

State of Maine  
**COMPREHENSIVE  
HIV PREVENTION PLAN**



2010



2014



# **State of Maine Comprehensive HIV Prevention Plan**

**2010 ~ 2014**

**Maine  
HIV Prevention  
COMMUNITY  
PLANNING  
GROUP**

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# Maine HIV Prevention Community Planning Group

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## **Dedication:**

*This Plan is dedicated to CPG members who have participated in HIV prevention planning through the years and have since passed away. The CPG wishes to acknowledge the contributions that they have made. A special dedication to:*

Declan Buckley  
Bob McFarland  
Ron Goben  
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## **Chapter 1**

### **INTRODUCTION**

The Maine HIV Prevention Community Planning Group (ME CPG) proudly presents the 2010-2014 Comprehensive HIV Prevention Plan. The Plan informs the Maine CDC, and other stakeholders involved in HIV prevention efforts, of the CPG's recommendations for HIV prevention services. This stand-alone document supplants the 2004-2008 Maine Comprehensive HIV Prevention Plan, and the subsequent 2006-2010 Updates.

### **GOALS FOR HIV PREVENTION**

With the new federal prevention funding cycle beginning in 2012, it is expected that the CPG Plan will reflect the National AIDS Strategy.

The vision statement of the National AIDS Strategy is: "The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity, or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination."

The three primary goals of the National Strategy are as follows:

- 1) Reducing new HIV infections
- 2) Increasing access to care and improving health outcomes for people living with HIV
- 3) Reducing HIV-related disparities and health inequities

The President's statement regarding the strategy says, "This moment represents an opportunity for the Nation. Now is the time to build on and refocus our existing efforts to deliver better results for the American people".

With our focus on the National AIDS Strategy, the State of Maine CDC has two HIV prevention goals for all HIV prevention activities. These are:

**Goal 1:** The health of all Maine people will be improved by promoting behaviors, attitudes, community building and/or knowledge that reduces the risk of HIV.

**Goal 2:** HIV+ persons in Maine will have reduced morbidity and mortality through increased access to early medical and related service interventions, with linkage to care being a vital requirement.

In order to accomplish these HIV prevention goals, the ME CDC uses the information contained in this HIV Prevention Plan in making funding decisions and for purchasing HIV prevention services. The Plan provides information about the characteristics of the populations prioritized for HIV prevention and includes information about the types of interventions that would best address their needs.

## **CPG MEMBERS AND THE HIV PREVENTION PLAN OVERVIEW**

The priority populations, needs, and interventions included in this Plan are the result of a prioritization process undertaken by CPG members. The CPG members are made up of one ME CDC representative and a diverse group of community members who come from Maine communities most affected by the HIV epidemic. These members bring a wealth of personal knowledge and experience to the planning process. This knowledge of community norms and values is combined with an examination of behavioral science data about effective HIV prevention techniques, and the study of local HIV/AIDS epidemiological data in order to formulate the recommendations included in this Plan.

CPG members reviewed an enormous amount of data in order to write this Plan, including HIV and STD EPI data (2005-2009 Epi Profile, ME CDC); hepatitis C data; and the Community Services Assessment (CSA). See page 9 for more information about the CSA.

## **HIGHLIGHTS OF THIS HIV PREVENTION PLAN**

- The first priority population in this Plan is people who are HIV+. See Chapters 3 and 5 for more information.
- In keeping with the CDC's Advancing HIV Prevention Initiative, the CPG continues to recommend the CDC's Serostatus Approach to Fighting the Epidemic (SAFE) model as a basis for prevention activities in the State. See Chapters 3 and 6 for information on this model and how to implement it. If you would like more information on the Advancing HIV Prevention Initiative, visit the CDC website: <http://www.cdc.gov/hiv/partners/ahp.htm>.
- Prevention activities and interventions for the behavioral populations in this Plan include a distinction between people at "high risk," and people at "very high risk" of infection. See Chapter 6 for details.
- The CPG has retained the recommendations for Counseling, Testing and Referral (CTR). See Chapter 6 for details.
- The CPG recommends that the ME CDC continue to retain a cross-disciplinary work group to address the overall system needs in Maine.

- Three behaviorally based populations remain at risk for HIV in Maine and they have been prioritized throughout the State as follows:
  - Males who have Unsafe Sex with Males (MSM)
  - Injection Drug Users who Share Needles and/or Injection Equipment (IDU)
  - Heterosexual Females at Very High Risk (FVHR)
  - See Chapters 3 and 5 for more information about these prioritized populations.
- Three regions were used in this Plan to divide the State geographically, however they have been prioritized in the following order:
  - Southern: Cumberland and York Counties
  - Central: Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo Counties
  - Northern: Aroostook, Hancock, Penobscot, Piscataquis and Washington Counties
  - See Chapter 3 for more information on these regional priorities.
- The CPG recognizes there are populations that have characteristics requiring special prevention strategies and cultural competencies. These populations may include the deaf community, youth, people who are transgendered, people who have a mental illness or other disability, people who are homeless, incarcerated, or are members of racial and/or ethnic minorities, etc. Chapter 4 contains revised, updated information about these populations.

**It is the charge of the CPG, after reviewing the epi data and trends, to determine where to focus HIV prevention services to prevent as many new infections as possible given the amount of funding available. It is our hope that this Plan will help to accomplish this. The CPG acknowledges that this does not diminish the needs of other populations in Maine and encourages efforts to find increased funding and cooperation between service providers to serve these populations.**



## **Chapter 2**

### **THE COMMUNITY PLANNING PROCESS**

This Chapter provides a summary of the overall goals and objectives of community planning as well as specifics about the process used to develop this Plan.

### **HISTORY AND PURPOSE OF COMMUNITY PLANNING**

Community planning began in 1994 when the Centers for Disease Control and Prevention (CDC) directed states and other jurisdictions that receive CDC funding for HIV prevention to begin a community process for HIV prevention. The intent of the process was threefold: to increase meaningful community involvement in prevention planning, to improve the scientific basis of program decisions, and to target resources to those communities at highest risk for HIV transmission/acquisition.

Maine has one statewide planning group. The purpose of the ME CPG is to write and update the State of Maine Comprehensive HIV Prevention Plan. The CPG uses the most recent information about HIV incidence, prevalence, trends, information about who is infected in Maine and interventions that work to change peoples' behavior, to decide the most important ways to prevent the spread of HIV. The CPG is charged with developing a comprehensive plan in which populations are prioritized and interventions are chosen based on their ability to prevent as many new infections as possible.

The CPG works in collaboration with the ME CDC to develop this Plan. To ensure that the Plan includes the norms and values of the community, the CPG tries to recruit a diverse group of members to reflect the different groups that are affected by HIV in Maine. In this way, populations that carry the largest burden of HIV infection are an integral part of the planning process. Community members, health care providers, health scientists, HIV prevention providers and people living with HIV all work together to understand the epidemic in Maine and come up with the best ways to prevent new infections. This is an ongoing process intended to improve the effectiveness of HIV prevention programs funded by the ME CDC.

### **GOALS AND OBJECTIVES OF COMMUNITY PLANNING AS DEFINED BY THE CDC**

- **Goal One:**  
Community planning supports broad-based community participation in HIV prevention planning.

**Objective A:** Implement an open recruitment process (outreach, nominations, and selection) for CPG membership.

**Objective B:** Ensure that the CPG membership is representative of the diversity of populations most at risk for HIV infection and community characteristics in the jurisdiction, and includes key professional expertise and representation from key governmental and non-governmental agencies.

**Objective C:** Foster a community planning process that encourages inclusion and parity among community planning members.

- **Goal Two:**

Community planning identifies priority HIV prevention needs (a set of priority target populations and interventions for each identified target population) in each jurisdiction.

**Objective D:** Carry out a logical, evidence-based process to determine the highest priority, population-specific prevention needs in the jurisdiction.

**Objective E:** Ensure that prioritized target populations are based on an epidemiological profile and a community services assessment.

**Objective F:** Ensure that prevention activities/interventions for identified priority target populations are based on behavioral and social science, outcome effectiveness, and/or have been adequately tested with intended target populations for cultural appropriateness, relevance, and acceptability.

- **Goal Three:**

Community planning ensures that HIV prevention resources target priority populations and interventions set forth in the comprehensive HIV prevention plan.

**Objective G:** Demonstrate a direct relationship between the Comprehensive HIV Prevention Plan and the ME CDC Application for federal HIV prevention funding.

**Objective H:** Demonstrate a direct relationship between the Comprehensive HIV Prevention Plan and funded interventions.

## **THE MAINE HIV PREVENTION COMMUNITY PLANNING GROUP**

According to its current Bylaws, the CPG consists of no less than twelve (12) and no more than fifteen (15) voting members. Members represent the populations most at risk for HIV according to the Maine Epidemiological Profile with a minimum of 50% being people living with HIV. Due to Conflict of Interest, service providers and employees of organizations that receive HIV prevention funding are not eligible for membership. CPG members participate in the community planning process as a representative and a voice for the populations at high risk for HIV infection.

Membership applications are available from the CPG office. Completed application packets, including reference checks, are reviewed by the Membership Committee; population gaps are assessed; and recommendations are presented by the Membership Committee Chair to the Executive Committee for approval. If the Executive Committee approves the recommendation(s) made, the Membership Committee Chair will present the recommendation to the full CPG membership, based on Parity, Inclusion and Representation as defined in the CDC Guidance for Community Planning. The full CPG will elect eligible applicants by a simple majority vote.

Members shall serve a minimum of one, one-year term; beginning on the date of the first meeting attended and may serve a maximum of five consecutive renewable one-year terms. Members are required to attend an orientation, six to eight full day meetings and one two-day retreat per year. All prioritization decisions are made during the scheduled meetings.

Members may also participate on CPG sub-committees. Sub-committee work is brought back to the full CPG; final decisions are made by the CPG through a modified consensus decision-making process. Sub-committees in effect during this planning process include the:

- Executive Committee
- Membership Committee

The Community Co-Chair of the CPG serves as a CPG representative on the Maine HIV Advisory Committee, the HIV Prevention Providers Group and the Ryan White B Advisory Committee. The representative provides information about the CPG to the committees and reports information from the committees to the CPG during the Committee Reports at the next CPG meeting and provides minutes if available.

In order to ensure Parity among members of this diverse group, training and technical assistance is provided during all phases of the planning process. This facilitates members' understanding of the work of the group and enables them to participate fully in the decision making process. Training and technical assistance is provided by CPG members, the CPG Project Assistant, and/or experts from the ME CDC, as needed.

The CPG Community Membership profile during this Plan update was as follows:

**CPG MEMBERSHIP REPRESENTATION**

<b>Primary Prioritized Population Groups</b>	<b>Current Members</b>	<b>Gender</b>	<b>Regional Representation</b>
People living with HIV/AIDS (PLWHA)	6	3-male 3-female	Northern: 1 Central: 3 Southern: 2
Men who have Unsafe Sex with Males (MSM)	6	6-male	Northern: 1 Central: 4 Southern: 1
Injection Drug Users who Share Needles and/or Injection Equipment (IDU)	1	1-female	Northern: 0 Central: 0 Southern: 1
Heterosexual Females at Very High Risk (FVHR)	3	3-female	Northern: 0 Central: 1 Southern: 2
Total Community Members	9	5-male 4-female	Northern: 1 Central: 4 Southern: 4
ME CDC Member	1	1-male	

<b>Race</b>	<b>Current Members</b>	<b>HIV+</b>
White	8	Currently 60% of CPG members are PLWHA
African American/Black	0	
Asian	0	
Pacific Islander	0	
Native American	0	
More than one race	2	

## **Chapter 3**

### **PRIORITIZATION**

The term “Prioritized Populations” is used to describe groups of individuals whose behaviors put them at high risk for HIV infection, and are most in need of HIV prevention services. Priority setting is a very difficult process as the amount of money available for prevention is not enough to provide HIV prevention programs to meet all the needs of the populations at-risk identified by the CPG. Before beginning, the CPG clarified roles and responsibilities, reviewed its decision-making process, and provided ongoing training to members covering all aspects of the prioritization process. This Chapter reviews how priorities were set and the prioritized target populations and regional priorities that resulted.

### **THE PRIORITY SETTING PROCESS**

The priority setting process was undertaken by the entire Community Planning Group (CPG). All voting CPG members (both HIV+ and negative) represent a prioritized behavioral population and one of the three (3) regions of the State. Members participated in corresponding committees that reviewed pertinent data and then set the priorities laid out in this HIV Prevention Plan. The three (3) behavioral populations are: Males who have Unsafe Sex with Males (MSM), Injection Drug Users who Share Needles and Injection Equipment (IDU), and Females at Very High Risk (FVHR).

The development of this HIV Prevention Plan was conducted at monthly CPG meetings and supplementary meetings between October 2008 and April 2011. Due to the low incidence and prevalence of HIV/AIDS in Maine the Executive Committee decided to adopt a process that involved data review and discussion by CPG members using a modified consensus decision-making process. This process identified target populations, their prevention needs, and the interventions that would be most effective for these individuals.

CPG members reviewed the following sources of information in making their decisions. Unless otherwise noted, these documents are available from the Maine Center for Disease Control and Prevention (ME CDC), HIV/STD/VH Program at (207) 287-3747.

- **Epi Profile** Produced by the ME CDC HIV/STD/VH Program. It describes how HIV/AIDS affects people living in Maine including: which populations, age groups and ethnic groups are affected by HIV in a defined area; HIV and STD incidence and rates; etc.

- **Hepatitis C data** General information on hepatitis A, B and C and recommendations for HIV prevention planning was provided by the ME CDC Adult Viral Hepatitis Coordinator, (207) 287-3817.

**Community Services Assessment (CSA)** The CSA includes Needs Assessments, a Resource Inventory and a Gap Analysis. The following documents are included in the CSA and were reviewed by the CPG:

- **Prioritized Population Needs Assessments completed between 2006 -2010:** Produced by the CPG and the ME CDC. These documents provide information on the knowledge, attitudes, beliefs and behaviors of people at risk.
- **Resource Inventories between 2006 -2011** Produced by the ME CDC these provide information on current HIV prevention related resources, activities and services throughout the State regardless of funding source.
- **Gap Analyses completed between 2006 -2011** These provide a description of the unmet HIV prevention needs of the populations at high risk that were identified in the Epi Profile. The unmet needs are identified by comparing the needs of the populations (as indicated in the Needs Assessment) to the services available (as listed in the Resource Inventory).
- **Updates to the *HIV Prevention Plan* completed between 2006 -2010.** The CPG reviewed the previous priorities. Contact the CPG office at (207) 622-7566, ext. 233 for more information.
  
- **Ryan White B case management data** Information, including the Coordinated Statement of Need, was provided by the Ryan White B Program Coordinator at the ME CDC.
- **The Compendium of HIV Prevention Interventions with Evidence of Effectiveness from the CDC.** Available on the web at:  
<http://www.cdc.gov/hiv/pubs/hivcompendium/HIVcompendium.pdf>
- **Procedural Guidance for Selected Strategies and Interventions for Community Based Organizations Funded under Program Announcement 04064** from the CDC which contains information on targeted outreach and prevention interventions. Available on the web at: <http://www2a.cdc.gov/hivpra/pa04064.cbo.html>

The CPG also reviewed the Center for Disease Control and Prevention's (CDC) Advancing HIV Prevention: New Strategies for a Changing Epidemic.

([www.cdc.gov/hiv/topics/prev\\_prog/AHP/default.htm](http://www.cdc.gov/hiv/topics/prev_prog/AHP/default.htm) ) This initiative was announced in April 2003 and focuses on reducing barriers to early diagnosis; improving referral to prevention services, medical care, and treatment; and ensuring that prevention programs are in place to assist people living with HIV.

The CPG also reviewed the National AIDS Strategy released July 2010. This ambitious plan is the nation's first-ever comprehensive coordinated HIV/AIDS roadmap with clear and measurable targets to be achieved by 2015.

As part of the priority setting process, the CPG decided to continue to adopt the *Serostatus Approach to Fighting the Epidemic* (SAFE). This is a CDC strategy for HIV prevention. The CPG felt with limited resources, adopting the basic components of this initiative would be an effective shift for HIV prevention in the State and follow the *Advancing HIV Prevention* initiative. The SAFE model is designed to complement existing HIV prevention activities. It requires activities be focused on recruitment into Counseling, Testing and Referral services (CTR) and to addressing the needs of very high-risk negative and HIV positive people.

Using the SAFE model, the CPG identified activities, services and interventions that would facilitate recruitment for testing, assess risk, and address the HIV prevention needs of HIV+ people and those at very high risk of infection. The goal of these interventions is to support the adoption and maintenance of HIV risk reduction behaviors among very high-risk members of the behavioral populations and HIV+ people.

The CPG also identified critical needs for the populations through review of needs assessment data and other community input. Note that the needs detailed in this Plan are not inclusive of all the needs of the populations, or the individuals within each population, and are not listed in priority order.

For information regarding other populations identified in this Plan that require additional considerations in HIV Prevention please see Chapter 4.

The full CPG reviewed the final draft of this Plan and approved it by consensus.

## HIV PREVENTION PRIORITIES ~ Target Populations

As a result of the priority setting process the CPG decided on the following prioritized target populations for all three (3) regions in Maine. These behavioral populations are listed in priority order. The justifications used in determining the priorities are also included.

### PRIORITIZED TARGET POPULATIONS: Southern, Central and Northern Regions of Maine

Rank	Behavior	Gender	Race/Ethnicity	HIV Status
1.	MSM, IDU, FVHR	Male, Female, Transgender	All	Positive
2.	MSM	Male, Transgender	Caucasian/White African American/Black Latino/Latina/Hispanic Native American	Unknown or negative
3.	IDU	Male, Female, Transgender	Caucasian/White African American/Black Latino/Latina/Hispanic Native American	Unknown or negative
4.	FVHR	Female, Transgender	Caucasian/White African American/Black Latino/Latina/Hispanic Native American	Unknown or negative

MSM = Males who have Unsafe Sex with Males

IDU = Injection Drug Users who Share Needles and Injection Equipment

FVHR = Females at Very High Risk

## **JUSTIFICATION FOR PRIORITIZATION**

The CPG reviewed all of the data listed at the beginning of this Chapter in making its decisions. In particular, the following information from the CPG prioritization process helped to inform the final decisions:

- The epi data provided by the ME CDC clearly shows that MSM continue to carry the burden of HIV infection in Maine (EPI Profile, 2010) and that, in fact, there has been an increase in the number of new infections in this population over previous years. MSM also have increased rates of gonorrhea and syphilis according to the STD data provided by the ME CDC. In 2010 there was a 179% increase in syphilis (39 cases).
- According to the EPI Profile (ME CDC, 2010) in 2010 93% of people infected with HIV were 30 and over, and 7% were under 30. Concurrent diagnosis of HIV and AIDS continues to be a major issue comprising almost half of the new diagnoses. Therefore, many people are waiting until they become ill before they test and were likely infected years before being diagnosed. In addition, the proportion of people under 30 who became infected remains steady therefore rather than categorizing age groups the CPG will continue to put the focus on CTR outreach using the SAFE model.
- African Americans/Blacks, Latinos/Latinas/Hispanics, and Native Americans have a low incidence of HIV but continue to have disproportionate rates of infection according to the epi data. The non-White and Hispanic population of Maine comprises approximately 3% of the state's total population (2010 Census), but 14% of people diagnosed during the past five years were from racial/ethnic minority groups (2010 ME CDC EPI Profile). Most prominently represented among these groups were African American/Blacks, comprising 14% of total diagnoses. In addition, in 2010, People of Color comprised 30% of the new diagnoses. These populations were therefore included in Plan priorities for culturally competent services.

Since every new HIV infection involves an HIV+ infected person and the opportunity for transmission is far greater in this group in 2005 the Federal CDC instructed CPG's to make people living with HIV/AIDS the number one priority population for HIV prevention services. Not all people living with HIV or AIDS (PLWHA) are at equal risk for transmitting HIV or for becoming re-infected and this must be taken into consideration when recommending or providing HIV prevention services.

### **HIV PREVENTION PRIORITIES ` Regional Priorities**

The CPG also reviewed regional data in order to determine prevention priorities. The regional priorities as decided on by the CPG are listed below followed by pertinent information from the 2010 Census for each of these three regions of the State.

### **REGIONAL PRIORITIES**

Following review of the epi data and trends in the epidemic, the CPG recommends the following priority be given to the three regions of the State for prevention activities:

<b>Rank</b>	<b>Region</b>	<b>Counties</b>
1.	SOUTHERN	Cumberland and York Counties
2.	CENTRAL	Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo Counties
3.	NORTHERN	Aroostook, Hancock, Penobscot, Piscataquis and Washington Counties

➤ **Based on Epidemiological data the greatest allocation of HIV prevention resources should occur in the Southern Region of Maine (2010 EPI Profile, ME CDC).**

**SOUTHERN MAINE REGIONAL DESCRIPTION:**

**Counties in Southern Maine:** Cumberland and York Counties

**Some Pertinent Regional Facts** from the US Census and State Government websites are as follows:

	<b>Cumberland</b>	<b>York</b>
<b>Land area</b>	836 square miles	991 square miles
<b>Cities</b>	Portland (metropolitan area), South Portland, Westbrook	Biddeford, Saco

**CENTRAL MAINE REGIONAL DESCRIPTION:**

**Counties in Central Maine:** Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo Counties

**Some Pertinent Regional Facts** from the US Census and State Government websites are as follows:

	<b>Androscoggin</b>	<b>Franklin</b>	<b>Kennebec</b>	<b>Knox</b>	<b>Lincoln</b>	<b>Oxford</b>	<b>Sagadahoc</b>	<b>Somerset</b>	<b>Waldo</b>
<b>Land area</b>	470 square miles	1,698 square miles	868 square miles	366 square miles	456 square miles	2,078 square miles	254 square miles	3,926 square miles	730 square miles
<b>Cities</b>	Lewiston/Auburn (metropolitan area)	None, County Seat-Franklin	Augusta, Gardiner, Hallowell, Waterville	Rockland	None, County Seat-Wiscasset	None, County Seat-Paris	Bath	None, County Seat-Skowhegan	Belfast

**NORTHERN MAINE REGIONAL DESCRIPTION:**

**Counties in Northern Maine:** Aroostook, Hancock, Penobscot, Piscataquis and Washington Counties

**Some Pertinent Regional Facts** from the US Census and State Government websites are as follows:

	<b>Aroostook</b>	<b>Hancock</b>	<b>Penobscot</b>	<b>Piscataquis</b>	<b>Washington</b>
<b>Land area</b>	6,672 square miles	1,588 square miles	3,396 square miles	3,966 square miles	2,568 square miles
<b>Cities</b>	Caribou, Presque Isle	Ellsworth	Bangor (metropolitan area), Brewer, Old Town	None, County Seat- Dover-Foxcroft	Calais, Eastport

## **Chapter 4**

### **POPULATIONS REQUIRING ADDITIONAL CONSIDERATIONS**

For HIV prevention interventions to be successful, they must be tailored to meet the specific needs of those at risk. Some populations require distinct HIV prevention strategies and cultural competencies on the part of HIV prevention educators. These populations include, but are not limited to:

- People who are deaf or hard of hearing
- People who have developmental disabilities
- People who are homeless
- People who are incarcerated
- People with mental illness
- Racial and ethnic minority populations
- Transgendered persons
- Youth

Although information about the behaviors that put each of these populations at risk for HIV is included in the information found in Chapter 7, this section offers supplemental information specific to the abovementioned groups. It is important to recognize that the information included here can augment, but not substitute, the actual cultural competence required to work effectively with these various populations.

#### **PEOPLE WHO ARE DEAF OR HARD OF HEARING**

The D/deaf community is a socio-linguistic and culturally autonomous community of individuals who have American Sign Language (ASL) as their primary language. Based on 2008 data, the Census estimates that 5.11% of the population of Maine, almost 66,500 people, experience hearing difficulty. Many of these people are isolated from hearing communities due to linguistic and cultural distinctions. Deaf people are not easily reached by HIV prevention interventions, since interventions are typically designed by hearing persons, for hearing populations, in a hearing culture.

Studies looking at persons who are D/deaf or hard of hearing are limited and it is unclear exactly how many people in this community are living with HIV/AIDS with estimates ranging from 8,000 to 40,000 individuals in the United States. A study comparing deaf and hard of hearing people to hearing people (Woodroffe et al., 1998) revealed that deaf people's attitudes about HIV transmission often differ from the attitudes of hearing people. Deaf people in the study were more likely to believe that they were not at risk for HIV than hearing people, and were less likely to modify their risky behaviors. The study found that, like many other minority populations, deaf people have less access to culturally competent HIV prevention messages, and are more distrustful of these messages than the general population.

Likewise, substance abuse is more prevalent in the deaf community, which may put this population at increased risk for HIV transmission. For example, within the hearing community 1 in 10 people have a substance abuse problem; within the Deaf community, 1 in 7 people has a substance abuse problem (Peinkoffer, 1994). Additionally, deaf individuals may be at increased risk because of histories of sexual abuse; data indicates that this population is twice as likely as hearing people to be victims of sexual abuse (Sullivan, 1998).

### **Considerations for HIV Prevention:**

- It is crucial that interventions targeting this population use methods of communication appropriate for people who are deaf/hard of hearing. For this reason, interventions must be delivered by those fluent in American Sign Language (ASL).
- Because of fundamental differences between English and ASL, written materials designed in English for hearing people are often not easily understood by those who are deaf/hard of hearing. Any written materials used for HIV prevention should use written ASL and be specifically designed for this population. Print materials should have a minimal English requirement and be very visual and graphic in nature.
- Because of the cultural autonomy of the deaf community, effective interventions must be delivered by peers, or by those with intimate knowledge of ASL and the deaf community.
- Qualified, licensed ASL interpreters should be used for instances where hearing people need to communicate with those who are deaf/hard of hearing (such as during Counseling, Testing and Referral CTR). Interpreters may need special training to provide HIV/AIDS services. The importance of confidentiality should be affirmed with both the client and the interpreter.

**Resources Providing More Information about HIV Prevention for this Population:**

Maine Center on Deafness, 68 Bishop Street, Suite 3, Portland, ME 04103; (207) 797-7657 (voice/TTY), 1-800-639-3884 (voice/TTY), (207) 797-9791 (FAX)

Center for AIDS Prevention Studies at the University of California San Francisco, “What Are Deaf Persons’ HIV Prevention Needs?” available on the web at:

<http://caps.ucsf.edu/resources/fact-sheets/>

Deaf Inc. Project HOPE Online Resources for Deaf and HIV Information

<http://www.deafinonline.org/services/phr.html>

**PEOPLE WITH DEVELOPMENTAL DISABILITIES**

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments, which manifest before age 22 and are likely to continue indefinitely. Based on the 2008 American Community Survey, an estimated 12.1% of the population in the United States reported a disability with 15.7% in Maine reporting a disability. Intellectual disabilities affect about one in ten families in the USA (The Presidents Committee for People with Intellectual Disabilities Fact Sheet, 2003). Nationally the Administration on Developmental Disabilities estimates that there are four million people with developmental disabilities in the US (ADD Fact Sheet, 2002).

Unfortunately, there is a lack of information about how people with developmental disabilities are affected by HIV/AIDS. Some studies indicate that this population may be at increased risk for HIV transmission, and may be difficult to reach through traditional HIV prevention efforts.

A primary issue of concern is that people with mental retardation are particularly vulnerable to victimization through sexual abuse. Some studies estimate that more than 90% of people with developmental disabilities will experience sexual abuse at some point in their lives (Valenti-Hein et al., 1995). In addition, some people with mental retardation may have difficulty controlling sexual feelings and desires, making them more vulnerable to sexual coercion and risky behaviors (McCarthy et al., 1993).

Frank discussions about sexual behavior may not regularly occur for many members of this population. Traditionally family members and caregivers have treated people with mental retardation as children, creating strong taboos and prohibitions around sexual behavior. For this reason, both people with mental retardation and their caregivers may be reluctant to discuss sex and sexuality, making HIV prevention education difficult or impossible (Christensen, 1993). In addition, it is likely that this population lacks access to public health messages in general, including HIV prevention resources (McCarthy et al., 1993).

Finally, because of frequent staff turnover, it is often difficult to train direct care personnel to provide one-to-one HIV prevention interventions to this population. HIV prevention efforts need to be integrated into larger care models for this population (Walkup et al., 1999).

**Considerations for HIV Prevention:**

- Care providers should acknowledge that sexual activity occurs among this population, and encourage frank discussions about sexual feelings and sexual activity. People with Developmental Disabilities may more frequently go to sex workers due to lack of opportunity for other interactions. Also, lack of privacy for those persons who may live in a group home or other institutional setting make people engage in riskier behaviors. Additionally, caregivers and family members should be discouraged from treating adults with mental retardation like children.
- Sexual abuse and coercion should be addressed in an open, safe and supportive fashion. Members of this population should be educated to recognize abusive situations and help prevent their occurrence.
- It is crucial that interventions targeting this population be clear and understandable. Some have suggested that photographs may be an appropriate method for reaching this population (Christensen, 1993). In addition, it is often necessary to precede HIV education with more basic discussions of sex and sexuality. Concrete practice with condoms and role-playing may also be helpful.

**Resources Providing More Information about HIV Prevention for this Population:**

The Arc, National Headquarters Office; 1660 L Street, NW, Suite 301, Washington, DC 20036; phone: (800) 433-5255; web: <http://www.thearc.org>

The American Association on Intellectual and Developmental Disabilities; 501 3<sup>rd</sup> Street, NW, Suite 200; Washington, DC 20001; phone: (800) 424-3688; web: <http://www.aamr.org>

Maine Office of Adult with Cognitive & Physical Disability Services, web: <http://www.maine.gov/dhhs/OACPDS/>

Planned Parenthood of Northern New England: 1 Pleasant Street, #4, Portland, ME 04101, (207) 221-2288, web: <http://www.plannedparenthood.org/ppnne>

**PEOPLE WHO ARE HOMELESS**

We have limited information about the number of homeless people living in Maine, and the number of homeless people living with HIV. The Maine State Housing Authority, in their “Annual Point in Time Survey” reports that 885 people reported being homeless in January of 2010. Information about homelessness is not collected during AIDS case reporting. However, reports of positive HIV tests in Maine do include questions about homelessness. During 2003, three people (6%) of 55 people newly diagnosed with HIV in Maine were homeless at the time of their diagnosis (ME CDC, 2004).

Homeless people may be at increased risk for HIV for a myriad of reasons. A disproportionately large number of homeless people suffer from substance abuse disorders and many inject drugs intravenously and may share or reuse needles (National Coalition for the Homeless, 2009). Homeless people also encounter many challenges to their health due to factors such as poor hygiene and exposure to inclement weather, making them three to six times more likely to become ill and have a reduced immune system (National Health Care for the Homeless Council, 2008). There is also a greater chance of higher risk sexual behaviors, such as trading sex for food, money or other goods and services and many shelters offer limited privacy which makes it difficult to form stable sexual relationships (University of CA, San Francisco Center for AIDS Prevention Studies, 2005).

People who are living with HIV/AIDS often have health care and medication costs that are too high to keep up with. Additionally, PLWHA may lose employment due to frequent health-related absences or discrimination. The National Alliance to End Homelessness estimates that up to 50% of PLWHA are at risk of becoming homeless. Homelessness also makes it difficult to obtain and use medications properly as they don't always have access to clean water, bathrooms and refrigeration (National Alliance to End Homelessness, 2006).

**Considerations for HIV Prevention:**

- People who provide services to the homeless should be trained about HIV, STD's and hepatitis prevention and referrals. Appropriate HIV prevention education services, including HIC counseling and testing and HIV prevention case management, should be integrated into existing services for this population.
- Appropriate prevention materials, including condoms, dental dams, lubricant, etc. should be distributed in locations accessible to this population, such as shelters and soup kitchens.
- Group level interventions in shelters that are integrated into other regular shelter activities may be an effective way to promote HIV risk reduction in this population.

**Resources Providing More Information about HIV Prevention for this Population:**

Center for AIDS Prevention Studies at the University of California San Francisco, "What are homeless persons' HIV prevention needs?" available on the web at:

<http://caps.ucsf.edu/resources/fact-sheets/>

National Coalition for the Homeless, 1012 Fourteenth Street, NW, #600, Washington, DC 20005-3471; phone: (202) 737-6444; fax: (202) 737-6445; email: [info@nationalhomeless.org](mailto:info@nationalhomeless.org)

National Alliance to End Homelessness, 1518 K Street NW, Suite 410, Washington, DC 20005; phone: (202) 638-1526; fax (202) 638-4664; <http://www.endhomelessness.org>

## **PEOPLE WHO ARE INCARCERATED**

The prevalence of infectious diseases such as HIV/AIDS, Hepatitis C and Tuberculosis infection is on average 4 to 10 times greater among inmates than the general population (Davis, 2002). The identified number of HIV+ inmates and juvenile residents under the jurisdiction of the State Department of Corrections is relatively low, usually between 6-10 people (with 1 or 2 being reported per year), with an average population of 2,120. This number may be low due to such factors as: voluntary versus mandatory testing policies, hesitancy of prisoners to be tested due to concerns about medical confidentiality, fear of HIV status impacting correctional opportunities that may be available (i.e. housing and job assignments) and concerns about safety if an inmate's or resident's HIV+ status is discovered by other inmates or residents.

Increased efforts to encourage testing and assure inmates and residents about confidentiality are needed. Behaviors that are associated with increased risk for infectious diseases such as tattooing, unprotected sex and drug use are common.

A contracted provider, Correctional Medical Services (CMS), currently provides medical services for the State Department of Corrections. During an inmate's period of incarceration CMS is responsible to provide HIV counseling and testing, prevention and education services and appropriate medical management. Support services and case management during incarceration are available to inmates and residents from correctional social work and mental health staff and through collaborations with community based HIV/AIDS agencies or programs.

A critical case management component for all inmates or residents is the transition planning that takes place prior to release. This is especially true for HIV+ inmates or residents. In addition to the transition plan which typically might include housing, financial support, employment, family reintegration and counseling services it is imperative that community based case management and medical services are secured prior to release. Good transition planning enhances continuity of care and increases inmates or residents chances of being successful at staying out of the correctional system.

**Considerations for HIV Prevention:**

- Collaboration between inmates, corrections administrators, corrections staff, and public health organizations need to occur in order to promote HIV prevention in prisons.
- Prison staff should be trained about HIV prevention and sensitized to the needs of HIV+ inmates.
- Appropriate HIV prevention education services, including HIV counseling and testing and HIV prevention case management, should be offered to prisoners.
- Coordinated discharge planning, after care and follow-up should be provided to inmates released from jails and prisons.
- Inmates should be trained to serve as peer HIV-prevention educators and advocates.

**Resources Providing More Information about HIV Prevention for this Population:**

Center for AIDS Prevention Studies at the University of California San Francisco, “What is the role of prisons and jails in HIV prevention?” available on the web at:

<http://caps.ucsf.edu/resources/fact-sheets/>

Maine Department of Corrections, State House Station 111, Augusta, ME 04333; phone: (207) 287-4360

**PEOPLE WITH MENTAL ILLNESS**

It is estimated that approximately one out of every four adults in the United States (18 years of age and older) suffer from a mental disorder with 6% of the adult population (one out of every 17) suffering from a serious mental illness (National Alliance for the Mentally Ill, 2010). This means that there could be as many as almost 80 thousand people in Maine suffering from a serious mental illness (U.S Census 2010). There is little evidence about the number of people in Maine who have both a mental illness and are also living with HIV, although 7% of those who tested positive in 2003 has some form of mental illness (ME CDC, 2004).

Individuals living with mental illness, diagnosed or undiagnosed, may be at increased risk of HIV infection for a number of reasons. Some people with mental illness are easily victimized by others and may have difficulty negotiating safe sexual behaviors. Others have illnesses which, when not in remission, involve impulsivity and risk taking behaviors that could also contribute to increased risk of exposure. When a co-occurring substance use disorder is involved, the risk of exposure increases as intoxication can result in impulsive and unprotected sexual activity or use of IV drugs.

In addition, despite the fact that people with mental illness, including those with serious mental illness, are sexually active, many mental health professionals and caregivers perceive them to be asexual or not sexually active, and don't provide them with appropriate education about HIV.

People with serious mental illness are often living in poverty, in substandard housing and in homeless shelters. Fifty percent (50%) of people with a mental disorder will also have co-occurring substance abuse and eighty percent (80%) of adolescents with a mental illness will have a co-occurring substance abuse disorder. In addition, many people with mental illness are incarcerated. The 2003 report from the Maine Civil Liberties Union, *Health Status of Maine's Prison Population: Results of a Survey of Inmates Incarcerated by the Maine Department of Corrections*, notes that 38.5% of inmates incarcerated in the Maine Department of Corrections system report that they have a mental illness.

### **Considerations for HIV Prevention:**

- It is important to know that people with mental illness are at increased risk for HIV infection and to provide them with appropriate education about prevention. Because people with mental illness may not hear about HIV in the usual places that prevention materials and education are available, it is important to integrate HIV education into regular mental health and substance abuse treatment.
- Mental health practitioners should be trained about the risks their clients face and the need to include HIV education in their clinical work.
- Social clubs, peer support centers, NAMI support groups, and other places where people with mental illness or their families meet should be approached regarding material dissemination or educational forums.
- Peer education about safe sex would be extremely helpful as would education for family members.

- Training updates and multiple educational forums can also help reach larger numbers of people, and reinforce messages that may be forgotten or difficult to process.

**Resources Providing More Information about HIV Prevention for this Population:**

American Psychiatric Association, 1000 Wilson Boulevard, Suite 1825, Arlington, Va. 22209-3901 1400; phone: (703) 907-7300; email: [apa@psych.org](mailto:apa@psych.org); web: [www.psych.org](http://www.psych.org)

National Alliance for the Mentally Ill (NAMI); 803 N. Fairfax Dr., Suite 100, Arlington, Va. 22203; phone: (703) 524-7600; web: [www.nami.org](http://www.nami.org)

NAMI Maine, 1 Bangor Street, Augusta, ME, 04330; phone: (207) 622-5767, web: <http://www.namimaine.org>

**RACIAL AND ETHNIC MINORITY GROUPS**

Many racial and ethnic populations are at high risk for HIV infection, not because of their race or ethnicity, but because of the risk behaviors in which they engage. As with any population, it's not who you are but what you do that puts you at risk for HIV. It is important to note that while the non-White and Hispanic populations of Maine comprise approximately 4.8% of the state's total population, 15.3% of HIV diagnoses between 2004 and 2008 were among racial and ethnic minority groups. These groups include African American/Blacks (9.8%) and Hispanics (5.5%) (ME CDC, 2008). The following section provides basic information on three of Maine's racial and ethnic groups that have been shown to be at increased risk for HIV according to the current epidemiological data. It is not meant to be inclusive of all racial and ethnic groups in Maine, nor provide comprehensive information about the groups that are included.

HIV prevention interventions serving racial/ethnic minority populations need to recognize and address the negative effects of systemic racism and discrimination which underlie health disparities in these populations. Institutionalized racism, cultural interruption and disenfranchisement have had a major impact on these populations resulting in distrust and suspicion of public health efforts, particularly if they are perceived as coming from the

White majority. It is therefore recommended that as much as possible, programming should be provided by actual members of the community who can better understand the cultures and customs of the group.

When working with racial and ethnic minority groups, it is crucial that HIV prevention providers demonstrate a thorough understanding of the cultures of the target populations. This may include language, symbols, rituals, and cultural dynamics. Although some general information about different races/ethnicities is provided below, it is beyond the scope of this document to comprehensively address cultural competency for any of the races/ethnicities discussed herein.

Specific considerations for HIV prevention among each of these groups is described in the following subsections.

### **AFRICAN AMERICAN/BLACKS**

According to the 2010 US Census data, there were 15,707 African American/Blacks in Maine, an increase of approximately 9,267 people from 2000 Census data. Anecdotal information from CPG members indicates that many people in this population are bi- or tri-racial, and in fact, another 6,057 people in the Census stated that they were Black or African American in combination with one or more of the other races listed. This is a total of 21,764 people or 1.6% of Maine's total population.

During 2008, 4 (9%) of 46 people newly diagnosed with HIV in Maine were African American/Black. Likewise 11% of HIV diagnoses between 1999 and 2003 were among this group and one third of these (8 of the 24) were foreign born and likely acquired HIV *before* coming to the US (ME CDC, 2003 EPI Profile). Nationally, this population comprises 37% of AIDS cases, yet makes up only 13% of the US population (CDC, 2000).

As in the rest of the nation, many African American/Black people are economically disadvantaged. Existing social networks are largely connected to churches and other organizations including the National Association for the Advancement of Colored People (NAACP).

**Considerations for HIV Prevention:**

- Because community-based HIV prevention efforts are important to this population, it is essential that Black civic and religious groups understand that HIV in Maine is an issue relevant to their members and community.
- It is essential that HIV prevention be provided by people who either come from the African American/Black community or who are culturally competent providers.
- HIV prevention efforts should emphasize that being in Maine does not prevent HIV infection and that people in this population may be infected through male-to-male sex, injection drug use and heterosexual sex.
- Media campaigns are needed to provide positive images and messages pertaining to healthy behaviors and risk reduction to counteract the pervasive negative and risk-taking behavior generally portrayed by the media at large.
- Unequal treatment in the justice system has resulted in Black people being disproportionately incarcerated. Providing comprehensive prevention education programs in the corrections systems is therefore recommended.
- Easy access to HIV prevention interventions, including outreach, clinics and other sources of confidential testing and counseling, should be provided. Access could be increased with the provision of childcare and transportation.
- Community-building efforts are important for the many members of this population who have recently relocated to Maine from elsewhere in the United States or from foreign countries.
- HIV prevention messages and testing provided to the immigrant and refugee communities should be provided by peers if at all possible, or by culturally competent providers.
- Needs Assessment data, including behavioral data, about the African American and other Black populations in Maine (including immigrants and refugees) is needed to better understand their HIV prevention needs.

**Resources Providing More Information about HIV Prevention for this Population:**

Center for AIDS Prevention Studies at the University of California San Francisco, “What Are African-Americans’ HIV Prevention Needs?” available on the web at:

<http://caps.ucsf.edu/resources/fact-sheets/>

National Minority AIDS Council (NMAC), 1931 13<sup>th</sup> Street, NW. Washington, DC 20009; phone: (202) 483-6622; fax: (202) 483-6622; fax: (202) 483-1135; email: [info@nmac.org](mailto:info@nmac.org); web: [www.nmac.org](http://www.nmac.org)

Gay Men of African Descent (GMAD), 44 Court Street, Suite 1000, Brooklyn, NY 11201; phone: (718) 222-6300; fax: (718) 488-1872; email: [gmad@gmad.org](mailto:gmad@gmad.org); web: [www.gmad.org](http://www.gmad.org)

## **LATINOS/LATINAS/HISPANICS**

The 2010 US Census data indicates that Hispanic or Latino ethnicity accounts for 1.2% of the Maine population, or just under 16,935 people. However, the exact number of people who are Hispanic is not known because of two important complicating factors: lack of accurate data of individuals who may be illegal immigrants, and Hispanic migrant workers who may not be accurately accounted for in Census data. The 2010 Census data shows concentrations of Latinos in five counties of Maine: Cumberland, York, Penobscot, Androscoggin and Kennebec although Latinos are dispersed throughout the State. The Census data shows that the majority of Latinos in Maine are originally from Mexico, Puerto Rico and Cuba while other countries are also represented. Note that within the community, people refer to themselves by their country of origin (Mexican, Puerto Rican, Cuban, Guatemalan, etc.) rather than using the terms Hispanic or Latino.

During 2003, 4 (7%) of 55 people newly diagnosed with HIV in Maine were Latino/Hispanic. Likewise 3% of HIV diagnoses between 1999 and 2003 were among this group (ME CDC, 2004). Nationally, Hispanics account for 17% of all AIDS cases, but make up only 9% of the population. Highest concentrations of HIV+ Hispanic people are located in urban centers in the northeastern US, including New York and Boston (CDC, 2000).

### **Considerations for HIV Prevention:**

- Greater understanding and respect for Latino cultures will lead to better HIV prevention efforts. Cultural dynamics including machismo (an expression of masculinity in males), familismo (importance of the family), simpatia (importance of polite social norms), and personalismo (preference for familiarity in relationships) can all affect the delivery of HIV prevention interventions.

- More behavioral data about the Latino community in Maine is needed to better understand the HIV prevention needs of these people. In particular, more needs to be learned about the needs of the Hispanic migrant farming community. Services for migrant workers are currently being provided by the Maine Migrant Health Program which provides services in Androscoggin, Aroostook and Washington Counties.
- Language-specific barriers need to be addressed, in particular, language-specific literature needs to be provided that is easily understood, including materials that do not require reading skills in English or Spanish.
- Increasing access to HIV prevention interventions and provision of testing out in the community is important. Transportation and childcare during HIV prevention-related activities could also increase access.
- In addition, easy access should be provided to clinics that offer confidential and anonymous HIV testing and counseling by providers fluent in Spanish. Often even Latinos that are comfortable with spoken English are best served in Spanish.
- In Maine over 90% of Latinos are Catholic (Latino Health and Community Service, Inc. 2004), so partnering with the church to provide information could be useful.
- Media using well known Latino leaders to provide prevention messages is also recommended.

**Resources Providing More Information about HIV Prevention for this Population:**

National Minority AIDS Council (NMAC), 1931 13<sup>th</sup> Street, NW, Washington, DC 20009; phone: (202) 483-6622; fax: (202) 483-1135; email: [info@nmac.org](mailto:info@nmac.org); web: [www.nmac.org](http://www.nmac.org)

Center for AIDS Prevention Studies at the University of California San Francisco, “What Are U.S. Latinos’ HIV Prevention Needs?” available on the web at:

<http://caps.ucsf.edu/resources/fact-sheets/>

The Body, “HIV/AIDS in the U.S. Latino Community” Web:

<http://www.thebody.com/index/whatis/latino.html>

## **NATIVE AMERICANS**

There are five Native American communities in Maine: two Passamaquoddy reservations (Pleasant Point and Indian Township in Washington County), and one Penobscot reservation (Indian Island in Penobscot County). The Aroostook Band of Micmac and the Houlton Band of Maliseet are both located in Aroostook County. There are off-reservation population clusters of Native Americans in general areas of Portland and Bangor, and in Aroostook and Washington Counties. Native American migrant workers are originally from both the US and Canada. Many Native Americans are mobile, traveling back and forth across the Canadian border. Some of this mobility is due to seasonal employment.

The 2010 US Census indicates that approximately 8,500 Native Americans (.6% of the total population) live in Maine, although anecdotal information provided by CPG members suggests that the actual population may be much higher. The US Census shows an additional 9,900 people who said they were Native American in combination with one or more other races.

During 2003, 2 (4%) of 55 people newly diagnosed with HIV in Maine were Native American. Likewise 3% of HIV diagnoses between 1999 and 2003 were among this group (ME CDC, 2004), although these figures may be inaccurate because of frequent misclassification of the race of Native Americans by medical providers. Nationally, this population comprises less than 1% of AIDS cases (CDC, 2000).

### **Considerations for HIV Prevention:**

- It is important that any HIV prevention materials be responsive to the particular needs of each tribe in Maine. Ideally, HIV prevention programs should be delivered by Native American providers who can provide culturally-specific services. If non-Native providers deliver services, they must be culturally competent and recognize that outsiders need to build trust and credibility within the community and that Native culture is more conservative about talking about sexual behavior.
- HIV prevention providers need to be aware of mistrust in the Native population of government-sponsored health initiatives.
- Strict confidentiality is of utmost importance when working in small, closed, tribal communities.

- Support for gay, lesbian, bisexual and transgender Native Americans could include events to bring people in to learn about support groups or development of an anonymous way for people to communicate such as a website.
- Services should include easy access to affordable and confidential HIV counseling and testing. Messages should emphasize that HIV/AIDS is also a Native American problem. In addition, messages to help make individuals aware of the connections between sexually transmitted diseases, unintended pregnancies, substance use and abuse, and HIV are very important and should be stressed.
- Alternative ways to gather information on the CTR counseling form could be explored with the ME CDC in order to be more sensitive to cultural norms.
- Messages should include ways of obtaining clean needles (pharmacies and/or needle exchange if one is nearby) and the importance of not sharing needles as there are limited resources for clean needles on the reservations.
- Education and prevention should target the youth through group activities and conferences that are culturally appropriate and led by Native Americans.
- Safer sex supplies should be available at a variety of places in the community.

**Resources Providing More Information about HIV Prevention for this Population:**

National Minority AIDS Council (NMAC), 1931 13<sup>th</sup> Street, NW, Washington, DC 20009; phone: (202) 483-6622; fax: (202) 483-1135; email: [info@nmac.org](mailto:info@nmac.org); web: [www.nmac.org](http://www.nmac.org)

National Native American AIDS Prevention Center, 720 S. Colorado Blvd, Suite 650-S, Denver, CO 80246; phone: (720) 382-2244; fax: (720) 382-2248; email: [information@nnaapc.org](mailto:information@nnaapc.org); web: [www.nnaapc.org](http://www.nnaapc.org)

Wabanaki Mental Health Association, 187 Exchange Street, Bangor, ME 04401; phone: (207) 990-0605; or email Sharon Tomah at: [stomah@wabanaki.org](mailto:stomah@wabanaki.org)

## **TRANSGENDERED PERSONS**

Transgendered is an umbrella term used to describe all persons who do not conform to the societal gender norms usually associated with male and female. A transgender (Trans) person is someone who has a different sex, gender identity, and/or gender expression than the one assigned to them at birth, regardless of their sexual orientation. However, not everyone who is transgender wants hormone therapy or surgery to change their physical characteristics. Transgender persons may self-identify as female, male, trans-women or –men, non-operative transsexuals, Gender Queer, M2F or F2M and pre-operative transsexuals among others. It is important to remember that there is a distinction between one's biological sex, one's gender expression, and one's sexual orientation. Transgender individuals may identify as heterosexual, bisexual, pansexual or homosexual.

### **Considerations for HIV Prevention:**

- Pervasive social stigmatization of transgender persons greatly increases HIV risk in this population and results in social marginalization and denial of educational, employment and housing opportunities. This can lead to low self-esteem, drug use, and can increase the need for survival sex work. All of these factors can increase HIV risk.
- HIV risk through hormone injection varies due to the availability of hormones and hormone syringes. Needle exchange programs should offer needles for hormone injection such as 22 gauges, 1 inch Intramuscular needles among others.
- Although Maine transgender risk behavioral survey data does not show increased risk in the transgender population, nationally transgender individuals are at risk for HIV infection and male to female (MTF) transgender individuals are at the highest risk of HIV infection.
- When working with this population, acknowledgement and acceptance of a transgender person's expression of their gender identity is very important. Forms should be as inclusive as possible and offer more than just two "genders". It is important to note that for some individuals gender identity can be fluid and may not remain the same over time. There is a great need for transgender sensitivity training for all public service providers.
- Due to the many and varied needs of transgender individuals; a comprehensive health-based approach is useful. This can be facilitated by training peers to do outreach to the population, providing CTR services and referrals to other needed services.

**Resources Providing More Information about HIV Prevention for this Population:**

Center for AIDS Prevention Studies at the University of California San Francisco “What are male-to-female transgendered persons’ (MTF) HIV Prevention needs?” available on the web at: <http://www.caps.ucsf.edu/pubs/FS/revMtF.php>

Center of Excellence for Transgender HIV Prevention, “8 Best Practices for HIV Prevention among Trans People” (2008) <http://transhealth.ucsf.edu/pdf/bp-prevention.pdf>

Kenagy, G. P. (2002) HIV among transgendered people. *AIDS Care*, 14(1), 127-135.

Clements-Nolle, K., Marx, R. et al. (2001) HIV prevalence, risk behaviors, health care use, and mental health status of transgender persons: Implications for public health intervention. *American Journal of Public Health*, 91(6), 915-922.

**YOUTH \***

In the context of this document, the noun “youth” is used to be inclusive of young people who are age 24 and under and who exhibit high-risk behaviors or who are in situations that place them at higher risk for HIV infection. Despite these risks, few have routine access to protective health services. Half of young people who are HIV+ are unaware of their status (compared to 21% of the 1 million Americans currently estimated to be living with HIV). Nationwide, 13% of all high school students have been tested for HIV (CDC, 2008).

The CDC estimates that nationwide, about half of the 56,300 HIV infections that occur each year are among those under 25 years of age (CDC, 2009). During 2008, of the 46 people who received a new HIV diagnosis in Maine, 8 (17%) were less than 30 years of age (ME CDC, 2008).

The 2009 Maine Integrated Youth Health Risk Survey data show the presence of HIV risk behaviors. 12% of middle school and 46% of Maine high school students were sexually active. 61% of high school students who were sexually active used a condom during last intercourse. 6% of high school students reported having sexual intercourse for the first time before the age of 13. 12% of high school students had four or more sex partners. A little over 12% of high school students reported sexual contact with a person of the same sex. Almost 6% of high school students have used a needle to inject any illegal drug into their body. Almost 13% of high school students reported having been forced to have sexual intercourse against their will at some time in their lives. Youth who are homeless and out-of-school report a 40% sexual victimization rate (Maine 2006 Homeless Youth Survey).

Typically, adolescence is a period of intense physical, emotional, intellectual and sexual development. As part of development and exploration, young people may experiment with drugs, alcohol and sexual behaviors. In addition, youth often experience social, cultural and peer pressure to become sexually active. At the same time, many youth lack access to accurate information about sexual behavior and physical development.

### **Considerations for HIV Prevention:**

- For youth-focused interventions to be effective, youth must be involved as equal partners with equal power in the design, implementation, and evaluation of the intervention. It is clear from the epi data that young men who have sex with men are at a much higher risk for HIV infection in the youth population. They need specific HIV prevention interventions that meet their unique needs.
- HIV prevention should be integrated into all youth services including education and other HIV interventions and services. In particular, youth need access to school-based health clinics with sexual health services in high schools.
- Prevention services should allow for HIV risk reduction skills practices in as close to “real” risk situations as possible, and include open, non-judgmental messages and discussions about alcohol/drug use and its connection to sexual behaviors that put one at risk for HIV.
- Youth need access to caring, accepting adults and peers who can share positive HIV prevention messages, skills and harm reduction strategies.
- Youth need access to sex positive, non-judgmental comprehensive sexuality education, health services, and media messages. In addition, there needs to be increased community awareness and acceptance of youth sexual needs specific to HIV/STD’s.

- HIV prevention and testing services should specifically target male youth who have sex with males and lesbian or bi-sexually identified females who have sex with males. These services should also target youth who are homeless, out of school, and incarcerated.
- **The CPG wishes to thank Jean Zimmerman from the Maine Department of Education for information on needs and interventions included in this section.**

**Resources Providing More Information about HIV Prevention for this Population:**

OUTRIGHT Lewiston/Auburn: <http://www.outrightla.org/>

Proud Rainbow Youth of Southern Maine (PRYSM): <http://www.commcc.org/our-programs/special-initiatives-community-programs/prysm/>

GLSEN-Southern Maine: <http://chapters.glsen.org/cgi-bin/iowa/southernme/home.html>

Maine Department of Education HIV Prevention Education Program, 23 State House Station, Augusta, ME 04333: phone: (207) 642-6692; web: [www.maine.gov/education/hiv/index.html](http://www.maine.gov/education/hiv/index.html)



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## **ABOUT THE TARGET POPULATIONS:**

### **Population Descriptions, Risk Profile, Key Needs Assessment Findings**

This Chapter provides a description of each of the target populations listed in Chapter 3. It also lists the factors contributing to risk in each of the four priority populations, as well as their critical needs.

#### **PRIORITY 1: People Who Are HIV+ (PLWH/A) 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 1,500 people are known to be living with an HIV/AIDS diagnosis. In addition, the ME CDC estimates that as many as 500 people in Maine may be infected with HIV, but are unaware of their HIV status (ME CDC, 2010). Of those people living with diagnosed HIV in Maine 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 Maine and should continue to be the main focus of prevention activities. IDU (Intravenous Drug Users) and FVHR (Females at Very High Risk) follow respectively and remain a priority for prevention activities in Maine. Of the 1,500 people already diagnosed and living with HIV/AIDS in Maine in 2010, 757 have been served by one of the Ryan White Part B case management agencies, and 795 people have been enrolled in the AIDS Drug Assistance Program (ADAP). (ME CDC, 2010)

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**

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. Every new HIV infection involves an HIV positive person, who may or may not know their status, engaging in unsafe behavior.

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-infection<sup>s</sup> and contracting other sexually transmitted diseases.

During focus groups conducted with HIV positive people in Maine many people reported 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. 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 affects 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.

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. 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.

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 co-infection.

## **Behaviors**

Certain behaviors, called HIV risk behaviors, increase the level of risk for HIV transmission and/or co-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
- 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 preventative 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 tested<sup>positive</sup> for HIV antibodies in their body; negative meaning that there are 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 reported 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.

Disclosure of ones 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. Many 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 time. 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 recommendations<sup>for</sup> 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, some positive people 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 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 that 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 estimates that more than half of HIV infected adolescents don't know it because they haven't been tested.
3. The U.S. CDC estimates 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 it.
- HIV positive 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. (CPG Needs Assessment, 2007)

- “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 ME CPG 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, peer support, partner services 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 services. There continues to be a lack of information being collected from those HIV positive people who are not in case management. 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.

## **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 they 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
- 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, 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 that 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 (small town/rural culture)
- Transportation was indicated as a barrier to accessing prevention services, (e.g. rural state with community based organizations spread out over long distances)

## **Key PLWHA 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 partner
  - 25% one oral sex partner
  
  - Most Vaginal Sex Partners – 48
  - Most Anal Sex Partners – 48
  - Most Oral Sex Partners – 80
  
- 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 it's 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 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

2A) **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

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

**ADDITIONAL RESOURCES: PLWHA**

National Association of People With AIDS (NAPWA)  
8401 Colesville Rd., Suite 505, Silver Spring, MD. 20910  
Telephone 240-247-0880--Toll Free 866-846-9366 --Fax 240-247-0574  
Email: <http://www.napwa.org>

ME CDC HIV/STD/VH Program (administers Ryan White B funding in Maine)  
Contact: Ryan White B Coordinator  
11 State House Station, Key Bank Plaza, 9<sup>th</sup> floor, Augusta, ME. 04333  
Telephone 202-287-3747

**PRIORITY 2: Males who have Unsafe Sex with Males (MSM)  
BEHAVIORAL POPULATION DESCRIPTION**

MSM represent a wide variety of men of different ages, races, ethnicities, socioeconomic backgrounds and gender identities. They have diverse health and social needs. They are at risk for acquiring or transmitting HIV because of the unprotected sexual behaviors they engage in, not because of how they identify themselves. Anecdotal information indicates that gay-identified males make up the majority of infections in Maine and should be the main focus of prevention activities for MSM.

For males who have unsafe sex with HIV+ males or males of unknown HIV status, unprotected receptive anal intercourse remains the greatest risk for HIV infection. Unprotected anal intercourse is engaging in anal intercourse without using a condom. A latex condom is the most commonly recognized protective device when engaging in anal sex. HIV is transmitted from an HIV positive man to an HIV negative man through HIV- infected bodily fluids, including blood, semen, and pre-ejaculate fluid.

The HIV epidemic has become strongly associated with gay men in the U.S. Both the reality and the myths of HIV are woven into the physical, psychological, emotional and social aspects of gay men's lives including dating and intimacy, sexual desire and love, abuse and coercion, alcohol and recreational drug use. Many forms of discrimination, such as racism, socio-economic classism, heterosexism, homophobia, and transphobia, affect the individual self-esteem of gay men and impact the spread of HIV among MSM. It is important that HIV prevention activities acknowledge these factors and address them when possible.

**Risk Profile for MSM**

There are several factors, usually acting in combination, that influence the level of risk for HIV infection among MSM. Some of these factors exist within each person, such as behavior, HIV status, attitudes, feelings and beliefs, individual mental health status, and addictions, and are affected by outside forces. Other factors exist outside of the person, such as social and cultural norms, institutions and systems, but affect individual decisions about HIV prevention. Each of these HIV prevention factors are important to the work of HIV prevention and are described in what follows.

## Behaviors

Certain behaviors, called HIV risk behaviors, increase the level of risk for infection among MSM. The following is a list of HIV risk behaviors for MSM. 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
- Having unprotected insertive anal 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, other behaviors that result in higher, but not complete, levels of prevention, behaviors that offer a low level of prevention, and those behaviors that offer no preventative benefit.

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)**

In combination with HIV risk behaviors, the HIV status of partners is a key factor that influences HIV infection. HIV infection is the result of HIV passing from a person (positive) infected with HIV to a person (negative) uninfected with HIV. Semen and blood are the most common vehicles that transport HIV. For MSM, unprotected receptive anal intercourse is the most common risk behavior that causes infection.

To reduce their risk of infection, some 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 men engage in

unprotected anal intercourse there is no risk of infection because HIV is not present. Similarly, if two positive men engage in unprotected anal 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 men, we know that new and different strains of HIV can be passed to each other, including drug-resistant strains that can adversely affect health. For negative men, the accuracy of the negative result is called into question. Accuracy of a negative result depends on two primary factors that both must be present: (1) The negative result must be reported truthfully and (2) both partners must understand for a negative result to be accurate, all three of the following conditions must be met:

- The test giving a negative result must have been performed at least 3 months after the last episode of engaging in a risk behavior for HIV
- At least 3 months have passed since the person with the negative result was tested
- The person with the negative result has not engaged in a risk behavior for HIV since he received the test

Because the criteria for accuracy of negative results are so exacting and understanding of these requirements are not well understood or discussed, negative MSM who are sero-sorting may not be doing so correctly.

The group of people who are untested for HIV, and therefore, whose HIV status is unknown represent 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 estimates that more than half of HIV infected adolescents don't know it because they haven't been tested.
3. The U.S. CDC estimates 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 prevention and HIV risk behaviors and HIV status is 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. Individual attitudes, beliefs and feelings must support positive HIV prevention actions, in order to up the chances for the actions to occur. By support, Men must believe that HIV is a serious enough threat to them to do something about.

Men must believe their bodies and health are worth protecting.

Men must believe that the information they are given by science, the government, and community providers is true.

Men 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 the recent needs assessment of MSM in Maine are not supportive of HIV prevention. (CPG Needs Assessment, 2006)

- The feeling that unprotected sex is better and the belief that condoms decrease sexual pleasure
- The belief that HIV is not a big deal anymore

### **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.

### **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. For MSM, gay male cultural norms can have a strong influence on individual behaviors. Examples of gay cultural norms that adversely affect HIV prevention include the belief that HIV is no longer a big problem because of available treatments and the belief that HIV is a gay man's destiny. Norms of society or of

other dominant cultural groups also influence HIV prevention among MSM. Societal norms of homophobia and oppression of gay people are examples.

### **Systems and Institutions**

Systems and institutions are broadly organized and established entities that function for some specific purpose. Examples include the education system, the criminal justice system, religious institutions, governmental services, mental health systems, and substance abuse treatment systems. These systems and institutions have norms and values that are specific to the individual system or institution. Some systems and institutions impact the lives of MSM more than others. For example, discrimination of gay people is an accepted norm for certain religious institutions. Stigmatization of people living with HIV is an accepted norm in many institutions. Most health care and mental health and substance abuse service systems have a norm of not being gay-friendly in concrete and visible ways. In many cases, norms influence whether or not a person can and will access necessary services that would support HIV prevention behaviors.

### **Key MSM Needs Assessment Findings**

Based on the 2006 CPG Needs Assessment Report for MSM, MSM behavioral surveillance pilot, and epidemiological information, important evidence concerning HIV infection among MSM has been identified. Epidemiological evidence clearly identifies that MSM risk continues to be the greatest risk factor for HIV infection in Maine. While the number of new diagnoses remained level for the period 2001-2005, the number of diagnoses among MSM increased. New HIV diagnose among MSM are predominantly among white males between the ages of 30 – 49 years. STD data indicate that MSM engage in behaviors that put them at risk for HIV infection and/or reinfection.

During the period 2002-2006, Southern and Central Maine experienced the biggest proportion of new diagnoses. During the same time, the population centers of Portland (30%), Lewiston-Auburn (11%), Augusta-Waterville (10%), and Bangor (6%) accounted for 57% of new diagnoses among MSM.

Needs assessment evidence identifies that while MSM are, on average, informed about HIV and risk, significant rates of risk behaviors exist. In the CPG Needs Assessment Report of 2006 involving 263 MSM, almost 30% reported never using a condom for receptive anal intercourse, the highest known risk for infection. In a 2007 behavioral surveillance report among MSM in high-risk venues, between 50% and 61%, reported unprotected anal sex.

The most frequently reported factors associated with not using condoms were: drinking alcohol, the feeling that condoms reduce pleasure, younger age, and anal sex with a steady or primary partner.

There were some differences among MSM based on their age. Younger MSM were more likely to report trading sex for money, shelter or drugs and less likely to report talking with casual partners about HIV. The internet was the most frequently reported meeting location for sex partners among younger MSM. They were more likely to report receiving STD treatment and Hepatitis A and B vaccinations. Finally, younger MSM reported wanting HIV testing to be more mainstreamed as a part of routine medical care instead of targeted to high-risk groups.

There were also some differences among MSM based on race and ethnicity, Non-white MSM reported access to HIV prevention services to be more problematic. Non-white MSM were less likely to report being concerned about HIV and more likely to report believing that new drugs lessened the concern about HIV. Non-white MSM were more likely to report having sex with an injection drug user. Native American MSM reported the internet as the most frequent meeting location for sex partners and reported wanting off-reservation HIV prevention services.

Based on review of needs assessment data and member expertise, the following is a list of critical needs that exist for this population. These needs are directly related to the factors that affect risk mentioned above and may be useful in designing interventions. They are not listed in order of priority.

- Attitudes, beliefs, and feelings about HIV and sex
- Motivation, intention and commitment to prevent HIV infection
- Behaviors that reduce the risk of HIV infection
  - Unprotected anal intercourse
  - Number of sexual partners
- Access to protective sex devices and supplies
- Partner communication skills related to preventing HIV transmission including talking about protected sex, refusing to participate in unprotected sex, and disclosure of HIV status
- Problem solving, coping and decision-making skills that reduce HIV transmission
- Knowledge about HIV and sex that is accurate and comprehensive enough to make valid and reliable decisions concerning HIV prevention
- Awareness of personal risk
- Awareness of mental health issues and resources to address them
- Knowledge of HIV and the conditional nature of test results
- Access to HIV testing through low barrier, peer led, targeted outreach testing as well as testing in all health care settings as a routine part of health care
- Integrated understanding of important HIV, other STD's and Hepatitis A, B and C information and services

**ADDITIONAL RESOURCES: MSM**

Centers for Disease Control and Prevention, 1600 Clifton Rd, Atlanta, GA 30333, USA  
800-CDC-INFO (800-232-4636) TTY: (888) 232-6348, 24 Hours/Every Day - [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)  
<http://www.cdc.gov/hiv/topics/msm/index.htm> (updated Sept. 2010)

<http://www.cdc.gov/hiv/topics/msm/resources/other/AAMSMhighlights.htm> (updated Jan. 2011)

**PRIORITY 3: Injection Drug Users/Needle Sharers (IDU)  
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 1,500 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, 2010). Of those people living with diagnosed HIV in Maine it is estimated that 84% are male and 16% are female with less than one percent of the estimated diagnosis among those with a male to female transgender identity. Men who identify their risk as having unprotected sexual contact with other men (MSM) continue to make up the majority of HIV infections in Maine<sup>2</sup> and should continue to be the main focus of prevention activities. IDU (Intravenous Drug Users) and FVHR (Females at Very High Risk) follow respectively and remain a priority for prevention activities in Maine. Of the 1,500 people already diagnosed and living with HIV/AIDS in Maine in 2010, 757 have been served by one of the Ryan White Part B case management agencies, and 795 people have been enrolled in the AIDS Drug Assistance Program (ADAP). (ME CDC, 2010)

HIV transmission happens when the blood of an HIV positive person is injected along with the intended drug into the body of another person through a shared syringe. Many co-existing factors such as the addictive effects of substance use, the stigmatization surrounding drug use and the lack of understanding by law and health care systems make HIV prevention in this population particularly challenging. People who use needles to inject drugs are found across all socioeconomic groups, racial or ethnic backgrounds, gender identities, sexual orientations, and geographical locations. That being said we must be aware that certain populations, representing certain demographic characteristics that identify as IDU are disproportionately affected by HIV. Nationally approximately 53% of new infections among IDU are among the Black (Non-Hispanic) Population, 23% of Hispanics and approximately 22% among White/Caucasians. Here in Maine IDU represent 16% of all new HIV infections. Of those people living with HIV/AIDS in Maine whose mode of transmission was identified as IDU 11% are African Americans and 5% were Hispanic.

In 2008 7% (3 out of 46) new HIV diagnoses were identified as IDU. All of the new infections were white non-Hispanic Males. According to the Maine Office of Substance Abuse intake treatment data over a five year span (2003-2008), 7% of those who reported ever injecting drugs also reported sharing needles within the last year.

Nationally it is estimated that 50-90% of HIV infected IDU are also co-infected with Hepatitis C. In Maine 37% of IDU responding to the needs assessment survey indicated they had Hepatitis C. Only one of the respondents indicated being HIV positive. (CPG Needs Assessment, 2008) While these numbers don't reflect national trends we know that only a fragment of the IDU population responded to the needs assessment.

## **Risk Profile IDU**

There are several factors, usually acting in combination, that influence the level of risk for HIV infection among IDU.

Some of these risk factors exist within each person, such as behavior, addiction level, attitudes, feelings and beliefs, individual mental health status, and HIV status, and are affected by outside forces. Other factors exist outside of the person, such as social and cultural norms, institutions and systems, but affect individual decisions about HIV prevention. Each of these HIV prevention factors are important to the work of HIV prevention and are described in what follows.

## **Behaviors**

Certain behaviors increase the level of risk for infection among IDU. The following is a list of behaviors that put IDU at risk for acquiring or transmitting HIV. While they are not listed in order of priority, sharing injection apparatus (works) is the primary risk behavior for IDU. Secondary transmission behaviors such as unprotected anal or vaginal sexual contact are also important when doing prevention with IDU.

- 1) Sharing needles and/or works (injection apparatus)
- 2) Sharing needles or having unprotected sex while using or abusing drugs, alcohol and other chemicals
- 3) Engaging in unprotected sex
- 4) Exchanging unprotected sex for money, goods, drugs and/or survival needs
- 5) Injecting vitamins and/or steroids or hormones
- 6) Engaging in unlicensed body piercing or tattooing

The following circumstances were identified as increasing the likelihood that a person may engage in unsafe or risky behavior:

- Fear of being exposed as an injection drug user and the stigma and discrimination that can come from that while accessing services
- Lack of understanding of perceived risk
- Not knowing the status of themselves and partners

HIV risk behaviors have the most direct relationship to HIV prevention. Over 25 years of research has identified the specific behaviors that result in 100% prevention, other behaviors that result in higher, but not complete, levels of prevention, behaviors that offer a low level of prevention, and those behaviors that offer no preventative benefit.

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.

## **Impacts of Addiction and Substance Abuse for the IDU**

The stigma and discrimination faced by the IDU community directly affect the self-esteem of the IDU person. This effect is both internal and external. The internal effect of stigma may lead to depression, fear of seeking help, not trusting the help that's available and may even contribute to continued substance use. "It's hard to look for clean needles when you might get arrested". The external effect is felt by the IDU individual when judgment is placed on the substance use instead of helping the person to reduce their risk.

The main risk for HIV is sharing needles, works and cotton (materials used in injection drug use) with a person who is infected with HIV.

For the IDU person the addiction often overrides the concern about HIV infection, Hepatitis and other STD's that might be acquired because of the stigma surrounding injection drug use.

People who use needles to inject drugs do not fit any one description. He/she may be from any walk of life, social standing, education, religion, race or ethnic background.

According to the 2008 Maine needs assessment with IDU 50% of the people participating in a survey about needle use were women, 50% were men. Most of the respondents were between the ages of 20-49. The majority were white while African American/Black and Hispanic respondents were represented at twice the national rate. Respondents were represented almost equally from Southern, Central and Northern Maine.

About 25% of the people who tested positive for HIV and identified as IDU over the last five years were from Cumberland County in southern Maine followed by Androscoggin, York, Knox and Penobscot counties. With the majority of infections reported in the greater Portland area.

### **HIV Status (HIV negative, positive, unknown)**

People who have been diagnosed as being HIV positive have reported that knowing their HIV status has helped them to change unsafe behavior for safer behavior. Knowing your HIV status is important. However for those whose HIV risk is sharing needles the knowledge of one's status may not be a motivating factor for behavior change. Many IDU report that that the addiction accompanied by the chemical effects of the substance being used, often is in control of ones actions and that "getting high" is more important in the moment than reducing ones risk of HIV transmission.

Certain individuals in certain circumstances, who know their status do change risk behaviors. According to the key informant input and group discussions with recovering and active IDU, a person would be more likely to change a risky behavior for a less risky behavior while in treatment for the addiction, and or once recovery has begun.

It was very clear from the group conversations portion of the needs assessment that addressing the addiction, through treatment and recovery programs, was crucial to a person's ability to make decisions that reduce the risk of acquiring or transmitting HIV.

People, who are untested for HIV, and therefore whose HIV status is unknown, represent 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 estimates 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.

### **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. The IDU population as well as the general population must believe that HIV is a serious enough health issue to do something about. The IDU population must believe that their sexual partners are important enough to protect.

While needle sharing is the primary risk for acquiring or transmitting HIV for the IDU, a secondary risk factor is unprotected sexual contact. Again, the addiction and substance use often "override" safer decision making. Some IDU have reported that sex and more specifically unprotected sex can be used as an exchange for drugs or other necessities such as a place to stay or food.

The overwhelming message from the recent needs assessment speaks to how this population is perceived. Stigma is a constant shadowing factor for the IDU population, especially in a rural state such as Maine. (CPG Needs Assessment, 2008)

- The IDU population must believe that information they are given by science, the government, and the community providers is true.
- The stigma and perception that only gay men get HIV needs to be confronted through outreach efforts to the IDU community.
- Treatment and care services need to be provided in a way that reduces stigma and promotes the best harm reduction strategies for the IDU as possible.

### **Social and Cultural Norms**

Social and cultural norms are the generally accepted rules and beliefs of a society as a whole or groups of people who share some common characteristics. The IDU population is not a homogenous group. The virtual invisibility of the IDU population driven by punitive treatment at

the hands of law enforcement as well as health care and treatment facilities and society in general instill a sense of discrimination both within the IDU community, internal towards providers, as well as a perceived external discrimination aimed at the community itself. Discrimination whether perceived or real is a tremendous barrier to treatment as well as acceptance of HIV prevention within the IDU population and a valid concern.

Of HIV prevention services accessed by respondents of the IDU Needs Assessment, the most frequently used HIV prevention services are HIV counseling, and testing, access to free condoms and using needle exchanges to obtain clean needles. The availability of “clean works kits” and face to face counseling were also identified as useful prevention services. The vast majority of respondents, (76%), are pleased with the service they get. Yet many people participating in the discussion groups talked about extremely stigmatizing experiences with providers of care and treatment services. Those not utilizing services, 38% do not know where to get them and 8% state they are not available in their area.

It must be noted that the majority of HIV testing and counseling sessions as well as access to safer sex supplies happened through the Needle Exchange Programs. It is the recommendation of the CPG that prevention services such as HIV testing and counseling as well as access to safer sex supplies continue to be delivered through the needle exchange. While needle exchange programs are well utilized here in Maine, 47% of the respondents to the IDU needs assessment reported fear of law enforcement when using the needle exchange. It is the recommendation of the CPG that prevention educators and needle exchange program staff develop and maintain a collaborative relationship with local and state law enforcement entities.

### **Systems and Institutions**

There is much discussion of the current status of existing treatment programs and the need for more of them. Reliance on insurance and third party payment methods for program costs are barriers to seeking treatment for many. Those treatment programs in place are often hard to navigate. Institutions like Maine Care, and other state or federal assistance programs, for example, were identified as being hard to navigate and often overwhelming. This often leads to clients feeling despondent towards seeking treatment.

Treatment systems and institutions are often not managed in a way that provides long term beneficial outcomes for the client. Providers of these treatment services also reported feeling overwhelmed by the lack of resources needed to do the job right.

Participants in the recent needs assessment also expressed the cultural incompetence of some health care providers working in treatment and recovery programs. Many participants and key informants expressed frustration with pharmacists who would not sell new clean needles to individuals who they assumed to be using them to inject illegal drugs.

It is the CPG's position that whenever possible prevention programs work with local treatment programs and pharmacies to understand the public health benefit of reducing the transmission of HIV through the availability of clean unused needles.

Needle Exchange Programs are gateways to HIV prevention for this population and are tremendously important in order for the systems of care and treatment currently in place to service this community effectively. Availability and access to the Needle Exchange Program is vital for HIV prevention.

Those individuals using the Needle Exchange Program over time report building a trusting relationship with staff and are often more willing to access the HIV prevention services offered.

IDU have reported that certain barriers exist and need to be addressed:

- Access to Needle Exchange Programs
- Lack of transportation in rural areas
- Mistrust of governmental sources of information
- Perceived law enforcement and health care bias
- Substance use and abuse

The CPG supports collaboration between HIV prevention programs and Needle Exchange Programs in hopes it will help in the reduction of HIV transmission within the IDU population of Maine.

### **Key IDU Needs Assessment Findings IDU Survey**

As this is only the second needs assessment done among the IDU population in Maine, we are able to present a few findings that are new and of interest. Of the 54% of respondents who think they are *not* at risk for HIV, 55% report sharing needles, 50% report sharing works and 55% report using condoms rarely (15%) or never (40%). Nearly half (47%) say that there are not enough places to get clean needles and 60% asserted that those locations where needles *are* available are not open when they are needed.

Over half of the respondents are concerned about getting HIV, but only a little over a third are concerned about getting Hepatitis C. About 88% of respondents have been tested for HIV and 80% have been tested for Hepatitis C. Only one respondent was HIV positive, while 37% were Hepatitis C positive.

Almost one third of IDU's surveyed do not have a regular physician. Over half (53%) of the more than two thirds who *do* have one, have not told the doctor they inject drugs. Over half the respondents, nearly 58% have gotten hurt from injecting. Only 31% of them saw a doctor or went to the hospital as a result.

These results, while not definitive, are remarkably congruent with key informant and group discussion findings below and, in that context, speak for themselves. They raise, and at least partially answer, several important questions: How great a barrier for IDU's is stigma in obtaining medical and addiction services? Is education about HIV and Hepatitis C transmission necessary? Is access to addiction treatment programs adequate? How can we help health care providers provide better treatment to addicts? Do we have enough needle exchange availability?

### **Key Informant Surveys**

There was a high degree of similarity among key informants and group interview participants in areas relating to obstacles for and needs of the IDU population. Stigma was mentioned by both groups as a dominant presence and a barrier to treatment both for drug use and other health problems. This type of rejection affected other aspects of life, too. Lack of health insurance and treatment opportunities were both regarded by nearly all as highly problematic in obtaining treatment.

It was difficult to assess whether there was congruence between IDUs and the service providers in the area of HIV/Hepatitis prevention. Three specific survey questions were asked to determine activity in this area. An HIV/Hepatitis prevention question was introduced in the group discussion, but was lightly pursued. It would be hard to assert that it is of great concern *only* to providers, but based on the material in the discussion, one could say that needle exchange may be, for some, as important in obtaining *sharp* needles as *clean* needles. It is not that prevention is of no importance. For example, some were concerned about safe sharps disposal. As in previous needs assessments, participants are focused on their own health and service needs. Public health professionals are, by the nature of their work, perhaps more likely to express concern about prevention.

### **Discussion Group**

The overwhelming message from the group interview is a sad one. Stigma appears to be the constant companion of the IDU, at least in Maine. Even if slighting, rudeness and refusal are not *really* everywhere, they are so common and so readily perceived, that they may as well be. Nevertheless, each person in the group demonstrated resilience in describing experiences of success, hope, belongingness, feistiness, humor, anger and change. No one in this group has given up.

There was much discussion of treatment programs and the need for more of them. People, of course, rely heavily on insurance and other third party payment for the program costs. They spoke of the lack of such resources and/or the frustrations in obtaining them. For example, it is difficult to work when you are in a methadone maintenance program (if you have to drive hours to get to it), an active user, or in residential treatment. Bureaucratic hassles impede treatment progress when you are dependent on Maine Care.

But that was not the only problem described. There were many stories of waiting for months for admission to both in- and out-patient programs, including detox. People coped in different ways

during the wait, but they revealed with clarity how fragile their own lives are and how impaired the treatment system is.

Another strong theme of the discussion was the experience of interacting with health care providers. Some of the participants had long-standing health problems apart from their addictions and made frequent doctor/ER visits. There were many opportunities for experience in the health care system. Tales of insensitivity and ignorance from professionals and ancillary personnel were common in the lives of these IDUs. Care was certainly provided – with a notable exception related to a pregnancy described above – but not in a generous-spirited way, it seems. On the other hand, participants frequently noted good experiences and providers whom they regarded with warmth and respect.

Pharmacists in particular seem to be regarded by some with frustration. It is not obvious what the problem is exactly. There may be something going on related to the exchange of money for a product that is viewed with disdain or fear by most in society. Personal, health, socio-economic and legal issues may combine to create discomfort. Whatever the situation, this interaction is often difficult for everyone involved.

There was agreement that professional training in the area of addictions for providers at every level could be helpful for everyone.

An individual who is using injection drugs surely has personal barriers to overcome, or at least come to terms with – depression, physical health problems, lack of readiness for treatment, anger, loss – but the socio-economic realities of current treatment options, as they see them, are frustrating indeed. Participants made a few basic suggestions.

### **Recommendations from the needs assessment**

#### **Key Informants:**

The five professionals who returned their surveys alluded to several areas in which improvements or changes could be made. There was a high degree of compatibility with those taken from the group discussion and support IDU recommendations fully. There were a couple of thoughts, though:

#### **More staff for support programs**

Professionals describe the need for additional staff to provide crucial services. Funders are seemingly ready to provide money for supplies, but if there is no staff, they won't be used appropriately, effectively or at all. As one staff person exclaimed, "I cannot be in the jails and in the needle exchange at the same time...."

#### **More education for users on harm reduction techniques**

Needle users require information on Hepatitis C transmission and other infections related to needle use, overdose prevention and safer injecting methods in general.

**Group Discussion:**

The structure of the group interview did not allow for a separate presentation of suggestions for improvement in the various troublesome areas. Although recommendations were not made specifically, they can be extrapolated easily from the discussion. The same issues and deficits were introduced in different ways and frequently. The ones most important to group participants follow:

**More treatment programs and easier access**

Easier access to treatment programs is, of course, a function of money. In this case, respondents suggested shorter waiting periods and greater ease in obtaining Maine Care eligibility or subsidized treatment. Further, travel difficulties to service locations in this rural state are common.

**More needle exchange and clean needle opportunities**

The limitations of living in a rural area were obvious when discussing availability of these and other services. If a local pharmacy elected not to sell clean needles or if a person lives in a remote area not serviced by needle exchange programs, then clean needles might not be available.

**Training for health care providers in addictions and related topics**

Participants suggested that education and training for health care providers in the area of addiction treatment and related topics could help consumers of medical, nursing, lab and pharmaceutical services. General medical care, pain management and understanding of the difficulties of addiction and addiction treatments are specific areas of concern.

**Education intended to reduce stigma**

Painful stories of rejection were related by most respondents in the group. Stigma associated with addiction, and, perhaps especially injection drug use is deep and widespread in society.

**ADDITIONAL RESOURCES: IDU**

Centers for Disease Control and Prevention, 1600 Clifton Rd, Atlanta, GA 30333, USA  
800-CDC-INFO (800-232-4636) TTY: (888) 232-6348, 24 Hours/Every Day -  
[cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov), <http://www.cdc.gov/hiv/resources/qa/qa26.htm> (updated Jan. 2007)

AVERT 4 Brighton Rd. Horsham, West Sussex, RH13 5BA, U.K.  
<http://www.avert.org/injecting.htm> (updated Sept. 2008)

#### **PRIORITY 4: Females at Very High Risk for HIV (FVHR) BEHAVIORAL POPULATION DESCRIPTION**

The National Center for Disease Control and Prevention (CDC) estimate that 1.1 million people in the United States are living with HIV infection, 21% of those undiagnosed and therefore unaware of their HIV status. It is also estimated that there are about 56,300 people newly infected annually with HIV. (CDC 2010)

In Maine, approximately 1,500 people have been diagnosed with HIV and there may be as many as 300-500 people in the state living with HIV that are unaware of their status. Of those people with diagnosed HIV infection, 16% are female. In 2009, Maine diagnosed 56 new HIV infections, 25% (14) of those were among women. (ME CDC HIV/AIDS Surveillance Program 2009)

Although we realize that any unsafe sexual and/or injection drug use can put females at risk for HIV infection, a particularly high risk for females is unsafe heterosexual sex. Heterosexual females who have unsafe sex refers to females who engage in unsafe behaviors (a sexual episode in which there is no or very little protection put in place to prevent HIV infection) that could put them at high risk for HIV infection from their opposite sex partner because that partner is HIV positive, an injection drug user, or is a male who also has sex with other males.

Research shows that men transmit HIV more easily to their partners than women do. Women are more susceptible to HIV infection through heterosexual, vaginal intercourse for several biological reasons.

- The lining of the vagina provides a large area, which can be exposed to HIV infected semen
- Semen has higher levels of HIV than vaginal fluids do
- Usually more semen is exchanged during sex than vaginal fluids
- Having untreated sexually transmitted infections (STIs) makes it more likely for women to contract HIV ([www.womenshealth.gov/hiv/women-at-risk/](http://www.womenshealth.gov/hiv/women-at-risk/))

Of the 14 women in Maine who were newly diagnosed with HIV in 2009, 50% were white and 50% were black. Among those females living with HIV, there is a larger proportion of minority females as compared to their male counterparts, 74% are white, 22% are black/African American, and 3% are American Indian/Alaskan Native as compared with their male counterparts of whom 91% are white. It is also of note that 50% of the women newly diagnosed with HIV in 2009 were foreign born. (ME CDC HIV/AIDS Surveillance Program 2009)

### **Risk Profile, FVHR:**

U.S. Centers for Disease Control and Prevention recognize eight risk factors and prevention barriers for HIV among women (ME CPG Needs Assessment page 7). The needs assessment data (page 49) show that all of these factors increase the risk of HIV transmission among women in Maine:

1. Younger age (15-39)
2. Lack of recognition of partner's risk factors, such as unprotected sex with multiple partners,
3. Sex with men, or injection drug use
4. High-risk heterosexual risk factors, such as lack of HIV knowledge, lower perception of risk,
5. Drug or alcohol use, and different interpretations of safer sex
6. Biologic vulnerability and history of STDs
7. Substance use
8. Lower socioeconomic status
9. Racial/Ethnic differences
10. Multiple risk factors such as inequality in relationships, socioeconomic stresses, substance abuse, and psychological issues.

In addition, needs assessment data shows us that 44% of women are/have been in an abusive or fear inducing relationship, which contributes to the inability of women to access HIV prevention and properly protect themselves. The exchange of sex for money, drugs, basic survival needs, and to take care of family is also a reality for many of the women of Maine and provides its own challenges to accessing HIV prevention.

### **Behaviors**

Certain behaviors, called HIV risk behaviors, increase the level of risk for infection among females. There are four general behaviors which put women at higher risk for HIV:

- 1) Having unprotected sex with a man/men who are HIV positive, men who have sex with other men, and men who inject drugs; having anonymous sex partners; multiple sex partners
- 2) Using and/or abusing drugs and/or alcohol
- 3) Trading sex for money, drugs, and/or other basic survival needs; and
- 4) Obtaining a tattoo or body piercing in a non-sterile/unsanitary setting

Over 25 years of research has identified that HIV is a preventable disease. Research has also identified the specific behaviors that result in 100% prevention, other behaviors that result in higher, but not complete, levels of prevention, behaviors that offer a low level of prevention, and those behaviors that offer no preventative benefit.

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 preventative behaviors from occurring on a case-by-case basis.

### **Impacts of addiction and substance abuse (SA)**

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:

- 1) Drugs
- 2) Alcohol; and
- 3) Sex

Of the women surveyed who reported using drugs in the past year, Marijuana (48%), Oxycontin (17%) and Cocaine (powder) 15% were the most popular choices. Also, 7% of women surveyed have injected a drug in the past six months.

Alcohol and drugs play a huge role in having unprotected sex. It lowers inhibitions and allows a person to behave in a way they may not have while not under the influence of drugs and alcohol and also limits a person's ability to negotiate condom use. Of the women who reported having had sex in the past six months, 43% had sex while drunk or high.

### **HIV Status (HIV positive, negative, unknown)**

The information that was collected during the recent needs assessment shows that behaviors and needs for HIV positive and negative women were similar. It should also be noted that the sample of HIV positive women taking part in this assessment was too small to draw any further conclusions about this population of women. (CPG Needs Assessment, 2009)

Other research has shown that people who have been diagnosed as being HIV positive have reported that knowing their HIV status has helped them to change unsafe behavior for safer behavior. Knowing your HIV status is important. People who have not been tested for HIV, and therefore are of unknown HIV status, represent a challenge for HIV prevention. There are three important facts related to unknown status:

- 1) The U.S. Centers for Disease Control and Prevention (CDC) estimate that about 21% 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 estimates that more than half of HIV infected adolescents don't know it because they haven't been tested
- 3) The U.S. CDC estimates 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

### **Individual attitudes, beliefs, feelings, etc.**

How a person feels, the things they believe in, and the attitudes they hold are other important factors that influence HIV prevention. The FVHR population as well as the general population must believe that HIV is a serious enough health issue to do something about. For the female population it is very important that they understand that women can be/are infected with HIV and that the percentage of women with HIV is growing at alarming rates.

More than half of the recent needs assessment respondents reported having unprotected intercourse within the past 6 months and of those 77% did not use a condom during their last sexual encounter and 25% of women never use condoms. The reasons most women give for not using condoms are because they don't like them and/or they know or believe that their partner doesn't like using them.

There appears to be a lack of overall education about HIV prevention; as many women feel they are not at risk, simply because they are women. Over 50% of the respondents, who have not had an HIV test in the past 6 months, when questioned why, gave the reason that they did not believe they were at risk.

Many women assume they know their partners' HIV status, even though they may have never asked their partner(s) about HIV status and their partner(s) have never disclosed either positive or negative status to them. It was also noted that 10% of women are afraid to know their status, mostly because they don't want to know if they have HIV. Another barrier to HIV prevention is the belief of many women over the age of 25 that condoms are for pregnancy only and are not thought of for HIV/STD protection. This is true especially for older women who have gone through menopause. Since pregnancy is no longer a concern, they feel free to have unprotected sex without giving much thought to HIV and other STDs.

### **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.

Mental illness and/or depression can present challenges for HIV prevention. When diagnosed they can cause real or perceived stigma and undiagnosed they can lead to behavior and/or addiction problems. Both cases can lead to feelings that undermine HIV prevention.

The recent needs assessment shows that 44% of respondents are/have been in an abusive or fear inducing relationship. This can lead to lower self-esteem; less self-care; lack of condom negotiation.

Co-occurring disorders; addiction; even living in a rural area are also concerns for HIV prevention. Feeling isolated, stigmatized, and/or alone can undermine HIV prevention messages or in some cases keep people from even getting the messages.

### **Social and Cultural Norms**

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

Of HIV prevention services accessed by respondents of the FVHR needs assessment, it appears there are two main HIV prevention methods Maine women are using, HIV testing and condoms. Two thirds of the respondents state that they have had an HIV test and know their HIV status and one in five women used a condom the last time they had sex.

Of the barriers to HIV prevention services in Maine for FVHR the following were noted:

- Lack of HIV knowledge (Basic 101)
- Lack of understanding/perception of risk
- Lack of HIV screenings as part of routine STD screenings
- Lack of consistent HIV testing in prison/jail system
- Lack of media messaging
- Lack of self-esteem
- The belief of most women over 25 that condoms are for pregnancy, not STD/HIV prevention
- The belief of most young women that anal sex prevents pregnancy and maintains virginity, while not realizing that it puts them at more risk for STD's/HIV
- Inability or lack of empowerment to negotiate safer sex
- Gender power imbalances/inequity
- Lower socio-economic status (Lack of access/affordability for health care as well as provider inconsistencies)
- Immigration status in country
- Minorities (disproportionately affected as well as lack of cultural competence in providers)
- Lack of care takers/family supporters
- Accessibility of services (too far away; no transportation; unaware of services)

### **Systems and Institutions**

Systems and institutions are broadly organized and established entities that function for some specific purpose. Examples include the education system, the criminal justice system, religious institutions, governmental services, mental health systems, and substance abuse treatment systems. These systems and institutions have norms and values that are specific to the individual system or institution.

In the recent needs assessment for FVHR there were several barriers noted to HIV prevention systems in Maine:

- Lack of routine HIV screening as part of routine health care
- Lack of perception/knowledge of risk among FVHR
- Services too far away
- No transportation
- Unaware of the service location
- Inconvenient times of service

### **Key FVHR Needs Assessment Findings**

In reviewing the 2009 CPG Needs Assessment Report for Females at High Risk for HIV and epidemiological information, several key points regarding this population emerge.

There are barriers for Maine women at risk for HIV to accessing HIV prevention services. The most common barriers described by women are: services are too far away, there is no transportation, there is unawareness of the service and/or the service location, and times of service are inconvenient.

The needs assessment shows that Maine women have similar risks to women in the U.S.:

- More than one quarter of the respondents had between two and 30 sex partners
- Almost half of the respondents noted that they have been in an abusive or fear-inducing relationship
- One in eight of the respondents had anonymous sex partners in the past six months
- One third of the respondents do not know their HIV status
- The majority of those who had sex in the last six months did not discuss HIV with their sex partners; rates for STDs are only slightly better
- Almost one quarter of the respondents stated that they do not know if their partners have HIV or an STD
- Seven percent of women report injecting substances, and just under half have shared their needles or works
- Almost three quarters of the respondents have used substances to get high in the last year
- Almost half have had sex while drunk or high in the last six months
- Rates of condom use among women in Maine are poor and inconsistent: more than half had sex without a barrier in the past six months and more than a quarter of the women never use a condom – only 21% of women used a condom the last time they had sex

There are several factors associated with inconsistent condom use. Apart from not using a condom because being in a monogamous relationship, Maine women report five top reasons for not using a condom:

- Personal dislike
- Partner dislike (known and/or assumed)
- Knows and/or assumes partners are HIV negative
- Discomfort
- Substance use

Women aged 25 and younger are the most likely to use condoms, based on condom use at last sexual encounter.

The needs assessment gathered data on eight prevention services. All services were known to a good extent, and all showed common barriers:

- Free Conventional HIV Testing: 36% did not know about the service. Only nine people stated that they had difficulty getting the service or were unable to get the service
- Free Rapid HIV Testing: 50% did not know about the service. Only five people stated that they had difficulty getting the service or were unable to get the service
- Counseling: How to tell sex partners HIV status: 58% did not know about the service; this, however, is not surprising, as this is a service reserved for people with HIV. Only two people stated that they had difficulty getting the service or were unable to get the service
- HIV Testing for a Sex Partner: 38% did not know about the service
- HIV Status Disclosure to Partners: 65% did not know about the service
- Information on How to Prevent HIV and STDs: 28% did not know about the service and ten people stated that they had difficulty getting the service or were unable to get the service
- Information on How to Decrease Behaviors that Increase Risk of HIV Infection: 33% did not know about the service and seven people stated that they had difficulty getting the service or were unable to get the service
- HIV Prevention Messaging: 73% of the women only see or hear prevention messages occasionally, rarely, or never. Of those who have seen or heard HIV prevention messages, the majority of them have seen or heard the messages on television, a doctor's office or medical clinic, at the hospital, or at an STD clinic.

The sample of people who report not knowing about one or both of the free HIV testing services does not differ significantly from the whole respondent group. Those not knowing of the services might be:

- Slightly younger (under 25 years of age)
- Greater likelihood to be non-white
- Less stable housing situation
- Less likely to inject drugs

- More likely to use the internet, particularly dating sites
- Somewhat less likely to have had sex in the past six months
- Slightly less likely to use condoms

When it comes to HIV testing, two thirds of the respondents state that they have had an HIV test and know their HIV status. The most frequently noted reasons for not being tested is the respondent does not feel that they are at risk for getting HIV and/or because they don't have sex.

- The most frequently reported reason for getting an HIV test in the past six months was because it was offered by the doctor during a routine exam, offered at an event or club, or because they knew they were at risk.
- The majority of people test in a medical setting including the doctor's office, a family planning clinic, a public clinic, or at a hospital.
- Those who do not get their HIV test results after their last test list the three top reasons were that they forgot, they moved, and that they were homeless.

**Recommendations:**

- Meet women at venues where they already congregate for socialization or to access other services and provide education, testing, etc.
- More community building, outreach provided by women and partnerships made with women at risk for HIV, both positive and negative, to provide outreach, education, and testing.
- Create partnerships with existing systems and institutions to provide outreach/education.
- Use appropriate language for target population
- Increase awareness of risk and perceived susceptibility and vulnerability
- Increase knowledge of status through low barrier, targeted outreach, and CTR.
- Include STD and hepatitis messages during outreach
- Provide risk assessment and referrals for hepatitis C testing and hepatitis A/B vaccines as appropriate.
- Increase access to substance abuse and mental health services particularly services that can accommodate women and single parents and are available to people who do not have private insurance or Maine Care.
- Increase self-esteem and confidence that one can use risk reduction behaviors under a variety of situations and circumstances.
- Increase communication, problem solving and decision making skills that reduce HIV transmission including negotiation skills, and skills that lead to empowerment and assertiveness.
- Advocate for changes to decrease HIV stigmatization.

**ADDITIONAL RESOURCES: FVHR**

The National Women's Health Information Center - U.S. Department of HHS (Office of Women's Health) Telephone: 1-800-994-9662 TDD: 1-888-220-5446  
<http://www.womenshealth.gov/hiv/prevention/> (updated March 2009)

Centers for Disease Control and Prevention, 1600 Clifton Rd, Atlanta, GA 30333, USA  
800-CDC-INFO (800-232-4636) TTY: (888) 232-6348, 24 Hours/Every Day - [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)  
<http://www.cdc.gov/hiv/topics/women/index.htm> (updated Feb. 2007)  
<http://www.cdc.gov/hiv/topics/women/challenges.htm> (updated Feb. 2010)

## Chapter 6

### INTERVENTIONS: SAFE IN MAINE

This chapter provides an overview of the Serostatus Approach to Fighting the HIV/AIDS Epidemic (SAFE) model which the CPG has recommended as the basis for prevention planning throughout the State. It also includes a chart that reviews the different intervention types as categorized by the CDC and used by the ME CDC. The last section of this Chapter lists interventions recommended by the CPG for use in implementing SAFE in Maine.

### AN OVERVIEW OF THE SAFE MODEL

As was mentioned in Chapter 3, the CPG has adopted the SAFE model which requires activities be focused on recruiting people at high risk for HIV infection into Counseling, Testing and Referral services (CTR), and then addressing the prevention needs of people who test HIV+ or who are very high-risk negative. Following the goals of the National AIDS Strategy; the SAFE model is aimed at those who are HIV+, including those not aware of their status, as well as those who have been tested and found to be HIV- but are at continued very high behavioral risk. Providers should incorporate the SAFE model into their prevention programs in order to identify activities that would effectively recruit members of the targeted behavioral populations into CTR and risk assessment services. CPG recommendations of locations for recruitment and outreach CTR can be found on pages 45-48.

- In this Plan the term “high risk” refers to persons of unknown or negative serostatus engaging in behaviors that put them at risk for HIV or other STD’s with people who are HIV+, or in settings where there is a high prevalence of HIV.
- “Very high risk” refers to someone who, within the past 6 months:
  - has had unprotected sex with a person who is living with HIV
  - has had unprotected sex in exchange for money or drugs
  - has had multiple (greater than 5) or anonymous unprotected sex or needle-sharing partners
  - has been diagnosed with a sexually transmitted disease.

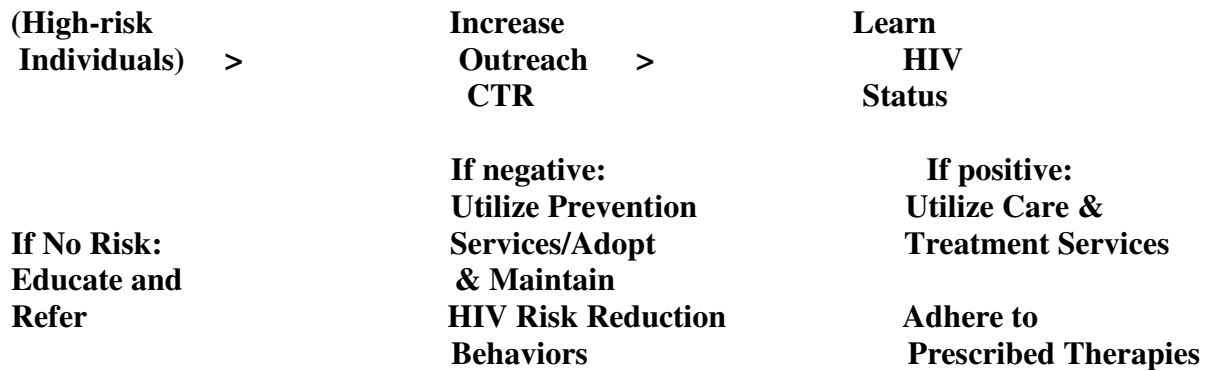
The following information provides an overview of SAFE\* All prevention services should be based on this model with a focus on outreach CTR to populations at high risk of infection. This results in a two tiered system of activities/interventions:

1. Interventions to recruit people at high risk to test and learn their serostatus
2. Follow-up HIV prevention interventions for people who test positive or who test negative but are at very high risk of becoming infected.

**The 5 steps of the SAFE model\* are as follows:**

1. Increase the number of HIV+ persons who know their serostatus ~ encourage testing by those at risk
2. Increase the use of health care and prevention services by HIV+ persons
3. Increase the number of HIV+ persons receiving high-quality care and treatment
4. Increase adherence to antiretroviral therapies
5. Increase the adoption and maintenance of HIV risk reduction behaviors by people who are HIV+ or at high risk.

**The blueprint for a serostatus approach to fighting the HIV/AIDS epidemic:**



## Examples of How to Implement Serostatus-Specific HIV Prevention Interventions\*

<b>Population</b>	<b>HIV Prevention Interventions</b>
Unaware of serostatus; behavioral risk of infection	Provide current, essential HIV-related information Encourage voluntary HIV counseling and testing among those at increased risk including anonymous testing Reduce stigma of HIV disease and services
Recently tested HIV negative; no apparent behavioral risk of infection	Educate to provide HIV prevention messages to family, friends, partners
Recently tested HIV negative; Behavioral risk of infection	Offer intensive individual or small-group counseling Develop community-level interventions Establish linkages to STD, substance abuse, mental health, hepatitis, and social services as needed Provide Comprehensive Risk Counseling Services (CRCS) for those at highest risk Develop structural interventions (e.g., decrease discrimination)
Tested HIV positive	Provide intensive prevention services Offer Partner Services (PS) Establish linkages to STD, substance abuse, mental health, hepatitis, and social services as needed Provide Comprehensive Risk Counseling Services (CRCS) Develop structural interventions (e.g., decrease discrimination)

\*The information on SAFE was adapted from the following source:

Janssen, Robert S. et al. (2001). The serostatus approach to fighting the HIV epidemic: Prevention strategies for infected individuals. *American Journal of Public Health* 91(7): 1019-1024.

**INTERVENTION TYPES**

The following chart provides a general overview of different types of interventions as categorized by the CDC and used by the ME CDC. This listing can be helpful in understanding the interventions recommended for targeted recruitment, as well as those recommended for people who are HIV+ and for people who are very high risk HIV negative.

This chart suggests which intervention type would be appropriate to use to address the critical needs of the priority populations. See Chapter 7 for information regarding the critical needs of each of these populations. See the last section of this Chapter for the actual recommendations regarding CTR and HIV prevention interventions.

Intervention Type	Description	
<b>Counseling, Testing and Referral (CTR)</b>	<b>An Individual Level Intervention. Component of an Effective HIV prevention intervention activity by which a person may learn their HIV sero-status. CTR services are offered free of coercion. Individuals have the opportunity to accept or refuse HIV testing. Can increase knowledge about HIV transmission/acquisition, knowledge of status, and change attitudes related to risk and testing.</b>	
	<b>Examples/Method</b>	<b>Recommended/Effective in addressing</b>
	<b>Anonymous</b>	<b>Low barrier service. High risk clients. Can be done in an outreach setting.</b>
	<b>Confidential</b>	<b>Can be done in outreach setting</b>
	<b>Oral</b>	<b>Can be done in outreach setting</b>
	<b>Rapid Test</b>	<b>Can be done in outreach setting</b>
	<b>Serum</b>	<b>Clinic setting</b>

**Individual Level (ILI)**

Health education and/or risk reduction counseling provided to one person at a time. ILI's assist clients in making plans for individual behavior change and ongoing appraisals of their own behavior and include skills building activities. These interventions also help clients make plans to obtain services in clinics and community settings in support of behaviors and practices that prevent the transmission of HIV.

<b>Examples/Method</b>	<b>Recommended/Effective in Addressing</b>
Single Session	HIV knowledge, information, referrals, skills
Multi Session	Attitudes, skills and behaviors
Peer-Led	Recommended for all interventions targeting youth, females and people of color. Can be single or multi-session

**Group Level (GLI)**

Health education and/or risk reduction counseling with a skills building component provided to more than one person at a time. Provide education and support in group settings to promote and reinforce safer behaviors and to provide interpersonal skills training in negotiating and sustaining appropriate behavior change to persons at increased risk or already infected.

<b>Examples/Method</b>	<b>Recommended/Effective in Addressing</b>
Single Session	HIV knowledge, information, referrals, skills
Multi Session	Attitudes, skills, behaviors
Peer-Led	Recommended for all interventions targeting youth,

females and people of color. Can be single or multi-session

**Community Level (CLI)**

Health education and/or risk reduction services directed at changing community norms, rather than those of the individual or a group, to increase community support of the behaviors known to reduce the risk of HIV transmission. The primary goals of these interventions are to improve health status, to promote healthy behaviors, and to change factors that affect the health of community residents. They are designed to promote community support of prevention efforts by working with the social norms or shared beliefs and values held by members of the community. Community may be defined in terms of a prioritized population or a geographic area as a way to capture the social networks that may be located within those boundaries.

<b>Examples/Method</b>	<b>Recommended/Effective in Addressing</b>
Community Building Events	Community norms, populations with strong identifications, isolated populations, addressing issues in a culturally competent way
Social Marketing	See above
Structural/Systems Interventions	See above

**Outreaches (OR)**  
by

**Interventions are** defined by the location of activity and the content of services provided. They reach persons at high risk, individually, or in groups, on the street or in community settings. The fundamental principle of outreach activities is that the outreach worker establishes

face-to-face contact with the client in his or her environment to provide HIV risk reduction information, safer sex/harm reduction products and referrals. It may be recruitment strategy. The outreach intervention may happen distinctly or in conjunction with other interventions.

<b>Examples/Method</b>	<b>Recommended/Effective in addressing</b>
Peer Education	HIV knowledge, information, referrals, safer sex/harm reduction products, recruitment into other interventions, reaching high risk individuals
“Street Outreach”	See above
Needle Exchange	See above
Popular Opinion Leaders	See above

**Partner Services (PS)**

A voluntary and confidential prevention activity conducted by trained individuals that provides services to a source patient and their sex and/or needle-sharing partners so they can reduce their risk for infection or, if already infected, may prevent transmission to others. PS also works to help partners gain earlier access to individual counseling, HIV testing, medical evaluation and other prevention and support services.

**Recommended/Effective in addressing**

Continuation of CTR, reducing risk of partners, early entry into testing, treatment and services

**Comprehensive Risk Counseling Services (CRCS)**

Provides client-centered, intensive, on-going, individualized prevention counseling, support, education and service referral. The goal is to promote the adoption and maintenance of HIV risk-reduction behaviors by clients with multiple, complex problems and risk-reduction needs. It is intended for persons having difficulty initiating or sustaining behaviors that reduce or prevent HIV acquisition, transmission or re-infection.

**Recommended/Effective in addressing**

At risk HIV+ individuals, individuals at high risk for HIV with multiple, complex problems and risk-reduction needs

**Health Communication/ Public Information (HC/PI)**

Information delivered as planned prevention messages to support risk- reduction, increase awareness, build support for safer behavior. HC/PI does not include group level interventions that include a skill component. Can be used for recruitment.

**Examples/Method**

**Recommended/Effective in addressing**

Presentations/  
Lectures

“One shot” education intervention delivering targeted information to specific populations in group settings such as jails or substance abuse treatment facilities

Electronic &  
Print Media

Media campaigns delivering targeted information to specific populations

Clearinghouse/  
Internet based

Basic prevention messages and referral information delivered to MSM online.

## RECOMMENDATIONS FOR CTR, LOCATIONS AND HIV PREVENTION INTERVENTIONS

The following Tables list the recommended activities and interventions that should be used when working with the high risk\* prioritized populations in this Plan. See Chapters 3 and 7 for details on these populations and their prevention priorities. Table I lists recommended activities to recruit people into Counseling, Testing and Referral Services (CTR). Table II lists recommended interventions for people who are HIV+, and Table III lists recommended interventions for people who test negative but are at very high-risk\*. The activities and interventions listed in these Tables are not in priority order.

The CPG recommendations for interventions listed in these Tables include CDC evaluated interventions as well as other general intervention types (see the previous Chart). The CDC evaluated interventions are listed in **bold** type in Table I. It is important that when program planners modify these CDC interventions, that the modification is culturally competent, suits the specific needs of the populations being served, and maintains the core elements of the original intervention. According to the CDC, core elements are those components that are critical features of an intervention's intent and design and are considered to be responsible for its effectiveness. They are essential to the implementation of the program and cannot be ignored, added to, or changed.

- Further information about these CDC evaluated interventions and their core elements is available on the Disseminating Effective Behavioral Interventions (DEBI) project website at <http://www.effectiveinterventions.org> and the Replicating Effective Programs (REP) project website at <http://www.cdc.gov/hiv/projects/rep/>
- When choosing one of the CDC interventions listed in Table I, the core elements (as listed on the DEBI and REP websites) must be followed, however the interventions can be adapted (to a different population or location) and tailored (changed to deliver a new message, or use a different timeframe, or be delivered in a different manner) than was originally described.

In addition, the CPG continues to recommend that all HIV prevention providers use the information contained in Chapter 6 regarding criteria for effective interventions and programs, and use behavioral/social science theory in their HIV prevention planning.

\*As mentioned previously, the term “**high risk**” refers to persons of unknown serostatus engaging in behaviors that put them at risk for HIV or other STD's with people who are HIV+ or in settings where there is a high prevalence of HIV.

**“Very high risk”** refers to someone who, within the past 6 months:

- has had unprotected sex with a person who is living with HIV
- has had unprotected sex in exchange for money or drugs
- has had multiple (greater than 5), or anonymous unprotected sex or needle-sharing partners
- has been diagnosed with a sexually transmitted disease

## **CTR RECOMMENDATIONS AND LOCATIONS**

### **COUNSELING, TESTING AND REFERRAL (CTR)**

- The number one recommended intervention for all targeted behavioral populations is Counseling, Testing and Referral (CTR). The CPG makes the following recommendations for implementing CTR:
  - The primary method of CTR delivery should be field outreach
  - CTR services must also be available on a regularly scheduled basis including some night or weekend hours and by appointment as needed
  - CTR services for the prioritized populations should be available anonymous and free of charge
  - All paid and volunteer staff conducting HIV prevention interventions are required to have ME CDC certification in CTR
  - CTR services should be more aggressively promoted via marketing and media statewide
  - Targeted outreach Group Level Interventions (GLI) and Individual Level Interventions (ILI) should be used as a strategy to get people to test

## LOCATIONS

- In addition the CPG recommends the following locations for CTR and other outreach interventions. The locations are not listed in priority order.

### **Locations for Reaching MSM**

- Websites such as manhunt.net, craigslist.org, squirt.org, Adam4Adam.com, Recon.com, bear411.com, etc.
- Internet chat rooms such as gay.com; and sex party hookups using the Internet
- Smartphone specific apps. Such as; Grindr and Encountr
- Adult bookstores and porn shops
- Bars
- Malls (Portland and Bangor)
- Ogunquit (Summertime)
- Bangor, Portland and Lewiston/Auburn public sex environments (PSE's)
- MSM community events such as PRIDE celebrations, retreats, etc.
- College LGBTI groups, Teen Centers
- Mental Health Treatment & Counseling Centers
- Streets/areas known for sex work

### **Locations for Reaching IDU**

- Needle (Syringe) Exchange Programs (NEP's)
- Drug treatment centers
- Second Offenders (DEEP) Programs for O.U.I.

- Coastal Fishing locations
- Methadone Clinics
- Jails, prisons, and pre-release centers
- Homeless Shelters
- Soup Kitchens
- Group Homes/Halfway Houses
- Native American Reservations
- Parks and rest areas
- Teen Centers
- Health Clinics
- Streets/areas known for sex work
- Mental Health Treatment & Counseling Centers
- Tattoo/Piercing Parlors
- Plasma Centers

### **Locations for Reaching FVHR**

- Substance abuse facilities especially those targeting women
- Women's Health Clinics
- Battered women's shelters
- Jails, prisons, pre-release centers
- Homeless Shelters

- Youth Shelters such as New Beginnings and Shaw House
- Teen Centers
- STD Clinics
- Mental Health Treatment & Counseling Centers
- Streets/areas known for sex work

## INTERVENTION RECOMMENDATIONS

In keeping with the SAFE model, the activities and interventions listed in Table I below should result in Counseling, Testing and Referral (CTR) and risk assessment of individuals at high risk of HIV transmission/acquisition. **Bolded** items refer to CDC evaluated interventions which require the use of their core elements as described previously in this Chapter.

**TABLE I**

<b>CPG Recommended Interventions &amp; Activities to Encourage Testing for High-Risk Members of the Target Populations (<u>not</u> listed in priority order)</b>
COUNSELING, TESTING AND REFERRAL (CTR) ``primarily: <ul style="list-style-type: none"><li>• Targeted Outreach CTR (see recommended locations beginning on page 46)</li></ul>

<p>COMMUNITY LEVEL INTERVENTIONS (CLI) AS FOLLOWS:</p> <ul style="list-style-type: none"><li>• Popular Opinion Leader (adapted and tailored for implementation in Maine’s Metropolitan Statistical Areas (MSA’s) –Portland MSA, Lewiston MSA and Bangor MSA</li><li>• Mpowerment Project (adapted and tailored for implementation in Maine’s three MSA’s</li><li>• Safety Counts (IDU) (adapted and tailored for implementation in Maine’s three MSA’s</li><li>• Community wide events</li></ul>
<p>HEALTH COMMUNICATION/PUBLIC INFORMATION (HC/PI) including</p> <ul style="list-style-type: none"><li>• Targeted, provocative, contemporary electronic and print media campaigns</li><li>• Coordinated internet based interventions for MSM</li><li>• Presentations/lectures delivering targeted information to specific populations in the community such as at jails and substance abuse treatment facilities (see recommended locations beginning on page 46)</li></ul>
<p>INDIVIDUAL LEVEL INTERVENTIONS (ILI) including but not limited to:</p> <ul style="list-style-type: none"><li>• Comprehensive Risk Counseling Services (CRCS)</li></ul>
<p>PARTNER SERVICES (PS)</p>
<p>GROUP LEVEL INTERVENTIONS (GLI) conducted both onsite and out in the community (see recommended locations beginning on page 46)</p>

CTR and risk assessment should lead to the following interventions in Table II (below) for people who tested HIV+, or to the interventions in Table III for individuals who test HIV- but whose behaviors put them at very high risk.

**TABLE II**

<b>CPG Recommended Interventions for People Who Test HIV Positive (not listed in priority order)</b>
<p><b>GROUP LEVEL INTERVENTIONS (GLI)</b> Including social support groups which should be run by a trained facilitator (such as an LCSW or a trained peer) and not the case manager. They should be supportive in nature while working on the skills and obstacles mentioned under Critical Needs for People who are HIV+ in Chapter 7.</p>
<p><b>INDIVIDUAL LEVEL INTERVENTIONS (ILI)</b> (Recommended for people who are newly diagnosed, and could include peer advocates /buddies)</p>
<p><b>COMPREHENSIVE RISK COUNSELING SERVICES (CRCS)</b> (Referral for people with multiple, complex issues and risk reduction needs that can't be served through GLI's or ILI's)</p>
<p><b>HEALTH COMMUNICATION/PUBLIC INFORMATION (HC/PI)</b> (Related to education about the disease and treatment options)</p>
<p><b>COMMUNITY LEVEL INTERVENTION (CLI)</b> (Related to reducing stigma and encouraging disclosure as the norm)</p>
<p><b>PARTNER SERVICES (PS)</b></p>

**TABLE III**

<b>CPG Recommended Interventions for People At <u>Very High-Risk</u> Who Test Negative (<u>not</u> listed in priority order)</b>
<b>INDIVIDUAL LEVEL INTERVENTION (ILI)</b> <ul style="list-style-type: none"> <li>• Single session ILI</li> <li>• Multi session ILI</li> </ul>
<b>GROUP LEVEL INTERVENTION (GLI)</b> (Multi session including social support groups)
<b>COMPREHENSIVE RISK COUNSELING SERVICES (CRCS)</b> (Facilitated referrals for people at very high risk who have multiple, complex issues and risk reduction needs that can't be served through GLI's or ILI's)
<b>PARTNER SERVICES (PS)</b> (as appropriate)

The components of this Chapter work together by prioritizing high-risk individuals for outreach that gets them into CTR. The CTR process follows the SAFE blueprint. Using these listed interventions will ensure that the National AIDS Strategy's priority goals are reached. The National AIDS Strategy also makes it very clear that linkage to care for people testing HIV+ is critical. With this in mind, it is imperative that this linkage to care is a vital part of all interventions. There must be a way of ensuring that this happens through a thorough follow-up process.

## Chapter 7

### **DESIGNING EFFECTIVE PROGRAMS: BEST PRACTICES AND EVALUATION**

This chapter contains information about developing and evaluating HIV prevention activities in the state of Maine. HIV Prevention Activities for all prioritized populations must contain basic criteria. The Maine CPG has accepted the following elements as the most important attributes of an effective activity or program. Funding decisions should be based, at least in part, on these criteria. Activities should focus on getting people to know their HIV status and prevent as many new infections as possible.

#### **Activities should:**

- Encourage individuals to get tested
- Provide a low barrier method of getting tests results
- Link newly identified positives to medical care
- Link clients to Partner Notification Services
- Provide prevention and risk reduction information to both negative and positive individuals

#### **Effective prevention activities do the following things:**

Clearly define the population at risk or being targeted by the prevention activity.  
(Refer back to population definitions and characteristics in Chapter 4 and 7)

Address a demonstrated HIV prevention need

Are modeled on evidence based practices. **(Footnote with definition)**

Focus on specific risk behaviors

- Knowledge and understanding of the factors responsible for risk and the behavioral changes needed to reduce risk of HIV infection.

- Myths and misconceptions about HIV/AIDS are corrected
- Counseling, Testing and Referral (CTR) services.
- Provides numerous opportunities to practice relevant skills including condom and lubrication use, safer sex practices, assertiveness skills, negotiation and communication skills, and self-management skills to reduce risk vulnerability.
- Assistance in accurately appraising an individual's level of risk.
- Encourage the development of self-efficacy (belief that one can effectively make behavioral changes and that change will reduce one's risk).
- Assistance in planning and strategizing ways to avoid and cope With high-risk situations and/or lapses.

**Have clearly defined goals that are measurable**

- Activities are client centered and focused on client needs, not the service provider
- Involve the target population in evaluation of the effectiveness of the prevention activity
- Are cost effective and do not duplicate services already being provided for that population and geographical area
- Provide necessary referrals and linkages to medical care and other support systems Example: Alcohol and Substance abuse counseling, mental health, etc.
- Integrate STD and Hepatitis (AB&C) prevention and treatment information and referrals

### **Addressing barriers:**

It is important to understand the unique characteristics, challenges and issues of each population in order to reduce barriers to service.

Examples:

- a. Services being delivered at a time and location that is accessible and convenient in order to reach the greatest number of people at risk in your target population / area.
- b. Address community wide norms, attitudes, beliefs and values by providing consistent messages and reinforcement for reducing the risk for acquiring or transmitting HIV.

### **Evaluation**

What is Program Evaluation?

Program evaluation is carefully collecting and analyzing specific information in order to help you determine the effectiveness of the services you are providing. This information may help you improve your service delivery, reduce costs or even in some cases help you to make a hard decision about the services you are providing. Evaluation can verify if the program is running as originally planned, show you where services are lacking or could be more effective, show you where services are on target and hopefully show you new ways to be more efficient and better your outcomes.

There are many ways that evaluation can happen. It is important to know what information you will need in order to do an evaluation. The following questions will help you to create an effective evaluation process:

- What are you evaluating, a goal or a procedure?
- Are you collecting the right information?
- Do you have a process for collecting the right information?
- Do you know if you have met your goals for this service?  
How do you know? What mechanisms are in place to capture  
This information?
- How will you report your results and to whom?

- How will you use the results to influence your program or services?
- Do you need to change how things are being done?
- Are we reaching individuals in our prioritized populations with CTR?
- Are the activities we use to recruit people for CTR effective?  
Do they reach the right people?
- Are our services culturally competent?
- Are we achieving our HIV testing goals?
- Are we linking those testing positive to care?
- Do we provide or refer for Partner Services (PS)?
- Do the education/harm reduction activities we use seem to be effective?
- Are we getting high-risk individuals to learn their status?
- How do we deliver results?
- What percent of the time are we able to deliver results?
- What about anonymous testing?
- What are the desired outcomes?
- How are we achieving outcomes?
- How do we know?

**Some examples for evaluating activities (collecting data):**

- Questionnaires, surveys, checklists (Can be used to quickly and/or easily get information from people in a non-threatening way)
- Interviews (Can be used to fully understand people's impressions, experiences, or to learn more about their answers to questionnaires or surveys)
- Documentation Review (Can be used to get an idea of how the program operates without interrupting the program; by reviewing finances, memos, minutes, etc.)
- Observation (Can be used to gather information about how a program actually operates; particularly about processes)
- Focus groups, Community/Consumer Advisory Boards (Can be used to explore a topic in depth through group discussions; re: reactions to intervention/activity strategies, discussion of common complaints, etc.)

**Evaluating HIV Prevention Services in Maine:**

It is the expectation of the ME CPG that the ME CDC will, through its contracting process, monitor and evaluate funded HIV prevention and testing activities.

Performance goals should be set for each prevention activity. These goals should reflect the National AIDS Strategy's 3 primary goals:

- 1) Reducing new HIV infections.
- 2) Increasing access to care and improving health outcomes for people living with HIV.
- 3) Reducing HIV-related disparities and health inequities.

It is imperative that all HIV Prevention Activities follow the basic criteria of evidence based practices. Activities should focus on getting people to know their HIV status and preventing as many new infections as possible.

Services must address barriers to increase access to services, so that we can reach as many high-risk individuals as possible.

Programs must have a means in place for evaluating services and by reviewing these findings improving services and/or making them more efficient/effective. As resources tighten and need grows, we must be sure that our activities are achieving the best outcomes possible.

- (footnote) **These interventions represent the strongest HIV behavioral interventions in the literature to date that have been rigorously evaluated and have demonstrated efficacy in reducing HIV or STD incidence or HIV-related risk behaviors or promoting safer behaviors.**

<http://www.cdc.gov/hiv/topics/research/prs/evidence-based-interventions.htm>

For further references/resources:

CDC Revised Guidelines for CTR Implementation and Evaluation

<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5019a1.htm>

CDC Designing and Evaluating Intervention Plans

[http://www.cdc.gov/hiv/topics/evaluation/health\\_depts/guidance/designing.htm](http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/designing.htm)

CDC Monitoring and Evaluating the Implementation of HIV Prevention Programs

[http://www.cdc.gov/hiv/topics/evaluation/health\\_depts/guidance/monitoring.htm](http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/monitoring.htm)

CDC Monitoring Outcomes of Health Education/Risk Reduction Individual- and Group-Level HIV Prevention Interventions

[http://www.cdc.gov/hiv/topics/evaluation/health\\_depts/guidance/outcome-mon.htm](http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/outcome-mon.htm)

CDC Evaluating Outcomes of HIV Prevention Programs

[http://www.cdc.gov/hiv/topics/evaluation/health\\_depts/guidance/outcome-eval.htm](http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/outcome-eval.htm)

CDC Evaluation Guidance Handbook: Strategies for Implementing the Evaluation Guidance for CDC-Funded HIV Prevention Programs

[http://www.cdc.gov/hiv/topics/evaluation/health\\_depts/guidance/strat-handbook/index.htm](http://www.cdc.gov/hiv/topics/evaluation/health_depts/guidance/strat-handbook/index.htm)

**In conclusion:**

**We have an advantage today in doing HIV prevention work in that we have the advantage of three decades of research to help us define critical needs for the priority populations of people that are at risk for HIV infection.**

**To maximize shrinking budgets available for HIV prevention efforts, the CPG considers it imperative to leverage existing resources and service delivery through greater coordination at federal, state and local levels.**

**“Countless Americans have devoted their lives to fighting the HIV epidemic and thanks to their tireless work we’ve made real inroads. People living with HIV have transformed how we engage community members in setting policy, conducting research, and providing services. Researchers have produced a wealth of information about the disease, including a number of critical tools and interventions to diagnose, prevent, and treat HIV. Successful prevention efforts have averted more than 350,000 new infections in the United States. And health care and other services providers have taught us how to provide quality services in diverse settings and develop medical homes for people with HIV. This moment represents an opportunity for the Nation. Now is the time to build on and refocus our existing efforts to deliver better results for the American people”. – President Obama - (Taken from the opening remarks of the National HIV/AIDS Strategy)**

**<http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>**

# Maine HIV Prevention Community Planning Group

## Glossary of Commonly Used Terms and Acronyms \*

- ADAP**            **The AIDS Drug Assistance Program**  
The AIDS Drug Assistance Program (ADAP) is a federally funded program, operating at the state level, which ensures access to the prescription medications needed to manage and treat HIV. The ADAP assists clients to access the prescription medications deemed necessary to manage and treat HIV, and to prevent and treat illnesses that develop as a result of a suppressed immune system, or are commonly associated with HIV (e.g. Opportunistic Infections). The ADAP is designated as a 'payer of last resort'
- AIDS**            **Acquired Immuno-Deficiency Syndrome**  
A disease caused by the human immunodeficiency virus (HIV) in which the body's immune system breaks down leaving the person open to developing a variety of life-threatening illnesses (opportunistic infections). The clinical definition of AIDS requires a medical diagnosis that includes a CD4 count less than or equal to 200, or one or more opportunistic infections.
- AIDS Prevalence**    A statistical term referring to the number or percentage of people living with AIDS in a given population or time period.
- All About Prevention**    An AIDS service organization located in Augusta and Brunswick.
- AMH**            **Office of Adult Mental Health**  
AMH is a division of mental health.
- ASO**            **AIDS Service Organization**  
An agency that provides HIV/AIDS related services to the community such as support, health services, case management, prevention, housing, advocacy, intervention, information and referral.
- Behavioral Science**    The study of human behavior, including psychology and sociology, that seeks to understand the behaviors and actions of individuals or groups of people in a given situation, i.e., why people do what they do.
- Bylaws**            Standing rules written by a group to govern the way they function in order to achieve their goal. Bylaws address issues of voting, quorums, attendance, etc.
- CDCP**            **Center for Disease Control and Prevention**  
An agency of the Maine Department of Health and Human Services. The HIV, STD and Viral Hepatitis Program is part of the Maine Center for Disease Control and Prevention is often called **MECDC** for convenience.

- C & T**      **Counseling and Testing**  
A process to determine your HIV status that includes counseling before and after the test. The counseling helps clients assess their own risk and develop methods to decrease their risk or change their behavior. See also CTR.
- Capacity Building**    Strengthening the abilities and knowledge of individuals or groups so that they may do their work better.
- CARE Act**      The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act is the federal legislation created to address the health and support service needs of persons in the US living with HIV/AIDS.
- CBO**      **Community-Based Organization**  
An agency providing services to specific groups of people in a defined area. Examples of the types of groups served include minority groups, the homeless, and people with a mental illness. An AIDS service organization is a type of CBO that provides services to people at risk of or living with HIV.
- CDC**      **The Centers for Disease Control and Prevention**  
The federal agency responsible for the public health of the nation. It tracks diseases that endanger public health, such as HIV and tuberculosis. The CDC is located in Atlanta, Georgia.
- CD4 cells**      Immune cells, also called T-helper cells, which help your body fight off infection and disease. HIV kills these cells.
- CHCS**      **Community Health and Counseling Services**  
CHCS is a private, non-profit community home health, hospice and mental health services provider, serving individuals and their families living in eastern, central and northern Maine. CHCS is both licensed by the State of Maine and certified by Medicare as a home health and hospice provider.
- CL**      **Community Living**  
Community Living works in partnership with the community to serve individuals with dignity, respect and independence in safe supportive living environments.
- CLI**      **Community Level Intervention(s)**  
A type of intervention providing health education and/or risk reduction services or interventions aimed at changing community norms to increase community support of the behaviors known to reduce the risk of HIV transmission.
- Comprehensive HIV Community Prevention Plan**      The result of the community HIV prevention planning process. This is a plan that has taken into account many different points of view and perspectives in order to provide the most effective prevention efforts for a specific area and population. It identifies prioritized target

populations and describes what interventions will best meet the needs of each target population.

- CMS**      **Centers for Medicare & Medicaid Services (Federal)**  
An agency of the U.S. Department of Health and Human Services (HHS) responsible for administering Medicare, Medicaid, State Children's Health Insurance Program (SCHIP), Health Insurance Portability and Accountability Act (HIPAA), Clinical Laboratory Improvement Amendments (CLIA), and other health related programs.
- CSA**      **Community Services Assessment**  
The CSA describes the prevention needs of populations at risk for HIV infection, the interventions and activities that are in place to meet those needs, and service gaps. It is made up of three documents: a Needs Assessment(s), Resource Inventory, and a Gap Analysis.
- CTR**      **Counseling Testing and Referral Services**  
Components of an effective HIV intervention activity by which a person may learn what their HIV status is and get appropriate referrals for follow-up services.
- Concurrence** A process in which CPG members vote to determine whether the health department and the CPG successfully worked together in revising the HIV prevention plan, and whether the activities, programs and services, for which the health department is requesting CDC funds, respond to the priorities in the plan. The results of this process are reported in a letter, agreed upon by the CPG, and signed by the Co-Chairs. A letter of concurrence, concurrence with reservations, or non-concurrence is required as part of a health department's application to the CDC for federal HIV prevention funds.
- Conflict of Interest** A conflict between one's self-interest and the public good; for example, if the board of a community-based organization is deciding whether to receive services from Company A and one of the board members also owns stock in Company A, that person would have a conflict of interest.
- Cumulative Cases** The total number of cases of HIV or AIDS reported from a given date to the present.
- DEAN**      **Down East AIDS Network**  
An AIDS service organization located in Ellsworth.
- Demographics** The statistical characteristics of human populations such as age, race, ethnicity, sex and size.
- DHHS**      **Maine Department of Health and Human Services**  
The lead state agency addressing health and human service needs.

<b>DIS</b>	<b>Disease Intervention Specialist</b>
<b>DOE</b>	<b>Maine Department of Education</b> The lead state agency addressing educational needs.
<b>Epidemic</b>	The rapid spread or sudden existence of something, such as a disease.
<b>EPI</b>	<b>Epidemiology</b> The study of the causes, spread, control and prevention of disease in humans.
<b>EPI Profile</b>	<b>Epidemiologic Profile</b> The State of Maine Epidemiologic Profile is produced for the CPG by the Bureau of Health HIV/AIDS Epidemiologist. It describes how HIV/AIDS affects people living in Maine including which populations, age groups and ethnic groups are affected by HIV in a defined area.
<b>Ethnicity</b>	A group of people who share a common characteristic such as the same place of origin, language, race, behaviors, or beliefs.
<b>Evidence Based</b>	In prevention planning, this means using interventions that have been tested and proven to work.
<b>Fiscal Year</b>	A twelve-month period set up for accounting purposes. For example, the federal government's fiscal year runs October 1 to September 30 of the following year.
<b>Focus Group</b>	A special type of group in which people who have certain characteristics provide information about a topic of interest. This qualitative data is collected during a focused discussion led by a skilled facilitator in a non-threatening environment.
<b>FPC</b>	<b>Frannie Peabody Center</b> An AIDS service organization located in Portland.
<b>FVHR</b>	<b>Female at Very High Risk</b> Heterosexual females who have unsafe sex
<b>GLBTI</b>	<b>Gays, Lesbians, Bi-sexual, Transgender, Intersex</b>
<b>GLI</b>	<b>Group Level Intervention(s)</b> A type of intervention providing health education and/or risk reduction counseling to more than one person at a time. GLI must include learning new skills to reduce the risk of HIV transmission.
<b>Grantee</b>	The organization receiving funds from an outside source.

<b>Guidance</b>	A CDC document that defines the process of HIV prevention community planning, and gives additional information and rules about applying for HIV prevention funds.
<b>HAART</b>	<b>Highly Active Antiretroviral Therapy</b> Defined as treatment with at least three active anti-retroviral medications (ARV's).
<b>HC/PI</b>	<b>Health Communication/ Public Information</b> Prevention messages to support risk reduction that do not include learning a new skill. They can include hot lines, presentations and media campaigns.
<b>HE/RR</b>	<b>Health Education and Risk Reduction</b> Interventions and efforts to reach people at increased risk of becoming HIV-infected or, if already infected, of transmitting the virus to others in order to reduce the spread of the virus. These can include individual, group or community level interventions.
<b>HETL</b>	<b>Health and Environmental Testing Lab</b>
<b>High-Risk Behavior</b>	A behavior in a high prevalence setting that places an individual at risk for HIV or STDs or in any setting in which either partner is infected.
<b>HIV</b>	<b>Human Immunodeficiency Virus</b> The virus that damages the immune system and causes AIDS.
<b>HIV/AC</b>	<b>Maine HIV/AIDS Advisory Committee (Advisory Committee)</b> A group formed by the legislature that makes recommendations to all departments and agencies of the State on the subject of HIV/AIDS.
<b>HIV-Related Mortality Data</b>	Statistics that represent the number deaths caused by HIV infection.
<b>HIV Seroprevalence Data</b>	Statistics that measure the amount of HIV infection among selected populations.
<b>Horizon Program</b>	An AIDS service organization located in Gardiner.
<b>HRSA</b>	<b>Health Resources and Services Administration HIV/AIDS Bureau.</b>
<b>IDU/IVDU</b>	<b>Injection Drug User/Intravenous Drug User</b> A term used to refer to people who inject drugs directly into their bloodstream by using a needle and syringe.
<b>ILI</b>	<b>Individual-level Interventions</b> A type of intervention providing health education and/or risk reduction counseling to one person at a time. ILI's include skill building activities.

**Incidence** The number of new cases of a disease that occur within a certain time period. It is important to understand the difference between HIV incidence, which refers to new cases, and new HIV diagnosis, which does not reflect when a person was infected.

**Inclusion** According to the CDC, inclusion means involving the views, perspectives, and needs of all communities affected by HIV in a meaningful way in the HIV prevention community planning process.

**Intervention** An activity designed to help people change or avoid behavior that may result in HIV infection.

**Jurisdiction** The CPG's geographic or service area. CDC funds 65 jurisdictions, which include: all 50 states; the District of Columbia; 6 directly funded cities; Puerto Rico, U.S. Virgin Islands and 6 affiliated Pacific Island jurisdictions.

**KABB** **Knowledge, Attitudes, Behavior and Belief Surveys**  
KABB is people's knowledge, attitudes, behaviors and beliefs about HIV/AIDS. A common way we get this information is through surveys that ask people what they know, think and do about HIV/AIDS.

**Key Informant Interview** A method of collecting information by asking questions and recording the answers of individuals with specialized knowledge about the topic of interest, either because of their position in the community or organization, or because of their personal experience/expertise.

**Letter of Concurrence/Non-Concurrence** See Concurrence

**MCAP** **Maine Community Aids Partnership**  
This organization raises money here in Maine for local programs and services. The Maine funds are distributed to local organizations that provide education, prevention, services, or care to people living with, at risk for, or otherwise affected by AIDS in Maine.

**MEAETC** **Maine Aids Education and Training Center**  
This program is administered by Health Resources and Services Administration (HRSA) HIV/AIDS bureau. The goal of the program is to provide education and clinical training opportunities for health care providers addressing effective counseling, diagnosis, treatment, care management of individuals living with HIV/AIDS, as well as to assist in prevention efforts.

**MIYHS** **Maine Integrated Youth Health Survey**

Questions about risk and protective factors and sexual health, alcohol and other drug use, nutrition and physical inactivity, violence risk behaviors.

**MPHA**      **Maine Public Health Association**  
This program seeks to create an environment which sustains and improves the health and well-being of Maine residents. It serves to promote and protect the public's health through service, education, & advocacy. In 2010, the Maine Public Health Association merged with the Health Policy Partners of Maine, adding to MPHA's growing strength in the public policy realm.

**MSM**      **Men who have sex with men**  
Men who have sexual contact with other men whether or not they identify as "gay."

**NASTAD**      **National Alliance of State and Territorial AIDS Directors**  
NASTAD represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS healthcare, prevention, education, and supportive service programs funded by state and federal governments.

**Needs Assessment**      The process of obtaining and analyzing community needs. Needs assessments may use several methods of information and data collection to determine the type and extent of unmet needs in a particular population or community. For example, a needs assessment may use personal interviews or questionnaires with a diverse group of community members in order to determine what they know about protecting themselves from HIV infection.

**NGO**      **Nongovernmental Organization**  
A private agency that is not associated with federal, state, or local government. Nongovernmental organizations may provide programs or services that are similar to those offered by governmental agencies.

**NHAS**      **National HIV AIDS Strategy**

**OAS**      **Office of Advocacy Services**  
Provide services to individuals with mental retardation or autism.

**OCFS**      **Office of Child & Family Services**  
OCFS serves Maine's children and their families through the Divisions of Child Welfare, Children's Behavioral Health, Early Childhood, and Public Service Management.

**OES**      **Office of Elder Services**  
Promotes programs and services for older adults, their families and for people with disabilities.

<b>OIAS</b>	<p><b>Office of Integrated Access and Support</b></p> <p>OIAS is responsible for determining consumers' financial eligibility for MaineCare (Medicaid). OIAS also administers programs that are designed to give temporary support to Mainers in financial need. The Division of Support Enforcement and Recovery, in the Office of Integrated Access and Support, assists in collecting child support payments by non-custodial parents. The people served are Individuals, adults, children, and families.</p>
<b>OISQI</b>	<p><b>Office of Integrated Services and Quality Improvement</b></p> <p>Collects and reports information gathered around specific indicators of quality and overall satisfaction with services and supports</p>
<b>OMS</b>	<p><b>Offices of Maine Care Services</b></p> <p>OMS administers the Department's major health care financing programs and health care benefits.</p>
<b>OSAS</b>	<p><b>Office of Substance Abuse Services</b></p> <p>OSAS is the single state administrative authority responsible for the planning, development, implementation, regulation, and evaluation of substance abuse services</p>
<b>Outcome Evaluation</b>	<p>A type of evaluation that seeks to measure the effect of a program or intervention and answers questions about the results of the program such as the change that was achieved.</p>
<b>Outreach</b>	<p>HIV/AIDS interventions conducted face-to-face with high-risk individuals out in the community.</p>
<b>PCHC</b>	<p><b>Penobscot Community Health Center</b></p> <p>An AIDS service organization located in Bangor.</p>
<b>PEPFAR</b>	<p><b>The U.S. President's Emergency Plan for AIDS Relief</b></p> <p>PEPFAR is the U.S. Government initiative to help save the lives of those suffering from HIV/AIDS around the world. PEPFAR investments also help alleviate suffering from other diseases across the global health spectrum.</p>
<b>Pandemic</b>	<p>Disease that occurs throughout a country or globally, over a long period of time, as with HIV and AIDS.</p>
<b>Parity</b>	<p>According to the CDC, parity is a situation in which all members of the community planning group are provided opportunities for orientation and skills building in order to participate in the planning process and to have an equal voice in voting and other decision-making activities.</p>
<b>PCCM</b>	<p><b>Primary Care Case Management</b></p>

Programs that typically involve linking beneficiaries to primary care providers.

**PEMS**

**Program Evaluation and Monitoring System**

An internet based reporting and evaluation system developed by the CDC and required for those receiving federal HIV prevention funding.

**PIR**

**Parity, Inclusion and Representation**

According to the CDC, PIR is a term used in HIV prevention community planning that requires that members have equal voice in the process, that differences are valued, and that membership is representative of all populations affected by HIV.

**PLWH/A**

**People Living with HIV Aids**

A person living with HIV or AIDS. This is the preferred terminology, rather than AIDS patient or AIDS victim.

**Prevalence**

The number of persons living with a disease or condition during a given time period. Prevalence does not give an indication of how long a person has had a disease.

**Prevention Program** A group of interventions designed to reduce a disease among individuals whose behavior, environment or genetic history places them at high risk for exposure.

**Prevention Services** Interventions, strategies, and programs designed to help people stop behaviors that may lead to their becoming infected with HIV; may include condom education, counseling that reduces the number of sex partners, HIV antibody testing/counseling, or needle exchange programs and drug abuse counseling.

**Primary Prevention** Reducing risk factors for HIV to prevent disease transmission.

**Priority Population** A population identified through the Epi Profile and Community Services Assessment that requires prevention efforts due to high rates of HIV infection and the presence of behavior that puts them at risk for infection.

**Process Evaluation** A type of evaluation that seeks to answer questions about a program such what services were delivered and how many people received the service.

**Process Objectives** Specific activities involved in the implementation of a program in order to produce the desired results.

**PS**

**Partner Services**

A trained professional provides a voluntary and confidential approach to notifying sex and needle-sharing partners of HIV infected persons of their possible exposure to HIV and offers them testing and referral services.

**PSE            Public Sex Environment**

Public places where people meet and have sexual encounters such as parks, rest areas, adult book and video stores, adult movie theaters, bars, truck stops, etc.

**PWA/PLWA    Person with AIDS/Person Living with AIDS**

A person living with HIV or AIDS. This is the preferred terminology, rather than AIDS patient or AIDS victim.

**Qualitative Data** Information that cannot easily be counted and is presented in the form of words, observations and descriptions.

**Quantitative Data** Information that can be counted and is presented in the form of numbers, rates and percentages.

**Rates** Show the percentage or proportion of people either living with a disease (prevalence rate) or the number of new cases (incidence rate) in a defined population, during a specific time period. This proportion is obtained by dividing the incidence or prevalence of disease in the population by the total population. Rates are usually expressed per 100,000 persons. Rates provide a measure of the impact of disease relative to the size of the population.

**Representation** According to the CDC representation is the assurance that those who are representing a specific population truly reflect that community's perspectives including their values, norms, and behaviors.

**RFP            Request for Proposals**

A funding agency or organization's request seeking grant proposal submissions from service providers for the delivery of certain types of services. Bids that are accepted would then receive funding to provide the services outlined in their submitted proposal.

**RMCL/Healthways    Regional Medical Center of Lubec/HealthWays**

RMCL is one of Maine's largest rural community health centers and covers five Northern Counties of Maine: Aroostook, Hancock, Penobscot, Piscataquis and Washington.

**Ryan White    Ryan White Comprehensive AIDS Resources Emergency (CARE) Act**

An Act passed by Congress in 1990 that provided the first federal funding levels for HIV/AIDS care.

**Secondary Prevention** Prevention programs that serve the needs of people infected with HIV, informing them about how they can protect their health and prevent the further spread of the virus.

**Sero-Incidence** A statistical term that refers to the number or rate of new HIV diagnoses in a particular period of time (one year, five years, etc.).

**Seroprevalence** A statistical term referring to the number or percentage of people living with HIV in a defined population.

**Stake Holders** Those individuals/groups that have a major interest and involvement in a process or procedure.

**STD**           **Sexually Transmitted Disease**  
A disease that is spread through sexual contact, such as HIV, herpes, syphilis, gonorrhea, etc. Sometimes referred to as STI or sexually transmitted infection.

**Surveillance Data** Data about communicable diseases, including HIV and AIDS, which are collected by public health officials. These data are collected from testing sites, hospitals and health care facilities and are used to monitor communicable diseases in populations and describe how they affect public health.

**TCM**           **Targeted Case Management**  
Targeted Case Management is a community based service focused on a specific population. Case Managers conduct intake, coordinate comprehensive assessments of the strengths and needs, produce an individualized support plan (ISP) to address those needs, coordinate, advocate for and develop services identified in the plan, monitor progress, and evaluate the appropriateness and effectiveness of services.

**TA**           **Technical Assistance**  
Training and skills development, which allows people and groups to do their jobs better, including education and knowledge development in areas that range from leadership and communications, to creating an effective needs assessment tool and understanding statistical data.

\* Note: There are many different definitions of these terms. These are the ones that the Maine CPG uses.