

ILLINOIS HIV PREVENTION COMMUNITY PLANNING GROUP 2012 FOCUS GROUPS REPORT

AUTHORS:

**FANGCHAO MA, ILLINOIS DEPARTMENT OF PUBLIC HEALTH HIV EVALUATION ADMINISTRATOR;
JANET NUSS, ILLINOIS DEPARTMENT OF PUBLIC HEALTH HIV PREVENTION COMMUNITY PLANNING GROUP
COORDINATOR;
ASHLEY THOMPSON, ILLINOIS DEPARTMENT OF PUBLIC HEALTH HIV COMMUNITY PLANNING INTERN**

TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
BACKGROUND	4
METHODOLOGY	5
FOCUS GROUP ANALYSES	7
BERWYN- HISPANIC MEN SLEEPING WITH MEN FOCUS GROUP (MSM)	7
EAST ST. LOUIS- TRANSGENDER FOCUS GROUP	14
JOLIET- PEOPLE LIVING WITH HIV/AIDS FOCUS GROUP	20
PEORIA- AFRICAN AMERICAN MALES FOCUS GROUP	25
COMPARISON OF FOCUS GROUPS	31
APPENDICES	34
APPENDIX A. HIV PREVENTION COMMUNITY PLANNING GROUP PROTOCOL FOR FOCUS GROUPS 2012-2013	35
APPENDIX B. 2012-2013 HIV FOCUS GROUP FACILITATOR DISCUSSION GUIDE	36
APPENDIX C. HIV PREVENTION AND EDUCATION NEEDS ASSESSMENT 2012-2013 FOCUS GROUP CONSENT FORM	39
APPENDIX D. 2012 HIV FOCUS GROUP PARTICIPANT DEMOGRAPHICS SURVEY	41
APPENDIX E. COMPILED NOTES AND OBSERVATIONS	42

EXECUTIVE SUMMARY

Annually, the Illinois HIV Prevention Community Planning Group (PCPG) conducts 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 and 2013, the PCPG 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 four of the prevention regions in 2012. 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 PCPG would like to thank its leadership, the members of the Evaluation Committee and the focus group subcommittee, Department HIV Section staff, regional lead agents, focus group facilitators and participants, who all played a major role in the successful completion of this project. The PCPG 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 PCPG Executive Committee 2012 strategic planning meeting, PCPG 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. 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 strategy included conducting four facilitated focus group discussions in March (Region 4-East St. Louis), April (Region 8-Berwyn), May (Region 2-Peoria), and June (Region 7-Joliet) 2012. 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: East St. Louis-transgender, Berwyn-Hispanic men who have sex with men (MSM), Peoria- African American males, and Joliet-people living with HIV or AIDS (PLWHA).

A focus group subcommittee was formed, comprised of the Department's HIV Section Prevention Administrator, the Department's PCPG Coordinator, selected members of the PCPG Epi/Needs Assessment Committee, members of the PCPG Evaluation Committee, and 2 former community PCPG members. The subcommittee was tasked to establish the protocol, discussion guide, objectives, and procedures used to conduct and evaluate the focus group discussions. The subcommittee met several times between December 2011 and February 2012, researched and reviewed sample documents, and finalized the planning and development of all documents that were used for the focus groups. The HIV Prevention Community Planning Group Protocol for Focus Groups 2012-2013 (Appendix A) summarized the process that was followed to plan for, recruit participants, conduct, and evaluate the focus groups. The 2012-2013 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 2012-2013 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 HIV Focus Group Participant Demographics Survey (Appendix D) tracked demographic and risk information for all participants.

The subcommittee decided that the Co-chair of the Evaluation Committee, assisted by the coordinator of each of the support groups to be used for focus group recruitment, would facilitate the focus groups. In collaboration with the HIV Section Training Unit, training on “Facilitating Focus Groups” was provided at the February 2012 PCPG Meeting. Conference calls were later scheduled by the PCPG Coordinator and held before each of the regional focus groups to ensure the facilitators were educated on the protocol and discussion guide and comfortable with the planned flow of the meetings and their role as facilitators. The participants were provided with an HIV epidemiologic and vital statistic fact sheet handout 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-PCPG participant received a \$20.00 gift card to compensate for time and travel expenses and as thanks for their participation.

METHODOLOGY

Following the protocol developed by the PCPG 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, and PCPG members from the designated focus group regions. Expecting to recruit eight to 12 participants, the support group facilitators invited an average of ten to fifteen possible participants from the targeted regions (East St. Louis, Berwyn, Peoria, and Joliet) and high risk populations to take part in the focus groups (including Transgender, Latino men sleeping with men (MSM), African American MSM, and PLWHIV populations).

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. As previously stated, the focus group sessions were facilitated by the co-chair of the PCPG Evaluation Committee and co-facilitated by the identified support group facilitator. After explanation, each member was asked to sign a consent form and the demographic survey form established by the focus group subcommittee.

The focus group facilitators were instructed to try their best to follow the discussion questions, as developed; however, they were able to ask probing questions to solicit additional information and 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:

Introductory:

- 1) What are the three greatest challenges in your life that you are struggling with right now?
- 2) How does HIV come up in discussions with your peers?
- 3) What are the circumstances leading to a sexual encounter?
- 4) How do you prepare to go out with the possibility to hook up?

Open Ended:

- 1) Now that we have talked about what is important to you, what kinds of activities might appeal to the community of your peers?
- 2) Based upon what we have discussed, how do we go about changing people's perceptions and behaviors in dealing with HIV?
- 3) Can you provide us with some examples of where you experienced or have seen HIV-related stigma or homophobia in your community?
- 4) 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?

With the acknowledgement and permission of the focus group members, each session was tape recorded and observations were notated by an assigned note taker. An explanation was given to the participating focus group members on how the Department and the PCPG planned to utilize the focus group results to 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 focus group subcommittee 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 eight initial questions in the focus group facilitator discussion guide and all additional/modified probing questions were categorized into according to the four main focus group objectives. Responses from the transcripts were then categorized into the following four types of barriers:

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

After categorization, frequency of the problems identified and brought up in the focus group discussion was calculated.

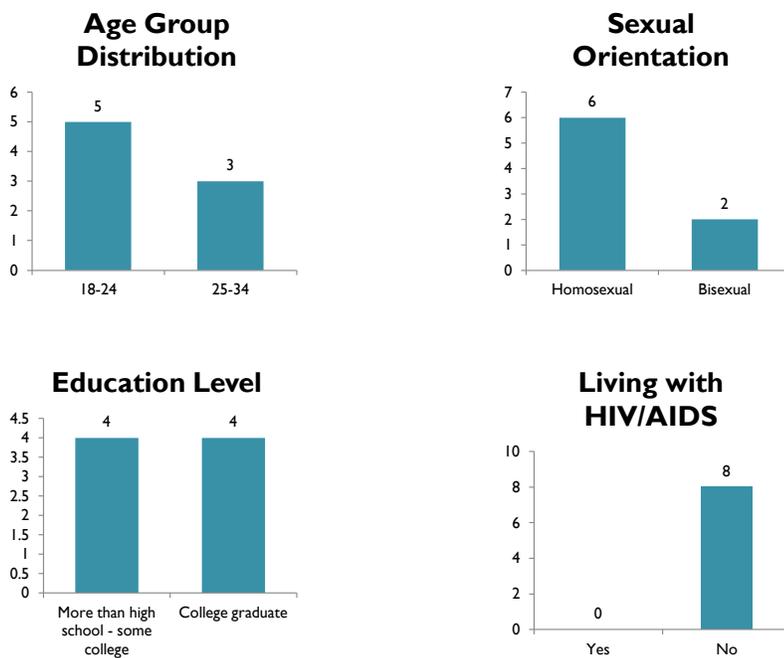
The results of the 2012 focus groups were summarized and presented to the PCPG at the August 2012 meeting. The PCPG and the focus group subcommittee realize there are limitations to the use of the data and information gained from the conduct of these focus groups and acknowledge the results may not be 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 PCPG 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 ANALYSES

Focus Group 1: Berwyn- Hispanic Men Sleeping with Men (MSM), April 23, 2012

Number of Participants: 8
Location of Meeting: PCC Wellness Center

Demographic Characteristics of Hispanic/Latino MSM Focus Group in Region 8: Berwyn



Discussion Questions, Responses, and Results

Series One Questions:

The following question was asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: “What would you do to reduce stigma and stop HIV?”

Quotes (categorized by type of barrier):

- Economic Barriers
“I actually got paid to test at Circuit.”
- Psychological Barriers
“When I think about me then and me now, I would consider myself weak then.”
- Social Barriers
“I’ve known about my sexuality since first grade, but you don’t learn anything about your sexuality for years. When you’re younger, it would be good to be taught respect.”

“I still get shocked that I meet guys who are 25-35 and they have the most ignorant ideas about HIV. I look at sex as just sex, but I’m educated how to protect myself. I meet guys and I can’t believe how little they know and what wrong things they believe!”

“The campaigns for HIV prevention -if you aren’t worried about it, you’re not going to use a condom. But if you never get checked! They also need to know to come back in three months. Also, people need to understand HIV so they aren’t so scared of it that they avoid getting checked. People will slip eventually. So the fear [presumably, of a positive result] cannot outweigh the prevention. “

“Parents just don’t know. They might mean well, but if they aren’t in denial, they don’t know what to say to kids about it.”

- **Structural Barriers**

“Most of us spend a lot of time on the internet. There should be laws that if you have a website, there should be prevention ads, not just ads for porn.”

Results:

Figure 1. Hispanic/Latino MSM Pie Chart of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

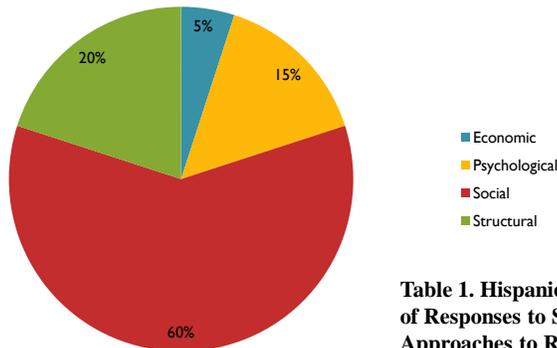


Table 1. Hispanic/Latino MSM Frequency Table of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

Barriers	Question 1	Total	Frequency
Economic	1	1	5%
Psychological	3	3	15%
Social	12	12	60%
Structural	4	4	20%
Total	20	20	100%

Conclusions:

- **Psychological Barriers**
-Low self-esteem
- **Social Barriers**
-Lack of knowledge/awareness about sexuality and HIV among general population
-Greater need for more public awareness campaigns
-Greater need for education

Series Two Questions:

The following questions were asked to assess risk behavior practices in areas/populations hardest hit by HIV. 1. “How does HIV come up in discussions with your peers? How often does HIV come up? What exactly are they talking about? Is HIV an issue? What are people (in the community) saying about HIV+ people? How many people do you know personally who are HIV positive?” 2. “Who do you hang out with? Mostly gay folks? Mixed?” 3. “What about partying and substance abuse?”

Quotes (categorized by type of barrier):

- Economic Barriers

“They tell you to go to the dentist twice a year, but then you go and it’s so expensive.”

- Psychological Barriers

“For me, it’s scary, because it’s getting closer and closer. I hear about a friend or someone I used to date turning up positive. It’s okay ‘cause I’m still safe.”

“I was going to school in Champaign, and I went into depression and isolated myself for a while.”

“For me, I just have one boyfriend. But for me, I don’t get turned on with condoms, even when I’m watching porn I don’t get turned on [if there’s condoms]. I’m a really optimistic person, so if something happens I think I’d be okay.”

- Social Barriers

“I’ve only had straight relationships and I haven’t had sex with a guy yet. My straight friends never talk about getting tested.”

“When I came out, I told my friends, and two of my girls started crying. I said ‘B*s, why are you crying?! I’m the one coming out!’”

“I was straight until I was 25. But I was molested when I was little; my first sex was with a man when I was little. Among my frat brothers, it was never about HIV. It was STDs they worried about, itching or burning.”

- Structural Barriers

“You wait a long time. I waited 3-4 hours for a test. Then you come back out, and you have to wait even longer for your result.”

Results:

Figure 2. Hispanic/Latino MSM Pie Chart of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

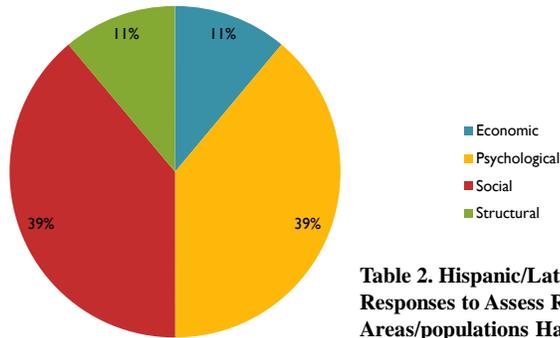


Table 2. Hispanic/Latino MSM Frequency Table of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

Barriers	Question 1	Question 2	Question 3	Total	Frequency
Economic	2	0	0	2	11%
Psychological	4	1	2	7	39%
Social	3	4	0	7	39%
Structural	2	0	0	2	11%
Total	11	5	2	18	100%

Conclusions:

- Psychological Barriers
 - HIV is not discussed
 - Great frequency of depression and isolation
- Social Barriers
 - Lack of social acceptance of different sexualities
 - Lack of discussion about HIV
 - Sexually transmitted diseases (STDs) are talked about among peers as if something to be proud of

Series Three Questions:

The following questions were asked to assess knowledge and utilization of HIV prevention, care, and treatment services: 1. “Are you comfortable coming out to your doctor”? 2.

“Anyone ever go to counselors”?

Quotes (categorized by type of barrier):

- Economic Barriers

“Counselors cost. How do you pay for that?”

- Social Barriers

“I went to the doctor ‘cause I noticed some bumps in my anus. I went to ___ ___Health Center. He takes 2 seconds. He said. ‘Yup, those are genital warts.’ My boyfriend was with me. He asked if they were contagious. The doctor said, ‘If you stick your penis in his anus, you’ll get them too.’ I went somewhere else to get them treated and they said they were hemorrhoids. That [first] doctor just assumed since I was there with my boyfriend that they were warts. I will never go back to that ___ clinic.”

“With my family, I pretty much grew up on my own. I didn’t know it was not normal to grow up getting hit all the time. If I talked about it, it got back to home and it got me in trouble.”

“My friend was always sick with something. I asked him to go get checked out, but he was too scared to go.”

Results:

Figure 3. Hispanic/Latino MSM Pie Chart of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

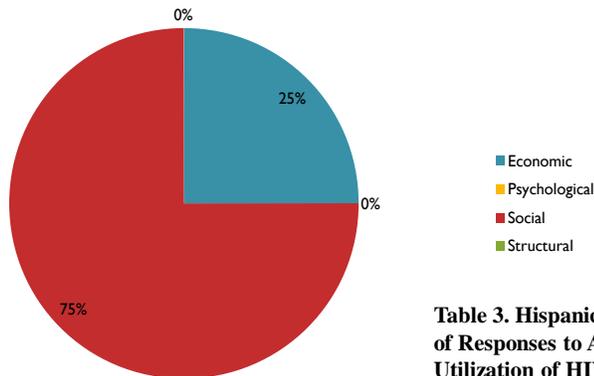


Table 3. Hispanic/Latino MSM Frequency Table of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

Barriers	Question 1	Question 2	Total	Frequency
Economic	0	1	1	25%
Psychological	0	0	0	0%
Social	2	1	3	75%
Structural	0	0	0	0%
Total	2	2	4	100%

Conclusions:

- Economic Barriers
-Expense of receiving services

- Social Barriers
 - Stereotypes
 - People find it difficult to talk to their families, friends, doctors, counselors.

Series Four Questions:

The following questions were asked to identify facilitators and inhibitors of HIV risk and risk reduction: 1. “What are the three greatest challenges in your life that you are struggling with right now?” 2. “Many of you mentioned a theme of families. Is there a lot of pressure about coming out to families?” 3. “How much does religion play a role in your life?” 4. “Is the immigration issue a barrier to testing?” 5. “As young gay men, do you feel safe in your community?”

Quotes (categorized by type of barrier):

- Economic Barriers

“They tell to go to the dentist twice a year, but then you go and it’s so expensive.”
- Psychological Barriers

“I’m terrified of sex.”
- Social Barriers

“Coming out to my parents - I did it at a family picnic, and I had money ready in my savings account in case I had to move out. It’s weird because they’re here straight from Mexico. And where we’re from, people have no education about gay people.”

“It depends on your religious background. My family is Pentecostal, and it’s not accepted at all. I told my grandma, and she said ‘You’re dead.’”

“We’re all educated guys. But for most guys, there’s not a lot of knowledge about where to get them.”
- Structural Barriers

“I have friends that avoid going to the doctor because they don’t have papers.”

Results:

Figure 4. Hispanic/Latino MSM Pie Chart of Responses to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

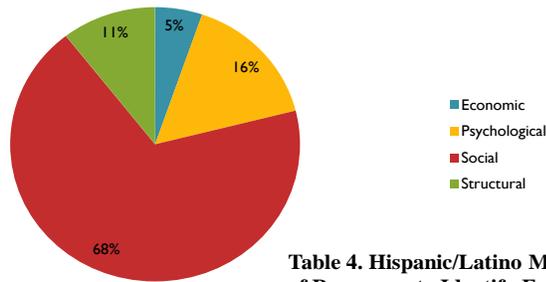


Table 4. Hispanic/Latino MSM Frequency Table of Responses to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

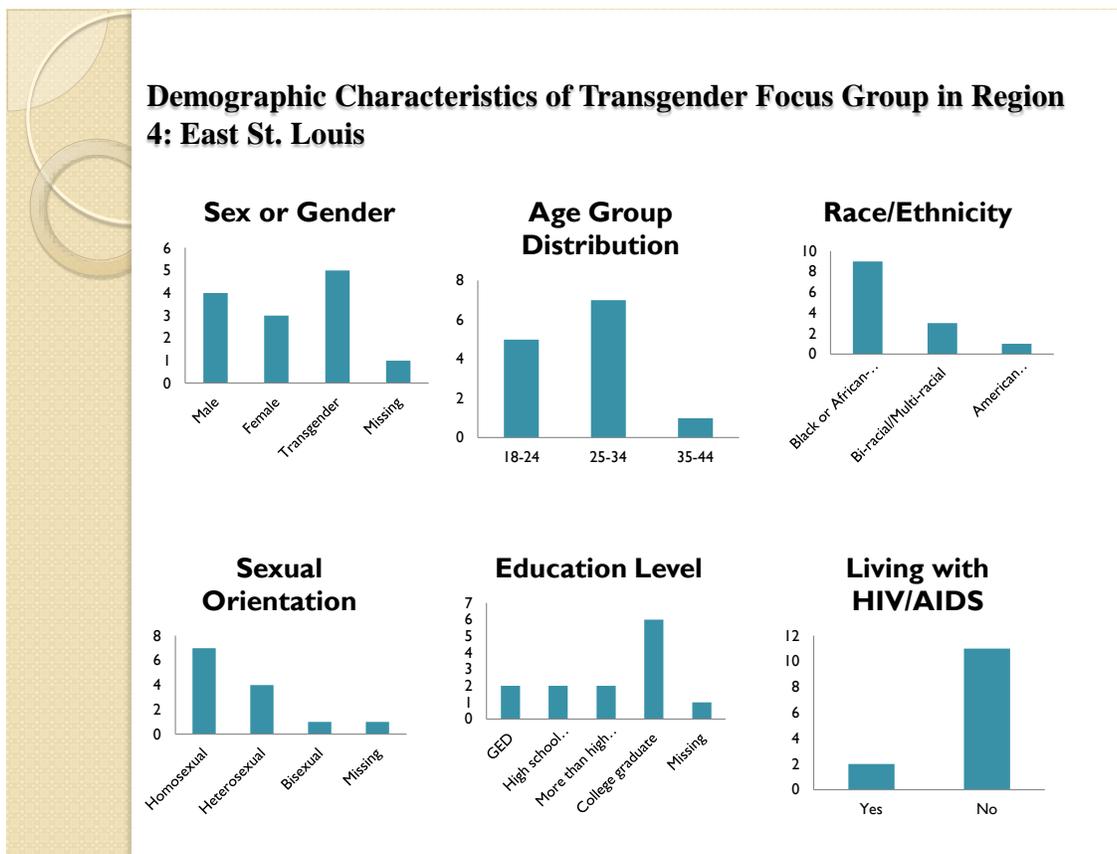
Barriers	Question 1	Question 2	Question 3	Question 4	Question 5	Total	Frequency
Economic	0	0	0	1	0	1	5%
Psychological	3	0	0	0	0	3	16%
Social	4	4	4	1	0	13	68%
Structural	0	0	0	1	1	2	11%
Total	7	4	4	3	1	19	100%

Conclusions:

- Economic Barriers
-Expense of medical care
- Psychological Barriers
-Feeling terrified of sex
- Social Barriers
-Cultural, religious barriers
-Some cultures have no/little education about gay people.
- Structural Barriers
-A large number of people don't go to doctors because of their immigration status

Focus Group 2: East St. Louis- Transgender, March 8, 2012

Number of Participants: 13
Location of Meeting: East St. Louis Library



Discussion Questions, Responses, and Results

Series One Questions:

The following questions were asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: 1. “What kinds of activities might appeal to the community?” 2. “If you were put in charge of the funds, what would you fund?”

Quotes (categorized by type of barrier):

- Economic Barriers
“Transition assistance.”
- Social Barriers
“Transgender is invisible. Gay men and MSM have some recognition now. Trans needs greater visibility.”
“Trans feel exiled from both the straight and gay communities.”
“Community education to help people understand the difference between sexual orientation and gender identity”
- Structural Barriers
“Building a center with the right educators and the right resources”

“Places to provide holistic care: Health literacy, political empowerment, entertainment, therapy, medical services”
“Transportation to get people safely to services”

Results:

Figure 5. Transgender Pie Chart of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

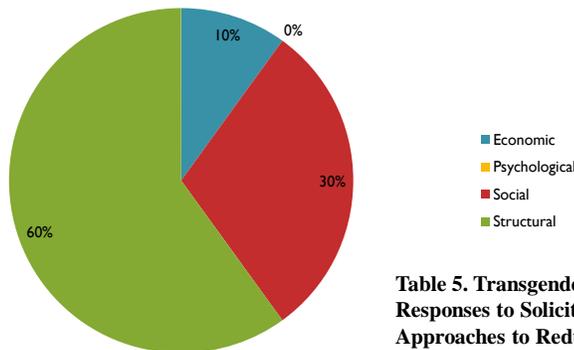


Table 5. Transgender Frequency Table of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

Barriers	Question 1	Question 2	Total	Frequency
Economic	0	2	2	10%
Psychological	0	0	0	0%
Social	6	6	6	30%
Structural	2	10	12	60%
Total	8	18	26	100%

Conclusions:

- Economic Barriers
-Transgenders need transition assistance
- Social Barriers
-Lack of education and awareness on sexuality
-Trans are not included in either straight or gay communities
-Need visibility
- Structural Barriers
-Lack of resources (center, educators, care, and services)

Series Two Questions:

The following questions were asked to assess risk behavior practices in areas/populations hardest hit by HIV: 1. “How does HIV come up in discussion?” 2. “What are the circumstances leading to sexual encounters?” 3. “How do you prepare to go out?”

Quotes (categorized by type of barrier):

- Economic Barriers
“A lot of Trans women are escorts or selling sex.”
- Social Barriers
“Misinformation on how HIV is transmitted kept me at a distance from people with HIV.”

“Black community is not well educated on HIV.”

- Structural Barriers

“It is easier for Trans to get care as an HIV+ rather than a Trans without HIV.”

“We need this data and not be grouped in with MSM or HRH.”

Results:

Figure 6. Transgender Pie Chart of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

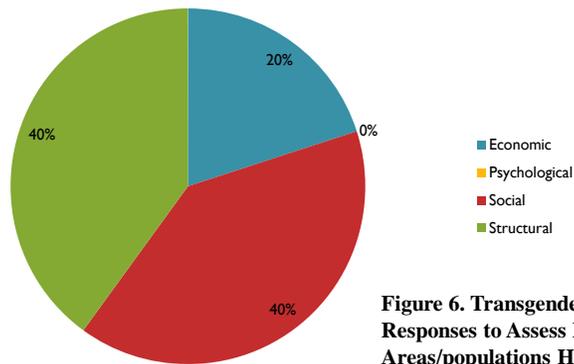


Figure 6. Transgender Frequency Table of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

Barriers	Question 1	Question 2	Question 3	Total	Frequency
Economic	1	2	0	3	20%
Psychological	0	0	0	0	0%
Social	6	0	0	6	40%
Structural	6	0	0	6	40%
Total	13	2	0	15	100%

Conclusions:

- Economic Barriers
-Need to sell sex to pay for care and transition services
- Social Barriers
-Lack of education and misinformation
- Structural Barriers
-Difficulty of transgenders without HIV to access care and services
-Miscategorization of transgender as MSM or HRH

Series Three Questions:

The following questions were asked to assess knowledge and utilization of HIV prevention, care, and treatment services; 1. “What do you think about HIV?” 2. “What are you seeing to help your transgender community stay safe?”

Quotes (categorized by type of barrier):

- Economic Barriers

“Cash incentives would be best to get people to participate; when we offered gift cards, they asked ‘Where are they from?’”

- Social Barriers

“Trans(gender) people do not have their own statistics. There’s no research. They get lumped in with the MSM. We need cultural competence and cultural sensitivity. Even with law enforcement, we need education. Take the term LGBT, it used to be LGB, and the T was just added! People need to be made aware that TG does exist. Maybe training for teachers in comprehensive sexuality education would help.”

“In the heterosexual community, when they are not educated on something, they are scared of it. If we have TV commercials on condoms and vaginal creams, we can have commercials on TV to educate people about transgenders.”

“Project Arc “HEY” (Health Education for Youth) project in St. Louis.”

- Structural Barriers

“BABA used to provide services here when I was young.”

“Transportation is a huge issue. Agencies need a shuttle to get people to places safely.”

Results:

Figure 7. Transgender Pie Chart of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

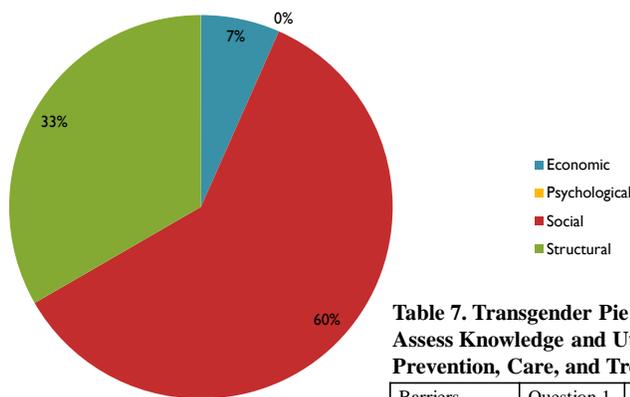


Table 7. Transgender Pie Chart of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

Barriers	Question 1	Question 2	Total	Frequency
Economic	0	1	1	7%
Psychological	0	0	0	0%
Social	5	4	9	60%
Structural	0	5	5	33%
Total	5	10	15	100%

Conclusions:

- Social Barriers
 - Miscategorization of transgenders as MSM or HRH
 - No research studies are done on transgenders
 - No education on (transgender) sexuality is happening
- Structural Barriers
 - Need more places that provide services

Series Four Questions:

The following questions were asked to identify facilitators and inhibitors of HIV risk and risk reduction; 1. “What are the three greatest challenges in your life? What are the key challenges you are dealing with?” 2. “What puts TG people at risk?”

Quotes (categorized by type of barrier):

- Economic Barriers
 - “Help with transitioning.”
- Psychological Barriers
 - “Now that I’m more comfortable with myself, if someone calls me out, I say, “You got that right! Good job!” But we have low self esteem.”
 - “When someone finds out they are positive, the first thing they worry about is, ‘what are the fags going to say?’”
- Social Barriers
 - “Education.”
 - “Trans(gender) women have difficult time getting employment.”
 - “Transgenders are all discriminated against of whatever race. White people have more economic and educational resources, and they are more supportive of their trans kids.”
- Structural Barriers
 - “You wait a long time. I waited 3-4 hours for a test. Then you come back out, and you have to wait even longer for your result.”
 - “We have much HIV prevention, but we also need HIV care.”

Results:

Figure 8. Transgender Pie Chart of Responses to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

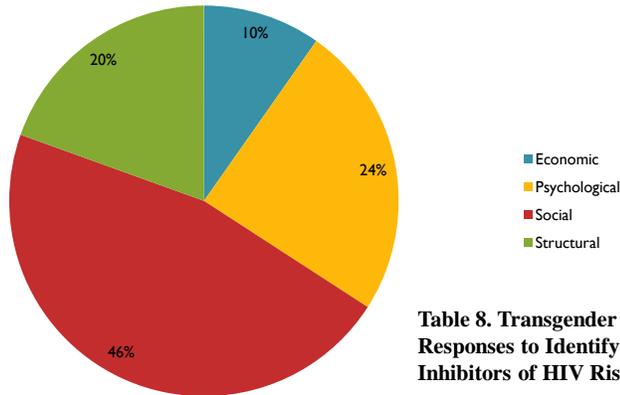


Table 8. Transgender Frequency Table of Responses to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

Barriers	Question 1	Question 2	Total	Frequency
Economic	4	0	4	10%
Psychological	8	2	10	24%
Social	16	3	19	46 %
Structural	5	3	8	20%
Total	33	8	41	100%

Conclusions:

- Psychological Barriers
-Low self esteem, internalized self-limitations
- Social Barriers
-Lack of education
-Discrimination
- Structural Barriers
-Requires a long time to actually receive services
-Many prevention services compared to actual HIV care services

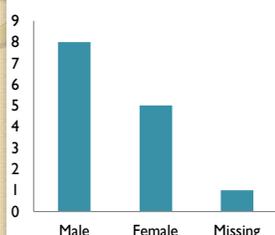
Focus Group 3: Joliet- People Living with HIV/AIDS (PLWHA), June 7, 2012

Number of Participants: 14

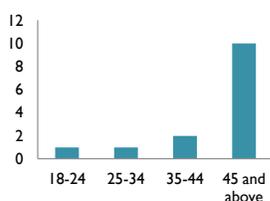
Location of Meeting: Will County Health Department

Demographic Characteristics of PLWHA Focus Group in Region 7: Joliet

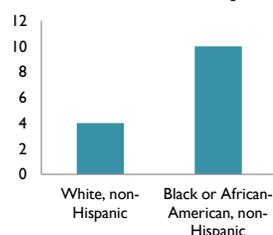
Sex or Gender



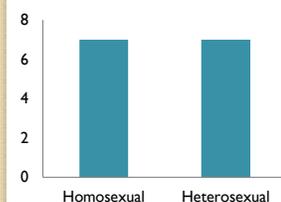
Age Group Distribution



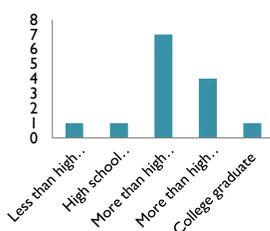
Race/Ethnicity



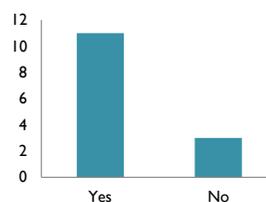
Sexual Orientation



Education Level



Living With HIV/AIDS



Discussion Questions, Responses, and Results

Set One Questions:

The following questions were asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: 1. “What kinds of activities might appeal to your community of peers?” 2. “How do we go about changing people’s perceptions and behaviors with HIV?”

Quotes (categorized by type of barrier):

- **Social Barriers**

“(People need) educating that HIV is not only a gay disease.”

“We need education for our children.”

- **Structural Barriers**

“We need places like Howard Brown, Core Center and Center on Halsted to get comprehensive prevention, care and other support services.”

“As of July 1, Medicaid is only covering 4 medications.”

Results:

Figure 9. PLWHA Pie Chart of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

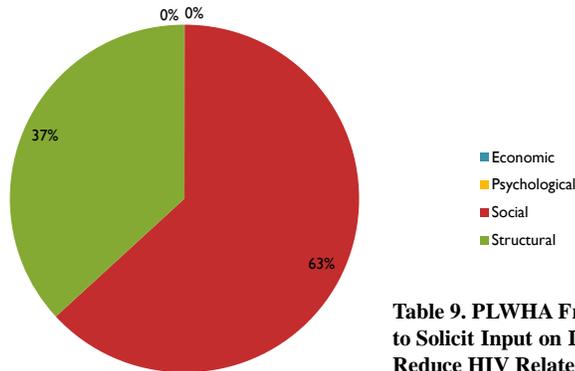


Table 9. PLWHA Frequency Table of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

Barriers	Question 1	Question 2	Total	Frequency
Economic	0	0	0	0%
Psychological	0	0	0	0%
Social	4	8	12	63%
Structural	7	0	7	37%
Total	11	8	19	100%

Conclusions:

- Social Barriers
-Lack of education
- Structural Barriers
-Not many centers to get prevention, care, and support services
-Medicaid not covering enough medicines

Set Two Questions:

The following questions were asked to assess risk behavior practices in areas/populations hardest hit by HIV: 1. “How does HIV come up in discussion with your peers?” 2. “What are the circumstances leading to a sexual encounter?” 3. “What do the people you hang around with talk about HIV?”

Quotes (categorized by type of barrier):

- Psychological Barriers
“I have not had sex in 2 ½ years because I don’t want to infect anyone.”
- Social Barriers
“There needs to be more general education and awareness of HIV, especially in elderly adults.”
“My husband found out I was HIV positive and he has grown cold to me and treats me like poison. We have been married for 30 years.”
“They don’t really talk about it, but when they do, it is negative.”

Results:

Figure 10. PLWHA Pie Chart of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

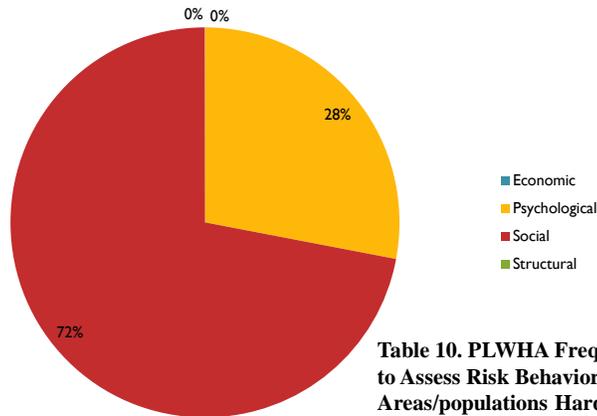


Table 10. PLWHA Frequency Table of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

Barriers	Question 1	Question 2	Question 3	Total	Frequency
Economic	0	0	0	0	0%
Psychological	0	7	0	7	28%
Social	13	2	3	18	72%
Structural	0	0	0	0	0%
Total	13	9	3	25	100%

Conclusions:

- Psychological Barriers
-Fear of having sex because of constant concern about infecting others
- Social Barriers
-Lack of education (especially elderly adults)
-Stereotypes about PLWHA

Set Three Questions: The following questions were asked to assess knowledge and utilization of HIV prevention, care, and treatment services: 1. “Do you have any suggestions on things LHDs and CBOs can implement?” 2. “What is needed?”

Quotes:

- Economic Barriers
“More funding”
- Social Barriers
“Joliet has Victorian attitude”
“More education/pamphlets in Drs’ offices”
“Rally – community outdoor event that focus on HIV”
“More internet education sites”
- Structural Barriers
“A buddy system for people who are HIV positive”
“Ease of access to services/case management – times four”
“Make it easier to get a Medicaid card”

Results:

Figure 11. PLWHA Pie Chart of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

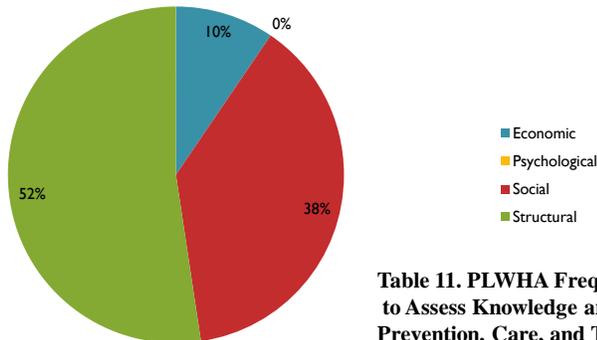


Table 11. PLWHA Frequency Table of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

Barriers	Question 1	Question 2	Total	Frequency
Economic	0	2	2	10%
Psychological	0	0	0	0%
Social	7	1	8	38%
Structural	7	4	11	52%
Total	14	7	21	100%

Conclusions:

- Economic Barriers
-Lack of funding
- Social Barriers
-Lack of education
-Stereotypes
- Structural barriers
-Difficulty in accessing services
-Hard to get Medicaid card

Set Four Questions:

The following questions were asked to identify facilitators and inhibitors of HIV risk and risk reduction; 1. “What are the three greatest challenges?” 2. “Where else have you encountered stigma/homophobia?”

Quotes:

- Economic Barriers
“Medicines cost a lot – co pays for HIV meds and other meds.”
- Psychological Barriers
“Mental health”
“If I get sick, it will come out to everybody.”
- Social Barriers

“Being able to tell my family – they don’t know.”

“Churches – unaccepting”

“Drs don't focus on clients - they treat us like our side effects are in our heads.”

- Structural Barriers

“Insurance -so much goes for co pays and deductibles and other medical needs”

“People on Medicaid don't know where they can go because there are so few physicians who accept Medicaid and those that do are overwhelmed with numbers of patients and there is such a wait list to see Drs.”

Results:

Figure 12. PLWHA Pie Chart of Response to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

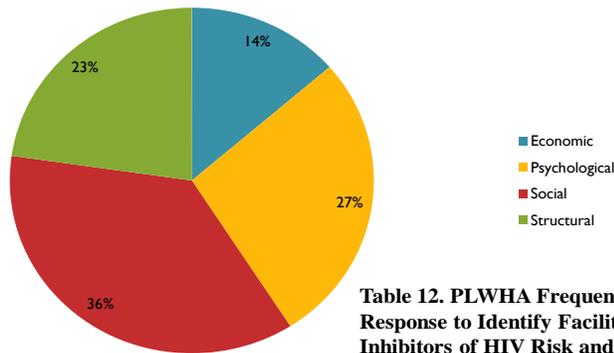


Table 12. PLWHA Frequency Table of Response to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

Barriers	Question 1	Question 2	Total	Frequency
Economic	3	0	3	14%
Psychological	4	2	6	27%
Social	4	4	8	36%
Structural	5	0	5	23%
Total	16	6	22	100%

Conclusions:

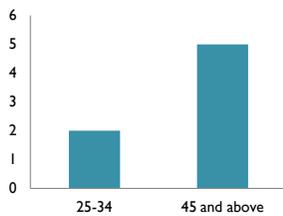
- Economic Barriers
-Expense of medicines
- Psychological Barriers
-Mental health
-Fear of disclosing one’s health status
- Social Barriers
-Difficult to tell one’s families
-Churches can be unaccepting
-Stereotypes
- Structural Barriers
-Other associated medical needs are not supported

Focus Group 4: Peoria- African American Males, May 9, 2012

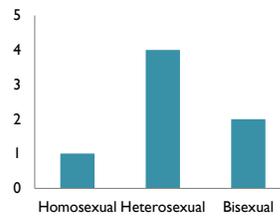
Number of Participants: Seven
Location of Meeting: Workforce Network

Demographic Characteristics of AA Male Focus Group in Region 2: Peoria

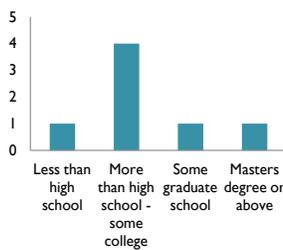
Age Group Distribution



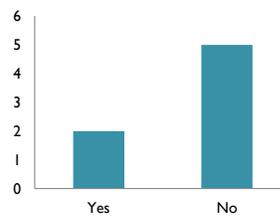
Sexual Orientation



Education Level



Living with HIV/AIDS



Discussion Questions, Responses, and Results

Series One Questions:

The following questions were asked to solicit input on innovative approaches to reduce HIV related stigma and homophobia: 1. “What is your ideal for your community?” 2. “What one thing would you like to see done to get the word out to youth about HIV and prevention?”

Quotes (categorized by type of barrier):

- **Social Barriers**

“We have to educate the general population, especially the youth...prevention, education, services, drug prevention (substance abuse prevention).”

“Need more information disseminated about HIV epidemic in area and services available.”

“How can we reach the young black guys? Have more than one person go into communities to educate young black men. Mobile unit?” Participant said he is afraid to go into some areas of Peoria.

Structural Barriers

“We need more places that provide (co-located) services (care, treatment, support) like Noah’s Ark.”

Results:

Figure 13. AA Male Pie Chart of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

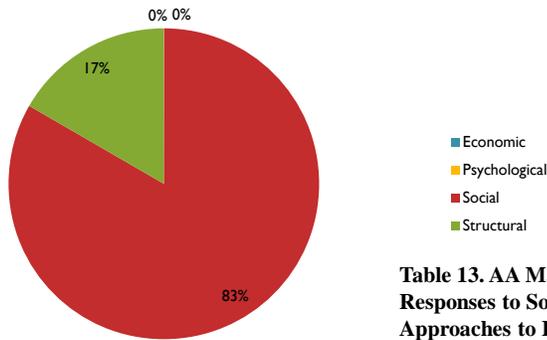


Table 13. AA Male Frequency Table of Responses to Solicit Input on Innovative Approaches to Reduce HIV Related Stigma and Homophobia

Barriers	Question 1	Question 2	Total	Frequency
Economic	0	0	0	0%
Psychological	0	0	0	0%
Social	0	10	10	83%
Structural	2	0	2	17%
Total	2	10	12	100%

Conclusions:

- Social Barriers
-Lack of education
-How to reach and educate black young guys
- Structural Barriers
-Lack of places that provide services

Series Two Questions:

The following questions were asked to assess risk behavior practices in areas/populations hardest hit by HIV: 1. “How does HIV come up in discussions in the community?” 2. “Is sex work highly visible in Peoria?” 3. “How is being gay looked at in the community?”

Quotes (categorized by type of barrier):

- Economic Barriers
“They are doing what they need (sex) to get drugs.”
- Psychological Barriers
“People don’t tell others they are HIV positive because they know others will say they are gay.”
“We have to be comfortable as who we are – black, MSM, HIV positive- before others are comfortable with us.”

- Social Barriers
“People are not talking about HIV and STDs.”
“Being black and gay isn’t really accepted now. It is ignored and looked at as the pink elephant in the room.”
- Structural Barriers
“Yes, sex work is highly visible in Peoria, especially around the Civic Center and more so with male sex workers.”

Results:

Figure 14. AA Male Pie Chart of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

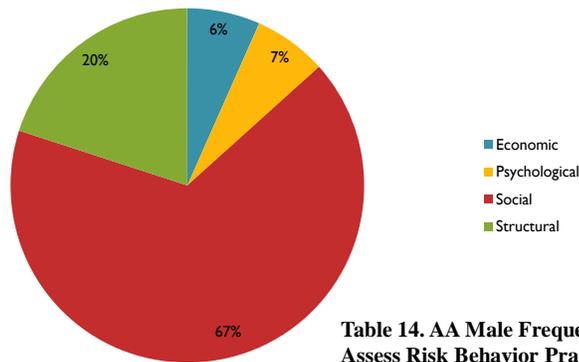


Table 14. AA Male Frequency Table of Responses to Assess Risk Behavior Practices in Areas/populations Hardest Hit by HIV

Barriers	Question 1	Question 2	Question 3	Total	Frequency
Economic	1	0	0	1	6%
Psychological	1	0	1	1	7%
Social	7	0	3	10	67%
Structural	0	3	0	3	20%
Total	9	3	4	16	100%

Conclusions:

- Economic Barriers
-Need to have (sell) sex to get drugs
- Psychological Barriers
-Low self-esteem
-Difficult to disclose their health status because they are afraid of what others will say about them
- Social Barriers
-No discussion about HIV and STD
-Being black and gay at the same time is not accepted
- Structural Barriers
-Highly visible sex works (many male sex workers)

Set Three Questions:

The following questions were asked to assess knowledge and utilization of HIV prevention, care, and treatment services; 1. “Does your Health Dept get out there with prevention messages and testing?” 2. “Where do you go for HIV testing?” 3. “How about education in the community?”

Quotes:

- Social Barriers
 “People in Peoria aren’t getting harm reduction education.”
 “People may know the testing is available but they don’t understand the nature of the disease and don’t know, or believe, they are at risk.”
- Structural Barriers
 “No. We don’t see Health Dept getting out in the community here.”
 “There are 3 HIHAC clinics located in the Southside that are available for free testing.”
 “Peoria won’t do the right thing.”
 “I was in Decatur yesterday and they had a big bus going through community providing condoms and HIV education. The people were excited about it.”

Results:

Figure 15. AA Male Pie Chart of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

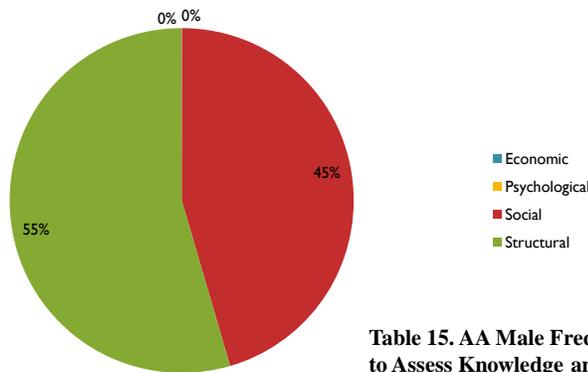


Table 15. AA Male Frequency Table of Responses to Assess Knowledge and Utilization of HIV Prevention, Care, and Treatment Services

Barriers	Question 1	Question 2	Question 3	Total	Frequency
Economic	0	0	0	0	0%
Psychological	0	0	0	0	0%
Social	1	2	2	5	45%
Structural	2	3	1	6	55%
Total	3	5	3	11	100%

Conclusions:

- Social Barriers
 -Lack of education
 -People do not understand the importance of getting tested
- Structural Barriers
 -Health departments not getting out in the community enough
 -Lack of clinics that provide free testing

Set Four Questions:

The following questions were asked to identify facilitators and inhibitors of HIV risk and risk reduction: 1. “What are the three greatest challenges in your life that you are struggling with right now?” and “What kind of problems are you seeing in the neighborhoods?” 2. “What would you say the reason is for the perceived lack of outreach/services in the community?”

Quotes:

- Economic Barriers
“Economy impacts sales so I cannot get the job I like, recovering from narcotics addiction, I’m homeless now.”
- Psychological Barriers
“Substance abuse – constant struggle”
- Social Barriers
“No family structure and morals. A lot of this has deteriorated because of unemployment.”
“Peoria discriminates against blacks in hiring. Not a good place for blacks to live.”
- Structural Barriers
“They closed a big school here. Now two rival schools are together and there is a lot of gangbanging.”
“There are no activities for young people now. A lot of the places people used to go to hang out and play have been closed down.”

Results:

Figure 16. AA Male Pie Chart of Responses to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

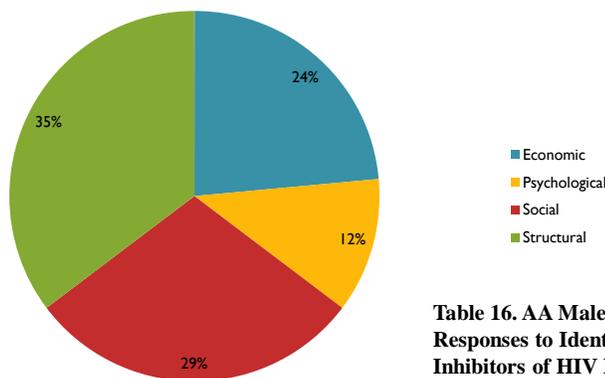


Table 16. AA Male Frequency Table of Responses to Identify Facilitators and Inhibitors of HIV Risk and Risk Reduction

Barriers	Question 1	Question 2	Total	Frequency
Economic	4	0	4	24%
Psychological	2	0	2	12%
Social	3	2	5	29%
Structural	4	2	6	35%
Total	13	4	17	100%

Conclusions:

- Psychological Barriers
 - Substance abuse
- Social Barriers
 - Discrimination against blacks in hiring
 - Unemployment
 - No family structure and morals
- Structural Barriers
 - No school activities and community activities for young people

Comparison of Focus Group by Objectives

Focus Group Comparison on Objective 1: To solicit input on innovative approaches to reduce HIV related stigma and homophobia

Figure 17. Focus Group Comparison on Objective 1

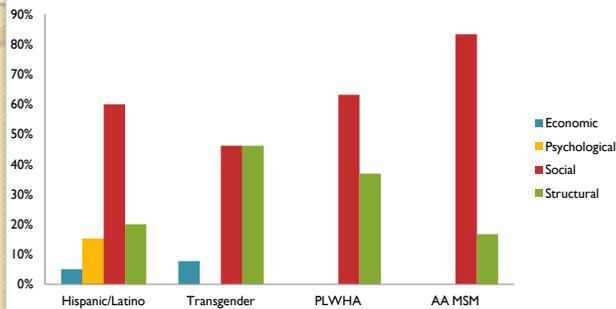


Table 17. Focus Group Comparison on Objective 1

Barriers	Focus Groups			
	Hispanic/Latino	Transgender	PLWHA	AA MSM
Economic	5%	8%	0%	0%
Psychological	15%	0%	0%	0%
Social	60%	46%	63%	83%
Structural	20%	46%	37%	17%

Focus Group Comparison on Objective 2: To assess risk behavior practices in areas/populations hardest hit by HIV

Figure 18. Focus Group Comparison on Objective 2

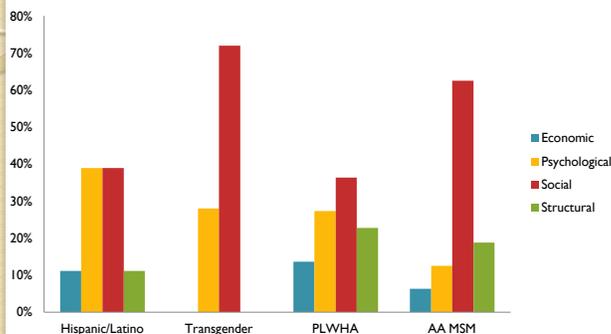


Table 18. Focus Group Comparison on Objective 2

Barriers	Focus Groups			
	Hispanic/Latino	Transgender	PLWHA	AA MSM
Economic	11%	0%	14%	6%
Psychological	39%	28%	27%	13%
Social	39%	72%	36%	63%
Structural	11%	0%	23%	18%

Focus Group Comparison on Objective 3: To assess knowledge and utilization of HIV prevention, care, and treatment services among representatives of at risk communities.

Figure 19. Focus Group Comparison on Objective 3

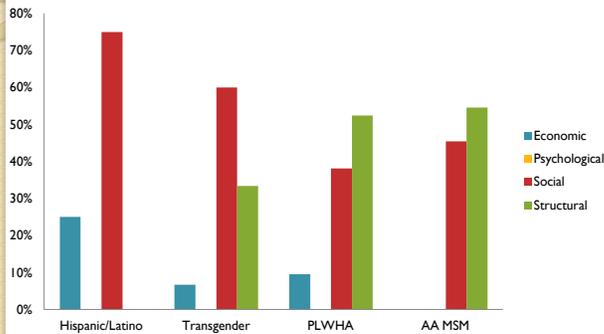


Table 19. Focus Group Comparison on Objective 3

Barriers	Focus Groups			
	Hispanic/Latino	Transgender	PLWHA	AA MSM
Economic	25%	7%	10%	0%
Psychological	0%	0%	0%	0%
Social	75%	60%	38%	45%
Structural	0%	33%	52%	55%

Focus Group Comparison on Objective 4: To identify facilitators and inhibitors of HIV risk and risk reduction

Figure 20. Focus Group Comparison on Objective 4

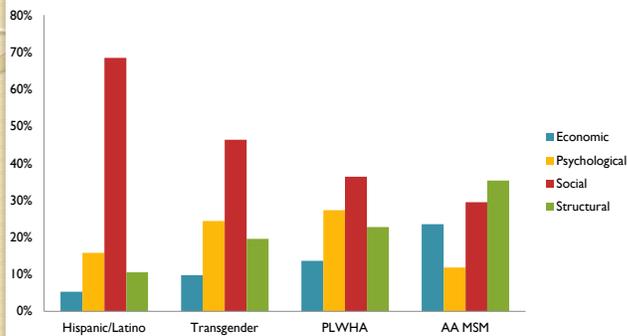


Table 20. Focus Group Comparison on Objective 4

Barriers	Focus Groups			
	Hispanic/Latino	Transgender	PLWHA	AA MSM
Economic	5%	10%	14%	24%
Psychological	16%	24%	27%	12%
Social	68%	46%	36%	29%
Structural	11%	20%	23%	35%

Focus Group Comparison on 4 Combined Objectives

Figure 21. Focus Group Comparison on 4 Combined Objectives

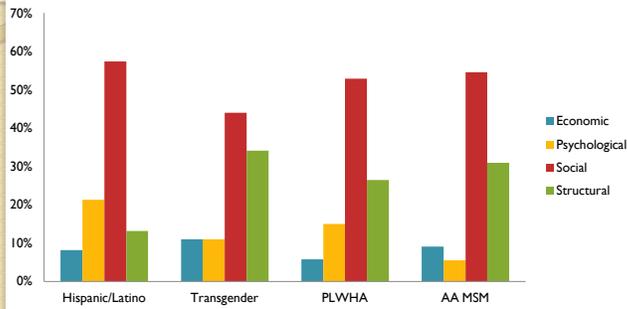


Table 21. Focus Group Comparison on 4 Combined Objectives

Barriers	Focus Groups			
	Hispanic/Latino	Transgender	PLWHA	AA MSM
Economic	8%	11%	6%	9%
Psychological	21%	11%	15%	5%
Social	57%	44%	52.87%	55%
Structural	13%	34%	26.44%	31%

APPENDICES

Appendix A
HIV Prevention Community Planning Group (PCPG)
Protocol for Focus Groups 2012-2013

1. A Focus Group Committee, composed of members of the PCPG Evaluation Committee, the Co-Chair of the Epi/Needs Assessment Committee, the IDPH PCPG 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 PCPG plans to select focus group participants by reaching out through the Regional Lead Agents to facilitators of already established HIV discussion/support groups in the designated area. Many of these support groups are currently funded by either/and HIV RIG and Care dollars to provide those services. Participants will be recruited to participate in the regional focus group through the support group facilitator.
3. The plan will be to include 8-12 participants in each focus group. The target participant group (i.e., PLWHA, African-American MSM, Latino MSM, Transgender, etc.) will be selected based on the regional epidemic/trends and established groups.
4. After its explanation, the participants will be asked to sign a Consent Form to participate which explains the purpose of the focus groups, the risks and benefits of participating, and the confidential manner in which the data will be collected and used.
5. The focus group participants will be provided with refreshments during the focus group. A \$20 gift card will be provided to participants, not including PCPG 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 Epi and Vital Statistics fact sheet specific to Illinois and possibly their risk group as a handout they can take with them after the focus group. It will be explained to the participants how IDPH and the PCPG 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 co-facilitated by the support group facilitator and a facilitator identified by the Focus Group Committee, Carlos Meyers. The IDPH PCPG Co-Chair will attend all focus groups and provide needed support.
8. The Evaluation plan includes the following: The group discussion will be tape recorded with the permission of the group and assigned note takers (Sherry Leo, Vanessa Smith, and Lyyti Dudczyk) will add observations. Notes will be compiled by Sherry Leo, typed and sent to Dr. Ma 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.

Appendix B

2012 HIV FOCUS GROUP FACILITATOR DISCUSSION GUIDE

Facilitators 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 no 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: men who have sex with men (MSM), injecting drug users (IDU), 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+ people; How many people do you know personally who are HIV+.

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

Listen for: What are they 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

- Now that we have talked about what is important to you, what kinds of activities might appeal to the community of your peers?
- 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 status: Preparing for sexual encounter.

- 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.

- 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 read to you some information and statistics about HIV in the state of Illinois.

Closing and Next Steps

End Discussion

Thank you

Distribute Incentives

Appendix C
HIV PREVENTION AND EDUCATION NEEDS ASSESSMENT
2012-2013 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 IL HIV Prevention Community Planning Group.
- 2) Agree to respect the confidentiality of the other discussion group members.
- 3) The discussion is being noted and recorded by members of the IL HIV Prevention Community Planning Group 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.

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 the Illinois Department of Public Health. If you decide to take part in the discussion group, you are free to withdraw at any time without affecting those relationships.

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.

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

This discussion group is being sponsored by the IL HIV Prevention Community 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
Prevention Community 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

Appendix D
2012 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

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"/> Masters degree or above

Revised February 1, 2012

Appendix E
Transgender Focus Group
East St. Louis Library
March 9, 2012
Compiled notes and observations

Overall impression: Welcoming/accepting

Prior to start, participants are relaxed. During group, everyone appears to be paying attention; continue to be relaxed.

Question 1 – What are the three greatest challenges in your life?

- 6 Healthcare insurance - no access - transitioning is expensive
- 2 Shelter--for homeless adults or throwaway youth (no gender neutral space for transgender (TG)
No Jobs for “Trans” (name on resume does not match gender)
- 3 Education
Prevention/Empowerment
Government acknowledgement of “Trans” (legal status, inclusion on forms)
Finding a sensitive knowledgeable doctor
Accessible education about Transitioning
- 2 Family ostracism
Self-esteem
Expecting/internalizing victimization
Substance abuse
Nondisclosure about known HIV status
More resources needed for PWHIV
Internalized self-limitations, support to overcome it
Discrimination, being fired for being discovered, legal protections
Family therapy, inclusion in transitioning
- 2 A center where we can go for support services
Social marketing to provide positive role models
Help with transitioning
- 4 Employment
Trusting others
Trusting confidentiality
Rejection
Discrimination *within* our own community, hurting each other
Self-hatred
Networking with other TG needed

Probing question -What are the key challenges you are dealing with?

- Having the resources to go to a doctor who is knowledgeable and sensitive to TG
- TG’s get “put in a box” with MSM. No programs just for us - I am not a man who has sex with men. I do not identify as a man.
- To get a passport, I had to go through an ordeal because the system wasn’t prepared to handle TG identity.

- Forms should include “Trans”, not force people to choose between male and female.
- Doctors have to see you are serious about being Transgender before they will help you transition. You have to be serious enough.
- Seeing my best friend killed in front of me put a block in my progress in owning my transgender status. She had had sex with a man who did not believe her when she told him she was transgender. We were out together and she saw him. She told me to run in the opposite direction. He shot her 22 times and still she didn’t die—until he shot her in the head at close range. He told me, “You’re next.”
- How you carry yourself makes a difference in how people respond to you, in whether the consequences you don’t want come to you. Being loud, carrying yourself like a homosexual male with makeup will attract problems. Carrying your self like a woman brings a better reaction.
- We face a lot of emotional turmoil within ourselves. We have to get ready every day to face whatever could happen out there. I am always scared. There are some vicious people out there who will kill you simply for who you are. I didn’t choose to be Transgender, to feel this way. I just chose to express my feelings.
- It would help if “Trans” issues were discussed at school. We are not the problem. The problem is out there in society. We need to make them aware that there are different sexual orientations and different gender orientations.
- Due to cost and lack of healthcare, ordering hormones online
- Lack of empowerment
- Needs to be more openness concerning “Trans”
- Observation: While discussing issues, there was a lot of head nodding in agreement.

Question 2 - How does HIV come up in discussion?

- It is easier for “Trans” to get care as an HIV+ rather than a “Trans” without HIV.
- A lot of “Trans” women are escorts or selling sex.
- Being “Trans” puts people at high risk for HIV.
- Black community is not well educated on HIV.
- “Trans” community is scared to get testing.
- Misinformation on how HIV is transmitted kept me at a distance from people with HIV.
- There is no scientific data on number of “Trans” infected with HIV.
- We need this data and to not be grouped in with MSM or HRH.
- There is not a big voice for “Trans” in the community.
- There needs to be a call to duty for those who have "made it" and are established in the community.
- If you hang out with HIV+, you must have it.
- However you are born, be yourself - media message.
- Great listening, active participation by several participants.
- Prevention for those who are HIV+ will not be the same as for someone who is not infected.

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

- Escorting
- Survival sex

Question 4 - How do you prepare to go out?

- Not asked and answered.

Question 5 - What kinds of activities might appeal to the community?

Harold: Would a “Trans” center help? The Transgender Empowerment Center is opening 3/15. Tyler and Joel have helped make this happen. You told me “If you build it, we will come.” We are building it.

- Nothing is here for us.
- TG is invisible. Gay men and MSM have some recognition now. Trans needs greater visibility.
- Bathrooms pose a problem. People should be able to use the bathrooms they feel most comfortable in. We need more single person bathrooms or stalls, so people can use the facilities that they want.
- Trans feel exiled from both the straight and gay communities.
- Being able to pass is a “catch 22”. Being able to pass can get you killed, and not be able to pass can be dangerous or painful too.
- Employment is so important. “Trans” girls can get jobs like normal women. You can work and own a business.
- Parents need education and support groups.
- Needs to be more visibility in community of “Trans” women.

Question 6 -What do you think about HIV?

- When I hear HIV, I think of our black community. A lot of us are scared to get tested. I was. I said if I found out I was HIV+, I would take my life. I was afraid to be around people with HIV. Now I often hang around people with HIV+ and AIDS. Growing up, I was told they were contaminated, and could infect you just by touching you.
- “Trans” people do not have their own statistics. There’s no research. They get lumped in with the MSM. We need cultural competence and cultural sensitivity. Even with law enforcement, we need education. Take the term LGBT, it used to be LGB, and the T was just added! People need to be made aware that TG does exist. Maybe training for teachers in Comprehensive Sexuality Education would help.
- The heterosexual community when they are not educated on something, they are scared of it. If we can have TV commercials on condoms and vaginal creams, we can have commercials on TV to education people about TG.
- Transgender People are afraid to come out which keeps our voice small. We need to call some of the older girls back to serve as role models for us.
- Include more discussion and education of “Trans” in school and have a place in the community where “Trans” can come together and talk/get support from peers.

Question 7 -What puts TG people at risk?

- “Trans” girls have no ability to access hormones unless they are HIV+. So what incentive does that give to a girl who wants to transition?
- We have so much HIV Prevention, but we also need HIV Care.

- Many people only know how to support themselves through escorting. The only thing we see our friends doing is selling sex, we don't see anything else.
- Another thing pushing us that way is that transitioning is very expensive. My mom used to take me to the doctor, but since I turned 18 I had to pay my own doctor's bills. With that pressure, this has become our predominate profession of our community.
- Now that I'm more comfortable with myself, if someone calls me out, I say, "You got that right! Good job!" But we have low self esteem.
- Not a lot of guys are willing to be husbands with TG. But a lot of heterosexual guys who are used to having *unprotected* sex with their girlfriends or wives will have sex with a transgender. And some DL (down low) guys who have sex with guys will have sex with transgender.
- When someone finds out they are positive, the first thing they worry about is, "What are the fags going to say?"
- "Trans" women have a difficult time getting employment.
- Some "Trans" get fired just for being "Trans" when their bosses find out.

Probing question - What are you seeing to help your TG community stay safe?

- We tested recently at the high school.
- BABA used to provide services here when I was young.
- Project Arc "HEY" (Health Education for Youth) project in St. Louis
- Latex balls happen annually in NYC.
- The gay scene is segregated. Blacks and whites are not together. White HIV events are not inclusive, held in towns far away that we can't get to and we are invited at the last minute if at all. All the clubs in the Grove are strictly white now, and they used to be mixed.
- Transgenders are all discriminated against of whatever race. White people have more economic and educational resources, and they are more supportive of their trans kids.
- Cash incentives would be best to get people to participate; when we offered gift cards, they asked "Where are they from?"
- Peer educators—hire people within the TG community to promote events.
- Provide support for peer workers because they work and play and live in the same community—like a 24/7 job. They need therapeutic support to handle that pressure.
- Transportation is a huge issue. Agencies need a shuttle to get people to places safely.

Question 8 - If you were put in charge of the funds, what would you fund?

- Building a center with the right educators and the right resources
- HIV+ peer educators to role model living with HIV
- Networking database (possibly meant website or list serve?)
- Transition assistance
- Holistic care: Health literacy, Political empowerment, Entertainment, Therapy, Medical services
- Transitioning half-way house units
- Employment assistance
- Hiring peers within the community
- Community education to help people understand the difference between sexual orientation and gender identity
- Transportation to get people safely to services

- Stiffer penalties for HIV+ who knowingly transmit disease.
- More gender neutral issues - bathrooms are a huge issue.
- Need a place in the community where we are accepted.
- Services are geared toward lesbians and MSM and not much for transitioning women.
- More "Trans" specific cultural competency and sensitivity trainings.
- Need psychotherapy resources for Trans.
- Need tips for survival.
- Need more networking opportunities.
- Need more employment support.
- Focus on care of "whole" person.

My observation: HIV important but maybe not the highest priority with this group.
They spoke softly.

Question asked by Harold that was not part of goals and objectives: How do we get the Black Church to be supportive? _____

- You can't always go to the Church. You have to go to God himself. Instead of going to church, I stay home and read my Bible and that's how I get my Word.
- My church is welcoming and is building a TG community, MTF and FTM.
- We need to educate our faith leaders about both Transgender and Homosexuality.
- One church in community is very Trans friendly.

Final comments?

- Isolation
- Poor self-image drives poor decisions
- Lady Cherelle went to court in the 1970's to fight for the right of Trans to work in the public arena every day. She's low key now, but she provides support to me now. We need those role models.

How do we make advocacy happen?

- We all should contribute something, talking to people, getting people to the center.

Appendix E
2012 Focus Group Notes
Young Adult Latino MSM
Berwyn, IL
April 23, 2012
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?

- Staying focused. I have so much going on I lose track. Maybe it's my ADD.
- Being comfortable in my home with my family. With me being gay or bi(sexual), I feel like I can't bring people around. It's out of sight, out of mind.
- Procrastination
- My relationship & friendships. My friends want to spend time with me, and my boyfriend wants to spend time with me.
- Challenge of losing weight.
- Waking up in general is hard for me. I sleep 12 hours a day on average, but it's improving. It was worse in the summer.
- I'm terrified of sex.
- I'm a senior (at University). I need to get a job. I don't know if I should to go on in academia or get a job.
- I've been away from family for so long. I need to get back to campus soon.

Lately, there's been a lot of backlash from religious groups against gay people on campus. The blank blank are doing a campaign pushing the message that you're going to hell if you don't accept Jesus Christ. I don't surround myself with extremists, but I do surround myself with Catholics.

Note: Hector stopped the discussion and asked the group to be honest and "play big" and tell the real struggles that they are dealing with. Katie added that the facilitator and note takers are very experienced in working with the gay community so no one need be concerned about shocking them.

- My two greatest challenges are:
 - Passing my GED exam.
 - Coming out to my parents. I did it at a family picnic, and I had money ready in my savings account in case I had to move out. It's weird because they're here straight from Mexico. And where we're from, people have no education about gay people.
- Trying to juggle school with work. I work 30 hrs per week, then school.
- Life with my parents. I have not come out to them. I don't know if I should even tell them. I consider myself bisexual and I've never been in a relationship with men, only girls.
- For me, it's my immigration status. I was brought here when I was three. So many things others can do, I can't. To get by, you gotta hustle. I work where I get paid under the table. I pay cash for school out of what I make as I get it.
- Another challenge: I can't decide what to do career-wise.

- Family is another challenge. I live with my mother and 5 siblings. A lot of times I have to act like a father figure. My little sisters come to me complaining about something.
- I'm scared of losing my mom so that all the responsibility would fall on me. She works two jobs, leaving at 2:00am in the morning to take the bus to the first job.
- My biggest challenge is trusting people. I've been alone since I was 15. I've lived alone. It's hard to trust that someone loves me and wants to be in my life. My mom and dad were very abusive. I was molested from 3 years old to 12 years old. I would always tell my mom, and she would ignore it. My sister told my mom that she was molested and she did nothing, so my sister went to foster care. I moved out, lived in Florida. I know there are people who care, but I can't open my eyes to it. I double think myself and start thinking the worst.

Question 2- Many of you mentioned a theme of families. Is there a lot of pressure about coming out to families?

- It depends on your religious background. My family is Pentecostal, and it's not accepted at all. I told my grandma, and she said "You're dead."
- I had a girlfriend. I did a lot of club promotions, was in advertisements, and knew a *lot* of people, so if word got out about me, I knew it would come back to me. I was so afraid of how my brother would react.
- It was so hard for me because I lived with my mom and her boyfriend. She is Pentecostal and she told me and my sisters that if we turned out gay or lesbian she would kill us herself. Her boyfriend was really abusive to her and to us. I moved out. Eventually she got tired of his abuse, and she asked me to move back in. Eventually, I came out to her, and then she took it pretty well. She saw me as a good person.
Observation: Others nodding their heads
- For me it was an issue, but not so difficult. My parents are very strict Catholics. My boyfriend is out. He's black and Puerto Rican. He hates that I'm not out and can't openly spend as much time with him as he'd like. I'm scared to cause my family pain by coming out. I'm not ready to handle their pain when I'm not sure I can handle mine.

Question 3- Who do you hang out with? Mostly gay folks? Mixed?

- I surprised my friends after I came out to family. Like me and a [male] friend made out in front of my friends just to shock them! Well, my childhood friends have their own little gay tendencies. I had a good "outing" compared to other people.
 - I came out at 25. My 25th birthday I had all my friends there, and after that I cut that off. I hit the gay lifestyle. I had no friends, knew no one. I was angry about it. Gradually, I started making friends.
 - Now I don't have a problem with my Mom. I bring friends from here home to meet my family and it's good.
 - Now When I came out, I told my friends, and two of my girls started crying. I said "B*s, why are *you* crying?! *I'm* the one coming out!" My boyfriend told me he was upset that I didn't share more of my pain with him. I was going to school in Champaign, and I went into depression and isolated myself for a while.
-

Question 4 - Where do you hook up and meet guys?

- You can meet anywhere! Work!
- For me at first it was a website. Now I go to clubs and meet people. I don't know how to talk to guys online any more. But even at clubs, it's hard to get to know someone on deeper level than "let's dance." (*Observation: cultural isolation*)
- I've only had three boyfriends. The first one I met at work. The second I met at T-Mobile when activating my phone. Third....(notetaker couldn't hear)
- I haven't been on the scene for long. I meet friends through other friends.
- I've only had one boyfriend. I met him on Facebook®. I'm only 20 so I can't go to bars.
- Maybe we don't do it in *this* group, but for hookups, most people are going to Grindr® and Craigslist®. You go online and you see a menu of guys. Most of them are there for the same reason you are. So you pick and you hook up.

Question 5 - How does HIV come up in discussions with your peers? How often does HIV come up? What exactly are they talking about? Is HIV an issue? What do people say about HIV+ people? How many people do you know personally who are HIV+?

- For me, it's scary, because it's getting closer and closer and closer. I hear about a friend or someone I used to date turning up positive. It's okay 'cause I'm still safe.
 - For me, I just have one boyfriend. But for me, I don't get turned on with condoms, even when I'm watching porn I don't get turned on [if there's condoms]. I'm a really optimistic person, so if something happens, I think I'd be okay.
 - I think HIV is another reason I don't have sex. I fell in love with a person who was HIV+, and we never had sex. *Observation: Covers his mouth as if crying.*
 - A lot of my friends are straight. So HIV is something we never talk about, either because it's not there or they never check. HIV is a scary word. But I decided a long time ago to separate myself from my family, so I use different pronouns [note: presumably, switching from "he" to "she" to describe his dates] and when they ask [about dating], I don't answer questions about it. So I'm not going to have a relationship. I am going to have sex. I believe HIV will be curable within the next 50 years. I wouldn't put myself in that situation, but I would be willing to date someone with HIV. It's a disease. It's like herpes which is unpleasant and aesthetically gross, but it won't kill you. *Observation: Others nodding.*
 - I work in an ER. I've dated one guy with HIV and we're always safe. I've never had sex without a condom, period. I got taught that in HS by my Guidance Counselor. And I also learned it at Project Vida.
 - I've only had straight relationships and I haven't had sex with a guy yet. My straight friends never talk about getting tested.
 - It's scary. I like to be a healthy person because I'm uninsured, and I think about how much it would cost if I had to pay for that medication myself.
 - It's scary to me too. My friend's Mom died of AIDS from prostituting herself to take care of her kids. A friend in Florida is sick too, and I always go visit him when I'm there.
 - My friend told me he was positive. I said, "Who cares? I'm not here for your status, I'm here for your personality."
 - Among my friends, I advocate testing.
-

- I was straight until I was 25. But I was molested when I was little; my first sex was with a man when I was little. Among my frat brothers, it was never about HIV. It was STD's they worried about, itching or burning.
- I live in a neighborhood that's mixed black and latinos, and we have only one clinic nearby. Not everyone has time to take a trip to "boystown". I just got tested two weeks ago. I called another place (*Observation: others listening attentively*) and they said they charge \$98 dollars.
- You wait a long time. I waited 3-4 hours for a test. Then you come back out, and you have to wait even longer for your result.

Question 6 - Is the immigration issue a barrier to testing?

- I have friends that avoid going to the doctor because they don't have papers.
- Undocumented Participant: They tell you to go to the dentist twice a year, but then you go and it's so expensive.
- We're all educated guys. But for most guys, there's not a lot of knowledge about where to get them.
- We like Trojans and Directs.

Question 7 - How much does religion play a role in your life?

- When I was young, I was scared by it.
- My mom's boyfriend was religious and so judgmental. After her boyfriend left, my Mom has not been so religious. I don't like Church anymore, because there's so much high school drama going on in Church.
- I go to a Christian non-denominational church, and it's not so bad. As long as I have a relationship with God, I don't care about Church.
- My dad doesn't speak to us because of his religion. He says, what are you, a girl or a boy?
- I'm Catholic, and they talk about Sodom and Gomorra. At the Christian church, they say "God loves you no matter who you are or what you do."
- My parents believe ... I remember hearing gay people go to hell. And I was like "oh f...!" Everyone laughs. Others seem to nod and seem more relaxed.

Question 8- As young gay men, do you feel safe in your community?

- It depends on what area you live in. I live in a bad neighborhood but they know about me.
 - I remember as a kid a transgender person lived in the neighborhood, and some gangbangers gave her a hard time. But I don't see that now.
 - In Little Village, a lot of stuff is washed under water. My uncle is a mega-character. He's in his 50's, transgender, a drug dealer. He goes to a club where all the Mexican guys go in stereotypical boots and cowboy hats. My uncle is in drag and they want him to f... them.
 - In the media, gays are everywhere. Now it's not common for someone to be so disrespectful as to harass someone.
 - Now the harassment is mostly from gangs. I've been harassed by gangs.
 - In Waukegan, it's not accepted at all. *Observation: Others pay attention attentively.* When I was in high school, they beat someone in high school.
-

Question 9 - Are you comfortable coming out to your doctor?

- I went to the doctor 'cause I noticed some bumps in my anus. I went to blank blank Health Center. He takes 2 seconds. He said. "Yup, those are genital warts." My boyfriend was with me. He asked if they were contagious. The doctor said, "If you stick your penis in his anus, you'll get them too." I went somewhere else to get them treated and they said they were hemorrhoids. That [first] doctor just assumed since I was there with my boyfriend that they were warts. I will never go back to that ... clinic.
- [Self-identified bisexual participant]: I told my doctor that I had only sex with girls.

Question 10 - What would you do to reduce stigma and stop HIV?

- You can preach to people as much as you want, and they'll do what they want, often because of how they grew up. I grew up in an abusive home being told "You're nothing." And I believed it. Focus more on the human being and their internal issues.
 - Nothing can replace HIV education, but focusing on the whole/real person is key.
 - We have to teach these kids to value themselves. My mom installed good morals and values and built our confidence. Whatever you think of me, I don't care. She taught me to be the best I can be. I'm not going to do anything with anyone. Kids aren't getting what they need, so they go out searching for what they lack. They have no self-respect. It's just sex for them, just fun. We have to start intervening with the younger, 'cause it's getting worse. With cell phone usage and computers, everything starts younger, even smoking.
 - Kids are the future, and whatever you instill is what the next generation will be.
 - I still get shocked that I meet guys who are 25-35 and they have the most ignorant ideas about HIV. I look at sex as just sex, but I'm educated how to protect myself. I meet guys and I can't believe how little they know and what wrong things they believe!
 - The campaigns for HIV prevention, if you aren't worried about it, you're not going to use a condom. But if you never get checked! They also need to know to come back in 3 months. Also, people need to understand HIV so they aren't so scared of it they avoid getting checked. People will slip eventually. So the fear [presumably, of a positive result] cannot outweigh the prevention.
 - Most of us spend a lot of time on the internet. There should be laws that if you have a website, there should be prevention ads, not just ads for porn. I've never seen [prevention] ads on Grindr or Websites. How many people get their news from Facebook? We all do. Someone prints a story and we share it. Look how the Travon Martin story got pushed through the virtual world! We can do the same to push the stories of kids with HIV.
 - It's always the mentality that it's the Gay disease. I got most of my education in high school. CPS has a curriculum, but now there's so many Charter Schools, and I don't know what's happening there.
 - We all go to "boystown" a lot. I don't see it in the bars at all. Who gets tested inside the bar?
 - I actually got paid to test at Circuit.
 - Parents just don't know. They might mean well, but if they aren't in denial, they don't know what to say to kids about it.
 - My parents who came from Mexico don't speak English and they don't know about this stuff.
 - I pretty much had to educate my mom about using condoms.
-

- I just recently had a conversation with my mom about HIV. My friend of 4 years just came out on TV as HIV+. My mom told me about it. I had been with him and I didn't know.
- You don't go with your family to go to a physical or to get tested. We have vaccination requirements, but no one tells you to get *tested* every semester—especially in high school.
- I've known about my sexuality since first grade, but you don't learn anything about your sexuality for years. When you're younger, it would be good to be taught respect.
- In high school on the south side, there were people who were open, but I never saw anyone get gay bashed.
- We did a program called Landmark. Sometimes the issues we have now, it goes much deeper than we think. Why was I afraid to speak up? I was afraid of getting hit, getting yelled at.
- I wanted to get to a place where I could bring my boyfriend home to meet my parents and feel comfortable.
- When I think about me then and me now, I would consider myself weak then.
- In bringing HIV to us, we need to bring someone that we can see ourselves in, who could tell us his story. We idolize the media. It's as simple as him blogging. Have him come out to meet us. Just a normal latino guy partying, and let us be faced with that reality.
- I'm still scared of HIV. Only my friend coming out as HIV+ on TV helped me to be less scared. I cried and I think, "Wow. You're such a strong person."

Question 11 -Anyone ever go to Counselors?

- When I first came out, I went to peer counseling.
 - With my family, I pretty much grew up on my own. I didn't know it was not normal to grow up getting hit all the time. If I talked about it, it got back to home and it got me in trouble.
 - Counselors cost. How do you pay for that?
 - My friend was always sick with something. I asked him to go get checked out, but he was too scared to go.
-

Question 12 -What about partying and substance abuse?

- I've come so long in my drinking, my counselor wanted me to go to AA. But if I quit one thing, I just start up another thing, like sex or whatever.
- At times, I've drunk so much, I can't remember what happened. I remember flashes, like I was walking around talking to people but I'm not there.

Question 13 –(not related to objective) Where are you from? How many live in the City of Chicago?

Seven of 8 participants raised their hands.

Other Thoughts:

.....

- *Observation -Immigration was brought up but it was not a big discussion topic – there was only one undocumented in the group (he struggles and brought up the issues in the beginning of the focus group)*
- Access/Transportation is an issue
- Waiting long times for testing is an issue (city of Chicago)
- Access to condoms – not a lot of advertising for free condom. They prefer Durex®/Trojan®

Observations: Very cohesive group with a strong and trusted facilitator. It might be good to have another focus group with consumers who are not as tight-knit and/or not as informed or supported. Discussion was closed. Participants were thanked. Travel reimbursement gasoline cards were distributed.

.....

Appendix E
African American Male Focus Group
Peoria, IL
May 9, 2012
Compiled Notes and Observations

Chris Wade reviewed purpose of the focus group and the objectives.

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

- Church environment- finding a good church home, job is hard to come across.
- Finding a full time job, public transportation is limited.
- Economy impacts sales so I cannot get the job I like, recovering from narcotics addiction, I'm homeless now.
- Church - have not found a "church home."
- Jobs- hard to find.
- Family - trying to remain stable even though I have not had a job in 6 months. I do not have any family support now. I cannot rely on family for anything.
- Substance abuse - constant struggle.
- Homelessness - when I came here I was recently released from prison and had a job. I lost that job. Unemployment - I can go back to Chicago but I am afraid I would get back on the streets and be in the same situation that got me into prison.
- I am a single Dad - hard to provide for son. I need the support of my parents.

Question 1 (probing question) - What kind of problems are you seeing in the neighborhoods?

- Southside of Peoria is predominantly black and there is a lot of drug use (crack, cocaine, heroin) and violence in that community. A lot of teenagers and young adults are shooting up heroin which is the primary mode for us.
Observation: Mood of participants seems a bit depressed and frustrated with their situation - homeless, unemployed.
- Rap music is telling kids it is cool to have sex, be violent, etc. - encourages negative sides of life.
- The authorities target young black men here because of what is shown on TV - guns, drugs, violence, gangs.
- There are no activities for young people now. A lot of the places people used to go to hang out and play have been closed down. Young people are our future.
- No family structure and morals. A lot of this has deteriorated because of unemployment. Peoria discriminates against blacks in hiring. Not a good place for blacks to live.
- They closed a big school here. Now two rival schools are together and there is a lot of gangbanging.
- Problem: No leaders in the neighborhoods to guide them.

Question 2. How does HIV come up in discussions in the community?

- People are not talking about HIV and STD. They are doing what they need (sex) to get drugs.
- We need to stop blaming the government.

- We need to take responsibility for our youth and be role models. We aren't doing that.
- People don't tell others they are HIV+ because they know others will say they are gay. There is homophobia here.
- Black men wait long to go to the doctor. Black men don't take care of themselves like they should.
- There needs to be more verbal communication out there - not email, not internet - summits, public service announcements.
- There are some neighborhoods I just can't go in - gangs, people.
- After reading CDC fact sheet: "I did not realize how bad the statistics are for African Americans. This is bad."

Question 2 (probing question) - Are there any HIV messages getting out to African Americans in Peoria?

- Not many and not very visible.
- Giving out condoms in Projects.
- No MSM program. There are no support groups for HIV+.
- It is not a priority.

Question 3 - How is being gay looked at in the community?

- Being black and gay isn't really accepted now. It is ignored and looked at as the pink elephant in the room.
- I wouldn't teach my kids it is acceptable to be like that. I have morals.
- I can't say I am gay because being gay is associated with being immoral. If we say half of us wouldn't show up if the shutters were open because we would be identified as gay we are promoting that perception. We have to be comfortable as who we are - black, MSM, HIV+ - before others are comfortable with us.

Question 4 - Where do you go for HIV testing?

- HIHAC just down the street (downtown). The Community Services Center (10-15 mins.). There are 3 HIHAC clinics located in the Southside that are available for free testing. People may know the testing is available but they don't understand the nature of the disease and don't know, or believe, they are at risk. We need to target ages 17-25 years.
- In Chicago, HIV prevention services are all over the place because gays are all over the place. It isn't like that here.

Question 5 - Does your Health Dept get out there with prevention messages and testing?

- We don't see them out in the community here.
- Street-based needle exchange is prohibited by ordinance now. It has to be done (along with education) in a building now.
- People in Peoria aren't getting harm reduction education.
- I was in Decatur yesterday and they had a big bus going through community providing condoms and HIV education. The people were excited about it.
- It does not happen here.
- Peoria won't do the right thing.

Observation: Participants very frustrated and angry - perceived lack of HIV services/education to the African American community here with no visible presence of outreach in the AA communities.

Question 6: What would you say the reason is for the perceived lack of outreach/services in the community?

- There has been a shift in emphasis in the services. Outreach – zip
- Clerical/paperwork more important now.
- There used to be a vibrant support group in Peoria. There isn't anymore.
- There are all white women here @ _____ Center, no blacks. Blacks aren't comfortable going there for services.

Question 7: What is your ideal for your community?

- Places that provide services (care, treatment, support) like Noah's Ark. Also, provide a continuum of services to the community and based/located in the community.

Question 8: What 1 (one) thing would you like to see done to get the word out to youth?

- More programs (educational) like ones they provide at the homeless program.
- How can we reach the black young guys? Have more than 1 person go into communities to educate young black men (mobile unit) Participant said he is afraid to go into some areas of Peoria.
- Need more information disseminated about HIV epidemic in area and services available. (Summits and information like this are helpful to me) Information from peers and information I locate/obtain on my own are helpful.
- Have information like these Fact Sheets available at places where youth are: bus stops, schools, public places. Something needs to be done to get the attention of youth.
- We have to educate the general population, especially the youth - prevention, education, services, drug prevention (substance abuse prevention).

Observation: Participant slap table with hand. He is also sitting with baby in lap. Concerned about the future for this child?

- Incorporating HIV prevention in substance abuse treatment site, some not all, aren't educating with HIV prevention.
- The blank Center here isn't really addressing the black or the black MSM community. Agencies need to be held accountable.

Observation: There is much head nodding and voices will heightened emotion.

- There needs to be education in schools and there is not here.
- There is a lack of commitment here.

Question 9: Is sex work highly visible in Peoria?

- Yes, especially around the Civic Center and more so with male sex workers.
- A lot of male prostitutes around Downtown warehouse area.
- Also, seeing needles on the street in the same corridor.

Observations: This focus group was extremely difficult to listen to for those of us in the field. There is such a huge lack (or even perceived lack) of services in Peoria. The men seemed most concerned with the youth. That gave the impression that they are beyond help but are begging to help the youth. Most of the men were very adamant about the need for syringe exchange/education especially for the youth. There seems to be a huge proportion of youth injecting heroin. Also, there was a participant that actually believed that if you step on a piece of broken glass, cutting your foot, that an HIV+ person has used, you become HIV+. Throughout the group, there was a feeling that these men were very, very frustrated. The frustration comes not only from lack of HIV services but from the economy, lack of jobs, housing, the same circumstances that affect all of IL but with great impact in that area. There was a large Caterpillar plant there that was moved from there. Evidently, Caterpillar had been one of the biggest providers of employment in the area.

Appendix E
People Living with HIV or AIDS (PLWHA) Focus Group
Joliet, IL
June 7, 2012
Compiled Notes and Observations

Question 1-What are your three greatest challenges?

- My health - physical and mental well-being
- Being HIV+ and hepatitis C+
- Being able to tell my family - they don't know
- Income and being positive
- Mental health
- Disclosure - family members disclosing my status
- I don't want everyone to know because they treat me different
- If I get sick, it will come out to everybody.
- Staying on schedule with meds and side effects of meds
- Doctors who don't focus on clients - they treat us like our side effects are in our heads
- Forgetful taking meds
- Taking my medicines around family and others when they don't know my status
- Problems with getting a medical card
- Medicines cost a lot - co pays for HIV meds and other meds
- Lack of referral services for other existing issues (hip replacement)
- Managing health care on a budget
- Caught in the middle - makes too much for Medicaid but not enough to have private insurance. So much goes for co pays and deductibles and other medical needs
- People on Medicaid don't know where they can go because there are so few physicians who accept Medicaid and those that do are overwhelmed with numbers of patients and there is such a wait list to see doctors

Observations: Clients seem to have big issues with HIV meds and other meds for other illnesses (trying to get other meds covered)

Lots of nodding of heads in agreement

- I am on Aetna - it doesn't cover a lot of meds I need. Medicare gave us only two choices.

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

- Never told my kids. I have only told my uncle.
- Peers ask "Why are you sick all the time?"
- There needs to be more general education and awareness of HIV, especially in elderly adults.
- My sons were very understanding and supportive but my sister won't let me tell her husband because she is worried how he will act.
- I don't have to disclose to anyone I don't feel comfortable with - it's on a need to know basis.
- I have only disclosed to my immediate family.
- I don't want the world to know because of the stigma attached to it.
- As long as I am healthy I don't tell my family because of the stigma and because they will tell others.
- My son is now HIV+ and has not disclosed to anyone but his mothers who is HIV+

- I correct a lot of misinformation in the community with HIV.
- I think stigma is getting worse but is not as obvious.
- My family (sister) puts bleach on everything after I leave.
- Awareness of HIV is decreasing. You don't see HIV discussed on TV.
- What are the circumstances leading to a sexual encounter?

Probing question asking about sex practices:

- Sex? Who's having sex?
- If I were to get in a relationship I would use protection and have to tell him I am HIV+
- I have not had sex in 8 years
- I would rather have a relationship with another HIV+
- I am in a relationship with someone who is HIV- and it gives me motivation to be adherent to my meds and use protection.
- I have only been in a relationship once in 8 years. I told him before we started dating.
- Male- I have not had sex in 2 1/2 years because I don't want to infect anyone.
- My husband found out I was HIV+ and he has grown cold to me and treats me like poison. We have been married 30 years.
- Most people answered they are not having sex.
- I was with an HIV- person who said he did not care if he got HIV, but I told him I cared
- HIV testing - my partner gets tested every 6 months.
- I was in a relationship with a married man who I think is HIV+ and he won't get tested

Observation: There was a lot of agreement with these statements

Question 3 - What kinds of activities might appeal to your community of peers?

- Massages
- Yoga
- Education for our children
- Support groups for kids of HIV+ persons - my kids don't talk to their friends about it
- More camps for children
- More retreats/camps for HIV+
- Camp Getaway - they had counselors/sessions for the kids and then there were activities for adults
- A place in Will County we can go for prevention, counseling and other needs. Regional Care is the only place we have, but people who go there can be stigmatized as HIV+."
- As of July 1, Medicaid is only covering 4 medications.
- We need places like Howard Brown, Core Center and Center on Halsted to get comprehensive prevention, care and other support services.
- Transportation to Chicago is undesirable and costly.

Question 4 -How do we go about changing people with HIV's perceptions and behaviors?

- Through education
- Through awareness
- Change perception by action and attitude
- TV programs need to be more targeted
- Having people HIV+ come out of the closet - people who are the "faces" of HIV

- Educating that HIV is not only a gay disease
- HIV+ people have to be comfortable disclosing so they can be advocates for HIV and show "faces" to HIV
- More focus groups where HIV+ speak out on what they need
- Where else have you encountered stigma/homophobia?
- Churches – can be unaccepting
- Silence is death and we need to change it
- Universities - some professors actually foster stigma and ignorance and don't know what is really going on in the community
- Churches - I don't see them actually doing anything in the community to spread awareness of HIV, behaviors that can lead to HIV, etc.
- Young man 22 years old (diagnosed Dec. 2011) - I worry about having to take medicine for the rest of my life and not being able to have children. There are a lot of things I want to do in life. I have told one person - my mother
- "You were born to die so you have to live in between."

Question 5 - What do the people you hang around with talk about HIV?

- They don't really talk about it, but when they do, it is negative.
- School did not talk about it
- No education - no condoms

Probing question –Any suggestions on things LHDs and CBOs can implement?

- More internet education sites
- Rally - community outdoor events
- More PSAs
- More education/pamphlets in doctors' offices
- Peer education at doctors' offices
- I want to be trained on peer education - times three
- A buddy system for people who are HIV+
- Newly diagnosed Oct. 2011 would like someone she can go to when she has questions.
- No buddy systems in Will County
- Have to go through AFC for case management –this is a barrier. We have to wait for referrals from AFC
- HIV case managers need to coordinate with Medicare and Medicaid case managers
- Joliet has Victorian attitude
- Better coordination of services in Will County is needed

Probing question - What is needed?

- More funding
- Ease of access to services/case management - times four
- More mental health and support services for HIV+
- Funds to train peer educators
- Train the pastors
- Things to help relax us - alternative therapies
- Make it easier to get a Medicaid card