

**Las Vegas EMA  
HIV/AIDS NEEDS ASSESSMENT REPORT**

**Prepared for**

**Clark County Health District and the Las Vegas  
EMA Ryan White Title I Planning Council**

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## TABLE OF CONTENTS

<b>1. INTRODUCTION .....</b>	<b>1-1</b>
<b>2. METHODS.....</b>	<b>2-1</b>
Consumer Survey.....	2-2
Sample Design.....	2-2
Interviewing.....	2-2
Focus Groups .....	2-3
<b>3. DEMOGRAPHIC PROFILE OF PLWH/A.....</b>	<b>3-1</b>
Women.....	3-2
Ethnicity and Mode of Transmission .....	3-2
Education .....	3-3
Age Distribution .....	3-5
Relationships.....	3-5
Income .....	3-6
Employment Status .....	3-8
<b>4. CO-MORBIDITIES.....</b>	<b>4-1</b>
Housing & Homelessness .....	4-1
Substance Abuse.....	4-2
STDs .....	4-4
Mental Illness.....	4-6
Tuberculosis.....	4-7
<b>5. STAGES OF DISEASE.....</b>	<b>5-1</b>
Diagnosed with AIDS .....	5-1
Symptomatic .....	5-2
Eligible for Medical Care.....	5-3
<b>6. INSURANCE AND BENEFITS .....</b>	<b>6-1</b>
Access to Health Care .....	6-1
Insurance Coverage .....	6-1
Entitlements and Benefits .....	6-4
VA, CCSS, and WIC .....	6-4
Drug Reimbursement.....	6-4
Other Benefits .....	6-5
Disability .....	6-5
Supplementary Income .....	6-5
<b>7. OUT-OF-CARE .....</b>	<b>7-1</b>
Demographic Profile:.....	7-2
Stage of Infection.....	7-3
Medication Adherence .....	7-3
Co-Morbidities.....	7-4
Housing: .....	7-4
Need for Care: .....	7-5
Top Service Need .....	7-5
Main Reasons for Not Obtaining Care.....	7-6
Out-of-care – Qualitative Comments.....	7-7
Affordability and Inadequate Insurance.....	7-7
State of Mind .....	7-8
<b>8. OUTCOMES .....</b>	<b>8-1</b>
Mortality .....	8-1
Quality of Life .....	8-2
<b>9. MEDICATION AND ADHERENCE.....</b>	<b>9-1</b>
Medication and Adherence .....	9-1
Medication and Adherence – Qualitative Comments .....	9-3
<b>10. SERVICES .....</b>	<b>10-1</b>



Services Ranked.....	10-1
Ranked Needs .....	10-1
Most Important Needs by Gender.....	10-5
Most Important Needs by Ethnicity.....	10-6
Most Important Needs by Risk Group.....	10-7
Most Important Needs by Special Populations.....	10-7
Most Important Needs by Geography.....	10-7
Most Important Need by Stage of Infection .....	10-8
Service Gaps .....	10-8
<b>11. BARRIERS.....</b>	<b>11-1</b>
Overall PLWH/A Score for Barriers.....	11-1
Categorizing Individual Barriers Reported by PLWH/A.....	11-1
Ranking of Specific Barriers.....	11-2
How to Read the Barrier Attachment.....	11-2
Total Population Ranking of Barriers.....	11-3
<b>12. SERVICE AND BARRIER TEMPLATES .....</b>	<b>12-1</b>
Primary Medical Care.....	12-3
Case Management.....	12-6
Mortgage/ Rental Assistance .....	12-9
Housing Referrals/Assistance.....	12-10
Medication Reimbursement.....	12-13
Food Pantry.....	12-15
Group Meals .....	12-16
Nutritional Supplements .....	12-17
Dental Care .....	12-19
Transportation.....	12-21
Mental Health Treatment /Counseling.....	12-23
Nutritional Counseling.....	12-25
Health Insurance Continuation .....	12-27
Emergency Financial Assistance .....	12-29
Client Advocacy .....	12-31
Peer Counseling.....	12-33
Assistance taking medications as prescribed - Adherence Assistance.....	12-35
Health and Treatment Education/Referrals.....	12-37
Complimentary Treatment.....	12-39
<b>13. CONCLUSION .....</b>	<b>13-1</b>
Epidemiology.....	13-1
Health Care System for PLWH/A.....	13-1
Insurance.....	13-1
Drug Reimbursement.....	13-2
Entitlements and Benefits .....	13-2
Co-Morbidities.....	13-3
Homelessness and Housing .....	13-3
Substance Abuse.....	13-3
STDs.....	13-3
Mental Illness .....	13-4
Out-of-Care.....	13-4
Improved Outcomes.....	13-5
Death Rates.....	13-5
Quality of Life .....	13-5
Medication and Adherence .....	13-5
Top need, Utilization, and Service Gaps.....	13-6
Barriers .....	13-7
Overall Assessment.....	13-7



**14. ATTACHMENTS ..... 14-1**

**TABLES**

Table 2-1 Stratified Sample ..... 2-2

Table 2-2 Focus Group ..... 2-4

Table 2-3 Analysis Populations ..... 2-5

Table 2-4 Sample Frame ..... 2-6

Table 3-1 Number of Survey Respondents (N=334)..... 3-1

Table 5-1 AIDS Diagnosis and Time Known HIV+ ..... 5-2

Table 7-1 Out-of-care Surveys: Disposition ..... 7-1

Table 7-2 Out-of-care: Demographic Profile ..... 7-2

Table 7-3 Length of HIV Infection ..... 7-3

Table 7-4 Top Reasons for Skipping Medications ..... 7-4

Table 7-5 Substance Use ..... 7-4

Table 7-6 Reasons for Not Seeking Care ..... 7-6

Table 10-1 Summary of Priority Services to be Funded in FY 2001 ..... 10-2

Table 10-2 Lower Ranked Needs ..... 10-4

**FIGURES**

Figure 1-1 Definition of Needs and Gaps ..... 1-1

Figure 3-1 Gender by Mode, Ethnicity, and Geographic Location ..... 3-2

Figure 3-2 Ethnicity by Mode of Transmission ..... 3-3

Figure 3-3 Level of Education by Gender, Mode, and Race ..... 3-4

Figure 3-4 Age by Risk Group and Race ..... 3-5

Figure 3-5 Relationship Status by Gender, Mode and Ethnicity ..... 3-6

Figure 3-6 Income by Gender, Mode and Ethnic groups ..... 3-7

Figure 3-7 Employment Status by Gender, Mode, and Ethnicity ..... 3-8

Figure 4-1 Currently Homeless or In Transition ..... 4-1

Figure 4-2 Homelessness & Transitional Housing ..... 4-2

Figure 4-3 Substance Use Among PLWH/A ..... 4-3

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

Figure 4-5 STDs among PLWH/A by Race ..... 4-5

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

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

Figure 5-1 AIDS Diagnosis and Time Known HIV+ ..... 5-2

Figure 5-2 Percentage With and Without Symptoms by Gender, Mode, and Ethnicity ..... 5-3

Figure 6-1 No Insurance ..... 6-2

Figure 6-2 Insurance Coverage ..... 6-3

Figure 6-3 Long Term Disability ..... 6-5

Figure 6-4 Supplemental Income ..... 6-6

Figure 7-1 Top Service Needs for Out-of-care ..... 7-5

Figure 8-1 HIV/AIDS Deaths by Ethnicity per 100,000 of Nevada Population ..... 8-1

Figure 8-2 Quality of Life – Physical Health ..... 8-4

Figure 8-3 Quality of Life – Emotional Health ..... 8-4

Figure 9-1 Never Skipped Medication ..... 9-1

Figure 9-2 Reasons for Stopping Medications by Ethnicity ..... 9-2

Figure 10-1 Top Ten Needs by PLWH/A ..... 10-3

Figure 10-2 Second Tier of Needs by PLWH/A ..... 10-4

Figure 10-3 Top Ranked Needs by Gender ..... 10-5

Figure 10-4 Top Ranked Need by Ethnicity ..... 10-6

Figure 10-5 Top Ranked Need by Risk Group ..... 10-7

Figure 10-6 Service Gaps ..... 10-8



Figure 11-1 Types of Barriers ..... 11-2  
 Figure 11-2 Types of Barriers ..... 11-3  
 Figure 11-3 Type of Barrier by Subpopulation ..... 11-4  
 Figure 11-4 Top Barriers to Care ..... 11-4  
 Figure 12-1 Service & Barrier Template ..... 12-1

**ATTACHMENTS**

Attachment 1 Project Advisory Group Roster ..... 14-1  
 Attachment 2 Las Vegas EMA Needs Assessment Survey of PLWH/A ..... 14-1  
 Attachment 3 Focus Group Outline for PLWH/A ..... 14-1  
 Attachment 4 PLWH/A Demographics ..... 14-1  
 Attachment 5 Service Need ..... 14-1  
 Attachment 6 Services Received ..... 14-1  
 Attachment 7 Service Usage ..... 14-1  
 Attachment 8 Service Barriers ..... 14-1  
 Attachment 9 Focus Group Coding Schema ..... 14-1  
 Attachment 10 Out-of-Care Survey ..... 14-1

**Abbreviations**

ADAP	AIDS Drug Assistance Program
AHCCCS	Arizona Health Care Cost Containment System
API	Asian / Pacific Islander
ASO	AIDS Service Organization
CAPP	Centralized Access Point Project
CCHD	Clark County Health District
CCSS	Clark County Social Services
Council	Las Vegas EMA Ryan White Title I Planning Council
EMA	Eligible Metropolitan Area
HARS	HIV/AIDS Reporting System
HET	Heterosexual
IDU	Injecting drug user
Mentally	Mental Illness
Mentser	Serious mental illness
MSM	Men-who-have-sex-with-men
MSMC	MSM of Color
NHIMS	Nevada HIV/AIDS Information Management System
OI	Opportunistic infection
PCH	Partnership for Community Health
STD	Sexually transmitted diseases
VA	Veteran’s Assistance
WCB	Women of Child Bearing Years



## 1. INTRODUCTION

In March 2001, PCH won a competitive request for proposal from the Clark County Health District (CCHD) and the Las Vegas EMA Ryan White Title I Planning Council (Council) to conduct an HIV/AIDS Needs Assessment for the three county Las Vegas EMA. The goal of the needs assessment is to provide the CCHD and the Council with data on HIV/AIDS that is necessary for effective services planning.

The full needs assessment has three reports. The first is an epidemiology report that provides an estimate of who will need services based on the HIV/AIDS reporting system (HARS). The second report describes the findings of the needs assessment and presents information obtained through a survey of 334 PLWH/A and 16 focus groups with various populations including African Americans, Latinos, heterosexual men and women, and injecting drug users (IDU). The third and final report incorporates the information in the provider information forms in estimating capacity of the system, related gaps and unmet demand (or excess capacity).

The conceptual framework for the needs assessment is shown in Figure 1-1. Needs, unmet needs, and barriers were determined for 29 services.

**Figure 1-1 Definition of Needs and Gaps**

<i>Service need or absolute need</i>	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.
<i>Perceived need and demand</i>	Perceived need and demand of PLWH/A for services based on qualitative and quantitative data is highly correlated.
<i>Fulfilled need</i>	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.
<i>Service capacity</i>	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.

<i>Unmet absolute need</i>	This refers to a need-capacity gap and is the difference between the number needing a service and the capacity of the system.
<i>Unmet perceived need</i>	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.
<i>Unmet demand or perceived excess capacity</i>	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.
<i>Need-demand gap</i>	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.



## 2. METHODS

Four data collection methods were used by PCH for the Las Vegas EMA comprehensive HIV/AIDS Care Needs Assessment. They included:

- A review of secondary information, including past needs assessments, epidemiological data from the HIV and AIDS Reporting System (HARS) provided by CCHD and aggregate client data from individual client reporting systems from providers, contract monitoring sources, and the Nevada HIV/AIDS Information System (NHIMS). HARS information was used to estimate the incidence and prevalence of HIV and AIDS and the sampling frame. NHIMS and individual reporting systems were used to estimate 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 conducted from June-September 2001. The survey allowed updated estimates of the demographics of PLWH/A and co-morbidities including homelessness, substance use, STDs, mental illness, and tuberculosis. The survey also measured the number of PLWH/A at various stages of HIV infection and their access to health care. Mortality, quality of life, and adherence to medication were measured as outcomes of the care system. Current estimates of need, demand, and utilization frequency of HIV/AIDS care services were measured and perceived barriers related to each services were captured.
- A series of 16 focus groups among target populations permitted in-depth discussion of needs and barriers to services that allow a greater depth of analysis by providing support and exceptions to findings from the survey.
- A provider survey among all recipients of Ryan White Care funds collected information on the services provided, all funding for services, number of client services, and unduplicated client counts and provider perception of service barriers.

A Project Advisory Group (PAG) was formed to provide oversight to 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 consulted throughout the project. The names of those on the project advisory list are shown in Attachment 1.

The needs assessment focused on the three counties that make up the Las Vegas EMA: Clark, Nye and Mohave (Arizona) Counties. An additional division by urban and rural areas of the EMA was created. The urban area of the EMA includes Las Vegas, North Las Vegas, and the communities of Blue Diamond, Boulder City, Henderson, and Mt. Charleston. The rural area of the EMA includes all of Mohave and Nye County plus the following communities of Clark County: Cal Nev Ari, Cottonwood Cove, Goodsprings, Indian Springs, Jean, Laughlin, Mesquite, Moapa, Nelson, Overton, Primm, Sandy Valley, Searchlight, Sloan, and Warm Springs.



## Consumer Survey

The consumer survey is shown in Attachment 2. The list of services developed by PCH was derived from the list of funded services and were approved by CCHD as representing services that were funded, or of interest to, the Council. They are shown in question 43 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 later in the report. Barriers to services were asked in questions 43 and 44 of the consumer survey. A list of frequent barriers is shown on page 10 of the consumer survey. Respondents were also asked about “other” barriers using an open-ended format and these were coded.

Participants for the focus groups received a \$15 cash incentive and participants of the consumer survey received a \$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 raffle with a grand prize of a computer and smaller prizes consisting of gift certificates to local grocery stores, movie theatres, and shopping centers.

### 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. For difficult to reach populations, intercept, snowball, and outreach were used to obtain sufficient sample sizes. Females, Latinos, heterosexuals, and IDUs were oversampled to assure that there were sufficient numbers of respondents to analyze. The stratified sample obtained is shown in Table 2-1.

**Table 2-1 Stratified Sample**

Risk Group	MSM	MSM/IDU	IDU		HET		TOTAL Sample
			Male	Female	Male	Female	
African American	33	3	26	9	9	28	108
Anglo	42	22	14	8	10	21	117
Latino	36	2	5	2	25	18	88
Other	8	2	2	1	4	4	21
<b>Total</b>	<b>119</b>	<b>29</b>	<b>47</b>	<b>20</b>	<b>48</b>	<b>71</b>	<b>334</b>

### Interviewing

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. The survey instrument was designed and approved by June 14, 2001. It was pre-tested with focus group participants.

In order to recruit a representative sample while maintaining confidentiality, participants were recruited by personal invitation, through the collaboration of case managers, receptionists, and other staff of these agencies and through outreach.



Two strategies were used to identify respondents:

1. CCHD assisted by drawing lists of clients by agency that matched the quota sample design, and these lists were distributed to the various agencies. Agencies were requested to call the clients to ask them to participate in the project, and no contact was made by PCH interviewers until there was agreement. Agencies made calls between June 14 and August 15, 2001.
2. Agencies were asked to contact and help recruit hard-to-reach populations. Over 17 agencies, physicians, and providers were directly contacted through personal visits and various memoranda from the CCHD and PCH describing the Needs Assessment project and underscoring the need for assistance locating particularly hard to reach populations. Considerable efforts were made to reach eligible individuals among those hardest to reach including Native Americans, Asian Pacific Islanders (APIs), and Latinos. Prospective participants from these groups were identified by AFAN, NALA, the Health District Annex A clinic, and the Community Counseling Center.

Interviewing was conducted in the Centralized Access Point Project (CAPP) office that was centrally located and in the same building as AFAN and the Wellness Center, both of whom have large client loads, at agencies, and at sites in rural areas of Kingman, Henderson, Pahrump and Laughlin. Although some people in the smaller towns were reluctant to participate for fear of identification, excellent rural participation was achieved, through the assistance of the Mohave County Health Department, the Nevada Rural AIDS Project, and the St. Therese Center. In several instances where participants could not travel, interviews were conducted by telephone.

Due to the limited amount of time allotted to meet with the HIV positive women at the Women's Detention Center, PCH conducted the focus group with the women but the consumer survey was not administered to the participants. Candice Nichols and Chris Reynolds of AFAN administered the survey to HIV positive females in the detention center. Interviewing was also conducted with men in the County Jail.

By maintaining a list of unique confidential identifiers (created at the time of survey administration), no respondent was allowed to complete more than one survey.

### **Focus Groups**

The focus group outline was developed and approved in July 2001 and is shown in Attachment 3. The purpose of the focus groups was to supplement the quantitative findings of the consumer survey and to gain greater insight into the perception of needs, gaps, and barriers. Sixteen focus groups were held with consumers as shown in Table 2-2. PCH attempts to have between eight and ten individuals in a group, however sizes vary depending on recruiting efforts and high rates of no-shows. More than 10 participants in a group make it difficult for every one in the group to have an opportunity to share their viewpoints and opinions. As shown in Table 2-2, nine of the sixteen groups had eight or more participants.



**Table 2-2 Focus Group**

<b>Population</b>	<b>Date</b>	<b>Attendance</b>
1) Latino females (including undocumented)	6/13/01	8 Females
2) African American females (hets & IDU)	6/14/01	8 Females
3) Heterosexual male (mixed race)	6/14/01	2 Male – 1 Latino, 1 Anglo
4) Women (mixed race)	6/14/01	9 Females - 1 Latina, 3 African American, 5 Anglo
5) MSM – Anglo	6/14/01	9 Males
6) Incarcerated	6/15/01	14 Females- 1 Latina, 4 Anglo, 9 African American
7) MSM – African American	6/15/01	8 Males
8) IDU (mixed race and gender)	6/15/01	9 participants - 2 Females, 7 Males
9) African Am heterosexual males	6/15/01	5 Males
10) Rural (mixed risk group) – Mohave Co. (AZ)	6/19/01	8 Anglo participants - 7 Males, 1 Female
11) In-Migrants – moved to LV in last year	9/21/01	6 participants – 4 Males, 2 Females
12) Out-of-care (History)	9/21/01	6 participants – 3 Males, 3 Females
13) Homeless (History)	9/21/01	8 participants – 5 Males, 3 Females
14) Youth (between 18-24 years)	9/22/01	3 participants – 2 Males, 1 Female
15) Latino MSM	9/22/01	3 Males
16) Undocumented Latinos	9/22/01	2 participants – 1 Male, 1 Female

There were two separate focus group recruitment efforts. The first occurred early in the summer of 2001 in order to reach participants representing different risk groups and communities of color. The other recruitment effort took place at the end of the summer of 2001 and was focused on recruiting the hard to reach populations.

Several methods were used to select and recruit participants for focus groups, while maintaining their confidentiality:

1. The primary source for recruiting participants in the focus groups was through Aid for AIDS of Nevada (AFAN), based upon a randomly selected list of confidential identifiers provided by the CCHD Surveillance office. Based on instructions by PCH, agencies selected names off their lists that matched the demographics of potential participants. Confidentiality was maintained by having agencies contact clients.<sup>1</sup> Most of the Latino participants were recruited through NALA, although a secondered staff member also recruited Latinos from the AFAN client list of approximately 85 names. Notably, of the 577 confidential identifiers provided by AFAN, only four fell into the adolescent (16-24) age group.
2. Participants were recruited through flyers distributed at the AFAN offices, Wellness Center, Coalition Offices, St. Therese Center, Caminar, NALA, physician's offices, and the Clark County Health District's HIV testing and counseling offices. Some probably learned by word of mouth as well. Those participants called PCH directly to schedule their participation.
3. Recruiting for the hard to reach populations (including those with a history of being homeless or out-of-care) was based on a survey participant's response to a question on the consent form asking if they would like to join a focus group for the end of September. Once it was apparent which clients were in which populations, PCH called up to twenty individuals for each group to ask them to participate in a focus group. An announcement was also made at the August 2<sup>nd</sup> Contractor's Meeting of the need of their assistance in referrals and recruiting for these hard to reach populations for the survey and focus groups. Additional recruiting occurred with flyers that announced the populations we were seeking for the focus groups.

<sup>1</sup> To ease the burden for some agencies, PCH secondered staff to the agency for recruitment; that is PCH paid for and trained staff that worked for the agency.



These flyers were posted in the high client traffic offices of AFAN, St. Therese, and the Wellness Center.

The first set of focus groups were conducted at the MRC Group Research Institute in the center of Las Vegas near the Convention Center. The Latino focus group was conducted at the recreational space of the NALA offices. And the second set of focus groups were conducted at the student union building of the University of Nevada Las Vegas campus.

The rural focus group was conducted at the St. Mary’s Parish Center in Kingman, Arizona (Mohave County - site for other HIV/AIDS peer services). Participants were recruited with the assistance of Mr. Ron Schilousky, Intake Officer of Mohave County Department of Health and Social Services. He referred two care representatives in Mohave County to assist in recruiting for focus groups: Karen Dunton, Registered Nurse and HIV/AIDS Educator of Kingman Regional Medical Center; and Father Joseph O’Brien of St. Therese Center of HIV/AIDS Outreach. Both conduct a monthly support group for those infected and affected with HIV/AIDS. Ms. Dunton conducts her group in Kingman, AZ and Father O’Brien conducts his in Laughlin, NV for residents in Bullhead City. Ms. Dunton also recruited four additional PLWH/A with a history of being homeless in the last two years. These four completed a consumer survey and a brief key informant interview.

A focus group was held at the Southern Nevada Women’s Correction facility. Ms. Candice Nichols, Director of Education at AFAN, coordinated and facilitated access to an established support group that meets every other Friday with potentially up to 30 participants. The challenge was to select 10 participants to allow for a focused discussion, and one of the inmates coordinated the selection of a diverse group of 14 women.

### 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 2-5 below:

**Table 2-3 Analysis Populations**

<ul style="list-style-type: none"> <li>1. Total</li> <li>2. Gender               <ul style="list-style-type: none"> <li>2.1 Male</li> <li>2.2 Female</li> </ul> </li> <li>3. Mode of Transmission               <ul style="list-style-type: none"> <li>3.1 MSM</li> <li>3.2 MSM/IDU</li> <li>3.3 IDU</li> <li>3.4 Heterosexual (HET)*</li> </ul> </li> <li>4. Race               <ul style="list-style-type: none"> <li>4.1 African American (AfAm)</li> <li>4.2 Anglo</li> <li>4.3 Latino</li> </ul> </li> <li>5. Geographic Location               <ul style="list-style-type: none"> <li>5.1 Urban</li> <li>5.2 Rural</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>6. Special Population               <ul style="list-style-type: none"> <li>6.1 In-Migrants</li> <li>6.2 MSM of Color (MSMC)</li> <li>6.3 Undocumented (UNDOC)</li> <li>6.4 Youth (under the age of 24)</li> <li>6.5 Women of child bearing age (WCB)</li> <li>6.6 Substance Users (SUBSUSE)</li> <li>6.7 Mental Service History (MI)</li> <li>6.8 Serious Mental Illness (MI-Ser)</li> <li>6.9 Recently Incarcerated (RECINC)</li> <li>6.10 Homeless (HOMELSS)</li> </ul> </li> <li>7. Stage of Infection               <ul style="list-style-type: none"> <li>7.1. HIV, asymptomatic (H asymp)</li> <li>7.2. HIV, symptomatic (H symp)</li> <li>7.3 AIDS, asymptomatic (A asymp)</li> <li>7.4. AIDS, symptomatic (A symp)</li> </ul> </li> </ul>
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\*Abbreviations shown in parenthesis are used in Graphics throughout the text

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. Also when subpopulations are compared, the weighted sample is used. When special populations are analyzed, unweighted data is presented because they are purposefully oversampled to obtain adequate sample sizes for analysis. The population estimates are based on epidemiological information, and are shown in Table 2-4. The unweighted sample shows the over-sampled populations, while the weighted sample is very close to the projected population estimates of PLWH/A.

**Table 2-4 Sample Frame**

		<b>% Total Pop (2000)</b>	<b>Weighted</b>	<b>Unweighted</b>
<b>Gender</b>	Male	82.7%	84.1%	73.2%
	Female	17.3%	15.9%	26.8%
<b>Race</b>	African American	23.8%	22.5%	32.3%
	Anglo	59.7%	59.0%	35.0%
	Latino	14.0%	15.4%	26.3%
	Other	2.1%	3.2%	6.3%
<b>Risk Group*</b>	MSM	62.1%	62.4%	35.6%
	MSM/IDU	8.7%	8.2%	8.7%
	IDU	16.3%	16.4%	20.1%
	HET	12.7%	13.0%	35.6%
<b>County</b>	Clark (NV)	96.3%	77.3%	88.6%
	Mohave (AZ)	3.1%	19.1%	9.9%
	Nye (NV)	0.7%	3.6%	1.5%

\* 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. The barrier analysis was based on a multidimensional framework created by PCH using several needs assessment surveys. This analysis is further discussed in the barrier chapter of this report.

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 8.

Focus group were audio taped, transcribed professionally, and were coded by PCH staff for qualitative analysis. Focus groups were transcribed and coded using the coding scheme shown in Attachment 9. All focus group participants were informed about the purpose and use of the recordings and the confidentiality of all participants was assured. 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

Table 3-1 shows the total weighted survey sample of the 334 PLWH/A who 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. Within the weighted sample, there is a small over-representation of Latino MSM and Latino IDUs, however it is likely that the HIV/AIDS Reporting System (HARS) undercounts Latinos who are infected but have not been included in the HARS database.

Below are some highlights of the demographic analysis:

- The total weighted sample consists of 84% males and 16% females.
- The majority of the sample is non-Latino Anglo (59%), followed by African Americans (23%) and Latinos (15%). Three percent are “other” or multi-racial which includes Native American and 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, Latinos, Native Americans, and Asian/Pacific Islanders, represent 41% of the sample.
- MSM represent the largest proportion of PLWH/A at 62%, followed by (non-MSM) IDUs at 16%, heterosexuals at 13% and MSM/IDU at 8%.
- PLWA represent 48% of the sample and PLWH account for 52% of the sample.
- According to the HIV/AIDS reporting system (HARS), 96% of the PLWH/A live in Clark County, 3% in Mohave County, and 1% in Nye County. PLWH/A living in Mohave and Nye counties were oversampled to allow an analysis of those living outside of Clark County. The weighted analysis continues to over-represent those living in Nye and Mohave county with 77% of the weighted sample living in the urban areas of the EMA and 23% living in the rural areas. Latinos and African Americans are overwhelmingly urban compared to Anglos.
- In all areas within the EMA, MSM are the majority, but heterosexuals and IDUs are more likely to be found in the urban areas.

**Table 3-1 Number of Survey Respondents (N=334)**

	TOTAL		African American		Anglo		Latino		Other	
	N	% wt	N	% wt	N	% wt	N	% wt	N	% wt
<b>TOTAL</b>	<b>334</b>	<b>100.0%</b>	<b>75</b>	<b>22.5%</b>	<b>197</b>	<b>59.0%</b>	<b>51</b>	<b>15.3%</b>	<b>11</b>	<b>3.3%</b>
<b>Male</b>	281	84.1%	55	72.5%	173	87.7%	45	87.9%	9	80.6%
<b>Female</b>	53	15.9%	21	27.5%	24	12.3%	6	12.1%	2	19.4%
<b>MSM</b>	208	62.4%	34	45.2%	133	67.3%	37	71.6%	5	47.8%
<b>MSM/IDU</b>	28	8.2%	3	3.8%	21	10.6%	2	3.7%	2	17.9%
<b>IDU</b>	55	16.4%	22	29.5%	26	13.4%	6	11.2%	0	4.5%
<b>Heterosexual</b>	43	13.0%	16	21.5%	17	8.7%	7	13.5%	3	29.9%
<b>Rural</b>	78	23.0%	4	4.9%	71	36.0%	1	2.8%	2	20.9%
<b>Urban</b>	256	77.0%	63	95.1%	126	64.0%	50	97.2%	8	79.1%
<b>HIV asymptomatic</b>	101	30.2%	29	38.9%	53	26.7%	16	31.0%	3	29.9%
<b>HIV symptomatic</b>	73	21.7%	20	27.1%	44	22.5%	7	13.4%	1	10.4%
<b>AIDS asymptomatic</b>	27	8.1%	6	8.0%	9	4.7%	10	20.0%	1	13.4%
<b>AIDS symptomatic</b>	134	40.0%	20	26.1%	91	46.1%	18	35.6%	5	46.3%

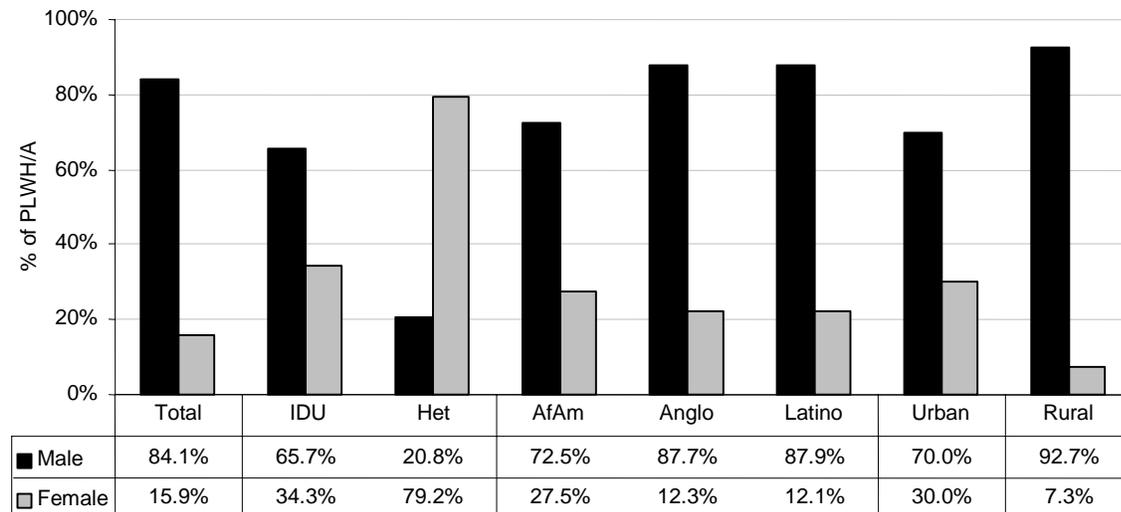


## Women

As seen in Figure 3-1, while women represent 16% of the PLWH/A sample, they represent 79% of the heterosexuals, and 34% of the IDUs. Amongst ethnic groups, women are 28% of the African American population, 12% each of the Anglo and Latino populations.

Though not shown in the graph, women living with HIV/AIDS tend to have less formal years of education than men, and are less likely than men to live in their own apartment or house. Women are also less likely to have been diagnosed with AIDS and are more likely to report being asymptomatic than men.

**Figure 3-1 Gender by Mode, Ethnicity, and Geographic Location**



## Ethnicity and Mode of Transmission

Figure 3-2 shows the overall proportion of each of the ethnic group by the mode of transmission. It indicates that:

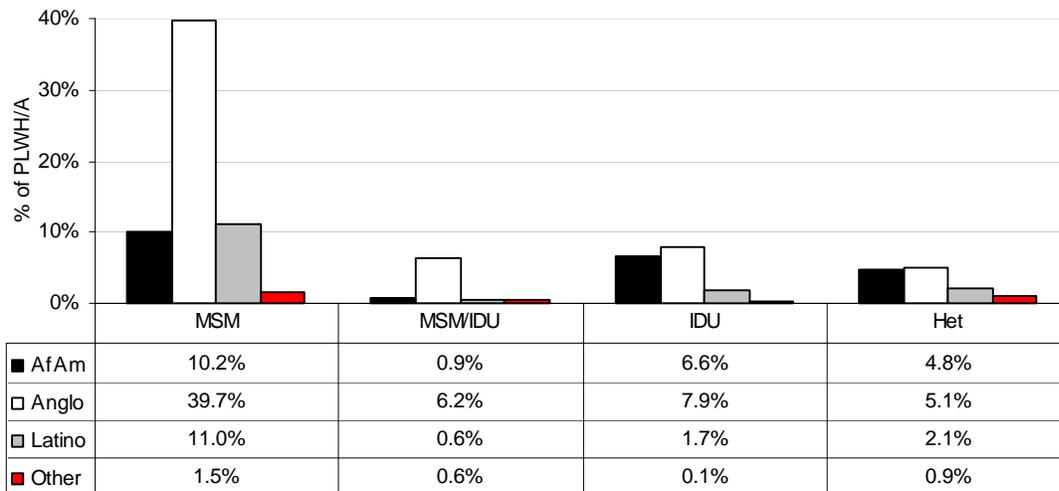
- Among the total weighted sample, the largest numbers of PLWH/A are Anglo MSM (40%) followed by Latino MSM (11%) and African American MSM (10%).
- IDUs represent about 16% of all PLWH/A, and they are about equally divided between Anglos (8%) and African Americans (7%). About 2% of all PLWH/A are Latino IDUs (although the number of IDUs in the sample is small and this may not be a reliable estimate).
- Heterosexuals represent 13% of all PLWH/A. They are equally divided between Anglos and African Americans at 5% each.



Not shown in the graph:

- Latinos are the second largest ethnic group of the MSM population (18% compared to 16% of African Americans).
- Urban PLWH/A are more likely to be African American (35%), and Anglos and Latinos each represent 29% of the urban population. In rural populations, Anglos (91%) are the large majority followed by African Americans (5%).
- In-migrants are more likely to be Anglos (46%). African Americans and Latinos each represent about 25% of the in-migrants.
- Anglos are the majority of the sub-populations: substance users (65%), mentally ill clients (73%), the severely mentally ill (79%), recently incarcerated (61%) and recently homeless (63%). Amongst WCB, Anglos are the slight majority (43%) followed by African Americans (41%). In all categories, African Americans represent a larger percentage than they have in the general population, indicating the disproportionate impact the epidemic has on the African American community.

**Figure 3-2 Ethnicity by Mode of Transmission**



## Education

Seventy-six percent of the PLWH/A in the Las Vegas EMA have at least a high school diploma. Close to a third have graduated high school (32%), and 44% have some technical training beyond high school.



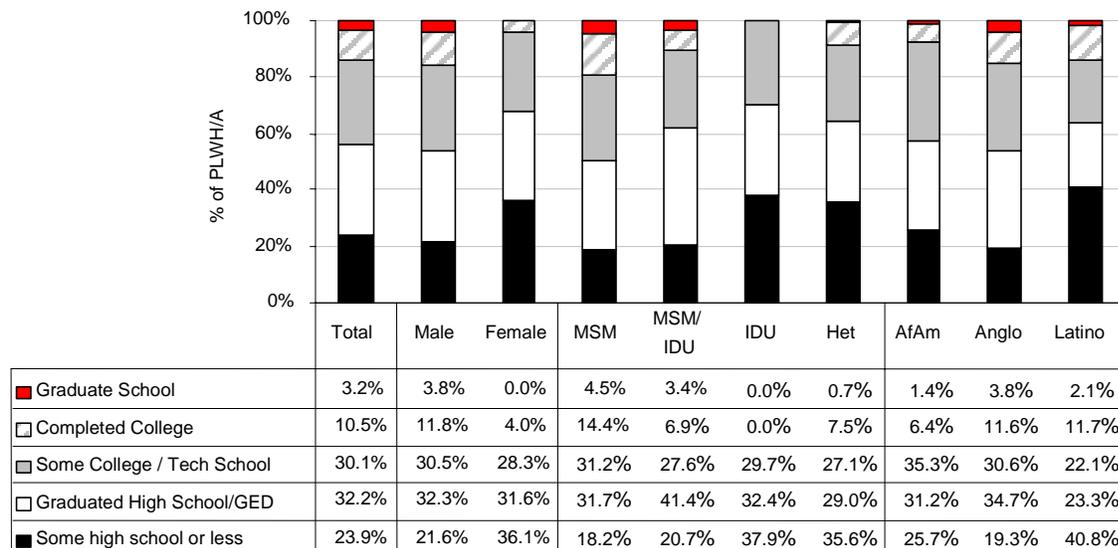
Figure 3-3 shows the different levels of education for the risk categories and racial/ethnic groups. It indicates that:

- MSM have the highest level of education, with about a fifth reporting at least a college education, compared to 10% of MSM/IDU, 8% for heterosexuals, and 0% for IDUs.
- Among gender groups, females have the least amount of education with only 64% having received a high school diploma and only about 32% having some college as compared to 46% of the males.
- Among racial/ethnic groups, African Americans have the lowest level of education. They fall below the average with 75% having completed high school. And only 6% of African Americans completed college as compared to 12% of both Latinos and Anglos.

Not shown in the graphic:

- Rural residents (52%) are more likely to have some college education compared to urban residents (41%). Forty-three percent (43%) of in-migrants have some amount of college education.
- In regards to the special populations, 57% of WCB have received a high school diploma compared to 72% of recently incarcerated and 69% of the recently homeless. Forty-two percent of the undocumented have received a high school diploma with 27% having some college education.

**Figure 3-3 Level of Education by Gender, Mode, and Race**





## Age Distribution

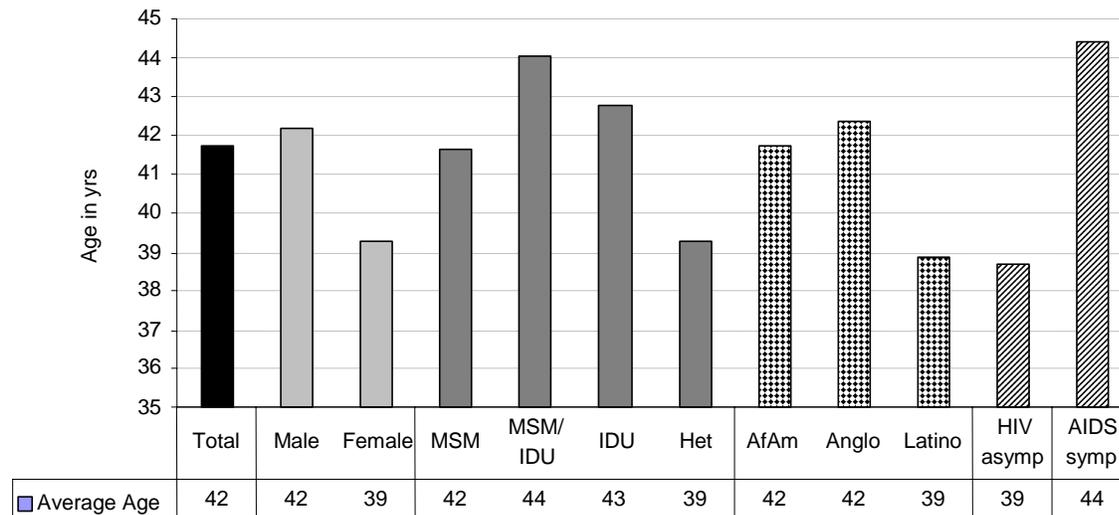
The average age of PLWH/A is 42 years, and 88% of the PLWH/A are between the ages of 25 and 54 years old. Figure 3-4 shows the mean age by gender, mode of transmission, ethnicity, and stage of disease. It indicates:

- Amongst risk groups, heterosexuals are the youngest, averaging 39 years old.
- Persons living with AIDS are the oldest population, reflecting their early infection and the slower progression of HIV to AIDS with current medication. Predictably, those with HIV (not AIDS) tend to be younger.
- Among the racial/ethnic populations, Latinos are the youngest averaging 39 years old.

Not shown in graph:

- In-migrants are 38 years on average while the rural residents of the EMA are 42 years old.
- Among the special populations, the undocumented are the youngest, averaging 34 years old, followed by women of child bearing age who average 36 years old.

**Figure 3-4 Age by Risk Group and Race**



## 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. Those 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, close to three-quarters live with one adult and 26% live with two or more adults. More African Americans live with more than one adult (40%) compared to the 25% of Latinos and Anglos. About 25% of PLWH/A live with another HIV positive person in their household.

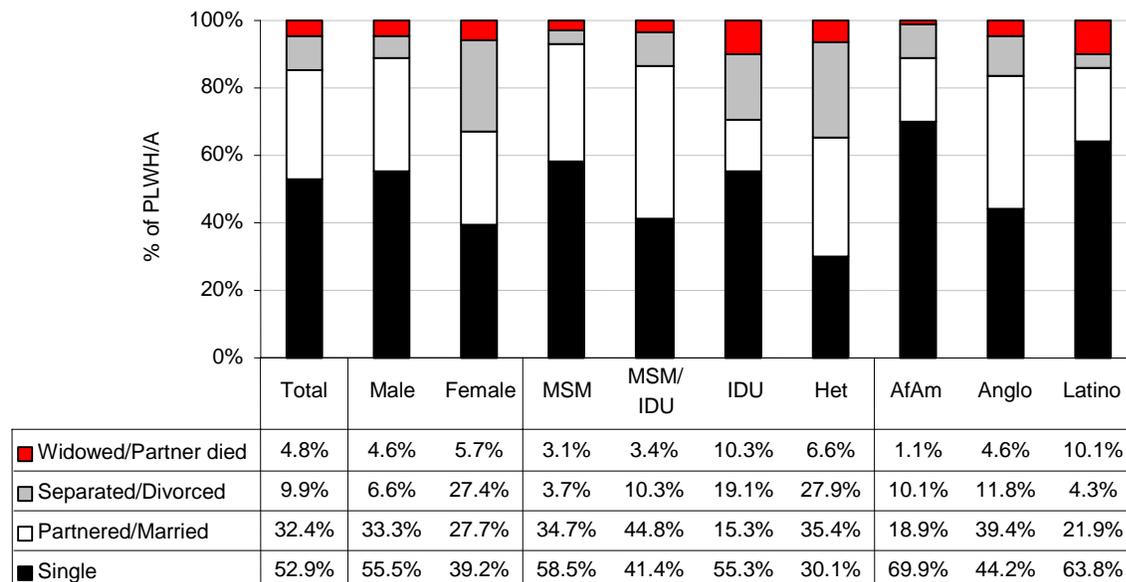
Sixteen percent (16%) of all PLWH/A report living with children and four percent of those children are HIV positive. Twenty-five percent (25%) of the women of child bearing age are currently living with one or more children.

As shown in Figure 3-5:

- 53% of all PLWH/A are single.
- Females and heterosexuals are more likely than other populations to be divorced or separated with about 27% of each population reporting such.
- Among ethnic/racial populations, more African Americans report being single (70%) than other racial populations.
- Within the risk groups, MSM are more likely to be single (59%) while MSM/IDU are more likely to be partnered (45%).

Not shown in the graphic is the smaller amount of single PLWH/A in the rural areas. The largest number of PLWH/A are married (38%). Thirty-seven report being single and 19% are divorced.

**Figure 3-5 Relationship Status by Gender, Mode and Ethnicity**



## 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. For instance, in order to qualify for



the AIDS Drug Assistance Program (ADAP) or other state-funded medication reimbursement programs, PLWH/A are eligible if they don't surpass 400% of Federal poverty levels (between \$33,000 and \$34,000 a year for a single person).

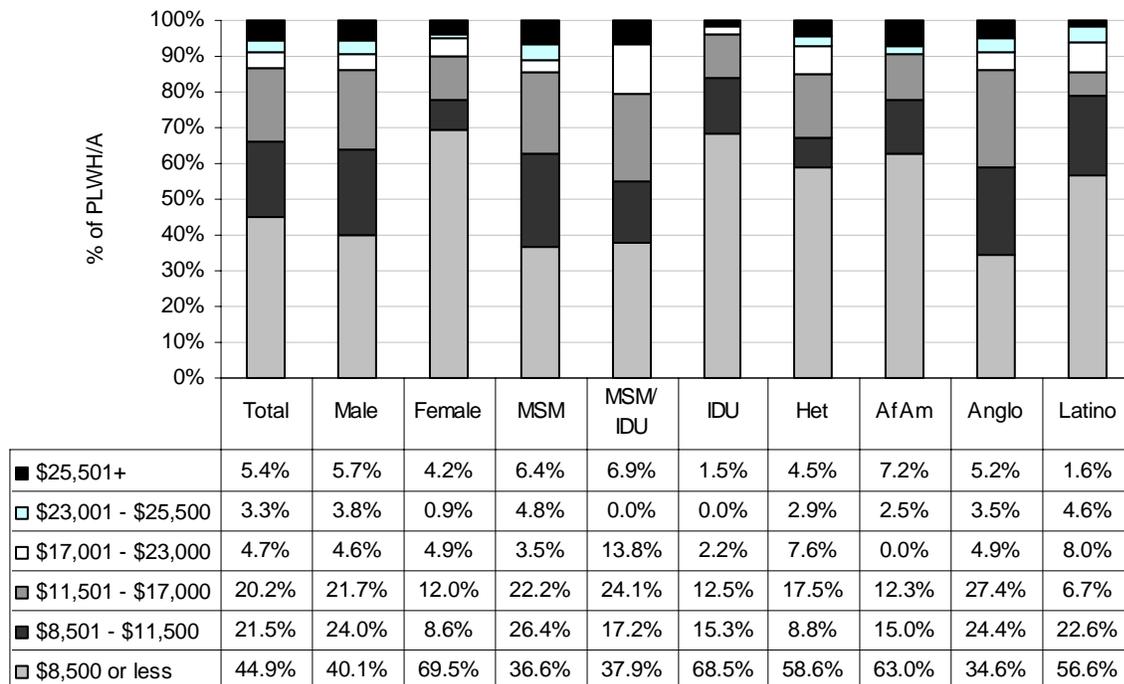
Figure 3-6 shows income levels by gender, mode, and ethnicity. It indicates that:

- In general, the participating PLWH/A have low incomes, with about 87% reporting earning less than \$17,000 and almost half reporting earning less than \$8,500.
- Females earn less than males, with about 70% females making less than \$8,500 compared to about 40% of males.
- Among risk groups, IDUs have the lowest income with 69% making less than \$8,500 followed by heterosexuals (59%). On the other hand, MSM/IDU have the highest income with 21% making more than \$17,000 followed by MSM and heterosexuals at 15% each.

Not shown in the graph:

- Almost half (48%) of the urban residents make less than \$8,500 compared with 35% of the rural residents.
- Those who are HIV symptomatic report lower income (65% make less than \$8,500) than those reporting AIDS and symptoms (37%).

**Figure 3-6 Income by Gender, Mode and Ethnic groups**





## Employment Status

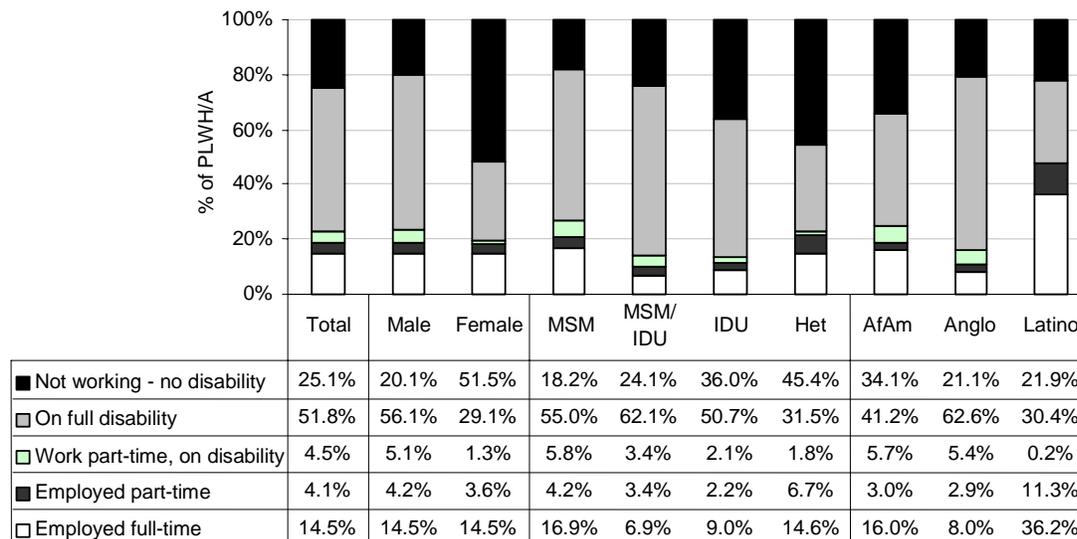
Many of those who are or were employed or on disability have access to care through private health insurance or Medicaid. As shown in Figure 3-7, about 55% of the of PLWH/A are on either short- or long-term disability. Slightly under a quarter (23%) are employed full- or part-time. A quarter of the PLWH/A are not currently working. This group includes the retired, students, and those having applied for disability. Figure 3-7 shows the following:

- Females are more likely not to work and not have disability (52%) than males (20%).
- Among risk groups, heterosexuals (45%) and IDUs (36%) are more likely not to be working and to have no disability, and therefore more likely to have a need for Ryan White funded services.
- Of all risk groups, MSM are the most likely to be employed with 27% reporting working full- or part-time. IDUs are the least likely to be employed with 13% reporting working at some level.
- Among ethnicities, African Americans (34%) are least likely to be on disability and more likely not to work, while Latinos (48%) report working the most.

Not shown in the graph:

- Sixty-three percent of the rural residents are on full disability compared to 48% of the urban residents.
- Forty-six percent of the in-migrants are on full disability.
- The undocumented are employed the most with 77% having reported working full- or part-time.
- WCB and the recently incarcerated are the sub-populations are the most vulnerable in the community with 55% and 49%, respectively, reporting not working and not on disability.

**Figure 3-7 Employment Status by Gender, Mode, and Ethnicity**





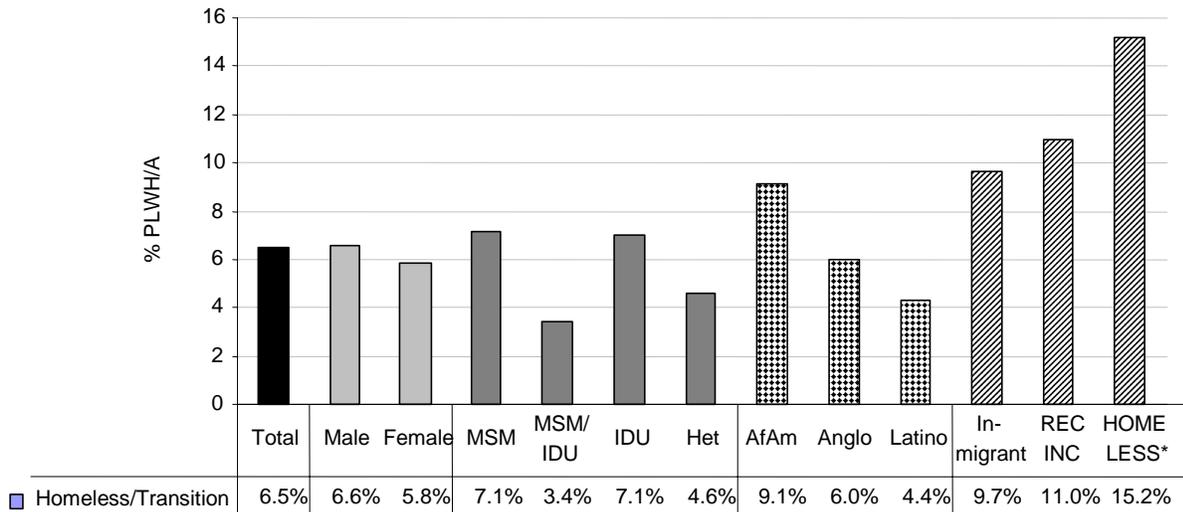
## 4. CO-MORBIDITIES

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

### Housing & Homelessness

Stable housing is often a prerequisite for a PLWH/A who is trying to adhere to a difficult medical regimen and improve their quality of life. About 7% of PLWH/A reported being currently homeless or in some form of transitional housing. Transitional housing includes living in a rooming or boarding house, a group home or residence including residential drug therapy, a half-way house, or transitional housing. As shown in Figure 4-1, the recently incarcerated, IDUs, in-migrants, and African American are more likely to be currently homeless or in transitional housing than other populations.

**Figure 4-1 Currently Homeless or In Transition**



\*Homeless in past two years

The instability of housing becomes more evident when PLWH/A are asked if they have been homeless or in transitional housing in the last two years. Of those PLWH/A interviewed, 19% have been homeless sometime in the last two years, and 16% have lived in some form of transitional housing.

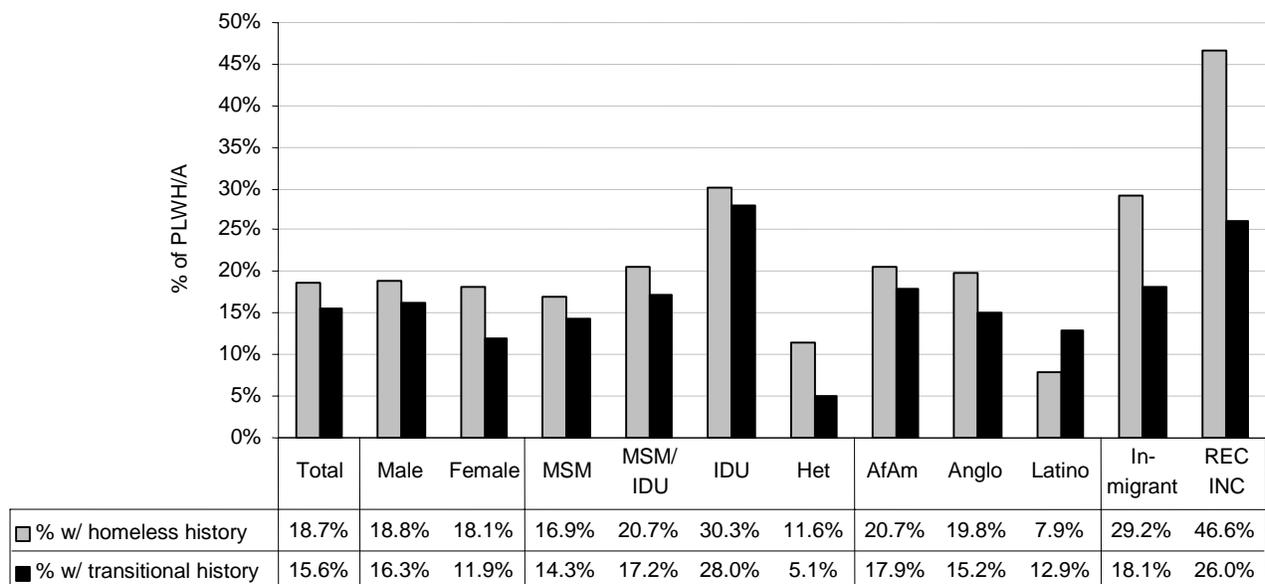
Figure 4-2 confirms:

- African Americans are more likely to have unstable housing and live in transitional housing than other ethnic groups.
- 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.
- Latinos have the lowest amount of homeless history (8%).



- The recently incarcerated are far more likely to experience a period of homelessness than other populations. Nineteen percent (19%) of all PLWH/A report having a history of being homeless compared to 47% of those who have been incarcerated in the last two years. This may be connected to the financial challenges and rules and regulations of public housing one faces after being released.
- A disproportionate number of in-migrants also have spent some time homeless in the last two years. This may be connected to the current housing market in the Las Vegas EMA
- Not shown in Figure 4-2 is that 31% of those with a history of substance use and 24% of symptomatic PLWH/A report being homeless in the last two years.

**Figure 4-2 Homelessness & Transitional Housing**



## Substance Abuse

The co-morbidity of substance use and HIV includes drugs that are typically injected such as heroin and crystal meth, but also includes non-injecting substances such as marijuana and “party drugs” such as ecstasy and poppers that have been related to unsafe sexual practices that place individuals at high risk for HIV infection.

The EMA epidemiological data indicate that in 2000, 16% of the HIV transmission is attributable to injection drug use, with lower incidence in the Clark County (14%) than in the more rural Counties of Nye (21%) and Mohave (2%). Compared to urban areas such as New York and Las Vegas, the percentage of infections due to injecting drug use in Clarke County is relatively small.<sup>2</sup>

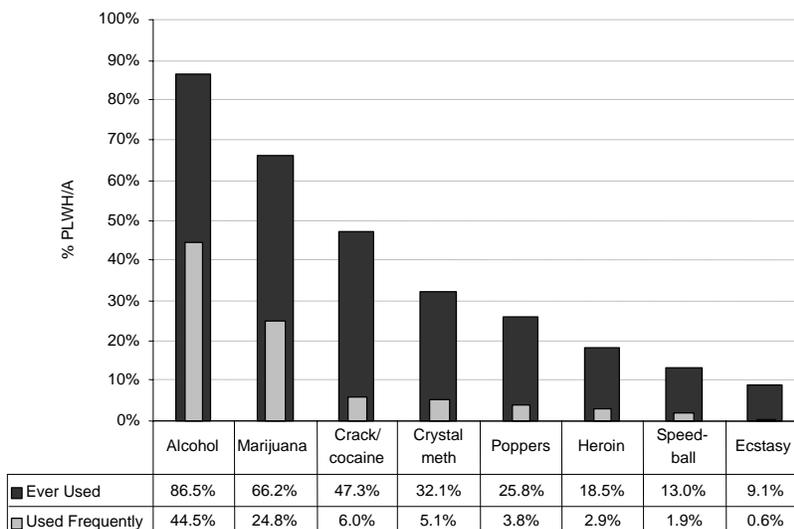
<sup>2</sup> “Drug-Associated HIV Transmission Continues in the United States”, CDC, September 2000. (See <http://www.cdc.gov/hiv/pubs/facts/idu.pdf>)



The survey data of self-reported drug use indicate that drug use for PLWH/A has substantially decreased. One quarter (25%) of the PLWH/A who were interviewed report a history of injecting drugs, but frequent use of heroin and crystal meth is low. The black bar in Figure 4-3 shows the percentage of PLWH/A who ever used a drug, and the gray 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 alcohol and about 15% saying they use marijuana more than once a week. Frequent marijuana use is much higher among Latinos than other ethnic groups.
- Of the opiates, 47% of the PLWH/A report ever using crack/cocaine and 19% report ever using heroin. About 6% of PLWH/A who use crack or cocaine say they continue to use the drugs frequently (more than once a week), and about 3% of PLWH/A who ever used heroin report using heroin in the past 6 months. African Americans and users of other substances are more likely to use crack than other populations. The recently incarcerated, mentally ill and symptomatic and PLWH/A are among the highest users of heroin, indicating the high level of co-morbidities among these populations.
- Because fatigue is a common side effect of HIV and its medications, it is not uncommon for PLWH/A to self-medication with crystal meth, a type of speed. While almost one third of PLWH/A in Las Vegas say they have used crystal meth, about nine percent report using it frequently.
- “Party drugs” include poppers and ecstasy. More than a quarter of the PLWH/A report using poppers, with about three percent saying they use it monthly. Nine percent (9%) 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. Rural PLWH/A report a higher use of party drugs than urban PLWH/A.

**Figure 4-3 Substance Use Among PLWH/A**





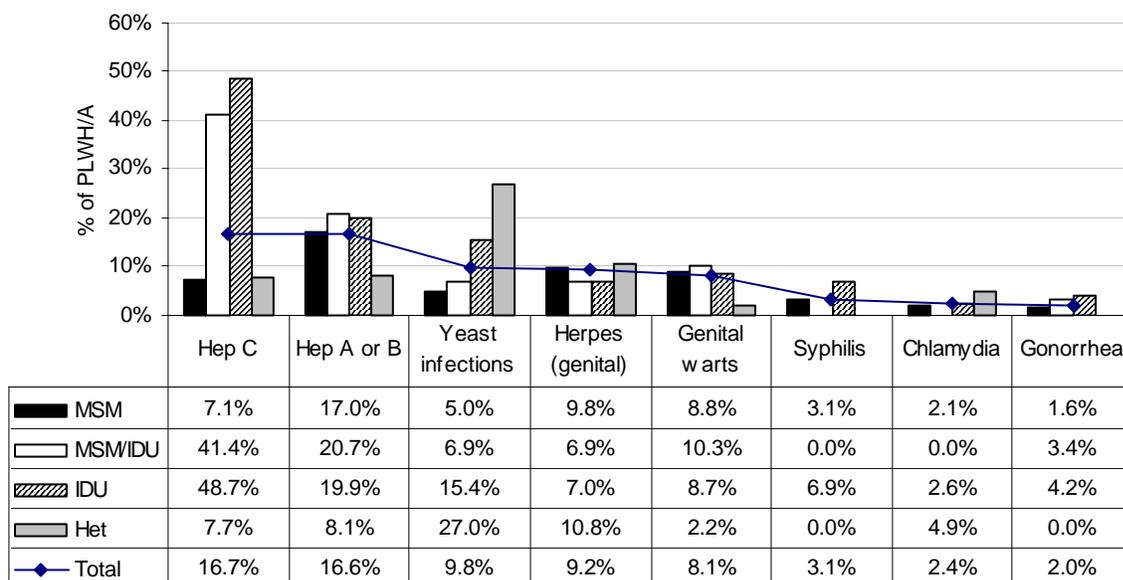
## STDs

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 the percentage of PLWH/A who report being diagnosed with STDs in the last two years. They indicate that:

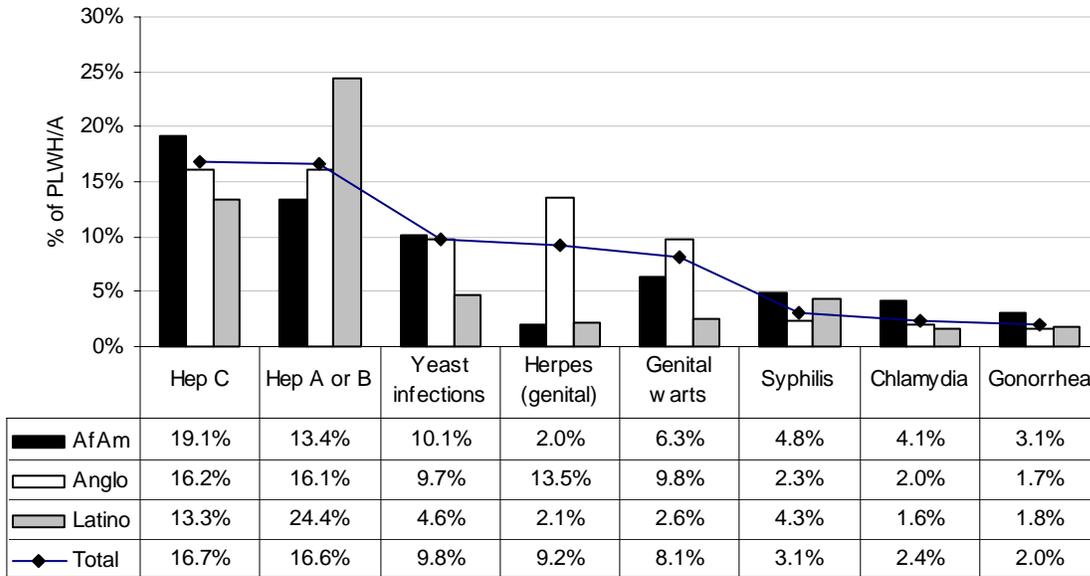
- About 17% of all PLWH/A report having been diagnosed with Hepatitis C in the last two years. Predictably, it is significantly higher among IDUs (49%) and MSM/IDUs (41%). Among ethnic communities, the incidence of Hepatitis C is higher among African Americans (19%). Twenty-five percent of those recently incarcerated have been diagnosed with Hepatitis C.
- Next highest incidence of STDs is hepatitis A or B (8%). It is significantly higher among Latinos (24%) and there is not much difference in incidence by risk group. Hepatitis A and B is reported to be lower among heterosexuals and African Americans.
- Amongst the heterosexuals, yeast infections are the highest diagnosed STD they report and is primarily by females. Syphilis, Gonorrhea and Chlamydia each have relatively low incidence. Syphilis is significantly higher among IDUs (7%), and genital warts among MSM/IDUs (10%).

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





**Figure 4-5 STDs among PLWH/A by Race**



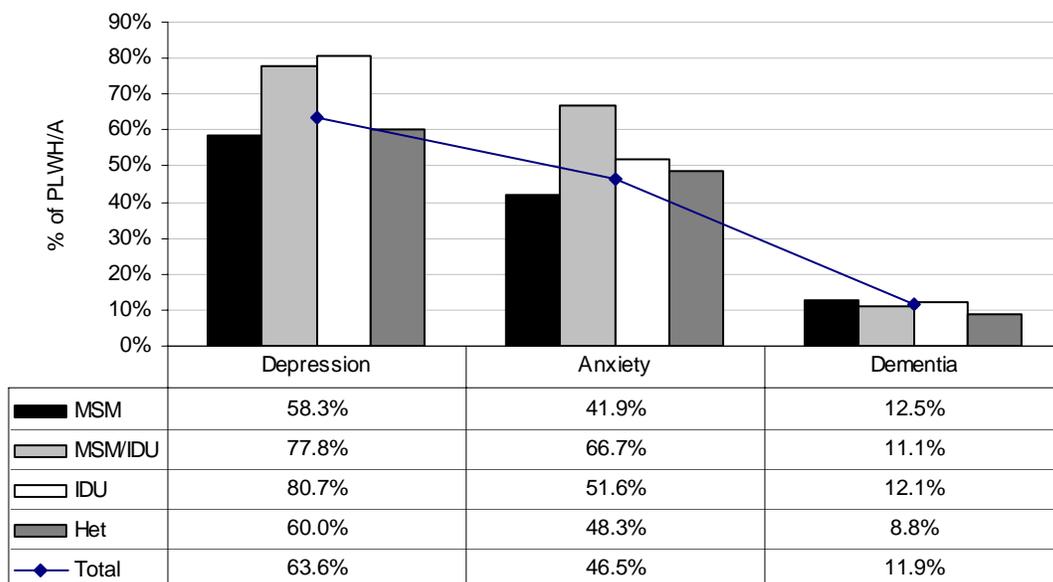


## Mental Illness

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 service needs. For the purpose of this needs assessment mental illness was defined as having a diagnosis of anxiety, dementia, or depression. Serious mental illness is defined as having received inpatient mental health services or receiving medication for psychological or behavioral problems. More than half of PLWH/A (53%) reported having been diagnosed with one of these conditions. The types of mental disorders that have been diagnosed are shown in Figure 4-6 and Figure 4-7. They indicate that:

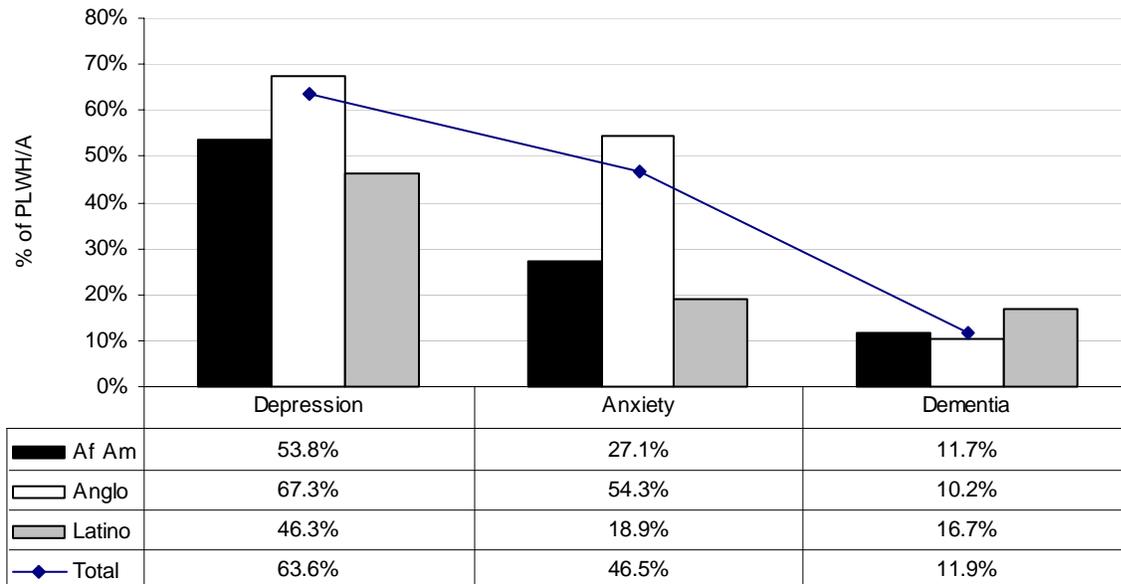
- Depression has been diagnosed among 64% of PLWH/A in the past year, and it is the most frequently diagnosed mental illness reported by PLWH/A.. It tends to be highest among MSM/IDU (81%) and IDUs (78%). It is also above average for Anglos (67%).
- Depression is particularly high amongst the homeless (89%), recently incarcerated (77%), WCB (72%) and in-migrants (71%).
- Close to half of the PLWH/A (47%) report a diagnosis of anxiety in the past year. It tends to be lower among Latinos and MSM of color (MSMC).
- Twelve percent report the more acute diagnosis of dementia. Serious dementia may be undercounted because they would not have been able to complete the survey.
- Latinos tend to report lower diagnosis of depression and anxiety than other racial/ethnic groups. This may reflect actual incidence or that they are less likely to see mental health professionals for a diagnosis.

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





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



More than three-quarters (79%) of PLWH/A reported having seen individual therapists and 33% of the PLWH/A report participating in professional group counseling. The percentage of those seeking mental health care is basically the same across all ethnic communities. Substance users and those with a history of homelessness are much more likely to report receiving therapy. Youth and IDUs tend to receive less treatment than other populations analyzed.

### **Tuberculosis**

In the survey PLWH/A were asked if they have ever been diagnosed with TB or had a positive skin test for TB. In addition they were asked if they were in treatment. Twelve percent of PLWH/A report a positive skin test but no active TB. This is probably an over-report, but it does indicate that African Americans, Latinos, and IDUs are more likely to report a positive skin test.

Three out of the 334 participants in the survey report active TB, and all three say they are out of treatment. While the small sample size does not make this generalizable, the fact that all three are out of treatment suggests that there may need to be more aggressive follow-up for those persons who have TB and HIV infection.



## **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. Recently the guideline to start retroviral treatment was changed from a CD4 count of 500 to 350 cells/uL. Treatment should be considered for HIV infected persons whose CD4 counts are above 350 cells/uL and their viral load level rises above 30,000 copies. 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 AIDS often have a need for buddy and companion services, home health care, hospice care, permanency planning, and other end-stage services.

For others in early stages of infection, case management, monitoring, medical case management, and mental health services can be critical for maintaining a negative status or controlling the infection. 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 (see Attachment 10) provided they meet income and geographic criteria.

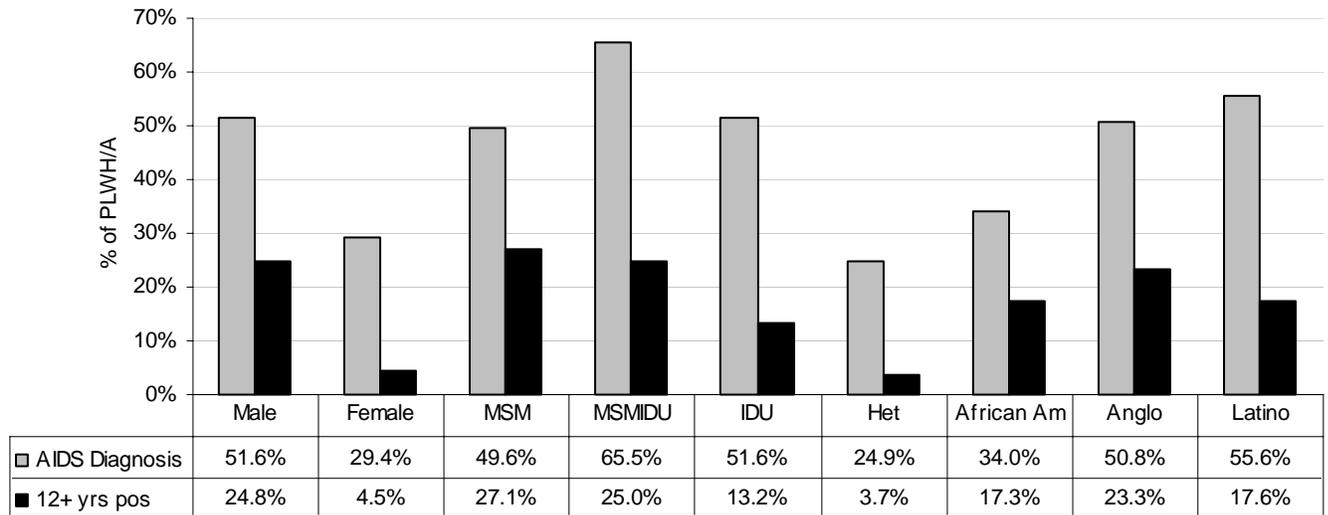
Given these criteria, the survey asked respondents to note if they are symptomatic or asymptomatic and if they have been diagnosed with AIDS. The survey also asks for self reported highest and most recent CD4 and viral load counts.

### **Diagnosed with AIDS**

Fifty-two percent of the PLWH/A who were surveyed reported that they were told by their doctor, nurse or other health care team member that their HIV had progressed to AIDS. Predictably, there is a significant relationship between the length of time a person knows they were HIV positive and an AIDS diagnosis. Typically, those who know their status longest are most likely to have been diagnosed with 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. The high incidence of reported AIDS among Latinos, given the relatively few who have known their status for several years, suggests a greater vulnerability to progression to AIDS, or testing at a later stage of infection. Given the small number of Latinos in the sample, this finding may not be generalizable to the all Latinos living with HIV/AIDS.



**Figure 5-1 AIDS Diagnosis and Time Known HIV+**



In addition, Table 5-1 shows that IDU, heterosexuals, and Latinos are disproportionately more likely than any of the other groups to have an AIDS diagnosis within the first three years of knowing their HIV positive status. Also, women are more likely than men to be diagnosed with AIDS within the first three years of infection. This is consistent with the epidemiological trends. Taken at face value, it suggests that IDUs and heterosexuals are likely to progress to AIDS earlier than MSM and MSM/IDU, and Latinos are more likely to progress to AIDS than other ethnic groups. It also suggests that HIV is being detected among these vulnerable populations at a later stage of infection.

**Table 5-1 AIDS Diagnosis and Time Known HIV+**

	Male	Female	MSM	MSMIDU	IDU	Het	Af Am	Anglo	Latino
Less than 3 years	19.6	22.3	11.7	16.7	46.1	32.5	19.2	18.4	26.9
3 to 6 years	24.7	12.1	30.0	5.6	9.3	27.8	19.2	27.2	16.7
6 to 12 years	27.9	65.6	28.0	38.9	37.8	38.9	36.6	29.8	33.8
More than 12 years	27.8	0.0	30.3	38.9	6.7	0.9	25.1	24.5	22.5

### Symptomatic

The findings indicate that about 54% of PLWH/A surveyed currently have symptoms associated with their HIV infection. Of those diagnosed with AIDS, three quarters (75%) report being symptomatic. Among HIV positive, non-AIDS diagnosed respondents, 34% report symptoms.

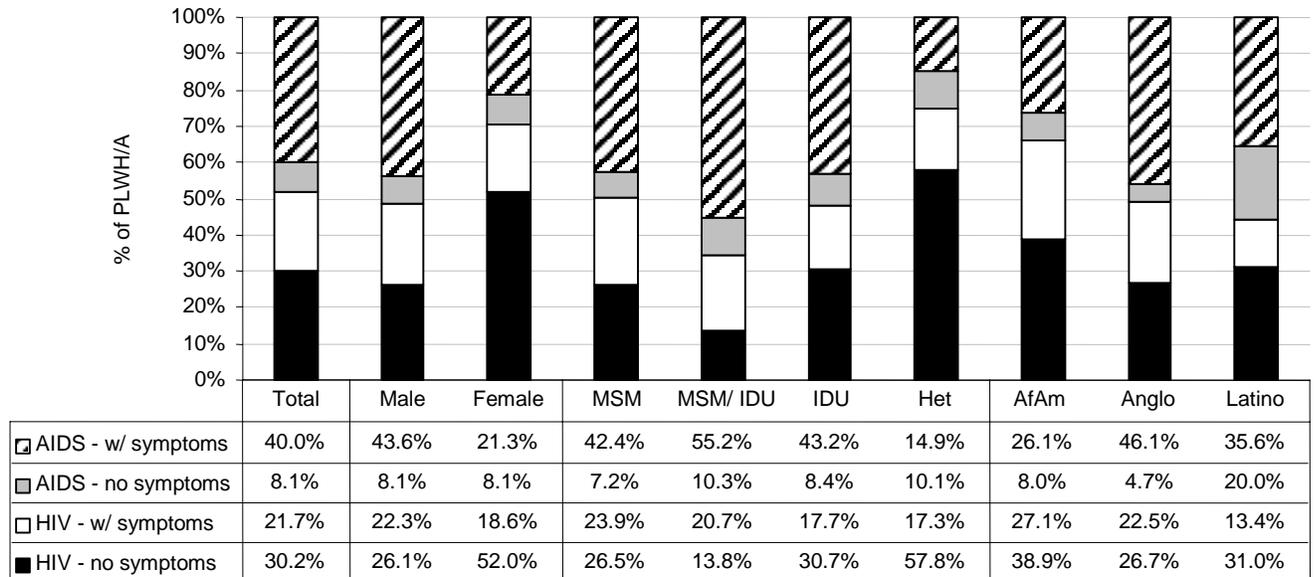
Figure 5-2 shows the percentage reporting symptoms by risk category.

- There are 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 more 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 5-2 Percentage With and Without Symptoms by Gender, Mode, and Ethnicity**



### Eligible for Medical Care

Based on the criteria for antiviral treatment, 62% of the HIV positive population report symptoms and would be recommended for treatment. In addition, based on survey data, there are 6% of all PLWH/A who report an AIDS diagnosis, are asymptomatic, and report a current t-cell count below 350, suggesting, that 68% of PLWH/A are likely to need medical treatment for their infection.



## **6. INSURANCE AND BENEFITS**

### **Access to Health Care**

The vast majority of PLWH/A, whether insured or not, access medical care and wrap around services through the same clinics and organizations in the EMA. For primary outpatient care and adherence, The UMC Wellness Center serves the vast majority of PLWH/A, and several doctors at the wellness center have private practices that largely serve insured PLWH/A. The VA and Clark County Health District also provide care to a substantial number of PLWH/A. Case Management is provided by several agencies, but the majority of PLWH/A in Clark County report using AFAN. Those in Mohave, use the Mohave County Department of Health and Human Services. Several rural clients report using Kingston Arizona HIV/AIDS services. Within Clark County, Clark County Health District Transitional Care Case Management serves those newly infected, NALA and Caminar serves many in the communities of Color.

### Insurance Coverage

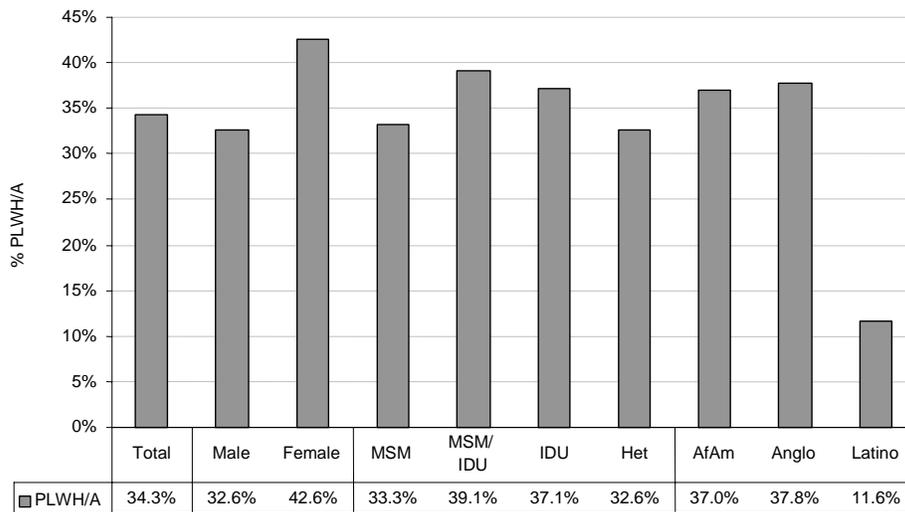
Clinics and case management organizations and other AIDS service organizations (ASOs) serve PLWH/A with and without insurance. For medical care, the major providers are equally likely to service those insured as not insured. The VA tends to serve PLWH/A without insurance, and PLWH/A who use private practices are much more likely to be insured.

In response to demand, the EMA has increased its allocation to health insurance continuation in the 2002 allocations by over 80%. Still, it accounts for just 6.6% of the Title I allocations, and most services are provided through direct payment to providers.

More than one third of the PLWH/A who were surveyed reported having no form of insurance. As shown in Figure 6-1, women (43%) and MSM/IDU (39%) are most likely to report not having insurance. Surprisingly, Latino's are less likely to report not having insurance, although the small sample size and sampling methods may overstate the number of Latinos who are insured.



**Figure 6-1 No Insurance**



Usually in EMAs where Ryan White does not pay for the majority of insurance, women tend to be more insured than men because of the various Medicaid programs for families and single mothers with children, such as SCHIP and TANF. However, in Las Vegas men have more insurance than women. The reason requires further investigation, but may be due to the difficulty in applying for and obtaining Medicaid, and the problems associated with the mandated managed Medicaid care programs in Nevada and Arizona.

Among the various ethnic/racial groups Anglos tend to be insured more than African Americans and Latinos because they often have higher incomes to purchase insurance, or are more likely to qualify for SSDI because of past work history. Seventy percent of Anglo PLWH/A report having insurance compared to about 60% of African Americans and Latinos. Interestingly, MSM/IDU (79%) are the group most likely to be insured while heterosexuals (50%) are the group least likely to report having any form of health insurance, again pointing out the disparity between men and women insured (the majority of heterosexuals are women).

Rural compared to urban residence appears to be related to insurance coverage more so than length of residency in the EMA. For instance, rural PLWH/A are more likely than urban PLWH/A to be on full-time disability and to have health insurance coverage. PLWH/A who have resided in Las Vegas for longer than two years also tend to report higher insurance coverage, however, in regard to full time disability, there is very little difference noted among the two groups, with about 40% of both in-migrants and longer term residents being on full-time disability. Not surprisingly the homeless, recently incarcerated and HIV asymptomatic are the groups most likely to be uninsured. On the other hand, people with an AIDS diagnosis, whether symptomatic or asymptomatic, report the among highest levels of insurance.



As shown in Figure 6-2 several types of insurance are reported by PLWH/A.

**Figure 6-2 Insurance Coverage**

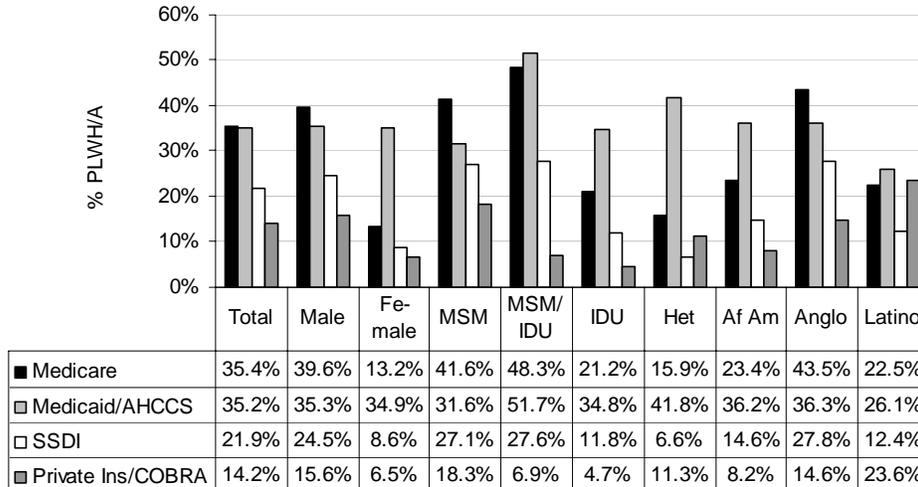


Figure 6-2 indicates that:

- Medicaid, Medicare and the combination of the two are major sources of insurance for all populations infected with HIV/AIDS.
- About 35% of PLWH/A report having Medicaid/AHCCCS (Arizona Health Care Cost Containment System).

Further analysis of the data indicate that:

- 15% of all those with insurance report Medicaid or AHCCCS as their sole form of insurance. Forty percent of the rural PLWH/A report having AHCCCS and for 14% of the rural PLWH/A AHCCCS is their only form of insurance.
- 35% of PLWH/A report Medicare with 12% having only Medicare.
- 13% of PLWH/A report dual Medicaid/AHCCCS and Medicare coverage.
- 14% of PLWH/A report some form of private insurance or COBRA. Of those, 23% also report Medicaid or Medicare coverage.

Different types of coverage vary by population.

- Medicare, suggesting disability and prior work history, is more likely to cover a greater percentage of males, MSM and MSM/IDU, and Anglos, than females, other risk groups or race groups. PLWA (48%) are more likely to receive Medicare than PLWH (24%).
- Medicaid/AHCCCS is more likely to cover MSM/IDUs and heterosexuals. Medicaid/AHCCCS is the most likely insurer among females, heterosexuals, and IDUs.
- Private insurance is relatively high among Anglos and Latinos.



## **Entitlements and Benefits**

PLWH/A access health care through non-insurance benefits, including Veteran's Assistance (VA), Clark County Social Services (CCSS), WIC, and through drug reimbursement programs. Drug reimbursement programs like ADAP can be the only form of drug assistance or it can supplement existing insurance coverage.

### VA, CCSS, and WIC

About 8% of the PLWH/A report VA benefits . Of those 8%, about 48% (about 4% of all PLWH/A) report having no insurance. As expected, most of those with VA benefits are men than women. MSM are equally likely to report VA benefits as all men. Among racial groups Anglos and African Americans are most likely to have VA benefits. Interestingly, those at the later stages of infection are more likely to report VA benefits suggesting that they are used more for acute care than monitoring the early stages of infection.

Eleven percent (11%) of PLWH/A report receiving CCSS benefits. While CCSS is not a form of health insurance it provides PLWH/A in need of medical care access to a medical provider.

Less than 1% of all PLWH/A but 4.5% of the women living with HIV and AIDS and over 7% of the women of child bearing age report receiving WIC, a program designed for women, infants and children that provides supplemental nutritious foods, nutrition education and counseling at WIC clinics, screening and referrals to other health, welfare and social services.

### Drug Reimbursement

The data suggest that PLWH/A do not have a good idea of how their medication is purchased. When PLWH/A are asked in the survey whether they receive medication reimbursement, only 14% say "yes". With about 90% of the sample reporting taking some medications, 21% reporting ADAP, and 35% reporting Medicaid it is likely that PLWH/A interpret the question as direct reimbursement to them and not reimbursement to the provider or pharmacy, as would be the case with ADAP, Medicaid, and other insurance.

When probed in later questions participants of the survey give realistic responses to some sources, unrealistic to others. When participants of the survey were probed for sources of reimbursement, 21% reported that ADAP paid for some of their drugs, and that is likely to be in the ballpark -- if not a bit high --for the last year. Five percent (5%) say private insurance, 6% veterans benefits, 4% out-of-pocket, and 12% other sources such as compassionate care programs, trials, and clinic programs. The unrealistic estimate is that 13% reported that Medicare/Medicaid reimbursed their medication. In fact, given that about 70% of PLWH/A report having Medicaid or Medicare, it is likely that a much larger proportion of the medication is reimbursed by Medicaid and/or Medicare.

The reason for the responses may be that clinics and doctors make the process fairly easy for patients so that their insurance pays without much participation by the PLWH/A. In the focus



groups there was also a fair amount of discussion of co-pays and there may be feeling among some that this is the cost of the drug. Whatever the reason, the exact amount reimbursed is not critical to this needs assessment as Title I allocates under 2% of its funds to drug reimbursement, and the majority of ADAP’s funding comes from Title II.

The importance of the finding, however, is that there is a need to better articulate the questions in future surveys, and there may be a need to better educate PLWH/A of their medication reimbursement options to better gauge their need.

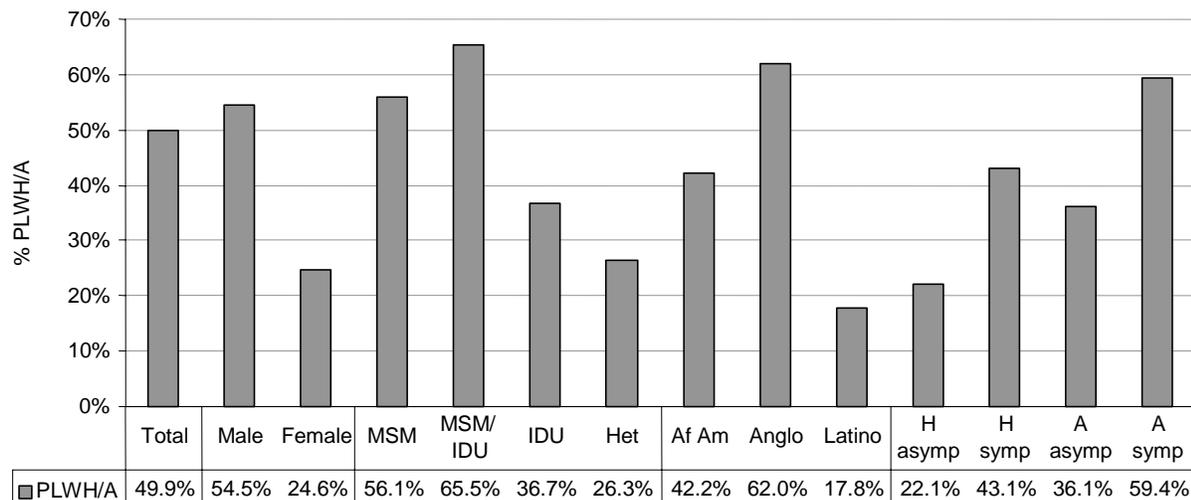
### Other Benefits

PLWH/A receive a variety of other services, such as food, housing, and financial assistance that are funded through a variety of sources. These entitlement and benefits are triggered by low income and disability. When PLWH/A are asked if they qualify for benefits, 7% report not being eligible for benefits with an additional 10% not knowing whether they qualify or not.

### Disability

As shown in Figure 6-3, about 50% of PLWH/A report being on long term disability. As expected the rate of disability is higher among those infected earlier, such as males, Anglos, and PLWA. Interestingly, a larger percentage of symptomatic PLWH report being on disability than asymptomatic PLWA. There are a surprisingly low number of IDUs on long term disability, probably due to not qualifying for or not applying for disability.

**Figure 6-3 Long Term Disability**



### Supplementary Income

Income supplements include Supplemental Security Income (SSI), Temporary Assistance to Needy Families (TANF), emergency financial assistance, rent assistance, food stamps, and long term and short term disability payments. Social Security Income (SSI) and TANF is based on



family income and SSI also required a status of disability. Those on SSI usually qualify for Medicaid, although there is a waiting period. Ryan White funds direct emergency assistance, and PLWH/A have to demonstrate need. The program has limited funds and allows limited payments each year.

The proportion of PLWH/A reporting supplemental income through food stamps, in shown in Figure 6-4.

**Figure 6-4 Supplemental Income**

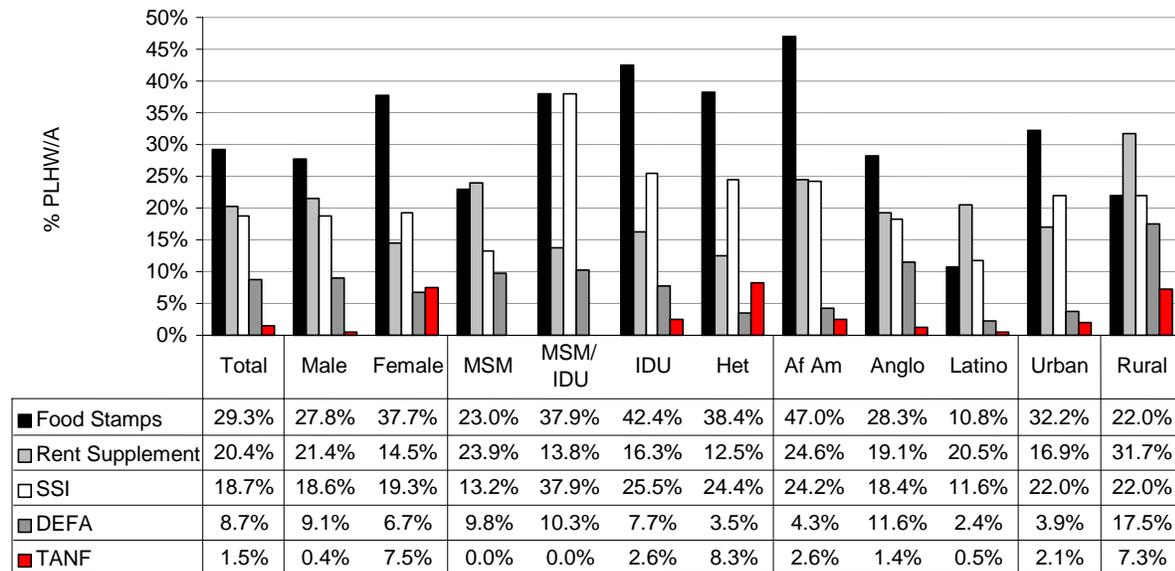


Figure 6-4 shows that:

- Indicative of the low income of PLWH/A, more than one quarter (29%) report receiving food stamps, and over 20% report receiving rent supplements. Females and heterosexuals, MSM/IDUs and IDUs, African Americans, and those living in rural areas are more likely to receive food stamps, and those in rural areas are also more likely to receive rent supplements. On the other hand, males and MSM are more likely to receive rent supplements.
- About 18% of PLWH/A report receiving SSI. MSM and Latinos are less likely to receive it than other populations.
- About 8% of the PLWH/A report receiving direct emergency financial assistance (DEFA), usually used for utilities, rent, or emergency medical treatment. Anglos and those in the rural areas are more likely to receive DEFA.
- Only about 2% of all PLWH/A report receiving TANF. Far more women (7%) report receiving TANF than men (less than 1%), reflecting their greater likelihood of having children and unavailability of other work-related coverage.



## 7. OUT-OF-CARE

The following section presents the profile of the PLWH/A who are currently or who have had a history of more than 12 months of being out-of-care. Two sources were used to analyze information about the out-of-care: the 2001 needs assessment survey of consumers based on a sample of 343 PLWH/A, and a specially designed survey, shown in Attachment 11, of those screened for out-of-care based on a sample derived from the HIV/AIDS Reporting System (HARS).

The out-of-care from the 2001 needs assessment survey were defined as those who have known they were HIV positive for five years or less and say that there was a period of a year or more when they did not see a doctor or go to a clinic. Twenty-three persons met this criteria out of 343 surveyed.

In addition to the 2001 Needs Assessment survey, a separate survey was designed and approved by the PAG for identifying out-of-care PLWH/A. Data collection for this survey began in May 2001 and concluded in November 2001. Based on the HARS database, initially 250 PLWH/A who had not had HIV-related lab work test in the past 18 months were identified. Subsequently, a second round group of potential participants was identified which included individuals who were shown not to have had any lab services in the 12 months. This increased the pool of potential participants to a total of 608 PLWH/A.

Surveillance staff who had the authority to contact those in the HARS data base made every effort to find the 608 PLWH/A based on information in the HARS database and public directories such as phone books. Despite the intensive effort, only 85 PLWH/A were found. Table 7-1 shows that from the 85, a total of 27 individuals had been out-of-care and completed the survey.<sup>3</sup> The 27 PLWH/A identified for the out-of-care survey consisted of individuals with a history of more than 12 months without seeing a medical care provider since knowing their HIV status. Five of the 27 were already in care, two refused care and 13 were subsequently brought into care.

**Table 7-1 Out-of-care Surveys: Disposition**

<b>DISPOSITION</b>	<b>Survey Completed</b>	<b>%</b>
Unable To Locate	--	--
Moved out of state / Other	--	--
Located, Already In Care	5	18.5
Located, Refused Care Services	2	7.4
Located, Brought Into Care	13	48.1
Missing disposition	7	25.9
<b>Total</b>	<b>27</b>	<b>100.0</b>

<sup>3</sup> A large percentage of the 608 did not have a history of being out of care, but instead were healthy enough to not have their lab work reported in the HARS, un-locatable because they either changed addresses or moved out of state, or they had died.



## Demographic Profile:

Data from the 21 PLWH/A who completed the out-of-care surveys and 23 PLWH/A who completed the NA survey was combined to create a profile of the PLWH/A who have known their HIV positive for five years or less and who have gone a period of at least 12 months without seeing a doctor. The analysis of the out-of-care are based on those 44 PLWH/A.

Table 7-2 presents the gender, racial/ethnic and risk group distribution for 44 PLWH/A with a history of being out-of-care. It indicates that:

- Thirty-one (71%) out of the 44 out-of-care are men, 20 are African American, 18 are heterosexual, and 15 are MSM. Two of the women have been pregnant since finding out their HIV status but none report having seen an OB/GYN during their pregnancy.
- More than one third (34%) of the out-of-care have lived in the Las Vegas area for more than ten years. Six PLWH/A have moved to the Las Vegas areas within the last two years which may explain their lack of continuity of care.
- Thirty-two percent of the out-of-care have less than a high school education. The majority of the out-of-care (60%) are single, divorced or separated. Nine of the out-of-care live with a partner/spouse who is also HIV positive.
- Over one third of the out-of-care are employed either part or full-time, yet more than 78% report an annual income of less than \$17,000, which is higher than the general population of PLWH/A.

**Table 7-2 Out-of-care: Demographic Profile**

N	Out-of-care		PLWH/A
	N=44	%	
<b>GENDER</b>			
Female	13	29.5%	17.3%
Male	31	70.5%	82.7%
<b>RACE/ETHNICITY</b>			
African American/Black	20	45.5%	23.8%
Caucasian/White	16	36.4%	59.7%
Latino	6	13.6%	14.0%
Other/mixed	2	4.6%	2.5%
<b>MODE</b>			
MSM	15	34.1%	52.6%
MSM/IDU	5	11.4%	7.4%
IDU	5	11.4%	13.8%
Hetero	18	40.9%	10.5%
Other/Not Spec	1	2.3%	15.7%

Demographically, compared to the general population of PLWH/A:

- Heterosexuals are much more likely to be out-of-care.
- While the majority of out-of-care are men, they are more likely to be women than those in-care.
- African Americans are disproportionately represented in the out-of-care.



## Stage of Infection

As expected, fewer of those out-of-care have been told their infection has progressed to AIDS. In the survey of PLWH/A 49% have been told they have progressed to AIDS, while 32% - (N=14) of the out-of-care report having been told that their HIV had progressed to AIDS.

The majority (68%) of the out-of-care have known their HIV status for less than three years and 63% report currently being asymptomatic. Compared to the overall sample of PLWH/A (where 27% have known they were positive for less than three years and 48% report being asymptomatic), out-of-care are more likely to be newly infected and more likely to report being asymptomatic.

**Table 7-3 Length of HIV Infection**

	N=	Percent
Less than 1 year	3	6.8%
1 year	4	9.1%
2 years	11	25.0%
3 years	12	27.3%
4 years	4	9.1%
5 years	10	22.7%

The majority of the out-of-care are unaware of their CD4 count. However, among those reporting their lowest t-cell count, almost half (45%) report cell counts below 200. Out-of-care PLWH/A are even less likely to be aware of their highest viral load than their CD4 count.

Those out-of-care are more likely than all PLWH/A to say that their physical and emotional health is good. Half of the out-of-care feel that their physical and emotional health is good or excellent and over 40% believe their health is currently better than when they were first diagnosed.

## Medication Adherence

The criteria for out-of-care was a period of being out of care for more than year in the past five years. Most (N=23) of the PLWH/A with a history of being out-of-care have gone back to see a doctor, but most said they have had to get sicker or find stable housing before seeking care.

Currently, forty-four percent of the out-of-care report taking medicines for their HIV infection. Out of the 19 who are currently taking medications, only two report adhering to the scheduled prescribed by the doctor. Two report suspending the medication all together and five report weekly interruptions.

Table 7-4 shows the top five reasons that the out-of-care report for not taking their medications as prescribed. The top reasons are the same as for all PLWH/A as shown later in the section on Adherence, page 9-1. Those out-of-care are more likely to say that they forgot to take them.



**Table 7-4 Top Reasons for Skipping Medications**

Top Reasons	N=	Percent
Forgot	13	68.4%
Difficult schedule	5	26.3%
Side effects	4	21.1%
Ran out	4	21.1%
Just did not want to take them	4	21.1%

Co-Morbidities

Two of the out-of-care report having active tuberculosis and an additional five have had a positive skin test for tuberculosis but never developed active tuberculosis. Four have had hepatitis C, four have had genital warts, and three report yeast infections. There is also one reported case of hepatitis A or B, herpes, gonorrhea, herpes, and chlamydia.

As shown in Table 7-5, the majority of the out-of-care have a history of alcohol and marijuana use. Also, more than one quarter of the out-of-care has used crack/cocaine and or crystal meth. Ten report a history of injection drug use. The drug use is slightly less than in the general populations of PLWH/A.

Currently, seven and six out-of-care PLWH/A report using alcohol and marijuana, respectively, at least once a week. Three use crack on a weekly basis.

**Table 7-5 Substance Use**

Substance	N=	Percent
Alcohol	37	84.1%
Marijuana or hash	26	59.1%
Crack / cocaine	17	38.6%
Crystal meth or met amphetamines	12	27.3%
Poppers	8	18.2%
Heroin	6	13.6%
Ecstasy	5	11.4%
Pills not prescribed by doctor	5	11.4%
Speedball	3	6.8%

Housing:

Those out-of-care are much more likely than all PLWH/A to have unstable housing and be recently released. While the majority (55%) of the out-of-care participants live in their own spaces, over two-third of all PLWH/A live in their own spaces. Over the past two years, three lived in half way houses, four in a treatment facility, and ten have been homeless with one currently being homeless. Thirteen (30%) have been in jail during the past 2 years. Five of the out-of-care are currently living in jail or a correctional facility.



Six PLWH/A reported a need for housing referrals and assistance finding housing over the past year. Five received the service and one reported not being eligible for the service as a barrier.

Twelve of the out-of-care needed rental assistance and nine received assistance. The amount of time required to get an appointment or be seen by someone plus not being eligible were identified as barriers to obtaining this type of assistance.

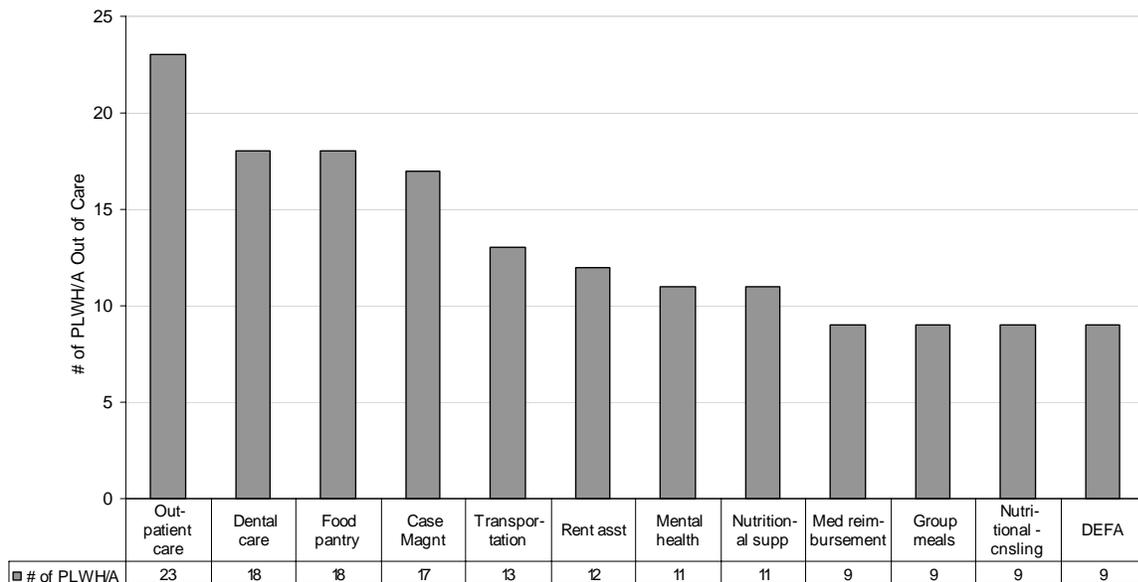
Need for Care:

Twenty-one out of 44 out-of-care PLWH/A say they have needed care and did not receive it – slightly more than all PLWH/A. The most common places where the out-of-care have been received care is the UMC Wellness Center or a community clinic (N=19), at a private doctor’s office (N=17), and in a hospital (N=17), indicating that more out-of-care go to a doctors office than all PLWH/A.

Top Service Need

Figure 7-1 shows the top service needs for the out-of-care who completed the NA survey. Consistent with the general PLWH/A population, the out-of-care report outpatient medical care, dental care, food pantry, and case management as their top needs. The other needs are also similar to those reported by all PLWH/A. The single exception is that several of those out-of-care said they needed group meals.

**Figure 7-1 Top Service Needs for Out-of-care**





## Main Reasons for Not Obtaining Care

Using a five point scale where “1” indicates not a reason for not seeking care and a “5” represent a main reason, participants were asked to rate 25 items in terms of the level of importance they represented for them not seeking care. Table 7-6 shows the top five reasons along with the average score indicating how important a reason each of the items represented for them. For 11 out of the 27 participants report not being able to afford to pay to see a doctor as a main reason for not seeking care, and a much higher percentage of those out-of-care, twenty-three (52%), reported having no form of medical insurance. While not the main reason, four additional participants reported that this was a very important or somewhat important reason for them not seeking care. On average, participants felt that affordability was a somewhat to very important reason for not seeking care.

Other reasons included good physical health, embarrassment about infection, trust in doctors, and unstable housing.

**Table 7-6 Reasons for Not Seeking Care**

<b>REASON</b>	<b>Average Score 5=main reason 1=not a reason</b>
I can't afford to pay to see a doctor	3.2
I feel fine and don't need to have medical care	2.9
I am embarrassed about my HIV infection	2.5
I don't trust the doctors	2.1
I need housing before I feel I can go for medical services.	2.0



## **Out-of-care – Qualitative Comments**

In addition to the quantitative data collection efforts, focus groups were connected among various populations with history of being out-of-care. The following comments from focus group discussions further highlight the barriers and concerns raised by PLWH/A who have had inconsistent care.

### Affordability and Inadequate Insurance

*An Anglo male said, “I’ve been in Las Vegas now for 3 years. Here I was not getting medical care or medications for a year because I couldn’t afford it. I just started taking medications in the last two months. I moved here from Florida. I found out I was HIV and AIDS at the same time when I was in Florida about 4 1/2 years ago. I was really, really sick. They gave me about a month back then, and I couldn’t get assistance. They wouldn’t give me assistance, because they told me I made too much money even though I couldn’t work, couldn’t walk, couldn’t breath. They said, “You will pay for it or you will just go.” They actually threw me out of the hospital and put me out in the streets. Now I have social security, so it comes with Medicare, but it doesn’t cover prescriptions, so now they still tell me I have to pay \$5,000 a month to get my medication, and I have to come up with that on my own. I currently have to work. I take off a month or two at a time, get far behind and then go back to work and almost kill myself to work for the next two or three months to catch myself up to get my medication, because I can’t get medication if I don’t.”*

*An African American MSM explained why he is at times delayed in getting medical care. He said, “You have to go through social services in order to get medical assistance if you don’t have insurance. Until you are with a job for six months or you have so many shifts with the union, you don’t have insurance unless you are paying for it out of pocket. Most times if you have a job of that capacity you can’t afford private insurance, so you go to Social Services. As soon as you get on an assignment they take you off. Then if the assignment doesn’t work you are waiting another two weeks to get back on. But within that transition period of being off and on you may get sick. You may need to see the doctor for whatever reason and you can’t because they take you off the assistance. In other words, they won’t even let you have an appointment even if you say, ‘I want to pay out of pocket.’ I told them I thought I had an ulcer and they said, ‘Before we can make an appointment you have to go to Social Services. They have to go through your financial, this, that and the other, and, then that we will know how much to charge you.’ There is so much red tape keeping the medical insurance from those that are not symptomatic or living with AIDS that it becomes unbearable and you don’t want to go. You try to do these things by yourself. I was working on a different assignment with the union and most of the times when you are working on a temporary assignment with the union it’s just that, temporary. They don’t seem to understand that this is not permanent yet. You keep taking me on and off of going to see the doctor, which scares me by not being on medication. What if this is it? What if it’s time for me, you know? I get scared, because they are lacking in helping me when I need it.”*

An Anglo male also had to interrupt his care because of lack of insurance but that was only one of the reasons for suspending care. He described his situation, “I’ve been in Vegas for six years,



*and I've been positive since 1993. The reason why I didn't see a doctor for a year was because I didn't have insurance through my work. But also because I didn't want to take medications. I went back to him because I was having stomach problems. For four or five years my t-cells were high and my viral load was undetectable, so when I went to the doctor my viral load had gone up to like 450,000. I was taking 22 pills a day. It was hideous. They would tear your stomach apart. I don't care who you are. You could give those pills to a horse and it could tear their stomach apart. So he lowered one of them and he gave me a resistance test. Now I'm only taking 16 a day. When I went to go get this insurance from [the medical ASO] I guess it's the Ryan White insurance or something. They told me, 'If you had COBRA we could have taken it over.' I said, 'I had no idea.' I didn't know. I just wasn't going to the doctor, so by then it was too late."*

### State of Mind

*An IDU female said, "I had no symptoms at the time of my diagnosis in 1985 and being the dope fiends that we were at that time, we just decided to ignore it and deny it all. For 11 long years I lived in denial. I wouldn't tell my family. I was afraid to tell them because of rejection. During those 11 years I was hospitalized twice. The first time it was with pneumonia. I came back kicking. I didn't find out any status of my T-cell count or what have you, because I didn't have any interest in that, because I was still the dope fiend that I was at that time. That was in 1989. In 1995 I had kidney failure and was on dialysis. My kidneys came back. Now I've been living a life of being clean and sober going on six years now. I knew I was positive, but I didn't know anything about PCP at that time anyway. I got my paperwork so I could prove my disability. My pneumonia wasn't associated with my virus. My kidney failure was associated with me just tearing my body down with heroine and cocaine. It wasn't HIV related. So therefore, I have had no symptoms related to the virus. In 1997 when I started taking my medication they weren't doing viral loads, so I don't know what it was at that time. But since I started taking my medication and they started counting the viral loads I've been undetectable. I'm undetectable today and my T-cell count today is 1,289. From day one and until this day I have had no problems with my medication."*

The absence of symptoms can further lead individuals to feel they are not affected by the virus. For instance a heterosexual female said, *"I found out I was HIV positive when I was pregnant with my daughter back in 1996. She is four now and she has been negative and I'm in perfect shape. I don't see a doctor. I stopped medication 2 years ago on my own. I don't drink, don't smoke. I feel pretty good about myself. I'm in perfect health. I was on AZT medication before my daughter. She was fine and I was fine. They put me on more medication after I had her. I felt nauseous all of the time. I have never had symptoms."*

The lack of symptoms and fear lead PLWH/A to avoid seeking care. An Anglo heterosexual female described her experience. *"I'm 35, and I've lived in Vegas for about six years, and I've been HIV positive since March of '99. It's been over a year, but I finally just went back to the doctor, but I'm not on any medication. I was healthy like normal even though I carried the virus, but now I guess my t-cells or something had gone down a little bit. The reason I went back was because I started having my different sicknesses like my throat and stuff, and I started getting*



*worried. I didn't go to the doctor out of fear of trying to avoid thinking about it, because the person that gave it to me, he's really sick. He takes a lot of medicine and he has gotten real skinny and he coughs. Out of fear I guess I've just avoided it. Then I started realizing how important it is to keep checking on it and making sure, because he has had it for like 10 years or something and he just started getting the medicine."*

Also an Anglo male was more concerned about losing his job than the effects of the virus. He said, *"I got a job down in Parker, Arizona, and I had to go down there. I had been living in Reno at the time, and when I went down to Parker there was no health counseling or any of that situation set up down there. Also I was afraid to go there because of my job. I was afraid I might lose my job if they found out I was going there, so I just quit taking the pills, and I was fine anyway. It didn't seem to affect me. Then when the job ran out I came back to Reno and there was no work for union guys, so I had to live on the street for about 4 months, which was might rough."*



## 8. OUTCOMES

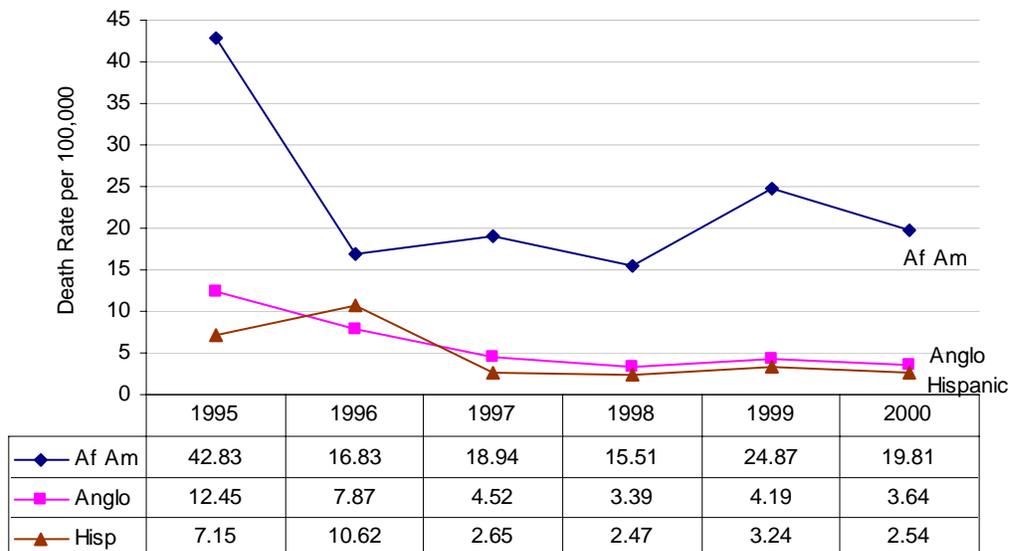
Fewer people dying of AIDS and improved quality of life for those living with HIV and AIDS are two outcomes measured in this needs assessment.

### Mortality

Figure 8-1 indicates that death rates have declined among all ethnic groups, with the sharpest decline among African Americans. Latinos, taking an upward turn in 1996, dropped below the Anglo death rate in 1997 and since that year have remained the lowest among the ethnic groups. In 2000, Latinos have the lowest death rate, followed by Anglos and African Americans.<sup>4</sup> Since the precipitous decline noted from 1995 to 1996, the death rates among Anglos and Latinos have leveled off with both communities displaying similar patterns.

Notably, the death rate among African Americans also dropped dramatically from 43 deaths per 100,000 in 1995 to 17 deaths per 100,000 in 1996. However, since 1996 the downward trend in death rate among African Americans has been inconsistent. In fact, the 2000 death rate represents an overall increase since 1996 and, as shown in Figure 8-1, the death rate remains substantially higher among the African American population and continues to be between five to six times the rate of Anglos and Latinos, respectively.

**Figure 8-1 HIV/AIDS Deaths by Ethnicity per 100,000 of Nevada Population**



<sup>4</sup> Latino deaths may be undercounted because of a substantial migrant population that returns home when fatally ill and the number who die who have undetected HIV and AIDS.



Overall, the death rates suggest that the care system is effectively reaching PLWH/A once they are in the system, but that the system continues to reach African Americans at a latter stage of infection. The recent uneven fatality rate among African Americans may be the result of reporting lags or it may reflect the success of outreach in bringing more persons into the care system – albeit at a later stage of infection. It may also represent continued uneven care for the African American community where there is more limited access to medical services and there is considerably less compliance to medical regimens. As discussed in the previous sections, African Americans are disproportionately represented among women and heterosexuals, and they are less likely to be insured and receive medical benefits.

The leveling of the death rate among Anglo and Latinos suggest that the impact of medication has reached a plateau. Significant side effect and fatal infections continue to manifest themselves among PLWA, and adherence is far from complete.

### **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 one of its major objectives.

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 8-2 and Figure 8-3 report the current and perceived change in physical health and emotional health. It is divided by PLWH who are asymptomatic and symptomatic and those who report being diagnosed with AIDS. Of those living with AIDS, three quarters (75%) said they were symptomatic, and 25% said they were asymptomatic.

As expected, the PLWH with no symptoms have an average rating of good physical health, and say that their physical health is a little better now as compared to when they first sought treatment. PLWH who are symptomatic report that their health is fair, but also say that their health is a little better now compared to when they first sought treatment.

Asymptomatic PLWA report that their health is even better than that reported by PLWH, and they report the greatest improvement in health compared to those at other stages of infection since they started treatment. Not surprising, symptomatic PLWA report the worse current physical health – but still say it is fair. They say that their physical health is also a little better now than it was when they started treatment.



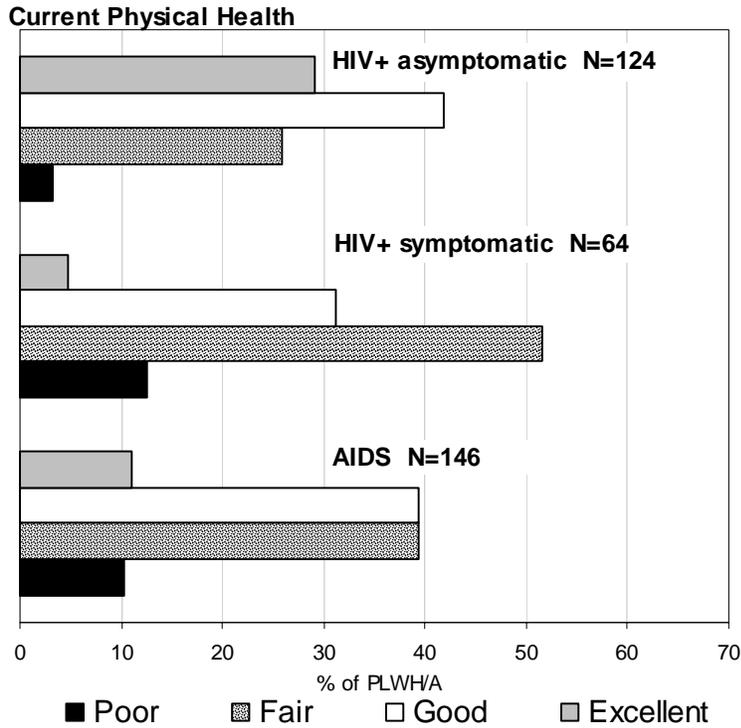
Women of child bearing years (WCB), heterosexuals, and African Americans report the best physical health whereas MSM and the rural report the worst current health.

The emotional health of asymptomatic PLWH is a little worse than their physical health, but it has also improved a little. PLWH who are symptomatic report the worst emotional health of those in any stage of infection, but they say that their emotional health has gotten better since they started treatment.

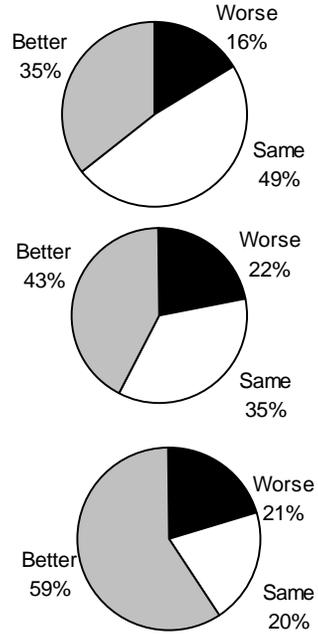
IDUs and PLWH/A with a history of mental illness report the greatest improvement in their emotional health, while Anglos, rural and those PLWH/A who have been admitted to a clinic or have received medications for mental illness report the poorest improvement in emotional health.



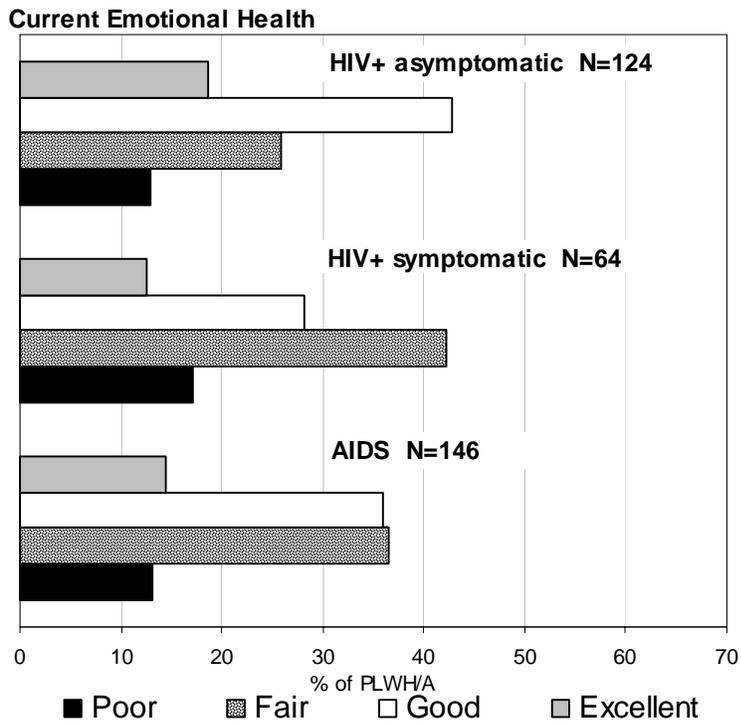
**Figure 8-2 Quality of Life – Physical Health**



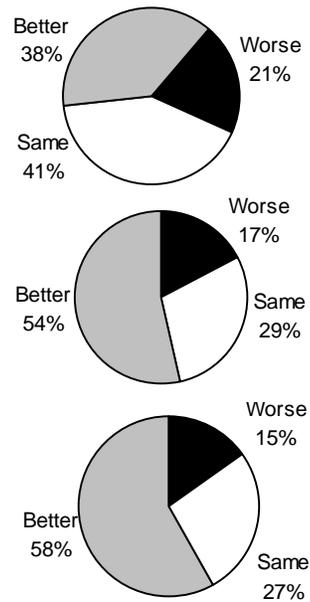
**Change in Physical Health**



**Figure 8-3 Quality of Life – Emotional Health**



**Change in Emotional Health**





## 9. MEDICATION AND ADHERENCE

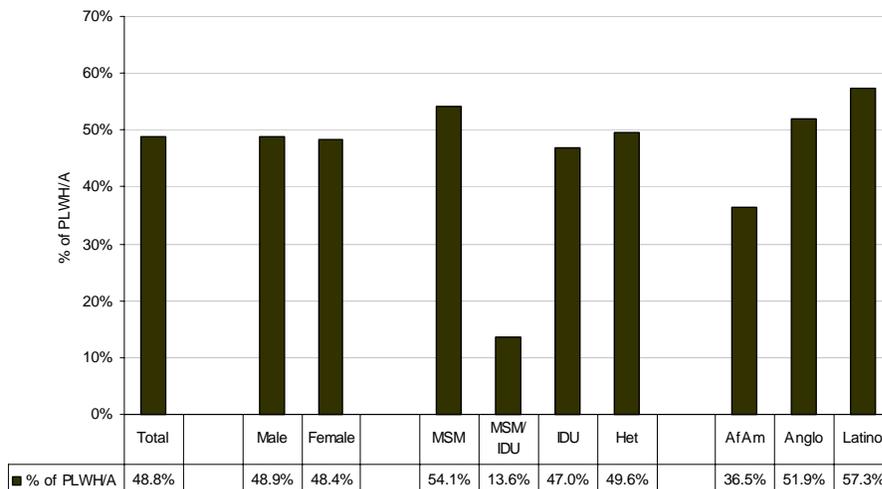
### Medication and Adherence

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. Continued and improved health status outcomes will depend, in part, on the availability, access, and adherence to properly prescribed medical regimens.

- Over 70% of PLWH/A are currently taking medicines to treat their HIV infection, and 88% of those are currently taking a drug cocktail. MSM/IDU, substance users, those with a history of a mental illness, and PLWA are most likely to be taking medication. Youth and asymptomatic HIV are least likely to have taken medication.
- While nearly half of PLWH/A report never skipping their medications, six percent have stopped taking the medicines. Notably, symptomatic PLWH/A are more likely to stop taking their medication than asymptomatic PLWH/A. The symptoms themselves may be a trigger for discontinuing the use of the medication. Also, 12% of Latinos and 15% of the undocumented have stopped taking their medications, and that may be connected to a language barrier regarding medical case management and the ability of providers to communicate symptoms and side effects. MSM of color (13%) and substance users (12%) also have higher rates of stopping their medications.

Figure 9-1 shows that there is little gender difference in regard to adhering to the medication regimen. However, IDU and particularly MSM/IDU have a difficult time taking their medications as prescribed. Also, African Americans are more likely to skip medications than Anglos or Latinos.

**Figure 9-1 Never Skipped Medication**





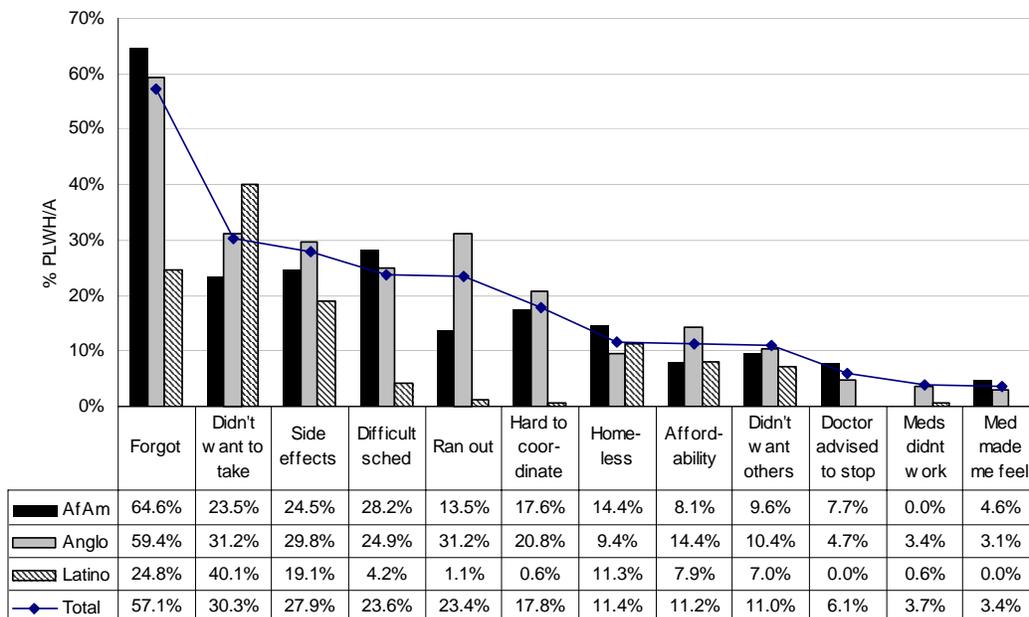
- Of the 51% of the PLWH/A who have skipped their doses, six percent had their doctors recommended stopping their regimen. Twenty percent of the females reported this reason for stopping their regimen

Figure 9-2 indicates that the top reasons for discontinuing medications for all PLWH/A were:

- Forgetting to take them (57%), is typically the major reason for skipping medication doses across the populations, with women, MSM/IDU and the PLWH/A with history of mental illness being the most likely to forget. MSM (48%) and Latinos (25%) are least likely to forget.
- Thirty percent (30%) of the PLWH/A reported they have skipped doses because they just did not want to take them. With numerous pills prescribed on a daily basis, PLWH/A report getting tired of taking the pills and also regret the constant reminder of having HIV/AIDS. Youth (50%) and Latinos (40%) name not wanting to take them as their main reason for skipping their medication doses. Asymptomatic PLWA, WCB, and heterosexuals (about 18% each) were least likely to report this reason.
- Side effects associated with the use of medications (28%) were most notable among rural, female, and heterosexual PLWH/A.
- The difficulty of the schedule and requirements (24%) and running out of meds (23%).

While relatively few PLWH/A mentioned not wanting others to see the medications (11%), Youth (50%) and MSM of color (20%) were much more likely to give this reason than other populations. Anglo PLWH/A were more likely to say that running out of medications was an issue for them (32%) compared to PLWH/A of other ethnicities.

**Figure 9-2 Reasons for Stopping Medications by Ethnicity**





## Medication and Adherence – Qualitative Comments

The focus group comments add depth to the quantitative findings.

Almost half of the PLWH/A report never deviating from their medication regimen. Many PLWH/A feel that medicines have not only extended their lives but have also improved the quality of their lives. They have established a strategy that allows them to negotiate the use of medicines with their doctors and adhere to their medicines. For example a heterosexual female said, *“I was diagnosed with the virus in 1985. I do take the cocktail. I’ve been on them a while, and now I’m undetectable and I’m happy as a little lark, going on every day, taking the medicine. Thank God for another day. I’ve only been hospitalized once, and that was when I was diagnosed. Other than that I’m fine. The medicine doesn’t make me sick. I can go and do a blood draw and my doctor will say my viral loads are high. I’ll say, ‘But doctor, I get so nauseated with it.’ He’ll say, ‘I tell you what. We are going to switch the medicine.’ He will switch it until it’s something your body agrees with. My body agrees with it. Sometimes I have difficulty eating with an appetite, but that’s about all. That’s about 15 years, so that’s not bad. So I am living with it. You can live with the virus and you can live healthy and you can live a successful life, but you have to take care of yourself.”*

Another heterosexual female also spoke of the importance of having support in taking the medications. She said, *“Get the help that you need whether it’s physical or emotional and take the medication, because it does help. A lot of people might not think so, but my counts were down so low when I started taking that medicine, and I’ve only been taking the medicine 3 years and it’s undetectable. So it is important to get the medicine that works for you and you can’t do that just with one doctor’s visit or taking the medicine one time. You’ve got to go for yourself and see what works for you.”*

Nonetheless, many PLWH/A face the challenge of being on a complex medication regimens and not all are able to adhere to the medication regimen.

### Forgot to take the medication

An Anglo MSM spoke about his multiple reasons for not taking the medications as follows, *“I don’t know if it’s a side effect but I feel that my memory is being really affected. I have problems getting up in the morning. I’ll take my insulin and take some [HIV/AIDS] pills and a couple of hours later I’ll forget if I’ve even taken them and sometimes I have. I don’t know if that’s a side effect or what. I’ve been taking medication for 30 something years anyway and I’m already tired of it. It’s just a few more pills to pop or another shot to take.”*

### Just did not want to take them

For a heterosexual female who has witnessed the effects of the medications on others, there is no motivation to take the medications. She says, *“They’ve asked me to take medication and I’ve denied them. I have never taken medication. I am going to do alternative treatment. I saw medication kill my fiancé, so I’m not taking medication. It was more of a cocktail. It turned his bones to mush. He had hypocalcaemia. His bones were turned to mush. This time last year he said, ‘I’m going to go to the doctor. My back hurts.’ He was in the hospital for two weeks. He*



*died three weeks later. My doctor is talking to me about it and he knows how I feel about it. My mother sells vitamins and she is very well stocked on them.”*

### Side effects

Several PLWH/A experience side effects associated to their HIV medications. An African American female described her experience, *“As soon as I found out I was infected they put me on something that broke me out real bad in a rash, hives and everything. They switched and put me on something else. It made me cramp up real bad. My insides were cramping to the point where I was paralyzed. They put me in the hospital for two days. It just paralyzed me. They put me on the third one and it made my lips swell; they popped out huge and they were red and bloody. I had a reaction to four different medications. My T-cells were up at 1659. They dropped down to 11 after I had started taking it. Then the second medication they put me on dropped down to 8. The third medication I dropped down to 500 something. They said they were going to wait. They put a gap in there. I went back up to about 800 and then they gave me that fourth medication and dropped me back down to 500 and something. So ever since then I have not been on anything. That was in my first year.”*

Another African American IDU female also shared her hesitation to take medications because of the fear of side effects, She said, *“Sometimes I feel the doctors are not really aware of our condition as they should be. They are not taking the time to get to know me. There is no physical examination on a yearly basis. They just check basic stats and go by what we tell them. They should be more precise and knowledgeable about the medications they give people. I'm very afraid of the side effects. That's why I haven't taken them yet.”*

Side effects also led a 55-year old Anglo MSM to discontinue the use of his medications. In his words, *“I stopped medications the last 2 1/2 months and people thought I would be a little nuts in doing this, but I felt I would feel a lot better. I had a lot of side effects from medication. My doctor told me not to do it. I decided I'm going to do it anyway, because he was going to put me on some stronger medication than I already was on and I know how hard I had to adapt to that medication to begin with. I had that choice and I'm going to acknowledge that choice and I'm not going to use [the medications]. This is what I felt was right for me. Probably what I have more than anything else is the fear they put in you that you are going to die, but now I know better. I know I'm not going tomorrow. It may take me another 10 to 20 years.”*

### Difficult schedule

Managing numerous medications on a fixed schedule is difficult for many PLWH/A. An Anglo MSM said, *“I couldn't take them at two specific times during the day, because I have 6 medications. Two I have to take in the morning, one on a full stomach, one on an empty stomach and then one more at noon, the other three at night, one before I eat, one after I eat, one while I'm eating. I don't know which pills are which. My doctor can't explain it to me. I just want one pill for the morning, one pill at night. Put it in a big old capsule. I tried it for like two weeks and I just can't take it. I can't do it. I kept getting scattered brain and I would forget which pill was for what and what time of day and how many of them, so I said no.”*



## **10. SERVICES**

This section provides an overview of which services PLWH/A perceived they needed, and the following chapter discusses overall barriers. Section 12 further compared need with utilization for each service, and shows service specific barriers reported by PLWH/A.

### **Services Ranked**

For 2001 the Council ranked 27 services and funded 20. For 2002, the Council broke out nutritional services, housing related services, and adherence compliance into their own services, and ranked 31 service categories, funding 21. The ranking and percentage awards are shown in Table 10-1. The list in Table 10-1 is in order of the FY 2002 priorities.

### **Ranked Needs**

A list of 29 services offered in the Las Vegas EMA continuum of care (COC) was listed in the consumer survey (see question 43, Attachment 2). PLWH/A were asked to report if they needed the service in the last year. Figure 10-1 shows the top ten needs while Figure 10-2 shows the next set of needs.

The services in the top ten are a combination of health care and basic needs. As shown in Figure 10-1, 95% of the sample expressed a continued need for primary medical care. This makes it the most important service offered through the continuum of care (COC). After that, close to three-quarters (72%) said that food pantry services were second in their need, and dental care was third with 66%. Case management was fourth most needed service (63%), followed by mortgage or rental assistance (54%) of the PLWH/A. Transportation was the sixth greatest need at 53%.

The next set of needs relate to an awareness by PLWH/A of the role of nutrition. Fifty percent (50%) expressed a need for nutritional supplements, and 41% expressed a need for nutritional counseling. The ninth ranked need is mental health with 41% expressing a need. Tenth is the need for DEFA (33%).

The Council's 2002 priority and PLWH/A ranking of top needs are similar. The largest difference in rankings is medication reimbursement, with the Council ranking it 4<sup>th</sup> and PLWH/A ranking it 14<sup>th</sup>. Other differences in ranking were for food and dental care. PLWH/A ranked food pantry second, while the Council ranked it 6<sup>th</sup>, and PLWH/A ranked dental 3<sup>rd</sup> and the Council ranked it 7<sup>th</sup>.



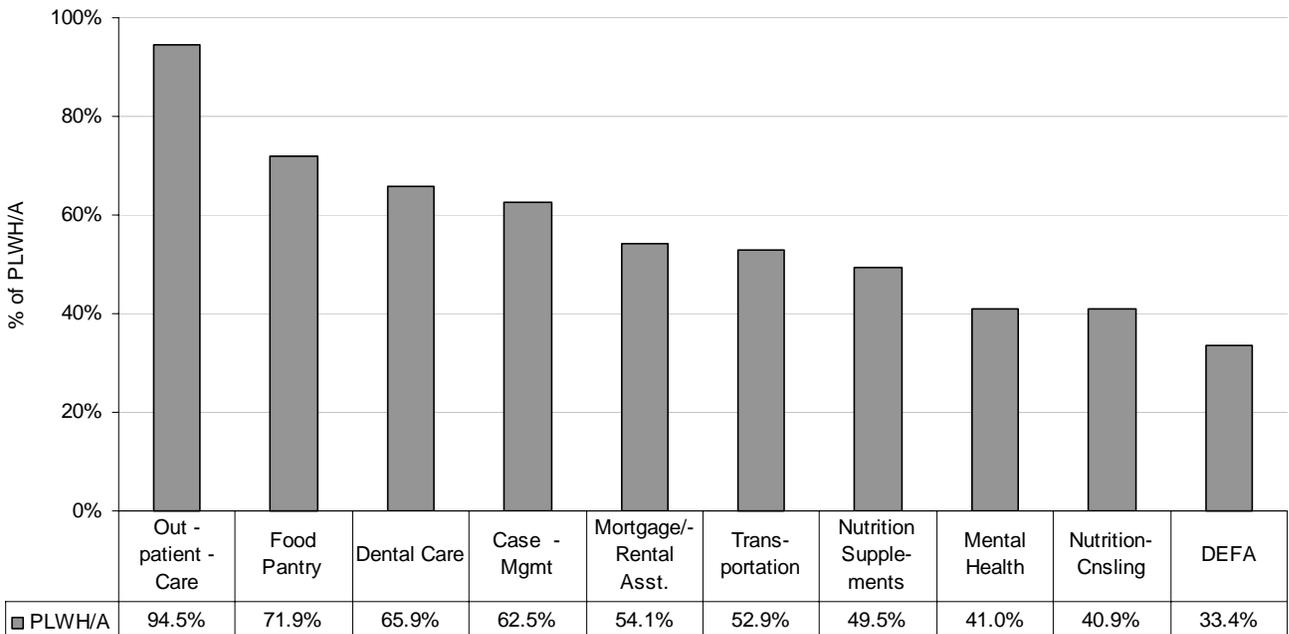
**Table 10-1 Summary of Priority Services to be Funded in FY 2001**

2001	2002	Priority / Sub-priority Service or Community	% FY 2001 Award	% FY 2002 Award
<b>2</b>	<b>1</b>	<b>Primary medical care</b>	<b>17.8</b>	<b>13.6</b>
2.1	1.1	Primary Medical Care	14.8	
<b>1</b>	<b>2</b>	<b>Case management</b>	<b>19.0</b>	<b>14.8</b>
1.1	2.1	Case Management – Clark and Nye Counties	17.3	13.4
1.2	2.2	Case Management – Mohave County	1.7	1.4
<b>4</b>	<b>3</b>	<b>Housing Assistance</b>	<b>9.3</b>	<b>4.3</b>
4.1	3.1	Housing Assistance – Short term	5.8	4.4
<b>3</b>	<b>4</b>	<b>Medication Reimbursement</b>	<b>1.3</b>	<b>1.3</b>
3.1	4.1	Medication Reimbursement – non-ADAP Drugs, Mohave Co.	1.3	1.4
4.2	<b>5</b>	<b>Housing Related Services</b>	<b>3.5</b>	<b>2.7</b>
<b>6</b>	<b>6</b>	<b>Food services</b>	<b>4.7</b>	<b>4.5</b>
6.1	6.1	Food – Meals	3.4	3.4
6.2	6.2	Food – Nutritional Supplements	1.3	1.1
<b>8</b>	<b>7</b>	<b>Dental Care</b>	<b>5.8</b>	<b>6.1</b>
<b>5</b>	<b>8</b>	<b>Transportation</b>	<b>7.8</b>	<b>8.1</b>
<b>7</b>	<b>9</b>	<b>Mental Health Treatment / Counseling</b>	<b>2.2</b>	<b>4.0</b>
<b>9</b>	<b>10</b>	<b>Substance Abuse Treatment Counseling</b>	<b>2.7</b>	<b>2.6</b>
6.3	<b>11</b>	<b>Nutritional Counseling</b>	<b>1.3</b>	<b>1.0</b>
<b>12</b>	<b>12</b>	<b>Health insurance Continuation</b>	<b>4.3</b>	<b>6.6</b>
12.1	12.1	Health Insurance Continuation – Clark and Nye Counties	4.0	
12.2	12.2	Health Insurance Continuation – Mohave Co.	0.3	
<b>10</b>	<b>13</b>	<b>Emergency Financial Assistance</b>	<b>1.6</b>	<b>1.3</b>
<b>15</b>	<b>14</b>	<b>Outreach</b>	<b>4.0</b>	<b>2.0</b>
15.1	14.1	Outreach and Case Finding	1.7	2.0
<b>14</b>	<b>15</b>	<b>Advocacy</b>	<b>0</b>	<b>1.0</b>
<b>11</b>	<b>16</b>	<b>Program Support</b>	<b>4.0</b>	<b>5.0</b>
<b>13</b>	<b>17</b>	<b>Child Care, Day Care, and Respite</b>	<b>1.2</b>	<b>0.0</b>
<b>17</b>	<b>18</b>	<b>Translation (CBC Initiative)</b>	<b>0.1</b>	<b>0.0</b>
<b>16</b>	<b>19</b>	<b>Counseling, Other</b>	<b>0.2</b>	<b>0.1</b>
2.3	<b>21</b>	<b>Primary Medical Care – Adherence Compliance</b>	<b>1.3</b>	
<b>19</b>	<b>22</b>	<b>Referral and Information</b>	<b>1.1</b>	<b>3.9</b>
	22.1	Referral and Information-CBC		25.5*
<b>18</b>	<b>23</b>	<b>Planning Council Support</b>	<b>5.0</b>	<b>5.0</b>
<b>20</b>	<b>24</b>	<b>Home Health Care</b>	<b>0.9</b>	<b>1.6</b>
<b>22</b>	<b>25</b>	<b>Hospice</b>	<b>0.0</b>	<b>0.0</b>
<b>21</b>	<b>26</b>	<b>Alternative (Complimentary) Therapy</b>	<b>0.3</b>	<b>0.0</b>
<b>23</b>	<b>27</b>	<b>Rehabilitation</b>	<b>0.0</b>	<b>0.0</b>
<b>25</b>	<b>28</b>	<b>Buddy and Companion</b>	<b>0.0</b>	<b>0.0</b>
<b>24</b>	<b>29</b>	<b>Permanency Planning</b>	<b>0.0</b>	<b>0.0</b>
<b>26</b>	<b>30</b>	<b>Adoption and Foster Care</b>	<b>0.0</b>	<b>0.0</b>
<b>27</b>	<b>31</b>	<b>Inpatient Care</b>	<b>0.0</b>	<b>0.0</b>
<b>28</b>	<b>20</b>	<b>Administration</b>	<b>5.0</b>	<b>5.2</b>
2.2		Primary Medical Care – Congressional Black Caucus Initiative	1.6	0.0
15.2		Outreach and Case Finding – CBC Initiative	2.3	74.5*
		CQM		5.0

\* Congressional Black Caucus funds.



**Figure 10-1 Top Ten Needs by PLWH/A**



The second set of most needed, ranging from between 30% and 10% of PLWH/A indicating, are shown in Figure 10-2. There is not a particular theme to the order of the services – some are medical and others wrap-around services. Drug reimbursement didn't make the top ten needs (26%) which may be based on very few PLWH/A ever having to be concerned about the full cost of medications. The Council give it a much higher priority (7<sup>th</sup>), and it is ranked 14<sup>th</sup> by PLWH/A. This supports the early discussion on medication reimbursement, page 6-4, where PLWH/A report relatively low use of drug reimbursement, indicating a lack of awareness of the role that is played by insurers or other organizations that provide medications.

The third set of need related to more specific personal needs including peer counseling, group meals, and client advocacy (at about 30% each). Housing related services is the fifteenth most needed service (23%) by PLWH/A although it is ranked 5<sup>th</sup> in priority by the Council. It is more likely to be needed by the homeless, recently released, and those in transitional housing.

Although complementary services are ranked relatively low by PLWH/A (16<sup>th</sup>) it is ranked near the bottom by the Council (26<sup>th</sup>). Health insurance continuation is needed by 17% of the PLWH/A which is less than the 28% who report being uninsured in the Las Vegas EMA.

PLWH/A agree with the Council on the low ranking of adherence assistance. The one cause of some attention, however, is the relatively low adherence reported and the leveling off of the death rates. The relationship between poor adherence and mortality has to be further studied.



**Figure 10-2 Second Tier of Needs by PLWH/A**

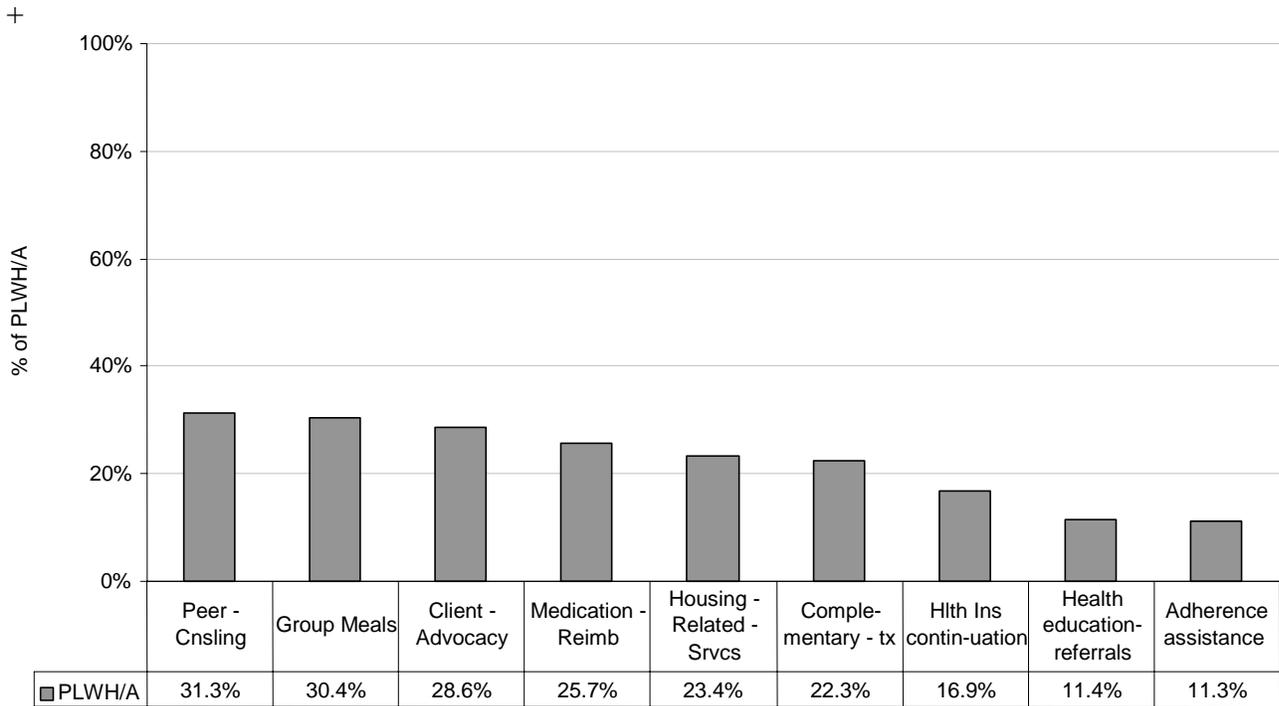


Table 10-2 lists the services needed by less than ten percent of the PLWH/A. The Council ranks both outpatient and residential substance abuse treatment higher than PLWH/A, but the rankings are consistent with the relatively low prevalence of injection drug use reported in the Co morbidity section, page 4-2.

**Table 10-2 Lower Ranked Needs**

Lower Ranked Needed Services	% PLWH/A
Employment Assistance	8.4%
Buddy/Companion	7.1%
Home health care	6.8%
Outpatient substance abuse treatment	5.7%
Home delivered meals	5.1%
Rehabilitation/physical/speech therapy	4.9%
Residential substance abuse treatment	3.8%
Hospice care	0.9%
Children day/respite care	0.8%
Adult day care	0.2%

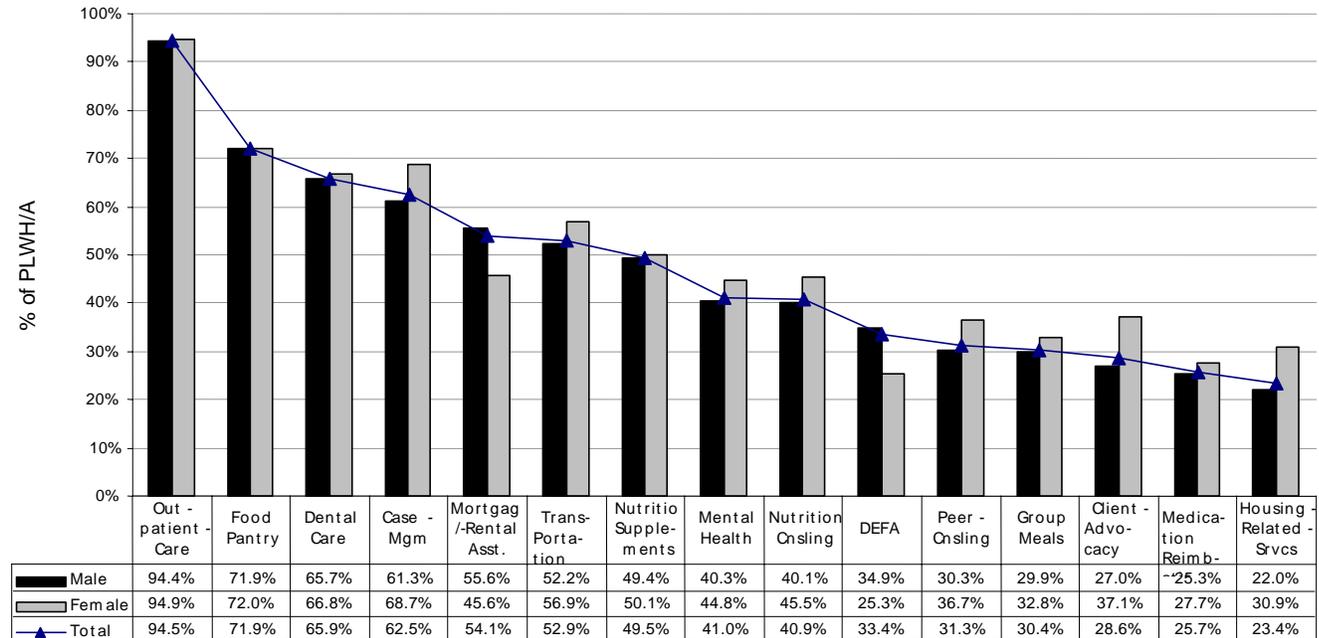


## Most Important Needs by Gender

Figure 10-3 shows the top fifteen needs by gender. The bar represents males and females and the line is the average ranking for all PLWH/A.

- Females and males report generally the same level of need. A larger percentage of females say they need case management, client advocacy, transportation, and nutritional and peer counseling. A greater proportion of males report a need for mortgage/rental assistance.
- For those services ranking lower than the top 15, men are more likely than women to say they need complementary care and buddy companion services. Women are more likely to say they need adherence assistance, residential drug treatment, and employment assistance.

**Figure 10-3 Top Ranked Needs by Gender**



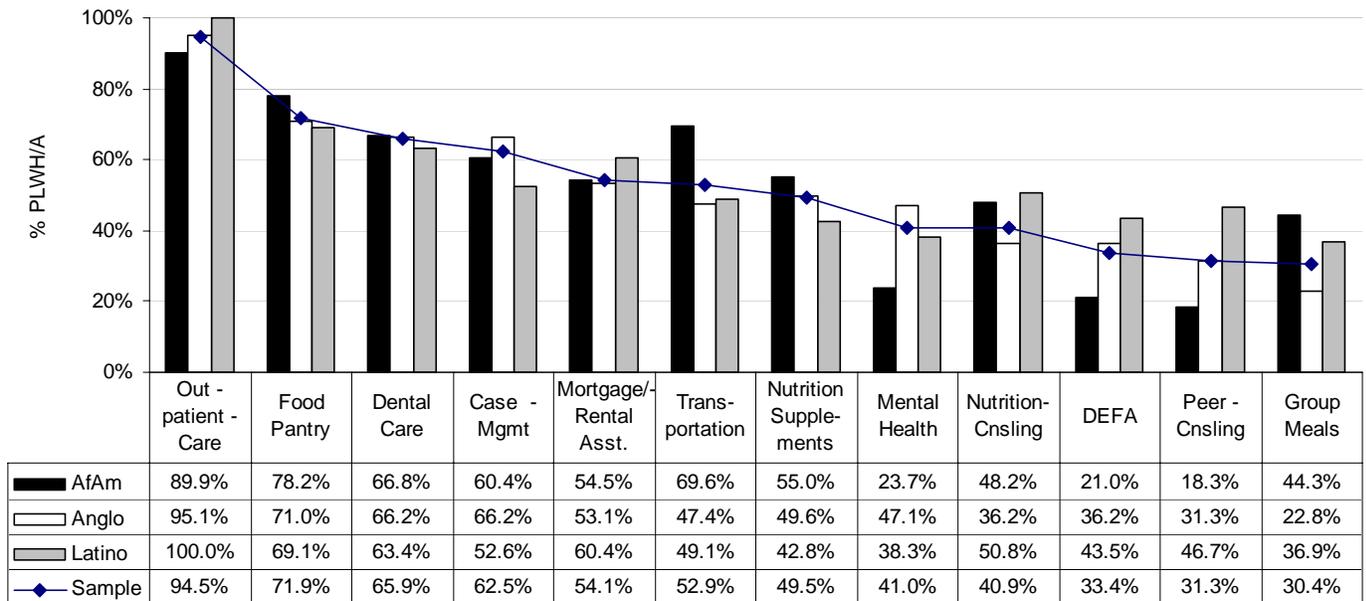


## Most Important Needs by Ethnicity

The rankings of top twelve services by race/ethnicity are shown in Figure 10-4. For the top four services, the three major racial/ethnic populations are similar.

- Far more African Americans (70%) report needing transportation. African Americans also report needing nutritional counseling, housing related services, group meals, and substance abuse services more than Anglos or Latinos.
- Latinos say that medical services are the most important and rank mortgage/rental assistance and nutritional counseling higher than either African Americans or Anglos.
- A larger percentage of Anglos say they need mental health, client advocacy, drug reimbursement, complementary care, adherence assistance, and insurance continuation services than Latinos or African Americans.

**Figure 10-4 Top Ranked Need by Ethnicity**



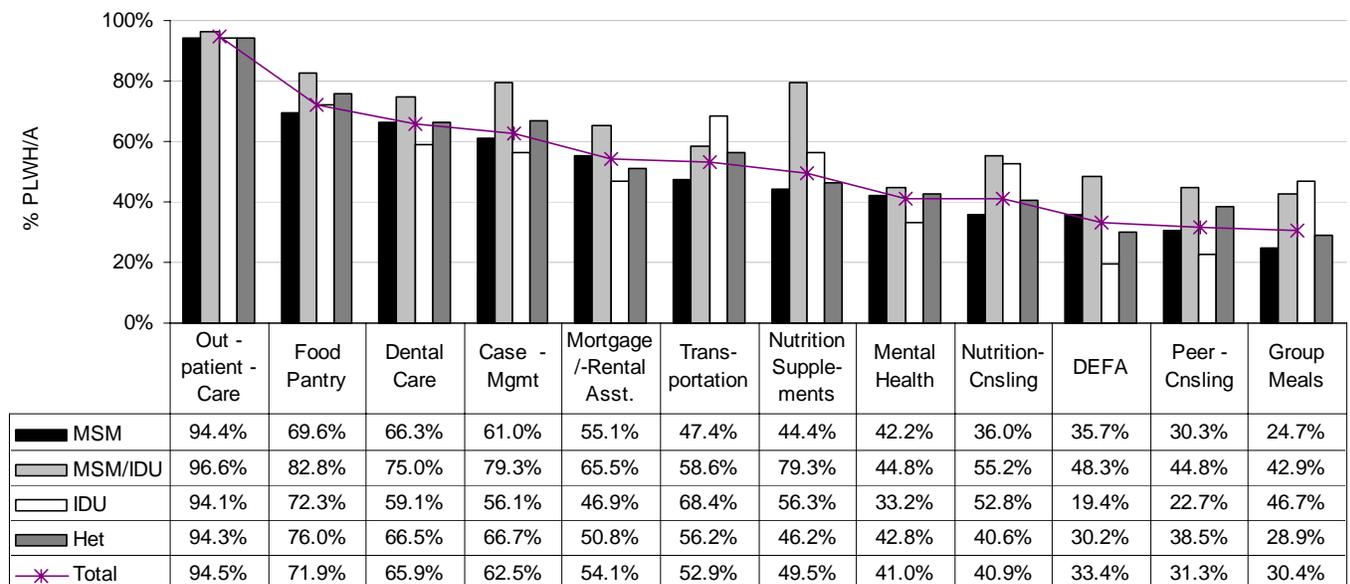


## Most Important Needs by Risk Group

When top needs are divided by risk group it indicates that:

- MSM/IDUs express more of a need for services. They are more likely than other risk groups to say that food pantry (83%), case management (79%), dental care (75%), and mortgage/rental assistance (66%) are among the most important services.
- IDUs expressed a higher need for transportation (68%), and like MSM/IDU have proportionately greater need for nutritional supplements (56%) and nutritional counseling (53%).
- Heterosexuals, reflecting their high percentage of women, are more likely than other risk groups to say that food pantry (76%) and case management (79%). They also say that vocational care is more important, and dental care less important than other risk groups.
- MSM express less need of services than other populations.

**Figure 10-5 Top Ranked Need by Risk Group**



## 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 the food pantry (80%), transportation (77%), case management (77%), and rental assistance (71%) of greater importance than the other populations.

## Most Important Needs by Geography

In-migrants have a larger need for case management (75%), mortgage/rental assistance (65%), and transportation (65%). Slightly more urban residents need the food pantry (74%) and dental



care (66%). Rural residents report needing nutritional supplements (56%), mental health services (44%) and client advocacy (42%).

### Most Important Need by Stage of Infection

There are different needs by stage of infection. Although PLWH/A at all stages of infection feel that outpatient care is the most important service and food is in the top three, HIV asymptomatic report needing them considerably less. Symptomatic PLWA report needing dental care more than those at earlier stages.

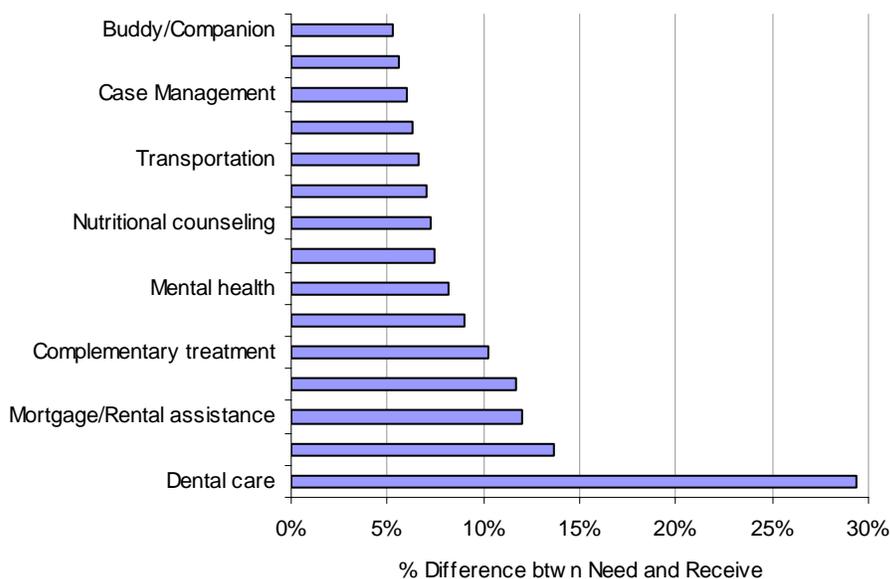
For most of the remaining top services, symptomatic PLWH and symptomatic PLWA have the greatest needs.

For DEFA, peer counseling and adherence, PLWA indicate a greater need than PLWH. Symptomatic PLWA are more likely to need adherence assistance, medication reimbursement, and food services than those at other stages of infection.

### **Service Gaps**

In addition to asking what services were needed in the past year, participants of the survey were asked whether they received them. One gap measure is the difference between those needing and those receiving a service. As shown in Figure 10-6, the largest perceived gaps are in dental care, direct emergency assistance, mortgage/rental assistance, client advocacy, complementary treatment, nutritional supplements, and mental health. Gaps by different risk groups, racial/ethnic populations, region, stage of infection, and special populations are shown in Section 12, Service and Barrier Template.

**Figure 10-6 Service Gaps**





## 11. 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, in the survey participants reported experiencing few barriers when accessing services. Nonetheless, the barriers noted highlight areas that need to be addressed in order to improve the access and quality of services provided. The focus group comments following the quantitative analysis, give more depth to the reasons PLWH/A say they have difficulty accessing services.

### Overall PLWH/A Score for Barriers

On the questionnaire, PLWH/A were presented with twenty-nine possible barriers to service and asked to rank the top five barriers they faced (see Barrier List at the end of the consumer survey, Attachment 2.) The twenty-nine barriers can be grouped into three general types of barriers:<sup>5</sup>

- Individual barriers. These refer to the individual's knowledge, physical and mental health and, while lack of treatment knowledge was the top barrier, as a category these were the most likely to be mentioned.
- 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, access to specialists, or lack of family-oriented services. After individual barriers, these were among the most frequently named barriers by PLWH/A.
- 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. These were less likely to be mentioned as barriers to accessing care.

### Categorizing Individual Barriers Reported by PLWH/A

Figure 11-1 groups each of the twenty-nine barriers into the more general categories of organizational, structural, or individual barriers. In total, both the focus group respondents and survey respondents rated eleven individual level barriers, nine organizational barriers, and nine structural barriers. They are shown in Figure 11-1.

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<sup>5</sup> 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 Pearson's correlation matrix was used as input. A varimax option was selected to better discriminate the factors.



**Figure 11-1 Types of Barriers**

<p><b>STRUCTURAL</b> <i>Rules and Regulations</i></p> <ol style="list-style-type: none"> <li>1. Lack of, or inadequate, insurance coverage.</li> <li>2. Can't afford the service.</li> <li>3. Waiting time for appointment or to see someone.</li> <li>4. Too much paperwork or red tape</li> <li>5. Ability to find my way through the system.</li> <li>6. Not eligible</li> </ol> <p><i>Access</i></p> <ol style="list-style-type: none"> <li>7. No specialist to provide the needed care</li> <li>8. No childcare.</li> <li>9. No transportation.</li> </ol> <p><b>ORGANIZATIONAL</b> <i>Provider Sensitivity</i></p> <ol style="list-style-type: none"> <li>10. Discrimination by providers or organizations</li> <li>11. Sensitivity of providers to issues and concerns.</li> <li>12. Providers not helpful.</li> <li>13. Fear of being reported to immigration or authorities.</li> <li>14. Fear of HIV/ AIDS status being found out by others – lack of confidentiality</li> <li>15. Provider makes consumer feel like a number.</li> </ol>	<p><b>ORGANIZATIONAL</b> <i>Provider Expertise</i></p> <ol style="list-style-type: none"> <li>16. Experience or expertise of providers</li> <li>17. Providers did not speak consumer's language</li> <li>18. Inadequate referrals</li> </ol> <p><b>INDIVIDUAL</b> <i>Knowledge</i></p> <ol style="list-style-type: none"> <li>19. Not knowing location of services.</li> <li>20. Not understanding instructions for obtaining service</li> <li>21. Medication adherence</li> <li>22. Not knowing who to ask for help.</li> <li>23. Not knowing that service or treatment was available</li> <li>24. Not knowing what medical services are needed</li> <li>25. Not knowing which organization to go to for service</li> <li>26. Ability to communicate or interact with provider.</li> </ol> <p><i>Well-Being</i></p> <ol style="list-style-type: none"> <li>27. State of mind or mental ability to deal with treatment.</li> <li>28. Not believe HIV/AIDS is a problem –denial</li> <li>29. Physical health</li> </ol>
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### Ranking of Specific Barriers

Attachment 8 shows the number of times each barrier was named by the total population, gender, risk group, ethnicity, regions, and special populations. It is summarized for all PLWH/A in Figure 11-4. Results for risk group, racial/ethnic, and special populations can be found in Attachment 8, but because of the small number of PLWH/A mentioning barrier results by be unreliable.

### How to Read the Barrier Attachment

Attachment 8 can be read down the column to determine the magnitude of the barrier for the total population and each subpopulation. They are ranked from the most frequently named barrier to the least named barrier for the general population. The rank orders tend to be similar, but not the same, for all subpopulations. For example, among women “not knowing who to ask for help” was the most frequently named barrier (N=14), while among men “not knowing that the service or treatment was available” was the most common barrier (N=69).

Barriers 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 “lack of insurance coverage,” HIV symptomatic individuals tend to see this as a barrier more often than most other groups.

The barrier attachment shows the absolute number of times a barrier was named. However, proportionately, some barriers impact a population more than another. For instance, 14 Latinos report providers not being helpful as their top barrier. This represents 27% of the Latino

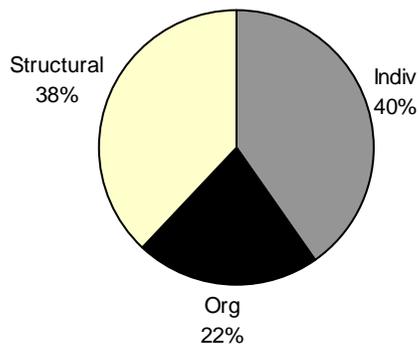


PLWH/A which compares to 13% among African Americans and 16% among Anglos who also feel providers have not been helpful. Due to the limited number of responses among some subpopulations, however, this type of analysis cannot be considered generalizable and instead should be used to explore potential differences among the various populations.

### Total Population Ranking of Barriers

Of the 334 participants of the consumer survey, 235 (70%) named 810 barriers to accessing care – or on average between 3 and 4 barriers each. As shown in Figure 11-1, of all the barriers mentioned, about 40% are individual and 38% are structural. There are fewer mentions of organizational barriers (22%).

**Figure 11-2 Types of Barriers**



The types of barriers differ by gender, race, risk group, and stage of infection. As shown in Figure 11-3:

- Except of MSM and MSM, individual barriers are mentioned the most. MSM and males mention structural barriers.
- Females are much more likely to mention individual barriers.
- IDUs and heterosexual are much more likely to mention individual barriers.
- Individual and structural barriers are equally likely to be mentioned by Anglos. Latinos are more likely to mention organizational barriers. African Americans are more likely to mention individual barriers.
- PLWH are more likely to mention individual barriers, while PLWA are more likely to mention organizational and structural barriers.



**Figure 11-3 Type of Barrier by Subpopulation**

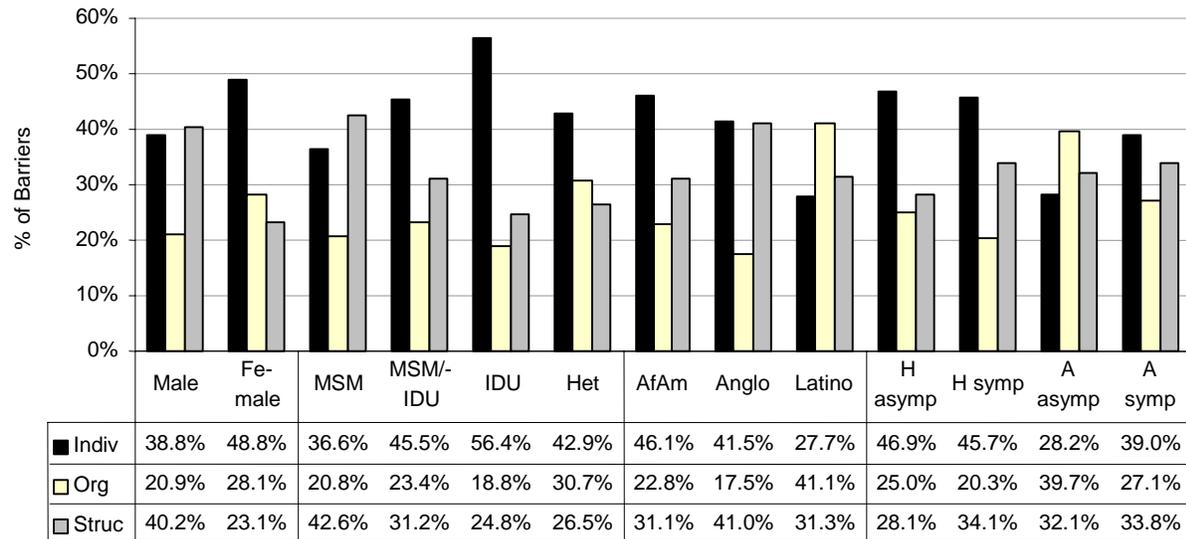
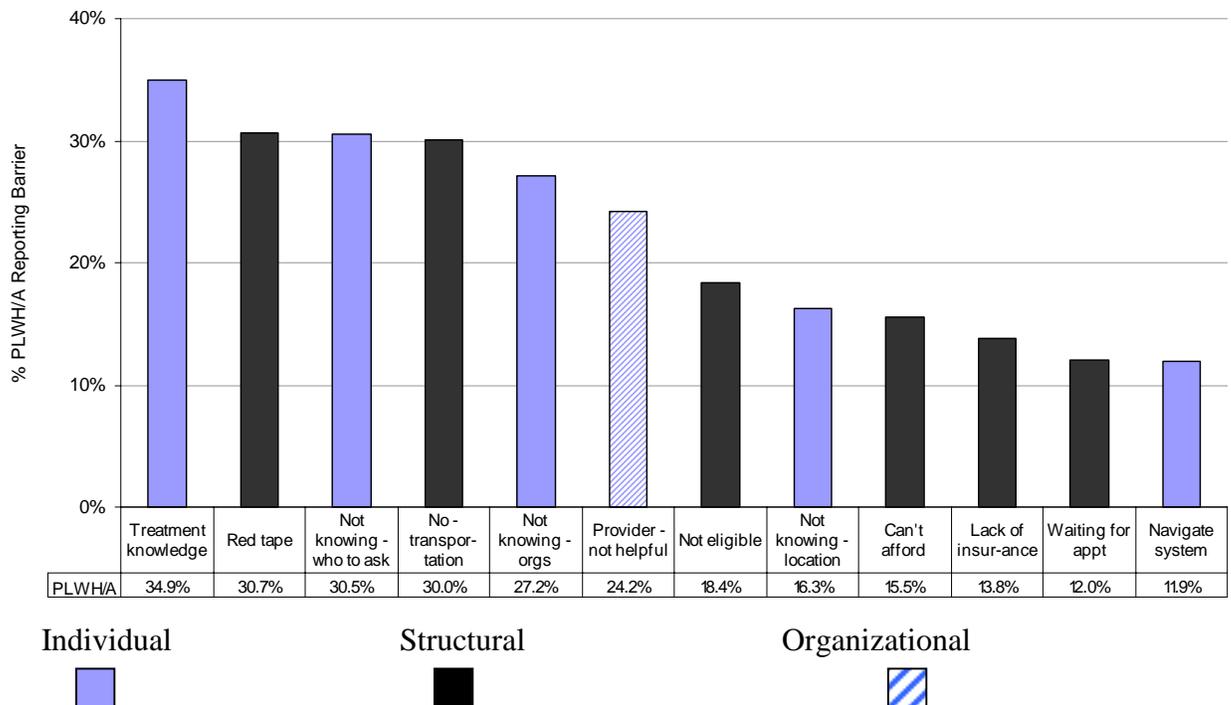


Figure 11-4 represents the top twelve barriers they mentioned. As shown below, the only organizational barrier noted in the top twelve barriers is that providers are not helpful.

**Figure 11-4 Top Barriers to Care**



The top barriers were:

- Not knowing that the service or treatment was available to me



- The amount of red tape and paperwork I had to fill out to get the service
- Not knowing who to ask for help
- Not having transportation
- Not knowing which organization to go to for the service
- The people providing services to me are not helpful
- Not being eligible to obtain services because of rules and regulations
- Not knowing the location of the services
- Can't afford service
- My lack of, or inadequate, insurance coverage.
- The amount of time I had to wait to get an appointment or to see someone
- My ability to find my way through the system

The qualitative comments reveal how inter-related these barriers become. Lack of knowledge is related to being connected to the service system and the often contradictory information PLWH/A receive from different providers.

Not knowing which organization to go to may be more a reflection of issues related to eligibility, insurance, and service availability. In addition, there appears to be considerable confusion about what agencies outside of Ryan White funded agencies provide services. Cost, for those who are not eligible for full Ryan White services is perceived of as a barrier.

Comments from rural participants emphasize the lack of expertise in rural areas and difficult, but not impossible, transportation to services. However, as will be seen in Section 12, rural residents do receive all services, and many of the wrap around services are particularly well provided.

From the comments by the participants, there appears to be considerable variability regarding the helpfulness of staff of agencies. The impression is that African Americans and mono-lingual Latinos may have a more difficult time accessing services because they perceive that staff is insensitive or doesn't understand their needs.

For further insight into these barriers, individual comments are listed in a sister report of focus group comments.



## 12. SERVICE AND BARRIER TEMPLATES

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 assess the need, utilization, and gap for each service. Services are presented by 2002 priorities.

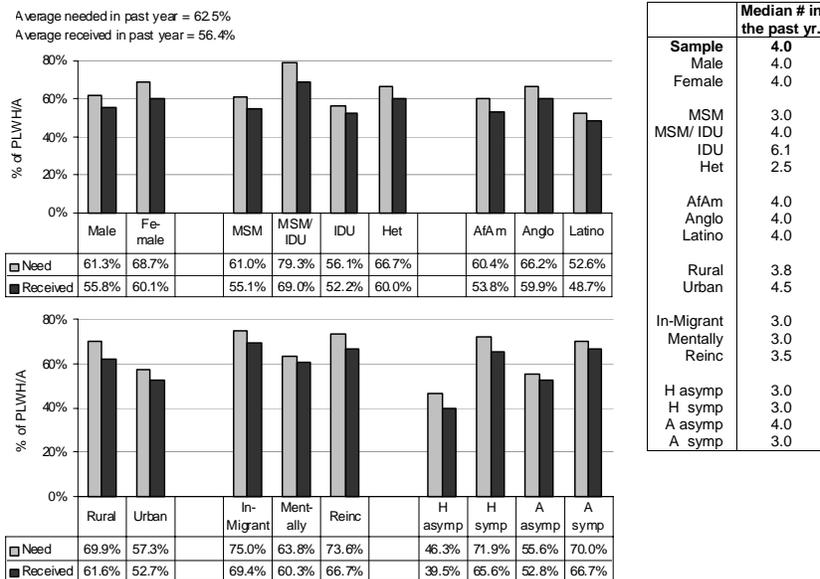
Each service is shown using the same graphs and page layout as shown in Figure 12-1. At the top of each template the average number needing the service is displayed. The difference between the two indicates a gap between needing and receiving a service.

The two graphs represent a cluster of subpopulations. The top graph shows gender, risk group, and race/ethnicity. The bottom graph shows region, special populations (in-migrants, mentally ill, and recently incarcerated), and stage of infection. Each graph shows the percentage of each population that reported needing and receiving each service. 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. For each barrier participants of the survey listed relevant barriers, and these are the ones listed. Notably, for many services only a handful of participants listed barriers.

Significant differences in service needs by race/ethnicity, risk group, and stage of infection are noted in bullet points on the page following the graphs along with a summary of the focus group comments regarding the service. Starting on the second page for each service relevant focus group comments are shown 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.

**Figure 12-1 Service & Barrier Template**

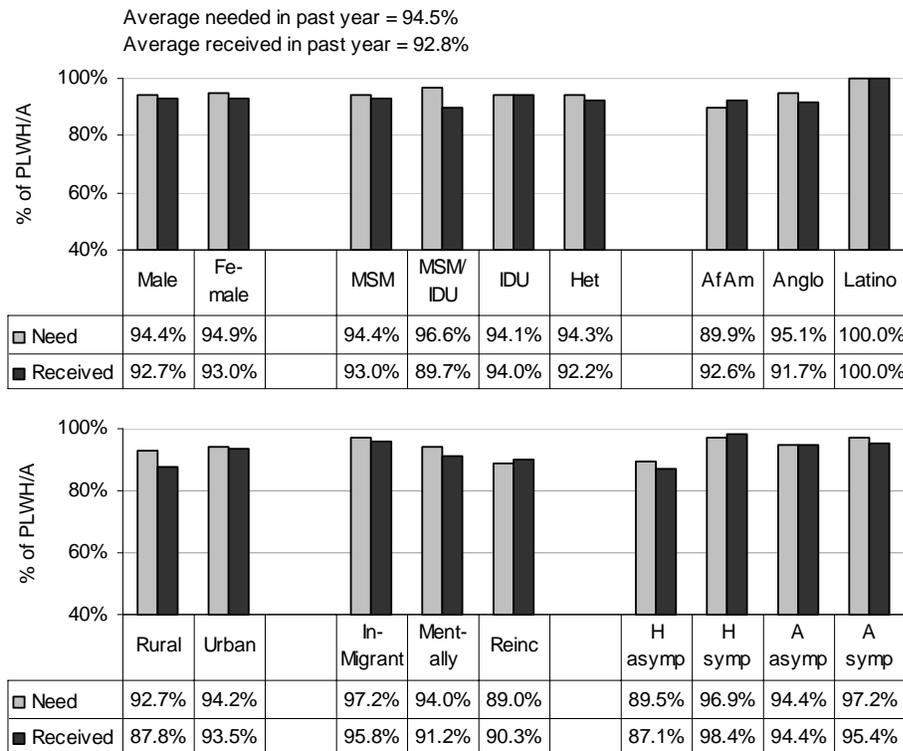




In the following sections only those services with sufficient sample size needing and utilizing the service are shown. Consequently, there are no templates for substance abuse services (residential or out-patient), home health care, hospice care, rehabilitation therapy, buddy companions, employment assistance, or adult day care. For general comments on these services see the prior section and the separate focus group report. For detailed information see Attachment 5 through Attachment 7.



## Primary Medical Care



	Median # in the past year
<b>Sample</b>	<b>6.0</b>
Male	6.0
Female	6.0
MSM	5.5
MSM/IDU	6.0
IDU	7.9
Het	4.3
AfAm	5.0
Anglo	4.3
Latino	6.0
Rural	4.8
Urban	6.0
In-Migrant	4.0
Mentally	6.0
Reinc	6.0
H asymp	4.0
H symp	4.0
A asymp	6.0
A symp	5.0

### Top Barriers

- Lack of transportation.
- The amount of time I had to wait to get an appointment or see someone.
- Not knowing that the service or treatment was available to me.
- Lack of sensitivity of the organization and person providing the service to my issues and concerns.
- The level of discrimination I experienced by the persons or organization.
- The organization providing the service made me feel like a number.
- The people providing services to me are not helpful.
- My state of mind or mental ability to deal with the treatment.

### Highlights

- Primary medical care is ranked as the highest priority by the Council and PLWH/A.
- On average, over 90% of PLWH/A say they currently need primary medical care, and have received the service during the past year.
- There is a very small service gap across all PLWH/A, but MSM/IDU say they need more primary care than they receive.
- On average, PLWH/A report 6 contacts with a physician or clinic. In-migrant PLWH/A, asymptomatic and symptomatic PLWH received fewer contacts.
- Among sex and risk groups, MSM/IDU report the greatest need.
- Among ethnic populations, 100% of Latino express they currently need and receive primary care.
- Barriers to primary care tend to be first organizational and then individual.



### Outpatient Care – Qualitative Comments

Overall PLWH/A were satisfied with the care they received. There were a few comments noting that the HIV/AIDS clinic was preferred over private practices.

A newly diagnosed Latino MSM said, *“Personally, every service I’ve been given has been excellent, especially the attention given by the front desk at the [medical ASO] and my doctor. I’d like to congratulate all who participate in this institution.”* A heterosexual Latino female said, *“Up until now I have no service barrier. I have medical care and they attend to me well. If it’s an emergency the doctor or nurse refers me somewhere else. Through social services, who pays my medical insurance, I receive medical care.”* An African American female said, *“I went to a private doctor. I was on COBRA and COBRA didn’t pay for the [medical ASO]. I had to go see a private doctor, because I was working and I had used COBRA. I would rather go to the [medical ASO] than a private doctor.”*

A newly diagnosed heterosexual Anglo male said, *“I’m pretty happy with my doctor. I just go in and tell him what’s wrong and tell him what is happening. I’ve had it for several months so they are still figuring out what to give me. He’ll take me off the medicine and put me onto another one.”*

Transportation and lack of expertise in the rural areas was mentioned often. A rural Anglo MSM said, *“They used to pick me up and take me down to the medical appointment and bring me back. Now I have to go to the bus stop, take a cab from the house to the bus stop, take the bus down at four in the morning for a doctor’s appointment at noon. Then take a cab from there to the doctor and then go through that routine again and get back. Or they put you up over night and they may or may not feed you.”*

The participants of focus group living in rural area clearly stated that there were no physicians trained in HIV/AIDS care in their area. They either traveled outside the County to Las Vegas or to Phoenix in Maricopa County. A rural Anglo MSM said, *“What I get here is just a primary care physician that does our referrals and that’s basically all they are for, but if we get something like a cold or the flu then we would go to that doctor, but as far as anything to do with AIDS care we have to have a doctor to do the referrals so we can go see our AIDS doctor.”* Another rural Anglo MSM said, *“A few years ago I was seeing a doctor in Bull Head who thought he was an AIDS specialist, and his idea of taking care of the problem was just loading you up on a cocktail of about 24 pills a day, and if that didn’t kill your liver or whatever you would be fine. Now I’m only on 4 pills a day, and I’m undetectable.”* One Anglo MSM from Mohave County was traveling a farther distance for medical care. He said, *“I still go back to L.A. I’m totally confused about where to go here. I want to go see one doctor and that’s it. They are very supportive. My doctor knows, the social worker knows, all the nurses know. On the computer system I have an address in California as far as they know, but they know that I’m here.”*

An in-migrant said, *“That’s one of the complaints I have is because living in Henderson to get any decent medical care you have to go to [an agency in Las Vegas]. To find a well*



*versed doctor, I don't think there is any in Henderson that I've found. Most of the people that I know, they go to [the agency in Las Vegas].”*

For Latinos language was noted as a problem, and supports the finding that organizational barriers are higher for the Latino population. For example, a recently diagnosed over 50 Latino MSM said, *“I go every 3 months to get my blood drawn. I never get any explanations or ask for them. I would like someone to explain more and have more information in Spanish.”*

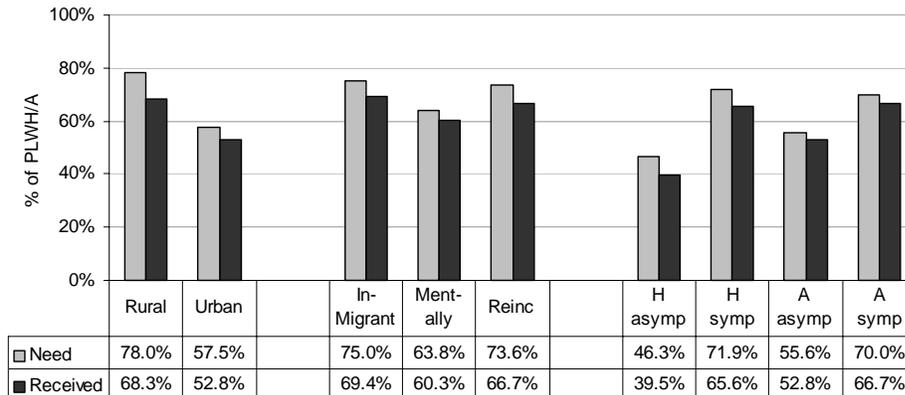
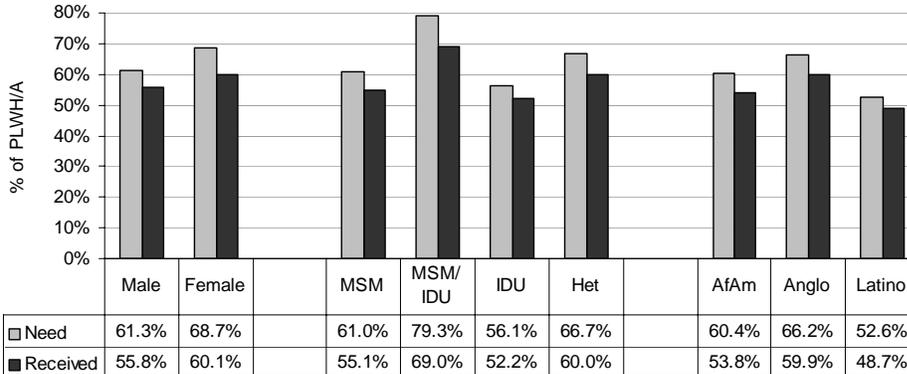
While not mentioned as a major barrier, cost and insurance was mentioned in the focus groups as reasons to limit care and medication. An African American female said, *“They expect you to pay. Now my income is just enough to pay my bills. I make \$8.50 an hour. That's enough to pay my bills.; it's not enough to go to the doctor and all of this. They have the Ryan White title, whatever, where you have to pay so much here to your doctor visits. Well, I might as well be seeing a private doctor and paying him payments. I have no insurance, because I just started my job. They want you to have no income, and if you have income then they try to charge you but it's not convenient for you. It's convenient for them. They will let me see the doctor through the program, however they can't pay for my prescriptions. Or it would be vice versa. They will give me the prescriptions and tell me to pay the doctor's visit. It's always something. It's not anything where it bounces into my favor.”*

A Latino MSM said, *“At the [medical ASO], they are charging me a \$500 co-pay annually and I find this excessive since I only see the doctor twice a year, am not taking medications, and I have not been sent for x-rays or other analysis.”*



## Case Management

Average needed in past year = 62.5%  
 Average received in past year = 56.4%



	Median # in the past yr.
<b>Sample</b>	<b>4.0</b>
Male	4.0
Female	4.0
MSM	3.0
MSM/ IDU	4.0
IDU	6.1
Het	2.5
AfAm	4.0
Anglo	4.0
Latino	4.0
Rural	3.8
Urban	4.5
In-Migrant	3.0
Mentally	3.0
Reinc	3.5
H asymp	3.0
H symp	3.0
A asymp	4.0
A symp	3.0

### Top Barriers

- Not knowing who to ask for help.
- Not knowing that the service or treatment is available to me.
- The people providing services to me are not helpful.
- Not knowing which organization to go to for the service.
- The amount of time I had to wait to get an appointment or see someone.

### Highlights

- Case Management is ranked second by the Council, and fourth by PLWH/A.
- Despite the high priority for case management services, just over a half of PLWH/A report a current need for case management.
- From the perspective of PLWH/A there is excess capacity; more PLWH/A report receiving it than needing it.
- Those accessing case management services report having received, an average of 4 contacts in the past year. Heterosexuals and MSM/IDU received fewer and more services respectively.
- Among sex and risk groups, MSM/IDU report a greater need.
- Among special populations, in-migrant and re-incarcerated PLWH/A report the greatest need.
- Among stages of infection, asymptomatic PLWH report the lowest need, and are less likely to access case management.



## Case Management – Qualitative Comments

Several PLWH/A had favorable comments about their case managers. An African American heterosexual female said, *“It's something that you need. I follow my case manager's directions and get everything I need.”* An Anglo female said, *“I have found that all the people that I dealt with are very good and they refer me from place to place. I was put on the inactive list, because I'm too healthy now. I still have another case worker but she is not a nurse like the other one was. This one is taking care of the insurance and what not. I have been very fortunate.”*

Others pointed out various barriers they have, and the comments of PLWH/A reinforce the barriers noted in the template. An African American female said, *“I think better networking is needed. Think about it, if somebody just found out they had HIV the doctor should be able to hand them the number, ‘This is where you call and they know where to get what.’ You say, ‘I need this, I need that. I can't afford medication.’ They should be able to send you to an office where all of that is taken care of right there.”*

A recently diagnosed Anglo heterosexual male said, *“Last year I felt my caseworker was not fully aware of all programs. I lived in an area with no transportation and was told there was no service available to get me to the M.D.'s office.”*

A 55 year old Anglo MSM said, *“I've used the service before and it was bull; they couldn't help and wasted a lot of my time.”* A recently diagnosed Anglo female with a history of being homeless said, *“There are two different associations working with you trying to get what they think you need not what you know you need and the doctor is going to need, what they think you need. You are okayed long enough so we can go to the doctor and between time you are getting all screwed around and told to go here and there when it's not even necessary. Told to give information they don't even need and they don't even want, but yet they ask for it instead of doing the important things like taking care of somebody's health and dealing with getting the funds in order to pay the doctor.”*

There were also comments about the organization and treatment of PLWH/A. A Latino female said, *“Well the only thing I have to say is that in this group that we here at [the Latino focused ASO] we need people that are going to be nicer to us. Because the fact that we are infected with AIDS, it is hard to say but, they treat us like animals or like dogs. The people get too aggressive with us and I don't think that is justified, because if we come here to ask for help it's because we really need it. They demand that we bring electricity, telephone and rent bills and when we bring them they argue that there aren't enough funds. Well then why do they ask us for so much proof of expenses if there are never funds? They haven't given us vouchers for 2 months, they say that they are held up, we are not to blame for these delays because I think there are enough organizations that are giving to this cause, and there is money we don't get because there isn't enough assistance.”*

The comments often noted that the problems were more structural, and that while their case managers tried to help, they could not. In Mohave County participants noted the limited

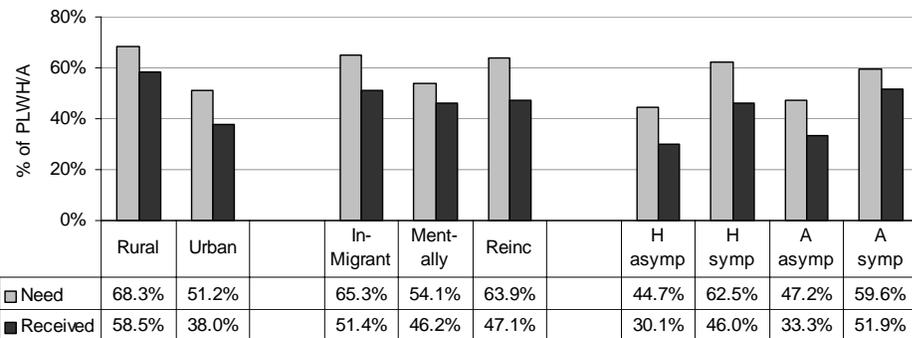
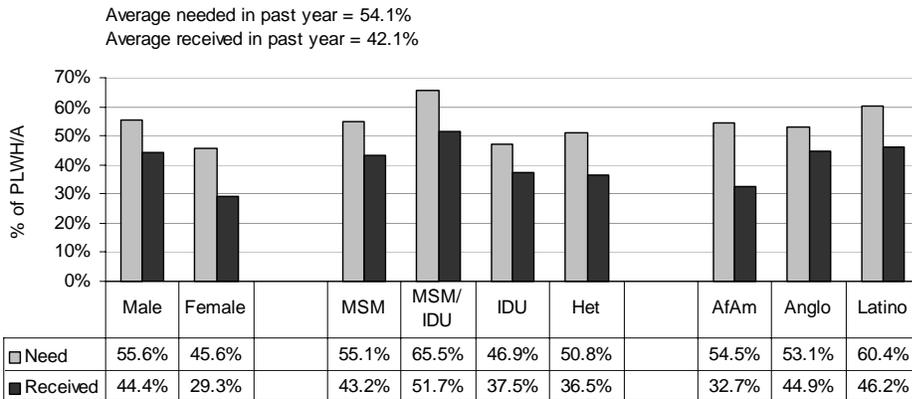


resources. One rural resident, speaking about his case manager, said, *“He is everything right now. He is the only person that can assist us. Whenever you need to get in touch with him you leave him a message. You are lucky if he calls you by the end of the day.”*

A Latino MSM said, *“I need help with my rent, but I’ve been told at two agencies that with the new case management program I can only get help once a year. They need to make more funds available.”*



## Mortgage/ Rental Assistance



	Median # in the past year
Sample	3.0
Male	3.0
Female	3.0
MSM	3.0
MSM/IDU	3.0
IDU	3.0
Het	8.0
AfAm	3.0
Anglo	2.0
Latino	3.0
Rural	3.0
Urban	3.0
In-Migrant	3.0
Mentally	3.0
Reinc	3.0
H asymp	3.0
H symp	3.0
A asymp	4.0
A symp	1.5

### Top Barriers

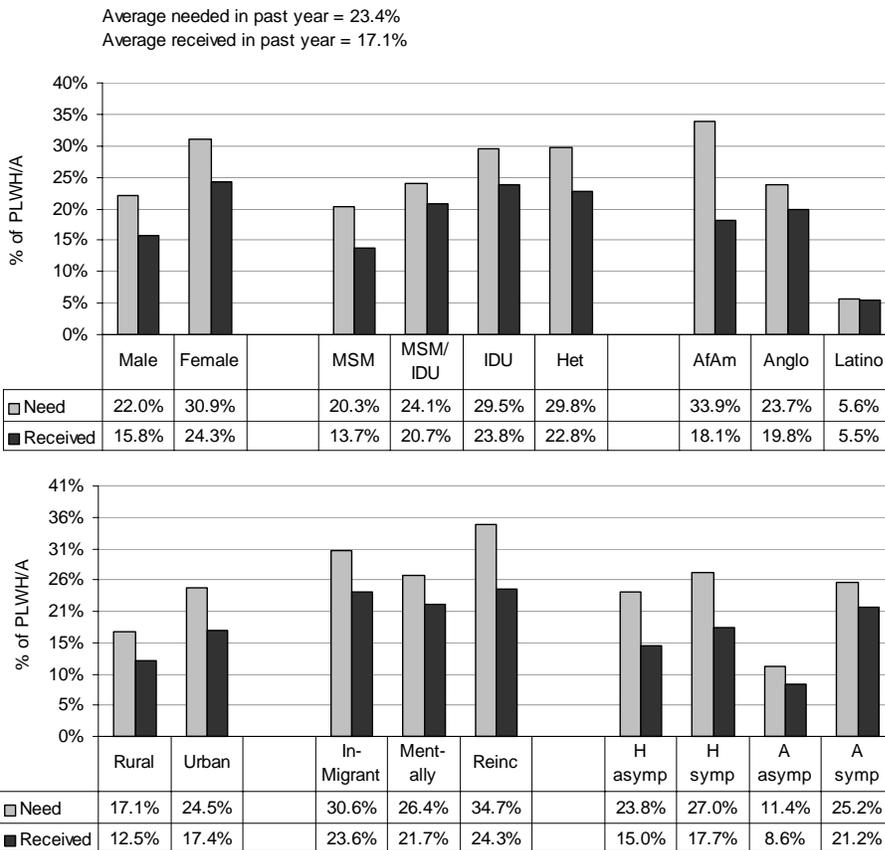
- I was not eligible for the service.
- Not knowing who to ask for help.
- There was too much paperwork or red tape.
- Not knowing which organization to go to for the service

### Highlights

- Mortgage/rental assistance is rated third by the Council and 5<sup>th</sup> by PLWH/A.
- On average, just over a half of PLWH/A report a need for mortgage /rental assistance, and less than half indicate to have received the service in the past year.
- One of the largest service gaps exists amongst all PLWH/A, with females presenting the largest gap.
- PLWH/A accessing the service say they were helped on an average of 3 during the past year.
- Among sex and risk groups, MSM/IDU report the greatest need.
- Among ethnic populations, Latinos proportionally indicate the greatest need for mortgage/rental service.
- For PLWH/A living in different regions, rural PLWH/A indicate the greatest need.
- Among stages of infection, the need for rental assistance appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater need for the service than asymptomatic PLWH/A.



## Housing Referrals/Assistance



	Median # in the past year
<b>Sample</b>	<b>2.0</b>
Male	1.0
Female	1.0
MSM	2.0
MSM/IDU	1.0
IDU	1.0
Het	2.0
AfAm	2.9
Anglo	1.1
Latino	1.9
Rural	1.0
Urban	2.0
In-Migrant	2.0
Mentally	2.0
Reinc	2.0
H asymp	3.5
H symp	2.0
A asymp	5.0
A symp	1.0

### Top Barriers

- Not knowing which organization to go to for the service.
- Not knowing who to ask for help

### Highlights

- Housing referrals/assistance is ranked fifth by the Council, but ranked 15<sup>th</sup> by PLWH/A.
- On average, slightly less than a quarter of PLWH/A say they need the service, and 17% report having received the service in the past year.
- Housing referral/assistance does not present a proportionally large service gap, however a very large gap exists among African Americans.
- PLWH/A accessing the service say they received assistance two times during the past year, with asymptomatic PLWH/A indicate receiving more assistance.
- Among sex and risk groups, females report the greatest need and receiving more services. MSM need and receive the less housing referrals and assistance than other risk groups.
- Among ethnic populations, African Americans proportionally indicate the greatest need for the service. Latinos indicate a very low need and having received fewer services in the past year.
- Among special populations, in-migrant and re-incarcerated PLWH/A report the highest need.
- Rural residents indicate less housing referral and assistance need than urban PLWH/A.
- Among stages of infection, asymptomatic PLWH/A report the lowest need for the service, and they receive the lowest level of service.



### Housing – Qualitative Comments

A few of the participants spoke favorably of housing services. A 55 year old Anglo IDU male said, *“I was fortunate. I was sharing a home with an elderly lady in Desert Shores for 5 years. She had a massive coronary and her family found out I was HIV positive, thought I was to blame for her death. They gave me 7 days to clear the property, so I wound up in a weekly motel on my social security disability, which was gone in less than 2 weeks. I was fortunate enough to get hooked up with Caminar who put me on the list for housing. It’s based on a sliding scale of my social security disability, and that’s where I am now. I’m very, very happy to be there. I feel very blessed to be there.”*

An African American male said, *“Living on the streets is no joke. It isn’t easy. It’s 24 hours, 7 days a week and you are trying to figure out how you are going to make it through the day and then when it starts getting night you have to wonder how you will make it through the night. Right now through the HOPWA program I get \$300 a month, which made it so I can pay \$250 rent a month. That’s been 8 months now, so it’s working out.”*

In some instances, rural residents choose to live in substandard housing. For example, A rural mixed race MSM said, *“I live in a camper 30 years old, no power, no water, no toilet. My partner lives in the pickup camper in which I used to do showers and cook. I use the solar power off of his to provide power for one light in my camper. I do all repairs and we haul our water 25 miles one way to have water. We need help getting USDA Agriculture well and septic loan so we can build a house. I have done all the road and pad leveling by hand. We are buying the land and we refuse to live in town’s exc. Too busy and anxiety prone. We don’t do well there. That is why we are 25 miles from the nearest town and it is very hard being out there, although better for us.”*

Many PLWH/A spoke about barriers they faced. Some talked about eligibility. An African American MSM said, *“...in reference to gaining information towards affordable housing. Being that my health is not of a “disabling” nature places me in a category not of urgent need of support.”*

An African American MSM said, *“When I needed a place to stay and was homeless my caseworker couldn’t help me. They are really not set up for emergencies.”* An Anglo MSM said, *“When I’ve tried to go to [the large ASO] for housing assistance or anywhere else they told me no.”*

An African American MSM said, *“When we got here to Las Vegas we were homeless. They supposedly have emergency shelter for people that are suffering with HIV and AIDS. This was dead winter. Some nights it was so cold you could probably freeze a steak outside, and we went to them [large ASO] for services. We had to wait. ‘Come back next week,’ they said.”*

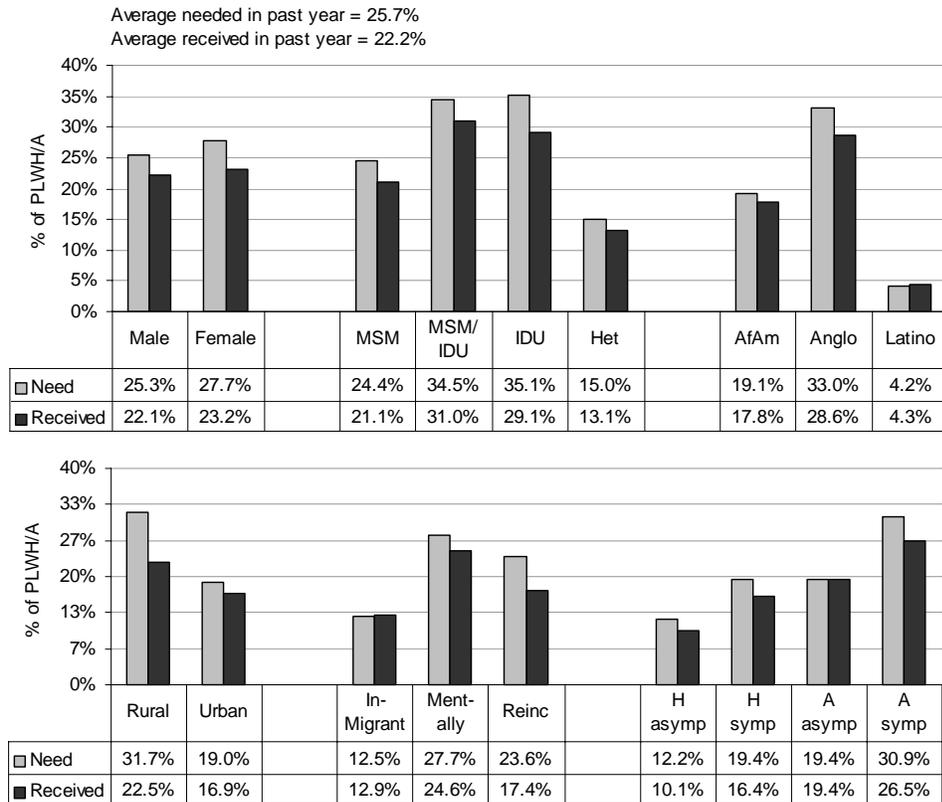
An Anglo IDU male said, *“I used to get HOPWA every month. They stopped giving everybody money. They existed before everybody was able to get social security and all of*



*that stuff. But when people started getting denied, more people are living longer, more people are getting on the list, so what happened was the only people that weren't getting any income was able to get this. And because I get VA and SSA and all of that stuff then I wasn't able to get HOPWA anymore, but before that happened they gave me money to move in where I'm staying at. They paid a month and a half rent. They gave me moving expenses and every month I got \$200 too. But when more people started needing they didn't have the money for it anymore. I haven't gotten that in years. But they did help me at the time very much."*



## Medication Reimbursement



### Top Barriers

- I was not eligible for the service
- I can't afford the service
- My ability to find my way through the system

### Highlights

- Medication reimbursement is ranked 14<sup>th</sup> by PLWH/A 4<sup>th</sup> by the Council.
- On average, just over a quarter of the PLWH/A report that a need for medical reimbursement, and 22.2% say they have received the service in the past year.
- Typically, PLWH/A have asked for reimbursement more than they have received them. There is a very low service gap across all PLWH/A, with the largest gap among rural and re-incarcerated PLWH/A.
- Among sex and risk groups, MSM/IDU and IDUs report the greatest need for medication reimbursement.
- Among ethnic populations, Anglos report the greatest need, whereas Latinos report a very low level of need for medication reimbursement.
- Among special populations, in-migrant PLWH/A report the lowest need, and they received fewer services in the past year. Re-incarcerated PLWH/A say they needed more services than they received in the past year.



### Medication Reimbursement – Qualitative Comments

Several PLWH/A confirmed that medication is assumed by many to be paid for. For example, a 55 year old African American heterosexual male said, “*Any new medication that comes out, the VA says I can have it. I don't have to worry about it.*” An African American heterosexual male said, “*Yeah. I get all of my meds. I like the Wellness Center for the fact that you can go there and get your medical attention and medicine at the same place. And it's quick.*”

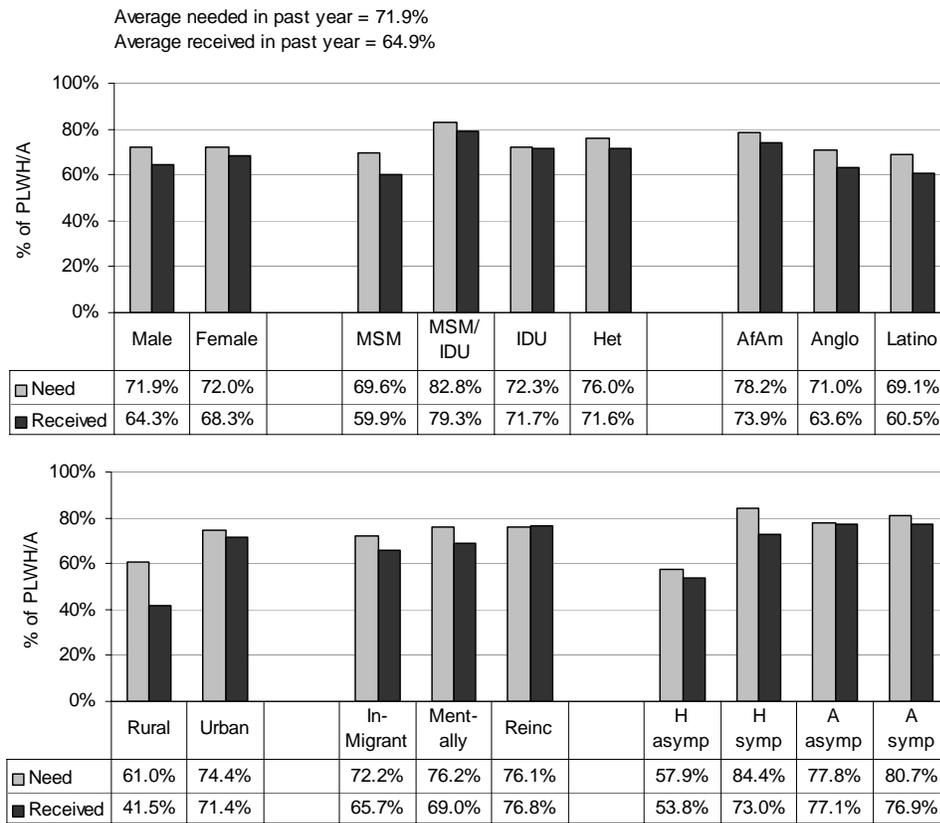
Medication is necessary, but method of reimbursement can be cumbersome. For example, An Anglo female said, “*Now I'm to the point that I don't have Medicaid, because once you are out of a care home they do not pay anything, and I'm not eligible for Medicare for a year. So in between, even if you are a survivor you drop dead is what it amounts to. Then it got to the point where they said 'You've got to have insurance or else you are not going to be able to get your pills. Your pills are like \$1,000 a month, your blood draws are \$1,000.' I looked at them and I said, 'Fine you can have the \$1,000. I'm moving all of my clothes and furniture to the park and you can find me there.' I mean that's how I felt. I still don't have health insurance. See up until now, my meds have been covered by Ryan White. I get my medication through there. They just drew my blood Monday, but I think they did it just because these people know what I've been through, and now I'm supposed to see somebody else that is supposed to look into my coverage. I said, 'I give up and I'm not paying this government a penny of nothing anymore.'”*

A Latino MSM said, “*I get social security disability and my Medicare doesn't pay for any medications. But they have the Health Department that picks up what the other people don't pay for, and [my case manager] never told me about it. I just found out about this about a week ago, because last week I went in to see the guy that takes care of all the paperwork. He works in the same building that [my case manager] is in, and they not once told me about him. He was real upset, because he said it's been over year. He said, 'You've been having a hard time getting all of these other medications when we could have been giving them to you.' Right away, like in 30 minutes he got me all signed. That should have been done a year ago. Up until now, Ryan White paid for the HIV meds, but there are other meds that you need. Like one time I had a rash all up and down my neck, but it wasn't considered an HIV med, so I had to pay for it myself because Medicare won't pay for it. Last week I had another prescription that was \$90...*”

Cost is a barrier for some. A newly diagnosed Latino heterosexual male said, “*This year they want me to pay 50% of my medical expenses through Ryan White and I can't afford this. I work, but I have to pay rent, car payment, car insurance, bills, etc... The bills I've been getting from [the medical ASO] for \$800.00 plus are unmanageable for me. I can't pay them.*”



## Food Pantry



	Median # in the past year
<b>Sample</b>	<b>12.0</b>
Male	12.0
Female	10.0
MSM	12.0
MSM/IDU	22.1
IDU	10.0
Het	10.0
AfAm	12.0
Anglo	12.0
Latino	12.0
Rural	10.0
Urban	12.0
In-Migrant	9.0
Mentally	10.0
Reinc	11.0
H asymp	10.0
H symp	12.0
A asymp	6.5
A symp	12.0

### Top Barriers

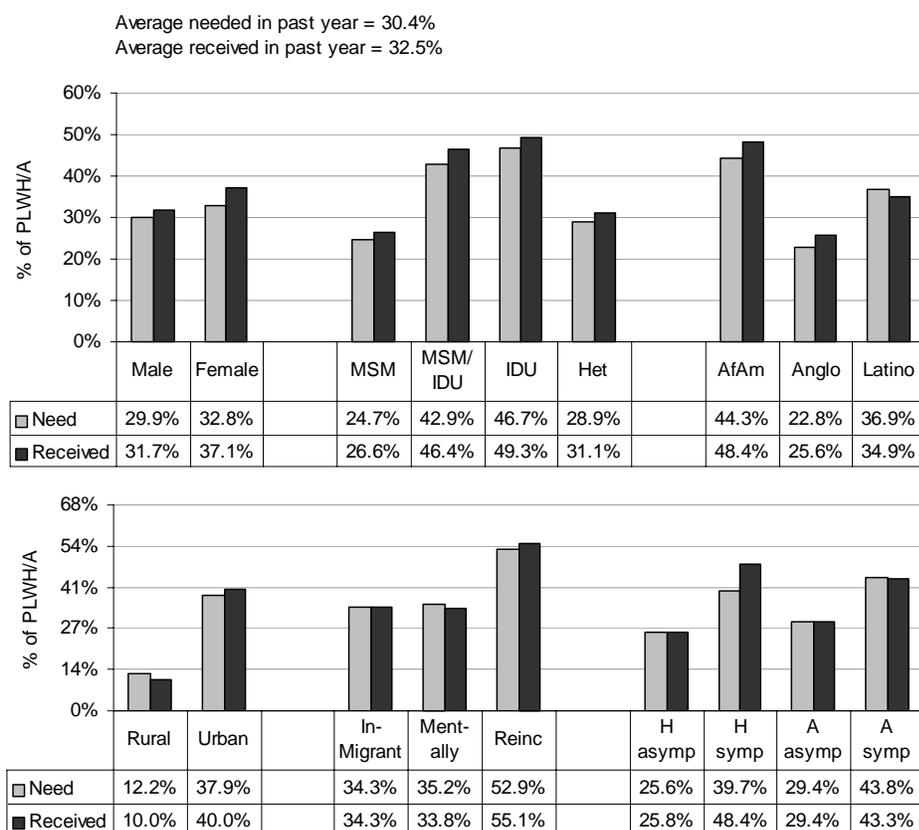
- No transportation.
- The people providing services to me are not helpful.
- I was not eligible for the service

### Highlights

- Food Pantry is ranked second by PLWH/A, and food and nutritional supplements is ranked 6<sup>th</sup> by the Council.
- On average, about 72% of PLWH/A say they need the service, and 65% report having received the service in the past year.
- Food pantry has a modest service gap.
- Those PLWH/A accessing the service, say they received an average of 12 visits during the past year, with MSM/IDU and asymptomatic PLWH/A report to have received more and less services, in the past year.
- Among sex and risk groups, MSM/IDU and IDU report the greatest need, and have received more services.
- Among special populations, rural PLWH/A report the lowest need, and having gone to the food pantry less during the past year.



## Group Meals



	Median # in the past year
Sample	10.0
Male	10.0
Female	4.0
MSM	6.0
MSM/IDU	10.0
IDU	10.5
Het	10.0
AfAm	10.0
Anglo	9.3
Latino	5.4
Rural	4.0
Urban	10.0
In-Migrant	5.0
Mentally	10.0
Reinc	16.0
H asymp	10.0
H symp	10.0
A asymp	10.0
A symp	10.0

### Top Barriers

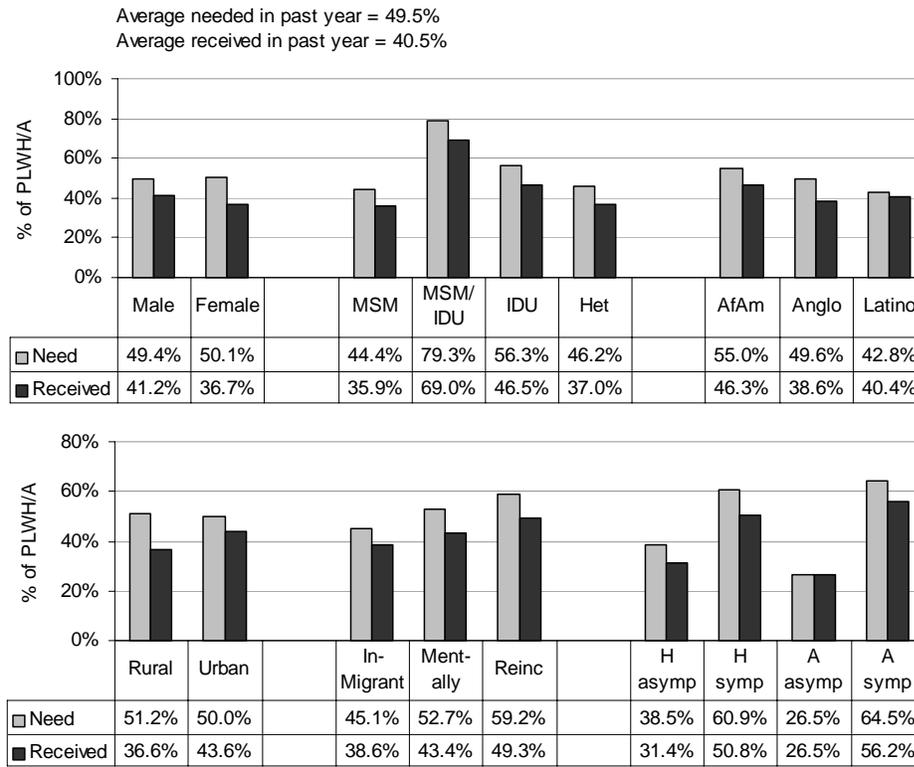
- No transportation.
- The people providing services to me are not helpful.
- Not knowing what medical services I need to treat my HIV.
- Not knowing who to ask for help.

### Highlights

- Group Meals is place with food as sixth ranked by the Council. It is ranked twelfth by PLWH/A.
- On average, about 30% of PLWH/A indicate a need and 32% report receiving group meals.
- Despite the low priority for group meals, there is a positive service gap for the group meals. PLWH/A say they received more services than they need in the past year.
- Those PLWH/A accessing the service, say they received an average of 10 meals, with rural and female PLWH/A having received fewer meals.
- Among sex and risk groups, IDUs and MSM/IDU report the greatest need, and having received more services in the past year.
- Among special populations, re-incarcerated PLWH/A report the highest need, and having received more services during the past year.
- Among stages of infection, the need for group meals appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater need for the service than asymptomatic PLWH/A.



## Nutritional Supplements



	Median # in the past year
<b>Sample</b>	<b>4.0</b>
Male	4.0
Female	2.0
MSM	4.0
MSM/ IDU	5.0
IDU	3.3
Het	3.0
AfAm	3.7
Anglo	4.0
Latino	2.2
Rural	4.0
Urban	3.0
In-Migrant	2.5
Mentally	4.0
Reinc	3.5
H asymp	2.0
H symp	4.0
A asymp	3.0
A symp	4.0

### Top Barriers

- Not knowing which organization to go to for the service
- Not knowing who to ask for help
- Not knowing that the service or treatment was available to me.

### Highlights

- Nutritional supplements are ranked 7<sup>th</sup> by PLWH/A, and 6<sup>th</sup>, as part of food services, by the Council..
- On average, slightly less than a half of PLWH/A indicate to need, and 41% have received nutritional supplements in the past year.
- There is a moderate service gap for nutritional supplements, on average less PLWH/A report having received nutritional supplements, compared to needing them. Females and rural PLWH/A have the greatest gap.
- Those PLWH/A accessing the service, say they used the service 4 times during the past year, with female and rural PLWH/A having received fewer visits.
- Among sex and risk groups, MSM/IDU report the greatest need, and having received more services in the past year.
- Among special populations, re-incarcerated PLWH/A report the highest need, and having received more services during the past year.
- Among stages of infection, the need for nutritional supplements appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater need for the service than asymptomatic PLWH/A.



Food Pantry, Meals, and Nutritional Supplements – Qualitative Comments

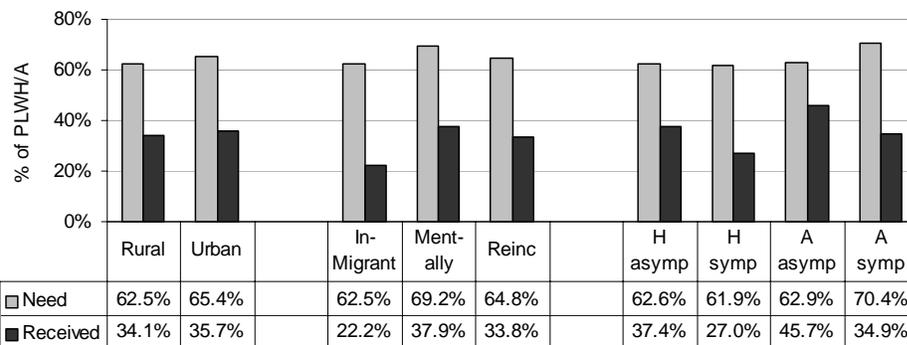
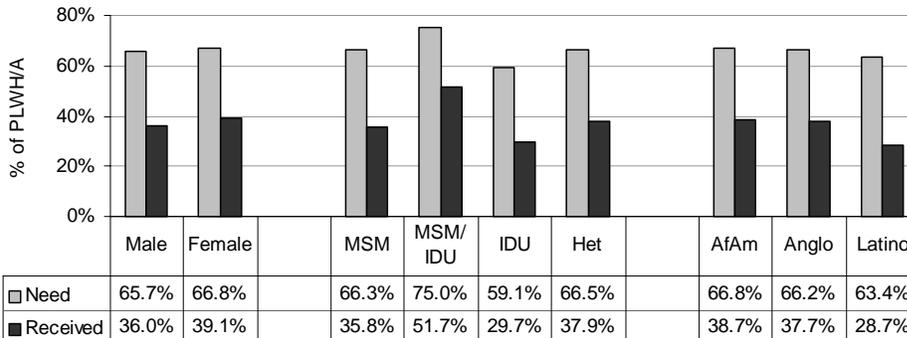
PLWH/A appreciate food pantries, but also note their limitations. For example, an African American MSM said, *“Thank God for the pantry because I know it's God's gift that some people donate those foods to us. But you don't know what you are getting out of that pantry. You go home open up a can, you've got a can of worms. I have opened up canned goods and cooked it and when I tasted it it tasted just like the can itself.”*

Food clearly affects the quality of life of PLWH/A. An African American MSM said, *“We talk about the quality of life and you figure people don't get that much money a month and all they are able to give you is \$10 a month for food stamps. When you talk about quality of life you are talking about the food that you are able to consume. Even when you take advantage of the pantries you can only get non-perishable foods. It takes more than just that. You need to be able to eat some good food.”*



## Dental Care

Average needed in past year = 65.9%  
Average received in past year = 36.4%



	Median # in the past year
Sample	2.0
Male	2.0
Female	2.0
MSM	2.0
MSM/ IDU	3.0
IDU	2.0
Het	2.0
AfAm	2.0
Anglo	2.0
Latino	2.0
Rural	2.0
Urban	2.0
In-Migrant	2.0
Mentally	2.0
Reinc	2.0
H asymp	2.0
H symp	2.0
A asymp	2.0
A symp	2.0

### Top Barriers

- Not knowing who to ask for help.
- Not knowing that the service or treatment was available to me.
- Not knowing which organization to go to for the service.
- The amount of time I had to wait to get an appt or see someone.
- I cannot afford the service.
- Not knowing the location of the services.
- No transportation.
- My lack of, or inadequate, insurance coverage.
- Service is not available; it has been discontinued.

### Highlights

- Dental care is ranked third by PLWH/A and seventh by the Council.
- On average, 66 % of PLWH/A indicate need for dental services, but only 32% report to have received the service in the past year.
- Dental care presents the largest service gap of all other services. Latinos, in-migrant PLWH/A and symptomatic PLWA indicate the greatest gap.
- Those PLWH/A accessing the service, say they went to the dentist 2 times during the past year. MSM/IDU received more services than any other PLWH/A.
- Among sex and risk groups, MSM/IDU report the greatest need, and having received more services in the past year.
- Among ethnic populations, Latinos indicate the greatest need, however they have received less services during the past year, than other populations.
- Among special populations, in-migrant PLWH/A report having received less services during the past year.
- Among stages of infection, symptomatic PLWA indicate the greatest need for dental care; symptomatic PLWH received less dental care during the past year.



### Dental Care – Qualitative Comments

Not knowing who to ask was mentioned by an African American MSM said, *“I needed access to a dentist and I was saying how good of a doctor [I have]. A lot of stuff we don't know, because our doctor's don't let us know. He requested that I go and see the dentist, so that's how I found out about it.” The only thing is with the dental is that it's an open clinic and it may take you a month and a half just to get in there. I hate going to the dentist, but I never felt discriminated because I know when the nurses read the chart they will see AIDS on there. I've never felt discriminated. It's just that with the dental it's an open clinic so they handle so much it's hard to get in sometime.”*

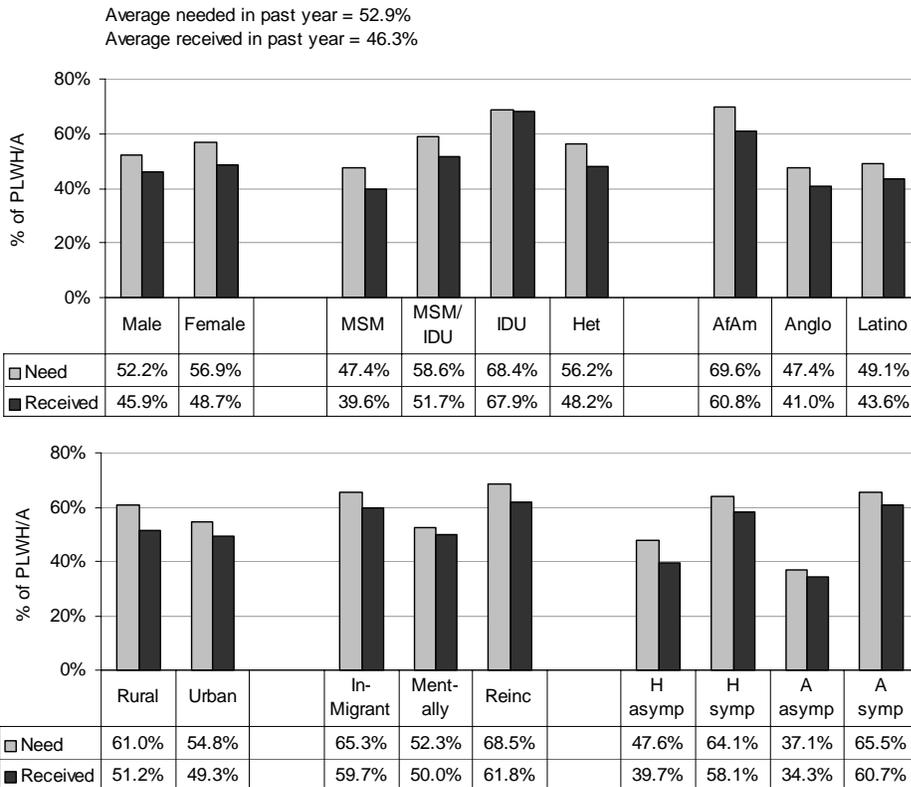
An African American MSM had problems with red tape and Medicaid rules. He said, *“Nevada seems like they make up their own criteria for everything. In California, my partner went and got his whole mouth done on just Medicare alone. But here you've got to go through all this red tape. ... They are taking some of the funding that is coming in for the disabled folks and the homeless folks and they use it for themselves. Let's just be real about it. They are building up all of these fabulous jail houses and these fabulous casinos and then they can't even give somebody like you \$5,000 to go get your mouth fixed. You might not be able to chew anything. How are you supposed to have nourishment if you can't chew.”*

An African American MSM in-migrant added, *“The only problem I had is with Medicare. They put me on it. I started seeing the dentist. After the dentist gets the results they have to get approval. They approved me, cut me off from Medicare at the same time, and they had all this work, and now I owe \$2200, and I still haven't had the work completed. They said I would be eligible for Medicaid in 18 months. Once you start receiving social security disability they just cut you off, and I thought they could have at least let you keep the Medicare until your Medicaid kicks in. To get dentist work you have to have insurance--they can't just work on you. They have to send out for approval.”*

Sensitivity of staff was also a problem for some PLWH/A. An African American heterosexual male said, *“I'm looking for dental help and unfortunately I didn't get it as smoothly, so I left. I had an emergency where the tooth was killing me. They make you wait and wait like you are living for HIV. These people have to be fired; put in people that will work for people not ordering people. They shouldn't look at us as a slave, as trash, as a dying sick individual. They should hire people that respect us that understand that we have AIDS. We are dying, but we don't need to be tortured in the short time that we are on this planet. That is my significant problem.”*



## Transportation



	Median # in the past year
Sample	12.0
Male	12.0
Female	12.0
MSM	12.0
MSM/IDU	8.0
IDU	11.8
Het	12.0
AfAm	12.0
Anglo	12.0
Latino	5.6
Rural	12.0
Urban	4.0
In-Migrant	12.0
Mentally	7.0
Reinc	12.0
H asymp	12.0
H symp	12.0
A asymp	12.0
A symp	11.0

### Top Barriers

- No transportation.
- Not knowing that the service or treatment was available to me.
- Not knowing who to ask for help.

### Highlights

- Transportation is ranked sixth by PLWH/A and ranked eighth by the Council.
- On average, just over a half of PLWH/A say they need the service, and 46.3% report having received the service in the past year.
- Transportation has a moderate service gap.
- Amongst PLWH/A accessing the service, in general they reported 12 round trips during the past year, with Latino and urban PLWH/A indicating a larger number of trips.
- Among sex and risk groups, IDUs report the greatest need, and they have received more services in the past year.
- Among ethnic populations, African Americans proportionally indicate the greatest need for the service and have received more services in the past year.
- Among special populations, in-migrant and re-incarcerated PLWH/A report the highest need. Recently incarcerated PLWH/A say they received more services in the past year.
- Among stages of infection, the need for transportation appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater need for the service than asymptomatic PLWH/A.



### Transportation – Qualitative Comments

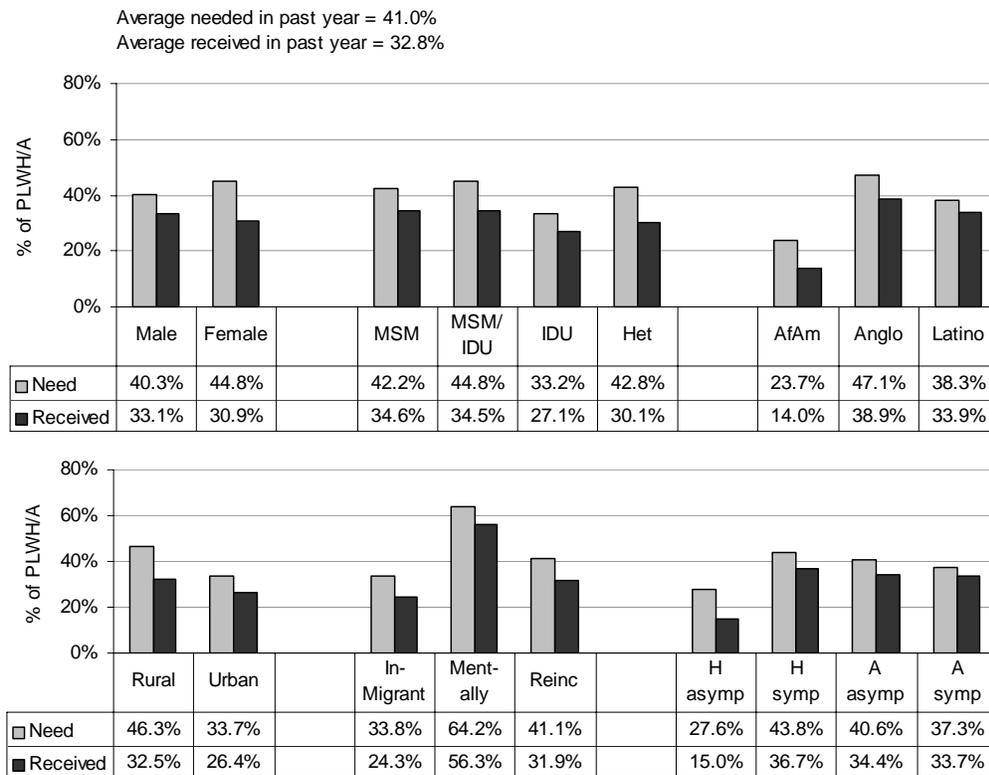
There was recognition of the transportation provided. A Latino MSM said, “*The free monthly bus passes are a blessing. I would not be able to get around the city without it. I use the free pass to make my medical appointments, etc. I love the convenience of having the pharmacy right here in the [medical ASO]. When it is 105 degrees outside and you are sick without a car, it is a life saver.*”

However, there were several comments suggesting it was not useful for emergency situation. An African American female said, “*I had vertigo where the room was spinning constantly and I could not drive my car, and I called [a transportation ASO] to get assistance to get to a doctor's appointment and they told me they weren't doing it anymore at that time. I called my caseworker and she called all over and couldn't find me a ride. She said the best thing to do was either get a cab or get a bus and I had vertigo. I couldn't even find the bus stop.*”

An African American heterosexual male said, “*We have transportation. They have the Para Transit, but it's very tedious. You call sometimes and you have to wait at least half hour or something like that. Some days they disconnect and you have to dial again. It's very hard to get through. In the morning it's impossible. There is no way until 10:00 and after 10:00 they are still busy. So transportation, this town needs a significant overhaul.*”



## Mental Health Treatment /Counseling



	Median # in the past year
Sample	5.0
Male	4.2
Female	6.0
MSM	3.0
MSM/ IDU	15.3
IDU	4.0
Het	6.5
AfAm	5.3
Anglo	4.5
Latino	4.7
Rural	2.0
Urban	6.0
In-Migrant	11.0
Mentally	6.0
Reinc	4.0
H asymp	4.0
H symp	5.0
A asymp	6.0
A symp	6.0

### Top Barriers

- Not knowing who to ask for help
- Not knowing that the service or treatment was available to me

### Highlights

- Mental health treatment/counseling is the eighth priority of PLWH/A and 9<sup>th</sup> by the Council.
- On average, 41% of PLWH/A indicate to need, and 32% to have received mental health treatment/counseling in the past year.
- There is a relatively large service gap for mental health counseling. On average more PLWH/A say they need than receive mental health services.
- Those PLWH/A accessing the service generally received five sessions during the past year.
- Among sex and risk groups, females need more mental health services than men, but receive less. IDUs report less need and they receive fewer mental health services.
- Among ethnic populations, African Americans say they need mental health services less than Anglo or Latinos.
- Among special populations, not surprisingly, the mentally ill recognize they have the greatest overall need for mental health services.
- Among stages of infection, HIV asymptomatic has less need for mental health services.



### Mental Health Services – Qualitative Comments

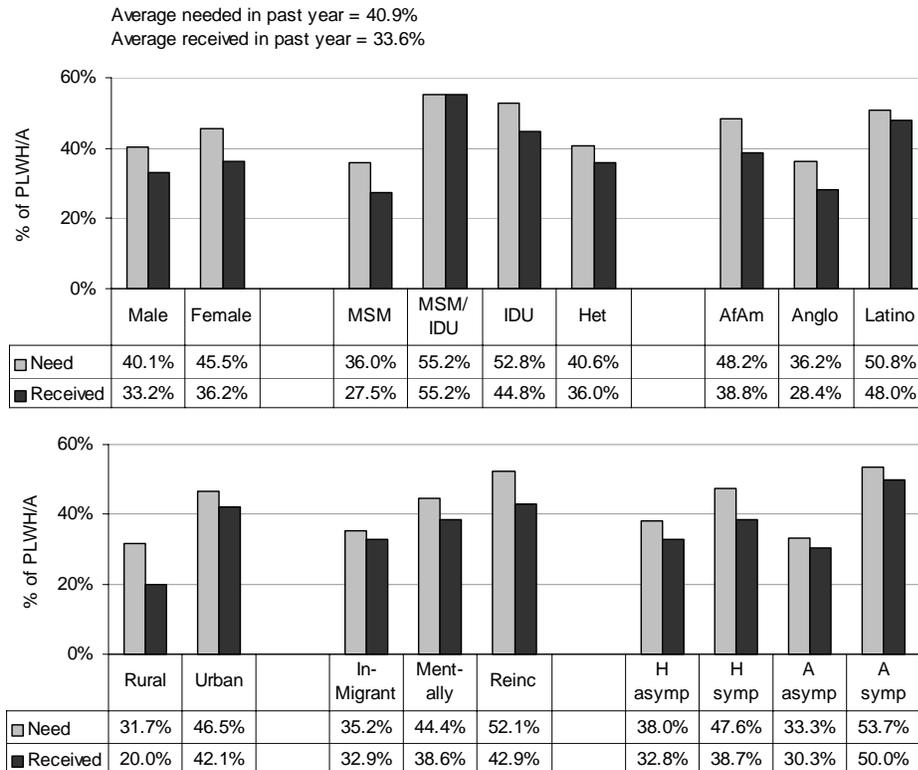
There is a recognition by many PLWH/A that they have a need for mental health services. For example, when asked what the first service needed upon diagnosis, an Anglo heterosexual female who delayed care mentioned mental services. She said, *“They gave me the information for it but I just haven't taken the step to do it. I know it would probably be good for me, because I don't have anyone to talk to. I have no family out here. I've got issues and stuff about it. I guess the thing that keeps me from going looking for help is dealing with it or facing up to it, which is stupid, because if I did I would probably be better off with myself.”*

A Latino heterosexual female talked about her individual barrier to getting mental health services. She said, *“I do not accept this illness - I can't accept it. I try, but when I am depressed I feel like I am going to die and it is terrible. Mental therapy is seriously lacking but it is very important. It is something that Anglos are able to use. Latinos don't form part of the programs even though I as a Latina need it because we have certain taboos about things that we don't want to say for some reason and we need someone to help us and that is what we don't have, and we are bothered with certain questions, things and comments.”*

An African American MSM notes that he was already seeing a psychiatrist before he found out he was infected, but that HIV/AIDS services enabled him to continue receiving mental health services. He said, *“I was already seeing a shrink or psychiatrist when I got diagnosed, so (inaudible) and I told her everything and she knew me very well, so I talked to her about it then. (Inaudible). She works with AFAN, and she told me all about the place, and I had a few other friends tell me I should go to AFAN and register (inaudible)”*.



## Nutritional Counseling



	Median # in the past year
<b>Sample</b>	<b>2.0</b>
Male	2.0
Female	2.0
MSM	2.0
MSM/IDU	3.0
IDU	2.0
Het	2.0
AfAm	2.0
Anglo	2.0
Latino	2.0
Rural	1.0
Urban	2.0
In-Migrant	1.5
Mentally	2.0
Reinc	2.0
H asymp	2.0
H symp	2.0
A asymp	2.0
A symp	2.0

### Top Barriers

- Not knowing who to ask for help.
- Not knowing which organization to go to for the service.
- The people providing services to me are not helpful.

### Highlights

- Nutritional counseling ranked 9<sup>th</sup> by PLWH/A and 11<sup>th</sup> by the Council.
- On average, about 40% of PLWH/A indicate a need for nutrition counseling and 34% report receiving it.
- There is not a relatively large service gap for nutritional counseling, on average. Rural, African American, and symptomatic PLWH present the greatest gap.
- Those PLWH/A accessing the service, say they received an average of 2 sessions during the past year.
- Among sex and risk groups, IDUs and MSM/IDU report the greatest need, and have received more services in the past year.
- Among ethnic populations, Latinos indicate the greatest need, and to have received more services during the past year, than other populations.
- For PLWH/A from different regions, rural PLWH/A report the greatest need, and the lowest in receiving nutritional counseling sessions.
- Among special populations, re-incarcerated PLWH/A report the highest need, and having received more services during the past year.
- Among stages of infection, the need for nutritional counseling appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater need for the service than asymptomatic PLWH/A. Interestingly, asymptomatic PLWA report a very low level of need for nutritional counseling, however they indicate to have received slightly more than they needed in the past year.



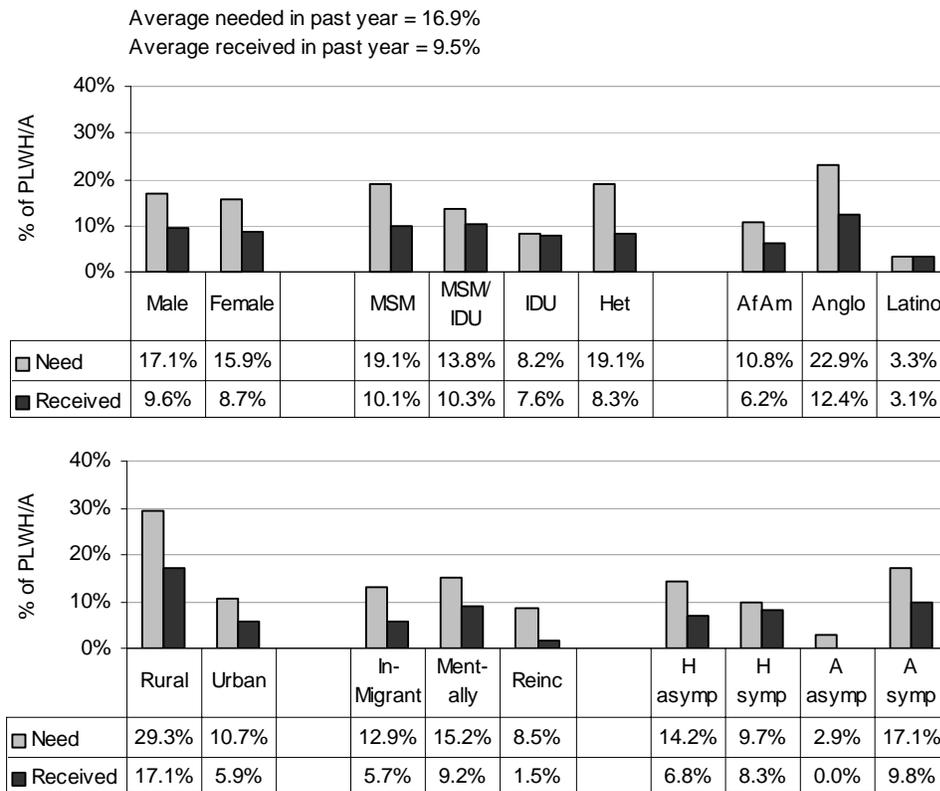
### Nutritional Counseling – Qualitative Comments

Most comments about nutritionists were complementary. A recently diagnosed Anglo MSM said, *“I use the nutritionist at [the large ASO], and she really helps me out. I realize that I wasn't eating properly before, and I always check if I'm going to take something from the health food store is that as good as it can get for me or whatever. I use the pantry there to supplement my food.”*

A Latino said, *“Yes, in that sense I've been taking care of myself a lot. Before I did not eat fruits nor vegetables, but now I do, even though I don't like vegetables very much I have to eat them because they're good for me.”*



## Health Insurance Continuation



	Median # in the past year
<b>Sample</b>	<b>8.9</b>
Male	7.8
Female	12.0
MSM	7.0
MSM/ IDU	12.0
IDU	9.0
Het	12.0
AfAm	8.0
Anglo	8.0
Latino	11.5
Rural	12.0
Urban	12.0
In-Migrant	6.5
Mentally	10.5
Reinc	4.0
H asymp	4.0
H symp	9.5
A asymp	0
A symp	12.0

### Top Barrier

- Insufficient response rate for this item

### Highlights

- Health Insurance continuation is ranked 12<sup>th</sup> by the Council and 17<sup>th</sup> by PLWH/A.
- On average, about 17% of PLWH/A say they need health insurance continuation, and even less (9.5%) report to have received the service in the past year.
- Health Insurance continuation has a moderate service gap. Heterosexual, re-incarcerated, and asymptomatic PLWA report the greatest gap.
- Those PLWH/A accessing the service, say they received an average of 8.9 payments during the past year, with re-incarcerated PLWH/A receiving fewer payments.
- Among sex and risk groups, IDUs report the lowest need, and have received less payments in the past year.
- Among ethnic populations, Anglos indicate the greatest need for health insurance continuation. Latinos report a very low need for the service, and report to have received less services than other populations in the past year.
- For PLWH/A in different regions, rural PLWH/A report the greatest need, while urban PLWH/A say they received fewer payments in the past year.
- Among special populations, re-incarcerated PLWH/A report having the lowest need for health insurance continuation, and only 1.5% reported to have received the service during the past year.
- Symptomatic PLWA need and receive more payments than those at other stages of infection.



### Health Insurance Continuation – Qualitative Comments

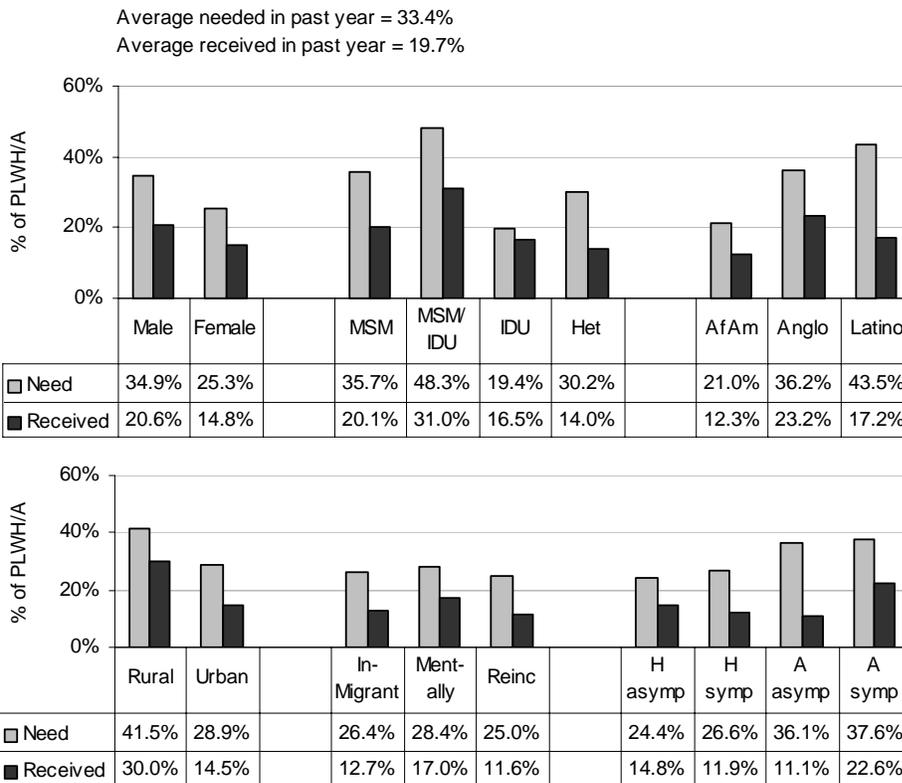
Health insurance continuation only provides payments for those who have insurance, thus the number of PLWH/A who can access the service are limited. For those who access the service, it works well.

*A female Latinos says, “Up until now I have no service barrier.... Through social services, who pays my medical insurance, I receive medical care. And when I need emotional help I have had the help of a therapist.”*

The most consistent, theme in the focus groups, however, was lack of knowledge about the service. A male Latino MSM says, *“I am confused about my medical insurance. CCSS assists me with COBRA. I have Culinary Insurance from where I used to work, but I always get bills. Right now, Denise at the Wellness Center is checking on something for me but hasn't called back.”* A white MSM says, *“I need expert help. I just lost my insurance coverage and I am not sure where to turn to right now.”*



## Emergency Financial Assistance



	Median # in the past year
<b>Sample</b>	<b>2.0</b>
Male	2.0
Female	1.2
MSM	2.0
MSM/ IDU	2.5
IDU	2.0
Het	1.7
AfAm	1.0
Anglo	2.0
Latino	2.0
Rural	2.0
Urban	1.0
In-Migrant	3.0
Mentally	2.0
Reinc	2.0
H asymp	1.0
H symp	2.0
A asymp	3.0
A symp	2.0

### Top Barriers

- I was not eligible for the service.
- Not knowing who to ask for help.
- There was too much paperwork or red tape.
- Not knowing that the service or treatment was available to me.
- Not knowing which organization to go to for the service.
- The people providing services to me are not helpful.

### Highlights

- Emergency financial assistance is the 10<sup>th</sup> ranked need among PLWH/A and is ranked 13<sup>th</sup> by the Council.
- On average, about a third of PLWH/A say they need emergency financial services, and less than a quarter report to have received the service in the past year.
- Emergency financial assistance has the second largest service gap of all other services. Latinos PLWH/A and asymptomatic PLWA indicate the greatest gap.
- Those PLWH/A accessing the service, say they received an average of 2 payments during the past year.
- Among sex and risk groups, MSM and MSM/IDU report the greatest need, and having received more payments in the past year. IDUs indicate the lowest need for the service. Heterosexuals, females and IDUs say they received less services last year.
- Among ethnic populations, Latinos indicate the greatest need. African Americans indicate having received less services during the past year, than other populations.
- Among special populations, re-incarcerated PLWH/A report having received less services during the past year.
- Among stages of infection, symptomatic PLWA have the greatest need and receive the most payments.



### DEFA – Qualitative Comments

At least one third of PLWH/A are low income and have occasional need for assistance in paying bills. The difficulty of making essential payments on SSI was noted by a Latino female who said, *“More economic assistance is also necessary, and lots of times I can’t request it because the people who administer it have their preferences. It should be equal because we all need it. There is no longer any type of assistance. I receive \$530 for this disability, \$124 in stamps and I can’t stretch it. I pay \$390 in rent, I pay the doctors, I pay electricity...there is no help.”* A recently diagnosed Anglo MSM said, *“The hard thing for me is I’m on the Section 8 housing. I have this limited income, and I live in a nice place, but it takes every penny that I have to live there, and the electric bill is killing me as well.”*

The biggest barrier to obtaining the service is the red tape and eligibility criteria. An undocumented Latino said, *“If you don’t take the paper with the court notice to pay the bills, the case manager won’t help you. I don’t like that. How am I going to wait for them to cut my electricity and then have to pay to reconnect it?”*

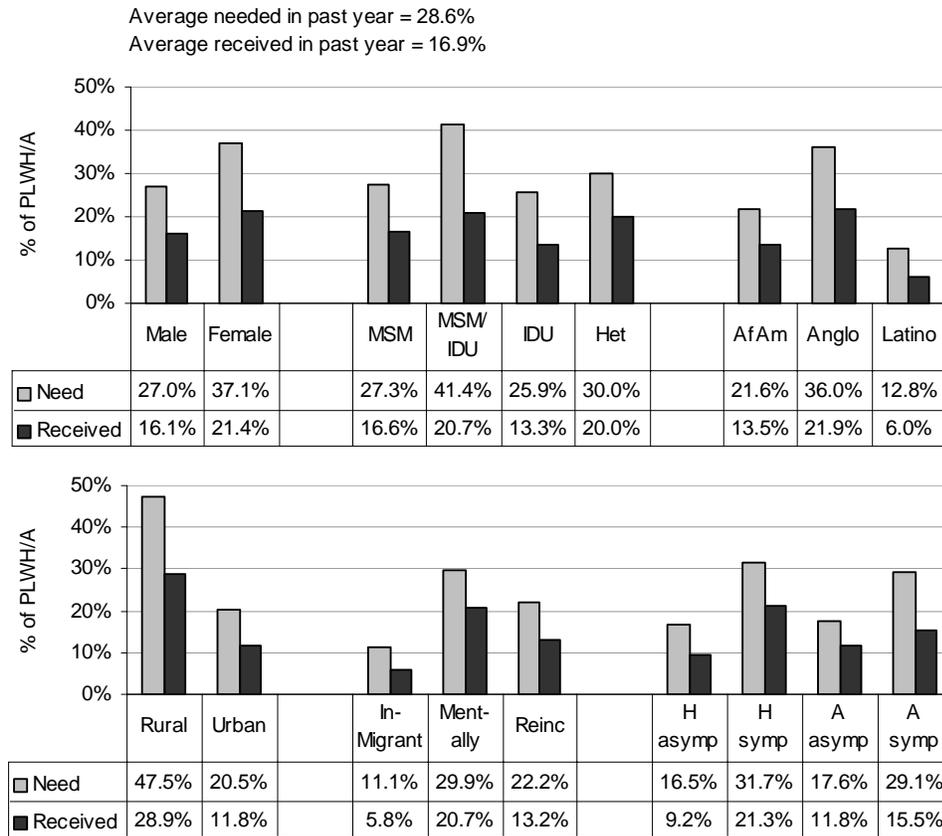
(Rules) A Latino IDU male said, *“The one time I needed help paying utilities I was told my income was too high and there were no funds available. I didn’t go to the support group for about one-two months after that. The next time I was told how good it was to see me and why didn’t I bring my utility bills in since funds were available now. When I needed help I couldn’t get it, and now that I’ve paid my bills on my own they want to offer it to me.”* An African American MSM said, *“This is the first state that considers the phone a luxury. When you are disabled, how is the phone a luxury? You need to dial 911, how is that a luxury?”*

A 19 year old African American heterosexual male said, *“...”I don’t understand why I need to have a nurse in order to get emergency money from [an ASO].”*

A 53 year old Latino MSM said, *“I asked for help at [the Latino focused ASO] with rent, bills, and food, but they told me I didn’t qualify because my income is too high. They don’t understand that my check varies because I have tip income.”*



## Client Advocacy



	Median # in the past year
<b>Sample</b>	<b>2.0</b>
Male	2.0
Female	2.0
MSM	1.0
MSM/IDU	4.1
IDU	1.2
Het	2.0
AfAm	2.0
Anglo	1.3
Latino	1.7
Rural	2.0
Urban	2.0
In-Migrant	1.0
Mentally	2.0
Reinc	2.5
H asymp	3.0
H symp	1.0
A asymp	1.5
A symp	2.0

### Top Barriers

- Not knowing who to ask for help.
- Not knowing which organization to go to for the service.
- Not knowing that the service or treatment was available to me.

### Highlights

- Client advocacy is ranked 13<sup>th</sup> by PLWH/A and 15<sup>th</sup> by the Council.
- Typically, just over a quarter of PLWH/A report a need for advocacy services, and 17% indicate receiving the service in the past year.
- Those PLWH/A accessing the service say they receive, in general, 2 contacts during the past year, with MSM/IDUs indicate having received more contacts.
- Client advocacy ranks 4<sup>th</sup> in services having the largest service gaps. Females, MSM/IDUs and rural PLWH/A indicate the greatest gap.
- Among sex and risk groups, MSM/IDUs report the highest need.
- Among ethnic populations, Anglos indicate the greatest need for advocacy services. Latinos report a very low need for the service, and report to have received less services than other populations in the past year.
- For PLWH/A in different regions, rural PLWH/A report the greatest need, while urban PLWH/A say they received less services in the past year.
- Among special populations, in-migrant PLWH/A report having the lowest need for the service, and only 5.8% reported to have received the service during the past year.
- Among stages of infection, the need for client advocacy services appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater need for the service than asymptomatic PLWH/A.

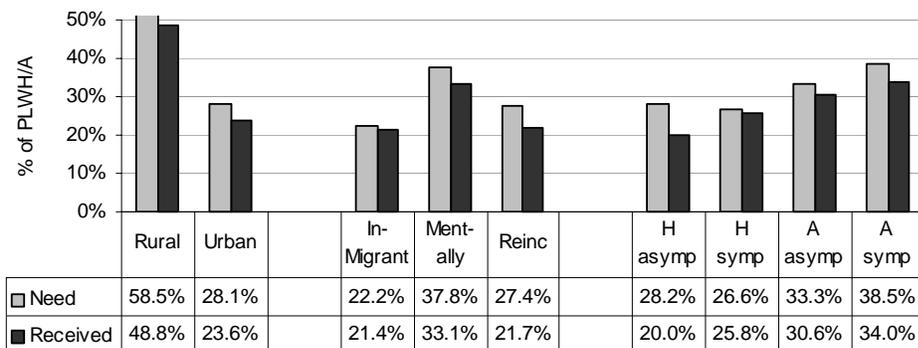
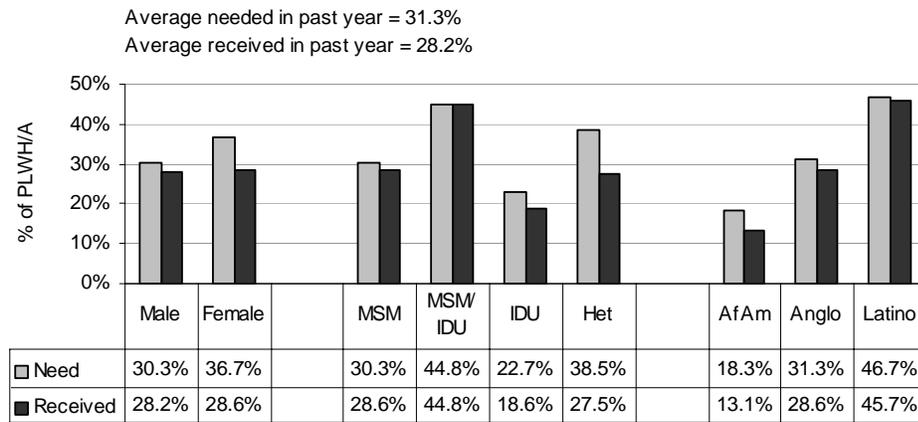


### Client Advocacy – Qualitative Comments

From the focus group comments, many PLWH/A are unclear about the difference between client advocates and case managers. The need, however, was made clear by a heterosexual female, who said, *“At the [medical ASO] I feel like I don't get the same quality of care as if I were paying out-of-pocket or with private insurance. I feel confused about my care sometimes, or that nobody really listens. I feel I need a client advocate or someone to help me sort through the system and help me before I really get seriously ill. Sometimes they give me different information and then they deny it. I feel frustrated and sometimes miss appointments because I feel like they're not going to help me anyway. That's my pet peeve, that no one really listens to my health issues.”*



## Peer Counseling



	Median # in the past year
Sample	10.0
Male	11.2
Female	9.3
MSM	9.1
MSM/IDU	12.0
IDU	10.6
Het	9.8
AfAm	3.0
Anglo	8.0
Latino	20.0
Rural	8.0
Urban	15.0
In-Migrant	20.0
Mentally	12.0
Reinc	5.0
H asymp	12.0
H symp	8.0
A asymp	13.0
A symp	12.0

### Top Barriers

- My state of mind or mental ability to deal with the treatment.
- My physical health has not allowed me to get to the place.
- Not knowing who to ask for help.

### Highlights

- Peer counseling is the 11<sup>th</sup> of priority to PLWH/A and ranked 19<sup>th</sup> by the Council
- On average, 31% PLWH/A report a need for peer counseling sessions, and 28% have attended sessions in the past year.
- Those PLWH/A accessing the service, say they received, in general, 10 sessions during the past year, with re-incarcerated PLWH/A having received more sessions.
- Peer counseling presents a low service gap. Females, African Americans, rural PLWH/A and asymptomatic PLWH indicate the greatest gap.
- Among sex and risk groups, MSM/IDUs report the highest need, and having attended more sessions in the past year.
- Among ethnic populations, Latinos indicate the greatest need and having attended more peer counseling sessions. African Americans report a low need for the service, and report to have attended less sessions than other populations in the past year.
- For PLWH/A in different regions, rural PLWH/A report the greatest need, while urban PLWH/A say they received less sessions in the past year.
- Among special populations, the mentally ill PLWH/A report having the highest need for the service, and have attended more sessions during the past year.
- Among stages of infection, the attendance of peer counseling sessions appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater attendance than asymptomatic PLWH/A.



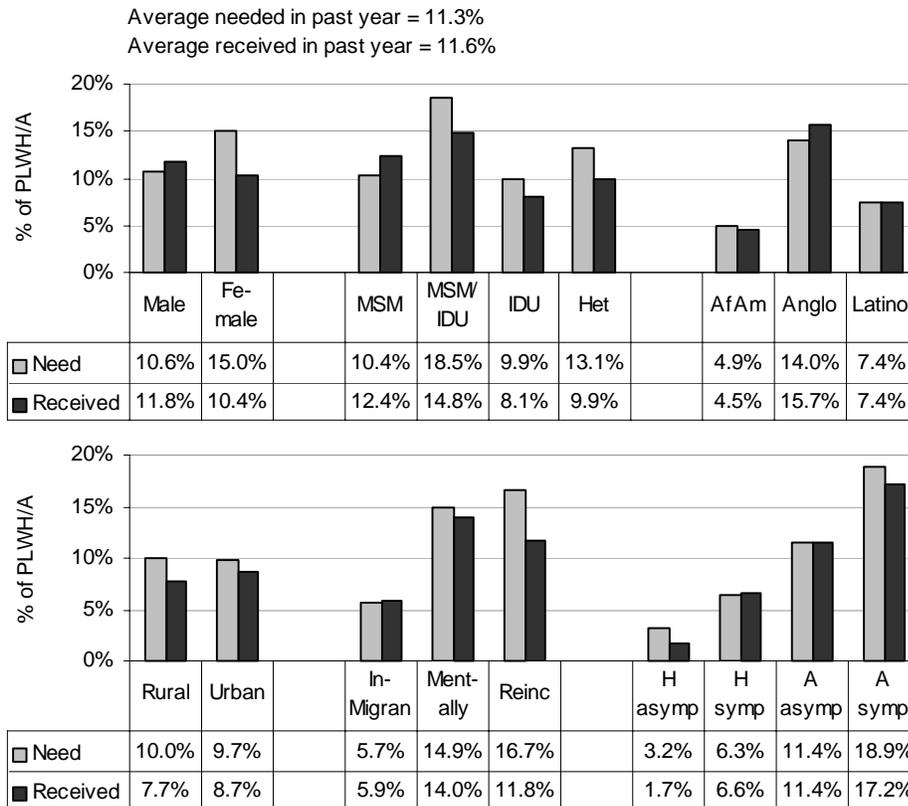
### Peer Counseling – Qualitative Comments

There was limited discussion in the focus groups about peer counseling. One theme, however is the need for information, and peer groups was one avenue cited to get current information. An in-migrant said an agency “*had a rap group and I went there and they told me about [another agency] and different other doctors. That's the best way to hear about doctors is through other people who have gone to them.*”

There is some sentiment that groups were used in a manipulative manner. A Latino IDU male said, “*At [the Latino focused ASO] the support group is not well directed and does not provide moral or emotional support. The presentations should include visits from speakers like doctors or counselors; instead it's just a front or smokescreen. The support group is used as extortion or blackmail if clients don't attend group regularly they can't get assistance. Food vouchers are passed out as a bribe to those who attend. Some people can't go on one occasion or another, and if they ask for vouchers the next day, they are told there are none. I maintain contact with [the Latino focused ASO] because they are within the Latino community and I go for information, etc. But the support group shouldn't be used this way to control clients; we shouldn't be obliged to go as a condition of receiving help. We should be getting more information and orientation from the group. Something to help us improve the quality of life, not just for gossip and conflict.*”



## Assistance taking medications as prescribed - Adherence Assistance



	Median # in the past yr.
<b>Sample</b>	<b>4.6</b>
Male	7.2
Female	4.0
MSM	6.3
MSM/IDU	12.3
IDU	5.4
Het	3.4
AfAm	3.2
Anglo	6.0
Latino	21.4
Rural	2.0
Urban	4.5
In-Migrant	55.0
Mentally	4.0
Recinc.	11.5
H asymp	3.0
H symp	6.0
A asymp	4.0
A symp	6.0

### Top Barrier

- Insufficient response rate for this item.

### Highlights

- Adherence assistance was ranked 19<sup>th</sup> by PLWH/A and 21<sup>st</sup> by the Council.
- On average, few PLWH/A (11.3%) perceive that they currently need the service. Only 11.6% report to have received the service in the past year.
- Although adherence assistance is not a top priority, PLWH/A typically report having received more assistance with their medications than they needed during the past year. Females, heterosexuals, and the reincarcerated express to have needed the service more than they have received it during the past year.
- Those PLWH/A accessing the service say they received an average of 4.6 visits during the past year. Latinos and In-migrants received more assistance with their medications.
- Among sex and risk groups, females, and MSM/IDU express the greatest need.
- Among ethnic populations, African Americans report a very low need for adherence assistance, and to have received the service during the past year.
- Among special populations and stages of infection, in-migrant and asymptomatic PLWH report a low need for adherence assistance. Asymptomatic PLWH say they received a very low level of assistance during the past year.



### Adherence – Qualitative Comments

Few focus group participants said they participated in any formal adherence programs. Several participants said they had difficulty with adhering to their drug regimen. For many their doctor was the main contact for adherence. A heterosexual female said, *“I was diagnosed with the virus in 1985. I do take the cocktail. I’ve been on them a while, and now I’m undetectable and I’m happy as a little lark, going on every day, taking the medicine. ... The medicine doesn’t make me sick. I can go and do a blood draw and my doctor will say my viral loads are high. I’ll say, ‘But doctor, I get so nauseated with it.’ He’ll say, ‘I tell you what. We are going to switch the medicine.’ He will switch it until it’s something your body agrees with. My body agrees with it. Sometimes I have difficulty eating with an appetite, but that’s about all. That’s about 15 years, so that’s not bad. So I am living with it. You can live with the virus and you can live healthy and you can live a successful life, but you have to take care of yourself.”* A heterosexual female warns, *“It is important to get the medicine that works for you and you can’t do that just with one doctor’s visit or taking the medicine one time. You’ve got to go for yourself and see what works for you.”*

Timing is sometimes mentioned as the barrier. An Anglo MSM said, *“I couldn’t take them at two specific times during the day, because I have 6 medications. Two I have to take in the morning, one on a full stomach, one on an empty stomach and then one more at noon, the other three at night, one before I eat, one after I eat, one while I’m eating. I don’t know which pills are which. My doctor can’t explain it to me. I just want one pill for the morning, one pill at night. Put it in a big old capsule. I tried it for like two weeks and I just can’t take it. I can’t do it. I kept getting scattered brain and I would forget which pill was for what and what time of day and how many of them, so I said no.”*

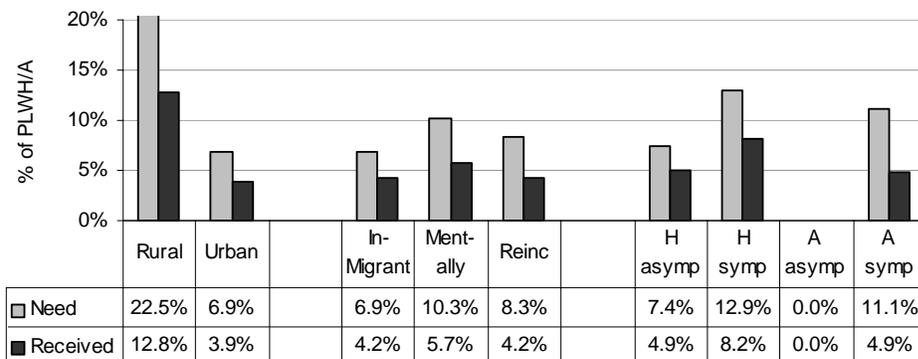
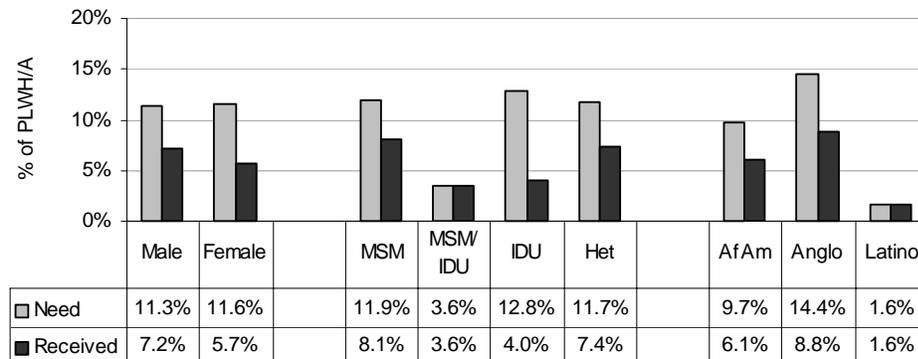
An African American female said, *“As soon as I found out I was infected they put me on something that broke me out real bad in a rash, hives and everything. They switched and put me on something else. It made me cramp up real bad. My insides were cramping to the point where I was paralyzed. They put me in the hospital for two days. It just paralyzed me. They put me on the third one and it made my lips swell; they popped out huge and they were red and bloody. I had a reaction to four different medications. My T-cells were up at 1659. They dropped down to 11 after I had started taking it. Then the second medication they put me on dropped down to 8. The third medication I dropped down to 500 something. They said they were going to wait. They put a gap in there. I went back up to about 800 and then they gave me that fourth medication and dropped me back down to 500 and something. So ever since then I have not been on anything. That was in my first year.”*

A few participants noted that the doctors do not spend enough time with them. An African American IDU female said, *“Sometimes I feel the doctors are not really aware of our condition as they should be. They are not taking the time to get to know me. There is no physical examination on a yearly basis. They just check basic stats and go by what we tell them. They should be more precise and knowledgeable about the medications they give people. I’m very afraid of the side effects. That’s why I haven’t taken them yet.”*



## Health and Treatment Education/Referrals

Average needed in past year = 32.8%  
Average received in past year = 3.0%



	Median # in the past year
Sample	3.0
Male	5.8
Female	1.8
MSM	6.0
MSM/IDU	12.0
IDU	2.0
Het	1.3
AfAm	4.9
Anglo	4.4
Latino	2.0
Rural	6.0
Urban	1.5
In-Migrant	5.0
Mentally	2.5
Reinc	1.5
H asymp	2.0
H symp	10.5
A asymp	0
A symp	6.0

### Top Barriers

- Not knowing which organization to go to for the service
- Not knowing who to ask for help
- Not knowing that the service or treatment was available to me.

### Highlights

- Health education is not a top priority for PLWH/A or the Council.
- On average, 11% of PLWH/A report a need for health education services, and only 7% report to have received the service in the past year.
- Those PLWH/A accessing the service, say they received an average of 3 sessions during the past year, with heterosexual PLWH/A and asymptomatic PLWA indicate having attended fewer and no sessions, respectively.
- Health education presents a very low service gap. Females, Anglos, and rural PLWH/A indicate the greatest gap.
- Among sex and risk groups, IDUs and heterosexuals report the highest need; MSM/IDU say they have the lowest need for health education sessions in the past year.
- Among ethnic populations, Latinos indicate the lowest need and having attended less health education sessions. Anglos report the greatest need.
- For PLWH/A in different regions, urban PLWH/A report the lowest need, while rural PLWH/A say they received more sessions in the past year.
- Among special populations, the mentally ill PLWH/A report having the highest need for the service, and have attended more sessions during the past year.
- Among stages of infection, the attendance of health education sessions appears to increase with onset of symptoms, such that symptomatic PLWH/A indicate a greater attendance than asymptomatic PLWH/A. Interestingly, none of asymptomatic PLWA say they received health education in the past year.



### HERR – Qualitative Comments

Although a small percentage of PLWH/A said they needed treatment and prevention education, when probed about barriers lack of information was one of the top reasons for not accessing services.

Some participants recognized the need for education. An Anglo female said, *“I would say an important service is education, updated education. I'm reading stuff all of the time. We need to have it frequently.”*

However, several participants said that the ASO did not freely provide information. A 55 year-old Anglo MSM said, *“I go down to California and seek a lot of information on my own. There is so much there of that type of treatment and we have absolutely nothing, so there is no support. This has been going on for 3 years in my head and it's driving me absolutely crazy.”*

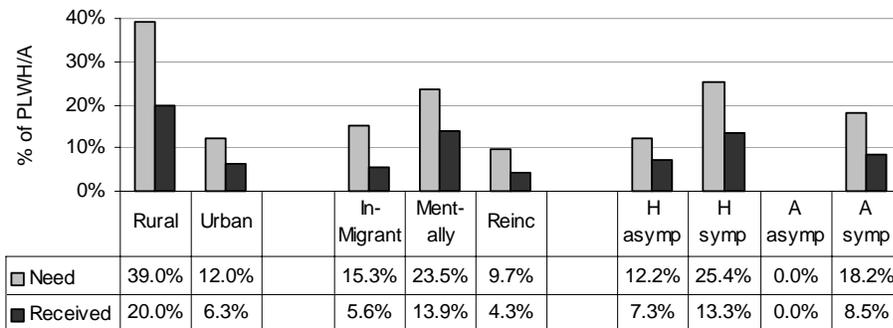
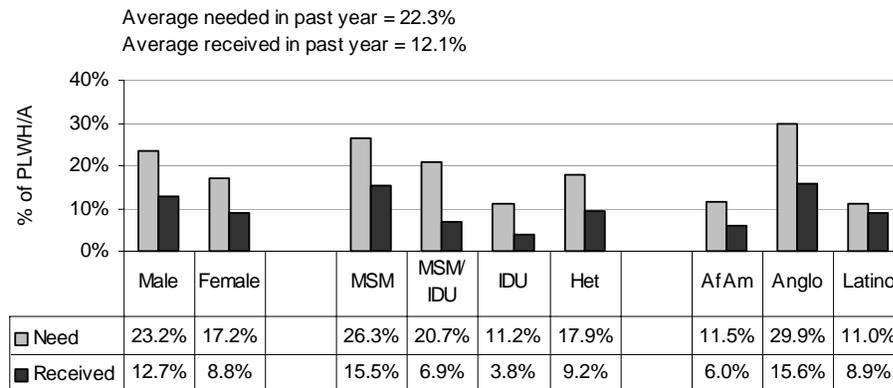
An Asian/Pacific Island heterosexual male said, *“I would like more information on HIV available. Everything is fine with the services but I need more information about the disease.”*

An Anglo IDU male said, *“We need education resources like a clearing house for information on HIV/AIDS, etc., as well as AZT therapies. We also need increased awareness and services for Hepatitis C for those co-infected with HIV because Hepatitis C numbers are increasing.”*

An African American heterosexual male said, *“On the west side (zip code 89106), there is a high rate of infection and no attention to the area. Lots of people are infected and infecting others, all the time in denial. We need services and attention to this community.”*



## Complimentary Treatment



	Median # in the past year
Sample	4.0
Male	4.0
Female	6.6
MSM	6.0
MSM/ IDU	1.6
IDU	12.2
Het	3.7
AfAm	2.9
Anglo	6.0
Latino	4.6
Rural	5.0
Urban	3.0
In-Migrant	6.0
Mentally	4.0
Reinc	2.0
H asymp	3.0
H symp	1.5
A asymp	0
A symp	8.0

### Top Barriers

- Not knowing who to ask for help
- I can't afford the service
- Not knowing which organization to go to for the service

### Highlights

- Complimentary treatment is ranked 16<sup>th</sup> by PLWH/A and ranked 26<sup>th</sup> by the Council.
- On average, slightly less a quarter of PLWH/A report a need for complimentary care, and only 12% report to have received the service in the past year.
- Complimentary care has the fifth largest service gap. Anglos and rural PLWH/A presents the largest service gap.
- Those PLWH/A accessing the service, say they an average of 4 sessions during the past year, with African American PLWH/A and asymptomatic PLWA attending fewer sessions.
- Among sex and risk groups, MSM report the highest need having received more of the service in the past year.
- Among ethnic populations, Anglos report the greatest need. Latinos and African Americans indicate a low need and having received less visits.
- For PLWH/A in different regions, rural PLWH/A report the greatest need..
- Among special populations, re-incarcerated PLWH/A report having the lowest need for the service, and have received fewer visits during the past year.
- Among stages of infection complimentary treatment visits appear to increase with onset of symptoms, such that symptomatic PLWH/A indicate greater visits than asymptomatic PLWH/A.



### Complementary Care – Qualitative Comments

Several participants noted a need for complementary care. A 55 year old Anglo MSM said, *“I think we have a lack of services here in the holistic and alternative. I would like every single thing; if it's available, why not;...I have that choice. Holistic is not the same [as prescribed medication]-- it is totally different. I know I'm not going to have any side effects. That's for darn sure. There doesn't seem to a negative for me at all.”*

For many it was not seen as alternative medication, but as complementary to their antiviral medication. A 55 year old Anglo IDU male said, *“I went against my first physician's strongly urge that I[get on AZT]. At that time it was still a high dose thing and people were dropping like flies when they took that stuff. I went into alternative care and nutritional support, various herbs and so forth, and committed myself to learn as much as I could about the disease and about alternative treatments. I'm still using alternative treatment but I'm not leaning so heavily on it anymore, but just at this time. I'm also on the cocktail right now.”*

An Anglo IDU male said, *“The doctor likes to prescribe drugs. The drug companies are like the world's biggest industry, so they will tell you to take your drugs regularly, but we need to have an arrangement with our doctors where we explore alternatives and so forth and the doctor doesn't just dismiss them out of hand, but they are willing to work with us in helping us to establish a protocol and that there is some understanding of what interactions are going on between the prescribed drugs and certain herbs and different things that we might be exploring.”*



## **13. CONCLUSION**

### **Epidemiology**

At the beginning of 2001, the Las Vegas EMA documented 4,122 people living with HIV/AIDS, with 57% living with HIV who had not progressed to AIDS, and 43% diagnosed with AIDS. Based on the criteria for antiviral treatment, where all PLWA, plus HIV symptomatic are recommended for treatment, 52% of PLWH/A would be eligible for treatment. In addition, there are roughly 20% of HIV positive persons who have a current t-cell count below 350, suggesting that 63% of PLWH/A are likely to need medical treatment for their infection.

Anglos represent 60% of PLWH/A, African Americans represent 24%, Latinos 14%, and other ethnicities about 2%. Women represent 7% of all PLWH/A and 41% of all women are African American. Heterosexuals represent 10.5% of the PLWH/A, and three-quarters of the heterosexuals are women and a third of the IDUs are women. Thirty-five percent (35%) of women living with HIV report living with children or teens. MSM represent over half (52%) of the PLWH/A, those “not classified” represent 15%, IDUs represent 14%, heterosexuals 11%, and MSM/IDUs 7%.

The trend data reveal that in absolute numbers, males (3,410), MSM (2,167) and Anglos (2,461) continued to add the largest number of HIV/AIDS cases each year through 2000. Between 1992 and the beginning of 2001, males have decreased as a proportion of the epidemic from 85% to 83% of the epidemic. During the same period, MSM have increased from 46% to 53%, and Anglos, have decreasing from 66% to 60% of PLWH/A.

Ninety-six percent (96%) of PLWH/A live in Clark County, 3% in Mohave, and about 1% in Nye.

To qualify for ADAP a PLWH/A has to be below 400% of the federal poverty level, and the Medicaid eligibility for PLWA is between 133% to 200% poverty level. For a single person poverty level is about \$8,600. Those on Medicaid are not eligible for ADAP. In the EMA, 87% of PLWH/A have income below \$17,000. Ninety-six percent (96%) have incomes below \$35,000. That suggests that the vast majority of PLWH/A meet the income threshold to receive medication reimbursement.

### **Health Care System for PLWH/A**

#### Insurance

More than one third of the PLWH/A who were surveyed reported having no form of insurance. Women (43%) and MSM/IDU (39%) are most likely not to have insurance. Insurance continuation payments are used by only very small number of PLWH/A who had health insurance and were in jeopardy of losing it.



Women living with HIV and AIDS tend to have less insurance than men. In theory, with State Children's Health Insurance Program (SCHIP) and other Medicaid related programs for women usually have more insurance and this finding suggests the need for further research to determine why women are under-insured.

Between 65% and 70% of PLWH/A have some form of insurance. The most common forms are Medicare (35%) and Medicaid (35%), with 13% reporting both. Twenty-two percent (22%) of PLWH/A report having SSDI and 14% report private insurance. Those qualifying for Medicaid in Arizona have AHCCCS, a form of Medicaid managed care. Nevada's Medicaid eligibility criteria are among the toughest in the nation, which may explain the relatively low number of women insured.

Based on the number of non-insured, about a third of those infected rely on Ryan White funded services (or other low or no cost services) to provide primary health care and medication. They are disproportionately women, African American, and Latino. For other wrap-around services such as case management, Ryan White funded services are the primary source of funding.

#### Drug Reimbursement

Self reports of drug reimbursement indicated that many PLWH/A do not know who pays for their drugs. It is likely that Medicaid pays for a good proportion of the drugs. Twenty-one percent (21%) reported that ADAP paid for some of their drugs. Five percent (5%) say private insurance, 6% veterans benefits, 4% out-of-pocket, and 12% other sources such as compassionate care programs, trials, and clinic programs. PLWH/A ranked medication reimbursement as the 14<sup>th</sup> highest need, and indicated only a small gap between perceived need and reported utilization.

#### Entitlements and Benefits

In addition to the RWCA funded services, PLWH/A access health care through non-insurance benefits, including VA, Clark County Social Services, WIC, and through drug reimbursement programs. About 8% of the PLWH/A report VA benefits. Of those 8%, about 48% (about 4% of the all PLWH/A) report having no insurance.

Eleven percent (11%) of PLWH/A report receiving Clark County Social Services (CCSS) benefits. While CCSS is not a form of health insurance it provides PLWH/A in need of medical care access to a medical provider. Over 7% of the women of child bearing age report WIC services.

PLWH/A receive a variety of other services, such as food, housing, and financial assistance that are funded through a variety of sources. These entitlement and benefits are triggered by low income and disability. About 50% of PLWH/A report being on long term disability. As expected, the rate of disability is higher among those infected earlier, such as males, Anglos, and PLWA.



Income supplements include Supplemental Security Income (SSI), Temporary Assistance to Needy Families (TANF), emergency financial assistance, rent assistance, food stamps, and long term and short term disability payments. More than one quarter (29%) report receiving food stamps, and over 20% report receiving rent supplements. About 18% of PLWH/A report receiving SSI. MSM and Latinos are less likely to receive it than other populations. About 8% of the PLWH/A report receiving direct emergency financial assistance (DEFA), usually used for utilities, rent, or emergency medical treatment. Anglos and those in the rural areas are more likely to receive DEFA.

## **Co-Morbidities**

### Homelessness and Housing

About 7% of PLWH/A reported being currently homeless or in some form of transitional housing. The instability of housing becomes more evident when PLWH/A are asked if they have been homeless or in transitional housing in the last two years. Of those PLWH/A interviewed, 19% have been homeless sometime in the last two years, and 16% have lived in some form of transitional housing. IDUs, in-migrants, and African American, recently incarcerated, and symptomatic PLWH/A are more likely to be homeless or have unstable housing than other populations living with HIV/AIDS.

### Substance Abuse

The co-morbidity of substance use and HIV includes drugs that are typically injected such as heroin and crystal meth, but also includes non-injecting substances such as crack and “party drugs” such as ecstasy and poppers. These substances have been related to unsafe sexual practices that place individuals at high risk for HIV infection.

Of the opiates, 47% of the PLWH/A report ever using crack/cocaine and 19% report ever using heroin. About 6% of PLWH/A who use crack or cocaine say they continue to use the drugs frequently (more than once a week), and about 3% of PLWH/A who ever used heroin report using heroin in the past 6 months. African Americans and users of other substances are more likely to use crack than other populations. The recently incarcerated, mentally ill and symptomatic PLWH/A are among the highest users of heroin, indicating the high level of co-morbidities among these populations.

More than a quarter of the PLWH/A report using poppers, with about three percent saying they use it monthly. MSM and MSM/IDU are among the heaviest users of party drugs. Rural PLWH/A report a higher use of party drugs than urban PLWH/A.

### STDs

About 17% of all PLWH/A report having been diagnosed with Hepatitis C in the last two years. Predictably, it is significantly higher among IDUs (49%) and MSM/IDUs (41%). Among ethnic communities, the incidence of Hepatitis C is higher among African Americans (19%). Twenty-



five percent of the recently incarcerated have been diagnosed with Hepatitis C. Next highest incidence of STDs is hepatitis A or B (8%). It is significantly higher among Latinos (24%) and there is not much difference in incidence by risk group.

### 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.

### **Out-of-Care**

While there is no way to sample out-of-care reliably, the multiple methods and extensive search conducted for out-of-care would suggest that those found are reasonably representative of those that know their infection status and have had a period of more than 12 months when they did not seek primary care in the past five years.

Out-of-care are more likely to be African American and heterosexual and they appear to be just as likely to have been infected for a long period of time as a short period of time. They are poor, but wealthier than the average PLWH/A, with 78% of those interviewed making over \$17,000.

As expected, fewer of those out-of-care have been told that their infection has progressed to AIDS. In the survey of PLWH/A 49% have been told they have progressed to AIDS, while 32% - (N=14) of the out-of-care report having been told that their HIV had progressed to AIDS.

Out-of-care are more likely to be newly infected and more likely to report being asymptomatic. The majority of the out-of-care are unaware of their CD4 count, but of those that do know their counts, 45% report current t-cell counts under 200.

The top five reasons for not taking medication are the same as the top five reasons for all PLWH/A; forgetfulness, difficult schedule, side effects, ran out, and didn't want to take them.

The overall picture of the out-of-care shows that they are not only those with more difficulty accessing care, but also fairly active and knowledgeable HIV positive individuals who have



delayed care because they were healthy, didn't like the side effects of medication, and had activities and work that kept them busy.

## **Improved Outcomes**

### Death Rates

Death rates have declined among all ethnic groups between 1995 and 2000, with the sharpest decline among African Americans. Still, in 2000, the death rate remains substantially higher among the African American population and continues to be between five to six times the rate of Anglos and Latinos, respectively.

Since 1977, Latino death rates have remained the lowest among the ethnic groups. In 2000, Latinos have the lowest death rate, followed by Anglos and African Americans. Since the precipitous decline noted from 1995 to 1996, the death rates among Anglos and Latinos have leveled off with both communities displaying similar patterns.

The leveling of the death rate among Anglo and Latinos suggests that the impact of medication has reached a plateau. Significant side effects and fatal infections continue to manifest themselves among PLWA, and adherence is far from complete.

### Quality of Life

Almost 90% of PLWH/A say their current physical health is excellent (12%), good (34%), or fair (43%), and about 85% say that their physical health has not gotten worse since they started treatment. Forty-six% (46%) say their physical health is better.

Similarly, 87% of PLWH/A say their current emotional health is excellent (13%), good (35%), or fair (38%), and 75% say their emotional health has not gotten worse since they started treatment.

Those doing worse physically and emotionally, tend to be HIV or AIDS symptomatic.

## **Medication and Adherence**

Over 70% of PLWH/A are currently taking medicines to treat their HIV infection, and 88% of those are currently taking a drug cocktail. MSM/IDU, substance users, those with a history of a mental illness, and PLWA are most likely to be taking medication. Youth and asymptomatic HIV are least likely to have taken medication.

While nearly half of PLWH/A report never skipping their medications, six percent have stopped taking the medicines. Notably, symptomatic PLWH/A are more likely to stop taking their medication than asymptomatic PLWH/A. The symptoms themselves may be a trigger for discontinuing the use of the medication. Also, 12% of Latinos and 15% of the undocumented have stopped taking their medications which may be connected to a language barrier regarding



medical case management and ability to communicate symptoms and side effects. MSM of color (13%) and substance users (12%) also have higher rates of stopping their medications.

The top reasons for discontinuing medications for all PLWH/A were forgetting to take them, (57%), not wanting to take them (30%), side effects (28%), and difficult scheduling (24%).

### **Top need, Utilization, and Service Gaps**

The top need, mentioned by 95% of PLWH/A, was primary medical. After that, nearly three-quarters (72%) of PLWH/A said that food pantry service was their top need. Dental care was third with 66%; case management was the fourth with (63%), followed by mortgage or rental assistance (54%). Transportation was the sixth greatest need with 53% of PLWH/A ranking it most needed.

The next set of needs relate to awareness by PLWH/A of the role of nutrition. Fifty percent (50%) expressed a need for nutritional supplements, and 41% expressed a need for nutritional counseling. The ninth ranked need is mental health with 41% expressing a need. Tenth is the need for DEFA (33%).

The Council's 2002 priority and PLWH/A ranking of top needs are similar. The largest difference in rankings is medication reimbursement, with the Council ranking it 4<sup>th</sup> and PLWH/A ranking it 14<sup>th</sup>. The difference may be partially due to a lack of awareness by PLWH/A of the role that is played by insurers or other organizations that provide medications. Other differences in ranking were for food and dental care. PLWH/A ranked food pantry second, while the Council ranked it 6<sup>th</sup>, and PLWH/A ranked dental 3<sup>rd</sup> and the Council ranked it 7<sup>th</sup>.

The third set of needs related to more specific personal needs including peer counseling, group meals, and client advocacy (at about 30% each). Housing related services is the fifteenth most needed service (23%) by PLWH/A although it is ranked 5<sup>th</sup> in priority by the Council. It is more likely to be needed by the homeless, recently released, and those in transitional housing.

PLWH/A agree with the Council on the low ranking of adherence assistance. The relationship between poor adherence and leveling off of the mortality rate, however, might further be studied.

There are differences by ethnicity, risk group, gender, and location. A larger percentage of females and heterosexuals say they need case management. Females are more likely to need client advocacy, transportation, and nutritional and peer counseling. A greater proportion of males report a need for mortgage/rental assistance.

Far more African Americans and IDUs report needing transportation. African Americans report needing nutritional counseling, housing related services, group meals, and substance abuse services. Latinos say that medical services are the most important and rank mortgage/rental assistance and nutritional counseling higher than either African Americans or Anglos. A larger percentage of Anglos say they need mental health, client advocacy, drug reimbursement,



complementary care, adherence assistance, and insurance continuation services than Latinos or African Americans.

Rural PLWH/A are more likely than urban PLWH/A to need nutritional supplements (56%), mental health services (44%), and client advocacy (42%).

The largest perceived gaps between needing a service and receiving it are in dental care, direct emergency assistance, mortgage/rental assistance, client advocacy, complementary treatment, nutritional supplements, and mental health.

### **Barriers**

No barriers are ranked as particularly high by PLWH/A. The highest barriers are individual and structural barriers, while organizational barriers are rated, on average, quite low. Males are much more likely to mention structural barriers such as cost and rules and regulations, while females are more likely to mention individual barriers, like knowledge of services. The top barriers for all PLWH/A were not knowing that the service or treatment was available to them, the amount of red tape and paperwork they had to fill out to get the service, not knowing who to ask for help, and not having transportation.

The next highest barriers were not knowing which organization to go to for the service, the people providing services are not helpful, not being eligible to obtain services because of rules and regulations, not knowing the location of the services, could not afford services, and lack of, or inadequate, insurance coverage.

### **Overall Assessment**

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

With the tremendous growth in population and PLWH/A moving into the Las Vegas EMA, the number of persons needing care has grown and will continue to grow significantly, and among all PLWH/A the proportion of MSM will continue to increase. The proportion of Anglos has decreased but still represent 60% of the epidemic. Heterosexuals have increased, but continue to represent only 10.5% of PLWH/A. While the growth of HIV among women and heterosexuals are critical in planning services in the continuum of care, services to treat males and MSM, particularly MSM in communities of color, will continue to be needed the most.

Women appear to be underinsured in the EMA. Particularly for women with families, enrolling them in SCHIP, TANF, and Medicaid should be high priority.

Because PLWH/A are living longer and not progressing to AIDS, they will not qualify for disability, SSI, or SSDI. However, many are likely to be poor and un- or under-insured and consequently, there will be a growing number of uninsured PLWH/A relying on Ryan White to



fund their treatment and care. Although medication reimbursement is the main responsibility of Title II, demand for ADAP is likely to grow. Ways to expand insurance coverage and insurance continuation should be given high priority. The Council's emphasis on assuring medication reimbursement, even though it is not a top priority of PLWH/A seems justified. Also the Council's higher ranking of insurance continuation seems justified. What the differences suggest is the need to educate PLWH/A and case managers of the importance of seeking insurance and entitlements outside of Ryan White funded or reimbursed services.

For primary care and case management, Clark County Health District has been very successful in patching together a set of benefits so that those without insurance have been able to receive care. There will be continued strain on the system, and navigating the system is not transparent to many of the PLWH/A. As the number of uninsured increases, the capacity of clinics will need to increase, especially if the clinics continue to service both those with and without insurance.

Dental care frequently is a top need of PLWH/A and a lower need for Councils. An interesting finding from the needs assessment is that symptomatic PLWH/A display much greater need than asymptomatic PLWH/A. This may indicate that there are significant oral problems among those with more advanced HIV disease that decrease quality of life and hasten the decline of physical health. This might be further explored.

The cluster of services in Las Vegas work well for PLWH/A and improving transportation to them and scheduling services to reduce waiting would improve ratings of services by PLWH/A. Rural services will continue to present a challenge, as the medical expertise does not exist and limited case management capacity leaves many PLWH/A who do not seek information in the dark about available services.

Several indicators in the needs assessment suggest that the communication between PLWH/A, providers, and the grantee could be enhanced. Most of the PLWH/A consider their physician and medical provider their main source of information, case managers are considered less informative. The grantee directly, or through providers, could distribute clearer written material on services. Using the Internet to distribute material on demand could improve distribution to those with computers or access to computers. Training providers in shelters, section 8 housing and clinics and providing appropriate material for their populations could enhance communication efforts. As well as their medical providers, Latinos report that spiritual and religious leaders are among important sources of communication. On the other hand, they say that written material, pamphlets and newsletters are not important at all. This suggests the need for targeting information to the Latino community and taking greater advantage of existing lines of communication.

The lack of emphasis on adherence is troubling. While it is a problem in the EMA, neither PLWH/A nor the Council considers it a priority. Combined with the leveling off of mortality, it suggests a greater need to improve adherence.

As in many EMAs the needs of the PLWH/A are also the needs of poor populations living near the boundaries of poverty. Consequently the need for housing, including rental and utility



assistance, and food services will continue to grow as newly infected tend to be poorer, and those already infected become poor before they qualify for assistance. While the HIV/AIDS care system cannot replace the systems of care for the poor, coordinating care and expanding capacity in housing and rental assistance will help PLWH/A. At the least, more intensive case management training emphasizing links to other State and Federal programs appear to be needed.

The need for substance abuse services seems relatively small. The number of PLWH/A attributable to substance abuse appears to be declining and the demand for services is small. Coordinating and training existing substance abuse programs on HIV/AIDS care is likely to close any gap in service, and encouragement of harm reduction programs that have been effective elsewhere could help the spread of Hepatitis as well as reducing transmission rates.

There appears to be few people out-of-care that wish to be in-care. Extensive case finding found a handful, and the largest message in the exercise was that the gap between the number of projected PLWH/A and those in care can best be explained by those who choose to remain out-of-care, have moved outside the Ryan White Care services to private services, or have moved out of the EMA. Bringing persons into care will most likely depend less on outreach and more on providing drugs with fewer side effects, convincing people in the early stages of infection that care is necessary, and improving the availability of insurance so that those infected, employed, and needing care can access it. An exception is the Latino community that appears to be more hidden. The epidemiology suggests that the overall numbers are small, but the number of Latinos living with HIV and AIDS is dramatically increasing. Finding Latino/a respondents, in spite of bilingual staff and instruments, was difficult. As in-migration grows and infection rates increase, focused outreach and services for Latinos are likely to be necessary.



## **14. ATTACHMENTS**

**Attachment 1 Project Advisory Group Roster**

**Attachment 2 Las Vegas EMA Needs Assessment Survey of PLWH/A**

**Attachment 3 Focus Group Outline for PLWH/A**

**Attachment 4 PLWH/A Demographics**

**Attachment 5 Service Need**

**Attachment 6 Services Received**

**Attachment 7 Service Usage**

**Attachment 8 Service Barriers**

**Attachment 9 Focus Group Coding Schema**

**Attachment 10 Continuum of Care**

**Attachment 11 Out-of-Care Survey**