

PRIORITY 1: People Who Are HIV Positive BEHAVIORAL POPULATION DESCRIPTION

The National Center for Disease Control estimates that over one million people are living with HIV in the United States. In Maine approximately 1,200 people are known to be living with an HIV/AIDS diagnosis. In addition, the Maine CDC estimates that as many as 500 people in Maine may be infected with HIV, but are unaware of their HIV status (ME CDC, 2007). Of those people living with diagnosed HIV in Maine¹ it is estimated that 84% are male and 16% are female. Men who identify their risk as having unprotected sexual contact with other men (MSM) continue to make up the majority of HIV infections in Maine² and should continue to be the main focus of prevention activities. IDU³ (Intravenous Drug Users) and FVHR (Females at Very High Risk) follow respectively and remain a priority for prevention activities in Maine. Of the 1,200 people already diagnosed and living with HIV/AIDS in Maine in 2007, 558 have been served by one of the Ryan White Part B case management agencies, and 527 people have been enrolled in the AIDS Drug Assistance Program (ADAP).

HIV Positive people are unique in that they require both prevention and care services. There must be effective coordination and integration of HIV prevention and care programs for these individuals. A new HIV diagnosis can provide strong motivation for an individual to change behaviors, allowing care providers an important opportunity to educate clients about HIV prevention. For HIV prevention educators, the prevention needs and care issues of people living with HIV need to be specifically addressed.

Risk Profile for People living with HIV and AIDS

Every new HIV infection involves a HIV Positive person engaging in unsafe behavior⁴. Despite this fact, it is the position of the Maine HIV Prevention Community Planning Group (the CPG) that **everyone**, regardless of HIV status, is responsible for their own behavior and the burden of HIV prevention does not rest solely with the HIV Positive community. It is crucial that HIV Positive individuals be aware of their role in preventing the spread of this disease. Not only does the HIV positive individual need to be aware of possible transmission to a negative partner but will also need to protect themselves from the risk of re-infection⁵ and contracting other sexually transmitted diseases.

¹ Griswold, Mark. "HIV and AIDS in Maine: Data from the Maine CDC HIV, STD and Viral Hepatitis Program" PowerPoint presentation. Maine HIV Prevention Community Planning Group, Augusta, ME

² 57% of the total number of people diagnosed in Maine and 69% of total males.

³ 13 % of total diagnosis in Maine.

⁴ The word "unsafe" is defined in this report as behavior in which there is no or very little protection put in place to prevent HIV infection. This behavior could be sexual or any other behavior that may include the swapping of bodily fluids. Unsafe means unprotected.

⁵ Re-infection: also known as co-infection. Each person's HIV infection is unique to that person. Having unprotected sexual contact or sharing needles can infect an already HIV positive person with a new strain of HIV infection.

During focus groups conducted with HIV positive people in Maine many people reported⁶ having a belief that their HIV positive peers were engaging in unsafe behavior. While survey results reported very few people engaging in behaviors that are defined as high risk.⁷ This highlighted the need to acknowledge the discrepancy between what people say and what they do when it comes to risky behaviors and prevention strategies. It was noted that this is an example of how stigma among HIV Positive individuals effects the larger population.

Many HIV positive people did report facing specific challenges, such as feeling hopeless, being trapped, or doomed as it related to their ability to negotiate safer sex / needle practices. The impact of “stigma” was also discussed as a major factor in a person’s ability to engage in safer behavior. Issues like disclosure of status and a lack of a sense of community with other positive people were important for people when discussing being HIV positive.

In Maine, the concept of Prevention for Positive people is often misunderstood and confusing. Many have said, “I already have HIV. Why do I need to practice prevention?” This way of thinking can increase the potential for transmission to a negative person or co-infection of a Positive person with a different strain of the HIV virus. That is why the CPG thinks it is crucial to focus prevention efforts on people who are already living with an HIV diagnosis.

Historically, prevention efforts had **not** been directed toward HIV Positive people for fear of “pointing the finger” or blaming HIV Positive people for the epidemic. Even though we want to emphasize the need to focus prevention on the HIV positive community, it is the position of the CPG that **everyone**, regardless of HIV status, is responsible for their own behavior and the burden of HIV does not rest solely with the HIV Positive Community.

It is important to note that not all people who are HIV Positive are in need of prevention services. Prevention services should focus on those who engage in unsafe sexual activity and/or share injection drug equipment, thereby putting themselves and others at risk for HIV infection or re-infection.

Behaviors

Certain behaviors, called HIV risk behaviors, increase the level of risk for HIV transmission and/or re-infection. The following is a list of HIV risk behaviors that put all people at risk. While they are not listed in order of priority, having unprotected receptive anal intercourse is the highest risk behavior for HIV infection.

- Having unprotected receptive anal intercourse

⁶ Cummings-Lawrence, Susan and Cotnoir, Jamie. “2007 CPG Needs Assessment Report

⁷ 250 surveys were returned and 239 were valid. It is important to note the limitations of this convenience sample. Is there somewhere that says what the limitations are? Just in case people don’t understand what a convenience sample is and the inherent limitations.

- Having unprotected insertive anal intercourse
- Having unprotected receptive vaginal intercourse
- Having unprotected insertive vaginal intercourse
- Having unprotected sex with multiple partners
- Having multiple unprotected sexual encounters
- Using alcohol and other drugs in combination with unprotected sex
- Exchanging sex for money (as in sex work or prostitution), and/or goods and/or services (e.g. lodging, food, clothing etc.)
- Having a sexual addiction or compulsive need to have sex
- Sharing needles and injection equipment to inject substances, including illegal drugs, hormones and steroids

HIV risk behaviors have the most direct relationship to HIV prevention. Over 25 years of research has identified that HIV is a preventable disease. Research has identified the specific behaviors that result in 100% prevention (No Risk Behaviors), other behaviors that result in higher, but not complete, levels of prevention (Safer Practices), behaviors that offer a low level of prevention (Moderate Risk) and those behaviors that offer no preventative benefit (Unsafe).

The other risk factors described in the following sections have a more indirect relationship to HIV prevention. They influence the decisions to engage in behaviors. As such these factors can either support or undermine preventive behaviors from occurring on a case-by-case basis.

HIV Status (HIV negative, positive, unknown)

A person's HIV status can be **positive**, meaning they have tested⁸ positive for HIV antibodies in their body; Negative meaning that they no antibodies present at the time of testing, or unknown meaning the person has not been tested or testing was done prior to engaging in unsafe behavior that could possibly have transmitted HIV.

People who have been diagnosed as being HIV positive have reported⁹ that knowing their HIV status has helped them to change unsafe behavior for safer behavior. While telling another person, especially a sexual partner, your HIV status is often scary and intimidating; many people report that disclosure of status has helped to negotiate safer behavior and boosted self esteem, at the same time the partners are able to have a conversation about the kind of behavior they are willing to engage in.

⁸ The most commonly used HIV tests for the presence of HIV antibodies in a person's body. Different kinds of tests can measure the amount of actual virus present in a person's body at the time of testing. This type of testing is usually done after a person tests positive for HIV antibodies.

⁹ Adoption of Protective Behaviors Among Persons With Recent HIV Infection and Diagnosis---Alabama, New Jersey, and Tennessee, 1997-1998. MMWR, Weekly, June 16, 2002/ 49(23):512-5

Disclosure of one's HIV status is a very personal decision. Each person needs the time and support to work through the many feelings and realities of having a positive diagnosis. This is a critical time period for the newly diagnosed person to get support and information around prevention and health information. Although some progress has been made in lessening the stigma of HIV/AIDS over the last 25 years, stigma and fear are still the number one reason for people not knowing or disclosing their status. AIDS activists and HIV Positive people have also feared the creation of laws which would criminalize risky sexual behaviors and result in further criminal prosecutions of Positive injection drug users. It should be the intent of prevention messages to bridge the gap between personal responsibility and civil rights, and between civil rights and public health and safety.

Many HIV positive people have talked about two opposing thought processes that happen with HIV/AIDS at the same time¹⁰. First, there is the fear of stigma and discrimination that happens to people living with HIV/AIDS. The second is an attitude and belief that HIV/AIDS is not a big deal anymore. A culture of shame and rejection for those living with HIV/AIDS seems to conflict with the message from drug companies who create media showing healthy looking HIV positive people living normal lives. Prevention strategies have to take these opposing messages into account.

Recent CDC recommendations¹¹ for routine HIV testing in the clinical setting have lessened some of the barriers for people to learn their HIV status. This move to make HIV testing part of regular health care is just one step toward lessening the stigma of HIV. The community based prevention programs that offer HIV testing have an equally important role in providing strong "community building" prevention messages that can affect the attitudes and beliefs of the people who use these community based services.

To reduce their risk of infection, many MSM, focus on the HIV status of partners rather than the risk behavior. Through a practice known as sero-sorting, the theory goes that if partners who know their status have the same HIV status (negative or positive), there is no risk of HIV infection or negative health consequences. Theoretically, if two negative people engage in unprotected intercourse there is no risk of infection because HIV is not present. Similarly, if two positive people engage in unprotected intercourse, no new infection will result and there will be no negative health consequences for the individuals because they both are already infected with HIV. However, while the theory seems to make common sense, research has shown that there is risk in sero-sorting. New infections do result among negative sero-sorters and there are serious negative health consequences for positive sero-sorters. For positive

¹⁰ Focus group transcripts

¹¹ Branson, B.; Handsfield, H.; Lampe, M.; et al. Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Healthcare Settings. MMWR: Recommendations and Reports. Sept.22 2006/55(RR14);1-17. from <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>

people, we know that new and different strains of HIV can be passed to each other, including drug-resistant strains that can adversely affect health.

The group of people who are untested for HIV, and therefore whose HIV status is unknown, represents a challenge for HIV prevention. There are three important facts related to unknown HIV status.

1. The U.S. Centers for Disease Control and Prevention (CDC) estimate that about 25% of people infected with HIV don't know it because they haven't been tested. In Maine, that proportion represents about 300-500 people.
2. The U.S. CDC estimate that more than half of HIV infected adolescents don't know it because they haven't been tested.
3. The U.S. CDC estimate that more than half, from 50% to 70%, of new infections are caused by people who are infected but untested and unaware of their infection.

In summary, the relationship between HIV risk behaviors and HIV status, and how they relate to HIV prevention are critical but complex. Many of the risk factors that follow are factors that influence behavior as well as a person's decision to be HIV tested and to clearly understand what test results mean.

Individual attitudes, beliefs and feelings concerning HIV and risk

How a person feels, the things they believe in, and the attitudes they hold are other important factors that influence HIV prevention.

It is imperative to remember that HIV positive people can and do engage in sexual behavior. Prevention programs and activities should recognize that sexuality is an important human behavior. Prevention services need to target unsafe sexual behavior that HIV positive people may engage in, not HIV positive people.

Individual attitudes, beliefs and feelings must support behavior that reduces the risk of HIV transmission and increases actions of HIV prevention.

- HIV positive people as well as negative people must believe that HIV is serious enough to do something about.
- HIV people must believe that their sexual partners are important enough to protect.
- Negative people must believe that they own some of the responsibility to protect themselves.
- All people regardless of their HIV status must believe their bodies and health are worth protecting.
- HIV positive people must believe that the information they are given by science, the government, and community providers is true.

- HIV positive people must believe they can carry out the behaviors they need to prevent HIV infection.

Some of the feelings and beliefs that have been identified by recent needs assessment of PLWHA in Maine are not supportive of HIV prevention.

- “Prevention for Positives” is a concept that had been until recently ignored. Many HIV positive people have the attitude of “I already have it why do I need to protect myself”. The MECPG recommends that prevention activities for HIV positive people target these attitudes and beliefs.
- Being HIV positive makes me less worthy of a healthy life.
- Dealing with the stigma of being HIV positive supersedes prevention practices.
- “If I disclose my (HIV) status, I might as well kiss my sex life goodbye.”

Individual mental and emotional status

A person’s mental and emotional health status is another important factor affecting HIV prevention. Such conditions as a diagnosed mental illness, depression (often undiagnosed), level of self-esteem, loneliness, and a history of trauma and/or abuse are factors, which can either support or undermine HIV prevention behaviors.

Having an HIV / AIDS diagnosis can exacerbate these negative mental and emotional conditions. It is critical that a newly diagnosed person be offered competent comprehensive counseling and/or case management at the time of diagnosis. In focus groups conducted through the needs assessment process, HIV positive people who were engaged in counseling, support groups, and/or effective case management reported having this type of support to work through those emotions and feelings helped to increase self-esteem and empowered individuals to be more in control of their own lives. This included knowing and practicing safer sex prevention methods such as condom use, relationship negotiation and status reporting with partners as well as having increased knowledge of services available and how to access them.

It was also noted that the majority of respondents to both the survey and the focus groups were enrolled in case management services¹². There continues to be a lack of information being collected from those HIV positive people who are not in case management (an estimated 642 people). Reaching these individuals for information gathering and targeting prevention services has been identified as a service gap. It is strongly realized that all people who are HIV positive do not need or want case management services and that more investigation needs to be done to ensure that those who are not accessing available services are doing so by choice and not because of system, cultural, or social barriers.

¹² 558 HIV positive people have been served by one of the Ryan White Part B case management agencies in Maine.

Substance Use, Substance Abuse and Addictions

Substance use:

- Alcohol and Marijuana / Hash are the most commonly used substances according to the needs assessment.

Substance Abuse

- 20% of respondents indicated that they were not or somewhat likely to practice safer sex when using alcohol or drugs.
- 17% of respondents agreed that when they were high on drugs they didn't think about transmission of HIV to others.
- 14% indicated that are usually high on alcohol or drugs when they have sex.

Addictions

There are three primary addictive states that can seriously undermine HIV prevention actions and behaviors. Untreated, these addictions exert strong control over a person's behavior in unpredictable ways. They are:

- Drugs
- Alcohol (the substance of choice in Maine for MSM)
- Sex

Social and Cultural Norms

Social and cultural norms are the generally accepted rules and beliefs of society as a whole or groups of people who share some common characteristics.

HIV positive people are not a homogenous group of people. It is often believed that HIV positive people are all alike and have the same needs, when in fact HIV positive people, including HIV positive people in Maine, come from all walks of life and are as unique as the population as a whole. At the same time there has been little visibility of HIV positive people here in Maine and in the US in general. This lack of visible role models and spokespersons has led to invisibility, increased stigma and lack of effective prevention messages. There is hope that with the CDC's recommendation for routine testing in the clinical setting that some of the stigma surrounding testing will be lessened. Also it is recommended that prevention and care initiatives for HIV positive people work together to provide comprehensive prevention messages in new and innovative ways, such as using the internet, faith based organizations and recommitting to public service announcements on the radio, television and in print.

Systems and Institutions

- 90 % of people who responded to the needs assessment survey indicated that they like to get HIV information from their doctor.
- 63% of people who took the survey indicated they used the internet to find HIV information.
- The biggest barrier to services indicated was the fear that someone in the community would find out a person's HIV status.
 - (Expand on the stigma of this)
 - Small town / rural culture

- Transportation was indicated as a barrier to accessing prevention services.
 - Rural state with community based organizations spread out over long distances.
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Key Needs Assessment Findings

2007 CPG Needs Assessment Report

Summary of Key Findings

Survey of PLWH

- 250 surveys completed
- 239 were valid

Demographics

- *Sex*
 - 20% Female
 - 79% Male
 - <1% Transgender
- *Age*
 - 1% 15-24
 - 38% 25-44
 - 58% 45-64
 - 3% 65+
- *Race and Ethnicity*
 - 84% White
 - 7% Native American
 - 5% African American
 - 5% Other Race
 - 7% Hispanic

Sex and Relationships

- 75% Men who have Sex with Men
- 76% Women who have Sex with Men
- 54% Females in Monogamous Relationship
- 27% Males in Monogamous Relationship
- 25% Males single and have had more than one sex partner in the last year
- 31% Females have not had sex in the last year
- 33% Males have not had sex in the last year
- 100% Transgender have not had sex in the last year

- 23% have had unprotected sex without disclosing status since diagnosis
- 30% have had unprotected sex with a person of unknown status

Sex Partners in the Past Year

Females

- 51% - one vaginal sex partner
- 41% - no vaginal sex partners
- 83% - no anal sex partners
- 15% - one anal sex partner
- 52% - no oral sex partners
- 35% - one oral sex partner
 - Most Vaginal Sex Partners – 30
 - Most Anal Sex Partners – 2
 - Most Oral Sex Partners – 60

Males

- 82% - no vaginal sex partners
- 54% - no anal sex partners
- 20% - one anal sex partner
- 39% - no oral sex partners
- 25% - one oral sex partner
 - Most Vaginal Sex Partners – 48
 - Most Anal Sex Partners – 48
 - Most Oral Sex Partners – 80

Transgender

- Both transgendered respondents reported having no sex partners of any type

Condom/Dental Dam Use

Females

- 13% never use condoms for Anal Sex
- 19% never use condoms for Vaginal Sex
- 35% never use a barrier when Oral Sex is being performed on them
- 40% never use a barrier when performing Oral Sex

Males

- 6% never use condoms for Anal Sex
- 2% never use condoms for Vaginal Sex
- 31% never use a barrier when Oral Sex is being performed on them
- 37% never use a barrier when performing Oral Sex

Transgender

- Both respondents report not having sex in the last year

- About 25% of people said they bring up barrier use
- About 5% said that their partner brings up barrier use
- About 30% of people said that they and their partner both bring up barrier use

- About 15% said that they never use condoms/dental dams

Risk Behaviors

- 42% of Females believe that their behaviors have little or no risk of transmitting HIV
- 59% of Males believe that their behaviors have little or no risk of transmitting HIV
- 50% of people disclose their HIV status to all of their sex partners before they have sex
- 83% feel that its their responsibility to disclose their status to all of their sex partners
- 44% report having a hard time disclosing their status to sex partners
- 50% feel that their sex partner has the responsibility of protecting themselves from HIV infection
- 60% of people report that they are always in control of whether or not they have protected sex
- 13% of people were diagnosed with Hep C since being diagnosed with HIV
- 12% with Genital Warts
- 11% with Herpes

Substance Use

Alcohol and Marijuana/Hash are the most commonly used substances.

- 27% use alcohol once a week or more
- 26% use marijuana once a week or more

35 people have ever used injection drugs.

- 5 people have shared needles in the past year
- 12 people said they do not know how to clean their works
- 10% of people said they were somewhat likely to practice safer sex when using.
- 10% said they were not likely to practice safer sex when using
- 34 people said they either strongly agreed or agreed some to the statement “When I have sex, I am usually high on alcohol and/or drugs.”
- 40 people said they either strongly agreed or agreed some to the statement “When I am high on drugs, I don’t think much about transmission of HIV infection to others.”
- 7 people said they always tell their HIV status to their drug using partners before they share needles with them.
- 5 people said they never tell their HIV status to their drug using partners before sharing needles.

Services

- Most people – 90% - like to get their HIV info from their doctor
- 63% of people like to get their info from the internet

- The biggest barrier to services is the fear that someone in the community will find out a person's HIV status
- Transportation is also a problem for people in accessing prevention services

Support Services

Case Management

- Most people – 91.2% or 218 people – have an HIV Case Manager.
- Of those people in case management, 72.5% or 169 people, said their case manager talks with them about safer sex or safer injecting.

Medical Care

- Most people – 98.3% or 235 people – have a doctor that they see for their HIV needs.
- Of those people with doctors, 65.3% or 156 people, said their doctor talks with them about safer sex or safer injecting.

GROUP INTERVIEWS

Ten discussion groups were held in different parts of the State.

- Forty-five people participated
- 32 men, 12 women and 1 transgender person.
- Ages ranged from 20 to 69.
 - 84% were between 30 and 59.
- 34 were “white.”
- 9 “black”
- 2 each of “native American,” “biracial,” “Hispanic,” and “other.”
- 29 were gay, 11 were straight.

Ten of the **16** Maine counties were represented: Androscoggin, Aroostook, Cumberland, Hancock, Kennebec, Oxford, Penobscot, Waldo, Washington and York.

Responses

1) What are people with HIV doing to increase their HIV-related risk?

- Not using condoms.
- Not using clean needles.
- Allowing drinking/drugging to interfere with prevention practices.
- Lacking the self-esteem and personal empowerment that help people practice prevention.
- Not able to accept the realities of their HIV status.
- Affected by depression and feel that nothing they do matters.

2) A. How are they lowering their risk?

B. Does risk reduction have anything to do with how long a person has known he/she has had HIV?

A. Group participants said that people with HIV are sometimes:

- Practicing safer sex by using condoms and dental dams.
- Practicing safer sex by using harm reduction practices, such as oral sex rather than anal sex.
- Exchanging used needles for clean ones.
- Getting risk reduction information from many sources:
 - Case managers.
 - Other HIV positive people.
 - Health care providers.
 - Medical journals and websites.
 - STD clinics.
 - Internet.
 - Social contacts/groups.
 - Conferences.
 - Support groups.
 - Magazines (POZ).

B. Group participants said that:

- In some cases, the longer people have known their HIV status, the more likely they will practice risk reduction. They are more aware of the dangers to themselves and others.
- Some people who have had HIV for a long time, get used to the idea and don't think so much about risks as time passes and they are doing well.

3) Do those with HIV know about HIV prevention services that are available especially for them?

Group participants said that sometimes they and other people know about services and sometimes they do not. People find out about services and use them because they get information from:

- Case managers.
- Other HIV positive people
- Support groups.
- Internet.
- Health care providers.
- Conferences.
- Social groups.
- Magazines.

4) What difficulties do people with HIV face in getting risk reduction services?

Group participants said the following are barriers:

- Geography/rural areas of Maine.
- Lack of transportation.
- Transportation costs.
- Lack of services in certain parts of the State.

- Health care and other providers who do not offer information.
- Political/social influences.
- Personal factors such as:
 - Embarrassment/self consciousness.
 - Denial.
 - Addictions.
 - Disagreements with or dislike of providers.

5) What responsibility do people with HIV have in not causing others to become infected?

Group participants believe that:

- People with HIV are responsible—no matter what.
- People with HIV and their sex partners, whether they are infected or not, are both responsible for preventing HIV and HIV superinfection.
- Everyone should make his/her own decision, even when knowing partner is HIV positive/negative.
- People with HIV are not responsible for protecting others.