State of Indiana

HIV/AIDS NEEDS ASSESSMENT REPORT

Prepared for

Indiana State Health Department

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In the final analysis, however, what made the needs assessment possible was the time and effort of the 404 PLWH/A and over 30 service providers and key informants who participated in the survey and focus groups. They were generous in their time and candid in their responses. The results presented in this report are their collective voice about their service needs and barriers.

TABLE OF CONTENTS

TABLES

FIGURES

ATTACHMENTS

ABBREVIATIONS

ADAP	AIDS Drug Assistance Program
ADL	Activities of Daily Living
ASO	AIDS Service Organization
COBRA	Consolidated Omnibus Budget Reconciliation Act of 1985
DEFA	Direct Emergency Financial Assistance
EIP	Early Intervention Program
EMA	Eligible Metropolitan Area
HARS	HIV/AIDS Reporting System
HET	Heterosexual
HIAP	Health Insurance Assistance Program
ICHIA	Indiana Comprehensive Health Insurance Association
IDU	Injecting drug user
ISDH	Indiana State Department of Health
MSM	Men-who-have-sex-with-men
OB/GYN	Obstetric and Gynecology
OI	Opportunistic infection
PAG	Project Advisory Group
PCH	Partnership for Community Health
PLWA	People living with AIDS
PLWH	People living with H IV
PLWH/A	People living with HIV and AIDS
RWCA	Ryan White Care Act
SSDI	Social Security Disability Insurance
SSI	Social Security Income
STD	Sexually transmitted diseases
TANF	Temporary Assistance for Needy Families
VA	Veterans Administration

1. INTRODUCTION

In April 2000, PCH won a competitive request for proposal from the Indiana Comprehensive HIV/AIDS Services Planning and Advisory Council (Council) and the Indiana State Department of Health (ISDH), Division of HIV/STD to conduct an HIV/AIDS health planning needs assessment throughout the State of Indiana. The goal of the needs assessment is to provide ISDH and the Council with data on HIV/AIDS that is necessary for effective services planning.

A contract was signed between PCH and AIDServe, a not-for-profit provider that was hired by ISDH to administer the Needs Assessment contract. Unfortunately, the bankruptcy of AIDServe and the time necessary for ISDH to pay overdue invoices and write a new contract delayed the needs assessment process for several months. Although PCH completed the data collection in December 2000, the approval to proceed on the analysis was not given until September, 2001, and field work on the provider information form was begun in November 2001.

The full needs assessment has three reports. The first is an epidemiology report that provides an estimate of who will need services. The second report describes the findings of the needs assessment and presents information obtained through a survey of 404 PLWH/A and 16 focus groups with African Americans, Hispanics, heterosexual men and women, and injecting drug users (IDU).

The conceptual framework for the needs assessment is shown in Table 1-1. Needs, unmet needs and barriers were determined for forty services.

Table 1-1 Definition of Needs and Gaps

Service need or absolute need	Theoretical estimate based on a policy protocol and standards / model of care. It is an estimate of the number of people who would benefit from a service, regardless of whether they are actually receiving it.
Perceived need and demand	Perceived need and demand of PLWH/A for services based on qualitative and quantitative data is highly correlated.
Fulfilled need	Actual utilization of services measured by surveys or other non-direct counts by source of funding. It is expressed by the fact that an HIV-infected individual has actually received a service that is paid for by a multitude of sources.
Service capacity	Number of clients who can be served and the number of slots available for a particular service, by funding source (RW, insurance, public assistance, grant-funded, compassionate drug programs, etc.)

From these four "raw" calculations, four gap measures are calculated.

Unmet absolute need	This refers to a need-capacity gap and is the difference between the number needing a service and the capacity of the system.
Unmet perceived need	This refers to the difference between the perceived need/demand and utilization. It is the services that PLWH/A say they need and what services they actually sought.
Unmet demand or perceived excess capacity	This refers to a demand-capacity gap and is the difference between the number seeking service and the capacity of the system. It is the difference between the units of service utilized and the number of units of service that are available.
Need-demand gap	This refers to individuals needing, but not perceiving they need, services and is the difference between the number who in theory should receive services and the number perceiving they need services.

This Needs Assessment Report specifically addresses the absolute service needs, the perceived needs or demand, fulfilled need, unmet absolute need, unmet perceived need, and barriers to care reported by PLWH/A.

The third and final report incorporates the information in the provider information forms to estimate capacity of the system and related gaps—unmet absolute need and unmet demand (or excess capacity).

2. METHODS

Introduction

Four different data collection methods were used by the Partnership for Community Health for the Indiana comprehensive HIV/AIDS Care needs assessment. They included:

- A review of secondary information, including epidemiological data from the HIV and AIDS Reporting System (HARS) provided by ISDH and aggregate client data from individual client reporting systems from providers and contract monitoring sources. This information was used to estimate the incidence and prevalence of HIV and AIDS, the sampling frame, and the number of units of service provided by the care system, and the general health status of PLWH/A.
- A survey among a representative sample of PLWH/A drawn from providers and from outreach to find those out-of-care and difficult to reach populations. The survey allowed updated estimates of the demographics of PLWH/A, including co-morbidities, and current estimates of awareness of services and perceived knowledge, need, demand, utilization, and barriers related to services, and levels of adherence and quality of life.
- A series of sixteen focus groups among target populations and key informant interviews. They permit an in-depth view of needs and barriers to services and allow a greater depth of analysis by providing support and exceptions to findings from the survey.
- A provider information form that collected information on the services provided, all funding for services, number of clients served, and unduplicated client counts, and provider perception of service barriers.

A Project Advisory Group (PAG) was formed to provide oversight of the execution of the needs assessment. The consumer survey and focus group outlines were part of a highly participatory process involving members of the PAG. All decisions regarding content and length were approved by the PAG and they continued to be consultant throughout the project. The names of the PAG participants are shown in Attachment 1.

The consumer survey is shown in Attachment 2, and the focus group outlines are shown in Attachment 3. The key informant interviews were based on a condensed version of the focus group protocols. The list of services developed by PCH was derived from the list of funded services and were approved by ISDH as representing services that were funded, or of interest to, the Council. They are shown in question 28 of the consumer survey (see Attachment 2). The list of barriers was developed based on prior needs assessments conducted by PCH using a multidimensional schema discussed in the Barriers Section starting on page 10-1. The questions related to barriers appear as question 29 of the consumer survey with the Barriers promoted from a “barrier list” shown to each participant. Respondents were also asked about “other” barriers using an open-ended format and the responses were coded.

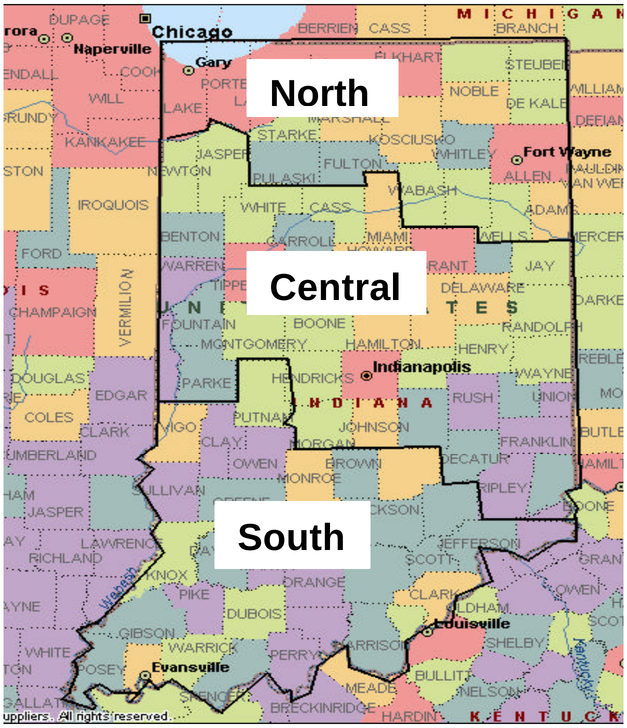
The consumer survey was an interviewer-assisted questionnaire, with trained interviewers available at all sites where the survey was administered to provide guidance and assistance to participants.

Participants for the focus groups received a $15 cash incentive and participants of the consumer survey received an additional $10 cash incentive. Anyone unable to complete the entire consumer survey for reasons such as illness or fatigue still received the cash incentive. Another incentive for participants to complete the survey was their inclusion in a lottery where the grand prize was a computer and smaller prizes consisting of gift certificates to local grocery stores, movie theatres, and shopping centers.

The consumer surveys were completed between June 2000 and December 2000. The length of time necessary to recruit the sample was due to several problems documented in the Status reports on file with ISDH.

For analysis purposes the consumer survey captured demographic information, including stages of HIV infection, mode of transmission, socioeconomic indicators, and location of residence. Location was analyzed by three areas shown in Figure 2-1. The survey also measured co-morbidities of HIV with mental illness, sexually transmitted diseases (STDs), and tuberculosis (TB).

Figure 2-1 Regional Divisions



Quantitative Survey

Sample Design

The focus group and survey recruitment strategies were based on an overall random quota sampling plan designed to draw a representative sample of clients from AIDS service organizations and clinics and other sites where PLWH/A were known to gather. Certain groups were oversampled to assure that there were sufficient number of women, Hispanic, heterosexual and IDU PLWH/A to analyze. For difficult to reach populations, intercept, snowball, and outreach strategies were used to obtain sufficient sample sizes.

Multiple strategies were used to recruit participants as part of the 2000 care needs assessment. The sample design started with a random selection of respondents from client lists produced by each of the 18 care coordination sites. Client ID's were used rather than names to protect the confidentiality of the clients. Based on these lists, a recruitment package was sent to each care coordination site with specific instructions. Although each site made a commitment to contact selected clients to determine if they would agree to be surveyed, there were varying levels of follow-through. Recruitment at the care coordination sites was conducted either by staff or volunteers from the respective agencies.

Clients who consented to being interviewed were scheduled to meet with trained interviewers at several sites throughout the EMA to complete the survey and receive the incentive. Efforts to recruit out-of-care, Hispanic, and heterosexuals took place concurrently with the overall recruitment efforts. PCH conducted intercept interviews at several service sites and outreach locations among these harder to reach populations.

Two field supervisors followed-up with the care providers and supervised outreach activities. One field supervisor was responsible for the Northern regions and the other was responsible for the Central and Southern regions.

For hard to reach populations and PLWH/A in rural areas where transportation was a barrier to completing an in-person survey, telephone interviews were conducted. The incentive was then mailed to the participant.

The stratified sample obtained is shown in Table 2-1 and Table 2-2.

Table 2-1 Stratified Sample

Risk Group	MSM	MSM/IDU	IDU		HET		TOTAL Sample
			Male	Female	Male	Female	
African American	48	9	8	2	27	33	**127**
Anglo	119	11	16	7	28	46	**227**
Latino	17	1	4	2	6	5	**35**
Other	7	2	1	1	1	3	**15**
Total	**191**	**23**	**29**	**12**	**62**	**87**	**404**

Table 2-2 Sample Design by Region & Mode

Risk Group	MSM	MSM/IDU	IDU		Heterosexual (not IDU)		TOTAL
			Male	Female	Male	Female	
NORTH							
Gary	33	3	7	2	14	15	74
South Bend	16	2	4	2	3	13	40
Ft. Wayne	18	3	1	2	8	11	43
Central							
Lafayette	13	0	3	0	3	1	20
Muncie	12	1	2	2	2	6	25
Anderson	1	0	0	0	1	0	2
Indianapolis	69	7	7	3	16	21	123
Terre Haute	5	0	1	0	1	3	10
Richmond	2	0	1	0	4	7	14
South							
Bloomington	2	3	0	0	3	1	9
Jeffersonville	5	2	1	1	3	7	19
Evansville	15	2	2	0	4	2	25
TOTAL	**191**	**23**	**29**	**12**	**62**	**87**	**404**

Focus Groups and Key Informant Interviews

To supplement the quantitative findings of the consumer survey and to gain greater insight into the providers' perception of needs, gaps and barriers, 16 focus groups were held with consumers and providers. In addition, interviews were conducted with key informants of special populations. The location and target populations of the focus groups and key informant interviews are shown in Table 2-3.

Table 2-3 Focus Group and Key Informant Interviews

1. East Chicago, Aliveness Project, Latino/as
2. Evansville, Over 55
3. Fort Wayne, African American IDU/heterosexual, men & women
4. Fort Wayne, Anglo IDU/heterosexual, men & women
5. Gary, African Am MSM
6. Gary, Aliveness Project, heterosexual men
7. Indianapolis, African American MSM/IDU
8. Indianapolis, Anglo MSM
9. Indianapolis, Anglo women
10. Indianapolis, Connor House, MSM in congregate housing
11. Indianapolis, Damien Center Women's Group
12. Indianapolis, Hispanic MSM
13. Indianapolis, Parkview, African American men and women
14. South Bend, AIDS Ministries, 2 females
15. Terre Haute :Rural
16. Valparaiso, Aliveness Project, Open session – men & women

Recruitment for the initial focus groups was done simultaneously with recruitment for the consumer survey. PCH staff and Jim Luther Consulting conducted the focus groups. Spanish language translators were used for all groups among Hispanic participants.

In addition to the focus groups, key informant interviews were conducted with medical and social service providers. Two key informant interviews were conducted with an out-of-care client. Interviews were conducted in several sessions over a one month period. All sessions were completed by telephone. Key informants were asked to comment on key issues raised by the Council/Consortium.

Analysis

The survey was analyzed using the statistical package Statistical Program for Social Sciences (SPSS). Analysis of the data was done by the "total sample" and key demographic groups shown in Table 2-4 below:

Table 2-4 Analysis Populations

1. Total
2. Gender
    - 2.1 Male
    - 2.2 Female
3. Risk Group
    - 3.1 MSM
    - 3.2 MSM/IDU
    - 3.3 IDU
    - 3.4 Heterosexual
4. Race
    - African American
    - Anglo
    - Latino
5. Region
    - 5.1. North
    - 5.2 Central
    - 5.2 South
6. Special Population
    - 5.1 Women of child baring age (WCB)
    - 5.2 Youth (13 – 24 years old)
    - 5.3 Recently Incarcerated
    - 5.4 Homeless
7. Stage of Infection
    - 7.1. HIV, asymptomatic
    - 7.2. HIV, symptomatic
    - 7.3 AIDS, asymptomatic
    - 7.4. AIDS, symptomatic

As noted above, selected populations were over-sampled to assure adequate sample sizes for analysis. For the total sample analysis, subpopulations are weighed back to their proportion in the estimated HIV population[1]. Also, when subpopulations are compared, the weighted sample is used. When special populations are analyzed, unweighted data is presented because they are purposefully over-sampled to obtain adequate sample sizes for analysis. The population estimates are based on the Epidemiological information, and are shown in Table 2-5. The unweighted sample shows the over-sampled populations, while the weighted sample is very close to the projected population estimates of PLWH/A, with the exception of an over representation of PLWH/A in the Northern region, and under-representation of those living in the Central region.

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[1] Based on PLWH/A reported in the HIV/AIDS Reporting System (HARS) through December 1999.

Table 2-5 Sample Frame

Sub Populations		% Total Pop (1999)	Weighted	Unweighted
Gender	Male	84.9	85.2	75.5
	Female	15.1	14.8	24.5
Race	African American	31.8	31.6	31.4
	Anglo	63.8	64.0	56.2
	Latino	3.9	3.9	8.7
	Other	0.5	0.6	3.7
Risk Group*	MSM	65.0	63.8	47.3
	IDU	13.9	13.8	10.1
	heterosexual	14.3	15.6	36.9
	MSM/IDU	6.8	6.8	5.7
REGION**	Central	56.1	48.1	45.5
	Northern	27.5	36.1	38.9
	Southern	16.5	15.8	15.6

* The risk categories have been adjusted to exclude “other” modes of exposure.
** Region based on 2000 data.

The following sections of this report analyze demographics, stage of infection, medication and adherence, outcomes, service needs and unmet needs, and barriers. Selected analysis is shown in graphic and table form in the text.

For those interested in further analysis, the basic demographic, services and barriers cross tabulations by each of the analysis populations are shown in Attachment 4 through Attachment 10.

All focus group participants were informed about the purpose of the groups and use of the taping equipment, and the confidentiality of all participants was assured. Focus groups were transcribed, and, using the coding scheme shown in Attachment 11, coded by PCH staff for qualitative analysis. Each comment was coded by relevant demographic group, service, and barrier. Comments are used throughout the report to add depth, reinforce, or emphasize minority positions of PLWH/A.

3. DEMOGRAPHIC PROFILE OF PLWH/A

Statewide Profile

In Indiana, 85% of PLWH/A are male, and 15% are female. The majority, 64%, of the PLWH/A, in Indiana is MSM, and about 7% are MSM/IDU. Fourteen percent (14%) of PLWH/A are IDU and 15% are heterosexuals. Anglos (non-Hispanic) are just under two-thirds of all PLWH/A in Indiana. African Americans (non Hispanic) represent about 32% of PLWH/A, and Latinos represent about 4% of PLWH/A in Indiana. As noted below, there are regional differences in the profiles of PLWH/A.

Regional Profiles

According to the HIV/AIDS Reporting System (HARS), over half (56%) of the PLWH/A live in Central Indiana, 28% in the North, and 16% in the South. In all areas MSM are the majority, but heterosexuals and IDUs represent a greater proportion of those living North. As shown in Table 3-1, Anglos represent over 50% of those living in the North, over 60% in the Central area and over 80% of PLWH/A in the South. The North has proportionately more African Americans and Latinos than the Central or South, but in absolute numbers, the Central region has more PLWH/A of every ethnicity and race.

Table 3-1 Region by Race

	Race				
Region	**Af Am**	**Anglo**	**API**	**Latino**	**Nat Am - Alaskan**
North	40.9%	52.4%	0.3%	6.3%	0.1%
Central	32.5%	63.6%	0.1%	3.6%	0.1%
South	12.6%	84.4%	0.6%	2.0%	0.4%

Demographic Analysis

Table 3-2 shows the total weighted survey sample of the 404 PLWH/A that participated in the consumer survey. In this demographic analysis, the weighted sample is used because it is representative of the proportion of the PLWH/A in each demographic category, with the exception of the overrepresentation of PLWH/A in the North.

Below are some highlights of the demographic analysis:

- The majority of the sample is non Hispanic Anglo (64%), followed by Non Hispanic African Americans (32%). Latinos represent about 4% of PLWH/A. Less than 1% is "other" or multi-racial. Other ethnicity includes Native American, Asian/Pacific Islanders. Due to the extremely small sample size, the "other" category will not be included as a separate category in the demographic analysis.
- People of color as a group, including African Americans, Hispanics, Native Americans, and Asian/Pacific Islanders, represent 36% of the sample.

- MSM represent the largest proportion of PLWH/A at 64%, followed by heterosexuals at 16%, IDUs at 14% and MSM/IDUs at 7%.[2]
- PLWA represent 43% of the sample, and PLWH account for 57% of the sample. (The HARS data indicate that the split is 45% PLWA and 55% PLWH).
- The total weighted sample consists of 85% males and 15% females.
- About 63% of PLWH/A are urban, 31% are suburban and 6% are rural. Latinos and African Americans are overwhelmingly urban.

Table 3-2 Number of Survey Respondents (N=404)

	TOTAL		**African American**		**Anglo**		**Latino**		**Other**	
	N	**% wt**	**N**	**% wt**	**N**	**% wt**	**N**	**% wt**	**N**	**% wt**
TOTAL	**404**	**100.0**	**128**	**31.6**	**259**	**64.0**	**16**	**3.9**	**2**	**0.6**
MSM	258	63.8	62	15.4	186	46.0	9	2.1	1	0.3
IDU	56	13.8	26	6.5	25	6.3	4	1.0	0	0.1
heterosexual	63	15.6	31	7.6	29	7.2	2	0.6	1	0.2
MSM/IDU	27	6.8	9	2.1	18	4.5	1	0.2	0	0.0
HIV -no symptoms	146	36.2	59	14.7	80	19.9	6	1.6	0	0.1
HIV with symptoms	82	20.3	32	8.0	46	11.3	3	0.7	1	0.3
AIDS -no symptoms	40	10.0	10	2.5	29	7.1	1	0.3	0	0.1
AIDS with symptoms	135	33.5	26	6.3	104	25.7	5	1.3	1	0.2
Rural	23	5.6	0	0.0	23	5.6	0	0.0	0	0.0
Suburban	127	31.5	20	4.9	104	25.8	3	0.7	1	0.2
Urban	254	62.8	108	26.7	132	32.6	13	3.2	2	0.4
Male	344	85.2	100	24.8	230	56.8	13	3.2	2	0.4
Female	60	14.8	27	6.8	29	7.2	3	0.7	1	0.2

Gender[3]

While women represent 16% of all PLWH/A, they represent 68% of the heterosexuals, and 28% of the IDUs. African American women form the majority of all heterosexuals. Women living with HIV and AIDS are disproportionately African American.

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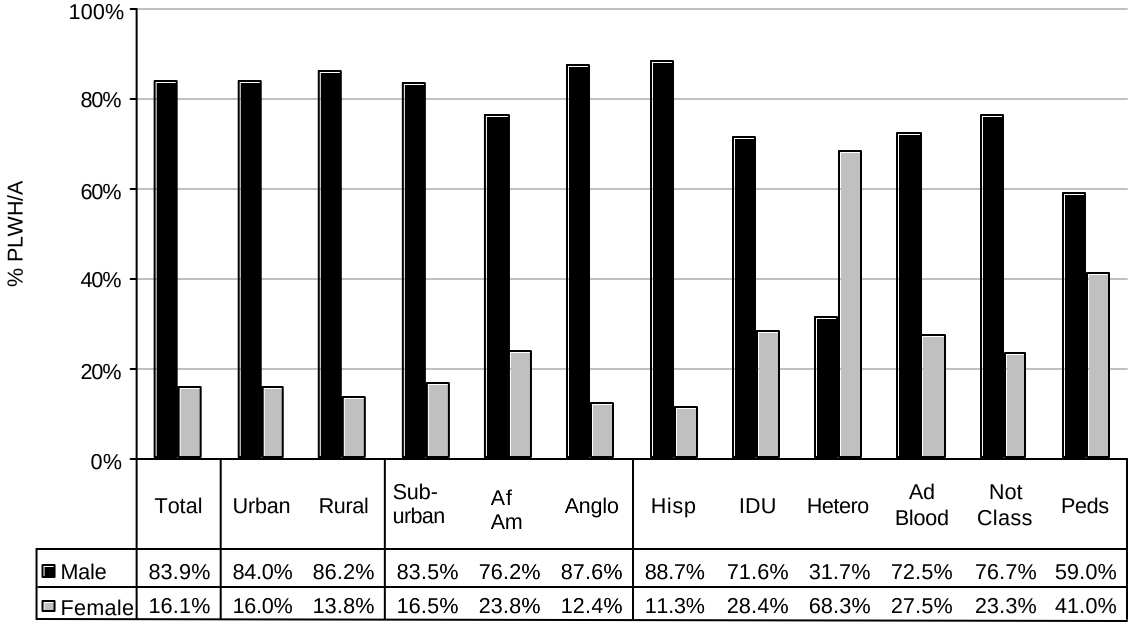
[2] This excludes those infected through transfusions, blood, or perinatal as these risk groups were not part of the sample.

[3] Male / Female information is from the 2000 Epidemiological information rather than survey information. The two are very close, but the epidemiological information allows the presentation of urban/rural and other risk factors.

Figure 3-1 Gender by Urban/Rural, Race, and Risk Group



	Total	Urban	Rural	Sub-urban	Af Am	Anglo	Hisp	IDU	Hetero	Ad Blood	Not Class	Peds
■ Male	83.9%	84.0%	86.2%	83.5%	76.2%	87.6%	88.7%	71.6%	31.7%	72.5%	76.7%	59.0%
▨ Female	16.1%	16.0%	13.8%	16.5%	23.8%	12.4%	11.3%	28.4%	68.3%	27.5%	23.3%	41.0%

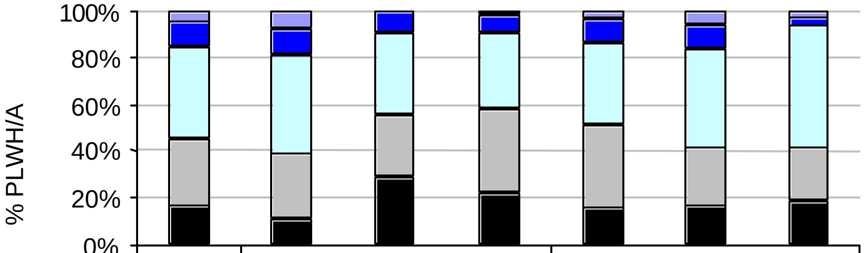
Education

Eighty-four percent of the PLWH/A in Indiana have at least a high school education. Over a quarter have graduated high school (28%) and 40% have some technical training beyond high school. Fifteen percent (15%) have graduated college.

Figure 3-2 shows the different levels of education for the risk categories and racial/ethnic groups. It indicates that:

- MSM have the highest level of education, with about a fifth reporting at least a college education, compared to 10% for IDUs and 8% for heterosexuals.
- African Americans have the lowest level of education. Still, 88% report completing high school.
- Over half of the Latinos report having some college or technical school.

Figure 3-2 Level of Education by Risk and Race



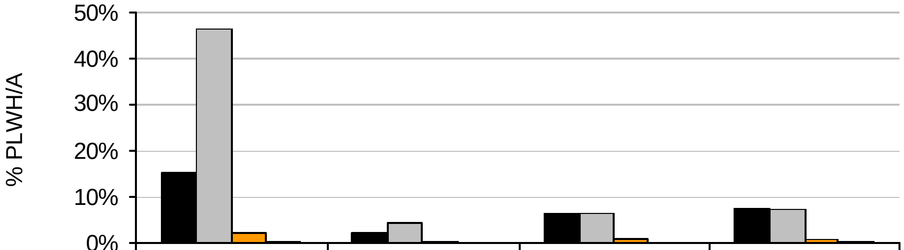
	Sample	MSM	IDU	HET	AfAm	Anglo	Latino
Grad school	4.9	7.2	0.0	2.3	3.8	5.6	3.2
College	10.3	11.9	9.6	6.1	9.2	11.1	3.2
Some Col or Tech	40.1	42.7	34.5	33.5	36.0	41.4	52.4
High School	28.3	27.4	26.7	36.0	35.6	25.1	23.3
Grade	16.3	10.9	29.2	22.0	15.5	16.8	17.7

Ethnicity and Risk Group

Figure 3-3 shows the ethnic/racial composition of each of the major risk categories. It indicates that:

- Among the total weighted sample, the majority of PLWH/A are Anglo MSM (46%) followed by African Americans MSM (15%).
- Heterosexuals represent about 15% of all PLWH/A. The majority are African Americans, and they represent about 8% of all PLWH/A.
- IDUs represent about 14% of all PLWH/A, and they are about equally divided between African Americans and Anglos. About 1% of all PLWH/a are Latino IDUs.

Figure 3-3 Ethnicity by Risk Group

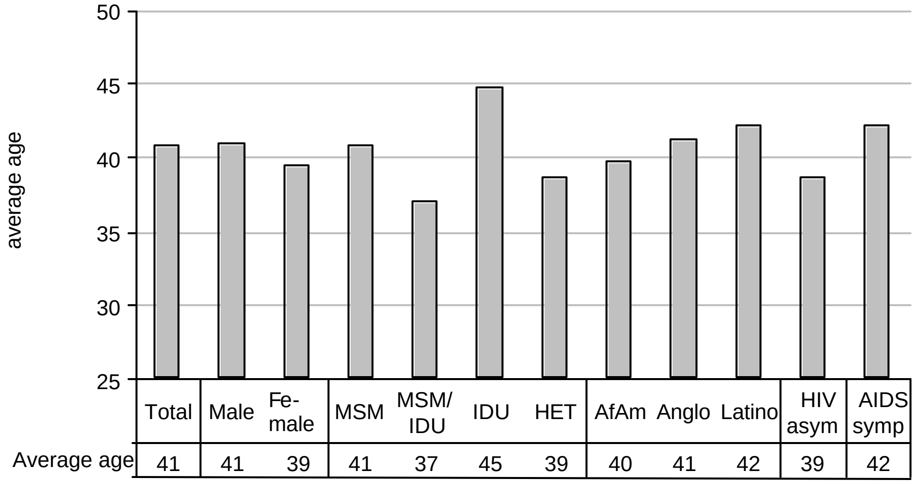


	MSM	MSM/IDU	IDU	HET
Af Am	15.4%	2.1%	6.5%	7.6%
Anglo	46.0%	4.5%	6.3%	7.2%
Latino	2.1%	0.2%	1.0%	0.6%
Other	0.3%	0.0%	0.1%	0.2%

Age Distribution

Over 90% of the PLWH/A are between the ages of 25 and 54 years old, and Figure 3-4 indicates that the average age of PLWH/A is slightly over 40. Predictably MSM and IDU are older reflecting their earlier infection. Those with HIV (not AIDS) tend to be younger. There are no large age differences among racial subpopulations.

Figure 3-4 Age by Risk Group and Race



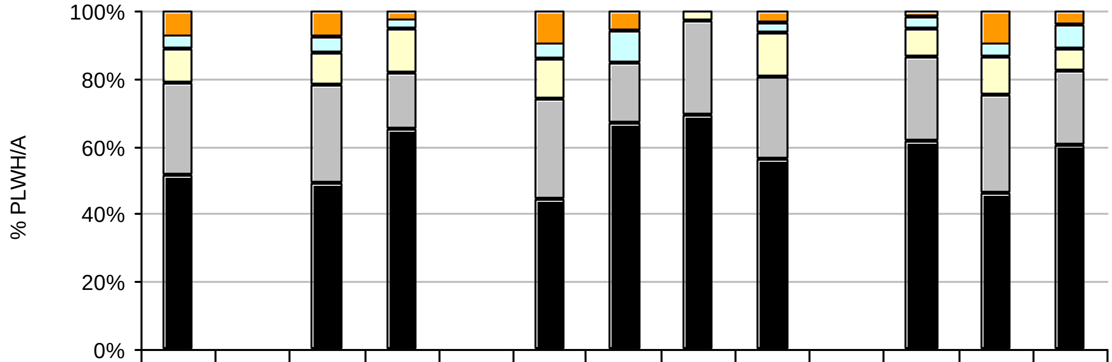
Income

In order to receive Ryan White and state supported benefits, the current HIV/AIDS care system has income restrictions depending on the service provided. In order to qualify for the AIDS Drug Assistance Program (ADAP) or other state-funded medication reimbursement programs, PLWH/A are eligible up to 300% of poverty (about $25,050 a year for a single person) based on Federal Poverty Levels.

Figure 3-5 shows income levels risk group and race. It indicates that:

- In general, those receiving Ryan White Services have low incomes, with almost 90% reporting earning less than $25,050, and half report earning less than $8,350.
- Females earn less than males, with about half the males making less than $8,350 compared to about 65% of females making less than $8,350.
- Among risk groups, injecting drug users (IDUs) have the lowest income. MSM have the highest income.
- (Not shown) Those who are HIV symptomatic report lower income than those with AIDS, and those in the South tend to report lower income.

Figure 3-5 Income and risk group



	Total		Male	Fe-male		MSM	MSM/ IDU	IDU	HET		AfAm	Anglo	Latino
🟧 $33400 +	7.2%		8.0%	2.3%		9.7%	6.0%	0.0%	3.3%		2.0%	9.8%	4.1%
☐ $25,051 - $33,400	4.0%		4.2%	3.0%		4.4%	9.5%	0.0%	3.4%		3.6%	4.0%	6.8%
☐ $16,701 - $25,050	10.0%		9.5%	12.9%		12.1%	0.0%	2.7%	12.6%		7.9%	11.1%	6.8%
▨ $8,351 - $16,700	27.4%		29.2%	16.9%		29.3%	17.8%	27.8%	24.2%		24.7%	29.1%	21.6%
■ $8,350 or less	51.4%		49.1%	64.9%		44.5%	66.7%	69.5%	56.5%		61.8%	46.0%	60.6%

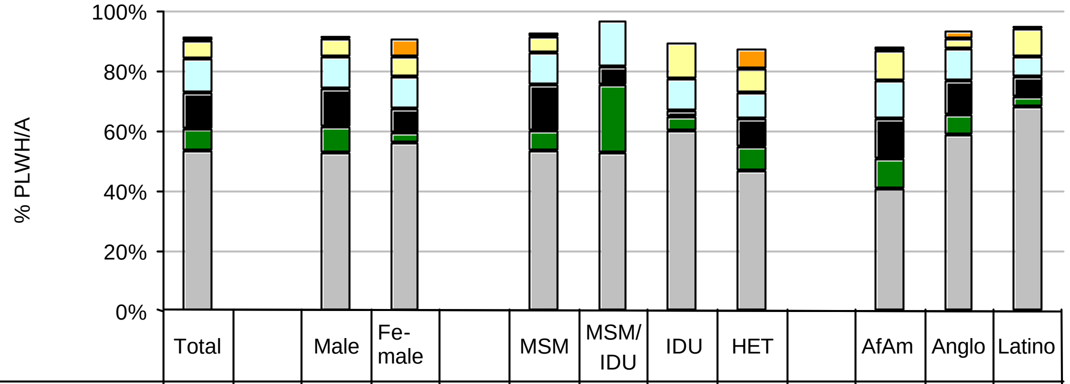
Employment Status

Many of those who are employed or on disability have access to care through Medicaid or insurance. As shown in Figure 3-6, over 60% of the of PLWH/A are on disability or have applied for disability. Slightly under a quarter (23%) are employed full or part time. Six percent are looking for work, and about 2% report being home makers.

Among risk groups and racial subpopulations:

- IDUs, Heterosexuals, and African Americans are less likely to be on disability, and therefore more likely to have a need for Ryan White Funded services.
- Latinos are more likely to report being on disability than other racial subpopulations.
- Females are more likely to report being homemakers with no disability income or employment.

Figure 3-6 Employment status: by Risk Group and Race



	Total		Male	Female		MSM	MSM/IDU	IDU	HET		AfAm	Anglo	Latino
🟧 Homemaker	1.8%		1.0%	5.9%		1.2%	0.0%	0.0%	6.5%		1.3%	2.1%	0.7%
🟨 Looking for work	6.0%		5.8%	6.7%		4.8%	0.0%	11.9%	8.2%		10.1%	3.8%	9.0%
☐ Employed part-time	10.9%		11.0%	10.8%		11.2%	15.5%	10.5%	8.5%		12.2%	10.4%	6.5%
■ Employed full time	11.9%		12.6%	8.0%		15.3%	6.0%	2.5%	9.4%		13.4%	11.3%	7.2%
🟩 applied for disability	7.5%		8.3%	3.0%		6.4%	22.5%	4.6%	8.0%		9.9%	6.7%	3.2%
▨ On disability	53.3%		52.9%	56.1%		53.4%	52.6%	59.9%	46.5%		40.9%	58.8%	67.9%

Relationships

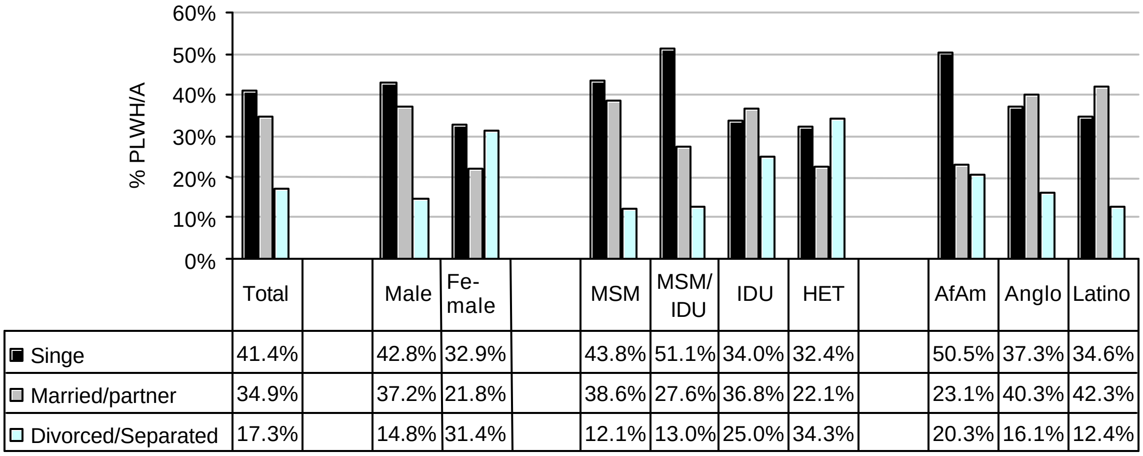
In determining the care needs of PLWH/A, the support system of a PLWH/A can play a significant role in providing their care, or, if other family members are HIV positive, can indicate situations where additional care is needed. Those who are married or living with partners often have a caregiver, but also may have larger financial needs if the partner is not working or disabled. PLWH/A with families also have particular needs, including day care and services for children when seeking care.

About 60% of PLWH/A report living with another adult. Of those, about three-quarters live with one adult and 25% live with two or more adults. African American and Latinos tend to live in larger households. About 28% of PLWH/A live with another HIV positive person in their household, about 14% say they are taking care of someone else in the household who is HIV positive, and 26% say they are being taken care of by someone else in their home. Interestingly, IDUs are less likely than PLWH/A from other risk groups to take care of someone else, but much more likely to be recipients of care from someone else. Latinos are both more likely to be taken care of and more likely to take care of someone else than other ethnicities.

While 20% of all PLWH/A report living with children, almost 60% of the women living with HIV and AIDS have one or more children. Latinos living with HIV and AIDS are more likely to live with one or more children. Less than one percent of the children are HIV positive.

As shown in Figure 3-7, of all PLWH/A about 41% are single. African Americans are more likely to be single than other racial groups. Less than half of the MSM sample are single and about a third of the heterosexuals report being single. Females and heterosexuals are more likely to be divorced or separated than men or MSM and IDUs.

Figure 3-7 Relationship status and risk category



	Total		Male	Fe-male		MSM	MSM/ IDU	IDU	HET		AfAm	Anglo	Latino
■ Singe	41.4%		42.8%	32.9%		43.8%	51.1%	34.0%	32.4%		50.5%	37.3%	34.6%
▨ Married/partner	34.9%		37.2%	21.8%		38.6%	27.6%	36.8%	22.1%		23.1%	40.3%	42.3%
□ Divorced/Separated	17.3%		14.8%	31.4%		12.1%	13.0%	25.0%	34.3%		20.3%	16.1%	12.4%

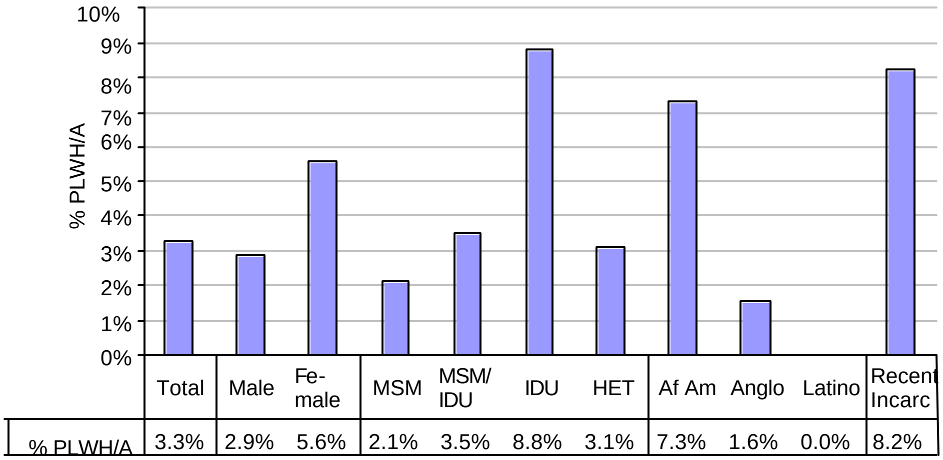
4. CO-MORBIDITIES

The co-morbidities of homelessness, STD's, TB, and drug use are discussed in this section.

Housing & Homelessness

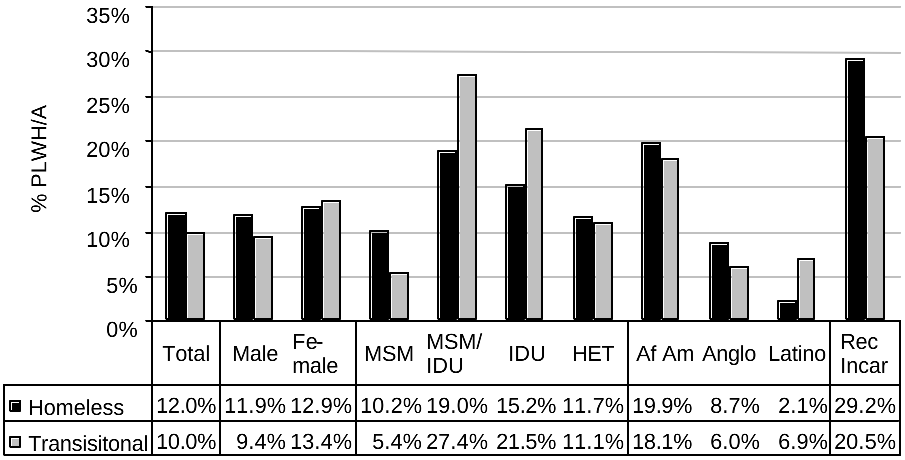
Stable housing is often a prerequisite for PLWH/A who are trying to adhere to a difficult medical regimen and improve their quality of life. About 3% of PLWH/A report being currently homeless, although, as shown in Figure 4-1, the recently incarcerated, IDUs, and African Americans are more likely to be currently homeless than other populations.

Figure 4-1 Currently Homeless



The instability of housing becomes more evident when PLWH/A are asked if they have been homeless anytime in the last two years. Of the PLWH/A interviewed, 12% have been homeless sometime in the last two years, and 10% have lived in some form of transitional housing. Figure 4-2 indicates that African Americans are much more likely to have unstable housing and live in transitional housing than other ethnic groups and among risk groups, IDUs and MSM/IDU are much more likely to have lived in transitional housing or have a history of homelessness than MSM or heterosexuals.

Figure 4-2 Homelessness & Transitional Housing in last two years



	Total	Male	Fe-male	MSM	MSM/ IDU	IDU	HET	Af Am	Anglo	Latino	Rec Incar
■ Homeless	12.0%	11.9%	12.9%	10.2%	19.0%	15.2%	11.7%	19.9%	8.7%	2.1%	29.2%
▨ Transisitonal	10.0%	9.4%	13.4%	5.4%	27.4%	21.5%	11.1%	18.1%	6.0%	6.9%	20.5%

The urgency with which housing should be addressed is indicated by about a quarter (23%) of the PLWH/A interviewed who say they will soon have to move. Continued housing instability is reported among those with history of homelessness; about half of those who have been homeless in the past two years say they expect to move soon. PLWH/A in the North appear to have the most unstable housing situation, while those in the South report more stable housing.

Substance Abuse

The epidemiological data indicate that 16% of the HIV transmission is attributable to IDU or MSM/IDU where individuals shared needles. Research shows that other substance abuse and addiction is also related to infection through unprotected sex by individuals trading unprotected sex for drugs or engaging in unprotected sex while high. Consequently, the co-morbidity of substance use and HIV includes drugs that are typically injected such as heroin, but also includes crack, non-injecting forms of crystal meth and "party drugs" such as ecstasy and poppers.

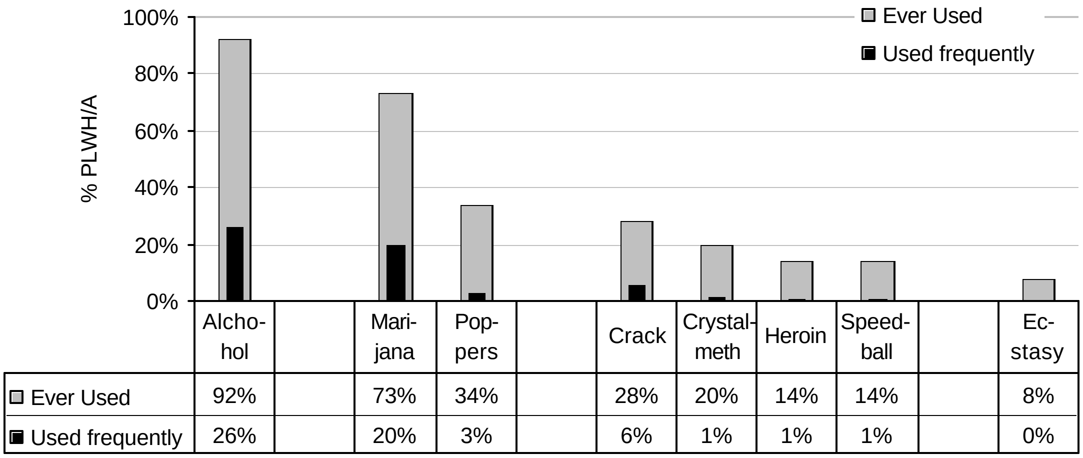
The survey data of self reported drug use indicate that drug use for PLWH/A has substantially decreased. Thirty percent of the PLWH/A who were interviewed report a history of injecting drugs, but frequent use of heroin and crystal meth is low. The gray bar in Figure 4-3 shows the percentage of PLWH/A who ever used a drug, and the black bar, show the percentage of all PLWH/A who use the drug relatively frequently.

- Over three-quarters of PLWH/A report ever using alcohol and marijuana, but frequent use is much lower with about 20% saying that they use marijuana more than once a week. Frequent use is much higher among special populations, including the recently released and homeless.
- While over 90% of PLWH/A have used alcohol, about 28% of PLWH/A reported using alcohol at least once a week. Frequent use is much higher among special populations, including the recently released and homeless.
- Of the opiates, 28% of the PLWH/A report ever using crack and 14% report ever using heroin. Six percent of all PLWH/A report continuing to use crack frequently (more than once a month), and about 1% of all PLWH/a report using heroin frequently. African Americans and

users of other substances are more likely to use crack than other populations. The homeless appear to be among the highest users of heroin, indicating the high level of co-morbidities among this population.

- Because fatigue is a common side effect of HIV and its medications, it is not uncommon for PLWH/A to attempt self-medication with crystal meth, a type of speed. While 20% of PLWH/A in Indiana say they have used crystal meth, only about 1% report using it frequently.
- “Party drugs” include poppers and ecstasy. About a third of the PLWH/A report using poppers, with 9% saying they use it monthly. Eight percent (8%) of all PLWH/A say they have used ecstasy, but it is not frequently used. MSM and MSM/IDU are among the heaviest users of party drugs.

Figure 4-3 Substance Use Among PLWH/A



	Alcho-hol		Mari-jana	Pop-pers		Crack	Crystal-meth	Heroin	Speed-ball		Ec-stasy
☐ Ever Used	92%		73%	34%		28%	20%	14%	14%		8%
■ Used frequently	26%		20%	3%		6%	1%	1%	1%		0%

STDs

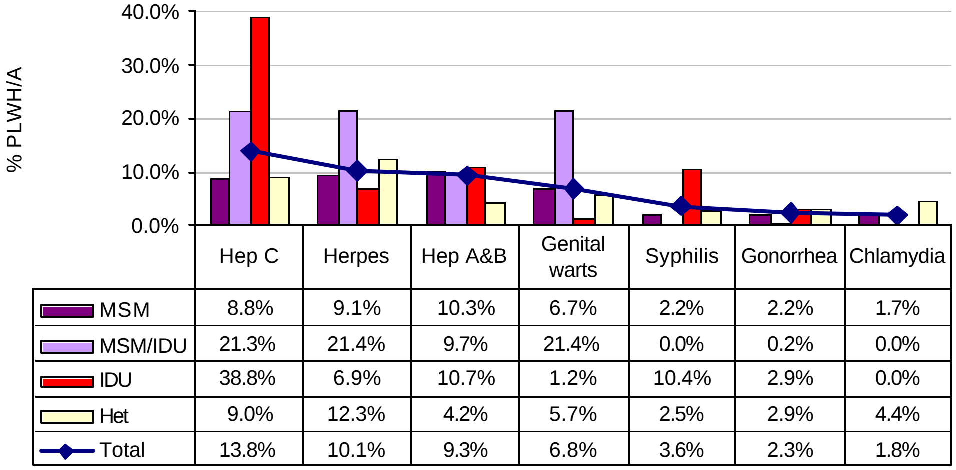
STDs have a dual impact on PLWH/A and those at risk for HIV infection. Individuals with a history of STDs are likely to have a compromised immune system and more likely to contract opportunistic infections (OIs). Also, manifestations of STDs such as open sores and genital ulcers make a person more vulnerable to HIV infection or re-infection. From an epidemiological perspective, a rise in STD rates, particularly gonorrhea and syphilis, indicate a rise in unprotected sexual intercourse that can lead to higher infection rates. Hepatitis, particularly Hepatitis C, is associated with needle sharing and is an indication of risk of HIV infection among IDUs.

Figure 4-4 and Figure 4-5 show STDs for the percentage of PLWH/A who report being diagnosed with STDs in the last year. They indicate that:

- 14% of all PLWH/A report having been diagnosed with Hepatitis C in the last year. Predictably, it is significantly higher among the risk groups IDUs (39%) and MSM/IDUs (21%). It is also higher among the Latinos (24%) and African Americans (21%).

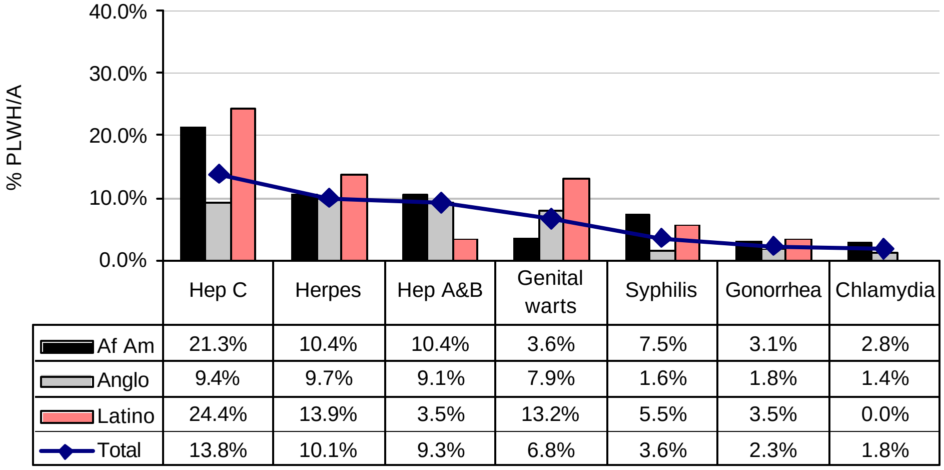
- Next highest incidence of STD's are herpes (10%) and hepatitis A or B (9%). Herpes is significantly higher among MSM/IDUs and there is not much difference in incidence by race or ethnicity. Hepatitis A and B is reported to be lower among heterosexuals and Latinos.
- Syphilis, Gonorrhea and Chlamydia each have relatively low incidence. Syphilis is significantly higher among IDUs, and genital warts among MSM/IDUs.

Figure 4-4 STDs among PLWH/A by Risk Group



	Hep C	Herpes	Hep A&B	Genital warts	Syphilis	Gonorrhea	Chlamydia
MSM	8.8%	9.1%	10.3%	6.7%	2.2%	2.2%	1.7%
MSM/IDU	21.3%	21.4%	9.7%	21.4%	0.0%	0.2%	0.0%
IDU	38.8%	6.9%	10.7%	1.2%	10.4%	2.9%	0.0%
Het	9.0%	12.3%	4.2%	5.7%	2.5%	2.9%	4.4%
Total	13.8%	10.1%	9.3%	6.8%	3.6%	2.3%	1.8%

Figure 4-5 STDs among PLWH/A by Race



	Hep C	Herpes	Hep A&B	Genital warts	Syphilis	Gonorrhea	Chlamydia
Af Am	21.3%	10.4%	10.4%	3.6%	7.5%	3.1%	2.8%
Anglo	9.4%	9.7%	9.1%	7.9%	1.6%	1.8%	1.4%
Latino	24.4%	13.9%	3.5%	13.2%	5.5%	3.5%	0.0%
Total	13.8%	10.1%	9.3%	6.8%	3.6%	2.3%	1.8%

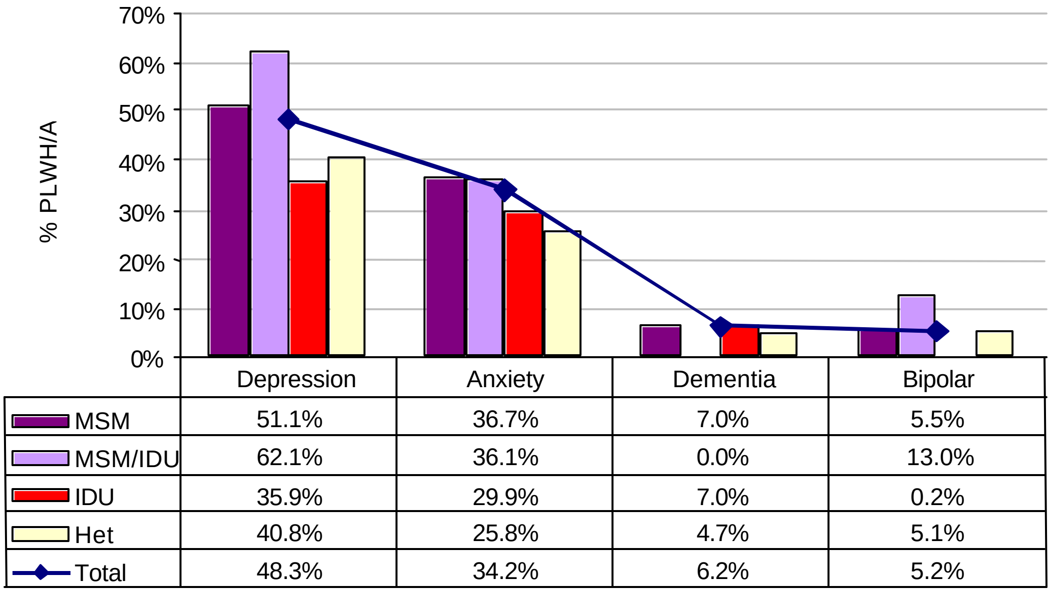
Mental Illness

Mental illness covers a broad array of mental disabilities. Many of those living with HIV and AIDS, particularly substance users, have had mental disabilities prior to becoming infected. For others, the diagnosis of HIV infection or its manifestations has led to mental disabilities. For the purpose of this needs assessment, mental illness was defined as having a diagnosis of bipolar disease, anxiety, dementia, or depression or receiving medication for psychological or behavioral problems in the past year. While there may be some over-reporting of bipolar disease, there is no question that bipolar disorder, depression, and anxiety are major problems.

More than half of PLWH/A (56%) report having been diagnosed with one of these conditions. The types of mental disorders that were diagnosed in the last year are shown in Figure 4-6 and Figure 4-7. They indicate that:

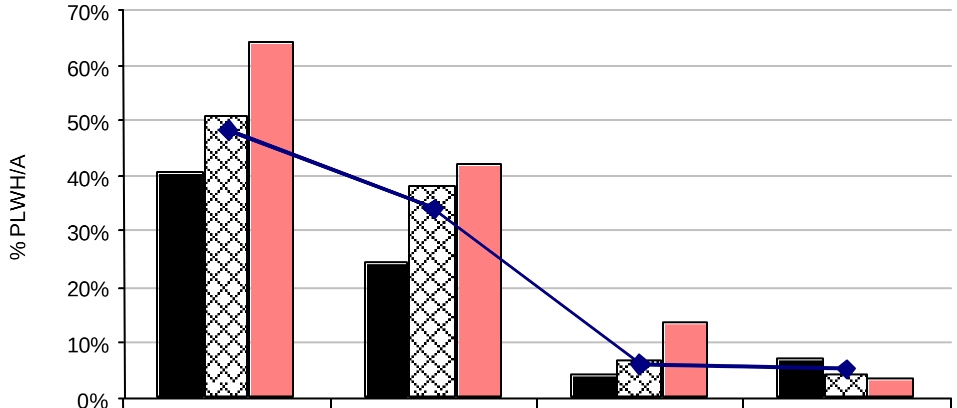
- Depression has been diagnosed among almost half (48%) of PLWH/A in the past year, and it is the most frequently diagnosed mental illness reported by PLWH/A. It tends to be highest among MSM/IDUs, and lowest among IDUs. It is also high among Latinos, although this may be unreliable due to the small sample size. It is also high among the homeless.
- About a third (34%) of the PLWH/A report a diagnosis of anxiety in the past year. It tends to be lower among African Americans and females.
- Between 5% and 6% report the more acute diagnoses of dementia and bipolar disease. Serious dementia may be undercounted because they would not have been able to complete the survey.
- Those who have been diagnosed with AIDS and are symptomatic tend to report a much higher incidence of mental illness. African Americans tend to report lower diagnosis of depression, anxiety, and dementia than other racial and ethnic groups. This may reflect actual incidence or the likelihood that they are less likely to see mental health professionals for a diagnosis. Notably African Americans are not less likely than other populations to report group or individual therapy.

Figure 4-6 Mental Illness Among PLWH/A by Risk Group



	Depression	Anxiety	Dementia	Bipolar
MSM	51.1%	36.7%	7.0%	5.5%
MSM/IDU	62.1%	36.1%	0.0%	13.0%
IDU	35.9%	29.9%	7.0%	0.2%
Het	40.8%	25.8%	4.7%	5.1%
◆ Total	48.3%	34.2%	6.2%	5.2%

Figure 4-7 Mental Illness Among PLWH/A by Race/Ethnicity



	Depression	Anxiety	Dementia	Bipolar
■ Af Am	40.7%	24.3%	4.4%	7.2%
▨ Anglo	51.0%	38.6%	6.6%	4.2%
🟥 Latino	64.5%	42.3%	13.6%	3.4%
◆ Total	48.3%	34.2%	6.2%	5.2%

Over 47% of PLWH/A reported having seen individual therapists and about a quarter of the PLWH/A (24.5%) report participating in group counseling. Those with a history of homelessness are much more likely to report receiving therapy, and there is no significant difference in the amount of therapy reported by different racial/ethnic populations. The youth sampled (13-24 years of age) tended to receive less treatment than other populations analyzed.

Tuberculosis

Six percent (6%) of PLWH/A surveyed reported that they had inactive tuberculosis (TB). One percent reported active TB, of which about a third say they are not in treatment. Two percent of the PLWH/A did not know their TB status. IDUs and African Americans are more likely to report inactive TB, and Anglos are more likely to report active TB, particularly those who have AIDS and are symptomatic. The numbers reporting TB are small and may not be generalizable.

5. STAGES OF DISEASE

Understanding the number of PLWH/A who are at different stages of infection is an important input for planning. Antiviral treatment is recommended for those individuals with acute viral syndrome or who have seroconverted within six months of infection and those who exhibit symptoms of acute HIV syndrome. For others in early stages of infection, case management and monitoring are important services. In addition, all those infected with HIV, regardless of stage are eligible for food, dental, and a variety of other services noted in the continuum of care.

Recently the guidelines to start retroviral treatment was changed from a CD4 count of 500 to 350. In HIV infected persons whose CD4 counts are above 350, treatment should be considered if their viral load level rises above 30,000. Previous guidelines would have called for treatment if the viral load rose above 10,000 copies. All symptomatic HIV infected persons are recommended for treatment, regardless of CD4 count or viral load level.

Those with more progressed HIV disease, often have a need for home health care, buddy and companion services, and hospice care, permanency planning, and other end-stage services.

Given these criteria, the survey asked respondents to note if they are symptomatic or asymptomatic and if they have been diagnosed with AIDS. The survey also asks for self reported highest and most recent CD4 and viral load counts.

Diagnosed with AIDS

Forty-four percent (44%) of the PLWH/A who were surveyed reported that they were told by their doctor that their HIV had progressed to AIDS. Predictably, there is a significant relationship between the length of time a person knows that s/he is HIV positive and having an AIDS diagnosis, with those who know their status longest being most likely to have AIDS. MSM and Anglos are those who were first infected in the epidemic and, as shown in Figure 5-1, they are more likely to have progressed to AIDS.

Figure 5-1 AIDS Diagnosis

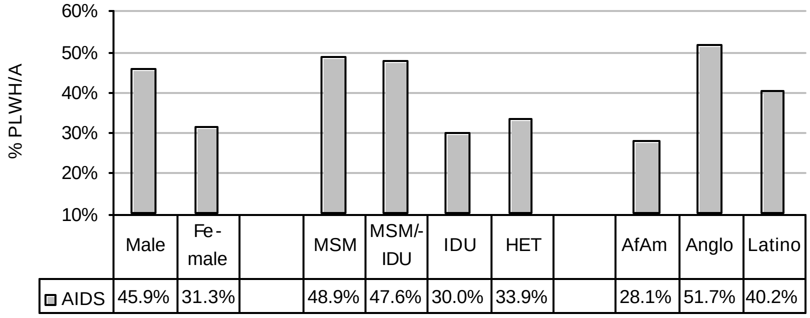
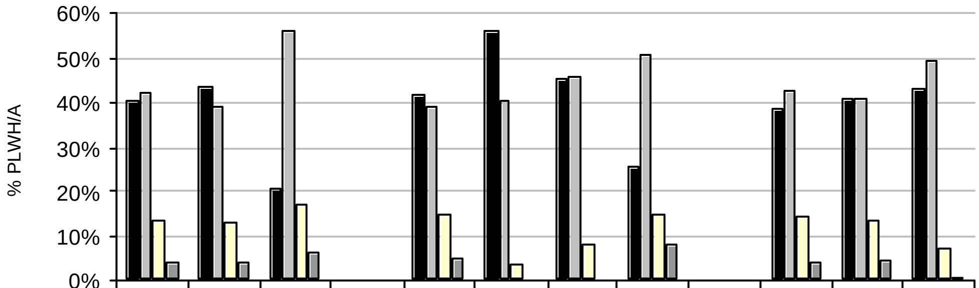


Figure 5-2 shows the length of time PLWH/A know they were HIV positive, and indicates that over 80% of PLWH/A have known their status for more than three years. About 40% have known their status for over eight years. Females, heterosexuals, Latinos, and, to a lesser degree, African Americans have known their HIV status for less time, indicating that newer infections are disproportionately among these populations.

Comparing Figure 5-1 and Figure 5-2 African Americans report proportionately fewer AIDS cases among those who have known their status for more than eight years, while Anglos report a relatively high number of AIDS cases among those who have known their status for more then eight years. Also 45% of the IDUs know that they have been positive for over eight years, but relatively few, 30%, report having progressed to AIDS. Alternatively, fewer MSM know they have been positive for more than eight years (41%), but a greater number have progressed to AIDS (49%).

There could be a few interpretations of these differences. Taken at face value, it suggests that MSM are likely to progress to AIDS earlier than other risk groups and Anglos are more likely to progress to AIDS than other ethnic groups. It could also mean, however, that HIV is being detected among IDUs, communities of color, and females at a later stage of infection, or that communities of color and females are inaccurately reporting their AIDS status.

Figure 5-2 Time Known HIV+



	Total	Male	Fe-male		MSM	MSM/-IDU	IDU	HET		AfAm	Anglo	Latino
■ 8+ yrs	40.3%	43.6%	20.5%		41.1%	55.8%	45.4%	25.7%		38.2%	41.1%	43.0%
▨ 3-8 yrs	41.7%	39.3%	56.2%		39.0%	40.7%	46.0%	50.8%		42.9%	40.8%	49.4%
□ 1-3 yrs	13.3%	12.7%	16.9%		14.6%	3.5%	8.6%	15.1%		14.4%	13.1%	6.9%
▩ <1 yr	4.7%	4.4%	6.4%		5.3%	0.0%	0.0%	8.5%		4.6%	5.0%	0.7%

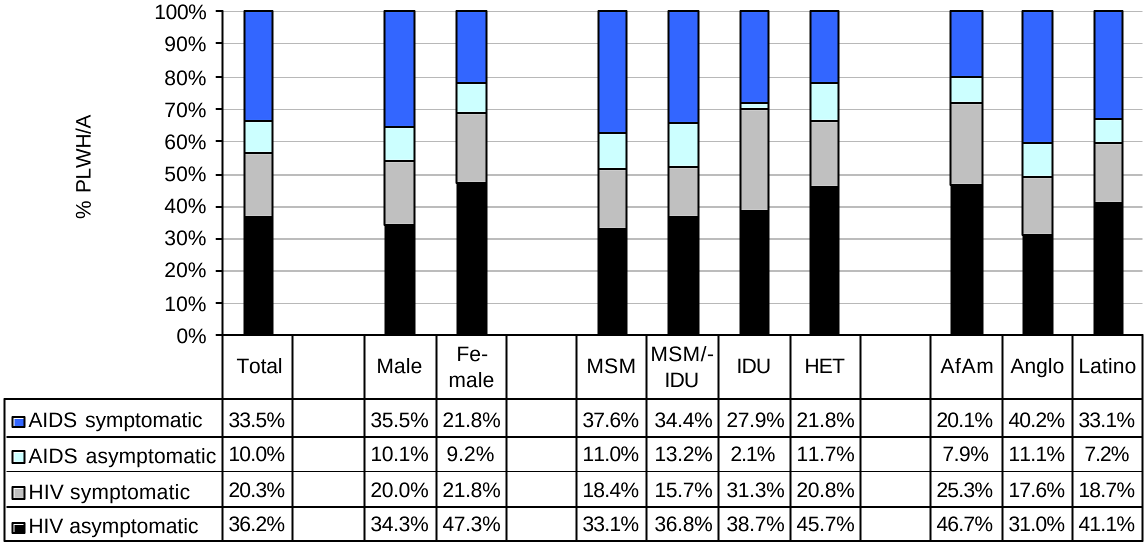
Symptomatic

The findings indicate that about 54% of PLWH/A surveyed currently have symptoms associated with their HIV infection. Of those diagnosed with AIDS, over 33% report being symptomatic. Among PLWH who have not progressed to AIDS, 20% report symptoms.

Figure 5-3 shows the percentage reporting symptoms by risk category:

- There are proportionately more females, heterosexuals, and African Americans who are HIV positive and have not progressed to AIDS, and they are more likely to be asymptomatic.
- IDUs also are less likely to have progressed to AIDS, but IDUs are the most likely to report being HIV positive and symptomatic.
- Among those with AIDS, Anglos, MSM, and males are the most likely to be symptomatic.
- Among the special populations, the homeless are more likely to report symptoms.

Figure 5-3 Percentage with and without symptoms by risk category



	Total		Male	Fe-male		MSM	MSM/-IDU	IDU	HET		AfAm	Anglo	Latino
🟦 AIDS symptomatic	33.5%		35.5%	21.8%		37.6%	34.4%	27.9%	21.8%		20.1%	40.2%	33.1%
☐ AIDS asymptomatic	10.0%		10.1%	9.2%		11.0%	13.2%	2.1%	11.7%		7.9%	11.1%	7.2%
▨ HIV symptomatic	20.3%		20.0%	21.8%		18.4%	15.7%	31.3%	20.8%		25.3%	17.6%	18.7%
■ HIV asymptomatic	36.2%		34.3%	47.3%		33.1%	36.8%	38.7%	45.7%		46.7%	31.0%	41.1%

Eligible for Medical Care

Based on the criteria for antiviral, there are 54% of the HIV positive populations who indicate symptoms and would be recommended for treatment. In addition, there are 15% who have been diagnosed with AIDS with no symptoms or have a current t-cell count below 350, suggesting that 69% of PLWH/A are likely to need medical treatment for their infection.

6. ACCESS TO HEALTH CARE

Insurance Coverage

In determining the scope of services needed under Ryan White, it is important to determine the access to health care for PLWH/A. Indiana has a progressive system where PLWH/A are encouraged to enroll in the State's high risk insurance pool through the Indiana Comprehensive Health Insurance Association (ICHIA), and Ryan White funds are used to purchase and supplement insurance payments to the ICHIA through the Health Insurance Assistance Program. On the other hand, Medicaid and Social Security Disability Insurance (SSDI) are relatively difficult to obtain compared to other States. In addition, during the survey period, procedural problems with AIDServe, the ASO that delayed payment to providers, caused several difficulties of both PLWH/A and providers.

As emergency funds, Ryan White Care Act funds should supplement and fund services that are not available through other channels. In Indiana, persons funded through Medicaid or Medicare or private insurance have access to medical services without Ryan White Funds. They may, however, need supplemental wrap-around services, dental, or mental health services paid for directly or reimbursed by Ryan White funds.

Table 6-1 provides the paths to insurance for PLWH/A in Indiana. When funds are available and enrollment is open through ICHIA, Ryan White Funds are used to pay HIAP which then purchases insurance through ICHIA.

Table 6-1 Paths to Care for PLWH/A in Indiana

Paths to Care for PLWH/A in Indiana

Income Eligibility: Below 300% federal poverty level (about $25,000)		**Comments**
Current Status	**Action**	**Coverage**
No Insurance	Obtain and/or maintain AIDS Drug Assistance Plan (ADAP), Early Intervention Plan (EIP), and apply for Health Insurance Assistance Plan (HIAP). Apply for Medicaid if meet income, asset, medical condition, and other requirements.	AIDS Drug Assistance Plan (ADAP) provides HIV related drugs. Early Intervention Plan (EIP) provides limited outpatient medical care while in application or pre-existing condition status with Health Insurance Assistance Plan (HIAP).
Social Security Disability Insurance and Medicare part A and B (based on prior work history and disability)	Maintain eligibility.	Those with a disability such as AIDS may be eligible for SSDI that continues until eligibility changes. Medicare eligibility begins after two years of eligibility of SSDI. Medicare A pays for hospitalizations, Medicare B pays outpatient doctor and lab fees. Medicare does not pay any pharmacy charges

Income Eligibility: Below 300% federal poverty level (about $25,000)		**Comments**
Current Status	**Action**	**Coverage**
Medicaid* (Low income, pregnant women, newborn, under age 19, disabled, Medicare – QMB, other qualified individuals)	Maintain eligibility. Eligibility in tandem with TANF for families and SSI for disabled. Families meeting the income and resource standards for the Temporary Assistance to Needy Families (TANF) program are also eligible for Medicaid whether or not they actually receive TANF cash assistance. For TANF the focus is on transitional services, and so TANF requires most clients to participate in work-related activities and will limit the time that clients can receive benefits.	A separate examination is required to be eligible for Medicaid disability. Pays for inpatient and outpatient care and drugs.
Indiana Comprehensive Health Insurance Assoc. (ICHIA) (high risk pool)	Purchased through Health Insurance Assistance Plan (HIAP). Maintain eligibility.	Indiana Comprehensive Health Insurance Association (ICHIA - High Risk Pool) pays for inpatient and outpatient care and drugs.
Early Intervention Plan (EIP)	Apply for HIAP.	Early Intervention Plan (EIP) provides limited outpatient medical care for the period before HIAP starts to pay for ICHIA.
AIDS Drug Assistance Plan (ADAP)	Apply for HIAP.	Provides HIV related drugs for the period before HIAP starts to pay for ICHIA
COBRA	Maintain. Near end of term apply for HIAP.	There is currently little insurance continuation assistance.
Private Insurance	Maintain. If canceled apply for HIAP.	There is currently little insurance continuation assistance.
Income Eligibility: Above 300% federal poverty level		**Comments**
Insurance Status	**Action**	
No Insurance	Obtain insurance in private marketplace, if denied, apply for ICHIA. Spend down to eligibility for Medicaid.	There is currently little insurance continuation assistance.
COBRA	Maintain. Near end of term apply for ICHIA.	
Private insurance	Maintain. If canceled apply for ICHIA.	
It is important to note that Indiana has the most restrictive Medicaid disability eligibility standard in the country. It is one of only two states that follow a more restrictive medical eligibility definition than is required by the federal Social Security Administration, which determines eligibility for the Supplemental Security Income (SSI) and Retirement, Survivors, and Disability Insurance (RSDI) program. Further, Indiana is one of only twelve states that has financial criteria that are more restrictive.		

There are a number of indicators that suggest the success of moving PLWH/A into insurance through the Health Insurance Assistance Program (HIAP). Three quarters of the PLWH/A who were surveyed report that they have insurance. There is little difference between the percentages of men and women who report being insured, and there are more African Americans living with HIV and AIDS who report being insured (78%) than Anglo living with HIV/AIDS (75%). Also, almost 80% of the IDUs report being insured, and about two-thirds of those who have been homeless in the past two years are insured. The insurance situation in Indiana differs from that of other EMAs where there is no mechanism to pay for insurance. In those EMAs, women tend to be more insured then men because of the various insurance programs for families and single mothers with children, and Anglo are insured more than African Americans because they often have higher incomes to purchase insurance, or are more likely to qualify for SSDI.

There are several types of insurance that are reported by PLWH/A. About 25% of PLWH/A report no insurance except HIAP or ICHIA, or EIP, or EIP limited[4]. That means that Ryan White Funds would have to pay for HIAP or pay for services directly.

For non-Ryan White reimbursements, Figure 6-1 indicates that:

- 20% of PLWH/A report only Medicaid
- 14% of PLWH/A report only Medicare
- 23% of PLWH/A report dual Medicaid and Medicare coverage, and 1% of those also have private insurance.
- 19% of PLWH/A report some form of private insurance through work, their partner, or COBRA. Of those 5% also report Medicaid or Medicare coverage.
- About 9% of those interviewed report Hoosier Healthwise. Among women with children, 63% have Hoosier Healthwise, while 30% of the men with children report Hoosier Healthwise.

In addition to Medicare, Medicaid, and private insurance, about 8% of the PLWH/A report VA benefits. Of those 8%, about 22% (under 2% of the all PLWH/A) report having no other insurance.

As shown in Figure 6-2 about 34% of the PLWH/A report having insurance through the Indiana Comprehensive Health Insurance Association (ICHIA), and 33% report using the Health Insurance Assistance Program that is largely funded through Ryan White to pay the ICHIA premiums, co-pays and deductibles. In addition, 27% use EIP Limited to obtain vision and dental care, 24% use EIP for covering early interventions and gaps in medical care, and 4% report using early intervention care reimbursed or paid for by Title III.

There is little overlap in Medicaid/Medicare and ICHIA, with less than 10% of those surveyed indicating both insurers. While PLWH/A should not have both Medicaid and ICHIA, there were instances where there was some overlap for a period of time during the period of interviewing. There is greater reported coverage by Medicare and ICHIA, with up to 25% of those with ICHIA stating that they had Medicare. Because Medicare does not pay for medication, PLWH/A may

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[4] EIP Limited was discontinued in July 2001, leaving a gap in coverage for vision and dental care.

have both, with Medicare as the primary insurer and ICHIA as the supplementary, primarily for medication.

Figure 6-3 further indicates that while Medicaid and ICHIA are major sources of insurance for all populations infected with HIV/AIDS, coverage varies by subpopulation.

- ICHIA is more likely to cover a greater percentage of males, including MSM, and Anglos, than females, African Americans, IDUs.
- Medicaid is more likely to cover females and IDUs and, due to disability, people living with AIDS.

Figure 6-1 Non Ryan White Reimbursed Health Insurance

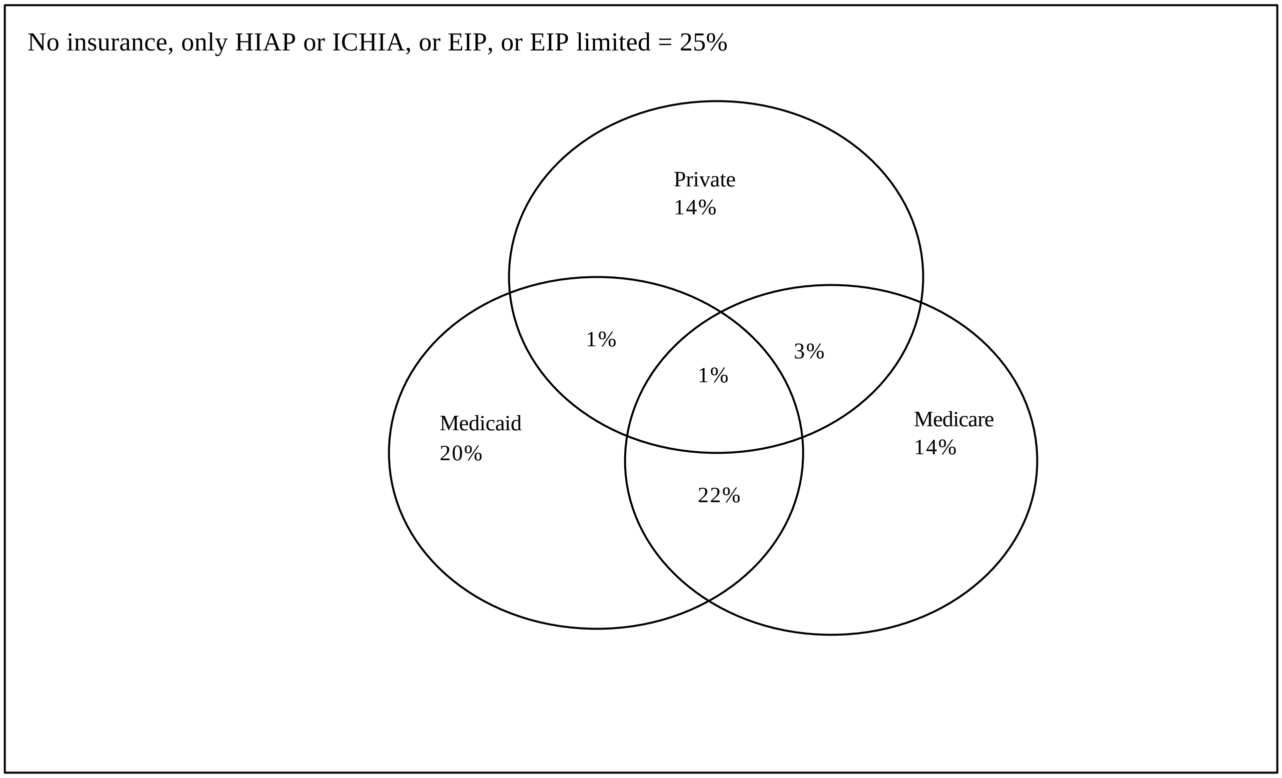


Figure 6-2 Ryan White Funded Insurance

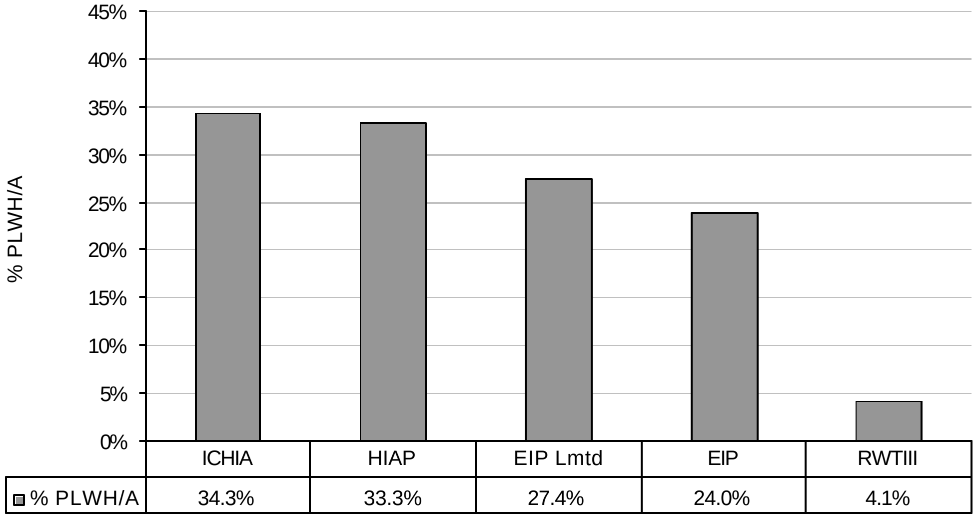
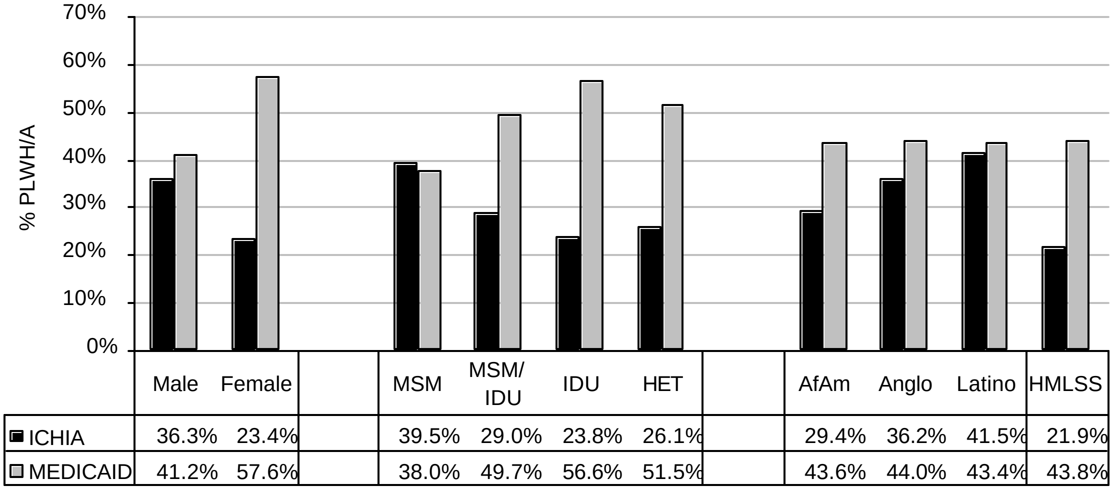


Figure 6-3 Medicaid and ICHIA Coverage by Subpopulations



Based on the self reported insurance data, Ryan White coverage is critical for over 50% of PLWH/A in Indiana. Ryan White funds are critical for the 25% of the PLWH/A with no insurance coverage, and for about the third of the population who receive ICHIA through Ryan White funded HIAP. Medicaid is more likely to be an option for women, particularly women with children (including Hoosier Healthwise, and CHIP) while ICHIA is more likely to be an option for men.

When asked who pays for insurance the data supports the finding that there is a great need for insurance assistance. While about a fifth (22%) do not know who pays for their insurance, the majority of those who know state HIAP pays the health insurance premium. Under 10% of PLWH/A surveyed say they pay all the premiums and 8% say they pay part of the premium.

When asked who pays the insurance premium, the data is consistent in showing high need. About three quarters of PLWH/A pay nothing or do not have insurance, and 28% pay under $200 a month. Five percent (5%) pay over $200 a month. It would appear that HIV symptomatic (not AIDS) individuals are most likely to pay nothing for insurance, and it probably reflects the newer and poorer communities infected by HIV.

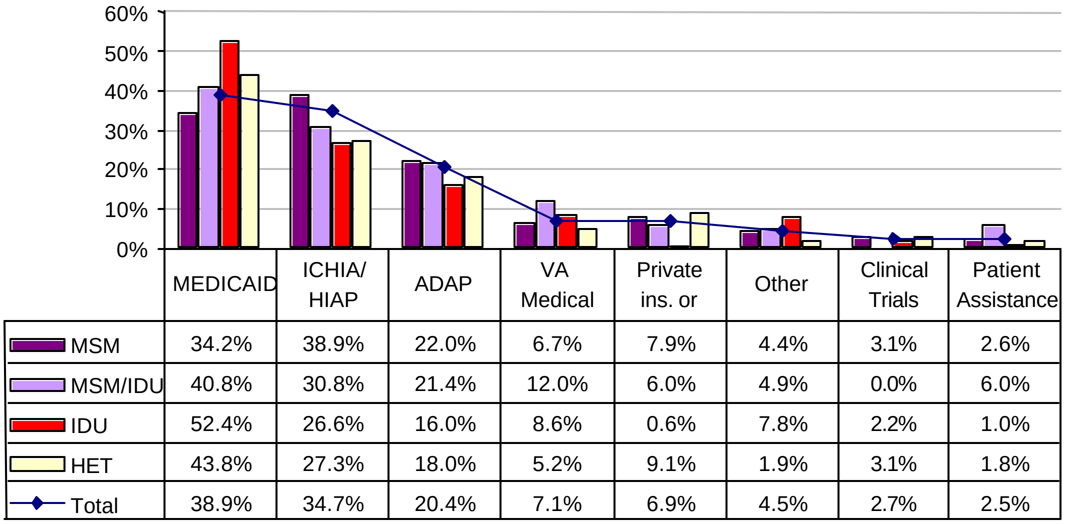
For those with insurance, the vast majority (72%) do not pay a deductible. For those who do pay, the majority pay less than $500 a year.

Drug Reimbursement

Over 90% of PLWH/A have their medication costs reimbursed. As shown in the line in Figure 6-4:

- The two largest sources of drug reimbursement are Medicaid (39%) and Ryan White funded ICHIA (35%). That is followed by Ryan White funded ADAP (20%).
- Several of the PLWH/A report multiple reimbursement sources for medication. Of the 50% who use ADAP and/or HIAP for drug reimbursement, 21% report using both. There is very little overlap, however, between ADAP or HIAP and Medicaid.
- Except for MSM, Medicaid is the largest payer for medication for all risk groups. MSM rely more on ICHIA for drug reimbursement. Medicaid is the primary insurer for health care for IDUs and heterosexuals, particularly women.

Figure 6-4 Sources for Drug Payment/Reimbursement



	MEDICAID	ICHIA/ HIAP	ADAP	VA Medical	Private ins. or	Other	Clinical Trials	Patient Assistance
MSM	34.2%	38.9%	22.0%	6.7%	7.9%	4.4%	3.1%	2.6%
MSM/IDU	40.8%	30.8%	21.4%	12.0%	6.0%	4.9%	0.0%	6.0%
IDU	52.4%	26.6%	16.0%	8.6%	0.6%	7.8%	2.2%	1.0%
HET	43.8%	27.3%	18.0%	5.2%	9.1%	1.9%	3.1%	1.8%
Total	38.9%	34.7%	20.4%	7.1%	6.9%	4.5%	2.7%	2.5%

Based on self reports from PLWH/A, about half, (49%) of all PLWH/A say they do not have a co-pay for their medication. Another 20% say they pay under $9.99 as a co-pay for their insurance. Twelve percent (12%) say they have a co-pay on mediation that is over $10.00.

Entitlements and Benefits

The entitlement and benefits received by PLWH/A are triggered by low income and disability. Social Security Income (SSI) is based solely on income and disability and those on SSI usually qualify for Medicaid. Eligibility for Social Security Disability Insurance (SSDI) is based on income, disability, and work history that pays into the social security fund. In both cases, if the person living with HIV or AIDS does not qualify for disability, they do qualify for benefits.

The majority of PLWH/A (52%) report being on SSDI, about a quarter report SSI, and another 11% report being on long term disability. As shown in Table 6-2:

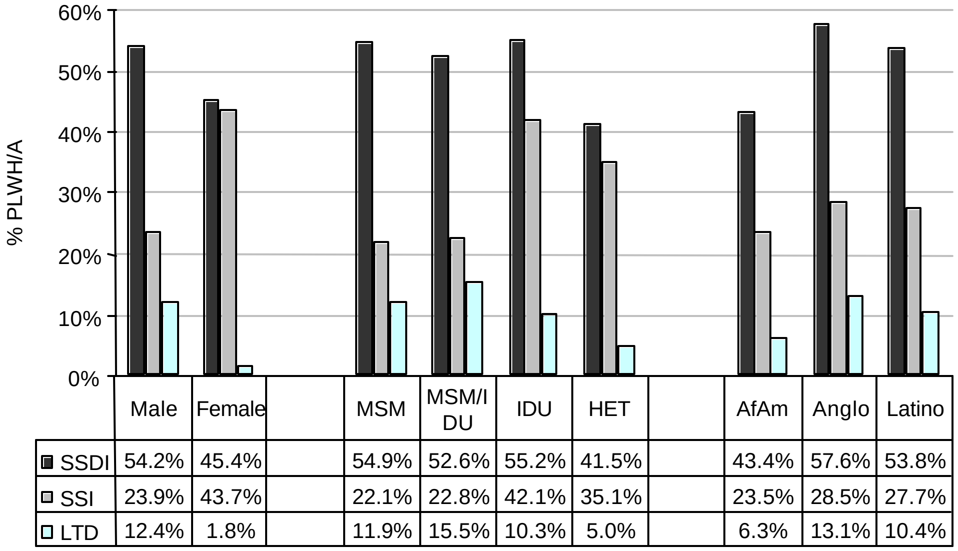
- More men, including MSM, and Anglos report being on SSDI and long term disability than women, suggesting that women are less likely to have had a work history that paid into the social security fund.
- As expected, more persons living with AIDS have SSDI and long term disability, reflecting their disability status. Women are more likely to report SSI than men, indicating lower income and less work history.

Indicative of the low income of PLWH/A, about half (49%) report receiving food stamps, and over a quarter (27%) report receiving rent supplements.

About 4% of all PLWH/A report receiving TANF, but as seen in Table 6-3:

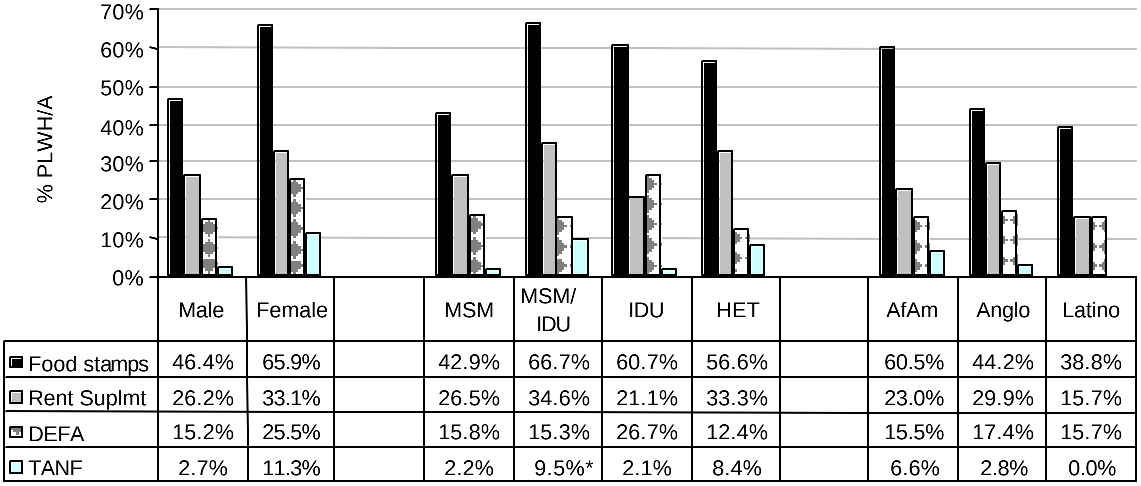
- Far more women (11%) report receiving TANF than men (3%), reflecting their greater likelihood of having children and unavailability of other work-related coverage.
- Food stamps are also more likely to be received by women, heterosexuals, and African Americans showing a greater need for basic services among these populations.
- About 17% of PLWH/A report accessing DEFA and it is usually used for utilities, rent, or emergency medical treatment. Over a quarter (27%) of the IDUs report accessing DEFA, indicating their higher financial instability and greater need for essential services.
- Twenty-six percent (26%) of the PLWH/A access rent supplements. Heterosexuals (33%) and Anglos (30%) are most likely to access rent supplements than other populations. Also those living in the South (41%) are more likely to access rent supplements than other geographic areas.

Table 6-2 SSDI, SSI, and Long Term Disability



	Male	Female		MSM	MSM/IDU	IDU	HET		AfAm	Anglo	Latino
■ SSDI	54.2%	45.4%		54.9%	52.6%	55.2%	41.5%		43.4%	57.6%	53.8%
▒ SSI	23.9%	43.7%		22.1%	22.8%	42.1%	35.1%		23.5%	28.5%	27.7%
□ LTD	12.4%	1.8%		11.9%	15.5%	10.3%	5.0%		6.3%	13.1%	10.4%

Table 6-3 Food Stamps, Rent Supplement, DEFA, & TANF



	Male	Female		MSM	MSM/IDU	IDU	HET		AfAm	Anglo	Latino
■ Food stamps	46.4%	65.9%		42.9%	66.7%	60.7%	56.6%		60.5%	44.2%	38.8%
▒ Rent Suplmt	26.2%	33.1%		26.5%	34.6%	21.1%	33.3%		23.0%	29.9%	15.7%
▨ DEFA	15.2%	25.5%		15.8%	15.3%	26.7%	12.4%		15.5%	17.4%	15.7%
□ TANF	2.7%	11.3%		2.2%	9.5%*	2.1%	8.4%		6.6%	2.8%	0.0%

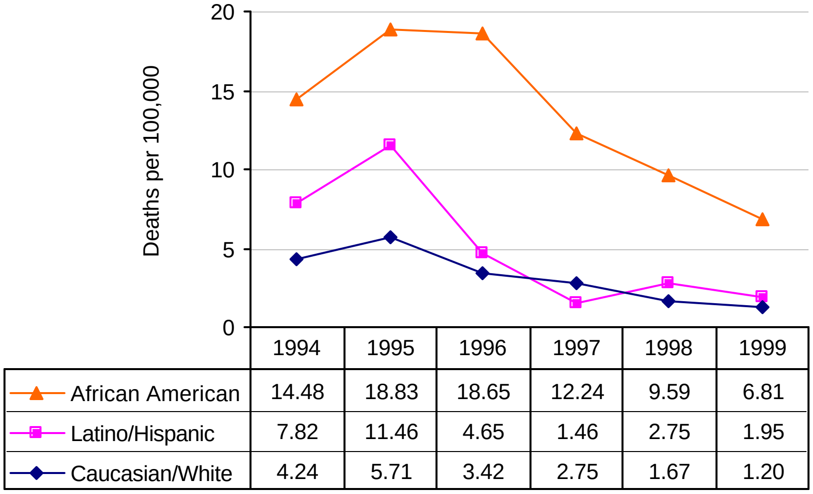
*MSM/IDU unreliable due to small sample size (n=3)

7. OUTCOMES

Mortality

Fewer people dying of AIDS and improved quality of life for those living with HIV and AIDS are two outcomes measured in this needs assessment. Figure 7-1 indicates that death rates have declined among all ethnic groups, with the sharpest decline among African Americans. Hispanics have shown the second largest decline in deaths, falling below the Anglo death rate in 1997. However, between 1997 to 1998 the death rate among Hispanics took an upward turn and since that time has remained above the Anglo death rate with about 2 deaths per 100,000 in 1999. Since the precipitous decline noted in the mid 1990s, the death rate among Anglos has leveled off while the rate among Hispanics has fluctuated and the high rate among African Americans continues to decrease. Nonetheless, in 1999 the death rate remains substantially higher among the African American population and continues to be between three to five times the rate of Hispanics and Anglos, respectively.

Figure 7-1 HIV/AIDS Deaths by Ethnicity per 100,000 of Indiana Population



	1994	1995	1996	1997	1998	1999
▲ African American	14.48	18.83	18.65	12.24	9.59	6.81
■ Latino/Hispanic	7.82	11.46	4.65	1.46	2.75	1.95
◆ Caucasian/White	4.24	5.71	3.42	2.75	1.67	1.20

Quality of Life

The second outcome measure for the system of care is improved physical and mental health. While no baseline physical or mental health measures are available for PLWH/A, survey participants rated their current physical and emotional health and then compared it to "when they first sought treatment for their HIV infection." The assumption is that access to care, and in particular to new HIV drug therapies, have had a positive impact on the physical and mental health of PLWH/A seeking care. Consequently, improved physical or emotional health after seeking treatment would suggest the system is meeting its major objective.

Drug therapies, however, may not have the same beneficial affect across all populations, and some PLWH/A may experience severe side-effects that compromise both physical and mental health. Additionally, there are disparities in access to care and treatment that may also impact quality of life. As a result of these factors, it is expected that some of the survey respondents will report decreasing physical and emotional health regardless of the quality of the treatment.

Figure 7-2 reports the current and perceived change in physical health. It is divided by PLWH/A who are asymptomatic and symptomatic and those who report being diagnosed with AIDS. PLWH/A who are symptomatic or asymptomatic are mutually exclusive. About three quarters (74%) of those living with AIDS said they were symptomatic, about 26% said they were asymptomatic.

As expected, 72% of those with no symptoms report excellent (24%) or good (48%) physical health, and about 2% report poor physical health. In contrast 46% of symptomatic HIV or AIDS report excellent or good physical health (46%) with over half (54%) reporting fair or poor physical health. Under 10% of those who are symptomatic or those diagnosed with AIDS report being in poor physical health. There is little difference by ethnic and risk group on the level of reported physical health. Among the special populations, those with diagnosed mental problems report somewhat worse physical health.

About 72% of those living with AIDS say that their physical health is better or the same as it was when they started treatment for their HIV infection. Slightly fewer, but still over 66%, of those with symptoms say they are doing better or the same. HIV positive persons with symptoms are more likely to say that their health status is worse than when they started treatment (34%) compared to asymptomatic persons living with HIV (16%).

Figure 7-3 reports the current perceived change in emotional health. Over 55% of asymptomatic PLWH/A report their emotional health is good or excellent, while 47% of those symptomatic report their emotional health is good or excellent. Those with AIDS are most likely to report their emotional health is "good".

A majority of all PLWH/A indicate an improvement in their emotional health since they started treatment. PLWA report the greatest improvements in emotional health (68%). Over 60% of symptomatic (63%) and those with no symptoms (60%) report emotional health improvements. Those persons with AIDS who are asymptomatic report the greatest improvement in their emotional health, while those diagnosed with a mental illness report the poorest improvement in emotional health.

Figure 7-2 Quality of Life – Physical Health

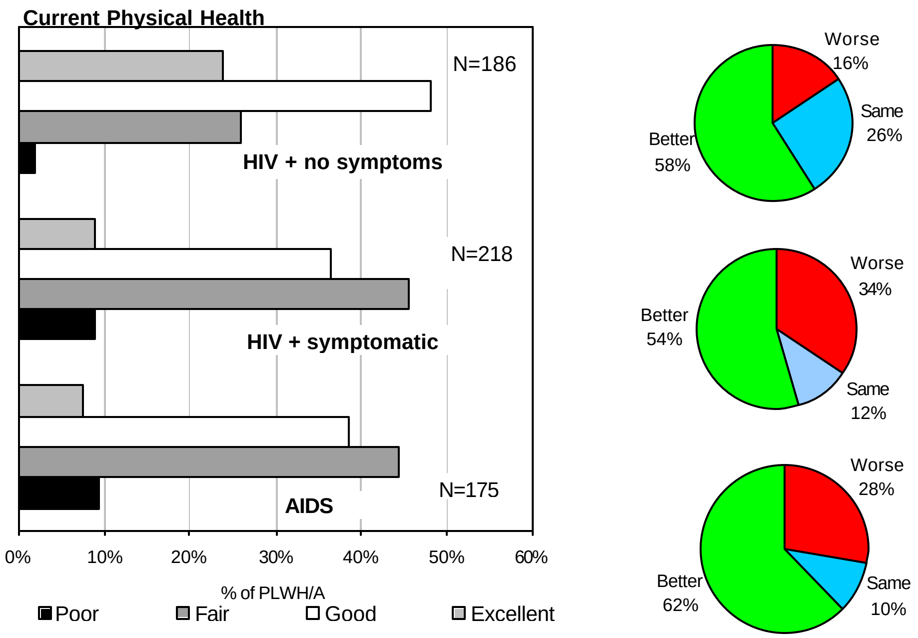
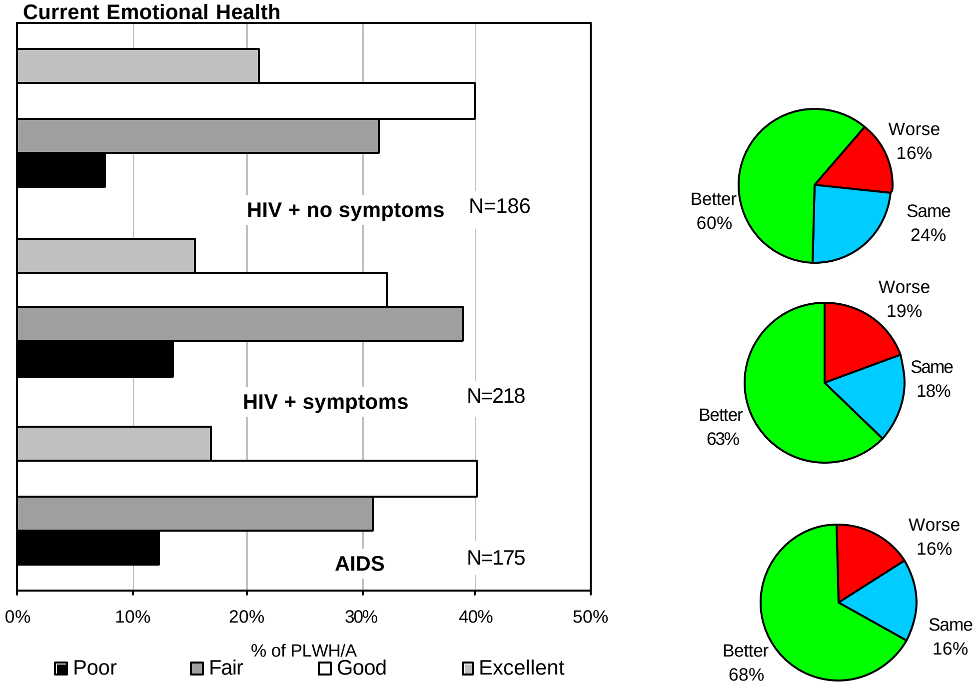


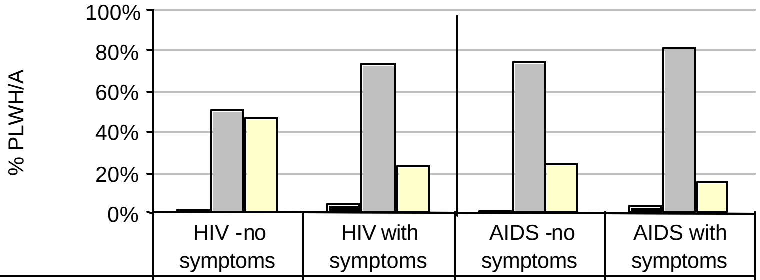
Figure 7-3 Quality of Life – Emotional Health



In addition to the reported physical and emotional health status, indexes of activities of daily living (ADL) can provide a means for understanding the service needs and barriers faced by PLWH/A. Using a standardized scale, PLWH/A were asked how limited they felt in performing seven types of activities. These activities included the ability to perform vigorous activities and moderate activities and then a set of daily functions such as bathing, toilet use, transferring, mobility, and feeding. (For exact wording see question 47 in the Consumer Survey, Attachment 2.) Each category was scored on a 1-3 scale, with 1 indicating that the individual is in need of help, and 3 signifying an individual who is independent and not limited at all. The scores for the seven categories were summed to give an overall ADL score. The overall score ranged from 7 to 21, with higher scores reflecting greater independence and less need for assistance. Overall, PLWH/A reported a high level of functioning with an average ADL score of 19 out of a possible high of 21.

There was no difference in the ADL score reported among gender, ethnic nor risk groups. However, as shown in Figure 7-4, and as would be expected, PLWH/A with symptoms are significantly more likely to need help than PLWH/A with no symptoms. Notably, those needing the most help are symptomatic whether they are HIV positive or have been diagnosed with AIDS.

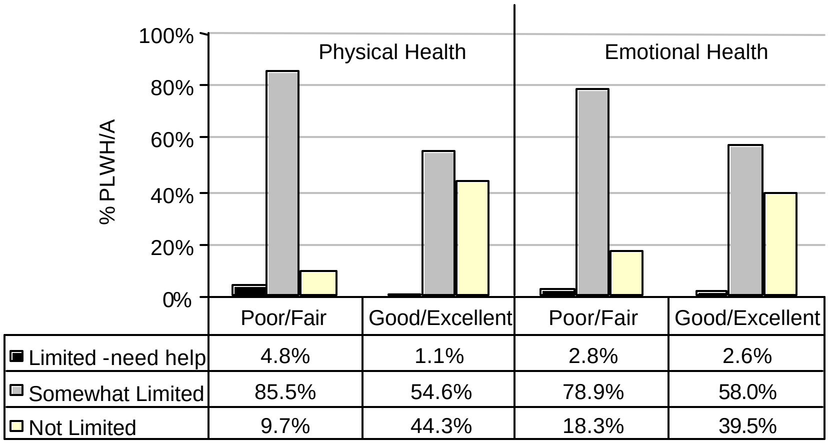
Figure 7-4 Ability to Perform Activities of Daily Living By Stage of Infection



	HIV -no symptoms	HIV with symptoms	AIDS -no symptoms	AIDS with symptoms
■ Limited -need help	1.9%	4.2%	0.8%	3.2%
▨ Somewhat Limited	50.8%	73.3%	74.5%	80.8%
☐ Not Limited	47.3%	22.6%	24.7%	16.0%

Similarly, Figure 7-5 shows that the individual's perceived functionality is directly related to their sense of physical and emotional health. That is, PLWH/A who report good to excellent physical health are less likely to need assistance than PLWH/A with poor to fair physical health. The same pattern is observed for PLWH/A's emotional health and functionality. However, PLWH/A with poor to fair emotional health are better able to function with less help than PLWH/A with poor to fair physical health. On average PLWH/A with poor to fair physical health report an average ADL score of 18. PLWH/A with good to excellent physical health report an average ADL score of 20. PLWH/A with poor emotional health report an average score of 18 and those with good to excellent emotional health report an average score of 19.

Figure 7-5 ADL by Emotional and Physical Health

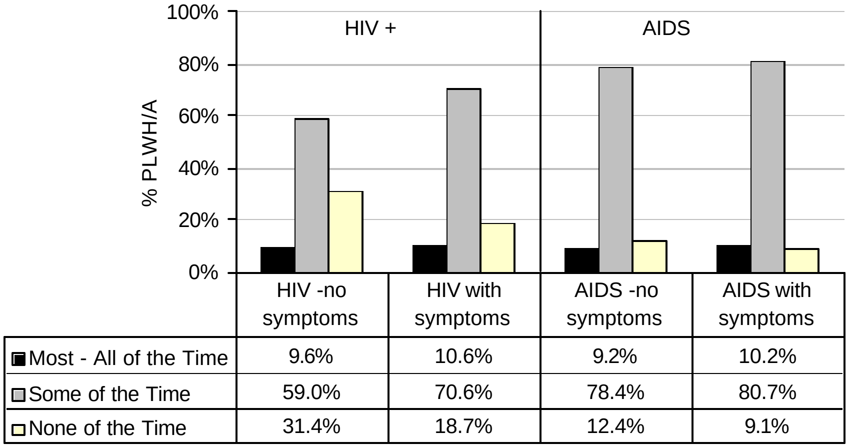


	Physical Health: Poor/Fair	Physical Health: Good/Excellent	Emotional Health: Poor/Fair	Emotional Health: Good/Excellent
■ Limited -need help	4.8%	1.1%	2.8%	2.6%
▨ Somewhat Limited	85.5%	54.6%	78.9%	58.0%
□ Not Limited	9.7%	44.3%	18.3%	39.5%

In addition to rating their physical functionality, PLWH/A were also asked to rate their mental and cognitive functionality. Using a three-item index, PLWH/A were asked to rate their problem solving ability, forgetfulness, and ability to concentrate. Each item on the index was scored on a six-point scale ranging from 1 "all of the time" to 6 "none of the time." The scores for the three items were summed to give an overall mental functioning score. The overall score ranged from 3 to 18, with higher scores reflecting greater functionality and less debilitation.

Similar to ADL, there was no difference in the mental functioning scores by gender, risk or race groups. However, as shown in Figure 7-6, stage of infection was significantly related to mental and cognitive functionality. As PLWH/A progress of HIV to AIDS, they are more likely to need help some of the time. Symptomatic PLWH/A are more likely to say they need help all of the time than asymptomatic PLWH/A.

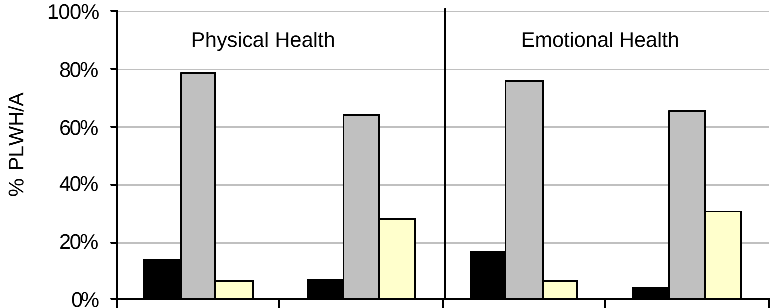
Figure 7-6 Mental Functioning by Stage of Infection



	HIV -no symptoms	HIV with symptoms	AIDS -no symptoms	AIDS with symptoms
■ Most - All of the Time	9.6%	10.6%	9.2%	10.2%
▨ Some of the Time	59.0%	70.6%	78.4%	80.7%
□ None of the Time	31.4%	18.7%	12.4%	9.1%

As seen in Figure 7-7, the majority of PLWH/A say they need help with basic functions at least some of the time. As expected, those who report good or excellent emotional and physical health status are less likely to need help than those who report poor or fair physical and emotional status. Notably, those with fair or poor emotional health are more likely than those with fair and poor physical health to report needing help most of the time.

Figure 7-7 Mental Functioning by Physical and Emotional Health



	Poor/Fair	Good/Excellent	Poor/Fair	Good/Excellent
■ Most - All of the Time	13.9%	7.2%	16.8%	4.2%
▨ Some of the Time	79.1%	64.2%	76.4%	65.4%
□ None of the Time	6.9%	28.6%	6.8%	30.4%

Quality of Life Qualitative Comments

The comments by focus group participants confirmed that the services designed to help PLWH/A can instead add stress and reduce their quality of life. For example, a Northern Anglo MSM said, *"I need access to services that allow me to continue my quality of life. That allows me to live what life I have left with the least amount of headaches from red tape and more services to allow me to keep what little dignity I have left."*

For many, quality of life is an adverse relationship with medication. For example a woman in the Central region said, *"I'm doing fine and I've been off of them for almost 6 months now. [Have you felt any withdrawal from leaving 33 pills a day?] Well, I still take some medication but not HIV meds. Yeah, I feel better. I hear people say that a lot of people let their medicines go because they would rather have a quality life. The quality of life is without the meds, I mean I feel so much better without them."*

Throughout the focus group, participants indicated that HIV/AIDS adds stress and reduced their quality of life by adding to already difficult situations. For example, a Northern Anglo MSM said, *"I have too much stress in my life, my Dad is dying, my body aches, and my stomach is messed up. I get migraines about 3 or 4 times a week, my doctor can not figure out that I have arthritis in my lower back and it aches all the time! I get confused, lose my train of thought, but still social security does not give a damn. I feel that I am just another number to them. I paid in to it for years, but yet I have to have a lawyer to go to my hearing with me to get my benefits and back pay what social security owes me. The lawyer can charge up to 25% of the back money social security owes me for doing an hours worth of work, when I have been dealing with this for over a year. That is not fair!"*

On the other hand for many long term survivors there are some clear improvements in quality of life. An Anglo MSM said, *"Having lived so long with HIV+ the next few years are going to be full wonderment. The last few have brought many good changes and knowing that there is life ahead, I can go on. Also being a caregiver myself I am well aware of the meaning of living."*

An overall impression that supports the quantitative findings is that the emotional stress of finding services and living off a fixed and inadequate income can contribute to a reduced quality of life equal to or more than physical health symptoms. The ability of persons to see and plan for the future is likely to have a positive impact on quality of life and functionality of PLWH/A.

8. MEDICATION AND ADHERENCE

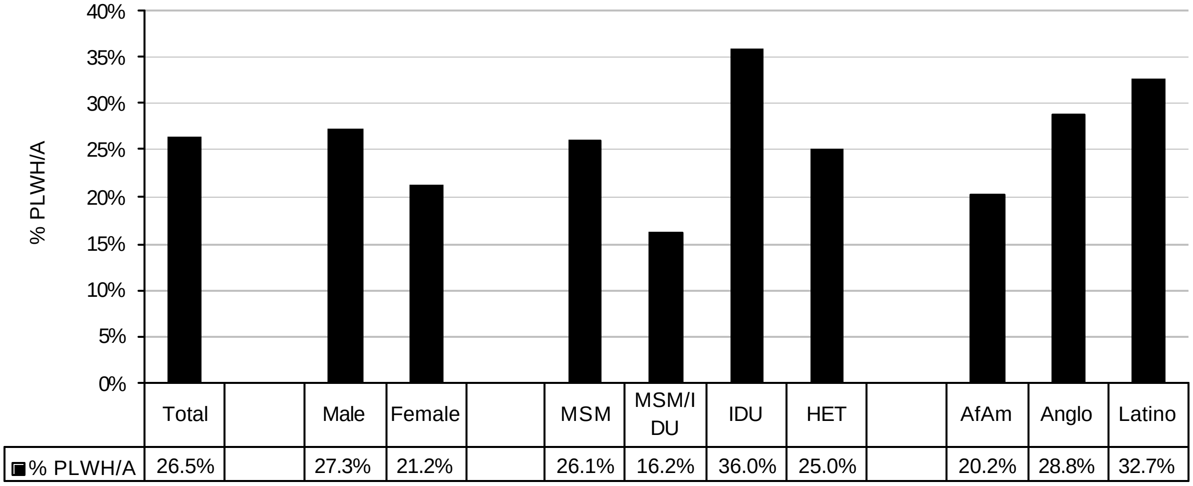
Medication and Adherence

The use of combination therapy and prophylactics to prevent opportunistic infections has greatly improved the length and contributed to the quality of life of PLWH/A. For those in the later stages of HIV infection, it has improved the quality of life. For those asymptomatic who start to take drugs, the side effects of the medication may decrease the quality of life of PLWH/A. Continued and improved health status outcomes will depend, in part, on the availability, access and adherence to properly prescribed medical regimens.

- 94% of PLWH/A report ever taking medicines to treat their HIV infection, and 89% report ever taking a drug cocktail. Males, and particularly MSM, are the most likely to have taken medication from all risk groups. Among special populations, youth and asymptomatic HIV are least likely to have taken medication.
- 15% of PLWH/A taking medications have stopped and 27% report never skipping a dose. Over 58%, however, have missed their medication schedule anywhere from once or twice a month (33%) to more than twice a week (12%). Symptomatic PLWH/A are more likely to stop taking their medication than asymptomatic PLWH/A.
- Of those stopping medication, 83% do it without the advice of their doctor. Women of childbearing age are particularly likely to stop medication without the advice of their doctor, and among ethnic populations, Latinos are more likely to have stopped without the advice of their doctor.

Figure 8-1 shows that men are more likely to have never skipped taking medication compared to women and that IDUs are least likely to have skipped medication.

Figure 8-1 Never Skipped Medication



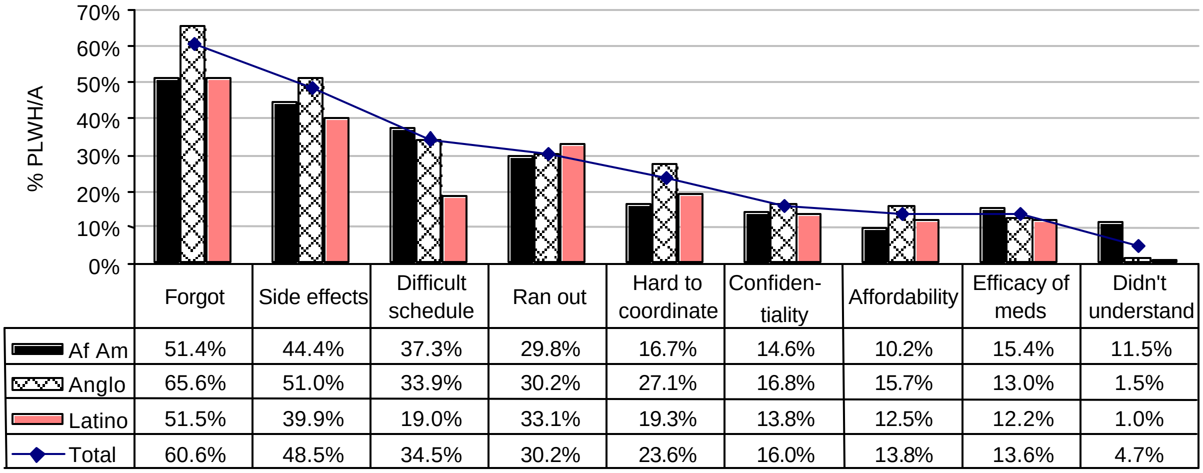
	Total		Male	Female		MSM	MSM/IDU	IDU	HET		AfAm	Anglo	Latino
■ % PLWH/A	26.5%		27.3%	21.2%		26.1%	16.2%	36.0%	25.0%		20.2%	28.8%	32.7%

Figure 8-2 indicates the top four reasons for discontinuing medications for all PLWH/A were:

- Forgetting to take them (61%). IDUs and African Americans are least likely to forget.
- The side effects associated with the use of the medications (49%), which were most notable among Youth.
- The difficulty of the schedule and requirements (35%) and running out of medications (30%).

While relatively few PLWH/A mentioned difficulty understanding directions (5%), African Americans (12%) were much more likely to give this reason than other ethnic populations. Youth were much more likely to say confidentiality was an issue for them (43%) compared to all PLWH/A (16%).

Figure 8-2 Reasons for Stopping Medications by Ethnicity



	Forgot	Side effects	Difficult schedule	Ran out	Hard to coordinate	Confiden-tiality	Affordability	Efficacy of meds	Didn't understand
■ Af Am	51.4%	44.4%	37.3%	29.8%	16.7%	14.6%	10.2%	15.4%	11.5%
▨ Anglo	65.6%	51.0%	33.9%	30.2%	27.1%	16.8%	15.7%	13.0%	1.5%
■ Latino	51.5%	39.9%	19.0%	33.1%	19.3%	13.8%	12.5%	12.2%	1.0%
◆ Total	60.6%	48.5%	34.5%	30.2%	23.6%	16.0%	13.8%	13.6%	4.7%

Medication and Adherence – Qualitative Comments

The focus group comments add depth to the quantitative findings.

Forgot to take the medication

A Central Anglo MSM said, *"The only one I have a problem with is the restrictions that you have to wait either one hour before or two hours after you eat to take the med. I have a problem about half of the week I usually end up forgetting to take it because you know I have either eaten or by the end of the day I realize oops, I have had it with me all day and I forgot to take it because I have been so busy, you know."*

A Central Latino MSM said, *"I've had trouble from time to time with remembering, because you are taking pills, but I ended up getting a weekly planner, and I just fill it up for the week. It was hard to remember, 'Well, did I take them already or not.' Now that I have it in a weekly planner I know if it's there I didn't take it. But still when you get into three or four doses per day with some of the medications it's easy to forget if you get busy doing something else, so it happens once in a while."*

A Northern Anglo female IDU said, *"When you do 18 pills a day you can't remember, "Did I take it or did I not" because our memories are not that good. So that's what I do. I just haven't done it yet because I just started and just dug them out and that's what I do and then I carry that one pill package for that day anywhere I go so I can take my medicine."*

A Northern male said, *"I forget to take my meds. I'm not going to lie. Sometimes I get up and I can't remember if I took it or I didn't take it. I've got to chain it to me because I'll walk off and leave it. I have a problem with remembering. When I get up don't let me go in there and do something because I won't remember if I took my medicine. If I get right up and run and take them then I'm alright. If I go in there and have to use the bathroom or somebody knocks on the door or I do something else, it doesn't even cross my mind."*

Side effects

While forgetfulness is the top reason given by PLWH/A in the quantitative data, side effects were the most reason to non-adherence in the focus groups.

An Anglo MSM said, *"I worry in the next few years about the possible side effects my medications may have. I have been taking medications now for 6 years and have tolerated them well. I hope that this continues. I have a belief that any challenges I cannot handle will be taken care of by a power much greater than myself."*

An Anglo heterosexual female said, *"Finding medications that will work for me without giving me the bad side effects and keeping the will and drive to want to keep fighting. I am not wanting to give up."* A Northern Latino male said, *"When I was first diagnosed, everything in my life was complicated. They diagnosed hepatitis C, inflammation in my kidney, and anemia and* *everything was complicated. I practically was finished already. The doctor that I was seeing recommended that I start medications for HIV. She told me it is a hard regimen and treatment, because the majority of the side effects that are experienced. So in a way, I was a little frightened. I went back to the hospital so they could treat all of the infections I had. They controlled them and started me on HIV medication. I would take them with fear but thank God I haven't experienced any side effects."*

An Anglo MSM said, *"The biggest challenges I face are medication compliancy, and the cardiac side effects of my medications."*

A Northern African American MSM expressed his concerns about the medications he is prescribed. He said, *"There have been some regimens that I have been prescribed I just am worried about because I'm so fearful of the side effects. First with the AIDS diagnosis, you start the medication and you want to do well, and then the side effects sets in and you get discouraged and you say, 'Am I going to feel like this for the rest of my life?' So you stop taking them and when you tell a doctor that you are not taking them they prescribe you another drug. Then you get a worse side effect than you had from the first one. I know everybody doesn't experience side effects, and everybody's body is different, but when they put all these toxins down in you. I guess the side effects can affect me just as well as it can affect a big person, but the way I see it is they are putting all of these little toxins in my little small body and it doesn't effect me the way it might effect somebody that has a more healthy body. I try to think about all of that stuff, but yet it's still I have a problem with adhering to it."*

A Northern African American MSM said, *"I have a very, very, very serious problem with staying adhered and staying compliant to my medical regimen. I will always start the medication, but the first spell that I have with a side effect I'm finished. It's gotten to the point to where I'm not adhering to any medications, but I also feel that I'm not resistant to any medications, because I don't stay on them long enough. The longest medication I stayed on was for about three months. It wasn't that much of a side effect, but it was giving me trouble. It was just I felt like I was asleep, but I was not sleeping."*

A Southern Anglo male said, *"One of the reasons I stopped taking my medicine was because the side effects were so horrible. It was a number of things: the dizziness, the falling down, the confusion, and I couldn't think straight. It's unbearable. I also stopped taking my medication for an amount of time because they led me to drinking."* A Northern Latino male said, *"Well it seems like when I am taking the medication I feel sicker. I was taking 30-40 pills a day in one sitting. And the combination of all those pills was making me feel worse. I quit taking some here and some there."*

A Central Anglo heterosexual female said, *"There are some side effects. I have to overcome that to be able to take the meds. There are night sweats, nausea, diarrhea, migraine headaches, and insomnia. And the Sustiva, I swear to God if you take that medication as often as they tell you to, you will be drunk for a week. You feel drunk. It does subside, if you bite the bullet and take it for two weeks straight, every dose and you don't miss one, the side effects will subside. But it's getting through that two weeks and try to take care of child when you feel drunk is challenging.*

Not only that, but they don't take into consideration about other illnesses. I have arthritis and my doctor's keep writing prescriptions to help me with my arthritis. Three of them made me so sick that I couldn't take my HIV medication so then I am back on square one with side effects. It's just a never ending cycle."

When a 54 year old Northern Anglo MSM was asked about any side effects he may have experienced, he replied, *"There is too many of them really. I hate it when they ask me that, "What's your symptoms". All kinds of symptoms. There's too many of them to say. But I am not skipping my meds because that is what has kept me alive this many years."* A 55 year old Northern Latino MSM in another group said, *"The main side effect I have and it's not pretty good to say, but it's diarrhea. I've had that side effect for about two years now. It has not made me stop taking the meds. I'm going to keep on going. My viral load is very low and my T-cells went up. The doctor was seeing me every two weeks, but now he is seeing me every 2 or 3 months. I don't look forward to getting off of it. I want to stay on it if it's going to help me."*

Difficult schedule

Taking pills at night or while working seemed to be the major problems with scheduling. As new and simpler regimens come to the market it should help reduce this barrier to adherence.

A Southern Anglo male said, *"I take one pill three times a day. I take it in the morning, at noon, and at night. But, I forget to take my noon medicine, because when I get ready to leave and go to work, I forget to carry it with it me. When I work, I usually come home for lunch and then take it. But, I have missed my dose, because I stay at work all day without taking lunch. Then I know it's going to be hard for me to get back on track, or it's going to be hard for my immune system to function right with the medicine. When I miss my noon medicine and take my night medicine, it's going to throw me off track for that next following day."*

Another Southern Anglo male said, *"I'm supposed to take two pills every eight hours, three times a day. I'm not setting an alarm to wake up in the middle of the night to take some pills. I'll either take them before I go to bed or when I wake up or however that works to where I can get all three doses in. As far as eating, it's not always convenient to be able to get food in you."*

A Northern African American MSM said, *"I don't have a problem getting sick. I only have to take it three times a day. But in the middle of the day it's hard to take it on time because I'm at work, and I'm busy doing my work and I don't even think about it until it's too late, and by that time it's too close to the next dose. So a lot of times I end up skipping a dose. I have not shared that yet with my doctor."*

Hard to coordinate with food

A Southern Anglo male said, *"With my medication regimen, I have to take two pills every eight hours on an empty stomach. If you have a busy life, like a job, or whatever, you don't know when you're going to eat lunch. It's hard to stay on a certain eating schedule. How are you supposed to take your pills? It gets all messed up."*

Didn’t want others to see the medications

Another Central Anglo MSM said, *“I have got to go ahead and agree that another barrier to the care was worrying about side effects and how it is going to impact my lifestyle because I lead a very busy professional environment. That was a big concern. I didn't want to but I had to watch where I was going to start the stuff so that again, it didn't reveal to the rest of the world what was going on with me*

A Central Anglo MSM said, *“I have been prescribed medications, but I have trouble swallowing the pills. I am trying to find a way to get around that.”*

Could not afford the medication

A Central Latino MSM said, *“When I realized I had no insurance coverage for prescriptions I quit taking them, and my doctor didn't like it. Thank goodness the [large ASO] was able to come up with about half of the medications I was on, but I just went without them, because I already owed $7500 and it's like I'm not going to keep charging it if I can't afford it. So I took a little medicine holiday. It wasn't good. I didn't feel good about doing it. I didn't think I had choice and I spent all of my savings, so it wasn’t possible to get the prescriptions.”*

Just did not want to take them

When asked for details about their adherence to their medication regimens, a Central Anglo MSM said, *“Too many pills and I am just tired after 12 years of taking them. So I don't take them anymore. I take Ibuprofen for my arthritis, but that is about it. I am tired of taking medication. I am tired of being sick; I am tired of throwing up when I take it. I tried them. I gave it all I could. For three weeks, I couldn't get out of the bathroom and I couldn't quit puking, and it was just like I would get to a point now where one medication, if I would get it to here [the throat area], I would throw up. That is how bad it was.”*

A Northern Anglo female IDU said, *“I was on a lot of them and taking them for a long period of time and then I would stop. You get tired of taking all of those pills a day. It's hard to swallow. You just sit there and swallow 30 pills at a time. It's pill time, you've got to eat. By the time you finish the pills, you are not hungry. So I would just get tired of taking them because I am an IV drug user.”* An Anglo male in the same group said, *“I'm not on any medicine right now but when I was taking them I was taking 33 pills a day. My problem was the timing, but I'm an alcoholic. I don't drink now but I used to have a real drinking problem and most of the time I wanted to drink so I wouldn't take my medication. I just didn't take it or if I took a period of time off where I wasn't drinking then I would take the meds. That's what I was doing. When I would leave the alcohol alone for a period of time and then I would go back to the medicine. Now I'm off of them.”*

Efficacy of medications and doctor instructions

A Northern Anglo MSM said, *"I was off of my meds for 13 months and my doctor thought it was a smart move. I probably saved my liver and kidney during that year. We watched my counts so I knew they didn't get too far and they couldn't be reversed."*

Other people have altered their adherence levels to the medication regimes based on an evaluation of their blood work counts. A Southern Anglo male said, *"They have relaxed the Crixovan, and you can go up to four hours without taking it and still take it. I'm the type of person, I have completely stopped taking my afternoon dose of Crixovan. When I started taking it, my T-cell count was 325. In the last three months of not taking that middle dose of medication, it's taken me close to 600."* Another Southern Anglo male said, *"I go off my medications frequently. I take little vacations. I have a bad habit of not taking them all day long. My viral load still remains intact. I stopped paying attention to the rigidity of the prescribed medications' instructions a couple years ago."*

Others alter their regimen schedules based on their own needs. A Northern African American MSM said, *"Sometimes I take them [the meds] and sometimes I don't because I don't feel like it. Today I took it because I knew it would effect me because of you. Like you said I feel like doing nothing. I don't want to do anything, that's why I didn't take it today. I make my own decisions and my doctor does now allow it. Yesterday I told my doctor that I take it sometimes and sometimes I don't."*

Fear can be the most pressuring motive to adhere to the drug regimen and schedule. A Central Anglo male said, *"One of my biggest fears is that if I do skip pills or something, especially with my doctor. Every time I go in there that one thing he really, really pushes is for me to take those pills. They even have studies where they took people off their medication like three or four months at a time and a lot of people got sick. A lot of people deteriorated. A lot of clinics just say take them when you're supposed to take them and do exactly that. My biggest fear is if you stop, your body can become immune that quick to them. They stop working for you, and we don't have that many of them out there; that is what I've been informed. There are new ones coming up all the time and everything, but they haven't been tested and aren't ready to be prescribed to us. If you get one that you become immune to and doesn't work anymore, how many chances do you get again?"*

A Southern Anglo female said, *"I really think that adherence to the prescribed medication is different for different people, and I think that if someone was taking their medicine very loyally, and if they missed a few doses or something, that could totally mess up everything. I think it could totally mess up. It could make their viral load go way up and their T-cells go down, and they could get sick. It scares me."* Another Southern Anglo female IDU said, *"The way they were treating it was if you missed a pill, God help you, you were going to die. They did make you feel like that. If you didn't take each dose you were harming yourself. We are living proof because we've all done it, didn't take a whole day or didn't want to because we didn't want to feel like shit. Don't you want to get up and run. I love to run around and be able to roll around in the grass with my grandbaby and put her up on my feet and do that stuff. I can't even pick her* *up, not just because of my leg but because I am that weak. She only weighs 25 pounds. That's nothing but I can't pick her up. It's very hard to say, 'I'm sorry honey I can't pick you up.'"* And a Central Anglo MSM/IDU male said, *"You see everybody's body is different. You can't judge me by her or her or her. And we all have different ways of doing things. My body is going to take it when you get ready to take it."*

But others are not having any severe problems with their drug regimens. A Northern African American MSM said, *"I'm taking Crixivan three times a day and Combavir twice a day. I haven't felt sickness from it, but I'm just blowing up. I can't wear any of my clothes anymore. But there's no tiredness, none of that. I'm very energized."*

Denial of HIV status

A Central African American Male IDU said, *"I do not think I have HIV. They are just using me as a guinea pig to try out their medicines. I take 13 pills in a day (24hrs). Somebody is doing something and they are not telling me, at one time I was taking medications Morning, Noon, and Night. Now I am just taking it Morning and Night."*

9. SERVICES

Services Ranked

The Council funds the twenty-three service categories ranked in Table 9-1 by amount expended for the top nine services and input from the care coordination sites for rankings 10 –23.

Table 9-1 Service Categories 2001-2002 Priorities Ranked by Priority*

SERVICES AND SUB-SERVICES	Rank 2001-2002
Health Insurance Continuation • Assistance obtaining health insurance. • Assistance with payments of health insurance premiums, co-pays or deductibles.	**1**
Drug Reimbursement • Drug reimbursement - assistance in paying for HIV/AIDS related drugs.	**2**
Outpatient Medical Care • Appointments with a doctor, nurse, or their assistants to monitor and treat your HIV infection. • Appointments for OB/GYN and/or Pediatric Care. • Visits to medical specialists such as skin, eye, intestinal tract, feet. (Not OB/GYN) • Lab tests for infections (e.g. viral loads or t-cell counts).	**3**
Case Management • Assistance in getting medical services or drugs that your health insurance does not cover. • Care coordination/case management—A case manager who is assigned to you to help you access and receive HIV/AIDS services and treatment. • Referrals to services. • Other care coordination services (such as Family Care and Prenatal Care Coordination)	**4**
Substance Abuse Treatment • Outpatient substance abuse treatment or counseling sessions. • Substance abuse treatment in a 24-hour-a-day residential setting.	**5**
Housing Assistance • Assistance in finding or getting emergency or transitional housing. • Assistance in finding or getting long-term independent housing.	**6**
Direct Emergency Financial Assistance • Emergency rental assistance. • Emergency financial assistance (for utilities, drugs, etc.).	**7**
Mental Health Therapy • Mental health therapy with a psychologist or social worker. • Peer counseling, support, or drop-in groups.	**8**
Dental Care • Dental care.	**9**
Transportation • Transportation to access HIV-related services.	**10**
Targeted Services for Women & Children • Child care when you're getting HIV services. • Adoption/foster care assistance for kids.	**11**
Food Bank/Home Delivered Meals • Food bank, nutritional supplements, or vouchers to buy food. • Home-delivered meals.	**12**
Client Advocacy • An advocate to help resolve legal issues or access to care.	**13**
Vocational Training • Employment assistance/vocational counseling and training.	**14**
Prevention, Health Education and Risk Reduction • Nutrition education and counseling. • Information about treatments and care from peers or providers.	**15**

SERVICES AND SUB-SERVICES	Rank 2001-2002
• Newsletters, leaflets or booklets about HIV / AIDS treatment and care. • Information about how to prevent infecting others with HIV. • A resource guide that lists HIV / AIDS services.	
Complementary Health Care • Holistic or complementary care, including acupuncture, massage, chiropractic care.	**16**
Home Health Care • In-home medical care from a nurse or professional home health agency. • In-home non-medical services to help with daily activities. • Someone who comes in to give caregivers a break (respite care).	**17**
Translation Services • Translation or interpretation services.	**18**
Legal Services • Legal help preparing wills or estate planning (including custody of children).	**19**
Buddy/Companion Services • Volunteers or peers who assist in household or personal tasks and provide support (pals/buddy/companions).	**20**
Rehabilitative Services • Rehabilitative services like physical therapy (authorized by your medical provider).	**21**
Day Care • Adult day care.	**22**
Residential Care • End of life hospice care.	**23**
For services 1-9, ISDH used dollar amounts allocated for each activity to rank priority. ISDH used what care coordination sites stated the needs are in the community for rankings 10–23.	

Ranked Needs

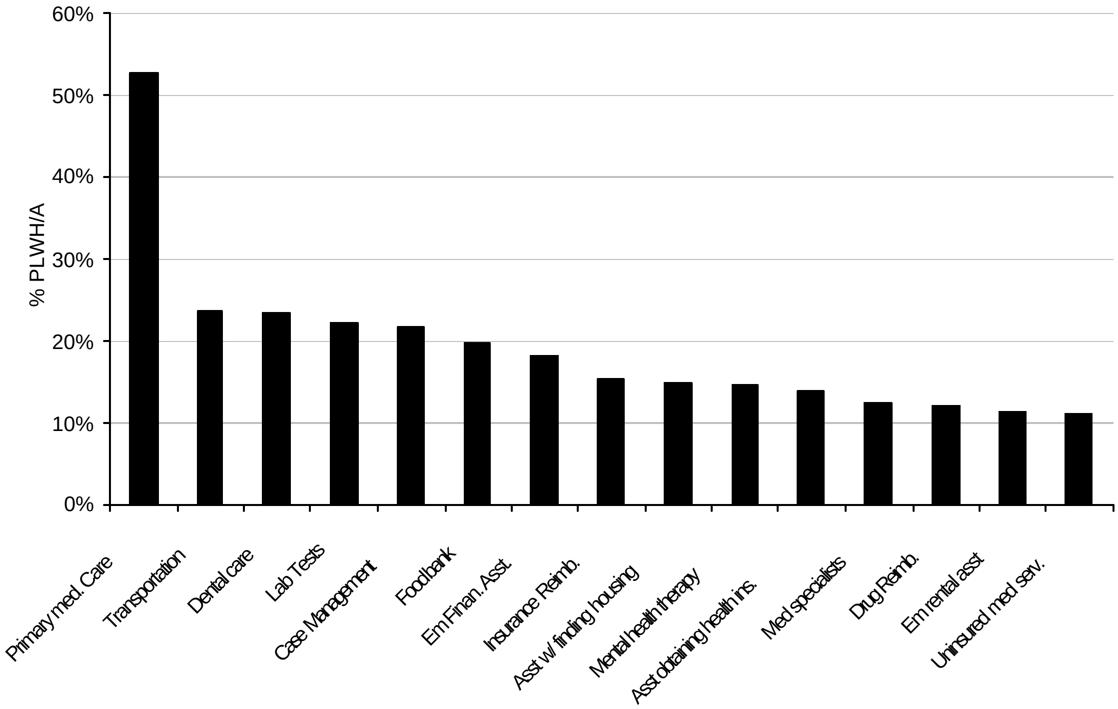
The PLWH/A surveyed indicated several dimensions of need for the 42 services shown in Table 9-1. They provided information on the availability, current need, request for, utility, satisfaction, and future need (see q. 28, Attachment 2).

After completing the ratings on each service, PLWH/A reported the top four services they felt they needed the most. As shown in Figure 9-1, over half (53%) said that primary medical care was the most important. After that, about a quarter (24%) said transportation and dental care was most important, followed by about 20% who reported lab tests, case management, and food bank as most important. Interestingly, drug reimbursement was thirteenth on the list, which was lower than mental health therapy which ranked tenth overall. Notably, even among substance users, substance abuse services were ranked relatively low.

Services in the top fifteen are a combination of health care and basic needs. Primary care is the top need and exceeds other needs significantly. The next set of needs with above 20% saying they are the most important, are two that involve access to care, transportation and case management, and two that relate to direct medical care, dental and lab tests.

The remaining top ranked needs include both basic daily needs such as food, emergency financial assistance, and assistance paying health insurance and indicate the low income level of PLWH/A and, probably, the difficulty in qualifying for Medicaid.

Figure 9-1 Top Ranked Needs by PLWH/A



The lowest ranked services, shown in Table 9-2, cluster in the following areas:

- Information services related to treatment, care, transportation, and nutrition, and newsletters.
- General referrals (case management was ranked number 5th)
- Specialized targeted services such as OB/GYN, employment assistance, or adoption assistance. When filtered for the target population , the need is magnified.
- Complementary or holistic care
- Peer contact
- Legal services
- End-stage services like hospice care, adult day care, and in-home medical care.

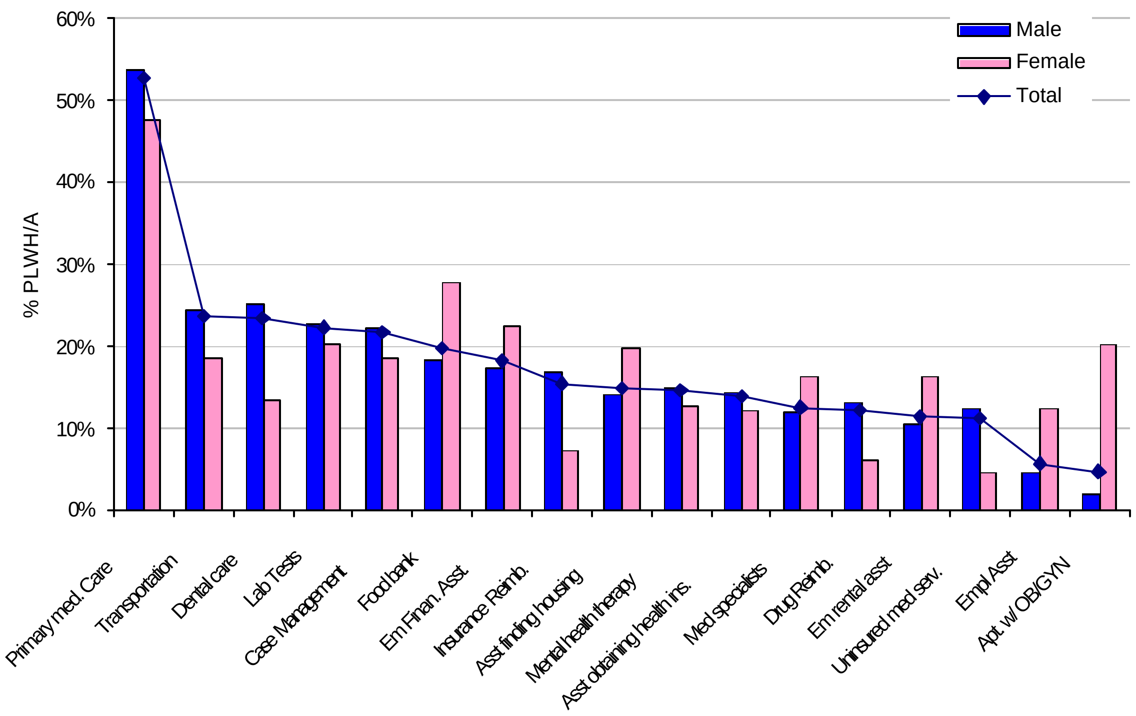
Table 9-2 Lower Ranked Top Needs

Lower Ranked Top Services	% PLWH/A Rating in top 4
Peer counseling	8.2%
Information about treatments & care from peers or providers	7.7%
Referrals	6.7%
Legal help	6.4%
Holistic care	6.3%
Nutrition education and counseling	6.3%
Assistance in finding or getting emergency transitional housing	5.7%
Employment assistance	5.6%
Other services	5.1%
Appt. for OB/GYN	4.7%
Newsletters	4.6%
Advocacy	4.4%
Resource Guide	4.3%
Prevention information	3.4%
Volunteers	2.3%
Hospice care	2.1%
Rehabilitative services	2.0%
Translation or interpretation svc.	1.9%
Outpatient care	1.4%
Home delivered meals	1.4%
Child care	1.4%
In home non medical services	1.2%
Respite care	0.7%
Adoption	0.7%
Other care coordination services	0.5%
Adult day care	0.4%
Substance abuse treatment in 24 hour residential setting.	0.4%
In-home medical care	0.3%
Life Insurance	0.3%
Outpatient care with focus on older age	0.3%
Emergency Medical Attention	0.3%

Most Important Needs by Gender

Figure 9-2 shows that women and men report different rankings of their most important services. After primary medical care, women tend to rank basic life services higher than men, with food bank ranked second and emergency financial assistance third. Logically, OB/GYN, received a much higher rank for women. Men living with HIV and AIDS place greater importance on receiving insurance than women living with HIV/AIDS. This confirms the finding presented earlier that men rely more on ICHIA and Ryan White because they are more likely to be ineligible for Medicaid.

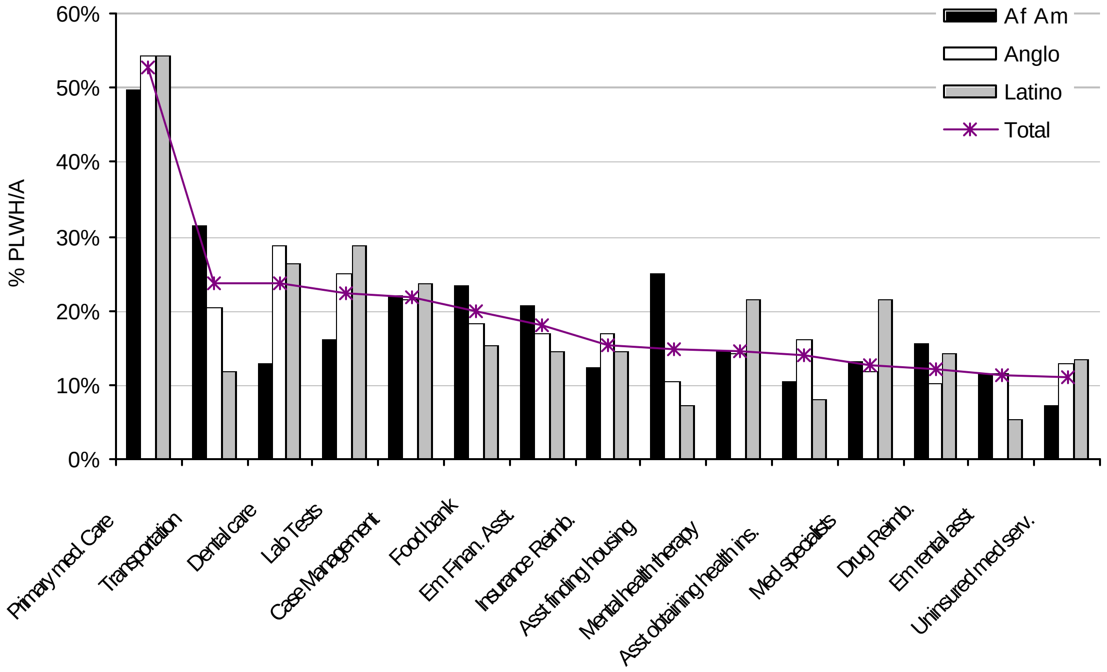
Figure 9-2 Top Ranked Needs by Gender



Most Important Needs by Race/Ethnicity

The rankings of most important services differ by race, as shown in Figure 9-3. Anglos, reflecting their higher income, are more likely to rank medical and dental services higher and less likely than African Americans to say they need basic services. African Americans rank transportation as their second most important service, followed by assistance finding housing, and food bank. Latinos say that medical services are the most important and rank mental health services and access to medical specialists higher than either African Americans or Anglos.

Figure 9-3 Top Ranked Need by Ethnicity



Most Important Services by Risk Group

When top needs are ranked by risk group, IDUs are more likely than other risk groups to say that primary care (64%), case management (25%), and assistance finding long term housing (26%) are among the most important services. MSM, like men in general, are more likely than other risk groups to say that dental care (26%) and assistance providing health insurance (19%) is more important. Heterosexuals, reflecting their high percentage of women, are more likely than other risk groups to say that OB/GYN services (15%) is more important. They also say that vocational training is more important, and dental care less important than other risk groups.

Most Important Needs by Special Populations.

There are few noteworthy differences among the special populations that have not previously been noted. However, the special needs of the homeless suggest that they consider transportation, housing, and employment assistance of greater importance than other PLWH/A.

Most Important Need by Stage of Infection

Although PLWH/A at all stages of infection feel that outpatient care is the most important service, there are differences in the ranking of the importance of services. While lab tests are ranked fourth for all PLWH/A they are ranked second most important for asymptomatic PLWH, who also are more likely than those at later stages of infection to feel that nutritional information is important.

HIV symptomatic and AIDS asymptomatic are more likely to feel that food banks services are more important than those with AIDS or at earlier stages of infection. Also, AIDS asymptomatic feel that case management is more important than PLWH/A at others stages of infection. Those who are symptomatic and have AIDS tend to rank services the same as others, except for services such as hospice care and advocacy. They also feel that referral to specialists, are more important.

Availability

PLWH/A were asked to indicate in the survey whether they knew that services were available to them. Over 60% of PLWH/A perceive that the services listed in Figure 9-4 are available to them. It indicates that large segments of PLWH/A perceive the availability of most medical services. PLWH/A who need specific services generally say they can access them. For example, the perceived availability of mental health services is much greater among those diagnosed with mental illness, or OB/GYN services is perceived as most available by women.

- Perceived availability to receive a service is over 90% for outpatient care (97%), lab tests (96%), and case management (96%). Perceived availability is over 90% for ethnicities, risk groups, and special populations.
- After medical services, prevention and information services are next highest in perceived availability, with about 90% of PLWH/A feeling that prevention information is available to them, and 87% reporting that newsletters are available. Perceived availability of prevention information and newsletters is over 80% for ethnicities, risk groups, and special populations.
- Between 70% and 80% of the PLWH/A perceive that the food bank services, referrals, information on treatment and care, and assistance with health insurance are available to them. About 75% of females felt that OB/GYN and pediatric care services were available to them. Notably, there was less perceived availability for OB/GYN by African Americans (66%) and Latinos (64%), and fewer females and Latinos perceive the availability of information about treatment and care.

- About 70% of the PLWH/A feel that peer counseling, mental health therapy and access to medical specialists are available to them. Youth have a relatively low awareness of mental health therapy (47%) and peer counseling (60%).
- Between 60% and 70% of PLWH/A perceive the availability of DEFA and emergency rental assistance, a resource guide, and dental care. More IDUs perceive DEFA as available than other risk groups.

Figure 9-5 shows those services that less than 60% of the PLWH/A perceive as available, and for many of the PLWH/A there are eligibility restrictions. Notable among those who believe that services are less available:

- Transportation, one of the highest ranked needs, is perceived by only about 59% of the PLWH/A as being available for them.
- Nutrition education, should be broadly available, but only about 60% of the PLWH/A perceive it is available to them.
- The services that PLWH/A perceive as least available are end-stage illness services and child care. Even among those who are HIV symptomatic, however, awareness of respite care and adult day care is low, and for child care, the perceived availability among females is very low (16%).

Figure 9-4 Services with High Awareness Ratings (>60%)

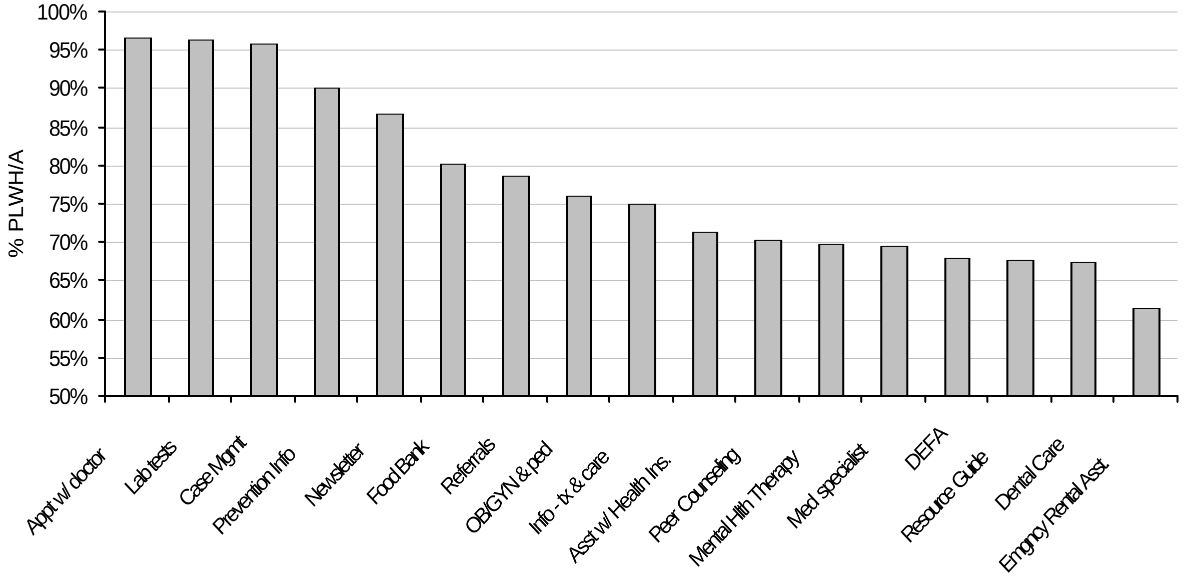
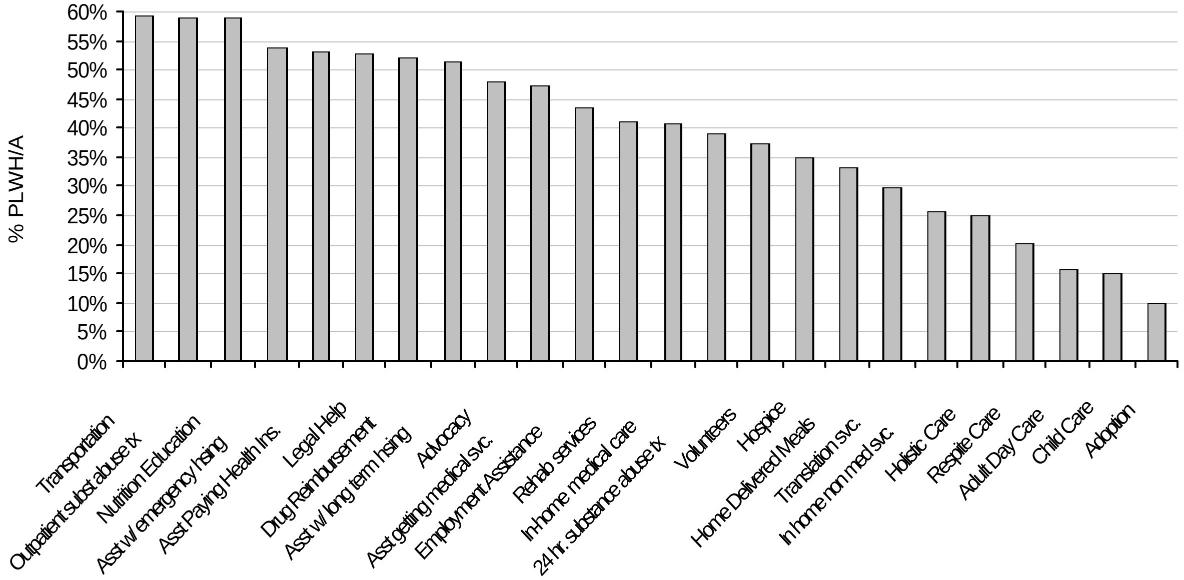


Figure 9-5 Services with Low Awareness Ratings (<60%)



Current and Future Need for Services

PLWH/A reported whether they currently need each of forty-two different services, and then said whether they need more, the same or less of the service in the coming year. Figure 9-6 displays the top current needs (bars) and the estimate of the future need (the hat above the bar). The larger the space between the hat and the bar, the greater the estimated future need.

As displayed in Figure 9-6:

- Over 80% of PLWH/A say they currently need lab tests, case management, and appointment with a doctor.
- 60% to 70% of PLWH/A say they need dental care and food bank.
- Between 50% and 60% of all PLWH/A express a current need for OB/GYN and pediatric care, newsletters, treatment information, resource guide, medical specialists, assistance getting and paying for health insurance, and referrals.
- There is a greater anticipated need for almost all services with relatively high current need.
- Of the top services currently needed, there is a greater anticipated need for dental care and case management.

Figure 9-6 Current Need and Future Need

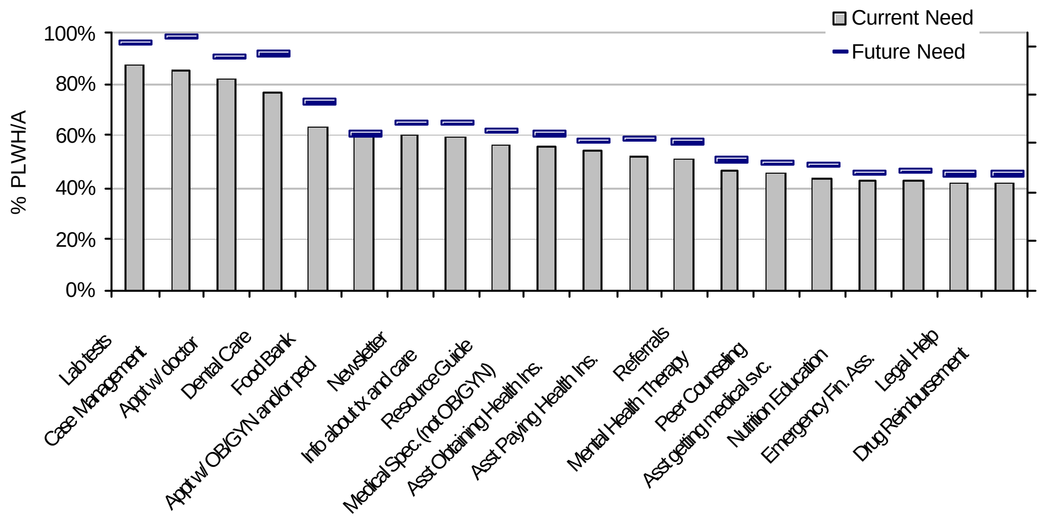


Table 9-3 displays services that less than 40% of PLWH/A report needing.

- Several services at the bottom of the list, such as hospice, adoption, adult day care, and home delivered meals are services needed by few individuals at the end stages of AIDS, and the expected need would be low.
- Given the incidence of substance use, there is a surprisingly low perceived current need for substance abuse services.

- Similarly, given the growing number of families with HIV, there is a surprisingly low perceived need for child care.
- More PLWH/A anticipate a need for holistic care and dental care than any other service.
- There is a relatively high anticipated need for more transportation and advocacy.

Table 9-3 Lower Ranked Current Needs and Future Needs

Current Need: Lower Ranking	% Needing	Average Future Need 1=less 2=same 3=more
Holistic Care	40.3%	2.5
Transportation	40.0%	2.3
Advocacy	35.0%	2.3
Emergency Rental Ass.	34.0%	2.2
Prevention Information	33.9%	2.0
Asst finding long term independent housing	29.9%	2.3
Employment Assistance	24.6%	2.2
Asst finding emergency transitional housing	22.9%	2.2
Volunteers	20.7%	2.1
Outpatient substance abuse treatment	16.2%	1.9
Home Delivered Meals	15.9%	2.1
In home non medical svc.	14.1%	2.1
Rehabilitative services	13.3%	2.0
Translation/interpretation svc.	10.1%	1.9
In-home medical care	7.3%	2.0
24 hr. substance abuse tx	6.3%	1.8
Respite Care	5.5%	1.9
Child Care	5.4%	1.9
Adult Day Care	4.4%	1.9
Adoption	3.5%	1.8
Hospice	2.4%	1.9

Demand, Utilization, and Perceived Demand-Utilization Gap

Figure 9-7 displays the services that PLWH/A ever asked for (black bar) and ever received (gray bar). The three top medical services are the same as those with the greatest need. Over 80% of the PLWH/A report asking for them and over 90% report receiving them. Except for the top three medical services and prevention information and newsletters, PLWH/A report asking for services more than they receive them, but the overall pattern is similar.

The top services asked for and received are generally the top services reported with the greatest current need. Transportation, prevention information, and emergency rental assistance are not reported as a high current need, but have been asked for relatively frequently. Like current need, those services with the lowest demand tend to be end stage services which are very important for the few individuals who are at the end stage of HIV illness. Like current need, the demand for substance abuse treatment and childcare seems lower than the epidemiology would suggest.

Figure 9-7 Demand and Utilization

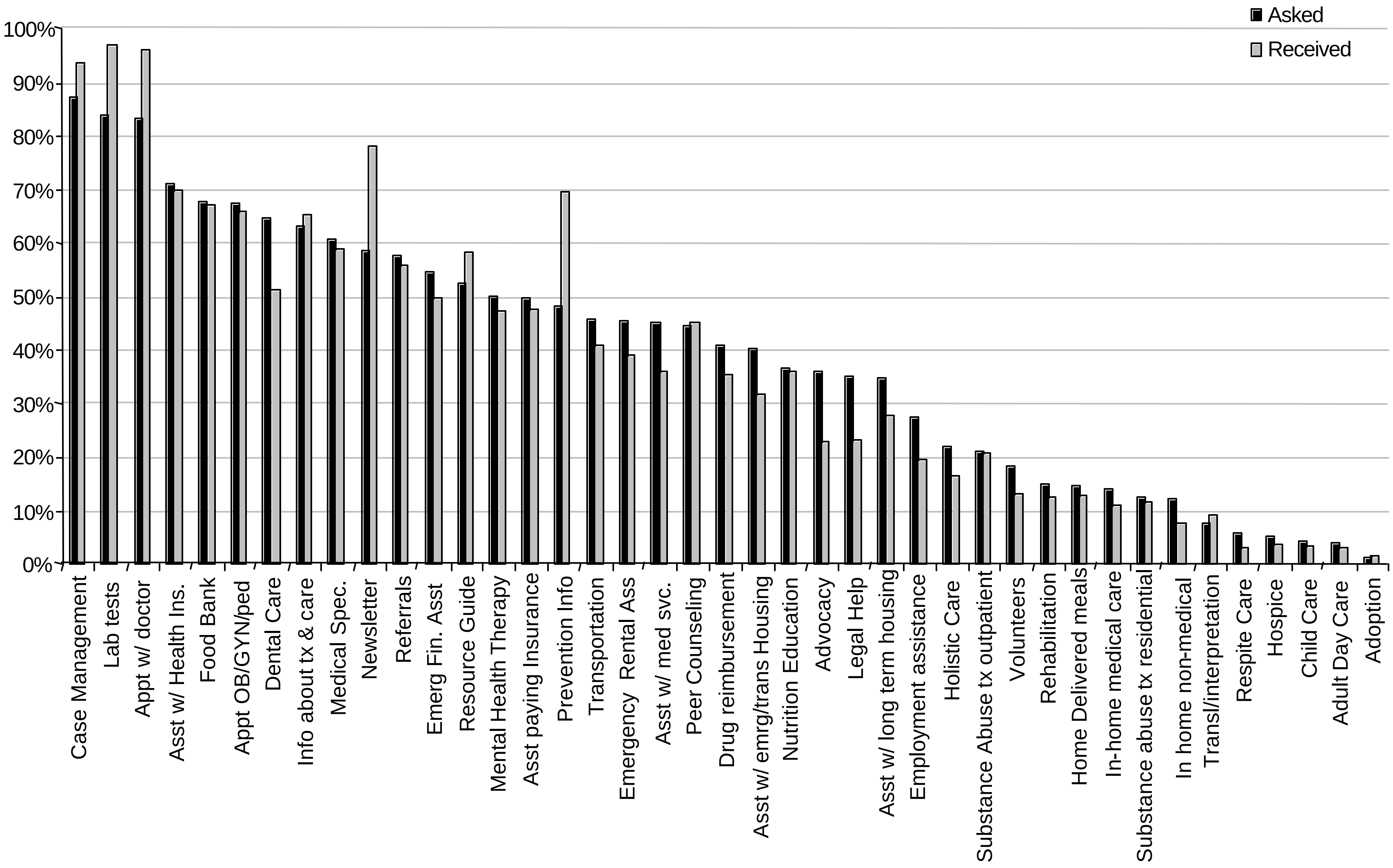


Figure 9-8 shows the perceived unmet demand and perceived excess capacity. It is the difference between the number who reporting asking and receiving each service.

Figure 9-8 Demand - Utilization Gap

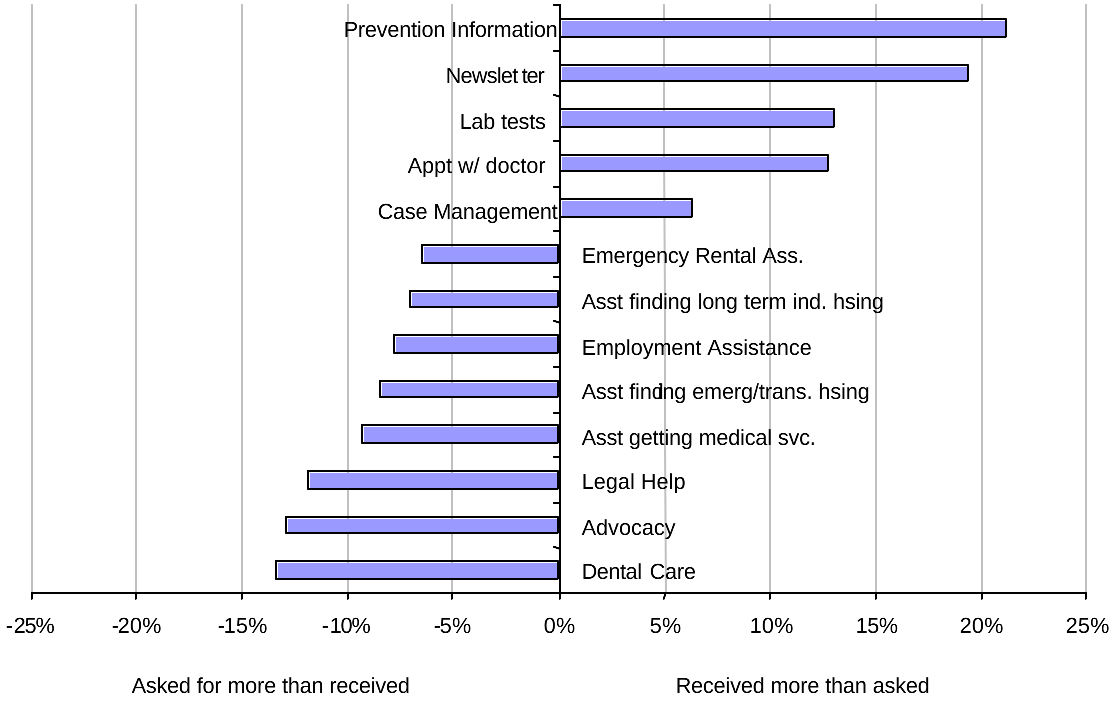


Figure 9-8 indicates that:

- PLWH/A report that they have the greatest unmet demand for dental care. With dental care ranked as the third most important service and ranked fourth for current need, dental care is also a service with the greatest anticipated need.
- Advocacy and legal help have the second and third largest unmet demand. While they are not among the most important services noted by PLWH/A, they say legal services have a moderately high current need. This suggests that capacity for providing legal services and advocacy are low.
- Assistance getting medical services has the fourth highest unmet demand, and is also a service with relatively high current need. It suggests that many PLWH/A do not consider their current case management adequate as a link to medical services.
- Among the top services with unmet needs, three are related to housing: assistance finding emergency transitional housing, assistance finding long term independent housing, and emergency rental assistance. This suggests the ongoing need to find affordable housing for PLWH/A.

- Employment assistance and vocational counseling is among the top unmet needs. While not mentioned by most PLWH/A as the most important service or as having a high current need, it does suggest an emerging need where capacity is inadequate.
- PLWH/A also report an excess supply of some services. Prevention information and newsletters, are received more often than they are asked for. This suggests that PLWH/A often feel overwhelmed by information and the need to respond more to the information needs of individuals rather than a general need to provide information that may not be read by PLWH/A.
- Lab tests and appointments with doctors are received more than they are asked for, and this suggests that medical protocols require medical visits more often than many PLWH/A feel are necessary.

Satisfaction and Access to Services

PLWH/A were asked if they were satisfied with services and how hard each service was to access. Table 9-4 indicates that:

- In general PLWH/A rated services as excellent to good, and most services, they said, were not difficult to access.
- Adult day care and in-home non-medical care received the lowest satisfaction scores by PLWH/A, but even those services were rated as good.
- Other relatively low satisfaction scores were given to peer counseling and volunteers.
- In-home non-medical care also received a relatively low access score, but this was between a moderate and easy service to access.
- The most difficult to access services were housing related – assistance finding emergency transitional housing, emergency rental assistance, and assistance finding long term housing. These were rated between moderately easy and easy services to access. These relatively low rankings further suggests the limited capacity for these services noted above in the discussion of demand gaps.
- Employment assistance had relatively low satisfaction and poor access.

Table 9-4 Satisfaction and Access to Services

	ALL PLWH/A (N=404)*	
SERVICES	**Satisfaction** 1=Excellent 2=Good 3=Fair 4=Poor	**Access** 1=Easy 2=Moderate 3=Hard
Adult Day Care	**2.14**	1.43
In home non medical service	**2.12**	**1.58**
Employment Assistance	**1.98**	**1.68**
Rehabilitative services	**1.91**	**1.62**
24 hr. substance abuse treatment	**1.91**	1.39
Peer Counseling	**1.90**	1.46
Volunteers	1.85	1.54
Nutrition Education	1.84	1.42
Hospice	1.83	1.44
Assistance finding emergency transitional housing	1.82	**1.71**
Emergency Rental Assistance	1.81	**1.71**
Mental Health Therapy	1.81	1.47
Adoption	1.79	**2.01***
Transportation	1.78	1.49
Respite Care	1.77	1.51
Outpatient substance abuse treatment	1.76	1.29
Referrals	1.75	1.49
Dental Care	1.74	1.50
Advocacy	1.73	1.55
Asst Paying Health Ins.	1.72	1.54
Info about treatment and care	1.70	1.39
Emergency Financial Assistance	1.70	**1.65**
In-home medical care	1.68	1.39
Asst Obtaining Health Ins.	1.68	1.53
Asst finding long term independent housing	1.67	**1.64**
Appt w/ OB/GYN and/or pediatric care	1.66	1.42
Medical Spec. (not OB/GYN)	1.65	1.39
Drug Reimbursement	1.65	1.42
Home Delivered Meals	1.64	1.36
Food Bank	1.64	1.42
Asst getting medical svc.	1.63	1.51
Case Management	1.61	1.42
Resource Guide	1.60	1.43
Appt w/ doctor	1.58	1.39
Translation/interpretation svc.	1.56	1.30
Lab tests	1.56	1.28
Newsletter	1.54	1.26
Child Care	1.51	1.35
Holistic Care	1.50	1.44
Prevention Information	1.45	1.28
Legal Help	1.43	1.26
*Not everyone answered every item / low N		

10. BARRIERS

The sample of PLWH/A and the focus group respondents reported that the HIV/AIDS services are, on average, pretty easy to access. In general, they ranked barriers as "small" to "moderately" high. Still, several barriers were identified that could be lowered in order to improve the access and quality of services provided.

Overall PLWH/A Score for Barriers

On the questionnaire, PLWH/A rated and discussed thirty-seven barriers.[5] They rated the barriers on a four-point scale ranging from a "big barrier" to "no barrier at all.". The thirty-seven barriers can be grouped into four general types of barriers:[6]

- Individual barriers. These refer to the individual's knowledge, physical and mental health.
- Organizational barriers. These are further divided into two types: 1) sensitivity and 2) expertise. Sensitivity barriers are related to sensitivity that providers have to their clients. Expertise barriers reflect the expertise of the provider and quality of care.
- Structural barriers refer to rules and regulations and levels of access. Rules and regulations include insurance coverage, cost of services, red tape, eligibility, and problems navigating the system of care. Access barriers have to do with lack of transportation and access to specialists.
- Family-related barriers refer to lack of family oriented services, including lack of on-site childcare or single site for HIV care for multiple members of a family unit.

Overall, when the ratings of all of the barriers are averaged, none of the risk groups or ethnic populations reported a big barrier. As shown in Figure 10-1, the highest overall barrier score is less than 2.0 - or a rating of between a "no barrier" (score of 1) and "small barrier" (score of 2.0).

Men and women report about the same general level of barriers; MSM reported slightly higher barriers than other risk groups and African Americans reported higher barriers than other ethnicities. On the other hand, PLWH/A from the Southern region reported the lowest barrier score (1.7).

Figure 10-2 shows the average barrier score for the six special populations and four stages of disease. PLWH/A with history of mental illness and those who are HIV symptomatic reported the highest barriers among all the participants, with an average overall barrier of 1.9. Perhaps indicative of higher functionality and perceived quality of life, asymptomatic individuals tend to report the lowest barriers to accessing services.

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[5] For exact wording see question 29 in the questionnaire, Attachment 2, and the Barrier section in the focus group outline, Attachment 3.

[6] The determination of the types of barriers was based on a statistical technique called factor analysis. This technique indicates which barriers were most likely to be sorted into the same group by the PLWH/A survey participants. It is as though the PLWH/A were given a deck of cards with each barrier printed on it and asked to sort them in stacks, with each stack reflecting a common underlying theme. A pairwise Pearsons correlation matrix was used as input. A varimax option was selected to better discriminate the factors.

Figure 10-1 Average Barrier Scores by Risk Group

1=no barrier at all, 2=small barrier, 3=moderate barrier, 4=big barrier

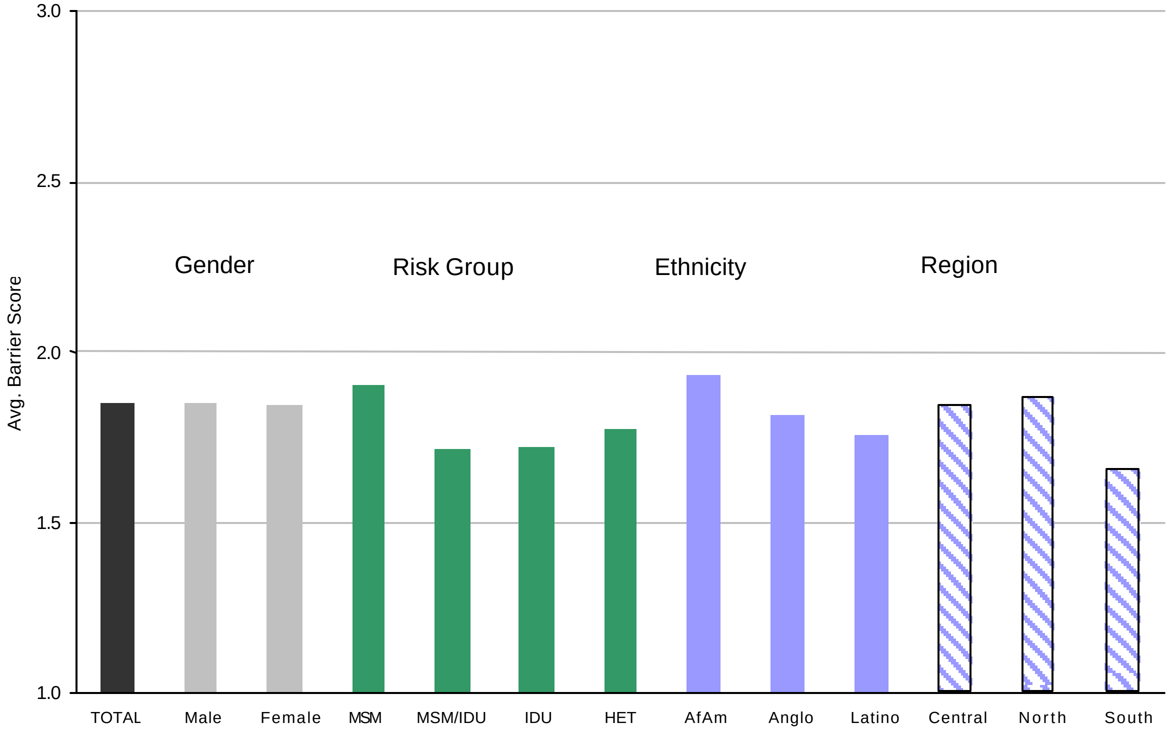
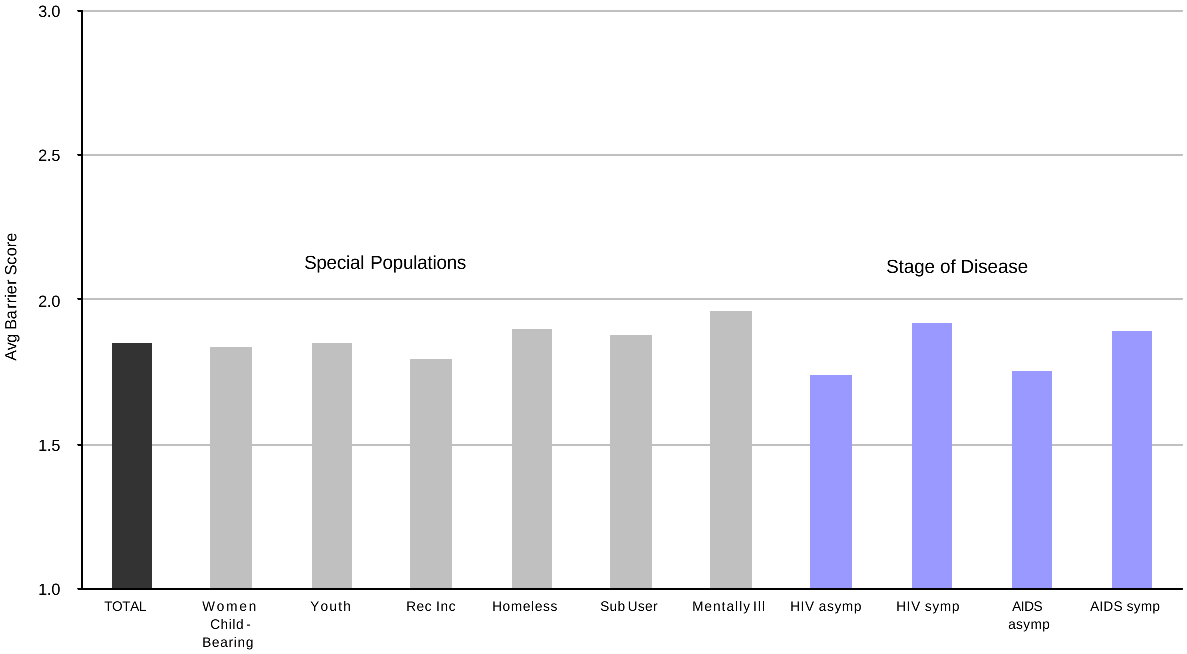


Figure 10-2 Average Barrier Scores for Special Populations

1=no barrier at all, 2=small barrier, 3=moderate barrier, 4=big barrier



Categorizing Individual Barriers Reported by PLWH/A

Table 10-1 groups each of the thirty -seven barriers into the more general categories of organizational, structural, individual barriers, or family related barriers. In total, both the focus group respondents and survey respondents rated nine individual level barriers, thirteen organizational barriers, twelve structural barriers, and three family-related barriers.

Table 10-1 Types of Barriers

Structural

Rules and Regulations

1. Not enough insurance
2. Red tape
3. Cost of service
4. Wait too long for appointment
5. Service needed does not exist
6. Rules and regulations regarding eligibility
7. Ability to navigate system

Access

8. No transportation
9. No access to specialist
10. Options for treatment
11. Location of organization

12 Referrals

Organizational

Provider Sensitivity

13. Made to feel like a number
14. Racial Discrimination
15. Discrimination due to sex id
16. Discrimination due to diagnosis
17. Lack of sensitivity
18. Lack of sensitivity to beliefs and spiritual concerns
19. Afraid of being reported to authorities
20. Fear breach of confidentiality
21. No sensitivity to use of comp treatment

Provider Expertise

22. Poor coordination
23. Provider did not speak consumer's language
24. Quality of service
25. Provider expertise

Individual

Knowledge

26. Communication with provider
27. Adherence
28. Not knowing services needed
29. Not knowing what treatment is available
30. Do not understand the treatment instructions

Well-Being

31. Denial
32. Worried that someone would find out HIV status (lack of confidentiality)
33. Physical health
34. State of mind

Family-Related

Access

35. No services for families
36. No on-site childcare
37. Single location for family primary care

Ranking of Specific Barriers[7]

Total Population Ranking of Barriers

Figure 10-3 graphs the "overall" barrier score shown for the top barriers in the first column Attachment 10 ranking from the highest to the lowest barrier.

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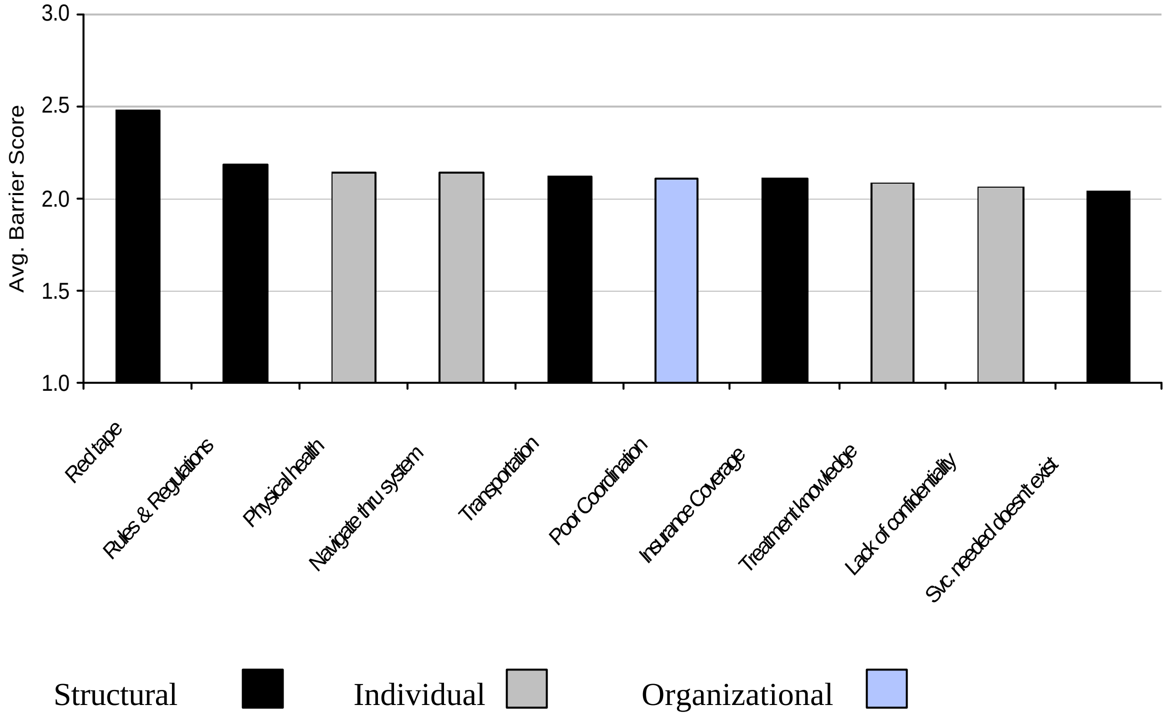
[7] **Attachment 10** shows the average score for barriers for the total populations, gender, risk group, ethnicity, regions, and special populations. It can be read down the column to determine the magnitude of the barrier for the total population and each subpopulation. They are ranked from highest to lowest barrier for the general population. As seen looking down the "Total" column, the top five barriers fall in the range of small to moderate barriers. The remainder falls in the range of "no barrier at all" to a "small barrier." The rank orders tend to be similar, but not the same, for all subpopulations. For example, African Americans rank "transportation" as their top barrier.

Barrier scores can also be compared across columns to determine different perceptions of each barrier among the different subpopulations. Comparison can be made to the "Total" population or another subpopulation. For example, looking across the row for "concern others learn status," women rate this barrier higher than most other groups.

As indicated in the overall barrier scores, no single barrier is ranked as a “big barrier.” For everyone, “red tape” is the highest barrier, considered between a “moderate barrier” and a “small barrier.”

Figure 10-3 Highest Barriers

4=big barrier 3=moderate barrier 2=small barrier 1=no barrier at all



As seen in Figure 10-3 the highest barriers were “system” related. Out of the top ten barriers, with a barrier score of 2.0 or higher mentioned, half are structural barriers, four are individual and one organizational. The top barriers were:

- The amount of red tape and paperwork I had to fill out to get the service.
- Not being eligible to obtain services because of rules and regulations. PLWH/A with a mental disorder found this barrier relatively high (2.4 compared to an average of 2.2).
- My physical health was ranked overall as the third highest barrier. PLWH/A reporting a mental disorder and the homeless ranked this barrier relatively high.
- My ability to find my way through the system was ranked relatively high by MSM and Youth.
- Not having transportation, ranked fifth highest, was ranked particularly high by youth and the homeless, and relatively high by IDUs and African Americans.
- Poor coordination among the organizations providing services.
- Not having enough insurance coverage.
- Not knowing what treatment is available to me.

- My concern that other people may see me when I go to get care or learn about my HIV infection (lack of confidentiality) was the 9th highest barrier, but was of particular concern to women of child bearing age.
- My concern that the services I need do not exist, the 10th highest barrier, was highest for the Latinos.

Barrier – Qualitative Comments for Top 10 Barriers

While the survey participants did not rank barriers particularly high, the focus group respondents seemed to suggest that at least for a large number of PLWH/A barriers play a significant role in obtaining services.

Red Tape

In regards to unmet needs and barriers, a Central Anglo MSM said, *"For me, I think getting the Medicaid and Food Stamps and cutting through the red tape. I have never experienced so much trouble just getting a return phone call to answer simple questions."* Another Central Anglo MSM said, *"It is frustrating. I am from Seattle and the programs there all work together. I was surprised here that I had to wait three months to get on state programs, which I had only been here two months when I got the PCP, so there is that hospital bill that I can't pay for. And while I was in the hospital, I had an appointment scheduled with an ASO case manager and a social worker at another ASO came to talk to me because I mentioned having this appointment, my first appointment. It was like they weren't going to work, you know, it had to be one or the other."*

A Northern Anglo MSM said, *"Getting services through the state contains too much red tape and limits that only allow access a few times a year. The spend down on Medicaid is stupid. With a limited income there is no extra money for a pre-payment before you receive care and medication."*

A Northern Anglo MSM said, "*It is super hard to deal with red tape! I tried to do it by myself - and sometimes I need help! I wait and then I am turned down because I work! So why try to use what is not available to me! Hope something can be done."*

A Southern Anglo female said, *"The amount of red tape and paperwork I had to fill out to get the service, I think that's just absolutely ridiculous. I mean I know that they need all this information, but some of it is very repetitive."* An Anglo male in the same group said, "*When she was talking about the amount of red tape, I think it's ridiculous for them to send out paperwork for us every six months to reissue us cards for EIP Limited and HIAP. What a waste of paper and money and postage. If the same person is going to be on the program, do it once a year, once every two years. Have the caseworker re-certify and do something. When you think of all the clients that they're sending out, the postage and all the paperwork for them to fill out all those forms. Then, they send me out a letter letting me know that I'm on these programs. I've been on the programs for two years. I've got the cards. I know I'm on the programs."*

A Northern African American MSM said, *"HIAP and ICHIA are problematic. You fill out the paperwork and you turn it in to your care coordinator and they do the appropriate things they* *are supposed to do and it comes back and says that it's not filled out right or it's not on the right type of paper or something, something, and then they do it again. I know people who have had to send their applications off three and four times. I've been applying for this for the last eight months, and I work in it. And I'm just now receiving it. Just received it."*

A Central Anglo MSM said, *"It has happened to me twice that the [large ASO] has lost my file each time I have changed care coordinators. The last time they lost my file, it ended up God knows where. I almost lost ICHIA, which took me two years to get. They are telling me now, because the State Board of Health and Medicare are trying to work together, they want me to go on Medicaid and give up my ICHIA. They are telling me well you can't have both. I am not asking for both. I want ICHIA because it covers my meds and I don't have a hassle with the spend down."*

Rules & Regulations

A Northern Latino female said, *"My family is 100% behind me. I was diagnosed and I was refused for services. They refused me twice. I had to fight it. I had to bring a letter saying I was diagnosed HIV positive. I am a single parent. My kids are tested and they don't have it. Because I made so much money last year they said I can get out there and get back into the working field, but because I am back here there are no army jobs here…. I am flipping burgers. I quit that job because I couldn't stand it anymore. I am trying to get back into the hospital right now. I fought it and I got the medical insurance but I had to bring in papers showing that I was HIV positive. They right away granted it to my kids, but they didn't grant it to me. In fact I was just granted it six weeks ago. So I haven't seen a doctor since I have been back."*

Northern Anglo participants discussed between them the way to work around eligibility rules for a benefit. The discussion was the following: *"I've gone through the whole process. I've gone through the, where you file it and appeal it and then we went to court and appealed it. Hired a lawyer out of Chicago, no luck. Now I've reapplied and I'm in the process again."* "You filled out the application?" *"I went all the way through."* "It's been so long since I filled it out but you have to like say you can't bring a clothes basket up the steps. Little things like that can get it." *"But I can sometimes."* "Well, I know. We all can. But on the apps, it's like you've got to just say that you can't. I mean I look really good today but." *"You don't want to lie about it."*

A Northern Anglo MSM said, "*My biggest problem with getting services through the state is having so many damn forms to fill out and all the qualification loops I have to jump through. And then just to say that I am not qualified. Also, not being able to get assistance while working a full time job, but still cannot afford some services that I need."*

A Central Anglo MSM brought up the rules and regulations in place regarding income. He said, *"One of the things I think is an issue too is my partner is negative. We have been together over two years now, and one of the obstacles that we have is not only insurance, but because of where I live in regards to income. If we live together, I don't qualify for benefits. I mean they don't want to give us joint benefits because we can't be 'a married couple'."*

A Southern Anglo male said, *"If you return to work, you lose your benefits, and then you can't get your medicine, because you're working. It's like a no-win situation. Either you're healthy and you can't work, or you go to work, and you can't afford to take your drugs, so you're no longer healthy."*

A Southern Anglo female said, *"I applied for disability, and I got turned down three times. Then, I had a court date, and they denied me. I would just like to say that that's really stupid, because if you have HIV, you should have a better chance of getting disability or SSI than someone who maybe has another problem. I think that the process is too slow."* An Anglo male in the same group responded, *"The whole disability evaluation process is draining. It is emotionally and physically draining on someone that's going through the stress of all these pills and all this burden being taken on them. And, to have the stress of the government telling you you're not sick or qualified for SSI. I feel that one of the biggest barriers, as far as Social Security and receiving Social Security/Disability benefits is you can't work for a year prior to applying. Otherwise, they'll say you can obviously work, but once you've not worked for a year in order to apply, then you get denied. Then, you have to go for another year without working. There's no way anybody can support themselves to get through that unless you have family or someone to stand beside you to do that."* A Northern Latino male said, *"They don't give you Medicaid. You have to fight for it."*

A Northern Latino male said, *"There is more money here than in Puerto Rico and other countries, and here there is no place where a HIV/AIDS homeless person with no place to sleep can go to and get taken in. Other poorer countries offer places and services to their HIV/AIDS infected populations. Here you have to fight to get SSI and they give it to you when you are getting ready to die. Why do you want it then? They need to give it to you now. They need to treat you better."* Another male said, *"And if you have done drugs and have been in prison it affects you, but that is in the past. And no one is perfect."*

A Northern Latino male said, *"With the SSI, when my wife was on it by herself she was getting $500. Once they approved me, between both of us we get $769 because we are a married couple. We don't get $500 each we only get $300 each. They said it is because we are married, if we separate and said we lived in separate houses we would get more, but we would need to separate."*

A Central African American MSM said, *"You would have to go down there and ask them why I am not eligible for disability. I didn't qualify for food stamps; I had too high of an income. I have no income, but it was too high for the food stamp office. You have to dig into the system to find out what you are qualified for, because there are a lot of things out there that we don't even know that we are able to get. It's almost like it's not a conspiracy, but it's almost as if they don't want you to find out, because they don't want to spend the money. It's frightening. It's horrifying. I've had people at the [large ASO] tell me when I came up with certain questions and I ask people down there or a social worker, case worker, whatever, and they would tell me that that fund was not even available. The particular fund that I was asking for was not available, but you could go out to [another ASO] and the very same fund was available."*

Navigate – ability to find my way through the system

A Northern African American MSM said, *"I'm in a situation personally I came to Ft. Wayne with a certificate of housing in Kansas City, MS. When I came to Ft. Wayne, I got involved with the ASO because I needed housing assistance because I had lost my job. I was not able to go directly into the system, I had to go all the way around the world. I got assistance through the Wayne/Allen Co. Township system. It was a big old mess. They sent me to the Township, then to the food stamp office, then I was referred to somewhere else. On some of these occasions, I had fever and flu.*

A Central Anglo MSM said, *"There are so many HIV-related organizations in Indiana, I it is hard to figure out the system and know where to get specific services. Thankfully, I made it ."*

A Central Anglo MSM/IDU said, *"Anything to do with the [large ASO] I am completely and totally dissatisfied with. You must be willing to get in their maze and follow exactly what they want you to do. You have no input into, 'Well, I think it would be best for me if.' You get it in and do it this, and you go here and go there and then okay, you are done. I'll leave. And you must do that within 15 minutes, within their allotted time."*

Transportation

Two Central Anglo heterosexual females expressed the lack of transportation available for services outside Marion County. One said, *"They Indianapolis ASO only serves Marion County and my doctor is in Danville. But even if they tried to get on that program or if I try to use Metro - they don't make it out to where my doctor is. If my car breaks down, I don't know what I would do."* Another said, *"They don't go to Shelby County and that is where my primary care doctor is. Usually I try to get a ride w/ someone that is going to that doctor that day. There is not even a bus that goes out there to Shelby. None of the transportation programs in Indianapolis doesn't help me because they don't go outside Marion Co."*

A Central Anglo MSM/IDU said, *"I was in the hospital for 18 days, and I called the [large ASO] and tried to get a ride home. They suggested I would have to come down and fill some forms out so they can get state funding. They say if it's a non emergency situation they cannot provide the transportation."*

A Central Anglo MSM in another group said, *"Transportation is needed because I take the bus and sometimes the weather is just bad. Especially when it's pouring down rain or there is snow on the ground because I have trouble walking and I don't like to walk when it's icy and snowy."*

Coordination –amongst the organizations providing services

A Southern Anglo male brought up the tangled coordination between AIDServe Indiana (ASI) and other care providers. He said, *"ASI has everything to do with everything. All of our programs are through that. That is why it is a big problem. All of our programs, housing, insurance, dental. All is through ASI. Then, all of our funding for Area 7 for any of the programs that we have locally is funded through ASI."* He later continued, *"I think that the* *services that ASI provides are fabulous, and people out there need them. I just think that it's a misrepresentation or a mismanagement of the organization that causes all these programs to run so inefficiently. For instance, one client, for rental assistance, he was receiving double checks for months and months and months. He reported it and explained to them. His landlord kept it in a separate account. They kept sending him double checks, but they can't figure out why they don't have and money."*

An Anglo male who had the similar problem said, *"They overpaid my landlord for six months. We finally got it stopped on the double payments, but we still haven't got it straightened out as to where to reimburse the money to. There's $1800 sitting in the bank of ASI's money."* Another Anglo male in the same group said, *"I wasn't getting my emergency assistance checks from ASI, and the only reason why I haven't been given the boot is because my mom is friends with my landlord, and my landlord understands my situation. She's been very understanding. I feel bad about it. I think we've done the best that we can do. People have been complaining long enough. There should be some kind of change."*

A Central Anglo MSM said, *"Agencies seem to become more and more complex. Even though information is more accessible -there is no cohesion between relating agencies. If Medicaid/Medicare office worked in conjunction with case management, and related services should be all in one Central location for the sanity of those accessing services."*

A Central Anglo MSM said, *"The [administrative agents] are not paying the doctors or the providers. They are sending me and the collection agencies bills who are in turn calling me. It is an annoyance, but I imagine that it will probably be a barrier, you know, later on for me. It has been a barrier for me, because I went to a lab to get treatment so that I could get a viral load and a CD4 count, and they wouldn't take my card. They wouldn't take it because they said, 'Well we haven't been paid by so and so.' It is like well okay, so my doctor's office took enough initiative after having it happen to at least ten of their patients that I know of, and got a new lab to do the testing of their office."*

A Southern Anglo male also mentions the problems he has had in getting his services paid. He said, *"If the services that we were on now didn't create so many problems in our life, that would be a relief right there. I mean it's a constant battle. I'm constantly in collections from lack of payment from insurance providers. I've got three insurances. I shouldn't be in collections. The insurance company doesn't care. The provider doesn't care. The provider tells me, "Oh, I've got a bounced check here from your insurance company." The insurance company tells me that they don't bounce checks. Who's lying to me? I'm on EIP Limited, which is useless, because they don't pay them [providers], and my providers no longer provide for me. I'm on HIAP, ICHIA, and Medicare. Since there's only Area 7 in this area, everything comes through ASI. The only thing that I get that isn't affected by ASI is my Medicare."*

Insurance Coverage

See Insurance Continuation Under "Services"

Treatment Knowledge

A Central Anglo MSM said, *"But they don't want to take the time, the care coordination sites here don't want to take the time to get you help. I went to them and asked what is available for me. If it wasn't for my doctor, and the pharmacist that I deal with helping me get my meds, I wouldn't have gotten ICHIA because it was them and not the care coordinator that had just started there that took the time to initiate the paperwork and to deal with the programs. A lot of them up there don't want to take the time and don't have the knowledge of what is available themselves, because they are so new."*

A Central Anglo MSM said, *"Agencies get a lot of state funding, they have a lot of programs that you can get into. They have a lot and they are going to direct you towards assistance. I guess I am a little aggravated. There are avenues out there, I worked in homeless prevention for five years, so I am pretty aware of where to go and what to do. But you have to take the initiative. You can't walk in with an attitude and condone somebody for, especially I am not stepping on anybody's toes."*

A Southern Anglo male said, *"I probably would have lived healthier if I had correct and better information, rather than figuring six more months to live as I was originally told. I thought I may as well party it up. I took a seven year sabbatical and just went downhill partying and not taking care of myself since I was dying anyway. I probably would have tried preserving myself with healthy things rather than alcohol."*

A Central African American summed up want many others said. He noted, *"They need to have more of a community effort to give information. It needs to be more accessible and there needs to be a specific place you can go to for information. You need to know because people don't tell you."*

Confidentiality (agencies would breach confidentiality)

A Northern African American MSM said, *"It just seems like to me that here in this city, they don't have a good hand for people living with HIV. I use to work at the ASO, some of that stuff that goes on over there is not confidential. They are wrong and they treat people different. They treat people different based on who you are. Those people will go and talk to each other about you. When you go to a counselor to talk to them and it's supposed to be confidential, isn't that where it's supposed to stay. They will say they sometimes have to go get input from someone else. I know how professional businesses run, you don't worry about each person talking to each other about one person especially when you are dealing with people with AIDS. That whole building shouldn't know your whole business, you could walk through there and people know everything about you."*

A Central Anglo IDU male said, *"My Medicaid case worker called my job. She was supposed to fax all of my information to housing, because of where I live they need to update every year to make sure I'm eligible. My job already knew I was HIV positive. After she faxed that information, called them, talked to my boss and said, 'Did you know that he was HIV positive?' 'Well, yeah. Who are you?' Then she hung up and called the receptionist and said, 'Did you* *know he was HIV positive?' Well, the receptionist's brother just found out he was HIV positive. She said, 'Why is that my business and who are you?' 'Oh, these people just make me sick and I can't stand it.' This is what she told the receptionist. 'I can't stand it when they come to my office. They just make me sick. I don't even like opening the letters they send.'"*

Confidentiality (concern others would learn about HIV status)

A Northern African American female said, *"I found out [my status] in prison here in Indiana. When I found out I couldn't talk to anybody. So it was very hard especially to keep it very private. I was an IV drug user so any time they asked if I wanted an HIV test, I said yes and just went on about my business. Next thing I knew they called me in and said I was positive so they did the actual test to see exactly where I was with my T-cells and all of that. I had 6 weeks to go and to keep it from all of the other prisoners because it, it is bad for the guys out here, the gay guys but in prison, they have it where nobody wants to bunk with you, nobody wants to sit next to you when you eat. It was very hard to hide it when they give you the pills and everybody knows what the medication looks like. It was very, very difficult. We had a couple of counseling sessions which when they pull six people out of a whole prison to go to a room, people think something is wrong. So it was very easy for the other prisoners to figure out that there was something wrong with us."*

See individual service qualitative comments in the following section.

For additional focus group comments on other barriers not rated as high, see the accompanying document, "Selected Focus Group Comments: PLWH/A In Indiana Speak About HIV/AIDS Service Needs And Barriers In 2000 - 2001", and focus group comments following each service description in the following section.

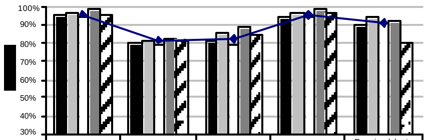
11. Service Summaries by Race, Risk Group, and Stage of Infection and Top Barriers

Summary statistics for each service is shown graphically in this section. Readers may go to the service of interest (page numbers are in the Table of Contents) and quickly view the knowledge, need, demand, and utilization of the service by sex, risk group, ethnicity, region, and stage of infection. Each service is shown using the same graphs and page layout as shown in Table 11-1 below. Each of the four graphs represents a cluster of subpopulations. Each graph represent those subpopulations reported knowledge, need, demand, and utilization (ever and in the past year). The box to the right reports the average number of times different subpopulations accessed the service. Under the graphs the top barriers to those services are shown. Significant differences in service needs by race/ethnicity, risk group, and stage of infection are noted in bullet points on the section following the graphs along with a summary of the focus group comments regarding the service.

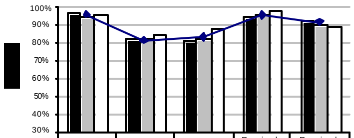
The third section for each service displays relevant focus group comments that give depth to the quantitative findings, or present examples of needs and barriers that may not rank high in general, but have great relevance for some PLWH/A.

Table 11-1 Example of Service Template

Appointment with a doctor, nurse, or their assistants to monitor and treat your HIV infection

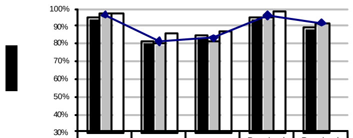


	Available	Need	Asked	Received ever	Received last year
Male	96.5%	81.7%	82.8%	95.7%	91.3%
Female	98.2%	82.3%	86.4%	98.2%	94.7%
MSM	95.6%	80.6%	80.2%	94.5%	92.1%
IDU	100.0%	82.9%	90.2%	100.0%	93.5%
HET	97.0%	82.5%	84.9%	97.2%	81.0%
Total	96.7%	81.8%	83.3%	96.1%	91.8%

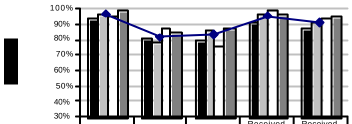


	Available	Need	Asked	Received ever	Received last year
Central	97.8%	82.9%	82.2%	94.5%	93.3%
North	95.5%	82.7%	82.7%	96.8%	90.9%
South	96.8%	85.7%	88.9%	98.4%	89.3%
Total	96.7%	81.8%	83.3%	96.1%	91.8%

	Average # past yr.
Sample	10.3
Male	10.7
Female	8.5
MSM	11.4
MSM/IDU	7.8
IDU	8.9
Hetero	8.8
Afr American	9.2
Anglo	10.8
Latino	11.9
Central	11.8
North	8.6
South	9.6
H asymp	7.5
H symp	7.7
A asymp	7.9
A symp	15.5



	Available	Need	Asked	Received ever	Received last year
Af American	95.2%	81.7%	86.3%	96.2%	89.4%
Anglo	97.3%	81.2%	81.8%	96.1%	93.0%
Latino	97.1%	87.0%	88.4%	98.6%	
Total	96.7%	81.8%	83.3%	96.1%	91.8%



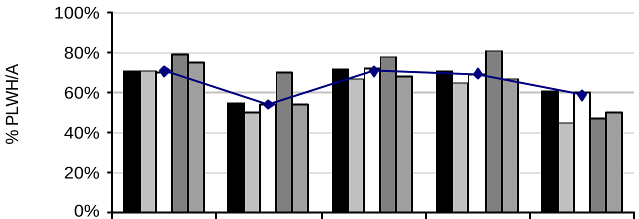
	Available	Need	Asked	Received ever	Received last year
HIV Asymp	94.5%	82.1%	80.7%	92.4%	88.0%
HIV Symp	97.6%	79.3%	86.6%	97.6%	91.4%
AIDS Asymp	95.6%	88.9%	75.6%	100.0%	93.5%
AIDS Symp	99.2%	85.2%	87.4%	97.7%	95.5%
Total	96.7%	81.8%	83.3%	96.1%	91.8%

Top Barriers

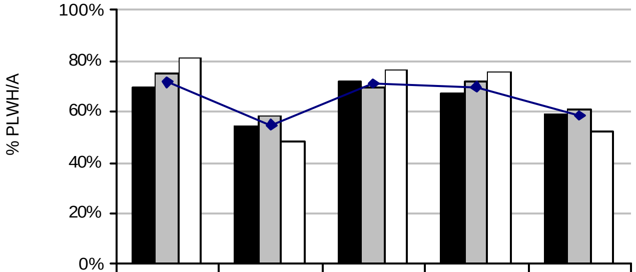
- Not knowing what service is available to me.
- The level of expertise of the person providing the service.
- The amount of red tape and paperwork I had to fill out to get the service.
- The cost of the service to me.

Once the reader is familiar with the format he or she can quickly review the different services – page numbers are noted in the Table of Contents. Greater detail, including the need, demand, and utilization by special populations, are shown in Attachment 5 through Attachment 9.

Assistance obtaining health insurance

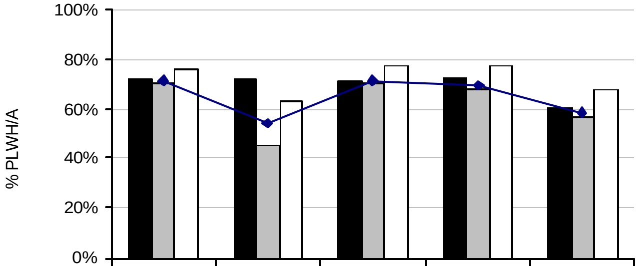


	Available	Need	Asked	Received ever	Received last year
■ Male	71.2%	55.2%	71.8%	70.7%	60.8%
▒ Female	71.3%	50.4%	67.1%	64.6%	45.2%
□ MSM	70.0%	54.6%	72.5%	69.4%	60.4%
▨ IDU	79.3%	70.5%	77.5%	81.0%	47.1%
▨ HET	75.9%	53.9%	68.7%	67.5%	50.3%
◆ Total	71.2%	54.5%	71.1%	69.8%	58.5%

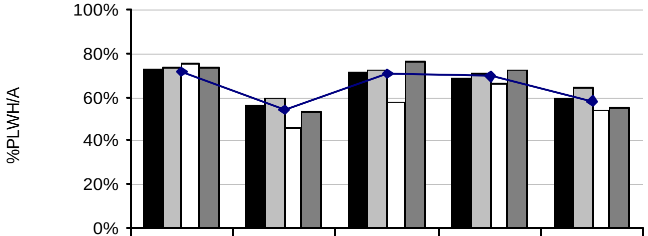


	Available	Need	Asked	Received ever	Received last year
■ Central	69.6%	54.4%	72.1%	67.2%	58.7%
▒ North	75.2%	58.3%	69.7%	72.1%	60.8%
□ South	81.0%	48.4%	76.2%	75.8%	52.4%
◆ Total	71.2%	54.5%	71.1%	69.8%	58.5%

	Average # Past Year
Sample	**3.6**
Male	3.7
Female	3.1
MSM	3.6
MSM/IDU	3.2
IDU	3.4
HET	4.9
Af Am	2.9
Anglo	3.9
Latino	4.4
Central	3.7
North	3.3
South	4.2
H asymp	3.2
H symp	3.6
A asymp	3.2
A symp	4.1



	Available	Need	Asked	Received ever	Received last year
■ Af Am	72.0%	71.8%	71.4%	72.6%	60.6%
▒ Anglo	70.5%	45.3%	70.5%	68.0%	56.9%
□ Latino	76.2%	63.5%	77.2%	77.4%	67.4%
◆ Total	71.2%	54.5%	71.1%	69.8%	58.5%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	72.6%	56.2%	71.7%	69.0%	59.5%
▒ H Symp	73.5%	59.8%	72.0%	70.7%	64.3%
□ A Asymp	75.6%	46.7%	57.8%	66.7%	53.9%
▨ A Symp	73.4%	53.2%	76.2%	72.2%	55.7%
◆ Total	71.2%	54.5%	71.1%	69.8%	58.5%

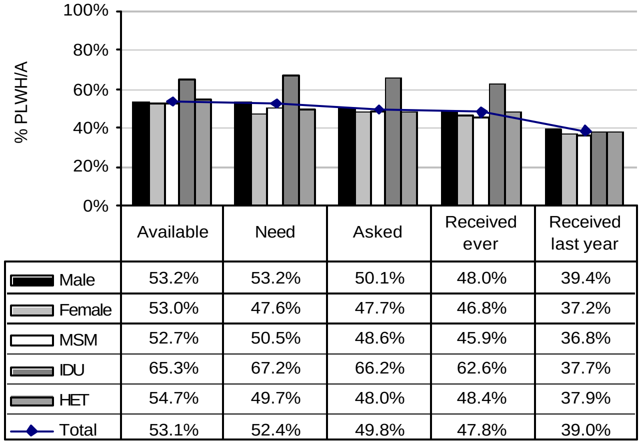
Top Barriers

- The amount of red tape and paperwork I had to fill out to get the service.
- The level of expertise of the person providing the service.
- Not being eligible to obtain services because of rules and regulations.
- Not having enough insurance coverage.
- Poor coordination among the organizations providing services.

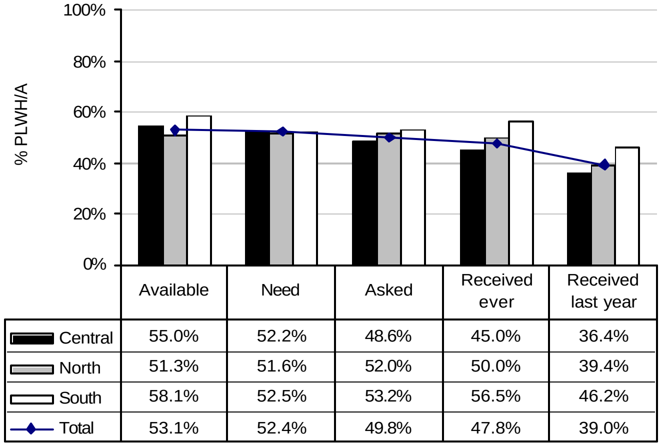
Highlights

- Health insurance continuation is ranked as the top need by the ISDH, and assistance with payment of health insurance premiums, co-pays or deductibles is part of that service, and it is ranked in the top needs by PLWH/A.
- On average, PLWH/A report 3.6 session of insurance assistance. Heterosexuals, Latinos, and symptomatic PLWH/A receive more help.
- Given the priority, there is room for increased awareness – 70% of PLWH/A are aware of assistance obtaining health insurance. Over half report needing it, but about 70% have asked for and ever receive it. About 60% reported receiving it last year.
- Among sex and risk groups, IDUs have greater knowledge, report greater need, and are more likely to ask and ever receive assistance. In the last year, assistance has dramatically decreased. Probably because of other insurance options for females, males are more likely to need and receive assistance from payments, and males and MSM are more likely to receive services.
- Among PLWH/A in different regions, those in the South have greater awareness, and while their need is lowest, they are morel likely to ask for and ever receive insurance assistance. Those in the North are next most likely to receive insurance assistance. The level of service has decreased in all regions last year.
- Among ethnic populations, African Americans report the highest in need, and they have a similar pattern for inquiring and receiving health insurance. Latinos express a lower need, and ask for and receive less health insurance assistance. Latinos were more likely to report receiving services.
- Symptomatic PLWH express the greatest need, and, along with symptomatic PLWA are likely to receive insurance assistance.

Assistance with payments of health insurance premiums, co-pays or deductibles

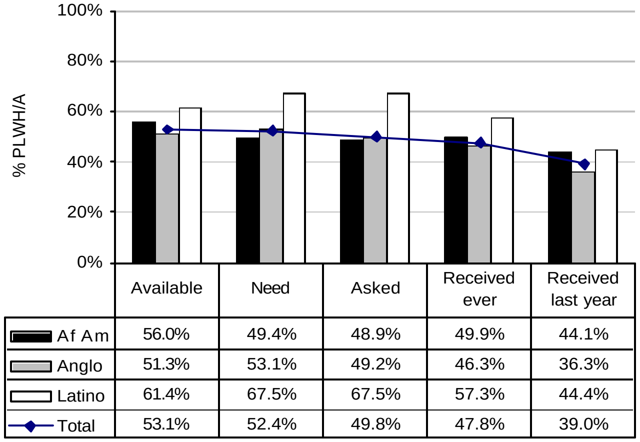


	Available	Need	Asked	Received ever	Received last year
■ Male	53.2%	53.2%	50.1%	48.0%	39.4%
▒ Female	53.0%	47.6%	47.7%	46.8%	37.2%
□ MSM	52.7%	50.5%	48.6%	45.9%	36.8%
▓ IDU	65.3%	67.2%	66.2%	62.6%	37.7%
▓ HET	54.7%	49.7%	48.0%	48.4%	37.9%
◆ Total	53.1%	52.4%	49.8%	47.8%	39.0%

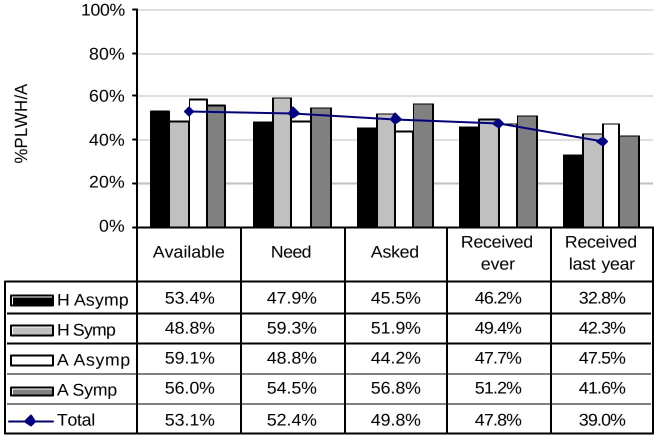


	Available	Need	Asked	Received ever	Received last year
■ Central	55.0%	52.2%	48.6%	45.0%	36.4%
▒ North	51.3%	51.6%	52.0%	50.0%	39.4%
□ South	58.1%	52.5%	53.2%	56.5%	46.2%
◆ Total	53.1%	52.4%	49.8%	47.8%	39.0%

	Average # Past Year
Sample	**8.1**
Male	8.1
Female	8.3
MSM	7.5
MSM/IDU	10.1
IDU	6.8
HET	11.6
Af Am	7.6
Anglo	8.5
Latino	8.5
Central	7.9
North	8.1
South	8.6
	5.9
H asymp	9.2
H symp	10.8
A asymp	8.4



	Available	Need	Asked	Received ever	Received last year
■ Af Am	56.0%	49.4%	48.9%	49.9%	44.1%
▒ Anglo	51.3%	53.1%	49.2%	46.3%	36.3%
□ Latino	61.4%	67.5%	67.5%	57.3%	44.4%
◆ Total	53.1%	52.4%	49.8%	47.8%	39.0%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	53.4%	47.9%	45.5%	46.2%	32.8%
▒ H Symp	48.8%	59.3%	51.9%	49.4%	42.3%
□ A Asymp	59.1%	48.8%	44.2%	47.7%	47.5%
▓ A Symp	56.0%	54.5%	56.8%	51.2%	41.6%
◆ Total	53.1%	52.4%	49.8%	47.8%	39.0%

Top Barriers

- The amount of red tape and paperwork I had to fill out to get the service.
- Not being eligible to obtain services because of rules and regulations.
- The cost of the service to me.
- The level of expertise of the person providing the service.
- Not having enough insurance coverage.

Highlights

- A top priority of ISDH is to use Ryan White funds to pay for insurance to PLWH/A who cannot obtain it elsewhere. PLWH/A also perceive it as a top priority.
- On average, PLWH/A report over 8 payment a year, with Heterosexuals receiving the largest number of payments.
- Given its high priority, awareness is little low; about half of PLWH/A know assistance with premiums is available, and about half need, ask, and receive assistance.
- Among sex and risk groups, IDUs have greater knowledge, report greater need, and are more likely to ask and receive assistance. Probably because of other insurance options for females, males are more likely to need and receive assistance from payments. MSM and females have the lowest need. Among all groups, the among of assistance fell last year.
- Although Central, Northern and Southern PLWH/A report approximately the same need for assistance with health insurance payments, Southern PLWH/A say they have receive a little more assistance, while those in the Central area a little less.
- Among ethnic populations, Latinos indicate a relatively high level of awareness, but say they have the lowest need. They receive about the same amount as other ethnic populations. Proportionately, more African Americans ands Latinos reporting receiving assistance paying health insurance premiums and co-pays then Anglos.
- By stage of infection, symptomatic PLWH/A are more likely to need and ask for assistance with health insurance payments.

Insurance Qualitative Comments

Several comments by PLWH/A indicated that the system worked for them. For example, A Southern Anglo male said, *"When I first found out I was diagnosed with HIV, I was in the hospital, and it was really hard. Then, it really got harder, because I wasn't on any kind of insurance. I didn't have any insurance to get my medicine. The nurse at the hospital called my doctor. She was helping me get the medicine and the service that I needed. I finally got in touch with an ASO here. They helped me get the services and insurance I needed. I was on EIP for a while and then finally I got on Medicaid to help me get my medicine and stuff like that."*

A Southern Anglo female expressed how her coverage works for her. She said, *"Everything as far as medical things go, as far as counseling and psychologists and psychiatrists and just like physical health, I don't really have any problems with that because I have Medicaid."* A Northern Anglo male said, *"I'm very happy with my insurance. I have Medicaid and Medicare. I don't have to pay for any of my medicine. I have an excellent doctor. I couldn't be happier with him."*

The need and concern about insurance was often mentioned by participants. An Anglo MSM says he was able to get assistance when his insurance from work stopped. He says, "*t I am still concerned now [that I am beginning full time employment.} Before, we were able to work things out where I have had ADAP and ICHIA and Title III and those types of things, because I didn't really have enough money …. Now I am going into full-time work with full-time benefits. I am afraid of what could happen to that insurance when I do get that insurance and the cost of my meds and medical care. Will I still be able to maintain this same level of care that I am starting to establish and at a critical time?"*

For many PLWH/A it is clear from the comments that insurance coverage includes managing several sources of insurance and reimbursement, including Medicaid. A Central Anglo MSM said, *"Need number one would be making sure that my insurance is straightened out because ICHIA and Medicaid somehow got intertwined there and Medicaid has me on their file when I haven't had Medicaid in a year."*

Obtaining and maintaining Medicaid is difficult for many PLWH/A and was a constant theme throughout the focus groups. A growing concern is how to assure insurance continuation when going back to work. For example, one MSM said, *"I have been trying to get on Medicaid. I moved here the end of September last year to take a job. The beginning of December, I got PCP and couldn't go back to work. I applied for Medicaid and disability. I got my disability, but with Medicaid I have gotten one letter that said nothing on it. I can't get anywhere with them. They don't return phone calls, I qualify for it but don't have it yet."* A Southern Anglo male said, *"The kind of services that I anticipate needing in the future having medical insurance that will take a* *pre-existing condition because I'd really like to return to work. I would need an insurance that is going to somehow cover medications, because the medications are outrageously expensive."*

Clearly the process to quality for Medicaid and SSDI is not easy. As one women's comments summarized what several participants mentioned. She said, *Indiana puts you through the ringer [to qualify for SSDI and successfully obtain it]*.

A Central Anglo heterosexual female said, *"The Medicaid was difficult to get. I got the pregnancy Medicaid until I had my daughter. And then a month after her birth they dropped me. My daughter is covered but they dropped me because they said that I didn't have any symptoms. So I went through ADAP to the EIP program. That was a big joke to me because they send you to hospital in which you can only go to the [ASO]. I went there for almost a year and during the time I was there my viral load climbed to 3,000 and my t-cell count dropped to under 200. I was just getting into bad shape. I feel that when I was there, I never saw my doctor in that one year of time. I couldn't tell you what he looked like and I couldn't tell you his name. I saw his nurse practitioner and she made out all my prescriptions and blood work and had me in pretty bad shape. Once I did get my Medicaid back and could go back to my regular doctor he finally got it straighten back out and has my viral load down."*

A Northern Anglo female IDU discussed the fortune she has with health insurance coverage through the VA. She said, *"I pick and choose my doctors when I'm in my right mind because of my injuries and stuff I do see them quite often. I can't say that I have any problems with my doctors. I have never gotten a bill. One hospital sends bills, the other ones don't because I have had a lot of surgeries since I've been positive, accidents, emergency room, STAT care, just incident little things that I don't want to go to the doctors office. So I go to STAT care but I've never gotten a letter saying, 'You are spending too much. You need to go to your family doctor or what.' When I'm sick, I go. I'm not going to wait until the doctors office opens if I can't breathe. I'm going to go get a breathing treatment. I am fortunate and I know that. I wish other people were as fortunate. I know they struggle paying health insurance. It's a lot of money. $400 is a lot of money for insurance and right now you could be using that for a lot of other things. And a $10 co-pay is a lot. That adds up when you've got as many medications as we have. Even the $3 adds up."*

Eligibility continues to be a concern, and among the PLWH/A who do not qualify for Medicaid or ACHIA, there may be a problem with coverage. A Northern African American MSM said, *"I don't have any of those assistance programs for my insurance, and with my private insurance there are some things that are not covered, and what I would like to see if they can actually do something on the insurance for full coverage. They can take up where the private insurance leaves off. My case manager is working on that, but what the problem we run into is that I make too much money to be under some of their insurances. So either I need some information or some other groups to help out with that."*

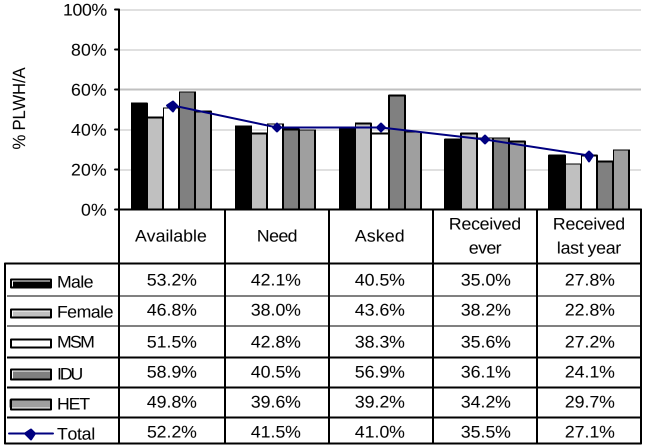
The barriers of red tape and paper work were confirmed in the focus groups. One Male Latino MSM said, *“My first application somehow got lost after three months of waiting for it to be approved. Meanwhile for that three months I had no prescription coverage, and I didn't find out until I charged all of these medications at my pharmacy. When ICHIA finally admitted to my case worker that they didn't know where my application was then I had to redo the whole thing and start the process over. So that's why they don't want to pay, because they don't feel I have applied yet. But the case worker had documentation …”* An Anglo female says, *I applied for disability, and I got turned down three times. Then, I had a court date, and they denied me. I would just like to say that that’s really stupid, because if you have HIV, you should have a better chance of getting disability or SSI than someone who maybe has another problem. I think that the process is too slow.”*

The complexity of the insurance for consumers was apparent in reviewing focus group comments. Many like a Central Latino MSM recognized the importance of insurance. He said, *“My first needs were medical assistance to help to cover the drugs through insurance. The first year was big for all of my medication. I remember they spent like $40,000 just on medication and doctors.”* A Latino female further noted, *“I think they need to get more help with the medical coverage, because there are a lot of doctors who won't give you medicine without the medical coverage, and the medical coverage doesn't cover all the medicines. We need some kind of help with that because I have medicines that are really expensive.”*

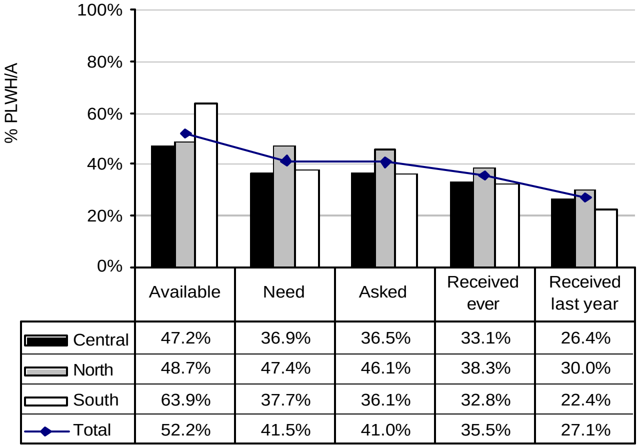
Several focus group participants mentioned their concern about the coordination between the ASO what has primary insurance responsibility and the provider. Many mentioned that their physicians had not received payments and were concerned that they received cancellation notices and felt their services were jeopardized.

A Southern Anglo male said, “The insurance system is so screwed up. We have businesses here in town, ophthalmologists, pharmacists, even doctors, refusing patients now because they're not getting their money because of these state funded insurances.”

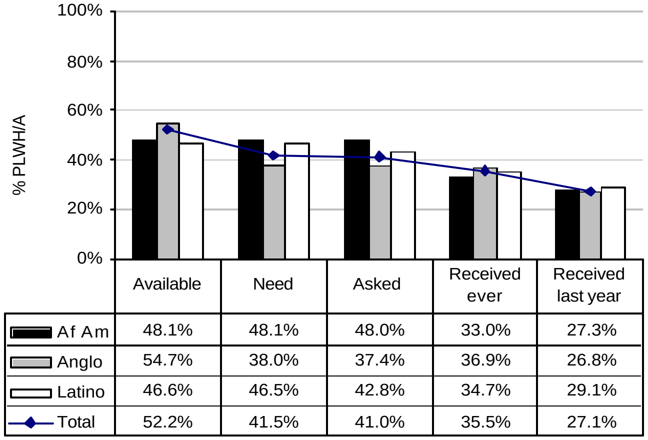
Drug Reimbursement – assistance in paying for HIV/AIDS related drugs



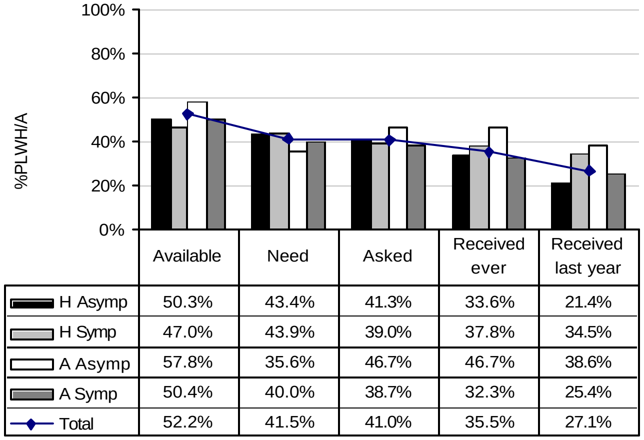
	Available	Need	Asked	Received ever	Received last year
Male	53.2%	42.1%	40.5%	35.0%	27.8%
Female	46.8%	38.0%	43.6%	38.2%	22.8%
MSM	51.5%	42.8%	38.3%	35.6%	27.2%
IDU	58.9%	40.5%	56.9%	36.1%	24.1%
HET	49.8%	39.6%	39.2%	34.2%	29.7%
Total	52.2%	41.5%	41.0%	35.5%	27.1%



	Available	Need	Asked	Received ever	Received last year
Central	47.2%	36.9%	36.5%	33.1%	26.4%
North	48.7%	47.4%	46.1%	38.3%	30.0%
South	63.9%	37.7%	36.1%	32.8%	22.4%
Total	52.2%	41.5%	41.0%	35.5%	27.1%



	Available	Need	Asked	Received ever	Received last year
Af Am	48.1%	48.1%	48.0%	33.0%	27.3%
Anglo	54.7%	38.0%	37.4%	36.9%	26.8%
Latino	46.6%	46.5%	42.8%	34.7%	29.1%
Total	52.2%	41.5%	41.0%	35.5%	27.1%



	Available	Need	Asked	Received ever	Received last year
H Asymp	50.3%	43.4%	41.3%	33.6%	21.4%
H Symp	47.0%	43.9%	39.0%	37.8%	34.5%
A Asymp	57.8%	35.6%	46.7%	46.7%	38.6%
A Symp	50.4%	40.0%	38.7%	32.3%	25.4%
Total	52.2%	41.5%	41.0%	35.5%	27.1%

	Average # Past Year
Sample	**12.0**
Male	12.0
Female	12.0
MSM	12.0
MSM/IDU	9.2
IDU	12.0
HET	12.0
Af Am	12.0
Anglo	7.6
Latino	8.1
Central	7.0
North	12.0
South	12.0
H asymp	9.0
H symp	12.0
A asymp	12.0
A symp	12.0

Top Barriers

- The cost of the service to me.
- Not knowing what service I need for treating my HIV infection.
- The amount of red tape and paperwork I had to fill out to get the service.
- The level of expertise of the person providing the service.
- My concern that the services I need do not exist.
- My thinking that I was not being affected by the infection (denial).
- Not being eligible to obtain services because of rules and regulations.

Highlights

- Drug reimbursement is the second highest priority of ISDH and is among the highest priority of PLWH/A.
- Overall, slightly fewer PLWH/A receive drug reimbursement than ask for it, but the gap is particularly large among IDUs and African Americans.
- Those accessing drug re-imbursement assistance, report having received an average of 12 payments during the past year. Anglos say they received fewer payments in the past year.
- On average, 52% of PLWH/A perceive drug reimbursement is available to them. 42% say they currently need it. 41% have ever asked for it, and 36% report having received it. 27% report that they received it last year.
- Among sex and risk groups, females report slightly lower current need, but have history or asking for and receiving more drug reimbursement. IDUs are much more likely to ask for drug reimbursement, and only slightly more likely to receive it.
- Among PLWH/A living in different regions, those in the South are more likely to perceive that drug reimbursement is available to them. However, they are least likely to receive it. PLWH/A living in the North are more likely to ask and receive drug reimbursement.
- Among ethnic populations, Anglos perceive greater availability of drug reimbursement and African American perceive greater need and are more likely to have asked for drug reimbursement. About the same proportion of each ethnic population receive drug reimbursement.
- Although asymptomatic PLWA indicate they are less likely need drug reimbursement than symptomatic PLWA, they ask for and receive higher levels of service.

Drug Reimbursement Qualitative Comments

Establishing an effective program of drug reimbursement is critical for maintaining drug regimens. Without drug reimbursement, PLWH/A will opt to not take the medications instead of getting into debt for the medications. re. A Central Latino MSM said, *"When I realized I had no insurance coverage for prescriptions I quit taking them, and my doctor didn't like it. Thank goodness the Damian Center was able to come up with about half of the medications I was on, but I just went without them, because I already owed $7500 and it's like I'm not going to keep charging it if I can't afford it. So I took a little medicine holiday. It wasn't good. I didn't feel good about doing it. I didn't think I had a choice, and I spent all of my savings, so it wasn't possible."* A Latino MSM in the same group said his immediate need was to get medications because *"the insurance where I worked would not cover those medications. It would cover some of it."*

Like insurance of medical coverage, the options and coordination of ADAP, Medicaid, Medicare, EIP, and ACHIA can be a barrier for PLWH/A. For example, a Central Latino MSM expressed his need for better medication assistance. He said, *"If I make my Medicaid spend down, they will pay for them. I have to pay anywhere from $20 to $25, sometimes $15 whatever out of my pocket. If I don't meet my spend down then I can't get my medication."* He continued, *"I'm on Medicare, and of course they don't pay for prescriptions. I went through a situation where my supplemental insurance cancelled, and I'm currently in debt to my pharmacy for about $7500 that everybody is still complaining they don't owe; ICHIA doesn't want to pay it, and my supplement doesn't want to pay it. I'm not having any luck, because I was in that period with no insurance where I was waiting to get accepted into the program and never got any paperwork. ADAP says it's a past bill and therefore they don't owe it, so I'm getting all of my current medications taken care of, but I still owe $7500 and I'm not sure where that's going to go. I can't afford that, but I don't know what's going to happen."*

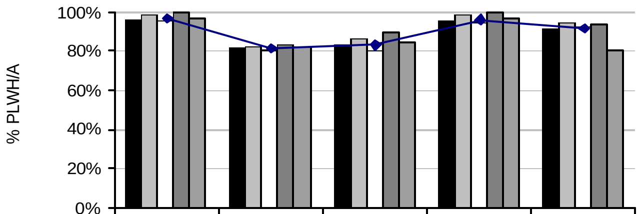
The relatively high level of effort by PLWH/A to qualify was mentioned several times by participants. A Northern African American MSM/IDU said, *"Mississippi is easy, Florida is easy, Alabama is easy but for some reason Indiana and Gary it's hell. It's hell trying to get help. My biggest problem is getting the medication. In Mississippi I had Medicaid, you only have to spend a buck. I've been disabled since 1985 and I come to Gary and they want to start all over again. I told them that I've been disabled since '85 why should I go through all of this again? Their response was 'You've got to be disabled through Indiana.' In the meantime what about my medicine? During all of that time I've never been without my medicine for 3 months. I took my prescription to the pharmacy and that medicine is expensive. I took it down there and I knew they weren't going to help. Sustiva is $600 and I went down there with these prescriptions and it come out to about $1,500 worth of medicine. They told me that there was no way that they could help me because it cost too much. Wait a minute, what do you mean it's too much? They told me that they could only help me with so much. I told them that I cannot afford this medicine but I need this medicine, they just said we're sorry. You don't hear that in Mississippi, you don't hear that in Alabama. You don't hear that in Florida."*

An African American MSM/IDU said, “..W*hen the Lord found me, and I was literally unable to work my t-cells had just dropped to 198, which in New York is technically AIDS. So it was Medicaid, no spend down, no questions asked. They paid my rent on 71st between Central Park West and Columbus, $160 some dollars every two weeks and $110 in food stamps a month. Bam. I mean just bam, and I thought that's just the way it is. My medications were all paid for. Come here, and it's like this state wants people to die and they don't care. It's like the only state where if you are disabled you do not automatically qualify for Medicaid. It's madness. It's unbelievable.*

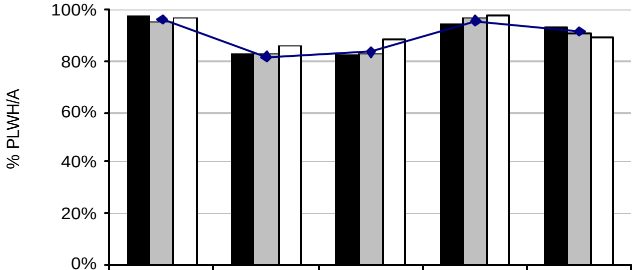
PLWH/A expressed concern about co-pays for medication. A Northern Anglo IDU female said, *“I don't have any problems with insurance coverage. I like it because I can walk into any hospital and not get billed. If something happens to me I can walk into any hospital and get it taken care of, get good medical attention and I'm covered. The only thing I can say is about the co-pay on the medications. Like I said it adds up when you have 10 different medications that you have to pay $3 each for every month. That's $30 a month out of my social security check. I have to fork out of my own pocket for my medicines. That money there I could use to put towards other things like my bills and stuff. That's the only problem I have with it.”* A Central Anglo MSM said, *“The co-pays that I have for my medications is where I am not being reimbursed. When you take 15 different prescriptions and I am also diabetic… You still have to have the insulin to put into the pump or the pump is not going to do you any good. So it is going to be in the catch 22 where you are getting some of it, but your co-pays that you are paying eats up the same amount.”*

The way in which PLWH/A have their medication paid for can make a difference in their quality of life. For example, A Northern African American MSM said, *“..when you go to the private pharmacies like Walgreen's and Osco, they won't take EIP, but if you go through Stat Script they take just about anything. I called them the other day when I came to the doctor. The doctor prescribed medications for me, and he said it may not be covered at Walgreen's. I called Stat Script and they said, ‘Oh, sure we will Fed Ex it out to you the next day. No problem.’ Anything that you have a problem with the insurance company you don't have to deal with it. Stat Script will deal with it.”*

Appointment with a doctor, nurse, or their assistants to monitor and treat your HIV infection

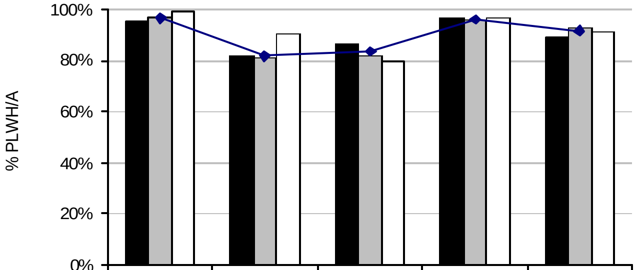


	Available	Need	Asked	Received ever	Received last year
■ Male	96.5%	81.7%	82.8%	95.7%	91.3%
▨ Female	98.2%	82.3%	86.4%	98.2%	94.7%
□ MSM	95.6%	80.6%	80.2%	94.5%	92.1%
▩ IDU	100.0%	82.9%	90.2%	100.0%	93.5%
▩ HET	97.0%	82.5%	84.9%	97.2%	81.0%
—◆— Total	96.7%	81.8%	83.3%	96.1%	91.8%

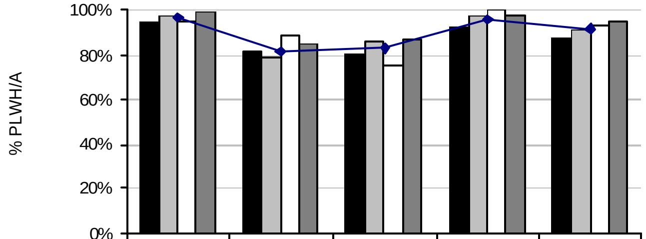


	Available	Need	Asked	Received ever	Received last year
■ Central	97.8%	82.9%	82.2%	94.5%	93.3%
▨ North	95.5%	82.7%	82.7%	96.8%	90.9%
□ South	96.8%	85.7%	88.9%	98.4%	89.3%
—◆— Total	96.7%	81.8%	83.3%	96.1%	91.8%

	Average # Past Year
Sample	**10.3**
Male	10.7
Female	8.5
MSM	11.4
MSM/IDU	7.8
IDU	8.9
HET	8.8
Af Am	9.2
Anglo	10.8
Latino	11.9
Central	11.8
North	8.6
South	9.6
H asymp	7.5
H symp	7.7
A asymp	7.9
A symp	15.5



	Available	Need	Asked	Received ever	Received last year
■ Af Am	95.2%	81.7%	86.3%	96.2%	89.4%
▨ Anglo	97.3%	81.2%	81.8%	96.1%	93.0%
□ Latino	99.3%	90.4%	80.2%	96.6%	91.4%
—◆— Total	96.7%	81.8%	83.3%	96.1%	91.8%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	94.5%	82.1%	80.7%	92.4%	88.0%
▨ H Symp	97.6%	79.3%	86.6%	97.6%	91.4%
□ A Asymp	95.6%	88.9%	75.6%	100.0%	93.5%
▩ A Symp	99.2%	85.2%	87.4%	97.7%	95.5%
—◆— Total	96.7%	81.8%	83.3%	96.1%	91.8%

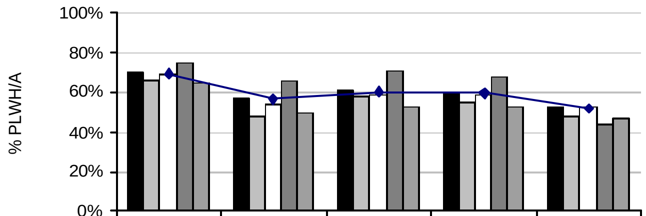
Top Barriers

- Not knowing what service is available to me.
- The level of expertise of the person providing the service.
- The amount of red tape and paperwork I had to fill out to get the service.
- The cost of the service to me.

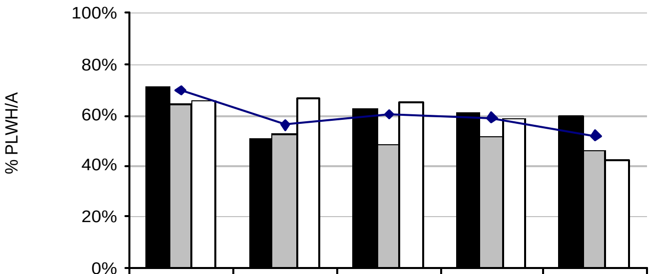
Highlights

- PLWH/A perceive primary care as their top ranked need, but also say they receive more than they ask for. *ISDH ranked it as their third highest priority,*
- On average, 97% of PLWH/A say the know about primary medical care, 82% to 83% say they need and asked for it, 96% say they received since they knew they were infected, and 92% report receiving it last year.
- Among risk populations, IDUs are more likely to ask and receive primary care. While all populations say they have received more services than they ask for since they were positive, heterosexuals say they asked for more primary care than they received <u>last year.</u>
- Among the different regions, PLWH/A in the South is more likely to need and ask for primary care, but less likely to have received services <u>last year</u>.
- Among ethnic population, Latinos (87.0%) say they need and asked for more primary care than other populations.
- Among stages of infection, asymptomatic PLWA report greater need, but are less likely to ask for services than PLWH (not AIDS) or those PLWA who are symptomatic. Despite lower requests for services, they are more likely to report receiving services.
- PLWH/A have, on average 10.3 visits a year to outpatient clinics. As expected, those symptomatic PLWA report a greater number of visits (15.5) while those in other stage report between 7.5 and 7.9 visits.

Visits to medical specialists such as skin, eye, intestinal tract, feet. (not OB/GYN)

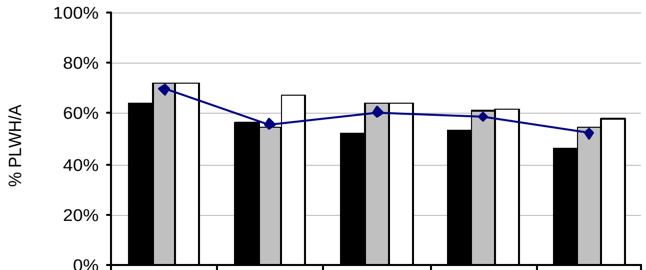


	Available	Need	Asked	Received ever	Received last year
■ Male	70.3%	57.6%	61.1%	59.9%	52.9%
▨ Female	66.0%	47.9%	58.1%	55.3%	48.3%
□ MSM	69.6%	54.2%	59.1%	58.6%	52.8%
▨ IDU	74.7%	66.0%	71.2%	67.8%	44.0%
▨ HET	64.5%	49.4%	52.7%	52.5%	47.5%
◆ Total	69.6%	56.1%	60.6%	59.2%	52.2%

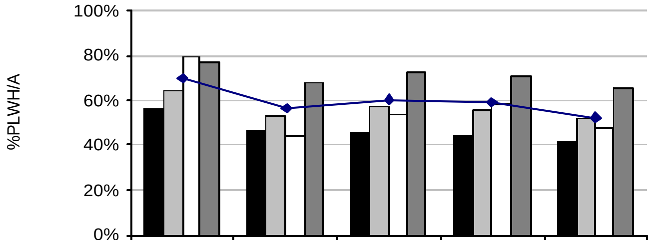


	Available	Need	Asked	Received ever	Received last year
■ Central	70.8%	51.1%	62.7%	61.0%	60.0%
▨ North	64.7%	52.9%	48.4%	51.6%	46.0%
□ South	65.6%	66.7%	65.0%	58.3%	42.8%
◆ Total	69.6%	56.1%	60.6%	59.2%	52.2%

	Average # Past Year
Sample	**5.6**
Male	5.8
Female	4.1
MSM	5.9
MSM/IDU	4.4
IDU	4.2
HET	8.1
Af Am	4.5
Anglo	6.1
Latino	4.9
Central	11.8
North	8.6
South	9.6
H asymp	7.5
H symp	7.7
A asymp	7.9
A symp	15.5



	Available	Need	Asked	Received ever	Received last year
■ Af Am	64.6%	56.9%	52.7%	53.7%	46.4%
▨ Anglo	72.0%	55.0%	64.3%	61.7%	54.7%
□ Latino	72.1%	67.5%	64.7%	62.3%	58.2%
◆ Total	69.6%	56.1%	60.6%	59.2%	52.2%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	56.3%	46.4%	45.4%	44.0%	41.6%
▨ H Symp	64.2%	53.1%	56.8%	55.6%	51.7%
□ A Asymp	79.1%	44.2%	53.5%	58.1%	47.7%
▨ A Symp	77.2%	67.5%	72.2%	71.4%	65.5%
◆ Total	69.6%	56.1%	60.6%	59.2%	52.2%

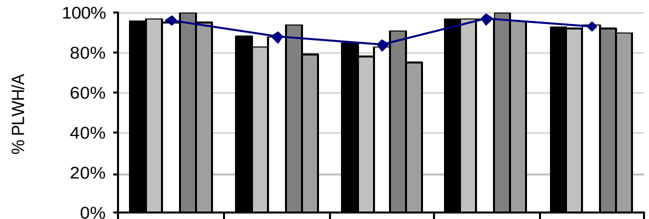
Top Barriers

- The location of the organization providing services.
- Not knowing what service is available to me.
- My physical health.
- Not having transportation.
- The amount of time I had to wait to get an appointment or see someone.

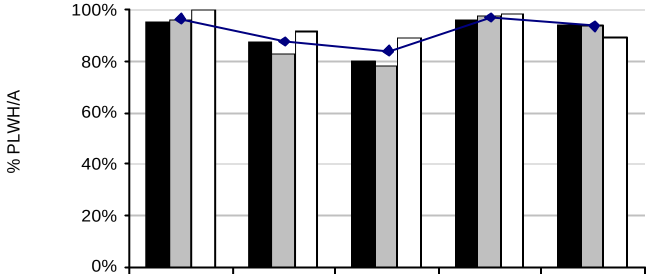
Highlights

- Specialist care is a subcategory of outpatient care that ISDH ranked as their third highest priority. PLWH/A rank care from medical specialists as their 12th most needed service.
- On average, about 70% of the PLWH/A know about accessing medical specialists, about 60% say they need, have asked for, and received care from medical specialists. Last year, about 52% report receiving care from medical specialists.
- For the PLWH/A who use specialist services, they report about 7 specialist visits a year. Symptomatic PLWA report substantially more visits.
- Among risk groups, IDUs are more likely to need, ask for, and ever receive care from medical specialists. In the last year, they are least likely to report needing specialist care.
- Among the regions, PLWH/A in the Central and North regions report needing less specialist services than those in the South. while those in the South report needing more. Those in the South report asking for more care from medical specialist than they received.
- Among racial/ethnic groups, African Americans report less knowledge about care by medical specialists, and they are less likely to ask for and receive care from specialists than other ethnic groups. Latinos express less need for specialists and report receiving less care from medical specialists.
- Among stages of infection, not surprisingly, knowledge, need, demand, and utilization are highest among symptomatic PLWA. Those PLWH who are symptomatic are slightly more likely to ask for and receive services last year than asymptomatic PLWA.

Lab Tests for Monitoring Infection (e.g. Viral Loads or T-cell counts)

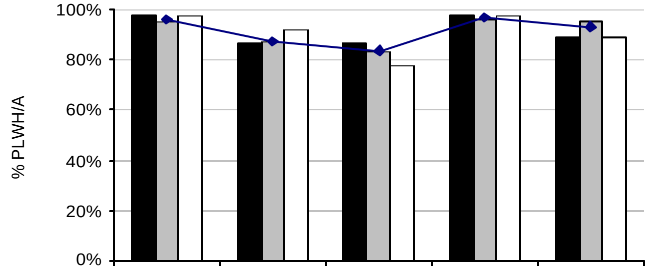


	Available	Need	Asked	Received ever	Received last year
■ Male	96.1%	88.3%	85.0%	97.1%	93.5%
▨ Female	96.9%	83.3%	78.6%	96.9%	92.5%
□ MSM	95.8%	87.8%	83.4%	97.0%	93.7%
▨ IDU	100.0%	94.3%	90.8%	100.0%	92.2%
▨ HET	95.4%	79.7%	76.0%	96.0%	90.3%
◆ Total	96.2%	87.5%	84.0%	97.1%	93.3%

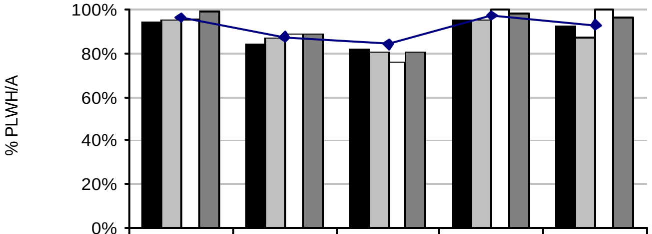


	Available	Need	Asked	Received ever	Received last year
■ Central	95.6%	87.8%	80.0%	96.1%	94.2%
▨ North	96.2%	83.2%	78.2%	97.4%	93.9%
□ South	100.0%	91.9%	88.7%	98.4%	89.4%
◆ Total	96.2%	87.5%	84.0%	97.1%	93.3%

	Average # Past Year
Sample	**7.1**
Male	7.2
Female	6.6
MSM	7.6
MSM/IDU	5.6
IDU	7.4
HET	5.1
Af Am	6.9
Anglo	7.2
Latino	7.2
Central	11.8
North	8.6
South	9.6
H asymp	7.5
H symp	7.7
A asymp	7.9
A symp	15.5



	Available	Need	Asked	Received ever	Received last year
■ Af Am	98.0%	86.8%	86.6%	98.2%	89.1%
▨ Anglo	95.3%	87.5%	83.4%	96.5%	95.7%
□ Latino	97.9%	92.4%	77.6%	97.9%	89.2%
◆ Total	96.2%	87.5%	84.0%	97.1%	93.3%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	94.5%	84.0%	82.2%	95.2%	92.1%
▨ H Symp	95.1%	86.6%	80.2%	95.1%	87.2%
□ A Asymp	95.6%	88.9%	75.6%	100.0%	99.9%
▨ A Symp	99.2%	89.0%	80.3%	98.4%	96.4%
◆ Total	96.2%	87.5%	84.0%	97.1%	93.3%

Top Barriers

- Not knowing what service is available to me.
- My physical health.
- The amount of red tape and paperwork I had to fill out to get the service.
- The location of the organization providing services.

Highlights

- Labs tests fall under outpatient care, and PLWH/A say it is their 4th most important service.
- On average, 96% of PLWH/A know about lab tests, 84% report asking for and 97% report ever receiving lab tests. 93% report receiving lab tests last year.
- On average, PLWH/A report 7 lab tests a year. As expected PLWH/A who are symptomatic receive more lab tests. Those in the Central area report more lab tests than other regions. Heterosexuals report the least number of lab tests.
- Among risk groups, heterosexuals report the lowest need for lab tests, but they are equally likely to receive them as other risk groups.
- Among ethnic populations, Latinos are much less likely ask for lab tests, but are just slightly less likely to receive them.

Outpatient Care Qualitative Comments

Participants of the focus groups confirmed the importance of outpatient care, and highlighted some of the barriers such as knowledge, the amount of red tape or waiting time. A Central African American MSM/IDU said, *"My number one concern would be appointments with doctors, nurses or assistance in an office or clinic. I had Medicaid with no spend down for 10 years. My Medicaid lapsed, because of an infraction in the mail or whatever and I moved, so I lost Medicaid, so I applied for Advantage at Wishard. They don't have infectious disease doctors on staff; they just have internal medicine in an infectious disease clinic. Getting appointments can be quite a while, anywhere from two to four weeks for an appointment. What really makes the ball roll are the nurse practitioners and the people that work under the doctors. The doctors simply see you when they can see you."*

Ability to see local doctors and levels of expertise were issues for PLWH/A. A Southern Anglo female said, "*I demanded to see a doctor here, and I started going to someone in Terre Haute. She had moved to Bloomington, and then I went to my regular doctor. I'm very satisfied with him, and I feel that no matter where you're at, you should be able to go to a doctor. You shouldn't have to travel to Indianapolis or Chicago or anywhere else. You should be able to stay within 15 miles of your home."* But an Anglo male in the same group didn't think this was possible. He said, "*Medical services are not familiar with dealing with HIV in this area. If you go to Indianapolis, you can get these services, but here locally in Terre Haute, it's practically impossible."* A Northern African American MSM brought up the quality of the medical care he receives. He said, *"We've had six or seven different doctors since '95. It seems as though here they are not as prepared. … A lot of it is that a lot of the doctors that treat HIV patients aren't HIV specialists, and they are learning as they go."* Another African American MSM added, "*The doctors need more HIV education as well as the consumers. That's another thing that we need to get to the doctors is more education about transmission and how to be more passionate to consumers when they come to the office for services."*

PLWH/A in the veterans system discussed the experience of doctors. A Southern Anglo MSM said, *"I am a Vietnam Veteran and I had medical services at the VA hospital. They don't have an HIV doctor there anymore. So they don't have the same program. I almost didn't make it through an appendectomy in March. My appendix was full of gangrene and it almost burst before they got in. I was in the VA hospital and they didn't catch the symptoms because they didn't have an HIV doctor available. That's why the Task Force put me on the state program so that I can go to the right doctors. That was a big scare. I almost didn't come out of the hospital."*

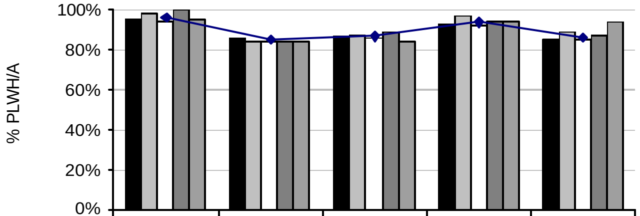
Integration of general health care with HIV care was a concern of several participants. An Anglo female IDU said, *"They go by what the blood work says. Any doctor could do that. Seeing that she's our doctor, she should be doing the other things that a regular would do not just take care of the HIV and the infections that set in."* An Anglo male in the same group said, "*When you go to this doctor's office that she is talking about, it is made very clear to you that they are handling the infectious disease, period.*

They don't want to be called with a cold. They told me that straight out. 'Don't call me. You've got to have a general doctor. We are too busy with our people.'"

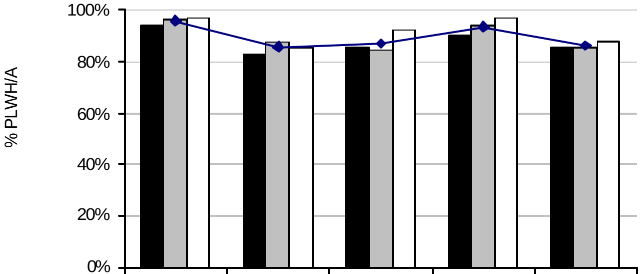
A few of the women made a point of saying that their OB/GYN did have enough experience and knowledge of HIV treatment. A Northern Anglo hemophilic female said, *"For women there are limited services i.e. OB/GYN, Oncology specialist. They do not know a lot about special issues. There is a lot of stigma prejudice when it comes to services in Indiana. You have to hope that the doctors know what they are doing to you."* A Central Anglo female said, *"I had a gynecologist that didn't know what AZT was so she dismissed me."*

For lab tests, a few participants in the focus groups commented on lack of quality in the labs. A Southern Anglo female said, *"I did have a lot of trouble with the lab when they went to do my blood work. They have messed up over six times with just drawing my blood and different things."* An Anglo male in the same group concurred by saying, *"I also have the same problem with lab work incompetence. I go to a different lab. A viral load is supposed to be refrigerated but they will not have done that, so they have to redraw. Problems like this plus waiting around an hour, hour and a half, to get your lab work done."*

Case Management

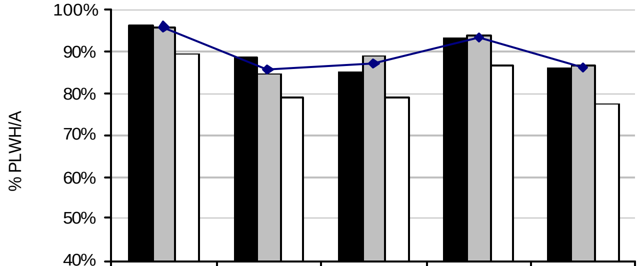


	Available	Need	Asked	Received ever	Received last year
▬ Male	95.5%	85.9%	87.2%	93.0%	85.7%
▭ Female	98.2%	85.0%	87.9%	97.2%	89.5%
▭ MSM	94.7%	84.7%	86.2%	92.4%	85.8%
▬ IDU	100.0%	84.9%	89.0%	94.7%	88.0%
▬ HET	95.5%	84.6%	84.4%	94.5%	94.0%
—◆— Total	95.9%	85.8%	87.3%	93.6%	86.3%

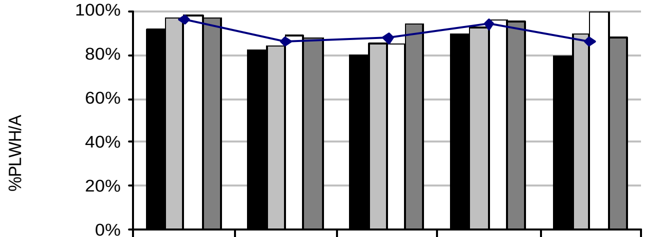


	Available	Need	Asked	Received ever	Received last year
▬ Central	93.9%	82.8%	85.6%	90.6%	86.0%
▭ North	96.2%	87.7%	84.6%	94.2%	85.9%
▭ South	96.8%	85.7%	92.1%	96.8%	87.9%
—◆— Total	95.9%	85.8%	87.3%	93.6%	86.3%

	Average # Past Year
Sample	**9.7**
Male	9.5
Female	11.2
MSM	9.5
MSM/IDU	8.7
IDU	10.6
HET	11.7
Af Am	11.5
Anglo	9.0
Latino	6.8
Central	10.4
North	8.6
South	10.3
H asymp	9.4
H symp	8.9
A asymp	11.4
A symp	10.0



	Available	Need	Asked	Received ever	Received last year
▬ Af Am	96.5%	88.8%	85.0%	93.4%	86.1%
▭ Anglo	96.1%	84.7%	89.0%	94.4%	87.0%
▭ Latino	89.6%	79.2%	79.2%	86.8%	77.6%
—◆— Total	95.9%	85.8%	87.3%	93.6%	86.3%



	Available	Need	Asked	Received ever	Received last year
▬ H Asymp	91.7%	82.1%	80.0%	89.7%	79.5%
▭ H Symp	96.4%	84.1%	85.4%	92.7%	89.4%
▭ A Asymp	97.8%	88.9%	84.4%	95.6%	99.0%
▬ A Symp	96.9%	87.4%	93.8%	95.3%	88.1%
—◆— Total	95.9%	85.8%	87.3%	93.6%	86.3%

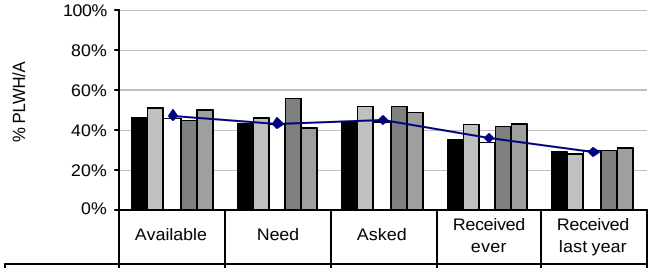
Top Barriers

- The level of expertise of the person providing the service.
- Not knowing what service is available to me.
- Not having transportation.
- Poor coordination among the organizations providing services.
- The location of the organization providing services.
- The quality of service.

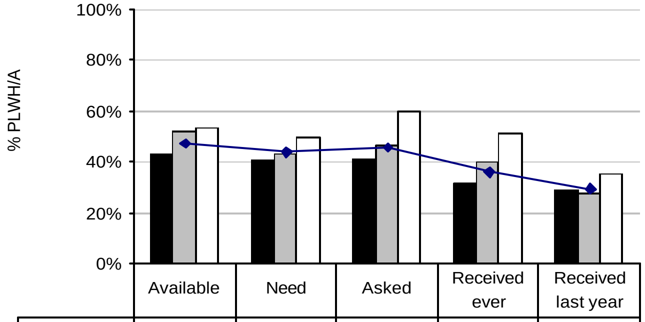
Highlights

- Case Management is ranked fourth most important by the ISDH and fifth by PLWH/A.
- On average, PLWH/A report nearly 10 case management sessions a year. Females report more sessions than males, and symptomatic PLWA report more sessions than those living at other stages of illness.
- Typically PLWH/A receive more case management than they ask for, particularly females and heterosexuals.
- Overall, case management is highly available, needed, asked for, and accessible for all PLWH/A despite their sex, race, locality, disease status and risk group.
- Among ethnic groups, Latinos report less knowledge about case management services, and they are less likely to ask for and receive the service than other ethnic groups. Latinos express less need for the service, and report receiving the less case management services. Latinos also report having received the lowest level of services during the past year.
- Notably, a larger proportion of symptomatic PLWA report receiving case management than those at other stages of illness.

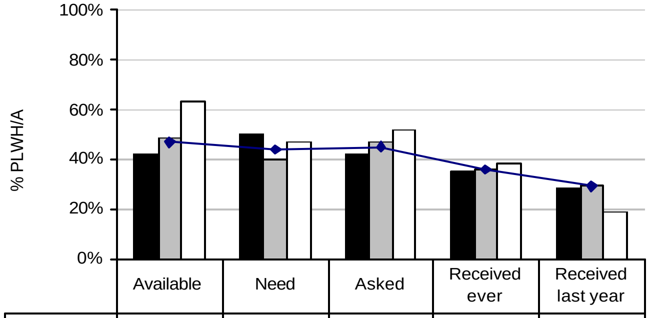
Assistance in getting medical services or drugs that your health insurance does not cover



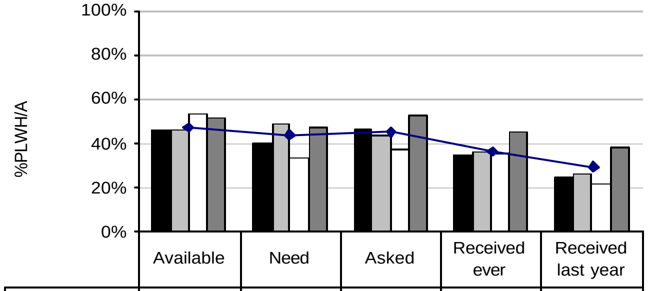
	Available	Need	Asked	Received ever	Received last year
▬ Male	46.5%	43.2%	44.2%	34.8%	29.3%
▭ Female	51.2%	46.5%	51.7%	42.9%	28.4%
▭ MSM	46.1%	43.7%	44.1%	33.7%	29.7%
▬ IDU	44.7%	55.4%	51.6%	41.8%	29.9%
▬ HET	50.1%	41.5%	49.2%	43.2%	31.3%
◆ Total	47.2%	43.7%	45.3%	36.0%	29.2%



	Available	Need	Asked	Received ever	Received last year
▬ Central	43.3%	41.0%	41.6%	32.0%	28.6%
▭ North	52.2%	42.9%	46.8%	39.9%	27.2%
▭ South	53.2%	50.0%	60.0%	51.7%	35.6%
◆ Total	47.2%	43.7%	45.3%	36.0%	29.2%



	Available	Need	Asked	Received ever	Received last year
▬ Af Am	41.9%	49.9%	41.9%	35.5%	28.7%
▭ Anglo	48.9%	40.5%	46.7%	36.1%	30.1%
▭ Latino	63.3%	46.9%	51.6%	38.2%	19.0%
◆ Total	47.2%	43.7%	45.3%	36.0%	29.2%



	Available	Need	Asked	Received ever	Received last year
▬ H Asymp	45.9%	40.6%	46.5%	34.8%	24.7%
▭ H Symp	45.8%	48.8%	43.9%	36.6%	26.4%
▭ A Asymp	53.3%	33.3%	37.8%	35.6%	21.8%
▬ A Symp	51.6%	47.2%	52.4%	45.2%	38.2%
◆ Total	47.2%	43.7%	45.3%	36.0%	29.2%

	Average # Past Year
Sample	**4.4**
Male	4.4
Female	4.5
MSM	4.6
MSM/IDU	3.4
IDU	4.9
HET	3.2
Af Am	4.5
Anglo	4.3
Latino	6.0
Central	5.1
North	3.3
South	4.5
H asymp	3.1
H symp	4.2
A asymp	3.9
A symp	5.5

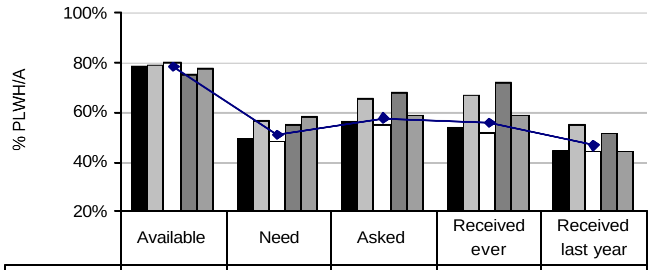
Top Barriers

- The cost of the service to me.
- Not having enough insurance coverage.
- Not being eligible to obtain services because of rules and regulations.
- The amount of red tape and paperwork I had to fill out to get the service.

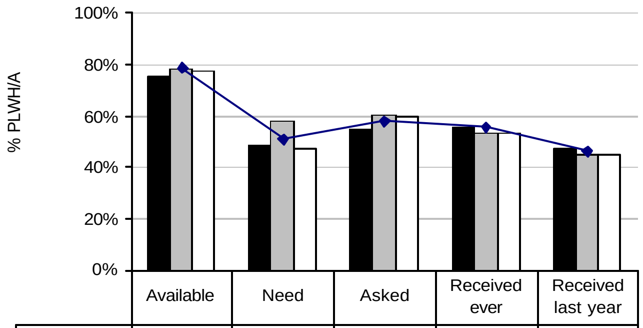
Highlights

- PLWH/A say that assistance getting medical services that is not covered by their insurance is a among their top priorities. Classified as a component of case management, it is ISDH's fourth highest priority.
- Assistance getting medical services not covered by insurance has one of the highest gaps, where more PLWH/A ask for the service than receive it.
- On average, about half of PLWH/A know assistance getting services that health insurance does not cover is available, and less than half say they need it. 45% ask for this service, and 36% report receiving it, creating on of the largest gaps in services.
- On average, PLWH/A who access the service, receive over 4 sessions a year. Latinos and symptomatic PLWA are more likely to get more sessions.
- Among sex and risk groups, IDUs are more likely to need assistance in getting medical services or drugs not covered by health insurance. Females are more likely than males to ask for and receive assistance in getting medical services or drugs not covered by health insurance.
- PLWH/A in the South say they are more likely to ask for and receive assistance in getting medical services or drugs not covered by health insurance.
- Among ethnic populations, African Americans say their need is higher than Anglos and Latinos, but all populations report about the same utilization. Latinos say they received less services than other ethnic populations during the past year.
- Symptomatic PLWA are much more likely to ask for and receive this service.

Referral to services

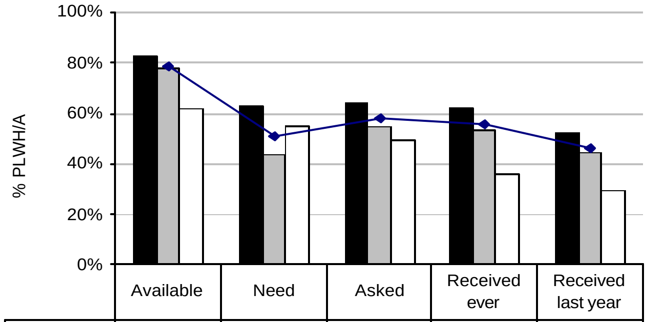


	Available	Need	Asked	Received ever	Received last year
Male	78.5%	49.5%	56.4%	54.0%	44.7%
Female	79.3%	57.2%	65.7%	66.7%	55.3%
MSM	80.5%	48.1%	55.2%	51.8%	43.7%
IDU	75.3%	55.2%	68.2%	72.1%	51.4%
HET	77.8%	58.4%	58.6%	58.6%	44.1%
Total	78.6%	50.6%	57.8%	55.9%	46.3%

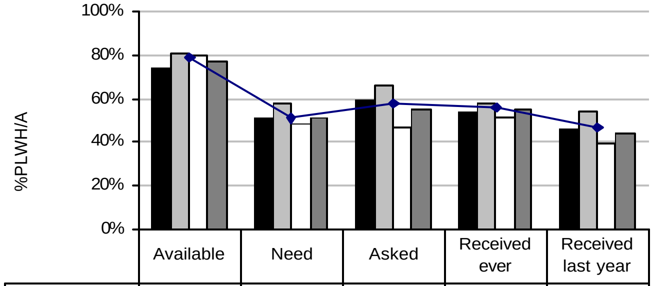


	Available	Need	Asked	Received ever	Received last year
Central	76.0%	48.3%	55.1%	55.6%	47.6%
North	78.2%	57.8%	60.1%	53.2%	45.1%
South	77.4%	47.5%	59.7%	53.2%	44.7%
Total	78.6%	50.6%	57.8%	55.9%	46.3%

	Average # Past Year
Sample	**4.2**
Male	4.0
Female	4.8
MSM	3.8
MSM/IDU	6.3
IDU	3.7
HET	3.9
Af Am	5.7
Anglo	3.3
Latino	3.7
Central	4.6
North	4.0
South	3.1
H asymp	4.5
H symp	4.0
A asymp	4.9
A symp	3.8



	Available	Need	Asked	Received ever	Received last year
Af Am	82.4%	62.9%	64.4%	62.5%	52.4%
Anglo	77.7%	44.0%	54.7%	53.6%	44.1%
Latino	61.5%	55.0%	49.9%	36.0%	29.1%
Total	78.6%	50.6%	57.8%	55.9%	46.3%



	Available	Need	Asked	Received ever	Received last year
H Asymp	73.6%	50.7%	58.7%	53.5%	45.6%
H Symp	80.7%	57.3%	65.9%	57.3%	54.5%
A Asymp	80.0%	47.7%	46.7%	51.1%	39.9%
A Symp	77.0%	50.8%	54.8%	54.8%	43.8%
Total	78.6%	50.6%	57.8%	55.9%	46.3%

Top Barrier

Insufficient response rate on this service

Highlights

- Referral to services is categorized under case management, which is ranked the fourth highest priority by ISDH. PLWH/A rank overall case management as a very high priority, but rank referrals as much lower.
- On average there is no perceived gap between the percent of PLWH/A who ask and receive referrals, but IDUs tend to say they receive more referral services than they ask for, and those PLWH/A who live in the North say they receive less referral services than they ask for.
- On average, females (57.2%) are more likely to need referral to services than males (49.5%), females (65.7%) are also likely to inquire for referral than males (56.4%). In addition, females (66.7%) rank higher than males (54.0%) in service accessibility.
- MSM rank highest in needing, asking and receiving assistance compared to IDUs and heterosexuals.
- African Americans (63.0%) and Latinos (60.0%) rank higher in requiring referral to services than Anglos (44.0%). They are also more likely to ask and receive the service than Anglos.
- Overall, symptomatic PLWH rank highest in needing, inquiring and receiving referral to services than other PLWH/A, while asymptomatic PLWA rank lowest in needing, asking and receiving referrals to services.

Case Management – Qualitative Comments

PLWH/A have varying feelings toward their case manager. It often depends on the individual and relationship that develops between the case manager and the PLWH/A. For example, a Central Anglo MSM expressed how his case management didn't make him feel like a number. He said, *"My case manager was the one that helped me find a way for me to get my medical care beyond that initial insurance program. I haven't seen my doctor maybe once, but that is okay with me, because I am getting my care done. I don't need that direct physician involvement. The main thing is I feel a part of and in control of my care. It is not being dictated to me. And they assist me in what my needs are and not just we are going to do this or that. They also helped me get dental care and eye care, so I mean it is there if I want it and they help me find ways, they reach out and do those things. They are proactive. And they kind of let me take my options. You know, they didn't chase me down."*

Participants in a Southern focus group of Anglo males were very pleased with their case management. One said, *"Well, my case manager, she helps me out a lot, and I really love her to death. When I need something, I can call her up and ask her, and she will do what she can to help me out. It may take a couple days, but she comes around for me. I want to stay with her. I don't want to change to anybody else."* Another said, *"My case manager has been very helpful, and the staff that works up there has been great to me."* And another said, *"My case manager has been, for what I've needed, has always been there. This whole thing that I talked earlier about on the insurance and the bills and stuff getting paid, there's really nothing that she can do. She's just getting her information from a bigger organization that we are affiliated with I guess. I think she's trying everything that she possibly can do right up to the point of, 'Well, why don't you call. I've talked to them.'"*

A Northern African American male said, *"The guys of [the ASO] were good to me. I have to say, the guy that helped me is still there. They really helped me get my disability through real quick; they really helped me do what I had to do."*

There was recognition that some ASO, and the case manager, was responsible for some difficulties. An Anglo male said, *"I think that any other problems I have are stemmed from xxxxxx, but they put the blame somewhere else. …It's in their office where the problem is. At the beginning I believed them when they'd say, ….'Your case worker didn't mail that to us.' I don't believe that anymore. I believe it's been sitting on your desk for a month and a half and [they] just haven't chosen to do anything with it. It's like the care coordinators have their hands tied behind their back, because all the programs that are available to us stem from somewhere else, and they have no control over what's going on. They feel awful, because they're supposed to be there for us, but they can't do anything for us."*

Another Southern Anglo male in the same group said, *"There are not enough case managers. They've told us that the reason why there aren't enough case managers for all the people is because they don't have the funding to pay more case managers."*

There were a fair number of participants that felt care coordination did not work. A Central Anglo MSM said, *"I have no idea who my care coordinator is.* A Southern Anglo male said, *"Care coordination seems to be totally useless in my opinion. …This has been going on for years and nothing ever changes. Care coordination - there is no coordination."* A Central African American MSM said, *"I don't have a case manager because I don't need one. I had them but they didn't do anything. I did it myself, so why have them. I don't need them; it's a waste of time. Somebody else can use them and take two or three years to get what they need. I don't need it, no."*

An Anglo MSM was more ambivalent, *"The case managers don't always know their job.* But he acknowledged, *"If it wasn't for a care coordinator that is no longer at the [large ASO] now, if she hadn't taken the time to investigate what was available to me, what I could and could not qualify for, I would not have ICHIA now."* A Central African American MSM said, *"I needed to go to the hospital and they would not give me the medical treatments I needed because they said that I had a $250 deductible to meet. I did not have the money so I cannot get the treatment… I have asked for help at Aliveness but they really do not know how to help either, it is very confusing to me."*

While some participants felt that a problem with case managers that they were not more pro-active, others felt that the obligation to contact the case manger should rest with the PLWH/A. For example a Northern African American female said, *"The ASO should be there for us. They are right there, and they know you are suppose to be at that place, they call you to tell you that you should be aware of your appointments. The case worker should be working harder for you and handling your appointments and transportation arrangements."* On the other hand, a Northern African Male said, *"If I want to know if there is something new, I can call them and find out; I don't wait until they tell me."*

Consistency of case management and experience of case managers was a problem discussed by PLWH/A. A Central MSM said, *"I'm a long term survivor. I've gone through four counselors and the latest one I got the other day is like twenty years old. What did she do, read two books? You are going to tell a fifty-seven year old man what he should be doing? She said, 'Well we are just here to facilitate for you.' And I said to myself, 'Okay. How will that work for me.' And I told her, 'Well okay, if you are my new Care Coordinator, I will work with you.' My youngest kid is 32 so what am I going to do with a 20 year old now? So that kind of scares me but I guess that is what you are going to have to live with if you are a long-term survivor. So I shouldn't be complaining. I mean people were dropping like flies years ago."*

Another issue that some PLWH/A mentioned is that a lot of decisions are based on the discretion of the case manager. A Central Anglo MSM said, *"I think care coordination sites should have to be more upfront about what is going on in their facilities so they don't have the choice to play God over who gets what benefits. The very critical thing especially about two care coordination sites* *that I know of, one in Bloomington and one here in Marion County, that care coordinators seem to choose who will and who will not get services."*

Medical case management was a need expressed by several participants in the focus groups. A Northern African American MSM said, *" I need someone to help people understand the medication that I am taking and the possible side effects. All of this stuff that the doctors don't have time to explain and can't explain. A person to meet and explain to them how to take the medication, to take it or not take it with food, and help you try what is going to be most effective for you. Right now I always have to call a pharmacist to find out whether or not you can take this pill with that pill but they don't tell you nothing."*

Focus group participants did not, as a rule, speak highly of referral and coordination. A Central Latino MSM said, *"There are a lot of services in town that are available, but I didn't find out until someone else just mentioned it. So there are a lot of services, but I don't know how well they are being relayed to the community that they are out there. I think it may be a problem especially with the complicated system that we have here where so many different organizations are involved."*

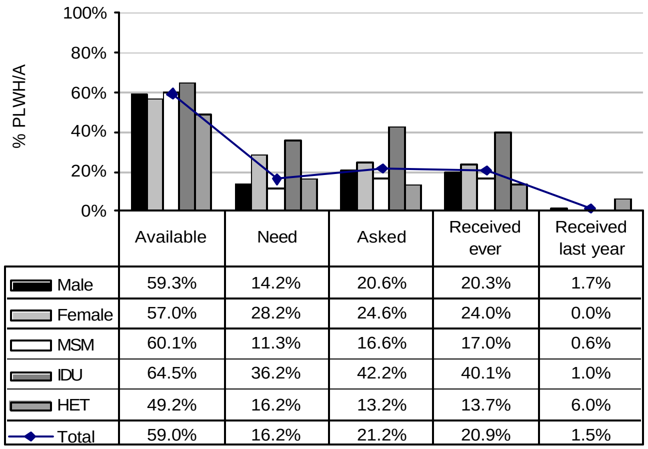
A Northern African American female said, *"I know just looking at the people in the community, I know these people are here and I know the activities that are going on in the neighborhood that would cause it to sky rocket. But I don't see the services. I don't see the outreach between the ASO and the churches, the schools, and the jobs."*

A more general complaint is the role case managers play as gatekeepers to benefits. A Northern African American MSM said, *"This message goes for every agency that works in any capacity. We are supposed to work for one government and one people. And I don't think it is fair that people, whether they are sick or whatever, of any race or any income status. If these people are in their agencies and doing their jobs, why does a person have to go to them to ask for these benefits. These benefits are available, make it known that they are available. I accept a lot of things. If I don't receive a lot of things, I make do. I know how to survive and get around. I ask for things - I just hope I don't wait to ask when it is too late. I have had to be so dependent on me so many times, I personally rely on that and so I do that. I just wish these agencies that are being funded so much money would just try harder. And these people that , if not for me but for someone else, if there is something that they need why would they have to be in a position to need it if the agency is in the position to provide it. And then when you ask for it, it is as if it is coming out of their personal pocket."*

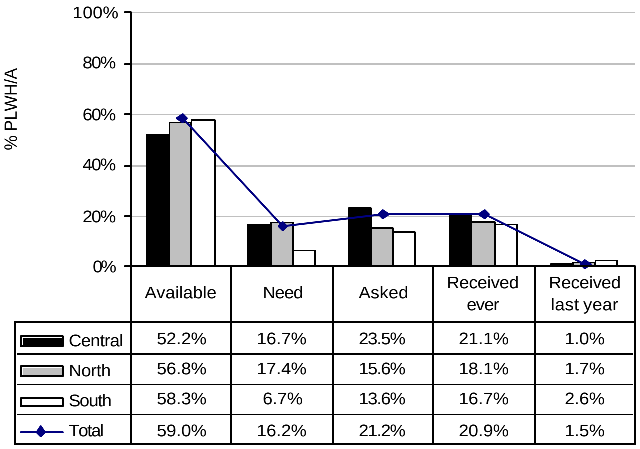
A frequently heard criticism was that case mangers have to be asked before they reveal benefits. A Northern African American MSM said, *"A lot of people don't know that certain types of services are here that will benefit you in the long run. If you don't ask nobody is going to tell you. It's just like a lot of times we walk around here, if we don't ask we don't think that somebody else has got it."* A Northern Anglo MSM said, *" I would really like to be informed of the services that are available to me. It's very* *aggravating to hear of things I qualify for from friends. Also it is very embarrassing to ask for some services."* A Southern African American heterosexual male said, *"I am not satisfied that the people that need the service don't ask or that people that are providing services are only giving what you need and nothing more."*

For many participants, it was not the lack of service, but the effort it took to access case management services. A Central Anglo heterosexual female said, *"I don't need a list of phone numbers for services. I get referrals to other places but the service is not available. Plus there is a lot of rules and regulations to get this or that - particularly through the needed assistance of your case worker. There are more and more days where I just can't get motivated. And there is no one you can call to say you are drained."*

Outpatient substance abuse treatment or counseling sessions

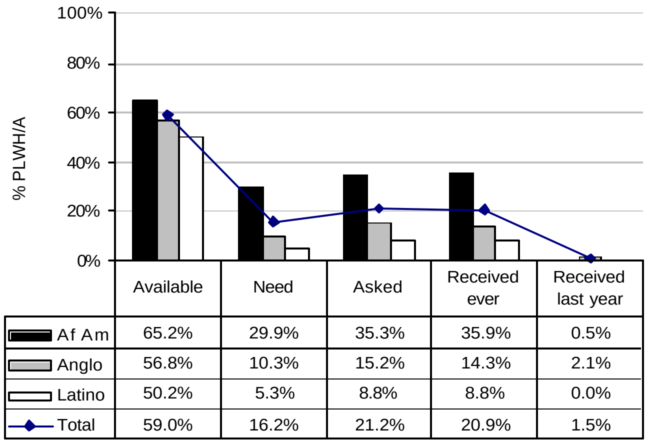


	Available	Need	Asked	Received ever	Received last year
■ Male	59.3%	14.2%	20.6%	20.3%	1.7%
▨ Female	57.0%	28.2%	24.6%	24.0%	0.0%
□ MSM	60.1%	11.3%	16.6%	17.0%	0.6%
▩ IDU	64.5%	36.2%	42.2%	40.1%	1.0%
▩ HET	49.2%	16.2%	13.2%	13.7%	6.0%
◆ Total	59.0%	16.2%	21.2%	20.9%	1.5%

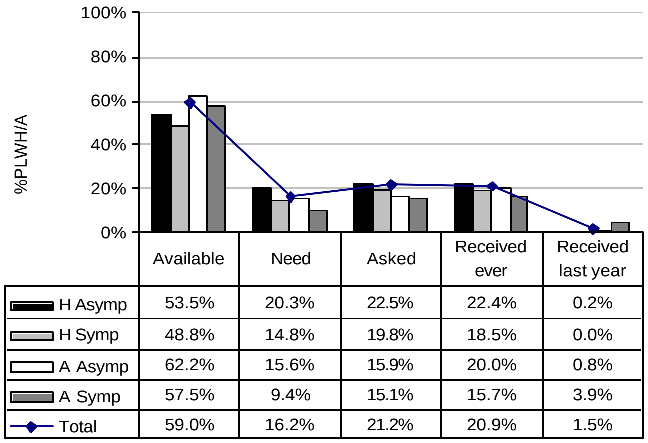


	Available	Need	Asked	Received ever	Received last year
■ Central	52.2%	16.7%	23.5%	21.1%	1.0%
▨ North	56.8%	17.4%	15.6%	18.1%	1.7%
□ South	58.3%	6.7%	13.6%	16.7%	2.6%
◆ Total	59.0%	16.2%	21.2%	20.9%	1.5%

	Average # Past Year
Sample	**17.6**
Male	16.2
Female	22.9
MSM	19.3
MSM/IDU	17.5
IDU	13.1
HET	15.0
Af Am	10.2
Anglo	26.6
Latino	9.3
Central	20.1
North	18.5
South	5.0
H asymp	22.7
H symp	10.2
A asymp	17.2
A symp	14.9



	Available	Need	Asked	Received ever	Received last year
■ Af Am	65.2%	29.9%	35.3%	35.9%	0.5%
▨ Anglo	56.8%	10.3%	15.2%	14.3%	2.1%
□ Latino	50.2%	5.3%	8.8%	8.8%	0.0%
◆ Total	59.0%	16.2%	21.2%	20.9%	1.5%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	53.5%	20.3%	22.5%	22.4%	0.2%
▨ H Symp	48.8%	14.8%	19.8%	18.5%	0.0%
□ A Asymp	62.2%	15.6%	15.9%	20.0%	0.8%
▩ A Symp	57.5%	9.4%	15.1%	15.7%	3.9%
◆ Total	59.0%	16.2%	21.2%	20.9%	1.5%

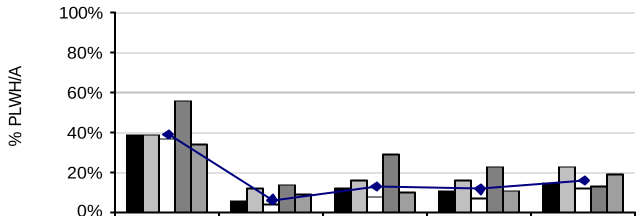
Top Barrier

Insufficient response rate on this service

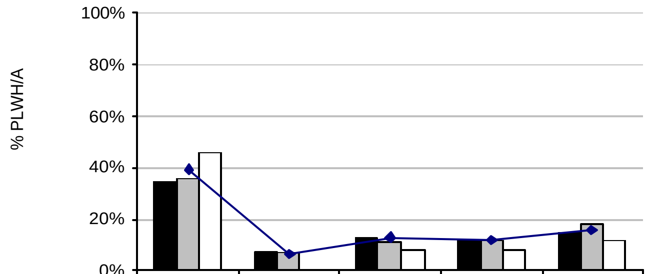
Highlights

- Outpatient substance abuse treatment or counseling sessions are categorized as part of substance abuse services and is ranked as the fourth service priority by ISDH. It is not ranked among the important services by PLWH/A.
- Overall almost 60% of PLWH/A perceive the service is available for them, but 16% indicate a current need. About 20% say they have asked for outpatient substance abuse services and have received them. Less than 2% say they have received them last year.
- The PLWH/A who use the outpatient substance abuse services say they attend, on average 18 sessions a year.
- Among sex and risk groups, over a third of the IDUs and a quarter of the females report a current need. About 40% of the IDUs and a quarter of the females report having received outpatient substance abuse services.
- Among ethnic populations, African Americans rank highest in needing, asking for and receiving outpatient substance abuse treatment. In the last year Latinos and African Americans report a drastic drop in service.

Substance Abuse treatment in a 24 hour a day residential setting

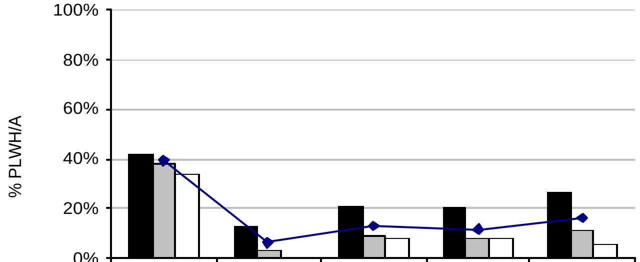


	Available	Need	Asked	Received ever	Received last year
Male	39.2%	5.3%	12.2%	11.0%	14.4%
Female	39.0%	12.3%	15.8%	16.1%	22.7%
MSM	36.6%	3.9%	7.3%	7.2%	12.4%
IDU	55.9%	13.5%	29.4%	22.9%	13.2%
HET	34.2%	9.1%	10.1%	10.3%	19.0%
Total	39.2%	6.3%	12.8%	11.8%	15.7%

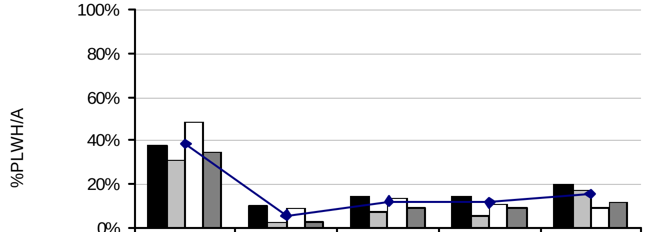


	Available	Need	Asked	Received ever	Received last year
Central	34.8%	7.9%	13.0%	11.8%	14.9%
North	35.7%	7.1%	11.0%	11.5%	18.3%
South	45.9%	0.0%	8.3%	8.2%	12.0%
Total	39.2%	6.3%	12.8%	11.8%	15.7%

	Average # Past Year
Sample	**35.7**
Male	19.8
Female	91.9
MSM	14.1
MSM/IDU	134.1
IDU	19.1
HET	12.4
Af Am	50.3
Anglo	19.3
Latino	31.0
Central	65.5
North	8.5
South	4.7
H asymp	47.8
H symp	69.9
A asymp	26.4
A symp	8.3



	Available	Need	Asked	Received ever	Received last year
Af Am	41.7%	13.0%	20.7%	20.1%	26.5%
Anglo	38.3%	3.4%	9.1%	7.9%	11.0%
Latino	34.0%	0.0%	8.3%	8.3%	5.3%
Total	39.2%	6.3%	12.8%	11.8%	15.7%



	Available	Need	Asked	Received ever	Received last year
H Asymp	38.2%	10.4%	14.7%	14.6%	20.2%
H Symp	31.3%	2.4%	7.3%	6.1%	17.1%
A Asymp	48.9%	8.9%	13.6%	11.1%	9.4%
A Symp	34.4%	3.2%	9.7%	9.6%	11.9%
Total	39.2%	6.3%	12.8%	11.8%	15.7%

Top Barrier

Insufficient response rate on this service

Highlights

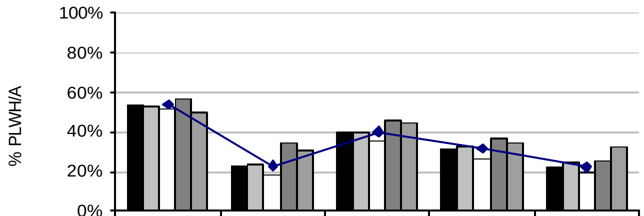
- Residential substance abuse treatment is categorized as part of substance abuse services which is ranked as the fourth service priority by ISDH. Like outpatient substance abuse services, it is not ranked among the important services by PLWH/A.
- Overall almost 40% of PLWH/A perceive the service is available for them, but 6% indicate a current need. About 12% say they have asked for residential substance abuse services and have received them. 16% say they have received residential substance abuse services last year.
- The PLWH/A who use the residential substance abuse services say they spend, on average, a little more than a month.
- Among sex and risk groups, under 15% of the IDUs and females report a current need. About 23% of the IDUs and a 16% of the females report having received residential substance abuse services.
- Among ethnic populations, African Americans rank highest in needing, asking for, and receiving residential substance abuse treatment.
- Asymptomatic PLWH/A tend to ask for and receive residential substance abuse treatment more the symptomatic PLWH/A.

Substance Abuse Treatment – Qualitative Comments

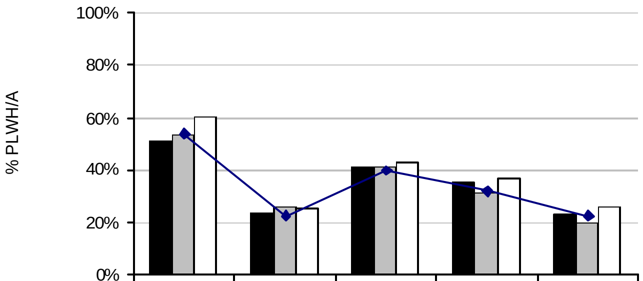
There were a surprisingly few comments by participants about substance abuse treatment in the focus groups. Some, like those an Anglo MSM, were complementary to the system. He said, "Th*e staff there, they are phenomenal. I went in for severe depression and drug and alcohol abuse. I have come a long ways. I didn't really want to do the group session, so now I am seeing them on a one-on-one basis, and they have no problem with that. It's being covered under my Medicaid."* Another Anglo MSM in the same group said, *"I requested help or information on substance abuse [from the large ASO] and I didn't have a problem getting that information. I mean somebody actually did return a phone call right away."* A Southern Anglo male said, "*When I was diagnosed, I was in drug rehab. Immediately the lady who gave the diagnosis, and she gave me a set of cards of names of people to contact. It was like it was so simple. It was like, oh okay. They'll help you. Then I got the help, which was great. I cried when I found out."*

From the comments, however, it seems like the care is dependent upon the facility. A Central MSM/IDU brought up the concern he had regarding his sexual orientation with previous substance abuse services. He said, *"I was sitting in a group and a guy said, 'Lesbian, well shoot the bitch.' There was no input from the facilitator. Of course I didn't want to say, 'I'm a fag with AIDS. If you are going to shoot a lesbian what are you going to do to me?' I simply quit going to the group. If I have to go to inpatient treatment I would go to Illinois. For outpatient, it's pretty limited if you are gay. With inpatient, I was discouraged from it."*

Assistance in finding or getting emergency or transitional housing

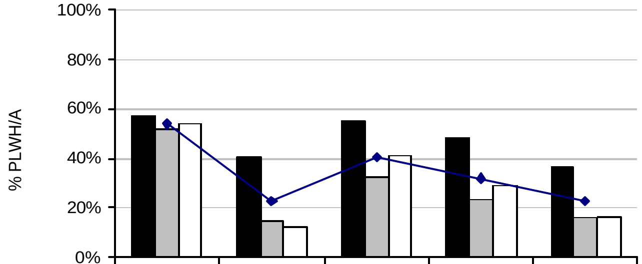


	Available	Need	Asked	Received ever	Received last year
Male	53.9%	22.7%	40.2%	31.5%	22.3%
Female	53.4%	24.0%	40.2%	33.0%	24.4%
MSM	51.8%	18.5%	35.2%	26.4%	19.8%
IDU	56.9%	34.5%	45.9%	36.7%	25.5%
HET	50.3%	30.8%	44.5%	34.9%	32.3%
Total	53.8%	22.9%	40.2%	31.7%	22.6%

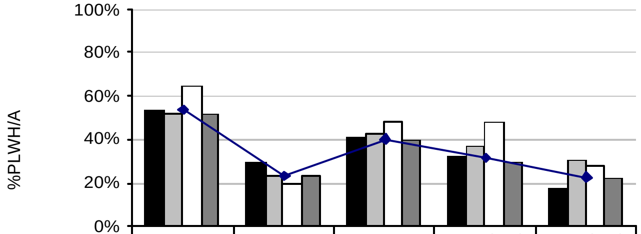


	Available	Need	Asked	Received ever	Received last year
Central	51.4%	24.0%	41.3%	35.4%	23.4%
North	53.2%	26.0%	41.4%	31.4%	20.1%
South	60.3%	25.4%	42.9%	37.1%	26.0%
Total	53.8%	22.9%	40.2%	31.7%	22.6%

	Average # Past Year
Sample	**2.4**
Male	2.4
Female	2.4
MSM	2.8
MSM/IDU	1.4
IDU	2.5
HET	1.4
Af Am	2.3
Anglo	2.5
Latino	3.4
Central	2.4
North	2.3
South	2.5
H asymp	2.1
H symp	2.4
A asymp	2.4
A symp	2.7



	Available	Need	Asked	Received ever	Received last year
Af Am	56.8%	40.7%	55.1%	48.2%	37.1%
Anglo	52.3%	14.6%	32.7%	23.5%	15.7%
Latino	54.1%	12.1%	41.3%	28.9%	16.4%
Total	53.8%	22.9%	40.2%	31.7%	22.6%



	Available	Need	Asked	Received ever	Received last year
H Asymp	53.4%	29.9%	40.6%	32.2%	17.9%
H Symp	51.8%	23.2%	42.7%	36.6%	30.2%
A Asymp	64.4%	20.0%	48.9%	47.7%	28.2%
A Symp	51.2%	23.0%	39.2%	29.6%	21.6%
Total	53.8%	22.9%	40.2%	31.7%	22.6%

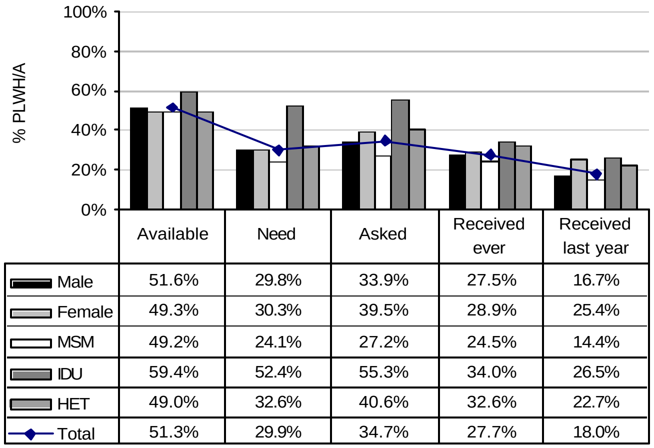
Top Barriers

Insufficient response rate on this service

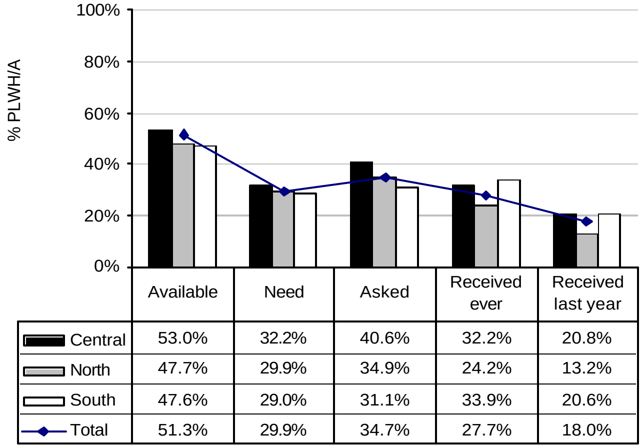
Highlights

- Housing assistance is the 6th priority of ISDH, but finding emergency or transitional housing is not among the perceived top need of PLWH/A.
- On average, over half the PLWH/A know that assistance finding emergency and transitional housing is available, 23% say they currently need it. 40% have ever asked for it, and 32% have ever received it. 23% reported receiving it last year.
- PLWH/A ask for more emergency or transitional housing than they receive.
- On average, PLWH/A who receive the service, say they go to between 2 and 3 sessions.
- Among the sex and risk groups, IDUs and heterosexuals express greater need, ask for, and are more likely to receive services than MSM or females.
- There are not strong regional differences.
- Among ethnic populations, African Americans have about the same awareness as other populations, but express a higher need. They ask for and receive more emergency or transitional housing than other populations. Anglos report the lowest need.
- Assistance with transitional housing appears to have decreased for all groups over the last year, and is more likely to be asked for and received by asymptomatic PLWA.

Assistance in finding or getting long-term independent housing

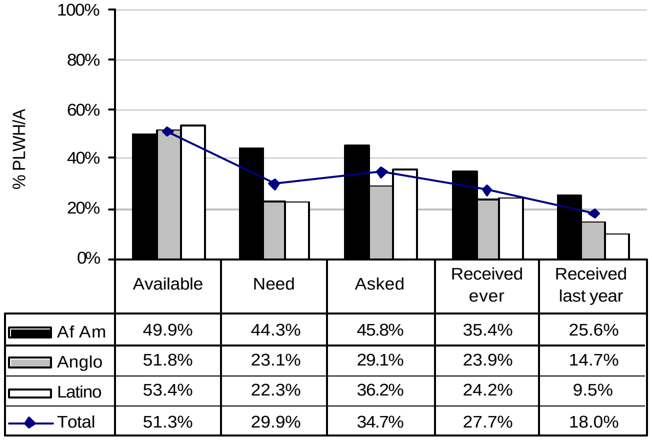


	Available	Need	Asked	Received ever	Received last year
■ Male	51.6%	29.8%	33.9%	27.5%	16.7%
▒ Female	49.3%	30.3%	39.5%	28.9%	25.4%
□ MSM	49.2%	24.1%	27.2%	24.5%	14.4%
▓ IDU	59.4%	52.4%	55.3%	34.0%	26.5%
▨ HET	49.0%	32.6%	40.6%	32.6%	22.7%
◆ Total	51.3%	29.9%	34.7%	27.7%	18.0%

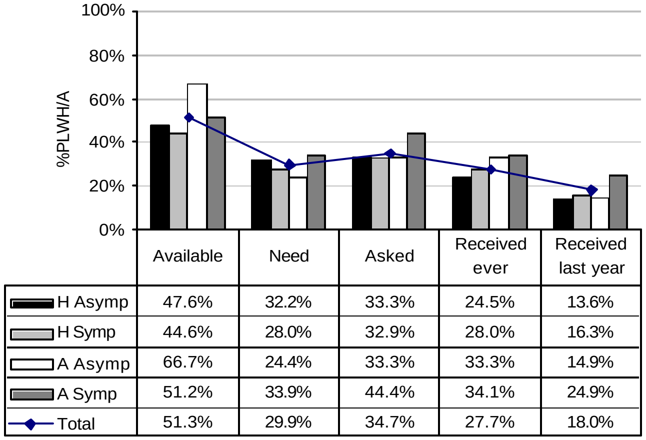


	Available	Need	Asked	Received ever	Received last year
■ Central	53.0%	32.2%	40.6%	32.2%	20.8%
▒ North	47.7%	29.9%	34.9%	24.2%	13.2%
□ South	47.6%	29.0%	31.1%	33.9%	20.6%
◆ Total	51.3%	29.9%	34.7%	27.7%	18.0%

	Average # Past Year
Sample	**3.8**
Male	3.7
Female	4.4
MSM	4.1
MSM/IDU	3.2
IDU	3.8
HET	3.4
Af Am	3.9
Anglo	3.9
Latino	1.8
Central	4.2
North	1.8
South	5.5
H asymp	1.8
H symp	2.9
A asymp	5.5
A symp	5.1



	Available	Need	Asked	Received ever	Received last year
■ Af Am	49.9%	44.3%	45.8%	35.4%	25.6%
▒ Anglo	51.8%	23.1%	29.1%	23.9%	14.7%
□ Latino	53.4%	22.3%	36.2%	24.2%	9.5%
◆ Total	51.3%	29.9%	34.7%	27.7%	18.0%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	47.6%	32.2%	33.3%	24.5%	13.6%
▒ H Symp	44.6%	28.0%	32.9%	28.0%	16.3%
□ A Asymp	66.7%	24.4%	33.3%	33.3%	14.9%
▓ A Symp	51.2%	33.9%	44.4%	34.1%	24.9%
◆ Total	51.3%	29.9%	34.7%	27.7%	18.0%

Top Barriers

- Not being eligible to obtain services because of rules and regulations.
- The amount of red tape and paperwork I had to fill out to get the service.
- The cost of the service to me.

Highlights

- Assistance finding long term housing is the sixth highest priority of ISDH, and among the top priority of PLWH/A.
- On average, 50% of PLWH/A perceive the service is available to them, and 30% of all PLWH/A say they need assistance finding and getting long term housing. About a third have asked for and over a quarter of PLWH/A have received some assistance since they were infected. 18% say they received assistance last year.
- On average, PLWH/A received 3.8 sessions of housing assistance. Symptomatic PLWH/A receive more sessions of service than asymptomatic PLWH/A. PLWH/A in the North report the fewest number of sessions each year.
- Assistance in finding or getting long-term independent housing has one of the largest gaps of all services, with far more PLWH/A asking but not receiving services.
- Among sex and risk groups, IDUs express a much greater need than other groups and are much more likely to ask for assistance. They also receive more assistance, but the gap between the percentages of IDUs asking and receiving assistance is large. MSM have the lowest need and fewer MSM receive assistance finding or getting long term housing.
- PLWH/A in the South express less need for assistance, but are more likely to receive assistance with long term housing. PLWH/A living in the center region have a far larger percentage asking than receiving long term housing services.
- Among ethnic populations, African Americans are more likely to report needing, asking for, and receiving assistance with long-term housing.
- PLWA who are symptomatic are most likely to feel that assistance is available to them, but they are much less likely to ask for assistance than PLWA who are symptomatic. About the same percentage of symptomatic and asymptomatic PLWA tend to receive assistance with long term housing.

Housing Assistance – Qualitative Comments

Several themes were emphasized in the focus group comments regarding housing. For those who obtained housing, many were complementary and grateful. For example, A Central Anglo heterosexual female said, *"I have lived in housing provided by the ASO that I paid 10% of my income. I liked that program a lot and if I could have stayed there longer I would have. But in getting the program, you had to say you would get on the waiting list for Section 8. So I was on the waiting list for two years and so they picked me up. The ASO however was flexible about the rent and what the total rent is. I was living in Clairmonte and it is a lot nicer than it is uptown in Indianapolis. When I lived there, my rent was $600 a month and all I had to pay was 10%. You just picked your own housing or apartment and they pay all but 10%. This was only available if you were living with HIV."*

On the other hand, for many looking for housing, the services did not meet their needs. A Northern Latino male said, *"There is no residence assistance for HIV/AIDS people. I would like to live independently. I live at home right now with my mom, dad, and little sister, but the time will come when they pass away, and then what will happen to me. The government needs to take care of us. Like in Puerto Rico there is a program where if you are HIV positive you can go and stay there and eat there, and get therapy. But here there is none of that and it is needed. In addition, here you get $500 on SSI, and my brother in Florida gets more, there he gets $800."* Another Latino in the same group said, *"I would like it if this program here could help us in that area. Help us to tell the government that the patients need a program, and they can do it because they have a lot of money. Help us with housing, because there are a lot of patients who are homeless and sleep on the streets and are afraid that people will find out they are positive. Once they are in a program, they will be least likely to be drug addicts, there will be less drug addiction, and crime, and infection. Such a type residence where we can have access to services."*

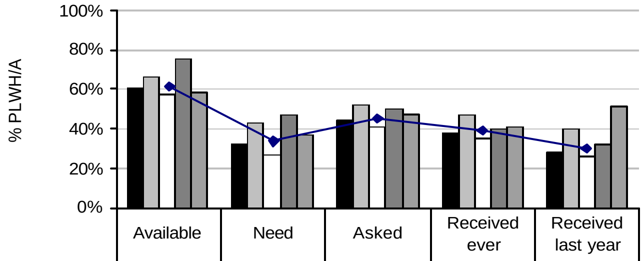
In part the reason may be lack of knowledge or difficult to access information. A Northern African American MSM said, *"I feel that the services that are here in xxxxxxx they should let people know about them. Like there is housing assistance that they can give to people. You could move anywhere you want to in the county district but you have to deal with the ASO in order to do it. Because they have to approve everything. They can pay up to 1/3 of your rent. And that is not temporary assistance. Because this lady came from the city county building and she has nothing to do with them. She was telling me about things and this is how I found out."*

The location of the housing in relation to services is important for some residents. One Central Anglo MSM said, *"I make $667 a month in disability and in order to keep near my doctor's office, and so I don't have a long commute, I opt to stay and live downtown, and you can't find very good, affordable, decent housing downtown. And if you try to go out, you know, outside of the downtown area, sure you can find something decent and affordable, but at the same time, you know, if you don't have transportation or someone to take you, it can take you all day just to go to one doctor's visit or you know, to get your medications* *or something."* A Central Anglo MSM said, *"My foremost challenge besides managing health issues would be that of affordable and long term safe housing, which is accessible to basic needs and medical."*

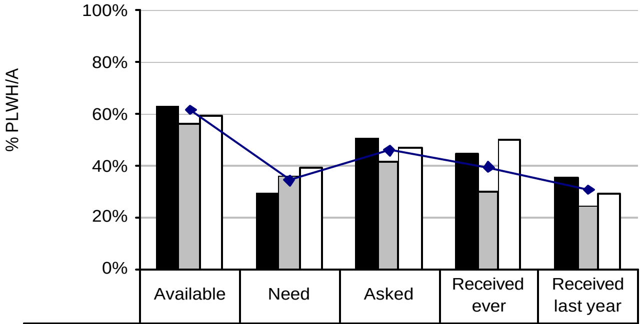
Several participants reported a desire for independent housing. A Southern Anglo male said, *"For me [the most important service] would be housing. The situation that I'm in now is not working out. I would like to have my own place."* Others suggested that plans consider subsidizing home ownership. A Northern Anglo IDU female in a different group said, *"My future need, I get tired of this renting and renting and renting apartments and stuff like that. I move from apartment to apartment. I want a house. That's going to be my future thing right now. I wish they would come up with some kind of program where people on disability can try to get a house and stuff like that to help out with the mortgage payment and stuff like that."*

Some PLWH/A said that they faced discrimination because of their status in gaining housing. Regarding looking for transitional housing while being homeless, a Northern African American MSM said, *"I called a place in Hammond that was supposed to be a shelter. They told me to come on over, they were a shelter. When I got there and filled out the paperwork and it asked if I had the virus, I was honest and I put yes. They put me right back on the street again. This is the hardest place that I have been where it is difficult getting help. It really is."*

Emergency Rental Assistance

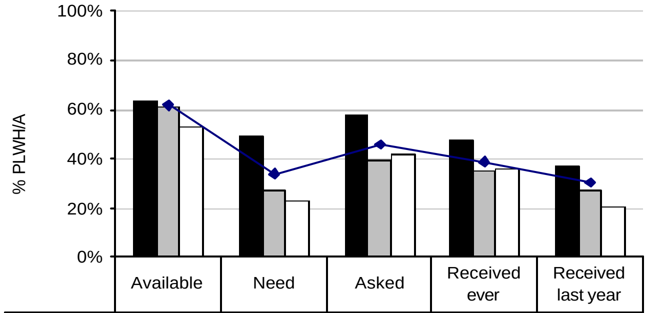


	Available	Need	Asked	Received ever	Received last year
■ Male	60.7%	32.4%	44.5%	37.8%	28.6%
▨ Female	66.5%	43.1%	51.9%	47.0%	40.2%
□ MSM	57.9%	26.8%	40.4%	35.1%	26.1%
▨ IDU	75.5%	47.1%	49.8%	39.9%	32.3%
▨ HET	58.8%	37.0%	47.6%	40.8%	51.3%
◆ Total	61.6%	34.0%	45.6%	39.2%	30.4%

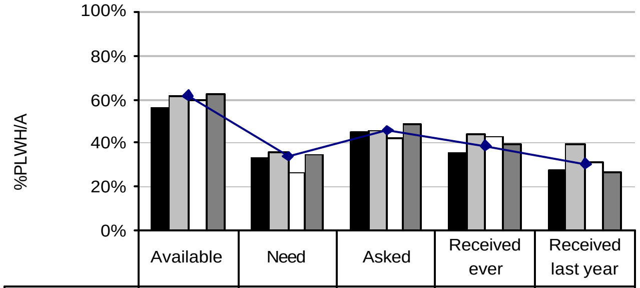


	Available	Need	Asked	Received ever	Received last year
■ Central	63.0%	29.4%	50.6%	44.7%	35.2%
▨ North	56.5%	35.7%	41.8%	30.3%	24.3%
□ South	59.7%	39.3%	46.8%	50.0%	29.5%
◆ Total	61.6%	34.0%	45.6%	39.2%	30.4%

	Average # Past Year
Sample	**2.7**
Male	2.6
Female	3.0
MSM	2.6
MSM/IDU	1.6
IDU	3.4
HET	3.6
Af Am	2.5
Anglo	2.8
Latino	2.6
Central	1.9
North	3.1
South	4.8
H asymp	2.1
H symp	3.0
A asymp	2.1
	3.2



	Available	Need	Asked	Received ever	Received last year
■ Af Am	63.8%	49.6%	58.0%	47.5%	37.2%
▨ Anglo	60.9%	27.0%	39.6%	35.0%	27.4%
□ Latino	53.4%	23.1%	41.8%	35.9%	20.6%
◆ Total	61.6%	34.0%	45.6%	39.2%	30.4%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	56.6%	33.6%	45.5%	35.7%	27.8%
▨ H Symp	61.7%	35.8%	45.7%	44.4%	39.9%
□ A Asymp	60.0%	26.7%	42.2%	43.2%	31.2%
▨ A Symp	62.2%	34.6%	48.8%	39.7%	27.0%
◆ Total	61.6%	34.0%	45.6%	39.2%	30.4%

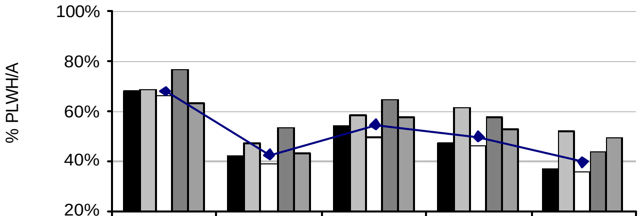
Top Barriers

- The amount of red tape and paperwork I had to fill out to get the service.
- Not being eligible to obtain services because of rules and regulations.
- The cost of the service to me.
- The level of expertise of the person providing the service.
- My concern that the services I need do not exist.
- Not knowing what service I need for treating my HIV infection.

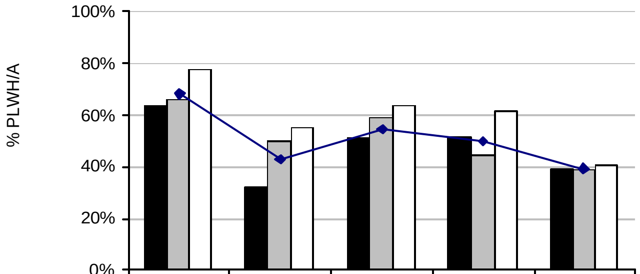
Highlights

- Emergency rental assistance is categorized under Direct Emergency Financial Assistance (DEFA) which is the seventh highest ranked service by ISDH, and is a top ranked service need by PLWH/A.
- On average, PLWH/A receive 2.7 payments a year, with those in the South reporting a larger number of payments than in other regions.
- Many more PLWH/A ask for rental assistance than receive it, particularly among IDUs and African Americans.
- On average, 61% of the PLWH/A believe the service is available for them, and 34% currently needing it, and 46% have ever asked for it. 39% have ever received it, and last year 30% reported needing it.
- Among sex and risk groups, females and heterosexuals are more likely to need, ask and receive for emergency rental assistance than males. MSM are less likely to ask for emergency rental assistance than IDUS and heterosexuals.
- Among regional groups, PLWH/A residing in the South indicate greatest need, and they receive more rental assistance. The greatest gaps are in the North.
- Among ethnic populations, African Americans are more likely to need, ask and receive emergency rental assistance.

Direct Emergency Financial Assistance

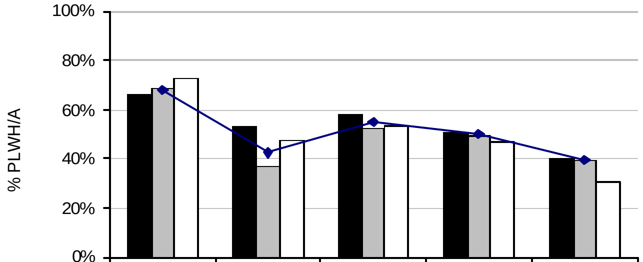


	Available	Need	Asked	Received ever	Received last year
■ Male	68.0%	41.9%	54.0%	47.7%	37.1%
▒ Female	68.6%	47.3%	58.4%	61.7%	52.5%
□ MSM	66.5%	39.1%	50.1%	46.4%	35.8%
▓ IDU	76.9%	53.4%	64.9%	57.7%	43.7%
▓ HET	63.6%	43.4%	58.0%	52.8%	49.1%
◆ Total	68.1%	42.7%	54.6%	49.9%	39.4%

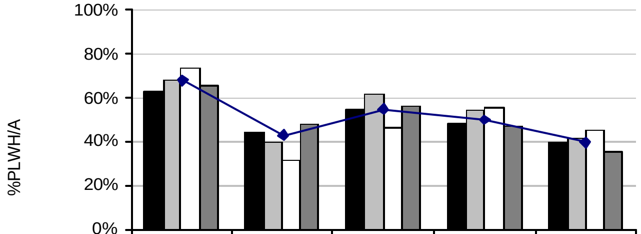


	Available	Need	Asked	Received ever	Received last year
■ Central	63.5%	32.6%	51.1%	51.7%	39.3%
▒ North	65.8%	50.0%	59.1%	44.4%	38.9%
□ South	77.8%	55.6%	63.5%	61.9%	40.4%
◆ Total	68.1%	42.7%	54.6%	49.9%	39.4%

	Average # Past Year
Sample	3.7
Male	3.1
Female	5.9
MSM	2.7
MSM/IDU	4.2
IDU	6.6
HET	3.5
Af Am	5.1
Anglo	3.0
Latino	3.1
Central	2.5
North	5.7
South	2.7
H asymp	2.7
H symp	2.8
A asymp	3.0
A symp	4.3



	Available	Need	Asked	Received ever	Received last year
■ Af Am	65.9%	53.4%	58.3%	50.6%	40.2%
▒ Anglo	68.7%	37.3%	52.7%	49.5%	39.3%
□ Latino	72.8%	47.4%	53.9%	46.9%	30.9%
◆ Total	68.1%	42.7%	54.6%	49.9%	39.4%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	63.0%	44.5%	54.8%	48.6%	39.7%
▒ H Symp	68.3%	39.5%	61.7%	54.3%	41.6%
□ A Asymp	73.3%	31.1%	46.7%	55.6%	45.1%
▓ A Symp	66.1%	47.6%	56.5%	47.2%	35.5%
◆ Total	68.1%	42.7%	54.6%	49.9%	39.4%

Top Barriers

- The amount of red tape and paperwork I had to fill out to get the service.
- The level of expertise of the person providing the service.
- Not being eligible to obtain services because of rules and regulations.
- Not knowing what service I need for treating my HIV infection.

Highlights

- Direct Emergency Financial Assistance (DEFA) is ranked seventh by ISDH and PLWH/A.
- Slightly more people ask for it than receive it, with the largest gap being among symptomatic PLWA.
- On average, 68% of PLWH/A believe emergency financial assistance is available to them. 43% say they need it currently, and 55% have asked for it since they were infected. Half of the PLWH/A report having received DEFA, and 39% reported receiving some payment in the last year.
- On average, PLWH/A report nearly 4 payments a year, with IDUs and PLWH/A in the North reporting the most payments.
- Among sex and risk groups, IDUs tend to believe they have greater access to DEFA than other risk groups. Females and heterosexuals tend to receive DEFA more than males or other risk groups. MSM indicate to least likely to ask for and receive emergency financial assistance.
- Among PLWH/A in different regions, those in the South report greater need, but also greater access to services.
- Among ethnic populations, although all three race groups show a similar pattern in needing direct emergency financial assistance, African Americans are more likely to receive the service than the other ethnic populations.
- Among stages of infection, the data indicate that a greater proportion of PLWA who are symptomatic receive DEFA.

Direct Emergency Assistance and Rental Assistance – Qualitative Comments

The focus group participants generally agree that their resources are stretched to meet basic daily expenses. Rent is a large part of their bill, but utilities and telephone are mentioned frequently, as well as food and medication. A frequent theme was voiced by a Southern African American MSM who said, *"Financial - I am not making enough income for my bills and for my food, I need help getting bills paid."* A Central African American MSM said, *"I don't think [rental assistance] exists here. You get sick, you get tired, and can not work- a lot of people lose their income. I can not get them to help with my rent or my utilities. There is no one here to help me. That is a point of people's dignity, being able to maintain their home and I fear that I can not do that at times."*

For a few PLWH/A the system appeared to work. A Northern Anglo female said, *"Well, I went straight to the ASO because I already knew where to go because I was already hooked up with them before I left the state this last time. I knew right where to go. I knew pretty much what to do. They helped me out with emergency rental assistance and stuff like that."*

It was clear from the comments, that participants used several different sources of financial assistance. An Anglo female said, *"The Red Cross offers additional assistance too if there is a month that comes up and you can't come up with your portion of the rent. They will help you. Have you been to the Community Action Program - they will pay your utilities and about $250 towards your rent. And during the summer, they will help you with air conditioners. That's for everyone, not necessarily PLWH/A. They put you on a list where they cannot shut your electricity off between September - March."* A Northern African American MSM said, *"There was assistance with Greater Hammond Community Services for the energy assistance program, but that's something that's annual of the money they receive, and they always hit a certain point and then over the year that fund is no longer available. Salvation Army might offer $50 off of your utility bill, because then they offer some other portion of assistance. But it requires individuals to beat the pavement and go to so many different agencies."* A Northern African American female added, *"Things that I needed and I didn't have deposits for … I am also on social security. $500 does not cut it every month. It will pay your rent but what about your other bills?"*

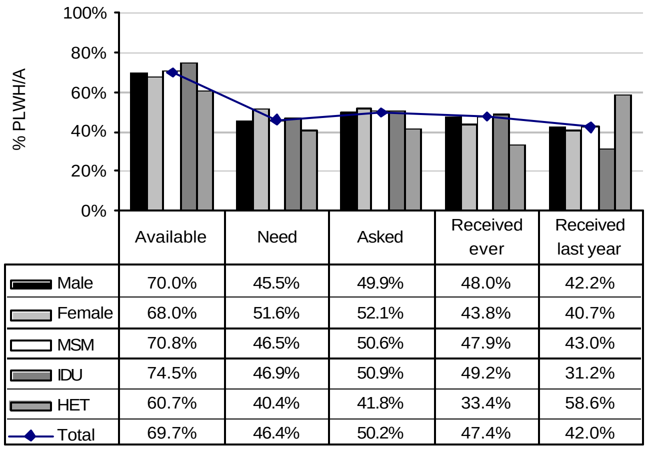
One theme that was expressed several times is the red tape and the length of time it took to get emergency services. A Southern Anglo male said, *"We have the emergency assistance service available to us. However, I know my partner and I have both applied for emergency assistance. Back in March we were approved, and we are still waiting for the assistance. To me, that is not an emergency service"* Another Anglo male in the same group brought up another example of delayed DEFA funds. He said, *"I know a client's gas was being shut off. It was in the wintertime, and the case manager had to pay out of her own pocket down at some payment place in order to keep his gas on, because they couldn't issue money out of funds until Indianapolis approved it. Otherwise, this client was going to be without heat for the wintertime."*

In a few instances, PLWH/A just gave up trying to get rent support. A Central Latino MSM said, "*The rent support. It's impossible. It's a promise that never comes. I just tell it the way it is.*"

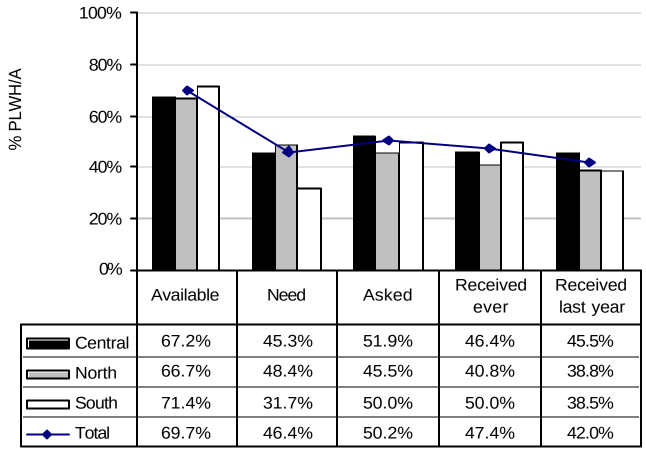
Several PLWH/A said that the system of emergency care was not well documented. An African American MSM said, "*The things I need as far as services go is a better understanding of how the housing program works and the emergency assistance program, because if it's an emergency you can't wait a month. If it's an emergency it's an emergency now. They need to formulate some type of easier way to apply for and obtain the emergency services in the time that the emergency is happening. Not a month later. Their definition of emergency and ours is totally different.*"

For many PLWH/A there was a concern about the future and a sense that funds were limited. A Northern Anglo male said, "*My main concern is the HOPWA situation. What am I going to do when my HOPWA runs out? Now I have to think of other alternatives. I have to move. I have to go to a different state. I have to; it's either that or be homeless. It used to be that the HOPWA lasted longer than two years and now it's only two years. So it's like what am I going to do? Move to another state so I can get better assistance or what.*"

Mental health therapy with a psychologist or social worker

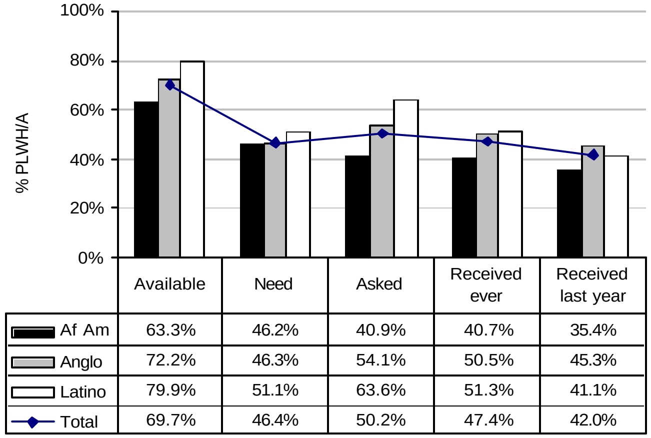


	Available	Need	Asked	Received ever	Received last year
Male	70.0%	45.5%	49.9%	48.0%	42.2%
Female	68.0%	51.6%	52.1%	43.8%	40.7%
MSM	70.8%	46.5%	50.6%	47.9%	43.0%
IDU	74.5%	46.9%	50.9%	49.2%	31.2%
HET	60.7%	40.4%	41.8%	33.4%	58.6%
Total	69.7%	46.4%	50.2%	47.4%	42.0%

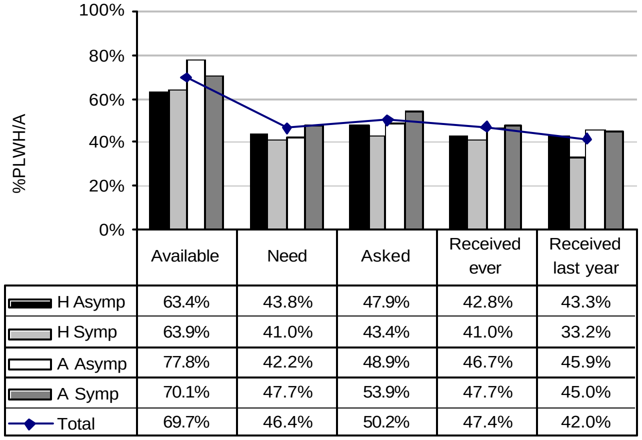


	Available	Need	Asked	Received ever	Received last year
Central	67.2%	45.3%	51.9%	46.4%	45.5%
North	66.7%	48.4%	45.5%	40.8%	38.8%
South	71.4%	31.7%	50.0%	50.0%	38.5%
Total	69.7%	46.4%	50.2%	47.4%	42.0%

	Average # Past Year
Sample	**11.1**
Male	10.9
Female	12.3
MSM	11.7
MSM/IDU	11.4
IDU	12.0
HET	5.7
Af Am	7.9
Anglo	12.4
Latino	9.1
Central	13.3
North	9.6
South	6.8
H asymp	13.6
H symp	7.1
A asymp	16.3
A symp	8.7



	Available	Need	Asked	Received ever	Received last year
Af Am	63.3%	46.2%	40.9%	40.7%	35.4%
Anglo	72.2%	46.3%	54.1%	50.5%	45.3%
Latino	79.9%	51.1%	63.6%	51.3%	41.1%
Total	69.7%	46.4%	50.2%	47.4%	42.0%



	Available	Need	Asked	Received ever	Received last year
H Asymp	63.4%	43.8%	47.9%	42.8%	43.3%
H Symp	63.9%	41.0%	43.4%	41.0%	33.2%
A Asymp	77.8%	42.2%	48.9%	46.7%	45.9%
A Symp	70.1%	47.7%	53.9%	47.7%	45.0%
Total	69.7%	46.4%	50.2%	47.4%	42.0%

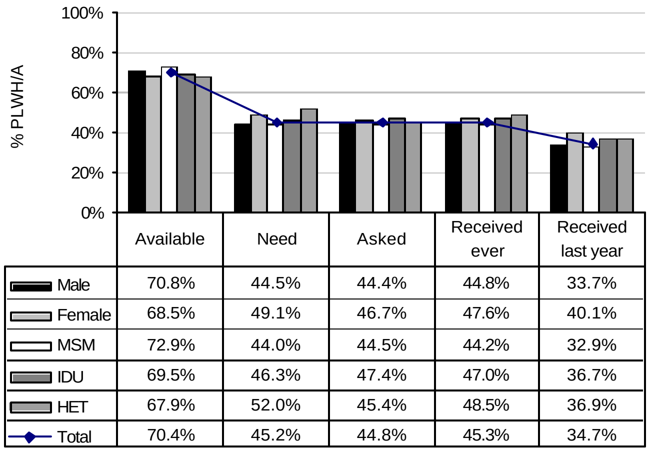
Top Barriers

- My state of mind or mental ability to deal with the service & treatment.
- The level of expertise of the person providing the service.
- Not knowing what service is available to me.
- The cost of the service to me.

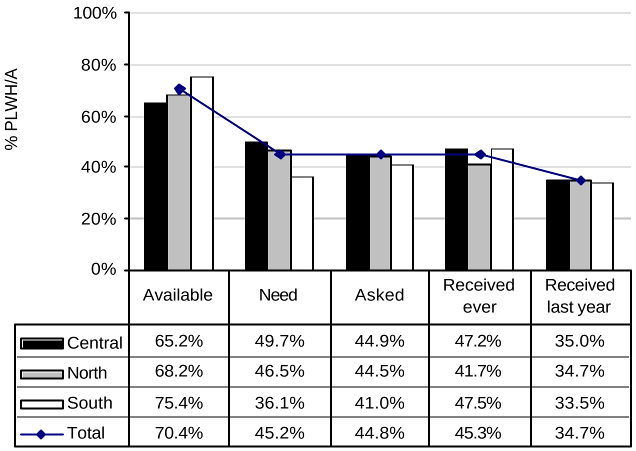
Highlights

- Mental health therapy is the 8th ranked service priority of ISDH, and among the top needs of PLWH/A.
- On average, about 70% of the PLWH/A perceive that mental health counseling is available to them. 46% say they have a need. About half of the PLWH/A say they have asked for and report having received mental care services. Last year, about 42% of PLWH/A received mental health services.
- Those PLWH/A who access mental health services, typically have about 11 sessions a year. Symptomatic PLWA have a somewhat higher number of sessions.
- Among sex and risk groups, the general trends are the same for all groups. Heterosexuals tend to have lower need and have asked for and received proportionately less services. There is some indication that heterosexual have received a substantial increase in services in the last year.
- Regionally, PLWH/A living in the South express less current need than other regions for mental health services, perhaps reflecting their higher utilization patterns of these services.
- Among ethnic populations, Latinos report slightly greater need, but proportionately less Latinos receive mental health services.

Peer counseling, support, or drop-in groups

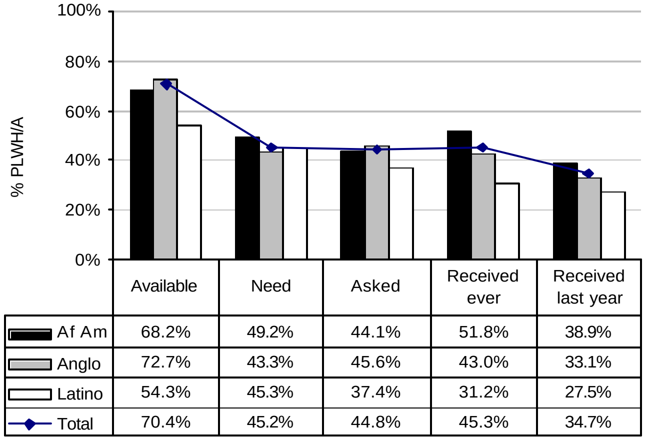


	Available	Need	Asked	Received ever	Received last year
Male	70.8%	44.5%	44.4%	44.8%	33.7%
Female	68.5%	49.1%	46.7%	47.6%	40.1%
MSM	72.9%	44.0%	44.5%	44.2%	32.9%
IDU	69.5%	46.3%	47.4%	47.0%	36.7%
HET	67.9%	52.0%	45.4%	48.5%	36.9%
Total	70.4%	45.2%	44.8%	45.3%	34.7%

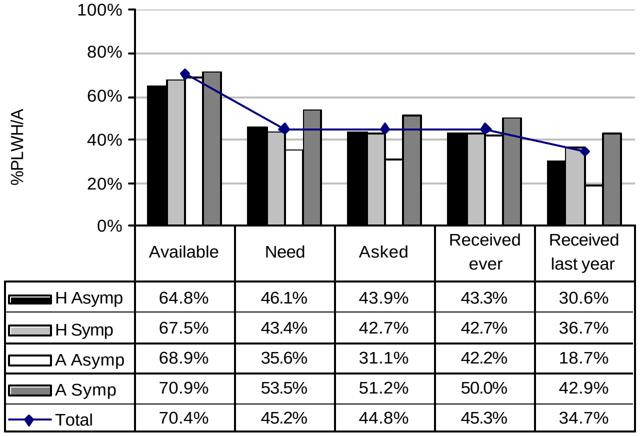


	Available	Need	Asked	Received ever	Received last year
Central	65.2%	49.7%	44.9%	47.2%	35.0%
North	68.2%	46.5%	44.5%	41.7%	34.7%
South	75.4%	36.1%	41.0%	47.5%	33.5%
Total	70.4%	45.2%	44.8%	45.3%	34.7%

	Average # Past Year
Sample	**15.8**
Male	16.2
Female	13.8
MSM	16.9
MSM/IDU	17.1
IDU	10.7
HET	15.3
Af Am	15.6
Anglo	15.9
Latino	16.2
Central	21.7
North	9.2
South	12.6
H asymp	12.8
H symp	22.8
A asymp	8.1
A symp	15.5



	Available	Need	Asked	Received ever	Received last year
Af Am	68.2%	49.2%	44.1%	51.8%	38.9%
Anglo	72.7%	43.3%	45.6%	43.0%	33.1%
Latino	54.3%	45.3%	37.4%	31.2%	27.5%
Total	70.4%	45.2%	44.8%	45.3%	34.7%



	Available	Need	Asked	Received ever	Received last year
H Asymp	64.8%	46.1%	43.9%	43.3%	30.6%
H Symp	67.5%	43.4%	42.7%	42.7%	36.7%
A Asymp	68.9%	35.6%	31.1%	42.2%	18.7%
A Symp	70.9%	53.5%	51.2%	50.0%	42.9%
Total	70.4%	45.2%	44.8%	45.3%	34.7%

Top Barriers

- My concern that the services I need do not exist.
- My concern that other people may see me when I go to get care or learn about HIV infection (lack of confidentiality).
- My state of mind or mental ability to deal with the service & treatment.
- Not knowing what service I need for treating my HIV infection.

Highlights

- Peer Counseling is categorized under mental health services, and is the eighth ranked priority by ISDH, and, unlike therapy with a psychologist or social worker, it is not a top priority for PLWH/A.
- On average 70% of PLWH/A perceive the service is available to them, and about 45% say they currently need it, have asked for it, and report having received it. 35% say they received it last year.
- For those using the service, they attend, on average between 15 and 16 sessions a year. Symptomatic PLWH tend to report more session than those at other stages of infection.
- Among risk groups, Latinos indicate the greatest need for peer counseling and support groups but about the same proportion of Latinos ask for peer counseling and drop in groups as other ethnicities.
- There are few other differences in the current need, demand, and utilization of peer services among different populations.

Peer Counseling, Support, or Drop-In Groups – Qualitative Comments

PLWH/A often expressed a need for individual or group counseling. The types of issues PLWH/A cover a broad range. For example, a Central African American female who became infected through blood products said, *“One of the things that I needed after getting diagnosed was one-on-one counseling through some type of agency. I needed that really bad because I was at a suicidal level. I felt like giving up. My husband and I had split up three years before that. And I had four children and on top of all that, this was dropped on me. I had nobody to go to - no help. So I was really on edge. On top of that I was drinking alcohol real bad. I didn't have any counseling for alcohol abuse or for the emotional abuse. I think that is something they need to provide more.”*

A Southern Anglo male who’s been positive for 10 years said, *“I'm having to go to a shrink because I'm developing panic issues between stress from other problems and anxiety from other problems. It's causing a problem with taking my pills where I even walk to approach my pills, and I start salivating in the mouth, getting sick to my stomach. Sometimes I throw them back up two or three times before I can manage to get them down. The shrink thinks it's due to other anxieties and stress in my life. That's how it's manifesting.”*

A Central Anglo MSM said, *“I had a very odd situation, which I had never heard of before. I was date raped, which I thought only happened to women. That is why I got tested and why I found out. I needed that emotional support, because I didn't want to tell my family and I didn't want to tell my friends.* A Northern mixed race heterosexual female said, *"It is hard deciding whether to reveal/disclose HIV positive status. Afraid of what co-workers and friends will say and how they will react. This has caused me depression. I have been prescribed anti-depressants, which I believe are helping. I would like to know of support groups, because I would like to go to one. Someone told me of one but it is for gay men. I want to go to one where there are other women experiencing exactly what I am going through."*

Very few participants in the focus groups said that their needs were met. For example, a Central Anglo MSM said, *“One of my most important needs, which is being met, is mental health because I have borderline personality disorder which isn't real fun.”* More common, was the comment by a Central Anglo heterosexual male who said, *"There is a REAL lack of services for the mental and psychological aspects of the illness. Other than that services have been at least good"*

Some participants reported poor response from ASOs. An MSM in the Central region, *I called someone there and he cancelled my appointment the first time with no reason. I was like okay, whatever. And then I called the second time about four months later to try again because I was more depressed, and he cancelled it again, the same guy. So I just got totally pissed off at the* *whole idea, and told my doctors that I would not go to the [large ASO] and I wouldn't rely on them in any way, because of my needs. Just now I am seeing a counselor in my local area."*

PLWH/A often resort to group services when they would like individual counseling. A Latino MSM who said he wanted individual counseling, but can't afford it so settles for peer counseling. He said, *"I've kind of used my support group as my therapy only because I haven't always needed it, but it has been recommended by my doctor that I maybe go to some counseling just because of my continued decline with my health. I tried to do that, but my insurance doesn't cover it, and therefore I've been going without counseling and just going to my support group. So now I'm managing."*

However, once in group counseling, a number of PLWH/A found it useful. For example, A Central Latino MSM said, *"I attend a support group, which I think was the best thing that I've done for myself. In the beginning I didn't tell anybody except my immediate family, because of the fear. In fact at first we didn't even know very much about the disease, and so I was afraid to say anything, but I felt that my immediate family would possibly understand and deal with it. My father doesn't and we no longer have contact, so today my needs are to keep with a good doctor and keep up with the medications. But I think I will get along with my support group. That is really my main help mentally."*

In support of peer counseling, many of the PLWH/A stressed the importance of finding and talking to others who are infected. A Northern Anglo MSM said, *"The only services that I need is that I feel so isolated out there [about 45 minutes outside of Fort Wayne]. I know nobody. I moved there to take care of my mother and I'm out there and I don't know anybody out there. They need some kind of referral service or something so that, I've asked them to tell anyone that's out there in my area that's HIV positive that I'm there if they want to talk to somebody or something because there is nobody out there at all."* A Central MSM/IDU said, *"I think people find out more information talking to one another than they do from a case manager or someone at the ASO."*

A Central Anglo MSM in need of local peer counseling said, *My biggest problem is I don't know other people that are in the same boat as me around my same age. It has been something that I am talking with the counselor about. I am like it makes it hard for me to go on my day-to-day business when I don't have support. My friends that are my same age, none of them are positive. They don't understand. They try, but they just can't. You know, you have to be in those shoes. So that is my biggest need is finding people."*

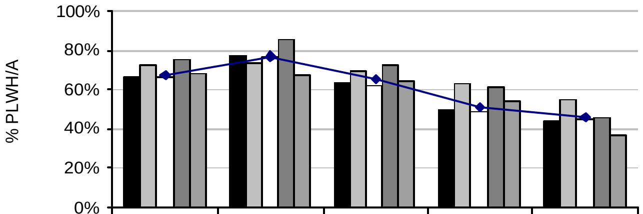
A Northern African American MSM said, *"It seems like Chicago and other bigger cities have HIV support groups. I've been to a couple in Chicago. Sometimes it helps to know that people are in the same situations and same dilemmas and have the same problems with medications that even though you may know what it should be, but we need people that we can talk to about your* *situation. More people to give you some insight into what's going on. Maybe you are taking this, and it's not working for you. Maybe I took that and I told my doctor or whatever and he took me off of that. Have you talked to your doctor about checking your medications? We do not have a support group here for HIV positive people in this area, which that is something that is really what we need."*

Several PLWH/A voiced concern about finding adequate mental health services. A Central mixed race heterosexual female said, *"Well, I believe my major challenge will be receiving mental health service and support groups for my illness, I feel these things need to improve in order for me to survive the remainder of my life in a positive manner".*

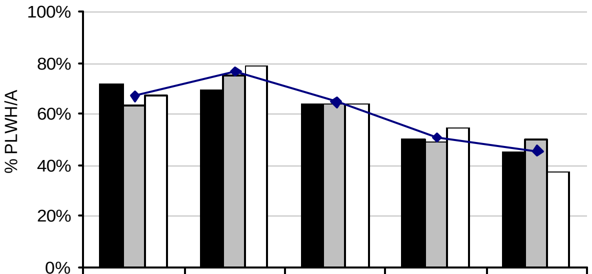
A few noted that services for younger people were not available. An Anglo MSM said *""There is not much for younger people over 21 to like 30 or 35."*

For some participants it was a question of awareness of available services and/or costs. A Central Latino MSM said, *"Another unmet need I think maybe I would consider going to counseling, but again I can't afford to do that currently. It's a matter of money and my insurance doesn't cover it."*

Dental Care

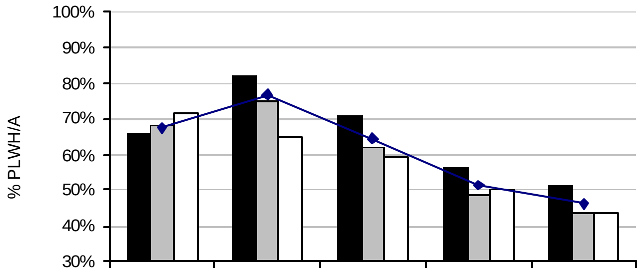


	Available	Need	Asked	Received ever	Received last year
■ Male	66.5%	77.7%	63.8%	49.3%	44.5%
▒ Female	72.7%	73.4%	70.0%	63.1%	54.8%
□ MSM	66.3%	76.6%	62.0%	48.5%	44.6%
▓ IDU	75.1%	85.5%	72.8%	61.4%	45.5%
▓ HET	68.4%	67.2%	64.2%	54.4%	37.0%
—◆— Total	67.4%	77.0%	64.7%	51.3%	46.0%

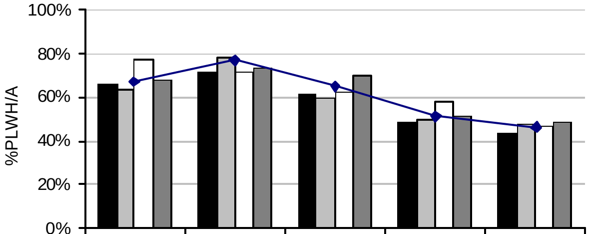


	Available	Need	Asked	Received ever	Received last year
■ Central	71.9%	69.7%	64.0%	50.6%	45.5%
▒ North	63.7%	75.8%	64.1%	49.7%	50.4%
□ South	67.7%	79.0%	64.5%	54.8%	37.5%
—◆— Total	67.4%	77.0%	64.7%	51.3%	46.0%

	Average # Past Year
Sample	**3.2**
Male	3.3
Female	2.4
MSM	3.6
MSM/IDU	2.6
IDU	2.3
HET	2.1
Af Am	2.7
Anglo	3.4
Latino	3.5
Central	3.7
North	2.8
South	2.7
H asymp	2.6
H symp	2.7
A asymp	2.9
A symp	4.1



	Available	Need	Asked	Received ever	Received last year
■ Af Am	65.7%	82.0%	70.9%	56.6%	51.4%
▒ Anglo	67.8%	75.3%	62.0%	48.9%	43.5%
□ Latino	71.6%	65.1%	59.4%	49.9%	43.7%
—◆— Total	67.4%	77.0%	64.7%	51.3%	46.0%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	65.7%	71.3%	61.5%	48.3%	43.1%
▒ H Symp	63.9%	78.3%	59.8%	49.4%	47.4%
□ A Asymp	77.8%	71.1%	62.2%	57.8%	47.1%
▓ A Symp	67.7%	73.2%	70.1%	51.2%	48.1%
—◆— Total	67.4%	77.0%	64.7%	51.3%	46.0%

Top Barriers

- Not having enough insurance coverage.
- Not being eligible to obtain services because of rules and regulations.
- The cost of the service to me.
- The level of expertise of the person providing the service.
- Not knowing what service is available to me.

Highlights

- Dental care is ranked ninth by ISDH and third by PLWH/A.
- Dental care has the largest perceived gap, with nearly 15% more PLWH/A asking for and not receiving dental care. The gap is particularly large for males and MSM, and is large among all ethnic populations.
- On average, PLWH/A who receive dental care report going about 3 times a year. Symptomatic PLWA report going slightly more often.
- On average, about two thirds of PLWH/A perceive dental care is available to them, 77% perceive a current need, 65% have ever asked for dental care, and just over half report having received it. 46% report receiving dental services in the last year.
- Among sex and risk groups, IDUs report the greatest need, and females and IDUs report asking and receiving the most dental service.
- Among ethnic populations, African Americans are more likely to need, ask for, and receive dental services. Latinos say they have a lower need for dental care report receiving about the same as African Americans.
- The largest gap for dental care is among symptomatic PLWH/A.

Dental Care – Qualitative Comments

Cost and location of dental care were the major themes presented by PLWH/A in the focus groups.

A Northern Anglo MSM said, *" I will have more problems accessing [dental care], because they are costly. Agencies who offer these services will often say they do not have money to offer assistance with these things."*

A Southern Anglo heterosexual male said, *"I have not been [to the dentist] because I can not make an appointment. But I do need it. It is kind of hard to access because I have to find a dentist that takes Medicaid and then I have to arrange a ride to the office. Currently I don't know of a dentist that will see me."* Another Southern Anglo male said, *"We have dental care in Terre Haute here available to us, but since our dentist hasn't been paid in over a year by our provider, they're no longer accepting any programs. So now we're having to drive 89 miles to another dentist. They will continue to see us, but we've got to pay out of pocket. We can't afford it."*

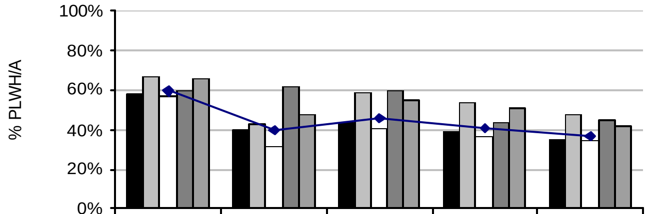
A Central Anglo heterosexual female said, *"I can not find a dentist that takes Medicaid. I have asked my case manager and she can not find one either. They are hard to find. Right now my teeth need to be cleaned and I have pains in my teeth, when I eat and stuff. Then my teeth act up."*

Several PLWH/A are aware that there is coverage through EIP, and minimal coverage through Medicaid. A Central Latino MSM said, *"I have seen my dentist this year, and the only reason I have coverage is because of EIP, but I also I have met my limit and I owe a little bit and I better not have any more problems for the rest of the year or I'm in trouble."*

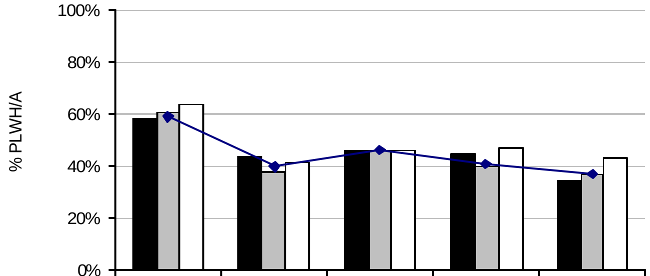
A Northern Anglo male said, *"The Medicaid and Medicare only pays for so much towards dental work. Why doesn't the ASO have some type of dental plan to where they will pay to get my teeth fixed right and not half a job. Medicaid will only cover to get my teeth cleaned or to have fillings put in. That's the only thing they will cover. They won't cover a bridge or something like that. I've never heard of any other dental plans or anything like that."*

A number of participants commented on the difficulty in getting a dental appointment. For example, a Central Anglo MSM said, *"The barrier I have is with the dental school. They will set up an appointment and then they will cancel the appointment. It is very hard to actually talk to a real live person to set up another appointment. You can get dental services through the EIP Insurance Program setup through AIDServe. And they cancel the appointments. And when I call them, all I get are recordings. It has been very difficult to set another appointment."*

Transportation to access HIV-related services

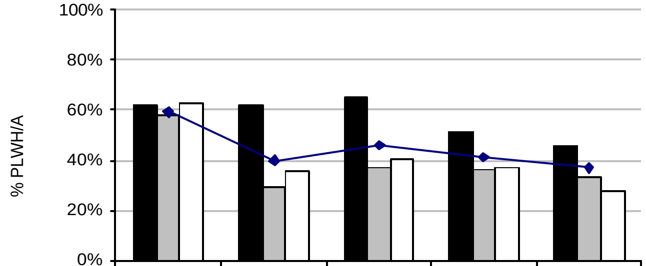


	Available	Need	Asked	Received ever	Received last year
■ Male	58.0%	39.4%	43.7%	38.6%	35.0%
▒ Female	66.1%	43.0%	58.6%	53.7%	47.0%
□ MSM	57.5%	31.5%	40.2%	36.9%	34.3%
▓ IDU	59.3%	61.9%	59.2%	43.6%	45.3%
▓ HET	65.3%	47.2%	54.7%	51.4%	41.8%
—◆— Total	59.2%	40.0%	45.9%	40.8%	36.8%

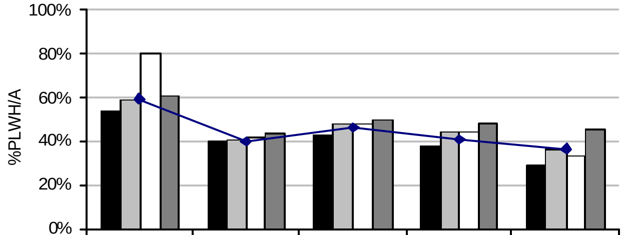


	Available	Need	Asked	Received ever	Received last year
■ Central	58.6%	44.1%	46.4%	45.0%	34.8%
▒ North	60.9%	37.8%	46.5%	39.7%	36.6%
□ South	63.5%	41.3%	46.0%	47.6%	43.1%
—◆— Total	59.2%	40.0%	45.9%	40.8%	36.8%

	Average # Past Year
Sample	**15.9**
Male	15.6
Female	17.1
MSM	14.5
MSM/IDU	14.6
IDU	24.7
HET	6.5
Af Am	20.0
Anglo	12.9
Latino	20.2
Central	22.1
North	11.0
South	10.0
H asymp	11.3
H symp	10.9
A asymp	53.2
A symp	13.5



	Available	Need	Asked	Received ever	Received last year
■ Af Am	62.2%	62.0%	65.2%	51.3%	45.7%
▒ Anglo	57.7%	29.4%	36.9%	35.9%	32.8%
□ Latino	62.8%	35.3%	40.1%	36.9%	27.5%
—◆— Total	59.2%	40.0%	45.9%	40.8%	36.8%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	54.1%	40.0%	42.5%	37.7%	29.3%
▒ H Symp	58.5%	40.7%	47.5%	44.4%	36.9%
□ A Asymp	80.0%	42.2%	47.7%	44.4%	32.9%
▓ A Symp	60.9%	43.8%	50.0%	48.4%	45.7%
—◆— Total	59.2%	40.0%	45.9%	40.8%	36.8%

Top Barriers

- Not having transportation.
- The cost of the service to me.
- My concern that the services I need do not exist.

Highlights

- Transportation is the second highest need reported by PLWH/A, and tenth ranked service by ISDH.
- There is not a large gap between those asking for and receiving transportation. 5% more PLWH/A report asking for transportation than receiving it.
- On average, PLWH/A report taking about 16 trips a year using transportation services.
- On average, about 60% of the PLWH/A are aware that transportation services exist. About 40% report needing it, 46% report asking for it, and 41% report ever receiving it. 37% report receiving it last year.
- Among sex and risk groups, female and heterosexuals are more likely to be aware of, need, and receive services. IDUs are more likely to ask for, but not receive services.
- Among regions, the PLWH/A living in the South report the greatest awareness and are most likely to receive services. Those in the Central area have the greatest need, and those in the North report the lowest need, but also are more likely than any area to ask for but not receive transportation
- Among ethnic groups, African Americans report far greater need, and while they are more likely than other ethnic populations to receive transportation, they also have the largest gap between asking for and receiving transportation. Anglos are much less likely to say they need transportation, and while they are least likely to report receiving transportation, they also have no gap between asking for it and receiving it.
- Transportation services are most likely to be accessed by PLWA who are symptomatic.

Transportation – Qualitative Comments

PLWH/A who participated in the focus groups had little positive to say about transportation services, and the few positive comments were not related to ASO services. For example, A Northern African American MSM said, *"Transportation is excellent. But it isn't an ASO service, it's a Ft. Wayne thing."* A Northern Anglo male said, *"Well, I have a mother and we have a car. I can get around. The ASO has volunteers. If I ever need anything, I've had to ask for it a couple of times. I've always gotten transportation. The VA provides transportation too if I need them to come and get me. They will send the VA van. I'm fortunate."*

A Central African American MSM talked about an ASO that provides transportation services. He said, *"We have seen more complaints than even the City Transit System. I personally don't like needing to call in advance for the service because that is an added responsibility that I have to do as a part of my work. They often encourage that you do it two or three days in advance. But the personnel they have are just there for their paycheck. They will be way down the street and then go back and write you up as a no show. With a no show, you can't ride their service for a whole month unless you call down there and raise holy hell. And it ain't free. It costs $1.75 per trip and you have to buy the tickets in a ten pack series. So that is $17.50 and you can't buy the tickets separately either. And those are tickets you can use only for that ASO. You can't use nothing else. I can't pull out my employee I.D. and ride it. I can't use a city service, it has to be that ASO."*

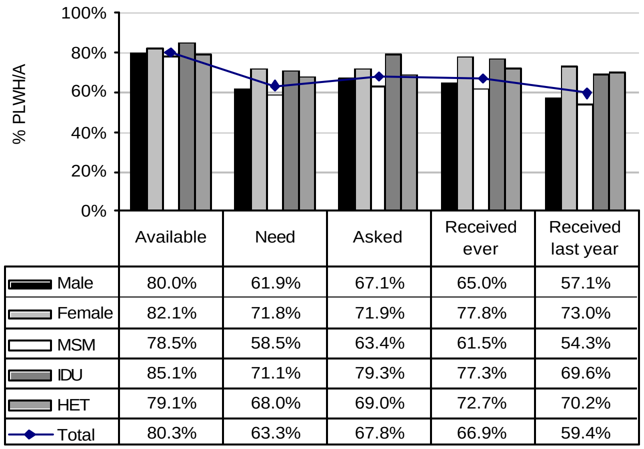
Regular mass transit was not viewed as an option for many PLWH/A. A Central Latino MSM said, *"The buses run infrequently [in Indianapolis]. And you can't count on the bus company to get you to your doctor's appointments or to the [ASO] where you need to be.'* A Southern Anglo MSM said, *"Medications causing me to suffer from side effects, gaining weight. I am also visually impaired so transportation is very important to my health care."*

Even with mass transit, token are not always available. A Southern Anglo heterosexual male said, *"At times there are not enough bus tokens to go around, so we need to find a way to access transportation needs through METS, bus passes or any way to make things easier for those who have transportation needs."*

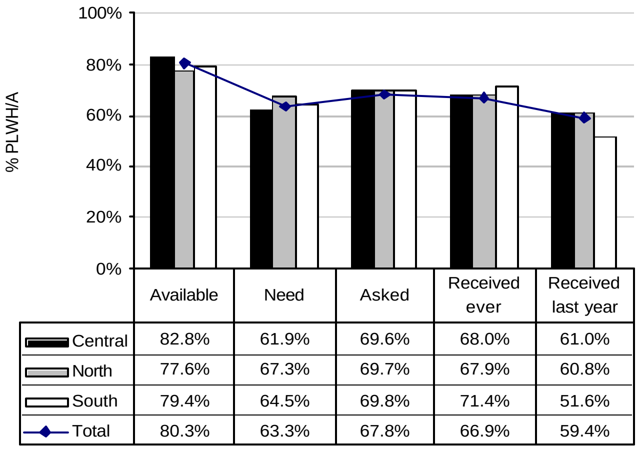
In short, almost all PLWH/A expressed some dissatisfaction. A Central Anglo heterosexual female said, *"In regards to transportation, it's not that I want someone to pick me up to go everywhere but I do need some help sometimes to get from one point to another."* A Southern African American MSM expressed the same thought by saying, *"Transportation - it is a problem for me just to get from A to B - especially when their double booked. I suggest they get bus passes."*

A Southern Anglo male said, *"I think we need better transportation provided for us. For instance, I've used one of those little shuttle buses for seniors. They took me to a doctor's appointment, which was fine. I mean it was a pallable experience. I managed* *to get through it, although it took me 100 times longer than it would have taken me to drive myself. Then, my partner gets an appointment for them to take him to a doctor's appointment. They call him the night before to tell him that they can't take him. That's unacceptable. Somebody was sick. He still has an appointment in Indy. Now, he has no way to get there and no advance notice to tell his doctor he can't get there."*

Food Bank, Nutritional Supplements, or Vouchers to buy food

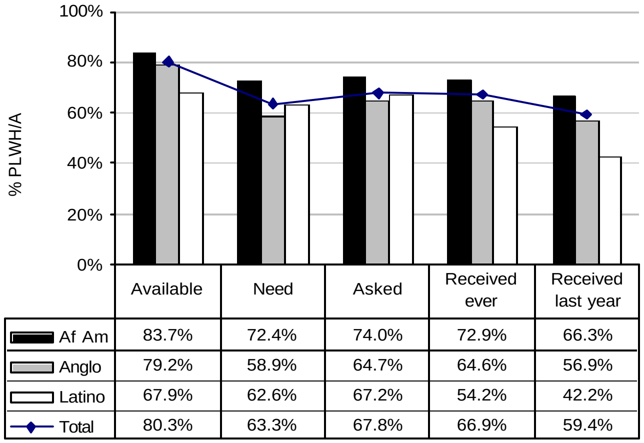


	Available	Need	Asked	Received ever	Received last year
Male	80.0%	61.9%	67.1%	65.0%	57.1%
Female	82.1%	71.8%	71.9%	77.8%	73.0%
MSM	78.5%	58.5%	63.4%	61.5%	54.3%
IDU	85.1%	71.1%	79.3%	77.3%	69.6%
HET	79.1%	68.0%	69.0%	72.7%	70.2%
Total	80.3%	63.3%	67.8%	66.9%	59.4%

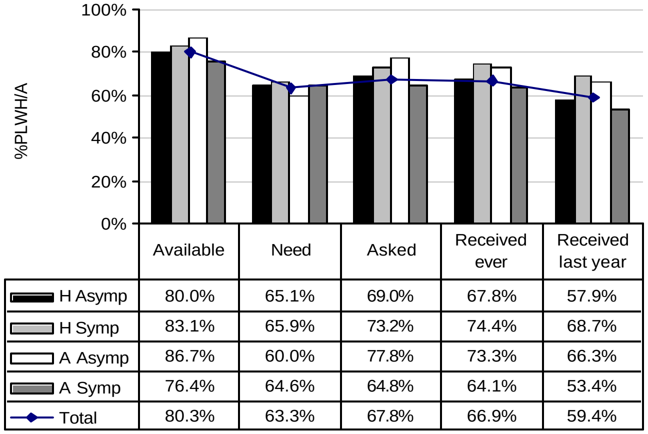


	Available	Need	Asked	Received ever	Received last year
Central	82.8%	61.9%	69.6%	68.0%	61.0%
North	77.6%	67.3%	69.7%	67.9%	60.8%
South	79.4%	64.5%	69.8%	71.4%	51.6%
Total	80.3%	63.3%	67.8%	66.9%	59.4%

	Average # Past Year
Sample	**60.8**
Male	9.8
Female	289.6
MSM	9.8
MSM/IDU	337.1
IDU	13.2
HET	6.5
Af Am	12.0
Anglo	92.1
Latino	5.0
Central	111.1
North	14.0
South	5.8
H asymp	10.3
H symp	13.3
A asymp	7.4
A symp	177.0



	Available	Need	Asked	Received ever	Received last year
Af Am	83.7%	72.4%	74.0%	72.9%	66.3%
Anglo	79.2%	58.9%	64.7%	64.6%	56.9%
Latino	67.9%	62.6%	67.2%	54.2%	42.2%
Total	80.3%	63.3%	67.8%	66.9%	59.4%



	Available	Need	Asked	Received ever	Received last year
H Asymp	80.0%	65.1%	69.0%	67.8%	57.9%
H Symp	83.1%	65.9%	73.2%	74.4%	68.7%
A Asymp	86.7%	60.0%	77.8%	73.3%	66.3%
A Symp	76.4%	64.6%	64.8%	64.1%	53.4%
Total	80.3%	63.3%	67.8%	66.9%	59.4%

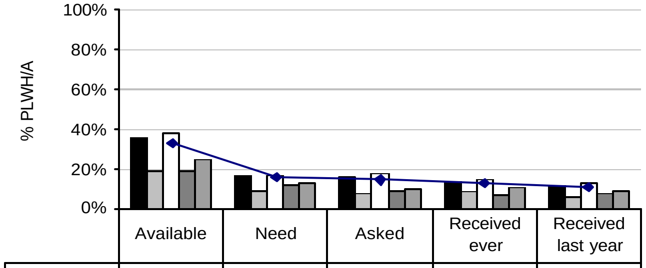
Top Barriers

- Not being eligible to obtain services because of rules and regulations.
- My concern that the services I need do not exist.
- Not knowing what service is available to me.
- The cost of the service to me.
- The quality of service.

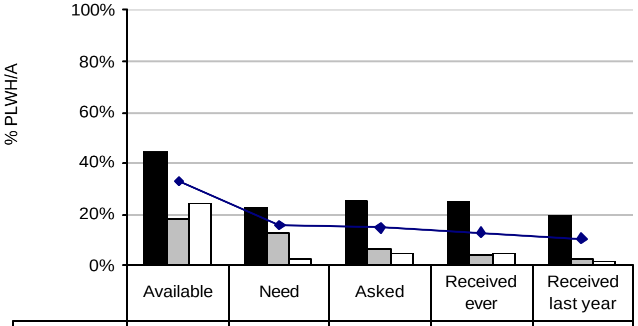
Highlights

- Food bank, nutritional supplements, and vouchers are ranked as the 12th service priority by the ISDH, and is the 6th ranked most important service by PLWH/A.
- On average, 80% of PLWH/A perceive it is available to them, and 63% say they currently need food services. About two-third of PLWH/A say they have ever asked for the service and have received it. Almost 60% say they have received food services last year.
- Among the PLWH/A who access food services, they report using it for about two months a year.
- There is no gap between asking for and receiving food services.
- Among sex and risk groups, females, IDUs, and heterosexuals are more likely need, ask for, and receive food services.
- There are not significant regional differences in the need for food services.
- Among ethnic communities, African Americans and Latinos are more likely to need and receive food services.
- Symptomatic PLWH and asymptomatic PLWA report receiving food services more than asymptomatic PLWH and symptomatic PLWA.

Home delivered meals

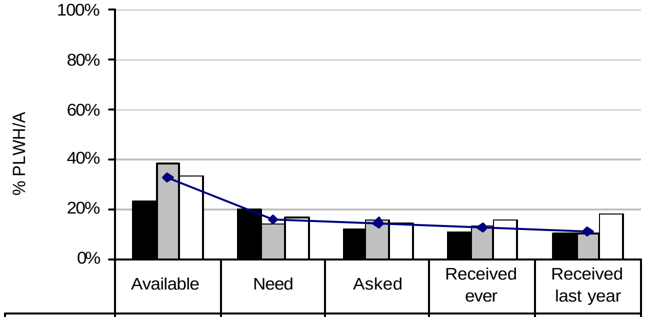


	Available	Need	Asked	Received ever	Received last year
■ Male	35.7%	17.1%	16.1%	13.6%	11.7%
▒ Female	19.0%	8.9%	7.9%	8.3%	6.1%
□ MSM	38.0%	16.9%	17.3%	14.6%	13.2%
▩ IDU	18.8%	12.0%	9.1%	6.6%	7.9%
▩ HET	24.6%	12.8%	9.9%	10.3%	9.5%
◆ Total	33.2%	15.9%	14.9%	12.9%	10.9%

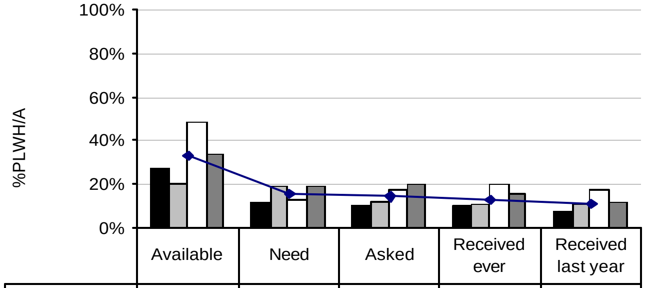


	Available	Need	Asked	Received ever	Received last year
■ Central	44.4%	22.6%	25.6%	25.0%	19.8%
▒ North	18.2%	13.2%	6.6%	3.9%	2.9%
□ South	24.2%	3.2%	4.8%	4.8%	2.0%
◆ Total	33.2%	15.9%	14.9%	12.9%	10.9%

	Average # Past Year
Sample	**4.2**
Male	4.0
Female	4.8
MSM	3.8
MSM/IDU	6.3
IDU	3.7
HET	3.9
Af Am	5.7
Anglo	3.3
Latino	3.7
Central	4.6
North	4.0
South	3.1
H asymp	4.5
H symp	4.0
A asymp	4.9
A symp	3.8



	Available	Need	Asked	Received ever	Received last year
■ Af Am	22.9%	19.9%	12.3%	10.8%	10.4%
▒ Anglo	38.5%	13.7%	16.1%	13.6%	10.6%
□ Latino	33.5%	17.1%	14.6%	16.1%	18.0%
◆ Total	33.2%	15.9%	14.9%	12.9%	10.9%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	27.5%	12.1%	10.7%	10.6%	7.9%
▒ H Symp	20.7%	19.8%	12.3%	11.1%	11.0%
□ A Asymp	48.9%	13.3%	17.8%	20.0%	17.8%
▩ A Symp	34.1%	19.2%	20.2%	16.1%	12.1%
◆ Total	33.2%	15.9%	14.9%	12.9%	10.9%

Top Barrier

Insufficient response rate on this service

Highlights

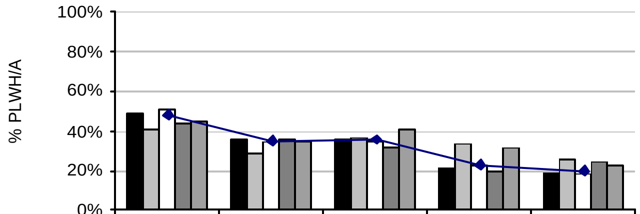
- Food services are ranked as the twelfth service priority by the ISDH, and home delivered meals is part of that service. While food bank services are ranked as a top priority by PLWH/A, they do not consider home delivered meals among the most important services.
- On average, about a third of the PLWH/A perceive that home delivered meals was available for them, and 16% say they have some current need for them. About 15% of PLWH/A say they have asked for them and 13% report having received them. 11% of PLWH/a report receiving them last year.
- For those receiving them, the average use is 4.2 meals a year.
- Among sex and risk groups, males and MSM are much more likely to believe they are available and to need them. Males and MSM are also more likely to ask for and receive home delivered meals.
- PLWH/A in the Central region say they are more available, and there is more demand and utilization of home meals in the Central region.
- Among ethnic communities, the proportion of Anglos and African Americans who need, ask for, and receive home meals is about the same. Latinos perceive they are less available, ask for them less, and receive them less.

Food Bank/Home Delivered Meals – Qualitative Comments

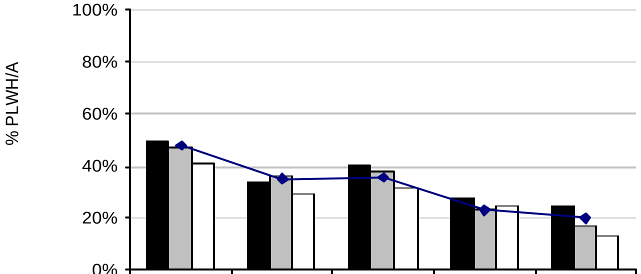
While many participants of the focus groups mentioned the need for food, most were grateful and reasonably satisfied with the food banks. There were almost no comments on home delivered meals. For example, a Central Anglo heterosexual female said, *"I have gone to and used the food pantry. At times it is really stocked great, and then there are times when it is under stocked. But if they are under stocked, they will refer me to another food pantry."* A Northern African American MSM said, *"I don't want it to be said that I am not grateful. However, some of those things you have to be careful and look at the dates because I got a carton of milk and I wouldn't have expected a carton of milk to be bad. I got it home, took the lid off, and I could smell it."*

Some dietary needs may not be met. For example, a Northern African American female said, *"I am sometimes struggling with food. I need special foods because I am a diabetic. I have to use the food pantry where people donate stuff. But there are certain things I can not eat. I need a food voucher to get stuff that I could eat."*

Advocacy

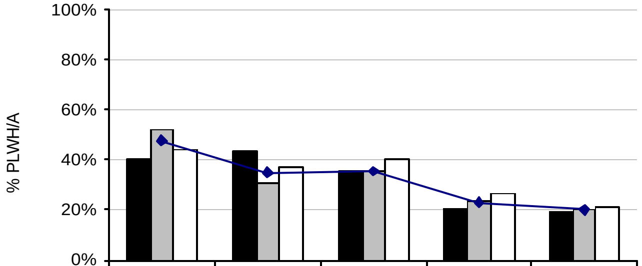


	Available	Need	Asked	Received ever	Received last year
■ Male	49.1%	36.0%	35.8%	21.1%	18.7%
▒ Female	41.5%	29.2%	36.6%	33.5%	25.8%
□ MSM	51.1%	34.2%	35.2%	22.6%	18.3%
▩ IDU	44.5%	35.7%	31.9%	20.1%	24.3%
▩ HET	45.4%	34.7%	41.6%	31.0%	22.8%
◆ Total	48.0%	35.0%	35.9%	22.9%	19.8%

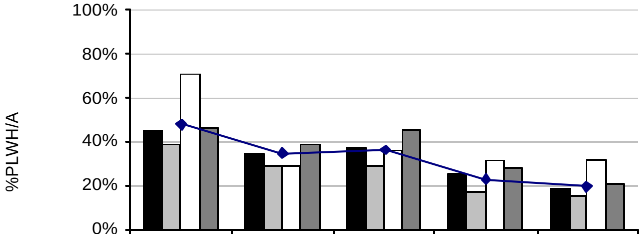


	Available	Need	Asked	Received ever	Received last year
■ Central	49.7%	33.7%	40.3%	27.4%	24.3%
▒ North	47.1%	36.4%	38.1%	23.2%	16.9%
□ South	41.0%	29.5%	31.7%	24.6%	12.6%
◆ Total	48.0%	35.0%	35.9%	22.9%	19.8%

	Average # Past Year
Sample	**2.8**
Male	2.8
Female	2.6
MSM	2.8
MSM/IDU	3.0
IDU	2.8
HET	2.2
Af Am	3.5
Anglo	2.5
Latino	1.3
Central	2.4
North	3.7
South	2.3
H asymp	2.5
H symp	3.2
A asymp	3.6
A symp	2.4



	Available	Need	Asked	Received ever	Received last year
■ Af Am	40.5%	43.5%	35.5%	20.4%	19.5%
▒ Anglo	51.9%	30.8%	35.8%	23.9%	19.8%
□ Latino	44.4%	37.7%	40.4%	26.8%	21.3%
◆ Total	48.0%	35.0%	35.9%	22.9%	19.8%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	44.8%	34.5%	37.6%	25.9%	18.5%
▒ H Symp	38.6%	29.3%	29.3%	17.3%	15.0%
□ A Asymp	71.1%	28.9%	36.4%	31.1%	31.7%
▩ A Symp	46.4%	39.2%	45.6%	28.5%	20.7%
◆ Total	48.0%	35.0%	35.9%	22.9%	19.8%

Top Barrier

Insufficient response rate on this service

Highlights

- Advocacy is ranked fourteenth by ISDH and is not among the top ranked services by PLWH/A.
- Despite its relatively low ranking in importance, far more PLWH/A ask for it than receive it, with the gap being particularly large among MSM and males, and African Americans and Anglos.
- On average, PLWH/A report receiving almost three sessions of advocacy a year. The number of sessions is lowest among Latinos.
- On average, 48% of PLWH/A believe advocacy is available for them. 35% say they currently need it, and 36% say they have asked for it since they were infected. 23% report having received it, and 20% report receiving it in the last year.
- Among sex and risk groups, males report a greater need, but a higher proportion of females and heterosexual report receiving advocacy.
- Regionally, the PLWH/A in the North express the greatest need, and those in the Central region are more likely to ask for it, and receive it.
- Among ethnic populations, African Americans say they are more likely need an advocate. Interestingly however, Latinos are more likely to access the service than the other ethnic populations.
- Symptomatic PLWA rank higher than other PLWH/A in needing, asking and accessing the service, with the largest gap for advocacy being among symptomatic PLWA.

Advocacy – Qualitative Comments

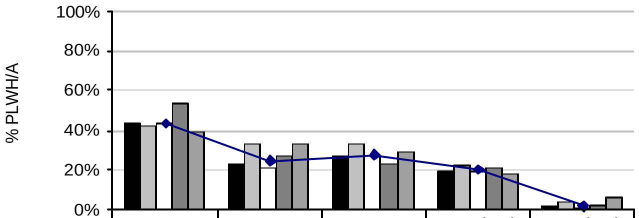
In the focus groups, most PLWH/A did report receiving client advocacy, although they did indicate a need. People expressed the need for someone to help them when a case manager wasn't able to adequately assist them in getting a service. A Central Anglo heterosexual female said, *"The Medicaid and Social Security system is complicated. My case manager can help fill out the applications, but when it comes to going to the meeting groups and helping you getting through the process, she looks at the questions and are just as confused. We need someone that would know the system of Social Security and Medicaid and know how to get around those kind of things."*

A Central Anglo heterosexual female said, *"I need to find someone to help with care when my liver fails completely. Help getting Social Security disability. Someone to help me to not lose my home (only 7 more payments). Our care site closed because there was no funding."*

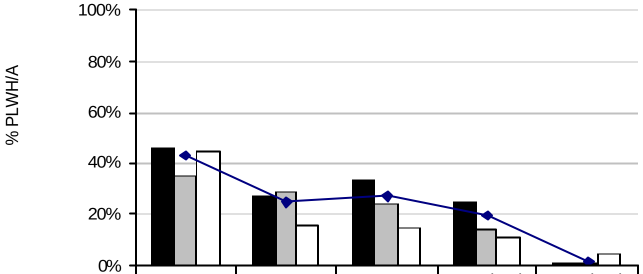
A Southern Anglo male said, *"I had a problem with a medical lab and some issue that I had. I really didn't know what to do at the time. I was very scared. I had a job at the time, and I had quit my job, because I was not open about my status then. I was afraid that my status was going to be divulged to other people that I was working with. I called the Indiana AIDS Hotline, which I don't think exists anymore, and they got me through to an advocate who helped me with that problem. I really liked him, and he did a really good job for me. It worked out."*

A Central Anglo heterosexual female mentioned a need for a client advocate based on what her case manager was not able to assist. She said, *"They helped me with the paper work but as far as the attorneys or anything like social security, they weren't helpful. And I heard you don't get it without an attorney."*

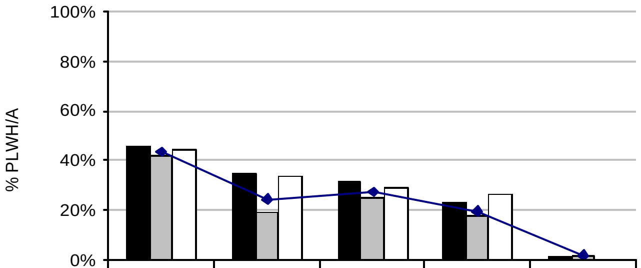
Employment Assistance/Vocational Counseling and Training



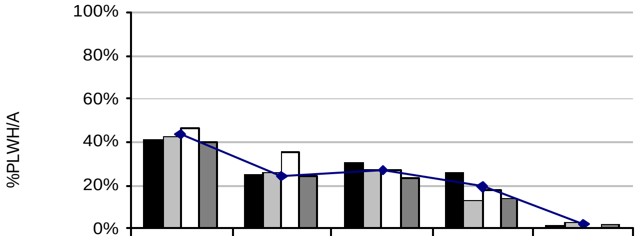
	Available	Need	Asked	Received ever	Received last year
Male	43.7%	23.2%	26.4%	19.0%	1.5%
Female	41.8%	32.7%	32.8%	22.5%	3.5%
MSM	43.2%	20.7%	26.8%	18.9%	1.1%
IDU	53.4%	26.6%	22.9%	20.8%	2.5%
HET	38.6%	32.9%	29.2%	17.6%	6.0%
Total	43.4%	24.6%	27.4%	19.6%	1.8%



	Available	Need	Asked	Received ever	Received last year
Central	46.1%	27.4%	33.7%	24.7%	1.4%
North	35.0%	28.8%	24.5%	14.1%	1.0%
South	45.2%	16.1%	15.0%	11.3%	4.6%
Total	43.4%	24.6%	27.4%	19.6%	1.8%



	Available	Need	Asked	Received ever	Received last year
Af Am	45.5%	34.5%	31.8%	22.9%	1.5%
Anglo	42.2%	19.1%	25.1%	17.5%	2.0%
Latino	44.4%	33.7%	29.3%	26.1%	0.0%
Total	43.4%	24.6%	27.4%	19.6%	1.8%



	Available	Need	Asked	Received ever	Received last year
H Asymp	41.0%	25.2%	30.5%	25.4%	1.3%
H Symp	42.2%	25.6%	26.8%	13.4%	2.5%
A Asymp	46.7%	35.6%	27.3%	17.8%	0.8%
A Symp	40.6%	24.2%	23.6%	14.1%	2.2%
Total	43.4%	24.6%	27.4%	19.6%	1.8%

	Average # Past Year
Sample	**14.5**
Male	16.2
Female	8.6
MSM	17.4
MSM/IDU	14.5
IDU	6.9
HET	3.0
Af Am	22.7
Anglo	9.0
Latino	2.8
Central	6.7
North	40.0
South	2.6
H asymp	7.0
H symp	2.3
A asymp	70.5
A symp	3.1

Top Barrier

Insufficient response rate on this service

Highlights

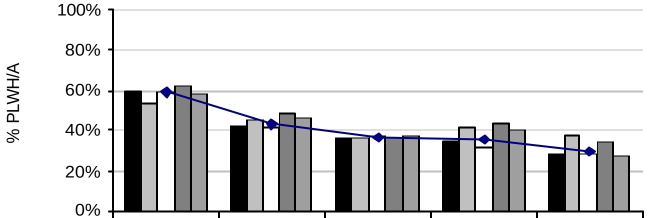
- Vocational training is ranked as the fourteenth service priority by ISDH and it is not among the most important services for PLWH/A.
- On average, over 40% of PLWH/A perceive that the employment assistance is available for them. A quarter of the PLWH/A have a current need. While over a quarter reports having asked for employment assistance, less than 20% report receiving it, leaving it as one the largest gaps between asking for and receiving services. Less than 2% report receiving vocational services last year.
- Those who received employment services, went to, on average, 15 days of service, with the large average number of days used by those in the North.
- Among sex and risk groups, females report needing and asking for vocational services more than men, but they receive just slightly more services than men. Although employment assistance is more available and accessible to IDUs than to heterosexuals and MSM, IDUs are less likely to inquire for the service than the other risk groups.
- Regionally, vocational services appear more accessible in the Central region.
- Southern PLWH/A indicate the least need for employment assistance compared to Central and Northern PLWH/A, however Central PLWH/A rank highest in asking and receiving the service.
- African Americans and Latinos are much more likely to need, ask and access employment assistance than Anglos.
- Overall, asymptomatic PLWA rank highest in need for employment assistance.

Vocational Services – Qualitative Comments

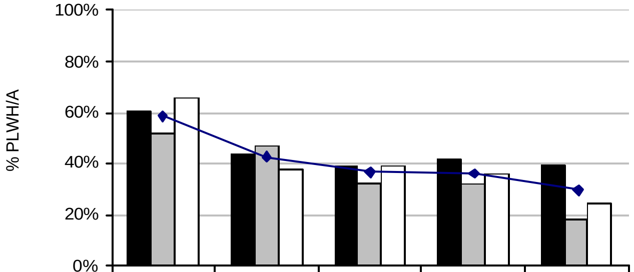
In the focus groups, several PLWH/A noted a desire to go back to work, are reluctant because they were unsure what would happen to their disability and unsure whether they would continue to have the stamina to engage in regular work. For example, a recently released Anglo MSM said, *"My biggest need actually is the vocational rehab. I am going from outside on my own and it is extremely hard to get into. The barrier with it is the time and effort that I am putting into it and not getting anywhere and they are telling me it is going to be at least a three month process, whereas I have the need now."* A Southern Anglo male said, *"A future need would be services on returning to work. Diseases take a certain toll on the body, and the type of work I did at one time, I'm not going to be able to do. There would have to be some type of free education for those trying to return to work.*

In many instances the confusion stems from the conflicting information they receive about going back to work. An Anglo male said, *"From what I understand based on what I heard at a peer group, if we were to go to school to further our education or something or get some other training, as soon as we were to graduate from school, we'd be taken off disability, and we'll probably have to go back to work. You've got nine months while you're going to school, and after that, you get taken off of disability and required to go back to work. That's considered your trial period."* And yet another group member contributed, *"Hearing what we have been told, he's been told one thing. I've been told something else. He's been told something else. She's been told something else. If you get somebody in this room right now who would tell us this is the way it is, I'd laugh at them. I would laugh at them for the simple reason that when he'd walked out of this room, somebody else would come in here and say, 'No. This is the way it is.'"*

Nutrition Education and Counseling

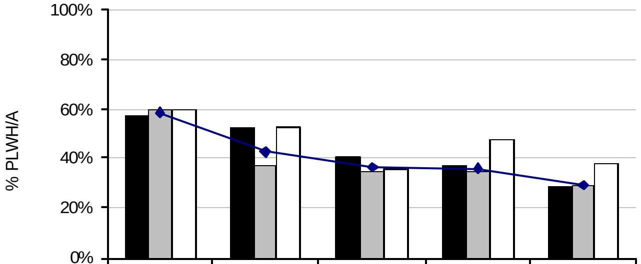


	Available	Need	Asked	Received ever	Received last year
Male	59.7%	42.5%	36.5%	34.9%	28.1%
Female	53.9%	45.1%	36.5%	42.0%	37.9%
MSM	58.9%	41.8%	36.9%	32.1%	27.8%
IDU	61.8%	48.8%	36.7%	44.1%	33.7%
HET	58.3%	46.4%	37.4%	39.9%	27.5%
Total	58.8%	42.9%	36.5%	35.9%	29.5%

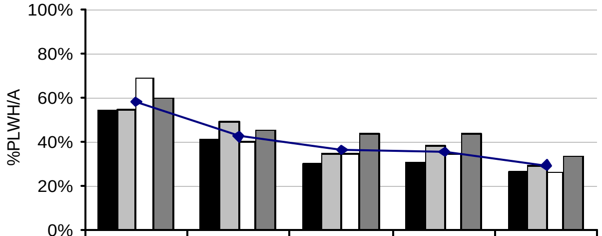


	Available	Need	Asked	Received ever	Received last year
Central	60.1%	44.0%	38.9%	42.0%	39.7%
North	52.3%	46.8%	32.5%	32.0%	18.1%
South	65.6%	37.7%	39.3%	36.1%	24.7%
Total	58.8%	42.9%	36.5%	35.9%	29.5%

	Average # Past Year
Sample	5.1
Male	4.6
Female	7.1
MSM	4.1
MSM/IDU	5.1
IDU	8.6
HET	3.9
Af Am	5.6
Anglo	4.8
Latino	5.3
Central	4.7
North	4.4
South	7.9
H asymp	6.0
H symp	4.8
A asymp	4.9
A symp	4.5



	Available	Need	Asked	Received ever	Received last year
Af Am	57.6%	52.7%	40.7%	37.1%	28.7%
Anglo	59.5%	37.3%	34.5%	34.7%	29.5%
Latino	59.9%	52.8%	35.8%	47.7%	37.6%
Total	58.8%	42.9%	36.5%	35.9%	29.5%



	Available	Need	Asked	Received ever	Received last year
H Asymp	54.8%	41.7%	30.3%	31.3%	26.9%
H Symp	55.0%	50.0%	35.4%	38.8%	29.9%
A Asymp	68.9%	40.9%	34.9%	34.9%	26.0%
A Symp	59.7%	45.5%	44.4%	44.4%	33.5%
Total	58.8%	42.9%	36.5%	35.9%	29.5%

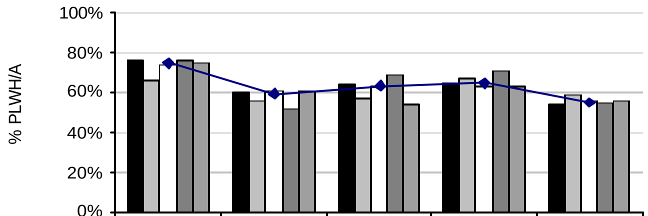
Top Barriers

Insufficient response rate on this service

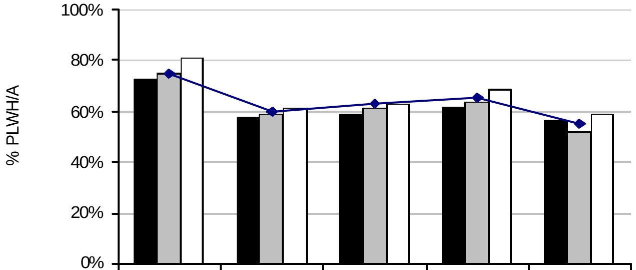
Highlights

- Nutrition education and counseling are not perceived to be among the top needs by PLWH/A.
- On average, almost 60% of PLWH/A know about nutrition and education counseling, about 43% say they need it, and 36% ask and receive it. Last year about 30% reported receiving nutrition education counseling.
- PLWH/A received nutritional counseling on average about 5 times a year. IDUs, Asymptomatic PLWH, and PLWH/A residing in the South accessed nutrition education and counseling more than other subpopulations.
- Among sex and risk groups, there is little difference in knowledge. IDUs report needing nutrition education counseling more than other risk groups, and they receive it more. Heterosexuals, who are disproportionately female, report receiving more nutrition education and counseling than other risk and sex groups.
- Among different regions, PLWH/A living in the North tend to ask for and receive less nutrition and educational counseling.
- Among ethnic populations, African Americans are more likely to need and ask for nutrition education and counseling than Latinos and Anglos. However they are about as likely to receive the service as other ethnic populations.
- Among different stages of infection, HIV symptomatic appear to have a high need, but may not ask for the service.

Information Education and Counseling

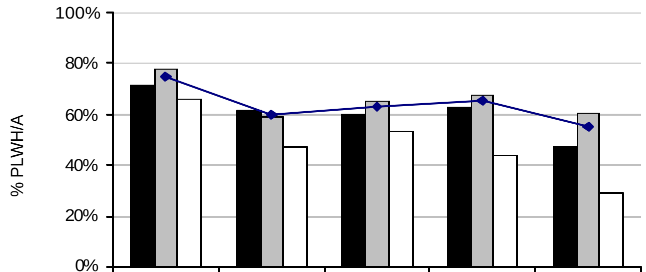


	Available	Need	Asked	Received ever	Received last year
Male	76.6%	60.4%	64.0%	64.8%	54.4%
Female	66.3%	55.4%	57.4%	67.4%	58.4%
MSM	74.4%	60.8%	63.6%	63.3%	55.7%
IDU	76.1%	52.2%	68.5%	70.7%	55.3%
HET	74.5%	60.7%	54.4%	63.7%	56.0%
Total	75.1%	59.7%	63.1%	65.2%	55.0%

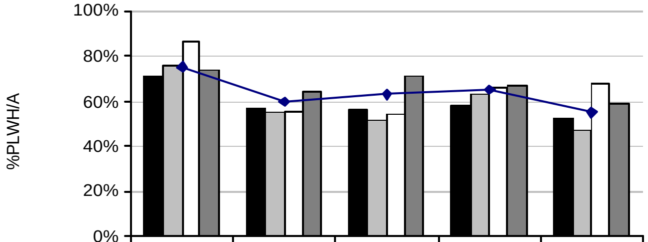


	Available	Need	Asked	Received ever	Received last year
Central	72.2%	57.3%	58.4%	61.5%	56.3%
North	74.8%	58.8%	60.8%	63.6%	51.8%
South	80.6%	61.3%	62.9%	68.9%	58.5%
Total	75.1%	59.7%	63.1%	65.2%	55.0%

	Average # Past Year
Sample	**7.2**
Male	7.2
Female	7.2
MSM	7.3
MSM/IDU	5.7
IDU	9.4
HET	4.1
Af Am	8.8
Anglo	6.7
Latino	5.5
Central	6.9
North	90.6
South	5.4
H asymp	91.3
H symp	4.3
A asymp	11.3
A symp	6.9



	Available	Need	Asked	Received ever	Received last year
Af Am	71.0%	61.7%	59.8%	62.7%	47.5%
Anglo	77.8%	59.6%	65.3%	67.7%	60.4%
Latino	66.1%	47.5%	53.5%	43.7%	29.1%
Total	75.1%	59.7%	63.1%	65.2%	55.0%



	Available	Need	Asked	Received ever	Received last year
H Asymp	70.8%	56.7%	56.3%	58.7%	52.4%
H Symp	75.6%	54.9%	51.9%	63.4%	47.0%
A Asymp	86.7%	55.6%	54.5%	66.7%	68.0%
A Symp	74.0%	64.3%	70.9%	66.9%	59.3%
Total	75.1%	59.7%	63.1%	65.2%	55.0%

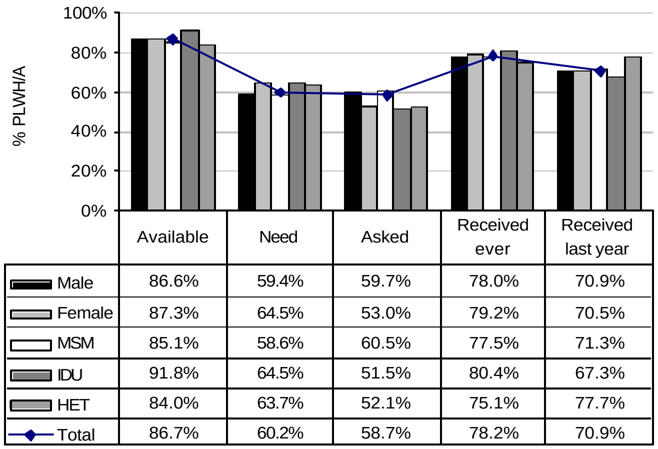
Top Barriers

- Not knowing what service is available to me.
- The level of expertise of the person providing the service.
- The cost of the service to me.
- The quality of service.

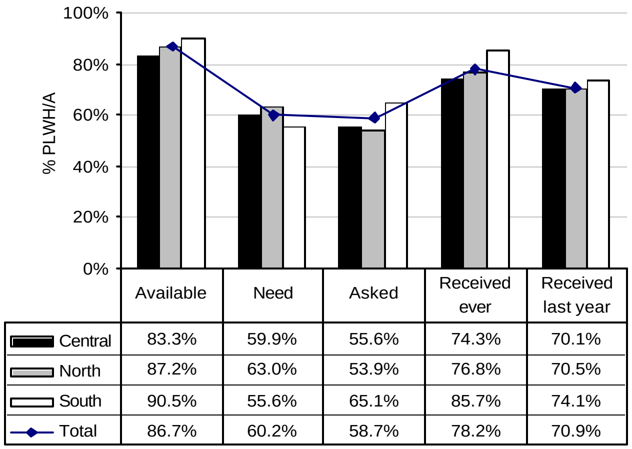
Highlights

- On average, about three quarters of the PLWH/A know about information, education and counseling (IEC), 60% - 65% need, ask for, and ever receive IEC, with 55% receiving it in the past year.
- IEC is not perceived to be among the top needs of PLWH/A, and more IEC is received than asked for.
- PLWH/A receive IEC on an average of 7.2 times a year, with fewer sessions being accessed by heterosexuals and MSM/IDU.
- Among sex and risk groups, males are more knowledgeable about IEC than females, but females report receiving IEC at the same level as males. IDUs are among the most knowledgeable about IEC and they have utilized it more than other risk groups.
- PLWH/A in the South have greater knowledge, need, and use of IEC.
- Latinos are less likely than African Americans and Anglos to ask for IEC, and Latinos and African Americans report receiving IEC less than Anglos.
- Although PLWH/A at all stages of infection have the same access to IEC, symptomatic PLWA tend to ask for IEC services more than asymptomatic.

Newsletter, Leaflets or Booklets about HIV/AIDS Treatment and Care

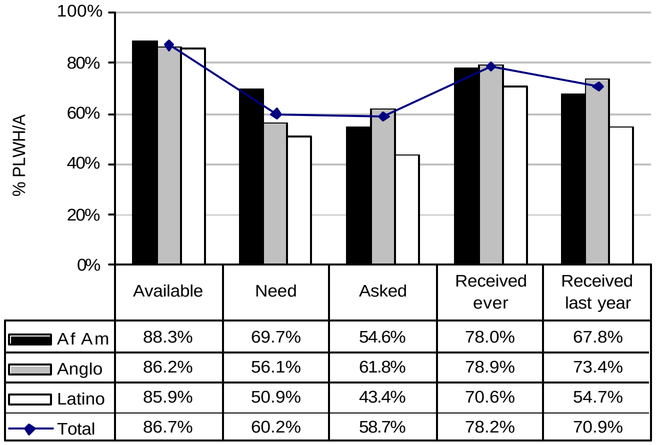


	Available	Need	Asked	Received ever	Received last year
Male	86.6%	59.4%	59.7%	78.0%	70.9%
Female	87.3%	64.5%	53.0%	79.2%	70.5%
MSM	85.1%	58.6%	60.5%	77.5%	71.3%
IDU	91.8%	64.5%	51.5%	80.4%	67.3%
HET	84.0%	63.7%	52.1%	75.1%	77.7%
Total	86.7%	60.2%	58.7%	78.2%	70.9%

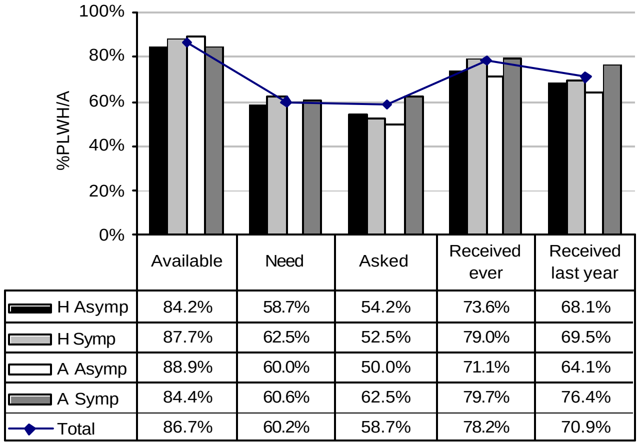


	Available	Need	Asked	Received ever	Received last year
Central	83.3%	59.9%	55.6%	74.3%	70.1%
North	87.2%	63.0%	53.9%	76.8%	70.5%
South	90.5%	55.6%	65.1%	85.7%	74.1%
Total	86.7%	60.2%	58.7%	78.2%	70.9%

	Average # Past Year
Sample	**13.4**
Male	13.6
Female	12.2
MSM	10.7
MSM/IDU	14.0
IDU	14.9
HET	32.6
Af Am	13.8
Anglo	12.9
Latino	23.3
Central	12.7
North	9.0
South	25.0
H asymp	9.2
H symp	15.0
A asymp	9.7
A symp	17.0



	Available	Need	Asked	Received ever	Received last year
Af Am	88.3%	69.7%	54.6%	78.0%	67.8%
Anglo	86.2%	56.1%	61.8%	78.9%	73.4%
Latino	85.9%	50.9%	43.4%	70.6%	54.7%
Total	86.7%	60.2%	58.7%	78.2%	70.9%



	Available	Need	Asked	Received ever	Received last year
H Asymp	84.2%	58.7%	54.2%	73.6%	68.1%
H Symp	87.7%	62.5%	52.5%	79.0%	69.5%
A Asymp	88.9%	60.0%	50.0%	71.1%	64.1%
A Symp	84.4%	60.6%	62.5%	79.7%	76.4%
Total	86.7%	60.2%	58.7%	78.2%	70.9%

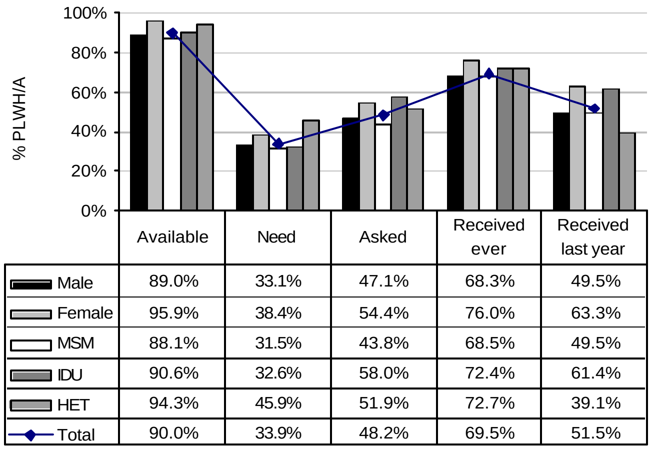
Top Barriers

Insufficient response rate on this service

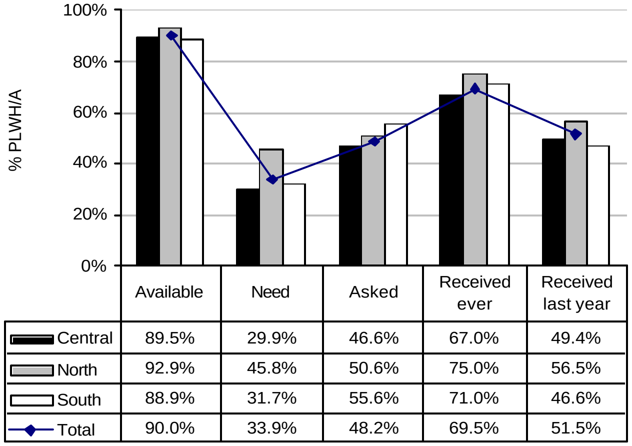
Highlights

- Newsletters, leaflets, and booklets about HIV/AIDS treatment are <u>not</u> perceived as one of the top services by PLWH/A.
- On average, 87% of the PLWH/A know about newsletters, leaflets, and booklets about HIV/AIDS treatment and care. About 60% say they need it and ask for it. 78% say they have ever received them, and 71% say they received it last year.
- Of those who receive information, on average PLWH/A report receiving over 13 items a year. MSM report receiving the fewest items in the last year.
- PLWH/A report receiving more newsletters, leaflets, and booklets than they ask for.
- Among sex and risk groups, males and MSM are most likely to ask for information, but there is little difference in the percentage of each risk group reporting receiving material. In the last year, however, heterosexuals reported they were more likely to receive material.
- Regionally, PLWH/A in the South are more likely to ask for and receive information.
- Among ethnic populations, African Americans report the greatest need for newsletters, while Anglos report the lowest need. Yet, Anglos ask for newsletters, leaflets, and booklets the most, and receive them the most.
- Among PLWH/A at different stages of infection, more symptomatic PLWA ask for this service, and HIV and AIDS symptomatic tend to receive more of newsletters, leaflets and booklets.

Information about how to prevent infecting others with HIV

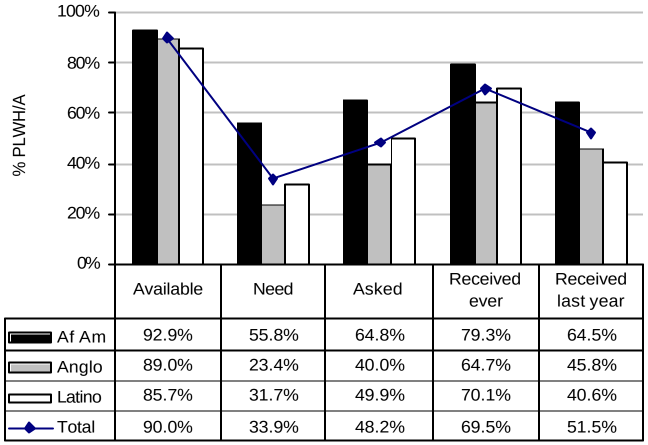


	Available	Need	Asked	Received ever	Received last year
Male	89.0%	33.1%	47.1%	68.3%	49.5%
Female	95.9%	38.4%	54.4%	76.0%	63.3%
MSM	88.1%	31.5%	43.8%	68.5%	49.5%
IDU	90.6%	32.6%	58.0%	72.4%	61.4%
HET	94.3%	45.9%	51.9%	72.7%	39.1%
◆ Total	90.0%	33.9%	48.2%	69.5%	51.5%

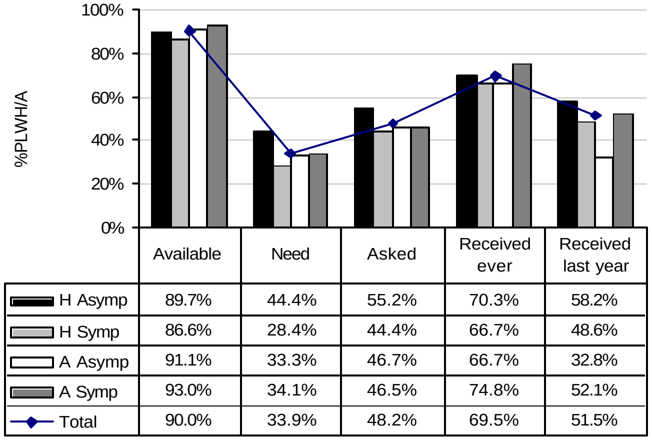


	Available	Need	Asked	Received ever	Received last year
Central	89.5%	29.9%	46.6%	67.0%	49.4%
North	92.9%	45.8%	50.6%	75.0%	56.5%
South	88.9%	31.7%	55.6%	71.0%	46.6%
◆ Total	90.0%	33.9%	48.2%	69.5%	51.5%

	Average # Past Year
Sample	9.6
Male	10.1
Female	7.1
MSM	11.1
MSM/IDU	6.6
IDU	7.8
HET	6.1
Af Am	8.2
Anglo	10.8
Latino	5.2
Central	13.7
North	6.7
South	4.3
H asymp	6.3
H symp	6.4
A asymp	48.0
A symp	8.1



	Available	Need	Asked	Received ever	Received last year
Af Am	92.9%	55.8%	64.8%	79.3%	64.5%
Anglo	89.0%	23.4%	40.0%	64.7%	45.8%
Latino	85.7%	31.7%	49.9%	70.1%	40.6%
◆ Total	90.0%	33.9%	48.2%	69.5%	51.5%



	Available	Need	Asked	Received ever	Received last year
H Asymp	89.7%	44.4%	55.2%	70.3%	58.2%
H Symp	86.6%	28.4%	44.4%	66.7%	48.6%
A Asymp	91.1%	33.3%	46.7%	66.7%	32.8%
A Symp	93.0%	34.1%	46.5%	74.8%	52.1%
◆ Total	90.0%	33.9%	48.2%	69.5%	51.5%

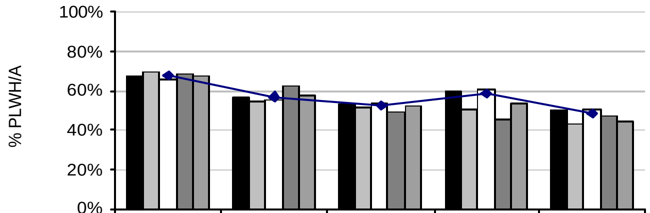
Top Barriers

Insufficient response rate on this service

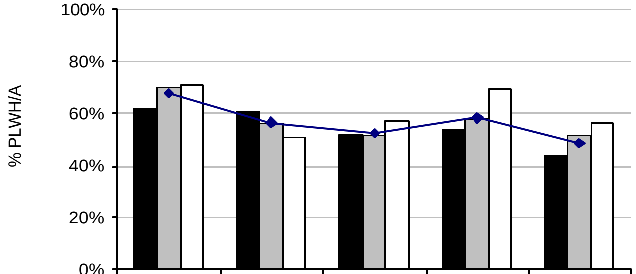
Highlights

- Prevention information is <u>not</u> perceived among the top needs by PLWH/A.
- On average, 90% of PLWH/A have heard of information about preventing infecting others with HIV. Thirty-four percent say they need it, almost half have asked for it, and about 79% have received it.
- PLWH/A perceive receiving far more prevention information than they need or ask for.
- Among sex and risk groups, heterosexuals perceive the greatest need, however IDUs ask for it the most. A larger proportion of Females report receiving information. On average all three risk groups have the same level of accessibility to prevention information.
- Among PLWH/A living in different regions, Northern PLWH/A reported a higher need for prevention information.
- Among ethnic populations, Anglo reported the lowest need for prevention information, while African Americans reported the highest need. More African Americans ask for and receive prevention information than Latinos and Anglos.
- Among PLWH/A at different stages of infection, asymptomatic PLWH report a higher need for prevention information, and are much more likely to ask for the service compared to symptomatic PLWH/A.

Resource Guide that lists HIV/AIDS services

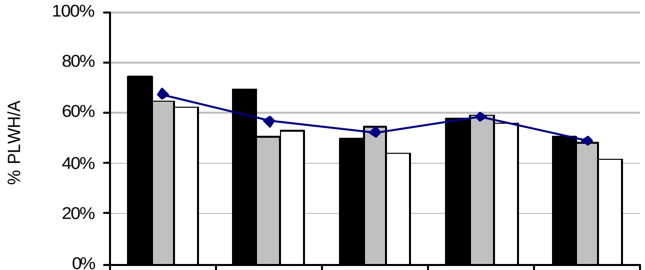


	Available	Need	Asked	Received ever	Received last year
Male	67.4%	57.1%	52.8%	59.7%	49.6%
Female	68.9%	54.4%	51.7%	50.6%	43.0%
MSM	65.8%	55.5%	53.6%	61.2%	51.1%
IDU	68.6%	62.6%	48.9%	45.6%	47.1%
HET	67.4%	57.7%	52.2%	53.7%	44.3%
Total	67.6%	56.7%	52.7%	58.3%	48.7%

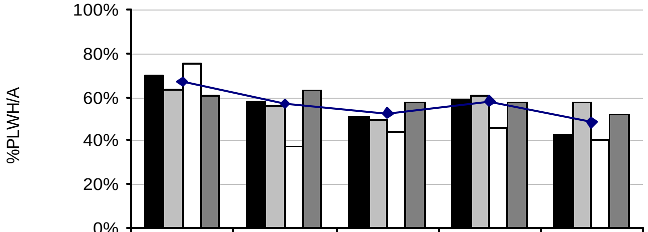


	Available	Need	Asked	Received ever	Received last year
Central	61.9%	60.6%	52.2%	53.9%	43.9%
North	70.1%	56.1%	51.6%	58.1%	51.6%
South	71.4%	50.8%	57.1%	69.8%	56.5%
Total	67.6%	56.7%	52.7%	58.3%	48.7%

	Average # Past Year
Sample	**4.2**
Male	4.0
Female	5.5
MSM	4.1
MSM/IDU	3.8
IDU	5.8
HET	2.8
Af Am	5.0
Anglo	4.0
Latino	1.7
Central	4.0
North	4.2
South	4.9
H asymp	4.6
H symp	4.4
A asymp	2.8
A symp	4.2



	Available	Need	Asked	Received ever	Received last year
Af Am	74.7%	69.2%	49.8%	57.6%	50.8%
Anglo	64.6%	50.8%	54.7%	59.0%	48.2%
Latino	62.1%	53.1%	44.1%	55.8%	41.8%
Total	67.6%	56.7%	52.7%	58.3%	48.7%



	Available	Need	Asked	Received ever	Received last year
H Asymp	69.9%	58.3%	51.4%	59.0%	42.8%
H Symp	63.9%	56.1%	50.0%	61.0%	57.7%
A Asymp	75.6%	37.8%	44.4%	46.7%	41.0%
A Symp	60.9%	63.3%	57.8%	57.8%	52.2%
Total	67.6%	56.7%	52.7%	58.3%	48.7%

Top Barriers

Insufficient response rate on this service

Highlights

- Having a resource guide that lists HIV/AIDS services is not perceived as a top need among PLWH/A.
- On average, 68% of PLWH/A are aware that a resource guide is available, and between 50% and 60% need, ask for and receive a resource guide. More PLWH/A report receiving a guide than asking for one.
- Among PLWH/A who receive guides, they report, on average, 4 guides a year. African Americans receive on average five guides a year while Latinos report receiving two.
- Among sex and risk groups, males report a greater need and they ask for and receive guides more guides. IDUs report the greatest need, but are less likely to ask for resource guides.
- Among PLWH/A in different regions, Southern PLWH/A access and receive the largest number of guides.
- Among ethnic populations, African Americans and Latinos are much more likely to need resource guides, but less likely to ask for and receive them compared to Anglos. Latinos are far less likely to receive guides.
- Among PLWH/A at different stages of infection, asymptomatic PLWA report less need and are less likely to ask for and receive guides.

Prevention, Health Education and Risk Reduction Qualitative Comments

This service category includes five subcategories: 1) Nutrition education and counseling, 2) Information about treatments and care from peers or provider, 3) Newsletters, leaflets or booklets about HIV/AIDS treatment and care, 4) Information about how to prevent infecting other with HIV, and 5) a resource guide that lists HIV/AIDS services.

Comments from several participants of the focus group confirmed the need to continue an aggressive program of information about care and prevention. For example, a Northern African American heterosexual female said, *"I never thought I could catch HIV. I was young and I wasn't thinking about it. I got a phone call one day and they told me it was the Board of Health and they had a call saying that I should come in and take a test. I said 'Take a test for what?' I thought that it was for a bit of pneumonia. But somebody said they had come in and taken an AIDS test and that I now need to come in. I went into the Board of Health and said to myself 'I know that I can't have AIDS.' I kept saying it and I was praying to God that I wouldn't have AIDS. But it came out that I did have AIDS. …My kids were one and two and they have not been diagnosed with HIV. I felt very low because here it is they have a protection and I can't blame nobody but myself. You can't sit up here and blame anybody but yourself.'*

As well as prevention material, many PLWH/A noted their appreciation of information about the medications they were taking, and the availability of person who can provide further information. For example , an Anglo Male living in the South said, *"I found out the best thing to do with the new medications and be positively aware…. As soon as I get [a newsletter] and I read it I don't take it to my doctor. I take it to my pharmacist. I ask him, "How much better is this going to be for me than say the Crixovan or Combavir?"… If you keep up on it, and you read the publications, if you don't understand them, take them to your pharmacist or take them to your doctor."* An Anglo Male from the South emphasized the need to stay informed. He said, *" I am getting information on what's new and what's available [medications]. This is what you're on. You're going to stay there the rest of your life."*

The use of material by PLWH/A of all ethnicities was clear from comments like those from a Latino MSM from the Central region. He said, *"I definitely need and use the newsletters, leaflets and booklets. I get a number of publications all about HIV like Poz Magazine. Fortunately they provide that free if you are on disability. There is a newsletter that I actually purchase, but I like to read up on all of this stuff and all of the medications, so I know what I'm dealing with, and so that I have ideas for my doctor. I do need that service, but of course that's all either donated or you pay for it yourself."*

Differences in the amount and quality of information by region was suggested by focus group participants, with participants living in the North often citing the greater availability of information in the Central region. A Northern African American MSM said, *"I have a friend that lives in Indianapolis that gave me a handbook. As I went through the book, I don't hardly see any of these* *things going on here in Ft. Wayne. But I looked into this book and saw that there are things going on through the country - so I know they are accessible. This is the first time that I have heard that they may be accessible here in Ft. Wayne and there are things we are not getting or certain people are being chosen to receive. But I don't know anything about all that."*

A Northern African American MSM said, *"A news bulletin board about different treatment options would be great. None of that is currently here - it may be available, but it's not mentioned I guess you should say. It's not mentioned. It's available in the Chicago area. The services are available here but they are just hard to get to."* Another African American MSM from the North, said, *"There is only one AIDS service organization for three counties [in the Gary region]. There is only one AIDS service organization satellite offices and they are for consumer services or client related services. Other than Internet access one of the groups our brothers were working on, putting a newsletter together with current treatment information that they haven't spoken about. Now that is available."*

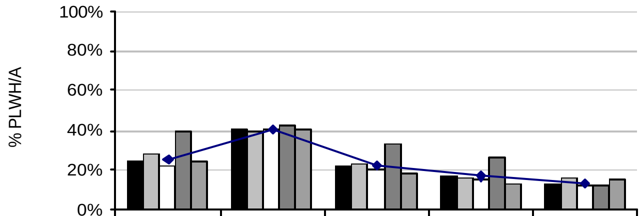
There was some indication from focus group participants that there was poor distribution of information to the rural areas. An Anglo Male IDU living in the Central region said, *"You were asking do I know any people in rural areas, and yes I know two people. I know this one person and I know a lot of times he has come up to visit and he will see magazines or handouts from things that I may have picked up at the [large ASO] and, "Oh, wow. What's that? What's this all about?" They don't have any access to general magazine subscriptions."*

Focus groups participants also said that the amount and quality of information varied by site. For example, an Anglo MSM from the Central region said, *"The people there at xxxxx don't know anything, they said we don't even know that much about nutrition. It is a hospital, of course they don't. You only take one course in nutrition to be a medical doctor. You know, what a load of crap."*

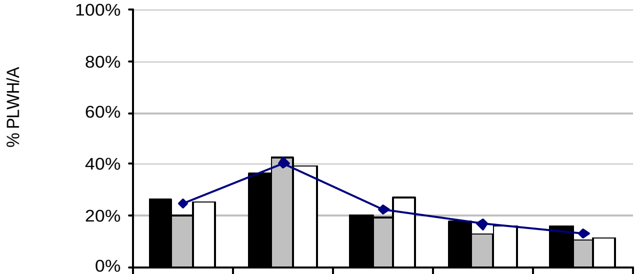
Another PLWH/A from the South said, *"For me, since I'm on a Statewide Consumer Advisory Board [CAB], I get a lot of information about new medications and drug trials and what not through CAB. I think that it should be more circulated. I think it should be more circulate out to the rest of the consumers that aren't on the board. You should not have to be on the board to be getting this information."*

Even with information, focus group participants said they needed a care giver to help sort through information. A Northern Anglo male said, *"I've sent off, by myself I have called different agencies and I've gotten pamphlets and stuff but it really doesn't tell me much. My doctor just told me that I was positive for Hepatitis C."*

Holistic/Complimentary Care

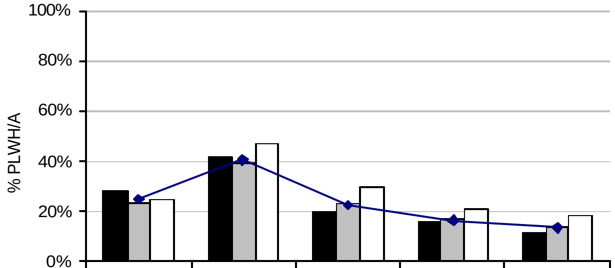


	Available	Need	Asked	Received ever	Received last year
■ Male	24.3%	40.4%	22.1%	16.6%	12.7%
░ Female	28.4%	40.0%	23.1%	16.2%	16.2%
□ MSM	22.5%	40.7%	20.4%	15.4%	12.3%
▓ IDU	39.8%	42.9%	33.1%	26.6%	11.9%
▒ HET	24.3%	40.2%	18.3%	13.2%	15.5%
—◆— Total	24.9%	40.3%	22.3%	16.6%	13.2%

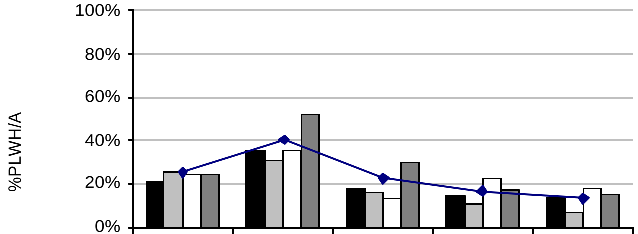


	Available	Need	Asked	Received ever	Received last year
■ Central	26.4%	36.5%	20.1%	17.9%	15.7%
░ North	20.0%	42.9%	19.5%	12.8%	10.7%
□ South	25.4%	39.7%	27.0%	15.9%	11.3%
—◆— Total	24.9%	40.3%	22.3%	16.6%	13.2%

	Average # Past Year
Sample	13.4
Male	14.8
Female	7.3
MSM	18.3
MSM/IDU	4.3
IDU	9.4
HET	5.4
Af Am	5.3
Anglo	17.7
Latino	3.6
Central	19.1
North	7.2
South	3.1
H asymp	21.8
H symp	7.0
A asymp	2.5
A symp	11.0



	Available	Need	Asked	Received ever	Received last year
■ Af Am	28.2%	41.7%	19.6%	15.8%	11.7%
░ Anglo	23.4%	39.3%	23.1%	16.7%	13.7%
□ Latino	25.0%	46.9%	29.6%	21.3%	18.0%
—◆— Total	24.9%	40.3%	22.3%	16.6%	13.2%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	20.8%	35.2%	18.2%	14.5%	13.6%
░ H Symp	25.6%	30.5%	15.9%	11.0%	6.7%
□ A Asymp	24.4%	35.6%	13.3%	22.2%	18.3%
▓ A Symp	24.6%	52.4%	29.9%	17.3%	15.3%
—◆— Total	24.9%	40.3%	22.3%	16.6%	13.2%

Top Barrier

Insufficient response rate on this item

Highlights

- Complementary or holistic care is ranked sixteen in importance by ISDH and is not among the top ranked services by PLWH/A.
- On average, about a quarter of PLWH/A perceive holistic care is available for them. About 40% say they currently need holistic care. About 22% have asked for holistic care, and 17% report having received it. 13% report having received it in the last year.
- More PLWH/A ask for holistic care than receive it, and the largest gap is among symptomatic PLWA. A larger proportion of PLWH/A report getting the service (39.8%) than MSM (22.5%) and heterosexuals (24.3%). Despite that, similar pattern exists for the need of holistic care for all three ethnicities. IDUs are much more likely to inquire and access the service, compared to MSM and heterosexuals.
- Holistic care is less available to Latinos (17.1%) compared to African Americans (28.2%) and Anglos (23.4%). All three ethnicities indicate a similar pattern in needing, inquiring, and accessing holistic care.
- Although asymptomatic PLWA are less likely to need and ask for holistic care than symptomatic PLWA, they are more likely to access the service than symptomatic PLWA; however during the pat year, symptomatic PLWA accessed holistic care on average more frequently (11 times) than asymptomatic PLWA (2.5 times).
- Asymptomatic PLWH are more likely to need, ask for and receive holistic or complimentary care.

Complementary Health Care – Qualitative Comments

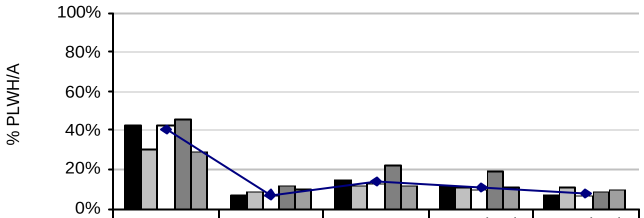
Focus groups participants noted that complementary or holistic care was not usually emphasized as part of their treatment. Although there were numerous testimonials to the value of acupuncture or message, it usually was not discussed as part of an overall treatment regimen. For example, a Southern Anglo male said, *"I really have to strike out on complimentary treatment. I've found no assistance with that. I am interested in taking vitamins, nutrition, and those types of therapies as opposed to the medication. "*

A Central Anglo MSM said, *"Actually the people at [the medical ASO], my doctors there, they couldn't even stand the idea of me trying to like feed HIV with nutrition and herbal alternatives. I chose another doctor. I said sayonara."*

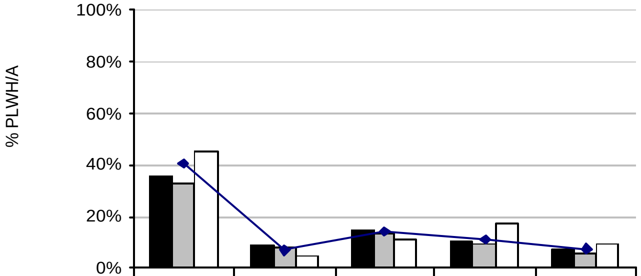
Cost was factor in seeking complementary care. A Southern Anglo female in another group said, *"If there were holistic therapies available, I don't think we'd be able to have the money, like vouchers, to go get it done if we couldn't afford it. I just think that a lot of the problems with getting holistic care is the fact that we are in a rural area. I think if we were in Indianapolis or Fort Wayne or someplace like that, that it would be a lot easier for us to get access to those types of things."*

A Central Latino MSM said, *"I've tried acupuncture and I like that. I've had massages and that worked really well. Of course those were all in another state where the services were provided free for people with AIDS. In fact there was medicinal marijuana as well provided in that state, and I have used those services, but I don't currently use them here because I can't get them."* Another Latino MSM in the same group said, *"I think my need is access to alternative treatments to supplement the medication. I sure miss the massages and acupuncture. I really found out it was very helpful and very relaxing. I would like some help with paying for supplements, but of course none of that is covered and that comes down to insurance."*

In-home medical care from a nurse or professional home health agency

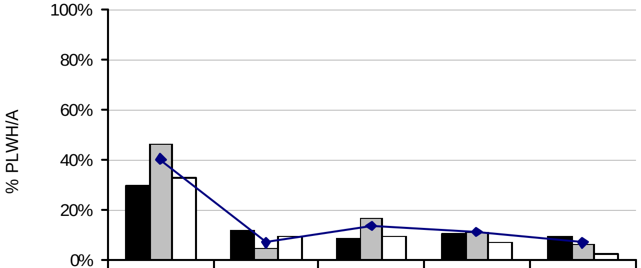


	Available	Need	Asked	Received ever	Received last year
Male	42.5%	7.1%	14.5%	11.2%	6.9%
Female	30.2%	8.7%	11.7%	11.0%	10.9%
MSM	42.8%	6.5%	12.5%	9.2%	5.8%
IDU	46.0%	12.0%	22.3%	19.3%	8.6%
HET	28.7%	9.8%	11.6%	10.5%	9.5%
Total	40.7%	7.3%	14.1%	11.2%	7.5%

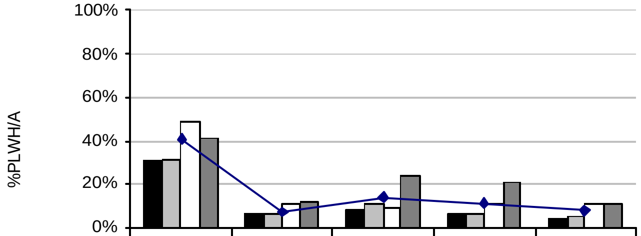


	Available	Need	Asked	Received ever	Received last year
Central	35.8%	9.1%	14.9%	10.9%	7.9%
North	33.1%	8.3%	13.5%	9.6%	6.1%
South	45.2%	4.8%	11.3%	17.7%	9.3%
Total	40.7%	7.3%	14.1%	11.2%	7.5%

	Average # Past Year
Sample	**39.2**
Male	37.3
Female	46.3
MSM	54.1
MSM/IDU	7.3
IDU	52.3
HET	13.0
Af Am	86.1
Anglo	7.2
Latino	1.0
Central	54.9
North	11.7
South	39.4
H asymp	76.2
H symp	11.8
A asymp	51.5
A symp	27.1



	Available	Need	Asked	Received ever	Received last year
Af Am	30.2%	12.2%	8.9%	10.9%	9.6%
Anglo	46.6%	4.6%	16.9%	11.6%	6.6%
Latino	33.3%	9.9%	9.9%	7.2%	3.2%
Total	40.7%	7.3%	14.1%	11.2%	7.5%



	Available	Need	Asked	Received ever	Received last year
H Asymp	30.8%	6.3%	8.5%	6.3%	4.5%
H Symp	31.3%	6.1%	11.0%	6.2%	5.1%
A Asymp	48.9%	11.1%	8.9%	11.1%	11.1%
A Symp	41.6%	11.9%	24.0%	20.6%	11.1%
Total	40.7%	7.3%	14.1%	11.2%	7.5%

Top Barrier

Insufficient response rate on this service

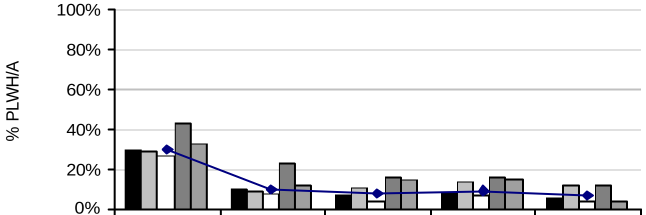
Highlights

- In home medical care is categorized as part of home health care, and it is ranked as the seventieth service priority by ISDH, and, given the relatively few PLWH/A who need it, it not perceived as a top need by all PLWH/A.
- About 40% of PLWH/A perceive the service is available for them, but only 7% say they currently need the service. 14% report they have ever asked for the home medical care, and 11% say report having received it. 7% say they have received it in the last year.
- Among the PLWH/A who receive home medical care, they report 39 visits a year, on average. African Americans report significantly above average number of visits.
- Among sex and risk groups, IDUs indicate they are more likely than MSM and heterosexuals to ask for and receive in-home medical care.
- A greater percentage of PLWH/A in the South report receiving home medical services, although they do ask for them in greater numbers than those in other regions.
- Among ethnic population, Anglos perceive home health care to be more available and ask for it more than other populations.
- Symptomatic PLWA are more likely to receive in-home medical care than other PLWH/A.

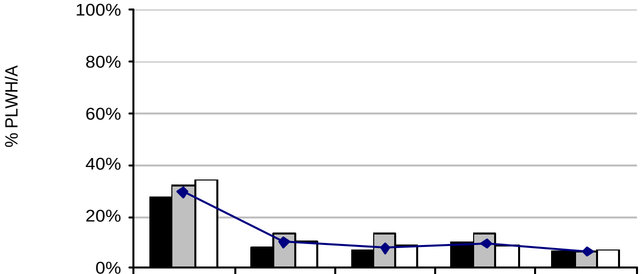
Home Health Care – Qualitative Comments

Home health care, both professional and non-professional were not mentioned frequently in the focus groups. The data indicated that there was a gap in the delivery of the service, and some of the comments supported a lack of knowledge. For example, a Northern African American female said, *"At one point, I needed the in-home services and I always thought that I had to pay for it. I didn't know it was available to me. My case worker never said anything."*

Translation or Interpretive Services

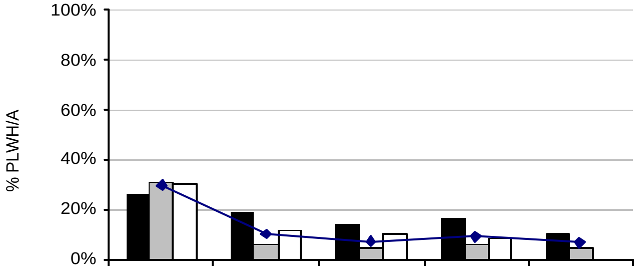


	Available	Need	Asked	Received ever	Received last year
■ Male	29.8%	10.3%	7.1%	8.5%	5.7%
▒ Female	29.0%	9.1%	10.3%	13.5%	12.1%
□ MSM	27.0%	7.4%	4.1%	6.6%	3.7%
▓ IDU	43.7%	22.9%	16.0%	16.2%	12.1%
▓ HET	32.7%	12.6%	14.4%	15.0%	3.5%
◆ Total	29.7%	10.1%	7.6%	9.3%	6.6%

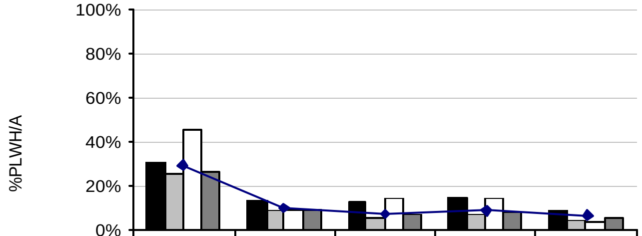


	Available	Need	Asked	Received ever	Received last year
■ Central	27.4%	8.5%	7.3%	10.2%	6.3%
▒ North	32.2%	13.3%	13.5%	13.4%	6.7%
□ South	33.9%	10.7%	8.9%	8.9%	7.2%
◆ Total	29.7%	10.1%	7.6%	9.3%	6.6%

	Average # Past Year
Sample	**6.7**
Male	12.0
Female	3.0
MSM	10.7
MSM/IDU	50.0
IDU	3.7
HET	2.0
Af Am	12.0
Anglo	5.0
Latino	82.2
Central	12.0
North	5.0
South	50.0
H asymp	3.0
H symp	50.0
A asymp	22.5
A symp	12.0



	Available	Need	Asked	Received ever	Received last year
■ Af Am	26.3%	18.8%	13.8%	16.5%	10.4%
▒ Anglo	31.1%	5.9%	4.8%	5.9%	4.9%
□ Latino	30.4%	11.6%	10.1%	8.7%	
◆ Total	29.7%	10.1%	7.6%	9.3%	6.6%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	30.8%	13.6%	13.0%	15.1%	8.9%
▒ H Symp	25.9%	8.8%	6.3%	7.5%	4.9%
□ A Asymp	46.3%	9.8%	14.6%	14.6%	3.9%
▓ A Symp	26.8%	9.8%	7.3%	8.1%	6.0%
◆ Total	29.7%	10.1%	7.6%	9.3%	6.6%

Top Barriers

Insufficient response rate on this service

Highlights

- Translation and interpretive services are not a top priority for ISDH or the PLWH/A.
- From responses to the service item, it appears that PLWH/A considered the category not only translation from or to a foreign language, but also interpretation of difficult to comprehend information.
- On average, just over a quarter of the PLWH/A perceive the service is available to them. Only 10% report a current need for translation services, and 7% report asking for the service. Less than 10%of the PLWH/A have ever received the service.
- Typically, PLWH/A have asked for translation services more than they have received them, but there is a very small service gap.
- Those PLWH/A accessing translation services say they receive, on average, 6.7 sessions in the past year. Heterosexuals and females report fewer sessions each year.
- Among ethnic populations African Americans report the greatest need for translation services, and perceive the service to be less available to them. Latinos ask less for translation services and receive slightly less of the service compared to Anglos. African Americans access the service more than the other ethnic populations.
- For PLWH/A who live in different regions, those living in the North report slightly higher need. Those in living in the Central are less likely to ask for translation services. All groups receive the same level of services.

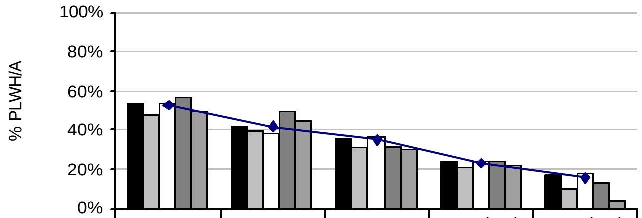
Translation and Interpretive Services – Qualitative Comments

The lack of a translator to assist a monolingual speaker makes receiving adequate service difficult. A Central Latino MSM said, *"I take my medicine on time all the time but I got sick and had to go to the hospital and had thousands of dollars in bills. I am concerned about them. I sought help to pay those bills with a counselor at the [ASO] to see if they could help out with the medical bills. But the way it's looking is they can take care of what my bills are now, but I am having a hard time with the light bills. I think I have problems because I am not able to speak English, not able to express himself to the insurance people. They want to talk to me and I ask if they would just talk to my wife I would understand. She could explain it to them. But they need to talk to me and they just want to talk to me."*

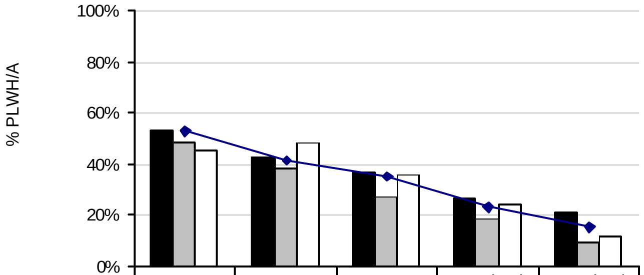
A Northern Latino male said, *"They are giving us support but there needs to be more people. Enough so that they could have an office where people spoke Spanish. There are a lot of Hispanics and since there are a lot who don't speak English like me it would be good. The only one who speaks Spanish here in this office speaks bad Spanish. Someone else who spoke Spanish use to come here but she didn't work here. She was here like you guys - she was contracted to do some work. She is gone now. The person here who needs support is the patient, because when one gets this illness and you go to an office where they know you have it they look at you as if just by talking to you they are going to contract the disease. They are wrong."*

Throughout the focus groups, participants note that they often lacked a general understanding of medication, protocols or eligibility. In some instances they received help, but in many others there was a growing sense of frustration at comprehending treatment.

Legal Help preparing wills or estate planning (including custody of children)

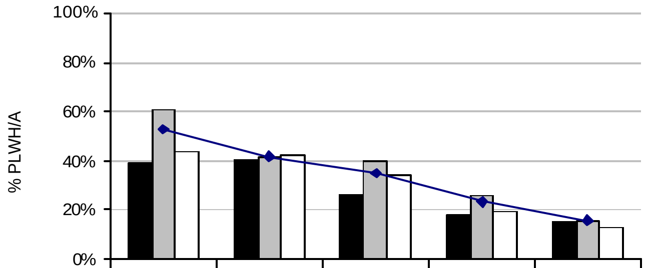


	Available	Need	Asked	Received ever	Received last year
■ Male	53.7%	41.9%	36.0%	23.7%	16.7%
▨ Female	48.1%	39.6%	30.9%	20.9%	9.9%
□ MSM	53.3%	37.6%	36.6%	23.9%	17.7%
▨ IDU	56.3%	49.9%	31.9%	23.8%	13.4%
▨ HET	49.9%	44.9%	30.3%	22.0%	3.5%
◆ Total	52.9%	41.5%	35.2%	23.3%	15.7%

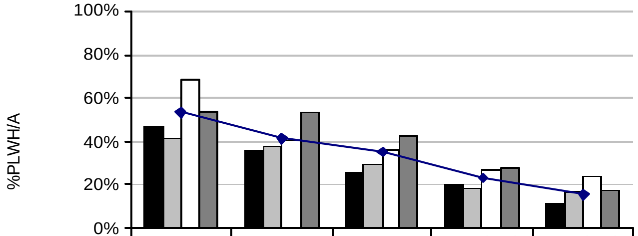


	Available	Need	Asked	Received ever	Received last year
■ Central	53.4%	42.7%	37.1%	27.0%	21.4%
▨ North	49.0%	39.0%	27.5%	18.2%	9.7%
□ South	46.0%	48.4%	35.5%	24.2%	12.0%
◆ Total	52.9%	41.5%	35.2%	23.3%	15.7%

	Average # Past Year
Sample	**1.7**
Male	1.7
Female	1.6
MSM	1.7
MSM/IDU	1.7
IDU	2.0
HET	1.0
Af Am	1.8
Anglo	1.7
Latino	1.3
Central	1.8
North	1.8
South	1.1
H asymp	1.6
H symp	1.6
A asymp	1.5
A symp	2.0



	Available	Need	Asked	Received ever	Received last year
■ Af Am	39.0%	40.5%	26.3%	18.3%	15.2%
▨ Anglo	60.6%	41.8%	39.7%	26.1%	16.1%
□ Latino	43.7%	42.5%	34.4%	19.9%	13.0%
◆ Total	52.9%	41.5%	35.2%	23.3%	15.7%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	46.5%	35.7%	26.1%	20.3%	11.2%
▨ H Symp	41.0%	37.8%	29.3%	18.3%	16.6%
□ A Asymp	68.2%	40.9%	36.4%	27.3%	23.5%
▨ A Symp	54.0%	53.2%	42.9%	27.8%	17.8%
◆ Total	52.9%	41.5%	35.2%	23.3%	15.7%

Top Barrier

Insufficient response rate on this service

Highlights

- Legal services are not a top priority for ISDH or the PLWH/A.
- On average, just of half of the PLWH/A perceive that the service is available for them. Forty-two percent report a current need for legal services. Thirty-five percent say they have ever asked for legal services, and 23% report having received legal services. Sixteen percent say they have received legal services in the past year.
- Typically, PLWH/A have asked for legal services more than they receive them, and although it is not a high priority, legal services have one of the largest gaps of any service, and is very large among symptomatic PLWA.
- Those PLWH/A accessing legal services say they receive, on average, 1.7 sessions in the past year. Latinos and heterosexuals report fewer session each year.
- Among sex and risk groups, IDUs and heterosexuals report greater need. However, a greater proportion of MSM ask for legal services, and all groups report having received the same level of service. There is some indication that services have fallen off considerably in the last year, particularly among heterosexuals.
- For PLWH/A who live in different regions, those living in the South report slightly higher need. Those in living in the North are less likely to ask for legal services, and they receive less legal services.
- Among ethnic populations Anglos perceive, ask for, and receive the proportionately more legal services. African Americans tend to ask for and receive proportionately lower levels of legal services.
- Among stage of infection, the perceived availability for legal services grows as people become diagnosed with AIDS. Those in the later stage of disease ask for and receive more legal services.

Legal – Qualitative Comments

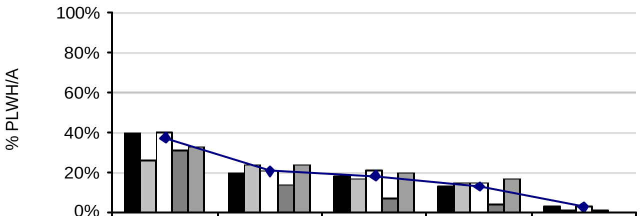
Legal services are needed by many to resolve disability, housing, or discrimination issues. For some focus group participant legal services offered through ASOs met their need. A 21 year old Southern female said, *"As far as legal services go, I have use of legal services from the ACLU in Indianapolis, and that turned out really well."* A Central Latino MSM said, *"I have had a need for legal services this year. I had my living will taken care with my health care directive which includes all four pieces that are required. I have taken care of that, and fortunately I was able to get that done through the ASO."*

However, most focus group participants who talked about legal services confirmed the quantitative finding that legal services are difficult to access and use. A Northern African American female said, *"I was for four years going around to different doctors who didn't know what was wrong with me. I couldn't pay for all that and I couldn't work. I was disabled but I couldn't get a check. I had to get a lawyer and just started getting it two years ago although I've been sick for 10 years."*

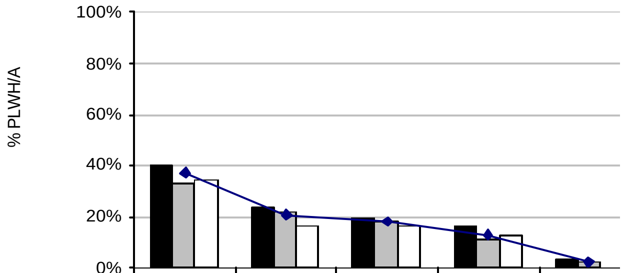
A Southern Anglo male said, *"I've been denied SSI and disability and I had legal aid helping me. I got a letter about a week ago from them. They turned me down saying they lost some of their people that work for them. They weren't going to rehire anybody, so they're not going to handle my business."* A Central Anglo female said, *"They don't have any legal services here. If you call an attorney to ask them to help you with their social security case, they want 25-30% of your benefits. When you get your big check after fighting it for two years, they want a big chunk. The people at the ASO do not help with Social Security. They handle matters such as criminal acts or discrimination."*

A Central Anglo MSM said, *"I understand the ASO has an attorney available but the problem with that is he is overwhelmed with his full-time job, the things that he is doing for the ASO that he has limited access to what he is able to do for you. I mean I am in a situation where I have to file bankruptcy. I don't have an option. I have got medical bills from when I didn't have insurance for a year and a half. That, you know, I will never get out from under."* When asked if there were other legal services available in Indianapolis to meet his needs, another participant replied, *"No, you can't. I mean you either make too much, you have too much money or you live in this area and they can't help you."*

<u>Volunteers or Peers who assist in household or personal tasks and provide support</u>

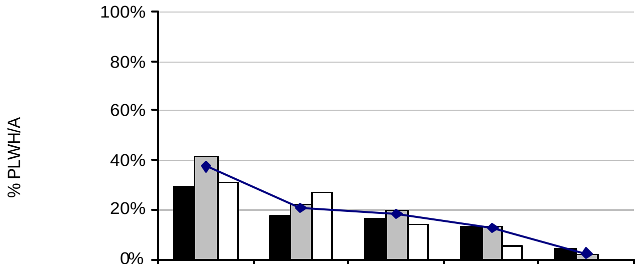


	Available	Need	Asked	Received ever	Received last year
Male	39.4%	20.1%	18.6%	12.9%	2.9%
Female	25.8%	23.9%	16.9%	14.3%	1.1%
MSM	40.3%	20.7%	21.1%	14.3%	2.8%
IDU	31.2%	13.5%	7.1%	4.2%	1.0%
HET	32.7%	24.0%	20.0%	16.9%	0.0%
Total	37.4%	20.7%	18.3%	13.1%	2.6%

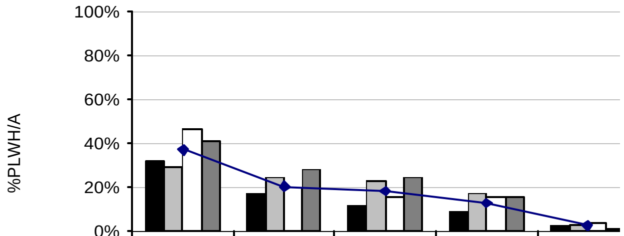


	Available	Need	Asked	Received ever	Receive last yea
Central	40.1%	23.9%	19.3%	16.5%	3.8%
North	33.3%	22.1%	18.1%	11.0%	2.1%
South	34.4%	16.4%	16.4%	13.1%	0.0%
Total	37.4%	20.7%	18.3%	13.1%	2.6%

	Average # Past Year
Sample	**90.0**
Male	82.3
Female	117.8
MSM	87.0
MSM/IDU	24.0
IDU	107.3
HET	5.0
Af Am	73.6
Anglo	100.0
Latino	3.0
Central	103.6
North	64.1
South	32.5
H asymp	130.6
H symp	53.0
A asymp	29.2
A symp	107.4



	Available	Need	Asked	Received ever	Received last year
Af American	29.6%	17.5%	16.3%	13.8%	4.6%
Anglo	41.7%	22.0%	19.7%	13.3%	1.8%
Latino	31.4%	27.1%	14.1%	5.3%	0.0%
Total	37.4%	20.7%	18.3%	13.1%	2.6%



	Available	Need	Asked	Received ever	Receive last yea
H Asymp	32.6%	16.9%	11.9%	9.1%	2.7%
H Symp	29.6%	24.7%	23.5%	17.3%	3.5%
A Asymp	46.7%	20.0%	15.6%	15.6%	3.9%
A Symp	41.6%	28.2%	25.0%	16.1%	1.6%
Total	37.4%	20.7%	18.3%	13.1%	2.6%

Top Barrier

Insufficient response rate on this service

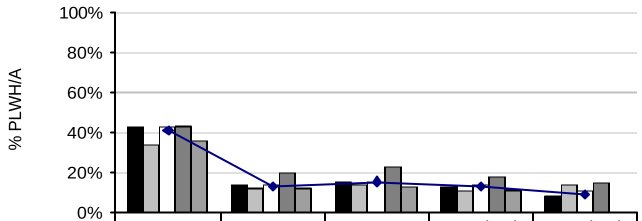
Highlights

- Volunteers services to help PLWH/A (also known as buddies or companions) are ranked near the bottom priority for services by ISDH and is not among the most important services ranked by PLWH/A.
- On average, about 37% of PLWH/A perceive that volunteers are available to them, and 20% say they currently need them. About 18% have asked for them, and 13% have reported receiving them. Just 3% reported receiving them last year.
- Of those PLWH/A using services, the average number of volunteer visits is about 3 months.
- Among sex and risk group, there is little difference between men and women in their perceive need, asking for, or receiving volunteer services. IDUs rank relatively low in needing, asking and receiving "volunteer" or "buddy" services.
- Among ethnic populations, their patterns of demand and utilization are the same.

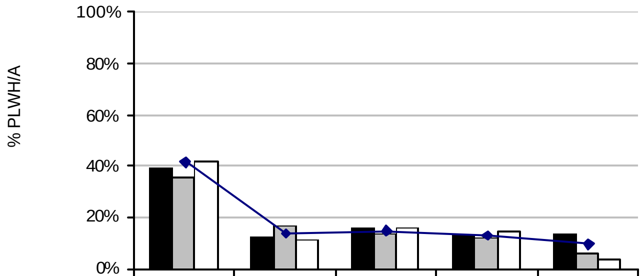
Buddy/Companion Services – Qualitative Comments

Despite its low ranking, PLWH/A in the focus groups said they had a need. In general PLWH/A felt isolated and they wanted companionship more than help in any particular activity. For example, a Central Anglo Female IDU said, *"I have been here 8 months with no friends, just a cat. I would like someone to be a buddy to me in hopes that they would help me read and write a little bit better. I also want them for the company."* A Central Anglo MSM said, *"I hope to get full use of my arm and my left leg. Getting mentally stronger - through depression. I am sure that a buddy or group activities would make it better."* A Northern Latino female said, *"I really do think that they need a buddy system out here. Just to feel like you know someone. Sometimes your family can't be there, but to know that you have that one friend who can be there."*

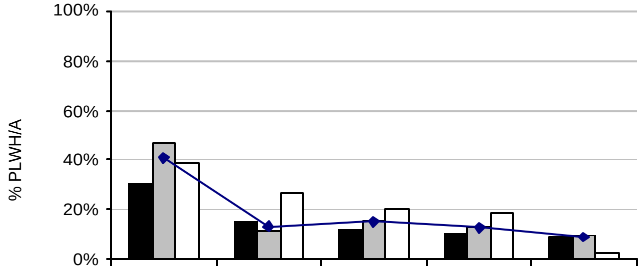
Rehabilitation services like physical therapy (authorized by a medical provider)



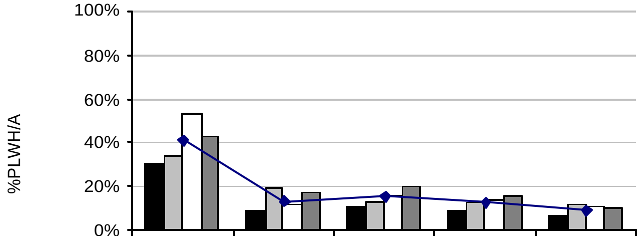
	Available	Need	Asked	Received ever	Received last year
■ Male	42.5%	13.5%	15.2%	13.1%	8.6%
▒ Female	33.5%	12.3%	14.1%	10.5%	13.6%
□ MSM	43.0%	13.7%	15.5%	13.5%	10.6%
▓ IDU	43.2%	19.8%	23.1%	17.6%	14.4%
▓ HET	35.7%	12.2%	13.2%	11.2%	0.2%
◆ Total	41.1%	13.3%	15.0%	12.7%	9.3%



	Available	Need	Asked	Received ever	Received last year
■ Central	39.0%	12.5%	15.9%	13.1%	13.7%
▒ North	35.3%	16.8%	13.5%	11.7%	5.9%
□ South	41.9%	11.5%	16.1%	14.5%	3.8%
◆ Total	41.1%	13.3%	15.0%	12.7%	9.3%



	Available	Need	Asked	Received ever	Received last year
■ Af Am	30.6%	15.4%	12.5%	10.4%	9.1%
▒ Anglo	46.7%	11.4%	16.0%	13.6%	9.8%
□ Latino	38.8%	27.1%	21.0%	19.0%	3.2%
◆ Total	41.1%	13.3%	15.0%	12.7%	9.3%



	Available	Need	Asked	Received ever	Received last year
■ H Asymp	30.3%	9.1%	11.1%	9.0%	6.7%
▒ H Symp	33.7%	19.5%	13.4%	12.2%	11.9%
□ A Asymp	53.5%	11.6%	16.3%	14.0%	11.2%
▓ A Symp	43.2%	17.6%	20.0%	16.1%	10.1%
◆ Total	41.1%	13.3%	15.0%	12.7%	9.3%

	Average # Past Year
Sample	**13.8**
Male	13.1
Female	20.4
MSM	13.2
MSM/IDU	9.8
IDU	24.5
HET	.
Af Am	8.1
Anglo	15.5
Latino	10.6
Central	19.0
North	9.1
South	7.4
H asymp	45.3
H symp	5.4
A asymp	9.6
A symp	11.4

Top Barrier

Insufficient response rate on this service

Highlights

- Rehabilitation services are ranked near the bottom priority by ISDH and they not among the most important services ranked by PLWH/A.
- On average, about 41% of PLWH/A perceive that rehabilitation services are available to them, and 13% say they currently need them. About 15% have asked for them, and 12% have reported receiving them. 9% reported receiving them last year.
- Of those PLWH/A using services, the average number of days of rehabilitation is about two weeks.
- Among sex and risk group, there is little difference between men and women in their perceive need, asking for, or receiving volunteer services. IDUs are slightly more likely to need and use rehabilitative services.
- Among ethnic populations, their patterns of demand and utilization are the same.
- Symptomatic PLWH/A appear to need and ask for “volunteer” or “buddy” services, more than asymptomatic PLWH/A.
- IDUs rank highest in needing, asking and receiving rehabilitation services.
- Rehabilitation services indicate to be highly available to Anglos than to African Americans and Latinos.
- Despite that asymptomatic PLWH rank the least in needing, asking and accessing rehabilitation services than other symptomatic PLWH/A, they on average accessed the service much more frequently (45.3 times) than the rest of PLWH/A.

12. CONCLUSION

Epidemiology

At the beginning of 2001, Indiana documented 5,917 people living with HIV/AIDS, with 55% living with HIV who had not progressed to AIDS, and 45% diagnosed with AIDS. Based on the criteria for antiviral treatment, there are 54% of the HIV positive populations who indicate symptoms and would be recommended for treatment. In addition, there are 15% who have been diagnosed with AIDS with no symptoms or have a current t-cell count below 350, suggesting that 69% of PLWH/A are likely to need medical treatment for their infection.

Anglos represent 63% of the PLWH/A, African Americans represent 32%, Latinos just over 4%, and other ethnicities about 1%. Women represent 15% of all PLWH/A of whom 36% are African American. Over two-thirds of the heterosexuals are women and over a quarter of the IDUs are women. Notably, 60% of women living with HIV have children. MSM represent over half (52%) of the PLWH/A, those "not classified" represent 17.5%, and both IDUs and heterosexuals each represent about 11% of PLWH/A.

The trend data reveal that in absolute numbers, MSM (3,090) and Anglos (3,727) continued to add the largest number of HIV/AIDS cases each year through 2001. However, both are decreasing as a percentage of PLWH/A, with the fastest growing populations of PLWH/A being heterosexuals (707, up from 303 in 1994) and females (950, up from 485 in 1994 and who are the majority of heterosexuals), Hispanics (247,up from 131), and then African Americans (1,919 up from 1069 in 1994). The percentage increase of APIs and Native Americans are also high, but the small absolute numbers suggest that these populations will represent a small number of people seeking care in the near future who may need culturally specific services.

Forty four percent of the population of Indiana and 56% of the PLWH/A live in the Central areas of Indiana, 33% of the population and 28% of PLWH/A in the North, and 23% of the population and 16% of PLWH/A live in the South. This suggests that the Central area has been disproportionately affected by the epidemic. While Anglo and MSM make up the majority of PLWH/A in all regions, the North has proportionately more African Americans (41%) and Latinos (6.3%) than other regions. Due to the larger proportion of PLWH/A in the Central region, however, in absolute numbers, more PLWH/A representing every racial and ethnic populations and risk group live in Indianapolis and the surrounding area.

For drug reimbursement, a PLWH/A has to be below 300% of the federal poverty level. Ninety percent report falling below that level and 50% report earning less than $8,350. Women report less income than men, and, between risk groups, IDUs report the lowest income.

Health Care System for PLWH/A

Insurance

Indiana has a progressive system where PLWH/A are encouraged to enroll in the State's high risk insurance pool through the Indiana Comprehensive Health Insurance Association (ICHIA), and Ryan White funds are used to purchase or supplement insurance payments to the ICHIA through the Health Insurance Assistance Program (HIAP).

Based on the self-reported insurance data, Ryan White coverage is critical for over 50% of PLWH/A in Indiana. Ryan White funds are critical for the 25% of the PLWH/A with no insurance coverage, and for about the third of the population who receive ICHIA through Ryan White funded HIAP. Medicaid is more likely to be an option for women, particularly women with children (including Hoosier Healthwise, and CHIP) while ICHIA is more likely to be an option for men.

About 34% of the PLWH/A report having insurance through ICHIA, and 33% report using HIAP that is largely funded through Ryan White to pay the ICHIA. In addition, 27% use the Early Intervention Program (EIP Limited) to obtain vision and dental care, 24% use EIP for covering early interventions and gaps in medical care, and 4% report using early intervention care reimbursed or paid for by Title III.

Although Medicaid and Social Security Disability Insurance (SSDI) are relatively difficult to obtain compared to other States, 20% of PLWH/A report only Medicaid, 14% of PLWH/A report only Medicare, 23% of PLWH/A report dual Medicaid and Medicare coverage, and 1% of those also have private insurance.

About a fifth of PLWH/A report some form of private insurance through work or COBRA, and about 9% of those interviewed report Hoosier Healthwise. Among women with children, 63% have Hoosier Healthwise, while 30% of the men with children report Hoosier Healthwise. In addition to Medicare, Medicaid, and private insurance, about 8% of the PLWH/A report VA benefits. Of those 8%, about 22% (under 2% of the all PLWH/A) report having no other insurance.

Drug Reimbursement

Over 90% of PLWH/A have their medication costs reimbursed. The two largest sources of drug reimbursement are Medicaid (39%) and Ryan White funded ICHIA (35%). They are followed by Ryan White funded ADAP (20%). Several of the PLWH/A report multiple reimbursement sources for medication. Of the 50% who use ADAP and/or HIAP for drug reimbursement, 21% report using both. There is very little overlap, however, between ADAP or HIAP and Medicaid.

Based on self reports from PLWH/A, about half, (49%) of all PLWH/A say they do not have a co-pay for their medication. Another 20% say they pay under $9.99 as a co-pay for their insurance. Twelve percent (12%) say they have a co-pay on mediation that is over $10.00.

Based on focus group information, for many PLWH/A the co-pays on several medications are a significant barrier to maintaining their drug regimen.

Entitlements and Benefits

Eligibility criteria for benefits is discussed in the section "Entitlements and Benefits" page 6-7. The majority of PLWH/A (52%) report being on SSDI, about a quarter report SSI, and another 11% report being on long-term disability. As expected, more persons living with AIDS have SSDI and long term disability, reflecting their disability status. Women are more likely to report SSI than men, indicating lower income and less work history.

Indicative of the low income of PLWH/A, about half (49%) of the PLWH/A report receiving food stamps, and over a quarter (27%) report receiving rent supplements. About 17% of the PLWH/A report receiving direct emergency financial assistance, usually used for utilities, rent, or emergency medical treatment. Over a quarter (27%) of the IDUs report accessing DEFA, indicating their higher financial instability and greater need for essential services.

Twenty-six percent (26%) of the PLWH/A access rent supplements. Heterosexuals (33%) and Anglos (30%) are most likely to access rent supplements than other populations. Also those living in the South (41%) are more likely to access rent supplements than other geographic areas

Intake and Referrals

Intake into the system, referrals, and coordination of care for PLWH/a are handled through 17 care coordination sites. More information on the services offered and capacity of the HIV Care system are found in a companion report, HIV/AIDS Providers and HIV/AIDS Service Capacity.

Notably, when the needs assessment was conducted, an ASO, AIDServe, was the primary agency that handled contracts of day-to-day management of all Title II programs, including insurance payments. During the process, AIDServe became insolvent and that greatly affected the provision, coordination, and payment of needed services for PLWH/A.

Co-Morbidities

Homelessness and Housing

Three percent (3%) of PLWH/A report being currently homeless. The instability of housing becomes more evident when PLWH/A are asked if they have been homeless anytime in the last two years. Twelve percent (12%) report having been homeless sometime in the last two years, and 10% have lived in some form of transitional housing. African Americans are much more likely than other racial populations to report unstable housing.

The urgency with which housing should be addressed is indicated by about a quarter (23%) of the PLWH/A interviewed who say they will soon have to move. Continued housing instability is reported among those with history of homelessness and about half of those who have been homeless in the past two years say they expect to move soon. PLWH/A in the North appear to have the most unstable housing situation, while those in the South report more stable housing.

Substance Abuse

While current use of substances is reported to be much lower than previous substance use, 6% of all PLWH/A report continuing to use crack frequently, and 1% report using heroin frequently. The homeless are among the highest users of heroin.

The use of party drugs is known to be related to unsafe sexual behavior, and about a third of PLWH/A report using poppers, with 9% saying they use it frequently. MSM and MSM/IDU are among the heaviest users of party drugs.

STDs

Fourteen percent (14%) of all PLWH/A report having been diagnosed with Hepatitis C in the last year. Predictably, it is significantly higher among the risk groups IDUs (39%) and MSM/IDUs (21%). It is also higher among the Latinos (24%) and African Americans (21%).

Syphilis, gonorrhea and chlamydia each have relatively low incidence, but syphilis is significantly higher among IDUs, and genital warts among MSM/IDUs.

Mental Illness

More than half of PLWH/A (56%) report having been diagnosed with depression, bipolar disease, anxiety, and/or dementia. Depression has been diagnosed among almost half (48%) of PLWH/A in the past year, and it is the most frequently diagnosed mental illness reported by PLWH/A. It tends to be highest among MSM/IDUs, and lowest among IDUs. About a third (34%) of the PLWH/A report a diagnosis of anxiety in the past year, and between 5% and 6% report the more acute diagnoses of dementia and bipolar.

Those who have been diagnosed with AIDS and are symptomatic tend to report a much higher incidence of mental illness. African Americans tend to report lower diagnosis of depression, anxiety, and dementia than other racial and ethnic groups. This may reflect actual incidence or the likelihood that they are less likely to see mental health professionals for a diagnosis. Notably, African Americans are not less likely than other populations to report group or individual therapy.

Improved Outcomes

Death Rates

Because of a relatively effective continuum of care, presently PLWH/A can expect a longer and a better quality of life than those living with HIV and AIDS only a few years ago. Since 1994, fatality rates for all ethnic communities have decreased from about 5.1 deaths per hundred thousand in 1994 to about 1.7 deaths per hundred thousand in 1999.

The death rate is substantially higher among the African American population, and while it has significantly declined from a rate of 19 per 100,000 in 1995 to 7 per 100,000 in 1999, it continues to be between three to five times the rate of the Anglo and Latino death rate, respectively. In terms of number of deaths reported each year, Anglos represent 64% of the deaths reported from AIDS in 1999 and African Americans accounted for 33%. Latinos and other ethnicities combined accounted for less than one percent of the deaths reported from AIDS that year.

There is some indication that the rapid decline between 1994 and 1997 among Latinos and Anglos is leveling off, indicating a lower but continuing need for acute medical care among those for whom medical therapies are ineffective, or those who are experiencing serious side effects of prolonged medication. The declining death rates among African Americans continue at a rapid pace, and may approach the rates of Anglos and Latinos if the trend continues.

Quality of Life

While there is no trend data, it would be expected that a successful continuum of care would continue to keep persons in good physical health, including those with AIDS. As expected, most (72%) of those with no symptoms report excellent (24%) or good (48%) physical health, and about 2% report poor physical health. While somewhat worse, almost half the symptomatic HIV or AIDS also report being in excellent or good physical health (46%). Over half (54%), however, reporting fair or poor physical health with under 10% of those who are symptomatic or those diagnosed with AIDS report being in poor physical health.

About 72% of those living with AIDS say that their physical health is better or the same as it was when they started treatment for their HIV infection. Slightly fewer, but still over 66%, of those with symptoms say they are doing better or the same.

A majority of PLWH/A indicate an improvement in their emotional health since they started treatment. PLWA report the greatest improvements in emotional health (68%). Over 60% of symptomatic (63%) and those with no symptoms (60%) report emotional health improvements.

In addition to the reported physical and emotional health status, indices of physical activities provided a means for understanding the service needs and barriers faced by PLWH/A. As would be expected, PLWH/A with symptoms are significantly more likely to need help than PLWH/A with no symptoms. Notably, those needing the most help are symptomatic whether they are HIV positive or have been diagnosed with AIDS.

Mental and cognitive functionality was more directly related to state of infection with those reporting AIDS more likely to need help some of the time than those with HIV, and those symptomatic AIDS needing the most help.

Medication and Adherence

Ninety-four percent (94%) of PLWH/A report ever taking medicines to treat their HIV infection, and 89% report ever taking a drug cocktail. Males, and particularly MSM, are the most likely to have taken medication from all risk groups. Among special populations, youth and asymptomatic HIV are least likely to have taken medication.

Fifteen percent (15%) of PLWH/A taking medications have stopped and 27% report never skipping a dose. Over 58%, however, have missed their medication schedule anywhere from once or twice a month (33%) to more than twice a week (12%). Symptomatic PLWH/A are more likely to stop taking their medication than asymptomatic PLWH/A. Of those stopping medication, 83% do it without the advice of their doctor. The top four reasons for non-adherence are: forgetting, side effects, difficult schedule, and ran out.

Women of childbearing age are particularly likely to stop medication without the advice of their doctor, and among ethnic populations, Latinos are more likely to have stopped without the advice of their doctor.

Top, Current, and Future Needs

PLWH/A reported the top services they felt they needed the most. Services in the top fifteen are a combination of health care and basic needs. They also said whether they had a current need or future need for each of 42 different services.

With 53% naming primary care as their top need, it exceeded other needs significantly. The next set of needs with above 20% saying they are the most important, are two that involve access to care, transportation and case management, and two that relate to direct medical care, dental and lab tests.

With the exception of transportation, the largest current needs followed the services PLWH/A said they needed the most, with over 80% of PLWH/A saying they need medical care, dental care or case management. Interestingly, between 70% and 80% of PLWH/A say they have current need for information about treatment and care and want newsletters and resource guides, but these services are not considered all that important to them. Dental is ranked as important and as a top current need because it is a service that PLWH/A would not be able to get without Ryan White assistance, and it is clearly viewed by PLWH/A as improving their quality of life.

The remaining most important services and top currently needed services include both basic daily needs such as food, emergency financial assistance, and assistance paying health insurance. These reflect the low-income level of PLWH/A and, probably, the difficulty in qualifying for Medicaid. Mental health services are also among the most important services and are reported with relatively high current need.

The Council rated drug reimbursement second in 2001-2002, but consumers ranked drug reimbursement as their 13th most important service and in the middle of their current needs. This is likely reflected by the high level of drug reimbursement existing in the system that occurs without much active participation by PLWH/A.

Notably, even among substance users, substance abuse services were ranked as relatively unimportant and with low current need.

Specialized targeted services such as OB/GYN, employment assistance, adoption assistance, and end stage services were rated as less important and has a lower current need by all PLWH/A. However, when filtered for the women, those looking for work and those with advanced HIV infection, the need is greater.

There is greater anticipated need for almost all services with relatively high current need. The greatest anticipated need is for case management and dental care.

There are some differences by sex and ethnicity among top needs. Women tend to rank basic life services higher than men, with food bank ranked second and emergency financial assistance third. Logically, OB/GYN services received a much higher ranking for women than men. Men living with HIV and AIDS place greater importance on receiving insurance than women living with HIV/AIDS, probably because they are more likely to be ineligible for Medicaid.

The differences by race and ethnicity reflect ease of access to services. Anglos, reflecting their higher income, are more likely to rank medical and dental services higher and less likely than African Americans to say they need basic services. African Americans rank transportation as their second most important service, followed by assistance finding housing, and food bank. Latinos say that medical services are the most important and rank mental health services and access to medical specialists higher than either African Americans or Anglos.

Among risk groups, IDUs are more likely than other risk groups to say that primary care (64%), case management (25%), and assistance finding long term housing (26%) are among the most important services. MSM, like men in general, are more likely than other risk groups to say that dental care (26%) and assistance providing health insurance (19%) is more important. Heterosexuals, reflecting their high percentage of women, are more likely than other risk groups to say that OB/GYN services (15%) is more important. They also say that vocational care is more important, and dental care less important than other risk groups.

Availability of Services

PLWH/A where asked to indicate in the survey whether they knew that services were available to them. Over 60% of PLWH/A perceive that the services offered are available to them. It indicates that large segments of PLWH/A perceive the availability of most medical services. PLWH/A who need specific services generally say they can access them. For example, the perceived availability of mental health services is much greater among those diagnosed with mental illness, or OB/GYN services is perceived as most available by women.

Those services with moderate availability (60% to 70% say it is available) include DEFA emergency rental assistance, a resource guide, and dental care.

Those services with lower availability – under 60% say it is available, include transportation and nutrition education. They also include services that are available during end-stage illness. Even among those who are HIV symptomatic awareness of respite care and adult day care is low, and for child care, the perceived availability among females is very low (16%).

Demand, Utilization, and Demand-Utilization Gap

The top services asked for and received are generally the top services reported with the greatest current need. Transportation, prevention information, and emergency rental assistance are not reported as a high current need, but have been asked for relatively frequently. Like current need, those services with the lowest demand tend to be end stage services that are very important for the few individuals who are at the end stage of HIV illness. Notably, the demand for substance abuse treatment and childcare seems lower than the epidemiology would suggest.

The greatest unmet demand is for dental care. Combined with dental care as the third most important service, and fourth ranked for current need, it is also a service with the greatest anticipated need.

Advocacy and legal help have the second and third largest unmet demand. While they are not among the most important services noted by PLWH/A, they say legal services have a moderately high current need. This suggests that capacity for providing legal services and advocacy are low.

Assistance getting medical services has the fourth highest unmet demand, and is also a service with relatively high current need. It suggests that many PLWH/A do not consider their current case management adequate as a link to medical services.

Among the top services with unmet needs, three are related to housing: assistance finding emergency transitional housing, assistance finding long term independent housing, and emergency rental assistance. This suggests the ongoing need to find affordable housing for PLWH/A.

Employment assistance and vocational counseling is among the top unmet needs. While not mentioned by most PLWH/A as the most important service or as having a high current need, it does suggest an emerging need where capacity is inadequate.

PLWH/A also report an excess supply of some services. Prevention information and newsletters, are received more often than requested. This suggests that PLWH/A often feel overwhelmed by information and the need to respond more to the information needs of individuals rather than a general need to provide information that may not be read by PLWH/A.

Lab tests and appointments with doctors are received more than they are asked for, and this suggests that medical protocols require medical visits more often than many PLWH/A feel they are necessary.

Barriers

Although no barrier was rated as particularly high by PLWH/A, the focus groups highlighted several areas where PLWH/A reported problems receiving services. Men and women reported about the same low level of barriers. Among risk groups, MSM reported slightly higher overall barriers scores, and among racial populations, African Americans reported slightly higher barriers. Those living in the Southern region reported slightly lower barriers.

Among the highest barriers, were the amount of red tape and paperwork that needed to be completed to obtain services, and not being eligible to obtain services because of rules and regulations. These were emphasized in the focus groups as particular problems. They often dealt with the difficulty in qualifying for Medicaid and housing assistance, but they often discussed the problems with having insurance paid for, and general problems with referrals.

The PLWH/A's physical health was ranked overall as the third highest barrier. PLWH/A reporting a mental disorder and the homeless ranked this barrier relatively high.

The PLWHJA ability to find their way through the system and poor coordination among the organizations providing services were ranked as relatively high barriers, particularly by MSM and Youth. In focus groups, Indiana was mentioned as much more difficult to navigate than other care systems where PLWH/A reported having received care.

Reliability and having emergency transportation was ranked as a relatively high barrier, particularly by youth and the homeless, and relatively high by IDUs and African Americans.

Not having enough insurance coverage was a moderately ranked barrier, and as explained in the focus groups, this related to co-pays, and uncovered types of care. The barrier was often coordinating the different types of coverage and arranging for continuous coverage during the progression of the HIV disease.

Not knowing what treatment were available to the PLWH/A and not knowing what services existed were expressed more by Latinos than other populations. Concern about lack of confidentiality was of particular concern to women of child baring age.

Overall Assessment

The needs assessment indicated that the Indiana continuum of care of PLWH/A provides the necessary services to produce a drastic decline in mortality, improve or maintain a reasonable quality of life, and provide reimbursement for medical care and necessary medication.

Moving PLWH/A into insurance has been a success. With the difficulties surrounding AIDServe, however, many PLWH/A report the poor administration of the insurance system. The new system, once established, should be reassessed.

The populations that appear to be underserved include those with mental illness and homeless and those with a history of IDU appear to have greater unmet needs.

Among MSM, who represent the majority of PLWH/A, the needs vary by economic status. Among those who are of a higher socio-economic status, the gap insurance coverage for medication and cost of care is likely to be a problem.

Unmet need is particularly great for dental care, and while legal advocacy is not among the most important services, it has one of the highest unmet needs.

There is unmet need for assistance getting medical services, and this supports the relatively high perceived barrier of difficulty navigating the system. It suggests that for many their current case management does provide adequate referrals. Accessing the system is made all the more difficult by poor, and unreliable transportation.

Housing continues to be a challenge. With the vast majority of PLWH/A living below or near poverty, affordable independent housing will continue to be a challenge.

Vocational assistance and counseling will increase in importance as newly infected do not progress to AIDS, and disability benefits become more difficult to obtain. PLWH/A are not clear on the process of finding jobs that allow them to continue benefits, and what types of jobs are available.

With the many changes in the care system since the interviewing for the needs assessment was completed, the progress in maintaining a high level of insurance and care and improving on access to care should be assessed to assure that PLWH/A are receiving adequate services to meet their needs.

13. ATTACHMENTS

Attachment 1 Project Advisory Group Roster

Attachment 2 Indiana Needs Assessment Survey of PLWH/A

Attachment 3 Focus Group Outline for PLWH/A

Attachment 4 PLWH/A Demographics

Attachment 5 Service Knowledge

Attachment 6 Service Need

Attachment 7 Services Asked

Attachment 8 Service Received

Attachment 9 Service Accessibility

Attachment 10 Barriers by Total Population and Subpopulations

Attachment 11 Focus Group Coding Scheme