

CHSPAC – COMPREHENSIVE HIV SERVICES PLANNING AND ADVISORY COUNCIL

# Final Results: Indiana Consumer 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  
Indiana University-Purdue University Indianapolis (IUPUI)  
Investigator for the Institute for Research on Social Issues (IRSI)  
Chair of the CHSPAC Evaluation Subcommittee**

**Regina Pessagno B.A. IUPUI  
Sociology MA Student IUPUI**

**Sarah Lynn B.A. IUPUI  
Sociology 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
- Jodi 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
- Katie Lesko, Hospital/Health Planning Agency
- Bridgette McLaurin, Bridging the Gap
- Noelle Redmond, Walgreens Pharmacy
- Dale Richmond, Richmond Center for Mental Health Region 9
- Bud Shipley, CAB Representative District 12
- Stephanie Simmons, Anderson Center for Mental Health Region 8
- Linda Vest, Meridian Nursing /Rehabilitation
- 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 Sarah Bradley

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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

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 One Gary Area (Lake, Porter, Laporte)

Region Two South Bend Area (St. Joseph, Marshall, Starke, Elkhart, Fulton, Pulaski)

Region Three Fort Wayne Area (Allen, Whitley, Dekalb, Huntington, Kosciusko, LaGrange, Wabash, Wells, Adams, Steuben)

Region Four Lafayette Area (Tippecanoe, Jasper, Newton, White, Carroll, Clinton, Montgomery, Fountain)

Region Five Muncie Area (Delaware, Grant, Jay, Blackford, Randolph)

Region Six Anderson Area (Madison, Cass, Miami, Howard, Tipton, Hamilton, Hancock)

Region Seven Indianapolis Area (Marion, Boone, Hendricks, Morgan, Johnson, Shelby)

Region Eight Terre Haute Area (Vigo, Vermillion, Parke, Putnam, Clay, Sullivan)

Region Nine Richmond Area (Wayne, Henry, Rush, Decatur, Ripley, Dearborn, Ohio, Union, Franklin, Fayette)

Region Ten Bloomington Area (Monroe, Brown, Bartholomew, Lawrence, Owen, Greene, Lawrence)

Region Eleven Jeffersonville Area (Clark, Switzerland, Jeffersonville, Jennings, Jackson, Orange, Crawford, Floyd, Harrison, Washington, Scott)

Region Twelve 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 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 consumer survey was part of the 2009 Needs Assessment, which included two components: (1) Survey of people living with HIV/AIDS who are receiving ISDH funded care coordination services, and (2) 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 HIV-affected community are also addressed in the research. This increased rapport among the parties and greatly increased participation rates. 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 been HIV positive for over twenty years, and brought a community perspective to the project as a consumer of HIV related care and services in Indiana.

Dr. Foote worked directly with CHSPAC and ISDH to complete the project. The community members who make up 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 evaluation subcommittee of the Comprehensive HIV Services and Planning Council (CHSPAC) developed a 35-question survey tool to assess the HIV related needs and gaps in service provision of the Indiana HIV-infected population (See Appendix 1). The response and results to the consumer survey are presented in this report. The findings for the provider survey are presented separately in the Provider Survey Report. The study received IRB approval from the IUPUI/Clarian IRB, Study Number EX0907-12.

## B. Survey Distribution and Response

The target population included approximately 3,042 clients currently receiving HIV care coordination services in Indiana. These clients represent 33% of those men and women presumed to know their HIV status in Indiana. We mailed approximately 2,500 surveys (including about 100 Spanish language surveys) to HIV care coordination clients. We also delivered 800 surveys (about 50 were Spanish language) to each of ISDH funded HIV care coordination sites to target clients who did not wish to receive HIV-related mail or who were not included in the ISDH centralized care coordination data base. Care site staffs were instructed to deliver the surveys to these clients. We received 746 surveys of which 36 (5%) were completed in Spanish and 35 (5%) came from no-mail clients. Only 27 (4%) clients had help completing the survey from their care coordinator.

Table 1 compares the sample size as a percentage of all clients in care coordination and as a percentage of the Indiana HIV-infected population.\*

- The sample represents a quarter of clients who have received HIV care coordination in the last 12 months.
- The sample represents 8% of the estimated 9,253 persons living with HIV/AIDS in Indiana who are presumed to know their HIV status.

**Table 1: Survey Sample as Percent of Clients in Care Coordination and the Indiana HIV Population\***

	As % of Clients in Care Coordination Jan-Mar 2009	As % of the Indiana HIV Population Currently Living as of December 2008
Total N	3,042	9,253
%	25%	8%

\*All comparison figures in the distribution and response section are from either the ISDH 2009 *HIV Services Quarterly Report 3<sup>rd</sup> Quarter 1/1-3/31 2009* or the ISDH *Spotlight on HIV/STD/Viral Hepatitis, Indiana Semi-Annual Report* February 2009

To track return rates, and assess service needs in different parts of the state, the surveys asked the client for his or her zip code. Zip codes were then coded as one of the 12 ISDH HIV care coordination regions.

Table 2 shows survey returns by region and compares them to the overall percent of clients in care coordination and within region. Less than 5% did not provide a zip code (n=35) which left 711 surveys coded for region.

- These region sample figures closely align with the profile of clients in HIV care coordination with only a +/-1% difference across all regions except for region 7.
- Region 7 is under represented when compared to overall clients receiving care coordination in region 7. Region 7 represents 33% of the survey sample but 38% of clients receiving care coordination.

**Table 2: Sample Region Characteristics Compared to All Clients in Care Coordination (CC) and within Region**

Region	# Returned	% of Total	# (%) Clients in CC	As % of CC Clients Within Region
1 Gary Area	98	14	389 (13)	25
2 South Bend Area	55	8	265 (9)	21
3 Fort Wayne Area	67	9	316 (10)	21
4 Lafayette Area	18	3	89 (3)	20
5 Muncie Area	22	3	69 (2)	32
6 Anderson Area	32	5	123 (4)	26
7 Indianapolis Area	238	33	1,159 (38)	21
8 Terre Haute Area	16	2	38 (1)	42
9 Richmond Area	22	3	68 (2)	32
10 Bloomington Area	35	5	157 (5)	22
11 Jeffersonville Area	53	7	183 (6)	29
12 Evansville Area	55	8	186 (6)	30
TOTAL	711	100	3,042 (100)	100

**Comment**

- The underrepresentation of care coordination clients from Region 7 may stem from the high percentage of clients at the Damien Center who were not checked to receive mail (nearly 400 of their clients were not checked to receive mail). In addition, clients receiving care coordination at Wishard are not in the ISDH centralized care coordination database. Therefore, we were unable to directly mail the questionnaire to many clients in the Indianapolis area.

## C. Client Overview

### C1. Race and Gender Characteristics

Table 3 presents the sample characteristics by race and gender and compares them to the Indiana HIV population and to those receiving HIV care coordination services. Although not a random sample, and therefore not generalizable to the HIV population at large or those in care coordination, it is still useful to compare the gender and race of this sample with the state profile.\*

**Table 3: Sample Characteristics – Race and Gender**

	<u>Survey Sample</u>		<u>Indiana PLWH</u>	<u>HIV Care Coordination</u>
	N	%	%	%
<b>Gender (N=717)</b>				
Male	573	80	80	77
Female	140	19	20	23
Transgender	4	<1	n/a	n/a
<b>Race (N=740)</b>				
Black	153	21	35	30
White	508	69	56	60
Hispanic	50	7	7	6
Multi-racial	18	2	n/a	n/a
Asian	4	<1	<1	n/a
Other	7	1	2	4

- Gender characteristics are consistent with the Indiana HIV diagnosed population (20% of people living with HIV/AIDS in Indiana are women, 80% are men). These figures also closely align with the profile of clients in HIV care coordination; the percentage for women in care coordination is slightly higher (23%) and slightly lower for men (77%). Less than 1% of the survey sample identified as transgendered.
- White clients are overrepresented in the survey sample when compared to the population and care coordination figures. Whites living with HIV/AIDS are 56% of the Indiana epidemic, 60% of care coordination clients, and 69% of the survey sample. Blacks are 35% of the Indiana epidemic, 30% of care coordination clients, but only 21% of the survey sample. Hispanic representation in the sample (7%) is closely aligned with both populations (Indiana epidemic 7%, care coordination 6%).
- Multi-racial, Asian and Other groups represent less than 4% of the sample.

\*All comparison figures in the race and gender tables are from either the ISDH 2009 *HIV Services Quarterly Report 3<sup>rd</sup> Quarter 1/1-3/31 2009* or the ISDH *Spotlight on HIV/STD/Viral Hepatitis, Indiana Semi-Annual Report* February 2009

## C2. Household Characteristics

Table 4 presents the sample household characteristics, including the client's yearly household income and whether the client had any people in their household under the age of 18.

**Table 4: Sample Household Characteristics**

	N	%
<b>Yearly Household Income (n=710)</b>		
Under \$10,000	315	44
\$10,000-\$25,000	320	45
More than \$25,000	75	11
<b>Household People Under Age 18 (n=736)</b>		
Zero	606	82
1-2	103	14
3 or more	27	4

- The vast majority of the sample was living at less than 225% of the 2009 federal poverty guidelines (89%). Half of these (44%) were living at <100% of the poverty level. For a family of one, the 2009 poverty level is \$10,830\*.
- Most clients had no children in their households (82%), 14% had 1-2 children in their households, and a very small percentage (4%) had 3 or more children.
- There was no difference in household income between those clients who had children in the home and those who did not.

\*The 2009 HHS poverty guidelines can be found at: <http://aspe.hhs.gov/POVERTY/09poverty.shtml>

### C3. Health and Care Characteristics

The survey asked clients to rate their current health and to indicate how many months they had been receiving care coordination services. To examine whether the clients were receiving consistent HIV related care, it also asked how long it has been since their last HIV lab tests. These results are shown in Table 5.

**Table 5: Sample Health and Care Characteristics**

	N	%
<b>Self Rating of Health Today (n=725)</b>		
Poor-Fair	213	29
Good-Very Good	402	56
Excellent	110	15
<b>Months in Care Coordination (n=721)</b>		
1-6 Months	58	8
7-12 Months	50	7
More than 12 Months	613	85
<b>Months since last HIV Lab Tests (n=732)</b>		
1-6 Months	656	90
7-12 Months	38	5
More than 12 Months	38	5

- The majority of clients reported good to excellent health (71%). Just under a third reported poor-fair health (29%).
- Most clients had been in care coordination for more than 12 months (85%).
- Ten percent were receiving inconsistent HIV blood lab care; 5% of clients reported not doing HIV lab tests in the last 6 months. An additional 5% reported not doing a HIV lab test in the last 12 months.

#### C4. Health Insurance Coverage Characteristics

The survey asked clients to report which types of health insurance programs they had. Table 6 breaks these findings into three sections 1) by number of health insurance plans, 2) by type of insurance plan, and 3) by the different combinations of plans for those who reported more than one plan. In the tables below, 'ISDH Programs' include HIV Medical Services Programs (ADAP, EIP, MDAP, and HIAP/ICHIA). 'Other Programs' include Wishard Advantage, Ryan White Parts A and C, and other non-ISDH Medical Assistance Programs.

**Table 6: Sample Health Insurance Characteristics**

	N	%
<b>Number of Health Insurance Plans (N=725)</b>		
Single (ISDH, 22%; Medicaid 13%; Other, 9%; Medicare, 8%, Private, 7%)	427	59
Multiple	269	37
Uninsured	29	4
<b>Type of Health Insurance (N=725)*</b>		
Private	67	9
Medicare	278	38
Medicaid	223	31
ISDH Programs	300	41
Other Programs	131	18
None	29	4
<b>Health Insurance Combinations for Clients with More than One Form of Coverage. The primary insurance is listed first. (N=269)</b>		
Medicare, Medicaid	92	34
Medicare, ISDH	80	30
ISDH, Other	27	10
Medicare, Other	18	7
Medicare, Medicaid, ISDH	10	4
Medicaid, ISDH	10	4
Medicare, ISDH, Other	7	3
Medicare, Medicaid, Other	6	2
Medicaid, Other	6	2
Private, Medicare	5	2
Private, Other	2	< 1
Medicare, Medicaid, ISDH, Other	1	< 1
Medicaid, ISDH, Other	1	< 1
Private, Medicaid	1	< 1
Private, Medicare, Other	1	< 1
Private, ISDH	1	< 1
Private, Medicare, ISDH	1	< 1

\*Does not equal 100% as about a third of the sample had multiple types of insurance

- The majority of the sample had some form of health insurance (96%). Most had a single plan (59%). Just over a third had more than one plan (37%) and 4% were uninsured.
- Only 9% (n=67) had private insurance. Relatively few of these individuals supplemented their plan with other insurance plans (n=11/16%).
- Among the public insurance programs, 40% of the sample had ISDH programs, 37% had Medicare, 30% had Medicaid, and 18% had other programs.
- A third of the publicly insured clients supplemented their plans with other plans. While 9% of the Other plan holders and 18% of the ISDH plan holders had an additional form of health insurance, almost 30% of the federally funded plan holders did (29% of those with Medicaid and 27% of those with Medicare).

### Racial Differences

- Black clients were the least likely to have ISDH programs (22%), then Hispanics (34%) followed by White clients (47%) (p<.001).
- Hispanic clients were the least likely to be insured by Medicare (16%) followed by Black (29%) and White (43%) clients (p<.001).
- 7% of the Blacks, 5% of the Hispanics, and 3% of the Whites had no insurance (p<.001).
- More than half of Hispanics (80%), Blacks (64%), and Whites (56%) attempt to meet their health care needs using only one plan (p<.001).
- Whites (42%) were the most likely racial group to have multiple insurance plans; Blacks (29%) and Hispanics (16%) were less likely to have more than one plan (p<.001).

### Gender Differences

- Being uninsured is more common for women (6%) than for men (4%) (p<.05).
- Men (39%) are more likely than women (27%) to be covered by multiple plans (p<.001).
- Men (40%) are more likely than women (27%) to have Medicare coverage (P<.01), but there is no gender difference for ISDH, private health insurance, or Medicaid.

### **Comment**

- These findings highlight how clients piece together multiple plans to meet their health needs. The open-ended comments (summarized later in the report) suggest that many clients with a single plan may not qualify for supplementary plans and therefore have difficulties meeting their health needs due to costs of care and medications. Although Ryan White and Medicaid programs do apply income/asset guidelines on eligibility, the survey did not collect enough data to speculate on the specific characteristics of these clients that may explain their difficulties with cost. For example, if many of the Hispanics are undocumented immigrants, they may be ineligible for certain plans.

## D. Gaps in Services

Clients were asked a series of questions about the number of times in the last 30 days in which they experienced a particular hardship (e.g., the number of times in the last 30 days the client was hungry or unable to get food). The clients were able to answer "None," "1 to 3," "4 to 6," or "7 or more." The survey also asked clients to report the number of times in the past year that he/she felt services of any kind were withheld from them due to discrimination because of their HIV status. Table 7 contains the results.

**Table 7: Gaps In Services In the Last 30 Days and Discrimination in the Last Year**

Times in <u>last 30 days</u> were/have you....	Frequency (%)			
	None	1-3	4-6	7 or more
been hungry and unable to get food?	551 (75)	114 (15)	36 (5)	38 (5)
been homeless or in unstable housing?	669 (91)	31 (4)	7 (1)	26 (4)
missed work, etc.* due to unstable housing?	680 (93)	42 (6)	7 (1)	5 (<1)
missed work, etc.* due to mental distress?	451 (62)	176 (24)	49 (7)	55 (8)
missed work, etc.* due to illness?	373 (51)	249 (34)	63 (9)	52 (7)
missed work, etc.* due to transportation?	555 (76)	107 (15)	26 (4)	44 (6)
missed work, etc.* due to childcare?	699 (97)	14 (2)	4 (<1)	4 (<1)
missed work, etc.* due to alcohol and drugs?	682 (93)	43 (6)	2 (<1)	10 (1)
<u>Times in the past year felt services were...</u>				
withheld due to discrimination?	567 (78)	125 (17)	22 (3)	15 (2)

\*Refers to work, school or a doctor's appointment

### In the last 30 days...

- A quarter of the sample had experienced hunger or difficulties getting food at least once (25%). Less than half of these people had experienced food hardships 4 or more times.
- Just under ten percent of the sample (9%) had experienced homelessness or been in unstable housing, of which 5% experienced housing hardship 4 or more times.
- Less than ten percent of clients reported missing work, school, etc. at least one or more times due to housing (7%), alcohol or drugs (7%), or childcare (3%) hardships.
- Most clients who missed work, school or a doctor's appointment at least one or more times did so because of illness (49%), mental distress (38%), and transportation (24%). 10-16 percent in these categories missed work, school, or a doctor's appointment four or more times due to these hardships.
- Just over 20% of the sample felt services had been withheld from them at least once in the last year. For most of these, it happened between 1-3 times in the past year (17%).

Clients were also asked a series of questions about the number of times in the last year in which they experienced a particular hardship (e.g., the number of times in the last year they had been notified of possible eviction from their home). The clients were able to answer "None," "1 to 3," "4 or more." The core service questions also included a "did not seek response" and the medication questions included a "not on meds" response. Tables 8, 9, and 10 present the results. The results to the service use questions in Tables 8 and 9 only include clients who sought services, or who are on HIV medications for the medication questions.

We also measured whether clients sought HIV medical care appointments at any time in the last 12 months. This result was extracted from the question that asked, "how many times in the past year did you have trouble getting HIV medical care appointments". One response was 'did not seek care'. We recoded the answers to 'did not seek care' and 'sought care'. We similarly extracted a result for whether the client sought dental care in the past 12 months. Table 10 presents results for clients who did not seek HIV medical or dental care.

**Table 8: Gaps in Services in the Last Year**

How many times in the <u>past year</u> have you....	Frequency (%)		
	None	1-3	4 or more
gone to the emergency room because you were unable to get an appointment to see your HIV doctor?	634 (85)	98 (13)	10 (1)
been notified of possible eviction from your home?	620 (85)	96 (13)	13 (2)
been notified of possible disconnection from your utilities?	511 (69)	168 (23)	63 (9)
been unable to get medications (lack of health insurance)?	140 (41)	143 (42)	58 (17)
been unable to get medications (lack of money)?	121 (34)	165 (46)	75 (21)

- Over 100 clients sought care in an emergency room at least once because they were unable to get an appointment with their HIV doctor (n=108/14%)
- A moderate percentage had been notified of possible eviction from their homes (15%) and even more of possible disconnection from their utilities (32%).
- Among those who were on medication, well over half had been unable to get medications at least once due to lack of health insurance (59%) and lack of money (67%).

**Comment:**

- Obtaining medications remains problematic for many clients. However, it is important to note that these figures apply to a small percentage of the sample. Only 48% of clients answered the money question, 46% answered the insurance question. This is because the final questionnaire administered accidentally omitted the "none" category for both medication questions. Several clients wrote the answer response as none or wrote N/A. For those who wrote none or N/A, we coded them as none and they were included in the final results reported here.

**Table 9: Gaps in Services in the Last Year**

Among those who sought the following services... how many times in the <u>past year</u> have you....	Frequency (%)		
	None	1-3	4 or more
had trouble getting dental care?	277 (53)	163 (31)	81 (16)
had trouble getting vision care?	324 (65)	129 (26)	49 (10)
had trouble getting specialty care?	333 (83)	54 (13)	15 (4)
had trouble getting mental health care?	306 (80)	52 (14)	22 (6)
had trouble getting alcohol/drug abuse services?	272 (94)	12 (4)	7 (2)
had trouble getting care coordination services?	546 (82)	81 (12)	39 (6)
had trouble getting HIV medical care appointments?	564 (83)	86 (13)	27 (4)

- Clients had the most difficulty getting dental care (47%) followed by vision care (36%).
- Clients had the least difficulty obtaining alcohol and drug abuse services (6%).
- About the same percentage of clients had difficulty getting specialty care (17%), mental health care (20%), care coordination services (18%) and HIV medical care appointments (17%).

**Table 10: Sought Core Medical Services**

	N	%
<b>Whether Sought Core Medical Services in the Last 12 Months (N=726)</b>		
Did not Seek Dental Care (N=726)	205	28
Did not Seek HIV Medical Care Appointments (N=733)	56	8

- Eight percent did not seek HIV medical care appointments in the last 12 months.
- Nearly a third of the sample had not sought dental care in the last 12 months (28%).

**Comment**

- The DHHS recommends that HIV labs normally be done every 3-6 months.\*
- According to the American Dental Association, the standard dental care recommendation is to visit your dentist twice a year for check-ups and cleanings.\*\*
- Most dental care that a person with HIV needs is the same as what an uninfected person would typically need. However, good dental care for PLWH is not a routine matter because oral health is a crucial component of overall health care for an infected person.\*\*

\*See DHHS *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*, <http://aidsinfo.nih.gov/contentfiles/AdultandAdolescentGL.pdf>

\*\*See HRSA Publication on Dental Partnerships, Ryan White HIV/AIDS program <ftp://ftp.hrsa.gov/hab/cbdpp.pdf>

## E. 2009 Service Gaps Compared to 2005 Service Gaps

Several of the questions from the ISDH 2005 Client Survey were included on the 2009 survey for comparisons. The 2009 survey modified some of the questions in an attempt to improve them. In addition, the 2005 survey did not allow for a ‘did not seek’ option to the services questions nor a ‘not on meds’ option to the medication questions. These response options were included on the 2009 questionnaire. The chart below compares the questions.

2005 Survey	2009 Survey
1. How many days in the last month were you hungry and unable to get food?	1. How many days in the last 30 days were you hungry and unable to get food?
How many times in the last month did you miss work, school, or a doctor’s appointment due to	How many times in the last 30 days did you miss work, school, or a doctor’s appointment due to
2. illness?	2. not feeling physically well or serious illness?
3. lack of transportation?	3. difficulty getting transportation?
How many times in the last year were you prevented from getting your medications due to	How many times in the past year were you not able to get your medications due to
4. lack of insurance?	4. lack of health insurance?
5. lack of money to pay for the co-payments or deductibles?	5. lack of money for the co-payments or deductibles?
How many times in the last year have you	How many times in the past year have you
6. been notified of possible eviction from your home or disconnection from your utilities?	6. been notified of possible eviction from your home or disconnection from your utilities?*
7. had trouble accessing dental care?	7. had trouble getting dental care?
8. had trouble accessing vision care?	8. had trouble getting vision care?
9. had trouble accessing specialty medical care (such as cardiology, endocrinology, or gynecology)?	9. had trouble getting specialty medical care (such as cardiology or gynecology)?
10. have you gone to the Emergency Room?	10. have you gone to the Emergency Room because you were unable to get an appointment with your HIV doctor?
11. have you felt that services were withheld from you due to discrimination against your HIV status?	11. did you feel that services of any kind were withheld from you due to discrimination because of your HIV status?

\* The 2009 survey asked the eviction and utility questions as two questions (one for each). We then computed the answer to match the question to the 2005 survey.

For each question, we analyzed if the 2009 percentage breakdown is statistically the same as the percentages from the 2005 survey. In cases where the percentages were not statistically the same as the 2005 results, we made an assessment as to whether the survey responses were "better" or "worse" than the 2005 results. As these items are negative events or hardships, a "better" outcome would be one where a higher percentage of clients than expected indicated that they have never experienced the particular hardship (i.e. those that are in the "None" category).

This technique is called a chi-square goodness-of-fit test. This statistical test gives the probability that a data set fits a particular prediction (i.e. the percentages from the 2005 survey). A limitation of this technique is that it is comparing two nonrandom samples and there were some slight differences in question wording in the two surveys. The advantage though is that it compares empirical data of similar groups – clients in HIV care coordination. Five hundred and fifty clients participated in the 2005 survey as compared to 746 in the 2009 survey. Table 11 presents the results below.

**Table 11: Question Comparisons to 2005 HIV Client Survey Findings**

Question	2005 Percentage None/1 or more	Frequency (%)		Outcome
		None	1 or more	
Days Hungry	66/34	551(75)	188(25)	Better
Missed work, school, medical appt. (illness)	60/40	373(50)	363(50)	Better
Missed work, etc. (transportation)	78/22	555(76)	177(24)	Same
Unable to take medications(no insurance)	79/22	140(41)	201(59)	Worse
Unable to take medications(no money)	69/31	121(34)	240(66)	Worse
Eviction/Utility disconnect	64/36	476(65)	252(35)	Same
Trouble getting dental care	56/44	277(53)	244(47)	Same
Trouble getting vision care	66/34	324(65)	178(35)	Same
Trouble getting specialty medical care	82/18	333(83)	69(17)	Same
Time in the emergency room	49/51	634(85)	108(15)	Better
Services withheld (discrimination)	75/34	567(78)	162(22)	Better

- For most measures, the gaps remained the same from 2005-2009. There was no statistical difference for work missed due to transportation, eviction/utility disconnect, or for trouble getting dental, vision, and specialty care.
- The number of times hungry in the last months may have improved since 2005 with nearly 10% less people experiencing hunger.
- The medication indicators show a marked increase in difficulties getting medications. Whereas only a third of individuals had trouble in 2005, nearly two thirds did in 2009. Importantly, this may be due to the 2005 sample not offering a ‘not on meds’ option. Nearly all individuals answered the medication questions in 2005 and it is highly unlikely that all 550 of those clients were taking medications. It may be safe to infer that the none category in 2005 was inflated with people who were not on medications in the past year.
- The number of people missing work, etc. due to illness also increased in 2009 by 10%.
- The number of people going to the emergency room was much less than in 2005 (15% in 2009 versus 51% in 2005). It is safe to infer that the high rate of use in 2005 was likely not due to difficulties getting a HIV medical appointment but rather because of other emergencies or accidents.
- Experiences of perceived discrimination also decreased in 2009 by 3%.

## F. HIV Services, Other Medical Services, and Support Services Needs and Gaps

Clients also indicated their degree of comfort sharing problems with their care coordinator. They were also asked to identify which HIV service they had the most trouble getting and to identify which other medical and support services were most important to them. They were only asked to check one category in each of the four areas. However, several clients checked more than one answer and were as such not included in the findings for all but two services. Separate figures were calculated for anyone who checked needing dental or vision services. At least half of the people who checked more than one service checked dental and vision. Table 12 reports the findings.

**Table 12: HIV, Other Medical, and Support services Needs and Gaps**

	N	%
Do you feel comfortable sharing your problems with your care coordinator? (N=704)		
None of the time	102	15
Sometimes	120	17
Most of the time	127	18
All the time	355	50
Which HIV service do you currently have the most trouble getting? (N=687)		
Help paying for HIV/AIDS Medication	76	11
HIV Case Management	42	6
HIV/AIDS Medical Care Appointments	29	4
No trouble getting these	540	79
Which of these other care services is most important to you? (N=465)		
Dental Care	147	32
Specialty Medical Care	112	24
Mental Health Care	54	12
Nutritional Care	43	9
Vision Care	37	8
Other	38	8
Home Health Care	15	3
Alcohol/Drug Abuse Services	10	2
Hospice Care	9	2
Which of these other care services is most important to you? (the numbers reported here include people who checked more than 1 service) (N=746)		
Dental	321	43
Vision	193	26
Which of these support services is the most important to you? (N=619)		
Services Not Needed	206	33
Emergency Financial and Food	201	33
Housing Assistance	155	25
Transportation	45	7
Translation/Literacy Services	10	2
Childcare	2	<1%

- The majority of the sample felt comfortable sharing problems with their care coordinator all (50%) or most of the time (18%), but some only felt comfortable sometimes (17%) and others never feel comfortable (15%).
- The vast majority (79%) reported no trouble getting HIV related services. 11% reported having difficulties with help paying for HIV/AIDS medications, followed by trouble getting HIV case management services (6%), and the least trouble for HIV Medical Care appointments (4%).
- When asked about other care services, clients considered dental care (32%) to be the most important, followed by specialty medical care (24%), and mental health care (12%).
- Forty-three clients prioritized the need for nutritional care (9%). Thirty-seven cited vision care (8%) as the most important service, and 38 requested "other" care (8%).
- Home health care (3%), alcohol/drug abuse services (2%), and hospice care (2%) were rarely mentioned as the most important services.
- When including people who checked more than one service as being the most important, 43% of clients prioritized the need for dental care and 26% considered vision care to be very important.
- Support services such as transportation or housing were not needed by 33% of the clients.
- Those who did need support services considered emergency financial and food assistance (33%) and housing assistance (25%) to be the most important, followed by transportation (7%), translation/literacy services (2%), and childcare (<1%).

## G. Cross Tabulations of Service Gaps and Needs by Select Sample Characteristics

We also examined whether significant gaps in services existed by five client characteristics: gender, race, whether the client has children in his/her household, care coordination region, and time the client had been in care coordination. Again, we used a Chi Square goodness of fit test. For the characteristics differences, this statistical test gives the probability that a pattern, or difference in-group characteristics, could have happened by chance alone. A statistically significant finding suggests that the pattern holds true for the sample. These results are presented below in Tables 13-18.

### G1. Gender Differences

**Table 13: Significant Findings for Gender**

	N	Men	Women	P Value
Has been notified of possible disconnection from utilities at least once in the past year.	711	28%	42%	<.001
Did not seek any dental care in the last 12 months.	694	26%	38%	<.005

Few gender differences emerged.

- Women were significantly more likely than men to have been notified of a possible utility disconnection in the past year.
- Women were also significantly less likely than men to have sought dental care in the last 12 months.

## G2. Race Differences

**Table 14: Significant Findings for Race**

	N	White	Black	Hispanic	P
Has been hungry one or more times in the last 30 days.	705	23%	26%	38%	<.05
Has been homeless or living in unstable housing at least once in the last 30 days.	700	6%	13%	23%	<.001
Has been notified of possible disconnection from utilities at least once in the past year.	709	28%	39%	39%	<.05
Has missed work* at least once in the last 30 days due to homelessness or unstable housing.	701	6%	12%	9%	<.05
Has missed work* at least once in the last 30 days because of transportation issues	699	20%	34%	28%	<.001
Has missed work* at least once in the last 30 days due to drug or alcohol abuse	704	6%	13%	4%	<.01
Has had trouble getting medications due to lack of insurance in past year	325	50%	77%	70%	<.001
Has had trouble getting medications due to lack of money in past year	350	59%	83%	86%	<.001
Has had trouble getting vision care in the past year	482	39%	29%	24%	<.05

\*Refers to work, school, or a doctor's appointment

Significant racial group differences exist for poverty indicators, problems that interfere with ability to work, and situations that interfere with ability to receive medical care. For each of these types of differences, Whites tended to fare better overall than either Blacks or Hispanics.

- Hispanics (38%) were more likely than either Blacks (26%) or Whites (23%) to have been hungry in the last 30 days.
- Being homeless or living in unstable housing within the last thirty days was also more likely for Hispanics (23%) than for other groups; the disparity between Whites (6%) and Blacks (13%) for this poverty indicator was also pronounced.
- Experiencing possible disconnection from utilities was equally likely for Blacks and Hispanics (39%) and 28% of the Whites had this same experience.
- Blacks had a higher likelihood of having problems that interfered with work than did Whites or Hispanics.
- Blacks (12%) were more likely than Hispanics (9%) or Whites (6%) to miss work, school, or a doctor's appointment due to homelessness or unstable housing.
- Blacks (34%) were also more likely than Hispanics (28%) or Whites (20%) to miss work, school, or a doctor's appointment because of transportation issues.

- Hispanics (4%) were the least likely of the three groups to report missing work, school or a doctor's appointment due to drug or alcohol abuse; Whites (6%) experienced this slightly more often, and Blacks (13%) were the most likely to report this problem.
- The situations that interfered with ability to receive medical care differed for each racial group.
- Blacks (77%) had trouble getting medications because of a lack of insurance. The majority of Hispanics (70%) also had problems getting medications for this reason. Fewer Whites (50%) reported this problem than did other groups.
- Lacking money for medication interfered with one's ability to receive medication slightly more for Hispanics (86%) than it did for Blacks (83%), and substantially more than it did for Whites (59%).
- Experiencing trouble receiving vision care is the only measure on which Whites (39%) fared more poorly than did Blacks (29%) or Hispanics (24%).

### **Comment**

- There are many possible explanations for why fewer Hispanics experienced problems that interfered with work than did Blacks. One is that the form and function of community networks may differ for these groups in such a way that the effect of problems like homelessness or unstable housing, transportation issues, and drug or alcohol problems are more effectively mitigated for Hispanics than for Blacks. Another could be the kinds of jobs held by Hispanics and Blacks. Blacks could occupy more "front stage" jobs where it may be difficult to go to work and deal with customers when under stress. Hispanics are more likely to occupy "behind the scenes" jobs where they have to worry less about appearance due to less face-to-face interactions with customers. This explanation would also suggest that our measure for homelessness and unstable housing might not be capturing poverty for Hispanics in the same way as it does for racial groups with different community support networks.

### G3. Households with Children Differences

**Table 15: Significant Findings for Households with Children**

	N	No Kids	Yes Kids	P Value
Has been hungry one or more times in the last 30 days.	730	23%	34%	<.05
Has been homeless or living in unstable housing at least once in the last 30 days.	725	8%	14%	<.05
Has been notified of possible disconnection from utilities at least once in the past year.	734	28%	44%	<.001
Has missed work, school or a doctor appointment at least once in the last 30 days due to distress such as depression.	723	37%	46%	<.05
Has missed work, school or a doctor's appointment at least once in the last 30 days due lack of childcare.	714	1%	13%	<.001
Has felt that services of any kind were withheld due to discrimination because of one's HIV status?	722	20%	31%	<.05

When comparing those living in households with children and without children, there are significant differences in poverty indicators, experiencing problems that interfere with ability to work, and experiencing HIV status discrimination. Households with children fare consistently worse.

- Individuals in households with children (34%) are more likely than those who live without children to have been hungry in the last 30 days.
- Homelessness and unstable housing affects those in households with children (14%) more often than those without children (8%).
- Clients living with children (44%) are far more likely than those without children (28%) in the household to be notified of possible utility disconnection as well.
- Forty-six percent of clients living with children suffer from depression or some other form of distress that they report has resulted in missing work at least once in the past 30 days. For clients in households without children, thirty-seven percent missed work, school, or a doctor's appointment in the past 30 days for this reason.
- Predictably, those living with children (13%) were far more likely to miss work, school, or a doctor's appointment due to lack of childcare than those without children (1%).
- Discrimination in the form of being denied services is more common among clients living with children (31%) than those living without children (20%).
- Women were significantly more likely than men to have someone in their household under the age of 18; 38% of the women versus only 13% of the men had children or youth in their household (p<.001).

#### G4. Care Coordination Region Differences

**Table 16: Significant Findings for Care Coordination Region Differences**

Region	Trouble HIV Care	Trouble HIV CC	Trouble Dental	Trouble Vision	Need Dental
Total N	649	637	500	486	711
P Value	<.01	<.001	<.05	<.05	<.05
1. Gary Area	17%	17%	52%	30%	51%
2. South Bend Area	14%	10%	49%	35%	56%
3. Fort Wayne Area	7%	7%	47%	24%	42%
4. Lafayette and Terre Haute Area	7%	11%	73%	67%	62%
5. Muncie, Richmond, Anderson Area	19%	19%	55%	36%	47%
6. Indianapolis Area	24%	28%	39%	34%	36%
7. Bloomington Area	19%	26%	27%	25%	31%
8. Jeffersonville Area	6%	6%	43%	35%	38%
9. Evansville Area	12%	6%	56%	50%	42%

Access to care and need for care vary across Care Coordination Regions.

- Clients in the Indianapolis area (24%) are more likely to have trouble getting HIV care than those from any other region. The Muncie, Richmond, and Anderson (19%) and the Bloomington (19%) areas are second most likely to have trouble with this. The Gary (17%), South Bend (14%), and Evansville (12%) areas were less likely to have trouble getting HIV care, and the Fort Wayne (7%), Terre Haute and Lafayette (7%), and Jeffersonville (6%) areas were least likely to have trouble.
- The disparity in clients' ability to get care coordination appointments followed a similar pattern. Those in the Indianapolis area (28%) were the most likely to have problems getting care coordination appointments. Bloomington area (26%) clients were nearly as likely to have experienced problems. Muncie, Richmond and Anderson (19%), Gary (17%), Lafayette and Terre Haute (11%), and South Bend area clients were less likely to report problems getting care coordination appointments. Those in the Fort Wayne (7%), Jeffersonville (6%), and the Evansville (6%) areas were the least likely to have trouble.
- Nearly three-quarters of clients reported trouble getting dental care in the Lafayette and Terre Haute area (73%). More than half of clients reported trouble getting dental care in the Evansville (56%), the Muncie, Richmond, and Anderson (55%) and in the Gary (52%) areas. The South Bend (49%), Fort Wayne (47%), and Jeffersonville (43%) areas fared better, but Indianapolis (39%) and Bloomington (27%) were the least likely to report problems.
- Clients were more likely to rank dental services as their most important need in the Lafayette and Terre Haute (62%), South Bend (56%) and Gary areas (51%). Dental is least in demand in areas that have access to Ryan White Dental funding, Indianapolis - 36% and Jeffersonville – 38%. The Bloomington area has the least need for dental (31%)

- The Lafayette and Terre Haute area (67%) was also the region with clients who were most likely to report problems getting vision care. Evansville (50%), Muncie, Richmond, and Anderson (36%), South Bend (35%), Jeffersonville (35%), and Indianapolis (34%) area clients were less likely to have problems, and Bloomington (25%) and Fort Wayne (24%) clients were the least likely to indicate having trouble getting vision care.

**Table 17: Significant Findings for Care Coordination Region Differences**

Region	MissWork Transport	Last 30 DaysHungry	Last Year Eviction
Total N	700	705	699
P Value	<.05	<.05	<.05
1. Gary Area	24%	25%	19%
2. South Bend Area	15%	15%	11%
3. Fort Wayne Area	17%	13%	9%
4. Lafayette and Terre Haute Area	27%	33%	6%
5. Muncie, Richmond, Anderson Area	25%	28%	15%
6. Indianapolis Area	32%	30%	21%
7. Bloomington Area	15%	14%	9%
8. Jeffersonville Area	20%	30%	6%
9. Evansville Area	13%	17%	15%

- The proportion of clients who missed work, school or a doctor’s appointment due to transportation problems was highest in the Indianapolis area (32%). Lafayette and Terre Haute area (27%), Muncie, Richmond, Anderson (25%) and Gary (24%) also had a fairly large proportion of clients with this problem. Jeffersonville (20%), Fort Wayne (17%), South Bend (15%), Bloomington (15%) and Evansville area clients were less likely to miss work, school, or a doctor’s appointment for this reason.
- Differences between care coordination regions also appeared for these poverty indicators. Being hungry within the last 30 days and being notified of eviction in the past year followed a similar pattern with the notable exception of the Lafayette and Terre Haute Area and the Jeffersonville Area. Clients in these care coordination areas were the most likely to indicate that they had been hungry in the last thirty days (33% and 30%) but the least likely to report being given an eviction notice (6%).
- Regions with the most hungry clients were Lafayette and Terre Haute (33%), Jeffersonville(30%), and Indianapolis areas (30%). Muncie, Richmond, Anderson (28%), and Gary areas (25%) followed, and Evansville (17%), South Bend (15%), Bloomington (14%), and Fort Wayne (13%) areas had the fewest clients reporting hunger.
- Eviction notices were most common in the Indianapolis (21%) and Gary (19%) areas. Muncie, Richmond, Anderson (15%), Evansville (15%), and South Bend areas (11%) had fewer, and Bloomington (9%), Fort Wayne (9%), Lafayette and Terre Haute (6%) and Jeffersonville areas (6%) had fewer still.

## G5. Time in Care Coordination Differences

**Table 18: Significant Findings for Time in Care Coordination**

	N	1-12 Months	> 12 Months	P
Been homeless or living in unstable housing at least once in the last 30 days.	711	14%	8%	<.05
Missed work, school or a doctor's appointment at least once in the last 30 days due to homelessness or unstable housing.	720	14%	6%	<.01
Had trouble getting HIV medications (lack insurance).	334	80%	54%	.001
Had trouble getting HIV medications (difficulty paying).	348	78%	66%	.05
Did not seek any dental care in the last 12 months.	702	37%	27%	.05
Had trouble getting mental health care in last 12 months.	367	35%	17%	.01
Had trouble getting HIV medical care appointments in the last 12 months.	656	25%	15%	<.05
Did not seek any HIV medical care in the last 12 months.	710	17%	6%	<.001

Those in care coordination for longer than 12 months consistently fare better on the above measures of poverty, care seeking, and care stability than those in care coordination for shorter periods.

- Those in care coordination longer than 12 months were less likely to experience homelessness or unstable housing (8%), miss work, school, or a doctor's appointment due to homelessness or unstable housing (6%), have trouble getting medicines due to lack of health insurance (54%) or money (66%), have trouble getting mental health care (17%), and HIV medical care appointments (15%), than those who had been in care for shorter periods (14%, 14%, 80%, 78%, 35%, 25% respectively).
- Failing to seek dental care was less common among those in care longer than 12 months (27%) than those in care shorter periods (37%).
- Seeking HIV medical care in the past year was also more likely among those in care longer than 12 months; Seventeen percent of those in care coordination for a shorter period failed to seek HIV medical care, and only 6% of those in care coordination for longer than 12 months failed to seek HIV medical care.

### Comment

- Another explanation for these patterns is that the most difficult clients drop out of care coordination, which may artificially decrease the hardship experienced among the greater than 12 month group. Likely the pattern, however, is a combination of both factors. Care coordination is having a positive effect on client's needs, at the same time that some of the most difficult clients do not stay in care coordination past a year.

## **H. Analyses of Open-Ended Question – Indiana Core Service Needs**

The final question on the survey invited clients to “please use the space below to tell us, in your own words, how you think the State of Indiana can improve its services for HIV positive people?” About a third of the clients provided comments to this question.

Analyses of their answers provide additional insights into the difficulties clients have meeting their needs. This section is organized using headers that correspond to Indiana priority service areas (these also correspond to HRSA Core service areas).

For each section, we provide a summary of findings from the statistical tables presented earlier in the report. We then summarize the major themes in the open-ended responses and follow these with select quotes to illustrate the findings. In cases where responses were nearly identical, i.e., ‘we need dental’ only one was included. Quotes include the client’s region. In some cases, clients did not provide their zip code so their region is not known. Other descriptors such as race and gender were not included to ensure anonymity for the client.

## **H1. Primary Medical Care**

The survey found that about 17% (n=126) of clients had some difficulties with primary medical care. Eight percent of the sample had not sought a HIV medical appointment in the last 12 months and slightly more had not done their HIV lab test in the previous 6 months (10%). In addition, 14% of the sample sought HIV-related care in an emergency room because they were unable to get an appointment to see their HIV doctor. Specific concerns regarding the cost of primary medical care, which emerged in the context of difficulties with co-payments, spend-downs, and premiums, are discussed in the insurance section of this report. Here the report illustrates non-financial concerns with primary HIV care that were reflected in the clients' answers.

### **Lack of Infectious Disease Providers**

- In my city, there is only one infectious disease doctor. Receiving poor care from this doctor has forced myself into seeking care 60 miles away (Region 4).
- Better doctors in Delaware County. The one here is not the greatest. We only have one here, need more, so we don't have to go to other cities to find good care (Region 5).
- Have more infectious disease doctors available (Region 11).

### **Difficulties Getting Appointments**

- Only one Dr. for HIV. Can't ever get in to the Dr. Usually wait more than 30 days for appointment or go to emergency room or walk in clinic which sucks (Region 10).
- Quicker appt. (usually have to wait 1-2 months) (Region 7).

### **Provider Insensitivity**

- New doctors that aren't part of the good old boys network of apathy, disdain, and discrimination (Region Not Listed).
- Have doctors in public medical clinics take your illness more seriously instead of just a revolving door, like I was treated at the East Chicago medical center, luckily I found a true caring doctor after I almost died twice (Region 1).
- I feel Community Anderson emergency room doesn't give a shit (Region 6).

### **General Negative Care Experiences**

- I give Wishard a 3 on getting appointments, a 4 on follow-ups, 8 for friendliness face to face. If I was not getting away from Wishard I feel I could be dead in a year (Region 7).

### **Patient Choice**

- Let a person choose their own doctor. It is abusive to see a new doctor every time the assigned decided to not see patients for various other reasons. Each time I have to get a referral to my own HIV doctor (a specialist, but the only one I need), which wastes my time, the doctors time and taxpayers money (Region 2).

## **H2. HIV-Related Medication**

Even though the majority of the sample had insurance coverage of some kind, paying prescription costs were still a problem for many. Of those clients on HIV medications (about 360 clients), over half reported difficulties getting HIV medications due to lack of health insurance (59%) or difficulty paying because of lack of money (67%). In addition, some clients pointed out that the HIV medications themselves cause additional health problems. Others have multiple health issues, requiring numerous non-HIV medications that they have difficulty affording. Some also expressed frustration with bureaucratic ‘red tape’ and experience the available assistance as a hindrance. These concerns are illustrated below.

### **HIV Medications Can Cause Other Health Problems**

- My teeth are rapidly decaying due to meds (Region 10).
- My teeth are rotting due to the medications (Region 1).
- Having had this illness well into my second decade, you (these people) end up developing more and more complications due to virus and medications (Region 1).
- If certain medications result in a physical handicap. I believe a bit of assistance or insured financing should be immediately available. The other alternative is to quit taking effective HIV fighting meds. I have lumps the size of small potatoes behind my ears and skull. It acts just like a vice squeezing to a great degree of discomfort. Compounded with additional lipodystrophy between my shoulder blades. I do not sleep much. Hinders mobility and head movement (Region 10).

### **Multiple Health Issues that Require Medications for /non-HIV care**

- I have multiple health issues; 12 oral meds and 4 scripts for diabetes supplies (Region 2).
- I’m not in need of HIV meds but my overall health has some issues that need taken care of (Region 6).

### **Costs of Medications**

- It’s the cost of the meds and the insurance that [is hard]. I haven’t been on meds for over 4 months cause I can’t afford them. I believe there should be free clinics and financial aid to be able to help us get the meds. Our meds is what saves our lives. I don’t want to die because I can’t afford my meds (Region 6).
- It would be better service if HIV + people with commercial insurance didn’t have such high co pays for medication. I’m currently not on meds but if I had to pay for expensive meds I would seriously consider not taking any meds at all (Region 7).
- My insurance plan has a \$10,000 cap on meds so I feel getting the medications to patients is very important. I hope the state can help in this area. Providing the medications needed in the case of HIV/AIDS patients (Region 1).
- My Medicaid spend-down is close to \$1,000.00 and often times I have to go without medicine since I can’t afford this amount and still pay my bills (Region 1).

- If you have insurance that the insurance doesn't cover medication for HIV it is impossible to get it, I been 3 months trying to get medications and still no one can't help me (Region 7).
- I'm on a waiting list to get on insurance to help me get the meds I need to take. State of Indiana needs to help make getting the drugs we as HIV people need available (Region 7).
- Have their own type of insurance for HIV + patients so they won't have a problem paying for meds or doctors visits (Region 7).
- They haven't been able to get my meds yet for insurance purposes (Region 11).
- If I had a copy on my 7 monthly meds, I could not be able to keep my home, already struggling. (Region 7).
- Medication co pays. there are some meds the Medicare won't cover (Region 8).
- I just (after 3yrs.) got private ins but still cannot afford my meds... (Region 11).
- The 1-year residence requirement prevents getting a lot of meds on that ADAP formulary (Region Not Listed).

### **Red Tape**

- Improve the Damien Center services the case workers are seriously lacking in their ability to help or even to do their job! They don't file paper work on time etc. etc. etc. making you lose your medical and prescription coverage for months at a time even though you filed necessary paperwork (Region 7).

### **H3. Oral (Dental) Health**

Meeting the dental care needs of people with HIV/AIDS in Indiana is a challenge. Nearly a third of the surveyed clients (28%) did not seek dental care in the last 12 months. Among those who sought care, nearly half had trouble getting dental care (47%). Further, 43% of the sample identified dental care as the non-HIV service most important to them. Over 100 clients mentioned troubles accessing dental care in response to the open-ended question.

These responses suggest that most clients do not have private dental insurance and/or cannot afford, or lack knowledge of, free to low-cost dental care. Coverage that is specifically available for people with HIV/AIDS has time-use and region restrictions. For example, the State funded EIP program only provides dental coverage during the three months that ICHIA approved clients must exhaust before ICHIA will cover HIV-related medical expenses. Medicaid offers dental coverage, as does Ryan White part A and C for residents of the Transitional Grant Area (Marion and surrounding counties), and Wishard Advantage for residents of Marion County. However, Medicaid has high spend-downs which may be difficult for many people with HIV/AIDS to meet and the Ryan White and Wishard Advantage coverage is limited by residence. Medicare does not provide dental coverage.

Although several dental clinics and providers throughout the state work with low-income clients via sliding scales, people with HIV/AIDS may have difficulty even meeting these small fees, and others may fall outside the income required to qualify for a sliding fee scale. Finally, some clients may not go to a dentist because they fear they will be treated poorly or that the dentist may be afraid to provide them with services. These barriers are illustrated in the clients' responses. In addition, their comments highlight some of the unique dental needs of people living with HIV/AIDS. Select comments follow below.

#### **Dental Coverage and Assistance Needed**

- Better dental coverage for all counties (Region 10).
- Dental care. I need teeth to eat with (Region 2).
- Dental care needed badly! (Region 10)
- Dental insurance ASAP (Region 1).
- Help with dental! Help with dental! Help with dental (Region 2).
- There is not HIV dental service in Vigo county!!! There is HIV dental service in Marion and surrounding counties??? This geographic discrimination called redlining (Region 8).

#### **Oral Health Problems because of Medications/HIV**

- Dental care has been my #1 problem. My teeth are rapidly decaying due to meds (Region 10).
- I hope to see the return of dental. Twenty years of medications has done a lot of damage to my teeth (Region 12).
- Offer dental care. Can't afford out of pocket but need teeth removed because of recurring infections due to HIV status. Therefore my health is always poor (Region 4).

- Due to lack of dental ins. My teeth are rotting due to the medications. I have been to the dentist; out of pocket is too expensive!! I cannot afford to pay the amounts dentist charge. Need dental coverage (Region 1).

### **Dental as it Relates to Other Health Issues**

- HIV can cause problems w/dental; problems can affect HIV (Region 7).
- Offer dental care! Please! With HIV, oral health is very important, and since many health conditions can be found early in oral exams, this would be very helpful to all with HIV/AIDS (Region 12).
- A serious program for dental. A lot of issues stem from dental problems should be included in health services (Region 3).
- We need dental care very bad. When your teeth start to rot and fall out it can cause dangerous problems for your health. We need dental very badly (Region 3).
- Provide dental services. Dental affects other health issues and should be addressed as such (Region 1).
- I think dental care is much needed. Dental problems can lead to more issues. Having bad dental health not only leads to heart disease but bleeding gums, which put others in risk. I haven't even been able to afford to get to the dentist in almost 8 years now and am having major problems. Teeth ½ to ¾ gone and am having raw sores in roof and jaw to even get a tooth pulled is \$75.00 (Region 12).
- Dental and vision coverage would be helpful especially dental as prevention of mouth problems would not go into something more serious (Region 12).

### **Financial Difficulties**

- More aid for dental care would be wonderful. Can't afford (Region 10).
- As for me dental care is hard. I am low income and can't afford dental insurance so I let my teeth cleaning etc. go now I need lots of work done. I am missing fillings, lost a crown. I do the best I can without this services (Region 3).
- Dental care would greatly help people not on Medicaid. Dental care is so far out of my reach. My teeth are in horrible condition but without financial asst. I have to just let them go (Region 9).
- I have some broken teeth I can't afford to fix (Region 9).

### **Dental Residency Restrictions**

- If dental can be offered in Marion County it should be available to everyone in the state (Region 12).

### **Discrimination and Stigma**

- Dentists are afraid to provide services to HIV patients (Region 6).

#### **H4. Case Management**

Case management, or HIV care coordination, assists people with HIV to access needed medical and social services and to maintain a continuum of care. Over 100 of the clients surveyed (18%) had difficulty getting care coordination services at least once in the last year, a quarter of these had trouble four or more times. Fifteen percent of the sample never feels comfortable sharing their problems with their care coordinator. An additional 17% only sometimes feel comfortable. Some of the barriers to care coordination services are illustrated below.

Many clients also praised care coordination services (see section L). Similarly, the longer a client is in care coordination (less than one year when compared with more than a year), the more he/she improves on several needs indicators, including improved percentage of clients meeting their food, housing, utility, mental health care, HIV medication, and HIV medical care needs (see previous section G5). These findings suggest that despite continued difficulties meeting the care coordination needs of clients, the provision of such services is having a positive effect on client need outcomes.

#### **Negative Experiences**

- Our care coordinator is always forgetting to bring paperwork, gas cards, bus passes or even out of them and can't seem to help when in need of one. She seems to be overwhelmed so easily and not able to handle workload; not helpful and uninformed but will find out and get back. She never does. I feel that care coordinator is not in it for each individual client, but likes to pick and choose who she will help (Region 8).
- The organization ARG never helps or makes contact with me, even when I go to the office looking for help. I think ARG need to be investigated (Region 12).
- Improve the DFC and Damien Center services. The caseworkers are lacking in their ability to help! Will not return phone calls; really bad services; don't file paper work on time making you lose your medical and prescription coverage for months at a time even though you filed necessary paper work. When you try to speak with the caseworker's bosses they won't return your phone calls either and your left hanging, and told to take matters up w/case worker. It's a never cycle of bull crap and red tape (Region 7).
- Better care coordination! Damien sucks! They are rude, crude and cold! (Region 7).

#### **Care Coordinators not well Informed about Services**

- When I first went on Medicare at age 65, my care coordinator at that time was not aware of the MDAP program. My first year on Medicare cost me serious financial hardship. Had my care coordinator been aware and/or helped me with MDAP at that time it would have been very helpful (Region 10).
- Better-informed care coordinators (Region 1).

#### **Need for Bilingual Care Coordinators**

- We don't read or speak English, our coordinator is of great help (Region 2).

## **Geographic Related Barriers**

- There is no care coordinator office in my town (Region 2).
- I live in a small town. My care coordinator is in Indpls. This past winter I was sick to drive to and from Indy. Lay in bed days at a time unable to even fix a can of soup for myself. I was just too sick even to call 911. Called the Damien Center to find out my new care coordinator name; no one knew. They said someone would call me back. I never got a call back. I do not know the name of my new caseworker (Region 9).

## **Difficulties Reaching Care Coordinator and Getting Appointments**

- I only had trouble reaching my care coordinator to ask a question. I can't leave a message for her. Called multiple times on various days, at different times of day. I simply got a voice mail message. I realize they are busy but not in their office even once (Region 6).
- When I call, they are never in. Takes 3-4 days to return calls (Region 8).
- Make sure care coordinators follow up when their clients call. I'm fortunate that I don't need many services, but when I need help it would be nice for my C.C. at the Damien Center to call me back. I was very disappointed in her lack of help (Region 7).
- Not particularly fond of the "we'll call you back" atmosphere for case management. Sometimes need help with new cases, stress and no ear to listen (Region 10).
- Need to improve the availability of HIV care coordination appt (Region 7).

## **Care Coordinator Turn Over Issues**

- I do find it difficult because it seems that caseworkers change very often (Region 7).
- I have been HIV + 9 months. I have been 4 different care coordination. It is now April and now I have the proper insurance for my HIV treatment. To sum it all up, my HIV treatment could have began a long time ago (Region 7).
- My care coordinator was promoted and I currently do not have one. I have been patiently waiting (Region 7).
- My care coordinator is very great and helpful to and for me I have one problem. Stop changing them every 6 to 1 year I don't like to get close then you change them I feel that's wrong!! (Region 1).
- To fine the funds to keep the good care coordinators around (Region 7).

## **Other**

- More responsible case managers (Region 7).
- Of course, more employees for case management and care coordinators (Region 7).
- Care coordination sites should have 5% of their caseworkers HIV + regardless of a college degree. Good people who want and can do the job are being discriminated against by this prerequisite (Region 12).

## **H5. Mental Health and Substance Abuse Treatment**

Just over 10% of the sample identified mental health needs as the most important non-HIV specific medical service that they needed the most. Additionally, nearly 40% of the sample had missed work, school, etc, due to mental distress at least once in the last 30 days. Among those who sought mental health services, 20% had experienced difficulties obtaining these services at least one or more times in the past year. Six percent of those who sought drug and alcohol services had difficulties obtaining such services. Only 2% identified drug and alcohol services as their most important non-HIV specific medical service need. Some clients provided further insight into difficulties with mental health and substance abuse services in the open-ended responses. These findings are highlighted below.

### **General Alcohol/Drug Abuse and Mental Health Services**

- I feel that mental health care and alcohol/drug abuse services is where Indiana should improve. It should be easier to get this help. Dealing with the stigma of HIV in society makes so many of us unstable mentally or turn to drugs/alcohol to deal (Region 7).
- Expand healthcare to mental health, and alcohol and drug abuse services. These are critical to HIV positive individuals (Region 1).
- Would like more aid for mental health (Region 12).
- Very few (none covered by Medicaid/Medicare) services for alcohol and drugs inpatient service in Elkhart county (Region 2).

### **Clients Experiencing Depression and Anxiety**

- I find it hard to find solid employment and happiness in my life due to the depression and emotional stress having AIDS and HIV gives me (Region 3).
- I am concerned with help for mental health for anxiety, depression, etc. (Region 9).
- Provide information on how deal with stressful situations (Region 11).

### **Being Unhappy with Mental Health Facilities**

- Need more mental health services other than Midtown (Region 7).
- Provide better mental health facilities that listen to the patient and not make personal recommendations about patients. Places that provide mental health along with HIV treatment (Region 7).

## **H6. Transportation**

Transportation can be a huge barrier to accessing services. A quarter (25%) of surveyed clients had missed work, school, or a doctor's appointment at least once in the last 30 days because of difficulties with transportation. Ten percent had missed work, school, or a doctor's appointment at least 4 times or more in the last 30 days. Of those who need support services (e.g., housing assistance, childcare, transportation), 7% listed transportation as their most important need. Responses to the open-ended question also mentioned transportation concerns. Some clients requested financial assistance for maintaining their own vehicles, gas cards, and bus passes in order to get to appointments. Transportation needs are not limited to reaching care services or employment. Clients also requested help with transportation to other kinds of destinations such as church or social events. Finally, rather than framing their problem as related to transportation, some clients suggested that the issue was the location of care and service sites. Clients suggested alternatives to shuttling themselves to different locations, including allowing for doctors and care coordinators to make home visits or clustering HIV services in the same locations. These transportation themes are highlighted below.

### **General Transportation Needs**

- Provide more transportation for those HIV+ people who need the help (Region 10).
- More help with long distant Dr's appts. So care coordinator could take me if needed. There is no care coordinator office in my town, so it's not as easy to access some services (Region 2).
- Transportation for folks who can't get a car or drive (Region Not Listed).
- Need transportation to and from Dr. as my Dr. left the area. Now have to find another Dr. in Indy or Fort Wayne. Too far to walk for grocery and bank (Region 5).

### **Missed Medical Appointments due to Transportation Barriers**

- Transportation has been a very hard impediment to accessing services in Indianapolis. Bus passes are always gone when I ask. Can't keep appts. Because of no transportation or money to afford bus (Region 7).
- I feel as though some transportation could be provided for people over a 50-mile radius because sometimes I have to wait for my monthly check to make sure I have gas to put in my mom's car to go to my doctor or coordinator (Region 12).
- It's difficult for many HIV + people to get to and from appointments with various doctors and coordinators due to transportation issues. Allowing people with HIV/AIDS to have the same type of public transportation allowances that are given to the elderly and handicapped would be a tremendous help (Region 7).

### **Gas Assistance for Long-Distance Appointments**

- Gas to get to coordinator which is 25/30 miles away (Region 1).
- I live in Grant Co. My doctors are at I.U. 70 miles one way. When the price of gas is high gas cards would be great (Region 5).

- A gas card could help paying for fuel, since I have to drive 150 miles for medical services for HIV (Region 6).

### **Rural Transportation Needs**

- Finding a ride is very difficult in my rural location (Region 9).

### **Provide Bus Passes**

- Provide some more bus passes for our transportation would be nice (Region 7).
- I think transportation (i.e. Bus fare and or cab) would help greatly, to get back and forth to appointments, banks, and grocery stores and pharmacies (Region 7).

### **Vehicle Repair Help to Maintain Transportation**

- Set aside funds for vehicle repairs. I have a car but its 15 years old and I sometimes can't afford the upkeep. Just had to cancel my 6 month HIV check up because my brakes are bad (Region 9).
- In my city, there is not a choice of other then one infectious disease doctor. Receiving poor care from this doctor has forced myself into seeking care 60 miles away at IU Medical Center. This difficulty in having the help with vehicle maintenance. This is a must (Region 4).

### **Requesting Transportation Assistance for non-HIV Related Destinations**

- Make available transport for those who go to church on Sat/Sun (Region 2).
- I think that there should be more activities programs out there for HIV clients to attend free, people don't go anyway now, no money, no transportation (Region 7).

### **Need for In-home Services and One-stop-shops**

- It would also be a major help if the different HIV/AIDS agencies had an outreach program for those with transportation difficulties. i.e., at home appointments (Region 7).
- I believe that the services for HIV patients would be more utilized and be easier to maintain and improve if everything were in one location i.e. care coordination physicians, lab, pharmacy, support groups and etc. in one facility (Region 10).
- Care Coordinators are helpful especially when they can come to your home (Region 6).

## **H7. Housing**

Although housing is not currently defined as a HRSA priority area, Indiana has included housing among its priority areas. Findings from the survey clearly show that stable housing is critical to the care of people living with HIV/AIDS. Nine percent of the sample had experienced homelessness or unstable housing at some time within the previous year. 7% had missed work, school, or a doctor's appointment at least once in the last 30 days because of unstable housing, and 15% of the sample had been notified of possible eviction from their home. A quarter of the sample identified housing assistance as the second most needed support service. The need for housing assistance also emerged in the clients' answers to the open-ended question. The housing needs were varied, including need for rental and mortgage assistance, need for drug free housing, need for assistance in finding better housing, and more transitional housing options. These themes are illustrated below.

### **General Housing Needs**

- The housing assistance can be much better and if we have apartments and stable housing we'll be able to relieve a little stress (Region 1).
- Better assistance on a person's mortgage, rent and utilities (Region 5).
- I work with the federal government, I revise the elevated rental housing costs for people living with disabilities and terminal illnesses so that there is the possibility that they can live on their own and afford their residence (Region 11).
- I would like to see better housing assistance more funding, better and more rental options, nicer rentals in better neighborhoods (Region 7).
- More help with housing regardless of amount of work hours (Region 11).
- Housing, If you get SSI most rent 550 monthly then you pay utilities. Nothing left to live on. I need HOPWA (Region 7).

### **Better and Lengthier Rental Assistance**

- There needs to be more access to rental assistance. I've been on a waiting list for over 2 years and was bumped off of it because I couldn't get an appointment. Due to my schedule for work to get in to see my coordinator. That shouldn't be a stipulation. I'm being responsible and working, but I'm the one that was cut off the list (Region 7).
- I think the housing help \$ was great but it needs to be longer than 9 months (Region Not Listed).
- And make the rent \$ programs longer than 2 years. I have been on rent assistance, filed for SSI/SSDI in 2007 (still pending) cannot work, do to many health problems. Loss of pt. job to health no \$ coming in. Lease is up in June 2009 and have to find a place and fast (Region 6).

### **Emergency Financial Assistance**

- More help in the emergency financial and housing would help greatly. Esp. for people like me on a fixed income. Prices keep going up but my income stays the same (Region not listed).

## **Help for Homeowners**

- We have a mortgage and I'm told housing assistance is limited. If I were renting I would be eligible for housing asst. This seems unfair and causes me a lot of stress well's Fargo threatens foreclosure monthly (Region 12).
- I own my house. I need a roof. The state should have a way to improve a person's habitat without waiting till I'm 62 (Region 6).
- Help us pay utility, home insurance, taxes, etc. for those of us who OWN our own homes and cannot get help without first going through the local trustee's office, who are hateful (Region 6).
- I am disabled an unable to meet my monthly expenses. I have a mortgage rather than a lease so I do not qualify for HOPWA. My payments are less than most rentals. I would not gain anything by selling my home. I have gradually gone 13,000 in credit card debt over the past ten years to meet my budget shortfalls. Please expand HOPWA parameters to include mortgages as well as rentals, within reason, of course. Maybe a cap on home value (Region 1).

## **Need for Housing Services to Find Housing**

- Please help me find drug free housing please (Region 7).
- Help me to get my own place to stay. I don't need a large place, a studio apt. or a kitchenette would be fine, right now I am staying with other people. I am not comfortable living here (Region 7).
- I think the state could help with housing for people with HIV that can't work and have children to care for. Not sharing a house with others when we have children to take care of (Region 3).
- State should be able to help people that have HIV to get a place to live on their own. I came from prison a year ago and I'm still in a half way housing (Region 12).

## **Other Housing Concerns**

- Have other options for people trying to get a place to live when there are no women's shelters in the city where they live and don't have transportation to get to one in another city (Region 6).
- Have housing for HIV'ers and their partners (Region 6).
- I live in Jefferson county IN. and am getting assistance by HOPWA for housing, but I would like to apply for section 8-HUD. I am continually told they are not accepting applications by the people at the Ohio Valley Opportunities office (Region 11).
- It would be nice to not have to worry about being evicted. We don't qualify for buying a home due. I wish Indiana had something similar to Section 8 for people with HIV/AIDS. We are on disability and make too much for Section 8 but not enough for rent, security deposit and moving expenses. We fall through the cracks (Region 7).
- Get the legislative to appropriate their share of funds and stop relying exclusively on Ryan White and HOPWA (Region 7).

## **I. Analyses of Open-Ended Question – Other Service Needs**

### **II. Financial Assistance**

Nearly 90% of the sample was living at less than 225% of the poverty level, half of whom were living at less than 100% of the poverty level. It's not surprising then, that 33% of the sample listed emergency financial assistance and food as their most needed support service. For some the need for financial assistance is periodic, but for others the need is ongoing. Financial help is needed for transportation, food, medical bills, utility bills, housing and household costs, caregiver costs, car repairs, and to provide semi-durable personal items like clothing and shoes. Many people also complained of falling into a 'gray area' in terms of what kind of financial support they are able to access. Counter intuitively, an increase in benefit eligibility on one program can lead to an overall decrease in benefits. Perhaps in an attempt to undercut victim blaming, some clients point out that they do not partake in everyday luxuries. We described several of these financial challenges previously, in the following sections: transportation, housing, food, medications, health insurance, and dental. Financial concerns associated with Vision and Food related needs are discussed in subsequent sections. Here, we emphasize general financial constraints and those associated with utilities, and household expenses.

#### **Complexity of Financial Constraints**

- I live in a small town. When it comes to paying bills, I know no one will keep a roof over my head but me. So at times, I have no money for food. This past winter my electric bills were high. I pay \$350.00 a month payments on my trailer \$185.00 for lot rent. Phone bill no cable or internet. It's just not something I can afford. I do have to pay care insurance and trailer Ins. Lost my roof 2 xs last year, my water heater quit so I had to buy a new one that meant no food for the month. Need a tire fixed on my car to get back and forth to Indpls. I guess what I'm trying to say is there no help for people living in small towns. I'm 61 years old; it's hard to get to and from Indpls. I would hope you know that it's important to me not to be homeless ever again so before I would buy food, I'd pay my rent (Region 9).
- I am disabled and unable to meet my monthly expenses. The SSI benefit increase was negated by an increase in Medicaid spend down, increase in Medicare D premiums, and a decrease in food stamps. Thus I am in worse financial shape than before the increased SSI. I have a mortgage rather than a lease so I do not qualify for HOPWA. My payments are less than most rentals. I would not gain anything by selling my home. I have gradually gone 13,000.00 in credit card debt over the past ten years to meet my budget shortfalls. Also, at the rate Medicaid spend downs increase each year at both reassessment and SSI increase, it will soon become useless. There comes a time when Medicaid spend down exceeds Medicare out of pocket percentile. There are days that I feel I am being punished by out living my projected life expectancy (Region 1).
- I am not only dealing with HIV alone I also have 6 other disabilities. I fall in a gray area due to the amount of my Soc. Sec. income of \$1752 s month. I cannot qualify for any programs that would help me with food, housing, eye care or dental (Region 1).

#### **Semi-durable Personal Items, Household Items, and Holiday Expenses**

- Help with new shoes and clothing once a year at less (Region 7).

- Help getting clothes, shoes, household items, help during holidays such as getting food and put on waiting list for Thanksgiving, Christmas (Region 3).
- I know I needed some help with my bills and my child Christmas and clothing and shoes and I didn't get any help (Region 7).

### **Utility Bills**

- The SSI check just doesn't cover it all. Last winter I was sick always cause I had to keep my heat at 62 degrees so I could almost afford my heat bill (Region 3).
- My biggest problem is my utility bills. In the last 10 years my phone, gas service, and electricity and water and sewage have in many cases tripled and in some cases quadrupled. My Social Security has not kept up with these increases. My gas for heating, water heating and cooking is probably going to be turned off I have made arrangements but may not be able to make the current bill (Region 5).
- The state can give more assistance on heating bills during the winter (Region 7).
- The only thing I need is occasional monetary assistance with food, utilities, and basics. Social security is difficult to live on even with all luxuries of any kind being given up. Just trying to survive now. Could use a back up kerosene heater or generator for power outages. I have no back up heat (Region 11).

### **Help Paying for Family Care and End of Life Costs**

- I think that people who are more serious with the virus (like spouses that care for a love one should be some type of services for the family like financial. The caretaker should be able to get paid for taking care of someone (Region 1).
- Provide low cost burial services (that accounts can be set up) (Region 1).

### **Problems with Accessing Social Security Disability Benefits**

- Well, maybe get us more of an increase in our monthly disability pay from SSI instead of a \$20 to \$30 dollar a year raise (Region 7).
- I would like to see us get full disability without waiting a year with no income, I have trouble every day wanting to go to work, and I just want to be with my family full time (Region 11).
- I'm trying to get my disability for almost 3 years. Can't work (Region 9).
- Expedite social security disability cases! (Region 7).
- I feel the government is being very unfair with my situation. For my situation is very critical my CD-4 count is only 11 at this moment. I applied for SSD/disability and I was denied for they say they cannot find a reason why I cannot work even though my doctor says I cannot continue working (Region 3).

## **I2. Food and Food Banks**

A quarter of the clients (25%) surveyed reported being hungry and unable to get food at least once in the last 30 days. Ten percent had experienced food needs four or more times, half of whom had been in need of food for a week or longer (n=38). Although not a core medical service, having food services remain critical towards supporting client's HIV related medical care.

The main theme in comments about food needs and services had to do with difficulty affording food. Insufficient assistance with basic needs like food also gives the impression to some clients that Indiana does not care about HIV+ people. Further, going without food can make it more difficult to seek and maintain employment, making being unable to afford food an impediment to becoming more self-sufficient. Occasional assistance with food and other needs is necessary for those living on the edge. Clients mentioned needing better access to food stamps and higher dollar amounts available. Some suggested being frustrated when food banks are empty or do not contain healthy food. It is difficult to stay healthy without proper nutrition. Clients request help in understanding how to meet their nutritional needs, help in accessing nutritional foods and help preparing meals. Meaningful access to affordable, nutritious food also requires that HIV+ people have transportation or delivery services available. These themes are illustrated below.

### **Affording food**

- I cannot qualify for any programs that would help me with food (Region 1).
- The SSI benefit increase was negated by an increase in Medicaid spend down, increase in Medicare D premiums, and a decrease in food stamps (Region 1).
- At times, I have no money for food... it's important to me not to be homeless ever again so before I would buy food, I'd pay my rent (Region 9).
- I think Indiana really should check up on the people that have HIV from time to time. Show that you care because I still don't have no money to get food or I don't have food stamps either (Region 7).

### *Occasional help*

- The only thing I need is occasional monetary assistance with food (Region 11).
- Help with financial help at least once a year, when we fall behind rent or phone that and food. I get only 40 dollars for the whole month. That's about \$1 a day (Region 1).
- Make it easier for those who are trying so hard to get a job to make sure they have a roof over their needs and food in their house...and to make it easier for them to get food stamps until their life situation improves (Region 7).
- My water heater quit so I had to buy a new one. That meant no food for the month (Region 9).

### *Food stamps*

- Provide food stamps for all HIV patients (Region 11).

- The state of Indiana needs to work on food stamps and Medicaid for HIV + individuals to prevent any gaps in medical care and nutritional care (Region 7).
- I only receive \$16/month in food stamps (Region 8).
- I can't get food stamps because of an old case with drugs. So my caseworker helps me get 110lbs food a month (Region 3).
- Any HIV + person should be eligible for food stamps to ensure they are able to afford a more healthy diet (Region 11).
- Give us more food stamps to eat (Region 6).
- A lot of us can't work and I get SSD which is only \$389.00 and \$120.00 in food stamps. I'm not sure how to fix it but how is a person going to live on that with meds, paying toiletries and then pay bills (Region 7).

#### *Food Banks and Pantries*

- Damien Center has no food in the pantry (Region 7).
- Help replenish the food banks (like at the Concord Center) (Region 7).
- Better food bank to cater to the HIV needs, better healthy foods, nutritional supplement and personal care items. The food bank is the worst in the USA (Region 1).

#### **Nutrition and Need for Healthy Food**

- Food assistance is very important due to not being able to purchase "nutritional" food it's taken a toll on my health in present time (Region 4).
- Early adult onset problems require a great deal of nutritional advice (Region 1).
- Food should be given at least twice a month to boost nutritional care (Region 2).
- Help with more nutrition classes (Region 7).
- Help with nutritional needs. I cannot afford proper nutrition (Region 7).
- Doctors should give more nutritional advice or tell us where to get it (Region 1).
- Contact Ensure see if they will send us some free shakes (Region 8).

#### **Transportation to Buy Food and Help Preparing Food**

- Transportation or grocery and bank etc.( Region 5).
- I firmly believe that a buddy program (volunteers) should be reestablished. It most definitely helped me get to appointments and go grocery shopping (Region 7).
- I need someone to help me get around for groceries (Region 1).
- This past winter I was sick...unable to even fix a can of soup (Region 9).

### **I3. Linguistic Services (Interpretation and Translation)**

Only 2% (n=10) of the survey sample identified linguistic services as the most critical support service. However the responses to the open-ended question reveal that for those folks who do need them, it is essential to insuring access to HIV related care services.

#### **Critical Need for a Bilingual Care Coordinator**

- We don't read or speak English, our coordinator is of great help (Region 2).
- What is missing is bilingual personal in the AIDS ministry of Elkhart. We only have Laura Prado and they are planning on removing her. This is the worst they could do, for all the Latino people need her here. Other than that everything is excellent but we need help with trying to keep out coordinator Laura with us. (4 Clients in Region 2 Expressed this Concern).

#### **I4. Employment Services**

Clients also mentioned the need for services to help them find work.

##### **Employment Assistance**

- I find it hard to find solid employment (Region 3).
- Job placement assistance would be spectacular (Region 12).
- Help with job seeking/employment services (Region 5).
- We need our own employment agency and job training services (Region 1).
- All I am asking for now is assistance in getting job, because it's so difficult at times (Region 1).

## **I5. Specialty Care**

Nearly twenty percent (17%) of the clients had difficulties seeking specialty care services such as OB/GYN and cardiology care. Others mentioned the need to better educate non-HIV providers about HIV. These themes are illustrated below.

### **Need for Better Education for Non-HIV Providers about HIV**

- I know of a friend who went to a doctor for one ailment and was given a treatment that would compromise his immune system. I feel his Dr. neglected to inquire into his HIV status before giving him a medical treatment that depleted his immune system. Drs need to know! (Region 1).

### **Difficulty Getting Appointments**

- It took me a long time to get in to the dermatology clinic because they kept making appointments after the time I told them I could come in which is only mornings. I had major skin issues and it seemed they just didn't care enough to get me in and help me feel better (Region 7).
- I have had lots of trouble getting a general practitioner and I mean lots (Region 9).

### **Difficulties with Specialty Care Coverage Restrictions**

- Getting my physical therapy approved. It's approved but there are breaks between approved unit and dates (Region 1).

### **Other Specialty Care Issues**

- I need to get massages (Region 3).
- Chiropractic coverage (Region 12).

## **I6. Vision Care**

Just over a quarter (26%) of all the clients surveyed identified vision care as among the most important non-HIV medical service needed. In addition, among those who sought vision care services (n=502), just over a third of the sample (35%) had trouble getting vision care. The open-ended question responses provide some insights into the barriers to vision care. Barriers centered around the lack of health insurance coverage and difficulties paying for co-pays. Select quotes follow below to illustrate these issues.

### **Lack of Coverage for Vision Care**

- Vision care. My eyes are getting worse (Region 2).
- We need eye care (Region 12).
- Offer vision care optometrist, ophthalmologist. Antibiotic I was on had side effects of blindness; needed eyes checked every 6 mos. Ins. Didn't want to pay (Region 11).
- Eyeglass and vision coverage (Region 7).

### **Financial**

- Please find a way to get vision. It is costly. I need glasses and can't get them not enough on SSD (Region 10).
- I feel vision care is very important due to the possible eye diseases that are associated with HIV/AIDS. It's not just the examination but the cost of the glasses that is such a barrier (my glasses generally cost \$300-\$400 so I haven't been in over 3 years to the eye doctor (Region 12).
- Provide vision care services. Vision services are very costly to anyone who does not have insurance and therefore is neglected in order to pay for other necessary things (Region 1).
- I need new glasses I can't afford (Region 9).
- I think we need better vision program of some sort. I myself have a Medicaid spend down of over \$400 and it is hard to meet (Region 11).
- We need help getting free or affordable vision. Most of us are on fixed income and can't afford it. I am 54 and my eyes have gotten bad. I can't read without glasses, which I don't have because I don't ever have the money. I need help soon (Region 3).
- Providing and/or assisting with vision care because of the cost, I've had to postpone or hold off on going to eye doctor until absolutely necessary. Eye doctor are helpful but want me to see them more often than I can afford to (Region 12).

## **I7. Client Support Services**

Several clients mentioned the importance of peer support, especially in the form of a buddy system and support groups.

### **Buddy System**

- Create a paid “Buddy System” have training and then use a “Big Brother” approach for newly diagnosed patients (Region 7).
- I firmly believe that a buddy program (volunteers) should be reestablished. I most definitely helped me get to appointments, go grocery shopping, and other shopping outside the immediate downtown area. I realize that is difficult for others to devote extra time for someone else. Until a better means of transp. exists, there needs to be someone available after business hours. I mean besides using an ambulance to an ER. I know there is the crisis and suicide hotline (Region 7).

### **Support Group Recommendations**

- A network of people who can befriend patients (Region Not Listed).
- More local support groups in rural areas, not just in big towns, cities (Region 4).
- There are also no support groups close to me at all (Region 4).
- More support groups in our area (Region 4).
- Offer most caring support groups (Region 7).
- I wish there were support groups that I knew about. Others to talk to. I’m very healthy, I do what I’m supposed to but I’m also very scared. Scared that at any moment I could die. (Region 2).

## **J. Central Issues Across Service Categories**

Several barriers emerged that crossed service categories. That is, such barriers make it difficult to access a multitude of services. This also means that reducing these barriers would go a long way to eliminating access to a variety of HIV and support services. These barriers include the need for more information, education and better communication around AIDS and about services, gaps in health insurance coverage, HIV related stigma, and various issues at the client level. Client level barriers include, disempowerment and the aging of the HIV-infected population. These barriers are illustrated below.

### **J1. Information, Education, and Communication**

Consumers call for several different types of education efforts. Some make the general suggestion that more education is needed, but others specify the content and audience that need to be targeted. For example, some call for better education about the negative effects of medication, better information about how to navigate care, greater visibility, education to destigmatize AIDS, and better education for prevention of HIV infection. Enhancing HIV related and service information targeting both consumers and providers may promote service utilization.

#### **HIV Education (for HIV+ people)**

- Have a doctor give a class on HIV. I belong to a support group but it doesn't give enough information concerning HIV (Region 8).
- Give class about HIV and how to live with it (Region 1).
- More up to date educational materials regarding medications, research, new studies and local involvement (Region 7).
- Continue to make it more possible for people living with HIV + to receive their meds without a lot of problems and continue to explain how and why they need there meds. They take their meds to keep health and well (Region 7).
- More up to date educational materials regarding medications, research, new studies and local involvement (Region 7).
- I would suggest to more easier the understanding of the system available. Not only about what we can and cannot do the access to services (health care) but the rest of care providers I have myself a hard time to access it on internet (Region Not Listed).

#### **General HIV Education and Awareness (for the public)**

- I think if we could get more higher ranking city leaders to get involved with fund raisers, and activities such as the AIDS Walk, it would get more attention and awareness from the general public (Region 9).
- Educating the general population so positive individuals can feel comfortable. Discuss their condition as people with other health issues such as heart disease, CA, etc. (Region 3).

- I believe that you all can get better by having commercials in the field. At times, I feel like everyone is not on the same level with the HIV/AIDS area (Region 7).
- Need to talk more openly on TV, radio about HIV/AIDS (Region 2).
- I see nothing on TV, news or paper about anything with people with HIV or ADIS. The public needs to be more aware of this problems and that it will never go away and they don't have to be afraid of us that have it (Region 2).
- I think everyone needs to understand HIV it has a bad label like being nasty and good people get this disease. I'm a good mother and a good person and I won't tell no one because the word is ugly and it scares people because there ignorant. Knowledge better education. (Region Not Listed).
- Talk more about the reasons people don't need to be scared of us on a day-to-day basis i.e.: work/jobs (Region 6).
- Get the word out more that there is a very scary virus out there that is being passed unknowingly because people are not getting tested and some are still not using protection! (Region 6).
- People are ultimately responsible for themselves, however more prevention and education should be available because too many people are testing positive (Region 7).
- More education to younger groups T.V. radio billboards. They think it no AIDS or HIV anymore (Region 7).

### **Broader sex and relationship education and HIV Testing**

- Condom availability, and mandatory screening by primary care doctors (Region 7).
- If more places were aware of the program such as family planning/health connections or other places that do testing, it would help (Region 12).
- Should have mandatory classes for relationships and diseases in high schools (Region 3).

### **Educating Doctors**

- I know of friends who went to a doctor for one ailment that the treatment would compromise his immune system. I feel his Dr. neglected to inquire his HIV status before giving him a medical treatment that depleted his immune system. Drs need to know! (Region 1).

## **J2. Gaps in Health Insurance Coverage**

Lack of health insurance, substandard plans, and/or misinformation about programs is a huge barrier to care. Health Insurance refers to a service that provides some degree of financial assistance with premium payments, co-payments, deductibles, and other medical related bills. Although only 4% of the sample was uninsured, those who were insured with at least one or more forms of health insurance expressed numerous concerns about gaps in their insurance coverage. These concerns included difficulties paying insurance premiums, copayments, deductibles, and Medicaid spend-downs. Difficulties paying medical bills not covered by insurance can lead to failure to seek necessary care. In addition, the comments to the open-ended question suggest that there seems to be a lot of miscommunication about insurance programs which may warrant more direct client education. These concerns are illustrated below.

### **Lack of Knowledge about Ryan White Programs**

- Have their own type of insurance for HIV + patients so they won't have a problem paying for meds or doctors visits (Region 7).

### **Help with Co-Pays and Deductibles**

- Having a program that will help people with insurance pay for medicine when the insurance company wants to put it toward your deductible (Region 9).
- I think there should be a program for persons on Medicaid to pay co pays. I recently went off of ICHIA insurance which covered meds and co pays. Having no income I must come up with about \$100.00 a month to get my meds. I have multiple health issues which comes to 12 oral meds and 4 scripts for diabetes supplies (Region 2).
- Continue paying our medical bills such as co payments and deductibles (Region 3).

### **Medicaid Concerns – spend downs, being denies and other negative experiences**

- My Medicaid spend-down is close to \$1,000 and often times I have to go without medicine since I can't afford this amount and still pay my bills (Region 1).
- The Medicaid spend down system is misused. Those that are healthy and can work and make extra money are rewarded with lower monthly spend downs for their meds whilst those who are ill and cannot maintain an extra job for additional monthly income are punished with higher monthly spend downs and being healthier. I want to further my education instead of working so I may return to the work force and no longer rely on any Medicaid care select coverage at all (Region 6).
- People need more help w/spend down. If we can't meet spend down we can't get our meds and if we miss our meds I could be really bad for our health (Region 12).
- I feel like I'm being punished for working all my life. My spend down is 2051.00 a month. That's about every penny I bring in a month (Region 11).
- The deductible or spend downs are ridicules if your HIV meds cost 1800 w/out insurance, I receive 1368 disability rent 500, how do you eat if you don't meet your spend down if I have a 604 spend down? The system is crazy. You have to choose to not eat or buy meds (Region 3).

- I am not happy with Medicaid because they always denied my case. I am fed up, frustrated, very tired...health not easy and 51 years old (Region 7).
- I am having trouble finding an adult primary care physician that accepts Indiana Medicaid. The new privatized Medicaid system is a nightmare, unresponsive, inefficient, and a travesty to the most dysfunctional populations (Region 12).
- Medicaid is constantly blocking my pt due to limits on time. I've not been able to go regularly because of surgeries etc. Then when Dr. clears me I have no time left and then my time is up and I have to reapply (Region 12).
- Getting my physical therapy approved. It's approved but there are breaks between approved unit and dates (Region 1).

### **Restrictive Eligibility and Coverage Requirements**

- Offer more medical assistance, insurance assistances. I was denied Medicaid and have multiple medical problems (Region 4).
- By allowing HIV + people to receive the private state health insurance regardless if the HIV+ person has insurance available at their employment. My personal situation is that my employer provides insurance but all of our personal information such as doctor visits med. etc. has to go through the office manager to review. I know there are still a lot of people who are ignorant to HIV/AIDS and I don't feel comfortable applying for my employment insurance for lack of confidentiality (Region 3).
- Ryan White Insurance should cover HIV doctor and a primary care of family doc. At this time I'm not in need of HIV meds but my overall health has some issues (Region 6).
- Cover pap smear (annual) (Region 1).

### **Waiting List Concerns**

- Able to get into ICHIA without waiting (Region 7).
- Shorter waiting lists to get on state health insurance (Region 3).
- I think the waiting period for ADAP and related service is long. I have been on the waiting list about 8 months (Region 6).
- The 1-year residence requirement prevents getting a lot of meds on the ADAP formulary. Keeps you from making appts. with specialists for a full year (Region Not Listed).

### **ICHIA**

- ICHIA has much room for improvement. I do not qualify for ISDH programs and pay the ICHIA premium myself. ICHIA needs to do a better job of training ACS to interpret and pay for covered services in a more timely manner. Members should not have to repeatedly be the conduit of payment between ICHIA and providers (Region 7).
- Do all HIV patients a favor and put them on ICHIA. They cover everything. Medicaid sucks, double bills you and sucks all available cash. Doctors don't listen (Region 7).

- Coordination with ICHIA. They don't pay care coordinators so if you have difficulty with ICHIA you're on your own but ICHIA says see your care coordinator! They say that is for you to pursue with ICHIA (Region 10).
- I have had to quit jobs due to my not having enough money to cover my portion of health bills just to stay on ICHIA. There is nothing to help people that are caught in the middle of a good paying job with crappy insurance (Region 8).

### **Uninsured or Underinsured**

- Better programs for people w/out private insurance. In the year I was unemployed. I tried to get Wishard Advantage for 6 mos. and never received approval (Region 7).
- More interest should be given to those that have no medical insurance (Region 11).
- I have been laid off from work for at least 6 months and money is getting tight. The health insurance I do have is a mini health plan, which I can see any doctor for 3 times a year. The max spending is only 10 K a year. If I have any major medical expense it will bankrupt me. The state insurance is way too expensive (Region 2).

### **Private Insurance and Out of Pocket Costs Concerns**

- The only problem I am facing is helping to pay for lab fees. I have private health insurance and what they don't pay. I have to pay for it (Region 12).
- It would be better service if HIV + people with commercial insurance didn't have such high co pays for medication. I'm currently not on meds but if I had to pay for expensive meds I would seriously consider not taking any meds at all (Region 7).
- I work a full time job that offers health insurance but I have stress added when I have to pay insurance premiums and co pays. Even when a person has private insurance, there should be a state insurance that picks up the co pays for an HIV + patient, not restricting them from enjoying the ability to work and enjoy life while they are healthy (Region 11).
- Those of us who can work and have insurance have to pay more out of our own pocket than those who don't have a job or insurance. Where is the incentive to keep my job and insurance. If I didn't have either, then the Gov. would pay! I feel screwed (Region 12).
- I go from month to month not knowing if I am going to be able to get my meds because the co pay is so high. I have insurance and work a full time job but I also have other bills too. Out of my meds now and I don't get paid until the 30<sup>th</sup> of April (Region 12).
- Sometimes I miss my appointments due to high cost in my deductibles since I have private insurance I have been taken to court 2 times for medical bills not paid (Region 7).

### **Billing Issues**

- Coordination of medical claims between medical providers and ICHIA = \$800 in collections because ICHIA hasn't paid a claim from a year ago (Region 7).
- My hospital seems to have trouble filing claims after my appointments (Region 4).
- I think that the entire process for insurance billing needs work. I know I am not alone in this situation for being turned over to collection agencies for nonpayment of medical bills (Region 10).

### **J3. The Stigma of HIV/AIDS**

The stigma of HIV/AIDS can be a significant barrier to care. Just over 20% of the sample felt services had been withheld from them at least once in the past year due to their HIV status. Stigma can prevent men and women with HIV/AIDS from seeking proper medical and support care for HIV. Stigma related barriers are highlighted below.

#### **Concealing the Stigma**

- I myself don't tell people I'm HIV +. In a small town of Madison the word would get around (Region 7).
- Public perception. The stigma. I am in my 13<sup>th</sup> year being HIV + living with it and the meds. I shouldn't have to keep it a secret from employers and society (Region 7).
- My employer provides insurance but all of our personal information such as doctor visits has to go through the office manager to review 2. I know there are still a lot of people who are ignorant to HIV/AIDS and I don't feel comfortable applying for my employments insurance for lack of confidentiality (Region 3).

#### **Others' Reactions (to self)**

- I was fired from a good paying job because they found out my HIV status and had to take a lesser paying job, now I really need that housing assistance (Region 7).

#### **Others' Reactions (to HIV+ people as a group)**

- Dentists are afraid to provide services to HIV patients. (Region 6).
- With the economy being what it is I fear that funding for HIV/AIDS will be in even greater need that it has ever been before it. I also fear the funding will be cut from its current meager allotment (Region 8).
- This July I will have survived HIV for 22 years! I would not be alive without the help I receive from the state of Indiana. Thank you very much! One thing that would help a great deal is freedom from the never-ending fear of losing these services due to politics, or the lack of funding. I'm afraid all the time and it is very stressful (Region 6).

#### **Requests and Demands for Destigmatizing of HIV Positivity**

- Treat HIV and AIDS patients like any other person (Region 7).
- I think everyone needs to understand HIV it has a bad label like being nasty. Good people get this disease. I'm a good mother and a good person and I won't tell no one because the word is ugly and it scares people because they are ignorant (Region not listed).
- New doctors that aren't part of the good old boys network of apathy, disdain, and discrimination (Region Not Listed).
- No discrimination against the people (Region 2).
- When that find out you are sick in any way you look at something different. It makes life much harder than it should be. And everyone should know more about this before you judge a HIV or AIDS person (Region not listed).

- With more funding to centers such as the Damien Center or better yet provides us with medical coverage for our illness and then leave us alone and let us go to work and live like normal people. Instead of giving us enough to not make it each month (Region 7).

### **Managing a Spoiled Identity**

#### *Fault*

- Organizations of all kind should stop discriminating us once we disclose our health status. Some of us did not choose to be HIV+ (Region 2).

#### *Identifying as part of a group, drawing strength from shared experience*

- My biggest problem is we (the people with HIV) are being discriminated against having life insurance. I feel this is unfair (Region 12).
- I wish there were support groups that I knew about. Others to talk to I'm very health, I do what I'm supposed to, but I'm also very scared. Scared that at any moment I could die (Region 2).

### **Discrimination within HIV+ communities/organizations**

- Good people who can do the job are being discriminated against by prerequisites (Region 12).
- Great discrimination in Elkhart Co. re: GLBT services/lack of services (Region 2).
- Do not discriminate between races. Do not try (successfully in some cases) to find ways to kick people of a certain race off the program to open up space for another race. This information was made known via the minutes kept during a meeting. We all need services regardless of age, race, or statistical numbers. Without services available to all there will be more people sick, dying, and spreading the disease to health individuals (Region 7).
- There is not HIV dental service in Vigo county!!! There is HIV dental service in Marion and surrounding counties??? This geographic discrimination called redlining (Region 8).

### **Stigma Issues and Insurance**

- By allowing HIV + people to receive the private state health insurance regardless if the HIV+ person has insurance available at their employment. My personal situation is that my employer provides insurance but all of our personal information such as doctor visits med. Etc. has to go through the office manager to review 2. I know there are still a lot of people who are ignorant to HIV/AIDS and I don't feel comfortable applying for my employments insurance for lack of confidentiality (Region 3).

## **J4. Client Level Issues**

Several themes emerged that emphasized the importance of clients taking more initiative for their own welfare as well as the need to involve more clients in decision making processes and in the provision of HIV services. Finally, as people with HIV/AIDS age they may start to experience problems associated with older age such as increased financial difficulties, having to deal with other chronic illness, and decreased social activities. These different client level themes are illustrated below.

### **Client Initiative and Involvement**

- Programs to empower HIV + people to get involved with volunteering, work, the community, etc. It seems that a lot of people basically give up due to illness, mental health, red tape, etc. Even if it is on a very small scale they can contribute to society. CC's could let poz people know what they can do to help as well (Region 7).
- Better communication about programs, services, advocacy, and consumer involvement. Does the SWCAB still exist? If so, why don't we ever hear anything from them. It seems Indiana is missing the boat when it comes to consumer involvement and communication. There are a lot of capable and talented people living with HIV who could contribute to and benefit from the opportunity to be involved (Region 7).
- If one works to get help, help is there, I was released from prison and applied myself for help and got everything I need. Thank God, I have everything I need. (Region 7).
- My concern is clients who are not willing to become advocates for their own care. Some won't take their meds as prescribed and miss scheduled medical appts. Why then pay for these client's services? (Region 1).

### **Aging of the HIV Population Issues**

- I'm 61 years old; it's hard to get to and from Indpls. It hurt my feelings the Damien Center no longer cares about its older clients to even return a phone call (Region 9).
- We need help getting free or affordable dental, vision. Most of us are on fix income and can't afford it. I am 54 and my eye have gotten bad. I can't read without glass, which I don't have because I don't ever have the money. I need help soon. Thanks (Region 3).
- Have more meetings so a person can have friends with the same problem. I myself don't tell people I'm HIV +. In a small town of Madison the word would get around. I worked with the public for 43 years. I'm 70 and not a day doesn't go by I wonder how I got infected with HIV (Region 7).
- Also, at my age, 57, I need hearing aids very much but they are incredibly expensive. I've given up almost all "Social Activities" such as playing cards because I can't participate in "low volume" conversations so I stay home most of the time (Region 6).
- I am fed up, frustrate very tired. That why! I am not rich and very poor. Health not easy and 51 years old (Region 7).

## **K. Recommendations**

Finally, clients had several recommendations that did not fit neatly into any of the previous categories. These are listed below.

### **General**

- Get rid of that narrow-minded governor that you all put in office (Region 7).
- Be less concerned about paper work and more concerned about people's health, mentally, spiritually, and emotionally (Region 11).
- A lot of help from the government no matter whether we work or not because we work in order to meet daily necessities but our bodies are getting tired (Region 2).
- Would like to see better representation on SWCAB and CHSPAC from people with experience and from HIV + people who have been so for at least 2 years or more. Please try to get more interest from the whole state of Indiana (Region 3).
- Expand services more outside of Marion County (Region 6).
- More info on how to obtain support from your office [contact info] (Region 7).
- I think Indiana really should check up on the people that have HIV from time to time. Show that you care (Region 7).
- I think the state could probably do better for HIV + people in lower income brackets and for people who are not on disability that need it (Region 7).
- Health care reform (Region 5).
- Quit wasting taxpayer's money by having these surveys (Region 2).
- I could use more help trying to find a cure (Region Not Listed).
- Stop paying for stupid stuff like Lucas Oil Stadium (Region 7).
- My brother has moved out of Indiana because of poor care he was getting in Michigan City, IN. He moved to Nashville, Tenn. He gets something called Nashville Care's Health Care. This is what we need in Indiana. He has the best health care I've ever heard of. Please! Please! Look into this (Region 3).
- Medical research is a must (Region 11).
- Mandatory screen by primary care doctors (Region 7).

### **Funding**

- Find a way to channel more monies into not for profit care for PLWHA (Region 7).
- Keeping the Indiana State government aware of the importance of full funding for ISDH and related programs viable (Region 2).
- More funding in all areas. With the economy being what it is I fear that funding for HIV/AIDS will be in even greater need that it has ever been before it. I also fear the funding will be cut from its current meager allotment (Region 8).

- Get the legislative to appropriate their share of funds and stop relying exclusively on Ryan White and HOPWA (Region 7).
- By fully funding the Ryan White Act. This would help the people with HIV that require assistance with housing, medications, and other areas within the community (Region 7).
- More money should go to the smaller cities serving rural areas. There is literally nothing in my county or those that surround me to point any one to a care coordination site, and not everyone has a computer or access to one/knowledge (Region 12).

### **Laws**

- Change the law that makes discrimination against gays legal in Indiana (Region 1).
- Pass a law forbidding persons to reveal someone's HIV status as Illinois has on the books (Region 1).
- Legalize gay marriage would help with the legalities of dealing with the care and death of a loved one or (spouse) (Region 12).
- I would ask to have higher penalties for those who spread it knowingly (Region 12).

### **Need for a One-Stop-Shop Approach to Care**

- I believe that the services for HIV patients would be more utilized and be easier to maintain and improve if everything were in one location i.e. care coordination physicians, lab, pharmacy, support groups and etc. in one facility (Region 10).
- Have health care to case management all in one facility (Region 1).
- The state, the TGA and all of those who work in HIV/AIDS education, prevention, and treatment should provide uniform and consistent and complete one stop service for every person diagnosed with HVI/AIDS. The current hodge podge system of the left hand not knowing what the right hand is doing is Bush era mismanagement (Region 7).

## **L. Showing Appreciation**

Despite the numerous challenges expressed by clients, they also made an effort to express the positive aspects of services. Many expressed praise, thankfulness and appreciation for the services they received. These comments are illustrated below.

### **L1. Appreciating the State of Indiana**

- The state has been very helpful to me by helping me pay for my medicines. I would not be able to take them if I didn't have help. I am not working and my company went out of business and I lost my pension. The state has been great (Region 7).
- Services have been great. 1 ½ years system is working for me. Regular testing and meds being covered helps make ends meet. Keep up the good work. Thanks (Region 1).
- I have 100% trust & confidence in services for HIV + people. Thank you! (Region 11).
- I think ISDH is doing a great job providing services and coordination. I've been a client of the Damien since 1988. When ISDH stepped in everything has gotten better and better. The greatest service for me is the HIAP/ICHIA program. That's why I'm still here. Thanks to all who are working so hard to help me! (Region 7).
- The state of Indiana is one of the best states that take care of the HIV positive people (Region 7).
- Indiana is a whole lot better than Kentucky (Region 7).
- I think that Indiana does provide enough services. I am very satisfied! (Region 1).
- For people in my income bracket Indiana is doing an A+ job for HIV + people in my opinion (Region 7).
- This July I will have survived HIV for 22 years! I would not be alive without the help I receive from the state of Indiana. Thank you very much! (Region 6).
- I am so blessed to have the state of Indiana's help and care for my meds (Region 10).
- Services is best in the country (Region 11).
- Personally, I have nothing really to complain about. If it weren't for the services that I do receive I probably would have died a long time ago! (Region 2).
- I am very appreciative of the HIAP/ICHIA that I now have. Thank you (Region 12).
- I have insurance with ICHIA and I thank God for that. I have had a care coordinator over 15 years. We need you! Thank you! (Region 6).

### **L2. Appreciating Doctors**

- Dr. Baker is always very helpful, knowledgeable, and professional (Region 6).
- I am lucky to receive assistance and support from my Dr. and care coordinator, also the support of my psychiatric therapist and dr. is helpful (Region 10).

- Also, my doctor at Wishard Special Medicine, Helen Rominger is super awesome, she gets on me and makes sure I am taking my medicine correctly. Also, she always asks me how am I feeling not body wise, but mentally. I love that she cares about me (Region 7).

### **L3. Appreciating Care Coordinators and Care Sites**

- I have always been treated fairly by our care coordinators (Region 11).
- I would give my care coordinator an A (Region 11).
- My care coordinator is great and helps whenever she can (Region 12).
- I am also thankful for the help from my care coordinator (Region 7).
- Katie Bennett is a very special person. Care Coordinators are helpful especially when they can come to your home (Region 6).
- I am lucky to receive assistance and support from my care coordinator (Region 10).
- My Care Coordinator is the BEST! (Region 7).
- My care coordinator at the Damien Center is awesome, she is there for me always. I appreciate that Mrs. Paulette Majors (Region 7).
- State of Indiana my care coordinator have been very good to me. Gina is a God sent and an asset to any organization (Region 7).

### **AIDS Task Force**

- We have a wonderful “AIDS Task Force” here and wonderful personal (Region 3).
- I am thankful for the Task Force and my care coordinator (Region 3).
- The Fort Wayne Task Force has made living with HIV easier (Region 3).
- I am happy with the ATF of Fort Wayne, Indiana (Region 3).
- Ft. Wayne’s AIDS Task Force does a wonderful job helping those in need of meds, food, etc. At least they did a wonderful job for me. I owe them a lot (Region 3).

### **Project Aliveness**

- Project Aliveness is doing great job. Work together as a team and very friendly to listen. Treat everyone the same. Program works to reach to the clients to service them better life. I am happy to receive their service and write them a letter to tell Project Aliveness staff good job! Keep up the good work. I am grateful (Region 1).
- Aliveness Project in Merrillville, IN is wonderful (Region 1).
- The Aliveness Project of Northwest Indiana is a true godsend organization they showed me how to believe in a life with HIV (Region 1).

### **Positive Link**

- I have been blessed with the case management. I’ve received from the folks of Positive link Bloomington, Thank You! (Region Not Listed).

# APPENDIX 1: CONSUMER SURVEY ENGLISH

## THE INDIANA STATE DEPARTMENT OF HEALTH NEEDS YOUR HELP...

Please take a few minutes to complete this **ANONYMOUS** questionnaire. Your answers will help us improve our services for people living with HIV.

### You can make a difference!

Please use the postage-paid envelope to return your survey by **May 15th**.

### THANK YOU!

We appreciate your participation. You can get a copy of the survey results from your care coordinator after June 1. For questions, please call Lisa at 1-866-588-4948, option 3.

### ABOUT YOU... Please tell us about yourself...

What is your zip code?	_____		
What is your gender?	<input type="checkbox"/> Female	<input type="checkbox"/> Male	<input type="checkbox"/> Transgender
What is your race?	<input type="checkbox"/> Black	<input type="checkbox"/> Hispanic	<input type="checkbox"/> Asian
	<input type="checkbox"/> White	<input type="checkbox"/> Multi-racial	<input type="checkbox"/> Other
How many months have you been in Care Coordination?	<input type="checkbox"/> 1 to 6 months	<input type="checkbox"/> 7 to 12 months	<input type="checkbox"/> More than 12 months
How long ago did you get a CD4 or Viral Load test?	<input type="checkbox"/> 1 to 6 months	<input type="checkbox"/> 7 to 12 months	<input type="checkbox"/> More than 12 months
What is your yearly household income?	<input type="checkbox"/> Under \$10,000	<input type="checkbox"/> \$10,000 to \$25,000	<input type="checkbox"/> More than \$25,000
How many people in your household are under 18?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 2	<input type="checkbox"/> 3 or more
How would you rate your health today?	<input type="checkbox"/> Poor to Fair	<input type="checkbox"/> Good to Very Good	<input type="checkbox"/> Excellent
Which health insurance do you have? (Check all that apply)	<input type="checkbox"/> Private	<input type="checkbox"/> Medicaid	<input type="checkbox"/> Other programs**
	<input type="checkbox"/> Medicare	<input type="checkbox"/> ISDH Programs*	<input type="checkbox"/> I have none of these

\*Includes HIV Medical Services Programs (ADAP, EIP, and HIAP/ICHIA).

\*\*Includes Ryan White Parts A & C, Wishard Advantage, and other non-ISDH medical assistance programs.

### MINDING THE GAPS... Please tell us about your experiences...

#### How many times in the last 30 days were you...

...hungry and unable to get food?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
...homeless or in unstable housing (such as staying at a shelter or friend's)?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more

#### How many times in the past year have you...

...gone to the Emergency Room because you were unable to get an appointment with your HIV doctor?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...been notified of possible eviction from your home?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...been notified of possible disconnection from your utilities?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more

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### MINDING THE GAPS... Please tell us about your experiences...

#### How many times in the last 30 days did you miss work, school, or a doctor's appointment due to...

...homelessness or unstable housing?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
...mental distress such as depression?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
...not feeling physically well or serious illness?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
...difficulty getting transportation?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
...difficulty getting child care?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
...problems with alcohol or drug abuse?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more

#### How many times in the past year were you not able to get your medications due to lack of...

...health insurance?	<input type="checkbox"/> Not on meds	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...money for the co-payments or deductibles?	<input type="checkbox"/> Not on meds	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more

#### How many times in the past year did you have trouble getting ...

...dental care?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...vision care?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...specialty medical care, such as cardiology or gynecology?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...mental health care?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...alcohol or drug abuse services?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...HIV care coordination services?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more
...HIV medical care appointments?	<input type="checkbox"/> Did not seek	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 or more

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### IN YOUR OPINION... Please tell us...

How many times in the past year did you feel that services of any kind were withheld from you due to discrimination because of your HIV status?	<input type="checkbox"/> None	<input type="checkbox"/> 1 to 3	<input type="checkbox"/> 4 to 6	<input type="checkbox"/> 7 or more
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#### Do you feel comfortable sharing your problems with your care coordinator?

<input type="checkbox"/> None of the time	<input type="checkbox"/> Sometimes	<input type="checkbox"/> Most Times	<input type="checkbox"/> All of the Time
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#### Which HIV service do you CURRENTLY have the MOST TROUBLE getting?

<input type="checkbox"/> Help paying for HIV/AIDS Medications	<input type="checkbox"/> HIV/AIDS Medical Care Appointments
<input type="checkbox"/> HIV Case Management	<input type="checkbox"/> No trouble getting these

#### Which of these OTHER CARE services is MOST IMPORTANT to you? (CHECK ONE)

<input type="checkbox"/> Specialty Medical Care	<input type="checkbox"/> Mental Health Care	<input type="checkbox"/> Nutritional Care
<input type="checkbox"/> Home Health Care	<input type="checkbox"/> Alcohol/Drug Abuse Services	<input type="checkbox"/> Vision Care
<input type="checkbox"/> Dental Care	<input type="checkbox"/> Hospice Care	<input type="checkbox"/> Other _____

#### Which of these SUPPORT services is the MOST IMPORTANT to you (CHECK ONE)

<input type="checkbox"/> Childcare	<input type="checkbox"/> Transportation	<input type="checkbox"/> Housing Assistance
<input type="checkbox"/> Translation/Literacy Services	<input type="checkbox"/> Emergency Financial & Food	<input type="checkbox"/> Services not needed

Please use the space below to tell us, in your own words, how you think the State of Indiana can improve its services for HIV+ people?

Did your care coordinator help you complete this survey?	<input type="checkbox"/> No	<input type="checkbox"/> Yes
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## APPENDIX 2: CONSUMER SURVEY SPANISH

### **EL DEPARTAMENTO DE SALUD DEL ESTADU DE INDIANA NECESITA SU AYUDA...**

Por favor, tome unos minutos para terminar este cuestionario ANÓNIMO. ¡Sus respuestas nos ayudarán a mejorar nuestros servicios para la gente que viven con el virus del VIH!

### **¡Usted puede hacer la diferencia!**

Utilice Por favor utilice el sobre de franqueo pagado para devolver su cuestionario en o antes del 30 de mayo.

### **¡GRACIAS!**

**Apreciamos su participación. Usted puede conseguir una copia de los resultados del cuestionario a través de su cocordinador de cuidado después del 15 de junio. Para más información, favor de llamar a Lisa al 1-866-588-4948 de opción 3.**

#### **SU CUIDANDO...** Por favor cuéntenos sobre sus experiencias...

##### **¿Cuántas veces en los pasados 30 días ha usted faltado a su trabajo, escuela, o cita medica debido a...**

- ...no tener un hogar o vivienda estable?  Ninguno  1 a 3  4 a 6  7 o mas
- ...salud mental tal como depresión?  Ninguno  1 a 3  4 a 6  7 o mas
- ...no sentirse bien físicamente o seriamente enfermo?  Ninguno  1 a 3  4 a 6  7 o mas
- ...dificultad de conseguir el transportacion?  Ninguno  1 a 3  4 a 6  7 o mas
- ...dificultad de conseguir cuidado para los niños?  Ninguno  1 a 3  4 a 6  7 o mas
- ...problemas con abuso del alcohol o las drogas?  Ninguno  1 a 3  4 a 6  7 o mas

##### **¿Cuánta veces en el pasado año no pudo conseguir sus medicamentos debido a la falta de ...**

- ...seguro de salud?  No en medicamentos  1 a 3  4 o mas
- ...dinero para pagar los co-pagos o las deducibles?  No en medicamentos  1 a 3  4 o mas

##### **¿Cuántas veces en el pasado año tuvo usted problemas para tener acceso de cuidado?**

- ...cuidado dental?  No buscó  Ninguno  1 a 3  4 o mas
- ...cuidado la vista?  No buscó  Ninguno  1 a 3  4 o mas
- ...medico de especialidades (tal como cardiologo, o ginecologo)?  No buscó  Ninguno  1 a 3  4o mas
- ...Cuidado médico mental?  No buscó  Ninguno  1 a 3  4 o mas
- ...Servicios del abuso del alcohol o las drogas?  No buscó  Ninguno  1 a 3  4 o mas
- ... Servicios de coordinación del cuidado del VIH?  No buscó  Ninguno  1 a 3  4 o mas
- ...Asistencia médica del VIH?  No buscó  Ninguno  1 a 3  4 o mas

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#### **SOBRE USTED...** Por favor cuéntenos sobre usted...

- ¿Cuál es su código postal? \_\_\_\_\_
- ¿Cuál es su género?  Hombre  Mujer  Transgenero
- ¿Cuál es su raza?  Negro  Hispano  Asiatico  
 Blanco  Multi-racial  Otro
- ¿Cuántos meses usted ha estado en el servicio de coordinación de cuidado?  1 a 6 meses  7 a 12 meses  Mas de 12 meses
- ¿Hace cuanto tiempo usted se hizo una prueba de CD4 o de carga viral?  1 a 6 meses  7 a 12 meses  Mas de 12 meses
- ¿Cuál es su renta de casa anual?  Menos de \$10,000  \$10,000 a \$25,000  Mas de \$25,000
- ¿Cuántas personas en su casa son menores de 18 años?  Ninguno  1 a 2  3 o mas
- ¿Cómo usted clasificaría su salud hoy?  Pobre  Estable  Excelente
- ¿Qué clase de seguro médico tiene usted? (Marques todos los que apliquen).  Seguro privado  Medicaid  Otros programas\*\*  
 Medicare  Programas de ISDH\*  Ninguno

\*Incluye programas de los servicios médicos del VIH(ADAP, EIP, and HIAP/ICHIA).  
\*\*Incluye Titulo III Services (EIS), Wishard Advantage, y otros programas médicos de la ayuda del no ISDH

#### **CUIDADO / DETALLES...** Por favor cuéntenos sobre sus experiencias...

##### **¿Cuántas veces en los últimos 30 días estuvo usted...**

- ...hambriento y no pudo conseguir comida?  Ninguno  1 a 3  4 a 6  7 o mas
- ...desalojado o sin vivienda estable (tal como permanecer en un alojamiento publico o con amistades porque usted no tenia un hogar)?  Ninguno  1 a 3  4 a 6  7 o mas

##### **¿Cuántos veces durante el año pasado ...**

- ...fue a la sala de emergencia porque usted no pudo conseguir una cita con su doctor del VIH?  Ninguno  1 a 3  4 o mas
- ...fue notificado del posible desalojo de su hogar?  Ninguno  1 a 3  4 o mas
- ...fue notificado de la posible desconexión de sus utilidades servicios de (luz, agua, gas)?  Ninguno  1 a 3  4 o mas

#### **EN SU OPINION...** Por favor cuéntenos sobre...

##### **¿Cuántas veces durante el pasado año sintió usted que no le fueron brindado los servicios debido a la discriminación por su estatus de VIH?**

- Ninguno  1 a 3  4 a 6  7 o mas

##### **¿ Se siente usted cómodo para compartir sus problemas con su coordinador de cuidado?** Nunca A veces La mayoría de las veces Siempre

##### **¿Cal servicio de VIH iene usted ACTUALMENTE el MAYORÍA problem en conseguir?**

- Ayuda para pagar los medicamentos de VIH  Citas para asistencia médica del VIH/SIDA  
 Manejo de su caso de VIH  Ningún problema servicios

##### **¿Cuál de estos OTROS CUIDADOS es EL MÁS IMPORTANTE para usted?( MARQUE UNO)**

- Asistencia médica de la especialidad  Cuidado médico mental  
 Cuidado alimenticio  Nutricion  
 Servicios del abuso del alcohol y las drogas  Cuidado para la visión  
 Cuidado dental  Cuidado de hospice  
 Otros \_\_\_\_\_

##### **¿Cuáles de estos servicios de AYUDA son los MÁS IMPORTANTES para usted?(MARQUE UNO)**

- Cuidado para los niños/Childcare  Transportacion  Vivienda  
 Servicios de la traducción/instrucción  Emergencia financiera y de alimento  
 No necesitos estos servicios

**Por favor utilice el espacio debajo para decirnos en sus propias palabras, cómo usted piensa que el estado en Indiana puede mejorar los servicios que ofrecen para las personas VIH+ positive?**

¿ Su coordinador de cuidado le ayudó a terminar este cuestionario?  No  Si

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