

2012 HIV/AIDS Strategy
Stakeholder Engagement Meetings Report
Illinois HIV Planning Group

Authors:

Mary McGonigel, Illinois HIV Planning Group Consultant

Janet Nuss, Illinois Department of Public Health HIV Planning Group Coordinator

Ashley Thompson, Illinois Department of Public Health HIV Planning Intern

Table of Contents

Acknowledgements

Introduction and Overview

- Background
- The Planners
- The Participants
- The Agenda

Meeting Objectives and Questions

- The Objectives
- The Questions
- Breakout Group Discussions

Meeting Results

- Region One—Northwest Illinois Meeting
- Region Four—Southwest Illinois Meeting
- Region Six—East Central Illinois Meeting
- Common Threads

Recommendations for Stakeholders

- Follow Up

Appendices

- Appendix A: The HIV Prevention Community Planning Group Protocol for 2012-2013 HIV/AIDS Strategy Stakeholder Engagement Meetings—Final Draft
- Appendix B: The 2012-2013 HIV/AIDS Strategy Stakeholder Engagement Meeting Agenda—Final Draft
- Appendix C: The 2012-2013 HIV/AIDS Strategy Stakeholder Engagement Meeting Roundtable Discussion Questions—Final Draft
- Appendix D: Combined Meeting Notes

Acknowledgements

The Illinois HIV Planning Group (ILHPG) would like to thank everyone who contributed to the successful completion of the stakeholder engagement meetings—especially the members of the Evaluation Committee and the engagement meeting workgroup, Department of Public Health (Department) HIV Section staff, regional lead agents, and engagement meeting facilitators, recorders, and participants.

It is only through collaborative efforts such as this one that state, regional, and local planners and community organizations and other stakeholders are able to develop effective HIV programs to meet the needs of people living with HIV in our communities and population groups at highest risk for HIV.

Janet Nuss
Illinois HIV Planning Group Coordinator

Introduction and Overview

This report is the outcome of a series of three stakeholder engagement meetings that the Illinois HIV Planning Group (ILHPG)—formerly called the Illinois HIV Prevention Community Planning Group—held in 2012 as part of a larger effort to increase coordination across HIV care, treatment, and prevention programs across the jurisdiction (the state of Illinois outside the city of Chicago). The meetings were part of the Illinois Department of Public Health 2012 HIV Engagement Plan, which aligns with the Illinois HIV/AIDS Strategy (IHAS).

The insights and information gained from the stakeholder engagement meeting discussions should be used by state and regional HIV planners and providers to help identify community service needs gaps and to plan and develop more effective HIV prevention policies and programs that better address the needs of the targeted high risk populations and communities.

Background

In July 2010, President Obama released The National HIV/AIDS Strategy, described as a comprehensive HIV/AIDS roadmap for addressing the national HIV epidemic. In response, the Illinois Interagency AIDS Task Force (IIATF) developed The Illinois HIV AIDS Strategy in 2011-2012, with state-specific goals and objectives that align with the national strategy. Responding to the IHAS, the Illinois HIV Planning Group developed the Illinois Department of Public Health 2012 HIV Engagement Plan. In an effort to reduce rates of new HIV infections, the plan identifies strategies for increasing coordination across HIV care, treatment, and prevention programs across the jurisdictions. It recommends bringing HIV consumer representatives, community stakeholders, and service providers together to identify gaps, deficiencies, and barriers to accessing HIV services and to strategize on enhancing collaboration and coordination in HIV program planning, delivery, evaluation, and assessment. The 2012 HIV/AIDS Strategy Stakeholder Engagement Meetings were the result of that recommendation and a response to Centers for Disease Control and Prevention (CDC) guidance.

Region One—Northwest Illinois, Region Four—Southwest Illinois, and Region Six—East Central Illinois were the sites of the 2012 engagement meetings, which had two goals: (1) to increase community stakeholders' awareness and understanding of the national and Illinois HIV/AIDS strategies and how they translate to state and local HIV care, treatment, and prevention programs, and (2) to achieve a more coordinated response to the HIV epidemic by engaging community stakeholders and enhancing collaboration and coordination among HIV programs. Meetings were held in two additional regions in 2013 and will be reported on in a separate document.

The Planners

At the November 2011 meeting of the ILHPG Planning Group Executive Committee—as part of the 2012 HIV Engagement Plan—the Evaluation Committee was tasked with planning a series of

regional HIV strategy stakeholder engagement meetings to occur over a three-year period. To accomplish this, an engagement meeting workgroup was formed that included members of the Evaluation Committee, the Department's Evaluation Administrator, and the ILHPG Coordinator.

Among the workgroup's responsibilities were establishing the protocol, discussion guide, objectives, and procedures for conducting and evaluating the meetings, including the breakout group discussions. The workgroup met frequently between February and May 2012—researching and reviewing sample materials, and planning for and developing the meeting documents. For more information about that work, see Appendix A, “The HIV Prevention Community Planning Group Protocol for 2012-2013 HIV/AIDS Strategy Stakeholder Engagement Meetings.” The protocol summarizes the process established to plan for, identify and invite participants and to conduct and evaluate the meetings.

Initially, our plan for 2012 was to conduct a half-day stakeholder engagement meeting in each of the three named regions. In January of that year, however, the U.S. Department of Health and Human Services (HHS) Region V HIV/AIDS Regional Resource Network Coordinator—who is headquartered in Chicago—suggested jointly planning the meeting in Region Four. As a result of that collaboration, the Region Four—Southwest Illinois (East St. Louis area) meeting was an all-day event that included a remote keynote presentation by Dr. Laura Cheever, the Associate Administrator for the HIV/AIDS Bureau at the HHS Health Resources and Services Administration (HRSA). A special Region Four workgroup was formed to plan that meeting; members included the Region V HHS liaison, a liaison from the Region V HRSA office, the ILHPG Coordinator, the Director of the Midwest AIDS Training and Education Center, a representative from Gilead Science, and the care and prevention lead agents for the region.

The Participants

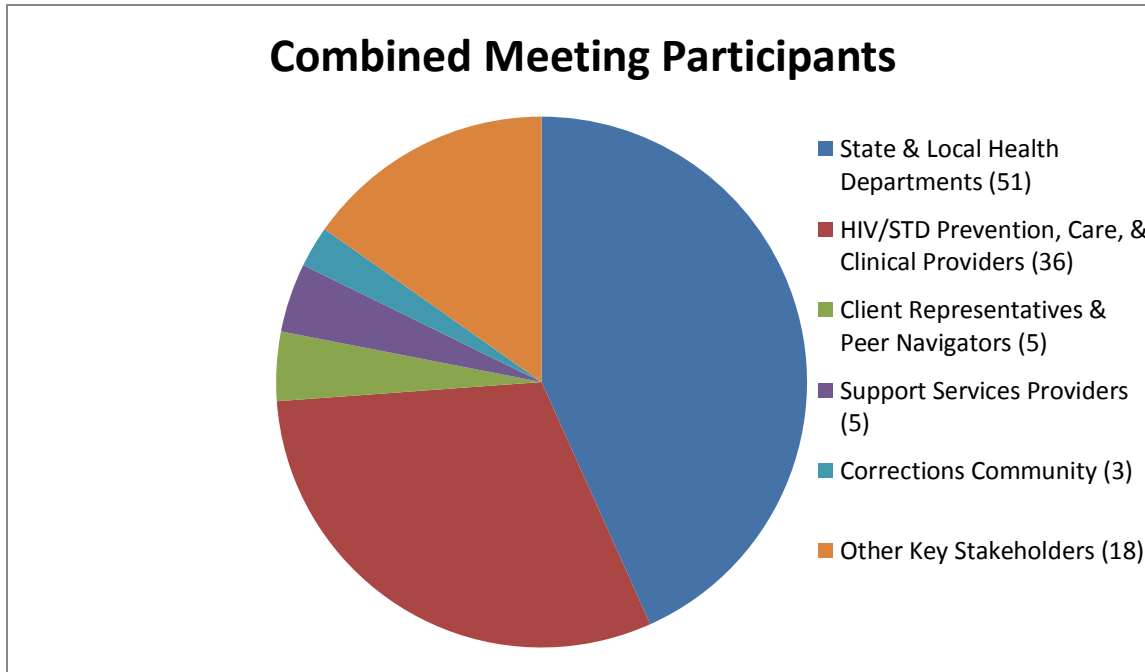
The ILHPG Coordinator worked with the HIV care and prevention lead agents from Regions One and Six and the Region Four workgroup to identify key stakeholders and develop a comprehensive 50-100 person invitation list for each regional engagement meeting. Included on the lists were the following categories of invitees:

- Representatives from state and local health department HIV and STD programs
- HIV and STD prevention, care, and clinical providers
- Client representatives and peer navigators
- HIV support services providers (including substance abuse, mental health, and housing)
- Correctional community representatives
- Other key stakeholders

We were pleased with the response rate—229 people were invited, and 118 people attended. Thirty-nine people took part in the Region One meeting in Rockford, 57 attended the Region Four meeting in Collinsville, and 23 attended the Region Six meeting in Champaign. We applied what we learned from the invitation process in 2012 to the 2013 stakeholder engagement meetings, and those were even better attended. Figure 1 is the combined breakdown of attendees by category. Participants who were not ILHPG members or Department-funded providers were

offered a \$25 gift card in appreciation for their participation and to help compensate for their time or travel expenses.

Figure 1



The Agenda

The 2012-2013 HIV/AIDS Strategy Stakeholder Engagement Meeting Agenda (see Appendix B) details the content, presenters, and breakout group discussions for the half-day meetings. Every meeting included presentations on the National HIV/AIDS Strategy, the Illinois HIV/AIDS Strategy, the Department's HIV Engagement Plan, and the epidemic specific to the region.

A facilitator opened each stakeholder engagement meeting by welcoming participants and reviewing the meeting's purpose and structure. She or he then referenced the protocol and discussion guide to establish the ground rules for the group, help put participants at ease with their possible lack of knowledge about the HIV/AIDS strategies, and encourage them to share their opinions and concerns during the breakout group discussions. Following the presentations, time was available for questions and answers. The breakout discussions were guided by the meeting questions, which are provided in the next section of this report. The meetings closed with a report back to the group.

Meeting Objectives and Questions

Using the protocol established for the meetings, the stakeholder engagement meeting workgroup developed meeting objectives, breakout discussion group questions, and a discussion guide over a period of several weeks (See Appendix C). Workgroup members invested this time in the objectives and questions to ensure that the meetings were positive experiences for participants and resulted in information and insights for use in state and regional program planning.

The Objectives

Five stakeholder engagement meeting objectives were developed; each aligned with a goal of the national and Illinois HIV/AIDS strategies:

- Objective 1: To engage local health departments, other HIV programs (care, treatment, and prevention), and other key stakeholders in HIV planning.
- Objective 2: To identify opportunities for collaboration and coordination across all HIV programs, statewide and local.
- Objective 3: To develop strategies to reduce new HIV infections and reduce HIV-related disparities and health inequities.
- Objective 4: To increase linkage and access to care and improve health outcomes for people living with HIV.
- Objective 5: To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.

The Questions

A series of questions then were developed for each objective to focus the breakout group discussions. Time limits were allotted for each question, and great care was taken to ensure that the questions would be open-ended, address the objectives, and be capable of qualitative analysis. Most questions included an introductory statement linking the question back to the Illinois strategy:

- Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.
 - 1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?
 - 1.2 What would you like to see come out of these planning efforts?
- Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.
 - 2.1 What potential opportunities for collaboration and coordination of activities do you see?
 - 2.2 What are the challenges or barriers to this?

- Question 3: The strategy says three critical steps we must take to reduce HIV infection are: (1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.
 - 3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?
 - 3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?
 - 3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

- Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.
 - 4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?
 - 4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?
 - 4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Question 5—Note that questions 5.1 and 5.2 were prefaced by an epidemiological profile summary of the epidemic specific to the region for each meeting.
 - 5.1: What does your organization need to implement effective, appropriate interventions for this population?
 - 5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Breakout Group Discussions

Presentations on the NHAS and IHAS, the Department's HIV Engagement Plan, and the epidemic in their region prepared the engagement meeting participants for the breakout group discussions. They also were given maps plotting out regional HIV incidence and prevalence by race/ethnicity and risk groups.

Assigned breakout group facilitators kept the discussions to the questions as written, and the meeting facilitator moved among the breakout groups, answering questions, monitoring time, and keeping participants moving to ensure that all the discussion questions were covered. An assigned note taker captured the discussion and recorded comments that were summarized in a report out to participants at the end of the session. These notes are the primary source for this report, and a compilation of the notes from all three meetings is included as Appendix D.

The breakout group discussions were a rich source of information and ideas arising from the diverse experiences and perspectives of the stakeholder engagement meeting participants. Our initial data analysis focused on looking for differences among the groups. We assigned each response to one of four categories—economic, psychological, social, and structural—and developed charts and tables showing the breakdown of responses by type for each meeting. As we looked at that initial analysis, however, we realized that, contrary to our expectations, there were not significant differences in responses by region. And, as we delved deeper into the data, we also realized that our categories were not a good match for the complexity and richness of the responses. In the end, we went with a more descriptive analysis that focused on common threads across the regions—an approach better suited to yielding usable information for stakeholders.

The following section summarizes the discussion results separately for each meeting and then highlights those common threads.

Meeting Results

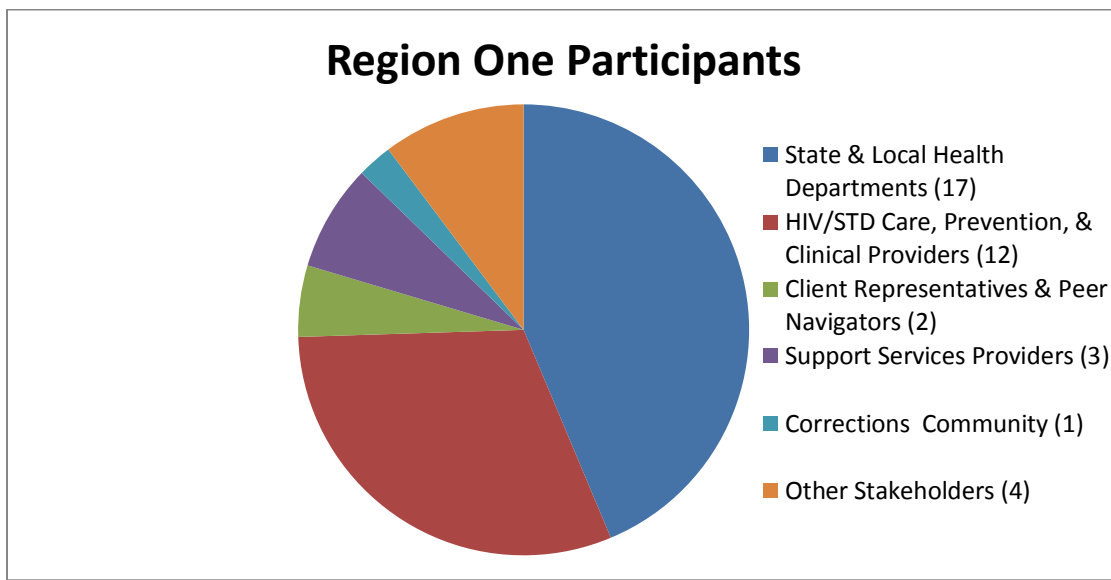
The three 2012 stakeholder engagement meetings took place between July and September. The first meeting was held in Region Six, the last in Region Four. They were well attended by a diverse group of stakeholders, with more participants at each successive meeting.

Responses to each question are highlighted in the following meeting summaries. Space constraints dictate that not every response is included in these summaries. For more detailed information, see Appendix D. Please note that all participant comments, ideas, and suggestions captured in the notes—whether or not they appear below—have been reviewed by leadership of the Department’s HIV Section and the ILHPG and are being used to inform their work.

The Region One—Northwest Illinois Meeting

The Region One stakeholder engagement meeting was held on August 9, 2012 at Crusader Community Health in Rockford. Seventy-three people were invited; 39 attended. Table 2 shows participant affiliations.

Table 2



About Region One

Region One—Northwest Illinois includes the following counties: Boone, Bureau, Carroll, DeKalb, Henry, Jo Daviess, Lee, Mercer, Ogle, Rock Island, Stephenson, Whiteside, and Winnebago. The Region One care lead agent is the Winnebago County Health Department, and the prevention lead agent is the Illinois Public Health Association. For more information, see Region One: Northwest Illinois HIV Care Connect, <http://www.hivcareconnect.com/mobile/northwest.php>.

HIV/AIDS incidence in Region One increased at the same time that it decreased statewide—between 2006 and 2011, the number of new HIV/AIDS diagnoses increased 24 percent, while new diagnoses decreased 19 percent statewide. The number of people living with HIV/AIDS also increased at a greater rate in Region One (31 percent) than statewide (22 percent) during the same period. From 2006 to 2011, new HIV/AIDS cases in Region One were more likely to be male, white, and older. In 2006, 61 percent of new cases were diagnosed among men; by 2011, that number had risen to 75 percent. Blacks made up 43 percent of new cases in 2006, and whites accounted for 44 percent. By 2011, those numbers had changed to 30 percent and 54 percent, respectively. Across the state, new HIV/AIDS cases diagnosed among adults ages 20-29 rose from 26 percent in 2006 to 33 percent in 2011, while the proportion of new cases decreased in that age range in Region One and increased among people ages 40-49, from 22 percent to 36 percent. Risk categories for new HIV/AIDS cases in 2011 were the following: MSM—36 percent, IDU—12 percent, high-risk heterosexual (HRH)—19 percent, and no risk reported (NRR)—30 percent. The proportion of NRR cases almost doubled between 2006 and 2011.

Discussion Questions and Responses

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged? (Note: Although the question asked for entities other than those named in the strategy, some responses were so frequent that they are included here and in the other meeting summaries.)

- Client representatives, peer educators, client peer representatives
Ideas included that client representatives need to be more included in HIV program planning, that case managers may not be aware of the community work client representatives do, and that client representatives are needed for specific populations including women, HIV-positive men, veterans, people who are homeless, and children and families. Other ideas included having a core group of HIV-positive individuals that would be a visible partner at the HIV planning table, and focus groups to get the views of specific population groups.
- Mental health and substance use agencies, organizations, and providers
- Housing agencies, shelters and other organizations serving people who are homeless or near homeless
- Veterans Health Administration (VA) and organizations serving veterans
- Corrections
- People of color organizations
Local Latino organizations were suggested including La Voz Latina in Rockford and Casa Guadalajato in Quad Cities.
- Agencies and organizations serving immigrants and refugees
- Organizations serving people who are gay, lesbian, bisexual, transgender, and questioning (GLBTQ)

Parents & Friends of Lesbians and Gays (PFLAG) was suggested, along with a sense that many community-based GLBTQ serving organizations no longer exist because of funding losses and communities therefore need to identify who provides these services.

- Faith-based organizations and the faith-based community
- Plasma centers and blood banks
Local plasma centers and blood banks were described as not providing adequate HIV information.
- Physicians and hospitals
Suggestions were that local physicians should be educated about HIV services to improve referrals.
- Schools of medicine and nursing—many physicians and nurses need to know more about HIV prevention and care services.
- Colleges and universities
Suggested institutions were Northern Illinois University, Western Illinois University at Macomb and in the Quad Cities, Augustana College, Black Hawk College, Kishwaukee College
- Youth and the agencies and organizations that serve them
- Seniors and the agencies and organizations that serve them

1.2 What would you like to see come out of these planning efforts?

- More people getting tested and into care
- Prompt diagnosis and linkage to treatment
- Better informed and educated communities regarding HIV testing and access to care
- More community engagement
- Better directories and resource lists—comprehensive and electronic
- A coalition to identify gaps in services in the community
- More cost effectiveness, better use of money, fewer political barriers
- Better use of technology and media resources

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Education among agencies and organizations
- Updated directory, robust local referral lists for every testing and care agency
- More efficient case management to get the word out about testing and services
- Better collaboration between case managers and client reps
- Coalition building, regular outreach meetings
- Clients learning about other services when accessing medical care
- World AIDS Day—a venue for local agencies to come together in one place to offer HIV information to clients

- A Summit of Hope for everyone living with HIV/AIDS

2.2 What are the challenges or barriers to this collaboration and coordination?

- Money, funding
In addition to an overall lack of adequate funding, the competition for resources was felt to contribute to adversarial relationships among agencies and resulting duplication of effort and services.
- Competing funding streams that contribute to silos (Part B and Part C, for example)
- No incentives for state agencies to collaborate
- Geographic distance, hindering collaboration and service access
- Transportation
- HIV/AIDS complacency—a sense that AIDS is no longer a problem—both among communities and at the state level
- Illinois/Iowa border issues
- Language and cultural factors
- Stigma

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Promote knowing one's status, but focus on highest risk
- Use general HIV/AIDS education campaigns
Education targeting the general population was suggested as a way to reach high-risk populations who are closeted in a conservative region.
- Provide comprehensive sexuality education in schools
- Engage volunteer groups to fill in the gaps
- Use radio, television, and billboard public service announcements (PSAs)
Social marketing and social networking campaigns were suggested for young and old alike.
- Reach people through new technologies
Suggestions included the use of QR codes to provide localized prevention and care messages, and "We need an app for that!"
- Integrate services so clients get both care and prevention messages at the same time
- Work with organizations to diversify their services

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Use HIV-positive volunteers and community volunteers

- Use peer navigators in the schools to work with teens
- Engage schools of medicine and nursing and public health intern programs
- Increase collaboration among HIV service agencies
- Continue surveillance-based partner services and prevention for positives
- Continue collaboration and communication between the Department's STD and HIV sections
- Find funding for Diffusion of Effective Behavioral Interventions (DEBIs)
- Get care involved in prevention—work to eliminate care and prevention silos

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Inequities:

- Poverty, discrimination, and limited education
Clients have difficulty accessing services because of poverty, discrimination, and limited education, especially low literacy.
- Funding imbalances across the state
There was a strong sense that funding tied primarily to epidemiology results in rural and smaller communities being neglected. Participants were clear that disparities exist outside Chicago and other metropolitan areas of the state.
- Few resources in rural areas
- No resources to pay for all the services immigrants and refugees need
Expensive translation for languages other than Spanish was an example (\$60 an hour for some Asian or African languages).
- Lack of access to dental care and vision services

Strategies:

- Empowering people with knowledge and self-esteem/promoting community activism
- Explore remote service delivery by Skype
- Make Wellness on Wheels (WOW) vans more usable outside hubs
- Work with agencies outside the traditional HIV/AIDS providers
- Provide access to legal and other resources to combat discrimination
- Explore policy strategies including the Affordable Care Act (ACA)

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the Strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Meet client priority needs first, then address HIV
- Provide more resources and better tools to locate those lost to care
- Create, maintain, and use better referral lists

- Explore standardized referral forms and processes
- Fix transportation
- Support and improve case management
- Address the case management mandate to provide partner services at the same time that funding is decreasing

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Money and staff
- Training, training, training
Suggestions included providing training in anti-retroviral treatment and access to services (ARTAS) and DEBIs, including training leading to DEBI certification; offering local and Web-based trainings to avoid travel costs
- Take advantage of the medical community
- Explore resources for pre-exposure prophylaxis (PrEP)
- Find independent funding streams

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Stigma and discrimination keep clients away from services
- Clients' fears about others knowing their business in small communities
- Language, culture, and gender barriers
- Not enough money
- Not enough staff/staff stretched too thin
- Too few qualified staff
- Staff stretched too thin

Question 5: In Region One, the latest epidemiological data suggest that a disproportionate number of HIV infections occur among MSM (54 percent overall from 2006-2011 and 51 percent in 2011)—particularly white MSM who accounted for 60 percent of all diagnoses among MSM overall from 2006-2011 and 58 percent in 2011—and IDU (13 percent overall from 2006-2011 and 17 percent in 2011, compared to 7 percent statewide).

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- More funding
- More staff
- Volunteers
- Diverse and culturally competent staff
- Testing in HIV clinics
- Interventions for white MSM
- Intervention that work for treatment adherence

- Translation services beyond Spanish
- Outreach to the immigrant and refugee community
- Help with outreach to LBGQTQ populations

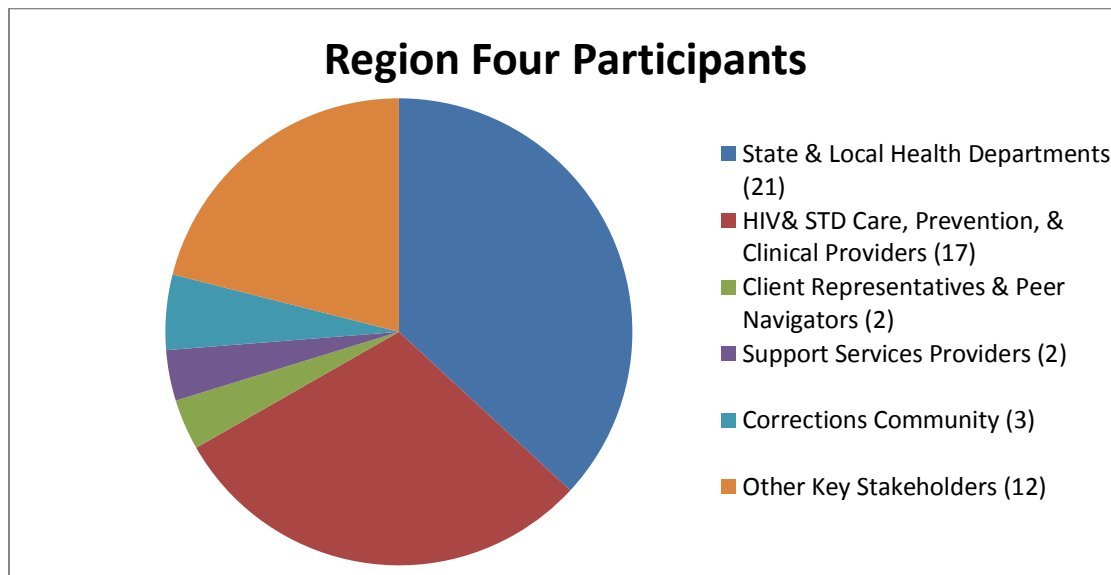
5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- Provide cultural competence training for staff
- Coordinate with the Center for Minority Health Services on the Illinois Communities of Color Minority AIDS Initiative
- Get cultural competence curriculum into schools of medicine, nursing, and public health
- Normalize prevention messages
- Seek better access to local health department surveillance records
- Encourage schools to teach acceptance and enforce anti-bullying policies
- Encourage agencies to be creative and change with the changing epidemic

The Region Four—Southwest Illinois Meeting

The Region Four stakeholder engagement meeting was held on September 13, 2012 at the Doubletree Hotel in Collinsville. Ninety-six people were invited; 57 attended. Table 3 shows participant affiliations.

Table 3



About Region Four

Region Four—Southwest Illinois includes the following counties: Bond, Calhoun, Clinton, Fayette, Jersey, Macoupin, Madison, Marion, Monroe, Randolph, St. Clair, and Washington.

The care lead agency in Region Four is the St. Clair County Health Department, and the prevention lead agent is the Illinois Public Health Association. For more information, see Region Four: Southwest Illinois HIV Care Connect, <http://www.hivcareconnect.com/mobile/southwest.php>.

HIV/AIDS incidence in Region Four increased at the same time that it decreased statewide—between 2006 and 2011, the number of new HIV/AIDS diagnoses increased 16 percent, while new diagnoses decreased 19 percent statewide. The number of people living with HIV/AIDS increased at a greater rate in Region Four (43 percent) than statewide (22 percent) during the same period. From 2006 to 2011 in Region Four, the proportion of new HIV/AIDS cases among women increased 4 percent (from 24 to 28 percent) and decreased from 76 percent to 72 percent among men. Blacks made up 61 percent of new cases in 2006, and whites accounted for 31 percent. By 2011, those numbers had changed to 59 percent and 35 percent respectively. New HIV/AIDS cases in the region diagnosed among adults ages 20-29 rose from 26 percent in 2006 to 38 percent in 2011, while new cases diagnosed among 40-49 year-olds were nearly constant. Risk categories for new HIV/AIDS cases in 2011 were the following: MSM—49 percent (an increase of 14 percent since 2006), IDU—6 percent, HRH—19 percent, and NRR—24 percent.

Discussion Questions and Responses

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

- Consumers in planning groups and on the planning council
- Medicare
- Medicaid and public aid caseworkers, Department of Human Services (DHS)
- Social Security Administration
- Division of Rehabilitation Services, DHS
- Department of Education
- Mental health agencies
- Housing authority for planning and referral; homeless shelters for testing and treatment
- Legal system
Suggestions were the Attorney General's Office, States Attorneys' Offices, law enforcement, and corrections including parole officers
- Secretary of State's Office (literacy and identification)
- Local physicians and hospitals
- Medical and other professional organizations
Suggestions included medical associations for planning, county medical associations for referral, primary health care associations, rural health associations, pharmacists
- Colleges and universities
- Media outlets for planning

- Social media, public access channels

1.2 What would you like to see come out of these planning efforts?

- Reduced barriers for consumers
- Improved viral outcomes through treatment
- Better linkage to care, retention, and antiretroviral therapy
- Increased testing linked to care
- More knowledge and awareness
- Messages getting out to high risk communities
Populations mentioned included MSM, co-infected youth, and young adults.
- More available support groups
- Better transportation for medical and support services
- More behavioral health services
- Multidisciplinary case managers familiar with all the systems
- Local and regional directories and resource lists, in hard copy and electronically
- Continuity of care from bringing stakeholders together so that consumers can navigate the system
- Faith-based engagement
Suggestions included a faith-based alliance and faith-based organizations and families getting involved to reduce HIV stigma.
- Better coordination
- More providers and solutions to other workforce issues
- Capacity building
- More affordable housing for people who are homeless and near homeless

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Linkages between and among HIV and other services
Linkages or stronger linkages were seen as a part of the solution for many problems including links between the state and local levels, between STD and HIV programs, between housing and care, and between corrections and care. Linking HIV providers to local hospitals to provide care was seen as an opportunity, as was linking HIV status to housing through financial incentives. How county health departments link care units in the community was identified as an issue.
- Taskforces and workgroups
Existing and new taskforces and other joint efforts were seen as an opportunity including using the IATF as a means to work together and developing a Ryan White taskforce to work on the ACA in each region and at the state level.
- Meetings

Suggested were strategic planning meetings, local meetings.

- Education, training, and capacity building
Suggested in this category were conferences, training opportunities on co-infection, agencies with capacity helping other (often small) organizations, coordinating training workshops, and identifying the needs of providers outside the HIV realm.
- Opportunities to co-case manage clients with co-morbidities
- Opportunities to collaborate on grant writing
- A Summit of Hope for people living with HIV
- Faith-based organizations
- County jails
- Community colleges and universities
- School administrators
- Labor organizations and businesses

2.2 What are the challenges or barriers to this collaboration and coordination?

- Funding
In addition to the lack of adequate funding, the competition for funding opportunities was seen as inhibiting collaboration and service coordination.
- Territoriality
- Roles and purposes not adequately defined from the state to local level
- Problems with data transparency and information sharing
- Agencies and organizations with competing missions
- Service duplication by outside agencies and organizations
- Lack of provider knowledge
- Transportation
- Laws, rules, and regulations that disrupt collaboration
The AIDS Confidentiality Act was an offered example.
- Discrimination
- Distrust of systems and agencies in some communities

Question 3: The strategy says three critical steps we must take to reduce HIV infection are: (1) intensify prevention efforts in communities where HIV is most heavily concentrated, (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches, and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Provide early and consistent intervention
- Normalize HIV testing, provide routine HIV
- Use national or statewide community public awareness campaigns
- Use public service announcements (PSAs)
- Use strategic social marketing
- Reach people through social media and new technologies

Examples were Facebook, Twitter, and apps.

- Provide comprehensive sexuality education in schools and in programs outside schools
- Expand peer counseling
- Eliminate disparities at all levels

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Mobilize volunteers
Suggestions included using volunteer centers and groups such as AmeriCorps and the Serve Illinois Commission on Volunteerism and Community Service, using trained peer educators to provide youth with comprehensive sexuality education, and mobilizing parents to advocate for programs.
- Engage colleges and universities
- Engage community health centers
- Collaborate with outside parties—don't assume who is connected, work to breakdown silos
- Continue prevention services for positives and their partners
- Find ways to re-engage those lost to care
- Increase comprehensive sexuality education, starting early
- Allow for home grown interventions
- Get care providers involved in prevention
- Fund health educators with prevention dollars
- Look for prevention funding/support through the ACA
- Keep the Red Ribbon Lottery Grant Program

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Inequities:

- Same as with other diseases
- Oversaturated with services in hardest hit areas, not enough elsewhere in the state
- Too few physicians, physician assistants, and nurses specializing in HIV in Region Four
- Lack of general public interventions for specific populations
Included in the discussion were Black and Hispanic populations, people with low literacy, and the need for faith-based testing.
- Distrust of the medical system by many Hispanics

Strategies:

- Look at how opening and welcoming agencies are as part of quality review
- Reach medical students with training before they choose a field
- Locate services in Black and Latino communities
- Increase health literacy

- Promote access to health insurance

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- More consumer representation
Suggestions included giving clients a voice, more consumer advisory board opportunities, and redefining the role of consumer representatives.
- Consumer therapeutic groups and non-therapeutic support groups—safe places for consumers to discuss their needs and get education
- Improve referral
Suggestions focused on working with private providers so that they could make more and better referrals, as the majority of cases come from the private sector, including giving them more information about care services in the community and how to make referrals to those services, as well as cards on how to link patients to HIV case management.
- Improve information sharing
- Continue surveillance-based programs
- Provide primary care doctors with HIV telemedicine support from regional medical centers
- Build staff capacity
- Offer training for hospitals, emergency departments, case managers, and nurses on linkage to care
- Provide for satellite offices in rural areas
- Make partner services a routine part of all programs and services—surveillance, care, prevention, and case management
- Improve transportation
- Increase available housing
- Provide more case management
- Make treatment adherence programs more available
- Explore and provide DEBIs
Mentioned were Healthy Relationships, Women Involved in Life Learning from Other Women (WILLOW), Comprehensive Risk Counseling and Services (CRCS), and VIBES (Very Informed Brothers Engaged for Survival).
- Promote chronic disease self-management

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Funding
- Staff
Mentioned staff included therapists and counselors.
- Transportation

- Capacity building
Suggested were partnerships with experienced community-based organizations (CBOs) in urban areas and implementing Ask, Screen, Intervene (ASI) at the clinical level.
- STD services included in HIV treatment services
- Prevention appointments scheduled with case management appointments

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Client burnout
- Client compliance
- Stigma
- Money and space
- Transportation and services not close enough to clients
- Too few case managers
- Lack of coordination, data sharing, and collaboration
More collaboration was suggested for rural areas for Summits of Hope and testing events.
- Inability to bill for HIV education and prevention services
- Client recruitment
- Implementation of effective, appropriate interventions for specific populations

Question 5: In Region Four, the latest epidemiological data suggest that a disproportionate number of HIV infections occurred among MSM (61 percent overall between 2006 - 2010 and 49 percent in 2010). In addition, African Americans accounted for 54 percent of overall infections between 2006 - 2010 and 57 percent in 2010. Among new infections in youth (ages 13-24), African Americans accounted for 64 percent of infections among this age group between 2005 - 2010; whites accounted for 22 percent on average.

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- More funding
- More staff
- Diverse and culturally competent staff
This item was specific to hiring staff who represent the populations they serve and staff who are culturally competent (in addition to training existing staff).
- Staff training
Cultural competence, social networks, and social media were mentioned as education and training topics.
- Collaboration with those able to reach the targeted populations
- Resources and supports for serving LBGTQ populations
- Coordinated capacity building
Included were sharing calendars and workshops.
- Youth advisory councils and focus groups
- Testing in HIV clinics

- General education
- Outreach on the street
Suggestions were offered for reaching youth at the places they go.
- Social network leaders and incentives to bring people to events
- Services where the clients are
- Extended evening programs
- Engaged religious organizations

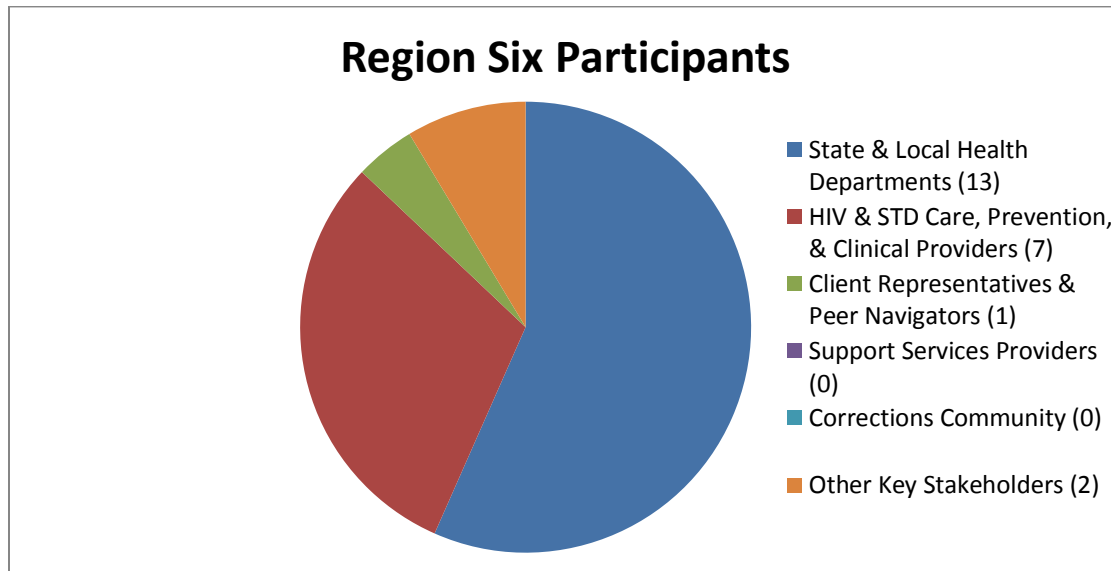
5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- Increase budgets to enable testing of all populations
- Hire culturally competent staff, hire African Americans, hire youth
- Reduce institutional and cultural barriers
- Use social media and social networking
Suggested was a “Text It to Fix It” campaign.
- Educate politicians to overcome AIDS complacency
- Change disclosure laws
- Change laws to allow condoms in prison

The Region Six—East Central Illinois Meeting

The Region Six stakeholder engagement meeting was held on July 12, 2012 at the Champaign-Urbana Public Health District. Sixty people were invited; 23 attended. Table 4 shows participant affiliations.

Table 4



About Region Six

Region Six—East Central Illinois includes the following counties: Champaign, Clark, Clay, Coles, Crawford, Cumberland, Douglas, Edgar, Effingham, Ford, Iroquois, Jasper, Kankakee, Lawrence, Livingston, Richland, and Vermillion. The care and prevention lead agency is the Champaign-Urbana Public Health District. For more information see Region Six: East Central Illinois HIV Care Connect, <http://www.hivcareconnect.com/mobile/eastcentral.php>.

From 2006 to 2011, the number of new HIV/AIDS cases diagnosed in Region Six decreased at a greater rate (23 percent) than new cases diagnosed statewide (19 percent), and the number of people living with HIV/AIDS increased at about the same rate (23 percent) as statewide (22 percent). From 2006 to 2011 in Region Six, the proportion of new HIV/AIDS cases that were male increased 15 percent (from 60 to 75 percent) while the proportion of new female cases decreased from 40 to 25 percent. Risk categories for new HIV/AIDS cases in 2011 were the following: MSM—59 percent (an increase of 10 percent since 2006), IDU—less than 10 percent, and HRH—29 percent (a decrease of 5 percent).

Discussion Questions and Responses

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

- Mental health and substance use agencies, organizations, and providers
- Housing agencies
- Homeless shelters
- Food services that support clients
- VA and organizations serving veterans
- Smaller county jails (not contracted)
- Non-governmental organizations (NGOs)
- Faith-based organizations
Organizations serving communities of color were especially mentioned; the Balm in Gilead was an example.
- People of color CBOs
- NAACP
- African American cultural centers
- GLBTQ centers
- Plasma centers
- Physicians, administrators, clinics, and hospitals
Among the examples were university health center administrators, non-contracted community clinics, and smaller family practices, all of which may get positive patients and not know what to do with them.

- Schools, Boys and Girls Clubs
- Community leaders and politicians

1.2 What would you like to see come out of these planning efforts?

- More people getting tested
Included in the discussion were: free or easy-to-access testing, better access to testing throughout the region—not just in high-volume areas—and people in areas that are not high volume getting tested and into other services.
- A statewide public awareness campaign—get tested and where
- Increased linkage to care and partner services
- More awareness
- People know where to go for services
- Better access to care
- More case managers
- Better communication among agencies

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Testing at other events, especially in rural areas
- Testing as part of routine physicals
- Training
Cultural competence training for physicians and more training on HIV testing were specifically mentioned.
- More people invited to community meetings, more follow up after
- Information about HIV services where people go to get other services (food banks, etc.)
- More involvement in policy making (including city and county boards and hospitals)

2.2 What are the challenges or barriers to this collaboration and coordination?

- Not enough money, time, and other resources
A concern expressed was that organizations make the most of the resources they have, but doing without doesn't get the message across that more funding is needed.
- Transportation
- Too few trained testers
- More training needed
- Programs and staff that are not culturally competent
- People unaware of the needs in their communities—lack of knowledge about HIV
- Cultural barriers in organizations
Examples were the Salvation Army and Catholic hospitals.

- Stigma and fear

Question 3: The strategy says three critical steps we must take to reduce HIV infection are: (1) intensify prevention efforts in communities where HIV is most heavily concentrated, (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches, and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Increase funding for targeted groups
- Activate broader education systems
Schools and faith-based organizations were examples of systems that could be activated around HIV prevention and could build an intellectual platform for accomplishing that.
- Provide comprehensive sexuality education in all schools—advocate for this
- Strengthen interaction and collaboration between prevention and care
The concern was that prevention staff may not know enough about accessing care, and clients may not be linked appropriately to care and services.
- Integrate HIV, STD, and other services
- Plan well to avoid waste of money

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Reallocate funds saved from vacant state positions to fund these programs
- Increase targeted HIV testing to conserve resources
- Provide screening at events for high risk populations
- Promote routine testing
- Encourage the use of trained peer volunteers
Suggestions were to educate and empower peers, and let them create programs.
- Get creative about collaborating
- Avoid service duplication
- Identify what works—what programs are most effective

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Inequities:

- Inadequate HIV care and services in some areas
The lack of access to medical care—including HIV specialty care—in some areas within the region was felt to be a major inequity.
- Stigma in rural areas—concern about everyone knowing one’s business

An example was that some MSM would rather be thought to be injection drug users than MSM.

- Black MSM test positive at higher rates and are diagnosed later in the disease than their white peers.

Strategies:

- Increase advocacy
- Increase general education and awareness of HIV services
- Make better use of peers
- Make more support groups available for young black MSM (emphasizing support rather than testing)

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Do needs assessments—ask clients about their needs and their opinions of services
- Make it easy to get tested—improve communication about getting tested
- Increase awareness about where to find care—keep the Care Connect website updated
- Encourage informal appointments for clients to talk about risk reduction and partner services
- Make more education available for clients, partners, and their families
- Create small satellite clinics and ensure timely payment from the State
- Improve transportation and move services closer to clients—some travel as much as two hours for care
- Provide more education in school districts

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Funding
- Training!
- Prevention services marketed through case managers
- Outreach services for people who are positive and not in care
- More peers and locations from which they can work
- Peer-based groups for people who are positive

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Programs cut when funding is lost
- Staff time constraints

- Staff fatigue
- Training
Training difficulties included a lack of funding for CRCS, getting the right people together at the same time (scheduling and location), and trainings limited to funded grantees only.
- Limited places to refer people to for services
- Lack of prevention awareness and service integration

Question 5: In Region Six, the latest epidemiological data suggest that a disproportionate number of HIV infections occurred among MSM (54 percent overall between 2006 -10 and 78 percent in 2010)—particularly white MSM who accounted for 57 percent of all diagnoses among MSM overall between 2005 – 2010, IDU (17 percent overall between 2006 - 10 and only 5 percent in 2010), and African Americans regardless of risk groups, who accounted for 52 percent of all infections overall between 2006 - 10 and 53 percent in 2010). There was a sharp increase in the number of infections among IDUs 2007—31 percent—followed by a sharp declines, although still high, in 2008 (23 percent) and 2009 (16 percent).

5.1 What does your organization need to implement effective, appropriate interventions for these populations?

- Enough money and staff
- More money to reach rural areas
Vermillion County was an example (see Appendix D).
- Fewer inconsistencies in the availability of programs and in program requirements
- Staff trained before beginning service delivery
- More staff participation in ILHPG meetings (meetings could be archived as podcasts for staff education)
- Outreach to LBGQT populations at social events
- Finding and engaging hard to reach populations
- Places to engage young MSM and other targeted populations

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- Provide staff training in cultural competence
- Educate the general public on risks—public awareness campaign
- Encourage schools to provide comprehensive sexuality education and teach LGBTQ acceptance
- Change disclosure laws
- Legalize gay marriage, promote LGBTQ equality
- Lift the ban on syringe exchange

Common Threads

Despite the diversity of the regions and the participants, common threads ran throughout all three stakeholder engagement meetings. In part, these commonalities were a result of the workgroup's careful crafting of the discussion questions and the success of the meeting and discussion facilitators in keeping the discussions on topic. Primarily, they reflected the shared complexities of planning, delivering, and evaluating HIV care, prevention, and treatment services in an era when budgets are shrinking but needs are not. The following seven themes emerged from an analysis of the discussions across the meetings:

- Funding and What It Can Buy
- Transportation
- Training and Education
- Cultural Competence
- Collaboration and Integration
- Stigma and Discrimination
- System Barriers and Opportunities

Funding and What It Can Buy

Each region identified inadequate funding as a barrier, and many proposed strategies require more money and the things that money buys—more staff, more time for staff to spend on certain activities, more staff training, more HIV tests, expensive translation services, more and better transportation, new HIV services in geographic areas where few or none currently exist. Competition for scarce funds was mentioned in two of the three regions as an impediment to collaboration and other desired outcomes.

Transportation

Although transportation is referenced above, it deserves to be considered separately because the topic was so important in each meeting. Too few providers and programs in some areas combined with the lack of transportation to get clients to the services that do exist was seen across the board as a serious barrier to access. Even in areas where transportation is more available, it was considered problematic—hard to arrange and hard for clients to use.

Training and Education

Training was a hot topic for every region—each wanted more training on an array of topics for a variety of audiences, ranging from HIV program staff to local physicians and hospitals to school administrators. Among the most often mentioned topics were training on cultural competence, training on DEBIs and other specific interventions, training to enhance case management, training on how to find and reach specific populations, training on using social media and social networking to reach youth and other populations, and HIV awareness education and training for referral sources. HIV/AIDS awareness education for the general public through a variety of public service campaigns also was a frequently expressed need across regions.

Cultural Competence

Although cultural competence was discussed across many other categories, especially training, the frequency with which it was raised merits treating it as a separate theme. Culturally competent staff were seen as necessary, as were staff who are representative of the communities that agencies and programs serve. Two of the three regions would like to reach medical and other health professionals with education and training in cultural competence while they are still in school.

Collaboration and Integration

Each region felt the need for more collaboration and saw collaboration and service integration as a key strategy for providing more and better HIV services, especially where gaps existed, but also as a mechanism for expanding the capacity of organizations. Although considered to be very necessary, collaboration also was seen as difficult to achieve.

Stigma, Discrimination

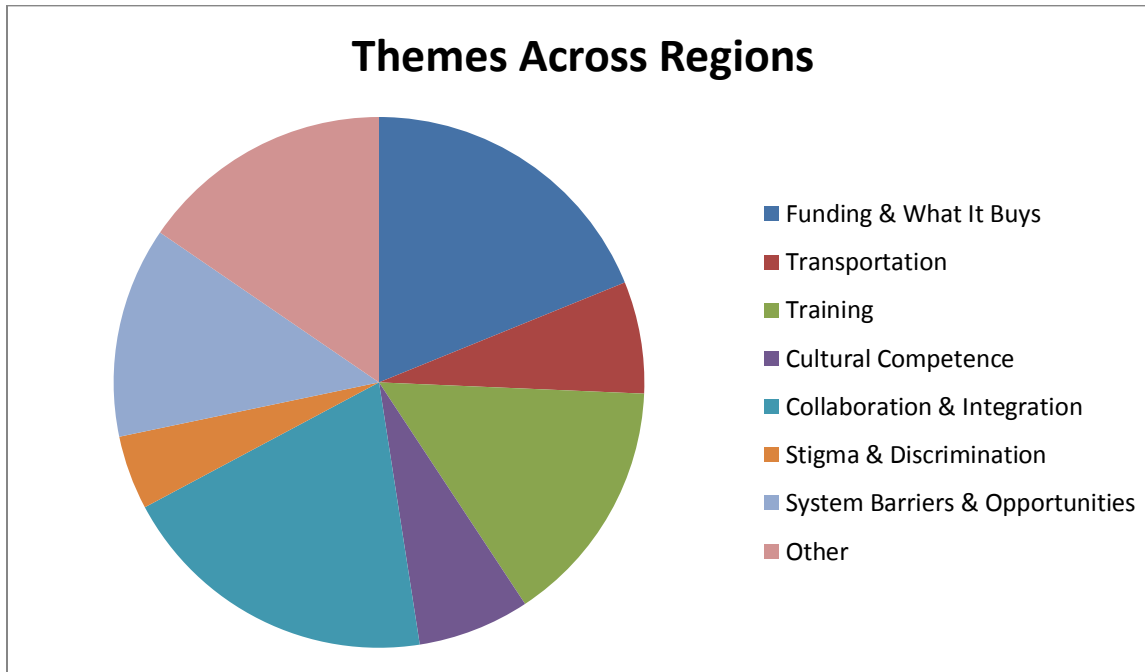
HIV/AIDS stigma was identified as a problem in all three regions, as was stigmatization of and discrimination against LGBTQ individuals. These were most often described in terms of rural or small communities, and were seen as keeping people in need away from services. In Region One and Region Six, a desire that others not know one's business was raised as a related issue. Strategies for addressing stigma and discrimination in all regions focused primarily on education and on policy solutions.

System Barriers and Opportunities

Like cultural competence, system barriers were discussed across every other category in all three regions. Although some of these, such as poverty and homelessness, are beyond the ability of the Department, localities, and other stakeholders to eradicate, together we can chip away at them and work to mitigate the resulting health disparities. Other identified system barriers are within our joint ability to overcome.

Region One and Region Four participants expressed concern about funding formulas that they viewed as too closely tied to absolute number of cases, which they saw as resulting in services heavily concentrated in some parts of the state while other areas had severe service gaps. Similarly, Region Six participants expressed that communities still need services even if just a few HIV-positive people live there. System-determined funding methods also were seen as contributing to territoriality, silos, and competition rather than collaboration.

These common threads—and other participant responses—are the foundation for the recommendations for stakeholders that follow in the next section of this report. Tables 5 through 8 on the following pages show the focus on the seven themes across the regions.

Table 5

Note that this categorization of responses by theme is a rough—rather than precise—indicator of the outcomes of the discussion groups. It reflects the number of times that these themes appeared in the discussion notes, but it does not capture the intensity of the opinions expressed, the energy certain points generated, or whether a discussion item was one person’s opinion or the consensus of the group. Note also that the questions themselves, by design, directed the groups’ attention to certain topics, in particular, to collaboration. Responding to those questions may be why, for example, there was about the same emphasis on collaboration in the discussion groups across the regions—18-21 percent of the responses. The real story is in the meeting summaries and the notes, and we encourage you to refer to Appendix D, Compiled Meeting Notes, and the summaries in the body of the report for a more complete picture of the discussions by region.

Readers also may be curious about the “other” category in this chart set. We categorized as “other” any response that did not clearly fit within the seven most common themes that emerged from the groups. That analysis was solely for the purpose of this report—it allowed us to summarize hundreds of responses here in an accessible format—and there is no more importance or validity attached to a response that falls within the seven themes than one that was categorized as “other.” Certain questions elicited more “other” responses, and therefore Region Four, which had by far the largest attendance, also had considerably more responses in the “other” category. The Department and the ILHPG have been using, and will continue to use, the full data set to inform their work.

Table 6

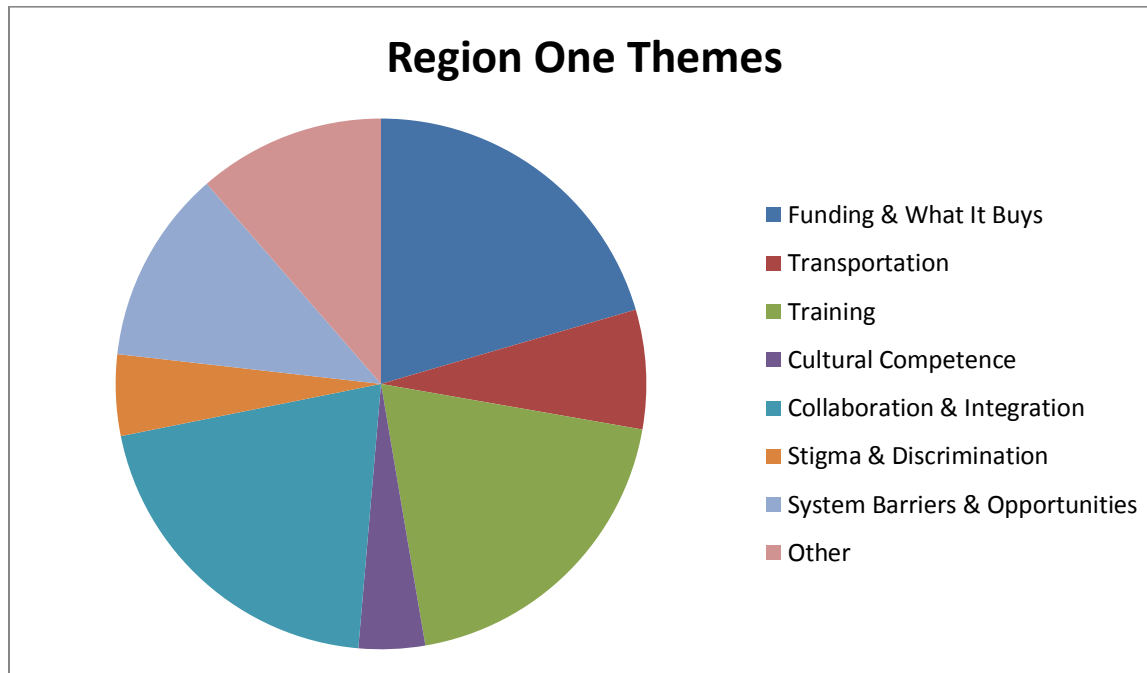


Table 7

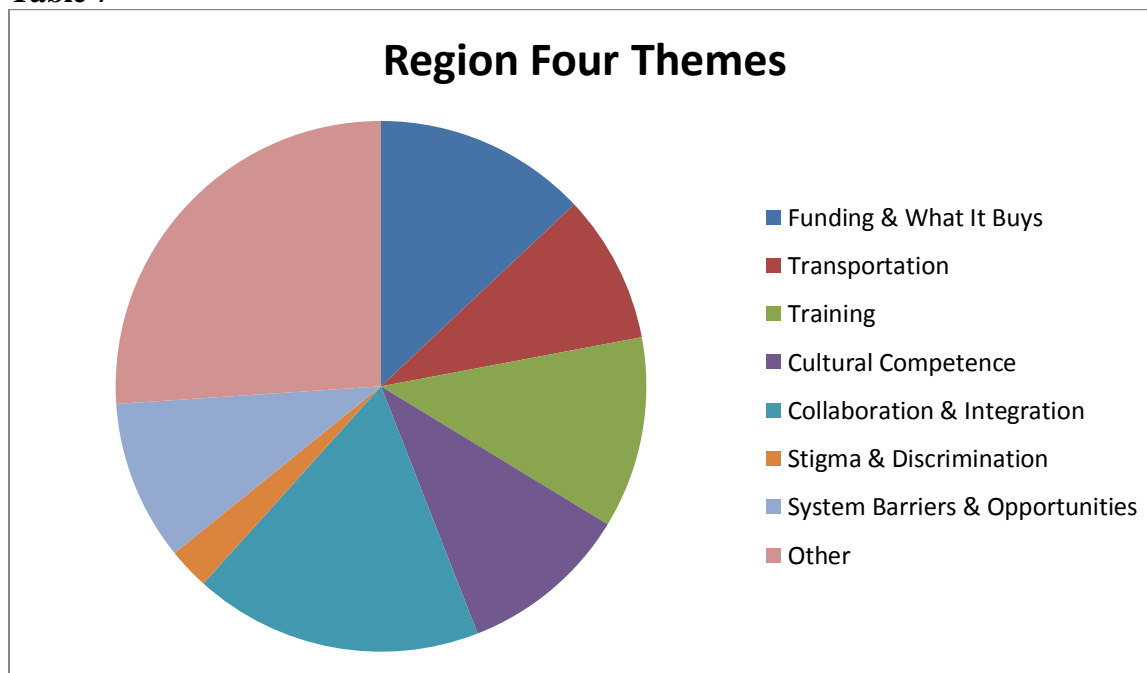
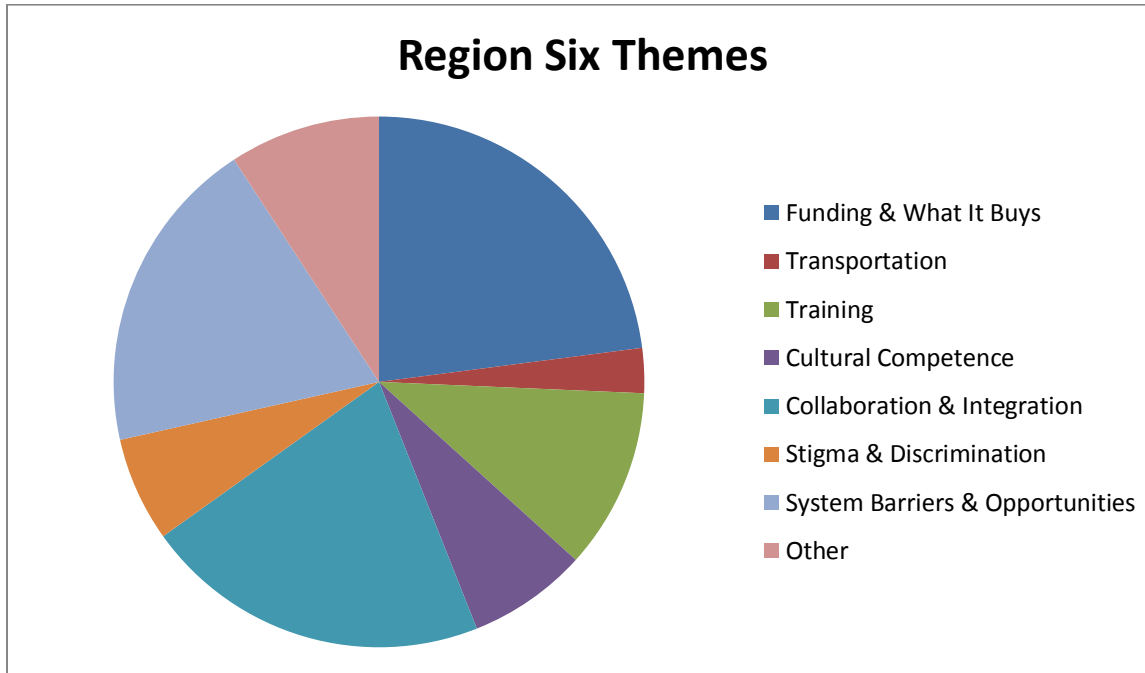


Table 8



Recommendations for Stakeholders

State, regional, and local HIV planners and providers face a common challenge in creating, operating, and evaluating systems and programs that better meet the needs of people living with HIV/AIDS and high risk populations and communities. The Department and the ILHPG cannot rely on the federal government to solve our State's problems, and localities and communities cannot rely solely on the State. Instead, all stakeholders must work together toward solutions that work. As the 2012 stakeholder engagement meetings made clear, there are many opportunities for improvement and a wealth of ideas to inform change at all levels of the HIV prevention, care, and treatment services system.

Throughout 2013, the Department and the ILHPG have been using the service gap information, recommendations, and other insights from the 2012 stakeholder engagement meetings to inform our work including the Department's application to the CDC for a Care and Prevention in the United States (CAPUS) grant. CAPUS grants are three-year federal cross-agency demonstration projects designed to reduce HIV and AIDS-related morbidity and mortality in the U.S., particularly in areas where minority populations, who routinely experience more health inequities in accessing prevention and care services, account for a disproportionate number of HIV infections. The Department received one of only eight such grants nationwide. Initiatives funded through our CAPUS grant were developed based on needs and service gaps identified through the stakeholder engagement meetings.

Following are ideas for stakeholders across the system to consider as they look at what they can do at their level to improve the quality and availability of HIV prevention, care, and treatment services in Illinois. The ILHPG will ensure that these ideas continue to inform our planning work and that of the Department.

Funding and What It Can Buy

- Commit to stronger collaboration across state agencies to maximize funding that can be directed to services for people living with HIV/AIDS.
- Explore funding resources in addition to State HIV/AIDS funding sources including private and public sources that fund health, social services, immigrant and refugee issues, advocacy, antidiscrimination and other areas germane to HIV/AIDS.
- Make the most of existing funding.
 - Reduce duplication of services.
 - Explore co-location and other partnerships that reduce costs.

Transportation

- Make transportation assistance a priority across regions.
- Look at strategies that other counties and regions are using to improve transportation and reduce the need for clients to travel a long way to receive services.
- Subcontract with providers that have satellite clinics to improve access to care locally and reduce the need for lengthy commutes to services.
- Explore expanded use of telemedicine, Skype, and other remote delivery strategies to reduce the need for clients and staff to travel long distances.

Training

- Ensure that HIV prevention, care, and treatment providers have the training they need to provide high quality services.
 - Assess staff training needs regularly, develop individualized training plans, and provide training to meet identified needs.
 - Include training on hot topics such as cultural competence, social media, DEBIs/EBIs, and CRCS.
 - Provide training in a timely way so that staff are fully trained before being asked to deliver complex interventions.
- Explore sharing HIV/AIDS training opportunities with local partners and potential partners.
 - Get the word out about training opportunities through existing collaboration channels.
 - Remove barriers to shared training such as restrictions on who is eligible to attend.
- Use online resources and Web-based training to reduce the cost of training and increase its availability across the state.
- Promote HIV/AIDS education and training in the curriculum for health professionals including schools of medicine, nursing, and public health.
- Work with local professional organizations to encourage continuing education in HIV/AIDS topics.

Cultural Competence

- Hire staff who are culturally competent and staff who are representative of high risk communities and communities being served.
- Provide existing staff with education and training to build their cultural competence.
- Value and reward culturally competent staff and organizations.
- Promote partnerships and collaboration among HIV/AIDS organizations and people of color organizations, LGBTQ organizations, faith-based organizations, and other organizations with a history of successfully reaching and serving targeted populations.

Collaboration and Integration

- Model at the state level the same kind of collaboration that is needed at the local level.
- Work to break down silos that inhibit collaboration including:
 - silos between care and prevention;
 - silos among competing community partners; and
 - silos among disciplines.
- Integrate some HIV and STD services to improve testing, referral, and continuity of care.
- Invest in building stronger relationships among referral sources.
- Build cultural competence through partnerships among HIV/AIDS providers and CBOs successfully reaching and serving specific populations such as people of color, immigrants and refugees, and LGBTQ communities.
- Engage local faith-based communities in HIV/AIDS prevention, care, and treatment services.
- Engage with LGBTQ organizations and community leaders to get HIV, care, prevention, and treatment messages out to the community and to engage members in HIV testing and care.

Stigma and Discrimination

- Combat HIV/AIDS stigma and discrimination through education and advocacy.
- Review disclosure laws and policies and amend those that promote stigmatization.
- Combat LGBTQ discrimination through education and advocacy.
 - Provide/advocate for provide comprehensive, age-appropriate sexuality education in the schools, beginning early.
- Promote LGBTQ awareness and acceptance in the schools and in other programs for youth.
 - Encourage adoption and enforcement of anti-bullying policies in the schools and other youth-serving agencies.
 - Advocate for laws and policies that promote LGBTQ equality, such as anti-discrimination in employment.

System Barriers and Opportunities

- Examine funding formulas to determine how they can be improved.
- Examine funding approaches to determine if they contribute to silos, territoriality, and unproductive competition rather than encouraging collaboration.
- Collaborate to solve workforce issues including too few providers in some areas.
- Clarify roles and responsibilities between and among state agencies and localities.
- Create real incentives that motivate organizations to collaborate.
- Combat AIDS complacency—seek to raise the profile of HIV/AIDS as a priority issue for the State of Illinois.
- Be open to changing organizations and services to keep pace with changes in the epidemic.

Follow Up

The ILHPG continued to host community engagement meetings in 2013, and we have three more scheduled in 2014, so that all regions in the jurisdiction will have an opportunity to participate. We are analyzing the results of the 2013 meetings and will prepare a report early in 2014. Like this document, the Department and the ILHPG will share future reports with regional lead agents and subgrantees, meeting participants, and other stakeholders for their use. Our hope is that the regional stakeholder engagement meetings and the resulting reports will be useful resources as they engage in developing a collaborative response to HIV in Illinois that reduces new HIV infections, improves health outcomes for people living with HIV/AIDS, reduces HIV-related health disparities and inequities, and addresses HIV/AIDS stigma and discrimination.

Appendices

- Appendix A: The HIV Prevention Community Planning Group Protocol for 2012-2013 HIV Strategy Stakeholder Engagement Meetings—Final Draft
- Appendix B: The 2012-2013 HIV Strategy Stakeholder Engagement Meeting Agenda—Final Draft
- Appendix C: The 2012-2013 HIV Strategy Stakeholder Engagement Meeting Roundtable Discussion Questions—Final Draft
- Appendix D: Combined Meeting Notes

Appendix A

HIV Prevention Community Planning Group Protocol for 2012-2013 HIV Strategy Stakeholder Engagement Meetings (Final Draft)

1. A workgroup, composed of the IDPH PCPG Coordinator, the PCPG Community Co-Chair, and members of the PCPG Evaluation Committee, was formed to develop the protocol, discussion questions, objectives, and procedures to be used in planning and conducting the July and August 2012 stakeholder engagement meetings. The PCPG Coordinator developed a first draft of the documents, utilizing as a guide the protocol and discussion questions that had been developed by the workgroup planning the September 14, 2012 Southern IL NHAS Meeting in Collinsville. Members of this workgroup then participated by conference calls to develop, finalize, and approve all documents to be used in the stakeholder engagement meetings. This included ensuring that the discussion questions would meet the objectives of the meeting and were open-ended questions capable of qualitative analysis.
2. The following are the overall goals of the meeting(s):
 - A. OVERALL MEETING GOAL 1:** To achieve a more coordinated response to HIV by engaging key community stakeholders and increasing collaboration and coordination among HIV programs.
 - B. OVERALL MEETING GOAL 2:** To increase community stakeholders' awareness and understanding of the National and Illinois HIV/AIDS Strategies and how that translates to state and local HIV care, treatment, and prevention programs.
3. The meeting(s) will be scheduled from 12-4:30 p.m., the afternoon before the PCPG meeting. The agenda for the meeting will include a working lunch, an introduction of all participants, an overview of the purpose of the meeting, presentations on the regional epidemic (to include a demographic breakdown of HIV incidence, prevalence, and late diagnosis), on the NHAS/IHAS, and on the PCPG Strategic Plan and Engagement Plan as an example of how the NHAS/IHAS translate down to the state/local programmatic level.
4. Five objectives that align with the goals of the NHAS/IHAS have been developed. A minimum of two discussion questions will be developed to address each objective. Time permitting, all objectives and discussion questions will be discussed. The PCPG may limit the objectives and questions, however, if time does not permit discussion of all.

- A. OBJECTIVE 1:** To engage local health departments, other HIV programs (care, treatment, and prevention), and other key stakeholders in HIV planning.
 - B. OBJECTIVE 2:** To identify opportunities for collaboration and coordination across all HIV programs, statewide and local.
 - C. OBJECTIVE 3:** To develop strategies to reduce new HIV infections and reduce HIV-related disparities and health inequities.
 - D. OBJECTIVE 4:** To increase linkage and access to care and improve health outcomes for people living with HIV.
 - E. OBJECTIVE 5:** To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.
5. The PCPG plans to invite participants in the stakeholder engagement meetings by reaching out through the regional care and prevention lead agents to provide a listing of HIV care and prevention providers in the region. In addition to these providers, representatives from the following agencies in the area will be invited: HIV program directors and STD clinic/DIS staff from local health departments, staff from any HIV housing facilities, staff from substance abuse and mental health agencies, discharge planners at correctional facilities, and client representatives. PCPG members from the respective region and the PCPG Co-Chairs will be invited to participate in each meeting.
 6. The IDPH PCPG Coordinator and Co-Chair will attend all focus groups and provide needed support. The focus groups will be facilitated by Jamie Burns, HIV/AIDS Section Trainer. The regional HIV epidemic presentation will be provided by a representative from the IDPH HIV/AIDS Section Surveillance Unit. Mildred Williamson, the IDPH HIV/AIDS Section Chief, will present on the NHAS and the IHAS. Janet Nuss and/or the Community Co-Chair, Lytti Dudczyk, will present on the PCPG Strategic Plan.
 7. The evaluation plan includes the following: IDPH staff and PCPG members will be assigned to participate, to take notes and to facilitate discussion when the larger group breaks out into smaller groups in the afternoon for roundtable discussion. Notes will be compiled by the Evaluation Committee, typed, and sent to Dr. Ma who will analyze and develop a report for each engagement meeting, using qualitative analysis. Responses to each objective and corresponding questions will be evaluated using qualitative, generalized, descriptive analysis. These reports will be completed by November 30, 2012, distributed to the participants in the regional meetings, disseminated to the regional care and prevention lead agents for distribution to their providers, and posted on the www.ilpcpg.org website.

8. Each stakeholder engagement meeting will be limited to 30-40 participants, total.
9. Participants will be provided with a working lunch.
10. Participants will be asked to complete a meeting evaluation survey and a participant profile form at the end of the meeting. Non-PCPG member representatives from agencies not funded by IDPH and/or not able to claim travel reimbursements from their employer will be provided with a \$25 gas card at the end of the meeting to help defray the cost of their transportation and participation and as thanks for their participation.

Appendix B

2012-2013 Region _____ HIV/AIDS Strategy Stakeholders Engagement Meeting Agenda (Final Draft)

- 12:00 – 12:30 p.m. Registration and Networking Box Lunch
- 12:30 –12:45 p.m. Welcome, Introductions, and Meeting Purpose
- *Janet Nuss, IDPH HIV-AIDS Section Prevention Community Planning Coordinator*
- 12:45 – 1:15 p.m. National and Illinois HIV/AIDS (NHAS/IHAS) Strategies and PCPG Engagement Strategy
- *Mildred Williamson, IDPH HIV-AIDS Section Chief*
 - *PCPG Co-Chairs—Janet Nuss and Edwin Corbin-Gutierrez*
- 1:15 – 1:45 p.m. Regional HIV Epidemic
Cheryl Ward or designee– IDPH HIV-AIDS Section Surveillance Administrator
- 1:45 – 2:00 p.m. Break
- 2:00 – 4:00 p.m. Roundtable Discussions
- *Draft Goal: Identify community challenges, successes, and strategies in implementing the concepts of the NHAS/IHAS, focusing most on opportunities for collaboration and coordination at all levels*
 - *Participants will break out into groups. Facilitators (IDPH staff and/or assigned PCPG members) at each table will lead Discussion Questions based on the NHAS/IHAS Objectives*
- 4:00 – 4:30 p.m. Report Out, Closing Discussion, & Next Steps
- 4:30 p.m. Adjourn

Revised February 1, 2012

Appendix C

2012-2013 HIV Strategy Stakeholder Engagement Meeting Roundtable Discussion Questions (Final Draft)

OVERALL MEETING GOAL 1: To achieve a more coordinated response to HIV by engaging key community stakeholders and increasing collaboration and coordination among HIV programs

OVERALL MEETING GOAL 2: To increase community stakeholders' awareness and understanding of the National and Illinois HIV/AIDS Strategies and how that translates to state and local HIV care, treatment, and prevention programs

(20 MINUTES) **OBJECTIVE 1:** To engage local health departments, other HIV programs (care, treatment, and prevention), and other key stakeholders in HIV planning.

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

1.2 What would you like to see come out of these planning efforts?

(20 MINUTES) **OBJECTIVE 2:** To identify opportunities for collaboration and coordination across all HIV programs, statewide and local.

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

2.2 What are the challenges or barriers to this?

(30 MINUTES) **OBJECTIVE 3:** To develop strategies to reduce new HIV infections and reduce HIV-related disparities and health inequities.

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

1. Intensify prevention efforts in communities where HIV is most heavily concentrated.
2. Expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches.
3. Educate all Americans about the threat of HIV and how to prevent it.

- 3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?
- 3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?
- 3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

(30 MINUTES) **OBJECTIVE 4:** To increase linkage and access to care and improve health outcomes for people living with HIV.

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

- 4.1 What needs to be done to ensure HIV positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?
- 4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?
- 4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

(20 MINUTES) **OBJECTIVE 5:** To identify ways to mitigate the impact of stigma and discrimination on HIV care, treatment, and prevention.

Question 5: (*Note: Data to be revised for each region*): In this region, the latest epidemiology data suggest the following: A disproportionate number of HIV infections occur among MSM (61% overall between 2006 -10 and 49% in 2010). In addition, African Americans accounted for 54% of overall infections between 2006 -10 and 57% in 2010. Among new infections in youth (ages 13-24), African Americans accounted for 64% of infections among this age group between 2005 -2010; whites accounted for 22% on average.

- 5.1 What does your organization need to implement effective, appropriate interventions for this population?
- 5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Appendix D

Compiled Notes—Roundtable Discussion Questions

Region 1—Northwest Illinois 2012 HIV Engagement Meeting August 9, 2012

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

Group One

- Client peer representatives need to be engaged in HIV program planning
- Peer educators, case managers—in some instances case managers are not aware of the community work client representatives do within the communities
- Need client reps from the community—one for women, one for HIV-positive men, one for veterans and homeless people, one for families and children
- Need focus groups from all of the different populations in the communities
- Fundraising in the communities to raise more awareness of local community businesses and engagement
- Idea of an HIV-positive social group and their ability to be visible and at the table of planning efforts; this addresses home-bound individuals who may not have a voice
- Use phone trees, use sex adds to get word out about program meetings and social HIV-positive groups; do not use the word “support” groups! This turns people off to and makes them feel like they have a disease. “Social group” is more positive use of the terminology.

Group Two

- More housing units should be involved (housing units for Rock Island, Moline)
- Local Latino organizations (La Voz Latina in Rockford, Casa Guadalajara in Quad Cities)
- Refugee services (Burma, African)
- NIU in DeKalb (all campus people who test positive are reported to DCHD)
- Western Illinois University in the Quad Cities (new campus)
- Western Illinois University at Macomb are open to prevention education
- Augustana College
- Black Hawk College (won’t allow health educators to say “condoms”)
- Community Colleges (Kishwaukee, Malta, etc.)
- Hospitals (Trinity & Genesis in QC)
- Youth Outlook (has links to school districts)
- Parents & Friends of Lesbians and Gays (PFLAG)

Group Three

- Local physicians should be engaged in the process, as many do not refer to care. Perhaps packets to local physicians explaining HIV services and linkage to CARE would be appropriate. Often, physicians are not seeing patients until late diagnosis.
- Plasma centers and blood banks should be engaged, as they are not providing basic education. They are providing minimal information and simply being told they can't donate. Some of these clients are testing negative at the local health department, some are positive, and some may be in the window period.
- Medical schools and nursing schools need to be involved and educated regarding HIV services and care. There needs to be re-education that this is simply not an MSM issue. They need to learn how to conduct sexual risk histories—not just when was the last sexual encounter, but what type of sex, etc.
- Would like to re-engage the LGBT community as in years prior. However, due to funding, many agencies that serve this population no longer exist. Communities must identify who provides these services or consider providing them themselves (if a CBO).

Group Four

- Referrals—all entities should be engaged in planning, and all should know how to make referrals to other agencies
- VA
- Domestic Violence
- Substance Abuse
- Faith-Based Community
- Corrections
- Housing
- Homeless
- Schools K-12, appropriate for each stage
- Youth Corrections
- Refugees/ Immigrants
- Senior Population

1.2 What would you like to see come out of these planning efforts?

Group One

- More community engagement and database development to contact key stakeholders
- To get folks that cannot get into the system of care into the system, especially the homeless population. The Blood Borne Related Infectious Emergency Service model was shared by Tom Hughes as a model program in Jackson County, where the local health department staff and staff from a major medical center emergency care center providing emergency assistance can make an immediate referral to see a care doctor if they present in the ER with an infectious disease Tom is willing to share the model and work with others.
- A 25 year old could not get into care, and he committed suicide—indicating the need for regionally based client or peer assistance instead of just locally based reps. Need for a peer educator available with testing.

Group Two

- Resource sharing, making each other aware of services
- Prompt diagnoses and linkage to treatment

Group Three

- A better informed and educated community regarding HIV testing services and access to care
- Earlier diagnosis of clients
- Better linkage to care and adherence treatment for clients
- A coalition to identify gaps in services in the community to address the above mentioned issues

Group Four

- Cohesion of service
- Cost effectiveness, use of money—political barriers
- Increased use of email blasts of updated service/ better use of technology
- Directory/resource list needs to be comprehensive and electronic; look for key members of each group to participate
- Use of media resources to educate/develop community planning

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

Group One

- World AIDS Day program should have more agencies there in one spot as a “one stop shop” including veterans services
- Many organizations do not want to collaborate because they feel it is too much work
- Accessing medical care once diagnosed and having the ability to learn about all the other services that exist; many don’t know about them
- Have a Summit of Hope, but not just for parolees; what about everyone with HIV?
- Every testing and care agency should have robust local referral lists
- Have case managers work more efficiently with getting the word out about testing and services when doing client intake
- There needs to be better collaboration with the case managers and their client reps. It was mentioned that at least in this region there does not appear to be good collaboration with the care agencies’ client reps and case managers. IDPH needs to provide some technical assistance to this region to assure that better collaboration between these groups is occurring in this region.

Group Two

- Currently, coordination is as follows:

- In Quad Cities, case management and prevention are in the same building, so synergies occur. Treatment occurs across the river at Community Health Care.
- In Rockford, care and prevention are in the same building, so synergies occur. Treatment occurs nearby at Crusader Clinic.
- In DeKalb, no prevention is IDPH-funded, case management is at the health department, and treatment at Rockford, Open Door at Aurora or Elgin, or private docs
- Coordination needs are:
 - The two newly funded Region One prevention CBO's will need to work with case management and treatment providers

Group Three

- Coalition building is an excellent opportunity for collaboration—could bring together STD, TB, substance abuse, mental health services, etc. on a regular basis. There needs to be a discussion as to what is appropriate for a CBO to do vs. a local health department.
- We would like to see collaboration and communication regarding what services are available and where, at what times, and if there are criteria for someone to be seen.

Group Four

- Education among/between services, needs to be collaborative in communication
- All people have different needs
- Collaboration is better, cost efficiency, collaborate to connect resources
- Directory—keep it updated; need to identify resources in the HIV community, also will increase chance of face-to-face meetings or counseling
- Outreach meeting twice a month; look at already established community sites. Mayor's task force should look at overall social service entities. A listserv should be created to connect all entities/organizations. If an organization has needs, an email list should be accessible to connect services and fulfill needs.

2.2 What are the challenges or barriers to this collaboration and coordination?

Group One

- Funding—there needs to be resources for care services by region and county, and collaboration among the groups and agencies. Many operate in silos due to competing resources and competitive funding streams (e.g. Part B and Part C).
- Agencies need to help each other out rather than be adversaries. Because of this relationship, there is a lot of duplication of effort and services. The Interagency AIDS Task Force has not dealt with a very important issue—there is no driver or incentive for DHS, IDPH, other related agencies, and the Governor's office to collaborate. The Governor's office should force collaboration among state agencies around HIV-related services.

Group Two

- Geographic distance makes collaboration and service access difficult
- Providers at this meeting (all case managers) talk to each other all the time
- Referrals between agencies create transportation challenges
- Clients are supposed to use Medicaid transportation, but it's hard to use

- Ryan White as the last resort forces clients to use Medicaid transport, which can be very challenging to use and not always medically appropriate (e.g., a current client living with HIV/AIDS is taking cancer treatments that suppress immunity and can't ride the Medicaid van for fear of catching infectious diseases from other patients on the van)
- The regional case managers meet quarterly together
- Transportation and Medicaid are more complacent about HIV—as fewer are dying now, it's not viewed by them as a serious problem
- Housing waiting lists are all closed
- DeKalb was funded for HIV testing for many years, but funding was cut
- DeKalb sends people for testing to WCHD, Lee County Health Department and, Tri County Health Department for testing
- Could Medicaid use a voucher system for transportation so clients could arrange their own rides?

Group Three

- Territorial issues regarding competition for funding
- Illinois/Iowa border issues (transportation, testing, reporting, CARE services)
- The attitude that HIV/AIDS is not a problem in our area
- Funding—hours, lack of staff
- Language and cultural issues in populations being seen

Group Four

- Silos of the many organizations
- Time is a barrier, how to get information disseminated
- Duplication/redundancy of services
- Traveling, lack of money is always a barrier to services
- Stigma can be a barrier
- Culture of corrections—"no sex" belief can be a barrier
- HIV is not a top priority on the statewide agenda

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

Group One

- Activating broader education systems to do a more effective job (schools, faith organizations) to build more intellectual platform
- D.C. says everyone needs to be tested; the grants or programs say targeted testing only. The message is misleading.
- The money isn't there to do HIV routine opt-out testing for all

- No sexuality education or comprehensive sexuality education in schools, which is badly needed with the age group of 14-19 years of age prior to becoming sexually active
- Local health departments are not giving out condoms routinely
- The paperwork (CTR assessments forms) to test drives some people away from testing
- Need to engage volunteer groups and depend on them to fill in the gaps in the communities
- Various forms of public service announcements on television to radio to mass social marketing and social networking campaigns need to be implemented to reach young and old alike

Group Two

- In this conservative region, “the closet” pressures high risk people to hide their risk and blend in to the general population; so education targeting the general population needs to be provided simply to get messages to the high risk populations
- The use of PSAs and billboards can be effective reaching our targeted populations
- Comprehensive school health education is badly needed
- Messages need to be very localized, using local data to be taken seriously and personally by residents of this region
- Messages should promote risk reduction instead of always focusing on testing, as our testing resources are too scarce to test everyone
- STI risk reduction messages: “We need an app for that!” (see app developed by Alabama AIDS as an example)
- Use QR Codes (the little checkered scanner codes) on posters to give more detailed information. Place them on billboards and on condoms to inexpensively connect people to more detailed, localized prevention and care messages.
- IDPH should centrally develop and make available to the regions PSAs and messaging appropriate for rural, small town, and small city residents that can be cheaply adapted by local agencies for local use
- TPQC has run PSAs that have attracted interest from both high risk clients and potential referring and collaborating agencies
- Even the region’s very high risk target populations like MSM don’t perceive getting HIV as a problem—it’s a treatable condition now
- This group is very connected to people living with HIV/AIDS, but they’d like to see more resources directed to risk reduction education with the general population

Group Three

- Focus efforts on prevention for positives
- Promote knowing your status, but provide most education to those at highest risk
- Adapt DEBIs to the needs of the area
- Integration of services is vital—multiple messages at the same time, since we may not see the client again—HIV, STD, TB, hepatitis

Group Four

- Work with organizations to divide services—work to diversify the focus of organizations (rotate services/sites)

- State increase advertising/media advertisement PSAs; have local area work on advertisements, also
- General education public awareness campaign should focus on areas where high risk populations are located (food stamp providers, etc.)
 - Should be targeted
 - Increase education in schools—should be appropriate “sex education”—science based
 - Child care education
 - Education contracted with services/agencies
 - Go to corrections sites

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

Group One

- Utilization of community volunteers and HIV-positive volunteers. State government needs to build a volunteer agency, engaging people with disabilities to assist.
- Hard to reach 15 year olds—we can’t do anything with them due to limitations, but by the time they turn 19 it can be too late. Peer navigators need to be in all schools working with 15 to 19 year olds now.
- Need to engage medical colleges, nursing schools, and intern programs and collaborate with schools of public health intern to have them work in the communities.
- Put a nurse out there to do education in the community or schools all over the entire state.
- Find creative ways to get to the young with the prevention messages before it is too late.

Group Three (Group Two comments are included in 3.1 responses)

- Collaboration among HIV services agencies is a MUST.
- Provide education to schools and physicians regarding what services are available in the community
- Surveillance-based partner services and prevention for positives must continue to be priorities, and additional trainings should be held
- Continue collaboration and communication between IDPH STD and HIV Sections

Group Four

- Look at funding for DEBIs. (education modules)
- Work to get care involved in prevention (no silo between care/prevention)
 - Funding, staffing, responsibility, accountability
 - Look at how to connect with care and prevention
 - Work with positive patients with care and case load
- Work with providers to be a part of the education/care/prevention team, focus on how to work when location is a barrier

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Group One

- Limitations on accessing care and other essential services because of lack of transportation, poverty. There is a mindset that disparities only exist in large epi centers of Chicago or the larger metropolitan areas; however, they exist in rural communities as well! HIV positive gay men do not just reside in Chicago but also reside all over the state.
- There appeared to be agreement among the group that all efforts seem to be focused only around the epi, leading to unbalanced funding in other regions of the state. Rural regions and areas outside of large urban cores have limited providers, and other positives were recently found in southern Illinois in Jackson County. It was suggested to look at percentage of positives found per capita per region for funding allocation.

Group Two

- Rural means few resources available
- Refugees (Burmese, African) require translation services at \$60 /hour, with no funds available to reimburse
- Transportation is a huge issue with inadequate funds to reimburse. Solutions—Skyping might provide a solution for remote service delivery. Perhaps counseling sessions (PWHIV support or risk reduction) could be conducted by smart phone or tablet video calls when clients would otherwise miss their sessions. Perhaps nurses could provide more in-person services (blood tests, etc.) with doctors providing remote medicine through videoconferencing for rural patients.
- The WOW Vans are now based in hubs (Joliet and Springfield) when they may be needed more in western and southern Illinois

Group Three

- Discussion about poverty, education (especially literacy), and race
- Access to food, shelter, and jobs would reduce risky behavior
- Empowering people with knowledge, self-esteem, and getting engaged with community activism would reduce HIV health inequities
- Strategies would include messages on billboards, public service announcements, working with nontraditional agencies such as churches and wellness fairs
- Many strategies must come from the policy level; the ACA was an example

Group Four

- Dental care—issues with Medicaid, lack of preventative care and only covering extractions—not appropriate dental care for HIV-positive people; need to work with providers
- Vision services—overlooked with all clients, service is not provided now
- Educate on fair housing rights, need to know they exist
- Need access for legal resources, support for discrimination

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

Group One

- Address tools and other navigational resources to get better in touch with people. This population can be mobile, and, if they are lost to care or services, sometimes it is almost impossible to locate them unless they enter the system on their own.
- More resources to get representatives out into the communities to try and locate people lost to care; 19 to 24 year olds are accessing the Internet, Facebook, and Twitter, so these may be ways to connect and reach them where they are.

Group Two

- All classes of services need to have referral lists for the other services
- Standardized paper referral forms and referral process
- Possibly Provide Enterprise System can play a role, as its interagency referral capabilities are expanded, to (1) transmit care-to-prevention referrals and prevention-to-prevention referrals and (2) provide licenses to key service providers funded by non-IDPH sources (i.e., private infectious disease treatment providers, substance abuse providers, etc.)
- Awesome case managers help ensure access!
- The case management-enrolled clients who “disappear” tend to do so due to: incarceration, death, move out of state, and drug relapses (nicknamed the “Houdinis”). Providers do call each other now to help find missing clients they both serve.

Group Three

- Meet them where they are in terms of needs—create rapport by addressing other important issues first, then addressing HIV status
- Know what services are available for the clients
- Address transportation issues for the clients, especially the Iowa/Illinois border issues with care
- Outreach to high risk individuals, especially those lost to care
- Case managers need to keep engaged with clients, conduct partner services, feel comfortable discussing clients as sexual beings, and keep open lines of communication

Group Four

- Retention in care is hard—work with surveillance and with local health departments to identify new HIV(+) in area
- Getting them connected to care is key
- Keeping them in the care program
- Partners need to be identified
- Care mandates and populations increase, while services and funding decrease; programs to assist in condom distribution, food services, and transportation have been cut
- Specialty doctors are needed—need to be local or available transportation to site
- Due to services being catered at one specific location
- Can hinder access to service

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

Group One

- Take advantage of the medical community. We are not utilizing them as a resource to do more work with prevention with positives, and reaching out in the community to reach home bound individuals

Group Two

- Professional training in ARTAS & DEBIs for positives
- Local trainings to avoid travel costs
- Web-based trainings and evaluation leading to certification to avoid travel costs

Group Three

- Training in how to have discussion with partners, ensure treatment adherence, testing of partners and new partners
- Staff willing to conduct surveillance-based partner services, access to the trainings

Group Four

- Need to find independent funding streams to assist partners
- Doing testing in the community—on the street—with community outreach organizations
- Money and staff
- Look at PrEP treatment, seek additional funding streams and education

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

Group One

- Not enough money and funding
- No qualified HIV educators
- Stigma—clients think it is present by accessing services
- Females and Hispanics—no one identifies with them
- Language barriers to engage
- People with HIV just don't want to be out there—stigma, fear, the belief that it is still a gay man's disease; more education is needed
- No one wants other people to know their business within communities and smaller groups within those communities—everyone can learn or know of everyone's business—fear associated with that and discrimination
- Again, look at cost of care and treatment in rural areas and urban areas per person rather than looking at the overall epi in giving out resources; rural areas are overlooked
- Concerns about home testing—IDPH was asked to develop a policy and guidelines to have available concerning home testing that will be made available in stores by October 1, 2012

Group Two

- One more time demand on staff already stretched thin
- Unable to send staff to training due to internal restrictions
- Funding
- Willingness of clients to participate

Group Three

- Funding
- Lack of time due to other required duties
- Staffing levels
- Education of staff
- Not being able to address clients with multiple diagnosis or those that fall out of care

Group Four

- Money and staffing
- Transportation for clients
- Incentive program needs to be balanced
- Explore methods to disperse ADAP drugs at local pharmacies

Question 5: What does your organization need to implement effective, appropriate interventions for these populations?

Group One

- There needs to be interventions for MSM as a whole or white MSM, not just AA or Latino MSM
- Need to access volunteer staff and find interventions that actually work with treatment adherence issues
- Many of the interventions people are not even showing up for, especially if it is a gay event
- To reduce stigma get away from the Magic Johnson “pretty boy, it gets better campaigns” and show reality; put pictures of sick HIV-positive men living with the disease to show youth and others what this disease really does and looks like; let them know that you feel like you have flu every day for the rest of your lives, that’s what living with the disease is really like
- Get away from the bar venues and traditional outreach settings and find gay channels, and broadcast the reality of the disease; consider getting reality adds out there

Group Two

- More staff positions
- Additional funding
- \$200 per counseling session is insufficient for some health departments to offer this service
- Travel for training is costly, and comp time for training/travel is costly
- More local and more Web-based training would help us participate

Group Three

- Identify LGBT services in the community to assist with outreach to the population when they can be found; most not going to gay bars, so need community gatekeepers to assist in identifying locations frequented, social networking sites, and house parties
- Utilize social networking sites to identify MSM, HIV positives and their partners
- Additional funding to provide appropriate services by trained personnel

Group Four

- Staffing, time, and money
- Offer translation services beyond Spanish; diversify languages in the community
- Outreach to the refugee/immigrant communities to educate
- MSM social networking/ prevention counseling
 - Reaching out to “Grinder”—social networking site for outreach/ PSAs
 - Reach out to young black men in location, all are going to Chicago
 - Adam 4 Adam (also can use organization for outreach to put PSAs out)
- Testing in STD clinics

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Group One

- Many clients don’t want to use safer sex practices.
- There was mention of an HIV-positive man’s wife wanting to become positive to get the benefits, housing, etc.

- Policies and laws are needed to engage nurses and physicians to get comprehensive HIV/AIDS and cultural competency curriculum into the public health student programs in colleges to teach them how to better serve their clients and the population.

Group Two

- The climate is very conservative (e.g. picketers at first Rockford Pride); we need to normalize the message that “Everyone is at risk for HIV.”
- The criminal transmission law aggravates the stigma.
- Better access to surveillance records by local health departments including surveillance-based partner services referrals) would help reach isolated PWHIV and connect them to care.

Group Three

- The group believes that education when you are young not to be prejudiced is the first step. The parents must be educated so that they do not pass the ignorance on to their children. Schools need to enforce anti-bullying policies, especially towards those that are LGBT or infected with HIV/AIDS.
- The group discussed that it is important to have staff that represent the clients that you serve in order to be culturally appropriate. If you cannot do that, then have a plan in place for an interpreter or language line so there is no language barrier. Education regarding some of the cultures seen and their beliefs would certainly be of value.
- Agencies need to be creative and think outside the box when providing services. Partner with nontraditional agencies and do things that haven’t been done in the past. The epidemic has changed; therefore, the way in which we provide service must change.

Group Four

- More people are entering or moving into the state with HIV.
 - Connection to Prevention
 - PSA (Public Service Announcements)—social sites
- Need handouts or guidance on laws to work with immigrants
 - Refugee outreach
- More coordination with Minority AIDS Initiative (MAI), Changing policy/laws, *legislative issue*
 - HIV positive students need to report status to principal; law should not be enforced because it can “re-victimize” the student
- Criminalization law, *legislative issue*
 - No teeth in law
 - How does HIPPA/confidentiality set in/ what part does it play?
- Need good lobbyist to work at the state level

Region Four—Southwest Illinois 2012 HIV Stakeholder Engagement Meeting September 13, 2012

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

Group One

- Office of rehabilitative services for developmentally delayed (DRS)
- DHS—Medicaid—public aid case workers
- Corrections, mainly discharge planners concerning linkage to care
- Medical associations, professional associations, such as primary health care, rural health
- Medicare
- Social Security
- Secretary of State—literacy, ID help
- Attorney General’s Office, States Attorney
- Local doctors
- Emergency rooms, hospitals
- Law enforcement

Group Two

- TB hot topic, need training in TB/co-infection w/ HIV
 - Reach out to staff at IDPH and other local health departments on how to refer, link HIV(+) to care
 - Reach out to homeless shelter—testing/treatment
- Entities other than IDPH that also fund testing, need more coordination
 - Department testing and how linkage occurs with existing care system; DASA units also need to know what funding and resources exist
- Hepatitis—no treatment for hepatitis, need to expand
 - Limited resources on eastside of river (Illinois)
 - No feedback comes back from St. Louis; linkage is there
- Distance issue—transportation for treatment

Group Three

- Client consumers on the planning council/group
- County medical society—referral level
- County sheriff—planning and
- Client consumers on the planning council/group
- Media outlets—planning
- Department of Education—planning

- Housing authority—planning, referral
- Mental health—planning and mental health
- Social media, public access channels

Group Four

- Parole agents
- Social Security Administration
- Case managers
- Medical, physicians associations in planning
- Illinois primary healthcare associations
- Pharmacists
- Universities, academic institutions

1.2 What would you like to see come out of these planning efforts?

Group One

- A regional or local guide or resource list (hard copy and electronic)
- Reduce barriers for the consumer regarding services
- Multi-disciplinary case managers familiar in all systems
- Bringing all the stakeholders together for continuity so the consumer can navigate the system easier

Group Two

- Better coordination; know where all DASA sites are that would help with linkage, and who local contacts are
- Testing improvement, but needs to be linked to care
- Work on improving viral load outcome through treatment
- Transportation for care (identification of HIV(+), treatment, connecting the two)
- How to expand number of providers, workforce issues
- Being able to test outside facility
- Linking behavior health with services

Group Three

- Increase knowledge and awareness
- Increase testing efforts
- More available and affordable housing for homeless and near homeless
- Increase linkage to care, retention, and antiretroviral therapy (ART).
- Available support groups (intervention)
- Improved transportation for medical and social support services.
- Capacity building
- Faith-based alliance

Group Four

- Getting messages out to high risk populations including the MSM co-infected youth and young adult populations
- Faith-based organizations and families to get more involved to reduce stigma associated with HIV

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

Group One

- Housing
- Summit of Hope
- Labor organizations and businesses
- Community colleges
- County jails
- Conferences—state /national
- Strategic planning meetings
- Local community meetings
- Bring HIV providers to local hospitals for care
- Administration from schools

Group Two

- Linkage from state level to local level
- Look at training opportunities on co-infection
- Look at opportunities to co-case manage clients with co-morbidities
 - TB/HIV to ensure comprehensive/cooperative care of clients
- STD linkage to HIV programs, see how to change that linkage
 - Family planning centers to have HIV testing—should always be happening
- Issue is how county health department reaches out to link care units in the community

Group Three

- Universities, community (group already in process)
- Faith-based
- Agencies that have the capacities to assist smaller organizations; identify needs of the other providers outside of realm of HIV
- CMA-Smarts (Methadone)
 - Grant writing collaborating
- MOU—tracking referral, coordinating workshop trainings

Group Four

- Linkage and reengagement into care
- Strong collaborations with care and housing
- Department of Corrections linkage to care
- Business owners to promote balls and HIV testing
- All agencies have the same goals to keep individuals virally suppressed
- Link funding of HIV status to housing, if you can make linkages to care and housing financially incentivize this

2.2 What are the challenges or barriers to this collaboration and coordination?

Group One

- Funding
- Territorial attitudes
- Transparency of data, sharing of information
- Rules/regulations, i.e. “AIDS Confidentiality Act”
- Transportation services are too far for consumers
- Rules and laws can be barriers that disrupt these collaboration policies

Group Two

- Getting over the disconnect, knowing who is who and who to link
- Use the HIV strategic task force as a means to work together.
See how systems can work together.
Develop work groups to address copies
- How to engage community services to work together
- Develop a RW task force—work on the ACA in each region
Interagency task force at state level should do same

Group Three

- Funding—collaboration
- Lack of knowledge by providers
- Lack of communication
- Lack of define role and purpose of the agency (state to local)
- Outside agencies duplicating services
- Coordinated efforts of each agency
- Lack of community trust

Group Four

- Discrimination of individuals
- Agencies with different missions and goals
- Territorial issues and competing for funding opportunities that do not foster collaboration and coordination of services

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

Group One

- Education in all aspects
- Facebook, Internet, apps, Twitter
- National or statewide campaign (community/public awareness)
- Routine HIV testing including routine guidelines
- “Normalize” HIV testing

Group Two

- St. Louis side—Ryan White Minority AIDS Initiative and CDC funding (overlap), HIV testing and counseling, “Health HIV integration team”
 - Prevention/care weekly meet up to coordinate prevention services
- Peer counseling expansion is effective
 - Think of ways for funding sources and those doing the work together to strategize
- Putting teams together to gain workforce to get the services coordinated
- Using social media as a means to outreach to community

Group Three

- Early and consistent intervention
- Strategic social marketing
 - Organize calendars
 - Public service announcements (PSAs)
- Collaboration with stakeholders.
 - Define roles of responsibility
- Needs for balance
- Eliminate disparities on all levels

Group Four

- Intensity at the base level, start with education at the high school and college level, down to churches and parents to make them feel comfortable talking and educating their children about sex.
- Adoption of comprehensive sex education in all school settings, program outside of schools such as the Urban League and other similar afterschool programs to get the message

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

Group One

- Schools—advocate to parents for programs
- Colleges/universities
- Community Health Centers
- Standardized testing
- School-based health centers
- Increase sexuality education from young ages
- Prevention can fund the health educators

Group Two

- Collaborate with outside parties to produce networking; need not to make assumptions about who is connected; work to break silos.
- Look at Affordable Healthcare Act and look at ways to find support for prevention programs
- Need to have a means to follow up with those that have been closed, look at mechanism to reconnect individuals

Group Three

- Prevention for positives and their partners
- Identify provider resources to increase knowledge and decrease duplicity (for best evidence-based practices)
- Allow for the development of growth of home grown intervention (we know the problems)
- Keep Red Ribbon Lottery

Group Four

- Mobilize a volunteer base or volunteer centers and groups such as AmeriCorps, Illinois Commission on Voluntary Services; peer educators with youth providing comprehensive sex education, intensive interventions for very high risk individuals

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

Group One

- Oversaturating “high risk” areas—need to target everywhere
- Lack of knowledge

Group Two

- Same inequalities you see in the populations in the other disease sets are the same in HIV; how to reduce the increase in virus every year
- Do a quality review of client population by HIV/AIDS Bureau standards. Break down by gender/race/age/risk group; look at how open or welcoming agencies are

Group Three

- Lack of general public interventions for Hispanic population
- Faith-based testing
- High rates of illiteracy—Black and Hispanic populations
- Lack of trust of medical entity—Hispanic

Group Four

- Lack of physicians and assistants and nurses specialized in HIV trained in Region Four—strategy is to train providers in medical schools on HIV, train residency students to get an interest in HIV before they go into their chosen field of residency.
- Access to insurance, health literacy, getting services to the African American and Latino communities

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

Group One

- Transportation
- Housing
- Satellite offices in rural areas
- Telemedicine at a regional medical center for primary HIV docs
- Drug education-treatment adherence programs
- Chronic disease self-management

Group Two

- Single payer health care for everybody
- Partner services in all centers; see how each works together in surveillance, care, prevention, and ultimately in case managers
- How do you keep (+) virally suppressed and (-) not infected partners
- Consumer-therapeutic group needs a place to discuss the needs they are facing; use of DEBIs on support groups (not therapeutic), create a safe place-education

Group Three

- Encouragement-education-reinforcement (patient)
- Training linkage to care in these settings: hospitals, case managers, emergency departments, nursing

- Merging of case managers and case findings
- Continue to develop surveillance-based program
- Give client a voice (teaching individually)—Consumer Advisory Board
- Redefine role of consumer reps
- Information sharing
- Capacity building for staff

Group Four

- Conduct different DEBIs, such as Healthy Relationships, WILLOW, CRCS, and VIBES with young HIV-negative adults
- Take them to case management
- Referral to the right doctors (the majority of cases come from the private sector)—give cards to doctors on how to link patients to HIV case management; work more with private providers in the community to know about care services and how to make referral to these services

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

Group One

- Funding
- Schedule prevention appointment with case management appointment
- Transportation
- Therapist-counselor
- Satellite case managers

Group Two

- Need money, training, time, and transportation
- Housing and staff
- Look at prevention items

Group Three (Same as responses to 4.1)

Group Four

- Prevention for both—educate the patient, educate the organization, STD services need to be included in treatment services
- Implement ask, screen, intervene at the clinical level in care, partnerships with CBOs and big organizations in urban communities

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

Group One

- Funding
- Transportation

- Finding clients to participate-recruitment
- Patient compliance
- Stigma
- Client burnout

Group Two

- Space
- Money
- Transportation
- Better coordination and data sharing (database that can be open)
- Stigma is a key issue

Group Three

- Lack of coordination
- Lack of case managers
- Decrease of funding to implement
- To implement effective appropriate interventions for these populations

Group Four

- Clients aren't going to travel an hour to get services
- More collaboration in rural areas, Summits of Hope and similar testing events
- Health care organizations are not "billable"—a big problem—can't bill for education or prevention services for HIV

Question 5.1: What does your organization need to implement effective, appropriate interventions for these populations?

Group One

- Funding
- Youth advisory councils/focus groups
- General education
- Religious organizations
- Hire culturally competent staff

Group Two

- Money
- Need lesbian, gay, bisexual, transgender resource support sites
- Carefree shift in prevention—connected on where we do and how we do it (shifting cultures)
- Education (raining on culture competency)
- Bring services where clients are

Group Three

- Staff training
- Cultural competency training
- Stick to your mission
- Staff that represents population
- Collaborate people who are reaching the population
- Calendar and share workshops (coordinated capacity building)
- Social media training
- Social networking training

Group Four

- Extend evening programs
- Outreach on the street
- Reach families in church
- Recruit a leader of social networking to bring people to the events, incentives to bring them in. Have a hummer and a music box on the street to bring youth out to the places where they may test, etc.

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

Group One

- Hire culturally competent staff—AA, hire youth, variety of staff options

Group Two

- Institutional/ cultural barriers

Group Three

- Education of state and local communities of need (representation at table)
- Change laws regarding condoms in prison
- Change disclosure laws
- Money to test all populations

Group Four

- Educate politicians. If it does not affect them or their jurisdictions, they are less likely to take up the cause. There is complacency among legislators. Even if services are there, it does not mean individuals will access them. For legislative issues it has to be pertinent to their constituents in their communities.
- Go more with social media; have a “Text It, To Fix It” slogan or campaign. More social networking and social media are necessary to reach younger audiences with prevention messages.

Region Six—East Central Illinois 2012 HIV Stakeholder Engagement Meeting July 12, 2012

Question 1: The strategy impels us to engage entities from HIV prevention, care, and treatment; STD, TB, and viral hepatitis; mental health and substance use; housing; related supportive services; and other key stakeholders in HIV planning.

1.1 What other entities need to be engaged in this process and at what level (referral, planning) should they be engaged?

- Faith-based organizations –especially people of color and reaching out to them, "Balm in Gilead" a faith-based group
- Non-governmental organizations
- Substance abuse centers with adult role models
- Schools , Boys & Girls Clubs—keep trying to get in
- Medical (hospitals)
- Homeless shelters
- Mental health providers (invited but none regularly present)
- Housing and food services that support clients
- University health center administrators, LGBTQ centers, African American cultural centers
- Linkage to care agencies, more collaboration between prevention and care
- Plasma centers
- Smaller family practices, community clinics that may get a positive person and not know what to do with them—not contracted
- Smaller county jails—not contracted
- Politicians, community leaders, NAACP, sororities/fraternities

1.1 What would you like to see come out of these planning efforts?

- Increased linkage to care and partner services
- Those not testing in high volume areas getting testing and other services
- Need more testing sites throughout region
- More access to services
- More awareness of services
- More case managers
- Communication among agencies
- Free available or easy access to testing
- Need to know where to go for services—need a state public awareness campaign that says get tested and where to go to get tested

Question 2: The strategy impels us to increase coordination and collaboration across HIV prevention, care, and treatment; STD, TB, and viral hepatitis services; mental health and substance use services; housing and other supportive services.

2.1 What potential opportunities for collaboration and coordination of activities do you see?

- Finding events you can test at, especially in rural areas—people come for other services and may end up getting an HIV test—flu vaccines, info, other health related services
- Inviting more people to community meetings with more follow up with them after the meetings
- Include HIV services with other services (advertising at food banks, etc.)
- Cultural competency training with physicians (mentioned a bad experience while testing) at medical clinics and providers
- More staff trained for testing—training is not always accessible, need more
- Getting more involved in policy making (i.e. city, county board, hospitals)
- Part of routine physical, Kankakee Hospital has routine Hep C screening prior to surgery
- STD clinics need State funding
- Collaboration—council meetings should show the impact HIV/STD has on the community—needs assessment to see what is needed

2.2 What are the challenges or barriers to this collaboration and coordination?

- Need more training, more training, more training
- Need more people trained to do testing
- Not enough funding. We make the most of the resources, but sometimes doing without doesn't get the message across that more funding is needed to enhance our programs
- Cultural barriers—Catholic hospitals, Salvation Army
- Lack of community awareness of the need that exists
- Class cultural competency

Question 3: The strategy says three critical steps we must take to reduce HIV infection are:

(1) intensify prevention efforts in communities where HIV is most heavily concentrated; (2) expand targeted efforts to prevent infections using a combination of effective, evidence-based approaches; and (3) educate all Americans about the threat of HIV and how to prevent it.

3.1 How do we balance the demand to intensify targeted interventions for the most impacted populations and the need to provide general education and prevention services?

- Activating broader education systems to do a more effective job (schools, faith organizations) to build more intellectual platform
- Risk reduction, HIV vs. STD risk (people coming in for testing that are being sent away because low risk for HIV)
- Provide HIV services along with others so those not tested because low risk can test for other STIs
- Prevention staff do not always know enough about accessing care, may lose clients linking to care, or do not feel competent when sending clients to others—maybe sharing roles—not enough interaction or collaboration between prevention and care (some clients don't want care staff talking to case manager)

- Comprehensive harm reduction, safer sex, age appropriate sex education in ALL U.S. schools, and lobby laws to make this happen
- Need more funding for targeted groups
- Talk to jail populations, outreach, to young MSM projects, gay test sites, typical young people behavior
- There should be very good planning, so no money is wasted
- Scopes direct proportion to high risk populations

3.2 Federal and State HIV prevention funds for Illinois were cut this year and may be cut in future years. Knowing that, what recommendations can you provide the State about ways to best intensify prevention efforts in communities where HIV is most concentrated?

- Increase targeted HIV testing to reserve resources
- Routine testing—being able to test more people is a positive outcome—may not be good for same high risk populations though (these populations would need counseling)
- Provide screening for high risk at health fairs, events
- Reallocate funds from vacant state positions to funding for these programs
- Encourage peer volunteers—let the peers create the program, educate the peers, give them power
- Get creative about collaborating
- Try not to duplicate services
- Find people resources and link them there
- Identify what is working; what programs are most effective

3.3 What HIV health inequities do you see and what strategies can you suggest to address them?

- Black MSM test statistically higher and later on in disease than white MSM. Strategy: Starting and maintaining young, Black MSM support group—creating environment about support rather than testing; Strategy: Need more advocating, peers, awareness, support groups
- Not enough STD clinics—no resources, one doctor per county, inadequate medical care
- Limited resources for medical care—only one community hospital in some areas, no specialists in HIV care, no insurance = no care
- Provide services to those who most need it. Counties with less than five people infected need to be accounted for and provided with services as well
- There is risk, stigma in rural areas—they would rather be identified as IDU than MSM, and everyone knows your business there

Question 4: Comprehensive prevention services (including partner services) for persons living with HIV are a priority of the strategy.

4.1 What needs to be done to ensure HIV-positive individuals have access to prevention, care, treatment, and supportive services to decrease the risk of HIV transmission to their partners and retain them in care?

- Set up informal appointment for clients coming in to talk to staff about other services, including risk reduction and partner services
- Needs assessment—ask clients' opinions of services and what they think their needs are ("What can we do to make things better for you?")
- Increase awareness to find access to care (those who go to doctor thinking they have the flu and get diagnosed with HIV may not think to go to Care Connect website; keep website updated)
- Educate hospitals and local workers on referrals
- More education in school districts!
- Funding for small satellite clinics and timely payment by the State so clinics don't have to close down
- Good communication—clear communication on who to contact; make it as easy as possible to get tested
- More comprehensive education including family of clients, partners and family of partners
- Effort should be made to get clients back into care
- Transportation is difficult here—it may take 1-1/2 - 2 hours to get to a care provider
- The attitude that “if I do not know, then I can continue to do what I want”

4.2 What does your organization need to incorporate prevention for HIV positives into its array of services?

- Marketing prevention services through case managers
- Outreach services to reach positive people who are not in care
- Training! (2)
- Funding (2)
- More peers and locations for them to operate out of
- Peer based groups, so if you are HIV+ you can make contact there

4.3 What are some challenges or barriers your organizations face in providing comprehensive prevention for positives services?

- Getting the right people together at the same time (schedule, funding, location) for training (2)
- Lack of awareness of prevention services (when clients come in for certain services such as care or testing, other prevention counseling isn't offered/provided)
- Constraints on staff time
- Programs being cut due to loss of funding (2)
- If you are not a funded grantee, you can't get into HIV trainings
- No place to refer people to for services
- Fatigue
- Training for CRCS (Comprehensive Risk Counseling and Services), and because of lack of funding agencies cannot afford to get employees trained
- Lack of service integration

- 75 percent of prevention dollars needing to be used for prevention with positives, talk about merging care/prevention

Question 5: What does your organization need to implement effective, appropriate interventions for these populations?

- Appropriate funding, staff, education
- Funding restrictions and time limits, outreach quotas, scopes
- Need staff trained before implementation period
- Finding population first (hard to find IDU populations in certain areas); planning for a population you don't yet have much access to is difficult
- More staff should participate in PCPG meetings to be involved in strategies and ideas—maybe have presentations archived on a podcast so staff can get a heads up on what may be happening
- Fewer inconsistencies in program requirements and availability
- The need for gay bar LGBT social events; they are doing a good job, but need a "pink" page or "rainbow" page in the phone book
- Need someplace to engage the young MSM, or people who are HIV positive or at risk for HIV, and encourage them to participate in groups
- More money to reach rural areas—Vermillion County was cited as an example. Prisoners are released into the community and sleeping on the street, having sex with others. The only testing in Vermillion County is at the public health department. The mobile unit from Champaign goes there two times a month for two hours. A needs assessment should be done to see what is needed.

5.2 What needs to be done at the structural level (policies, laws, and infrastructure) to reduce stigma and to ensure clients have access to services that are culturally appropriate?

- More education at an earlier level—comprehensive sex ed, equality, marriage, LGBTQ, etc. education in schools! (3)
- Law about principal being notified of student being HIV positive needs to be eliminated—breach of confidentiality
- Lift the ban on syringe exchange, LGBT community room—lobby in support of LGBT lifestyle and cultural competence
- Legalize gay marriage, may reduce stigma
- Public awareness campaign to educate the general public—educate on risks (3)
- Prevention itself can be stigmatizing. Clients feel demonized. Those who are losing hope cannot improve if everyone is put in the same mold.