

2008 CPG Needs Assessment Report

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2008 CPG/IDU Needs Assessment Report

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CPG/IDU Needs Assessment Report 2008

A. Introduction

This report summarizes the results of a year-long HIV Prevention Needs Assessment that focuses on the prevention needs of injection drug users (IDUs) in Maine. Beginning in the spring of 2008, the HIV Prevention Program and the HIV Prevention Community Planning Group (CPG) developed and implemented this investigation.

Background

Public health experts estimate that 1,200 people in Maine are living with a diagnosed HIV infection. Maine CDC estimates that another 400 are infected, but are unaware of their HIV status. The total number of Maine people with HIV is probably 1,600.

Injection drug use is a significant contributor to the spread of HIV and Hepatitis C in Maine and across the country. Since the epidemic began, injection drug use has accounted for 36% of AIDS cases in the United States. In order to create and implement effective prevention programs and other interventions, we must identify the relevant needs of the injection drug using population. Reaching members of this community presents special challenges, as IDU behavior is often secretive. Gaining trust among members of the community can be difficult.

Through 2007, IDU risk has been identified among 16% of the people in Maine who are also living with HIV/AIDS. Injection drug use is reported more frequently among women (24%) than men (15%). Between 2003 and 2007, IDUs represented an average 6% of new diagnoses, with a high of 15% in 2003.

Our inquiry was conducted between June and September, 2008. This report documents the *specific aims* of the needs assessment, describes the *methods* that were used to gain information, presents and discusses the key *findings* and makes *recommendations* for future program planning.

B. Specific Aims

The purpose of this needs assessment was to investigate attitudes and knowledge related to HIV, Hepatitis C and HIV prevention services. Further, we wanted to learn about drug use and drug using behaviors related to HIV and Hepatitis C risk. Information from the needs assessment will be used to support future program planning. The goal of these programs will be to prevent as many new infections as possible.

C. Methods of Data Collection and Analysis

The HIV Prevention Needs Assessment used three methods to address the research questions: a written survey; a key informant e-mail survey; and a facilitated discussion group. The survey data is presented in simple tables; no tests for significance were performed. Data obtained from the e-mail survey are interpreted and presented by the authors. Verbatim data

was extracted from the discussion group transcript, organized and presented in a simple format. A brief discussion of the data obtained from each method is discussed below.

1. Survey

The paper-and-pencil survey was developed by HIV Prevention Program staff and the CPG after reviewing previous Maine and other states' HIV prevention needs assessments. It was administered by either a Maine CDC staff member, a member of the CPG, or by a staff member of one of the four operating needle exchange programs. Surveys were conducted in a variety of settings including needle exchanges and treatment centers. They were distributed equally among the three regions of the state, fifty each to southern, central and northern. One hundred and fifty surveys were distributed and 147 were returned—all usable. Data were analyzed using Epi Info 2000. A \$10 incentive card was provided to respondents upon completion of the survey. (See Appendix A.)

2. Key Informant Survey

The eleven question survey was developed by HIV Prevention Program staff and the CPG after reviewing Maine and other states' HIV Prevention previous needs assessments. It was distributed using a convenience sample by e-mail to a contact person at each of the four operating needle exchange programs—DownEast AIDS Network, Eastern Maine AIDS Network, Next Step Needle Exchange (HealthReach Harm Reduction), Portland Public Health—and the four opiate treatment centers in the state—Discovery Houses in Bangor, Waterville, South Portland and Calais. Each completed the survey designed to elicit information associated with HIV/Hepatitis, injection drug use and related issues in Maine. The return rate was 62.5 percent: eight surveys were distributed and five were returned. (See Appendix B)

3. Group Discussion.

A single discussion group was held in central Maine. A staff member from HealthReach Harm Reduction and the Next Step Needle Exchange recruited twenty-four participants for this group from the needle exchange and a local substance abuse treatment center. The participants received a \$30 incentive card for taking part in the group. The discussion questions were designed to focus on access to and gaps in prevention services, as well as needle exchange programs and experiences with healthcare professionals. The group discussion lasted one-and-a-half hours and was audio taped. (See Appendix C for questions. Transcripts are available by contacting Maine CDC, HIV, STD and Viral Hepatitis Program.)

D. Survey Results

One hundred fifty paper-and-pencil surveys were distributed through needle exchange programs and methadone treatment centers. The surveys were administered in person by needle exchange program staff, a Maine CDC staff member or a member of the Community Planning Group (CPG).

One hundred forty-seven surveys were completed; all of them were usable.

Survey data are divided into seven sections:

- Sample characteristics
- HIV prevention services
- Alcohol use
- Injection drug use
- Needle use
- Beliefs about risk for HIV and hepatitis
- Sex and drugs

Sample Characteristics

Sex

The sex of respondents was evenly divided between male and female with one transgender individual.

Table 1: Sex of Respondents

	Survey Respondents	
	Frequency	Percent
Female	73	49.7%
Male	73	49.7%
Transgender	1	0.7%
Total	147	100.0%

Age

Ages ranged from under 20 to over 50 with the majority between 30 and 39.

Table 2: Age of Respondents

	Frequency	Percent
15 – 19	5	3.4%
20 - 24	32	21.8%
25 – 29	37	25.2%
30 - 39	46	31.3%
40 - 49	24	16.3%
50 - 59	3	2.0%
Total	147	100.0%

Race and Ethnicity

- The majority (85.8%) of respondents are White/Caucasian corresponding with the statewide rate of 90%.
- Two percent of respondents are African-American/Black. This is twice the state rate.

- Native Americans are 1% of Maine’s population and represent 2% of respondents.
- Twelve individuals (9%) report that they are Hispanic. This is almost twice as high as the state rate of 5%.

Table 3: Race and Ethnicity of Respondents

	Survey Respondents	
	Frequency	Percent
African-American/Black	3	2.0%
Asian	0	--
Native American/Alaskan Native	3	2.0%
Native Hawaiian/ Pacific Islander	1	0.7%
White/Caucasian	127	85.8%
Other Race	2	1.4%
Two or more races	12	8.1%
Hispanic	12	9.0%
Not Hispanic	121	91.0%

Region of Residence

Respondents are evenly distributed among the three Maine DHHS regions.

Table 4: Region of Residence

	Survey Respondents	
	Frequency	Percent
Southern Maine – DHHS Region I	46	31.9%
Central Maine – DHHS Region II	50	34.7%
Northern Maine – DHHS Region III	48	33.3%

DHHS Region I – York and Cumberland

DHHS Region II – Androscoggin, Kennebec, Knox, Lincoln, Oxford, Franklin, Somerset and Waldo

DHHS Region III – Hancock, Penobscot and Washington

HIV Prevention Services

Table 5: Have you ever used any HIV prevention services?

	Survey Respondents	
	Frequency	Percent
Yes	115	78.2%
No	32	21.8%
Total	147	100%

HIV prevention services

The most frequently used HIV prevention services are needle exchange, HIV counseling and testing and free condoms, all used at a rate of slightly more than 20%, followed by clean works kits at 14%. One on one conversation with a counselor was used the least at under 10%.

People want to be protected in their activities. They indicate that by saying they like the services because they help them learn how to be safer. They (15%) appreciate having supportive and non-judgmental people with whom to speak. An overwhelming majority (76%) indicate that they find nothing to dislike about the services they receive. Nevertheless, 16% find them difficult to access.

For those who have not availed themselves of the services, 38% don't know where to get them and 8% say they are not available in their area.

Forty-seven percent fear using needle exchange services because of the police.

Table 6: If yes, which of these services have you used?

	Frequency	Percent
Needle Exchange	75	20.7%
Safety Counts Group	12	3.3%
HIV Counseling and Testing	83	22.9%
Free Condoms/Dental Dams/Lube	77	21.3%
Accessing clean works kits	51	14.1%
One on One with HIV counselor	30	8.3%
Talking with outreach worker	34	9.4%

Table 7: What do you like about these services?

	Frequency	Percent
Learn about HIV	66	13.6%
Learn about Hepatitis	68	14.1%
Learn how to be safer	65	13.5%
Learn my HIV status	46	9.5%
Helps me to be safer	78	16.1%
Nonjudgmental and supportive people to talk to	72	14.9%
Receive referrals to other services I need	40	8.2%
Easy to access	48	10%

Table 8: What don't you like about these services?

	Frequency	Percent
Difficult to access	16	14.8%
Don't receive the information I want/need	4	3.7%
Don't feel I can talk to people offering the services	6	5.5%
Nothing. I like these services	82	76%

Table 9: If no, why haven't you accessed HIV prevention services?

	Frequency	Percent
Services not available in my area	8	19%
I don't know where to get HIV prevention services	16	38%
I don't need these services	11	26%
I'm not interested in these services	7	16.6%

Table 10: Have any of these services changed the way you think about HIV?

	Survey Respondents	
	Frequency	Percent
Yes	68	63.0%
No	40	37.0%
Total	108	100.0%

Table 11: What HIV prevention services are you interested in using?

	Frequency	Percent
Needle Exchange	105	70.9%
Safety Counts Group	25	16.9%
HIV Counseling and Testing	69	46.6%
Free Condoms/Dental Dams/Lube	72	48.6%
Assessing clean works kits	58	39.2%
One on One with HIV counselor	33	22.3%
Talking with outreach worker	45	30.4%
Other	17	11.4%

Table 12: Does a fear of police or getting arrested make you nervous to use the needle exchange program?

	Survey Respondents	
	Frequency	Percent
Yes	66	46.8%
No	75	53.2%
Total	141	100.0%

Alcohol Use

Alcohol Use

While nearly half of the respondents indicate that they drink alcohol, only 15 individuals say they drink often with the intention of getting drunk or buzzed. Occasional use is the norm, whether to get drunk or buzzed intentionally or not.

Table 13: Do you drink alcohol?

	Survey Respondents	
	Frequency	Percent
Yes	68	47.9%
No	74	52.1%
Total	142	100.0%

Table 14: How often and how much do you drink?

	Frequency	Percent
Have one or two casually on occasion	28	36%
Drink once in awhile to get buzzed	13	16.6%
Drink once in awhile to get drunk	22	28.2%
Drink often to get buzzed	6	7.7%
Drink often to get drunk	9	11.5%

Injection Drug Use

Are you currently injecting drugs?

- 60% of survey respondents indicated they were injecting at the time of the survey.
- 50% of the respondents had injected within the last 3 months.
- Almost 20% had injected less than a month ago.

Table 15: Are you currently injecting drugs?

	Survey Respondents	
	Frequency	Percent
Yes	88	60.3%
No	58	39.7%
Total	146	100.0%

Table 16: When was the last time you injected?

	Survey Respondents	
	Frequency	Percent
Less than 1 month	11	18.6%
1-3 months	19	32.2%
4-6 months	11	18.6%
7-11 months	9	15.3%
1 year or more	9	15.3%
Total	59	100.0%

What is the drug you have injected most often in the past month?

Cocaine was identified by 24% of respondents as the drug they injected most often in recent weeks, but Suboxone, an addiction treatment drug, was identified nearly as often. Heroin, morphine and OxyContin were named by approximately 10% of respondents as the drug injected most often in the past month.

Needle Use

Where have you gotten needles?

- 70% of respondents got their needles at a pharmacy.
- 80% identified that it was easy for them to get clean needles.
- 53% said there are enough places to get clean needles, but 60% of respondents indicated that the places were not open when needed.
- One obtained them from a diabetic and a former RN has a large supply.

Table 17: Where have you gotten needles?

	Survey Responses	
	Frequency	Percent
Needle Exchange	73	49.3%
Family Member	26	17.6%
Pharmacy	103	69.6%
Shooting Partner	36	24.3%
Friend	53	35.8%
Other	4	2.7%

Table 18: Is it easy for you to get clean needles?

	Survey Respondents	
	Frequency	Percent
Yes	116	80.6%
No	28	19.4%
Total	144	100.0%

Table 19: Do you think there are enough places near you to get clean needles?

	Survey Respondents	
	Frequency	Percent
Yes	77	53.1%
No	68	46.9%
Total	145	100.0%

Table 20: Are these places open at times when you need them to be?

	Survey Respondents	
	Frequency	Percent
Yes	53	39.6%
No	81	60.4%
Total	134	100.0%

Have you ever shared needles?

- 68% of respondents indicated they had shared needles
- 50% had shared with a sex partner
- Eleven said they had shared with their dealer (2) and/or family member (9).
- 24% indicated they share once or twice a month, while 55% indicated they share rarely

Table 21: Have you ever shared needles?

	Survey Respondents	
	Frequency	Percent
Yes	99	67.8%
No	47	32.2%
Total	146	100.0%

Table 22: If yes, who have you shared with?

	Survey Respondents	
	Frequency	Percent
Sex Partner	71	49.6%
Stranger	10	6.9%
Friend	62	43.4%
Total	143	100.0%

Table 23: How often do you share?

	Survey Respondents	
	Frequency	Percent
Always- every time I shoot up	4	4.4%
Often- more that once a week	8	8.9%
Sometimes- once a week	7	7.8%
Occasionally- once or twice a month	22	24.4%
Rarely- only once or twice every six months	49	54.5%
Total	90	100.0%

Health status of needle-sharing partner

Of those who say that they share needles with others, almost 30% say they do not know whether they are sharing with someone who has HIV or Hepatitis.

Table 24: Do you know the status of your needle-sharing partners?

	Survey Respondents	
	Frequency	Percent
All of them	55	56.1%
Some of them	23	23.5%
None of them	20	20.4%
Total	98	100%

Sharing injection drug works

The rate of sharing works is 63%, sharing needles, 68%. Only 56% of those sharing needles believe they know the “status” of those with whom they share.

Table 25: Have you ever shared your works –spoons, cottons, tie-offs, cookers, etc.?

	Survey Respondents	
	Frequency	Percent
Yes	89	62.7%
No	53	37.3%
Total	142	100.0%

Table 26: If yes, who did you share with?

	Survey Respondents	
	Frequency	Percent
Sex Partner	66	49%
Stranger	13	9.7%
Friend	62	46%
Total	141	104.7

Respondents may choose more than one option.

Table 27: How often do you share?

	Survey Respondents	
	Frequency	Percent
Always- every time I shoot up	8	9.3%
Often- more that once a week	13	15.1%
Sometimes- once a week	11	12.8%
Occasionally- once or twice a month	21	24.4%
Rarely- only once or twice every six months	33	38.4%
Total	86	100.0%

Do you inject yourself?

The vast majority, over 90%, of those injecting drugs, inject themselves.

Table 28: Do you inject yourself?

	Survey Respondents	
	Frequency	Percent
Yes	132	90.4%
No	14	9.6%
Total	146	100.0%

Bleach kits

About 58% of respondents have never used bleach kits to disinfect their needles. Of the 42% of those who have, 32% obtained them from a needle exchange, 22% from a friend and 36% answered “other.”

Table 29: Have you ever used bleach kits?

	Survey Respondents	
	Frequency	Percent
Yes	61	41.8%
No	85	58.2%
Total	146	100.0%

Table 30: If yes, where did you get them?

	Survey Responses	
	Frequency	Percent
Needle Exchange	23	32%
Shooting partner	6	8.4%
Friend	16	22.5%
Other	26	36.6%

Purchasing clean needles.

Over 30% of respondents report having a difficult time buying needles at pharmacies. Represented in this category are ten of Maine's sixteen counties: Cumberland, Franklin, Hancock, Kennebec, Knox, Lincoln, Penobscot, Somerset, Waldo and Washington. Around 9% have never tried to buy them.

Table 31: Have you had a hard time at pharmacies when trying to purchase clean needles?

	Survey Respondents	
	Frequency	Percent
I have never tried to buy needles	13	9.2%
Yes	48	33.8%
No	81	57.0%
Total	142	100.0%

Beliefs about risk for HIV & Hepatitis**Are you concerned about getting HIV?**

- 56% are concerned about getting HIV, but only 47% think they are at *risk* for HIV.
- 35% believe they are at risk for Hepatitis C and are concerned about it.
- Over half of the respondents are concerned about getting HIV, but only a little over a third are concerned about getting Hepatitis C.
- 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.
- 63% have ever been vaccinated for Hepatitis B.
- Of the 63 respondents who are *not* concerned about getting HIV, 64% have used needle exchange services.
- 59% of respondents who are *not* concerned about getting HIV *and* have shared needles have used needle exchange services.

- Of those respondents who *are* concerned about getting HIV *and* have shared needles, 79% have used needle exchange services.
- Of the clients who don't consider themselves to be at risk for HIV:
 - 55% reported sharing needles.
 - 50 % reported sharing works.
 - 55% reported using condoms rarely (15%) or never (40%).

Table 32: Are you concerned about getting HIV?

	Survey Respondents	
	Frequency	Percent
Yes	79	55.6%
No	63	44.4%
Total	142	100.0%

Table 33: Do you think you are at risk for HIV?

	Survey Respondents	
	Frequency	Percent
Yes	67	46.5%
No	77	53.5%
Total	144	100.0%

Table 34: Have you ever had an HIV test?

	Survey Respondents	
	Frequency	Percent
Yes	128	88.3%
No	17	11.7%
Total	145	100.0%

Table 35: Have you ever been vaccinated against Hepatitis B?

	Survey Respondents	
	Frequency	Percent
Yes	87	63.0%
No	51	37.0%
Total	138	100.0%

Are you concerned about getting Hepatitis C?

- Rates are similar among those who *are* and *are not* concerned about getting Hepatitis C; 70% and 75% respectively have used needle exchange services.
- Further, 27 respondents are *not* concerned about getting Hepatitis C *and* have shared needles. 74% of this group has utilized needle exchange services. Similarly, of those

who are concerned with getting HCV *and* have shared needles, 75% have utilized needle exchange services.

- Of those respondents who have ever tested for Hepatitis C, 43 respondents, or 37%, tested positive for Hepatitis C.

Table 36: Are you concerned about getting Hepatitis C?

	Survey Respondents	
	Frequency	Percent
Yes	46	35.1%
No	85	64.9%
Total	131	100.0%

Table 37: Do you think you are at risk for Hepatitis C?

	Survey Respondents	
	Frequency	Percent
Yes	46	35.9%
No	82	64.1%
Total	146	100.0%

Table 38: Have you ever been tested for Hepatitis C?

	Survey Respondents	
	Frequency	Percent
Yes	113	79.6%
No	29	20.4%
Total	142	100.0%

Medical concerns

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

Table 39: Have you ever gotten sick or hurt from injecting?

	Survey Respondents	
	Frequency	Percent
Yes	83	57.6%
No	61	42.4%
Total	144	100.0%

Table 40: Do you have a regular doctor?

	Survey Respondents	
	Frequency	Percent
Yes	101	69.7%
No	44	30.3%
Total	145	100.0%

Table 41: If yes, does your doctor know that you inject drugs?

	Survey Respondents	
	Frequency	Percent
Yes	43	47.3%
No	48	52.7%
Total	91	100.0%

Sex & Drugs

STDs

- Almost one fifth (18.4%) report having had an STD in the past year.
- Of those 26, 42% had chlamydia. Since 38 instances of STD were reported, clearly some had more than one STD.
- Over 23% always or usually use a condom.
- Over one third (34.8%) said that they *never* used a condom in the past year.

Table 42: Have you had any STDs in the past year?

	Survey Respondents	
	Frequency	Percent
Yes	26	18.4%
No	115	81.6%
Total	141	100.0%

Table 43: If yes which ones?

	Frequency	Percent
Chlamydia	16	42%
Gonorrhea	5	13%
Syphilis	3	7.9%
Herpes	6	15.8%
HPV/Genital Warts	8	21%

Table 44: How often have you used condoms when having sex in the past year?

	Survey Respondents	
	Frequency	Percent
Always- every time	20	14.2%
Often- most of the time	17	12.1%
Sometimes- about half of the time	18	12.8%
Occasionally- less than half of the time	13	9.2%
Rarely- hardly ever	21	14.9%
Never	49	34.8%
N/A- I haven't had sex in the last year	3	2.1%
Total	141	100.0%

Sex and drug use

- Approximately one third (31%) of respondents have traded sex for drugs or money.
- 44% of respondents combine sexual activity and drug use at least half the time.
- 29% always or most of the time combine sex and drugs.

Table 45: Have you ever traded sex for drugs or money?

	Survey Respondents	
	Frequency	Percent
Yes	45	31.0%
No	100	69.0%
Total	145	100.0%

Table 46: How often have you combined drug use and sexual activity in the past year?

	Survey Respondents	
	Frequency	Percent
Always- every time	18	12.7%
Often- most of the time	23	16.2%
Sometimes- about half of the time	22	15.5%
Occasionally- less than half of the time	26	18.3%
Rarely- hardly ever	23	16.2%
Never	28	19.7%
N/A- I haven't had sex in the last year	2	1.4%
Total	142	100.0%

E. KEY INFORMANT SURVEY RESULTS

The following selected quotations represent answers to the survey questions and include other relevant information.

Important questions associated with the **drug treatment needs** of IDUs include:

What are the greatest obstacles for injection drug users to get clean?

What can be done to eliminate these obstacles?

What are some needs of the IDU population?

Key informants said:

- ...finances: insurance doesn't usually cover the cost, MaineCare is making sweeping cuts of who is eligible for coverage, fuel costs are skyrocketing...
- ...stigma: negative attitudes toward medication assisted treatment coming from the criminal justice system, families and employers...
- ...lack of treatment availability: Maine is rural and people have to travel long distances to get to clinics...
- Stigma is the biggest!
- Lack of access to detox and substance abuse services. Long wait lists for methadone and suboxone, and a shortage of providers. MaineCare is providing only thirty weeks of SA treatment.
- Being in the correctional system (is an obstacle).
- We feel that recovery could be improved with increased access to affordable treatment that includes inpatient detox and rehab centers.
- Education is the key—educating health care professionals is a MUST!!!! Doctors, nurses, ER staff especially!
- Public transportation would be a wonderful help...
- Access to clean needles.
- Many of their needs though are the same as those of everyone else—food, clothing, shelter, increased access to medical care, crisis, and mental health services as well as Hepatitis, HIV and STI testing.

Three questions that asked about **HIV/Hepatitis prevention concerns** are:

Is HIV/Hepatitis risk and prevention a priority for IDUs?

What are some barriers that your organization has experienced when trying to provide HIV prevention services to IDUs?

What are some successes your organization has experienced when providing HIV prevention services to IDUs?

Key informants said:

- Many clients feel as though Hep C is a lost cause for them to try and prevent...

- As treatment providers, we think it's a priority, and we believe that IV users would believe the same thing, but the reality of daily life of addiction interferes with practicing safety around these issues.
- Clients often take advantage of testing offered through the clinic and do see these issues as important.
- ...we feel that we could better serve our needle exchange clients if we had a better grasp of how everything works. We want to know how the drugs are being used, how all the equipment is used, some safer methods of using drugs, how to prevent and care for a "blow out."
- We have seen an increase in client numbers. We have been successful in getting some of the exchangers to come in for HIV and Hepatitis testing...One of our more recent successes is the creation of a collaborative partnership with the Bangor STD Clinic and the Bangor Dept. of Public Health to provide free Hepatitis testing and vaccines at the EMAN offices once a month.
- When folks first come to the exchange, I like to test them right away for HIV...Getting folks into treatment when they are ready—this happens occasionally, but would happen more often if there were enough treatment programs available.
- Educational groups (and testing) at Cumberland County Jail, presence at the Preble Street Resource Center.

F. GROUP DISCUSSION RESULTS

Sample information:

The discussion group was composed of thirteen men and eleven women from Next Step Needle Exchange and Discovery House in Waterville. Their ages were in the 18-28 range, with one man and one woman in their 30's. All had used IV drugs in the last six months. Ten were in treatment; half of those were still occasionally using. All but two were non-Hispanic, with those two being Caucasian and Native American.

What Group Participants Said:

It is possible to show the group discussion findings in several ways. The data can be grouped according to **1.** research questions, **2.** group leader questions, **3.** common areas of concern expressed by attendees.

To make the results as clear and useful as possible, it was decided to arrange the discussion results section by using the **research questions** shown below. Before starting the investigation, the partners involved in this inquiry decided they wanted information on several issues. These issues led to a consideration of the following five questions:

Research Questions:

In regard to Injection Drug Users in Maine:

1. What factors are associated with access to HIV/Hepatitis C and IDU prevention and treatment services?
2. What gaps exist in the service delivery system?
3. How can program managers and organizations that serve the IDU community advertise services?
4. What do IDUs think about needle exchange programs?
5. What has been the experience of IDUs with health care providers and other professionals in regard to addiction?

1.) What factors are associated with access to HIV/Hepatitis C and IDU prevention and treatment services?

Group participants identify the following factors:

- Transportation: distance, lack of money, lack of driver's license
- Stigma perceived everywhere: AA, NA, health care providers, pharmacists.
- Lack of health insurance.
- MaineCare bureaucratic delays and confusions.
- Fear of treatment.
- Lack of "readiness."
- Detox programs too short.
- Long waiting periods—months—for treatment programs.
- Lack of knowledge on the part of health care providers of addiction issues, including pain management.
- Fear of losing children.
- Drug court seen as a good alternative by some.
- Needle exchange services helpful.
- Methadone and Seboxyn programs highly valued.

In their own words:

- ❖ ...it's hard to tell a job employer, oh, I can't come to work tomorrow because I got to go take a three hour drive to a methadone clinic...
- ❖ And I also don't have a driver's license, either.
- ❖ And if you're on methadone and you mention it in an AA, forget it...
- ❖ But when I had my daughter I was using, and they were horrible to me...I was looked down upon by all of them, the doctors, the nurses...

- ❖ I've never had any problems getting them (needles).
- ❖ And if you're in excruciating pain, they will leave you in excruciating pain and they won't give you enough medication.
- ❖ I was going through withdrawals for like, for eight months, you know, before I got in the methadone clinic.
- ❖ Lie, lie, lie. That's how I got in...I said I was living around kids...and that jumped me up the list and I got in in four months.
- ❖ Going to detox the first time I think was the scariest thing I've ever done.
- ❖ I wasn't even ready to leave and they, I was there for three days, you know, and they sent me home and I'm like, you know, what does that do?
- ❖ I was always scared to go and check into a detox, that they would try and take my kid. So I never went.
- ❖ That's why I choose to go to drug court, because the judge will be on my side (after completing program).
- ❖ I don't have any medical coverage at all, and I've been trying to get in and I'm on a waiting list now to get it.
- ❖ With MaineCare I've been on the waiting list since March (interview 9-25-08.)

2.) What gaps exist in the treatment and prevention service delivery system?

Group participants identify the following gaps:

- Lack of public sharps disposal opportunities.
- Scanty advertising of needle exchange services.
- Regional variation in pharmacies selling needles.
- Lack of treatment facilities in parts of the State.
- Lack of methadone maintenance programs in parts of the State.
- Lack of informed health care providers and pharmacists.
- Lack of needle exchange availability.

In their own words:

- ❖ They should have pit stops like they do in New York where you can discard biohazard type things.

- ❖ You know what would be nice, if there was a list of doctors...family doctors that know how to deal with people that are on methadone.
- ❖ ...you get up at five, four-thirty in the morning and then you drive and then get back...
- ❖ Well, they think that somehow they're stopping you from using drugs if they won't give you needles.
- ❖ ...before, as long as you had proper identification and you said they were for your own use, they couldn't refuse the sale of the syringes. But then they changed it so it's at the store's own discretion.
- ❖ I didn't know Maine had a needle exchange program until I ran into you at...a friend's house.

3.) How can program managers/ME-CDC advertise prevention and treatment services and distribute prevention information publically?

Group participants suggest providing information in the following locations:

- Methadone clinics.
- Detox programs.
- Youth groups.
- Public schools.
- Probation officers.
- Pharmacies.
- Grocery stores.
- Bars and clubs.
- Emergency rooms.
- Public bathrooms.
- Churches.
- Jails and prisons.
- Laundromats.
- Public libraries.

4.) What do IDUs think about needle exchange programs?

Group participants have the following suggestions and opinions:

- More programs around the State.
- Mobil units providing services to remote areas or areas currently without services.

In their own words:

- ❖ The needle exchange is actually a benefit to the cause, because they are people too, you know.
- ❖ In Lynn, Massachusetts, in the Commons, they (unintelligible) to the needle exchange, they have a van that comes by.

5.) What has been your experience with health care providers and other professionals in regard to your addiction?**Group participants describe the following issues:**

- Lack of understanding of pain management in an addicted or previously addicted person.
- Disparaging behavior and attitudes toward patients/customers *whether in or out of* treatment.
- Refusal to provide non-addiction related medical services to addicted people.
- Appreciation of health professionals able to provide high quality, compassionate care.
- Training for health care professionals at all levels, including pharmacists, and ancillary personnel.

In their own words:

- ❖ Thirty-five frickin' doctors in a phone book. Not one of them would take me because I was six months pregnant, and I was using.
- ❖ I told her I had to take two or three because of the pain...she said I was abusing them and cut me down to a weekly supply. I'm having a hard time just to get up. I eat my scrip before it's time because of the pain...
- ❖ I mean if you're already being put down, then why not do what they're putting you down for?
- ❖ They're entitled to their own opinion, but it shouldn't affect your care.
- ❖ I went to get some blood drawn at Inland Hospital and one of the phlebotomists said, how beat up my arms looked. She was nice until I took my shirt off and she could see my arms.
- ❖ There was no drugs in my daughter's system, but they had tested my placenta and every drug I'd done since (unintelligible) was there, so I was looked down upon by all of them, the doctors, nurses.

- ❖ There's a doctor in FMI that just started prescribing Seboxyn and she's great and you can tell her the truth.
- ❖ My doctor says she loves me and I love her, she's been heaven sent, you know? She's really happy I'm going to the methadone clinic.

G. DISCUSSION OF FINDINGS

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 IDUs 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.

H. RECOMMENDATIONS

Key Informant:

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.

I. STRENGTHS AND WEAKNESSES

The research methods used in this Needs Assessment are both quantitative (survey) and qualitative (group interviews). The most commonly used methods of qualitative research are individual interviews, group interviews, direct observation and written records. In this study, we used a facilitated discussion group. To gather quantitative data, we used a written survey and a key informant e-mail survey.

Qualitative research has a major strength and a major weakness.

Strength:

Qualitative methods can be used by the researcher to study issues or people in *great depth and detail*. It says a *lot* about a *few* issues and people.

Weakness:

It cannot say anything about anyone who was not studied. It cannot be generalized (applied to many other people) as quantitative research can be. It does not represent the views of anyone else.

Quantitative research has a major strength and a major weakness.

Strength:

Surveys are an affordable way to reach many people.

Weakness:

One of the biggest drawbacks to written survey, especially as it relates to the mail-in, self-administered method, is the low response rate.

Convenience sampling

Convenience sampling is used when it would otherwise be difficult or impossible to select people in a scientific way. In the case of the CPG/IDU Needs Assessment, group interview

participants were found through several sources. The only requirement was that they be injection drug users, past or present. They were selected because they were available. This means that information obtained applies only to the person giving it. Other kinds of sampling (scientific) allow investigators to apply findings from one group or person to another. Respondents chosen by all three of our data gathering methods for this project were selected by *convenience*.

Limitations of this study

The written survey used convenience sampling (as did the e-mail key informant survey and the discussion group). It was administered by a staff member of one or another of the research partners. While the personal element may have helped with access, anxiety and literacy concerns, there may have been some bias introduced by the presence of the staff member, as we believe we see in the group discussion.

While it was composed of IDUs from different parts of the state, and all three DHHS regions were equally represented, there was only one discussion group. It was very large, probably too large, with twenty-four participants. Because of previous difficulty attracting participants for other projects, it was over-recruited. Research questions were introduced, but it was difficult to pursue them at times because of the group's size.

Convenience sampling is probably the most common approach in group interviewing, but is the least desirable. Certainly convenience and cost are important, or even crucial, considerations, but strategic sampling usually produces more useful data.

Nevertheless, all three data sources produced results with distinct commonalities and the findings appear consistent across methodologies.