

Priority 3: Injection Drug Users / Needle Sharers

Behavioral Population Description

The National Center for Disease Control estimates that over one million people are living with HIV in the United States. In Maine approximately 1,200 people are known to be living with an HIV/AIDS diagnosis. In addition, the Maine CDC estimates that as many as 500 people in Maine may be infected with HIV, but are unaware of their HIV status (ME CDC, 2007). Of those people living with diagnosed HIV in Maine¹ it is estimated that 83% 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 Maine² and should continue to be the main focus of prevention activities. IDU³ (Injection Drug Users) and FVHR (Females at Very High Risk) follow respectively and remain a priority for prevention activities in Maine. Of the 1,200 people already diagnosed and living with HIV/AIDS in Maine in 2007, 558 have been served by one of the Ryan White Part B case management agencies, and 527 people have been enrolled in the AIDS Drug Assistance Program (ADAP).

HIV 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.⁴ There is no typical Injection Drug User. People who use needles to inject drugs are found across all socioeconomic groups, racial or ethnic back grounds, gender identities, sexual orientations, and geographical locations. That being said we must be aware that certain populations, representing curtain demographic characteristics that identify as IDU are disproportionately effected by HIV. Nationally approximately 53% of new infections

¹ Robert Funa. State of Maine:2008 HIV/AIDS Epidemiologic Profile; pp17.

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

³ 13 % of total diagnosis in Maine.

⁴ See needs assessment group discussion quotes.

among IDU are among the Black (Non-Hispanic) Population, 23 % Hispanics and approximately 22 % among White/Caucasians.⁵ 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) of new HIV diagnoses were identified as IDU.⁶ All of these 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 with in 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. 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. These risk factors include:

- behavior
- addiction,
- individual attitudes
- beliefs and feelings
- individual mental and emotional health status
- HIV status
- social and cultural norms

⁵ <http://www.cdc.gov/hiv/idu/resources/slides/slides/idu.ppt#356,7,Slide 7>

⁶ Robert Funa. Maine HIV Incidence, January1 to December 31st 2008

- both from within the IDU population and from the society as a whole
- A variety of institutions and systems.

Some of these 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 being proactive in seeking the status of themselves and partners

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.

Impacts of Addiction and Substance Abuse for the IDU

The stigma and discrimination faced by the IDU community directly 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"⁷. 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 cottons (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.

⁷ 2008 IDU Needs Assessment: Group Conversations

Respondents were represented almost equally from Southern, Central, and Northern Maine.⁸

About 1/4th 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.⁹

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 ones status may not be a motivating factor for behavior change. Many IDU report 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,

⁸ See the 2008 IDU Needs Assessment

⁹ 2008 Annual HIV/AIDS Surveillance Report; Robert Funa pp12.

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 marginalized, perceived and /or actual. Stigma is a constant shadowing factor for the IDU population, especially in a rural state such as Maine.

- 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 as 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.¹⁰ 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. Of those not utilizing services, 38% indicated they 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 a 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

¹⁰ all used at a rate of more than 20%

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 cost 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 pharmacist who would not sell new clean needles¹¹ to individuals who they assumed to be using them to inject illegal drugs.

It is the CPG's position that when ever 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.

¹¹ Needles can be purchased legally from pharmacies at the discretion of the pharmacist.

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
- Transportation in rural areas
- Mistrust of governmental sources of information
- Perceived law enforcement and health care bias
- Substance use and abuse

The CPG continues its support of the current collaboration between HIV prevention programs and Needle Exchange Programs as well future opportunities for collaboration, in hopes it will help in the reduction of HIV transmission within the IDU population of Maine.

Key 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 of 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 IDUs 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 survey.

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 MaineCare.

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 additional 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 MaineCare 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.