

CHSPAC – COMPREHENSIVE HIV SERVICES PLANNING AND ADVISORY COUNCIL

# Final Results: Indiana Provider Survey

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## A Component of the 2009 HIV Services Needs Assessment

**Needs Assessment Conducted and Report Prepared by**

**Carrie Foote Ph.D.  
Associate Professor of Sociology at IUPUI  
Investigator for the Institute for Research on Social Issues (IRSI)  
Chair of the CHSPAC Evaluation Subcommittee**

**Regina Pessagno, MA Student, IUPUI**

**Sarah Lynn, MA Student, IUPUI**

**In collaboration with  
The Indiana Comprehensive HIV Services Planning and Advisory Council and  
The Indiana State Department of Health**

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To obtain an electronic copy, email Shawn Carney at the ISDH: [Scarney@isdh.IN.gov](mailto:Scarney@isdh.IN.gov)

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#### **Members of the CHSPAC Evaluation Subcommittee**

- Carrie Foote, Chair, Indiana University-Purdue University Indianapolis
- Tammy Dutkowski, Vice Chair, Positive Link Region 10
- Thomas Bauer, Scribe, CAB At-Large District 1,2,3
- Kristen Arnold, HOPWA
- Tracy Droll, CAB District 6
- Portia Duff, Part C Region 7
- Kelli Fuller, Housing Region 8
- Jody Grieb, CAB Representative District 9
- Jessica Hillis, CAB Representative District 2
- Alisha Hooks, Marion County Health Department Part A
- Kevin Johnson, CAB Representative District 7
- Kellie Kaneshiro, Ruth Lilly Medical Library
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- Mike Wallace, Marion County Department of Health
- Kris Wise, AIDS Task Force Region 11
- Jim Helvey, CAB Representative District 3

#### **Spanish Translators**

Crismara Meece, Wishard Infectious Disease, and Rachel Reich, CAB Representative District 11

#### **Dedicated Staff at ISDH**

Lisa Lloyd, Neal Carnes, Darin Foltz, Kristi Montgomery, Shawn Carney, Meredith Upchurch, Satin Hill, and Sara Bradley

#### **Student Staff and Graduate Student Research Assistants at IUPUI**

Jeremiah Sterkel, Asia Danzy, Regina Pessagno, and Sarah Lynn

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## **ACRONYMS IN THE REPORT**

ADAP = AIDS Drug Assistance Program

AIDS = Acquired Immune Deficiency Syndrome

ASO = AIDS Service Organization

CAB = Consumer Advisory Board

CC = Care Coordination

CD4 = T-Helper Cell

CHSPAC = Comprehensive HIV Services Planning and Advisory Council

DHHS = Department of Health and Human Services

EIP = Early Intervention Program

HIAP = Health Insurance Assistance Program

HIV = Human Immunodeficiency Virus

HOPWA = Housing Opportunities for Persons with AIDS

HRSA = Health Resources and Services Administration

ICHIA = Indiana Comprehensive Health Insurance Association

IRB = Institutional Review Board

ISDH = Indiana State Department of Health

IUPUI = Indiana University-Purdue University Indianapolis

MDAP = Medicare Part D Assistance Plan

## CARE COORDINATION REGION LOCATIONS

This list includes the ISDH care coordination region number, major city area in that region, and the region's counties.

Region 1	Gary Area (Lake, Porter, Laporte)
Region 2	South Bend Area (St. Joseph, Marshall, Starke, Elkhart, Fulton, Pulaski)
Region 3	Fort Wayne Area (Allen, Whitley, Dekalb, Huntington, Kosciusko, LaGrange, Wabash, Wells, Adams, Steuben)
Region 4	Lafayette Area (Tippecanoe, Jasper, Newton, White, Carroll, Clinton, Montgomery, Fountain)
Region 5	Muncie Area (Delaware, Grant, Jay, Blackford, Randolph)
Region 6	Anderson Area (Madison, Cass, Miami, Howard, Tipton, Hamilton, Hancock)
Region 7	Indianapolis Area (Marion, Boone, Hendricks, Morgan, Johnson, Shelby)
Region 8	Terre Haute Area (Vigo, Vermillion, Parke, Putnam, Clay, Sullivan)
Region 9	Richmond Area (Wayne, Henry, Rush, Decatur, Ripley, Dearborn, Ohio, Union, Franklin, Fayette)
Region 10	Bloomington Area (Monroe, Brown, Bartholomew, Lawrence, Owen, Greene, Lawrence)
Region 11	Jeffersonville Area (Clark, Switzerland, Jeffersonville, Jennings, Jackson, Orange, Crawford, Floyd, Harrison, Washington, Scott)
Region 12	Evansville Area (Vanderburgh, Posey, Perry, Knox, Daviess, Martin, Pike, Gibson, Dubois, Warrick, Spencer)

## **A. Background and Process**

The Comprehensive HIV Services and Planning Council (CHSPAC) is a community based HIV advisory group to the Indiana State Department of Health (ISDH) HIV/STD Division. The council consists of a variety of HIV providers and HIV-infected men and women representing diverse communities across the state of Indiana. ISDH gave the council the charge to oversee the completion of the 2009 HIV Needs Assessment.

The provider survey reported upon here was part of the 2009 Needs Assessment, which included two components: (1) A survey of people living with HIV/AIDS who are receiving ISDH funded care coordination services, and (2) a HIV provider survey.

A community-based participatory research model was used to complete the needs assessment. This research model brings together professional, university-based researchers with key players in the processes at issue, such as HIV-positive residents and HIV-focused community groups, to produce research that is useful to all participants. Not only do the collaborative efforts of these combined entities yield improved insights on the problems, but they can ensure that the priorities of the relevant community are also addressed in the research. This increases rapport among the parties and will generally greatly increase participation rates. In this instance, it also guarantees that the HIV community has a stake in, and benefits fully from, all of the efforts' outcomes.

Carrie E. Foote, a medical sociologist at IUPUI and the chair of the CHSPAC evaluation subcommittee, directed the proposed research. Dr. Foote was uniquely qualified to direct this project because of her extensive experience conducting applied research on AIDS related issues in Indiana. She has also been HIV positive for over twenty years, and she thus brought a community perspective to the project as a consumer of HIV related care and services in Indiana along with her professional expertise.

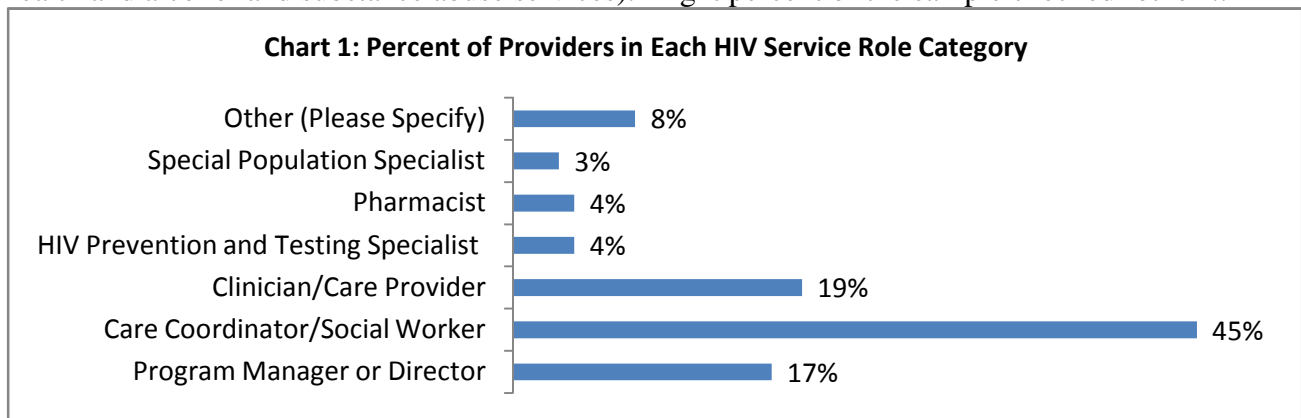
Dr. Foote worked directly with CHSPAC and ISDH to complete the project. The community members who make up the CHSPAC participated in nearly every stage of the research process, from research design, to research implementation, and to reviewing findings and assisting with report dissemination. The team had assistance from two graduate student interns from the IUPUI Department of Sociology. The interns assisted with data entry, data analyses, and report preparation. The study received Institutional Review Board (IRB) approval from the IUPUI-Clarian IRB board (Study # EX0907-12).

Accordingly, the evaluation subcommittee of the Comprehensive HIV Services and Planning Council (CHSPAC) developed and fielded an 11-question survey tool to assess the HIV related needs and gaps in service provision of the Indiana HIV-infected population from the perspective of the providers (See Appendix 1). The responses and results of the provider survey are presented in this report. (The findings of the related consumer survey are presented separately in the Consumer Survey Report.)

## B. Survey Distribution and Response

The target population included HIV service and clinical care providers across the state of Indiana. We emailed 134 providers an internet link to complete the survey using surveymonkey.com. We received 111 surveys. Chart 1 shows the percentage of respondents by service role category.

The majority worked as HIV care coordinators/social workers (45%), followed by HIV clinical providers (19%). Program managers (most of whom were in care coordination) made up 17% of the sample. The remaining providers were HIV prevention and testing specialists (4%), pharmacists (4%), and special population specialists, which included providers working with clients with mental health and substance abuse problems (3%). (These are providers of mental health and alcohol and substance abuse services). Eight percent of the sample checked 'other' .:

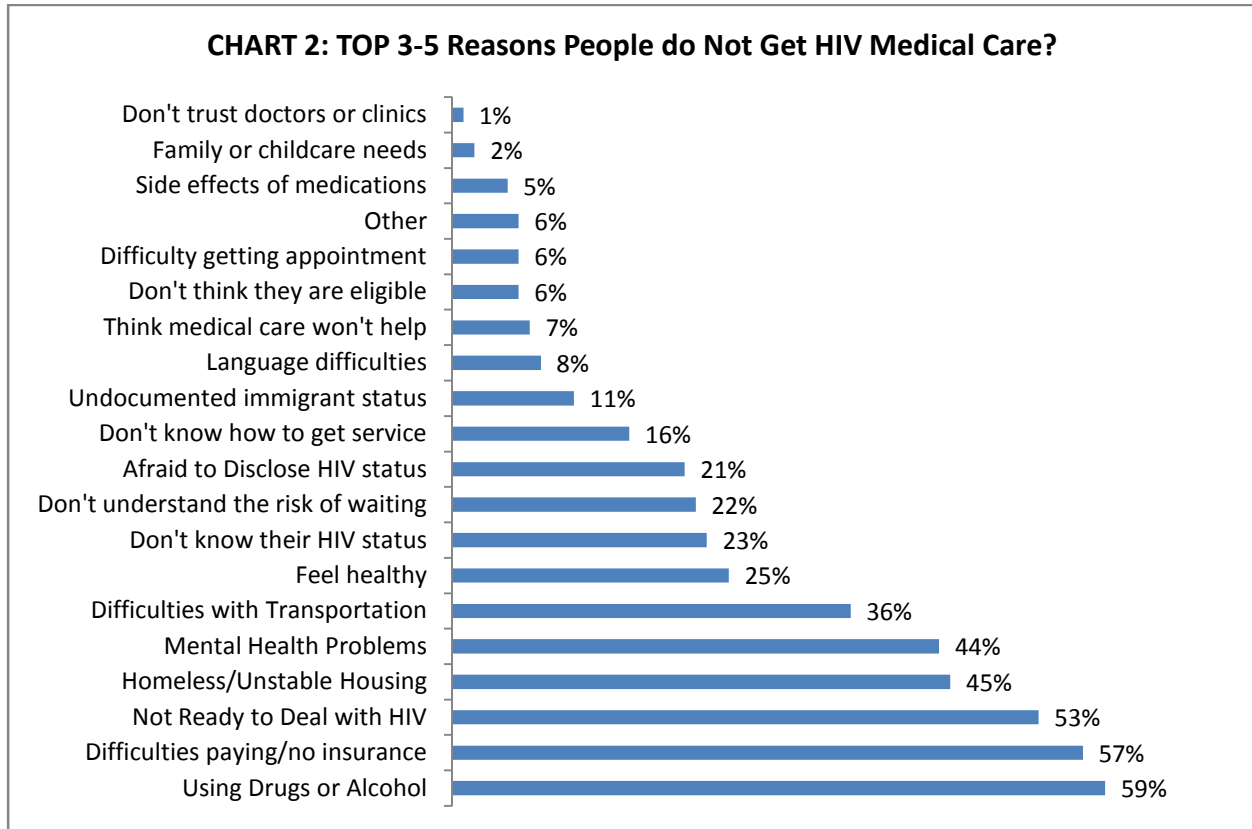


To track return rates, and assess provider experiences in different parts of the state, the surveys asked the provider to identify which of the 12 ISDH HIV care coordination regions he or she served. Table 1 shows survey returns by region and reports the response rate. Of the 134 providers targeted for the survey, 111 completed it. The overall response rate was 83%.

Region	# in Target Sample	# Returned	% of Total	Response Rate
1 Gary Area	16	14	13%	88%
2 South Bend Area	8	6	5%	75%
3 Fort Wayne Area	13	12	11%	92%
4 Lafayette Area	5	4	4%	80%
5 Muncie Area	4	4	4%	100%
6 Anderson Area	4	3	3%	100%
7 Indianapolis Area	52	39	35%	75%
8 Terre Haute Area	3	3	3%	100%
9 Richmond Area	2	2	2%	100%
10 Bloomington Area	7	7	6%	100%
11 Jeffersonville Area	10	9	8%	90%
12 Evansville Area	10	7	6%	70%
Missing		1		
<b>TOTAL</b>	<b>134</b>	<b>111</b>	<b>100%</b>	<b>83%</b>

### C. Reasons for Not Receiving HIV Medical Care

Providers were asked to check what they thought were the TOP 3-5 reasons that some HIV-positive people are not getting HIV medical care. Each respondent could check up to five of 21 categories. Nearly all of the providers completed the question (N=104). Chart 3 reports these findings.

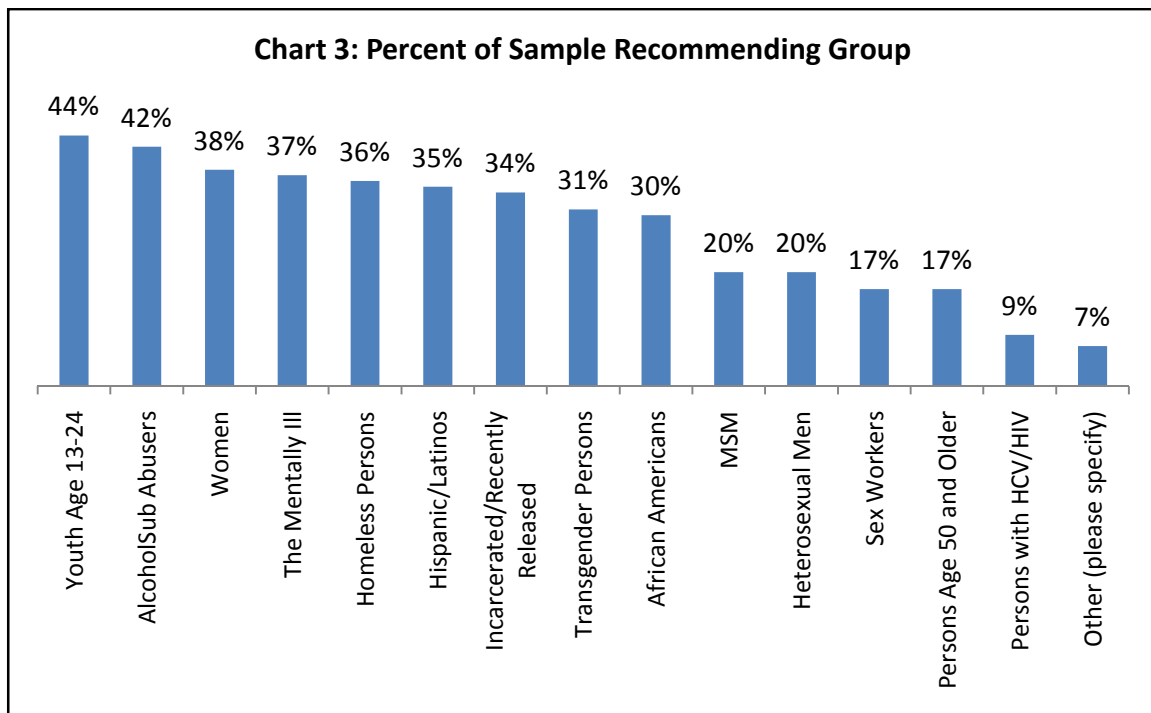


Nearly 60% of the sample felt that using drugs or alcohol (59%) or difficulties paying for health care (57%) were the main reasons for not receiving care. This was followed closely by clients not being ready to deal with HIV (53%), homelessness or unstable housing (45%), mental health problems (44%) and difficulties with transportation (36%).

Six percent of the providers checked the other category and specified the following reasons there: not being able to get off of work for an appointment, lack of client effort or responsibility, legal issues, lack of direct linkage to care from testing site, and no outside support system to encourage care.

## D. Recommended Focus Groups

Providers were given a list of 15 special populations affected by HIV/AIDS (e.g., women, African Americans, youth). They were then asked to check up to five of these groups that they thought were the most important groups to assess their HIV related needs using focus groups. Chart 4 presents the results. Just under half the sample felt it was critical to conduct groups with youth age 13-24 (44%) and persons with alcohol and substance abuse problems (42%). Other important groups were women, the mentally ill, the homeless, Hispanics, and the incarcerated or recently released.



Although only 7% of the sample checked the other category, it's important to note that these groups included the following special populations: Three people listed the Burmese population in the Fort Wayne area, one mentioned races other than White, another mentioned refugees, and the final person mentioned combined groups – African American and Hispanic men who have sex with men (MSM).

**Important Note:** Several of these groups are federally defined protected research populations and should have oversight by an institutional IRB board to insure the ethical conduct of research.

## E. Integration of Care and Services

Three questions asked about how, if at all, the provider's clinic or agency coordinates their services with providers of alcohol and substance abuse services, and/or mental health services. These questions and the providers' responses are presented below.

Nearly all of the providers engage in referral services (96%). Some of these providers do not have a way of tracking referrals for alcohol and substance abuse (10%) or mental health services (11%). Others are unaware of whether tracking mechanisms exist (14% and 10% for each respective service). About 30% of the providers rarely or never experience difficulties making referrals. About half experience difficulties sometimes, and just under 25% experience difficulties most of the time or all of the time.

### 1. Does your agency/clinic ever refer their HIV-positive clientele for alcohol abuse, substance abuse, or mental health services? (N=105)

	<u>%</u>	<u>N</u>
Yes	96%	101
No	4%	4

### 2. Does your agency/clinic have a way of tracking referrals (such as by paper, computer) made to agencies providing... (N=Region 101)

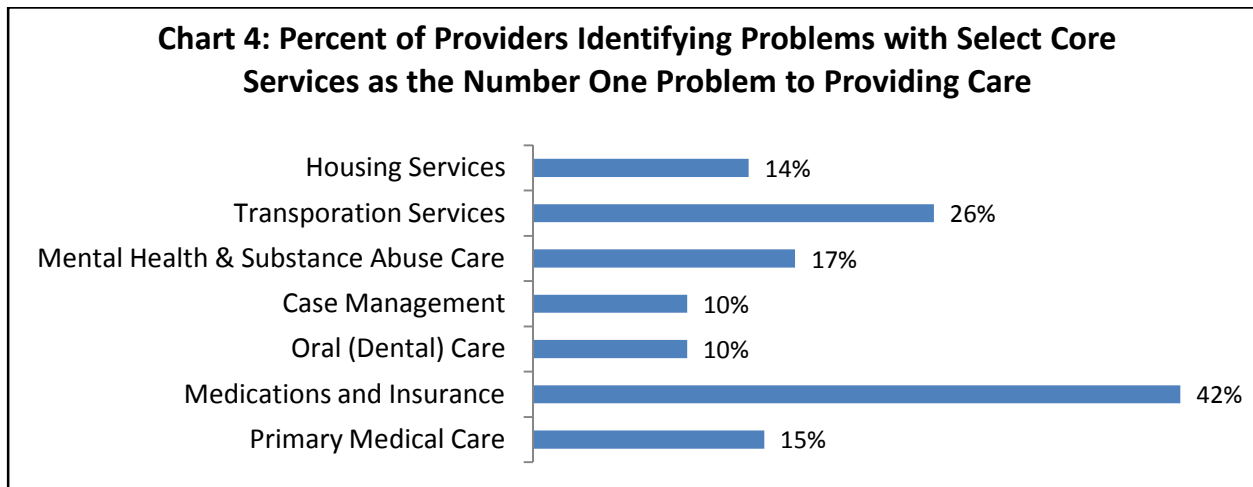
	<u>Yes</u>	<u>No</u>	<u>DK</u>
alcohol and substance abuse services?	76%	10%	14%
mental health services?	79%	11%	10%

### 3. How often do you (or your agency/clinic) face difficulties when making referrals for... (N=Region 101)

	<u>Never-Rarely</u>	<u>Some Times</u>	<u>Most-All Times</u>
alcohol and substance abuse services?	28%	50%	22%
mental health services?	32%	43%	25%

## F. Biggest Problem Providing Services and Recommended Changes

**Biggest Problem:** The questionnaire asked providers to “*briefly describe the biggest problem that you have faced when providing care or services to people living with HIV/AIDS*”. Nearly all of the providers answered this question (87%). The chart below summarizes the percent of providers identifying problems providing the eight HIV-related services identified by ISDH as priority funding area (Chart 1). (These services also correspond to HRSA Core service areas).



Among the priority services, providers had the most problems with clients’ access to medications and adequate health insurance coverage (42%), followed by barriers to care services due to the lack of transportation (26%), difficulties associated with clients’ mental health and/or substance abuse concerns (17%), and difficulties meeting housing needs (14%). They were less likely to identify problems associated with case management and dental care as the number one problem experienced when providing services.

Analyses of their answers provide insights into the difficulties providers encounter when trying to meet the needs of their HIV positive clientele. Below we provide a summary of the findings in each category and then follow this with illustrative quotes that support the summary. In addition, we also include a section on “problems that cross service categories”. Quotes include the provider’s region. The service role was not included to protect the participant’s identity. Some service regions only have one clinical provider and as such the provider could easily be identified.

**Recommended Changes:** The questionnaire also asked Providers to “*briefly describe the single most important change (other than increased funding, per se) that you would recommend for improving the provision of HIV related care and/or support services for people living with HIV/AIDS in Indiana.*” Just over three quarters of the providers answered this question (80%). The providers’ recommendations are presented below and follow the discussion of the problems.

## **F1. Primary Medical Care**

Providers mentioned several problems related to receiving and accessing primary HIV care. These included difficulties getting prompt HIV care for the newly diagnosed, the lack of infectious disease providers in their region, insensitive providers, and difficulties scheduling appointments and returning calls regarding HIV primary care. These themes are illustrated below.

### **Lacking Prompt HIV Care for the Newly Diagnosed**

- We provide counseling and testing. Therefore, we get the newly diagnosed clients. We also follow up on individuals newly diagnosed in the community, (ERs, DOC, etc). PROMPT access to medical care (physical and mental) when uninsured is the biggest problem we face. When a client learns they are HIV +, it WOULD BE IDEAL to draw the initial labs (CD4s, Viral Loads, etc) and schedule them an appointment with a doctor to review the labs and start a care plan within the week. The drawn out time from diagnosis to doctor visit seems to increase anxiety for clients (Region 3).
- Making sure those clients who test positive get into services and care in a timely manner (Region 7). Access to health care after initial testing (Region 8).
- Prompt Viral load/CD4 count testing after HIV seropositive confirmed (Region 7).
- No treatment on demand for clients (Region 7).

### **Needing More Infectious Disease Doctors and Physician Sensitivity Training**

- Lack of qualified infectious disease specialists in the immediate area. Most of our client's have to go to Indianapolis (Region 9).
- Finding adult providers to transition pediatric patients to at the appropriate time as few want to take on the prenatally infected (Region 7).
- The availability of Primary Care Physicians and GYN Services expert and sensitive to the physical, social and psychological needs of our patients. Often our patients have difficulty choosing, and feeling comfortable seeing other providers (Region 7).
- We do not have an Immunologist that comes to our hospital. Patients have to go to Columbus Regional for care; that physician is only there a limited amount of time because he comes to CRH from Indianapolis (Region 11).
- There also seems to be an issue with competent primary care providers, especially those who are willing to work openly with gay / transgendered clients. Our Infectious Disease office is also very busy at this time, and I have a number of clients who have complained to me about the timeliness of returned calls / scheduled appointments with the office. There is also no choice of provider (in regards to Infectious Disease specialists) when it comes to our area, either the client goes to the doctor in FW, or they are referred to providers in Indy and South Bend, which is problematic for clients with transportation issues (Region 3).
- There is also a massive lack of Infectious Disease Doctors in rural areas of the state. All of our clients have to go to Indianapolis for Infectious Disease Care. For many clients

there are no transportation resources to get them to Indianapolis--even if gas cards are provided, the actual transportation is not available (Region 6).

- We don't have enough Doctor's in our area willing to work with people that have HIV (Region 2).
- Access to care. I am the primary provider for HIV. I have no coverage for hospital work. When I retire, there will be a very sizeable population of folks who will be left high and dry (in the present circumstances) (Region 2).
- Limited clinic time to schedule all patients in a timely fashion, e.g. new patients w/in 4 wks. of referral, follow-up patients every 3 months, insufficient appointment slots for triage appointments (Region 11).

### **Recommended Changes**

#### **Need for More HIV Clinical Providers, More Affordable Care, and Home Health Care**

- More Infectious Disease practitioners, larger choice of doctors, better access to medical care in rural areas (Region 7).
- Recruit more medical providers (physicians, nurse practitioners, physician's assistants) who are interested in treating HIV infected patients (Region 11).
- Our region needs additional Infectious Disease providers (Region 10).
- Increased access to medical care. In Lafayette there are only 2 infectious disease doctors. Many clients travel to Indy for ID care. A third ID doctor in the area would help clients with transportation costs to Indy (Region 4).
- Access to more medical care options (Region 12).
- Access to affordable, personalized care (Region 3).
- Establishment of a Title III care site in South Bend (Region 2).
- Expanding HIV specific hospice/home health care facilities (resources for enrollment) (Region 7).
- Educating and recruiting primary care physicians concerning HIV's general impact on other health concerns (Region 3).

## **F2. HIV-Related Medication and Health Insurance**

The biggest problems cited by providers had to do with helping clients to get medications and problems associated with lack of, or insufficient, health insurance coverage. Problems included those typically associated with clients who have insurance such as difficulties paying for co-pays, deductibles, spend-downs, and other out-of-pocket costs. They also included problems getting health insurance or medication assistance in a timely manner for those who are eligible for public insurance programs or medication assistance programs. Finally, they included problems providing medical care for the uninsured and helping clients apply for, and understand, the different public insurance programs and the services covered by those programs. These themes are illustrated below.

### **Getting HIV Medications**

- Lack of access to medications for persons who are uninsured or underinsured (Region 5). Lack of agency funds for medication (Region 2). Access to medications for insured individuals (Region 7). Access to meds (Region 1). Ability to afford their medication (Region 3). They can't afford meds (Region 7). Getting access to funds that I know exist for meds (Region 7). Access to medications and medical care (Region 7).
- Medication cost assistance for people that do not qualify for Medicare or ISDH programs. There is a large group of patients that have \$2000 deductibles each year or have \$250+ copays on their meds. We try to work with them the best we can, but in the end, we cannot give out the meds for free. The co-pay assistance cards from the manufacturers have helped (Region 7).
- The cost of medications, even when folks have insurance, seems to be unmanageable for many. Also, having funds to pay for basic needs (food, housing and transportation) when too sick to work has been an issue for many (Region 10).
- Patients unable to pay for medication (Region 3).
- Insufficient funds for medications to treat HIV-related conditions that are not covered by pharmaceutical assistance programs for patients w/o insurance coverage (Region 11).
- The inability of certain patients to be able to access antiretroviral agents quickly (Region 7).
- Medication co-pays assistance for clients who are working (Region 1).

### **Affording Insurance and Out-of-Pocket Costs**

- It is difficult for patients to find affordable prescription insurance. The patients who have private insurance available to them can rarely afford the co-pays, but are ineligible for additional assistance (Region 7).
- High co-pays (Region 7). Copay (Region 1). Costs of services, co-pays, high applicable deductibles (Region 3). Clients who have insurance but still cannot afford their co-pays for meds (Region 3). High Medicaid spend-down amounts (Region 11).
- I often feel that there are programs for folks who are not working (often times by choice) but for those who need medication and they have medical coverage (via work based

insurance coverage) and their co-pay, deductible or spend down is too high, and then they are left without assistance. This is very frustrating and unbalanced (Region 7).

- Additionally, when ICHIA chose to stop paying for Vaccines at the end of 2008, this created a huge problem for a number of clients who need vaccinations such as Flu Shot and Pneumovax Shot. These are now not covered by ICHIA, nor is it being picked up - therefore the client is becoming responsible for the bill - and some providers have threatened to cut off client from med services until their vaccination bill (usually around \$85) are paid for - this creates a huge problem (Region 4).

### **Getting Health Insurance in a Timely Manner and Frustrating and Complicated Application Processes**

- Neal Carnes is awesome, but there is always a large wait list for ICHIA (Region 3). Insurance waiting list for HIAP/ICHIA/ADAP/EIP (Region 3). The waiting list for getting people on ADAP/ ICHIA (Region 3).
- The greatest obstacle I have faced in providing services to clients is the ICHIA insurance process. Assisting in navigating clients through Medicaid and ICHIA application is a long process. This problem is magnified when a waiting list is present (Region 3).
- Healthcare/medications-- while I do think that the IDSH HIV Medical Services programs provide a great service to our clients and I do appreciate them, there is limited funding which means a lot of waiting and having to jump through several hoops. If a client comes to me with a very immediate need for medications and/or lab work and/or medical care, there are very few, if any, referrals I can make and very few resources for clients to utilize. I can refer them to the Volunteers in Medicine clinic, but there is generally a wait-list and that takes time and they also have to qualify. I can help them apply for Patient Assistance Programs, but that includes a lengthy application process and also takes time. I can help them apply for Bloomington Hospital charity/indigent patient program, but that takes time and they also have to qualify. I can help them apply for ICHIA/ISDH programs, but that is a VERY lengthy application process, takes a great deal of time, and they have to qualify. There are no quick solutions for helping people who are uninsured access medical care and medications. And what about those who don't qualify for any of these programs?? What am I supposed to tell them?? Sorry about your luck?? (Region 10).
- I have problems trying to get medical care for my people living with HIV/AIDS. So many are unable to get insurance due to lack of jobs in our area, waiting list for ICHIA, and not being eligible for Medicaid. We have to continue to send them back for Medicaid when we know they don't qualify to keep their ICHIA and this makes them angry because the staff at Medicaid are short with them and want to know why they are applying for Medicaid when the only health problem they have is HIV and we know they can't provide health care for them (Region 2).
- PROMPT access to medical care (physical and mental) when uninsured is the biggest problem we face (Region 3).
- Little funding to help those during the insurance waiting list (Region 3).

- Helping them understand the insurance process and what they need to do to get help. For example, the process for Ryan White is a bit overwhelming for the client and then when I add in that this is a temporary supplement and they still need to apply for Medicaid/Medicare and/or ICHIA they really become confused and overwhelmed. The process is complicated for clients that have never dealt with these issues before (Region 7).

### **Uninsured/Underinsured**

- Underinsurance and no insurance are big issues (Region 7). Lack of insurance (Region 1). Uninsured patients (Region 3).
- The lack of services for individuals who are new and do not have insurance and need medical care to facilitate the applications for Medicaid and ICHIA (Region 8).
- Most clients are not insured and we have only two providers in our area. Neither one provides pro bono services (Region 8).
- Patient's with inadequate health insurance that makes them ineligible for any assistance (Region 7).

### **Other Insurance Problems**

- Dealing with the privatized Medicaid system is also very difficult and requires a lot of valuable time (Region 5).
- Limits in program for insurance (Region 12).
- Working class insurance issues (Region 7).
- Poor reimbursement for care (Region 7).
- Medicare D donut hole private insurance costs/stipulations (Region 11).
- The Medicaid system (we are part of the pilot program) is probably the largest barrier (Region 5).

## **Recommended Changes**

### **Improve Medicaid**

- Easier access to programs. Getting access to Medicaid is a nightmare and impossible for clients to navigate (Region 10).
- Advocacy with Medicaid Office of Policy and Planning. Recent changes have resulted in HIV positive individuals having huge spend-downs (one client on my caseload with upwards of \$1900 per month) rather than being denied based on income. The fact they are eligible for Medicaid with a huge spend-down makes them ineligible for ICHIA/ISDH programs; the result-they cannot access services or meds (Region 7).

### **Need for Universal Coverage**

- Universal Health Care / Insurance for everyone, thereby eliminating the necessity for 12 different private companies in Indiana to handle Medicaid poorly, solving the problem of high co-pays for HIV medications for those who have insurance, providing consistency of medical care and accessibility to that care (Region 3).
- There is an uneven distribution of assistance. People who are willing to work and have work based insurance often times have a very difficult time paying the \$400.00+ copays on their medication coverage. It appears they are being penalized for being a responsible and contributory member of society. Very few programs (if any) assist people with co-pay. Due to the great diversity of those living with HIV, I find it very difficult to find ONE single recommendation, outside of make access to care (including treatment) equal for ALL, not just those who choose not to work (Region 7).

### **Expansion of State Funded Health Insurance to Cover Dental and Vision Care**

- Allowing ICHIA to cover Dental and Eye exams. I have recently had a few clients unable to get dental services in a timely manner and have reoccurring infections because they were unable to pay for dental costs (Region 9).

### **Simplify Application Process and Reduce Wait List**

- The process for receiving free/discount medications through the task force must be more streamlined; I think patients have to wait too long to find out if they qualify (Region 3).
- An easier method of getting approved for health insurance (Region 1).
- Decrease the medical services waiting list (Region 10).

### **Addressing the Needs of the Uninsured or Underinsured**

- Spreading out the wealth a little. ICHIA covers everything but I have pts that don't qualify that have TERRIBLE insurance plans (Region 7).
- Lesser restrictions for insurance programs, e.g. Medicaid, ICHIA, Medicare (Region 11).
- Changing the way we do ADAP so more people can be covered and people getting out of prison/moving here from another state won't have a gap in medical care (Region 3).

### **Other Suggestions**

- Identify providers who accept the HIP plan, Medicaid and Medicare plans (Region 7).
- Allow reimbursement to pharmacy providers for medication therapy management. This would allow time for pharmacists in all settings to provide one on one patient counseling and management. Since pharmacotherapy is the key treatment for HIV it only makes sense to focus future funding in this area (Region 1).

### **F3. Oral (Dental) and Vision Health**

A few of the providers identified dental and/or vision care as the largest barrier encountered. Problems included the lack of insurance coverage for dental and vision care, lack of providers who accept the state funded dental programs, and need for more HIV related education for Dentists.

#### **Lack of Coverage for Dental and/or Vision Care**

- Several clients are in need of dental care but are without coverage for the services they need (Region 6).
- Client's need more access to dental care (Region 12).
- Lack of resources to meet the clients' needs-funds for dental care, optical care (Region 6).
- Dental care is almost impossible to get (Region 2).
- Dental issues continue to plague a good amount of clients, but outside of a basic cleaning at IU Northwest, little in the way of advanced dental/ortho care exists (Region 1).
- Little to no adequate access to dental or vision services for clients (Region 12).
- There are limited dental options for clients here (Region 11).
- Dental services (Region 1).

#### **State Funded Dental Insurance Programs and Educating Dentist**

- Not having enough Dental referrals or dentists who accept EIP. The East Chicago Community Health Center months ago lost the only dentist who is based on a sliding fee scale and accepted EIP (Region 1).
- Finding dental providers, as there are very few in the area that will accept ISDH insurance, and other insurance does not cover it. Also a lack of education re: HIV for dentists (Region 12).

### **Recommended Changes**

#### **Need for Better Access to Dental Care**

- More dental coverage/assistance and transportation (Region 6).
- Provide preventative dental care & oral surgery for dentures (because of recurring infections leading to heart problems, sinus problems, potential for septicemia (Region 4).
- Access to more dental and medical care options (Region 12).
- Access to dental care (Region 12).
- Clients could really use better access to dental care (Region 11).

## **F4. Case Management**

The providers mentioned several problems that dealt with providing case management, i.e., care coordination services. These included having large caseloads, care coordinators lacking knowledge about services, the lack of collaboration with care coordinators, lack of on-site care coordination services, lengthy time it takes to help clients access services, and problems working with clients whose primary language is not English.

### **High Case Loads**

- Carrying a caseload that is way too large (Region 7).
- My region is very spread out. I spend a lot of time driving to meet clients at their homes. As my caseload expands, I feel I am not spending as much time with each client (Region 5).
- Not being able to invest the time in each person that I would like to (Region 7).
- Have increased our programming significantly but not our staffing. Funds for staff salary are limited, so staff are doing more and more, both in terms of the number of clients we see and the level of services we offer (Region 10).

### **Not Knowing about Services**

- Having care coordinators educated on services that are available (Region 7).
- Finding care coordinators that know available services (Region 7).

### **Lack of On-Site Services and Inadequate Collaboration among Providers**

- A lack of understanding from the service providers regarding the need for collaboration between them and the Care Coordinators (Region 6).
- Lack of SW services in our clinic (Region 7).

### **Language Problems**

- It has been a problem working with clients that only speak Spanish. Often an interpreter is a family member, so there are fewer options for the client to keep their confidentiality (Region 4).
- Some of the biggest problems I face is with the Burmese community. We only have a part-time translator therefore providing services can be difficult. Especially, when they do not read or write even Burmese (Region 3).
- Insurance confusion: what the first cards pay and will not pay is hard for my Spanish speaking ct's and ct's that get confused easy (Region 4).

### **Lengthy Time it Often Takes to help Clients Access Services**

- The length of time to get services in place (Region 10). Waiting lists for services or having to jump through hoops to get services (Region 3).
- Another problem would always be people with unique circumstances, which cannot be helped. Some come with no ID, no birth certificate, they have NOTHING! Jumping

through hoops in order to help these always takes a great deal of time, therefore it is hard to obtain the services that they may need right away (Region 3).

### **Additional Difficulties Providing Case Management**

- Consistent collaboration of other providers (Region 12).
- Inconsistent information from ISDH re: application rules, regulations, worrying about losing funding if receive incorrect information (Region 12).
- We do a lot of referring to programs that never seem to provide ultimate aid or help to the client (Region 1).
- PAP's are a problem because if you let the ct take charge of getting the signatures of the doctors they lose it, forget about it, or just do not do it, and the ct never gets their medication. If We take care of it, We are constantly in the doctor's office requesting signatures. The program is time consuming. First enter the ct QR, then update the care plans on another screen, If the care plan is not there you have to go to another screen and add it. and then go back to the previous screen and update it. and so on. The fact that you can add more than one of the same days in the computer is a problem (Region 4).

## **Recommended Changes**

### **Implement Stricter Requirements to Become a Care Coordinator**

- Mandatory social work or related field degree to be a care coordinator (Region 7).
- Agencies should be run from a social work perspective - client empowered. Social workers should be hired as Care Coordinators if at all possible (Region 7).

### **Improve Follow Up With Clients and Reduce Case Loads**

- All care coordinators following through with clients to help prevent the number of client transfers that seem to occur (Region 7).
- More care coordinators that have lower case loads to allow us to provide better service to each client (Region 7).

### **Eliminate Travel Barriers**

- Satellite offices would be very helpful. I think people would be more inclined to get the help that they needed if they didn't have to travel so far to get it. Or just more CC offices in general—decreasing the size of the coverage areas (Region 10).

### **Simplify Service Qualification Procedure**

- Quit changing requirements for things. I know that it is important to have proper documentation, but when things change constantly then we have to spend more time worrying about paperwork and less time with clients (Region 3).

- Reducing the amount of paperwork a person has to complete in order to receive services. Some clients do not come in for reviews or services after seeing the amount of paperwork required (Region 12).
- Making the process for accessing services a little easier. For example Care Coordinators should be able to access the state case workers that deal with Medicaid to help advocate for our clients, answer questions etc (Region 1).
- When someone is denied Medicaid they should not have to reapply unless their health care needs change enough to allow them to qualify for Medicaid. This would take some work off both the care coordinator's and the Medicaid case workers (Region 2).

## **F5. Mental Health and Substance Abuse Treatment**

Clients with mental health and/or substance abuse problems can be among the most challenging clients to serve. Providers noted that challenges stem from the lack of coordination between medical and mental health/substance abuse providers, impairment from these problems that make it difficult for clients to follow through with referrals, insufficient availability of services, not addressing these issues, limited kinds of substance abuse programs (nearly all follow 12-step and abstinence only philosophies; lack of harm-reduction based programs), and long waiting lists to receive mental health and/or substance abuse care.

- Access to mental health services (Region 7). Psych support (Region 1). Getting clients in counseling services (Region 7). Depression, alcohol and drug abuse (Region 3). Substance abuse (Region 7).
- Convincing some patients that they need psychological or psychiatric services. Lack of drug dependence treatment and rehabilitation programs (Region 5).
- Lack of mental health services available, and clients' mental health issues not being addressed (Region 12).
- Dual, triple diagnoses of mental illness, addictions, HIV or AIDS making access to care, consistent treatment, and good decision making problematic (Region 3).
- My biggest issue at the moment is a chronically homeless individual; it is difficult to gain and maintain benefits and appointments for someone with no home, no phone, and no means of contacting the person outside of drop-in appointments; for this individual there is a gap in services between medical care and mental health treatment (Region 3).
- Drug and alcohol abuse and lack of treatment resources are problematic. Difficulty in accessing psychiatric care is a big problem, too (Region 7).
- We also have a large population of substance users and we provide the clients with the referrals and resources and they are unable to follow through (Region 9).
- Mental health care has a waiting list for months before anyone can be seen (Region 2).
- Difficulty finding SA treatment other than 12 step programming. Detox and in-patient psych and SA continues to become more and more difficult to find (Region 10).
- Many substance abuse treatment providers operate under an "Abstinence Only" practice, which prevents many of our consumers from participating in treatment programs. Sometimes even legitimately prescribed medications prevent consumers from attending substance abuse treatment programs (Region 6).
- Research is finding that HIV can cause anxiety and various mental health issues for individuals diagnosed with HIV. This plays a role in substance use and recovery. These two issues cannot be separate, substance use and mental health in the HIV+ (Region 11).
- For those uninsured and facing either drug/alcohol addiction, no access to inpatient treatment. This same issue applies to those with mental illness requiring hospitalization and psychiatric care by a Psychiatrist (Region 11).

## **Recommended Changes**

### **Early Assessment of Need**

- When a client is newly diagnosed with HIV and seeking services assessments for mental health and substance issues should be done early as part of treatment and care plans (Region 11).
- Ready availability of psychiatric and psychological services. I think this should be addressed at time of persons entry into HIV care program (Region 5).

### **Improve Access to Mental Health Medications**

- Easier access to medications for mental health issues would be my first response (Region 3).

### **General Need for More MHSA Services**

- More resources. Limited mental health and substance programs in the area. Limited support groups (Region 11).
- Better access to mental health services (Region 12).
- Broaden availability of effective drug/alcohol/psychiatric services (Region 7).
- More support for psych/anxiety issues (Region 7).
- Provision of support groups and activities for individuals to be involved in (Region 1).
- Finding a way to help people feel less isolated/alone (Region 10).

## **F6. Transportation**

Transportation was identified as a major problem providing services. Lacking transportation makes it difficult for clients to get to places of need. As a result, the lack of transportation can lead to missed care coordination and HIV care appointments.

### **General Transportation**

- Transportation (Region 2). Transportation (Region 12). Transportation is often our greatest challenge (Region Region 7). Transportation issues (Region 1). Also, transportation is a BIG problem (Region 7). Transportation (Region 1). Access to office transport (Region 1). Transportation services (Region 1). Transportation (Region 9). Obtaining transportation to their appointments (Region 7). Transportation (Region 7). Transportation issues (Region 1). Transportation (Region 1). Lack transportation (Region 1). Lack of transportation services (Region 1). Lack of transportation (Region 11).
- Transportation: The client has limited means to get to doctor visits, agency, and other places of need (Township office, etc.) (Region 1).
- Transportation needs. We are able to provide bus tickets which helps. Although I think that if patients had a driver pick them up and return them home, missed appointments would decrease (Region 7). My clients often have limited access to transportation for appointments (Region 11).

### **Transportation for Rural and Long-Distance Clients**

- Transportation for rural clients (Region 3).
- There is also no choice of provider (in regards to ID specialists) in our area, either the client goes to the doctor in FW, or they are referred to providers in Indy and South Bend, which is problematic for clients with transportation issues (Region 3).
- All of our clients have to go to Indianapolis for Infectious Disease Care. For many clients there are no transportation resources to get them to Indianapolis--even if gas cards are provided, the actual transportation is not available (Region 6).
- Transportation to medical visits, especially those who live outside of Marion county (Region 7).
- Transportation-- we serve a very large area (6 counties) and most of those counties are very rural and do not have any form of public transportation. It is very difficult and expensive for clients to make it to the main office for meetings and due to the large caseloads that Care Coordinators carry, it is difficult to make frequent trips to meet with clients in the surrounding counties. Some sort of transportation system that was specific to Care Coordination sites would be really helpful (Region 10).
- Transportation issues for patients living 40-60 miles from the clinic (Region 11).

### **Recommended Changes**

- A fleet for transportation for consumer's w/o transportation (Region 1). More transportation (12). Better access to transportation (24). Better transportation in the rural areas (Region 11). Making more transportation available (Region 6)

## **F7. Housing**

There is a shortage of affordable and safe housing. Providers also had concerns regarding wait lists for public housing assistance and obtaining services for homeless clients.

### **General Housing**

- Lack of housing resources (Region 7). Homelessness (Region 12). Finding someone who will look past their past credit history and rent to them (Region 1). Limited housing options for clients (Region 11). Housing assistance (Region 1). Shortage of affordable housing or housing vouchers (Region 3). Providing funds to assist with housing and other household needs (Region 7). Obtaining stable income to maintain housing (Region 6). Finding affordable/pleasing housing (Region 7)

### **Specific Issues with HOPWA and/or Section 8**

- Rent assistance from HOPWA take too long up to three weeks. Another problem with them is Rules for HOWPA change for example one request must have proof of community services and the next request may not (Region 4).
- There is limited funding for ALL housing resources and almost always a waitlist. I can have them apply for Section 8, Public Housing, and HOPWA programs, but they all have waitlist and oftentimes (at least in Bloomington) Section 8 and Public Housing are not accepting applications. If the client has absolutely nowhere to live, our homeless shelter network in Bloomington is poor. Of our two homeless shelters, one is not 24 hours and has very limited space. The other is run by a religious organization which requires people to attend church regularly and abide by other strict, unnecessary rules (Region 10).
- With section 8 waiting lists closed for several months, just because housing dollars are available does not mean that actual housing is available between HOPWA, Section 8 and other community housing resources. Housing seems to be the biggest resource that will keep clients engaged in medical health services. We need to ramp up housing resources so we don't just process moot applications for which there is no funding (Region 7).

### **Homelessness as a Barrier to Care**

- My biggest issue is a chronically homeless individual; it is difficult to gain and maintain benefits and appointments for someone with no home, no phone, and no means of contacting the person outside of drop-in appointments; for this individual there is a gap in services between medical care and mental health treatment, also - there is no key provider to assist with transitional housing, which makes it difficult to assist the client in succeeding with long-term housing placement (Region 3).

### **Recommended Changes**

- Decrease restrictions for housing and other financial assistance to enable more extensive assistance and supportive services (Region 12).
- Practical alternatives for accessing financial and housing resources besides Township Trustees offices which are already saturated (Region 7).

## **F8. Problems that Cross Service Categories**

Finally, when asked about the biggest problems that the providers experienced several providers mention issues that cross service categories. These issues can make it difficult for clients to access a variety of services. This also means that addressing these issues may also help providers better serve clients across a variety of services. The major theme in this category included issues located at the level of the client such as the client's difficulties with adherence, following through with appointments, lack of responsibility, and attitudes of entitlement. Lesser mentioned themes included AIDS stigma, the lack of general resources such as funding, poverty, limited community support and the lack of HIV education for providers and at-risk groups. These themes are illustrated below.

### **Client Issues and Expectations**

#### *Adherence and Compliance Issues*

- Clients non-adherent behavior (Region 7). Client compliance is a huge issue that we face (Region 7). Noncompliance on the part of the client (Region 2). Non-compliance on the client's end (Region 11)
- Ongoing issues with compliance in the days when attention to the devastation of the disease is rarely reported in the media (Region 7).
- Difficulty impressing upon patients the importance of compliance (Region 7).

#### *Client's Lack of Following Through*

- Clients not making appointments (Region 7). Client's lack of follow through with plans of care (Region 2). Lost to follow-up (Region 7). Correct contact information; little follow through by clients (Region 12).
- Getting the patients to make all of their clinic and out of clinic test appointments (Region 7).
- Problems continue with clients who attend an initial appointment at care coordination, but then through lack of follow up (Region 1).
- We also have a large population of substance users and we provide the clients with the referrals and resources and they are unable to follow through (Region 9).
- It is sometimes difficult to follow-up on clients issues because some clients frequently drop in and out of care. Because of this, you sometimes have to try to get as much done in each session as possible and it can be overwhelming at times (Region 7).
- Clients not having an understanding of their own role in their care--expecting the Care Coordinators to do everything and then clients not following through (Region 6).

#### *Client Responsibility*

- The inability for those diagnosed w/HIV/AIDS to assume responsibility for their care. I do not speak of those mentally unstable or those w/extreme substance abuse concerns (Region 1).

- Lack of "care" from the client as far as being responsible for self, which usually results in lack of compliancy (Region 2).
- It is easy to fill out an application with a client and then send them on their way, but what is more sustainable and more effective is to try and help them and to challenge them to live their life in more manageable and sustainable ways. This is a process that often takes more than one hour every 2 weeks (Region 7).

#### *Attitudes of Entitlement*

- A big problem is clients' feelings of entitlement, especially when it comes to financial assistance. Too many clients feel that because they have HIV/AIDS they should be given financial assistance whenever they ask and for any reason they have. Too many clients do not want to be self-sufficient and feel they don't have to take the same steps as the rest of the community in need (Region 2).
- Secondly, the greatest problem faced would be empowering clients to recognize the privilege of having the coverage and accessing the comprehensive care it offers (Region 3).

#### *Other Client Issues*

- Criminal Legal Services - some clients have criminal legal issues related to their use of IV drug use. finding criminal legal resources is a challenge (Region 4).
- I will typically interact with patients either through direct diagnosis at the CTR or when providing DIS services. In providing DIS and partner notification services actually obtaining information on partners for referral has proven most difficult. Either the patient really does not have locating information or chooses not to share it with me for follow-up (Region 4).

#### **Stigma**

- Stigma (Region 2). Stigma and precontemplative states (Region 1).
- We don't have enough Doctor's in our area willing to work with people that have HIV. Food for our pantry is another problem as the agencies in this area will not donate to AIDS Ministries and private individual's don't know we are here as we are hidden from the public (Region 2).
- A general lack of understanding of the unique situations facing our consumers (i.e. HIV/AIDS related stigma; transgendered clients) (Region 6).
- Social stigmas stemming from lack of education and leading to community support issues (Region 12).
- I think the biggest problem we face is stigma. Of course there are funding shortages, apathy and ignorance, but these problems could be eliminated by a thorough understanding of HIV disease and how it affects all those to which in comes in contact (Region 12).

#### **Lack of General Resources (e.g., funding, services, and financial assistance)**

- Limited resources (Region 1). Limited funding (Region 2). Resources drying up (Region 7). Lack of financial resources (Region 10).

- Resources for referral are not always available (Region 5). Lack of resources to refer client to in my region (Region 3).
- Annual changes in programming at new grant years (Region 12).
- Lack of funding for client's needs... -meds or medication co-pays -food -low-cost housing options (Region 7).
- Lack of funding, especially in the area of prevention (Region 12).
- With all of the services we offer to clients, from insurance to housing to financial assistance, some of the resources are inconsistently available or very limited (Region 7).
- We do a fair job with what we have, but so much more need exists that what is available to meet the need (Region 1).
- Lack of funding for programs to assist clients with their financial struggles which relate to nutrition, housing, and ability to obtain medical services (Region 7).
- Grant dollars to fund the positions and services properly (Region 11).
- As a care coordinator, I find that not enough resources are available to HIV + persons living at or below poverty, in Northwest Indiana (Region 1).
- Fluctuation of the amount of monies available to assist persons - some months there is a lot of money for assistance and other months there is none (Region 7).
- Lack of funding for prevention programs (Region 12).
- Lack of resources/information in our county (Region 11).

### **Poverty**

- Poverty (lack of food and housing) no or limited income (Region 7).
- Financial limitations (Region 10).
- Food (Region 12).
- Food card, Gas cards, (Region 4).
- Also, having funds to pay for basic needs (food, housing and transportation) when too sick to work has been an issue for many (Region 10).

### **Community Support**

- Lack of community support (Region 12).
- Lack of community support when it comes to community events and large fundraisers, even when it comes to food pantry donations and programming (Region 12).

### **Education**

- Around this area a lot of providers do not know our services exist. We do our best by sending our brochures but providers can not refer clients for care coordination if they do not know the services are there (Region 9).

- So many youth and organizations could benefit from prevention information that cannot be provided d/t decrease in funding (Region 12).

## Recommended Changes

### **Increasing Responsibility and Accountability of Clients**

- Greater client accountability and involvement for active participation in health care and other essential needs (Region 2).
- Educating and recruiting primary care physicians concerning HIV's general impact on other health concerns. Increase personal responsibility and ownership of clients health care and concern to the client by requiring a small co-pay, deductible, or premium similar to some Medicaid programs. Educational/Marketing initiatives to educate communities about engaging in health care and treatment of HIV before it causes OI's etc (Region 3).

### **Better Collaboration and Networking among Providers**

- Regional provider continual care networking (Region 1).
- Increase networking in regions to provide better referrals and not duplicate services (Region 3).
- More collaboration between agencies serving the same populations so we can provide the best care possible for them without unnecessarily duplicating services (Region 7).
- More collaboration and real partnerships between testing, care and other providers (Region 7).
- I think ASO's desperately need to network with other existing social service agencies in their area. Due to the economy and funding cuts, everyone is drowning on their own, which makes it even more necessary to know what else is going on in the community. We need to know what other agencies are doing so that they can do what they do best and we can do what we do best (Region 7).
- I would like to be linked with PCP and GYN providers within the Clarian system which provide services to our patients (Region 7).

### **Need for One-Stop-Services**

- Better integration of programs--i.e. medical care with social work in one stop shopping with an educator on site to continue to push the need for compliance (Region 7).
- Better integrated support for the neediest patients. Often we are asking those with limited abilities to act on their own behalf in order to bring in paperwork, make a number of appointments etc. I think we need to do a better job of one stop one time service to access all available assistance (Region 7).
- Try to make some of the agencies a one stop service agency for the sake of the clients getting everything done at once, and not having to go to multiple agencies (Region 7).
- Provide viral load testing and CD4 counts to places that diagnose HIV (Region 7).

## Miscellaneous

- Discontinue privatization at FSSA: bring back Food Stamp, Medicaid, TANF caseworkers (Region 3).
- I think having everyone on board with a single, comprehensive plan of action would best benefit those living with HIV/AIDS in Indiana. The department of HIV/STD at ISDH does a wonderful job and are very knowledgeable about the disease and its processes (and complications), but I think the State as a whole should take a vested interest in the health of the citizens of this state. I would like to think I could talk to the governor or our representatives about issues we are having and they would understand what I was talking about (Region 12).
- Increased testing / outreach within un-reached populations - also within the populations where there are language barriers, namely Burmese (Region 3).
- More diverse agency's providing care (Region 7).

## Increase Education Around HIV

### *Increase Awareness of Existing Programs*

- Increased awareness of care coordination services for patient's outside of ISDH's programs. As a pharmacist, I have referred several patients to care coordination who never knew it existed (Region 7).
- Need to advertise services (Region 7).
- Increased advertising-let people know there are lots of services available and an 800-number to call. Use billboards, radio, community and local newspapers, etc (Region 7).
- More advertising of the resources that are available to people living with HIV/AIDS. Since it differs so much state to state, people often do not know what Indiana offers (Region 10).
- More advertisement on the radio and TV. Telling the public that we are here to help (Region 4).
- Public information campaign detailing HIV care coordination in Indiana and a listing of the ASOs that provide HIV/AIDS care coordination (Region 9).
- Knowledge and advertisement. Many people don't know much about HIV and don't know where to go to get services (Region 2).

### *HIV Educating and HIV Prevention*

- Greater Public Awareness Campaign! This implies more funding (Region 1).
- More information to young people of color, on how the virus can and do affect their world. Emphasis on the younger group of population, being aware of the disease and how it can be prevented, and what steps to take to ensure, non infection risk (Region 1).
- Much stronger advertisement/outreach that is specific on the populations most affected (African American men and women). The syphilis outbreak in 1999 - 2000 went WAY out in the notification that there was a problem in our city. I was a Disease Intervention Specialist and there was door to door notification, billboards, ads in newspapers, etc.. I do

not see any public advertisement about the current status/rate of newly infected HIV populations. Outreach is mainly in high risk environments (bath houses, gay bars, some youth organizations). This is not reaching the mainstream population who still have no clue as to how susceptible they are to being infected (I say this based on the countless intakes/new patients I see every week who have little to no knowledge about HIV) (Region 12).

- Educate the patients. So few patients understand the disease, or the treatment they are receiving. Patients are more likely to adhere to their doctors instructions if they understand the importance of adherence (Region 7).
- The single most important change would be the message regarding risky behavior and person's who are at risk. Taking away the labels and separation of demographics and addressing all people no matter their race, gender identity, ethnicity, profession, education, etc. Somehow some way there needs to be a universal message that everyone who is sexually active and/or using any form of drugs legal or illegal should get tested (Region 7).
- Educational/Marketing initiatives to educate communities about engaging in health care and treatment of HIV before it causes OI's etc (Region 3).
- More prevention efforts need to be made to reduce new infections (Region 5).
- Reducing stigma's and false information (Region 8).
- Need more educational materials that explain, in a simple manner, how HIV can impact ones physical, mental, social and sexual health (Region 7).
- More education being offered to clients (Region 2).
- What comes to mind is being able to teach about HIV/AIDS and safe sex in middle and high schools (Region 5).
- Making the system of care more easily to understand (Region 7).
- Increased testing / outreach within un-reached populations - also within the populations where there are language barriers, namely Burmese (Region 3).

### **Other Recommendations**

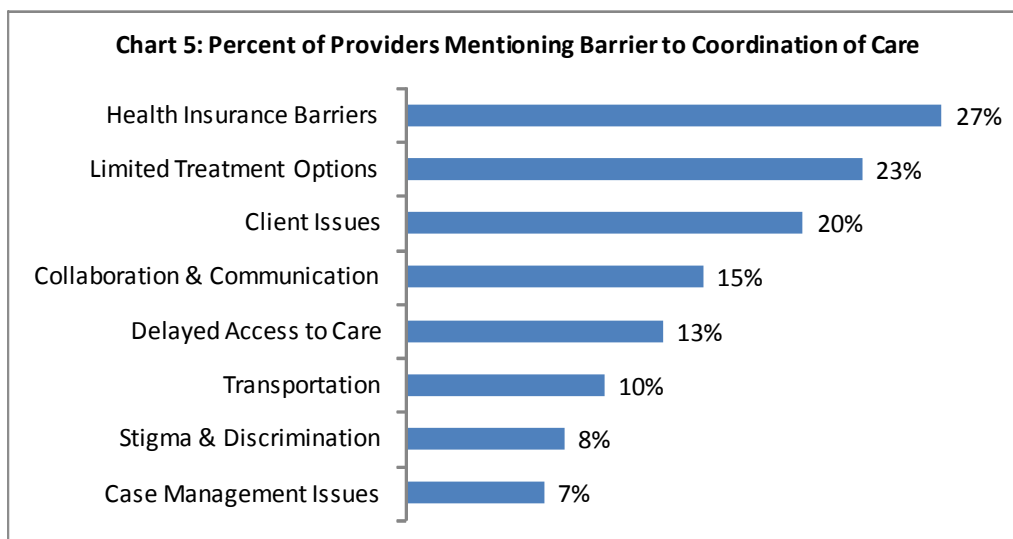
- Addressing other issues that HIV clients deal with daily: housing , food, family, stigmas, and substance abuse (Region 7).
- The improvement of communication between the patient and health care provider. The communication is often impeded from the patient not having a working contact number (Region 7).
- Assess outcomes of services already provided. Implement new care and support services as needed (Region 7).

## G. Biggest Barrier to Coordination of Care -- HIV, Substance Abuse, Mental Health

The questionnaire stated: *The co-occurrence of HIV, alcohol and substance abuse, and mental illness poses unique challenges to meeting the health needs of people with HIV. The next set of questions are about how, if at all, your clinic or agency coordinates your services with providers of alcohol, substance, and/or mental health services.*

Providers were then asked to: *Briefly describe what you think are the BIGGEST barriers to coordination of care among HIV, mental health, and/or substance abuse agencies in your region.* Most of the providers answered the question (83%). Their responses follow below.

Chart 5 shows the most cited barriers to coordination of care.



Nearly 30% of the providers ranked barriers related to health insurance as the number one barrier. This was followed by limited treatment options (23%) and client related issues (20%). Issues related to difficulties with collaboration and communication among agencies (15%) and delayed access to care because of waiting lists and appointment availability (13%) were also problems. Finally, providers mentioned problems related to the lack of transportation (10%), HIV/AIDS and/or mental health stigma and discrimination (8%), and case management issues (7%). These themes are illustrated below.

## **G1. Problems with Collaboration and Communication among Agencies**

- No working relationships between agencies. We know of each other but sometimes don't have an agreement as to how we will work together to serve clients. This can sometimes lead to misunderstandings between agencies or long wait times for client appointments, when these issues could be avoided (Region 7).
- Agencies are not accustomed to networking together to meet the needs of the clients due to funding issues (Region 8).
- Communication. It seems that many providers underestimate the importance that care coordination plays in this process (Region 11).
- There is a lack of clear communication as far as what is needed, what is expected, what is available, and to whom (Region 7).
- In our area we are connected to and work closely to the medical clinic. They have a therapist on staff that meets with our clients and works closely with the staff as well and medical providers. If we have to go outside of this for treatment it becomes more difficult for communication between agencies and following up with treatment (Region 11).
- Barriers to coordination are significantly reduced when there is an established working relationship with the agency and updated releases of information (Region 7).
- Lack of communications (Region 12).
- Psychiatrists and drug treatment caregivers tend to have policies that limit or prevent such communications (Region 7).
- Multiple agencies with duplicated clients accessing the same services. However, enrollment requirements are not always clear and coordinating intake times with urgency of need seems to be an issue. Follow-up with client as a multidisciplinary group to better address client's needs (Region 7).
- Inadequate communication between providers of services to HIV patients (Region 5).
- Making the referral, I think that a lack of clear communication is a huge hindrance. For example, it is difficult to speak directly to someone that the referral will be made to rather than a secretary, etc and often the guidelines are not clearly explained. Also, as hard as I try to be, I am often not fully aware of all of the programs that an agency may offer (Region 12).
- Not having them all available in one place (Region 7).
- Would like to have a substance abuse counselor in clinic (Region 7).
- Lack of an integrated and coordinated approach to these problems at one site. To access care, a person has a buffet of services. But access is not always easy and various agencies have various requirements (Region 2).

## **G2. Transportation**

- Transportation to service providers (Region 6). Travel difficulties (Region 12). Transportation to different agencies (Region 1). Transportation is also a barrier (Region 7). Transportation (Region 7). Transportation (Region 12). Transportation (Region 7).
- Working with individuals in rural counties really is a large barrier to care. This is usually related to lack of transportation or providers not being available in their areas (Region 11).
- In our largest county we are housed with the mental health/addictions center and have a wonderful working relationship. It is sometimes difficult to find services in the less populated areas and clients often have difficulty with transportation (Region 5).
- For clients who live in remote areas, transportation to mental health/substance abuse providers for regular treatment is very difficult (Region 6).

### **G3. Delayed Access to Care due to Wait Lists or Appointment Availability**

- Long waiting list (Region 7). Time it takes to access mental health care (Region 3). Long wait times (Region 7). Long waiting lists for mental health services (Region 3). Getting people seen and followed up in a timely fashion (Region 7). Timeliness to appointments (Region 3).
- Length of time before appointment can be had and between appointments (Region 12).
- Referrals to Wabash Valley Hospital have to be on a particular day, and the client has to pay 15 dollars for an evaluation (Region 4).
- DMH facility has lengthy period of waiting from point of referral until first assessment (usually 4 weeks or more) at which point the individual is assessed and then referred to another portion of their agency which takes yet another week or more for appointment. Many clients may not be chronically mentally ill to the point of needing commitment or on-going case management, but their mental health or substance uses greatly impedes their quality of life, ability to engage in health care, have housing, meet their daily needs. Many have engaged in treatment in the past and didn't like the medications or don't want people in their business. Many personality disorders and bipolar disorders go untreated (Region 3).
- Waiting list for mental health care due to not enough psychiatrists in the area (Region 2).
- In our region, there are only a few providers. There is often a waiting list for folks to get into substance abuse treatment (Region 10).
- Getting an appointment. The agencies are overwhelmed in this area that it is hard to get an appointment within the week or next week for new patients unless you are considered a threat to yourself. We need appointments sooner than later when the clients are motivated to change behaviors or address their issues (Region 1).

#### **G4. Stigma and Discrimination**

- Stigma of being positive (Region 9).
- There is still massive stigma associated with HIV/mental health services (Region 8).
- Halfway Houses are still reluctant to take in people with HIV or at least are perceived to have problems due to the question "Do you have HIV?" being on every intake application at every Halfway House in Fort Wayne. The question itself poses a barrier to clients since it encourages them to be dishonest about an important part of their lives in a program that supposedly emphasizes complete honesty. Our new SPSP staff will be working to educate Halfway Houses about this issue. Our Community Mental Health agency is Park Center. It takes a long time to get in as a patient and staff seem uneducated and uninterested about issues surrounding HIV and being gay and sometimes downright hostile to people with substance abuse issues. One of their psychiatrists is rude and condescending to staff and clients and clients cannot switch to another psychiatrist without their current Dr's permission! (Region 3).
- There is still stigma associated with HIV, even among providers of mental health and substance abuse treatment. Persons living with HIV are often treated poorly (Region 7).
- Halfway houses in Ft. Wayne won't take HIV + individuals so people have to lie to get services if they want to be in a halfway house (Region 3).
- Our providers have little specific content for HIVers - some have even discouraged disclosure in substance or mental health groups - how can help occur in that environment? (Region 1).
- Substance abuse treatment is a hard sell no matter which population you work with. I think we have a great referral system here because we have an SPSP program that allows for referrals to be internal. With mental health concerns, the case managers struggle to make completed referrals due to lack of follow up on the client's part. While many of them recognize they need to see a mental health professional, stigma and disclosing to yet another individual does not seem appealing or even reasonable. For that reason, I would like to see increased funding to supplement Care Coordination sites with funds to provide mental health services to CC clients to combat these identified barriers (Region 12).

## **G5. Case Management Issues**

- Difference of opinion on what to make the primary focus: HIV, mental health or substance abuse (Region 3).
- Staff obligations that do not allow for making sure each person gets to each appointment (Region 7).
- We have also seen that the case workers at the mental health facilities have such large case loads that they are unable to work with clients on a regular basis (Region 9).
- Everyone is overwhelmed by their caseloads! (Region 1).
- I think that consistency has become an issue. When there is a change in staff at a care site, many patients are not notified that they have a new care coordinator, and those patients fall through the cracks (Region 7).
- I think like any other service provision, there is problems with all providers understanding the importance of the whole picture - how all the parts affect the whole; clients also seem to have problems linking all of the parts to the whole. There can also at times be issues with providers owning the problems, and rather pinpointing who "should" be claiming a problem and assisting the client with said problem (Region 3).

## **G6. Limited Treatment Options**

- Lack of good programs to refer people to (Region 11). Few referral sources (Region 12). Limited referral sources for mental health and/or substance use agencies (Region 7). No rehabilitation programs in the immediate area (Region 5). Lack of more support groups (Region 7).
- In our largest county we are housed with the mental health/addictions center and have a wonderful working relationship. It is sometimes difficult to find services in the less populated areas (Region 5).
- Lack of trained professionals to counsel HIV positive clients. Lack of diversity training to address different lifestyles (Region 1).
- Lack of facilities that will take children/young adults (Region 7).
- Sometimes people need more than a support group, they need in-house stay program (Region 7).
- Not enough agencies providing detox that clients can afford (Region 7).
- Shortage of mental health professionals dedicated to this area of expertise (Region 7).
- Very few programs (only 1) will serve people with co-occurring substance use and mental health issues (Region 10).
- **THERE ARE VERY FEW SUBSTANCE ABUSE TREATMENT RESOURCES!** Many of the resources, at least in Bloomington, require a certain amount of sobriety before entering them and many of them are self-pay, which most clients can't afford. There are no inpatient facilities in the Bloomington area, other than the hospital to send clients. If clients are in need of inpatient care, we have to refer them to facilities that are hours away and most likely are full and have a limited number of beds (Region 10).
- Availability of mental health inpatient beds (Region 7). Bed vacancies for residential programs (Region 1).
- Providers in geographic range with interest availability (Region 1).
- Working with individuals in rural counties really is a large barrier to care. This is usually related to providers not being available in their areas (Region 11).
- There is a lack of choices when it comes to service providers. Clients are sometimes forced into going to one provider because it is the only one available or who takes their insurance or they have no insurance (Region 12).
- The largest provider of mental health services in our area sort of has a monopoly on services and is not necessarily the best (Region 10).
- Limitations of programs that require you to have co-occurring issues rather than services for each of the above categories (Region 10).
- The traditional ideologies of Community Mental Health Centers can make it very difficult for our clients. CMHCs rarely utilize harm reduction philosophies and it continues to be difficult to find treatment for dually diagnosed individuals. Clients who are required to take pain medications are usually rejected from all options of SA treatment in our region (Region 10).

## **G7. Inability to Access because of Insurance Issues**

- Funding/insurance (Region 2). Insurance coverage (Region 1). Financial barriers also exist (Region 5). Insurance (Region 4). Health insurance issues (Region 7). Lack of payment sources (Region 12). Lack of insurance to continue receiving services (Region 1). Paying for treatment (Region 2). Lack of insurance coverage (Region 5). Money (Region 3). Client ability to pay for services (Region 12). Patients' inability to pay (Region 7).
- Not having insurance or insurance not covering substance abuse (Region 10).
- Cost of intensive outpatient programs. Lack of insurance coverage for inpatient treatment limited availability of psychiatrists (Region 7).
- The biggest barrier is the many hoops pts have to go thru to get on the Wishard advantage program. I feel that every financial counselor has a different view of what is needed to apply for the advantage program (Region 7).
- Clients who do not have insurance are turned away from mental health assistance. Or we have had a few clients get mental help with no insurance and later get insurance but have such a high bill they are afraid to continue to receive mental health help because they are unable to pay for their previous bill. We recently had a client lose Medicaid because his caseworker did not turn in the re-cert paperwork (Region 9).
- Ability to pay for mental health and substance treatment. The mental health and substance abuse agencies in this area will not see people that don't have insurance or means to pay (Region 2).
- Not enough agencies providing detox that clients can afford (Region 7).
- If the clients do not have Medicaid. The agencies are limited on the ICHIA coverage amounts and Medicare requires a specific clinician for services. Most of the clients cannot afford sliding scale (Region 8).
- Depending on what type of insurance the client has/or does not have, can prolong client's enrollment with obtaining insurance (Region 7).
- Access to Methadone clinics for those who are struggling with heroin addiction. The clinics are very expensive (for our population who are mostly low socioeconomic status) and Ryan White insurance does not cover this (Region 7).
- Our area providers do a really good job working together for continuity of care. The barrier that exists is when a client does not have health insurance and the waiting list to see a psychiatrist is months. without insurance inpatient substance treatment is nonexistent (Region 3).
- There are a lot more resources for mental health care, but one big barrier that I see is insurance. So many of our clients utilize ICHIA/ISDH insurance and it only covers limited mental health services (Region 10).
- Other providers in our region do not take Medicaid or do not have a sliding fee scale so people cannot afford them (Region 10).
- Insurance coverage-private providers don't take Medicare/Medicaid; availability of mental health inpatient beds (Region 7).

## **G8. General Client Compliance, Cooperation, Follow-up, etc.**

- The recognition that the problem does exist & the need for service-DENIAL (Region 1).
- Client's self-determination (Region 7).
- Gaining the cooperation of the client in need of these services. Without the client seeing a need and motivation for treatment they will not agree to participate (Region 7).
- Patients refusal of receiving services (Region 1).
- The biggest barrier are the clients themselves. If they are not willing to seek treatment, then it is difficult to get them to follow through. Transportation is usually easy to solve. It is the client who really needs to seek treatment, but drag their legs about going to appointments or seeking treatment that causes the biggest barrier (Region 3).
- A big barrier is follow up. It can be difficult to locate these individuals and they only come around when they need something (Region 2).
- Client compliance (Region 5).
- The client following through with the referral and getting releases for all agencies to ensure coordination of services (Region 12).
- Client follow through when things are put into place...such as appointments for medical, mental health, or substance use (Region 7).
- Getting the client to follow thru (Region 11).
- A lot of not understanding the client. Trying to make clients do what they want them to do (Region 7).
- Most clients who need these services are homeless and/or transient to ensuring maintenance in these programs if often difficult (Region 7).
- Clients not wanting to discontinue use of drugs or alcohol, or clients not admitting to the use of substances (Region Not Listed).
- Clients are more likely to drop in and out of care, thus making it more difficult to keep track of them. Also, many times, they will transfer to a mental health or substance abuse agency out of our area (Region 11).
- Within our program the Social Workers refer patients. They are always able to identify appropriate programs. I would like all patient's with substance abuse, and mental health issues to be in care however, patient's won't engage until they're ready (Region 7).
- Resistance on the patient's part to engage in mental health & substance abuse treatment--keeping initial appointments, F/U appointments, following treatment/care recommendations (Region 11).
- As well as clients not identifying the need to have that particular service (Region 7).
- Need for baby sitters (Region 7).

## **H. Other Comments**

The last question on the survey invited providers to, *“Please enter anything else you would like to add. You may also use this space to elaborate on any of the previous questions.”* Almost a third of the providers responded to this question (N=28). Their answers are grouped into similar concerns below.

### **Need for a new approach**

- Service coordination stinks, funding schemes are backwards, ... There are too many needs going unmet, and the time for a new approach has been with us now for several years (Region 1).

### **Expanding vs. Focusing Service Types**

- I think that Care Coordination services have gotten too broad and try to encompass too many issues outside of HIV. Granted, substance abuse, mental illness, and homelessness are all secondary factors that may increase individuals' likelihood of transmitting and contracting HIV, but services need to gear themselves more towards prevention as a way to keep client's from increasing their risk because of secondary/or even primary socio-economic maladies (Region 7).
- There should be more money available to buy test kits for agencies and more diverse services (Region 7).
- If substance abuse and mental health programs would develop or incorporate the specifics of living with HIV within the program, it may offer comfortability, or a feeling of openness, acceptance to the patient (Region 7).
- Having additional SPSP's that address special populations such as the chronically chemically addicted is an excellent first step in identifying and reaching out to those who are HIV positive. As you take steps toward addressing other special populations, I believe this model will prove to be most effective (Region 6).

### **Underserved Populations**

- As a care coordinator who provides case management services to children, I believe this population is under served in Indiana (Region 7).

### **Provider Access to information and uncomplicated processes**

- It appears that the Indiana State Department of Health (ICHIA) gives preferential treatment to BioScrip with regards to issues surrounding 3rd party reimbursement for pharmacy services. As a competitor of BioScrip, I have always found difficulty obtaining the necessary information to bill for pharmacy services. In some cases I was instructed to have patients utilize BioScrip even though ICHIA has an open pharmacy network. Maintaining a fair and competitive open network ensures that HIV patients are able to utilize a pharmacy provider that best suits their individual needs (Region 1).
- Clients continue to receive bills for medical care that is covered by ICHIA and HIAP. Could the cards be changed to clarify how providers should bill for these services (especially the secondary coverage) (Region 11).

- It would be helpful in tracking referrals to mental health and substance abuse providers if there were a standard statewide form that could be filled out whenever a referral is being made (Region 9).
- Make seeking care and moves toward self-sufficiency the most rational choices, rather than ones which are viewed as having the potential for more harm than good. Also frustrating process encouraging pts to get back to work as pts fear loss of coverage no incentive to get off disability (Region 1).

### **Education**

- In my position, I see a lot of clients who, despite having been diagnosed with HIV several (sometimes 10+) years ago, still know little to nothing about their disease. In some cases, they have been miseducated, and in some cases, they have not been educated at all. Programs should be developed to provide the entire population, not only those living with HIV/AIDS, with at least basic HIV/AIDS education. That way people know how to protect themselves, protect others, and in the case of those living with HIV/AIDS, know how to live with their disease (Region 7).
- I would just like to reiterate the fact that there is very little public education on HIV. I have had so many young patients when I was a Disease Intervention Specialist who were not concerned about becoming HIV positive because "there is medicine that I can take that will keep me healthy" They have no clue about the side effects of the medications, the health problems so many have even when they are on medication and what is is like to have to make sure you take your medications every day or you can become resistant. None of this information is getting out to the mainstream public! (Region 7).
- Public awareness of the importance of getting tested is only mentioned at certain times. Need more awareness (Region 7).
- Indiana has a long way to come in its attitudes; we have to find ways to communicate that HIV issues are public health ones, not moral ones (Region 1).
- I think the recent surveys and the Medical Monitoring Project have been extremely helpful gathering information from actual clients. I believe more work needs to be done to decrease stigmatization, educate the public, and the medical community (Region 7).

### **HIV Medication**

- Adherence to meds is a huge, huge issue. I have a fairly large subset of patients that I have to literally hound each month to get their refills. Each time we discuss the importance of adherence and risk of resistance and methods to help them with meds. Some get better about their refills, others don't. Prescribers should definitely utilize pharmacists (if they don't already) for insight into their patient's med issues and adherence. We see them every month, so often may know things that are going on that other care providers do not (Region 7).

### **Waitlists, Delays, and inability to access**

- Providers connect delays and waitlists to funding problems. Funds are needed for creating staff positions. At current funding levels, providers are burdened with overwhelming caseloads and clients experience delays or are unable to access services.

- Additional funding would create more positions so that we can get to clients in a more timely manner is vital (Region 7).
- More funding is definitely needed to assist this population in this area for transportation to appointments. We want our consumers to get help and go to the agencies in which we referred, but it is impossible for any care coordinator to take everyone of their clients to each appointment if they are lacking transportation. Therefore some consumers go with out the care they need due to lack of transportation (Region 1).
- I fear we have reached a point where things have to change. Where as I firmly believe every individual needing any type of health care in the world should be able to engage in it at no cost and receive any treatment they need for any health concern. I fear to meet the continuing needs of HIV treatment we must begin to look at how Medicaid is administered, how costs can be shared by the client for insurance, if clinic options would be cheaper rather than insurance, or if services have to be cut in order to serve more in stead of fewer. We are one of the few states operating with a waiting list at times. I'm not saying I know how to fix it, but with the continuing economic strife being suffered in our communities I fear this need will not decrease. I hope that I am wrong (Region 3).
- I wish we had more money for counseling and rehabilitation services. If folks don't have insurance, or the proper insurance, they don't have access to these services. I know right now ICHIA/ADAP/EIP cover some services, but then we have a large waiting list because we, as a state, pay for these services. It's a double edged sword (091).
- [S]ubstance abuse is an ongoing problem. The cost of treatment and the waiting times deters clients from change (Region 7).
- I would like to have more housing in Elkhart area, many of our client's have family in Elkhart county but are asked to move to South Bend because of lack of housing in Elkhart. I would like to see us try to raise more funds to help our clients, it seems like other states do much more fund raising events and are able to provide many services we can't (Region 2).

### **Care Coordination Practices and Recognizing Provider Work**

- 90 day Reviews for Care Coordination clients is too often for both clients and care coordinators. Semi-annual Reviews would ease the overwhelming caseloads and subsequent workloads (Region 1).
- The phrase "client empowerment" to be given "lip service," not fully understood or addressed (Region 1).
- Our office is unique with the level of cooperation and communication with Care Coordination, medical treatment and substance issues. This flows well so the clients can receive the best care available (Region 11).
- Overall, Fort Wayne does an excellent job working together toward best practice with clients. I am an independent contracted therapist and have a good working relationship with the Health Department and the AIDS Task Force (Region 3).
- Complexity of care of these patients is time demanding and not well recognized rewarded keeping out of hospital should be commended (Region 1).

# APPENDIX 1: PROVIDER SURVEY

**Indiana HIV Provider Survey**

**1.**

**1. Please choose your agency's assigned region from the drop down list. Regions are organized by the ISDH as HIV Care Coordination Regions 1-12. As shown, all counties lie within a specified region.**

Agency Region

**2.**

**2. What is the PRIMARY role in which you personally interact with the HIV-positive clientele?**

Program Manager or Director     Clinician/Care Provider     Pharmacist  
 Care Coordinator/Social Worker     HIV Prevention and Testing Specialist     Special Population Specialist (alcohol/substance abuse, mental health)  
 Other (please specify)

**3.**

**3. Briefly describe the biggest problems that you have faced when PROVIDING care or services to people living with HIV/AIDS.**

**4.**

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**Indiana HIV Provider Survey**

**4. Please check what you think are the TOP 3-5 reasons that some HIV-positive people are NOT getting HIV medical care?(CHECK UP TO FIVE)**

Homelessness/unstable housing     Difficulties paying/no insurance     Family or childcare needs  
 Using drugs or alcohol     Don't think they are eligible     Language difficulties  
 Mental health problems     Feel healthy     Difficulty getting appointment  
 Afraid to disclose HIV status     Think medical care won't help     Physical disability  
 Not ready to deal with HIV     Undocumented immigrant status     Don't understand the risk of waiting  
 Difficulties with transportation     Don't trust doctors or clinics     Don't know their HIV status  
 Don't know how to get service     Side effects of medications  
 Other, please specify

**5.**

**5. We will conduct exploratory focus groups with a few of the SPECIAL populations living with HIV/AIDS in Indiana. Which of the following SPECIAL populations do you think are MOST important to have their HIV-related needs assessed at this time? That is, which populations are the most underserved and/or do we know the least about? (CHECK UP TO FIVE)**

Men Who Have Sex with Men     Transgender Persons     The Mentally Ill  
 Women     Youth Age 13-24     Persons Coinfected with Hepatitis C  
 Heterosexual Men     Persons Age 50 and Older  
 African Americans     Sex Workers     Incarcerated/Recently Released  
 Hispanic/Latinos     Homeless Persons     Persons with Alcohol and Substance Abuse Problems  
 Other (please specify)

**6.**

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**Indiana HIV Provider Survey**

**6. Briefly describe the SINGLE MOST IMPORTANT change (other than increased funding, per se) that you would recommend for improving the provision of HIV related care and/or support services for people living with HIV/AIDS in Indiana.**

**7.**

The co-occurrence of HIV, alcohol and substance abuse, and mental illness poses unique challenges to meeting the health needs of people with HIV. The next set of questions are about how, if at all, your clinic or agency coordinates your services with providers of alcohol, substance, and/or mental health services.

**8.**

**7. Does your agency/clinic ever refer their HIV-positive clientele for alcohol abuse, substance abuse, or mental health services?**

Yes  
 No

**9.**

**8. Does your agency/clinic have a way of tracking referrals (such as by paper, computer, or something else) made to agencies providing...**

	Yes	No	Don't know
alcohol and substance abuse services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
mental health services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**10.**

**9. How often do you (or your agency/clinic) face difficulties when making referrals for...**

	Never	Rarely	Sometimes	Most of the time	All of the time
alcohol and substance abuse services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
mental health services?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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**Indiana HIV Provider Survey**

**11.**

**10. Briefly describe what you think are the BIGGEST barriers to coordination of care among HIV, mental health, and/or substance abuse agencies in your region?**

**12.**

**11. In the space below, please enter anything else you would like to add. You may also use this space to elaborate on any of the previous questions.**

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