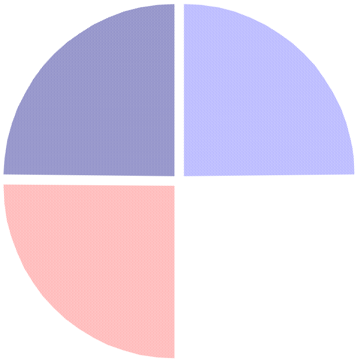


Sacramento
2003 HIV/AIDS NEEDS ASSESSMENT REPORT

Prepared for
The Sacramento HIV Health Services Planning Council

June 2003

Submitted by: Partnership for Community Health, Inc.
245 West 29th Street
Suite 1202
New York, NY 10001

Project Team: Dr. Mitchell Cohen, Ms. Lucia Orellana, Ms. Irene Hung, and Ms. Carol Maytum

Primary Contact: Mitchell Cohen, Ph.D.
Executive Director
Partnership for Community Health
Telephone: 212.564.9790 X 26
Fax: 212.564-9781
E-mail: PCH@pchealth.org

ACKNOWLEDGMENTS

The 2003 Sacramento Eligible Metropolitan Area (EMA) Title I Needs Assessment was a collaborative effort among researchers, service providers, government officials, public health departments, consumers of services, and community members. This broad partnership has created a needs assessment with the input of many key players in providing and receiving HIV/AIDS Care, and the Partnership for Community Health (PCH) in New York City wishes to acknowledge the many individuals, organizations, and institutions who assisted in the design, recruitment, execution, coordination, data analysis and writing of this needs assessment report.

Foremost, PCH would like to thank Alan Lange and Kay Merrill of the Community Services Planning Council. Alan coordinated our activities and meetings and the Council was generous in providing a desk and computer connection.

Several persons at the Grantee, the County Department of Health and Human Services assisted us. Adrienne Rogers was an active participant in meetings and provided us access to the SEMAS database. Alix Gillam, the epidemiologist at the Department of Health and Human Services assisted us in compiling the latest epidemiological data. Robert Nelson gave us excellent feedback throughout the process.

Providers and Council members helped PCH access PWLH/A. Marty Keale, Peter Feeley, Jeff Cowen, Lisa Ashley, John Rambo and Lynn Zender were particularly helpful.

Without the assistance of our Sacramento staff we would not have been able to organize the recruitment of the participants in the survey or focus groups. Ms. Carol Maytum provided coordination. For recruitment of Non-CARES clients, Lynell Clancy and Monica Bernardo overcame significant obstacles in recruiting participants. At CARES, Socorro Padilla and Jesse Davis helped recruit participants.

A special thanks to the individuals trained to conduct the survey in the field. Their enthusiastic participation and commitment to the many communities they represented made it possible to implement a complex survey instrument to a large number of people in a short period of time. We would also like to acknowledge their professionalism in working with clients to collect the data, and adjusting their schedules to accommodate clients who required special assistance.

We would like to thank Hugh Miller and Magda Cooling of Opinions, a professional focus group facility, who gave us a significant discount that enabled us to use their excellent facility. Their staff treated all participants with respect and was helpful in the logistics.

In the final analysis, however, what made the needs assessment possible was the time and effort of the nearly 400 PLWH/A who participated in the survey and focus groups and the many service providers and key informants who participated in the recruitment efforts. They were generous in their time and candid in their responses. The results presented in this report are their collective voice about their service needs and barriers.

TABLE OF CONTENTS

TABLES

FIGURES

ATTACHMENTS

Abbreviations

ADAP	AIDS Drug Assistance Program
API	Asian / Pacific Islander
ASO	AIDS Service Organization
CDC	Center for Disease Control
Council	Ryan White Title I Planning Council
EMA	Eligible Metropolitan Area
HARS	HIV/AIDS Reporting System
HET	Heterosexual
HHSPC	HIV Health Services Planning Council
HRSA	Health Resources and Services Administration
IDU	Injecting drug user
MSM	Men-who-have-sex-with-men
OI	Opportunistic infection
PAG	Planning Advisory Group
PCH	Partnership for Community Health
PLWH/A	Person living w/ HIV/AIDS
RWCA	Ryan White Care Act
SEMAS	Sacramento County Department of Health and. Human Services database
SDPHAO	Sacramento Department of Public Health AIDS Office
STD	Sexually transmitted disease
TB	Tuberculosis
TG	Transgender
VA	Veteran's Assistance
Youth	PLWH/A 24-years of age or younger

1. INTRODUCTION

In December 2002 the HIV Health Services Planning Council (HHSPC) awarded Partnership for Community Health (PCH) a contract to conduct a comprehensive HIV/AIDS Needs Assessment and Comprehensive Plan for Sacramento EMA, including Sacramento, El Dorado, and Placer counties. The goal of the needs assessment is to provide the HIV Health Services Planning Council (HHSPC) with data on HIV/AIDS necessary for effective services planning.

This report presents the needs, unmet needs (or gaps), and barriers to HIV/AIDS care of PLWH/A in Sacramento, El Dorado, and Placer counties. Primary information was obtained through a survey of 383 PLWH/A, 8 focus groups with key populations and key informant interviews with adolescents and parents of HIV positive children.

The report is divided into twelve chapters. The next chapter discusses the methods used to collect and analyze the data. Chapter three is a demographic profile of PLWH/A, taken from the epidemiological data and survey data. The fourth chapter describes the co-morbidities of homelessness, substance abuse, STDs, and mental illness. Chapter five describes the populations by stage of disease and estimates the number eligible for medical care. Chapter six continues the theme of eligibility through the discussion of access to health care, including insurance, entitlements and other benefits.

Chapter seven describes the outcomes of mortality, morbidity, and self reported physical and mental health. Chapter eight describes the medication taken and adherence issues reported by PLWH/A. These behaviors might also be viewed as outcomes of the continuum of care.

Chapter nine discusses the funding, need, demand, and utilization of services. Chapter ten provides feedback on barriers to obtaining HIV/AIDS care services.

Given the emphasis that HRSA is placing on out-of-care, chapter eleven describes the demographics and needs of PLWH/A who have delayed seeking care, are unconnected to care, or who have been out-of-care at some time during their infection.

Finally, chapter twelve provides a summary of the information and makes recommendations to the Council about service gaps.

Conceptual Framework

The conceptual framework for the needs assessment is shown in Table 1-1. Needs, unmet needs, and barriers will be determined for twenty-three different service categories and forty-two sub-services. This needs assessment focuses particularly on the perceived need, the demand, the fulfilled need and the unmet perceived need and need-demand gap. The Comprehensive Plan, to be completed in July 2003, will address the unmet absolute need and the issues of capacity.

Table 1-1 Definition of Needs and Gaps

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

From these four “raw” calculations, four gap measures are calculated.

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

2. METHODS

Three data collection methods were used by PCH for the Sacramento EMA HIV/AIDS Care Needs Assessment:

1. Secondary analysis of existing needs assessments and epidemiological information in order to estimate incidence and prevalence of HIV and AIDS, develop a sampling plan, and obtain mortality and morbidity data as outcome measures for the continuum of care.
2. A consumer survey was conducted among 383 PLWH/A to determine their HIV/AIDS care needs, unmet needs, barriers, and relevant behaviors, such as adherence to medical regimens, drug use, and quality of life.
3. A series of eight 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 quantitative findings from the survey. In addition, one-on-one interviews were conducted with parents of HIV positive children and youth. As part of the process several discussions were held with providers.

A Project Advisory Group (PAG) was formed to provide oversight to the needs assessment process and feedback on survey and focus group tools and draft reports. 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 task force are shown in Attachment 1.

Secondary Analysis

Secondary information included past needs assessments, epidemiological data available from the Sacramento County Department of Health and Human Services Public Health Promotion and Education Division, Epidemiology and Disease Control Branch, and aggregate client data from SEMAS, the central client database for Ryan White Title I. A list of secondary sources is shown in Attachment 2.

Consumer Survey

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. A majority of the interviewers were students from the University of California, Davis.

The survey instrument was designed and approved on March 14, 2003. The process included a draft submitted by PCH and several rounds of revisions based on comments and specifications of the HHSPC and PAG. The final consumer survey is shown in Attachment 3. The initial part of the questionnaire captured key demographics, insurance and benefits, level of care, stage of infection, medication and adherence, and quality of life. Question 43 measures awareness, current need, demand, and utilization of services. The list of services developed by the research team was derived from the continuum of care and includes the twenty-three categories of services funded by Ryan White, and forty-two sub-services that were reviewed by the HHSPC as representing services that were funded, or of interest to, the HHSPC. At the end of each major service category, PLWH/A had an opportunity to say what problems s/he had in obtaining the services.

Following the measurement of service need, PLWH/A ranked different barriers to care. The barriers assessed were based on prior needs assessments conducted by the research team using a multidimensional schema discussed in the Barriers Section later in the report. The final questions in the survey measured drug-use and residency status.

The survey instrument was pre-tested with the interviewers during the instrument training session. The consumer survey was translated into Spanish by Ms. Lucia Orellana of PCH, and checked by a second Spanish translator.

Interviewer Training

Sixteen community interviewers were trained to administer the consumer survey. Interviewers were recruited through flyers posted at provider sites and the university campus and through an on-line employment service. Interviewers were hired based on experience, aptitude, and meeting with senior study staff. Selected interviewers attended a half-day training session conducted by Dr. Mitchell Cohen. During the session the interviewers were introduced to the needs assessment process and the survey was reviewed. Service categories were reviewed, and the difference between knowledge (awareness), current need, demand, and utilization were reviewed. Basic procedures such as circling responses and answering all applicable questions were emphasized. In those questions with a “yes”, “no” option, interviewers were asked to check each questionnaire to assure that each item was complete. Interviewers role-played administering the questionnaire to each other. They were asked to note any questions that were confusing or not clear to them.

Interviewers that were given assignments were asked to report directly to the on-site Project Director, Ms. Carol Maytum. Due to availability and based on the review of the interviewers’ work, the initial pool of sixteen interviewers was subsequently reduced to eight. There was ongoing review of interviewers’ performance in administering the surveys including accurate data collection and ability to work independently in the field.

Incentives

Participants of the consumer survey received a $20 grocery food certificate. Anyone unable to complete the entire consumer survey for reasons such as illness or fatigue still received the incentive. Another incentive for participants to complete the survey was their inclusion in a raffle with a grand prize of a computer.

Sample Design

The survey recruitment strategies were based on a stratified quota sample based on race and risk group, and is shown in Attachment 4. It purposely oversamples specific subpopulations in order to have adequate sample sizes for females, heterosexuals, Latinos and other difficult to reach populations. Because the oversampled subpopulations were known, they were weighted back to their populations-proportionate-to-size in the analysis of all PLWH/A.

Recruitment

Every effort was made to select participants randomly from a wide variety of venues. The study team produced lists of clients by provider agency through the SEMAS database. This list was particularly helpful to identify the agencies frequented by the hard-to-reach populations including youth, females, and heterosexual non-IDU males. The Ryan White funded agencies were directly contacted through personal visits and various memoranda from the research team describing the Needs Assessment project and underscoring the need for assistance locating particularly hard-to-reach populations.

Providers and recruiters were given detailed instructions on selecting participants randomly. In order to recruit a representative sample while maintaining the confidentiality of PLWH/A, case managers, receptionists, and other provider staff recruited designated participants, or substitutes of the same profile. In instances where designated respondents were not contacted, two callbacks were required before substitution was allowed. In addition, with the permission of the providers, individuals were recruited when they sought service. Some interviews were scheduled in advance while other participants were recruited through "intercepting" them at providers. In order to protect the confidentiality of PLWH/A, there was no contact with clients without the participants' explicit permission.

Difficult to reach populations and out-of-care participants were recruited through outreach by PCH staff. Notably, those clients who were homebound or were seriously disabled with dementia are underrepresented in the sample.

Recently incarcerated PLWH/A contacted through their parole offices were surveyed and asked to participate in a focus group to discuss their experience accessing care while incarcerated and upon release.[1]

Interviewing

Interviewing was conducted over three months from mid-March through the end of May 2003. There were three types of interviews: 1) interviewer assisted where the interview was conducted in a group setting and the participant received assistance on questions with which he or she had difficulty, 2) one-on-one where the person was not at a sufficient cognitive or literacy level, and 3) over the phone where participants could not travel or were concerned about their confidentiality.

There was no centralized location for interviewing. Providers typically provided a space in their agency where interviews were scheduled and conducted. In addition "intercept" interviews were

---

[1] Because of the time necessary to obtain clearances and organize interviewing in the corrective jail systems currently incarcerated PLWH/A were not interviewed.

conducted at four different agencies in the EMA.[2] Where possible race and sex were matched of the interviewer was matched with the respondent. The interview was offered in Spanish or English, and selected interviewers were bi-lingual.

Quality Control

To assure complete and high quality data, interviewers were instructed to check each questionnaire before providing the incentive, and field supervisors, prior to sending them to data entry, checked them again. At data entry, there was third check for missing data, and critical missing information was sent back to the field and the respondent was re-contacted. Last, there was a quality check for consistency, skip patterns, and out-of-range codes prior to analysis.

Surveys with incentives are vulnerable to duplicate respondents who would like additional incentives. This was minimized by circulating a list of unique confidential identifiers that were created by the participant using a combination of personal information. It allowed the early identification of duplicate surveys unless the respondent cleverly lied on the survey to create two separate confidential IDs. Still, nineteen duplicate surveys were identified and removed prior to analysis. In addition a few interviews were not entered because they were largely incomplete and the participants were unwilling to complete the survey.

Data Entry and Cleaning Data

Data was entered by trained data entry personnel in Sacramento and New York. All open-ended questions were coded and entered by PCH staff. Most interviews were double-punched to check for data entry errors. In addition data was checked for consistency, skip patterns, and out-of-range codes through printed output at PCH.

Survey Analysis

The survey data permits the analysis of needs, unmet needs, and barriers among different key populations. It also permits the estimates of co-morbidities including homelessness, substance use, STDs, mental illness, and tuberculosis among PLWH/A. The survey included measures of quality of life and adherence to medication as additional outcomes of the care system.

For the total sample analysis, over sampled subpopulations are weighed back to their proportion in the estimated HIV population. When subpopulations are compared, the weighted sample is used. However, when special populations are analyzed unweighted data is used to take full advantage of the oversamples.

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, geographic, and stage of infection subpopulations. These are shown along with the unweighted sample size, and weighted and unweighted sample proportions in Table 2-1 below:

---

[2] "Intercept interviews" are when the respondent is recruited based on the stratification criteria at the time he or she sought service, and is interviewed immediately after recruitment.

Table 2-1 Analysis Populations

Analysis Subpopulation	Unweighted N	Unweighted %	Weighted %
1. Total	383	100%	100%
2. Gender			
2.1 Male	278	73%	82%
2.2 Female	102	27%	18%
2.3 Transgender	3	1%	0%
3. Mode of Transmission			
3.1 MSM	132	35%	55%
3.2 MSM/IDU	68	18%	11%
3.3 IDU	100	26%	16%
3.4 Heterosexual *	82	21%	18%
4. Race			
4.1 African American	159	42%	26%
4.2 Anglo	152	40%	61%
4.4 Latino	59	15%	11%
4.5 API and other ethnicities, including Native Americans	13	3%	3%
5. Medical Visit			
5.1 Within last six months (< 6 mos.)	354	94%	95%
5.2 Six months or longer (>= 6 mos.)	21	6%	5%
6. Stage of Infection			
6.1 HIV, asymptomatic	104	28%	23%
6.2 HIV, symptomatic	77	20%	19%
6.3 AIDS, asymptomatic	65	17%	18%
6.4 AIDS, symptomatic	131	35%	40%

In reading the data in the text and Attachments, it is important to note that the actual sample size may be larger than the “weighted sample size” shown. For example, 102 women were interviewed, but by weighting women back to their proportion in the population, they are shown as having a weighted sample size (N) of 68. The percentage or mean reported, however, uses the data from all 102 PLWH/A participated in the survey. The same logic is applied to other populations that were oversampled.

Focus Groups and Key Informant Interviews

The purpose of the focus groups and key informant interviews was to gain greater insight into the perception of needs, gaps, and barriers of selected key populations. They supplement the quantitative findings of the consumer survey and, for populations where sample sizes are too small such as immigrants and migrants, they provide the main information for the report. The key informant interviews for the parents of children living with HIV/AIDS addresses a key population not included in the survey.

Eight focus groups and seven key informant interviews among parents and adolescents were held with consumers from the target populations and providers shown in Table 2-2. The focus group outlined was developed and approved in March 2003 and is shown in Attachment 5. All participants in the focus groups were informed about the purpose of the groups and the use of the recordings. The outline for key informant interviews conducted with parents of youth and adolescents was finalized in June 2003 and is shown in Attachment 6. All participants were assured that their responses would be confidential and quotes used from the focus groups and key informant interviews would never be associated with their names.

Recruitment

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

1. The primary approach was to recruit participants through an initial contact at a provider. Using SEMAS, the project team produced lists of clients to be recruited. When the client was unreachable, recruiters were instructed to substitute the intended client with another client with similar demographics.
2. Participants were also recruited through flyers distributed at various agencies. Those participants called a member of the research team directly to schedule their participation.

The research team recruited between fifteen and twenty PLWH/A per group with the expectation that eight and ten individuals would participate. 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. However sizes varied, as shown in Table 2-2.

The key informant interviews with parents and adolescents were recruited through UC Davis by referral. Ms. Lisa Ashley, who worked at UC Davis, was instrumental in identifying families and adolescents to participate and made the initial phone contact. With the permission of the client, PCH staff followed-up with the key informant interview.

Table 2-2 Focus Group

Population	**Size**
1. MSM	12
2. MSM of Color	7
3. Recently incarcerated Men	7
4. Women with children and adolescents with HIV	6
5. Heterosexuals	10
6. Recently incarcerated Women	7
7. Rural Men and Women	8
8. Immigrants/Migrants	7
Key informant Interviews (1-1)	
1. Parents of children living with HIV/AIDS	5
2. Adolescents	2
3. Staff of providers	5

Parents and adolescents were obtained through referrals from a provider who contacted clients to determine their interest in participating in the survey.

Incentives

Focus group participants received a $20 grocery food certificate as their incentive. All focus groups were audio taped and six out of the eight were held at Opinions of Sacramento, a professional focus group facility. The rural groups were held at the Sierra Foothills AIDS Foundation. The immigrant and migrant group was held at CARES.

Qualitative Analysis

Focus groups were audio taped, transcribed, entered into a database. PCH staff coded comments by basic demographics and the service and/or barrier they referred to. The coding schema is shown in Attachment 7. Notes were taken for key informant interviews.

Study team members sorted these comments based on services and barriers and they were selected for inclusion in the report based on the comment's ability to substantiate and add depth to the quantitative findings or show a view of consumers that is contradictory or different from the quantitative findings. In some instances, such as adolescents and youth, the main source of information in the report was obtained through qualitative methods. In reading these comments, recall that they are not representative of all PLWH/A.

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

For those interested in further analysis of the data, the basic demographic, services and barriers cross tabulations by each of the analysis populations are shown in Attachment 8 through Attachment 14 and they contain a wealth of data not reported in this needs assessment.

3. DEMOGRAPHIC PROFILE OF PLWH/A

Epidemiological Overview[3]

The Sacramento EMA includes Sacramento, El Dorado, and Placer Counties with a population of 1,699,868. As shown in Table 1-1, it is ethnically diverse with 64% white, 14% Latino, 9% Asian Pacific Islander, 8% African American, and about 5% other ethnicities including Native Americans and mixed races.

The HIV/AIDS Reporting System (HARS) documents 1,435 people living with AIDS as of December 2002, a 20% increase since 1997. There were 180 new AIDS diagnoses in the last two years, or 12% of living AIDS cases. Ninety-one percent (91%) of living AIDS cases is in Sacramento, with about five percent (5%) in Placer and four percent (4%) in El Dorado. Table 3-1 shows PLWA are disproportionately male, African American, and MSM.

- MSM represent 58% of living AIDS cases in the Sacramento EMA.
- MSM/IDU account for a larger share of the epidemic in the EMA than in most other parts of the country. They account for 12% of living AIDS cases, and over 40% of all injection-related HIV cases in the EMA, compared to only 6% of national cases.
- People of color represent about 31% of all AIDS cases prior to 1990, but account for 53% of new cases diagnosed in 2002.

At the end of 2002, it was estimated that there were about 1,987 people living with an HIV (not AIDS) in Sacramento County alone (Department of Public Health, 2002).[4] A disproportionate number of HIV/AIDS cases are among African Americans. They comprise only 8% of the Sacramento EMA's population, yet 22% of living AIDS cases, 29% of estimated HIV infections, and 27% of people newly diagnosed with AIDS.

Table 3-1 indicates that there is an estimated 3,422 people living with HIV infection in the Sacramento EMA, who know their HIV status. At the end of 2002, there were about 1,435 PLWA and an estimated 1,987 people living with HIV (not AIDS) in the EMA (Department of Public Health, 2003). An estimated 95 HIV cases are in Placer and 86 HIV cases in El Dorado County. Of those, according to the SEMAS database, there are over 1,770 PLWH/A accessing CARE-funded services. People of color make up 39% of clients receiving Title I-funded services (in contrast to representing about 36% of all PLWH/A), women make up about 18%, and IDUs represent about 16% of the PLWH/A in care.

MSM continue to be the vast majority of people living with HIV/AIDS and the community most affected by the epidemic in the EMA. MSM includes both those men who identify as gay or bisexual and those who reported male same sex transmission of HIV.

---

[3] This profile is largely taken from the Fiscal Year 2003 Application for Grant Funds Under Title I, Ryan White Comprehensive AIDS Resources Emergency Act.

[4] Using that same estimate, approximately 95 cases would be found in Placer and 86 cases in El Dorado. Therefore, there would be approximately 3,600 estimated cases of PLWH in the Sacramento EMA.

Table 3-1 Demos of General Population, PLWA, and PLWH in Sacramento County

		GENERAL POP*	PLWA 2002**	PLWH 2002^{+}	TOTAL PLWH/A
	Population	**1,699,868**	**1,435**	**1,987**	**3,422**
Gender**	Male	49%	86%	80%	82%
	Female	51%	14%	20%	18%
Race	African American	8%	22%	29%	26%
	Anglo	64%	63%	58%	61%
	Asian/Pacific Islander	9%	1%	1%	1%
	Latino	14%	12%	10%	10%
	Other	5%	2%	2%	2%
Risk Group***	MSM	NA	58%	53%	54%
	MSM/IDU	NA	12%	17%	11%
	IDU	NA	15%	10%	16%
	HET	NA	15%	20%	18%

* Census Bureau, 2002 ** HARS + RWCA Title I Application, 2002-2003

Detailed Demographic Description

Table 3-2 provides a detailed demographic profile of PLWH/A living in the Sacramento EMA[5], based on the weighted consumer survey sample of 383 PLWH/A.
Below are some demographic highlights of PLWH/A:

- 82% are males, 18% are females. Women represent a far greater proportion of African Americans living with HIV/AIDS than other ethnic populations.
- The majority of the PLWH/A is non-Latino Anglo (61%), followed by African Americans (26%), Latinos (10%), and other ethnicities, including Asian Pacific Islanders and Native Americans at about 3%.
- People of color as a group, including African Americans, Latinos, Native Americans, and Asian/Pacific Islanders, represent 39% of PLWH/A.
- Among Anglos, 93% are male, and 68% percent of them are MSM. Twenty-five percent (25%) report a history of IDU, and 8% are heterosexual.
- African Americans PLWH/A are 44% female and 42% report being heterosexual. Thirty-five percent (35%) report a history of IDU, and 29% report being MSM.
- Latinos have a profile similar to Anglos: Mostly male (88%), about a quarter (23%) with IDU history, and 16% heterosexual.
- PLWA represent 58% of the sample and PLWH account for 42% of the sample. This distribution is actually the opposite of the breakdown presented in the Title I application. Notably in this sample, Anglos (representing majority MSM) are much more likely to have progressed to AIDS. This could reflect the greater likelihood of survey participants, who are recruited through care services, of being in later stages of HIV infection.

---

[5] The data was weighed back to Placer and El Dorado County populations and therefore is not generalizable to those counties.

Table 3-2 Demographic Analysis (N=383)*

	TOTAL	Anglo	African Am	Latino	API /Other
TOTAL N	**383***	**232**	**100**	**40**	**10**
Gender					
Male	82%	93%	57%	88%	78%
Female	18%	7%	44%	12%	22%
Risk group					
MSM	55%	68%	23%	62%	66%
MSM/IDU	11%	15%	6%	6%	4%
IDU	16%	10%	29%	17%	14%
Hetero	18%	8%	42%	16%	16%
Stage of Infection					
HIV asymptomatic	23%	17%	34%	30%	17%
HIV symptomatic	19%	16%	26%	20%	0%
AIDS asymptomatic	18%	19%	17%	20%	7%
AIDS symptomatic	40%	48%	22%	30%	76%

* Weighted sample from the Needs Assessment Survey. The total count may not sum to 383 due to weighting and rounding effect.

The following graphs detail the demographics of several specific subpopulations.

Women

Figure 3-1 shows that women represent 18% of the PLWH/A sample, yet among ethnic groups, women make up the largest percentage of the African American population at 44% and the smallest percent of the Anglo population at 7%.

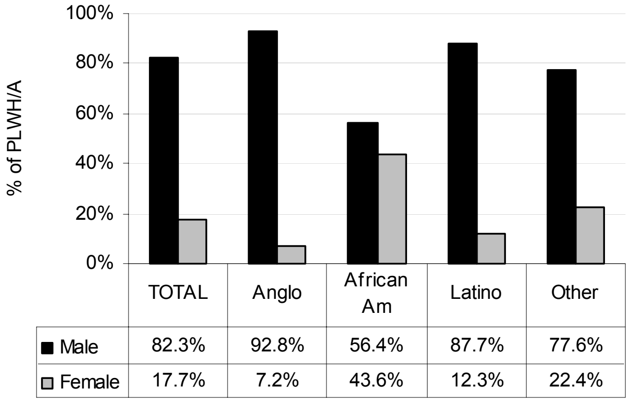
Figure 3-2 further shows that women represent 68% of the heterosexuals, and 36% of the IDUs. As newcomers to the HIV epidemic, women are more likely to be HIV positive without an AIDS diagnosis. In general, women are about evenly distributed among the asymptomatic and symptomatic PLWH/A. However, as shown in Attachment 8 women living with HIV are more likely to be asymptomatic (40%) than symptomatic (29%), but women living with AIDS are much more likely to be symptomatic (21%) than asymptomatic (11%).

The detailed demographic analysis in Attachment 8 further reveals:

- Women are more likely than men to postpone seeing a doctor after receiving their initial HIV diagnosis. Twenty percent (20%) of women have waited at least seven months to see a doctor compared to 15% of men.
- Women (35%) are more likely than men (27%) to have lived with HIV less than six years. Less than one third of women have lived with HIV 12 years or more compared to over 41% of men.
- Women are much less likely to live alone than men and are more likely to consider their home safe, habitable, and stable.

- Women have a higher history of homelessness than men, with over 25% having lived in a homeless shelter over the last two years and almost 40% report having lived in the street or in a car.
- Considering the high incidence of homelessness among women living with HIV/AIDS in Sacramento it is surprising that a lower percentage of women have been diagnosed with depression and anxiety than men. This may reflect their greater access to mental health therapy than men. For instance, 28% of women have received group counseling compared to 13% of men. Women are also far more likely than men to have received peer counseling, family counseling, and bereavement counseling.

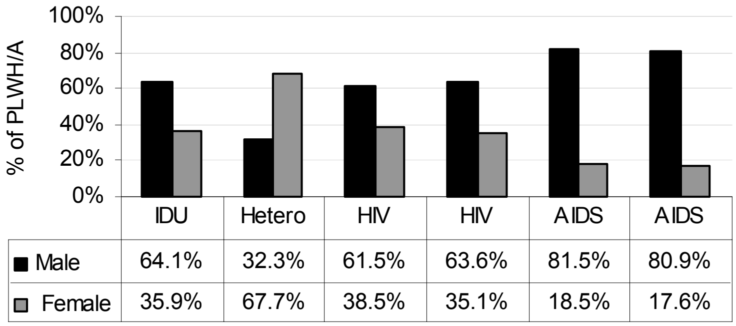
Figure 3-1 Gender by Ethnicity*



	TOTAL	Anglo	African Am	Latino	Other
■ Male	82.3%	92.8%	56.4%	87.7%	77.6%
□ Female	17.7%	7.2%	43.6%	12.3%	22.4%

*Based on weighted sample

Figure 3-2 Gender by Mode and Stage of Infection*



	IDU	Hetero	HIV	HIV	AIDS	AIDS
■ Male	64.1%	32.3%	61.5%	63.6%	81.5%	80.9%
□ Female	35.9%	67.7%	38.5%	35.1%	18.5%	17.6%

*Based on weighted sample

Ethnicity/Race and Mode of Transmission

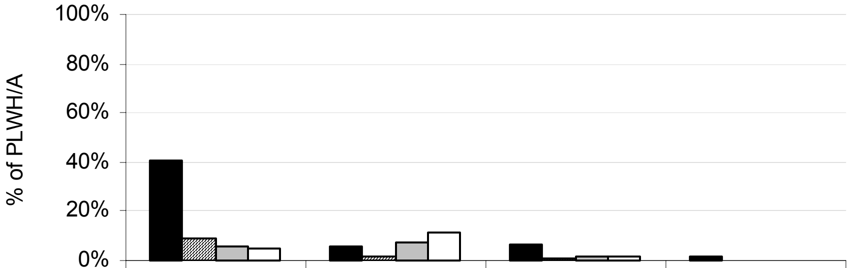
Figure 3-3 shows the overall profile of PLWH/A in Sacramento. It is divided by race and risk group. For example, the first bar shows that in of all PLWH/A in Sacramento, 41% are MSM. Figure 3-3 indicates that:

- Anglo MSM (41%) represent the largest number of PLWH/A, followed by African American heterosexuals (11%), and Anglo MSM/IDU (9%).
- IDUs represent 16% of all PLWH/A and are distributed among African Americans (8%), Anglos (6%), and Latino (2%). The majority of MSM/IDU are Anglo (9%), while the majority of IDU are African American (8%).
- Heterosexuals represent 18% of all PLWH/A. They are mostly African Americans (11%), with about 5% Anglos, and 2% Latinos and other ethnicities.
- MSM represents the largest proportion of PLWH/A in all ethnic groups, except among the African Americans. MSM represents over 60% of Anglos and Latinos living with HIV/AIDS, but they represent less than a quarter of the PLWH/A among African Americans.
- African Americans show the widest distribution in exposure categories. 42% of African Americans report being heterosexual, 29% IDU, 23% MSM, and about six percent (6%) are MSM/IDU.

Based on data in Attachment 8:

- In nearly every ethnic group, the largest proportion of women report heterosexual exposure. Within the Anglos, 71% of women report heterosexual contact, the highest of all ethnic groups.
- Latinas report the largest IDU exposure with more than 38% reporting IDU as their mode of transmission.

Figure 3-3 Ethnicity by Mode of Transmission



	Anglo	African Am	Latino	API and other
■ MSM	41.0%	6.1%	6.4%	1.7%
▨ MSMIDU	8.9%	1.6%	0.6%	0.1%
▩ IDU	6.1%	7.5%	1.8%	0.3%
□ Hetero	4.7%	11.0%	1.6%	0.4%

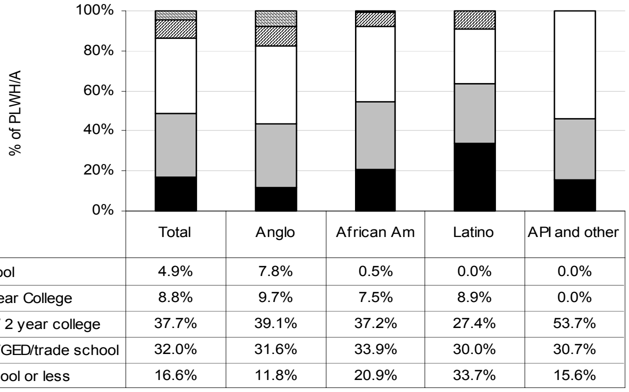
Education

More than half (51%) of the PLWH/A have some college, completed a four-year college degree, or have graduate school experience. Seventeen percent (17%) of PLWH/A have less than a than a high school education.

Figure 3-4 shows educational levels across the ethnic/racial categories and Figure 3-5 shows the different levels of education for gender and risk groups. The data reflects the socio-economic divisions within the epidemic:

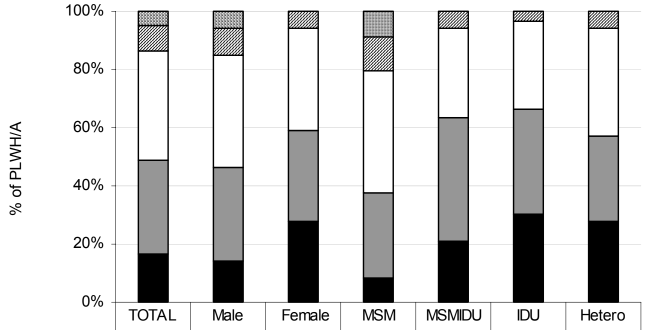
- Anglos have the highest rate of education with over 18% reporting a college education.
- African Americans represent the largest group having completed high school without having gone to college.
- Latinos are the least educated ethnic group, with over a third having some high school or less.
- Among risk groups, heterosexuals have the lowest level of education. MSM have the highest level of education, with 21% of MSM reporting that they have at least a four-year college degree, compared to 6% of MSM/IDU and heterosexuals. Over 60% of IDU PLWH/A have some level of high school education.
- Men living with HIV and AIDS, reflecting the disproportionate Anglo MSM epidemic, have a higher education than women living with HIV who are disproportionately African American.

Figure 3-4 Level of Education by Race



	Total	Anglo	African Am	Latino	API and other
▤ Graduate School	4.9%	7.8%	0.5%	0.0%	0.0%
▨ Completed 4 year College	8.8%	9.7%	7.5%	8.9%	0.0%
□ Some College / 2 year college	37.7%	39.1%	37.2%	27.4%	53.7%
▩ Graduated HS/GED/trade school	32.0%	31.6%	33.9%	30.0%	30.7%
■ Some high school or less	16.6%	11.8%	20.9%	33.7%	15.6%

Figure 3-5 Level of Education by Gender and Mode



	TOTAL	Male	Female	MSM	MSMIDU	IDU	Hetero
▦ Graduate School	4.9	5.9	0.0	8.8	0.0	0.0	0.0
▨ Completed 4 year College	8.8	9.4	5.9	11.9	6.0	3.2	5.9
□ Some College / 2 year college	37.7	38.3	35.2	41.6	30.4	30.4	37.0
▩ Graduated HS/GED/trade school	32.0	32.2	31.1	29.5	42.7	36.0	29.2
■ Some high school or less	16.6	14.2	27.8	8.2	20.9	30.4	28.0

Age Distribution

The average age of PLWH/A who participated in the survey is 43 years. Four percent (4%) are under 30, 84% are between 30 and 50, and 13% are over 50.[6] Latinos and African Americans are slightly younger, indicating their later entry into the epidemic. In the SEMAS database, about 7% of PLWH/A are between 18 and 30.

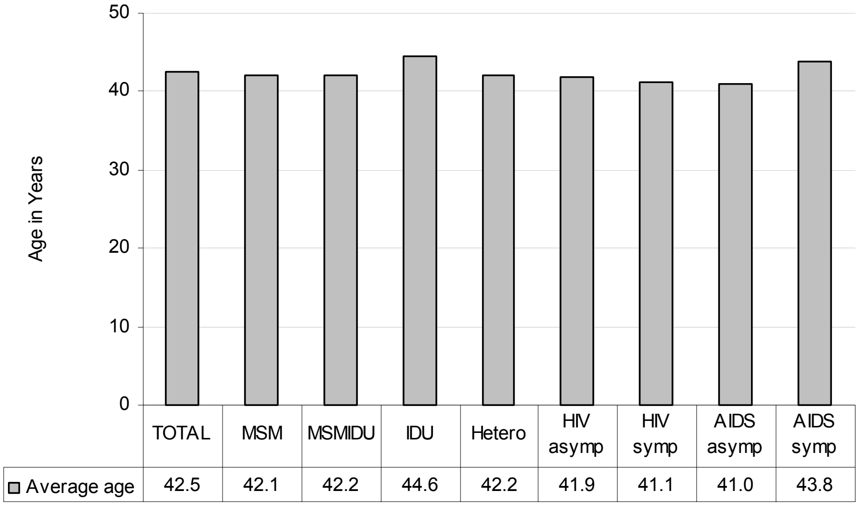
Figure 3-6 shows the average age by mode and stage of HIV infection. The data indicates:

- Amongst risk groups, IDUs are the oldest, averaging 45 years of age.
- Reflecting the progression of HIV to AIDS, PLWA are older than those living with HIV.

---

[6] Based on the epidemiology of PLWA at the end of 2002, the sample is slightly younger but, since it includes PLWH, it is likely to approximate the population.
Using that same estimate, approximately 95 cases would be found in Placer and 86 cases in El Dorado. Therefore, there would be approximately 2,162 estimated cases of PLWH in the Sacramento EMA.

Figure 3-6 Age by Mode and Stage of Infection



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. PLWH/A who are married or living with partners often have a caregiver, but may also have larger financial needs if the partner is not working or disabled. PLWH/A with families also have particular needs, including day care and services for children when seeking care.

- 11% PLWH/A reported living with children in the same household. African Americans (25%) are more likely than Latinos (19%) and Anglos (5%) to live with children.
- As shown in Attachment 8, 35% of PLWH/A report living alone. Men are more likely (39%) to live alone than women (19%). Sixteen percent (16%) of PLWH/A live with an HIV positive partner.

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 the Federal poverty levels (between $33,000 and $34,000 a year for a single person).

The sample drawn from Ryan White funded providers is likely to over-represent persons living at or near the poverty level. Still, only 2% of the sample report making over $35,000, making the vast majority eligible for Ryan White care services including ADAP.

Figure 3-7 shows income levels by gender and mode. It indicates that:

- In general, those participating in the survey have low incomes, with about 87% reporting earning less than $16,500 and approximately 48% reporting earning less than $8,600.
- Women report significantly lower income than men. Seventy-two percent (72%) of women report an annual income of $8,600 or less.
- Among risk groups, the vast majority of IDUs (98%) and heterosexuals (96%) have incomes of $16,500 or less per year. MSM have the highest income with 18% making more than $16,500 followed by MSM/IDU (16%). While MSM living with HIV/AIDS are at every income level, heterosexuals and IDUs tend to be very poor or have incomes above $16,500. However, even among MSM and MSM/IDU, less than 4% report earning more then $35,000 – the usual limit to qualify for ADAP.

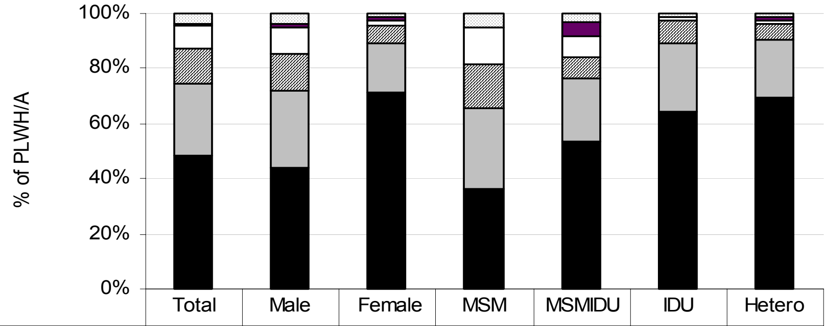
Figure 3-8 shows income by ethnicity. This graphic indicates that:

- Over half the Latinos and African Americans report earning $8,600 per year or less.
- Anglos report the highest income of any group, with 17% earning $16,500 or more per year.

Data in Attachment 8 further indicate:

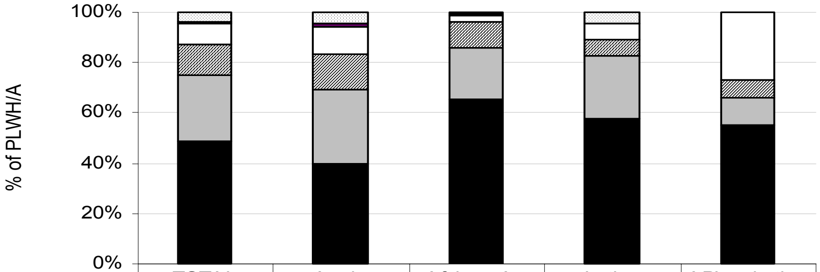
- Over 80% of the homeless and recently incarcerated report earning less than $11,600 a year with over 60% report earning less than $8,600 a year.
- PLWH report the lowest income, suggesting that the newly infected are from the lowest socio-economic brackets, and are coming into the epidemic with a high level of need of social and medical services.

Figure 3-7 Income by Gender and Mode



	Total	Male	Female	MSM	MSMIDU	IDU	Hetero
□ Greater than $26,001	3.5%	4.0%	1.3%	5.0%	3.2%	1.4%	1.3%
■ $23,201 - $26,000	0.9%	0.8%	1.3%	0.2%	4.8%	0.0%	1.3%
□ $16,501 - $23,200	8.5%	9.9%	2.0%	13.1%	8.0%	0.9%	1.1%
▨ $11,601 - $16,500	12.3%	13.5%	6.3%	16.3%	7.6%	8.3%	6.2%
□ $8,601 - $11,600	26.2%	28.0%	17.5%	28.9%	23.2%	25.2%	20.6%
■ $8,600 or less	48.6%	43.7%	71.6%	36.5%	53.2%	64.2%	69.5%

Figure 3-8 Income by Ethnicity



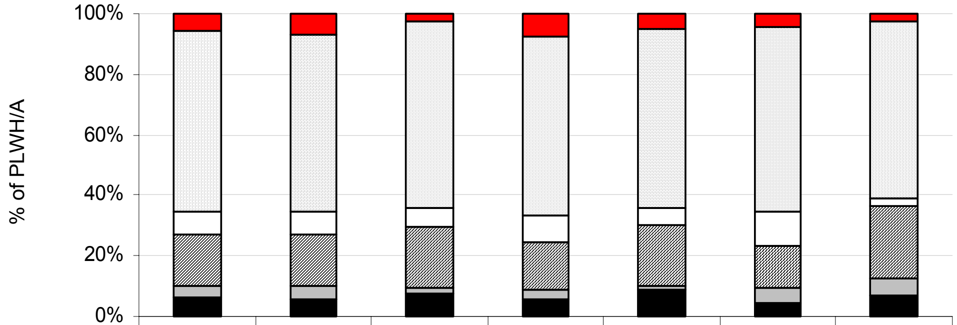
	TOTAL	Anglo	African Am	Latino	API and other
□ Greater than $26,001	3.5%	4.7%	0.9%	4.3%	0.0%
■ $23,201 - $26,000	0.9%	1.3%	0.5%	0.0%	0.0%
□ $16,501 - $23,200	8.5%	10.7%	2.6%	6.4%	26.7%
▨ $11,601 - $16,500	12.3%	14.4%	9.9%	6.9%	7.5%
▒ $8,601 - $11,600	26.2%	29.5%	20.4%	24.7%	10.7%
■ $8,600 or less	48.6%	39.4%	65.7%	57.7%	55.1%

Employment Status

Figure 3-9 and Figure 3-10 shows employment status by gender and mode and by ethnicity. The figures show the following:

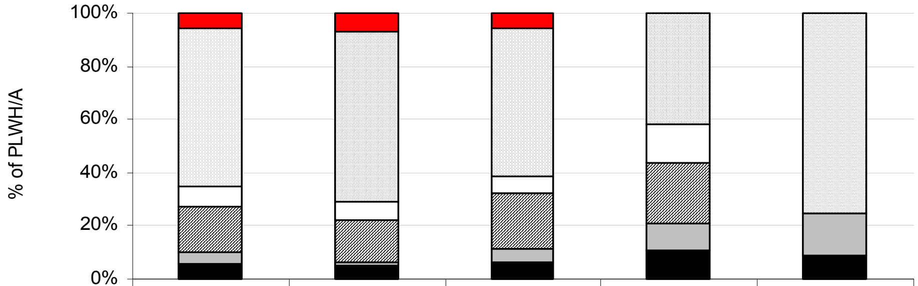
- The majority of PLWH/A are not currently working (89%). Seventeen percent (17%) of those not working are actively looking for work, 7% are students or homemakers, 6% are retired, and 59% are not looking for work. About 10% are either employed part- or full-time.
- Men and women are equally likely to not be working, however, more women (20%) report looking for work than men (17%), and slightly more women are employed full time (7.3%) compared to men (5.6%).
- Among risk groups, MSM/IDU have the highest percent of persons employed full-time (9%), followed by heterosexuals (7%), MSM and IDUs at 5%.
- Among ethnic populations, Latinos have the highest percent of PLWH/A who are currently employed full-time at 11%. More Latinos (23%) and African Americans (21%) report looking for work than any other ethnic group.

Figure 3-9 Employment Status by Gender and Mode



	Total	Male	Female	MSM	MSMIDU	IDU	Hetero
🟥 Retired	5.8%	6.5%	2.4%	7.4%	4.8%	4.4%	2.5%
☐ Not working/not looking for work	58.8%	58.2%	61.5%	58.4%	59.2%	61.3%	57.3%
☐ Not working - student/ homemaker	7.4%	7.5%	6.8%	8.4%	5.6%	10.9%	2.2%
▨ Not working/looking for work	17.2%	16.6%	19.7%	15.6%	20.0%	13.8%	23.4%
◻ Employed part-time	3.8%	4.1%	2.2%	3.3%	1.3%	5.2%	5.7%
■ Employed full-time	5.9%	5.6%	7.3%	5.4%	8.8%	4.5%	6.7%

Figure 3-10 Employment Status by Ethnicity



	Total	Anglo	African Am	Latino	API and other
🟥 Retired	5.8%	7.0%	5.9%	0.0%	0.0%
☐ Not working/not looking for work	58.8%	62.5%	55.3%	41.9%	74.1%
☐ Not working - student/ homemaker	7.4%	6.7%	6.6%	14.7%	0.0%
▨ Not working/looking for work	17.2%	15.4%	20.7%	22.7%	0.0%
◻ Employed part-time	3.8%	1.7%	5.1%	9.8%	15.6%
■ Employed full-time	5.9%	4.7%	6.5%	10.9%	8.8%

Regional Variation

Sacramento County is divided into five districts. The Board of Supervisors is the governing body of the County of Sacramento and each of the five members of the Board represent one of five districts. The map of the district boundaries is shown in Figure 3-11. In addition the EMA includes Placer County to the North East and El Dorado County to the East. Both include the western part of Lake Tahoe and the State of Nevada. The Council had decided to use these supervisor districts to geographically distinguish the needs of PLWH/A in Sacramento County.

Figure 3-11 Map of Sacramento County Districts

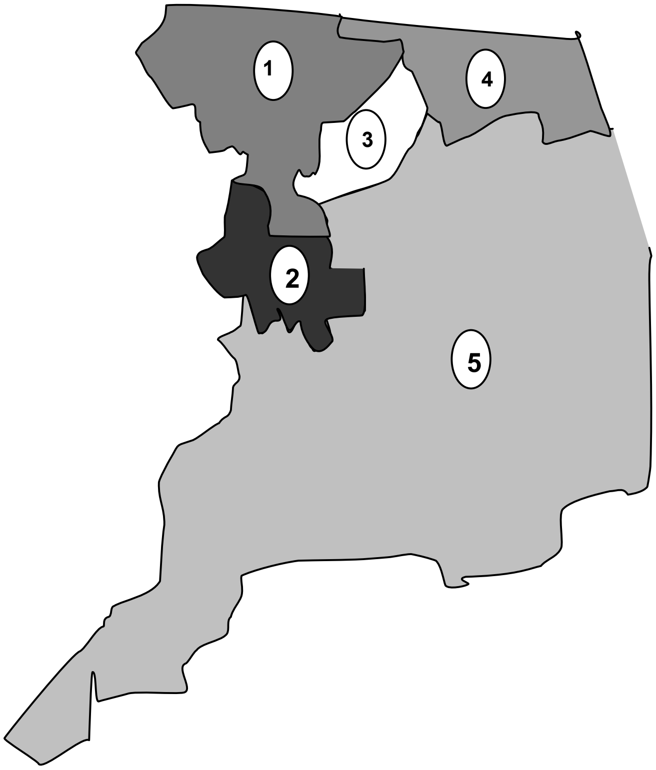


Table 3-3 PLWA in 2002 by Geographic Location shows the profile of PLWA in 2002 by district. When adjusted for PLWH, the percentage of females, African Americans, and IDUs is slightly greater while the percentage of males, MSM, and Anglos is slightly smaller. It shows:

- 43% of PLWA live in District 1.
- 15% of PLWA live in District 2
- Between 11% and 8% of PLWH/A live in each of the three other Supervisor Districts.
- District 1,with the vast majority of AIDS cases is fairly representative of everyone with AIDS.
- District 2 is more female, African American, Latino, and heterosexual. District 3 is more Anglo.

Table 3-3 PLWA in 2002 by Geographic Location

	TOTAL	District 1	District 2	District 3	District 4	District 5
N=	**1402**	**603**	**216**	**158**	**112**	**126**
Gender						
Male	85.6%	88.1%	79.2%	86.1%	82.1%	80.2%
Female	14.4%	11.9%	20.8%	13.9%	17.9%	19.8%
Ethnicity						
Anglo	63.3%	61.2%	44.9%	75.3%	67.0%	58.7%
African American	22.2%	23.5%	33.8%	14.6%	19.6%	27.8%
Latino	12.1%	12.1%	18.1%	8.2%	11.6%	11.9%
API and Other	2.4%	3.2%	3.2%	1.9%	1.8%	1.6%
Risk Group						
MSM	58.2%	58.8%	53.1%	63.8%	58.6%	53.9%
MSM/IDU	12.1%	13.9%	12.4%	7.9%	8.1%	9.6%
IDU	14.6%	14.9%	12.4%	12.5%	13.1%	15.7%
Heterosexual	15.2%	12.3%	22.0%	15.8%	20.2%	20.9%

*Based on HARS 2002, as reported in 2002.. Total of district counts does not sum to total in EMA due to missing data.

Table 3-4 Geographic Distribution shows the weighed sample distribution for all districts. It shows that the sample is not very generalizable to the district level with the greatest discrepancies being in District 4 where the sample is heavily weighted to the Latino population, and District 3 where African Americans are over represented in the sample.

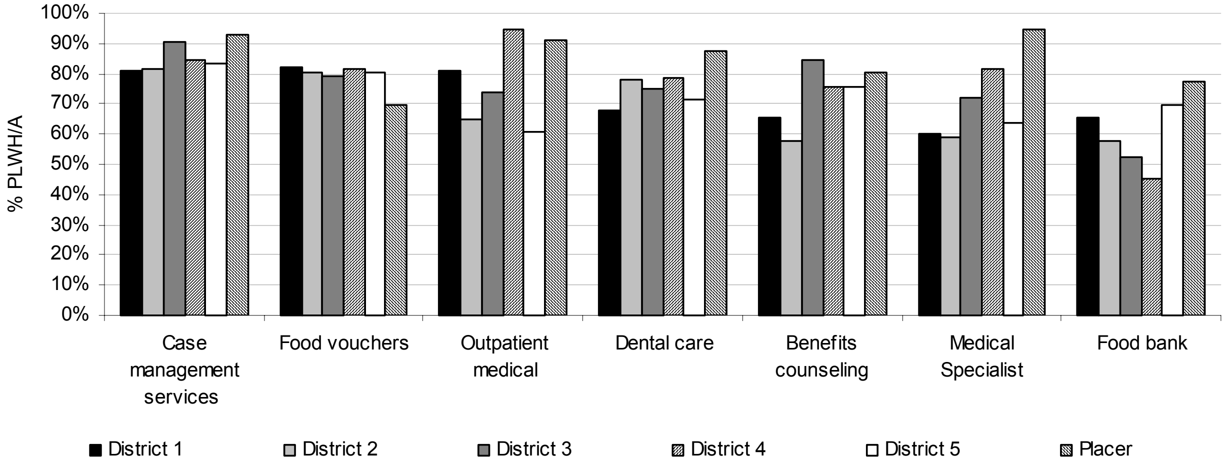
Table 3-4 Geographic Distribution

	TOTAL	District 1	District 2	District 3	District 4	District 5	Placer	Other
N=	**383**	**213**	**41**	**48**	**17**	**27**	**12**	**18**
Gender								
Male	82.3%	80.6%	80.1%	87.2%	85.0%	82.9%	90.3%	82.9%
Female	17.7%	19.4%	19.9%	12.8%	15.0%	17.1%	9.7%	17.1%
Ethnicity								
Anglo	60.7%	60.1%	55.9%	69.1%	42.3%	68.1%	92.8%	45.1%
African Am	26.2%	28.0%	35.9%	20.5%	9.1%	23.6%	0.0%	35.9%
Latino	10.5%	9.1%	6.6%	9.1%	48.6%	5.9%	7.2%	18.2%
API and other	2.5%	2.8%	1.6%	1.4%	0.0%	2.4%	0.0%	0.8%
Risk Group								
MSM	55.2%	55.0%	52.5%	59.3%	56.6%	56.2%	51.4%	46.7%
MSM/IDU	11.3%	10.3%	8.8%	10.0%	14.4%	15.6%	26.5%	13.5%
IDU	15.8%	15.5%	14.0%	17.2%	15.8%	16.7%	14.8%	21.1%
Hetero	17.8%	19.2%	24.7%	13.5%	13.3%	11.5%	7.3%	18.7%

Figure 3-12 shows the top service needs by geographic location and ordered by the reported needs of the overall sample of PLWH/A. Because the districts are not proportionately sampled, the findings may not be representative of the specified region. Still, the consistency in rank orders across regions is interesting.

Despite the lack of generalizability, Figure 3-12 demonstrates that consistency of top needs across districts, with case management, food vouchers being the most consistent, and outpatient medical care and medical specialist being the least consistent across districts. Those with the greater medical needs tend to be the districts furthest away from the main providers.

Figure 3-12 Top Services Needs by Geographical Location



PLWH/A were asked to report whether each of the items represented a barrier to care. Unlike the needs, the barriers proved to be quite different by district, suggesting the need for further analysis of the districts when the sampling plan allows for sufficient sample size by district.

4. CO-MORBIDITIES

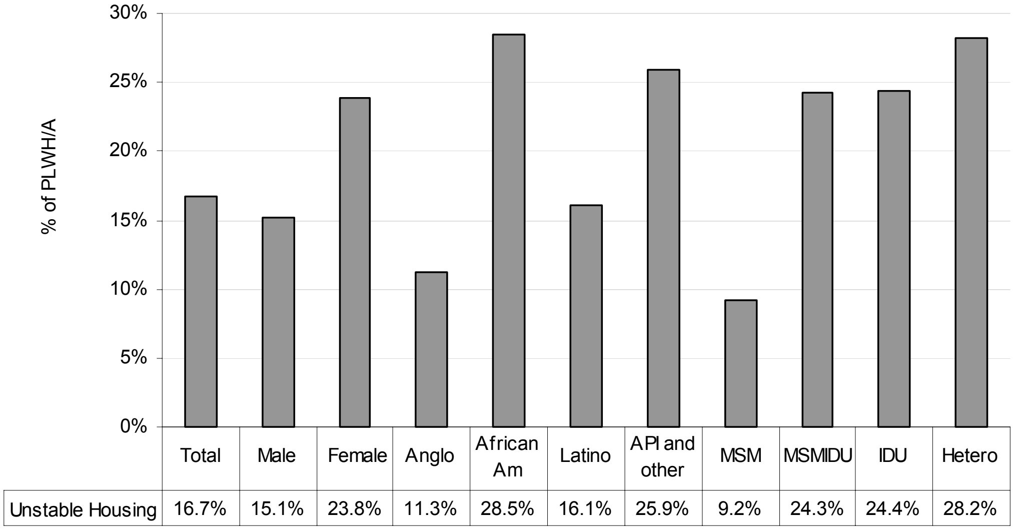
The co-morbidities of homelessness, mental illness, and STDs and drug use are discussed in this section.

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. Living in shelters with inconsistent access to food and proper nutrition, or sharing living spaces with strangers further aggravates the difficulty in adhering to medications.

In the 2003 needs assessment survey, PLWH/A were asked about their current living arrangements. For the purpose of this report, an unstable living situation was defined as currently being homeless in the street or living out of a car, in a shelter, with someone and not paying for rent, single room occupancy without tenancy, group home, half-way house or living in transitional housing. Figure 4-1 shows that close to 17% of the PLWH/A are currently in unstable housing situations, with close to 30% of African Americans and heterosexuals having unstable housing. Anglos, MSM, and men are less likely to be homeless or living in unstable housing.

Figure 4-1 Currently Homeless or In Transition



	Total	Male	Female	Anglo	African Am	Latino	API and other	MSM	MSMIDU	IDU	Hetero
Unstable Housing	16.7%	15.1%	23.8%	11.3%	28.5%	16.1%	25.9%	9.2%	24.3%	24.4%	28.2%

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 the PLWH/A interviewed, 31% have been homeless sometime in the last two years, and 25% have lived in some form of transitional housing, including treatment facilities.

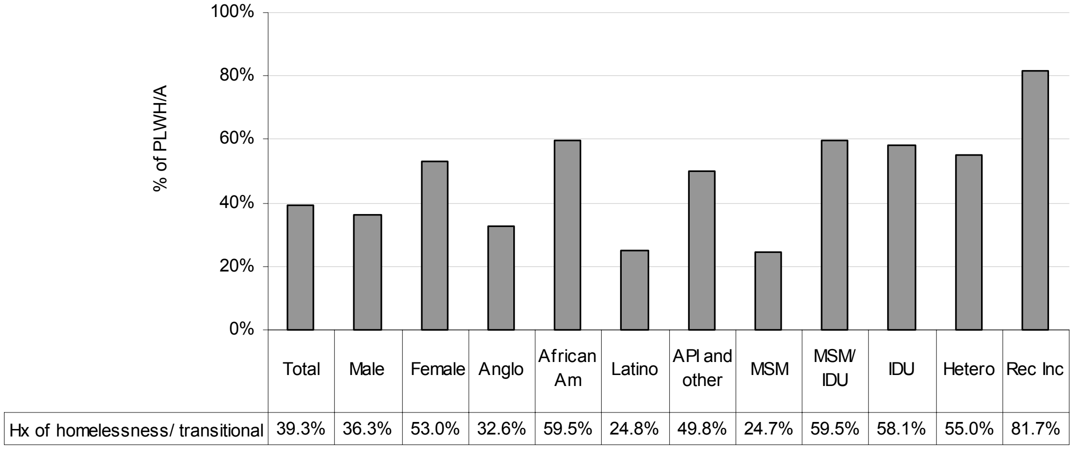
Figure 4-2 shows the percent of PLWH/A who have been homeless or in some form of transitional housing over the past two years and indicates that:

- Overall, nearly 40% of PLWH/A have experienced unstable housing during the past two years.
- Men are less likely (36%)to have a history of homelessness or living in transitional housing than women (53%).
- African Americans are more likely (60%) to have a history of unstable housing and live in transitional housing than other ethnic groups.
- With one quarter reporting past unstable housing, Latinos represent the ethnic group with the lowest incidence of homelessness.
- Among risk groups, well over half of heterosexuals, IDUs, and MSM/IDU have been homeless or living in transitional housing over the past year.

Attachment 8 further indicates that:

- Among the different stages of HIV infection, symptomatic PLWH (55%) are more likely to have been homeless in the last two years than any of the other groups.
- Recently incarcerated PLWH/A shown in Figure 4-2 as “Rec Inc,” are far more likely to experience a period of homelessness than other populations. Thirty-nine (39%) of all PLWH/A report having a history of being homeless compared to 82% of those who have been incarcerated in the last two years. This may reflect the financial challenges and rules and regulations of public housing one faces after being released from the jail system.

Figure 4-2 Homelessness & Transitional Housing by Gender, Ethnicity and Mode



	Total	Male	Female	Anglo	African Am	Latino	API and other	MSM	MSM/ IDU	IDU	Hetero	Rec Inc
Hx of homelessness/ transitional	39.3%	36.3%	53.0%	32.6%	59.5%	24.8%	49.8%	24.7%	59.5%	58.1%	55.0%	81.7%

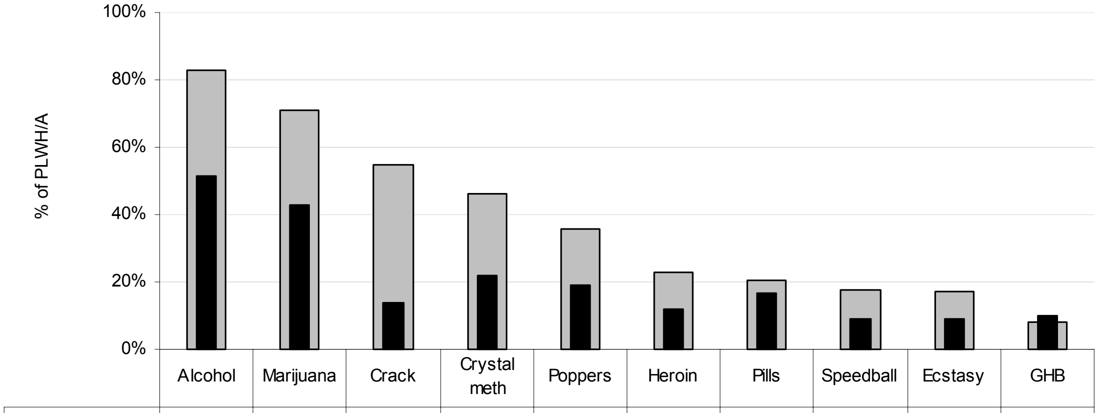
Substance Abuse

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 gray bar in Figure 4-3 shows the percentage of PLWH/A who have used a drug sometime in their life, and the black bar shows the percentage of those who ever used the drug who continue to use the drug in the last 6 months.

- The vast majority of PLWH/A report having used alcohol (83%) and marijuana (71%) sometime in the past, but use in the past six months is lower – 51% of those who ever used alcohol and 43% of those who ever used marijuana. Almost one quarter (24%) of PLWH/A report weekly use of marijuana and more than 20% report weekly alcohol use. Frequent marijuana use is highest among men, MSM, and Anglos.
- Of the opiates, 55% of the PLWH/A report ever using crack/cocaine and 23% report using heroin sometime in their life. About 14% have used crack/cocaine in the last six months and 6% of PLWH/A who use crack or cocaine say they continue to use the drugs at least once a week. About 12% of those who ever used heroin have used it in the last 6 months.
- Shown in Attachment 8 is that the recently incarcerated (75%) and PLWH/A with a history of homelessness (70%) are more likely to use crack than other populations. The recently incarcerated, homeless, symptomatic PLWH and IDU are among the highest current users of heroin, indicating the high level of co-morbidities among these populations.
- While almost half (46%) of PLWH/A in Sacramento say they have used crystal meth and 22% continue to use crystal meth, less than a 10% report using it frequently (once a week or more).
- "Party drugs" include poppers, ecstasy, and Gamma Hydroxybutyrate (GHB). More than one third (36%) of the PLWH/A report using poppers, with about nine percent (9%) saying they use it monthly. Party drugs are much more commonly used by men, Anglos and MSM with as much as three quarters of the MSM/IDU and 43% of the MSM reporting having used poppers in their lives. More than a quarter of MSM/IDU and about six percent of MSM have used GHB. A very small percentage of heterosexuals (3%) report using ecstasy compared to seventeen percent (17%) of all PLWH/A.

Figure 4-3 Substance Use Among PLWH/A



	Alcohol	Marijuana	Crack	Crystal meth	Poppers	Heroin	Pills	Speedball	Ecstasy	GHB
▨ Ever Used	82.7%	71.0%	54.6%	46.2%	35.7%	22.9%	20.2%	17.5%	16.9%	8.2%
■ % Currently Use	51.4%	42.6%	13.7%	21.9%	19.2%	11.9%	16.6%	9.2%	9.1%	9.9%

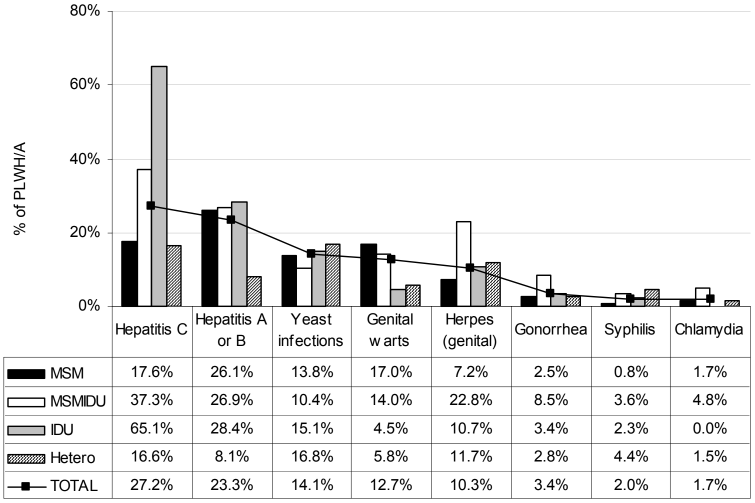
STDs

Sexually transmitted diseases (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 are 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, Figure 4-5 and Attachment 8 show the percentage of PLWH/A who report being diagnosed with STDs in the last year. They indicate that:

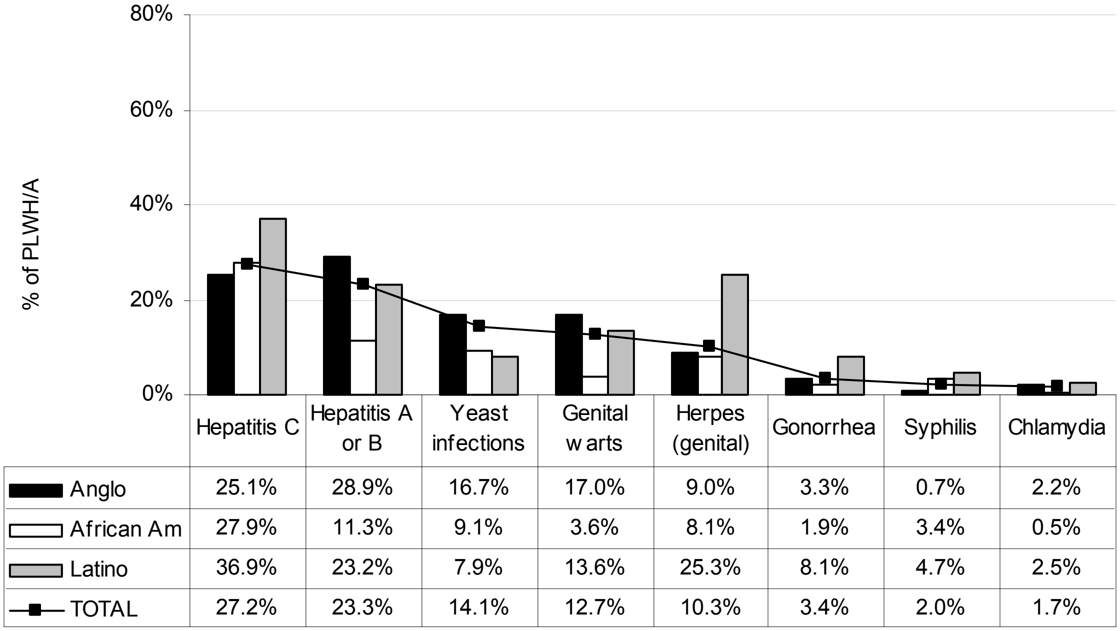
- Over one quarter of the PLWH/A report having been diagnosed with hepatitis C in the last year. Predictably, the incidence of hepatitis is significantly higher among IDUs (65%), MSM/IDU (37%), and the recently incarcerated (33%).
- Among ethnic communities, the incidence of hepatitis C is highest among Latinos (37%). The data shows that Latinos (23%) report a lower use of intravenous drugs than African Americans (35%) and Anglos (25%), suggesting that they are under-reporting IDU or have other routes of transmission.
- Next highest incidence of STDs is hepatitis A or B (23%). It is significantly higher among men (26%), Anglos (29%) and Latinos (23%). Among the risk groups, heterosexuals (8%) report the lowest incidence of hepatitis A or B.
- The recently incarcerated (23%) and the symptomatic PLWA (32%) report the highest incidence of hepatitis A and B.
- Herpes is the fifth most frequently reported STD (10%). It is highest among MSM/IDU (23%), Latinos (25%), symptomatic PLWA (17%), and the homeless (13%).

Figure 4-4 STDs among PLWH/A by Mode of Transmission



	Hepatitis C	Hepatitis A or B	Yeast infections	Genital w arts	Herpes (genital)	Gonorrhea	Syphilis	Chlamydia
■ MSM	17.6%	26.1%	13.8%	17.0%	7.2%	2.5%	0.8%	1.7%
□ MSMIDU	37.3%	26.9%	10.4%	14.0%	22.8%	8.5%	3.6%	4.8%
▒ IDU	65.1%	28.4%	15.1%	4.5%	10.7%	3.4%	2.3%	0.0%
▨ Hetero	16.6%	8.1%	16.8%	5.8%	11.7%	2.8%	4.4%	1.5%
—■— TOTAL	27.2%	23.3%	14.1%	12.7%	10.3%	3.4%	2.0%	1.7%

Figure 4-5 STDs among PLWH/A by Ethnicity



	Hepatitis C	Hepatitis A or B	Yeast infections	Genital w arts	Herpes (genital)	Gonorrhea	Syphilis	Chlamydia
■ Anglo	25.1%	28.9%	16.7%	17.0%	9.0%	3.3%	0.7%	2.2%
□ African Am	27.9%	11.3%	9.1%	3.6%	8.1%	1.9%	3.4%	0.5%
▒ Latino	36.9%	23.2%	7.9%	13.6%	25.3%	8.1%	4.7%	2.5%
—■— TOTAL	27.2%	23.3%	14.1%	12.7%	10.3%	3.4%	2.0%	1.7%

Mental Illness

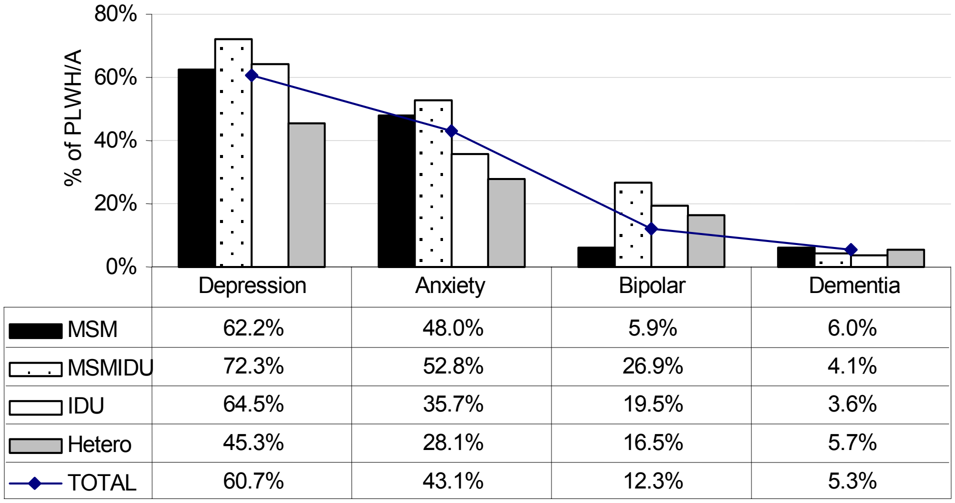
Mental illness covers a broad array of mental disabilities. Many people living with HIV and AIDS, particularly substance users, have had mental disabilities prior to becoming infected. For others, the diagnosis of HIV infection or its manifestations has led to mental health service needs. For the purpose of this needs assessment mental illness was defined as having a self-reported diagnosis of anxiety, dementia, or depression. More than two thirds of PLWH/A (69%) reported having been diagnosed with one of these conditions.

Serious mental illness is defined as having received inpatient mental health services or receiving medication for psychological or behavioral problems. More than 40% report serious mental illness.

The types of mental disorders that have been diagnosed are shown in Figure 4-6, Figure 4-7, and Attachment 8. They indicate that:

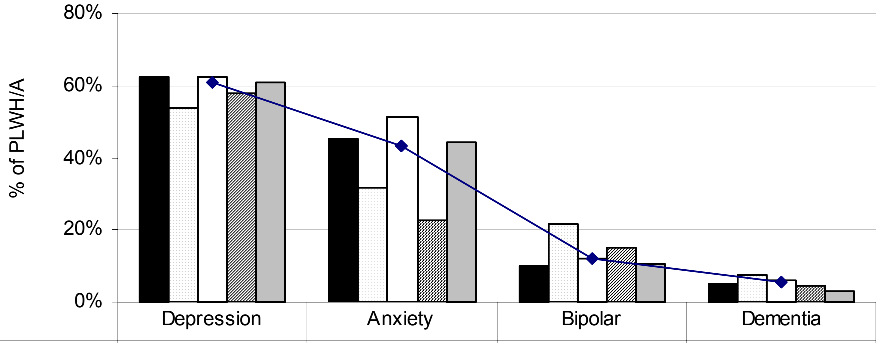
- Depression has been diagnosed among 61% of PLWH/A in the past two years, and it is the most frequently diagnosed mental illness reported by PLWH/A. It tends to be highest among men (62%), Anglos (62%), symptomatic PLWA (71%), and MSM/IDU (72%).
- Asymptomatic PLWH (41%), heterosexuals (45%), women (54%), and African Americans (58%), recently incarcerated (58%) and PLWH/A with a history of homelessness (59%) report less than the average incidence of depression. While the lower incidence rates among these populations may suggest greater access to support systems, it may also reflect a lower likelihood of seeking mental health professionals for a diagnosis.
- Forty–three percent (43%) of PLWH/A report a diagnosis of anxiety in the past two years. Anglos (51%) and MSM/IDU (53%) tend to have received a diagnosis of anxiety more than any of the other race and risk groups. Attachment 8 further indicates that African Americans and asymptomatic PLWH tend to report the lowest incidence of anxiety.
- Twelve percent (12%) of PLWH/A report bipolar disease, with asymptomatic PLWH (20%), IDU (20%), women (22%) and MSM/IDU (27%) reporting a significantly higher incidence than any of the other populations.
- About five percent (5%) of the participants report the more acute diagnosis of dementia. Serious dementia may be undercounted because they would not have been able to complete the survey.

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



	Depression	Anxiety	Bipolar	Dementia
■ MSM	62.2%	48.0%	5.9%	6.0%
⬚ MSMIDU	72.3%	52.8%	26.9%	4.1%
□ IDU	64.5%	35.7%	19.5%	3.6%
▨ Hetero	45.3%	28.1%	16.5%	5.7%
◆ TOTAL	60.7%	43.1%	12.3%	5.3%

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



	Depression	Anxiety	Bipolar	Dementia
■ Male	62.2%	45.5%	10.3%	4.8%
░ Female	53.7%	31.8%	21.7%	7.7%
□ Anglo	62.3%	51.1%	12.0%	5.9%
▨ African Am	57.7%	22.5%	14.9%	4.6%
▒ Latino	60.8%	44.2%	10.5%	3.1%
◆ TOTAL	60.7%	43.1%	12.3%	5.3%

Mental Health Treatment

More than 70% of PLWH/A reported having received mental health counseling or treatment since having been infected with HIV. Among those, more than half (53%) have received medication for psychological or behavioral problems and 22% have been hospitalized for their mental illness.

Symptomatic PLWA (81%), Anglos and MSM/IDU (80%) tend to have the greatest need for mental health services. A much higher percentage (86%) of PLWH/A report receiving individual counseling than group counseling (37%).

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. Treatment should be considered for HIV infected persons whose CD4 counts are above 350 cells/uL and if their viral load level rises above 30,000 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, early treatment, and mental health services can be critical for controlling the infection. In addition, all those infected with HIV regardless of stage may be eligible for food, dental, and a variety of other services noted in the continuum of care provided they meet income and geographic criteria.

Given these criteria, the survey asked participants 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 as well as any history of opportunistic infections (OIs) since finding out that they were HIV positive.

Diagnosed with AIDS

Figure 5-1 shows that 58% 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. Notably this is greater than the estimate in the 2003 Title I application. One probable explanation is that this sample of PLWH/A are recruited from caregivers and are more likely to represent those more likely to have symptoms and be engaged in AIDS.

As shown in Figure 5-1, over 60% of Anglo, males and MSM – the first wave of HIV infection – report having AIDS. The percent of IDUs with AIDS (56%) is slightly less than the Anglos and MSM. With under a third reporting AIDS, women and heterosexuals interviewed report the lowest incidence of progressing to AIDS.

Attachment 8 shows that just over half of the PLWH/A report being diagnosed with HIV for over 8 years. Heterosexuals are the only group reporting living with HIV for a significantly shorter period of time, suggesting that they are the newest wave of infections in Sacramento.

Figure 5-1 AIDS Diagnosis and Time Known HIV+ by Gender, Mode and Ethnicity

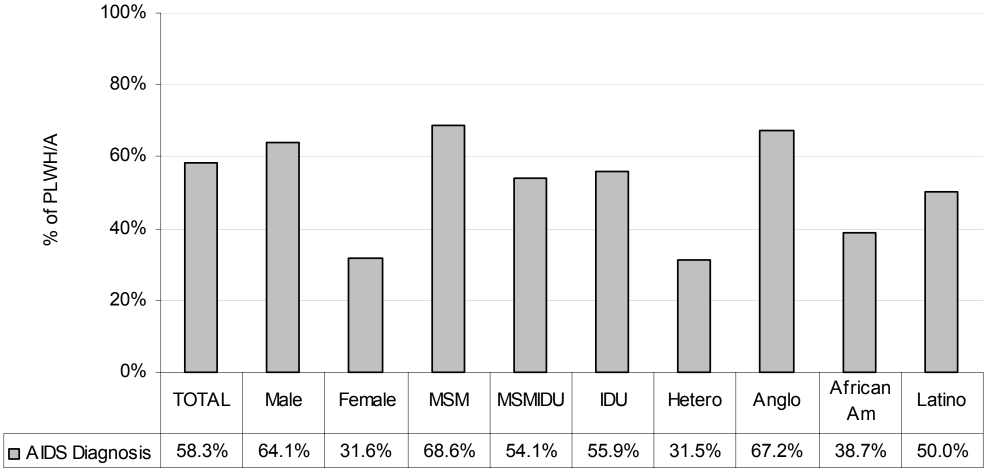


Table 5-1 shows that the most recent populations with HIV and AIDS diagnosis are heterosexuals, African Americans, and women. In the past three years, between 29% and a third of these populations have been diagnosed with AIDS. Nearly half of African Americans and Latinos living with AIDS have been diagnosed in the past six years. The pattern is somewhat different for women. While almost one third of women have been diagnosed over the past three years, more than half have been diagnosed for more than six years.

MSM/IDU, heterosexuals, and Latinos are the least likely to have lived with an AIDS diagnosis longer than 12 years. This may again reflect the later entrance of these populations into the HIV epidemic, the greater fatality of HIV among these populations, and that HIV is being detected among these vulnerable populations at a later stage of infection.

Table 5-1 Time of AIDS Diagnosis

	Total	Male	Female	Anglo	African Am	Latino	MSM	MSMIDU	IDU	Hetero
Less than 3 years	21.4%	20.6%	29.7%	19.0%	34.6%	18.3%	19.9%	20.8%	19.4%	36.8%
3 to 6 years	18.4%	19.0%	13.5%	17.5%	14.6%	33.0%	16.9%	15.0%	30.9%	12.0%
6 to 12 years	36.7%	37.3%	30.3%	38.2%	30.4%	31.3%	37.3%	50.1%	26.3%	34.5%
More than 12 years	23.5%	23.2%	26.5%	25.3%	20.4%	17.4%	25.9%	14.1%	23.3%	16.7%

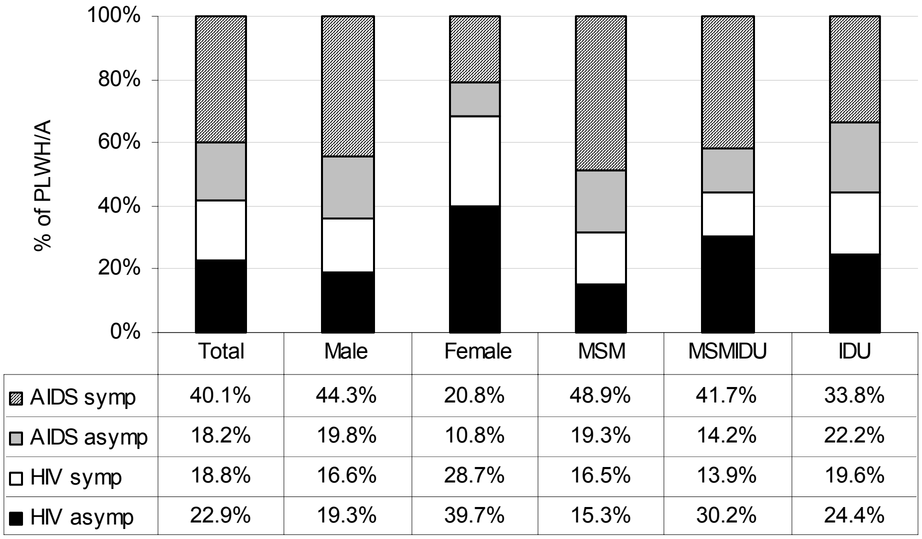
Symptomatic and Asymptomatic

The data indicates that nearly 60% of PLWH/A surveyed currently have symptoms associated with their HIV infection. Of those diagnosed with AIDS, almost 70% report being symptomatic. Among HIV positive non-AIDS diagnosed respondents, 45% report symptoms.

Figure 5-2 and Figure 5-3 show the percentage reporting symptoms by gender, mode of transmission and ethnicity. The graph shows:

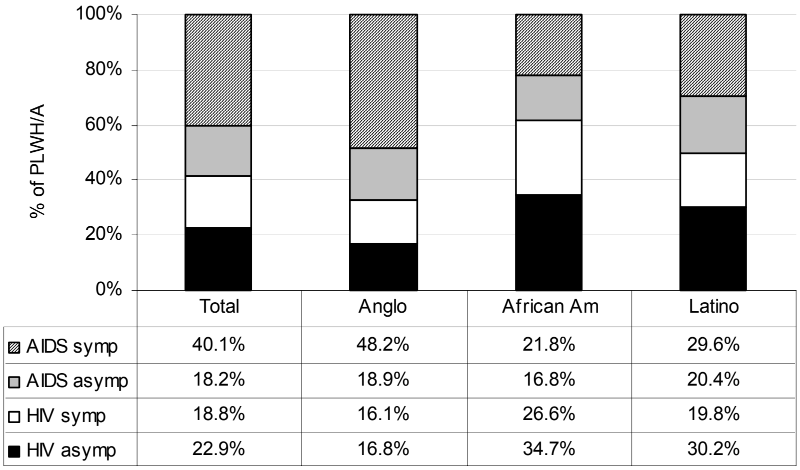
- Women, African Americans, and heterosexuals are more likely to report being asymptomatic.
- MSM and Anglos are the populations most likely to have symptomatic AIDS.

Figure 5-2 % With and Without Symptoms by Gender and Mode



	Total	Male	Female	MSM	MSMIDU	IDU
▨ AIDS symp	40.1%	44.3%	20.8%	48.9%	41.7%	33.8%
▒ AIDS asymp	18.2%	19.8%	10.8%	19.3%	14.2%	22.2%
☐ HIV symp	18.8%	16.6%	28.7%	16.5%	13.9%	19.6%
■ HIV asymp	22.9%	19.3%	39.7%	15.3%	30.2%	24.4%

Figure 5-3 % With and Without Symptoms by Ethnicity



	Total	Anglo	African Am	Latino
▨ AIDS symp	40.1%	48.2%	21.8%	29.6%
▒ AIDS asymp	18.2%	18.9%	16.8%	20.4%
☐ HIV symp	18.8%	16.1%	26.6%	19.8%
■ HIV asymp	22.9%	16.8%	34.7%	30.2%

Although MSM and Anglos have been infected longer, even when controlling for length of infection, the differences in reported symptoms by subpopulations persist. This suggests that MSM are more prone to OIs.

Opportunistic Infections

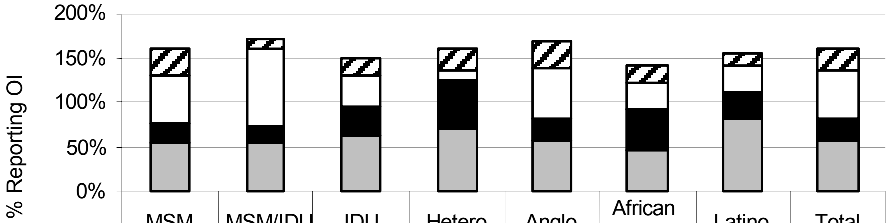
Along with CD4 counts and viral load, an HIV-infected person receives a diagnosis of AIDS after developing one of the CDC-defined AIDS indicator illnesses or opportunistic infections (OIs). Prior to antiviral medications, OIs, particularly PCP, was a major predictor of mortality. However, with the beginning of more effective combination antiviral therapies, there are fewer OIs, and they are less predictive of a continued deterioration of health status.

In the survey, PLWH/A were asked if they have been diagnosed with any of several OIs since learning of their HIV status. Sixty percent (60%) of the participants reported having had an OI, with those infected the longest, MSM and Anglos, reporting significantly more OIs.

Figure 5-4 shows the top OIs reported by PLWH/A:

- Almost 60% of the people reporting OIs said they had herpes or shingles. Latinos and heterosexuals report herpes and shingles more frequently.
- Just over 50% of those who report OIs say they have had thrush or Candidiasis. Over three-quarters of the MSM/IDU who report an OI, report thrush or Candidiasis. Over half of the MSM and Anglos report these OIs.
- The OI with that is the best predictor of mortality is PCP. Over a quarter of those who have had an OI report a history of PCP or pneumonia. It is surprising to see that it is most frequently reported by those newest to the epidemic, heterosexuals and African Americans. It is much greater among women (not shown in the figures), although this finding may not be reliable due to small sample sizes.
- Last, wasting is reported by about a quarter of those who have had an OI. This is a disease that seems to be more prevalent among those who have been infected longest, with those newer to the epidemic, such as communities of color, report less wasting.

Figure 5-4 Opportunistic Infections



	MSM	MSM/IDU	IDU	Hetero	Anglo	African Am	Latino	Total
▨ Wasting	28.2%	12.7%	20.3%	22.9%	28.4%	19.5%	14.7%	24.9%
☐ Thrush	54.3%	84.3%	35.1%	12.1%	57.4%	30.3%	29.5%	51.9%
■ PCP	22.7%	20.4%	32.0%	53.9%	23.8%	45.1%	29.3%	26.5%
▩ Herpes	54.8%	54.2%	63.6%	71.1%	57.8%	47.9%	82.3%	57.3%

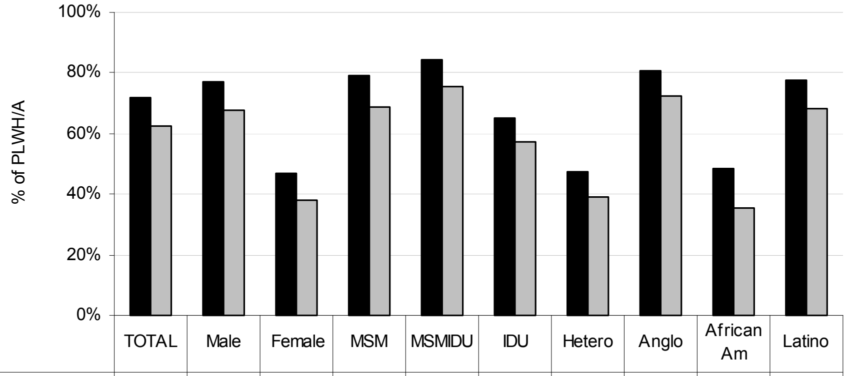
Eligible for Medical Care Based on Stage of Infection

Based on the criteria for antiviral treatment, 63% of the HIV positive population reports symptoms and would be recommended for treatment because their T-cell count is below 350 cells/uL (Figure 5-5). In addition, currently about 40% of PLWH/A report t-cell counts and more than half (72%) report having had T-cell counts drop below 200 cells/uL at some point in their disease progression suggesting and AIDS diagnosis. Consistent with the length of time of infection and the trend in the epidemic, currently Anglos (73%), MSM (67%), and men (68%) are more likely than other populations to have T-cell counts below 350 cells/uL.

In addition to these individuals, based on survey data, there are eight percent (8%) of all PLWH/A who report an AIDS diagnosis, are asymptomatic, and report a current T-cell count below 350. Using these criteria, it is estimated that 68% of PLWH/A are likely to need medical treatment for their infection.

In addition, even for those in early stages of HIV, there is considerable support for early intervention. As noted previously, about 20% of the participants reported becoming infected in the last three years, and several of them are likely to have a choice for early treatment.

Figure 5-5 Current and Lowest T-Cell Counts



	TOTAL	Male	Female	MSM	MSMIDU	IDU	Hetero	Anglo	African Am	Latino
■ Ever below 200 cells	71.9%	77.3%	46.6%	79.0%	84.4%	65.3%	47.5%	80.6%	48.3%	77.7%
▨ Currently below 350 cells	62.5%	67.6%	38.1%	68.6%	75.7%	57.2%	39.3%	72.6%	35.5%	68.4%

6. ACCESS TO HEALTH CARE

Where PLWH/A Go For Medical Care

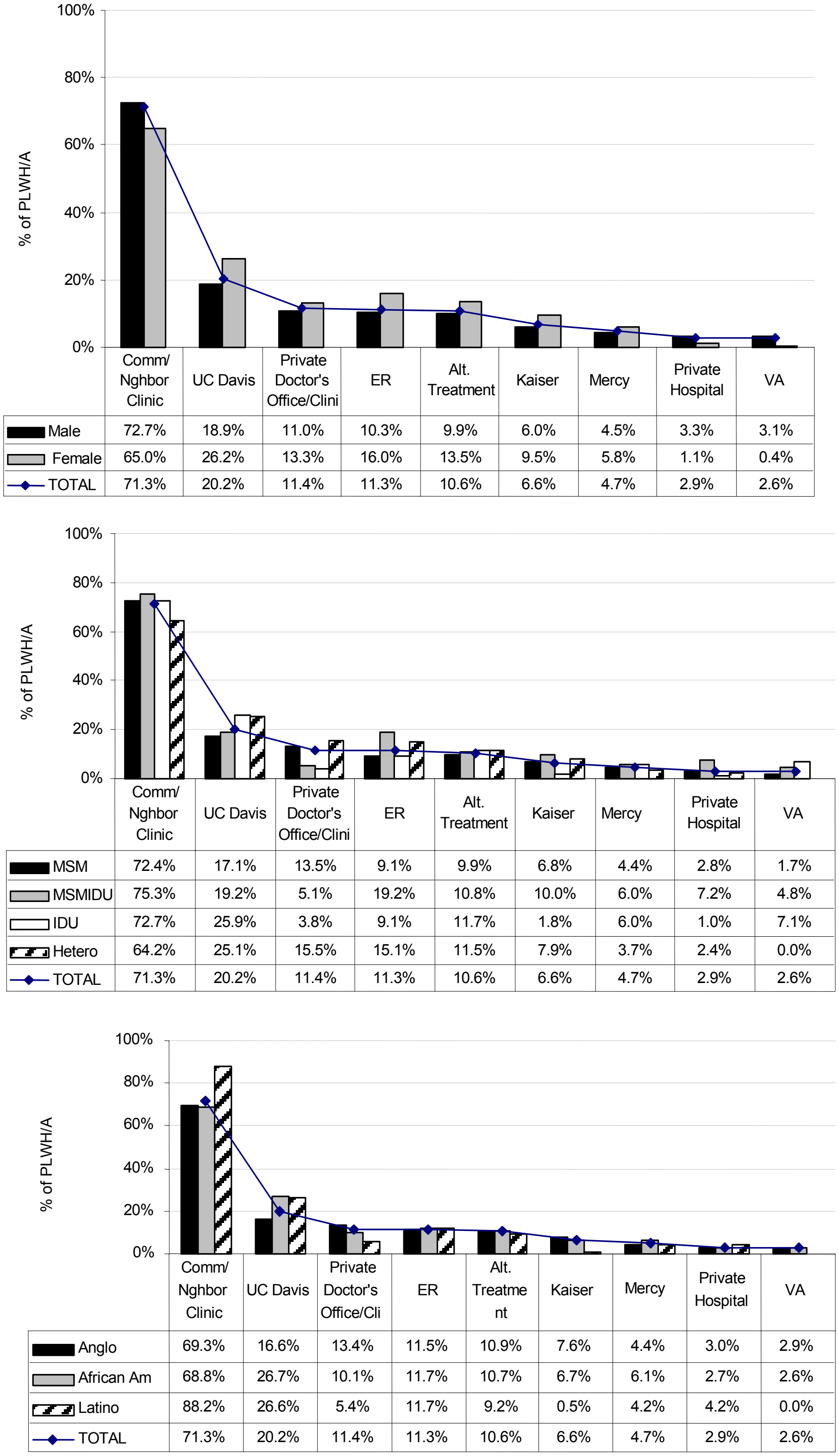
Ryan White Care Act has an objective of 100% access to care for all persons living with HIV/AIDS, regardless of ability to pay. Because Ryan White Care Act funds are to be used as a last resort, it is important to know how many persons have different types of benefits and what those benefits cover.

The vast majority of PLWH/A, whether insured or not, access medical care through a number of clinics and community organizations in Sacramento. By far the largest medical provider to PLWH/A is the community clinic at CARES but UC Davis, private doctors, VA, Kaiser, ER, and other clinics offer HIV/AIDS care as well.

In the survey participants were asked where they received their medical care most often. Of the 383 participants, all but twelve (3%) noted a place of care. About two-thirds reported one place for medical care, 17% report two, and 8% report three. Figure 6-1 displays the sites for the total sample, sex/gender subpopulations, race/ethnicity, and risk group. They are not mutually exclusive – as noted above over a quarter of the PLWH/A reported more than one site where they usually receive their medical care. Overall:

- The vast majority (71%) of PLWH/A receive medical care from community clinics such as CARES and County Clinics.
- While community clinics are the most common site for all populations, Latinos (88%) are more likely than other populations to use community clinics for their care.
- Men living with HIV and AIDS use community clinics, private hospitals, and the VA more than women living with HIV/AIDS, while women use all the other care facilities slightly more than men.
- About 20% of PLWH/A report using UC Davis Medical Center, with women, IDUs, African Americans, and Latinos being more likely to use this site for medical care.
- Slightly more than 11% of the PLWH/A say they use a private doctor or private clinics. Women, heterosexuals, and Anglos are more likely to use private facilities. Because the sample was recruited through community based providers this may be an underestimate.
- Emergency rooms are visited by about 11% of PLWH/A. Women and MSM/IDU are more likely to go to the emergency room than other subpopulations.
- About 11% of PLWH/A receive their medical care from alternative treatment facilities. Alternative treatments are used more by women than by men. Of those reporting alternative care, they also receive medical care. About 30% say they use UC Davis, and about 22% use private doctors, clinics or hospitals.
- About 8% of PLWH/A report using Mercy Hospital and Kaiser Permanente Hospital System.
- About three percent (3%) of PLWH/A report using the VA. Not surprisingly men are much more likely to report using the VA than women. IDUs are also more likely to use the VA for medical care than other populations.

Figure 6-1 Medical Care Sites



	Comm/ Nghbor Clinic	UC Davis	Private Doctor's Office/Clini	ER	Alt. Treatment	Kaiser	Mercy	Private Hospital	VA
■ Male	72.7%	18.9%	11.0%	10.3%	9.9%	6.0%	4.5%	3.3%	3.1%
▭ Female	65.0%	26.2%	13.3%	16.0%	13.5%	9.5%	5.8%	1.1%	0.4%
◆ TOTAL	71.3%	20.2%	11.4%	11.3%	10.6%	6.6%	4.7%	2.9%	2.6%

	Comm/ Nghbor Clinic	UC Davis	Private Doctor's Office/Clini	ER	Alt. Treatment	Kaiser	Mercy	Private Hospital	VA
■ MSM	72.4%	17.1%	13.5%	9.1%	9.9%	6.8%	4.4%	2.8%	1.7%
▭ MSMIDU	75.3%	19.2%	5.1%	19.2%	10.8%	10.0%	6.0%	7.2%	4.8%
□ IDU	72.7%	25.9%	3.8%	9.1%	11.7%	1.8%	6.0%	1.0%	7.1%
▨ Hetero	64.2%	25.1%	15.5%	15.1%	11.5%	7.9%	3.7%	2.4%	0.0%
◆ TOTAL	71.3%	20.2%	11.4%	11.3%	10.6%	6.6%	4.7%	2.9%	2.6%

	Comm/ Nghbor Clinic	UC Davis	Private Doctor's Office/Cli	ER	Alt. Treatment	Kaiser	Mercy	Private Hospital	VA
■ Anglo	69.3%	16.6%	13.4%	11.5%	10.9%	7.6%	4.4%	3.0%	2.9%
▭ African Am	68.8%	26.7%	10.1%	11.7%	10.7%	6.7%	6.1%	2.7%	2.6%
▨ Latino	88.2%	26.6%	5.4%	11.7%	9.2%	0.5%	4.2%	4.2%	0.0%
◆ TOTAL	71.3%	20.2%	11.4%	11.3%	10.6%	6.6%	4.7%	2.9%	2.6%

Insurance Coverage

Non-Insured

In the survey participants were asked to report if they had insurance and, if so, the various forms of health insurance coverage they have. Twenty percent (20%) of the PLWH/A who were surveyed reported having no form of insurance. Figure 6-2 and Figure 6-3 display a profile of those without insurance.

- Despite that fact that poor women often have more insurance options than men, women (23%) and MSM/IDU (26%) are more likely to report not having insurance than other populations of PLWH/A. However, about 87% of the women with at least one child report having insurance.
- Latinos are more likely than any of the other ethnic populations to not be insured.
- People with HIV are slightly more likely to be non-insured, and those that are HIV asymptomatic are much more likely to be noninsured.

Figure 6-2 No Insurance by Gender and Exposure Category

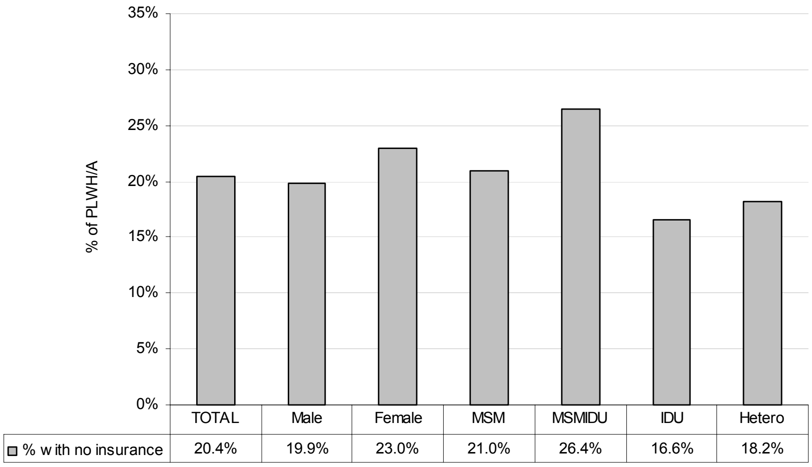
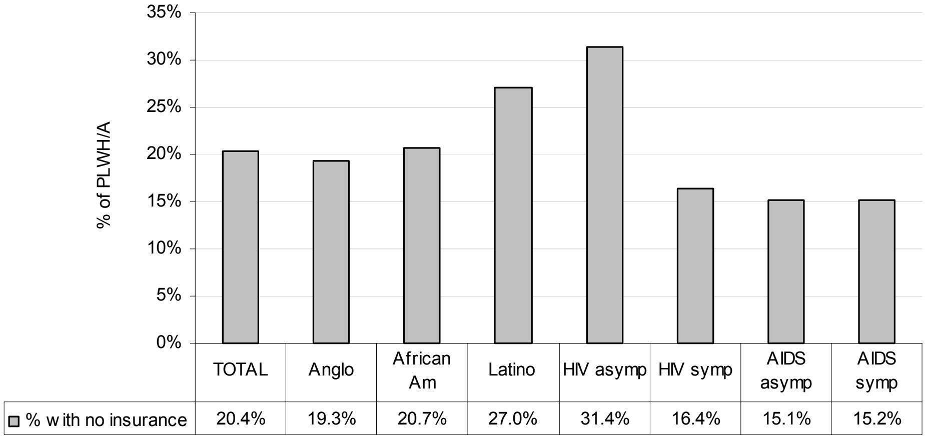


Figure 6-3 No Insurance by Ethnicity and Stage of Disease



In other EMAs women are more insured than men. In California, they have greater access to insurance though various sources including Medi-Cal, Healthy Families (SCHIP) and California Children's Services and have access to care and benefits through programs related to WIC and TANF. While a greater percentage of women in Sacramento receive WIC and TANF than men, a substantially lower percentage report receiving SSI, SSDI, or Medi-Cal/Medicaid.

Insurance Profile

About 80% of the PLWH/A interviewed report some type of insurance. There appears to be an impact of counseling in obtaining benefits as HIV disease progresses; about two-thirds of HIV asymptomatic participants have insurance.

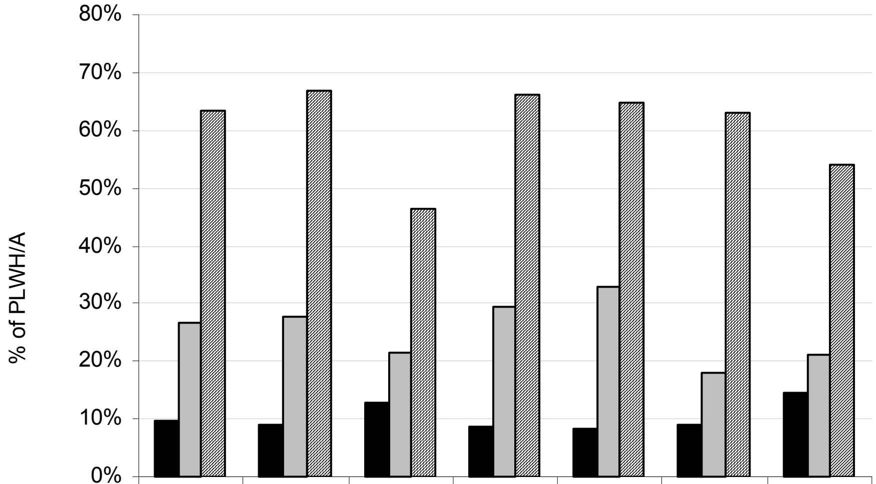
Confirming that insurance is a barrier to obtaining care, only 56% of those out-of-care report having insurance (this may be an unstable estimate due to the small sample size (N=23).

While the level of insurance is not dramatically different by subpopulations, the types of insurance vary by life experience. As expected, Anglos and MSM, due to their generally higher incomes and past work experience, and greater likelihood of having AIDS, are more likely to be eligible for Medi-Cal and/or Medicare. Interestingly, IDUs (83%) are more likely to be insured than other risk groups, while MSM/IDU (74%) are least likely to report having any form of health insurance.

As shown in Figure 6-4 and Figure 6-5 several types of insurance are reported by PLWH/A. Figure 6-4 and Figure 6-5 indicate that the different types of coverage vary by population.

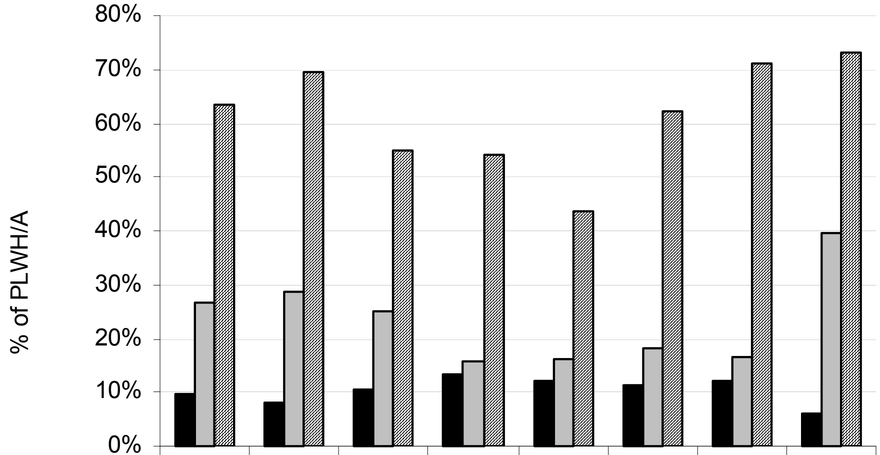
- Medi-Cal/ Medicaid are by far the most common form of insurance for all populations infected with HIV/AIDS in the Sacramento area, with men, Anglos, and PLWA being the groups most likely to have this type of insurance.
- Medicare is the second most common form of insurance for PLWH/A in Sacramento. Overall, more than one quarter of PLWH/A report receiving Medicare. However, a much lower percentage of IDUs, Latinos, and asymptomatic PLWH report receiving Medicare than other groups.
- Overall, a much lower percentage of PLWH/A (10%) report having private insurance than Medi-Cal or Medicare. However, women, heterosexuals, and Latinos report the highest private insurance coverage. This is consistent with their reported higher level of employment.

Figure 6-4 Insurance Coverage – Gender and Exposure Category



	Total	Male	Female	MSM	MSMIDU	IDU	Hetero
■ Private/COBRA	9.8%	9.1%	12.9%	8.7%	8.4%	9.1%	14.7%
□ Medicare	26.5%	27.6%	21.4%	29.5%	32.8%	17.9%	21.0%
▨ Medi-Cal / Medicaid	63.3%	66.9%	46.5%	66.1%	64.8%	63.0%	54.2%

Figure 6-5 Insurance Coverage – Ethnicity and Stage of Disease



	Total	Anglo	African Am	Latino	HIV asymp	HIV symp	AIDS asymp	AIDS symp
■ Private/COBRA	9.8%	8.2%	10.6%	13.4%	12.2%	11.2%	12.1%	6.2%
□ Medicare	26.5%	28.7%	25.2%	15.7%	16.0%	18.3%	16.5%	39.6%
▨ Medi-Cal / Medicaid	63.3%	69.7%	54.9%	54.0%	43.7%	62.4%	71.2%	73.2%

Entitlements and Benefits

PLWH/A access health care through non-insurance benefits, including Veteran's Assistance (VA), public health services, WIC, and through drug reimbursement programs, like ADAP.

VA and Public Health Services

About three percent (3%) of the PLWH/A report VA benefits and an additional one percent (1%) report receiving CHAMPUS, a form of VA for non-military personnel. Among the recipients of VA benefits, about 12% report having no insurance.

Less than one percent of the PLWH/A report receiving public health services or Bureau of Indian Affair benefits. Which is consistent with the small percentage of Native Americans who participated in the needs assessment survey.

Drug Reimbursement

The data suggest that PLWH/A do not have a clear sense of how their medication is purchased. While up to 22% and 44% of the PLWH/A report that ADAP or Medi-Cal/Medicaid paid for their medications, respectively, more than 30% do not know the amount of prescriptions paid for by any of their sources of drug reimbursement.

In addition, 6% of the PLWH/A report that their medication was reimbursed by private insurance, 7% of PLWH/A reports out-of-pocket medication cost, and about two percent (2%) report receiving VA benefits to cover their medications.

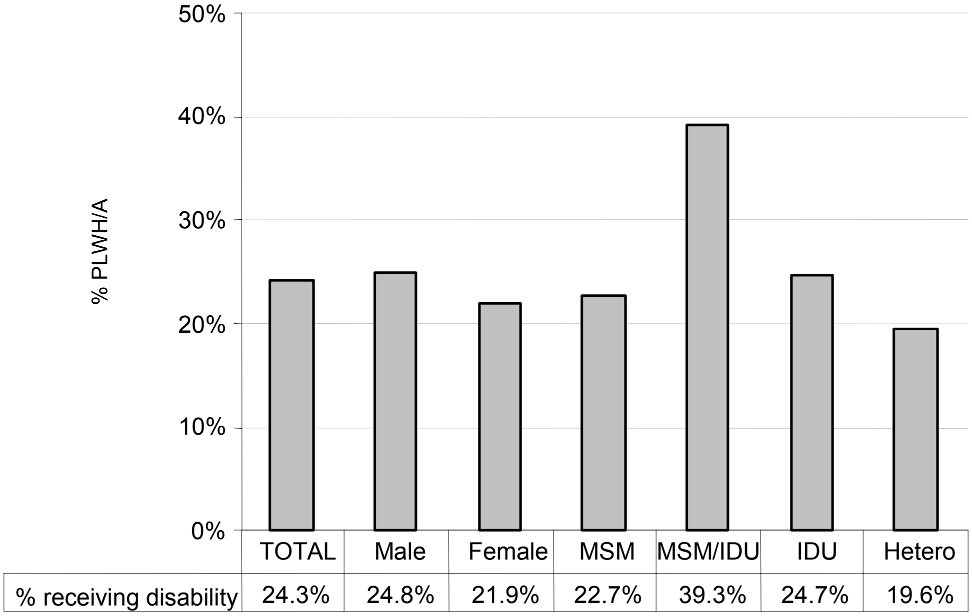
Other Benefits

PLWH/A receive other benefits, 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, eight percent (8%) report not being eligible for benefits with an additional six percent (6%) not knowing whether they qualify or not.

Disability

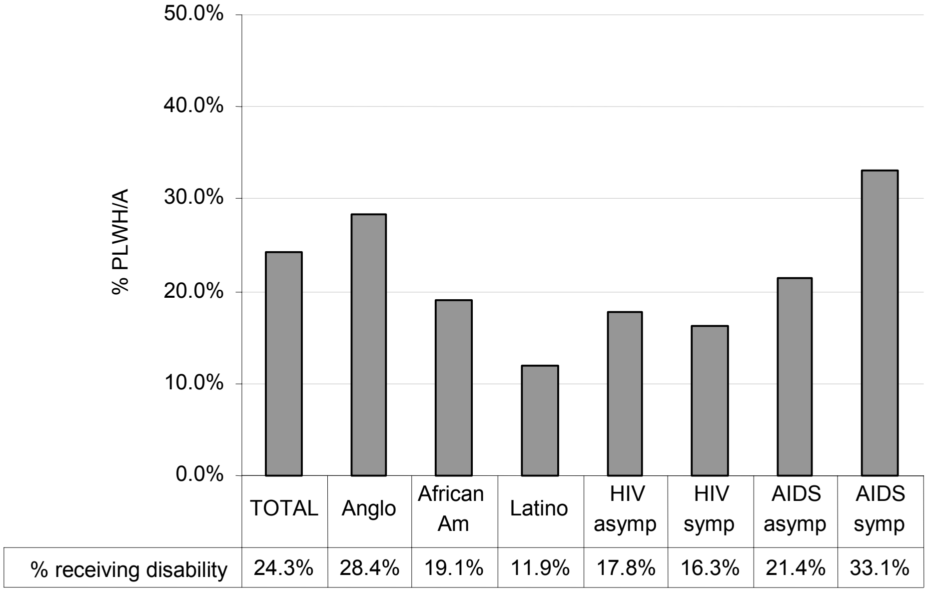
As shown in Figure 6-6 and Figure 6-7, about 24% of PLWH/A report being on long term disability. As expected the rate of disability is higher among those infected earlier, such as males, Anglos, MSM, MSM/IDU, and symptomatic PLWA. Latinos, heterosexuals, women and PLWH are the least likely to receive long term disabilities.

Figure 6-6 Long-Term Disability by Gender and Exposure Category



	TOTAL	Male	Female	MSM	MSM/IDU	IDU	Hetero
% receiving disability	24.3%	24.8%	21.9%	22.7%	39.3%	24.7%	19.6%

Figure 6-7 Long-Term Disability by Ethnicity and Stage of Disease



	TOTAL	Anglo	African Am	Latino	HIV asymp	HIV symp	AIDS asymp	AIDS symp
% receiving disability	24.3%	28.4%	19.1%	11.9%	17.8%	16.3%	21.4%	33.1%

Supplementary Income

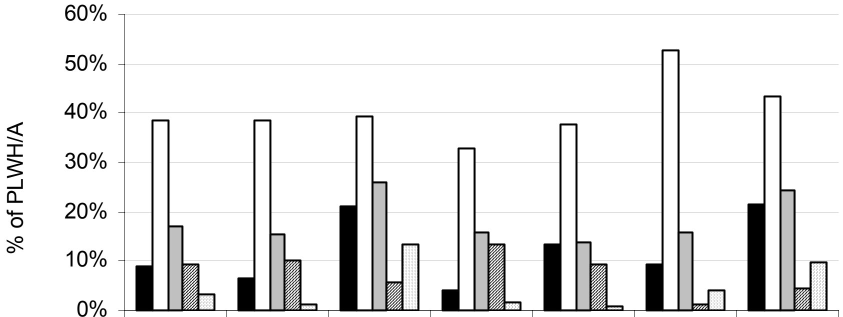
Income supplements include Supplemental Security Income (SSI), Temporary Assistance to Needy Families (TANF), emergency financial assistance, rent assistance, food stamps, and long-term and short-term disability payments. SSI and TANF are based on family income and SSI also required a status of disability. Those on SSI usually qualify for Medi-Cal/Medicaid.

Emergency assistance paid for by Ryan White usually covers rent, utilities, food, or medication reimbursements. Access to emergency financial assistance is through a case manager.

The proportion of PLWH/A reporting supplemental sources of income is shown in Figure 6-8 and Figure 6-9. The data show that:

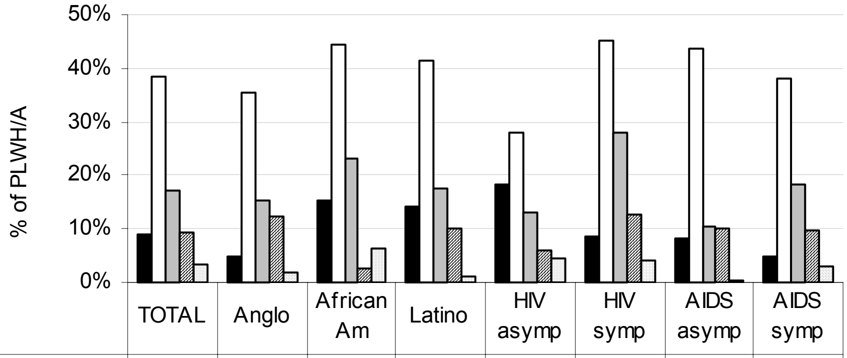
- Indicative of the low income of PLWH/A, more than one-third (39%) report receiving SSI and 17% report receiving housing subsidies. IDUs, heterosexuals, African Americans, and symptomatic PLWH are more likely to receive SSI. With the exception of IDUs, these are basically the same groups that receive rental subsidies. In addition, women are much more likely than men to receive rent supplements.
- About 9% of the PLWH/A report receiving direct emergency financial assistance (DEFA), usually used for utilities, rent, or emergency medical treatment. However, women, African Americans, heterosexuals, IDUs, and asymptomatic PLWH are the least likely to receive DEFA.
- Surprisingly, only 9% report receiving food stamps and three percent (3%) report receiving TANF/CalWorks. However, women (21%), heterosexuals (22%), and African Americans (15%) are much more likely to receive food stamps than any other group. Not surprisingly, women (13%) are much more likely to receive TANF/CalWorks than men.

Figure 6-8 Supplemental Income – Gender and Exposure Category



	TOTAL	Male	Female	MSM	MSMIDU	IDU	Hetero
■ Food stamps	9.1%	6.5%	21.1%	4.0%	13.3%	9.4%	21.6%
□ SSI	38.6%	38.4%	39.2%	33.0%	37.9%	52.9%	43.5%
▒ Subsidized housing	17.1%	15.2%	26.0%	15.9%	13.9%	15.7%	24.4%
▨ DEFA	9.3%	10.2%	5.5%	13.3%	9.2%	1.3%	4.4%
□ TANF / CalWorks	3.3%	1.1%	13.4%	1.4%	0.8%	3.9%	9.9%

Figure 6-9 Supplemental Income-- Ethnicity and Stage of Disease



	TOTAL	Anglo	African Am	Latino	HIV asymp	HIV symp	AIDS asymp	AIDS symp
■ Food stamps	9.1%	4.8%	15.4%	14.2%	18.3%	8.5%	8.2%	4.9%
☐ SSI	38.6%	35.6%	44.6%	41.4%	28.1%	45.0%	43.8%	37.9%
▒ Subsidized housing	17.1%	15.2%	23.0%	17.4%	12.9%	28.1%	10.3%	18.3%
▨ DEFA	9.3%	12.5%	2.7%	10.2%	6.0%	12.7%	10.1%	9.8%
☐ TANF / CalWorks	3.3%	2.0%	6.3%	1.3%	4.6%	4.3%	0.4%	2.9%

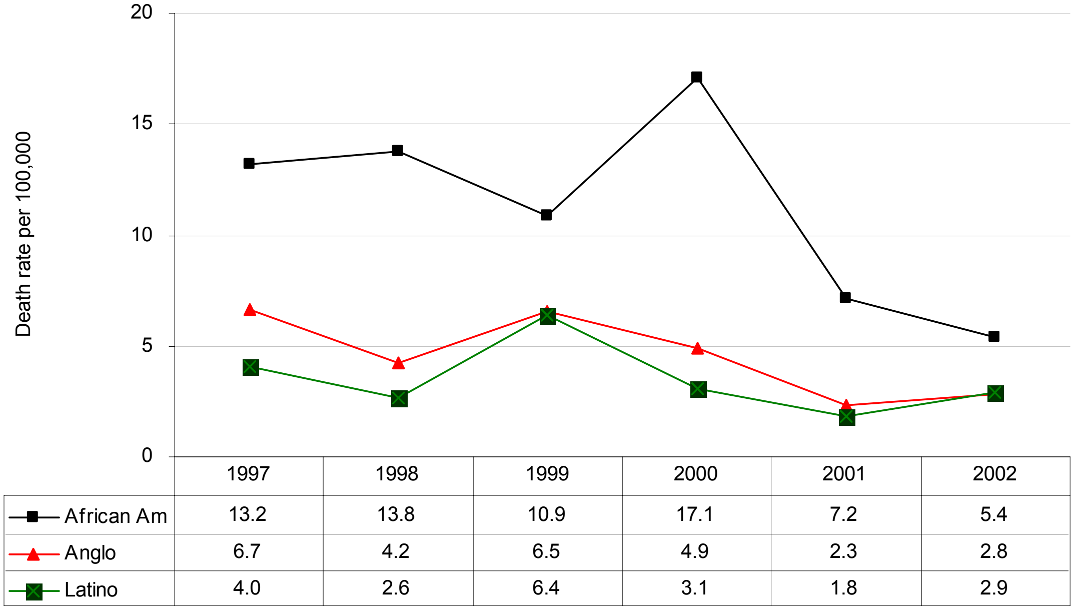
7. OUTCOMES

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

As a decline in diagnosed AIDS cases and increase in those living with AIDS is observed, it is not surprising to see that the overall death rate (defined by the crude death rate per 100,000[7]) has declined. As shown in Figure 7-1, a sharp decline in death rates has occurred among all ethnic populations since 1997. However, the death rate among the African American population has remained higher than that of the Anglo and Latino populations. At the end of 2002, the death rate among African Americans was almost twice as high as that of Anglos and Latinos.

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



	1997	1998	1999	2000	2001	2002
■ African Am	13.2	13.8	10.9	17.1	7.2	5.4
▲ Anglo	6.7	4.2	6.5	4.9	2.3	2.8
☒ Latino	4.0	2.6	6.4	3.1	1.8	2.9

This large discrepancy between African Americans and other ethnic populations is somewhat moderated by the case fatality rates shown in Figure 7-2. The "case fatality rate" measures the death rate among a cohort diagnosed with AIDS during a certain calendar year. This "fatality rate" measures the death rate among a cohort diagnosed with AIDS during a certain calendar year and tracked to determine year of death. For instance, in 1997, 192 were diagnosed with AIDS, of which as of this date 46 have died, indicating a fatality rate of 24%. This is a more accurate reading of the impact of the continuum of care than death rates. Out of the 45 new cases that have been diagnosed in 2002, three have died, indicating a fatality rate of 7%. This

---

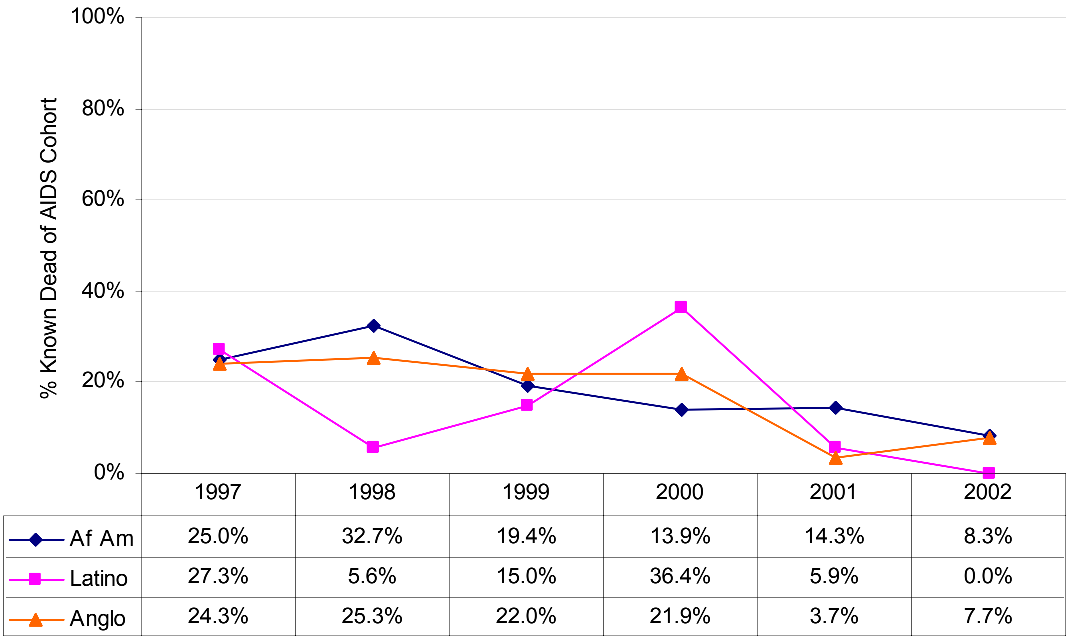
[7] The mortality rate, or rate of death per 100,000 reflects everyone who was recorded by a doctor on the death certificate as dying of AIDS-related disease for a specific year. .

probably reflects some reporting lag in the newly diagnosed AIDS cases since case fatality rates are expected to decline for more recently diagnosed cases because of improved care and shorter periods of time with AIDS.

Figure 7-2 indicates that fatality rates have fluctuated for African Americans, Anglos, and Latinos. For instance, in 1997, Latinos had the highest fatality rate, yet, with the exception of the peak 2000, they have had the lowest fatality rates among the three ethnic groups. Anglos, on the other hand, maintained a 205 fatality rate through the late 1990s into 2000. This probably reflects their earlier infection and more advanced HIV status. By 2001, the fatality rate among Anglos dropped sharply to 4%. The fatality rate for African Americans increased from 1997 to 1998 but has fallen since and is comparable to the Anglo in 2002.

The fatality rates for Latinos and Anglos appear to decrease sharply from 2000 to 2001 and this is not the case for African Americans. As mortality rate decreases for all populations there a few deaths reported each year. The sharp variations in rates may be explained by the small number of total deaths each year. For instance, there were a total of eight deaths reported among the cohort diagnosed in 2001: four African Americans, two Anglos, one Latino, and one Native American.

Figure 7-2 % Fatality Rate - Deceased by Year of Diagnosis



	1997	1998	1999	2000	2001	2002
◆ Af Am	25.0%	32.7%	19.4%	13.9%	14.3%	8.3%
■ Latino	27.3%	5.6%	15.0%	36.4%	5.9%	0.0%
▲ Anglo	24.3%	25.3%	22.0%	21.9%	3.7%	7.7%

Physical and Mental Health

Other outcomes measured for the system of care are current and changed 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 tested is that access to care, and in particular to new HIV drug therapies, have 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 care 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 7-3 and Figure 7-4 report the current and perceived change in physical health and emotional health. It is divided into three independent groups: 1) PLWH who are asymptomatic 2) PLWH who are symptomatic, and 3) those who report being diagnosed with AIDS (69% symptomatic and 31% asymptomatic).

Physical Health of PLWH With No Symptoms

- Over 60% of PLWH rate their physical health as good or excellent.
- Nearly half (47%) say that their physical health is better now as compared to when they first sought treatment and another 42% say their health is the same.

Physical Health of PLWH With Symptoms

- In contrast, far fewer asymptomatic PLWH (39%) in Sacramento report that their health is good or excellent. About 52% report their physical health as fair.
- While about the same percentage of symptomatic PLWH as asymptomatic PLWH say their health is a little better now that when they first sought treatment, the biggest difference between the asymptomatic and the symptomatic PLWH is that far more symptomatic PLWH (43%) say that their health is worse than before they sought treatment.

Physical Health of PLWA

- Not surprisingly, PLWA have a higher percentage than PLWH reporting poor health (16%). Still, about 40% say they have good to excellent health. Not surprisingly, they report the least improvement in health compared to those at other stages of infection since they started treatment (43%). In comparison to symptomatic PLWH, symptomatic PLWA are currently doing slightly better with 41% reporting good to excellent health compared to 39% of the symptomatic PLWH.
- Women, heterosexuals, and African Americans report the best physical health with about 20% reporting excellent health.

Emotional Health of PLWH With No Symptoms

The emotional health of PLWH is a little worse than their physical health. Symptomatic PLWH in particular 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.

- Nearly half of the asymptomatic PLWH in Sacramento report good to excellent emotional health, and 44% say it is better now than when they started treatment.

Emotional Health of PLWH With Symptoms

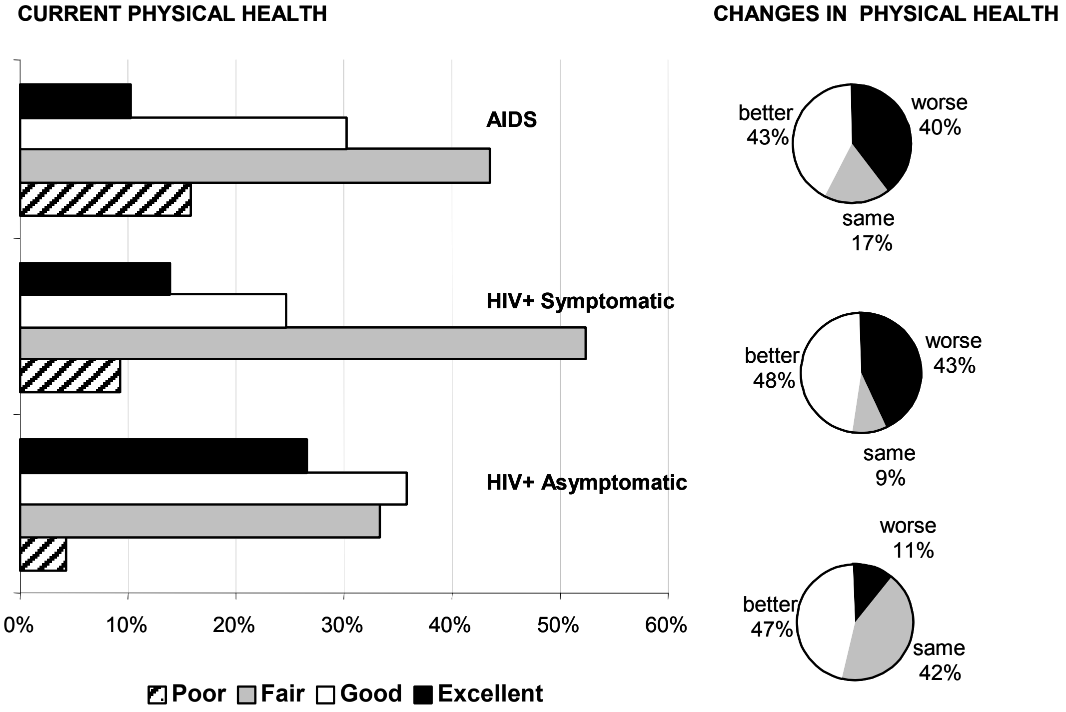
- Compared to both asymptomatic PLWH and PLWA, a larger percentage of symptomatic PLWH report poor (19%) or fair (52%) emotional health. This may be connected to concern of their recent diagnosis. But a majority (57%) reports better emotional health than their initial diagnosis.
- In contrast, about the same number of symptomatic PLWH say their emotional health is good or excellent, and significantly fewer say their emotional health is better now than when they first started treatment.

Emotional Health of PLWA

- About 47% of PLWA report excellent or good emotional health, and over 56% report an improvement in health since they started treatment.
- While more than half of PLWH/A report an improvement in their mental health, MSM/IDU (44%) report the poorest improvement in emotional health.

Overall, based on improvement in both physical and emotional health, the care system is making an impact. Well over half of PLWH/A report that their physical and emotional health are the same or better. HIV symptomatic populations report the having the worst outcomes.

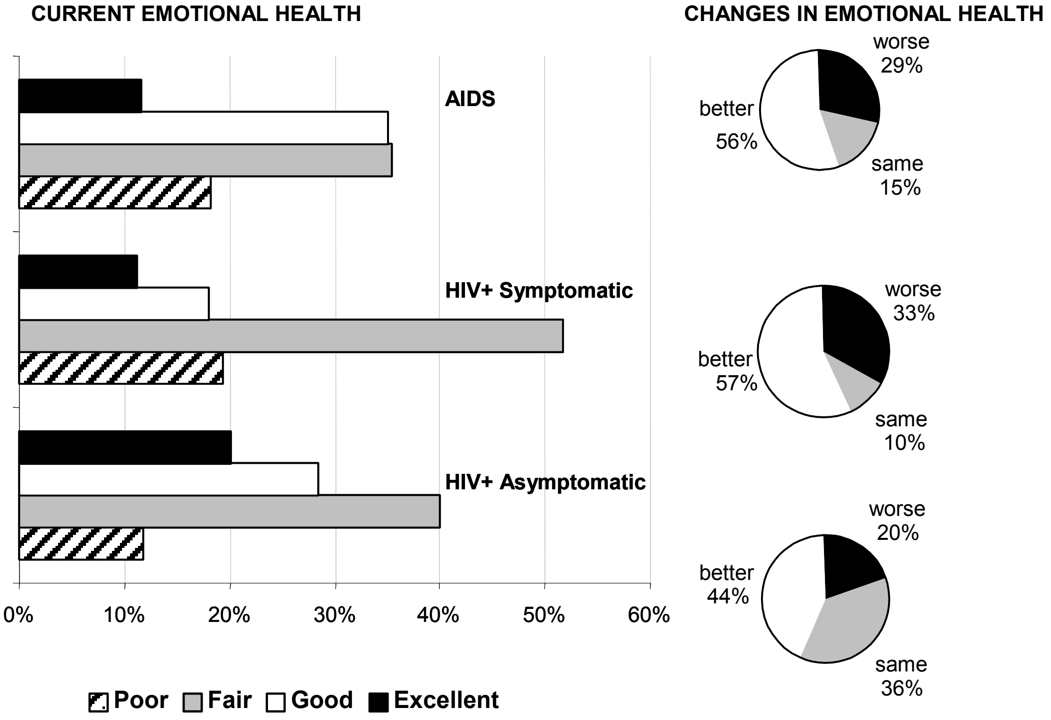
Figure 7-3 Quality of Life – Physical Health



CURRENT PHYSICAL HEALTH

CHANGES IN PHYSICAL HEALTH

Figure 7-4 Quality of Life – Emotional Health



CURRENT EMOTIONAL HEALTH

CHANGES IN EMOTIONAL HEALTH

Quality of Life – Qualitative Comments

While there were many participants who said their mental and physical health on a whole were currently satisfactory, they recount times of difficulty, which may have occurred in the past. The following qualitative comments from focus groups and survey commentary illustrate the current quality of life concerns of the participants.

The majority express a similar state of mind to this heterosexual male who says, "*As far as my mental state, it's a seesaw. There are times that I struggle but I'm down and back and there are other times that I'm up and everything is good.*" Another IDU female acknowledges that, *"I'm doing pretty good*", although she's experienced times of very poor health. *"I've had pneumonia twice ten months apart and I could have died both times. I'm getting better now they've got me on the right medicines. I was taking more than 100 medicines a day. I got so sick on them that they took them off a year and put me on and I was getting sick on them."* She says, *"Emotionally it's like a little roller coaster. It goes up and then it goes down and then it goes up and then it goes down. When I start going down I just try to deal with what I need to deal with. My life has gotten a little better in the last six years."*

Similarly, a heterosexual female compares her prior state to the current one, showing her improved quality of life comparatively speaking. She says, *"I was diagnosed bipolar in 1996. I used to get thrush all the time and I had (name not recognized) and I had blood clot in my groin. And now I'm cool again. And everything seems to be going okay. [I've] Been in the mental hospital several times down in Orange County. One day I was lying in bed watching TV and it felt like someone cut off the top of my head and plugged in a big electrical socket, and my blood pressure was down to 20/15 and I thought I was dying. I thought for sure I was gone, but it took them four days to raise my blood pressure up to normal. And now I take medication to keep my blood pressure up. So, I'm doing okay. The AIDS medication I was on, I was on three different kinds, and [my doctor] did a blood test, he said they weren't working for me. He switched me to two other medications and one I broke out with a rash all over one face and that has calmed down..."*

The desire to self-medicate on illegal substances to forget the constant pain was expressed by an incarcerated female who says, "*It seems like the drug use seems to help, self-medicate yourself so the pains and the things that you are feeling from the affects of the HIV to your body and to your system, so you don't feel these things. You put it out of your mind that you have this disease… sometimes all that will take my pain away is a drug. I know its part of my emotional and my mental health. I was talking to my case manager and she said, 'did it make you feel better?' and I was like,' yeah'. I almost felt normal doing that. It's like, what can we do to help ourselves mentally?"*

On the contrary, this incarcerated male believes the opposite when it comes to drug use and his quality of life, claiming that in the time he has stayed clean, *"in those six months, my T-Cells have gone up three fold, my attitude has gotten better and my anger has gotten better."*

A heterosexual male tries his best to look past all the medical problems and pain by being a *"very spiritual person and there is nothing much that can get me down. I've got a lot of things wrong with me internally. I've got Stage 4 liver disease and they are looking to start me on the Interferon. My memory is like an old man's memory. I've got a valve collapsed and a few other things that are going on. I've got … arthritis. I'm kind of a mess and I don't look it. People always say hey you look good and I hate it. I take it in stride."* He finds consolation in peer settings. He says, "*it's nice to be in a group such as this like the group that we have at [name of agency] where I can express that and it can be understood"* though *"I stay pretty much at a 10 in pain. I live with pain every day of my life and that's just the way it is. I wake up with pain and I go to sleep with pain. I'm on a lot of meds."*

Considering the pressures some of the PLWH/A deal with, the fact that many of them cope as well as they do is surprising. For example, one incarcerated African American MSMs expressed very low mental and physical states due to the stress of everything surrounding being positive. He says, "Y*ou have to remember that most of us with HIV are dealing with having HIV, being ostracized from our families because of it. We have spousal or partnership problems, either heterosexual or homosexual. There are drug abuse problems that are happening. Sometimes there are mental health issues that you are being involved with; you are on psychotropics and things along those lines. You are dealing with your disease and your fatigue from it. You've got five, six, or seven things going on at one time plus unemployment and things along those lines. You are trying to dive through this massive maze of paperwork and also try to stay clean and sober. For the person who is educated and who's diligent, it's a difficult task to begin with."*

A heterosexual female also agrees *"my emotional health is not very well right now because I'm going through the grieving process. It's very scary because sometimes I stay with my mom and my children and other times I stay other places. My family also has problems with me because they want me to eat out of paper cups and paper plates and bleach toilets and showers and wash my clothes separately."*

This focus group participant suggests that until there is a cure, his best method is *"living all these years without taking anything. And I've been traveling and I've been doing all these good things. So I've been living my life the way I've been living...Europe, South America, Central America, nothing about HIV or having AIDS. That's what kills you. Thinking about it."*

8. MEDICATION AND ADHERENCE

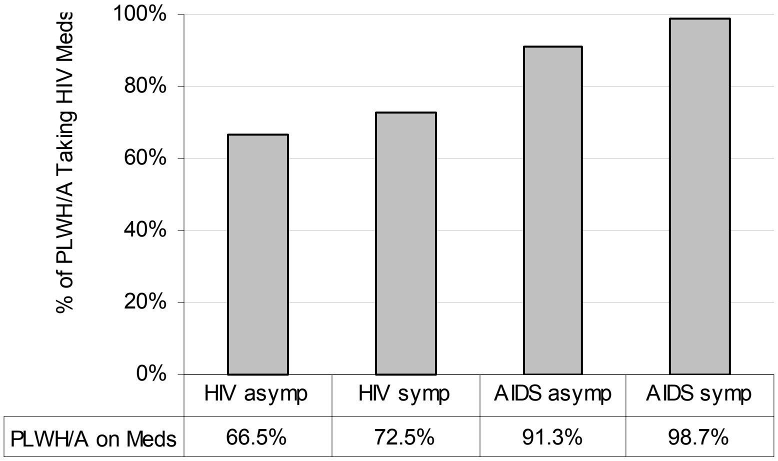
Medication and Adherence

Taking Medication

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.

Eighty-five percent (85%) of all PLWH/A report taking medicines to treat their HIV infection, but as shown in Figure 8-1, there is a linear relationship with stage of disease, starting with 67% of asymptomatic PLWH taking medication to 99% of symptomatic PLWA reporting taking medication.

Figure 8-1 Medication by Stage of Infection



PLWH/A with a longer history of HIV disease are more likely to be have taken HIV medications. For instance, nearly 90% of men, MSM, and Anglos report having taken medications. On the other hand, women (70%) and heterosexuals (63%) are the least likely to have taken HIV medications – most likely as a function of their newer HIV status.

Adherence

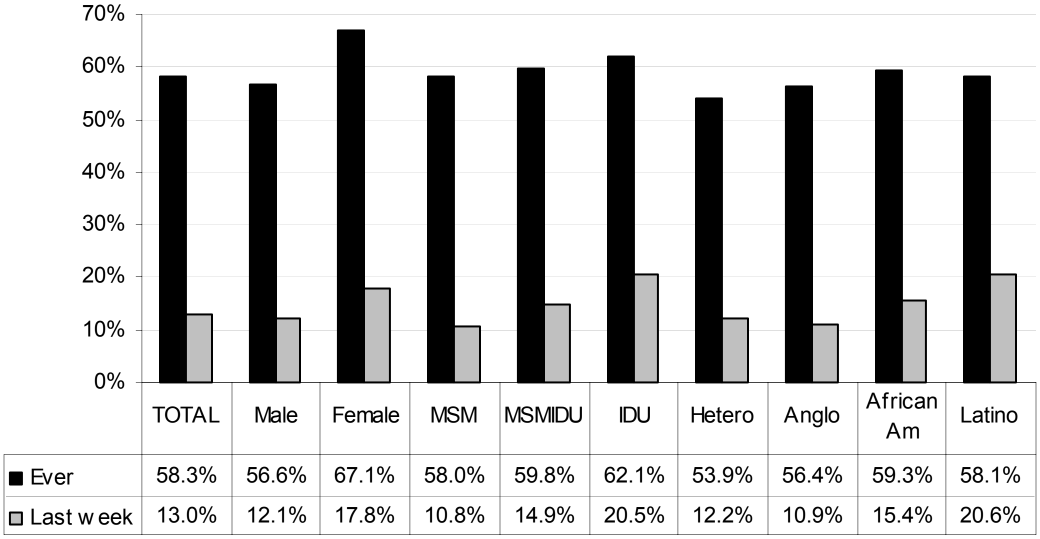
Forty-two percent (42%) of PLWH/A report never skipping their medications, and at the other extreme, ten percent (10%) have stopped taking their medicines.

- Women are more likely to skip taking their medications than men and almost 20% have stopped taking the medications.

- On the other hand, heterosexuals adhere substantially more than other exposure categories, with nearly half reporting never skipping their medicines.
- Notably, symptomatic PLWA are more likely to skip taking their medication than asymptomatic PLWH/A or symptomatic PLWH (shown in Attachment 8 through Attachment 14).

Figure 8-2 shows adherence to medications across different subpopulations. The black bar represents never stopping medication, and the gray bar indicates stopping at least once in the last week. Women and IDUs report a slightly greater problem adhering to their medication schedule, and Latinos indicate that they are less likely to take their meds in the last week.

Figure 8-2 PLWH/A Who've Skipped Their Medications

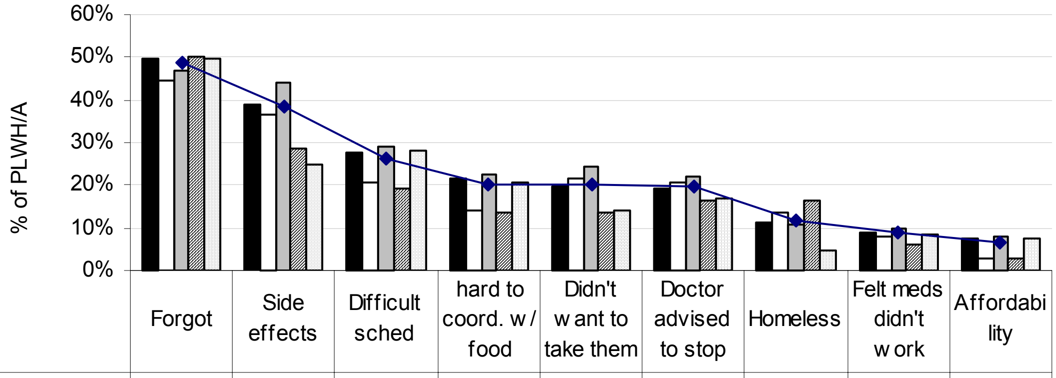


	TOTAL	Male	Female	MSM	MSMIDU	IDU	Hetero	Anglo	African Am	Latino
■ Ever	58.3%	56.6%	67.1%	58.0%	59.8%	62.1%	53.9%	56.4%	59.3%	58.1%
▨ Last week	13.0%	12.1%	17.8%	10.8%	14.9%	20.5%	12.2%	10.9%	15.4%	20.6%

Figure 8-3 and Figure 8-4 indicates that the top reasons for discontinuing medications for all PLWH/A.

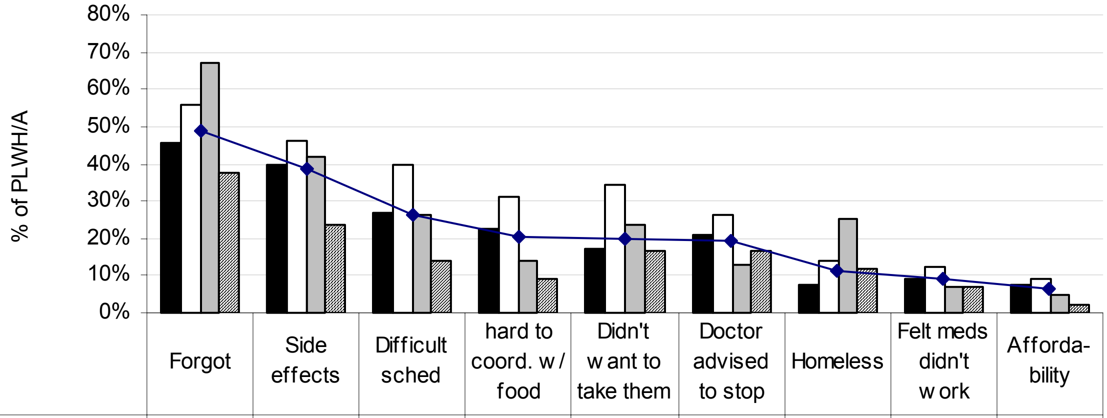
- Among all groups, forgetting to take them (49%) is typically the major reason for skipping medication, with IDU (67%) and MSM/IDU (56%) being the most likely to forget.
- PLWH who are symptomatic and PLWA who are asymptomatic also have higher rates of forgetting than asymptomatic PLWH and symptomatic PLWA.
- The next two most common reasons cited for skipping doses were side effects of medications (39%) and the difficult medication schedules (27%). MSM/IDU (46%) and Anglos (44%) appear to have a greater problem with side effects than other groups. MSM/IDU (40%) also report the most trouble with the medication schedule.
- The three least cited reasons for skipping medications include not understanding the instructions (less than one percent), not wanting others to see taking medications (6%) and the feeling that medicines were no longer needed (6%).

Figure 8-3 Reasons for Skipping or Stopping Medications by Gender and Ethnicity



	Forgot	Side effects	Difficult sched	hard to coord. w/ food	Didn't want to take them	Doctor advised to stop	Homeless	Felt meds didn't work	Affordability
■ Male	49.8%	38.8%	27.7%	21.4%	19.9%	19.3%	11.1%	9.1%	7.3%
□ Female	44.6%	36.8%	20.4%	14.1%	21.4%	20.7%	13.7%	7.9%	2.6%
▒ Anglo	46.9%	43.9%	29.2%	22.5%	24.5%	22.0%	10.9%	9.9%	8.0%
▨ African Am	50.2%	28.6%	19.4%	13.8%	13.6%	16.3%	16.2%	6.1%	3.0%
░ Latino	49.9%	25.0%	28.3%	20.7%	14.0%	16.9%	4.7%	8.5%	7.6%
—◆— TOTAL	49.0%	38.5%	26.5%	20.2%	20.1%	19.6%	11.5%	8.9%	6.5%

Figure 8-4 Reasons for Skipping or Stopping Medications by Mode of Transmission



	Forgot	Side effects	Difficult sched	hard to coord. w/ food	Didn't want to take them	Doctor advised to stop	Homeless	Felt meds didn't work	Afforda-bility
■ MSM	45.6%	39.7%	27.0%	22.3%	17.3%	20.8%	7.3%	9.2%	7.6%
□ MSMIDU	56.1%	45.9%	39.8%	31.0%	34.1%	26.3%	14.0%	12.2%	8.9%
▒ IDU	66.9%	42.1%	26.3%	14.2%	23.4%	12.7%	25.2%	7.0%	4.7%
▨ Hetero	37.6%	23.5%	13.9%	9.0%	16.7%	16.7%	11.6%	7.1%	2.3%
—◆— TOTAL	49.0%	38.5%	26.5%	20.2%	20.1%	19.6%	11.5%	8.9%	6.5%

Overall, 20% of PLWH/A report they stopped taking their medications under advice from a doctor. MSM/IDU (26%) and Anglos (22%) cited this reason more frequently than other groups.

Medication Adherence – Qualitative Comments

Though most of the quantitative analysis shows forgetting to take medication (49%) as the largest problem with medical adherence, the focus groups participants tended to speak more about the adverse side-effects (39%) of the medications themselves.

A heterosexual woman describes her problems with the side effects of the medication and its effect on her life saying, *"I've had some serious problems. I had an allergy where I was getting hives about two inches on me, that's not a small hive…I've had several problems…because my T-Cells were almost 1,000 and the medicines were killing me. They were constantly sending me to the hospital and I wanted to get off of the meds so bad. [My doctor] told me that I was crazy, that I needed to get serious medical care, that I was choosing to die, that there was something wrong with me. Instead of taking me off of medications he was going to put me on some other meds. I was in tears. All I wanted to do was stop taking my medicines because I was just sleeping all day long."*

Another woman talked about the difficulties of being pregnant and taking the HIV medications. She says, *"I was just three months pregnant a week ago and the medication was making me so sick and I ended up having a miscarriage because I was throwing up all day long. This time during my pregnancy I started getting so sick from the medication that I stopped taking it because I was throwing up all day long and I couldn't handle that. I ended up having to drink this and drink that because I was dehydrated. With the medication I had to stop because I was also not able to drink fluid or eat anything all day long. I just stopped taking it without asking my doctor. Then when I went back into the doctor he asked me why did you do that?"*

Interestingly, while overall in the survey men are more likely to adhere to medications and less likely to abandon their regimen, in focus groups, men were more likely to express their difficulty continuing with the medications and decidedly discontinue with the regimen. A Heterosexual male recounts, *"When I started this thing I had one of those doctors that told me the best thing to do was to take the medicine right away. I got on the medicines and I actually had a TV in my bathroom because I spent the majority of my life in the bathroom. I got tired of crawling from the bathroom to the bed so I took a holiday once and I felt so much better. I went back on the drugs again and it started over so I said to hell with that stuff."*

An African American Male IDU says, *"It's my plan to come completely off the medicines forever. It's my belief that if I don't it will be the medicines that kill me. I plan to put in a proper diet and eat properly and I believe that I will cure myself. I know someone who has done it."*

In addition to the physical side effects, an African American MSM also discussed the effects of the medications on his appearance. He candidly related, *"I was taking Coletro for a while and that was started when I was first diagnosed and I was spending the whole day on the drum. I was also having side effects of the bloated abdomen and a hump on my back. I said to my doctor if I have to look deformed to live I would rather die. I know that sounds vain*."

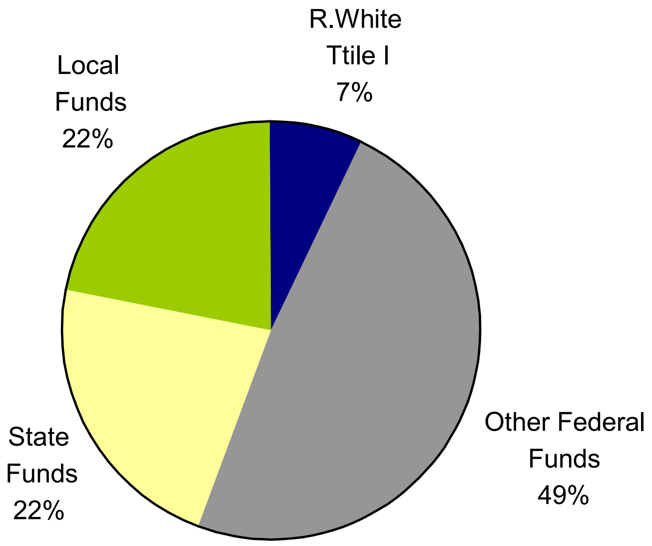
A recently incarcerated African American man brought to light the challenges of adhering to a medication schedule while in prison. He says, in jails*, "breakfast is served at 4:00 or 4:30 in the morning, lunch is served at 10:00 or 10:30 in the morning and dinner is served 4:00 or 4:30 in the afternoon. If you are having to take your medications, med call is twice a day and a lot of time you have to take these meds with food. None of it corresponds, they could care less."*

9. SERVICES

Funding Sources for HIV/AIDS Services

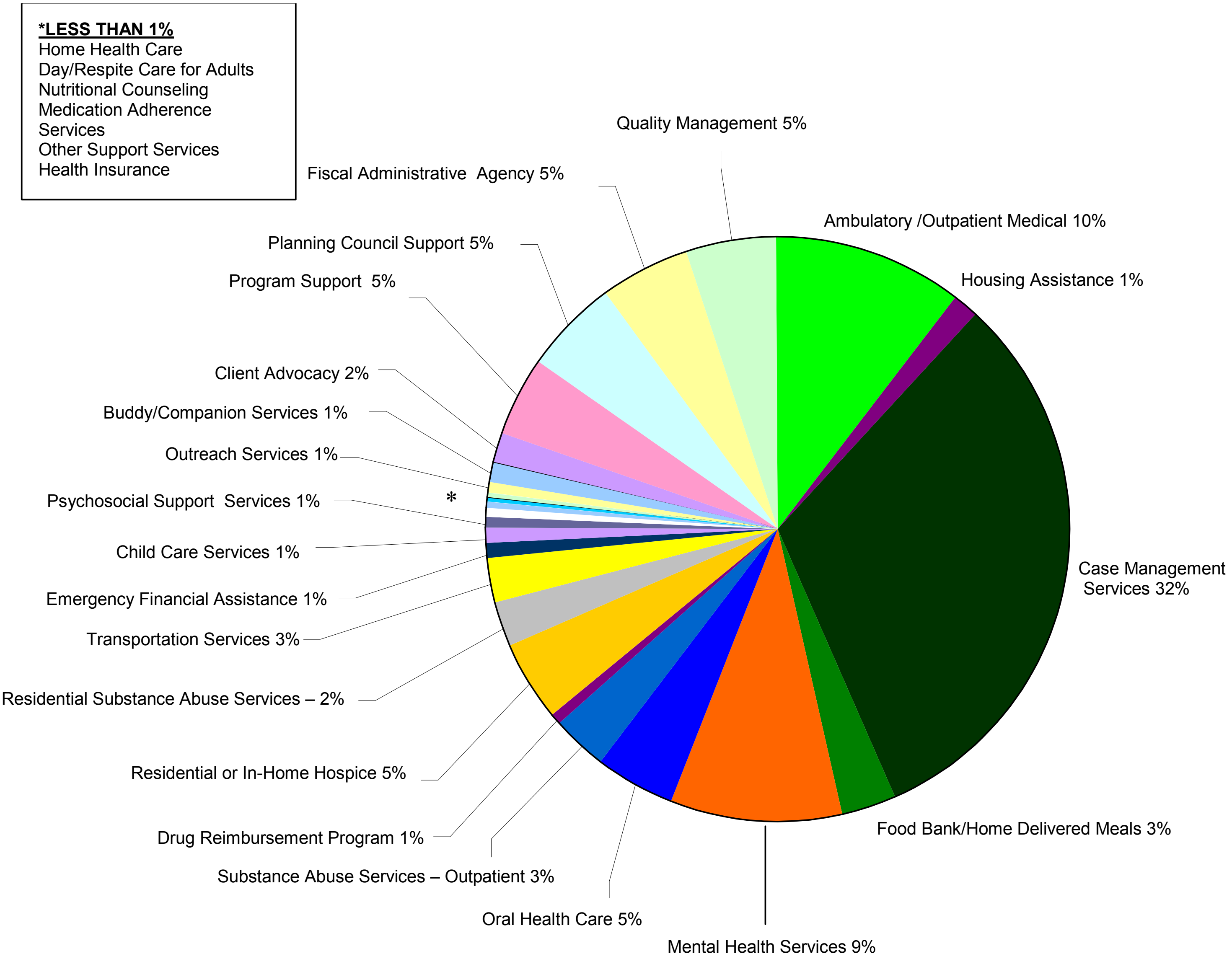
Based on the 2003 Title I application, the Sacramento EMA has about $38.8 million in public funding for HIV/AIDS care. That includes about $2.8 million in Ryan White Title I funds, or under 8% of all funding. The majority of other federal funds ($18.7 million) are for Medi-Cal and Medicare. State funds include the ADAP program ($3.4 million) and home and community based support services ($2.9 million). The remainder includes 8.5 million in local funds. The distribution of funds is shown in Figure 9-1.

Figure 9-1 Distribution of $38.8 Million HIV/AIDS Funding – 2003



Within Title I, the planned 2003 allocation of the projected $3 million in RWTI funds for each service is shown in Figure 9-2. By far, case management has the largest allocation, 32% ($943,263). It is followed by outpatient medical care with an allocation of 10% ($311,389) and mental health services, with an allocation of 9%. After that dental care and residential or in-home hospice care were each allocated 5%. Food, transportation, and outpatient substance abuse were each allocated 3%.

Figure 9-2 Ryan White Title I Allocations



Service Categorization

Consumers were asked to rank their awareness of, need, demand, and utilization for forty-two services, representing twenty-three service categories shown Table 9-1. The twenty-three service categories are shown in order of the Council's 2003 service priorities.

Table 9-1 Service Categories 2002 Priorities

2003 Priority	Service
1	**Ambulatory Outpatient Medical Care** Outpatient medical care Medical Specialist Complementary care
2	**Housing Assistance** Housing info Rental asst Supportive housing
3	**Case Management Services** CM help w/ benefits Benefits counseling Intake session Vocational referrals
4	**Food Bank / Home Delivered Meals** Food bank Food vouchers Delivered meals Nutrition supplement
5	**Mental Health Services** MH 1-1 Family counseling Bereavement counseling
6	**Oral Health Care** Dental care
7	**Substance Abuse Services - Outpatient** Subst abuse counseling Subst abuse assessment Subst abuse 1-1 counseling Subst abuse Grp Subst abuse family counseling Subst abuse peer group
8	**Drug Reimbursement** Medication Reimbursement
9	**Residential or In-home Hospice Care** Residential Hospice Care
10	**Substance Abuse Services - Residential** Sub Abuse Serv – Residential
11	**Transportation Services** Transportation Taxi vouchers
12	**Emergency Financial Assistance** Financial asst
13	**Child Care Services** Child care
14	**Psychosocial Support Services** MH group Peer counseling
15	**Medication Adherence Services** Adherence support
16	**Other Support Services**
17	**Nutrition Counseling** Nutrition counseling
18	**Home Health Care** Home health care
19	**Health Insurance** Insurance Asst
20	**Outreach Services**
21	**Buddy/Companion Services** Buddy emotional support Buddy household tasks Buddy advocate
22	**Day/Respite Care for Adults** Adult day care
23	**Client Advocacy** Client Advocacy

While ambulatory/outpatient care has remained the top priority, other priorities have changed considerably from 2002-2003. The following text will determine the “agreement” between the Council and consumer for needed services.

Most Needed Services

Top Rated Needs

Each PLWH/A who participated in the survey was asked if “you needed the service in the past year.” The percentage needing the service is shown in Figure 9-3 starting on the next page.

The graphs are presented in order of the 2003 Service priorities of the Council. Within the twenty-three service priorities, sub-services are ranked by the percentage of PLWH/A who report they needed the service in the past year. The numbers on top of some bars represent the ranking of the top twelve sub-services by the consumer.

Figure 9-3 indicates that, from the perspective of stated need, the Council and PLWH/A have some differences.

- The top two most needed services[8] are not within health care: 1) case management and 2) food vouchers. These correspond to the third and fourth ranked services by the Council, although case management is, by far, the category that received the greatest RWTI allocation.
- Housing information is ranked as a 2nd priority by the Council, but in the quantitative data, is not perceived as such a great need by the PLWH/A. The qualitative focus groups, however, show that there are strong feelings about the need for housing.
- Outpatient care is ranked as the third highest need by PLWH/A, and is ranked as the first priority by the Council.
- Three of the top ten highest priorities are in the case management category, and two of the top ten are in outpatient medical care and food.
- Dental care is ranked 4th by consumers and 6th by the Council.
- Taxi vouchers are ranked 11th by consumers and transportation is ranked 11th by the Council.
- Notably, the perceived need for substance abuse treatment is relatively low even though it is ranked 7th out of 21 categories (excluding support categories) by the Council. While ranked higher among IDUs, it is not near their top needs that include outpatient medical care, food pantry, rental assistance, and case management.
- Nearly 54% of PLWH/A reported they needed one-on-one mental health counseling. The other mental health services, family counseling and bereavement counseling, were needed by under 20% of PLWH/A. In contrast, mental health is ranked 5th out of 21 services by the Council.

---

[8] “Most needed” refers to aggregate ranking of consumers who say they needed each service; it is not the report of individual rankings or sorting of services.

Services—Qualitative Comments

The top ranked consumer need for case management was reflected in focus group discussion. In focus groups there were far more complaints than complements about case management. However, as demonstrated by the large number receiving care and drugs, the system does move PLWH/A into care. Several participants were complementary. For example, female said, *"I'm going to tell you right now that [name of agency] are the most knowledgeable people that I've seen. Even with my caregivers at [name of agency], my physician, my case worker, my AOD counselor, I love them, they are great, they get a lot rolling when there's things that need to be taken care of they get things rolling. When it comes down to the information and knowledge..."*

There is a sense that the level of care is related to finding the right case manager. For example, an African American MSM says, *"[name] is the best case manager that they've got there. I met him when he was walking and helping somebody. That's when I first got to [name of agency] and I just overheard this conversation that said see me tomorrow and I'll take care of it for you. I thought damn just like that? I talked to him that day and that next day he was my case manager. He's helped me ever since I've been out here."*

There is also a perception that case managers are more a gatekeeper to services than facilitating the process of obtaining medical and wrap around services. For example, one female said, "*They act like they won't tell you what's available so when you screw up or there's something that you can't handle, you don't know a lot of times. I didn't know that they could help me with my rent. I didn't know that they could help me with my bills until today when you guys were talking. I didn't know that that service was even available. The counselors act like that money, those food vouchers, those bus tickets are theirs and they don't inform the clients."* A male said, *"If they did the job that I think they should be doing we wouldn't be in meetings like this, things would be working a lot better. Their function should be to access other organizations for the funds and they don't do that. They have no idea. They have no training and they have no desire".*

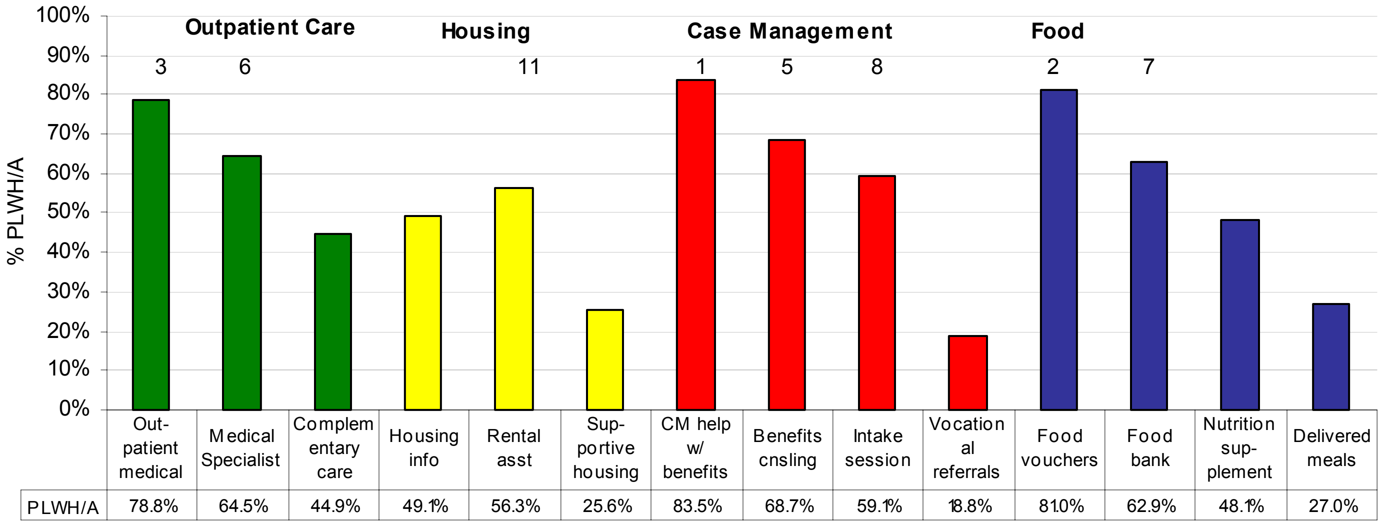
The need for basic services like food and housing was a prevalent theme in the focus groups, and the link to case management was clear in the focus group discussions. One woman echoed the sentiments of many when she said, "*Vouchers that they give away, they run out at the beginning of the month, they give them to who they want to give them to. We can't get them when we need them, which is usually at the end of the month. They give them out at the beginning of the month and when you run out of food and need them there's none."* A male experiences the same issue, saying, *"For me it depended on availability. If she [case manager] had twenty of them in her desk drawer she could spend one but if she only had nine she couldn't spare it."*

While housing was not among the most needed services ranked by consumers, many persons in the focus groups referred to the difficulty in finding and keeping housing. One participant said that, *"When [we were] homeless and living in a car they kept telling me [about housing] and we made four or five appointments and then they said they didn't have anything or the funding for it ran out. We just ended up staying in the car."*

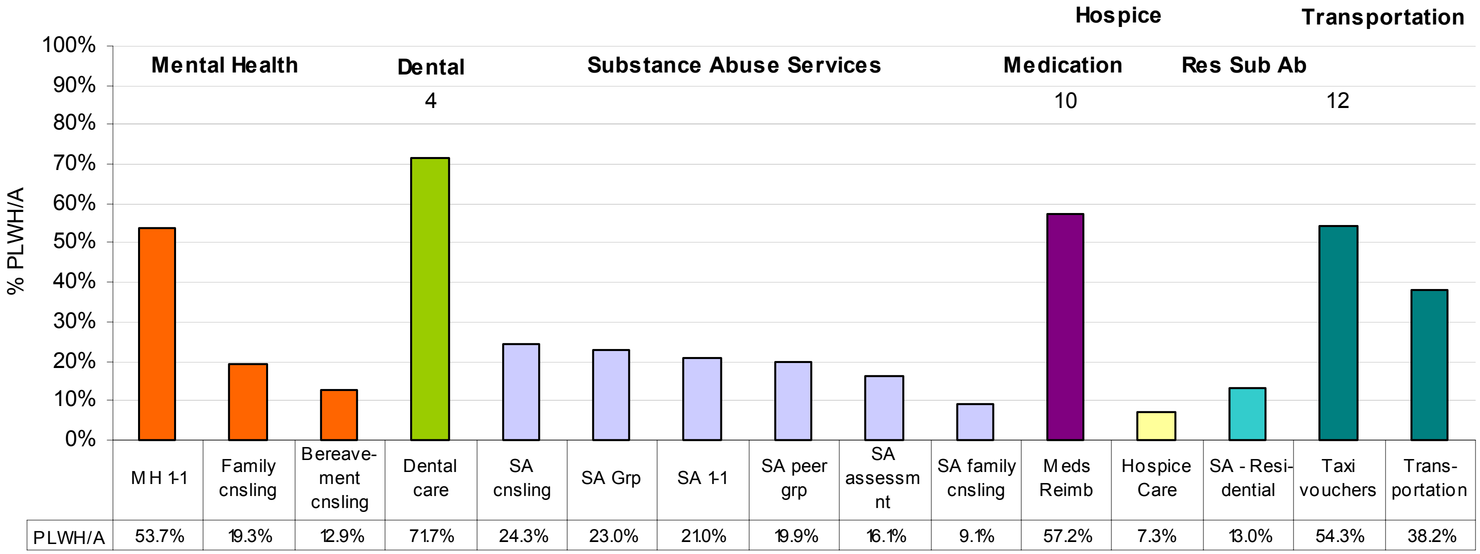
One theme in the focus group, among all types of participants, is the feeling that the system is becoming "less personal" and bureaucratized. A white consumer sees *"the Catch 22 is about three or four years ago the planning council put a healthy amount of money towards a central system that took away from direct services for us. Somehow that money got swallowed up and nothing happened."* Another Latino consumer contrasted his past service with the present tension of cutbacks. *"He's been good to me but he's not my regular doctor. And when I called about some of my problems, he really took care of them. And now this place is all about the bureaucracy and this place lost a lot of money and I understand the short staff and I understand that, but I just want them to be more compassionate. They just seem like they don't care. And I'm fortunate that I'm working…but the attitude is really shitty here and that's what I don't like and I don't like to be waiting or treated like a second class citizen."*

Complementary care was not perceived as a high need by the consumers. However, focus group participants indicated some interest. For example, a woman who uses complementary therapies felt that it greatly helped with circulation. She said, *"I was doing the acupuncture but I had to do the co-pays and I was doing that for awhile until my money ran out. Then I didn't get the massage therapy but I recently started getting it again because they got some extra funding from Ryan White. I'm still doing the massage therapy because it helps my legs"*. Another Anglo MSM noted, *"I don't want to sound like a broken record but they are providing 60% of the effort is on staff rather than client services. In '95 I started taking acupuncture now I have to pay $10.00 each visit. Why is it that my herbs and vitamins for a three months supply cost me just as much as medication?*"

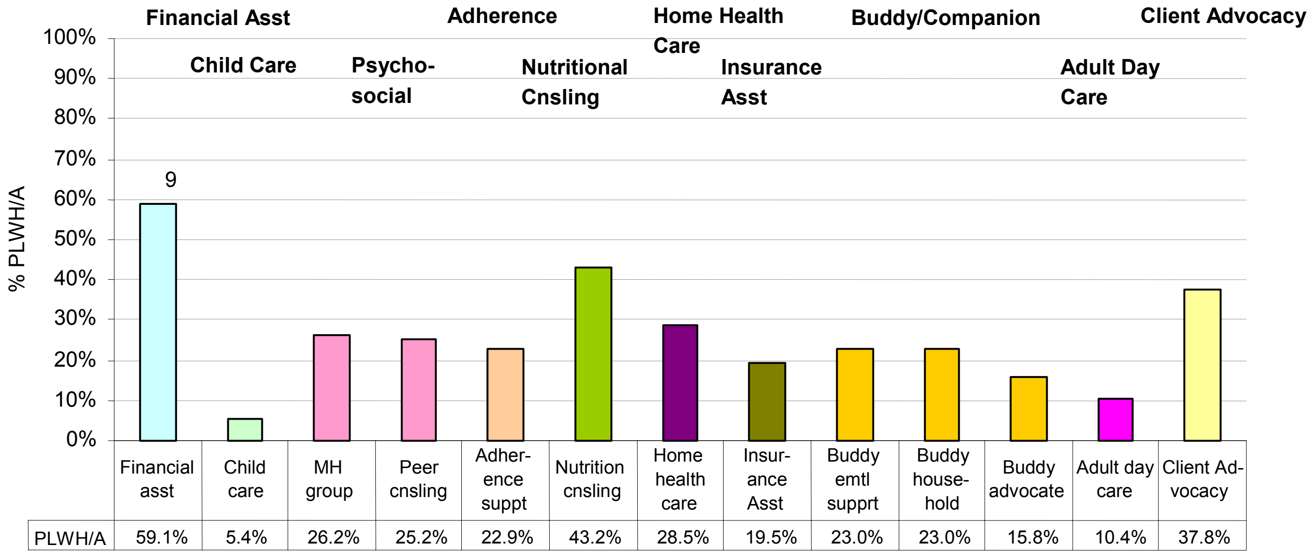
Figure 9-3 Ranked Service Needs



	Out-patient medical	Medical Specialist	Complementary care	Housing info	Rental asst	Sup-portive housing	CM help w/ benefits	Benefits cnsling	Intake session	Vocational referrals	Food vouchers	Food bank	Nutrition sup-plement	Delivered meals
PLWH/A	78.8%	64.5%	44.9%	49.1%	56.3%	25.6%	83.5%	68.7%	59.1%	18.8%	81.0%	62.9%	48.1%	27.0%



	MH 1-1	Family cnsling	Bereave-ment cnsling	Dental care	SA cnsling	SA Grp	SA 1-1	SA peer grp	SA assessment	SA family cnsling	Meds Reimb	Hospice Care	SA - Resi-dential	Taxi vouchers	Trans-portation
PLWH/A	53.7%	19.3%	12.9%	71.7%	24.3%	23.0%	21.0%	19.9%	16.1%	9.1%	57.2%	7.3%	13.0%	54.3%	38.2%



	Financial asst	Child care	MH group	Peer cnsling	Adherence suppt	Nutrition cnsling	Home health care	Insurance Asst	Buddy emtl supprt	Buddy household	Buddy advocate	Adult day care	Client Advocacy
PLWH/A	59.1%	5.4%	26.2%	25.2%	22.9%	43.2%	28.5%	19.5%	23.0%	23.0%	15.8%	10.4%	37.8%

Service Needs: Differences by Gender, Ethnicity, and Risk Group

Need Differences by Gender

There are significant differences by gender in the perceived needs for HIV/AIDS services. Selected services with a difference between men and women of more than 8% are shown in Figure 9-5. This figure shows that men perceive a greater need for medical care, and women perceive a greater need for support services, but, for the most part, for other top services men and women have about the same rankings.

While they may have similar rank order, the greatest gap in perceived need between men and women is for dental care, with men reporting a much higher need. This may be because of more advanced symptoms of AIDS or greater demand. For example, one male focus group participant echoed many others when he described his need for dental care. He complained about the *"availability of the doctors."* Noting that there *"is only one dentist on staff there and he's there two or three days a week. He's so booked and if you need an appointment now but the next available one is three months out…it's frustrating."*

Men also report a higher need for medical specialists. Interestingly, in the focus groups, women were more likely to bring up specialty care. For example, one woman said, *"Referrals to any specialist that we need like a podiatrist or to somebody for our teeth or a neurologist, that takes a long time. I have a problem with the referrals taking so long to see these people or to see these specialists or the people who specialize in what we need; that's a problem."*

Among the top perceived needs, women report a much greater need than men for transportation. One woman in a focus group said, *"Transportation is a real big issue especially when you have children. We can't always run around in the last minute trying to get to where you need to be is really a bitch."* Another said, *"A lot of funding should go to transportation, hiring people specifically for transporting patients to and from their appointments or more funding towards bus passes… A lot of it is transportation because there are people that make appointments for themselves and can't get to it so they end up not being able to go which does affect their health."*

While more women were likely to mention transportation in the groups, men also noted a need for transportation. For example, one said, *"Transportation sucks here in this town. To get from Culfax to Arbor, one bus leaving in the morning. If you have like one appointment, you're here for the day waiting and waiting and waiting…until 3:15 to get on that bus. Now, if you have your own car it takes like 15 minutes to get here. On the bus it takes two and a half hours."*

Another noted, *"Sometimes I call [provider name] for rides and they cancel because they don't get a volunteer out to me so I'll have to reschedule my doctors appointments for a later date and hopefully [provider name] will find me a ride for that day."*

Most of the largest gaps in perceived need between men and women are among the services with lower overall need. As might be expected there is a greater perceived need among women for childcare. However, there is also a greater perceived need for bereavement counseling, adult day-care and respite care, and emotional support from buddies.

One mother described her dependence on an informal network of childcare saying, *"Childcare is different because in the clinic it's a family and you know women that are there and have an appointment it's like can you watch my kids for a little bit while I go take care of this? Nobody is going to say no."* While there is no childcare available, she depends on the clinic staff and clients to be responsible for her children during her appointments.

This informal accommodation does not work for everyone. Another mom is more reluctant to bring her child. She says, *"I have a 5-year-old so sometimes to get to my appointments it's really a drag especially if you don't have a way to get there…then the appointments are so spread out … really keeps you from it. [Y]ou've got to try to figure out where you are going to put your kid when you get to your appointments. It's a drag."*

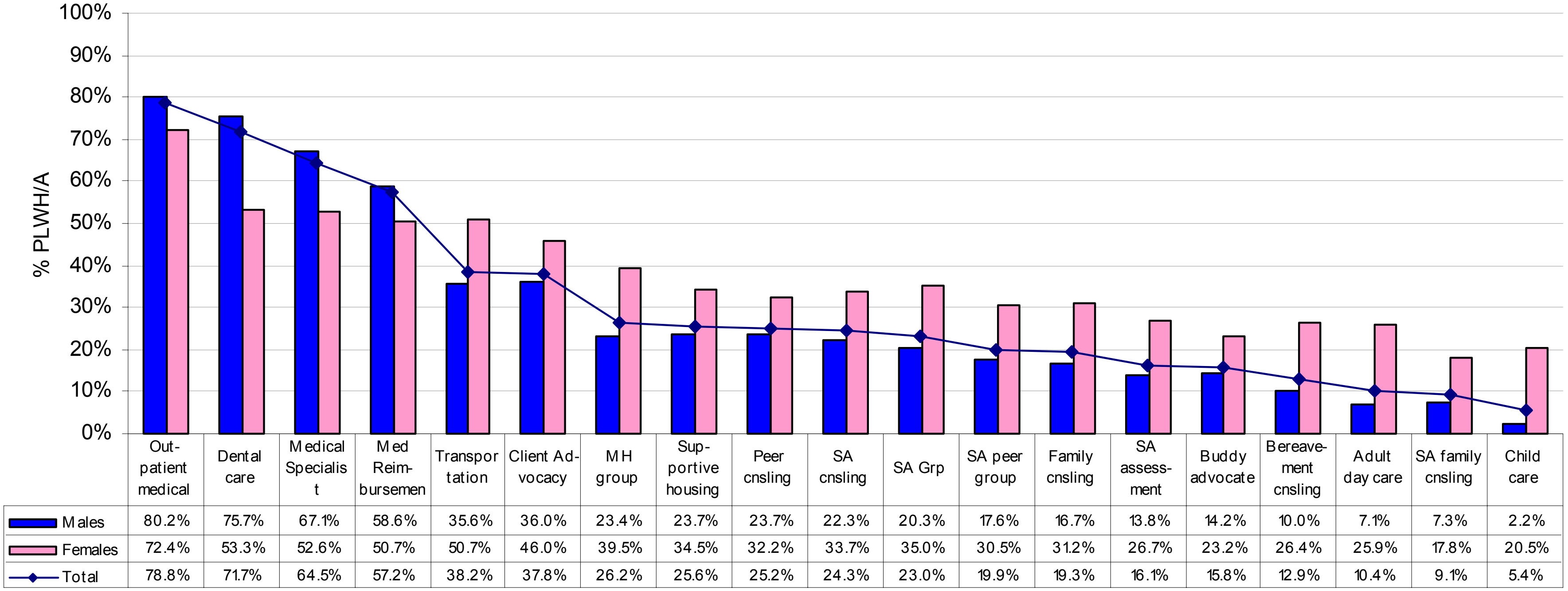
Bereavement counseling is also a greater need among women. This may reflect an actual increase in the number of women losing family members, or that women may feel the impact more strongly. One woman who experienced a death noted, *"Actually I had to be hospitalized because I didn't know what was going on. I thought it was postpartum depression."*

Women are also more likely than men to report the need for mental health services. One woman, for example, said, *"Things in the past year or two have been to men, to gay men in particular and now they are starting to listen to us because many more women with children have the disease. We need more mental health and I don't know what to do to help that, maybe hire more psychiatrists, open it up to where our medical is accepted by different psychiatrists."*

Women are also more likely to need counseling for the family. One wife and mother says, *"My husband right now is going through it with me because I'm having some mental health issues and he's about to loose his mind pulling all of his hair out. So counseling for the spouses, if the spouse is not infected they're basically forgotten so that's a big issue. ...Even just regular counseling for non-HIV related issues for the children for the spouse for what they go through and what my husband goes through with me."*

Although the need for substance use counseling is relatively low, for almost all substance abuse services, women report a greater need than men. In part this represents other family needs as well. For example, one woman said, *"I still have the problem with ...finding continuing care for the drug [abuse] itself. [Housing and substance use]...those are my two main problems, do you know what I'm saying? I think that I need to work on my substance abuse more than anything right about now but I also need stabilized housing."* For men, those who refer to drug treatment in the focus groups often link it to housing. For example, one man of color noted, *"For an addict that used [provider name] wants to send you to a lot of [substance abuse] services around that area and I'm not comfortable. I understand that's where the resources are, but I'm safe where I'm at.*

Figure 9-4 Need by Gender



	Out-patient medical	Dental care	Medical Specialist	Med Reimbursemen	Transportation	Client Advocacy	MH group	Supportive housing	Peer cnsling	SA cnsling	SA Grp	SA peer group	Family cnsling	SA assessment	Buddy advocate	Bereavement cnsling	Adult day care	SA family cnsling	Child care
▬ Males	80.2%	75.7%	67.1%	58.6%	35.6%	36.0%	23.4%	23.7%	23.7%	22.3%	20.3%	17.6%	16.7%	13.8%	14.2%	10.0%	7.1%	7.3%	2.2%
▭ Females	72.4%	53.3%	52.6%	50.7%	50.7%	46.0%	39.5%	34.5%	32.2%	33.7%	35.0%	30.5%	31.2%	26.7%	23.2%	26.4%	25.9%	17.8%	20.5%
—◆— Total	78.8%	71.7%	64.5%	57.2%	38.2%	37.8%	26.2%	25.6%	25.2%	24.3%	23.0%	19.9%	19.3%	16.1%	15.8%	12.9%	10.4%	9.1%	5.4%

Need Differences by Race

Figure 9-5 shows the ethnic/racial differences among the top ranked services.

PLWH/A of different races/ethnicities rate needs differently. As seen in Figure 9-5 Anglos and then Latinos perceive a higher need for medical services, including dental care. Anglos perceive a higher need than Latinos or African Americans for mental health services and complementary care.

The need by African Americans for mental health services was explored in the focus groups. A male African American PLWH/A commented, *"There are no blacks. I'm in a situation where I'm dealing with somebody gay and white or gay and Mexican and you expect them to understand me? It's not going to happen. That's why I have to keep [my agency] at a distance; I don't think that they work towards helping the minorities. I don't believe that. If that's sounding like I'm racist or something I apologize for that but that's just the way I see the picture. It's really a shame because there are a lot of blacks, Mexicans, and women that are heterosexual and we go to that place and it's not for us. That's just my opinion."* Another African American male participant noted a need but also said, *"The person that I talked to is cool but he's not a psychiatrist. There is no access to that because I do have some problems that I don't discuss with everybody but I [will] talk about them ... with him."*

For those services where there are differences in perception of need among ethnic groups, Latinos perceive a slightly higher need for medical reimbursement. During one of the focus groups, one Latino noted to another participant, *"that's great that your insurance covers you. Because they give me so many medicines that my insurance doesn't cover. I go and I say, okay, call the doctor and ask him to give me something equal that is covered because I'm not going to pay for anything out of my pocket…If I pay three thousand dollars a month. Three or four thousand dollars a month. If I had to pay that money, can you imagine? I mean, that is what it shows on the receipt. Three to four thousand dollars a month. Who has that kind of money? Not even a person if they make $25 an hour could pay three, four thousand dollars a month."*

African Americans perceive a higher need for most support services, particularly substance abuse services, including assessment and group session, and transportation services. Reflecting the disproportionate number of African American women infected, they also have a higher need for childcare and family counseling. In the focus group, however, one African American noted, *"I think that ultimately the decisions… is on me. I've been an addict and been in and out of recovery for a long time. Until I get ready and really want to stop and change, what I find is when I'm doing the footwork and doing the things that I needed to do the doors that needed to be opened for me are open.*

Another African American man noted that he finds the church providing many services. *"In the church settings you are going to find a lot of heterosexuals and married couples bringing their children there because that's always been a group place for blacks to congregate and we have our leadership there."*

The quantitative data clearly indicated that African Americans and Latinos express a higher need than Anglos for housing services and rental assistance. Again, in focus groups there is a perception of a growing bureaucracy without added services. An African American said, *"About the homeless situation I think that staff has increased but I think homeless services have decreased. I remember when I first started getting services from [name of agency] I didn't have enough income to pay my rent and it was subsidized and you can't get that now. You can't get that now. When I didn't have my own place to go to they were able to get me a motel voucher, I remember."*

The quantitative data shows that, for most support services, Latinos have a lower perceived need. This is typical in need assessments where the Latino population often has fewer expectations of services. For example, one Latino in the focus groups said that his group had to accept responsibility. He said, *"We have to be aware, you know, what is good for us. And if we don't do that we cannot be, 'this is what you gave me'…we have to learn English in this 21st century."* However, he moderated this a bit by later saying, *"There should be someone who can speak Spanish to us so we can understand."*

Need Differences by Risk Group

Figure 9-5 displays differences in perceived need by risk group. The quantitative data suggests that most risk groups have a similar high need for outpatient care and non-substance abuse mental health services.

However, MSM have substantially higher perceived need for dental care and medical specialists, medication reimbursement, and complementary care. Along with heterosexuals they have a higher perceived need for financial assistance.

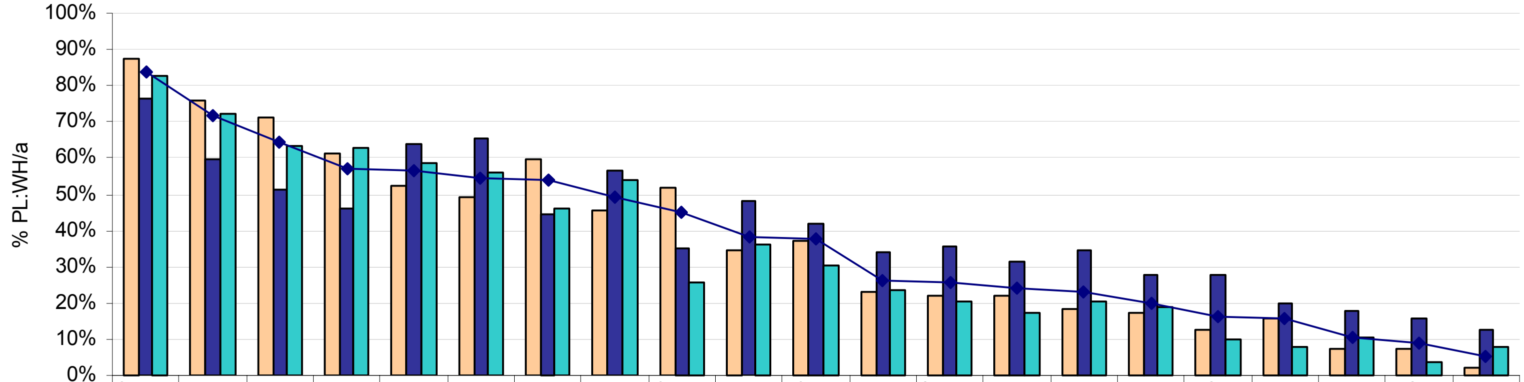
In the focus groups an Anglo MSM adds some depth to these needs. He said, *"Getting regular help with food vouchers, help with utility costs, complementary care, it's always a fight throughout the year. It's very iffy if it's going to happen. There is always under funding in those areas. Also being a former member of the HIV council I get very frustrated, as gay white men we are the largest group of people that have HIV and AIDS and yet the federal government does not categorically give us money. They will categorically give money to people of color, to women, and to children. They don't recognize gay white men as a category."*

The quantitative data found that MSM/IDUs and to a lesser degree, IDUs, have a greater perceived need for most substance abuse services, including group and one-on-one counseling. The focus groups suggest there may be a greater need for information about these services. For example an MSM/IDU said, *"Before I came here I didn't think that I could use group therapy but since we've been talking about this stuff I'm thinking I could use that and some therapy, too."*

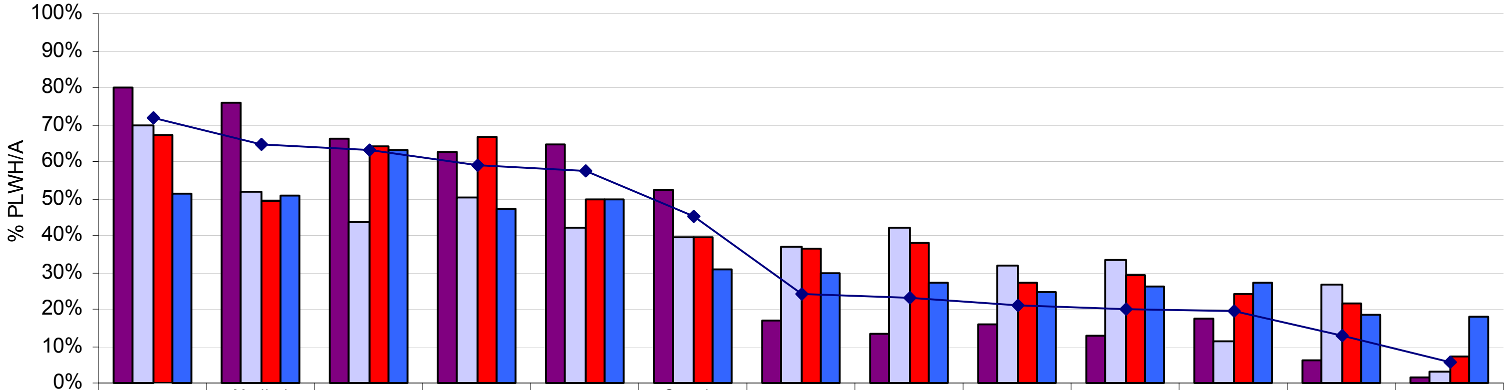
The quantitative data further suggested that IDUs and heterosexuals have a greater need for insurance assistance. However, as the focus group participants emphasized, even if a person has SSDI it is difficult to survive. An IDU noted, *"I'm on SSDI Social Security, $715.00 a month between the two, it's hard to survive on that. I'm not able to get Section 8 housing. I worked* *through the case management. I haven't dealt with them now in a long time because I'm frustrated. I wish I didn't have to work under the table illegally two jobs just to survive…I would be homeless almost if I didn't work under the table but I shouldn't have to."*

Last, the quantitative data shows that heterosexuals have a much greater need for childcare. As one heterosexual woman said in the focus groups, *"As much funding as we have for this we should be able to have transportation to where we need. We should have childcare for our kids. We should have dental plans and Medicare."*

Figure 9-5 Difference in Needs by Ethnicity and Risk Group



	CM help w/ benefits	Dental care	Medical Specialist	Med Reimbursement	Rental asst	Taxi vouchers	MH 1-1	Housing info	Complementary care	Transportation	Client Advocacy	MH group	Supportive housing	SA cnsling	SA Grp	SA peer group	SA assessment	Buddy advocate	Adult day care	SA family cnsling	Child care
▬ Anglo	87.3%	75.8%	71.0%	61.3%	52.2%	49.4%	59.5%	45.4%	51.8%	34.7%	37.1%	22.9%	21.8%	21.8%	18.6%	17.1%	12.4%	15.6%	7.3%	7.2%	1.8%
▬ Af Am	76.6%	59.6%	51.5%	46.3%	63.8%	65.3%	44.3%	56.4%	35.2%	47.9%	41.9%	34.1%	35.6%	31.2%	34.4%	27.9%	27.7%	20.0%	17.7%	15.9%	12.6%
▬ Latino	82.7%	72.3%	63.4%	62.7%	58.8%	55.9%	46.0%	54.2%	25.7%	35.9%	30.3%	23.8%	20.4%	17.1%	20.3%	19.0%	9.9%	8.0%	10.6%	3.6%	8.0%
—◆— Total	83.5%	71.7%	64.5%	57.2%	56.3%	54.3%	53.7%	49.1%	44.9%	38.2%	37.8%	26.2%	25.6%	24.3%	23.0%	19.9%	16.1%	15.8%	10.4%	9.1%	5.4%



	Dental care	Medical Specialist	Food bank	Financial asst	Med Reim	Complementary care	SA cnsling	SA Grp	SA 1-1 cnsling	SA peer group	Insurance Asst	SA residential	Child care
▬ MSM	80.2%	75.9%	66.4%	62.7%	64.8%	52.1%	16.7%	13.5%	15.9%	12.8%	17.3%	6.0%	1.5%
▬ MSM/IDU	69.7%	52.0%	43.7%	50.4%	41.9%	39.5%	36.8%	42.0%	31.7%	33.1%	11.5%	26.8%	2.8%
▬ IDU	67.0%	49.1%	64.2%	66.5%	49.9%	39.3%	36.3%	37.7%	27.2%	29.1%	23.9%	21.3%	7.2%
▬ Het	51.1%	50.9%	63.3%	47.0%	49.8%	30.9%	29.8%	26.9%	24.4%	26.1%	27.4%	18.6%	18.0%
—◆— Total	71.7%	64.5%	62.9%	59.1%	57.2%	44.9%	24.3%	23.0%	21.0%	19.9%	19.5%	13.0%	5.4%

Top Services by Special Populations

Stage of Infection

Symptomatic PLWH/A tend to have higher need for services than asymptomatic PLWH/A. Overall, symptomatic PLWH/A report higher needs for 35 out of 43 of the services. Symptomatic PLWH/A report an above average need for rental assistance and housing information. Asymptomatic PLWH/A report higher need than other PLWH/A for substance abuse support groups and substance abuse assessment services.

Immigrant PLWH/A

Twenty-five PLWH/A were born outside of the United States, with five currently being undocumented. On average, immigrant PLWH/A have lived in the US for 22 years, with a minimum of two and a maximum of 46 years of length of stay in the country. Outpatient medical care is the priority for immigrant PLWH/A (84%). The ranking of their service needs are similar to that of US born PLWH/A, with food vouchers, case management and benefit counseling being among their most important needs.

They report above average need for intake sessions, financial assistance, transportation, and mental health group therapy. On the other hand they report below average need of one-on-one counseling, substance abuse services, including counseling and assessment, and complementary therapy.

Recently Incarcerated

The top three service needs for the recently incarcerated correspond to the top needs reported by all other PLWH/A, i.e., food vouchers, case management, and outpatient medical care. Recently incarcerated PLWH/A report higher than average needs for substance abuse services including counseling, support groups and peer groups.

Homeless

The top three services needed by homeless PLWH/A are the same three reported by all PLWH/A, i.e., food vouchers, case management, and outpatient medical care. However, they report above average need for basic services impacting the quality of their day-to-day living including food, shelter, and transportation. They also report above average need of substance abuse services, including residential treatment facilities.

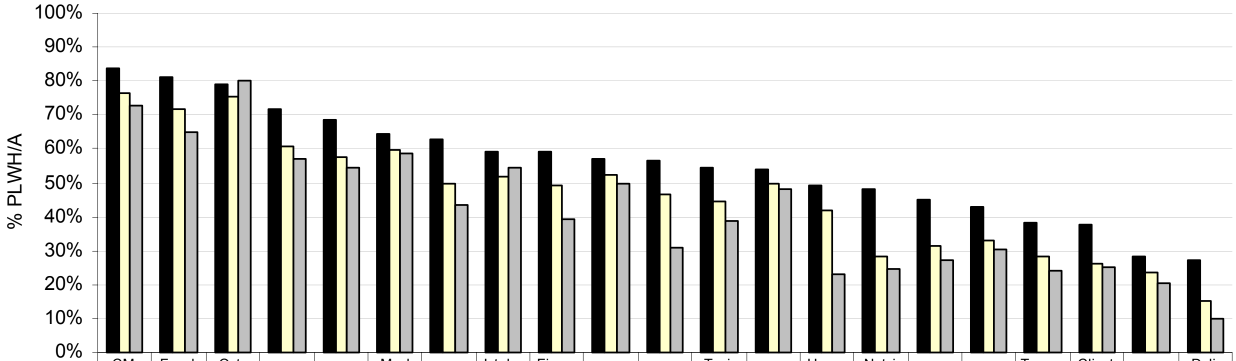
Asking for and Receiving Services

Participants in the survey were instructed to indicate whether they needed, had asked for, and received each of the 42 services in the past year. As shown in Figure 9-6, perceived need, reported demand (asking for a service), and reported utilization (receiving a service) follow a similar, but not identical pattern. Figure 9-6 indicates that:

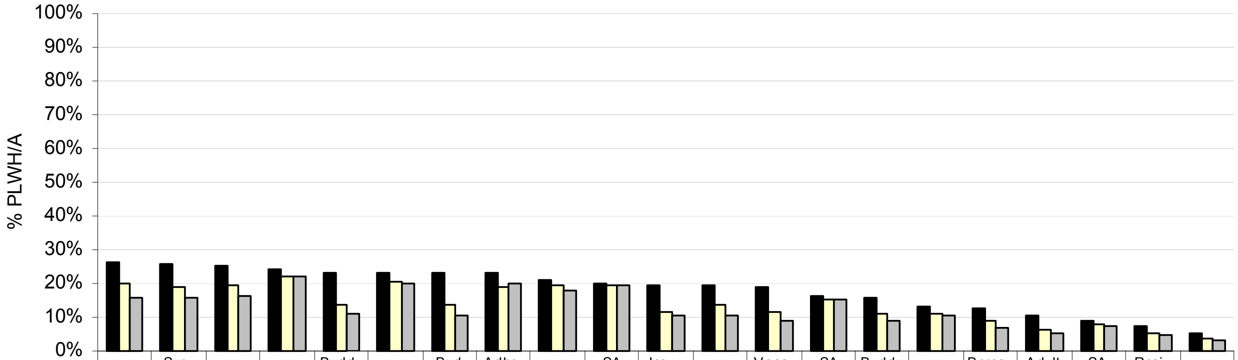
- With the exception of outpatient medical care, perceived need is higher than either the reported demand or utilization for each service.
- Demand is usually greater than utilization, with the exception of outpatient medical care, intake, and adherence support, where they are about the same.
- The demand for services follows reported need, with the exception of food vouchers and financial assistance where PLWH/A are considerably less likely to ask for them than other top ranked services. Among services with less perceived need, PLWH/A are considerably less likely to ask for nutritional supplements, counseling, and complementary care, and insurance assistance.
- There is a difference in the rank order of perceived need and utilization. The difference reflects the continuum of care's emphasis on outpatient care, and the much lower utilization of housing services, including rental assistance DEFA, and housing information. There is also low utilization of food vouchers relative to the high reported need for food vouchers.
- Demand is relatively low for substance abuse services, however, utilization is lower.

While Figure 9-6 shows the relative size of the need, demand, and utilization of services, another way to examine this data is by looking at the gaps between those who need and ask for services and the gap between those who ask for and receive services. The next section discusses these gaps.

Figure 9-6 Consumer Need, Demand, & Utilization



	CM help w/ benefit	Food vouchers	Outpatient med	Dental care	Bene cnsling	Med Specialist	Food bank	Intake session	Financial asst	Med Reim	Rental asst	Taxi vouchers	MH 1-1	Housing info	Nutri supplement	Compl care	Nutri cnsling	Transportation	Client Advocacy	Home health	Delivered meals
■ Need	83.5%	81.0%	78.8%	71.7%	68.7%	64.5%	62.9%	59.1%	59.1%	57.2%	56.3%	54.3%	53.7%	49.1%	48.1%	44.9%	43.2%	38.2%	37.8%	28.5%	27.0%
□ Ask	76.5%	71.8%	75.6%	60.8%	57.7%	59.6%	49.5%	51.9%	49.1%	52.3%	46.4%	44.4%	50.0%	41.8%	28.2%	31.5%	33.2%	28.1%	26.0%	23.3%	15.0%
▨ Received	72.9%	64.8%	79.9%	57.1%	54.6%	58.6%	43.3%	54.3%	39.5%	49.5%	30.9%	38.9%	48.3%	22.8%	24.5%	27.4%	30.2%	24.0%	25.3%	20.3%	9.8%



	MH group	Supportive hsing	Peer cnsling	SA cnsling	Buddy emo suppt	SA Grp	Bud hshld tsks	Adherence suppt	SA 1-1 cnsling	SA peer group	Insurance Asst	Family cnsling	Vocational ref	SA assessment	Buddy advocate	SA residential	Bereavmnt cnsling	Adult day care	SA family cnsling	Residential Hospic	Child care
■ Need	26.2%	25.6%	25.2%	24.3%	23.0%	23.0%	23.0%	22.9%	21.0%	19.9%	19.5%	19.3%	18.8%	16.1%	15.8%	13.0%	12.9%	10.4%	9.1%	7.3%	5.4%
□ Ask	20.1%	18.8%	19.3%	22.2%	13.6%	20.7%	13.9%	19.1%	19.4%	19.3%	11.5%	13.5%	11.5%	15.1%	10.9%	11.1%	9.0%	6.4%	7.9%	5.2%	3.7%
▨ Received	15.8%	16.0%	16.3%	22.3%	10.8%	20.2%	10.7%	20.3%	18.0%	19.2%	10.6%	10.7%	8.8%	15.0%	9.0%	10.8%	6.9%	5.3%	7.1%	4.7%	3.2%

Service Gaps

This section highlights a variety of differences between what services are needed by PLWH/A, what services are asked for, and what services are received. The larger the need-asked for gap the more likely the person was to need a service and not ask for it. This may be because the consumer is aware that they are not eligible for the service or it may reflect a frustration in trying to receive a service.

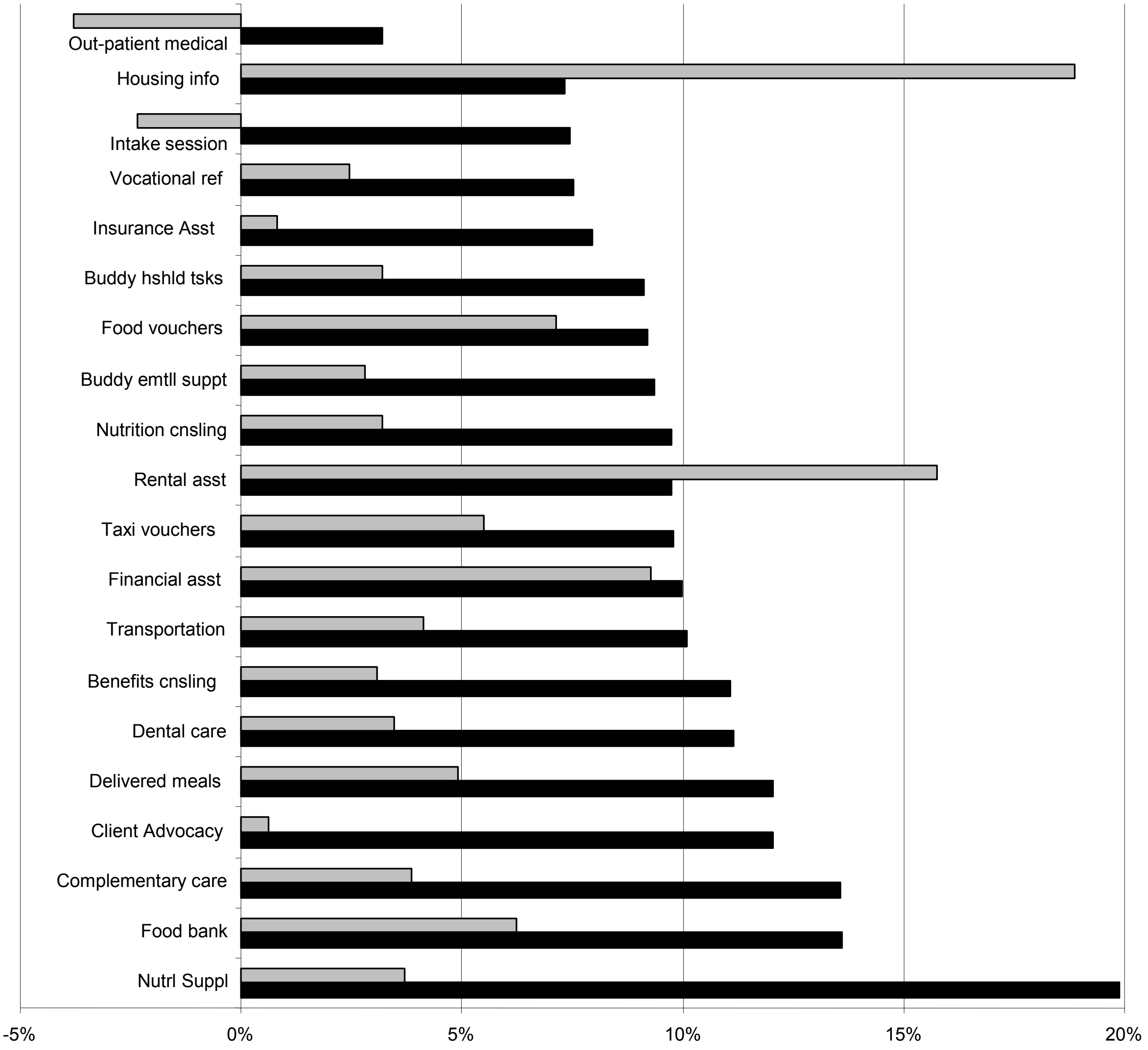
Figure 9-7 focuses on services where there was a large difference between PLWH/A who have needed but not asked for, and asked for but not received services. It is ranked by the "need-asked" for gap and indicates that:

- There is a relatively large gap between PLWH/A who need food and nutritional services and ask for them. Among the largest gaps are for nutritional supplements, food bank, and delivered meals. Once asked for, a smaller, but still significant number of PLWH/A, do not receive them.
- Many PLWH/A who perceive a need for complementary care, do not ask for it. Once asked for, they are fairly likely to receive it.
- There is over a 10% gap between those consumers who perceive a need but do not ask for client advocacy, benefit counseling, dental care, and transportation. In each of these instances, once consumers ask for the service most report receiving them.
- The opposite pattern is found for housing services. There is a substantial gap between those who ask for but do not receive housing information and rental assistance, but a smaller gap between those who need it and ask for it.
- Four percent (4%) of PLWH/A received outpatient medical care without asking for it, whereas three percent (3%) of them expressed a need for outpatient medical care but did not ask for it. One explanation for this discrepancy is the fact that most PLWH/A automatically seek out medical care with the knowledge they are eligible for service.

Consumers sometimes may be aware of a service, but not ask for it. As shown in Figure 9-8:

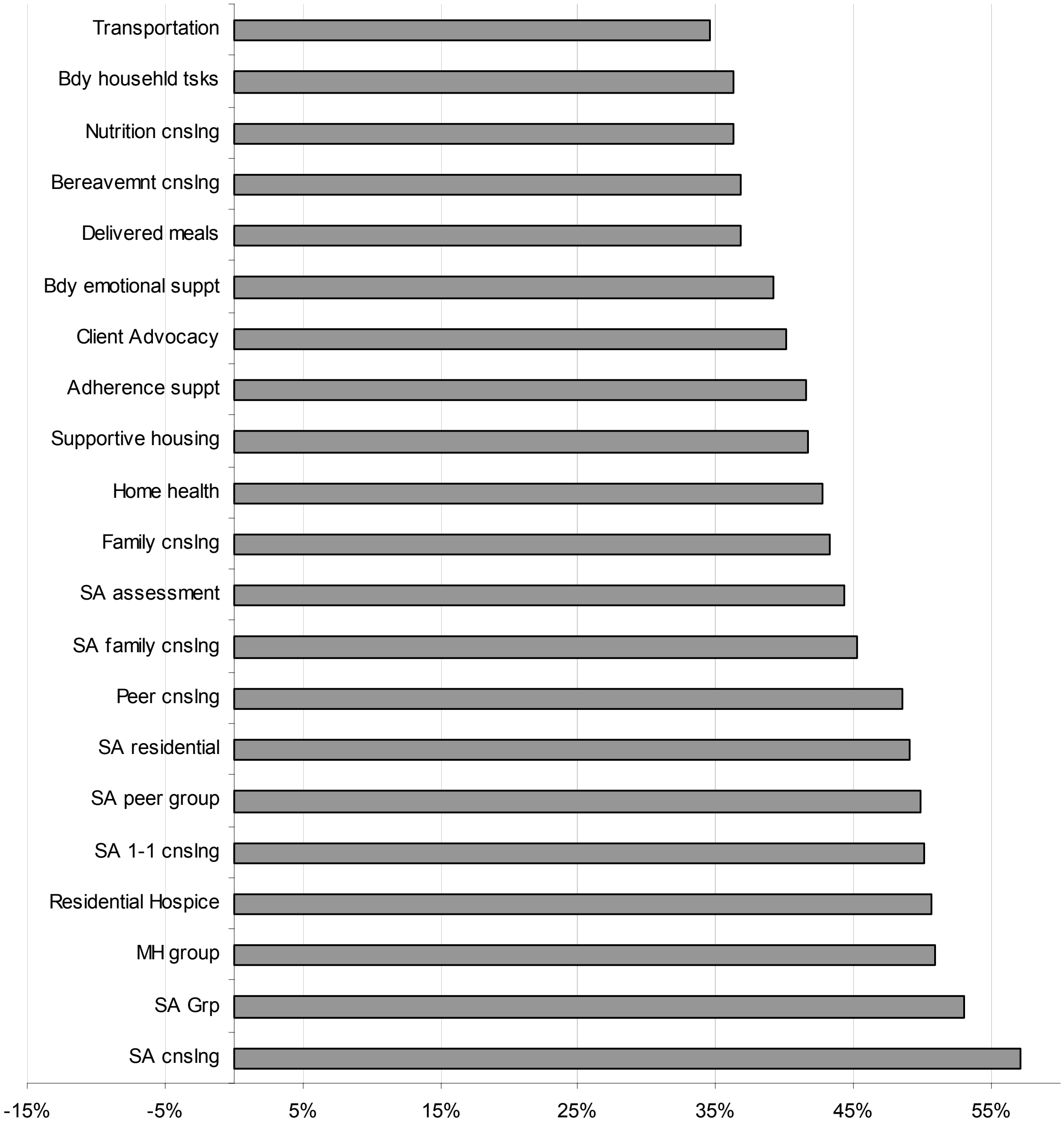
- Substance abuse services and mental health group counseling services are reasonably well known, but not frequently asked for.
- Housing services and transportation are similarly fairly well known, but not frequently asked for. Based on the focus group information, participants often anticipate that they are not eligible, or, based on experience, that requests are futile.
- Certain services are reasonably well known, but not asked for because the need is relatively low. Residential hospice and home delivered meals would fall in this category.

Figure 9-7 Service Gaps



	Nutrl Suppl	Food bank	Complemen ary	Client Advocacy	Delivered meals	Dental care	Benefits cnslin	Transportaton	Financial asst	Taxi vouchers	Rental asst	Nutriton cnslin	Buddy emtll suppt	Food vouchers	Buddy hshld tsks	Insurance Asst	Vocational ref	Intake session	Housing info	Out-patien medi
▨ Ask - Receive	3.7%	6.2%	3.9%	0.6%	4.9%	3.5%	3.1	4.1	9.3%	5.5%	15.8	3.2%	2.8%	7.1	3.2%	0.8%	2.4%	-2.4%	18.9	-3.8%
■ Need - Ask	19.9	13.6	13.6	12.0	12.0	11.1	11.1	10.1	10.0	9.8%	9.8%	9.7%	9.4%	9.2%	9.1	7.9%	7.5%	7.5%	7.3%	3.2%

Figure 9-8 Aware-Asked for Gap



	SA cnslng	SA Grp	MH group	Residential Hospi	SA 1-1 cnslng	SA peer group	SA residential	Peer cnslng	SA family cnslng	SA assessment	Family cnslng	Home health	Supportive housin	Adherence suppt	Client Advocacy	Bdy emotional	Delivered meals	Bereavemnt cnslng	Nutrition cnslng	Bdy household	Transportation
Aware-Ask	57.1%	53.0%	50.9%	50.6%	50.1%	49.8%	49.1%	48.5%	45.3%	44.3%	43.2%	42.7%	41.7%	41.5%	40.1%	39.1%	36.8%	36.8%	36.3%	36.2%	34.5%

10. BARRIERS

The PLWH/A participating in the survey were asked about barriers in two ways. In question 43 of the survey, at the end of each major service category, PLWH/A were asked, “what problems did you experience in accessing or using the service?”

In question 44 of the survey (see Attachment 13), PLWH/A were also asked to rank 30 different potential problems on a scale ranging from “not a problem” to a “very big problem”. These barriers were not “linked” to a particular service category. As shown in Table 10-1 Types of Barriers, the thirty potential problems can be classified into the more general categories of “organizational”, “structural”, or “individual” barriers.[9]

- 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. On average, more than half the PLWH/A are likely to have a problem with these types of barriers.
- Structural “access” barriers have to do with lack of transportation, access to specialists, or lack of family-oriented services. These are mentioned much less frequently than “rules and regulations” with less than 30% of PLWH/A registering that they had a problem with these types of barriers.
- Individual barriers refer to the individual’s knowledge and well-being. Like “rules and regulation” barriers, on average about half the PLWH/A mention knowledge and well-being barriers.
- Organizational barriers refer to provider sensitivity and provider expertise. Sensitivity barriers include the provider’s response to the PLWH/A’s issues and concerns, making the client feel like a number, and helpfulness of the provider. Provider expertise includes the perceived experience of providers, ability to provide correct referrals, and ability of providers to get along with clients. On average, about 40% of PLWH/A note that they have experienced these types of barriers.

The first column of data in Table 10-1 Types of Barriers shows the percent of PLWH/A who say that the specific barrier was a problem. For example, 63% of PLWH/A report that the amount of time they had to wait to get an appointment was a barrier. Over a third (36%) said it was a big barrier, and, for those that reported a barrier, it was, on average, between and moderate and big barrier (average score of 3.0 out of 5). The barriers are listed by subcategory, and within subcategory the items are listed by the percentage of those with a problem. The data is graphically presented in Figure 10-1.

---

[9] A factor analysis of the factors, not shown here, confirms these different dimensions of barriers. Results of the Factor Analysis are on file at PCH.

Table 10-1 Types of Barriers

STRUCTURAL 0= Not a Problem, 1=Very small, 2=Small, 3=Moderate, 4=Big, 5=Very big	**% WITH PROBLEM**	**% WITH BIG PROBLEM**	**AVERAGE BARRIER SCORE**
Rules and Regulations			
1. The amount of time I had to wait to get an appointment or to see someone.	63.3%	35.8%	3.0
2. My ability to find my way through the system.	50.1%	35.2%	2.9
3. There was too much paperwork or red tape.	48.7%	32.4%	2.8
4. There are too many rules and regulations.	45.9%	35.6%	3.0
5. I was not eligible for the service.	42.0%	32.9%	3.0
6. My lack of, or inadequate, insurance coverage.	38.8%	38.1%	3.1
7. I can't afford one or more of the services.	41.8%	36.4%	3.1
Access			
8. There was no specialist who could provide the care I needed.	42.5%	26.9%	2.8
9. No transportation.	50.0%	42.2%	3.2
10. I have been denied or have been afraid to seek services due to a criminal justice matter.	23.8%	32.7%	2.8
11. I have been terminated or suspended from seeking services.	20.5%	26.3%	2.5
12. No childcare.	16.6%	18.2%	2.1
ORGANIZATIONAL			
Provider Sensitivity			
13. Sensitivity of the organization and person providing services to me regarding my issues and concerns.	51.8%	35.1%	3.1
14. The organization providing the service made me feel like a number.	52.5%	29.1%	2.8
15. The people providing services to me are not helpful.	43.4%	24.2%	2.6
16. Fear of my HIV or AIDS status being found out by others – lack of confidentiality.	42.4%	39.4%	2.9
17. Discrimination I experienced by the persons or organization providing the services.	43.0%	34.2%	2.8
18. Fear that I would be reported to immigration or other authorities.	16.0%	23.8%	2.3
Provider Expertise			
19. Experience or expertise of the person providing services to me.	51.2%	26.5%	2.8
20. The organization did not provide the right referrals to the services I need.	41.9%	32.4%	2.9
21. I do not get along with the people providing services.	39.1%	22.3%	2.5
INDIVIDUAL			
Knowledge			
22. Not knowing that a service or treatment was available to me.	61.2%	38.5%	3.1
23. Not knowing the location of the service(s).	56.3%	34.6%	2.9
24. Not knowing who to ask for help.	55.7%	43.2%	3.2
25. Not knowing what medical services I need to treat my HIV infection or AIDS.	45.9%	38.0%	3.0
26. Not understanding instructions for obtaining service or treatment.	51.0%	25.8%	2.6
27. My ability to communicate or interact with the service provider.	35.9%	18.1%	2.4
Well-Being			
28. My state of mind or mental ability to deal with the treatment.	55.8%	35.6%	3.0
29. My physical health has not allowed me to get to the place where the service is provided.	52.7%	24.0%	2.6
30. I do not believe HIV/AIDS is a problem for me that requires assistance (denial).	61.2%	34.2%	3.0

Figure 10-1 graphs the three types of barriers. It shows that:

- The largest percentage of PLWH/A report individual barriers. Over 60% of PLWH/A said that not knowing about treatment and their own state-of-mind were barriers. For those naming them, they were, on average, moderate barriers.
- Over 55% said that not knowing who to ask for service was a barrier. Among those, it was a moderately high barrier.

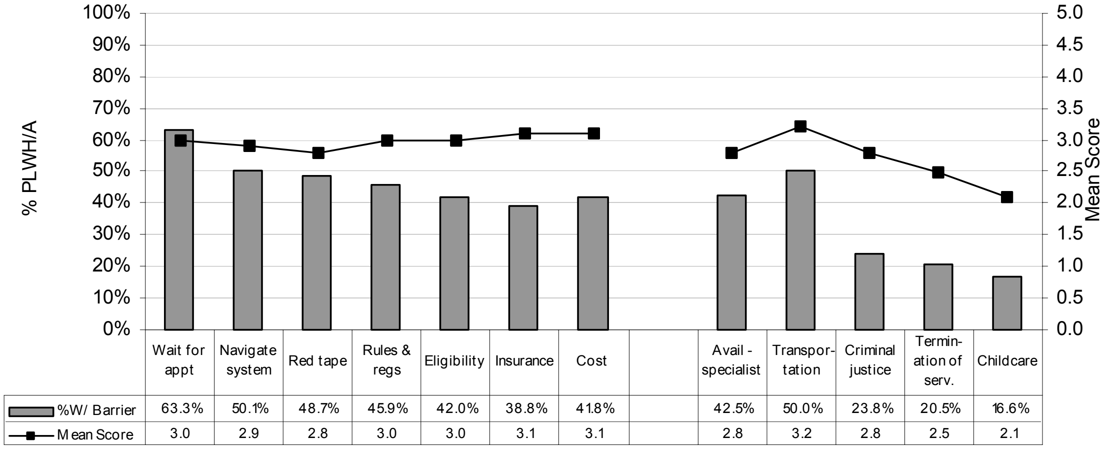
- About 46% said that knowledge of needed services was a barrier, and for them it was a moderately high barrier. An Anglo MSM reflected a sentiment that was often repeated in the focus groups. He said, *"For someone who doesn't know nothing, I feel sorry for them. It takes a long time to figure out WHAT people you need to talk to so you can get the information."*
- Among structural barriers, over 50% of PLWH/A have some problem with waiting for appointments and transportation. Between 40% and 50% have a problem with navigating the care system, the amount of red-tape, rules and regulations, including eligibility rules, and availability of specialist. An Anglo MSM said, *" we are stuck in a system that makes us lie and cheat to survive..."* because *"if you go to different organizations and if they find out that you went to this [other] organization, they won't help you with certain things. They'll say 'go to this one and they'll help you.' You have to go to several different places to get everything you need."* A Latino male said, *"My insurance wasn't up to date. And the paperwork…it was a mess of paperwork."* A Migrant adds, *"And now this place is all about the bureaucracy and this place lost a lot of money, and I understand the short staff and I understand that, but I just want them to be more compassionate."*
- For those who considered transportation a problem, over forty percent (40%) said it was a big problem. The need for transportation was consistently voice in the focus groups.
- For the 50% of PLWH/A who said that waiting and navigating the system was a problem, over a third said they were a big problem. A recently incarcerated male talks about the actual wait time at the appointment, saying, *"My appointment is at 9:30 and here it is 45 minutes after 11:00 fixing to be lunch time, I'm still sitting in the waiting room.* He adds that the problem may be administrative, *"They've already called me four times, [name of agency employee] just hasn't told me."* Another female contributes, *"as far as barriers for me, I see it as accessibility to the doctors for me. A lot of our doctors will only be there on one day of the week. You have to schedule your whole live, everything you are doing around that one day that you can see your doctor a week. I've got to be in court on the day that I'm supposed to see my doctor, what am I going to do? I can't ask to see him on a Tuesday because he's only in at [name of agency] on Thursday."*
- On average, among structural rules and regulation barriers, none were ranked as a big barrier. Yet, for those having a problem lack of adequate insurance, cost, eligibility, and rules and regulations represented moderate barriers. For example, a Latino male said, *"Well my insurance running out and I did not know I was supposed to renew it. My appointment and everything when I came to see a doctor the other day, they didn't take me in."* An African American MSM said, *"Like I said charging me $6.00 for something that I've never paid for before I kind of took that like I don't like you today. It's hard to know, I'm sure they have a co-pay thing there. I can understand the circumstances where it's not against you it's just the system isn't working well."*
- Among organizational barriers, sensitivity of the organization, feeling like a number, and provider expertise are reported as a barrier by over 50% of PLWH/A. Among those naming these barriers, provider sensitivity is reported to be the highest barrier with an average score of 3.1 out of 5. Lack of referrals and fear of losing confidentiality were also perceived as moderately high among those naming them as barriers. This topic was frequently discussed in the focus groups. A number of participants noted that they received excellent care from staff, particularly physicians. However there were a number of negative comments. For

example, one female participant said, "*A lot of the people over there had never dealt with the situation and didn't know what they were talking about; they haven't been there. Somebody is talking to you about a supposed drug problem or alcohol problem but they've never been there. For someone to sit and talk to you about something and they don't know what they are talking to you about, you don't feel comfortable talking about it. It's like talking to my mother."* An African American MSM said, *"it was kind of shaky because it seemed like I was always seeing a different doctor or attending all of the time until I started speaking up for myself and letting them know that I wanted to see one facility doctor. Usually when you first start they start you with a whole bunch of different doctors and that made me uncomfortable. I'm talking about my subject with a doctor and every time you turn around it would be a different doctor. Then they prescribe you these drugs at this window, no at this window, no at this window, and every time you come in they ask you if you take it and sometimes I didn't even know."* A male who transmitted heterosexually who complains about the level of knowledge of his doctor. He notes the doctor is "*kind and thorough but I'm more proactive. I do more research on my own behalf on my computer and in the library than I think she does towards my treatment."*

- Forty percent (40%) of PLWH/A named discrimination as a barrier and rank it as a relatively high barrier. Sixteen percent (16%) of those with a problem said it was a big problem. Several of these barriers were mentioned in the focus groups.

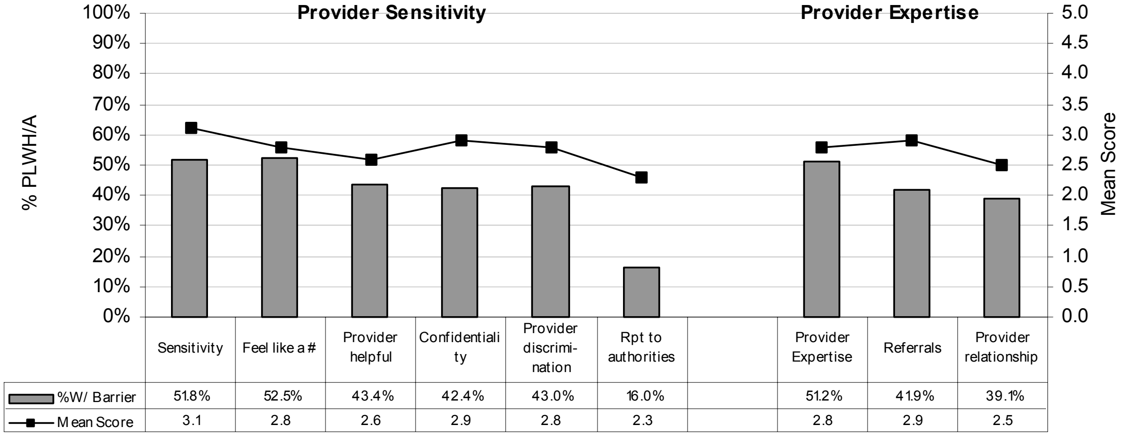
Figure 10-1 Barriers to Services

Structural



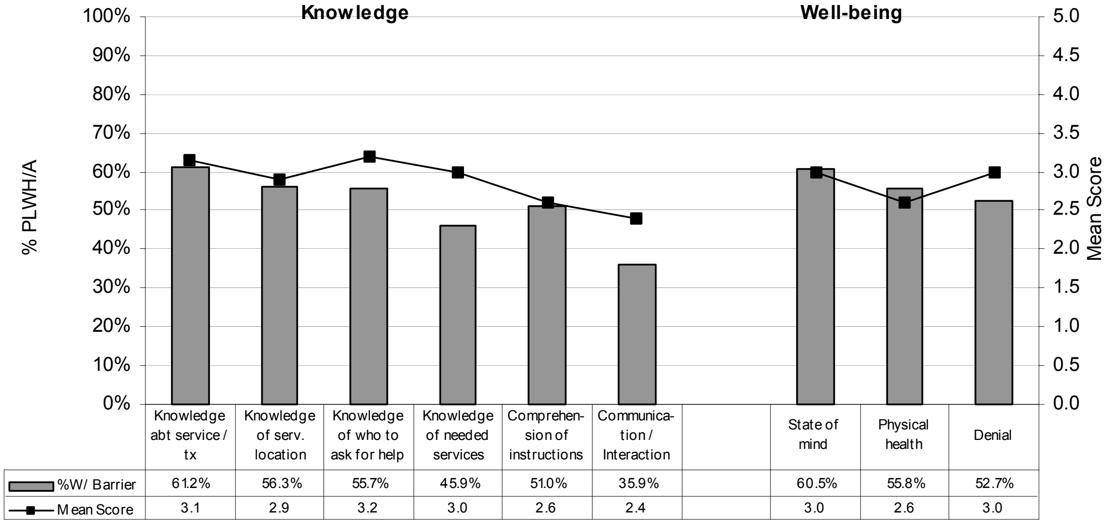
	Wait for appt	Navigate system	Red tape	Rules & regs	Eligibility	Insurance	Cost		Avail - specialist	Transpor- tation	Criminal justice	Termin- ation of serv.	Childcare
▨ %W/ Barrier	63.3%	50.1%	48.7%	45.9%	42.0%	38.8%	41.8%		42.5%	50.0%	23.8%	20.5%	16.6%
—■— Mean Score	3.0	2.9	2.8	3.0	3.0	3.1	3.1		2.8	3.2	2.8	2.5	2.1

Organizational



	Sensitivity	Feel like a #	Provider helpful	Confidentiality	Provider discrimi- nation	Rpt to authorities		Provider Expertise	Referrals	Provider relationship
▨ %W/ Barrier	51.8%	52.5%	43.4%	42.4%	43.0%	16.0%		51.2%	41.9%	39.1%
—■— Mean Score	3.1	2.8	2.6	2.9	2.8	2.3		2.8	2.9	2.5

Individual



	Knowledge abt service / tx	Knowledge of serv. location	Knowledge of who to ask for help	Knowledge of needed services	Comprehen- sion of instructions	Communica- tion / Interaction		State of mind	Physical health	Denial
▨ %W/ Barrier	61.2%	56.3%	55.7%	45.9%	51.0%	35.9%		60.5%	55.8%	52.7%
—■— Mean Score	3.1	2.9	3.2	3.0	2.6	2.4		3.0	2.6	3.0

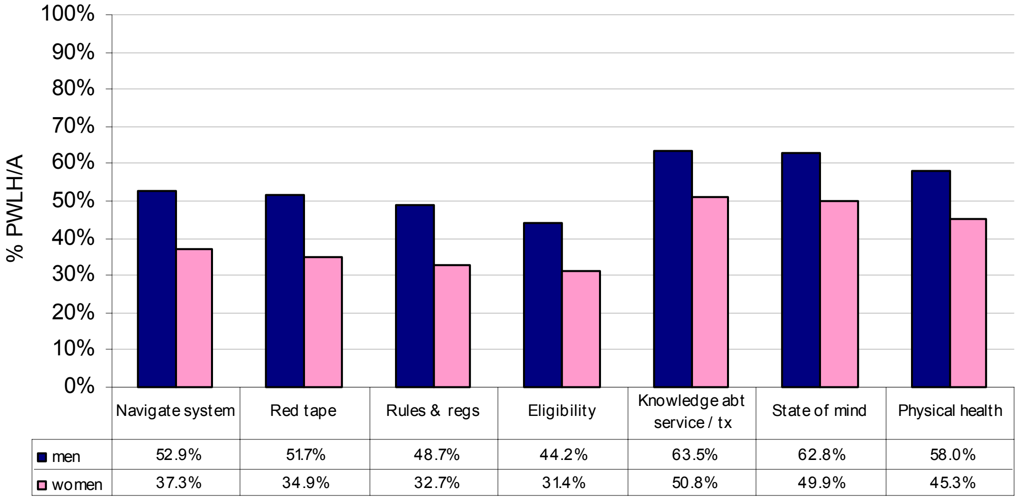
Severity of Problem

Although the highest average barrier was rated as a moderate barrier, as shown in Figure 10-2, different populations reported considerably higher barriers. Important differences are highlighted below.

Gender

Overall, males were more likely to report barriers than females, but among women who reported barriers they rated them as slightly bigger than men. As shown in Figure 10-2, men were significantly more likely to report structural problems than women, particularly red tape, rules and regulations, eligibility, and navigating the system. They were also more likely to report individual level problems than women, including knowledge about service treatment, their own state-of-mind and physical health.

Figure 10-2 Barriers - Gender Differences

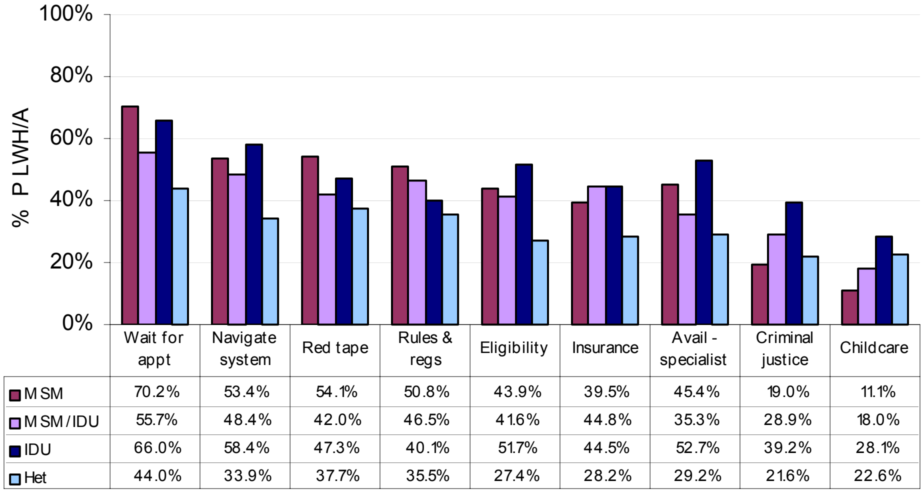


Risk Groups

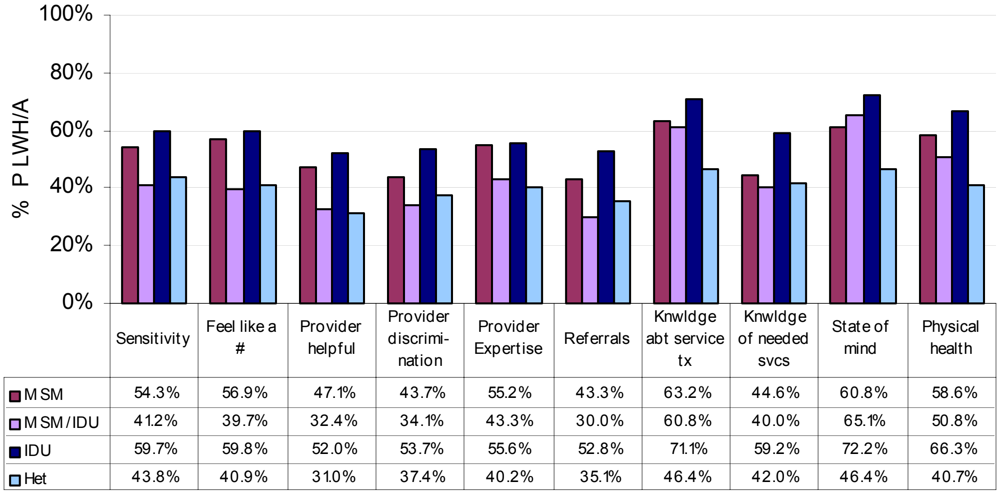
As shown in Figure 10-3, among risk groups, IDUs tend to report more problems than other risk groups, particularly individual and organizational barriers. MSM are more likely to report structural barriers particularly waiting for an appointment, red tape, and rules and regulations. Heterosexuals are less likely to report barriers than other risk groups.

For those reporting barriers, MSM/IDU tend to report bigger barriers, particularly related to problems with the justice system (along with IDUs), confidentiality, insurance, and transportation. IDUs tend to report that getting along with their provider is a bigger barrier than for other risk groups.

Figure 10-3 Barriers – Risk Group



	Wait for appt	Navigate system	Red tape	Rules & regs	Eligibility	Insurance	Avail - specialist	Criminal justice	Childcare
■ MSM	70.2%	53.4%	54.1%	50.8%	43.9%	39.5%	45.4%	19.0%	11.1%
■ MSM/IDU	55.7%	48.4%	42.0%	46.5%	41.6%	44.8%	35.3%	28.9%	18.0%
■ IDU	66.0%	58.4%	47.3%	40.1%	51.7%	44.5%	52.7%	39.2%	28.1%
■ Het	44.0%	33.9%	37.7%	35.5%	27.4%	28.2%	29.2%	21.6%	22.6%



	Sensitivity	Feel like a #	Provider helpful	Provider discrimi-nation	Provider Expertise	Referrals	Knwldge abt service tx	Knwldge of needed svcs	State of mind	Physical health
■ MSM	54.3%	56.9%	47.1%	43.7%	55.2%	43.3%	63.2%	44.6%	60.8%	58.6%
■ MSM/IDU	41.2%	39.7%	32.4%	34.1%	43.3%	30.0%	60.8%	40.0%	65.1%	50.8%
■ IDU	59.7%	59.8%	52.0%	53.7%	55.6%	52.8%	71.1%	59.2%	72.2%	66.3%
■ Het	43.8%	40.9%	31.0%	37.4%	40.2%	35.1%	46.4%	42.0%	46.4%	40.7%

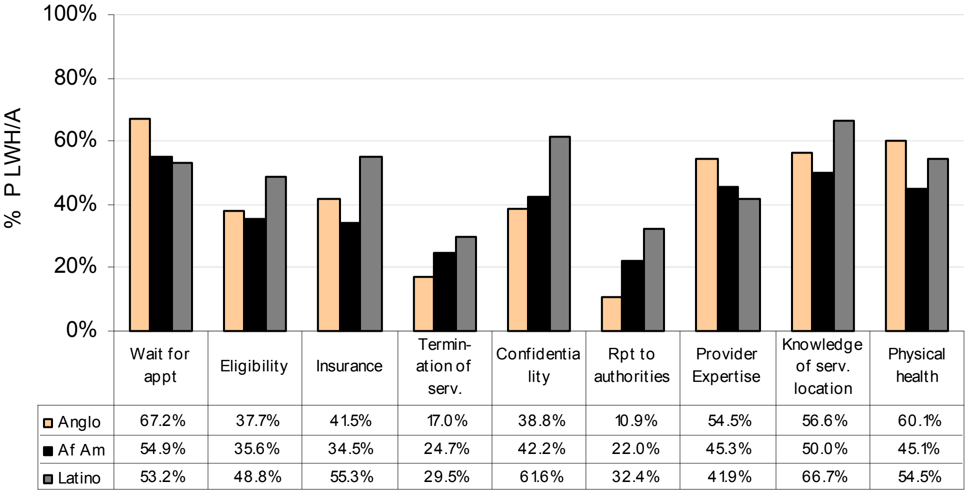
Ethnic Populations

There are fewer differences in reported barriers among Anglos, African Americans and Latinos. However, where there were differences they cut across structural, organizational, and individual factors. As seen in Figure 10-4, Latinos are more likely to name barriers. Over 60% say they have a problem seeking care because they have concerns about confidentiality or don't know provider locations. To a much smaller degree, they have a problem with fear about being reported to authorities. They also report significantly greater problems than other ethnic groups with eligibility and lack of insurance.

Anglos are more likely than other ethnic groups to have problems with waiting for an appointment, their physical health, and provider expertise. Notably the size of the problem was lower except for provider expertise.

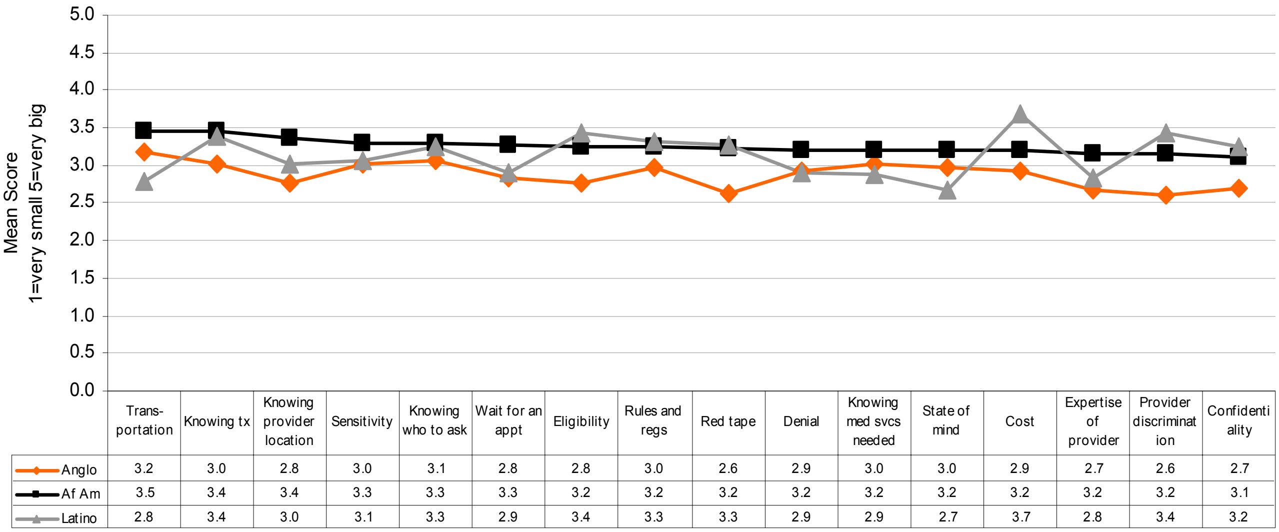
African Americans are less likely to report problems than either Latinos or Anglos. However, as shown by the black line in Figure 10-5, when African Americans do mention a problem, it is more sizable. The exception is that Latinos perceive cost as a bigger problem.

Figure 10-4 Barriers - Ethnic Population



	Wait for appt	Eligibility	Insurance	Termin-ation of serv.	Confidentiality	Rpt to authorities	Provider Expertise	Knowledge of serv. location	Physical health
▨ Anglo	67.2%	37.7%	41.5%	17.0%	38.8%	10.9%	54.5%	56.6%	60.1%
■ Af Am	54.9%	35.6%	34.5%	24.7%	42.2%	22.0%	45.3%	50.0%	45.1%
▨ Latino	53.2%	48.8%	55.3%	29.5%	61.6%	32.4%	41.9%	66.7%	54.5%

Figure 10-5 Barriers - Size of Barrier by Ethnicity



	Trans-portation	Knowing tx	Knowing provider location	Sensitivity	Knowing who to ask	Wait for an appt	Eligibility	Rules and regs	Red tape	Denial	Knowing med svcs needed	State of mind	Cost	Expertise of provider	Provider discrimination	Confidentiality
Anglo	3.2	3.0	2.8	3.0	3.1	2.8	2.8	3.0	2.6	2.9	3.0	3.0	2.9	2.7	2.6	2.7
Af Am	3.5	3.4	3.4	3.3	3.3	3.3	3.2	3.2	3.2	3.2	3.2	3.2	3.2	3.2	3.2	3.1
Latino	2.8	3.4	3.0	3.1	3.3	2.9	3.4	3.3	3.3	2.9	2.9	2.7	3.7	2.8	3.4	3.2

<u>Stage of Infection</u>

HIV and AIDS symptomatic participants reported higher barriers than asymptomatic persons. AID symptomatic reported moderate to big barriers for their own physical health and were more likely to say denial was a barrier to receiving care.

11. OUT-OF-CARE

Estimate of Out-of-Care

Earlier it was noted that there are an estimated 3,422 PLWH/A who know their status in the Sacramento EMA and they would be the individuals that have a possibility of seeking AIDS services. The SEMAS system shows about 1,770 clients receive services funded by Ryan White Care. For all services that would suggest that about half of PLWH/A who know their status and have an income of 300% of the federal poverty level are not receiving Ryan White funded services (although they may be accessing services through other sources).

Using the recommended CDC estimate that 25% of all those infected don't know their status, there would be an estimated 4,600 PLWH/A in the EMA. Based on the estimate that 96% of the PLWH/A accessing Ryan White Care services are at or below 300% poverty level, nearly 4,400 would be eligible for Ryan White funded services, and as outreach expands to reach those out of service, the system will have to accommodate new clients in the care system.

While HRSA defined out of care as individuals with HIV who are aware of their HIV status, but are not receiving regular HIV-related primary medical care, when the concept of out-of-care is more carefully defined it becomes much more complex. Care seeking is a dynamic process and might be seen along a continuum where one extreme is unconnected to care and the other is regular monitoring for HIV infection. Between those two extremes are those who have:

- A pattern of starting care after a period of delay and continuing care,
- Those who have started care and stopped, and
- Those who have an inconsistent pattern of starting and stopping care.

For the purpose of this report:

Currently not in care is defined as people living with HIV who know their HIV status and have not seen a clinician for HIV-related medical care in more than six months. Twenty PLWH/A (5%) report not seeing a doctor or clinician in more than six months. Notably this may be an underestimate of those out-of-care as the sample is mostly recruited from providers of HIV/AIDS services.

Delayed care seeker is a PLWH/A who has been diagnosed since 1995[10] who has not seen a primary care physician within six months after their diagnosis. Twenty-five participants (6.5%) of all PLWH/A participating in the survey report waiting more than six months to see a physician after receiving their HIV diagnosis.

Unconnected to care is defined as a recently diagnosed PLWH/A who has experienced a period of more than one year without seeing a doctor. Also, any PLWH/A who knows his/her infection

---

[10] 1995 is used because it was the year when antiviral medication became commonly used and known to be effective.

for over 6 months, and has not seen a physician in over a year, regardless of previous care practices, would be considered unconnected to care. Twenty PLWH/A (5%) report a period of time of more than one year when they didn't see a doctor or go to a clinic.

In all instances seeking emergency room care does not qualify as seeking primary care for HIV infection. Based on the definitions stated above, the categories are not mutually exclusive, that is, a person can be a delayed care seeker, unconnected to care and currently be out of care.

The following section presents the profile of the 25 PLWH/A who are considered delayed care seekers, 23 unconnected to care, and 20 currently out-of-care.

Demographic Profile

Table 11-1 presents the gender, ethnic and risk group distribution for the delayed care seekers and those with a history of being out-of-care. It indicates that:

- While over 60% of delayed care seekers and those unconnected to care are men, they are disproportionately women. Women represent 18% of all PLWH/A but 40% of those who are have delayed care and are unconnected to care.
- Men (80%) and women (20%) report being currently out-of-care.
- African Americans are much more likely to delay care, be unconnected to care, and be currently out-of-care. African Americans represent an estimated 26% of all PLWH/A, but represent 70% of those currently out-of-care, half of those unconnected to care, and 40% of those reporting delayed care.
- Latinos are disproportionately represented among participants who have delayed care or are unconnected to care.
- Among the risk groups, heterosexuals are most likely to be unconnected to care, and disproportionately represented among those delaying their care or those currently out-of-care.
- While underrepresented among those delaying care, unconnected to care, and currently out-of-care, MSM – due to their large representation among all PLWH/A, remain the group most likely to currently be out-of-care.

Table 11-1 Delayed Care Seekers and Out-of-care: Demographic Profile

	Total (wt)		Delayed		Unconnected		Currently Out-of-care	
	N =383	%	N=25	Col %	N=23	Col %	N=20	Col %
Gender								
Male	315	82.3%	15	60.0%	13	56.5%	16	80.0%
Female	68	17.7%	10	40.0%	10	43.5%	4	20.0%
Race/Ethnicity								
African Am	100	26.2%	10	40.0%	10	43.5%	14	70.0%
Anglo	232	60.7%	9	36.0%	7	30.4%	4	20.0%
Latino	40	10.5%	6	24.0%	5	21.7%	2	10.0%
API/Other	10	2.6%	0	0.0%	1	4.3%	0	0.0%
Mode								
MSM	211	55.2%	5	20.0%	6	26.1%	7	35.0%
MSM/IDU	43	11.3%	2	8.0%	1	4.3%	4	20.0%
IDU	60	15.8%	9	36.0%	6	26.1%	4	20.0%
Hetero	68	17.8%	9	36.0%	10	43.5%	5	25.0%

Data not shown in the table further shows that:

- Comparable to the overall sample of PLWH/A, over 80% of delayed care seekers and those with a history of out-of-care have at least a high school education, with 45% of the currently out-of-care having some level of college education.
- Three delayed care seekers, three unconnected, and six currently out-of-care report being employed in some capacity. With up to 30% of the currently out-of-care being employed, this is much higher than the 10% percent employment level reported by the overall sample.
- While the delayed care seekers and unconnected to care are slightly more likely to currently be employed, they are also much more likely than the PLWH/A in care to live in poverty. More than 70% of both groups report annual incomes of $8,600 or less. On the other hand, a slightly smaller proportion of the currently out-of-care (45%) than the PLWH/A in care (49%) report incomes below $8,600. This may reflect their greater likelihood of having earned income through employment.
- Overall, about 80% of PLWH/A in care report having medical insurance. Interestingly, from the three groups with inconsistent access to medical care, the currently out-of-care are more likely to have insurance (75%), compared to unconnected to care (70%), and delayed care seekers (64%). This would suggest that other factors besides medical coverage affect the PLWH/A's decision to seek care. While the sample is too small to be generalizable perhaps current work commitments interfere with a PLWH/A's ability to seek medical care.

Stage of Infection

The length of time infected with HIV or AIDS and presence of symptoms is related to care seeking behavior. As shown in Table 11-1, those currently out-of-care are more likely than all PLWH/A to be asymptomatic, but have lived with HIV and AIDS longer. The unconnected to care, in contrast, are more likely to be HIV symptomatic, and have had HIV a shorter period of time (3-6 years) and AIDS under 3 years. There is some indication that those who delayed their care seeking are both newer to the epidemic and have been diagnosed with AIDS more recently.

Table 11-2 Care Seeking Behavior and Stage of Infection

Stage		Total	Currently out-of-care	Unconnected to Care	Delayed Care
	HIV asymptomatic	27.6%	40.0%	21.7%	32.0%
	HIV symptomatic	20.4%	5.0%	26.1%	20.0%
	AIDS asymptomatic	17.2%	30.0%	21.7%	24.0%
	AIDS symptomatic	34.7%	25.0%	30.4%	24.0%
HIV	Less than 3 years	16.1%	20.0%	8.7%	24.0%
	3 to 6 years	16.4%	15.0%	47.8%	28.0%
	6 to 12 years	31.5%	20.0%	39.1%	48.0%
	More than 12 years	36.0%	45.0%	4.3%	0.0%
AIDS	Less than 3 years	24.6%	27.3%	41.7%	53.8%
	3 to 6 years	21.6%	18.2%	25.0%	23.1%
	6 to 12 years	34.7%	54.5%	33.3%	23.1%
	More than 12 years	19.1%	0.0%	0.0%	0.0%

For example, in focus groups, an African American MSM responds to the question of how long it took him to seek care. He said, *"It seemed like I didn't start having the symptoms until I was told that I had AIDS. I received some care a little bit down the line. I didn't even start having symptoms. There would be little things happening left and right here and there and I just brushed it off."*

Overall PLWH/A in care are more likely (60%) to report having had opportunistic infection since being diagnosed with HIV than are delayed care seekers (52%), unconnected to care (35%), or the currently out-of-care (35%). This may reflect the greater likelihood of those in care than those out-of-care to be diagnosed with an OI through their contact with the medical care system.

Knowledge of their CD4 count and viral load is also directly related to care seeking behavior. For instance, while about 16% of the PLWH/A in care report not knowing whether their CD4 count had dropped below 200 cells/UL, up to 28% of the delayed care seekers report not knowing whether their t-cell count had dropped below that level. Similarly, while 26% of the PLWH/A in care report not knowing whether their viral load had ever risen above 30,000 copies, 35% of the unconnected to care and almost half of the delayed care seekers do not know whether their viral load ever rose above that level.

The PLWH/A with an inconsistent access to medical care are more likely than all PLWH/A in care to say that their physical health is good to excellent. Also, more than half of the unconnected, delayed care seekers, and currently out-of-care say that their physical health has improved since they first sought treatment. Emotionally, however, they don't report doing as well. For instance, one quarter of the currently unconnected report poor emotional health compared to 17% of the PLWH/A in care. Similarly, up to 35% of the unconnected to care report worse emotional health now than before seeking treatment, compared to 28% of the PLWH/A in care.

Medication Adherence

Delayed care seekers and PLWH/A with a history of being out-of-care are less likely to take medication than PLWH/A in care. Those unconnected to care are even less likely to take medication (68%) compared to 85% of the PLWH/A in care. Interestingly, however, once on medication, the delayed care seekers (58%) are more likely to adhere to their medication regimen than are the unconnected (47%), the currently out-of-care (33%), and even the PLWH/A in care (43%). Notably, two-thirds of currently out-of-care struggle taking their medications as prescribed.

Table 11-3 shows the top reasons reported by the PLWH/A for not adhering to medication regimens. Among PLWH/A in care, delayed care seekers and the currently out-of-care, forgetting to take the medications was the number one reason for not adhering to medications. For the unconnected to care side effects of the medications was the number one reason for skipping medications.

Table 11-3 Top Reasons for Skipping Medications

	TOTAL		Delayed Care		Unconnected		Currently Out-of-care	
	N	%	N	%	N	%	N	%
Forgot	115	50.0%	5	45.5%	3	30.0%	7	70.0%
Side effects	90	39.4%	5	45.5%	5	50.0%	3	30.0%
Difficult schedule	62	27.0%	2	18.2%	3	30.0%	3	30.0%
Hard to coordinate with food	47	20.7%	1	9.1%	2	20.0%	1	10.0%
Didn't want to take them	47	20.6%	3	27.3%	2	20.0%	1	10.0%
Doctor advised me to stop	45	19.9%	2	18.2%	0	0.0%	0	0.0%
Homeless	24	10.4%	2	18.2%	3	30.0%	2	20.0%
Feel that medications didn’t work	22	9.5%	2	18.2%	1	10.0%	1	10.0%
Affordability	16	6.9%	0	0.0%	0	0.0%	0	0.0%
Didn't want others to see the meds	14	6.1%	2	18.2%	2	20.0%	3	30.0%
Felt didn't need meds anymore	14	6.1%	2	18.2%	1	10.0%	0	0.0%

Co-Morbidities

A larger proportion of the delayed care seekers and the unconnected to care report a higher incidence of hepatitis C compared to the overall sample of PLWH/A. About 30% of the unconnected to care and 32% of the delayed care seekers have had hepatitis C since being diagnosed with HIV. Delayed care seekers and those unconnected to care also report a higher incidence of herpes, gonorrhea, and chlamydia than other PLWH/A.

As shown in Table 11-4, current levels of alcohol and crack/cocaine use are comparable among the delayed care seekers, the unconnected to care, and PLWH/A in care. However, the currently out-of-care report lower levels of alcohol and crack. While the numbers are very small, proportionately the PLWH/A with inconsistent access to medical care tend to report higher levels of heroin and crystal meth use than PLWH/A in care.

Table 11-4 Current Substance Use

	TOTAL		Delayed Care Seekers		Unconnected to Care		Currently Out-of-care	
Substance	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Alcohol	160	51.4%	11	55.0%	8	50.0%	7	46.7%
Crack/cocaine	115	42.6%	8	47.1%	6	50.05	4	30.8%
Marijuana	28	13.7%	5	26.3%	5	41.7%	2	16.7%
Heroin	11	11.9%	3	37.5%	1	33.3%	3	50.0%
Crystal meth	38	21.9%	4	30.8%	2	28.6%	5	45.5%
Speed	6	9.2%	2	20.0%	0	0.0%	1	14.3%
GHB	3	9.9%	0	0.0%	0	0.0%	0	0.0%
Poppers	25	19.2%	1	20.0%	0	0.0%	0	0.0%
Ecstasy	6	9.1%	2	40.0%	1	20.0%	1	25.0%

Housing

As previously noted in this report, the instability of housing and the risk of homelessness is a concern among all PLWH/A. However, for delayed care seekers, the unconnected to care and the currently out-of-care homelessness is a major problem with more than half of these PLWH/A having a history of being homeless. Not having adequate housing affects the PLWH/A's ability to seek medical care and to adhere to medications. Currently, three delayed care seekers, two currently out-of-care, and one unconnected to care are homeless, living either in the street or in a homeless shelter.

In addition, about 36% of delayed care seekers, 39% of the unconnected to care, and 55% of the currently out-of-care report a history of transitional housing, with about 32–45% spending time a drug treatment facility.

About one quarter of the unconnected to care and the currently out-of-care do not feel that their housing is stable. Moreover, the currently out-of-care report needing more rental assistance and supportive housing than PLWH/A in care; the unconnected to care report needing more financial assistance for utilities, more housing information, and more supportive housing than PLWH/A in care; and with the exception of supportive housing, the delayed care seekers report needing less housing service than all of the other PLWH/A.

In addition, delayed care seekers and PLWH/A with a history of being out-of-care are much more likely to have been in jail. Forty percent (40%) of the delayed care seekers, 39% of the unconnected to care, and 35% of the currently out-of-care have been in jail for some length of time over the past two years while about 20% of all PLWH/A report some contact with the correctional system in the past two years. Their past experience with the criminal justice system perhaps plays a role in the greater instability of housing for the delayed care seekers and PLWH/A with a history of being out-of-care.

Need for Care

While more than 80% of all the PLWH/A report seeing a physician on a regular basis during the past year, a much lower proportion of the delayed care seekers (68%), currently out-of-care (65%), and unconnected to care (52%) report having on-going care. Interestingly, delayed care seekers (50%) are more likely than other PLWH/A to have had the same physician since finding out their HIV status.

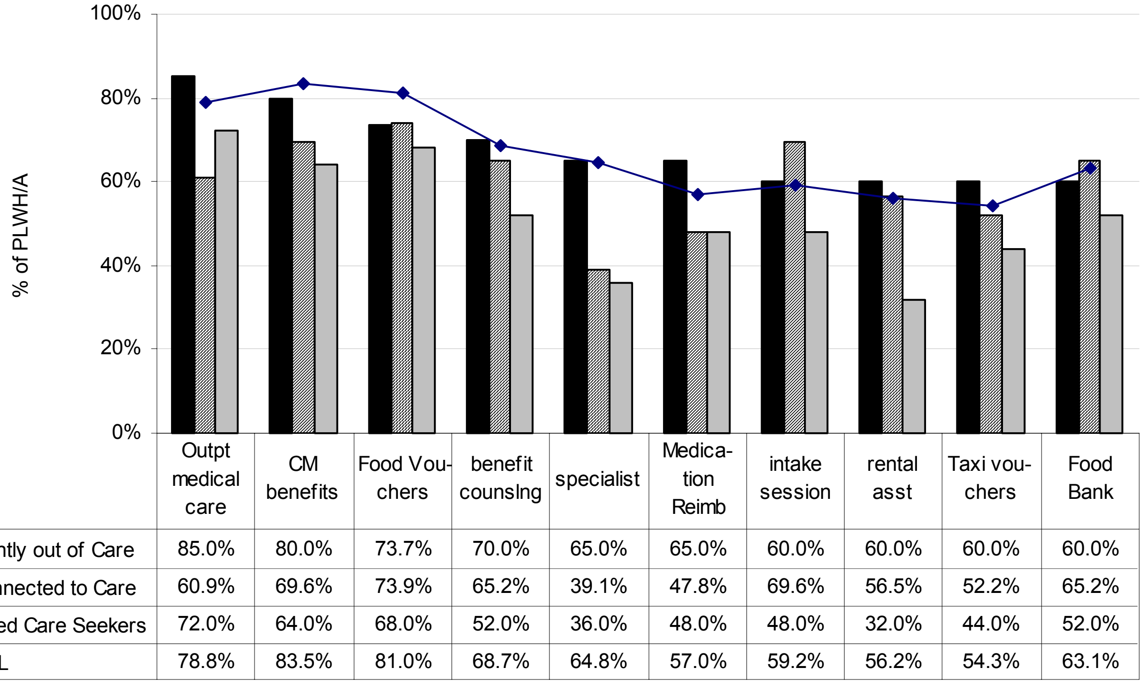
Comparable to the other PLWH/A, the most common places where the PLWH/A with a history of being out-of-care have received care are community clinics like CARES and UC Davis. As expected, the unconnected to care and the currently out-of-care are much less likely than other PLWH/A to seek care from a private doctor. Also, PLWH/A with a history of being out-of-care are more likely than PLWH/A in care to report relying on the emergency room for their medical care.

Top Service Need

Figure 11-1 shows the top service needs for the delayed care seekers, the unconnected to care, and the currently out-of-care ranked by the need reported by the currently out-of-care. Overall, the currently out-of-care report greater service needs than other PLWH/A. While case management is the number one service need of the general PLWH/A population, the currently out-of-care and the delayed care seekers ranked outpatient medical care as their number one need. The unconnected to care ranked food vouchers as their number one service need.

Specialist care and medication reimbursement were a particularly high need for the currently out-of-care. The unconnected to care ranked intake sessions and food bank services as a higher need than other PLWH/A. Generally, the unconnected to care reported lower needs than other PLWH/A.

Figure 11-1 Top Service Needs for the Delayed Care Seekers and Unconnected to Care



	Outpt medical care	CM benefits	Food Vou-chers	benefit counslng	specialist	Medica-tion Reimb	intake session	rental asst	Taxi vou-chers	Food Bank
■ Currently out of Care	85.0%	80.0%	73.7%	70.0%	65.0%	65.0%	60.0%	60.0%	60.0%	60.0%
▨ Unconnected to Care	60.9%	69.6%	73.9%	65.2%	39.1%	47.8%	69.6%	56.5%	52.2%	65.2%
▭ Delayed Care Seekers	72.0%	64.0%	68.0%	52.0%	36.0%	48.0%	48.0%	32.0%	44.0%	52.0%
◆ TOTAL	78.8%	83.5%	81.0%	68.7%	64.8%	57.0%	59.2%	56.2%	54.3%	63.1%

Barriers to Care

PLWH/A were asked to rate the barriers they face to accessing services on a scale from 1 to 5, where “1” represents a very small barrier and “5” represents a very big barrier. Overall, PLWH/A feel that services are relatively easy to access and feel that, even when they face barriers, on average, these barriers are between small to moderate.

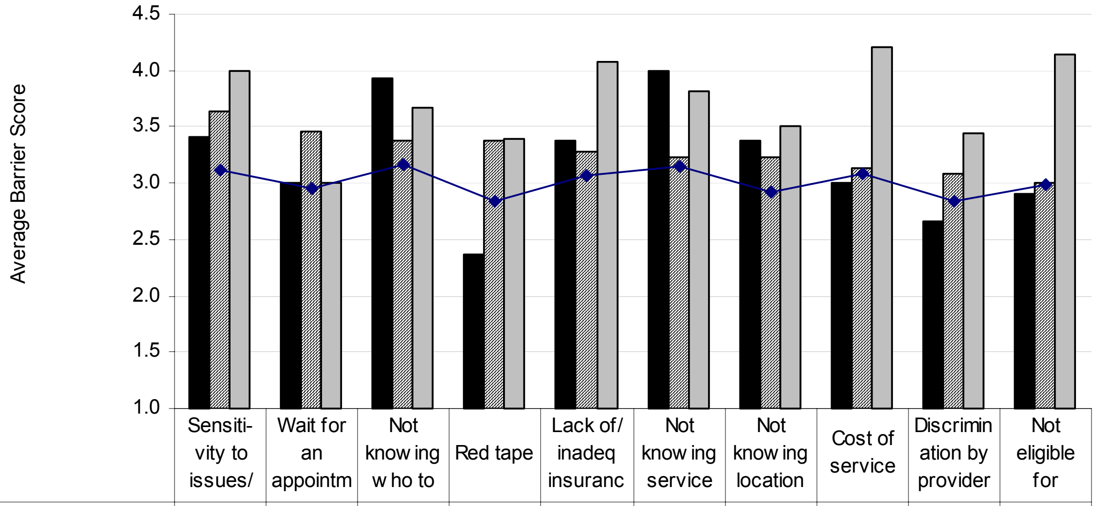
The delayed care seekers report higher barriers, with an average barrier score between moderate to big (score 3.5). Figure 11-2 shows the top 20 barriers to care, ranked by barrier scores reported by the currently out-of-care. It shows that for delayed care seekers the cost of the service, not being eligible for services, lack of or inadequate insurance coverage, denial, the providers’ sensitivity to the PLWH/A’s issues and concerns, and not knowing what medical services where needed represent big barriers to accessing care.

For the unconnected to care the biggest barriers to care are not knowing that the service was available and not knowing who to ask for help. For the currently out-of-care the biggest barriers are the providers’ sensitivity to their issues and the waiting time required for an appointment. In focus groups, among the recently incarcerated, one reason for those in-prison to be unconnected to care was that services were not available. Those in denial tend to delay care. For example, A Heterosexual/ IDU Latina says, *“First of all, for me I never felt like [getting infected] was a thing that could happen to me. I will always have my clean needles. In my head I thought it was a man-made virus. Like if I go there they'll say that I had it because I'm telling them that I did this. That's why I was afraid. And my cousin died from AIDS. She warned me. She said the pills they kill you faster than if you take care of you and don't use drugs.”*

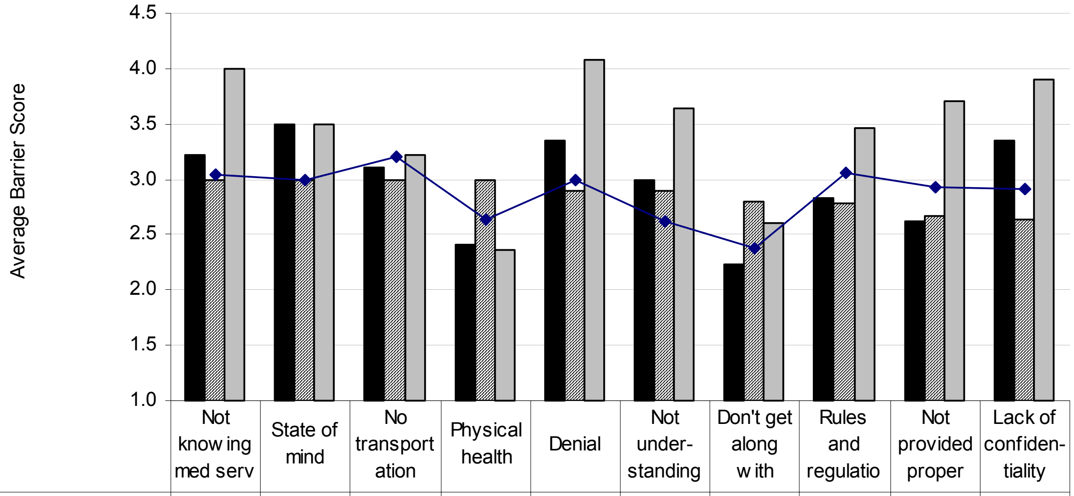
In focus groups, a clear reason for delayed care becoming unconnected to care was the belief that the medication hurt more than it helped. For example, a Latino male says, *"the reason I didn't start, or I didn't go see a doctor was because they said when you start your treatment you can't stop the virus and I wasn't ready to be taking pills everyday and take my pill in the morning and at night and taking a whole bunch."*

Figure 11-2 Top Barriers - Delayed Care and Unconnected to Care

(1= very small barrier, 2 = small, 3 = moderate, 4 = big, 5= very big barriers)



	Sensitivity to issues/	Wait for an appointm	Not knowing who to	Red tape	Lack of/ inadeq insuranc	Not knowing service	Not knowing location	Cost of service	Discrimination by provider	Not eligible for
■ Unconnected to Care	3.4	3.0	3.9	2.4	3.4	4.0	3.4	3.0	2.7	2.9
▨ Currently out of Care	3.6	3.5	3.4	3.4	3.3	3.2	3.2	3.1	3.1	3.0
□ Delayed Care Seekrs	4.0	3.0	3.7	3.4	4.1	3.8	3.5	4.2	3.4	4.1
◆ Total	3.1	3.0	3.2	2.8	3.1	3.1	2.9	3.1	2.8	3.0



	Not knowing med serv	State of mind	No transportation	Physical health	Denial	Not understanding	Don't get along with	Rules and regulatio	Not provided proper	Lack of confidentiality
■ Unconnected to Care	3.2	3.5	3.1	2.4	3.4	3.0	2.2	2.8	2.6	3.4
▨ Currently out of Care	3.0	3.0	3.0	3.0	2.9	2.9	2.8	2.8	2.7	2.6
□ Delayed Care Seekrs	4.0	3.5	3.2	2.4	4.1	3.6	2.6	3.5	3.7	3.9
◆ Total	3.0	3.0	3.2	2.6	3.0	2.6	2.4	3.1	2.9	2.9

12. CHILDREN AND ADOLESCENTS

Based on a request from the Council to include the needs of adolescents and infants in the Needs Assessment, PCH conducted key informant interviews among adolescents and caretakers of children. Limited time and access to these populations did not permit for a quantitative survey. However, seven key informant interviews were completed. As shown in Table 12-1 two were completed with adolescents and five with the guardians of infected children. All the key informant interviews were recruited from UC Davis (see Focus Groups and Key Informant Interviews, 2-6).

Table 12-1 Key Informant Interviews

Relation	Age of Child	Race	Sex
Parent/Guardian			
Grandmother	8	Af Am	female
Mother	10	Af Am	female
Guardian	11	Nat Am	female
Guardian	9	Mixed	male
Guardian	8	Af Am	male
Adolescent			
	17	Anglo	female
	17	Anglo	female

Key Informant Highlights

Given the small number of persons interviewed and limited venues for recruitment, the analysis is not generalizable to all families. Still, certain themes were consistent across those interviewed and they highlight areas that need further and more systematic inquiry. The common themes are that:

- The children and adolescents do not want to be seen or labeled as HIV positive.
- Most families try to keep the status of the child a secret from friends. Most don’t feel comfortable talking to their schools or churches about support.
- UC Davis receives high marks for medical care for competency and sensitivity. There was one notable exception.
- The medications work to reduce viral loads, but have side effects. The intensity of the side effects varies. It appears that parent and guardians are able to work with their doctors to refine the medication regimen.
- Mental health services are more difficult to receive and reimbursement is often difficult to coordinate and obtain.
- Dental care is difficult to find. Dentists that accept Medi-Cal are rare.
- Several key informant interviews noted nurses visiting their homes. When mentioned the nursing care was often criticized as “unprofessional”.

- Insurance and reimbursement for medication and care is often uncoordinated and requires substantial effort on the parent or guardian.
- The logistics required to receive drugs and drug reimbursement often requires substantial effort by the parent or guardian. For low-income families, co-pays are often perceived as large barriers. There is little mention of assistance from case-managers or caregivers in coordinating insurance. Providers can be more concerned about reimbursement than consistency of care.
- Some families with working parents fall in the crack of not being eligible for benefits and Medi-Cal, but not having sufficient funds or adequate insurance to cover care.
- Adequate housing is a problem. It can lead to separation of children and stress on families.
- Transportation is sometimes a problem, and it is not always reliable.
- The families report other significant social and health problems, which can add to lack of stability to obtaining HIV and AIDS care. Stabilizing the family would help stabilize the child's care. Where the child is placed with a guardian, the ability of the guardian to navigate the care system is related to the quality of care they report.
- Many of the children are born with problems related the drug use of their parents, most notably attention deficit disorders. However, none of the seven families interviews reported current substance abuse problems, and none felt comfortable talking about drug and alcohol abuse or treatment programs.
- Although eating habits and nutrition of the children are often mentioned as concerns, the nutritionist is often perceived as offering little help.
- Respite care was mentioned as needed. Summer camp opportunities were welcome, and there was expressed need for more local and frequent respite opportunities.

Five of the seven participants reported whether they were aware, needed, and received the service. While not generalizable to the child and adolescent populations, some trends are noted:.

- Given that the participants were recruited from the UC Davis clinic, it is not surprising that they were aware, needed, asked for and received all direct medical services.
- Surprisingly, since adherence support is specifically supported for children and adolescents, 3 out of the 5 participants were unaware of the services. Notably, all five said they did not need it. In the interview, it is clear that their doctors did review instructions for medication and discussed side effects.
- Most said they didn't need or ask for home health care – but several did report a nurse that came to administer medication.
- Although everyone was aware of case-management, 2 out of 5 said they didn't need it or receive it. Given the reported lack of coordination in insurance benefits and transportation, it is clear that these families could use additional assistance.
- Some participants were not awarene that they could receive assistance paying insurance premiums. Given the almost universal discussion of the difficulty with co-pays and premiums this is an area where parents and families could use assisatance.

- Most were aware of direct financial assistance, but most reported not receiving it even if they asked for it.
- Most said they were unaware of Ryan White housing assistance, and most said they did not ask for it. Only 1 of the 5 reported receiving rental assistance.
- All participants were aware of one-on-one mental health services and 3 out of 5 asked for it and received it. No families said they asked for group counseling services. Three out of the five were aware of family services, but only one family asked for and received them. In the interviews the need was apparent, but access to mental health services was often difficult and the difficulty in receiving insurance coverage was noted by a few participants.
- All the families were aware of child care, and 2 out of 5 asked for it. One reported receiving it.
- It was clear from the interviews that many of the families felt that they were dealing with their child's HIV/AIDS without much peer support. Most said they were aware that emotional support was available, but no participants asked or received support from their peers.

Summary

In reviewing the information from the five guardians and two adolescents, there is a sense that these families receive excellent medical care for UC Davis. Wrap around services, particularly benefit counseling and case management seem less well coordinated and needed.

Although most of the children do no want to be labeled as HIV positive, it was clear from the interviews that the parents and guardians often felt like they had to manage a difficult system in isolation. They were not in an HIV positive community and often weren't aware of medical or social issues that effect PLWH/A. Many appeared reluctant to talk to their children about the HIV infection and its management. Greater support in understanding the system and greater awareness of the insurance and wrap-around services would greatly help these families care for their HIV positive children.

13. SUMMARY AND CONCLUSION

Epidemiological Estimates and Trends

The analysis presented in this report often discusses differences by gender, ethnicity, and risk group. They are not independent subpopulations, but overlap. When African Americans are discussed, recall that they are more likely to be female, heterosexual, and IDU. Anglos are more likely to be male and MSM. Latinos, like Anglos, are more likely to be male and MSM. In the demographic trends below, basic demographics and incidence and prevalence figures, gender, risk group, and race are derived from the HARS database. Some demographics such as education, income, and substance use are estimated based on the weighted sample.

General Demographic Trends

- At the end of 2002, there was an estimated 3,422 PLWH/A in the Sacramento EMA. Of those, an estimated 58% are PLWH who have not progressed to AIDS. A disproportionate number of HIV/AIDS cases are among African Americans. They comprise only 8% of the Sacramento EMA's population, yet 22% of living AIDS cases, 29% of estimated HIV infections, and 27% of people newly diagnosed with AIDS.
- While the number of women and people of color is increasing, PLWH/A are majority males (82%) and Anglos (61%).
- People of color represent about 31% of all AIDS cases prior to 1990, but account for 53% of new cases diagnosed in 2002.[11]
- African American PLWH/A are 44% female and 42% report being heterosexual. Thirty-five percent (35%) report a history of IDU, and 29% report being MSM.
- Latinos have a profile similar to Anglos: Mostly male (88%), about a quarter with IDU history, and 15% heterosexual.
- Women represent 18% of the PLWH/A. They represent 68% of the heterosexuals and 36% of the IDUs. Most females are more recently infected than males and are more likely to report HIV without progressing to AIDS and be asymptomatic. However, women who have progressed to AIDS are more likely than men to be symptomatic.
- Heterosexuals represent 18% of PLWH/A, and over half are African American.
- MSM/IDU account for a larger share of the epidemic in the EMA than in most other parts of the country. They account for 11% of living AIDS cases, and nearly half of all injection-related HIV cases in the EMA, compared to only 6% of national cases. MSM/IDU tend to be Anglo.

---

[11] Based on the 2002-3003 Title One Application.

- IDUs represent 16% of all PLWH/A and are more likely to be African American than either Anglo or Latino. Latinos, while small in number, report relatively high drug use (although due to small sample sizes, this trend may not be reliable.)
- Latinos and African Americans living with HIV and AIDS report lower education. Women of color report the lowest level of education.
- Adults over 30 years of age continue to represent the vast majority of PLWH/A. While there is a focus on serving youth, of greater concern is planning for the needs of the growing number of PLWH/A who are over 50.
- People of color and women – the more recently infected – tend to be younger than the males, Anglos, and MSM.
- Sixteen percent (16%) of the PLWH/A live with an HIV positive partner, and African American and Latino households are much more likely to have children than Anglo households.
- Virtually all PLWH/A interviewed have an income that is 400% of poverty level or less with 87% reporting earning less than $16,500 and approximately 48% report earning less than $8,600. The sample, while biased toward those receiving Ryan White Services, gives data that demonstrates that the population of PLWH/A is poor, and newly infected are among the poorest of all PLWH/A. These populations are eligible to receive services reimbursed by Ryan White Care Act funds, Medi-Cal, and Medicare.
- The majority of PLWH/A interviewed are not currently working (89%). Seventeen percent (17%) of those not working are actively looking for work, 7% are students or homemakers, 6% are retired, and 59% are not looking for work. About 10% are either employed part- or full-time. Latinos are more likely to be working than other ethnic groups.
- Men and women are equally likely to not be working, however, more women (20%) report looking for work than men (17%), and slightly more women are employed full time (7.3%) compared to men (5.6%).

Co-morbidities

Housing

- Over 20% of those interviewed currently report unstable housing. Thirty-one percent (31%) of PLWH/A interviewed have been homeless in the past two years, and 40% indicate unstable housing in the last two years.
- Recently incarcerated have the highest rate of homelessness and unstable housing.

Substance Use

- Sacramento has relatively high drug use, particularly for opiates, crystal meth, and party drugs. Fifty-five percent (55%) of the PLWH/A report using crack/cocaine in the past with 14% of those who have used it in the past saying they used it in the last six months. Twenty-three percent (23%) report using heroin sometime in their life, and 12% of those have used it in the last 6 months.

- Recently incarcerated are among the most frequent abusers of drugs.
- “Party drugs” include poppers, ecstasy, and Gamma Hydroxybutyrate (GHB). More than one third (36%) of the PLWH/A report using poppers, with about 20% of those saying they used in the last six months. Party drugs are much more commonly used by men, Anglos and MSM with as much as three quarters of the MSM/IDU and 43% of the MSM reporting having used poppers in their lives. More than a quarter of MSM/IDU and about six percent (6%) of MSM have used GHB. A very small percentage of heterosexuals (3%) report using ecstasy compared to seventeen percent (17%) of all PLWH/A.
- Drug use is significantly correlated with symptomatic HIV, suggesting that those who use opiates such as heroin or crack and frequently users of marijuana and alcohol may not be seeking adequate prophylactic treatment and that drug use may be related to the manifestation of symptoms. Those self-medicating with Crystal Meth or speed show little impact on stage of infection.

STDs

As expected, STDs are a significant co-morbidity among PLWH/A. What is surprising, however, is that Latinos report one of the highest levels of STDs. This may be a function of the small sample size, but it does suggest that these high levels of STDs among Latinos be further investigated.

- Nearly one quarter of the PLWH/A report having been diagnosed with hepatitis C in the last year. Predictably, the incidence of hepatitis is significantly higher among IDUs (65%) and MSM/IDU (37%).
- Among ethnic communities, the incidence of hepatitis C is highest among Latinos (37%). The data shows that Latinos (23%) report a lower use of intravenous drugs than African Americans (35%) and Anglos (25%), suggesting that they are under-reporting IDU or have other routes of transmission.
- Next highest incidence of STDs is hepatitis A or B (23%). It is significantly higher among men (26%), Anglos (29%) and Latinos (23%). Among the risk groups, heterosexuals (8%) report the lowest incidence of hepatitis A or B.

Mental Illness

- Depression has been diagnosed among 61% of PLWH/A in the past two years, and it is the most frequently diagnosed mental illness reported by PLWH/A. It tends to be highest among men (62%), Anglos (62%), symptomatic PLWA (71%), and MSM/IDU (72%).
- Asymptomatic PLWH (41%), heterosexuals (45%), women (58%), and African Americans (54%), recently incarcerated (58%) and PLWH/A with a history of homelessness (59%) report less than the average incidence of depression. While the

lower incidence rates among these populations may suggest greater access to support systems, it may also reflect a lower likelihood of seeking mental health professionals for a diagnosis.

- Forty–three percent (43%) of PLWH/A report a diagnosis of anxiety in the past two years. Anglos (51%) and MSM/IDU (53%) tend to have received a diagnosis of anxiety more than any of the other race and risk groups.

Stage of Infection and OIs

- Based on the criteria for antiviral treatment, 60% of the HIV positive population reports symptoms and would be recommended for treatment because their T-cell count is below 350 cells/uL. Also, currently about 40% of PLWH/A report t-cell counts below 350 cells/uL and more than half report having had T-cell counts drop below 200 cells/uL at some point in their disease progression suggesting an AIDS diagnosis. Consistent with the length of time of infection and the trend in the epidemic, currently Anglos (47%), MSM (47%), and men (42%) are more likely than other populations to have T-cell counts below 350 cells/uL. In addition, based on survey data, there are eight percent (8%) of all PLWH/A who report an AIDS diagnosis, are asymptomatic, and report a current T-cell count below 350.
- Using accepted medical criteria, it is estimated that 68% of PLWH/A are likely to need medical treatment for their infection. And for those in early stages of HIV, there is considerable support for early intervention; about 20% of the participants reported becoming infected in the last three years, and a significant part of that population is likely to be eligible for early intervention.

<u>OIs</u>

- Almost 60% of the people reporting OIs said they had herpes or shingles. Latinos and heterosexuals report herpes and shingles more frequently.
- Just over 50% of all PWLH/A who report OIs, and 75% of MSM/IDU say they have had thrush or Candidiasis.
- Over a quarter of those who have had an OI report a history of PCP or pneumonia. It is surprising to see that it is most frequently reported by those newest to the epidemic, heterosexuals and African Americans. It is much greater among women (not shown in the figures), although this finding may not be reliable due to small sample sizes.

Access to Care

- Of the 383 participants, all but twelve (3%) noted a place of care. About two-thirds reported one place for medical care, 17% report two, and 8% report three. The most common places for care are community-based organizations. By far, the largest provider is CARES. Other main providers include UC Davis, private doctors, VA, Kaiser, ER, and other clinics that offer HIV/AIDS care.
- Twenty percent (20%) of the PLWH/A who were surveyed reported having no form of insurance. Although women have more opportunities for insurance, more women

(23%) are uninsured than men. This is somewhat mediated by the greater level of insurance reported by women with at least one child.

- Latinos are more likely than any of the other ethnic populations to not be insured.
- People with HIV are slightly more likely to be non-insured, and those that are HIV asymptomatic are much more likely to be non-insured.
- Confirming that insurance is a barrier to obtaining care, only 56% of those out-of-care report having insurance (this may be an unstable estimate due to the small sample size (N=23).
- While the level of insurance is not dramatically different by subpopulations, the types of insurance vary by life experience. As expected Anglos and MSMs, due to their generally higher incomes and past work experience, and greater likelihood of having AIDS are more likely to be eligible for Medi-Cal and/or Medicare. Interestingly, IDUs (83%) are more likely to be insured than other risk groups, while MSM/IDU (74%) are least likely to report having any form of health insurance.
- Medi-Cal/ Medicaid is by far the most common form of insurance for all populations infected with HIV/AIDS in the Sacramento area, with men, Anglos, and PLWA being the groups most likely to have this type of insurance. Medicare is the second most common form of insurance for PLWH/A in Sacramento. Overall, more than one quarter of PLWH/A report receiving Medicare. However, a much lower percentage of IDUs, Latinos, and asymptomatic PLWH report receiving Medicare than other groups.

Non Insurance Benefits

- About three percent (3%) of the PLWH/A report VA benefits and an additional one percent (1%) report receiving CHAMPUS, a form of VA for non-military personnel. Among the recipients of VA benefits, about 12% report having no other form of insurance.
- The data suggest that PLWH/A do not have a clear sense of how their medication is purchased, but most report some type of reimbursement.
- Indicative of the low income of PLWH/A, more than one-third (39%) report receiving SSI and 17% report receiving housing subsidies. IDUs, heterosexuals, African Americans, and symptomatic PLWH are more likely to receive SSI. With the exception of IDUs, these are basically the same groups that receive rental subsidies. In addition, women are much more likely than men to receive rent supplements.
- About 9% of the PLWH/A report receiving direct emergency financial assistance (DEFA), usually used for utilities, rent, or emergency medical treatment. However, women, African Americans, heterosexuals, and asymptomatic PLWH are the least likely to receive DEFA.
- Surprisingly, only 9% report receiving food stamps and three percent (3%) report receiving TANF/CalWorks. However, women (21%), heterosexuals (22%), and African Americans (15%) are much more likely to receive food stamps than any other

group. Not surprisingly, women (13%) are much more likely to receive TANF/CalWorks than men.

Improved Outcomes

Mortality

The continuum of care is having the expected positive impact on mortality and morbidity. There has been a sharp decline in death rates of all PLWH/A. However, the death rate among the African American population has remained higher than that of the Anglo and Latino populations. At the end of 2002, the death rate among African Americans was almost twice as high as that of Anglos and Latinos. When a cohort of those in care are tracked, African Americans do better, suggesting that once in care, they have similar outcomes to other ethnic populations.

Physical and Emotional Health

While there is no trend data, it would be expected that a successful continuum of care would continue to keep persons in good physical health, including those with AIDS. Overall, based on improvement in both physical and emotional health, the care system is making an impact. Well over half of PLWH/A report that their physical and emotional health are the same or better. HIV symptomatic populations report having the worst outcomes.

Medication and Adherence

- Eighty-five percent (85%) of all PLWH/A report taking medicines to treat their HIV infection, and there is a linear relationship with stage of disease, starting with 67% of asymptomatic PLWH taking medication to 99% of symptomatic PLWA taking medication.
- PLWH/A with a longer history of HIV disease are more likely to have taken HIV medications. For instance, nearly 90% of men, MSM, and Anglos report having taken medications. On the other hand, women (70%) and heterosexuals (63%) are the least likely to have taken HIV medications – most likely as a function of their newer HIV status.
- Forty-two percent (42%) of PLWH/A report never skipping their medications, and at the other extreme, ten percent (10%) have stopped taking their medicines. Women are significantly more likely to stop their medication than men.
- Notably, symptomatic PLWA are more likely to skip taking their medication than asymptomatic PLWH/A or symptomatic PLWH.
- Among all groups, forgetting to take them (49%) is typically the major reason for skipping medication, with IDU (67%) and MSM/IDU (56%) being the most likely to forget.

- PLWH who are symptomatic and PLWA who are asymptomatic also have higher rates of forgetting than asymptomatic PLWH and symptomatic PLWA.
- The next two most common reasons cited for skipping doses were side effects of medications (39%) and the difficult medication schedules (27%). MSM/IDU (46%) and Anglos (44%) appear to have a greater problem with side effects than other groups. MSM/IDU (40%) also report the most trouble with the medication schedule.
- The three least cited reasons for skipping medications include not understanding the instructions (less than one percent), not wanting others to see taking medications (6%) and the feeling that medicines were no longer needed (6%).

Services

Funding Sources for HIV/AIDS Services

- Based on the 2003 Title I application, the Sacramento EMA has about $38.8 million in public funding for HIV/AIDS care. That includes about $2.8 million in Ryan White Title I funds, or under 8% of all funding.
- The majority of other federal funds ($18.7 million) are for Medi-Cal and Medicare. State funds include the ADAP program ($3.4 million) and home and community based support services ($2.9 million). The remainder includes 8.5 million in local funds.

Top Needs

Each year the Council ranks services by priority as part of the Ryan White Title I application. The ranking reflects the consumers perceived need, epidemiological trends, and other data. Based on FY 2003 ranking, the services needed most by consumers match the Council's priority rankings. Notably, the Council ranks housing 2nd, but the consumers place it relatively lower on their list of needed services. Given reports of high levels of homelessness and difficulty finding stable housing other factors then the consumers perceived need is reflected in the Councils ranking. Another difference is the approach to case management. Consumers understand that their access to services is often through their case manager, and it is not surprising that they rank it among their most needed service. That is followed by food and outpatient care. The Council perceives case management as a means to access service, so ranked it lower than direct medical services. From the consumers' point of view, however, because they perceive case managers as the gatekeepers to care, it is logical that their need for it would be very high.

When each PLWH/A who participated in the survey was asked if "you needed the service in the past year":

- Three of the top ten highest priorities are in the case management category, and two of the top ten are in outpatient medical care and food. The top two most needed services[12] are not within health care: 1) case management and 2) food vouchers. Notably in 2003, case management received the greatest RWTI allocation.

- Outpatient care is the top rank of the Council and is needed by the third largest number of PLWH/A.
- Dental care is among the top services needed by PLWH/A.
- Taxi vouchers and transportation are important, but in the second tier needs by both PLWH/A and the Council.
- Notably, the perceived need by PLWH/A for substance abuse treatment is relatively low even among drug users. While ranked higher among IDUs, it is not a top need, with far more saying they need outpatient medical care, food pantry, rental assistance, and case management. It was perceived as more important by the Council, and that is justified by the high non-IDU drug use and strong relation to poor adherence and high service needs.
- Nearly 54% of PLWH/A reported they needed one-on-one mental health counseling. Still it was not among the top services needed by all PLWH/A, and the other mental health services, family counseling and bereavement counseling, were needed by under 20% of PLWH/A. However, the Council is likely to have responded to the very high incidence of depression, anxiety, and other emotional problems reported by PLWH/A, in giving mental health services a ranking of 5 out of 21 services.
- Men perceive a greater need for medical care, and women perceive a greater need for support services. For example, among the top perceived needs, women report a much greater need than men for transportation and mental health services. For the most part, men and women have about the same rankings for other top services.
- Most of the largest differences in perceived need between men and women are among the services with lower overall need. As might be expected there is a greater perceived need among women for childcare. However, there is also a greater perceived need for bereavement counseling, adult day-care and respite care, and emotional support from buddies.
- Anglos and then Latinos perceive a higher need for medical services, including dental care. Anglos perceive a higher need than Latinos or African Americans for mental health services and complementary care.
- African Americans perceive a higher need for most support services, particularly substance abuse services, including assessment and group sessions, and transportation services. Reflecting the disproportionate number of African American women infected, they also have a higher need for childcare and family counseling.

Asking For and Receiving Services

---

[12] "Most needed" refers to aggregate ranking of consumers who say they needed each service; it is not the report of individual rankings or sorting of services.

Participants in the survey reported whether they had asked for each of the 42 services in the past year, and whether they received the service:

- With the exception of outpatient medical care, perceived need is higher than either the reported demand or utilization for each service.
- Demand is usually greater than utilization, with the exception of outpatient medical care, intake, and adherence support, where they are about the same.
- The demand for services follows reported need, with the exception of food vouchers and financial assistance where PLWH/A are considerably less likely to ask for them than other top ranked services.
- Among services with less perceived need, PLWH/A are considerably less likely to ask for nutritional supplements, counseling, complementary care, and insurance assistance.

Gaps

This report highlights three gap measures: 1) what services are needed by PLWH/A but not asked for, 2) what services are asked but not received, and what services are known, but not asked for. In the first instance the reason may reflect the consumer knowledge that they are not eligible, that the service is not available in the continuum of care, or it may indicate a lack of knowledge. The need-ask gap reflects an expectation on the part of the consumer that the service is available, but that the system was unable to provide it. The "aware-ask" gap

- For the most part, consumers know what services they are eligible for. The biggest "need – ask" gap is for food services, particularly nutritional supplements, and food bank and delivered meals. (Consumers say they need but do not report asking for the service)
- Other services with relatively large need-ask gaps are complementary care, client advocacy, benefits counseling, dental care, transportation, financial assistance and rental assistance.
- For the "ask – receive" gap (services consumers ask for but do not receive), housing has, by far, the largest gap. More consumers ask for but do not receive housing information and rental assistance, and financial assistance. After that food vouchers and food bank have a greater than 5% gap.
- The largest "know-ask" gaps are for substance abuse and mental health counseling. As noted earlier, even among IDUs, the perceived need for substance abuse services is low, and this provides further evidence that the barrier is not lack of knowledge.
- Many PLWH/A who perceive a need for complementary care, do not ask for it. However, once asked for, they are fairly likely to receive it.
- There is over a 10% gap between those consumers who perceive a need but do not ask for client advocacy, benefit counseling, dental care, and transportation. In each of these instances, once consumers ask for the service most report receiving them.

- The opposite pattern is found for housing services. There is a substantial gap between those who ask for but do not receive housing information and rental assistance, but a smaller gap between those who need it and ask for it.
- Four percent (4%) of PLWH/A received outpatient medical care without asking for it, whereas three percent (3%) of them expressed a need for outpatient medical care but did not ask for it. One explanation for this discrepancy is the fact that most PLWH/A automatically seek out medical care with the knowledge they are eligible for service.

Consumers sometimes may be aware of a service, but do not ask for it.

- Case management is ranked as the most needed service, yet 18% of PLWH/A who were aware of it did not ask for it.
- The two services with the highest "need-ask" gap are nutritional supplements and food bank services. For nutritional supplements, 48% say they need it and 28% say they asked for it. For food bank services, 63%of PLWH/A indicated that the food bank is a need but only 49% have asked for it. Complementary care, client advocacy, delivered meals, and dental care and benefit counseling have similar "need-ask" gaps.
- Certain services such as dental care and financial assistance for housing, utilities, and/or insurance premiums, although known and needed by PLWH/A, were not asked for by PLWH/A. This is likely due to eligibility constraints.

Barriers

PLWH/A were asked to rank problems on a scale ranging from "not a problem" to a "very big problem". They ranked thirty potential problems. Two analyses are presented. First is the percent who have a problem. Second, is the size of the problem. The barriers are classified into the more general categories of "organizational", "structural, or "individual" barriers.

- The largest percentage of PLWH/A report individual barriers. Over 60% of PLWH/A said that not knowing about treatment and their own state-of-mind were barriers. The size of these barriers was moderate.
- Over 55% said that not knowing who to ask for services was a barrier. Among those, it was a moderately high barrier.
- About 46% said that the lack of knowledge of needed services was a barrier, and for them it was a moderately high barrier.
- Among structural barriers, over 50% of PLWH/A have some problem with "waiting for appointments or to see someone" and transportation. Between 40% and 50% have a problem with navigating the care system, the amount of red-tape, rules and regulations, including eligibility rules, and availability of a specialist.
- On average, among structural rules and regulation barriers, none were ranked as a big barrier. Yet, for those having a problem with the lack of adequate insurance, cost, eligibility, and rules and regulations represented moderate barriers.

- For the 50% of PLWH/A who noted that transportation was a problem, over forty percent (40%) said it was a big problem. The need for transportation was consistently voiced in the focus groups.
- Fifty percent (50%) of PLWH/A said that waiting and navigating the system was a problem, and for them, over a third said it was a big problem.
- Among organizational barriers, sensitivity of the organization, feeling like a number, and provider expertise are reported as a barrier by over 50% of PLWH/A. Among those naming these barriers, provider sensitivity is reported to be a moderate barrier. This topic was frequently discussed in the focus groups. A number of participants noted that they received excellent care from staff, particularly from physicians. However there were a number of negative comments, mostly directed at case managers, and these are noted, particularly in Services—Qualitative Comments, page 9-4.
- Lack of referrals and fear of losing confidentiality were also perceived as moderately high among those naming them as barriers.
- Forty percent (40%) of PLWH/A named discrimination by "the persons or organizations providing services" as a barrier and ranked it as a relatively high barrier. Sixteen percent (16%) of those with a problem said it was a big problem. In focus groups, person of color and IDUs were most likely to mention discrimination.

Severity of a Problem

Although the highest average barrier was rated as a moderate barrier, different populations reported considerably higher barriers. Important differences are highlighted below.

Overall, males were more likely to report barriers than females, but among women who reported barriers they rated them as slightly bigger than men. Men were significantly more likely to report structural problems than women, particularly red tape, rules and regulations, eligibility, and navigating the system. They were also more likely to report individual-level problems than women, including knowledge about service treatment, their own state-of-mind and physical health.

Among risk groups, IDUs tended to report more problems than other risk groups, particularly individual and organizational barriers. MSM are more likely to report structural barriers particularly waiting for an appointment, red tape, and rules and regulations. Heterosexuals are less likely to report barriers than other risk groups.

For those reporting barriers, MSM/IDU tend to report bigger barriers, particularly related to problems with the justice system (along with IDUs), confidentiality, insurance, and transportation. IDUs tend to report that getting along with their provider is a bigger barrier than for other risk groups.

African Americans, while less likely to mention barriers, generally reported higher barriers than other ethnic populations when they were mentioned, particularly regarding individual and organizational barriers (see the Section BARRIERS, page 10-7).

Children and Adolescents

The data is limited to seven key informant interviews, but from these there is a sense that these families receive excellent medical care for UC Davis. Wrap around services, particularly benefit counseling and case management seem less well coordinated and needed.

Although most of the children do no want to be labeled as HIV positive, it was clear from the interviews that the parents and guardians often felt like they had to manage a difficult system in isolation. They were not in an HIV positive community and often weren't aware of medical or social issues that effect PLWH/A. Many appeared reluctant to talk to their children about the HIV infection and its management. Greater support in understanding the system and greater awareness of the insurance and wrap-around services would greatly help these families care for their HIV positive children.

Overall Assessment

With close to $38.8 million dollars available to fund the continuum of care in the Sacramento EMA, the services provided meet the vast majority of their medical and social service needs. Outcomes in terms of mortality, physical, and emotional health show the continuum of care is effective for most PLWH/A. However, consumers identify gaps in services that reflect the changing demographics of the epidemic.

The Sacramento EMA continuum of care has two main features. First the EMA has one large community-based provider that supplies the vast majority of the medical services and a large portion of the case-management and wrap around services. A number of other providers provide alternatives to medical care, including housing, transportation and other wrap-around services that, in a sense, support the person seeking and maintaining medical care. With this continuum of care model, most persons who ask for medical care and medication receive it on a routine basis. The system of care, both benefits from this model, as well as suffers from what many perceive as a lack of options for care. From a structural perspective, with such a concentration of services at one agency, the oversight and quality control of that agency is critical.

A second feature of the continuum of care is that there is a strong case management model where PLWH/A are required to go through their case manager to access many HIV/AIDS services reimbursed by Ryan White. As reflected in the focus group comments, consumers understand this feature; more consumers say they need case management than any other service. But, it is clear from focus group comments, that they also are critical of the case management system. They often perceive case managers more as gatekeepers than facilitators of services.

In part, the problems of red tape and bureaucracy reflect a more mature system that is responding to increased rules and regulations. However, the frequency of comments about insensitivity and favoritism by case managers, especially among communities of color, suggests a systemic problem in the quality and standards of case management that need to be addressed. More African Americans name these problems, and they are of greater intensity than among either Anglo or Latino populations.

Trends

The epidemic in Sacramento continues to be majority Anglo (61%) and MSM (58%). However, new HIV cases are rapidly evolving to poorer populations that are disproportionately represented by African Americans. The significantly disproportionate infection rate, higher mortality rate, and progression to AIDS among African Americans reflect national trends, and present a warning to the Council and providers that the needs of these communities have to be addressed.

As the epidemic grows disproportionately in the African American population it will include larger numbers of women and affected children. As shown in both the qualitative and quantitative needs assessment data, these women have specific needs related to their gender, poverty, and family status.

National trends further suggests that infection rates are much higher among young gay men and, specifically, young gay men of color, and recent syphilis outbreaks in California have included increases in Sacramento primarily among gay men[13], indicating a growing risk in this population.

When talking to providers and the Council, there is some emphasis on meeting the needs of the younger adolescents and young adults for services. While important, the number of adolescent and young adults (under 30) who know they are living with HIV and AIDS is well under a hundred. In contrast, there are probably well over 700 adults over 50, and that number is likely to substantially increase, given the lower mortality rates. Planning for the needs and entitlements of these older persons living with HIV/AIDS should be a high priority of the Council. Compared to lower age groups, they have higher perceived needs for case management, medical services, medication reimbursement, peer interaction, advocates, and housing information.

Last, there is reason to believe that Latinos are under-represented in this needs assessment, and they have a substantial risk for being unconnected to care. There are a few reasons why their reported infection rates may be low. One explanation is that, due to their more transient and undocumented status, they are less likely to be tested and find their way into the care system. Also, those in the care system may not take full advantage of services offered because of lack of knowledge

---

[13] CA STD Control Program Data Files, July 9, 2003.

The recruitment effort among Latinos highlights the difficulty in reaching this population. Despite the bilingual instruments and interviewers, the difficulty in assessing their needs was evident when significantly fewer Latinos were recruited. Latinas were particularly difficult to recruit. Providers and recruiters were not able to find and persuade Latinos to participate suggesting that providers have not developed the rapport with this community to enlist their cooperation in needs assessments, and probably in encouraging them to seek testing and services.

Outcomes

Mortality is a good measure of the effectiveness of the system, and it shows the continuum of care works. However, the higher mortality rates among African Americans is disturbing. Given a similar fatality rate among a cohort of PLWH/A, the most likely reason is that African Americans are coming into the system later, and sicker. This is further supported by the much higher reported incidence of PCP among African Americans. There is also a higher reported incidence of PCP among heterosexuals, many of whom are African Americans, but also majority women. Focus group comments also reveal that African Americans are less likely to seek care.

Other outcomes are physical and mental health. Overall the patterns in self-reported physical and mental health suggest an effective continuum of care. There is room for improvement, particularly among those who have HIV but have not progressed to AIDS. They report some of worst physical and mental health outcomes. This is further supported by the very linear relationship between stage of infection and being in consistent care. There appears to be considerable potential to bring HIV positive persons into early treatment.

Service Needs and Gaps

The Sacramento EMA is facing at least three simultaneous epidemics with different needs and demographic profiles.

The first is a maturing epidemic populated by gay, largely Anglo men who have a relatively stable, but serious and chronic condition that requires extensive medical monitoring and adherence to an often difficult medical regime that has toxic side effects. Still, these men tend to have more traditional, insurance-reimbursed access to care and to have their medical care reimbursed by non-Ryan White CARE funds. They tend to have attained higher levels of education and as long-term survivors have a better understanding of the system and have learned to be astute self-advocates. MSM say they have the largest ask-receive gaps in the areas of nutritional counseling and complementary care – but they also are not likely to ask for these services.

The medical challenges facing them are obtaining dental care, keeping their medication reimbursement, and assuring that they have access to medical specialists as the challenges of long term medication including liver disease and cancer begin to manifest themselves. Surprisingly, those infected longer report the greatest adherence problems – mostly because they forget or have side effects.

A second epidemic is among drug users, IDU and non-IDU, including MSM/IDU. MSM/IDU account for a larger part of the Sacramento epidemic than most other EMAs. Those who were infected through IDU and MSM/IDU account for a quarter of the epidemic. They have in common recent encounters with the penal system, and both say they were denied or have been afraid to seek services due to criminal justice matters.

MSM/IDU and IDUs are, however, different populations. IDUs are more likely to be African Americans and are, on average, older than other risk groups. MSM/IDUs are more likely to be Anglo and younger. They are much more likely to use party drugs, including cocaine, while IDUs are more likely to use heroin and crack/cocaine. MSM/IDUs have one of the highest incidences of STDs and are more likely to report being symptomatic. They report higher needs for substance abuse services including individual and group counseling and residential substance abuse. MSM/IDU have one of the largest adherence problems. IDUs have a greater need for transportation and client advocacy, and rental assistance. Recently incarcerated report the highest abuse of drugs.

Drug use, in addition to being highly correlated to unsafe practices, is related to becoming symptomatic. This suggests the continued linkage of HIV/AIDS care with drug services and an expanded counseling and awareness effort to increase awareness of the dangers of drugs and to change drug use behaviors.

A third epidemic is among the communities of color that are newly infected, who tend to be poor, and are much more likely to be female and have families. Of particular concern is that many of those coming to the epidemic delay treatment. There is a need to improve coordination between testing and moving a person who tests positive into care.

Assuring that those newly infected receive entitlements is critical. Women, particularly, appear to not be fully enrolled in Medi-Cal and SCHIP. A majority of the newly infected are African Americans and they are already suspicious of the medical system. They are also in need of housing assistance, emergency financial assistance, transportation, and food, and report higher barriers to receiving them. Further, they report significant gaps in transportation and housing.

Latinos are less likely to become infected than African Americans, and are more likely to request medical services, including mental health services when they do. They are more likely to work, less likely to ask for social services. This is likely to be more a function of expectations than need, as Latinos are less educated and often poorer than African Americans. It suggests a concerted outreach effort to the Latino community to encourage those at risk to test and seek treatment.

For those who are newly infected or new to the continuum of care, knowledge about treatment and who to ask for services are among the most frequently mentioned barriers to care. The fear of losing confidentiality is also perceived as a barrier, particularly among Latinos and women. Among those who are in the system, red tape, waiting time, and insensitivity are frequently mentioned barriers. From focus group information, it is clear that any payment, including co-payment for care or medication, presents significant barriers for seeking services.

Special Populations

Among special populations, the homeless and recently incarcerated have higher needs, particularly in housing, transportation, and food services. These populations have in common a demand for substance abuse services, and have a high incidence of co-morbidities that could be addressed with comprehensive case management and care that coordinates their high need for HIV/AIDS and other social and medical services.

Housing and food are a basic concern among this population that tends to be overwhelmingly poor. The largest "need-ask" gap is food services, including nutritional supplements, food bank and home delivered meals. Of those, food bank services also have a relatively large "ask-receive" gap. The largest "ask-receive" gaps are housing services. This suggests that a decision has to be made to build infrastructure or links to existing food services and assure that PLWH/A are informed and use these services. On the other hand, the Council can make a decision to decrease funding for food services, develop links to existing food services, and inform the consumer of other food options. This would encourage links with existing services and lowering expectations of Ryan White funded food services. For housing there are fewer options for PLWH/A who can't qualify or wait for Section 8 housing. Given the intensity of need, further effort is necessary to link HIV/AIDS care with housing services.

Many of the newly infected come to the epidemic with emotional problems or serious mental illness. That is, in turn, often related to substance abuse. Strong links to mental health programs and substance abuse programs could improve options and access to care for those needing drug abuse or mental health services. The fact that many of those with substance abuse issues do not perceive a problem also indicates the need for greater and more persuasive outreach.

As new persons enter the system there is a continued demand for case management. In focus groups, we hear often that case managers act more as gatekeepers to services rather than facilitating care. Perceived lack of sensitivity and responsiveness on the part of providers, particularly case managers, presents a significant barrier to receiving and maintaining care. Many of the currently out-of-care individuals have been in the system of care, but have been turned-off by what they feel is inadequate of insensitive care.

There is a small perceived "need-ask" gap for outpatient care, and that is likely to reflect a number of PLWH/A who perceive they have no access and therefore don't ask for it.

One plausible group are those that fall into a crack where they are insured or make sufficient income to disqualify from assistance, but don't make enough to obtain quality care. Another subpopulation are active drug addicts who may say they need the service, but their drug use keep them from asking.

There is need to reinforce standards, establish consumer expectations, and assure that case managers are trained to provide the appropriate linkages. Greater sensitivity to the lifestyles of a wide spectrum of clients is necessary for case management to provide adequate services.

Out-of-Care

When talking about out-of-care it is useful to divide the populations into three segments:

- A pattern of starting care after a period of delay and continuing care,
- Those who have started care and stopped, and
- Those who have an inconsistent pattern of starting and stopping care.

Given the number of men who are infected, there are more men and MSM in each of these categories. However, women are disproportionately represented in delay care seekers. Proportionately, African Americans are much more likely to delay care, access care inconsistently, and stop care.

Delayed care seeking is related to education, and the data indicate that those with less education are more likely to name lack of knowledge as a barrier to seeking care. Low literacy and Spanish language campaigns to inform person about where and when to seek care could make a significant impact. Delayed care seekers and those out-of-care are much more likely to have been recently incarcerated, and there is ample evidence to show that care in jails is not adequate.

Those currently out of care are much more likely to say that reasons for not going to care is some problem with a provider and a feeling that there are few alternatives. Where there are few alternatives for where to access care, providers need to assure that there is an accessible grievance procedure.

Those unconnected to care name structural problems with getting into the system as greater barriers, and it is clear from the data that basic home and food needs trump HIV/AIDS care services as necessities.

Last Word

The Sacramento EMA is meeting the basic medical and wrap-around services of PLWH/A. The EMA serves those who have been in the system longest best. With the exception of adherence, those who have experience with the system report doing best.

Several suggestions and areas for improvement in care have been made for drug using PLWH/A, and for those who have more recently entered the continuum of care, including African Americans and women. The data on children and adolescents suggests that they receive excellent care, but need better coordination of benefits, wrap around services, and accessing information and support. Perhaps the most over-riding theme for these individuals is that HIV/AIDS care is important, but competes with many other basic needs. Coordinating general health care with HIV/AIDS care and having more comprehensive case management may improve the outcomes of PLWH/A.

14. Attachments

Attachment 1 Project Advisory Group

Sacramento EMA Needs Assessment / Comprehensive Plan
PROJECT ADVISORY GROUP

NAME	EMAIL	AFFILIATION
Adrienne Rogers	rogersad@saccounty.net	Ryan White Fiscal Administrative Agent
Alix Gillam	gillama@saccounty.net	Epidemiologist
Bill Puryear		Planning Council Alternate Member: Affected Community
Craig Spatola	cspatola@yahoo.com	Planning Council Chair
David Pilcher	pilched@sutterhealth.org	Physician
Jeff Cowen	sfafjeff@jps.net	Planning Council Member: Non-elected Community Leader; Provider
Julie Gallelo	galleloj@saccounty.net	HIV/AIDS Education and Prevention Program Coordinator
Kane Ortega		Planning Council Member: Affected Community
Katana Barnes	katanabarnes@aol.com	Planning Council Vice-Chair
Lisa Boch	cdcw@cwo.com	Planning Council Member: Substance Abuse Provider; Needs Assessment Committee Chair
Lisa DaValle	lisa.davalle@ucdmc.ucdavis.edu	AIDS Education and Training Center
Marty Keale	mkeale@caresclinic.org	Planning Council Member: Title III; Provider
Michael Ungeheuer	munger@co.el-dorado.ca.us	Planning Council Member: El Dorado County Dept. of Public Health
Ola Adams Best	oadams@dhs.ca.gov	HIV/AIDS Service Provider
Otashe Golden	ogolden47@aol.com	Planning Council Member: Physician
Peter Feeley	pfeeley856@aol.com	Planning Council Member: AIDS Service Organization; Priorities and Allocations Committee Chair

Please forward the names of interested participants to HHSPC staff at 447-7063 x360 or alange@communitycouncil.org.

Attachment 2 Secondary Information Citations

1. "2000 Needs Assessment Update for the Sacramento Eligible Metropolitan Area" Sacramento HIV Health Service Planning
    a. Council Needs Assessment Committee. June, 2000.

2. "AIDS Data for Sacramento County" Sacramento County Department of Health and Human Services. 2003.

3. Bevard, H., Castner, J., Foster, T., Hansen III, G."Service Needs of Out-of-Care People with HIV/AIDS" The Center for Applied
    a. Local Research. Richmond, CA. July, 2003.

4. "Communicable Diseases: Sacramento County 1994-1998" Sacramento Department of Health and Human Services Epidemiology and Disease Control Branch. August, 1999.

5. "Findings from the 2000 Needs Assessment Update for the Sacramento Eligible Metropolitan Area''. June, 2000.

6. "Findings from the Consumer Satisfaction Survey for the Sacramento Eligible Metropolitan Area" Sacramento, CA. 2000, May.

7. "Findings from the 1999 Client Services Access Project for the Sacramento Eligible Metropolitan Area" Sacramento, CA. 1999,

8. Hutchison, C., Stoebel, D."Sacramento Region HIV Services Comprehensive Plan" Stacy J. Powell & Associates. Sacramento, CA. 2002.

9. Janney, J., Kahn, J., Franks, P."A Practical Guide to Measuring Unmet Need for HIV Primary Medical Care for Ryan White Title I and II CARE Act Grantees, Planning Councils, and Consortia" Institute for Health Policy Studies, School of Medicine, University

10. Paterniti, D."HIV Transmission Prevention Project: Report of Focus Groups and Telephone Interviews with Risk Reduction
    a. Specialists" University of California, Davis. April, 2002.

11. "www.sacdhhs.com" Sacramento, CA. Jan, 2003.

Attachment 3 Sacramento EMA Needs Assessment Survey of PLWH/A

CONSENT FORM
2003 SACRAMENTO EMA HIV/AIDS CARE NEEDS ASSESSMENT

The HIV Health Services Planning Council serving the three counties of the Sacramento EMA, in collaboration with the Sacramento Department of Health and Human Services is conducting a needs assessment of HIV and AIDS services.

You have been invited to participate and contribute your experiences, knowledge, and opinions about the service needs for people like yourself living with HIV/AIDS. Completing this survey gives you a voice in the planning for HIV and AIDS treatment services throughout the Sacramento EMA. You will receive $20 in food vouchers for completing this survey and be eligible for a grand prize.

This survey is entirely confidential. This assurance of confidentiality means that no information about your participation can be obtained by anyone outside of the needs assessment group. While we ask some questions about your background for the purposes of analysis, your name will never be linked to your answers. The results of this needs assessment may be published, but your name will never be used in any report or publication.

Your consent is entirely voluntary and your decision to participate or not will have no effect on the care you are receiving or the relationships you have with providers and caregivers at this agency.

By signing below, you consent to complete the survey.

PARTICIPANT'S SIGNATURE: ____

PARTICPANT'S NAME: ____

Address: ____

City ___________________________ CALIFORNIA Zip Code ________________

Telephone: __ __ __ - __ __ __ - __ __ __ __ Date: __ __/ __ __/ 2003

If you have any questions, please call Carol Maytum at (916) 684-0567.

RECEIVE ANOTHER $20 FOOD VOUCHER AND ANOTHER CHANCE TO WIN THE GRAND PRIZE.

Would you be interested in participating in a focus group where 10 –12 people discuss HIV/AIDS services, during the week of March 24th? ☐ YES ☐ NO

Focus group participants will receive an additional $20 in food vouchers and also be eligible for a grand prize.

Day care and transportation are provided if needed. If you check "yes" someone from the "Needs Assessment Project" will give you a call to arrange for your participation.

SACRAMENTO EMA NEEDS ASSESSMENT SURVEY OF PEOPLE LIVING WITH HIV AND AIDS

Sponsored by the Ryan White HIV Health Services Planning Council

INTRODUCTION

Thank you for agreeing to participate in this important survey. Completing this survey gives you a voice in the planning of HIV and AIDS treatment services throughout the Sacramento EMA.

For each question below, circle or write in an answer. There are no right or wrong answers. Please take as much time as you need to answer each question based on your experiences. If you have any questions or need help reading the survey or interpreting the questions, please ask for assistance.

Your responses are completely confidential. Your name will never be linked to your answers.

Thank you in advance for completing this survey. Please create your confidential ID as described below.

Confidential ID Needed for Grand Prize Drawing

We will be obtaining responses from many people living with HIV and AIDS over the next few weeks. In addition to the food voucher you will receive you are eligible for a grand prize. In order to select a grand prizewinner, please create a confidential identifier, which you will place on the top of every page of your survey. This ID is unique to you, and will protect your confidentiality.

______	______	______ ______	______ ______	______
What is the *first* letter of your first name	**What is the *last* letter of your last name**	**What is the month of your birthday** **(For January through September use a leading "0" e.g. 01 for January)**	**What is the day of your birthday** **(For days 1 - 9 use a leading "0" e.g. 01)**	**What is the first letter of your mother's first name? (If you don't know, list the first letter of your father's first name)**

(01=Jan, 02=Feb, 03=Mar, 04=Apr, 05=May, 06=June, 07=July, 08=Aug, 09=Sept, 10=Oct, 11=Nov, 12=Dec)

Please copy the confidential ID you have created to the top right of each page of the survey.

Name of Interviewer: ________________________

Location of Interview: ________________________

Interview Start Time: ________________________

Today's Date: _____ / ___ / ___

1. Are you currently **(Circle number next to the answer)**

HIV+ with disabling symptoms	1
HIV+ with no symptoms	2
HIV negative	3 →

Please see the interviewer.

2. When were you born? .... __ __/__ __ **Mo. Yr.**

3. Are you...

Male	1
Female	2
Transgender - Male to female (MTF)	3
Transgender - Female to male (FTM)	4
Intersex	5

4. What do you consider your ethnic background?

African-American / Black	1
Asian Pacific Islander	2
Hispanic / Latino	3
Native American	4
White/Caucasian (non Hispanic)	5
Other **(Specify)** ______________________	6

4a. What language(s) do you speak most frequently at home? ______________________________

5. Do you consider yourself **(circle one)**

Heterosexual/Straight	1
Homosexual - Gay male	2
Homosexual - Lesbian	3
Bisexual	4
Other **(Specify)** ______________________	5

6. What is the highest level of education you completed?

Grade school or less	1
Some high school	2
Graduated high school/GED/trade school	3
Some college/2 year college degree	4
Completed 4 year college	5
Graduate level or professional study	6

7. What is the zip code and city and/or neighborhood where you live?

___ ___ ___ ___ ___ **Zip**

______________________ **City and/or Neighborhood**

8. Where do you currently live? **(Circle one)**

In an apartment/house I own	1
In an apartment/house I rent	2
At my parent's/relative's apt./house	3
Living/crashing with someone & not paying rent	4
Single Room Occupancy (SRO) with tenancy	5
Single Room Occupancy (SRO) without tenancy	6
In a "supportive living" /assisted living facility	7
In a group home or residence including residential drug therapy	8
In a half-way house or transitional housing	9
Skilled Nursing Home	10
Homeless (on the street/in car)	11
Homeless shelter	12
Jail or correctional facility	13
Hospital / Institution	14
Residential Hospice Facility	15
Other **(Specify)** ______________________	16

9. How much do you pay monthly for housing? ________

10. Is your living situation ...?

(Circle 1 for "Yes" or 2 for "No" for each item)

	Yes	No
Safe	1	2
Habitable (clean and livable)	1	2
Stable	1	2

11. IF YOU LIVE IN SACRAMENTO, are you on a waiting list to get into housing?

Yes	1
No (CIRCLE 2 AND GO TO Q.12)	2

11b. IF RECEIVED A REFERRAL FOR HOUSING, did it result in a housing placement?

Yes	1
No	2

12. In your household, how many.... **(fill in #)**

Other adults are living with you?	☐
Children and teens are living with you?	☐

IF YOU DO NOT LIVE WITH ANYONE, SKIP TO Q. 13.

12a. Is anyone else in your household HIV positive? **(Circle 1 for "yes", 2 for "no" or 8 for "Don't Know" for each item)**

	Yes	No	Don't Know			Yes	No	Don't Know
Partner/wife/husband	1	2	8		Other adults	1	2	8
Adult family member / relative	1	2	8		Children	1	2	8

13. Over the last two (2) years, how long (total time) have you lived in each of the places listed below?

(Circle one answer for each of the items below)	**Never**	**Less than a month**	**1-3 months**	**4 months to 1 yr.**	**More than 1 yr.**
In a half-way house or transitional housing	1	2	3	4	5
In a treatment facility (drug or psychiatric)	1	2	3	4	5
Homeless (on the street/in car)	1	2	3	4	5
Homeless shelter	1	2	3	4	5
Jail or correctional facility	1	2	3	4	5
Other **(Specify)** ______________________________	1	2	3	4	5

14. What best describes your current job (work) situation? **(Circle one)**

Employed full-time (33-40 hours a week)........	1
Employed part-time (less than 33 hours a week)	2
Not working – looking for work	3
Not working – student /homemaker /other	4
Not working – not looking for work	5
Retired..	6
Other **(Specify)** __________________________	7

15. What is your reported estimated **yearly** income from all sources and before taxes?

$0 - $ 8,600 (up to $716 a month).........	1
$8,601 - $11,600 ($717 - $967 a month)........	2
$11,601 - $16,500 ($968 - $1375 a month)	3
$16,501 - $23,200 ($1376 - $1933 a month).....	4
$23,201 - $26,000 ($1934 - $2167 a month).....	5
$26,001 - $35,000 ($2168 - $2917 a month).....	6
Greater than $35,001 ($2918 or more a month)	7

16. Do you have any health insurance?

Yes	1
No	2

16a. What kind of health insurance do you have?

(Circle 1 for "Yes" or 2 for "No" for each item)	**Yes**	**No**
Insurance through work....................	1	2
COBRA or OBRA (insurance through my last employer)	1	2
Private insurance, not through work	1	2
Medicare – HMO	1	2
Medicare – non-HMO........................	1	2
Medi-Cal / Medicaid	1	2
Other Insurance **(Specify)**_____________	1	2

17. Which of the following benefits do you receive?

(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	**Yes**	**No**	**Don't Know**
Food stamps..........................	1	2	8
Long term disability	1	2	8
Short term disability................	1	2	8
Supplemental Security Income (SSI)	1	2	8
Public Health Service, Bureau of Indian Affairs (BIA)	1	2	8
State Disability Insurance (SDI) ...	1	2	8
Social Security Disability Insurance (SSDI)...................	1	2	8
Veteran's benefits (VA)	1	2	8
TRICARE / CHAMPUS (VA Assistance for military retirees and their dependents)	1	2	8
Worker's compensation	1	2	8
Annuity/Life insurance payments	1	2	8
Retirement	1	2	8
Rent supplement	1	2	8
Subsidized housing (HOPWA Subsidy, Section 8 certificate or Shelter Plus Care)	1	2	8
General Assistance (GA)............	1	2	8
Emergency Financial Assistance From whom **(Specify)** ________________________	1	2	8
WIC	1	2	8
TANF/CalWORKS – formerly AFDC	1	2	8
Other **(Specify)** ________________	1	2	8
Not eligible for benefits	1	2	8

18. In the past year, how many agencies have provided case management to you at the same time? ____________ **Write #**

19. What was the month and year that you first tested positive for HIV? __ __ Mo. __ __ Yr.

20. After receiving your HIV diagnosis, when did you have your first visit with a doctor for your HIV/AIDS? **(Circle one)**

Within a month after diagnosis	1
One to three months after diagnosis	2
Four to six months after diagnosis	3
Seven months to a year after diagnosis	4
More than a year after diagnosis	5
I haven't seen a doctor for my HIV	6

21. What is the most likely way you were infected by HIV? **(Circle one)**

Having sex with a man	1
Having sex with a woman	2
Having sex with a transgender	3
Sharing needles	4
Blood products/Transfusion (blood or tissue recipient)	5
Hemophilia	6
Acquired at birth	7
Other **(specify)**________________	8
Don't Know	9

22. Have you ever been told by your doctor, nurse, or other health care team member that you have AIDS?

Yes	1
No **(CIRCLE 2 AND GO TO Q.23)**	2

22a. **IF YES TO Q. 22,** when were you told that you had AIDS? __ __ Mo. __ __ Yr.

22b. Where were you diagnosed with AIDS?

____________________ City ____________________ State

23. In general, would you say that today your <u>physical</u> health is…

Excellent	4
Good	3
Fair	2
Poor	1

23a. How would you rate your <u>physical</u> health now as compared to when you first sought treatment for your HIV infection?

Much better	5
A little better	4
About the same	3
A little worse	2
Much worse	1

24. In general, would you say that today your <u>emotional</u> health is…

Excellent	4
Good	3
Fair	2
Poor	1

24a. How would you rate your <u>emotional</u> health now as compared to when you first sought treatment for your HIV infection?

Much better	5
A little better	4
About the same	3
A little worse	2
Much worse	1

25. Has your T-Cell count ….?

(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	**Yes**	**No**	**Don't Know**
Ever dropped below 500 cells/UL	1	2	8
Ever dropped below 350 cells/UL	1	2	8
Ever dropped below 200 cells/UL	1	2	8
Now dropped below 350 cells/UL	1	2	8
Now dropped below 200 cells/UL	1	2	8

26. Has your viral load ….?

(Circle 1 for "Yes", 2 for "No" or 8 for "Don't Know")	**Yes**	**No**	**Don't Know**
Ever rose above 30,000 copies	1	2	8
Ever rose above 10,000 copies	1	2	8
Currently above 10,000 copies	1	2	8

27. What was the date of the last visit you had with a doctor for your HIV infection **(ESTIMATE IF NECESSARY)**? __ __/__ __ **Mo.** **Yr.**

☐ I have never seen a doctor or gone to a clinic since I found out I was HIV+. **(GO TO Q.33)**

28. Since you found out you were HIV positive,		
(Circle 1 or "Yes" or 2 for "No" for each item)	**Yes**	**No**
Has there ever been a period of time of more than a **year (12 months)** when you didn't see a doctor or go to a clinic?	**1** **(GO TO Q.28a)**	**2**
Has there ever been a period of time of more than **six months** when you didn't see a doctor or go to a clinic?	**1** **(GO TO Q.28a)**	**2** **(GO TO Q.29)**

28a. Since that time have you gone back to see a doctor?

Yes	1	**(GO TO Q.28b)**
No	2	**(GO TO Q.29)**

28b. **IF YES TO Q.28a**, What happened to make you seek medical care after not seeing a doctor or clinic professional for more than six months?

(Circle 1 or "Yes" or 2 for "No" for each item)	**Yes**	**No**
I got sicker	1	2
Change in my income	1	2
Change in my insurance status	1	2
Heard about new doctor / clinic	1	2
There was a change in my doctor's or clinic's attitudes	1	2
There were different drugs or treatments available	1	2
I had stable housing	1	2
Other **(specify)** ____________________	1	2

29. Where do you receive your medical care most often?

(Circle 1 or "Yes" or 2 for "No" for each item)	**Yes**	**No**
Alternative treatment/medical facility	1	2
Community / Neighborhood Clinic (CARES, MAPP, County Clinics)	1	2
Mercy	1	2
UC Davis Medical Center	1	2
Veteran's Administration Medical Center	1	2
Emergency Room	1	2
Private Hospital	1	2
Private Doctor's Office/Clinic	1	2
Kaiser Permanente	1	2
Other **(specify)** ____________________	1	2

30. Thinking about the past year, how often did you get medical care from any physician or clinician that can prescribe medications from a pharmacy?

Never **(Circle 1 AND GO TO Q.33)**	1
Only when you were sick	2
On a regular on-going basis	3

31. Have you had the same doctor or gone to the same clinic for your HIV infection … **(Circle one)**

Since you found out you were HIV+	1
For two or more years	2
Since last year	3

32. Did you miss any medical appointments in the last year?

Yes	1	**(GO TO Q.32a)**
No	2	**(GO TO Q.33)**

32a. **IF MISSED**, did you reschedule for the next available appointment?

Yes	1	**(GO TO Q.32b)**
No	2	**(GO TO Q.33)**

	Yes	**No**
32b. **IF RESCHEDULED**, did you make it to the rescheduled appointment?	1	2

33. At any time in the last year, have you been diagnosed with any of the following diseases listed below?

(Circle 1 for "yes", 2 for "no" or 8 for "Don't Know)	**Yes**	**No**	**Don't Know**
Hepatitis A or B	1	2	8
Hepatitis C	1	2	8
Syphilis	1	2	8
Herpes (genital)	1	2	8
Gonorrhea	1	2	8
Chlamydia	1	2	8
Genital warts	1	2	8
Yeast infections	1	2	8
Other **(specify)** ________________	1	2	8

34. Since you found out you were HIV positive, have you ever had any opportunistic infections?

Yes	1	**(GO TO Q.34a)**
No	2	**(GO TO Q.35)**

34a. What types of infections or symptoms? (**Write in below—see list)**

Names of different infections:

Candidiasis
Cryptococcosis
Cryptosporidiosis (chronic intestinal)
Cytomegalovirus disease (usually of the retina)
HIV encephalopathy
Herpes
Histoplasmosis
Isoporiasis
Kaposi's Sarcoma (KS)
Lymphoma (including Burkitts, immunoblastic, or the brain)
Mycobacterium avium complex (MAC)
Pneumonia or pneumoncystis carinii pneumonia (PCP)
Salmonella
Shingles
Toxoplasmosis
Tuberculosis
Wasting syndrome

	Yes	No
35. Have you ever taken any medicines for your HIV infection?....................................	1	2

(IF YES, GO TO Q. 36. IF NO THEN GO TO Q.40)

36. How many prescription drugs are you currently taking? **(IF NONE GO TO Q.38)** ______ #

36a. How many of your prescription drugs are paid for or reimbursed by each of the following sources?

(IF YOU DON"T KNOW, CIRCLE "8")	**Write #**	**Don't Know**
ADAP	__________	8
Medi-Cal/Medicare	__________	8
Private insurance	__________	8
Veterans benefits	__________	8
Out-of-pocket	__________	8
Other **(specify)**__________________	__________	8

37. Are you taking any of the following?

(Circle 1 for "Yes", 2 for "No" or 8 for DK)	**Yes**	**No**	**Don't Know**
Anti-retrovirals and/or protease inhibitors...........................	1	2	8
Antibiotics (such as Bactrim) that fight off infections	1	2	8
Antifungal (such as Diflucan) that are for body rashes or thrush....	1	2	8
Steroids which help you with your appetite or build weight	1	2	8
Antidepressants for depression or anxiety	1	2	8
Herbal and/or other supplements.	1	2	8

38. How often have you skipped taking your HIV/AIDS medication as prescribed by your doctor?

Never / Have not skipped **(Go to Q.40)**............	1
Once or twice a month	2
Once or twice a week..............................	3
More than twice a week	4
I have stopped taking my medicine..............	5

39. If skipped or stopped taking your HIV/AIDS medication, why?

(Circle 1 for "Yes" or 2 for "No" for each item)	**Yes**	**No**
Side effects	1	2
Difficult schedule and requirements	1	2
Didn't want others to see the medications	1	2
Didn't understand the directions	1	2
Felt that medication didn't work.........	1	2
Could not afford medication..............	1	2
Forgot to take the medication	1	2
Hard to coordinate with food	1	2
Just did not want to take them	1	2
Homeless....................................	1	2
Medication made me feel good so I felt I didn't need them anymore	1	2
My doctor advised me to stop taking my medications	1	2
Other **(specify)** ______________________	1	2

40. Since you were infected with HIV have you received mental health counseling or treatments?

Yes	1	→ **Go to Q.41**
No	2	→ **Skip to Q.42**

41. Which of the following mental health counseling or treatments did you receive?

(Circle 1 for "Yes" or 2 for "No" for each item)	**Yes**	**No**
Inpatient (in a hospital at least overnight)	1	2
Individual counseling/therapy............	1	2
Group counseling/therapy	1	2
Medication for psychological or behavioral problems....................	1	2

42. At any time in the last two years have you been diagnosed with any of the following mental health problems?

(Circle 1 or "Yes" or 2 for "No" for each item)	**Yes**	**No**
Anxiety	1	2
Bipolar Disorder............................	1	2
Dementia	1	2
Depression	1	2
Other **(specify)** ______________________	1	2

43. For each of the services below:

1. Under column A, circle 1 for "yes" if you know that the service is available for people living with HIV/AIDS or circle 2 for "no" if you don't know if it the service is available for people living with HIV or AIDS.
2. Under column B, note if you *needed* the service in the past year.
3. Under column C, note whether you *asked* for this service this past year.
4. Under column D, note if you *received* this service this past year.

MEDICAL AND DENTAL CARE		**A**		**B**		**C**		**D**	
	For each health care service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Visits with a doctor, nurse, or assistant to take care of your HIV - Outpatient medical care.	1	2	1	2	1	2	1	2
2	Visit to a medical specialist based on a referral from your doctor.	1	2	1	2	1	2	1	2
3	Dental care or oral health care.	1	2	1	2	1	2	1	2
4	Medication or prescription payment such as ADAP that provides assistance paying for HIV/AIDS related drugs (including methadone).	1	2	1	2	1	2	1	2
5	Home heath care from a nurse or aide (including medical care or rehabilitation).	1	2	1	2	1	2	1	2
6	Help adhering to medication from a counselor, doctor, nurse, or nurses aide.	1	2	1	2	1	2	1	2
7	Complementary care - includes acupuncture and chiropractic care.	1	2	1	2	1	2	1	2
8	Residential hospice care.	1	2	1	2	1	2	1	2

For the health services noted above, what problems did you experience in accessing or using the service? (SEE PROBLEMS HANDOUT)

CASE MANAGEMENT AND BENEFITS COUNSELING		A		B		C		D	
	For each health care service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Case management - session(s) with a case manager to help you coordinate your HIV/AIDS care and help access benefits.	1	2	1	2	1	2	1	2
2	Benefits counseling - session(s) with a case manager or benefits counselor to help you access benefits.	1	2	1	2	1	2	1	2
3	Intake session when you first come to an agency and a staff member assesses your care needs.	1	2	1	2	1	2	1	2
4	Client advocacy where the client advocate helps resolve particular problem in obtaining a service, or in a complaint against a service provider.	1	2	1	2	1	2	1	2

For the case management and benefits counseling services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

EMERGENCY FINANCIAL ASSISTANCE		A		B		C		D	
	For each financial assistance service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Assistance paying health insurance premiums for those who have private health insurance.	1	2	1	2	1	2	1	2
2	Emergency financial assistance for housing and utilities.	1	2	1	2	1	2	1	2

For the financial assistance services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

HOUSING		**A**		**B**		**C**		**D**	
	For each housing service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Housing information services – assistance in finding or getting housing from a housing specialist.	1	2	1	2	1	2	1	2
2	Rental assistance paid to landlord or owner of housing.	1	2	1	2	1	2	1	2
3	Supportive housing where services such as case management or nursing care is available.	1	2	1	2	1	2	1	2

For the housing services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

TRANSPORTATION		**A**		**B**		**C**		**D**	
	For each transportation service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Van and taxi transportation to HIV/AIDS services.	1	2	1	2	1	2	1	2
2	Taxi vouchers or tokens and passes to mass transit (bus and rail).	1	2	1	2	1	2	1	2

For the transportation services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

MENTAL HEALTH TREATMENT		A		B		C		D	
	For each mental health treatment service below…	Are you aware that the service exists?		Did you *need* this service this past year?		Did you *ask for* this service this past year?		Did you *receive* this service this past year?	
		Yes	No	Yes	No	Yes	No	Yes	No
1	One-on-one psychological or psychiatric counseling (NOT FOR SUBSTANCE ABUSE).	1	2	1	2	1	2	1	2
2	Group counseling led by a psychologist or social worker (NOT FOR SUBSTANCE ABUSE).	1	2	1	2	1	2	1	2
3	Support groups led by peer or non-licensed group leader (NOT FOR SUBSTANCE ABUSE).	1	2	1	2	1	2	1	2
4	Counseling for your family (children, spouse, partner).	1	2	1	2	1	2	1	2
5	Bereavement counseling by phone or in-person.	1	2	1	2	1	2	1	2

For the mental health services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

FOOD AND NUTRITION SERVICES		A		B		C		D	
	For each health care service below…	Are you aware that the service exists?		Did you *need* this service this past year?		Did you *ask for* this service this past year?		Did you *receive* this service this past year?	
		Yes	No	Yes	No	Yes	No	Yes	No
1	Food bank or pantry.	1	2	1	2	1	2	1	2
2	Food vouchers.	1	2	1	2	1	2	1	2
3	Home delivered meals.	1	2	1	2	1	2	1	2
4	Nutrition counseling by licensed nutritionist.	1	2	1	2	1	2	1	2
5	Nutritional supplement, vitamins, and herbs	1	2	1	2	1	2	1	2

For the food and nutrition services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

FOOD AND NUTRITION SERVICES	**A**		**B**		**C**		**D**	
For each health care service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
	Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**

SUBSTANCE ABUSE TREATMENT		**A**		**B**		**C**		**D**	
For each substance abuse treatment service below…		**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Outpatient substance abuse treatment or counseling.	1	2	1	2	1	2	1	2
2	24 hour-a-day residential substance abuse counseling (can include detox).	1	2	1	2	1	2	1	2
3	An assessment of your substance use need.	1	2	1	2	1	2	1	2
4	Substance abuse one-on-one psychological or psychiatric counseling.	1	2	1	2	1	2	1	2
5	Substance abuse group counseling.	1	2	1	2	1	2	1	2
6	Substance abuse Support groups led by peer or non-licensed group leader.	1	2	1	2	1	2	1	2
7	Substance abuse counseling for your family (children, spouse, partner).	1	2	1	2	1	2	1	2

For the substance abuse services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

OTHER SUPPORT SERVICES		**A**		**B**		**C**		**D**	
	For each service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Buddy / Companion services where a community member provides emotional support.	1	2	1	2	1	2	1	2
2	Buddy / Companion services where a community member helps you with household tasks, such as shopping, cleaning, laundry.	1	2	1	2	1	2	1	2
3	Where a peer or buddy provides advocacy services on your behalf.	1	2	1	2	1	2	1	2
4	Day care or respite services for you or your caregiver can go for services.	1	2	1	2	1	2	1	2
5	Child care.	1	2	1	2	1	2	1	2
6	Vocational referrals.	1	2	1	2	1	2	1	2
For the support services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)									

44. Below is a list of problems that you may have had when trying to obtain or use HIV/AIDS services. Mark an X on the line beside each item to say how big a problem it has been for you. The line goes from a "very big" to a "very small" problem. A "very big" problem means that it stopped you from getting the service(s). A "moderate" problem means that you faced substantial problems but that you were able to get the service most of the time. A "very small" problem caused you minor concern and delays in obtaining the service(s). If you have not had the problem at all, circle "0".

Very Big = it stopped you from getting the service **Moderate = you faced substantial problems but were able to get the service** **Very Small = caused you minor concern and delays in obtaining the service**	**Very Big**	**Big**	**Mod-erate**	**Small**	**Very Small**	**Not a problem**
Example: The survey is difficult to complete	____|_____|_______|______|___x_					0
1. Not knowing that a service or treatment was available to me.	____|_____|_______|______|_____					0
2. Not knowing a location of the service(s).	____|_____|_______|______|_____					0
3. My physical health has not allowed me to get to the place where the service is provided.	____|_____|_______|______|_____					0
4. I do not believe HIV or AIDS is a problem for me that requires assistance.	____|_____|_______|______|_____					0
5. Not knowing what medical services I need to treat my HIV infection or AIDS.	____|_____|_______|______|_____					0
6. My state of mind or mental ability to deal with the treatment.	____|_____|_______|______|_____					0
7. Not understanding the instructions for obtaining the service or treatment.	____|_____|_______|______|_____					0
8. Not knowing who to ask for help.	____|_____|_______|______|_____					0
9. Sensitivity of the organization and person providing services to me regarding my issues and concerns.	____|_____|_______|______|_____					0
10. Discrimination I experienced by the persons or organization providing the services.	____|_____|_______|______|_____					0
11. Experience or expertise of the person providing services to me.	____|_____|_______|______|_____					0
12. The amount of time I had to wait to get an appointment or to see someone.	____|_____|_______|______|_____					0
13. The organization providing the service made me feel like a number.	____|_____|_______|______|_____					0
14. I do not get along with people providing services	____|_____|_______|______|_____					0

44. (continued) Below is a list of problems that you may have had when trying to obtain or use HIV/AIDS services. Mark an X on the line beside each item to say how big a problem it has been for you. The line goes from a "very big" to a "very small" problem.

Very Big = it stopped you from getting the service **Moderate = you faced substantial problems but were able to get the service** **Very Small = caused you minor concern and delays in obtaining the service**	**Very Big**	**Big**	**Mod-erate**	**Small**	**Very Small**	**Not a problem**
15. I have been denied or have been afraid to seek services due to a criminal justice matter.						0
16. My ability to communicate or interact with the service provider.						0
17. The people providing services to me are not helpful.						0
18. The organization did not provide the right referrals to the services I need.						0
19. My ability to find my way through the system.						0
20. There was no specialist who could provide the care I needed.						0
21. Fear of my HIV or AIDS status being found out by others – lack of confidentiality.						0
22. Fear that I would be reported to immigration or other authorities.						0
23. No transportation.						0
24. No childcare.						0
25. I was not eligible for the service.						0
26. There was too much paperwork or red tape.						0
27. I can't afford one or more of the service.						0
28. There are too many rules and regulations.						0
29. My lack of, or inadequate, insurance coverage.						0
30. I have been terminated or suspended from seeking services						0
31. Other ________________________________						0

45. What type of transportation do you use the most, and which form works best for you?		
	Type of transportation used the most in the past year: **(CIRCLE ALL THAT APPLY)**	Transportation OR transportation assistance that works best for you: **(CIRCLE ALL THAT APPLY)**
Bus tokens	1	1
Rail passes	2	2
Cab fare	3	3
Van Services	6	6
Other transportation: **(specify)**__________________________	7	7

46. Have you ever used any of the following substances?			46a. **IF YOU HAVE USED**, During the past 6 months, how often have you used any of the following substances?			
	Ever used			**If used in last 6 months**		
	No	**Yes**	**Not used in last 6 months**	**Used less than once a month**	**Used at least once a month**	**Used once a week or more**
Alcohol	2	1	1	2	3	4
Marijuana or hash	2	1	1	2	3	4
Crack / Cocaine..........................	2	1	1	2	3	4
Heroin	2	1	1	2	3	4
Crystal Meth or Methamphetamines	2	1	1	2	3	4
Speedball	2	1	1	2	3	4
GHB (Gamma Hydroxybutyrate).......	2	1	1	2	3	4
Poppers	2	1	1	2	3	4
Ecstasy (X)	2	1	1	2	3	4
Pills not prescribed by my doctor **(specify)**__________________________	2	1	1	2	3	4
Other substances **(specify)** ______________________________	2	1	1	2	3	4

47. **IF YOU HAVE USED ANY SUBSTANCES**, Have you ever injected any substances not prescribed by a medical person?

Yes	1
No	2

48. **IF YOU HAVE INJECTED SUBSTANCES**, How many people have you shared needles with in the past year?

Write Number of times __________

49. Where were you born?

The United States **(IF BORN IN THE US, GO TO Q50)**	1
Mexico..	2
Puerto Rico or other US Territories...........	3
Central America	4
China	5
Other **(specify)** _________________________	6

49a. **IF NOT BORN IN THE UNITED STATES**, in what year did you first come to the United States? ________ **Year**

49b. How would you describe your residency status in the United States?

Citizen	1
Have a visa (student, temp or permanent) ..	2
Have legal refugee or asylum status	3
Undocumented....................................	4
Other **(specify)** __________________________	5

50. **(Optional)** Before we finish this survey, do you have any other comments about your satisfaction with the way you get HIV or AIDS related services? **If not enough space, please continue your comments on the other side.**

FOR OFFICE USE ONLY
COMPLETED BY THE FIELD INTERVIEWER

Interview End Time: ________________

Mode of transmission (Q21)

MSM	1
IDU	2
Heterosexual Transmission	3
MSM/IDU	4
Adult Hemophiliac/blood products	5
Don't Know (DK)	8

Race/Ethnicity (Q4)

White	1
African American	2
Hispanic/Latino	3
Asian/Pacific Islander	4
Native American/Alaskan Native	5
Mixed Race	6

Gender (Q3)

Man	1
Woman	2
Transgender	3

Special Population

None	0
MSMAnglo	1
MSM Af Am	2
MSM Latino	3
IDU / Substance user - Male	4
IDU/Substance user - Female	5
Hetero - Male	6
Hetero - Female	7
Out of care (medical)	8
Immigrants / Migrants	9
Out of care	10
Recently incarcerated	11

Interviewer Initials.................................. ☐☐

County of Residence

Sacramento	01
El Dorado	02
Placer	03
Other ____________	04

Attachment 4 Sample Plan

Risk Group	**MSM**	**MSM/IDU**	**IDU**		**Hetero**		**Total**	**Sample**	**PLWA**
Sex	**Male**	**Male**	**Male**	**Female**	**Male**	**Female**		**%**	**%**
Race									
Anglo	50	20	15	15	15	15	**130**	37%	61%
African Am	30	20	15	20	20	20	**125**	35%	26%
Latino	20	10	15	5	10	20	**80**	23%	10%
API	0	0	0	0	0	0	**15**	4%	1%
Other ethnicity	0	0	0	0	0	0	**5**	1%	2%
TOTAL							**355**	100%	100%
Special Pop									
Adolescent (13-24)							20		
Immigrants/Migrants*							15		
TOTAL	**100**	**50**	**45**	**40**	**45**	**55**	**390**		
* Recently incarcerated and out-of-care are included in the overall sample design.									

.

Attachment 5 Focus Group Outline for PLWH/A

FOCUS GROUP OUTLINE FOR PEOPLE LIVING WITH HIV/AIDS

Sacramento EMA, February 2003

QUESTION [*Moderator will probe for special populations*]	CONCEPT
1. Set up ground rules: purpose, confidentiality, incentive, taping.	INTRO
2. Please introduce yourself – first name only --and tell the others in the group a little about yourself, including age, mode of transmission, and how long you have known that you have been HIV positive? How would you describe your current physical and emotional health? Have you had any symptoms or opportunistic infections related to your HIV infection? *[Place in notes the gender and ethnicity of each participant.]*	Warm up, stage of infection
3. How many of you are on antiviral or protease inhibitors? Why? Why not?	

Medical Care: Delayed Care Seeker / Unconnected To Care

4. How often do you think you should see a doctor? Do you go that often? *(PROBE FOR THOSE WITH SELF-DEFINED AIDS)*	Delayed care seeker
5. How long after you found out that you were infected with HIV did you seek medical care? Did anyone not see a physician for three months after you were first diagnosed with HIV but then started to see a physician within six months (delayed care seeker)? Did anyone wait six months or longer after you were diagnosed with HIV to see a doctor (unconnected to care)? (*PROBE FOR REASONS*)	Initial access to services Newly diagnosed
6. Since 1995, has there ever been a period of more than 6 months when you have not seen a doctor? Has there ever been a year of more when you haven't seen a doctor or gone to a clinic? Why? (*PROBE FOR INDIVIDUAL, ORG, STRUCTURAL REASON*)	Unconnected to care & barrier to care
7. Where do you go for treatment? Do you know if Ryan White Care Act pays that doctor or clinic for your treatments?	Non RW care

Medications / Complementary Therapy

8. Many people living with HIV/AIDS find it difficult to adhere to the schedule of taking drugs. What is your experience with adhering to the schedule of medication? *(PROBE FOR SIDE EFFECTS)*	Adherence & compliance
9. For those not on medications, did you know about them? Why did you choose not to take medications? What are some of the reasons that you had that kept you from seeking treatment? *(PROBE FOR DENIAL, KNOWLEDGE, FEAR, etc.)*	Barriers
10. How many of you are using complementary therapy (i.e. Chinese medicine, acupuncture, etc…)? Do you use complementary therapy in combination of traditional medical care or to replace it?	Complementary Medical care

Health Insurance / Benefits

QUESTION [*Moderator will probe for special populations*]	**CONCEPT**
11. Do you find there are times you can't get your medication? Why? 11a. Who is paying for your medications? *(PROBE FOR ADAP AND RW CARE SUBSIDIES)*	Barriers to getting medications Medication reimbursement
12. What insurance do you have including SCHIP (State Children's Health Insurance Program), COBRA, insurance through work, Medicare, Medi-Cal/Medicaid? Do you think you should be getting insurance? Does the insurance adequately pay for your HIV/AIDS health care? How many of you are in managed care? Does it work as well for you? WHY, WHY NOT?	Insurance
13. What type of benefits and supplementary income do you get, including Social Security Disability Insurance (SSDI), SSI, TANF, Emergency Assistance, Section 8 housing, etc? Are they sufficient?	Benefits

Housing

14. Who has adequate housing? What are the barriers to finding good housing? (Pay particular attention to criminal justice history, difficulty obtaining a security deposit, and landlord discrimination.)	Housing barriers
15. Have any of you had to leave your housing? Why? What could have prevented it?	Housing loss
16. For you, has having stable housing been necessary before you could start scheduling and maintaining appointments with a doctor or a clinic regularly?	

Current HIV Services

17. List the services you currently need the most. You can take a look at this list to remind you of some of the services available. Are there any on the list that you did not know about? Now that you know about these services, are any of them very important to you?	Need, Knowledge
18. Are there any HIV or AIDS services that you feel you need but aren't available? Why do you think the service(s) aren't available?	Demand and unmet demand.
19. For the services needed the most, how would you describe the quality of them? What services work well? What services work poorly?	Quality of service
20. What problems have you had in receiving the services you need and how big were they? *PROBE FOR RULES AND REGULATIONS, ORGANIZATIONAL BARRIERS AND INDIVIDUAL BARRIERS.*	Barriers
21. Do you feel you know how to get through the Care system? Do you feel you know enough about benefits to apply to what you are entitled to? Do you need help? What has been your experience with case-management services and client advocacy?	Demand for case management and client advocacy
22. What information about care and treatment of your HIV infection do you need and have a hard time finding it? *(PROBE FOR ACCESS TO THE INFO)*	
23. What has been your experience with referrals from one service to another?	Linkages

QUESTION [*Moderator will probe for special populations*]	**CONCEPT**
24. Was there anything in particular that made getting services easier?	Organizational facilitators
Special Population Needs	
25. What are the specific challenges or difficulties you face because you are --------?	Special population needs
26. Are there special needs of your community? What are they? Are they available?	Special population needs
Additional Needs	
27. How many of you would like to work or work more? What are the barriers to going back to work?	Job training / placement
28. Is there anything else that you would like to tell us about your service needs or gaps in services, or barriers to care?	Considered open end

Attachment 6 Key Informant Outline for Youth and Adolescents

KEY INFORMANT OUTLINE FOR PARENTS OF INFANTS AND CHILDREN LIVING WITH HIV AND AIDS

Sacramento EMA, June 2003

QUESTIONS	CONCEPT/ INSTRUCTIONS
29. Hello, I would like to talk to [NAME REFERRED BY LISA ASHLEY]. (IF NOT THERE – Can you tell me when I can contact her/him?	Be sure you are talking to the right person
30. Hello, Lisa Ashley from UC Davis Medical Center gave me your name and said you would be willing to talk about the HIV care needs for you and your child. My name is ___________ and I am calling from the Partnership for Community Health, an organization that is assessing the care needs of PLWH/A in Sacramento. I want to confirm that you are willing to discuss your and your child's care needs. Our discussion is entirely confidential. No provider, not even UC Davis Medical Center, will be able to link your comments to your name. We at PCH are taping this conversation so we can analyze it, but you name will never be associated with your answers. Once our conversation is completed we will send you a $20 food voucher. GET CONFIRMATION). Where should I send the food voucher? (NOTE ADDRESS)	INTRO and confirmation
31. Do you mind if I call you by [FIST NAME]? And what is the name of your infected child? Can you tell me your race, ages, modes of transmission, and how long you have known that you and your child have been HIV positive? How would you describe you and your child's current physical and emotional health? Has your child had any symptoms or opportunistic infections related to their HIV infection?	Demographics and stage of infection
32. Is your child currently taking any medication? Are they a combination therapy? Are they antiviral or protease inhibitors?	Medication
33. Many people living with HIV/AIDS find it difficult to adhere to the schedule of taking drugs. Have you had any problem keeping giving your child his or medication on schedule? How about yourself, what is your experience with adhering to the schedule of medication? *(PROBE FOR SIDE EFFECTS)*	Adherence & compliance
34. Do you find there are times you can't get your medication? Why?	Barriers to getting medications
35. Who usually gives you instructions on how to take and refill the medications for you and your child?	

QUESTIONS	**CONCEPT/ INSTRUCTIONS**
36. [FOR THOSE WITH ADHERENCE PROBLEMS] Why did you choose not to give your child or take your own medications on schedule? *(PROBE FOR DENIAL, KNOWLEDGE, FEAR, etc.)*	Barriers

Medical Care: Delayed Care Seeker / Unconnected To Care

37. How often do you think your child should see a doctor? Do you go that often? Are there any problems in going to a doctor that often?	Delayed care seeker
38. Has your child ever gone for more than 6 months without seeing a doctor or going to a clinic for their HIV infection? How long did it take you to start regular appointments after your child was born? [IF DELAYED CARE] Why did you wait to take your child to see a doctor	Initial access to services Newly diagnosed
39. [IF PARENT IS INFECTED]Since 1995, has there ever been a period of more than 6 months when you have not seen a doctor? Has there ever been a year of more when you haven't seen a doctor or gone to a clinic? Why? (*PROBE FOR INDIVIDUAL, ORG, STRUCTURAL REASON*)	Unconnected to care & barrier to care
40. Where do you go for treatment? What other care services do you use? How are they paid for?	Reimbursement

Health Insurance / Benefits

41. What insurance do you have for yourself and for your infected child? [PROBE FOR SCHIP (State Children's Health Insurance Program), COBRA, insurance through work, Medicare, Medi-Cal/Medicaid]? Do you think you should be getting [better] insurance? Does the insurance adequately pay for your child's HIV/AIDS health care?	Insurance
42. What type of benefits and supplementary income do you get, including Social Security Disability Insurance (SSDI), SSI, TANF, Emergency Assistance, Section 8 housing, etc? Are they sufficient to meet your and your child's need?	Benefits

Housing and Direct Financial Assistance

43. Do you have adequate housing? What are the barriers to finding good housing? (Pay particular attention to criminal justice history, difficulty obtaining a security deposit, and landlord discrimination, problems finding safe and acceptable housing for children.)	Housing barriers
44. Have any of you had to leave your housing? Why? What could have prevented it?	Housing loss
45. For you, has having stable housing been necessary before you could start scheduling and maintaining appointments with a doctor or a clinic for child regularly?	

QUESTIONS	CONCEPT/ INSTRUCTIONS
46. Do you have any problems paying the electricity and other utility bills? Have you ever sought financial assistance to pay those bills? What was the outcome?	Financial assistance

HIV Services

47. I am now going to read you a list of HIV services. **[GO TO SERVICE QUESTION ON THE NEXT PAGE AND FILL IN QUESTIONS TURN OFF RECORDER]**	Need, Knowledge
48. Are there any other HIV or AIDS services that you feel you need but aren't available? Why do you think the service(s) aren't available?	Demand and unmet demand.
49. In general, how would you describe the quality of HIV care services for your child? What services work well? What services work poorly?	Quality of service
50. Was there anything in particular that made getting services easier for your child?	Organizational facilitators

Special Population Needs

Additional Needs

51. Is there anything else that you would like to tell us about your service needs or gaps in services, or barriers to care?	Considered open end

NAME: ____

Now I am going to read a list of services and for each service I mention I would like you to tell me four things:
!. If you know that the service is available for your child infected with HIV.
2. If you have needed this service in the past year for your child infected with HIV.
3. If you asked for the service in the past year.
4. And last, if you received the service for your child infected with HIV in the past year.

MEDICAL AND DENTAL CARE		**A**		**B**		**C**		**D**	
	For each health care service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Visits with a doctor, nurse, or assistant to take care of your child's HIV - Outpatient medical care for your child.	1	2	1	2	1	2	1	2
2	Visit to a medical specialist for your HIV infected child based on a referral from your doctor or pediatrician.	1	2	1	2	1	2	1	2
3	Dental care or oral health care for your HIV infected child.	1	2	1	2	1	2	1	2
4	Medication or prescription payment for your child's medication.	1	2	1	2	1	2	1	2
5	Home heath care from a nurse or aide for your child.	1	2	1	2	1	2	1	2
6	Helping your child adhere to medication from a pharmacist, counselor, doctor, nurse, or nurses aide.	1	2	1	2	1	2	1	2

For the health services noted above, what problems did you experience in accessing or using the service?

CASE MANAGEMENT AND BENEFITS COUNSELING		**A**		**B**		**C**		**D**	
	For each health care service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Case management - session(s) with a case manager to help you coordinate your child's HIV/AIDS care and help access benefits.	1	2	1	2	1	2	1	2
2	Intake session when you first come to an agency and a staff member assesses your child's care needs.	1	2	1	2	1	2	1	2

For the case management and benefits counseling services noted above, what problems did you experience in accessing or using the service?

EMERGENCY FINANCIAL ASSISTANCE		**A**		**B**		**C**		**D**	
	For each financial assistance service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Assistance paying health insurance premiums for those families who have private health insurance.	1	2	1	2	1	2	1	2
2	Emergency financial assistance for housing and utilities.	1	2	1	2	1	2	1	2

For the financial assistance services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

HOUSING		**A**		**B**		**C**		**D**	
	For each housing service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Housing information services - assistance in finding or getting housing from a housing specialist.	1	2	1	2	1	2	1	2
2	Rental assistance paid to landlord or owner of housing.	1	2	1	2	1	2	1	2

For the housing services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

TRANSPORTATION		**A**		**B**		**C**		**D**	
	For each transportation service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Van and taxi transportation to HIV/AIDS services.	1	2	1	2	1	2	1	2
2	Taxi vouchers or tokens and passes to mass transit (bus and rail).	1	2	1	2	1	2	1	2

For the transportation services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

MENTAL HEALTH TREATMENT		**A**		**B**		**C**		**D**	
	For each mental health treatment service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	One-on-one psychological or psychiatric counseling for your HIV infected child (NOT FOR SUBSTANCE ABUSE).	1	2	1	2	1	2	1	2
2	Group counseling led by a psychologist or social worker for your infected child (NOT FOR SUBSTANCE ABUSE).	1	2	1	2	1	2	1	2
3	Counseling for your family (children, spouse, partner).	1	2	1	2	1	2	1	2

For the mental health services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

FOOD AND NUTRITION SERVICES		**A**		**B**		**C**		**D**	
	For each health care service below…	**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Food bank or pantry.	1	2	1	2	1	2	1	2
2	Food vouchers.	1	2	1	2	1	2	1	2
3	Home delivered meals.	1	2	1	2	1	2	1	2
4	Nutrition counseling by licensed nutritionist.	1	2	1	2	1	2	1	2
5	Nutritional supplement, vitamins, and herbs	1	2	1	2	1	2	1	2

For the food and nutrition services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

SUBSTANCE ABUSE TREATMENT		A		B		C		D	
For each substance abuse treatment service below…		**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Outpatient substance abuse treatment or counseling for your infected child with substance abuse problems.	1	2	1	2	1	2	1	2
2	An assessment of your child's substance use need.	1	2	1	2	1	2	1	2
3	Substance abuse counseling for your family (children, spouse, partner).	1	2	1	2	1	2	1	2

For the substance abuse services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

OTHER SUPPORT SERVICES		A		B		C		D	
For each service below…		**Are you aware that the service exists?**		**Did you *need* this service this past year?**		**Did you *ask for* this service this past year?**		**Did you *receive* this service this past year?**	
		Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
1	Buddy / Companion services where a community member provides emotional support.	1	2	1	2	1	2	1	2
2	Buddy / Companion services where a community member helps you with household tasks, such as shopping, cleaning, laundry.	1	2	1	2	1	2	1	2
3	Where a peer or buddy provides advocacy services on your behalf.	1	2	1	2	1	2	1	2
4	Child care.	1	2	1	2	1	2	1	2

For the support services noted above, what problems did you experience in accessing or using the service? (SEE HANDOUT)

Attachment 7 Focus Group Coding Schema

Sacramento Focus Group Coding Schema

INSTRUCTIONS

The attached coding sheet and codes are to be used in coding focus groups.

In the coding sheet the first eight columns describe the demographics of the participant:

- GROUP, the focus group that they participated in (Survey means that this is qualitative text that was written in the consumer survey by the participant);
- SEX, the gender of the participant;
- RACE, the race/ethnicity;
- AGE;
- GEO, geographic residence of the participant (urban or rural or name of city);
- RG, the risk group the participant is in;
- YR SERO, the year of the participant's Serostatus;
- PCH ID, the unique identified given to the participant to maintain their anonymity.

The next column is for the actual quote.

Once the quote is typed in, then it has to be coded for the service and barrier. Use the codes in the "code" worksheet. If there is more than one applicable code, separate the code by a comma.

Once this is done, we can sort using EXCEL by any of the categories, or we can enter it into a database for analysis.

Below is a small list of items that do come up in the focus groups and could be helpful in reviewing of the qualitative data. Please place any coding from this list in the Barrier column.

Disabilities	Disability
Drugs	Drugs
Fatalism	Fate
Homeless	Homeless
Jail	Jail
Prevention	Prevention
Rural	Rural
Side effects	Side
Phone	Phone
Church	Church
Services are good	DALLAS
Community Support	Community
Comparison to other cities	Compare

Focus Groups Services Codes

#	Services	Service Code
32	Adult day care	ADC
5	Adherence support – assistance taking your medication as prescribed	Adhere
23	Benefits counseling	Benefit
33	Baby-sitting or child care services – respite care	CC
27	Case management - someone to help you coordinate your HIV / AIDS health care	CM
26	Consumer Advocate – assists you to work through a grievance process w/ care funded agency	Consumer
11	Supportive Housing - living in congregate housing – housing in a group setting	CongHsing
10	Direct Emergency Financial Assistance (for utilities, drugs, etc…)	DEFA
2	Dental care	Dental
22	Detox and/or methadone maintenance (for those addicted to heroin)	Detox
3	Drug reimbursement – assistance in paying for HIV / AIDS related drugs	Drug $
12	Place to obtain food / food bank – including nutrition supplements	Food Bank
7	Health Insurance Assistance – help in paying premiums	HealthIns
30	Health Education/Risk Reduction – info about med tx services & how to prevent spreading HIV & referrals	HERR
4	Home health care para OR professional care	HHC
8	Housing Information Services - assistance in finding or getting housing.	Hsing
25	Legal Services –preparing wills/estate planning; assistance w/ evictions & housing disc.	Legal
14	Home-delivered meals	Meals
16	Mental health therapy with a psychologist or social worker in individual or group sessions	MH
24	Money Management	Money
15	Nutrition Education and Counseling	Nutrition
1	Appts w/ a dr, or nurse in an office or clinic for a problem or to monitor HIV	Out
3	Medication reimbursement such as ADAP that provides assistance paying for HIV/AIDS related drugs	Reimburse
19	Peer counseling, support groups, drop-in grps conducted by a nonlicensed counselor	Peer
29	Peer Advocate – PLWH/A helps in dealing w/ problems and issues faced in living with HIV such as emotional support, information, and advocacy of services on your behalf	PLWH
17	Psychiatric assessment – one or two psychiatric sessions to determine type of care	Psych
9	Rent or mortgage assistance	Rent
20/21	Substance abuse treatment or counseling sessions (outpatient or residential)	SAT
35	Taxi vouchers or bus tokens	Taxi
18	Crisis mental health intervention including suicide hotline	Tele
34	Van transportation assistance to access HIV/AIDS services	Trans
28	Treatment Advocate – someone to help you understand your tx options & help you access tx	Tx
31	Employment assistance/vocational counseling and training	Voc
13	Food Vouchers	Vouch
6	Holistic or complementary, including acupuncture, massage or chiropractic practitioner	Well

Focus Group Barrier Codes (Sorted by code)

#44	BARRIER	BARRIER CODE
m.	The organizations providing the service making me feel like a number.	#
w.	No transportation	Trans
x.	No childcare.	CC
y.	I was not eligible for the service	Eligible
p.	My ability to communicate or interact with the service provider.	Comm
g.	Not understanding the instructions for obtaining the service or treatment.	Comp
z.	There was too much paperwork and redtape	Redtape
u.	Fear of my HIV/AIDS status being found out by others – lack of confidentiality	Conf
aa.	The cost of the service to me – I cannot afford the service.	Cost
o.	I've been denied/have been afraid to seek services due to a criminal justice matter.	Crime
d.	I do not believe HIV is really a problem for me that requires assistance.	Denial
j.	The discrimination I experienced from people providing service(s) to me.	Disc
k.	Experience of expertise of the person providing services to me.	Expert
q.	The people providing services to me are not helpful.	Helpful
a.	Not knowing that the service or treatment was available to me.	Know–srvcs
b.	Not knowing the location of the service	Know-loc
f.	My state of mind or mental ability to deal with the treatment.	MH
e.	Not knowing what medical services I need for treating my HIV infection or AIDS.	Need
s.	My ability to find my way through the system	Ability
c.	My physical health has not allowed me to get to the place where the service is provided.	PH
h.	Not knowing who to ask for help	Know-help
n.	I do not get along with the people providing the services	
r.	The organization did not provide the right referrals to the services I need.	Ref
v.	Fear that I would be reported to immigration or the other authorities.	Reported
bb.	Too many rules and regulations to get the service	Rules
i.	The lack of sensitivity of the service provider to my issues and concerns.	Sense – issues
t.	There was no specialist who could provide the care I needed.	Spec
dd.	I have been terminated or suspended from seeking services.	Term
l.	Length of time for service to go into effect	Time
cc.	My lack of, or inadequate, insurance coverage.	Uninsured

ATTACHMENT 8 THROUGH 14, DATA TABLES, CAN BE FOUND IN A SEPARATE DOCUMENT

Attachment 8 PLWH/A Demographics

Attachment 9 Service Awareness

Attachment 10 Services Needs

Attachment 11 Services Asked

Attachment 12 Services Received

Attachment 13 Service Barriers

Attachment 14 Service Gaps