Exhibit, “Fight HIV, Not People Who Have It”, seen statewide and scheduled for a national tour. The students have been awarded a number of grants for these projects, as well as an America's Future Award in May 1994 for their ongoing work in HIV education.

This level of HIV integration and activity is unusual in traditional schools, where staff capacity is lower and student-teacher ratios higher—and where schools sometimes have no formal written HIV policy. In this example, because the REAL School teacher had two aides working with her, she was able to participate in 160 hours of professional teacher training specific to HIV.

ACTION STEPS

■ Parents:

- Get the facts; familiarize yourself about HIV/AIDS issues before discussing them with your young people: call your local AIDS service organization, the AIDS Hotline, or check your local library.
- Talk with your sons and daughters about HIV;
- Support HIV prevention programs in schools.

■ Maine Department of Education (DOE):

- Mandate HIV/AIDS education for all grades in all schools

A Blueprint for Action

- Incorporate HIV/AIDS education into the comprehensive health curriculum and across other content areas.
- Establish an external, community-based group to monitor and make recommendations on HIV prevention activities in schools.
- Faculty and Administrators: Initiate or participate in ongoing professional teacher training specific to HIV and “high risk” youths.
- Community Members: Provide financial and political support for faculty education and student-directed AIDS education and HIV prevention projects.
- DOE and Community leaders: Set up local community groups to focus on a more holistic approach to healthy schools. Membership should include local school administrators, teachers, coaches, parents, students and other interested residents. Issues could include the environment, physical, mental and sexual health, risk behaviors, substance use and abuse, family relationships, communication skills, etc.
- Alternative Education Schools: Look at models of school HIV prevention education. Develop your own programs that are appropriate for your students.

Suggested Content Guidelines for School-Based HIV/AIDS Education

The following recommendations are in agreement with the Center for Disease Control. More detailed content description can be found in the CDC’s Guidelines for “Effective School Health Education to Prevent the Spread of HIV/AIDS” (*Morbidity and Mortality Weekly Report*, Jan. 29, 1988).

Early Elementary School (K–3)

Education about HIV/AIDS principally should be designed to allay fears of the epidemic and of becoming infected. It should begin with basic information on germs and infection control.

Late Elementary/Middle School (4–6)

Education about HIV/AIDS should be presented within the context of family life education’s section on sexually transmitted diseases (STD’s). Such a program should begin with lessons addressing self-esteem, family and friends, peer pressure, and decision-making and communication skills, including refusal skills. Students should be aware that sexual beings have responsibilities to themselves and to others. One of those responsibilities is understanding the nature and causes of STDs, including basic information on transmission, prevention, and treatment.

Junior High (7–9)

Education about HIV/AIDS should continue within the context of family life education and include a general and basic overview of transmission, prevention, and treatment of AIDS/HIV; guidelines and suggestions for healthful behavior choices (addressing decision-making skills, communication skills, assertiveness training and self-esteem building); information on the ways HIV/AIDS is affecting their community; the emotional impact of HIV/AIDS; and where to turn for advice, help, and support.

High School (10–12)

Education about HIV/AIDS should continue to integrate information about HIV/AIDS discussed at the junior high level with programs for values clarification, decision-making and assertiveness, along with efforts to promote self-esteem.

*by the Family Life Advisory Group, 1989
Maine Department of Education*

Teen Parenting Programs

Teen parenting programs may be described as any program, public or private, that serves a pregnant or parenting teen. Teen parenting programs have emerged in response to high rates of teen pregnancy and the special needs of teens who are pregnant or parenting. The goal is to provide life skills training while helping the young woman through a healthy pregnancy.

The Maternal and Child Health Division (MCHD) of the State Bureau of Health funds ten teen parent programs in Maine. Eight others are funded through the Bureau of Child and Family Services. Each agency running a teen parent program determines the criteria for that program and trains employees accordingly.

The MCHD-managed programs are on two-year funding cycles, with annual review and evaluation. Staff training requirements include the OSHA bloodborne pathogens standard. MCHD funding supports teen parent services for more than 700 young women each year. Agencies may also offer services to fathers, babies, and the children's grandparents.

The state has not issued guidelines regulating teen parenting programs. One employee of MCHD believes that because of Maine's rural nature and lack of resources, regulation might be harmful, diminishing the flexibility which has been key to the program thus far. In Maine, local communities design teen parent programs appropriate to the needs of the particular teens. Programs are typically staffed by licensed social workers or volunteers.

Currently no comprehensive information exists on the number of programs for pregnant and parenting teens, nor is there a list of the agencies offering those programs. The services are often interwoven through a variety of other programs. In other words, a program partially funded by MCHD might be run by another organization that offers maternal care, such as an after-school support group or home-based service providers.

While teen parent program guidelines do not mandate HIV prevention education (nor do funding requirements), interviewees told us that HIV education is an essential component of their work with clients.

An Example

The Portland YWCA Teen Parent Program provides classes to 175 pregnant or parenting teens (including fathers) on a variety of subjects, such as prenatal care, parenting education, nutrition, self-esteem, the impact of drug and alcohol use on pregnancy, GED preparation, etc.

All staff are either licensed social workers or degreed professional counselors, and are expected to be prepared to deal with HIV and to have attended workshops in the last 18 months. (The YWCA is not aware of having had any HIV+ clients). Part of the program is peer leadership, whereby some clients receive special instruction about teen parenting issues, including HIV.

In order to keep its current MCHD funding status, the program must maintain a focus on physical health and must have links with health care providers in the area. The staff initially talks about HIV with the client during the intake interview. Here the client is asked if she/he has ever been tested for HIV. This question begins a dialogue about HIV prevention, which is then integrated in all subsequent classes. Currently the YWCA lacks funding for a coordinated HIV prevention education effort.

Issues

Pregnant and parenting teens are clearly at high risk for becoming infected with HIV. Therefore, teen parenting programs have a responsibility to make sure that basic HIV education is part of their programs. At the same time, they have a good opportunity for developing model programs for HIV risk reduction—but probably too little funding to do so.



- Teen Parent Programs:
 - Document exactly how HIV education is integrated into current programs; keep exploring new ways to teach HIV prevention.
 - Evaluate the impact of your HIV education on clients (e.g., through periodic surveys)
- The Maternal and Child Health Division and the Bureau of Child and Family Services:
 - Research the literature and then develop model HIV prevention program practices for teen parent programs.
 - Provide financial support for program evaluation.

Condom Crusaders

Christina Mason has a van that will soon be wearing a condom. She and other members of FATE—Fight AIDS, Transform Education—a statewide, teen-led effort to promote access to condoms and more comprehensive sexuality education in schools, plan to go on another of their “condom crusades.” “This one,” she says, “will catch people’s eye.”

They plan to go to beach and school parking lots, play music with safer sex messages, tie red ribbons on cars, and hand out flyers and condoms. Mason, a 1995 Deering High School graduate and FATE staffer, says, “FATE is a way of empowering students to stand up for what they want.”

Adopting an up-front, in-your-face organizational style similar to ACT-UP, its parent organization, FATE began organizing school-based groups in 1993. Richard Fried, one of the adult organizers, explains, “The teens were saying, ‘If the schools won’t protect us, we’ll do it ourselves.’”

With names like KISS (Kennebec Individuals for Safer Sexuality), SLAB (Students for Latex Availability in Biddeford), and SAFE (Students Against False Education), local teen groups hand out self-produced safer sex ‘zines, condoms, and petitions to their peers.

Mason, the current FATE coordinator, reflects on why she got involved, “I didn’t feel my sex ed training in school was adequate. Kids were being denied basic



information for their survival.” Regarding FATE’s methods of education versus those in traditional school settings, she offers, “It can be less intimidating to get information or condoms from a friend than from a school nurse.”

But FATE groups aren’t content with only this approach. The South Portland group, SAFE, tried to deliver a petition to their principal, advocating for condom distribution in the school. Although the petition had 300 signatures, it was rejected. In response, the group handed out condoms every Friday outside the school, with 30 to 40 students wearing FATE T-shirts in support.

“We held a Die-In on World AIDS Day outside my school,” Mason reports. “We generally have a core group of ten, but that day about 65 students participated. It’s an effective way to get the message across, because students see their peers active on the issue. Then they have to decide whether it’s important to them, too.”

Post-secondary Education

Maine has seven public university campuses and one maritime academy. There is one state-sponsored school of nursing, 11 private four-year colleges, and six private colleges (including two seminaries). In 1992 the total student enrollment in Maine was 57,922. More than 24,000 of that number were full-time undergraduates aged 18-24.

The typical college or university often functions as a discrete “community within a community,” including students, faculty, professional and classified staff, alumni, parents and trustees.

College students are a dynamic population. For many, it is the first time they have lived away from home. With a new and often changing population, social opportunities abound, including opportunities for having sex.

Colleges are often safe places for gay/lesbian/bisexual students to begin expressing themselves, getting correct information, meeting others and

developing relationships. The school environment should be a place that promotes health and safety, HIV prevention, and respect for diversity, etc., rather than an environment that allows misinformation through inattention and inaction.

While data on the health of Maine college students is sparse, we do know some things. Nationally, college students fall into the age group (18-24) that has the second heaviest consumption of alcohol and the second highest prevalence of sexually transmitted diseases (STDs). Among new HIV infections in the U.S., 1 out of 2 is 25 years old or younger.

Among new HIV infections in the U.S., 1 out of 2 is 25 years old or younger.

In Maine, rates for all STDs have declined from 1992 rates. Nevertheless, two-thirds (387) of the cases of AIDS (592) reported through December 1994 have been in people between the ages of 20 and 39.

An informal telephone survey conducted in 1994 at the University of Southern Maine showed that HIV education and prevention efforts by Maine's institutions of higher education ranged from non-existent to vigorous. On those campuses where HIV education existed, it appeared to be general in nature, without much direct prevention activity.

For example, many colleges provide HIV education by integrating it into other health subjects, such as occupational exposure training, alcohol abuse, or STDs, apparently assuming that health science students, at least, are receiving all necessary personal HIV prevention education from their academic education.

At least ten Maine colleges reported strong links to community HIV organizations for programming and training. While too much dependence on outside organizations and speakers may prevent an institution from developing its own resources in campus health promotion on HIV, collaborations with local ASOs can help the college develop and maintain its own HIV prevention program (providing trainer trainings, for example).

Some HIV-education strategies at work in Maine colleges:

- student-based education
- student peer educators
- campus-wide AIDS awareness week
- first-year student orientation sessions
- condom availability on campus
- internship placement in community HIV agencies
- persons with AIDS offering education sessions
- informal participation in local AIDS events
- support for gay/lesbian/bisexual student groups

Some campuses undertake more innovative efforts:

- distribution of safer sex packets
- HIV prevention committees with staff, faculty and student membership
- awarding of academic credit for attendance at non-academic HIV education events
- informal attitudinal surveys conducted by students

Issues

Adolescents and young adults are contracting HIV at higher rates than other age groups. Post-secondary schools need to know how to respond to those who become infected while they are enrolled in school, and to those who are HIV+ when they arrive.

Schools are dynamic places with diverse populations. Students come from all parts of the country—and the world—often transferring from other schools. However, because symptoms of HIV disease may not occur until ten years after infection, many students may enter and leave post-secondary school without knowing their HIV status. On the other hand, others in the school setting—undergraduates, graduate students, faculty and staff—may be aware of their HIV status or may just be entering the symptomatic stage of the disease.

While most of Maine's post-secondary schools offer students some form of health promotion, for a variety of reasons, HIV prevention can remain absent from health promotion programming.



■ Parents:

- Find out what your sons and daughters know about HIV prevention. Ask them—they may know more than you do;
- Explore ways to learn about HIV with your sons and daughters; investigate school or local resources for information;
- Ensure that the school your child attends provides HIV prevention and education, along with resources;
- Volunteer to support those efforts if they exist; if they do not, work to establish them.

■ Administration:

- Start campus-wide awareness campaigns (for staff and students) that promote diversity and discourages homophobia and the spread of misinformation;
- Require HIV prevention education for all students in teaching, health or social service degree programs.

■ Health Center Staff:

- Develop and implement comprehensive HIV risk assessment and education programming for students and faculty;
- Ensure that services are “gay-friendly” in order to be accessible to all students.

■ Faculty:

- Watch for ways to integrate HIV into your class discussions (history, math, sociology, the sciences, etc.)

When Students or Their Family Members Have HIV

Students of any age who have HIV choose to confide in staff who they feel are safe—who will keep information confidential and who are respectful and non-judgmental. Students indicate that these confidants are in differing roles within the school. They are often the sole connection for the young person who feels confused, isolated and in pain.

It might be helpful for school personnel to go through the anonymous testing procedure themselves.

Appropriate school personnel—respectful and non-judgmental—should be identified and trained in order to carry out individual HIV risk assessment. Sometimes referrals must be made for the student wanting an HIV test or for the HIV+ student who needs social or health services for him/herself or for a friend or family member. School staff should be knowledgeable about the rights of youth regarding health care (including alcohol and drug counseling and mental health services).

It is important that the referral agency have the reputation of being sensitive to the needs of young people. They should also be sensitive to issues relating to adolescent sexuality, such as date violence, sexual abuse, reproductive health, homosexuality and bisexuality.

The school staff member may be the only resource for the adolescent who is considering HIV counseling and testing. Being helpful requires knowledge of the testing protocol and a willingness to support the young person through the process. It might be helpful for school personnel to go through the anonymous testing procedure themselves prior to doing this work. Referral to treatment and social services should be coordinated with the family whenever possible. However, because of confidentiality concerns—the infected student may not wish to involve his/her relatives—this may not always be an option.

For the student who is HIV+ and decides to share this information with the school, there must be guidelines in place. Particularly with younger students, while communication with the family is optimal, it requires extraordinary effort as other family members may be ill with HIV disease and may not always be as responsive as needed. The family will decide who among the staff is to be informed. This should be done in writing, to prevent any misunderstandings and to expedite settlement of any possible litigation related to alleged breaches of confidentiality. Schools should also have protocols in place to deal with rumors of a student's positive HIV status.

Schools should also have protocols in place to deal with rumors of a student's positive HIV status.

Another issue that may arise, but which has yet to be tested, is that of an HIV-infected student who needs special education services. Schools already face the challenge of serving the medically fragile child. This is often a new area of responsibility for the special education staff. The issue of confidentiality and the Maine HIV law adds another challenge if the child needs medical or other services, yet the family does not want the staff to know that the child has HIV.

Support for students whose family member(s) have HIV disease requires the same special effort as that needed for dealing with any chronic or terminal disease. Emotional support from within the school may be sufficient to assist the student. If it is not, the school and family can engage the services of organizations such as the Center for Grieving Children. Death-and-dying education for all involved can be a source of comfort and even inspiration as the disease progresses.

Homophobia (the irrational fear and/or hatred of homosexuality) creates a barrier to effective HIV education. Programs which teach about diversity and encourage understanding of differences can help to provide an environment that is accepting of students and staff who reveal that they are HIV+. Anti-harassment policies, along with appropriate education and training, can send a clear message about where the school community stands. There must also be a willingness to respond to incidents of discrimination or harassment.

Exposure to a wide range of HIV+ people, through photos, panel presentations, and even the Names Project Quilt (banners memorializing those who have died of AIDS), has been successful in helping people overcome their anxieties or incorrect ideas about people who may have HIV. The school community needs policy development and education to achieve the elimination of homophobia and ignorance about HIV.

HIV+ staff need support and acceptance too. A major concern with employees, as it is with students, is confidentiality. Unfortunately, HIV disease is not treated as are other life-threatening diseases. Until there is greater acceptance of this disease and the people who have it, many will choose not to disclose the nature of their illness for fear of rejection and discrimination, loss of health insurance and even violence.

The Americans With Disabilities Act and the Maine Human Rights Act (*see Appendix*) protect the HIV+ person and his/her family and associates from some things. But laws alone do not change attitudes. Respect and tolerance will be put to the test when an HIV+ teacher reveals his or her positive HIV status. As of this time, no school staff member in Maine has revealed publicly that he or she is HIV+.

Homophobia (the irrational fear and/or hatred of homosexuality) creates a barrier to effective HIV education.

Many choose not to disclose the nature of their illness for fear of rejection and discrimination, loss of health insurance and even violence.



Policy for students and personnel who are HIV+ should be:

- In writing;
- Consistent with Maine law on HIV antibody status and confidentiality;
- Reviewed annually along with the OSHA Standards;
- Included in a handbook and made available to employees, students and parents;
- Followed up by appropriate procedures, protocols, and training.

Education Resources

Materials

The Maine State Department of Education has designed model policies for students and staff which are available to Maine schools. The Department has also assisted communities and schools which have had HIV+ students and parents. The Reiche School in Portland and the Towns of Searsport and Dover-Foxcroft, to name just three, have had the experience of preparing for the presence of an HIV+ student.

HIV Prevention Education Program
Maine Department of Education
State House Station #23
Augusta, ME 04333
207-287-5930

AIDS Education on Maine College Campuses.
University of Maine at Orono, Cutler Health
Center Report, 1989.

"Guidelines for Effective School Health Education to Prevent the Spread of AIDS," *Morbidity and Mortality Weekly Report*, Vol. 37 No. S-2, Jan. 29, 1988

Centers for Disease Control
Center for Health Promotion
Atlanta, GA 30333
also available through the National AIDS
Clearinghouse
1-800-458-5231

Listen to the Students: The AIDS Education Research Project. A student-centered approach to HIV/AIDS education and prevention
Family Planning Association of Maine
P.O. Box 587
Augusta, ME 04332-0587
207-622-7524

Performance Standards for School HIV/AIDS Education Curricula for Adolescents Checklist
SIECUS (Sexuality Information and Educational
Council of the US)
130 West 42nd St., Ste. 2500
New York, NY 10036
212-819-9770

Reducing The Risk: Building Skills to Prevent Pregnancy, STD and HIV

by Richard Barth, MSW, PhD
ETR Associates
PO Box 1830
Santa Cruz, CA 95061-1830
1-800-321-4407

Teaching Your Children About Sexuality
The American College of Obstetricians and
Gynecologists
409 12th St, NW
Washington, DC 20024-2188
202-638-5577

Organizations

Administration on Children, Youth and Family
Department of Health and Human Services
Washington, DC 20201-0001

Centers for Grieving Children
PO Box 1438
Portland, ME 04104
207-799-1112

Licensing and Registration for Childcare
Department of Human Services
State House Station #11
Augusta, ME 04333
207-287-5060

Maine College Health Association, and Task Force
on ME College HIV Prevention
c/o Chris Lyman
University of Southern Maine
96 Falmouth St.
Portland, ME 04103
207-780-5164

Maine Department of Higher Education
State House Station #23
Augusta, ME 04333
207-287-5803

Maine Head Start Association
PO Box 1162
Bangor, ME 04401
207-941-2830

(continued on next page)

Education Resources *(continued)*

Maternal and Child Health Division
Bureau of Health
221 State Street
Augusta, ME 04333
207-287-2312

New Beginnings, Inc.—youth-serving residential
program
436 Main Street
Lewiston, ME 04240
207-795-4077

Office of Head Start
Department of Human Services
State House Station #11
Augusta, ME 04333
207-287-5060

Office of Truancy, Dropout and
Alternative Education
Maine Department of Education
State House Station #23
Augusta, ME 04333
207-287-5110

State Office on Labor Standards
Station #82
Augusta, ME 04333
207-624-6460

Physical Health Care Sites

- Public health departments and clinics
- Primary medical care offices and rural community health centers
- Hospitals
- Long-term care facilities and boarding homes
- Home health agencies
- Hospice agencies
- Ambulance services
- Dental offices
- Nontraditional health care offices (acupuncturists, massage therapists, homeopaths, etc.)

The health care sector has been among the most active in society dealing with the prevention and treatment of HIV/AIDS. Nevertheless, in Maine we are approaching a time when 60 to 100 people will die each year of AIDS—and this figure will vastly increase if more effort and resources are not dedicated to prevention.

Opening Doors on Indian Island

Ila Nicola says that she has seen just about everything. As community health nurse of the Penobscot Nation Health Department, Nicola works with diabetes and other community health issues. She also works in the school—and she works on HIV. The health department serves the 420 Penobscot residents on the island, as well as other Native Americans living on the island and Penobscots living elsewhere.

Nicola believes there is still a frightening level of denial among the people she serves. She is striving to show others that discussion of HIV and AIDS does not need to be taboo. “Even though I know of no one here who is HIV+, it is going to happen—and the staff needs to be prepared. We need workshops. Fears need to be set aside.”

In July, 1995, Nicola assisted in bringing the Maine HIV Prevention Community Planning Group to Indian Island to hold group information sessions. The CPG wanted to hear firsthand what the people knew. They also wanted input into the kinds of prevention



efforts the people themselves believed would work within their own community.

“This is a community,” she says, “and I need community involvement. I believe if people are actively involved, they are also more open. There needs to be someone in the community who can open doors to the person who has HIV.”

It is clear that our health care professionals and health care facilities must prepare themselves for an ever-increasing burden of care for a complicated and devastating disease. Few primary care practitioners have treated a patient with HIV/AIDS, yet all have the potential for doing so. As health care facilities and their staffs become absorbed with the complicated medical care of persons who have HIV/AIDS, providers cannot lose sight of the important contributions they can make toward prevention.

Because distances can be great between centers of specialty care in Maine, more local health care facilities will have to assume responsibility for HIV/AIDS care, from testing and counseling to end-stage home, institutional or hospice care.

Hospitals, health clinics and nursing homes are not only places that dispense health care. They are also workplaces. As such, they need to conform to recommendations developed for workplaces, by:

- making sure they have a comprehensive, up-to-date HIV/AIDS policy in place for their employees; and
- providing their employees with education programs about personal as well as occupational exposures.

In no other disease is the need for universal access to health care as glaring as in HIV/AIDS, with its demand for a huge array of services and its immense expense. Caring professionals will need to become more active in the health-care-reform debates, lending a united voice to the struggles that persons with HIV (and others) face in living with their disease and dying in dignity.

In no other disease is the need for universal access to health care as glaring as in HIV/AIDS.

General Recommendations

- All health care sites and staffs:
 1. Protect your community to prevent HIV/AIDS by:
 - providing risk assessment and counseling;
 - speaking about HIV/AIDS in schools or to community groups, and
 - making condoms available to the public on-site;
 2. Care for persons with HIV/AIDS in your facilities. These responsibilities are especially crucial in rural areas, where health care resources can be remotely distributed.
 3. Have a comprehensive, written HIV policy in place that, among other things:
 - maintains confidentiality of employee medical records;
 - observes non-discriminatory policies for HIV+ employees; and
 - provides employees with education programs about personal as well as occupational exposures.
- Health care providers and third party payers (Medicaid, Medicare and all insurers):
 - Encourage home-based patient care for persons with HIV/AIDS.

Municipal Public Health Departments

In many states public health services are delivered by county health departments. However, since Maine has minimal government at the county level, there are no county health departments. In fact, only two municipali-

ties maintain public health departments—Bangor and Portland. In other areas of the state, public health functions are provided by the State Bureau of Health, which sends public health nurses, public health educators, health engineers and restaurant inspectors from county to county to provide needed services. For other public health services the Bureau contracts out to private health agencies at the local level.

The Portland and Bangor public health departments fulfill a wide range of services which include immunization, public health nursing, STD (sexually transmitted disease) clinics, dental services, lead poisoning prevention, smoking cessation, and maternal and infant care. Residents of these two cities who meet certain income guidelines are eligible for services, which are available at clinic sites and in clients' homes.

The city of Portland also provides HIV awareness and bloodborne pathogens training for people in occupations considered high-risk, such as nurses, dental personnel and health promotion specialists. Training is being phased in for other employees in moderate- and low-risk occupations.

Bangor's STD Clinic serves 2500 people per year (75% of whom are male), while Portland's STD Clinic serves 675. In both clinics, anonymous HIV counseling and testing are offered. In addition, the health departments and nurses may assist HIV+ persons with their medication. Through their work with the homeless, particularly in Portland, these kinds of health departments also address some needs of people at-risk for HIV infection.

In fact, only two municipalities maintain public health departments—Bangor and Portland.

In both clinics, anonymous HIV counseling and testing are offered.

STD Clinic Births New Program

Patty Miles has been with the Bangor STD/HIV Clinic since 1984. Her enthusiasm about the services her organization provides comes in part from the close working relationships among the employees there. "We have all been touched both personally and professionally by this disease," she explains.

The clinic's identity has shifted since 1984, as services have expanded. The change to providing primary HIV services from their initial role of providing HIV testing and counseling (and other STD services) seemed a natural one. But Miles remembers being frustrated in the early days. Many people were receiving their initial HIV+ diagnosis from the clinic, then leaving without knowing who they could safely turn to; or not trusting the confidentiality of insurance companies, being fearful that their employers would find out if they used their health insurance, or that community members might know if they used local medical services. Some began seeking medical care under an alias. The promises of confidentiality and anonymity, particularly early on, were essential to the services.

The frustration Miles felt extended throughout the staff, and almost everyone there felt that a change to providing primary care for HIV+ individuals made sense. They checked with the medical staff, found an internist who would be available via the phone, went through other necessary bureaucratic steps, and then approached the Board of Registration for the license to expand their scope. "They saw the need, and they supported it."

"There are some real advantages for being involved with the clinic," she explains. "Now we have the luxury of scheduling a two-hour initial appointment, and have the luxury of extending half-hour sessions to an hour. We talk about partners, we talk about what the lab results mean. Clients have a real comfort base here. We have been there for them since day one."



Issues

Access to traditional public health resources is lacking in Maine, except in Bangor and Portland.

Residents in rural areas may have to travel long distances to obtain anonymous testing and counseling.



Immediate

- Municipal health departments:
 - Link with local ASOs (AIDS service organizations) wherever appropriate. Such efforts could include:
 - public information,
 - school health education, and
 - condom distribution programs.
 - Periodically assess the HIV risk status of the populations you serve, to take advantage of education and prevention opportunities.

Long-term

- Health care facilities in rural areas and small cities:
 - Obtain training to become anonymous testing sites, modelled after the examples of the Bangor and Portland health departments.
- Multi-county organizations or groups of municipalities:
 - Band together to develop resources in rural areas; for example, start a traveling HIV clinic and training unit.

Ambulatory Care Settings

Maine is served by approximately 1200 primary care physicians (both allopathic M.D.s and osteopathic D.O.s), 200 physician assistants and 300 nurse practitioners in ambulatory care settings, which include:

- clinics,
- rural community and migrant health centers,
- private offices,
- emergency rooms, and
- family planning clinics.

In 1993 a total of 108 newly-diagnosed cases of AIDS were reported by 51 physicians in Maine (Maine Bureau on Health 1994). The vast majority of primary care practitioners in Maine have never treated or even identified a patient with HIV/AIDS—and therein lies one of the chief shortcomings of HIV/AIDS treatment in Maine. As of this writing, more than 600 people have

been diagnosed with AIDS (half have died), and another 2,000 are living with HIV in the state.

About ten infectious disease physicians practice in Maine (all of whom can be consulted on HIV/AIDS issues). In addition, at least three other physicians, one oncologist and two family physicians specialize in the care of persons with HIV/AIDS and are available for consultation. Specialized ambulatory care services are offered in three STD clinics and six other anonymous HIV testing sites in Maine.

Many people in rural areas don't have easy access to health care providers—particularly to those providers able (and willing) to treat HIV. When people with HIV were surveyed about their problems obtaining primary health care (Maine Community AIDS Partnership [MCAP] Report, 1994), geographic differences became apparent. It's little surprise that the greatest access to care was found in southern Maine, where only 2.7% of those surveyed reported problems, yet the numbers rise in central (7%) and rural northern (10%) Maine for those unable to find adequate health care in their area. These differences are not just a function of finances, but reflect the shortage of providers in rural areas as well as the low comfort level providers have in general when dealing with HIV/AIDS.

HIV testing and counseling is offered at six anonymous testing sites and three STD clinics in the state. (*See Resources.*) The private medical community accounts for over 50% of HIV tests performed and 50% of positive tests reported to the Bureau of Health.

Expansion of public testing sites in the state may be hampered by:

- a low-priority status,
- confusion about the law,
- the shortage of personnel trained in counseling, and
- reluctance to provide services to clients with HIV.

For example, the OB/GYN Clinic at Maine Medical Center had for some time declined to offer HIV counseling and testing. However, when they re-examined their patient population, they found significant numbers of at-risk individuals. After appropriate training, the clinic now offers counseling and testing. Until more emergency rooms, primary care offices and other health care settings acknowledge their own capability for HIV counseling and testing, the need for publicly-funded testing sites will continue.

The spread of HIV poses particular problems for rural health care providers, who may believe that local HIV risks and prevalence rates are lower than they actually are. In fact, recent cases of AIDS are more likely to have occurred in the rural central and northern regions of the state than in the more densely populated southern areas. These regions already have difficulty maintaining an adequate number of primary care practitioners, which means that existing practitioners will face increasing responsibility for HIV detection and the care of persons with AIDS—once again pointing to the need for a wider dispersal of testing, consultation and professional education services in the state.

Many people in rural areas don't have easy access to health care providers—particularly to those providers able (and willing) to treat HIV.

Until more ERs and health care offices provide HIV counseling and testing, the need for publicly-funded testing sites will continue.

In fact, recent cases of AIDS are more likely to have occurred in central and northern Maine than in the more densely populated southern areas.

A Team Approach to Health Care

The AIDS Consultation Service (ACS), a program of the Maine Medical Center in Portland, began only three years ago, but they haven't wasted any time. "This year alone we've had over ten nurse practitioners and five to ten physicians do a mini-residency here," reports Sandy Putnam, nurse coordinator of the service. She and Rob Smith, MD, are the medical staff providing answers to health care practitioners who might be faced with their first HIV patient.

"Everybody who has sent a patient is interested in learning about the disease," she says. The ACS has received client referrals from every county, with about 200 new referrals so far this year, and the number increases every year. "This program has proven our assumption that Maine's force of primary care providers is really strong. They follow up. They're responsive to recommendations. No one's been defensive; no one's wanted to dump their patient on us."

Funded by the Maine Medical Center, along with fees for service and private grants, ACS offers multiple services for Maine's busy providers, who can't always stay current in a complex field such as HIV/AIDS. "We use a team approach," explains Putnam. Health care providers can consult with ACS over the hotline phone about a patient, or send the person to ACS for more in-depth evaluation, or to enroll in a drug research protocol or connect with social services for



people with HIV. A quarterly newsletter brings more than 3000 providers up-to-date information regarding HIV and nutrition, opportunistic infections, new drugs, and other related issues. ACS also offers education sessions for health care providers, assists in organizational planning, and holds an annual education conference for Maine providers.

"Our goal is to support the primary care providers, offer technical assistance as needed to keep them at home and develop their own expertise," Putnam states. "This way people with HIV don't have to travel two hours for decent care. They can stay in their own community."

"This is a unique model," she continues. "And we're constantly evaluating our services. The results so far are very positive. We hope this type of service can evolve in other places in Maine. In the meantime, we'll take hotline calls from any provider in the state."

Compounding the problem is the situation in which one provider becomes an area's "AIDS doctor," and the sudden and profound absence of care in the area should that provider's services, for whatever reason, be terminated. The capital region suffered recently when a physician with a large AIDS caseload died suddenly. People with AIDS in her care were forced to travel 50 miles or more for similar expertise or start from scratch with another local physician. This is why the aim of the AIDS Consultation Service is for every hospital and clinic in every community to begin providing HIV-related services.

The shortage of providers and facilities is only one problem facing Maine people living with HIV. Access to HIV care is often compromised by a patient's ability to pay. In 1992 the national average cost of treating a person with AIDS was around \$32,000 a year. About 30% of Maine people with HIV are uninsured; 40% are covered by Medicaid (which in Maine reimburses for only 40% of a physician's usual fee). Both of these financial liabilities limit the number of physicians willing to treat these patients. Still, Maine has 29 community health centers that provide primary care regardless of a patient's ability to pay. A few, such as the Russell Medical Center, in Leeds, and the Searsport Family Practice, serve HIV+ patients.

Although health care workers represent 8% of Maine's HIV+ population, all cases have resulted from non-occupational exposures. It bears repeating that there are no documented cases of health-care-worker transmission in Maine. Less than .01% of all U.S. AIDS cases (450,000) are attributed to occupational exposure.

Certainly, the low risk of infection among the thousands of Maine health care workers is due in large part to the practice of universal precautions by health care personnel. (The OSHA bloodborne pathogens standard requires all health professionals to observe universal precautions and also requires all professionals to obtain yearly training on infection-control techniques.) Maine's Department of Human Services also recommends that formal training and compliance in infection control techniques be required of health professionals to qualify for licensure, license renewal or certification.

The spread of HIV has forced a dramatic improvement in the availability of protective equipment, as well as in the level of universal precautions education. Numerous education programs have been provided by hospitals, professional societies, local ASOs, home care agencies, health center networks, and other professional education providers throughout the state, such as the AIDS Consultation Service and the Acadia Health Education Coalition.

In addition to infection-control responsibilities, health care workers have a responsibility to public health by promoting education about HIV prevention. This responsibility is crucial in rural areas, where at-risk people might not be frequently exposed to this information.

Health care workers and institutions are looked to as leaders in their communities. As such, they need to assume leadership roles in the prevention of HIV/AIDS. For example, pediatricians are in a unique and positive position to provide HIV prevention education to adolescent patients, as well as to their parents. Subject matter could include:

- basic HIV facts,
- the rights of minors to public and private services,
- sexual decision-making, and
- a person's responsibility for his/her own sexual health.

About 30% of Maine people with HIV are uninsured; 40% are covered by Medicaid (which reimburses for only 40% of a physician's fee).

Less than .01% of all U.S. AIDS cases (450,000) are attributed to occupational exposure.

Issues

HIV/AIDS education may not be reaching those Mainers who aren't attached to large institutions or agencies.

All Maine health-care providers need HIV-specific education beyond the scope of universal precautions, for example:

- HIV testing and counseling,
- risk assessment skills,
- confidentiality, and
- knowledge of available social and related services.

Strict confidentiality should be upheld everywhere, but breaches in confidentiality are of most concern in rural areas, where disclosure of someone's HIV status can lead to not only loss of employment and insurance, but estrangement from family, friends and community.

Confusion still exists over procedures to follow when a possible blood-borne-pathogens exposure occurs in the clinical setting.

HIV/AIDS education may not be reaching those Mainers who aren't attached to large institutions or agencies.

Many health care providers need to broaden their level of comfort with gays/lesbians/bisexuals and their issues.

Rural providers in Maine continue to need adequate professional education in HIV testing and consultation.

All providers (but particularly rural providers) continue to need consultation on acute problems for HIV+ patients. The AIDS Consultation Service at Maine Medical Center provides such consultation through a statewide hotline, but the availability of this service needs to be more widely publicized and its use encouraged.

Many health care providers need to broaden their level of comfort with gays/lesbians/bisexuals and their issues.

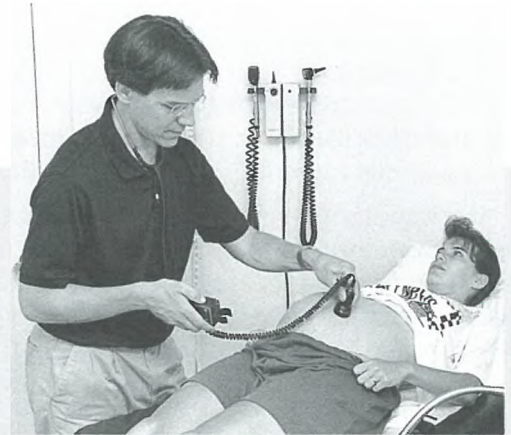
A Family Doctor Responds

When Dr. David Loxterkamp came to practice family medicine in Searsport, Maine in 1984, he didn't think he'd be dealing with HIV. "AIDS had been unknown when I was in medical school and during my residency. But now HIV has moved from urban to rural areas, as people who have contracted the disease come back to their families and the places they were raised."

It wasn't until 1988 that he had his first experience with HIV. "A patient of mine, whom I had been seeing for three years, told me he was HIV+ and wanted to know if I would still take care of him. My initial response was, 'Are you sure you want me to? I know virtually nothing about HIV care.' He reassured me that he wanted me to be his doctor. So, with consultation help from the AIDS specialist at Maine Medical Center, I continued treating him.

"In 1990 I took a year off from my practice and went to teach at San Francisco General Hospital. It was an eye-opening experience. Many of the patients had HIV and AIDS, and I found myself confronting a disease I knew nothing about. When I found myself learning as much from the residents as they were learning from me, I took a month-long residency myself, and concentrated exclusively on HIV+ patients."

When asked how he would advise other family doctors, Dr. Loxterkamp responds. "I'm not an HIV



specialist. I'm a family doctor who's taken it upon himself to get more training. The best advice I can give to colleagues is to follow my example. You jump into the fray and then do the best job you can.

"It's important to realize that there are other people who can help—and you need to feel comfortable asking for help. When I have a question I call the AIDS Consultation Service in Portland. They've been a tremendous help to me."

A family clinic may lack the specialist staff and state-of-the-art equipment that large hospitals have, but the small clinic setting has benefits for HIV patients that hospitals cannot provide.

"I think family doctors make good AIDS doctors," Dr. Loxterkamp maintains. "We can help patients feel comfortable coming here so they'll feel free to seek help when they need it. We can help them accept their diagnosis and maybe turn it into something positive. We also prepare them for the time when they will become sicker, by helping them to resolve family conflicts, or to find resources. Ultimately, we help them live with it."



■ Ambulatory health care settings:

- Assume greater responsibility for providing HIV risk-assessment, and obtain appropriate training. Continuing educational opportunities are available throughout MMC's AIDS consultation Service, New England AIDS Education and Training Center, Acadia Health Education Coalition, hospitals, and professional associations. (*See health care resources.*) If counseling and testing are not currently allowed, facilities should re-evaluate their policies in order to capture the moment when an at-risk individual appears for care.

■ Maine Bureau of Health:

- Provide practitioners with clear guidance on HIV counseling and testing. This could be done with a simple, straightforward handbook that:
 - communicates the law and its implications,
 - covers issues of confidential HIV risk-assessment and pre-/post-test counseling,
 - discusses the maintenance of confidentiality, and
 - reviews procedures to follow in case of occupational exposure;
- Expand the availability of competent ambulatory-care testing resources by developing a half- to whole-day training course on HIV counseling and testing that busy primary care practitioners can attend.

■ Maine Bureau of Health along with Maine Medical Center:

- Promote the AIDS Consultation Service so that ambulatory care providers can consult by telephone about particular HIV clinical and social service problems.

Intermediate

■ All health care providers:

- Review office practice and procedures to ensure that all patients are comfortable in the setting, regardless of their sexual orientation.

Long-term

■ All health care providers:

- Expand access to treatment and care for persons with HIV/AIDS, participate in or advocate for state or federal initiatives that would provide universal access to health care.

In a recent survey conducted by the Maine Community AIDS Partnership, dental care was cited as the one medical service most needed but least received by people with HIV.

Dental Care Setting

Dental care continues to be a high-priority need for persons with HIV/AIDS. Gingivitis, periostitis and candida are common dental health problems that become exacerbated by the poor immune response caused by HIV. In a recent survey conducted by the Maine Community AIDS Partnership (MCAP), dental care was cited as the one medical service most needed but least received by people with HIV.

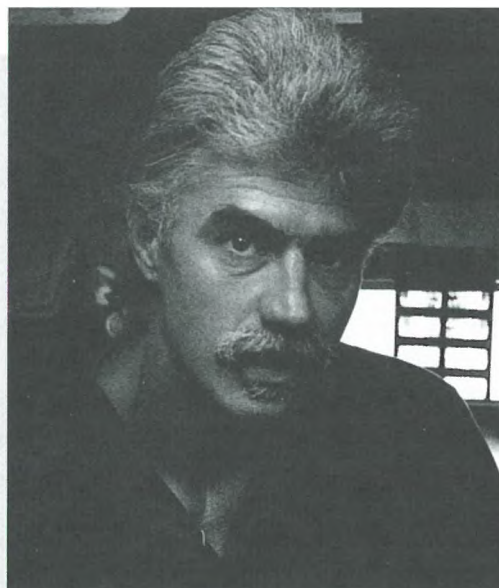
Currently, 387 general dentists and 128 specialist dentists practice in Maine, a number that marginally meets the population demands in some parts of the state—particularly southern and urban areas—but falls short in several northern, western and rural areas.

Treating People Who Need Help

"One of my patients was a family doctor who treated some people with HIV," recalls Paul Nielsen, a general dentist with the Family Dental Practice, in Augusta. "One day she was in my office, and she told me that some of her patients were having a hard time finding a dentist who would treat them. She asked if she could send them to me.

"My first thought was that I really didn't want to be the 'AIDS dentist.' But, really, there was only one right thing to do. I'm in the medical field. I treat people who need help." At that point Nielsen called his staff together and asked them if they'd be comfortable treating HIV patients. They talked about the importance of protocol and their infection control procedures.

"One of the things I said to them was that we don't know when someone's going to walk in and present with HIV. So we always have to be prepared to protect ourselves and our other patients.



"I asked them to go home and think about it, and talk to their families. The next day everyone came back and supported my efforts to do this, which blew me away. I thought there'd be much more resistance. There was none. They felt the same way I did, that this was the right thing to do."

Lack of health insurance contributes heavily to dental health access problems. In fact, half the MCAP survey respondents who reported a lack of dental service had no health insurance. This is not surprising, considering that less than half the general population in Maine has dental insurance coverage. Included in this statistic is Medicaid and Medicare, neither of which provides funding for (non-emergency) dental care to anyone aged 21 and over.

Those persons with HIV/AIDS who do have Medicaid dental coverage may find access limited by the availability of dentists currently accepting new Medicaid patients. All dentists, whether in hospital settings, clinics or private practices, are pressed to balance their responsibility to public service with their need to maintain economic viability.

Ability to pay notwithstanding, one reason that people with HIV often have trouble finding dentists who will treat them is that some dentists are afraid they will lose regular patients if it becomes known that they treat people with HIV. (The only documented case in the U.S. of a health care

Lack of health insurance contributes heavily to dental health access problems.

worker with HIV transmitting the virus to patients is that of a dentist.) While these fears have lessened somewhat over time, they still remain a barrier to care.

Lack of knowledge regarding treatment of HIV dental problems is another often-used excuse for inability to treat patients—but the dental profession has found that most oral problems experienced by persons with HIV/AIDS are exaggerated forms of routine infections. Additionally, a wide range of continuing education opportunities is available for dentists in HIV infection control and therapy—through the Maine Dental Association, New England dental schools, the AIDS Consultation Service and the Acadia Health Education Coalition. However, training for office staffs is less available.

Because dental care for people with HIV is mostly routine, nearly all HIV+ patients can be treated in a private practice setting, with appropriate consultation with the patient's physician. To the extent that a patient might have a more advanced condition, such as a high-risk, opportunistic infection, care in hospital settings may sometimes be appropriate. Unfortunately, the adequacy of dental treatment programs in hospitals has been debated for years in local communities and hospital board meetings.

Finally, because general dental care of people with HIV can be regularly performed in dentists' offices, there is no need for an "AIDS dentist" to become established in any region of the state. Sometimes this does occur when a dentist becomes known in the HIV community as someone willing to provide them care. While such a strategy may seem convenient, it is not a responsible use of the community's dental resources, considering the potential void created should that dentist suddenly become unavailable.

In 1992, the Maine Dental Association investigated the feasibility of establishing regional AIDS dental treatment centers but concluded that such clinics might be perceived as discriminatory (thus ruling out eligibility for Medicare/Medicaid funding) and that, in any case, such clinics would not relieve non-clinic dentists from legal liability for refusing to treat HIV+ patients.

Issues

Positive role-modeling in treating people with HIV should be encouraged among dentists as a peer-education technique to improve access to dental care for HIV+ persons.

Specialty dental clinics are neither feasible nor advisable to provide adequate dental care to persons with HIV. Instead, efforts must focus on widening accessibility to the traditional community dentist's office.

Ongoing, continuing education of the generalist dental team is needed in order to stay abreast of OSHA and CDC guidelines as well as changes in the therapeutic needs of the HIV+ community.

Funds are needed to assist uninsured or indigent HIV+ persons in obtaining dental care.

Those persons with HIV/AIDS who do have Medicaid coverage may find few dentists currently accepting new Medicaid patients.

Some dentists are afraid they will lose regular patients if it becomes known that they treat people with HIV.

Because general dental care of people with HIV can be regularly performed in dentists' offices, there is no need for an "AIDS dentist" to become established in any region of the state.



Immediate

■ Maine Dental Association:

- Expand continuing education to include role-modeling by dentists who provide care for persons with HIV/AIDS;
- Maintain monitoring and professional education efforts around infection control in dentistry, especially for general dentists;
- Stress the responsibility of general dentists to care for the HIV+ people in their communities;
- Provide adequate educational opportunities for generalists to provide such care.

Long-term

■ Maine legislators and ASOs:

- Continue to search for funding mechanisms to support needed dental care for the many indigent persons with HIV/AIDS.

■ Maine Dental Association:

- Lobby to include dental coverage in any health-care-reform initiative.

Hospital/Inpatient Setting

There are no blatant access-to-care issues in Maine's hospitals, since the Hill-Burton Act requires hospitals to provide indigent care.

There are 42 hospitals in Maine, which include two for-profit, psychiatric/chemical dependency hospitals and one rehabilitation hospital. Three non-profit hospitals—Maine Medical Center, Eastern Maine Medical Center, and St. Mary's Hospital—are equipped with in-patient psychiatric units.

As discussed earlier, Maine Medical Center has a specialty clinic targeted specifically to AIDS care—the AIDS Consultation Service (ACS). In addition, about ten infectious disease physicians, one oncologist, and two family physicians are available in Maine for specialty consultation and in-patient management of patients with HIV/AIDS.

There are no blatant access-to-care issues in Maine's hospitals, since the Hill-Burton Act requires hospitals to provide indigent care. As a matter of choice, patients or referring physicians will choose some hospitals over others because of their capability to provide adequate care for complications brought on by HIV/AIDS. For those hospitals, this tendency can result in extraordinary burdens for uncompensated care.

A major recommendation of this plan is to encourage outpatient rather than inpatient management of AIDS complications. It is always preferable to keep persons with HIV/AIDS out of the in-patient service as long as possible because of the adverse effects of emotional stress, crowded hospital settings, and their own weakened immune systems—not to mention the higher costs of in-patient care.

Of particular importance, then, are clinical education efforts aimed at improving practitioners' skills in managing AIDS patients on an out-patient basis. Such management has improved in the past several years, a promising trend that should be further encouraged.

Psychiatric wards in hospitals should ensure that educational programs address the link between HIV and mental health. Not only do patients with HIV disease appear in psychiatric wards with dementia, but psychiatric ward staff must be mindful of the higher risk for HIV that their other patients may have experienced due to sexual abuse, substance abuse and other factors.

Because of OSHA's bloodborne pathogens standard, hospitals' educational programs regularly offer universal precautions and infection control to their employees. However, the hospital's role in educating the private physicians on their medical staff has not always been clear. Some hospitals (such as Brighton Medical Center, Kennebec Valley Medical Center, Maine Medical Center and others) have not only provided such education, but have consistently gone beyond the infection control issues to include risk assessment, counseling techniques, confidentiality, and other topics integral to HIV care.

It is always preferable to keep persons with HIV/AIDS out of the in-patient service as long as possible.

Some hospitals (such as Brighton Medical Center, Kennebec Valley Medical Center, Maine Medical Center and others) have not only provided such education, but have consistently gone beyond the infection control issues to include risk assessment, counseling techniques, confidentiality, and other topics integral to HIV care.

The hospital, in addition to caring for HIV/AIDS patients, is also a workplace. In many communities it is the largest employer. Hospitals should therefore adhere to the recommendations of the Workplace Subcommittee Report regarding development of a comprehensive HIV policy. For health care workers who are HIV+, the Maine Bureau of Health has developed detailed recommendations in its publication "Policy Statement and Guidelines to Prevent Transmission of HIV and Hepatitis B Virus through Medical/Dental Procedures" (1994).

Approximately 250 ambulance services employ 4000 pre-hospital (emergency) personnel statewide. These services are based largely in municipal departments (such as fire departments) but are also affiliated with hospitals, health centers and private ambulance firms. Approximately 75% of the emergency services rely on volunteers who receive training in universal precautions. Some emergency services contract out for training.

Of particular importance, then are clinical education efforts aimed at improving practitioners' skills in managing AIDS patients on an out-patient basis.

Emergency Medical Services require personnel to undergo five annual trainings:

- bloodborne pathogens,
- airborne pathogens,
- hazardous materials,
- hazardous communications, and
- sexual harassment.

Obviously, funding for annual training is a major issue, especially for volunteer services in small towns with tight budgets.

A significant concern for emergency personnel in the past has been their right to know the HIV status of a bleeding client they are serving. This concern has been mitigated by the Designated Infection Control Officer

Universal Precautions are always necessary in emergency situations.

Program (under the 1991 Ryan White Act), which requires officers in both hospital and emergency service settings to inform the other setting of the infectious status of a transported patient, if known. HIV is among the eight communicable diseases covered under this program. Of course, many clients served by emergency services do not know their HIV status—and some, in emergency situations, will be unable to communicate this—so universal precautions are always necessary.

Issues

Some hospitals question whether they are responsible for educating private physicians in infection control and other HIV issues.

Outpatient management of patients with AIDS should be stressed as the therapeutic strategy of choice.

Because of the high numbers of uninsured and underinsured people living with HIV, hospitals are often reluctant to serve as HIV counseling and testing sites.

Information on HIV-related community resources is often lacking in hospital discharge planning.

Some hospitals question whether they are responsible for educating private physicians in infection control and other HIV issues.

Hospitals, like all workplaces, need to develop policies for HIV-infected workers, covering such issues as nondiscriminatory employment practices, confidentiality of records, maintenance of benefits, education of fellow employees, etc.

Specific guidelines for post-exposure management are lacking in many hospitals' HIV policies, especially for exposures to non-employee students or other trainees.



Immediate

No insurer may provide a more restrictive coverage for AIDS or HIV or exclude it from coverage altogether.

- All hospitals:
 - Expand the availability of HIV testing and counseling services in your emergency, outpatient, medical, and OB/GYN departments.
- Maine Bureau of Health, together with appropriate professional societies:
 - Develop clear, written protocols for bloodborne post-exposure management, including recommendations for blood-drawing and clinical/drug management.
- The AIDS Consultation Service:
 - Widely distribute the ACS Resource Guide and expand on-line access to it;
 - Publicize the availability of your telephone consultation services, especially as it regards referrals to community resources at the time of discharge planning.

Private Insurance

Under state law, canceling coverage on the basis of HIV status is a civil offense. No insurer may provide a more restrictive coverage for AIDS or HIV or exclude it from coverage altogether. Maine law requires that insurance companies base their policies toward HIV on sound actuarial (risk calculation) principles. This protection prevents an employer from offering one million dollars worth of insurance for heart failure and five thousand dollars worth of insurance for HIV. Furthermore Maine law prevents insurance companies from reducing benefits for which an individual has already paid, because of a positive diagnosis for HIV. State law does not allow insurance companies to further "punish" people with HIV by denying or restricting the coverage to which those individuals are entitled.

However, not all benefit programs are covered under state law. Through the Employee Retirement and Income Security Act (or ERISA), the Federal Government began regulating employee benefit programs in 1974. ERISA supersedes any and all state laws that relate to employee benefit plans. While ERISA does not supplant state laws that regulate insurance, employers have discovered that by establishing 'self-insured benefit programs' they can escape the regulation of state law. Twenty-six % of health insurance plans in the State of Maine fall under the exclusive jurisdiction of the Federal law; beneficiaries of these plans do not receive the protections against discrimination that are provided by state law. Under ERISA,

an employer can arbitrarily reduce an employee's health benefits after she or he has earned a right to them. Efforts are being made to make the ADA applicable to the insurance industry, thereby preventing insurance providers from discriminating on the basis of HIV status.

ERISA does perform several beneficial functions for an individual with HIV. First, administrators of benefit plans are required to provide a written description of the plan, and of benefit rights. Second, ERISA makes it illegal to discontinue coverage because an individual has claimed a benefit. Most importantly, in the Comprehensive Omnibus Budget Reconciliation Act (COBRA) of 1988, Congress went further to require that the "plan sponsor of each group health plan shall provide each qualified beneficiary, who would lose coverage as a result of a qualifying event," the opportunity to elect continued coverage for up to 18 months after the loss of employment. A "qualifying event" is defined as dismissal or reduction in hours, and a "qualified beneficiary" includes the covered worker, his or her spouse and the designated recipient of their benefits. Although it prevents an immediate cancellation of health care coverage upon dismissal, the beneficiary is still required to pay for the cost of their coverage. COBRA can allow an individual with HIV to continue receiving health care benefits until Social Security Disability Insurance and MEDICARE begin to function.

Long-term

- Hospitals:
 - Steer your educational programs toward the most up-to-date research on outpatient maintenance of patients with HIV/AIDS.
- Maine Bureau of Health and Maine Hospital Association:
 - Promote development of a model hospital policy regarding HIV-infected workers.
- Maine Bureau of Health and the Maine Emergency Medical Services Office:
 - Develop more cost-effective training in bloodborne pathogens (e.g. videotapes, ITS programs, etc.) to ensure that volunteer EMS staff receive the same quality training as full-time EMTs.

One-fourth of all health insurance plans in Maine fall under the exclusive jurisdiction of the Federal law; beneficiaries of these plans do not receive the protections against discrimination that are provided by state law.

Most importantly, in the Comprehensive Omnibus Budget Reconciliation Act (COBRA) of 1988, Congress went further to require that the "plan sponsor of each group health plan shall provide each qualified beneficiary, who would lose coverage as a result of a qualifying event," the opportunity to elect continued coverage for up to 18 months after the loss of employment.

Public Insurance Programs

Social Security Disability Insurance (SSDI), commonly called Social Security, is a government sponsored insurance program that provides benefits to people who were employed and have retired or can now no longer work due to a disabling condition. Social Security benefits depend upon the amount of money earned and the length of time worked. In 1995, the highest monthly payment was \$1300. MEDICAID becomes available if the recipient's income level falls below a certain level; individuals who have received SSDI for 24 months become qualified for MEDICARE regardless of their income.

The law, for these purposes, defines disability as the inability to do any substantial gainful activity by

reason of any medically determinable physical or mental impairment which can be expected to result in death. Symptomatic HIV is covered under this definition.

Supplemental Security Income (SSI) is a federally sponsored protection to disabled individuals with no income. SSI benefits in 1995 included \$458 dollars a month, a ten dollar state supplement, food stamps, and automatic MEDICAID coverage. Assets, not including a house and car, must be less than \$2000 for a single individual. The definition of disability is much the same.

Medical Benefits

MEDICAID is a state and federal program that provides medical benefits to people who are medically and categorically (financially) needy. MEDICAID will pay for insurance deductibles, prescription medication, doctors' visits, and hospital care. To qualify you must have a medical and financial need for the services. If your income is so minimal that you qualify for **Supplemental Security Insurance**, you automatically qualify for MEDICAID. If you qualify for **Social Security Disability Insurance**, then you automatically satisfy the medical requirements for MEDICAID, but still need to establish the income requirements. The maximum income level for a single individual to receive MEDICAID in Maine in 1995 was 623 dollars per month, plus a 75 dollar deductible.

If your income is over the maximum income level but you have exorbitant medical bills, you may still qualify for MEDICAID under the 'spend down' provisions.

The 'spend down' requirements are based upon a calculation over a six month period, during which you must incur medical bills that are equal to your countable income minus \$1890 (The predetermined amount for 1995). Any medical bills that you incur over that amount are covered by MEDICAID.

Other programs attempt to assure that people with HIV are able to get their medications. The State provides eight identified drugs to individuals whose income level does not qualify them for MEDICAID, but who cannot afford the cost of prescription. Some AIDS support organizations raise funds to assist individuals in paying for some medications. As well, towns have been known to provide money for prescription drugs not covered under the State's drug reimbursement program.

MEDICARE

MEDICARE benefits provide hospital care, outpatient treatment, hospice, and therapy to people over 65, the blind and the disabled. MEDICARE is an insurance program run by the Federal Government; there are no income requirements to receive MEDICARE, and qualification depends solely upon age or health status. A person who has been receiving Social Security Disability Insurance for 24 months qualifies for MEDICARE benefits. They should apply after the 21st month of their disability. MEDICARE entitles a beneficiary to 90 days of hospital care during each spell of illness. There must be sixty days between each spell of illness. A hospitalized beneficiary must pay a deductible for each day they are hospitalized; if the individual qualifies for MEDICAID, it will pay that deductible. Each individual has a life-time supply of 150 days of additional hospital care which can not be replenished. Because HIV may result in numerous hospitalizations, it is vital that reporting doctors note each different spell of illness so as to not prematurely deplete the lifetime supply of hospital care.

MEDICARE covers home health services in full, with no deductible or co-payments if the coverage criteria, below, is met:

- 1) the care is medically necessary
- 2) the physician signs a plan of care
- 3) the patient needs personal assistance, such as nursing care,
- 4) the patient is confined to the home (this does not prevent a patient from taking short or infrequent walks)

5) home health care is provided by or under arrangement with a MEDICARE certified provider.

If this criteria is met, then home health care services include:

- 1) part time or intermittent nursing care under the supervision of a registered nurse
- 2) physical or occupational therapy
- 3) medical social services under the direction of a physician
- 4) part time or intermittent services of a home health aid. Courts have made clear that full time care means seven days a week. Therefore, home health care services provided five days a week, 8 hours a day may be considered intermittent or part time.

MEDICARE also covers hospice care. Regardless of whether an individual has any days left in their life-time supply of hospital coverage, s/he may receive additional care. Hospice, under MEDICARE, provides support and comfort to the terminally ill and their families rather than treatment. If a doctor determines that a patient is terminally ill, and the patient decides not to pursue heroic measures or experimental treatment, the patient will qualify for hospice. Hospice provides for nursing care, a physician, counseling, medical social services, short-term inpatient care, home health aides, homemaker services, medical supplies such as pain medication, and physical, occupational, and speech therapy.

Home Health Settings

Included in this category are home-care agencies, visiting-nurse associations, and home-infusion companies. There are 24 home-health agencies and 27 other providers of home health-care services licensed to provide care in Maine. The range of their services can include:

- homemaker services, (performing normal household tasks)
- continuous care services (provided through home health aide visits and visiting nurses),
- social work services, and
- related services (such as physical therapy, occupational therapy and speech).

As with our prior inpatient vs. outpatient discussion, a major emphasis in this plan is to encourage home health care as a strategy of choice over nursing home care. In most cases it will be the more cost-effective option. More

Nearly all chronically or seriously ill people prefer to remain in their homes as long as possible.

Policies of some third party reimbursers complicate and even prevent home-based care by restricting options for therapies given at home and limiting resources for expensive medications.

Third-party payers are used to an acute care model of reimbursement rather than a home-care model, which would better serve a person with HIV/AIDS.

importantly, it is the preference among nearly all chronically or seriously ill people to remain in their homes as long as possible.

In addition, availability of nursing home beds for HIV-infected individuals in Maine is constrained by a general discomfort nursing homes have expressed for HIV/AIDS clients. Public policy efforts, therefore, should encourage measures that enable persons with HIV/AIDS to remain in their own homes.

Unfortunately, the policies of some third party reimbursers serve to complicate and even prevent home-based care, by restricting options for therapies given at home and limiting resources for expensive medications. For instance:

- Homemaker and social services are not always covered;
- Many insurance companies require people to pay for oral medications up front and then make them wait a long time for reimbursement (and most HIV-related drugs, which can be very expensive, are not covered at all);
- Managed care companies offer a flat, per-diem payment for a course of antibiotic therapy, a rate that is not diagnosis-specific and does not reflect the various costs for HIV antibiotics;
- Medicaid requires a biannual "spend-down," requiring over-income recipients to pay a certain deductible before Medicaid funding kicks in;
- Persons with HIV/AIDS who qualify for Medicare must wait two years after being certified as disabled before receiving benefits—and then, even though Medicare covers homemaker, no oral drugs and only some IV drugs are covered.

It is apparent that third-party payers are used to an acute care model of reimbursement rather than a homecare model, which would better serve a person with HIV or AIDS.

One hopeful sign is the state's application to the federal government for a 1115(b) Medicaid waiver, which would allow Maine Medicaid to expand its homecare coverage. This option will divert people with HIV/AIDS from inpatient hospital care to homecare (or send them home early). The purpose of this option is to establish more comprehensive coverage of homecare services, adding personal care services, more intensive nursing services, homemakers, home modifications, home-delivered meals and home counseling.

Some federal funds, from the Ryan White Care Act (Title II), are also available for supportive services for persons with HIV/AIDS. In Fiscal Year 1995, the state received \$163,401 to supplement state funds for supportive services. The money was distributed to four case management agencies, who used the funding for case management as well as drug reimbursement and financial assistance with health insurance and home health care. The Ryan White Care Act permits the funding to be used for several other types of services that could help maintain people in their homes, including:

- buddy/companion services,
- day and respite care,
- direct emergency assistance,
- home-delivered meals,
- hospice care,
- housing-related services, and
- transportation.

Implied in these discussions of homecare is that persons with HIV/AIDS have adequate and affordable housing in which to remain. However, housing is a major issue for people facing a severe disease with astronomical medical costs. Because of huge medical expenses and discrimination, persons with HIV/AIDS are especially vulnerable to becoming homeless or living in substandard housing. Measures to enable persons with HIV/AIDS to remain in supportive living environments are essential. For example, it is probably more cost-effective (and practical) to subsidize rent or mortgage payments for a person with HIV/AIDS than to eventually move that person into fully-subsidized public housing.

Housing is a major issue for people facing a severe disease with astronomical medical costs.

Issues

Insufficient funds are available for homecare.

Third party reimbursement policies discourage the full range of home-based care services needed by persons with HIV/AIDS.

Various state and federal funding sources should be examined to ensure that homecare is encouraged.

Measures to enable persons with HIV/AIDS to remain in supportive living environments are essential.



Immediate

- State policymakers, insurers and other funders:
 - Homecare should be encouraged as the strategy of choice for extended care of persons with HIV/AIDS.
- Nursing Homes:
 - Assess ability to provide care to people with HIV/AIDS and connect with local AIDS organizations for outreach, information, and training.
- Maine Bureau of Health:
 - Convene a task force to examine the distribution of federal/Ryan White, state, and private monies to maximize support for direct patient-care services in the home.

Long-term

- Third-party payers and insurers:
 - Shift from an acute care model of reimbursement to a homecare model of reimbursement for care of persons with HIV/AIDS. Barriers to reimbursement should be examined and minimized.

Long-term Care Settings

According to the Maine Bureau of Health, between 1500 and 2500 people are currently living with HIV in Maine. As of June, 1995, 650 cases of AIDS have been diagnosed in Maine, and the numbers creep upward. Over the next few years we can expect to see 60 to 100 people dying of AIDS per year in Maine. Issues of extended and long-term care for these people are of immediate and vital concern to policymakers.

As indicated earlier, the Maine AIDS Plan endeavors to promote home health care as the strategy of choice for long-term care of persons with HIV/AIDS. However, efforts should be made on a statewide basis to ensure that a basic level of nursing beds are available in the nursing home system for people with HIV disease.

There are 150 nursing homes in Maine licensed as nursing facilities and skilled nursing facilities (including hospital "swing" beds). With the state currently working to move people out of nursing homes and into residential housing, for the first time in many years Maine has a surplus of nursing facilities. However, there still seems to be a shortage of nursing home beds for people with HIV or AIDS. The reasons nursing homes have given are both real and perceived:

- social and other services for nursing homes are geared to the elderly, while HIV patients are generally younger;
- it's often difficult to obtain counseling and mental health services for people with HIV-related dementia;
- many HIV patients in need of nursing home services are on Medicaid, and nursing homes have only a certain number of beds allocated for Medicaid reimbursement;
- nursing home staffs are not usually trained to deal with the sometimes complicated care of people with HIV/AIDS.

Candid speculation suggests that the reluctance of nursing homes (which fortunately has diminished over time) to accept HIV patients seems to have stemmed as much from social bias against people with HIV/AIDS, fear of an ominous new disease that has no cure, and fear that the presence of HIV patients would discourage some non-HIV patients from becoming residents.

The extent of boarding home demand (or use) by people with HIV/AIDS is unknown at this time. Examples of boarding home models in the state of Maine include the Peabody House in Portland and the Raphael House in Lewiston-Auburn. Further development of such homes for care of persons with HIV/AIDS is needed.

With regard to staff education in long-term care settings, the Maine Health Care Association has provided statewide education programs on universal precautions to nursing home staff. OSHA mandates such training on an annual basis, and the Maine Department of Human Services surveys facilities for compliance with infection-control standards. Although infection control seems to be thoroughly covered in education programs, that may not be true of other HIV-related issues (such as nutrition, dementia, infections, drugs, social problems, etc.).

Issues

An inadequate number of beds exist in Maine for nursing home care of persons with HIV disease.

Third-party payers are inconsistent about reimbursing for palliative (pain management) care.

Long-term-care professionals are not often offered education on the broad-based issues of HIV treatment and patient care, beyond the usual universal precautions curriculum.



Immediate

- Representatives of the nursing home industry, medical community, Department of Human Services, along with HIV+ persons and their advocates:
 - Establish a working group to assure adequate regional distribution of skilled nursing-home beds for advanced care of persons with HIV disease.
 - Address the wide range of barriers to care in nursing homes for persons with HIV or AIDS.
- Managers of long-term care settings:
 - Provide routine infection-control education for your staffs.
- Professional education providers (such as the Maine Health Care Association, the AIDS Consultation Service and AIDS service organizations):
 - Expand educational programs to long-term-care staffs to include comprehensive HIV education.

Long-term

- Legislators, third-party payers and insurers:
 - Work toward reducing barriers to reimbursement for homecare services.

Hospice Care

The first hospice in Maine was opened in 1976. According to the Maine Hospice Council, in 1994 there were 26 hospice programs in Maine that served 1,200 individuals and families.

Hospice service is based on a philosophy of palliative (pain management) care for individuals and families during the process of dying and bereavement. It is life-affirming and seeks to strengthen the client's role in making informed decisions about care. Services are delivered in the least restrictive setting possible (and with the least amount of technological intervention) by volunteers and professionals who are trained to help clients with the physical, social, psychological, spiritual and emotional needs related to terminal illness.

Early in the AIDS epidemic, many hospice providers educated themselves about HIV/AIDS and how to address the needs of people living and dying with the disease.

Hospice care can be hospital-based, community-based or part of a home health agency. Since 1984, hospice care has been Medicare-reimbursable. In Maine, thirteen hospice care providers are certified for the purpose of receiving Medicare reimbursement. Since April 1995, all programs that call themselves hospice, or that offer hospice services, must be licensed by the state. This measure was initiated by the Maine hospice community to ensure consumer protection for high-quality care.

A Guide to Hospice in Maine, published by the Maine Hospice Council, outlines the special role that hospice can play in HIV caregiving: "Hospice has been a leader in response to the AIDS epidemic. The Maine Hospice Council has been a strong advocate for people living with AIDS and their CAREGIVERS. Hospice is committed to helping individuals overcome the social isolation that has marked this devastating illness."

The Maine Cancer Pain Initiative, a committee of the Maine Hospice Council, is a collaborative effort among health care professionals and consumers to improve the quality of life for people in severe pain. Committed to research, policy development, and education in pain management, the Institute advocates for people with HIV and other serious illnesses (not solely cancer patients). Meetings are open to the public.

Access to in-home hospice care is generally available to people with HIV/AIDS in Maine. However, such clients can place a burden on hospices because they require approximately twice as many volunteer hours as other clients. (MCAP Report, 1994).

Hospice care is covered through Medicare and many insurance plans but, as with home care, hospice care does not yet qualify for state Medicaid benefits.

Issues

Hospice care for people with HIV/AIDS can require more than usual volunteer and staff time of local hospice organizations.

Hospice care as a service is not covered by Medicaid.



Immediate

- Maine Bureau of Health and professional education providers (such as the Maine Bureau of Health, AIDS Consultation Service, Maine AIDS Alliance, AIDS service organizations and others):
 - Create more opportunities for hospice providers to share their expertise and patient-advocacy skills with other providers who care for persons with HIV/AIDS;

- Create more opportunities for hospice managers to share their expertise regarding adjustments their programs have made to accommodate the varied situations of persons with HIV/AIDS.
- All people familiar with HIV and AIDS—advocates, people living with HIV, and medical personnel:
 - Participate in the Maine Cancer Pain Initiative.
- Community members:
 - Volunteer your time at a local hospice organization.

Long-term

- Maine Bureau of Health, professional health associations, and state legislators:
 - Work toward reducing Medicaid barriers to reimbursement for hospice care and other homecare services.

Nontraditional Health Care Settings

Many HIV+ people, realizing the importance of maintaining optimal health in combatting their disease, are attracted to the holistic approach of alternative or nontraditional practitioners. Included in this category are such providers as homeopaths, naturopathic physicians, herbalists, acupuncturists, polarity therapists and massage therapists. Practitioners in these categories are distributed throughout the state, although accurate numbers are not available.

Issues

Primary care providers may not be aware that their patients are using alternative health care providers—and may know little about those therapies.

Nontraditional providers may have little or no formal training in infection control.

Because of the increasing role of nontraditional care-givers in treating persons with HIV/AIDS, reimbursement issues will become increasingly important.



Immediate

- Alternative providers:
 - Seek out information and training on HIV/AIDS as it pertains to your field;
 - Contact the local AIDS service organization (ASO), the AIDS Consultation Service, or your national professional association;

- Investigate with ASOs and your professional association a strategy for qualifying your services as reimbursable.
- Primary care practitioners:
 - Become familiar with alternative health care used by your HIV+ patients.
 - Communicating with the practitioner will improve care for your HIV+ patients.
- Professional education providers (such as the Maine Bureau of Health, AIDS Consultation Service, Maine AIDS Alliance, AIDS service organizations and others):
 - Target nontraditional providers for infection control education.

Resources

Anonymous HIV Antibody Counseling and Testing Sites

BIDDEFORD

York County STD Clinic
207-282-1516

ELLSWORTH

Downeast Family Planning
207-667-5304

PORTLAND

The AIDS Project
207-774-6877, 1-800-851-AIDS

Portland STD Clinic
207-874-8444

ROCKLAND

MidCoast Family Planning
207-594-2551

LEWISTON

The Clinic
207-795-4019

BANGOR

Bangor STD Clinic
207-947-0700

AUGUSTA

Augusta Family Planning
207-626-3426

PRESQUE ISLE

ACAP Family Planning
207-764-3721

Organizational Contacts

Acadia Health Education Coalition

103 Water Street, Suite 203
Hallowell, ME 04347
207-626-5774

AIDS Consultation Service

Maine Medical Center
22 Bramhall Street
Portland, ME 04102
207-871-2099

Another Way

RFD 1, Box 970
Searsport, ME 04974
207-338-4476

(information, referral, and consultation service to help consumers find appropriate alternative health care practitioners)

Association of Nurses in AIDS Care/Southern

Maine Chapter
P.O. Box 1224
Portland, ME 04104-1224

Bureau of Medical Services (Medicaid)

DHS, Station #11, Western Avenue
Augusta, ME 04333
207-287-3957

Citizens for Health/Maine Chapter

RFD 1, Box 970
Searsport, ME 04974
207-338-4476

(Coalition of alternative health care practitioners and supporters).

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Resources (continued)

City of Bangor, Health and Human Services
Department
103 Texas Avenue
Bangor, ME 04401
207-941-0258

City of Portland, Health and Human Services
Department
Public Health Division/Social Services Division
389 Congress Street
Portland, ME 04101
207-874-8300

Family Planning Association of Maine
P.O. Box 587
Augusta, ME 04332
207-622-7524

HIV/STD Program, Bureau of Health
DHS, Station #11
Augusta, ME 04333
207-287-5392

Home Care Alliance of Maine
One Park Drive
Rockland, ME 04841
207-594-9561

Maine AIDS Alliance
112 State Street
Augusta, ME 04330
207-621-2924

Maine Ambulatory Care Coalition
P.O. Box 390
Manchester, ME 04351
207-621-0677

Maine Association of Acupuncture and Oriental
Medicine
P.O. Box 10912
Portland, ME 04104

Maine Association of Naturopathic Physicians
4 Milk Street
Portland, ME 04101
207-773-2517

Maine Dental Association
Association Drive
Manchester, ME 04351
207-622-7900

Maine Emergency Medical Services
16 Edison Drive
Augusta, ME 04330
207-287-3953

Maine Health Care Association
(association of nursing homes)
303 State Street
Augusta, ME 04330
207-623-1146

Maine Hospice Council
16 Winthrop Street
Augusta, ME 04330
207-626-0651

Maine Hospital Association
150 Capitol Street
Augusta, ME 04330
207-622-4794

Maine Medical Association
P.O. Box 190
Manchester, ME 04351
207-622-3374

Maine State Nurses Association
P.O. Box 2240
Augusta, ME 04330
207-622-1057

Maine Osteopathic Association
Route 202
Manchester, ME 04351
207-623-1101

National Association of Social Workers/Maine
P.O. Box 5065
Augusta, ME 04330
207-622-7592

New England AIDS Education and Training Center
University of Massachusetts Medical Center
55 Lake Avenue North
Worcester, MA 01655
617-566-2283

Materials

AIDS Treatment News
PO Box 411256
San Francisco, CA 94141

AIDS/HIV Infection: a Reference Guide for Nursing Professionals, Flaskerud JH. (1989). New York: W.B. Saunders Co.

AMFAR AIDS /HIV Experimental Drug Directory
1515 Broadway, Ste. 3061
New York, NY 10036

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"Bloodborne Pathogens Standard." *Federal Register*, 1991, 56(235): 64175-64182. Occupational Safety and Health Administration.

Centers for Disease Control National AIDS Clearinghouse, 1-800-458-5231 (many different publications and guidelines available regarding treatment of patients with HIV).

Early Care for HIV Disease (2nd Edition). Baker R.A., Moulton J.M., Tighe J. San Francisco AIDS Foundation (1992)

"Guidelines for prevention of transmission of HIV and HBV to health care and public safety workers." *Morbidity and Mortality Weekly Report*, 38(S-6) Centers for Disease Control, 1989.

HIV Infection: A Clinical Manual. H. Libman and R.A. Witzburg (Eds.) Boston: Little Brown & Co.

HIV Prevention Counseling Trainers Guide. Centers for Disease Control, 1993.

Journal of the International Association of Physicians in AIDS Care

Medical Publishing Corporation
101 West Grand Avenue, Ste. 200
Chicago, IL 60610
312 755-1227

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Public Places

These institutions, individuals, and organizations can influence how Public Places are used:

- Chambers of Commerce
- Business Owners and Managers
- Arts Associations
- Park and Recreation Departments
- Department of Transportation
- Bureau of Tourism
- Municipal Governments
- Law Enforcement Officials and District Attorneys
- Fraternal and Service Organizations
- Professional Trade Associations
- Community Health Educators and Health Care Providers
- AIDS Organizations

Examples of Public Places:

- Malls, stores, gas stations, laundromats, hair salons, barber shops
- Restaurants, bars, clubs
- Motels, hotels, inns
- Public transportation, airports, bus lines, ferries, taxi companies, parking garages
- Parks, rest areas, public bathrooms, beaches, tourist information centers
- Municipal and public buildings, town offices, civic centers, courthouses
- Museums, galleries, libraries, theaters
- Adult book and video stores, adult movie theaters, cruising areas
- Trade shows, fairs, beano halls, festivals, athletic events, concerts, health clubs, gyms, saunas, racquet clubs
- Ice and roller skating rinks, bowling alleys, arcades, pool halls, ski areas



Public places are locations that people use for recreation, entertainment, shopping, eating, sleeping, socializing and transportation. The Maine Mall is a public place; so is the Fryeburg Fair, and the Bangor International Airport. Unlike other settings in our research (workplaces, health institutions, schools, etc.), which have ways of addressing HIV, most public places are settings in which people are not used to seeing references to HIV.

To prevent the spread of HIV—and to make sure we protect future generations—we can start taking advantage of the vast potential of our public places by drawing people's attention to HIV issues, with the ultimate goal of changing attitudes and risky behavior. Accomplishing this will require a commitment of will, not only by the people in charge of these facilities, but by the general public who frequents them.

Vast numbers of people could easily be reached with subtle messages about HIV awareness through posters, scoreboard messages, programs and ticket stubs.

To begin with, public places could do many of the same things that AIDS service organizations (ASOs) do—such as distributing information on HIV prevention, making condoms readily available, and providing access to group counseling and phone counseling.

The public attends thousands of athletic and entertainment events every year, including Sea Dogs and Pirates games, college and high school athletic events, concerts, theater performances, art exhibits and crafts fairs. Each year Maine hosts 24 major agricultural fairs which attract around 500,000 visitors; smaller events, like the Seafood Festival and Clam Festival, take place almost constantly between May and December, each attracting as many as 50,000 people. These vast numbers of people could easily be reached with subtle messages about HIV awareness, through posters, scoreboard messages, programs and ticket stubs.

Thousands of Maine businesses serve the public every day. For example, Maine has over 2,000 hair salons and over 1,900 places of lodging that also serve food. Maine's public transportation industry alone has two jetports and several smaller airports that see considerable daily traffic.

Taxis and public bus lines operate in the cities, while interstate bus lines move people in and out of Maine daily. In the summer, beach trolleys transport vacationers in southern Maine; when the snow flies, a passenger train carries skiers to and from Sunday River Ski Resort; soon a year-round train will run from Portland to Boston. Public and private ferries are a major mode of transportation for island-goers in Casco and Penobscot Bays. Because travelers encounter advertising and public service messages almost everywhere they go, reaching them with appropriate HIV-related messages could be easily and effectively done.



Because travelers encounter advertising and public service messages almost everywhere they go, reaching them with appropriate HIV-related messages could be easily and effectively done.

Health clubs, gyms, tanning salons and saunas dot the state, whether independent facilities or part of a hotel or ski resort. While some are well-known settings for sexual contact and, as such, great places for straightforward messages about HIV prevention, the presence of families at these same places requires that messages be discreet. Even so, some health clubs—like the “Y,” for example—are important community entities that could provide not only messages but other valuable HIV services as well.

Movie theaters, video arcades, athletic events, county fairs, ski areas, bowling alleys, malls, skating rinks and parks are all places where teenage boys and girls get together. While these might seem ideal settings to reach teens with frank HIV messages, many younger children also frequent these locations. (According to one video arcade owner in Portland, two-thirds of his patrons are under 12, and the other third are between 12 and 16.) Therefore, HIV messages could be prevalent but also general and low key.

There are between 30 and 40 adult book/video stores and adult movie theaters throughout Maine. There is no way to know how many customers they attract, but they obviously are ideal sites for explicit HIV messages.

Places for Sex

Places where people may engage in sex, or meet to have sex elsewhere, such as parks, beaches, gyms, theaters, public bathrooms, adult book/video stores and bars are important locations for HIV prevention services.

One HIV prevention activity that takes place in some parks, rest areas, and beaches that are known public sex environments (also called “cruising” areas) is one-to-one intervention, targeting a sector of the gay male community and the hard-to-reach population of men who do not identify as gay, yet occasionally have sex with other men. In these locations, outreach workers approach men to discuss HIV and safer sex. They also offer condoms and information on health resources. These outreach activities are not part of any statewide program, and are often carried out without the knowledge or cooperation of local law enforcement, Department of Transportation or other governmental authorities.

A street outreach program in Portland and Lewiston targets sex workers and injection drug users. The educator makes contact with individuals in outdoor areas or in soup kitchens, shelters, and drop-in centers.

Some gay bars have already taken responsibility for condom distribution, poster displays, fund-raisers for AIDS organizations, and presenting special attractions, like “Safer Sex Cheerleaders.” But, except for stores and health facilities that sell condoms, few “non-gay” businesses provide HIV prevention materials, despite the fact that all bars, bottle clubs and fraternal organizations would be ideal places for condom machines and educational posters.

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Goals

Over the next five years, public places can be used to:

- Build community support for HIV-related activities;
- Develop appropriate programs, services and policies for public places;
- Overcome people’s discomfort with HIV-related activities.

Obstacles

- Most public places are under-used for HIV awareness and prevention;
- The places that are used often lack the creativity necessary to attract attention and, thus, to effect changes;
- Some public proprietors resist HIV-related programming. Their resistance is usually based on fear of negative community response, concerns over how HIV/AIDS would be presented in a family entertainment setting, or bias against homosexuality, drug use, or sexuality in general. Another attitude, especially regarding rest areas and parks, is that HIV outreach efforts in those places will increase their use as public sex environments. (While that is a commonly held concern, it is not supported by any available evidence.)

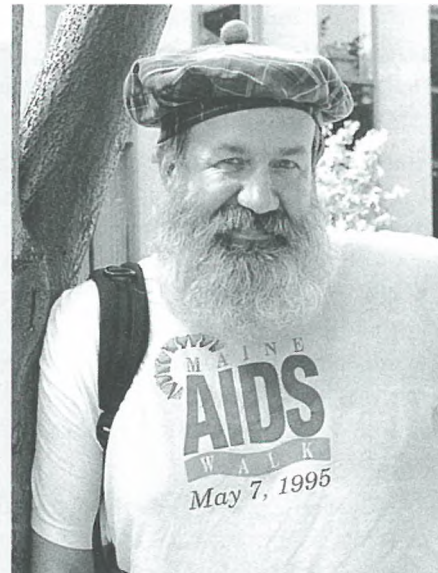
The Condom Man

"I pass out 40,000 condoms a year," says Willy Willette, who works as an HIV prevention educator for The AIDS Project in Portland. "I've been doing this for six years, two days on the streets in Lewiston, two days a week on the streets in Portland." When Willette is on the street, he's hard to miss. A commanding presence with a full, bushy beard, he wears a plaid beret with a pom-pom on top and a supply of condoms underneath.

"I work with IV drug users, male and female sex workers, homeless, mentally ill, mentally retarded, both children and adults. I do HIV trainings in detox centers and jails. They call me the Condom Man."

When asked how he keeps from burning out under such a caseload, he laughs and explains, "Because I do damn good work during the day, and I sleep well at night. The hardest thing is that people keep dying on me. I lost four good friends last month. And another couple of clients and two acquaintances. But you try to keep a sense of humor, you know, scream in your car and all that."

Willette starts his day at a place like the Preble Street Resource Center, where he'll eat breakfast with around 200 homeless people. He'll move around, talking and answering questions about HIV and handing out condoms. Later he might do some education at a detox center or a group home. Then he hits the streets.



"If you look like you're doing prostitution, I'll say, 'Hey, you want some free condoms?' I know they're using them because every so often a police officer will come up to me and say, 'Hey, we busted so and so with your condoms.'"

"Most of the street people I already know. But new people are always landing in town. I might see you carrying a backpack or getting off a bus. I'll come up and ask you if you're looking for a place to spend the night, tell you where the shelters and the soup kitchens are. People that don't know me think I might be a cop. But one of the old-timers'll come over and say, 'He's cool.'"

General Recommendations

1. Business people, civic organizations, religious groups, ASOs, municipal government, law enforcement and other entities could form collaborative projects to win community support, develop policy, and provide HIV prevention education and support services that are appropriate to each setting.
2. Most public settings are used by a broad cross-section of people. Depending on the venue, HIV messages should be appropriately geared to the people using those settings.
3. HIV policies, services, and projects should be continually reviewed—and improved.
4. Positive public relations are important. Projects should be creative and reflect cooperative effort. In the face of negative reaction from some people, overall community support is crucial.



Immediate

- Collaborate with ASOs, government, law enforcement, religious groups, chambers of commerce, restaurants, hotels, civic organizations, et al., to:
 - Develop a local action plan: develop age- and setting-appropriate HIV programs
 - Raise funds to meet local needs
 - Develop strategies to respond positively to potential negative community action directed at public HIV messages
 - Respond positively to negative community action
 - Help colleagues and others overcome AIDS-phobia and homophobia

Mid-term

- Build coalitions and collaborative relationships and recruit new participants
- Update policies and activities
- Identify new opportunities for activities
- Review model activities from other cities or states
- Target activities for specific populations

Long-term

- Celebrate coalitions and collaborative relationships
- Evaluate activities:
 - Survey participating sponsors, local residents and people with HIV to assess activities
 - Continue successful activities from previous years
 - Achieve full implementation of all activities from original plan
- Update information, messages, materials and trainings
- Publicly recognize exemplary programs and community leadership
- Formally meet in coalitions to develop the next five-year plan

How to design a sound HIV policy for public settings

- Adhere to the Maine Human Rights Act, Americans With Disabilities Act, and other HIV-related statutes and rules (*see Appendix*)
- Institutionalize your commitment to participate in and co-sponsor community awareness events, train staff and employees, and make donations to support AIDS organizations and people with HIV/AIDS
- Form community-based coalitions with other public venue entities to develop plans, and publicly recognize major community leadership and successes
- Persuade trade and professional associations to discuss HIV in newsletters, at meetings, etc.
- Work with legal and law enforcement bodies to establish alternative educational sentences for people arrested/convicted for having sex in public settings

Family Entertainment and Recreation Settings

These settings include theaters, video arcades, skating rinks, bowling alleys, ski areas, and gyms. While children and families patronize some of these areas, other areas cater specifically to teens. This provides an ideal environment for low-key messages about HIV, especially in the context of health, fitness, and the enjoyment of family and life in general.

Business owners should be aware that people with HIV/AIDS and their family members are among their customers and patrons.

Issues

- Some business owners are reluctant to integrate HIV into their settings because of the negative, “anti-fun” connotations of the disease, or because of the implication of sexuality in a family environment.
- Because of the wide range of people found in entertainment and recreation areas, these settings are best used for programs appealing to the general public.
- These settings can be used to heighten support and compassion for people with HIV/AIDS
- The presence of HIV-related educational materials in family recreation spots could promote greater community awareness while providing a model for other similar places.
- Business owners should be aware that people with HIV/AIDS and their family members are among their customers and patrons.



Public venue businesses, in collaboration with ASOs:

- Provide age-appropriate posters with HIV/AIDS-awareness messages;
- Exhibit displays that express support for people living with HIV (Names Quilt, etc.);

- Present HIV/AIDS programs with family themes;
- Present teen-oriented HIV/AIDS programs and promotionals.

Fairs, Festivals, Athletic Events

Fairs, festivals and athletic events attract teenagers and families, as well as tourists and out-of-towners. As in other forms of family entertainment, HIV messages should be subtle, to appeal to a wide variety of people yet engaging enough to attract attention. Because these events often have local traditions, HIV-related activities could be tailored to fit.



Issues

- As above, sponsors may be reluctant to integrate HIV into their events because of the negative, “anti-fun” connotations of the disease or because of the implication of sexuality in a family environment.
- Some of these events are sponsored by religious, fraternal or civic organizations, who may be reluctant to address HIV publicly.
- Because these events attract a broad range of people, HIV programs should be geared to the general public.
- The successful implementation of HIV activities at family events can lead to greater public acceptance, while providing a model for future events.
- Sponsors should be aware that people with HIV/AIDS and their families are among the attendees at these events.



Event sponsors, in collaboration with ASOs:

- Use message boards for HIV information (hotline numbers, etc.)
- Include HIV information on printed programs
- Provide display booths or tables for local AIDS organizations
- Hold events such as “Athletes Against AIDS,” featuring high school and college athletes, Sea Dogs, Pirates, Joey Gamache, etc.

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Public Transportation

People using public transportation are a captive audience, both while they are riding and while they are waiting. Commuters and travelers are constantly exposed to printed matter—schedules, tickets, ticket folders and other displays—that are used for public service or advertising. Posters, for

example, are a source of diversion for travelers and could be used effectively to broadcast HIV-related messages.

Issues

- Most forms of public transportation have a long tradition of displaying public service ads and messages; depots and stations serve as “community bulletin boards” with the posting of local notices.
- Because of the wide range of people who use public transportation, HIV campaigns should be geared to the general public.
- Transportation companies should be aware that people living with HIV/AIDS are among their passengers and employees.
- Taxi drivers have a unique opportunity to provide certain HIV prevention information or safer sex materials (condoms) because they often talk with passengers as they transport them to adult entertainment venues.



Public transportation companies, together with AIDS organizations and ad agencies:

- Develop a simple ad campaign for travelers who are waiting or en route.

AIDS organizations:

- Help taxi companies develop appropriate programs (hotline number in cabs; cabbies who can answer simple questions about HIV prevention, such as where to buy condoms or where to get tested).

Maine Department of Transportation (DOT) and transportation companies:

- Work with AIDS organizations to print HIV information on schedules, tickets, etc.

Museums, Galleries, Libraries, Arts Associations, Symphonies, Performance Companies

The arts community has been profoundly affected by this epidemic. Both nationally and in Maine, many artists, actors, photographers, musicians, writers, dancers, designers, and others in the art world have succumbed to HIV. As staggering as the personal and community loss may be, the deaths of people like writer John Preston and concert violinist Pierre Menard are a deep loss to Maine's cultural richness.

As a result of the connections between HIV and well-known artists, the public has gained a measure of empathy for people living with HIV. They have responded well to performances, benefits, art auctions, and events like “Day Without Art.” The Maine media has covered some of these events, and

As a result of the connections between HIV and well-known artists, the public has gained a measure of empathy for people living with HIV.

in many cases TV/radio stations or local newspapers have co-sponsored cultural activities related to HIV.

The arts community is uniquely qualified to bring HIV to people's attention in dynamic ways—by designing dynamic, graphic representations of HIV and the people it affects, or by using drama to convey messages about prevention, compassion and public policy. For example, Keith Haring's ACT-UP posters and ads, acclaimed for their blunt but appealing approach, have been adopted by other causes, such as the breast cancer movement.

Issues

- Public recognition of the connection between the arts and HIV contribute to the fact that creative and unusual messages are accepted and sometimes even expected.
- The arts use a multitude of media to reach different audiences: children's theater, symphony orchestras, poetry readings, gay men's choruses, rock performances, artists-in-the-schools, visual art displays in banks and hotels, public television and public cable access, etc.
- Art and literature can be used for both general projects and targeted projects for specific populations.
- In some parts of Maine a tradition of cooperation already exists between the artistic community and ASO's.



Museums, galleries and libraries, in collaboration with AIDS organizations:

- Feature all the AIDS books available at the library;
- Have art displays specific to HIV;
- Hold cultural events related to HIV;
- Host AIDS Quilt displays;
- Sponsor a "Day Without Art" (include music and literature);
- Schedule art auctions, openings and receptions;
- Organize sales of art items/books to benefit AIDS organizations and people with HIV/AIDS;

Museums and galleries:

- Donate works of art for exhibition at AIDS organizations;

Performance companies and symphonies:

- Hold benefit performances of works by and about people with HIV/AIDS.

Public Buildings, Civic Centers, Town Offices, Police Stations, Courthouses

These locations are often managed and administered by local or county government. With the exception of civic centers, people usually visit these

Effective posters and leaflet racks can often be found in these settings.

buildings to take care of personal business—paying taxes, registering vehicles, etc.—and stay only as long as needed to complete their transactions. Because visitors are not generally in a “teachable” frame of mind, municipal buildings are good places for small amounts of information about HIV. Effective posters and leaflet racks can often be found in these settings.

Civic centers, where athletic events and entertainment occur, can provide much of what has been previously recommended for athletic and cultural events.

Issues

- County and municipal government could lead the way in bringing HIV awareness to public places.
- County and municipal employees, including law enforcement and first responders, are public trustees and should be given proper HIV education and training.
- Government is in a strong position to model positive behavior by making responsible and compassionate policies regarding the treatment of local people with HIV.
- County and municipal government, including law enforcement, should be aware that people with HIV and their loved ones live and work among them.



Local government leadership (Mayor, Councils, Selectmen) and local law enforcement leadership (Police Chief, Sheriff): Meet with AIDS service organizations (ASOs) regularly, to:

- Share information about HIV/AIDS and the problems facing people living with HIV/AIDS;
- Collaborate on addressing community HIV issues;
- Display posters advertising hotline numbers and local AIDS organizations;
- Provide space on brochure rack for HIV-related materials;
- Provide public meeting space and conference rooms for local AIDS organizations and community AIDS events;
- Support special events; for example, the mayor could issue a proclamation for World AIDS Day or seek support from local government for an annual AIDS walk, etc.;
- Help place AIDS organizations on town warrants for annual town meetings so they can request funds from town/city budget;
- Help municipal governments to develop specific procedures that ensure that HIV+ people are not discriminated against when applying for public assistance, reporting crimes, etc.;
- Help AIDS organizations monitor discrimination complaints related to public assistance, municipal services and law enforcement.

Malls, Gas Stations, Stores, Banks, Laundromats, Bars, Restaurants, Hair Salons, Barber Shops, Hotels, Inns, Motels

These are private businesses that the public frequently visits or passes through. They are often locally-owned or operated, and they employ local people. Usually a strong connection exists between these local businesses and the surrounding community. Many business people belong to local organizations, such as Rotary or Kiwanis, that address important community concerns.

Some store owners allow the posting of community announcements on their bulletin boards, and they display posters in their store windows or allow local groups to hold fund-raisers, like bake sales and raffles, on their premises.

Malls have been recognized as quasi-public places (like parks and community centers) where community events can be found that benefit local charitable causes.

Some establishments, especially hair salons, barber shops and laundromats, are places where customers and business people develop personal relationships over time, and where it's common for them to discuss topics related to family, work and health.

Other businesses provide places for patrons to socialize. Some bars and restaurants are meeting places for singles, where people come with the possibility of having sex. Hotels and motels accommodate overnight guests, some of whom are sexually active with more than one partner. Such businesses are fitting for HIV prevention activities.



Issues

- Many HIV resources have been specifically developed for the business community;
- Some types of businesses could easily provide customers and patrons with HIV prevention information and condoms;
- Business owners may be reluctant to integrate HIV into their businesses, fearing that negative implications of HIV would turn customers away;
- Business people can play key behind-the-scenes roles in fund-raising and support, leading to positive public relations for the business.

Cutting Hair for a Good Cause

"There was no one particular person [with AIDS] that I was close to," reflects Linda Hollis, owner of Belfast hair salon The Upper Cut. "In my profession, there's a lot of awareness." And holding a cut-a-thon to raise money for the local AIDS organization just seemed like a good idea. "I wanted to do this because the money we raise stays right here in the community, impacting people that I come in contact with.

"It has to start on a small scale. Each community has to depend on itself," she says. "At first we seem so isolated here, and stuff from urban areas doesn't seem to affect us. But AIDS is something that could happen to you very easily."

Hollis says that at first, other stylists thought giving haircuts for free all day would be like a busman's holiday. The \$6 charged goes directly to the Waldo-Knox AIDS Coalition, as does the proceeds from any products sold that day. "A lot of them didn't realize how much fun it would be."

Hollis invited other stylists from the area to come and cut hair for two hours at a time. Begun in 1989, the annual cut-a-thon has raised almost \$1,200 for the Coalition. "It's like a party, with refreshments. Last time we cut over 70 people's hair in just the afternoon." By the end of the day, the stylists had pooled their tips as a contribution to the effort, as well.



"It's important as a business to support those who live here," states Hollis matter-of-factly. "And I met a lot of new people. One woman was in the Rotary, and she mentioned it at a meeting. As a result, a lot of Rotarians came. In a roundabout way, it does increase clientele, though that wasn't the intention. People like to support businesses that support issues they care about."

ACTION STEPS



Local business organizations, individual business people, merchants, innkeepers, etc.:

- Seek HIV/AIDS training from your local ASO; then, in collaboration with the ASO, develop a positive strategy to deal with HIV (such as "Business Responds To AIDS," a national model sponsored by the National Centers for Disease Control), making sure to include local chambers of commerce, trade associations and service organizations. In addition:

All employers:

- Train employees to respond to customer apprehension about HIV;

Bars, restaurants, gas stations, laundromats, hair salons, barber shops:

- Install condom machines in bathrooms;

Stores and laundromats:

- Use bulletin boards to display information about local AIDS organizations and events, support groups, hotline numbers, etc.;

AIDS organizations:

- Use shopping center and mall spaces for display tables, bake sales, and Quilt events;
- Work with bars to supply condoms, posters, matchbooks, place mats and coasters, and to provide HIV training to bartenders;
- Train both female and male hair stylists/barbers to provide simple HIV information to their customers;
- Furnish HIV reading material for merchants' waiting rooms;

Local businesses:

- Offer discounts to people with HIV/AIDS;
- Hold raffles, point-of-purchase collections or other fund-raising activities, and donate a percentage of profits to ASOs;

Motel managers and innkeepers:

- Offer your guests condoms along with other hospitality items.

*Motel managers and innkeepers:
Offer your guests
condoms along with
other hospitality
items.*

Opinion Leaders Save Lives

Innovative prevention programs like Project Lifeguard—Gay Bar Opinion Leaders Training Project can't be found just anywhere. But many individuals involved in HIV education and prevention efforts know that getting advice from people you're comfortable with is a necessary ingredient for effecting behavior changes.

When Claire Gelinas, director of the AIDS Coalition of Lewiston/Auburn first heard of a similar project at an educators' retreat, she brought her idea to Richard Hinkley.

Sometimes known to his friends as Memère, Hinkley recalls, "I was flattered that they thought people might listen to what I had to say. Lord, I've been around for so long, I think everybody has talked to me about something. Besides, I've been mixed up in the AIDS business since the beginning. I helped the first one [Maine person diagnosed with AIDS] die, and I've been in the bar for 25 years."

After years of being an unofficial ear to other people's problems and offering advice, Hinkley knew that the same approach could work with safer sex discussions. "Some need to be flattered, cajoled, or teased," he says, "and some can be plain talked to directly."



Two years later, Hinkley feels that, as an opinion leader, he has made a difference in some people's lives and has helped to influence some safer sex practices, although not everyone has been willing to listen, or to change their behaviors. "Some people will be helped by this project, others will not."

So the efforts of the Project Lifeguard go on. The relatively short training period, the minimal expense of the training, combined with outcomes that can save lives, make this project appealing on many fronts. And it works.

Hair salons and barber shops:

- Offer condoms and brochures to customers (something to read under the dryer);
- Offer discount personal care services, such as facials, haircuts, manicures, etc., to people with HIV/AIDS;
- Sponsor fund-raising events, like fashion shows, cut-a-thons, etc.;

Large businesses, such as banks, realtors, law firms, etc.:

- “Loan” your executives and staff to AIDS organizations as volunteers.

All merchants:

- Print HIV messages on receipts, menus, place mats, coupons, etc.;
- Develop seasonal activities promoting HIV messages (for example, World AIDS Day falls between Thanksgiving and Christmas). A seasonal theme could be tied to donating a percentage of profits to HIV-related causes.

Health Clubs, Gyms, Saunas

These establishments vary in type and include private health clubs and gyms, hotel health facilities, YMCAs, tanning salons and rustic saunas. While most are frequented by adults, some have a young clientele.

Although it is not widely known, many gyms, clubs and “spas” are places where adults meet to have sex, either on or off the premises. Some gyms and health clubs have long-standing reputations as “cruising areas” for men who have sex with other men.

While these kinds of businesses would seem like ideal places for HIV prevention activities, few of them, if any, are taking advantage of these opportunities.



A natural link exists between health/fitness establishments and HIV prevention activities.

Issues

- A natural link exists between health/fitness establishments and HIV prevention activities.
- Because some people erroneously believe that sexually transmitted diseases such as herpes or HIV can be transmitted in pools, hot tubs or

saunas, operators of health/fitness establishments may worry that raising HIV issues with customers will hurt their business.

- Some clubs, gyms and health facilities are places where risky sexual behavior takes place.



Owners/managers of health/fitness businesses, in collaboration with local AIDS service organizations (ASOs):

- Donate space for meetings and events;
- Offer free or discounted services, such as massages, whirlpools, etc., to people with HIV/AIDS;
- Display HIV information on posters and brochures;
- Train aerobics instructors, weight trainers, etc. to provide simple HIV education to customers;
- Integrate HIV information into discussions of safety, first aid, etc.;
- Sponsor community health programs that include HIV;
- Install condom machines in men's and women's locker rooms;
- Supply HIV/AIDS-related reading materials in waiting rooms and lobby areas;
- Collaborate with other clubs on theme-based fund-raisers tied to events for example, anyone using the sauna on World AIDS Day gets a free red ribbon or coupon for condoms at the local drug store.

Adult Book/Video Stores, Adult Movie Theaters, Public Sex Environments

These are locations where sex is marketed as a product, or where actual sexual activity takes place. Stores, bars and theaters that offer sexually-oriented entertainment or products are ideal places to also offer HIV prevention products (condoms, latex dams, safe sex erotica, "marital aids," etc.) and to show videos or movies depicting safer sex. Because these are adult-oriented businesses with a purely sexual theme, explicit safer sex messages would probably not offend their clientele. We must keep in mind, however, that HIV has negative implications concerning death, homophobia, and sexual fear and confusion, and owners' financial concerns may override their desire to integrate HIV prevention messages into their establishments.

Public sex environments are widely defined, from bathrooms at shopping malls and bus stations to parks and beaches and rest areas on highways. People who use such places for sex often know which local gravel pit, cemetery, rest area or campground is popular for cruising and sexual activity. Discarded condoms at public parks and beaches, and the presence of "glory holes" (holes in the walls of adjoining toilet stalls) and sexual graffiti at highway rest areas all testify to the wide array of public sex environments in Maine.

Because these are adult-oriented businesses with a purely sexual theme, explicit safer sex messages would probably not offend their clientele.

Adult entertainment businesses and public sex environments are common locations for men to have sex with other men. These sexual interactions are usually brief and often occur between people who remain anonymous to each other. In fact, many of the participants do not identify themselves as “gay,” and this may be the only same-sex activity they engage in. (In many of these cases their female partners are unaware of their high-risk behavior).

Despite the low profile of these activities, some ASOs (AIDS service organizations) conduct HIV prevention outreach at public sex environments. The discreet distribution of condoms and low-key presence of non-judgmental counselors have been employed to encourage safer sex practices among public sex participants.

Standing for Safety

“I’m not a sex policeman,” John Holverson explains. “I come at this from a personal, ethical, moral place.” As Supervisor of HIV Prevention Education for The AIDS Project, in Portland, Holverson also spends a good part of his week doing field outreach in many of Maine’s public sex environments, places like adult book stores, highway rest areas, and some of Maine’s beaches. These are places that attract both women and men, but primarily these are places where men have sex with other men.

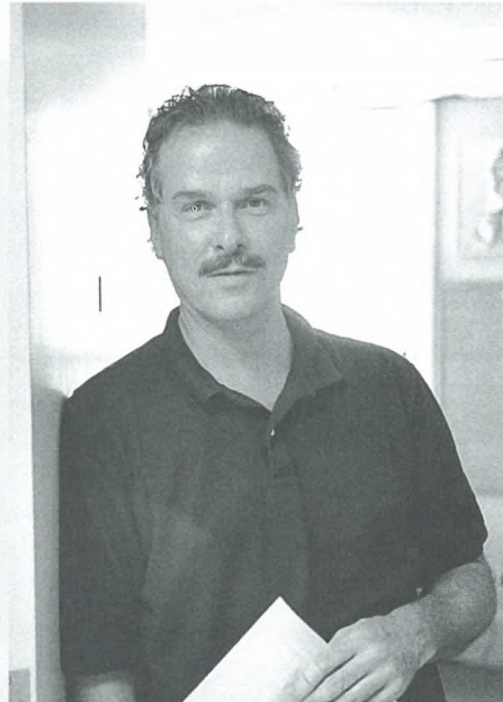
“If I see a couple of guys having sex or going off to have sex, I’ll just say, ‘Keep it safe, guys.’ A lot of times, it’s enough to puncture the trance.”

While some men who meet for sex may identify as gay or bisexual, others may be married and consider themselves straight, despite these occasional encounters.

“Sometimes their reaction is denial, and some get belligerent,” Holverson says. “But that’s rare. Generally the reaction is positive. Some people are visibly moved that there’s someone out there who cares enough to do something for them. If I can get a guy to start talking, maybe I’ll see him the next time I go there, and we’ll talk again.”

But talking is only the beginning. Even though Holverson has sometimes encouraged people, over a series of conversations, to start counseling or to take an HIV test, he knows that the condoms or pamphlets that he hands out may not significantly change many lives.

“This isn’t about education and knowledge. Everybody knows how you get HIV. This is about behavior, which is much more complicated. The reasons



people come to these places have to do with self-esteem and isolation. They may be trying to fill some void in their lives that makes them feel bad about themselves. For gay men, there aren’t many places that are safe, where they can socialize and feel good about themselves. A gay man in Jackman may feel that he’s the only gay man in Jackman. That’s real.”

Holverson does interventions in private businesses too, such as adult video and book stores, where people can go in other rooms and have sex in private booths.

“Occasionally some proprietor might feel like I’m driving his business away or cutting into his condom sales by giving away condoms. ‘All right,’ I tell him, ‘you show me how many condoms you’ve sold today.’ But I’m not there to argue. As a politically active gay man, I can’t ignore this. I know what has to be done, and I do it. I stand my ground.”

Because public sex is against the law, and because this activity takes place in venues of common public use, HIV prevention programs sometimes acquire the stigma of the activities they're designed to discourage. But these outreach programs work best when law enforcement personnel cooperate and let HIV educators work with public sex participants.

Issues

- Risky sexual activity takes place in public sex environments and in some adult entertainment businesses.
- Because public sexual activity is illegal, people often don't want to be identified or bothered, and so HIV messages may meet with hostility.
- While many people engage in sex in public areas, those who are arrested for this activity are most often gay men.
- Despite the stigmas associated with adult book/video stores and adult movie theaters, a natural connection exists between these establishments and materials that promote safer sex.
- Adult book/video stores and adult movie theaters are vulnerable to negative community response, so it may appeal to them to "do the right thing" and work with ASOs to promote safer sex.



Proprietors of adult entertainment businesses and public sex environments:

- Begin active collaboration with local ASOs.

AIDS organizations:

- Contact owners of adult entertainment businesses and provide HIV prevention posters, brochures, condoms, etc.
- Try to persuade owners of adult stores and theaters to carry safer sex videos that can be loaned free-of-charge, or shown in peep show booths;
- Offer to conduct brief training sessions to employees, so they in turn can provide simple HIV information to their customers;

Adult entertainment businesses:

- Sell or give away condoms, dental dams, lubricants, etc.;
- Carry videos and publications that have a "safer sex seal of approval" from your local AIDS organization—or offer free condoms with the purchase or rental of safer sex items;
- Offer explicit safer sex workshops;

Adult stores and theaters:

- Hand out cards with AIDS information and hotline numbers;
- Provide information specific to different types of customers (men who have sex with men, men who have sex with women, women who have sex with men, women who have sex with women, etc.);

Affix to X-rated videotapes stickers imprinted with HIV information.

Maintain condom machines in public rest rooms.

Electronic message boards can be used for HIV awareness messages at athletic events.

- Allow AIDS organizations to conduct prevention outreach to their customers;

Owners of ordinary video rental stores:

- Affix to their X-rated videotapes stickers imprinted with HIV information.

Local government and law enforcement:

- Support AIDS organizations in their outreach programs at parks, beaches, public bathrooms, "red light" districts and other public sex locations; outreach activities would be non-intrusive, such as HIV-related resources left in discreet places—condoms in bird feeders, for example, and resource numbers on small posters or incorporated into graffiti; one-to-one intervention would also be part of outreach;
- Cooperate with AIDS organizations that provide public sex outreach by protecting outreach workers from violence and wrongful arrests;

DOT and state and local parks departments:

- Maintain condom machines in public rest rooms.

Local district attorneys and court systems:

- Work with AIDS organizations to develop alternative sentencing (mandatory HIV education and volunteer time to an AIDS service organizations) for people arrested in public sex locations.

Different Ways to Use Public Places for HIV Programming

HIV Education and Prevention Services

- Customer-appropriate display of HIV posters, brochures and hotline numbers in all public places
- Booths and displays at local fairs, festivals, parades and athletic and cultural events
- Community HIV-related events (like World AIDS Day, Names Quilt, etc.) sponsored by local businesses, museums, libraries, municipal governments, et al.)
- Condom vending machines in bars and clubs, restaurants, motels, gas stations, city busses, laundromats, adult book/video stores, etc.
- Community-supported outreach in public sex environments
- Community-supported outreach to sex workers, drug addicts, homeless people
- Condoms/matchbooks/coasters with safe sex messages and hotline numbers given away at bars, restaurants, hotels, adult book/video stores, etc.

- Integration of HIV information into wider community health activities (HIV and first aid, HIV and substance abuse, etc.), especially at health clubs and gyms
- Electronic message boards used for HIV awareness messages at athletic events
- Use of taxis and drivers as HIV prevention resources
- Basic HIV training for bartenders, aerobics trainers, hair stylists and barbers, so they can pass information on to customers
- Public service campaigns targeting tourists (i.e., "Have A Safe Visit")
- Use of adult book/video stores and adult movie theaters for targeted, explicit education

Public Support for People with HIV/AIDS

- Wide display of red ribbons, AIDS posters, etc., showing support for people living with HIV
- Prominent acknowledgment that people with HIV/AIDS are welcome in public areas and businesses
- Co-sponsorship of community events that honor and respect people with HIV/AIDS (i.e., Names Quilt, art exhibits)
- Discounts for people with HIV/AIDS (free haircuts, swimming, movies, etc.)
- Special events for people with HIV (i.e., a restaurant could offer a free Thanksgiving dinner to people with HIV/AIDS)
- Assurance (and public acknowledgment) that events and facilities are fully accessible to people with disabilities
- Donated public and business spaces for meetings, support groups and events
- Donated employees as volunteers for AIDS organizations and events
- Funds from the sale of tickets or promotional items (T-shirts, buttons, etc.) donated to AIDS organizations

Public Places Resources

Materials

The following materials, and many others, are available through the National AIDS Information Clearinghouse, 1-800-458-5231

America Responds to AIDS: It's Your Move, Prevent AIDS. A Community Kit

Preventing HIV and AIDS: What You Can Do

HIV/STD Program, ME Bureau of Health,
207-287-3747—has videos, informational materials, speakers, etc.

The Los Altos Story award-winning video on what a community can do about HIV; \$25 donation.

Rotary AIDS Project

PO Box 794

Los Altos, CA 94023

415-688-6164

Organizations to Contact to Pursue HIV/AIDS Policy Development

Librarian's Association
Local Government Center
Community Drive
Augusta, ME 04330
1-800-452-8786

Maine Arts Commission
State House Station #25
Augusta, ME 04333
207-287-2724

Maine Arts Sponsors Association
P.O. Box 2352
Augusta, ME 04338
207-626-3277

Maine Association of Agricultural Fairs
R#1, Box 1610
Litchfield, ME 04350-9730

Maine Chamber of Commerce & Industry
7 Community Drive
Augusta, ME 04330
207-623-4568

Maine Department of Transportation
State House Station #16
Augusta, ME 04333
207-287-2551

Maine Innkeepers Association
305 Commercial Street
Portland, ME 04101
207-773-7670
207-773-7668 FAX

Maine Municipal Association
37 Community Drive
Augusta, ME 04330
207-623-8428

Maine Office of Tourism
State House Station #59
Augusta, ME 04333
207-287-5711

Maine Restaurant Association
5 Wade Street
Augusta, ME 04330
207-623-2178

Maine Turnpike Authority
430 Riverside
Portland, ME 04101
207-871-7771

Residential Settings

- Homeless shelters for adults, children, and families
- Battered women shelters
- Correctional facilities (adult prisons and the Maine Youth Center)
- Substance abuse treatment facilities for adults and adolescents
- Group care and foster homes for children
- Residential treatment facilities for children
- Group care and foster care for adults (funded by the Bureau of Mental Retardation)
- Institutions (Pineland, Augusta Mental Health Institute, Bangor Mental Health Institute, Private psychiatric hospitals)

Residential settings are sites that are “homes away from home.” They range from foster care for infants to jails for adults; homes for homeless families or homeless and runaway adolescents, and people with mental disabilities; shelters for women and children who have been physically and sexually abused; and halfway houses for people with substance-abuse problems.

The length of stay in these settings ranges from overnight at an emergency shelter to nearly a lifetime spent in an institution or prison. Thousands of Maine citizens annually spend some time living in one or another of these facilities.

Background

The HIV epidemic has not spread equally across all segments of our society. Higher rates of infection have occurred in some of the settings and among some population groups discussed in this report.

While men who have sex with men still constitutes the highest-risk group for HIV, a higher-than-average prevalence of HIV exists among other specific groups, such as injection-drug users, homeless people, sex workers, street youth, youth in Federal Job Corps programs, prisoners, and some racial and ethnic minorities. The residential settings we discuss in this chapter contain many members of these at-risk people.

Even though Maine’s residential settings meet a wide variety of different needs, the facilities all share some common traits:

- They all receive some public funds (some are actually owned by the state);
- They operate under government regulations (local, state or federal);
- Most are non-profit agencies open to public scrutiny;
- Nearly all operate 24 hours a day and are staffed by people who are required to have some level of skills and training.

Another similarity among these programs is that they exist to serve people who are having some kind of problem which prevents them from living at home, at least temporarily. The issues faced by many of the people are often the same issues associated with an increased risk of HIV infection: poverty, homelessness, alcohol or injection-drug use. Thus, it is critical that effective

The issues faced by many of these people are often the same issues associated with an increased risk of HIV infection: poverty, homelessness, alcohol or injection-drug use.

State and federal laws on confidentiality and discrimination are being interpreted differently by various agencies.

education and other prevention programs be made available to the people housed in these facilities.

In addressing HIV and AIDS issues, residential settings have advantages over some other settings:

- The large role played by government in their funding and operations make them more accountable to the public;
- As social service providers, they are frequently required to educate and train employees to deal with issues like HIV;
- The fact that people live 24-hours-a-day in these settings means there is more time available to provide prevention and treatment.

State and federal laws regarding confidentiality and discrimination are being interpreted differently by various agencies.

As a result, some agencies appear to be functioning in violation of these laws. Furthermore, regulations are inconsistent among different state departments, confusing compliance issues for agencies that must hold several licenses. Finally, there is no clear direction or monitoring from the state regarding HIV policies for various residential settings. This lack of coordination at the state level causes a fragmented approach to HIV policy development, staff training and service delivery.

Some providers believe that the disorganization will continue until a crisis occurs ("We'll have to deal with it when we get our first HIV+ resident") or until a clear mandate finally comes from some branch of government. At this time the only federal or state requirement is the OSHA (Occupational Safety and Health Administration) bloodborne pathogens standard.

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The investigation conducted for this report turned up only one estimate of the number of people with HIV or AIDS who were being served in these facilities. Many providers acknowledged that they had served some HIV+ people (or at least assumed that some of their clientele were infected), though only one official was willing (or able) to offer a figure. The Department of Corrections (DOC) acknowledged that as of May 1994, there were three HIV+ individuals and six others with AIDS in the correctional system. Most providers cited confidentiality of HIV status as the reason they did not know or could not share this information.

Information in this report regarding HIV+ individuals in residential settings is either anecdotal or based on studies conducted in other parts of the country on particular population groups. Attempting to apply this data to Maine programs may result in an inaccurate portrayal of our situation. Nevertheless, we do know that HIV prevention education does not currently exist for all staff and all clients in any of the residential programs we contacted. While HIV education and training ranges from non-existent to adequate, few agencies have instituted serious, on-going programs.

Issues of time, money, lack of political consistency, and "morality" are often cited to explain the absence of HIV programming in residential settings. From an economic viewpoint, HIV is one of many issues seen as peripheral and one that can draw needed resources away from a program's primary mission (the provision of shelter, detention, or treatment).

HIV is primarily a sexually-transmitted disease; injection drug use is the second most frequent mode of transmission. For many people, these facts move HIV out of the realm of public health and into a moral or religious one—and then the prevention measures that would customarily be used in the case of a life-threatening disease (such as tetanus, which is also prevent-

able) are seen as controversial. In those cases, the religious affiliations of some of the agencies can prevent meaningful HIV programming.

The political influence on public funding also inhibits HIV prevention education. Funders are sensitive to prevailing political winds; with no government mandate directing them, many officials and program managers steer clear of offering certain services that could be regarded as controversial.

Another obstacle mentioned by several people is the “unreality” of the disease, especially in facilities populated by adolescents and young adults. Because of the small number of youth who have tested positive for HIV, few if any staff in these agencies have ever encountered the disease. Many feel that HIV in their program is only a theoretical possibility. To complicate matters even more, minors (and persons with disabilities) must have their legal guardian decide whether or not they receive HIV prevention education services.

For agencies that want to provide HIV prevention education for their clients, the issues of time and money present overwhelming difficulties. Residential programs can incur high costs for staff training, both in terms of paying for the training and in paying the replacement staff who cover for personnel taking the training. None of our respondents reported having funds specifically budgeted for HIV education.

Funders are sensitive to prevailing political winds; with no government mandate directing them, many officials and program managers steer clear of offering certain services that could be regarded as controversial.

General Issues

Our interviews with providers and officials of residential settings reveal that very little attention has been paid to HIV. Although there are some differences, four strong themes emerge:

- Policies and practices vary tremendously from agency to agency, with no consistent oversight from the state or other funding agents.
- Despite attempts by provider agencies and others, the state has not instituted or clarified HIV-related policies and programs for these settings.
- The good HIV prevention work which is being done is the result of individual initiative and is carried out by caring and concerned staff and administration.
- People in residential facilities are often at higher-than-average risk for HIV.

Our interviews with providers and officials of residential settings reveal that very little attention has been paid to HIV.

General Recommendations

State agencies responsible for residential settings (Department of Corrections, Bureau of Mental Health and Retardation, Department of Human Services, and local agencies, etc.):

1. Develop a consistent set of HIV-related regulations in order to coordinate your approach to HIV.
2. Advocate for resources from the Legislature and allocate the funding necessary to carry out policy and program mandates in all the settings.



Immediate

- Request leadership from state officials on HIV policy development.
- Survey residential program managers, workers, and clients to assess HIV-related needs.
- Request uniform HIV-related licensing requirements for all state-funded residential programs.

Mid-term

- Work with the Bureau of Health (or other state office responsible for HIV policy development) to institute policies for uniform treatment of residents, employees and guests who are infected with HIV.
- Secure state funding for periodic, high-quality, comprehensive HIV education and training for management, staff and clients. (HIV education should be provided to staff prior to offering it to clients, in order to allay misconceptions and fears, and to ensure staff cooperation.)
- Make sexuality education and condoms available to potentially sexually active clients in all state-funded residential programs.
- Allocate or obtain funding necessary to carry out policy and program mandates.

Long-term

- Evaluate and modify (as necessary) all HIV policies, protocols and programs

Homeless Shelters for Adults, Children and Families

This section addresses shelter programs for the “general” homeless population rather than for those who are homeless with a specific focus (such as domestic violence shelters or substance abuse facilities). They include licensed shelters for children and adolescents, shelters serving only adults, and shelters serving families. Maine has six youth shelters that in 1993 reported serving a total of 1,599 clients. According to data compiled by the Maine State Housing Authority (MSHA), 13 adult shelters provided 37,479 nights of shelter to 3,123 clients (single adults and families with children) in the first six months of 1994. Maine has other shelter programs that are operated primarily by religious groups, who do not report to MSHA.

The people served in these programs are designated as “homeless,” that is, not having a fixed or adequate nighttime residence. The circumstances that have led them to homelessness include child abuse and neglect, loss of employment, poverty, family crisis, substance abuse problems and mental

illness. Services provided by shelters also vary, although basically a shelter is a place to spend the night. Some shelters are open only at night and some provide a daily meal. Adolescent shelters may provide 24-hour care, food, counseling, transportation and education.

Reaching the Homeless Where They Live

"Portland has the largest caseload in the state of homeless people with HIV," says Nate Nickerson, director of adult health services for the city. "This is a vulnerable population. There is mental illness, substance abuse, poverty. And homeless persons are very much over-represented in the numbers of HIV+ people."

It is hard to negotiate risk factors, he says, when survival is a more pressing issue. "Sexuality, like cigarettes, becomes the currency of the street," Nickerson explains. "And most of these people have neither the tools nor the power to negotiate anything." He goes on to explain that availability of condoms is not the problem. Neither is knowledge—many of these people have had 'AIDS 101' in testing and counseling sites. They even know their HIV status, he asserts. But sexuality as an issue for homeless people raises a whole lot of problems, only one of which is safer sex practices. And, says Nickerson, "traditional textbook interventions may not be useful or possible."

For more than six years Nickerson has represented the Maine Coalition for the Homeless on the Maine HIV Advisory Committee. He knows shelters, clinics, outreach, substance abuse and mental health intervention from many perspectives, and in general he



tries to put services where the people are, rather than have people come to him.

The city of Portland runs a homeless health program through shelters and walk-in clinics. Primary health care, basic information and education on a variety of health issues, and even trainings are provided free of charge to people on the street. The city runs an anonymous HIV testing site, easily accessible for homeless people. The program also trains staff of shelters and other service providers in Cumberland and York Counties on homeless health issues, including HIV. Nickerson says these health and HIV prevention services need to be in place in any program for the homeless, but the individuals carrying out the services need to be considered an integral part of their effectiveness. A condescending attitude can negate a whole lot of help.

He continues, "In the healing profession, the number one tool is you, and your relationship with that person."

The following information was gathered from the eight programs that responded to a questionnaire designed and distributed by the Maine AIDS Plan project. Shelters that serve homeless adults were under-represented in the responses.

All of the shelter programs responding had some type of HIV/AIDS education for staff, most of which was provided by an outside agency. It is unclear how many of the staff were included in this training. Most respondents also reported some form of client education, offered individually or in groups. All of the youth shelters have sent some staff to the 3-day High-Risk Adolescent AIDS Prevention training (sponsored by the Department of Education); several programs send staff on a regular basis. One shelter requires all staff to attend this training, and one has an ongoing HIV prevention program for clients. Five of the eight programs have condoms available for clients on-site.

Issues

Homelessness as an HIV-Risk Factor

A significant portion of Maine people (16%) who tested positive for HIV in 1993 were homeless. Homelessness is a real factor in increasing a person's risk of HIV infection.

Lack of HIV programming

Only one shelter program provides regular prevention information, counseling and support for HIV antibody testing. Several were connected to a local AIDS service organization (ASO) for staff training.

Lack of Resources and Training

According to respondents, the barriers to providing HIV prevention education are lack of time, money and adequately-trained personnel. The special problems of a transient population who are in crisis (and who have many other needs) also complicate matters for these providers.

Vague and Inconsistent Regulations

All of the programs studied were licensed by one or more of the following licensing bodies: Department of Human Services (DHS), Department of Mental Health (DMH), Office of Substance Abuse (OSA), and the City of Portland. All but one program had policies regarding clients with HIV as well as policies covering confidentiality of HIV status. Several had two licenses and one had three. One agency noted that they needed clarification of vague and conflicting rules (and laws) that hampered interpretation of their policies.



- State funding agencies: Provide regional, adequately-funded, periodic training for all shelter providers in prevention education, counseling techniques, referrals, and HIV-related interventions. Include funding for stipends for shelter staff attending training off-hours, or for substitute shelter coverage.
- Shelters and AIDS service organizations: Begin coordinating with one another to provide services and referrals.
- Shelters for adults: Provide condoms and education on their proper use to clients in all facilities.
- State licensing agencies: Coordinate with one another to develop uniform HIV-related licensing requirements for all shelters.
- All shelters: Develop HIV policies that address the safety & confidentiality of personnel and guests in homeless shelters, making sure that infection-control protocols are consistent with OSHA regulations.
- All shelters: Provide free health-care clinics that offer nursing care, basic health education, materials and referrals.

Battered Women's Shelters

The Maine Coalition for Family Crisis Services is an association of ten domestic violence programs from Caribou to Sanford. All of the member agencies have shelters or safe home networks or both. They also have other services, such as hotlines, outreach, support groups and education groups.

The most recent data published (1993) show that 6,786 individual clients were served in 1993 by nine member agencies (the 10th member is new). The shelter/safe-home programs accumulated a total of 17,670 clients, with 43% of their clients women, 57% children and .2% men.

Domestic violence programs in Maine must comply with OSHA blood-borne pathogens standards; they must offer employee training in the areas of infection control and infectious disease information.

Nine of the ten Coalition members have provided HIV education and training for the staff and volunteers. The programs range from annual sessions with AIDS service organizations to "as-needed" programs—one agency held two training sessions in four years; another agency last held a training program three years ago; one agency has had no staff training at all.

Three Coalition members reported that they provide HIV information or education services to clients. One agency distributes condoms to clients; one gives out HIV information at client request; and one provides information and printed material from the same AIDS Service Organization (ASO) that conducts the annual staff training. No specific HIV-related services were reported. Four of the ten agencies have some type of HIV policy for personnel, but the content varies widely. One agency has added "HIV status" to an existing fair-treatment policy for employees. Another agency has an infection-control policy but nothing else. One agency's policy contains a section pertaining to life-threatening illnesses.

Two agencies have HIV policies for clients as well as for personnel. Another agency is in the process of writing a client policy for its shelter program. None of the other programs has an HIV policy for clients.

Because the clients of domestic violence shelters are predominantly women and children, it is likely that providers do not feel compelled to offer HIV prevention services. But the number of Maine women becoming infected with HIV is growing—in 1993 over 15% of all who tested positive were women. Over half of that number were infected through heterosexual sex. Women in abusive relationships may be particularly at increased risk for HIV infection, since they often have little knowledge of—or control over—their partner's activities.

Women in abusive relationships may be particularly at increased risk for HIV infection, since they often have little knowledge of—or control over—their partner's activities.

Issues

There is a lack of consistency in HIV training programs for staff and volunteers at family violence facilities;

No policy exists at the licensing level regarding distribution of HIV education information and safer-sex materials to clients;

Women may be mistakenly viewed as not-at-risk for HIV.



The Maine Coalition of Family Crisis Services:

- Develop a comprehensive HIV-related policy for all battered women's programs. Policy should include:
 personnel policies,
 client policies, and
 infection-control protocols consistent with OSHA regulations;
- Identify barriers to offering prevention education to clients, and then address those barriers;
- Provide regular training for all staff and volunteers on HIV-related topics;
- Provide routine HIV education, information, and referrals for clients, as well as free condoms and dental dams;
- Provide support for clients who are HIV+ or who request HIV counseling and testing.

Correctional Facilities

The state's residential corrections system consists of four state prisons, 16 county sheriff's departments, and the Maine Youth Center (MYC). County sheriff departments are administered by each county but are operated according to Department of Corrections (DOC) guidelines, which are adapted to fit each site. Levels of security and types of services vary for each facility.

As of September 1994, 1,449 adults were incarcerated in the state of Maine's correctional facilities. A DOC spokesperson estimated their office knew of nine inmates who were living with HIV or AIDS. Because inmates don't have to be tested, the actual number is probably higher.

The Maine Youth Center (South Portland) is Maine's only correctional facility for children and adolescents. Its population ranges between 200 and 260 youth, the large majority being male. Virtually all of the youth are under 18 years old (although special circumstances sometimes dictate that a juvenile can be held past his 18th birthday). While the Youth Center provides some social services, such as substance abuse counseling, and has an on-site school, its primary function is detention.

For example, HIV education sessions for residents that used to take place in the intake cottage have been discontinued. Condoms are still designated as "contraband" in the institution.

Under a contract with Planned Parenthood of Northern New England, all residents of the Maine Youth Center annually receive eight hours of education on HIV disease and sexuality; health education is also provided in the school. However, because it is reported that MYC has no money for staff training, HIV training beyond the minimal OSHA-mandated training on bloodborne pathogens has been sporadic. For example, three years ago several staff attended a three-day training on High Risk Adolescent AIDS Prevention (sponsored by the Department of Education), but not since.

Some of MYC's policies on HIV seem to reflect an inconsistency in HIV training. For example, HIV education sessions for residents that used to take

place in the intake cottage have been discontinued; and, according to DOC policy, condoms are still designated as "contraband" in the institution.

All of Maine's adult correctional facilities comply with OSHA regulations for staff training on bloodborne pathogens, including HIV. In 1994 the Department of Corrections updated its protocol in this area, and now county jails are using the DOC protocol to formulate their own policies. Among jail personnel there appears to be a high level of concern about the possibility of HIV transmission from inmates who become violent or who are bleeding at the time of incarceration.

HIV Prevention Does Time

"I want everyone to know that this was initiated by an inmate!"

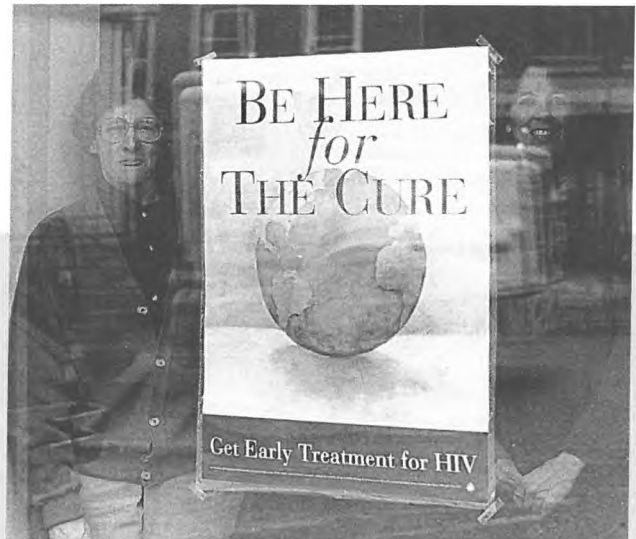
In 1991 the Waldo/Knox AIDS Coalition received a request for HIV literature from the friend of an HIV+ inmate who was afraid to tell people inside the walls of Thomaston State Prison. He got the literature, and the attention of Nan Stone, the Coalition's Director, and soon the Belfast organization began their presence in the prison with education to two different groups, one under the umbrella of substance abuse services, the other to the 'long timers.'

Nan Stone found an HIV/AIDS conference in New Hampshire that offered workshops on HIV prevention in prisons, and she took four staff people from the prison complex with her. Although her agency was able to pay the expenses, the administration made its own commitment by allowing those four to attend and paying their salaries.

In 1993 a peer education program began at the prison, with six peer educators. Their training and education included ten weeks of two-and-a-half-hour classes which included information and skills acquisition.

Some education and training for both staff and inmates of adult jails has been provided through local AIDS service organizations (ASOs) and the HIV/STD Programs of the Bureau of Health, notably at the State Prison in Thomaston. During the period from 1993-95 the Department of Labor provided three hours of training to all staff at correctional institutions in HIV, Hepatitis B Virus and TB management, covering OSHA standards.

While the DOC was aware of six incarcerated adults with an AIDS diagnosis and three other HIV+ inmates in 1994, real figures are probably higher. HIV testing can be performed on-site in some facilities, while others send



When asked about her success, Nan says, "I work hand in hand with the administration." They have made commitments to prevention efforts, support services and case management within the prison walls, and Nan Stone appreciates how far they have come in a few short years. An inmate initiated the contacts, and inmates continue to support the efforts of the Waldo Knox AIDS group through fund-raisers inside the prison, through information posters, and of course through peer leadership. And the administration, particularly in the person of Deputy Warden Bruce Wentworth, has made those activities acceptable.

Now, one day a week Mary Leigh Welch, project coordinator with the AIDS Coalition, occupies an office close to the prison library. A library pass will allow someone to stop by and talk.

inmates to local test sites. Inmates with HIV disease are sometimes treated in the prison; other times they are referred elsewhere for services.

At the Youth Center, an on-site nurse performs confidential HIV testing upon request. The nurse also provides pre- and post-test counseling. While accurate numbers of HIV+ juveniles are unknown, it is reported that there are no links with ASOs for referrals or case management. Neither is there money for transporting clients to these services.



Because the DOC's policy on confidentiality of HIV status is more loosely defined than that of DOE, Youth Center staff report different interpretations of the "need to know" clients' HIV status.

The DOC administers both the adult and juvenile correctional systems. The school at the Youth Center is licensed by the Department of Education (DOE). Because the DOC's policy on confidentiality of HIV status is more loosely defined than that of DOE, Youth Center staff report different interpretations of the "need to know" clients' HIV status. The HIV Advisory Committee organized a subcommittee on Criminal Justice and HIV, to look into these and other issues. This subcommittee, which had representation from various sectors of corrections and law enforcement, AIDS service organizations, substance abuse experts, and the Bureau of Health, produced a report in the summer of 1995. The report detailed the extent to which staff of correctional systems and police departments took part in HIV-related trainings. It also provided recommendations for future programming. A summary follows.

Issues

Lack of funding for current resident education and future staff training;

Lack of coordination between correctional facilities and AIDS service organizations to meet needs of residents;

Condoms, which protect against HIV, are not allowed in the Maine Youth Center.

HIV Advisory Committee Criminal Justice Training Sub-Committee Report, August, 1995

Recommendations Summary

This committee was convened at the request of the legislature to provide further information and guidance on program and policy within the criminal justice system on HIV/AIDS.

Education Recommendations

Staff Training: address the issues of liability, safety, confidentiality laws, and dispel myths

1. The bloodborn pathogen (BBP) curriculum cover the following:
 - psychosocial aspects of BBP/HIV on and off the job
 - modes of transmission; disease process
 - occupational exposure controls
 - anonymous/confidential testing and counseling
 - prevention on and off the job
 - post-exposure procedures
 - community resources
 - legal issues, covering OSHA, ADA, ME Human Rights Act, confidentiality laws and liability
 - policies and procedures
2. Add BBP training to all Criminal Justice Academy new officer trainings
3. Consider a fulltime DOC BBP/HIV educator

Inmate Training:

1. Require court-ordered HIV education programs for all inmates convicted of violence, sexual offense, drug or alcohol abuse
2. Mandatory HIV education for all inmates seeking good time credit and other benefits, and as a release pre-requisite
3. Support inmate peer education efforts
4. Emphasize HIV education for younger inmates
5. Make free HIV literature available to inmates

Policy/Procedures

1. Availability of confidential/anonymous testing for all inmates
2. Anonymous testing on-site by State-certified HIV antibody counselor
3. Align DOC policy to support medical record confidentiality law
4. Allow for inmates to become State-certified HIV antibody counselors
5. Condom availability in all facilities
6. Availability to inmates of HIV prevention materials with explicit safer sex information
7. Standardization of policies, procedures and training through Maine law enforcement agencies and departments
8. Basic HIV education for all Criminal Justice Academy graduates

Services (In addition to those identified in Policy/Procedures)

1. Support system for HIV+ inmates including access to hotline, buddy system, case management
2. Discharge planning should include referrals to medical, social services and AIDS service organizations
3. Substance abuse treatment and condoms should be provided to both County and State inmates
4. Condoms should be made available to inmates going on furlough
5. Hospice care program should be established and provided for inmates in late stages of AIDS.
6. Compassionate release/medical furlough for late-stage HIV+ inmates should be legislated



The Department of Corrections and the Criminal Justice Academy:
Develop regular, in-house staff training on HIV issues (such as confidentiality and infection control).

- Link with the AIDS service system for case management and medical care of HIV+ inmates.
- In DOC facilities provide condoms and education on their proper use.
- Organize private support groups for people affected by HIV inside the facility.
- Invite people with HIV infection to give presentations to staff and inmates.
- Incorporate findings of HIV Advisory Committee Report on Criminal Justice and HIV Training.

Substance Abuse Facilities for Adults and Adolescents

Residential substance abuse treatment facilities include hospital-based treatment programs for adults and adolescents (generally lasting 28 days), detoxification centers, and halfway houses or group homes. According to the Office of Substance Abuse (OSA), in fiscal year 1993, state programs of this type admitted a total of 2,000 people. Basic services include:

- detoxification;
- individual, group and family therapy;
- self-help support groups; and
- aftercare (ongoing, weekly outpatient sessions following inpatient care)

Approximately ten% of those receiving services report a history of injection drug use.

Training for substance abuse counselors on HIV issues has been coordinated by OSA, which sponsored a "train-the-trainers" conference in 1989. The basic two-day course has been offered sporadically since then. Approximately 120 licensed substance abuse counselors have completed the HIV course. Many staff of substance abuse facilities who work primarily with adolescents have attended the three-day High Risk Adolescent Prevention training course sponsored by DOE. Residential centers are all required to comply with OSHA regulations for training on universal precautions for bloodborne pathogens. (*Also see chapters "Populations & HIV: Substance Abuse" and "Settings and HIV: Social Services, Mental Health and Substance Abuse Treatment"*).

Issues

A strong link exists between increased substance use, decreased judgment and increased risk for HIV. Yet very few resources and little emphasis is placed on HIV prevention education for substance users.

HIV training of treatment personnel is sporadic.

HIV-infected residents need to connect with AIDS service organizations (ASOs) before leaving their facilities.



Substance Abuse Treatment Centers:

- Require periodic, comprehensive HIV training of all employees, with a focus on the interactions between substance abuse and HIV infection.
- Create stronger ties between ASOs and substance abuse programs to facilitate referrals and services.
- Institute HIV-related policies for personnel and clients, as well as infection-control protocols consistent with OSHA regulations.
- Make sexuality/HIV education, referrals and condoms available to all clients.
- Provide support for clients who are HIV+ or who request HIV counseling and testing.

Group Care and Foster Homes for Children

Group care facilities and Department of Human Services (DHS) foster homes provide services to children from birth to age 21 in foster homes and in Transitional Living Programs (for age 18-21). In Maine, approximately 25 group care facilities house 400 to 500 youth, most of whom are adolescents. Foster homes care for another 1,800 children from birth to age 18 who are in state custody.

Group care facilities for children range in capacity from six beds to over 150 beds. The level of service provided by each program also varies, but most are community-based and refer residents to local providers for specialized services.

It is important for service providers to recognize that the youth in their care have a higher-than-average risk for HIV. About half the children in group care are in DHS custody, having been removed from their homes due to serious abuse, neglect or abandonment. Others are runaways, homeless clients or residents of DOC facilities. Most of the youth in these programs have personal or family histories which include substance abuse, mental health problems, physical or sexual abuse, family violence, and school problems. Many move from one facility to another, with stops in foster homes, shelters, the Maine Youth Center, and on the streets.

Youth in group care have a higher than average risk for HIV.

The most extensive staff training available in Maine is the High Risk Adolescent AIDS Prevention (HRAP) training offered by the DOE.

HIV prevention activities vary widely, from agencies with fairly intensive in-house training to those with no HIV policies or training. Most group homes refer youth to local family planning and health care facilities for information, counseling and testing, rather than having their staff handle these issues.

The most extensive staff training available in Maine is the High Risk Adolescent AIDS Prevention (HRAP) training offered by the DOE. This workshop is designed specifically for service providers who work with out-of-home youth.

Funds are available to cover some costs of replacing the HRAP attendees while they are at the workshop. Eleven of the 25 group homes have sent staff to HRAP training since 1990, with a total of 57 staff participating. Three or four foster parents from therapeutic foster home programs have also attended, as have many DHS caseworkers.

DHS licensing regulations do not require group care facilities to offer staff training on HIV issues. Neither do foster parents receive specific training, yet they (and DHS workers) are responsible for teaching their foster children about HIV-related issues. Workshops designed for foster parents have been poorly attended.



HIV Prevention In a Youth Shelter

"Change is hard, and we have staff who go beyond talking about it to doing it." Robert Rowe, Director of New Beginnings in Lewiston, a residential program for at-risk youth, is referring to the inclusion of HIV prevention in their program. "We always sent kids directly to Family Planning," he explains, but the staff initiated an internal shift.

"Mary Ruchinskas [now the HIV prevention program director] led the effort to develop the policies and helped us to think about the issues. One barrier we had to address was how to make the model work around the people we serve, rather than around the people offering the service." Rowe and his staff not only wrote "Policy 23: Policy and Procedures for HIV Infection and Disease," but also designed and implemented HIV prevention education and other efforts for individuals using the services of New Beginnings. Adopted in June 1990, the comprehensive nature of "Policy and Procedure" attests to the commitment of this team.

"My role is very political," says Rowe, speaking of his role with the board. "I get the stamp of approval. But of all the things that have made a difference in implementing the HIV policy, it is having other people committed to making it happen."

But the policy wasn't without controversy. New Beginnings had some board members resign over the language of this policy and related issues. "We distribute condoms, we have non-discriminatory hiring practices, we talk in the language of the youth we serve," Rowe explains.

Many days the realities of stabilizing young lives in the face of addiction, suicide, and splintering families are all that staff can manage. It's not easy running a shelter, plus offering a 10-session HIV curriculum to clients who come and go. "Kids are busy," Rowe says plainly. But the HIV prevention efforts go on, mixed in with large amounts of real life and an occasional affirmation that the effort is worth it. Recently one youth wrote on a feedback form after an HIV education session—"Thanks for being concerned for my safety."

Inevitably, foster parents have a great deal of discretion as to the nature of the HIV education they provide and how it will be offered. Condom availability is determined by the foster parent, DHS worker and family physician.

In group care settings, condom availability varies. A minority of programs make condoms available; others report “indirect” accessibility. Client education is most often handled by outside agencies for both group care and foster care homes. Very few programs have an ongoing HIV education program for youth. And no group homes offer specific services to youth with HIV.

Issues that prevail among the youth in group homes and foster care are those stemming from histories of sexual abuse and/or perpetration, which require sensitive handling in the context of HIV prevention education. This age group is characterized by widespread denial of personal risk, as well as extreme transience. Providers report that the youth they serve are at least as sexually active as the youth population at large, if not more so. (A DOE survey found that 91% of out-of-school youth have had sexual intercourse.) The widespread presence of homophobia in group care settings is another complicating factor in presenting HIV education; few programs have dealt with this issue effectively.

All agencies are required to have policies covering universal precautions for infectious diseases. Most foster parents also follow these policies. However, debate continues over confidentiality of HIV test results. Many agencies and foster parents feel they are in a unique position where they should know if a client is infected.

On the state level, different policies exist among DHS, DOC, and the Department of Mental Health and Mental Retardation (DMHMR). The fact that many providers rely on more than one funding source (and licensing agency) adds to the general confusion and lack of clarity over policies.

Agency directors report that their attempts to get state officials to clarify state and federal laws have resulted in frustration. Some directors have been told to have their agency’s lawyer develop policies and procedures, as no guidance is forthcoming from the state level.

A DOE survey found that 91% of out-of-school youth have had sexual intercourse.

The fact that many providers rely on more than one funding source (and licensing agency) adds to the general confusion and lack of clarity over policies.

Issues

The clientele of group homes and foster homes has a higher risk for HIV due to esteem issues and a tendency toward recklessness.

A wide disparity exists in the types and extent of HIV prevention activities carried out in facilities.

HIV issues are not required training for group home managers.

Homophobia is an obvious barrier to presenting clear, accurate information about HIV to residents and staff.

A lack of agreement exists (and thus lack of uniformity in policies) regarding confidentiality of a client’s HIV status.

ACTION STEPS



- DHS:
 - Develop a fundamental HIV policy that will dictate specific HIV-related licensing requirements for group homes and foster care facilities.
 - Issue statement which clarifies confidentiality regarding HIV status of a client and identifies the specific exceptions which allow for disclosure.
- DHS and other state agencies who fund these facilities: Develop funding to support regular in-house training programs and to encourage participation in existing training programs.
- Group homes and foster care facilities:
 - Institute HIV-related policies for personnel, clients and infection control according to OSHA and state regulations.
 - Develop comprehensive HIV prevention education for staff and youth which also offers referral information and free condoms.

Residential Treatment Facilities for Children

Residential Treatment Centers have special education programs and therapeutic programming on-site for all residents. Placement in these facilities requires a recommendation from a school's Pupil Evaluation Team (PET) and is most often made as a result of emotional or behavioral problems which cannot be dealt with in a public school setting. Three agencies in Maine provide these services for children aged six through twenty.

These programs annually provide all direct-care staff with specific training on infectious diseases and universal precautions as mandated by OSHA. Two programs also report training staff on HIV awareness and education as it pertains to workplace and client needs. One agency holds this training annually and another has offered it every three years. Staff from two agencies have also attended the High Risk Adolescent AIDS Prevention (HRAP) training.

Education in sexuality and HIV varies from program to program. One has a Sexuality Education Task Force that coordinates training, education and awareness, and which has created a developmentally-focused sexuality education curriculum that includes HIV. All students participate during the school year. Another agency reports that sexuality education for clients is determined on an individual basis as part of the youth's individual treatment plan. A sexuality education curriculum is also available.

None of the programs report having any medical treatment services on site. One program provides individual risk assessments, pre-test counseling and referrals for HIV testing, as well as referrals to ASOs for clients and their family members. Staff report that issues related to HIV+ family members are becoming more common.

All programs have policies that cover infectious disease precautions, discrimination and confidentiality regarding HIV. One agency bases its confidentiality policy on that of the public schools, with strict guidelines on

Staff report that issues related to HIV+ family members are becoming more common.

release of information. The primary physician who has information on HIV status communicates this information only on an “absolute-need-to-know” basis, with the permission of the child’s guardian.

Residential treatment centers must be licensed by DHS, DMHMR and the DOE. No specific HIV directives exist in the licensing regulations.

Issues

All centers should receive uniform trainings on HIV regularly. Increasingly, HIV is affecting family members of students.



Department of Human Services:

- Require HIV-related training for both staff and youth, including risk-assessment and skill-building.
- Require training on how to work with youth and/or family members who are HIV+.
- Identify HIV educational resources specific to this special-needs population.

State Mental Health Institutions (AMHI/BMHI/Pineland)

Pineland is Maine’s institution serving persons with developmental disabilities. Under the terms of a federal consent decree, the Department of Mental Health and Mental Retardation (DMHMR) has been transferring residents from Pineland into community-based settings over the past decade. Only a small number of people still live there, all under the age of 21, and the institution will be empty by 1997. The residents who remain there need intensive care.

The Augusta Mental Health Institute (AMHI) and Bangor Mental Health Institute (BMHI) serve adults with mental illness. Each of these institutions has also reduced its client population over the past few years in favor of community placements. In 1991 AMHI closed its adolescent unit.

Staff at each institution receive mandatory training on infectious diseases and universal precautions. It is not known if additional training on sexuality issues is offered. Education for residents is limited. Every resident of Pineland has a guardian who must approve of any education, intervention or care. It has been difficult to gain permission from guardians for sexuality education. The limited amount of educational materials which have been created for special-needs populations is another problem. Sexual behavior among the residents is practiced, though officially prohibited.

At Pineland, condoms are not available unless they have been approved for a specific resident. HIV testing and medical care for HIV+ residents can be performed on-site with guardian approval. BMHI has a policy regarding the

The limited amount of educational materials which have been created for special-needs populations is a problem. Sexual behavior among residents is practiced, though officially prohibited.

admission and treatment of people with HIV. Testing may be offered, but written informed consent from the client is required.

These institutions are subject to the DMHMR's licensing regulations. They must comply with HIV policy on confidentiality and discrimination. The Department has begun developing a policy regarding sexuality, but it is still only in draft form. There appear to be different interpretations among staff of who has a "need to know" regarding a resident's HIV status, so the policy is variously interpreted.

Issues

Residents have limited or no access to HIV prevention education.

Very few available educational materials address this population's specific HIV issues.



There appear to be different interpretations among staff of who has a "need to know" regarding a resident's HIV status, so the policy is variously interpreted.

Department of Mental Health and Mental Retardation:

- Clarify any confusion regarding HIV-related policies.
- Train all direct-care staff of each institution in the implementation of policies.
- Provide training to staff on all aspects of HIV.
- Identify educational resources that are available for clients, and ensure clients' access to them.

Resources

Bureau of Child and Family Services
 State House Station #11
 Augusta, ME 04333
 207-287-5060

Bureau of Mental Health
 State House Station 40
 Augusta, ME 04333
 207-287-4230 or 207-287-4238
 TDD: 207-287-7285
 FAX: 207-287-7286

Bureau of Mental Retardation
 State House Station 40
 Augusta, ME 04333
 207-287-4242

Department of Corrections
 State House Station 111
 Augusta, ME 04333
 207-287-2711
 TDD: 207-287-4472

HIV Advisory Committee
 Subcommittee on HIV and Criminal Justice
 c/o Red Cross
 524 Forest Avenue
 Portland, ME 04101
 207-874-1192

Maine Coalition for Family Crisis Services
 PO Box 89
 Winterport, ME 04496
 207-941-1194

Maine Coalition for the Homeless
 PO Box 415
 Augusta, ME 04332
 207-626-3567

New Beginnings, Inc.
 (youth-serving residential program)
 436 Main St.
 Lewiston, ME 04240
 207-795-4077

Office of Substance Abuse
 Information/Resource Center
 Stevens School Complex
 State House Station 57
 Augusta, ME 043303
 207-287-6330
 TDD: 207-287-4475
 FAX: 207-287-4334

Portland Homeless Health Program
 389 Congress St. #305
 Portland, ME 04101
 207-874-8300

Social Services, Mental Health Agencies and Substance Abuse Treatment Programs

- Social Services (non-residential):
 - AIDS Service Organizations
 - General Assistance: CAP Agencies, Municipal Offices
 - Crisis Support: Hotlines, Sexual Assault and Domestic Violence Services, Red Cross
 - Legal Services: Pine Tree Legal, Elderly, Law Clinics
 - Veterans' Centers
- Mental Health
 - Private Practitioners: LCSWs, LCPCs, psychologists, psychiatrists, pastoral counselors, clergy
 - Community Mental Health Centers
 - State Government
- Substance Abuse Programs
 - Inpatient and outpatient treatment providers
- State Mental Health offices

Because HIV is a public health concern, individuals and agencies that work with the public—providing counseling of substance abuse treatment and other social services—can take a lead role in promoting HIV prevention. A few agencies and individual practitioners have established notable HIV-related protocols and standards, particularly those whose clientele appear to have a heightened need for HIV awareness—sexual assault victims, for example, or IV-drug users. On the whole, however, Maine's mental health services, social support services, and substance abuse treatment programs (those offered separately from health or residential services) are not at all uniform even within their own disciplines in terms of awareness and response to HIV.

For many people seeking assistance, HIV education and risk assessment are secondary to their presenting concern. But all mental health practitioners and providers of social service and substance abuse treatment are in advantageous positions to help such individuals assess their risk for HIV, and to then direct them toward further assistance, whether anonymous testing and counseling or prevention education.

General Recommendations

- All state-funded and licensed facilities and practitioners:
 1. Conduct needs assessment on HIV policy and program.
 2. Provide all personnel with comprehensive training on HIV, including client risk assessment. (*For sample risk assessment guidelines, please see information sheet on page 12.*)
 3. Incorporate HIV risk assessment in client services.
 4. Develop cooperative agreements with local AIDS service organizations (ASOs) to provide and target services more effectively.

5. Provide leadership to increase HIV awareness and service delivery within state and national professional associations, in conjunction with local and state AIDS organizations.



Immediate

- All mental health/mental retardation, social service and substance abuse treatment settings:
 - Assess the need for HIV policies and programs. Survey: management, workers and/or union leadership, mental health/social service/substance abuse treatment officials and clients.
 - Establish a relationship with local and state AIDS service organizations (*for a list of ASOs, please see Resource Section*).
 - Request and expect leadership on HIV-related issues from: the Bureau of Health, Department of Human Services, Department of Mental Health/Mental Retardation, State HIV Advisory Committee, Office on Substance Abuse, Maine's religious leadership, state professional associations
- Elected representatives; government officials; mental health, social services, substance abuse treatment officials; management; workers and union leadership:
 - Provide uniform, up-to-date HIV policies in all state funded or licensed mental health/social service/substance abuse treatment settings. Policies should address:
 - confidentiality;
 - prevention education;
 - discrimination;
 - infection control;
 - care of HIV-infected staff and clients.
 - Provide comprehensive, up-to-date HIV education programs for all employees which promote:
 - accurate understanding of HIV and related risks;
 - tolerance for diversity of gender, race, ethnicity, language, sexual orientation and other conditions, beliefs and behaviors;
 - comprehension of the effects of homophobia and the need to eliminate it.
- All mental health/social service/substance abuse treatment alliances and professional organizations, such as Maine Psychological Association; Maine Psychiatric Association; National Association of Social Workers, Maine Chapter; Maine Council of Churches; Maine Association of Substance Abuse Providers; Licensed Clinical Professional Counselors:
 - Conduct needs assessment regarding HIV-related concerns;
 - Develop HIV task forces, policies and membership education programs.

Long-term

- All providers:
 - Investigate development of outreach program offering services to populations with increased risk for HIV.
 - Obtain and allocate funding for all HIV policy and program mandates.

Social Services

- AIDS organizations
- General Assistance
- Crisis Support
- Legal Services
- Veteran Centers
- State Government Social Service Offices

Many social service agencies offer multiple services. Those that provide health and welfare services—such as city health departments, family planning clinics, hospice programs and anonymous testing sites—can be found in the “Settings and HIV: Physical Health Care Sites” chapter on page 93. Descriptions of agencies that provide residential programs as well as social services—such as substance abuse treatment centers and programs for abused women—are located in the “Settings and HIV: Residential Facilities” chapter on page 139.

Agencies and individuals that primarily offer support services and not shelter or health care are discussed below, though this is by no means an exhaustive list of types of providers in Maine.

Because HIV disease is long-term, many people with HIV are forced to deplete their financial resources and eventually request public assistance. Most publicly-funded social welfare agencies offer services free of charge, or for nominal fees. In fact, many of them rely on trained volunteers to carry out their service missions.

But are Maine’s social services prepared for HIV? Are providers ready to work respectfully with HIV+ patients? And are staff knowledgeable about their own risk for HIV infection? Irrational fear or lack of information may result in inadequate provision of services.

Perhaps even more importantly, front-line workers can provide the invaluable service of helping individuals determine their own risk for HIV and the steps to prevent it.

Currently, most social service agencies that lack a health or residential component have not significantly addressed HIV. However, a few specific agencies, such as People’s Regional Opportunity Program (PROP) in Portland and some individual practitioners, have established notable protocols and standards in client assistance.

AIDS Service Organizations (ASOs)

As HIV rates began increasing in other parts of the country, the knowledge that the same thing would eventually happen in Maine inspired the development of community-based organizations to assist people who have HIV infections. In 1985, The AIDS Project was founded in Portland. Over the next ten

years many other agencies and organizations were founded to meet the needs of local people with HIV and their family members.

In 1987 and in 1989, the state legislature appropriated funds to support the work of these community-based organizations. This funding helped to establish the Maine AIDS Alliance, an umbrella organization of these local agencies. The goals of the Maine AIDS Alliance are:

- to assess HIV/AIDS needs and issues in Maine;
- to present a unified voice in addressing those needs and issues;
- to coordinate community-based services and education efforts through the sharing of resources;
- to encourage and assist in the development of community-based organizations in under-served areas of Maine;
- to acquire and distribute funds;
- to provide a forum for the exchange of support, professional skills and technical resources to Alliance members.

Fourteen AIDS service organizations (ASOs) currently provide a variety of education and support services in Maine, depending upon local needs and the availability of funds. These agencies are funded by state and federal monies made available through grants from the State Department of Human Services, Bureau of Health, Bureau of Child and Family Services, local United Ways, Medicaid fees, client fees, other public and private sources, and substantial agency resource development.

Currently five ASOs also provide case management to people with HIV/AIDS. They link clients to social services, health care, drug reimbursement programs and assist them in applying for benefits. As of this writing, approximately 330 clients are assigned to eight case managers statewide.

In 1994, Maine's HIV case management program (which includes money for drug reimbursement and for the AIDS Lodging House) was funded by \$246,311 in state funds and \$163,401 in federal Title II (Ryan White) funds. As much as one quarter of an individual agency's case management budget is supplied by Medicaid fees and private donations.

The Maine Bureau of Health's HIV prevention education program was funded by \$180,154 of 1994 state funds. Supplemental federal funds of \$28,000 were also available that year, jumping to \$560,000 in 1995, due to grassroots lobbying efforts and support from the Center for Disease Control, the federal agency that oversees HIV funds. (This level of support is not expected to continue, however.) While Maine's ASOs are not set up to be self-supporting, up to one-quarter of an individual agency's budget for prevention education comes from fees for service and private donations. Together, the agencies provide hundreds of educational sessions for thousands of people statewide each year. Those served are primarily thought to be at higher-than-average-risk for HIV, and include people of all ages.

All of the AIDS service organizations have policies that address confidentiality for clients, staff and volunteers.



■ All AIDS Service Organizations:

- Develop cooperative agreements with area service providers—CAP agencies, substance abuse treatment centers, mental health centers, shelters, etc.—for referrals, client education, staff training and HIV prevention program development.
- Work with the state to establish:
 - uniform evaluation of programs
 - uniform standards for case management services and prevention programs
 - internal quality assurance mechanisms for services provided
 - training for thorough assessment of mental illness and substance abuse
- Work with state to increase state and federal funding for ASOs
- Create supportive services to staff regarding serial losses they experience to prevent burn-out.

General Support Services

(Community Action Agencies, Municipal Social Service Departments, and General Assistance Offices)

Community Action Agencies

Eleven community action agencies from all parts of Maine are members of the Maine Community Action Association (MCAA). The services offered by these agencies include:

- housing
- health
- economic development
- employment assistance
- transportation
- information and referral
- crisis intervention
- law and special services for children and the elderly.

The mission of MCAA is to empower low-income people to lift themselves and their families out of poverty. The funding is a mix of federal, state, local and private sources, with the largest share coming from the federal government.

Four of the 11 agencies provide anonymous HIV counseling and testing, along with a variety of family planning services such as medical exams, sexually-transmitted-disease diagnosis and treatment, and birth control services.

Another of the agencies, the People's Regional Opportunity Program (PROP), in Portland, works closely with the case management program at The AIDS Project to provide social work services to people with HIV infection.

In 1993, PROP created an exemplary HIV-related policy for its own program. Strong and fair-minded, up-to-date and detailed, the policy covers concerns related to infection control, confidentiality, education and training for staff, and education for clients. PROP's policy (*see Appendix*) would serve as a good model for any agency that serves the public.

Employees Create a Model HIV Policy

"The staff was becoming concerned that they might have a child or parent who was HIV+," recalls Bill Gould, a parent involvement program manager with Head Start and Preschool Child Care. "In fact, we did."

"And I had a couple of clients with full-blown AIDS," explains Maurice Geffory, a direct-service case manager/social worker.

Both men are employed by PROP (the People's Regional Opportunity Program), in Portland, a Community Action Agency that administers dozens of programs (Head Start, Affordable Housing, Weatherization, WIC, etc.) designed to assist Portland-area families on the road to self-sufficiency.

"Another big hurdle," adds Gould, "was in child development. We had counselors who were doing finger sticks on children to draw blood—they felt that they had to know if any of the kids had HIV. And then the whole confidentiality issue came out."

That was in the mid 1980s, when a small group within PROP took it upon themselves to create a detailed HIV/AIDS policy for the entire organization that would work for employees, clients, and the agency itself.

"There were six or seven of us," Geffory explains, "a bookkeeper, family service worker, some mid-managers—and we looked at several policies from across the country. I worked on a draft, and the committee picked it apart. And we kept at it until we were satisfied."

"Then we began having several in-service trainings on HIV and on the agency's policy," Gould adds.



"Three of our managers went through the Red Cross training for trainers. Ever since, we've had a big drive on educating parents and parents. It's been ongoing." Part of PROP's policy (*see Appendix*) is a very clear statement that discrimination or any negative treatment of a co-worker or client with HIV would not be tolerated.

"We had a couple of people at meetings," Gould remembers. "One staff member stood up and made some very judgmental remarks. Another said she didn't want to touch the same pen that someone with HIV had used. It blew people away. Those individuals are still working with us, but with a major attitude change."

"What we try to emphasize in our training," says Geffory, "is not that you'll lose your job, but what those kinds of comments do to the other person."

"I think what also calmed them down was when they realized that they should treat all people the same way. That's why we stress universal precaution, and why we keep reinforcing it. It diffuses fear."

"Once you view HIV in the same way you look at other infectious diseases," Geffory explains, "you have a much better perspective: it's easy to prevent, and difficult to catch."

Outline of PROP's HIV/AIDS Policy and Procedures:

1. Background

Facts about HIV/AIDS, including known methods of transmission, with an emphasis on the safety of casual contact.

Commitment to educate clients and staff about HIV, with strong guidelines calling for respectful treatment of people with HIV.
2. Policy Statement

"AIDS and HIV education will be a regular and integral part of PROP's training/counseling programs for both clients and staff, in order to allay fear, misconceptions or prejudice about AIDS and HIV. Prejudicial behavior, isolation, ridicule, or inappropriate actions based on irrational fear, directed at clients or staff with AIDS or HIV infection, will not be tolerated, and appropriate disciplinary actions will be undertaken."
3. Policy for Employees

Rights and expectations of HIV+ employees

Statement on routine HIV screening (not recommended, not required)

Discrimination

 - by employer, by co-workers

Confidentiality

 - regarding HIV status and sexual orientation
 - penalties for breaches in confidentiality

Commitment by employer to provide HIV education
4. Policy for Clients

Rights of HIV+ clients

Guidelines for HIV+ clients

Confidentiality

 - regarding HIV status and sexual orientation
 - penalties for breaches in confidentiality

Commitment to provide clients with HIV education

Commitment by employer to review and upgrade policy
5. Recommended Procedural Guidelines for Specific Groups within PROP
 - food service workers
 - handling blood and other body fluids
 - cleansing and disinfecting procedures

Prejudicial behavior, isolation, ridicule, or inappropriate actions based on irrational fear, directed at clients or staff with AIDS or HIV infection, will not be tolerated, and appropriate disciplinary actions will be undertaken.

ACTION STEPS



- All Community Action Programs:
 - Develop written cooperative agreements with local AIDS service organization for consulting, training and collaborating.
 - Determine the needs of staff and clients regarding HIV.
 - Review PROP's HIV policy and develop a policy for your agency.
 - Provide comprehensive training to all personnel.
 - Develop an HIV Task Force within the Maine Community Action Association to address
 - (1) statewide Community Action Program services to people living with HIV, and

- (2) the role of the CAP Agency in HIV prevention for its client population. The MCAA Task Force should include representation from the AIDS community.

Municipal Social Service Departments and General Assistance Offices

Our cities' social service departments provide a variety of functions, though their effectiveness depends greatly on local funding. All municipalities must offer general assistance to town residents who do not have enough money for basic needs, such as rent, food, fuel and other items essential to maintaining a household.

Bangor and Portland are the only two Maine municipalities with public health departments. For income-eligible residents of those cities, the health departments provide a wide range of services, both at clinic sites and in the home: immunization, public health nursing, sexually-transmitted-disease (STD) clinics, dental services, smoking cessation, lead poisoning prevention, and maternal and infant care. Both cities' health departments also provide anonymous HIV counseling and testing, and Bangor's STD Clinic has spawned the HIV Wellcare Program, which provides a full range of HIV-related services (*see "Settings and HIV: Physical Health Care Sites" chapter on page 93*).

Other Maine communities can certainly learn from Bangor and Portland as they develop a municipal response to HIV. Obviously, smaller towns will be hard-pressed to enact any programming of their own due to a scarcity of resources. However, by law, general assistance must be available to all residents—confidentially, and without requiring recipients to reveal their HIV status.

Small town communities in Maine are known to stand by their own people and lend a hand to each other in times of need. This kind of neighborly charity can easily be extended, with a little education and leadership, to help those families affected by HIV.



■ **Municipal social service departments:**

- Contact local or state ASOs to collect information about area needs; assess municipal capacity and responsibility.
- Develop a cooperative agreement with area AIDS service providers for staff training, referrals and program development.
- Review guidelines and practices of the general assistance program to ensure its confidential availability to town residents without requiring them to disclose their HIV status.
- Secure training for all personnel and town officials, particularly those who administer municipal social services.
- In collaboration with local AIDS service organizations, institute a local task force for addressing HIV in the community.

- Provide HIV prevention information to all residents, via poster campaigns, public notices, training sessions, etc.

Crisis Support

(Hotlines, Programs for Victims and Survivors of Domestic Violence and Sexual Assault, Red Cross)

People in crisis are concerned with one thing: getting out of crisis. Often they will turn to friends, neighbors, the police, or else will call a hotline for help. While HIV may not be uppermost in the person's mind, individuals who are trained to respond to crises should be aware of how HIV might relate to the situation and be prepared to provide information.

Hotlines

Many state and local agencies offer hotline services, especially in response to certain types of crises such as domestic violence or suicide attempts. Calling a hotline is often the first step in reaching out for help. While the initial phone call may not allow the support person enough time to offer basic HIV prevention information to the caller (even if it seems appropriate), the hotline worker should have an understanding of HIV and related issues, especially since many conditions that place an individual in a crisis mode might also place the person at risk for HIV.

Maine has a specific AIDS hotline, 1-800-851-AIDS, which fields approximately 5,000 HIV-related calls a year. Run by The AIDS Project in Portland, the hotline is utilized by service providers as well as by concerned citizens.



All hotline trainers: Provide volunteers and staff with basic information about HIV, risk assessment, needs of people living with HIV, and referrals. Many issues that place people in crisis may also put them at risk for HIV.

Programs for Victims of Domestic Violence

(Please see "Settings and HIV: Residential Facilities" chapter on page 139.)

Programs for Victims and Survivors of Sexual Assault

Ten centers around the state provide hotline, support and advocacy services for victims and survivors of sexual assault and their families (*see Resource list*). In 1993 over 4,000 individuals received direct assistance state-wide, while 473 cases of rape were reported to the centers in the same period.

Generally, sexual assault victim hotlines and advocacy services are staffed by one or two volunteers per shift. All centers offer services with the philosophy of self-help—that is, they do not offer advice. The person seeking help is provided information and support to make her or his own decision. Therefore, if callers request information about HIV (i.e., sexual assault victims may

Having an HIV test show up on a medical record, even with a negative result, is a red-flag for insurance companies and can result in loss of coverage.

need clarification of their risk for HIV) that information and possible referrals will be provided; otherwise, probably not.

The Maine Coalition Against Sexual Assault (which is the statewide umbrella organization of the ten local centers) currently has no specific HIV-related protocol for its members. Most volunteer trainings cover HIV generally, as a part of the medical section. However, one center reports having a separate section on HIV, with regular, updated trainings.

Staff from at least one center, when accompanying victims to the hospital for examination, encourage persons who are considering getting an HIV test to be tested at an anonymous test site and not at the hospital. A few emergency room physicians reportedly offer the same advice. (Having an HIV test show up on a medical record, even with a negative result, is a red-flag for insurance companies and can result in loss of coverage.) This is not universal practice among all centers, however.



■ Sexual Assault Centers:

- Standardize HIV protocol and trainings around the state, addressing risk assessment, testing options, legal issues, and referrals.
- Incorporate presentation from an HIV educator during all volunteer trainings, with annual, updated trainings for staff.
- Maintain contact with local and statewide AIDS organizations.

Red Cross

The Red Cross is known for conducting blood drives and offering blankets, food and shelter to disaster victims at no cost. Being thrust into the forefront of HIV awareness, Red Cross nationally has responded by putting more emphasis on comprehensive HIV prevention.

The seven chapters of the Maine Red Cross offer HIV/AIDS education in a variety of ways. For example, at donation centers or mobile blood drive units, Red Cross staff provide potential blood donors with basic HIV risk-assessment, while also providing education on blood supply safety.

In addition, the national Red Cross has prepared ten basic HIV-related brochures that any Maine chapter will provide to both public and private organizations upon request, or they will mail the brochures to individuals:

Teenagers and AIDS

Your Job and HIV: Are There Risks?

Women, Sex and HIV

Children, Parents and HIV

School Systems and HIV: Information for Teachers and School Officials

Testing for HIV Infection

Living With HIV Infection

HIV and AIDS

Giving and Receiving Blood

A Guide to Home Care for the Person With AIDS

The Red Cross also offers standardized HIV prevention education training to schools, workplaces, church and community groups, and other organizations. The four education programs offered are:

- Community HIV/AIDS Program (two days, with a prerequisite four-hour instructor candidate training)
- Workplace HIV/AIDS program (three days, with a prerequisite four-hour instructor candidate training)
- Hispanic HIV/AIDS Program
- African-American HIV/AIDS Program

Currently, four instructor-trainers work for Maine's Red Cross chapters—two in Portland, one in Auburn and one in Bangor—providing trainings either at their chapters or on-site across the state.

In 1995, the Portland Chapter (the lead chapter for HIV/AIDS education) provided trainings to the Portland Boys and Girls Clubs, PROP, the Cumberland County Sheriff's Department, and to a group of community people. Although the Portland chapter currently provides about four trainings per year, they and other chapters have the capacity to provide many more.

Nationally, the American Red Cross has a new training for 1996 called the Prevention Skills Course, which will cover such topics as decision-making, risk-reduction and condom negotiation skills.



■ Red Cross:

- Look for ways and seek assistance to more widely promote Red Cross HIV prevention training programs
- Develop a committee of community people to assist in outreach development

Legal Services

People with HIV are faced with a wide variety of legal questions, ranging from "Do I have a right to keep my medical records confidential?" to "How do I qualify for Medicaid?" People with HIV often have a disproportionate need for legal services because of discrimination, governmental bureaucracy, and early estate planning issues. In addition the line between legal representation and general support and advocacy is often blurred for individuals unfamiliar with state and federal assistance.

In Maine, there is no central location to which all people with HIV can turn for help with their legal problems. However a network of organizations provide legal assistance on the basis of financial need, legal complaint, and medical condition. While it is a piece-meal solution, there are services designed to solve legal problems for the disabled and the indigent for which individuals with HIV sometimes qualify.

Pine Tree Legal Assistance provides free legal services for families and individuals whose income is below 125% of the poverty line (\$9,338 dollars a year for a single individual in 1995). Pine Tree Legal provides assistance

getting Welfare benefits, Medicaid, Aid for Families with Dependent Children and Social Security Disability. It will represent tenants in eviction cases, in habitability cases and homeowners in the case of foreclosure.

The Volunteers Lawyers Project will assist individuals with similar financial constraints write estate plans, file for divorce and perform other legal services.

Maine Advocacy Services assists individuals who have been discriminated against on the basis of disability. Maine Advocacy Services will represent people with HIV who have been discriminated against in housing, employment, education, medical care, public accommodations and public services.

The University of Maine Law School's estate planning clinic has provided estate planning services for the indigent and for people with HIV.

However, while many of these organizations are willing to solve problems that some individuals with HIV face, few are designed specifically to fulfill the needs of all people with HIV. Some AIDS service organizations provide legal and support services for people with HIV who are trying to receive disability benefits, who have been discriminated against, or who are trying to manage their estate.

The AIDS Project has a legal referral network which helps provide free or low-cost legal aid to many of their clients. But individuals with HIV who do not live in the Portland area are often unable to avail themselves of that service.



Attorneys, law firms, legal associations, state and county bar associations:

- receive basic HIV education and a basic understanding of HIV and gay/lesbian issues
- develop relationship with state and local AIDS organizations (ASOs)
- offer pro bono legal services to clients of local ASOs

Legal associations, Maine Bar Foundation and other funders:

- provide funding and technical assistance to develop a statewide HIV/AIDS law project to:
 - meet all the needs of individuals with HIV, including bankruptcy, estate planning, employment discrimination, Medicaid, Social Security Disability, privacy and insurance
 - offer trainings to attorneys and clients around the state
 - provide low-cost or free legal services to individuals with HIV
 - provide internships to law students
 - establish state case law which demonstrates the scope and meaning of relevant statutes

Veterans' Centers

The Readjustment Counseling Program is part of (and funded by) the Veterans Administration (VA). In Maine, five "Vet Centers" (located in Lewiston, Bangor, Portland, Caribou and Sanford) offer readjustment counseling services, such as crisis intervention, medical referrals, VA benefits information, employment counseling, substance abuse counseling, and counseling for families, couples, groups and individuals.

Counselors at each site include HIV as a potential problem area on each client's intake sheet. Further information and/or counseling occurs as necessary.

Although this type of program was mandated by the U.S. Congress to meet the needs of Vietnam era vets, currently the program serves those who served in the conflict zones of Vietnam, Lebanon, Panama, Grenada, Persian Gulf and Somalia. Those who served in World War II or in the Korean conflict are not eligible for these services, although they may take advantage of the medical and mental health services provided by the Veterans Administration Medical Center (VAMC) in Togus, Maine.

Each of the five vet centers in Maine has an HIV coordinator who has received extensive training through the VA. While there is no state-level HIV coordinator, each center is supported in all of its work by the "support facility," the VAMC at Togus. Personnel training sessions have been organized by a different center coordinator each year, utilizing the services of The AIDS Project, Eastern Maine AIDS Network and the AIDS Consultation Service.

The Centers receive a monthly AIDS reference guide from the VA and have online access to NEWSLINK, which provides information on HIV and other topics. In 1994 the Clinton administration issued a training packet and videotape related to HIV-infected VA employees, co-workers and family members. Each VA employee in Maine is required to view the tape at the VAMC location.



■ Veterans' Centers:

- To complement HIV education, provide comprehensive staff trainings on diversity, sexuality, and community resources;
- Conduct outreach to veterans regarding HIV prevention, including information on safer sex and injection-drug use;
- Institute a peer education program regarding HIV prevention;
- Develop a relationship with local and state AIDS agencies.

Department of Human Services

The Department of Human Services (DHS) was established to preserve and protect the health and welfare of Maine citizens. In fulfilling its mission, the Department directs the following social service bureaus and their programs:

Bureau of Child and Family Services Administers Maine's Social Service Block Grant program, child protective services, foster care and residential treatment services for children, adoption and adoption assistance. Through contracted and support services, DHS administers the State Refugee program, the Adult and Child Care Food Program, and the AIDS Case Management Program .	Bureau of Elder and Adult Services Helps the state's older citizens secure equal opportunities and maintain dignity, independence and authority in planning and managing their lives. It also manages Maine's Adult Protective Services and Guardianship Programs.
Bureau of Health Preserves, protects and promotes the health and well-being of the population through programs designed to reduce the risk of disease. These programs include Public Health Nursing, Disease Control, Maternal and Child Health, Public Health Laboratories, Health Promotion and Education, Dental Health, and Health Engineering. The HIV/STD Program , which is housed in the Bureau of Health, administers HIV prevention funds, promotes HIV prevention activities around the state, and processes and analyzes HIV epidemiological data.	Bureau of Income Maintenance Administers Aid to Families with Dependent Children (AFDC), the Food Stamp Program, General Assistance, Emergency Assistance, Medicaid, Child Support Enforcement, and ASPIRE.
	Bureau of Medical Services Administers the major healthcare financing programs (which include Medicaid Services, Drugs to Maine's Elderly, and the Residential Care Program) and licenses and certifies hospitals, nursing homes and a variety of other agencies that provide health services.

All DHS residential program facilities and other programs must comply with the Occupational Safety and Health Administration (OSHA) bloodborne pathogens standards.

The DHS's Staff Education and Training Unit offers a section on HIV as part of its orientation program for new employees. The 1.5-hour-long session is titled "Confidentiality Issues," but actually focuses on basic HIV information. The Education and Training Unit also offers several "AIDS/HIV" sessions at various locations around the state. Although not well-regarded in the field (more comprehensive trainings are available through the Red Cross, for example), the course offers basic information about HIV and confidentiality.

A detailed policy statement regarding HIV and Hepatitis B infection control was published by DHS in February 1994. Their intention was to review the guidelines within a year of full implementation, and thus assess the need for updating.

As of June 1992, all new and current employees of DHS have been required to read, discuss and sign a document called "Confidentiality Rules and Statement." This work rule, which pertains to HIV, specifies the need for client confidentiality.



- Department of Human Services and Bureaus
 - Establish uniform, mandatory HIV and confidentiality training for all employees and contact agencies ;
 - Establish uniform regulations on confidentiality of client's HIV status;
 - Designate an HIV specialist within each office who will attend trainings and assist with policies, training, client services, etc.;
 - Advocate aggressively for increased services and prevention funding for local ASOs.
- Education and Training Unit: Evaluate HIV Education sessions, utilizing external consultation for program development.

Mental Health

Private Practitioners

Although many kinds of mental health service providers practice in Maine, for the purposes of this report, we will focus on:

- social workers and counselors (LCSWs—licensed clinical social workers, LCPCs—licensed clinical professional counselors)
- psychiatrists,
- psychologists,
- clergy and pastoral counselors.

These practitioners provide mental health services (counseling, therapy or psychotherapy) as part of individual or group practices, in community mental health centers (addressed in more detail on page 176) or hospital inpatient and outpatient units. Clients range from those who are essentially well (but with temporary difficulty) to those who have serious chronic mental illness (and may require medication and/or hospitalization). Practice specialties include relationship/family therapy, sexual abuse therapy, geriatric therapy, child therapy, behavioral therapy, et al.

HIV/AIDS research has shown that mental health services are one of the top needs of people with HIV in Maine. In a recent survey of people with HIV conducted by the Maine Community AIDS Partnership, respondents rated mental health fifth in a list of services deemed most important to them. About 50% of respondents claimed to have needed mental health services; only about two-thirds of those people were able to obtain such services.

While many types of support can be beneficial, practitioners with certain specializations can offer particular assistance regarding HIV. For example, neuropsychology is quite relevant to HIV dementia, a common condition in the later stages of AIDS; and experts on death and dying can be helpful to HIV+ individuals and their families.

*50% of people
with HIV report
needing mental
health services.*

—(MCAP, 1994)

In general, Maine's social workers, counselors and some clergy have been active in their self-education efforts and policy development regarding mental health and HIV/AIDS. However, the state's psychologists and psychiatrists, as a whole, have been much less active (although their national associations have formed HIV task forces and developed policies).

It's important for all private providers to realize that they have the opportunity to enhance their practice to include some aspect of HIV/AIDS as one of their specialties.

Clinical Social Workers

The Maine Chapter of the National Association of Social Workers (NASW) has recently designated an HIV Task Force, the immediate goal of which is to address specific modes of practice regarding HIV and AIDS.

NASW's policy states that, given the high incidence of HIV infection and the rapid increase of the pandemic over the past 15 years, the social work profession must act to mitigate the overwhelming psychological and social effects of the illness and to assist clients in reducing their risk of infection with the virus. The policy also states that social workers must take an active role in the workplace (and elsewhere) to seek solutions to the complex problems that HIV has exacerbated.

The policy statement includes recognition of the strong leadership demonstrated by social workers since the beginning of the pandemic and urges them to continue responding to the social impact of HIV infection as mandated by the NASW Code of Ethics.

The NASW Policy of HIV and AIDS contains a list of 13 action areas:

- research
- public education and dissemination of information
- psychological and social support
- workplace
- service delivery and the development of resources
- civil rights
- professional accountability
- HIV testing
- duty to warn
- responsibility of agencies and social work institutions
- political action
- definition and diagnosis of AIDS
- HIV and tuberculosis

In addition to developing its own policy, the Maine Chapter of NASW has a representative on the Maine HIV Advisory Committee.

Pastoral Counselors and Clergy

Ministers, rabbis, priests and other religious leaders are often called upon to address the social issues their communities wrestle with each day outside their practice of worship.

The Maine Council of Churches was founded in Lewiston in 1938 to assist faith communities and their leaders with this task. The Council is comprised

of eight member denominations and 12 associate members, representing more than 300,000 people throughout Maine.

"... The Council provides a forum for Maine's religious community to discern the impact of faith on contemporary issues, especially social and moral ones, to determine the goals and strategies concerning these issues, to empower churches and parishes to take action, and to provide a context to address the people of Maine . . ."

— from *The Mission Statement of the Maine Council of Churches*

In September 1993, The Maine Council of Churches printed its fourth edition of the *Pastoral Handbook for the AIDS Crisis in Maine* (see Resource list). Prepared by the Maine Interfaith Coalition on AIDS, the Handbook begins:

"Ministry and caregiving to and with people with AIDS is the proper role of faith communities, the clear call of God. This ministry must be like any other: compassionate, empowering, justice-centered and faithful.

"Faith communities were thrust into the forefront of AIDS as children of religious families came home to die. Too often the word 'AIDS' was not mentioned in funeral services and during grief counseling. Dividing along theological lines, some communities denounced persons with AIDS as immoral pariahs, while others, steeped in the healing traditions of faith, brought the witness of compassion, healing, and reconciliation to persons living with AIDS. Beginning with few resources and little understanding of the enormity of the task ahead, they did what they could with what they had."

The *Handbook* contains sections on:

- fear of AIDS
- pastoral care and support
- worship services
- scriptures and prayers
- religious education
- action and outreach
- list of educational resources

Psychiatrists

The Maine Psychiatric Association (MPA) is a 150-member organization (connected to the American Psychiatric Association—APA), that represents the professional interests of Maine psychiatrists. One of its functions is to provide educational opportunities for its membership. At each of four meetings held annually in different parts of the state, the group conducts its official business, and then a guest, usually another physician, makes a presentation. In the last decade, the MPA has had two presentations on HIV.

Several years ago a member requested that MPA affiliate with the APA's National Task Force on AIDS by forming a local committee. Although the committee was formed, it has never actually had a membership nor engaged in any activities. In 1992 an MPA member conducted a survey of the membership to find out if there was any interest in HIV-related education in order to study the relevant issues of HIV+ patients. The survey return rate was very low, indicating either a lack of interest or a need for more information. However, two members participated in national two-day training sessions, sponsored by the APA, in Washington, D.C. The trainings focused on the needs of HIV+ people in rural areas of the country.

Although three or four of the MPA members remain active in community AIDS activities and in providing psychiatric services to HIV+ people, the Maine Psychiatric Association has no policies related to HIV. Their AIDS committee has lapsed, and at the time of this writing no other AIDS activities are planned.

Psychologists

The Maine Psychological Association (MEPA) is a statewide organization that advances the science and represents the professional practice of psychology. It maintains an affiliation with its national organization, the American Psychological Association (APA), but operates independently, much the same as the Maine Psychiatric Association.

According to their executive director, MEPA has no policy or mission statement regarding HIV. There have been a couple of workshops on HIV presented for members at annual meetings, but no other training or continuing education for the membership has been available. The director maintains a file of various HIV-related materials from APA; these are made available to members upon request.

MEPA is currently engaged in an effort to bring itself up to date by establishing policies and initiating activities in the areas of continuing education, research and advocacy. MEPA will probably designate an ad hoc committee to address these issues, with technical support from the APA (which has had an active HIV task force for several years). Regional training in professional practice issues related to HIV is made available to Maine psychologists by the APA.

A representative from MEPA has a seat on the Maine HIV Advisory Committee. Several of its members have been involved in HIV-related client care and other activities for some time.



All private mental health practitioners and professional associations:

- Develop network for all disciplines to:
 - provide a regular forum for exchange of information, HIV/AIDS update, inservices, and mutual support
 - hold an annual statewide conference targeting substance abuse, mental health and HIV/AIDS issues

Licensing boards and mental health professional associations:

- Add to license renewal CEU requirements a category for HIV/AIDS training

Local mental health centers offer counseling at affordable rates by charging sliding scale fees.

Community Mental Health Centers

Nonprofit community mental health centers are located throughout the state, providing services primarily within their catchment areas. (Each community in the state falls in one of these catchment areas.) Services may

vary somewhat from center to center; however outpatient psychotherapeutic services are consistently available throughout. Developed to make quality mental health services more accessible to the public statewide, these local centers offer counseling and education at affordable rates by charging sliding scale fees.

Services are generally provided through a continuum of care, varying from short-term residential, day treatment, substance abuse treatment, time-sensitive outpatient, case management, and psychoeducational services.

Many community mental health centers have provided consistent and thorough HIV/AIDS in-service trainings for staff, ranging from universal infection disease precaution to the psychosocial impact on clients and the client's support network. On-going HIV trainings and updates are essential, though may be difficult to maintain for agencies which have many other demands and stresses affecting their programming.

Support for Families

"We felt compelled to develop a family-focused response to HIV," says Perry Sutherland, LCSW, coordinator of community programs at the Community Counseling Center, located off of busy Forest Avenue in downtown Portland. Cumberland County clients of all ages come and go, seeking assistance on a wide variety of topics. Soon, people with HIV and their families will also be coming for low-cost, quality mental health services geared specifically towards their needs.

"We recognized that we could fulfill a need," he adds. "If the Bureau of Health statistic of 1500 Mainers living with HIV is accurate, then three times that many people may need family services. If half reside in southern Maine, that need exceeds 2000."

Sutherland worked with others at the agency to develop the HIV/AIDS Family Therapy Project, which received a start-up grant of over \$15,000 from the Maine Community AIDS Partnership (MCAP). Laura Gottfried, LCSW, recently hired to run the program, describes how this service differs from other emotional support services. "Support groups for people with HIV or their families are really valuable. This is different because we offer clinical family therapy, with weekly individual or family sessions, resolving specific goals, and it is time-limited, not long-term."

When asked why this center, and not an AIDS-focused service organization, should offer this service, she answers, "We felt it was important to integrate families addressing HIV into a regular family counseling center.



"We define 'family' how the person with HIV does— whoever is significant in their life," Gottfried explains. "People with HIV/AIDS can initiate contact, or family members can. Even if the affected person doesn't live in this area, or has died, we can still work with his or her family here."

Examples of issues that might be explored in session are caretaking, addressing the mode of transmission, homophobia, or bereavement. Individual and group sessions are available, depending on the needs of clients. The program relies on referrals and some publicity to generate interest in the service. "This is a new program for us and for Maine. So far people have been very interested and enthusiastic, especially health care and service providers," says Gottfried.



- Ensure all staff have received appropriate HIV training
- Institute policies on confidentiality, risk assessment, HIV testing and counseling information
- Target funding to provide outreach treatment to infected and affected families free of charge
- Establish satellite offices in inconspicuous locations in rural areas
- Offer transportation for clients in rural areas unable to drive
- Prioritize people diagnosed with HIV/AIDS on agency waiting lists
- With other community groups, provide leadership and education in MH/AIDS communities about the real risks of HIV infection for people with psychiatric and mental disabilities

Substance Abuse Treatment

The chapter "Populations and HIV: Substance Use and Abuse" on page 38 describes in some detail the issue of substance use and HIV. That chapter should be read as a companion piece to this section on substance abuse treatment. Clearly, two points establish major links between substance abuse and HIV:

- First, nationally, at least 25% of all AIDS cases were attributed to IV drug use. (Among women with AIDS, it is over 40%.)
- Second, use of alcohol and other substances is well-documented to impair judgement, particularly around risky behavior such as unprotected sexual activity.

While many people in Maine are active users and abusers of substances (and therefore perhaps at increased risk), many also have sought treatment:

From July 1, 1993 to June 30, 1994:

- A total of 13,476 persons were admitted to all categories of substance abuse treatment settings.
- Self-reported injection drug users made up:
 - 3% of adult outpatients admitted;
 - 3% of adolescent outpatients admitted;
 - and 3.5% of intensive care outpatients admitted.

(Percentages were greater for drug users admitted to residential programs, with a high of 17% of the halfway house resident population.) *For more information on residential services, see "Settings and HIV: Residential Settings" on page 139.*

The Office of Substance Abuse (OSA), the single agency within state government accountable directly to the Governor, is the state administrative office for multiple substance abuse services including the many substance abuse treatment programs in Maine. Although OSA declined to estimate how

Nationally at least 25% of all AIDS cases were attributed to IV drug use. (Among women with AIDS, it is over 40%.)

many programs fall under its auspices, eight categories of treatment service exist:

- Emergency shelter
- Extended shelter
- Detoxification
- Extended residential
- Residential rehabilitation
- Halfway house
- Nonresidential rehabilitation
- Outpatient care

The outpatient services group is comprised of three types:

- Adult outpatient
- Adolescent outpatient
- Intensive outpatient

At least two special projects which receive funding through OSA, the Women's Project and the Injecting Drug Users Project, address HIV. Though not treatment-based, both address the overwhelming evidence of connections between substance use and abuse and HIV infection rates in disenfranchised women and in injection drug users. Since the state's first two for-profit methadone clinics moved into South Portland in 1994, issues of methadone treatment, regulations and policy development have arisen. OSA, the members of a task force and the legislature have worked closely together to create reasonable policy and procedures in a relatively uncharted area.

At least two special projects which receive funding through OSA, the Women's Project and the Injecting Drug Users Project, address HIV.

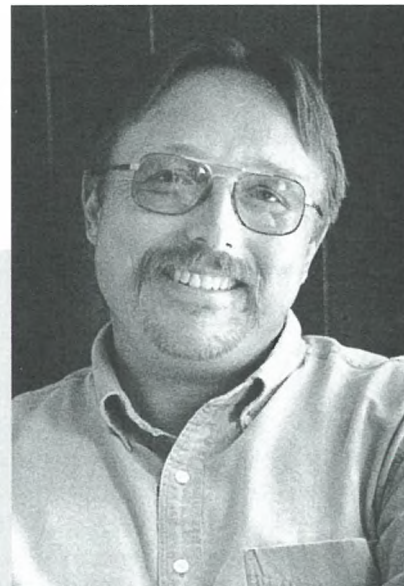
Other areas of OSA services which have direct relevance to HIV prevention, treatment and policy include the Driver Education and Evaluation Programs (DEEP), Substance Abuse Prevention and the Information Resource and Information Center (formerly known as the Clearinghouse). DEEP provides education and evaluation of potential substance abuse problems among those persons who have been offenders of Maine's 'drunk driving' laws; this may include a two day 'residential', a 22.5-hour experience for those with multiple OUI violations. The Substance Abuse Prevention program offers grant monies and technical assistance for prevention efforts in school and community-based settings. The Resource and Information Center maintains a wide variety of literature for distribution to individuals, people in treatment, agencies and other organizations. The Center is also a reference and resource site with up-to-date prevention information including literature on the intersection of HIV and substance abuse prevention efforts and concerns.

Outpatient Services

The Office of Substance Abuse maintains an audit system that rates its agencies in a number of areas. When the programs receive their yearly assessment, managers are asked if they have provided training in HIV-related topics for staff and clients. A negative answer would be noted, but at this time it is unclear what if any sanctions result from this negative response.

By federal law, substance abuse programs are required to provide OSHA bloodborne pathogens standards training for staff members (*see Appendix*). Some employees, when queried, could not recall such training (or any HIV-related training). They also expressed a lack of confidence in dealing with HIV+ clients.

Currently OSA employs Adcare Institutional Institute to contract for and market substance abuse trainings to agencies and individual practitioners, including HIV/Substance Abuse Prevention trainings. There is a small but well-trained cadre of HIV/substance abuse training professionals certified by the federally sponsored Center for HIV/Substance Abuse Prevention. These trainers include personnel from the State HIV/STD Programs, New Beginnings (a program for at-risk youth in Lewiston), The AIDS Project in Portland, Maine's HIV Prevention Community Planning Group and OSA.



Counselor Learns by Doing

"It wasn't out of meanness," recalls Dale McGee. "It was out of ignorance."

Back in 1981 when the Department of Corrections was trying to decide how to handle their first diagnosed AIDS case (the sixth in the state), McGee was a correctional case worker. The man with AIDS was his client. The Department of Corrections wanted daily counseling sessions, lots of observation, and they had already isolated the man from other inmates.

But before Dale could comply with the requests, he felt he needed more information—and more information is what he set out to get. At the time, the fears and myths of the day were running high, as most people knew very little about the routes of infection, or how someone could become infected.

For the languishing inmate, hospice care was desperately becoming necessary, but most of the facilities McGee approached turned down his client. When Auburn's Clover Manor accepted him, two staff people quit their jobs. Then, a few months later, the man passed away, and it was McGee's job to make arrangements. Funeral directors hung up on him.

From the beginning, McGee's quest to become more knowledgeable has been linked with his need to inform others about this disease. "I went to every workshop I could get my hands on," he remembers.

"The field of knowledge has grown volumes since then, and so have educational efforts.

Today most of my high school and college youth could teach the classes I was presenting back then. And that's great."

Today McGee sits on the Maine HIV Advisory Committee. As a Licensed Substance Abuse Counselor, Licensed Clinical Social Worker and Certified Hypnotherapist, he reaches a number of people who are considered to be marginalized—bikers, drug users, alcoholics, teens and families struggling to survive—many of the people believed to be at increased risk for HIV. No matter how diverse the settings, or the people, or why he is seeing them, HIV prevention remains a high priority.

"The next boom in HIV+ diagnosis will be on college campuses," he says, "and we need peer trainers for everyone." When asked how he can keep working in a field with such a high burnout rate, he responds, "Because this really hurts me. And that's what keeps me invested in HIV prevention."

Programs for 1994 and 1995 included a total of only five sessions but covered such areas as human sexuality, the needs of women, and death and dying. These programs were specifically designed for substance abuse counselors either in private practice or in all settings listed above. The decision to participate in HIV trainings is at the discretion of the person, and according to one respondent, are not well attended.

In 1994 OSA conducted a survey of its contracted agencies. Forty-two inpatient and outpatient program representatives responded to questions pertaining to HIV policies, training and HIV+ clients.

For seven years, The AIDS Project in Portland has employed an HIV educator who works primarily on the streets in Portland and Lewiston, offering HIV information and condoms to substance users/abusers and/or sex workers. He also has provided some training on HIV prevention to staff and clients at various substance abuse treatment programs.

The pilot IDU Project has provided training to staff at some treatment sites which had previously focused solely on alcohol abuse treatment among people who are homeless or without other resources. These trainings have emphasized the special needs of injecting drug users. It is too early in the project to judge how this additional information impacts treatment practices and outcomes, and ultimately HIV prevention.

A document entitled "AIDS in Maine: Background and Policy" (1990), obtained from the HIV/STD Programs of the Maine Bureau of Health, states: "... The Office of Alcohol and Drug Abuse Prevention [now OSA], recognizing the high-risk status of many IV-drug-users for HIV infection, was one of the first Bureaus to develop a comprehensive model AIDS policy for use in substance abuse centers. This policy was drafted in cooperation with public health professionals from the Department of Human Services and was designed to be integrated into already existing program policies."

While this statement is almost certainly true, repeated attempts have failed to elicit these policies in writing from OSA, the State Human Resources Office, or the Maine Association of Substance Abuse Providers (MASAP).

A spokesperson from MASAP, an organization representing many substance abuse professionals in Maine, was unaware of any existing HIV-related policies. Spokespersons could not recall any serious conversation or any projects regarding HIV in membership meetings or publications.



■ MASAP:

- Conduct a survey of your membership to gather information regarding HIV policies and procedures in place and HIV educational activities needed.
- Use the results of the survey to make recommendations for trainings, either in awareness or skill building.
- Facilitate the opportunities for members to receive the trainings.
- Collaborate with the Maine AIDS Alliance to improve networking among substance abuse treatment providers and local AIDS service organizations.

■ OSA Licensing and Certification:

- Review and redistribute model AIDS policy to substance abuse treatment centers and counselors and AIDS organizations;
- Train agencies, substance abuse program staff and individual practitioners to incorporate the policy into action;
- Coordinate HIV prevention education efforts with BOH, DOE, and Maine AIDS Alliance to enhance participation and effectiveness of trainings;

- Create or clarify consequences of noncompliance of agencies regarding HIV prevention education for staff and clients;
- Create a minimal standard of HIV knowledge and HIV prevention skills for administration, staff and individual practitioners.
- Facilitate the attendance of counselors and staff at training sessions in creative ways: release time, reduced client load requirements, etc.
- OSA Prevention Efforts
 - Create avenues for combining substance abuse prevention monies and HIV prevention monies to benefit both areas of need;
 - Market substance abuse prevention and HIV prevention as a total endeavor, not as separate missions, objectives and goals;
 - Create connections and information-sharing among contracted individuals and agencies working on substance abuse or HIV prevention and State offices such as the Department of Education, the Bureau of Health and OSA.
- OSA Resource and Information Center
 - Investigate including online HIV/Substance Abuse information such as research findings or prevention strategies.
- OSA Drivers Education and Evaluation Program
 - Incorporate HIV prevention information and education within the existing Weekend Intervention Program. A logical location might be the Pathology Lecture.

State Mental Health Offices

Department of Mental Health/Mental Retardation

The Department of Mental Health/Mental Retardation (DMH/MR) was established in 1939 to enhance the quality of life for persons with mental illness and developmental disabilities by helping them meet their needs for personal, social, educational, vocational and economic development; to enable them to function at maximum levels of potential and maintain their dignity as human beings and citizens in a free society; and to profit from the variety of options open to all citizens of the state of Maine.

The DMH/MR operates a system of programs that provide advocacy and support services to the mentally ill and developmentally disabled through both institutional and community-based programs. Several advisory committees support and serve the MHMR Commissioner, and the following offices and bureaus carry out the work of the Department.

- Office of Advocacy
- Division of Mental Retardation
- Bureau of Children with Special Needs
- Office of Consumer Affairs
- State Forensic Service

Division of Mental Health

The Division of Mental Health is charged with developing a comprehensive, integrated system of quality mental health services and expanding community mental health services, encouraging the participation of community residents in these programs. The Division operates the Augusta Mental Health Institute (AMHI), the Bangor Mental Health Institute (BMHI) (see *"Residential Settings" chapter, page 139*) and the Office of Community Mental Health Services which serves adults 18 years and older, who have severe mental illness, through OCMHS-funded programs. Approximately 26,000 adults are served annually.

According to a DMH/MR personnel official, HIV policies and programs in the Department are tailored to the needs of each facility to "make them work." Infection control policies are in compliance with OSHA standards. The policies regarding confidentiality and HIV antibody testing were written in accord with the Medical Conditions law. We were unable to obtain any other information about HIV policies and training programs.



State Mental Health Offices:

- Work aggressively to expand federal Ryan White funds for HIV case management and drug reimbursement
- Conduct a needs assessment of all facilities run or funded through DMH/MR
- Establish required, regular HIV/AIDS training for all staff as criteria for licensure and funding of all agencies and practitioners
- Acquire funding specifically for children infected or affected by HIV/AIDS to provide outreach services, support groups, intervention/collaboration in the schools, etc.

Resources

Organizations for information or to pursue HIV policy development

AIDS Consultation Service
Maine Medical Center
22 Bramhall St.
Portland, ME 04101
1-800-871-2701
207-871-2099

AIDS Family Therapy Initiative
Community Counseling Center
343 Forest Avenue
Portland, ME 04101
207-874-1030

Bureau of Mental Health
State House Station 40
Augusta, ME 04333
207-287-4230/4238
TDD: 207-287-7285
FAX: 207-287-7286

Bureau of Mental Retardation
State House Station 40
Augusta, ME 04333
207-287-4242

Health and Human Services Department
Public Health Division/Social Services Division
City of Portland
389 Congress Street
Portland, ME 04101
207-874-8300

Health and Human Services Department
City of Bangor
103 Texas Avenue
Bangor, ME 04401
207-947-0700

Maine Association of Substance Abuse Providers
Office of Substance Abuse
24 Stone Street
State House Station #159
Augusta, ME 04333
207-287-6330

Maine Coalition Against Sexual Assault
PO Box 5326
Augusta, ME 04332-532

Maine Community Action Association
12 Spruce St., PO Box 5402
Augusta, ME 04332-5402
207-622-5838

Maine HIV/STD Programs
State House Station 11
Augusta, ME 04333
207-287-3747

Maine Council of Churches
15 Pleasant Avenue
Portland, ME 04103
207-772-1918

Maine Psychiatric Association
PO Box 1560 RR 1
North Whitefield, ME 04353
207-549-5786

Maine Psychological Association
12 Spruce St.
Augusta, ME 04330
207-621-0732

National Association of Social Workers,
Maine Chapter
PO Box 5065
181 State Street
Augusta, ME 04332
207-622-7592

Office of Substance Abuse
State House Station 159
Augusta, ME 04333
207-287-6330
TDD: 207-287-4475
FAX: 207-287-4334

People's Regional Opportunity Program (PROP)
HIV/AIDS Education and Universal
Precautions Committee
510 Cumberland Avenue
Portland, ME 04101
207-874-1140

(continued)

Resources *(continued)***Legal Services Resources**

Maine Advocacy Services
 Advocates for the legal rights of disabled people in
 employment discrimination cases.
 P.O. Box 2007
 Augusta, Maine 04338
 1-800-452-1948 or 207-626-2774

Maine Civil Liberties Union
 Provides assistance in constitutional litigation on
 issues such as public dissemination of confidential
 information, the rights of the disabled, and pris-
 oners rights.
 97 Exchange St.
 Portland, ME 04101
 207-774-5444

Maine Human Rights Commission
 Provides assistance in litigation and conciliation
 on issues of discrimination on the basis of HIV-
 status in employment, housing and public accom-
 modations.
 State House Station 51
 Augusta, ME 04333
 207-624-6050

Pine Tree Legal Assistance Inc.
 Provides legal services for low-income persons
 civil matters such as Social Security, Medicaid, and
 eviction proceedings.
 Central Office P.O. Box 547 DTS
 Portland, ME 04112
 207-774-4753, 207-774-8211

Volunteer Lawyers Project
 Provides legal assistance to low-income people.
 P.O. Box 547 DTS
 Portland, ME 04112
 1-800-442-4293 or 207-774-4348

Civic and Social Organizations and Communities of Faith

- Communities of Faith: organized and unorganized religions, churches, synagogues, temples, and related groups
- Organizations of communities of color, sovereign nations, ethnic groups
- Fraternal, civic, and service organizations
- Youth organizations
- Senior organizations
- Women's organizations
- Cultural support and social groups
- Lions Club, Rotary Club, League of Women Voters, Chambers of Commerce
- YMCA, YWCA, tribal youth groups, Girl Scouts, Boy Scouts, 4-H Club
- Area Agencies on Aging, American Association of Retired Persons
- Maine Women's Lobby, Women's Business Development Corporation, American Association of University Women
- Hadassah, Knights of Columbus, Maine Council of Churches
- Native American Nations, Franco-American groups, NAACP, Khmer Council

When Mainers are not working, raising families, or pursuing personal interests, many of us tend to associate to varying degrees with groups of people that share something in common. This might be heritage, religion, social views, athletics, or cultural interests. These connections and groups are important to our sense of community, of belonging, of making our lives richer and more meaningful.

In addition to the central focus which brings people together, many groups also make efforts to improve the quality of life for their members as well as for the broader community.

Public service and charity have long been the hallmark of America's community organizations. Religious organizations, like the Maine Council of Churches, for example, have a history of promoting tolerance, giving aid to the needy and comfort to the distressed. Fraternal groups, like the Shriners, are widely admired for their dedication to young burn victims.

Groups like these represent the backbone of many communities, and are often viewed as leaders, dedicated to community development, service and philanthropy. Often it is through their leadership that social needs—like HIV prevention and care—are best met.

Civic and service organizations (Rotary Clubs, Knights of Columbus, League of Women Voters, Chambers of Commerce, etc.), social and cultural organizations (Franco-American groups, NAACP, etc.), sovereign nations of Native Americans, and communities of faith (Hadassah, Maine Council of Churches, various local churches, etc.) can all play a vital role in HIV prevention and care.

Public service and charity have long been the hallmark of America's community organizations.

Often it is through their leadership that social needs—like HIV prevention and care—are best met.

It's hard to exaggerate how valuable even small gestures of support can be.

HIV is a community problem, with medical, social and economic impact on all communities. It's likely that a majority of people living in Maine have already been personally affected—directly or indirectly—by having a family member, friend or acquaintance contract the virus. Rather than wait for state government to lead the way, local community groups can take a leadership role now in encouraging widespread understanding of this disease, educating people on how to prevent it, and helping those who have been infected.

Unfortunately, medical problems aren't the only hardships caused by HIV. Financial difficulties, discrimination, alienation and depression are just some of the burdens borne by the person living with this virus. It's hard to exaggerate how valuable even small gestures of support can be.

In the area of HIV, some groups—Native American Nations in northern Maine, for instance—have done considerable work on related activities, such as sponsoring activities to educate their membership. Other groups have yet to see how HIV prevention and support for those afflicted relates to their mission, or how they as individuals can help.

Fortunately, many things can be done:

To begin, community organizations can contact their local AIDS service organizations (ASOs) (*see Resources*) or other groups, like the Volunteer Center, for example, (*see resource list at end of chapter*), to ask for suggestions. Organizations like these can provide suggestions for a wide range of services that volunteers could provide. For the individual living with HIV, and his or her loved ones, every gesture means a lot. Some services—help with transportation, for example—require personal, daily contact with people who need help. Others require a lighter commitment, such as occasional help with errands.

ASOs themselves need constant help. Answering the phone, raising money or staffing the hot-line are just some of the things volunteers can do.

General Recommendations

All Civic, Social and Faith-based Organizations:

1. Educate your memberships about the impact of HIV/AIDS on your local communities and individuals, and about methods of prevention and control.
2. Contact your national offices/affiliates to determine nationally-established HIV-related programs, and then implement those programs locally.
3. Work with local AIDS service organizations (ASOs) to arrange volunteer services (like transportation and medical deliveries, for instance) or fund-raising projects (like AIDS walks, raffles and auctions).
4. Establish a permanent service to help people living with HIV—maintaining a year-round residence, for example, or forming an ongoing support group for people with HIV and their loved ones.

Some local Rotary chapters have also invited physicians and people living with HIV to speak at their luncheon meetings.

An Organized Response to HIV

Following are six specific kinds of community organizations and some of the activities they could sponsor in the area of HIV prevention and care.

Fraternal, Civic and Service Organizations

(Lions Club, Rotary Club, Chambers of Commerce, community radio stations, etc.)

These organizations vary widely in the ways they view HIV issues. Some groups, like the League of Women Voters, do not presently consider HIV education or fund-raising to be in line with its mission.

The Rotary Club, on the other hand, has developed a videotape presentation that's available to its membership throughout the U.S. and is used to educate other community groups as well. Some local Rotary chapters have also invited physicians and people living with HIV to speak at their luncheon meetings.

The Maine Civil Liberties Union, for another example, has been active offering free legal advice to some people with HIV and engaging in legislative lobbying on behalf of HIV concerns.

Fortunately, we still have hundreds of active groups in Maine with the resources and membership to make a huge difference in preventing HIV and helping those community members who are living with the virus.



Fraternal, Civic, and Service Organizations:

Immediate

- Educate membership
 - Give presentations on HIV, prevention and community response;
 - Discuss ways in which members can support people with HIV and their local ASOs—and then spread the word to the various chapters through newsletters.
- Take message to community
 - Show visible support for local school sexuality/HIV education programs;
 - Sponsor public-service announcements or media campaigns designed to educate the general community about HIV;
 - Team up with other organizations in fund-raising or public speaking efforts.

Mid-term

- Develop volunteer system
 - Provide transportation for those with HIV;
 - Provide respite care service (such as help with housework, etc.);
 - Coordinate a volunteer work day at a local ASO or other support organization;
 - Offer legal assistance.

- Develop a community service project
 - Initiate fund-raising activities for local ASOs (*see Resources section*) Create emergency funds to help HIV victims with rent, fuel, groceries, etc.;
 - Develop a peer-counseling project;
 - Join with other organizations to sponsor a community event (commemorating World AIDS Day, for example).

Long-term

- Establish permanent service
 - Work toward establishing a year-round residence for people living with HIV;
 - Organize a nutrition program for people living with HIV;
 - Form an ongoing support group for people with HIV and those close to them;
 - Provide opportunities for families and people with HIV and their loved ones to attend special summer camps.

Youth Organizations

(YMCA, YWCA, Tribal Youth Groups, Girl Scouts, Boy Scouts, 4-H Clubs, etc.)

Because it is now known that many people with HIV were infected when they were teenagers, some youth groups have taken the lead in working to protect themselves and other teens.

Various chapters of the YMCA and YWCA have sponsored activities that address HIV education. The YWCAs in Lewiston, Auburn and Portland, for example, have established outreach programs that offer education on HIV risk-reduction for street youth and youth-at-risk (those with characteristics that place them at a higher-than-average risk of contracting HIV). The Portland YWCA has sponsored the Names Project and displayed the Names Project Quilt, large handmade cloth panels that commemorate the lives of people lost to AIDS. It has also served as a meeting place for ACT-UP, a national AIDS activist group that stages demonstrations. The YMCA in Portland sponsors a “Young Fathers” program, which provides ongoing education in HIV prevention.

Outright, a network of organizations supporting gay and lesbian youth in Maine, has focused on HIV as a major program issue in the past. ACT-UP has provided staff support to FATE (Fight AIDS—Transform Education), a youth-led effort for teens become more involved in their own HIV/AIDS education.

The national 4-H Club and local Boys and Girls Clubs have also offered HIV prevention education. Girl Scouts and Boy Scouts in other states have sponsored major HIV education programs that could be replicated in Maine.

Thousands more Maine teens are represented by groups who will have tremendous impact when they join the effort. Church youth groups, for example, are important social structures for some teens, especially in rural Maine. Such groups could provide invaluable influence in educating their members about HIV prevention.

It is now known that many people with HIV were infected in their teens.

Condom Crusaders

Christina Mason has a van that will soon be wearing a condom. She and other members of FATE—Fight AIDS, Transform Education—a statewide, teen-led effort to promote access to condoms and more comprehensive sexuality education in schools, plan to go on another of their “condom crusades.” “This one,” she says, “will catch people’s eye.”

They plan to go to beach and school parking lots, play music with safer sex messages, tie red ribbons on cars, and hand out flyers and condoms. Mason, a 1995 Deering High School graduate and FATE staffer, says, “FATE is a way of empowering students to stand up for what they want.”

Adopting an up-front, in-your-face organizational style similar to ACT-UP, its parent organization, FATE began organizing school-based groups in 1993. Richard Fried, one of the adult organizers, explains, “The teens were saying, ‘If the schools won’t protect us, we’ll do it ourselves.’”

With names like KISS (Kennebec Individuals for Safer Sexuality), SLAB (Students for Latex Availability in Biddeford), and SAFE (Students Against False Education), local teen groups hand out self-produced safer sex ‘zines, condoms, and petitions to their peers.

Mason, the current FATE coordinator, reflects on why she got involved: “I didn’t feel my sex ed training in school was adequate. Kids were being denied basic information for their survival.” Regarding FATE’s



methods of education versus those in traditional school settings, she offers, “It can be less intimidating to get information or condoms from a friend than from a school nurse.”

But FATE groups aren’t content with only this approach. The South Portland group, SAFE, tried to deliver a petition to their principal, advocating for condom distribution in the school. Although the petition had 300 signatures, it was rejected. In response, the group handed out condoms every Friday outside the school, with 30 to 40 students wearing FATE T-shirts in support.

“We held a Die-In on World AIDS Day outside my school,” Mason reports. “We generally have a core group of ten, but that day about 65 students participated. It’s an effective way to get the message across, because students see their peers active on the issue. Then they have to decide whether it’s important to them, too.”

ACTION STEPS

A Blueprint for Action

Immediate

■ Educate membership

- Contact your national headquarters to determine any official HIV policies—and then implement them locally;
- Start peer education programs or integrate your organization into existing educational programs elsewhere;
- Bring in guest speakers, pass out pamphlets or view video presentations—such resources are readily available through local ASOs (*see Resource section*)

- Take message to community
 - Educate other community and/or youth organizations about HIV prevention;
 - Organize small groups to educate parents;
 - Voice support for school sexuality/HIV education programs that are designed to prevent the spread of HIV among young people;
 - Participate in and/or sponsor public-service announcements about HIV awareness.

Mid-term

- Develop volunteer system
 - Organize volunteer projects through which members can help HIV+ people with housekeeping chores and outside errands (such as assisting with pet care, car repair, etc.).
- Develop community service projects
 - Initiate fund-raising projects for local ASOs (*see Resource section*)
 - Start peer-counseling education projects.

Long-term

- Establish permanent service
 - Integrate the above programs into the organization's permanent agenda;
 - Establish an annual service day or fund-raising activity.

Ethnic, Cultural and Social Organizations, Sovereign Nations, Organizations of People of Color

(Franco-American organizations, Native American Nations, Khmer Council, NAACP, etc.)

One HIV coordinator working out of the health center has conducted school programs on the reservation and a community awareness evening regarding HIV risk.

Small, closely-knit communities, such as those represented by some of Maine's ethnic, racial and cultural groups, have tended to be particularly susceptible to HIV in other parts of the country, unless those communities have taken steps to increase awareness and prevention of the virus. Native American Nations centered in Maine in particular have responded commendably. The Penobscot Indian Nation, through its health center in Old Town, has organized a wide range of activities related to HIV, including public events scheduled in conjunction with a two-day conference on HIV (co-sponsored by the Nashville Office of Indian Health Services and the New England AIDS Education and Training Center). The Nation has also hosted a two-day tribal conference on HIV. In addition, an HIV coordinator, working out of the health center, has conducted school programs on the reservation and a community awareness evening regarding HIV risk.

As other examples, the Passamaquoddies at Pleasant Point and Indian Township have, through the Indian Health Service, enlisted the National Native American AIDS Prevention Program to provide tribal representatives with HIV prevention education training. The Micmac tribe has commissioned similar programs for its membership from the Pine Tree Chapter of the

American Red Cross in Bangor (which also provides an HIV outreach and education program for migrant workers).

Opening Doors on Indian Island

Ila Nicola says that she has seen just about everything. As community health nurse of the Penobscot Nation Health Department, Nicola works with diabetes and other community health issues. She also works in the school—and she works on HIV. The health department serves the 420 Penobscot residents on the island, as well as other Native Americans living on the island and Penobscots living elsewhere.

Nicola believes there is still a frightening level of denial among the people she serves. She is striving to show others that discussion of HIV and AIDS does not need to be taboo. “Even though I know of no one here who is HIV+, it is going to happen—and the staff needs to be prepared. We need workshops. Fears need to be set aside.”

In July, 1995, Nicola assisted in bringing the Maine HIV Prevention Community Planning Group to Indian Island to hold group information sessions. The CPG wanted to hear firsthand what the people knew. They also wanted input into the kinds of prevention efforts the people themselves believed would work within their own community.



“This is a community,” she says, “and I need community involvement. I believe if people are actively involved, they are also more open. There needs to be someone in the community who can open doors to the person who has HIV.”

International refugees and immigrants who have settled in Maine have formed various support groups focused primarily on issues of family settlement and adaptation. An HIV peer education program for refugees and immigrants has just been refunded for its fourth year by the Maine HIV/STD Programs (through The AIDS Project in Portland). The program was designed and is managed by a public health consultant, but the education itself is provided by several non-professional, trained educators who are matched ethnically and linguistically with their students.

With regard to social organizations, the Singles Network in Portland has offered three evening presentations on AIDS/HIV issues to members during the last three years and plans to continue its HIV-related activities.



Show support for school sexuality/HIV education programs.

Immediate

- Educate membership or constituency
 - Organize presentations to increase HIV awareness and prevention strategies;
 - Publish HIV-related newsletter articles/stories;
 - Hold public meetings to assess the HIV-related concerns of members.
- Take message to community
 - Hire and train outreach workers who can help relatives and neighbors become informed about HIV;
 - Ask community elders to lead the way in accepting the need for HIV-education in your communities;
 - Show support for school sexuality/HIV-education programs;
 - Sponsor public-service announcements regarding HIV awareness and prevention.

Mid-term

- Develop volunteer system
 - Provide transportation to people with HIV;
 - Help them with housekeeping and errands;
 - Offer respite care;
 - Provide interpreting services for those with limited proficiency in English;
 - Provide legal assistance.
- Develop a community service
 - Raise funds to help local AIDS service organizations (*please see Resources*) offer culturally specific services;
 - Create an emergency fund to help HIV+ people with food, fuel, rent, etc.

Long-term

- Establish a permanent service
 - Establish a nutrition program for people living with HIV;
 - Organize hospice services that are culturally sensitive

Senior Organizations

(Area Agencies on Aging, American Association of Retired Persons, etc.)

Our older community members can be invaluable resources in helping to prevent the spread of HIV and giving aid and comfort to those afflicted by the virus. More than any other segment of society, our seniors have lived through the loss of loved ones and illness. Many have valuable lessons for younger generations now facing personal losses through HIV. Able-bodied elders, unencumbered by work and young families, are well-suited to give compassion and comfort to others. It's also likely that they have adult children, growing grandchildren and even great grandchildren who are entering a time in their lives when the risk of HIV infection—and the need for prevention—is critical.

Many leaders of community activities are older people, now able to volunteer their free time. Frannie Peabody, a Portland woman in her 90's, has been a leading force in the local AIDS community for years, garnering broader awareness and financial support for HIV services.

Seniors have gained impressive organizational and political power through large national organizations like the American Association of Retired Persons (AARP). Unfortunately, as yet, HIV/AIDS has not been a topic of emphasis either in Maine or national AARP committees. Likewise, few statewide Area Agencies on Aging have raised the issue of HIV prevention, mainly because it is not viewed as germane to their mission.

A promising exception in Maine is the Eastern Area Agency on Aging (Brewer), which uses its local ASO for staff education. As voluntary home health providers, their members are active serving people living with HIV.

We take hope in the fact that our senior population represents a tremendous potential in our goal to stop the spread of HIV and help those living with the disease.

A Portland woman in her 90's has been a leading force in the local AIDS community for years.



Immediate

- Educate membership
 - Arrange presentations to better inform membership about HIV;
 - Publish newsletter articles/stories for the same purpose.
- Take message to community
 - Educate other senior or community groups;
 - Show support for school sexuality/HIV programs;
 - Spread public awareness of HIV by sponsoring public-service announcements or media campaigns.

Mid-term

- Develop a volunteer system
 - Provide transportation to people with HIV;
 - Assist them with housekeeping chores;
 - Provide respite care;
 - Offer legal assistance.
- Develop a community service project
 - Run a fund-raising project for local ASOs (*see Resource section*);
 - Create an emergency fund to help HIV+ people in your community with food, fuel, rent, etc.

Long-term

- Establish a permanent service
 - Open and maintain a group residence for people living with HIV;
 - Organize an ongoing program of volunteer assistance;
 - Implement a nutrition program for people living with HIV.

The number of women contracting HIV is rising faster than any other group.

Women's Organizations

(League of Women Voters, Maine National Organization for Women (N.O.W.), Women's Business Development Corporation, American Association of University Women, etc.)

Unfortunately, in Maine, the number of women contracting HIV is rising, from one case before 1988 to 11% of Maine's total AIDS cases in 1993—and 15% of those testing positive for HIV in 1995. No other constituency is rising at a faster rate. The majority of these women are being infected by their male partners who may be using IV drugs or having clandestine sexual relations with other men. Because of traditional male/female roles in relationships, even if a woman suspects her husband may be at risk for HIV, many women would not feel comfortable or even safe requesting the use of condoms.

Several important women's groups exist, but so far only a few have addressed the need for HIV prevention. For example, Maine N.O.W. has published articles about HIV in its statewide newsletter, and the Maine Women's Lobby has worked actively on legislative issues regarding HIV/AIDS.

Other Maine women's groups, however, like the American Association of University Women (AAUW), the Business and Professional Women's Organization, and the Home Economics Association, have yet to get involved in HIV-related issues. These and all other women's groups will powerfully affect the lives of their members—and of all Maine women—when they begin addressing HIV.

All women's groups will powerfully affect the lives of their members—and of all Maine women—when they begin addressing HIV.



Immediate

- Educate membership
 - Through meetings, discussion groups and newsletters, inform members of HIV prevention and treatment strategies, particularly as they relate to women.
 - Invite women with HIV to speak at local presentations or at state-wide conferences.
- Take message to community
 - Combine with other chapters or other organizations in HIV-awareness presentations;
 - Actively support school sexuality/HIV education programs;
 - Sponsor public-service announcements or media campaigns.

Mid-term

- Develop a volunteer system
 - Provide transportation to people with HIV;
 - Help them with housekeeping and errands;
 - Provide respite care;
 - Offer legal assistance.
- Develop a community service project
 - Develop a project to raise funds for local ASO, (*see Resource section*)
 - Maintain an emergency fund to help HIV+ persons with food, rent, fuel, etc.

Long-term

- Team up with AIDS activists to forward legislation for increased funding to help with prevention, research and other HIV-related services for women
- Establish a permanent service
 - Open and maintain a group residence for women with HIV;
 - Implement a nutrition program;
 - Organize support groups for women with HIV and their loved ones;
 - Support a summer camp for women with HIV and their loved ones.

Communities of Faith

(Hadassah, local religious congregations, churches, synagogues, mosques, Maine Council of Churches, etc.)

Traditionally, churches and other faith-based organizations have provided not only moral leadership in our communities, but food for the hungry, shelter and clothing for the needy, and compassion for the grieving. With HIV and AIDS causing so much pain and suffering, several faith-based organizations are courageously and compassionately leading the way in the struggle to deal with this tragic disease.

With HIV and AIDS causing so much pain and suffering, several faith-based organizations are courageously and compassionately leading the way in the struggle to deal with this tragic disease.

The Maine Interfaith Coalition on AIDS, for example, has developed an excellent orientation program and packet of materials to help community religious leaders engage in the pastoral care of HIV patients. Titled "The Pastoral Handbook for the AIDS Crisis in Maine," this handbook and accompanying information has been distributed by the Maine Council of Churches and denomination offices to nearly every clergy in the state (*please see Settings Chapter: Social Services, Mental Health Providers, Substance Abuse Treatment Sites, page 159*).

Churches all over Maine have become involved in a wide array of activities related to HIV/AIDS. The Episcopal Diocese of Maine has established an HIV Task Force to make recommendations to their member churches. The First Parish Church in Portland has held World AIDS Day celebrations and sponsored memorial concerts. In rural areas many Methodist churches have also held services on World AIDS Day. The Gray Episcopal Church has sponsored an AIDS Awareness Education Day. The Woodfords Congregational Church in Portland regularly provides meeting space for the Parents and Friends of Lesbians and Gays, while the Mexico Congregational Church hosts a support group for people with HIV.

Other churches continue to provide similar valuable functions throughout the state, affirming their status as models of concern and activism, not only in the case of people's souls but in the care of human lives.

Affirming Persons, Saving Lives

Cindy Bowman has a unique background, one that led her to co-author the United Church of Christ curriculum on HIV titled "Affirming Persons—Saving Lives." With a midwest Protestant upbringing, she studied elementary education and later adult education and finally settled in with the fledgling AIDS Project in Portland in 1986.

When The AIDS Project received a \$3,000 grant from the Maine Council of Churches to design ecumenical education for leaders of churches throughout the state, Bowman became part of the team working on that grant. During the same time period she was an active member of the Woodfords UCC Congregation, and was a founder of the AIDS Lodging House.

She has found that being part of a compassionate response to HIV prevention is a way to express her spiritual side. The "Affirming Persons—Saving Lives" curriculum is a learning series for adults, parents and youth, with specific sections for preschool and kindergarten, Grades 1-2, Grades 3-4, and Grades 5-6. Guidelines, handouts, teacher support materials and video tapes combine to encompass a curriculum that can be used by the congregation without the need of an outside expert. The intent is that the



adults will be educated first about HIV and surrounding issues, then the youth and children.

And the curriculum is not only about learning facts, it is about skill building, empowerment, ministry and mission. "I'm thrilled," says Bowman. "It's very exciting for me that I can be public in my spirituality with an organization that is open and affirming and compassionate in its response to HIV and AIDS."

ACTION STEPS



Immediate

- Educate membership and promote compassion
 - Preach tolerance and charity toward HIV+ community members and their families;
 - Invite guest speakers who are living with HIV to address your congregations;
 - Print articles in church newsletters pertaining to the realities of living with HIV;
 - Offer sexuality and family-life classes to youth groups and their parents.
- Take message to community

- Sponsor public-service announcements in newspapers and on radio and TV;
- Join other faith-based groups in developing HIV-related projects and programs.

Mid-term

- Develop a volunteer system
 - Provide transportation for people with HIV;
 - Help them with housekeeping chores and errands;
 - Offer respite care;
 - Develop and maintain a group of hospice workers;
 - Offer legal assistance.
- Develop a community service project
 - Develop fund-raising events for local ASOs (*please see #*);
 - Create an emergency fund for fuel, food or rent, etc.;
 - Develop a peer pastoral counseling project;
 - Organize support groups of people living with HIV and their loved ones.

Long-term

- Establish a permanent service
 - Provide housing to help HIV+ people live independently;
 - Organize a nutrition program for people living with HIV;
 - Start a summer camp for HIV+ people and their loved ones.

Resources

Organizations

AIDS National Interfaith Network
110 Maryland Ave., NE Ste. 504
Washington, DC 20002
1-800-288-9619

Cooperative Extension Service
4-H Office
University of Maine
105 Libby
Orono, ME 04473

National Alliance to End Homelessness,
AIDS Housing Network
1518 K St., NW, Ste. 206
Washington, DC 20005
202-638-1526

New England Rural AIDS Network
Department of Health
23 Service Center
Northampton, MA 01060

Sponsors training programs in AIDS issues, including development of community resources and support networks.

The Volunteer Center
One Post Office Square/400 Congress St.
PO Box 15200
Portland, ME 04112-5200
207-847-1000

(continued)

Resources (continued)

Materials/Organizations

AIDS Is Your Business: A Guide to Corporate HIV/AIDS Grantmaking, a handbook designed for small and large businesses, providing practical advice on how to provide financial assistance to organizations on the front-line of the fight against AIDS. Free copy available from:
 Funders Concerned About AIDS
 310 Madison Avenue, Suite 1630
 New York, NY 10017

America Responds to AIDS: It's Your Move, Prevent AIDS, a community action kit
Preventing HIV and AIDS: What You Can Do
 Both are available from:
 National AIDS Clearinghouse 1-800-458-5231

Breaking New Ground: Developing Innovative AIDS Care Residences, a guide for those interested in building or renovating HIV/AIDS housing. \$39.95 + \$5 for shipping and handling. Available from:
 AIDS Housing of Washington
 2001 Western Avenue, Suite 300
 Seattle, WA 98121

Congregation-based Care Teams: A Guide and Resource Manual for Practical Support and Pastoral Care of Persons Living with AIDS.
 \$15.00 per copy. Also, *Volunteers Nurturing Life Through Faith*, \$2.00 per copy.
 Both available from:
 Regional AIDS Interfaith Network
 1000 Howard Avenue, Suite 1200
 New Orleans, LA 70113

Knight Vision, a comic book on AIDS written specifically and explicitly for street youth. \$1.25 each for 1-99 copies, \$1.00 each for 100-499, \$.90 each for 500-1,000. Add 15% charge for shipping and handling. Available from:
 Communications Department
 Planned Parenthood of New York City
 26 Bleecker Street
 New York, NY 10012-2413

Pastoral Handbook for the AIDS Crisis in Maine
 Maine Council of Churches
 15 Pleasant Avenue
 Portland, ME 04103
 207-772-1918

Positive Nutrition, a newsletter designed to provide practical information concerning nutrition and HIV. Free printed copies available from:
 Project Open Hand
 2720 17th Street
 San Francisco, CA 94110-1405

Pro Bono in the AIDS Epidemic, a 30-minute video by the American Bar Association AIDS Coordinating Committee; highlights the way lawyers can help people with HIV and AIDS. \$15 per copy. Available from:
 American Bar Association
 AIDS Coordination Project
 1800 M Street, NW
 Washington, DC 20036

"The Los Altos Story" video for Rotary International chapters member education and mobilization on HIV/AIDS; available for \$25 donation from:
 Rotary AIDS Project
 PO Box 794
 Los Altos, CA 94023
 415-608-6164

Appendices



Appendices



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Glossary of Frequently-Used Terms and Acronyms

ADA	Americans with Disabilities Act
AIDS	Acquired immunodeficiency syndrome; the end stage of HIV disease in which the body's immune system has been destroyed to the point where it is susceptible to life-threatening infections.
ASO	AIDS Service Organization A local social service agency which primarily provides services to people with HIV and AIDS, and education for the general public.
BLOODBORNE PATHOGEN	Virus that lives in, and is transmitted by, body fluids such as blood or semen.
BOH	Bureau of Health A bureau of the Maine Department of Human Services, houses the Office of Disease Control and the HIV/STD Programs
CDC	The Centers for Disease Control and Prevention, Atlanta, GA The federal agency responsible for responding to HIV through research, policy, and funding to states for prevention, research, and treatment.
DHS	Maine Department of Human Services
DOC	Maine Department of Corrections
DOE	Maine Department of Education
EPIDEMIC	The occurrence in a community or region of cases of an illness clearly in excess of expectancy.
HIV	Human immunodeficiency virus; the disease that causes AIDS.
HIVAC	Maine HIV AIDS Advisory Committee Formerly the Committee to Advise the Department of Human Services on AIDS, a legislated, governor-appointed body now advising all departments and agencies of the State.
HIV/STD	Programs (aka Office on AIDS) Within the Bureau of Health, the State office responsible for addressing HIV in Maine and administering state and federal prevention, testing and outreach funds locally.
LCSW	Licensed Clinical Social Worker Mental health services offered by LCSW, are not currently Medicaid-reimbursable.
MAA	Maine AIDS Alliance A consortium of 15 local organizations providing direct services to people with HIV or AIDS and awareness programs for the community. MAA provides

technical assistance, pools resources, and offers guidance on state and local policy development.

MAP Maine AIDS Plan
Begun in 1992, a statewide, community effort to develop a comprehensive 5-year AIDS and HIV action plan for Maine, including prevention, treatment, and policy issues.

MCAP Maine Community AIDS Partnership
A recipient of the National Community AIDS Partnership grant initiative begun here in June, 1993. Through needs assessment and community involvement, the objective is to increase community resources to address HIV in Maine. Administered by the United Way of Greater Portland and the Maine Community Foundation.

PWA/HIV Person with AIDS or HIV
This is the preferred terminology, rather than AIDS patient or AIDS victim.

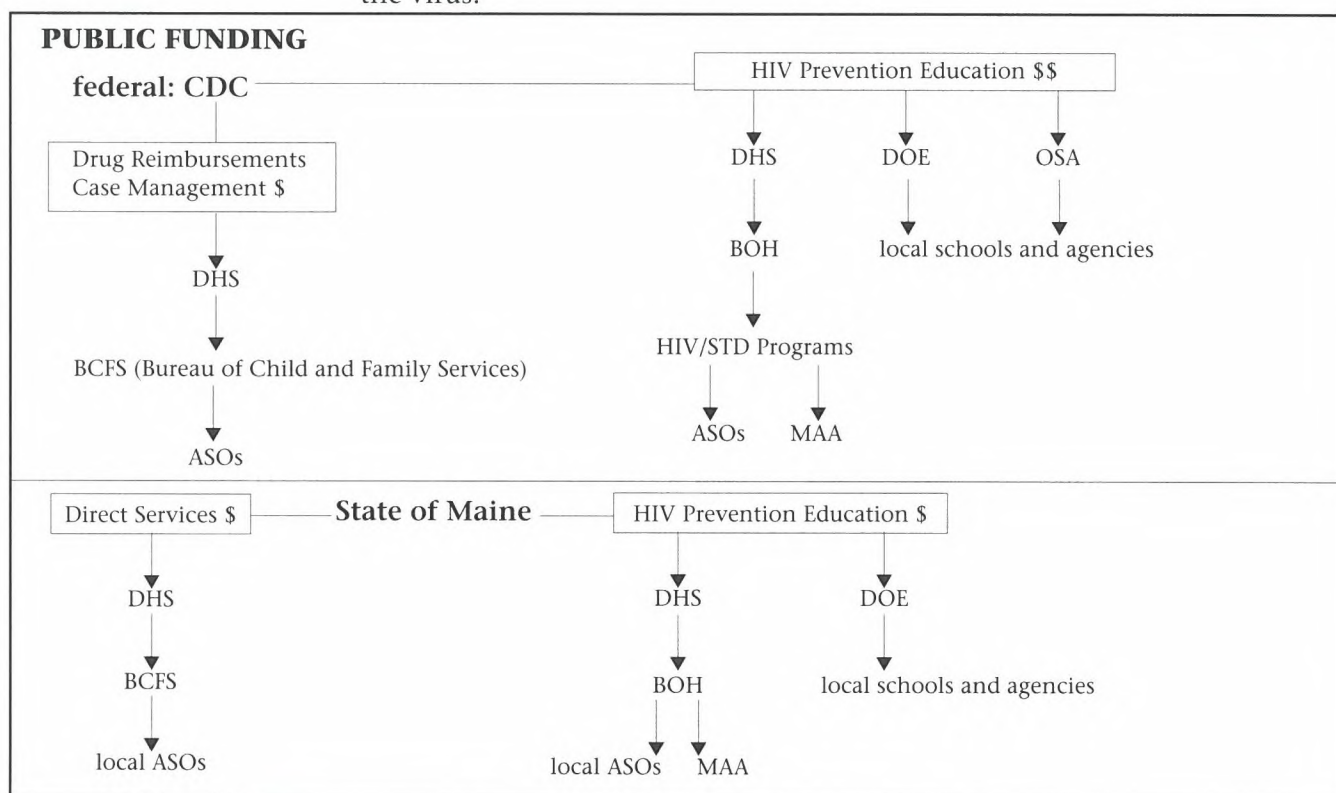
PWAC People with AIDS Coalition
An organization based in Portland which provides support and solidarity for people living with HIV or AIDS.

OSA Office of Substance Abuse
The State agency responsible for addressing substance abuse prevention and treatment and administering state and federal funds locally.

OSHA Occupational Safety & Health Administration

RYAN WHITE CARE ACT The act providing federal funding to support a continuum of direct care services for PWHIV. Maine receives Title II funds.

SEROPREVALENCE The presence of an antibody to HIV in the blood, indicating the presence of the virus.



Maine Law

Included on the following pages are Maine statutes relevant to HIV and AIDS. Summaries are provided below.

Title 5 of the Maine Revised Statutes deals with Administrative Procedures and Services. Within it, Public Health Chapter 501 is the portion of Maine Law that specifically addresses issues related to medical conditions and HIV:

Title 5

Section 19201

This Section gives 'legal' definitions of words and phrases, such as HIV, Health Care Provider, and Seropositivity. The purpose of this Section is to provide a uniform language for dealing with HIV, and HIV related legal issues.

Section 19202

This Section establishes the membership and duties of the Maine HIV Advisory Committee.

Section 19203

An HIV test is confidential; the results may be disclosed to the subject of the test and other individuals specified under this Section. This Section establishes how, and to whom, the results of an HIV test may be disclosed. The results of a confidential HIV test may be disclosed in a variety of instances, to health care providers, research facilities, the Department of Corrections, Human Services and Mental Health and Retardation, and included within an individual's medical record.

Section 19203(A)

An HIV test cannot generally be performed without the consent of the subject. Under this Section, an individual must give his or her informed consent to an HIV test, before the test can be performed. Without informed and freely given consent, testing an individual for HIV is considered battery. However, under a recently passed version of this Section, consent need not be obtained if the court finds that there was occupational exposure or exposure from gross sexual assault; the constitutional validity of these exceptions has not been tested.

Section 19203(B)

The Department of Human Services has the authority to establish anonymous testing sites so that an individual who requests an HIV test can be assured of his or her anonymity.

Section 19203(C)

This Section describes the conditions under which judicial consent can be obtained for HIV testing from an occupational exposure. Facilities may request the Bureau of Health to determine whether a bona fide occupational exposure has occurred. The Bureau of Health annually reports the number

and nature of all bona fide occupational exposures of HIV to the Maine HIV Advisory Committee.

Section 19203(D)

This Section describes how and when the release of a medical record, that includes the results of an HIV test, may occur.

Section 19203(F)

In a recently passed version of this Section, an individual who has been convicted of a sexual crime may be tested for HIV without consent, upon the petition of the individual who was the “victim of the sexual crime.” The state and federal constitutional validity of this section has not been tested.

Section 19204(A)

Under Maine Law, counseling must be offered and provided for each individual who consents to an HIV test. This Section establishes the requirements for offering counseling to individuals who receive an HIV test.

Section 19204(B)

Enforced by the Maine Human Rights Commission, this Section protects a person’s employment status if an employer requests HIV testing. An employee is not required to submit to an HIV test except when based on a bona fide occupational exposure.

Section 19204(C)

Insurers and hospitals may not require results of past HIV tests when a person applies for coverage.

Section 19205

The State of Maine shall provide services to people with HIV or AIDS, coordinated by the Department of Human Services.

In dealing with insurance regulation, Title 24 of the Maine Revised Statutes establishes several important protections for individuals with HIV:

Title 24

Section 2332(B)

This Section prohibits a medical service organization, like a hospital or an HMO, from providing more restrictive coverage for HIV, HIV-related diseases, or AIDS than it does for all other sicknesses and disabilities.

Section 2452

This Section prohibits discrimination against the beneficiary of an insurance plan based upon HIV status; it prohibits an employer from offering insurance that provides more restrictive benefits for HIV and conditions related to HIV than it does to other sicknesses or disabilities.

Title 5 of the Maine Revised Statutes also deals more generally with discrimination, and establishes an individual's Civil and Human Rights under Maine Law. The Maine Human Rights Commission has the authority to investigate and file grievances under the Maine Human Rights Act. In particular, the following Sections pertain to people with HIV/AIDS:

Title 5

Section 4552

This Section enunciates the policy of the State of Maine "to keep continually in review all practices infringing on the basic human right to a life with dignity," and the State's policy to prevent discrimination in employment, housing, or access to public accommodations. The Section extends this policy to individuals with disabilities. Symptomatic HIV, under State and Federal Law, is considered a disability.

Section 4571

This Section establishes that the right to be free from discrimination in employment on the basis of a disability is a civil right.

Section 4572

It is unlawful to discriminate in employment on the basis of disability. This Section describes unlawful employment discrimination. Newly enacted Subsection 2 of 5 MRS Section 4572 makes it unlawful for an employer (or potential employer), to discriminate against a qualified individual on the basis of a disability in hiring, job training, employee compensation, advancement and discharge, or the conditions and privileges of employment.

Other State and Federal Laws may also be applicable to specific situations relevant to an individual's HIV status.

MAINE REVISED STATUTES
 TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
 PART 23. PUBLIC HEALTH
 CHAPTER 501. MEDICAL CONDITIONS
 5 M.R.S. § 19201 (1995)

§ 19201. Definitions

As used in this chapter, unless the context indicates otherwise, the following terms have the following meanings.

1. ANTIBODY TO HIV. "Antibody to HIV" means the specific immunoglobulin produced by the body's immune system in response to HIV.

1-A. Bona fide occupational exposure. "Bona fide occupational exposure" means skin, eye, mucous membrane or parenteral [needle puncture] contact of a person with the potentially infectious blood or other body fluids of another person that results from the performance of duties by the exposed person in the course of employment.

2. HEALTH CARE PROVIDER. "Health care provider" means any appropriately licensed, certified or registered provider of mental or physical health care, either in the public or private sector or any business establishment providing health care services.

3. HIV. "HIV" means the human immunodeficiency virus, identified as the causative agent of Acquired Immune Deficiency Syndrome or AIDS.

4. HIV ANTIGEN. "HIV antigen" means the specific immune-recognizable marker proteins of HIV.

4-A. HIV TEST. "HIV test" means a test for the presence of an antibody to HIV or a test for an HIV antigen or other diagnostic determinants specific for HIV infection.

5. HIV INFECTION. "HIV infection" means the state wherein HIV has invaded the body and is being actively harbored by the body. "HIV Infection Status" means the results of an HIV test.

5-A. INFORMED CONSENT. "Informed consent" means consent that is:

A. Based on an actual understanding by the person to be tested:

- (1) That the test is being performed;
- (2) Of the nature of the test;
- (3) Of the persons to whom the results of that test may be disclosed;
- (4) Of the purpose for which the test results may be used; and
- (5) Of any reasonably foreseeable risks and benefits resulting from the test; and

B. Wholly voluntary and free from expressed or implied coercion.

6. PERSON. "Person" means any natural person, firm, corporation, partnership or other organization, association or group, however organized.

7. SEROPOSITIVITY. "Seropositivity" means the presence of antibody to HIV as detected by appropriate laboratory tests.

8. VIRAL POSITIVITY. "Viral positivity" means demonstrated presence of HIV.

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5 M.R.S. § 19202 (1994)

§ 19202. Maine HIV Advisory Committee

1. DUTIES. The Maine HIV Advisory Committee, as established in section 12004-I, subsection 42 and referred to in this section as the "committee," shall advise all departments and agencies of the State on:

- A. Prevention of the human immunodeficiency virus, referred to in this section as "HIV," and education related to HIV;
- B. Crises that may develop related to HIV;
- C. Services to persons with HIV;
- D. Services for family members and other persons providing care and support to persons with HIV;
- E. HIV-related policy, planning, rules or legislation; and
- F. All fiscal matters related to HIV.

2. MEMBERSHIP. The Maine HIV Advisory Committee consists of 36 members as follows:

- A. One physician who treats a substantial number of children, one physician who treats people with AIDS and one surgeon. Members appointed pursuant to this paragraph must be selected from nominees submitted by the Maine Medical Association and the Maine Osteopathic Association;
- B. One provider of services to homeless persons from nominees submitted by the Maine Coalition for the Homeless;
- C. One nursing home administrator from nominees submitted by the Maine Health Care Association;
- D. One social worker from nominees submitted by the Maine Chapter of the National Association of Social Workers;
- E. One public school health educator from nominees submitted by the Maine School Health Education Committee;
- F. One school nurse from nominees submitted by the Maine School Nurses Association;
- G. One superintendent of a school administrative unit;
- H. One service provider for youth in high-risk situations;
- I. One representative from labor from nominees submitted by the AFL-CIO;
- J. One nurse from nominees submitted by the Maine State Nurses Association;
- K. One person from nominees submitted by the Maine Hospice Council;
- L. One person appointed from nominees submitted by the Maine Hemophilia Treatment Center and the Maine Chapter of New England Hemophilia Association;
- M. One representative of the gay community from nominees submitted by the Maine Lesbian/Gay Political Alliance;
- N. Two persons living with HIV from nominees submitted by the Maine Persons with AIDS Coalition;
- O. One representative from the insurance industry;
- P. One dentist from nominees submitted by the Maine Dental Association;
- Q. Two members of the public, including one parent of a school-age child;
- R. One mental health professional from nominees submitted by the Maine Psychological Association and the Maine Council of Community Mental Health Services;
- S. One member representing hospitals from nominees submitted by the Maine Hospital Association;

- T. One member representing public health professionals from nominees submitted by the Maine Public Health Association;
- U. One infection control practitioner from nominees submitted by the Maine Council for Infection Control Practitioners;
- V. One person from nominees submitted by the Maine Human Rights Commission;
- W. One substance abuse counselor appointed by the Director of the Office of Substance Abuse;
- X. One member of the clergy from nominees submitted by the Maine Council of Churches;
- Y. One representative of AIDS service providers from nominees submitted by the Maine AIDS Alliance;
- Z. One family planning service provider from nominees submitted by the Family Planning Association of Maine;
- AA. One women's health advocate from nominees submitted by the Maine chapter of the National Organization of Women;
- BB. One representative from the American Red Cross from nominations submitted by the American Red Cross State Service Council;
- CC. The Commissioner of Human Services or the commissioner's designee, who serves during the commissioner's term of office;
- DD. One human resources manager from the private sector from nominations submitted by the Maine Chamber of Commerce and Industry; and
- EE. Two Legislators, one Senator appointed by the President of the Senate and one member of the House of Representatives appointed by the Speaker of the House of Representatives.

The members, except for those specifically designated in paragraphs W, CC and EE, must be appointed by the Governor for their competence and experience in connection with these fields, and the field of HIV disease.

3. **TERMS; COMPENSATION.** The term of office of each member is 3 years; except that of the members first appointed, 1/3 must be appointed for a term of one year, 1/3 for a term of 2 years and 1/3 for a term of 3 years; the Commissioner of Human Services or the commissioner's designee serves during the commissioner's term of office; and Legislators serve during the term for which they were elected. The Governor shall designate a chair and vice-chair to serve at the pleasure of the Governor. The chair is the presiding member of the committee. All vacancies must be filled for the balance of the unexpired term in the same manner as original appointments. The members of the committee are entitled to compensation in accordance with chapter 379.

4. **MEETINGS.** The committee shall meet at least 4 times a year and more frequently if needed to respond to the duties of this committee as specified in subsection I. Special meetings may be called by the chair and must be called at the request of the State Epidemiologist, the Director of the Bureau of Health, the Director of Disease Control, the Director of Sexually Transmitted Diseases or by 3 or more members of the committee.

5. **ANNUAL PROGRAM AND BUDGET REVIEW.** The committee shall make an annual assessment of the policies, programs and budget proposals related to HIV of state agencies and may make recommendations related to those policies, programs and budgets.

6. **COMMITTEE MAY ACCEPT FUNDS.** The committee may vote to accept or refuse gifts, grants or other funding that may be offered to the committee.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
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5 M.R.S. § 19203 (1994)

§ 19203. Confidentiality of test

No person may disclose the results of an HIV test, except as follows:

1. SUBJECT OF TEST. To the subject of the test;

2. DESIGNATED HEALTH CARE PROVIDER. To a health care provider designated by the subject of the test in writing. When a patient has authorized disclosure of HIV test results to a person or organization providing health care, the patient's health care provider may make these results available only to other health care providers working directly with the patient, and only for the purpose of providing direct medical or dental patient care. Any health care provider who discloses HIV test results in good faith pursuant to this subsection is immune from any criminal or civil liability for the act of disclosing HIV test results to other health care providers;

3. AUTHORIZED PERSON. To a person or persons to whom the test subject has authorized disclosure in writing, except that the disclosure may not be used to violate any other provisions of this chapter;

4. CERTAIN HEALTH CARE PROVIDERS. A health care provider who procures, processes, distributes or uses a human body part donated for a purpose may, without obtaining informed consent to the testing, perform an HIV test in order to assure medical acceptability of the gift for the purpose intended. Testing pursuant to this subsection does not require pretest and post-test counseling;

5. RESEARCH FACILITY. The Department of Human Services, a laboratory certified and approved by the Department of Human Services pursuant to Title 22, chapter 411, or a health care provider, blood bank, blood center or plasma center may, for the purpose of research and without first obtaining informed consent to the testing, subject any body fluids or tissues to an HIV test if the testing is performed in a manner by which the identity of the test subject is not known and may not be retrieved by the researcher;

6. ANONYMOUS TESTING SITES. To an anonymous testing site established pursuant to section 19203-B;

7. OTHER AGENCIES. To employees of, or other persons designated by, the Department of Corrections, the Department of Human Services and the Department of Mental Health and Mental Retardation, to the extent that those employees or other persons are responsible for the treatment or care of subjects of the test. Those agencies shall promulgate rules, within 90 days of the effective date of this subsection, pursuant to the Maine Administrative Procedure Act, chapter 375, subchapter II, designating the persons or classes of persons to whom the test results may be disclosed;

8. BUREAU OF HEALTH. To the Bureau of Health, which may disclose results to other persons only if that disclosure is necessary to carry out its duties as provided in Title 22, sections 3, 7 and 42 and chapters 250 and 251;

9. MEDICAL RECORDS. As part of a medical record when release or disclosure of that record is authorized pursuant to section 19203-D; or

10. COURT ORDERED DISCLOSURE. To:

A. A person authorized by section 19203-C to receive test results following an accidental exposure; or

B. A victim-witness advocate authorized by section 19203-E to receive test results of a person convicted of a sexual crime as defined in Section 19203-F, Subsection 1, Paragraph C, who shall disclose to a victim under section 19203-F, Subsection 4.

This section does not prohibit limited administrative disclosure in conjunction with a mandatory testing program of a military organization subject to Title 37-B.

Nothing in this section may be construed as prohibiting the entry of an HIV test result on the patient's medical record in accordance with this chapter.

MAINE REVISED STATUTES
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5 M.R.S. § 19203-A (1995)

§ 19203-A. Informed consent required

1. **INDIVIDUAL TESTED.** Except as provided in this section and section 19203, subsections 4 and 5, no person may perform an HIV test without first obtaining the written informed consent of the person to be tested. Informed consent is not required for repeated HIV testing by health care providers to monitor the course of established infection. Anonymous test sites under section 19203-B are exempt from the requirement that the informed consent be in writing.

2. **INSURERS.** Persons required to take an HIV test by an insurer, nonprofit hospital or medical service organization or nonprofit health care plan must provide their written informed consent on forms approved by the Superintendent of Insurance. Pretest and post-test counseling must be provided by the person or organization requesting the test. The Superintendent of Insurance may promulgate rules to define language requirements of the form.

3. **ACCESS TO MEDICAL CARE.** No health care provider may deny any person medical treatment or care solely for refusal to give consent for an HIV test. No health care provider may request a person's written consent to an HIV test as a precondition to the provision of health care. All written consent to testing shall be in accordance with section 19201, subsection 5-A. Nothing in this section may prohibit a health care provider from recommending an HIV test for diagnostic or treatment purposes. No physician or other health care provider may be civilly liable for failing to have an HIV test performed for diagnostic or treatment purposes if the test was recommended and refused in writing by the patient.

4. **OCCUPATIONAL EXPOSURE.** Consent need not be obtained when a bona fide occupational exposure creates a significant risk of infection provided that a court order has been obtained under section 19203-C. The fact that an HIV test was given as a result of an occupational exposure and the results of that test may not appear in any records of the person whose blood or body fluid is the source of the exposure. Pretest and post-test counseling must be offered. The subject of the test may choose not to be informed about the result of the test.

5. **EXPOSURE FROM SEXUAL CRIME.** Consent need not be obtained when a court order has been issued under section 19203-F. The fact that an HIV test was given as a result of the exposure and the results of that test may not appear in a convicted offender's medical record. Counseling on risk reduction must be offered, but the convicted offender may choose not to be informed about the result of the test unless the court has ordered that the convicted offender be informed of the result.

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5 M.R.S. § 19203-B (1994)

§ 19203-B. Anonymous testing sites

The Department of Human Services may designate or establish certification and approval standards for and support anonymous testing sites where an individual may request an HIV test under conditions which ensure anonymity.

MAINE REVISED STATUTES
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5 M.R.S. § 19203-C (1995)

1. Petition. Any person who experiences a bona fide occupational exposure may petition the District Court with jurisdiction over the facility or other place where the exposure occurred to require the person whose blood or body fluid is the source of the exposure to submit to an HIV test provided that the following conditions have been met:

- A. The exposure to blood or body fluids creates a significant risk of HIV infection, as defined by the Bureau of Health through the adoption of rules in accordance with the Maine Administrative Procedure Act, chapter 375;
- B. The authorized representative of the employer of the person exposed has informed the person whose blood or body fluid is the source of the occupational exposure and has sought to obtain written informed consent from the person whose blood or body fluid is the source of the exposure; and
- C. Written informed consent was not given by the person whose blood or body fluid is the source of the exposure and that person has refused to be tested.

2. Prehearing duties of the court. Upon receipt by the District Court of the petition, the court shall:

- A. Schedule a hearing to be held as soon as practicable;
- B. Cause a written notice of the petition and hearing to be given, in accordance with the Maine Rules of Civil Procedure, to the patient who is the subject of the proceeding;
- C. Appoint counsel, if requested, for any indigent client not already represented; and
- D. Furnish counsel with copies of the petition.

3. Hearing. The hearing shall be governed as follows.

- A. The hearing shall be conducted in accordance with the Maine Rules of Evidence and in an informal manner consistent with orderly procedure.
- B. The hearing shall be confidential and be electronically or stenographically recorded.
- C. The report of the hearing proceedings must be sealed. No report of the hearing proceedings may be released to the public, except by permission of the person whose blood or body fluid is the source of the exposure or that person's counsel and with approval of the court.
- D. The court may order a public hearing at the request of the person whose blood or body fluid is the source of the exposure or that person's counsel.

4. Determination. The court may require the person whose blood or body fluid is the source of the exposure to obtain an HIV test only if the petitioner proves, by a preponderance of the evidence, that:

- A. The exposure to blood or body fluids of the person created a significant risk of HIV infection as determined by the Bureau of Health through the adoption of rules in accordance with the Maine Administrative Procedure Act, chapter 375;
- B. An authorized representative of the employer of the person exposed has informed the patient of the occupational exposure and has sought to obtain written informed consent from the person whose blood or body fluid is the source of the exposure; and
- C. Written informed consent was not given by the person whose blood or body fluid is the source of the exposure and that person has refused to be tested.

In determining whether to order the test, the court shall consider the balance of benefit and harm to both individuals if the test is ordered.

5. Consent. The court may not order a person whose blood or body fluid is the source of the exposure to obtain an HIV test unless the employee exposed to the blood or body fluids of that person has consented

to and obtained an HIV test immediately following that documented exposure.

6. Cost. The employer of the person exposed is responsible for the petitioner's reasonable costs related to obtaining the results of an HIV test pursuant to this section, including the payment of the petitioner's attorneys' fees.

7. Appeals. A person required to undergo an HIV test may appeal the order to Superior Court. The appeal is limited to questions of law. Any findings of fact of the district court may not be set aside unless clearly erroneous.

9. Subsequent testing of the patient. Subsequent testing arising out of the same incident of occupational exposure must be conducted in accordance with this section.

10. Bureau of Health Report. The Bureau of Health shall report on an annual basis to the Maine HIV Advisory Committee the following information:

A. The number of incidents in which the Bureau of Health is requested to determine under subsection 1, paragraph A, whether a bona fide occupational exposure has occurred; and

B. With regard to the incidents reported in paragraph A, the occupations represented, the nature of or description of the incidents determined to be or not to be bona fide occupational exposures.

MAINE REVISED STATUTES
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5 M.R.S. § 19203-D (1995)

§ 19203-D. Records

When a medical record entry is made concerning information of a person's HIV infection status, including the results of an HIV test, the following shall apply to the release of that information as a part of the medical record.

1. **AUTHORIZED RELEASE.** The person who is the subject of an HIV test, at or near the time the entry is made in the medical record, shall elect, in writing, whether to authorize the release of that portion of the medical record containing the HIV infection status information when that person's medical record has been requested. A new election may be made when a change in the person's HIV infection status occurs or whenever the person makes a new election. The release form must clearly state whether or not the person has authorized the release of that information. The person must be advised of the potential implications of authorizing the release of that information.

A. When release has been authorized, the custodian of the medical record may release, upon request, the person's medical record, including any HIV infection status information contained in the medical record. Release of HIV infection status information pursuant to this paragraph is not a violation of any of the confidentiality provisions of this chapter.

B. When release has not been authorized, the custodian of the medical record may, upon request, release that portion of the medical record that does not contain the HIV infection status information. Except as otherwise provided in this section, HIV infection status information may be released only if the person has specifically authorized a separate release of that information. A general release form is insufficient.

2. **AUTHORIZED DISCLOSURE.** A medical record containing results of an HIV test may not be disclosed, discoverable or compelled to be produced in any civil, criminal, administrative or other proceedings without the consent of the person who is the subject of an HIV test, except in the following cases:

- A. Proceedings held pursuant to the communicable disease laws, Title 22, chapter 251;
- B. Proceedings held pursuant to the Adult Protective Services Act, Title 22, chapter 958-A;
- C. Proceedings held pursuant to the child protection laws, Title 22, chapter 1071;
- D. Proceedings held pursuant to the mental health laws, Title 34-B, chapter 3, subchapter IV, article III; and
- E. Pursuant to a court order upon a showing of good cause, provided that the court order limits the use and disclosure of records and provides sanctions for misuse of records or sets forth other methods for ensuring confidentiality.

3. **UTILIZATION REVIEW; RESEARCH.** Nothing in this section may be interpreted to prohibit reviews of medical records for utilization review purposes by duly authorized utilization review committees or peer review organizations. Qualified personnel conducting scientific research, management audits, financial audits or program evaluation with the use of medical records may not identify, directly or indirectly, any individual patient in any report of such research, audit, evaluation or otherwise disclose the identities of persons tested in any manner.

4. **ACCESS BY HEALTH CARE PROVIDERS.** Nothing in this section may prohibit access to medical records by the designated health care provider of the person who is the subject of an HIV test in accordance with section 19203, subsection 2.

5. **CONFIDENTIALITY POLICY.** Health care providers and others with access to medical records containing HIV infection status information shall have a written policy providing for confidentiality of all patient information consistent with this chapter. That policy must require, at a minimum, action consistent with the disciplinary procedures for violations of the confidentiality policy.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
PART 23. PUBLIC HEALTH
CHAPTER 501. MEDICAL CONDITIONS
5 M.R.S. § 19203-F (1995)

§ 19203-F. HIV Test After Conviction for Sexual Assault

I. DEFINITIONS. As used in this section, unless the context otherwise indicates, the following terms have the following meanings.

A. "Convicted Offender" means a person who has been convicted of a sexual crime or, in the case of a juvenile, a person who has been adjudicated as having committed a sexual crime.

B. "Incapacitated Adult" means an adult who is impaired by reason of mental illness, mental deficiency, physical illness or disability to the extent that the individual lacks sufficient understanding or capacity to make or communicate responsible decisions concerning that individual.

C. "Sexual Crime" means a crime involving a sexual act, as defined in title 17-A, section 251, subsection 1, paragraph C, subparagraph (1).

2. REQUEST FOR TESTING. A person who is the victim of a sexual crime, or that person's parent, guardian or authorized representative if that person is a minor or incapacitated adult, may petition the court at any time prior to sentencing or no later than 180 days after conviction to order the convicted offender to submit to HIV testing and to order that the convicted offender be informed of the test results.

3. DUTIES OF THE COURT. Upon receipt of the petition, the court shall order that the convicted offender obtain HIV testing conducted by or under authority of the Department of Human Services and, if requested by the petitioner, that the convicted offender be informed of the test results.

4. REPORTING AND COUNSELING. The health care facility in which a convicted offender is tested pursuant to this section shall disclose the results of the test to the victim-witness advocate, who shall disclose the results to the petitioner. The test results may not be disclosed to the petitioner until the petitioner has received counseling, pursuant to section 19204-A, regarding the nature, reliability and significance of the convicted offender's HIV test and has been offered referrals for health care and support services for the victim. The health care facility shall, upon order of the court, disclose the results of the test to the convicted offender.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
PART 23. PUBLIC HEALTH
CHAPTER 501. MEDICAL CONDITIONS
5 M.R.S. § 19204-A (1995)

§ 19204-A. Counseling

Except as otherwise provided by this chapter, persons who are the subjects of HIV tests must be offered pretest and post-test counseling. Persons who are authorized by section 19203-C or 19203-F to receive test results after exposure must be offered counseling regarding the nature, reliability and significance of the HIV test and the confidential nature of the test. Persons offered counseling under this section may decline the offer by signing a waiver stating that counseling has been offered and is being declined.

1. PRETEST COUNSELING. "Pretest counseling" must include:

A. Face-to-face counseling that includes, at a minimum, a discussion of:

- (1) The nature and reliability of the test being proposed;
- (2) The person to whom the results of the test may be disclosed;
- (3) The purpose for which the test results may be used;
- (4) Any reasonably foreseeable risks and benefits resulting from the test; and
- (5) Information on good HIV preventive practices and HIV risk reduction plans; and

B. A written memorandum summarizing the contents of the discussion concerning at least the topics listed in paragraph A, subparagraphs (1) to (5) given to the person being counseled. A written informed consent form may be used to satisfy the requirement for a written memorandum in this paragraph if it contains all the required information. A written consent form does not satisfy the requirement for personal counseling in paragraph A.

The provider of an HIV test may offer group pretest counseling, but individual counseling must be provided if the subject of the test requests it.

2. POST-TEST COUNSELING. "Post-test counseling" must include:

A. Personal counseling that includes, at a minimum, a discussion of:

- (1) The test results and the reliability and significance of the test results;
- (2) The social and emotional consequences of the information;
- (3) Information on good preventive practices and risk reduction plans; and
- (4) Referrals for medical care and information and referrals for support services, including social, emotional support and legal services, as needed;

B. A written memorandum summarizing the contents of the discussion given to the person being counseled; and

C. The offer of face-to-face counseling. If the subject of the test declines, the provider of the test may provide an alternative means of providing the information required by paragraph A.

MAINE REVISED STATUTES

TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES

PART 23. PUBLIC HEALTH

CHAPTER 501. MEDICAL CONDITIONS

5 M.R.S. § 19204-B (1995)

1. Employee testing. An employee or applicant for employment may not be required to submit to an HIV test or reveal whether the employee or applicant for employment has obtained an HIV test as a condition of employment or to maintain employment, except when based on a bona fide occupational qualification. The Maine Human Rights Commission shall enforce this subsection.

2. Employee rights. The employment status of any employee may not be affected or changed:

- A. If the employee declines to be tested pursuant to section 19203-A;
- B. If the employee testifies or assists in any proceeding under this chapter;
- C. If the employee asserts any other rights exercised in good faith pursuant to this chapter; or
- D. Because of the result of any test taken pursuant to this chapter.

MAINE REVISED STATUTES

TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES

PART 23. PUBLIC HEALTH

CHAPTER 501. MEDICAL CONDITIONS

5 M.R.S. § 19204-C (1995)

§ 19204-C. Restrictions upon revealing HIV antibodies test results

An insurer, nonprofit hospital or medical services organization, nonprofit health care plan or health maintenance organization may not request any person to reveal whether the person has obtained a test for the presence of antibodies to HIV or a test to measure the virus or to reveal the results of such tests taken prior to an application for insurance coverage.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
PART 23. PUBLIC HEALTH
CHAPTER 501. MEDICAL CONDITIONS
5 M.R.S. § 19205 (1995)

§ 19205. Coordination of services to persons with AIDS, AIDS Related Complex and viral positivity

1. Policy; services. It is the policy of the State to provide to persons who test positive for HIV or have been diagnosed as having AIDS the services of departments and agencies, including, but not limited to, the Department of Education, the Department of Mental Health and Retardation, the Department of Human Services and the Department of Corrections.

2. Coordination of services. A person designated by the Commissioner of Human Services shall ensure coordination of new and existing services so as to meet the needs of persons with HIV or AIDS and identify gaps in programs.

The committee established in section 12004-I, subsection 42, shall work with the person designated in this chapter to ensure the coordination of services to meet the needs of persons with HIV or AIDS.

3. Development of a client support services system. A client support services system shall be developed to assist individuals infected with the Human Immune Deficiency Virus and to ensure that they receive necessary services. The client support service, arranged by the staff of community-based agencies, shall include, but not be limited to, assisting the individual's needs and assisting the individual with obtaining access to necessary health care, social service, housing, transportation, counseling and income maintenance services. The Department of Human Services shall be responsible for providing overall direction for the development of the client support services system.

MAINE REVISED STATUTES
TITLE 24. INSURANCE
CHAPTER 19. NONPROFIT HOSPITAL OR MEDICAL SERVICE ORGANIZATIONS
SUBCHAPTER I. GENERAL PROVISIONS
24 M.R.S. § 2332-B (1994)

§ 2332-B. Acquired Immune Deficiency Syndrome

1. DEFINITIONS. As used in this section, "HIV" and "antibody to HIV" have the same meanings as set out in Title 5, section 19201.

2. PROHIBITIONS. No individual or group hospital, medical or health care service contract delivered or issued for delivery in this State, other than a contract that provides benefits for specific diseases or accidental injuries only, may provide more restrictive coverage for Acquired Immune Deficiency Syndrome, or AIDS, AIDS Related Complex, or ARC, HIV-related diseases or for related services, than for any other disease or sickness, or exclude coverage for AIDS, ARC or HIV-related diseases, except through an exclusion under which all diseases and sicknesses are treated equally.

3. TEST RESULTS. No nonprofit hospital or medical services organization or nonprofit health care plan may request any person to reveal whether the person has obtained a test for the presence of antibodies to HIV or a test to measure the virus or to reveal the results of such tests taken prior to an application for coverage.

MAINE REVISED STATUTES
TITLE 24-A. MAINE INSURANCE CODE
CHAPTER 27. THE INSURANCE CONTRACT
24-A M.R.S. § 2452 (1994)

§ 2452. Employee benefit excess insurance; nondiscrimination; prohibited clauses

1. DISCRIMINATION PROHIBITED. A policy of employee benefit excess insurance may not discriminate unfairly among or against beneficiaries of the underlying benefit plan, or treat conditions related to the Human Immunodeficiency Virus, or HIV, more restrictively than other sicknesses or disabling conditions.

2. COMMUTATION CLAUSE. A policy of employee benefit excess insurance may not contain a commutation clause that extinguishes the excess carrier's gross claims liability to the insured person through the recapture of loss reserves, unless the policy contains a provision giving the insured the option of requiring that the funds transferred in support of such a commutation have been evaluated by a qualified health actuary who is a member of the American Academy of Actuaries and has certified that the aggregate value of reserves to be recaptured are reasonably adequate to discharge the insured's expected liability for future costs of the health benefits covered by the excess policy.

3. REVIEW. An employee benefit excess insurance form is not exempt from the review provisions otherwise applicable under section 2412 on the ground that the form is designed for insurance on a particular subject.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
PART 12. HUMAN RIGHTS
CHAPTER 337. HUMAN RIGHTS ACT
SUBCHAPTER I. GENERAL PROVISIONS
5 M.R.S. § 4552 (1994)

§ 4552. Policy

To protect the public health, safety and welfare, it is declared to be the policy of this State to keep continually in review all practices infringing on the basic human right to a life with dignity, and the causes of these practices, so that corrective measures may, where possible, be promptly recommended and implemented, and to prevent discrimination in employment, housing or access to public accommodations on account of race, color, sex, physical or mental disability, religion, ancestry or national origin; and in employment, discrimination on account of age or because of the previous assertion of a claim or right under former Title 39 or Title 39-A and in housing because of familial status; and to prevent discrimination in the extension of credit on account of age, race, color, sex, marital status, religion, ancestry or national origin; and to prevent discrimination in education on account of sex or physical or mental disability.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
PART 12. HUMAN RIGHTS
CHAPTER 337. HUMAN RIGHTS ACT
SUBCHAPTER III. FAIR EMPLOYMENT
5 M.R.S. § 4571 (1994)

§ 4571. Right to freedom from discrimination in employment

The opportunity for an individual to secure employment without discrimination because of race, color, sex, physical or mental disability, religion, age, ancestry or national origin is recognized as and declared to be a civil right.

MAINE REVISED STATUTES
TITLE 5. ADMINISTRATIVE PROCEDURES AND SERVICES
PART 12. HUMAN RIGHTS
CHAPTER 337. HUMAN RIGHTS ACT
SUBCHAPTER III. FAIR EMPLOYMENT

5 M.R.S. § 4572 (1994)

§ 4572. Unlawful employment discrimination

1. UNLAWFUL EMPLOYMENT. It is unlawful employment discrimination, in violation of this Act, except when based on a bona fide occupational qualification:

A. For any employer to fail or refuse to hire or otherwise discriminate against any applicant for employment because of race or color, sex, physical or mental disability, religion, age, ancestry or national origin, because of the applicant's previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions taken by the applicant that are protected under Title 26, chapter 7, subchapter V-B; or, because of those reasons, to discharge an employee or discriminate with respect to hire, tenure, promotion, transfer, compensation, terms, conditions or privileges of employment or any other matter directly or indirectly related to employment; or, in recruiting of individuals for employment or in hiring them, to utilize any employment agency that the employer knows or has reasonable cause to know discriminates against individuals because of their race or color, sex, physical or mental disability, religion, age, ancestry or national origin, because of their previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions that are protected under Title 26, chapter 7, subchapter V-B;

(1) This paragraph does not apply to discrimination governed by Title 39-A, section 353;

B. For any employment agency to fail or refuse to classify properly, refer for employment or otherwise discriminate against any individual because of race or color, sex, physical or mental disability, religion, age, ancestry or national origin, because of the individual's previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions taken by the individual that are Protected under Title 26, chapter 7, subchapter V-B; or to comply with an employer's request for the referral of job applicants if a request indicates either directly or indirectly that the employer will not afford full and equal employment opportunities to individuals regardless of their race or color, sex, physical or mental disability, religion, age, ancestry or national origin, because of previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions that are protected under Title 26, chapter 7, subchapter V-B;

C. For any labor organization to exclude from apprenticeship or membership or to deny full and equal membership rights to any applicant for membership because of race or color, sex, physical or mental disability, religion, age, ancestry or national origin, because of the applicant's previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions taken by the applicant that are protected under Title 26, chapter 7, subchapter V-B; or, because of those reasons, to deny a member full and equal membership rights, expel from membership, penalize or otherwise discriminate with respect to hire, tenure, promotion, transfer, compensation, terms, conditions or privileges of employment, representation, grievances or any other matter directly or indirectly related to membership or employment, whether or not authorized or required by the constitution or bylaws of that labor organization or by a collective labor agreement or other contract; to fail or refuse to classify properly or refer for employment or otherwise discriminate against any member because of race or color, sex, physical or mental disability, religion, age, ancestry or national origin, because of the member's previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions taken by the member that are protected under Title 26, chapter 7, subchapter V-B; or to cause or attempt to cause an employer to discriminate against an individual in violation of this section, except that it is lawful for labor organizations and employers to adopt a maximum age limitation in apprenticeship programs, if the employer or labor organization obtains prior approval from the Maine Human Rights Commission of any maximum age limitation employed in an apprenticeship program. The commission shall approve the age limitation if a reasonable relationship exists between the maximum age limitation

employed and a legitimate expectation of the employer in receiving a reasonable return upon the employer's investment in an apprenticeship program. The employer or labor organization bears the burden of demonstrating that such a relationship exists;

D. For any employer, employment agency or labor organization, prior to employment or admission to membership of any individual, to:

(1) Elicit or attempt to elicit information directly or indirectly pertaining to race or color, sex, physical or mental disability, religion, age, ancestry or national origin, any previous assertion of a claim or right under former Title -9 or Title 39-A or any previous actions that are protected under Title 26, chapter 7, subchapter V-B, except when a physical or mental disability is determined by the employer, employment agency or labor organization to be job related or when some privileged information is necessary for an employment agency or labor organization to make a suitable job referral;

(2) Make or keep a record of race or color, sex, physical or mental disability, religion, age, ancestry or national origin, any previous assertion of a claim or right under former Title 39 or Title 39-A or any previous actions that are protected under Title 26, chapter 7, subchapter V-B, except under physical or mental disability when an employer requires a physical or mental examination prior to employment, a privileged record of that examination is permissible;

(3) Use any form of application for employment, or personnel or membership blank containing questions or entries directly or indirectly pertaining to race or color, sex, physical or mental disability, religion, age, ancestry or national origin, any previous assertion of a claim or right under former Title 39 or Title 39-A or any previous actions that are protected under Title 26, chapter 7, subchapter V-B, except under physical or mental disability when it can be determined by the employer that the job or jobs to be filled require that information for the well-being and safety of the individual. This section does not prohibit any officially recognized agency from keeping necessary records in order to provide free services to individuals requiring rehabilitation or employment assistance;

(4) Print, publish or cause to be printed or published any notice or advertisement relating to employment or membership indicating any preference, limitation, specification or discrimination based upon race or color, sex, physical or mental disability, religion, age, ancestry or national origin, any previous assertion of a claim or right under former Title 39 or Title 39-A or any previous actions that are protected under Title 26, chapter 7, subchapter V-B, except under physical or mental disability when the text of printed or published material strictly adheres to this Act; or

(5) Establish, announce or follow a policy of denying or limiting, through a quota system or otherwise, employment or membership opportunities of any group because of the race or color, sex, physical or mental disability, religion, age, ancestry or national origin, the previous assertion of a claim or right under former Title 39 or Title 39-A or because of previous actions that are protected under Title 26, chapter 7, subchapter V-B, of that group; or

E. For an employer, employment agency or labor organization to discriminate in any manner against individuals because they have opposed a practice that would be a violation of this Act or because they have made a charge, testified or assisted in any investigation, proceeding or hearing under this Act.

2. Unlawful discrimination against a qualified individual with a disability. A covered entity may not discriminate against a qualified individual with a disability because of the disability of the individual in regard to job application procedures, the hiring, advancement or discharge of employees, employee compensation, job training and other terms, conditions and privileges of employment. A qualified individual with a disability, by reason of that disability, may not be excluded from participation in or be denied the benefits of the services, programs or activities of a public covered entity, or be subjected to discrimination by any such covered entity relating to job application procedures, the hiring, advancement or discharge of employees, employee compensation, job training and other terms, conditions and privileges of employment.

A. The prohibition of this subsection against discrimination includes medical examinations and inquiries.

B. Except as provided in paragraph C, a covered entity may not conduct a medical examination or make inquiries of a job applicant as to whether the applicant is an individual with a disability or as to the nature or severity of the disability. A covered entity may make pre-employment inquiries into the ability of an applicant to perform job-related functions.

C. A covered entity may require a medical examination after an offer of employment has been made to a job applicant and prior to the commencement of the employment duties of the applicant and may condition an offer of employment on the results of the examination, if:

- (1) All entering employees are subjected to the same examination regardless of disability;
- (2) Information obtained regarding the medical condition or history of the applicant is collected and maintained on separate forms and in separate medical files and is treated as a confidential medical record, except that:
 - (A) Supervisors and managers may be informed regarding necessary restrictions on the work or duties of the employee and necessary accommodations;
 - (B) First aid and safety personnel may be informed, when appropriate, if the disability might require emergency treatment; and
 - (C) Government officials investigating compliance with this act are provided relevant information on request; and
- (3) The results of the examination are used only in accordance with this Act.

D. A covered entity may not require a medical examination and may not make inquiries of an employee as to whether the employee is an individual with a disability or as to the nature or severity of the disability, unless the examination or inquiry is shown to be job-related and consistent with business necessity.

E. A covered entity may conduct voluntary medical examinations, including voluntary medical histories, that are part of an employee health program available to employees at that work site. A covered entity may make inquiries into the ability of an employee to perform job-related functions. Information obtained under this paragraph regarding the medical condition or history of an employee is subject to the requirements of paragraph C, subparagraphs (2) and (3).

F. For purposes of this subsection, a test to determine the illegal use of drugs may not be considered a medical examination.

(1) A covered entity:

- (A) May prohibit the illegal use of drugs and the use of alcohol at the workplace by all employees;
- (B) May require that employees may not be under the influence of alcohol or be engaging in the illegal use of drugs at the workplace;
- (C) May require that employees behave in conformance with the requirements established under the Federal Drug-free Workplace Act of 1988, 41 United States code, section 701 et seq.; and
- (D) May hold an employee who engages in the illegal use of drugs or who is an alcoholic to the same qualification standards for employment or job performance and behavior to which that entity holds other employees, even if any unsatisfactory performance or behavior is related to the drug use or alcoholism of the employee, provided that an employer shall make reasonable accommodation to an alcoholic or drug user who is seeking treatment or has successfully completed treatment.

Americans with Disabilities Act Summary

The Americans With Disabilities Act: 42 USCA @ 12101

Recognizing the effects of pervasive discrimination against the sick and the disabled, Congress passed the **Americans with Disabilities Act** in 1990 to prohibit discrimination on the basis of disability in employment, the provision of public services and access to public accommodations. Congress has defined a disabled person as one who (i) has a physical or mental disability which substantially limits one or more of such person's life activities, (ii) has a record of such impairment, or (iii) is regarded as having an impairment. Under state and Federal law, the people of Maine who have asymptomatic HIV are covered under the first and or third sections of this definition. HIV is considered a physical disability that substantially limits major life activities such as sex and procreation.

Employers with more than fifteen employees may not discriminate against a qualified individual in 'regard to job application procedures, the hiring, advancement or discharge of employees, employee compensation, job training and other terms, conditions and privileges of employment.' The ADA protects an otherwise qualified employee (or candidate for employment) from discrimination if he or she can perform the essential functions of his/her positions with the help of reasonable accommodations. Reasonable accommodations include modifying work schedules, transferring the employee to another position and other changes which do not create undue hardship for an employer. The fear of co-workers or customers can never constitute an undue burden, and employers have a legal obligation to support the rights of an employee with HIV.¹

In addition, Congress extended the **Americans with Disabilities Act** to protect against discrimination on the basis of disability in the provision of services by a public accommodation. The ADA proscribes that 'no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of goods, services, facilities, privileges, advantages or accommodations of any public place.' A public accommodation includes, but is not limited to, a hair salon, a bar or restaurant, a hotel, and a retail store. In a recent New Hampshire case the court suggested that an insurance provider was a public accommodation and could thus not discriminate in the distribution of services on the basis of disability. Although religious groups and private clubs are excepted from coverage under the ADA, any service that is provided to the public at large must be made available to individuals who are HIV+.

1. Cline, Geoffrey, *AIDS PRACTICE MANUAL*, National Lawyers Guild AIDS Network (3rd Ed., 1991), Chapter 10.

OSHA Bloodborne Pathogen Standards Summary

Occupational Safety and Health Act: 29 CFR @ 1910. 1911

The Occupational Safety and Health Administration (OSHA) has developed a policy on bloodborne pathogens to protect employees from occupational exposure to diseases like HIV. Whenever it may be reasonably anticipated that a specific eye, mouth, other mucous membrane, non-intact skin or parenteral (needle puncture) will be exposed to blood or other potentially infectious material as a result of the performance of an employee's duties, an employer must develop a written exposure control plan. The plan must be designed to eliminate or minimize employee exposure, and shall contain (1) the methods of compliance (treating all body fluids as infectious, providing sanitation and disposal facilities, minimizing splashing blood), (2) provisions for personal protection (gloves, masks and gowns where needed), (3) specific rules of HIV research and production facilities, (4) post-exposure evaluation and, where possible prophylactic treatment, (5) signs warning of the hazards, and (6) record keeping of the names and personal information of each employee who has been exposed to a bloodborne pathogen while performing work duties.

HIV PREVENTION COMMUNITY PLANNING GROUP

REPORT OF HIV PREVENTION EDUCATION PRIORITIES

The HIV Prevention Community Planning Group (CPG)

(previously the Priority Review Task Force)

HIV Prevention Education Priorities

REPORT— February, 1995

CPG Goal: *To define and prioritize Maine's populations at high risk for HIV and define prevention intervention efforts for each population.*

Over the summer and fall of 1994, the Priority Review Task Force, now the HIV Prevention Community Planning Group (CPG) of the Maine AIDS Plan, utilized existing research and documents—the Maine Community AIDS Partnership Needs Assessment, the Plan's Population and HIV Subcommittee Reports, etc.—and compiled first-hand data in certain areas to assist in this prioritization process.

These preliminary recommendations were incorporated into the final report to the Maine Bureau of Health and the Centers for Disease Control at the end of the first year, 1994, of CDC-funded HIV community planning. The priorities and interventions are continually being reviewed and revised each year by the CPG with extensive community input.

These recommendations determine the types of intervention activities that will receive HIV prevention funding through the Bureau of Health from the CDC.

Recommendations outlined in the following pages:

A. Prioritized High Risk Populations in Maine

Defined and supported by epidemiological data, infection prevalence and infection trends in Maine.

B. Prioritized Prevention Strategies for High Risk Populations

Current prevention strategies and funding do not always respond in a practical and appropriate manner to the most basic prevention needs. The PRTF addressed some of the issues hampering effective prevention within each of the prioritized populations, and recommended prioritized strategies reflecting an epidemiological, sociological, and cultural assessment.

C. General Recommendations for Improving Prevention Efforts in the State

Some issues arose affecting all prevention activities which should be addressed on a statewide level.

A. Prioritized High Risk Populations in Maine

Data for assessing the HIV epidemic in Maine comes from a number of sources: physician AIDS case reports, reports of HIV infection (without identifiers) from physicians and Anonymous HIV Testing and Counseling Sites, blinded seroprevalence surveys among childbearing women and STD clinic patients, hospital discharge data, and HIV screening of Maine military recruits and blood donors.

Additional useful information includes reports of other sexually transmitted diseases and on Hepatitis B infection.

1. Males Who Have Sex With Males (MSM) includes male youth and HIV+ males

The majority (73%) of recently-diagnosed cases of AIDS continue to be seen among gay and bisexual men, as is true in most non-urbanized areas of the U.S., where levels of injection drug use are relatively low. As with AIDS cases in general, there is a trend to more rural residence among AIDS-diagnosed men who have sex with men. Of the 476 adults reported to date (July, 1994) in Maine, 355 (75%) have had male-male sexual risk.

2. Females Who Have Sex With MSM or Injecting Drug Users (IDUs) includes female youth and HIV+ females

The incidence of women being infected has slowly but persistently been increasing in Maine as elsewhere. While only one case of AIDS in a woman had been reported prior to 1988, 11% of 1993

Maine AIDS cases were female. Almost twice as many women with AIDS in Maine were infected through heterosexual exposure (24), in most cases to a male with an IV drug history, as were exposed through their own IV drug use (13).

3. Injecting Drug Users (IDUs) includes HIV+ IDUs

Potentially 13% of all AIDS cases in Maine so far are the result of using shared needles for IV drug abuse. A population very difficult to define and localize, IV drug users are at extremely high risk for HIV infection.

4. People of Color

While racial and ethnic minorities constitute less than 2% of the Maine population, almost 5% of Maine's AIDS cases have been diagnosed among non-white and Hispanic persons. Through mid-1994, these included 13 cases among African-Americans, 7 cases among Hispanic whites, and 5 among Native Americans.

The majority of these cases occurred among persons who had male-male sexual risks (38%), or a history of injection drug use (35%).

5. Other Populations With Certain Markers for High Risk:

Some population sub-groups in Maine are perceived to be at relatively higher HIV risk despite the paucity of hard local data to demonstrate increased HIV prevalence or AIDS incidence in those populations. They include:

- Homeless/transient
- "At-risk" Youth
- Substance Abusers
- Mentally Ill
- Developmentally Disabled

The concerns for these populations are based largely on the potential for increased levels of risk for sexual exposure; the sexual risks may be increased because of impaired judgement in sexual behavior and/or a likelihood of encountering partners with high HIV risk, such as injection drug use.

Homeless/Transient Populations

Many of these persons travel between Maine and other areas with significantly higher HIV/AIDS incidence, including urban communities in middle-Atlantic and southern states. Seroprevalence studies in some cities have demonstrated very high rates of HIV prevalence among the homeless, varying from 3% to over 24%.

In Maine, 16% of persons testing HIV-positive in 1993 were homeless, up from 8% that reported to be homeless in 1992. There are at least 3500 persons homeless on any given night in Maine. In 1993, 7,000 individuals spent at least one night in a Maine shelter.

Substance Abusers

Non-injection drug and alcohol abusers—including persons without male-male sexual risk — have been shown in some national studies to have significantly higher HIV prevalence rates than the general population. The increased risk is related in large part to sexual behaviors that may be related to substance abuse.

In Maine, 28% of persons reporting HIV-positive in 1993 had histories of alcohol or non- injection drug abuse. The Maine Office on Substance Abuse (OSA) estimates that there are 80,000 alcoholics residing in the state.

"High Risk" Youth

High-risk youth include adolescents and young adults with low educational attainment, possible high-risk sexual behaviors, lower-level socioeconomic status, joblessness, and often a variety of forms of substance abuse.

While little supplemental demographic and socioeconomic data is now collected in HIV and AIDS reporting, it is noteworthy that 22% of all cases of AIDS in Maine have been diagnosed among residents between the ages of 20 and 29, most of whom were infected through sexual contact. The

long incubation period for AIDS suggests that many of these persons were infected while still adolescents. Recent CDC directives have included this population as a national priority for HIV intervention.

Mentally Ill and Developmentally Disabled

In 1993, 6 of 83 persons testing HIV-positive in Maine were reported to suffer from severe mental illness. The numbers of infected persons who are developmentally disabled is unknown.

There is little national data available on the role of mental illness or mental retardation as a marker for increased HIV risk. There is, however, a widely shared concern that impaired judgement may increase the vulnerability of this population to the risk of sexual exposure to HIV.

B. Prioritized HIV Prevention Strategies

The Priority Review Task Force outlined approaches to be taken to address the HIV prevention needs of the populations below. The strategies range from rather general to very specific.

1. Males Who Have Sex With Males (MSM) HIV Prevention Strategies

a. Community Outreach

Because of the difficulties in reaching many individuals in this category, diverse and innovative methods of providing education must be used. Some examples are:

- individuals or teams visiting public sex environments such as parks or rest areas, equipped with brochures and condoms
- showing safer-sex videos to small groups in people's homes
- offering safer sex materials and educational variety shows in gay bars
- running ads and safer sex promotions in gay newspapers

b. Peer and Opinion Leader Counseling/Education

This approach is very useful when an identified gay male community exists, however loosely. Hire individuals from within the community who are well-known and well-respected, and provide them with training, resource information and supervision. Through being insiders, they can approach many more individuals, either one-on-one or in group settings, than an agency could.

Utilizing peers to offer information and support provides more safety for the target population, is more accessible and therefore better received than other approaches, no matter how "expert." CDC and other health education resources support the effectiveness of this strategy.

c. Condom Mass-Marketing and Distribution

This method requires a generalized, (not gay-oriented) broad marketing effort to enhance the cultural acceptability of condoms. Data shows effectiveness of condom use in preventing HIV, yet social discomfort is the main barrier to condom acquisition. Efforts include Public Service Announcements; promotion by social service agencies, entertainment centers, public social events, etc.

d. Promotion of HIV Prevention to More Targeted Audiences

Broad media messages extolling condom use and HIV prevention in general is important, and should be simultaneous with more targeted efforts towards specific audiences. Some examples:

- Materials should be developed that are Maine-specific, reflecting Maine's culture. Most literature is produced elsewhere and it shows.
- Highly focussed education/messages to heterosexual men:
Develop messages for use in mainstream media. Gay-oriented messages miss this population, and men outside gay "lifestyle" (bars, magazines) are not being reached either. Rural and homophobia issues make gay self-identity difficult.
- Age-specific materials for gay male youth and older gay men:
Media images of gay men are most often of 25-40 year-olds. Older gay men are not immune to

risk-taking behavior simply because of their age. It is important for gay teens to have accurate information since most school and agency-based prevention programs ignore gay youth.

e. Risk Reduction for MSM Living With HIV

People living with the virus are not immune from further HIV infection, nor are they necessarily experts at HIV prevention. There is a need for risk reduction workshops or one-on-one sessions for PWHIVs, led by peers, case managers, or HIV prevention educators, focussing on skill building: learning new behavior while not reinforcing old habits, getting support, information, etc.

f. Gay Male Leadership Development and Community Mobilization

Many of the leaders in Maine AIDS organizations today are women. Clearly greater representation and involvement needs to be fostered from the constituency with the highest numbers of HIV infection. Activities could include leader identification and recruitment, community organizing training and technical assistance provision, and barrier identification and reduction.

g. Assure Accessibility to Counseling/Testing and Partner Notification

2. HIV Prevention Strategies:

Females Who Have Sex With MSM or IDUs

a. Increase Accessibility, Development and Use of Education and Materials Targeted to Women

All literature, publicity, presentations, workshops, videos, one-on-one sessions should:

- Be accurate and up-to-date
- Use women staff to provide services whenever possible
- Include materials/information for safer sex practices, i.e. latex barriers.
- Incorporate cultural, class, regional awareness
- Ensure other needs are met first such as transportation or childcare
- Target places women frequent and provide training to workers: hairdressers, childcare providers, CNA classes, WIC intake workers, private health care practitioners, etc.
- Utilize innovative strategies that are realistic about women's lives
- Incorporate a quality assurance mechanism

b. Provision of Personalized Risk Assessment

Develop tools (worksheet, checklist, presentation, etc.) for reviewing personal and partner's past behavior. Possibly initiated by provider, in a pamphlet, etc. These are useful to assess individual's need for HIV prevention skill-building.

c. Offer Testing and Counseling Accessible to Women

Services should be offered for free or on a sliding scale, with childcare and transportation provided if needed. They should include one-to-one interviews, personalized risk assessment, awareness building and prevention education.

3. HIV Prevention Strategies: Injecting Drug Users (IDUs)

a. More and Better Data

No data currently exists regarding IDUs in Maine—incidence of shared needles, locations, numbers, ages, etc. No prevention programming currently targets IDUs due to this lack of information. Further research is necessary for program development for HIV prevention.

An analysis of needle exchange effectiveness is also needed for Maine. Further research could be done on the incidence of other forms of needle sharing such as home tattoos, blood rituals, and body piercing.

b. Street Outreach

Maintaining workers who are accessible on the street, in public, (rather than in an office), is known

to be effective in reaching people not in the “system,” and IDUs are a large percentage of people living on the streets. A street outreach approach could specifically target people bartering for sex.

c. Peer Education/Counseling/Support

This is an extension of street outreach, and involves hiring an individual from the target population, in this case, IDUs, to provide education and demonstrate safer practices is known to be effective.

d. Regulatory Mechanisms to motivate/require drug treatment programs to develop protocols and practices re HIV prevention

Substance abuse treatment services are not currently reaching clients with HIV. Training is necessary on various topics to reduce barriers to treating IDUs and working with people with HIV:

- anti-addict bias
- reduction of prejudice towards gay/lesbian/bisexual communities
- education on sexuality and homosexuality
- HIV prevention skill-building

e. HIV risk reduction for HIV+ users, both current and former

Current or former IDUs living with HIV are still at risk of further infection to themselves and to others, such as partners and children. One-on-one or group skill-building sessions are needed to interrupt infection through sharing of needles and through having unsafe sex.

f. Improve “System” Collaboration: substance abuse counselors, HIV service agencies, medical care providers, criminal justice

More comprehensive, cost-effective programming could result with better cooperation among service providers. This would also improve data gathering, service provision, and outreach efforts.

4. HIV Prevention Strategies: People of Color

a. Continue Outreach to Native American communities

Enhance community-building efforts around HIV awareness that are culturally specific, with accurate, up-to-date information. Development of peer education programs, perhaps run by the tribal health centers with assistance from HIV educators, is one example.

b. Improve connections with local communities of color to increase awareness and receive more focused input on prevention efforts

Identify and connect with institutions and organizations which serve the community, no matter how dispersed it is. Provide materials and information which is pertinent to that population. Identify their needs as they articulate them.

c. Maintain involvement of representatives of affected communities in HIV planning process

Extra efforts may be necessary to ensure involvement of individuals representing these communities such as group prejudice reduction, or needs assessment for further representation.

5. HIV Prevention Strategies:

Other Populations With Certain Markers for High Risk

a. Train providers who work with these populations, i.e. WIC, DHS, shelter providers, clergy

Basic “HIV 101” and HIV prevention for specific populations, with accurate, up-to-date information, is desperately needed for people addressing these constituencies.

b. Outreach to :

- at-risk youth
- homeless
- substance abusers
- victims of sexual/family violence
- mentally ill
- developmentally delayed

Outreach includes presentations by HIV prevention educators, development of peers as educators and trainers within the target population, and follow-up presentations and technical assistance. Additional emphasis should be on assertiveness and self-esteem with most of these groups.

c. Personalized Risk Assessment

Develop tools (worksheet, checklist, presentation, etc.) for reviewing personal and partner's past behavior. Possibly initiated by provider, in a pamphlet, etc. These are useful to assess individual's need for HIV prevention skill-building.

d. Improve Service Delivery

- Maintain, improve resources for existing projects
- Increase staff
- Include a quality assurance mechanism
- Develop network for HIV prevention workers re meeting non-HIV needs for these populations. Make referrals, identify gaps, improve data and collaboration on issues such as housing, rehabilitation, financial assistance, counseling

C. General Recommendations for Improving Prevention Efforts in the State

1. Increased funding

Includes funds for infrastructure supporting HIV prevention programming, innovative HIV prevention, and projects which reflect the priorities established in this report

2. Need for rural models of working with:

- people of color
- males who have sex with males
- injecting drug users

Urban programs and materials do not reflect Maine's needs. Reaching people in rural environments, especially where small numbers of these populations exist, requires special approaches.

3. Training professionals and providers on:

- addiction
- sexuality/sexual orientation
- homophobia reduction

These topics, including HIV prevention, should be incorporated into any training program for people providing care or guidance to members of these constituencies.

4. Policy development and standardized protocols throughout Maine's institutions and agencies to ensure HIV prevention programming

5. Develop information systems with the capacity to gather and disseminate data efficiently and effectively, including Medicaid information and HIV prevention and intervention funding

6. ME Bureau of Health should utilize standardized program assessment mechanism for all new HIV prevention funding and for FY 1996 contracts

HIV Prevention Community Planning Group

(formerly Priority Review Task Force)

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Preliminary HIV Prevention Priorities Outlined: 8/1994

Draft Report Distributed: 12/94

First Final Version: 2/95

SAMPLE WORKPLACE POLICY

UNUM CORPORATION
PORTLAND, ME



Date November 17, 1993	To UNUM America and First UNUM Employees	Memorandum
From Karen Lukas Human Resources	Re HIV/AIDS Position Statement	

In 1988, UNUM issued a position statement regarding how we as an organization intended to respond to the potential presence in our workforce of employees who had been infected with AIDS.

In conjunction with the UNUM Medical Department's annual HIV/AIDS education initiative, which this year focuses on HIV infection in the workplace, Human Resources is reissuing that position statement.

Although our basic position has not changed, we've updated "HIV/AIDS in the Workplace" to incorporate what society and the medical profession have learned in the past several years relative to HIV and AIDS, and to put this disability into the context of the Americans with Disabilities Act.

We encourage you to use the attached material and the forthcoming brochure from the Medical Department to continue your understanding of this serious epidemic. Both materials identify resources where you can obtain additional information.

HIV/AIDS in the Workplace

UNUM America's Position:

In our hiring and retention practices, we will treat applicants and employees who are HIV positive the same as persons with other medical or physical conditions. We will actively communicate with and educate employees about HIV and AIDS prevention.

How We Respond:

If an employee tells you that he/she is HIV positive, you will want to respond with sensitivity, support and concern, just as you would with any other serious illness.

Fundamental to UNUM's response to HIV is the desire to respect the rights and concerns of those with the virus, as well as those who are free of the virus. An employee's decision to disclose his/her diagnosis to others is a very personal one. An employee's medical diagnosis shall be considered highly confidential in accordance with our Corporate Privacy Policy. Disclosure of an employee's condition could expose both the company and you to legal liability.

Accommodation:

As with other disabling conditions, an HIV positive employee may require reasonable accommodation in order to continue working. "Reasonable Accommodation" as defined under the Americans With Disabilities Act, includes a modification to a job, the work environment, or the way work is usually done that enables a "qualified individual with a disability" to perform the essential functions of the job or to enjoy the same benefits and privileges of employment as other employees.

Accommodations are based on the specific circumstances of the employee, the employer and the job. Managers should be creative and flexible in working directly with the individual to determine any reasonable accommodations.

Co-workers' Concerns:

Employees may experience sadness at the thought of a co-worker's illness and potential death. They will require their manager's support and possible referral for EAP counseling, either individually or as a work group.

Co-workers may also raise objections related to their fear of contact with a person infected with HIV. Sensitivity should be shown for these concerns. The resources described below are available to help co-workers deal with their concerns.

Resources for Support:

Medical Department:	Will coordinate responses to HIV related inquiries and will ensure that current information about the HIV virus is available to employees.
	Will provide information, education, and presentations for co-workers that allow for Q&A's and discussion of the company's position.
HR Division Director/Manager:	Will provide advice and support for HR related management issues such as performance management and reasonable accommodation.

EAP: The Employee Assistance Program is available to individuals or work groups who may be dealing with an HIV positive co-worker. In the Portland area, our EAP is provided through Community Counseling (874-1030). Outside Portland, it's through HAI (1-800-424-1737).

HIV Update:

The following information serves to provide us with a common understanding of HIV infection:

How HIV Related Impairment is Similar to Other Medical Impairments

HIV infection, like other medical conditions, such as epilepsy and diabetes, may produce certain limitations, and may require certain restrictions. Physicians address limitations and restrictions for individuals who are HIV infected in the same manner as other medical conditions.

HIV infection is also treated the same as other medical conditions under employment laws. Like a variety of other conditions, HIV infection and AIDS are considered impairments that may result in disabilities protected under ADA.

How HIV is Different, in Some Respects

HIV is a communicable disease (i.e., an infectious disease), but unlike staph or strep or flu, fellow workers are not exposed to risk of infection in any casual way. Workstations, office equipment and workspaces can be shared without risk.

HIV infection is also unique. At present it is ultimately a fatal disease. Until such time as a cure becomes possible, this disease calls for our understanding, knowledge, and compassion.

What this Means for UNUM's Workforce:

UNUM is a growing and global company, and HIV is a global epidemic. Many parts of the U.S. and the world have been deeply affected by AIDS and HIV. Sooner or later we will all experience the enormity of this disease, through people we know or care about.

UNUM's workforce will continue to grow and change. Having co-workers and colleagues who are HIV infected will become more common, and in the 1990's and beyond, we all must learn to live and work within this reality.

Additional Information:

The key to ending HIV/AIDS lies in educating ourselves - especially our young people - about how to prevent the disease. UNUM America's Wellpower Library has several videos and brochures on HIV infection. For more information on AIDS prevention, contact the AIDS Clearinghouse at 1-800-458-5231 or the AIDS HOTLINE, 1-800-342-AIDS.

SAMPLE
SERVICE AGENCY
POLICY

PEOPLE'S REGIONAL
OPPORTUNITY
PROGRAM
(PROP)
PORTLAND, ME

HIV/AIDS POLICY AND PROCEDURES

I. BACKGROUND

AIDS, or Acquired Immune Deficiency Syndrome, is an advanced stage of an often fatal illness caused by a virus. This virus is known as Human Immunodeficiency Virus, or HIV.

HIV attacks certain white blood cells which are part of the body's immune system. When the immune system is weakened by HIV, rare cancers and infections can invade the body, eventually leading to death.

The virus that causes AIDS, HIV, is found in certain body fluids - especially blood, semen, and vaginal secretions. People become infected with HIV from direct contact with infected semen, vaginal secretions, blood and breast milk.

HIV is spread:

- By unprotected vaginal, anal, and oral sex: that is, sex without using a latex condom or dental dam correctly from start to finish, preferably with a spermicide. Use of these implements provides "safer" sex; only abstinence is totally safe.
- By direct contact in or exchange of blood and blood products: e.g. shared use of needles for injectable drug use (including steroids), nonprofessional tattooing, or ear piercing; **or**
- From mother to infant prior to, during, or shortly after birth (especially if the mother is breast feeding).

There is absolutely no evidence of "casual" transmission of HIV - that is, HIV transmission from handshakes, toilet seats, door knobs, hugs, sharing food and beverages, living in the same household, playing together, sharing toys, swimming together, and so on. In fact, research on the risk to household members of AIDS patients resoundingly reaffirms the lack of casual transmission.

II. POLICY STATEMENT

AIDS and HIV education will be a regular and integral part of PROP's training/counseling programs for both clients and staff, in order to allay fear, misconceptions or prejudice about AIDS and HIV. Prejudicial behavior, isolation, ridicule, or inappropriate actions based on irrational fear, directed at clients or staff with AIDS or HIV infection, will not be tolerated and appropriate disciplinary actions will be undertaken.

III. POLICY FOR EMPLOYEES

PURPOSE: To establish guidelines and policies for employees in order to protect the rights of employees and promote an educational program directed at prevention and reduction of fear of HIV infection and the syndrome known as AIDS.

POLICY: These guidelines shall be individually applied, taking into consideration the psychological, physical and behavioral characteristics of the individuals involved. Employees of PROP who know or suspect they are infected with HIV are encouraged to seek medical treatment and assistance from community support groups and medical services.

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III. POLICY FOR EMPLOYEES (cont'd)

These guidelines shall be reviewed periodically and revised as necessary to reflect new medical and legal information regarding HIV and AIDS.

Consistent with federal and state discrimination laws, it shall be the policy of PROP not to unlawfully discriminate against any individual applicant, employee, or client because he or she may have AIDS or may have tested positive for HIV.

GUIDELINES:

1. Routine screening of employees for HIV is not recommended and shall not be a requirement for employment eligibility.
2. An employee's medical diagnosis (and HIV status) is personal information and such information, if known, shall not be released without the employee's permission, as provided by law. Disciplinary action will be taken against any employee who inappropriately discloses medical information about any other employee or client.
3. Sick leave and leave of absence shall be granted to all employees with illnesses, including HIV/AIDS, according to standard PROP procedures for granting such leave.
4. Employees shall not be terminated, demoted, suspended, transferred, or subject to adverse action based solely on the fact that they are HIV-infected (or are perceived to be infected). PROP, however, reserves the right to terminate, demote, suspend or transfer employees who, despite reasonable accommodation, are unable to perform the essential functions of their assigned positions, or who present a direct threat to the safety of themselves or others, due to an injury or illness no matter what the cause or origin of said injury or illness. Such employees shall be treated like any other employee with a serious illness or injury and shall remain eligible for all benefits that are provided for agency employees with other serious illnesses.
5. As with other illnesses, employees who become ill as a result of an HIV infection or seek to return to work after such an illness, may be asked to provide a physician's statement certifying their ability or inability to work or documenting their current medical status including the amount of time needed for recuperation.
6. The sexual orientation of an employee shall not constitute reasonable cause to believe that he/she has HIV infection. No employee or potential employee shall be required to provide information as to his/her sexual orientation.

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III. POLICY FOR EMPLOYEES (cont'd)

GUIDELINES (cont'd):

7. PROP shall provide to all employees education and information about HIV and AIDS and its transmission as the need arises. Refusal to work with a person infected with HIV does not excuse an employee from fulfilling assigned responsibilities and such refusal can result in disciplinary action. No special consideration shall be given for employees who feel threatened by a co-worker's or client's illness.

IV. POLICY FOR CLIENTS

PURPOSE: To establish guidelines and policies for clients in order to protect the rights of clients and promote an educational program directed at prevention and reduction of fear of HIV infection and the syndrome known as AIDS.

POLICY: These guidelines shall be individually applied, taking into consideration the psychological, physical and behavioral characteristics of the individuals involved. Clients who know or suspect they are infected with HIV are encouraged to seek medical treatment and assistance from community support groups and medical services.

These guidelines shall be reviewed periodically and revised as necessary to reflect new medical information regarding HIV and AIDS.

NOTE: Epidemiologic studies show that AIDS is a syndrome and caused by a viral infection known as HIV and transmitted via intimate sexual contact, blood to blood contact, or breast milk. Since there is no evidence of casual transmission by sitting near, living in the same household, or playing with an individual with HIV/AIDS, the following guidelines shall be implemented at PROP.

GUIDELINES:

1. Routine screening of clients for HIV is not recommended and shall not be a requirement for program acceptance.
2. **Confidentiality**
 - a. The right of the individual client or staff member to confidentiality with regard to his/her HIV antibody status or AIDS diagnosis will be respected by the administration and staff of PROP and will comply with Maine Law (5 MRSA, Part 23, Chapter 501, § 19203). Information that is shared with a staff member regarding an individual's antibody status must be held in strict confidence and shared only with the Executive Director or Clinical Director for purposes of supervision. No mention of a client or staff member's HIV antibody status is to be made in the files or in other written records.

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IV. POLICY FOR CLIENTS (cont'd)

GUIDELINES (cont'd):

- b. The sharing of this information with other clients or staff will be a right reserved for the infected individual. To strive for appropriate and minimally disruptive disclosure, staff and clients will discuss the ramifications only with appropriate staff prior to making the disclosure. PROP personnel may share information regarding HIV antibody status with other agencies or individuals only with the specific written consent of the infected individual and/or their guardian.
 - c. Furthermore, the only legitimate context for such disclosures as described above will be that of providing comprehensive services to said individual.
 - d. Disciplinary action will be taken against any employee who inappropriately discloses medical information about any other employee or client.
- 3. The sexual orientation of a client shall not constitute reasonable cause to believe that he/she is an infected individual.
- 4. Education of clients should ensure that proper and current information about HIV and AIDS is available.
- 5. These guidelines shall be reviewed periodically and revised as necessary to reflect new medical information regarding HIV and AIDS.

V. RECOMMENDED PROCEDURAL GUIDELINES FOR SPECIFIC GROUPS WITHIN PROP

A. Food Service Workers:

- 1. Food service workers known to be infected with HIV should not be restricted from performing their normal duties, including using equipment or utensils in the food facility unless they have an illness, or signs and symptoms of an illness, for which job and other restrictions would be warranted.
- 2. All food service workers should follow recommended standards and practices of personal hygiene and food sanitation.
- 3. All food service workers should avoid personal injuries during food handling. Foods tainted with blood or other body fluids must be discarded whether or not the handler is infected with HIV.
- 4. A disinfectant solution (household bleach is effective) should be available for treating any equipment contaminated by blood or other body fluids, whether or not the handler is infected with HIV. The disinfection solution will consist of one part bleach to ten parts water. This solution will be mixed fresh daily.

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IV. RECOMMENDED PROCEDURAL GUIDELINES FOR SPECIFIC GROUPS WITHIN PROP (cont'd)

B. All Other Personnel:

1. Existing medical evidence and research indicates that no specific risks of transmission of HIV, either from or to service personnel, are identified in routine performance of duties. This holds true in special circumstance of exposure to blood and bodily fluids, etc., provided universal precautions are followed according to sound medical protocol and as established by Agency procedures. (See PROP's Bloodborne Pathogen Exposure Control Plan.)
2. Broken glass or any sharp instruments which may have been contaminated by blood or body fluids should be properly discarded in puncture resistant containers. Broken glass should be swept up and disposed of properly. Latex gloves should be worn during necessary handling.
3. All surface areas, such as counter tops, sinks, and toilet seats shall be disinfected daily with a 1:10 solution of household bleach. Floors, tables or other surfaces contaminated with vomitus, blood, or other body fluids should be promptly cleaned and disinfected. Latex gloves should be worn during such procedures. All materials used in clean up should be disinfected or placed in a plastic bag before discarding. All persons involved should wash their hands thoroughly.
4. All items contaminated by blood or body fluids pose no risk to handlers if the fluids have dried. However, in strictly adhering to Universal Precautions, it is recommended that gloves be worn. The virus is inactivated by ordinary laundering procedures.

C. Post-exposure Procedure:

Refer to PROP's Bloodborne Pathogen Exposure Control Plan.

/bac

Methodology

Volunteers from all over the state representing a wide array of experience—from people living with the disease to those with little knowledge of the disease but expertise elsewhere—were initially recruited in April, 1993, to participate in developing the Plan. Notices were sent to all AIDS organizations, many service providers, educators, professional associations, and individuals.

Ninety people convened at the first Maine AIDS Plan Project gathering in June, 1993, when committees were established and the work was begun. Additional volunteers were solicited to join committees, provide feedback to draft reports, offer their experience in a focus group discussion, or conduct research within their organization. Many people from state offices, local agencies, and private workplaces graciously offered their time to gather requested information or be interviewed. (We have made every attempt to include all participants in the Contributors lists on page 251, yet apologize for any oversights.)

Each chapter of the *Maine AIDS Plan* originated as a final report from a committee of five–ten people who gathered to focus specifically on that topic, such as the impact of HIV on women in Maine, or HIV/AIDS in the Maine workplace. Sixteen committees met for various lengths of time over the course of two years, beginning in June, 1993.

Population subcommittees were asked to:

1. Define and describe the population and its various subgroupings, including relevant statistics, resource list, etc.
2. Define, describe and prioritize ways in which this population may require special, or more specific, attention regarding HIV and AIDS
3. Provide examples of ways other individuals could meet some of those needs
4. Compile a report

Settings subcommittees were asked to:

1. List all possible areas which apply under the setting
2. Define the ideal approach to HIV in this setting
3. Review current activities which address HIV in the setting, noting problems and successes
4. Define and prioritize the steps each area can take in the shortterm, and in the longterm, over a five-year period if necessary, to move toward the ideal approach
5. Be as specific as possible, offering examples, pertinent data, etc.
6. List additional resources, programs, or policies which would facilitate this setting to achieve the ideal approach as outlined
7. Provide a report

Investigation and research methods employed by the committees included:

Telephone and on-site interviews

Review of public and private agencies' and organizations' manuals, guidelines and policies

Investigation of State and Federal laws and regulations

Focused discussion groups

Surveys of providers

Personal observations

Review of research conducted by other Maine and national organizations

Reports were reviewed and edited by staff, Coordinating Committee (CC) members, and people in the field solicited to volunteer feedback. Missing or additional information was compiled by staff and the CC. Final drafts were edited by staff and a writer to facilitate accessibility of the information.

All information included here was compiled through these methods. The bibliography includes those organizations and resources which were the sources of this information.

Contributors

Many people have assisted in this effort. Volunteers have worked on committees, responded to requests for information, participated in discussion groups, answered questions, conducted research, provided feedback to draft reports, or offered editing expertise.

Below are the names of those individuals who worked on committees or provided feedback to early drafts. (We apologize if some names have escaped us.) Collectively, many hours were contributed to this effort. Simply put, the Maine AIDS Plan would not exist without you.

Thank you.

In addition we would like to thank the many people in state and local agencies, schools, businesses, schools or HIV-affected communities who did not work on committees but graciously provided materials or answered questions. We do not have all your names, but please know that your contributions are greatly appreciated.

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Geoff Beckett—HIV/STD Programs
Sheryl Benjamin—Penquis Family Life Education Services
Larry Bliss—HIV/AIDS Task Force, University of Southern Maine
Joel Bowie—Merrymeeting AIDS Support Services
Cathy Bradeen Knox—Maranacook Community School
Mary Cathcart—State Representative
Dale Cloutier—AIDS Coalition of Lewiston/Auburn
Lois Cooper—Waterville High School
Jennifer Curtis—Student in Nursing
Deborah Curtis—Bureau of Medical Services
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Kip DeSerres—Maine Municipal Association
Nancy Drapeau—Pan Atlantic Consultants
Kimberly Edwards—Planned Parenthood
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Sarah Haggerty—Maine Ambulatory Care Coalition
Jayson Hunt—Outright
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Pat Lacey—Dayspring
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Lee Longnecker—Critical Care America
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Chris Lyman—University of Southern Maine
Sarah MacColl—Public Health Consultant
Mary Madden—Education Consultant
Anthony McCann, MD

Dale McGee—Tamarack Family Services
 Gloria Mitchell—Department of Human Services
 Jim Mitchell—Former state legislator
 Mary Jean Mork—Sweetser Children's Services
 Laura Neal—Media consultant
 Nathan Nickerson—City of Portland Public Health Department
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 Susan Parks—Maine Department of Education
 Bob Philbrook—We Who Care
 Bobby Poulin—Down East AIDS Network
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 Martin Sabol—Bangor Health & Welfare Department
 Betsy Saltonstall—Congressman Thomas Andrews
 Stephen Sears, MD—Kennebec Valley Medical Center
 Nan Stone—Waldo Knox AIDS Coalition
 Ed Suslovic—American Red Cross
 William Tarr—Maine Independent Living Services, Inc.
 Susan Tibbetts—Dayspring
 Diana White—Maine AFL-CIO

Settings and HIV Committees

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Tom Bancroft—Maine Bureau of Child and Family Services
 Jamie Clough—Maine Office of Substance Abuse
 Deb Curtis—Maine Bureau of Medical Services
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 Lisa Miller—Public Health Consultant

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 Beth Huntley—Chairperson, Family Living and Sexuality Committee City of Portland
 Chris Lyman—University of Southern Maine
 Mary Madden—Family Planning Association of Maine
 Kandyce Powell—Maine Hospice Council

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 Laurie Broberg, RN—former administrator at Maine Veterans Home, Scarborough
 Terry Clifford, RN, MS—Mercy Hospital
 Sherry Dirrigle, RN—Infection Control, Brighton Medical Center
 Cindy Heelan, RN, BSN—VNA and Hospice, South Portland
 Katie Lewis—Bangor Health Department Sexually Transmitted Disease/HIV Clinic
 Lee Longnecker, RN, MSW—Critical Care Systems
 Patty Miles—Bangor Health Department Sexually Transmitted Disease/HIV Clinic
 Jim Mitchell—former legislator, now with LL Bean
 Nancy O'Neill, MD—community physician, Presque Isle
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 Mark Reynolds, DDS—dentist, Augusta
 Stephen Sears, MD—Kennebec Valley Medical Center

Ann Wheeler—Office on AIDS, Bureau of Health

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Judy Feinstein— Division of Dental Health
 Mark Griswold— The AIDS Project
 Martin Sabol— Bangor Health Dept.
 Peaches Bass— Maine AIDS Alliance
 Sharon Pree— Southern Kennebec Family Planning
 Susan Cummings-Lawrence— Public Health Consultant

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 Kimberly Edwards—formerly of Planned Parenthood of New England
 Mary Jean Mork—Sweetser Childrens Home
 Susan Parks—Maine Department of Education
 Bob Rowe—New Beginnings
 Patrice Roy—Maine Medical Center
 Susan Cummings-Lawrence—Public Health Consultant

Social Services/Mental Health Committee Members

Patrice Roy—Maine Medical Center
 Jane O'Rourke—The AIDS Project
 Sally-Lou Patterson—HIV/STD Programs, Maine Bureau of Health
 Susan Heckaman—Caremark (previously)
 Deborah Shields—The AIDS Project
 Susan Cummings-Lawrence—Public health consultant
 Jackie LePine—Social work student

Workplace Committee Members

Kip DeSerres—Maine Municipal Association
 Steve Fleming—Maine HIV/STD Program
 Stephanie Locke—Maine AFL-CIO
 Ned McCann—Maine AFL-CIO
 Nan Stone—Waldo-Knox AIDS Coalition

Feedback Respondants

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 Peaches Bass—ME AIDS Alliance, ME HIV Advisory Committee
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 Kathleen Beecher, R.N.—Public Health Nurse
 James Boisvert—Biddeford Teacher
 Joel Bowie—Merrymeeting AIDS Support Services
 Simone Carter—Houlton Band of Maliseet Indians
 Cary Collette—Saco PTO, ME HIV Advisory Committee
 Darylen Cote—Aroostook County Action Program
 Dan Crocker—Rural Health Centers of Maine
 Dean Curtis—Prisoners for AIDS Support
 Francia Davis—Maine Human Rights Commission, ME HIV Advisory Committee
 Mary Derosier—United Way of Androscoggin County
 Carl Duplessis—Small Business Owner
 Sandra Eastman, RN—St. Joseph's Hospital, ME HIV Advisory Committee
 Anne Emidy—ME Council of Churches
 Steve Fleming—HIV/STD Programs
 Joni Foster—ME Department of Education
 Larry Gilbert—Private Citizen
 Kevin Gildart—Bath Iron Works
 Bill Gould—People's Regional Opportunity Program

Ken Hamilton—HOPE
 Tom Hanrahan—Maine State Prison
 Sara Hayes—Tri-County Health Services
 Susan Higgins—Kelly Temporary Services
 John Holverson—The AIDS Project
 Beth Huntley—Chair, Family Living and Sexuality Committee, City of Portland
 Steve James—Hope House, Inc.
 Cathy Kidman—HIV Prevention Community Planning Group
 Sharon Kuhrt, RNC, MSN—Central Maine Medical Center
 Robin Lambert—Konica
 Cecilia Leland—ME Department of Mental Health & Retardation
 Donna Levi—Maine Municipal Association
 Dora Lievow—The Community School
 Stephanie Locke—Maine AFL-CIO, ME HIV Advisory Committee
 Marjorie Love—Management Services for the Human Services
 Trish Macomber—American Red Cross
 Mary Madden—Education Consultant
 Joe Maynard—Veterinarian
 Dale McCormick—State Senate, HIV Advisory Committee
 Dale McGee—Tamarak Family Services, HIV Advisory Committee
 Susanne McNamara—Maine State Nurses Association, HIV Advisory Committee
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 Macey Orme—Student
 Sally-Lou Patterson—HIV/STD Programs
 Kate Perkins—Maine Community AIDS Partnership, HIV Advisory Committee
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Cindy Flye—Education Consultant
 Joni Foster—ME Department of Education
 Kathy Jones—ME Arts Commission
 Pat Lacey—Dayspring
 Fran Mullin—Family Planning Association of Maine
 Sally-Lou Patterson—HIV/STD Programs, Bureau of Health
 Lisa Pohlmann—ME Center on Economic Policy

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Resources



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Local Resources

AIDS Service Organizations

AIDS Lodging House
PO Box 3820
Portland, ME 04104
874-1000

The AIDS Project
615 Congress St.
PO Box 5305
Portland, ME 04101
774-6877

Community AIDS Awareness Program
c/o Mexico Congregational Church/UCC
43 Main St.
Mexico, ME 04257
364-8603

Community Task Force on AIDS Education
PO Box 941
Naples, ME 04055

Dayspring AIDS Support Services
32 Winthrop St.
Augusta, ME 04330
626-3435

Down East AIDS Network
114 State St.
Ellsworth, ME 04605
667-3506

Eastern Maine AIDS Network
236 State St.
PO Box 2038
Bangor, ME 04401
990-3626

Merrymeeting AIDS Support Services
PO Box 57
Brunswick, ME 04011
725-4955

Names Project/Maine
PO Box 10248
Portland, ME 04104
774-2198

Oxford Hills Community AIDS Network
PO Box 113
Paris, ME 04271
743-7451

Peabody House
14 Orchard St.
Portland, ME 04102
774-6281

People With AIDS Coalition of Maine
696 Congress St.
Portland, ME 04102
773-8500

Pets Are Wonderful People (PAWS)
PO Box 5305
Portland, ME 04101
775-7297

Waldo-Knox AIDS Coalition
PO Box 956
Belfast, ME 04915
338-1427

also:
Raphael House Sisters of Charity Health System
PO Box 7291
Lewiston, ME 04240
777-8944 or 783-7308

Anonymous HIV Antibody Counseling and Testing Sites:

BIDDEFORD
York County STD Clinic
282-1516

ELLSWORTH
Downeast Family Planning
667-5304

PORTLAND
The AIDS Project
775-1267, 1-800-851-AIDS

Portland
STD Clinic
874-8444

ROCKLAND
MidCoast Family Planning
594-2551

LEWISTON
The Clinic
795-4019

BANGOR
Bangor STD Clinic
947-0700

AUGUSTA
Augusta Family Planning
626-3426

PRESQUE ISLE
ACAP Family Planning
764-3721

Family Planning Clinics

Downeast Health Services
PO Box 1087
Ellsworth, ME 04605
667-5304

Full Circle Women's Health Center
One Weston Court
Augusta, ME 04330
626-3426

Health 1st
Box 1116
Presque Isle, ME 04769
764-3721

KVCAP Family Planning
PO Box 1529
Waterville, ME 04901
873-2122

Penquis Health Services
262 Harlow St.
PO Box 1162
Bangor, ME 04401
941-2836

Planned Parenthood of NNE
970 Forest Avenue
Portland, ME 04101
874-1100

Tri-County Family Planning
PO Box 200
East Wilton, ME 04234
645-3764

also:
Mabel Wadsworth Women's Health Center
PO Box 20
Bangor, ME 04402
947-5337

American Red Cross Maine Chapters

Portland Chapter—coordinates statewide HIV prevention education
524 Forest Avenue
Portland, ME 04101
874-1192

Hancock County Chapter
PO Box 586—City Hall
Ellsworth, ME 04605-0586
667-4737

Kennebec Valley Chapter
6 Wabon St.
Augusta, ME 04330
626-3446

Mid Coast Chapter
9 Bank St.
Brunswick, ME 04011-2811
729-6779

Mid-Maine Chapter
179 Main St.
Waterville, ME 04901-6625
873-6176

Penobscot Bay Chapter
312 Broadway
Rockland, ME 04841-2604
594-4576

Pine Tree Chapter
33 Mildred Avenue
Bangor, ME 04401-4305
941-2903

Aroostook Branch:
Presque Isle
762-5671

United Valley Chapter
PO Box 439
70 Court St.
Auburn, ME 04212-0439
795-4004

Branch Offices:
Farmington 778-3554
Augusta 626-3446

York County Area Chapter
PO Box V
203 Main St.
Sanford, ME 04073-1330
324-4071

New Beginnings, Inc.
—a youth-serving residential program
436 Main St.
Lewiston, ME 04240
795-4077

City of Bangor Health and Human Services
Department
103 Texas Ave.
Bangor, ME 04401
941-0258

City of Portland
Public Health Program
389 Congress St.
Portland, ME 04101
874-8300

People's Regional Opportunity Program
HIV/AIDS Education and Universal Precaution
Committee
510 Cumberland Ave.
Portland, ME 04101
874-1140

State Resources

AIDS Organizations

Maine AIDS Hotline
1-800-851-AIDS

AIDS Consultation Service, ODP
Maine Medical Center
22 Bramhall Street
Portland, ME 04102
871-2099
1-800-871-2701

Camp Chrysalis
c/o Waldo-Knox AIDS Coalition
P.O. Box 956
Belfast, ME 04915
338-1427

HIV/STD Programs, ME Bureau of Health
State House Station # 11
Augusta, ME 04333
287-3747

HIV Prevention Education Program—statewide
American Red Cross—Portland Chapter
524 Forest Avenue
Portland, ME 04101
874-1192

HIV Prevention Education Programs
Department of Education
State House Station #23
Augusta, ME 04333
287-5930

Maine AIDS Alliance
112 State Street
Augusta, ME 04330
621-2924

Maine AIDS Plan
112 State St.
Augusta, ME 04330
622-2962

Maine: A Report on HIV/AIDS Needs, 1994.
Maine Community AIDS Partnership
PO Box 15200
Portland, ME 04112-5200
874-1000

Maine HIV Advisory Committee
c/o American Red Cross
524 Forest Ave.
Portland, ME 04101
874-1192

Maine HIV Prevention Community Planning
Group
112 State St.
Augusta, ME 04330
622-2962

People with AIDS Coalition of Maine
696 Congress St.
Portland, ME 04102
773-8500

The AIDS Project
Athena: a newsletter for women affected and
infected by HIV in Maine
PO Box 5305
Portland, ME 04101
774-6877

General Organizations Addressing HIV/AIDS

Bureau of Child and Family Services
Maine Department of Human Services
State House Station #11
Augusta, ME 04333
287-5060

Bureau of Medical Services
State House Station #11
Augusta, ME 04333
624-6058

Center for Grieving Children
PO Box 1438
Portland, ME 04104
799-1112

Ingraham Volunteers, Inc.—general hotline
774-4357, 1-800-870-9998

*Listen to the Students: The AIDS Education
Research Project*
Family Planning Association of Maine
P.O. Box 587
Augusta, ME 04332-0587
622-7524

Maine Advocacy Services
P.O. Box 2007
Augusta, ME 04338
1-800-452-1948, 626-2774

Maine AFL-CIO
PO Box 2669
Bangor, ME 04402-2669
947-0006

Maine Bisexual People's Network
PO Box 10818
Portland, ME 04104

Maine Civil Liberties Union
97A Exchange Street
Portland, ME 04101
774-5444

Maine Coalition for the Homeless
P.O. Box 415
Augusta, ME 04332-0415
626-3567

Maine College Health Association
c/o Chris Lyman
University of Southern Maine
96 Falmouth St.
Portland, ME 04101
780-5164

Maine Council of Churches
Interfaith Council on AIDS
15 Pleasant Avenue
Portland, ME 04103
772-1918

Maine Hemophilia Treatment Center
Maine Medical Center
Portland, ME 04101
871-2871

Maine Human Rights Commission
State House Station #51
Augusta, ME 04333
624-6058

Maine Lesbian Gay Political Alliance
PO Box 232
Hallowell, ME 04347
1-800-55-MLGPA

Northern Lambda Nord
Social and educational programs serving lesbian,
gay and bisexual people in northern Maine
498-2088

Office of Substance Abuse
State House Station # 159
Augusta, ME 04333
287-2595

Office of Substance Abuse
Information/Resource Center
Stevens School Complex
State House Station #57
Augusta, ME 04333
287-6330 TDD: 287-4475

Outright—statewide support network for gay
youth
PO Box 5028, Station A
Portland, ME 04102-5028

Pine Tree Legal Assistance
P.O. Box 547 DTS
Portland, ME 04112
774-4753

Portland Homeless Health Program
389 Congress St #305
Portland, ME 04101
874-8300

The Volunteer Center
One Post Office Square/400 Congress St.
PO Box 15200
Portland, ME 04112-5200
874-1000

National Resources

People With AIDS Coalition National Hotline
1-800-828-3280

AIDS Hotline for the Deaf
1-800-293-7889

Centers for Disease Control
National AIDS Clearinghouse (CDC NAC)
PO Box 6003
Rockville, MD 20849-6003
1-800-458-5231
TTY/TDD: 1-800-243-7012
FAX: (301) 738-6616

email: aidsinfo@cdcnac.aspensys.com

NAC WWW homepage:
<http://www/cdcnac.aspensys.com:85>

NAC ONLINE direct, from a modem:
1-800-851-7245
communications software configuration:
8, N, 1, VT100

Information resources/databases include:

- Resources and Service
- Educational Materials
- Funding
- Business and Labor Resource Service
- Morbidity and Mortality Weekly Report
- Periodicals
- Federal Information
- Conference
- Comprehensive School Health Education

Advocates for Youth, Teens for AIDS Prevention
Program
1025 Vermont Ave., NW, Ste. 210
Washington, DC 20005
202-347-5700

AIDS Action Committee
131 Clarendon St.
Boston, ME 02116
617-437-6200

American Red Cross
1-800-422-0743

American Civil Liberties Union AIDS Project
132 West 43rd St., Box ADA
New York, NY 10036

Gay Men's Health Crisis
129 West 20th St.
New York, NY
212-807-6664

HIV/AIDS and Disabilities Access and Information
Project
c/o Latino Health Institute
95 Berkeley St.
Boston, MA 02116
617-350-6900

IMPACT AIDS
415-861-3397

Kairos—magazine for HIV/AIDS caregivers
114 Douglass St.
San Francisco, CA 94114-1921

National Association of People with AIDS
(NAPWA)
NAPWA News
PO Box 18345
Washington D.C. 20036

National Association of State Alcohol and Drug
Abuse Directors
AIDS Policy Project
444 N. Capitol St., NW, Ste. 642
Washington, DC 20001
202-783-6868

National Minority AIDS Council
1931 13th St, NW
Washington, DC 20009-4432
202-483-6622

National Native American AIDS Prevention Center
6239 College Ave., Suite 201
Oakland, CA 94618
415-658-2051

National Network of Libraries of Medicine/NE
Region—offers 3 medical AIDS data bases free of
charge (must have "Grateful Med" software)
University of Connecticut Health Center
263 Farmington Ave.
Farmington, CT 06030-5370
203-679-4500

National Network of Runaway and Youth Services,
Safe Choices Project
1319 F St., Ste. 401
Washington, DC 20004
1-800-878-2437

National Resource Center on Women and AIDS
Center for Women Policy Studies
2000 P St. NW, Ste. 508
Washington, DC 20036
202-872-1770

National Task Force on AIDS Prevention
944 Market St, #210
San Francisco, CA 94102
415-403-3800

New England AIDS Education and Training Center
UMass Medical Center
55 Lake Avenue
N. Worcester, MA 01655
617-566-2283

OSHA Bloodborne Pathogens Standard
OSHA Proposed Airborne Pathogens Standard
available through:
HIV/STD Programs
ME Bureau of Health
State House Station #11
Augusta, ME 04333
207-287-3747

Rotary Club AIDS Project
PO Box 794
Los Altos, CA 94023
415-688-6164
award-winning video "The Los Altos Story" available for \$25 donation

Sexuality Information and Education Council of
the U.S. (SIECUS)
130 West 42nd St., Ste. 2500
New York, NY 10036
212-819-9770

Test Positive Aware Network
Positively Aware
1340 West Irving Park, Box 254
Chicago, IL 60613

WORLD: Women Organized to Respond to Life-
Threatening Diseases
PO Box 11535
Oakland, CA 94611
510-658-6930

Online Resources:

CDC National AIDS Clearinghouse (CDC NAC)
NAC ONLINE direct: 1-800-851-7245
software configuration: 8, N, 1, VT100
<http://www/cdcnac.aspensys.com:85>
<gopher://cdcnac.aspensys.com:72/11/>

The AIDS BBS
San Juan Capistrano, CA
714-248-2836
Specs: 1200, 2400, 9600 (8,1,n)

AIDS Book Review Journal
<gopher://ucsbuxa.ucsb.edu:3001/11/Journals/.A/.AIDS>

AIDS Treatment News
<gopher://gopher.cic.net:70/11/e-serials/alpha-betic/a/aids-news;>

Safer Sex Page
<http://cornelius.ucsf.edu/~troyer/safesex/>

Maine AIDS Plan Evaluation Form

Please take a few minutes and fill out this evaluation form. Your feedback will help us improve the distribution and promotion of the *Plan*, and, if we print again, make the next version even better.

How did you receive your copy of the Maine AIDS Plan?

- | | |
|---|--|
| <input type="checkbox"/> at kick-off event in October | <input type="checkbox"/> at a presentation |
| <input type="checkbox"/> through the mail | <input type="checkbox"/> through a friend or colleague |

When did you first hear about the Maine AIDS Plan?

How did you first hear about it?

- | | |
|---|--|
| <input type="checkbox"/> at work | <input type="checkbox"/> through an AIDS organization |
| <input type="checkbox"/> was a Plan volunteer | <input type="checkbox"/> at a presentation |
| <input type="checkbox"/> read about it | <input type="checkbox"/> through a friend or colleague |

The Maine AIDS Plan Report Card

What really works about this document for you and what doesn't?

Please give the items below a grade—A through F

- | | |
|--|--|
| <input type="checkbox"/> layout/overall look | <input type="checkbox"/> how it reads |
| <input type="checkbox"/> action steps | <input type="checkbox"/> data and background information |
| <input type="checkbox"/> examples and personal stories | <input type="checkbox"/> how to find a general topic |
| <input type="checkbox"/> how to find specific information | <input type="checkbox"/> information sheets |
| <input type="checkbox"/> resource lists | <input type="checkbox"/> distribution/PR |
| <input type="checkbox"/> community involvement in Plan development | |
| <input type="checkbox"/> other _____ | |

OVERALL GRADE: ☐

What you liked best:

What is missing:

One way you'll use this:

How can we improve our promotion of the *Plan*?

Other people who should have a copy:

Additional comments/questions:

Would you like us to contact you for further information?

- ☐ No, I do not need a response.
- ☐ Yes, please contact me about coming to give a presentation.
- ☐ Yes, please contact me about _____

Optional:

Name _____

Organization _____

Address/Phone _____

Thank you very much!

Please send/fax to:

Maine AIDS Plan
112 State Street
Augusta, ME 04330

phone/fax (207) 622-2962

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Organization _____

Mailing Address _____

Street Address (if different) _____

Telephone/Fax _____

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(Organizations exempt from
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payment enclosed. Make checks payable to "Maine AIDS Plan." Thank you!

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112 State Street
Augusta, ME 04330

phone/fax (207) 622-2962

In accordance with Title VI of the Civil Rights Act of 1964 (42 U.S.C. §2000d *et seq.*), Section 504 of the Rehabilitation Act of 1973, as amended (29 U.S.C. §794), the Age Discrimination Act of 1975, as amended (42 U.S.C. §6101 *et seq.*), and Title IX of the Education Amendments of 1972, the Maine Department of Human Services does not discriminate on the basis of sex, race, color, national origin, handicap or age in admission or access to or treatment or employment in its programs or activities. Ann Twombly, Affirmative Action Officer, has been designated to coordinate our efforts to comply with the U.S. Department of Health and Human Services Regulations (45 C.F.R. Part 80, 84, and 91) and the U.S. Department of Education (34 C.F.R. Part 106) implementing these Federal laws. Inquiries concerning the application of these regulations and our grievance procedures for resolution of complaints alleging discrimination may be referred to Ann Twombly at 221 State Street, Augusta, Maine 04333, Telephone Number: (207) 289-3488 (Voice) or 1-800-332-1003 (TTY), or to the Assistance Secretary of the Office of Civil Rights, Washington, D.C.