

ILLINOIS HIV PLANNING GROUP 2014 HIV FOCUS GROUPS REPORT (DRAFT)

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TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
BACKGROUND	4
METHODOLOGY	5
FOCUS GROUP ANALYSES	8
ROCKFORD – INJECTION DRUG USERS (IDU) FOCUS GROUP	8
CARBONDALE – AT RISK YOUTH FOCUS GROUP	16
COMPARISON OF FOCUS GROUPS	24
SUMMARY	24
APPENDICES	25
APPENDIX A. HIV PREVENTION COMMUNITY PLANNING GROUP PROTOCOL FOR FOCUS GROUPS 2012-2014	26
APPENDIX B. 2012-2014 HIV FOCUS GROUP FACILITATOR DISCUSSION GUIDE	27
APPENDIX C. HIV PREVENTION AND EDUCATION NEEDS ASSESSMENT 2012-2014	
FOCUS GROUP CONSENT FORM	30
APPENDIX D. 2012-2014 HIV FOCUS GROUP PARTICIPANT DEMOGRAPHICS SURVEY	32
APPENDIX E. COMPILED NOTES AND OBSERVATIONS	33

EXECUTIVE SUMMARY

Annually, the Illinois HIV Prevention Community Planning Group (former PCPG), now newly named and from here after referred to as the Illinois HIV Planning Group (ILHPG), has conducted various community services and needs assessment activities in an effort to identify and further explore the multitude of factors associated with HIV risk and the HIV prevention needs of high risk groups within the jurisdiction. As part of its strategic plan for 2012-2014, the ILHPG Executive Committee asked its Evaluation Committee to plan for, conduct, and evaluate a series of focus groups targeting specific risk group populations in each of the eight HIV prevention regions outside the city of Chicago. Two focus groups were conducted in 2014, one in region 1 and the other in region 5. This report summarizes the planning activities and methodology used to conduct and evaluate the focus groups, and provides an analysis of each focus group.

The ILHPG would like to thank its leadership, the members of the Evaluation Committee and the focus group subcommittee, Department HIV Section staff, regional lead agents, regional support group facilitators, focus group facilitators and participants, who all played a major role in the successful completion of this project. The ILHPG cannot stress enough the importance of community services and needs assessment activities to guide HIV planning. It is through collaborative efforts such as this that state, regional and local planners and organizations are able to develop effective HIV programs that meet the needs of the communities and population groups at highest risk for HIV infection.

BACKGROUND

At the November 2011 Executive Committee 2012 strategic planning meeting, ILHPG leadership tasked the Evaluation Committee with planning for the conduct and evaluation of four targeted community focus group discussions in 2012, with four more to be planned for 2013 and 2014. Thereafter, four focus groups were conducted in Regions 4, 8, 2, and 7 in 2012 and in Regions 3 and 6 in 2013. Reports on these focus groups, "Illinois HIV Prevention Community Planning Group 2012 Focus Groups Report" and "Illinois HIV Planning Group 2013 HIV Focus Groups Report" were subsequently developed and disseminated. These reports are available to view and download at <http://www.dph.illinois.gov/topics-services/diseases-and-conditions/hiv-aids/illinois-hiv-planning-group>. This report summarizes the results from the final two focus groups conducted in 2014 in Region 1 (Rockford – June 25, 2014) and Region 5 (Carbondale – September 17, 2014).

The purpose of the focus groups was to gather information from representatives of the populations at greatest risk for HIV throughout the jurisdiction on risk behavior practices, facilitators and inhibitors of HIV risk and risk reduction, innovative approaches to reducing HIV stigma and homophobia, concerns of HIV/AIDS within their communities, and knowledge and utilization of HIV and STD prevention and care services. The information gained from the focus groups would be used by state and regional HIV planners to help identify community service needs and develop/plan more effective HIV prevention policies and programs to address the needs of the targeted high risk populations and communities.

The targeted risk group for each focus group was determined by collaborating with the HIV care and prevention lead agents in the respective regions to identify the hardest hit risk group(s) or population at most need of further assessment in the region. The following targeted risk groups were identified for the two focus groups in 2014: Rockford, IL - injection drug use (IDU) and Carbondale, IL – at risk youth.

The same protocol, discussion guide, objectives, and procedures that had previously been developed by the subcommittee comprised of the Department's HIV Section Prevention Administrator, the Department's ILHPG Coordinator, selected members of the ILHPG Epidemiology/Needs Assessment Committee, members of the ILHPG Evaluation Committee, and two former community ILHPG members, was used to plan the focus groups. The HIV Prevention Community Planning Group Protocol for Focus Groups 2012-2014 (Appendix A) summarized the process that was followed to plan for, recruit participants, conduct, and evaluate the focus groups. The 2012-2014 HIV Focus Group Facilitator Discussion Guide (Appendix B) detailed the process to be followed to facilitate, record, and make observations of the focus group discussions. The HIV Prevention and Education Needs Assessment 2012-2014 Focus Group Consent Form (Appendix C) informed participants of the purpose of the focus groups, the potential risks and benefits of participation, the recording/use of information gained from the discussion, and requested voluntary and informed consent for participation. The 2012-2014 HIV Focus Group Participant Demographics Survey (Appendix D) tracked demographic and risk information for all participants.

An independent facilitator, educated on the protocol and discussion guide, was engaged to facilitate the 2014 focus groups. The participants were provided with HIV epidemiologic/vital statistic handout and fact sheets specific to their identified race/ethnicity and/or risk group to take home after the focus group meeting. Refreshments were served at each focus group and each non-ILHPG participant was offered a \$25.00 gift card to compensate for time and travel expenses and as thanks for their participation.

METHODOLOGY

Following the protocol developed by the ILHPG Focus Group Subcommittee, participants representing the hardest hit and high risk target populations were identified and recruited through communication efforts with regional lead agents, identified support group facilitators or representatives from HIV prevention agencies, and ILHPG members from the designated focus group regions. Expecting to recruit eight to 12 participants, the support group facilitators was instructed to recruit an average of ten to fifteen individuals representing the targeted risk group populations to participate in the focus groups.

Each focus group began with the facilitator acknowledging the purpose and structure of the focus group. The facilitator followed the protocol and discussion guide to establish the ground rules for the group and help put participants at ease with sharing their opinions and concerns. After explanation, each member was asked to sign the consent form and complete the demographic survey form.

As instructed, the focus group facilitator tried his best to follow the discussion questions, as developed; however, he was able to ask probing questions to solicit additional information and to delve deeper into participant comments brought up during the discussion. These are the introductory and open-ended discussion questions established by the focus group subcommittee:

Discussion Questions:

Question 1: **What are the three greatest challenges in your life that you are struggling with right now?** -This question was asked to identify facilitators and inhibitors of HIV risk and risk education.

Question 2: **How does HIV come up in discussions with your peers?** – This question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

Question 3: **What are the circumstances leading to a sexual encounter (or injection drug use)?** – This question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

Question 4: **How do you prepare to go out with the possibility to hook up?** – This question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

Question 5: **Now that we have talked about what is important to you, what kinds of activities might appeal to the community of your peers?** – This question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

Question 6: Based upon what we have discussed, how do we go about changing people's perceptions and behaviors in dealing with HIV? – This question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

Question 7: Can you provide us with some examples of where you experienced or have seen HIV (or injection drug use) - related stigma or homophobia in your community? – This question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

Question 8: Do you have any suggestions on things community based organizations and local health departments can implement to reduce HIV related stigma or homophobia to enhance utilization of prevention and care services? – This question was asked to assess knowledge and utilization of HIV prevention, care, and treatment services.

With the acknowledgement and permission of the focus group members, assigned note takers were present during the discussion to record participant comments and make observations. An explanation was given to the participating focus group members on how the Department and the ILHPG planned to utilize the focus group results to possibly assist in making recommendations and decisions about prioritized populations, strategies and interventions and enhancing the effectiveness of programs designed to reduce HIV transmission, increase linkage and retention in HIV care services, and reduce stigma associated with HIV.

All of the notes, observations, and information recorded were compiled by the ILHPG Coordinator and forwarded to the Department's HIV Section Evaluation Administrator for qualitative and descriptive analysis. The Compiled Notes and Observations for each of the focus groups are included as Appendix E. The discussion responses to the eight initial questions in the focus group facilitator discussion guide and all additional/modified probing questions were reviewed according to the four main focus group objectives. Responses from the transcripts were then categorized into the following four types of issues:

- Economic- financial aspects related to individual access to healthcare (transitioning cost, funding, etc.)
- Psychological- self-perception and emotional aspects as psychological state of individual (low self-esteem, substance use, internalized self-limitations, etc.)
- Social- influence of the social values and behaviors the community/group/society has on individuals (family, education, peer pressure, etc.)
- Structural- issues beyond individual's personal control in context of environmental aspects (networking, facilities with necessary services, etc.)

After categorization, frequency of the issues brought up in the focus group discussion was identified and calculated for each question. It should be noted as a limitation of the data that some of the responses might be related to multiple issues which made categorization into one primary issue difficult. For example, a response categorized as psychological might have had some social and structural connotations as well. That response would only be captured in the frequency value for psychological issues.

CONCLUSION

The following results of the 2014 focus groups were summarized and presented to the ILHPG at the December 2014 ILHPG quarterly meeting in Urbana, Illinois. The ILHPG and focus group subcommittee realize there are limitations to the use of the data and information gained from the conduct of these focus groups and acknowledge the results may not be generalizable to the risk groups/communities as a whole. The focus groups were not intended to be a formal research project. They were developed as one mechanism for the ILHPG to assist the Department's HIV Section in assessing risk group behaviors and opinions within the hardest hit communities. Input from the focus groups will hopefully be reviewed and used by state, regional and local community based organizations and health departments to guide or enhance HIV programs or to assist in planning additional needs assessment activities.

FOCUS GROUP MEETING ANALYSES

Region 1 Focus Group Meeting: Injection Drug User (IDU), June 25, 2014, Rockford, IL

Number of Participants: 7

Location of Meeting: Restoration Café

Seven individuals participated in the Region 1 focus group discussion held in Rockford. The diverse distribution of the participants' gender, age, race/ethnicity, education, and sexual orientation is provided in the tables below.

Demographic Characteristics of the Focus Group Meeting participants

Gender		Sexual orientation	
Male	4	Bisexual	2
Female	3	Heterosexual	5
		Homosexual	0

Age		Education	
18-24 Yrs	4	GED	1
25-34 Yrs	1	High school	2
45 or above	2	Some college	4

Race/ethnicity	
Black	2
Multi-racial	3
White	2

Discussion Questions, Responses, and Results

Question One:

The following question was asked to identify facilitators and inhibitors of HIV risk and risk reduction: *“What are the three greatest challenges in your life that you are struggling with right now?”*

The responses for this question centered on the following challenges:

- Drug use and addiction
- Personal and social relationships
- Finances and employment
- HIV

Selected Quotes (categorized by type of issues):

- Economic
“I use all my money on drugs then have no money to live.”

"My drug use is a barrier to my getting and keeping a job."

- Psychological

"I'm an addict. I need them to function."

"Drugs get me into trouble."

"HIV is high on my list of issues, but when I am using I let my guard down and put it in the back of my mind."

- Social

"I have friends with HIV. People have misconceptions about HIV and how it is acquired, so people judge them."

"People stay away from people with HIV, even friends who have HIV."

- Structural

"I had 5 years of sobriety. I need help but can't get it because of insurance and because of my violent past. I feel hopeless then I use. It is a constant cycle."

Results for Question 1:



Conclusions:

The greatest challenges the IDU focus group participants expressed were mainly psychological in nature (65% of all responses), followed by economic (15% of all responses), centering on drug use and addiction, personal and social relationships, finances and employment, and HIV.

Question Two:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV: *How does HIV come up in discussion with your peers?*

Selected Quotes (categorized by type of issue):

- Economic

"People still think only people like Magic Johnson can afford HIV medicines."

- Psychological

"One of my friends has HIV. We talk about her HIV and I support her. I don't judge her but I won't drink after her."

- Social

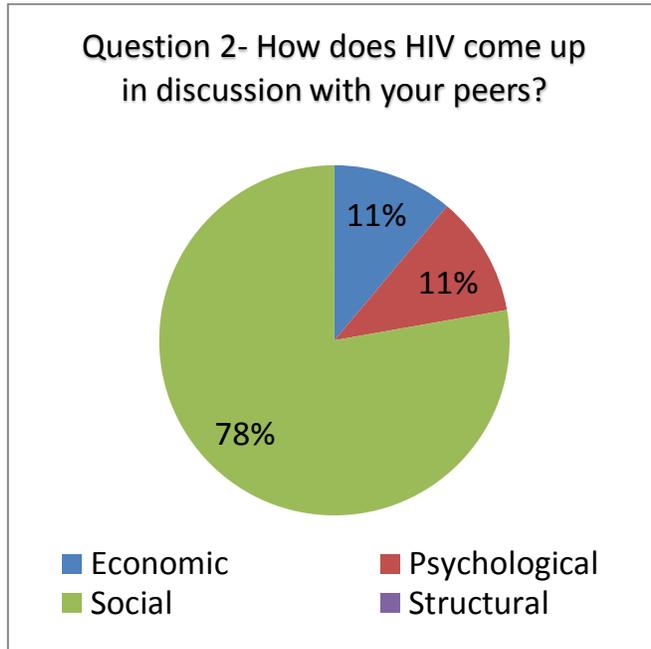
"HIV comes up when people say "Let's share a needle". I won't share someone else's needle, but if they want to share mine after I use, that's OK."

"My peers are concerned about HIV after having sex or injecting, but that doesn't stop us."

"HIV isn't talked about in the youth groups I hang with. It is a taboo subject among peers."

"I know a few people with HIV who don't tell others their status because they are afraid of how they will be treated."

Results:



Conclusions:

When discussing HIV among peers, most participants identified issues and experiences within a social context as the predominant theme in their responses (78%). Economic and psychological issues were briefly touched (11% each).

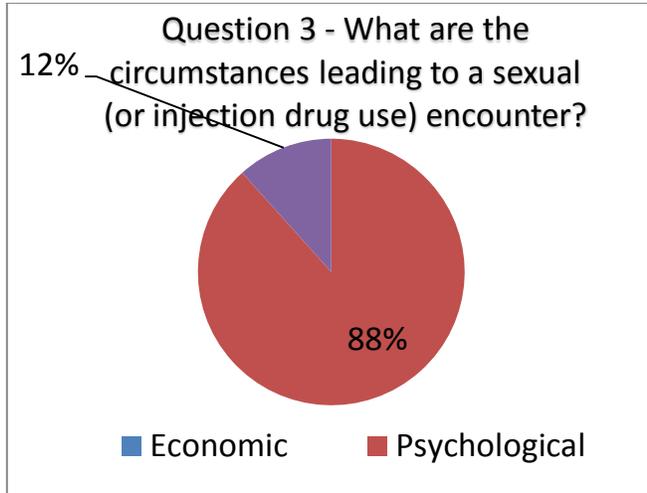
Question Three:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV: *What are the circumstances leading to a sexual (or injection drug use) encounter?*

Selected Quotes (categorized by type of issue):

- Psychological
 - "When I meet someone, I first ask "Do you get high?", then "Do you party?" If they say yes, we go to a hotel."*
 - "I worry about HIV after sex and taking drugs, but it doesn't stop me from having sex or using."*
 - "I have had the same partner in the last 5 years."*
 - "I will let somebody use my syringes, but I won't use theirs."*
- Structural
 - "I won't put my syringes in bottle caps that others are using to inject drugs."*

Results:



Conclusions:

Overwhelming responses to this question were related to psychological issues (88%). Awareness and concern about HIV risk played a role in circumstances leading to an injection drug use (or sexual) encounter; however, it did not always result in risk-reducing behaviors such as using condoms and clean needles.

Question Four:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV: *How do you prepare to go out with the possibility to hook up?*

Selected Quotes (categorized by type of issue):

- Economic

"I think about having condoms before I go out but I am not spending any of my drug money on condoms. I don't know where to get them free and I won't ever ask for them. I probably wouldn't use them if I had them."

- Psychological

"I won't have sex without using condoms."

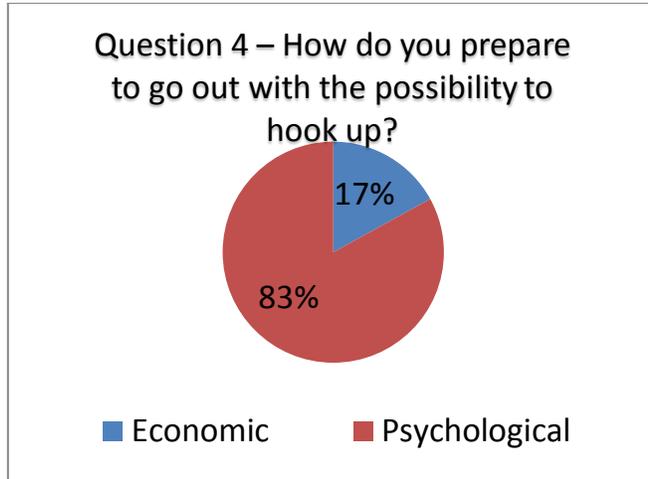
"I know my girlfriend gets high when she's not with me, so I can't trust her. She's an addict, too, so she's probably had sex with other men."

"Most of my relationships have lasted two plus years. I get tested for HIV and HCV every few months."

"My partner and I got tested for HIV together."

"I plan to go in for a test next Monday."

Results



Conclusions:

Similar to the responses for circumstances leading to an injection drug use (or sexual encounter), the vast majority of responses for preparations to a hook up laid in psychological issues. These results suggest that the participants were well aware of the HIV risk but struggled to practice safer sex and drug use because of their addiction.

Question Five:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: *Now that we have talked about what is important to you, what kinds of activities might appeal to the community of you peers?*

Selected Quotes (categorized by type of issue):

- Structural
 - “Needle exchange needs to be more widespread. “*
 - “Children and youth need education about HIV earlier and in schools and in the media. There isn’t enough education out there. “*
 - “There needs to be support services for youth. In addition to sex and drug education classes in the schools, they need more activities and recreational centers in the community that provide mentors and social support systems for youth. Having these might keep them from using and becoming addicted in the first place. “*
 - “We need education for the homeless. “*
 - “Services should be more readily available and should not be limited or restricted based on people’s insurance, background or histories. “*
 - “There are very few resources for substance abuse treatment here. The centers here don’t want to or say they aren’t able to take people. “*
 - “When you have substance abuse problems, providers want to give you anti-anxiety and anti-psychotics. These don’t treat the addiction and sometimes make it worse. “*
 - “I need help with my addiction in order to keep a job and I can’t get services here. “*

Results and Conclusions:

All responses for this question were related to structural issues and the need for more needle exchange, education, social support systems, prevention and treatment services.

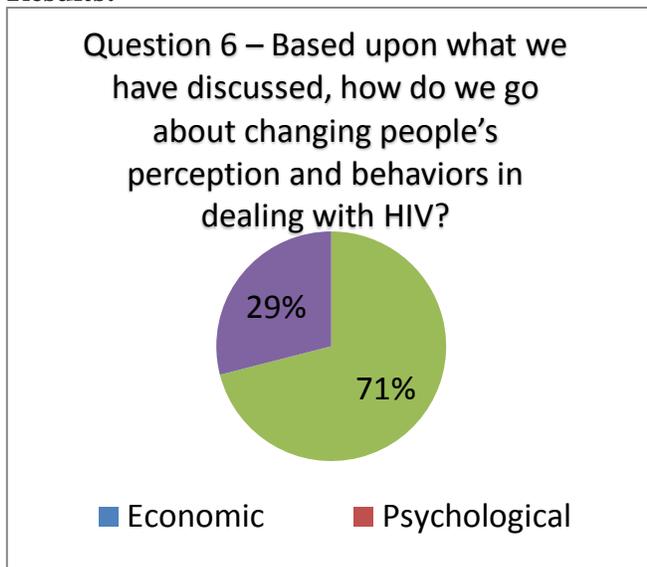
Question Six:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: *Based upon what we have discussed, how do we go about changing people’s perception and behaviors in dealing with HIV?*

Selected Quotes (categorized by type of issue):

- Social
 - "Every community should have active support groups and events for people with HIV and their families."*
 - "Make HIV more personal and positive."*
 - "Provide stories on actual people with HIV so it personalizes the messages."*
 - "Have a general public messaging/marketing campaign."*
 - "Positive messages about HIV might decrease stigma."*
- Structural
 - "Have a place for people with HIV to meet together to get support from others with HIV and empower them. Then, have opportunities for people with HIV to speak at schools, at businesses, at churches, etc., so others can learn from them and realize they are just like us."*
 - "In this community, abstinence is still promoted and schools don't talk about condoms. People need to educate the youth on using condoms and talk about it openly – lectures, demonstrations, free condoms, options for condoms, and community discussion about these things. That doesn't happen. Until it does, things won't change. In a lot of cases, if youth do not get that education from schools, they won't get it because their parents don't feel comfortable or feel informed enough themselves to discuss issues like that."*

Results:



Conclusions:

In reviewing the recommendations provided by participants on changing peoples' perception and behaviors in dealing with HIV, 71% of the responses were social in nature, such as reducing stigma, whereas 29% of the recommendations made focused on structural issues, such as the need for support centers and more access to condom distribution.

Question Seven:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: *Can you provide us with some examples of where you experienced or have seen HIV (or injection drug use) related stigma or homophobia in your community?*

Selected Quotes (categorized by type of issue):

- Social

"It's everywhere. Even staff at some institutions that provide services to people with HIV or drug users use defaming language and act judgmental when providing services."

"I have seen fights and arguments between people with HIV and gays and it gets mean, yelling and fighting and using stigmatizing language."

"There is also workplace stigma. It may not be as obvious because people are afraid of civil rights suits, but it is there. You especially see a lot of stigma against gay men."

Results and Conclusions:

All responses to this question were related to social issues. It is evident that stigma against individuals with HIV, homosexuals, and injection drug users is still widespread in the community.

Question Eight:

The following question was asked to assess knowledge and utilization of HIV prevention, care, and treatment services: *"Do you have any suggestions on things community based organization and local health departments can implement to reduce HIV related stigma or homophobia to enhance utilization of prevention and care services?"*

Selected Quotes (categorized by type of issue):

- Social

"HIV should be discussed more openly and there should be more education in the community. In the 90's we saw a lot of educational and public information messages about HIV, but we don't see them anymore. Our children are becoming ignorant about HIV."

- Structural

"Provide more education on HIV to the general public and to providers."

"HIV testing should be offered routinely as a regular part of doctor visits like flu shots and pap smears. HIV testing should also be offered by a wider variety of agencies and in a wider variety of places."

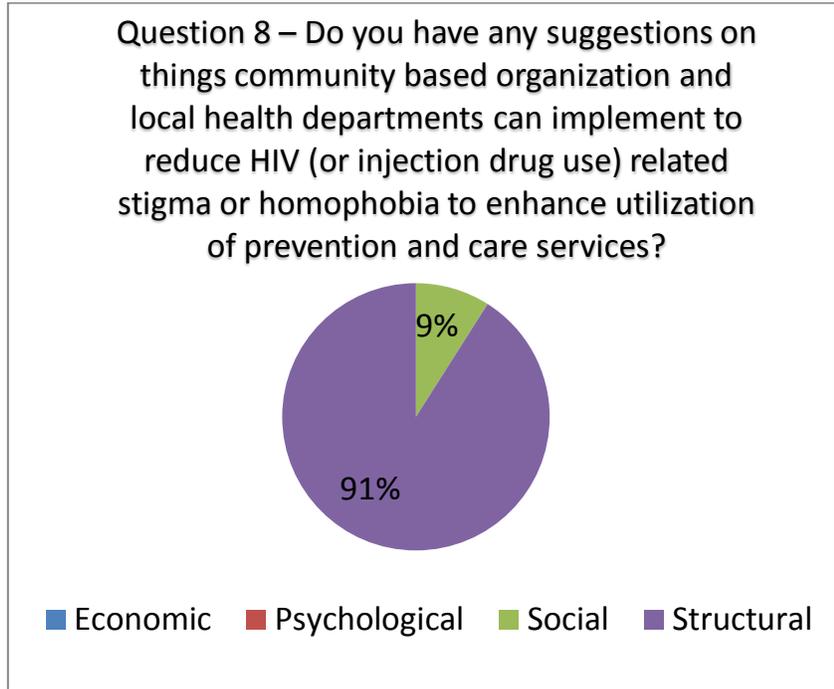
"Provide HIV education at local libraries instead of at missions and agencies. Take the education to the people. Many people on the streets go to the libraries."

"Job training programs for people with addictions and ex-felons to provide them with job skills and give them motivation to change."

"Have more focus groups and discussions with people like us in the community like this event. It is nice for someone to show an interest in us. It shows us that someone cares and wants to help us."

"More re-entry and re-integration programs are needed. I have been in jail six times. I always say I will never go back, but I always do, because I can't change my addiction that got me into trouble in the first place."

Results:



Conclusions:

Participants suggested that in order to reduce HIV-related stigma and homophobia, more education, job training, re-entry or re-integration programs are needed. These programs were viewed as important to enhancing utilization and access to prevention and care services. Overwhelmingly, the discussions and recommendations focused on the structural issues (91%).

Focus Group Meeting Two: At Risk Youth, September 17, 2014, Carbondale, IL

Number of Participants: 22

Location of Meeting: Rebound High School

The Region 5 focus group discussion was held at an Alternative High School in Carbondale for youth considered to be at high risk for HIV and STDs. There was a greater turnout for this focus group with a total of 22 youth participating in the discussion. Most of the participants were females (16 females vs 6 males), and all of them were in the age group 18-24 years. There was a mixed representation of race/ethnicity, with 9 African-Americans, 7 whites, 4 multi-racials, 1 Hispanic, and 1 American Indian/Alaskan Native. The majority were self-reported heterosexuals (13), 8 reported as bisexual, and 1 homosexual. More than half of the participants (14/22) reported less than high school education. The detailed demographic characteristics of the focus group meeting participants are shown in the tables below:

Demographic Characteristics of the Focus Group Meeting participants

Gender	Male	Female
	6	16

Age	18-24 Yrs	25-34 Yrs	45 or above
	22	0	0

Race/ethnicity	Black	Multi-racial	White	Hispanic	American Indian/Alaskan Native
	9	4	7	1	1

Sexual orientation	Bisexual	Heterosexual	Homosexual
	8	13	1

Education	Less than High School	GED	High school	Some college	Some graduate
	14	2	4	1	1

Discussion Questions, Responses, and Results

Question One:

The following question was asked to identify facilitators and inhibitors of HIV risk and risk reduction: “*What are the three greatest challenges in your life that you are struggling with right now?*”

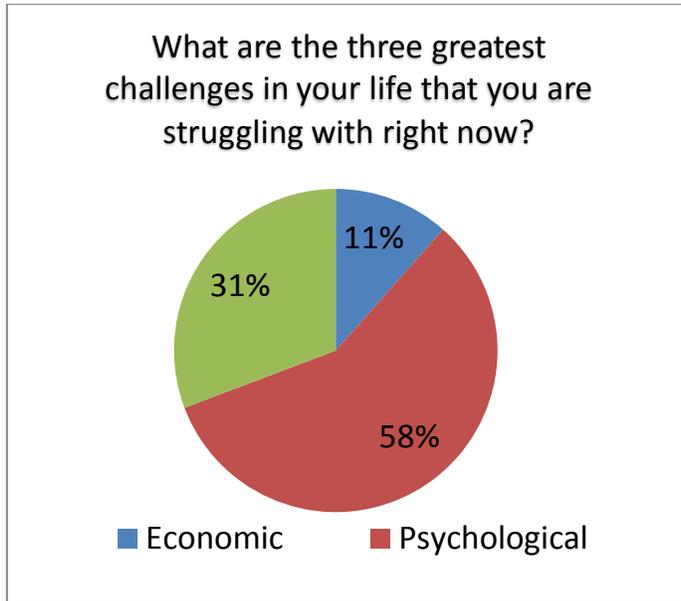
The responses for this question centered on the following challenges:

- Finances and employment
- Balancing family/social life
- Peer pressure
- STD and HIV

Selected Quotes (categorized by type of issues):

- Economic
 - “Getting a job”
 - “Money to get to school”
- Psychological
 - “Being a single mom; the large rates of STD/HIV makes me scared of having sex.”
 - “Motivation”
 - “Self-esteem”
 - “I’m trying to build my own self-esteem so I can become something.”
 - “Relationship problems”
 - “HIV is low ranked in my life.”
 - “I’m scared for the people in my life that I care about.”
- Social
 - “People judging you”
 - “Peer pressure”
 - “Lots of judging from friends”
 - “Balancing family/social life/life (in general)”

Results:



Conclusions:

The greatest challenges the participants mentioned included finances and employment, balancing family/social life, peer pressure, and STD and HIV. Most of these challenges were related to psychological issues (58%), followed by social (31%) and economic issues (11%).

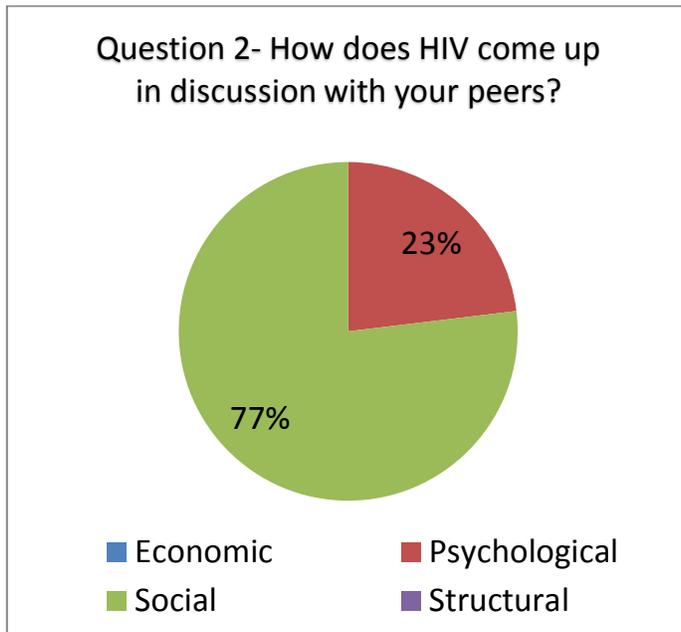
Question Two:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV: *How does HIV come up in discussion with your peers?*

Selected Quotes (categorized by type of issue):

- Psychological
 - “Talked about HIV with a friend that was a drug user”*
 - “I can understand why people that are HIV+ are being labeled.”*
 - “(When) someone has died from HIV”*
- Social
 - “Only comes up if you’re gossiping – “that girl has HIV.”*
 - “It does worry you that your friends are talking about (having) unprotected sex.”*
 - “Tell your friends and family to be cautious about HIV.”*
 - “Start the conversation (with) Do you have this or that?”*
 - “It comes up when older people start having sex with younger kids – offering gifts, money.”*
 - “self-esteem”*
 - “Rape”*
 - “They feel bad for those that are HIV positive.”*
 - “Some people have very negative attitude about people with HIV – don’t want to be around them.”*

Results:



Conclusions:

Social issues dominated the responses to this question (77%). HIV status, stigma, and concerns about HIV were all brought up and discussed when this question came up.

Question Three:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV: *What are the circumstances leading to a sexual (or injection drug use) encounter?*

Selected Quotes (categorized by type of issue):

- Psychological
 - “If in a relationship, may not - heat of the moment; feels better; girl doesn’t like condom”-3*
 - “If they are cheating, why are they still involved?”.*

"You should tell them if you are in a personal relationship."

- Social

"Use a Condom – no glove/no love."

"We use condoms throughout the whole relationship / not wanting to take any chances – especially if not trustworthy."

- Structural

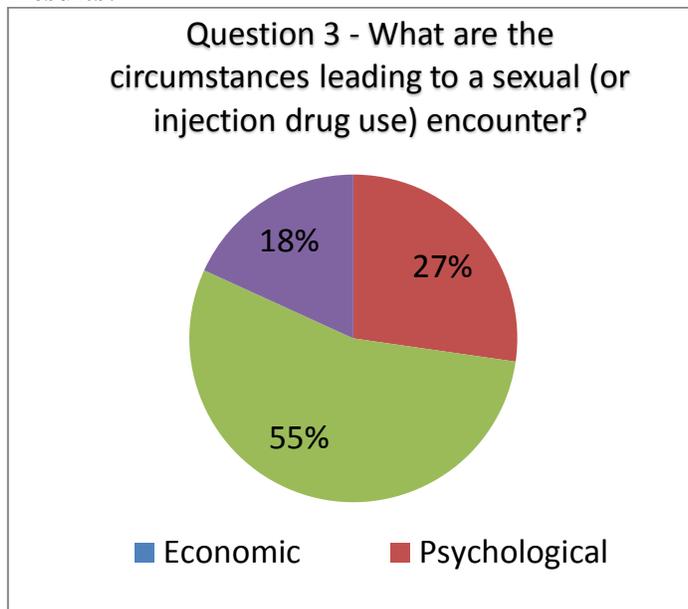
There was a question and discussion about disclosure of HIV. The facilitator discussed the criminal transmission law.

"If someone has HIV and they have unprotected anal/vaginal sex without disclosing is against the law."

"Places to get condoms: Health department; adolescent health/Shawnee health center; tanning places; Copies and More; barbershops."

"Put your condoms where you have sex somewhere not in your bedroom alone."

Results:



Conclusions:

More than half of the responses to this question were related to social issues (55%). Psychological (27%) and structural issues (18%) were also mentioned. Most emphasized importance of using condom, however, they also indicated a need for greater availability of condoms.

Question Four:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV: *How do you prepare to go out with the possibility to hook up?*

Selected Quotes (categorized by type of issue):

- Psychological

"Discussed female condom as an option"

"Carry condom in purse / pocket"

Results and Conclusions:

All responses to this question were related to psychological issues, specifically about having or using a condom. It appeared that youth heterosexuals were well aware of the risk of STD/HIV infection and knew that use of condom protects them from these infections.

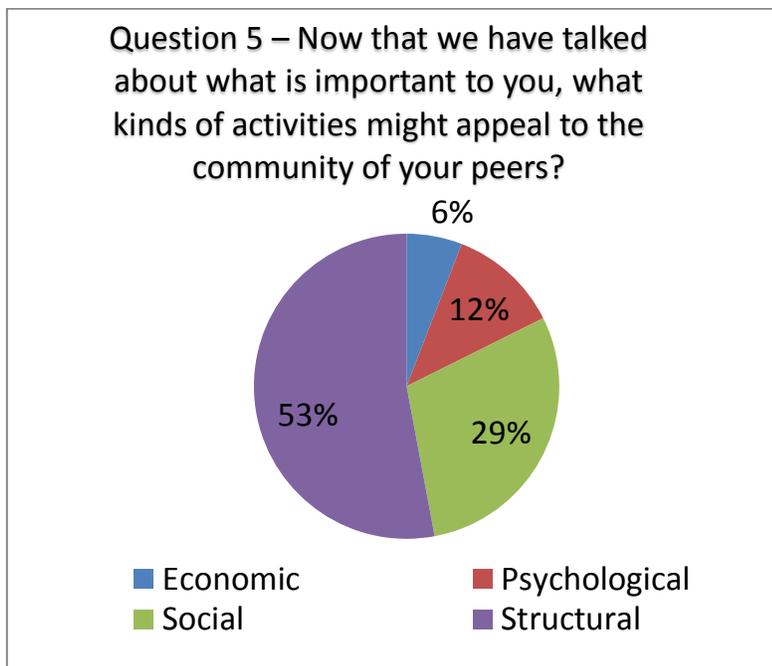
Question Five:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: *Now that we have talked about what is important to you, what kinds of activities might appeal to the community of you peers?*

Selected Quotes (categorized by type of issue):

- Economic
“Incentives” – mentioned numerous times
- Psychological
“Male/female condoms – prepare ahead of time.”
“You should protect yourself as well.”
- Social
“Having someone with HIV talk about their experiences - hearing from someone that has HIV”
- Structural
Prevention in the community:
“More testing facilities”
“Forced testing”
“Think people will have to sign up like child molesters; website to sign up and list of names for people in your area”
“Ads on TV”

Results:



Conclusions:

About half of the discussion were related to structural issues (53%), followed by social (29%), psychological (12%), and economic issues (6%). More testing facilities, public education on HIV, and female condom were discussed.

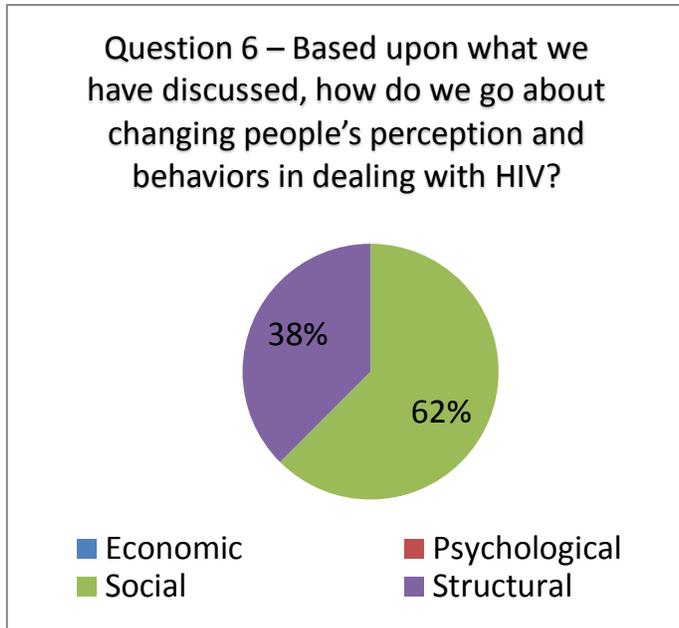
Question Six:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: *Based upon what we have discussed, how do we go about changing people’s perception and behaviors in dealing with HIV?*

Selected Quotes (categorized by type of issue):

- Social
 - “I don’t think there is a way to be comfortable; like racism; people that judge for no reason.”*
 - “More informative information”*
 - “Take meds. Be healthy.”*
 - “Is there a cure? – No, but living a full healthy life is possible – researchers are working on an answer.”*
- Structural issues
 - “Need resources for a cure”*
 - “They need to show you how STDs can be transferred in groups -a chart and how it got transferred, how it multiples when sharing multiple partners.”*

Results:



Conclusions:

Social issues dominated the topic for this question (62%). However, structural issues were also brought up (38%). The main theme was about greater awareness of HIV infection.

Question Seven:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: *Can you provide us with some examples of where you experienced or have seen HIV (or injection drug use) related stigma or homophobia in your community?*

Selected Quotes (categorized by type of issue):

- Hear anything about gay people in the community?
“Not as common; not a big deal; not accepted in 2008 – way more accepted now” - Only this social issue was raised.

Conclusions:

Even with additional questions and hints, there were limited responses to this question, probably due to limited exposure to stigma for this group of youth who predominantly identified as heterosexuals. Only one social issue was raised in the discussion for this question.

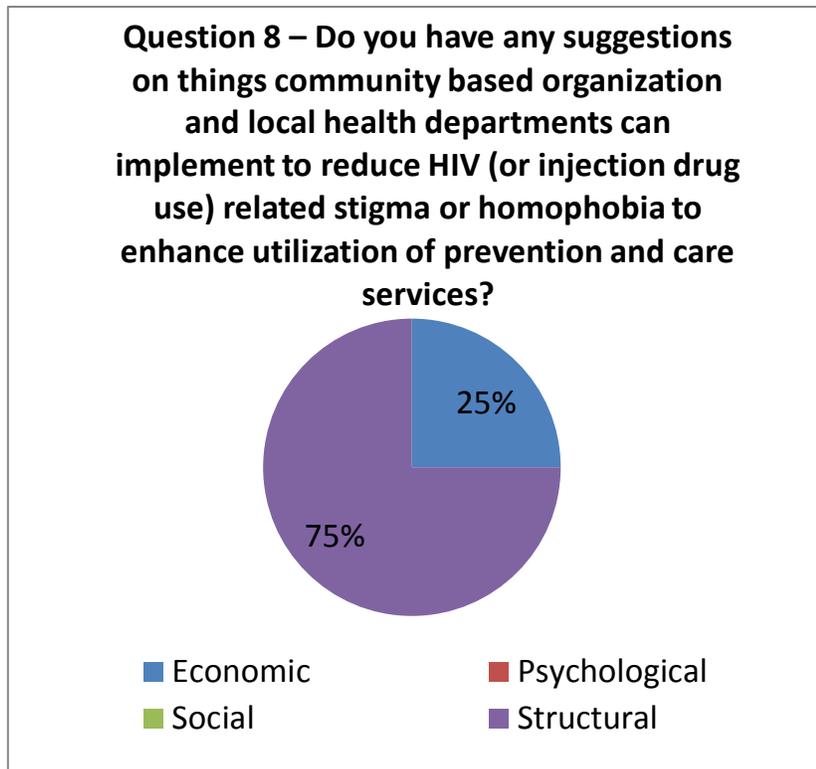
Question Eight:

The following question was asked to assess knowledge and utilization of HIV prevention, care, and treatment services: *“Do you have any suggestions on things community based organization and local health departments can implement to reduce HIV (or injection drug use) related stigma or homophobia to enhance utilization of prevention and care services?”*

Selected Quotes (categorized by type of issue):

- Economic
“Incentives to get tested – some people care about themselves/ others don’t”
- Structural
“More testing/more health fairs”
“Free services at the health department”
“Forcing people to get tested when getting married”

Results:



Conclusions:

Three-quarters of the suggestions on ways to reduce HIV (or injection drug use) related stigma and enhance utilization of prevention and care services were structural in nature, and one-quarter economic issues. More testing facilities and providing incentives for testing were the themes for this question.

COMPARISON OF FOCUS GROUPS

Even though the two focus groups are of great differences in their risk to HIV, they shared similar challenges in life: money and job, relationships, and HIV. Both groups considered stigma a social issue and education most important in reducing HIV-related stigma. IDUs identified more psychological and structural issues related to HIV while youth HRH emphasized more on family and social issues.

SUMMARY

Completing the series of eight focus group discussions conducted from 2012-2014 with people representing groups at high risk for HIV was a big accomplishment. Overall, the focus groups have been a wonderful opportunity to gain insight into the barriers and facilitators of risk behaviors as well as challenges and other issues experiences by representatives from the targeted population groups. It was remarkable having these participants open up and share concerns, challenges, barriers, experiences, and perceptions about HIV in general, and about HIV within the context of their societal culture and beliefs within their own population groups. It was also enlightening to hear some of their suggestions, which for the most part seemed practical and genuine, on what could be done to improve the systems of prevention and care and make services more accessible and sensitive to the needs of their population groups. The ILHPG strongly recommends that the findings and the reports generated from the focus groups are used by state and local entities to guide, enhance, and develop existing and new HIV programs and related supportive services, and to assist in the planning for additional needs assessment activities that will continue to provide us with deeper insight in the psychological, social, economic, and structural issues impacting these communities.

APPENDICES

Appendix A
Illinois HIV Planning Group (ILHPG)
Protocol for Focus Groups 2012-2014

1. A Focus Group Committee, composed of members of the ILHPG (formerly the Illinois Prevention Community Planning Group or PCPG) Evaluation Committee, the Co-Chair of the Epi/Needs Assessment Committee, the IDPH ILHPG Coordinator, the IDPH Prevention Administrator, and 2 community members who formerly were PCPG members, was formed to develop the protocol, discussion guide, objectives, and procedures to be used in planning and conducting the focus groups. The members participated in conference calls to develop and approve all documents to be used in the focus groups.
2. The ILHPG plans to select focus group participants by reaching out through the Regional Lead Agents to already established HIV discussion/support groups in the designated area. Many of these support groups are currently funded by HIV regional implementation prevention or care dollars to provide those services. Participants will be recruited to participate in the regional focus group through the existing support group facilitator(s).
3. The plan is to include 8-12 participants in each focus group. The target participant group (i.e., youth, MSM, PLWHA, female HRH, African-American MSM, Latino MSM, Transgender, etc.) will be selected based on the regional epidemic/trends and established groups.
4. After a brief welcome and introduction, the participants will be asked to sign a consent form to participate. The form details the purpose of the focus groups, the risks and benefits of participating, and the confidential manner in which the information will be collected and used.
5. The focus group participants will be provided with refreshments during the focus group. A \$25 gift card will be provided to participants, not including ILHPG or IDPH members, at the end of the focus group to help defray the cost of their transportation and participation and as thanks for their participation.
6. The participants will be provided with an HIV Epidemic and Vital Statistics fact sheet specific to their risk group as a handout they can take with them after the focus group. The facilitator will explain to the participants that IDPH and the ILHPG intend to use the results of the focus groups in making decisions about policy and program needs aimed at reducing HIV transmission, increasing linkage to and retention in HIV care services, and reducing stigma associated with HIV.
7. The focus groups will be facilitated by a neutral subcontracted facilitator. The IDPH ILHPG Co-Chair will attend all focus groups and provide needed support.
8. The Evaluation plan is as follows: The group discussion will be tape recorded with the permission of the group and assigned note takers will add notes and observations. Notes will be compiled by the IDPH HIV Community Planning intern, typed and sent to the IDPH Evaluation Administrator who will analyze and report findings using qualitative analysis. Responses to the questions will be evaluated for each risk group and for each location using qualitative, generalized, descriptive analysis.
9. By the end of CY2012, 2013 and 2014, the IDPH Evaluation Administrator and the ILHPG Coordinator will compile a report of all focus groups conducted in that year, summarizing each focus group individually and comparing the responses.

Revised January 2013

Appendix B
2012-2014 HIV FOCUS GROUP FACILITATOR DISCUSSION GUIDE
(not to be shared with the participants)

Facilitator should arrive 20 minutes early

As participants arrive:

1. Ask participants to write their names on a sign in sheet. This is to account for the meeting facilitation cards that will be distributed after the focus group.
2. Give participants a copy of the consent form and participant survey (demographics, etc.) and a pen.
3. Ask participants to complete the consent form and survey, letting them know it is to be completed anonymously and returned to the staff member.
4. Offer the participants refreshments and direct them to finding a seat.

Introduction (5 minutes)

1. Introduce yourself and the recorder/note taker(s).
2. Thank the people for coming.
3. Go over the purpose of the focus group and the objectives of the meeting.

Purpose: To gather opinions from the community on risk behaviors, practices, ways to reduce HIV stigma and homophobia, and utilization of HIV and STD prevention and care services. This input will help local community organizations and health departments improve HIV and STD programs.

Objectives:

- To solicit input on innovative approaches to reduce HIV related stigma and homophobia.
 - To assess risk behavior practices in areas/populations hardest hit by HIV.
 - To assess knowledge and utilization of HIV prevention, care, and treatment services among representatives of at risk communities.
 - To identify facilitators and inhibitors of HIV risk and risk reduction.
4. Ask permission from the participants to tape record the focus group discussion. Stress to them that no names or identifying information will be associated with the recording.
 5. Go over the flow of the meeting - how it will proceed and how the focus group participants can contribute.
 6. Lay out the ground rules and encourage open participation.

Ground Rules

- Your opinions about HIV and issues in your community that may affect HIV prevention and treatment services is important to us, so please say what you think without hesitation.
- Everyone is entitled to an opinion, so listen respectfully.
- There are not any right or wrong responses, so please be honest with your responses. We will not expect you to share any information you are uncomfortable sharing.
- We would like everyone's opinions, so I may call on some of you directly to express your thoughts.

- We want to hear from everyone, but please, only one person speaks at a time. And when you speak, please speak loud enough for everyone in the group to hear.
- We are interested in all comments, positive and negative, so please say what you really think.
- During the discussion, I may say things like "you and other people that you know" or "your community." When I say these, I want you to think about what you and others in the community you represent (for example: youth, men who have sex with men (MSM), injecting drug users (IDU), female HRH, transgenders, young MSM, people living with HIV (PLWHA), etc.) think and do in terms of risk behaviors and HIV services.

Focus Group Protocol

The rest of the meeting will take about 60 minutes. If, at the end of the 60 minutes, we have remaining questions, we will acknowledge the end of the time and ask permission from the group to continue. The questions that I will ask have to do with HIV stigma, risk behaviors, and prevention and care services. Each of you will have a chance to respond. Talk openly and respectfully with the idea that you are contributing to improving health programs for you and your peers in your community.

Introductory Questions

Note taker: Record summary of responses and direct quotes, including observations. Number the responses to align with the questions (i.e., 1, 2, etc.).

1. What are the three greatest challenges in your life that you are struggling with right now?

Listen for: Issues they are grappling with and what is important to them. Do they see HIV as an issue in their life? How do they rank HIV disease in becoming infected or transmitting it to others?

2. How does HIV come up in discussions with your peers?

Listen for: How often HIV comes up. What exactly are they talking about? Is HIV an issue? What do people say about HIV positive people? How many people do you know personally who are HIV positive?

3. What are the circumstances leading to a sexual encounter?

Listen for: What they are doing to meet each other and what happens at the location. Before they get into a sexual relationship, do they talk about HIV?

4. How do you prepare to go out with the possibility to hook up?

Listen for: Do they practice risk reduction? Do they prepare differently with a primary partner as opposed to a secondary partner? If they are in a serious relationship, are they more likely to be safer with primary partner or the person on the side? How many of them have gone for testing with their primary partner?

Open-ended Ending Questions

- 5. Now that we have talked about what is important to you, what kinds of activities might appeal to the community of your peers?**
- 6. Based upon what we have discussed, how do we go about changing people's perceptions and behaviors in dealing with HIV?**
Listen for: Making HIV easier to talk about; making it easier to disclose HIV status; better preparing for sexual encounters.
- 7. Can you provide us with some examples of where you experienced or have seen HIV-related stigma or homophobia in your community?**
Listen for: church, schools, physician's office, etc.
- 8. Do you have any suggestions on things community based organizations and local health departments can implement to reduce HIV related stigma or homophobia to enhance utilization of prevention and care services?**

HIV Key Vital Statistics

I am going to provide you with some information and handouts about HIV specific to your risk group.

Closing and Next Steps

End discussion.

Thank the group for their participation and input.

Distribute meeting facilitation cards.

Revised January 2013

Appendix C
HIV PREVENTION AND EDUCATION NEEDS ASSESSMENT
2012-2014 FOCUS GROUP CONSENT FORM

You have been invited to be a part of a discussion group with other people from your community. The discussion group is part of a community HIV/STD prevention and education needs assessment for this region. By sharing your opinions and experiences you will contribute to our understanding of how the sponsoring organizations can improve HIV/STD prevention health education programming that is offered in your community.

Please read this form and ask any questions you have before agreeing to be a part of the focus group.

Procedure

If you agree to participate in this discussion group by signing your name on the back of this page you will do the following:

- 1) Participate in one co-facilitated group discussion that will last about 90 minutes. The co-facilitators will be the facilitator that normally leads this group, as well as a co-facilitator from the Illinois HIV Planning Group (ILHPG).
- 2) Agree to respect the confidentiality of the other discussion group members.
- 3) The discussion is being noted and recorded by members of the ILHPG and the Illinois Department of Public Health (IDPH) to insure that the information that you provide is accurately recorded.

Risks and Benefits of Being in the Discussion Group

First, since people may be talking about their own life experiences during the discussion group, there is a possibility that sensitive issues may arise. There is a risk that you, or others, may become upset or that the discussion may trigger painful memories.

Second, although every effort will be made to ensure confidentiality, there is a risk that other participants or observers might share information that they hear during the discussion group and thereby not honor the confidentiality of the group.

A **benefit** from being part of the project is that you will have the opportunity to provide your insight, experiences, and suggestions to health organizations that develop and implement HIV/STD prevention programs. Ultimately, our goal is to improve life for people in your community.

Confidentiality

Every effort will be made to ensure that your identity remains confidential. You may use a pseudonym or a made-up name for yourself so that you will not be identifiable. Any information that is gathered will be generalized.

Your Participation is Voluntary

Your decision whether or not to participate will not affect your current or future services with the sponsoring organizations, your local health department or with IDPH. If you decide to take part in the discussion group, you are free to withdraw at any time without affecting those relationships.

The person facilitating this discussion group is Jeffery Erdman. You may ask him any questions you have now or before the discussion begins.

This discussion group is being sponsored by the Illinois HIV Planning Group. If you have any questions about the discussion group or concerns about your rights or your treatment as a participant in this group, please contact:

*Janet Nuss, RN, MPH, CHES, CPHA, CERC, IPEM
HIV Planning Coordinator
Illinois Department of Public Health
HIV/AIDS Section
525 West Jefferson St., 1st Floor
Springfield, IL 62761
(217) 524-4759 (Phone)
(217) 524-5984 (Phone)
(217) 524-6090 (Fax)*

Statement of Consent

I have read and understood the information above and voluntarily give my consent to participate in this focus group. I agree to maintain confidentiality of other group members. My signature below means that I have freely agreed to participate in this focus group discussion.

Name (please print) _____

Signature _____ Date _____

Adapted from Community Discovery/Focus Group Consent Form/01-20-11/ctp/Final-All Regions

Revised January 2013

Appendix D
2012-2014 HIV Focus Group Participant Demographics Survey

Demographic Information: Providing this information will help ensure that input obtained from the focus groups reflects the needs of populations most impacted by the HIV epidemic in Illinois. This information will be kept confidential and will only be used to describe the focus group participants in the aggregate.

Race/Ethnicity	Sex or Gender
<input type="checkbox"/> White, non-Hispanic <input type="checkbox"/> Black or African-American, non-Hispanic <input type="checkbox"/> Hispanic/Latino <input type="checkbox"/> Asian <input type="checkbox"/> Native Hawaiian/Pacific Islander <input type="checkbox"/> American Indian/Alaskan Native <input type="checkbox"/> Bi-racial/Multi-racial	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender female to male <input type="checkbox"/> Transgender male to female

Age Group: 18-24____ 25-34____ 35-44____ 45 and above____

The following information will be kept STRICTLY CONFIDENTIAL.

Which of the following best represents <u>your personal</u> current or former HIV risk category- Please check all that apply:	
<input type="checkbox"/> Men who have sex with men (MSM) <input type="checkbox"/> Men who have sex with men and injection drug user (MSM/IDU) <input type="checkbox"/> Injection drug user (IDU) <input type="checkbox"/> Partner of an HIV-positive individual <input type="checkbox"/> Female partner of an MSM <input type="checkbox"/> Partner of an IDU	<input type="checkbox"/> Sex worker (sex for resources) <input type="checkbox"/> Heterosexual male or female with 2 or more STDs in 12 months <input type="checkbox"/> Male recently released from incarceration <input type="checkbox"/> Female partner of male recently released from incarceration <input type="checkbox"/> None of the above

Sexual Orientation	Optional information:
<input type="checkbox"/> Heterosexual <input type="checkbox"/> Homosexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Other, specify_____	<input type="checkbox"/> I am living with HIV/AIDS

Please identify the zip code in which you live: _____

What was your highest level of education attained: (Please check one)	
<input type="checkbox"/> Less than high school <input type="checkbox"/> GED <input type="checkbox"/> High school diploma <input type="checkbox"/> More than high school –vocational training	<input type="checkbox"/> More than high school –some college <input type="checkbox"/> College graduate <input type="checkbox"/> Some graduate school <input type="checkbox"/> Masters degree or above

Revised January 2013

Appendix E
Injection Drug User
Rockford
June 25, 2014

Compiled notes and observations

Participants signed in, completed consents and surveys.

The facilitator introduced himself and the note takers, described the goals, confidentiality and process of the focus group

Question 1- What are the three greatest challenges in your life that you are struggling with right now?

Drug Use and Addiction

- I can't stop using
- I'm an addict. I need them to function.
- I had 5 years of sobriety. I need help but can't get it because of insurance and because of my violent past. I feel hopeless then I use. It is a constant cycle.
- Drugs get me into trouble.
- I need drugs. I will find any money I can to get drugs, then I don't have money to live.
- I'm also addicted to sex

Personal and social relationships

- I don't know if God loves me because of what I do
- I have problems in relationships because of my drug use so I don't have any support.
- My violent past interferes with me getting needed help
- My background is a barrier to me getting employment

Finances and Employment

- I use all my money on drugs then have no money to live.
- Lack of employment
- My drug use is a barrier to my getting and keeping a job

HIV

- This is about 5th on my list of issues because I try to protect myself by practicing safe sex and not using shared needles
- HIV is always on my mind but other issues are more important to me.
- I take steps to avoid HIV but it is always something I'm thinking about.
- HIV is high on my list of issues, but when I am using I let my guard down and put it in the back of my mind.
- I have friends with HIV. People have misconceptions about HIV and how it is acquired, so people judge them.
- People stay away from people with HIV, even friends who have HIV.
- Having HIV causes more problems with relationships and employment.

Question 2- How does HIV come up in discussion with your peers?

- HIV comes up when people say "Let's share a needle". I won't share someone else's needle, but if they want to share mine after I use, that's OK.
- My peers are concerned about HIV after having sex or injecting, but that doesn't stop us.

- The people I hang around with aren't faithful to their partners, so I worry about getting HIV, but I still don't wear condoms.
- HIV isn't talked about in the youth groups I hang with. It is a taboo subject among peers.
- One of my friends has HIV. We talk about her HIV and I support her. I don't judge her but I won't drink after her.
- People with HIV are called nasty, dirty, prostitutes, and treated like aliens.
- People post nasty comments on Facebook about a young friend of mine with HIV.
- I know a few people with HIV who don't tell others their status because they are afraid of how they will be treated.
- People still think only people like Magic Johnson can afford HIV medicines.

Question 3 - What are the circumstances leading to a sexual (or injection drug use) encounter?

- When I meet someone, I first ask "Do you get high?", then "Do you party?" If they say yes, we go to a hotel.
- I meet people through my friends and sometimes just walking down the street. I won't ask people to have sex or do drugs if I know they have HIV because I'm concerned they might say yes.
- I worry about HIV after sex and taking drugs, but it doesn't stop me from having sex or using.
- I have had the same partner in the last 5 years.
- I meet people at bars and in the grocery store. I will start by introducing myself, then start with smoking pot, leading to harder drugs. Most of my sex encounters include drug use.
- I won't put my syringes in bottle caps that others are using to inject drugs.
- I will let somebody use my syringes, but I won't use theirs.

Question 4 – How do you prepare to go out with the possibility to hook up?

- I think about having condoms before I go out but I am not spending any of my drug money on condoms. I don't know where to get them free and I won't ever ask for them. I probably wouldn't use them if I had them.
- I won't have sex without using condoms.
- I know my girlfriend gets high when she's not with me, so I can't trust her. She's an addict, too, so she's probably had sex with other men.
- Most of my relationships have lasted two plus years. I get tested for HIV and HCV every few months.
- My partner and I got tested for HIV together.
- I plan to go in for a test next Monday.

Question 5 – Now that we have talked about what is important to you, what kinds of activities might appeal to the community of your peers?

- We would like to see more places offer services and make them more available to us.
- Needle exchange needs to be more widespread.
- Children and youth need education about HIV earlier and in schools and in the media. There isn't enough education out there.

- There needs to be support services for youth. In addition to sex and drug education classes in the schools, they need more activities and recreational centers in the community that provide mentors and social support systems for youth. Having these might keep them from using and becoming addicted in the first place.
- We need education for the homeless. There is nothing for HIV prevention on the street. Flyers need to be posted and education needs to be provided on the streets where the people are. The people don't have the information and the facts about HIV they need. They won't go to the doctor's office so unless it is taken to them, they won't see it.
- Services should be more readily available and should not be limited or restricted based on people's insurance, background or histories.
- There are very few resources for substance abuse treatment here. The centers here don't want to or say they aren't able to take people.
- When you have substance abuse problems, providers want to give you anti-anxiety and anti-psychotics. These don't treat the addiction and sometimes make it worse.
- I need help with my addiction in order to keep a job and I can't get services here.

Question 6 – Based upon what we have discussed, how do we go about changing people's perception and behaviors in dealing with HIV?

- Have a place for people with HIV to meet together to get support from others with HIV and empower them. Then, have opportunities for people with HIV to speak at schools, at businesses, at churches, etc., so others can learn from them and realize they are just like us.
- Every community should have active support groups and events for people with HIV and their families.
- Make HIV more personal and positive.
- Provide stories on actual people with HIV so it personalizes the messages.
- Have a general public messaging/marketing campaign.
- Positive messages about HIV might decrease stigma.
- In this community, abstinence is still promoted and schools don't talk about condoms. People need to educate the youth on using condoms and talk about it openly – lectures, demonstrations, free condoms, options for condoms, and community discussion about these things. That doesn't happen. Until it does, things won't change. In a lot of cases, if youth do not get that education from schools, they won't get it because their parents don't feel comfortable or feel informed enough themselves to discuss issues like that.

Question 7 - Can you provide us with some examples of where you experienced or have seen HIV (or injection drug use) related stigma or homophobia in your community?

- It's everywhere. Even staff at some institutions that provide services to people with HIV or drug users use defaming language and act judgmental when providing services.
- I have seen fights and arguments between people with HIV and gays and it gets mean, yelling and fighting and using stigmatizing language.
- There is also workplace stigma. It may not be as obvious because people are afraid of civil rights suits, but it is there. You especially see a lot of stigma against gay men.

Question 8 – Do you have any suggestions on things community based organization and local health departments can implement to reduce HIV (or injection drug use) related stigma or homophobia to enhance utilization of prevention and care services?

- Provide more education on HIV to the general public and to providers.
- When someone commits a drug crime or a crime against someone who is HIV positive or gay, the court system should require them to do some public service related to HIV, substance abuse, or homophobia. They may see things from a different perspective after that.
- HIV testing should be offered routinely as a regular part of doctor visits like flu shots and pap smears. HIV testing should also be offered by a wider variety of agencies and in a wider variety of places.
- HIV should be discussed more openly and there should be more education in the community. In the 90's we saw a lot of educational and public information messages about HIV, but we don't see them anymore. Our children are becoming ignorant about HIV.
- Since agencies say they don't have enough funding or resources to provide the needed services, maybe they should sponsor some community fundraising activities to help pay for more HIV and substance abuse services in the community.
- Provide HIV education at local libraries instead of at missions and agencies. Take the education to the people. Many people on the streets go to the libraries.
- Job training program for people with addictions and ex-felons to provide them with job skills and give them motivation to change.
- We need more agencies like Rosecrance. There is a new drug that can stop cravings for a month, but the drug is limited and without a job and insurance, it isn't available to everyone. We need something like this to get us back on the right track.
- Have more focus groups and discussions with people like us in the community like this event. It is nice for someone to show an interest in us. It shows us that someone cares and wants to help us.
- More educational programs for drug offenders at an early age so they can become educated on what got them into trouble and maybe find a way out before in too deep.
- More re-entry and re-integration programs are needed. I have been in jail six times. I always say I will never go back, but I always do, because I can't change my addiction that got me into trouble in the first place.

Appendix E
2014 Focus Group Notes
High Risk Youth
Carbondale, IL
September 17, 2014
Compiled notes and observations

Participants signed in, completed consents and surveys.

The facilitator introduced himself and the note takers, described the goals, confidentiality and process of the focus group

1. What are the three greatest challenges in your life that you are struggling with right now?

- Getting a job
- Being a single mom; the large rates of STD/HIV makes me scared of having sex
- Money to get to school
- Finishing school
- Being a parent in general
- Motivation
- Self-esteem. I'm trying to build my own self-esteem so I can become something
- People judging you
- Peer pressure; lots of judging from friends
- Balancing family/social life/life
- Having to take care of other people; family/younger and older
- Relationship problems
- Illnesses – Cancer: HIV; Diabetes
- HIV is low ranked in my life
- A lot other STDs to worry about
- You can't get rid of HIV
- HIV can be scary for the people that do have it. You can affect your non HIV partner/baby
- People that have it and don't use protection
- Unprotected sex/ everyone should be worried about that
- Make sure you get tested before becoming involved in a relationship
- People cheat – people lie – can't trust what they say
- Protect yourself first
- I'm scared for the people in my life that I care about.
- Support

2. How does HIV come up in discussions with your peers?

- Only comes up if your gossiping – “that girl has HIV”
- It does worry you that your friends are talking about unprotected sex
- You hear about outbreak of STD and that guy with HIV- passing the word to your friends in conversation / taking care of each other
- Tell your friends and family to be cautious about HIV
- Talked about HIV with a friend that was a drug user
- Start the conversation (with) Do you have this or that?

- It comes up when older people start having sex with younger kids – offering gifts, money, self-esteem
- Rape
- They feel bad for those that are HIV positive - stigma
- Some people have very negative attitude about people with HIV – don't want to be around them
- I can understand why people that are HIV+ are being labeled
- Someone that has died from HIV? – 3

Follow up Questions:

- Are there a lot of rumors about HIV? – No
- How many people know someone with HIV? – 1

3. What are the circumstances leading to a sexual encounter?

- Disclosure of HIV – discussed the criminal transmission law – if someone has HIV and they have unprotected anal/vaginal sex without disclosing is against the law.
- You should tell them if you are in a personal relationship

Follow up Questions:

- Can you get HIV through saliva? No

Sounds like most of you talk about HIV before sexual engagement?

- Use a Condom – no glove/no love
- We use condoms throughout the whole relationship / not wanting to take any chances – especially if not trustworthy
- If they are cheating / why are they still involved.

Have you used a condom before?

- Everyone has; use most of the time/half of the time;
- If in a relationship may not - heat of the moment; feels better; girl doesn't like condom-3
- Places to get condoms; Health department; adolescent health/Shawnee health center; tanning places; Copies and More; barbershops; condoms here. Put your condoms where you have sex somewhere not in your bedroom alone.

How many have gone for HIV testing?

- All

Where do you meet your partners?

- On campus / school / library
- Church
- Social media – Facebook /Twitter / POF

Anyone going on line to meet sexual partners?

- Plenty of fish (website)

How many of you have met on line socially first?

- 5

Before you have sex do you discuss HIV?

- Yes; not HIV specific/but are you clean/ddf

How many have gone with HIV testing with partners?

- 4

4. How do you prepare to go out with the possibility of hook up?

- Discussed female condom as an option

- Carry condom in purse / pocket

5. Now that we have talked about what is important to you, what kinds of activities might appeal to the community of your peers?

- Male/female condoms – prepare ahead of time. Talked about female condoms/
- Prevention in the community:
 - billboards
 - more testing facilities
 - forced testing
- Having someone with HIV talk about their experiences. - hearing from someone that has HIV
- Think people will have to sign up like child molesters; website to sign up and list of names for people in your area
- If you got it – you don't have to tell anybody – legally you don't have to
- You should protect yourself as well.
- Promote more testing days – promote testing in general; restaurants; clinics; malls; blood drive / HIV testing drive; when doing flu shots
- More health fairs
- Incentives – mentioned numerous times
- Ads on TV
- Doesn't work; Facebook ads/internet; Instagram

Follow Up questions:

- Does your doctor's office have the information? – 3 yes
- Do they ask if you are sexually active or have you ever been tested? – not a lot of information is provided
- If tested/do you want to be tested again? – Not asked.

6. Based upon what we have discussed, how do we go about changing people's perceptions and behaviors in dealing with HIV?

- I don't think there is a way to be comfortable; like racism; people that judge for no reason
- Need resources for a cure.

Follow Up Questions and Comments:

- How do you make it better; make it look like HIV is not so nasty?
 - More informative information –
 - Takes meds be healthy
 - Is there a cure? – No, but living a full healthy life is possible – researchers are working on an answer
 - Always working on new meds – it's a smart disease/hides in places where drugs cannot get
- Do the schools talk about HIV in the community? Is it talked about any place outside of your health class?
 - They show you how STDs can be transferred in groups. A chart and how it got transferred. How it multiplies when sharing multiple partners
 - How much time is devoted to it? Talked about a little in health class. I need to ask questions that haven't been asked or answered. Should provide more information. Ask students if they would like to get tested if available.

7. Can you provide us with some examples of where you experienced or have seen HIV-related stigma or homophobia in your community?

Follow Up Questions:

- Hear anything about gay people in the community?
 - Not as common; not a big deal; not accepted in 2008 – way more excepted now.

8. Do you have any suggestions on things community based organizations and local health department can implement to reduce HIV related stigma or homophobia to enhance utilization of prevention and care services?

- More testing/more health fairs
- Free services at the health department
- Incentives to get tested – some people care about themselves/ others don't
- Forcing people to get tested when getting married.