HOUSTON EMA & HOUSTON HSDA

NEEDS ASSESSMENT REPORT

Survey and focus group report of Consumers and Providers

Prepared for

Ryan White Title I Planning Council and the Houston HIV Service Delivery Area Care Consortium

August, 1999
Revised October 13, 1999
Revised October 19, 1999
Revised November 15, 1999
Revised December 14, 1999

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ACKNOWLEDGMENTS

Several individuals and organizations assisted in the design, recruitment, execution, data analysis and writing of this needs assessment report. Foremost, PCH would like to thank Ryan White Title I Planning Council and the Houston HIV Service Delivery Area Care Consortium, and their respective administrative agents. Mr. Charles Henley, Ms. Jennifer Janney, Dr. David Whittier and Dr. David Erickson from Harris County and Mr. Michael Springer, Mr. Christopher Schmitt, and Mr. Clay Allison from the Resource Group were very helpful in providing information and reviewing drafts. Mr. Ken Malone provided much background information on the Continuum of Care and issues related to insurance and medical reimbursement. Mr. Tom Fricke from the Lovett Inn gave PCH discounted rates while staff of PCH was in Houston.

A Project Advisory Group (PAG), convened especially for this project and chaired by Mr. Steve DeCorte, provided guidance and comments throughout the project. Ms. Emily Reeves and Mr. Bruce Turner provided invaluable assistance to the Project Advisory Group. In addition to those mentioned above, the participants of the PAG included: Norma Acker (Houston HSDA Care Consortium, Ft. Bend Family Health Center), City of Houston Bureau of HIV/STD Prevention, Michael DeGuzman (Texas Children's Hospital), David Hendren (Alternate Resources), Kay Kirkland (Harris County HIV Services), Patrick Leung, Ph.D. (University of Houston), Ann McFarland (University of Houston), Michelle Paul (Houston EMA Ryan White Planning Council), Emily Reeves (Southeast Texas Legal Clinic), Marcia Sanderson (University of Houston), Michael Steiner (Houston EMA Ryan White Planning Council), Bruce Turner (Houston HSDA Care Consortium).

In the final analysis, however, what made the needs assessment possible was the time and effort of the more than 450 PLWH/A and caregivers who participated in the survey and focus groups. They were generous in their time and candid in their responses. The results presented in this report are their collective voice about their service needs and barriers.

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ABBREVIATIONS

AIDS Drug Assistance Program	ADAP
AIDS Service Organization	ASO
Community Based Organization	CBO
Counseling and Testing	C&T
Eligible Metropolitan Area	EMA
Focus Group	FG
HIV Service Delivery Area	HSDA
HIV Services Harris County Health Department	HSHCHD
Housing Opportunities for People With AIDS	HOPWA
Houston Volunteer Lawyers Association	HVLA
Injection Drug User	IDU
Mail Order Meds	MOM
Men who have Sex with Men	MSM
Office of Community Projects, University of Houston	OCP
Opportunistic Infections	OI
Partnership for Community Health	PCH
Persons living with HIV/AIDS	PLWH/A
Person living with AIDS	PLWA
Person living with HIV	PLWH
Post Traumatic Stress Disorder	PTSD
Sexually transmitted disease	STD
Social Security Disability Income	SSDI
Soon-To-be Released	STR
Statistical Program for Social Sciences	SPSS
Texas Department of Health	TDH
Tuberculosis	TB

1 INTRODUCTION

The Ryan White Title I Planning Council and the Houston HIV Service Delivery Area Care Consortium contracted with the Partnership for Community Health (PCH) and the Office of Community Project, University of Houston (OCP) to conduct a needs assessment. The needs assessment identifies service needs, gaps, and barriers for persons affected by HIV/AIDS in the Houston Eligible Metropolitan Area (EMA) and HIV Service Delivery Area (HSDA). The goal of the needs assessment is to facilitate informed decisions regarding all medical and support services for persons living with HIV/AIDS (PLWH/A) that are funded by the Ryan White CARE Act and other sources.

The conceptual framework for the needs assessment is shown in Table 1-1. To facilitate that task, a list of relevant services and barriers was created that was used throughout this needs assessment and are described in greater detail in the following METHODS section.

Table 1-1 Definition of Needs and Gaps

Service need or absolute need:	Theoretical estimate based on a policy protocol or model of care. It is an estimate of the number of people who would benefit from a service, regardless of whether they are actually receiving it.
Perceived need or demand:*	Perceived need/demand of PLWH/A and providers based on qualitative and quantitative data.
Fulfilled need:	Actual demand based on utilization figures, surveys or other non-direct counts. It is expressed by the fact that an HIV-infected individual has actually sought, or received a service or identified a service as a future need.
Service capacity:	Number of clients who can be served; the number of slots available for a particular service.

From these four “raw” calculations, four unmet 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, that is the services that a PLWH/A say they need and what services they actually sought.
Unmet demand:	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.

* “Perceived need” can be further defined as those services PLWH/A would like but do not ask for because they are not available or accessible for some reason. In the report, “perceived need” is operationalized as those service asked for my PLWH/A.

The full needs assessment has three reports. The first is an epidemiological report that provides an estimate of who will be needing services. A separate epidemiological report was prepared for the EMA and for the HSDA, reflecting their different geographic areas.

This is the second report, and it provides the results of the survey and focus groups of PLWH/A and the provider survey. It documents the perceived levels of need and demand for services, reviews the barriers to obtaining those services, and provides information on the capacity of the system and barriers perceived by the providers. This report presents information obtained through the survey and focus groups of PLWH/A and specifically addresses the perceived needs, demands, and barriers to care.

The third and final report summarizes information from the prior two reports to determine the unmet need, unmet demand and need-demand gap.

2 METHODS

A literature review, focus groups, and a consumer and provider survey were the major components of this part of the needs assessment. The focus groups and consumer survey were sampled from all PLWH/A subpopulations in the Houston area defined by risk category and ethnicity. Provider surveys were sent to providers funded by Ryan White and other providers who are listed in the "Blue Book", a resource guide.

Needs Assessment Survey and Focus Group

Process

PCH/OCP staff met with the Council, Needs Assessment Committee and HIV Services Harris County Health Department (HSHCHD) to finalize the design of the needs assessment, including the sampling design, survey tools, focus group outlines, and field protocols.

Based on these discussions, a focus group outline and a thirteen-page consumer survey, with primarily close-ended questions, were developed. The consumer survey was produced in English and Spanish, and was administered in group settings or one-on-one by trained interviewers. The consumer survey generally took 30 to 45 minutes to complete. In cases where individuals had difficulty reading or comprehending the questions, the questionnaire was administered orally. All surveys were checked for completeness by PCH/OCP staff at the end of the interview.

The focus group outline is shown in Attachment 1 and the consumer survey is shown in Attachment 2. The provider survey was developed with the collaboration of the Needs Assessment Committee and the Resource Group. It provides information on the personnel and finances of each agency and provides detailed information on programs provided by each of the AIDS Service Organizations (ASO). The survey and instruction letter are shown in Attachment 3.

The lists of services developed by PCH/OCP and the Needs Assessment Committee were derived from the list of funded services and service priorities set by the Planning Council. They are shown in question 46 of the consumer survey (Attachment 2). The list of barriers were developed based on prior needs assessments conducted by PCH using a multidimensional schema discussed in the Barriers Section. The questions related to barriers appear as question 47 of the consumer survey. Respondents also completed open-ended questions where they list needs and barriers.

For analysis purposes, the consumer survey captured demographic information, including stages of HIV infection, mode of transmission, socioeconomic indicators, and location of residents. Location was analyzed by urban and rural. Urban was defined as all those living in zip codes within Beltway 8 (or outer loop) and rural as those living in zip codes outside, or straddling, the Beltway 8. The survey also measured co-morbidities of HIV with mental illness, sexually transmitted diseases (STDs) and tuberculosis (TB). In addition, the survey included questions related to HIV prevention and behavior.

As shown in Table 2-1, a total of 24 focus groups were held with participants of different ethnicity/risk category populations. Nineteen (19) groups were ethnic or risk category specific while five groups were “open groups”. The different ethnic groups were recruited from providers and through outreach. The open groups consisted of participants of diverse ethnic backgrounds and/or various risk categories who were recruited through newspaper advertisements and brochures announcing focus groups (see Attachment 4) and word of mouth. Focus groups were held between April 1999 and June 1999. The consumer surveys were completed between April 1999 and July 1999.

Table 2-1 Sample Groups

POPULATION	NUMBER OF GROUPS
MEN WHO HAVE SEX WITH MEN (MSM)	
African American	1
Hispanic	1
Anglo	1
INJECTION DRUG USER (IDU)	
African American men	1
African American women	1
Anglo men & women	1
HETEROSEXUAL	
African American men	1
African American women	1
Hispanic men	1
Hispanic women	1
Anglo men	1
IN PRISON SUBPOPULATION	
Men	1
Women	1
RURAL	
Conroe	2
Fort Bend	1*
ADOLESCENTS	1
UNDOCUMENTED	1
PEDIATRIC CAREGIVERS	1
OPEN GROUPS	5
TOTAL	24
*There was also a discussion with 2 persons in Ft. Bend	

Sampling

PLWH/A Survey

The focus group and survey recruitment strategies were based on an overall sampling plan designed to draw a representative sample of clients from AIDS service organizations and clinics. Respondents of the focus group and respondents to the survey were recruited from 42 agencies serving PLWH/A, prevention outreach programs, and from organizations and venues known to serve undocumented clients. The participating providers are shown in Attachment 5. In order to recruit PLWH/A who may not have accessed the AIDS service agencies, some respondents were also recruited through the outreach efforts of organizations providing HIV prevention services and from community clinics within hospitals.

For the focus groups, the sampling goal was to have ten persons in each of the focus groups representing a broad spectrum of people living with HIV/AIDS. The recruitment of focus group participants represented part of the larger sampling of PLWH/A for the survey that was being conducted simultaneously. Individuals agreeing to participate in the focus groups were asked to complete the needs assessment survey prior to the focus groups.

Table 2-2 shows the sampling frame for each subgroup, with an expected sample size of 431. The actual sample recruited varied from this plan, with a total of 455 persons completing interviews. The sample composition is described in the following section.

Table 2-2 Sample Frame

Risk Group	**MSM**	**IDU**		**Heterosexual (not IDU)**		**TOTAL**
	Men	**Men**	**Women**	**Men**	**Women**	
African American	20	10	10	10	10	60
Hispanic	20	10	10	10	13	63
Anglo	20	11	10	12	11	64
Other ethnicity	10	10	7	5	0	32
Adolescent	5	3	2	2	3	15
In prison subpopulation	10	10	10	10	0	40
Undocumented*	10	10	10	10	0	40
Rural PLWH/A*	19	16	15	15	12	77
Pediatric (caregiver)			5		5	10
Families		5	10	5	10	30
TOTAL	114	85	89	79	64	431
*Included in special studies.						

Provider Survey

The provider survey was sampled from the service providers which were established at the onset of the project and which were included in the initial sample frame. A total of 31 provider surveys were submitted by target agencies. In addition, 13 other non-Ryan White funded agencies submitted completed surveys. These are shown in Table 2-3.

Table 2-3 Provider Surveys Completed

Provider Name
AIDS Foundation Houston, Inc.
Alternate Resources of Texas, Inc.
Amigos Volunteers in Education and Services
The Assistance Fund, Inc.
Bering Omega Community Services
Brentwood Community Foundation
Covenant House Texas
Donald R. Watkins Memorial Foundation
Family Service Center
Fort Bend Family Health Center, Inc.
Foundation for Interfaith Research & Ministry
Harris County Hospital District (HCHD)

Provider Name
Harris County Sheriff’s Dept., HIV Dept
Houston Area Community Services, Inc.
Houston Challenge Foundation
Houston Volunteer Lawyers Program
The Life Center Inc.
Memorial Hermann Home Health
Montrose Clinic, Inc.
Montrose Counseling Center, Inc.
NAACP Houston Branch
Northwoods AIDS Coalition, Inc.
People With AIDS Coalition – Houston, Inc.
Planned Parenthood of Houston & Southeast Texas
Riverside General Hospital
Southeast Texas Legal Clinic
Texas Children's Hospital
FHC, Inc.- UTMB Healthcare Systems
University of Texas @ Houston Health Science Center/ Dept. of Pediatrics
UT Health Science Center for Houston Recovery Campus
UTMB Family Medicine – Conroe
Visiting Nurse Association of Houston, Inc.
Art League of Houston
The Center for AIDS: Hope & Remembrance Project
Coalition for the Homeless of Houston/Harris Co., Inc.
Diocesan AIDS Ministry, A Program of Associated Catholic Churches
Houston Area Women's Center
Kids in Need of Drug Evaluation & Re-Treatment Clinic
Mendez Counseling
Mental Health Mental Retardation Authority of Harris Co.
Nightingale Adult Day Center
Sign Shares
St. John Vianney Catholic Church Social Services
Steven's House
Young Women's Christian Association

Recruiting Participants

Protecting the confidentiality of the respondents was a prime concern. Agencies were asked to generate a list of their active clients and to randomly sample a certain number of clients based on an interval derived from their client load. For instance, if an agency had a total of 150 African American heterosexual female clients and the sample plan required ten to be recruited from the agency, the instructions were to sample every 15th client. Once the agencies generated the randomly selected list, they were asked to contact the clients to determine if they would participate in both the focus group and survey, or the survey only. Their responses were recorded on a log sheet (shown in Attachment 6). Agency staff was instructed to indicate interested clients by a first name, alias, or other unique identifier. Once the level of participation was ascertained and the necessary consent was obtained, PCH/OCP staff contacted the interested clients with specific information on where the focus groups and surveys were being conducted.

While in some cases agencies were able to implement the protocol and recruit participants with their own staff, in other cases PCH/OCP assisted in the development of lists and telephone calls to the designated clients.[1] This random selection procedure produced about half of the sample, but due to poor response rates of designated clients, the random sample was supplemented with intercept interviews at providers.

Focus group participants were recruited using the same methods and between 8 and 15 persons were recruited for each of the focus groups. The objective in focus group recruiting is to have 8-10 participants per group. Although PCH/OCP tried to recruit fifteen persons for each group to account for "no-shows", most groups consisted of 6 to 8 persons. In total, 24 focus groups were conducted and a total of 145 persons participated. The exact make up of the focus groups is shown in Table 2-4.

Table 2-4 Number of Focus Groups

Risk Group	**MSM**	**IDU**	**Heterosexual (not IDU)**		**TOTAL**
	Men	Men & Women	Men & Women		
African American*	1	2	1	1	5
Hispanic*	1	0	0	1	2
Anglo*	1	1	1	1	4
TOTAL	**4**	**4**	**2**	**3**	**13**
Other ethnicity	0				0
In prison subpopulation*					2
Adolescent	1				1
Undocumented	1				1
Rural PLWH/A*	3				3
Open groups	2				5
Pediatric care givers	1				1
				TOTAL	**24**

*****Separate groups were conducted among men and women.

Once the focus groups were completed and interviews were completed with the "random" selection, in order to increase sample size and fill quotas for difficult to reach populations, memorandums of agreements were established between PCH/OCP and AIDS service organizations to conduct intercept interviews at their sites. In addition, two drop-in group sessions were held at the Hollyfield Foundation for participants who had been recruited by or referred by the local ASOs. In total, 455 respondents were interviewed. The demographic breakdown of the sample is described in the section on Demographics, starting on page 3-1.

Two provider discussion groups were conducted. The Council mailed letters to all their grantees and other service providers listed in the blue book. A morning session was open to Ryan White service providers and the afternoon was for non-Ryan White agencies. Fifteen (15) providers

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[1] Standard protocol included for PCH/OCP staff to explain that they were calling on behalf of the agency and that their names would be treated confidentially.

attended the morning session and seven participated in the afternoon session. Notes were taken at each group and have been compiled by PCH.

Logistics

The focus group sessions were held at a local multi-service community organization, The Hollyfield Foundation. Respondents were asked to arrive one hour before the group session to complete the needs assessment survey. Sandwiches, fruit, drinks and snacks were served. Childcare was provided. The survey was available in English and Spanish, and PCH/OCP staff members were present to assist the participants in completing the survey. All the surveys were reviewed to assure completeness.

At the scheduled starting time of the focus group, respondents were directed to the focus group room. The room was arranged with a conference table and a flip chart. Dr. Mitchell Cohen, Ms. Lucia Orellana, Mr. Christopher Schmitt, Ms. Ann McFarland and Ms. Marcia Sanderson, from PCH/OCP conducted the focus groups along with peer facilitators representing the same ethnicity and gender of the group participants. The duration of the sessions was between one-and-a-half and two hours. At the start of each focus group session, respondents were given a brief introduction about the purpose of the group, and informed that the session would be video and audio taped. The moderators assured the respondents that their responses and the results of the session would be confidential.[2] Upon completion of the focus group, each participant was given a $15.00 incentive and told he/she would be eligible for a grand prize and smaller prizes. All focus group respondents and survey respondents were asked if they would be interested in participating in a lottery for a number of prizes contributed by local merchants. Those respondents who consented were entered in the lottery.

Surveys were conducted with the assistance of OCP/PCH staff. Interviewers went to several organizations and conducted interviews at the providers' sites with designated respondents.[3] Clients unable or unwilling to travel to the designated site were interviewed over the telephone. The number of interviews conducted at each site is shown in Attachment 7.

Provider Surveys

The provider surveys were distributed by the administrative agents for Ryan White Title I and Ryan White Title II. In addition, an on-line version of the provider survey was prepared and distributed on request by PCH. When returned, PCH/OCP provided follow-up telephone calls to obtain further information, clarify outstanding questions and provide assistance in completing the survey.

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[2] Video and audio tapes will be stored at PCH under lock and key for a period of one year in the event that direct quotes or original sources are required to respond to questions about the final report. All tapes will be destroyed after the one-year period.

[3] Interviewers were instructed to select respondent based on race, sex and/or age to fill quotas. If more than one met the requirement, interviewers chose respondent randomly.

Analysis

The survey was analyzed using the statistical analysis package Statistical Program for Social Sciences (SPSS). Univariate and bivariate analysis was conducted for services and barriers and a factor analysis was used to empirically verify the underlying dimensions of the barriers PLWH/A confront when accessing services. Analyses were replicated for each subpopulation for purposes of comparison between different risk groups, ethnic groups, and special populations groups.

Analysis of the "total" sample is weighted. Subpopulations were weighted to a population estimate based on PLWA. The weights were derived by weighting risk factor, sex and ethnicity subpopulations based on a population estimate derived from PLWA. The results, as shown in Attachment 8, reflect the population estimates provided by the Texas Department of Health.

Comments from the focus groups were coded by risk group, ethnicity, service and barrier (See Attachment 9). Coders from OCP reviewed the video and audiotapes and systematically selected and coded participants’ comments. In the following sections, quotes from the focus groups are used to highlight, add depth, and, in some instances, suggest alternative findings from those in the survey. The quotes selected bring the “voice” of the participants to this report. Each participant was assigned a unique identifier indicating his/her risk category and gender which is used to introduce the quotes. By using this identifier, the report humanizes the data. Together their quotes serve to build more complete characters in the qualitative part of this report.

3 DEMOGRAPHICS PROFILE OF PLWH/A

Four hundred and fifty five (455) people living with HIV/AIDS completed surveys. An overview of the survey sample is shown in Table 3-1 below. The sample sizes for MSM, heterosexuals, IDUs, African Americans, Anglos, Hispanics, PLWH/A with families, and rural is adequate to make generalizations to the all PLWH/A in those populations. In looking down the columns "N" or sample size columns in Table 3-1, several subpopulations have sufficient cell sizes to be analyzed and generalizations to the populations they represent will be reliable estimates.[4]

Generalizations from the soon-to-be released (N=17), the undocumented (N=31) and other ethnicities (N=25) should be interpreted with caution. Analysis of youth (N=20) and pediatric caregivers (N=16) may not be generalizable to all youth with HIV/AIDS or all pediatric caregivers. For the combinations of major risk groups by ethnicities, there are insufficient Hispanic IDUs for a reliable analysis.

The last column in Table 3-1 shows the weighted estimate of PLWH/A. This indicates that people of color, and youth populations have been oversampled in order to allow analysis of those subpopulations, but weighted back to their appropriate proportion for analysis of all PLWH/A. Rural populations are over-represented in the weighted sample.

Table 3-1 Number of Survey Respondents (N=455)

	MSM		**Heterosexuals**		**IDU**		**TOTAL SAMPLE**		
	N*	% tot sample	N*	% tot sample	N*	% tot sample	N*	% unwt	% wt
African American	62	14	146	32	50	11	213	47	35
Anglo	81	18	36	8	43	9	121	27	41
Hispanic/Latino	45	10	51	11	9	2	97	21	18
Other Ethnicities**	10	2	15	3	6	1	25	5	6
Recently Incarcerated	9	2	32	7	21	5	43	9	--
In prison subpopulation	3	1	13	3	6	1	17	4	--
Youth	4	1	16	4	1	1	20	4	2.6
Pediatric Caregivers	0	0	15	3	1	1	16	4	--
PLWH/A with children	10	2	88	19	10	2	100	22	--
Undocumented	11	2	20	4	2	1	31	7	--
Rural	46	10	65	14	22	5	111	24	24
PLWA	113	25	105	23	60	13	223	49	49
Total	198	44	248	55	108	24	455	100	100

* The population groups are not mutually exclusive

** Includes Asian/Pacific Islanders, Native Americans, mixed ethnicities and other

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[4] The randomness in which the sample was selected and sample size are the two most important factors in determining whether the sample accurately represents the overall population. While ethnic and risk groups were selected using random methods, other subpopulations were selected using convenience sampling methods, and thus caution should be taken in generalizations. Also generalizations to those groups with a sample size less than 40 should be interpreted with caution.

Attachment 10 is a table of the demographics for those who completed the surveys. The "Total" column in this table shows the "weighted" sample so that it is representative of the total population of PLWH/A (see Attachment 8 Sample - Populations Comparison).

In order to make this large table more accessible, many of the demographic factors that describe the sample are shown and described in the figures below. For those seeking more information, Attachment 10 has more detailed demographic descriptions.

Basic Demographics

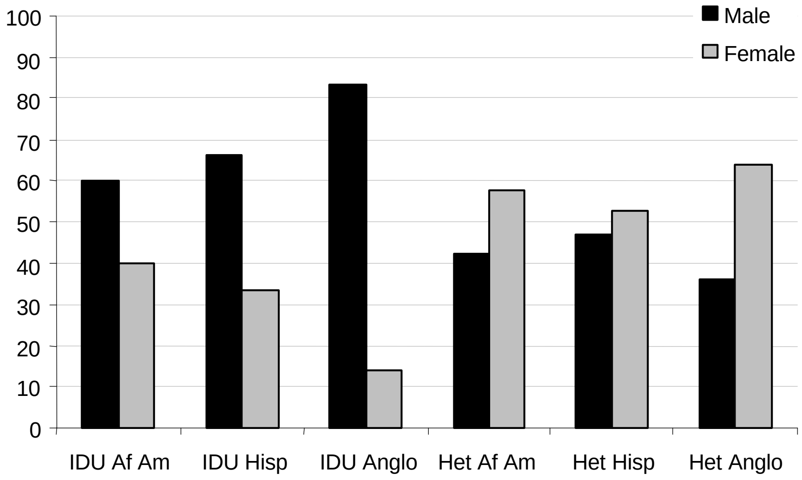
The majority of the following figures show the basic demographics for the three risk categories, MSM, heterosexual and IDU. When figures are provided for the total sample, over sampled populations are weighted back to their proportion in the population. The value of these tables is to have a full understanding of the sample being analyzed and to determine what biases may be introduced by the sampling strategy that combined random and convenience sampling.

Gender

Figure 3-1 displays the respondents by gender.

- There were three transgender PLWH/A among the MSM group (not shown in Figure).
- 69% of the IDU group is male. This compares to the 1999 Epidemiological Report showing 63% of male IDUs among the PLWA.
- 58% of the heterosexual PLWH/A are women and 42% are men. The Epidemiological Report of all PLWH/A reports 55% female and 45% male.
- The total weighted sample consists of 81% males, 18% females and one percent transgender. This compares to 83% male and 17% female living with AIDS in the Epidemiological Review.

Figure 3-1 Gender Identity



Education

Figure 3-2 through Figure 3-4 show the different levels of education for each of the risk categories. The figures in the bar chart show the unweighted values for each risk population by ethnicity. The pie chart shows the percentages for the whole risk group.

- Over 45% of the PLWH/A have some level of college education.
- Half of the MSM have some level of college education, but for more than 60% of the Hispanic MSM high school is the highest level of education achieved.
- Among the heterosexuals, 44% have less than a high school education. Heterosexual Hispanics have the lowest level of education with nearly 40% having a grade school education.
- High school is the highest level of education achieved by over 50% of the IDU participants. Fourteen percent of Anglo IDU are college graduates.

Figure 3-2 MSM Education Levels

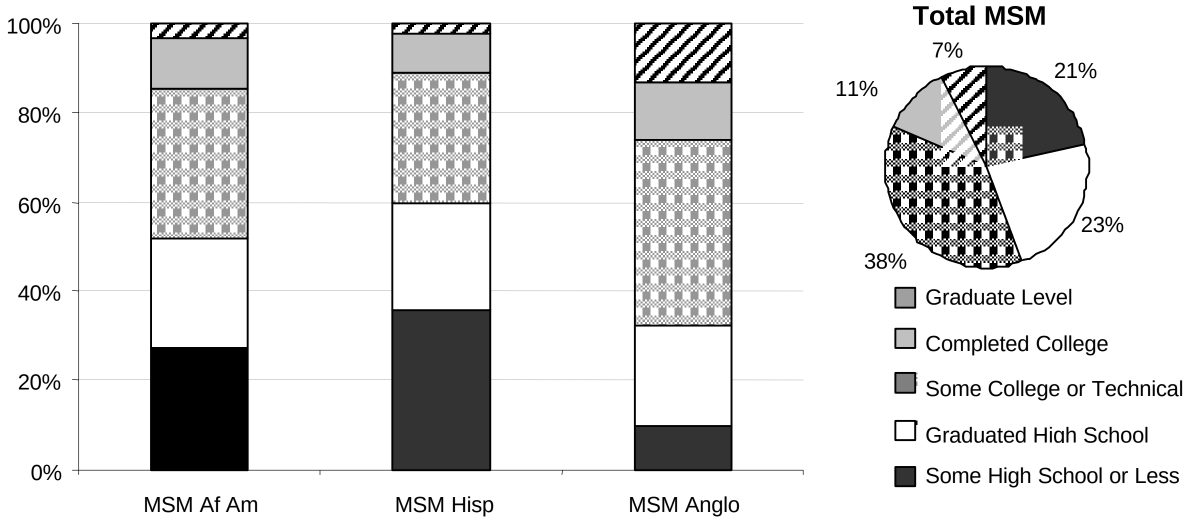


Figure 3-3 Heterosexual Education Levels

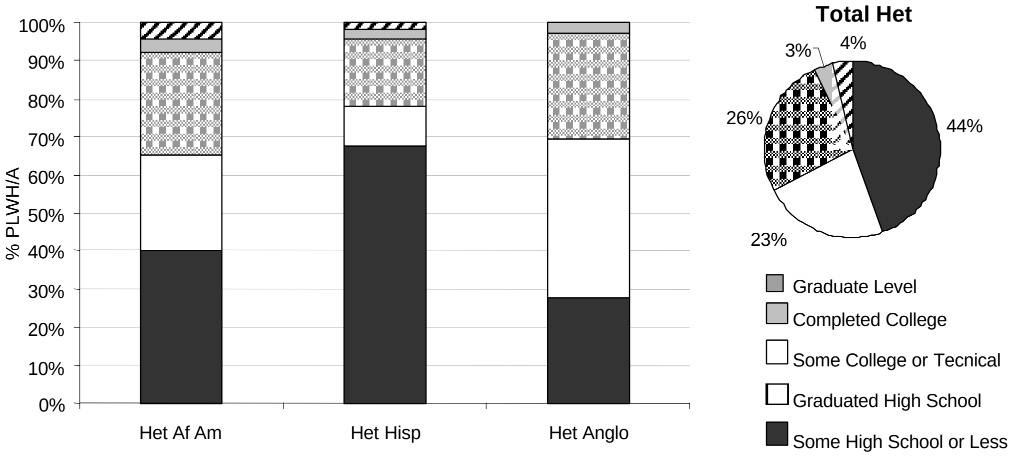
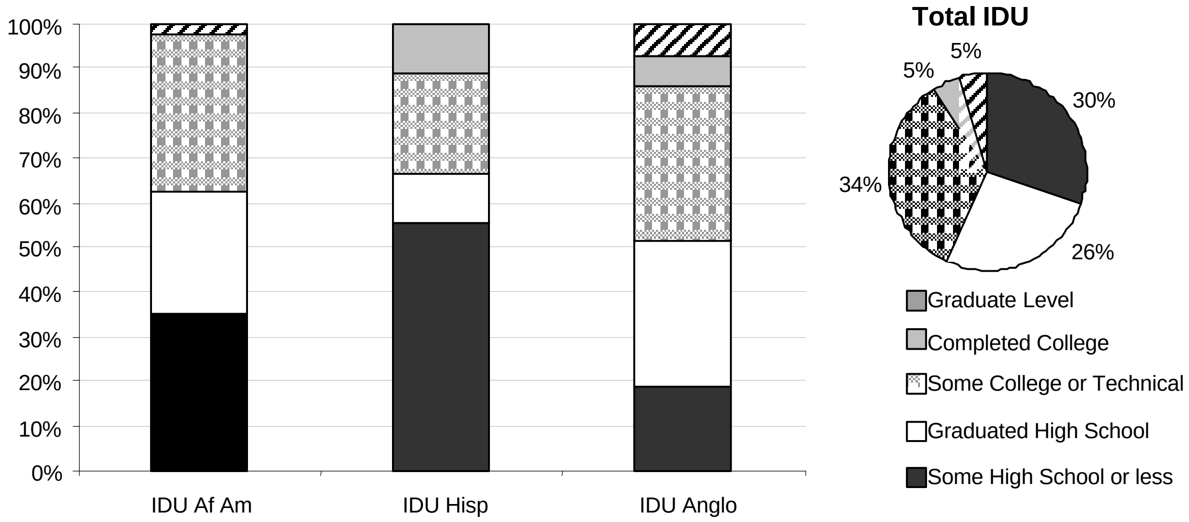


Figure 3-4 IDU Education Levels



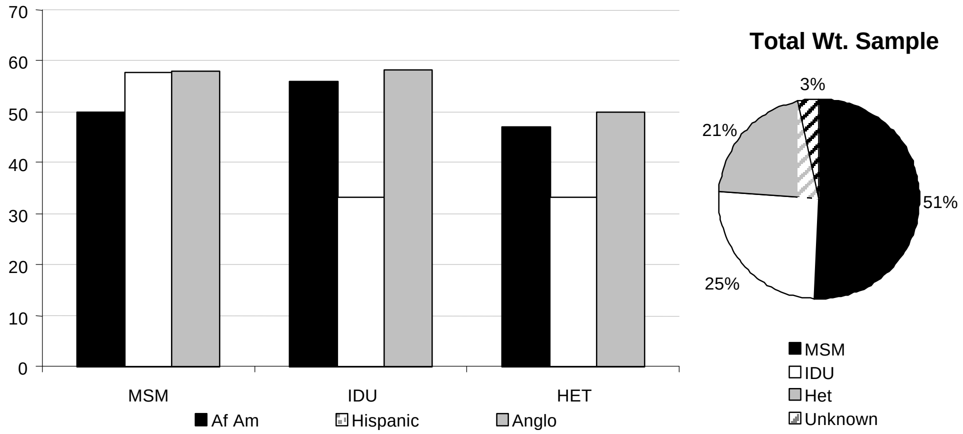
Ethnicity and Risk Group

Figure 3-5 shows the ethnic/racial composition of each of the risk categories. The pie chart shows the proportion of PLWH/A for each risk group.

- Within the MSM group 41% are Anglo, 31% African American, 23% are Hispanic, and 5% are either Asian/Pacific, Native American, multi-cultural or other ethnicity. This shows the oversampling of African Americans and Hispanics, based on the known epidemiology of PLWA (MSM Anglo 59%, MSM African American 23%, MSM Hispanics 17%).

- The IDU group is composed of 46% African Americans, 40% Anglos, 8% Hispanics and 6% other ethnicities.[5]
- Among the heterosexuals, 58% are African American, 21% Hispanic, 16% are Anglo and five percent are other ethnicity. The heterosexual category used here includes some IDUs, but the percentages are very close to those of PLWA in the Epidemiological Review (heterosexual African Americans 60%, heterosexual Hispanics 20%, and heterosexual Anglos 19%.)
- As seen the pie chart, the majority, (51%), of the PLWH/A are MSM, 25% are IDU, 21% are heterosexual and 3% are "unknown". This compares to the 52% MSM, 22% IDU or MSM/IDU, 16% heterosexual and 8% unclassified among PLWA in the 1999 Epidemiological Review.
- In the total weighted sample, 41% of the participants are Anglo, 34% African American, 18% Hispanic, and 6% other ethnicities (not shown in figure). This compares to 45% Anglo, 38% African American, 17% Hispanic, and about 1% other ethnicities among the PLWA in the 1999 Epidemiological Review.

Figure 3-5 Ethnicity by Risk Group



Income

In order to receive Ryan White and other state supported benefits, the current HIV/AIDS care system has income restrictions depending on the service provided. In general, those receiving Ryan White Services have low income. Figure 3-6 shows income for each of the risk categories, and it shows that:

- More than 80% of PLWH/A make less that $15,000 a year; 51% make less than $6,000 a year.

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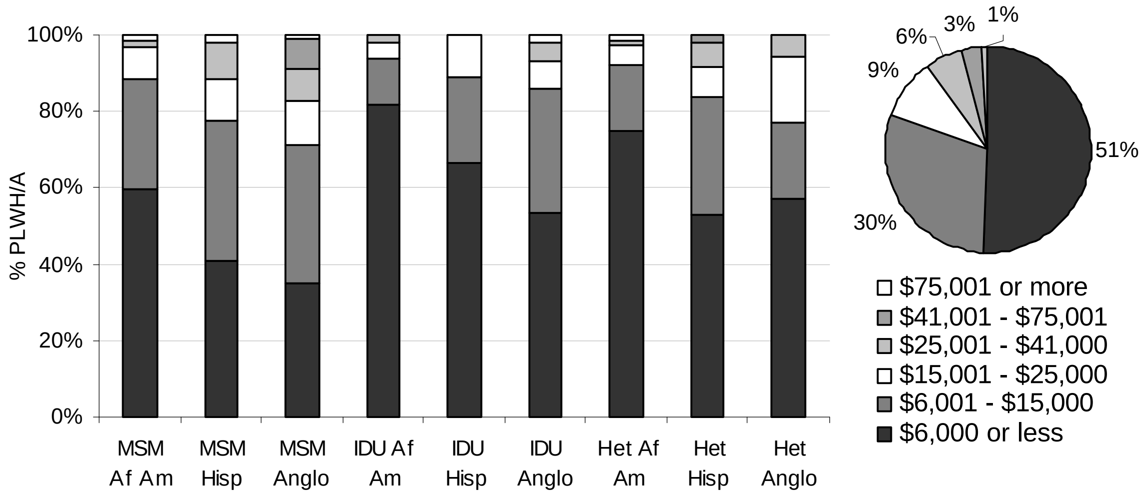
[5] This categorization of IDUs is not comparable to the Epidemiological Review because IDUs also reflect heterosexuals and MSM.

- African Americans report the least income across all risk groups, with about 70% of the African American living with HIV and AIDS reporting an income of less than $6,000. More than three quarters of the African American IDU and heterosexuals make less than $6,000 a year.
- MSM report the highest income of all risk groups. Still, most of the MSM report an income between $6,000 and $15,000 (71%), with about 5% reporting an income greater than $41,000. Nearly 60% of the Hispanic MSM report an annual income below $6,000.
- Nearly 70% of the IDU and heterosexual PLWH/A report an income of $6,000 or less.

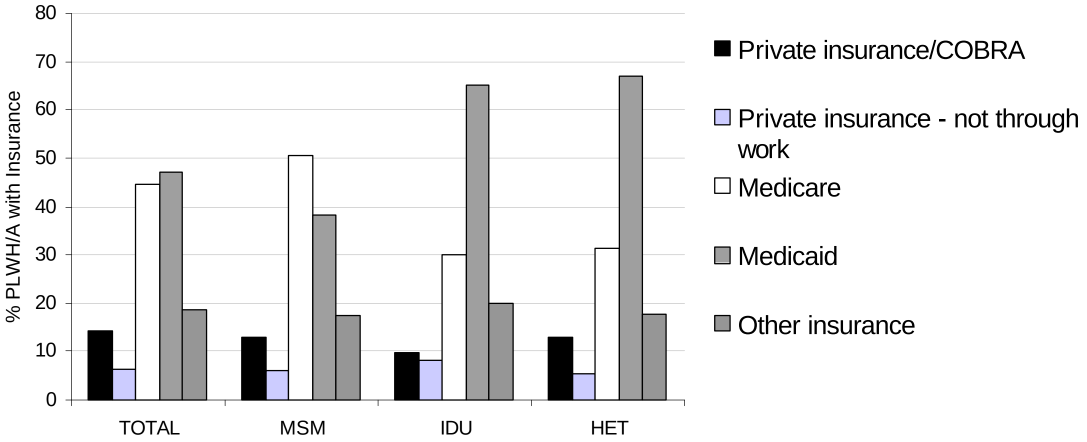
Figure 3-6 Income Levels



Insurance

Given the low income, it is not surprising that 53% of PLWH/A report no health insurance. For the remaining 47%, for all risk groups, the most frequent provider of insurance is Medicare and Medicaid (Figure 3-7). Those with some work history, such as MSM, are more likely to receive Medicare. Those who have not paid into the system are more likely to receive Medicaid. The higher Medicaid benefit among IDUs and heterosexuals reflect, in part, a larger proportion of women.

Figure 3-7 Insurance held by PLWH/A



Entitlements and Benefits

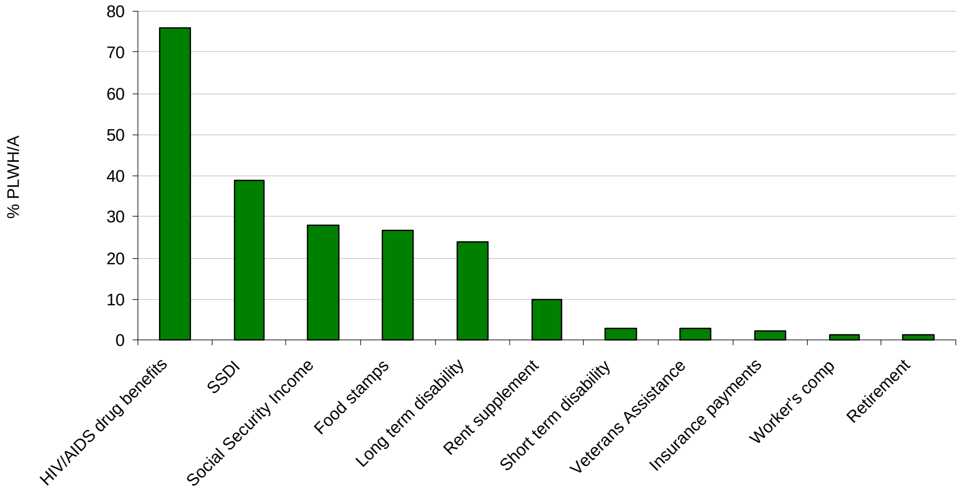
As shown in Attachment 10, PLWH/A who have insurance are most likely to have a combination of benefits. One of the reasons that the care system in Houston has favorable health status and mortality outcomes is that almost 80% of PLWH/A have access to drug reimbursement. Drug reimbursement may come from a number of Federal, State, local, or private channels, and many PLWH/A understand that ADAP, MAP, drug compassion programs and clinical trials are not "insurance". Yet, in focus groups, many have indicated a fear that drug assistance will be discontinued or made more difficult to obtain. As shown in Figure 3-8, a small number, about 2% of PLWH/A, receive insurance assistance, but based on employment figures (shown later in this chapter) it appears that there is a larger pool that would be eligible if they were aware of the program.

The other benefits, such as disability, food stamps, and rent and utility assistance are often more difficult for PLWH/A to obtain than drug benefits. They are necessary because of the large number of PLWH/A who are living in or near poverty.

- The three most common forms of benefits received are SSDI, Social Security, and food stamps. More than 40% of the MSM participants reported receiving SSDI.
- Food stamps are the number one benefit received by IDU participants, with almost 40% of the IDU participants receiving this benefit.
- More than one third of the heterosexuals receive food stamps.
- Over 75% of all the respondents receive assistance paying for HIV/AIDS medications.
- More than 60% of all the respondents receive their HIV medications through ADAP or TDH.
- Females are significantly less likely to receive ADAP or TDH medical reimbursement than males.

- Among heterosexuals, Hispanics and African Americans are less likely to receive ADAP than Anglos.
- MSM are more likely to get ADAP or TDH drug reimbursements than other risk groups, and among MSM Anglos are the most likely to receive drug reimbursement.

Figure 3-8 Benefits



Employment Status

As seen in Attachment 10, one quarter of the PLWH/A are employed in some capacity, either part-time or full-time, and of those about 7% are on some form of disability. As might be expected, PLWA are much more likely to be on full time disability (50%) than PLWH (28%), and PLWH are much more likely to be unemployed and looking for work (21%) than PLWA (10%).

Figure 3-1 through Figure 3-11 shows employment status by ethnicity for MSM, Heterosexual, and IDUs.

- The figures below indicate that over 40% of the MSM are on full-time disability. In all risk groups Anglos are more likely to be on disability. Among the MSM, more Hispanics (33%) are employed than African Americans or Anglos.
- A large proportion, 87% of the IDUs are unemployed. More than 50% of the Anglo IDUs are on full-time disability compared to 36% of the African Americans and none of the Hispanics.
- More than one third of the heterosexuals are not working and are on full-time disability. Almost one quarter of the Hispanic heterosexuals are employed in some capacity. Fifty percent of the Anglo heterosexuals are unemployed receiving full-time disability.

Figure 3-9 MSM Employment Status

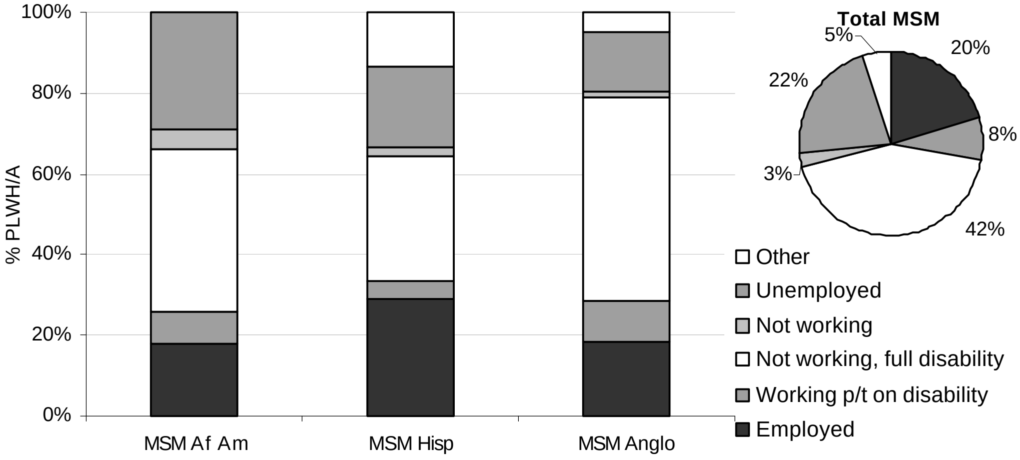


Figure 3-10 Heterosexual Employment Status

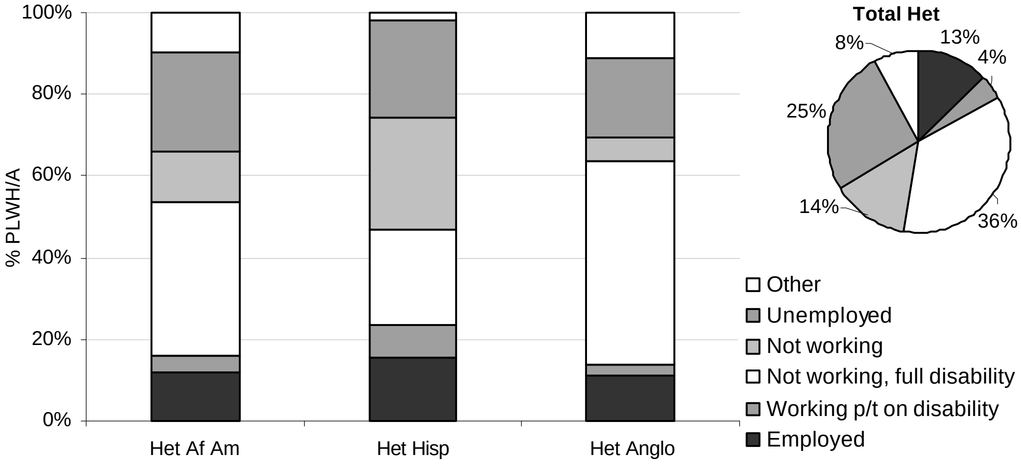
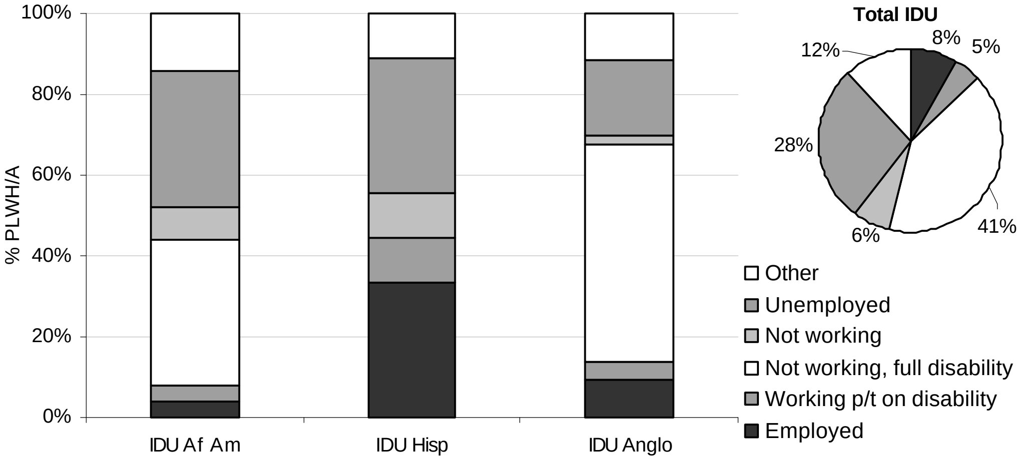


Figure 3-11 IDU Employment Status



Age and Place of Birth

Attachment 10 further indicates that:

- The age range for the young adults is from 13 to 21. Twenty participants under the age of 21 completed the survey. The majority of the participants (72%) are between 21 and 45 years of age, with an average age of 40. Five participants are over 65 years of age.
- Over 85% of all the respondents were born in the US. Within the Hispanic group, over 50% of the respondents were born outside of this country. Thirteen percent are US citizens.

Living Situations and Relationships

Relationship Status

Figure 3-12 through Figure 3-14 indicate that respondents are involved in many different types of relationships.

- The "Total" column in Attachment 10 indicates that 57% of PLWH/A are single. About 5% have lost a spouse or a partner.
- Among the MSM, close to 70% are single. Eighteen percent report being married or living with a partner. The other 12% are either divorced, separated, or have lost their partner. Hispanic MSM are more likely to report being married or living with a partner than Anglo or African American MSM. Nearly 30% of the Hispanic MSM are either married or living with a partner.
- Among the heterosexuals, 44% are single and never married while 24% are either married or living with a partner. Over half of the African Americans are single. Hispanic heterosexuals are more likely to be married or living with a partner than any of the other ethnic groups.
- About half of IDUs are single with over 60% of Anglo IDUs reporting single status. Over 30% of the African American IDUs are either separated or divorced. An additional 8% of the African Americans have lost a partner.

Figure 3-12 MSM Relationship Status

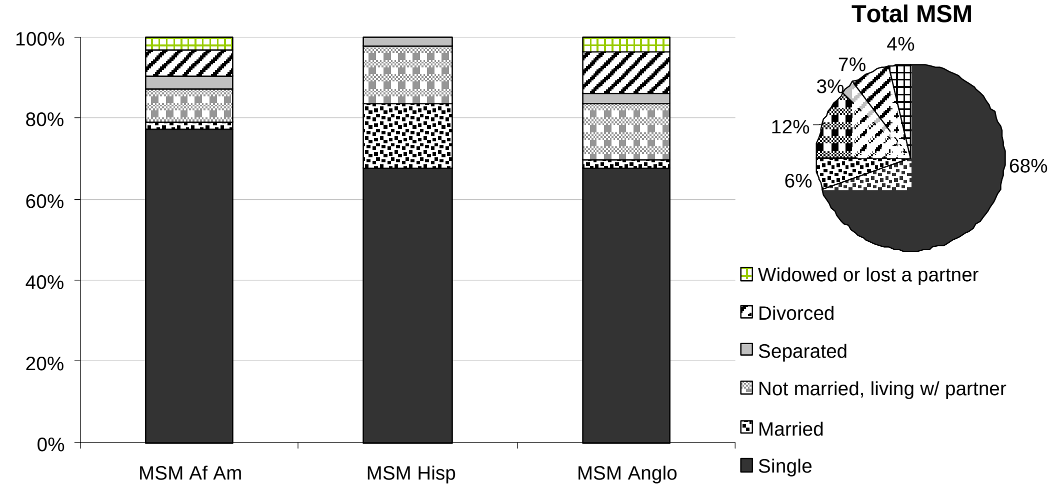


Figure 3-13 Heterosexual Relationship Status

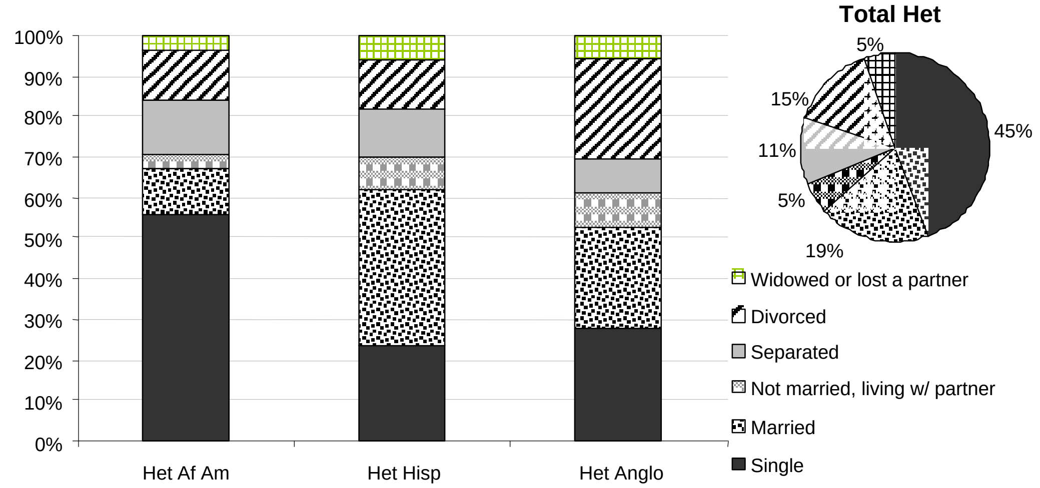
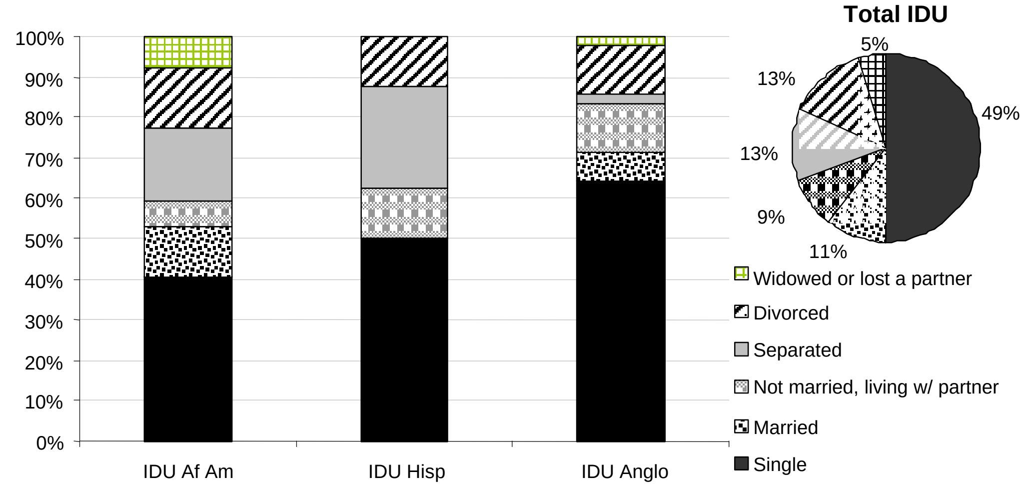


Figure 3-14 IDU Relationship Status



Living Arrangements

Figure 3-15 through Figure 3-17 shows the different profiles of living arrangements for the participants of the survey.

- In Attachment 10, "current living situation” and "living situation" indicates that over half of all PLWH/A live in their own house or apartment (52%) and over 60% live with spouses, family and/or friends.
- The majority of MSM live in their own house or apartment and more than one third live alone. African and Hispanic MSM are less likely to have their own place than are Anglo MSM. Nearly three quarters of the African Americans and Hispanics live with other people (not shown in the figures but seen in Attachment 10**)**. The majority of the homeless MSM are Anglos.
- Over half (54%) of the heterosexuals live in their own home or a relative’s place and over 75% live with other people. African American heterosexuals are less likely than Hispanics to live in their own place but are more likely to live alone. Hispanic heterosexuals are more likely to live with a partner or spouse than any other group. The majority of the homeless heterosexuals are Anglos.
- Almost one quarter of the IDUs live in group homes, correctional facilities, or other types of transitional housing, more than one third report living alone. Anglo IDUs are more likely to live in their own place than African American or Hispanic IDUs. The majority of the homeless IDUs are Hispanics.

Additional living arrangements shown in Attachment 10:

- Up to 17% of PLWH/A live with another HIV positive individual.
- Anglo PLWH/A are significantly more likely to live with an HIV positive partner or roommate. Thirty-two percent of Hispanic females live with an HIV positive partner. Twenty-eight percent of Anglo MSM live with an HIV positive friend or roommate and fourteen percent live with an HIV positive partner. Twenty-three percent of Anglo heterosexuals have an HIV positive partner.
- Almost one quarter of PLWH/A receive rent assistance from a public or private agency. African American heterosexuals are more likely to receive rent assistance than any other group.

Figure 3-15 MSM Living Arrangements

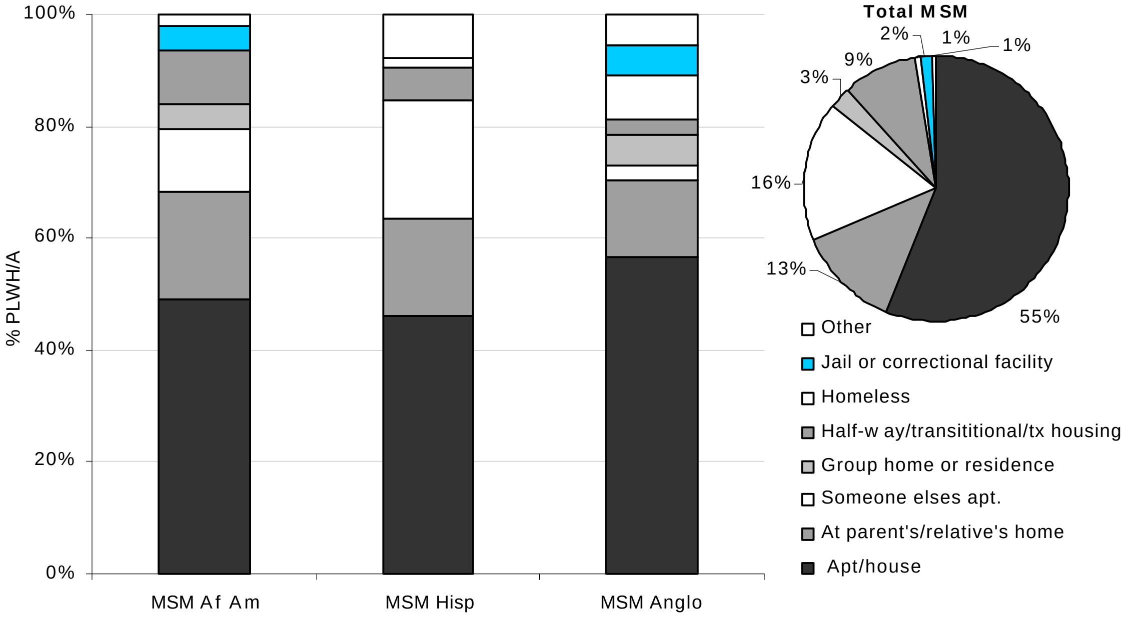


Figure 3-16 Heterosexual Living Arrangements

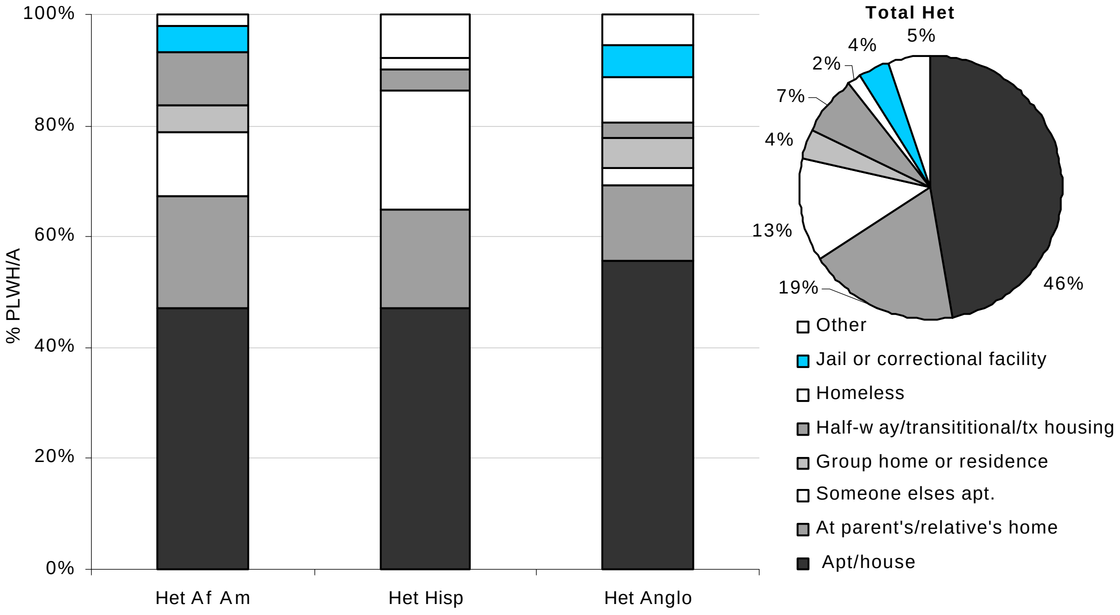
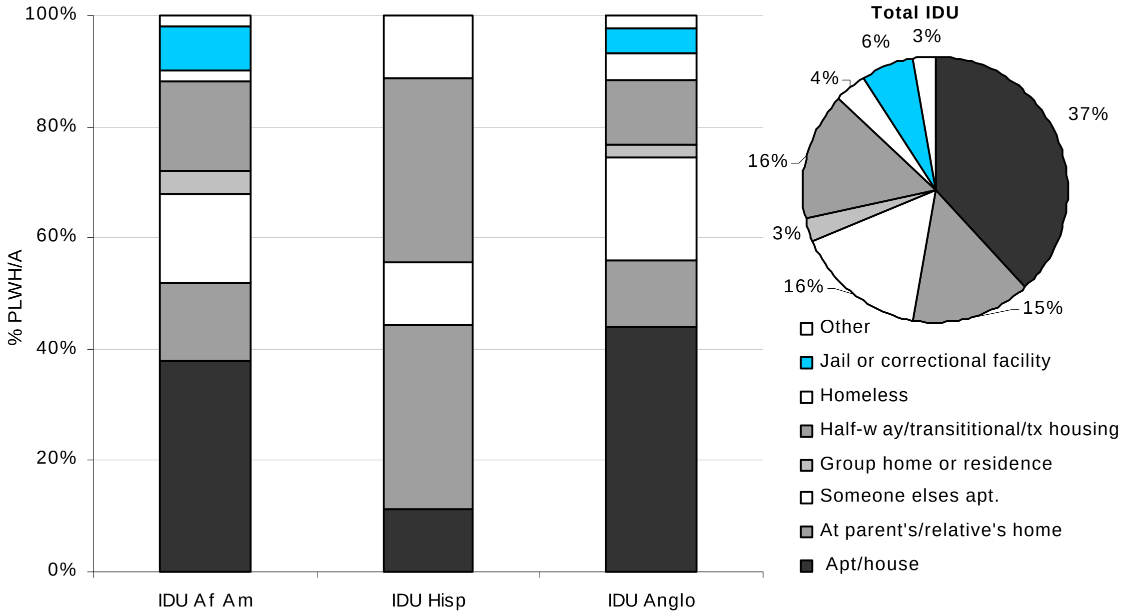


Figure 3-17 IDU Living Arrangements



4 SPECIAL POPULATIONS

Throughout the Services and Barriers sections of this report, the needs of eight special populations are discussed. They include: 1) recently incarcerated, 2) in-prison subpopulation, 3) undocumented, 4) youth, 5) pediatric caregivers, 6) families with children, 7) rural population, and 8) people living with AIDS (PLWA).

Recently Incarcerated

In the sample there are 43 individuals (9% of the sample) who have been in prison or jail for more than one year over the past two years, and they are the group analyzed as "recently incarcerated". While 30% of the total 455 the participant report some contact with the prison system, an analysis of this entire group is less likely to reveal the needs and barriers of those with over a year in prison. When the risk categories are weighted back to their correct proportion, less than 10% of the PLWH/A report having been incarcerated in the last two years for more than one year.

- Of the 43 PLWH/A incarcerated in the past two years, 21% are MSM, 74% are heterosexuals, and 49% are IDUs. The IDUs overlap with both the MSM and heterosexuals.
- The large majority, 72%, of the recently incarcerated are men and African Americans (79%).
- More than one third of the recently incarcerated have less than a high school education.
- Sixteen percent are either married or living with a partner.
- About 40% of the recently incarcerated live in their own place or a relative's place. Another 30% live in some type of transitional housing, group home or boarding house. Seven percent are correctly incarcerated and five percent are homeless. Seven percent have been homeless for more than one year in the past two years.
- More than three quarters of the recently incarcerated live with other people. Eleven percent have an HIV positive partner and close to a quarter live with someone else who is HIV positive.
- More than 40% receive rent assistance from a public or private agency.
- About 85% of the recently incarcerated are currently unemployed. Twenty-eight percent are on full time disability and nearly one third say they are looking for work.
- Less than one third of the recently incarcerated PLWH/A have health insurance. Among those that do, Medicaid is the most common type of insurance.
- Recently incarcerated individuals do not receive many entitlements. The top three benefits received include food stamps (28%), Social Security Income (28%)and long-term disability (21%).
- Almost three quarters of the recently incarcerated receive assistance with their HIV medications. This compares to 81% who are currently taking medications. Fifty-six percent receive their medications through ADAP or TDH and 50% report some other form of medication assistance programs. This would include MAP and prison system.
- Sixty percent have been diagnosed with AIDS and 58% report having symptoms.

- The top three STDs among the recently incarcerated are hepatitis (47%), syphilis (47%) and gonorrhea (42%).
- More than 20% of the recently incarcerated have some form of tuberculosis, active or inactive.
- Recently incarcerated individuals report high history of substance use. The most common substances used have been alcohol (93%), marijuana (84%), crack (67%) and cocaine (65%). Forty-nine percent of the recently incarcerated have injected drugs. Sixty-nine percent consider themselves in recovery. About eight percent report being a current IDU and each of them say they clean their needles sometimes.
- Eight-five percent of the recently incarcerated individuals report an income of less than $6000 a year.

In-prison[6]

Seventeen PLWH/A were interviewed while in prison. Three of the "in-prison" PLWH/A are MSM, 13 are heterosexual and six are IDU. Nine of the in-prison participants are men, eight are women. Their profile is similar in many respects to the recently incarcerated. Some differences are that a larger percentage (65%) of the in-prison subpopulation are asymptomatic, and a much lower percentage (35%) have been diagnosed with AIDS. Seventy-one percent are currently taking HIV medications and only 47% receive HIV/AIDS drug benefits.

Undocumented

Interviewers were instructed to ask all non-US citizens about their residency status. Undocumented PLWH/A (N=31) include all participants who reported being undocumented or not having a legal residency status in the United States, with six also participating in a focus group.

- Fifty-two percent of the undocumented are heterosexual, thirty-two percent are MSM and sixteen percent are bisexual. Twelve percent of the undocumented are IDUs.
- The majority (65%) of the undocumented participants are male.
- Twenty out of 31 undocumented PLWH/A are Latinos. Five are either Caribbean Black, Indian, or other multi-cultural ethnicity.
- Grade school is the highest level of education completed by nearly one-third of the undocumented participants.
- Thirty-nine percent are married or living with a partner.
- Less than 20% have their own place and more than 60% live in a relative's or someone else's place. More than 85% live with other people and a large percent (77%) receive some form of assistance in paying the rent.
- Three undocumented participants have an HIV positive partner.

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[6] In-prison are referred to in the tables as soon-to-be released (STR). Some of those in-prison, however, have lengthy sentences.

- Less than 13% of the undocumented have been in prison or jail over the past two years.
- Similarly, less than 14% have been homeless over the past two years.
- One quarter of the undocumented participants are currently employed in some capacity, part- or full-time.
- Less than 13% of the undocumented PLWH/A have any form of health insurance. Two people reported having Medicare and two have Medicaid. Three report having some other type of insurance.
- Undocumented PLWH/A receive few benefits or entitlements. The top three benefits received are food stamps (19%), Social Security Income (16%) and rent supplements (16%).
- Seventy-seven percent receive assistance obtaining their HIV medications. Out of those who receive assistance, 65% report receiving ADAP or TDH and 50% receive other type of assistance, namely MAP.
- Fifty-two percent are symptomatic, 45% have symptoms and three percent are unaware of their HIV status. Thirty-five percent have an AIDS diagnosis and 71% are currently taking HIV medications.
- Less than 20% of the undocumented report any STD. The most common types of STDs are herpes (19%), syphilis and gonorrhea, both at 13%.
- Two undocumented individuals report having active tuberculosis which is being treated.
- The most common substances used by undocumented individuals are the same as those reported by the overall sample only reported at a lower level. Those include alcohol (77%), marijuana (39%) and cocaine (36%).
- Seventy-seven percent of the undocumented PLWH/A report an annual income of less than $6000.

Youth

The youth special population includes young adults, under the age of 21, recruited and interviewed as part of the overall sampling plan. Identifying and recruiting HIV positive youths always represents a challenge. The experiences and opinions of the twenty young adults who completed the survey can therefore provide useful information about the service needs and gaps among this community. Twenty PWLH/A 21 years or younger completed the survey. The profile of the youth includes:

- Four are MSM and all four are African American.
- There are 16 heterosexuals, four males and twelve females. Eleven are African American, two are Hispanic, two are Anglo and one “other ethnicity”.
- One Hispanic IDU male participated in the survey.
- Two young adults have some college education and a third has some graduate level education.
- Four young adults are married or living with a partner. All others are single.

- Half of the young people live with family, yet one is in transitional housing, one is in some type of city or state housing and one reports being homeless. More than half of the young people receive rent assistance from family or friends. None of the young people live alone.
- Two young adults have a partner who is HIV positive.
- Four young adults are currently working part-time and five others say they are looking for work.
- Thirty percent of the young people have some experience with criminal justice system over the past two years. And one quarter have been homeless during that same period of time.
- Half of the young people have some form of health insurance. Medicaid is the most common (67%) type of insurance coverage.
- Very few young people receive entitlements. Five receive Social Security benefits, four receive food stamps, two receive SSDI, one receives long term-disability and one receives rent supplements. Forty percent of the young people receive their HIV medications through ADAP, private insurance or other type of HIV drugs assistance program, such as the MAP. This figure is consistent with the percent of young adults (45%) who are currently taking HIV medication.
- Seventy percent are asymptomatic and 20% have been diagnosed with AIDS.
- Yeast infections and chlamydia are the most common types of infections affecting the genital area among the young adults.
- One young person reports having active tuberculosis and is not in treatment.
- The most common substances used by young adults are alcohol and marijuana.
- More than 60% of the young adults report an annual income of less than $6000.

Pediatric Caregivers

Pediatric Caregivers include parents of children who are HIV positive. Sixteen parents and/or guardians of HIV positive children completed the survey. The profile for the pediatric caregivers includes:

- Fifteen of the caregivers identifies as heterosexual and one is an IDU.
- Twelve are women and four men.
- Ten are African American, three Hispanic, one Anglo, one Native American and one multi-cultural.
- Pediatric caregivers are the group with the lowest education with over 43% of the participants having a grade school education.
- Second only to African American MSM, pediatric caregivers are more likely to be single than any other group. Four young adults are married or living with a partner. All others are single.
- The majority of the caregivers live in their own place or at a relative’s apartment. As expected, the large majority (94%) live with their children, six percent live with other adults (friends or family members). None live alone.

- Slightly less than one third report receiving no rent assistance from anyone, 31% receive help from spouse or partner and 38% receive assistance from a public or private agency.
- Twenty-nine percent are currently working part-time and on disability.
- Twenty percent have had some experience with the criminal justice system over the past two years. And seventeen percent have experienced some length of homelessness over the same period of time.
- Close to 70% have some form of health insurance. Medicaid is by far (92%) the most common form of insurance.
- Seventy-five percent receive Social Security Income, twenty-seven percent receive SSDI and nineteen percent receive food stamps. Twenty-six percent receive other forms of benefits including insurance payments.
- Seventy-five percent receive assistance obtaining their HIV medications. ADAP is the most common source of medications (62%) reimbursement followed by other assistance programs at 43%.
- Fifty percent are asymptomatic and 38% have been diagnosed with AIDS. Eighty-eight percent are currently taking HIV medications.
- When asked about infections that may be sexually transmitted, yeast infections (38%) and hepatitis (20%) are the most common types of infections among the pediatric caregivers.
- One caregiver reports having inactive tuberculosis.
- Caregivers report very low substance use. Marijuana is the most common substance used by 31% of the caregivers.
- About 44% of the caregivers report an income between $15,000 and $41,000.

Families with Children

Families with children include HIV positive individuals who live with children in their household, whether the child is HIV positive or not. Of the 455 PLWH/A surveyed, 100 say they are living with children. About 13% of the total weighted sample of PWLH/A have children.

- Eighty-eight percent of the PLWH/A with families are heterosexual, 10% are MSM and 10% are IDU.
- Seventy-one percent are women and twenty-nine percent are men.
- PLWH/A with families are 63% African American, 22% Hispanic, eight percent other ethnicity and seven percent Anglo.
- High school is the highest educational level achieved by about 66% of the families.
- Forty-seven percent reported being single. One quarter of the family's members are either married or living with a partner. Eight percent have lost a partner.
- Nearly three quarters of the PLWH/A with families live in their own place or a relative's place. Ninety five percent live with children and more than one quarter live with a partner or spouse. About 13% have an HIV positive partner.

- Families have partners/other family members (38%) or agencies (29%) helping them pay the rent. Forty-one percent report not getting any help towards paying their rent.
- Twenty percent have had some experience with the criminal justice system over the past two years, with 7% spending more than one year in prison or jail.
- Seventeen percent have experienced some length of homelessness over the last two years.
- Less than one quarter of the PLWH/A with families are working either part or full time.
- Less than half of the families have health insurance.
- Families receive various benefits. The top three are food stamps (40%), SSDI (32%) and Social Security Income (29%). More than 78% receive HIV/AIDS drug reimbursement.
- ADAP provides HIV medications for about 56% of the families and other drug assistance programs provide benefits to 37% of the families.
- More than half of the PLWH/A with families have symptoms. Four persons report being HIV negative or not knowing their HIV status. Thirty-eight percent have an AIDS diagnosis and 82% are currently taking HIV medication.
- Among diseases that can be sexually transmitted, yeast infections (48%) and syphilis (20%) are the most common types of infections among the PLWH/A with families.
- Ten percent of the families report having inactive tuberculosis. One person has active tuberculosis and is in treatment.
- Alcohol is the number one substance used by families, followed by marijuana (48%) and crack (26%).
- Eighty-three percent of the PLWH/A with families earn less than $15,000 a year.

Rural

The rural population was defined as individuals who live in zip codes outside of Harris county plus rural zip codes within Harris County (those outside the Beltway). Using this definition, 111 rural PLWH/A completed the survey.

- Forty-one percent of the rural PLWH/A are MSM, 59% are heterosexuals and 20% report being IDUs.
- The rural participants are 67% male, 33% female.
- Thirty-nine percent are African American, thirty percent Anglo, eighteen percent Hispanic and six percent other ethnicity.
- About 44% of the rural participants have some level of college education.
- More than three quarters of the rural PLWH/A are single, divorced, separated or widowed.
- The large majority of rural participants live in their own place or a relative’s place.
- Most rural participants live with partners, family and children and about forty-two percent receive help from their family in paying the rent. Twenty-two percent have a partner or family member that is HIV positive.
- Less than 25% of the rural participants have been in prison or jail over the past two years. However, seven individuals have been incarcerated more than one year over the past two years.
- Twelve percent of rural participants have been homeless for some length of time ranging from less than week to less than one year.

- Twenty-two percent are currently employed in some capacity, part or full time and thirty-eight percent are on full-time disability.
- Less than half of the rural participants have any form of health insurance. For those insured, Medicaid and Medicare are the most common insurance providers.
- The top three benefits received by rural participants are SSDI (49%), food stamps (32%) and Social Security Income (32%). Over 80% receive assistance paying for their HIV/AIDS medications. ADAP pays for HIV medications for three quarters of the rural participants.
- Fifty-four percent are asymptomatic and less than half have an AIDS diagnosis.
- Eighty-five are currently taking HIV medications and more than one-quarter say they never skip a dose.
- Among diseases that can be sexually transmitted, hepatitis, yeast infections and gonorrhea are the most common types of infections among rural participants.
- Slightly over 10% report having some form of tuberculosis, active or inactive.
- Similar to urban and the total sample populations, alcohol (78%), marijuana (56%) and cocaine (41%) are the top three substances used by rural participants.
- More than one third of the rural participants make between $6,000 and $25,000 a year.

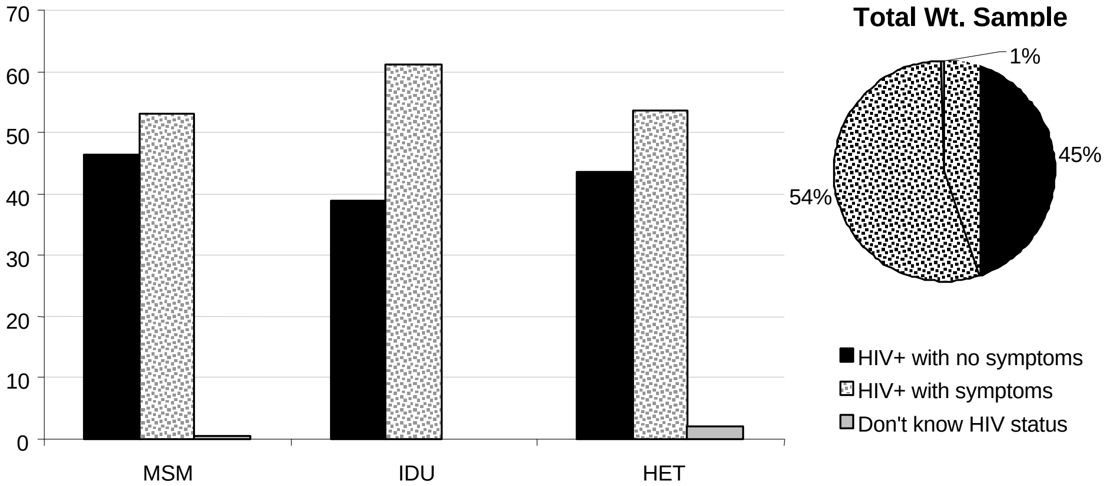
Stages of Disease

Symptomatic

The findings indicate that more than half of the participants currently have symptoms associated to their HIV infection.

- Fifty-four percent (54%) of PLWH/A report being symptomatic, and over 50% of participants from each risk group report being symptomatic.
- Among the MSM, almost half of the African American and Anglo MSM reported no symptoms.
- IDUs are more likely (61%) to report being symptomatic. About two thirds of the African American IDUs have symptoms.
- Six participants were either unaware of their current HIV status and two reported being HIV negative. These two were included as part of the pediatric caregivers' group.

Figure 4-1 Percentage Reporting Symptoms by Risk Category

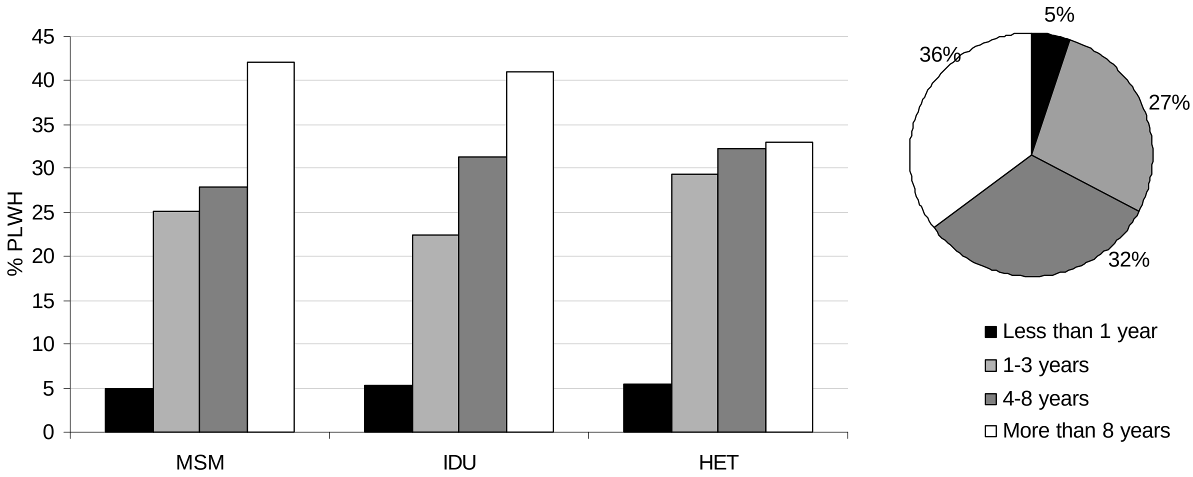


Length of Time of Infection

Figure 4-2 shows the length of time that people have been living with HIV.

- Indicating the progression of the epidemic, MSM and IDUs are more likely to be diagnosed with HIV infection longer. Almost 40% of the heterosexuals knew they have been infected for three years or less. Fifty-six percent of the Hispanic heterosexuals report they have been diagnosed less than three years.
- Over one third of all PLWH/A have been infected for more than eight years. Close to 70% of the IDUs and MSM participants have been infected for over four years, and about 40% of both groups have been infected for over eight years.
- Men (35%) are more likely to be infected for more than eight years than women (16%).
- About 5% of each risk group report being infected for less than a year.
- MSM are the group with the longest length of infection.

Figure 4-2 Length of Time Known HIV Positive by Risk Group

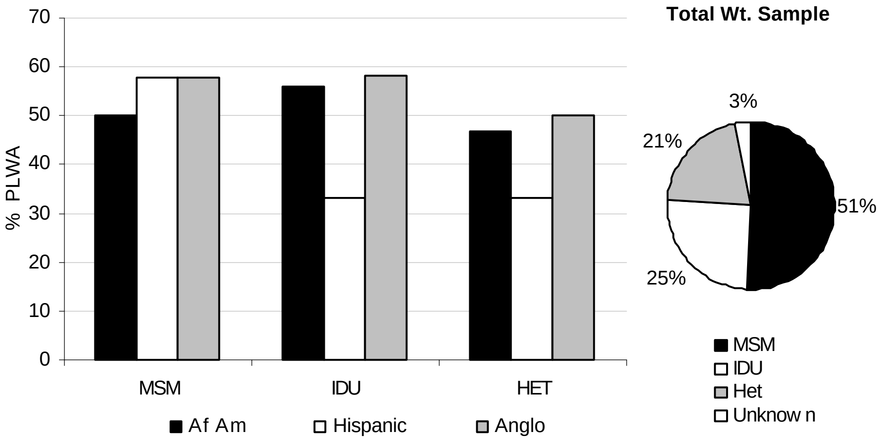


People Living with AIDS

PLWA includes only respondents who report they have an AIDS diagnosis, and is not verified by a clinical diagnosis. Of the 455 PLWH/A surveyed, 223 have received an AIDS diagnosis and represent 54% of the total weighted sample. Given the length of time of the infection in the different groups there is a dramatic difference noted among the gender groups, with significantly more males (55%) saying they have been diagnosed with AIDS than females (36%). More than 50% of MSM and IDUs said they had an AIDS diagnosis, while about 43% of the heterosexual participants report that they have been diagnosed with AIDS. In addition, as shown in Figure 4-3 and Attachment 10:

- IDU Hispanics are slightly less likely to report an AIDS diagnosis than African American or Anglo IDU.
- Most PLWA are either African American (45%) or Anglo (30%). The remaining 25% are Hispanic (19%), multi-cultural (2%), or other, including Asian or Native American.
- While nearly three quarters of the total sample have completed high school, about two-third of the PLWA are high school graduates.
- Comparable to the overall sample, PLWA are more likely to be single than involved in a relationship.
- Close to 70% live in their own place (54%) or at a relative’s apartment (15%). About one-third live alone while others live with partners, family and/or children. Up to 15% have a partner, family member or adult friend that is also HIV positive.
- Half of the PLWA report receiving no rent assistance from anyone, yet, 29% receive assistance from a public or private agency and 27% have a spouse or partner who helps.
- Fifty percent of the PLWA are on full time disability and close to eighteen percent are currently working part- or full-time.
- Twelve percent have been incarcerated for more than one year in the past two years. And more than twenty percent have experienced homelessness over the same period of time.
- More than half of the PLWA have some form of health insurance. Medicaid and Medicare are the most common type of insurance.
- Forty-two percent receive SSDI, 35% Social Security Income, 32% long-term disability.
- Twenty-eight percent (28%) receive food stamps.
- Eighty percent receive assistance obtaining their HIV medications, with ADAP being the most common source (62%) of medication reimbursement.
- Close to three quarters of the PLWA are symptomatic and more than 87% are currently taking HIV medications.
- Hepatitis (36%), herpes (31%), and syphilis (29%) are the most common types of STDs among PLWA.
- Twenty percent have some form of tuberculosis, active or inactive.
- Similar to the overall sample, alcohol, marijuana and cocaine are the most common substances used by PLWA.
- The large majority of PLWA report an annual income below $15,000.

Figure 4-3 AIDS by Risk Category

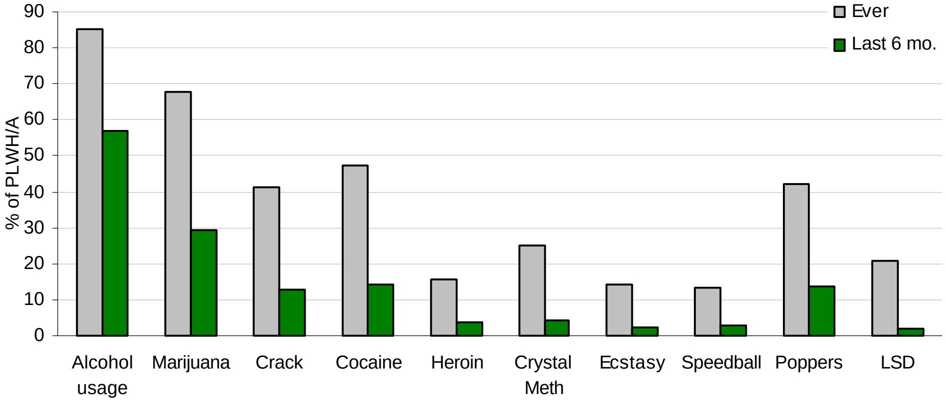


5 CO-MORBIDITIES

Substance Use

A relatively high number of PLWH/A use substances, and, IDUs are growing as a proportion of all PLWH/A. In recent reported seroprevalence data, the number of positive IDUs has significantly increased. Figure 5-1 shows self reported drug use by PLWH/A.

Figure 5-1 Substance Use Among PLWH/A



This figures indicates that:

- Alcohol is used by the large majority of participants, with almost 60% of PLWH/A reporting using it in the last month, and over a quarter of the MSM and IDUs saying they have used it once or more in the last week.
- Marijuana is the second most frequent substance used by PLWH/A. Thirty percent of all PLWH/A say they have used it in the last 6 months and roughly fifteen percent of the IDUs and over ten percent of the MSM say they use it at least once a week. Heterosexual Hispanics report the lowest marijuana use among all ethnic populations.
- Crack and Cocaine are the third and fourth most popular substances among all the groups, except among Anglo MSM and African American heterosexuals. About 30% of the IDUs say they have used these opiates in the last 6 months, and between 11% and 15% of IDUs say they have used them in the last week.
- Among white MSM, the third most common substance used is poppers. Under 10% report using it once a week or more.
- Among the IDUs, 71% of the respondents consider themselves in recovery, and over 40% of the MSM and heterosexuals living with HIV and AIDS consider themselves in recovery.
- Of the 15% of the IDUs who continue to report use, 22% report sharing needles frequently or sometimes.
- The data confirms that the Hispanic population is among the least likely to use opiates and Hispanic MSM are less likely to report injection drug than other populations.

The data clearly shows that IDU is an increasingly important factor in the transmission of HIV and progression to AIDS. Drug use and sharing needles in the Houston community continues to present a challenge for the treatment and prevention of HIV and AIDS.

Sexually Transmitted Diseases

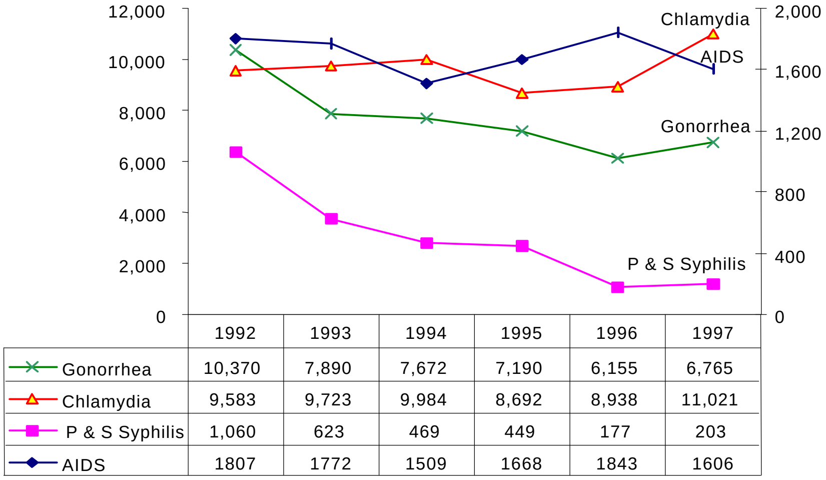
STDs have a dual impact on PLWH/A and those at risk for HIV and AIDS. Individuals with a history of STDs are likely to have a compromised immune system and more likely to contract opportunistic infections (OIs). Also STDs are related to becoming infected because of open sores and genital ulcers.

Figure 5-2 plots the incidence of STDs from 1992 to 1997. The relationship is not very strong between incidence of STD and AIDS. However, given the lag between infection and AIDS diagnosis, the decline in newly diagnosed AIDS in 1996 and 1997 may reflect the 1992-1993 decrease in gonorrhea and syphilis. If this is causal, then a continuous drop in newly diagnosed AIDS may be seen for three more years.

On the other hand, the relationship between STD and HIV is stronger. The increase in the rate of syphilis and gonorrhea rates between 1996 and 1997 send a warning that there may be more unprotected sex that could result in a rise of HIV. Given the current treatment alternatives, it is uncertain whether individuals diagnosed with HIV will progress to a diagnosis of AIDS.

Chlamydia, while an indicator of sexual activity, is not necessarily an indicator of unprotected sex. Yet, chlamydia is known as the "silent epidemic" because 75% of women and 50% of men have no symptoms of disease. The increasing rates of chlamydia are of concern as individuals with sexually transmitted diseases (STDs), both male and female, are believed to be at a three- to five-fold increased risk of acquiring HIV if exposed to that virus.[7]

Figure 5-2 General Population STDs and AIDS



	1992	1993	1994	1995	1996	1997
Gonorrhea	10,370	7,890	7,672	7,190	6,155	6,765
Chlamydia	9,583	9,723	9,984	8,692	8,938	11,021
P & S Syphilis	1,060	623	469	449	177	203
AIDS	1807	1772	1509	1668	1843	1606

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[7] As reported during a satellite symposium in November 1997, presented by the Centers for Disease Control and Prevention in cooperation with the American Social Health Association and the National Association of Nurse Practitioners in Reproductive Health. Notably the rise in the chlamydia is, in part, due to an increase in the number of TDH reporting centers by 27%.

Self reported prevalence of STDs captured in the Needs Assessment generally follows the more clinical data except for chlamydia, which is largely asymptomatic, and many PLWH/A may not have been tested or aware they are infected.

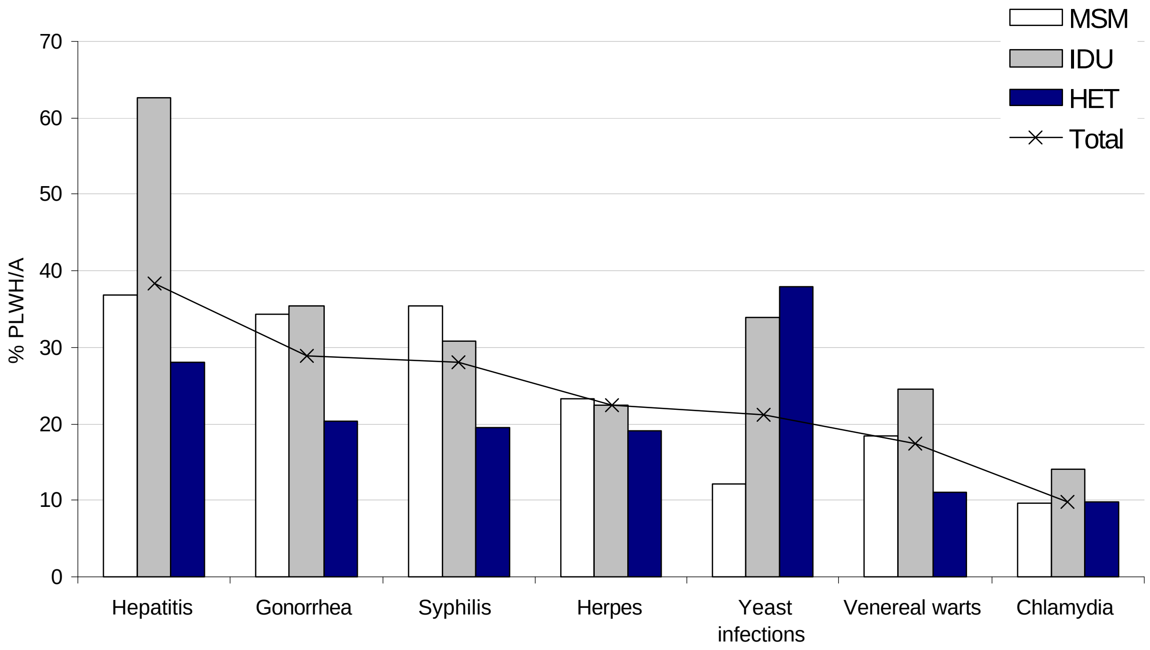
As shown in Figure 5-3, over 60% of the IDUs report having had hepatitis, and between 25% and 30% of MSM and heterosexuals also report hepatitis, indicating a potential need to treat a co-existing hepatitis epidemic.

Gonorrhea is a reasonably good indicator of unprotected sex and it is found to be relatively high among MSM and among IDUs, with more than 40% of the Hispanic and Anglo IDUs reporting having had gonorrhea. This may suggest sex-for-drugs and unsafe practices while using drugs.

The sharp decline in syphilis between 1992 and 1996 was good news, but the data suggest it has leveled off and may be increasing. Among the MSM, more than 50% of the African Americans have had syphilis. Given its relationship with several OIs, this co-morbidity will be a marker for HIV and AIDS that should be carefully monitored and interventions put in place to sustain safer sexual practices.

Yeast infections are the most common genital infections reported by heterosexuals. Anglos report more STDs than African American or Hispanic heterosexuals.

Figure 5-3 STDs among PLWH/A



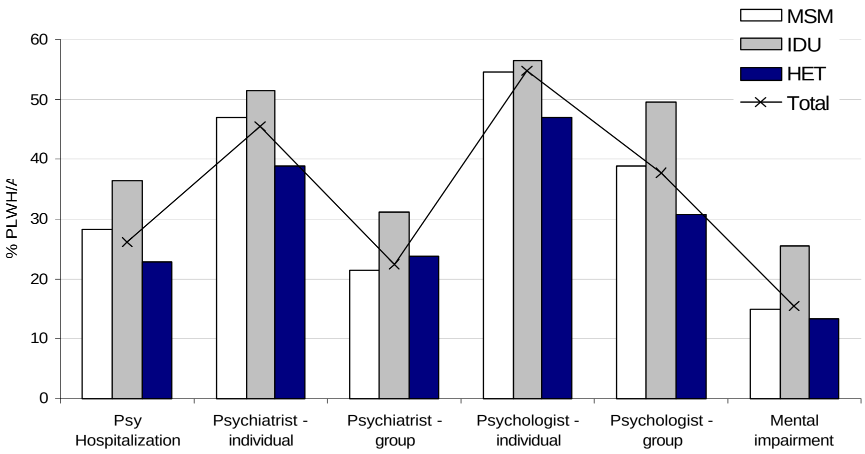
Mental Illness

Mental illness covers a wide range of diseases including major depression, bipolar depression, post-traumatic stress disorder (PTSD), anxiety disorders, schizophrenia or psychotic disorders, and dementia. It may include those with mental illness or those with less debilitating forms of depression and anxiety. Still, even less severe mental illness can negatively impact adherence to medical regimens and significantly reduce the quality of life of PLWH/A.

For some PLWH/A drug and alcohol addiction, depression, or other forms of mental illness predated infection. For others, the infection itself and side effects of medication, such as lack of libido, have triggered depression, anxiety, and problems with sexual identification and relationship. Participants from the survey, as seen in Figure 5-4, reported high levels of seeking psychiatric help. In addition:

- More than 15% of all the participants reported having mental impairments, with up to one third of the Hispanic IDUs reporting mental impairment.
- Over 26% of all the participants have been hospitalized for a psychiatric or emotional problem after their HIV diagnosis. Over one third of the African American and Anglo MSM have been hospitalized for an emotional problem
- More than 50% of all PLWH/A see an individual therapist for counseling, and IDUs and MSM report the greatest use of individualized treatment.
- IDUs are more likely to receive some type of counseling than other risk populations.

Figure 5-4 Self Reported Treatment for Emotional/ Mental Disabilities



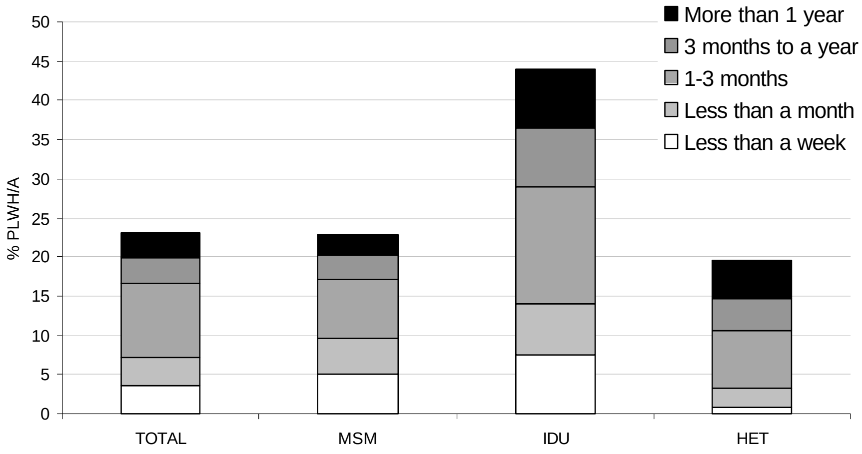
Homelessness

In the 1999 Needs Assessment survey, 1.4% of all PLWH/A reported they were currently homeless. However, far more have been homeless in the past two years. As shown in Figure 5-5, almost 45% of the IDUs have been homeless for some period of time in the last two years. Between 20% and 25% of MSM and heterosexuals say they have been homeless. Overall more women report being homeless for over three months during the past two years (10%) than men (6.6%).

A challenge to caregivers is to provide service to individuals with multiple co-morbidities. The chronically mentally ill living with HIV and AIDS are also likely to be homeless, and have a further co-morbidity of substance abuse. IDU and homeless often go together. As seen in Figure 5-5 below, IDUs are much more likely to have been homeless. They are also more likely to have mental illness and have STDs.

When PLWH/A were asked if they were worried about being homeless, 35% said they were concerned, and about half the Hispanics living with HIV/AIDS (49%) reported being concerned.

Figure 5-5 Homeless PLWH/A



Tuberculosis

Despite the heightened vulnerability to tuberculosis (TB) among PLWH/A due to their weakened immune system, Houston EMA TB rates among those living with HIV and AIDS has been declining since 1993. In 1993, there were 728 new TB cases, 142 (19.5%) were infected by HIV/AIDS. In 1994, there were 747 new TB cases, 143 (19.1%) were infected by HIV/AIDS. In 1995, there were 786 new TB cases, 123 (15.6%) were infected by HIV/AIDS. In 1996, there were 607 new TB cases, 95 (15.6%) were infected by HIV/AIDS. In 1997, there were 623 new cases of TB in Harris County. Of these, 98 (15.7%) were infected by HIV/AIDS.

The majority of TB cases in the Houston EMA occur among the foreign-born populations which is predominately Hispanic/Latino and Asian. Although these populations have low HIV rates, the continued population growth among these immigrant groups suggests continued monitoring of TB.

The 1999 Needs Assessment finds that 18 persons reported active TB and 59 report inactive TB. The highest prevalence, about one-quarter of the population was among the in prison subpopulation and recently released populations.

6 TESTING AND PREVENTION

In the survey a series of questions were asked about where PLWH/A are tested for HIV, their frequency of sex, frequency of needle sharing, and the use of condoms. These responses suggest the number of PLWH/A who may put others at risk for HIV or re-infection, or the percentage of HIV positive persons who use a condom and therefore engage in one method of safer sexual behavior.[8] Responses to the prevention questions are shown in Attachment 11. Graphic representations of several questions are presented and discussed below.

HIV Testing

The most popular places for HIV testing are community clinics, hospital clinics, doctors' offices, and the health departments.

As shown in Figure 6-1, almost 50% of the all the participants reported receiving their test at a community clinic (black line). All three risk groups utilized clinics about the same. About 15% of PLWH/A reported being tested at least twice (not shown in graph).

About 40% reported being tested in hospital clinics. Heterosexuals are slightly more likely to use a hospital clinic for testing. About one third of those who said they were tested in a hospital clinic were tested more than once.

About a third were tested in private physician offices. MSM were much more likely (39%) to be tested in a doctor's office than are IDUs (24%) or heterosexuals (18%). Over 40% of those who were tested in a private doctor's office said they were tested more than once.

About a quarter of the participants were tested in a counseling and testing (C&T) center. Heterosexuals were less likely to use C&T clinic. Over 40% of those tested in a C&T clinic were tested more than once. One possible reason why heterosexuals are less likely to use this venue is that they are more likely to be concerned about their confidentiality and not seek testing in a specialized clinic.

Twenty-two percent of the participants report being tested at the Health Department. IDUs are much more likely to say they were tested at the Health Department than other risk groups, and about 20% of all those tested have been tested more than once at the Health Department.

IDUs are also much more likely to say they were tested in prison (30%) than MSM (9%) or heterosexual (18%). About 43% of those tested in prison, say that they were tested more than once in prison.

Under 7% of the PLWH/A use health fairs, the military, and home tests for HIV testing. For the 2% who said they used home tests, over half have used them more than once.

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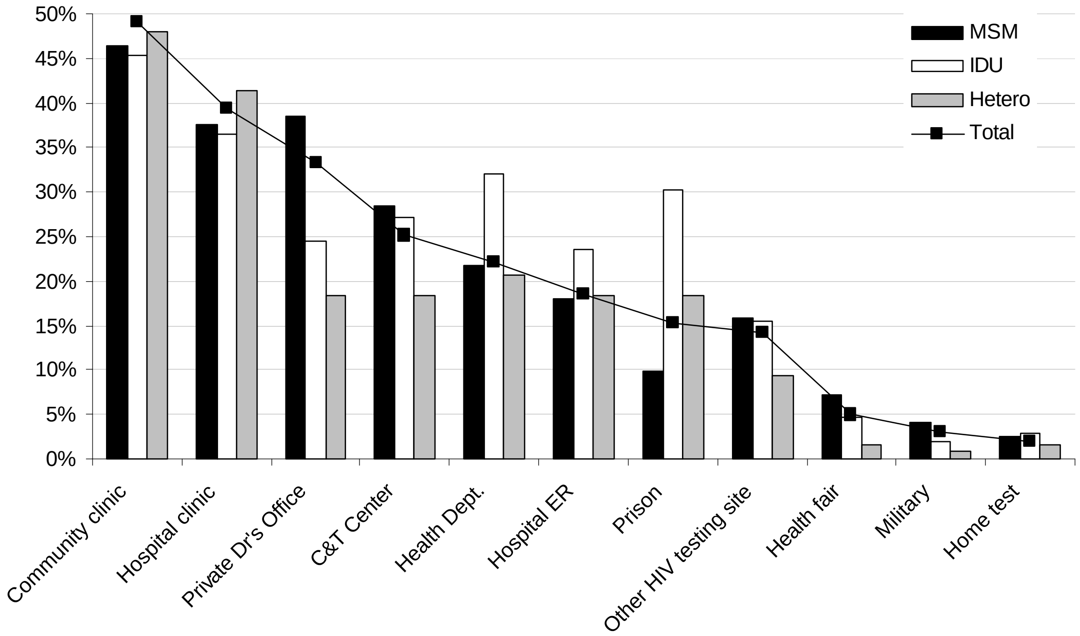
[8] The questions in the survey were of interest to the Prevention Planning Group, but should not be interpreted as a comprehensive examination of prevention behavior.

Figure 6-1 Place of Testing



Reported Methods of Reducing Risk for HIV Transmission from Sex

The participants who said they had sexual intercourse in the past two years reported on several ways they tried to reduce their risk of re-infection or becoming infected with a sexually transmitted disease. As shown in Figure 6-2, increasing condom use, increasing withdrawing before ejaculation (cumming), and increasing washing before sex were methods that were the most popular to decrease the chances of (re)infection or STDs. About 70% said they increased their use of condoms. For MSM this was the most frequent method reported. For heterosexuals it was the second most frequently used method, after picking a partner. For IDUs it was third after picking a partner and washing before having sex.[9] Hispanic MSM reported increasing condom use and picking a partner more than Anglo and African American MSM. On the other hand, Hispanic heterosexual reported less condom use than African American or Anglo heterosexuals.

Over 60% of PLWH/A are more likely to increase taking care in picking a partner. For IDUs and heterosexuals, the increase was greater than for condom use. African American MSM and IDUs were more likely to report an increase in being more careful in choosing a partner than Anglo MSM or IDUs.

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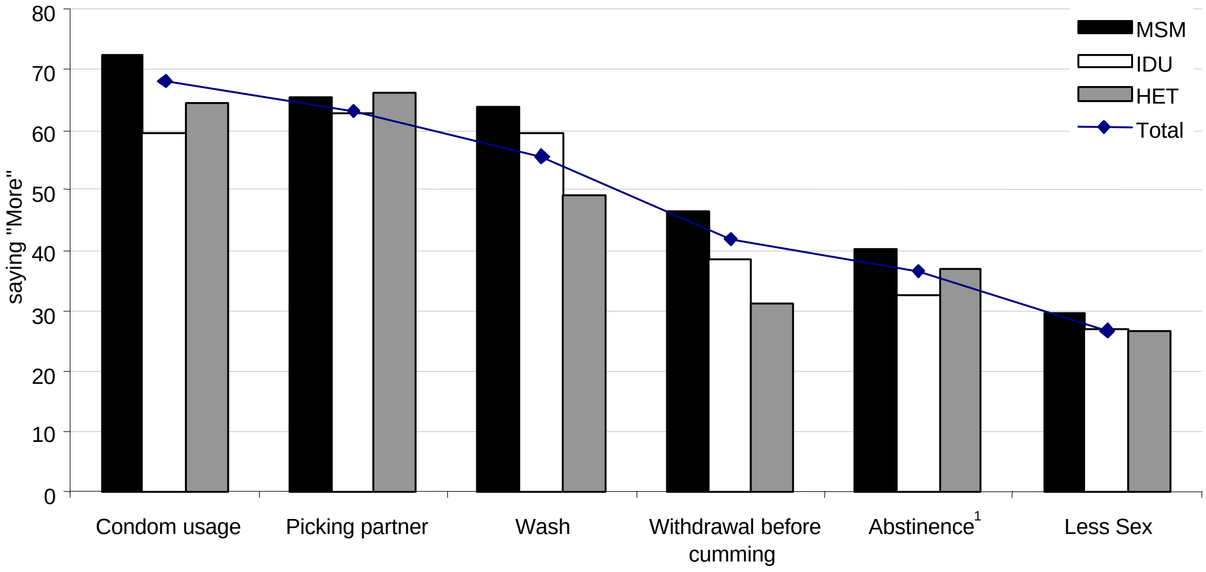
[9] Washing is not considered an effective way to prevent HIV infection and STDs, and care in choosing a partner by appearances without knowing their HIV status is not an effective prevention method.

Over 55% of the PLWH/A reported an increasing in washing before sex as a way to protect themselves from (re)infection and STDs. MSM were more likely to report an increase in washing then other risk groups.

The frequency with which PLWH/A had less sex, increased abstinence and increased the incidence of withdrawing before ejaculation (cumming) ranked behind increased use of condoms and greater care in choosing a partner. As shown in Figure 6-2, the rankings differed among risk groups.

Figure 6-2 Ways to Reduce Risk of HIV Infection



1 In the consumer survey, participants were asked how often they "abstained from sexual intercourse to reduce the risk of infection by HIV or a sexually transmitted disease in the last year?"

Using Condoms with Regular and Casual Partners

PLWH/A were asked how frequently they used condoms with a regular partner and with a casual partner. Figure 6-3 indicates that between 60% and 80% reported "frequently" or "always" using a condom with both. Most risk groups, except for IDUs, were slightly more likely to use condoms with a casual partner than regular partners. IDUs were a little more likely to use them with a regular partners, and Anglo heterosexuals were much more likely to use condom with a regular partner than a casual partner. One likely reason is that heterosexuals are much more likely to be women, and typically, they are less in control of condom use, particularly in a casual relationship.

When asked why they don't always use a condom, Figure 6-4 shows that most frequently stated reasons were the beliefs that their partners do not like condoms or that they "really love" their partner. For IDUs and heterosexuals between 50% and 60% give these reasons and between 40% and 50% MSM give these reasons.

Between 35% and 55% of PLWH/A say they don't always use them because they "don't like them". About 55% of the heterosexuals believe this in comparison to just under 40% of the MSM. More than a third of PLWH/A say they don't always use condoms because they are high. As might be expected IDUs are much more likely to report this than MSM or heterosexuals. Still, over a third of the MSM report this as the reason.

About a third of the participants said that the reason they did not always use a condom was because there "were none available" or they "didn't care". About 25% said that using a condom was not "real sex", and about 20% said they didn't know how to talk about condoms or they knew the HIV status of their partner. Under 10% said the reason they didn't always use a condom was because they were trying to have a baby.

Figure 6-3 Frequency of Using Condoms

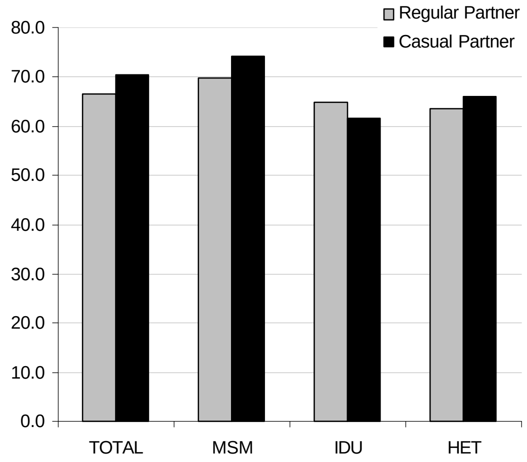
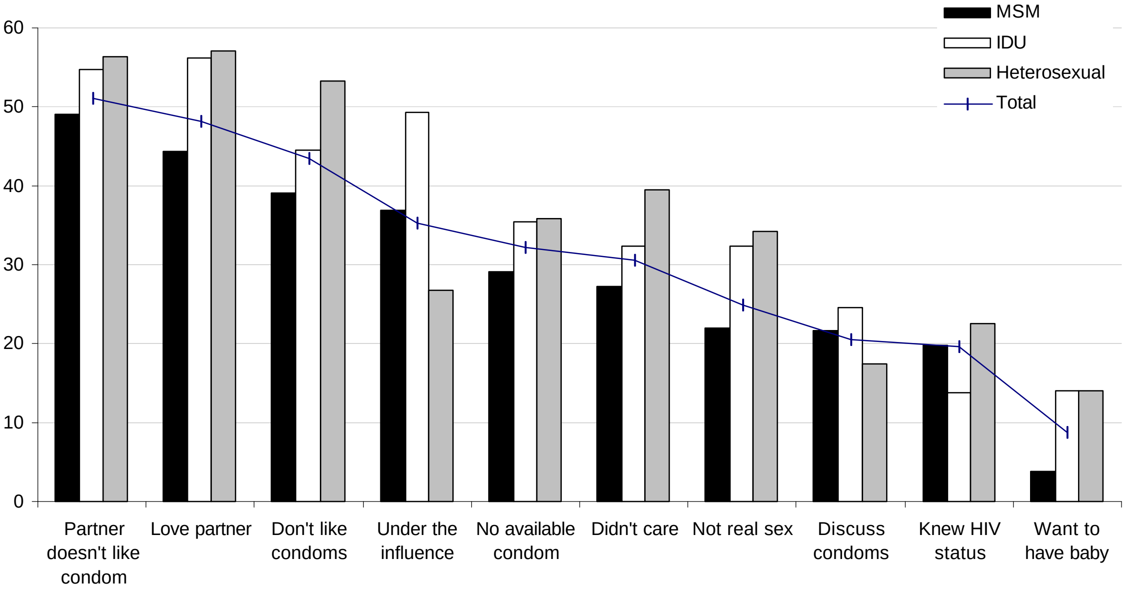


Figure 6-4 Reasons for Not Using Condoms

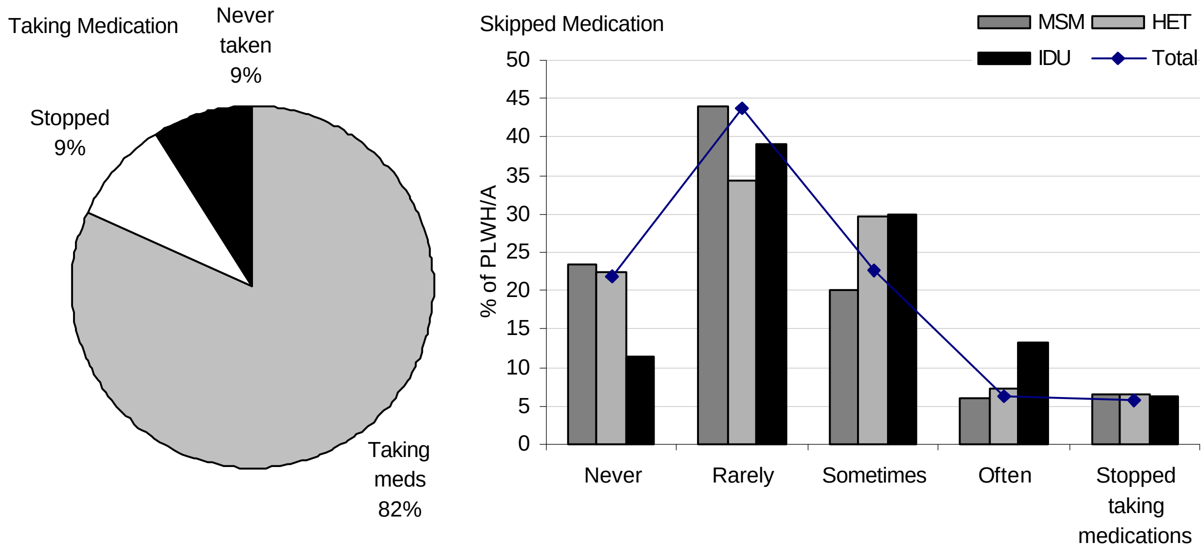


7 MEDICATION AND ADHERENCE

Medication

As shown in Figure 7-1, about 80% of PLWH/A are currently taking medicines for their HIV infection. This is fairly consistent across most risk groups and ethnic subpopulations. On average about 9% of the participants have never taken medication for HIV infection and 9% have taken medications but stopped. These percentages are constant across most subpopulations, with the exception of 21% of the Hispanic females who report never taking medication for HIV (see Attachment 10). This finding should be interpreted with caution because of the small sample size of 28 for Hispanic females.

Figure 7-1 Medications



For those taking medication, as shown in Figure 7-2 between 80% and 90% take anti-virals and/or protease inhibitors, with the exception of heterosexual Hispanics. About 85% of all PLWH/A report taking more than one anti-viral or protease inhibitor. Anglo males are the most likely to take combination treatment (92%), with 95% of Anglo MSM reporting combination therapy. Heterosexuals are least likely to report being on combination therapy, with less than 63% of the heterosexual Hispanics reporting combination therapy.

Attachment 10 indicates that of those taking medication, about 85% are taking more than one anti-viral or protease inhibitor. Hispanics (74%) and African Americans (79%) are taking them less than Anglos (90%). Female Hispanics and Female Anglos appear to be taking them less than male Hispanics and Anglos, but given the small sample sizes for females in these groups, these differences have to be interpreted with caution.

Antibiotics are the next most commonly taken medication (60%), followed by anti-depressants (44%) and anti-fungal medications (37%). As seen in Figure 7-2 and Figure 7-3, there is little variation by risk group or ethnicity with the exception of anti-depressants. IDUs and Anglos are slightly more likely to report taking them as part of their medical regimen.

Figure 7-2 Medication Taken by Risk Group

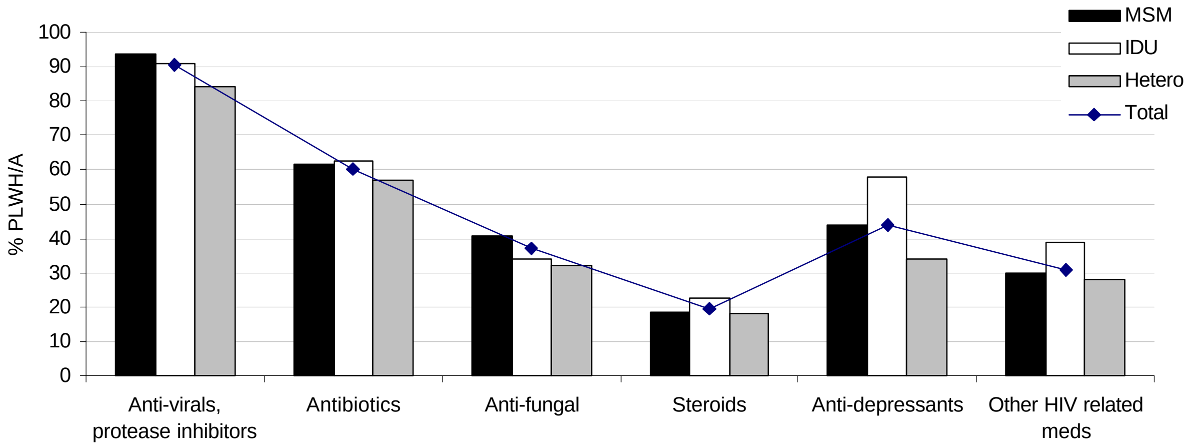
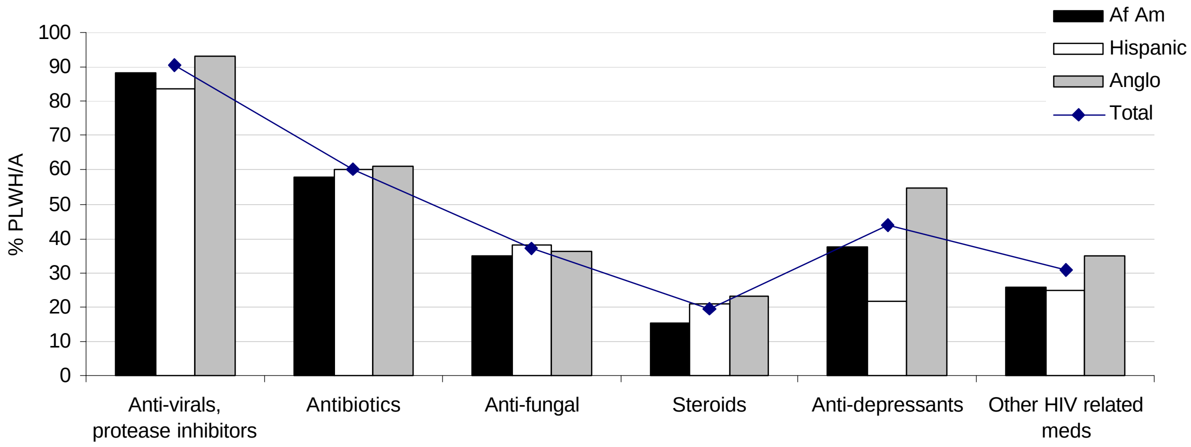


Figure 7-3 Medication Taken by Ethnicity



Adherence

- More than 70% of most subpopulations who took medication prescribed by their doctor report skipping the medication. As shown in Figure 7-1, over 40% skip their medication rarely and under 10% skip it often. As seen in Attachment 10, of those who skip their medication, over 80% of the participants skipped or stopped taking medication without the advice of a doctor.
- Figure 7-4 indicates that over 60% of the respondents say they have skipped or stopped their medications because they have forgotten to take it. The next most frequent reason is side effects (49%) followed by difficult schedules (36%). There is little variation by risk group, with MSM being slightly more likely to mention side effects. As seen in Figure 7-5, there is some variation by ethnicity, with African Americans and Hispanics being more likely than

Anglos to mention "side effects" and African Americans more likely than other ethnicities to say they "didn't understand the instructions".

Figure 7-4 Reasons for Stopping Meds by Risk Group

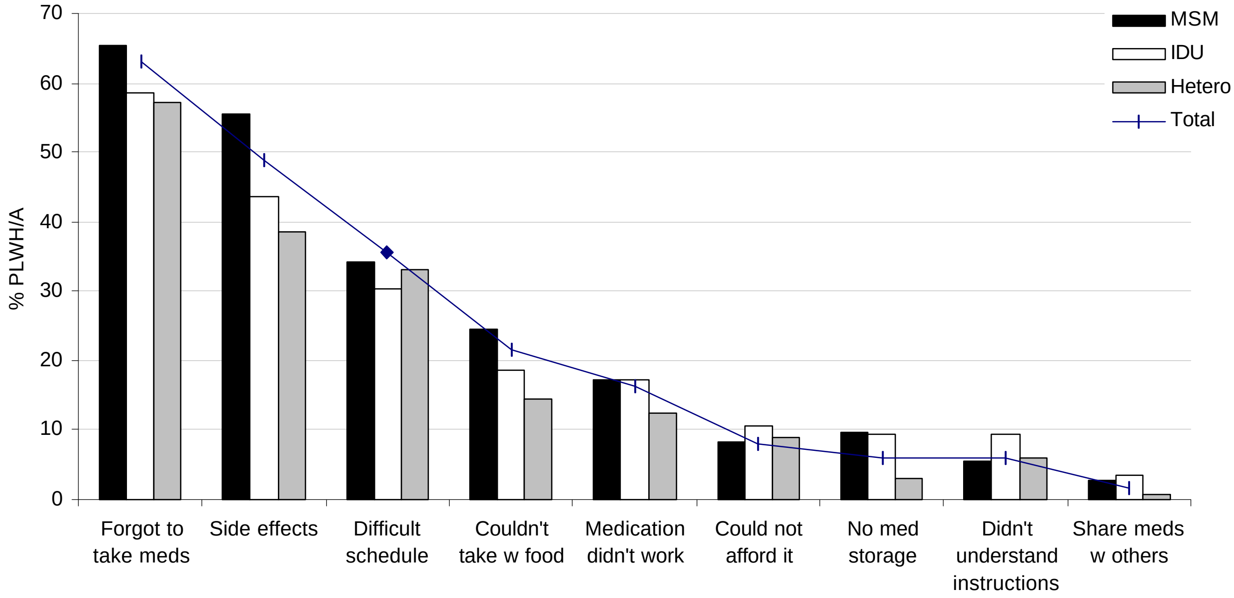
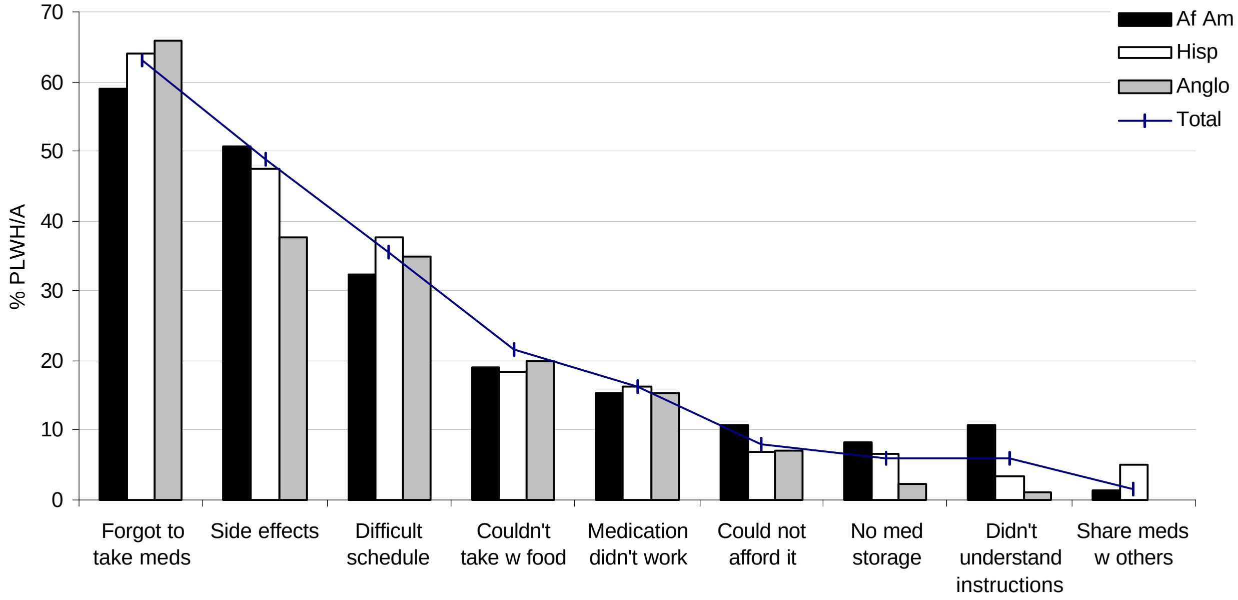


Figure 7-5 Reasons for Stopping Meds by Ethnicity



Side Effects

Diarrhea, fatigue, and stomach pain are the most common side effects reported. For all the PLWH/A, as noted from the line in Figure 7-6, diarrhea (67%) and fatigue (60%) are the two most serious side effects followed by stomach pain (49%), headaches (49%), neuropathy (48%), and weight loss (46%). As expected, PLWA (white bar) are more likely to have side effects. Figure 7-7 shows that there are small differences among risk groups, with MSM more likely to report side effects. Heterosexuals are less likely to mention diarrhea, fatigue or stomach pain and liver problems. IDUs are more likely to mention liver problems. Figure 7-8 shows that men are more likely than women to have the most serious side effects, but overall the differences are small. A likely reason for men and MSM to have the most serious side effects is that they are most likely to have more advanced HIV infection.

Figure 7-6 Serious Side Effects by Stage of Infection

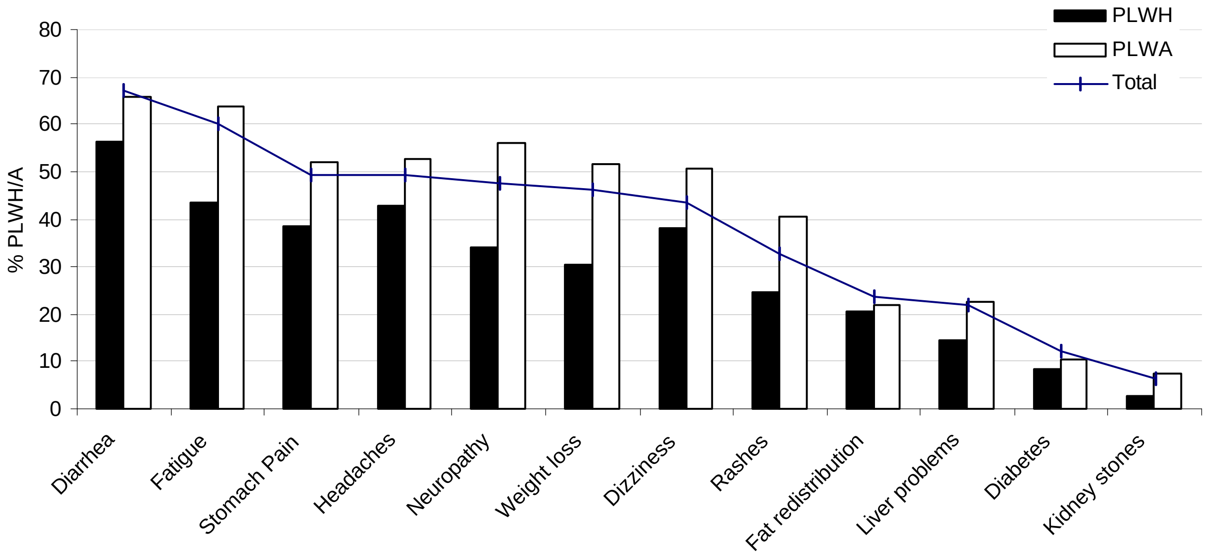


Figure 7-7 Serious Side Effects by Risk Group

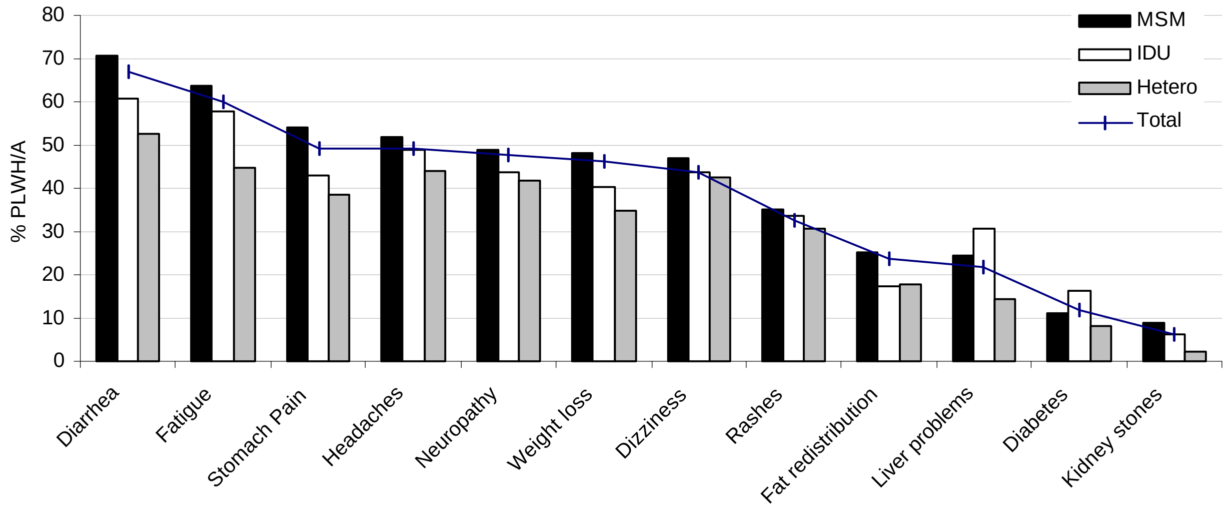
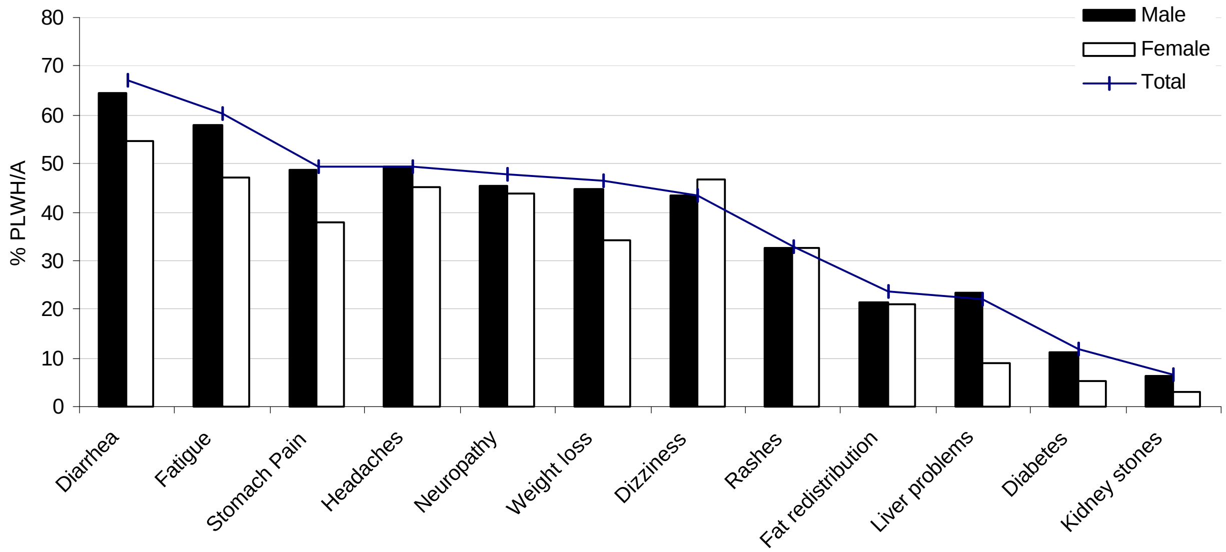


Figure 7-8 Serious Side Effects by Gender

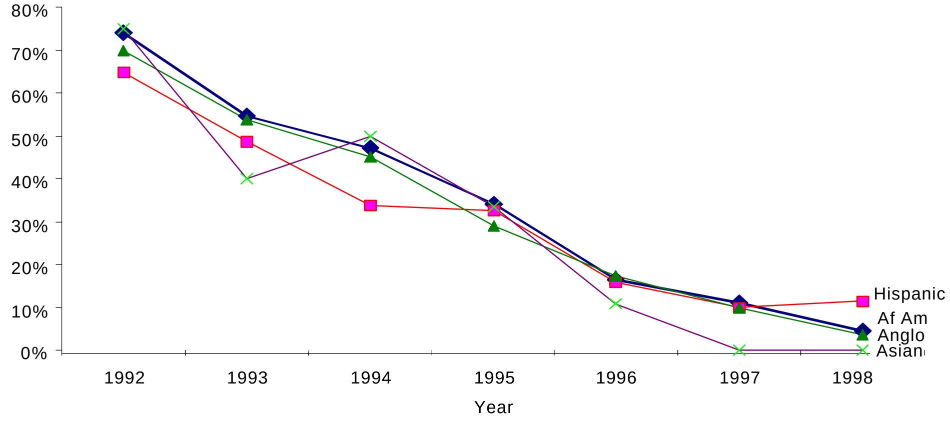


8 OUTCOMES

Mortality

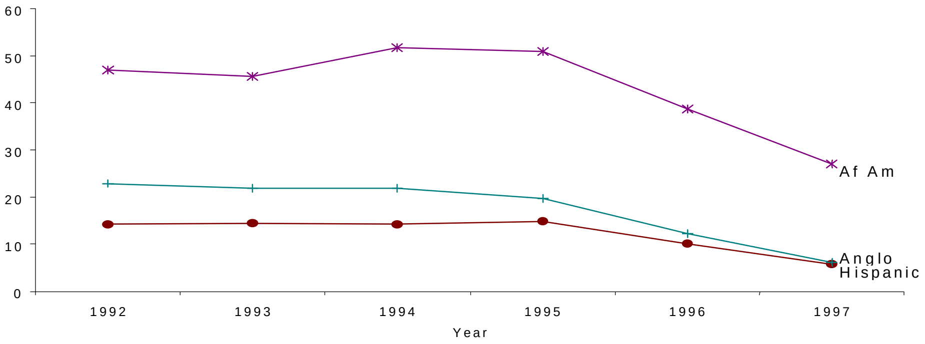
Fewer people dying of AIDS and improved quality of life for those living with HIV and AIDS are two outcomes measured in this needs assessment. Figure 8-1 shows that the fatality rates have declined among all ethnic groups at about the same pace for those persons in care[10]. In 1998, Asians have the lowest fatality rates, followed by Anglos and African Americans. Hispanics, taking an upward turn, increased from 10% to 11% between 1997 and 1998, but this may be due to reporting error.

Figure 8-1 % Deceased by Year of People with AIDS in a Cohort Tracked by TDH



Unfortunately, as shown in Figure 8-2 for all deaths, there is an indication that African Americans are dying at a considerably higher rate from AIDS than Anglos or Hispanics.[11] One likely explanation for the difference in the death rates among the cohort and all deaths reported for AIDS is that many African Americans may not be entering the system of care until a very late stage of the illness. However, the small difference in fatality rates among ethnic populations in the cohort may suggest that those African Americans who access the system are surviving at the same rate as Anglos and Hispanic persons living with AIDS.

Figure 8-2 HIV/AIDS Deaths by Ethnicity per 100,000 of Houston Area Population



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[10] These refer to those persons in care in the TDH cohort. *

[11] Houston EMA Epidemiological Report, 1999, pp 7 –8.

Quality of Life

Other outcome measures for the system of care is improved physical and mental health. While no baseline physical or mental health measures are available for PLWH/A, survey participants rated their current physical and emotional health and then compared it to "before they found out they were HIV positive." The assumption is when a person finds out they are HIV positive, they enter the continuum of care designed for PLWH/A. Consequently, improved physical or emotional health after seeking care would suggest the system is meeting its major objective.

As decreasing health status may occur, even with excellent treatment, it is expected that some of the survey respondents will report decreasing physical and emotional health regardless of the quality of the treatment.

Figure 8-3 reports the current and perceived change in physical health. It is divided by three stages of HIV infection. The first two stages of HIV infection, symptomatic and asymptomatic are mutually exclusive. The third is whether the survey participant said he or she was diagnosed with AIDS. While the majority of those said they were symptomatic, about 45% said they were asymptomatic.

As expected, those with no symptoms are more likely to report excellent (27%) or good (50%) physical health, and about 2% report poor physical health. Unanticipated is that more persons with AIDS say their health is excellent or good (46%) than those who are HIV positive with symptoms (35%). Less than 12% of those who are symptomatic or those diagnosed with AIDS report being in poor physical health. The majority of those who are symptomatic report that their health is "fair", with nearly a third of those living with AIDS say their health is good.

About 40% of those living with AIDS who are symptomatic or asymptomatic say their physical health status has improved. HIV positive persons with symptoms are more likely to say that their health is worse (40%) than asymptomatic persons living with HIV.

Figure 8-4 reports the current perceived change in emotional health. About 14% of those who are symptomatic and about 12% of those living with AIDS report poor emotional health, compared to about 9% of those who are asymptomatic. Over 45% of PLWH/A in all stages report their emotional health is very good or excellent.

While slightly more (46%) of the asymptomatic participants say their emotional health has improved, 40% of those diagnosed with AIDS, and about one third of those who are symptomatic, say their emotional health has improved.

The fact that a majority of those living with AIDS who are asymptomatic do not report poor physical or poor emotional health, and that a sizable minority say they have improved their physical and/or emotional health, suggests that the system is making a positive impact on the lives of PLWH/A.

Figure 8-3 Quality of Life - Physical Health

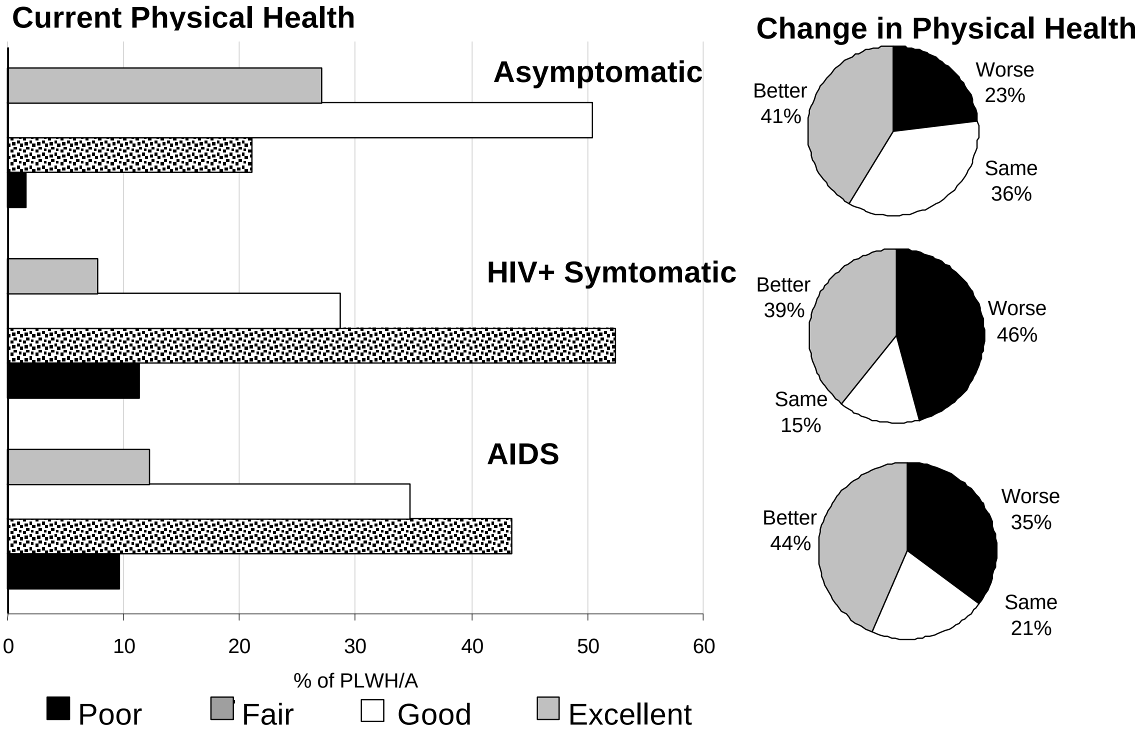
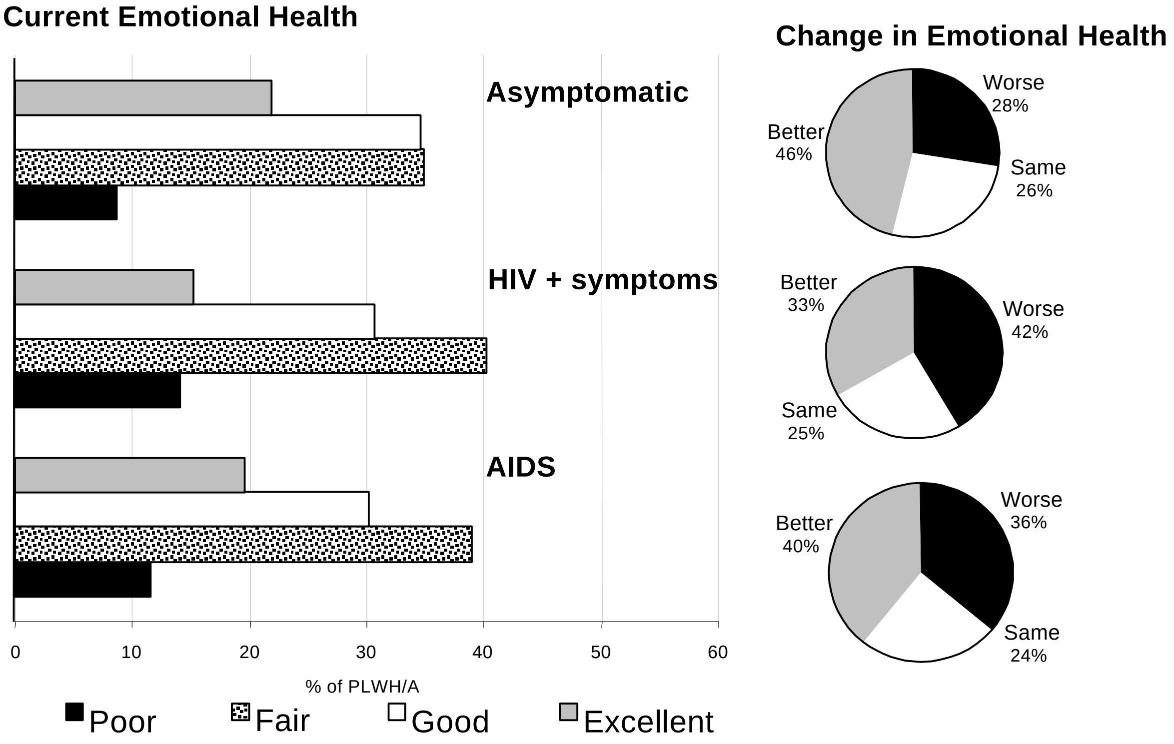


Figure 8-4 Quality of Life - Emotional Health



9 SERVICES

Dimensions of Service Need:

PLWH/A ranked each service on different dimensions of need, including:

1. The service that was perceived to be most important (each participant ranked the top four services in rank order)
2. Knowledge of the service ("Is this service available to you?")
3. Demand for the service ("Have you ever asked for this service?")
4. Utilization of the service "ever" and the number of times in the last year
5. Satisfaction with the service
6. Ease of access
7. Future Demand ("Do you think you will need this service more, the same or less in the coming year?")

Each dimension of service need is discussed below. Each dimension is reviewed for all PLWH/A. Because not all risk groups, ethnic populations, and genders report the same level of need, the data is also discussed by these subpopulations. In addition, the service needs of several special populations are discussed. These special populations include recently incarcerated (Rec Inc), soon-to-be-released (STR), undocumented, youth (13-21), PLWH/A who have children (Family), and a subset of parents/guardians who have HIV positive children (PEDI).

Presentation of the Data

The data for the most important services, service awareness, utilization, satisfaction, access, and anticipated need is presented in the tables found in Attachment 12 through Attachment 19. Each dimension is presented across three separate tables. The tables for each series are arranged by: 1) gender and risk group, subdivided by ethnicity, and 2) ethnicity subdivided by gender. A third table in each series presents six special populations noted above, rural versus urban, and PLWA versus PLWH.

- Attachments 12.1 - 12.3 present the services participants ranked as most important.
    - Attachment 12.1 presents levels of awareness for men and women and risk groups, and risk groups by ethnicity.
    - Attachment 12.2 presents awareness by race by gender.
    - Attachment 12.3 presents awareness for the six special populations, rural versus urban PLWH/A plus those living with AIDS.
- Attachments 13.1 - 13.3 present the percentage of participants that did <u>not</u> know services were available to them.
- Attachments 14.1 - 14.3 present the percentage of participants that asked for each service.
- Attachments 15.1 - 15.3 present the percentage of participants that say they used the service.
- Attachment 16.1 - 16.3 present the median number of times participants reported using each service in the past year.

- Attachment 17.1 - 17.3 present the average satisfaction score that participants reported for each service.
- Attachment 18.1 - 18.3 present the average access score that participants reported for each service.
- Attachment 19.1 - 19.3 present the average anticipated need score that participants reported for each service.

How to Read the Attached Tables

The first column in each table presents the values for the total weighted sample. That is, the respondent groups oversampled, such as women and heterosexuals, have been weighted back to their estimated size in the populations. Each table is presented in descending order by the total weighted sample.

In reading the table, the percentages across the different target groups can be compared. For example, in Attachment 11.1, under the column representing MSM African American, 57.6% said they ranked primary health care as one of the services they need the most. This is in contrast to over 74.5% of MSM Anglo participants.

In these tables, subpopulations can be compared by reading the table percentages across the rows. Group totals, such as MSM, IDU, or heterosexual can be used to compare across the different risk categories, ethnicities, or gender. Ethnic/racial differences can be compared within risk categories.

A second way to read Attachment 11.1 is to compare the different services by reading down the column. For example, 72 % of Hispanic heterosexual respondents reported that primary medical care was among their most important services, in contrast to 44% of Hispanic heterosexuals who felt that drug reimbursement was among their most important services.

Presentation of Graphs and Charts

Throughout the report the data in the Attachments are highlighted using bar graphs and pie charts. Not all the figures in the Attachments are graphed. Consequently, the Attachments have much detailed data for subgroups that are not discussed in the text, and the Attachments can be referred to for in-depth information.

Inclusion of Qualitative Information

In addition to the quantitative survey results, comments from the focus group discussions are incorporated into the text. They add insight into the numbers, and often highlight issues that are not apparent in the overall quantitative figures.

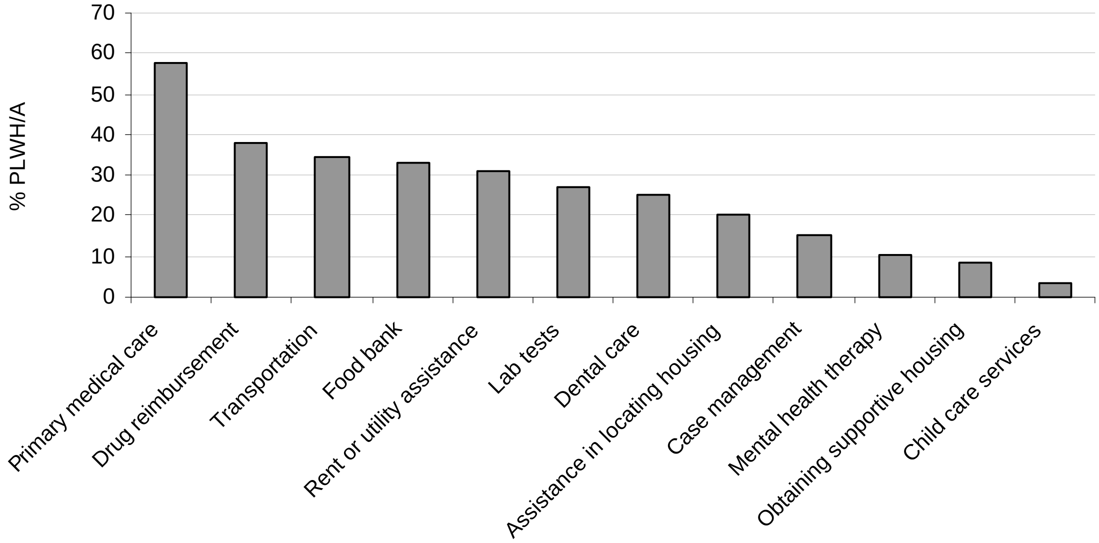
In reading these remarks it is important to remember that the statistical evidence shows a high level of satisfaction with and access to the system of care. There are many instances where PLWH/A have used the system very successfully. For example, P31, an Anglo IDU male, said, *"I've got my glasses through [the vision center of a HIV/AIDS specialty medical care provider], I got my teeth done at (an adult dental center of a HIV/AIDS CBO), I'm getting my insurance paid through the [HIV/AIDS drug reimbursement program], and my case manager with [an ASO that provides support services). I got a real good case manager. I'm being seen at [an outpatient care ASO] for medical care, I guess that's Harris County."* P120, an Anglo rural male, said, *"The first services were about the disease and medication, and how they affected me. I got what I needed and was very satisfied with it."*

For the most part focus group comments tend to highlight the negative aspects of services and barriers. In part, this is the nature of group discussions when the subject is HIV/AIDS services and barriers. Focus group moderators probed respondents for needs and barriers. The coders of the comments tended to look for needs and barriers rather than highlight positive remarks. In reading the focus group comments, they highlight issues that are of concern, but they should not be read as representative of everyone's view -- they are not "generalizable" to all PLWH/A.

Most Needed Services

Participants of the survey were asked to list the four services that “you need the most”. "Top needs" refer to the top four services ranked most important by PLWH/A. Based on this analysis, the rankings of the ten most important services are shown in Attachments 12.1-12.3 and graphically in Figure 9-1.

Figure 9-1 Top 10 Service Needs



Medical Services

For all populations, outpatient care was the greatest need, with medical reimbursement coming in second. Notably, lab tests have an overall rating of sixth, which indicates that for many, seeing a doctor for some symptom or problem is perceived to be of greater need than monitoring the HIV infection through lab tests.

Outpatient Care & Lab Tests FG Comments

Throughout the focus groups the need for outpatient care was evident. A female Anglo IDU, P32's comment represents a pro active PLWH/A. She said, *"I first went to [a university affiliated healthcare center] in Galveston, then to [an outpatient care ASO], then back to [the university affiliated healthcare center]. Now I have 2 private doctors. My first concern was medical treatment."* P64, a female Hispanic, simply stated, *"I need a physician to be there at all times when I get sick."* P60, a male in an open session, said, *"If you are sick, you should be able to see a doctor that day. [You] should not have to wait all day long to see a doctor or get your medications."*

The PLWH/A who are more educated and more familiar with the care system were more likely to seek lab services that monitor the disease. For example, P51, an Anglo MSM, said, *"The first thing I wanted to do was to find out "how far it had gone", so I went to the clinic for blood tests and then started therapy."* P124, an Anglo female living in a rural area, said, *"I needed to check my viral loads and CD cell 4 counts. And to see how progressive it was. And to get my medication..."*

Drug Reimbursement FG Comments

The second most important service tended to be drug reimbursement. As noted by P102, the father of an HIV positive infant, outpatient care and drug reimbursement are part of the same process. He said, *"Being an AIDS patient myself, I knew the first thing to do was to get him on treatment, get some medication in the boy*." And P120 noted, "*First thought was I needed medication, then knowledge and information about medication and the virus itself. I got it and was very satisfied."*

Based on the survey and focus group comments, knowledge and utilization of medication was very high. One male in an open session said, *"I get my HIV meds through [a drug reimbursement program funded by the State of Texas], which is an excellent program. [An ASO] hooked me up with it. They pay for my HIV drugs, and that cuts the cost down for me... You have to call in prescriptions and in so many days you have to pick them up. If you don't follow the policy so many times, they will cut you off*." P24, an IDU Anglo male, is typical. He said, *"The one thing I'd like to mention about [the outpatient care ASO] is the state assistance and HIV meds. They pay for the expensive meds."*

However, not all medications are covered and, PLWH/A often use different insurance and medication coverage to obtain their medication. P28, an African American female IDU, said, *"Medicare they allow 3 prescriptions a month. My pills are about 14 a day and each of them are about $100 a month apiece and they only pay for 3. I was told the only way I could get the unlimited is if I signed over my Medicaid and Medicare to an HMO."*

The care system has made strides toward making medication easier to obtain. The medication program at an outpatient case ASO coordinates the client's different reimbursement sources. P87, a male from an open group, recalled, *"For a long time there, a lot of us were having problems with getting medications because you were basically allowed three prescriptions, no matter where it was at. However, [the outpatient care ASO] was allowing you to have more prescriptions. I do not know where to get the money."*

Almost universally, those focus group participants who were in jail commented on their poor access to medication. While medication may be available, there is a perception it is not. As P135, a male in prison, said, "*Services I had before prison have been cut off... Meds – I paid for all of them, nothing was free. Refills and getting to see the doctor – that's a problem. I have not received my prescription for the pill for that takes care of diarrhea – and I won't take my HIV medication that causes diarrhea until I get the other pill. I have sent in a request 3 times, no response."*

Medication is available to undocumented, but it is not anonymous, and that poses a problem. As P126, a male Hispanic undocumented, noted, *"Since many of us that are here are not legal, I believe that aid for payment of medication [should be available] whether you are legal or not. I think that if they take away the assistance of Medicare or Medicaid or Goldcard that it is going to be very bad... You don't need to be legal to have a Goldcard, but you do need an ID, and just recently in Texas you could get an ID but now you can't if you are illegal."*

There were some instances where those seeking medication had some problem with service providers. For example, P9, an African American male adolescent said, "*I know about them (medical treatments), but I haven't taken any... they say they were getting ready to send me to the doctor... I had to go up there two times, so I thought that they were going to do that. I didn't know I was supposed to go up there and get the gold card. She didn't tell me that so I didn't know… I would have been started on the medicine, but I didn't know that, he didn't tell me."*

While very important, as discussed below, medication ranked behind food and transportation particularly for many African Americans.

Transportation

Reflecting a need to get to services, transportation was ranked third overall, but the need varied by risk group and ethnicity as discussed below.

<u>Transportation FG Comments</u>

A majority of the focus group participants were aware of the transportation service that are or were being offered by The Life Center, American Red Cross, Alternate Resources, United Cab, and Metro bus lines. P27, a female IDU, said, *"The only thing that is going pretty good is transportation… If I call I can get transportation."* P34, an IDU male said, *"I use transportation from [three different providers] It is essential because we are located far out. Of course we use [public transportation], and that is pretty efficient. [An ASO transportation* *provider] on the scale of 1 to 10, it's a 7. It seems like they are overbooked or overworked. They probably could use some more drivers. But when they do come, the service is great."* P110, a fifty-five year old male from Fort Bend, said, "*As far as transportation, I haven't had any problems with the [ASO transportation provider]. Sometimes you have to wait a little bit, but I guess that goes with it.*"

Many other PLWH/A had problems with the transportation system. There was a feeling that there were not enough options. P116, an African American heterosexual woman, felt that there was a "*need [for] more than one organization for transportation–everything's focused on [one transportation provider]. [The ASO transportation provider] has all the money for transportation and they're not fair."* Because transportation was categorized as both a service and potential barrier these will be discussed in the barrier section of this report.

Basic Services - Food, Rent and Utilities, and Housing

Food bank and rent and utility assistance ranked third and fourth in importance, and assistance locating housing ranked eighth overall. These top ranked services that provide basic needs indicate the growing numbers of PLWH/A who are living longer, but are in or near poverty and qualify for disability. For these individuals, SSI or other supplementary benefits were reported not to cover the basic needs of food or housing.

Food Bank FG Comments

Several participants noted a need for food. P104, an African American male with a 15-month-old child with HIV stated, "*A place to obtain food is important since I don't receive food stamps.*" And P123, a rural Anglo male, said, "*I use the food bank and I have had some assistance with my rent and utilities. Food bank is the most important one for me.*"

While participants were knowledgeable about food bank provider(s), comments regarding the quality of service from the food banks varied. P68, a thirty-year-old female, said, "*You really have to be careful because the food is not like what you get at the groceries. A lot of time when you get that food, it's old. Just for your own personal health and safety, you need to check everything before you put it in your cabinet.*" Regarding a different and very popular food pantry from a large provider, P62, a thirty-five year old male, said, "*My major concern about (them) is that it is not enough of the right foods that we eat (such as) fresh vegetables. A lot is damaged goods (such as) bad meat.*" P39, an African American MSM in his thirties, said about the same provider, "*I think they do a really good job with what they have…but all the burden of supplying us with food is on them and if you're not there early, when they open, when you get to shop, there's going to be a lot of things not there. They need more pantries.*" While P46, an Anglo MSM in his forties, countered about this provider as "*really the best in the city. It's a good service.*"

Rent and Utility Assistance FG Comments

Most focus group participants were aware of rent and utility assistance, but it is difficult for many to understand. For example, P36, an African American MSM, has talked to three ASO's and has received help from each agency once. He said, though, *"I just don't understand the system."* P72 a female from an open session noted, *"[One provider] is now a mess. [A new provider], they are getting ready to open up theirs. I went to [the ASO], and there wasn't no problem.*" There is a perception that emergency assistance is somewhat arbitrary. P46, an Anglo male MSM said, *"In order to access rent/utility assistance, you have to be in the right place at the right time."*

Also two different rural Anglo males complained that some things are not covered by utility assistance that should be. One said, "*There is utility assistance but septic tanks are not specifically addressed because people in the city wrote them [the grants] and they don't use septic tanks, and they say they can't do it"*

Locating Housing FG Comments

Locating housing is the eighth ranked need. Many of the focus group participants lived in some kind of state supported housing, and many found them adequate. P13 an African American male said, *"I live in an AIDS transitional house.... I found through the Blue Book, it's beautiful. I live in a 7 bedroom house with 3 people. All I need now is food."* P16, a heterosexual female, said, a big need is *"housing, especially if you've got kids."* P45, an Anglo MSM, concurred. He said, *"I don't care what they say officially, when they found out, if they find out you are HIV positive, there are a lot of apartment complexes that find some way to discriminate against you there. What I'm hoping to find, and I don't think it exists in Houston, is an actual apartment. I have a 15-year-old son who comes to stay with me."* P41, a heterosexual African American male, noted that you have to be homeless to get help in locating independent housing. He said, *"Right now, I'm living in independent housing, but I had to go through a whole lot of red tape. I had to go through a homeless shelter just to get in there."*

P66, an African American male observed that, *"Permanent housing is a problem. There is a lot of transitional housing. No long-term."* Later in the report evidence is shown that housing is more important among IDUs and heterosexuals. Still, several MSM in the focus groups said they could not find independent housing. P39, an African American MSM, said, "*Talking about housing it is so limited…because our incomes are fixed…for independent living, most apartments want you to make at least twice what the rent is…we have no one looking out for us…"*

Dental care

Dental care is ranked as the 7th most important, and it is a valued service among PLWH/A who find that their existing income levels limit their ability to find dental services elsewhere. It clearly adds to overall health and quality of life of PLWH/A. As discussed below, its ranking varies by risk group and ethnicity.

Dental Care FG Comments

P55, a female in an open session noted, *"[The dental services of an ASO] is good at getting dental assistance, because before I was positive, I could not get dental services."* Most participants rated the quality of dental services as high, but, as noted below in barriers, the wait and eligibility for dental services was seen by many PLWH/A as a barrier.

Typically P12, an African American male said, *"At [the dental services of an ASO] you get your dental. I like their services, they don't fool around. They take care of you and do a good job of it."* This particular ASO is open to all PLWH/A. As P129, a Hispanic undocumented female noted, *"I have dental assistance and am very happy with it. [An Hispanic CBO] referred me to dental and optometry clinics where I receive great care. I go to [an ASO] for dental."*

P23, an African American female, noted, *"I went for dental care services at [an ASO] and they made me some good teeth."* She noted, however, "*[They] did tell me they could take me on an emergency basis, then when I got there, I had to bring back paperwork, doctor's letter, etc."*

There were a few focus group participants that had complaints. P19 and heterosexual Anglo Male said, *"It took me 5 months to get that done [cavities filled]. Man I mean, I'm talking pain. [Censored], what are we guinea pigs or something?"* P39, an African American male, said, *"The service at [the ASO] is 'the worst'."* It is unclear whether he is referring to the actual service or the wait.

Case Management

Case management usually has an overall rank of ninth, and is usually ranked 8th, 9th or 10th by the different populations. As indicated by the Uniform Reporting System, the overall demand for case management is decreasing. However, most PLWH/A see it as an important need.

Case Management FG Comments

With improved health, some PLWH/A have a reduced need for case management. For example, P69 a female who participated in an open session said, *"I had some great case managers. Now, I'd rather do it myself. If you need something fast, then go to [the a large ASO]. It's very frustrating to have a case manager that is never there. You keep getting their voice mail. They make themselves nearly impossible to obtain or get on the phone."* P18, and adolescent male said, *"My case manager's, she's all right. We hardly talk, though, because I don't need nothing."* P16, a heterosexual African American female, commented on how she does not need a case manager. "*I can talk for myself. I have an education and basically I can talk for myself. I've had the worst people for case managers. They haven't done nothing so far.*" P60, a sixty-year-old male, simply states, "*Quality of case managers depends on their case loads.*"

Many PLWH/A in the focus groups felt very strong about their need for a case manager. P130, an undocumented Hispanic male, said, "*They asked me if I needed a case manager and I said yes because I don't read much so I don't have sufficient information. They told me that a case* *manager is for people that recently have found out and need the help, it is not long term. So I'm without a case manager, though I think I need one. Like for getting things like the Goldcard, sometimes you don't have the time to get everything you need and it helps to have a case manager to assist in cases like those.*"

P88, a male PLWH/A, said, "*The most important service for me is my case manager. I applied and receive long-term disability and Social Security. Since June '96, I haven't used that many services. But for the 6 months period when I was in flux, my case manager was extremely helpful to me. He was able to send me to different organizations for services that I needed for that particular time.*" P27, a lesbian African American IDU, said, "*When I was first dealing with (providers on my own), I could never do anything. You know, dealing with furniture, finding a place to stay, I was always getting the run around. When my caseworker gets on it, something comes through. They gave me the Blue Book and me personally calling someone in the blue book is like not calling at all. It looks like when I signed up to be a part of this organization, it seems like I should be able to talk for myself.*"

All participants in the pediatric focus group stated that case management is the most important service they receive. P101, a male PLWH/A, offered his opinion on why and when case management is necessary. "*When I first started out, I thought I could to this on my own. I don't need a case manager. I quickly learned that everyone should have one to get started because it cuts down on the red tape and frustration… I've been connected with a very good caseworker. I feel very confident that I'm getting the help that I need now. I referred my friend to my case manager. It just depends who you get. You have to stay on top of them and stress your needs.*"

Because several services are accessed through case managers, a number of focus group participants felt that case management was, in the words of P101, a male from an open session, *"a necessary evil"*. He clarified his feeling; *"I feel that the case manager should tell you what they can do for you instead of asking you. There are some things you know, but you are not knowledgeable of everything. They should know."* P119, a rural male, said, *"Your services are pivotal around who your case worker is... I've been screwed across the board by case workers since I've been here, I've been here for 4 years."*

One issue with case managers that is highlighted by the focus groups is the frequent change in staff. P122, a Hispanic female, noted, *"I've used case managers before, but they keep getting fired on me. I get what I need every once in a while, but they give me a hard time some times. I haven't had one in over a year and a half."* P130, a male undocumented, said, *"I don't have a case manager because the one I had left and I was put on a waiting list for one and they never called. They said that I shouldn't need a case manager because I should already know the places I need to go. So then I never got a new one."*

Several focus group participants pointed out that they felt the motivations of the case managers were suspect. They said, that they were really into it just for the money. For example, P16, and female heterosexual said, *"They need to hire case managers that are for people that are HIV, that are supportive of us being HIV. A lot of case managers are there for the money, they're in it for all the wrong reasons"*

Mental Health

Mental health therapy is not consistently among the top 10 service needs for all populations, but it is considered essential by many of the focus group participants.

Mental Health Services FG Comments

Several participants reported that when they first found out they were HIV positive the needed counseling. P14, an African American female, shows how well the system can work. She said, *"I went into a mental breakdown. I shut down, I didn't talk to anybody…I ended up going to [the outpatient psychiatric division of an ASO], they have a lot of facilities, and one of them is psychiatry... I'm just getting to the point now that I'm okay but that's through group meetings, talking to the psychiatrist. Everything's at [that ASO], whatever you need, it's there. It really wasn't my choice [to go to the psychiatrist]. It was my doctor, they had a patient advocate… My doctor said 'she has to go', because she knew I went into immediate depression. I'm just recently getting to a point where I'm okay."*

P99, a male from an open session, said, *"Initially I went through some counseling and dealt with everything... I used the [mental health division of an ASO] for counseling."* Others noted they went to other providers. P16, a heterosexual woman, identified mental health services among her top needs. She said, *"I need ... more support groups, one-on-one counseling. I have that, I have a licensed therapist that comes from [an ASO]."*

For those seeking mental health services they can find them. P149, a male Hispanic heterosexual, said, *" I receive medical treatment and psychiatric help at [the outpatient psychiatric division of an ASO]. I'm also receiving psychiatric counseling at [mental health division of an ASO]. I'm also involved with the [program of another ASO]. It is a group that takes a 100 hour course on all the services and organization here in Houston."*

An adolescent, P10, indicates her and her family's need for counseling. She said, *"I need my family to understand where I'm coming from because I've been pushing them away because I can't sit down and explain what's wrong with me and how I feel and you know my mom is like…she don't know if she can sit on the toilet behind me and [censored] it's so hard for me. I want to go up and hug her but then…that's the only thing I really need, I need for me and my family to get together."*

P133, an African American male in prison, has similar problems. *"My wife is good to my two boys (6 and 9). My kids know I'm sick, my wife told them. But it's hard for me, I don't know what to tell them. I need counseling to help them deal with that."*

Women in the focus group session asked for more women's groups. P100 said, *"I think we need more counseling for women. We don't have a lot of women HIV positive group. I was in [a hospital] and the doctor told me about some support groups."*

Some PLWH/A reported that the mental health services were not meeting their needs. For example, P87, a male from an open session, reported, *"I need more psychology, psychiatry. I go to [the outpatient psychiatric division of an ASO] and see a psychiatrist for maybe 10 minutes. It's how are you, having any problems, here's your medication, get the hell out the door... I tried the [mental health division of an ASO], I blew up, and walked out the door."*

Rural participants indicated that finding groups in their area was difficult. P102, an Anglo male from a rural area, said, *"The medical treatments are fine, but need more peer counseling and support groups. Where I live, Pasadena, it's tough."*

One bipolar PLWH/A reported a negative experience with the mental health system. P70, a male who attended the open session, said, *"I got dumped by [an ASO that provides support services] because of dual diagnosis. Because I'm bipolar and they're not equipped to handle that. Now, I'm with [AIDS community based case management team] and it does nothing. I have a case manager, I haven't heard from her in a month. I still have to do everything. You have to jump through a lot of hoops."*

Childcare

The service with the greatest variance between the different subpopulations is childcare, which is ranked among the top 10 most important services for heterosexuals and women, but not for other populations.

Many PLWH/A that were interviewed were knowledgeable and thankful for the childcare that is available. P14, a heterosexual female, noted, *"[A large ASO] just started child care for when you go to your appointments, and they have an area specific for your kids, and they watch your kids for you."* P14 added, *"My children are in school but where as if I have an appointment, they can go to a facility after school…so I don't have to make my appointments (scheduled around picking them up from school)."*

Some PLWH/A with children, like P144, a recently incarcerated female, has *"heard nothing about childcare"*. Another woman with children finds childcare is unavailable. P104 said, *"At this time, childcare is important and I'm not getting it."*

Most Needed Services by Risk Group

Figure 9-2 shows the top ten needed services for the total population and for each of the risk groups. The total is shown as a line in the chart, while the different risk groups are shown as bars. There are twelve items shown because obtaining supportive housing and child care was not in the top ten for the total population of PLWH/A, but supportive housing was in the top 10 for IDUs, and "child care services" was in the top ten needs for heterosexuals.

When interpreting these bar graphs, keep in mind that these are relative rankings, and a higher ranking by one population suggests a relative need with other services, not the absolute absence of need. Because one service is ranked lower by the overall population, it does not suggest that there it is a very important need by a special subpopulation or individual.

As seen in Figure 9-2, transportation, assistance locating housing, and childcare are greater needs among IDUs and heterosexuals than MSM. Food bank and obtaining supportive housing are reported to be of greater need for IDUs than other risk groups, and childcare is a greater need among heterosexuals. Lab tests are ranked significantly higher by MSM than other risk groups.

Figure 9-3 compares the top ten needed services for the different ethnic populations. African Americans tended to rate transportation and assistance locating housing significantly higher than other ethnic subpopulations. Food bank services were ranked higher by African Americans and Hispanics, and African Americans rated both transportation and food bank higher than drug reimbursement. Hispanics are more likely to rank drug reimbursement as a higher need than other ethnic subpopulations and Anglos and Hispanics were more likely to report needing lab tests more than African Americans. Anglos are more likely to report needing dental care.

As noted above, these are relative rankings, and a higher ranking by one population suggests a relative need with other services, not the absolute absence of need. For example, supportive housing is ranked as a top 10 need by African Americans, but not other ethnic subpopulations who tend to rank mental health services higher. This does not suggest that African Americans need less mental health services overall, but it does suggest that they perceive supportive housing to be a higher priority for them.

Figure 9-4 compares the top 10 service needs for men and women. Women ranked their need for transportation, assistance locating housing, and childcare higher than men. African American and Hispanic heterosexual women are much more likely to say they need assistance than Anglo women. For transportation, the reported need among Anglo and African American women is higher than among Hispanic women.

Figure 9-5 compares the top ten service needs for rural and urban PLWH/A. Rural PLWH/A indicate a slightly lower need for out-patient care and food bank, but show a higher need than urban PLWH/A for transportation, drug reimbursement, and rent and utility assistance.

Figure 9-6 compares the top 10 service needs for people living with AIDS and people living with HIV. Overall the pattern is the same as for all PLWH/A. Interestingly, PLWH reported a greater need for outpatient care. PLWA reported a greater need for transportation.

Figure 9-7 shows the top 10 services needs for those who have recently been in prison and those who are in prison. Those recently incarcerated have similar needs to others such as outpatient care, drug reimbursement, transportation, food bank, and utility assistance. The general pattern differs from all PLWH/A, with case management and assistance locating housing being higher than average for both populations. Both the recently released and those in prison reported a higher than average need for finding independent and supportive housing. The in prison subpopulation report a much higher than average need for case management and lab tests. Not surprisingly, both populations perceive a greater than average need for legal services.

Figure 9-8 compares the top 10 needs of parents of HIV positive children and PLWH/A who have children who may be positive or negative. Caution should be taken in interpreting the figures for families with HIV positive children, as the sample size is only 16. As seen in Figure 9-8, their top needs are for outpatient care, drug reimbursement, and transportation. They have the same ranking as the total population, but all drug reimbursement and transportation are higher than average for families with HIV positive children and transportation is higher than average PLWH/A with children. While child care is not their top need, as expected for both groups it is among the top 10 needs and it is higher than average. Assistance in locating housing is a higher than average need for PLWH/A with children.

Figure 9-9 shows the top 10 needs for the undocumented. Due to an unrepresentative sample and relatively small sample size of 31, caution should be taken when interpreting the figures. The figure indicates that the undocumented have generally the same pattern of top needs as the total population. They are slightly higher for outpatient care and drug reimbursement. They tend to have the same or lower rankings than the general population for their other top needs.

Figure 9-2 Top 10 Service Needs - Total Sample Compared to Risk Groups

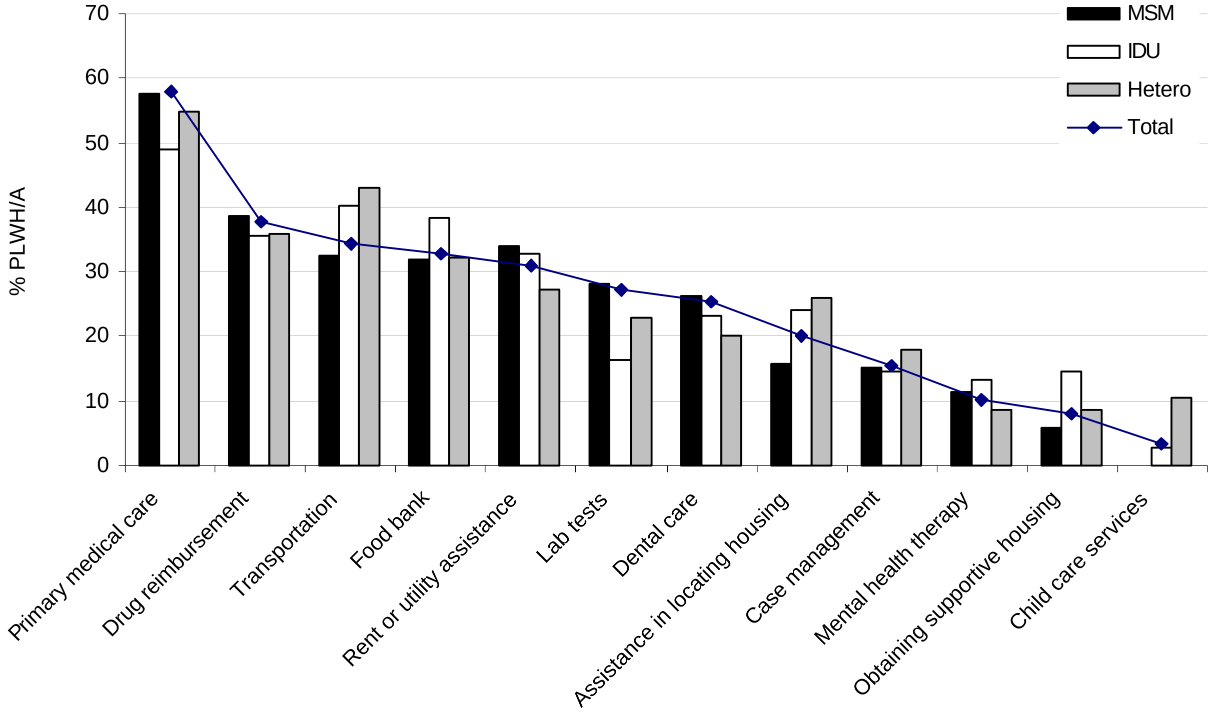


Figure 9-3 Top 10 Service Needs by Ethnicity

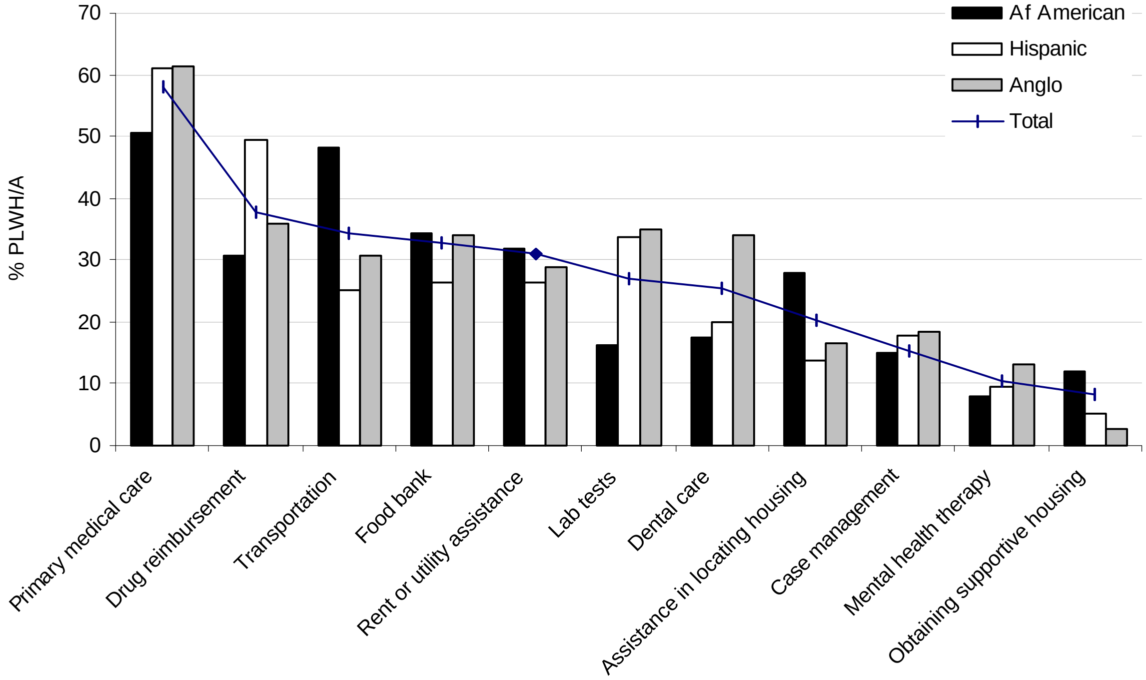


Figure 9-4 Top 10 Service Needs by Sex

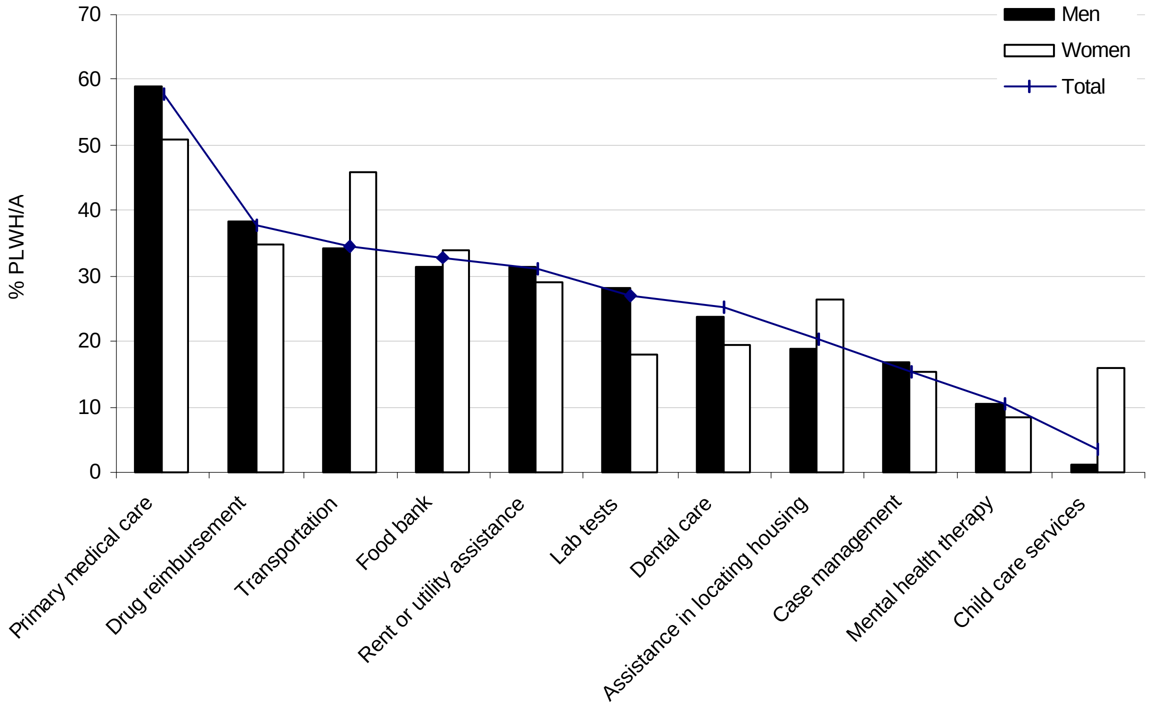


Figure 9-5 Top 10 Service Needs by Urban/Rural

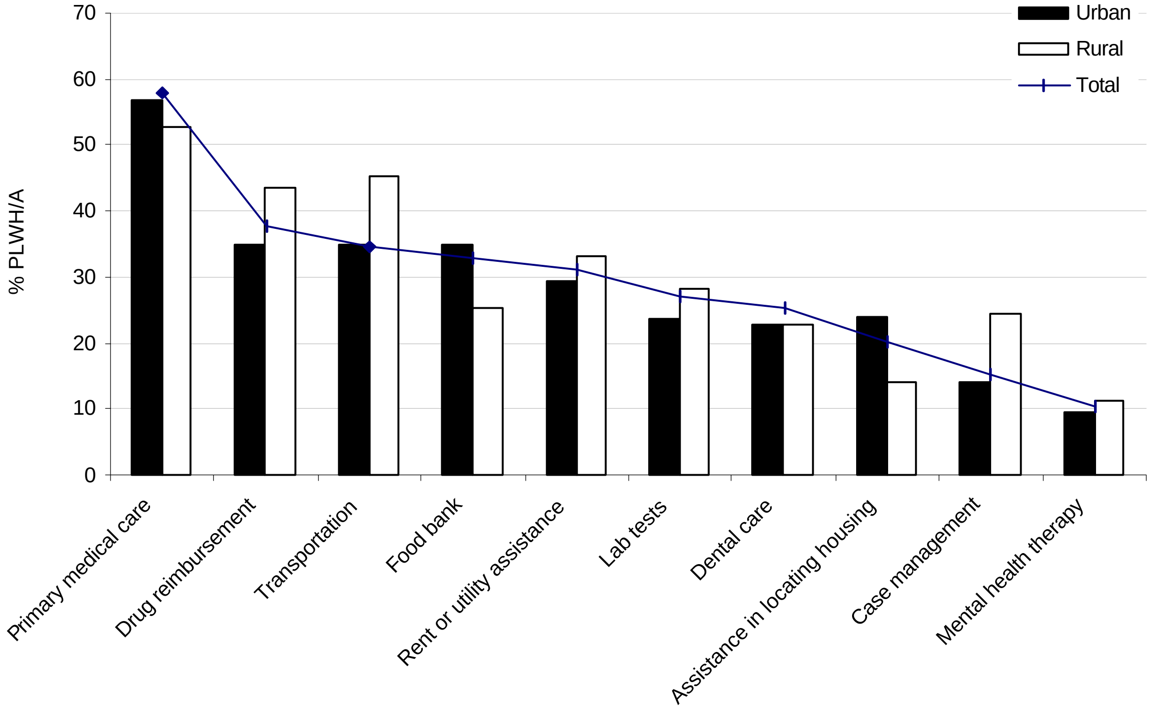


Figure 9-6 Top 10 Needs by Disease Progression

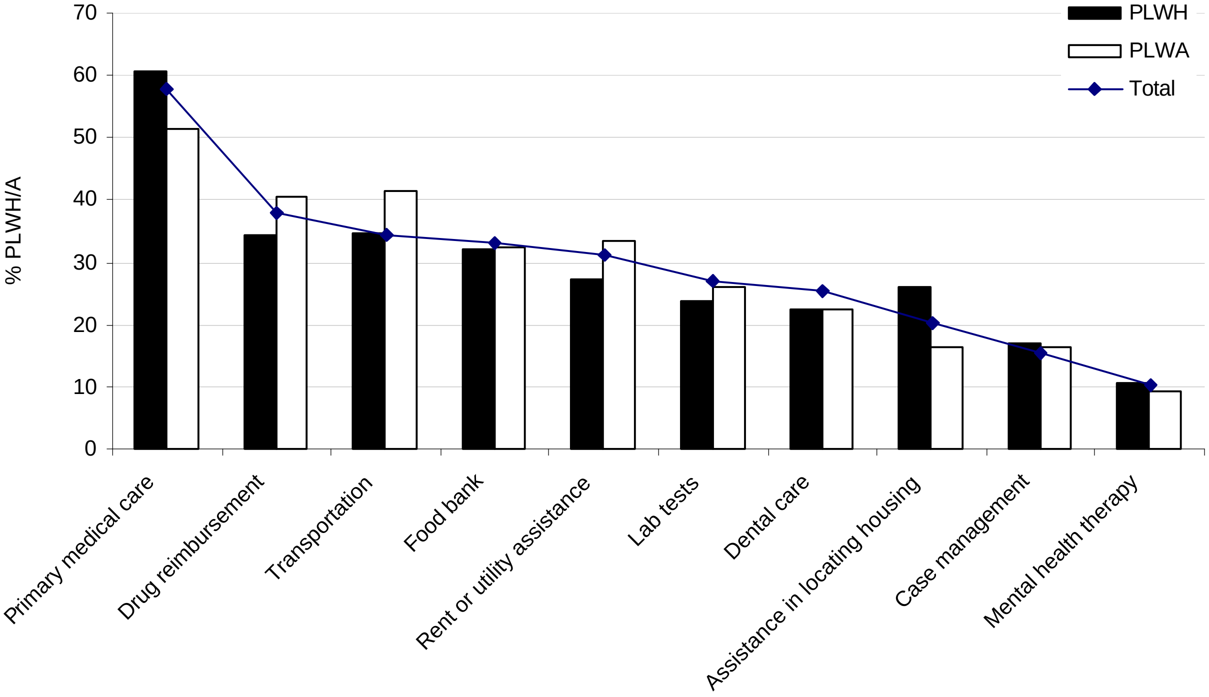


Figure 9-7 Top 10 Needs by Prison Status

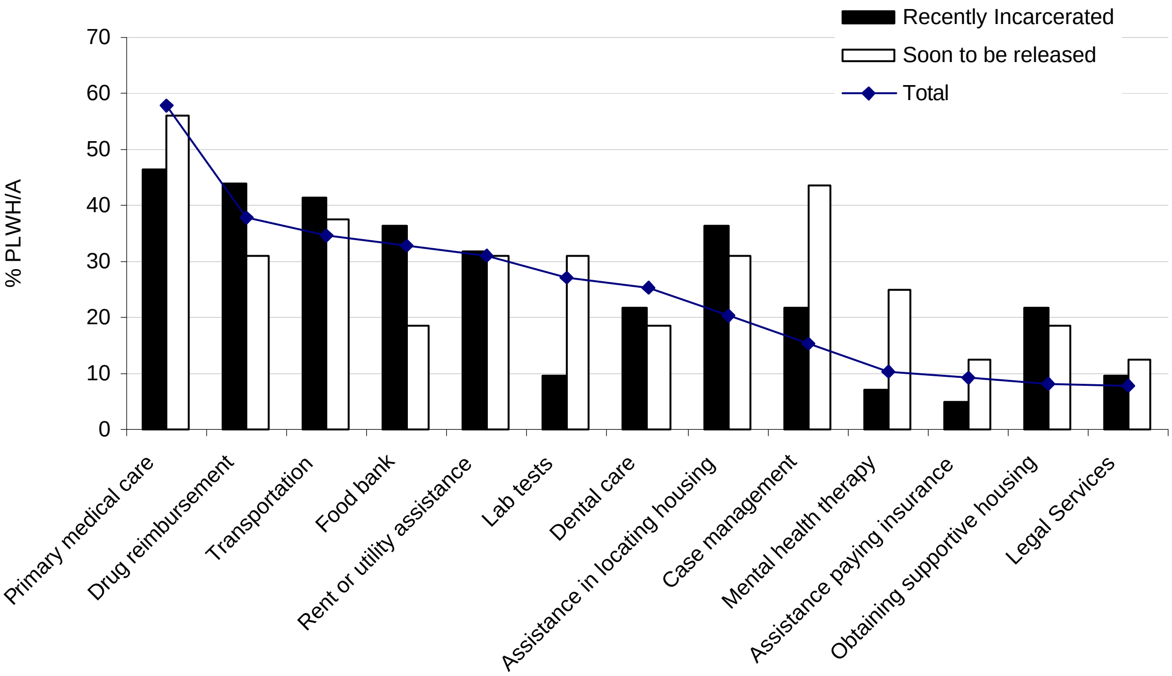


Figure 9-8 Top 10 Needs for Families w/ HIV+ Children and PLWH/A with Children

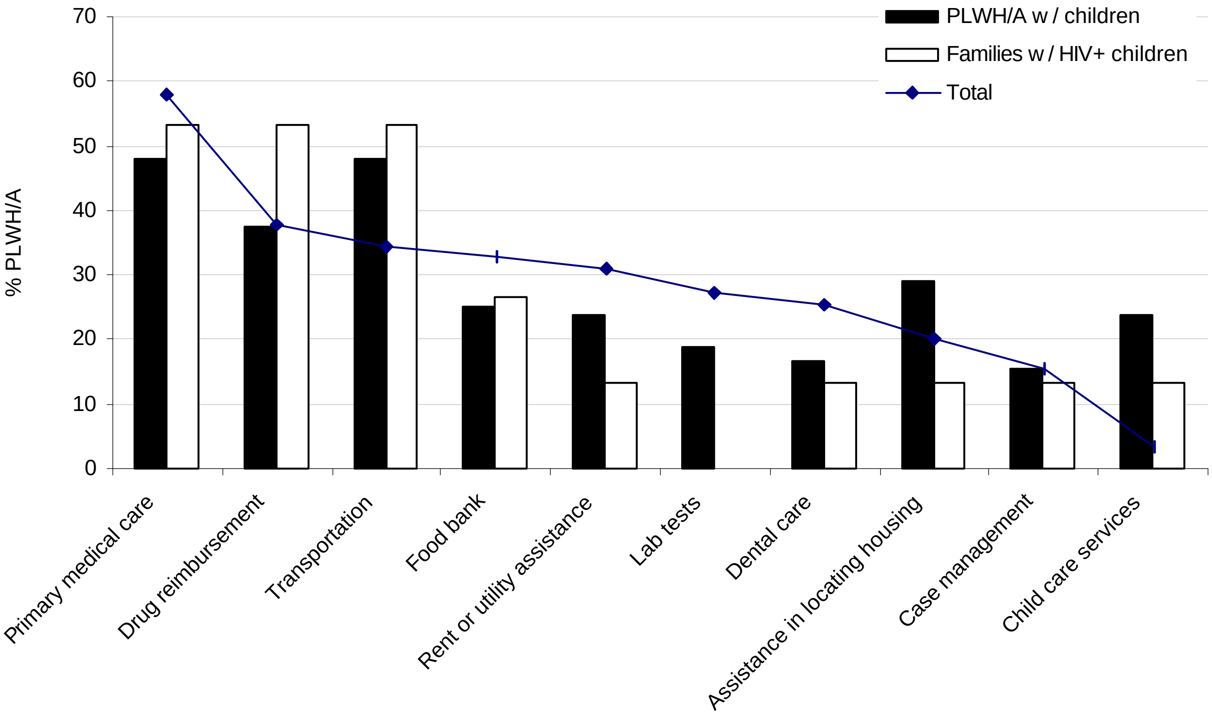
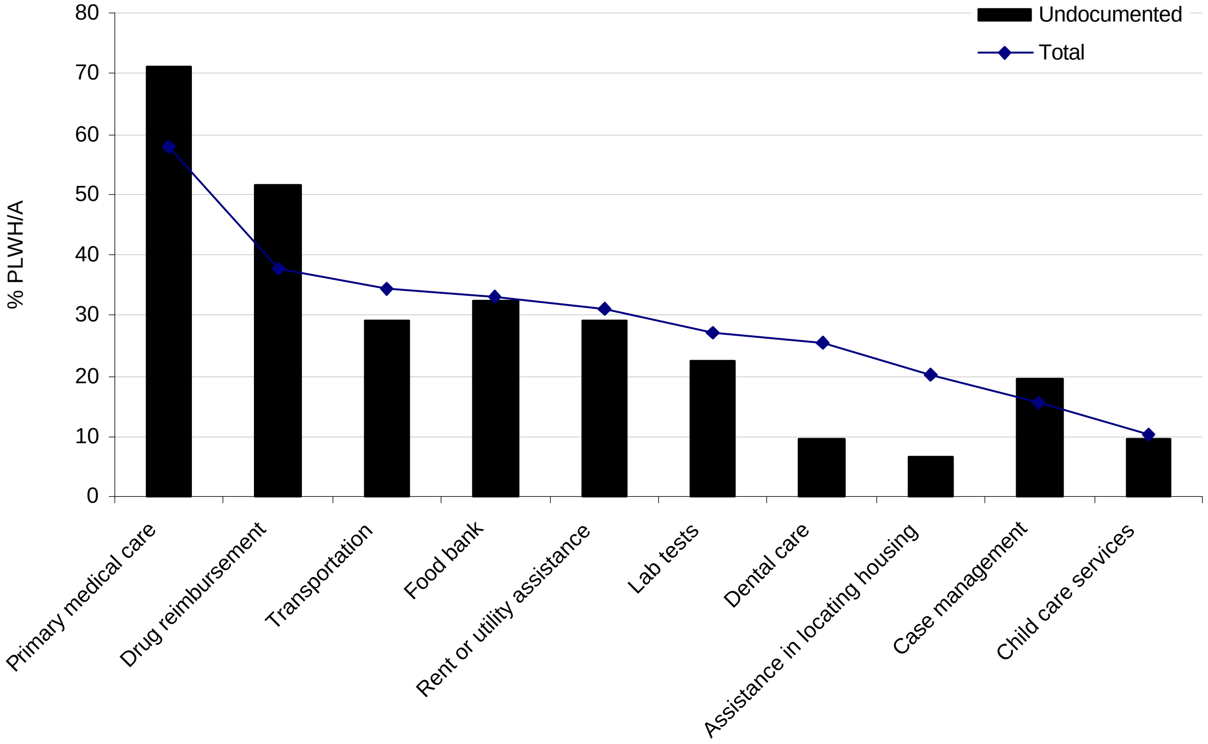


Figure 9-9 Top 10 Needs of Undocumented



Summary of Top Needs

Table 9-1 provides a summary for risk groups, ethnic subpopulations, rural, women, and recently released populations. The number in the cell is the rank order. A "+" beside the number means that the score is greater than the average score.

Table 9-1 Top Needs, Rank Order

	Tot	MSM	IDU	Het	Af Am	Hisp	Anglo	Rural	PLWA	Women	Rec Rel
Primary Medical Care	1	1	1	1	1	1+	1+	1	1	1	1
Drug reimbursement	2	2	4	3	5	2+	2	3+	3	3	2+
Transportation	3	4	2+	2+	2+	6	6	2+	2	2+	3+
Food bank	4	5	3+	4	3+	4	4+	6	5	4+	4
Rent or utility assistance	5	3+	5+	5	4	5	7	4+	4	5	6+
Lab tests	6	6	8	7	8	3+	3+	5+	6	8	10+
Dental care	7	7	7	8	7	7	5+	8	7	7	7
Assistance in locating housing	8	8	6+	6+	6+	9	9	9	9	6+	5
Case management	9	9	9	9+	9	8+	8+	7	8	10	8+
Mental health therapy	10	10	11+	12	12	10	10+	10	10	11	13
Obtaining supportive housing	12	16	10+	11	10+	15	20	15	17	14	9
Child care services	20	32	21	10	11	19	27	19	16	9+	14

The overall messages are:

All populations say that primary medical care is their top need, and drug reimbursement, transportation, food back and rent or utility assistance is in the top five for all populations.

- MSM reported an above average need for rent and utility assistance.
- IDUs reported high and above average need for transportation and food bank services. They also indicate an above average need for rent and utility assistance, assistance locating housing, mental health therapy and assistance obtaining supportive housing.
- Heterosexuals have a high and above average need for transportation. They reported an average need for assistance in locating housing and case management.
- African Americans have a high and greater than average need for transportation and food bank services. They have an above average need for assistance in locating housing and assistance in obtaining supportive housing.
- Hispanics reported a high and above average need for medical services, including lab tests and drug reimbursement. They also reported above average needs for case management.
- Anglos, like Hispanics, also have a high and above average need for medical services. They also have an above average need for food bank, dental care, case management, and obtaining supportive housing.
- Rural participants reported high and greater than average needs for medical services and transportation. They reported a higher than average need for rent and utility assistance and case management.
- PLWA have a high need for medical services, and an above average need for drug reimbursement, transportation, rent and utility assistance, and case management.
- Women have high need for medical services and above average need for transportation, food bank services, and assistance in locating housing.
- Recently released have a high need for medical services and an above average need for drug reimbursement, transportation, rent and utility assistance, lab tests, and case management.

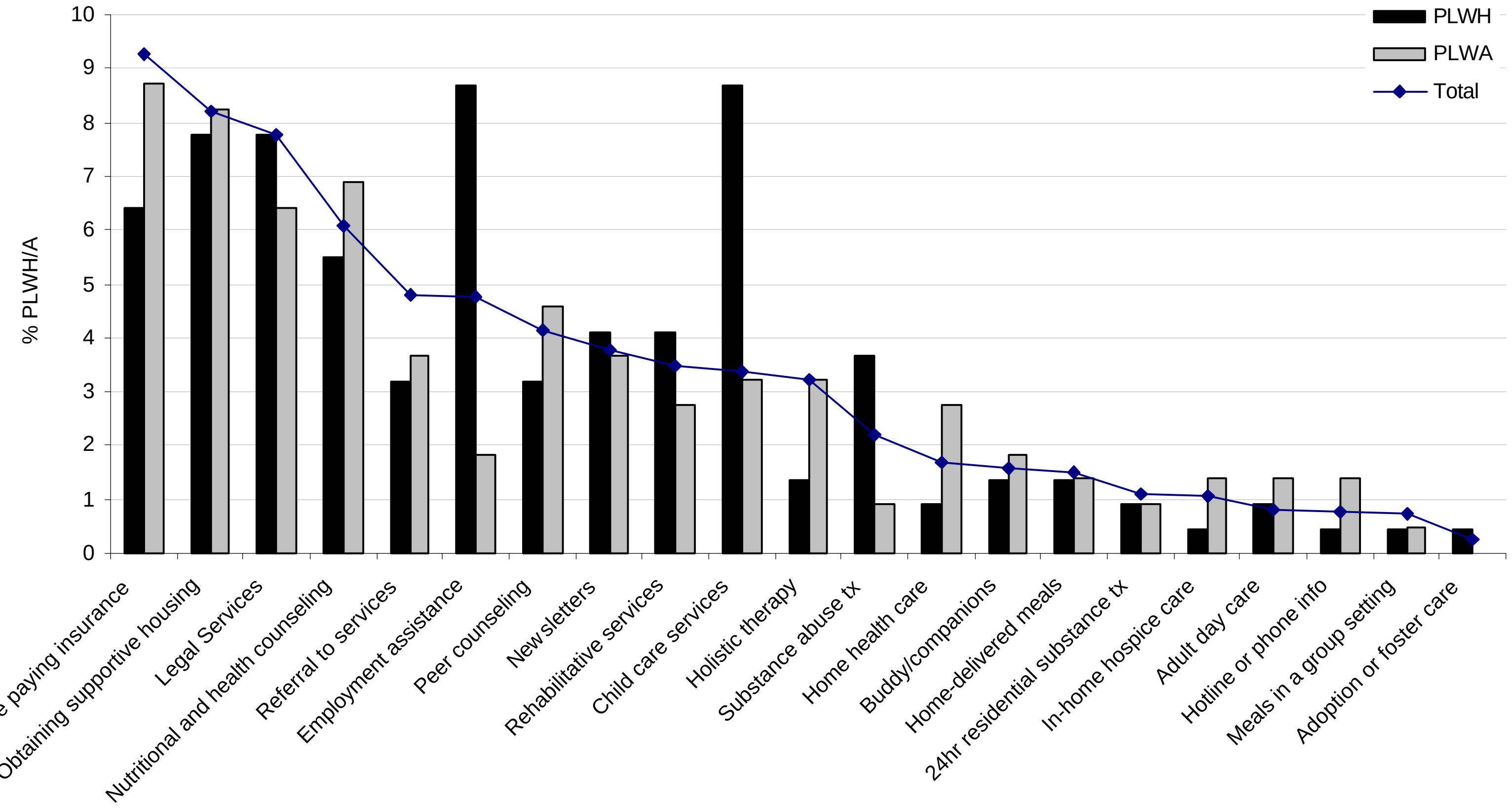
Less Needed Services

Attachments 12.1-12.3 and Figure 9-10 indicate the rank order need of the remaining 19 services for the total population. Under 10% of all PLWH/A express a top need for these services. There may be a number of reasons for a lower rank, including a true reflection that they are not as important as other services to all populations or that the service is not important to a majority of PLWH/A, but may be very important to a specific subpopulation. In this case, a lower rank does not suggest that these are unimportant services. One question for the HIV care system is whether to keep them as distinct services for PLWH/A or combine them with other services that serve people with end-stage illnesses.

For the subpopulations (see Attachment 12.3), there are some populations with greater than average needs among these lower ranking needs. These are highlighted in the bullets below:

- Anglo MSM are more likely to say they have a need for assistance paying health insurance.
- Female IDUs and heterosexual African American males are more likely than other populations to say they need assistance obtaining supportive housing.
- IDU and heterosexual males are more likely than other populations to say they need referrals to services.
- The need for employment assistance is higher among the African American MSM.
- Newsletters are in greater demand by the Hispanic population, particularly females.
- Childcare is a higher need among heterosexuals and female IDUs.
- Mental health therapy has a reported higher need among IDU Hispanics and Anglos.
- Substance abuse treatment is generally higher among African Americans and recently incarcerated.
- Food bank is stated to be a particularly high need among Anglo females.

Figure 9-10 Ranking of Lesser Needs - Total Population



Health Insurance Assistance

While less than 10% of PLWH/A say that assistance paying health insurance is among their top ranked service, a few participants in the focus groups suggested that it is an important need for leaving their jobs. P1, an Anglo male, noted, that one of the most important services he sought when he left his job was someone to help pay his health insurance premiums. P31 said, *"I've used the [an ASO's insurance assistance program] in helping me with my Cobra payments. That's working out all right."*

There may be some misperception that you need to be working to receive insurance payment assistance. P14, an African American female who left work said, *"I probably (need) the insurance premiums [but] I'm not working so with that I think you need to be working, so I really haven't done any checking into that. Basically... if I could get the Medicaid, I'm okay. Not necessarily for everything, but if nothing else for when I have to be hospitalized."*

Assistance Finding Supportive Housing

Just over 8% of the PLWH/A say that assistance in finding supportive housing and legal services are the most needed of these lesser ranked services. There is good awareness of supportive housing among the focus group participants, particularly those with some experience in drug abuse programs or for those PLWA who have been in the care system for some time. For example, P34, an Anglo male IDU, said, *"There are 8 different service providers staffed by Council and we have [two short-term housing centers] which are a level 2 transitional housing. It's a great program. We have drug therapy, chemical dependency, groups, reach out to the community for AA and CA meetings. It's a 2-year program, 3 levels. The first 90 days are residential. Level 2 is to move from there into transitional housing. Level 3 is when they'll set you up in an apartment of your choice, help with first month's rent, and will furnish it. And that comes through one of the service providers. My case manager is from [an ASO]. We have a doctor in residence in [a small hospital] which is on the staff and we also go to our different clinics "*

Legal Services

Under 8% of the PLWH/A placed legal services as their top need. In focus groups the responses were divided between those not knowing legal services existed, those satisfied with services, and those saying they needed services, primarily for housing. There were very few comments about needing wills or estate planning services.

In an open session P99, a male, is quit informed about legal services and believes avoidance and lack of awareness are the reasons that legal services are underutilized. He said, *" One recommendation that I'd make that hasn't been brought up is the legal services. I think that people are sometimes afraid to approach the legal services. We've got several good agencies. People tend to shy away from planning for the future and thinking of things, like wills. Even if you don't really own anything or whatever, still, for your medical needs, you need to have this paperwork in order. I've talked to a lot of people who are afraid to get their papers in order.*

Like a will or instructions to the physicians. These agencies are great, they're helpful, and I think they are underutilized. People need to be taught to go to them and get this in order because when you're really sick and don't want to deal with, it's better to have it out of the way."

Several persons in the focus groups said they did not know about legal services. P18, an Anglo heterosexual male, was looking for assistance regarding discrimination in the workplace. He said, *"If I thought there was a legal service that I felt was open to me, or willing to help me, I would have gone there already."* P52, an Anglo MSM, said, *"I've had the worst time finding an attorney. I called quite a few places [especially an ASO that specializes in legal issues] and some other places too and I got no help out of anybody."*

Several other focus group participants were aware and utilized legal assistance and their level of satisfaction varied. P82, a male in an open session said, *"Legal services- I'm dealing with [a minority legal firm that assists PLWH/A]. They are good for what I'm seeing them for."* P23, an African American women IDU, said, *"I have used [a volunteer lawyer organization] and they were very helpful."* P24, another African American women, added, *"I have gone through legal defense [organization] because I was being discriminated against at [a State funded employment training center] because of my HIV. It helped a lot."* P41, an African American MSM, said, *"I have 2 female attorneys that work with the NAACP, and they are real good."* Another MSM said, *"The (volunteer lawyer organization) is nice and patient."*

One participant complained about the lack of experienced lawyers. P83, a woman in an open session, said, *"They have the legal aides in [the legal division of an ASO] and they're real good. But the only thing I don't like about them is they have those young lawyers. They're not trained enough. I need professional help now."*

A few participants were unhappy with the legal advice they received. P76, a male attending an open session, said, *"I went to these people to get legal help about my student loans and I spent two years there. Not a darn thing I got out of it, except power of attorney and a will."* P117, a rural female, noted, *"I have the greatest need for legal services. I tried to get it once, you know that free legal service, and it didn't work. They talked about it's going to be $1000. Well, duh, if I had a $1000 I would have got it."*

Employment Assistance

Under 5% of the PLWH/A said employment assistance was among their top needs. While employment assistance was not frequently mentioned in the focus groups, participants were aware of a few opportunities. P18, an African American female, said, *"I'm not on section 8, I'm on what they call, scattered site and it's rent to own…they just started with vocational classes, and helping you find jobs, and child care when you go. They just started that this year*." P12, an African American male, has found a program through a large ASO. He said, *"I'm in…a substance abuse program for people with HIV and families. I got that through [an ASO] who funds it through [a minority CBO]. It's for people with HIV and homeless or HIV and dependency. They provide you with an apartment for 6 months; it's a 2-year program. It gives you working skills. I am very satisfied with it. They get you a job, job placement. You have an* *opportunity to go to school for the job."* P34 an Anglo male IDU said, *"For vocational counseling and training, I'm going through the [state funded employment training center]. I have an appointment with them about computer classes and getting CAD certified. I was referred through the [employment division of an ASO]."*

For some there is a desire to work, but it is balanced against their HIV disease. P110, a rural male participant, said, *"I've gone for employment through [an adult day center]. They're supposed to help people with HIV get a job. It's in Houston. Trouble is, I don't make enough money. And I'm not in good enough health to really do any work."*

Newsletters and Information

Newsletters and information is mentioned by less than 4% of PLWH/A as a top need, and hotline and phone information is mentioned by under 1% as a top need. Focus group participants make it clear that there are many avenues of information; both oral and written that are available. In fact, some participants expressed information overload. P58, a female participant at an open session said she gets, *"Too much information and newsletters from [an ASO]."*

There are participants who would like more of a certain type of information. For example, P66, an African American male, noted, *"I know enough information about the virus and how it affects my body, I think I need more education on the medication because I'm getting a lot of side effects from medications."*

It is clear that the care environment is rich with information. P18, an Anglo male heterosexual, like many others said, *"I pick up those newsletters, leaflets everywhere I go and I love them."* Some literature is available for Hispanic clients. P149, a Hispanic male, said, *"I find the newsletter and leaflets at [two ASOs]. I use them."*

Several participants said they used the Internet and national information services. P79, a Hispanic MSM, is an information seeker. He said, *"I go on the Internet. I have a computer at home. Also, [an ASO that provides support services] has an access computer over at [another ASO] in the volunteers office you can utilize. Also, I go to a lot of the different AIDS conferences. I travel to these conferences. I am also an activist to this disease. I go to a lot of clinical trials, I want to know the new research. I do a lot of research with [a university affiliated health center]."* P45, an Anglo MSM, is less likely to use the Internet because of 'bashers'. He said, *"I check on the Internet. But because of bashers on the Internet, it's too hard to get into chat rooms [for people living with HIV/AIDS], so I just read."* Other PLWH/A get national newsletters. P102, an Anglo male with an HIV positive child, said, *"You can subscribe to newsletters, like Project Inform that I get every month, that has all the new clinical studies and research finds. It's not in laymen's terms, but you can pretty much figure it out or there's a number you can call to ask questions."*

Less active information seekers also receive information. P115, a rural male, typically said, *"I'm receiving letters from my social worker and case manager. They always inform me."*

One participant, P31, an Anglo IDU male, suggested that they need more information aimed at straight people living with AIDS. He said, *"Maybe more for straight people. This stuff is geared toward gay people, which is more or less where the disease originated... There is a lot of straight people out there that are dying. Two years ago, all I knew about was that it was a gay disease. I've learned a lot since then."*

Holistic Therapy

Although over a quarter of the PLWH/A reported using some form of alternative or complimentary mediation, less than 3% of the PLWH/A name holistic therapy as a top need. Of those over half (53%) receive massage, 28% receive chiropractic treatment, and 6% receive acupuncture.

Awareness of holistic therapies is relatively low. P149, a Hispanic male, notes, *"I wasn't aware of any holistic medicines. I would like to look into it, don't know if I'd be interested."* P46, an Anglo MSM, did not know that holistic services existed. A minority of participants was aware and knowledgeable about programs. For example, P24 an African American female, noted, *"I heard that you can go to the multi-purpose center. They have a pool, weight room. Also [an ASO wellness center] doesn't have acupuncture, but they do have chiropractors."*

Those who use the sports center for PLWH/A like it. P62, a male from an open session, reported, "*The [sports center] is wonderful. Got personal trainer and massage therapy"* Some reported good results from exercise. P88 said, *"I'm in a 16 week program, working out 1 hour, 3 times per week with a personal trainer. I have added almost 4 pounds of mean muscle mass and loss a lot of fat. I feel better about myself. I'm not sleepy as much."* P18, a male IDU, said, *"Through an HIV program for substance abusers, [I] found out about an acupuncture program, and went there. It worked while I was in the program, but not once I had finished."*

Qualifying for holistic therapy can be difficult. P101, a male in an open session, noted, *"I understand that through [an ASO wellness center] they have the massage therapy, but my doctor referred me to that agency, I filled out this mountain of paperwork. They said they'd contact me in a day or two. It's been several weeks now. I don't know how I'm lost in their system and can't seem to get any answers."*

Substance Abuse

While over 20% of the PLWA are IDUs or MSM/IDU, just over 2% of PLWH/A say their top need is substance abuse treatment. There are several reasons that substance abuse treatment is not a greater need. First several focus group participants said they did not seek substance use current programs are too restrictive or they do not want to stop. P67, an African American male, said, *"I could not stay at [a housing center] for 90 days. The structure they have there is too much like a penitentiary system."* P39 said, *"[A small hospital] runs level 1 and its very structured. I don't like [the small hospital]."* A number of PLWH/A are like P35, an Anglo male IDU, who said, *"Substance abuse programs do not work for me."*

Several focus group participants were in different substance abuse programs, and most reported that they were integrated with their HIV/AIDS care. P34, an Anglo male, said, *"I checked in for drug treatment, [the residential treatment center] was perfect for me."* P83, a female attending an open session, said, *"When I found out I wasn't going to die, I went to [three treatment centers].* She adds, *"It's been real good to me. It's great. Maybe y'all are ready to move on and get your own apartments. They give you your own apartment, they don't harass you all day, they give you your own choice. They give you freedom and it makes you feel more incentive. I don't want less structure because right now, that's what I'm trying to go to recovery. They give you just enough for recovery and to enjoy yourself. It's a great program for me..."* P64, a Hispanic woman, said, *"I'm a recovering addict. The same woman who told me I was HIV positive turned out to be my case manager. She put me in a recovery center. I've been out of [the recovery center] for 9 mos. now, I'm now [in short-term housing]. I love it. I went to [an ASO] and they helped me find a job."*

P27, an African American female, told of her success with integrating her HIV and drug use treatments. *"I am gong to [an outpatient treatment center where] I am on a one on one basis with drug counseling, because at first I had a problem with groups. I'm dealing with HIV, homosexuality, and drugs. With my first substance abuse 30-day program, I had all those issues going on together and really didn't share. This is really my first group that I'm openly talking."*

End Stage Services

The services with the least expressed need tend to reflect services available at the end-stage of HIV illness.[12] This lower need is not surprising, since fewer PLWH/A are progressing to the end-stage of the illness. However, as shown in Figure 9-11 there is little difference in rankings of these services between PLWH and PLWA. Those with AIDS express a slightly higher priority for home health care than PLWH (.9% vs. 2.8%). The biggest difference is that PLWH are more likely to rank employment higher (8.7% vs. 1.8%) and childcare higher (8.7% vs. 3.2%) than PLWA.

In the focus groups there are few comments on services for end stage illnesses. In part participants are not likely to come from hospice or adult day care, and consequently they had

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[12] They are located in the AIDS Treatment to PLWA track in the continuum of care and include home health care, home delivered meals, in home hospice care, adult day care, and adoption services.

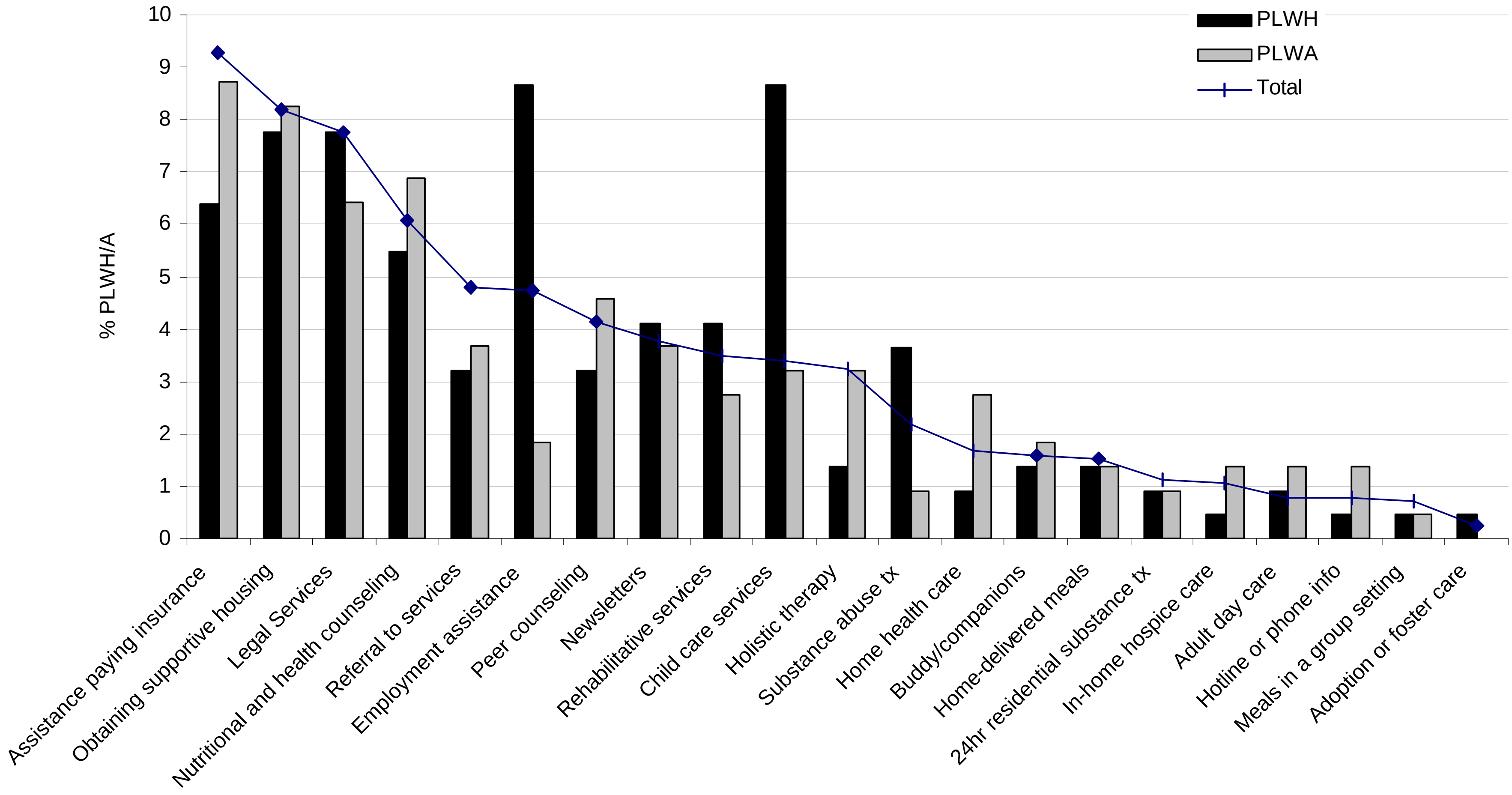
fewer experiences with end stage services. The few comments about end stage services were largely positive.

P125, a rural African American male, said, *"I used food pantries and (a meal delivery service). They are delivered hot and fresh, they are delicious. I get them once a day. Mine is delivered by (a religious group)."*

The few focus group comments about buddy systems were mixed. P69 spoke favorably of buddies. She said, *"It was great. They would come over and a couple of my friends would come over to [an ASO housing project] They would come and throw a turkey dinner on or bring a soup. Little things like that."*

On the other hand, P16, an African American female, said, *"I didn't like the way she [volunteer] presented herself when she came to my house... 'Oh, Miss Thing, this house don't have no life in it.' I said, Miss Thing, you can head out the door. What do you mean my house don't have no life in it, my children are over here, I have nice friends at my house. She was supposed to come and make me feel good but she made me tell her off."*

Figure 9-11 Ranking of Needs - Disease Progression



Service Awareness, Demand and Utilization

Service awareness, demand, and utilization are presented in Attachment 13-Attachment 15. In looking at these attachments, the percentages can be compared amongst the different target groups. For example, in Attachment 13.1, under the column representing Anglo MSM, 54.4% of the men said they were not aware of assistance with health insurance premiums. This is in contrast to over 62% of IDU respondents from all three ethnicities who were unaware of this service. The table percentages can be read within or across each of the subpopulations by reading across the rows.

As with the top needed services, a second way to read Attachment 13.1 is to compare the figures down the column. For example, 2.0% of Hispanic heterosexual respondents were not aware that outpatient care was available to them in contrast to 33.3% that didn't know mental health therapy was available to them.

Attachment 14.1 through Attachment 14.3 display the percentage of those who have ever asked for a particular service. As with awareness, the figures can be compared across the rows to determine the relative demand for the service by the different target populations, six special populations and people living with AIDS. They can also be compared down the column to see which services each specific target or special population seeks.

Attachment 15.1 through Attachment 15.3 display the percentage of those who have ever received the services. Attachment 16.1 through Attachment 16.3 show the average number of times that services were used over the last year and are reported as a median value. The median number of times each target and special population used a service over the past year can be compared by reading across the rows. The median number of times different services were used for each subpopulation can be compared by reading down the columns.

Graphic Presentation of Awareness, Demand and Utilization

In the following sections there are two pairs of graphs. Each graph plots the values for the total weighted sample. The first graph presents the first 17 services and the second presents the last 16 services. The first section discusses awareness, demand, and utilization. The following section discusses the perceived level of access and satisfaction with each of the service.

- Awareness refers to whether the PLWH/A is aware that the service is available to them, and this is shown as the solid line.
- Demand, shown as "ask", refers to whether the PLWH/A ever asked for the service, and is shown as the black bar.
- Utilization refers to whether the PLWH/A ever "received" the service, and it is shown as gray bar.

Figure 9-12 and Figure 9-17 on the following pages display the awareness of services (the line), the percentage of the total population asking for services (demand), and the percentage of the

PLWH/A who reported receiving services. The services are ordered by the percentage of persons asking for or demanding the services. Demand (black bar) and utilization (gray bar) follow the same pattern, with the largest percentage of PLWH/A being aware, asking for and receiving primary health care and lab tests.

Services Most Demanded and Utilized

In Figure 9-12, dental care, case management, food bank, and transportation follow the two out-patient care services, with the exception that newsletters are received by a higher percentage of persons than food bank or transportation. Between 60% and 70% of the PLWH/A report that they were aware of the availability of assistance locating housing, peer counseling, legal services.

Interestingly, demand and utilization patterns are somewhat different than the top ranked needs discussed above. When asked to name the top four services, drug reimbursement follows the top ranked primary care, indicating that it is perceived to be a critical service. However, it is asked for less than lab test, dental care, case management, food bank, transportation, rent and utility assistance, newsletter and referrals. Dental care, on the other hand, tended to rank lower among the most important needs than the third or fourth rank they are given in relation to demand and utilization. One reason is that while everyone is not eligible or receiving drug reimbursement, lab tests, dental care and case management are available to all PLWH/A.

Awareness - Demand Gap

Nutritional Advice

One gap measure is the difference between awareness and demand. For example, while awareness for nutritional counseling is relatively high (82%) for all PLWH/A, demand and utilization drop to about 50%. These differences are particularly noted among African American MSM who have a high awareness (92%) and demand and utilization values above 60%, compared to other groups who show lower values on all three measures. For example, nutritional counseling is less well known among Hispanic MSM (71%), Hispanics heterosexuals (73%), and African American male heterosexuals (69%). Similarly, their demand and utilization values drop to below 50%.

Referrals

Three quarters of PLWH/A were aware of referrals and slightly over 50% demand and/or receive the service. IDU Anglos were much more likely (88%) to be aware of referrals than other subpopulations, yet, they were not necessarily the most likely to demand or receive referrals. Hispanic females tend to be less aware of referrals (64%) and only about 50% were likely to seek or receive this service. Recently incarcerated PLWH/A tend to be among the most aware (86%) of referrals and tend to seek and receive them more than members of other groups. On the other hand, undocumented PLWH/A tend to be among the least aware of referrals (58%), second only to youth (30%). They were the least likely (23%) to seek referrals and the third least likely to receive them. Only youth and currently incarcerated PLWH/A reported receiving referrals more than undocumented PLWH/A.

Transportation

About three-quarter of the PLWH/A were aware of transportation (77%), but heterosexual Hispanics (92%), females (89%), particularly Anglo females (96%) were more aware than other subpopulations, and nearly 70% demanded and received transportation services. Rural females (95%) were more aware than rural men (76.4%), and were much more likely to seek the service and receive it. The undocumented and families with youth were also more likely to be aware of, demand and receive transportation than other subpopulations. At the lower end of awareness, 70% of the youth say they were unaware of transportation services, 15% ask for it and five percent receive transportation assistance.

Mental Health

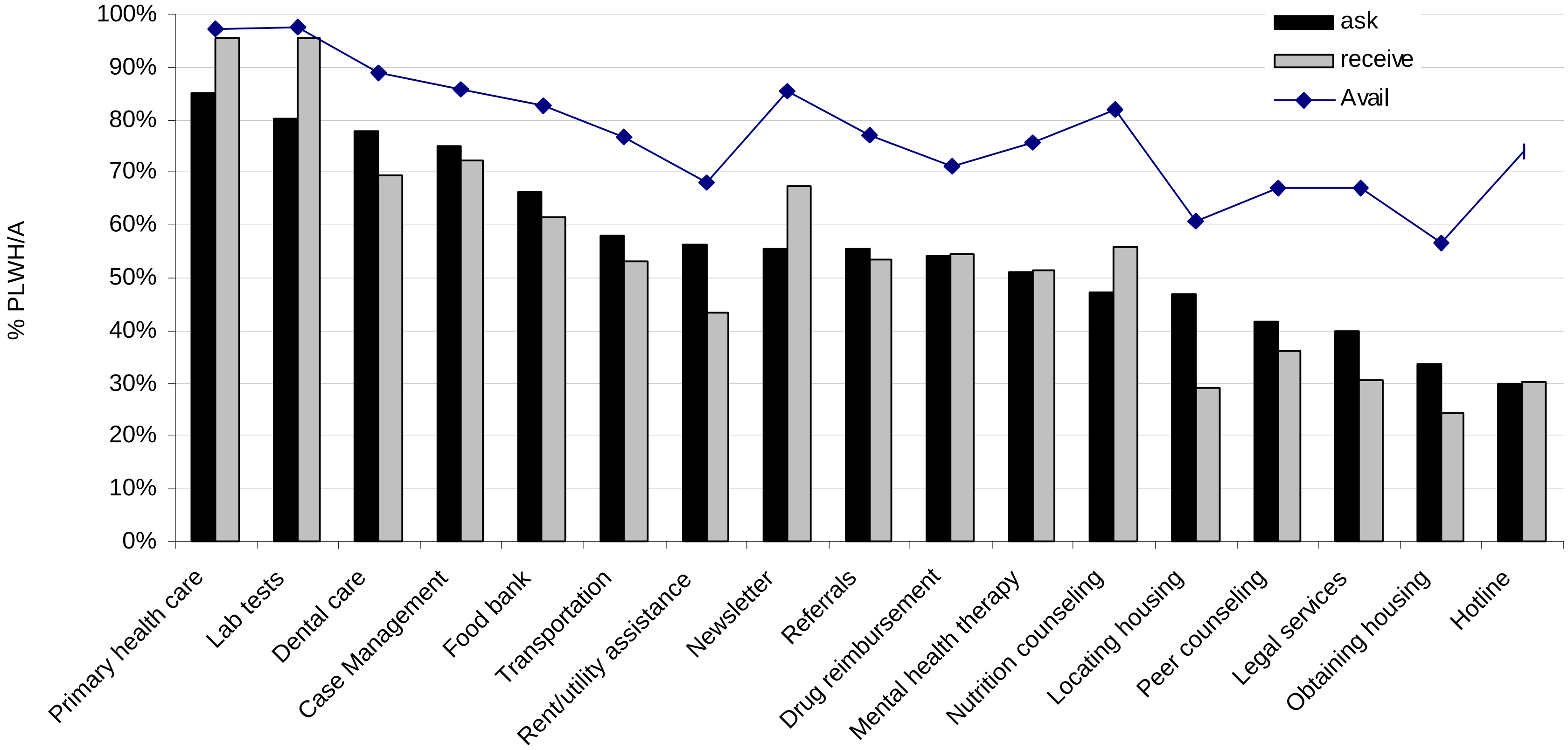
Similarly about three-quarters of PLWH/A were aware of mental health therapy and slightly over 50% seek and/or receive the service. While Anglo females tend to be more aware of this service (91%), Hispanic females were less aware (64%) than the other subpopulations of PLWH/A. Anglo women were also the top seekers and users of mental health therapy.

On the other hand, Hispanics were the least likely and ask and/or receive mental health services. Recently incarcerated males were much less likely to find mental health therapy available (65%). The same is true for young persons (55%) and families with children (50%). Also, youth, pediatric caregivers and families reported low utilization of the service. Notably, mental health service is the number one service sought out by youth yet less than 25% receive it.

Drug Reimbursement

About 70% of the PLWH/A knew the drug reimbursement is available and 54% seek and receive it. It is relatively more known by Anglo, in general (81%), particularly MSM Anglo (85%) and IDU Anglos (81%). Anglos were also more likely to ask for drug reimbursement and to receive it. Drug reimbursement is relatively less well known among females (60%) and African Americans (59%), with less than 50% seeking and/or receiving the service. African Americans were also less likely to seek and/or receive drug reimbursement than other groups. Particularly unaware were African Americans, IDUs, heterosexuals, and women (56%).

Figure 9-12 Services Awareness, Demand, and Utilization - top 17



Among the special populations, recently incarcerated were less likely to be aware of drug reimbursement than most other PLWH/A. Youth tend to be less informed (60%), as do PLWH/A with children (60%). In general, rural females were also less likely to know about drug reimbursement (56%). For special populations, youth (40%) and PLWH/A with children (50%) are less aware of rent and utility assistance.

While, youth were the least likely to demand or receive drug reimbursement, rural women were more likely to ask for the service and undocumented PLWH/A were the most likely to receive the service.

Rent and Utility Assistance

PLWH/A reported that one of the greatest needs is rent and utility assistance. Just over two-thirds of PLWH/A were aware of the service, 56% asked for it and 43% received it. Awareness of rent and utility assistance was greater among the MSM (76%), particularly the MSM African Americans (83%). It is also high among the Anglo IDUs (81%). However, the demand for rent and utility assistance is greatest among women, particularly African Americans and Anglos, and utilization was highest among men and Anglos. African Americans, particularly men and heterosexuals, reported the lowest utilization of rent and utility assistance.

Demand - Utilization Gaps

As noted above, demand and utilization usually follow the same pattern. However, a gap between what is asked for and what is received suggests an unmet perceived need (see Table 1-1). The demand-utilization gap measure is calculated by taking the difference between the aggregate percentage of those demanding services, or seeking services, minus those who actually receive the service. In the total sample, the demand-utilization gap ranges from 0% to 18%. As might be expected, demand usually exceeds utilization. However, as shown in Figure 9-13, reading from the bottom of the graph up, the key services of primary health care and lab tests were received more than they were asked for, and the same is true for newsletters and nutritional counseling.

Notably, utilization lags behind demand for assistance in locating regular and supportive housing, peer counseling, and legal services. Among the services most demanded, the largest unmet demand, with a gap difference of 18%, is assistance in locating housing. Figure 9-14 shows that this gap is even greater among African Americans, IDUs, and women.

Assistance with rent and utilities and legal services are the next biggest unmet demands. Among the risk groups, MSM tended to report smaller unmet demand than members of the other groups. An exemption is dental care, where MSM reported a higher unmet need demand than IDUs or heterosexuals.

The unmet demand gap varies from service to service among men and women. For women, the top two unmet demands were assistance locating housing and obtaining housing. For men, the top three unmet needs were locating housing, rent and utility assistance, and legal services. Both men and women reported receiving more primary care, lab test and nutritional counseling services than they sought.

The ethnic/racial differences reveal that African Americans have greater unmet demands than Anglos or Hispanics. The top three unmet demands for African Americans include assistance with locating and obtaining housing, and rent utilities.

Similarly, Hispanics would like more assistance in locating housing and rent and utilities. Anglos also share the unmet demand for locating housing and rent and utility assistance. In addition, Anglos show a demand-utilization gap in dental care.

All the ethnic/racial groups feel they get more primary care, lab tests and newsletters than they actually solicit.

Among the special populations, (not graphically presented), the recently incarcerated reported the greatest gaps in the services they seek and those that they actually receive. They reported gaps greater than 20% in dental care, locating and obtaining housing and rent and utility assistance. These are the same top three unmet demands reported by all other special populations but with less of a demand-utilization gap.

Figure 9-13 Total Sample Demand- Utilization Gap: Top 16 Services

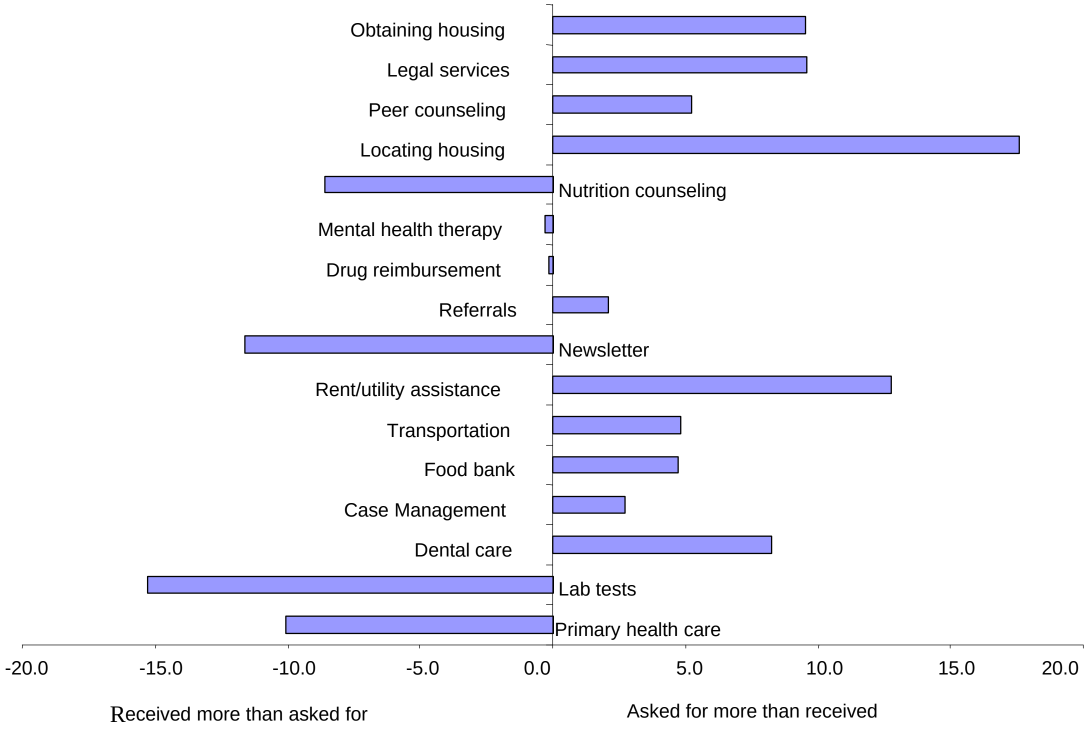


Figure 9-14 Demand Utilization Gap by Risk Group- First 16 Services

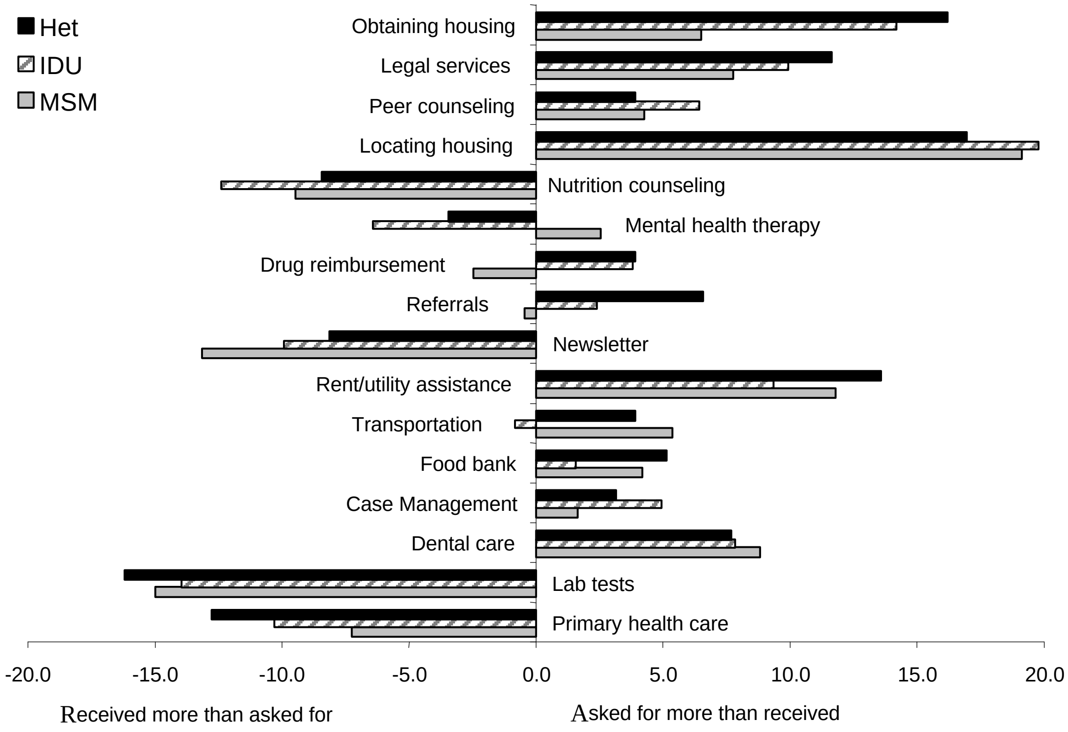


Figure 9-15 Demand Utilization Gap by Ethnicity - First 16 Services

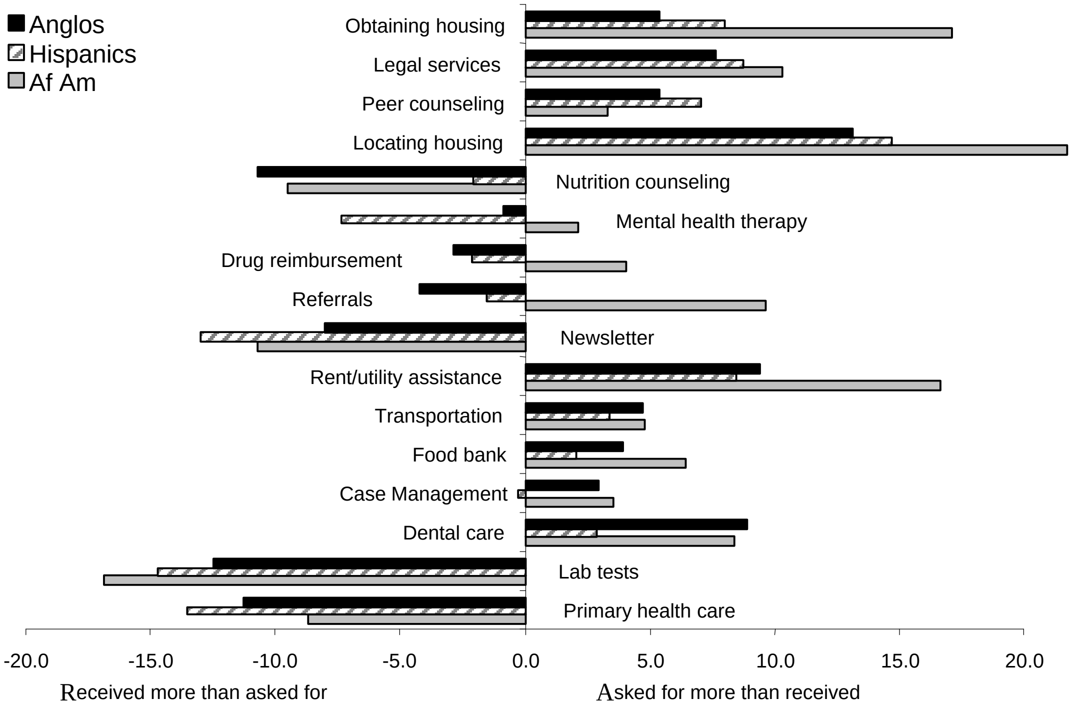
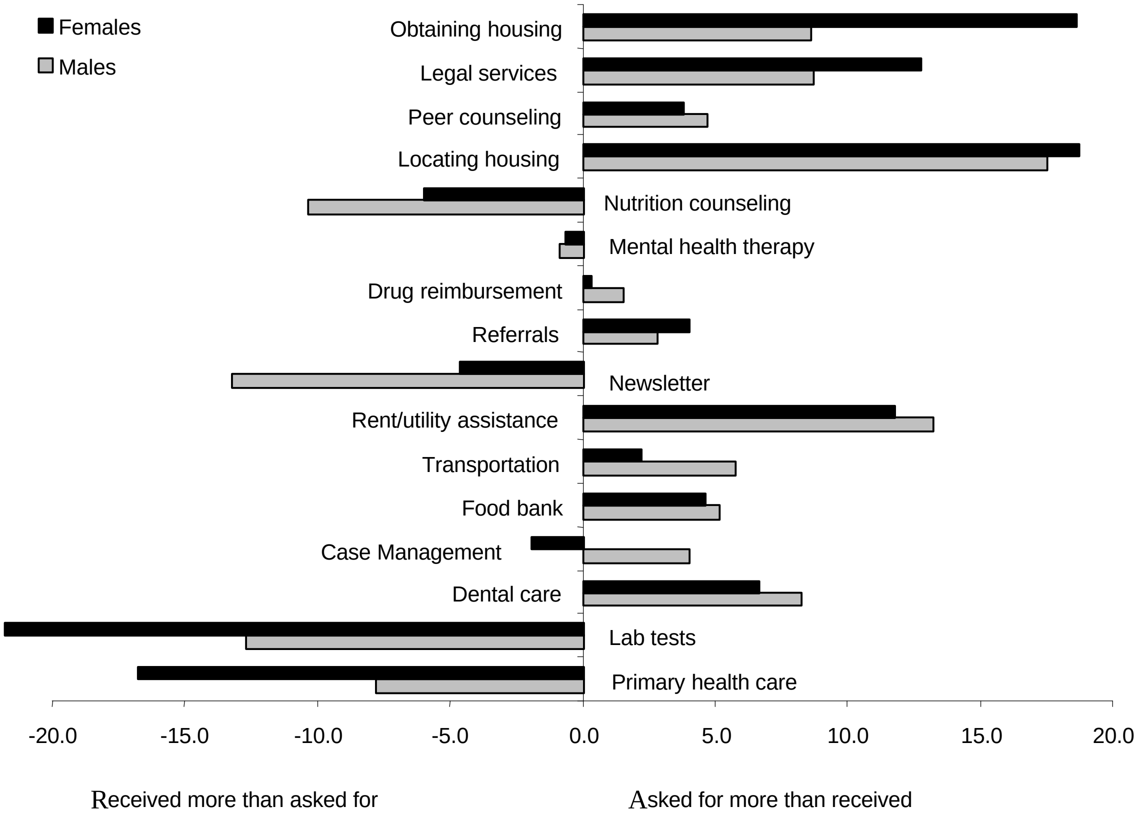


Figure 9-16 Demand Utilization Gap by Gender- First 16 Services



Services Less Demanded and Utilized

Figure 9-17 displays the services that have lower awareness, demand, and utilization. While in many instances the low awareness reflects the low need for these services, as shown in Figure 9-18 among PLWH/A, the demand for most services exceeded utilization. The gap was relatively large for health insurance assistance, employment assistance and holistic therapy. Among the least sought services, presented in Figure 9-18, group meals, out-of-home substance abuse treatment, and hotline services were received by PLWH/A more than they were solicited.

Figure 9-19 shows that IDUs and heterosexuals have a larger gap in perceived need/demand for health insurance assistance than MSM. Heterosexuals also have a greater gap in perceived need/demand for employment assistance, holistic therapy, and child care than other risk groups. Heterosexuals in general have a larger perceived need/demand gap.

For the less demanded services, Figure 9-20 indicates that generally African Americans have the largest gap in perceived need/demand. It is particularly large for employment assistance, holistic therapy and health insurance assistance.

Figure 9-21 indicates that women have a larger gap in perceived need/demand for childcare, employment assistance, and health insurance assistance than men.

Among the services with the greatest demand, awareness is generally at the same level for subpopulations. However, for some services, as seen in Attachment 13, Attachment 14, and Attachment 15 there were some notable differences between subpopulations for awareness and demand.

Figure 9-17 Services Awareness, Demand, and Utilization -Last 16

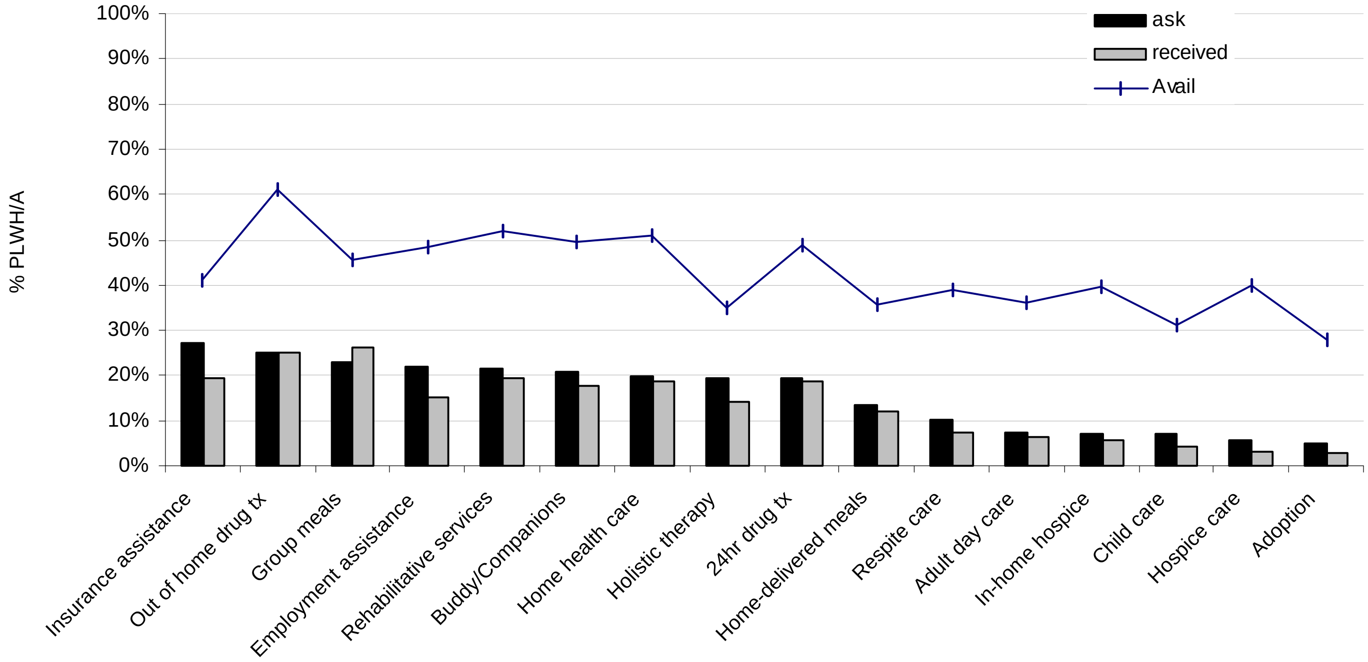


Figure 9-18 Total Sample Demand Utilization Gap - Last 17 Services

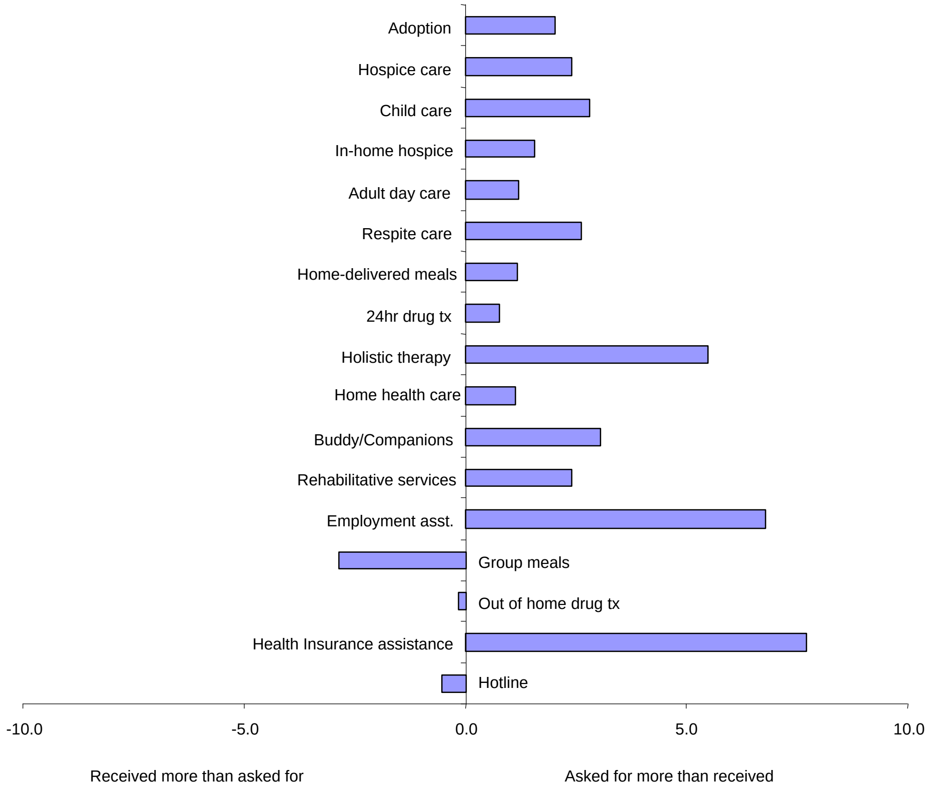


Figure 9-19 Demand Utilization Gap by Risk Group- Last 17 Services

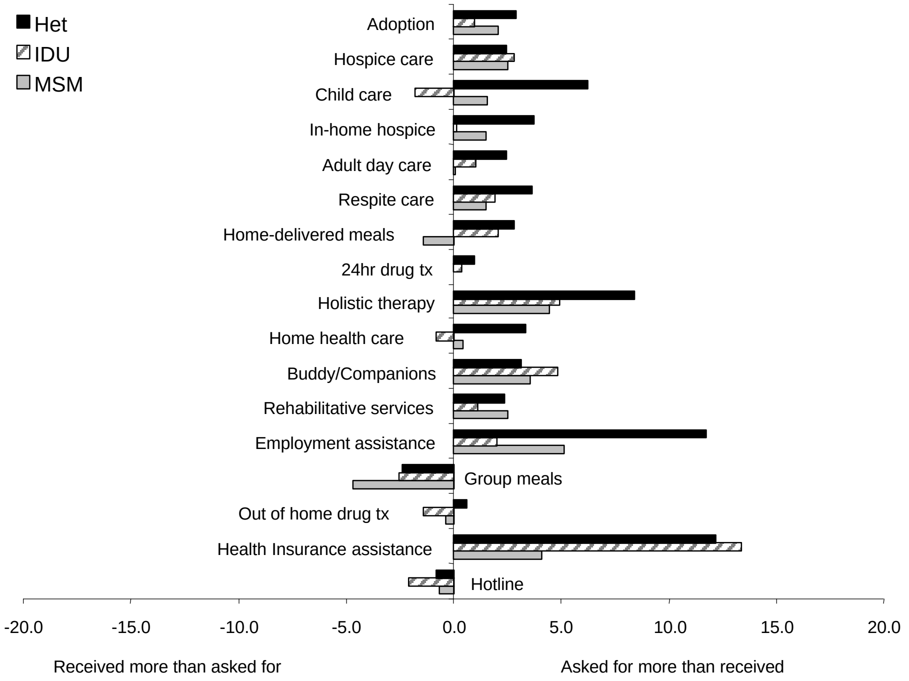


Figure 9-20 Demand Utilization Gap by Ethnicity - Last 17 Services

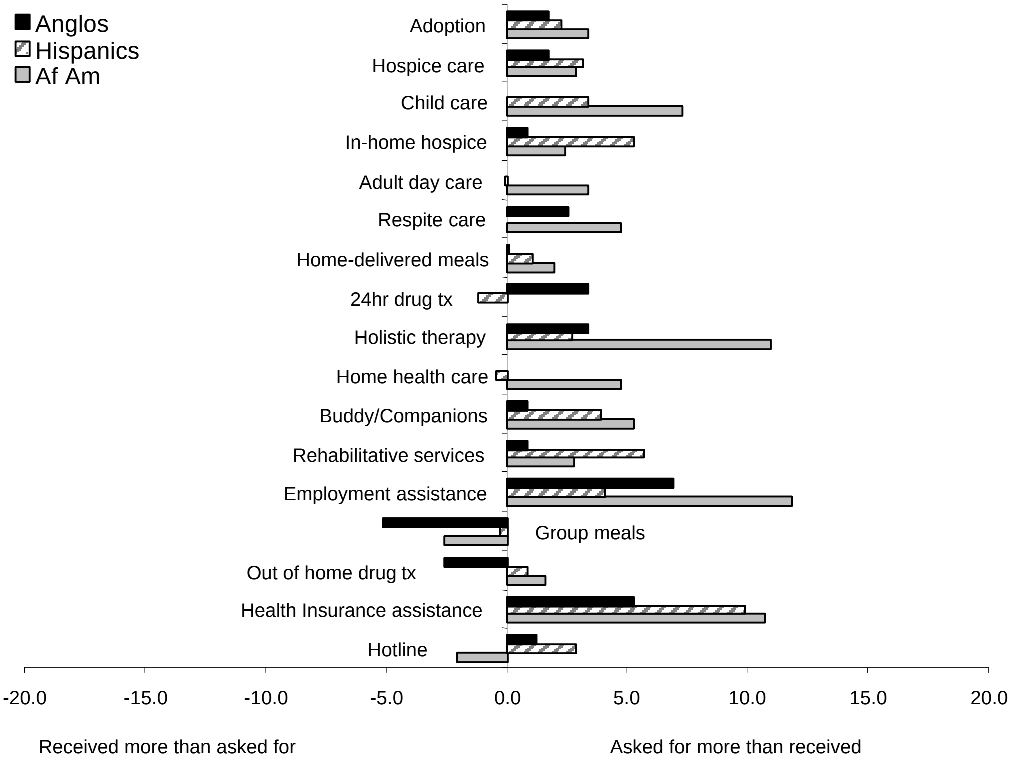
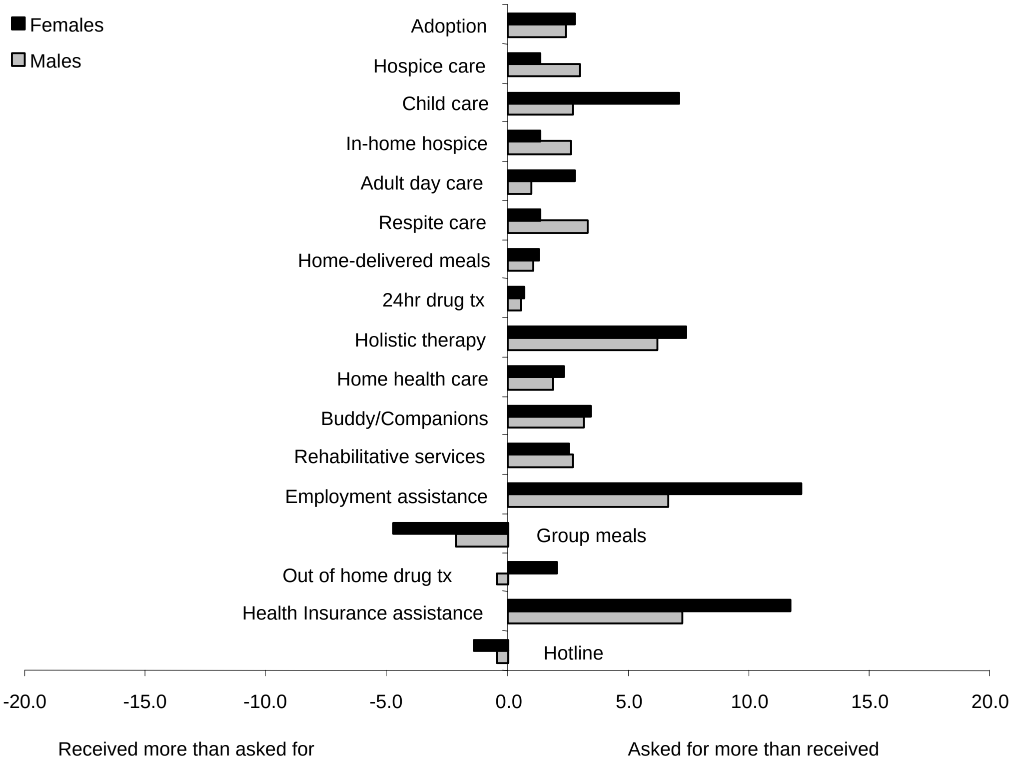


Figure 9-21 Demand Utilization Gap by Gender- Last 17 Services



Service Satisfaction and Access

PLWH/A were asked to say how satisfied they were with 32 services provided by the HIV/AIDS care system, and how difficult they were to access. Satisfaction was rated on a four-point scale ranging from "very satisfied" with a score of 4 to "not satisfied at all" with a score of 1. Access was ranked on a 3-point scale from "very easy to access" with a score of 3 to "hard to access" with a score of 1.

Attachment 17 shows the mean satisfaction score. The higher the score the greater the satisfaction with the service. As in the previous four tables, the numbers representing the average satisfaction scores can be compared for each service by reading down the columns. They can be compared within or across the rows representing services provided to each of the target populations, six special populations, and people living with AIDS. Similar to awareness, demand and utilization, Attachment 17 consists of a series of three tables showing the satisfaction scores for different subpopulations.

The series of tables in Attachment 18 show the mean scores for degree of difficulty in accessing services, ranging from 3, very easy to access, to 1, hard to access. The higher the score, the greater the accessibility to the service. As in the previous three tables, comparisons may be made within or across the target populations and six special populations.

Graphic Presentation of Satisfaction and Access

Figure 9-22 and Figure 9-23 display the perceived access and satisfaction with services. Figure 9-22 shows access and satisfaction for the top 17 services, ranked by access. In the chart, access is represented by the black bar, and the scale is on the right side of the graph, and satisfaction is shown as the line, with its scale on the left. Figure 9-23 shows the services which were ranked easier to access.

The reason for plotting access and satisfaction together was that they were thought to be related. As seen in the figures, they are related, but clearly access is only one component of satisfaction. While both levels of access and satisfaction are rated high by PLWH/A, levels of access stay relatively high for the top 17 services, and even among the services rated harder to access they fall between somewhat and very easy to access. IDU PLWH/A reported the lowest access level among all the subpopulations to lab tests.

Satisfaction levels range from very satisfied to less than somewhat satisfied.
PLWH/A are quite satisfied (3.7 out of a possible 4) with lab tests. Across all the subpopulations PLWH/A are between somewhat and very satisfied with this service. Perceived access is also relatively high among most groups.

Residential Drug Treatment

The service rated easiest to access, for those reporting using it, was residential (24 hour) drug treatment. However, there were differences among subpopulations. For instance, PLWH/A from most groups felt that residential substance abuse treatment is very easy to access, yet, heterosexual Anglos felt it is only somewhat easy to access as indicated by an average score of 2.0. Heterosexual Anglos also reported the lowest satisfaction (2.25 out of 4) with this service.

Nine out of the top 17 services that were rated as easiest to access were in low demand and used by less than 30% of the PLWH/A. Therefore their perceived high access may indicate the PLWH/A's experience with the service. Those who did not use the service were not asked to rank its ease of access. For example, childcare received the highest access and satisfaction ratings by women in all subpopulations, heterosexuals, parents of HIV children, and PLWH/A with children. However, in some subpopulations less than five persons reported using these items.

Despite the similarity of scores among the total scores PLWH/A seen in Figure 9-22 and the corresponding Attachment 17 and Attachment 18 there are several notable differences among subpopulations.

Drug Reimbursement

While drug reimbursement receives the second highest satisfaction scores, the perceived level of access differs among ethnic populations. For African American IDUs the access level drops below the total average of 2.51 to 2.36. On the other hand, with the exception of women, rural PLWH/A reported higher access to drug reimbursement than most other subpopulations.

Dental Care

For most groups, satisfaction with dental care is between somewhat and very satisfied. Hispanic IDU and parents of HIV positive children the most satisfied with dental care. These two groups also reported the highest levels of access. However, satisfaction with dental care services dips for African American IDUs (3.3), Anglo women (3.3) and PLWH/A of other ethnicities (3.2).

Out Patient Care

Overall, PLWH/A consider primary care as accessible as dental care and were more satisfied with primary care services than dental care services. Access level for primary care remains high and relatively similar throughout the different groups, with the exception of African American IDUs and rural IDU who reported lower access scores of 2.3 and 2.1 respectively. Youth and parents of HIV positive children reported the highest access level at 2.7. Satisfaction levels reflect the same pattern indicating a relationship between satisfaction and access. African American IDU and rural IDU were the least satisfied with primary care services while youth and parents of HIV positive children were the most satisfied.

Case Management

Perceived access to case management ranges from "somewhat easy to access" among African American IDU to "very easy to access" among Hispanic IDU. Notably, women reported greater access to case management than do men, especially among African American and Hispanic PLWH/A. Yet, access to case management services ranks relatively low for Hispanic MSM, African American IDUs, Anglo females, and rural females.

Satisfaction ratings for case management were low in comparison to other services. Anglo women were only somewhat satisfied with case management services, while Hispanic IDU and youth were very satisfied with this service.

Health Insurance

There is a wide variation in the perceived level of access to health insurance assistance. While the overall average score is between "somewhat easy to access" and "very easy to access", the scores range from less than somewhat easy to access for Hispanic and rural women to as high as very easy to access for Hispanic IDU, Anglo heterosexuals and Anglo women.

Health insurance assistance receives the tenth highest satisfaction rating, with PLWH/A with the highest access, i.e., Hispanic IDU, Anglo heterosexuals and Anglo women also being the most satisfied. Interestingly, other groups, with perceived lower access levels, such as the recently released, Hispanic women, undocumented and parents of HIV positive children were also very satisfied.

Transportation

As previously discussed, transportation is named as the third most important need for PLWH/A. However it is ranked among the bottom third in terms of access and satisfaction. PLWH/A reported both positive and negative experiences with the transportation service available to them. Access to transportation is similar for most groups, with most of the PLWH/A reporting an average access score in the range of "somewhat easy to access". A few exceptions include youth who feel that transportation was very easy to access. On the lower end of the scale, rural women feel that transportation less than somewhat easy to access.

Satisfaction with transportation services ranks between somewhat and very satisfied. However, compared to other services, it is ranked relatively low, with most groups reporting scores in the "somewhat satisfied" range (3.3-to 3.6). Some exceptions, with satisfaction ratings lower than 3.3 include African American IDUs, Anglo heterosexuals, African American men, Anglo women, families, and most rural PLWH/A. On the high end of the scale, Hispanic IDU recently incarcerated and youth reported satisfaction levels above 3.7.

Rent and Utility Assistance

Although rent/utility assistance and assistance locating housing are among the top 10 most important services mentioned by PLWH/A, these two services are among the hardest for PLWH/A to access. The majority of the subpopulations feel that rent/utility assistance is closer to somewhat easy to access than to very easy to access. Rural men and MSM felt that rent and utility assistance is less than somewhat easy to access.

Satisfaction ratings for rent/utility assistance show a broader range, with rural IDU being less than somewhat satisfied (2.8) and Hispanic IDUs and parents of HIV positive children reporting satisfaction scores of 4.0, very satisfied. MSM and most IDU and rural PLWH/A reported satisfaction levels below the total average. On the other hand, PLWH/A from the special populations tend to be more satisfied with rent/utility assistance than the total sample.

Assistance Locating Housing

Similarly, overall PLWH/A rate locating housing as the hardest service to access and it has one of the lowest satisfaction ratings. Hispanic and rural men and rural MSM felt that locating housing is less than somewhat easy to access. Males, particularly African American and Anglo, were among the least satisfied with assistance in locating housing.

Other Services

Figure 9-22 and Figure 9-23 show that PLWH/A were least satisfied with adult day care, adoption and hospice care services. These ratings however only reflect the opinion of 10 to 13 out of 455 PLWH/A who completed the survey. While the numbers are few, it may reflect a need to examine the quality of these end-stage services, to assure that lack of demand does not result in poor quality services.

Figure 9-22 Access and Satisfaction with Services - Top 17

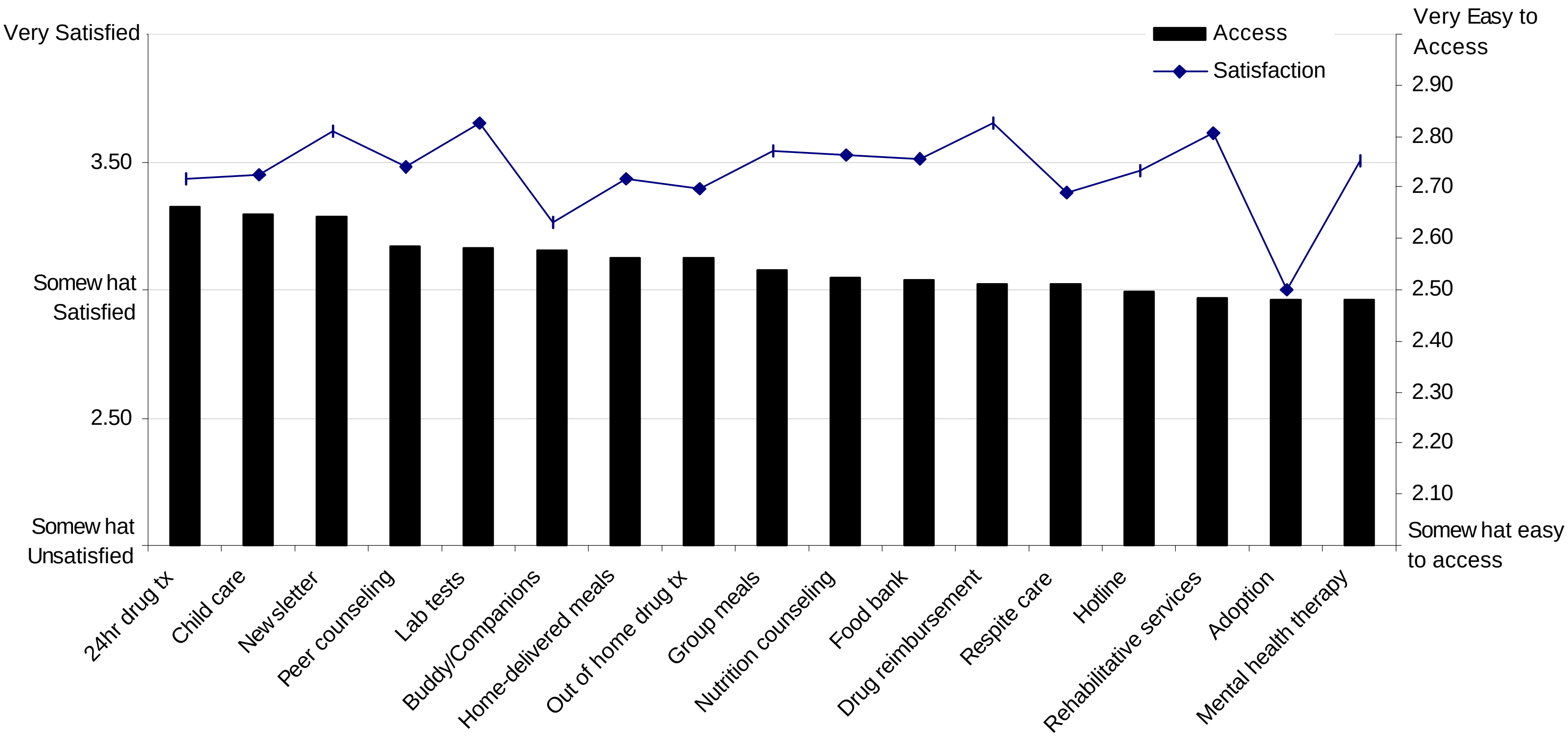
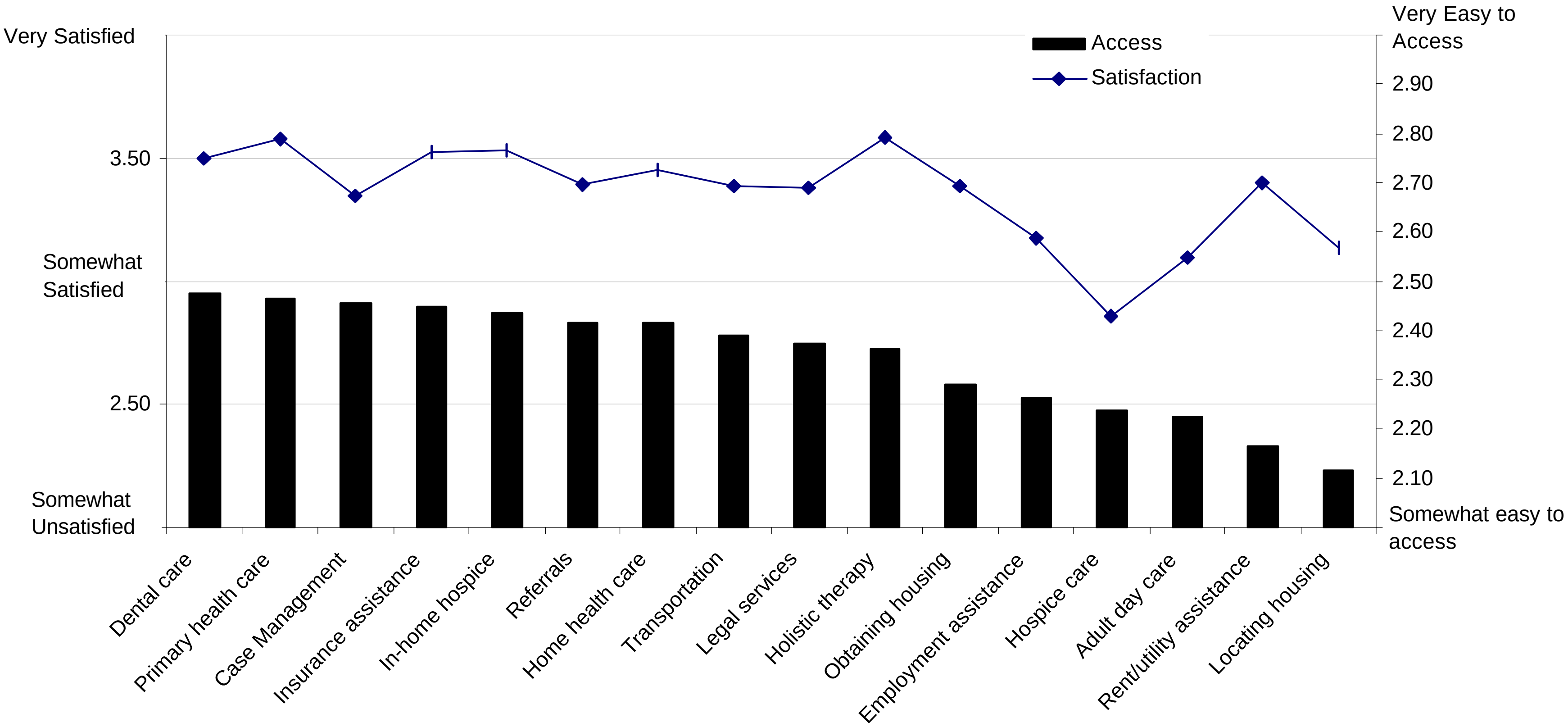


Figure 9-23 Access and Satisfaction with Services - Last 16



Service Future Demand

Participants were asked to indicate whether they would need the thirty-two services previously discussed more, the same or less in the coming year. The anticipated need for each service is shown in the tables in Attachment 19. The figures in the table are the mean score, and the higher the mean score the more likely that PLWH/A anticipate a growing need. In the tables, as with the other attachments, comparisons can be made across or down the columns.

Graphic Display of Anticipated Need

Figure 9-24 shows the thirteen services for which PLWH/A feel they have the greatest future need. Notably, all of these services have an average score of between "needing more" and "needing the same", indicating that, on average, the PLWH/A see an increasing need for services.

While primary health care is stated as the service most in demand, utilized, and important, PLWH/A reported that the services with the highest anticipated demand are those that help them meet their daily needs or maintain their health.

Dental Care and Rent and Utility Assistance

Interestingly, dental care and rent and utility assistance are the top two services with the highest anticipated need in the next year. Over 50% of PLWH/A say they will need dental care more, while only 5% see a declining need. While there may be a debate as to the essential nature of dental care for reducing mortality and morbidity, it is perceived as a needed service by PLWH/A. The reason for the high expected need for dental care is that dental care is often a service that is not available to persons who are in or near poverty. Consequently access to dental care is clearly seen as a needed enhancement to their health care that is not available elsewhere. As seen in Attachment 19, Table 18.1, MSM and IDUs are more likely to anticipate a growth in dental care demand than heterosexuals, and typically males say they expect to see a greater growing demand than females. Urban PLWH/A see a greater future need for dental care than rural PLWH/A.

Increased demand for rent and utility assistance is at about the same level as increased demand for dental care. Slightly less than half of the PLWH/A (48%) anticipate that they will need more of this service next year, with only 6% of PLWH/A suggesting that they will have a decline in rent and utility assistance. This reflects the evolution of HIV disease from an acute illness to a chronic illness and the fact that many PLWH/A are in poverty or have to spend down to near poverty levels to obtain Ryan White funded services. SSI and other disability are often not sufficient to meet the full spectrum of basic housing and nutritional needs. Among MSM and heterosexuals, African Americans were much more likely to see an increased demand for this service, while Hispanics were less likely than other ethnic MSM to anticipate a growth in service. Males were more likely to anticipate a need for rent and utility assistance than females, with Hispanic females among the least likely to see a growing demand for rent and utility assistance.

Food Bank

The next tier of services reported to have a growing need were food bank, locating housing, legal services, and case management. With the exception of case management, these services were also directed at meeting basic needs such as food and shelter.

While 17% of PLWH/A did not know if their future need for locating housing was going to grow, stay the same, or shrink, over half (56%) of the PLWH/A with an opinion, said that their need for locating housing would grow. It was particularly high among African American and Hispanic IDUs, and African American MSM. It tended to be lower among heterosexuals. As might be expected, it was also high among the recently released and those soon to be released.

About 46% of PLWH/A anticipate a growing demand for the food bank, and only 5% say they will use the food bank services less. MSM African Americans, all Anglos, and IDUs anticipate a higher use for the food bank than other subpopulations. Also rural IDUs expect a higher than average need for the food bank. In general, heterosexual Latino females and Anglo males anticipate a lower demand than other target populations. Perhaps indicating a lack of awareness or belief of lack of entitlement, the undocumented and PLWH/A also indicate a lower anticipated need for food pantry than other subpopulations.

Legal Services

Legal services have evolved from wills and estate planning, to discrimination in the workplace and financial assistance. While about a third (35%) of the participants didn't know if they will have more or less demand for legal services in the next year, over a third (37%) of PLWH/A anticipates a growing demand. Male recently incarcerated and African American IDUs express the greatest anticipated need for legal services.

Case Management

Less than half the PLWH/A (46%) anticipate needing more case management in the next year, but only 4.4% expect to have less need. The African Americans were more likely than other populations to anticipate greater future need. IDUs, recently released and soon-to be released of all ethnicities also reported anticipating greater future demand for case management. Surprisingly families were less likely than other populations to report an anticipated increased demand for case management, as were the undocumented.

Referrals

PLWH/A were somewhat less likely to anticipate a demand for referrals, with about a quarter not knowing what their future demand for referrals would be and 41% said that they anticipated more need. The greatest future need for referrals is among African America and Anglo MSM and all IDUs. Male recently incarcerated and the in prison subpopulation also reported a growing need for referrals. Rural PLWH/A indicate a below average demand for increased referrals.

Drug Reimbursement

Drug reimbursement is at about the same level as referrals. About a fifth of the PLWH/A did not know about their future demand, but about 41% said they anticipated a greater need for drug reimbursement services. It was particularly high among the Hispanic MSM, Female African American IDUs and Hispanic IDUs, male recently incarcerated and the in prison subpopulation, and the rural IDUs. It was lower than average urban females.

Other Services

The remaining set of services with a smaller anticipated need are shown in Attachment 19. They are a combination of direct services, education, and services used to access direct medical and social services. Notably, primary health care was far down the list of services with anticipated growth in demand, probably because it already has nearly universal coverage and PLWH/A may not anticipate needing more service than they currently have.

Figure 9-25 indicates those services with the least expected growth in demand. Where need more is equal to "3" and stay the same is equal to "2", the services shown in s Figure 9-25 are all ranked below 2.4. As with demand for existing services, anticipated demand is perceived to be the lowest for services needed during the end stage of HIV disease such as hospice care, home health care, and adult day care.

Drug abuse services -- both residential and outpatient is also perceived to have little increased future demand. While considerably higher among IDUs, except Hispanic IDUs, less than half the IDUs anticipated greater future need of drug abuse services. Of the IDUs, the female African American anticipated the greatest future need.

Comparisons of subpopulation differences on the remaining services for future need can be seen in Attachment 19.

Figure 9-24 Anticipated Need - Mean Score for Top 13

1=Less need, 2=Need stays the same, 3=More need

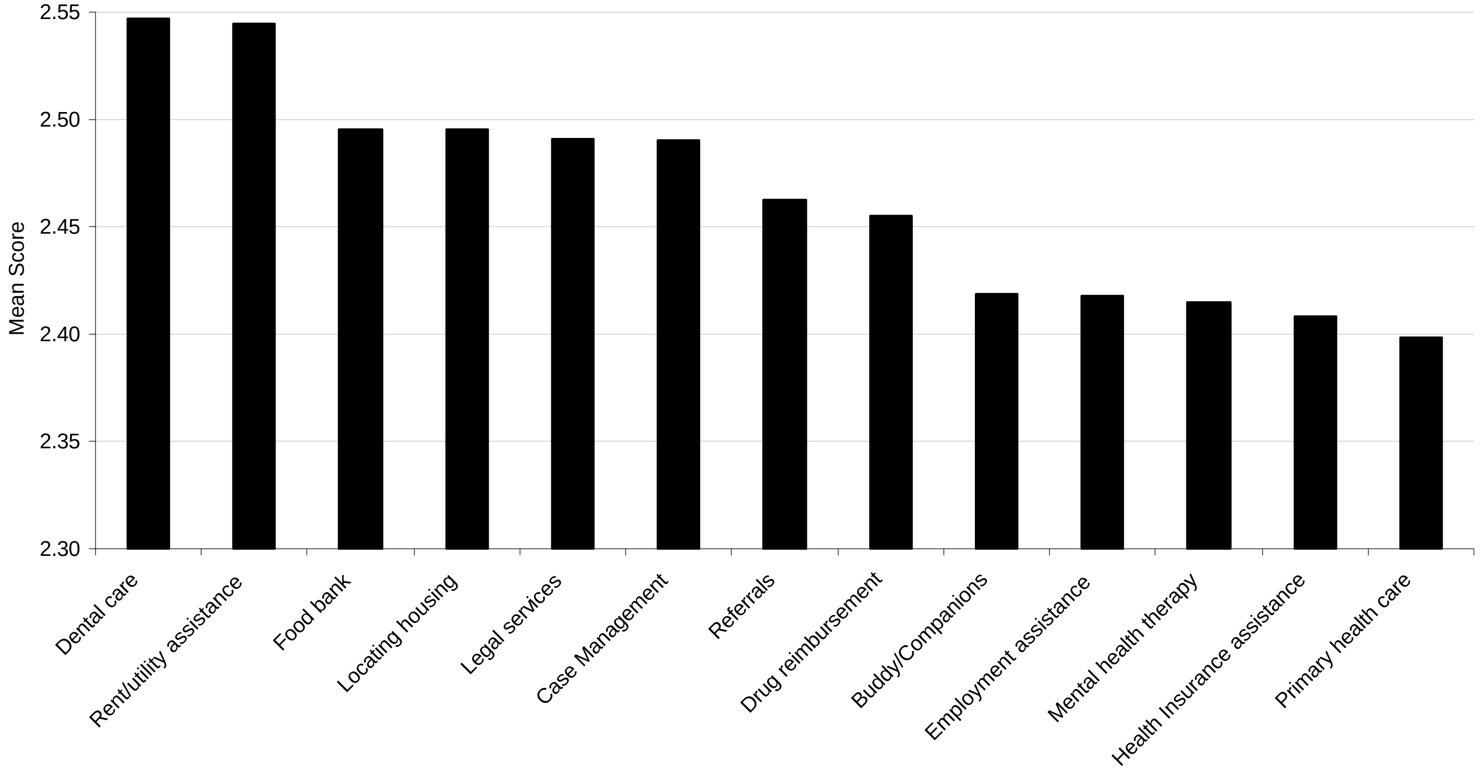
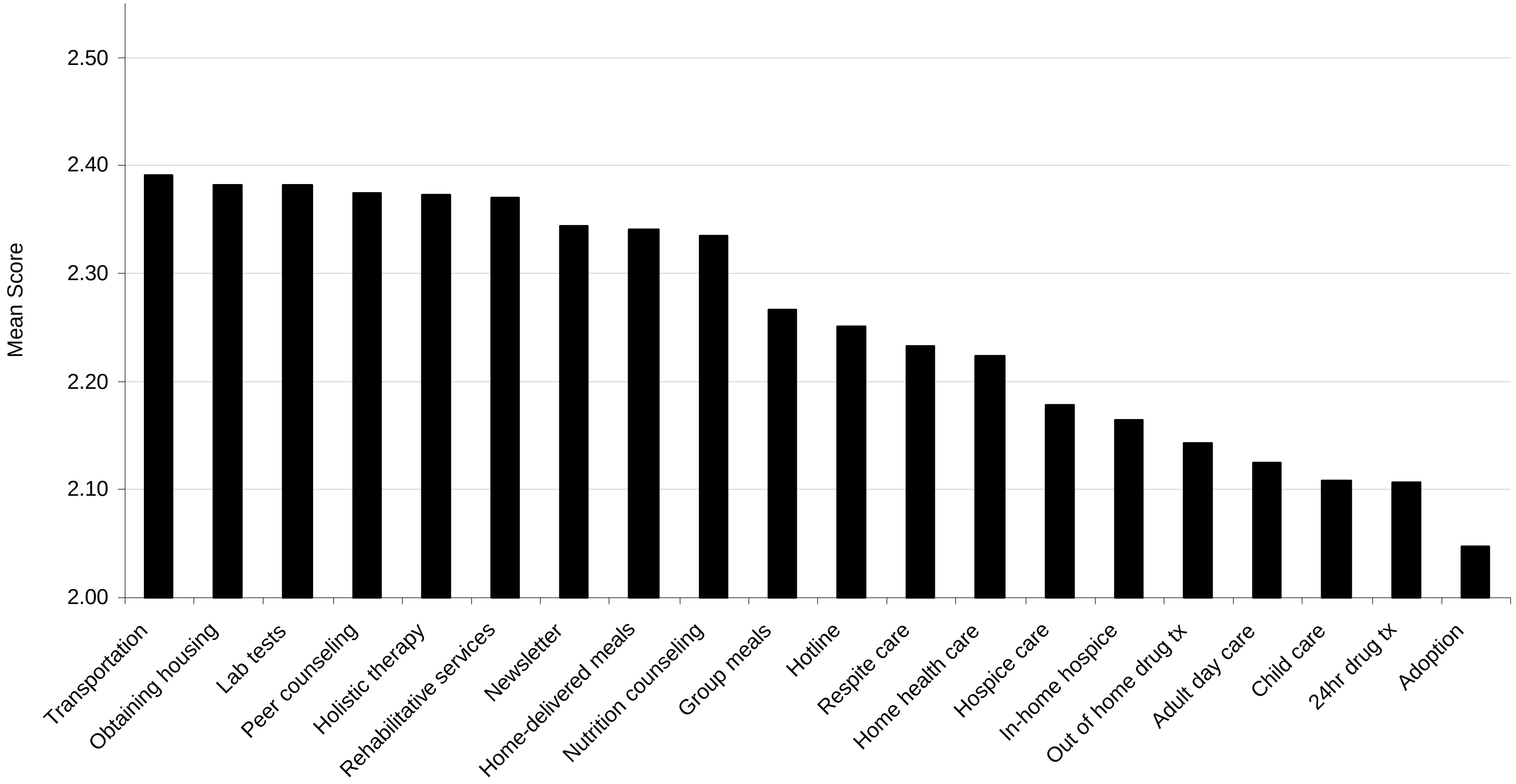


Figure 9-25 Anticipated Need - Mean Score for last 20 Services

1=Less need, 2=Need stays the same, 3=More need



10 BARRIERS

People living with HIV and AIDS (PLWH/A) and providers of HIV/AIDS services in the Houston EMA and Houston HSDA identified several barriers that could be lowered in order to improve the access and quality of services provided. In many instances PLWH/A feel the "system" is responsible for the barriers and does not attribute the barriers to agencies or staff. In contrast, providers are more likely to report the highest barriers are due to the individuals' lack of knowledge or physical health. In general, as suggested by the overall high marks for satisfaction, PLWH/A feel that services are available, accessible, and affordable.

Overall PLWH/A Score for Barriers

On the questionnaire, PLWH/A rated and discussed thirty-two barriers. They rated the barriers on a four-point scale ranging from a big barrier to no barrier at all.[13] The thirty-two barriers can be grouped into three general types of barriers: 1) individual, 2) organizational, and 3) structural barriers.

- Individual barriers are those that refer to the individual's skills, knowledge, physical and mental health.

- Organizational barriers are those that refer to the PLWH/A perception of how their providers handle issues related to access, treatment and confidentiality, including the providers; skills and sensitivity.

- Structural barriers are those related to rules and regulations and accessing the system of HIV/AIDS care (in contrast to accessing particular organizations).

The determination of the types of barriers was based on a statistical technique called factor analysis.[14] This technique indicates which barriers were most likely to be sorted into the same group by the PLWH/A survey participants. It is as though the PLWH/A were given a deck of cards with each barrier printed on it and asked to sort them into piles reflecting a common underlying theme.

Before discussing these different types of barriers, an overall barrier score is shown in Figure 10-1 for MSM, IDU, and heterosexual, divided by ethnicity, and gender.

When the ratings of all of the barriers are summed, none of the risk groups or ethnic populations reported a big barrier. As shown in Figure 10-1, the highest overall barrier score is less than 2.5 - or a rating of between a "moderate (score of 3) and small barrier (score of 2).

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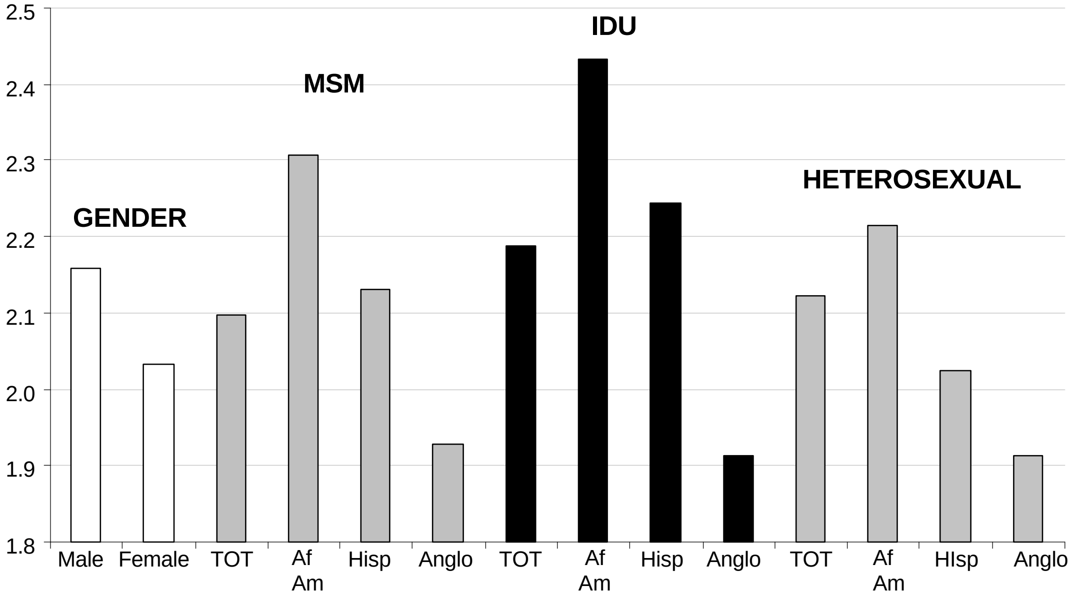
[13] For exact wording see question 47 in the questionnaire, Attachment 2, and the Barrier section in the focus group outline, Attachment 1.

[14] A pairwise Pearsons correlation matrix was used as input. A varimax option was selected to better discriminate the factors. The varimax solution is shown in Attachment 20.

As seen in Figure 10-1, IDUs reported the overall highest barrier (2.19), followed by heterosexuals (2.12) and MSM (2.1). Men tended to report higher barriers than women. Within each risk category, African American reported the highest barriers, followed by Hispanics and Anglos.

Figure 10-1 Average Barrier Scores by Risk Group

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



In Figure 10-2, the overall barrier scores are shown for the eight special populations, recently incarcerated, soon-to-be-released, undocumented, youth, families with HIV+ children, families with children, PLWH, and PLWA. Like the risk groups noted above, none of these special populations had an overall "big barrier". Of these groups, the recently incarcerated reported the highest overall barrier, and this was significantly lower than the overall score for the IDU African Americans.

Figure 10-2 Average Barrier Scores by Special Populations

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

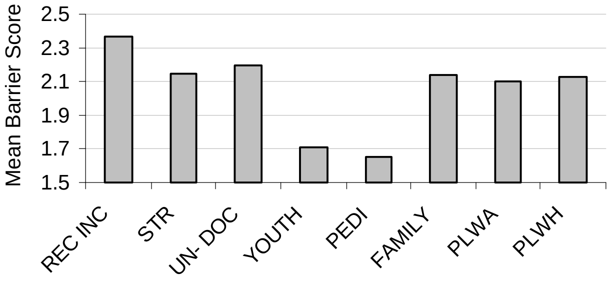
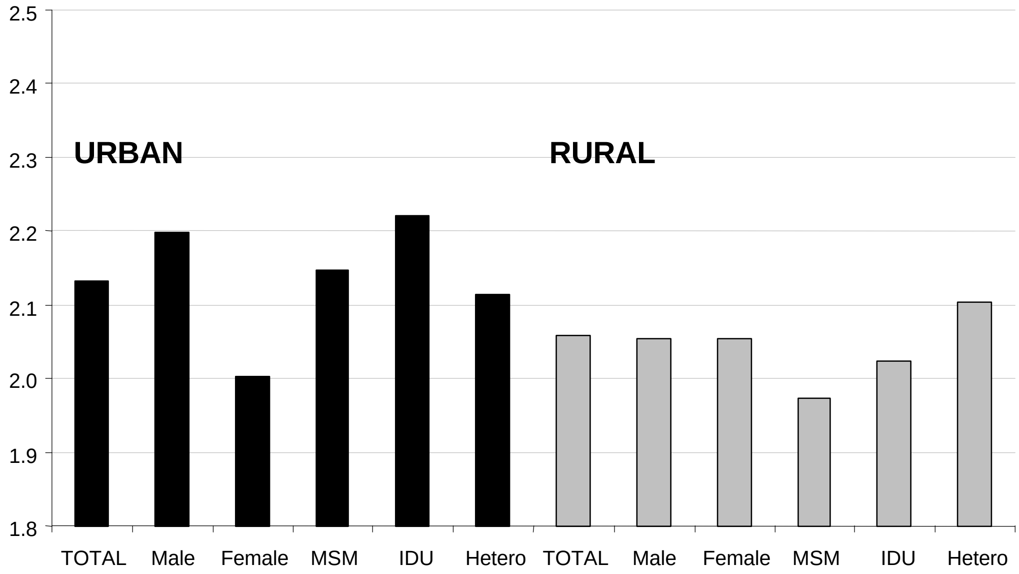


Figure 10-3 shows the barriers for the urban and rural PLWH/A. It is further divided by gender and risk group. Urban females living with HIV and AIDS report the lowest overall barrier scores. In the rural areas, the heterosexuals indicate the highest overall barrier, but no group indicates a very high overall barriers.

Figure 10-3 Average Barrier Scores by Urban - Rural

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



Categorizing Barriers Reported by PLWH/A

Table 10-1 divides each barrier into individual, organizational and structural factors. The individual factors are further divided into those barrier related to the participant’s knowledge or well-being. The organizational barriers were subdivided into provider sensitivity, accessing to providers, provider skills, access for families, and confidentiality. Also on the organizational factor are barriers related to treatment and adherence. They are included in the organizational barriers because PLWH/A tend to relate treatment barriers to other organizational barriers based on the factor analysis. The "adherence" item under treatment, conceptually, is more of an "individual" barrier.

Ranking of Specific Barriers

The rank order for the total population for each barrier is shown in Figure 10-4. As indicated in the overall barrier scores, no single barrier is ranked as a "big barrier". The highest barrier, "red tape" is considered between a "moderate barrier" and a "small barrier". When viewing the mean scores, a difference of about .1 is significant.[15]. Thus the difference between "red tape" (2.62)

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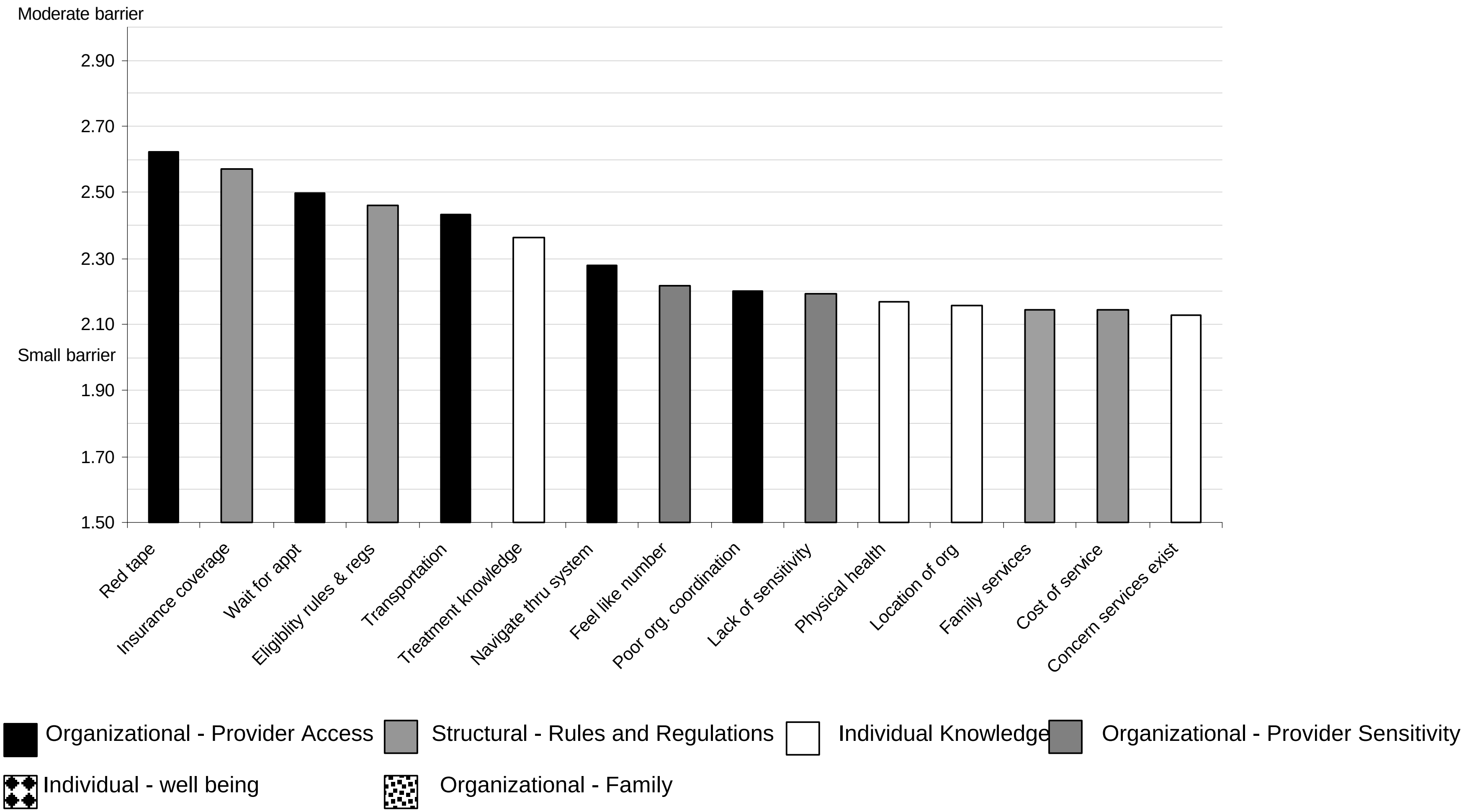
[15] Based on two-tailed t-test, with a confidence interval of 95%. This will vary somewhat for each barrier because of missing data (those persons said it was "not appliable" or left the iterm blank.

and "insurance coverage" (2.57) is not significant, but the difference between "red tape" and "eligibility rules and regulations" (2.50) is significant.

Table 10-1 Types of Barriers

Individual	**Organizational**	**Structural**
Knowledge	*Provider Sensitivity*	*Rules and Regulations*
1 Treatment knowledge	8 Feel like number	30 Insurance coverage
2 Knowing services needed	9 Lack of sensitivity	31 Cost of service
3 Location of organizations	10 Sensitivity to beliefs	32 Rules and regulations
4 Concern services don't exist	11 Communication with providers	
	12 Discrimination	
Individual well being		
5 State of mind	*Access*	
6 Denial	13 Poor org coordination	
7 Physical health	14 Wait for appt	
	15 Red tape	
	16 Navigate thru system	
	17 Transportation	
	18 Referrals	
	Treatment	
	19 No options re treatment	
	20 Understand instructions	
	21 Adherence	
	Provider skills	
	22 Speak client's language	
	23 Provider expertise	
	24 Quality of service	
	Confidentiality	
	25 Confidentiality	
	26 Reported to authorities	
	Family	
	27 Single family primary care location	
	28 Child care	
	29 Family services	

Figure 10-4 Individual Barrier Scores - Highest 15 for the Total Population



As seen in Figure 10-4, out of the top nine barriers mentioned, five are organizational access barriers (black bars) and two are structural barriers (dark gray bars). Most related to the ability to obtain direct services. The organizational access barriers included:

- The amount of red tape and paperwork I had to fill out to get the service
- The amount of time I had to wait to get an appointment or see someone
- Not having transportation
- My ability to find my way through the system
- Poor coordination among the organizations providing services.

Organizational Access Barriers

Red Tape - Focus Group Comments

The highest barrier reported by PLWH/A was red tape, P16 a female African American heterosexual finds both the amount and level of difficulty of the paperwork overwhelming. She said, "*Paperwork -- too hard to fill out, too long. Not too hard to read just takes forever to fill out. You sit there for 30 minutes filling it out, by the time you get there, you're too tired to answer the questions. And then they start using big words and different words. So I have a little paper dictionary."*

P30, a female Anglo IDU agrees and focuses on the frequency that agencies ask for information. She said, "*I go to [an outpatient care ASO]. I need to get a picture ID. I got my birth certificate and Social Security card. They make you reapply every month, which is a pain in the neck. I have to get all that stuff, even if it's a bus pass, before the end of the month. If you are not on Medicaid, you have to show them your lease agreement and everything. We get Food Stamps and I have to prove where I live. I have to get my ID or bus pass before I see my doctor or psychiatrist. I like my doctor and psychiatrist, but it's a pain in the neck, the gold card thing.*"

P96, a male participating in an open session, made a suggestion to help eliminate red tape. *"My only recommendation would be to have some type of centralized computer system. Where if you have a case manager and you fill out all your paperwork with them. If your case manager refers you to [an ASO's food pantry] for food, you have to contact [that ASO] and go through their whole smear with their application. Why can't everything just be all together instead of filling out 700 pages worth of questionnaires and stuff? Everything is just centrally computerized."*

Waiting Focus Group Comments

Waiting for services was the third highest ranked barrier by participants. They said that there are long waiting lists to be accepted as a new client and that there are waiting lists for appointments once they are accepted. For example, P14, an African American heterosexual female, said, *"There's nowhere (for child care). I looked through the Blue Book and it was like, you need to go to Neighborhood Centers, and I said, I've already went to Neighborhood Center, I've already filled out an application. I'm on a waiting list. You call the waiting list and they're like, call* *back in November [6 months]. I won't need them in November. They're like, you're on the waiting list and you're number 1000 and something. You're waiting forever."*

P49, a heterosexual Anglo male, goes to the outpatient care ASO. He said, "*Its "pretty good, but it's a long wait, that's the worst thing about it. ... I've learned to be patient, but there are a lot of people who are unhappy because you do have to wait a long time. You may go in for an 8:00 appointment and you're not seen until 10:00 and then sometimes another hour before you're discharged and then, if you have to go down and have blood drawn, then you have to wait there too. You really do have to practice your patience, but if you go there expecting to wait, its not so bad."*

Red tape and waiting were combined barriers for some. For example, a P75, a female in her 50's, said, *"You can go to [the outpatient care ASO], my appointment is at 9:30, I get there at 7:30 because I got to get my card for me to see the doctor. I've sit down here an hour for the card, then I have to run up here and tell the doctor I'm downstairs because they tell you to get there 30 minutes early. If you're not there, they'll send you another appointment in the mail. Then you have to wait 2 hours to get your medication. But [the outpatient care ASO] will get many medications filled, I have 6. With Medicaid you can't get but 3. Every time I go to [the outpatient care ASO], I get stressed out. My case manager tells me to go through the Blue Book."*

P66, an African American male, sums it up. He said, *"The biggest barrier for me is going through the red tape and going through the long process of filling out all this paperwork. Then you have to wait and then not meet different criteria! The bureaucracy!!"*

Several participants noted that they had to wait far too long for crisis care. P76, a male who attended an open session, represented this view. Speaking about the a government funded medical center and an outpatient care ASO, he said, *"if you have an appointment there is not any problem. If you get sick and try to get seen, it's a nightmare."* Because symptoms often occur with little notice, there was a perceived need to see a doctor quickly. For example, an African American female said, *" Right now I have a cold, but it takes so long to get a doctor's appointment the cold will have gone away or gotten worse…and sometimes it happens by the time you go to the doctor for whatever I had, it's gone…well I had a rash, and the rash is gone, then in two weeks it comes back, but by the time I go back again, the rash is gone.* Several participants echoed an undocumented Hispanic male who said, *"I was told that if I had an emergency to go to the emergency room."*

Several PLWH/A noted that while the dental services were excellent at an ASO, the wait can be a barrier. For example, P39, an African American male said, *" The day that I waited for 4 hours…they told me one of their doctors didn't show up…apparently this happens all the time, they just don't have enough dentists that will work with us [patients who are HIV positive]. They just have you sitting there all day."* P41, another African male, adds, *"I've been rescheduled 7 different times."*

Long waits are related to PLWH/As' perception of the quality of service. P83, a female who attended one of the open sessions, sounds a common refrain. She said, *"I have a bus pass and I use the [ASO transportation provider]. They are terrible. I call two days ahead of time, then they forget about me, they don't have me on the list. When they get ready to pick you up, you have to wait 2 or 3 hours."* P122, a rural Hispanic female, was aware that it may be funding problem, but she said, *"Sometimes I don't have transportation, because sometimes [the respite care ASO] loses it's funding. My dad has to take off with no pay, just to take me down to the doctor. We've been having a hard time with that."* And P69, a female in her 40's, said, *"They make things unobtainable if you don't have a car or they (the provider) don't provide some type of transportation."*

Housing was another area where PLWH/A state the waiting list was a barrier. P70, a male attending an open session, said, *"They got these long lists to get on housing. I get $520 per month, and my housing is $420 per month. I called several agencies. I have to have either an eviction notice or a 3 day notice to get service."* Another participant, P101 adds, *"Section 8, which is the federal program, ... there is a 15 or 18 month wait for Section 8 housing."*

Navigating the System - Focus Group Comments

The third highest organization access barrier is navigating the system. While most participants were aware of the Blue Book, some focus group participants were not. P2, a rural Anglo male, was among this group, and said, *"There seems to be no central base of information where I could find out where to go. You just kind of learn it as you go along. Sometimes it takes years…"* He adds a refrain heard many times. *"The politics stink. The politics that run the system. People have to realize that this is a very incestuous system. Bias exists, [there is] inherent agency competition, inconsistency of service [due to] changes year to year…. The consumer is the one who loses."*

Focus group participants often mentioned the Blue Book as a resource. Even with the Blue Book, however, several participants said they had trouble navigating the system. For example, P75, a thirty-five year old male, said, *"Sometimes when you call the agencies in the Blue Book, they tell you to have your case manager call them. I keep running into these brick walls."* P11, an African American male, noted, *"To me the Blue Book is like a joke. My caseworker tells me they can do this and that. When I was in prison a lady came out and said they would help me get a place to stay, help me get on SSI, and when I got out it was 'boom', here's the Blue Book, take care of your business."*

P18, a heterosexual male, like many participants, relies on personal referrals. He said, *"Most of the referrals I got, have been through other people who have the HIV that are either on the street or have been in a program. Generally, I don't feel like I've heard a lot from people like staff, clerks and like that. They know about their little job function, but that's about it."*

For several participants, their ability to navigate the system depended on the attention they received from their case manager. P67, an African American male, summed this up by saying, *"My biggest need is expertise in plugging me into things, like a better case manager."*

Coordinating Care and Referrals Focus Group Comments

For many PLWH/A the root of the difficulty in navigating the system was the perceived lack of coordination among agencies rather then the lack of information about providers. While, several participants said they received good referrals, some focus group participants commented on the lack of coordination between providers of services. P62, a male in an open session, makes one of the more extreme remarks. He said, *"It seems like none of the agencies work together at all. You have to fill out the same set of paperwork. Too much hassle for too little benefit. Creates a lot of anxiety, I would be better without it."*

More typical, was the feeling by P66, another open session male. He has been referred from one service to another by providers but, said, *"I need more continuity of care. One agency refers you to certain things, and another agency refers you to other things. If it were more of a universal thing to where you can be plugged into all the services. That's how you fall through the crack and loop holes."*

A handful of participants understood the need for better systems to enhance coordination. A female at an open session notes, *"I want to know why your case managers can't work with all the other agencies. You do the paperwork in one place, you do the paperwork in another place."* P48, a gay male, noted, *"It would help if there were 1 standardized form that they [service providers] all accepted."* P68, a female at an open session, observed, *"When you go to the Food Stamps office and other agencies, they always say they have this computer match system. I feel if they have this computer match system, you shouldn't have to do the paperwork. They need to coordinate this stuff."* She added, *"Confidentiality about sharing information is not really a concern, I don't care who knows."*

Advocating for greater coordination, P101 noted, *"If they [the agencies] were interconnected and a data base was kept to see who was getting what type of services and where, I think that would stop a lot of the abuse and open up funds and services for other people that are getting pushed away from them."*

The most common refrain among focus group participants was the feeling that the politics and personalities presented barriers to coordinated services. For example, P45, an Anglo MSM, said, *"In this town, it seems there are personality issues at all these agencies and everybody knows there's no way we're going to give that [information] to them [another agency]."*

Structural Barriers

In Figure 10-4 the second and fourth highest barriers were structural. These barriers are more outside of the control of the provider and require changes at the regulatory or legislative level and include:

- Not having enough insurance coverage
- Not being eligible to obtain services because of rules and regulation.

Insurance - Focus Group Comments

The focus group reveal that when participants say that insurance is a barrier they may mean the lack of life insurance, concern about caps on coverage, the limited choice of providers under their plan, or lack of hospitalization.

P13, and African American male, noted *"I don't have anything to give my son if and when I pass."* And P117, a rural female, said, *"My major concern was my family and if I die ... how they gonna have for money. ... I don't know how to get it. I'm scared if I do go get a burial plot, I must just die that day. My kids, I really want to leave them something."*

Several participants mentioned caps on coverage and limited coverage. P85, a fifty-year-old Anglo male, said, *"Biggest barrier - insurance caps, pharmacy caps, HMO's through Medicare. The money is going to have to be shoved out that I don't have for the drugs that the TDH won't cover. I really need those drugs."* P66, an African American male, said *"I need to get more insurance coverage, my Medicare is kind of limited, as far as I know, I'm not eligible for Medicaid. I've had trouble with meeting the expenses of my medications. I just filled out paperwork for state assistance. Having a bit of trouble because I'm having to get HIV meds and psyche meds and I'm having to go to all these different places."*

P14, an African American female, complained about the limited coverage. She said, *"I have Medicare they allow 3 prescriptions a month. My pills are about 14 pills a day and each of them are about $100 a month apiece and they only pay for 3. I was told the only way I could get the unlimited [coverage] is if I signed over my benefits."* While she recognized she could seek care without insurance, she noted, *" I have a gold card ... [the outpatient care ASO] is fine, I'm happy with [them], but what if I get sick and have to go to the hospital. I don't want to go to [a hospital funded by Harris County]. I won't go, I would die at my house, and that's a problem for me. What's most important is when I can get some kind of medical or Medicaid where I can pick where I go. I have to go to [the hospital funded by Harris County] where they switch doctors every month. The doctors don't know what your case is, they're asking your family members what's wrong with you."*

The recent switch to managed care providers has presented some concern about insurance. P15, an African American female, noted, *"They have this new stuff where you've got to pick your primary doctor... That part I don't like because it took me 4 –5 months to pick my doctor but I ended up with HMO Blue, and then when I went back to [the ASO], they said they couldn't take HMO Blue."*

Rules and Regulations Regarding Eligibility Focus Group Comments

The second highest structural barrier concerns rules and regulations regarding eligibility. The focus groups reveal several barriers that PLWH/A face regarding eligibility. In a general sense, P2, a rural Anglo male, noted, *"The agencies don't make the rules clear enough. There is no general information that we can all access."* P16, a heterosexual African American female, noted her difficulty in understanding the rules of providers. For example, she said, *"[A religion* *affiliated ASO] refused to help me because I was not case managed through their organization. They refused me help and I had faxed them my bills, my $280 light bill, only $500/mo, rent $200... At one point, I couldn't get my meds, they put my Social Security on hold. My godparents and my mother had to step in."*

Some participants found the process simply too intrusive. P51, an MSM Anglo male, noted, *"Food banks ...want to know too much information, about personal income…if you're living with somebody and that other person doesn't want that revealed."*

Many of the barriers involved the level of income required for eligibility. For example, P38 recalls his experience with [a large ASO]. He said, *"I called [them], and first of all, there is a very elaborate process…and I finally got to talk to them and gave them my spiel and they basically said we can't help you… They don't want to talk to me until I have no income."* Others note that the rules about income that include living with others in the household is unfair. P19, a heterosexual male, said, *"They pull that shit on you. They won't help you if you're married and your wife's working."* P14, a heterosexual female, made the point that, *"I'm married but I'm separated which means that the majority of the bills are in my husband's name and with them they won't touch your bills unless it's in your name. So that means I had to go and get my lights which was in my husbands name, and I had to get the water put in my name. That means I had to go and put another deposit down again and with the lights I would have had to pay $300 and something, and I would have to do a deposit to get it changed over to my name and that's just to get a bill paid."*

The difficulties in qualifying and maintaining SSI were mentioned by several participants. P12, an African American male, noted, *"SSI is a barrier because of their rules."* For example, he say, *"I have AIDS and was receiving SSI in 96. I went to prison and did 11 months, they cut me off. After a year, you have to reapply but I did less than a year. Reapplying for SSI is a pain in the ass."*

Several participants mentioned the hurdles that had to be overcome to qualify for housing. P39, a African American MSM noted, "*I applied there [a ASO community foundation] 2 or 3 times and been denied…I had been clean and sober for at least 8 months. The bad part is that they have 3 brand new group homes and each one is supposed to hold 6 people at any given time, the most they had there was 6 people... The facility is there but they're not putting people in it, so where's the money going? Independent living is virtually impossible because of the income barrier."* Others noted that they had to be homeless before they were eligible. The comment by P11, an African American male, was typical. He said, "*By me staying with my grandmother, I don't pay no utility bills and I don't pay no rent.... I don't have no job, no income. [A large ASO]... said they could help me with housing, but first I have to get out of my grandmother's house."*

Unfortunately, the "street smart" participants noted that the rules are sometimes so burdensome that the best way is to lie. P18, an Anglo heterosexual male, said, "*The obstacles that are put in front of us are almost impossible to overcome… If you lie, lie your ass off, you do better."* P79, a thirty-five year old male, said, "*I think it's sad sometimes that we have to lie to these people in* *order to get service... I was living with my grandmother, she is not the one sick. So, why did they need all of her income, if I applied for Food Stamps and Social Security? Right now, I need medical attention. So I lied and told them my grandmother wasn't taking care of me... I lied and told them Social Security turned me down when I never really applied. I had to lie to them and tell them I wasn't working in order to get treated. I don't think that was right. The criteria you have to go to get service, it's too hard for a person like me."*

Individual Barriers

The sixth highest barrier, "Not knowing what treatment is available to me" is an individual level barrier. Two other individual knowledge barriers are in the top 15, including, the location of the organization providing services, and my concern that the services I need do not exist.

Knowledge of Treatment Information Focus Group Comments

Despite a very high level of access and utilization of outpatient care and high levels of general information, some participants in the focus groups said they did not know certain medical information. P18, an Anglo heterosexual male, said, *"I needed information right away, as far as my T-cells and things like 'Was I in the proper place... to get treatment?' And it was hard for me to find that out. And so I did experience a period where I went right back to drug and alcohol abuse. The stress was so much that I went right back to drugs and alcohol. It was at least a month before I found out where I was supposed to go, the next step. And that period was so long and so stressful."* P66, an African American male, said, *"I know enough information about the virus and how it affects my body, I think I need more education on the medication because I'm getting a lot of side effects from medications. I was on AZT and now I'm on a cocktail and it keeps me nauseated, fatigued, diarrhea."* P148, a heterosexual Hispanic male, said, *"I'm starting over again. I need more education on how to take the drugs. That has stopped me from taking the drugs at one time."*

Concern and that Services Do Not Exist and Knowledge of Services Focus Group Comments

As noted above, the Blue Book is well known by PLWH/A. P16, a female African American, said she learned about services, *"Either through my case managers or like I said I pick that blue book and go through it. I even found out in case of burial, they have certain organizations that will bury you, and pay for it, or at least pay for half of it."*

Despite the Blue Book, there was a common refrain about "learning as you go". P18, an Anglo male said, *"There seems to be no central base of information where I could find out where to go. You just kind of learn it as you go along. Sometimes it takes years."*

Several focus group participants wanted to know more about specialized groups. For example, P23, an African American IDU female, said, *"I am gay and it is hard to find groups that is for lesbians and HIV positive substance abuse... I'm just not that cool when it's dealing with different issues. They have HIV groups I don't care for, but they need more programs for* *women's dealing with substance abuse."* P119, a male from Ft. Bend, noted, *"Services are not volunteered. You have to seek them out then you have to go through 12 people to find them."*

P7, a female, said, *"I don't need it right now but when I get sick will somebody be there to take care of me? Will somebody be there to provide food for me? Will somebody be there to give me my medication? Will somebody be there to clean my apartment because I probably won't be able to get up and do it myself? Will somebody be there to come pick me up and take me to my doctor's appointment? Stuff like that, that's really important."*

The soon to be released and recently released were particularly likely to say they didn't know about services. P69, a forty-year-old female, said, *"I was locked in the state pen in Dayton, Texas, and no, they do not have any services."* P75, a fifty year old female, said, *"When I found out, I was locked up in Tennessee and was called to the infirmary... I had to educate myself because I didn't have nobody. My family, they didn't know. I would go out to the clinic and just sit there and ask questions. I wanted to know what was going on to my body."* P139, an STR female, said *" When get out, I go back to being homeless. No one to help me. No one's helping me find a place to stay."*

Location of Provider Focus Group Comments

Because of the distances that both urban and rural PLWH/A have to travel for social and medical services, it is not surprising that several participants mentioned location as a barrier to accessing services. While statistically rural participants were no more likely to mention location as urban participants, many of rural focus group participants made a special point of mentioning transportation.

As one P116, a female from Ft. Bend, complained, *"you have to go to [downtown] Houston to get your lenses."* P15, an African American heterosexual woman stated that, *"I ride the bus but sometimes I don't make it to my appointment. If I could get a bus card (pass) every month, it would help me out a whole lot."*

The trip is not always to Houston. P113, a male from Ft Bend, noted, *"Anything major, you have to go to Galveston."* P4, a rural Anglo male, said, *"Transportation is a major concern for rural people living with HIV/AIDS. There are no buses at all."* P4, an Anglo rural male, echoed the sentiment, *"Transportation. They [rural PLWH/A] are royally getting screwed now."*

Coordinating traveling to services is more complex when both the parents and children are HIV positive. P102, a male Anglo, noted, *"Being an AIDS patient myself, I knew the first thing to do was to get him on treatment... Where I live, Pasadena, it's tough. I can't even get medical treatment for myself, much less for my son. I have to come into town to get treatment."*

Although most participants of focus groups say they would like services to be closer, a minority says they do not want them in their immediate area because of confidentiality. P5, and Anglo female, said she didn't want someone from her hometown, *"because of confidentiality."*

While going from rural to urban centers is a barrier, going from one section of Houston to another section can also present a barrier. P7, an African American female adolescent, said, *"All HIV services are located in the Montrose area, I think because it's a gay area that's where this got started, but people who stay in the North Side, Southwest, South Park and those services aren't available there. We want clinics too.*"

Physical Health Focus Group Comments

In the outcomes section of this report, well over 50% of the PLWH/A said their physical health was the same or better then when they found out they were HIV positive. Overall, physical health is not seen as a big barrier. Still, several participants in the focus group commented about their physical health being a barrier. P13, a heterosexual African American male, said, *"My physical health has been a serious barrier. I stayed in a wheelchair for one calendar year."* P149, a heterosexual Hispanic male, said, *"My physical health - the way I feel and if I have to travel to do it (an appointment). If I have to do anything, I have to plan ahead of time especially having two kids in the house. I know that [the ASO transportation provider] is an option, but I would rather leave that service for somebody that really needs it."* Some PLWH/A find they are not part of the overall trend toward better health. P38, a female, noted that at a large ASO *"they are really being inconsiderate with this HIV stuff for the people, they say we don't need it. I'm mentally and physically sick from this disease... It's not that [I am] living longer healthy, [I'm] living longer sick."*

Other Organizational Barriers

Other organizational barriers in the top fifteen barriers are related to provider sensitivity. The two are: "the organization providing the service making me feel like a number" and "the lack of sensitivity of people providing the service to my issues and concerns". Relative to other barriers they are quite small.

Feeling Like a Number - Focus Group Comments

While a small barrier, there is some expression by a few participants that, because of the waiting a bureaucracy, they feel like a number. The ability to provide feedback helps. P66, a thirty-two year old African American male, said, *"I've been HIV positive going on 10 years now and this is the first time I've participated in anything like this and I think this is really great. More things like this would really help our whole overall cause... As a HIV client I sometimes feel like I don't have a voice. I don't really matter, I'm just a number."* P97, a thirty-year-old male, said, *"I've gone to [a large ASO] waiting, and waiting, and waiting. It made me feel as if I was just a number. [They] told me to come back in 3 weeks, 2 weeks. Luckily a friend told me about [an ASO providing outpatient medical care]. It was a complete change in attitude in acceptance and service. As far as the services, it was we'll see you in a week, call us if you need us. That's what I needed to hear."*

Lack of Sensitivity to Issue, Concern, and Beliefs Focus Group Comments

Most participants noted that they were treated well by providers. However, several participants said they had at least one or two encounters with insensitive providers. This is likely to mean that there is not a systemic problem with insensitive providers, but there are provider staff that could use additional training about client contact. Several, like P16, an African American female, said the drivers of the cars were insensitive. She said, *"If you drop someone off at 11 and they ask you to pick them up at 12:30, then try to accommodate that person. You don't know what else that person's got to do, don't have that person waiting until 2:30."*

Several others mentioned the lack of sensitivity within the transportation system. P125, an African American male living in a rural area, said, *"[The drivers are] really not concerned with your problem or situation. Lack of sensitivity: I call to schedule transportation to go to a doctor. They tell me I either have to go there 2 hours before my appointment, or reschedule my appointment. They don't understand that if I miss going to the doctor or if I miss my medications, it's a problem. They don't really care."*

In one instance a P24, a gay MSM, noted that one staff member was particularly insensitive to his needs. He said, *"[Starting meds] was 2 days late because of a woman at [an outpatient care ASO] who has a chip on her shoulder…I hate to say this, but I think she is partially prejudiced against men, partially prejudiced against Whites, and she doesn't have time to be bothered with a lot of stuff."*

Several participants noted that promises to call back by staff are often not kept. P16, an African American female, noted, *"They need to make sure that the case managers that they're hiring to assist the people with HIV there because they care for the individual person, not just the salary.... I think they should be able to talk to us. They shouldn't put us on hold. They say, 'I'm going to call you back' and never call you back…'Well it's you calling again. Well I gave her the message and she'll call you back.' And you never hear from them."*

Some find the process of determining eligibility very insensitive. For example, P13, an African American woman, said, *"[At an ASO that provides support services], they are rude. You're going to them for help, that means, you actually need help as far as paying your utility bills. They ask you, why do you need help? And then they put you through hell. Is the bill in your name? How come you couldn't pay it? What happened to the money? What did you do with your money? If I'm coming to you for help that means I need help, why do I have to go through so much stress to get you to help me."* P45, an Anglo MSM, added, *"I've had a similar experience with [the ASO that provides support services]. Housing has become an issue and I'm looking for some kind of housing I can get into and I was referred to them and brushed off by them."*

Several PLWH/A commented on the lack of privacy of services at different providers. P134, an African American MSM, asked, *"Why can't they ask you about your medical history in a private space instead of with everyone in hearing distance (60-80 people), e.g. about STDs."*

While sensitivity to "beliefs" ranked much lower than sensitivity to "concerns", some participants of focus groups did indicate an intolerance to their personal beliefs. P18, a heterosexual Anglo male, said, *"There are a lot of them [services] that are church-affiliated and I don't like dealing with them. I've experienced religious discrimination at a halfway house for alcohol and drug abusers, I was refused admission specifically for my refusal to join in a group prayer. I would rather not deal with a church-sponsored organization. There's usually a minister running things and if I don't serve Jesus just in the way he wants me to, he can't do anything for me."*

Lower Ranking Barriers

Figure 10-5 presents the lowest ranking barriers.

Confidentiality Focus Group Comments

While confidentiality is considered a small barrier, it is often referred to in the focus groups. P38, an African American MSM, said, *"It was a big [issue] for me because I didn't know if it was going to effect my employment and my insurability and all that other stuff that seems to matter in the real world."* P23 said, *"I am concerned about confidentiality. Some of the agencies have volunteers. And I have seen even the staff members talk about other clients. Need stiffer penalty."*

Among many participants there was a feeling that one cost of being HIV positive means a loss of confidentiality. P2, an Anglo male, said, *"If you need or want the services, you pretty much have to accept that confidentiality may or may not be kept. I think for the most part, it's kept. I think there are some things that are not strictly kept in the way confidentiality should be, but at least it's shared with people for pretty much the right reasons."* P50, an Anglo MSM, confirmed, *"As far as I'm concerned, nothing is confidential."* P45, another Anglo MSM, said, *"I think pretty much you have to expect that it's on the street."* Still, as noted by P48, an Anglo MSM, *"Everywhere I'm going, I need to take a copy of my HIV status and I'm just real uncomfortable with all those copies that have my name on them floating around the city of Houston. It's like a lack of control of my HIV status."*

In communities of color the issues of confidentiality appear to be greater. The comment by P16 is fairly typical, *"I'd rather not have mail come to my house (newsletters). I'd rather not have anyone in my neighborhood know that I'm positive. I think that if I choose to tell them, fine. If I don't, fine."* P35, an African American male, said, *"Things that have kept me from getting help is the concern that the confidentiality will be kept.... Someone in that organization told someone, and it got back to me. That's one of my biggest fears. This is something I don't want people to know about."* P148, a Hispanic male, noted, *"I chose not to go to Bering because I know somebody that works there. Only my family knows about me, not my friends."*
Other individual factors of "state of mind" and "denial" are lower than "physical health" and are rated as a small barrier. While a small barrier, it was relevant for some PLWH/A. P100, a participant in an open session, said, *"I was in denial for 3 years. It is a mind boggler. You feel like you're being punished, you did something wrong. It takes a lot of support; friends, family to*

help bring you out of that." P135, an African American MSM who was in jail, said, *"In the beginning, by state of mind was a barrier to me. When I realized that my stress level affected by T-Cell count, it made me stop and think about where my mind was."*

Treatment Focus Groups Comments

Organizational treatment issues were among the lowest ranking barriers. Most were not issues of awareness, and in the focus groups there were a variety of comments regarding adherence to medication. Side effects are a main reason for poor adherence. P123, a rural Anglo male, said his problems consisted of *"scheduling for food and the side effects of nausea makes [me] psychologically not want to take it."*

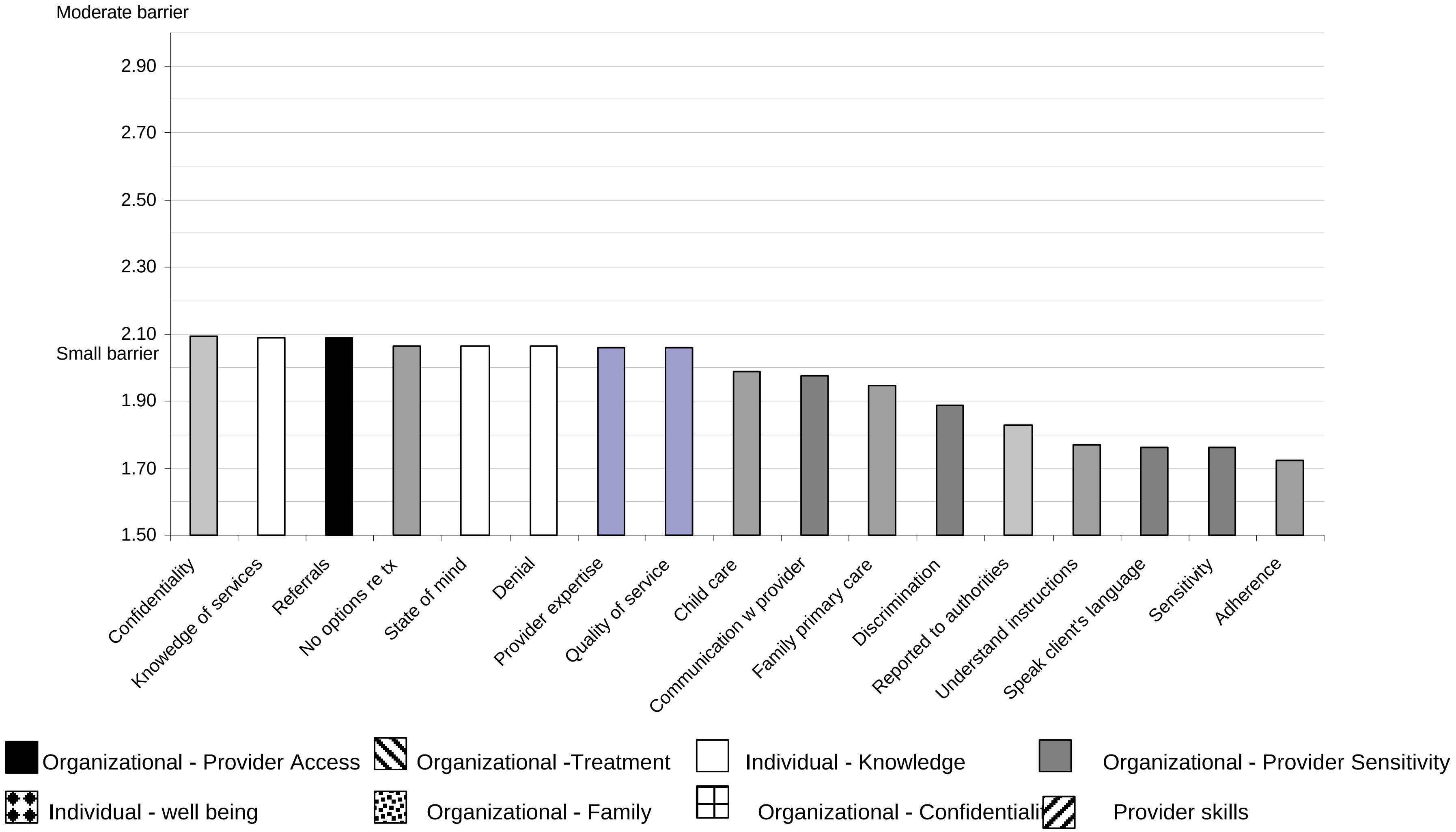
For others it was an unwillingness to keep difficult regimens or laziness. P7, an African American female adolescent, said, *"I'm just lazy (regarding medical treatments)…it's just that the regiment is so hard to follow."* P51, an Anglo MSM, said, *"I don't feel any different when I take them than when I don't so I feel like why take them, so I don't."*

Some participants said they had difficulty comprehending the medication's instructions. P148, a heterosexual Hispanic male, said, *"When I get my medications, they have to tell me 2 or 3 times which pills to take first. When I leave the room, I forget."* P61, a female, simply said, *"We want Laymen's terms when it comes to information."*

There is difficulty understanding providers. P80, a forty year old female, said, *"My biggest problem is explaining myself to a higher degree. Communicating with the provider. They tell me one thing, and I'm under the impression that it's another one."*

Another issue with several PLWH/A is a feeling that they want to participate in the selection of their medication. P70, a forty-year-old male, said, *"I like to choose what I take, because I've read a lot about the side effects."*

Figure 10-5 Individual Barrier Scores - Ranked 16-32 for the Total Population



Discrimination - Focus Group Comments

While discrimination is ranked as a small barrier, there were a number of comments in focus groups about discrimination by providers, state and city workers, and family. There was a perception that gay clients sometimes get preferential treatment. P18, an Anglo heterosexual male, said, *"I have seen what I consider preferential treatment given to gay clients by gay staff or counselors. A lot of these organizations that deal with HIV are staffed predominantly by gay people, so if you come in and are gay, you get a little better treatment…quicker and better treatment."* And P23, an African American IDU female, said, *"[An ASO that provides support services] discriminates. I've been dealing with them for years and they discriminate. If you are not White, you're not going to even know about them [doctor services]. If you are not White, if you don't know somebody, if you are not a friend with someone in that organization, you are not going to get the services that you deserve."* However, there was also a feeling among a Hispanic client that Blacks receive preferential treatment. P3, a rural Hispanic male, said, *"When I was at [a large ASO], I felt discriminated against because I wasn't Black…the nurses were rude…[but] if you were Black, they'd go out of their way to help you."*

One participant believes that there is a knowledge differential by race, a "discrimination thing." P23, an African American female, said, *"Black neighborhoods were not aware of HIV and AIDS. Nobody ever mentioned no bleaching needles. It was like hush, hush. [Then] Blacks knew more about it than Hispanics. It was like White to Black, then Black to Hispanic. To me, it was a discriminating thing. If you were not White, you were not going to get any information, just like the medication."*

Several of the STRs and recently released report discrimination by the police and guards at jails. P134, a male MSM, soon to be released noted, *"Gays are discriminated. Including Blacks. If you get real sick, guards find it difficult to respond because of a lack of trust. Guards won't help if you are on floor sick, you gotta crawl to the clinic – they won't help pick you up"* P2, an African American male, said, *"The police had an occasion to come to our old location…and [later] I happened to go to this gas station that the police have vouchers for to get their gas…and [they] called me the 'AIDS boy'. They don't know whether I am or not [and he wasn't at the time], but in a public place, I walk in the door and its, 'Hey, AIDS boy' for everybody there. And that's the police department!"*

While limited, there continued to be cases of discrimination reported at work sites. P1, a rural male, said, *"I had a regional manager tell me that I had to disinfect the office every time I left it because of my HIV, and I had to use disposable coffee cups. There is so much ignorance out there."*

Language - Focus Group Comments

Even among Hispanics, the language barrier was not perceived as high, and there were several instances where providers were complimented on having Spanish Speaking staff. Still, there were some incidences reported in the focus groups where undocumented and Hispanics felt they were not getting the appropriate level of treatment due to a language barrier. P130, an undocumented Hispanic male said, *"Because [a female PLWH/A friend] doesn't speak English they sometimes treat her poorly and speak to her in a rude way."* P129, an undocumented female, noted, *"Sometimes the people are very rude and they also don't speak Spanish and there is not one there to translate making it very difficult to communicate."*

Often Spanish speakers see themselves at fault. P131, another undocumented male, said, *"Sometimes I get embarrassed and frustrated because I don't know the words."*

Family - Focus Group Comments

Most PLWH/A with HIV positive children are receiving services, and knew of medical services. While lack of services for families is not perceived as a large problem, it is mentioned, particularly family counseling services.

P149, a Hispanic male living with HIV in a rural community, said, *"A lot of things that Ryan White does is great, but there is a lot of preventative that needs to be done. I'm more worried about others out there infecting or re-infecting. I know of a family where mother, father, and 1 out of 2 child have HIV. She is having problems with daycare and transportation. I noticed 1-½ months ago [a large ASO] started advertising childcare there and I think that's great. When you are first diagnosed, you should be sent to [an ASO] clinic."*

P117, a female from the rural area, said, *"Finances are always up there [as a concern]. But, [more importantly], I would like to see support groups for kids with parents who have HIV."*

One adolescent said she needs help communicating with her family. P10, a female adolescent, said, *"I feel like there should be a place or situation where your family -- my mother and my grandmother, my sister and my brother, that's all I have -- they don't really know what to say to me, or how to take care of me…and it's hard and I'm always crying because it's so hard, I'm trying to explain one thing and then I'm not sure if I know but I think counseling for the families*." Another adolescent female, P7, agreed. She said, *"And I think one more thing…family, that's very important…like me for my family to have, I've found I can easily get counseling, but my family could be affected."*

A number of participants with HIV negative children said they felt they did not have services. P16, an African American woman, said, "*There's no place for them [HIV- children] to go for the summer. Everything's offered to positive children. I think that's just horrible. I think we should have some programs where positive or negative kids can go. You're on the waiting list for years."* P2, an Anglo female, said, *"my [son] needs help with his [dental care] and there is nowhere I can take him. Since he is not HIV, they couldn't see him... I tried to get him on there and they called me and said he could not."*

Barrier Analysis by Ethnicity, Risk Groups, and Special Populations

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Not all subpopulations have the same ranking. Generally, as shown in Figure 10-6, men report higher barriers than women. Men have statistically higher barrier regarding organizational access, sensitivity, and expertise barriers. Despite the fact that women were more vocal than men in the focus groups, statistically, men reported higher access barriers regarding red tape, waiting for an appointment, and navigating the system. Men were also are more likely than women to have higher barriers for provider sensitivity, feeling like a number, and lack of sensitivity. Regarding treatment men are more likely than women to say they don't get treatment options. Men reported higher barriers with provider expertise, and communicating with their provider.

A pattern emerges from the barriers shown in the tables in Attachment 21. Attachment 21 shows that African American MSM and African American IDUs are much more likely to have higher barriers on organizational and individual level barriers. Hispanics have higher barriers on rules and regulations and fears of being reported to authorities, but lower than average barriers on navigating through the system. For heterosexual and IDU Hispanics, not having a single care location for themselves and their infant is a relatively high barrier. Not having access to child care is also a greater barrier for Hispanic and African American women.

The recently incarcerated also reported significantly higher barrier than average in the survey and have a number of comments in the focus groups. Some of the highest barriers are reported by the recently incarcerated for red tape and insurance coverage, and they have relatively high barriers for rules and regulations regarding eligibility and the individual barrier of treatment knowledge.

Providers not speaking the clients' language is rated between no barrier at all and a small barrier for all populations. It is ranked significantly higher (between as small and moderate barrier) for undocumented and slightly higher for Hispanics, particularly men. The undocumented also have higher than average barriers for rules and regulations regarding eligibility, family rated barriers, and knowing what services are needed.

PLWH/A with children generally reported the same level of barriers as all PLWH/A, and tended to report lower barriers for the access the systems. They did, however, report higher than average barriers with transportation and the lack of services for their families. Interestingly, those families with HIV positive children ran childcare significantly lower then all PLWH/A.

There are few urban-rural differences in barriers. Rural females are significantly more likely to say that childcare is a barrier as well as ranking rules and regulations regarding eligibility higher than average. Rural IDUs and heterosexuals said that lack of family services was a higher barrier than average.

PLWH and PLWA generally rate barriers about the same. PLWH have significantly higher barriers for rules and regulations regarding eligibility, confidentiality, and denial.

Figure 10-6 Individual Barrier Scores - Highest 15 for Males and Females

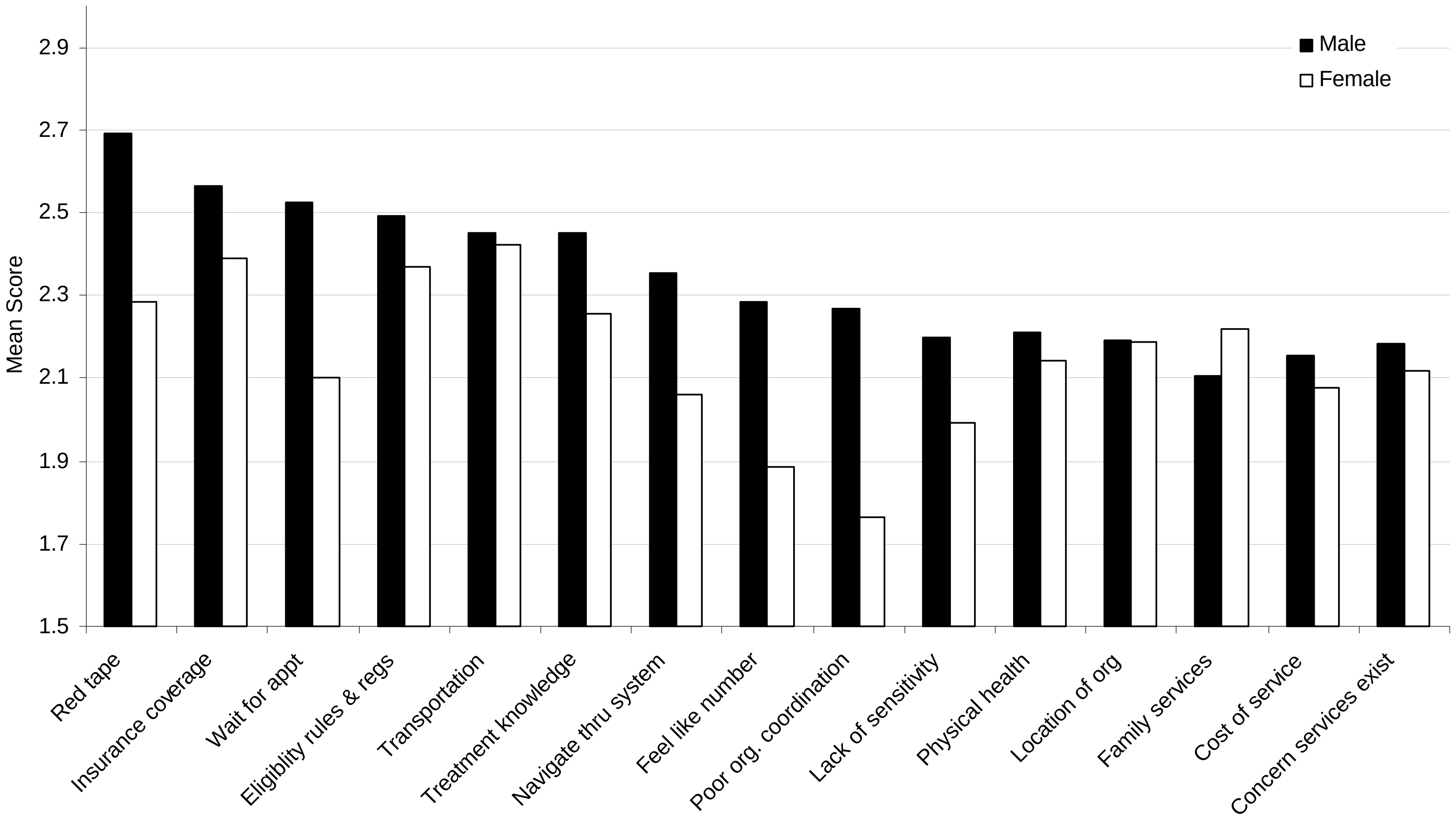


Figure 10-7 Individual Barrier Scores - Highest Barriers for MSM

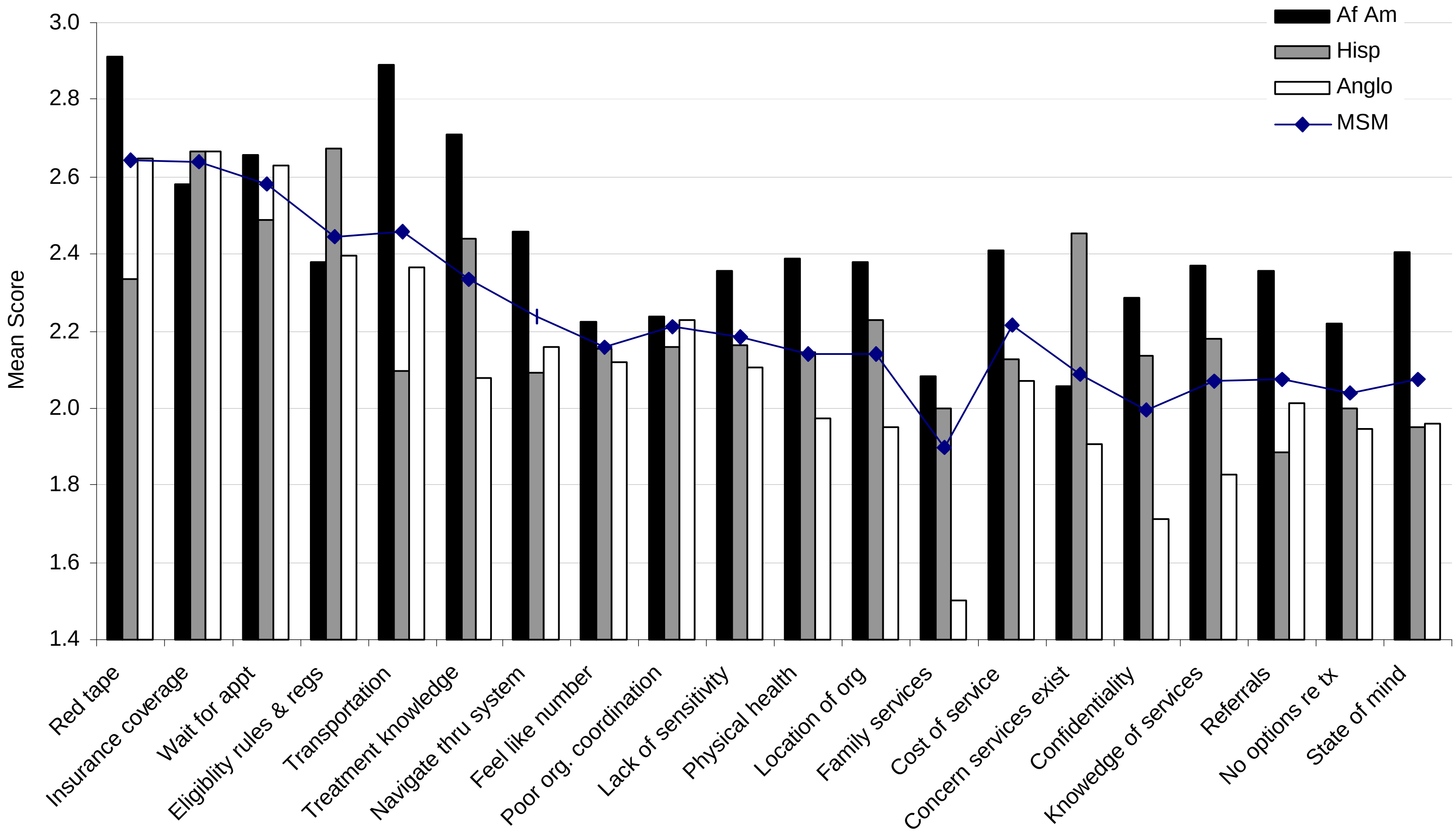


Figure 10-8 Individual Barrier Scores - Highest Barriers for IDU

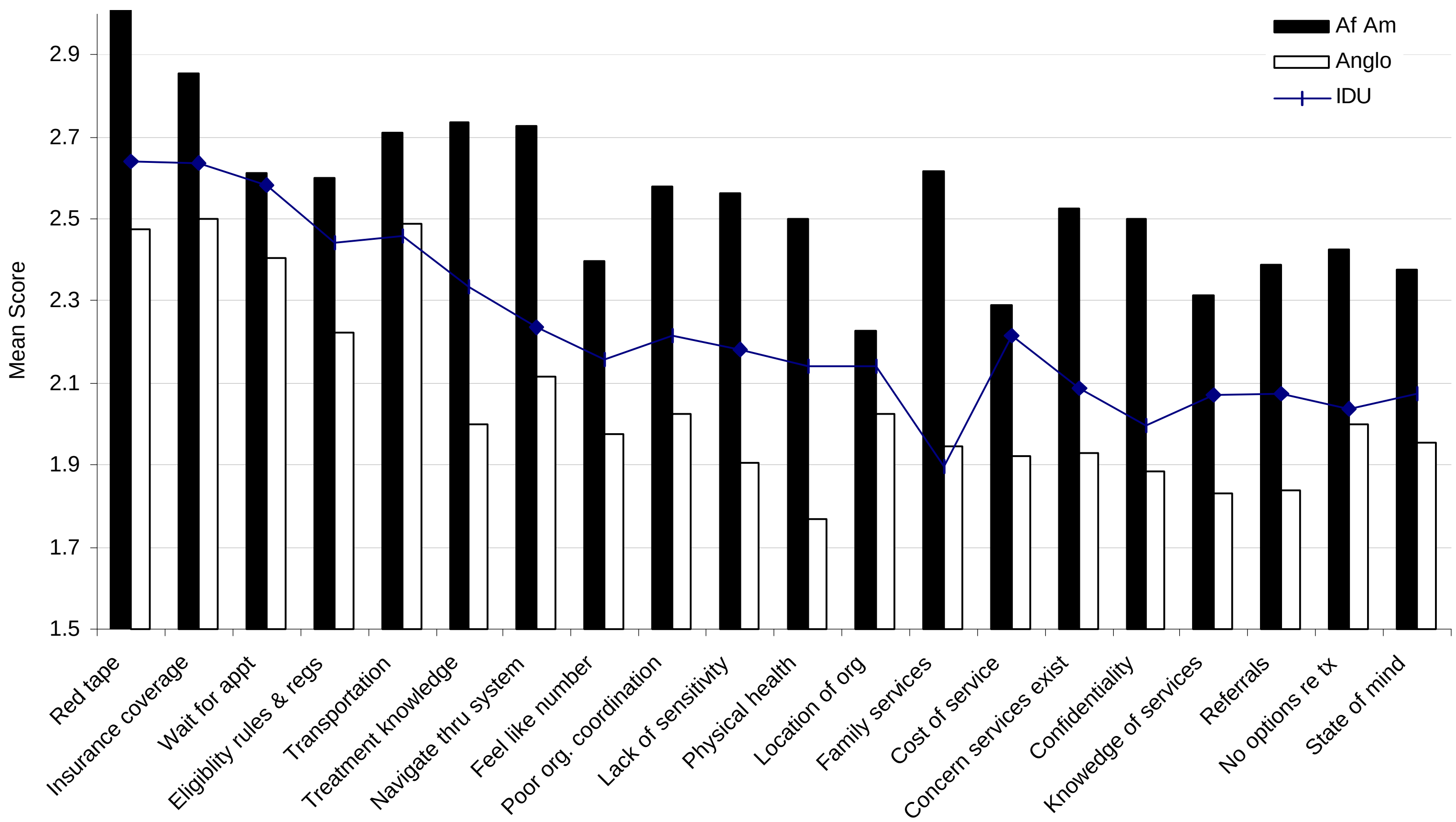


Figure 10-9 Individual Barrier Scores - Highest Barriers for Incarcerated & Recently Incarcerated

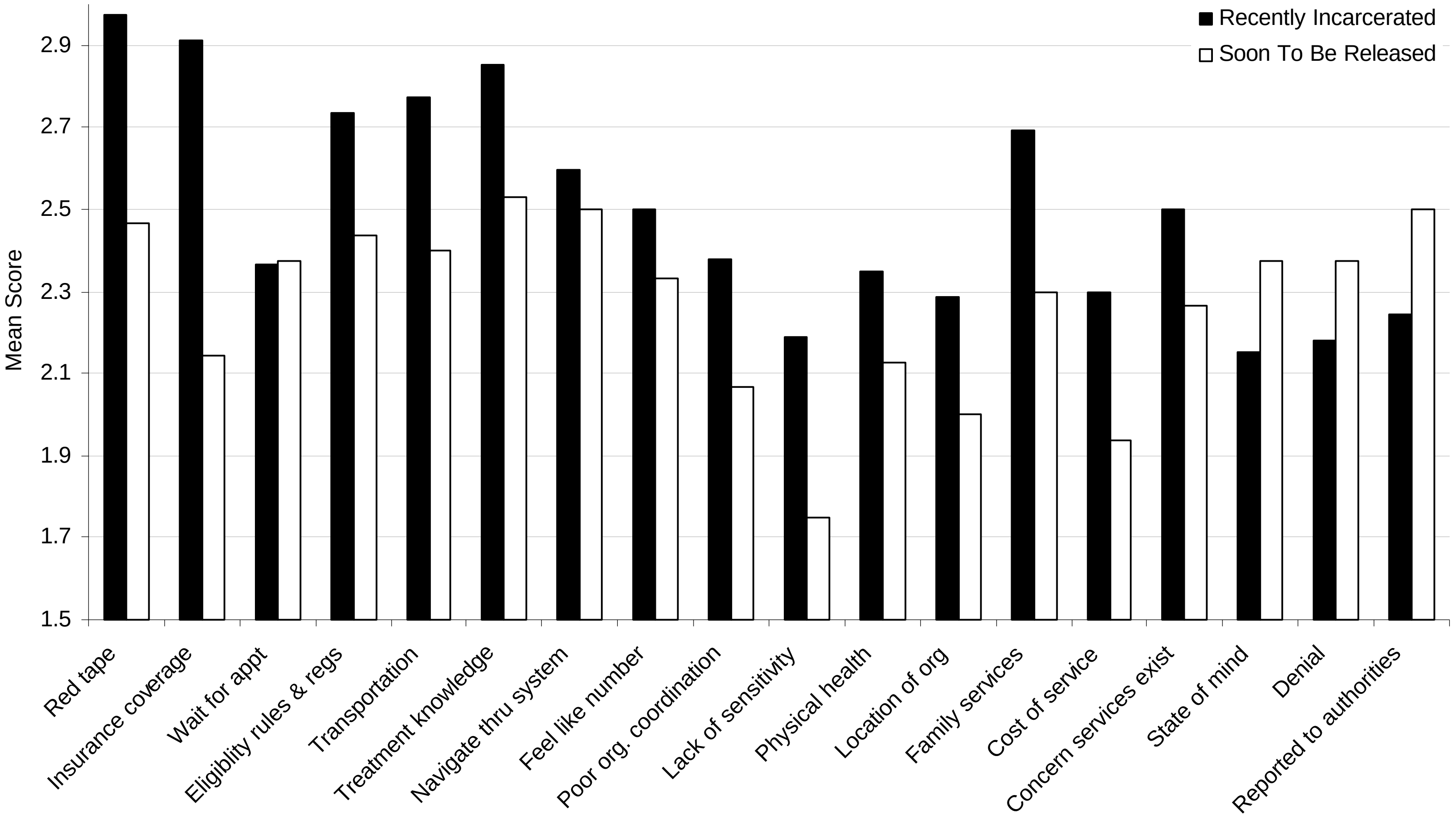
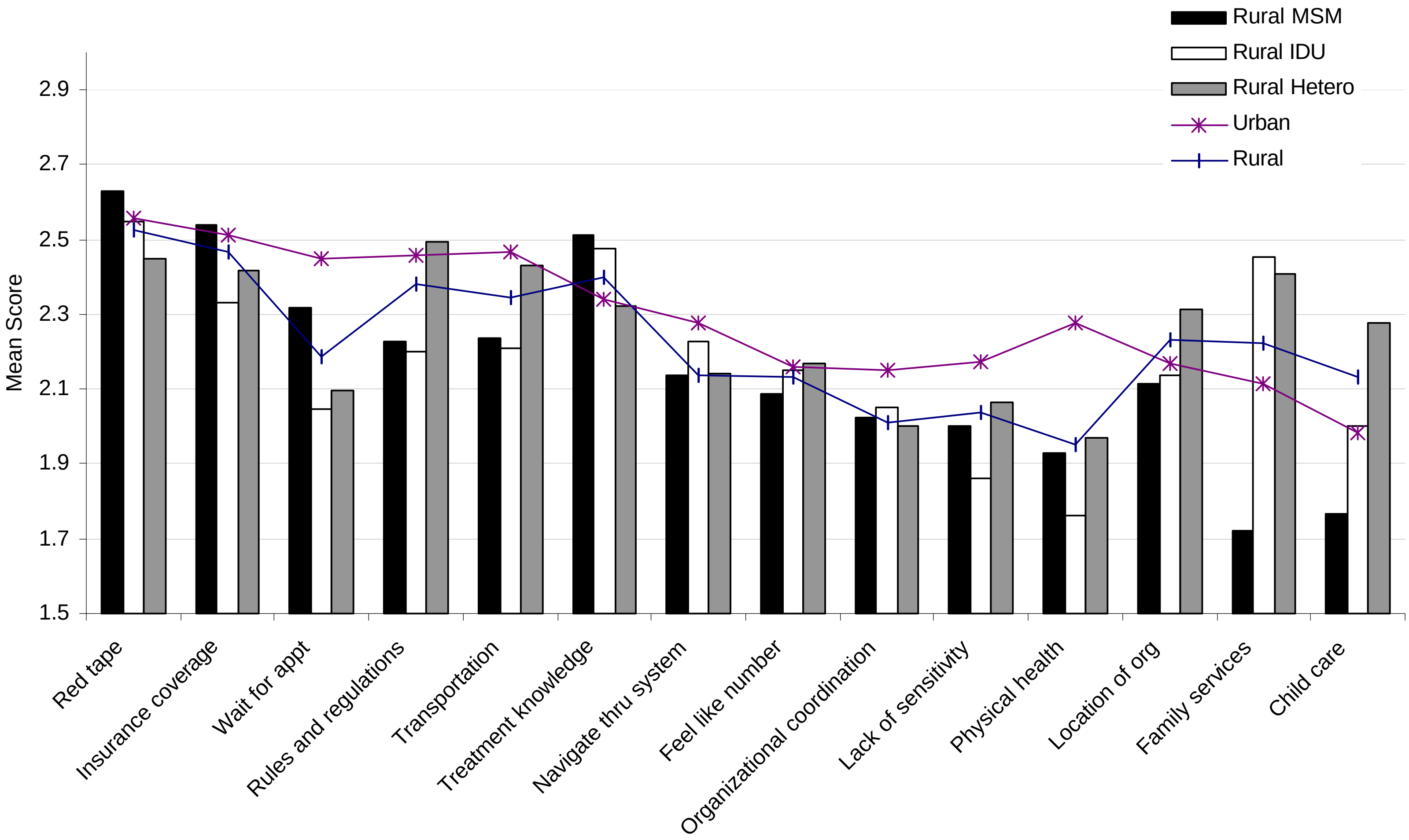


Figure 10-10 Individual Barrier Scores - Highest Barriers for Urban-Rural



Provider Perception Of Barriers

As part of the provider survey, 45 providers rated 98 HIV/AIDS care programs for PLWH/A on the same list of 33 barriers that the sample of PLWH/A rated. Using the same scale for rating barriers as PLWH/A, each barrier was rated on a four-point scale ranging from a big barrier to no barrier at all.[16] In both instances, respondents used their own point of reference to rate barriers. The following discussion presents the views of providers across different programs. An additional item was included to determine providers' perception of their own ability to treat dual diagnoses.

Ranking of the Specific Barriers

Attachment 22 illustrates the reported barriers to care as rated by the staff from 45 participating agencies. Attachment 22 is divided into two tables presenting 27 programs types rated by the providers. The number inside each cell represents the average barrier score provided by program staff for each barrier. The bold scores represent the top three scores for each program. If there was a "tie", then both scores are in bold so there may be more than three bolded figures in each column. In Attachment 22, the barriers are listed in the order of the overall barrier score.

How to read the Barrier Attachment

There are differences in the individual barrier scores among the 27 different programs. The tables in Attachment 22 can be read across columns to compare the different perceptions of each barrier among the different programs. For instance, when the specific barriers are analyzed, some barriers are rated higher by some programs than by others. For example, program staffs from the dental care, hospice care, and respite care feel that red tape is a big barrier for accessing their services. However, staffs from drug reimbursement, health insurance continuation, rehabilitation care, buddy companion, and transportation programs feel that red tape presents no barrier.

Although there is no overall barrier rating higher than 2.6, several programs report a number of big barriers among the 32 different barriers. For instance, the dental care, rehabilitation care, hospice care, respite care, and transportation programs report several "moderate" and "big barriers." Interestingly, program staff from the respite care programs, unlike staff at other agencies, attribute a greater number of barriers to systematic or regulatory factors than to individual characteristics. The specific barriers will be discussed in the text below.

Attachment 22 can also be read down the columns to compare the effect of each barrier within each program. For example, program staff from primary medical care report that the clients' adherence to medical regimens is a moderate barrier while options about treatment or ability to interact with the providers is less than a small barrier.

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[16] For exact wording see page 5 in the provider survey, Attachment 3. This is can be compared to the consumer barriers on the PLWH/A survey, question 43.

Before reviewing the individual barrier scores, the next section presents the “total” barrier score shown in the first column. The "total" score is the cumulative average for the 32 different barriers.

Overall Score for Barriers

Overall, similar to the PLWH/A, none of the providers reported “big barriers” to accessing care programs. As shown in the first column of Attachment 22, labeled “Total,” the highest overall barrier score is less that 2.6, representing a feeling that the barriers fall between a moderate (score of 3) and small barrier (score of 2).

Similarly, most programs report average barrier scores between no barrier and small barrier. Looking across the last row in Attachment 22, labeled “Program Average, ” The highest average barrier score of 2.3 is reported by outreach staff, still it is less than a moderate barrier. Drug reimbursement, health insurance continuation, and buddy companion programs report the lowest average barrier scores of 1.0, no barrier.

Overall Provider Compared to Overall Consumer Barrier Scores

The overall barrier scores of providers are compared to the barrier scores of consumers in Figure 10-11 and Table 10-2. Providers overall barrier ratings (1.8) tend to be lower than the PLWH/A who use their services (2.1).

While the specific rank of each barrier assigned by providers and consumers vary, five out of the top ten barriers are shared by both groups. These five barriers include knowledge of treatment, transportation, navigating through system, red tape and coordination among organizations.

In contrast to the perception of the PLWH/A, service providers attribute the greatest barriers to the individual and not the system. Seven out of the top ten barriers from the providers’ perspective relate to individual traits of the clients such as their treatment knowledge, ability to navigate through system, knowledge of needed services, client’s adherence, client’s state of mind, client’s physical health, and client’s comprehension of information. The consumers, on the other hand, rank red tape, insurance, waiting time, eligibility, organization making client feel like a number and lack of sensitivity as higher barriers to care than the providers.

Figure 10-11 Top Ten Barriers - Providers vs. PLWH/A

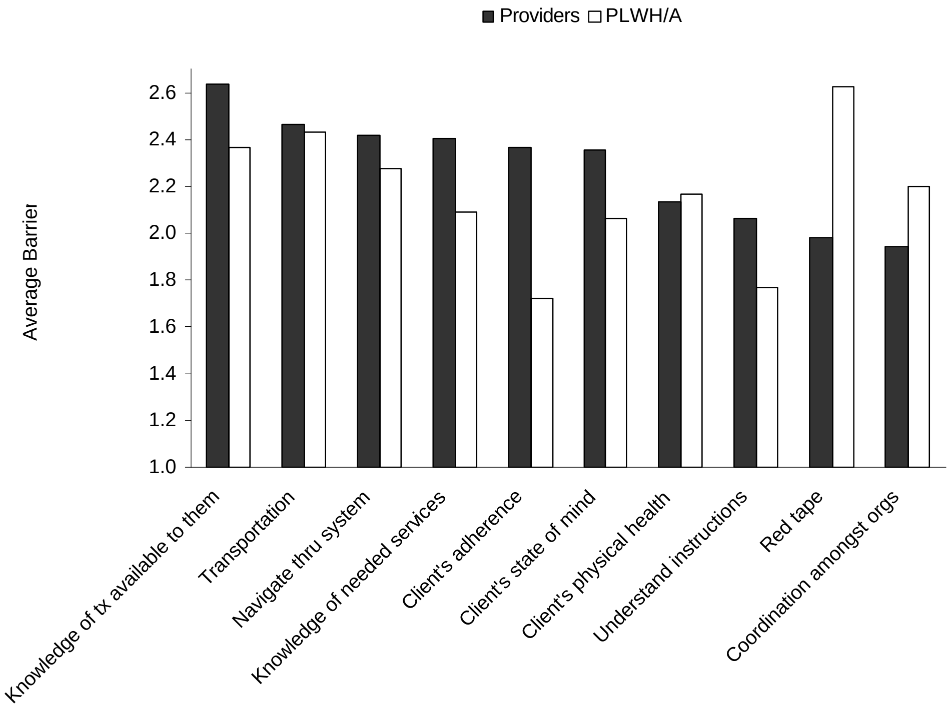


Table 10-2 Provider & PLWH/A Ranking of Barriers

Barrier	Provider Rank	PLWH/A Rank
Knowledge of tx available to them	1	6
Transportation	2	5
Navigate through system	3	7
Knowledge of needed services	4	17
Client's adherence	5	32
Client's state of mind	6	20
Client's physical health	7	11
Understand instructions	8	29
Red tape	9	1
Coordination amongst organizations	10	9

Individual Barriers Scores - Providers

Knowledge of Treatments and Services

Treatment Knowledge

The biggest barrier reported by providers is knowledge of treatment. Providers in the HIV research and housing assistance programs rated knowledge of treatment as the lowest barriers for PLWH/A. In contrast, staff from rehabilitation care, employment assistance, and art programs rate knowledge of treatment as a “big barrier.” In addition, staff from substance abuse treatment (3.7), communication services (3.5), outreach (3.3), and transportation (3.0) programs rated it is as a moderate barrier.

Not surprisingly, providers’ perspectives about what creates barriers to services differ from that of consumers'. While consumers rank it as their 6th highest barrier, about one quarter of the program staff feel that clients’ lack of knowledge regarding their own treatment represents at least a moderate barrier and feel that the clients’ lack of knowledge presents a higher barrier.

Most of the providers who rated knowledge as a "big" to "moderate" barrier provide "wrap around" services to primary care for PLWH/A. The higher barrier rankings may indicate that they see a broader range of clients, many of whom are less informed about the treatment options available to them, or it may mean that they are not as informed about patient knowledge as those in more direct medical services.

In the opinion of a staff member from an outreach program, it is important to educate clients about the HIV Continuum of Care and refer to case management if needed. Creating and informing clients of linkages, however, is not always easy. The experience of a staff member from a rehabilitation care program is that *“It has been impossible to get HIV case management organization… to participate in multi-disciplinary staffing; although Consortium agencies state need for service, requires intensive on-going outreach.”*

Understanding Treatment Instructions

Regarding client’s comprehension of treatment instructions, most providers perceive this as a small or no barrier at all. Staff from information and resources and outreach programs perceived this as the highest barrier among all the programs, yet it is rated less than a moderate barrier. In the providers’ opinion, this represents the eighth top barrier for accessing care. In discussing this barrier with staff from a primary care program, they feel that, despite the availability of bilingual staff, consumers still have difficulty understanding their treatment instructions. The staff feels that, *“Most of the barriers are due to the clients’ special needs. We do have bilingual staff which is informing clients of their medication.”* They recommend, *"More extensive patient medication education. Link it with case management services and more linkage to various psychosocial programs."*

Health Status and Denial

Mental Health

PLWH/A view their own mental status as less of a barrier than do service providers. Service providers rate mental ability as the sixth overall barrier, as compared to the PLWH/A rank of 20. Staff at HIV counseling/testing and rehabilitation care programs believe that a client’s state of mind or mental ability to deal with treatment represents a "moderate" to "big" barrier to care.

Denial

Service providers believe denial of HIV status represents a greater barrier to receiving health care than PLWH/A seeking care. Still, providers rank it eleventh -- a small barrier to care while PLWH/A ranked it 21st -- closer to no barrier at all. The service providers' perception of denial is likely to be a result of the clients' owns verbalization of this feeling. In focus group discussions, PLWH/A often mentioned their response to their initial HIV diagnosis being of shock and denial.

Physical Health

In terms of rank order, PLWH/A rank their individual well being as eleventh out of 32 compared to service providers who say denial is seventh out of 32. The average PLWH/A score of 2.2 is higher than the 1.9 rating it received from service providers, and both are in the range of a "small" barrier. Overall, the lower perceived barrier may reflect the improved health status of PLWH/A.

Program staff at dental care, hospice care, substance abuse treatment, respite care, outreach, camp and art programs, rate clients' physical health a moderate barrier, and that is higher than staff from other programs. This perhaps indicates the different stage of disease of the PLWH/A served by their programs, especially hospice and respite care.

Organizational Access Barriers - Transportation, Navigating the System and Obtaining Referrals

Transportation

For providers, transportation is the 2nd highest barrier PLWH/A have to overcome to obtain services. More than one third of the program staff felt that transportation was a moderate to big barrier. This compares to the 5th rank assigned by consumers. Its relative high rank for both providers and PLWH/A is consistent with comments by the focus group participants. Although several organizations arrange transportation for their clients, there is only one primary provider of transportation. Providers for dental, hospice, and respite care rate transportation as a big barrier for consumers accessing their services.

Navigating the System

The third barrier as perceived by service providers is the client's ability to navigate through the system. This contrasts to the 7th ranked barrier by PLWH/A. As the rules and regulations regarding eligibility change, both consumers and providers need to stay informed and learn how best to navigate the system to assure that consumers receive the services to which they are entitled.

Obtaining Referrals

Consistent with the findings of the needs assessment survey among PLWH/A, service providers also felt that obtaining referrals was not really a barrier.

Structural Barriers Providers Perspective

Red Tape

Although red tape emerged as the number one barrier among the PLWH/A, providers feel this is less of a barrier than individual factors and rank it as the 9th barrier. One respite care providers typically blamed the system. She said. *"Barriers are beyond the control of the organization."* A substance abuse provider suggested that the problem was with the grantee. She said, "*Paperwork is Ryan White's (your) doing and TCADA's doing – not ours, so I don't see how we can resolve that without turning money back."*

Like some PLWH/A, one mental health provider suggested a centralized patient care data management system. He noted, *"When it becomes a reality it will help minimize some of the information systems problem we are currently facing.*"

Waiting Time

As was expressed by participants of the needs assessment, red tape often results in additional barriers such as the waiting time to get to see a physician increases because documents have to be completed, references made, or eligibility criteria checked. For consumers this represents the 3rd highest barrier to care. From the providers' perspective, the amount of time clients have to wait to see someone or to get an appointment is not as significant a barrier, with an overall barrier score of between no barrier and a small barrier and a rank of 24 out of 32.

Lack of, or Poor, Insurance Coverage

Among the structural barriers, lack of, or poor, insurance coverage is rated as the 2nd highest barrier by consumer. In contrast it is ranked 17th by providers and is seen as less than a small barrier from the provider's perspective.

PLWH/A have to choose a health care plan from selected payers and there is a growing challenge among providers to enroll their clients in managed care plans and to assist PLWH/A who want to go back to work and find affordable insurance coverage. The consumers rating of insurance as a large concern reflects their experience with choosing managed care system and the quality of care. Providers may welcome this change as it insures a more uniform level of payment. In qualitative interviews, however, several providers expressed how poorly the system of selecting managed care was working.

Cost of Services

Overall, cost of service to clients is not considered a significant barrier to service. As previously discussed, most services are available free of charge or with minimal co-pays. However a notable exception is the opinion of staff from the direct emergency assistance program. Staff providing direct emergency assistance feel that the cost of services is a big barrier for their clients.

Rules and Regulations Regarding Eligibility

While rules and regulations regarding eligibility were among the top five barriers reported by PLWH/A, service providers perceive this as a lesser barrier to services and rank it as the 12th barrier. Staff from dental care, hospice care and respite care programs feel that rules about clients' eligibility represents a moderate barrier for consumers.

Organizational Barriers Perceived by Providers

Organizational Access - Child Care

Organizational barriers are reported to be a small but somewhat higher barrier by service providers than they are by PLWH/A. While the lack of childcare was rated as the 24th barrier by PLWH/A, service providers rate this slightly higher as the 15th barrier to care. Not surprisingly it was rated as a moderate barrier by providers providing outreach and to PLWH/A with children.

Organizational Access – Provider Location

Although transportation emerges as the second perceived barrier by service providers, the site of the organization does not. The location of the organizations ranks as the 12th barrier for PLWH/A but drops to 19th among providers.

Organizational Confidentiality & Being Reported to Authorities

Coordination Among Providers

Both consumers and providers rate lack of coordination among organizations as one of the top ten barriers.

Staff from health and risk reduction programs feel that the success of their program is dependent on communication between agencies. In the words of a staff member they are addressing this need as follows, “Better coordination with social service and healthcare providers to inform their clients/patients about the forums.”

Confidentiality

The concern regarding client confidentiality is largely in relation to information sharing. Overall, providers and PLWH/A see confidentiality as a small barrier, but providers who distribute information and referrals and those who do research rate confidentiality as a moderate to high barrier.

Treatment Options

Overall, service providers and consumers agree that lack of treatment options is less than a small barrier. However, program staff from the HIV testing and counseling programs feel this represents a big barrier for consumers, probably because for clients newly diagnosed, a lack of treatment options would be a high barrier.

Adherence or Following Instruction for Medication

While adherence was the lowest ranked barrier to obtaining services reported by PLWH/A, service providers feel that this is among the top barriers for clients.

Staff from primary medical programs feel that it is important to *"Strategize constantly for client to promote treatment adherence, address barriers raised by substance abuse, criminal activity, and mental illness."*

Organizational – Sensitivity to Concerns

Quality, Treatment like a Number, and Provider Expertise

Although not perceived as a high barrier by most service providers, consumers feel that agencies making them feel like a number is among their top ten barriers.

Organizational – Provider Skills

Provider Language and Sensitivity to Concerns

Relative to individual barriers, provider communication, sensitivity and language barriers are low.

Yet, several providers mentioned the need for culturally sensitive staff. Program staff from a health education and risk reduction program stated, "We could write a book about problems with clients getting meds in prison and residential treatment and insensitivity of that stuff. That's why we do cultural sensitivity training with staff and advocate one-on-one for clients."

Program staff from a substance abuse program feels that, "Some clients need level II residential. There is no one in Houston that is sensitive to or trained to do HIV. So we take some people that might be better served in residential."
Staff from an HIV testing and counseling program feels that it important to hire sensitive counselors to allay concerns of newly tested clients.

11 PROVIDER PROFILE

Funding, Expenditures, and Service Delivery

This section profiles provider funding and expenditures for service delivery. The revenue discussed in this text is based on self-reported data gathered from provider surveys completed by 45 agencies, and supplemented by reports from the administrative agents of Ryan White Title I and II. Of the 39 Ryan White Recipients, 32 returned a completed survey. Those not returning a survey were small or agencies not funded during the 1998-1999 fiscal year and included American Red Cross, Association for the Advancement of Mexican Americans, Body Positive, Casa de Niños Exempt, Inc., H.O.P.E. Project, Healthy Lunchbox, Loving Arms Foundation, New Hope Counseling Center, S.E.A.R.C.H. - House of Tiny, Trinity Life Center - Adolescent Day Care (Title IV), WAM Foundation. In general, these figures suggest that direct funding from all sources for HIV/AIDS services in the Houston area, including prevention is over $32 million.

The Houston EMA and agencies that receive Ryan White funds reported receiving about $29 million in funding from Ryan White, TDH, HOPWA, Federal grants and private funding sources for treatment and care services. The breakdown of these funds are shown in Table 11-1. The show the AIDS Service Organizations (ASOs), and they are ranked by the total budget. In the Houston EMA, Harris County Hospital District (HCHD), Bering–Omega Community Services, AIDS Foundation Houston and Texas Children Hospital are the top recipients of funds. The columns show the different funding sources and are arranged according the largest funding sources, from left to right. The second left hand column of the table shows the number of programs reported, which may include both care and prevention programs. AIDS Foundation Houston reports the most programs, 11, followed by HCHD with six, Bering-Omega, Montrose Clinic and People With AIDS Coalition each with five.

The sources of funding are shown across the columns and ranked from left to right according to total amount. The percentage of funding from each source is shown in the pie chart Figure 11-1. "Other" funding sources, Ryan White Title I, and Foundations are the top three sources of funding for treatment and care. "Other" funding, as shown in Table 11-2, includes such funding sources as FEMA, HUD, TDHSS, client fees, TDH/CDC, and local fundraisers. Other funding sources account for more than 50% or more of the annual total budget for Harris County Hospital District, Texas Children's Hospital, Montrose clinic, UT Dept of Pediatrics, and Diocesan AIDS Ministry.

Ryan White Title I is the second largest funding source for care. It accounts for a reported 100% of the funding for HIV programs at the Donald Watkins Foundation, Houston Area Community Services, Kids in Need of Drug Evaluation, Memorial Hermann Home Health, UTMB Family Medicine in Conroe, NAACP Houston Branch and Riverside General Hospital.

Tied for the third major funding source are foundations and Ryan White Title II. Foundation support accounts for 44% of funding for the Art League of Houston, 33% for Bering-Omega, 14% Southeast Texas Legal Clinic, 12% of Montrose Clinic and 11% of Amigos Volunteers in

Education. Ryan White Title II accounts for 73% of the total budget for Fort Bend Family Health Center, 56% for the Assistance Fund and 22% for Houston Challenge Foundation.

Table 11-3 shows the funding amounts for prevention activities and services. The total reported amount of funding received for prevention services is about $3.5 million, with TCADA, HCCG and TDH representing the top three funding sources. Table 11-4 shows the "other" funding sources for prevention.

Table 11-1 Reported Care and Treatment funding for FY 98

AGENCY	# of Programs	Other[1]	RWI[2]	Foundation	RWII	TDH	Indiv Donations	HOPWA	TCADA	RWIII	RWIV	Corporate	HCCG	Endow.	TOTAL BUDGET[3]
TOTAL	**75**	**$11,583,790**	**$10,826,620**	**$1,459,359**	**$1,382,886**	**$1,218,200**	**$1,003,022**	**$858,810**	**$634,383**	**$504,082**	**$150,385**	**$143,422**	**$94,250**	**$55,095**	**$29,914,304**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**	**0%**	**0%**	**0%**	**100%**
Harris County Hospital District (HCHD)	6	$5,400,314	$4,031,662	$0	$0	$0	$0	$0	$0	$490,002	$0	$0	$0	$0	$9,921,978
	8%	54%	41%	0%	0%	0%	0%	0%	0%	5%	0%	0%	0%	0%	100%
Bering Omega Community Services	5	$836,618	$507,145	$1,037,102	$149,957	$191,856	$307,313	$0	$0	$14,080	$0	$0	$0	$43,095	$3,087,166
	7%	27%	16%	34%	5%	6%	10%	0%	0%	0%	0%	0%	0%	1%	100%
AIDS Foundation Houston, Inc.	11	$338,820	$142,176	$17,204	$11,191	$204,951	$562,563	$180,834	$0	$0	$24,372	$5,422	$0	$0	$1,487,533
	15%	23%	10%	1%	1%	14%	38%	12%	0%	0%	2%	0%	0%	0%	100%
Texas Children's Hospital		$1,826,239	$0	$0	$0	$0	$0	$0	$0	$0	$81,032	$0	$0	$0	$1,907,271
		96%	0%	0%	0%	0%	0%	0%	0%	0%	4%	0%	0%	0%	100%
Montrose Clinic, Inc.	5	$750,000	$153,300	$185,000	$21,000	$87,000	$40,000	$0	$0	$0	$0	$135,000	$42,000	$0	$1,413,300
	7%	53%	11%	13%	1%	6%	3%	0%	0%	0%	0%	10%	3%	0%	100%
The Assistance Fund, Inc.	2	$100,000	$495,612	$0	$757,956	$0	$0	$0	$0	$0	$0	$0	$0	$0	$1,353,568
	3%	7%	37%	0%	56%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Montrose Counseling Center, Inc.	4	$37,236	$271,616	$18,270	$9,788	$28,935	$0	$0	$634,382	$0	$0	$0	$0	$0	$1,000,227
	5%	4%	27%	2%	1%	3%	0%	0%	63%	0%	0%	0%	0%	0%	100%
People With AIDS Coalition - Houston, Inc.	5	$86,020	$516,940	$0	$66,704	$355,861	$0	$22,186	$0	$0	$0	$0	$0	$0	$1,047,711
	7%	8%	49%	0%	6%	34%	0%	2%	0%	0%	0%	0%	0%	0%	100%
Family Service Center	3	$383,584	$513,850	$0	$40,112	$0	$0	$0	$0	$0	$0	$0	$0	$0	$937,546
	4%	41%	55%	0%	4%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Amigos Volunteers in Education and Services	4	$0	$196,230	$100,000	$30,000	$0	$30,000	$90,000	$0	$0	$0	$0	$50,000	$0	$496,230
	5%	0%	40%	20%	6%	0%	6%	18%	0%	0%	0%	0%	10%	0%	100%
Donald R. Watkins Memorial Found	1	$0	$803,387	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$803,387
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Houston Area Community Services, Inc.	2	$0	$580,726	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$580,726
	3%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
University of Texas at Houston Health	1	$310,735	$291,222	$26,171	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$628,128

AGENCY	# of Programs	Other[1]	RWI[2]	Foundation	RWII	TDH	Indiv Donations	HOPWA	TCADA	RWIII	RWIV	Corporate	HCCG	Endow.	TOTAL BUDGET[3]
TOTAL	**75**	**$11,583,790**	**$10,826,620**	**$1,459,359**	**$1,382,886**	**$1,218,200**	**$1,003,022**	**$858,810**	**$634,383**	**$504,082**	**$150,385**	**$143,422**	**$94,250**	**$55,095**	**$29,914,304**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**	**0%**	**0%**	**0%**	**100%**
Houston Health Science Center/ Dept. of Pediatrics	1%	49%	46%	4%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Diocesan AIDS Ministry, A Program of Associated Catholic Churches	4	$466,802	$0	$34,700	$0	$0	$12,000	$0	$0	$0	$0	$0	$0	$12,000	$525,502
	5%	89%	0%	7%	0%	0%	2%	0%	0%	0%	0%	0%	0%	2%	100%
Visiting Nurse Association of Houston, Inc.	1	$0	$369,044	$0	$0	$91,372	$0	$0	$0	$0	$0	$0	$0	$0	$460,416
	1%	0%	80%	0%	0%	20%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Houston Challenge Foundation	1	$72,336	$82,302	$0	$72,243	$106,500	$0	$0	$0	$0	$0	$0	$0	$0	$333,381
	1%	22%	25%	0%	22%	32%	0%	0%	0%	0%	0%	0%	0%	0%	100%
The Life Center Inc.		$0	$473,405	$0	$26,765	$0	$0	$0	$0	$0	$0	$0	$0	$0	$500,170
		0%	95%	0%	5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Brentwood Community Foundation	2	$0	$82,303	$0	$0	$0	$0	$210,352	$0	$0	$0	$0	$0	$0	$292,655
	3%	0%	28%	0%	0%	0%	0%	72%	0%	0%	0%	0%	0%	0%	100%
Kids in Need of Drug Evaluation & Re-Treatment Clinic	1	$0	$283,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$283,000
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Foundation for Interfaith Research & Ministry	1	$71,360	$163,882	$0	$0	$43,577	$0	$0	$0	$0	$0	$0	$0	$0	$278,819
	1%	25%	59%	0%	0%	16%	0%	0%	0%	0%	0%	0%	0%	0%	100%
UT Health Science Center for Houston Recovery Campus	1	$0	$0	$0	$0	$0	$0	$275,142	$0	$0	$0	$0	$0	$0	$275,142
	1%	0%	0%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	100%
Fort Bend Family Health Center, Inc.	1	$60,000	$0	$0	$160,136	$0	$0	$0	$0	$0	$0	$0	$0	$0	$220,136
	1%	27%	0%	0%	73%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Memorial Hermann Home Health	1	$0	$179,307	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$179,307
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Steven's House	1	$0	$0	$0	$17,860	$0	$50,000	$80,294	$0	$0	$0	$0	$0	$0	$148,154
	1%	0%	0%	0%	12%	0%	34%	54%	0%	0%	0%	0%	0%	0%	100%

AGENCY	# of Programs	Other[1]	RWI[2]	Foundation	RWII	TDH	Indiv Donations	HOPWA	TCADA	RWIII	RWIV	Corporate	HCCG	Endow.	TOTAL BUDGET[3]
TOTAL	**75**	**$11,583,790**	**$10,826,620**	**$1,459,359**	**$1,382,886**	**$1,218,200**	**$1,003,022**	**$858,810**	**$634,383**	**$504,082**	**$150,385**	**$143,422**	**$94,250**	**$55,095**	**$29,914,304**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**	**0%**	**0%**	**0%**	**100%**
Southeast Texas Legal Clinic	1	$7,108	$81,470	$20,878	$19,172	$33,146	$360	$0	$0	$0	$0	$0	$0	$0	$162,134
	1%	4%	50%	13%	12%	20%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Houston Volunteer Lawyers Program	1	$0	$100,000	$17,633	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$117,633
	1%	0%	85%	15%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
UTMB Family Medicine – Conroe	1	$0	$90,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$90,000
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
NAACP Houston Branch	4	$0	$272,774	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$272,774
	5%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Nightingale Adult Day Center	1	$0	$0	$0	$0	$75,000	$0	$0	$0	$0	$0	$0	$0	$0	$75,000
	1%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Northwoods AIDS Coalition, Inc.	1	$0	$68,529	$0	$0	$0	$0	$0	$0	$0	$0	$3,000	$0	$0	$71,529
	1%	0%	96%	0%	0%	0%	0%	0%	0%	0%	0%	4%	0%	0%	100%
Covenant House Texas	1	$0	$0	$0	$0	$0	$0	$0	$0	$0	$44,980	$0	$0	$0	$44,980
	1%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	0%	0%	0%	100%
Riverside General Hospital	1	$0	$75,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$75,000
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Art League of Houston	1	$0	$0	$2,400	$0	$0	$785	$0	$0	$0	$0	$0	$2,250	$0	$5,435
	1%	0%	0%	44%	0%	0%	14%	0%	0%	0%	0%	0%	41%	0%	100%

1. Other" funding sources include FEMA, HUD, TDHSS, client fees, TDH/CDC, local fundraisers, and others. Table 11-2.
2. Funded amounts have been revised by the Administrative agent. A comparison of the differences in amounts reported by agencies versus those reported by the Administrative agent is shown in Attachment 23.
3. Total budget amounts reflect the figures reported by providers, which may not represent the total of all funding amounts shown in the table.

Table 11-2 Other Funding Sources

AGENCY	Other Funding Source	Amount	Other Funding Source (2)	Amount	Total
AIDS Foundation Houston, Inc.	FEMA	$44,350	HUD	$294,470	$338,820
The Assistance Fund, Inc.	Fundraising	$100,000			$100,000
Bering Omega Community Services	Special Events	$84,842	Interest misc.	$46,120	$130,962
Bering Omega Community Services	Ind. DC Renov.	$685,577	Other Gov Grants	$20,079	$705,656
Family Service Center	UWTGC	$383,584			$383,584
Fort Bend Family Health Center, Inc.	THD EI	$60,000			$60,000
Foundation for Interfaith Research & Ministry	Contributions	$71,360			$71,360
Houston Challenge Foundation	Foun., Ind Cont, Corp., Endow	$72,336			$72,336
Harris County Hospital District (HCHD)	Thomas St. - HCHD	$5,400,314			$5,400,314
Montrose Clinic, Inc.	Fees	$50,000	Research Studies	$700,000	$750,000
Montrose Counseling Center, Inc.	Client Fees	$37,236			$37,236
People With AIDS Coalition - Houston, Inc.	TDHSS	$36,020	HCHDA	$50,000	$86,020
Southeast Texas Legal Clinic	Clients	$5,344	Fundraising	$1,764	$7,108
Texas Children's Hospital	Federal Grants/cntrts	$1,826,239			$1,826,239
University of Texas @ Houston Health Science Center/ Dept. of Pediatrics	TDH/CDC	$60,735	University/State	$250,000	$310,735
Diocesan AIDS Ministry, A Program of Associated Catholic Churches	Events, CIK	$297,802	Diocesan	$169,000	$466,802
TOTAL		**$9,215,739**		**$1,531,433**	**$10,747,172**

Figure 11-1 Funding Sources for Treatment and Care

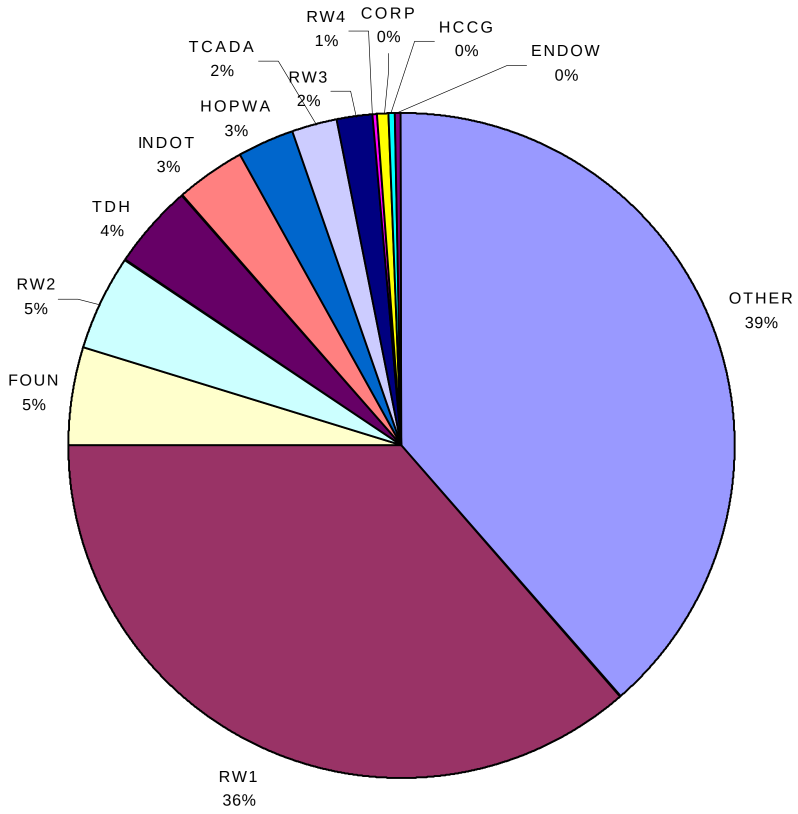


Table 11-3 Reported Prevention Funding for FY98

AGENCY	TCADA	HCCG	TDH	Other	CDC	Corporate	Indiv Cont.	Foundation	RWII	RWIII	RWI	Endow.	TOTAL BUDGET
TOTAL	**$722,713**	**$601,180**	**$585,585**	**$419,921**	**$409,429**	**$272,786**	**$142,138**	**$131,351**	**$97,049**	**$78,939**	**$31,348**	**$25,000**	**$3,525,439**
	20%	**17%**	**17%**	**12%**	**12%**	**8%**	**4%**	**4%**	**3%**	**2%**	**1%**	**1%**	**100%**
Montrose Counseling Center, Inc.	$722,713	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	**$722,713**
	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	**100%**
Amigos Volunteers in Education and Services	$0	$190,000	$190,000	$0	$210,000	$0	$0	$0	$0	$0	$0	$0	**$590,000**
	0%	32%	32%	0%	36%	0%	0%	0%	0%	0%	0%	0%	**100%**
Montrose Clinic, Inc.	$0	$262,000	$204,000	$0	$0	$100,000	$0	$0	$0	$0	$0	$0	**$566,000**
	0%	46%	36%	0%	0%	18%	0%	0%	0%	0%	0%	0%	**100%**
Planned Parenthood of Houston & Southeast Texas	$0	$0	$0	$278,000	$0	$0	$0	$0	$0	$0	$0	$0	**$278,000**
	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	**100%**
AIDS Foundation Houston, Inc.	$0	$44,022	$49,134	$0	$112,894	$56,830	$103,920	$9,946	$0	$0	$31,348	$0	**$408,094**
	0%	11%	12%	0%	28%	14%	25%	2%	0%	0%	8%	0%	**100%**
The Center for AIDS: Hope & Remembrance Project	$0	$0	$0	$96,921	$0	$84,956	$36,718	$106,405	$0	$0	$0	$0	**$320,000**
	0%	0%	0%	30%	0%	27%	11%	33%	0%	0%	0%	0%	**100%**
NAACP Houston Branch	$0	$49,308	$56,309	$0	$86,535	$0	$0	$0	$0	$0	$0	$0	**$192,152**
	0%	26%	29%	0%	45%	0%	0%	0%	0%	0%	0%	0%	**100%**
Alternate Resources of Texas, Inc.	$0	$0	$86,142	$0	$0	$0	$0	$0	$97,049	$0	$0	$0	**$183,191**
	0%	0%	47%	0%	0%	0%	0%	0%	53%	0%	0%	0%	**100%**
Kids in Need of Drug Evaluation & Re-Treatment Clinic	$0	$0	$0	$45,000	$0	$31,000	$1,500	$15,000	$0	$0	$0	$25,000	**$117,500**
	0%	0%	0%	38%	0%	26%	1%	13%	0%	0%	0%	21%	**100%**
Harris County Hospital District (HCHD)	$0	$0	$0	$0	$0	$0	$0	$0	$0	$78,939	$0	$0	**$78,939**
	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	0%	0%	**100%**
Young Women's Christian Association	$0	$35,850	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	**$35,850**
	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	**100%**
Mendez Counseling	$0	$20,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	**$20,000**
	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	**100%**
Riverside General Hospital[2]	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	**$13,000**
	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	**100%**

2. Funding source not specified.

Table 11-4 Other Funding Sources - Prevention

AGENCY	Other Funding Source	Amount	Other Funding Source (2)	Amount	Total Other
The Center for AIDS: Hope & Remembrance Project	Carryover	$95,367	Interest Income	$1,554	$96,921
Planned Parenthood of Houston & Southeast Texas	CDC thru TDH	$266,000	Patient Fees	$12,000	$278,000
Kids in Need of Drug Evaluation & Re-Treatment Clinic	Local Fundraisers	$25,000	Miscellaneous	$20,000	$45,000
TOTAL		**$386,367**		**$33,554**	**$419,921**

Figure 11-2 Funding Sources for Prevention Services

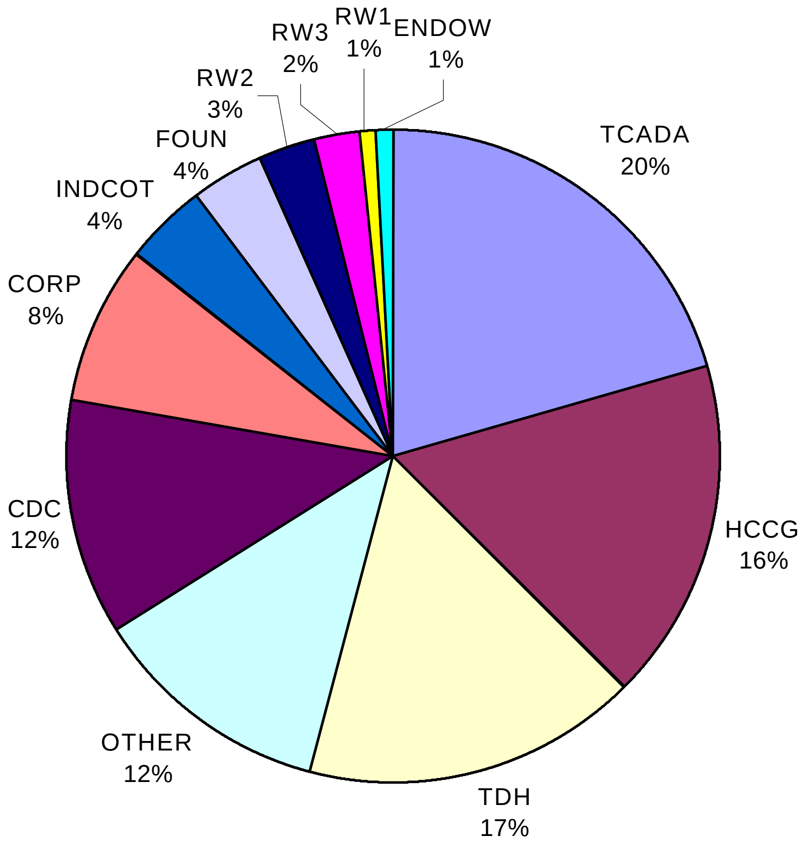


Table 11-5 indicates how the revenues reported in the survey were divided among the service categories. Based on Ryan White Funds, HOPWA, TCADA and other funds, the services that receive over a million dollars are medical care, case management, HIV early intervention and outreach, rental/emergency housing assistance, and dental.

Table 11-5 Funds Expended FY 98[1]

Service Category	**RW I, II, III, III, IV, HOPWA, TCADA, and Other Funding, Expended FY 98**	**%**
Outpatient Medical Care	$5,523,040	25.9%
Case Management	$2,504,458	11.7%
HIV Early Intervention & Outreach	$1,591,982	7.5%
Housing/Rental Assistance	$1,437,317	6.7%
Dental Care	$1,018,653	4.8%
Health Education Risk Reduction	$946,116	4.4%
Home Health Services	$943,335	4.4%
Medication Assistance Program	$792,612	3.7%
Food Pantry	$741,486	3.5%
HIV Counseling & Testing	$740,000	3.5%
Research	$700,000	3.3%
Direct Emergency Assistance	$573,192	2.7%
Outreach	$564,693	2.6%
Insurance Premium Assistance	$493,526	2.3%
General Transportation	$400,452	1.9%
Volunteer Services	$382,278	1.8%
Legal Assistance	$376,367	1.8%
Mental Health	$287,874	1.3%
Multiple Diagnosis Initiative	$275,142	1.3%
Hospice	$246,494	1.2%
Substance Abuse	$233,781	1.1%
Adult Day Care	$157,920	0.7%
Counseling other	$143,797	0.7%
Employment assistance/vocational counseling and training	$85,012	0.4%
Camp	$57,420	0.3%
In-Home Respite	$50,745	0.2%
Benefits and Resources Counseling	$42,784	0.2%
Sign Language & Oral Interpreting	$25,000	0.1%
TOTAL	**$21,333,226**	**100.0%**

This information is based on provider survey only. No program funding information was available from the Administrative agent.

Units of Service, Unit Costs, and Clients Served

The data presented below provides an estimate of the units of service delivered, unit cost, and clients served. The exact number of clients served and units of services provided by the care system is difficult to calculate. Data collected from the provider survey relies on self-reports from the agencies and in many instances the data is incomplete. Even when reported, it is clear from the data that the unit of service reported is not always defined in the same way and data collection by providers is often not very precise.

Because the units have not been clearly defined, and there is no direct way to calculate overhead and administrative burden on the services, the "unit cost" is the total amount budgeted for the service divided by the reported units delivered. As a next step in refining this measure, it would be useful to remove start-up and indirect administrative costs in order to derive a more accurate unit cost.

The summary data is presented by type of unit of service and type of service. In many instances the units of service are unique to a service. For example, case management is delivered in 15-minute increments by all providers, transportation is one-way trips, and buddy companion/volunteer service is by the hour. Visits consistently refer to outpatient care, dental care, food bank and home health care. Both "visits" and "sessions" are used to report counseling and complementary treatments. "Visits" and "contacts" are used to report outreach and education. The different use of the units of measure makes comparisons less than precise, but they do provide an overall picture of service delivery that is descriptive of the system.

An estimate of number of clients served was reported by the providers. Providers were asked to report total number of clients served as well as unduplicated clients served. However, often the two figures reported by providers were the same. This data should be verified and corrected before using it to report total clients served.

Visits – Medical Care, Counseling, Education and Food Services

As shown in Table 11-6, 60,847 visits were reported in 1998. Of those, 29,256 were outpatient care, 29,524 were visits to the food pantry or household items pantry, and 2,067 home health care, substance abuse or wellness visits.

The total number of clients served was 8,096, yet, it must be noted that not all programs reported this figure. The unit costs for visits for medical services ranges from $94 to more than $700. This wide range perhaps reflects the inaccuracy of the reporting of units of service provided or highlights the excess capacity to provide HIV primary care in the rural areas.

The cost to provide groceries to PLWH/A is under $28.00 per visit. Household items are more expensive at a cost of $67.00 per visit.

The "other visits' category includes a variety of services, such as wellness care, home health care and substance abuse treatment. A total of 499 clients were served through these programs. The cost for each of these visits ranged from $51.00 for a skilled nursing visit to more than $800.00 for a home health visit. Again these figures suggest reporting errors that require further investigation.

Table 11-6 Visits Provided

Outpatient Care Visits

Providers	Unit of Service	Total Clients served	1998 Units provided	Budget	Cost per visit	Type of Visits
Donald R. Watkins Memorial Found.	1 visit	568	8,542	$803,000	$94.01	Primary Medical Services
Fort Bend Family Health Center	1 visit	40	206	$160,136	$777.36	HIV Primary Health Care
Harris County Hospital District	1 visit	574	1,968	$490,002	$248.98	Early Intervention Program
Harris County Hospital District	1 visit	397	635	$163,430	$257.37	Outpatient Psychiatric Services
Harris County Hospital District	1 visit	2,159	12,816	$3,133,873	$244.53	Primary Medical Care
LBJ Hospital	1 visit	*205*	850	$330,770	$389.14	Women's Immunology Center
Montrose Clinic, Inc.	1 visit		4,239	$502,000	$118.42	Outpatient Medical Care
UTMB Family Medicine – Conroe	1 visit	*40*		$90,000		UTMB - Family Practice Residency Program
Total[1]		3,983	29,256	$5,673,211	$194.00	

1. The "Total" reflects the sum of the total clients served, 1998 units provided and budget. The total cost per visit is an average based on the total units and budget. The calculated cost per visit does not include units provided when no budget information is available.

Food and Toiletry Bank Visits

Providers	Unit of Service	Total Clients served	1998 Units provided	Budget	Cost per visit	Type of Visits
AIDS Foundation Houston.	1 visit	1203	11,872	$329,879	$27.79	Stone Soup
Houston Challenge Foundation	1 visit	1287	15,269	$261,045	$17.10	HIV Pantry
Northwoods AIDS Coalition.	1 visit	*106*		$68,529		Food Pantry
People with AIDS Coalition.	1 visit	1068	2,383	$158,811	$66.64	Household Items
Total		3,664	29,524	$818,264	$28.00	

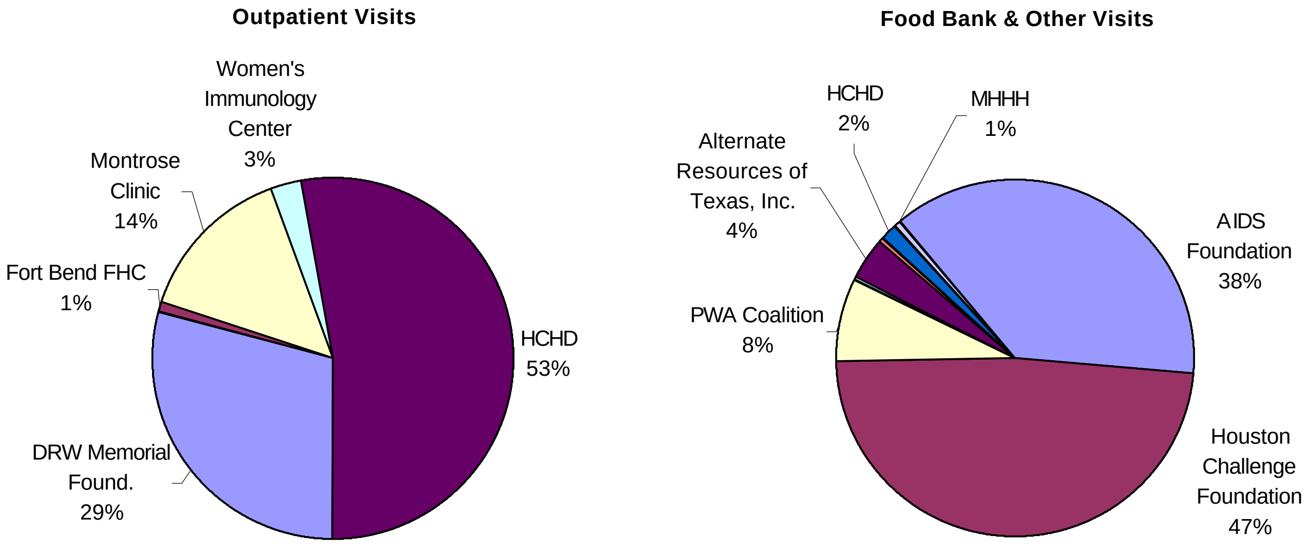
Other Visits

Providers	Unit of Service	Total Clients served	1998 Units provided	Budget	Cost per visit	Type of Visits
AIDS Foundation Houston	1 Visit	17	21	$1,259	$59.95	Spirit Wellness Center
Alternate Resources of Texas	1 Visit	159	1277	$65,500	$51.29	Skilled Nursing
Alternate Resources of Texas	1 Visit	7	34	$2,399	$70.56	Infusion Therapy
Harris County Hospital District	1 visit	96	516	$103,993	$201.54	Substance Abuse
Memorial Hermann Home Health	1 visit	20	219	$179,307	$818.75	Home Health
Montrose Clinic, Inc.	1 visit	*150*		$700,000		Houston Clinical Research Network
Total		449	2,067	$1,052,458	$509.00	

Figure 11-3 shows that Harris County Hospital District (HCHD) delivers more than half of the total medical care visits provided to PLWH/A. The Donald R. Watkins Foundation (DRW) which provides primary care through site physicians, physician extenders, and nurses delivers 29% of the medical care visits.

The second pie chart shows combined food bank visits and other types of visits. The AIDS Foundation Stone Soup food pantry combined with the Spirit Wellness Center account for 73% of non-medical visits.

Figure 11-3 Percent of Total Visits Delivered by Provider



Sessions – Mental Health, Substance Abuse Counseling and Wellness Education

Table 11-7 shows that about 8,127 sessions were delivered in 1998. The bulk of those sessions, 7,000 (96%) are counseling and testing sessions provided by Planned Parenthood. The remaining sessions involve some form of counseling or risk reduction education and are provided by AIDS Foundation and Montrose Clinic.

Based on these figures, approximately 11,365 clients were served through counseling and risk reduction sessions. The unit costs per session range from as little as $37 to as high as $415. This wide range reflects the multiple services defined by the same unit of measure. While an HIV testing and counseling session can be delivered for under $40.00, a risk reduction session with a licensed therapist can be very costly.

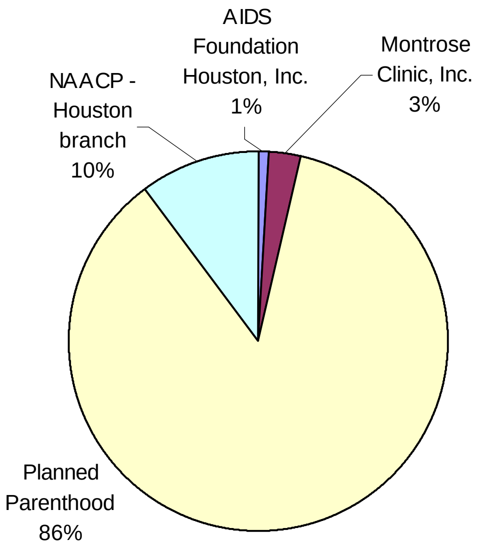
Table 11-7 Sessions Provided

Wellness Education, Holistic Therapy Sessions

Provider	Unit	Total Clients Served	1998 Units Provided *	Budget	Cost per Unit	Type of Visits
AIDS Foundation Houston, Inc.	1 Session	217	57	$9,793	$171.81	Counseling other - Project LAZARUS
NAACP – Houston branch	1 session	2,805	440	$43,000		City of Houston P.O.W.E.R. Program
NAACP – Houston branch	1 session	2,500		$56,309		NAACP – Houston Branch, HERR
NAACP – Houston branch	1 session	1,000	400	$85,656		Women Developing Solutions, counseling
Montrose Clinic	1 session	*343*	230	$95,500	$415.22	Health Education Risk Reduction
Planned Parenthood of Houston & Southeast Texas	1 Session	4,500	7,000	$260,000	$37.14	HIV Counseling & Testing
Total		11,365	8,127	$550,258	$68.00	

Figure 11-4 illustrates the distribution of sessions delivered by each of the providers. Planned Parenthood, with 7,000 sessions of HIV counseling and testing accounts for the overwhelmingly majority of sessions (96%).

Figure 11-4 Sessions Provided – Counseling and Risk Reduction Education



15- Minute Increments – Case Management

Fifteen-minute increments are generally reserved exclusively for case management sessions. However, in Houston service providers also use them to indicate employment and vocational counseling and outreach sessions. As Table 11-8 shows, over 150,000 15-minute increments were provided in 1998. HCHD was the primary provider of case management services delivering close to 70,000 fifteen-minute increments. HACS with their case management and outreach programs are the second largest providers of 15-minute increments. FSC ranks third with close to 42,000 units provided.

Unit costs for case management services range from one dollar to $247.00. Again the large discrepancies in units of service provided and calculated unit cost suggest the need for closer monitoring and more accurate reporting of actual units of services provided.

The range in unit cost for employment assistance and outreach services is much narrower, ranging from eight to fourteen dollars.

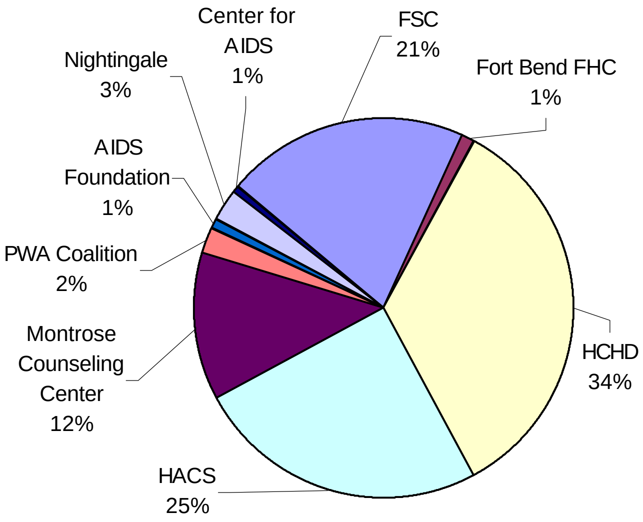
Table 11-8 15-Minute Increments Provided

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit	Type of Service
Covenant House Texas	15 minutes	45		$44,980		Adolescent Case Management
Family Service Center	15 minutes	443	41,939	$329,644	$7.86	Case Management
Fort Bend Family Health Center	15 minutes	44	2,200	$60,000	$27.27	HIV Primary Health Care
Harris County Hospital District	15 minutes	71	69,750	$78,939	$1.13	Case Management
Houston Area Community Services	15 minutes	324	7,084	$227,027	$32.05	CM Services
Montrose Clinic, Inc.	15 minutes	*27*		$46,800		Case Management
Montrose Counseling Center	15 minutes	421	25,238	$861,587	$34.14	Case Management
People With AIDS Coalition	15 minutes	388	4,500	$547,333	$121.63	Case Management
UTHHSC Dept Pediatrics	15 minutes	213		$227,116		Dept Pediatrics Case Management
Total		1,976	150,711	$2,423,426	$16.00	

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit	Type of Service
AIDS Foundation Houston, Inc.	15 minutes	75	1,820	$10,012	$11.00	Employment assistance / vocational counseling and training
Center for AIDS	15 minutes	60	1,200	$4,945	$4.12	Treatment Mixer
Houston Area Community Services, Inc.	15 minutes	231	43,575	$353,000	$8.10	Outreach
Nightingale Adult Day Center	15 minutes	119	5,519	$75,000	$13.59	Employment assistance / vocational counseling and training
Total		485	52,114	$442,957	$8.00	

Figure 11-5 shows that HCHD provides about the one third of the 15-minute increments through their case management program. HACS is the second largest provider of 15-minute increments delivered through case management program and outreach. Family Service Center (FSC) accounts for 21% of the 15-minute increments delivered in case management.

Figure 11-5 15- Minute Increments



Days – Respite, Hospice and Residential Services

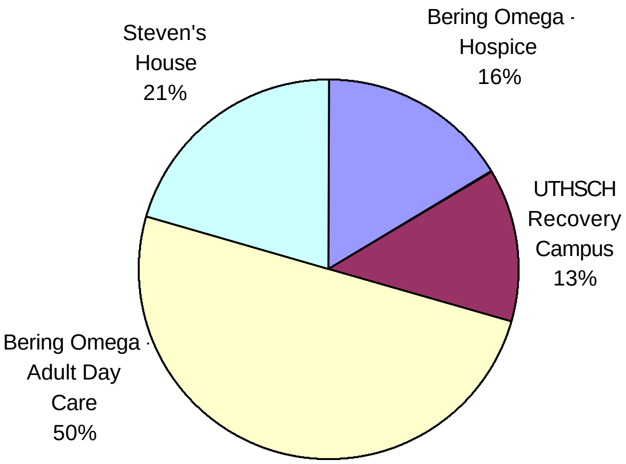
Hospice, adult day care, housing, and rehabilitation services are all measured in days. Table 11-9 shows that in 1998, 7,907 days of care were provided to 353 clients at a cost of $105 dollars per day. The cost of adult day care at $40.00 per day is substantially lower than the cost of hospice care at $189.00 per day.

Table 11-9 Days Provided

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit	Type of Service
Bering Omega Community Services	1 Day	71	1303	$246,494	$189.17	Hospice
Bering Omega Community Services	1 Day	191	3948	$157,920	$40.00	Adult Day Care
Steven's House	1 Day	17	1625	$148,154	$91.17	Residential facility
UT Health Science Center for Houston Recovery Campus	1 Day	74	1031	$275,142	$266.87	Multiple Diagnosis Initiative – rehabilitation services
Total		353	7,907	$827,710	$105.00	

Figure 11-6 shows that Bering-Omega's adult day care combined with the hospice care program account for 40% of the total days provided.

Figure 11-6 Days Provided



Hours – Home Health Care, Legal and Volunteer Services

Several services use hours as their unit of service. These services range from peer, volunteer driven programs to professionally licensed services. Table 11-10 shows that over 132,000 hours of service were provided in 1998. The large majority of these represent hours provided by buddies/companions and volunteers at a unit cost ranging from about $3 to $11 an hour.

Home care services, including in-home respite, home health aide services range in cost from $11.00 for in home services offered by Family Service Centers to $30.00 for home services provided by the Visiting Nurse Association of Houston. The difference in cost per hour may reflect the difference in using para-professional versus professional home health care providers.

Legal services are provided by through three programs, the NAACP legal program, the Houston Volunteer Lawyers Program and the Southeast Texas Legal Clinic. The unit cost per hour ranges from $63.00 to about $80.00.

A total of at least 6,600 clients were served through the variety of programs listed in Table 11-10.

Table 11-10 Hours Provided

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit[1]	Type of Service
AIDS Foundation Houston	1 hour	*2,405*	26673	$73,300	$2.75	Volunteer Services
Alternate Resources of Texas	1 Hour	115	7772	$88,253	$11.36	Home Health Aide
Art League of Houston[2]	1 Hour	312	52	$2,250	$43.27	HIV+ Art Outreach Program
Bering Omega Community Services	1 Hour	60	3587	$50,745	$14.15	In-Home Respite
Family Service Center	1 hour	*60*	791	$48,348	$61.12	Individual and Family Counseling
Family Service Center	1 hour	142	12885	$147,460	$11.44	In Home Services
FIRM	1 hour	1397	36000	$207,459	$5.76	AIDS Care Team- respite
Houston Volunteer Lawyers Program	1 hour	430	2060	$130,861	$63.52	Houston Volunteer Lawyers Program
Montrose Counseling Center[3]	1 hour	109	1077	$54,788	$50.87	Chemical Dependency Treatment
Montrose Counseling Center[3]	1 hour	401	2536	$124,444	$49.08	HIV/AIDS Counseling
NAACP – Houston branch	1 hour	120	1159	$75,355	$65.02	Legal Assistance Program
People With AIDS Coalition	1 Hour	580	19886	$101,519	$5.11	Volunteer Program
Southeast Texas Legal Clinic	1 Hour	*387*	2138	$170,151	$79.58	Legal Assistance
Visiting Nurse Association of Houston	1 hour	71	15394	$460,416	$29.91	Home Health Services
Total		6,589	132,009	$1,735,349	$13.15	

1. The calculated cost per unit does not include units provided when no budget information is available.
2. Based on 3 hours weekly.
3. Based on 1 hour for individual. 2 hours for group sessions.

Month –

Housing, rental and emergency financial assistance are the only services reported in months. A total of 1174 clients were served in 2,050 months. AIDS Foundation of Houston, with its multiple housing programs, accounts for the three quarters of the months provided in housing and rental assistance.

The unit cost of providing housing, rental or emergency assistance ranges from $240.00 to $1700 a month.

Table 11-11 Months Provided

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit[1]	Type of Service
AIDS Foundation Houston	1 Month	60	720	$292,220	$405.86	Tenant Based Rental Assistance
AIDS Foundation Houston	1 Month	35	360	$88,592	$246.09	Beecher Wilson –housing
AIDS Foundation Houston	1 Month	47	188	$293,621	$1,561.81	Life Road – housing
AIDS Foundation Houston	1 Month	35	360	$614,730	$1,707.58	A Friendly Haven- housing
People With AIDS Coalition	1 Month	422	422	$204,029	$483.48	Direct Emergency Assistance
Brentwood Community Foundation	1 Month	575		$210,352		Brentwood ECDC –DEA
Total		1174	2,050	$1,703,544	$728.39	

Contacts – Outreach

Outreach and prevention efforts have traditionally been the hardest activities to quantify and standardized. Some agencies count contacts by the number of material distributed while others attempt to obtain an actual person count in street outreach events. While contacts, as a unit of measure, have generally been reserved for outreach and prevention activities, in Houston, service providers used contacts to also report case management encounters.

As shown in Table 11-12, agencies report providing 6561 contacts in 1998. These contacts only represent the outreach activities and information exchange of two service providers.
The small amount of information that is available regarding the number of contacts provided suggests that there is no precise and consistent way of recording these contacts. Perhaps outreach and prevention activities are incorporated in the delivery of other services yet, it is unclear from the available data how these activities are quantified.

Table 11-12 Contacts Provided

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit	Type of Visits
The Center for AIDS	1 Contact	1,727	5,961			Information Center
People with AIDS Coalition	1 Contact	25		$36,020		Case Management
Montrose Counseling Center	1 Contact	600	600	$83,330	$138.88	HIV Early Intervention and Outreach
Total		2352	6561	$119,350	$138.88	

One -Way Trips – Transportation

Table 11-13 shows a total of 386,204 one-way trips were provided to 2,862 clients in 1998. The vast majority of one-way trips are provided by the main transportation provider, the Life Center, at an estimated cost of $1.00 a one-way trip.

Table 11-13 One-way Trips Provided

Provider	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit[1]	Type of Service
Alternate Resources of Texas, Inc.[1]	One way	82	1,540	$27,047	$17.56	RW II-TRX
The Life Center, Inc.	One way	2,500	348,977	$373,405	$1.07	General Transportation
The Life Center, Inc.	One way	280	35,687	35,687	$1.00	Rural Transportation
Total		2,862	386,204	$436,139	$1.13	

1 Based on roundtrip

Prescription – Drug Reimbursement

The medication assistance program operates out of the Assistance Fund. As shown in Table 11-14, in 1998, they served 516 clients and provided reimbursement for 1550 prescriptions.

Table 11-14 Drug Reimbursement Provided

	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit	Type of Service
The Assistance Fund, Inc.	Per Rx	516	1550	$792,612	$511.40	Medication Assistance Program

Test/Procedure – Lab Tests

Lab tests, HIV testing and dental procedures provided in 1998 are shown in Table 11-15. Although not all the services providers reported the number of clients served or units provided, in 19998, a minimum of 5000 clients were served and 11,200 HIV tests or dental procedures were provided. The estimated cost for tests provided through the HIV Early Intervention and Outreach program is about $94.00. The cost for a dental procedure is slightly over $100.00.

Table 11-15 Test & Procedures Provided

	Unit	Total Clients Served	1998 Units Provided	Budget	Cost per Unit	Type of Service
Bering Omega Community Services	1 Procedure	3,987	10,171	$1,018,653	$100.15	Dental Clinic
Montrose Clinic.	Lab test			$12,000		Outpatient Medical Care
Montrose Clinic.	1 test			$376,000		HIV Counseling & Testing
Montrose Counseling Center,	Test/PCPG	1,108	1,108	$104,000	$93.86	HIV Early Intervention and Outreach
Total		5,095	11,279	$1,510,653	$99.53	

Additional Units of Service

Table 11-16 shows other types of services that were provided to PLWH/A in 1998. These include services such as referrals, newsletters, classes, and sleep away camps. While some of the service providers did not indicate the type of unit of service provided, number of clients served, unit provided or budget information, overall, a minimum of 16,500 clients were served through this variety of serves.

The services and activities captured in this table show a broad range in the number of clients served and units provided as well as cost. The cost of a research and treatment newsletter is about $.61 while the cost of a week long camp can be up to $37,000.

Table 11-16 Additional Service Units Provided

Provider	Unit	Total Clients Served	Units Provided	Budget	Cost per Unit	Type of Service
AIDS Foundation Houston, Inc.	Referral	20	140	$1,026	$7.33	Benefits and Resources Counseling
AIDS Foundation Houston, Inc.	Referral	390	2738	$16,703	$6.10	Benefits and Resources Counseling
AIDS Foundation Houston, Inc.	Referral	590	4142	$25,055	$6.05	Benefits and Resources Counseling
AIDS Foundation Houston, Inc.	1 Week of camp	57	1	$36,515	$36,515.00	Camp Hope, AIDS Foundation
AIDS Foundation Houston, Inc.	Weekend Camp	64	1	$20,905	$20,905.00	Camp H.U.G.
AIDS Foundation Houston, Inc.	Workshop	247	87	$36,540	$420.00	Project IMPACT
Assistance Fund, Inc.	1 Payment	248	2,451	$493,526	$201.36	Insurance Premium Assistance
Brentwood Comm. Found.	2 visits	675		82,033		Project WAITT – food pantry
The Center for AIDS	Newsletter		16450	$10,000	$0.61	Research Initiative/Treatment Action! - Information
The Center for AIDS	Presentation		30	$73,129	$2,437.63	Information Center
The Center for AIDS	Forum (2 hours)	165	4	$47,702		Comm. Forums– provide medical updates for PWAs
Diocesan AIDS Ministry, Associated Catholic Churches				$128,173		Outreach
Harris County Hospital District	1 class	51	220	$25,800	$117.27	Health Education and Risk Reduction
Montrose Counseling Center, Inc.	1 course	8764		$535,383		HIV Early Intervention and Outreach
People With AIDS Coalition – Houston, Inc.	1 96 hour program	30		$75,000		Project L.E.A.P.
Riverside General Hospital	1 client	16	16	$13,000[1]	$812.50	Ryan White Day Treatment
Sign Shares		5000		$25,000		Sign Language and Oral Interpreting
Texas Children's Hospital	Research	148		$1,528,652		HIV Center – BCM/ICH AIDS Clinical Trial
	Total	16,465	26,280	$3,238,747	$123.24	

[1] Funded amount of $75,000 but used only $13,000.

Provider Access

Geographic Location of Service Providers

Harris County, which has historically had the vast majority of AIDS cases, also houses the majority of the service organizations.

Table 11-17 illustrates data collected from the provider survey. As shown, most services supported by Ryan White funds are available throughout the ten counties of the Houston area. These include primary care provided by up to eight providers in Harris County, case management provided by nine programs in Harris County and eight providers in Fort Bend and Montgomery counties. Dental care is provider by Bering-Omega and serves residents of all ten counties. Medication reimbursement and health insurance continuation program are provided by the Assistance Fund and serve all ten counties. Home health care is provided by several agencies serving Harris county residents as well as rural residents.

Information and resources, home health services, case management and primary care services are the most common services offered by several services providers in most of the counties.

Table 11-17 indicates several services are only offered by one single provided across the ten counties. This in fact often reflects an ASO based in Harris County serving clients in other counties. Those services include dental care, medication assistance, insurance premium assistance, hospice care, sign language, emergency services and community planning.

Wharton has the fewest services available. Emergency services and community planning are only available in Harris County.

Table 11-17 Location of AIDS Programs – Counties Served

SERVICE CATEGORY	TOTAL	Austin	Chambers	Colorado	Fort Bend	Harris	Liberty	Montgomery	Walker	Waller	Wharton
Primary Medical Care	**9**	5	3	4	6	8	5	6	4	6	4
Case Management	**9**	4	5	4	8	9	6	8	6	6	4
Dental Care	**1**	1	1	1	1	1	1	1	1	1	1
Drug Reimbursement	**1**	1	1	1	1	1	1	1	1	1	1
Health Insurance Continuation	**1**	1	1	1	1	1	1	1	1	1	1
Home Health Care	**12**	7	8	7	8	9	8	8	7	8	7
Hospice Care	**1**	0	0	0	0	1	0	0	0	0	1
Mental Health Therapies	**2**	1	1	1	1	2	1	1	1	1	1
Rehabilitation Care	**1**	1	1	1	1	1	1	1	1	1	1
Substance Abuse Treatments	**3**	1	1	1	2	3	1	2	1	1	1
Buddy Companion Services	**2**	0	1	0	1	2	0	1	0	0	1
Client Advocacy	**3**	2	3	2	3	3	3	2	2	3	2
Counseling Other	**4**	1	2	1	2	4	2	2	1	2	1
Respite Care	**2**	0	0	0	2	2	0	0	0	0	0
Direct Emergency Assistance	**4**	2	2	1	3	4	2	3	3	3	2
Food Bank	**4**	2	3	2	4	4	4	4	3	4	3
Information & Resources	**14**	5	5	5	7	14	5	6	6	5	4
Housing Assistance	**5**	4	4	4	4	5	4	4	4	4	4
Referrals	**2**	1	1	1	1	2	1	1	1	1	1
Outreach	**3**	1	1	0	2	3	1	2	1	2	0
Transportation	**2**	0	0	0	1	1	1	1	0	1	0
Employment Assistance	**2**	2	2	2	2	2	2	2	2	2	2
HIV Counseling & Testing	**3**	1	1	1	2	3	0	1	1	1	0
Camp	**3**	2	2	2	2	2	2	2	2	2	2
Communication services	**2**	2	2	2	2	2	2	2	2	2	2
Art classes	**1**	0	0	0	0	1	0	0	0	0	0
Community Planning	**1**	0	0	0	0	1	0	0	0	0	0
TOTAL	**98**	**47**	**51**	**44**	**67**	**92**	**54**	**62**	**51**	**58**	**46**

As shown later in this report, transportation is perceived among the highest barrier by providers and a significant barrier by PLWA. In planning for the distribution of services in the future, the delivery and transportation infrastructure should be assessed in light of the greater mobility of PLWA. Providers report that transportation services are only available in five out of the ten counties.

Accessibility of Services

Language

Service providers were asked to report the number of staff who spoke specific languages and to indicate whether their program had written materials available in the different languages. Table 11-18 shows the number of staff who speak English, Spanish, or other languages. It also presents the number of staff who are able to use sign language and the number of programs with written materials available in the different languages. The “other” languages include French, Asian (not specified) and Braille.

Home health services has by far the largest total number of staff and the most staff who speak English, and Spanish. This reflects the large personnel base of Memorial Home Healthcare agency. Primary medical care, case management, health education risk reduction and emergency services are also well staffed, with over 100 English speaking staff members. All programs have at least one Spanish speaking staff with emergency services having 75 Spanish speaking staff and primary medical care having 42.   Sixteen programs report having staff who are able to sign.

Table 11-18 Languages Spoken by Staff *

Program	# Staff English	# Programs Written English	# Staff Spanish	# Programs Written Spanish	# Staff Sign	# Staff Other Language [1]	# Programs Written Other
Primary Medical Care	224	9	52	9	3	3	1
Case Management	102	9	26	8	5	1	1
Dental Care	12	1	3	1	0	0	0
Drug Reimbursement	4	1	2	1	0	0	0
Health Insurance Continuation	4	1	2	1	0	0	0
Home Health Care	514	9	27	9	0	1	0
Hospice Care	9	1	8	1	8	0	0
Mental Health Therapies	16	2	2	2	1	1	0
Rehabilitation Care	5	1	1	1	0	0	0
Substance Abuse Treatments	14	3	3	3	1	1	1
Buddy Companion Services	11	2	2	1	0	1	0
Client Advocacy	10	3	3	3	1	0	0
Counseling Other	28	4	8	3	0	0	0
Respite Care	7	2	1	2	0	0	0
Direct Emergency Assistance	115	4	79	4	0	0	0
Food Bank	20	4	5	4	1	0	0
Information & Resources	102	14	20	9	3	2	1
Housing Assistance	20	5	4	3	1	0	0
Referrals	9	2	3	1	0	1	0
Outreach	21	3	7	2	2	1	1
Transportation	19	1	1	1	0	0	0
Employment Assistance	6	2	2	2	1	0	0
HIV Counseling & Testing	58	3	15	3	2	0	1
Camp	118	3	18	3	2	0	1
Communication services	49	2	4	2	45	0	0
Art classes	2	1	0	0	0	0	0
Community Planning	3	1	1	1	0	0	0

1 – Other languages include Vietnamese, Tangalese, Chinese, Mandarin, Russian, French, Urdu, Hindu, Portuguese, Japanese

Appointments, Referrals, and Walk-ins

Providers were asked to specify how clients accessed agencies. Table 11-19 indicates that most programs suggest a client have an appointment or a referral in order to receive services. Dental care, medication assistance program, respite, and sign language and oral interpreting do not offer walk-in services. Hospice care requires a referral. The referrals can be internal agency referrals, referrals from case managers from other agencies, or referrals from outreach staff.

The rest of the programs offer several points of entry, clients are seen on a walk-in basis, with an appointment, referral or other type of access.

The category "other access" includes programs that reported a combination of levels of access or that included intakes and assessments as a type of access. Some programs, such as case management and health insurance continuation require a client to go through an intake procedure and or a medical assessment.

Table 11-19 Type of Client Access

	Walk-in	Appointment	Referral	Other Access
Primary Medical Care	4	9	8	0
Case Management	7	7	7	0
Dental Care	0	1	1	0
Drug Reimbursement	0	1	1	0
Health Insurance Continuation	1	1	1	0
Home Health Care	6	6	8	1
Hospice Care	0	0	1	0
Mental Health Therapies	2	2	2	0
Rehabilitation Care	1	1	1	0
Substance Abuse Treatments	3	3	3	0
Buddy Companion Services	2	1	2	1
Client Advocacy	2	3	3	0
Counseling Other	4	2	4	0
Respite Care	0	2	2	0
Direct Emergency Assistance	2	3	3	0
Food Bank	4	2	3	0
Information & Resources	9	9	8	5
Housing Assistance	1	2	5	0
Referrals	1	1	2	0
Outreach	2	1	2	1
Transportation	1	1	1	0
Employment Assistance	2	2	2	0
HIV Counseling & Testing	2	2	1	1
Camp	0	0	1	0
Communication services	1	2	1	1
Art classes	1	0	1	0
TOTAL	**59**	**65**	**75**	**11**

Payment methods

The majority of the services provided to PLWH/A by providers, funded in whole or part by Ryan White, are free. The research program operated by the H.O.P.E. project is available to patients with Medicaid.

Table 11-20 displays the type of payments reported by providers. For example, according to data and comments from the provider surveys, there are several services, such as legal services, respite care, and home health care that are free of charge yet the agency does accept third party payments.

Table 11-20 Payment Accepted for Services

	FREE	Private Insurance/HMO	Medicaid	Medicare	Sliding Scale	Other Payment
Primary Medical Care	5	6	8	6	2	1
Case Management	9	0	0	0	0	0
Dental Care	1	0	0	0	1	0
Drug Reimbursement	1	0	0	0	0	0
Health Insurance Continuation	1	0	0	0	0	0
Home Health Care	8	7	7	7	2	1
Hospice Care	1	0	0	0	0	0
Mental Health Therapies	2	2	2	2	1	0
Rehabilitation Care	1	1	1	0	0	0
Substance Abuse Treatments	3	2	2	1	1	1
Buddy Companion Services	2	0	0	0	0	0
Client Advocacy	3	0	0	0	1	0
Counseling Other	4	0	0	0	1	0
Respite Care	2	1	0	0	1	0
Direct Emergency Assistance	4	0	0	0	0	0
Food Bank	4	0	0	0	0	0
Information & Resources	14	1	1	1	0	0
Housing Assistance	3	0	0	0	2	0
Referrals	2	0	0	0	0	0
Outreach	2	0	0	0	0	0
Transportation	1	0	0	0	0	0
Employment Assistance	2	0	0	0	0	0
HIV Counseling & Testing	3	0	0	0	1	0
Camp	3	0	0	0	0	0
Communication services	2	1	0	0	0	1
Art classes	1	0	0	0	0	0
TOTAL	**84**	**21**	**22**	**17**	**13**	**4**

Capacity

As HIV becomes more of a chronic disease, and less of an end-stage illness, service providers and planners are challenged to consider their own capacity to serve new needs, clients at different stages of illness, and serve clients over the course of a longer and healthier lifetime. Earlier the number of service units provided and number of clients served were presented as one indicator for capacity. Because of inconsistent definitions and reporting these numbers are not very precise.

No show rates and Waiting Periods

Other possible indicators of demand and capacity include data on waiting time for clients and the number of no-shows. If there are long waiting periods for appointments agencies may not be adequately responding to the demands of clients. If there are long waiting periods during some hours and none at others, it suggests that providers have to plan delivering services to meet the schedules of their clients. High no-show rates may also suggest that clients are dissatisfied with the services or there is poor follow-up on appointments that are made relatively far in advance. For many of the PLWH/A who do not live by a schedule and are not used to scheduled appointments, extra efforts should be made to provide reminders to keep appointments.

Table 11-21 shows the information obtained from the provider surveys regarding no show rates and the waiting time reported both in number of people and number of days for clients to be able to access services. Not all the programs provided this type of information yet the available data from the surveys indicate that a number of organizations have a waiting period to access services.

Table 11-21 No Show Rate and Waiting Periods[1]

	Monthly No-show rate	**# of people on waiting list**	**# of days on waiting list**
Primary Medical Care	35%	6	14
Case Management	20%	7	5
Dental Care	30%	0	0
Drug Reimbursement	0%	0	0
Health Insurance Continuation	0%	0	0
Home Health Care	1%	259	0
Hospice Care	0%	2	0
Mental Health Therapies	20%	0	0
Rehabilitation Care	0%	0	0
Substance Abuse Treatments	25%	0	0
Buddy Companion Services	0%	18	30
Client Advocacy	15%	12	20
Counseling Other	32%	0	0
Direct Emergency Assistance	5%	5	3
Food Bank	5%	20	3
Information & Resources	15%	0	0
Housing Assistance	0%	67	0
Outreach	20%	7	5
Employment Assistance	20%	0	0
HIV Counseling & Testing	0%	0	0
Communication services	0%	0	0
Community Planning	0%	0	0
TOTAL	**35%**	**259**	**30**

[1] Insufficient data is available to differentiate between the amount of time a client has to wait for an initial appointment with the provider and the amount of time the client has to wait before the service becomes available.

Agency Personnel

An agency's capacity to provide services is largely determined by the availability of personnel trained to provide services. Table 11-22 shows that among the 45 reporting service providers, there are 557 full-time equivalent staff members.

Table 11-22 FTE for RW Care Providers

Position	Male	Female	Anglo	African American	Hispanic	Other	Total	Total %
Program Admin.	61	72	87	18	24	2	133	24%
Case Manager	16	48	27	20	14	3	64	11%
Doctors	17	7	12	5	1	0	24	4%
Nurses/ Nurse practitioner	22	78	53	28	16	3	100	18%
Licensed counselor	15	29	24	12	5	0	44	8%
Paid non-licensed counselor	2	7	2	2	4	0	9	2%
Outreach workers	11	11	7	11	6	1	25	4%
Educators	9	24	11	15	7	0	33	6%
Clerical	12	57	6	29	33	0	69	12%
Drivers	25	4	2	8	19	0	39	7%
Maintenance	1	0	1	0	0	0	1	0%
Development (fund raising)	3	13	16	0	0	0	16	3%
TOTAL[1]	194	350	248	148	129	9	557	100%
%	36%	64%	46%	28%	24%	2%	100%	

[1] Personnel information was reported in percents of FTE and rounded-up to whole numbers. The sum of the whole numbers may add up to more than the total number. Gender and ethnicity/race data was missing for some programs.

Figure 11-7 Number FTE by Position, Male & Female

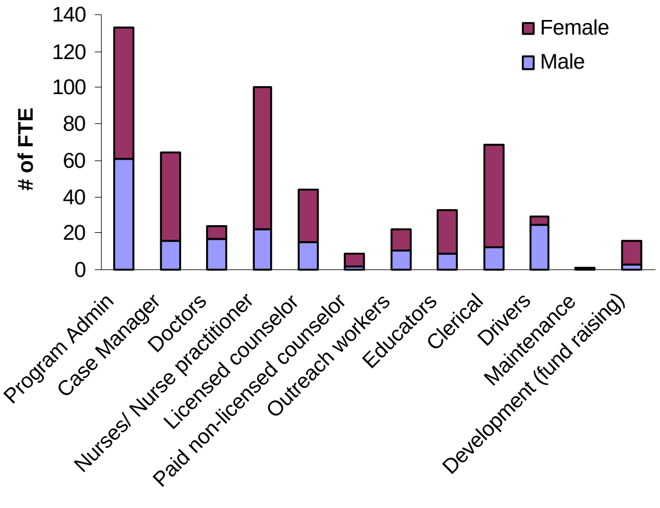
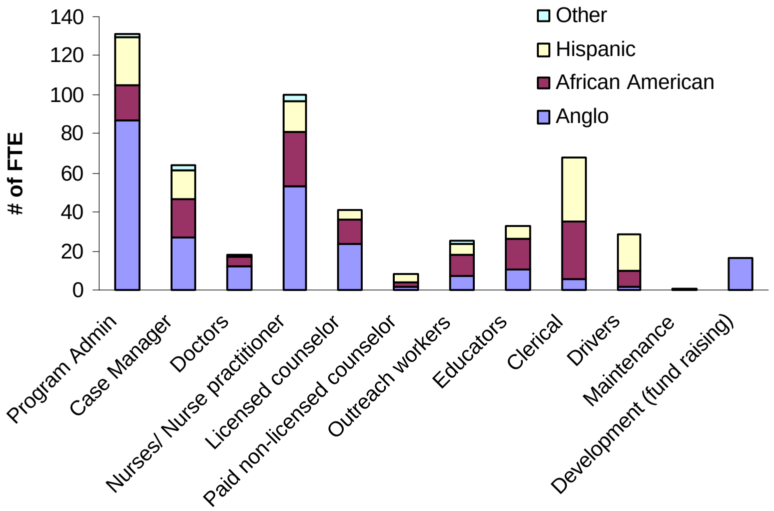


Figure 11-8 Number FTE by Position, Ethnicity



12 SUMMARY OF NEEDS, GAPS AND BARRIERS TO CARE

Introduction

This final chapter uses the information from the Continuum of Care, Epidemiological Review, and the data in this report to provide a summary of needs, gaps and barriers for PLWH/A. In this chapter PCH, as the consultant, provides some interpretation of data and reflects on its meaning in representing needs and barriers. In some instances the conclusions drawn go beyond the data, but draw from PCH's experience and knowledge of the HIV epidemic.

In quantifying the different types of need and gaps several assumptions are made regarding the number of times the average client needs to visit a provider or the number of units of service that they require for a specific service. For the most part these are taken from the provider survey and based on the experience of the provider. In some instances they are informed guesstimates. When made, these assumptions are mentioned in the text.

The quantification of the gaps should be seen as a first effort that will need refinement. This effort will continue under a HRSA grant for the next few year and allow PCH, the Council and Consortium to further refine the gaps and conclusions about the care system that are drawn from them. Notably, the gaps noted and conclusions are those of PCH and not necessarily those of the Council or Consortium.

Goals and Outcomes

The overall goal of the 1999 Epidemiological Review, Needs Assessment and Continuum of Care document is to provide the Houston Ryan White Title I Planning Council and Houston HIV Service Delivery Area Care Continuum with information and recommendations to facilitate the development and coordination of an effective and comprehensive community-wide response to HIV/AIDS.

In the "Identification and Description of the Continuum of Care Report" several outcomes were recommended as part of a modified continuum of care (COC) shown in Figure 12-1. The outcomes and the populations they most directly affect are shown in Table 12-1.

Table 12-1 Outcomes and Populations They Impact

OUTCOMES	POPULATIONS
1. Public support for HIV/AIDS services	General population
2. Awareness of serostatus for at-risk populations	At risk population; DK serostatus
3. Maintaining negative status for those who know their HIV negative status	HIV negative
4. No progression to AIDS for those who are HIV positive	HIV positive, symptomatic or asymptomatic
5. Improved health status & quality of life (QOL) or Death with Dignity.	AIDS diagnosis

These outcomes will be achieved through:

- Public understanding and support for prevention and effective treatment for PLWH/A including those traditionally not in service or underserved;
- Education, skill building and support to reduce the spread of HIV infection;
- Services to provide early intervention to limit the progression from HIV to AIDS;
- Services to assure that PLWH/A have the opportunity for the highest possible quality of life, including end-stage services for those with acute illness.

This report focuses on the services provided under the Ryan White Care Act, and consequently Tracks A, "Public advocacy", Track B, "Outreach to at-risk populations", and Track C "Prevention" are only discussed to the degree that care services are located on their track.

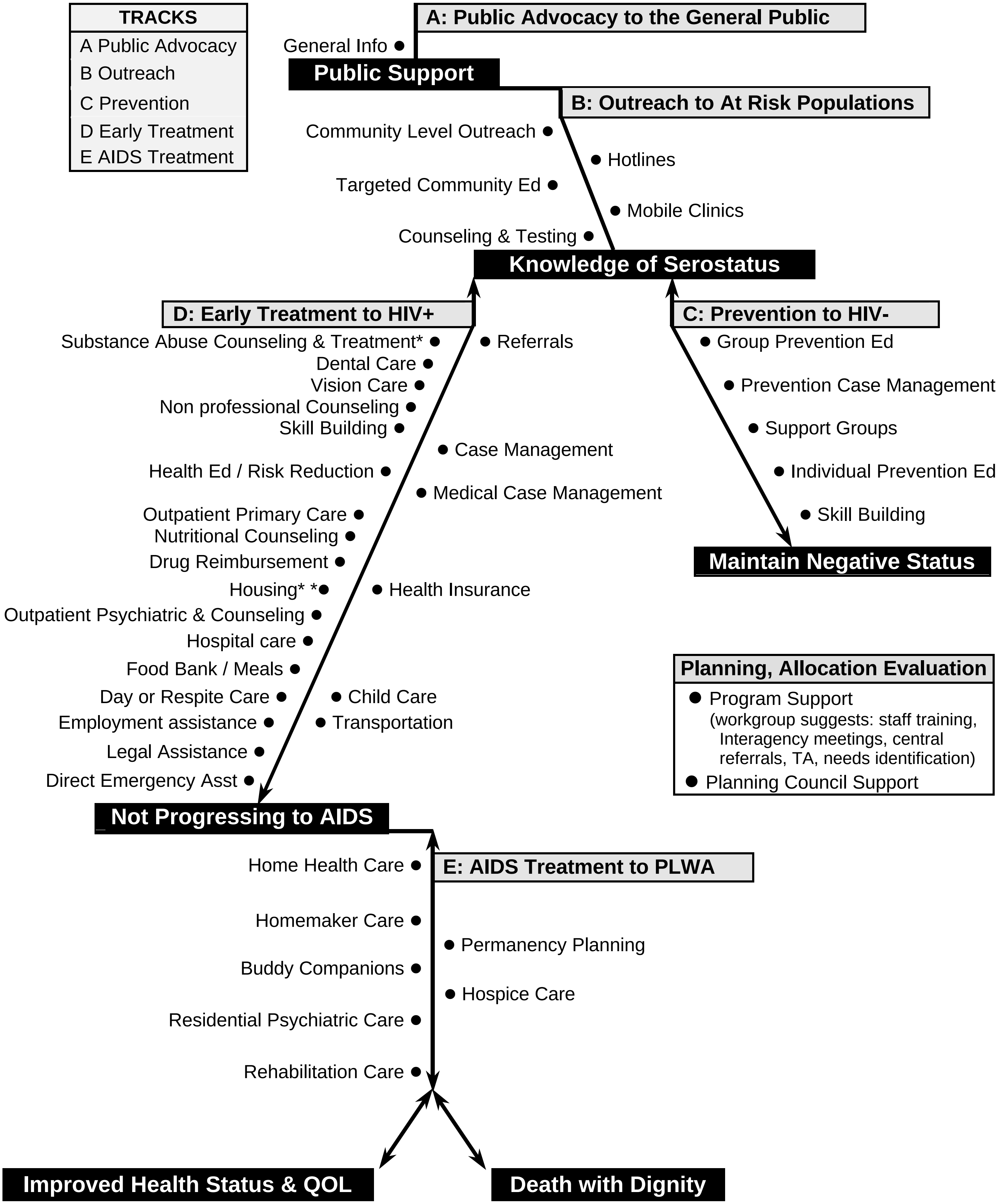
One of the challenges facing the Council and Consortium is the greater integration of the goals as part of the overall provision of services within the Continuum of Care. Two basic facts are essential in developing this integration. First is the awareness that funding and rules and regulations governing disability and benefits are a legislative process, and consequently public understanding of needs is essential. Second, is the awareness that prevention is an interactive process between those infected and eligible for care, and those who are uninfected and at risk for infection through sexual or drug use behaviors. Safer behaviors are often negotiated and that suggests greater integration between prevention and care.

Several areas of integration are possible. To name just a few:

- Public education is essential to assure that there is support for continued funding to provide care to the growing number of HIV positive individuals.
- Coordination between prevention outreach and outreach to identify persons infected with HIV is a logical combination of efforts.
- Prevention case management using the existing tools developed for care case management.
- Support groups and skill building groups for discordant partners.

In using the continuum of care as a guide to establishing priorities, another feature is the great emphasis on providing early treatment services to assure that people infected with HIV do not progress to AIDS. That means efforts to identify and bring into care those who are infected but not in the system, and improving accessibility to services to those not traditionally in care.

Figure 12-1 HIV/AIDS CONTINUUM OF CARE



*Includes Residential and medical detox; **Housing includes scattered site, aggregate, and temporary housing

Definitions of Need

In the first section of this report, several definitions of needs and gaps were provided. The first is "absolute need" or a theoretical estimate of need based on policy or protocol of the model of care. It is an estimate of the number of people who would benefit from a service, regardless of whether they are actually receiving it.

The second type of need is "perceived need", or “demand”, and is based on the service asked for by PLWH/A. The third type is “fulfilled need” which is based on the actual number of services sought and received.

Fourth is the capacity of the system and it refers to the number of clients who can be served, or the number of care slots in the system.

Based on these there are several gap measures:

- "Unmet absolute need" and it refers to the difference between the capacity and those theoretically needing a service.
- "Need-demand gap" or difference between those who receive a service and those who theoretically need the service.
- "Unmet demand" or the gap between the demand for services and the capacity of the system.
- "Unmet perceived need" or the gap between the number asking for and the number receiving the service.

From a practical point of view the unmet demand and unmet need are most useful in determine the needs of those currently accessing services.

Epidemiology and Demographics

To estimate absolute need and the needed capacity, there must be estimates of those currently utilizing the system and the number of PLWH/A who can access the care system. To determine absolute need, the first step is estimating the number of persons who are HIV positive and how many among those are in care. Based on the epidemiological review, it is estimated that there are about 7,580 persons living with AIDS in the Houston HSDA and 7,538 in the Houston EMA in 1998. There are between 13,373 and 20,900 person living with HIV in the HSDA in 1999, and slightly fewer in the EMA. For purposes of calculating unmet need, it is estimated that there are 7,600 PLWA in the Houston Area, and that there are about 7,600 additional persons living with HIV.

The 1999 Epidemiological Report and this Needs Assessment Report highlight several trends that impact the establishment of need and setting priorities. They include:

- With a declining number of deaths for AIDS, more people are living with AIDS and HIV and the care system will need to care for an increasing number of PLWH/A. By 2003 there is likely to be over 15,000 PLWH/A in the Houston Area.

- Over 80% of PLWA are male and 60% are MSM. The absolute number of females will increase while males decrease, but the impact on the overall proportion will be small.
- IDUs make up between 14% and 16% of the PLWH/A and about a third of those are women.
- In 1998, the largest number of AIDS cases were among Anglos (45%), followed by African Americans (38%) and Hispanics (17%). However, the majority of newly diagnosed cases are African American. Cases among Hispanics are staying relatively stable, while new cases among Anglos are declining.
- Heterosexuals represent between 14% and 16% of PLWA, 55% are female. A majority of those females are African American.
- Because people are living longer and with HIV and not progressing to AIDS, the risk group, and ethnicity profiles will be relatively stable.
- Based on estimates of PLWH, the profile of persons living with HIV will parallel that of PLWA, with a greater proportion of MSM and smaller proportion of IDUs and heterosexuals.
- About 5% of all PLWA are outside Harris County, but 25% of the all PLWA are outside or straddling the outer loop or Beltway.
- The greatest unknown in predicting the number of PLWH/A is the success of outreach to the African American Community. African Americans are more likely to be out-of-service, and successful outreach could bring substantially more African Americans into the system of care.

Outcomes

In the needs assessment, two outcomes of the care system are measured. The first is mortality. For those in care the reduction from between 65% to 75% mortality rate in 1992 to under 10% in 1998 is a striking testament to the success of the treatment and care in Houston. When all deaths are considered -- those in care and out-of-care, African Americans have a much higher mortality rate suggesting that they are entering the system later or not at all.

A second outcome is quality of life. The system shows that it has stabilized or improved the physical and emotional health of over half the PLWH/A. Less than 12% of those who are symptomatic or those diagnosed with AIDS report being in poor physical health, and less than 15% say they have poor emotional health. For those who are asymptomatic over 75% say their physical health is excellent or good. About 65% of those living with AIDS say their physical health has stayed the same or improved. Over 45% of PLWH/A say their emotional health is very good or excellent. For those asymptomatic, 46% say their emotional health has improved and over 26% say it has stayed the same. For those with AIDS over 40% say their health has improved and over 24% say it stayed the same.

The combination of medical care and social services has contributed to these outcomes and the challenge is to further improve the outcome by slowing the progression of HIV disease, providing services that continue to improve the quality of life of PLWH/A, and assuring access to members of all communities.

Priorities

The purpose of this chapter is to examine the data and apply the findings from epidemiology, continuum of care, survey, and focus groups to recommendations for service priorities. To set a context for this discussion, the year 2000 -2001 service priorities ranking are shown in Table 12-2. The top priorities of the Council, Consortium and PLWH/A are the same. Primary medical care is first and drug reimbursement is second.

Several top priorities are similar. Transportation is 3rd for the Consortium and PLWH/A and 4th for the Council. Housing is 5th for the Council, 4th for the Consortium and 8th for PLWH/A. Case Management is 3rd for the Council, 6th for the Consortium, and 9th for PLWH/A. Food pantry or food bank is 5th for the Council, 7th for the Consortium and 4th for PLWH/A. Dental services are 6th for the Council, 8th for the Consortium and 7th for PLWH/A.

Similarly ranked lower priority items include legal, health education, volunteerism or buddy companion services, and peer counseling.

Recognizing a greater focus on pediatric care, the Consortium ranks pediatric day care 7th and adult day care 19th, while the Council ranks day and respite care 12th. PLWH/A rank adult day care 29th. Hospice care is ranked higher by the Consortium (12th) than Council (21st). It is not mentioned among the top needs by PLWH/A. Nutritional counseling is seen as part of outpatient care and ranked 1st by the Council, but is a separate service for Consortium, and ranked 17th. PLWH/A rank nutritional counseling a little higher at 15th.

The Consortium services not ranked by the Council include assisted living, employment assistance, and interpreter services. Those ranked by the Council and not the Consortium include direct emergency assistance, substance abuse, program support, planning council support, and outreach. Items not included in the list of services in the consumer survey were pediatric day care, EMI/HERR, interpreter services, housing administration, program support, planning council support and outreach.

Estimating Needs and Gaps

As noted in the Introduction of this chapter, the calculation of needs and gaps are based on several estimates. The gap between those in service and those out of service drive many of the largest gap measures. These estimates are fairly crude, so in the text below they are usually rounded to the nearest 10 or 1000.

Before looking at individual services, two estimates are used throughout this chapter.

- About 5000 persons are estimated to be in the care system (see below for details).
- About 7600 are estimated to have AIDS in the Houston Areas, and another 7600 are estimated to be infected with HIV.

Table 12-2 Consortium and Council Service Rankings Yr. 2000 -2001

CONSORTIUM	Consortium Priority	COUNCIL	Council Priority	PLWH/A Survey Rankings
Primary Medical Care, Rural	**1**	Outpatient/Ambulatory/Nutritional Services	**1**	**1**
Medication Assistance	**2**	Drug Reimbursement	**2**	**2**
Transportation, Rural Non-rural gas vouchers (new)	**3**	Transportation	**4**	**3**
Housing	**4**	Housing	**5**	**8**
Food Pantry Food Pantry, Rural	**5**	Food Bank/ meals / nutritional supplements.	**7**	**4**
Case Management Case Management, Special Needs Primary Care Case Management Adolescent Services	**6**	Case Management	**3**	**9**
Day Care, Pediatric	**7**	Day or Respite Care	**12**	*****
Dental	**8**	Dental Care	**6**	**7**
Counseling Counseling, Rural	**9**	Mental Health	**11**	**10**
Health Insurance Premiums	**10**	Health insurance	**15**	**11**
Legal Legal Rural	**11**	Client Advocacy / Legal / Permanency Planning	**13**	**14**
Hospice	**12**	Hospice Care	**21**	**Not ranked**
Household Items (PWA)	**13**		*****	*****
Home Health Home Health, Rural	**14**	Home Health Care	**10**	**24**
EMI/HERR	**15**	Health Education / Risk Reduction	**14**	*****
Volunteerism	**16**	Buddy / companion	**19**	**25**
Nutritional Counseling	**17**	Outpatient/Ambulatory/Nutritional Services	**1**	**15**
Assisted Living (COSA)	**18**		*****	**13**
Day Care, Adult	**19**	Day or Respite Care	**12**	**29**
Employment Assistance	**20**		******	**17**
Interpreter Services	**21**		******	*****
Housing Administration (Stephen's House Admin. costs)	**22**	Housing	**5**	*****
Peer Counseling	**23**	Counseling (Peer / Other)	**16**	**18**
		Direct Emergency Services	**8**	**5**
		Substance Abuse	**9**	**27**
		Program Support	**17**	*****
		Planning Council Support	**20**	*****
		Referral	**22**	**16**
		Outreach	**23**	*****

Outpatient Care

Outpatient care, located on the Early Treatment to HIV track in the continuum of care, has the major objective of facilitating care for people with HIV so that they will not progress to AIDS. Obviously it continues to be available to those with AIDS and is directed toward improving their health status and quality of life.

Outpatient care should be available to everyone who is infected with HIV. For those in the system of care it is available. However, the epidemiology suggests that many infected people are not in the system of care and are not accessing outpatient care.

Perhaps the over-riding message in this needs assessment is that a projected two to three times as many infected persons are outside the care system as those accessing it. A major challenge is effective outreach to bring those eligible for care into the system before they progress to AIDS and need acute care. Among the survey participants, close to 50% of Hispanics, 39% of the African Americans and 28% of the Anglos diagnosed with AIDS only learned about their HIV status when they went to the hospital or clinic for some other problem. Close to 10% of women did not learn of their HIV status until they sought prenatal care.

Theoretical Need

From the survey, over 90% of PLWH/A say they receive primary health care. Applying that percentage to the epidemiological estimate (7,600), in theory the system should have a capacity to service between 7,000 and 8,000 people living with AIDS a year and over 12,000 PLWH/A. As the number of persons living with HIV/AIDS increases over the next 5 year, a system would have to have a capacity to serve 13,000 to 19,000 PLWH/A by the year 2003 if all eligible clients who demanded access received it.

Perceived Need or Demand

Based on survey data, between 80% and 90% of those in care ask for outpatient care. However, women, particularly, African American (75%) and Hispanic (70%) are less likely to seek outpatient care.

Fulfilled Need

Based on information reported by service providers, there are about 4,400 unduplicated clients who received outpatient care by the hospital district, Ft. Bend, Donald R. Watkins, Montrose Clinic, and the UTMB Family Medicine in Conroe.[17] This is likely to be an undercount because not all service providers participated in the survey.

The number of PLWH/A receiving drug reimbursement and number receiving case management serve as proxy measures for those needing outpatient care. The number eligible to receive ADAP and local drug reimbursement is between 2,700 and 3,500. While there will be more

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[17] This compares to about 4,011 clients reported in the COMPIS system from 4/1/98 to 9/30/98.

persons in treatment than receive drugs, everyone who receives drugs will have accessed the outpatient care system, so this sets the lowest boundary of those in care.

Most of those diagnosed with HIV are referred to case managers. Based on the provider survey, in 1998 there were about 2,000 unduplicated clients who received case management[18]. Based on the Uniform Reporting system, in 1995 there were about 4,000 PLWH/A who had received case management, and this dropped to about 3,800 in 1996 (the last year reported). In 1998 changes in rules allowed more individuals to access services without a case manager, and consequently there has been a drop in demand for case management. Still, the URS system suggests that there are at least 3,800 in care.

From these multiple methods it is likely that between 4,500 and 5,000 PLWH/A received outpatient care through Ryan White providers in 1998. For the purposes of estimating need, for the remainder of this chapter the higher estimate of 5,000 persons in service will be used.

Capacity of the System

The estimate for capacity is derived from the units of service delivery reported by the service providers. For outpatient care, service providers estimate that they provide about 30,000 visits. This is provided by a reported 24 full time equivalent (FTE) doctors and 100 FTE nurses and nurse practitioners. Based on the reported information, it is estimated that a full time physician can see, on average, 5 patients a day. It is assumed that they see patients 40 weeks a year. Based on these estimates, the doctors could provide 24,000 units of service a year. Patients are also seen for routine tests and monitoring by nurse practitioners and nurses. Of the 100 nurse practitioners, it is assumed that 25 are capable of seeing patients independently, suggesting that they could provide at least 25,000 units annually. In total, capacity of outpatient visits is estimated at about 49,000 visits.

Unmet Absolute Need

Using the data from the survey, over half the persons surveyed have a diagnosis of AIDS. If 60% of the estimated 5,000 persons in the system have AIDS, then the care system would have contact with about 3,000 PLWA and 2,000 PLWH. Based on an estimate of 7,600 living with AIDS in the Houston area, and, assuming at least the same number of persons infected with HIV, there would be 15,200 persons in need of outpatient care in the HSDA. That would result in about 10,200 persons who are either seeking care outside of Ryan White outpatient providers or not seen at all.

The question remains about the number of clients seen through private practices outside of the Ryan White system. For purposes of estimation, it is assumed that about half of those not in the care system are seen in private practices and half are not seen at all, leaving an unmet theoretical need of about 5,100 PLWH/A[19]. Of those about half would be living with AIDS and have a

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[18] This compares to between 1,300 and 1,400 "open clients' reported from the Case Management URS system as of 12/8/98.

[19] These assumptions are not based on empirical evidence, and need to be verified in further research.

more acute need for ongoing care. (Notably these are "guesstimates", and more precise estimates will be made in future work).

Theoretically, PLWH/A should see a doctor at least five times a year. Given that some are in the early stages of HIV and others have more acute needs, an average of five times a year for outpatient visits will be used to determine capacity. If all of the estimated 10,100 persons who needed care (5000 currently in care plus 5,100 needing care but not seeking it) were accessing it, then the system would need to supply about 50,500 visits annually. The current system has a capacity of between 40,000 and 49,000 units, but provides about 30,000. This leaves only a small gap between the theoretical need and capacity of the system.

Need Demand Gap

There are about 5,000 persons who receive services and an estimated 10,100 who need Ryan White Services leaving a theoretical gap of 5,100 persons. These are largely PLWH/A who are not demanding services and suggests the importance of outreach in bringing them into the system. Based on the epidemiological data, those not seeking care are likely to be disproportionately African Americans, who appear to enter the system at a later stage of HIV progression. Based on focus group information, undocumented people, largely Hispanic, living with HIV and AIDS also may not be seeking care.

Unmet Demand

The care system currently has more outpatient capacity than demand. Assuming that there are 5,000 persons in care and all get an average of five outpatient visits a year, the system would require 25,000 units of service. It provides about 30,000 units of service, and it has the capacity to provide between 40,000 and 49,000 units of service.

This is, however, a crude estimate, and does not refer to the distribution of resources and the efficiency with which they are allocated. Some monolingual Hispanics and African Americans living with AIDS noted in the focus groups that they needed additional care workers who are in their geographic area or more culturally sensitive to their needs. Notably, however, transportation or location were not perceived as high barriers to receiving outpatient care by African American or Hispanics in general. The recently incarcerated, those in jail may also have greater demand than the system can fulfill.

Unmet Perceived Need

The actual demand for outpatient care is considerably smaller than the absolute need, allowing the system to have a good match between those asking for and those receiving services. In fact, the participants in the survey from every risk group and ethnic population said that they received more outpatient care than they asked for.

The data from the waiting list supports the conclusion that there is adequate capacity to meet demand. There is a relatively high no-show rate for outpatient care of 35%. This could be due to several reasons, such as lack of transportation, poor childcare, forgetfulness or perceived lack of need. Another reason may be that people on medication are feeling better and do not find it necessary to go to their appointments. The barriers section of this report suggests that each of these may be a factor, but none of them are reported as very high barriers.

The reported 14-day waiting period and six persons on average on a waiting list of outpatient care suggest that the system could improve its efficiency in providing services. With greater efficiency it might also reduce its 35% no show rate, many of whom complain about the extensive red tape and waiting period.

Drug Reimbursement

Drug Reimbursement is located on the Early Treatment track of the continuum of care, with a major objective to prevent those who are infected with HIV from progressing to AIDS. As suggested in the Epidemiology Report, the effectiveness of drug treatment has significantly lowered the mortality rate among PLWH/A. There is strong evidence that early intervention with protease and anti-retroviral medication effectively stop the progression of HIV to AIDS. In addition, the continuing effectiveness of prophylactic medication and medication to respond to opportunistic infections is clear, and it continues to play an important role in preventing and treating opportunistic infections (OIs). The latest reports, however, indicate that between 15% and 25% of the PLWH/A do not respond to the medication or cannot tolerate the side effects.

Individuals have different responses to medications, so choosing the best treatment regimen involves informed decisions. If resistance to a treatment regimen develops, a change to another regimen may be necessary to produce better health outcomes or quality of life. In addition, there is mounting evidence of the adverse long-term effects of medication, including liver failure and cancer. Consequently, individuals have to weigh the evidence about when, or if, to start medication and the best treatment regimen for them.

Finally the evidence is clear that up to 40% of PLWH/A skip their medication and as many as 10% skip it often -- most without the advice of their doctor. Poor adherence will to reduce effectiveness and build resistance to medication.

Theoretical Need

In theory, everyone who is infected should have access to medication and, even allowing for those who do not respond to anti-viral and protease medication, a reasonable target is probably between 75% and 85% of PLWH/A in the care system being on some sort of medication.

Access to medication reimbursement is high in the Houston area. There are several sources for drug reimbursement including the TDH program (ADAP), a local program administered by the Assistance Fund, Medicare and Medicaid reimbursement, and private insurance. ADAP has a policy of 200% of poverty or an income for a single household or $16,480. Over 80% of the participants of the survey would qualify for ADAP, and over 60% report receiving ADAP. Between 40% and 50% of the participants say they receive Medicaid and/or Medicare and about half the PLWA and over a quarter of PLWH are on disability. Drug reimbursement programs, like those at Thomas Street Clinic, coordinate the various reimbursement streams and facilitate access to PLWH/A. The Assistance Fund provides coverage in emergency basis and fills gaps in coverage.

Using the same estimate as for outpatient care, the care system should have to have a capacity to serve 13,000 to 19,000 PLWH/A by the year 2003 if everyone who was eligible accessed services. Assuming that 80% would have an income that would qualify them for ADAP or other drug reimbursement and 85% would choose to take drugs, the theoretical need would be between 8,800 and 13,000 who should access drug reimbursement <u>if everyone eligible who demanded access received it.</u> The exact number will depend on the success of outreach in bringing those not in care into the system.

<u>Perceived Need or Demand</u>

Based on survey data, about 55% of those in care ask for drug reimbursement. Assuming between 4,800 to 5,400 people are in care, it would suggest that between 2,400 and 2,700 perceive a need for drug reimbursement.

<u>Fulfilled Need</u>

The reported number of unduplicated clients served are fewer than the epidemiological estimate would suggest. Based on reports from TDH[20] there are 2,634 persons eligible to receive ADAP from Harris County as of November 1999, and about 400 clients are served by the Assistance Fund's medication reimbursement program, suggesting that about 3,000 clients are receiving some direct medication reimbursement.

<u>Capacity of the System</u>

The capacity of the system is difficult to calculate because it is a combination of federal Medicaid and Medicare, ADAP, local drug reimbursement, drug company clinical trials and compassionate care programs, and private insurance. However, with the additional State Funds allocated to ADAP there is no shortfall in funds for drug reimbursement currently, and it is expected that there is sufficient capacity to meet need in the years 1999 through 2000.

<u>Unmet Absolute Need</u>

Using the same estimation procedure as above for outpatient care, theoretically there is a need to serve about 10,100 persons if everyone eligible accessed drug reimbursement. Of the estimated 5,000 currently in service, between 55% and 75% say they receive some drug reimbursement. That leaves a potential need of between 10% and 15% among clients currently in care. In addition there is an estimated 5,100 PLWH/A not in care and 85% of those would need drug reimbursement, leaving a total unmet absolute need of about 5000 PLWH/A.

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[20] Personal conversation with John Allen, TDH.

Need Demand Gap

There are about 3,000 persons who receive drug reimbursement services and an estimated 8,500 who could benefit from drug reimbursement, leaving a gap of about 5,500 persons. These are largely PLWH/A who are not demanding services and suggests the importance of outreach to those in service who are not accessing care and those out of service. As noted above, those not in care are disproportionately African Americans, who appear to enter the system at a later stage of HIV progression and undocumented.

Unmet Demand

The care system currently has adequate drug reimbursement capacity. Based on State Reports for ADAP and survey results there is no gap between the demand for drug reimbursement services and the capacity of the system. The gap between becoming eligible for ADAP or Medicaid / Medicare and getting drugs is met through the Assistance Fund, and no waiting list is reported.

From the focus groups, however, there is demand for expanded lists of drugs which can be reimbursed, and adding drugs that are necessary for improved health status and quality of life but not directly related to HIV infection. There is a need to reduce paperwork and red tape involved with becoming eligible for drug reimbursement.

Unmet Perceived Need

The actual demand for outpatient care is considerably smaller than the absolute need, allowing the system to have a good match between those asking for and those receiving services. About 5% more IDUs, heterosexuals, and African Americans say they ask for drug reimbursement than say they receive it. This small percentage, however, is within the error interval and should be interpreted with caution.

Case Management

Case Management is located on the Early Treatment track of the continuum of care, and it has a major objective to prevent PLWH from progressing to AIDS. It is available to PLWA. On the survey, PLWH/A reported that case management was between "somewhat easy" and "very easy" to access and satisfaction was high. The definition of case management is evolving. The purpose is to "assist clients with the procurement of needed services so that the problems associated with living with the disease are mitigated."[21] It requires at least one face-to-face encounter per month with active clients.

Less intense client advocacy is provided through "service linkage" workers. The purpose of service linkage is to assist clients who do not require the intensity of a case management relationship, as determined by service need level. Service linkage is primarily office-based. Prior to 1998 many services had to be accessed through case management, but that regulation

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[21] Based on Houston EMA Service Category Definitions for 1998 - 1999.

was changed, and PLWH/A can now access most serviced directly. This however is not widely known or understood by PLWH/A. The needs assessment survey highlights this for particular communities including communities of color, women, and pediatrics. Case management is among their top needed services.

Theoretical Need

In theory, everyone who is infected could receive some benefit from case management or service linkage. Using the same estimate as for outpatient care, the care system would have to have a capacity to provide case management or service linkage to 13,000 to 19,000 PLWH/A by the year 2003. The exact number will depend on the success of outreach in bringing those not in care into the system. Those that are most difficult to bring into the system are most likely to have a greater need for case management and linkages.

As persons become more familiar with the system and their HIV infection is stabilized they are likely to have a decreased need for case management, but as acute needs arise they may need continued access to service linkages.

Perceived Need or Demand

Based on survey data, about 75% of those in care ask for case management. That would suggest that between 3,300 and 3,750 PLWH/A perceive a need.

Fulfilled Need

Based on the URS system, in 1996 there was, on average, about 1,300 open clients in case management. Based on the provider survey, in 1998 there were about 2,000 unduplicated clients who received case management. In 1999 from January through September 1,250 clients received case management or service linkage. Projected to a full year it would suggest that over 1600 clients will receive case management or service linkage. Overall, then, the fulfilled need for case management in 1998 is likely to be between 1,600 and 2,000 clients.

Capacity of the System

The capacity of the system to provide case management appears to be adequate, and there may be, on average, excess capacity given current demand. Based on the reported equivalent full time staff of 64 case managers, they could provide over 225,000 units of service.[22] The system currently provides 150,711 units of service for about 2,000 clients.

While the data suggests extra capacity, the focus group comments and subgroup analysis suggests that some of the capacity may be poorly distributed among agencies and it may not be adequate for some populations. For example, rural clients report a greater need for case management, and the relatively poor adherence to medication suggests a need for greater medical

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[22] This is based on the assumption that each case manager could provide sixteen 15 minute units day (4 hours of seeing clients) for 44 weeks a year.

case management. Although it is perceived of as between somewhat easy and easy to access, and PLWH/A are somewhat satisfied with the case management, it ranks lower on these attributes than many other services.

Unmet Absolute Need

Using the same estimation procedure as above for outpatient care, theoretically there is a need to serve about 10,100 persons. Of the estimated 5,000 currently in service, about 75% report receiving case management. That leaves a potential need of about 25% who might use case management or service linkage among clients currently in care. In addition there is an estimated 5,100 PLWH/A not in care and virtually all could use some form of case management or service linkage. This suggests an unmet absolute need of about 6,350 PLWH/A who could receive case management or service linkages assistance.

Need Demand Gap

There are between about 2,000 persons who receive case management or service linkage assistance and an estimated 10,100 who could benefit from the service. This leaves a gap of about 8,100 PLWH/A. These are largely PLWH/A who are not demanding case management or service linkage and suggests the importance of outreach to those in service who are not accessing care and those out of service. As noted above, those not in care are disproportionately African Americans and undocumented.

Unmet Demand

The care system currently has adequate case management capacity. Based on the URS report, the demand for case management is well within the capacity of the system. Information on lack of adherence to medication, inability to find or obtain transportation and childcare, and difficulty with red tape and eligibility, however, suggest that there is a need to target case management services and hold providers to a standard of service. Medical case management is likely to play an increasing role in the care system.

From the focus groups it is clear that there continues to be a need for training among case managers to provide current service information, bring case managers up to date on current changes in eligibility, and to train them in sensitivity to full spectrum of clients seeking case management services.

Unmet Perceived Need

The actual demand for case management is considerably smaller than the absolute need, allowing the system to have a good match between those asking for and those receiving services. About 5% more PLWH/A ask for than receive case management, with slightly higher demand among IDUs and African Americans. Overall, however, most of those demanding case management services receive them.

Transportation

Transportation is available to PLWH/A through a variety of providers. Those diagnosed with AIDS have access to car service through the Life Center or cab vouchers, and those with HIV/AIDS have access through the public transportation system. To access these services there is an income requirement, 150% of poverty level ($12,360 for a single person household). Some PLWH/A also receive transportation services from their volunteer "buddy" or "companion". Transportation is easier to arrange within the EMA, but services are available to rural PLWH/A. Still, among rural PLWH/A it is the 2nd most needed service.

This study collected no figures on public transportation vouchers or volunteers who provide transportation. The figures below are only for taxi and car services. They may be over-estimated since some of the need is fulfilled by these other sources.

Theoretical Need

Based on the percentage of persons in care who are in and out-of Ryan White funded services, the eligibility of 150% of poverty and diagnosis of AIDS, about 5,210 PLWH/A will need transportation services <u>if everyone who could benefit did.</u>

Perceived Need or Demand

Based on survey data, about 58% of those in care ask for transportation. That would suggest that about among those in service, about 2,900 PLWH/A have a perceived need.

Fulfilled Need

Based on the provider survey, there were about 2,600 clients served with one-way trips by taxi or car service. There is no estimate of the number of PLWH/A who were given transportation vouchers for public transportation, so the number accessing transportation is likely to be higher.

Capacity of the System

The capacity of the system to provide taxi and car service is estimated to be about 311,500 one way trips. That would require each driver in the system to provide slightly over 25 one-way trips a day. This estimate is based on reported figures of what drivers are currently delivering, although it seems high, and the figures should be reviewed with the transportation providers.

Unmet Absolute Need

Based on reported figures, each client has a need for about 135 one-way trips a year, or 67 round trips by car or taxi. If that were true, then the estimated 5,200 who need services would require about 702,000 one-way trips. The system currently has a capacity to provide about 311,500 leaving an unmet absolute need of close to 390,100 one-way trips. Again, this is likely to be a high estimate because some transportation needs are met by public transit.

Need Demand Gap

There are between about 2,600 people who receive taxi or car service and an estimated 5,200 who could benefit from the service leaving a gap of about 2,600 PLWH/A. These are largely PLWA who are not demanding car or taxi services suggesting the importance of outreach to those in service who are not accessing care and those out of service.

Unmet Demand

If the reported units of service are accurate, then the system currently has the capacity to meet need. The fulfilled demand for services is 350,000 one-way trips and, in theory, the capacity of the system is about 311,500 leaving a gap of about 39,000 one-way trips. However, the service provider notes that it is providing the additional rides and does not report a waiting list for the urban system and a small waiting list for the rural PLWA.

From the focus groups and perceived need/demand, PLWH/A say that transportation services are somewhat easy to access and that they are somewhat satisfied. While this rating does not suggest a major problem, it is among the harder to access services and it has a relatively low satisfaction rating. From the focus group comments, PLWA suggest that the waiting period for a ride is an inconvenience and that there is some inconsistency regarding the attitude and service of the drivers. The limit of an AIDS diagnosis for the car and taxi service may be too restrictive and the needs fulfilled by the public transportation system needs to be further investigated.

Unmet Perceived Need

Slightly more PLWH/A ask for transportation than receive it. About 58% of all PLWH/A ask for the service and about 53% say they receive it. MSM are the most likely risk group to say there is a gap between asking for and receiving transportation services, but the gap is relatively small.

The qualitative responses about transportation highlight a greater problem in the consistency and quality of the transportation system. There is an expressed need for better coordination, more timely services, and better sensitivity to the needs of clients by drivers.

Housing (not Hospice)

Housing assistance includes assistance in locating and obtaining suitable, on-going or transitional shelter; costs associated with finding a residence and/or subsidized rent; and residential housing services, which are the provision of housing assistance in a group home setting. This service is located on the early treatment track, suggesting that it's goal is to stabilizing the living situation of those infected with HIV to enable them to engage in treatment that will slow or stop the progress of HIV infection. Notably, rental assistance is discussed under "direct emergency assistance" and is not part of this service. As noted in the accompanying Service Guide, rental assistance is available to PLWH/A through a variety of houses, including: Tenant-Based Rental Association, Beecher Wilson, Life Road, A Friendly Haven, and Steven's House. The first four listed are operated through AIDS Foundation Houston. Several of these housing units closely coordinate with drug treatment programs.

Theoretical Need

Based on the survey, 1.4% of the PLWH/A reported they were homeless. Based on an estimated 15,200 PLWH/A, that would mean that at any one time about 200 PLWH/A may be homeless. About 6.5% report being homeless for over 3 months in the past two years and 9.4% said they were homeless for 1-3 months in the past two years. That would suggest that of all the PLWH/A that close to 2,400 would have needed housing for at least a month over the past two years if everyone infected accessed services.

As another indication of potential need, 35%, over 5,000 of PLWH/A, fear that will become homeless. It is likely that the needs assessment survey underrepresented the homeless because they are most likely to be out of care or difficult to recruit.

Perceived Need or Demand

Based on survey data, about 46% of the PLWH/A have asked for assistance in locating housing, and 24% have asked for assistance in locating supportive housing. Some of that need would not translate into actual need for housing, but it does suggest a significant problem in locating housing among PLWH/A. In the focus groups housing was one of the most intensely mentioned needs, and there was a sentiment that long term, independent housing was needed. Locating housing was the 8th ranked service in anticipated needs, and obtaining supportive housing was 11th ranked with under 10% of the PLWH/A reporting they anticipated a need in 1999.

Fulfilled Need

While the perceived need is quite high, at any one time the number of PLWH/A who are homeless is low. Using the estimate of 1.4% of the PLWH/A who report being homeless, about 200 persons would need housing, and based on the provider survey, there are 134 clients receiving housing services.

Capacity of the System

The actual number of supportive and independent housing units available to PLWH/A was not collected in this needs assessment. However, the housing providers reported that they provided 962 months of service, excluding hospice care. That would translate in to 7 months of housing, on average, for every housing client reported. It is unknown if housing units available were fully occupied.

Unmet Absolute Need

The best estimate of capacity of the system is the reported 962 months of housing service provided in 1998 by the providers. As suggested by the data each client needs about 7 months of service. Given that about 213 PLWH/A would be homeless at any one time, there is an overall unmet need of about 550 units of service. If the estimate of 1.4% of PLWH/A being homeless at any one time were low, then the gap would be larger. There is no estimate of the capacity of the system to provide assistance in locating housing. Consequently there is no estimate of unmet absolute need for assistance in providing housing.

Need Demand Gap

A reported 134 PLWH/A receive housing services. An estimated 213 need services, and that leaves a gap of about 80 PLWH/A.

Unmet Demand

Using the estimate of 5000 PLWH/A in service, if 6.5% say that they have been homeless for over 3 months in last two years, then there is would be a demand for about 2,275 units of housing if each PLWH/A averaged an 7 month housing. This is compared to the 962 units of housing provided, leaving an unmet demand of about 1,300 units. Not all 6.5% who report being homeless for more than 3 months remain homeless, and there is a reported 1.4% homeless at any one time, so the estimate may be high. Still, providers report that there is a waiting list of 67 PLWH/A for housing, suggesting that there is a greater demand than capacity for services.

From the focus groups and perceived need/demand, PLWH/A say that housing is difficult to find and that there is a greater need for long-term independent housing. This is supported by the fact that most of the housing units available form AIDS organizations are supportive housing. Whether there is sufficient housing from other non-Ryan White supportive housing is not known.

Unmet Perceived Need

More PLWH/A ask for housing than receive it. About 34% of all PLWH/A ask for assistance obtaining supportive housing and about 24% say they receive it. About 47% of the PLWH/A said they asked for more general assistance locating housing and 29% said they receive it, suggesting a larger gap in assistance seeking general housing than supportive housing.

African Americans report the largest gap between asking for and receiving housing services. Heterosexuals are more likely to ask for, but not receive supportive housing IDUs have the greatest perceived need/demand for locating general housing.

While not part of the official criteria, there is a perception that in order to qualify for housing there is a requirement of homelessness. That may present some barrier to obtaining services before a person becomes homeless. There is also an eligibility criteria that persons be drug free to qualify for housing. That would also serve to limit demand, as many persons choose not to be drug free.

Dental Care

Dental services include restorative dental services, oral surgery, root canal therapy, dental surgery and procedures, including laser procedures, and maintenance. Oral medication (including pain control) for HIV patients 15 years old or older is based on a comprehensive individual treatment plan.

Located on the early treatment track in the continuum of care, anyone who is HIV positive and without dental insurance is eligible.

Theoretical Need

Basic dental care is a broad needs among most persons, including PLWH/A. The eligibility criteria includes a wide range of dental services and does not tie them to HIV related problems. The percentage of clients currently holding dental insurance was not asked in the needs assessment, but typically there are few persons who have dental insurance even among those employed. Consequently, it is assumed that 98% of the PLWH/A could use some form of dental care. Based on the estimated 15,200 PLWH/A, that would mean that almost 14,900 PLWH/A could theoretically use dental care.

Perceived Need or Demand

Based on survey data, about 78% of the PLWH/A have asked for dental services. Based on the estimated 4,800 PLWH/A in service who need dental care, that would translate into about 3,800 persons demanding services.

Fulfilled Need

About 70% of the PLWH/A say they have receive dental services. Given the estimated 4,800 in service that would need services, about 3,400 receive services. Confirming the accuracy of client reported data, Bering, the single dental provider in the Houston Area funded by Ryan White, says that it provided services to a total of about 4,000 total clients and 3,300 unduplicated clients in 1998.

Capacity of the System

The capacity of the dental services depends on the number of dentists and dental assistants, the efficiency in running the dental clinic, and the punctuality of clients with appointment. Based on the three FTE dentists at the clinic and 6 dental assistants, the history of the clinic is performing about 17 procedures a day. Based on a continuation of that average, and assuming that the dentists see patients for 40 weeks a year, the capacity of the dental clinic is 10,200 "procedures". In most instances it is assumed that there are three procedures a visit, and that would result in a capacity to see 3,400 clients a year.

Unmet Absolute Need

Assuming a theoretical need of 14,900 and a capacity to see 3,400 clients there is large unmet absolute need of over 11,500 clients a year.

Need Demand Gap

If about 3,300 PLWH/A receive dental services and, in theory, 14,900 need them, there is a need demand gap of about 11,600 PLWH/A.

Unmet Demand

Assuming that about 3,800 are demanding the service, and there is a capacity to provide services to about 3,400 clients a year, there is an unmet demand of about 400 PLWH/A. The data provided by the dental provider suggests adequate capacity, as there is no waiting list.

However, focus group comments and survey data indicate an unmet demand. While clients are generally satisfied with the service and access is relatively easy, several clients noted that they wait a long time in the waiting room and that this clinic could be operated with more concern for the clients' time.

In terms of future need, dental care tops the list of services suggesting that it is a service that will be in greater demand in the upcoming year.

Unmet Perceived Need

While about 78% of the PLWH/A ask for dental services, about 70% receive it leaving a gap of about 8%. The gap is virtually the same for all risk groups, and tends to be higher for Anglos and African Americans.

Food Bank, Meals, Food Vouchers

Food bank services can include food pantry, household supplies, food vouchers, group meals, or nutritional supplements. As noted in the companion resource guide there are a number of different qualifications, ranging from 500% to poverty level, with the largest food bank having an eligibility of 150% of poverty.

This section reports primarily on the food pantry.

Theoretical Need

The estimate for theoretical need is derived from the survey where 66% of the PLWH/A say they have asked for food bank services, and most think they will need more services in the upcoming year. Over 80% of PLWH/A meet the income criteria of 150% of poverty level. As one of the most used services, an average of 70% of PLWH/A is used to determine the theoretical need.

Applied to the estimated 15,200 PLWH/A there is need of about 8,500 PLWH/A who would use food bank services if everyone who was eligible accessed the food bank. On average PLWH/A report using the food pantry about 11 times a year, and that would result in a theoretical need for about 93,500 visits a year.

Perceived Need or Demand

Based on survey data, about 66% of the PLWH/A have asked for food bank services. Based on the estimated 4,000 PLWH/A in service who are eligible and demand food bank services, that would translate into over 2,600 persons demanding services.

Fulfilled Need

About 62% of the PLWH/A say they have received food bank services. Given the estimated 4,000 PLWH/A that would need food bank services, about 2,500 say they have received services. Excluding household items provided by PWA, providers reported serving about 2,600 clients. About another 1,100 were provided household items.

Capacity of the System

The capacity of the food bank, meal program, and ability to provide household items cannot be determined by the data collected in the provider survey. At a minimum they are able to sustain their current service of about 30,000 food bank visits and about 15,300 household item visits.

Unmet Absolute Need

Assuming that the absolute need is about 96,500 visits and the capacity of the system is about 30,000, the unmet absolute need is 66,500 visits, if everyone eligible were to access food bank services.

Need Demand Gap

In this instance the capacity and the number of units received is the same and therefore the need demand gap is the same as the unmet absolute need -- about 66,500 visits.

Unmet Demand

The unmet demand cannot be estimated because there is no accurate estimate of capacity. However, the evidence suggests it can be substantial. Providers report that there is a waiting list for food bank services with up to 20 or more persons, each waiting for an average of 3 days. There is a very low no show rate, and the food bank services are ranked the 3rd most anticipated need.

The focus groups reinforced the growing dependence on the food bank to provide the necessary food for survival, and if people with incomes at or near poverty continue to be infected, the need for food services will increase. Against an overall rating of very satisfied, the largest complaints were about the quality and choice of food.

Unmet Perceived Need

For food bank services, about 66% asked for food bank services and about 62% received services -- a small gap of about 4%. Within that small gap, Hispanics and IDUs tended to have slightly smaller gaps than other ethnicities and risk groups.

Direct Emergency Assistance

Direct emergency assistance refers to help with essential living needs include housing, utilities, rent, electricity, telephone, TTY, water and gas for HIV/AIDS infected individuals. There is a limit of $500 per client/family in a contract year. As discussed in the companion Resource Guide, assistance must be in vouchers made out to the vendor or supplier. There are several agencies that provide direct emergency assistance.

Like food services, direct emergency assistance becomes increasingly important as the overall income of PLWH/A approaches poverty and near poverty.

Theoretical Need

Given that there is no protocol or generally accepted guideline to determine the need for emergency assistance, the best estimate for theoretical need is derived from the survey. About 56% of the PLWH/A say they have asked for rent and utility assistance, and PLWH/A say that their need for direct emergency assistance will increase in the upcoming year. While the criteria is low income, there is no exact criteria noted. There is a mandate to prove emergency need. If 56% of the estimated 15,200 PLWH/A had a need for DEA, then about 8,600 would need some form of emergency assistance, if everyone eligible accessed DEA.

Perceived Need or Demand

Based on survey data, about 56% of the PLWH/A have asked for food bank services. Based on the estimated 5,000 PLWH/A in service who are eligible for services, that would translate into over 2,800 persons demanding DEA.

Fulfilled Need

About 43% of the PLWH/A say they have received food bank services. Given the estimated 5,000 in service that would need services, about 2,200 say they have received services. The providers report they served 1057 clients with 1629 months of service, but this does not include St. John Vianny Catholic Church Social Services, and other providers who did not receive Ryan White Funds.

Capacity of the System

The capacity of the system to provide DEA cannot directly be determined by the data collected in the provider survey. The providers indicated that they received about $706,600 in DEA funds for 1998. At an average of about $435.00 reported per month or one unit of service. Given that the capacity is the same as the level of service currently provided, the capacity of the system would be at least about 1,625 months of service a year.

Unmet Absolute Need

Assuming that about 8,500 PLWH/A could, in theory, use DEA, and that, based on past practices, each PLWH/A uses about 1.5 months of service, there would be a theoretical need of about 13,000 units of service. As about 1,600 are presently being provided that would leave an unmet absolute need of about 11,500 months of service if everyone eligible accessed DEA.

Need Demand Gap

An estimated 1057 PWLH/A receive services and an estimated 8,500 would need them if everyone eligible received them. This leaves a need demand gap of about 7,500 PLWH/A.

Unmet Demand

The unmet demand cannot be estimated because there is no accurate estimate of capacity. However, the evidence suggests it will be substantial. Providers report that there is a waiting list for DEA services of up to 5 or more persons, each waiting for an average of 3 days. There is a very low no show rate (5%), and DEA is the 2nd most anticipated need.

The focus groups reinforced the growing need for DEA as rents increase and there is a growing demand for independent living. If people with incomes at or near poverty continue to be infected, the need for DEA will increase.

The lack of availability is indicated by its low access score, compared to other services. The focus groups comments indicated the frustration and perceived arbitrary nature of DEA, suggesting a need for more clearly understood eligibility criteria and execution of those criteria.

Unmet Perceived Need

About 56% asked for rent and utility assistance and about 43% received them. This is one of the largest gaps among the services most in demand. There is a substantially greater gap among African Americans, and a slightly larger gap among heterosexuals. Together this suggests a greater need among African American women.

Substance Abuse Services

All PLWH/A with substance abuse disorders are eligible for services if they are not eligible for services from other programs/providers (i.e. MHMRA of Harris County) or any other reimbursement source (i.e. Medicaid, Medicare, Private Insurance), or if they are in crisis and cannot be provided immediate services from the other programs/providers.

There are several levels of substance use that are, theoretically available. Level one, detoxification and level IV substance abuse treatment is provided by the Hospital District. Level III and level IV outpatient care is provided by Montrose Counseling and Riverdale General Hospital. Residential drug programs are available at Houston Recovery Campus and substance abuse programs are available through Life Road and Friendly Haven. Most residential programs have a requirement of abstinence and participants have to be substance free.

Theoretical Need

The epidemiological evidence demonstrates that up to 22% of PLWH/A have a history of IDU or MSM/IDU. The co-morbidity data in the survey finds that over 10% of the PLWH/A said they have done Crack in the last 6 moths and about 15% say they done cocaine. Less than 5% say they done heroin the last 6 moths.

While the potential need is high, as was clearly noted in the focus groups, not everyone engaged in drug use desires drug treatment. Theoretically, however, those 3% of the PLWH/A who continue to share needles and the 10% who are doing crack or heroin are good candidates for drug treatment. That would suggest that of the estimated 15,200 PLWH/A, in theory about 1,520 would strongly benefit from drug abuse services. If an estimate of theoretical need was based on those PLWH/A demanding services, then there are 19% (2,890) of the PLWH/A who say they have asked for drug abuse services and the 25% (3,800) who say they want out-patient drug abuse counseling.

Perceived Need or Demand

About 25% of the PLWH/A From the reports that they asked for outpatient drug treatment and 19% indicated that they asked some type of residential drug treatment. Based on the estimated 5,000 PLWH/A in service who are eligible for services, that would translate into over 1000 PLWH/A having received some form of outpatient treatment and about 950 receiving some type of residential care.

Fulfilled Need

There was little difference between the number asking and the number receiving substance abuse services. Over 1,000 PLWH/A reported having received some form of outpatient treatment and about 950 received some type of residential care.

From the provider survey it is difficult to tell how many persons received treatment because drug treatment is provided through a variety of services, including housing, mental health counseling, and program not funded by Ryan White. There are about 426 clients who receive services from providers under drug treatment programs. However there are over 80 clients residing in Life Roads and a Friendly Haven. A large portion of the reported 800 clients at Montrose Counseling and Harris County psychiatric also receive some drug counseling. That suggests that well over 1,000 PLWH/A have probably received some from of drug counseling.

Capacity of the System

The capacity of the system to provide substance abuse counseling cannot be easily determined because of the resources provided outside of Ryan White. As suggested above the capacity under Ryan White agencies exceed 1,000 substance users, but the types and intensity of drug abuse counseling were not determined by this project.

Unmet Absolute Need

As noted above, from the estimated 15,200 PLWH/A between 2,800 and 3,800 might benefit and be receptive to either outpatient or in-patient drug abuse treatment. The capacity of the overall system is unknown, but within the Ryan White Care funded agencies, there is likely to be sufficient capacity to service about 1,000 PLWH/A.

Notably, residential and drug treatment programs are rated as relatively low future needs, suggesting that they may not be in as high demand as other services in the next year.

Need Demand Gap

An estimated 1,000 PWLH/A receive drug abuse services and an estimated 2,800 to 3,800 would need them if everyone eligible received them. This leaves a need demand gap of between 1,800 and 2,800 PLWH/A.

Unmet Demand

The unmet demand cannot be estimated because there is no accurate estimate of capacity. However, the evidence suggests it will be moderate to small. Providers report no waiting list and say there is a 25% no show rate for appointments. While active drug users may have more barriers to attending services, the no show rate, combined with the no waiting list indicates the relatively small unmet demand.

PLWH/A report that access to drug treatment is easy and that their satisfaction rating for both residential and outpatient treatment is high. The focus groups indicate some mixed reception to drug treatment programs; with some PLWH/A saying that the rules and regulations regarding abstinence and behaviors were exactly what they needed and others saying programs has to many rules and regulations. Whether the system adequately provides treatment options for those who are not prepared for abstinence requires further investigation.

Unmet Perceived Need

Supporting the lack of waiting list and the sense that there is adequate capacity to meet demand, there is no perceived difference between the number who ask for and receive either in-patient or outpatient substance abuse treatment.

Home Health Care

Home health care, located on the AIDS treatment track of the continuum of care, and is ranked the 10th priority by the Council and 14th by the Consortium. The goal of home health care is to improve the health status of PLWH/A or provide home-based care when possible instead of in-patient care.

As more fully explained in the companion Resource Guide, there are several types of in-home care including in-home skilled nursing, in-home intravenous therapy, in home health aide and in-home homemaker care. Several agencies provide these services, and most, but not all, require an AIDS diagnosis or that the client be symptomatic.

Theoretical Need

Those most likely to need services are symptomatic and do not have the mobility or ability to perform needed medical or homemaker functions. For the purposed of this analysis, the survey indicates that almost 20% asked for some type of home care, but 26% of those diagnosed with AIDS report a need, in contrast to 17% of those living with HIV. Given the estimated 7600 PLWH and 7600 PLWA, an estimated 3,300 PLWH/A would need some type of home care service, if all those eligible asked for home health care.

Perceived Need or Demand

As indicated above, based on survey data 26% of those diagnosed with AIDS report a home care need, in contrast t 17% of those living with HIV. Based on the estimated 5,000 PLWH/A in service who are eligible for services, of which 54% are diagnosed with AIDS and 46% are HIV infected, that would translate into a perceived need of about 2,000 PLWH/A.

Fulfilled Need

About 22% of those living with AIDS and 16% of those infected by HIV reported receiving home care. Assuming that there are 5,000 PLWH/A in the system that would result in slightly under 1,000 persons receiving home care.

Providers report serving about 510 clients with home care. This discrepancy may be because PLWH/A confuse volunteer homemakers or other services provided who provide services in the home with "home health care."

Capacity of the System

There is no direct data to determine the capacity of the home health care service. In total they report receiving about $945,000 for 1998, and have served about 510 clients. The most common home care service is homemaker followed by home health aide. The average cost per client served is estimated to b about $1,860 a year. As the organizations providing home care services tend to be larger agencies, it is expected that they have considerable excess capacity provided there were funds to pay for services.

Unmet Absolute Need

As noted above, about 3,300 persons might benefit from home health care, if everyone who was eligible accessed the system. The capacity of the overall system is unknown, but the agencies providing home health care tend to be larger agencies and can probably expand to meet this need.

Need Demand Gap

Providers reported that 510 PLWH/A received home health care services and there is an estimated 3,300 who would need them if everyone eligible received them. This leaves a need demand gap of about 2,800 PLWH/A who might benefit from home health care.

Unmet Demand

The unmet demand cannot be estimated because there is no accurate estimate of capacity. However, the evidence suggests that there will be a substantial demand. Providers report that there is a waiting list of about 260 PWLH/A, and there is a negligible no-show rate. It is estimated that about 1000 PLWH/A are asking for some kind of home care. Given that providers report they serve about 510 PLWH/A unless capacity is increased there will be considerable unmet demand.

Unmet Perceived Need

Given the potential for a large gap, it is surprising to find that PLWH/A reported that they asked for slightly more home health care than they received. The gap is more pronounced heterosexuals and African American.

Mental Health

Mental health services include professional counseling and outpatient psychiatric services. It includes individual and group counseling, including bereavement counseling. Counseling is available to those who are HIV positive or their affected significant other. Income restrictions are minimal (500% of the poverty level -- $41,200 for a single person) and include about 96% of PLWH/A. As detailed in the Resource Guide, there are several providers who offer mental health services.

Theoretical Need

An indication of future need for mental health services is past behavior, and up to 50% of all PLWH/A report having seen an individual therapist of counseling. Assuming that 96% of all PLWH/A fall within the income eligibility, and about half of those might seek care, and 60% seek care within the Ryan White System, about 3,900 PLWH/A, in theory have need for mental health services. The actual theoretical need would be smaller, as the need could be fulfilled over a number of years.

Perceived Need or Demand

Based on survey data about half of the PLWH/A asked for mental health services. Provided that an estimated 4,800 PLWH/A are eligible for mental health services, that would translate into a perceived need by about 2,400 PLWH/A.

Fulfilled Need

About 50% of PLWH/A say they have received mental health services, suggesting that about 2,400 persons have received some type of mental health services.
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In 1998, providers report serving about 800 clients with some type of metal health services, including individual, family, outpatient, or HIV counseling services. This discrepancy between PLWH/A reports and provider reports is most likely due to PLWH/A reporting "ever" accessing services, while providers report accessing services in the year 1998.

Capacity of the System

The system capacity to provide mental health services is dependent on the number of professional counselors in the system. The providers report about 23 FTE counselors. The number of units of service reported, however, needs further investigation to determine the number of service units each counselor can provide in his or her environment. If the providers are currently working at capacity, the system is capable of providing mental health services to about 800 PLWH/A a year.

Unmet Absolute Need

As noted above, about 3,900 PLWH/A might benefit from mental health services, if everyone who was eligible accessed the system. The number who might access services every year would be a fraction of that number. If the capacity of the system is about 800 clients a year, and, the absolute need can be handled over three years, then the each year the unmet absolute need is about 500 PLWH/A.

Need Demand Gap

Providers reported providing mental health services to about 800 PLWH/A a year and an estimated 3,900 would need them if everyone eligible received them. Assuming that these PLWH/A could be seen over three years, about 1,300 would, in theory need services yearly, leaving a gap of about 500 PLWH/A a year. Notably, since the capacity is assumed to be maximized at the current time, the unmet absolute need and the need demand gap are the same.

Unmet Demand

With about 50% of the PLWH/A demanding services, roughly 2,400 PLWH/A in service asked for mental health services. If these 2,400 could be seen over a period of three years, then there would be a need of about 800 PLWH/A a year. As capacity is about 800 PLWH/A a year, there is, on average, no unmet demand. However, as many PLWH/A have continuing mental health concerns, then ongoing therapy would create an unmet demand.

The data from the mental health providers support the conclusion that there is no unmet demand. They report no waiting list and a monthly no-show rate of 20%, suggesting that the current capacity is adequate to meet actual demand.

PLWH/A reported that they anticipate a moderate increase in need for mental health services, suggesting a growing demand. From the focus groups there is a sense that there is growing demand for family services and integration of HIV/AIDS therapy with other mental health needs of IDUs and those with a bipolar diagnosis.

Unmet Perceived Need

Overall, PLWH/A say there is no gap between asking for and receiving mental health services. Heterosexual and IDUs say they receive more mental health services than they ask for, while MSM say they ask for more than they receive. African Americans also report asking for more mental health services than they receive.

Day / Respite Care

Day or respite care is located on the Early Treatment to HIV positive track of the continuum of care, and is ranked the 12th priority by the Council. The Consortium ranks pediatric day care at 7th and adult day care as 19th. As noted in greater detail in the companion Resource Guide, the goal is for the volunteers of this service to provide social, emotional, and physical care to the PLWH/A or their caregiver.

The day care service can include a variety of social interactions including exercise programs, field trips, and peer support groups. It can also include the provision of nursing care. The in-home respite care service offers more one-on-one socialization, companionship and/or emotional support for either the PLWH/A or the caregiver. One agency that provides this service, Bering Omega, and it requires that the recipient be either HIV positive, diagnosed with AIDS, or the caregiver of a person who is HIV positive. The adult day care service is only offered to adults 18 years of age or older.

Theoretical Need

While the eligibility is broad for respite care, it is usually reserved for caregivers of PLWH/A who need regular or intensive care. For purposed of estimating the theoretical need, about 10% of the PLWH/A reported asking for that service. There is no census of caregivers, so it is difficult to know the number of persons who might qualify for these services, and therefore difficult to determine a theoretical need. A clue to the number of eligible persons is that over 60% of the PLWH/A say they live with a spouse, family or friend, and up to 17% live with another HIV positive person. The need may be greatest among families, and about 13% of the PLWH/A reported having families.

Perceived Need or Demand

Based on survey data about 10% of the PLWH/A asked for mental health services. As there is no estimate of the eligible population, perceived need cannot be calculated.

Fulfilled Need

About 8% of PLWH/A say they have received respite care, suggesting that about 380 PLWH/A received some type of respite care.
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In 1998, providers report serving about 251 clients with adult day care or in-home respite care. 57 persons also participated in a week long camp and 64 persons participated in weekend camp, but this was not restricted to Houston area PLWH/A and their caregivers. Also PLWH/A may have assumed that some of the buddy and companion services provided by FIRM may have been respite care.

Capacity of the System

With the current data, there is no accurate way to estimate capacity for respite care. The definition of respite care should be clarified and the capacity of the adult day care and other respite programs has to be further explored. Based on provider responses, there is no waiting list, suggesting that the services may have additional capacity.

Unmet Absolute Need

Since there is no estimate of capacity, unmet absolute need cannot be calculated. As the health status of person improve with medication, it is theoretically possible that the absolute need will decrease. Alternatively, if the failure rate of medication increases and/or side effects of long-term medication require more intensive caregiver participation, there may be an increase in need for respite care.

Need Demand Gap

Since there is no estimate of the theoretical need, it is impossible to calculate the need-demand gap.

Unmet Demand

With about 10% of the PLWH/A demanding respite care services, and assuming those demanding respite care are overwhelmingly from PLWH/A who have symptoms, roughly 200 PLWH/A in service are asking for respite care. The system currently serves over 200 PLWH/A suggesting that it has the capacity to respond to demand.

The data from the respite care providers support this conclusion. They report no waiting list. PLWH/A anticipate only a very small increase in the need for respite care.

Unmet Perceived Need

For a service with relatively low need, slightly more PLWH/A say they ask for respite care than receive it. As suggested above, families are more likely to need respite care and heterosexuals are more likely than other risk groups to ask for and not receive respite care.

Client Advocacy, Legal, and Permanency Planning

Legal assistance, located on the Early Treatment to HIV positive track of the continuum of care, is ranked the 13th priority by the Council and the 11th by the Consortium. One of the original goals of legal assistance was that the client's needed help with estate planning, power of attorney, and insurance disputes. As the length of a client' life has increased due to new medications, there is now an increase in litigation issues regarding back to work issues and discrimination and a decrease interest in estate planning requests. Other services provided to PLWH/A through legal assistance are consumer contracts, creditor problems, and representation in family law matters and medical directives.

Most of the providers of the legal assistance service require that clients be at 300% of Poverty level and that they be HIV positive or AIDS diagnosed. One provider, N.A.A.C.P., does offer its services to individuals who have been affected/effected by HIV.

Theoretical Need

For purposed of estimating the theoretical need, about 40% of the PLWH/A reported asking for legal services. Assuming that there are 15,200 PLWH/A and about 90% fall within the eligible income bracket, about 13,700 PLWH/A would be eligible to receive legal assistance. If 40% of those request legal assistance, then about 5,500 person would need legal assistance. Assuming that about 50% go to non Ryan White funded services, that would suggest that about 2,700 persons need legal assistance from Ryan White care providers. Not everyone of the 2,700

PLWH/A would need legal assistance in one calendar year, so the theoretical need on a yearly basis would be less.

Perceived Need or Demand

Based on survey data about 40% of the PLWH/A asked for legal services. Of the estimated 5,000 PLWH/A, 90% would fall in the eligible income bracket, suggesting a perceived need from about 1,800 PLWH/A.

Fulfilled Need

About 31% of PLWH/A say they have received legal services, suggesting that about 1,400 persons received some type of legal assistance. Not all of them received assistance, however, in the calendar year 1998. Providers report that they served about 550 PLWH/A legal services.
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Capacity of the System

The system currently provides about 3,200 hours of legal aid to about 550 clients. Each client, on average, received about 5.8 hours of assistance. One organization has about 14 volunteer lawyers and the other has about 2.5 FTE staff. Assuming that each of the volunteer lawyers give the equivalent of .2 FTE, that would result in about 2.9 FTE, for a total of about 5.4 FTE staff providing services. Each FTE lawyer provides about 3 hours of service a day. Given the volunteer nature of the majority of the lawyers, the system might have a small amount of additional capacity. For purposes of estimation, the system may be able to serve between 600 and 650 clients a year.

Unmet Absolute Need

Above, 2,700 PLWH/A were estimated to need legal assistance, if everyone eligible sought legal services. Assuming that about half would need services each year there is a theoretical need of about 1,350 PLWH/A. For a system that has a capacity to serve 600 to 650 clients a year, there would be a gap of between 500 and 550 clients.

Need Demand Gap

Assuming 1,100 PLWH/A could use services each year and 500 persons receive services, there is a need demand gap of about 750 PLWH/A.

Unmet Demand

With about 40% of the PLWH/A demanding legal services, and assuming that roughly 90% of the 5,000 PLWH/A in service are eligible for legal services and their demand can be performed over two years, there is a demand by almost 900 PLWH/A. If the system has a capacity to serve about 600 clients, there is an unmet demand of about 300 PLWH/A.

The data from the legal care providers suggests that there is more demand than capacity. There are 12 persons on the waiting list and each person has to wait an average of 20 days before being serviced. This is balanced against a no-show rate of about 15% each month.

The focus groups provide some insight into the problems of long waiting periods. Usually PLWH/A have some immediate legal problem and by the time they wait for a layer their need has become less urgent or disappeared.

Unmet Perceived Need

Legal services have a relatively large gap with 40% of PLWH/A asking for services and about 31% receiving them. Heterosexuals and IDUs have a greater gap than MSM, and females have a greater gap than men.

Health Education Risk Reduction

Health Education/Risk Reduction is located on the Early Treatment to HIV positive track of the continuum of care. The Council ranks it as 14th in priority and the Consortium ranks it 15th. The general purpose of this service is to offer PLWH/A information about medical and psychosocial support services and counseling. Providers of the health education and risk reduction service also offer medical and psychosocial support to their clients to educate them about methods to reduce the spread of HIV.

This service is offered in a variety of formats including workshops at the AIDS Foundation of Houston, community forums at The Center for AIDS, and Counseling/Testing, Referral and Partner Notification (CTRPN) at the City of Houston Department of Health and Human Services. Most of the providers require that the participant be HIV positive while others focus more on populations at high risk. Another requirement that varies from program to program is the age or sex of the participant depending on the content of the program.

Theoretical Need

For purposed of estimating the theoretical need, it is assumed that everyone has a need for some form of continuing health education and information about risk reduction. Assuming that there are 15,200 PLWH/A and everyone is eligible to receive education about risk reduction, and about 9,200 already receive services, that would leave that about 6,000 PLWH/A needing some form of health education and risk reduction information. As health education is a continuing process, the need also include those who have already reported receiving health education and, therefore, could be greater.

Perceived Need or Demand

Based on survey data about 56% of the PLWH/A asked newsletters, leaflets, or booklets about HIV and AIDS treatment and care. Of the estimated 5,000 PLWH/A, that would suggest that about 2,800 persons are requesting health education and risk reduction information.

Fulfilled Need

About two thirds, or about 2,800, PLWH/A say they have received some type of health education or risk reduction message in the form of newsletter, brochure, or other type of information about treatment and care.

Providers report serving over 9,200 unduplicated clients in 1998 and having encounters with a total of 13,450. That included seminars and workshops, as well as distribution of printed material, and is a broader array of services that PLWH/A were asked to report in the survey.

Capacity of the System

The system currently provides education services to over 9,000 unduplicated clients and reports serving over 13,000 total clients. There are several programs to provide clients with information about treatment and care, with a total of about 24 FTE's assigned to providing workshops and classes, contacts, newsletters, forums, and one-on-one sessions.

Unmet Absolute Need

Virtually everyone who is infected needs ongoing treatment and care information, suggesting that all of the 15,200 estimated persons living with HIV and AIDS should receive some information, provided everyone who was infected sought information. The system is capable of providing slightly less capacity.

The question, however, is not the quantity of information but the effectiveness of information in promoting adherence and less risky behaviors. The mix of printed and face-to-face and the type of interaction should be assessed in order to maximize the impact.

Need Demand Gap

Assuming 15,200 could use services each year if everyone eligible accessed services and at least 9,200 PLWH/A and those at risk receive information there is a need-demand gap of about 4,000 persons.

Unmet Demand

About 56% of the PLWH/A, or about 2,800 ask for information. The capacity of the health care system greatly exceeds the demand for information

The data from the information providers suggests that there is more capacity than demand. There is no waiting list and there is a no-show rate of about 15% monthly.

The data suggest, however, that the system faces certain challenges. Considerable unsafe behavior continues and adherence is a large problem. Knowledge about treatment varies considerably across ethnic communities and risk groups, and the link between knowledge and behavior needs to be further investigated.

The focus groups suggest that for some PLWH/A there is too much information and they feel they can't process it. Targeted message for persons seeking particular types of information may be more effective. Others continue to seek specific information and, particularly among rural participants, there was a request for more information.

Unmet Perceived Need

Supporting the finding that PLWH/A are inundated with information, overall PLWH/A say they receive more information than they ask for. About 56% say they ask for information, while over two-thirds say they receive information. Men are considerably more likely to say they receive more information than they ask for than women.

Health Insurance

The service of assisting in paying Health Insurance Premiums is on the Early Treatment to HIV positive track of the HIV/AIDS Continuum of Care. The Council rates it as 15th in priority and the Consortium rates it as 10th. Health insurance reimbursement allows client to maintaining their health insurance by paying the co-payments, deductibles, or insurance premium for a maximum of twenty-nine months.

The Assistance Fund, Inc. is the only provider offering this service. The requirements consist of the HIV positive client having an income below 250% of poverty, live in the ten county area in and around Houston, and have health insurance already in place.

Theoretical Need

The eligibility of the insurance continuation assistance suggests a fairly limited population. It requires a person already has private insurance and is in a situation, such as COBRA or continuation of an existing policy, where they have to pay for its continuation. The income eligibility, 250% of poverty, or about $20,600 for a single person, suggests that over 80% of the PLWH/A are within the income range.

About 6% of the PLWH/A report having private insurance not through work and another 14% report receiving insurance through work or COBRA. That would suggest a potential pool of about 20% of the PLWH/A who may benefit from insurance assistance. Assuming about 15,200 PLWH/A, that would mean that there may be up to 3,400 who could be eligible for health insurance continuation. The question is how many of those will become disabled or need insurance continuation. One clue is that currently about 24% of the PLWH/A report long-term disability. That would mean that of the potential 3,400 who have insurance, as many as 730 could have a need, assuming all that were eligible sought insurance.

Perceived Need or Demand

Based on survey data about 27% of the PLWH/A asked for health insurance assistance. It is likely that PLWH/A responding to this question were asking for more than insurance continuation, such as other forms of drug reimbursement assistance. Of the estimated 5,000 PLWH/A in service, that would suggest that over 1,300 persons are requesting insurance assistance. The number asking specifically for insurance continuation was not captured in this survey.

Fulfilled Need

About 20%, or 980 PLWH/A say they receive some type of insurance assistance. 2% of the PLWH/A say they receive insurance payments suggesting that 100 people say they receive insurance continuation.

Providers report serving about 250 PLWH/A with insurance assistance in 1998. The number being served at any one moment in time may be less. The difference between the survey result and the number reported by the provider is likely due to the small number of persons receiving insurance assistance and the oversampling of populations with lower income. The number provided by the provider is probably more accurate.

Capacity of the System

The system currently provides insurance service to about 250 persons. The capacity of the provider is largely determined by available funds and can be increased.

Unmet Absolute Need

Above, it was estimated that a potential need may exist for insurance continuation for over 700 persons. The system currently provides services to about 250 leaving an unmet absolute need of about 450 persons, provided everyone who was eligible for insurance continuation accessed services.

Need Demand Gap

As capacity is defined as the number currently being served, the need demand gap is the same as the unmet absolute need.

Unmet Demand

Over 1,300 PLWH/A said they asked for insurance assistance. Given the existing rules a small percentage would qualify for insurance continuation and all who qualified would be accepted. The fact that there is no waiting list indicates that at the current time capacity meets demand for those eligible. However, the gap indicates that the definition could be reconsidered to include other types of assistance with benefits.

There is a narrow window when a person is in danger of losing their private or personal insurance due to inability to pay. It is unclear how aware those persons are of the insurance continuation service and the adequacy of referrals to the provider. This is an area that requires additional investigation. Also given the number of PLWH/A who are reentering the workplace, the expansion of services to cover the gap between the period of employment and insurance eligibility might be considered.

Unmet Perceived Need

Far more PLWH/A ask for than receive health insurance assistance. In part this is due to the strict eligibility criteria. It does suggest, however, that there may be additional needs for insurance that could be considered, and greater awareness of the services could be made to employers and case managers.

Counseling - Other (Peer And Non-licensed)

Non-Professional counseling is located on the Prevention to HIV Negative track of the continuum of care, suggesting that it is seen as a prevention tools as well as way to treat PLWH/A. The Council ranks it as 16th in priority and the Consortium ranks it 13th. This service is offered in the form of a support group session to PLWH/A to assist in a variety of issues pertaining to their HIV infection and peer to peer counseling.

This service is offered to all PLWH/A who live in the Houston EMA or HSDA. One provider offers groups to those "at-risk" of HIV infection. Some providers require that the participant be substance free while others offer the groups to specific genders or ethnicities.

Theoretical Need

In theory almost anyone infected might benefit from non-professional counseling as a way of discussing the many personal and vocational issues triggered by HIV infection. A more realistic estimate, however, is the percentage of PLWH/A who recognize a need and request the services. In the survey, about 41% said they asked for peer counseling, support groups, drop-in and other services provided by a non-licensed counselor. Given the estimated 15,200 PLWH/A that would suggest a theoretical need of about 6,200 PLWH/A.

Perceived Need or Demand

Based on survey data about 41% of the PLWH/A asked for non-licensed counseling. Of the estimated 5,000 PLWH/A, that would suggest that over 2,075 PLWH/A would request nonprofessional counseling <u>if everyone eligible requested this service</u>. The N.A.A.C.P. offers nonprofessional counseling to "at-risk" populations regardless of infection status and that may increase the number of those who perceive a need.

Fulfilled Need

About 36%, or 980 PLWH/A say they receive some type of non-licensed counseling. Of the estimated 5000 PLWH/A in service, that would suggest that about 1,800 persons received non-licensed counseling.

Providers report serving about 3,300 PLWH/A with some form of peer counseling, support group. The reason may be that many of the support groups are targeted at specific populations such as women or African Americans and generalizing fulfilled need to the PLWH/A populations may undercount its overall reach.

Capacity of the System

The current project did not capture the number of groups or 1-1 peer sessions that would be potentially possible. The system currently provides peer counseling and/or group sessions to over 4,000 individuals and over 3,300 unduplicated persons. Providers report a no-show rate of about 15% a month and no waiting list, suggesting there may be additional capacity in the system for non licensed counseling.

Unmet Absolute Need

Above, it was estimated that a potential need for peer counseling and support groups may exist for over 6,200 PLWH/A. The system currently provides services to about 3,300 leaving an unmet absolute need of about 2,900 persons, provided everyone who was eligible for peer counseling and support groups accessed services.

Need Demand Gap

As capacity is defined as the number currently being served, the need demand gap is the same as the unmet absolute need.

Unmet Demand

Over 2,000 PLWH/A said they asked for peer counseling or support groups. Providers said they provide over 3,300 people with peer counseling and/or support groups, suggesting that there is no unmet demand.

However, the qualitative focus groups information suggests that some populations may be underserved. Those recently infected say they are often isolated or fear rejection. Additional resources might be considered on reaching the newly diagnosed. Poor adherence to medication is another area might be addressed through peer or support groups.

Unmet Perceived Need

Slightly more PLWH/A more ask for than receive peer counseling and support groups. From the survey, 41% reported asking for this service and 36% reported receiving it. This difference may be within the level of error in the survey. About the same gap exists for all risk groups and ethnic populations, and genders.

Buddy Companion (Volunteer Services

Buddy Companion services is located on the AIDS Treatment to PLWA track of the continuum of care, with a goal of improving the health status and quality of life of PLWH/A. It is ranked 19th in priority by the Council and 16th by the Consortium. To some degree there is an overlap in service with in-home care. However while a "buddy" may do some household services, he or she is assigned to provide personalized spiritual and emotional support and companionship.

Theoretical Need

There was little information collected in this project on the expected use of buddy and companion services. Located on the AIDS treatment track in the continuum of care, it is likely to be used to support persons who need assistance when ill. As noted in the companion Resource Guide, a new program was created in 1998 to focus on treatment adherence. This is a service that requires further clarification in order to determine its theoretical need.

Perceived Need or Demand

Based on survey data, about 21% of those in care ask for buddy companion services. That would suggest that about 1000 persons ask for buddy companion services.

Fulfilled Need

About 18%, or 980 PLWH/A say they receive some type of buddy companion services. Providers say they provide over 3,000 clients with volunteer services, of which buddy and companion services are a part. With the current data it is impossible to separate out only buddy companion services from other in-home services.

Capacity of the System

The providers note that they are able to provide over 3,000 clients with volunteer services. Given the large waiting list reported by providers, this is likely to be the capacity of the system.

The large unmet demand for buddy and companion services based on survey data is supported by provider information. Providers indicate there is a substantial waiting list of 18 persons who wait for up to 30 days before being assigned a buddy or companion. This may be the result of too few volunteers or lack of matches between volunteers and PLWH/A.

Unmet Absolute Need

Given the lack of clarity reported about the objectives and goals of the companion and buddy system, the number ideally needing the service could not be estimated and therefore no estimate of unmet absolute need is available.

Need Demand Gap

As there is no estimate for those who theoretically need the service, there is no estimate of need-demand gap.

Unmet Demand

Based on the survey data about 1,000 PLWH/A said they asked for buddy and companion services. Providers said they provide over 3,100 unduplicated clients with volunteer services, some of which include buddies and companions. The breakdown of buddy and companion services was not provided, but based on a substantial waiting list of up to 18 clients waiting for an average of 30 days, it appears that there is insufficient capacity to meet demand.

Unmet Perceived Need

Supporting that there is a lack of capacity, PLWH/A report that they ask for more buddy companion services than they receive. While about 21% ask for service, about 18% report receiving them. The percentage difference is small and likely to be within the sampling error, so it should be interpreted with caution.

Hospice Care

Hospice Care is located on the AIDS Treatment to PLWA track of the continuum of care. It is ranked 21st in priority by the Council and 12th by the Consortium. This service provides 24 hour nursing to PWAs in the terminal stage of their illness. Services also include psychosocial support, spiritual guidance, and bereavement services for the patient. The requirement for the service is that the client be at least eighteen years of age and have less than six-month prognosis. Although it would be expected that the success of new medications would lower the demand for hospice care, Bering Community Service Foundation experienced an increase in clients.

Theoretical Need

Since hospice care is a service only offered to PWAs in their last stage of life, and those entering this stage have greatly declined over the last years, the number needing the service is unknown. From the fatality data, about 370 persons died of AIDS in 1997, suggesting some portion of them might have had a need for hospice services.

Perceived Need or Demand

Based on survey data, about 7% of the PLWA have asked for hospice care suggesting about 530 PLWA perceived a need. This high figure suggests that there may not be a good understanding of hospice services, and PLWH/A may include in their response other home or hospital based services.

Fulfilled Need

About 4% of the PLWA say they have received hospice care. Given the estimated 530 PWA that would need hospice care, about 300 reported receiving services, again suggesting some misunderstanding by PLWH/A of hospice services, or use of hospice services outside of Bering Omega.

The provider, Bering Community Service Foundation, is the only Houston area provider funded by Ryan White, and they reported 71 clients were served in 1998 with 1303 days of service. The number of PLWA who sought hospice services outside of Bering is unknown.

Capacity of the System

Considering there are many other hospice care providers that are not Ryan White funded, the capacity of the total system is not known. Bering report a small waiting list for hospice services, suggesting it is at capacity serving 71 clients for an average of 18 days.

Unmet Absolute Need

As there is no reliable estimate of theoretical need, it is impossible to calculate unmet absolute need.

Need Demand Gap

As there is no reliable estimate of theoretical need, it is impossible to calculate a need demand gap.

Unmet Demand

The data do not permit an estimate of unmet demand because there is no reliable estimate of capacity, and demand specified by PLWH/A do not appear to correspond to the strict definition of hospice care.

Unmet Perceived Need

While about 7% of PWA ask for hospice care, about 4% receive it. This leaves a gap of 3% in the perceived need/demand for hospice care. Exactly what PLWH/A think hospice care involves needs further clarification.

Referrals

The Referral service is located on the Early Treatment track of the continuum of care and is ranked 22nd in priority by the Council. This service is not a category for the Consortium. Referrals help direct the client to a variety of services or programs offered in Houston and helps increase access to available, appropriate, affordable and acceptable services. This service is offered to all HIV positive persons living in the Houston EMA/HSDA.

Theoretical Need

In theory, a large amount of those infected would receive some benefit from referrals to services that meet their needs. Referrals can direct the PLWH/A to services or provides that they may need. The assumption would be that 90% of PLWH/A could use a referral service. Based on the estimated 15,200 PLWH/A, that would mean that almost 13,700 PLWH/A could theoretically use referrals.

Perceived Need or Demand

Based on survey data, about 56% of those in care ask for referrals. That would suggest that about 8,500 PLWH/A perceive a need for referrals.

Fulfilled Need

About 55% of the surveyed PLWH/A say that have received referral services. Given the estimated 8,500 that would need this service, about 4,700 PLWH/A receive referrals. AIDS Foundation Houston reported that it served 1,000 clients in 1998, approximately one-fifth of the PLWH/A population that receive referrals, but referrals may also have been given by case managers and other providers.

Capacity of the System

It is unclear where PLWH/A are receiving their referrals outside of a Ryan White funded referral program. As 55% of PLWH/A reported receiving referrals, it is likely that they are receiving their referrals from different sources such as their case managers or care physicians. It is projected that the system has the capacity to handle PLWH/A requests for referrals based on the multiple sources of access. The one provider that is funded to provide referral served one-fifth of the PLWH/A in need in 1998 and they have no waiting list, and other providers have noted that they provide referrals to other services when appropriate.

Unmet Absolute Need

Using the same estimation procedure as above for outpatient care, theoretically there is a need to serve about 13,700 persons. Since 55% have stated they receive referrals, about 45% will need to receive referral services. In addition, there is an estimated 5,100 PLWH/A not in care and virtually all could use some form of referral services. This suggests an unmet absolute need of about 11,000 PLWH/A who could receive this service if everyone eligible tried to access referrals.

Need Demand Gap

If about 8,400 PLWH/A (55%) receive referrals and, in theory, 13,700 need the service, there is a need demand gap of about 5,300 PLWH/A, if everyone who was eligible accessed referral services.

Unmet Demand

About 8,500 PLWH/A (56%) are demanding referral services, and there is no good estimate of capacity, so unmet demand is difficult to quantify. From the focus groups the need for better coordinated services is a recurring theme. Several participants noted that they do not obtain referrals because there is a sense that agencies are competitive and do not want to share information. Navigating the system is the third highest barrier, and participants of the focus groups often said they needed more information about what services are available. The need for referrals was particularly high among the recently incarcerated and Hispanic populations.

Unmet Perceived Need

Fifty-six percent of the PLWH/A ask for referral services and about fifty-four percent receive the service. This leaves a gap of just 2%. The gap is higher for Hispanics. It is slightly higher for heterosexuals than for IDUs. MSM slightly receive this service more than ask for it.

However, the anticipated need for referral is relatively high suggesting that PLWH/A recognize the importance of an integrated system of health care where providers work together to sustain and improve their quality of life and health status.

Conclusion

This chapter has integrated the epidemiology, provider and PLWH/A survey, and secondary information to provide estimates of need and gaps.

Outcomes

As discussed throughout this report, the Houston EMA and HSDA have a broad array of services for PLWH/A that are funded through the Ryan White Emergency Act. The positive news from the survey and focus groups is that PLWH/A find most services available and accessible and they are generally satisfied with the services. For PLWH/A as a whole, there was not a single barrier to services that was rated as “high.”

Outcomes of the system indicate that it works well. Deaths of PLWA have showed a dramatic decline over the past several years. The care system has a track record of improving and stabilizing the physical and mental health of PLWH/A. About 65% of those living with AIDS say their physical health has stayed the same or improved. For those asymptomatic, 46% say their emotional health has improved and over 26% say it has stayed the same. For those with AIDS, over 40% say their health has improved and over 24% say it has improved or stayed the same.

Headlines

The headline from the needs assessment is that there appears to be a large number of infected persons who are outside the system of care. There may be as many as 10,000 infected persons who do not access Ryan White services. Even allowing for a substantial number of PLWH/A that may see only private physicians, there is likely to be at least 5,000 PLWH/A that are eligible to receive care but who do not. That suggests a need for coordinated outreach to those communities most infected but least likely to get services like the African American Community and undocumented. The need to develop services and increase capacity will depend less on new infections and more on the success of outreach in attracting those infected who are not in service.

A second headline from the needs assessment is the large number of PLWH/A who have some contact with the correction system. PLWH/A who are incarcerated could be targeted for care and treatment information, but reports show that those in correctional institutions and those recently released are underserved in medical and support services.

Changing Face of the Epidemic

The face of the HIV and AIDS epidemic is changing, and there are constantly new considerations and adjustments in the care system that could be made to improve the health status and quality of life of PLWH/A.

The data strongly suggest the shift in care needs as AIDS evolves from an acute and fatal disease to a severe chronic disease managed by difficult-to-adhere-to and expensive medical regimens. The bottom line for providers is that there will be significantly more clients to serve in 2003 than now, as fewer people die and early treatment after HIV is detected becomes the standard of care.

While MSM will continue to be the majority of those living with HIV and AIDS, the profile of the PLWA will change. While the number of newly diagnosed cases among MSM is still larger than other populations, it is declining. IDUs and heterosexual cases remain level, and the number of females, while small in absolute terms, is increasing. African Americans have surpassed Anglos in the number of new infections diagnosed each year, and the ethnic profile suggests growing needs within the African American Community.

Before protease inhibitors and combination therapies, the goal of HIV services was to prolong the lives of PLWH/A by educating them about prophylactic treatment, managing opportunistic infections (OIs) and preparing them and their families for the fatal consequences of AIDS. The system had to build capacity for end stage illness, including home and institutional hospice services, home care, home delivered meals and other end-stage services.

Today the goal is to maintain and improve the health status and quality of life of PLWH/A by:

- Educating them about the treatment of a serious chronic disease that requires complex medical regimens and support systems;
- Providing them with quality basic health care and social services;
- Providing coordinated ongoing treatment;
- Monitoring outcomes to assure accountability;
- Modifying, sustaining and enhancing support systems that provide access to care, such as transportation, medical and continuing case management, health insurance, child care and culturally competent personnel.

Priorities

Among the many dimensions about service asked in the needs assessment, PLWH/A ranked the services they most needed, most used, and thought they needed in the next year. Most top services needed and most utilized were similar. Out patient care, lab tests, dental care and case management were the top four. The Council and Consortium mostly agreed in their 2000 - 2001 priorities, but placed dental care lower on their priority list than PLWH/A and transportation higher. The Consortium placed case management a little lower.

The demand for future services paints a different picture than rankings of existing services. PLWH/A, say that dental, rent/utility assistance, food bank, and assistance locating housing are their top four anticipated needs. To some degree this shows they are confident of the continuation of medical care, but it also shows the shift toward the concerns that any poor population confronted with a chronic disease would have. In order to access services, the eligibility criteria for services will keep persons relatively poor, and, not surprisingly, as people live longer they have a continuing need for basic services such as food and housing.

Overall capacity in the delivery system is good. For the critical services of outpatient care, drug reimbursement, and case management capacity is adequate to meet current demand. If a large number of persons are brought into the care system through outreach, capacity will have to be added. Dental care shows a small unmet demand where more persons request care than receive it, and it is likely to grow because eligibility criteria is low and anticipated need is high.

Most of the issues with outpatient care are related to its quality and the dreaded red tape of the system. The process of intake and care could be more efficient and the quality of service could be standardized. Care plans and coordination among providers could be developed to provide a more seamless care plan.

Case management is a service that needs continual review and the mix between service linkage, case management and medical case management needs to be further refined. PLWH/A continue to say that navigating the system and red tape are barriers, and they look to case managers to overcome those hurdles. Ideally case managers will have improved access to the clients records and can offer more informed advice on their eligibility for services and continuity of care. Training, retention and continuity of case management, and more interactive client contact are suggested by PLWH/A.

Transportation issues are fairly complex. The rural populations and urban populations both expressed a relatively high need. From reported utility and capacity data, it appears that there is unmet need, but the data seems suspect and needs further investigation. What is clear is that the quality of transportation varies, and the sensitivity and concern of the drivers and the expected deportment of riders require additional training or discipline. From the data it is clear that public and private transportation are not well integrated into a single system for the PLWH/A. From an eligibility perspective, having a diagnosis of AIDS may be too rigid for car and taxi service. If a major goal on the continuum of care is not progressing to AIDS, then this criteria might be relaxed. Another issue is making transportation available to families. However, it will be critical to develop infrastructure before inviting greater use.

Housing is identified as a top need by all the stakeholders, and is one of the highest anticipated needs by PLWH/A. The survey indicates a large gap for housing, particularly finding independent housing. Obtaining supportive housing is ranked somewhat lower by PLWH/A. The eligibility criteria for housing is complex, including homelessness in some instances, and housing and drug abuse services overlap. While increasing capacity for independent housing should be a priority, making the housing system more transparent to PLWH/A and changing criteria for eligibility might be considered.

Food is the other basic need that is addressed in the continuum of care. Based on a large waiting list, high anticipated need, and high demand there is a need to increase capacity. Overall PLWH/A are satisfied with the service and level of access. The role of the food bank in providing a primary source of nutrition for PLWH/A should be determined and there might be a more variable system of eligibility based on nutritional need.

Direct Emergency Assistance with rent and utilities, like food and housing, speak to meeting basic needs. There is a great demand and limited capacity. For PLWH/A the rules are seen as somewhat arbitrary, and access is seen as relatively difficult. The care system might make the process easier and rules clearer. As long as PLWH/A are overwhelmingly poor, the use of DEA will grow to whatever capacity is created. The challenge is determining when services will help improve the status and quality of life of PLWH/A and to decide what level of resource to provide to DEA. Developing an infrastructure to respond quickly to changes in demand would be helpful.

There is little unmet demand for treatment information and risk reduction information. However, the data suggest that information might be designed to be more targeted. Adherence continues to be inadequate and some populations are unaware of available treatment options. The challenge of the care system will to provide targeted information to populations in need.

While not a top need, insurance continuation deserves special mention in this final section. Insurance coverage is seen as one of the highest barriers by PLWH/A and there is a great perceived gap between the insurance asked for and received. The current insurance assistance is very limited to insurance continuation for those who already have insurance but are unable to pay. The role of insurance, however, might play a significantly greater role in the future. As a large number of PLWH/A are considering returning to work there may be an opportunity to create an insurance "start-up" policy. The recent mandate to require managed care may also suggest investigating models of insurance where PLWH/A can obtain insurance to cover health care plans through Medicare or Medicaid or emergency funds.

Other services are more fully described earlier in this report, but most have sufficient capacity. In the Houston system, a major concern is assuring quality and consistency of service now that accessibility is generally high.

Subpopulations Needs

Some targeted populations have needs that are different from the general population. Women have a greater need for childcare and are more likely to need referrals. Interestingly, case management is their most anticipated need. They find adult day care, home health care, and health insurance assistance harder to access than other services. Transportation is their highest barrier.

MSM, being the largest group of PLWH/A in Houston, largely follow the needs and barriers of the total populations. In terms of barriers they do not, however, speak in one voice. For example, African American MSM report the overall highest barrier score, while Anglo MSM report the lowest.

IDUs are more likely to need housing than other subpopulations. They have the highest barriers of any group, and are much more likely to mention transportation as a need as well as a barrier.

Heterosexuals are more likely to need childcare services than other subpopulations. They are also more likely to name their own physical health as a barrier to seeking care.

Undocumented PLWH/A are among the poorest PLWH/A and have the lowest educational level. While they have a lower use of medication, once prescribed they are more likely to adhere to a drug regimen. They express a higher than average need for case management and transportation. The undocumented PLWH/A report the lowest level of access for services. They are more likely to have children than PLWH/A in general and many of the barriers to care relate to family issues.

Rural participants are remarkably similar to all PLWH/A. They report being a little less informed about drug reimbursement. Rural PLWH/A consistently express their need for direct emergency assistance. Not surprisingly with the only dental provider located in central Houston, rural providers say that location of dental care is an issue for them.

Finally the moving of PLWH/A from emergency funds to more sustainable reimbursement streams will become more important in future years. Medicare, Medicaid and state programs offering substance abuse assistance and general medical coverage should continue to be integrated into the overall system of care. While Ryan White Emergency Funds will be available for at least a few more years, eventually AIDS is likely to become a chronic disease whose care will be integrated into the general health care system.

Attachment 1 Focus Group Outline

Attachment 2 PLWH/A Survey

Attachment 3 Provider Survey

Attachment 4 Announcement for Open Focus Groups

Attachment 5 Service Providers Where PLWH/A Recruited

Attachment 6 Log Sheet

Attachment 7 Number of Interviews Provided at Each Site

Attachment 8 Sample - Populations Comparison

Attachment 9 Focus Group Coding Schema

Attachment 10 Total Sample Demographics

Attachment 11 Condom Use & Prevention Behaviors

Attachment 12 Top 10 Service Needs

Attachment 13 Service Awareness

Attachment 14 Service Demand

Attachment 15 Service Utilization

Attachment 16 Frequency of Service Usage

Attachment 17 Service Satisfaction

Attachment 18 Service Access

Attachment 19 Future Demand of Services

Attachment 20 Factor Analysis of Barriers

Attachment 21 PLWH/A Barriers

Attachment 22 Provider Perception of Barriers

Attachment 23 Comparison of Funded Amounts : Provider Self-Reports vs. Administrative Agent