

ILLINOIS HIV PLANNING GROUP 2013 HIV FOCUS GROUPS REPORT

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INTRODUCTION AND ACKNOWLEDGEMENT

Annually, the Illinois HIV Prevention Community Planning Group (former PCPG), now newly named 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, each targeting specific risk group populations, and one to be held in each of the eight HIV prevention regions outside the city of Chicago. Focus groups were conducted in two of the eight prevention regions in 2013. 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 Prevention Community Planning Group (PCPG) – newly named and from here after referred to as the Illinois HIV Planning Group (ILHPG)- 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. Four focus groups were conducted in Regions 4, 8, 2, and 7 in 2012 and a report on these focus groups, “Illinois HIV Prevention Community Planning Group 2012 Focus Groups Report” subsequently developed. This report summarizes the results from two focus groups conducted in 2013 in Region 3 (Springfield – February 7, 2013) and Region 6 (Champaign-Urbana – August 7, 2013).

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 focus groups: Springfield -young men who have sex with men (MSM) and Champaign-Urbana- young MSM of color.

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 hired to facilitate the 2013 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. Because there was not an ongoing support group for young MSM in Region 3 (Springfield), the ILHPG Coordinator and the Region 3 prevention lead agent worked closely with the local lesbian, gay, bisexual, transgender (LGBT) community agency and the LGBT centers at the local community college and university to recruit for that focus group.

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 One:

The following question was asked to identify facilitators and inhibitors of HIV risk and risk reduction.

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

Question Two:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

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

Question Three:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

Question: What are the circumstances leading to a sexual encounter?

Question Four:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

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

Question Five:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Question Six:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Question Seven:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Question Eight:

The following question was asked to assess knowledge and utilization of HIV prevention, care, and treatment services.

Question: "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?"

With the acknowledgement and permission of the focus group members, each session was tape recorded and observations were notated by assigned note takers. 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 community planning intern and forwarded to the Department's HIV Section Evaluation Administrator for qualitative and descriptive analysis. The Compiled Notes and Observations for each of the four 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 (stigma, 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 results of the 2013 focus groups will be summarized and presented to the ILHPG at the March 2014 ILHPG quarterly meeting. 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

Focus Group Meeting One: Region Three (Springfield) Feb 07, 2013

Location of Meeting: Scheel's Community Education Center

Number of Participants: 1

Key Informant Interviews: 2

Overview: In discussion with the prevention and care lead agents for Region 3, the organizers decided to target the young MSM population, ages 18-24, for the focus group. There was not an existing support group in place from which to recruit participants, so the ILHPG Coordinator and Region 3 prevention lead agent collaborated with staff from an existing local LGBT HIV service organization and the coordinators of the LGBT centers at the local community college and university for recruitment. Staff recruited clients they knew fit into the target population group and a flyer promoting the focus group was placed at the bursar and LGBT centers at both schools. On the flyer, interested individuals were asked to register at a link on a meeting registration site. Although the organizers felt they made a serious effort to recruit individuals, only one individual registered for the focus group. Upon further conversation with the LGBT organization, the organizers decided the week before the focus group to expand the age range from 18-24 to 18-29 and to ask staff and peers to widely promote the focus group again to young MSM clients and students, expanding their focus to include the modified age range. Unfortunately, still only one individual turned up for the focus group.

The organizer and facilitator were in a quandary over how to proceed. Cancelling the focus group was briefly considered; however, the individual who did show up was very to provide input into our discussion questions and to learn information. The decision was made to conduct the focus group for the single individual. Since the responses of the single individual would technically be construed as a key informant interview, it was decided to advertise via the LGBT organization and social media and attempt to conduct a minimum of four more key informant interviews. After months of recruitment, we were still only able to conduct two more key informant interviews. The decision was made to proceed with analyzing the results. The organizer and facilitator felt the responses received were indicative of the barriers, challenges, and situations that occur in the young MSM communities that not only impact access to HIV care and prevention services and inhibit safe sex and drug use practices, but contributed to the lack of participation in the focus groups themselves.

Characteristics of Region Three Focus Group Meeting Participants

Among 3 participants in the key informant interviews, two identified themselves as non-Hispanic whites, and one didn't reveal his race/ethnicity. One participant was in the age group of 18-24 years while other two participants 25-29 years. They are all MSM with sexual orientation solely homosexual. Two participants had some college education (not graduated), and one had master or higher education.

Discussion Questions, Responses, and Results

Question One:

The following question was asked to identify facilitators and inhibitors of HIV risk and risk reduction.

Question: “What are the three greatest challenges in your life that you are struggling with right now?”

Quotes (categorized by type of issue):

- Economic Issues

“Money”

- *3 years out of grad school and trying to deal with student loan debt and living expenses.*

“Finding a better job - I don’t see HIV as an issue in my life. In terms of worrying about HIV infection, that is a low priority in my life.”

- Psychological Issues

“HIV scares me. I see HIV infection as a “potential happening”. The thought of HIV is always there for me, but I don’t talk about it all the time. It is a concern but not a “top three” concern.”

“HIV is always present as an issue in my life.”

- *It’s a fear, informs what I do and with whom and how often.*
- *Decrease in behaviors that lead up to sex as a result of HIV knowledge.*

- Social Issues

“College classes, time management”

“Social transition from college into professional setting

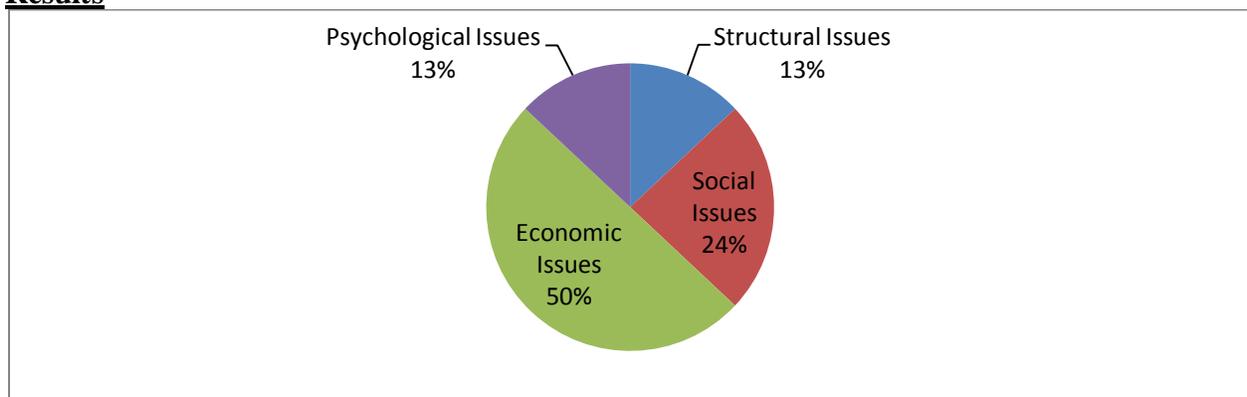
- *Student to young adult.*
- *Mentor role- being one who is supposed to know safe sex and still be social.*

“Starting college at Lincoln Land Community College”

- Structural Issues

“I know I have access to free condoms and lubes. I specifically know this and have no barriers. Before, in my (early) 20s, I was open about my sexuality, I did not know (about) free services and availability of testing.”

Results



Conclusions:

The greatest challenges the young MSM are struggling with mostly lay in economic issues (50% of all responses, lack of money due to student loan debt, living expenses and need for better jobs), followed by social issues (24% of all responses, such as starting college and transition into social networks). Psychological issues (such as fear) and structural issues (such as access to condoms and lubes) were less mentioned (13% of all responses, respectively).

Question Two:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

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

Quotes (categorized by type of issue):

- Economic Issues

No responses

- Psychological Issues

“HIV doesn’t come up often. It is like the big “elephant” in the room. However, I look out for others when they talk and hook up with someone I think is risky.”

“We feel bad for people that are HIV positive, but we also know those persons are risks to us. We are friendly with them but don’t really associate or socialize intimately with them.”

“My friends would be concerned if someone we knew had HIV because we would worry about their well-being.”

- Social Issues

“Has a team of peers who look out for each other:

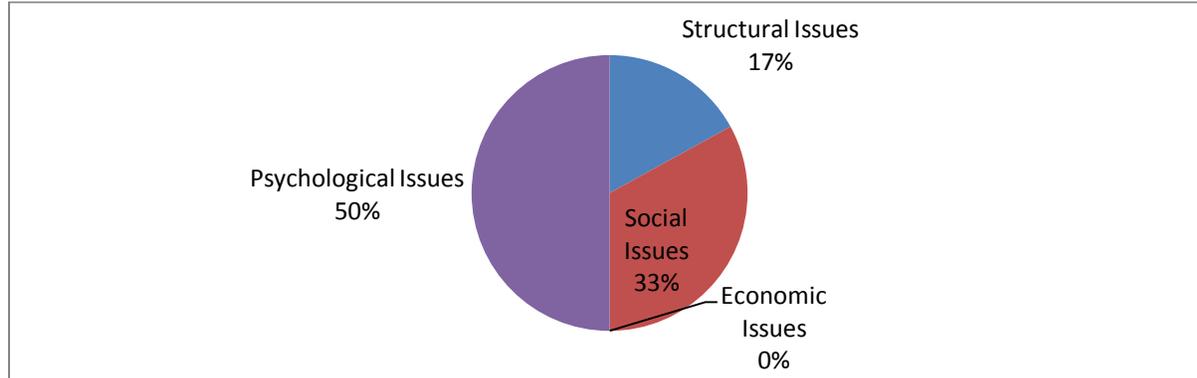
- *Safe sex.”*

“HIV doesn’t come up in discussions with my peers – it never gets brought up. I do talk to my mom about HIV, though. She is a nurse. She checks on me “being safe” and reminds me to use protection. My uncle who passed away was HIV-positive. We were really close. He helped me come out and he talked to me about HIV like my mom does.”

- Structural Issues

“HIV never comes up in discussions with my friends. I have gone to the Phoenix Center for HIV group education sessions but I don’t now due to school. I don’t personally know any HIV-positive people.”

Results



Conclusions:

The responses regarding the peer's view of HIV/AIDS mainly focused on psychological issues (50%, such as not socializing with HIV patients and concerned with the risk of socializing, stigma); social issues came next (33%, such as peers support, family support, and HIV not coming up in discussion with peers). Structural issues were less discussed (17%, such as availability of HIV education) and economic issues not mentioned.

Question Three:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

Question: What are the circumstances leading to a sexual encounter?

Quotes (categorized by type of issue):

- Economic Issues

No responses

- Psychological Issues

"May ask difficult question on dates, "When was the last time or have you been tested for HIV?"

- *Answer can lead to sex encounter*
- *Sometimes I postpone having sex with someone because I don't want to ask that question and I know I have to ask.*
- *Some answers don't ring true to me and I will stop corresponding or pursuing that relationship"*

"I'm in a monogamous relationship with another guy and I have been for 10 months now, so I don't go out to meet other people. We talked about HIV before we got together."

"Before I ever have sex I make sure that I have condoms. I always have them with me when I go out to meet people. I get them at County Market or at the pharmacies in town."

- Social Issues

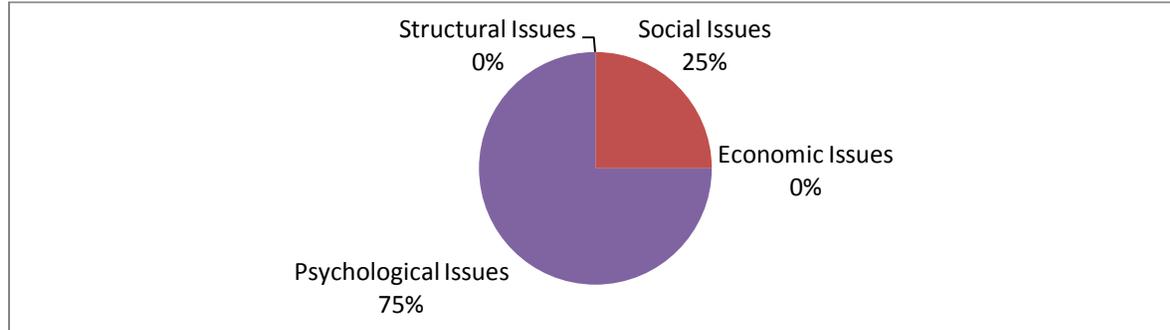
"There are a variety of ways to communicate":

- *Through other (gay) friends*
- *Online (Grinder, Facebook)...then will meet in person*
- *Going out on dates and talking to past partners*

- Structural Issues

No responses

Results



Conclusions:

The overwhelming responses on the circumstances leading to a sexual encounter were related to the psychological issues (75%, communicating directly with partners and possible partners about HIV before sex) and social issues (talking to peers and communicating with possible partners online) accounted for 25% of all responses on the topic. Economic and structural aspects were not mentioned.

Question Four:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

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

Quotes (categorized by type of issue):

- Economic Issues

No responses

- Psychological Issues

“If I go out, I always have condoms in my car that I can access.”

“Sometimes I wear a pair of ratty old underwear that I am embarrassed by so I know I won’t engage in risky behavior”

“I tested 3 months ago.”

“I have referred partners for testing, but never tested with partners.”

“My partner and I are monogamous and have no other partners. We were safe when we first got in the relationship, but now we have unprotected sex. I am the bottom. My partner has no other partners. I have not been tested for HIV but my partner has and he is HIV-negative.”

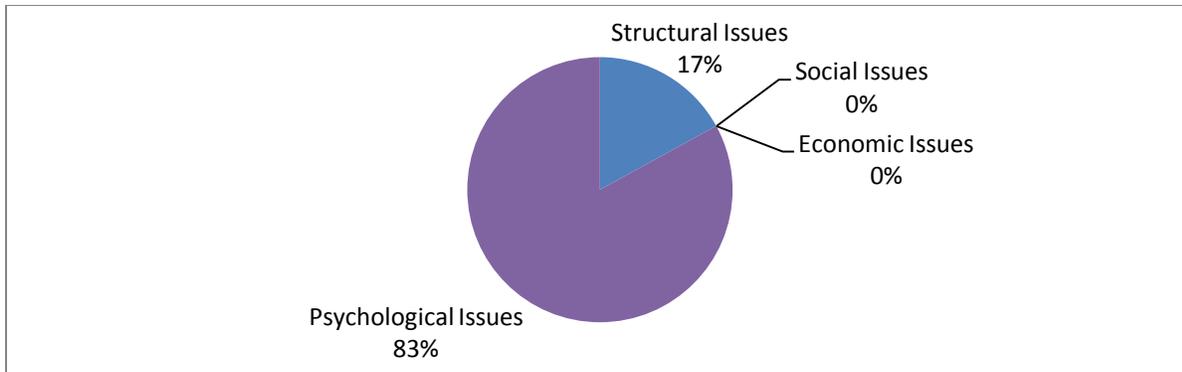
- Social Issues

No responses

- Structural issues

“I currently have a boyfriend and we use condoms. We both have been tested for HIV. Before we got in our relationship, we talked about HIV and we got tested together at the Phoenix Center. We get condoms at the Phoenix Center, too. I have one other friend who gets tested for HIV regularly at the Phoenix Center. My friends all practice safe sex.”

Results



Conclusions:

The responses on preparations for a potential hook up mainly focused on psychological issues (83%, such as practicing safe sex); and structural issues (such as obtaining and using condoms and getting testing routinely) were briefly discussed (17% of the responses).

Question Five:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

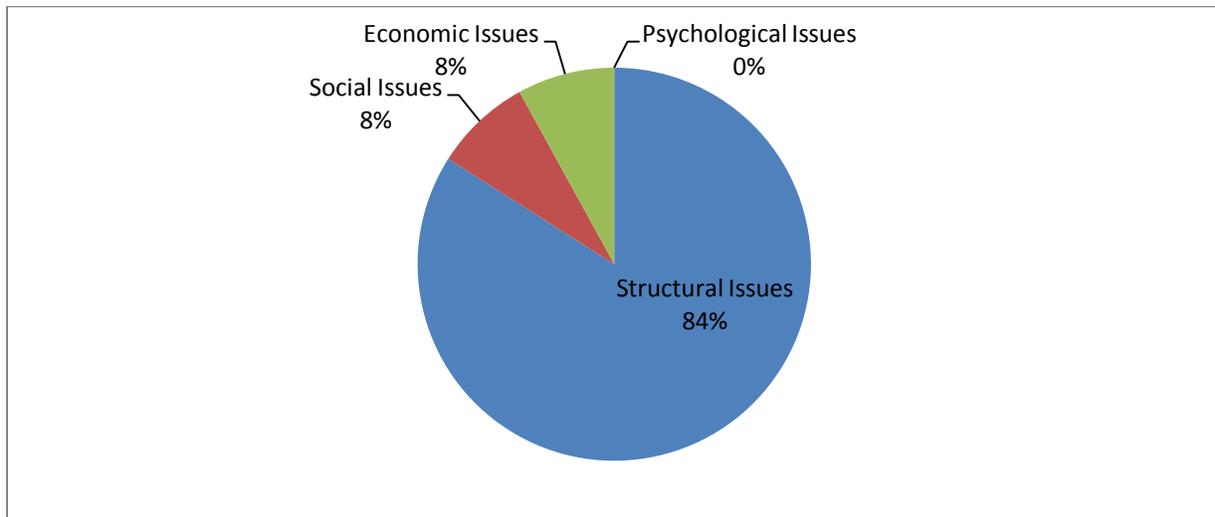
Question: Now that we have talked about what is important to you, what kinds of activities might appeal to the community of you peers?

Quotes (categorized by type of issue):

- Economic Issues
"We need to have free HIV testing at all community locations."
- Psychological Issues
No responses
- Social Issues
"Bar scene is primary outlet for gay young men in this town."
- Structural Issues
"Recommends that prevention agencies set up a Grinder box to inject prevention messages into hit on that application"
"We need more places like the Phoenix Center in town – it is a great resource. More HIV educators need to go out into the community. We need more HIV youth groups like the Phoenix Center has. HIV services need to be more widely available in the community, period."
"We need HIV prevention discussion boards online locally and online HIV prevention groups or online HIV-positive support groups locally."
"Training in education and giveaways at gay bars"
 - *Not regular condoms, but something else that may seem like a prize or reward.**"Turning HIV prevention into something gay men want (ex. certain clothing stores) may work better."*
"More age-appropriate activities for HIV prevention focused on younger people would be helpful."
"We need more media campaigns about HIV that are directed toward me and my peers."
"In bigger cities they have gay men's sports leagues. Here, they have a gay men's chorus but is mostly older men."
"More public speakers who have HIV are needed."

“More HIV-positive role models who can speak about their experiences.”

Results



Conclusions:

Most of the responses (83%) on what kinds of activities might appeal to the community of your peers were focused on structural issues (such as needing more prevention messages from prevention agencies, more places like the Phoenix Center (a local LGBT service agency), more prevention education and training at gay bars, gay men’s sports leagues, public speakers who are HIV positive and can be role models, HIV prevention discussion boards online, and media campaigns about HIV). Economic issues (such as needing to have free HIV testing offered routinely at community venues) and social issues (such as the bar scene being the primary social outlet in the area for gay young men) were also brought up (8% of responses, respectively).

Question Six:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Quotes (categorized by type of issue):

- Economic Issues
No responses
- Psychological Issues
“My perception and behaviors in dealing with HIV have changed since I met people who are HIV positive.”
“Having people with HIV talk at the schools has changed my perception.”
“In my social circle, safe sex with “few and far between” slip ups is the norm. Having sex with someone you just met that night is viewed as bad.”
- Social Issues
“A lot of times people will disassociate with someone they know (who) has HIV.”
“When I was younger (in college) I participated in less safe sex behaviors.”

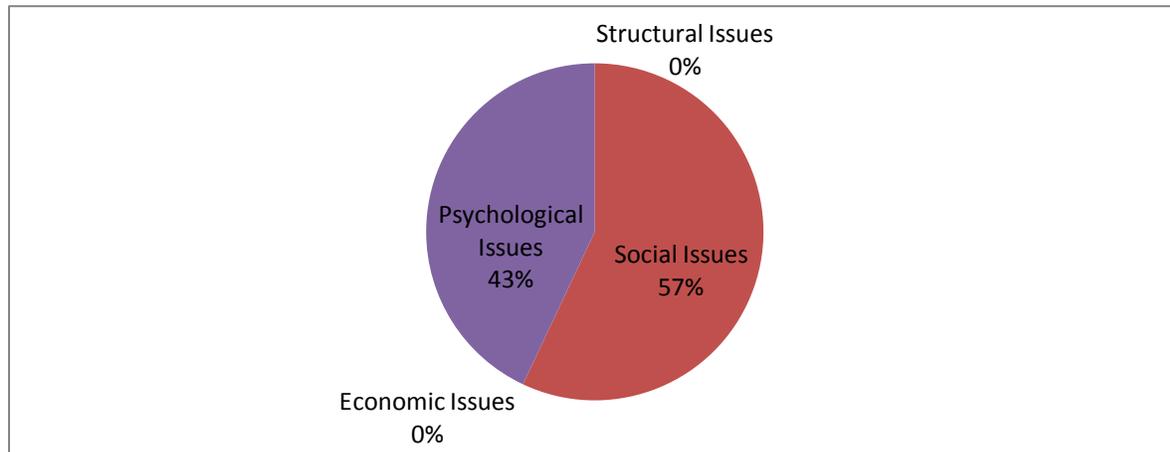
“We need to educate people about HIV and what it is like to have HIV. HIV-positive people couldn’t control getting infected necessarily and many regret it. There are too many stereotypes out there about people with HIV.”

“We need to talk about HIV openly in the community like my mom and my uncle did for me. People with HIV and young people need to talk about these things openly.”

- Structural Issues

No responses

Results



Conclusions:

The responses regarding how we go about changing people’s perception and behaviors in dealing with HIV mainly fell into social and psychological issues. Among all responses, 57% were on social issues (such as more education to the general public and to youth about HIV and what it is like to have HIV; talking more about HIV openly in the community) and 43% psychological issues (such as perceptions about HIV positive individuals and behaviors changing after meeting people who are HIV positive and having people with HIV talk at the schools).

Question Seven:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Quotes (categorized by type of issue):

- Economic Issues

No responses

- Psychological Issues

No responses

- Social Issues

“I participated in gay bar and event sponsored by Phoenix Center. Both focus on reducing stigma. Even in gay bars HIV positives are stigmatized. Bartender warns me if friends are showing interest in someone known or thought to be (HIV positive). Friend did not pursue relationship when person disclosed status. This led to hurt feelings on the person’s part.”

“Homophobia- Young teenagers’ school violence towards young gay men”

““Gay”, “Faggot”, “Dike” used derogatory sense. I haven’t experienced a lot of homophobia in community outside of schools. Likely because of whom I associate with.”

“There is lots of homophobia in this community. There is a lot in schools. The term “fag” was used in my high school all the time. There is lots of online homophobia and discrimination in this community, especially on Facebook and Twitter.”

“I experienced much homophobia at school because I was open about my sexuality. But I still think young people need to talk openly about their experiences so that these attitudes eventually end.”

Structural Issues

No responses

Results

All responses were centered on social-related issues and barriers (100% of the responses).

Conclusions:

All of the responses to this question focused on social barriers (100%, such as homophobia and stigmatization of people who are HIV positive in the community, schools and online).

Question Eight:

The following question was asked to assess knowledge and utilization of HIV prevention, care, and treatment services.

Question: “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?”

Quotes (categorized by type of issue):

- **Economic Issues**

“(Offer) more (opportunities for) free HIV testing”

- **Psychological Issues**

No responses

- **Social Issues**

“These agencies need to educate people about stigma.

- **Structural Issues**

“Having a presence in schools and starting early.”

“Instead of bringing students here [clinics], going to the schools or going to the bars and taking it to them.”

“It may be hard to reach students in public high schools, but maybe colleges and churches. Few churches are openly gay-friendly and supportive.”

“Take prevention services to gay youth making it as readily available as possible”

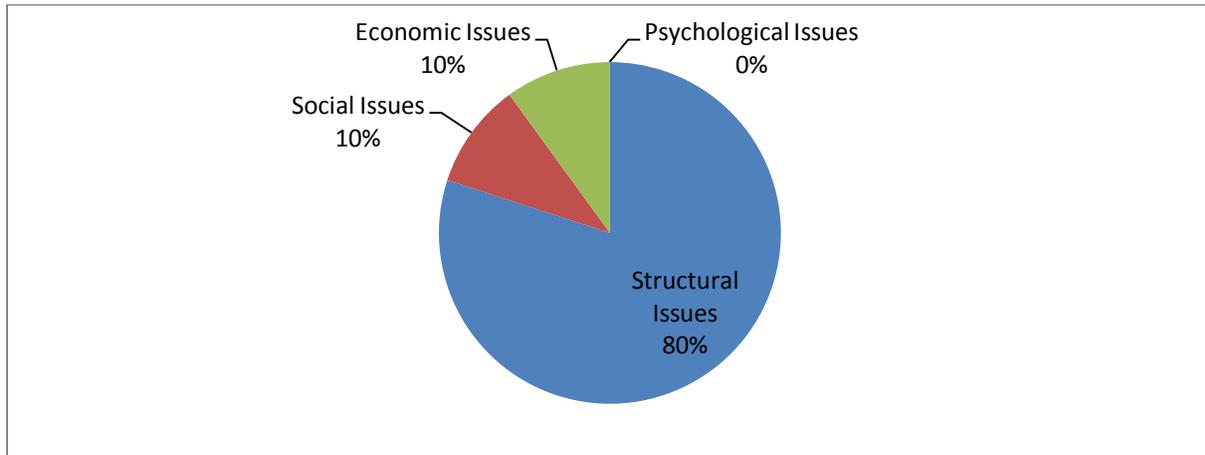
“Like I said, more media campaigns, more HIV services throughout the community. If people were always open and talking about HIV, we could change many opinions and behaviors.”

“HIV-positive speakers are needed to tell their stories publicly”

“Online HIV prevention forums or HIV-positive support groups are needed.”

“Getting an online presence to connect to youth, especially young gay men”

Results



Conclusions:

Most of the issues on enhancing utilization of prevention and care services were structural related (80%, such as taking prevention services to gay youth where they are instead of expecting them to come to us, and outreaching to youth in a variety of venues - schools, churches, online HIV prevention forums, and bars). Economic issues (such as needing more free HIV testing) and social issues (such as needing to educate people about stigma) were also brought up in the discussion (10% of all responses for each, respectively).

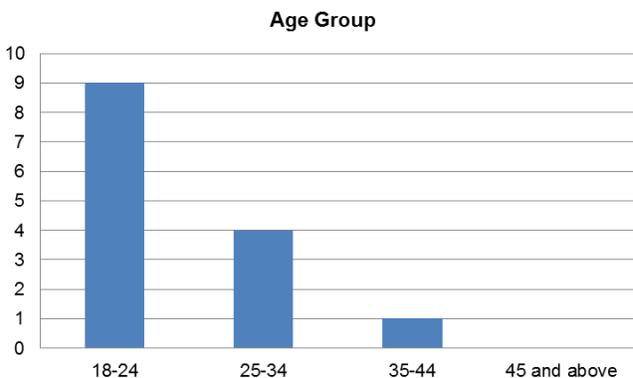
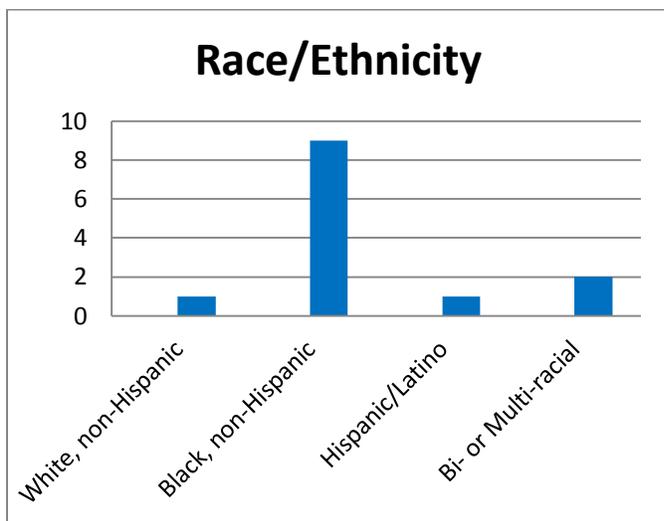
Focus Group Meeting One: Region Six (Champaign-Urbana) August 07, 2013

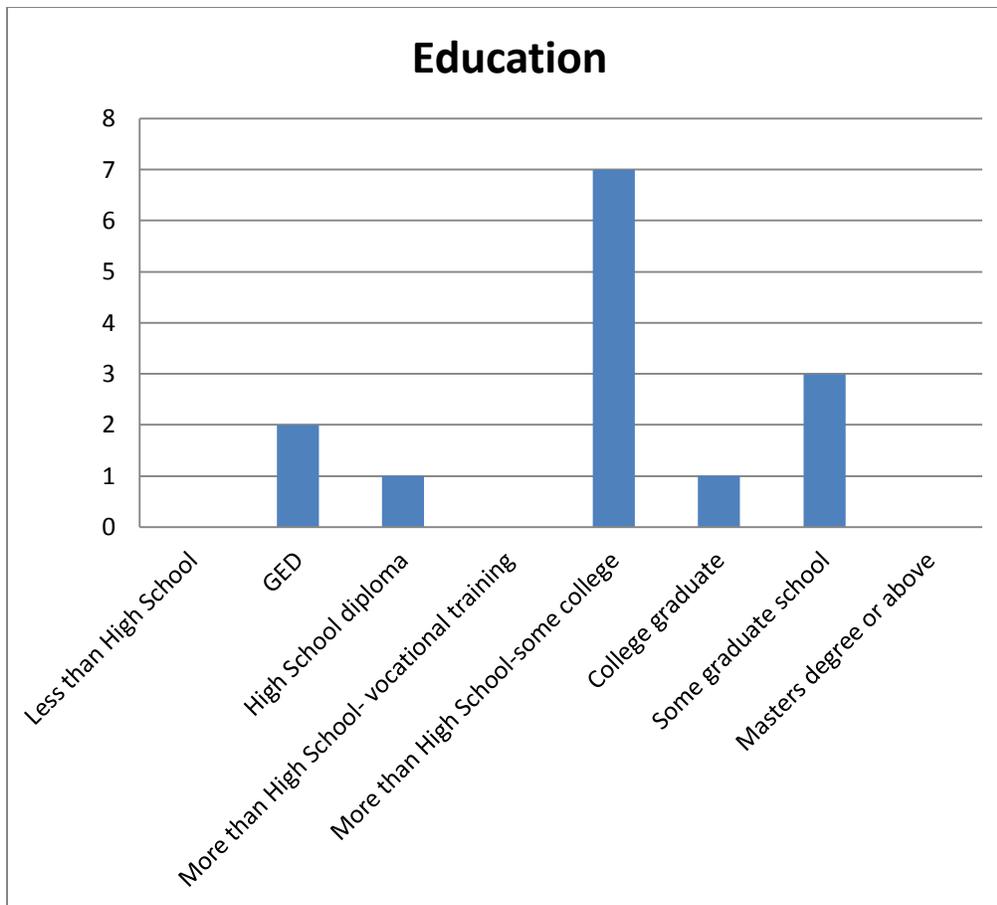
Number of Participants: 13
Location of Meeting: Champaign-Urbana

Overview: In discussion with the prevention and care lead agents for Region 3, the organizers decided to target the young (ages 18-29) MSM of color population for the focus group. There was already an existing support group in place from which to recruit participants, so the ILHPG Coordinator and Region 3 prevention lead agent collaborated with the facilitator of the support group for logistical arrangements and recruitment. In addition, we collaborated with an ILHPG member from Region Six who also worked at the African-American Cultural Center at the local university to assist with recruitment.

Characteristics of Region Six Focus Group Meeting Participants

All 13 participants were MSM, with 10 identified as homosexuals and 2 bi-sexuals. Distributions of race/ethnicity, age group, and education are provided in the charts below.





Discussion Questions, Responses, and Results

Question One:

The following question was asked to identify facilitators and inhibitors of HIV risk and risk reduction.

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

Quotes (categorized by type of issue):

- Economic Issues

No responses

- Psychological Issues

“Fear to get tested

- *Champaign is a small community, so may wonder “who’s watching me”, and thus may be judged”*

“Motivation”

“Living alone”

“Some peers I know care about HIV but a lot of people think it’s not a big issue anymore because it isn’t a death sentence any longer”

- Social Issues

“Being stigmatized”

“Because you are gay, you have HIV; being a person with HIV and a black MSM (even more stigmatized)”

“People feel stigmatized by HIV disease and not seen as a person”

“Cliques

- *Members of cliques may go against each other*
- *Relationship drama, such as “who slept with whose man” or “he’s my man!””*

“Social: sexuality, race, and social class

- *Nowhere to socialize besides the dance clubs*
- *No support”*

- **Structural Issues**

“Equal opportunity

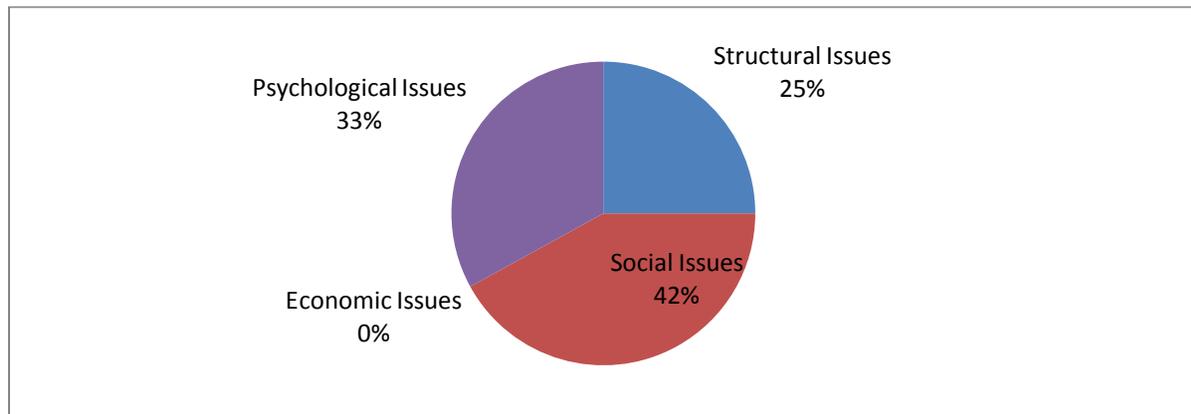
- *Being an MSM, there is a lack of “gay-friendly” places to go such as clubs”*

“School demands”

“HIV is a big concern; I have been to trainings and know what I need to do to keep safe.

This group helps me and gives me the knowledge I need.”

Results



Conclusions:

The responses included psychological issues (33%, such as the fear of being tested (and being seen testing), lack of motivation to get tested, and the belief in the community that HIV isn’t a big issue any longer); social issues (42%, such as the stigma associated with being gay, black, and HIV positive, the lack of support and “gay-friendly” places in the community, and complicated relationship with peers who are members of cliques); and structural issues (25%, such as lack of gay-friendly places for black MSM and need for more HIV trainings and support groups).

Question Two:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

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

Quotes (categorized by type of issue):

- Economic Issues
No responses
- Psychological Issues

“Once you know someone with HIV, it makes you have a different perspective about the disease and look at it more personally.

- *One’s lifestyle should change*

- **Social Issues**

“HIV comes up in discussion all the time with peers. I tell my peers they aren’t getting anything from me without a condom.”

“Social support from groups”

“HIV is perceived as a negative, a joke, as drama

- *People “with the package” have HIV*
- *If someone has it, “she/he is nasty...got the ‘claps’!”*
- *There are lots of rumors in the community about who has HIV*
- *Peers fight over it”*

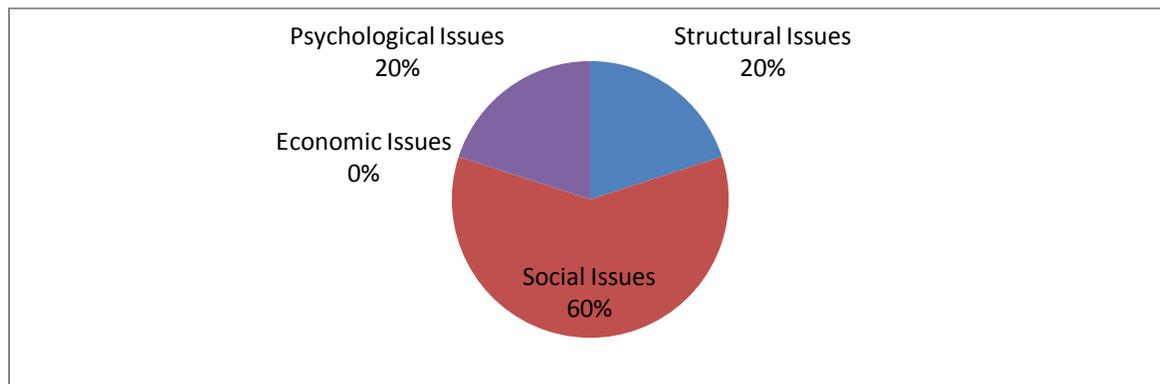
“We are trying to use information we learn and educate our peers about HIV

- *It’s a common conversation so peers can discuss and feel comfortable to discuss*
- *Educate peers at work*
- *“Put a glove on your pole”*

- **Structural Issues**

“Group interacts and learns about STD and HIV due to meetings.”

Results



Conclusions:

The responses included psychological issues (20%, such as knowing people with HIV gives people a new perspective about the disease); social issues (60%, such as discussions with peers about HIV, social support received via groups, and education received from peers); and structural issues (20%, such as group learning and interaction).

Question Three:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

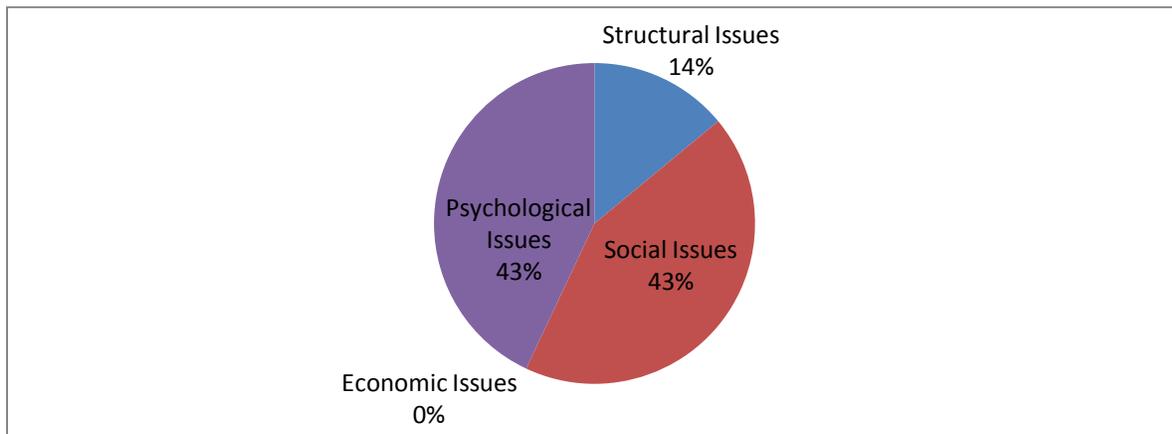
Question: What are the circumstances leading to a sexual encounter?

Quotes (categorized by type of issue):

- **Economic Issues**
No responses
- **Psychological Issues**

- *“Ask them about their status”*
 - *A lot of people may not know*
 - *Most people respond no or I don’t know. If they don’t answer, that’s a red flag. We are going to the clinic for a date!*
 - *“We ask people their HIV status when hooking up most of the time but not always.”*
 - *If I am at a party and drunk, I’m not having that conversation.*
 - *“HIV is still a fear”*
 - *I dated someone who was sleeping with other people and asked him about his HIV status*
- **Social Issues**
 - *“Websites and apps are the most common way to connect to other MSM these days.*
 - *Grinder, DownLink, Adam to Adam, Facebook*
 - *The Web is easy way to get into the “gay scene” when someone is just coming out. Seen as a safe way to feel people out and get to know them when deciding if you want to hook up.”*
 - *“Coffee shops, clubs, “out and about”*
 - *“There is no ball scene in Champaign/Urbana”*
- **Structural Issues**
 - *“We try to use this support group as a way for MSM to socialize”*

Results



Conclusions:

The responses included psychological issues (43%, such as being concerned about a potential partners’ HIV status and fear of HIV in general); social issues (43%, such as using websites, apps, and coffee shops to “hook up” before sexual encounters); and structural issues (14%, such as using support groups such as this to socialize).

Question Four:

The following question was asked to assess risk behavior practices in areas/populations hardest hit by HIV.

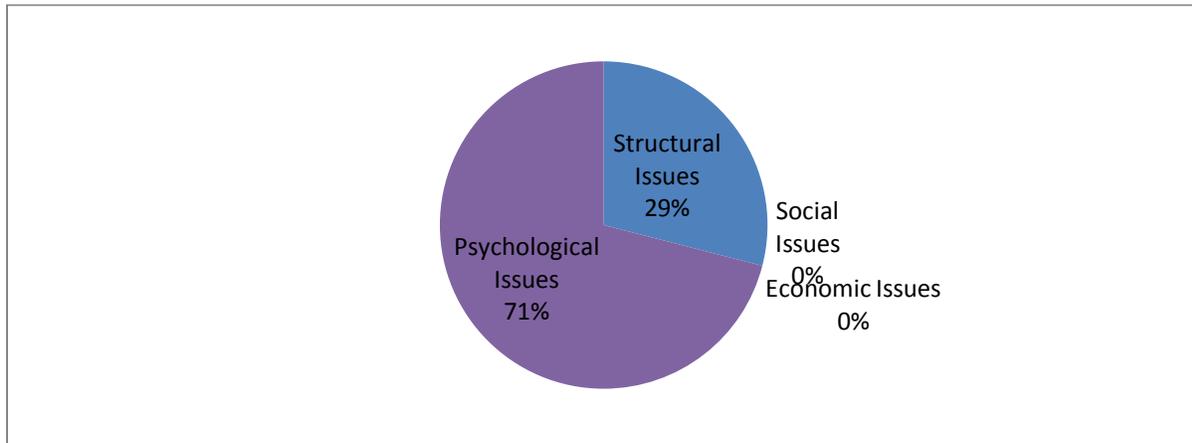
Question: How do you prepare to go out with the possibility to hook up?

Quotes (categorized by type of issue):

- **Economic Issues**

- *No responses*
- Psychological Issues
 - “I carry condoms with me all the time. I have them to share with friends.”
 - “Always carry a condom when going to social events”
 - “I don’t use condom with primary partner for two years, but we get tested all the time”
 - “Everyone had been tested for HIV at least once. Some had been tested along with their partners- pretty common.”
 - “Some have used female condoms and those that have experienced no problems in using them.”
 - *No stigma with using female condom*
- Social Issues
 - No responses*
- Structural Issues
 - “I get condoms at support group and at health department”
 - “No trouble here getting condoms or lube”

Results



Conclusions:

The responses mainly focused on psychological issues (71%, such as practicing safe sex behaviors and regular HIV testing); and structural issues (29%, such as being able to get condoms or lube at support group and health department, as needed).

Question Five:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Quotes (categorized by type of issue):

- Economic Issues
 - “Need to spread work that HIV testing is free at McKinley Health Center. They don’t do anonymous testing there. Results are available online with a pass code.”
- Psychological Issues
 - “You, yourself can be the best advertisement”
- Social Issues

“We’ve had parties, social events. What’s new?”

- *“Superhero” party, have thrown, events.*
- *A parade/barbecue that offers HIV testing and promote HIV prevention*
- *Skate Land/Bowling party that offers HIV testing and promote HIV prevention*
- *Fashion Show/Talent Show that offers HIV testing and promote HIV prevention”*

Structural Issues

“We are trying to come up with a commercial”

- *“Be a hero, know your status” - can be used for YouTube-advertising*

“Using Twitter for HIV prevention”

“Walk around campus, post flyers, and provide HIV awareness”

- *Themed condoms*

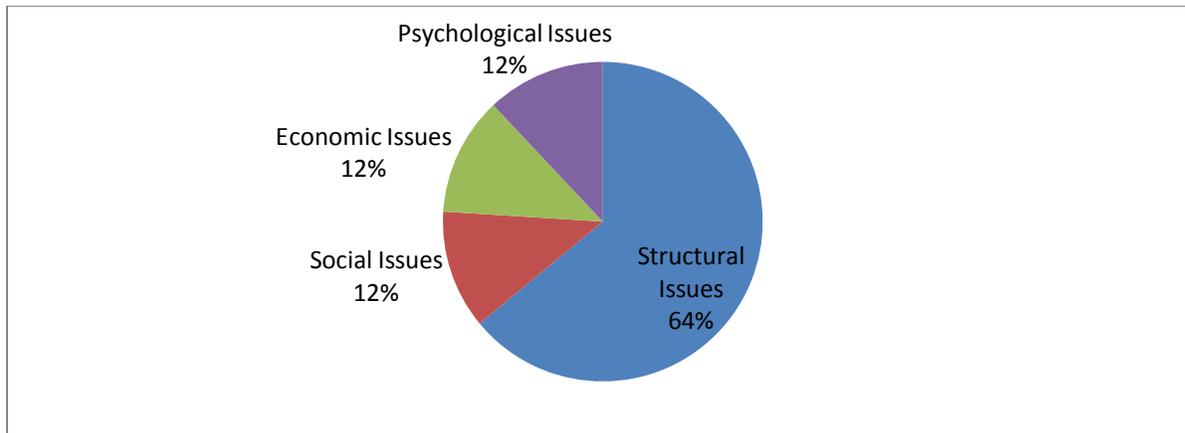
“Testing at hair salons”

- *“My friend does hair at a beauty shop and can give you a discount if you get tested”. Use her to promote HIV awareness and prevention.*
- *Collaboration with businesses.*

“Peers are the best method to appeal to members of their communities”

- *Promote HIV services online via Grinder, Facebook, Adam to Adam.*

Results



Conclusions:

The responses mainly focused on economic issues (12%, such as availability and knowledge about free HIV testing); psychological issues (12%, such as using one’s self to advertise HIV prevention and anti-stigma messages to peers); social issues (12%, such as having more social events and parties with peers); and structural issues (63%, such as promoting HIV services and events online and using social media, and providing HIV testing at venues such as hair salons).

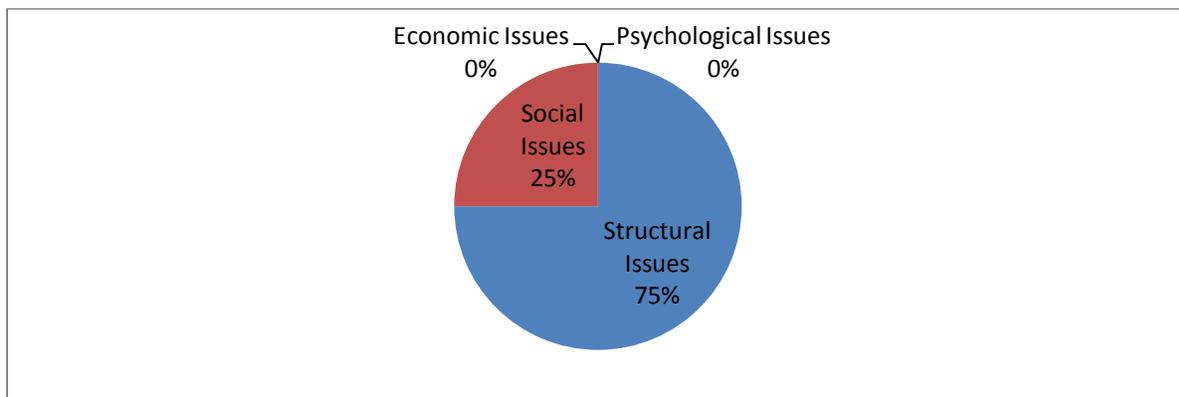
Question Six:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Quotes (categorized by type of issue):

- Economic Issues
No responses
- Psychological Issues
No responses
- Social Issues
 - “Introduce people to PLWHA, so they can eliminate “cancer” image”
 - *The stigma can be decreased.*
 - *They are seen as a person with an illness and not a disease.*
- Structural Issues
 - “Health Center to have a positive support center/group”
 - “A mass transit ad with someone who is HIV+ and proud”
 - “Random saying, “This person has HIV”
 - “Group session and positive people visit and speak”

Results**Conclusions:**

The responses mainly focused on social issues (25%, such as introducing and getting to know people to PLWHA to change one's perceptions) and structural issues (75%, such as a support groups for HIV positives in health centers, having advertisements about people living with HIV on mass transit, and having HIV positive people speak at group sessions and community events).

Question Seven:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia.

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

Quotes (categorized by type of issue):

- Economic Issues
No responses
- Psychological Issues
No responses
- Social Issues
 - “Gay community feels that people are seen as HIV positive because they are gay. People have been called names out in public and have been snickered at, called fags.”
 - “Through elementary and high school, being gay is not accepted. It is more accepted as an adult.”
 - Kids are “coming out” younger now.
 - “Being gay plus a minority is more stigmatized. White gay men are loved here.”
 - Black gays are viewed as ghetto, super feminine.
 - “There are two gay communities- closeted gay and an open gay community”
 - Clubs are viewed as a place where straight people can come see a show
 - “I know a lot of people that are gay that will not come to an event like this”.
- Structural Issues
No responses

Results

All responses were centered on social-related issues and barriers (100% of the responses).

Conclusions:

All of the responses to this question focused on social issues (100%, such as people assuming that gay people are HIV positive because they are gay; the lack of acceptance of being gay throughout elementary and high school, the large number of people that are still “closeted” gays, and the added stigma within the community of being a minority and gay).

Question Eight:

The following question was asked to assess knowledge and utilization of HIV prevention, care, and treatment services.

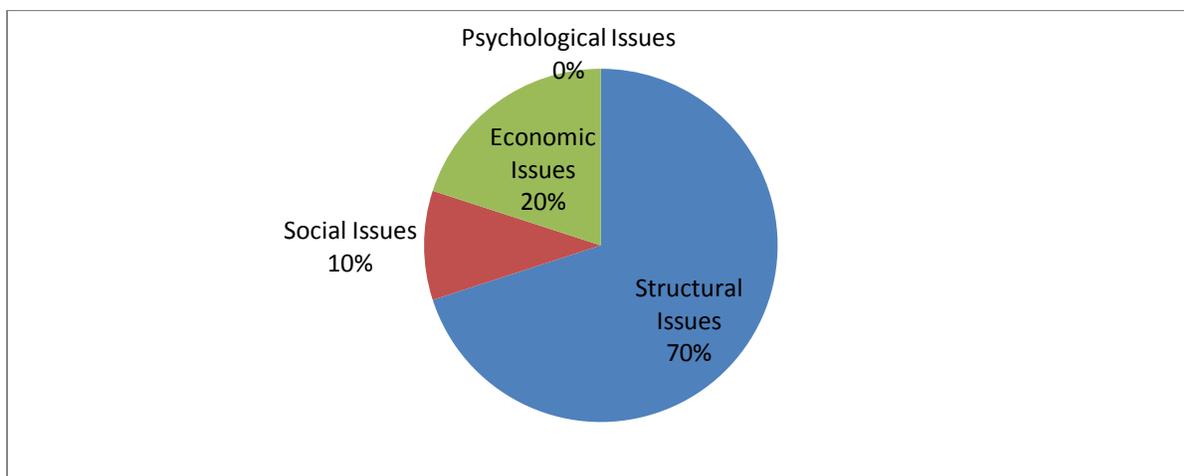
Question: “Do you have any suggestions on things community based organization and local health departments can implement to reduce HIV related stigma or homophobia to enhance utilization of prevention and care services?”

Quotes (categorized by type of issue):

- Economic Issues
 - “Free testing at hospitals and businesses”
 - “More money for HIV events that increase visibility and awareness of HIV”
- Psychological Issues
N/A
- Social Issues
 - “Something that brings the community out/together”
 - Mixers the night before event
 - AIDS walk this fall
- Structural Issues
 - “Training from home”

- *Having parent sit down and talk to kids about acceptance of gays and differences, diversities.*
- “A need of better health classes on HIV in schools”*
 - *They do this in Urbana not everywhere else.*
- “Public Health and McKinley routine after hour’s services”*
- “Having condoms readily available prevents or lessens risks”*
- “Need more corporations and public health departments to donate or participate in planning for events”*
- “In the next few years, there will be a need for HIV agency assistance”*
 - *More gay 13-14 year olds are coming out at schools*
- “Make things more specific because there is “red tape” around everything; makes you not want to do anything/plan events or programs.”*

Results



Conclusions:

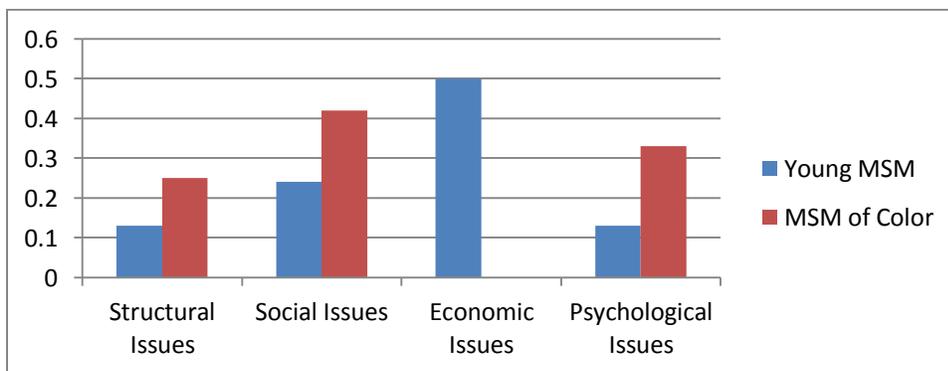
The responses included economic issues (20%, such as needing free testing at hospitals and more money for events like this); social issues (10%, such as need for activities that bring the community together); and structural barriers (70%, such as better health classes on HIV in schools, need for online training, need for more collaborations between public health and corporations, need for after hour services at the health department and McKinley Health Center, and need to have condoms more readily available).

Comparison of Focus Group Meetings by Questions

Comparison of the Two Focus Groups Responses by Questions

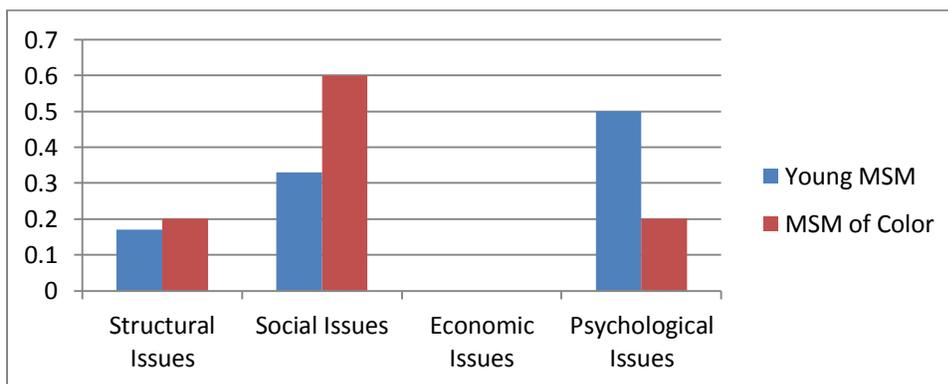
Although both focus groups were held in central Illinois regions among MSM, there was minor difference in the responses to the discussion questions between them. The focus group in Region Three targeted young MSM while the focus group in Region Six targeted MSM of color, predominantly young. Responses to the eight discussion questions therefore shared similarity but slight differences were observed. A brief discussion of the differences question-by-question is presented to summarize the findings from the two focus groups.

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



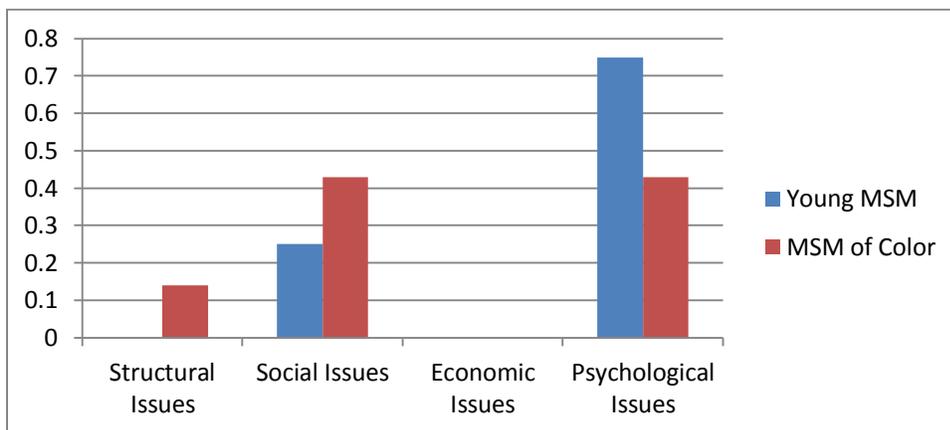
Young MSM voiced more challenges in economic issues while MSM of color brought up more about challenges in social and psychological issues.

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



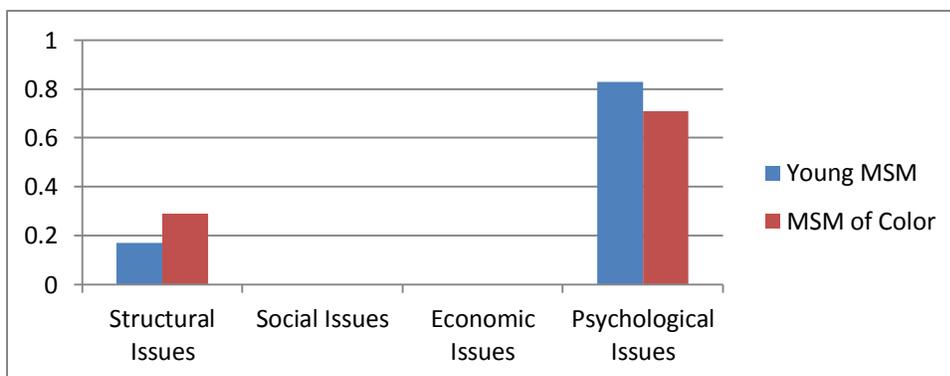
When discussing HIV with their peers, young MSM had more psychological issues than MSM of color, the later put more emphasis on social issues.

Question 3: What are the circumstances leading to a sexual encounter?



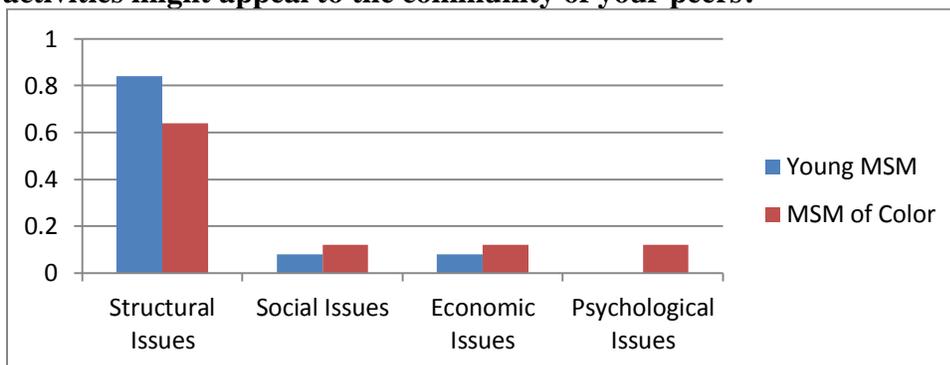
On the circumstances leading to a sexual encounter, young MSM were more concerned with psychological issues than their MSM of color counterparts. MSM of color were slightly more focused on social and structural issues.

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



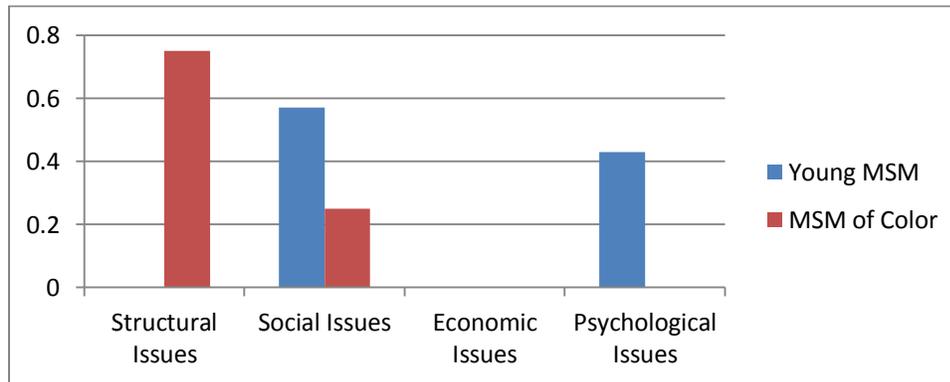
The responses on preparations to go out with the possibility to hook up were quite similar between young MSM and MSM of color, with concerns focused on psychological issues.

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?



Responses on what kinds of activities might appeal to the community of your peers were similar in the two groups. Promoting and making it easy to access HIV services and providing HIV testing at community venues were focused on during discussions.

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



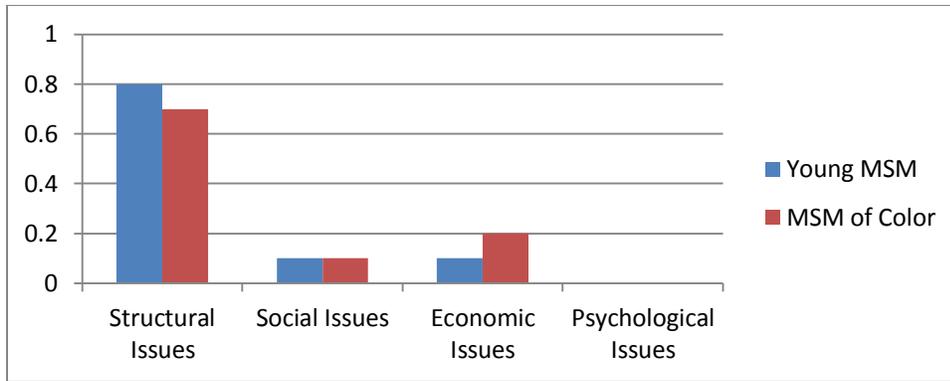
The biggest differences between the discussion responses by young MSM and MSM of color were observed in question six. On what to do to change people’s perception and behaviors in dealing with HIV, young MSM focused on social and psychological issues, whereas MSM of color were concerned more about structural issues.

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

Both young MSM and MSM of color attributed 100% of their discussion on social issues regarding HIV related stigma or homophobia in their community.

Question 8: “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?”

The responses to this question were basically the same between the two groups. Both young MSM and MSM of color centered their discussions on structural issues to reduce HIV related stigma or homophobia and to enhance utilization of prevention and care services. Some social and economic issues were raised during the discussions in both focus groups.



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 CY2013, the IDPH ILHPG Coordinator and the Community Planning intern will compile a report of all 2013 focus groups, summarizing each focus group individually as well as comparing the responses.

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 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; 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 does HIV come 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; 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 your 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.

Appendix C
HIV PREVENTION AND EDUCATION NEEDS ASSESSMENT
2012-2014 KEY INFORMANT INTERVIEW CONSENT FORM

You have been invited to be a part of a series of interviews with young gay males in the community in this region. These discussions are 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 key informant interview.

Procedure

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

- 1) Participate in one facilitated interview and discussion that will last about 90 minutes. The facilitators will be a consultant hired by the Illinois HIV Planning Group (ILHPG).
- 2) The discussion is being noted and recorded by 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 Interview and Discussion

Since you 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 may become upset or that the discussion may trigger painful memories.

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, you are free to withdraw at any time without affecting those relationships.

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

This interview/discussion is being sponsored by the Illinois HIV Planning Group. If you have any questions about the interview or concerns about your rights or your treatment as a participant in this interview, 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 key informant interview. My signature below means that I have freely agreed to participate in this discussion.

Name (please print) _____

Signature _____ Date _____

Appendix D 2012-2014 HIV Key Informant Interview 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/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"/> Master’s degree or above

Revised February 2013

Appendix E
Compiled Notes and Observations
Young (18-29) MSM Focus Group and Key Informant Interviews
Springfield, IL
February 7, 2013
 Compiled notes and observations

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

- Money
 - 3 years out of grad school and trying to deal with student loan debt and living expenses.
- Social Transition from college into professional setting
 - Student to young adult.
 - Mentor role- being one who is supposed to know safe sex and still be social.
- HIV is always present as an issue in my life.
 - It's a fear, informs what I do and with whom and how often.
 - Decrease in behaviors that lead up to sex as a result of HIV knowledge.
 - I know I have access to free condoms and lubes. I specifically know this and have no barriers. Before, in 20s, I was open about my sexuality, I did not know free services and availability of testing.
- My three greatest challenges are college classes, time management, and finding a better job. I don't see HIV as an issue in my life. In terms of worrying about HIV infection, that is a low priority in my life.
- My three greatest challenges are starting college at Lincoln Land Community College, adjusting to my night work schedule, and dealing with the stroke I had four years ago – I'm still adjusting to this because my left hand tenses up and my leg locks up. HIV scares me. I see HIV infection as a “potential happening.” The thought of HIV is always there for me, but I don't talk about it all the time. It is a concern but not a “top three” concern.

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

- HIV doesn't come up often. It is like the “elephant” in the room. However, I look out for others when they talk and hook up with someone I think is risky.
- Has a team of peers who look out for each other:
 - Safe driving, safe sex.
- We feel bad for people that are HIV positive, but we also know those persons are risks to us. We are friendly with them but don't really associate or socialize intimately with them.
- I know three people that are HIV positive.
- HIV never comes up in discussions with my friends. I have gone to the Phoenix Center for HIV group education sessions but I don't now due to school. I don't personally know any HIV-positive people. My friends would be concerned if someone we knew had HIV because we would worry about their well-being.
- HIV doesn't come up in discussions with my peers – it never gets brought up. I do talk to my mom about HIV, though. She is a nurse. She checks on me “being safe” and reminds

me to use protection. My uncle who passed away was HIV-positive. We were really close. He helped me come out and he talked to me about HIV like my mom does.

Question 3 - What are the circumstances leading to a sexual encounter?

- There are a variety of ways to communicate
 - Through other friends (gay)
 - Online (Grinder, Facebook)...then will meet in person
 - Going out on dates and talking to past partners
- May ask difficult question on dates, “When was the last time or have you been tested for HIV?”
 - Answer can lead to sex encounter
 - Sometimes I postpone having sex with someone because I don’t want to ask that question and I know I have to ask.
 - Some answers don’t ring true to me and I will stop corresponding or pursuing that relationship
- I’m in a monogamous relationship with another guy and I have been for 10 months now, so I don’t go out to meet other people. We talked about HIV before we got together.
- Before I ever have sex I make sure that I have condoms. I always have them with me when I go out to meet people. I get them at County Market or at the pharmacies in town.

Question 5 – How do you prepare to go out with the possibility to hook up?

- I don’t have a steady partner now
- If I go out, I always have condoms in my car that I can access
- Sometimes I wear a pair of ratty old underwear that I am embarrassed by so I know I won’t engage in risky behavior
- In past 3-4 years, most risky activity I have engaged in is making out and groping. In undergrad, going out with ex partners I know are risky
- I have referred partners for testing, but never tested with partners
- I tested 3 months ago.
- My partner and I are monogamous and have no other partners. We were safe when we first got in the relationship, but now we have unprotected sex. I am the bottom. My partner has no other partners. I have not been tested for HIV but my partner has and he is HIV-negative.
- I currently have a boyfriend and we use condoms. We both have been tested for HIV. Before we got in our relationship, we talked about HIV and we got tested together at the Phoenix Center. We get condoms at the Phoenix Center, too. I have one other friend who gets tested for HIV regularly at the Phoenix Center. My friends all practice safe sex.

Question 6 – Now that we have talked about what is important to you, what kinds of activities might appeal to the community of you peers?

- Training in education and giveaways at gay bars.
 - Not regular condoms, but something that may seem as a prize.
- I am against testing in bars because people may not be read and in a place where they can deal with the process and the results. But people might not otherwise get tested if not offered in bars.

- Bare scene is primary outlet for gay young men in this town.
- Recommends that prevention agencies set up a Grinder box to inject prevention messages into hit on that application.
- In bigger cities they have gay men's sports leagues. Here, they have a gay men's chorus but is mostly older men.
- Training HIV prevention into something gay men want (ex. certain clothing stores) may work better.
- More age-appropriate activities for HIV prevention focused on younger people would be helpful. More public speakers who have HIV are needed. More HIV-positive role models who can speak about their experiences. We need HIV prevention discussion boards online locally and online HIV prevention groups or online HIV-positive support groups locally.
- We need more media campaigns about HIV that are directed toward me and my peers. We need to have free HIV testing at all community locations. We need more places like the Phoenix Center in town – it is a great resource. More HIV educators need to go out into the community. We need more HIV youth groups like the Phoenix Center has. HIV services need to be more widely available in the community, period.

Question 7 – Based upon what we have discussed, how do we go about changing people's perception and behaviors in dealing with HIV?

- My perception and behaviors in dealing with HIV have changed since I met people who are HIV positive.
- Having people with HIV talk at the schools has changed my perception.
- A lot of times people will disassociate with someone they know have HIV.
- When I was younger (in college) I participated in less safe sex behaviors.
- In my social circle, safe sex with “few and far between” slip ups is the norm. Having sex with someone you just met that night is viewed as bad.
- We need to educate people about HIV and what it is like to have HIV. HIV-positive people couldn't control getting infected necessarily and many regret it. There are too many stereotypes out there about people with HIV.
- We need to talk about HIV openly in the community like my mom and my uncle did for me. People with HIV and young people need to talk about these things openly.

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

- I participated in gay bar and went sponsored by Phoenix Center. Both focus on reducing stigma. Even in gay bars HIV positives are stigmatized. Bartender warns me if friends are showing interest in someone know or thought to be. Friend did not pursue relationship when person disclosed status. This led to hurt feelings on the person's part.
- Homophobia- Young teenager's school violence towards young gay men.
- “Gay”, “Faggot”, “Dike” used derogatory sense. I haven't experienced a lot of homophobia in community outside of schools. Likely because of whom I associate with.
- There is lots of homophobia in this community. There is a lot in schools. The term “fag” was used in my high school all the time. There is lots of online homophobia and discrimination in this community, especially on Facebook and Twitter.

- I experienced much homophobia at school because I was open about my sexuality. But I still think young people need to talk openly about their experiences so that these attitudes eventually end.

Question 8 – 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?

- Having a presence in schools and starting early.
- Getting an online presence to connect to youth, especially young gay men.
- Take prevention services to gay youth making it as readily available as possible
 - Education
- Instead of bringing students here [clinics], going to the schools or going to the bars and taking it to them.
- It may be hard to reach students in public high schools, but maybe colleges and churches. Few churches are openly gay-friendly and supportive.
- These agencies need to educate people about stigma. HIV-positive speakers are needed to tell their stories publically. Online HIV prevention forums or HIV-positive support groups are needed.
- Like I said, more media campaigns, more free HIV testing, more HIV services throughout the community. If people were always open and talking about HIV, we could change many opinions and behaviors.

Appendix E
Compiled Notes and Observations
Young MSM of Color Focus Group
Champaign-Urbana, IL
August 7, 2013

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

- Equal opportunity
 - Being an MSM, there is a lack of “gay-friendly” places to go such as clubs
- Fear to get tested
 - Champaign is a small community, so may wonder “who’s watching me”, and thus may be judged
- Personal : Motivation, School demands, living alone
- Cliques
 - Members of cliques may go against each other
 - Relationship drama, such as “who slept with who man” or “he’s my man!”
- Social: sexuality, race, and social class
 - Nowhere to socialize besides the dance clubs
 - No support
- Being stigmatized
- “Because you are gay, you have HIV”; a person with HIV as a black MSM.
- HIV is a big concern, I have been to trainings and know what I need to do to keep safe. This group helps me and gives me the knowledge I need.
- Some peers I know care about HIV but a lot of people think it’s not a big issue anymore because it isn’t a death sentence any longer.
- People feel stigmatized by HIV disease and not seen as a person.

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

- HIV comes up in discussion all the time with peers. I tell my peers they aren’t getting anything from me without a condom.
- Social support from group
 - Group interacts and learns about STD and HIV due to meetings.
- HIV is perceived as a negative, a joke, as drama
 - People “with the package” have HIV
 - If someone has it, “she/he is nasty...got the ‘claps’!”
 - There are lots of rumors in the community about who had HIV
 - Peers fight over it
- Note: Most people in the room know 1-3 people with HIV
- Once you know someone with HIV, it makes you have a different perspective about the disease and look at it more personally.
 - One’s lifestyle should change
- We are trying to use information we learn and educate our peers about HIV
 - It’s a common conversation so peers can discuss and feel comfortable to discuss
 - Educate peers at work

- “Put a glove on your pole”

Question 3 - What are the circumstances leading to a sexual encounter?

- Websites and apps are the most common way to connect to other MSM these days.
 - Grinder, DownLink, Adam to Adam, Facebook
 - Web is easy way to get into “gay scene” when someone is just coming out. Seen as a safe way to feel people out and get to know them when deciding if you want to hook up.
- Coffee shops, clubs, “out and about”
- There is no ball scene in Champaign/Urbana
- We try to use this support group as a way for MSM to socialize
- Ask them about their status.
 - “A lot of people may not know”
 - Most people respond no or I don’t know. If they don’t answer, that’s a red flag.
 - “We going to the clinic for a date!”
- We asked people their HIV status with hooking up most of the time but not always.
 - “If I am at a party and drunk, I’m not having that conversation.
- HIV is still a fear
 - “I dated someone who was sleeping with other people and asked him about his HIV status”

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

- I carry condoms with me all the time. I get condoms at support group and at health department. I have them to share with friends. No trouble here getting condoms or lube.
- Always carry a condom when going to social events
- I don’t use condom with primary partner for two years, but we get tested all the time
- Everyone had been tested for HIV at least once. Some had been tested along with their partners- pretty common.
- Some have used female condoms and those that have experienced no problems in using them.
 - No stigma with using female condom

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

- We’ve had parties, social events. What’s new?
 - “Superhero” party, have thrown, events.
 - A parade/barbecue that offers HIV testing and promote HIV prevention
 - Skate Land/Bowling party that offers HIV testing and promote HIV prevention
 - Fashion Show/Talent Show that offers HIV testing and promote HIV prevention
- We are trying to come up with a commercial
 - “Be a hero, know your status”- can be used for YouTube-advertising
- Using Twitter for HIV prevention
- Walk around campus, post flyers, and provide HIV awareness
 - Themed condoms

- Need to spread work that HIV testing is free at McKinley Health Center. They don't do anonymous testing there. Results are available online with a pass code.
- Testing at hair salons
 - “My friend does hair at a beauty shop and can give you a discount if you get tested”. Use her to promote HIV awareness and prevention.
 - Collaboration with businesses.
- Peers are the best method to appeal to members of their communities.
 - Promote HIV services online via Grindr, Facebook, Adam to Adam.
 - “You, yourself can be the best advertisement”

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

- Introduce people to PLWHA, so they can eliminate “cancer” image.
 - The stigma can be decreased.
 - They are seen as a person with an illness and not a disease.
- A mass transit ad with someone who is HIV+ and proud
 - Random saying, “This person has HIV”
- Group session and positive people visit and speak
- Health Center to have a positive support center/group

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

- Gay community-feeling that people are seen as HIV positive because they are gay. People have been called names out in public and have been snickered at, called fags.
- Through elementary and high school, being gay is not accepted. It is more accepted as an adult.
 - Kids are “coming out” younger now.
- Being gay plus minority is more stigmatized white gay men are loved here.
 - Black gays are viewed as ghetto, super feminine
- There are two gay communities- closeted gay and an open gay community
 - Clubs are viewed as a place where straight people can come see a show
 - “I know a lot of people that are gay that will not come to an event like this”

Question 8 – 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?

- Training from home
 - Having parent sit down and talk to kids about acceptance of gays and differences, diversities.
- Public Health and McKinley routine after hours services
- Free hospitals at businesses
- Having condoms readily available prevents or lessens risks
- Something that brings the community out/together
 - Mixers the night before event
 - AIDS walk this fall

- Need more corporation from Public Health Departments to donate or participate in planning for events
- In the next few years, there will be a need for HIV/Agency assistance
 - More gay 13-14 year olds are coming out at schools
- A need of better health classes on HIV in schools
 - They do this in Urbana not everywhere else.
- More money for HIV events that increase visibility and awareness of HIV
- Make things more specific because there is “red tape” around everything; makes you not want to do anything/plan events or programs.