Final Draft

2013 HIV/AIDS Strategy Stakeholder Engagement Meetings Report

Illinois HIV Planning Group

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Acknowledgements

The Illinois HIV Planning Group (ILHPG) would like to thank everyone who contributed to the successful completion of the HIV stakeholder engagement meetings in 2013. This includes members of the Evaluation Committee and the workgroup that helped create the protocol, discussion guide, and evaluation plan for the meetings, the regional lead agents and ILHPG members who helped develop broad regional stakeholder invitation lists, Illinois Department of Public Health (Department) HIV Section staff, 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 second in a series of three annual reports on HIV stakeholder engagement meetings that the Illinois HIV Planning Group (ILHPG) has held across the state of Illinois outside the city of Chicago. The HIV/AIDS strategy stakeholder engagement meetings are a component of the Illinois Department of Public Health 2012-2014 HIV Engagement Plans—which align with the Illinois HIV/AIDS Strategy (IHAS)—and part of a larger effort to increase coordination across HIV care, treatment, and prevention programs. Five regional meetings have been held to date, and the remaining three will take place in 2014.

We know that state, regional, and local HIV planners and providers face common challenges as they work to meet the needs of people living with HIV and high-risk populations and communities. And we know, too, that the Department and the HIV Planning Group cannot rely solely on the federal government to address these needs. Nor can localities and communities rely solely on the State to do so. Instead, we must all work together to find solutions that work best for our communities. Opportunities for change are plentiful, and the stakeholder engagement meetings have already generated a wealth of ideas to inform new initiatives and improvements at all levels of the HIV prevention, care, and treatment services system. Our hope is that the meetings and the accompanying reports will assist stakeholders as they create, implement, and evaluate programs and services and—together—develop a response to HIV in Illinois that prevents new infections, improves health outcomes for people living with HIV, reduces HIV-related health disparities, and combats HIV/AIDS stigma and discrimination.

Background

In 2010, President Obama released a comprehensive roadmap for addressing the national HIV epidemic called The National HIV/AIDS Strategy (NHAS). The NHAS prompted several actions in Illinois. In 2011-2012, the Illinois Interagency AIDS Task Force (IIATF) developed the Illinois HIV/AIDS Strategy, with state-specific goals and objectives aligned with the NHAS. The Illinois HIV Planning Group then responded to the NHAS and the state strategy by developing the first Illinois Department of Public Health HIV Engagement Plan in 2012. The ILPG has continued to develop engagement plans in subsequent years. These plans identify strategies and activities to enhance coordination across HIV care, treatment, and prevention programs across the jurisdiction. A key component of the engagement plans has been conducting HIV/AIDS strategy stakeholder engagement meetings throughout the state in which community stakeholders are brought together to help identify gaps, deficiencies, and barriers in services and to strategize on enhancing collaboration and coordination in HIV program planning, delivery, and evaluation.

Following up on the 2012 stakeholder engagement meetings in Regions One, Four, and Six (Northwest Illinois, Southwest Illinois, and East Central Illinois, respectively), two engagement meetings were held in 2013: Region Three—Central Illinois and Region Eight—Cook County. Meeting goals were: (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. In 2014, meetings are planned for Regions Two, Five, and Seven.

The Planners and Participants

The stakeholder meetings were planned by an engagement meeting workgroup formed by the ILHPG Planning Group Evaluation Committee, which was tasked with responsibility for the meetings by the ILHPG Executive Committee. The engagement meeting workgroup included members of the Evaluation Committee, two community representatives who were past members of the ILHPG, the Department's Evaluation Administrator, and the ILHPG Coordinator.

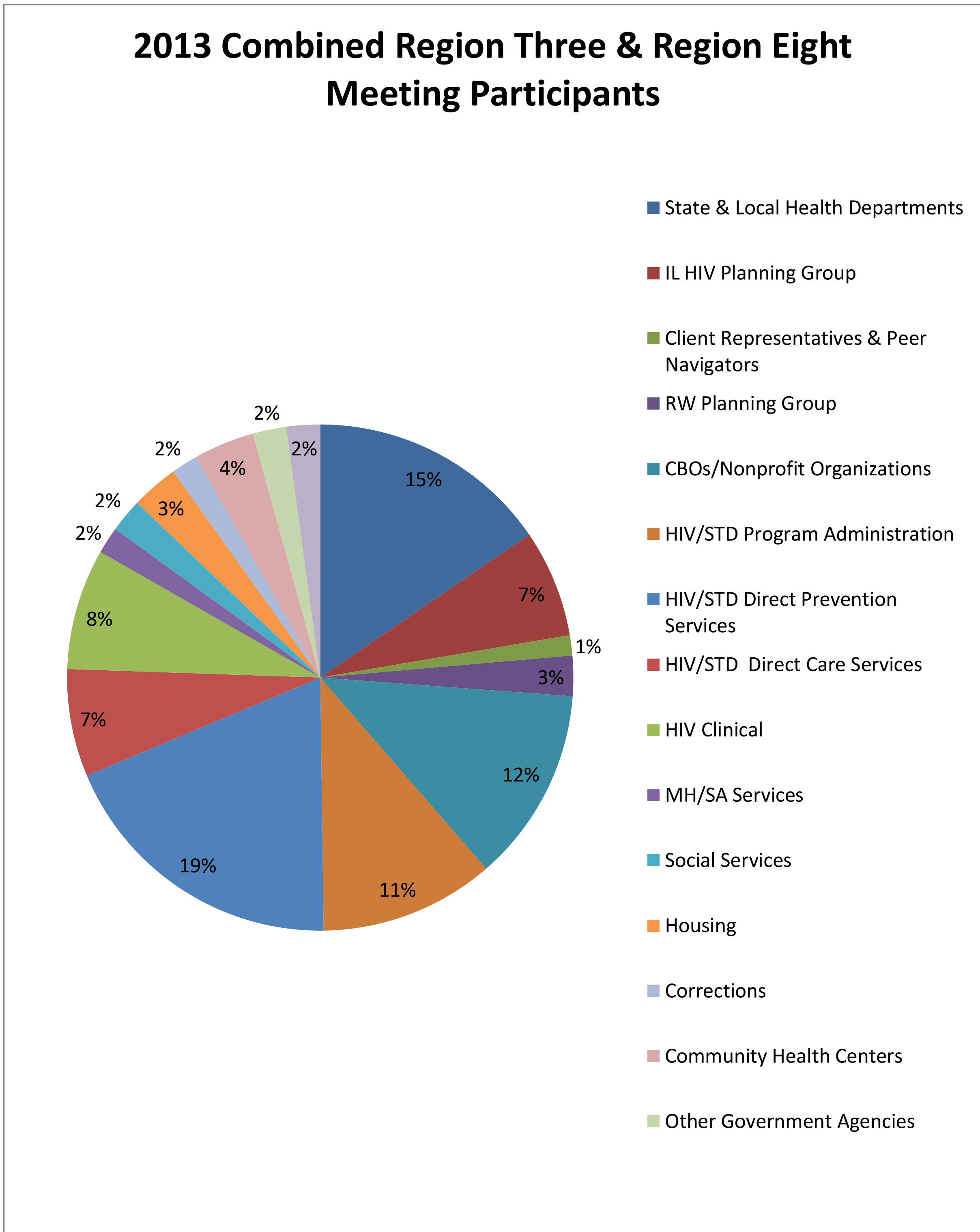
The workgroup established the protocol, discussion guide, objectives, and procedures for conducting and evaluating the meetings. Breakout discussions were a key feature of the meetings, with questions designed to elicit ideas and opinions from all participants. Meeting frequently between February and May 2012, the workgroup researched and reviewed sample materials, and conceived and developed 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," which summarizes the process established to plan, conduct, and evaluate the meetings including how to identify and invite participants to ensure a diverse, representative group of attendees at each meeting.

Using this process in 2013, the ILHPG Coordinator worked with the HIV care and prevention lead agents from Regions Three and Eight to identify key stakeholders and develop a comprehensive list of invitees for each meeting. Among the categories of representatives included on the invitation lists were the following:

- State and local health department HIV and STD programs
- Illinois HIV Planning Group
- Clients and peers
- Ryan White Advisory Group
- Community-based organizations/nonprofit organizations
- HIV and STD program administration
- HIV/STD direct prevention services
- HIV/STD direct care services
- HIV/STD clinical care
- Mental health/substance abuse services
- Social services
- Housing
- Corrections
- Community health centers
- Other government agencies
- Other key stakeholders

Figure 1 on the following page is the combined breakdown of attendees by category. See Appendix B for a breakdown of 2012 meeting participants.

Figure 1



The engagement meetings were well attended—210 people were invited; 95 people attended. Forty took part in the Region Three meeting in Springfield, and 55 in the Region Eight meeting in Palos Heights. To support their participation and express our appreciation, stakeholders who were not ILHPG members or Department-funded providers were offered a $25 gift card.

Meeting Objectives and Questions

Over a period of several weeks, the stakeholder engagement meeting workgroup developed meeting objectives, breakout discussion group questions, and a discussion guide (See Appendix C). The challenge of this work was twofold—to shape the events so that they would generate the most and best information and insights for use in state and regional program planning, and to ensure a positive, fruitful experience for meeting participants.

The Objectives

Five objectives—each aligned with a goal of the national and Illinois HIV/AIDS strategies — were developed as the foundation for the stakeholder engagement meetings.

- 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

Once the objectives were developed, questions were crafted for each objective to focus the breakout group discussions and help the groups stay on target. The questions were carefully designed to be open-ended, to address the meeting objectives, and to be capable of qualitative analysis. Time limits were allotted for each question to keep the discussions moving and to make sure that all groups considered every question. Four of the five 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?

Meeting Agenda

The HIV/AIDS strategy stakeholder engagement meetings were five to six hour events that included presentations on the National HIV/AIDS Strategy, the Illinois HIV/AIDS Strategy, the Department's HIV Engagement Plan, and the epidemic specific to each region. The meeting agenda template (see Appendix C) outlines the content, presenters, and breakout group discussions by timeframe.

The meetings, which were carefully facilitated for the maximum impact, opened with a welcome to participants and an overview of the meeting. The facilitator explained the protocol to be followed and the discussion guide that would be used. This established the ground rules for the group, eased any participant concerns about their level of knowledge about the HIV/AIDS strategies, and spurred their interest in sharing their opinions and concerns during the breakout group discussion period. Following the presentations, time was available for questions and answers before proceeding with the breakout group discussions. The meetings closed with a report back to the group.

Breakout Group Discussions

The breakout discussion groups were the heart of the stakeholder engagement meetings. The discussions were primed by presentations on the NHAS and IHAS, the Department's 2013 HIV Engagement Plan, and the epidemic in the region. Participants also were provided with regional maps showing HIV incidence and prevalence by race/ethnicity and risk groups.

Carefully chosen and prepared breakout facilitators kept the lively discussions on target and moving. For later comparison purposes across groups, the facilitators also ensured that the questions were discussed as written. The meeting facilitator moved among the breakout groups, answering questions, monitoring time, and helping focus participants so that each question was discussed. Assigned note takers 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. For a compilation of the Region Three and Region Eight meeting notes, see Appendix E.

True to their purpose, the breakout group discussions yielded a wealth of information and ideas representing participants' diverse professional and life experiences and perspectives. The process for analyzing the 2013 data arose from what we learned following the 2012 engagement meetings when we had focused initially on looking for differences among the regions. We had 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 and region. Contrary to our expectations, as we considered that initial analysis we realized that there were not significant regional differences in responses. When we dug 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. We are following that same descriptive analysis for the 2013 meetings.

The next section of this report summarizes the discussion results separately for Region Three and Region Eight, then highlights the common threads.

Meeting Results

The following meeting summaries detail responses to the meeting questions generated by the breakout discussion groups. To ensure that everyone had a chance to be heard, meeting participants were divided into small discussion groups—four groups for Region Three and five

for Region Eight. Space constraints dictate that not every response is included in these summaries, but every comment, idea, and suggestion in the notes has been reviewed by leadership of the Department's HIV Section and the ILHPG. These contributions, and the ones from 2012, are being used to inform the work of the Department and the HIV Planning Group.

The Region Three—Central Illinois Meeting

The Region Three stakeholder engagement meeting was held on February 8, 2013 at the Sangamon County Department of Public Health in Springfield. Seventy-seven people were invited; 40 attended. Figure 2 below shows a breakdown of participant affiliations.

Figure 2

About Region Three

Region Three—Central Illinois includes the following counties: Adams, Brown, Cass, Christian, DeWitt, Greene, Logan, Macon, Menard, Montgomery, Morgan, Moultrie, Piatt, Pike, Sangamon, Scott, Schuyler, and Shelby. The Region Three care lead agent is Southern Illinois University School of Medicine, and the prevention lead agent is the Sangamon County Department of Public Health. For more information, see Region Three: Central Illinois HIV Care Connect, http://www.hivcareconnect.com/westcentral.html.

HIV/AIDS incidence in Region Three steadily declined from 2007 to 2010, and then increased 21 percent (N=6) between 2010 and 2011. Note that because of the relatively small numbers involved in Region Three, caution should be used in interpreting changes in data as meaningful trends. The number of people living with HIV/AIDS increased at a lesser rate in Region Three from 2006 to 2011 (18 percent) than statewide (26 percent) during the same period. From 2006 to 2011 in Region Three, almost half of new diagnoses (49 percent) were among whites, 44 percent among blacks, and 5 percent among Hispanics. During the same period, males accounted for 70 percent of new HIV/AIDS cases, on average, and females accounted for 30 percent. The number of new cases among women increased 43 percent between 2010 and 2011. Risk categories for new HIV/AIDS cases from 2006 to 2011, on average, were the following: MSM—50 percent, IDU—19 percent, heterosexual contact—11 percent, and MSM/IDU—8 percent. Statewide figures during the same period were: MSM—66 percent, heterosexual contact—20 percent, IDU—10 percent, and MSM+IDU—3 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? (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.)

- People living with HIV/AIDS
  Ideas included strategies for supporting client and peer participation in planning meetings including creating environments that encourage people to come, providing information in advance, valuing the expertise of participants, and making meetings valuable, client centered, and beneficial to them.
- Mental health and substance use agencies, organizations, and providers
  Specifically mentioned were the Triangle Center (substance use) and the lack of places to refer to for mental health services in Region Three.
- Shelters and organizations serving people who are homeless such as the Phoenix Center
- Domestic violence organizations such as Sojourn Center
- Community-based organizations such as the Urban League

- Employment and job training services
- Churches and faith-based organizations
- Corrections
  Mentioned were county jails, juvenile detention centers, and probation.
- Physicians
  A suggestion was that physicians are needed to educate their peers and to convince them to take part in meetings such as this one.
- Local hospitals—Memorial Medical Center, St. John's Hospital
- Federally qualified health centers (FQHCs) such as Central Counties Health Centers and Southern Illinois University Center for Family Medicine
- Family planning centers
- Agencies listed in the resource assessment of the Jurisdictional HIV Prevention Plan
- Social Security Administration offices and recipients
- Medicaid offices
- Department of Children and Family Services (DCFS)
- Youth-serving organizations such as Boys & Girls Clubs, Big Brothers Big Sisters
- Education system
  Mentioned were school districts, middle schools, high schools, principals, superintendents, parent groups at schools, and Lincoln Land Community College (LLCC).
- Groups at colleges and universities for young black MSM and lesbian, gay, bisexual, and transgender (LGBT) students
- Media
  Examples were local TV news channels, newspapers (Illinois Times), PSAs, Twitter, and Facebook.
- Legislators

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

- Decreased incidence
- More clients getting tested and into care
- Reduced stigma, more comfort with testing
- Viral suppression
- Fewer gaps in knowledge about prevention and care, more awareness about how to reach high-risk populations
- Better informed and educated communities regarding HIV testing and access to care
- Better coordination of HIV-related and social services; providers sharing more information
- Less perceived competition among prevention providers
- Competitiveness taken out of funding so agencies have incentives to work together
- Engagement meetings among providers at the individual county level
- Increased access to referrals, especially mental health services
- Health fairs; booths at the Illinois State Fair
- Text code HIV Center for RX and appointment reminders
- HIV hotline—more information about prevention services
- Prevention education through the media

- The City of Springfield to put general messages out on the city website
- Awareness walks to engage the community
- Engaging parents and the PTA to get information and education out to families
- Business and other partners involved
- Higher salaries
  Mentioned was that current low salary ranges make it hard to retain staff; ARTAS is a high-end intervention, yet programs are using entry-level employees.

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?

- Good coordination among the agencies here, and working with others in the community
  There was a sense that the community is coming together at community events and some services, such as harm reduction programs and outreach are done together, but there were many more ideas about how agencies can and should collaborate.
- Agencies can share grant scopes and statistics, collaborate
- Non-traditional organizations—HIV staff can go to clinics serving people who are homeless, for example
- Agencies can do interventions together and learn from each other
  Phoenix Center and Fifth Street Renaissance working together with IDUs was an example, and Phoenix Center was mentioned as an organization that could visit other programs to make them aware of prevention, testing, and care services.
- Working agreements with medical providers—coordinating together
- Collaboration with the CAPUS (Care and Prevention in the United States) Demonstration Project to better target and serve clients
- Collaborations with schools to increase HIV education in schools; a challenge is not being allowed to give students condoms
  Some saw an increase in schools and churches that want to work with youth.
- Social services at community events
- Accepting patients with medical cards (few options) and no insurance
- Guidelines on how to navigate the systems—personal connections
- Use of Text 2 Survive to post announcements on events
- Monthly provider council appointment reminders
- Hosting tabletop exercises for service providers on barriers to getting people into care and other areas of collaboration

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

- Funding, funding cuts
  In addition to an overall lack of adequate funding, competition for resources was felt to make collaboration and coordination difficult, and low funding levels were viewed as a barrier that prevents some agencies from applying.
- Too many demands for too few Ryan White dollars

- Agencies have multiple duties and are stretched thin
- Slow grant notifications that can cause interruptions in services
- Bureaucratic red tape, policies and regulations that limit what can be done
- Uncertainty about what the future system will bring (Affordable Care Act)
- No grants focused just on women
- Men who are on the down low
- Denial—the belief that HIV does not happen here, an unwillingness to be tested
- Stigma and fear around HIV, testing, LGBTQ issues
  Mentioned was a fear of HIV criminalization.
- Transportation and logistics
- Treatment interruptions
- Difficulties getting buy in from other agencies—collaboration is outside many organizations' comfort zone
  Finding the right person to collaborate with at agencies was seen as difficult.
- Agencies that don't see themselves as having a role or relationship to HIV prevention
- Policies and a religious environment that prevent getting into schools

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 targeted prevention
- Reach the general public by elevating HIV to routine so that prevention staff and efforts can go to targeted populations—put the effort with those most at risk
- Test partners
- Test routinely in behavioral health settings
- Work with pregnancy centers; make HIV testing a routine part of care here
- Strategize where the targeted populations are going and socializing and then go where they are
- Create more opportunities to speak with African American groups, to motivate and engage them in the importance of testing and treatment
- Reach black churches by training gatekeepers to share messages; ask leaders in the community to have their pastors also spread the messages
- Offer monetary compensation or other incentives for listening to HIV information
- Let HIV-positive people tell their stories more often to reach out to others
- Counter the belief that HIV can be cured and is no longer a serious disease
  The suggestion was to focus on the challenges that people living with HIV/AIDS face such as medication side effects, challenges of taking meds every day, other programs that the state cannot fund because of HIV med costs, rising health insurance costs, etc.
- Work more creatively to reach people with different messages—messages that will be heard
- Use train-the-trainer approaches—allow agencies to go places to train others and spread the word

- Use social media to balance targeted messages and broader messages in a cost-effective way
- Provide general education and public service announcements about the risks for HIV and education whenever anyone asks or when you have an audience with them
- Make HIV screening routine within primary medical care to help address the general education need
- Address the general education need by reaching students with comprehensive, developmentally appropriate sexuality education beginning at a young age and continuing through high school

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?

- Hold fundraisers
- Engage new groups in the effort
- Collaborate with other organizations
- Have agencies focus on separate populations rather than duplicating grant scopes among agencies
- Provide HIV education with positive partners within prevention organizations
- Use social networking to reach gay men who are connecting online or by phone rather than going to bars or groups
- Combine testing opportunities with educational opportunities
- Incorporate testing into health fairs
- Invite resourceful people to meetings across a broad audience
- Meet to present and discuss resources in the community

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

Inequities:

- Severe healthcare access issues in Region Three
- Too much attention to MSM and IDU and not enough attention to women
- Not enough money to pay for round the clock testing
- Mental health services are nearly nonexistent; treatment is limited and lines are long
- Lack of safe and healthy housing

Strategies:

- Increase access to primary care and consults
- Improve reimbursement rates
- Make testing available to people without insurance or the money to pay for it
- Add after-work hours to make services more available and decrease health inequities
- Focus on the increasing incidence among women in Region Three
- Create and fund safe places for transitional housing
- Get at the addiction process—deal with shame and fear around relapse
- Address the workforce development issue—23 million new people may be insured

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?

- Link people with private resources to care and supportive services
- Combat stigma, shame, denial, and embarrassment around diagnosis and disclosure
- Feature people who are positive and in treatment on magazine covers and posters—let people see others like them who are in treatment
- Educate people, including those who are not sick and do not see the need for treatment and medical care—HIV care leads to positive health outcomes
- Get clients who need mental health services into care and keep them in care
- Target seniors for services
- Collaborate with drug treatment services
- Integrate prevention into the healthcare mainstream—put HIV on the radar of primary healthcare
- Train medical providers on sensitive diagnosis, outreach, follow up, and linkage to care
- Develop a resource referral list for medical providers in the area—use PSAs and outreach to make sure all primary medical care providers know where to refer for Ryan White services
- Improve transportation resources—provide more services remotely online, especially for rural areas
- Refer clients to federally qualified health centers (FQHCs) such as Southern Illinois University
- Train organizations together
- Develop and practice cultural competence to reach all populations
- Develop population-specific strategies to increase access to services
- Use legislation to encourage an increase in the number of providers

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

- Peer programs
- Collaboration with prompt care sites
- Training
- Sensitivity training for a paradigm shift
- More staff exposure to HIV-positive persons
- Outreach to medical providers so that they follow up after diagnosis
- MOUs with medical facilities
- Nurses working with case managers
- Education on other available services when client is linked to care
- Text 2 Survive appointment reminders (with release of information)
- Video loops
- Sensitivity training for a paradigm shift
- Mainstreaming of HIV to combat stigma

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

- Not enough funding
- Money and grant scopes are too targeted
- Need incentives to get positive people into care
- Lots of embarrassment about HIV and STIs
- No transportation to testing sites
- Client demographics, backgrounds, and needs are different—hard to have support groups
- Can't get into the schools—need comprehensive sexuality education
- Too few students disclose HIV-positive status
- Need to involve black churches in promoting comprehensive sexuality education, routine testing, and stigma reduction
- Condoms not easily available to all—need outreach to gay bars with condoms and testing, free condoms at gas stations
- Confidentiality concerns
- Communication problems

Question 5: In Region Three, the latest epidemiological data suggest the following: Injection drug users represent a significant proportion of new HIV infections. IDU accounted for 14.2% of infections on average between 2006 -2011, and 17% in 2011. Statewide, IDU accounted for 9.7% of infections on average between 2006 -2011, and 7% in 2011. In addition, women accounted for 40% of all infections in Region Three in 2011 compared to 20% of infections statewide. The proportion of new infections occurring among those in the 20-29 age category has grown considerably since 2006 when 14% of new infections occurred in this age category. In 2011, persons in the 20-29 age category accounted for 23% of all infections.

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

- More flexibility in grant scopes so that agencies can meet true local need
- Needle exchange and other harm reduction programs
- Behavioral health and substance use treatment partnerships
- More beds in treatment centers
- Increased access, family planning, and social media targeting women ages 20-29
- More work with colleges and universities
- More liberal views for Region Three
- Intervention for legislators to increase access to needle exchange

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 funding for HIV prevention and care
- Increase comprehensive sexuality education in the schools—make condom use a trend, make prevention cool
- Incorporate sexuality education in cultural competence trainings; think outside the box for ways to get the message out
- Train parents in how to educate their kids about HIV

- Get the message out—condom availability does not promote sex
- Promote adoption of routine HIV/STI testing by primary care providers
- Reconsider some separate HIV services that contribute to stigma
- Pass comprehensive school health education legislation
- Eliminate laws that contribute to stigma such as school principal notification and criminalization of HIV transmission
- Work on Hypodermic Syringes and Needles Act to increase access to clean needles

The Region Eight—Cook County Meeting

The Region Eight stakeholder engagement meeting was held on August 15, 2013 at Trinity Christian College in Palos Heights. Fifty-five people attended; 133 were invited. Figure 3 below shows a breakdown of participant affiliations.

Figure 3

About Region Eight

Region Eight—Cook County encompasses Cook County outside the City of Chicago.
The care lead agency for Region Eight is AIDS Foundation of Chicago, and the prevention lead agent is the Public Health Institute of Metropolitan Chicago. For more information, see Region Eight: Cook County, HIV Care Connect, http://www.hivcareconnect.com/cook.html.

HIV/AIDS incidence in Region Eight steadily declined from 2008 to 2011, and then increased 7 percent (N=18) between 2011 and 2012. This resulted in a total 7 percent decrease in the region from 2008 to 2012, compared to a 5 percent decline statewide during the same period. Again note that caution should be used in interpreting changes in data as meaningful trends, given the small numbers involved. From 2008 to 2012 in Region Eight, slightly more than half of new diagnoses (51 percent) were among blacks, 21 percent among whites, and 18 percent among Hispanics. The number of new cases among blacks in Region Eight increased by 14 percent (N=17) between 2011 and 2012, compared to a 2 percent decrease (N=20) among blacks statewide during the same period. In Region Eight between 2008 and 2012, males accounted for 79 percent of new HIV/AIDS cases on average, and females accounted for 21 percent. The number of new cases among women declined 46 percent between 2008 and 2012. Risk categories for new HIV/AIDS cases during the same period were the following: MSM—66 percent, IDU—6 percent, heterosexual contact—25 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?

- HIV-positive community members
- Local government officials, governmental bodies in high incidence townships and mayors' offices
- Large county health departments—can provide technical assistance to smaller health departments
- The Chicago Department of Public Health and the Chicago planning group should have more of a planning presence in suburban Cook County and be mindful of the needs of providers and clients not in the city
- Hospitals—including local community hospitals—emergency departments, private physicians and other healthcare providers
- Oncology and oncology support (medical care, beds, funding to help with linkage)
- Managed care plans and insurance companies, insurance marketplace
- Entities representing other diseases such as Hepatitis C
- Churches, religious and faith-based organizations
- Illinois Department of Corrections (IDOC)—parole and probation system, smaller jails, juvenile justice system

- Re-entry programs
- State and local boards of education, education agencies
- Schools at all levels, including colleges and universities, college wellness centers
- School-based clinics and health programs
- Elder programs
- CBOs—identify their specialties to inspire CBO networking
- Employer-based organizations
- Barber shops—high-risk populations, condom distribution
- Grassroots organizations
- Advocacy organizations

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

- Decreased incidence
- Better outcomes
- Fewer limitations and better planning by IDPH regarding grant scopes and money
- IDPH to look at grant scopes—open them up and make them more flexible
- Broader grant scopes to get people into care
- Information from this meeting used to facilitate smaller regional meetings and regional outcomes
- A list of IDPH grantees
- Updated data, because data is delayed—if updated, it will invite more people for care
- More communication with HIV prevention and care about stakeholders so efforts are more targeted, cohesive, and effective
- Mechanisms to enforce collaboration and keep agencies really engaged such as seed money to build partnerships
- More communication among providers to come together around the dwindling resources
- More collaborative partnerships, no silos
- HIV prevention programs viewing each other less competitively (competing for the same dollars works against this)
- Strong partnerships and relationships with all provider agencies—consider sharing Web design staff, accountants, IT across agencies to increase administrative cost effectiveness, freeing up resources or dollars for direct programming for clients
- Better referral source base
- More venues for outreach
- People to reach out to Spanish-speaking populations
- Linkage to care
- More best practices to increase linkage and retention
- More information made available about people affected by HIV
- More HIV education classes
- Better help for transgender populations in Region Eight
- More training for clinical staff at IDOC, more work with the prisons
- Training for case managers and outreach (prevention) providers on transgender populations
- Education about PrEP (pre-exposure prophylaxis) to ensure that services are high quality for everyone being served

- Very specific advocacy
- More lobbying for HIV prevention

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?

- Reassessment of funding opportunities
- More efficiency with strategy plans
- RFP at state level—include grant scopes on cross populations, linkage with other programs
- Screening clients not in a risk category as a percentage of a grant scope
- Better collaboration between IDPH and Chicago Department of Public Health on Ryan White (Part A and B) and prevention services
- Collaboration between prevention and care
- Consistency within and across regions, best practice models for collaboration
- Shared information about who is funded in each region
- Collaboration with the Department of Transportation—getting HIV-positive clients to care and follow-up appointments remains one of the central barriers for agencies
- Funding to ensure that there is infrastructure and free transportation services in the cities and to and from suburbs
- Use of technology and apps to improve transportation
- Services brought to where the clients are such as school clinics
- Advocate for Chicago Area HIV Integrated Services Council (CAHISC) to do an assessment on the transportation needs in Cook County and the collar counties (it may not be a need in the city as much as in the suburbs, or vice versa; agencies make referrals and do not realize that clients may encounter barriers in getting to the referral agencies
- Networking, interagency collaboration, and execution of plans
- Barrier identification and resource sharing among agencies—develop and use a large master resource list
- Identifying existing individuals and agencies and collaborating with them, for example Congress, Links, Howard Brown Health Center (HBHC)
- Models for CBOs for linkage to care
- Building upon existing relationships with Chicago Public Schools (CPS)
- Use of text messaging and other apps for youth to help them safely, securely, and confidentially access all services
- Collaboration between HIV/STI/hepatitis testing
- MOUs for linkage to care—not everyone has these or knows where to link for care
- Co-location of behavioral health and care services
- How to use peers in day-to-day business and increase outcomes; capacity is an issue
- How to work with undocumented populations to assist with immigration forms, provide linkage to care—how to build trust with clients
- Agencies to have meet and greets, which can be part of their contract

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

- Money, funding, a lack of resources for services
- Red tape
- CDC and HRSA aren't together at meetings
- Compliance and reports about scope of collaboration
- Territory and turf issues—competition, some agencies don't work well with others
- Inadequate sharing of medical data between Cook County and the State
- Chicago Department of Public Health does it one way, IDPH another way
- Different funding sources have different training requirements
- Political denial
- AIDS discrimination and phobia
- Poverty
- Stigma—homophobia, racism, gender-norms
- High staff turnover
- Lack of cultural competence on working with youth, transgender individuals
- Medical case management is no longer client centered
- Not enough reporting out best practices
- Limited days and times of operations for care and clinics
- TB and hepatitis are underfunded programs
- Criminal background checks for employment with federally funded HIV programs

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
- Provide more training on how to implement DEBIs
- Provide more general education on HIV (IDPH)
- Use CBOs to provide more training on program implementation
- Survey agencies that are doing the work already and see what is working for them; identify common problems and successes
- Balance the demand by following the data maps to find high-risk individuals
- Use geo-mapping to know where to test
- Make brochures and other print material available in more languages
- Use electronic outreach
- Educate the masses to alleviate disparities
- Address stigma for target population
- Normalize the idea of going to a mental health therapist for treatment or prevention services
- Support teachers in their roles as HIV and sexuality educators so that they don't view it as "one more thing to do"

- Encourage healthcare providers to talk to kids about safer sex, etc. during regular visits—don't assume that education is going on at home or that kids are getting accurate information from other kids
- Work to overcome taboos about safer sex conversations—people are still in denial about their sex practices
- Provide accurate information about LGBTQ issues
- Increase HIV information and prevention education for refugee and immigrant populations
- Ask corporate America to assist with general education

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?

- Have funding follow the epidemiology hot spots
- Promote and fund scalable interventions
- Use what works—promote workable, affordable interventions
- Address social elements in the development of prevention programming
- Upgrade DEBIs, health education, and testing
- Broaden understanding of what it means to protect oneself—that it is more than just using a condom—incorporate larger meaning and concepts into prevention interventions
- Encourage new agencies to work with established agencies
- Avoid reinventing the wheel—encourage MOUs and partnerships with agencies already doing work
- Use social networking
- Offer testing in more communities
- Increase linkage to care
- Provide more prevention for positives
- Identify gaps in services and hire who is needed such as transgender staff
- Link with universities to engage them in education
- Encourage parents to advocate with schools for programs
- Identify and work with mental health and homelessness CBOs
- Get connected with local medical homes
- Work to develop cultural sensitivity in the HIV care system—how can local care systems develop this capacity, which could open care options

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

<u>Inequities:</u>

- Finances = structural barriers
- Too few doctors and nurse practitioners experienced with HIV
- Poverty
- Alienation from the medical system (immigrants, for example)

- Lack of literacy and health literacy—clients who don't know or have anyone to explain
- Discrimination against people with HIV

Strategies:
- Institute structural changes
- Spread the disease response to other agencies—increase understanding that it takes more than public health programs, because HIV affects all facets of the lifecycle and intersects across many areas of life
- Bring local agencies to the table and see what's working
- Work with HIV-positive representatives of the communities most affected to develop services
- Work with ACA implementation—an opportunity for healthcare and other entities to come to the table to foster strategies to address the inequities
- Be more direct about HIV
- Recruit and train healthcare providers
- Target areas in the community that are most affected
- Make available adult education, vocational training, and job placement for clients
- Consider housing as a public health issue for people in recovery and other high-risk populations—provide transitional housing and support and education and life skills training
- Provide transportation—not every service can be Medicaid reimbursable
- Use social networking and social media
- Reduce stigma—create safe places in organizations
- Advocate for care

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?
- Resolve policy issues
- Have a separate funding stream for linkage to care; improve linkages to outreach services
- Fund different disciplines of services so that prevention and care agencies can increase collaboration and services to HIV-positive clients
- Examine the effectiveness of case management; case managers need to make sure that all new positives are taught about the importance of care and getting the best help
- Build wraparound care services that are onsite with the case managers—call and link them or have them onsite to be linked to care
- Improve linkage to case management in larger regions
- Address the lack of transportation to providers, appointments, and other necessities
- Look at patient general health and mental health indicators
- Have healthcare providers talk about HIV in general conversation to reduce stigma
- Improve understanding of patient-provider relationships

- Provide ongoing patient and provider education
- Involve faith-based organizations
- Address stigma
- Identify barriers to dismissing myths about HIV transmission
- Be client-centered—it's about the client, not us
- Don't make the client rely on you—teach self-care and self-reliance instead
- Create a system for health-seeking behaviors, establish relationships with providers, and use empowering models rather than dependency models

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

- Money (award letter)
- Reporting that is less overwhelming—collecting and entering data takes too much time
- A better understanding of what CDC needs versus what the state needs from agencies
- Funding for peer advocates and linkage coordinators
- More prevention and Ryan White partnerships
- Resources and training about working with undocumented populations
- Have prevention teams—it's about training, more commitment by agencies; make it a part of their mission statements; use subcontracted services with other agencies if necessary
- Client-centered care
- More free testing availability, ability to offer testing to partners
- Help maintaining prevention activities
- Partner services
- Transportation—it's a huge barrier
- Shared resources
- Group prevention support (GPS)
- Partnership for Health (PfH) DEBI
- Subsidized education and housing so that youth do not have to rely on parents or caregivers
- Help getting HIV on young people's radar—education for youth about taking care of themselves even though HIV is no longer a death sentence
- A strategy to link youth to case management
- Cultural competence training
- Disclosure training and assistance
- Education about PrEP—need to talk about and educate clients and providers
- Agencies really following HIPAA, not just what is convenient for them to understand and implement

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

- Money, lack of funding
- Funding issues—how we use funding and where to find new funding
- Grant scope allocation and allotments turn some people away from care
- Inability to bill for prevention for positive services
- No mental health and substance abuse dollars for west suburban Cook County

- Policies and interpretation of policies
- City does not analyze the gaps in care and mental health services needed for wraparound health in the collar counties
- It takes time to build relationships with clients, yet funding requirements may limit time
- HRH is poorly defined—many clients are lost
- Fragmented services
- Clients don't want to spend time or stay for long for fear someone may see them—30-minute sessions
- Need more collaboration between case managers for prevention with positives
- Clients don't want to tell their stories all over again, so they don't keep referral appointments outside their agencies
- Stigma
- Need trained board members, and board members willing to buy into new ideas
- Aging issues including services for HIV-positive people who are living longer with HIV
- Dental services

Question 5: In this Region, the latest epi data suggest the following: The proportion of new cases that are men has increased steadily since 2008. In 2008, men accounted for 74% of new infections; by 2012, men accounted for 85% of new infections. There were 46% fewer diagnoses among women between 2008 (N=76) and 2012 (N=41). In 2012, HIV incidence among men was more than six times higher than that of women (20.9 v. 3.2 per 100,000 of the population). Men who have sex with men (MSM) – particularly Black MSM, represent a significant proportion of HIV new infections. MSM accounted for 51.4% of new infection between 2008 -2012 (on average) and 55.1% of new infections in 2012. Black MSM accounted for 48.0% of all infections among MSM in 2012, followed by Hispanics (24.7%) and Whites (22.0%). In 2012, heterosexual contact accounted for 92.0% of all new infections among women for whom a risk was reported.

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

- Money, cash flow
- Best practices
- Local access to new, creative DEBIs for prevention
- Training in how to reach the MSM population
- Training in how to communicate to reach and find people
- Cultural competence, and cultural competence training for staff
- Local trainers that understand the population in the region
- Local region AIDS community training and network—Chicago and the suburbs are different
- Better understanding of the data and the reasons for the increase in HRH and MSM of color
- Information about risk behaviors from clients who do not identify a risk behavior at testing
- Healthcare system welcoming to men—black men, transgender men, and MSM

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?

- Address cash flow and time limits

- Implement joint applications, including funding and grant scopes, to encourage collaboration between prevention and care
- Fund providers that don't identify as or look like AIDS organizations
- Make harm reduction programs available
- Emphasize secondary prevention, not just counseling and testing
- Scale up biomedical prevention and adherence to medications—reach a wider population with this information
- Provide HIV education at large pharmacies and at clinics
- Have medical assistants and physician assistants spend time providing HIV education—build in the time
- Use age appropriate social marketing
- Provide HIV/STI education in schools
- Improve cultural competence of programs and staff, connect with gatekeepers
- Reduce stigma
- Hold lobby days and AIDS walks at the state and federal levels—teach people how to make their voices heard
- Work with clients on legal and policy barriers , and advocate for legal and policy changes that support clients and staff

Common Threads

Common threads connected the outcomes of the Region Three and Region Eight stakeholder engagement meetings and connected the 2013 meetings to those held in 2012 in Regions One, Four, and Six. Some of these commonalities resulted from the meeting structure and facilitation, but they chiefly reflected a shared challenge—the complexities of planning, delivering, and evaluating HIV care, prevention, and treatment services at a time when needs are growing and budgets are shrinking. The following 10 themes emerged from an analysis of the discussions across the meetings:

- Funding and What It Can Buy
- Best Practices in HIV Prevention and Care
- Transportation
- Training and Education
- Staffing
- Cultural Competence
- Collaboration and Integration
- Media and Public Awareness
- Stigma and Discrimination
- System Barriers and Opportunities

Some discussion responses overlapped themes and were included in multiple categories throughout the analysis.

Funding and What It Can Buy

Money—or the lack of it—was identified as a barrier in every meeting held to date, and many strategies proposed in every region require more funds to achieve. In Region Three and Region Eight a lack of funds was cited as a barrier to testing, peer advocates, implementation of best practices in HIV prevention and care, and an array of supportive services HIV-positive clients need to thrive and high-risk populations need to help them stay negative. Participants also saw inadequate funds—in the form of low salaries—as a barrier to retaining quality staff and having qualified staff to deliver complex DEBIs and other interventions. Cash flow difficulties, which were viewed as resulting from red tape, were described as barriers for agencies' program operations. Competition for scarce funds also was mentioned in both regions as a barrier to collaboration.

Transportation

The difficulty in getting clients to services and services to clients was seen as a significant barrier in both regions, although transportation was a topic of more discussion in Region Eight. Clients' ability to get to and from the suburbs was a concern, and one suggestion was that the Chicago Area HIV Integrated Services Council (CAHISC) should do an assessment of transportation needs in Cook County and the collar counties. Participants in both regions also looked for creative solutions such as using technology and transportation apps.

Best Practices in HIV Prevention and Care

There was a real hunger for information and training on best practices in HIV prevention and care, and also a sense that organizations had much they could share with each other about best practices if opportunities were created to exchange information and experiences. Participants across the board wanted to know more about how to deliver high-quality services to populations most at risk. The importance of evidence-based practices was recognized, but many responses indicated uncertainty about the specifics for various populations such as black MSM, youth, and transgender populations.

Training and Education

Training was seen as a solution to many ills. Both regions wanted more training on a broad range of topics. Mentioned most often as desired training topics were cultural competence, DEBIs, and strategies for reaching and working with high-risk populations. Many participants in both regions identified training that they considered important for others to have such as training for physicians on communicating diagnoses and other sensitive information to patients, referrals, and an orientation to the HIV prevention, care, and treatment systems.

Staffing

Staffing was a frequent topic of discussion in both Region Three and Region Eight. Some concerns around staffing were viewed as able to be solved with training. Other concerns

reflected broader systems issues that do not lend themselves to ready solutions. In particular, low salaries were seen as problematic—making it hard to retain qualified people and requiring programs to attempt complex interventions using inexperienced staff. Some participants were concerned about workforce size and the need to attract new providers to the field in response to anticipated increases in client numbers as a result of ACA implementation.

Cultural Competence

Cultural competence was identified as a pressing need in both regions. Participants acknowledged difficulty working within and across cultures and recognized limitations of experience and perspective among some staff and some agencies.

Collaboration and Integration

Collaboration and integration of services was seen as a key strategy for increasing access and improving the quality of services. HIV prevention and care programs were discussed in terms of integrating services. The most frequent entities presented as needing more collaboration were health and medical professionals and institutions, churches and faith-based organizations, and the public school system at all levels. Housing and drug treatment programs also were viewed as essential partners for collaboration. Participants recognized how difficult it is to collaborate and asked for incentives to spur and support collaboration.

Media and Public Awareness

Engaging the media and, through the media, the general public was a shared desire in both regions. Reaching out to the traditional media was seen as a strategy for raising public awareness about HIV prevention, allowing prevention dollars to be targeted toward high-risk communities. Participants were keyed in to the importance of social media and considered it as a tool for getting prevention messages to MSM and youth, especially.

Stigma and Discrimination

Stigma and discrimination against people with HIV/AIDS, LGBTQ individuals, and injection drug users were seen as major barriers that keep people away from care and services. Education, advocacy, and policy/legislation were the strategies most often suggested for overcoming them.

System Barriers and Opportunities

System barriers and opportunities crossed all other categories in both regions. Few of the barriers identified are easy fixes, and some are rooted in complex social injustices that may seem to defy solutions. Even the most intractable, however, can be chipped away at when stakeholders work together to mitigate the resulting health disparities, and many lesser barriers can be overcome by changes in system policies and procedures. Frequently mentioned was a concern that scopes in Department-issued HIV grants were restrictive and overly narrow, so that agencies did not have the flexibility to respond to true local need. Structures for allocating state and federal funding

also were identified multiple times as barriers to needed collaboration—competition for grants was viewed as fostering unproductive competition and territoriality.

These common threads—and other participant responses—are the foundation for the recommendations for stakeholders that close this report. Figures 4-6 on the following pages show the focus on the 10 themes in each region and across the two regions. For comparison purposes, Figure 7 provides the themes across regions for the 2012 stakeholder engagement meetings in Regions One, Three, and Six. Note that this categorization of responses by theme is an approximate indictor of the outcomes of the breakout group discussions. 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. The full story is in the meeting summaries and the notes, which are available as Appendix E.

Note also the "other" category in this chart set—"other" is any response that does not clearly fit within the 10 most common themes that emerged from the groups. That analysis is solely for the purpose of the stakeholder engagement meeting reports—it allows us to summarize hundreds of responses here in an accessible format. There is no more importance or validity attached to a response that falls within the 10 themes than one that was categorized as "other." The Department and the ILHPG have been using, and will continue to use, the full data set to inform their work.

Figure 4

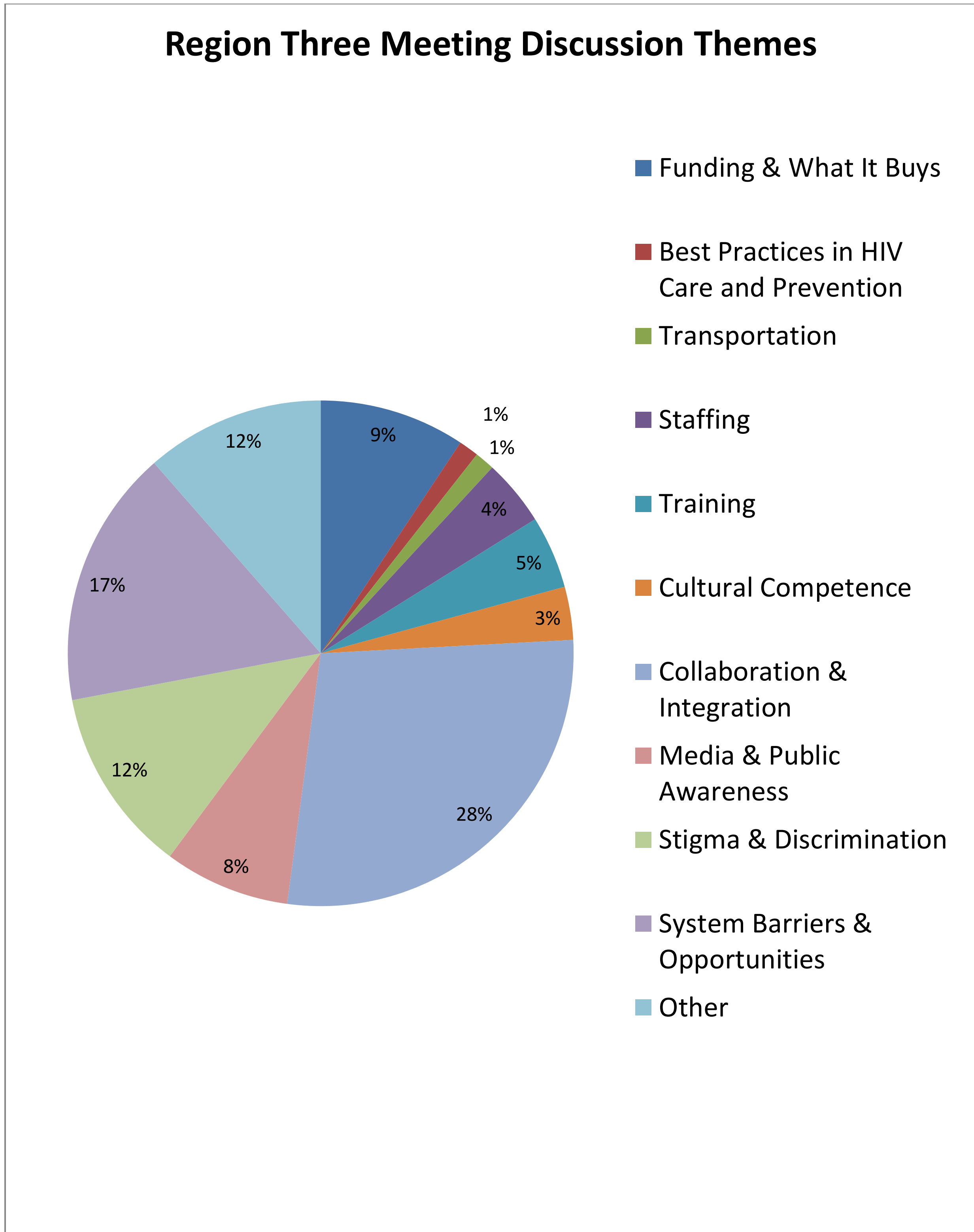


Figure 5

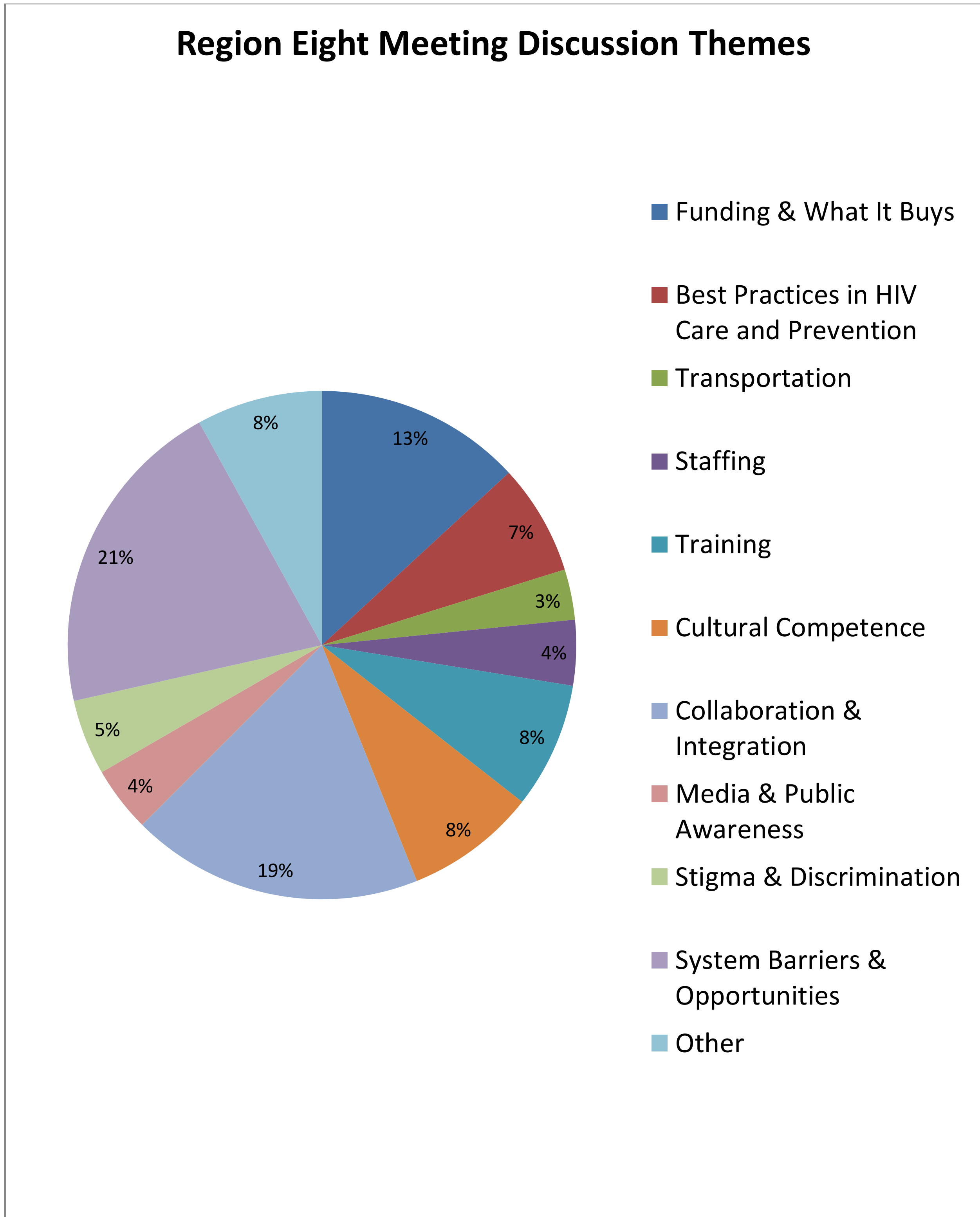
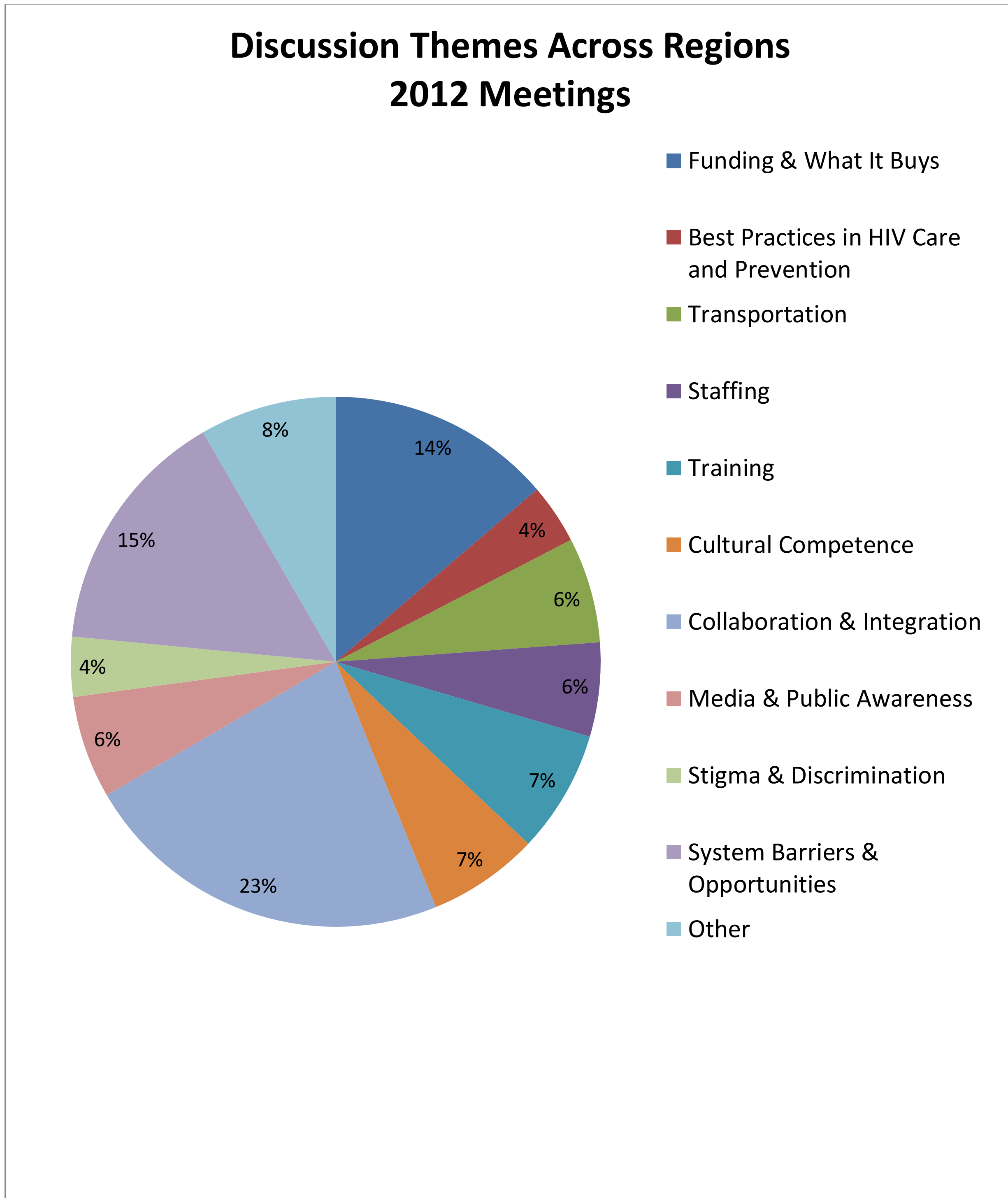


Figure 6

Figure 7



Recommendations for Stakeholders

Since the first HIV/AIDS strategy stakeholder engagement meeting was held in July of 2012, the Department and the ILHPG began using the service gap information, recommendations, and other insights offered by the planners, providers, client representatives, and other stakeholders who took part. Each successive meeting has added to the richness of that resource. The 2013 meetings brought us the diverse perspectives of 18 counties in the center of the State and suburban Cook County. We are grateful to everyone who participated—and to all who helped plan, conduct, and evaluate the meetings—and we eagerly look forward to the remaining meetings and what we will learn.

The following ideas to consider are drawn from the 2013 meetings in Region Three and Eight to inform the work of federal, state, and local stakeholders across the system as they work to improve the quality and availability of HIV prevention, care, and treatment services in Illinois. Some of these recommendations closely track the 2012 meeting recommendations and some are quite different, demonstrating both the similarities and differences in HIV prevention and care barriers, challenges, and opportunities across the State.

Funding and What It Can Buy

- Collect and share information about private and public funding opportunities for Illinois HIV prevention and care programs other than State HIV/AIDS resources such as foundation, corporation, and federal government sources.
- Look for funding opportunities related to ACA implantation and Medicaid expansion.
- Make the most of existing funds. Look for creative new partnerships and opportunities to share costs and jointly use resources such as training, space, and administration.
- Continue to look for opportunities to optimally plan, implement, and sustain effective HIV care and prevention strategies and interventions.

Transportation

- Conduct needs assessments as necessary to identify specific transportation needs in the regions.
- Explore strategies that reduce the need for transportation including Web-based approaches to remote service delivery.
- Collect and share strategies that are working across the state to eliminate transportation as a barrier to access to care and services.

Best Practices in HIV Prevention and Care

- Implement a system for identification and sharing of best practices.

- Commit the time necessary to build individual and organizational capacity to implement best practices in HIV prevention and care.
- Consider mentoring and other partnerships between large and small organizations, well established and newer organizations, and HIV/AIDS organizations and non-HIV/AIDS providers with the goal of developing best practice capacity.
- Take advantage of existing opportunities to keep up with the literature, such as online resources and updates from CDC, and create new opportunities such as hosting rotating local brownbag lunches where an organization is responsible for presenting best practice models or interventions and leading a discussion.

Training

- Remove funding restrictions or other system barriers to sharing training across agencies and programs.
- Enhance integrated staff development and training. Train staff from different kinds of agencies, programs, and disciplines together.
- Ensure that HIV prevention, care, and treatment providers have the right and timely training necessary to provide high quality services.
- Implement a staff development program—assess staff training needs regularly and provide tailored training to meet identified needs.
- Offer training on hot topics such as cultural competence, DEBIs/EBIs, PrEP, and high impact prevention.
- Provide hands-on training, role playing, and other opportunities for staff to practice what they are learning.
- Consider using trainers from a broad range of perspectives and experience such as CBOs or local experts with knowledge of the community.

Staffing

- Examine budget allocations to determine if salaries are adequate to recruit and retain high quality staff—are staff compensated fairly?
- Match the knowledge, skills, and abilities of staff to their positions and the duties they are asked to perform.
- Consider the career pathway of frontline HIV/AIDS service providers and create opportunities for progression such as training for disease investigation specialist certification.
- Create and support peer navigator positions.

Cultural Competence

- Explore the principles of cultural competence—does the program honor the full diversity of local communities including sexual and gender orientation?
- Value and reward culturally competent staff and organizations.

- Hire culturally competent staff, including people who reflect the diversity of local communities—and ensure that all staff are able to work effectively within and across cultures.
- Promote partnerships and collaboration among HIV/AIDS organizations and people of color organizations, LGBTQ organizations, faith-based organizations, immigrant and refugee centers, and other organizations with a history of successfully reaching and serving targeted populations.

Collaboration and Integration

- Build organizational capacity through partnerships with colleague and competitor organizations.
- Integrate certain HIV and STI services to expand HIV testing, get more people into care, and improve referrals and follow up.
- Collaborate with the ACA insurance market place at all levels.
- Invest in building a community referral network—identify providers across the spectrum of health, human services, and social justice organizations and build strong relationships among referral sources and partners.
- Engage with school systems to reach young people and families. Promote school-based, comprehensive, developmentally appropriate sexuality education and offer assistance with HIV education.
- Get prevention messages out to high-risk populations through partnerships with organizations that are already reaching and serving them such as immigrant assistance centers and LGBTQ organizations.
- Engage churches, pastors, and church gatekeepers in HIV/AIDS awareness and prevention.

Media and Public Awareness

- Engage with the media around getting HIV information, prevention messages, and features out to the general public.
- Collaborate with the media to develop and disseminate public service announcements.
- Use social media as a cost-effective strategy to reach MSM, youth, and other populations as appropriate with targeted HIV information and prevention messages.
- Explore expanding Text 2 Survive or using alternate systems to include appointment reminders and similar messages.

Stigma and Discrimination

- Build an education and advocacy mindset to combat HIV/AIDS stigma as well as discrimination against the LGBTQ community, injection drug users, and other stigmatized populations. Develop advocates with the skills to be heard.
- Review disclosure laws and policies and amend those that promote stigmatization.

System Barriers and Opportunities

- Examine funding formulas to determine how they can be improved.
- Examine the grant scopes system to see if greater flexibility can contribute to meeting local community need.
- Look for ways to encourage collaboration and integration at the community level through funding approaches.
- Create real incentives that motivate organizations to collaborate.
- Represent the needs of people living with HIV/AIDS as the State implements the ACA and Medicaid expansion.
- Advocate for and support comprehensive, developmentally appropriate, school-based sexuality education.

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In 2014, the ILPG will host the final three stakeholder engagement meetings to complete the cycle. Once all regions in the jurisdiction have had an opportunity to participate, we will develop a 2014 report and share it with regional lead agents and subgrantees, meeting participants, and other stakeholders, just as we have done for the 2012 and 2013 meetings.

The responses and recommendations in these reports should not be viewed as stand-alone documents. They should complement other community discovery and needs assessment activities that have been completed at the state and regional levels. Together, they can be used to maximize the delivery of effective HIV care and prevention services. Providing state of the art HIV treatment is only part of the answer. We must address the persistent gaps and barriers in accessing HIV prevention and treatment in order to achieve the National HIV Strategy goals of reducing new HIV infections, increasing linkage to care and positive health outcomes for people living with HIV, and eliminating health disparities. Success will require a comprehensive, coordinated effort across spheres—federal, State, and local government and non-governmental organizations, communities, and individuals—and across programs including HIV clinical and prevention programs, support services, corrections, mental health and substance use, housing, and academia, among others.

Appendices

Appendix A: The HIV Prevention Community Planning Group Protocol for 2012-2013 HIV Strategy Stakeholder Engagement Meetings—Final Draft
Appendix B: Combined Participants—2012 HIV/AIDS Strategy Stakeholder Engagement Meetings
Appendix C: The 2012-2013 HIV Strategy Stakeholder Engagement Meeting Agenda—Final Draft
Appendix D: The 2012-2013 HIV Strategy Stakeholder Engagement Meeting Roundtable Discussion Questions—Final Draft
Appendix E: Region Three and Region Eight 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, Lyyti 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.

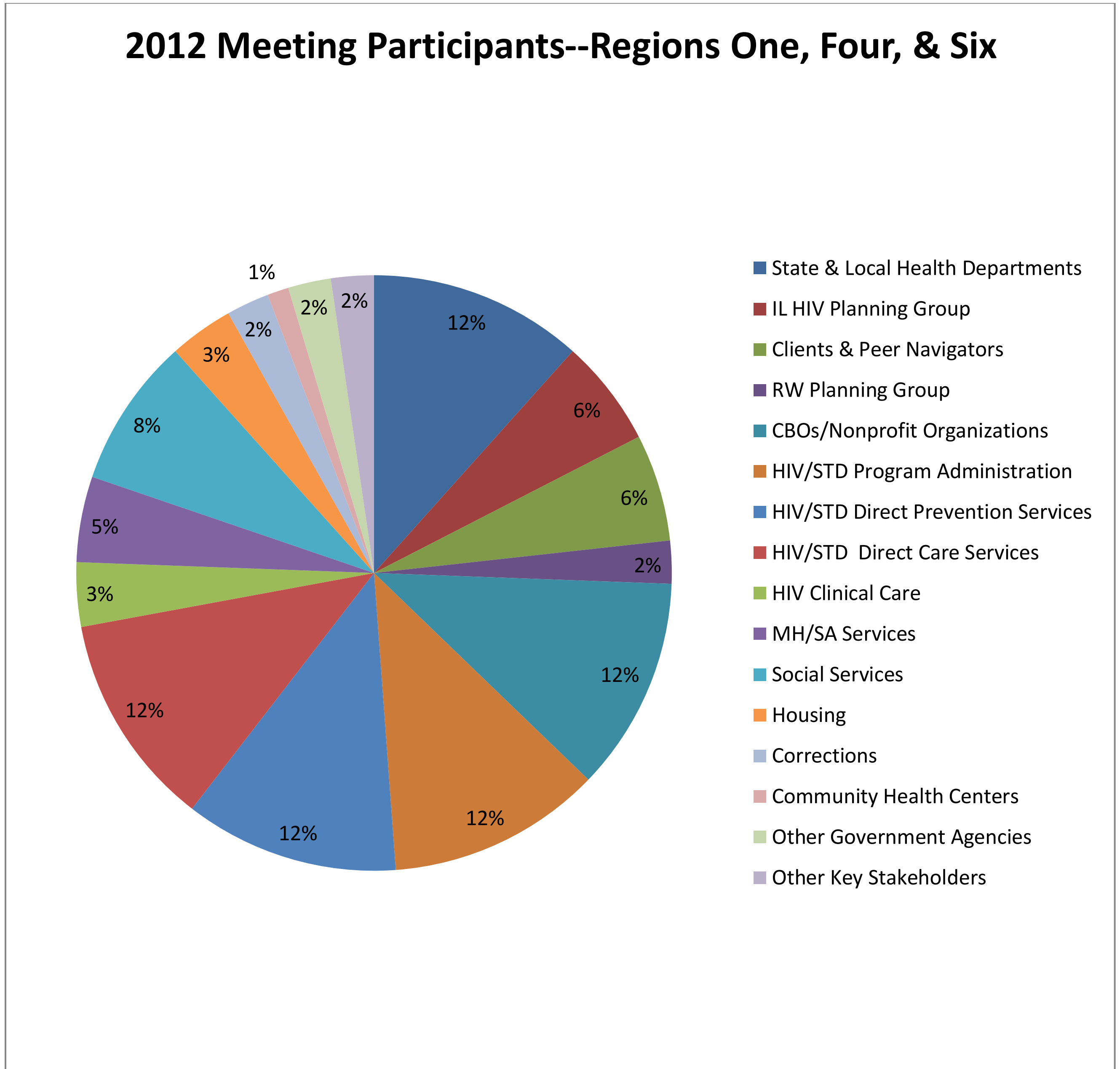
8. Each stakeholder engagement meeting will be limited to 30-40 participants, total.

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

Combined Participants—2012 HIV Strategy Stakeholder Engagement Meetings



Appendix C

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 D

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 E

Compiled Notes—Roundtable Discussion Questions

Region 3—Central Illinois 2013 HIV Engagement Meeting
February 8, 2013

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?

<u>Group One</u>
- Counselors—there seems to be limited services for children in HIV-positive families
    - DFCS
    - Some limitations come from boundaries around age groups
    - Girls and Boys Clubs
    - Big Brother/Big Sister Organizations
    - How to link into and engage them
    - Stigma issues around letting others know that HIV is a part of their family
    - Sojourn Center and other domestic violence centers could benefit from counseling and testing services on site, need to deal with confidentiality agreements
- Homeless shelters—reach out and network; the Phoenix Center works with them
- Have the community more involved (look at studies to see how well different programs work together and if they have positive outcomes—be sure to allocate funding to programs that work
- Churches/faith-based organizations
- Community-based organization such as the Urban League
- Agencies for substance abuse such as the Triangle Center
- Reach out to high-risk adolescents
    - Juvenile detention centers
    - Middle and high schools
    - Work with principals and superintendents
    - Work with parent groups at the schools to help educate parents—provide education brochures, present during parent/teacher days and at school conferences
- Legislators—need to provide them with good data to support HIV issues
- Testing for all STIs, not just HIV
- Public service announcements (PSAs)

Group Two

- Agencies listed in the Resource Assessment of the Jurisdictional Plan (pp. 113-128)
- Education system—school districts, middle schools, regional superintendents, Lincoln Land Community College (LLCC); a LLCC human sexuality instructor said her students were poorly informed about HIV and STIs
- Mental health programs—Mental Health Centers of Illinois (mental health programs have experienced huge budget cuts; patients need mental health services but lack insurance)
- Media (for prevention messages)
- Local TV news channels, newspapers (Illinois Times), PSAs
- Twitter and Facebook
- Substance abuse programs such as the Triangle Center
- Local hospitals—Memorial Medical Center, St. John's Hospital
- County jails
- Federally qualified health centers (FQHCs) such as Central Counties Health Centers and SIU Center for Family Medicine
- Family planning centers, private and local health department
- Physicians

Group Three

- Physicians (need physician peers to educate and convince physicians to participate in meetings like this)
- Faith-based organizations
- School districts
- People living with HIV should be part of the process (they value what their peers say)
    - Create environments that encourage people to come
    - Make meetings valuable and beneficial to clients
    - Provide information about meetings
    - Meetings should be client centered
    - Value the expertise of the participants

Group Four

- Employment and job training services
- Mental health services (no places in Region 3 for referral)
- Social Security Administration offices and recipients
- Medicaid offices (with changes due to the ACA and the impact on ADAP, we need to ensure that clients are referred to and stay in care and treatment)
- Probation
- Groups at colleges and universities for young black men who have sex with men (MSM) and lesbian, gay, bisexual, and transgender (LGBT) students

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

Group One

- Go to parents and PTA—start out planning with parent groups to get information and education out the families
- Need to look at social constructs
- Need to get business involved and other partners, even get the City Springfield to put general messages out on the city website

Group Two

- Health fairs
- Reducing stigma, increasing comfort with HIV testing
- Prevention education through the media
- Awareness of service location
- Awareness walks to engage the community
- Booths at the Illinois State Fair
- Make speakers available to visit schools
- An increase in testing
- A decrease in incidence rate
- Conduct engagement meetings among providers at the individual county level

Group Three

- More clients
- Services working together
- Providers sharing more information on their programs and knowing what others have to offer—better referral networks
- Text code HIV Center for RX and appointment reminders
- HIV hotline—more information about prevention services
- Viral suppression
- Fewer gaps in knowledge about prevention and care
- Less perceived competition among prevention providers
- ACA—access to services, need to know where to direct clients

Group Four

- Take competitiveness out of funding so agencies have incentives to work together rather than apart
- More awareness about how to reach risk populations
- Better coordination of HIV-related and social services
- Increased access to referrals, especially mental health services
- Higher salaries—current salary ranges (professional jobs at low salaries) make it hard to retain staff; ARTAS is a high-end intervention and programs are using entry-level employees

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

- Community is coming together at community events; harm reduction programs and outreach are done together
- Agencies need to share scopes and statistics, collaborate.
- Non-traditional organizations such as HIV staff going to clinics for homeless people
- Day shelters
- Seeing a growth with some schools and churches that want to work with the youth
- Summits of Hope are opportunities to collaborate
- Have working agreement with medical providers, not in meetings or one on one but coordinating together
- Good coordination among the agencies here, and working with others in the community

Group Two

- Opportunities for linkage to care collaborations between correctional release and community-based HIV care organizations
- Phoenix Center could visit other programs to make them aware of prevention, testing, and care services

Group Three

- Accepting patients with medical cards (few options) and no insurance
  - Ryan White case management
- Use Text 2 Survive to post announcements on events
- Monthly provider council appointment reminders
- Willingness to accept patients
- Job security
- Guidelines on how to navigate the systems—personal connections

Group Four

- Social services could be offered at community events
- Look at populations and collaborate in the CAPUS (Care and Prevention in the United States) Demonstration Project to better target and serve clients
- Host a tabletop exercise for service providers on barriers to getting people into care and other areas of collaboration
- Have agencies do interventions together and learn from each other, such as Phoenix Center and Fifth Street Renaissance are doing to target IDUs; doing interventions together results in more personnel resources, learning from each other and having backups if someone is sick
- Collaborate with schools to increase HIV education in schools; a challenge is not being allowed to give students condoms

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

Group One

- MSM who are on the down low
- No grants focused just on women, but we are seeing more women coming in for testing and noticing that more are going outside the relationship
- Belief that HIV does not happen here
- Stigma around LGBT issues.
- Social stigma—people shun HIV
- Fear about HIV criminalization, not knowing the laws, fear also around testing
- People do not want to know and do not get tested, such as many sex workers; others would like to know their status but do not want to be criminalized
- Inequities in how different agencies can record testing activities

Group Two

- Funding cuts
- HIV stigma
- Policies and regulations that limit what can be done
- Transportation and logistics to get services delivered
- Bureaucratic red tape

Group Three

- Taking information forward
- Treatment interruptions
- Chronic Illnesses
  - Uncertainty about what the future system will bring (Affordable Care Act)
  - Smooth transitions
- Slow grant notifications that can cause interruptions in services
- One thousand ADAP clients in Cook County will be eligible for expanded Medicaid
- Too many demands for too few Ryan White dollars—dental, undocumented, case management
- Long-time education of patients
- HIV RW: patient-centered medical home centers of excellence (Janet, might this be a reference to resources? Maybe the Center for Excellence in Primary Care in HIV and the HIV Medical Homes Resource Center?)

Group Four

- Policies and a religious environment that prevents getting into schools
- Competitive funding of agencies can make collaboration and coordination difficult
- Funding
- Difficulties getting buy in from other agencies—collaboration is outside many organizations' comfort zone
- Denial—agencies that don't see themselves as having a role or relationship to HIV prevention
- Agencies have multiple duties and are stretched thin
- Finding the right person at agencies to collaborate and coordinate with

- Some agencies may not apply for funds because the amount is too low to provide 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

- Need more opportunities to speak with African American groups, to motivate and engage them in the importance of testing and treatment
- Monetary compensation or incentives to sit and listen to HIV information (some stated that incentives do not always work)
- Let HIV-positive people tell their stories more often to reach out to others who will begin to see that this is a regular person—need to be able to relate
- Need to counter people's belief that HIV can be cured
- Need to strategize where the targeted populations are going and socializing and then go to where they are
- Reach the general public by elevating HIV to routine so that prevention staff and efforts can go to targeted populations—put the effort with those most at risk
- Provide general education and public service announcements about the risks for HIV and education whenever anyone asks or when you have an audience with them
- Work with pregnancy centers; make HIV testing a routine part of care here

Group Two

- Comprehensive sex education beginning at a young enough age could address general education need
- Routine HIV screening within routine primary medical care could help address general education need
- People no longer perceive HIV as a serious disease—focus on challenges that PWHIV face (medication side effects, challenges of taking meds every day, programs that the state cannot fund because of HIV med costs, rising health insurance costs, etc.)

Group Three

- Reach students in high schools; have case managers and doctors teach high school students about HIV
- General audience prevention
- Test partners
- Routine testing in behavioral settings
- Increase targeted prevention efforts

Group Four

- Work more creatively to reach people with different messages—messages that will be heard

- Use train-the-trainer approaches—allow agencies to go places and train others and spread the word
- Reach black churches by training gatekeepers to share messages; ask leaders in the community to have their pastors also spread the messages
- Use social media to balance targeted messages and broader messages in a cost effective way

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
- Collaborate with other organizations
- Combine testing opportunities with educational opportunities
- Have agencies focus on separate populations rather than duplicating grant scopes among agencies

Group Two
- Fundraisers
- Engaging new groups in the effort
- Incorporating testing into health fairs

Group Three
- Meetings—invite resourceful people across a very broad audience
- HIV education with positive partners within prevention organizations
- Meet to present and discuss resources in the community

Group Four
- Use social networking to reach gay men who are not going to bars or groups but are connecting online or by phone

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

Group One
- Testing needs to be made accessible for people without insurance or money to pay for testing
- Limited staffing and money to do round the clock testing
- Some people come to get tested but are told they cannot test as they are not in the agency's scope—this is a barrier and needs to be addressed
- Lack of safe and healthy housing; people go back to the same Section 8 housing (many stated that in some areas Section 8 equals drug houses) and start the drugging all over again—need safe places for transitional housing
- Mental health services are nearly non-existence; treatment is limited and lines are long
- Many consumers face a cycle—no motivation to move beyond environmental conditions—how do we create options for other housing choices for clients to move out of unsafe environments

- Need to get at the addiction process
- How to deal with relapsing and the shame and fear of reaching out for help again after they had been succeeding

Group Two

- Focus less attention on MSM and IDU
- Focus instead on the increasing incidence among women in Region Three

Group Three

- Access to primary care and consults
- Ryan White cannot pay
  - Right now, have nothing to offer them other than HIV-related care and services
  - Affordable Care Act
- May be a six-month wait for appointments
- Workforce development issue—23 million new people may be insured
- Reimbursement rates

Group Four

- Access issues because of health inequalities in Region Three
- Availability of services—need after work hours, which may decrease health inequalities

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

- People with private resources may not be linked to care and supportive services
- Disclosure is an issue; we are dealing with stigma
- Magazine covers and posters of people who share they are HIV positive and are in treatment—a way to let people see others like them who are in treatment
- Education is key: HIV care leads to positive health outcomes
- Struggling with those who are not sick and therefore do not see the need for treatment or medical care
- How to deal with shame, denial, and embarrassment about the diagnosis
- Training for medical providers
- Training and outreach to do follow up
- Training to be more sensitive when providing the diagnosis
- Develop a resources referral list for medical providers in the area—how do medical providers link clients to care
- Better transportation resources; more online services, especially for rural areas

Group Two

- Refer clients to federally qualified health centers (FQHCs) such as Southern Illinois University (SIU)
- PSAs and outreach to make sure all primary medical care providers know where to refer to for Ryan White services

Group Three

- Develop population-specific strategies to increase access to services
- Provide additional training for organizations together
- Use legislation to encourage an increase in the number of providers
- Cultural competence—reach all populations
- Prevention integrated into the healthcare mainstream
- Bill insurance for testing
- Target seniors for services
- Enlist someone who can influence providers to put HIV on the radar of primary healthcare providers

Group Four

- Mental health—get clients who need mental health services into care and keep them in care
- Collaborate with drug treatment services
- Outreach services should go where HIV-positive individuals are

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

Group One

- Many think they are already doing this; may need to add things like using the Internet and reaching out to physicians—Fifth Street Renaissance and Phoenix Center together reach out to medical facilities
- Need to work with prompt care sites as they do not do tests
- Work with medical providers and reach out to them to follow up after the initial diagnosis
- Look into having MOUs with medical facilities
- Education on other available services when client is linked to care

Group Two

Note: No care organizations were represented in this group. PWHIV typically are encountered only once or twice a year by agencies in the group and are referred to agencies with funding and expertise.

- Planned Parenthood does rapid and confirmation testing; when possible, a case manager is invited to the post-test session, and prevention counseling occurs with all clients whether the result is negative or positive

Group Three

- Promoting prevention services into mainstream healthcare—testing services and peer program for PWHIV

- Primary care physicians need to do more testing and discuss sexual health
- Nurses work with case managers
- Text 2 Survive appointment reminders (with release of information)
- Enhance communication
- Peer programs
- Video loop

Group Four

- More staff exposure to HIV-positive persons; we don't have worldly staff—maybe they are judgmental—and we may need to change the culture of the entire agency
- Sensitivity training for a paradigm shift
- Get HIV into the mainstream to decrease stigma—HCV is mainstream, HIV is not

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

Group One

- Lots of embarrassment about HIV and STIs—the initial diagnosis needs some more sensitive outreach and upfront care; medical staff can have access to a hotline so that they can reach out to bring someone else in for consultation
- Money and scopes are too targeted
- Can't get into schools
- No transportation to testing sites

Group Two

- Student population contains few students that disclose HIV-positive status
- Need comprehensive sex education and routine testing
- Need to involve black churches in promoting comprehensive sex education, routine testing, and stigma reduction
- Need outreach to gay bars with condoms and testing, need to market female condoms under a different name, health promotion flyers
- Make free condoms available at gas stations

Group Three

- Confidentiality
- Communication

Group Four

- Need incentives to get HIV-positive people to look for services
    - Offer something they can use such as gas cards to help pay for transportation
- Us vs them—neither can relate to the other (positive or negative)
- Funding, of course
- We have created an entitlement environment—clients need to know the service has value, so should we continue incentives
- Client demographics, backgrounds, and needs are different—hard to have support groups

Question 5: In Region Three, the latest epidemiological data suggest the following: Injection drug users represent a significant proportion of new HIV infections. IDU accounted for 14.2% of infections on average between 2006 -2011, and 17% in 2011. Statewide, IDU accounted for 9.7% of infections on average between 2006 -2011, and 7% in 2011. In addition, women accounted for 40% of all infections in Region 3 in 2011 compared to 20% of infections statewide. The proportion of new infections occurring among those in the 20-29 age category has grown considerably since 2006 when 14% of new infections occurred in this age category. In 2011, persons in the 20-29 age category accounted for 23% of all infections.

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

Group One
- Needle exchange
- More flexibility in grant scopes so that agencies can meet true local need

Group Two: No responses

Group Three
- Substance abuse agreement—referral only
- No harm reduction program in the area
- Behavioral health/substance abuse treatment partnerships might be needed
- Lack of bed spaces in patient treatment centers

Group Four
- More liberal views for Region Three
- Intervention for legislators to increase access to syringe exchange
- Social media targeting women, ages 20-29
- Working more with universities and colleges
- Increase access to STD clinics for women, ages 20-29
- Offer family planning services for women, ages 20-29

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
- Laws do not change stigma—only services and education can; make
- More sex education in the schools; make condom use a trend
- Make it cool: street boom block party, condom distribution (fear around asking and having access to condoms), sex with the light on campaign (awareness)
- Incorporate sex education in cultural competence trainings; think outside the box for ways to get the message out
- Condom distribution is not promoting sex—need to get this message out; same with IDU and needle exchanges

Group Two
- Funding increases for prevention and care
- Legislative passage of comprehensive school health education
- Training for parents in how to educate their kids
- Adoption by primary care providers of routine HIV/STI screenings

Group Three
- Routine HIV testing like other chronic diseases
- HIV education-only services stigmatize
- No reporting of school-aged children with HIV to principals
- Pamphlets are valuable
- Talk at schools
- Comprehensive sex education in schools
- School-based clinics

Group Four
- Lots of laws contributed to stigma
- Some HIV services are separate, which increases access but also increases stigma
- Criminal transmission and school principal notification laws add to stigma
- Work on Hypodermic Syringes and Needles Act so we can increase access to clean needles
- Legalization of gay marriage may reduce stigma
- Opt out HIV testing in hospital emergency departments with strong referrals to CBOs for counseling for people who are positive or have high-risk behaviors

Region Eight—Suburban Cook County 2013 HIV Stakeholder Engagement Meeting
August 15, 2013

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
- Entities representing other health issues such as Hepatitis C
- Elder programs (share resources)
- Where to get resources—instead of incarcerating non-violent drug offenders, we should have more money for programs

- How to get involvement—grassroots organizations, advocacy programs
- Thornton Township, more community involvement
  - Township presence—more awareness, they need to know this information
  - Park District, Leadership Council led by United Way—a variety of agencies to create awareness of services for the community
- Hospitals
- Stigma creates an issue with engagement
  - Religious organizations (churches) and education agencies/colleges/universities to address social issues
- Community members (HIV+)
- Local government officials

Group Two

- Governmental bodies in high incidence townships and mayors' offices—they need to know that there is high incidence in their communities to strengthen prevention and referrals to care and involve them in their community resources
- Local community hospitals, emergency departments, and private physicians—form opportunities to work with them, especially with ACA implementation
- Reach out to and make referrals to care through healthcare providers, not just counseling and testing prevention providers
- Form partnerships to engage managed care plans and insurance companies
- Education in general, especially with youth at college and universities

Group Three

- Engage local faith-based organizations
- Churches are where people come together from similar backgrounds—it may take several years to get churches to accept HIV
- Parole/probation agencies
- Illinois Department of Corrections (IDOC)—juveniles (nurses in correctional facilities doing prevention services)
- People are testing at correctional facilities but not finding out right away they are positive
- Partner services
- Create flyers and more outreach services
- Outreach to schools and LGBT organizations

Group Four

- Work with state and local boards of education (teachers are giving wrong information)
  - Involve schools
  - Have formal curriculum
  - Streamlined training
  - Involve parents through school
  - Secondary education/community colleges
- Active referrals, not passive
- MOUs

- Larger county health departments can provide technical assistance to smaller health departments
- Juvenile centers and smaller county jails (intake and discharge, no HIV education)
- Engage local churches (approach the pastor's wife)

Group Five

- Oncology and oncology support (medical care, beds, funding to help with linkage)
- Support groups
- Spiritual support and referrals
- Religious and faith-based organizations to help with retention in treatment
- College wellness centers
- Insurance market place to define plans and coverage
- Re-entry providers
- Employer-based organizations
- Juvenile justice system
- School system statewide, student-based health systems
- Agencies document outcome of HIV
- Linkage agreements with CBOs—identify their specialties and what they ought to be to inspire CBO networking
- Need to get advocacy involved in system enhancement
- The Chicago Department of Public Health and the Chicago planning group should have more of a planning presence in suburban Cook County and be mindful of the needs of providers and clients not in the city

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

Group One

- Broad base of inputs regarding health
- More collaborative partnerships
- Better referral source base
- Provide a list of contracts
- People to reach out to Spanish-speaking populations
- Make information more available about people affected by HIV
- More education classes regarding HIV
- Updated data, because data is delayed—if updated, it will invite more people for care
- More lobbying for HIV prevention
- Government agency needs to plan better regarding grant scopes and money, which affect planning for CBOs and program implementation throughout the community

Group Two

- More communication with HIV prevention and care about stakeholders so efforts are more targeted, cohesive, and effective
- Many HIV prevention programs are competing for the same dollars and see each other as competitors

- More communication among providers to come together around the dwindling resources
- Do statewide awareness events on continuity of care and the continuum of care—see prevention and care conceptually as a continuum so that all organizations can fit in or be a piece of the puzzle
- Some sites have specialties in areas that other sites do not, but there should be no silos or segmentation—do more group collaboration
- We need mechanisms to enforce collaboration and keep all agencies really engaged such as seed money to actually build partnerships; it is more cost effective to build partnerships to improve overall outcomes (and can take up to a year to build these relationships)
- Need strong partnerships and relationships with all provider agencies—consider sharing Web design staff, accountants, IT across agencies to increase administrative cost effectiveness, freeing up resources or dollars for direct programming for clients

Group Three

- Provide better help for the transgender populations in Region Eight
- More training for clinical staff at IDOC
- Training for case managers and outreach (prevention) providers on transgender populations
- Decreased incidence rates
- Broader grant scopes to get people into care
- New venues for outreach

Group Four

- Use information from the meeting to facilitate smaller regional meetings and regional outcomes
- Take it to the prisons
- Education about PrEP options

Group Five

- Better outcomes
- Linkage to care
- Names attached to specialized services—dots need to be connected in order to provide linkage
- Very specific advocacy
- Less limitations by funders (IDPH)
- IDPH to look at grant scopes
- IDPH to open up grant scopes and make them more flexible
- Additional best practices to increase linkage and retention
- Evaluation to ensure that services are high quality for everyone being served

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

- Better collaboration with IDPH/CDPH on Ryan White (Part A and B) and prevention services
- Incarceration funds can be used for more public health initiatives—push for a change for more advocacy
- Collaboration between prevention and care
- More room around integration—there is a lot of distance
- Consistency around regions, best practice models for collaboration
- Share information about who is funded in each region
- Reassessment of funding opportunities

Group Two

- The Department of Transportation—getting HIV-positive clients to care and follow-up appointments remains one of the central barriers for agencies
- Funding to ensure that there is infrastructure and free transportation services in the cities and to and from suburbs
- Stigma remains a huge concern
- Identify the barriers and then share resources among agencies—begin to communicate so we can address various barriers such as transportation; have a large master resource list
- Bring technology and apps for transportation
- Use text messaging and other apps for youth to help them safely, securely, and confidentially access all services
- Bring services to where the client is—meet people where they are, such as a school clinic
- Advocate for Chicago Area HIV Integrated Services Council (CAHISC) to do an assessment on the transportation needs in Cook County and the collar counties (it may not be a need in the city as much as in the suburbs, or vice versa; agencies make referrals and do not realize that clients may encounter barriers in getting to the referral agencies

Group Three

- Networking, interagency collaboration, and execution of plans
- Identifying existing individuals/agencies and collaborating with them, for example Congress, Links, HBHC
- Build upon existing relationships with Chicago Public Schools (CPS)
- Be more efficient with strategy plans

Group Four

- Collaboration between HIV/STI/hepatitis testing
- Barber shops—high-risk populations, condom distribution
- MOUs for linkage to care—not everyone has these or knows where to link for care
- Lack of information from infectious disease
- Models for CBOs for linkage to care

Group Five

- Division of Alcoholism and Substance Abuse (DASA) testing programs funded, not aware of routine testing—HIV to take the lead for testing everyone
- Co-location of behavioral health and care services
- Look at peers—how to use peers in day-to-day business and increase outcomes; capacity is an issue
- How to work with undocumented populations to assist with immigration forms, provide linkage to care—how to build trust with clients
- Have agency open houses—agencies to have meet and greets, which can be part of their contract
- Newsletters by organization, helps with transparency
- Integration of TB/Hepatitis—seed money to fund programs
- RFP at state level—include grant scopes on cross populations, linkage with other programs
- Screening clients not in a risk category as a percentage of a grant scope

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

Group One

- Money
- Territory and turf issues—for example, mayor in specific community won't allow collaboration
- Political denial
- Discrimination and phobia
- Poverty
- Lack of reliable public transportation
- State—geographically and legislatively

Group Two

- Funding—investing in staff , a facility, etc. is expensive; volunteers and peer leaders can only go so far

Group Three

- Stigma—homophobia, racism, gender-norms
- Lack of cultural competence on working with youth, transgender individuals
- Having youth listen to us
- Lack of resources
- CDPH does it one way, IDPH another way
- Red tape
- Funding
- Need new ways to find resources
- Inadequate sharing of medical data between the county and the state

Group Four

- Funding

- Competition—some agencies don't play nice with others (they want to do it all even though they are funded as a medical provider)
- Staff turnover rate
- Training—different training requirements for different funding sources
- Partner services
- Medical case management is no longer client centered
- Limited days and times of operations for care and clinics

Group Five
- TB and hepatitis are underfunded programs
- Funding silos is a barrier
- Compliance and reports about scope of collaboration
- Not enough reporting out best practices (talking about what is working and not working
- CDC and HRSA not together at meetings
- Poverty is a factor in why individuals are getting HIV
- Need best practices for how to get around structural barriers
    - Criminal background checks for employment with federally funded HIV programs

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
- Need resources
- More training on how to provide DEBIs
- IDPH should provide more general education on HIV
- Use CBOs to provide more training on program implementation
- Lack of diversity in languages of brochures and other printed material
- General education services
- Policies to provide education to high-impact communities
- Education—school abstinence education vs. comprehensive health education

Group Two
- Educate the masses to alleviate disparities
- Normalize the idea of going to a mental health therapist for treatment or prevention services
- Teachers need support for education in the schools so that they don't see teaching about HIV or healthy sex practices as "one more thing" to do.
- Bring LGBT information and education into the communities more and assure it is accurate information

- More education and efforts from healthcare providers to talk to kids about safe sex, etc. during visits—don't assume that education is going on at home or that they are getting accurate information from other kids.
- Still taboo to talk about safer sex—people are still in denial about their sex practices
- Refugee and immigrant populations need better information

Group Three

- Balance the demand by following the data maps to find high-risk individuals
- Go to general education in community
- Find out where black MSM hang out
- Survey agencies that are doing the work already and see what is working for them; identify common problems and successes

Group Four

- Use geo-mapping to know where to test
- Routine testing—collaboration of information
- Mobile society—moving often in states and regions
- Broader testing
- How to address stigma for target populations

Group Five

- Use of electronic outreach
- General education is not the answer—target it
- Routine testing in Medicaid and Medicare populations
- Routine testing in hospital emergency room
- Ask corporate America to assist with general education

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
- Fee for service (wasted money)
- Continue funds that follow the epidemiology hot spots
- Scalable interventions
- Offer testing in more communities
- Increase linkage to care
- ACA will take burden from Ryan White

Group Two

- There is a general lack of knowledge about prevention, and new generations need to learn critical thinking and decision-making skills to discontinue risk behaviors

- Address social elements in the development of prevention programming—structural interventions need to have embedded in them how risk behaviors play out in being a part of a larger group or population
- Broaden understanding to what it means to protect oneself—that it is more than just using a condom—incorporate larger meaning and concepts into prevention interventions

Group Three
- Work with others that are positive and their partners to see where they get help
- New agencies can work with agencies that have been around for awhile
- New agencies need to try to find where the epidemic is
- Social networking
- MOUs and partnerships with agencies already doing work—no need to reinvent the wheel
- Upgrade DEBIs, health education, and testing
- Best practices—use what works
- Identify gaps in services and hire who you need such as a transgender person

Group Four
- Linkage to care—some get it, some don't, some need help maintaining prevention activities
- Prevention for positives
- Workable, affordable interventions
- Educate everyone, from middle-aged people and middle school students—make it a norm so it is not stigmatized

Group Five
- Medical homes—CBOs start to come to medical homes
- Linkage with universities to assist with education
- Identify mental health and homelessness CBOs
- Get connected with local medical homes
- Work to develop cultural sensitivity in the HIV care system—how do local care systems develop this capacity, which could open care options
- Offer support to pharmacy
- Linkage to do testing
- Some agencies may not apply for funds because the amount is too low to provide services

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

Group One
- Need more peer support
- Structural changes
- Alienation from medical system, including immigrants
- Lack of literacy, health literacy (don't know or have anyone to explain)
- Training or recruitment of health providers, a lack of nurse practitioners, doctors
- Transportation

- More education and advocacy on care
- Finances = structural barriers
- People tend to avoid the topic—be more direct about HIV

<u>Group Two</u>

- Vocational training and job placement
- Completing education
- Stable housing—discrimination for people with HIV sets a cycle in place: those with the highest incidence or new infections are getting kicked out of homes, therefore have to engage in high-risk behaviors such as sex work, become addicted to substances, etc.
- Spread the disease response to other agencies—it is not just a public health program or condition; have other agencies and entities understand that it is a global condition that affects all facets of the lifecycle and intersects across many areas of life
  - Other organizational groups need to realize the magnitude of the disease economically across multiple sectors
- Work with collaborative, as the ACA is an opportunity for healthcare and other entities to come to the table to foster strategies to address the inequities

<u>Group Three</u>

- Target the areas in the community that are most affected
- Bring all agencies to the table and see what works the best
- Have representation from those who need the help (black MSM, IDUs, young BMSM)—identify where they hang out, bring them to a group, or start a group with them
  - What is their quality of life, where are they in terms of mental health, where do you refer that population
- Engage in transitional housing and support; provide education and life skills training
- Social networking
  - Prevention education
  - Social media
  - Where they hang out, where they meet (grinder, etc.)

<u>Group Four</u>

- Socioeconomic status (Cook County)
- Not client centered
  - Individual priorities
  - Options for negotiating care and services
- Transportation—not every service can be Medicaid reimbursable

<u>Group Five</u>

- Peer navigators
- Work with public aid offices to provide services; look at testing opportunities
- Reduce stigma—create safe places in organizations

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 lack of transportation to providers, appointments, other things
- Funding for different disciplines of services where prevention agencies and care agencies can increase collaboration and services to HIV-positive clients
- Address stigma
- Case management—due to the lack of prevention and care collaboration, it may take time to get into care
- Look at patient general health and mental health indicators

Group Two

- Create a system for health-seeking behaviors, establish relationships with providers, and use empowering models rather than dependency models
- Have healthcare providers talk about HIV in general conversation to reduce stigma
- Provide stronger linkages to outreach services
- How do we understand and work on patient/provider relationships
- Have a separate funding stream just for linkage to care programs; agencies can allocate resources for linkage to care

Group Three

- Identify barriers to dismissing myths on how you can get HIV (educate)
- Examine effectiveness of case management—case managers need to make sure that all new positives are taught about the importance of care and getting the best help that is out there
- Ways to build wraparound care services that are onsite with the case managers—call and link them or have them onsite to be linked to care
- Get your team on board with everyone
- Resolve policy issues
- Involve faith-based organizations

Group Four

- Lack of knowledge about this disease and what services are available in their community
- Lack of any kind of support service
- It's about the client, not us
- Not having the client rely on you—teach them self-care and self-reliance instead
- Ongoing patient and provider education
- Chronic disease model
- Easier linkage to medical case management in larger regions
- Mental health services

Group Five

- Prevention with positives and their partners—increased priority for negative partners
- Allow and encourage agencies with a high number of diagnoses to provide partner services—where does opportunity for partner services fit, may not be critical at time of testing/diagnosis

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

Group One

- Money (award letter)
- Being able to offer testing to partners (process to gain access to free testing)
- Reporting is overwhelming—collecting and entering data takes too much time
- A better understanding of what CDC needs versus what the state needs from agencies
- Partner services
- Partnership is important! (Ryan White and prevention)
- Resources and training about working with undocumented populations

Group Two

- Have prevention teams—it's about training, more commitment by agencies; make it a part of their mission statements; use subcontracted services with other agencies if necessary
- Transportation is needed—the lack of it is a huge barrier
- Share resources
- Need funding for subsidized school education and housing so that youth do not need to rely on parents or caregivers
- A strategy to link youth to case management to learn about all the programs and how to engage
- Funding for peer advocates and linkage coordinators

Group Three

- Educate nurses and staff, even clerical, by having an HIV-positive person come in and talk to them about how to treat an HIV-positive person
- Creating and providing group prevention support (GPS)
- Target high-risk and group prevention services education on co-infection with positive clients
- Partnership for Health (PfH) DEBI
- Addressing that young people don't care about HIV or have it on their radar
- Teaching youth that even though HIV is not a death sentence they still need to take care of themselves

Group Four

- Emotional accessibility
- Client-centered care
- Agencies really following HIPAA, not just what is convenient for them to understand and implement
- Cultural competence training

- Helping maintain prevention activities

Group Five

- Disclosure training is critical, disclosure assistance
- Tips and tricks on how to be different
  - How to tell children, family, partners
- PrEP—need to talk and educate
  - Money is not there
  - Provider awareness
  - Client awareness

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

Group One

- Money, lack of funding
- Stigma
- Clients don't want to spend time or stay for long
  - Fear someone may see them
  - Average 30 minute sessions
- Grant scope allocation and allotments may turn people away from services.
- Define HRH—many clients are lost
- It takes a long time to build conversation and build relationships, yet organizations may be time limited
- Prevention with positives—a need for collaboration between case managers

Group Two

- It appears to be easier in Chicago, as there are more resources—the suburbs have more problems or challenges
  - There appears to be fragmentation in services—need to streamline services
  - When providers make referrals outside their agencies, clients do not want to go to another agency and tell their story all over again., so they don't go to the referrals or keep appointments

Group Two

- Being able to create and repeat events and education that the high-risk population you serve would go to
- Board members willing to buy into new ideas—need trained board members
- Buy into community
- HIV and aging issues
- Services for HIV-positive people who are aging now that they are living longer with HIV
- There are zero mental health and substance abuse dollars for west suburban Cook County
- City does not analyze the gaps in care and mental health services needed for wraparound health in the collar counties
- Funding issues—how we use funding and where to find new funding
- Dental services

Group Four
- Case managers not passing information along to client
- Funding
- Policies, and interpretation of policies

Group Five
- Not being able to bill for prevention with positives services

Question 5: In this Region, the latest epi data suggest the following: The proportion of new cases that are men has increased steadily since 2008. In 2008, men accounted for 74% of new infections; by 2012, men accounted for 85% of new infections. There were 46% fewer diagnoses among women between 2008 (N=76) and 2012 (N=41). In 2012, HIV incidence among men was more than six times higher than that of women (20.9 v. 3.2 per 100,000 of the population). Men who have sex with men (MSM) – particularly Black MSM, represent a significant proportion of HIV new infections. MSM accounted for 51.4% of new infection between 2008 -2012 (on average) and 55.1% of new infections in 2012. Black MSM accounted for 48.0% of all infections among MSM in 2012, followed by Hispanics (24.7%) and Whites (22.0%). In 2012, heterosexual contact accounted for 92.0% of all new infections among women for whom a risk was reported.

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

Group One
- Money, cash flow
- Training to show ways to reach MSM population
- Local trainers that understand the population in the region
- Local region AIDS community training and network—Chicago and the suburbs are different

Group Two
- Cultural competence
- Better understanding of the data that Dr. Ma presented and why the jump in HRH and MSM of color
  - Heterosexual women are forgotten all the time, but they don't use condoms, and by 15 or 16 they are already at risk and engaging in risky behaviors
  - Youth do not always look at their behavior as risky—perception that risk is not there if they "don't sleep around"
  - Youth don't identify, because it is stigmatizing to say one is gay or bisexual or transgender, so they do not understand that their sexual behaviors and practices are putting them at risk of exposure
  - This data seemed to be an underestimate because of the "other" category

Group Three
- Use of best practices
- Cultural competence raining for staff

- How to communicate—reaching and finding people
- Role playing with staff—a chance for people to apply skills
- Local access to new, creative DEBIs for prevention
- IDPH to have more train-the-trainers for disease investigation specialist (DIS) training

Group Four
- Education
- Increased cultural competence among all providers
- Care opt-out

Group 5
- Need information about risk behaviors from clients who do not identify a risk behavior at testing
- Healthcare system welcoming to men—Medicaid expansion
  - Black men
  - Transgender
  - MSM
- Schools—possibly do testing

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
- Harm reduction
- Money flow, especially with time flow/time limits
- Recommendation to funders for collaboration between prevention and care—joint applications including funding and grant scopes

Group Two
- Provide HIV education at large pharmacies and at clinics
- Have medical assistants and physician assistants spend time providing education—build in the time
- Identify leaders who can work with certain populations due to cultural variance and acceptability; use gatekeepers for culturally appropriate sharing of information in certain populations
- A lot more emphasis on secondary prevention, not just counseling and testing
- Scale up biomedical prevention and adherence to meds—reach a wider population with this information
- Look at the demographics

Group Three
- Lobby days and AIDS walks, state and federal levels
- Train people on how to lobby so that there are advocates who can get their points across
- Reduce stigma
- Age appropriate social marketing

- Education in school on STIs

Group Four

- Need providers that don't look like an HIV clinic or identify as an AIDS organization
- Provide transportation
- Explain to clients about household definitions and document requirements for services (IRS income tax return)

Group Five

- Criminal background checks prevent people from getting jobs
- Changes in voter registration
- Look at changes with drugs/weed regulation
- Changes in aging population with HIV