

**Needs Assessment For The
HIV/AIDS Population in Central Indiana**

Study for the Marion County Health Department

April 2008

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Health and Hospital Corporation of Marion County**

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**Indiana University School of Medicine
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Focus Group Participants:

The authors are indebted to these 41 anonymous individuals who participated in the focus group sessions and responded to our request to provide their opinions. The valuable information they shared from their experiences and observation helped provide the foundation for the recommendations provided in this report.

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EXECUTIVE SUMMARY

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 provides federal funds to provide life-saving and life-extending services for people living with HIV/AIDS across the country who cannot otherwise pay for them. The program was originally enacted in 1990 as the Ryan White CARE Act, and has evolved to focus heavily on serving those individuals who know that they are HIV positive, but who are not receiving care for their HIV disease, and on eliminating racial, ethnic, and gender disparities in health outcomes among HIV positive individuals. The Marion County Health Department first received funding under Part A of this Act in 2007.

This report presents results of a community-based needs assessment for the central Indiana HIV/AIDS population in collaboration with the Marion County Health Department, Health and Hospital Corporation of Marion County. Initial project planning activities began in late 2007, with most of the data collected in early 2008. The purpose of this needs assessment was to: perform a community-based needs assessment of the HIV positive population in Marion County and the surrounding areas; identify the real and perceived health-related issues of HIV positive individuals groups across age, gender, racial and ethnic categories; uncover the barriers that keep these individuals from entering care, staying in care, and being adherent to treatment regimens; and, identify opportunities and initiatives that will address those barriers so that the needs of those infected with HIV can be better met. Targeted populations include: women (including pregnant women), substance users, the recently incarcerated, Hispanic immigrants, HIV positive people residing in the suburban areas surrounding Indianapolis, and men who have sex with men, including minority men who have sex with men.

Information included in this health needs assessment report was collected from focus groups and key informant interviews. Local HIV positive residents and providers with an understanding of the significant needs, potential solutions, and experiences of those with HIV were identified to participate in focus groups and key informant interviews. The analysis of the responses of individuals participating these focus groups and key informant interviews documented that serious barriers to health care and other services exist.

Based on the comments and responses from the interviewees and focus group participants, specific recommendations have been made in three broad areas. First, remove existing health care system barriers to care by improving the interaction and communication between providers and patients, increasing awareness of services and how to get them, and increasing the number of providers. Second, develop programs and initiatives to ensure that individuals with HIV have access to basic, social, educational, knowledge and employment needs. Finally, expand basic and specialized medical care services to the target population.

It is hoped that the findings in this report will provide the catalyst to develop strategies to ensure that all central Indiana residents living with HIV/AIDS can achieve the highest possible level of physical and mental health. In addition, this report can be used by policy makers, providers and program administrators to focus interventions on those components that are of great concern to this subpopulation.

CHAPTER I: INTRODUCTION

This needs assessment for the central Indiana HIV/AIDS population, was performed in collaboration with staff from the Marion County Health Department, Health and Hospital Corporation of Marion County. The purpose of this project was to assess service needs and gaps using key informant interviews and focus group sessions

Key Informant Interviews-

It is very important to obtain input from the community providers and advocates when identifying and prioritizing the health needs of the target population. Professionals [care coordinators] who provide healthcare, psychosocial support and other relevant services to this population were interviewed individually. Conducting structured interviews of these providers and advocates helped complete the information needed to identify and plan services necessary to tailor programs for this population.

Focus Group Sessions-

Focus groups are informal but structured sessions in which the participants were asked to discuss their experiences and observations in meeting their health care and other needs. The purpose of these sessions was to better understand the attitudes and beliefs of the HIV/AIDS population related to their healthcare, physical, and psychosocial needs.

The results of this needs assessment will be used to develop and implement interventions in the central Indiana area designed to specifically address the perceived and real needs of the HIV positive population.

Project Methods

Key Informant Interviews-

Twenty six [26] key informant interviews of providers, care coordinators, and out-of-care clients were conducted. The providers were identified by the Marion County Health Department, Health and Hospital Corporation of Marion County staff. Appointments were scheduled with these individuals to be interviewed by the research team. The targeted individuals were read the informed consent script [Appendix A] and given the opportunity to opt out of the interview. The providers were individually interviewed [via telephone] by the Principal Investigator and Co-Investigator who recorded their responses. These interviews were not audio taped. The participants received a \$20 gift certificate to a local department store as a compensation for their time. A script and protocol [Appendix B1, B2, and B3] were developed by the Indiana University Bowen Research Center team, in collaboration with appropriate Marion County Health Department staff, and approved by the IUPUI-Clarian Institutional Review Board.

Focus Group Sessions-

Five [5] focus group sessions were conducted, each comprising 10 men & women with HIV/AIDS. The participants were invited [Appendix C] with the help of care coordinators who had been identified by the Marion County Health Department, Health

and Hospital Corporation of Marion County staff. Care coordinators informed the participants the time, place and purpose of the meeting. Each session lasted approximately 90 to 120 minutes. Refreshments were provided to the participants. The sessions were facilitated and moderated by a facilitator, trained by the investigator. The facilitators were also required to pass the protection of human subjects' certification test. The Co-Investigator acted as the scribe at the focus groups. The sessions were audio-taped to supplement the notes taken by the scribe. No comments were attributed to specific individuals. The participants received a \$20 gift certificate to a local department store as a compensation for their time. Script and a protocol were developed in English [Appendix D-1] and Spanish [Appendix D-2] by the Indiana University Bowen Research Center team, in collaboration with Marion County Health Department staff, and approved by the IUPUI-Clarian Institutional Review Board. Scripts were specific to the population participating in the focus group. Prior to conducting the focus group sessions an IUPUI-Clarian Institutional Board Review approval was obtained.

The Indiana University Bowen Research Center team analyzed the responses of the interviewees and focus group participants and produced this report summarizing the findings of the key informant interviews and focus group sessions. This report includes a list of issues identified along with specific recommendations for addressing these issues.

CHAPTER II- KEY INFORMANT INTERVIEW RESULTS

The key informant interviews were conducted in central Indiana to provide a better understanding of the HIV/AIDS treatment access problems for Hoosiers. Obtaining information from three separate groups, each associated differently with the use and/or treatment of HIV/AIDS resulted in many similar opinions. The three groups consisted of:

- Primary Care Providers, which included physicians, nurse practitioners, care coordinators and case managers.
- Individuals who provided treatment to out-of-care HIV/AIDS clients
- Out-of-care HIV/AIDS clients

Three different instruments were used to gather information from these three groups of individuals. The key informant scripts can be found in Appendix A-1, A-2, and A-3.

I. Primary Care Providers

1. a. What population of HIV positive clients do you normally work with e.g. age, race, gender, risk factors?

- Majority are 18- 45 years old.
- African American > White> Hispanics.
- Males> Females.
- Risk factors-
 - Majority is MSMs [males having sex with males].
 - IDU [injection drug users].
 - Sex workers.
 - Substance abusers.
 - Alcohol abuse.
 - Unsafe sex.
 - Not using condoms.
 - At risk incarcerated youth in central Indiana.
 - Homeless / inadequate housing.
 - History of domestic violence.
 - Low income.
 - Under educated.
 - Under insured.
 - Acquired perinatally or through sexual abuse [for pediatric patients].

b. What proportion of your clients are HIV positive?

- About 60-100% of the clients were HIV positive.

c. What type of services do you provide or link people to?

Screening, Counseling and Testing

- STD screening.
- Follow up testing.

- Testing and counseling.
- Counseling for substance abusers.
- Psychological counseling.
- Treatment adherence counseling.
- Drug Rx for IV drug users or opiates addiction- methadone Rx.

Care Coordination

- Care coordination.
- Help in filling out the ICHEA, Ryan White program and Wishard Advantage programs application.
- Intense case management.
- Multi-disciplinary team comprising of physicians, infectious disease fellows, nurse practitioners, social workers; care coordination services- liaison between provider and patients and pharmacists.
- Spanish interpreter.

Referrals

- Referrals to care coordination sites.
- Referrals to testing, treatment and social services.
- Referrals to medical providers.
- Referrals to primary care services.
- Linked to a local infectious disease physician.
- Referrals to other specialists.
- Referrals to mental health providers.
- Referrals to behavioral health care providers.
- Referral for employment.
- Food pantry referrals.

Linked to other Agencies

- Linked to Fairbanks for outpatient services 3/week.
- Linked to Harbor Lights for 2 weeks inpatient stays.
- Linked to primary care services.
- Linked to Bethlehem House, Lifecare, Brothers United, Concord Center and Damien Center for care coordination.
- Linked with Medicaid program through H&HC-Wishard program.
- Linked with Healthcare for Homeless.
- Partnerships with the IU School of Dentistry.

Social Services

- Transitional housing.
- HIV support groups.
- Spiritual support groups.
- Advocacy group for clients.

Outreach

- Outreach services.
- Patient education.
- Benefits management.
- Emergency help with medications [as copayment].
- Patient assistance program.
- Insurance.
- Provide clean syringes.
- Provide condoms.

d. What other service providers do you work with to connect with PLWH/A?

- Bellflower Clinic.
- Wishard Hospital.
- Concord Center.
- LifeCare at Methodist.
- Wishard Advantage- for the infected and at-risk clients with no insurance.
- Damien Center- care coordination and food pantry.
- Bethlehem House.
- StepUp.
- Riley Hospital.
- Bridging the Gap.
- Primarily substance abuse [Midtown, Fairbanks] for detox treatment.
- Mental health services [like Gallahue, Midtown, Hamilton Center, Fairbanks, Salvation Army, and Transitional Housing].
- Infectious disease doctors.
- Wishard and Methodist—for medical needs.
- Medical providers.
- IU School of Dentistry- for dental services.
- Based on insurance type, Wishard Primary Care, Midtown and community clinics
- IUPUI Medical Center.
- AIDS service organizations.
- Parker Clinic on the west side.

e. What other service providers do you work with to link PLWH/A to services e.g.

What services do you refer your clients to?

- Transportation services.
- Housing assistance [transitional housing].
- Emergency shelters.
- Mental health services.
- Emergency clinic.
- Clothing.
- Appliances.
- Give them employment opportunities.

What service providers are you aware of that provide those services?

- Wishard Hospital for treatment services.
- Partners in Housing for subsidized housing.
- Conner House for apartments for HIV positive individuals.
- IU School of Dentistry for dental services.
- IU School of Optometry for eye appointments.
- Damien Center for the food pantry.

2. What are some of the special needs or characteristics of this population? What services do they most have a need for? Which do they access most often?

Medical Needs

- Biggest problem is getting medications and counseling.
- Need primary medical care services.
- Wait is too long for an appointment (up to 1 month) and to be seen in providers' offices (up to 3 hours).
- Need help getting into Wishard Advantage and Medicaid.
- Priority of taking medications is way down on the list because of other issues.
- Complexity of medication regimen.
- Improve provider attitudes.
- Medical needs are not being met because of relationship with providers- there is no continuum of care.
- Need more care coordination services
- Inability to pay for medication cost.
- Have no health insurance and are unemployed.
- Need optical care services.
- Need more dental services.
- Need psychological counseling especially for adolescents.

Social Needs

- Need rental assistance.
- Need help with housing.
- Lack of housing affects their ability to store medications and follow their treatment regimens.
- HOPWA dollars for HIV living. If they have a felony, they cannot get HOPWA.
- Finding adequate housing as "most of my clients are indigent and homeless."
- Need help with transportation.
- Giving out bus passes on a regular basis.
- Helping out with the day-to-day expenses.
- Need help with case management for copayment issues.
- Need help with the food pantry.
- Need child care services

Psychosocial Needs

- Fear and anxiety- need proper counseling.
- Need more support groups- ones that meet their needs. These would be different for newly infected individuals than for those who have been living with HIV for a while.
- Socialization support- more group activities as they may not have anyone to disclose their HIV status.
- Patients with low self esteem need a support group where they could share their experiences and barriers and the challenges faced.
- Need counselors to help them deal with cultural competency
- Better case management for appointments [e.g., ID, background, law enforcement services because of limited understanding].

Need for a Resource Guide- that would show where services are available and what type of insurance is accepted.

3. How well do you feel the needs of this population are met?

a. Which medical or support services are not being provided?

Access

- The major problem is low access to medical care.
- Long wait [up to a month] to get an appointment with the doctor.
- If hypertensive, diabetic or have mental health issues, they have a difficult time getting services.
- Need more primary care services; otherwise they use emergency rooms for acute needs.

Provider Attitudes

- There are too few providers for the demand.
- Need to have more doctors available for these clients.
- Improve relationships with providers.
- Need to have better follow through.
- Need for more psychiatric services.

Social / Support Services

- Housing is not adequate.
- Childcare services are needed.
- Social services are not enough- need more intense services early on in the process.
- Fear/ scared to get services because the care coordination agencies are not friendly.
- Lack of funding for services.
- Lack the basic living skills [like hygiene]- which is an ongoing problem.
- If caught in between poverty and just above poverty, they do not qualify for assistance and cannot apply either.
- Language barriers for Latinos.

Lack of Services

- Substance abuse treatment.
- Dental services are not adequate.
- Need for inpatient counseling services [group] for children.
- Vision, dental and cancer treatment.
- They need STD treatment.

b. Which medical or support services are not being adequately provided?

- Eye care services.
- Dental care services.

c. Which medical or support services are being provided, but are provided in such a way that they are inaccessible to people in this population?

Medical Services

- Medical services- go to the ER for getting their medical needs met.
- Dental services.
- Patient drug assistance program.
- Counseling- psychological and behavioral care.
- Have to wait too long for appointments.
- “A wide range of needed services are not accessed because people don’t know how to navigate the system.”
- Distrust the system.
- Lack of communication.
- Most cannot afford treatment.
- Do not have access to insurance.
- Language is a barrier- i.e., if no interpreter is available.

Support Services

- Need transportation services.
- Residential programs are not available for women with children.
- Need someone to accompany them to the clinic.
- Need more support groups.
- Psychological services do not accept Medicaid/Medicare.
- Do not have the willingness to seek care.

4. What unique characteristics of this population facilitate the delivery of services to them i.e., what strengths or skills do they have for self advocacy?

Have the Strengths/ Skills for Self Advocacy

- Yes, they do know about the locations by word of mouth [e.g., Bethlehem House, Damien Center, Urban League]- “The supportive attitudes of people working here is welcoming and not condescending, they look at you as family.”
- Yes, they do have the skills, but time and convenience is more of an issue.
- “Providers through the RW program are great. No issue of discrimination.”

- They have their own social networks to get information.
- Those who are very open about their HIV status tend to advocate for self and community.

Lack the Strength/ Skills for Self Advocacy

- Not open because of stigma, but only open up to similar race/ethnicity; or to individuals speaking the same language.
- “Not many lack the skills. We try to make it non-discriminating [like never use HIV in title] but they are so involved in meeting their basic needs that medical care becomes secondary for them. It is just not a priority.”
- “Yes, they fear the system because having a criminal background they might get arrested, which inhibits them to get treatment, but they do go to the outreach for food and blankets instead.”
- “There was more self advocacy 10 years ago when ISDH created the consumer advocacy board [CAB]- since they had to advocate for themselves.”
- Many are single females with kids and they are just learning to survive without a partner.
- No, they don’t have skills [because they are kids] but it would be beneficial to have more parenting skill courses.

Are there particular locations they are comfortable being served in?

- Damien Center.
- Concord Center.
- Brothers Uplifting Brothers (Gary area).

Are there methods of outreach that they are more likely to respond to?

- Methods of outreach should be group therapy [small groups of 3-4 people] and a one-on-one individual level counseling.
- Higher HIV support groups- which are non imposing and non-threatening.
- Indigenous people from their community that they can identify with- their peers- that have fallen out of treatment.
- Motivational theory approach.

5. What unique needs or characteristics of this population make it difficult to deliver services to them i.e., are there certain needs that must be addressed before they are able to seek HIV-related medical care (eg. Substance abuse, mental health services, etc.) ? Are they difficult to locate or enroll in social support services, and why?

Needs that must be addressed prior to seeking HIV treatment

- Mental health and substance abuse.
- “All of our clients have substance abuse issues.”
- 90% of HIV positive individuals have substance abuse issues and 70% have mental health issues.
- Mental health issues- need to stabilize them with medications [bipolar, depression, schizophrenia] only then adherence to Rx will be more successful.

- Substance abuse issues- not being sick from withdrawal is a priority before taking their medications.
- “Yes, homelessness, substance abuse, and mental health issues. A lot of people go in to denial and become destructive by using drugs, alcohol and tobacco. They just smoke it away.”
- Already feel ostracized because of HIV and then substance abuse makes it worse.
- Lot of stress- get involved in domestic problems and law enforcement issues- hence do not/can not access all services available to them.
- Fear and stigma of addiction and being HIV positive.
- Dealing with confidentiality issues- “HIV positive or being gay- which is worse?”
- Transportation issues.
- Education- HIV not being addressed in the schools or it is being downplayed.
- Ensuring that their parents have education especially for the pediatric HIV positive clients.
- HIV education is needed because once diagnosed these people feel like “the deer in the headlights.”
- More agencies need to be culturally competent.
- Need for cultural competency counseling- especially language.
- Safe housing/transitional housing issues.
- More need for social networks.
- “Damien Center [DC] is the only agency that has a harm reduction policy. However, DC does not take the time to serve because so many people are affected; therefore they get you in and out real quick.”
- Generally in-patient services are adequate, but there is a real shortage of outpatient services. The sites are very busy and it is difficult to get care in a timely fashion.

6. a. What are the most important barriers that keep them from entering into care?

Access Issues

- Transportation is huge.
- Transportation- “Wishard only allows a 9 mile cab ride.”
- Physical inability to get to the medical service.
- Large and big hospitals can be an overwhelming experience and they may decide not to get into care.
- “We have a very complex healthcare system.”

Social Issues

- Denial
- Fear, because of being undocumented [i.e., illegal residents] the established system might share their information.
- Fear of getting engaged into an established system.
- Stigma.
- “Not ready to take care of it yet.”

- Transitional housing- if they don't have a shelter where should they keep their medications.
- If homeless, then that's a barrier- first they need a place to stay.
- Need for Shelter Systems- where you can leave the facility at 9 am and come back at lunch/dinner time.
- "Sometimes our own policies can be a barrier, [i.e. if the person is an alcoholic then cannot get services]. We need to be a little more flexible."
- Rumor spreads very quickly within ethnic groups; hence they don't show up for treatment.
- Fear of losing their ability to make their own choices.
- Cannot get treatment because need to stand in line for food stamps as the food stamps office closes at 4pm.
- Need drug treatment services.
- Need child care services

Lack of Awareness and Education

- Lack of patient education.
- Lack of education about resources.
- Lack of good referrals.
- Lack of preparation for services and information.
- Lack of knowledge about HIV.
- Unaware of what may be available to them.
- Most do not even know if they qualify for medical care.
- "So many young folks [teens/early 20's] are complacent—they think they'll take a pill just like they would if they had diabetes. But that's because they don't know the long term effects of HIV yet."
- Need to have more focus on harm reduction.

Support System

- Lack of a family/support system.
- Poor relationship with caregivers in the family.
- Not having the skills to cope.
- Need help filling out the forms to get on the programs.
- Cannot be responsible for their own health care [especially if they are kids] therefore have to rely on other individuals to get medications; to make appointments thus, "sometimes the care giver can become a major barrier."
- Finances are a big concern.
- Copayments for medications- Indiana requires 50% of copayments for non-generic [brand name] medications

b. What are the biggest barriers to remaining in care?

Provider Attitudes

- Poor experiences with providers and/or their staff.
- Poor relationships with providers/care givers and counselors.

- If they don't feel sick, they do not go to the doctor.
- Do not ask questions of their doctor or the side effects of their medications.
- "We need to enable clients to be more empowered over their medical care."

Access

- Transportation- a lot of agencies do not give bus tickets because of their rules and guidelines.

Social Issues

- Lack stable housing.
- Homelessness issues.
- Stigma of addictions and of being HIV positive.
- Denial- "Just don't want to deal with it."
- Fear.
- Need support from partners.
- Need childcare services.
- Have zero income.
- Lack of insurance.
- Financial issues- not enough money.
- Need help with copayments.
- "If my client had to buy baby formula versus bus tickets for the Damien Center, they would go with the formula."
- "If a parent becomes ill/incapable of taking care of their HIV positive child, they remove the child from getting care, so there is a huge transitory period getting them back into care, because being adolescents, they are embarrassed to get back into care."
- Externally they have the "me against everybody" attitude.

Medical Issues

- Drug issues.
- Mental health issues.
- Substance abuse issues.
- Not very good at following through.
- General health is quite poor.
- Side effects of the medications that they are on.
- Always in critical condition before they get into care.
- They have to fend for themselves, which takes priority over their own medical, care e.g., rent before health care.
- Patients' own apathy.
- Fear because of the prognosis.

c. What are the biggest barriers to treatment adherence?

Medical Issues

- Complexity of treatment regimen.

- Forget to take medications.
- Just simply 'give up.'
- Increased number of medications.
- Overwhelmed with the strict treatment regimen.
- Tired of the long treatment process.
- Just remembering to take their medications on time.
- Daily intake of medications is a constant reminder of their "diseased state."
- Side effects of medications is a big barrier
- Fear of not knowing the side effects before starting treatment.
- Frustrated with the side effects.
- Feel too bad physically or emotionally.
- Believe that their medications are not helping them.
- Liquid medications need to be refrigerated, but many of them don't even have a fridge.
- Working with the pharmacy system to get refills.
- "Wait for services is too long"
- Increased number of visits to the emergency room.

Social Issues

- Costs associated with treatment is a barrier
- Have no resources to continue once short-term assistance runs out.
- "If already on substance abuse treatment, HIV treatment is not important because all they care about is when to get their 'next high'."
- Alcohol and drug abuse issues.
- Substance abuse issues.
- With housing or eviction pending, medical care is lowest on their list.
- Housing is very important on a long-term basis.
- Housing- they need a safe place.
- Living on the street and trying to keep up with the treatment regimen is hard.
- Uncertainty in livelihood.

Provider Attitudes

- Providers need to better prepare patients, e.g., "This will be terrible for 3 weeks, and then it will get better."
- Some providers/staff have bad attitudes and they tend to mistreat their patients.
- Communication with the provider- sometimes they cannot understand what their provider is trying to explain.
- Poor treatment from provider's office- it could be the nurse, receptionist or doctor
- Time spent with the provider is not enough.

Lack of Awareness and Education

- Need to educate providers to actively refer patients to care and follow up. There are 3-5 main physicians that HIV positive individuals go to. They risk 'lack of understanding' if they go somewhere else.

- Also, HIV positive individuals are reluctant to share information on sensitive subjects, [such as their sexual behavior] for fear of provider becoming critical of them.
- Lack of acceptance of their condition resulting in suicide contemplation.
- Lack of knowledge.

Support System

- Planning groups needed.
- Don't necessarily disclose their status, as it could worsen their family situation or they could lose their job.
- Always in fear, thus hiding from friends.
- Priorities change on a daily basis.
- There are too many variables to deal with.
- Basic physiological needs have to be met first.

7. a. What are some motivators for this population that might facilitate them to remain in care?

Support System

- A buddy system or support group is needed.
- Have a "mentor" – someone who is also HIV positive and who has learned how to negotiate the complex system.
- Link up clients with a "mentor."
- Care coordinator should check on them on a weekly basis.
- Appeal to their partner for support.
- Need a support group.
- Need a place just to hang out, maybe for movies or just socializing.

Provider Attitude

- Improve the attitude of providers.
- A personal touch is needed.
- Improve provider-patient relationship.
- Recruit motivated care givers.
- Providers/agencies need to get more service-friendly.

Education and Awareness

- More work is needed with recently diagnosed patients.
- More education on 'how to live with HIV.'
- "Tell them that they can live a healthy life with proper medical care and treatment."
- Many don't have hope and almost give up. To these individuals, the message should be that medical care can help them live a long and fairly normal life. Especially those who are newly diagnosed need help to get past the "it is a death sentence" attitude.
- Tell them "if they take their medications, they are going to be ok/well."

- Emphasize that there are less side effects now.
- Treatment regimens are getting less complicated.
- Treatment is more effective now.
- “If viral load disappears and T cells repair themselves—that by itself can be a huge motivator for them.”

Incentives

- Transportation services.
- All day bus passes.
- Bus tickets.
- Rental assistance.
- Help with utilities bill.
- Food pantry services.
- Childcare services for women.
- Day care center services.
- Hot meals per day.
- Schedule doctors’ appointments.
- “If they can see more tangible outcomes-- they’ll try to take their medications.”
- Street outreach to them.

b. What are some motivators for this population that might facilitate them to adhere to treatment?

Provider Attitudes

- Improve attitudes of providers.
- Provide more one-on-one care to them.
- “Increase social interaction among members of a support group. Like for instance, “a nurse practitioner took a support group bowling- this was a wonderful way to help the women bond and support each other.”
- Physical evidence showing that things are better [lower counts, lower triglycerides, lower cholesterol] all would make them feel healthier.
- Work with them through the side effects.
- Be culturally competent and understand what they are dealing with, “Let’s meet you where you are at and not where I want you to be.”

Incentives

- Rental assistance.
- Bus tickets.
- Rebate cards/coupons.
- Drugs from drug manufacturers.
- Cost saving measures.

Social Issues

- Housing issues.
- Help with paying for medications.

- Have a case manager work with them.

Education and Awareness

- Emphasize to women with children that they need to be healthy for their kids.
- Increase knowledge level.
- The message needs to be “take your medications as directed, even if you start feeling better.”
- Peer education is a must.
- More education is needed.
- Create awareness in society.
- Check with them- “Have you seen a doctor lately; when was the last time you saw your care coordinator or dental provider?”

8. If you were responsible for designing or improving the system of care for people living with HIV and AIDS, what would you do to help people find out about services and get the care they need?

Create Awareness

- Do more marketing.
- Do good advertising.
- Outreach to clubs, house parties and bathhouses.
- Give out literature and kits.
- More education for public through media.
- Make public service announcements [Clarian, Wishard, and IU] where each hospital can promote their own services for the HIV positive population.
- Target the teens/early 20s and the geriatric population.
- Advertisements on newspapers, radio, billboards—every minute every day
- Use media [billboards and TV] - just like in the 80s.
- Bring it back on media [billboards, TV, newspaper] just like for breast cancer awareness.
- Put fliers on brochure racks at individual clinics and care coordination sites.
- Put fliers especially in bathhouses and clubs.
- By word of mouth.
- AIDS has been around for a while but people need to do something “new.”
- Target the message in many different ways because people process information in different ways.
- “Keep AIDS fresh in people’s minds.”
- “Get some peers [especially long term survivors who are doing well] and train them well to do outreach.”
- Need more advertising via free newspaper [NUVO], Hispanic papers.
- Promote satellite locations of the Damien Center.

Access Issues

- More funding for transportation.
- Transportation- make it accessible.

- Pay services as “rentals” because lots of agencies are not financially stable.
- Ensure child care and transportation services for a doctor’s appointment.
- Simplify the system to get into care.
- Reduce the amount of red tape and paperwork.
- Make the Medicaid application simpler as it is very difficult and time consuming.
- Have more access to substance abuse services.

Social Issues

- Reduce the stigma related to the disease.
- Clinics should not have HIV or AIDs in their title.
- “Ryan White—the name itself gives away the disease.”
- Childcare services are needed.
- Housing assistance for persons with disability.
- More services are needed for women, particularly pregnant women.
- Have a “buddy system.”
- Go beyond medical care- include social and cultural components as well.
- Funding is a big issue.
- “It is not just about getting medical care, but getting housing, substance use treatment, mental health care and transportation.”
- Need for transitional housing.

Care Coordination

- Hold care coordinators accountable so they give a quick response to their clients.
- Help HIV positive individuals with their co-pays.
- Empower the agencies to be the advocate of first responder.
- Need to be very creative with the ethnic population because “one design does not fit all.”
- Need collaborative services to relay the system better.
- A portion of the funding should support training coordinators and patient educators.
- “This population will not just walk into care- you need outreach workers to bring them into care.”
- Access, follow up and long term planning with substance abuse issues.
- Need more social workers.
- Case managers have huge caseloads, thus only immediate needs are taken up.
- Lots of hoops to jump through.
- “Teach us how to use the system.”
- Damien Center has lots of services but they are not very user-friendly.
- “Keep things less complicated so we don’t have to deal with bureaucracy.”
- Have a person who knows the system.
- The system can be made simpler; patients should be able to call for questions.

Education

- Have more provider education.

- Have more peer education.
- “Emphasize that HIV is a life altering disease.”
- Lack of understanding of the seriousness of the disease.
- Conduct regular screenings.
- “No one who tests positive should leave the site without a concrete plan for the next steps.”
- Educate the public about services available and how people can connect to relevant programs.
- Education to remove the stigma.
- Educate the clients-what is available in their realm.

Provider- Patient Relationship

- Have a seamless interaction between providers and patients.
- Create sensitivity among providers.
- “Do not assume that the client already knows.”
- Need to have treatment available immediately if they want to eradicate the virus because “it is a war.”
- Respond in a timely manner because they may call you with an emergency.
- Need collaborative services to relay the system better.
- “There should be more training on treating HIV positive patients in medical school and during residency as well as among practitioners.”
- “Providers are quite insensitive and intolerant especially in the Midwest.”
- Have continued efforts to improve communication.
- “When we try to refer our patients, they get the operator and sometimes cannot even get in. Let them know that somebody cares about what’s going on with them.”

Outreach

- “The program must reach out to this population. If you set in your office and wait for them to come in, you will not be serving most of those who need these services.”
- Tie into the current street outreach services and look for the homeless people on the street, engage them and get them into some type of housing.
- Have mobile health care services targeted to the homeless population.
- More outreach services are needed.
- “Send care coordinators out on the streets and to the shelters- out of their offices to serve at the street level.”
- Need more mobile vans which are marked as “outreach services”
- “Street outreach workers need to be educated, give them a laptop and have them go to the streets, provide them with the technology, equip them with the right tools, train them on how to do outreach; get them out of their offices and onto the street corners.”

One-Stop Shop

- Develop a multi-specialty clinic so you can get your PAP, counseling, medications, all under one roof.
- Bring all services to one location- care coordination; pharmacists; and doctors.
- “If care coordinators come to the physicians, it will cut down the transportation costs for the patients and help the physicians tremendously. I’d rather the patient’s focus on their medications.”
- Provide a “one stop shop” for substance abuse, case managers and doctors.
- You may lose patients when you refer them to different places-cause then they say “forget it.”
- Need more wrap around services like a one-stop shop.

Resource Guide

- “Research needs to be put into action.”
- Need a guide on where to go, what services are available.

II. Providers for Out-of-Care Clients:

1. About what proportion of your clients over the past year or two have been HIV-positive? How do you find out they are HIV-positive?

- 47-48% of all Indiana HIV positive individuals living in Marion County

2. Of the people who are HIV-positive, about what proportion of them are not receiving HIV-related primary medical care?

- All or almost all.
- 90%.

3. Do these individuals typically know their HIV status before they become your clients, or do you encourage them to get tested, or is there another scenario?

- Yes, they are HIV positive for a while- but the individuals did not know they were infected.
- Indiana AIDS Foundation is the only organization in Indiana with “AIDS” in the name. They provide seamless services and their clients can move anywhere within Indiana.

4. What are some common reasons why people with HIV/AIDS are not receiving HIV-related medical care?

a. Are there different reasons for people that are newly diagnosed versus people that have known their status for a longer amount of time?

- Transportation- still a big gap
- Access and availability to services.
- “Especially medical services with Wishard Hospital. It is a convoluted system and sometimes even the care coordination system can be convoluted.”
- Housing issues.
- Denial.
- Fear due to stigma.
- They don’t want to file insurance claim.
- Childcare issues.

5. a. Where do they first learn of their diagnosis (i.e. what type of setting – emergency room, clinic, doctor’s office, community testing site, hospital, community, etc.)?

- Usually in a clinical setting.
- Doctor’s office.
- Hospital.

b. What are they told about treatment options, or where are they directed to find out this information?

- Wishard Hospital.
- LifeCare at Methodist.
- Concord Center for south-side patients.

- Damien Center for non-medical services.
- Routine HIV testing in ER in Wishard Hospital, Center of Hope in Wishard.
- Positive Link [Bloomington] for those in southern Johnson and Morgan counties.

6. a. How many of them ever received HIV-related primary medical care?

- Most have not received medical care.

b. Do they access mental health services, substance abuse services, housing assistance, food banks, transportation assistance etc.?

Medical Needs

- Mental health services—2 to 3 times/year
- Substance abuse services—10 calls /month
- Medical needs—Wishard, LifeCare @ Methodist
- Outreach gets 20 calls /month
- Training for Awareness Red.com
- Certify 150 people / year for HIV education

7. What are some of the biggest barriers that make it hard for your clients to get into HIV medical care?

a. Are certain barriers more important than others? Do multiple barriers need to be addressed in any particular order – do they need help dealing with some other needs before they are ready to enter primary medical care?

Barriers

- 50% have financial barriers.
- 30-40% don't know where to go.
- 1/3 find unsupportive providers a barrier.

Medical Needs

- Medical coverage.
- Lack of understanding on how to take their medications.
- Run out of medications.
- Don't have a good insurance to take care of their medications.
- Substance abuse issues.

Social Needs

- Transportation issues.
- Rental assistance issues.
- Food pantry issues.
- Clothing issues.

Need help with

- Incentives- not necessarily monetary.
- Just anything that will help them with daily housing.

- Bus tickets.
- Food coupons/vouchers.
- Money.
- Gas cards/vouchers.
- Cafeteria at the doctor's office.

b. Tell us about barriers specific to particular population groups you work with?

- Denial.
- Fear.
- Embarrassment.
- Don't want it to show up on their record.
- Don't have a stable place to live/maintain housing.
- Have difficulty maintaining their medical regimen.

c. How aware of the available services are they? Are they aware that they could receive services for free under Ryan White?

i) If yes, how do they hear about Ryan White?

ii) If no, where would be the best place to find out about Ryan White?

How would you suggest the program let them know that services are available?

- "I tell them about 'a Federal program' but don't use the name Ryan White program. I don't think they would know what it is or remember it."

d. Do they attempt to access services and are unsuccessful? Do they have problems accessing services because of where or when they were offered or for any other reason?

- No answer

8. What could be done to motivate more of your clients to enter HIV medical care?

- "See the information cards provided by the Consumer Advisory Board at ISDH. Barriers are addressed specifically in 3rd grade reading level words."
- Put fliers in the restrooms.

9. We are concerned with both getting people into HIV medical care and keeping them in care. What causes your clients to drop out of HIV-related medical care?

- Transportation issues.
- They don't perceive the care as needed.
- They stop going when they start feeling better.
- They need advocates/ombudsmen to help them navigate the system.

10. What are some of the biggest barriers to adhering to a treatment regimen?

- They get tired of taking pills.
- Treatment is too complex.
- They forget to take their medications.

11. What could be done to help people like your clients stay in primary medical care and follow their treatment regimens?

- Improve the transportation system.
- Increase support services.
- Increase training to providers.
- Improve the attitudes of providers.
- Have more forums- there is a big disconnect between clients and providers.
- Refer and provide resources.
- Provide some form of booklets with instructions to help.
- There is a great disconnect for individuals who speak Spanish.
- Lack of cultural competency.
- Increase entry into care and help them to maintain care.

12. In addition to primary medical care, what other services are most needed by your clients who are HIV positive? And to what extent are they able to obtain each of these services?

a. Which services are hardest to get? Are the services that are available appropriate for your clients?

- Transportation services.
- Rental assistance.
- Food pantry services.
- Clothing.

b. Would your clients be more likely to enter and stay in primary medical care if they first had other important service needs met? What services?

- Yes. Services needed are same as above.

13. Where do your clients find out about the HIV-related services that are available in the Indianapolis area? If they were interested in finding out about a particular service, who might they ask, or where would they look?

- Damien Center
- Concord Center

14. If you were responsible for designing or improving the system of care for people living with HIV and AIDS, what would you do to help people find out about services and get the care they need?

- Screen more people.
- Expand HHCORPS' Wishard ER screening to other hospitals, especially Methodist.
- Spend more time looking for HIV positive people who are unaware of their condition.
- Develop and run a mobile unit for screening and care.
- Get a Ryan White mobile unit to do HIV testing
- Find more providers in the network.
- Have a medical provider to see the clients.

III. Out-of-Care Clients:

1. Are you currently receiving HIV-related primary medical care? Have you had a CD4 count and/or viral load test and/or received anti-retroviral medications in the last 12 months?

- Yes, I have received treatment in the last 12 months but not in Marion County.
- Yes, I am on prescription. But since I get severe side effects, such as nausea, diarrhea, fatigue, and my eating habits changed, I don't take medications any more.
- I got a CD-4 count done 2-3 months ago.
- No, I am not on treatment, I do get my CD4 and viral reload done occasionally.

2. If you are now receiving care, was there a period in the last 5 years where you didn't receive HIV related medical care for a year or more?

- No
- No
- Yes, I am still not in care for HIV.

3. a. Where did you first learn you were HIV positive (i.e. what city, what type of setting – doctor's office, hospital, community, etc.)?

- Doctor's office in San Diego.
- Tested in a park at an outreach test site then sent to the Damien Center.
- Nurse practitioner on my case since the beginning.
- Got it through sexual transmission.
- I lived in an apartment complex where all chaos broke lose once the people came to know since they saw the reinforcement vehicle drive up to my apartment door.

b. What were you told about treatment options, or where were you directed to find out this information?

- Having been getting routine tests done every 6 months since the age of 14.
- I go for epilepsy treatment to an ER but not for HIV.
- Hooked up with an IU-Social worker.

c. Have you ever received HIV-related primary medical care? If so, how long was it between when you were diagnosed with HIV and when you first saw a doctor for an HIV related visit?

[i] If you did not see a doctor right away or at all, what were some of the reasons for the delay?

- "I don't want medical care for HIV- you can say I am on a "suicide mission". I am a paranoid schizophrenic and my mental health is a big part, sometimes even more of an issue than HIV."

[ii] If you did see a doctor, why did you see a doctor when you did? What were some of the factors that helped get you into care?

- “Yes, I saw a doctor, but not in Indiana. The process was pretty quick. It took about a year and a half.”
- I got IU for dental services and Wishard Hospital for everything else.
- I saw a doctor because I had fatigue and night sweats with the medications.
- I needed treatment for mental health/epilepsy.

d. Did you seek out other services before you saw a doctor for an HIV-related visit for the first time? What services did you seek?

- Yes, support groups.

e. Were you referred to care coordination? Who referred you to care coordination?

- Yes, I was referred by the people that did the testing.
- “Yes, I was referred to the Damien Center and Midtown Center for case management and support groups for HIV. They were set up immediately.”
- Yes, I was referred to care coordination, but I didn’t go in to it.

4. What are some of the biggest barriers to getting into HIV medical care for you or people you know who have HIV or AIDS?

a. [Acceptance issues] How did you feel about your HIV diagnosis and the need for treatment? Did you have symptoms? Did you feel that you would benefit from regular medical care? Did you receive any other non-HIV related medical care during this time?

- I thought I was going to die.
- No one counseled me.

b. [Knowledge issues] How aware of the available services for people with HIV/AIDS were you? Were you aware that people with HIV/AIDS could receive services for free under Ryan White?

- I have never heard of Ryan White.
- 3 years on Ryan White and I was not aware of the free services available--not even the Damien Center care coordinator told me. I found out about the free available services from the Bethlehem House.

c. [Stigma issues] Were you afraid friends/family/peers/co-workers would find out about your diagnosis? What sort of responses do you get from people when you disclose your HIV status? What consequences have you experienced as a result of disclosing your HIV status?

- I did not want my friends and family to know because of the stigma.
- My daughter does not let me hold my grandchildren.
- My son has kept disposable spoons, plates and cups for me.
- They came to my apartment complex and all my neighborhood got to know--because of the label on the car. Within a couple hours I had to vacate the premises.
- I lost my job once they got to know that I was HIV positive.

d. [Systems issues] Did you attempt to access services and were unsuccessful? If so, why?

- No, my care coordinator was very good.
- Bethlehem House has been very helpful.

e. [Access issues] Where do you live in relation to the services you need? Does that impact your ability to access those services?

- I am from another city and it took me 6 weeks to get into care.
- “I live with a friend and she is not aware of the disease and can’t tell if she’ll be affected. But I wish there was more information out there, so she can do things for me with a clear mind and not out of fear.”

f. [Other issues] What other things keep you from or kept you from accessing HIV related medical care during this time? What other priorities are/were you dealing with that impact your ability to access HIV related medical care?

- No roof over my head
- No bus tickets
- No food
- No money
- No job
- I am on disability and I can work, but no one wants to hire me.
- I don’t want to take my medications because of the side effects.
- I don’t want to take any medications- my son thinks I am on a suicide mission.

5. What could be done to make it easier for newly diagnosed people to seek care -- or to encourage other people with HIV/AIDS to enter care?

- Need more options.
- Need more counseling.
- “My T cells were very low [<200 =full-blown AIDS] but I didn’t get any kind of counseling. I only got to know from my support group.”
- Need to educate not just the doctors but the families of HIV positive people also
- “I think it is better to know than to not know.”

6. (If you ever previously received HIV related medical care) what made it hard for you to follow your treatment and remain in care?

a. What caused you to fall out-of-care?

- No options were given to me.
- No counseling—I thought if I have full-blown AIDS, then I’ll just die.

SECTION II

7. What other services do you need to help you live with your HIV/AIDS? Have you been able to get them? Tell us about your experiences. PROBES:

a. What services do you most need?

- Bus tickets.

- Rental assistance.
- Housing.
- Food vouchers.

b. Which services are hardest to get?

- Rental assistance.
- Signed up with the Damien Center for housing needs, food needs and emergency services. It all took 6 weeks to start.
- Making ends meet is very hard.

c. Which services have you accessed in the past year? Ever?

- Medical services to see a doctor.
- Gone to a few support groups.
- Disability and social services- took 2-1/2 years for approval.

8. Would you be more likely to enter and stay in primary medical care if you first had other important service needs met?

- Yes, if mental health is taken care of.
- Transportation, especially in the winter months.

a. Where do you go to find out about available services? If you were interested in finding out about a particular service, who might you ask, or where would you look?

- Damien Center.
- Bethlehem House.

SECTION III

9. Before this interview, were you aware that free services are available to people with HIV and AIDS through the Ryan White program? Think of other HIV positive people you might know that are not receiving services. Are they aware that Ryan White services are available?

If yes, how did you/they hear about Ryan White?

If no, how would you suggest the program let people with HIV/AIDS know that services are available?

- “No, 3 years on Ryan White and I was not aware of the free services available. Not even the care coordinator at Damien Center told me about it.”
- I found out about the free available services from the Bethlehem House.
- The care coordinators need to be more educated.

10. If you were responsible for designing or improving the system of care for people living with HIV and AIDS, what would you do to help people find out about services and get the care they need?

Treatment Issues

- “Offer treatment “right then” in the first 24 hrs. I remember I tried to commit suicide as soon as I got to know about it, because it is in the first 7-8 hrs that it hits real hard. After 24 hours the person may change his/her mind about taking medications.”
- Proper counseling for disclosing to your family.
- I would take each problem individually [mental health, HIV, drugs] and not use one approach for everyone.
- Work on other issues first then HIV, because HIV is not going to kill them in one day- so prioritize their problems/issues.

Education

- Educate the care coordinators, families and support system.
- Care coordinators need more education.
- More education should be offered to families for FREE.

Create Awareness

- Get more HIV positive individuals to give their first hand experience to the Ryan White Board that is providing funding- so that they can see for themselves where to put their dollars.
- “My friend is not aware of the disease and can’t tell if she’ll be affected but I wish there was more information out there, so she can do things for me with a clear mind and not out of fear.”
- They have quit promoting “safe sex” practices these days. It has been put on the back burner- they need to talk about it.
- “Talk about it on the TV and Internet. Let it be known to as many people.”

CHAPTER III- FOCUS GROUP RESULTS

Section I: Diagnosis and Primary Medical Care

1. Tell us about how you learned you were HIV-positive and what you did about it? PROBES:

a. Where did you first learn you were HIV positive (i.e. what city, what type of setting – doctor’s office, hospital, community, etc.)?

- In the hospital, became very sick and was diagnosed with full-blown AIDS.
- At Wishard, because I got pneumonia.
- Got tested, didn’t believe it, my attitude was “I feel good, can get OTC for regular infections” but then it got worse because of pneumocystis and ended up in the hospital. Have been taking medications since and have become undetectable.
- I had flu symptoms, like fever, chills, got tested for HIV, went on medications immediately and have been undetectable since. Hold a full time job and work even today, anywhere from 40-55/60 hours.
- I was diagnosed at Bellflower but didn’t get any help/options until 1990.
- I had to get electrolytes under control before I could even think about going on HIV treatment.
- At the VA hospital.
- In South Carolina.
- Told by a counselor at the hospital, since back then not too much was available, there were no care coordinators.
- Diagnosed on my 21st birthday and was told I wouldn’t be able to see my 22nd birthday, but here I am 19 years later.
- Doctor sent me to Bellflower clinic to get tested and from there I was referred to the Damien Center for treatment.
- I went to a hospital because I was losing a lot of weight. Thought it was due to the change in lifestyle because of the move to a new country.
- Found out through a medical study at Elli Lilly which invited me to get tested for HIV and got a positive result.
- At Wishard Hospital, went to get checked for Herpes and tested positive for HIV
- Sixteen years ago, I was diagnosed with HIV on a hospital bed in the delivery room. They came in with white suits and masks and goggles, I thought I had to be quarantined.
- I was working in the medical field and was diagnosed with Hepatitis C. I thought I could deal with that but then I was told by the doctor that the only reason I had Hepatitis C was because I was HIV positive and it knocked the wind out of me.
- Diagnosed more than 20 years ago.
- Infected by my husband- I am on a suicide mission- no medications, no care coordinator.
- Had gone to the blood bank- several weeks later the health department came to my house and broke the news that I was HIV positive. The doctor said he had good news and bad news: the bad news was that I had pneumonia and full-blown

AIDS but the good news was that I didn't have much virus in my body, so I wasn't hospitalized.

- Got a phone call from the Health Department and I was tested at Bellflower.
- I was tested positive and I started going to Wishard hospital but now I go to Methodist hospital.
- I found out in the prison. But when I was released they did not give me any medications to take with me instead they gave me the addresses and telephone numbers on where to call to address my issue.
- I was diagnosed at IU Hospital.
- I found out at IU Hospital.
- Tested at Horizon House.
- At Wishard Hospital.
- I needed some extra money so went to the blood bank. The guy who sat across the table from me told me "you are positive, but we are not 100% sure."
- I was tested positive at the Bellflower clinic and the lady who was with me said that "I'd much rather be diagnosed with HIV than cancer."

b. What were you told about treatment options, or where were you directed to find out this information?

- I go to the Damien Center to see HIV doctors for blood drawings and to the Bethlehem House for socializing and support groups.
- Bethlehem House rocks!
- I have a care coordinator at the Damien Center, found out about the Bethlehem House and infectious disease at Wishard Hospital and my health has improved since I moved to Indianapolis.
- I have been through drug addiction and single parenting-it didn't trip me out. But when I started coming to Bethlehem House and I was around people that had been affected and listened to their stories and their conversations, I went back into addiction.
- Bellflower never told me about any services available.
- I was not given many options.
- Diagnosed more than 20 years ago- I have a care coordinator and am receiving primary care.
- At Wishard they told me about the treatment options.
- Yes, the Lilly Clinic talked to me about a program from Indiana University (IDRC).
- Blood samples were taken and they were positive. Initially I got angry but I was told that back in the earlier days they had no knowledge about the drug treatment options but now we have more knowledge, more medications and more technology-so I found some hope.
- Not much. I was told I had an illness, and then they asked me to sign papers to send to the state. After being in the hospital for two days the doctor gave me some information about a local center (Damien Center), which did not share any information with me as they were not taking new patients at the time.

- The Damien Center representative scared me by asking questions like, “if I died, did I want to give my organs for research? The Damien Center did not help me. Someone at Wishard helped me.”
- The hospital made an appointment to start with but they never called him, until two months later a friend put him in contact with Casa Mateo Community Center. Casa Mateo helped him make contact with Wishard Hospital to make a medical appointment.

c. Have you received HIV-related primary medical care?

- They put me on medication when I first went in and things worked out because I had private medical insurance then, but no one told me that I could qualify for something else, until I joined this group [it took 2 years to get involved with this group before I knew that it even existed].
- My family doctor referred me to Lifecare at Methodist and they put me on treatment right away.
- I was in Wishard and got treatment right away with Wishard Advantage for about a year before coming to the Damien Center.
- My friend saw me and told me to contact the Damien Center and I ended up with treatment at Methodist- I was very pleased with the treatment.
- Wishard has good care coordination and the doctors treating HIV patients are actually from IU Hospital.
- I don’t want to take HIV medications because I feel I am as good as those who are on medications
- In the 19 years of HIV, I have only taken medications for 3 years since and I feel pretty good.
- Not too many HIV docs in Indiana and when you go see them they don’t listen to you. But “when you don’t listen to me I am not coming back to you”
- “You need to go see this doctor then that doctor...with HIV they send you round and round in circles.”
- “HIV alone hasn’t done much but all the other things with it are worse.”
- I thought the medication is going to kill me and that was one of the reasons I waited so long to do anything about it.
- The nurse practitioners are very good at Wishard and IU Hospitals.
- I got ICHEA insurance-Wishard and IU are very good.
- I got treatment immediately. They hooked me up with a doctor at IU and I was started on AZT/DDI.
- Once I was involved with IU all the doctors that I have dealt with have really been very informative; they kept an eye on the side effects.

d. How long was it between when you were diagnosed with HIV and when you first saw a doctor for an HIV related visit?

[i] If you did not see a doctor right away, what were some of the reasons for the delay?

[ii] Why did you see a doctor when you did? What were some of the factors that helped get you into care?

- If you get diagnosed today and call the care coordination services, they make appointments in 2 weeks and if you can't see them for some circumstances then you have to wait for your next turn.
- 2 months between diagnosis and treatment.
- Sometimes, you cannot get into care coordination because the care coordinators need proof that you are HIV positive.
- Several organizations are busy therefore they can get people in and so they lose people.
- People in hardship [e.g., homeless, addiction, substance abuse problem] miss their appointments sometimes.
- "I saw a care coordinator for 3-4 months after finding out. It was hard for me too- even though I know how the system works!"
- 3 weeks between diagnosis and treatment.
- Side effects of medications are the scary part. Yes, the medications help but it's also traumatizing the body as the body is being torn down from within.
- 3 months between diagnosis and treatment.
- Dealing with the stigma that goes with HIV.
- 2 months between diagnosis and treatment.
- It took me a year because when I was diagnosed they didn't tell me where I could go get help, they just told my diagnosis and left me alone.
- Right away I got treatment.
- Being diagnosed with HIV at Eli Lilly made it easier for him to find medical attention.
- Knowing a doctor from her country made it easier for her to find medical attention.
- By going to a community center (Casa Mateo) he found information on how to get into medical care.
- Being at the community center (Damien Center) made getting medical attention easier for him.

e. Did you seek out other services before you saw a doctor for an HIV related visit for the first time? What services did you seek?

- Yes, I did.
- No, at that point I only needed to see the doctor so I didn't seek any other services
- No, they did trials; I sought them out and then moved over to Indianapolis.
- Damien Center because of 1 family member already being HIV positive.
- Got into the Damien Centre.
- Bethlehem House is wonderful!
- Support groups are the best out here [Bethlehem House]- it has been god sent for me as I can talk and share experiences and it helps us find out about the different treatments and services/information available.
- Went directly into care.
- People got me hooked up with Damien Center..
- I had no option. I participated in a research study and could get medication. You hold on to the last hope. I was taking 17-20 pills/ day. I felt protected at the clinic.

f. Do you have a care coordinator? How long was it between your HIV diagnosis and when you first were connected to care coordination?

- Yes, my doctor helped me. It took 3 months to get into care coordination.
- To me, a care coordinator means that they will take care of me, but I have to go to them and tell them what I need; it should not be the other way around.
- Yes, 2 months later.
- It's been a real hard adjustment for me, since I was used to working and supporting myself, and now all of a sudden I have got to put my livelihood in somebody else's hands. It was a culture shock.
- Yes, 2 weeks later.
- No, he does not have one yet as he is newly diagnosed [2 months].

2. Are you currently receiving HIV-related primary medical care? Have you had a CD4 count and/or viral load test and/or anti-retroviral medication in the last 12 months [HRSA definition of unmet need]?

- No
- Yes
- Yes
- All of the participants responded, yes to this question, as they are all receiving care.
- Yes, all [the participants] are receiving primary care at this time.

3. Was there a period in the last 5 years where you didn't receive HIV related medical care for a year or more? [Uses HRSA unmet need time frame] If so, why I was out of treatment for 2 years?

- No one told me about available options.
- I just assumed since I couldn't afford it, because of no insurance, I was done.
- Yes, because there was none in South Carolina.
- Only one [participant] did not have HIV treatment for a week, other than that everyone else had been on HIV treatment since they first started taking it and have never stopped their medications.
- I just stopped as I had PCP pneumonia and I wanted it to kill me.
- I just didn't want to deal with it.
- Because of neuropathy, no painkiller was given so I felt why am I going to the doctor and I stopped taking medications.
- Out-of-care for more than 5 years, when I have a seizure, that's when I go see a doctor, but I don't take medications for HIV- I don't have a doctor for HIV.
- Being a single mom and working, after getting a letter from Medicaid saying that I had no insurance, I went for almost 2 years without medications.

4. What changes would you make to improve health care services for people like you living with HIV/AIDS?

Medical options

- When you are newly diagnosed, they need to hook you up with treatment. If I had been hooked up to the Damien Center or LifeCare right then, it would have been a lot easier.
- Doctors need to make a conscious effort to offer options to the patients when they are diagnosed instead of just saying, "Here are the drugs we are putting you on."
- When I go to LifeCare [health support] I have to plan either a long lunch from work or take an afternoon off to see the doctor. Health providers should provide services to their clients in the evening as well because there are a lot of people in full time jobs that are also HIV positive.
- To have other options to access the medicines (pharmacies) during the weekends.
- Some people who work full time don't qualify for any help because if you are on a salary you cannot get assistance.
- The discrimination from dental offices- it would be helpful if there were more dentists that worked with HIV positive patients.
- If person is in pain because they used too much crack/cocaine then the doctors should give these people another drug.
- Mental health services are needed.
- "When people tell you about your HIV positive diagnosis, they let you go. They need to counsel me right then, give me some resources, don't stick me back out on the streets with the drugs because I am upset and I will go out and infect others."
- To have access to health care within a 24 hour period.
- HIV positive patients should have priority when making appointments with other health care providers, and not have to wait.

Providers

- Need more doctors in the network.
- More infectious disease doctors in Indiana dealing with infectious disease care.
- Listening to people's needs- the doctors make their own determination because they went to medical school but they should listen to us too.
- If I am going to have side effects from the medications I want to be given other options: like for instance, learning about diet, nutrition and eating healthy; taking care of myself. The doctors just write prescriptions "oh, here's a pill for it" but they need to use a more holistic approach.
- PLWH/A need to see a HIV/AIDS doctors and not just a primary doctor. In my 20 positive years with HIV I have never had a HIV doctor!
- I moved to South Bend and there is no medical care- they only have 1 doctor and no practitioners.
- Nurse practitioners are fine but we need some doctors who have some education on AIDS.
- My case manager hooked me up with the practitioner right away- they make sure I am on top of my appointments and they call to schedule appointments.

Housing

- Housing plays the biggest part of our health- it is our number one issue.
- I was healthy enough so I started working and after being on my job for a year I got a letter saying that HOPWA can't help you with your rent, because you are self sufficient now. Well, without the help from HOPWA I couldn't be self sufficient- I was back to square one.
- Got to get through a lot of red tape for housing.
- They'll pay my rent for 2 years but still at the back of my head it's going on that what am I going to do next?
- With felony it's hard for me to get Section VIII housing.

Transportation

- The care coordinator will ask me "how long will it take for you to get here" and I say, "I can be there in half an hour." Whereas I hear other people talk about Wishard and having to make appointments 3-4 weeks ahead of time, because of their insurance. If transportation is made available, then that will take care of the barrier.
- Bus tickets.
- All day bus pass to get to our appointments.

Education

- Education is the key
- More education for HIV positive people about the different programs that are available to us in the city.
- More education for the care coordinators about other services that are available to us.
- Each individual needs to be treated differently as we all have different side effects
- "When I was growing up I thought that gay men, IV drug users and prostitutes were the only ones that contracted this virus so I was in no risk for any of that."

Process

- Get rid of referrals as it takes 3-4 months before you can see the doctor.
- If you make appointments it could take 3-4 months; but if you just walk in they will see you right away.
- Get rid of the referral process.
- People that are HIV positive and in crises need immediate medical care.
- HIV positive patients should have priority when making appointments with other health care providers, and not have to wait.
- To have access to health care with in a 24 hour period
- Make things more accessible to people.
- Eliminate red tape/bureaucracy.

Support Groups

- This group is very compliant and adherent and it's because of the group and the Internet, we always look out for each other—so support groups are an asset.

- I am working a full time job so I depend a lot on this group, for instance, no services are available in the evening, so I depend a lot on this group for the information I get.

Financial Assistance

- 20% of my blood tests cost \$230, that's a major chunk of my monthly income, let alone what my deductible is or my copayment is on the medications.
- We need more medications and more services whether we have got insurance or not.

Social and Psychosocial Needs

- "HIV/AIDS doesn't kill you- stress kills you!"
- The gay men get most or all the money- unless you are a woman with children, you get moved up, otherwise nobody cares about you.
- Need childcare services.
- "'Gay Model'—gay men are still being given the best care, they are kept in the hospital for 72 hours and given medication because they are considered to be 'high risk' to go spread to others, but why not women?"
- People look at your outer body but they do not know what is going on in the inside.
- Your children want you to be honest with them about everything- it is hard.

Cultural Sensitivity

- Infuse system with compassionate people.
- Get rid of the nasty nurses and find more knowledgeable doctors.
- Concord Center is the best. Their care coordinator is the best.

Self-Awareness

- "I would change myself first- how I think about the disease, how I am going to live with this disease because ultimately it is my responsibility to take care of myself."
- I have to take responsibility because ultimately it is up to me to get knowledgeable.
- "When you're sick, you are sick. You don't feel like filling papers, don't feel like writing, sometimes don't even feel like thinking At times, I feel it takes up all my energy to get up in the morning to do what I need to do."
- What really made me accept the fact that I was sick was when I went to the doctor and they said I was pregnant- that's when I realized that now I have another human beings life that could be affected and that's when I took the responsibility and started taking my medications.

Section II: Service Needs and Barriers

1. Beyond medical care, tell us about the service needs of people like you with HIV and AIDS and how well they are being met. PROBES:

a. What services are most needed?

Employment

- Needs to be a counselor or someone knowledgeable about people wanting to return to the workforce, what are the legalities, what insurance companies can do to you and that whole ramification.
- Because social security is reviewing it- they are saying that you are no longer disabled because you can sit at the computer and work. But with Indiana laws, there is no one good place to go for information.
- If you return back to the workforce, even if part time, you lose so many of the benefits, then you wonder is it even worth it?
- What you do make on salary, you turn around and pay every bit of that back, if not more, on your benefits or for some assistance!
- I know darn well that the insurance companies are talking to the CEOs and telling them which employees in their company are HIV positive and then they find a way to get rid of them.
- I do have to keep it quiet at work, nobody at work knows that I am HIV positive otherwise I'd probably be demoted or lose my job.
- Nobody can return to the workforce unless some employer offers guaranteed insurance.
- They don't want to hire you because of the medications that you are on.

Housing

- I am disabled and I went to housing to fill out my Section VIII. The top priority in housing goes to gay men first, and then white men, then women with children get bumped up, but if you don't have any kids then you are on a back burner for over a year- that is just not fair!
- My husband had full-blown AIDS and he qualified for housing but I still did not get it.
- I don't qualify for housing because of 2 felonies' [drugs possession and prostitution] that I got years ago!
- I have *no* criminal history and I still don't qualify for Section VIII housing- I just don't understand that!

Social Needs

- A lot of people complain that they are isolated; they need more social gatherings where everyone present is positive, not a support group.
- A social gathering where the 'affected and infected' people come and nobody knows who or what- the social gathering can be a great escape.
- "When I am down or sick I wish someone would call me and see what's going on with me since I live alone; follow up to see if something's going on- maybe a care coordinator could keep me on their radar."

Insurance Needs

- With Medicaid, I went for a dental appointment and as soon as I got there, they said they could not see me because I had insurance with Spin Dial.
- Spin Dial is something like, if you have insurance and you wreck your car, they won't do anything until you pay your deductible. Thus, for Spin Dial, you have to spend out of pocket before services kick in [\$387/month].
- Eliminate Spin Dial.
- Need a fund specifically to meet these huge amounts of Spin Dials because we don't need to meet the doctors every month, typically we are ok to see the doctors 3-4 times/year.

Resource Guide

- It would be nice to have a HIV guidebook that has every agency listed that offers all services and websites; has referrals. That can really make living with HIV/AIDS one of the easiest things to live with.

Provider Issues

- Holistic approach, which our primary care doctors don't do.
- The HIV doctors don't provide the necessary information instead they send you to the specialist.
- Mental health services available right now, they will take you and put you into observation for 72 hours. But before they give you drugs they should talk to you and do a one-on-one assessment.

b. Which services are hardest to get? Are there any specific issues (such as transportation, child care, financial problems, times services are offered, language barriers, fear of disclosure, stigma, etc.) that make it difficult for you to access services?

Transportation

- When bus tickets run out, it's just over. So you have to catch a bus to go get a bus ticket from the agency.
- To get to your care coordinator, you need bus tickets; to get to your support group, you need bus tickets.
- Have some kind of transportation system- where more bus tickets are available so people can get to their appointments. But if someone is really sick, then that is not really an option- your family or friend can do that for you, but what if you are all alone?
- "I used to catch a cab to my doctor's appointment since I lived only a mile away but they told me they could not pick me up anymore on Medicaid since I just moved a block away, because Medicaid goes on mileage."
- Allocate some source of funding for transportation where they can contract with somebody [IndyGo or yellow cab] and the patients can just call [2-3 days in advance] and take the cab/ride. Especially for HIV patients, the bus could go right to their house and that way people will be able to go their doctors' appointments. I believe it is called "open door."

Housing

- Housing is an issue. Outside Marion County, you can go to HOPWA and they will give you more assistance. In Marion County they have opted not to. “But if you lose everything, we can get you into an apartment or we’ll buy you a home.”
- Help with utility bills and emergency help.

Food Pantry

- I shouldn’t set up an appointment if food is not available in the pantry.
- Have more options for the food pantry because if they don’t have food, they should call up and have me come the next day instead.
- “These people are sick. If there is no food what should they do?”
- If no food at the pantry they should be given vouchers to go to Kroger’s.
- “If I can’t get food...it’s an emergency”
- If someone goes to them and they don’t have food they should at least offer a \$25 voucher.

Care Coordination

- The care coordinators may tell you one thing- you need to go here, at this time, to do that and you need to fill out all these forms before you can see the doctors- but you have to take 7 steps backward to take 1 step forward to see the doctor!
- The care coordinators who are doing the referrals should be better set up, better educated about the system to give people direction as it can be frustrating not only for the care givers but for the clients too.
- There should be a way for a newly diagnosed person, where the care coordinator should initiate the setting up of the first appointment and make sure the patient gets to that appointment. Especially for people who are out of town or maybe from here but too sick to get around.
- Have people who are more knowledgeable about the Rainbow Book.
- There shouldn’t be a limit on how many times people go to the Damien Center because if they need services they should be seen.
- Knowledge of community-based things that are going on.
- Make them aware of the Rainbow Book.
- I went to LifeCare and all I did was make an appointment and they gave me a \$20 gift card just for making an appointment!
- They are constantly going through this-“we’ve got new people, new people” they hire new people that might have a Masters degree but they have very little knowledge about how to get help for a client.
- Get them to work under other experienced people; other care coordinators so they can know better.
- Educate them!

Medical Needs

- Need mental health providers for HIV positive patients, because my mental mind is telling me I am going to die anyway, then why go through all this treatment?

Cultural Competency

- The staff has a lack luster attitude- they need to have some sensitivity in training and understand cultural competency.
- Part of the grants received should be for sensitivity and cultural competency training.
- People need to be more sensitive because they are not hurting “until it happens to them” and then the tables turn, somehow.

Social services

- Eliminate Spin Dial.
- Childcare problem for mothers.
- Financial management would help people.
- I haven't had too much of a hard time getting services but I don't see any urgency on the part of the staff at the agencies either!
- You are just blown off because of the diagnosis- makes me feel I am not wanted
- Help people manage their financials.

c. What are some of the biggest service gaps and problems for people with HIV and AIDS? Are the services that are available appropriate for you and people like you?

Transportation

- “Get the people to where they want to go, be it their appointments. Have a shuttle service- where you schedule the van for pick up. I would be happy to drive the van for them at no cost.”
- Transportation issues- a lot of organizations are strapped, as they have a cap on what they can do; need more finances for these agencies, so that our needs can be met. Like even getting a ride to the Damien Center is hard to get because the finances are not being met, so we can't get to the doctors' appointments.

Food Pantry

- Last 8 months I needed food stamps therefore I am eating decently, but after the food stamps expire I will be on disability and will not qualify for food stamps.
- At the food pantry, the shelves are empty so if you don't have services for me then I will not come back and will get out-of-care.

Communication

- Communication gap is very big. Agencies need to be collaborating together because half of them act as though it is a race.
- Agencies should collaborate so they can relay information out.

Providers

- Some patients get referred to the specialists but since there is no communication between the doctors the client is caught in the middle.
- There is no interdisciplinary strategy.

- Training and educating them better.

Process

- You have to have a person in the right place to be able to direct people. Like have a 'go to' person who can try to trouble shoot.
- Have a binder with all referral, transportation and mental health services.
- Make people more aware of the services available.

Cultural Sensitivity

- Need to hire people with more compassion.
- "I walk in and people look at me weird because I am gay, I am black and I have HIV but I want to tell them that they are weird because they are straight!"
- "The best service I get is at the Bethlehem House- someone who loves their job; someone who loves people; someone who wants to make sure you are ok. This is my house and I am going to respect it like my home. It is the best place in Indianapolis that I can go to- not at all complicated, everything is in the same room and all get the same information [be it gay, lesbian, straight, drug addict]"

Financial Assistance

- Have to bottom out into poverty before assistance will come in.
- That's something that worries me a lot, what if my health gets real bad. Am I going to have to go and totally lose everything, my house, my car, before they step in and pick up?
- "We can't help you now, but 6 months down the road, once you bottom out, we could help"
- They don't understand if you don't know how to use the system and once they tell you that you don't qualify for help, a lot of times you don't go back- you just quit looking.
- With limited income even lettuce is more expensive!
- We are in a dilemma when it comes to finances.

Peer Support

- Other states have grants that take care of people with HIV/AIDS: we could help people with their grocery shopping and sit and talk to each other, help each other get a gas card, get paid a little stipend maybe twice a month that would give everybody a chance to work and we could go to the HIV clinics and help.
- If somebody had told me that I would live as long as I did with HIV, it could have helped. We need more of our own peer educators.
- We could teach somebody else because people have homicidal and suicidal tendency once they learn about their HIV diagnosis.
- Bethlehem House has been a great, great inspiration. I was in denial; I didn't want to see nobody; but now I have found family here, I look forward to the Wednesday group, I look forward to seeing the people that actually care about me and I love the people. I don't know what I would do without Bethlehem House.
- Childcare services.

d. Where do you find out about the services that are available in the Indianapolis area? If you were interested in finding out about a particular service, who might you ask, or where would you look?

Care Coordinators

- Depends on who you get as your care coordinator.
- Some of them are good; some of them if they don't know the answer they will find out and call you back and others don't know and don't care and never call you back.
- Lots of inconsistency in the information that is being provided, a lot of times it depends on who you are and if you persist on something, it comes back to that old thing "squeaky wheel gets the oil"
- Nobody knows what the services are. The State doesn't have a little handy guide, nor does the Damien Center; most of the care coordinators at the Damien Center are new.
- I have not had good experiences with care coordination because of their making assumptions about me. They think, "Gosh, he can speak in English, he is White and therefore he must not need anything", sort of a reverse discrimination, if you will.
- We are left in ignorance because they don't tell us. So we are left to our own devices to get information.
- Certain care coordinators are very knowledgeable but when it comes to services, we need someone who knows how to handle the situation rather than someone who just reads from the book.
- People should know that there are other agencies they can go to besides the Damien Center.
- We get information from care coordinators who know our specific needs.
- We find information from places that have someone that speaking Spanish. For instance, Casa Mateo was the first one to help me.

Support Groups

- I learned a lot from this group, a lot of helpful information ahead of time from this group.

Resource Guide and Information Sources

- Doctor's offices and hospitals do not have a brochure rack, they always refer you.
- It would be helpful if a packet is made available- these are the services available but it's almost like it being put up on your shoulders- you have to investigate, you have to track this down, and you have to hunt this down.
- Do fliers.
- Do newsletters.
- Distribute them to people when they come in.
- Get the information out to people just like telemarketers.
- Sometimes people get the information, but don't share it.
- I would start on the Internet.

- Contact the different organizations and I would do a follow up by making a phone call.
- On the Internet.
- By word of mouth.
- Some of us may not have access to a computer.
- Get information out of the doctor's office; talk to their secretary, the nurses.
- You can benefit by going to a 'go to' person at those places.
- If they don't have a computer at home they could probably go get information from a library.
- "It's a good thing that Brothers United has those computers at the back. Sometimes when we meet in support groups and we want to look up something, we can easily go back and look it up on the Internet but not all agencies have that. Like at the Damien Centre there is only one computer that limits you to certain sites and you can't go outside those sites."
- At the public library.
- Brothers United.
- Urban League.
- Bridging the Gap.
- Have a concierge like some agencies have where you can call over and ask for some person that has all the information, just like the concierge knows what's going on in the neighborhood.
- With the care coordinator or the doctor's office.
- To the reference book.
- Casa Mateo Community Center.
- Concord Community Center (It is difficult to find information in Spanish).

2. Have you personally been able to get the HIV-related services you have needed over the past 12 months? PROBES: During the last 12 months, did you need a particular service? What service did you need?

a. If yes, did you receive the service?

Dental

- 4 people in the group have benefitted greatly by the dental services. It was godsend.
- My care coordinator at the Damien Center is the best care coordinator I could ask for.
- We just got dental assistance again.

b. If no, why not?

Lack of Information

- Damien Center has satellite offices in St Vincent's but most people don't know that.
- There's not a good promotion of the options out there and a lot of people will not come into a building like the Damien Center to get started on services.

- Doctors and receptionists should have information available for patients on where to go for services.

Financial Issues

- Insurance.
- Cost.
- These doctors' clinics need to have more compassion and give multiple options, like "hey if you don't have insurance we've got something to help you out."
- Spin Dial.
- We don't even know what Title VIII covers? Like with substance abuse and mental health services.
- How do I know what services they don't cover when I don't know what they are?
- Dental.
- Glasses-optometry.
- I lost hearing in one ear due to HIV- now I need help with a hearing aid and will need to see an ENT specialist- but some insurances don't like us to see a specialist, so eventually am I just going to be deaf?
- When I went to seek care, they said the medicines would cost me thousands of dollars; we need agencies that can cover the costs for us because people with HIV/AIDS have no income, therefore they can't pay the deductible or they should have to pay low co-pay.
- All I have is Ryan White Title III but that won't cover my medications.
- I don't have a roof over my head, where do I store my medications?

Stigma

- I didn't want to go to the Damien Center because what if someone saw me going in to the Damien Center?
- I recall, LifeCare used to say "infectious disease clinic" on the outside and I had to take one of my children there for my appointment and he asked me, "mom what are you coming here for" well, I was not ready to share that with my kids yet.
- Before when I went to the doctor's office they only had magazines regarding HIV/AIDS but now they have all kinds of magazines, not just AIDS specific.
- Stigma

Education

- Increase the number of HIV doctors since the doctors in Marion County are overwhelmed and cannot take any more patients.
- When you call a doctor's office it takes them 3-5 months to get an appointment. Because the wait is too long, you just chicken out.
- More case managers are needed that are educated and who can help you talk to your child about that.

3. We know it is hard for people who have been in jail to get HIV-related services after they are released. If you have been in jail or know someone well who has been

in jail, tell us about his or her experiences. How does it affect a person's ability to access services? Were there any needs that you or they had right after being released that were difficult to get met?

- It is appalling you don't test prisoners as they come in, and then you don't test them going out- so they go out into the world. And we all know what's going on in the prison.
- It's also discouraging that we cannot get our penal system to pass out condoms—they just won't!
- It's appalling that so many people that are sent to jail are either transgender or prostitutes—they are tested when they come in, they are everyone's [&*#@\$#] while they are there; they are not protected and when they are coming out they are not given any counseling or encouraged to get tested. Those are the kind of people that are already alienated and will not find services as they are sex workers and getting their money on the street is their livelihood, they just cannot lose it.
- They don't test them coming out anyway.
- People who are being released from jail need a place they can go to where they can get care, something like PACE.
- Psychological barriers.
- Because I hadn't been out of jail 6 months therefore I didn't qualify for care. They told me I had to wait for 6 months in order to get it.

4. Before coming to this focus group, were you aware that free services were available to people with HIV and AIDS through the Ryan White program?

a. If yes, how did you hear about Ryan White?

- I only know because of my care coordinator.
- Most of these folks are aware of some of the benefits I come and talk to them about, but it's still very confusing especially when things are thrown out at you, maybe that's why care coordinators don't do it. There should be some centralized simple way of passing on the information.
- This support group is very positive and supportive and we inform each other.
- You have to drop some low- almost have to abuse the system to qualify.
- There needs to be that gray area- neither completely black nor white; it would be nice to have that middle of the road.
- I have a good care coordinator, so I know.
- Here is not a whole lot of clarity about what is covered and what the enrollment is
- In our town, we have no pure advocates.
- Through a support group at Bethlehem House.
- By reading about Ryan White at the library- on a flier that was distributed outside.
- Brought up on the Wednesday group III in Bethlehem House about the Ryan White part A/B/C.
- Learned about Ryan White through 'Leap Program' from the Federal government and I went to a series of them so that's where I learned about it.
- When I was first initiated to the program, it seemed more open, there was no cap on things and then all of sudden I quit using the services because they put a cap on it. You can only use a certain amount or you have to be in a certain income

bracket. So it made me just not want to deal with it all, but thanks to our group I learned that they had taken the cap off and now I am going to get the dental services.

- I was introduced to it through the Bethlehem House care coordinator.
- I have had Ryan White for 3 years through Bethlehem House [Ryan White Part A and got enrolled in care coordination and IUSD]. I am pretty impressed with the system.
- Got to know from Bridging the Gap.
- The new Damien Center location and clinic is much better and my care coordinator told me what I was eligible for, she gave me my Ryan White Title III card, bus ticket, food pantry, but now the new care coordinator is also very sweet mannered.
- I got to know from Bethlehem House.

b. If no, where would have been the best place for you to find out about Ryan White? How would you suggest the program let others know that services are available?

- Honestly, no. I have even looked at the legislature, but I don't understand what is being offered as it is very confusing!
- The government makes everything so confusing!
- For instance, if your income drops below this, you will be entitled for this
- They need to let the clients know what they are paying for.
- Didn't know about Ryan White. I had Title III for 3 years and still didn't know about it- my care coordinator never told me.

Suggestions on how to get information about Ryan White Program

- Put it in pamphlets on Ryan White A/B/C.
- Fliers in community settings [at Bethlehem House, Damien Center].
- Because we are already looking for it, we will get attracted to information on HIV/AIDS.
- Send me a letter telling me about the Ryan White program.
- Have brochures on HIV testing and Ryan White Parts A, B, C.
- Information can be shared through support groups.
- Through care coordinators.
- Community centers and by sharing information with each other.
- In places that have someone that speaks Spanish.

Section III: Other Populations

1. Have you faced any specific challenges or difficulties because of your gender, ethnicity, or sexual orientation?

- Being gay, HIV positive and black is a big barrier for me!
- "I have to pretend I am like this macho guy when I walk into a doctor's office so I can be treated normal"

- “I think straight people are weird to me just like I am weird to them”
- Fear of their immigration status.
- “Being HIV positive and gay, my employer found every excuse in the book to fire me”
- Because of being gay, attitude of the physician changed- there’s prejudice out there.
- Language barriers for Latinos.
- By being Latinos we have fewer options and many times we do not seek help.

2. Do you think there are any special needs specific to your gender, ethnicity, or sexual orientation?

a. If yes, what are they? Do you think there are adequate services to meet those needs?

- Culture sensitivity would help.
- If you let a care coordinator know that you have an addiction problem their outlook changes on what services they will give you because they think you may have smoked all the money up.

(For focus groups with Women and Rural Populations, insert supplemental questions)

- Gay men get housing first followed by women with children. What about women with no children? That’s wrong- there should be no discrimination.

Section IV: Other Comments

1. Is there anything else you would like to share with us?

Services Needed

- “It’s like Wheel of Fortune game: they give you RSTLN- we need the same things: Transportation; childcare; housing; dental; mental health; eye glasses.”
- Need better glasses.
- Dental/optical.
- Mental health is a very big issue.
- Because I have a car, they refused to give me a bus ticket.
- Counseling and individual support needed.
- Hearing aid- agencies which could cover it. Ryan White, Medicaid, and Medicare do not give it.
- Need more jobs that can help the people.
- When I moved here, DEPA said they’d pay my rent but I could pay my first month rent and I have been waiting since.
- The people that abuse the system get a lot of benefits. People that are honest live by the guidelines while the abusers slide in even though they don’t qualify and avail the services. That makes a bad mark for those who really need it.
- There is a need for more Latino Centers to help HIV positive Latinos, for those diagnosed and yet to be diagnosed.

- The care coordinator at the Damien Center indicated that she had too many clients and could not help her. Referred her back to Wishard. “I would not go back for help to the Damien Center. Every time I asked for help I received a letter telling me that she had too many clients. We need Latino agencies with capable staff.”
- “Need staff that knows the Latino culture and language. We are different. Our immune system feeds off our mood. When we feel good- our immune system goes up; if we get to a place where they close the doors, we feel worse- like there is nothing left, no way out, no help, like we have nothing. In fact, our own Latino agencies would help. Agencies should not mail letters informing they are too busy instead they should refer elsewhere as needed.”

Education

- Literacy- you can give out information, but there are a lot of people that cannot understand or read the information, so help people get their GED.
- Peer education is a must.
- Programs provided on medications, education, side effects-- all would be very helpful.
- Need more Latino agencies that understand our culture.
- Need more Latino care coordinators that speak Spanish. Being Latinos we have fewer benefits. I have never had a support group. I did what I had to do, but not everybody has the strength.

Support System

- Create a buddy system. Damien Center has it. Have someone who is educated about the system so they can help people through, especially the newly diagnosed ones so that if they have questions could call them.
- We need more support groups in Spanish.

Information Sharing

- Damien Center sends out a newsletter out every month.
- Lots of churches have AIDS ministries and if you incorporate some of these different organizations and tell them to give this information out to the populations that they reach out to that would be helpful. So if someone who is HIV positive approaches them, they have a list that they can see and refer them to and make sure that those lists also get around to all the AIDS agencies because too many times this one don't know what that other one's doing.
- Care coordinators need to share more information.
- More Latino agencies are needed that understand our culture (Damien Center does not accept new patients).
- More Latino care coordinators that speak Spanish are needed.
- “We have already got a generation of kids out there that are called ‘bug chasers;’ they are out there looking to get infected because their mindset is that might as well get infected now, because I know I am going to end up with it.”
- Every time I hear about somebody talking about outreach in the community and sex education- the first word that comes out of their mouth is- Abstinence. We all

- know that isn't happening- the next generation not going to have the knowledge and its just going to blossom again.
- Look at other options to assist people, like maybe have a hotline; literature; a concierge; or a 211 or a 311 number.
 - Need to have a list or some information about each category of services available, so everybody can see what they need or don't need or what they qualify for and have a better understanding.
 - Educate the consumers so that they learn to share information with other people.

Stigma

- Stigma- a lot of people are just afraid for anyone to even know.
- Fear factor.
- Some people don't want to be seen walking in to the Damien Center.
- I don't want to be seen driving into the Damien Center and be seen by a friend as its one of those stigma things and the fear factor.
- Stigma- I know someone who is working full time and is afraid to come to the Damien Center, because what if somebody sees their car here and that way they could lose their job.

Care Coordination

- The gay men know more about our health than we do; they do, they know more!
- These care coordinators should verbally speak to us when we come in for a visit, tell us whatever we need to know, whatever is going to help us; it's not like we just came in or we are new, we have been going there from the beginning.
- They don't give you any more than you need to know.
- One stop shop is needed- with your dentist, care coordinator, medicines, prescriptions- everything under one roof.
- Getting care coordinators who are gay/lesbians. Match care coordinators with their patients because they will be better advocates; as sometimes patients may not want to go back to get care.
- Care coordination should tell us, what services we will still have, how much more this is going to cost us, when you go on Part D, how much more your drugs may/may not cost you, if we wanted to re-locate will we be eligible for a program there?
- Some agencies still play the race card. If you need to give services, you need to give services to people no matter what race, creed or sex- what's meant for one should be meant for the other.
- There is a need for more Latino Centers to help HIV positive Latinos.
- Need people who have the same needs, who can understand us better.
- All should be entitled to the same service.
- Some agencies hire the young out-of-college folks who do "what the book says." We need someone with experience who has HIV and helps us to live with HIV.
- The case managers should follow up.
- Care coordinator needs to assess every case on several areas and not just focus on HIV.

- I went to the Damien Center for help on DEPA [i.e. the emergency care] and they don't tell you about other programs, which can be really frustrating.
- At different places, we are not getting the same level of care.
- "If you are positive, you do want people walking in your shoes and helping you. If you *don't have a group*, then you are totally dependent on your care coordinator that is if you have one. If you don't have a *good* care coordinator, then you are screwed; but if you *don't have a care coordinator* at all, then you are totally screwed."

Grievance Board

- Agencies should have a grievance process where if you had a problem you can report it and it should be reviewed by some outside service and not by the agency itself- something like a complaint board/review board/advisory board so that if the agencies don't do something they should be charged some sort of penalty. Like, maybe cut their funding and give it to somebody else who is providing quality services and call it a Grievance Advisory Board that would resolve issues and conflicts.
- Talk for us. HIV positive people need to be educated and should go get grant dollars because they are the ones living with HIV/AIDS.

Aging Issues

- Aging population [>65 years] there is no more ICHEA- we don't have services available.
- For the aging population, with the disease manifestation, people living longer, the insurance, general health being better, being alone, not knowing what the future may hold, needing nursing care, "we could be prohibited from being in a Nursing Home, just because they don't want us there. None of us could go in to a Nursing Home unless we were really wealthy. And all of us are getting there."

Financial Assistance

- The poverty level is set by the Federal government: if below the poverty line you have to be 'living out of a box and under the bridge' and only then can you get services. They really need to revisit the requirements and change them in order for people to get services.
- Financial- is a very big part. Agencies need to help with the rent.

Advocacy

- Marion County needs a higher peer advocate that is HIV positive, does community work, that when people call in with problems they can talk to them one-on-one like, "What are your circumstances- I have been in your shoes."
- There are people who are HIV positive but they want other people to do the foot work for them. They need to be doing the same things that we are doing out here- advocating and going for these meetings.
- You've got to help yourself to get the help you need.
- I am still dealing with PTSD; have memory lapses; and the outreach has been very helpful. "I want a helping hand, not a handout!"

CHAPTER IV- SUMMARY OF FINDINGS

Below is a summary of findings from the key informant interviews and focus groups. Sections A to C are organized by the type of study participant in key informant interviews. Different versions of the interview script were used for the providers of care for clients “in-care,” for the providers servicing clients “not-in-care” and for clients “not-in-care.” All of the focus groups used the same script. Sections D to G summarize the comments made in the focus groups around topics covered in the script: diagnosis and medical care; non-medical services needs and barriers; and other comments.

A. Providers for Clients “In-Care”

Consumer Demographics

Majority of clients served by the providers were African American gay men, less than 50 years of age who were infected from unsafe sex. Most of the clients they saw were HIV positive. The providers typically initiated care coordination and testing if needed. The health providers reported referring clients to service providers such as; Damien Center, Bellflower, Wishard, Concord, IU, Life Care Methodist, and Fairbanks for those with substance use issues.

Services Needed

Transportation and housing – both permanent safe housing and transitional housing -- were the most frequently cited services needed from the providers perspective. In addition, substance abuse treatment and mental health treatment for clients should be provided since many of their clients have needs in these areas. Also, improving the communication and relationships between clients and service providers were frequently cited needs. Social support networks, counseling availability and education were some other services that were needed. It would be helpful to have a resource guide of all services available to increase awareness of available services, especially for clients that are newly diagnosed with HIV. Additionally, vision, dental, increased access to all care, including medication is needed. Providers reported that there were too few service providers and many clients ended up going to the Emergency Room for their acute needs.

Barriers to Accessing Care

Accessibility and waiting too long for services was a big problem. Transportation, lack of family support, fear, denial, stigma, unawareness of the services available and lack of education were all reported as barriers to entering into care. Providers also reported that lack of insurance, physical inability, and finances were major issues. Being a complex healthcare system it is sometimes difficult for their clients to navigate the system and receive services. Language barriers were also reported for the Hispanic population. Lack of good referrals for care; patient education programs and accessibility were also important barriers. Doctors need to better prepare their patients for the expected side effects of the medicine they prescribe.

Poor provider attitudes, accessibility, low finances, substance abuse, and side effects of medication treatment were barriers noted for remaining in care, in addition to complexity of treatment regimens and poor provider attitudes.

Providers reported that side effects from medication, forgetting to take medications and feeling bad physically and emotionally were all reasons for discontinuing treatment. Patient and provider communication, safe housing, lack of knowledge, embarrassment and poor coping skills were additional barriers.

Motivators to Enter and Stay in Care and Adhere to Treatment

Providers reported that the ‘buddy system,’ having a mentor living with HIV could help them navigate the system and remain in care. Improving provider attitudes, and providing more knowledge and awareness, transportation and rental assistance were additional motivators.

Interviewees reported that the clients responded better to providers who had similar characteristics such as; same language and race/ethnicity. Weekly checks on clients by culturally competent providers, rental assistance and peer education were also motivators to help clients adhere to treatment.

B. Providers for “Out-of-Care” Clients

Consumer Demographics

Most of their clients were HIV positive African American, gay males. Approximately, 90% of all clients were not receiving HIV related primary medical care. Most of the clients learned of their HIV status in a clinical setting and were directed to services at Wishard, Concord, and the Damien Center.

Services Needed

Providers reported that transportation, housing assistance, food pantry, mental health services, substance abuse services and HIV education were the most sought after services by the clients.

Barriers to Accessing Care

Out-of-care providers reported that majority of the reasons why clients were not receiving HIV positive related care was due to denial, fear, embarrassment, stigma associated with HIV. Additional barriers to accessing health included transportation, housing and not having any medical insurance.

Motivators to Enter Care and Stay in Care

Providers pointed us in the direction to “see the information cards for Consumer Advisory Board at ISDH.” However, it is important to keep the message simple, since clients may have a low reading level. Incentives, such as housing vouchers, gas cards, bus tickets, food vouchers, etc., would also be helpful.

Reasons for Discontinuing Care

Transportation needed to seek services and make appointments was one of the reasons clients discontinue treatment. Additionally, clients discontinued treatment when they felt better or got tired of the treatment regimen. Also, they forget to take medications partially because the treatment regimen is too complex for them to understand and follow.

C. Out-of- Care Clients

First Experience with Service

Most of the out-of-care clients reported learning of their HIV positive status in a clinical setting. Most reported being referred to the Damien Center for services and when initially diagnosed they were given referrals for services immediately.

Reason for Discontinuation of Medication

All the out-of-care clients reported discontinuing HIV medications due to the side effects. They reported limited options for services, unavailability of counseling, under-educated families/support, and lack of support groups as reasons for them to discontinue care.

Services Needed

Transportation, rental assistance, food assistance and emergency room services were reported as the greatest need. They also reported that housing, food, and transportation were the most difficult to acquire. All clients in this group reported that they were unaware of services under the Ryan White Program.

D. Diagnosis and Medical Care

Diagnosis and Referral

Majority of focus group participants reported that they learned of their HIV positive status in a clinical setting. Some participants were diagnosed while being hospitalized, participating in a medical study, an emergency room, a delivery room while giving birth. Other locations included IU, a health festival, prison, Wishard hospital and a blood bank.

Focus group participants reported gaining information about medical care options from a family doctor referral, some participants were given treatment immediately upon diagnosis, and some reported that IU doctors at Wishard referred clients to the Damien Center. Other study participants heard about the Damien Center and Bellflower from their social networks.

Medical Services

Study participants reported not receiving care for anywhere from two weeks to four months after being diagnosed. Some reported receiving care immediately and were hospitalized. However, once they got into care, they were informed of services available from Bethlehem House, Damien Center, Bridging a Gap, support groups and care coordinators. Currently all reported having care coordinators and HIV-related primary care services.

E. Service Needs and Barriers

Services Needed beyond Medical Care

Focus group participants reported that transportation, housing, and employment were some of their biggest needs. They need insurance to cover the entire cost of

medications and laws to protect them from being fired from jobs due to their HIV positive and/or gay status. In addition, a single informative guidebook with all resources and services would be very helpful. Also, support groups and social functions, where social interactions were not singly focused on discussing HIV, were reported as being helpful.

For individuals who wanted to pursue employment they need assistance with job placement, training and not be penalized for working by taking away needed services. Additionally, access to food pantry, dental and vision care were reported as an important service need. Also, more discrete environments of the service locations are needed. More education is needed about HIV for providers and clients. Sensitivity and cultural training for care coordinators and medical staff seemed to be lacking.

They also indicated a need for reducing communication gaps, having a ‘go to’ person for information, and encourage peer education. Most of them reported that they found out about the services from their care coordinators and support groups. All participants were appalled that prisoners were not tested either when they went in or came out of jail.

Ryan White Services

Most focus group respondents reported that services offered from the Ryan White Foundation were very confusing and complicated. Additionally, participants said it is unclear what is covered and what is required for enrollment.

Barriers to Care

Focus group participants reported that lack of cultural sensitivity was a big barrier to care. Fear of immigration status and judgment by providers were also barriers. Being HIV positive and having an addiction changes the provider’s outlook resulting in negative consequences.

F. Other Comments

Information sharing and lack of cooperation from the care coordination sites were the main areas of concern among the focus group participants. In addition, the aging population was unaware of their options and needed to be informed. Focus group participants also suggested that the federal government’s poverty line definition needs to be revisited. Additionally, Latino Centers need to be developed to help the HIV positive Latinos as well as have support groups in Spanish. Furthermore, participants reported that case managers should follow up with their clients and have programs that explain medications and the side effects to their HIV positive patients.

G. Specific Comments based on Race, Ethnicity, and Gender

In addition to the common themes of transportation, housing and creating awareness, some of the individual groups had few comments specific to their race, ethnicity, or gender, which have been listed below:

White MSM Focus Group

- I haven't had good experiences with care coordination because of their making assumptions about me—they think, "Gosh, he can speak in English, he is White and therefore he must not need anything", sort of a reverse discrimination, if you will.

Black MSM Focus Group

- Communication gap is VERY big. Agencies need to be collaborating together because half of them act as though it is a race.
- Some agencies still play the race card. If you need to give services, you need to give services to people no matter what race, creed or sex- what's meant for one should be meant for the other.

Hispanic Focus Group

- Not open because of stigma, but only open up to similar race/ethnicity; or to individuals speaking same language.
- Rumor spreads very quickly within ethnic groups.
- With ethnic population need to be very creative because "one design does not fit all."
- Language barriers for Latinos- need a Spanish interpreter.
- Cultural competency counseling- especially language.
- Individuals who speak Spanish there is a great disconnect with that population.
- We need more support groups in Spanish.
- More Latino care coordinators that speak Spanish are needed.

Women's Focus Group

- The gay men get most or all the money- unless you are a woman with children, you get moved up- otherwise nobody cares about you.
- "Gay Model"- gay men are still being given the best care, they are kept in the hospital for 72 hours and given medication because they are considered to be 'high risk' to go spread to others, but why not women?
- I am disabled and I went to housing to fill out my Section VIII. The top priority in housing goes to gay men first, and then white men, then women with children get bumped up, but if you don't have any kids then you are on a back burner for over a year- that is just not fair.
- Gay men get housing first followed by women with children. What about women with no children. That's wrong- there should be no discrimination.

CHAPTER V- RECOMMENDATIONS

Remove existing health care system barriers to care by:

- Improving the interaction between HIV patients and providers, by providing cultural and sensitivity training to insure that provider treat the patients with dignity
- Establish a trusting relationship between providers and patients, particularly for non-citizens, to remove their fear of being deported
- Expanding the number of providers who have expertise to address the needs of HIV patients, so that patients have more options for service providers, to cut down on appointment wait times, and to allow HIV patients to be treated in more cost effective ways, rather than in emergency rooms – particularly needed are providers with the same demographic characteristics as the patients
- Improving the communication between providers and patients, to insure that patients understand their treatment regimen, why it is important to stay on it, what side-effects they can expect and how to deal with them -- this is a special need for those patients who do not speak or read English well
- Providing up-to-date resource guides to HIV positive individuals, particularly those who are newly diagnosed, to help them navigate the health care system
- Provide discrete service locations that are convenient to reach
- Expand health insurance coverage for these individuals
- Institute a follow up system to check on patients' treatment adherence as well as when they don't show for scheduled visits
- Establish electronic record information exchanges among providers to reduce duplication of services and optimize treatment

Develop programs and initiatives to insure that individuals with HIV have access to non-medical services, including:

- Basic needs, such as, transportation, housing and food assistance
- Social needs, such as, social support networks, social interaction, help developing coping skills, and mentors
- Educational needs, including, formal education and job training
- Knowledge needs, such as, knowledge of HIV, availability of services, and navigating the health care system
- Employment needs that would lead to income, such as policies to protect employment and insurance eligibility

Expand medical care services to include:

- Basic care, such as primary care, vision, dental and medication
- Specialized care including substance abuse treatment, mental health treatment, emergency/urgent care, and perinatal care
- Counseling services to address individual barriers to care such as, denial, fear, dealing with stigma and embarrassment, low self-esteem, low self-efficacy, and motivation

APPENDICES

CONSENT STATEMENT FOR FOCUS GROUP PARTICIPANTS FOR HIV/AIDS

PROCEDURES FOR THE STUDY:

If you agree to be in the study, we would like to invite you to a two hour long focus group session, with 8-9 other individuals in the same room, sharing the experiences that you [or someone you know] had while getting treatment for HIV/AIDS.

We would like to tape record the focus group session to make sure the notes we take are complete and accurate. In some cases, we may use the tape recording to quote a truly significant comment. No signature or initials will be requested from you on the consent forms or on any other documentation to which the researchers have access.

RISKS OF TAKING PART IN THE STUDY:

While on the study, there are minimal foreseeable risks, however, you may feel uncomfortable answering the questions in a focus group setting. If you feel uncomfortable or do not care to answer a particular question, please feel free to refuse to answer any question at any given time. We value your opinions and perspectives and will try to minimize any feeling of discomfort for you.

ALTERNATIVES TO TAKING PART IN THE STUDY:

Since this is a voluntary study, your ability to receive services will not be affected in any way if you choose not to participate in the study or withdraw from the study.

CONFIDENTIALITY

No personal information will be collected. The focus group session will be audio taped and transcribed for data analysis. Upon completion of the analysis, the audio tapes will be erased and the paper used to document results will be shredded.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, study sponsor, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP) that may need to access your medical and/or research records.

PAYMENT

You will receive a \$20 gift certificate to a local department store for taking part in this study.

COMPENSATION FOR INJURY

In the event of stress or anxiety resulting from your participation in this research, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact Dr. Terrell W. Zollinger at 317-278-0300. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949. For questions related to the Ryan White program, contact Mike Wallace at 317-221-3354.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with your provider.

CONSENTIMIENTO PARA PARTICIPANTES DEL GRUPO DE ENFOQUE DE VIH/SIDA

Si usted está de acuerdo en participar en el estudio, nos gustaría invitarle a una sesión de grupo de enfoque de dos horas. Durante la sesión, estará con 8 o 9 individuos más en el mismo cuarto compartiendo experiencias que usted (o alguien que usted conoce) a tenido durante su tratamiento de VIH/SIDA.

Nos gustaría grabar la sesión del grupo de enfoque, para asegurarnos de que las notas que tomemos sean completas y correctas. En algunos casos, podríamos usar una audio grabadora para marcar un comentario verdaderamente significativo. No se le pedirá a usted su firma o iniciales en ninguna forma de consentimiento o cualquier otro documento al cual los investigadores tendrían acceso.

Riesgos de tomar parte en el estudio:

Durante el estudio, hay muy pocos riesgos que se puedan presentar, aun así, usted pudiese sentirse incomodo al contestar algunas preguntas en el ambiente de grupo de enfoque. Si usted se siente incomodo para contestar alguna pregunta en particular o no desea contestar en cualquier momento por favor siéntase libre de negarse a contestar en cualquier momento. Nosotros valoramos sus opiniones y perspectivas y trataremos de minimizar cualquier sentimiento de incomodidad para usted.

Alternativas a tomar en el estudio:

Dado a que este es un estudio voluntario, su posibilidad de recibir servicios no será afectada de ninguna manera en caso de que usted decida no participar, o dejar el estudio.

Confidencialidad:

No se le pedirá ninguna información personal. La sesión de grupo de enfoque será gravada y transcrita a un análisis de información. Una vez terminado el análisis, las grabaciones de audio serán borradas y los papeles utilizados para documentar resultados serán triturados.

Las organizaciones que pudieran inspeccionar y/o copiar los records de investigación para asegurar la calidad del análisis de información incluye grupos tales como los investigadores del estudio y sus asociados de investigación, el equipo de revisión institucional de IUPUI/Clarian o sus personas asignadas, patrocinadores de estudio, y (como permitido por la ley) agencias federales o estatales (Específicamente la oficina de protección de Investigaciones Humanas (OHRP) que pudieran necesitar acceso a su expediente medico y/o de investigación.

Pago:

Usted recibirá un certificado de regalo de \$20.00 de una tienda departamental local por tomar parte en este estudio.

Compensación por danos:

En caso de estrés o ansiedad causada por su participación en este estudio, es su responsabilidad determinar la cobertura de su plan de salud. No hay un programa establecido para otra compensación monetaria por tales danos. Aun así usted no esta renunciando a cualquier otro derecho o beneficio que usted pudiera tener.

Contactos para preguntas o problemas:

Para preguntas sobre este estudio o daño relacionado con la investigación, contacte a Dr. Terrell W. Zollinger al 317-278-0300. Si usted no puede contactar al investigador durante el horario regular (8:00am-5:00pm), por favor llame a la oficina Administrativa de Investigaciones de IUPUI/Clarian al 317-278-3458 o al 800-693-2949. Para preguntas relacionadas con el programa de Ryan White, comuníquese con Mike Wallace al 317-221-3354.

Naturaleza voluntaria del estudio:

El tomar parte de este estudio es voluntario. Usted puede decidir no tomar parte en el estudio o dejar el estudio en cualquier momento. El dejar el estudio no resultara en ninguna penalidad o pérdida de beneficios a los cuales usted tiene derecho. Su decisión de participar o no en el estudio, no afectará su relación presente o futura con su proveedor de salud.

Marion County Health Department HIV/AIDS Key Informant Interview Script (for providers)

OPENING STATEMENT: *My name is _____ from the Indiana University Bowen Research Center. The Health Department recently received a new kind of grant to provide HIV/AIDS services in the Indianapolis area. They want to provide the best possible system of care for everyone living with HIV and AIDS. So they have asked us to help with some needs assessment activities. We are particularly concerned with better understanding the service needs and barriers for particular populations, as well as why many people within those populations who know they are HIV+ are not receiving regular HIV-related primary medical care and other needed services.*

We invited you to participate in this discussion because you have special understanding of the service needs and barriers of a particular group of people living with HIV and AIDS: _____ [specify the group that applies to that key informant – e.g., youth 15-24, substance users, etc.] We value your perspectives and opinions and ask that you help us better understand this population so that we can improve the system of care for this group.

The information you share with us today will add to the information we have gotten from other sources. We will use your comments and suggestions along with information from other sources to better understand service needs and to improve the system of care for people living with HIV and AIDS in the Indianapolis area.

- 1. Please describe your experience working with people living with HIV and AIDS (PLWH/A). How do you see yourself fitting into the system of HIV/AIDS care in the Indianapolis MSA? [PROBES]**
 - a) What population of HIV+ clients do you normally work with? e.g. age, race, gender, risk factors?
 - b) What proportion of your clients are HIV+?
 - c) What type of services do you provide or link people to?
 - d) What other service providers do you work with to connect with PLWH/A?
 - e) What other service providers do you work with to link PLWH/A to services? e.g. What services do you refer your clients to and what service providers are you aware of that provide those services?

- 2. Let's talk a little bit more about the clients you typically work with. You were invited to participate in this discussion because of your unique experience working with PLWH/A that are _____. What are some of the**

special needs or characteristics of this population? (If you feel qualified to answer the following questions for another population group, please let us know, and we would welcome that additional information)

- a) What services do they most have a need for? Which do they access most often?
3. **How well do you feel the needs of this population are met?**
 - a) Which medical or support services are not being provided?
 - b) Which medical or support services are not being adequately provided?
 - c) Which medical or support services are being provided, but are provided in such a way that they are inaccessible to people in this population?
4. **What unique characteristics of this population facilitate the delivery of services to them?** i.e. what strengths or skills do they have for self advocacy? Are there particular locations they are comfortable being served or methods of outreach that they are likely to respond to? Etc.
5. **What unique needs or characteristics of this population make it difficult to deliver services to them?** i.e. are there certain needs that must be addressed before they are able to seek HIV-related medical care (eg. Substance abuse, mental health services, etc.)? Are they difficult to locate or enroll in social support services, and why?
6. **What are the biggest barriers for this population in getting into primary HIV medical care, staying in care, and adhering to their treatment regimens?**
 - a) What are the most important barriers that keep them from entering care?
 - b) What are the biggest barriers to remaining in care?
 - c) What are the biggest barriers to treatment adherence
7. **What could be done to motivate more PLWH from this population to get into primary HIV medical care?**
 - a) What are some motivators for this population that might facilitate them remaining in care?
 - b) What are some motivators for this population that might facilitate them adhering to treatment?
8. **If you were responsible for designing or improving the system of care for people living with HIV and AIDS, what would you do to help people find out about services and get the care they need?**

CLOSING STATEMENT: *Thank you so much for your help. We'll put together a report summarizing what you have told us and what we learn from other people. Our plan is to provide this report to our planning body and the people who run the local Ryan White program, and to policy makers who are trying to make sure people with HIV and AIDS get the services they need. Thank you very much for your valuable input. We appreciate your time.*

**Marion County Health Department
HIV/AIDS Key Informant Interview Script
(for providers to out of care consumers)**

OPENING STATEMENT: *My name is _____ from the Indiana University Bowen Research Center. The Health Department recently received a new kind of grant to provide HIV/AIDS services in the Indianapolis area. They want to provide the best possible system of care for everyone living with HIV and AIDS. So they have asked us to help with some needs assessment activities. We are particularly concerned with better understanding the service needs and barriers for particular populations – and why many **people within those populations who know they are HIV+** are not receiving regular HIV-related primary medical care and other needed services.*

We invited you to participate in this discussion because you have special understanding of the service needs and barriers of a particular group of people living with HIV and AIDS: _____ [specify the group that applies to that key informant – e.g., youth 15-24, substance users, etc.] We value your perspectives and opinions and ask that you help us better understand this population so that we can improve the system of care for this group, and especially how we can encourage people with HIV and AIDS to enter medical care right after they are diagnosed and then stay in care.

The information you share with us today will add to the information we have gotten from other sources. We will use your comments and suggestions along with information from other sources to better understand service needs and to improve the system of care for people living with HIV and AIDS in the Indianapolis area.

- 1. About what proportion of your clients over the past year or two have been HIV-positive? How do you find out they are HIV-positive?**
- 2. Of the people who are HIV-positive, about what proportion of them are not receiving HIV-related primary medical care?**
- 3. Do these individuals typically know their HIV status before they become your clients, or do you encourage them to get tested, or is there another scenario?**
- 4. You were invited to participate in this discussion because of your unique experience working with PLWH/A that are out of care that are _____ [specify the group that the key informant works with]. What are some common reasons why _____ [identify specific group] people with HIV/AIDS are not receiving HIV-related medical care?**
 - a) Are there different reasons for people that are newly diagnosed versus people that have known their status for a longer amount of time?
- 5. Tell us what you know about how your clients learn they are HIV-positive, and what kind of immediate help do they get in finding care? PROBES:**

- a) Where do they first learn of their diagnosis (i.e. what type of setting – emergency room, clinic, doctor’s office, community testing site, hospital, community, etc.)?
 - b) What are they told about treatment options, or where are they directed to find out this information?
- 6. Tell us what you know about why your clients seek out your services and what other services (medical, HIV-related medical, support) they receive. PROBES:**
- a) How many of them ever received HIV-related primary medical care?
 - b) Do they access mental health services, substance abuse services, housing assistance, food banks, transportation assistance, etc.?
- 7. We would appreciate any insights about your clients that would help us understand why they sometimes don’t obtain HIV-related care even if they know their status. What are some of the biggest barriers that make it hard for your clients to get into HIV medical care?**
- a) Are certain barriers more important than others? Do multiple barriers need to be addressed in any particular order – do they need help dealing with some other needs before they are ready to enter primary medical care, for example?
 - b) Tell us about barriers specific to particular population groups you work with.
 - c) How aware of the available services are they? Are they aware that they could receive services for free under Ryan White?
 - i) If yes, how do they hear about Ryan White?
 - ii) If no, where would be the best place to find out about Ryan White? How would you suggest the program let them know that services are available?
 - d) Do they attempt to access services and are unsuccessful? Why? Do they have problems accessing services because of where or when they were offered or for any other reason?
- 8. What could be done to motivate more of your clients to enter HIV medical care?**
- 9. We are concerned with both getting people into HIV medical care, and keeping them in care. What causes your clients to drop out of HIV-related medical care?**
- 10. What are some of the biggest barriers to adhering to a treatment regimen?**
- 11. What could be done to help people like your clients stay in primary medical care and follow their treatment regimens?**
- 12. In addition to primary medical care, what other services are most needed by your clients who are HIV+? And to what extent are they able to obtain each of these services?**
- a) Which services are hardest to get? Are the services that are available appropriate for your clients?

- b) **Would your clients be more likely to enter and stay in primary medical care if they first had other important service needs met? What services?**
- 13. Where do your clients find out about the HIV-related services that are available in the Indianapolis area?** If they were interested in finding out about a particular service, who might they ask, or where would they look?
- 14. If you were responsible for designing or improving the system of care for people living with HIV and AIDS, what would you do to help people find out about services and get the care they need?**

CLOSING STATEMENT: *Thank you so much for your help. We'll put together a report summarizing what you have told us and what we learn from other people. Our plan is to provide this report to our planning body and the people who run the local Ryan White program, and to policy makers who are trying to make sure people with HIV and AIDS get the services they need. Thank you very much for your valuable input. We appreciate your time.*

**Marion County Health Department
HIV/AIDS Key Informant Interview Script
(for out of care consumers)**

OPENING STATEMENT: *My name is _____ from the Indiana University Bowen Research Center. The Health Department has started a broad-based effort to identify the HIV/AIDS treatment services concerns in your county.*

*We invited you to participate in this interview because you have **direct experience with living with HIV/AIDS and dealing with barriers that make it hard to get into care and remain in care.** We value your perspectives and opinions and ask that you help us identify your experiences and challenges in obtaining care and the experiences of other people you know with HIV and AIDS. We will use your comments and suggestions along with information from other sources to better understand service needs and to improve the system of care for people living with HIV and AIDS in the Indianapolis area. We will keep your comments confidential. We would like to tape record the session to make sure the notes we take are complete and accurate. In some cases we may use the tape recording to accurately quote a truly significant comment, but again, no names will be connected to any reported results.*

- 1. [Verify that the interviewee is actually “out of care” according to the HRSA definition] Are you currently receiving HIV-related primary medical care? Have you had a CD4 count and/or viral load test and/or received anti-retroviral medications in the last 12 months?**
- 2. If you are now receiving care, was there a period in the last 5 years where you didn’t receive HIV related medical care for a year or more?** [Uses HRSA unmet need time frame] If so, why?

IF INDIVIDUAL IS NOW IN CARE AND WAS NOT OUT OF CARE DURING THE LAST FIVE YEARS, THANK THE INDIVIDUAL AND END THE INTERVIEW. THIS PERSON DOES NOT MEET CRITERIA FOR BEING OUT OF CARE.

- 3. Tell us about how you learned you were HIV-positive, what advice or referrals you received with your diagnosis, and what you did about it, including what, if any, HIV-related medical care you have received, what factors influenced your decision to seek or not seek care, and why you are not in care now. PROBES:**
 - a. Where did you first learn you were HIV+ (i.e. what city, what type of setting – doctor’s office, hospital, community, etc.)?
 - b. What were you told about treatment options, or where were you directed to find out this information?
 - c. Have you ever received HIV-related primary medical care? If so, how long was it between when you were diagnosed with HIV and when you first saw a doctor for an HIV related visit?
 - i. If you did not see a doctor right away or at all, what were some of the reasons for the delay?

- ii. If you did see a doctor, why did you see a doctor when you did? What were some of the factors that helped get you into care?
 - d. Did you seek out other services before you saw a doctor for an HIV related visit for the first time? What services did you seek?
 - e. Were you referred to care coordination? Who referred you to care coordination?
- 4. What are some of the biggest barriers to getting into HIV medical care for you or people you know who have HIV or AIDS? [PROBES]**
- a. [Acceptance issues] How did you feel about your HIV diagnosis and the need for treatment? Did you have symptoms? Did you feel that you would benefit from regular medical care? Did you receive any other non-HIV related medical care during this time?
 - b. [Knowledge issues] How aware of the available services for people with HIV/AIDS were you? Were you aware that people with HIV/AIDS could receive services for free under Ryan White?
 - c. [Stigma issues] Were you afraid friends/family/peers/co-workers would find out about your diagnosis? What sort of responses do you get from people when you disclose your HIV status? What consequences have you experienced as a result of disclosing your HIV status?
 - d. [Systems issues] Did you attempt to access services and were unsuccessful? If so, why?
 - e. [Access issues] Where do you live in relation to the services you need? Does that impact your ability to access those services?
 - f. [Other issues] What other things keep you from or kept you from accessing HIV related medical care during this time? What other priorities are/were you dealing with that impact your ability to access HIV related medical care?
- 5. What could be done to make it easier for newly diagnosed people to seek care -- or to encourage other people with HIV/AIDS to enter care?**
- a. If you have previously received HIV related medical care, what made you get in to see a doctor?
- 6. (If you ever previously received HIV related medical care) what made it hard for you to follow your treatment and remain in care?**
- a. What caused you to fall out of care?

SECTION 2 – Other services

- 7. What other services do you need to help you live with your HIV/AIDS? Have you been able to get them? Tell us about your experiences. PROBES:**
- a. What services do you most need?
 - b. Which services are hardest to get?

- c. Which services have you accessed in the past year? Ever?
- 8. Would you be more likely to enter and stay in primary medical care if you first had other important service needs met? Tell us about that. Where do you go to find out about available services?** If you were interested in finding out about a particular service, who might you ask, or where would you look?

SECTION 3 – Awareness of Ryan White

- 9. Before this interview, were you aware that free services are-available to people with HIV and AIDS through the Ryan White program?** Think of other HIV+ people you might know that are not receiving services. Are they aware that Ryan White services are available?
- a. If yes, how did you/they hear about Ryan White?
 - b. If no, how would you suggest the program let people with HIV/AIDS know that services are available?
- 10. If you were responsible for designing or improving the system of care for people living with HIV and AIDS, what would you do to help people find out about services and get the care they need?**

CLOSING STATEMENT: *Thank you so much for your help. We'll put together a report summarizing what you have told us and what we learn from other people. Our plan is to provide this report to our planning body and the people who run the local Ryan White program, and to policy makers who are trying to make sure people with HIV and AIDS get the services they need. Thank you very much for your valuable input. We appreciate your time.*

FOCUS GROUP PARTICIPATION LETTER

Dear Participant:

We would like to invite you to a two hour long focus group session, with 8-9 other individuals in the same room, sharing the experiences that you [or someone you know] had while getting treatment for HIV/AIDS.

We would like to tape record the focus group session to make sure the notes we take are complete and accurate for data analysis. Upon completion of the analysis, the audio tapes will be erased and the paper used to document results will be shredded.

During the session, if you feel uncomfortable or do not care to answer a particular question, please feel free to refuse to answer any question at any given time. We value your opinions and perspectives and will try to minimize any feeling of discomfort for you.

Since this is a voluntary study, your ability to receive services will not be affected in any way even if you choose not to participate in the study or withdraw from the study.

No personal information will be collected. No signature or initials will be requested from you.

You will receive a \$20 gift certificate to a local department store for taking part in this study.

For questions about the study or a research-related injury, contact Dr. Terrell W. Zollinger at 317-278-0300. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949. For questions related to the Ryan White program, contact Mike Wallace at 317-221-3354.

Once again, **taking part in this study is voluntary**. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with your provider.

Thank you for your time!

Sincerely,

Care Coordinator

DATE: _____

TIME: _____

PLACE: _____

CARTA DE PARTICIPACION EN EL GRUPO DE ENFOQUE

Estimado Participante:

Nos gustaría invitarle a una sesión de grupo de enfoque de dos horas, con ocho o nueve individuos más en el mismo cuarto, compartiendo las experiencias que usted (o alguien que usted conoce) a vivido durante sus tratamiento de VIH/SIDA.

Nos gustaría audio grabar la sesión del grupo de enfoque para asegurarnos de que las notas que nosotros tomemos estén completas y sean correctas para el análisis de información. Al término del análisis, las grabaciones de audio serán borradas y todo el papel utilizado para documentar resultados será triturado.

Durante la sesión, si usted se siente incomodo o no desea contestar alguna pregunta en particular, por favor siéntase libre de rehusarse a contestar cualquier pregunta en cualquier momento. Nosotros valoramos su opinión y perspectivas y trataremos de minimizar cualquier sentimiento de incomodidad para usted.

Dado a que este es un estudio voluntario, su habilidad de recibir servicios no será afectada de ninguna manera ya se que usted decida no participar en el estudio o dejar el estudio.

No se le pedirá ninguna información personal. No se le pedirá su firma o iniciales.

Usted recibirá un certificado de regalo de \$20.00 de una tienda departamental local por participar en este estudio.

Para preguntas sobre el estudio o para algún daño causado por la investigación, contacte a Dr. Terrell W. Zollinger al 317-278-0300. Si no puede contactar al investigador durante el horario normal (8:00am-5:00pm), por favor llame a la oficina Administrativa de investigaciones de IUPUI/Clarian al 317-278-3458 o 800-696-2949. Para preguntas relacionadas con el programa de Ryan White, comuníquese con Mike Wallace al 317-221-3354.

Una vez más, la participación en este estudio es voluntaria. Usted puede decidir no tomar parte o dejar este estudio en cualquier momento. El dejar el estudio no tendrá ninguna penalidad o pérdida de beneficios a los cuales usted podría se elegible. Su decisión de participar o no en el estudio no afectara su relación presente o futura con su proveedor de salud.

¡Gracias por su tiempo!

Sinceramente,
Coordinador de Cuidados

Fecha: _____

Hora: _____

Lugar: _____

Marion County Health Department

HIV/AIDS Focus Group Script

OPENING REMARKS

Introduction of facilitator/note taker

- Remind participants to help themselves to food/beverages.
- Group is scheduled to take 1.5 hours, may take less depending on the response.
- Reimbursements for transportation and childcare, if needed, are available.
- Remind participants that they cannot participate in more than one focus group (i.e., since they are in this one, they cannot attend another one)

Overview of Needs Assessment

- Needs assessment includes focus groups with participants and interviews with providers.
- Information will be used to assist with strategic planning and deciding how best to use funding from the Ryan White grant.

Informed consent and statement of confidentiality

- All discussion at this focus group will be kept strictly confidential.
- No names will be used in reporting focus group information.
- Group will be taped for effective transcription of statements – names will not be attached to any quotes.
- Assignment of individual names (use first names or initials only on name tags) can be real or made up.
- Distribute demographic survey (will be anonymous, but we need some basic information to report and analyze responses)

Ground Rules

- One person speaks at a time.
- Respect the opinions of everyone in the group.
- Talk about what's working as well as what needs improvement.
- Can talk about specific services and specific agencies but not about specific people.
- What is said in the room stays in the room.
- Everyone participates.
- Any other ground rules you want to identify?

Introduction of participants

- Ask each participant to introduce themselves (first name only – feel free to use a made-up name or nickname)
- Icebreaker: tell us something good that happened to you this week

QUESTIONS

Section I: Diagnosis and Primary Medical Care

1. Tell us about how you learned you were HIV-positive and what you did about it.

PROBES:

- a. Where did you first learn you were HIV+ (i.e. what city, what type of setting – doctor’s office, hospital, community, etc.)?
 - b. What were you told about treatment options, or where were you directed to find out this information?
 - c. Have you received HIV-related primary medical care?
 - d. How long was it between when you were diagnosed with HIV and when you first saw a doctor for an HIV related visit?
 - i. If you did not see a doctor right away, what were some of the reasons for the delay?
 - ii. Why did you see a doctor when you did? What were some of the factors that helped get you into care?
 - e. Did you seek out other services before you saw a doctor for an HIV related visit for the first time? What services did you seek?
 - f. Do you have a care coordinator? How long was it between your HIV diagnosis and when you first were connected to care coordination?
- 2. Are you currently receiving HIV-related primary medical care? Have you had a CD4 count and/or viral load test and/or anti-retroviral medication in the last 12 months? [HRSA definition of unmet need]**
- 3. Was there a period in the last 5 years where you didn’t receive HIV related medical care for a year or more? [Uses HRSA unmet need time frame] If so, why?**
- 4. What changes would you make to improve health care services for people like you living with HIV/AIDS?**

Section II: Service Needs and Barriers

1. Beyond medical care, tell us about the service needs of people like you with HIV and AIDS and how well they are being met. PROBES:

- a. What services are most needed?
- b. Which services are hardest to get? Are there any specific issues (such as transportation, child care, financial problems, times services are offered, language barriers, fear of disclosure, stigma, etc.) that make it difficult for you to access services?
- c. What are some of the biggest service gaps and problems for people with HIV and AIDS? Are the services that are available appropriate for you and people like you?

- d. Where do you find out about the services that are available in the Indianapolis area?
If you were interested in finding out about a particular service, who might you ask, or where would you look?
2. **Have you personally been able to get the HIV-related services you have needed over the past 12 months? PROBES:** During the last 12 months, did you need a particular service? What service did you need?
 - a. If yes, did you receive the service?
 - b. If no, why not?
3. **We know it is hard for people who have been in jail to get HIV-related services after they are released. If you have been in jail or know someone well who has been in jail, tell us about his or her experiences.** How does it affect a person's ability to access services? Were there any needs that you or they had right after being released that were difficult to get met?
4. **Before coming to this focus group, were you aware that free services were available to people with HIV and AIDS through the Ryan White program?**
 - a. If yes, how did you hear about Ryan White?
 - b. If no, where would have been the best place for you to find out about Ryan White?
How would you suggest the program let others know that services are available?

Section III: Sub-populations

1. Have you faced any specific challenges or difficulties because of your gender, ethnicity, or sexual orientation?
2. Do you think there are any special needs specific to your gender, ethnicity, or sexual orientation?
 - a. If yes, what are they? Do you think there are adequate services to meet those needs?
3. (For focus groups with Women and Rural Populations, insert supplemental questions)

Section IV: Other Comments

1. Is there anything else you would like to share with us?

THANKS AND CLOSING

We're sorry we are out of time, but this has been a valuable discussion. We'll put together a report summarizing what you have told us. Our plan is to provide this report to local and state level policy makers who are trying to make sure everyone's health needs are being met as much as possible. Thank you very much for your valuable input. We appreciate your time.

QUESTIONS FOR WOMEN FOCUS GROUPS

Section III Supplement:

1. Do you plan to have children in the future?
 - a. Has being HIV+ affected your plans to have children?
2. Do you currently have children?
 - a. If yes, how has that influenced your attitude and decisions surrounding your HIV care?
 - b. How has it influenced your ability to access care?

QUESTIONS FOR RURAL FOCUS GROUPS

Section III Supplement:

1. If you are receiving or have received primary medical care for HIV related reasons, how far do you or did you have to travel to get to your doctor? How far do you have to travel to get to any other services that you utilize?
2. Has the distance you would have to travel ever caused you to not access services you needed, or to access them later than you would have liked?
3. Do you prefer to receive HIV related medical care near your home for convenience, or farther away from your home where services may be more confidential?

Departamento de Salud del Condado Marion
Grupo Control del VIH/SIDA

COMENTARIOS PRELIMINARES

Introducción del Coordinador/Secretario

- Informar a los participantes que hay refrigerios a su disposición.
- La reunión durará una hora y media, pero según la respuesta de los participantes, puede durar menos tiempo.
- El reembolso por transporte y cuidado de los niños está disponible en caso de que sea necesario.
- Recordarle a los participantes que no pueden pertenecer a más de un grupo control, (ej., como ellos ya pertenecen a éste grupo, no pueden acudir a otro)

Revisión de la evaluación de necesidades

- La evaluación de necesidades incluye a los grupos de control y sus participantes y entrevistas con los proveedores.
- La información será usada para ayudar a planificar las estrategias y a decidir la mejor manera de utilizar los fondos de asistencia monetaria otorgado por el programa Ryan White.

Información de autorización y declaración de confidencialidad

- Todas las discusiones que realice éste grupo serán mantenidas en estricta confidencialidad.
- Ningún nombre será utilizado en el reporte que se elabore de la información obtenida del grupo control.
- Las discusiones que el grupo haga serán grabadas para lograr una transcripción efectiva de las declaraciones, pero ningún nombre se adjuntará a ninguna cita
- La asignación de los nombres pueden ser reales o ficticios (se debe utilizar sólo el primer nombre o sus iniciales en las etiquetas)
- Distribuir la encuesta demográfica (la encuesta será anónima, pero necesitamos alguna información básica para reportar y analizar las respuestas)

Normas de comportamiento

- Una sola persona debe hablar a la vez.
- Respetar las opiniones de todos los participantes del grupo.
- Hablar de aquello que está funcionando bien y de lo que necesite mejorarse.
- Se puede hablar sobre servicios y agencias específicas, pero no acerca de personas en específico.
- Lo que se diga en el salón debe permanecer dentro del salón.
- Todos deben participar.
- ¿Hay alguna otra norma (regla) que quisiera incluir?

Introducción de los participantes

- Pídale a cada participante que se identifique (con el primer nombre únicamente, pero si desea, puede usar un nombre ficticio o un apodo)
- Para romper el hielo, cuéntenos algo bueno que le haya ocurrido esta semana.

PREGUNTAS

Sección 1: Diagnóstico y cuidado médico primario

1- Díganos como supo que era VIH positivo y qué hizo al respecto. SONDEO:

- a- ¿Dónde estaba cuando supo que era VIH positivo? (Ej., en qué ciudad, qué tipo de escenario- consultorio médico, hospital, comunidad, etc.?)
- b- ¿Qué le dijeron acerca de las opciones de tratamiento o a dónde lo remitieron para obtener ésta información?
- c- ¿Ha recibido algún tipo de cuidado *médico para tratar* el VIH ?
- d- ¿Cuánto tiempo pasó desde que lo(a) diagnosticaron con VIH hasta que acudió a una cita médica relacionada con el VIH?
 - i- En caso de que no haya visto a un médico inmediatamente, ¿cuáles fueron las razones para la demora?
 - ii- ¿Porqué acudió al doctor en el momento que lo hizo? ¿Cuáles fueron los factores que le ayudaron a conseguir atención médica?
- e- ¿Buscó otro doctor antes de ver al doctor que le brindó atención médica para el VIH por primera vez? ¿Qué servicios buscó?
- f- ¿Tiene un coordinador de servicios médicos ¿Cuánto tiempo transcurrió desde que tuvo su diagnóstico del VIH hasta que se puso en contacto con su coordinador?

2- Actualmente, ¿está recibiendo cuidado médico para tratar el VIH? ¿ En los últimos meses le han hecho un conteo de CD4?, ¿ un examen de su carga viral y/o ha tomado medicina anti- retroviral? (Definición del HRSA acerca de las necesidades no satisfechas)

3- En los últimos cinco años, ¿hubo algún periodo, mayor de un año o más, en el cual no recibió cuidado médico para el VIH? (use el lapso de tiempo establecido por el HRSA para las necesidades no satisfechas) Si fue así, diga porque.

4-¿Qué cambios realizaría para mejorar los servicios para el cuidado de la salud de personas que, como usted, viven con VIH/SIDA?

Sección II: Servicios necesarios y barreras

1- Aparte del cuidado médico, díganos cuales servicios necesitan las personas que, como usted, tienen VIH/SIDA y en qué medida han sido satisfechas.

SONDEO (Preguntar) :

- a- ¿Cuáles son los servicios de mayor necesidad?
- b- ¿Cuáles servicios son los más difíciles de conseguir? ¿Existen algunos problemas específicos que dificulten su acceso a esos servicios? (tales como transporte, cuidado para los niños, problemas financieros, horario de servicios, barreras del lenguaje, miedo a que el diagnóstico del VIH sea divulgado, estigmas, etc.)

- c- ¿Cuáles son algunas de las mayores deficiencias en los servicios y cuáles son los problemas más grandes que enfrentan las personas diagnosticadas con VIH y SIDA.? ¿Son apropiados los servicios disponibles para usted para personas que, como usted, tienen VIH?
- d- ¿En dónde encontró información acerca de los servicios que están disponibles en el área de Indianápolis? Si le interesara obtener información sobre algún servicio en particular, ¿a quién le preguntaría o a dónde acudiría?

2- En los últimos 12 meses, ¿ha podido conseguir servicios relacionados con el VIH? SONDEO (Preguntar): Durante los últimos 12 meses, ¿necesitó algún servicio en particular?

- a- Si respondió “sí”, ¿recibió el servicio?
- b- Si contestó “no”, indique porqué

3- Sabemos que es difícil conseguir servicios relacionados con el VIH después de salir de la cárcel. Si usted o alguien que usted conoce ha estado en la cárcel, cuéntenos sus experiencias. ¿Come se vio afectada la capacidad de usted o de esa persona para conseguir esos servicios?, ¿hubo alguna necesidad que fue difícil de satisfacer poco después de ser liberado?

4- Antes de venir a este Grupo Control, ¿sabía acerca de los servicios gratis que el programa Ryan White ofrece a las personas con VIH y SIDA.

- a- Si contestó que “sí”, ¿cómo supo acerca del programa de Ryan White?
- b- Si contestó que “no”, ¿dónde habría sido el mejor lugar para obtener información acerca de Ryan White? ¿Qué sugerencias tiene para el programa de manera que se puedan dar a conocer que hay servicios disponibles?

Sección III: Subpoblación

- 1- ¿Encontró algún desafío o dificultad específica debido a su sexo, grupo étnico u orientación sexual?
- 2- ¿Usted piensa que existen algunas necesidades específicas para su sexo, grupo étnico u orientación sexual?
 - a- Si contesto “sí”, ¿cuáles son?, ¿piensa que existen los servicios adecuados para satisfacer éstas necesidades?
- 3- Para los Grupos Control de mujeres y poblaciones rurales, inserte las preguntas adicionales.

Sección IV: Otros comentarios

- 1- ¿Le gustaría comentar algo más?

AGRADECIMIENTOS Y CLAUSURA

Sentimos mucho que el tiempo se nos acabó, pero, está fue una discusión muy valiosa. Vamos a reunir y a resumir toda la información que nos brindó y a entregar este reporte a quienes elaboran las normas a nivel estatal y local. Ellos están tratando de que todas las necesidades, en el área de la salud, sean satisfechas lo mejor posible. Gracias por su valioso aporte y por su tiempo.

PREGUNTAS PARA EL GRUPO CONTROL DE MUJERES

Sección III Preguntas suplementarias:

- 1- ¿Planea tener hijos en el futuro?
 - a. ¿Ser VIH positivo afectó sus planes para tener hijos?
- 2- ¿Tiene hijos?
 - a. Si contesto que “sí”, ¿cómo influyó en sus actitudes y decisiones para obtener servicios para el cuidado del VIH?
 - b. ¿Cómo influyó en su habilidad para obtener servicios de salud?

PREGUNTAS PARA LOS GRUPOS CONTROL DE LAS ZONAS RURALES

Sección III Preguntas suplementarias:

- 1- Si actualmente está recibiendo o ha recibido cuidado médico primario por razones relacionadas con el VIH, ¿qué tan lejos tiene que viajar o viajó para ir al doctor? ¿Qué tan lejos tiene que viajar para obtener cualquier otra clase de servicios que usted utiliza?
- 2- ¿La distancia que tenía que viajar alguna vez le ha impedido obtener los servicios que necesitaba o a esperar más tiempo que el deseado?
- 3- ¿Por ser más conveniente prefiere obtener servicios médicos, relacionados con el VIH, más cercanos a su casa o, por el contrario, no importa si están más lejos pero son más confidenciales?