HOUSTON EMA & HOUSTON HSDA

1999
NEEDS ASSESSMENT REPORT

Prepared for:

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

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Houston EMA/HSDA

Houston EMA/HSDA

EXECUTIVE SUMMARY

HOUSTON EMA & HOUSTON HSDA NEEDS ASSESSMENT REPORT
Epidemiological review and Survey and focus group report of Consumers and Providers

Prepared by the Partnership for Community Health
For the Houston EMA & Houston HSDA
November 1999

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Introduction

In Spring 1999 The Houston Area HIV Services Ryan White Planning Council and the Houston HSDA CARE Consortium started an extensive needs assessment with a goal of facilitating informed decisions regarding all medical and support services provided through the Ryan White CARE Act and other funding sources for people living with HIV and AIDS (PLWH/A). Information from the needs assessment was designed to identify service needs, gaps, and barriers for PLWH/A.

Methods

A number of methods were used to collect data. In summer 1999, an Epidemiological Review and a review and recommendation for a Continuum of Care was completed. Secondary analysis of existing data was conducted, and, from April 1999 through June 1999, a survey of 455 PLWH/A and 24 focus groups were completed. Thirty-six provider surveys were completed in the early Fall of 1999. A complete description of sampling, recruitment, and surveying methods are discussed in the full needs assessment report.

Definitions

Guiding the effort was a set of definitions about service needs and gaps. They are shown in Table 1.

Table 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. This refers to services requested (but not necessarily received) by PLWH/A.
Fulfilled need:	Demand based on utilization figures, surveys or other non-direct counts. It is expressed by the fact that an HIV-infected individual has actually received a service.
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 difference between the services that a PLWH/A requested and what services they actually received/utilized.
Unmet demand:	This refers to a demand-capacity gap and is the difference between the number requesting 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 theoretically needing (but not necessarily perceiving) they need services and is the difference between the number who, in theory, should receive services and the number requesting services.

* "Perceived need" can be further defined as those services PLWH/A would like to have available to them but do not necessarily ask for because they are not available or accessible for some reason. In the report, "perceived need" is operationalized as those services asked for by PLWH/A.

Continuum of Care

The Houston Continuum of Care, shown in Figure 1, has 5 tracks, each relating to a specific population and each having a desired outcome. These are summarized in Table 2.

Table 2 Continuum of Care Outcomes and Populations They Impact

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

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.

The needs assessment focused 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 overlap or are located on these "tracks".

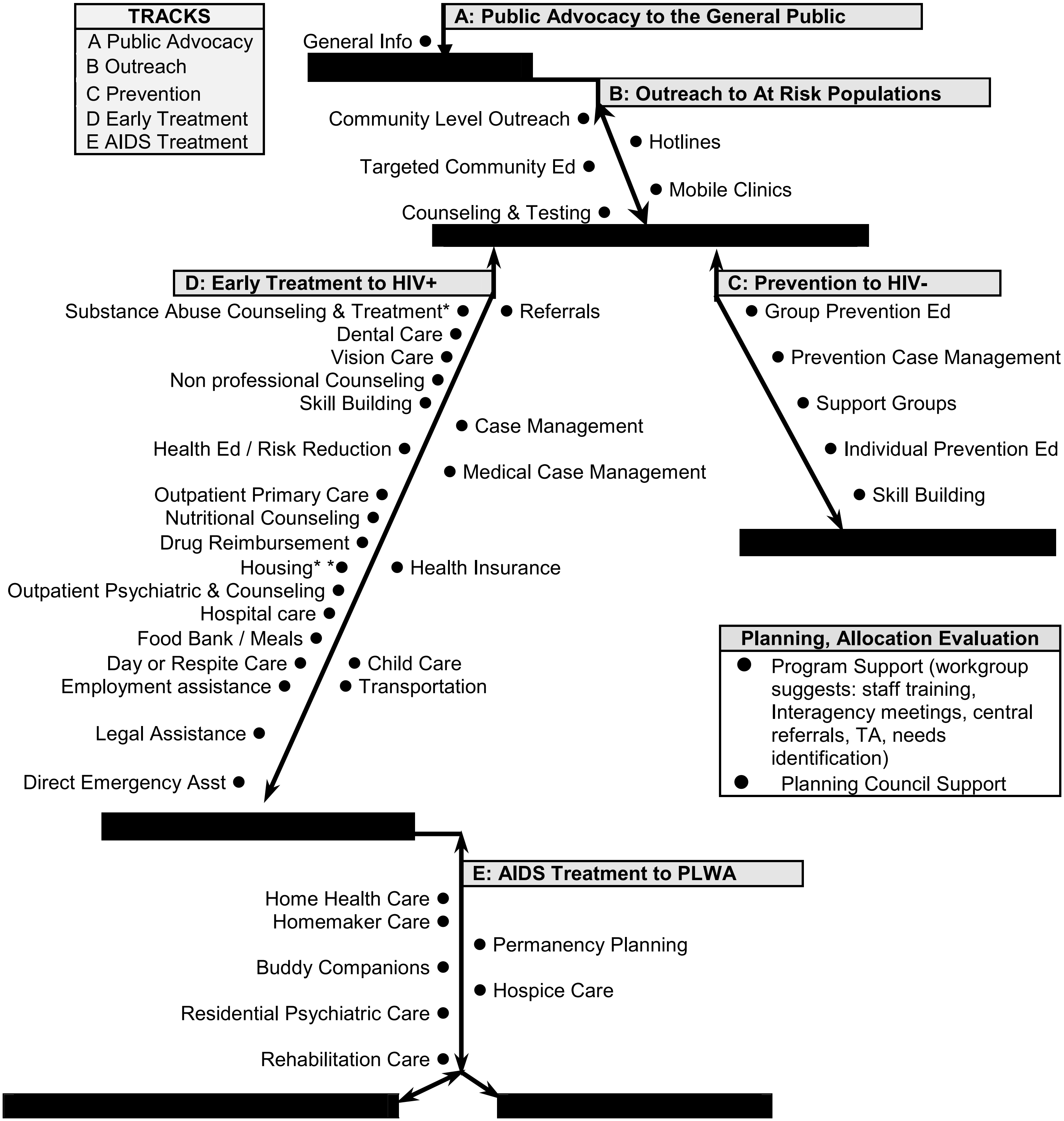
Track D on the Continuum of Care, "Early Treatment to HIV Infection", is a priority for the Council and Consortium. The goal of assuring that people infected with HIV do not progress to AIDS, suggests increased efforts to identify and bring into care those who are infected but not in the system, and improving accessibility to services to those not traditionally in care.

One of the challenges facing the Council and Consortium is the greater integration of tracks in the Continuum of Care. A greater integration of the general public track with early and AIDS treatment tracks is recommended. Many criteria for eligibility to the service system are established by the legislative process. For example, a concern is the ease with which PWLH/A can work without losing essential services, and the public understanding and support of legislation that facilitates maintaining benefits and working could lead to improved quality of life of PLWH/A. Educating the public about the increasing number of clients entering the care system and the need for continued support is an important part of the continuum of care.

It is recommended that the prevention and care tracks also become more integrated. Several areas of integration are possible. To name just a few:

- 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.
- Coordination between prevention outreach and early medical intervention outreach to identify persons infected with HIV is a logical combination of efforts.
- Greater emphasis on support and skill building groups to reinforce the need for medication adherence and safer practices for discordant partners. These could play an important role in improving adherence and lowering transmission.

Figure 1 HIV/AIDS CONTINUUM OF CARE



TRACKS
A Public Advocacy
B Outreach
C Prevention
D Early Treatment
E AIDS Treatment

Planning, Allocation Evaluation
- Program Support (workgroup suggests: staff training, Interagency meetings, central referrals, TA, needs identification)
- Planning Council Support

*Includes residential and medical detoxification; **Housing includes scattered site, aggregate, and temporary housing

Overview of Current Resources

Based on the 36 provider surveys (out of 39 agencies receiving Ryan White Funding), direct funding from all sources for HIV/AIDS services in the Houston area, including prevention, is over $32 million. These agencies reported receiving about $29 million in funding from Ryan White, TDH, HOPWA, Federal grants and private funding sources for treatment and care services. In the Houston area, Harris County Hospital District (HCHD), Bering–Omega Community Services, AIDS Foundation Houston, and Texas Children Hospital are the top recipients of funds. 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 percentage of funding from each source is shown in the pie chart Figure 2. “Other” funding sources, Ryan White Title I, and Foundations are the top three sources of funding for treatment and care. “Other” funding, as shown, 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 Department of Pediatrics, and Diocesan AIDS Ministry.

Figure 2 Funding Sources for HIV/AIDS Care

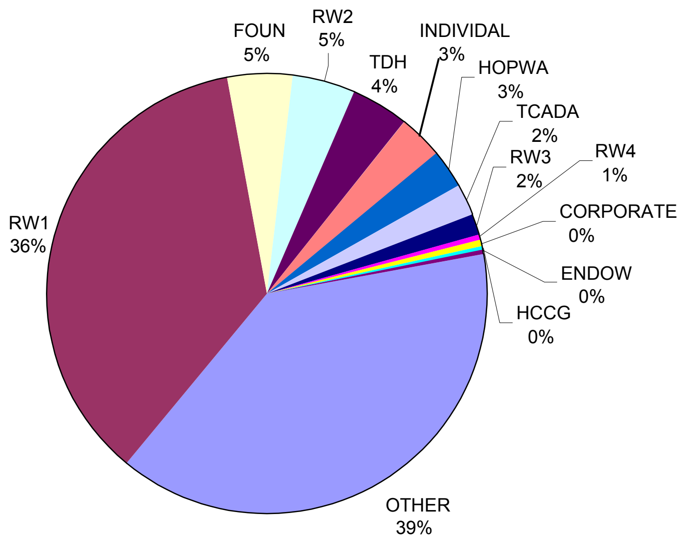


Table 3 indicates how the $21.3 million reported for direct programs was divided among the service categories. Based on Ryan White funds, HOPWA, TCADA and other funds, the services that received over a million dollars were medical care, case management, HIV early intervention and outreach, rental/emergency housing assistance, and dental.

Table 3 Funds Expended FY 98[1]

Service Category	RW I, II, 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%**

1. This information is based on provider self-report only. See the provider survey, an attachment in the full report, for how it was reported.

Epidemiology

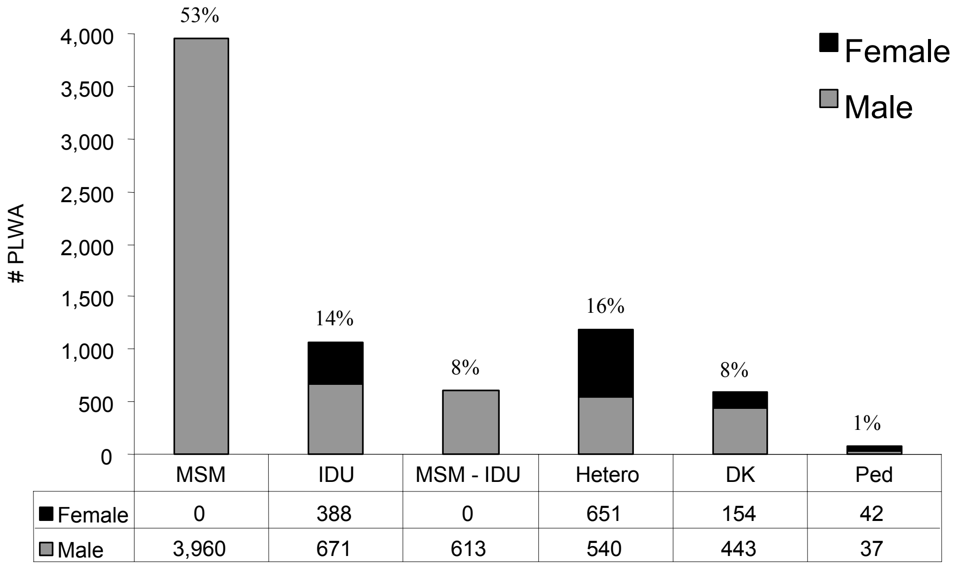
To estimate absolute need and service capacity for HIV/AIDS services, there must be reasonable estimates of those currently utilizing the system of care and the number of PLWH/A who are eligible to access the care system. Based on the epidemiological review, it is estimated by the Texas Department of Health (TDH) that there were about 7,580 persons living with AIDS in the Houston HSDA in 1998 and of those, 7,538 resided in the Houston EMA. Based on estimates derived in the 1999 Epidemiological Review, there are between 13,373 and 20,900 people living with HIV/AIDS in the Houston HSDA in 1999, and slightly fewer in the Houston EMA. For purposes of calculating unmet need in the 1999 Needs Assessment, PCH has used an estimate of 7,600 PLWA in the Houston area, and an additional 7,600 persons living with HIV who have not progressed to AIDS, for a total of 15,200 PLWH/A.

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

- A declining number of deaths for AIDS, more people are living with AIDS and HIV means that an increasing number of PLWH/A will be seeking and needing services in the next few years.
- Over 80% of PLWA are male and 60% are MSM. From 1992 to 1997, the number of newly diagnosed AIDS cases among females increased 94% while the number of males decreased 23%. However, in 1997, there were over three times more men who progressed to an AIDS diagnosis than women.
- 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.
- IDUs, including MSM/IDUs, make up between 22% and 25% of the PLWH/A. Among the IDUs who are not MSM, about a third are women.
- In 1998, the largest number of cumulative AIDS cases were among Anglos (45%), followed by African Americans (38%) and Hispanics (17%).
- African Americans have surpassed Anglos in the number of newly diagnosed AIDS cases each year, and data suggests growing needs within the African American Community. Newly diagnosed cases among Hispanics are staying relatively stable, while new cases among Anglos are declining.
- Heterosexuals represent between 14% and 16% of PLWH/A in 1998 which is an increase of about 20% since 1994. A majority, 55%, are female and a majority of those females are African American.
- 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. The proportion of MSM of color will increase.
- About 5% of all PLWA are outside Harris County, but 25% of the PLWA are outside or straddling the outer loop or Beltway 8.
- The greatest unknown in predicting the number of PLWH/A in care 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.

The profile of PLWA at the end of 1997 is shown in Figure 3.

Figure 3 PLWA at End of 1997



	MSM	IDU	MSM - IDU	Hetero	DK	Ped
■ Female	0	388	0	651	154	42
▨ Male	3,960	671	613	540	443	37

Because large proportions of the survey respondents were recruited through providers, those in contact with providers of HIV/AIDS care are over represented. Among survey participants:

- Over 80% of PLWH/A who access care make less than $15,000 a year; 51% make less than $6,000 a year.
- Fifty-three percent (53%) of PLWH/A report no health insurance. Over 40% of PLWH/A report receiving Medicare and/or Medicaid, and about 20% of PLWH/A report having private insurance or COBRA coverage. About 2% of PLWH/A report receiving insurance assistance.
- Over 80% of PLWH/A have access to drug reimbursement services. African Americans are less likely to receive ADAP than other populations.
- About 25% of PLWH/A are employed in some capacity, either part-time or full-time, and about 25% are on full-time disability.
- Twenty-one percent (21%) of the PLWH are looking for work in contrast to about 10% of PLWA who are looking for work.
- 1.4% of all PLWH/A reported they were currently homeless. However almost 45% of the IDUs have been homeless for some period of time in the last two years. Thirty-five percent (35%) of the PLWH/A are worried about being homeless in the next year.
- Over 25% of the PLWH/A indicate some contact with the prison system in the last two years. And up to 10% of the PLWH/A surveyed report having been incarcerated for more than one year in the last two years.
- With more heterosexuals and women becoming infected, there are more parents living with HIV and AIDS. About 13% of the sample of PLWH/A have children. PLWH/A with families are 63% African American, 22% Hispanic, 8% other ethnicity and 7% Anglo.

Based on the increased number of African Americans living in poverty that are becoming infected and progressing to AIDS, there will be a larger proportion of impoverished PLWH/A potentially entering the care system. Combined with greatly improved life expectancy of PLWH/A already in the care system, the demand on services will be greater for at least the next three to five years.

Current rules and regulations regarding access to several services include income eligibility; this discourages people from entering or re-entering the work force. For those on disability, common sense dictates that even if their health status improves, PLWH/A will be cautious before returning to work and sacrificing benefits that are difficult to have reinstated.

The barriers section of the needs assessment notes that there is a large concern by PLWH/A that they will lose insurance coverage and their disability income. While they may overestimate the risk for the next few years, ideally a system will evolve to allow persons to earn at least subsistence income and provide insurance to those able to work. However, until disability legislation and its implementation change, there will be a growing need to provide the basic services needed by PLWH/A near or below the poverty level, plus the medical and social services that they need to maintain their health.

Co-Morbidities

  - HIV and AIDS often co-exist with substance abuse, STDs, and mental disabilities. The relatively high use of opiates is of concern. About 15% of the PLWH/A say they have used cocaine in the last 6 months and about 5% report using heroin. Among IDUs, about 30% 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.
  - Of the 15% of the IDUs who continue to report using, 22% report sharing needles frequently or sometimes.
  - PLWH/A reported a high incidence of ever having an STD. Over 60% of the IDUs report having had hepatitis, and between 25% and 30% of MSM and heterosexuals report hepatitis. This suggests a 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 about 35% of all PLWH/A reporting being diagnosed with gonorrhea during their lifetime.
- Given that STDs are related to a more rapid progression of HIV infection, and STDs are often an indication of risky behavior that can transmit HIV infection, the data suggest a continuing need to coordinate STD care and prevention with HIV / AIDS care and prevention.
  - Mental disabilities cover a wide range of diseases including major depression, bipolar depression, post-traumatic stress disorders, anxiety disorders, schizophrenia or psychotic disorders, and dementia. Since they knew they were infected with HIV, 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, and over one third of the African American and Anglo MSM have been hospitalized for an emotional problem.
- In 1997, there were 623 new cases of TB in Harris County, the lowest number since 1993. Of these, 98 (15.7%) were also diagnosed with HIV/AIDS. The majority of TB cases in the Houston EMA occur among the Hispanic/Latino and Asian foreign-born who have relatively low HIV rates. Eighteen people reported active TB and 59 reported inactive TB in the 1999 Needs Assessment survey. The highest prevalence was among recently released and incarcerated populations.

Outcomes

In the needs assessment, two outcomes of the care system are measured. The first is mortality. A striking testament to the success of the treatment and care for those in care in the Houston area is the reduction from between a 65% and 75% mortality rate among all risks groups in 1992 to under 10% in 1998. When all deaths are considered, those in care and out-of-care, African Americans have a much higher mortality rate. However, when only those in care are considered, death rates among African Americans are about the same low rate as other ethnic groups. That suggests that African Americans tend to be getting into care at the later stages of HIV disease or not getting into services at all.

A second outcome is quality of life. Over half the PLWH/A report that the system has stabilized or improved their physical and emotional health. 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. For those living with AIDS, about 65% 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 has 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.

Changing Face of the Epidemic

In determining service needs and gaps, the changing face of the epidemic raises new challenges and suggests continued 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 in 1999 as fewer people die and early treatment after HIV is detected becomes the standard of care.

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.

While it is still important to continue to fund and support end-stage services for those who need them, today the primary 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.

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.

A small number, about 2% of PLWH/A, receive insurance assistance, but based on reported employment figures 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.

Regarding benefits:

- 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. Among MSM, Anglos are the most likely to receive drug reimbursement.

As the epidemic moves from the management of an acute disease to the management of a chronic illness, moving 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.

Current Priorities Rankings

Both the Council and Consortium have well-established committees with the responsibility of prioritizing service needs for each year as well as the focus of this report 2000-2001. They used input from formal and informal needs assessments and weighed the experience of service providers and PLWH/A. One form of input for their decision was the 1999 rankings of most important services determined in this needs assessment. Table 4 compares the ranking of most important services by PLWH/A and the Consortium and Council 2000-2001 priority rankings. (Other input included services most demanded, utilized, and those with the highest anticipated need, as discussed later). The categories may not refer to the same services and therefore are not exactly comparable. However, they do provide a good sense of the relative priorities of these three stakeholders in the HIV/AIDS system of care.

The top priorities of PLWH/A, the Council, and Consortium are the same. Primary medical care is first and drug reimbursement is second. Several top priorities are similar. Transportation is 3rd for PLWH/A and the Consortium and 4th for the Council. Housing is 8th for PLWH/A, 4th for the Consortium, and 5th for the Council. Food pantry or food bank is 4th for PLWH/A, 5th for the Consortium, and 7th for the Council. Rent and utility assistance is 5th for PLWH/A and 8th for the Council. Dental service is 7th for PLWH/A, 8th for the Consortium, and 6th for the Council. Case management shows a larger difference in ranking than other top services. Case management is 9th for PLWH/A, 6th for the Consortium, and 3rd for the Council.

Similarly ranked mid level priorities include assistance paying health insurance, legal services, health education, and peer counseling. A similarly ranked low priority services include volunteers or buddy companion services.

All PLWH/A rank baby-sitting and child care 20th, but it is ranked in the top 10 for parents living with HIV and AIDS. The Consortium ranks pediatric day care 7th. PLWH/A rank adult day care 28th, while the Consortium ranks it 19th and the Council ranks day and respite care 12th. In-home Hospice care is ranked 27th by PLWH/A (with no significant difference between PLWA and PLWH), and 21st by the Consortium. It is ranked higher by the Consortium (12th). Nutritional counseling is incorporated into outpatient care by the Council, but is maintained as a separate service for Consortium. When divided from outpatient care it is ranked 17th by the Consortium. PLWH/A rank nutritional counseling a little higher at 14h.

The Consortium services not ranked by the Council include employment assistance, assisted living, household items, 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, interpreter services, housing administration, program support, planning council support and outreach.

Table 4 PLWH/A Most Important Services in 1999 Compared to Consortium and Council Service Rankings Year 2000 -2001

1999 SURVEY	PLWH/A Survey Rankings*	CONSORTIUM	Consor-tium Priority	COUNCIL	Council Priority
Appointments with a doctor, nurse or their assistants in an office or clinic....[+]	**1**	Primary Medical Care, Rural	**1**	Outpatient/Ambulatory (includes Nutritional) Services	**1**
Drug reimbursement....	**2**	Medication Assistance	**2**	Drug Reimbursement	**2**
Transportation assistance to access physical or mental health care....	**3**	Transportation, Rural Non-rural gas vouchers (new)	**3**	Transportation	**4**
Place to obtain food / food bank	**4**	Food Pantry Food Pantry, Rural	**5**	Food Bank/ meals / nutritional supplements.	**7**
Rent, mortgage or utility assistance	**5**	NA	**NA**	Direct Emergency Services	**8**
Lab tests	**6**	(Included in primary medical care)	**NA**	(Included in outpatient/ambulatory)	**NA**
Dental care	**7**	Dental	**8**	Dental Care	**6**
Assistance in locating or obtaining suitable housing	**8**	Housing++	**4**	Housing++	**5**
Case management - someone to help you coordinate your HIV/AIDS health care.	**9**	Case Management, Primary Care Case Management, Adolescent Services	**6**	Case Management	**3**
Mental health therapy with a psychologist or social worker in individual or group sessions.	**10**	Counseling, Counseling - Rural	**9**	Mental Health	**11**
Assistance paying health insurance premiums	**11**	Health Insurance Premiums	**10**	Health insurance	**15**
Obtaining supportive housing	**12**	NA	**NA**	NA	**NA**
Legal services	**13**	Legal Legal Rural	**11**	Client Advocacy / Legal / Permanency Planning	**13**
Counseling about nutrition, treatments and	**14**	Nutritional Counseling	**17**	NA	**NA**

1999 SURVEY	PLWH/A Survey Rankings*	CONSORTIUM	Consor-tium Priority	COUNCIL	Council Priority
health					
Referral to services	**15**			Referral	**22**
Employment assistance / vocational counseling and training	**16**	Employment Assistance	**20**	NC	**NC**

1999 SURVEY	PLWH/A Survey Rankings*	CONSORTIUM	Consor-tium Priority	COUNCIL	Council Priority
Peer counseling, support groups, drop in.... conducted by a nonlicensed counselor/social worker	**17**	Peer Counseling	**23**	Counseling (Peer / Other)	**16**
Newsletters, leaflets or booklets about HIV/AIDS treatment and care.	**18**	EMI/HERR	**15**	Health Education / Risk Reduction	**14**
Rehabilitative service	**19**	NC	**NC**	NC	**NC**
Baby sitting or child care services	**20**	Day Care, Pediatric	**7**	Included in day or respite care	**NA**
Holistic or complementary therapy including acupuncture, massage or chiropractic from a licenses practitioner	**21**	NA	**NA**	NA	**NA**
Substance abuse treatment or counseling sessions (not in a residential setting)	**22**	NA	**NA**	Substance Abuse	**9**
Home healthcare form a nurse or professional home health agency....	**23**	Home Health Home Health, Rural	**14**	Home Health Care	**10**
Volunteers or peers who assist in household or personal tasks and provide support....	**24**	Volunteerism	**16**	Buddy / companion	**19**
Home delivered meals	**25**	NA	**NA**	NA	**NA**
Substance abuse treatment in a 24-hour-a day residential setting	**26**	NA	**NA**	(In substance abuse)	**NA**
In-home hospice care....	**27**	Hospice	**12**	Hospice Care	**21**
Adult day care	**28**	Day Care, Adult	**19**	Day or Respite Care	**12**
Hotline or telephone information	**29**	NC	**NC**	NC	**NC**
Meals in a group setting	**30**	(Service included in other categories)	**NA**	(Service included in other categories)	**NA**
Adoption or foster care	**31**	NC	**NC**	NC	**NC**
	Not ranked	Household Items	**13**	NC	**NC**
	Not ranked	Interpreter Services	**21**	**NA**	**NA**
	Not	Housing Administration	**22**	NA	**NA**

1999 SURVEY	PLWH/A Survey Rankings*	CONSORTIUM	Consor-tium Priority	COUNCIL	Council Priority
	ranked				
	Not ranked	Assisted Living	**18**	NC	**NC**
	Not ranked		**Not ranked**	Program Support	**17**
	Not ranked		**Not ranked**	Planning Council Support	**20**
	Not ranked		**Not ranked**	Outreach	**23**

*Rated services needed the most
+ "...."indicates incomplete wording. For exact wording see the Survey, question 46, in the Attachment
++Housing refers to different types of services supported by the Council and Consortium.
NC = Not classified
NA = Not Applicable (included in other services)

Demand and Utilization

In addition to the most important services needed, PLWH/A ranked the services they asked for, received, and thought they would need next year. Figure 4 shows the perceived availability of services and those most asked for and most received. Outpatient care, lab tests, dental care and case management were the top four demanded and utilized services by PLWH/A. The Council and Consortium mostly agreed that these should be top priorities 2000-2001. Notably the Consortium and Council placed dental care lower on their priority list of services (Figure 4) and transportation higher than would be suggested by current demand and utilization patterns. The Consortium placed case management a little lower than the rank order of services that PLWH/A asked for.

Figure 5 displays the unmet perceived need and shows that outpatient care and nutritional counseling is received more than it is asked for. A gap should not be interpreted that there is too much capacity. For example, in the case of outpatient primary care, the theoretical need is close to 100%. The system appropriately refers all persons tested positive to outpatient care, and clients don't need to ask for that service because they are part of standard treatment protocol. There are reported larger gaps in locating and obtaining housing, rent and utility assistance, dental care, and legal services. Among the services less demanded and utilized, gaps also were reported in health insurance assistance and employment assistance.

Figure 4 Services Awareness, Demand, and Utilization - top 17

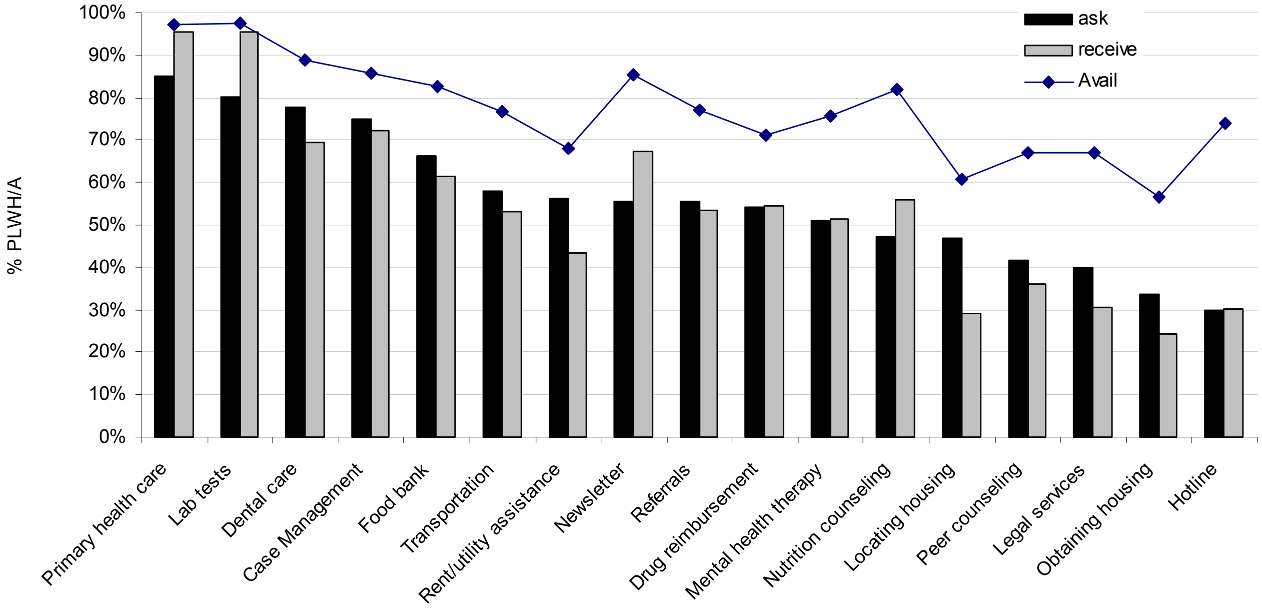
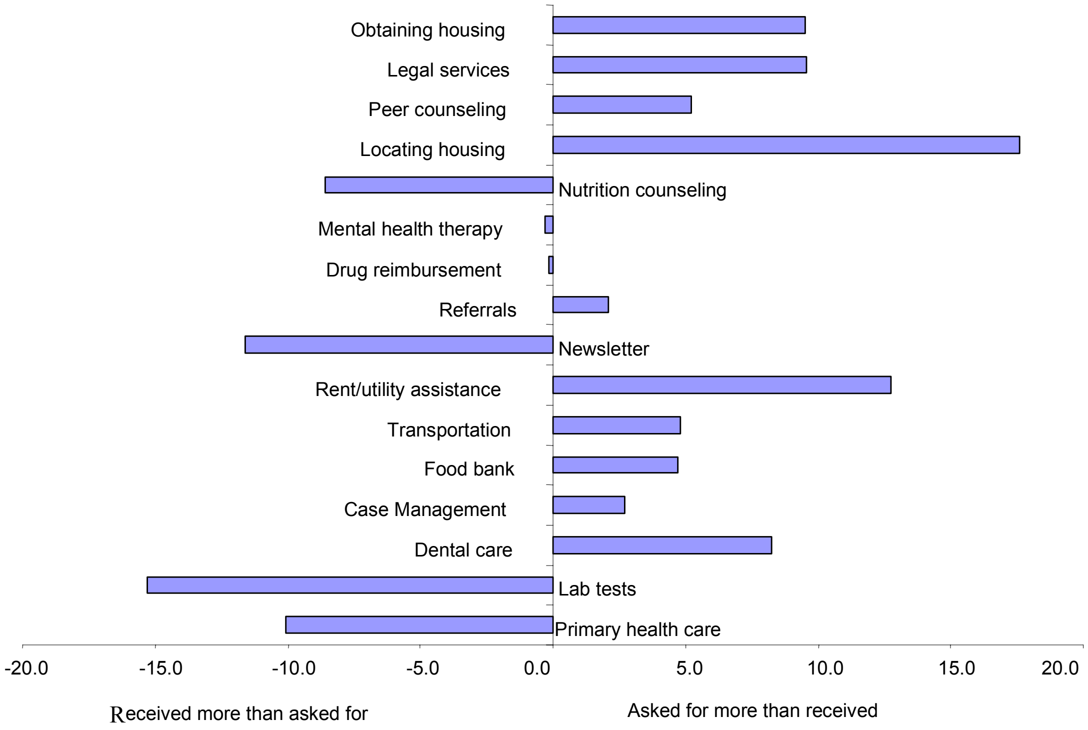


Figure 5 Total Sample Demand- Utilization Gap: Top 16 Services



Anticipated Need

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. The juxtaposition of the most needed services with those that have the greatest anticipated need suggests PLWH/A are confident of the continuation of medical care, as their needs are shifting toward the basic housing and food concerns that any population living in poverty confronted with a chronic disease would have.

Barriers

When the ratings of all of the barriers are summed, none of the risk groups or ethnic populations reported a big barrier. IDUs report the highest barriers -- on average between small to moderate barriers, followed by heterosexuals, and MSM. Men tend to report higher barriers than women. Within each risk category, African Americans report the highest barriers, followed by Hispanics and Anglos.

PLWH/A rated and discussed thirty-two barriers. They are 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).

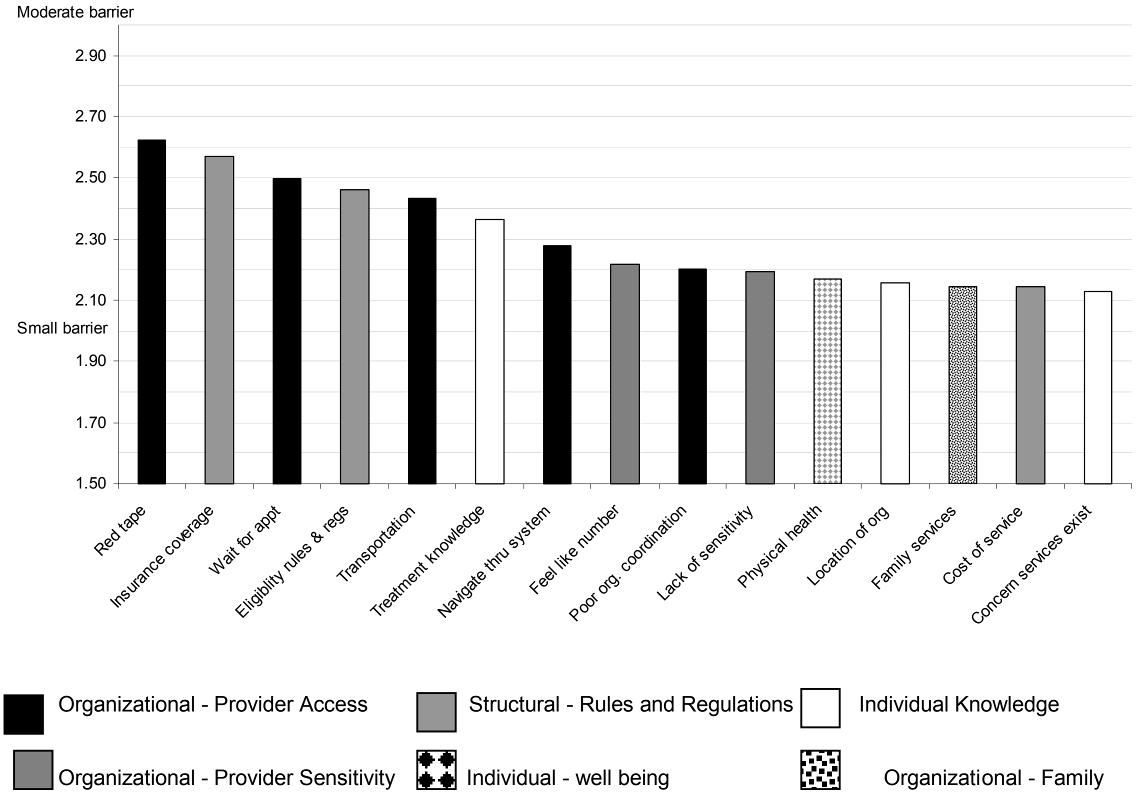
As seen in Figure 6, out of the top nine barriers mentioned, five are organizational access barriers (black bars) and two are structural barriers (dark gray bars). Most relate to the ability to obtain direct services. The organizational access barriers included:

- 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.

The second and fourth highest barriers are 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 regulations.

Figure 6 Top Barriers



Capacity and Service Gaps

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, service 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 PLWH/A have with outpatient care relate to its quality and the amount of red tape they have to go through to access services. The process of intake and care could be more efficient and the quality of service could be standardized. Individual treatment plans and client coordination among providers could be developed to provide a more seamless system of care for PLWH/A.

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. PLWH/A suggest improved training, retention of case management to assure continuity of care, and more interactive client contact.

Transportation issues are fairly complex. The rural and urban populations both expressed a relatively high need. From reported utility and capacity data, it appears that there is unmet need, but this requires additional investigation. What is clear is that the quality of transportation varies. The sensitivity and concern of the drivers toward riders, and the behavior of riders toward drivers is frequently an issue. This suggests additional training or discipline for the drivers and education for riders on what can be realistically expected. 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 raised in focus groups by HIV positive parents and parent with HIV positive children 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. The need to obtain 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 easily understandable to PLWH/A and, where possible, changing criteria to increase the pool of those eligible for housing should 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 a more graduated system of eligibility based on nutritional need might be considered.

Direct Emergency Assistance (DEA) with rent and utilities, like food and housing, meets a basic need. 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.

In the survey, PLWH/A indicate that they have little unmet demand for treatment information and risk reduction information. All risk groups and ethnic groups reported receiving more information than they asked for, although Hispanic and Rural populations indicated a greater need than other populations. The focus groups suggest that information might be designed to be more targeted. While PLWH/A say they receive adequate amounts, or too much, general information, they indicate the need for population specific information. The survey indicates that adherence continues to be inadequate and some populations are unaware of available treatment options. The challenge of the care system will be to understand the specific information needs of the different ethnic and risk group populations and provide targeted information to those populations.

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 an insurance policy in force but are unable to pay. There is no estimate for the number of PLWH/A who are eligible for insurance assistance but do not currently receive it. Given the history of those with AIDS going on disability, it is possible that greater outreach would significantly expand the program.

The role of assistance obtaining and paying for insurance, however, might play a significantly greater role in the future and the community could look at ways to increase access to insurance. A large number of PLWH/A are considering returning to work. This may present complex issues surrounding insurance coverage and an opportunity for advocacy on behalf of the clients. The recent mandate to require managed care may also suggest investigating ways that PLWH/A can obtain insurance to cover health care through Medicare or Medicaid or emergency funds.

Other services needs, barriers, and gaps are described more completely in the full report.

Subpopulations Capacity and Gaps

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. They report that 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. A majority of heterosexuals are women, and not surprisingly, they are more likely to need childcare than other subpopulations. They are also more likely to name their own physical health as a barrier to seeking care.

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, among MSM, African Americans 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.

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.

Special Considerations

One red flag raised by the needs assessment process 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 into services.

A second red flag 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 given treatment information, but reports show that those in correctional institutions and those recently released are underserved in medical and support services.

FINAL REPORT

Houston Area HIV Services
Ryan White Planning Council

Perceptions and Evaluation of HIV/AIDS Care and Prevention in Harris and Surrounding Counties.

BACKGROUND

Houston Area HIV Services Ryan White Planning Council is a 38 member volunteer planning group made up of community members who have been appointed by the CEO, County Judge Robert Eckels, to serve a two-year term. The Houston Area HIV Services Ryan White Planning Council is responsible for activities under Title I of the Ryan White Comprehensive AIDS Resources Emergency Act.

Council members, in collaboration with consumers, service providers, and other Experts determine what services are most needed by people living with HIV in the Houston area. The Council then prioritizes those services and decides the best way to allocate Houston's Title I grant award to fund those services according to the approved priorities. The Council is also responsible for determining the Standards of Care for each of the funded service categories and for developing a plan to provide those services within the comprehensive plan. Comprehensive planning is the process used by the Ryan White Council in determining the organization and delivery of HIV services.

Opportunities and Challenges

The Ryan White Planning Council's Office of Support contracted SUMA Partners to carry out confidential, semi-structured interviews with key informants segmented into two groups (Key Leaders and Experts). Key Leaders were defined as Elected Officials (City Council members; County Judges; State Representatives and County Commissioners) who could be expected to vote on or exercise authority over broad level decisions relating to HIV/AIDS. Experts were envisioned as Administrators, Planners and Community Advocates who are more likely to be responsible for directing and/or implementing HIV/AIDS programs or decisions. The universe contacted consisted of 25 Key Leaders and 44 Experts. The research was designed to collect data on three major topics:

- Care financing/regulatory issues
- Jurisdictional/political factors
- Public health infrastructure constraints on the provision of HIV/AIDS care and prevention services.

The Office of Support outlined the following questions for the semi-structured interview process in the draft version of their Comprehensive Plan:

- ➢ *What you can you tell us about the adequacy of financing for HIV/AIDS care and prevention in this geographical area? Please discuss how well the funds fit into the context of the available funding streams?*
- ➢ *How do you feel regarding the regulations that apply to the funding streams, including those related to HIV/AIDS care and prevention dollars? Do you find the regulations helpful or a hindrance to delivering needed services?*
- ➢ *What suggestions do you have related to the regulations that exist or should exist for funding HIV/AIDS care and prevention in this geographical region?*
- ➢ *What are the key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in this area?*
- ➢ *Would you want to modify these political and jurisdictional factors related to HIV/AIDS care and prevention? If so, how?*
- ➢ *What are the strengths of the public health system in this area with respect to the delivery of HIV/AIDS care and prevention?*
- ➢ *What are the weaknesses of the public health system in this area with respect to the delivery of HIV/AIDS care and prevention?*
- ➢ *What, if anything, do you think needs to be changed to help the public health system better provide HIV/AIDS care and prevention in this area?*

SUMA Partners worked closely with the Ryan White Planning Council to deliver accurate answers to these questions. The following **phased approach** was used.

  - **The Ryan White Planning Council, Office of Support** revised the series of specific questions to be asked of key informants during Phase Two. Questions were structured to limit interviews to no more than thirty minutes.
- **The Ryan White Planning Council, Office of Support** developed a list of prospective interview targets.
- **SUMA Partners, Inc.** developed a standard letter for the Ryan White Planning Council to fax/mail/e-mail to prospective interview targets.
- **The Ryan White Planning Council, Office of Support** contacted the targets from the prospective interview list and asked them to participate in a completely confidential survey conducted by an independent market research organization.
- **SUMA Partners, Inc.** conducted one-on-one telephone interviews, approximately twenty-five to thirty minutes in length.

  Interviewees were asked the same questions, in the same order. The interviewers probed for additional information, where appropriate.
- **SUMA Partners, Inc.** collected, organized and analyzed the interview information.

Interview Questionnaire

Hi, my name is _____________. I'm with SUMA Partners. I'm calling on behalf of Judge Eckels' Office and the Ryan White Planning Council. We're scheduled to interview you. (Is this still a convenient time for an interview?)

SUMA Partners is an independent consulting firm contracted by Judge Eckels' Office and the Ryan White Planning Council to conduct the interviews. All of your responses will be kept completely confidential. Your responses will be compiled along with 74 other Key Leaders and Experts to develop a report. The Ryan White Planning Council will use our report to develop their Comprehensive Plan. Judge Eckels' Office intends to publish a copy of the Comprehensive Plan to all who participated in the interviews before the end of this year.

We would like to hear your opinions about eight questions, all relating to HIV/AIDS care and prevention. If you find any of the questions outside your scope or area of Expertise, just say so and we'll move on. You will hear pauses as I take notes during the interview.

1. What you can you tell us about the adequacy of funding for HIV/AIDS care and prevention in your geographical area?

The next two questions deal with regulations:

2. Tell me about the regulations that apply to the funding streams, including those related to HIV/AIDS care and prevention dollars: Do you find the regulations helpful or a hindrance to delivering needed services?

3. What suggestions do you have regarding regulations that currently exist or should exist for funding HIV/AIDS care and prevention in your area?

The next two questions deal with political and jurisdictional factors:

4. What would you identify as the key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in your area?

5. Would you want to modify these political and jurisdictional factors related to HIV/AIDS care and prevention? If so, how?

The last three questions deal with the public health system:

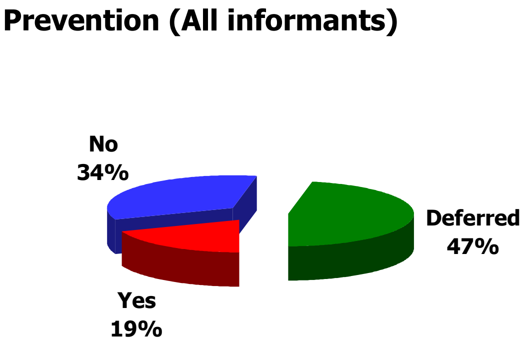
6. What would you identify as the strengths of the public health system with respect to the delivery of HIV/AIDS care and prevention?

7. What about the weaknesses of the public health system?

8. What, if anything, do you think needs to be changed to help the public health system better provide HIV/AIDS care and prevention in your area?

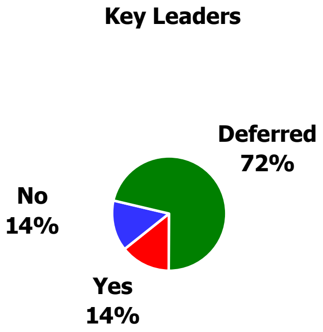
What you can you tell us about the adequacy of funding for HIV/AIDS care and prevention in your geographical area?

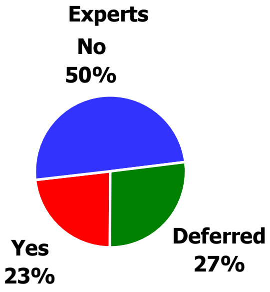
Responses were measured for both prevention and care. Thirty four percent (34%) of the respondents felt that prevention-related funding for HIV/AIDS was not adequate. Nineteen percent of the total respondents felt that funding for the prevention of HIV/AIDS was adequate. Significant in this question was the large number of total respondents that deferred by either saying that they did not know or that the adequacy of funding was the responsibility of another staff member.



When the responses were segmented between Key Leaders and Experts fourteen percent (14%) of Key Leaders responded that funding was adequate and fourteen percent (14%) responded that the funding for HIV/AIDS was not adequate. Significant was the large percentage (72%) of Key Leaders that **deferred** (See chart on page 8) indicating that the funding issues were delegated to staff or service providers and/or a lack of information on funding issues to form an opinion on funding adequacy.

Funding for Prevention

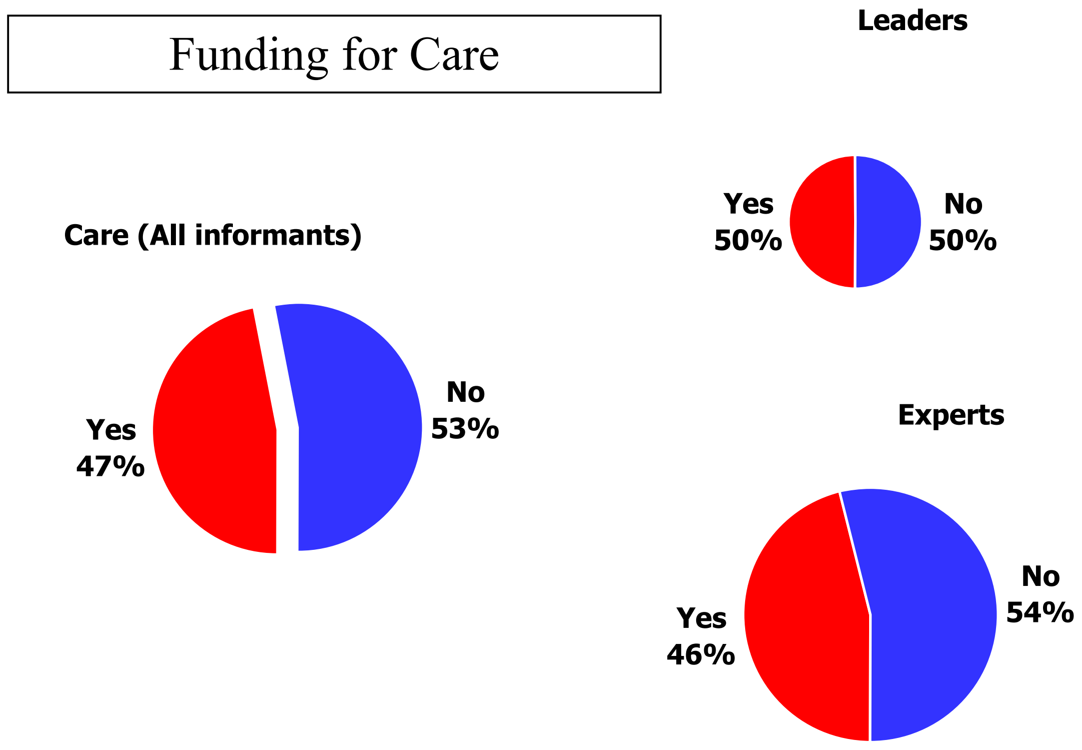




Fifty percent (50%) of the Experts interviewed indicated that the funding for HIV/AIDS prevention was not adequate. Twenty three percent (23%) indicated that the funding for prevention was adequate and twenty seven percent (27%) deferred.

Funding for HIV/AIDS care as rated by the total respondents showed forty seven percent (47%) indicating that funding was adequate and fifty three percent (53%) indicated that funding was not adequate. Of the Key Leaders responding, fifty percent (50%) indicated that funding was adequate and fifty percent indicated that funding was not adequate.

Forty six percent (46%) of the Experts indicated that funding for care was adequate and fifty four percent (54%) indicated that funding for care was not adequate.


Funding for Care

Leaders

Care (All informants)

Experts

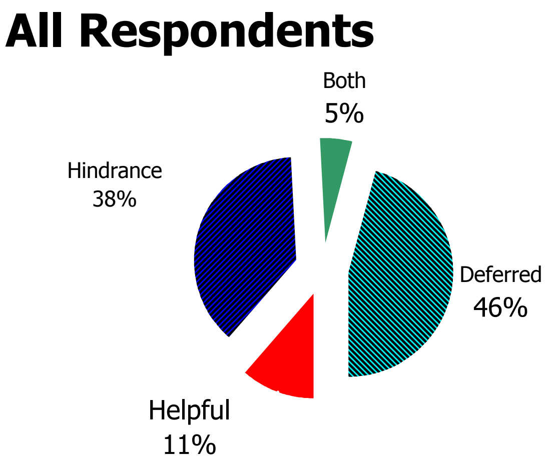
The following list of verbatim comments outlines the major themes related to prevention and care:

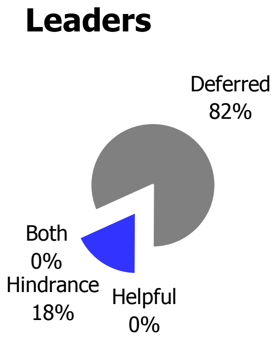
- *In terms of the funding of the "last resort" (populations that have no other means for paying for services) for the basic necessities, it seems to be adequate.*
- *We are meeting needs. But there have not been any real increases in funding to help develop new programs, yet we continue to get new clients.*
- *For HIV-infected people, those who are getting the services, the care and financing are adequate. However, if all the known and unknown existing HIV- positive people were to get treatment, there may be a problem --- a lack of funding.*
- *Whether it is adequate or not, I don't know, but it is probably as much money as most organizations can absorb.*

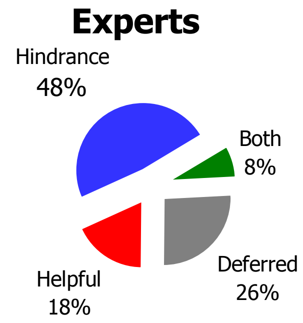
How about the regulations that apply to the funding streams, including those related to HIV/AIDS care and prevention dollars: Do you find the regulations helpful or a hindrance to delivering needed services?

For the evaluation of whether the regulations were **helpful or a hindrance** to delivering the needed services, thirty eight percent **(38%)** of the total respondents indicated that the regulations were a hindrance. Eleven percent **(11%)** indicated that the regulations were helpful and five percent **(5%)** indicated that the regulations were **both** helpful and a hindrance. Forty six percent **(46%)** of the respondents **deferred** and did not answer the question.

Among the **leaders** interviewed, eighteen percent **(18%)** responded that the regulations were a hindrance to delivering the needed services and eighty-two (82%) deferred.


All Respondents


Leaders


Experts

For the **Experts** interviewed, forty eight percent **(48%)** responded that the regulations were a **hindrance** and eighteen percent **(18%)** responded that the **regulations** were helpful. Eight percent (8%) of the **Experts** responded that the regulations were both helpful and a hindrance and twenty six percent **(26%)** deferred.

Verbatim comments:

- *Regulations behind specific funding are a hindrance…they do not allow for emergencies.*
- *For the most part the regulations have a purpose, however some are antiquated. We need to update them and encompass the family.*
- *Title III grants are relatively easy to apply for, but Title I are a nightmare.*
- *For housing, regulations are a hindrance, for primary care they (the regulations) can be very helpful.*
- *I find regulations between different funding sources conflicting -- that is a problem. HUD -- their regulations say one thing. HRSA for housing say another thing. We deal a lot with families and a lot of the regulations prevent us from using funds to help families.*
- *Regulations are not a hindrance. The problem is the lack of technical assistance from the national level or adequate technical assistance to bring us up to speed with the latest techniques in research on what works and doesn't work in AIDS prevention.*
- *I think it's a hindrance because when people are writing regulations, probably they are written around people who lobby the hardest. You have both proponents and opponents who look for strict rules and regulations.*
- *There are barriers for some organizations especially to smaller-based agencies to apply for funding for HIV care services.*
- *Both, they are both helpful and a hindrance. Helpful because they require accountability; they are a hindrance because they slow the delivery process of services.*

What suggestions do you have in terms of the regulations that exist or should exist for funding HIV/AIDS care and prevention in your area?

Analysis of the suggestions provided by the respondents revealed the following themes. Sixty one percent (61%) of the Respondents offered suggestions indicating that **better coordination** was necessary. Other recommendations included:

- **standardization of forms**
- allowing for migration of care from rural to urban areas
- provisions for clear explanation of the proposed regulatory changes before the changes are put in place
- need for **regulatory flexibility** to meet specific needs
- consolidation on a federal level, more government input on accountability

Verbatim comments:

- *There should be more training and consultations on the regulations by bringing in people who implement the programs and have some discussion on the proposed regulation before they are actually approved.*
- *Providing technical assistance to start-up organizations that may not fit the bill that we have typically funded in the past.*
- *I think that the allocation formula might need to be modified since it hasn't been changed in over 8 years.*
- *In the area of assessment and facility control, there need to be standardized forms for people who fill out information and a plan to design a new computer system to intake data.*

What would you identify as the key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in your area?

Opinions related to key political and jurisdictional factors that affect how HIV/AIDS care and prevention is delivered in their area fell into several distinct categories among the 53% of total interviewees that responded to the question. Sixty-two percent (62%) of those that responded identified **coordination, communication, politics** and education were factors affecting delivery. Thirty percent (30%) were Leaders and seventy percent (70%) were Experts. Respondents' comments regarding politics included some discussion related to relationships and processes within cross-departmental jurisdictions. The term "education" was interpreted as the need to inform key influencers of the problems that exist as well as educating the public on care and prevention. Several respondents from both the Key Leader and Expert categories indicated that the issue of education related to prevention is politically controversial.

Verbatim comments:

- *It seems as though the larger areas seem to always get more money and can manage to get their voices heard.*
- *You have many jurisdictional and political entities trying to accomplish different parts of the same goal, but they don't complement each other.*
- *A conflict of interest that the City has is its dual role of both a funding source for HIV prevention as well as a provider of some of these services.*
- *... Harris County Hospital district is limited to Harris County and cannot use Harris County taxpayer money for servicing people that reside outside the County. Then people have to get service from other places such as UTMB. This makes it difficult for people to get services if they don't live in Harris County. Money comes into the area for prevention and goes directly to the city for Houston and then finally to the surrounding areas. On the other hand, prevention funds stop at the city limits. This makes coordination and planning very difficult.*

Would you want to modify these political and jurisdictional factors related to HIV/AIDS care and prevention? If so, how?

Interviewees who responded that they would like modification of the political and jurisdictional factors related to HIV/AIDS care and prevention proposed several suggested changes. Respondents recommended an **independent board** be established to administer both HIV/AIDS care and prevention funds. Emphasis was placed on jurisdictional areas such as county versus city administration. There was no specific mention of funding streams. Accountability rated high among respondents for program justification. In addition, the respondents suggested **stronger communication** between groups be provided through networking and close coordination to break down the boundaries and eliminate redundancies in service jurisdictions. The interviewees also recommended that multiple year funding was more effective way to ensure effective programming than single year funding.

Verbatim comments:

- *Increasing communication. I would modify by mandating that a cross-jurisdictional committee is developed to discuss common issue and concerns and to exchange information on who is doing what.*
- *I would like to see the political climate change and improve collaboration and coordination.*
- *Both federal and state governments need not be so rigid in their geographical boundaries for funds offered.*
- *In the area of HIV prevention, people tend to take into consideration social and political factors and give them more weight than the scientific studies that demonstrate how to effectively prevent HIV.*
- *Whoever is getting the funding should have to register with local authority (e.g., start with County Judge's Office). #1 Accountability #2 Tap into Networking Groups -- won't find resources on own.*
- *Conflict of interest regarding its dual role, I would suggest along two lines: they should decide to completely contract out for these services and not have their own staff which do away with the conflict or if it is necessary because of location of these clinics and programs, they must have a portion of these funds for their programs, then they should set up administrative mechanisms that put their programs on the same competitive level as the other contractors other CBO's that have to compete against one another for the funding. The City Health Department clinic should also have to compete for with CBO's for funding. The second issue, CDC role, needs to expand its emphasis on*

quality, not quantity, and effectiveness on quality, and it increase its resources that are available to the local governments and CBO's to carry out these programs in an effective way. With regard to the competition with executive branch of the City government and the City Health Department, the City Council is presently being overly sensitive to program services aimed at reducing high-risk sexual and drug use behavior. It is a big detriment to these programs. They need to keep their authority at the level of policy and philosophy and principle, and let the city staff carry out the programs with some degree of autonomy.

- *When you start out with one pot of money and then try to split that pot up into many pots you end up with a lot of money wasted on administration salaries.*

What would you identify as the strengths of the public health system with respect to the delivery of HIV/AIDS care and prevention?

The respondents identified the major strengths of the public health system with respect to the delivery of HIV/AIDS care and prevention as:

1. the overall capabilities of the system, including a valuable database
2. the inherent knowledge available within the system
3. the **ability to track and document issues** involved with the care and prevention of HIV/AIDS system
4. the ability to provide **service to the indigent**
5. the strong track record in the area of **prevention.**

Most of the respondents referred to the public health system (medically indigent patients) in the generic sense, however, there were specific mentions of the Harris County Hospital District, CDC (as the ultimate public health system) and the Thomas Street Clinic.

Verbatim comments:

- *The public health system has good even world-renowned medical Expertise in the community.*
- *The strength I think comes from the coordination of care.*
- *Everybody who wants care can get it. I think that the system works very well. Bringing people into care involves the community and it is great. If can be cumbersome but it is a good model.*
- *The ability of the public health system to look at a situation scientifically with many different ethnicities and races in need and find some solutions that fit the need. Their technical Expertise is another invaluable tool for the public health system.*

What about the weaknesses of the public health system?

Respondents indicated that a major weakness of the public health system was the system was **not user friendly** to clients in terms of ease of access. They mentioned that the public health system is **not proactive** (outreach programs) and that people have to come to them using limited public transportation. Political issues related to funding affect both treatment and prevention, as does year-to-year **uncertainty about funding**. Also identified as a weakness of the public health system was the perceived lack of coordination, standardization and uniform quality control.

Verbatim comments:

- *On the whole, there is a lack of information.*
- *No outreach. People have to come to them.*
- *When funds are localized in the inner city and not spread around because then it might not reach the place where the greatest growth of HIV is occurring. An example of such is the aid not reaching the Hispanic population because they don't have Spanish-speaking counselors.*
- *The weaknesses are the ability to bring new clients into care- some of the paper work (eligibility as well as the new system the county has for co-pay).*
- *The weakness is the politics involved. We have a lot of competent and passionate people in this field, but I feel sometimes that their hands are tied.*
- *Lack of funding is the weakness. Funding is not available to reach the lower income minority population who tend to be more disenfranchised and don't take advantage of our services. Therefore, more resource is given to finding them.*
- *Not enough planning Experts and not enough people trained academically in Public Health.*
- *Weaknesses include the lack coordination even between the City Health Department and County Health Department. They duplicate services in some areas and then drop the ball in others.*
- *It is too big. It gets caught up in itself trying to manage multiple funding streams. He thinks that they commission too much volunteer workers that don't have the proper training to be doing what they are doing. This usually results in special interest needs being addressed and not the main population of those in need. The Texas Dept. of Health has*

trouble making sure that all its needs are met through their councils and consortiums.

- *They don't pay enough attention to the individual needs of people and try to find a one size fits all solution.*
- *Too early to tell. Ratio of HIV/AIDS seems to be rising among minorities. We need to look at that carefully. We need to explain to the public the importance of emphasizing prevention even though this disease is not the leading killer.*
- *Weaknesses include the lack coordination even between the City Health Department and County Health Department. This concerns even the HIV services they provide. The prevention and care services should be a seamless continuum of services that's coordinated. The City Health Department and County Health Department hardly even communicate with one another, let alone coordinated with one another. They duplicate services in some areas and then drop the ball in others.*

What, if anything, do you think needs to be changed to help the public health system better provide HIV/AIDS care and prevention in your area?

Respondents indicated that the public health system should develop **proactive outreach programs** and strengthen prevention through education. Further, respondents suggested that the public health system should **break down the jurisdictional boundaries** and search out and stop overlapping functions to provide better HIV/AIDS care and prevention in their area. The respondents suggested that there be **stronger coordination** and unity among agencies (Texas Department of Health, HRSA and CDC) and that the public health system get away from politics and get to the people they service. Additionally, the respondents' felt that the public health system be **provided more and more consistent funding for care.**

Verbatim comments:

- *Better education to all the people involved in the delivery of services, those who vote on money, etc. We need to address these issues publicly.*
- *Need to do a better job on education, involve the parents more and impress upon kids about prevention. Education is the key.*
- *Increase of funding, more collaboration across jurisdiction communication and more community input.*
- *Outreach! Be proactive and educate. Prevention is always cheaper than damage control. Given dollars to fix; what about dollars to prevent.*
- *We need to remember that HIV is both a communicable and sexually transmitted disease. We should provide service and care to people without regard to their ability to pay.*
- *I think that we need to change the overlapping of functions. There are too many people doing the same things.*
- *Dollars to help people get information they need: 1. To obtain social work, 2. Teach & help people how to deal with their problems and disabilities, 3. Help people plan their future.*
- *Need to have a mandate for patient care, not just for testing. Mission: To fund delivery of care -- Health Department should be involved. Ryan White should get involved in getting patients involved in clinical trials and make this a win/win situation. This is where the major disconnect occurs.*

SUMA Recommendations

- Respondents in the Key Leaders segment specifically mentioned their constituencies as sources of information including needs and successes of specific programs. Key Leaders indicated that they have not received information from their constituencies on HIV/AIDS prevention and treatment. Further, there were a significant number of Key Leaders that deferred (transferring responsibility to staff functions) on questions of funding adequacy. Therefore, SUMA recommends increased the **communication** to the Key Leaders across geo/political boundaries communicating both the successes and any unidentified needs, whether for funding and/or HIV/AIDS care and treatment within their individual jurisdictions.

- Respondents in both the Key Leader and Expert categories either alluded to, or made specific reference to, a lack of **coordination, collaboration and cooperation** among the various service providers. SUMA recommends a concerted effort be made among the various service providers to work together in order to maximize services without redundancies.

- SUMA recommends considering a systematic way to get information including the standardization of forms. Respondents identified general difficulty in getting **information.** Additionally, several respondents (Experts) suggested that **standardization** of forms would aid both administration and clients.

- Develop a system of **accountability** and quantify prevention and care successes and use of Title I and Title II funding. Experts' comments referred specifically to accountability as a method of providing quantitative information for political support and funding.

- **Survey** the HIV/AIDS community to identify unmet needs and barriers within the system. Respondents mentioned issues like the hours and/or days of operation of various services, outreach programs and other proactive programs that could be identified through frequent surveying of the client population. Both Experts and Key Leaders indicated a need for accountability and tailoring of services in both categories (care and prevention) to fit the needs of the community and neither indicated that surveys were a tool currently used to gather information. Frequent surveying will provide a database that will quantify service and prevention knowledge and quality, as well as provide guidelines for future strategy development.

- SUMA recommends, because of the comments of several Experts and Key Leaders, an independent board that can de-politicize the funding and administrative process.

- Experts referred to the time and effort required by staff members in the funding effort. SUMA recommends efforts be directed toward multiple year funding with annual milestones and deliverables, to encourage long-term programs and shift staff resources from developing request for funding to proactive care and prevention activities

- The public health system should proactively position themselves as both the data resource and authority for care and prevention information – both Experts and Key Leaders commented on the various strengths of the public health system and its usefulness as a resource.

- Facilitate educational funding in the form of grants for designated institutions of higher learning to academically train people in public health issues related to HIV/AIDS. Comments by Experts provided the background for this recommendation.

- Aggressively target the lower income and minority population in the services available for care and treatment of HIV/AIDS. Additionally, comments from Experts concluded that a prevention strategy among lower income and minority populations should be pursued.

HOUSTON AREA
EPIDEMIOLOGICAL REPORT

Prepared for

HOUSTON AREA HIV SERVICES RYAN WHITE PLANNING COUNCIL

FINAL COPY
Edited August 03, 1999 - Approved by Council August 12, 1999

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Abbreviations

API	Asian Pacific Islander
CDC	Centers for Disease Control and Prevention
EMA	Eligible Metropolitan Area
HHSD	City of Houston Health and Human Services Department
IDU	Intravenous drug user
MSA	Metropolitan Statistical Area
MSM	Men-who-have-sex-with-men
OI	Opportunistic infection
PCH	Partnership for Community Health
PHR6	Public Health Region Six
PPG	Prevention Planning Group (Public Health Region Six.)
STD	Sexually transmitted diseases
TCADA	Texas Commission on Alcohol and Drug Abuse
TDH	Texas Department of Health
TSDC	Texas State Data Center

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The Council and Consortium have been supportive throughout the process. The Project Advisory Group has provided supervision and comments. Dr. David Whittier and Ms. Jays Janney from the Council Office of Support and Mr. Michael Springer from the Resource Group provided insightful comments on the draft.

HOUSTON AREA EPIDEMIOLOGICAL REPORT

Prepared by the Partnership for Community Health

For Houston Area HIV Services Ryan White Planning Council

February 28, 1999

INTRODUCTION

The epidemiology of AIDS is changing.

The epidemiology of HIV and AIDS in the Houston Eligible Metropolitan Area (EMA), like other EMAs, is changing dramatically due to the success of medical treatment efforts. The basic statistics through 1998 for the six county Houston EMA and larger ten county area covered by the Consortium (Health Service Delivery Area (HSDA)) are shown in Table 1.

Table 5 AIDS Statistics for Houston

Cumulative Houston 10 county Health Services Delivery Area (HSDA) through 1997	16,955[1]
Cumulative Houston 6 county EMA AIDS Cases through 1997	16,855[1]
Living with AIDS in HSDA Area through 1998	7,580[1]
Living with AIDS in the Houston EMA area in 1998	7,538[1]
Projected number living with AIDS in 2003 in Houston area	10,845
Projected number of HIV infected in 1999 in Houston area	12,982 - 20,235[2]
Projected number of HIV infected in 2003 in Houston area	13,811 - 21,584

1. Texas Department of Health
2. See Table 11

People living with AIDS - those in need of services - are the focus of this report.

This document will be used as input into the Comprehensive Plan for AIDS Care. Rather than focus on cumulative AIDS cases, the trends of people diagnosed with AIDS and people living with AIDS (PLWA) – those who are in need of services – are presented below.

In the following section the trends for the yearly AIDS diagnosis and PLWA are reviewed from 1992 to 1997[1]. In the third section additional demographic and risk group information is presented for those living with AIDS in 1998[2].

The next to last section of this report includes a projection of HIV incidence and the last section presents co-morbidities of STD, drug use, and TB with HIV infection.

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[1] Because there is often a year or more lag in reporting all AIDS cases, trends are reported through 1997. Attachment 1 shows cases reported through 1998. Readers should note that 1998 figures will increase as more cases are reported.

[2] The most accurate data to report for PLWA is the latest cumulative figures. Consequently, cumulative PLWA figures through 1998 are used.

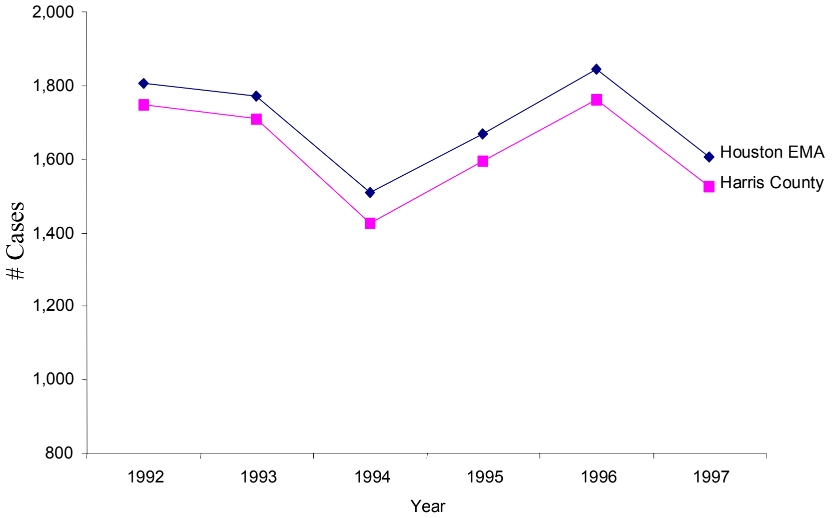
TRENDS[3]

People Diagnosed with AIDS Each Year

From 1992 to 1997, there was an 11% drop in the number of persons diagnosed with AIDS yearly.

As an outcome of successful anti-retroviral and prophylactic treatments, many HIV infected persons are not progressing to AIDS as rapidly as in the past. In 1992, 1,806 persons were diagnosed with AIDS in the Houston EMA, while in 1997, 1,606 persons were diagnosed, indicating a decline of about 11%. Between 1993 and 1994, there was a decline in AIDS cases. However, it should be noted that one reason for the steep decline between 1993 and 1994 was due to the change in the AIDS surveillance case definition in 1993.[4] As a result of these changes, the number of AIDS cases increased significantly as compared to 1994. Notably between 1994 and 1996 there was a reversal in the decline, but between 1996 and 1997 there was about a 13% decline. Harris County accounted for the vast majority of all AIDS cases in the Houston EMA. In Harris County, 1,749 AIDS cases were diagnosed in 1992 and 1,525 in 1997. Figure 7 displays the decline in AIDS cases reported yearly in the six county Houston EMA and Harris County.

Figure 7 AIDS Cases by Year of Diagnosis: Houston EMA



Outlying counties had a slightly smaller level of decline than Harris County.

Harris County's decrease in newly diagnosed AIDS cases is about the same level as the decrease in Fort Bend. There were smaller decreases in yearly-diagnosed AIDS cases in Liberty, Montgomery, and Waller Counties (Figure **8**)[5] while Chambers County had only a few newly diagnosed AIDS cases from 1992 to 1997.

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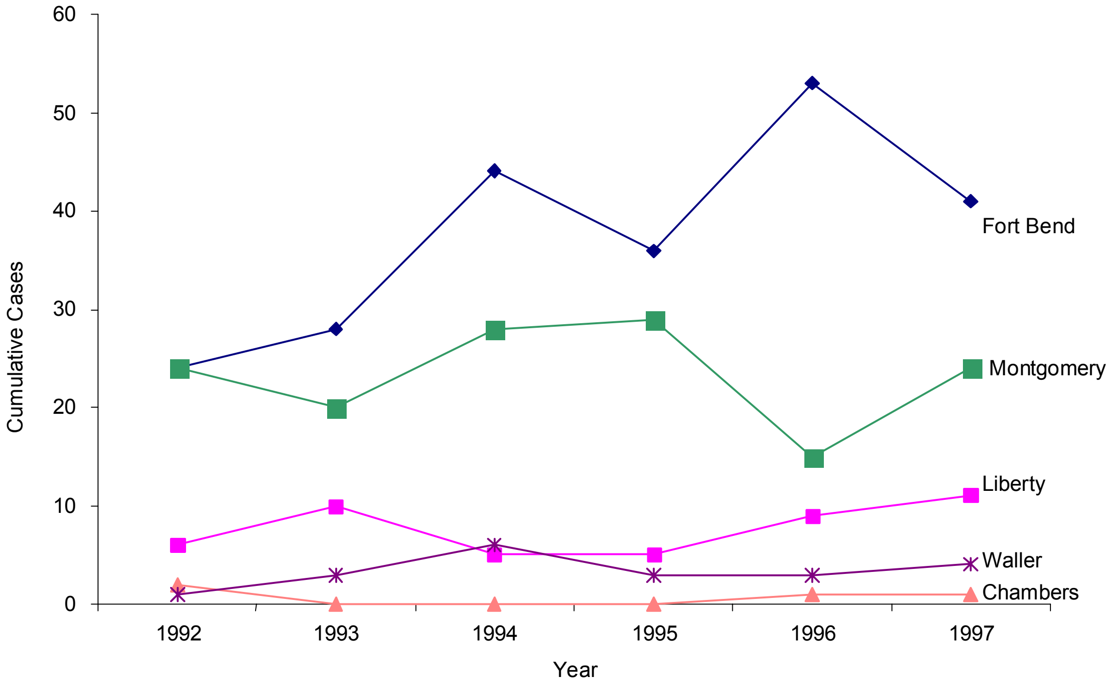
[3] The trend data are presented in graphic form in the text. The source data for the graphs are shown in Attachments 1–3, and they include cumulative AIDS cases.

[4] Effective January 1, 1993, the AIDS case definition expanded and included HIV-infected persons who had severely impaired immune function based on having a CD4+ cell count under 200, pulmonary tuberculosis, recurrent pneumonia, or invasive cervical cancer.

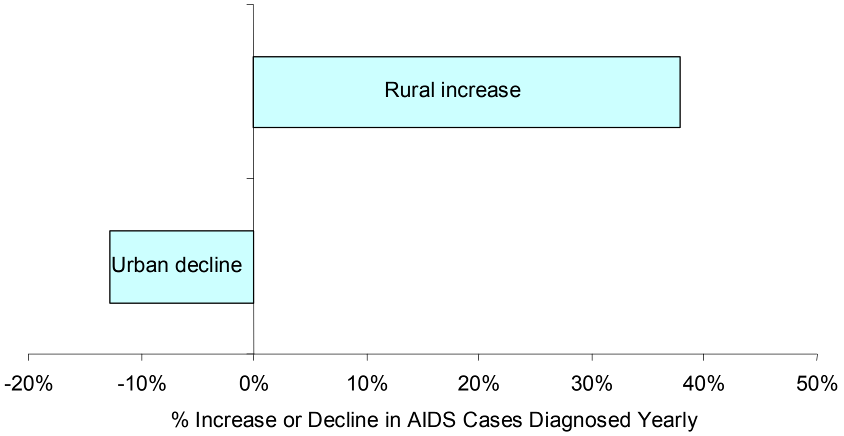
[5] The numbers reported in Figure 2 are very small. In theory the addresses provided are the actual addresses where people live, however some persons may give false addresses in order to qualify for services, and therefore numbers these small may not accurately represent trends.

Figure 8 AIDS Cases by Year of Diagnosis: Rural Counties



As seen in Figure 10, there was a 13% drop in the number of AIDS cases annually diagnosed for Harris County between 1992 and 1997. During this same period, there was a 38% increase in the number of AIDS cases in the rural counties of the Houston EMA, Fort Bend, Liberty, Chambers, Montgomery and Waller. Overall, the number of rural cases remains quite small. Out of 1,606 cases diagnosed with AIDS in 1997, 81(5%) were rural. Of those 81 cases, 76 lived in Fort Bend, Montgomery and Liberty Counties.

Figure 9 Percentage Change in Number of AIDS Cases

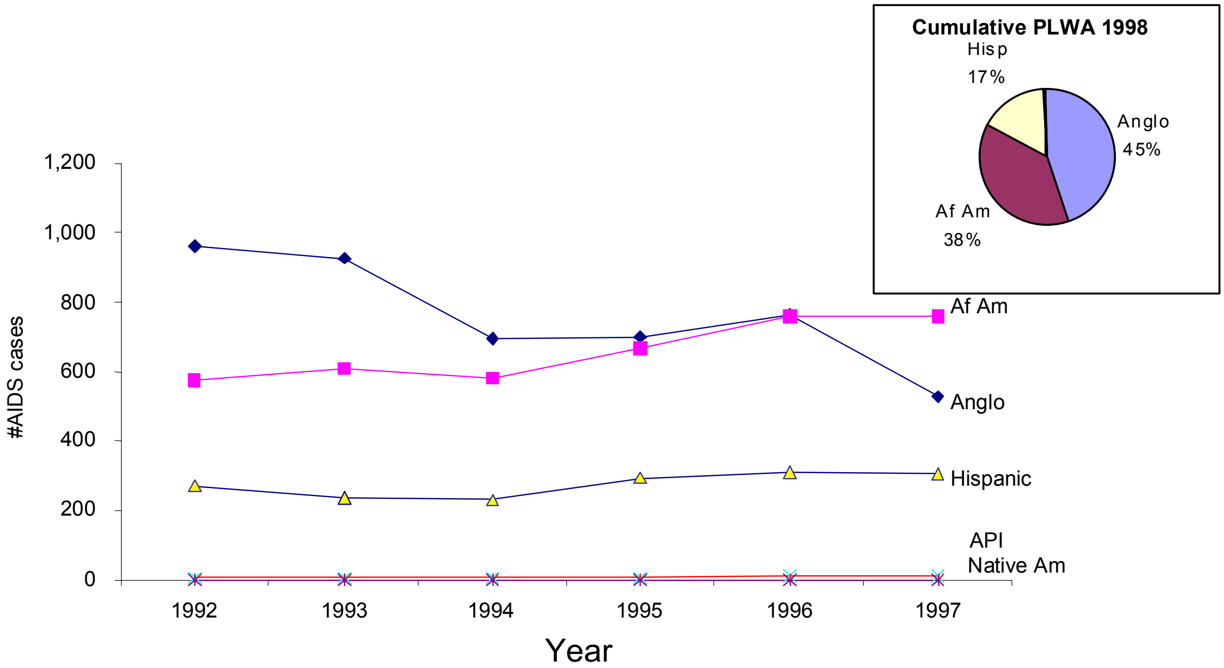


Anglos experienced a decline in newly diagnosed AIDS cases between 1992 and 1997, while African Americans and Hispanics experienced an increase during the same period.

As seen in Figure **12**, an unequal decline was observed in the diagnosed cases by race. From 1992 to 1997, the number of newly diagnosed Anglo cases dropped 45% from 959 per year to 528 per year. This compares to the increase in newly diagnosed African American cases from 574 to 760 per year (32%) and the increase in newly diagnosed Hispanic cases from 268 per year to 307 per year (15%). The 1998 figures reported in Attachment 1 suggest a modest decline in the number of African American and Hispanic cases, but the 1998 trend will not be reliable until the number of newly diagnosed cases is complete. In terms of absolute numbers, African Americans surpassed the number of newly diagnosed Anglos in 1996 and 1997.

Although the number of newly diagnosed AIDS cases is higher among African Americans as shown in the framed pie chart in Figure **12**, continuing into 1998 the highest percentage of people living with AIDS were Anglo (45% or 3,350 cases) followed by African Americans (38% or 2,883 cases), and Hispanics (17% or 1,267 cases). There were also 33 Asian Pacific Islanders.

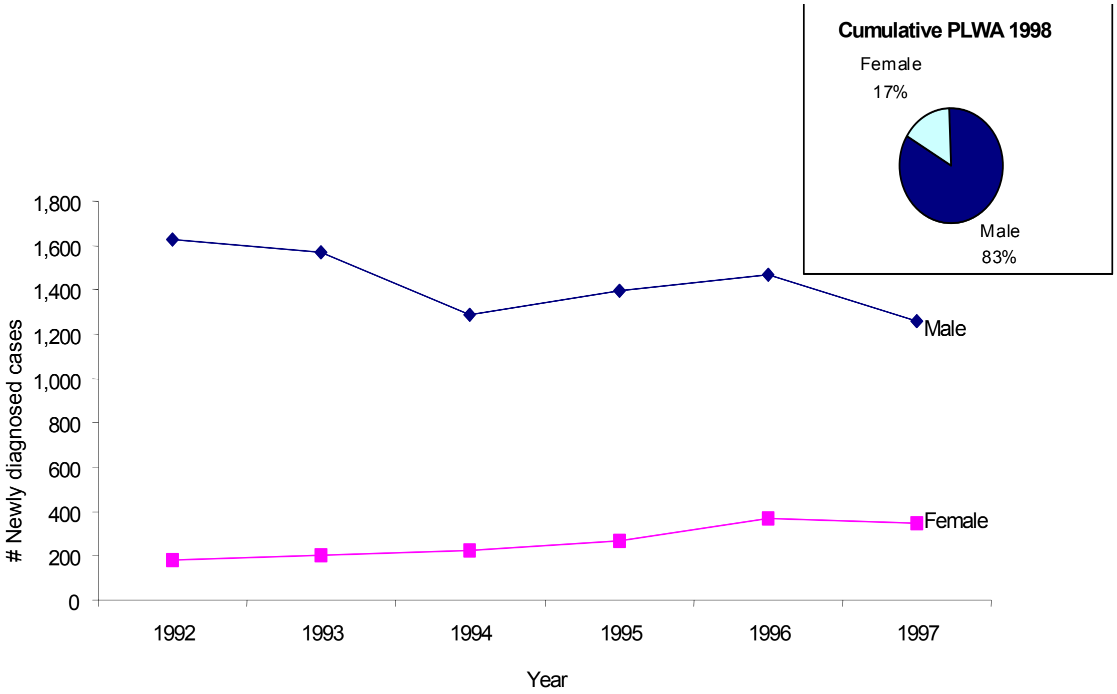
Figure 10 AIDS Cases by Year of Diagnosis by Race



Newly diagnosed AIDS cases are decreasing among males and increasing among females. Still in 1998 there are 5 times the number of males living with AIDS.

Figure 14 further indicates that while the number of newly diagnosed AIDS cases among males is declining, the number of newly diagnosed AIDS cases among females is increasing. From 1992 to 1997, the number of newly diagnosed male cases declined by 23%. However, from 1992 to 1997, the number of newly diagnosed female cases increased by 94%. Still, as shown in the framed pie chart in Figure 5, even with the increased number of females, in 1998 there were five times as many males newly diagnosed with AIDS as females.

Figure 11 AIDS Cases by Year of Diagnosis by Gender



MSM show the greatest decline in number of new AIDS cases reported.

Figure 16 shows an unequal decline in diagnosed AIDS cases for exposure groups. Men-who-have-sex-with-men (MSM) show a significant decline in number of AIDS cases diagnosed yearly, while IDUs, MSM/IDU, and heterosexuals show an inconsistent pattern.

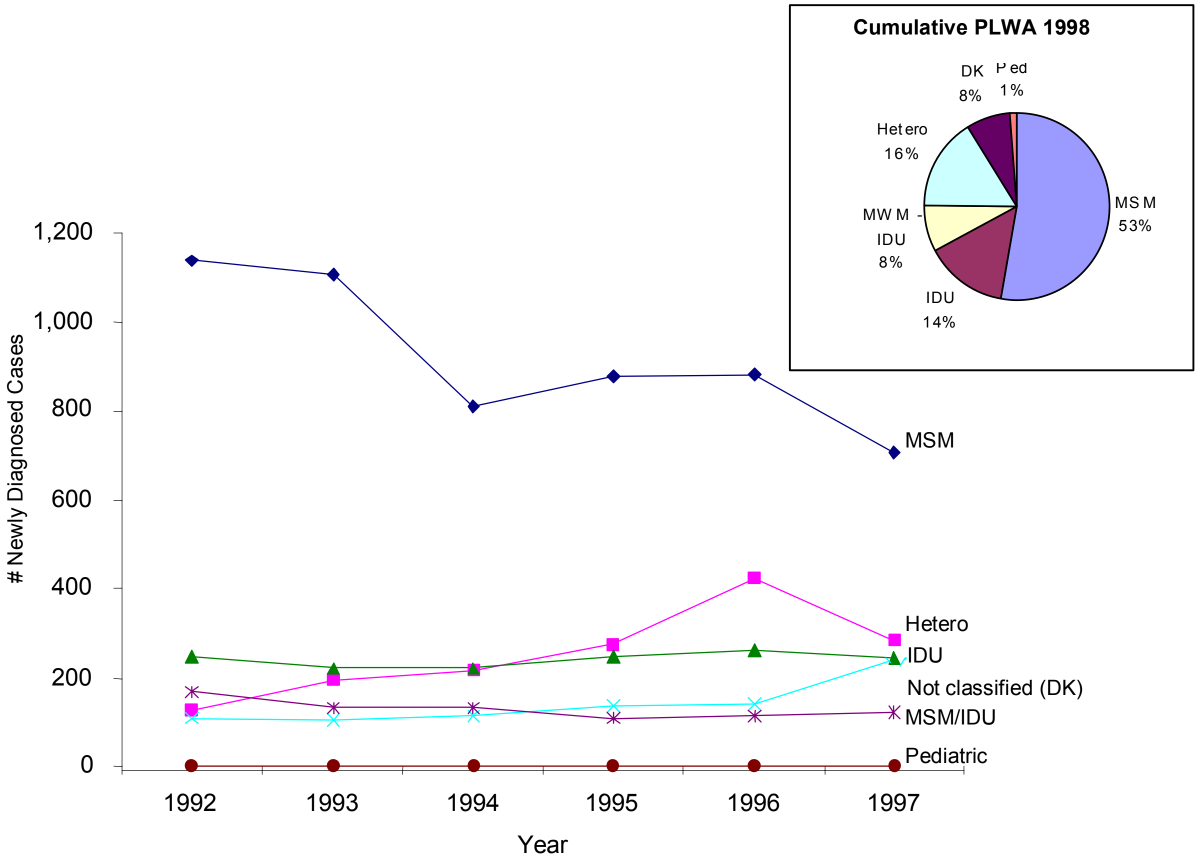
MSM has shown a significant drop in the number of AIDS cases diagnosed, while heterosexual cases have increased.

In 1992, MSM/IDU had a larger number of cases diagnosed yearly than heterosexuals. However in 1994, heterosexuals had more cases diagnosed yearly than MSM/IDU. Notably, there was a significant change in the profile of AIDS cases being diagnosed. In 1992, MSM constituted over 63% of known cases diagnosed yearly. By 1997, MSM decreased to 44%, while heterosexuals increased from 7% to over 17%.

In 1998, MSM constitute the majority of all PLWA.

Despite the large drop of newly diagnosed MSM AIDS cases, as shown in the framed pie chart in Figure 16, even in 1998 MSM continue to be the majority (53%) of all PLWA. This is consistent with the national data reported by CDC that MSM had the majority (45%) of all PLWA. Preliminary results from 1998, as shown in Attachment 1, indicate that the number of newly diagnosed cases will continue to drop among MSM and remain relatively constant among other risk groups.

Figure 12 AIDS Cases by Year of Diagnosis by Risk Group

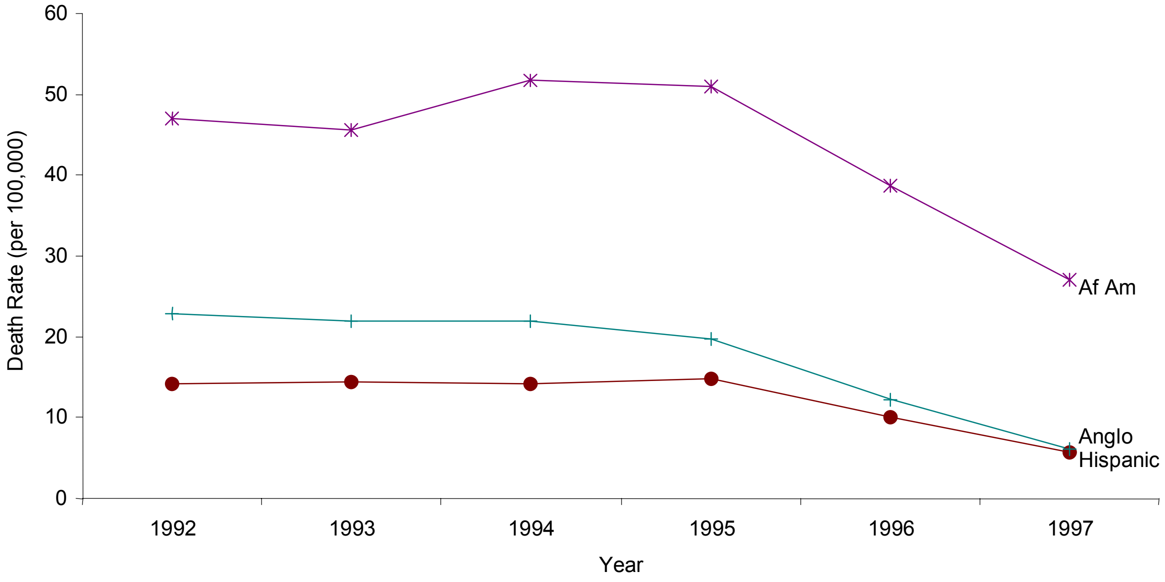


Fatality and Death Rates

Death rates are substantially higher among African Americans than Anglos or Hispanics.

As a decline in diagnosed AIDS cases and increase in those living with AIDS is observed, it is not surprising to see that the overall death rate (defined as rate per 100,000) has declined as measured by the crude death rate per 100,000[6]. As shown in Figure 18, the death rate is substantially higher among the African American population, and while it has declined faster than that of the Anglo and Hispanic populations, it continues to be between three or four times the rate of the Anglo and Hispanic death rate.

Figure 13 HIV/AIDS Deaths by Ethnicity per 100,000 of Houston Area Population



Those African Americans who have entered the system of care appear to have about the same fatality rate as Anglos or Hispanics.

This large discrepancy between African Americans and other ethnic populations is somewhat moderated by the fatality rates shown in

Figure 20. This "fatality rate" measures the death rate among a cohort diagnosed with AIDS during a certain calendar year and tracked by TDH.[7] Unlike the rate per 100,000, these PLWA have entered the care system and are tracked by TDH. Case fatality rates are expected to decline for more recently diagnosed cases because of improved care and shorter periods of time with

---

[6] The mortality rate, or rate of death per 100,000 reflects everyone who was recorded by a doctor on the death certificate as dying of AIDS-related disease for a specific year. The mortality rate captures trends in current deaths due to AIDS whether or not they were ever reported to TDH as a person with AIDS and regardless of when they were diagnosed.

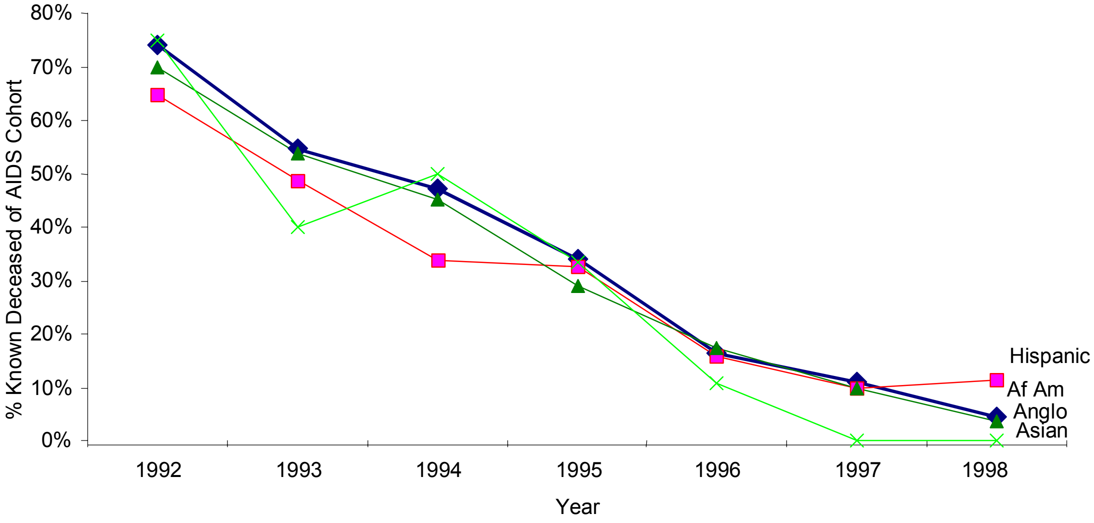
[7] TDH notes that the PLWA tracked is a cohort in the sense that it applies to people diagnosed with AIDS during a certain calendar year. They actively pursue death reports on reported AIDS cases, doing matching with Bureau of Vital Statistics death certificates and receiving reports of deaths from our local sites. Each AIDS case is not actively followed.

AIDS, but they are useful for comparing between groups how lethal it was over time to be diagnosed with AIDS.

Figure **20** indicates that fatality rates have declined among all ethnic groups at about the same pace. In 1998, Asians have the lowest fatality rates, followed by Anglos and African Americans. Hispanics, taking an upward turn, increased from 10% to 11%.

One likely explanation for the difference in the death rates among the cohort and all those 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 14 % Deceased by Year of People with AIDS in a Cohort Tracked by TDH



There is a dramatic increase of PLWA.

People Living with AIDS

With the decreased mortality rates, there is an increase in the number of people living with AIDS. As shown in

Figure **22**, the number of PLWA increased from 1,731 in 1992 to 7,538 in 1998. The increase in PLWA is consistent across all ethnic populations (
Figure **24**) and risk groups (

Figure 26). The counties outside of Harris generally show an increase in PLWA (Chambers County only had a few AIDS cases and therefore, they cannot be reflected on the graph)
Figure **28**).

Figure 15 Living with AIDS: Houston EMA and Harris County

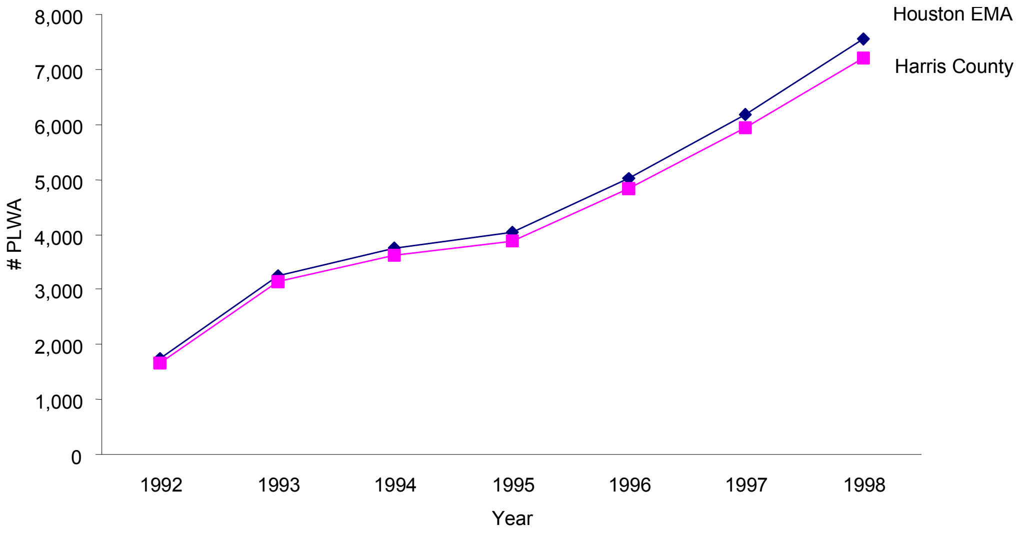


Figure 16 Living with AIDS by Ethnicity

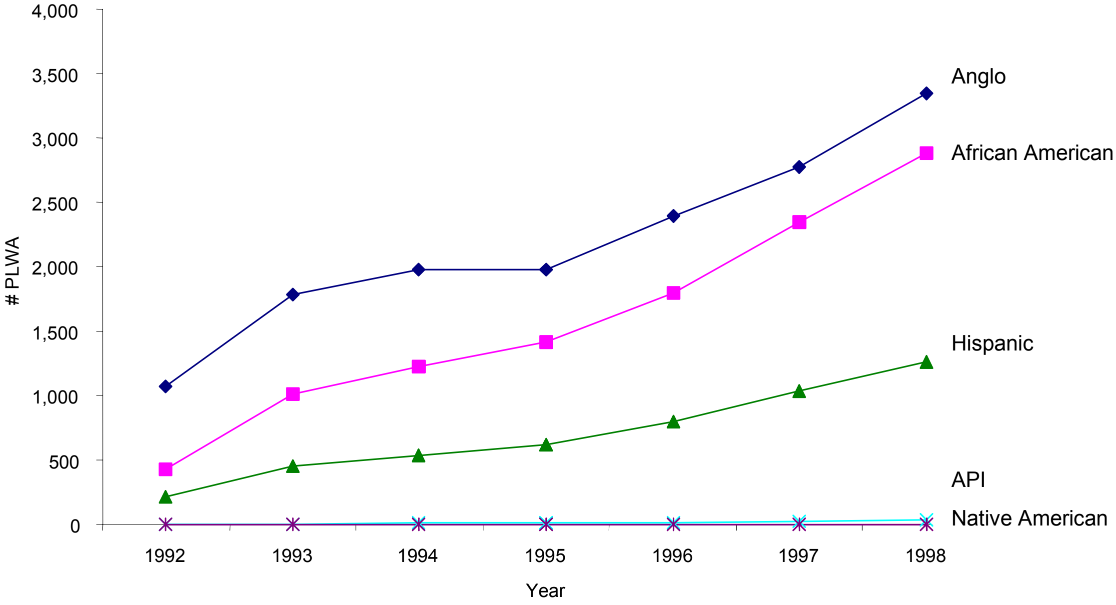


Figure 17 Living with AIDS by Risk Group

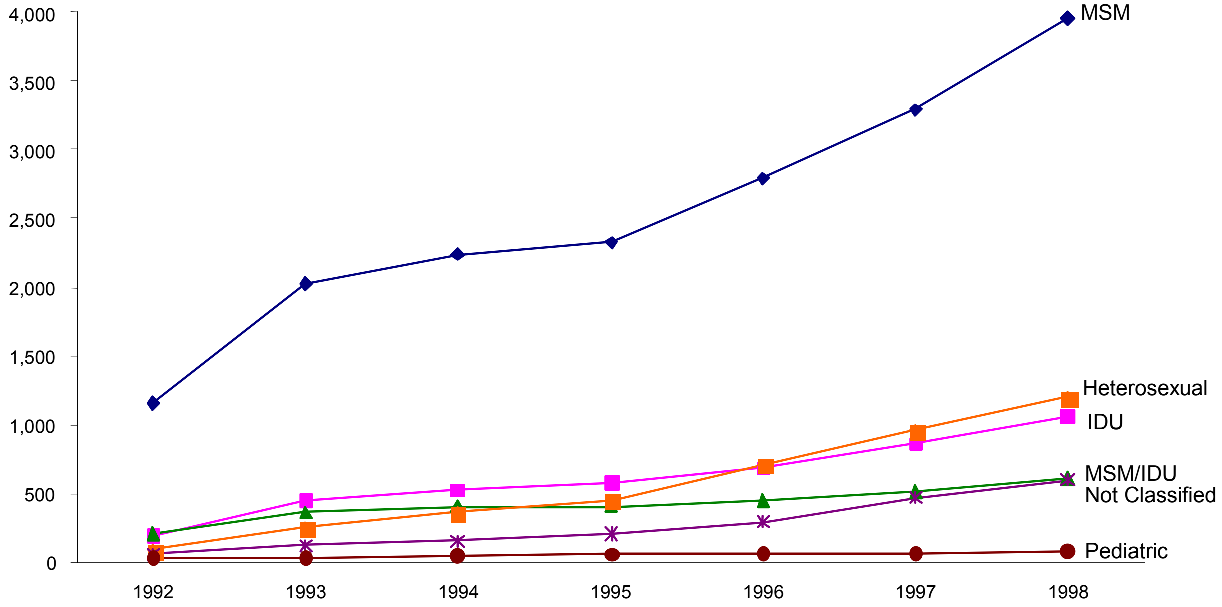
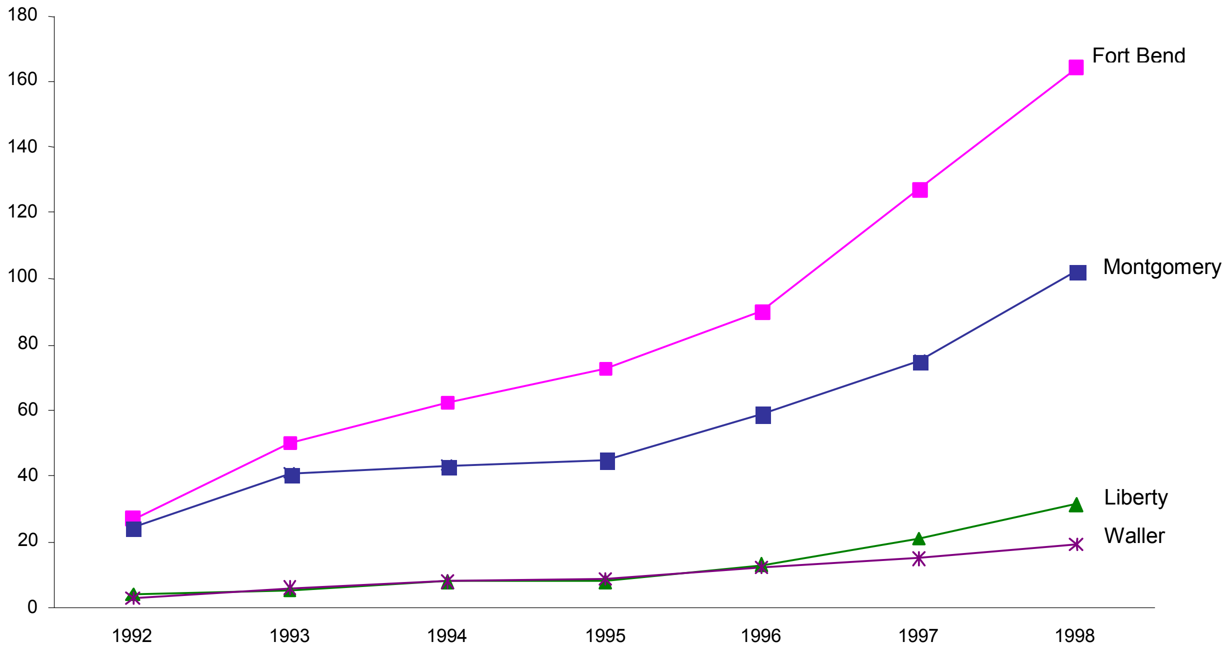


Figure 18 Living with AIDS by Counties

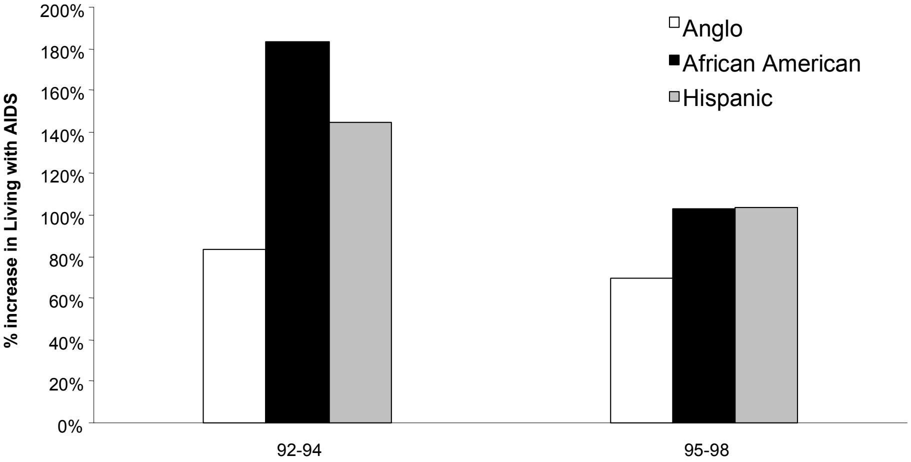
(Note: Chambers had 1 case each year from 1992 – 1997 and 3 cases reported in 1998.)



The rate of change in increase of PLWA is highest among the African Americans.

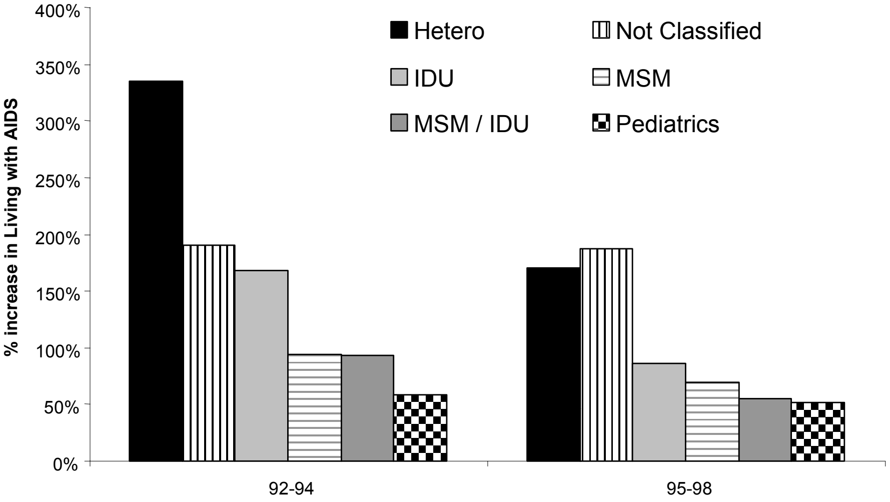
The rate of change in the increase of those living with AIDS is lowest among Anglos when compared to African Americans and Hispanics. Between 1995 and 1998, the rate of change substantially decreased for African Americans and Hispanics (
Figure 30).

Figure 19 % Increase in Living with AIDS from 1992-1998 by Race



As seen in Figure 32, of all the risk groups, heterosexuals show the greatest percentage increase of those living with AIDS from 1992 to 1994, but it was consistent with other groups from 1995-1998. In terms of actual numbers, 97 heterosexuals living with AIDS in 1998 remain relatively low.

Figure 20 % Increase in Living with AIDS from 1992 - 1998 Risk Group



MSM will continue to be the majority of PLWA for several years. African Americans and Anglos will be the two largest ethnic groups with AIDS.

The profile of persons living with AIDS will change slowly because of the decreasing number of persons diagnosed with AIDS and the low mortality. The percentage of Anglos (44%) who are living with AIDS in 1998 indicates that they will continue to be the largest number of those living with AIDS at least until 2003. However, the profile of those living with AIDS will begin to shift slowly toward African Americans. The majority of MSM (53%) in 1998, suggest they will be the dominant risk group for the foreseeable future. Overall, the trend toward increased numbers of PLWA should be sustained provided the efficacy of triple therapy continues.

Projecting the Number of AIDS Cases Diagnosed Each Year

There is no agreed upon formula for estimating future AIDS cases.

There is no agreed upon formula for estimating future AIDS cases. Provided the efficacy of treatment continues, fewer persons will die due to AIDS and fewer people will progress from HIV infection to AIDS as currently defined. In addition, there are different patterns of progression among different ethnic populations and risk groups. More widespread and earlier use of prophylactic treatments has delayed the onset of opportunistic infections (OI's) and the decline in T-cell counts. With the continued use of combination therapies people living with HIV are likely to maintain a higher T-cell count and low viral loads, and avoid the progression to AIDS.

There is some evidence of increased failure rates of medication.

There is growing evidence of increased failure rates in some medication and the potential for adverse side effects of medication for long-term survivors. Still, with new medications in the pipeline and the increased likelihood of early detection, the current trend in delay to AIDS will probably continue for the next several years.

There are many unknown elements in estimating AIDS cases.

While new treatments provide a more optimistic outlook for those infected, the impact of these new treatments on the number of AIDS cases is uncertain. As shown above there is already a trend toward fewer diagnosed cases each year. Yet, there are many unknown factors that make valid projections of AIDS cases unreliable, including:

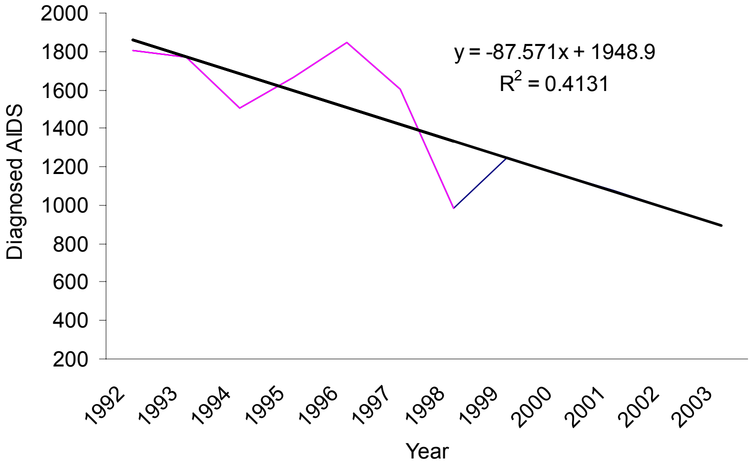
- the percentage of people living with HIV that will not be able to tolerate anti-retroviral treatments,
- the continued efficacy of treatments, and
- the access and availability of the treatments among the different communities most affected by HIV.

Given the great uncertainty, simple projections based on past history, plus some educated guesses about the progression of the disease is likely to be as accurate as more complex models based on equally uncertain assumptions. For the projected number of PLWA, three models are proposed.

Cases diagnosed each year will continue to decline.

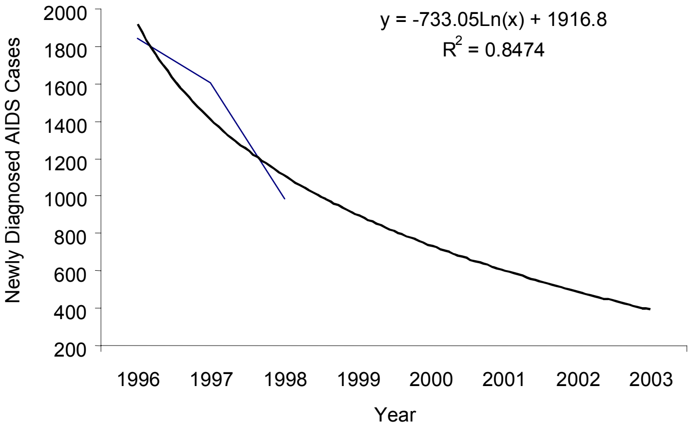
In the first model (Figure 34), a linear trend line is projected based on the decline from 1992-1998. The number of AIDS cases diagnosed each year in the Houston EMA is projected to decline from 1,806 cases in 1992 to about 900 in 2003. This is an unlikely scenario, however, because the current level is presently 930 new cases a year. Empirically, the correlation (R^2) is relatively low showing that the linear relationship is not strong. Still, as seen in Figure 34, the epidemic in Houston has not shown a straight downward trend in the past. The recent evidence of an increase in infection rates among young MSM nationally could be reflected in an increase in the number of AIDS cases if there is a high failure rate in medication or poor adherence to medical regimens.

Figure 21 Linear Trend for New AIDS Cases by Year of Diagnosis for Houston EMA



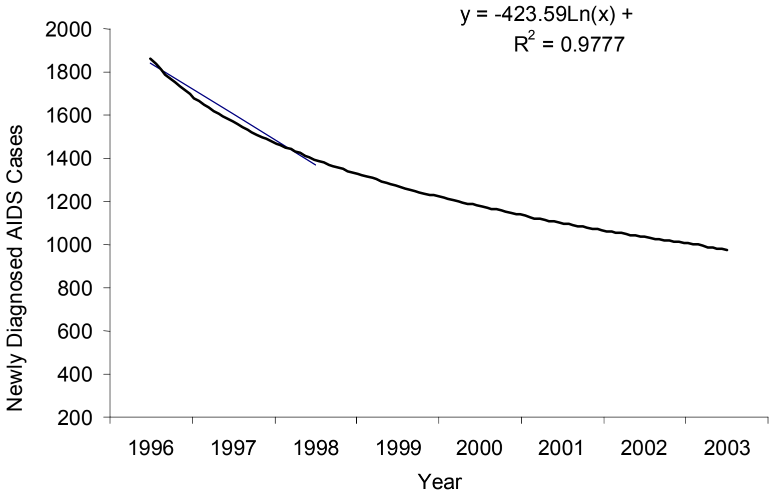
A second model, shown in Figure 35, shows a loglinear projection based on the years from 1996 to 1998. A loglinear projection is used because of the leveling off of newly diagnosed cases. Only the last three years are used because since 1996 there has been a consistent decline in the number of newly diagnosed cases that is likely to be the pattern given the efficacy of the medications. The “fit” is much improved as indicated by the high R^2 of .84 shown in Figure 35.

Figure 22 Loglinear Projection of Newly Diagnosed AIDS Cases (Reported 1998 data)



Because 1998 newly diagnosed cases have not been fully reported, the decline may be less steep than suggested in Figure 35. The same loglinear projection is made in Figure 36 assuming that the rate of decline in 1998 will be the same as it was in 1997. Since the decline would not be as steep, there would be just under 1,000 newly diagnosed cases projected for the year 2003.

Figure 23 Loglinear Projection of Newly Diagnosed AIDS Cases (Trend of 1998 cases based on 1996-1997 data)



Models show the decline in yearly-diagnosed cases from 1996 to 2003.

A fourth model, provided in Figure 37, projects the trend of declining AIDS cases diagnosed. The decrease in newly diagnosed AIDS cases is assumed to accelerate slightly, but not linearly. This is based on the assumption that new medications will prove more effective thus slowing the trend of progression from HIV to AIDS, but that for some persons the medications will be ineffective. The explicit assumptions are that in 1999 new cases will decline by 13%[8]. In this scenario, the cases diagnosed from 1992 to 2003 will decline from 1,628 to between 700 and 500 newly diagnosed cases each year for the Houston EMA.

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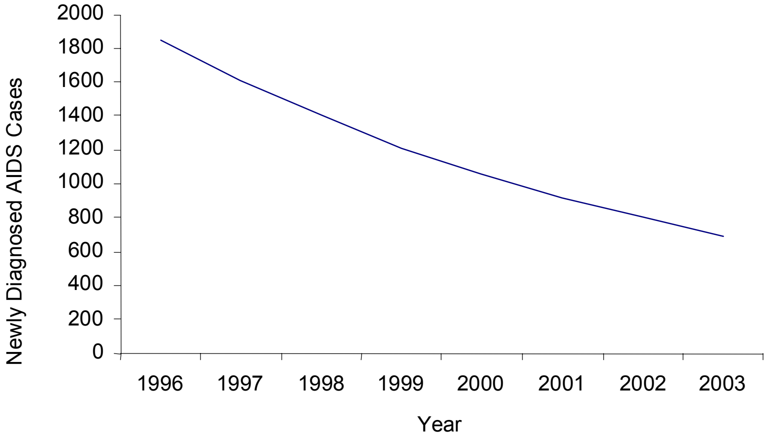
[8] The rate is based on the difference between the number of newly diagnosed AIDS cases in 1996 and 1997.

Figure 24 “Best Guess” Trend of Cases by Year of Diagnosis for Houston EMA



Projecting the Number of People Living with AIDS

Yearly cases decline while the number living with AIDS increases.

At the same time, the number of people living with AIDS will continue to increase, as mortality rates continue to decline. Two models are presented. The first is a logarithmic projection until 2002 based on the 1992-1998 data (Figure 38). It assumes that PLWA will continue to grow, but at a slowed rate because while fewer people die, fewer persons are also being diagnosed with AIDS. The estimates are that the cumulative number of PLWA will increase from 1,731 PLWA in 1992 to about 14,344 PLWA in 2003.

The projections assume continued effective treatment.

The second model (
Figure 39) assumes that 90% of those living with AIDS will continue to live in 1998. This will increase to 95% in 1999 and 2000 and further increase to 98% in 2001-2003. Given the fewer number of persons projected to progress to AIDS, this model projects that cumulative PLWA will increase from 1,731 persons in 1992 to about 10,845 in 2003.

The projected model assumes a greater efficacy of treatment and both models assume a relatively low mortality rate.

Figure 25 Trend for PLWA in Houston EMA: Loglinear Model[9]

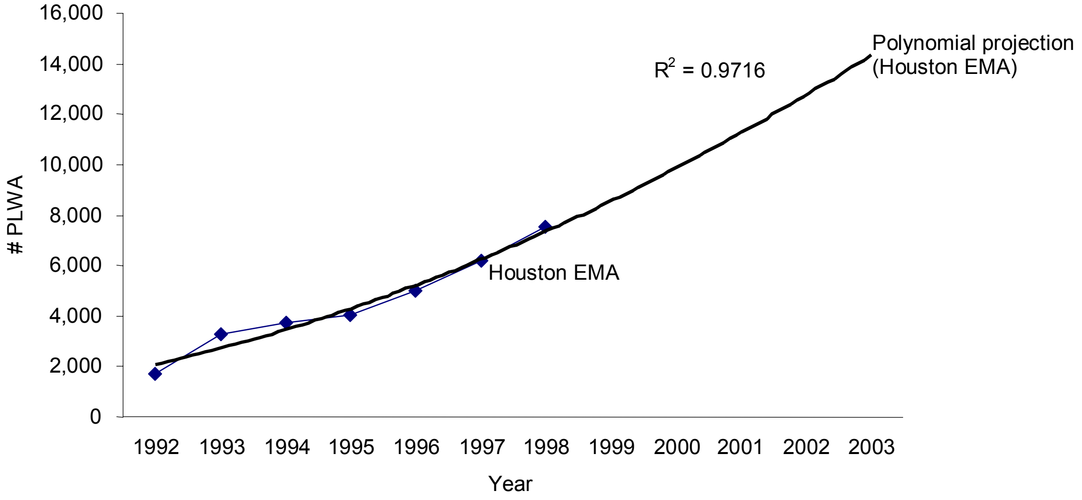
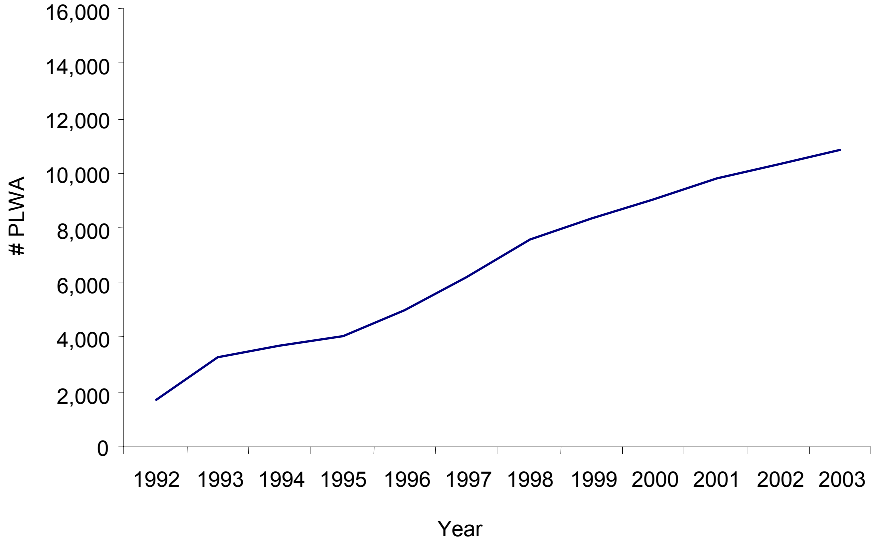


Figure 26 Trend for PLWA in Houston EMA: Revised Model



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[9] Calculates the least squares fit through points by using the following equation: $y = 47.19x^2 + 499.05x + 1559.6$ and represents the natural logarithm function.

PEOPLE LIVING WITH AIDS IN 1998

Ethnicity, Sex, and Risk Group

7,538 people were living with AIDS at the end of 1998.

The profile of PLWA is detailed below for 1998. The total number of living AIDS cases at the end of the 1998 was 7,538. Mode of exposure, race, and age, divided by sex, are shown in

Figure 41 – Figure 44.

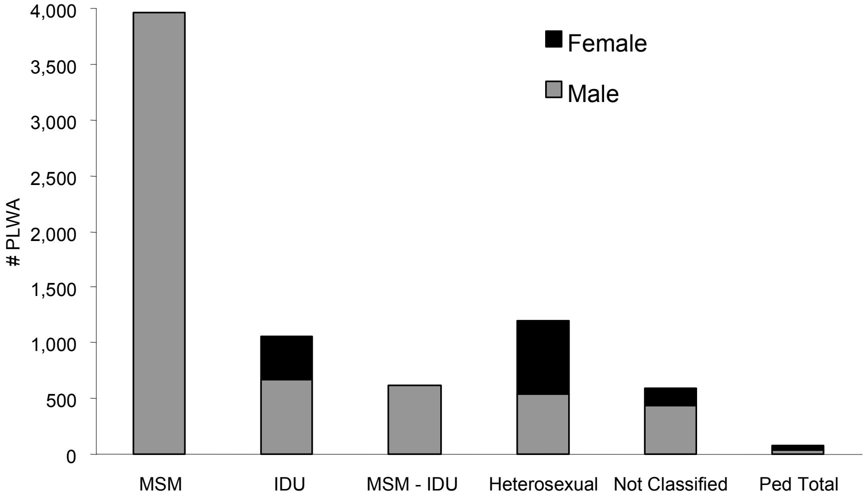
83% PLWA were male.

Heterosexuals are 55% female. IDUs are 36% female.

About 83% of the cases are male, representing 6,285 cases, and 17% are female, representing 1,243 cases. As shown in

Figure 41, more than half the PLWA are MSM. There are slightly more heterosexuals than IDUs. There are 651 females and they are the majority of the heterosexuals (55%). Females are a minority of the IDUs (36%), with 388 cases. The majority of females living with AIDS (68%) are African American.

Figure 27 PLWA through 1998 by Risk Group and Sex



Compared to the general population, PLWA are disproportionately African American.

Figure 28 indicates that the 3,350 Anglos living with AIDS constitute about 44% of all those living with AIDS, followed by 2,883 African Americans (38%). The proportion of Anglos in the epidemic are less than the proportion of Anglos in the general population (44% Anglos living with AIDS versus 60% in the general population). In contrast, the 44% representation of African Americans among PLWA is significantly greater than their 15% representation in the general population. There are 1,267 Hispanics living with

AIDS. There are proportionately fewer Hispanics living with AIDS (17%) than Hispanics in the general population (20%).[10]

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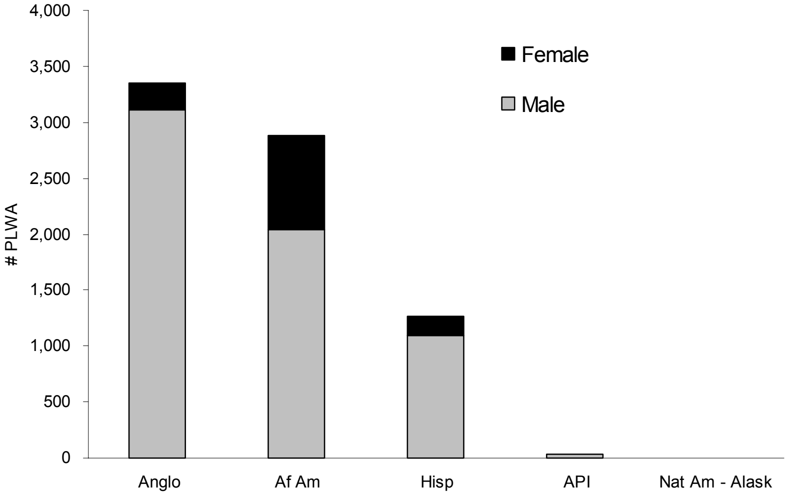
[10] General population figures are for 1997 in the Six County EMA as estimated by the Population Division of the U.S. Bureau of the Census, Washington, D.C.

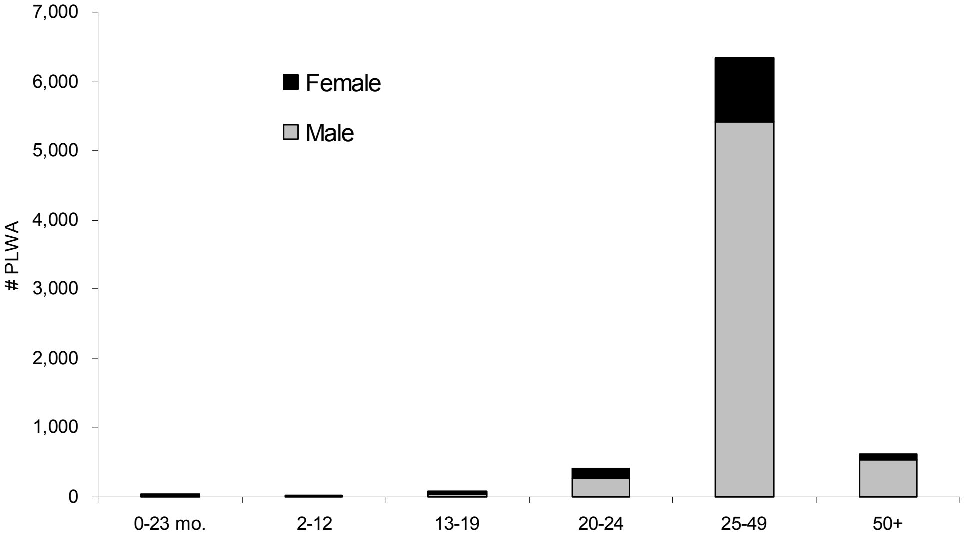
Figure 28 PLWA through 1998 by Ethnicity and Sex



84% of those living with AIDS are over 25. 8% are over 50 and 8% are under 25.

Figure **44** shows that the vast majority (84%) of those living with AIDS is between 25 and 49 years of age. About 8% of the PLWA are over 50 and 8% are under 25. There are 37 infants living with AIDS, 28 between the ages of 2 and 12, and 88 adolescents (13-19).

Figure 29 PLWA through 1998 by Age Group and Sex



In 1998, more adolescent. PLWA are African American (59 out of 88 cases) than other ethnic groups. Fifteen (15) adolescents living with AIDS are Hispanic and 13 are Anglo.

The profiles of the risk groups are different.   Figure 31 indicates that:

MSM are more likely to be Anglo.

- MSM living with AIDS are more likely to be Anglo (2,333) than non-Anglo (African American (928), Hispanic (681) and Native American (3)).

IDUs are more likely to be African American.

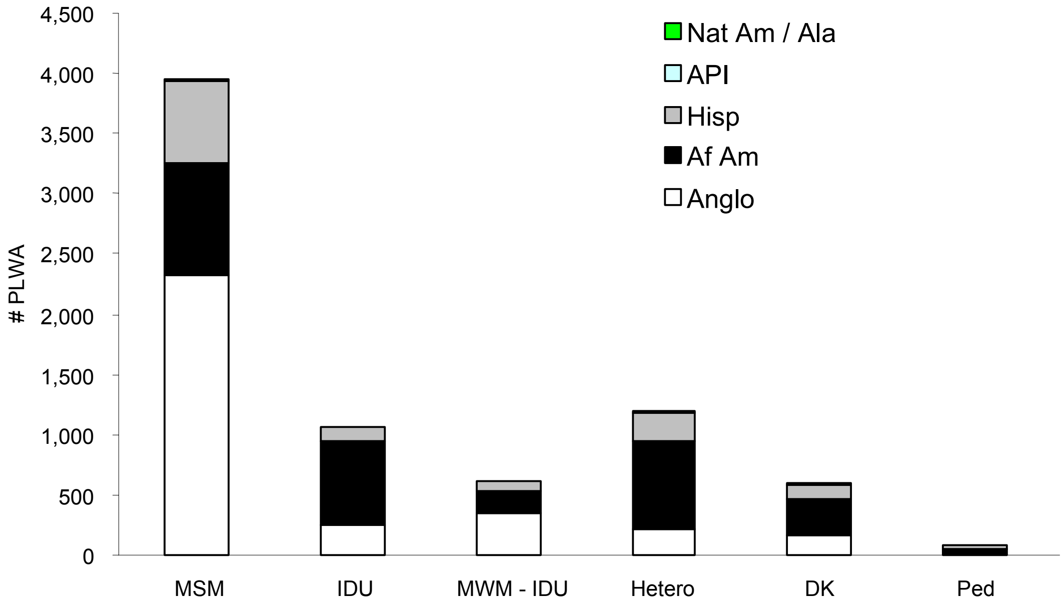
- IDUs are more likely to be African American (703) than Anglo (251) or Hispanic (113).

Heterosexuals are more likely to be African American.

- Over 60% of heterosexual cases are African American (721) followed by Hispanics (244) and Anglos (222).

As shown in Figure 31, about 53% of those living with AIDS are MSM. Heterosexuals represent about 15% and IDUs represent about 14%. MSM/IDUs comprise 8% of those living with AIDS. There are 79 PLWA who had perinatal exposure to HIV and 29 PLWA who have contracted AIDS through blood or blood products.

Figure 30 PLWA in 1998 by Risk Group and Race



Harris County accounts for 96% of PLWA in the EMA.

As shown in Figure 33, over 96% of the PLWA in 1998 come from Harris County. Fort. Bend has about 2% and Montgomery has about 1.5%. The remaining counties in the EMA have less than 1% of the PLWH/A.   Figure 35 indicates that 96% of the cases are urban.

Figure 31 PLWA by County in 1998

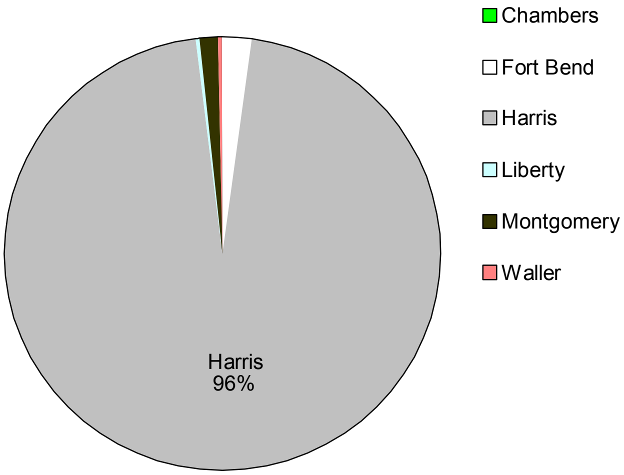
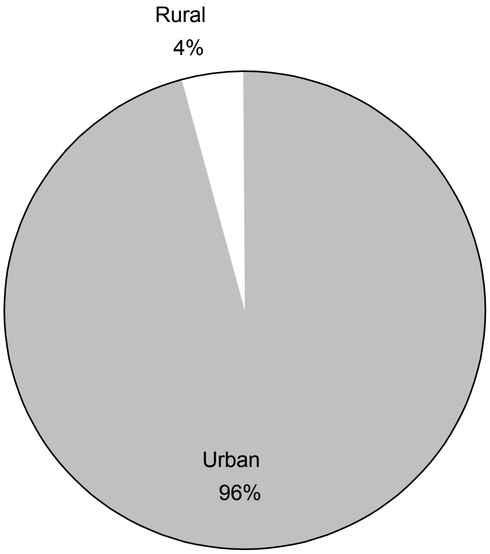
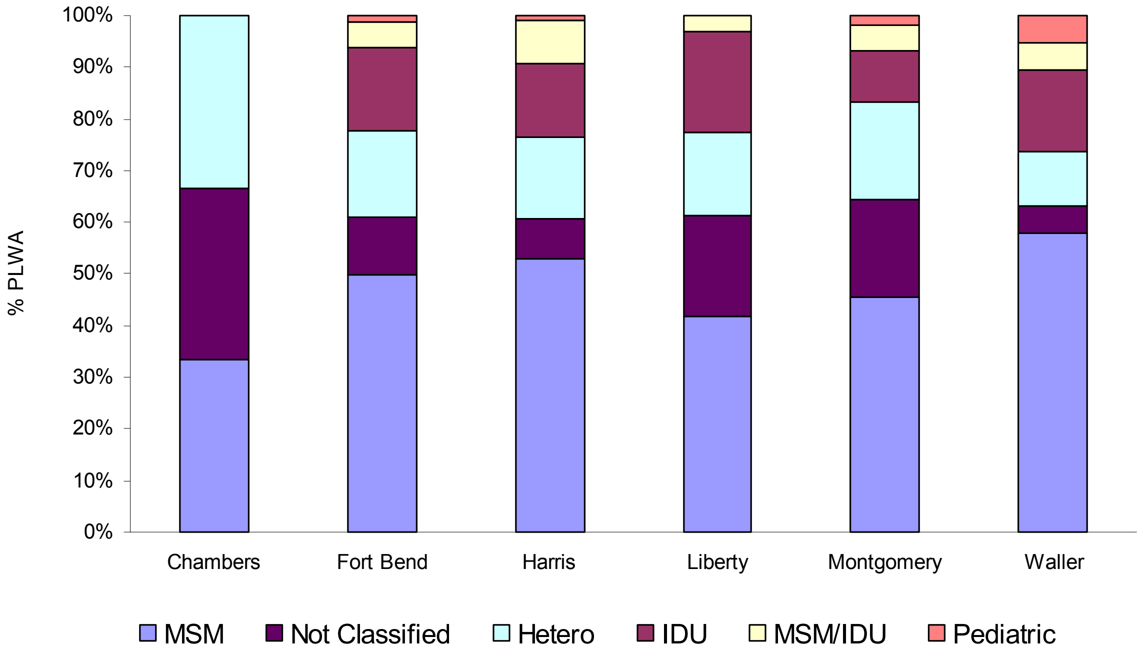


Figure 32 PLWA by Urban Rural in 1998



While the number of cases in the rural counties is small, as shown in Figure 37, the four counties with more than 30 cases, Harris, Fort. Bend, Montgomery, and Liberty have similar profiles. Waller County reports only 19 cases and Chambers County reports only three cases.

Figure 33 PLWA in 1998 by County and Risk Group

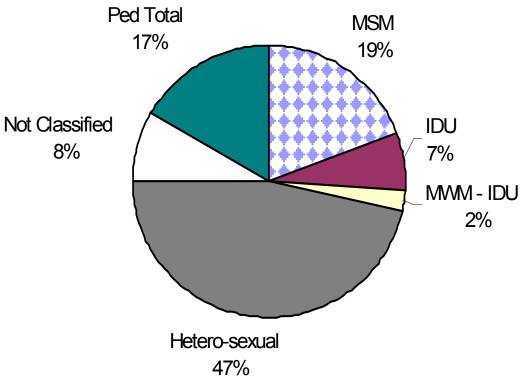


In 1998, there were 88 persons between the ages of 13 and 19 living with AIDS. They had a wide range of risk factors.

Subpopulations with Small Numbers of People Living with AIDS

Adolescent and pediatric PLWA have special needs. There are 88 adolescents with AIDS between 13 and 19 years old. These adolescents have a wide range of risk factors. As shown in Figure 39, 57% report heterosexual transmission, while about 19% report MSM, and 7% report IDU transmission. Indicating a growing survival rate for infants living with HIV, 17% of the adolescents indicated becoming infected as an infant (Pediatric).

Figure 34 Young Adults and Adolescents (Between 13 and 19 Years Old) Living with AIDS in 1998: Risk Factors

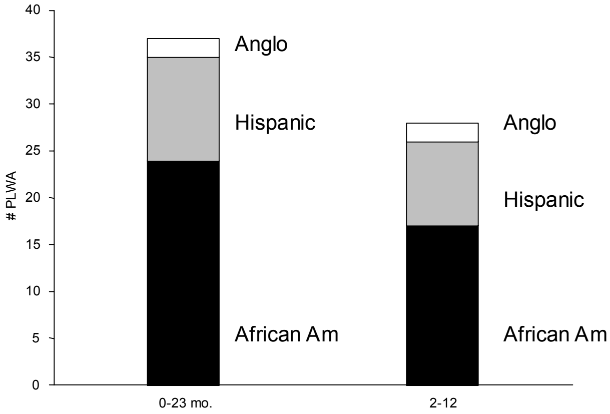


There were 37 infants with AIDS in 1998 and 28 two to twelve year olds living with AIDS.

In 1998, 37 infants age 0 to 23 months were reported living with AIDS, and there were 28 two to twelve year olds diagnosed with AIDS.

Figure 41 indicates that the majority of the 28 young persons living with AIDS are African American, followed by Hispanics. About half the young persons living with AIDS are male and half are female.

Figure 35 People less than 13 Years Old Living With AIDS by Race



Other PLWA Subpopulations

In 1998 there were 33 PLWA who were API and 5 Native Am.

Other small groups of PLWA included Asian-Pacific Islanders (API) with 33 cases and 5 Native Americans living with AIDS. Of the 33 APIs, 15 are MSM and 12 are not classified.

HIV ESTIMATES

Estimates of HIV infection are important in planning HIV services and AIDS care because they are an indicator of the magnitude of cases that will need to be treated in the future, and early treatment intervention is recommended to stop the progression to AIDS.

The challenges of estimating HIV were well put in a recent correspondence with Sharon King, head of the HIV/STD Epidemiology Monitoring Branch of the Texas Department of Health. She writes:

Valid estimates of HIV infection are impossible to estimate due to many unknown factors.

> The prevalence [of HIV] depends on two factors: new HIV infections and deaths, the recent advances in triple combo therapy have thrown everything into disarray. It will affect the number of AIDS cases reported. [This] will affect the number of deaths. As you [Dr. Cohen] mentioned, if more people are living with HIV, there are that many more chances for the virus to be transmitted unless the situation is ameliorated by prevention and clear evidence that lowered viral load is a big factor. Also we cannot predict what will happen with regimen compliance and with mutation of the virus to be resistant to the new drugs. We cannot predict if drug research will keep ahead of the virus. So almost any figure you [PCH] come up with is a really wild guess divined from sheep entrails. I always feel like putting on my “Merlin” outfit when I do these estimates.

It is clear that persons continue to be at risk. About 28.5% of the PLWA interviewed for the 1997 Greater Houston EMA/HSDA HIV Community Needs Assessment indicated that they had not used condoms during the last time they had either vaginal or anal intercourse. While over 60% reported that their partner was HIV positive, about 15% stated that their partner was HIV negative and 23% reported that they did not know the HIV serostatus of their partner. Although transmission rates cannot be estimated, this data indicate the continued risk of seroconverstion.

PPG and CDC HIV estimates, and HHSC population estimates are .used together to estimate HIV.

This report presents several alternative models for estimating the number of HIV infected individuals in the Houston EMA. In the text below, the HIV seroprevalence estimates made by the Prevention Planning Group (PPG) from Public Health Region 6 (PHR6), from various counseling and testing studies, and by CDC statisticians have been applied to population estimates of the Houston EMA. In addition, a new estimate is given based on applying the rates from the cohort studies at clinics in Houston and applying logistic regression and odds ratios, a statistical technique that provides the likelihood that HIV will infect different populations. They should be viewed as rough estimates that suggest trends in infection. Given the many unknown factors above, the infection rates could change substantially over the next few years.

At-Risk Population Estimates

HIV Estimates re: Holmberg / CDC with the Interim IDU Estimates

Dr. Scott Holmberg from CDC presented the most detailed estimates of at-risk populations living in the Houston Metropolitan Statistical Area (MSA) in an article "The Estimated Prevalence and Incidence of HIV in 96 Large US Metropolitan Areas".[11] His population estimates are shown in Table 2.

Table 6 At-Risk Population Estimates by Holmberg

Holmberg **Total Houston MSA (EMA)[1]**	**% of pop**	Census pop estimate **3,551,775[3]**	TSDC[2], 1999 pop estimate **3,931,269**
IDU	1.84%	65,200	72,166
MSM	1.35%	48,000	53,129
Heterosexual	2.29%	81,400	90,097
Total at risk	5.48%	194,600	215,392

1. The Houston EMA (a HRSA designation) is the same as the Houston MSA (a census bureau designation). Each has the six counties shown in the Attachments.
2. Texas State Data Center
3. Census estimate from Holmberg

When the figures presented by Holmberg were reviewed by the Houston Department of Health and Human Services (HDHHS), current experience with the incidence of HIV and AIDS suggest that Holmberg's estimate of IDUs was unrealistically high. The HDHHS believes that:

1. If Houston had the number of IDUs Holmberg projected, the epidemic would have shown a dramatic increase in the proportion of IDUs being diagnosed with AIDS, as shown in EMAs with a higher proportion of IDUs at risk.
2. In comparison to similar size EMAs, the number of IDUs in substance abuse programs is lower than would be expected if there were the number of IDUs projected by Holmberg.
3. The proportion of MSM in comparison to other at-risk populations is shown in the Holmberg's paper to be lower in Houston than in any other Texas EMA. There is no known reason why Houston would have a significantly different profile of at-risk populations than other Texas EMAs, i.e., the proportion of MSM at-risk should be much higher than the proportion of IDUs.

The consensus of a group of experts in the behavioral sciences and substance abuse fields is that there are no accurate data available on the number of injection drug users in the Houston EMA. The HDHHS staff is reviewing data from other EMAs to ascertain whether any accurate projections can be made from existing AIDS case data to

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[11] American Journal of Public Health, May 1996 (Vol. 86, No. 5).

estimate potential numbers of HIV-infected individuals by risk group. In the interim, a number half of the Holmberg estimate for IDUs at-risk is used for modeling projections. While this change is not empirically based, the HDHHS staff agrees that it is a more realistic estimate but that it may still significantly overestimate the extent of the IDU population in the Houston EMA. As a result, half the Holmberg estimate would result in 32,600 IDUs at-risk for HIV. Table 7 summarizes the estimates based on the revised IDU at-risk population.

Table 7 Interim At-Risk Population Estimates

HHSD **Total Houston MSA (EMA)[1]**	**% of pop**	**Census pop estimate** **3,551,775**	**TSDC[2], 1999 pop estimate** **3,931,269**
IDU	0.92%	32,600	36,083
MSM	1.35%	48,000	53,129
Heterosexual	2.29%	81,400	90,097
Total at risk	4.56%	162,000	179,309

1. The Houston EMA (a HRSA designation) is the same as the Houston MSA (a census bureau designation). Each has the 6 counties shown in the Attachments.
2. Texas State Data Center

The Prevention Planning Group has also presented an estimate of HIV infection as part of the Regional HIV Prevention Plan for Public Health Region Six.[12] The percentage of population at risk estimated by the PPG is applied to the 1999 Texas State Data Center (TSDC) population estimate of the EMA in Table 8

Table 8 At-Risk Population Estimates Recommended by PHR6

PPG **Total Pop PHR6**	**% of pop**	**PHR6 Pop estimate** **3,690,742**	**TSDC, 1999 pop estimate** **3,931,269**
IDU	0.68%	25,200	26,842
MSM	1.09%	40,300	42,926
Heterosexual	0.97%	35,800	38,133
Total at risk	2.74%	101,300	107,901

1. The Houston EMA (a HRSA designation) is the same as the Houston MSA (a census bureau designation). Each has the 6 counties shown in the Attachments.
2. Texas State Data Center

The TSDC population estimate and the percentage of at risk population derived by Holmberg with the HDHHS interim IDU correction are the basis for all HIV projections provided in Table 9 *and* Table 10*. The HIV estimates include PLWA.*

Using CDC methods, in 1999 there were between 16,876 and 19,420 people

Table 9 provides the estimated number of HIV infections for the Houston EMA based on Holmberg with an interim IDU estimate. It uses the "high" and "low" number of new infections estimated by Holmberg and adjusts it for TSDC estimated 1999 population. Table 10 uses the

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[12] Public Health Region .Six includes the Houston EMA counties plus Austin, Colorado, Brazoria, Galveston, Walker and Matagorda Counties. As the vast majority of HIV and AIDS cases are in Harris County, using PHR6 estimates may not be very precise, but it is one of the only available methods.

with HIV infections.

and adjusts it for TSDC estimated 1999 population. Table 10 uses the Holmberg estimate adjusted by the interim IDU estimate, but applies the 1999 population estimates supplied by TSDC. Notably the “low” 1999 estimates based on projected new cases (16,876) shown in Table 9 is lower than those shown in Table 10 that are based on population estimates (17,537) because of the impact of a substantially greater population.

Table 9 HIV Rates Based on the Interim IDU Estimate Using Holmberg’s “Low” and “High” Estimates for New Infection

Houston MSA: 3,551,775	**Estimated At-Risk for HIV**	**HIV Cases per 1000**	**% of at risk population infected**	**Est # HIV positive 1995**	**New infections per yr.**		**HIV positive 1999**	
					Low	**High**	**Low**	**High**
IDU	32,600	61	6.10%	2,000	110	413	2,440	3,152
MSM	48,000	260	27.0%	13,000	70	350	13,280	14,400
Heterosexual	81,400	11	1.1%	900	64	242	1,156	1,868
Total				15,900			16,876	19,420

Table 10 HIV Rates for Houston Based on the Adjusted Estimate of Holmberg Updated with 1999 TSDC Pop Estimate

Houston EMA	**Estimated at-risk for HIV 1999**	**Percent of at-risk population infected**	**HIV positive 1999**
IDU	36,083	6.1%	2,201
MSM	53,129	27.0%	14,345
Heterosexuals	90,097	1.1%	991
Total	179,309		17,538
1999=3,931,269 total population			

Population growth and trends greatly affect HIV projections.

Although both Table 9 and Table 10 use Holmberg assumptions, it is particularly instructive to note the impact of population growth on projected seroprevalence, holding constant the infection rate to 1995 levels.

HIV Estimates Based on Logistic Regression re: Cohort at Testing Centers

As a third estimate, the rate of HIV infection is determined by the logistic regression analysis using the database from the City of Houston HHSD. The database contains information of three STD clinics and one community-based clinic (1991-1998). There are four clinics represented, one in a service area frequented by predominately gay/bisexual men and the others in service areas that have lower socio-economic clients.

Although the clinics do not capture a random sample of respondents, the different clinics allow a reasonable estimate of at-risk populations based on the demographics of the cohort as described below. It is likely that those being tested perceive themselves to be at higher risk, and the results would be over-estimating infection rate.

The characteristics of people testing for STDs at the three clinics (N=40,621 over 8 years) that are used to estimate the heterosexual and IDU rates are as follows:

- About 8.4% of the subjects are White, 74.9% Black, 15.1% Hispanic, .8% Asian, .2% Native American, and .2% others.
- About 80% of the subjects are within the age range of 20 to 34.
- About 2.7% of the subjects are HIV positive.
- Over 95% are heterosexual.
- About 1.7% of the clients are MSM.
- 1.7% of the clients are IDUs.
- About 55.6% are male and 44.3% are female

The characteristics of the community-based clinic that are used to estimate the MSM rate are described below. The clinic is located in a traditionally gay area in Houston and serves a large number of MSM. The sample size of the Cohort over 8 years is 9,500. The demographic profile of all clients includes:

- About 63% are White, 20% Black, 14% Hispanic, 2% Asian, .1% Native American and .3% others;
- About 76 % are within the age range of 20 to 39;
- About 13% are HIV positive;
- About 38% are heterosexual;
- About 34% are MSM;
- Over 75% are male;
- Only .3% are IDUs.

A logistic regression is used to estimate the rate of HIV based on the probability of the various at-risk populations being infected (the odds ratios between MSM and non-MSM; IDU and non-IDU; heterosexual and non-heterosexual; male and female; White, Black, and Hispanic).[13]

Based on the data from the clinics, the HIV positive rates are identified as follows:

Table 11 Probability Estimates Based on City Cohort

Risk Group	Average Rate 1991-1998	Average Rate 1997-1998
IDU	.0531	.0509
MSM	.3064	.2193
Heterosexual	.0219	.0161

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[13] A logistic regression is used when the outcome variable contains nominal data. In this instance, the outcome that is being predicted is HIV status. The logistic regression includes two steps. First, the analysis will identify the overall relationships between the predictor and outcome variables. Second, the logistic regression will identify the effect of an predictor variable on the outcome variable when sexual id, race and gender are controlled. These include a maximum likelihood estimate procedure is used for the calculations.

Table 13 summarizes the estimates based on the 1991 to 1998 and 1997 to 1998 average HIV positive probability.

Table 12 Estimates of HIV for Subpopulations for 1999 Based on Clinic Data from the City of Houston HHSD

	At-Risk Population estimate	% population PLWA in 1998	Estimate HIV positive based on 1991-98 clinic data	Estimate HIV positive based on 1997 & 98 clinic data
IDU Total	36,083	100%	1,916	1,837
IDU Male	22,660	62.8%	1,203	1,154
IDU Female	13,423	37.2%	713	683
IDU African American	23,743	65.8%	1,263	1,209
IDU Anglo	8,480	23.5%	450	432
IDU Hispanic	3,825	10.6%	203	195
MSM Total	53,129	100%	16,279	11,502
MSM African American	12,432	23.4%	3,809	2,692
MSM Anglo	31,293	58.9%	9,588	6,775
MSM Hispanic	9,138	17.2	2,800	1,978
Heterosexual Total	90,097	100%	1,973	1,460
Het. Male	40,814	45.3%	894	661
Het. Female	49,283	54.7%	1,079	799
Het African American	54,509	60.5%	1,194	883
Het Anglo	16,758	18.6%	368	272
Het Hispanic	18,470	20.5%	405	299

Projection of HIV Rate

As noted above, any estimate of HIV infection is, at best, a "guesstimate." Yet for planning purposes, the Council requested that PCH provide an estimate for 1999 and 2003. The assumptions are:

- The overall population will grow from 3,551,775 in 1996 to 3,931,269 in 1999 and 4,196,400 in 2003 (based on the estimate from the Texas State Data Center, respectively.

The population increase indicates:

- There will be more gay and bisexual men in Houston. The number of gay men dying of AIDS is likely to decrease significantly and the number living with HIV will increase. If persons living with AIDS are infectious, there may be an increase in infection among MSM, but it is unlikely to be dramatic among gay men over 35 because they are likely to have fewer sexual partners. At the same time information from the sexually active young MSM show an increase in infection rates, especially among African Americans. Overall, the infection rate among MSM is likely to remain fairly constant.

- The relatively constant percentage of African Americans and the increase in percentage of Hispanics in the Houston EMA means that proportionately there should be a slight decline in rates of infection through injection drug use.

- The rate of heterosexual transmission of HIV will continue to increase, especially in African-American Women. The absolute number of HIV positive heterosexual and IDUs will be significantly smaller than the number of HIV positive MSM.

Based on these assumptions, Table 15 indicates the estimated HIV infection for 1999 and Table 17 provides HIV estimates for 2003. Four different approaches are used. The first uses the PHR6 estimate of at-risk populations and multiplies them by Holmberg's projected 1995 rate of infection. The second is based on Holmberg's 1995 HIV infection rate adjusted by the interim IDU estimate and TSDC population projections. The third estimate uses the average HIV estimate from the City clinics multiplied by the interim estimate and the adjusted TSDC population estimates. The fourth estimate is based on the average City clinics' HIV infection rates for the 1997 and 1998 multiplied by the interim estimate and TSDC adjusted population estimates.

Table 13 Estimated HIV Positive Prevalence Based on 1999 Estimated Population

At Risk Population	Based on PHR6 estimated Population	Based on TSDC estimated Population	Based on City's Clinics 91-98	Based on City's Clinics 97-98
IDU	1,637[1]	2,201[2]	1,916[3]	1640[4]
MSM	11,590	14,345	16,279	11,502
Heterosexuals	419	991	1,976	1,460
Total	13,646	17,537	20,171	14,602

1. From Table 2, take the TSDC adjusted PPG population estimate of 26,842 and multiply it by Holmberg's estimate of .061.in Table 3.
2. From Table 4, take the TSDC adjusted Holmberg population estimate of 36,083 and multiply it by .061, Holmberg's estimate in Table 3.
3. From Table 5, take the City Cohort probability from 91-98 average estimate of .0531 and multiply it by the TSDC adjusted Holmberg population estimate of 36,083.
4. From Table 5, take the City Cohort probability from 97-98 average estimate of .0510 and multiply it by the TSDC adjusted Holmberg population estimate of 36,083.

Table 14 Estimated HIV Positive Prevalence Based on 2003 Estimated Population

At Risk Population	Based on PHR6 estimated Population	Based on TSDC estimated Population	Based on City's Clinics 91-98	Based on City's Clinics 97-98
IDU	1,740	2,355	2,050	1,969
MSM	12,350	15,295	17,358	12,265
Heterosexuals	448	1,057	2,104	1,547
Total	14,538	18,707	21,512	15,781

After examining the approaches, we recommend that the estimates based on the City's clinics 1997-98 data be used because the data can closely reflect the epidemic of the Houston EMA. However, we also want to recommend a range (from high to low) for the estimates based on the trends of the data from 1996 to 1998. Table 8 summarizes the range of the estimates. The data suggest that the estimated number of people living with HIV in 1999 ranges from 13,014 to 20,376, and in 2003 the number of people living with HIV range from 13,811 to 22,016.

Table 15 Range of Estimates of HIV Positive for 1999-2003

Year 1999: At Risk Populations		Highest City Cohort 96-98	Average 97-98 City Cohort	Lowest City Cohort 96-98
IDU	38,583	2,165	1,964	1,034
	Rate from City Cohort	(.0561)	(.0509)	(.0268)
MSM	53,129	16,688	11,502	10,593
	Rate from City Cohort	(.3141)	(.2193)	(.1994)
Heterosexual	90,097	1523	1,460	1,387
	Rate from City Cohort	(.0169)	(.0161)	(.0154)
	Total	20,376	14,926	13,014
Year 2003: At Risk Populations		Highest City Cohort 96-98	Average 97-98 City Cohort	Lowest City Cohort 96-98
IDU	38,607	2,165	1,965	1,035
	Rate from City Cohort	(.0561)	(.0509)	(.0268)
MSM	56,651	17,794	12,265	11,296
	Rate from City Cohort	(.3141)	(.2193)	(.1994)
Heterosexual	121,696	2,057	1,547	1,480
	Rate from City Cohort	(.0169)	(.0161)	(.0154)
	Total	22,016	15,777	13,811

CO-MORBIDITIES[14]

STDs

High STD rates are an indicator that risk of HIV infection is high.

Gonorrhea and syphilis rates indicate the level of unprotected sexual contact, and, in theory, should provide an early warning system for increased HIV infection. It is also known that individuals who have a history of STDs are more vulnerable to HIV infection.

STD rates are not

Empirically, the relationship between STDs and AIDS is less clear. Given the latency period of AIDS, at best, increases in STDs may indicate an increase in AIDS over several years in the future. Other

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[14] The Needs Assessment Survey being conducted in the spring of 1998 among PLWA will provide more accurate co-morbidity rates for HIV and STDs.

a good predictor of AIDS.

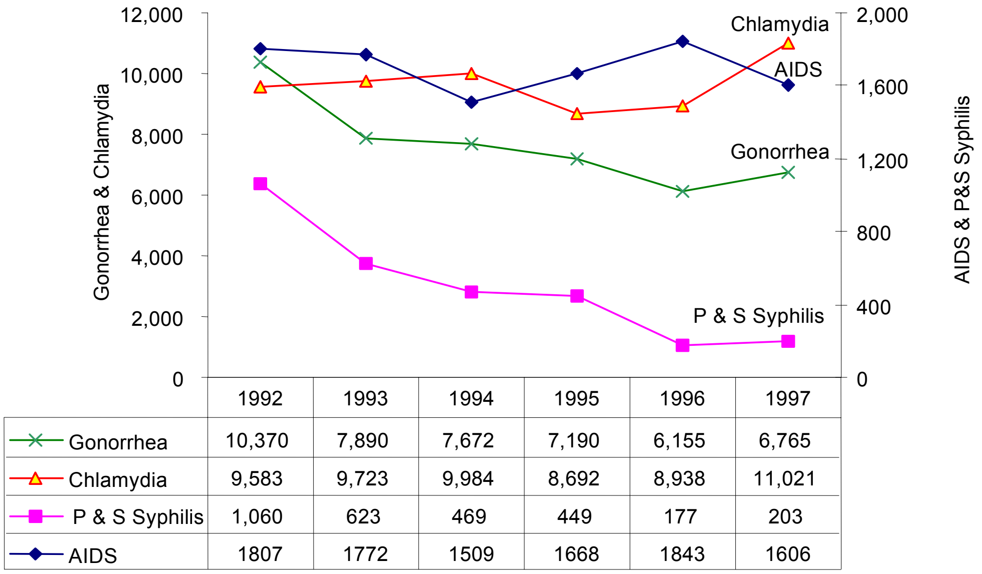
factors such as treatment of HIV and other medical factors make establishing a clear relationship difficult.

Even with increased HIV rates, it is not clear if these cases will progress to AIDS with the current medication.

Figure 43 STDs and AIDS plots the incidence of STDs from 1992 to 1997. 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 there is a relationship, a continuous drop in newly diagnosed AIDS will be seen for three more years.

The current 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 individuals diagnosed with HIV will progress to a diagnosis of AIDS.

Figure 36 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

As shown in Attachment 4, the rate of gonorrhea varies by county and type of infection. However in Harris County, this accounts for 96.5% of those living with gonorrhea, and there has been an overall decline in STDs from 1992 to 1997.

Chlamydia rates are rising. While not related to the prevalence of AIDS, it is a co-factor in susceptibility to

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 (Figure 43) are of concern as individuals with sexually transmitted diseases (STDs), both male and female, are believed to be at a susceptibility to HIV infection.

three- to five-fold increased risk of acquiring HIV if exposed to that virus. [15]

Tuberculosis (TB)

TB is much more likely to be contracted by persons with compromised immune systems. According to the statistics of the TDH, Harris County contains over 90% of all TB cases in the Houston EMA.

Between 15% and 16% of those infected with HIV have TB.

The data support that the co-morbidity rate in the TB / AIDS decreased from 1993 and the rate stayed the same from 1995 to 1997. In 1997, there were 623 new cases of TB in Harris County. Of these, 98 (15.6%) were infected by HIV/AIDS. In 1996, there were 607 new TB cases, 95 (15.6%) were infected by HIV/AIDS. In 1995, there were 786 new TB cases, 123 (15.6%) were infected. In 1994, there were 747 new TB cases, 143 (19.1%) were infected. In 1993, there were 728 new TB cases, 142 (19.5%) were infected (TDH).

The majority of new TB cases are among Latino and Asian immigrants.

The majority of TB cases in the Houston EMA occur among the foreign-born population which is predominately Hispanic/Latino and Asian. Although these populations have fairly low HIV rates, with the continuing population growth in these populations in the EMA, it is quite possible that the number of TB cases among those who are HIV positive will increase.

The survey of PLWH/A that is currently being conducted will provide further information on the incidence and profile of TB cases.

Substance Use and Abuse

There is little valid information about non-injection drug use co-morbidity with AIDS.

There is little available information that would provide a valid estimate of the co-morbidity of injection and non-injection drug abuse and AIDS. The survey among PLWH/A currently in process will provide more in-depth data on co-morbidities between drug use and HIV infection.

According to the TCADA's report on Substance Abuse Trends in Texas, "as of September 30, 1998, the proportion of adult and adolescent AIDS cases related to injecting drug use has risen from 15 percent in 1988 to 23% in 1998. Of these, in 1988, 6 % of the cases were IDUs, and 9 % were MSM/IDUs." As shown in Attachment 1, in 1998, over 14% were among IDUs and over 8% were among MSM/IDU.

The actual incidence of HIV among IDUs is unknown because there has been no generalizable sample of IDUs studied. From the Cohort reported earlier in this report for estimating HIV prevalence, the average incidence of HIV among drug users in three clinics between 1991 and

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[15] 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%.

1998 was 5.3%. The average rate between 1997 and 1998 was 5.1%. The estimate used by Holmberg reported earlier was 6.1%. In a recent study conducted in two drug treatment centers in Houston for TCADA by Dr. Michael Ross, University of Texas, (in press), he found that the rate of HIV among those seeking treatment varied widely. In one center he found the rate to be 6.2% and at the other he found the rate to be 0.7%. In a study conducted by Williams (1990), he found that the HIV seroprevalence was 8.4% in a sample of 921 heterosexual male IDUs in Houston who were not in drug treatment at the time of the study. He also indicated that 10% of the Black males in the study were HIV positive compared to only 7% for White males. The study also indicated that Black males were 2.8 times more likely to be HIV positive than Hispanic males.

Furthermore, in a recent study in Houston using a sample of not-in-treatment drug users (n=514), Williams, et al (1996) found that the odds that women would test positive for HIV infection were 1.8 times higher than for men. The study indicated that 15% of the women were HIV positive compared to only 9% for men. The study also found that 14% of the Blacks were HIV positive, 5% were Hispanics and 3% were White. Additionally, the study found that the odds that the subjects who tested positive for syphilis would also test positive for HIV were 3.46 times higher than those who were tested negative for syphilis. Moreover, the study indicated that women IDUs who reported having sex with women or who self-identified as lesbian or bisexual had 2.64 greater odds of testing HIV positive than did heterosexual subjects. The odds for MSM IDU would test HIV positive were 3.77 times greater than heterosexual.

Homeless

There is little available information that would provide a valid estimate of the co-morbidity of homeless and AIDS. The current survey needs assessment will provide additional information regarding homelessness and HIV.

There have been two studies done on adolescents that are homeless. Based on the information from these two studies, the rate of HIV infection among adolescent homeless in Houston ranges from 1.25% to 2.2 %. The CDC conducted one study in 1994, and the Houston figures are extracted from a national cross-sectional study to assess risk behaviors for HIV infection among homeless and runaway youth at four urban shelters. One of the sites was based in Houston. The data indicate that 1.25% of the homeless subjects were infected with AIDS.

The second study conducted in 1997 by the HDHHS was based on data from a homeless and runaway adolescent health clinic from 1990 to 1996. Of the 1,005 male subjects, 2.2 percent (n=22) were HIV positive. Of these 22 male adolescents, 3 were White and 19 were African American. Among the female adolescents, 1.3% (n=10) were HIV positive. Of the 10 female subjects, 2 were white and 8 were African American. The results from this study suggest that, among adolescents, that the percentage of homeless HIV positive adolescents is much higher among African Americans.

Mental Illness

There is little available information that would provide a valid estimate of the co-morbidity of mental illness and HIV/AIDS. According to the statistics produced by the Mental Health and Mental Retardation Authority of Harris County (MHMRA) (Johnson, 1999), only 15 HIV positive cases were identified between 1988 and 1999. However, Johnson (1999) indicated that this number is not a valid reflection of the exiting HIV/AIDS cases as MHMRA does not conduct HIV testing for their clients. The information was based on the self reports from clients. According to Johnson (1999), Jeffery Kelly at the University of Wisconsin Medical college estimated that the prevalence of HIV positive cases among people with mental illness was about 6.5% or 3% higher than the national norm. Further research is needed in this area. The Needs Assessment survey being conducted through June 1999 will provide additional information for estimating co-morbidity between HIV and mental illness.

CONCLUSION

Estimating the number of PLWH and PLWA is necessary in planning for HIV/AIDS services.

The number of people living with HIV and the number of people living with AIDS provide the best estimates for determining the needed capacity for HIV/AIDS services. Those with a diagnosis of AIDS are eligible for a greater number of services and have greater need for acute care services than those who are diagnosed with HIV. However, current treatment protocols are emphasizing early treatment for those diagnosed with HIV. In addition one outcome in the continuum of care is to prevent the progression from HIV to AIDS among those with HIV. These suggest increased services are needed among those living with HIV, and an expanded effort to identify those who are HIV positive.

From 1992 to 1998 the number of PLWA increased from 1,592 to 6,285.

Despite the declining number of newly diagnosed AIDS cases, the care system will be confronted with a growing number of PLWH/A. The declining mortality rate and longer life expectancy of those with AIDS demonstrates the effectiveness of the care system.

Overall, the profile of PLWA is likely to continue to be about the same as it is now. There will be some shift toward African Americans. The newly infected are likely to continue to be MSM, but the shift to African American MSM and the increasing heterosexual PLWH will be noticeable.

There is likely to be 10,500 PLWA in 2003.

From 1992 to 1998 the number of persons living with AIDS has increased from 1,592 to 6,285. As fewer PLWA die, the number of PLWA is expected to continue to increase to over 10,500 cases in 2003.

Most PLWA will continue to be MSM and MSM with AIDS will become more African American

Over 80% of the PLWA are male, and over 60% are MSM. MSM will continue to constitute the majority of PLWA for the foreseeable future, with over 4,000 cases in 1998. The proportion of Anglo MSM will decrease as African Americans are more likely to progress to AIDS. However, this will be offset by the increased likelihood of Anglo MSM to live longer with AIDS. Successful outreach in the African American community could substantially increase the number of African Americans living with AIDS who need to access care and services.

IDUs will continue to represent between 14% and 16% of PLWA with between a third and 40% being women.[16]

Heterosexuals will represent 14% - 16% of PLWA.

Heterosexuals will also represent between 14% and 16% of PLWA. The majority will be female, and the majority of those will be African American.

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[16] Given the conclusion that IDUs will continue to represent between 14% and 16% of the PLWA, it would appear that Holmberg's estimates is far too high for the IDU population.

Over 95% of PLWA lived in Harris County.

At the end of 1998, there were 7,538 PLWA in the Houston EMA. Most reside in Harris County, with 319 (4.2%) living in the remaining five counties that define the EMA. Of those five counties, Fort Bend had 164 and Montgomery had 102 PLWA.

The number of PLWH/A is likely to increase 10% to 22% between 1998 and 2203.

There is no way of knowing exactly how many persons will be HIV positive in the future. Using several methods of estimation, and given no dramatic change due to vaccines or medication, it is estimated that in 1999 there will be between 13,014 and 20,376 person living with HIV infection. By 2003 there will be a 6% to 8% increase in the number of PLWH/A. This translates into between 13,811 to 22,016 PLWH/A in the Houston EMA.

Although there are relatively a small number of heterosexuals presently infected, the proportion of HIV positive persons is likely to increase at a faster rate among heterosexuals than MSM. Still, MSM will remain a majority of the HIV positive persons for the foreseeable future.

The number diagnosed with AIDS each year will decline dramatically.

The good news is the number of persons diagnosed with AIDS each year is decreasing and is likely to continue to decrease provided that treatments continue to be effective. Over the past few years the average decrease has been 9.8% and from 1996 to 1997 the rate of decrease was about 13%.

Anglo MSM have the greatest decline in new AIDS diagnosis.

The largest number of newly diagnosed AIDS cases will continue to be among MSM through 1998. However, the largest decrease in newly diagnosed AIDS cases is also among MSM, and if current trends continues, heterosexuals may have more newly diagnosed cases by the turn of the century. The number of women, who make up the majority of heterosexual AIDS cases, will increase. However, this trend toward heterosexual AIDS cases may not reflect HIV infection rates, as most national data show a substantial increase in HIV infection rates among young gay men, and the MSM population continues to be significantly more at-risk because of the large pool of currently infected people living with HIV.

African Americans are the most likely to be diagnosed with AIDS.

Reflecting the large Anglo MSM population, all Anglos have shown a dramatic drop in newly diagnosed cases since 1996. In 1996, African Americans surpassed Anglos in the number of newly diagnosed AIDS cases. From 1994 to 1996, there was an increase in newly diagnosed cases among African Americans, and only since 1997 has there been a decline. The number of Hispanics cases has always been lower than Anglos and African Americans, but has shown only a small decline in new cases.

African Americans enter the care system later and die sooner than Anglos or

African Americans appear to be accessing services much later in the continuum of care. While death caused by AIDS is decreasing for all populations, in 1998, the death rate for African Americans is over five times that of Anglos and Hispanics. Death rates for Anglos have fallen

Hispanics.

from 18.6 per 100,000 AIDS cases to 5.7 per 100,000 AIDS cases between 1992 and 1998. Hispanic death rates have fallen from 14.4 per 100,000 AIDS cases to 4.1 per 100,000 AIDS cases. African Americans have had a decline in death rate, but it continues to be much higher at 35.3 per 100,000 than other ethnic populations.

Once in the care system, African Americans have about the same fatality rate.

The higher death rate does not necessarily translate into inferior service from the AIDS care system. In a TDH "cohort" of those with AIDS who were in care (see page 8), the fatality rate of African Americans is similar to other ethnic groups. This indicates that those entering care earlier have a similar declining likelihood to die from AIDS.

More females are being diagnosed with AIDS each year; still they are a small percentage of new cases.

There is a trend for an increase in newly diagnosed cases among females and a decrease among males. Still, for the foreseeable future, males will far exceed females in newly diagnosed cases. In 1997 there were 348 newly diagnosed female AIDS cases and 1,258 newly diagnosed male cases.

Overall, the epidemiology suggests several messages for those planning HIV services:

- The HIV/AIDS care system will have to build capacity to serve more people living with AIDS and an even higher number of people living with HIV.

- There will be a shift in services as mortality decreases to less acute care and more prevention of acute disease.

- The AIDS epidemic will continue to be largely a MSM epidemic. The profile of infected MSM will shift slowly from Anglo to African American and Hispanic over the next five years.

- African Americans are at greater risk than other populations of becoming infected, progressing to AIDS, and dying of AIDS. They enter the system later than other populations.

- From a service planning prospective, knowing the number and profile of persons living with HIV will be critical. To date there is little generalizable information available to make those estimates. Not only will the system have to serve substantially more persons living with AIDS over the next five years, the profile of services will change as the system will deal with the long term side effects of medication.

- If the care system is to successfully prevent to progression from HIV to AIDS, in addition to the increased number of PLWA, the system is likely to need to serve twice the number of people living with HIV as those with AIDS.

Attachment 1 TREND DATA 1992-1998 AIDS Cases and PLWA

Attachment 2 Cumulative AIDS Cases Reported

Attachment 3 PLWA Through 1998

Attachment 4 STD Rates

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

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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

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 . 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 0-1 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.

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 5 and the consumer survey is shown in Attachment 6. 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 7.

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 6). 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 0-1, 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 8) 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 0-1 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 9. 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 0-2 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 0-2 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 0-3.

Table 0-3 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

Provider Name
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)
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 10). 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.[17] 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 0-4.

Table 0-4 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

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[17] 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.

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 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 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.[18] 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.[19] Clients unable or unwilling to travel to the designated site were

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[18] 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.

[19] 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.

interviewed over the telephone. The number of interviews conducted at each site is shown in Attachment 12.

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.

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 14, 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 16). 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.

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 0-1 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 0-1, several subpopulations have sufficient cell sizes to be analyzed and generalizations to the populations they represent will be reliable estimates.[20]

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 0-1 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 0-1 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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[20] 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 18 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 14 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 18 has more detailed demographic descriptions.

Basic Demographics

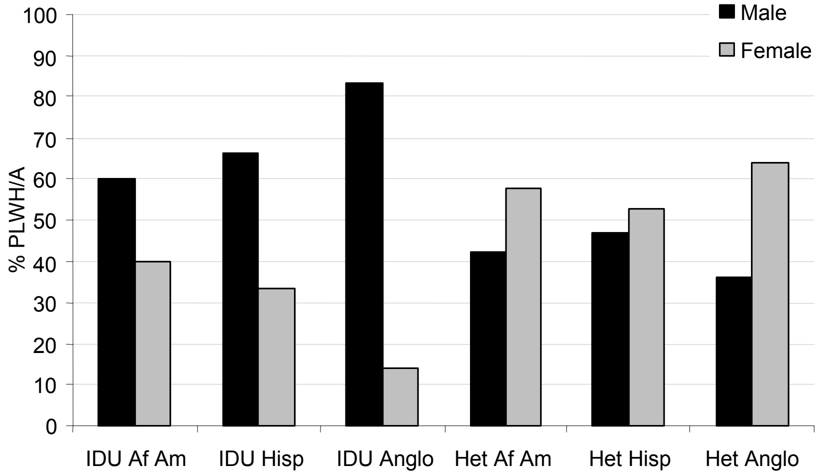
The majority of the following figures show the basic demographics for the three risk categories, MSM, heterosexual and IDU. When figures are provided for the total sample, over sampled populations are weighted back to their proportion in the population. The value of these tables is to have a full understanding 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 0-1 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 0-1 Gender Identity



Education

Figure 0-2 through Figure 0-4 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 0-2 MSM Education Levels

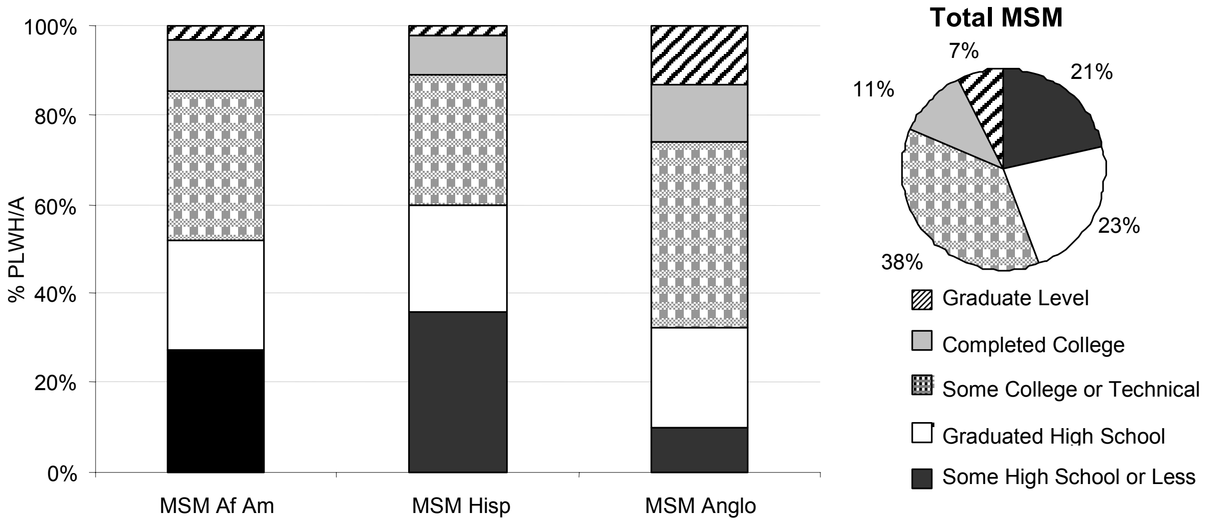


Figure 0-3 Heterosexual Education Levels

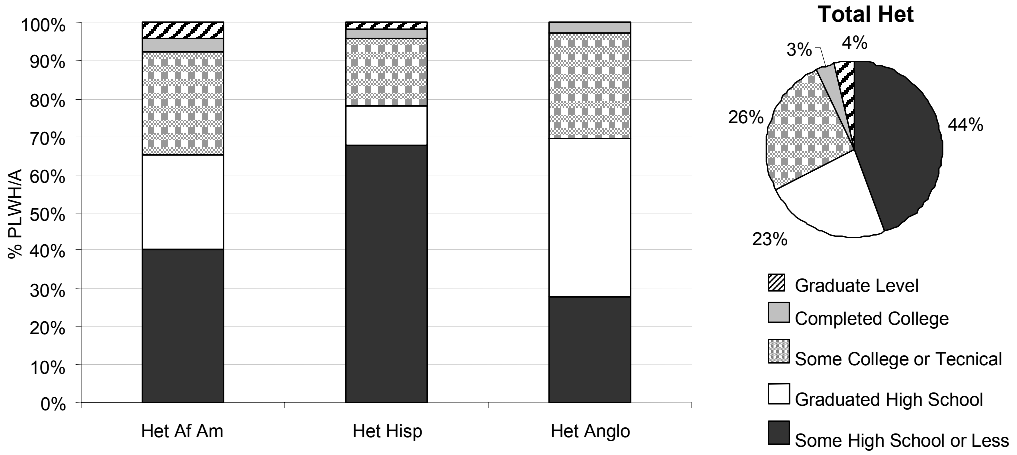
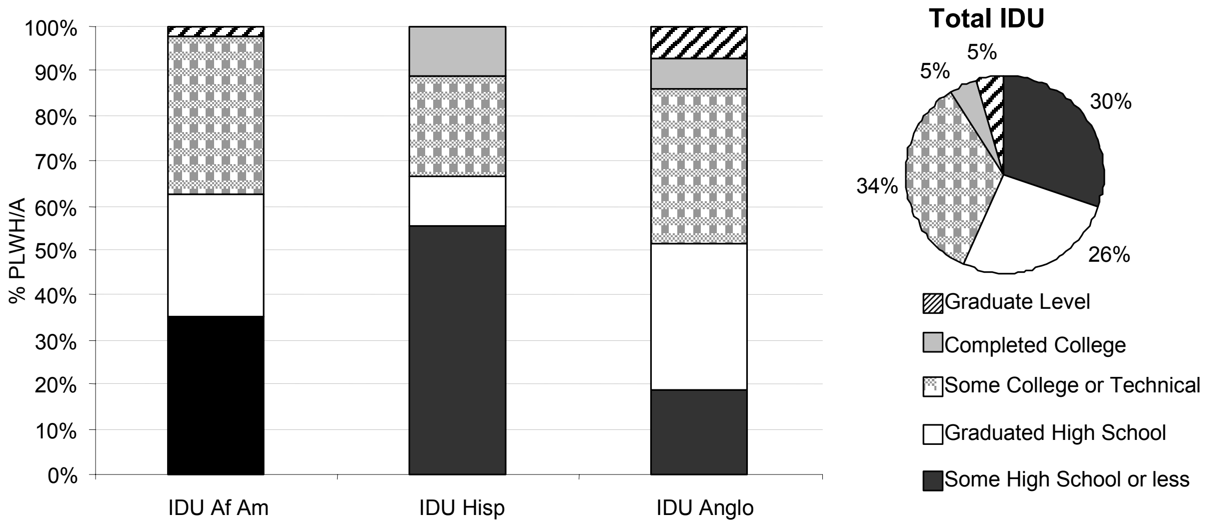


Figure 0-4 IDU Education Levels



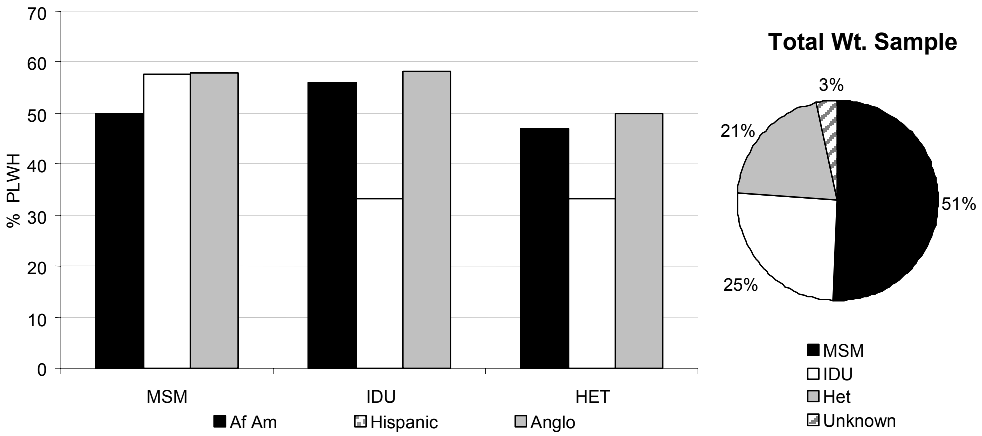
Ethnicity and Risk Group

Figure 0-5 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.[21]
- 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 0-5 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 0-6 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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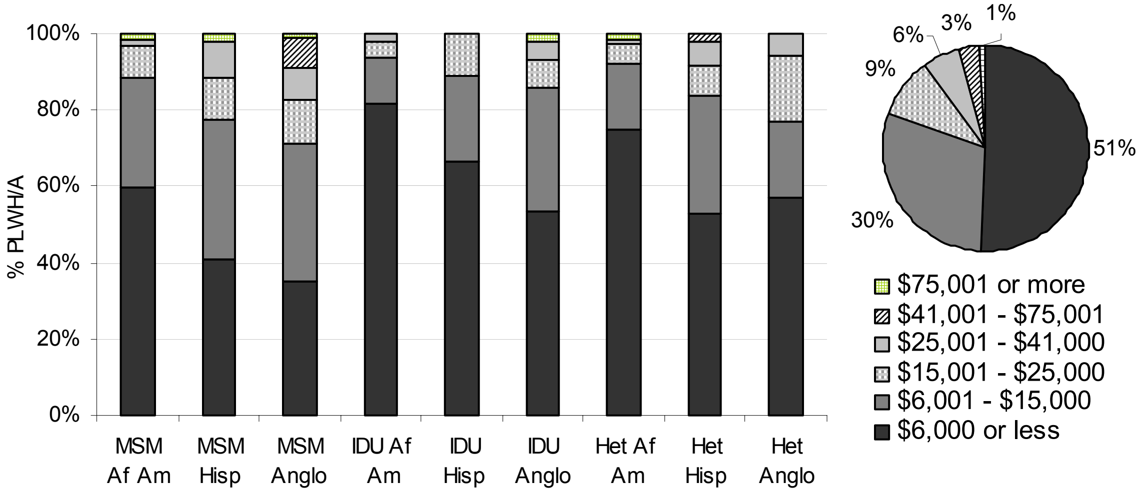
[21] This categorization of IDUs is not comparable to the Epidemiological Review because IDUs also reflect heterosexuals and MSM.

- 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.

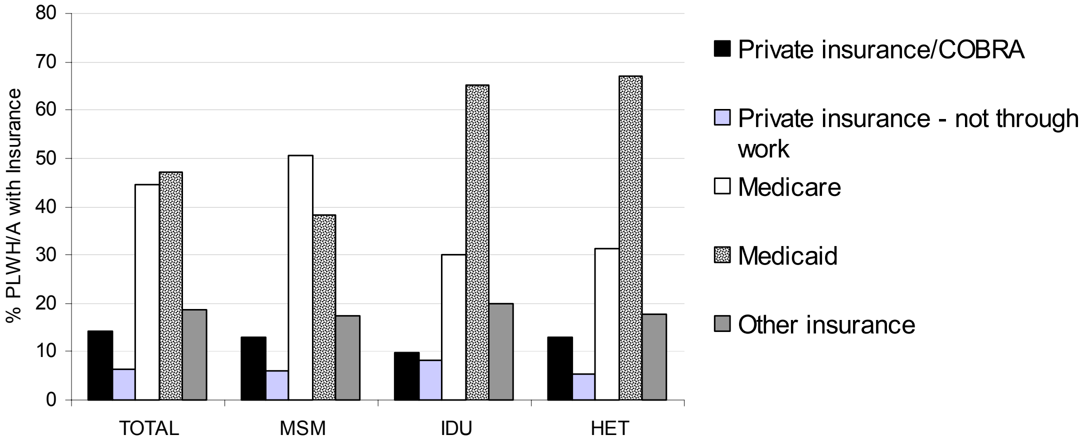
Figure 0-6 Income Levels



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 0-7). 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 0-7 Insurance held by PLWH/A



Entitlements and Benefits

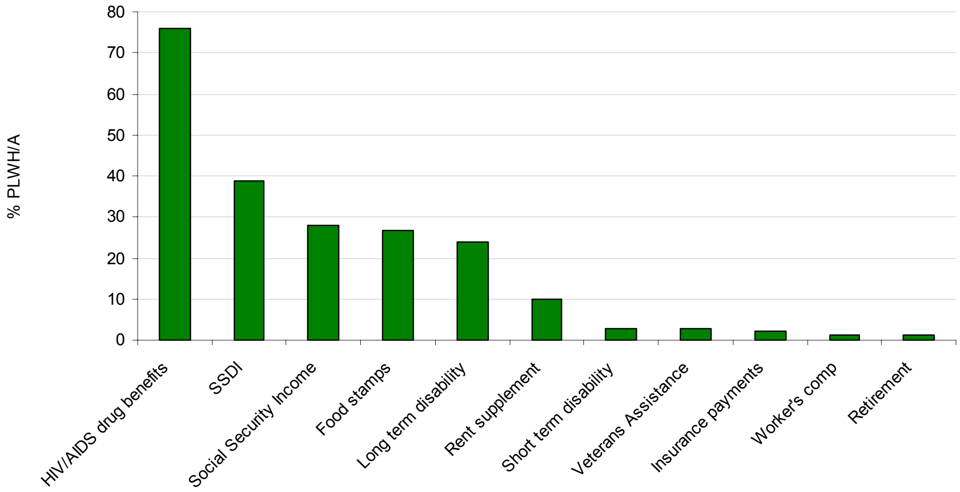
As shown in Attachment 18, PLWH/A who have insurance are most likely to have a combination of benefits. One of the reasons that the care system in Houston has favorable health status and mortality outcomes is that almost 80% of PLWH/A have access to drug reimbursement. Drug reimbursement may come from 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 0-8, 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 0-8 Benefits



Employment Status

As seen in Attachment 18, 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 0-1 through Figure 0-11 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 0-9 MSM Employment Status

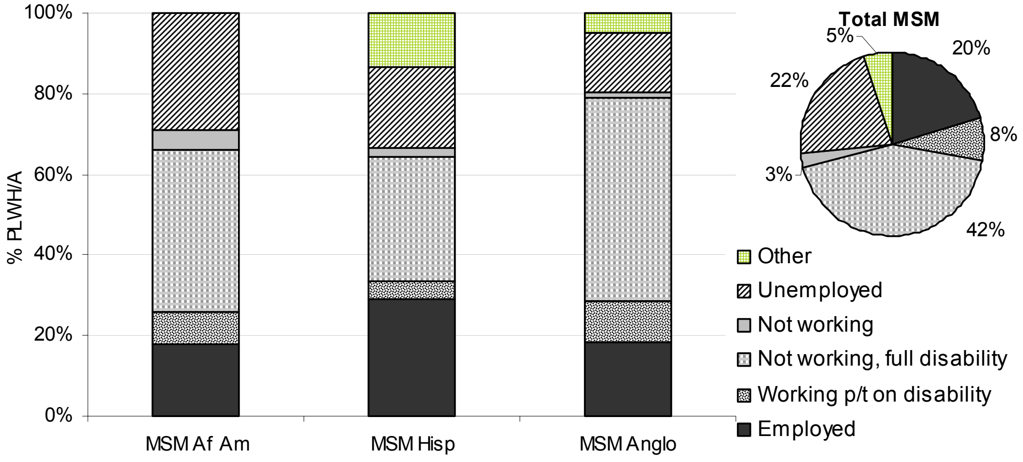


Figure 0-10 Heterosexual Employment Status

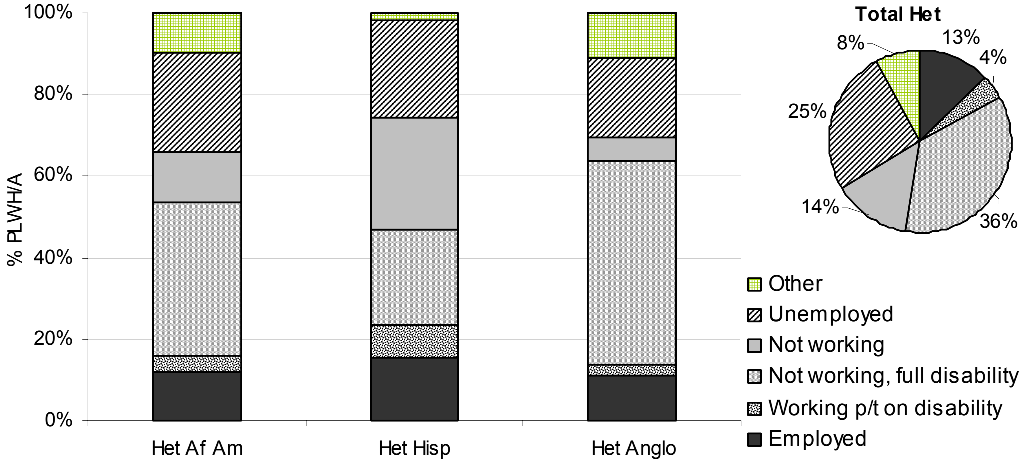
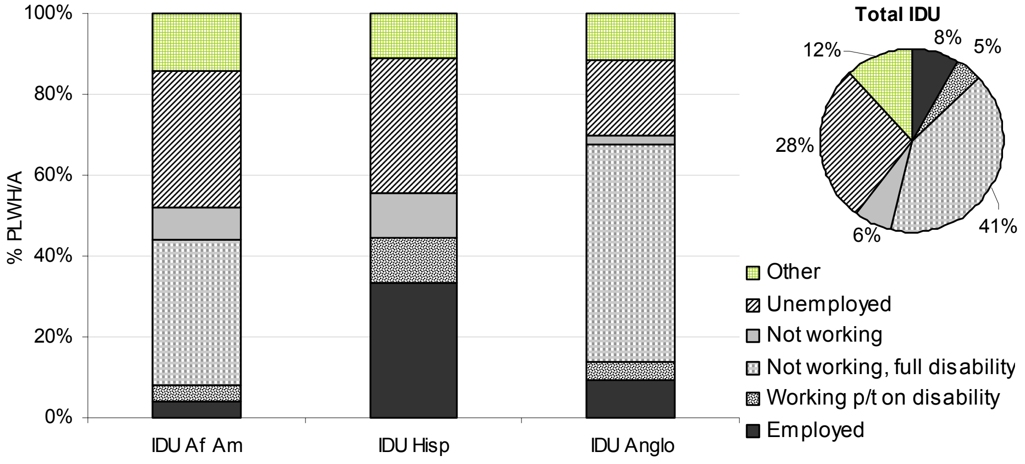


Figure 0-11 IDU Employment Status



Age and Place of Birth

Attachment 18 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 0-12 through Figure 0-14 indicate that respondents are involved in many different types of relationships.

- The "Total" column in Attachment 18 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 0-12 MSM Relationship Status

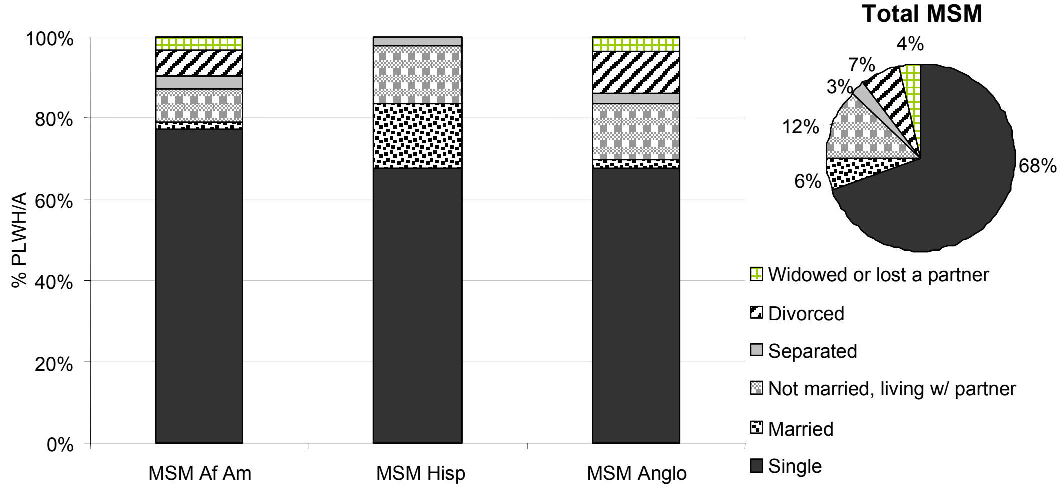


Figure 0-13 Heterosexual Relationship Status

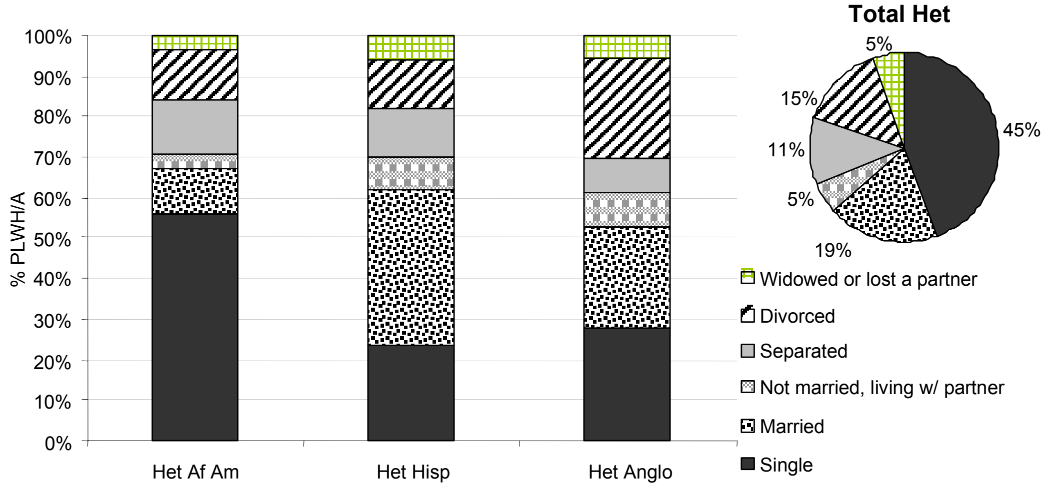
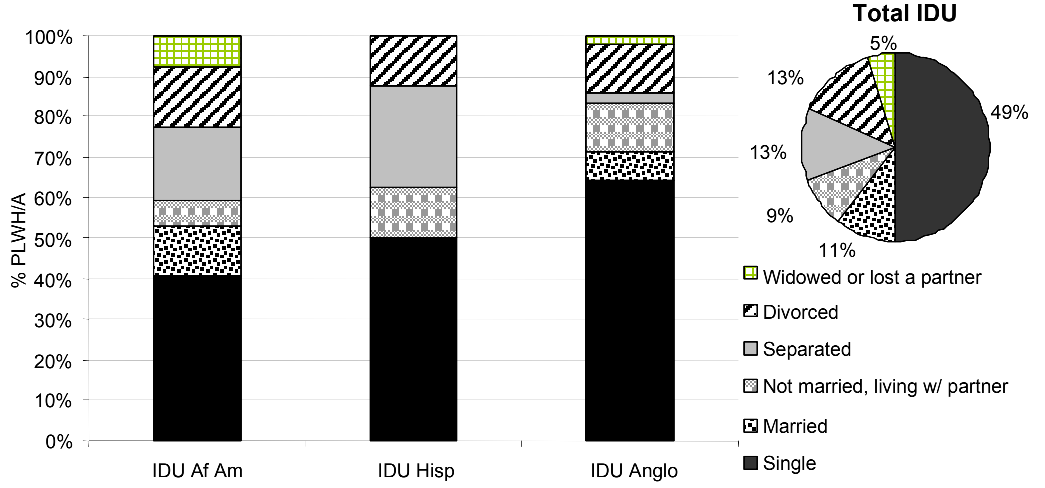


Figure 0-14 IDU Relationship Status



Living Arrangements

Figure 0-15 through Figure 0-17 shows the different profiles of living arrangements for the participants of the survey.

- In Attachment 18, "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 18**)**. 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 18:

- 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 0-15 MSM Living Arrangements

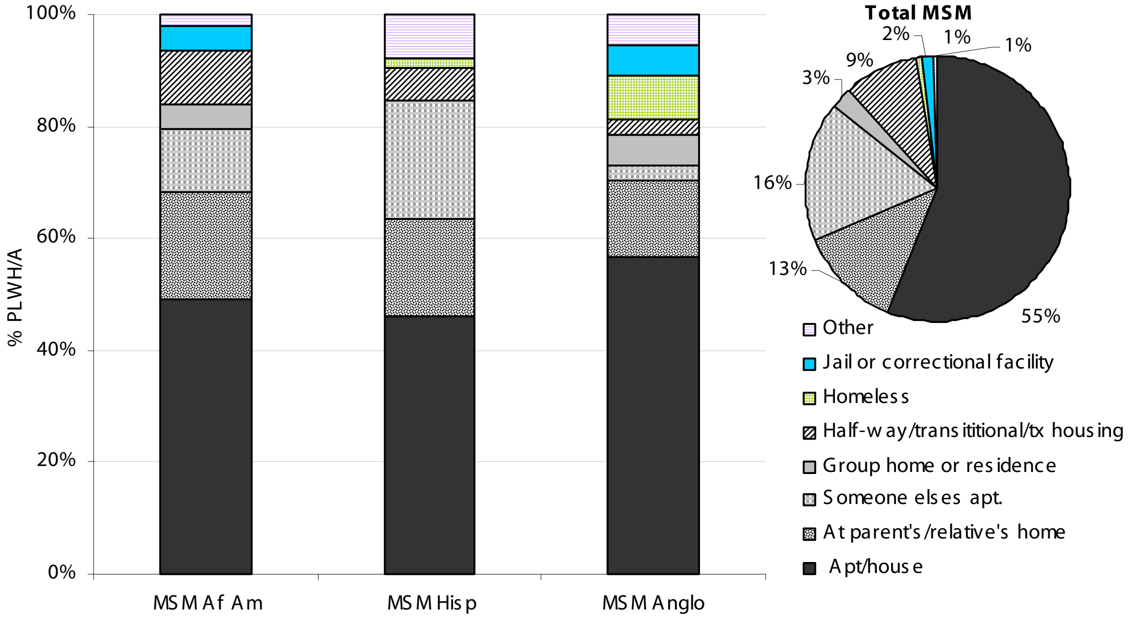


Figure 0-16 Heterosexual Living Arrangements

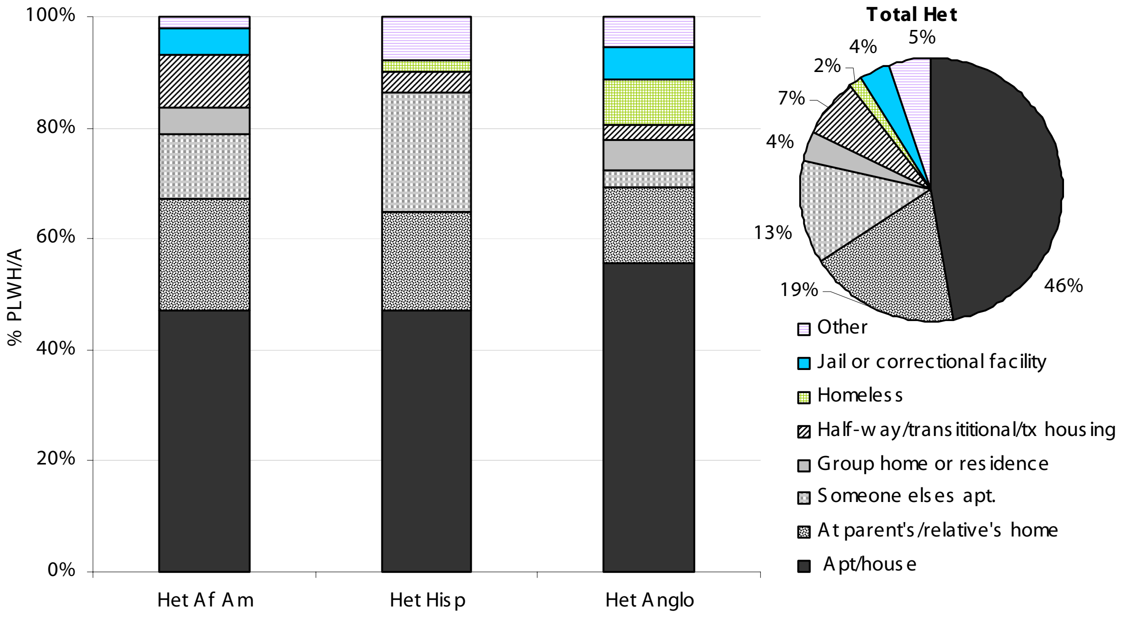
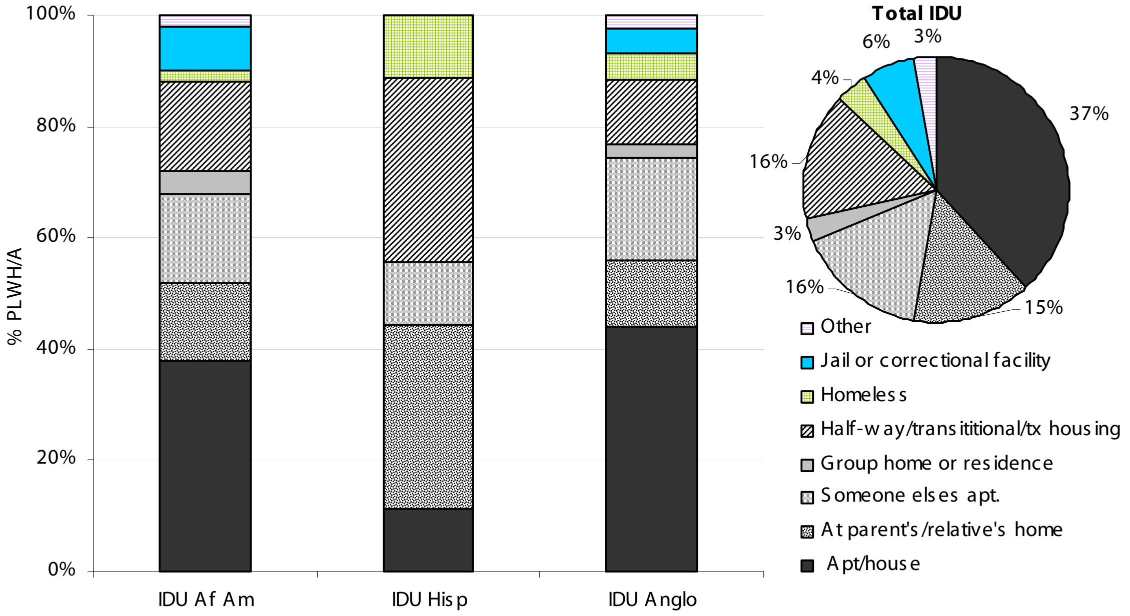


Figure 0-17 IDU Living Arrangements



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[22]

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.

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

- 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.
- 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.

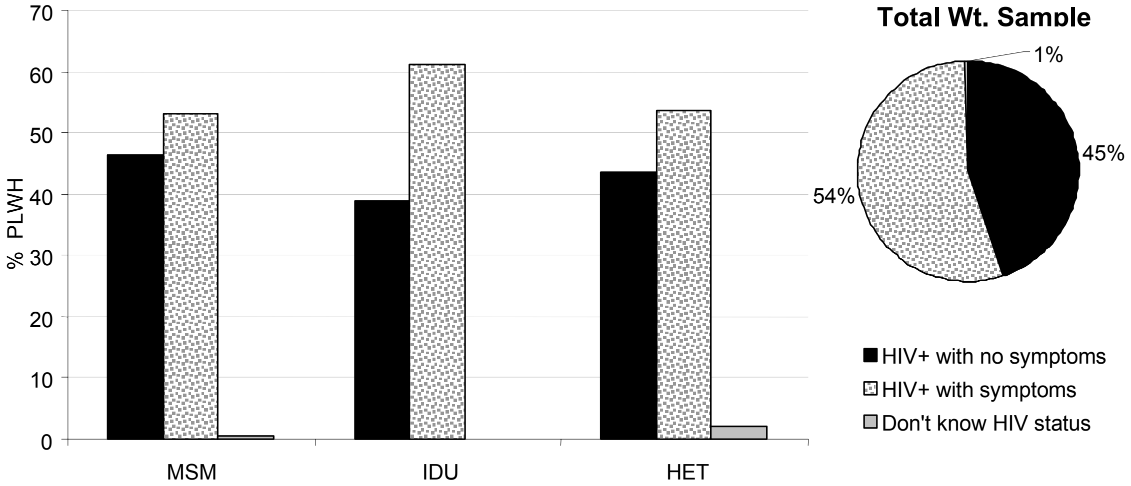
Stages of Disease

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 0-1 Percentage Reporting Symptoms by Risk Category

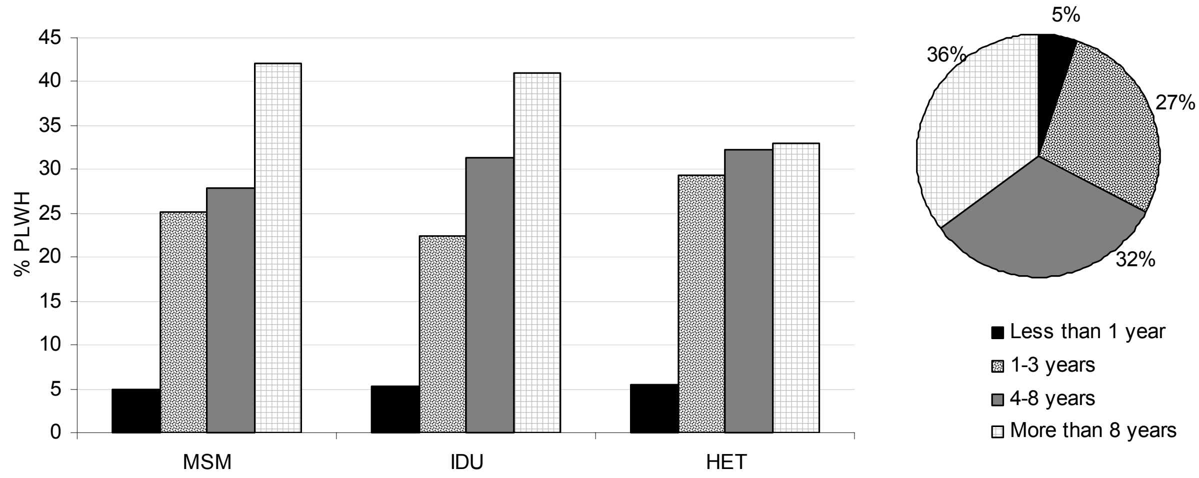


Length of Time of Infection

Figure 0-2 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 0-2 Length of Time Known HIV Positive by Risk Group



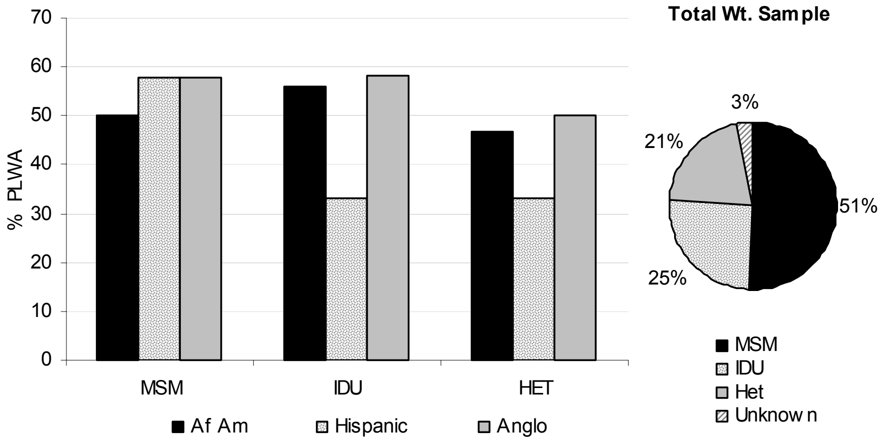
People Living with AIDS

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 0-3 and Attachment 18:

- 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 0-3 AIDS by Risk Category

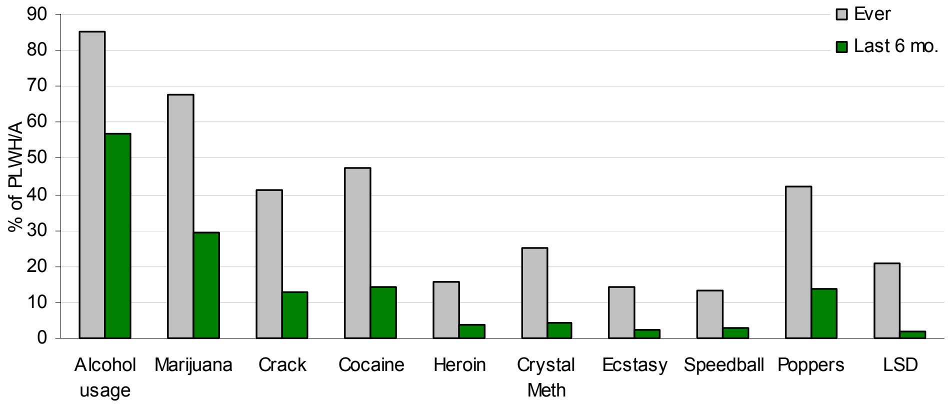


CO-MORBIDITIES

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 0-1 shows self reported drug use by PLWH/A.

Figure 0-1 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 0-2 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.[23]

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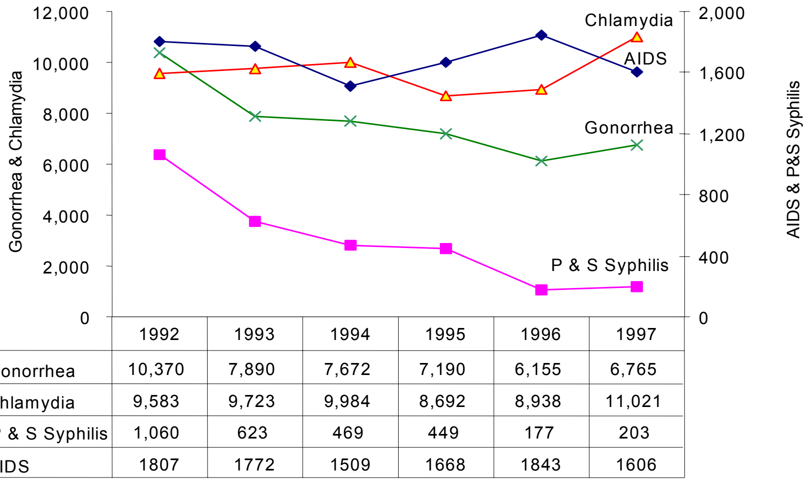
[23] As reported during a satellite symposium in November 1997, presented by the Centers for Disease Control and Prevention in cooperation with the American Social Health Association and the National Association of Nurse Practitioners in Reproductive Health. Notably the rise in the chlamydia is, in part,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

Figure 0-2 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

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.

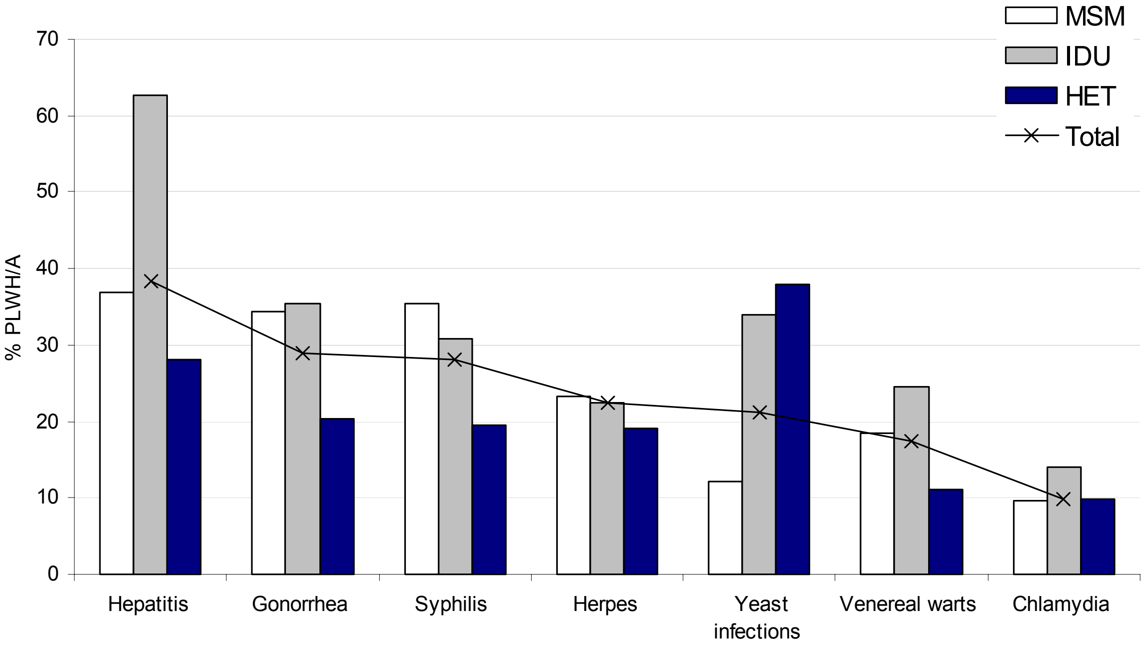
As shown in Figure 0-3, over 60% of the IDUs report having had hepatitis, and between 25% and 30% of MSM and heterosexuals also report hepatitis, indicating a potential need to treat a co-existing hepatitis epidemic.

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 0-3 STDs among PLWH/A



Mental Illness

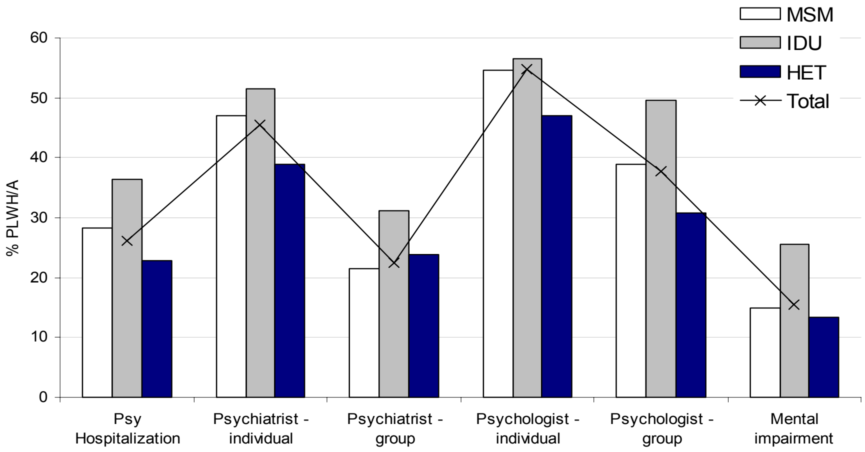
Mental illness covers a wide range of diseases including major depression, bipolar depression, post-traumatic stress disorder (PTSD), anxiety disorders, schizophrenia or psychotic disorders, and dementia. It may include those with mental illness or those with less debilitating forms of depression and 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 0-4, 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 0-4 Self Reported Treatment for Emotional/ Mental Disabilities



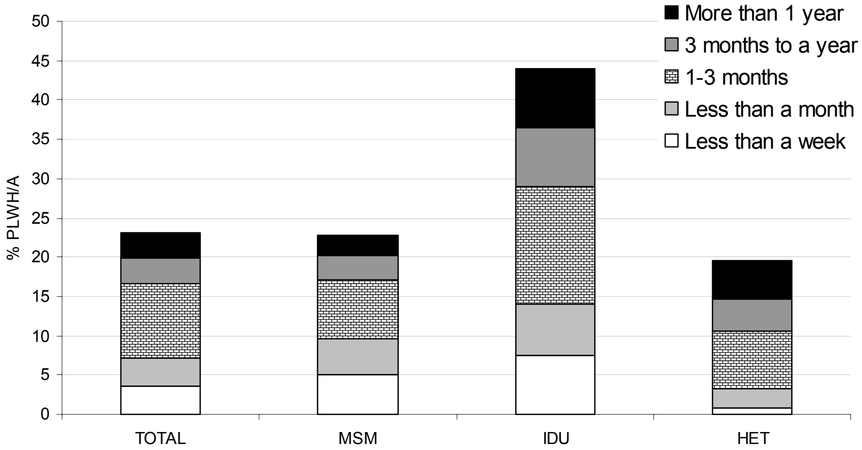
Homelessness

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 0-5, 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 0-5 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 0-5 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.

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.[24] Responses to the prevention questions are shown in Attachment 20. 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 0-1, 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.

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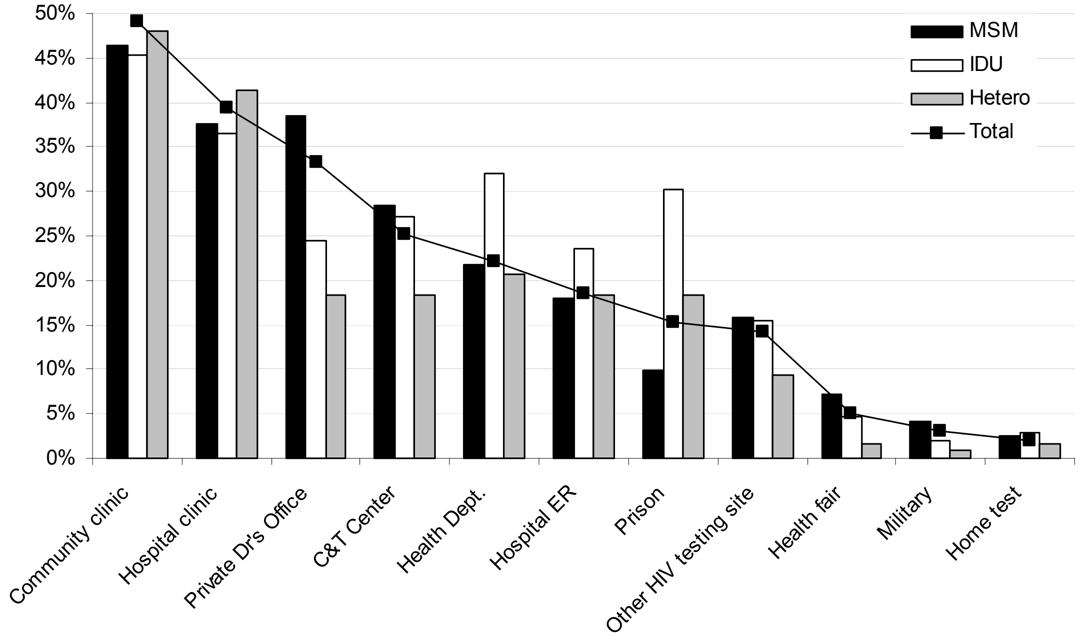
[24] The questions in the survey were of interest to the Prevention Planning Group, but should not be interpreted as a comprehensive examination of prevention behavior.

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.

Figure 0-1 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 0-2, 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.[25] 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

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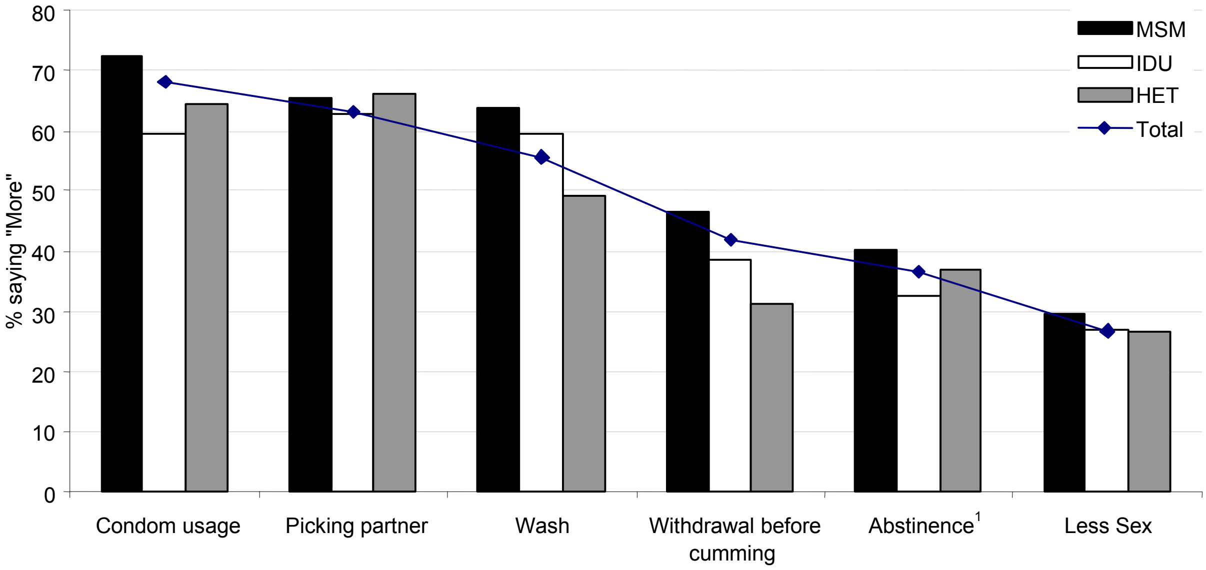
[25] Washing is not considered an effective way to prevent HIV infection and STDs, and care in choosing a partner by appearances without knowing their HIV status is not an effective prevention method.

American MSM and IDUs were more likely to report an increase in being more careful in choosing a partner than Anglo MSM or IDUs.

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 0-2, the rankings differed among risk groups.

Figure 0-2 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 0-3 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 0-4 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 0-3 Frequency of Using Condoms

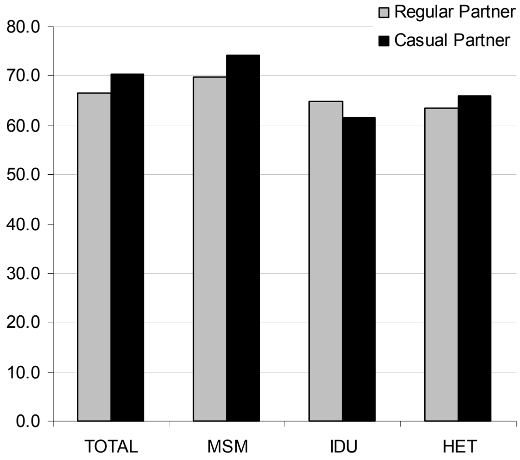
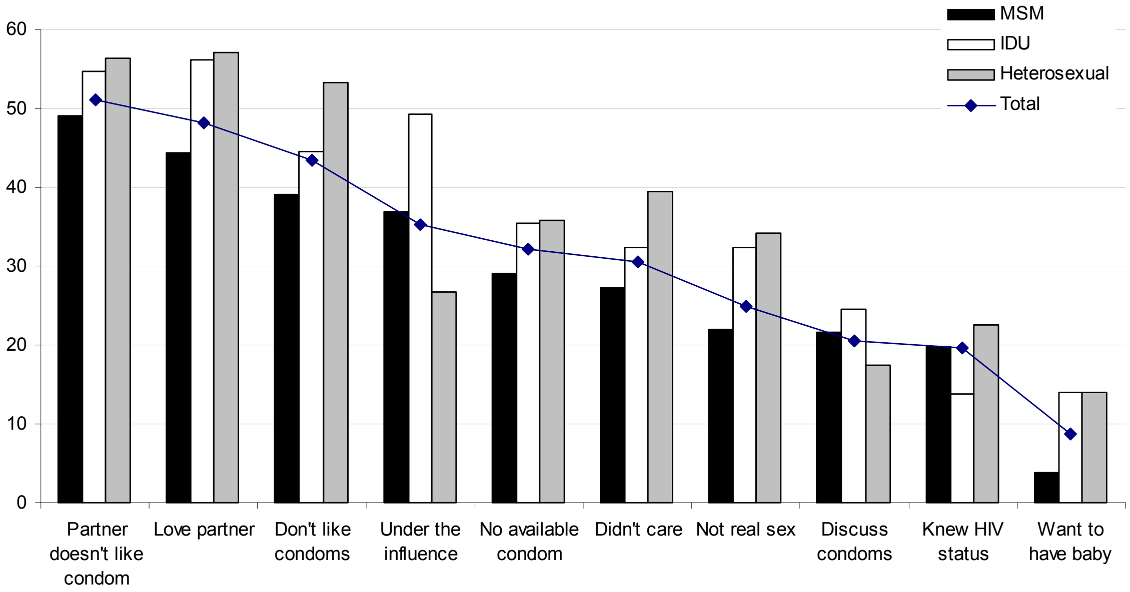


Figure 0-4 Reasons for Not Using Condoms

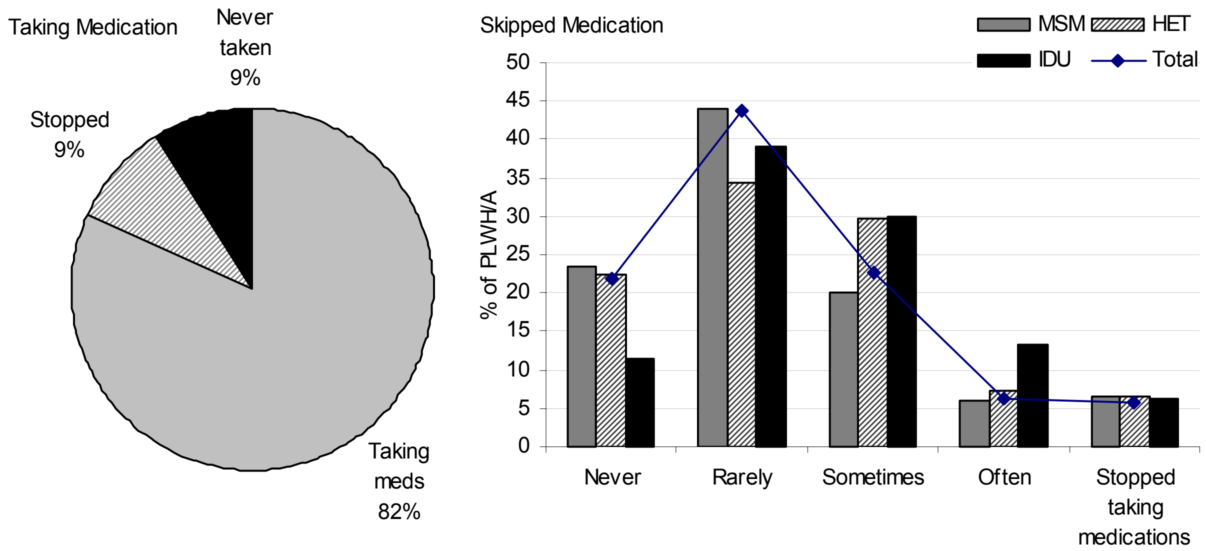


MEDICATION AND ADHERENCE

Medication

As shown in Figure 0-1, 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 18). This finding should be interpreted with caution because of the small sample size of 28 for Hispanic females.

Figure 0-1 Medications



For those taking medication, as shown in Figure 0-2 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 18 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 0-2 and

Figure 0-3, 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 0-2 Medication Taken by Risk Group

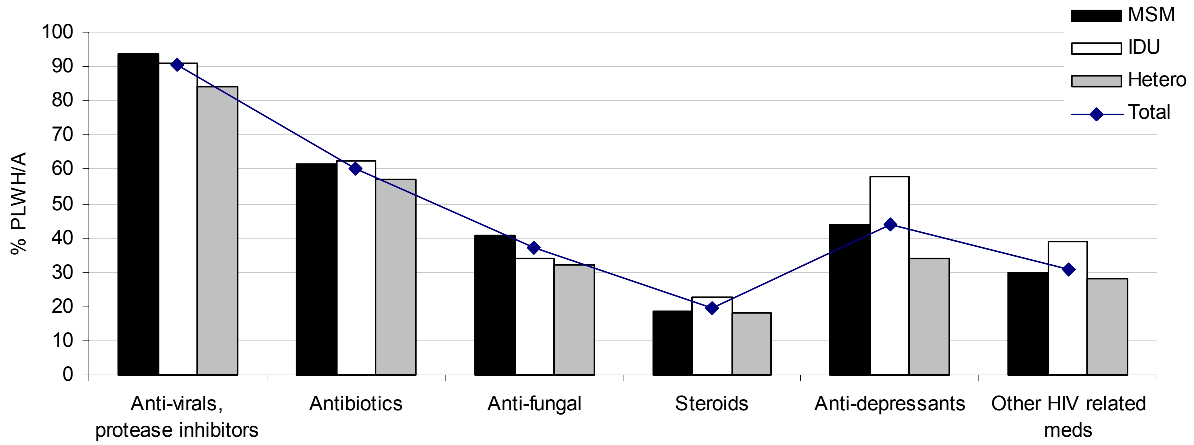
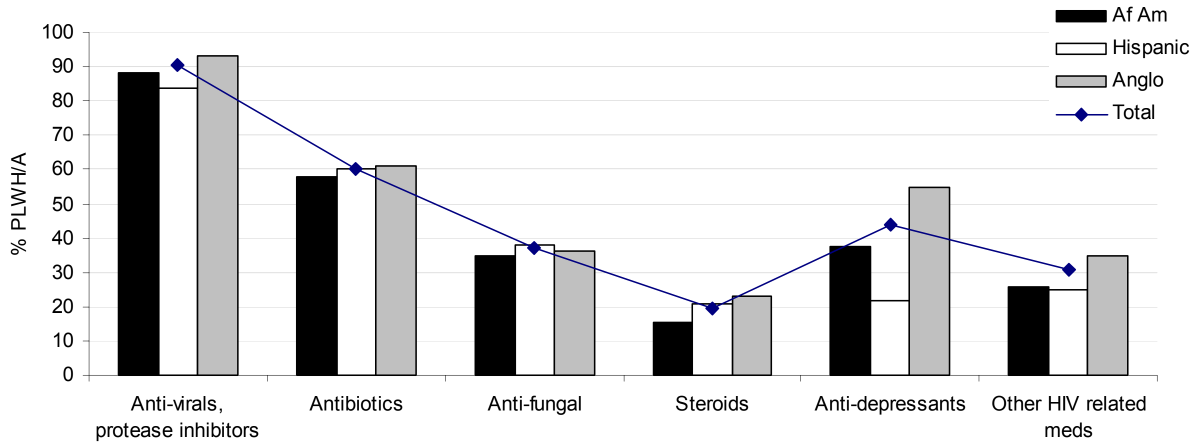


Figure 0-3 Medication Taken by Ethnicity



Adherence

- More than 70% of most subpopulations who took medication prescribed by their doctor report skipping the medication. As shown in Figure 0-1, over 40% skip their medication rarely and under 10% skip it often. As seen in Attachment 18, of those who skip their medication, over 80% of the participants skipped or stopped taking medication without the advice of a doctor.
- Figure 0-4 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 0-5, 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 0-4 Reasons for Stopping Meds by Risk Group

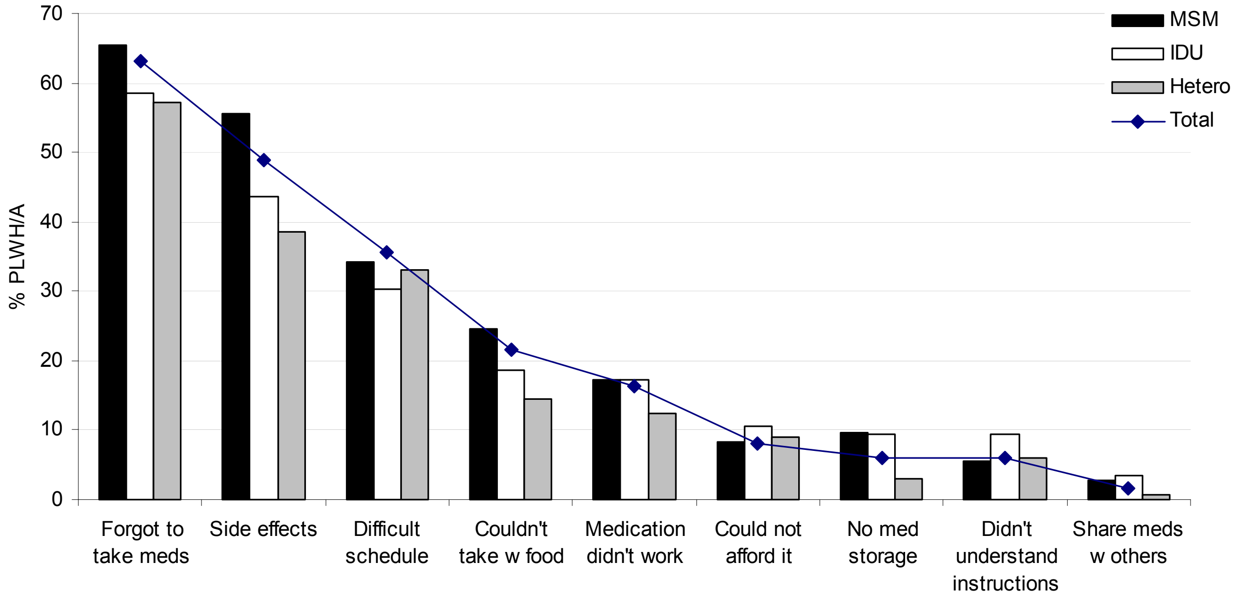
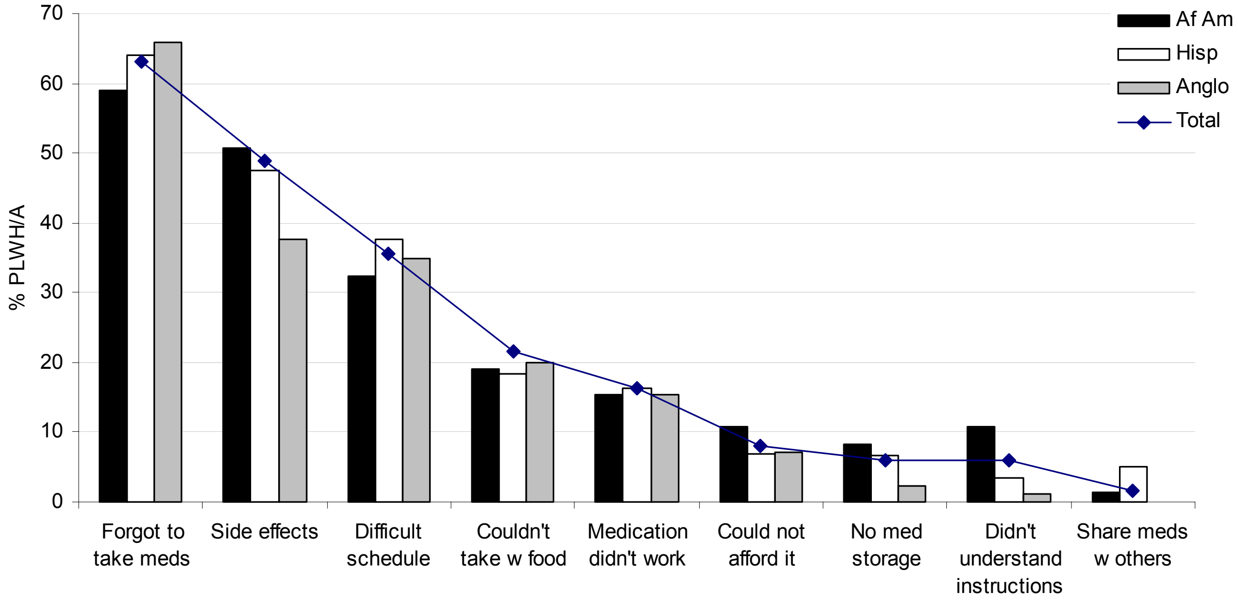


Figure 0-5 Reasons for Stopping Meds by Ethnicity



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 0-6, 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 0-7 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 0-8 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 0-6 Serious Side Effects by Stage of Infection

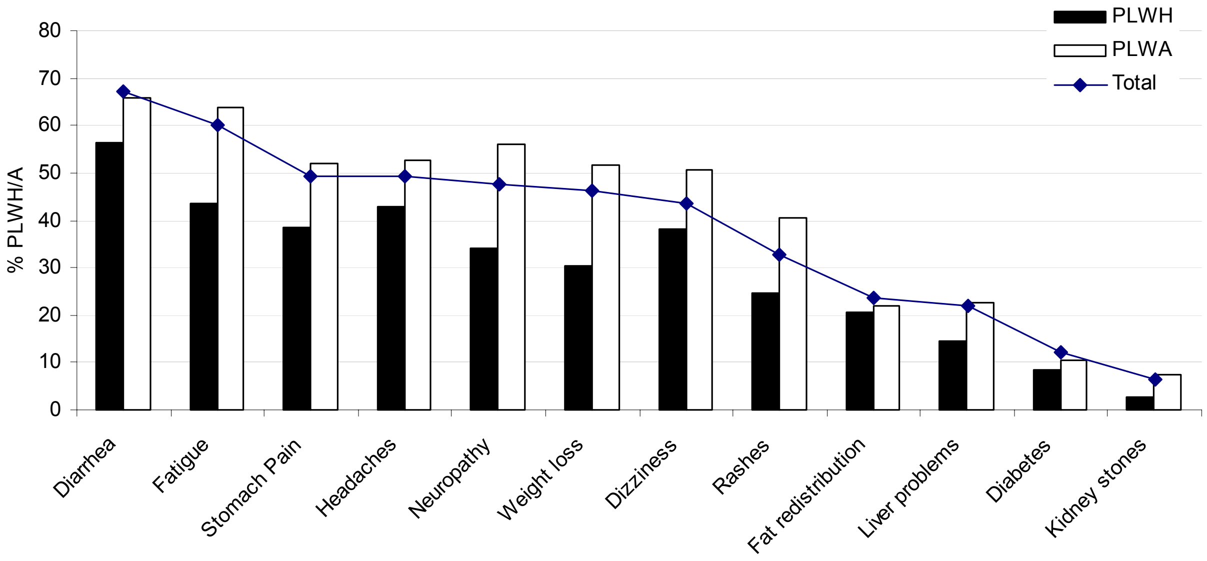


Figure 0-7 Serious Side Effects by Risk Group

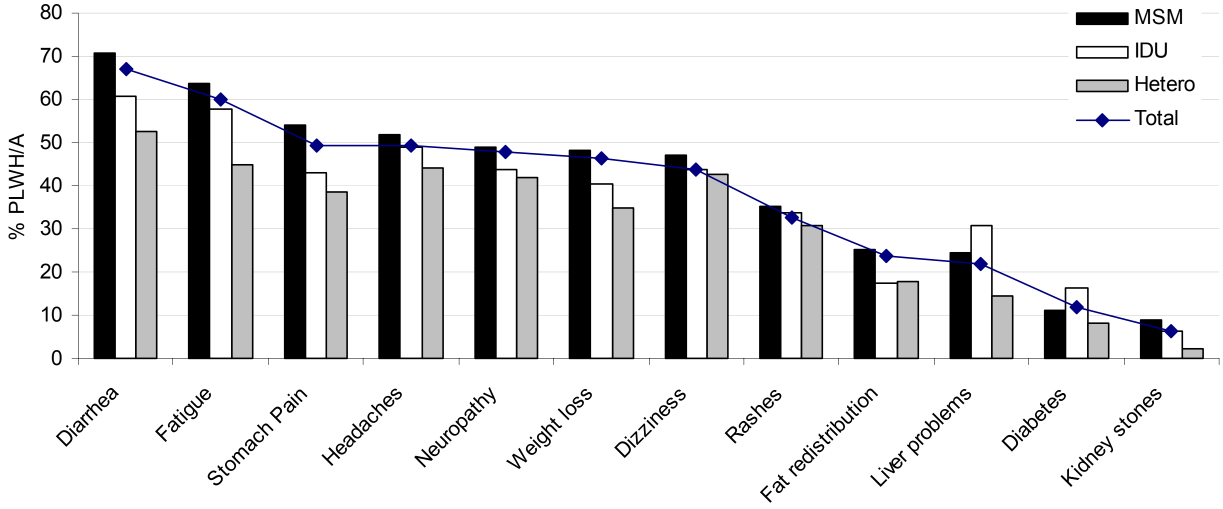
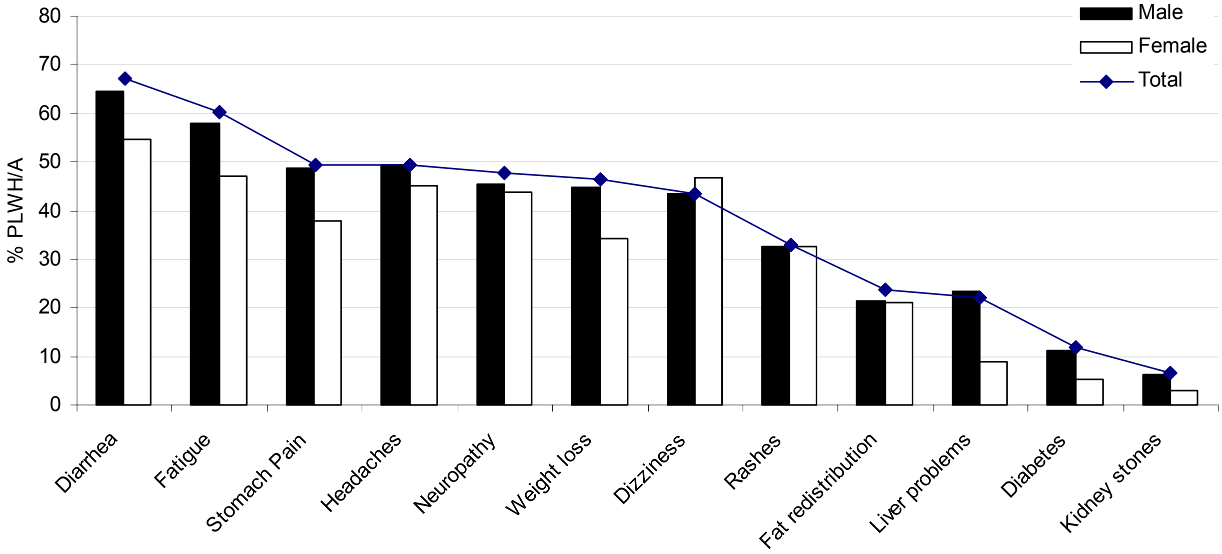


Figure 0-8 Serious Side Effects by Gender

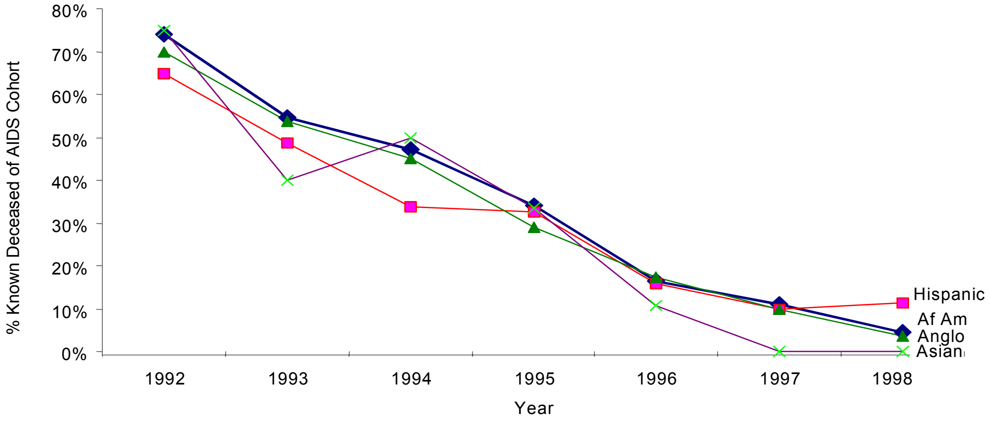


OUTCOMES

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 0-1 shows that the fatality rates have declined among all ethnic groups at about the same pace for those persons in care[26]. 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 0-1 % Deceased by Year of People with AIDS in a Cohort Tracked by TDH



Unfortunately, as shown in Figure 0-2 for all deaths, there is an indication that African Americans are dying at a considerably higher rate from AIDS than Anglos or Hispanics.[27] 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.

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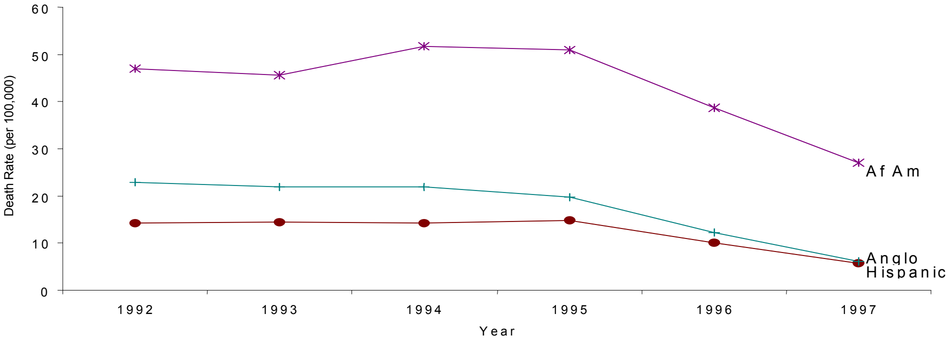
[26] These refer to those persons in care in the TDH cohort. *

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

Figure 0-2 HIV/AIDS Deaths by Ethnicity per 100,000 of Houston Area Population



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 0-3 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 0-4 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 0-3 Quality of Life - Physical Health

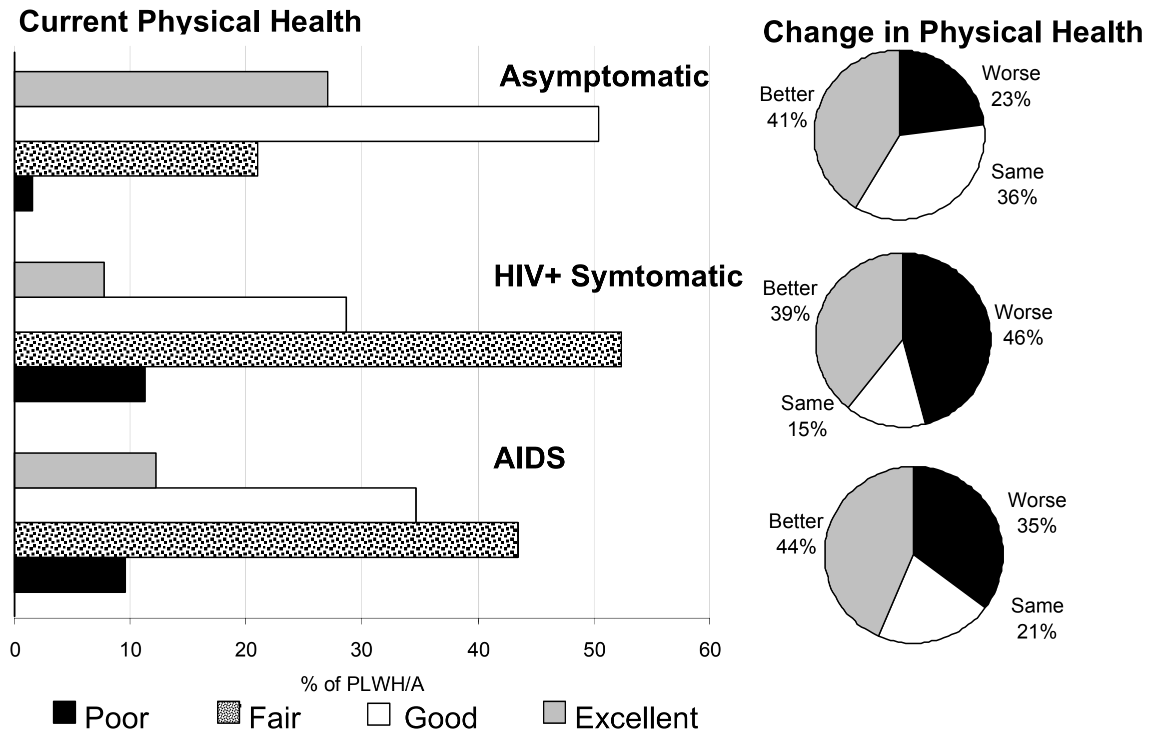
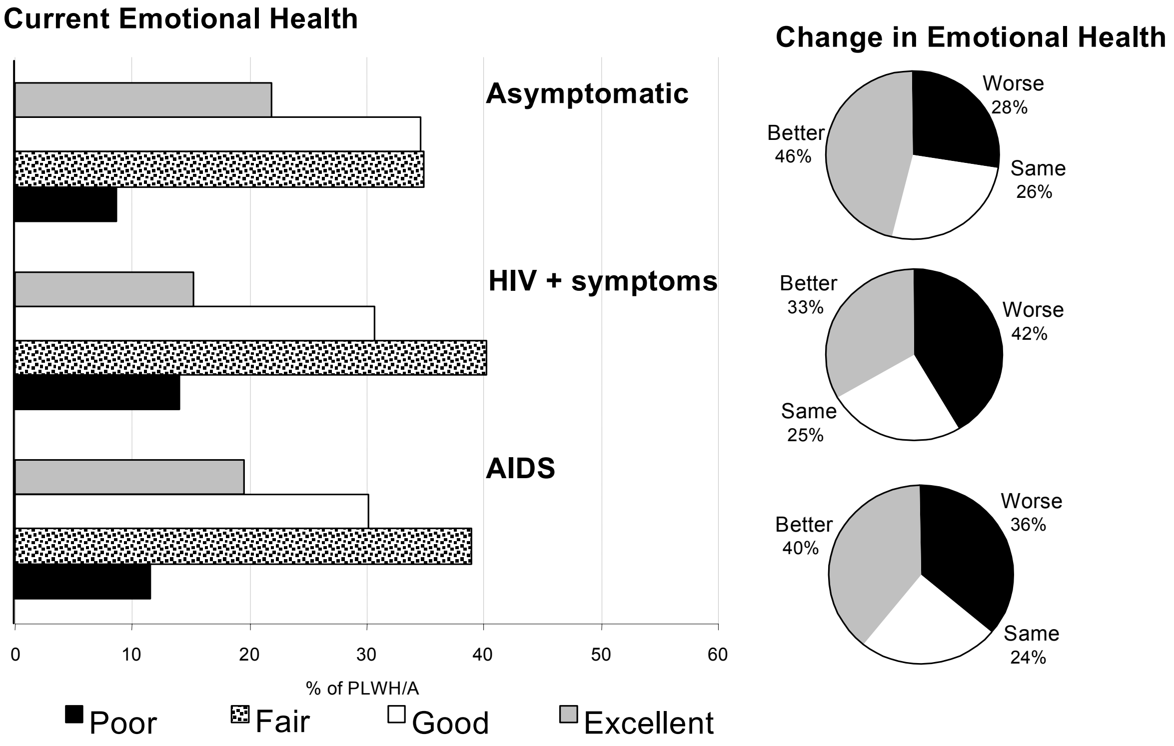


Figure 0-4 Quality of Life - Emotional Health



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 21 through Attachment 28. 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 not 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.

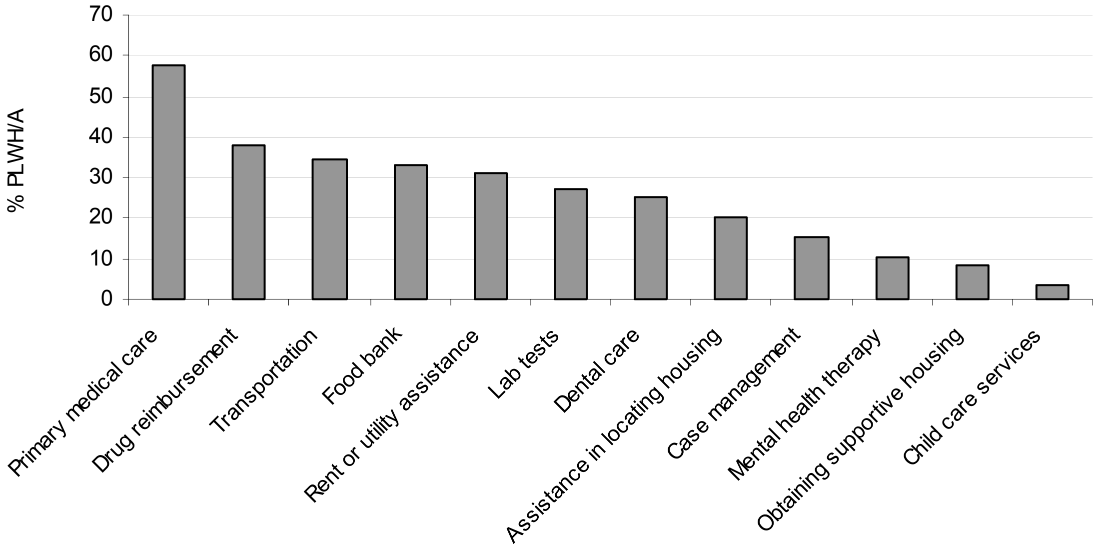
In reading these remarks it is important to remember that the statistical evidence shows a high level of satisfaction with and access to the system of care. There are many instances where PLWH/A have used the system very successfully. For example, P31, an Anglo IDU male, said, *"I've got my glasses through [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 0-1.

Figure 0-1 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.

Transportation FG Comments

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 0-2 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 0-2, 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 0-3 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 0-4 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 0-5 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 0-6 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 0-7 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 0-8 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 0-8, 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 0-9 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 0-2 Top 10 Service Needs - Total Sample Compared to Risk Groups

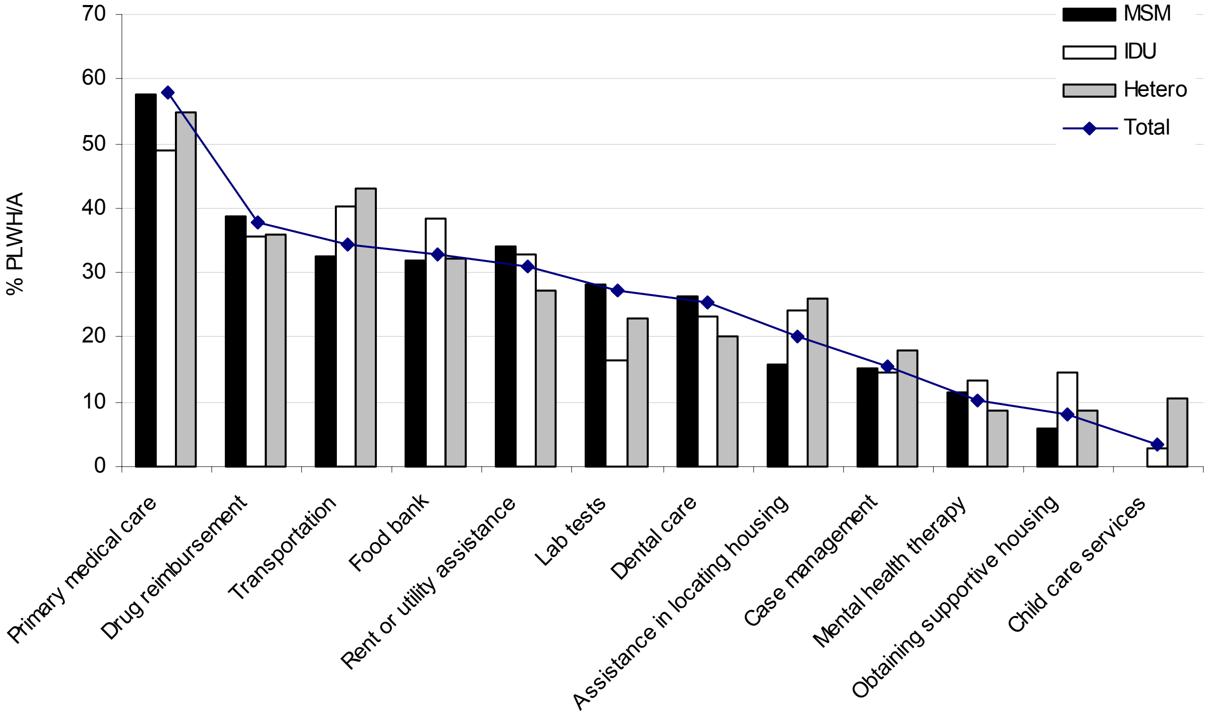


Figure 0-3 Top 10 Service Needs by Ethnicity

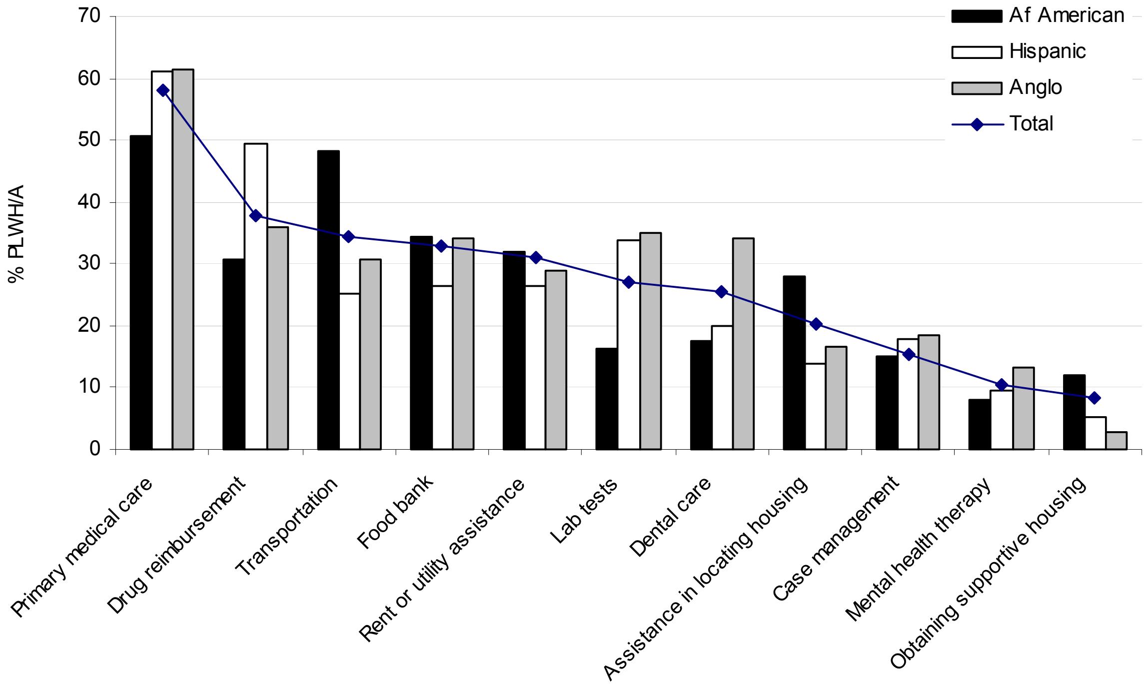


Figure 0-4 Top 10 Service Needs by Sex

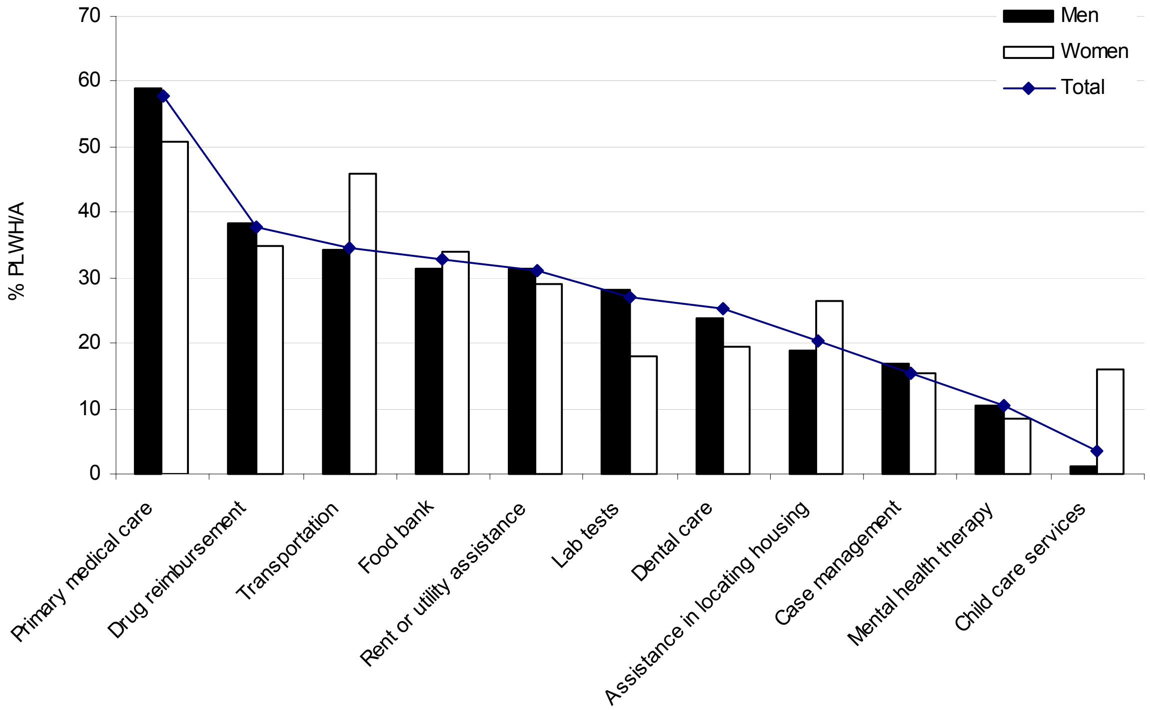


Figure 0-5 Top 10 Service Needs by Urban/Rural

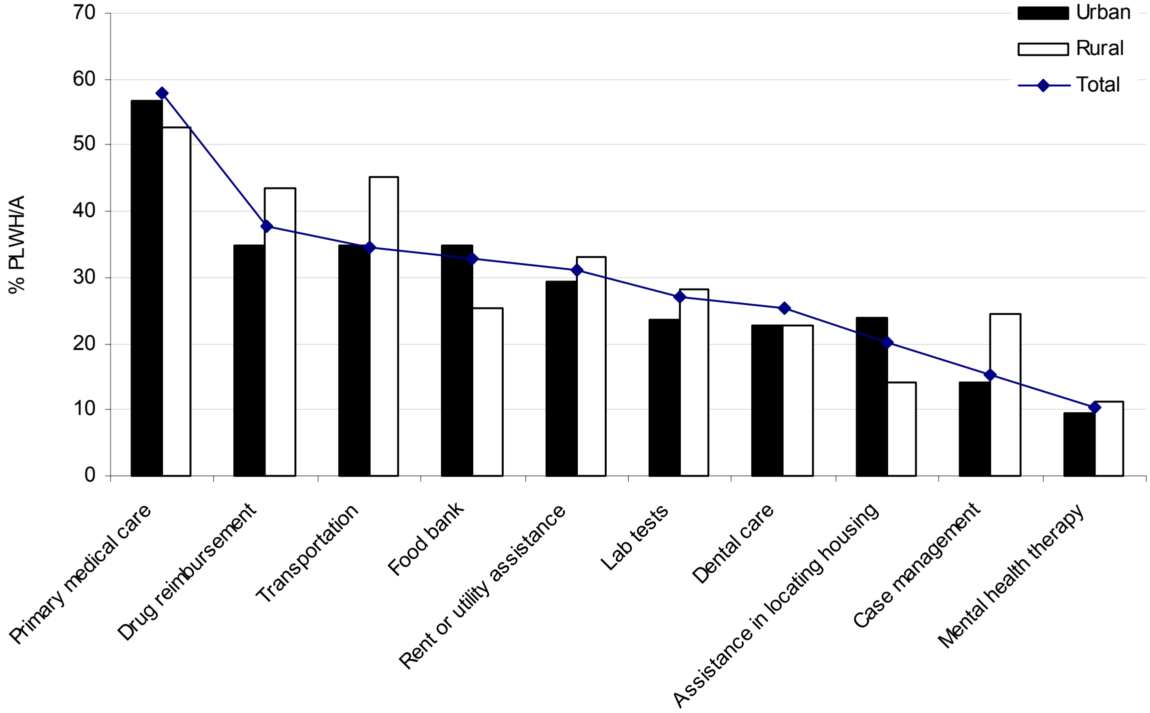


Figure 0-6 Top 10 Needs by Disease Progression

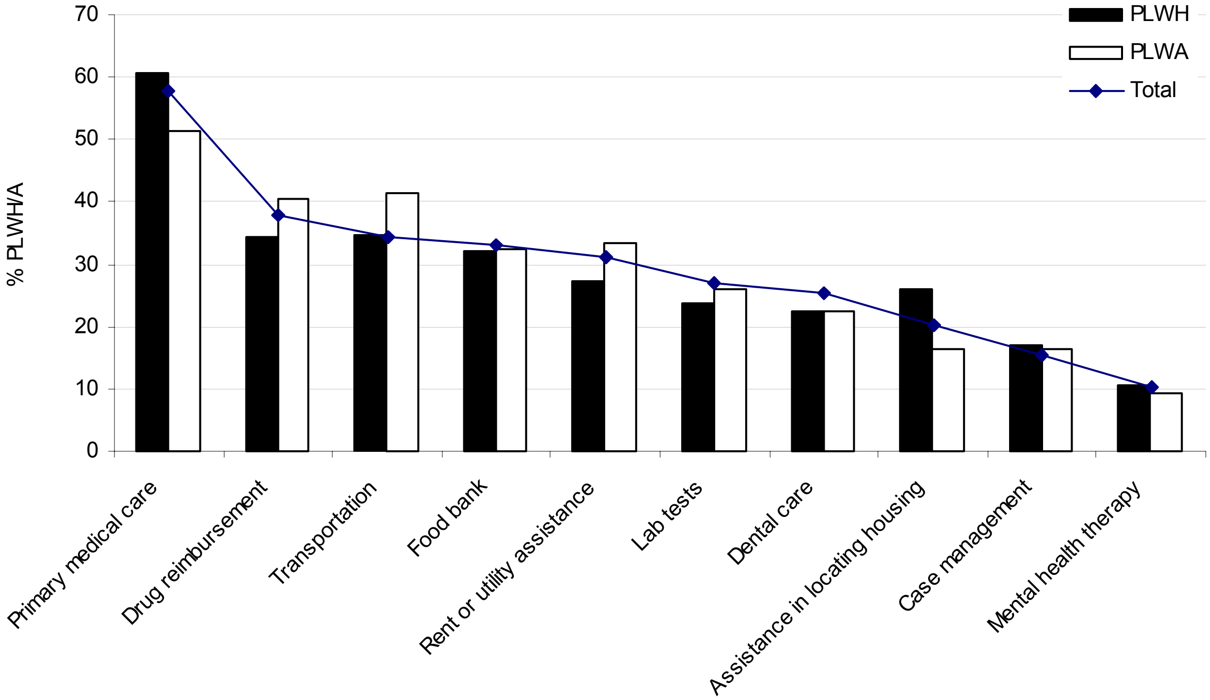


Figure 0-7 Top 10 Needs by Prison Status

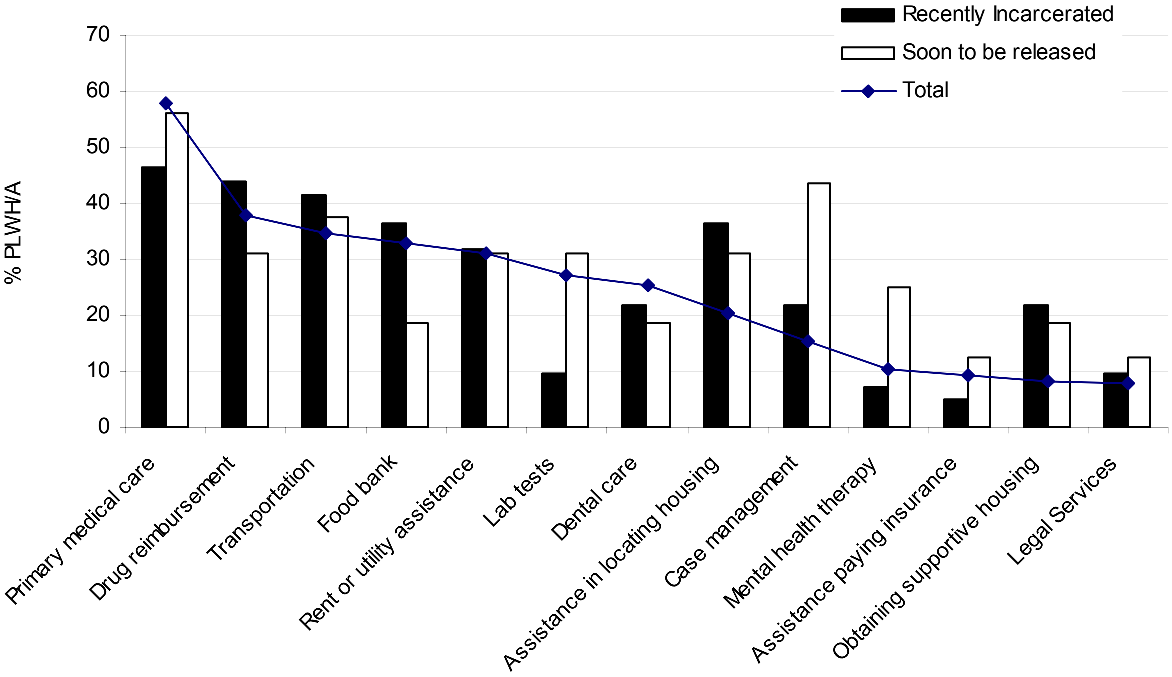


Figure 0-8 Top 10 Needs for Families w/ HIV+ Children and PLWH/A with Children

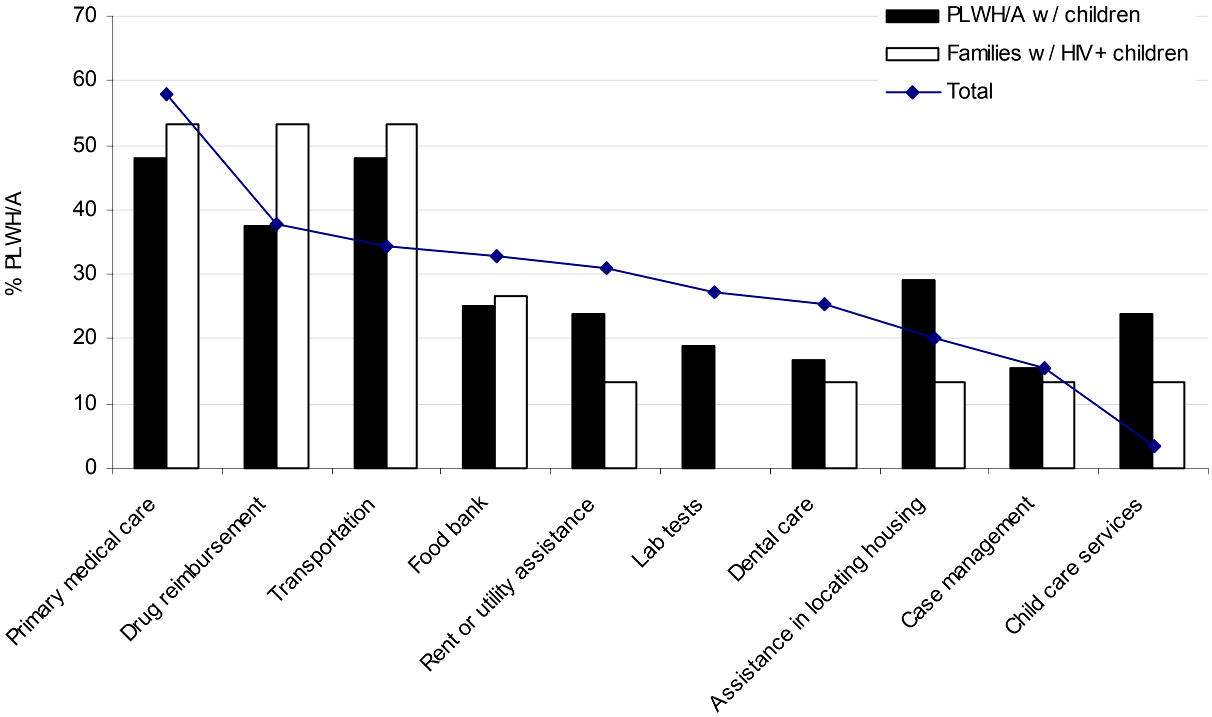
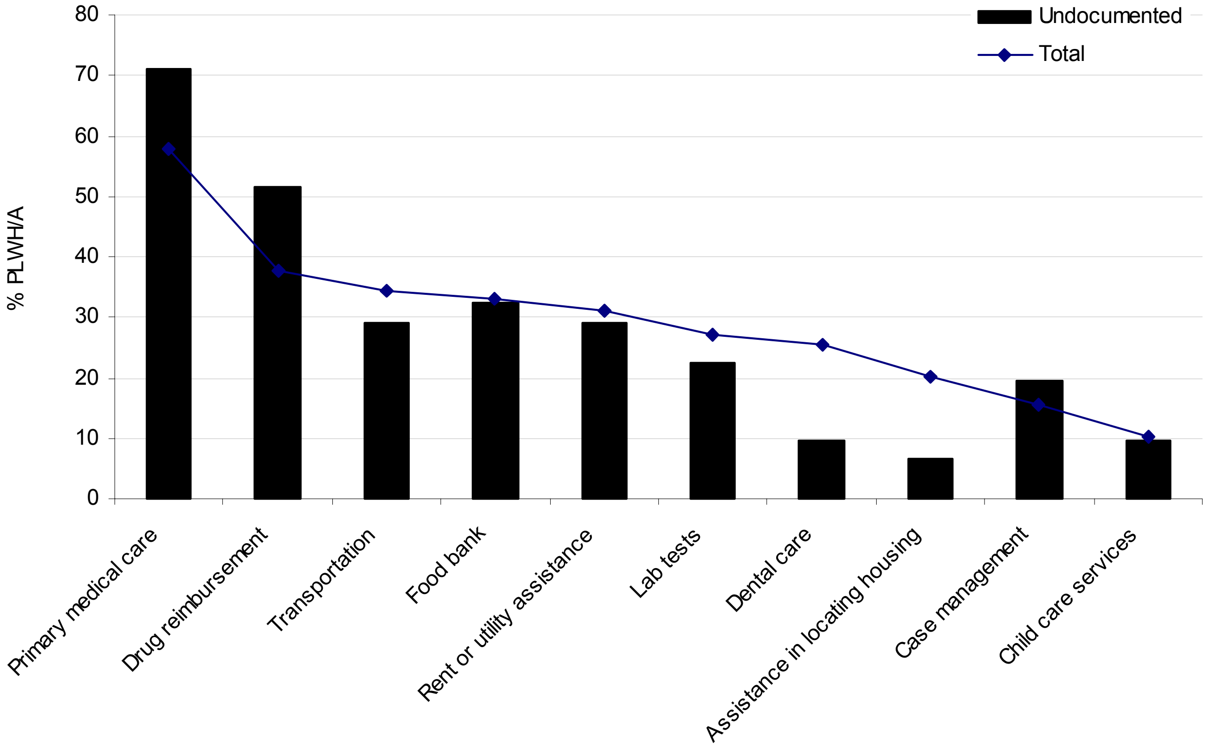


Figure 0-9 Top 10 Needs of Undocumented



Summary of Top Needs

Table 0-1 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 0-1 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 0-10 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 21.3), 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.

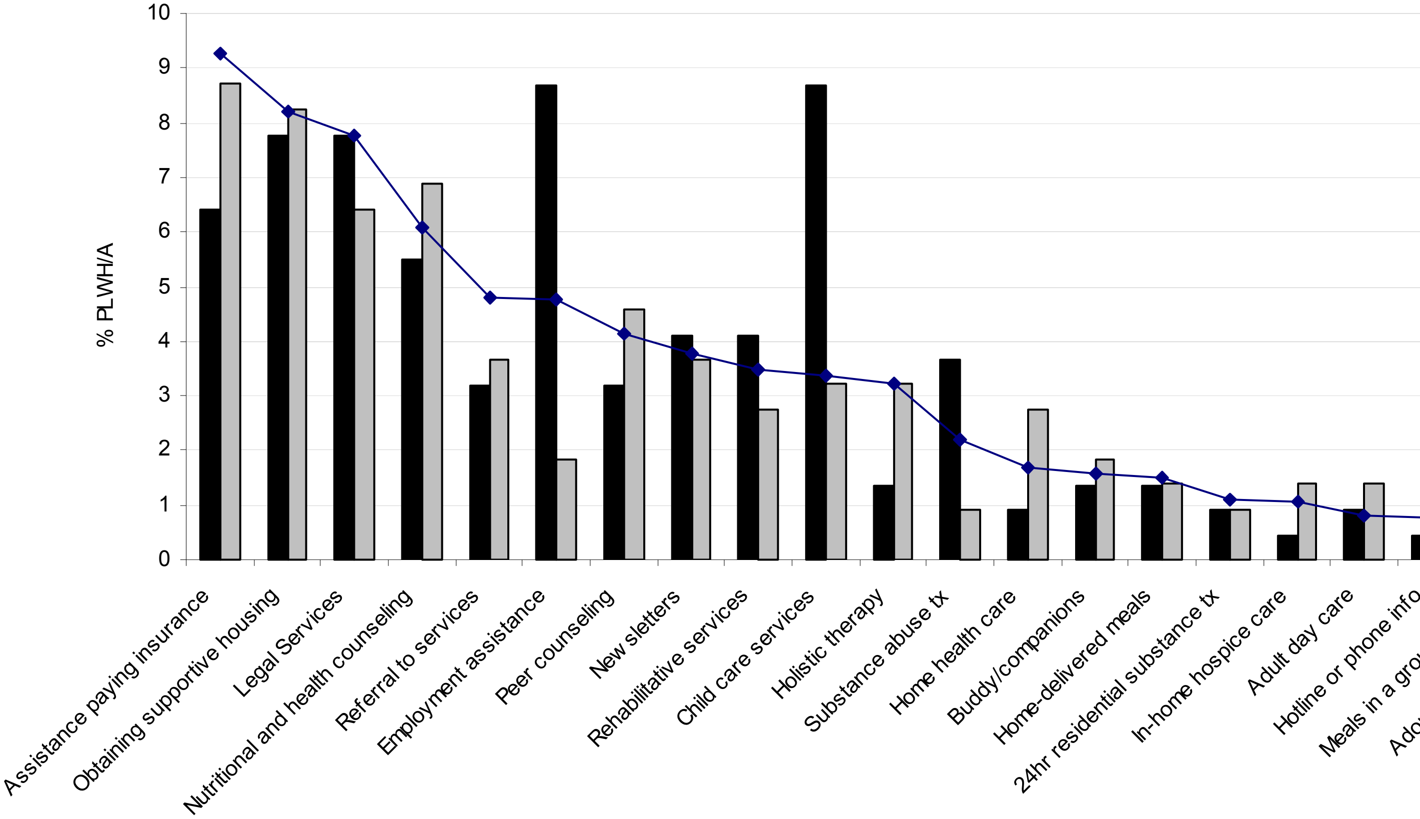


Figure 0-10 Ranking of Lesser Needs - Total Population

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.[28] This lower need is not surprising, since fewer PLWH/A are progressing to the end-stage of the illness. However, as shown in Figure 0-11 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.

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[28] 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.

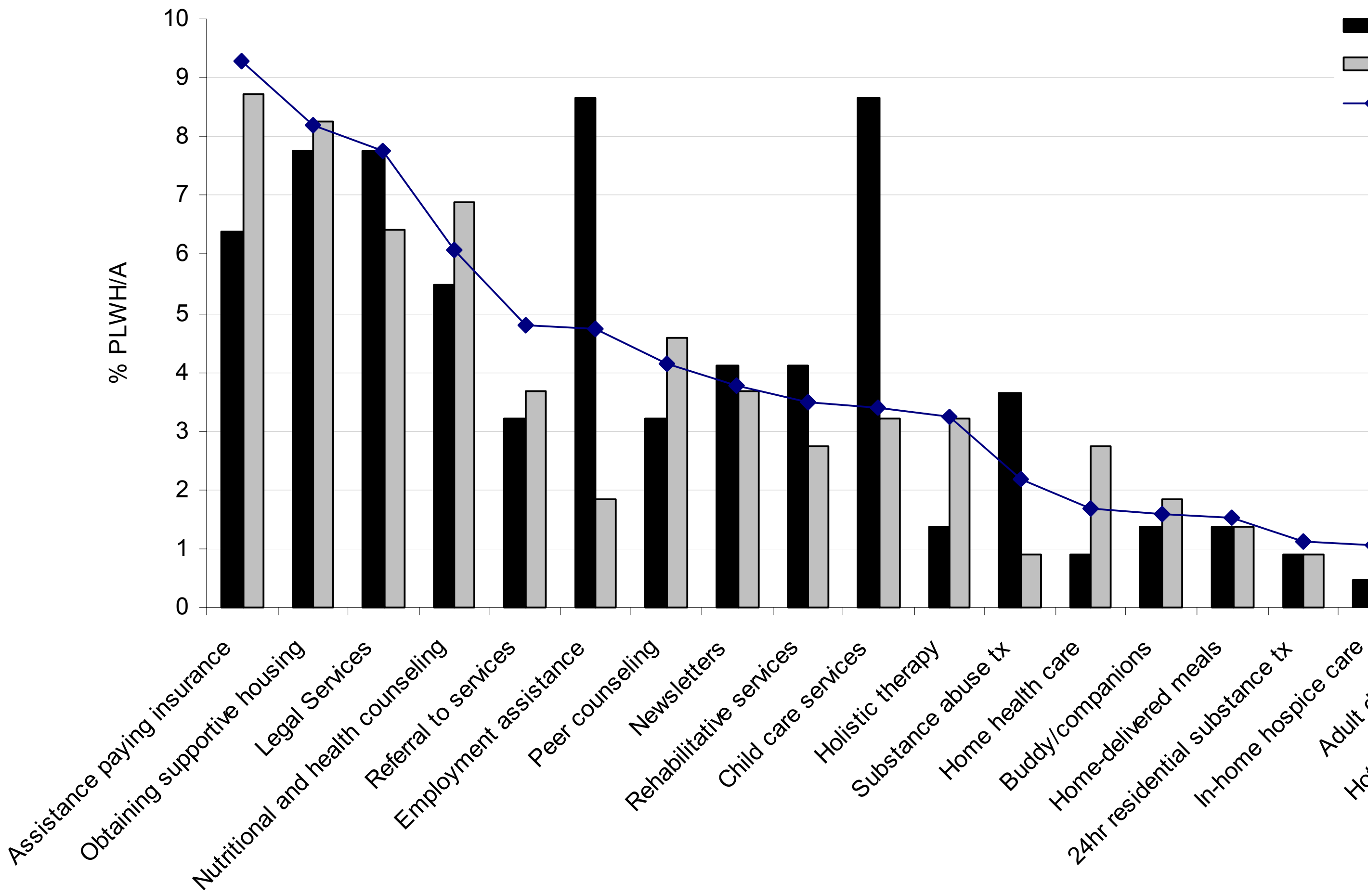
In the focus groups there are few comments on services for end stage illnesses. In part participants are not likely to come from hospice or adult day care, and consequently they had fewer experiences with end stage services. The few comments about end stage services were largely positive.

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 0-11 Ranking of Needs - Disease Progression



Service Awareness, Demand and Utilization

Service awareness, demand, and utilization are presented in Attachment 17-Attachment 19. In looking at these attachments, the percentages can be compared amongst the different target groups. For example, in Attachment 17.1, 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 17.1 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 18.1 through Attachment 18.3 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 19.1 through Attachment 19.3 display the percentage of those who have ever received the services. Attachment 20.1 through Attachment 20.3 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 0-12 and Figure 0-17 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 0-12, 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

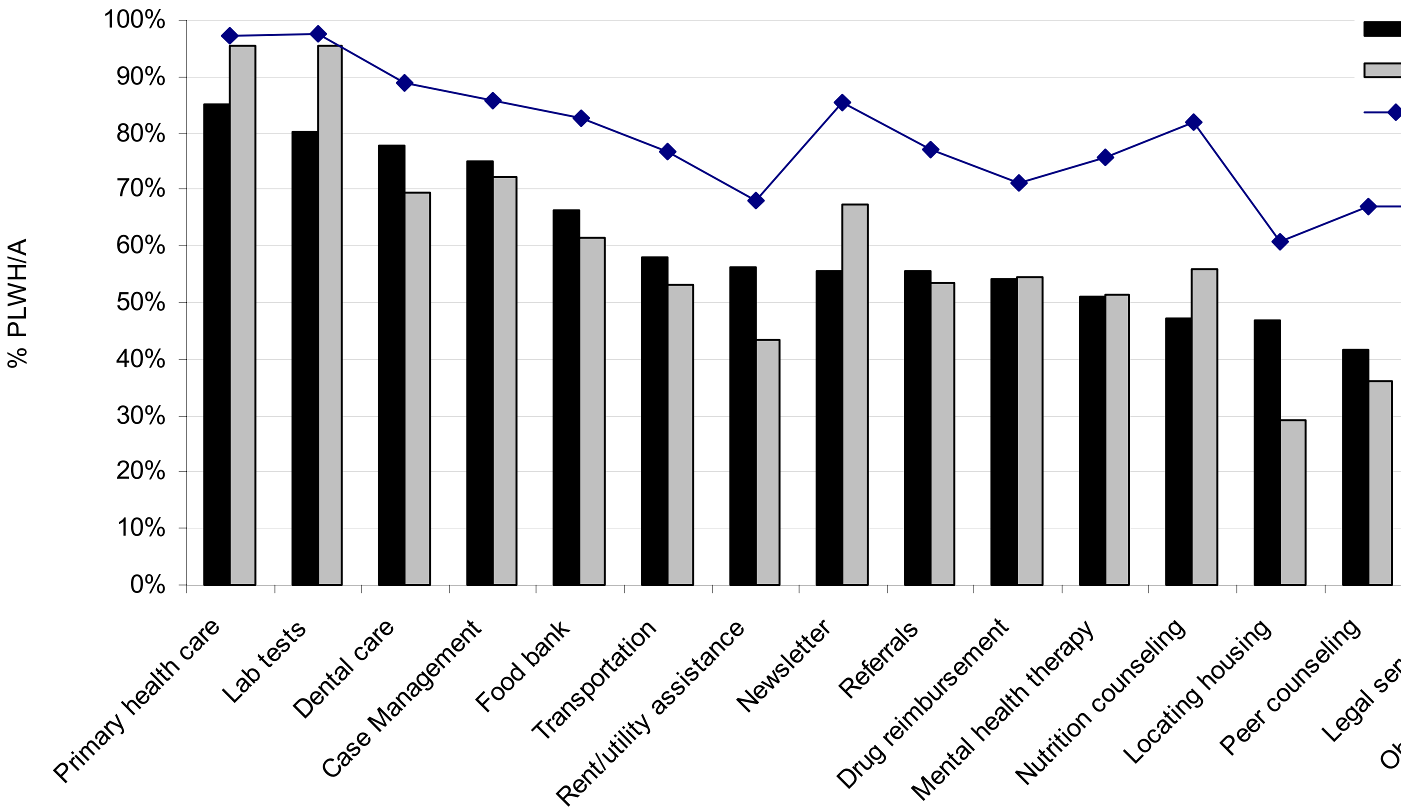
Similarly about three-quarters of PLWH/A were aware of mental health therapy and slightly over 50% seek and/or receive the service. While Anglo females tend to be more aware of this service (91%), Hispanic females were less aware (64%) than the other subpopulations of PLWH/A. Anglo women were also the 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 0-12 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). 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 0-13, 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 0-14 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 0-13 Total Sample Demand- Utilization Gap: Top 16 Services

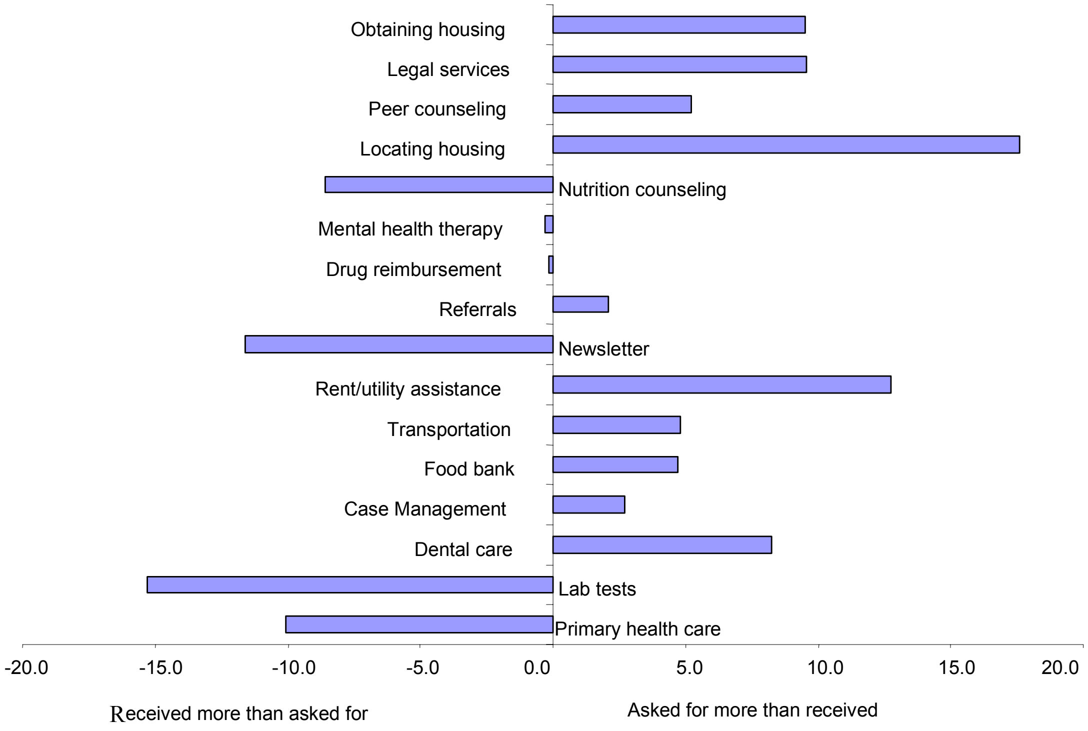


Figure 0-14 Demand Utilization Gap by Risk Group- First 16 Services

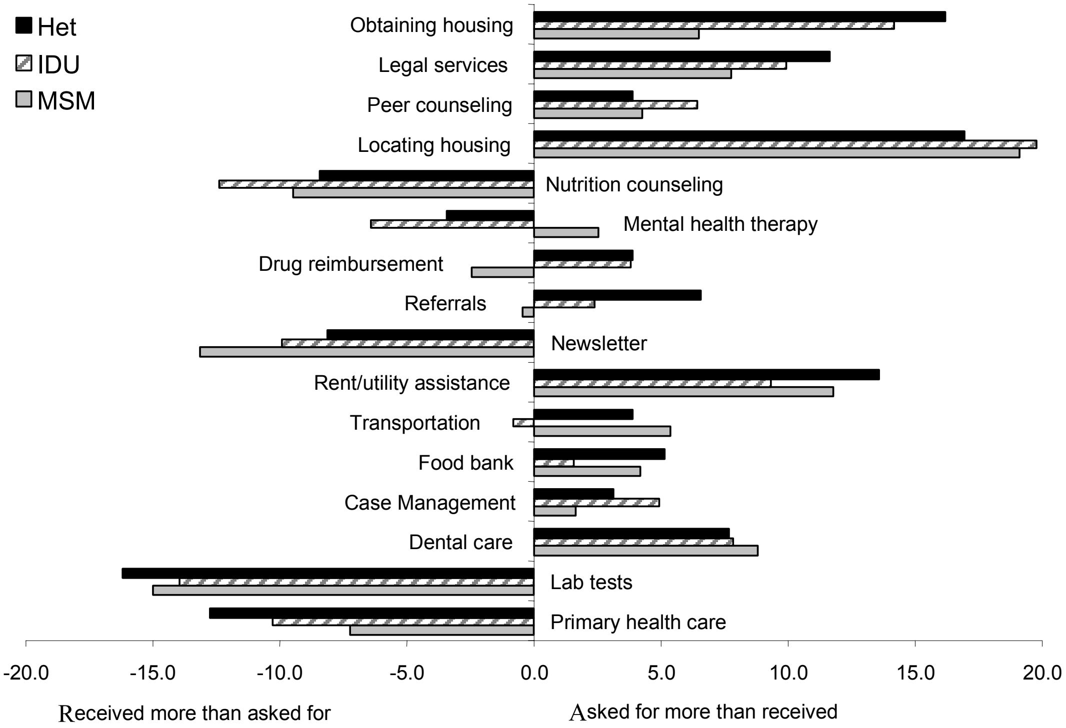


Figure 0-15 Demand Utilization Gap by Ethnicity - First 16 Services

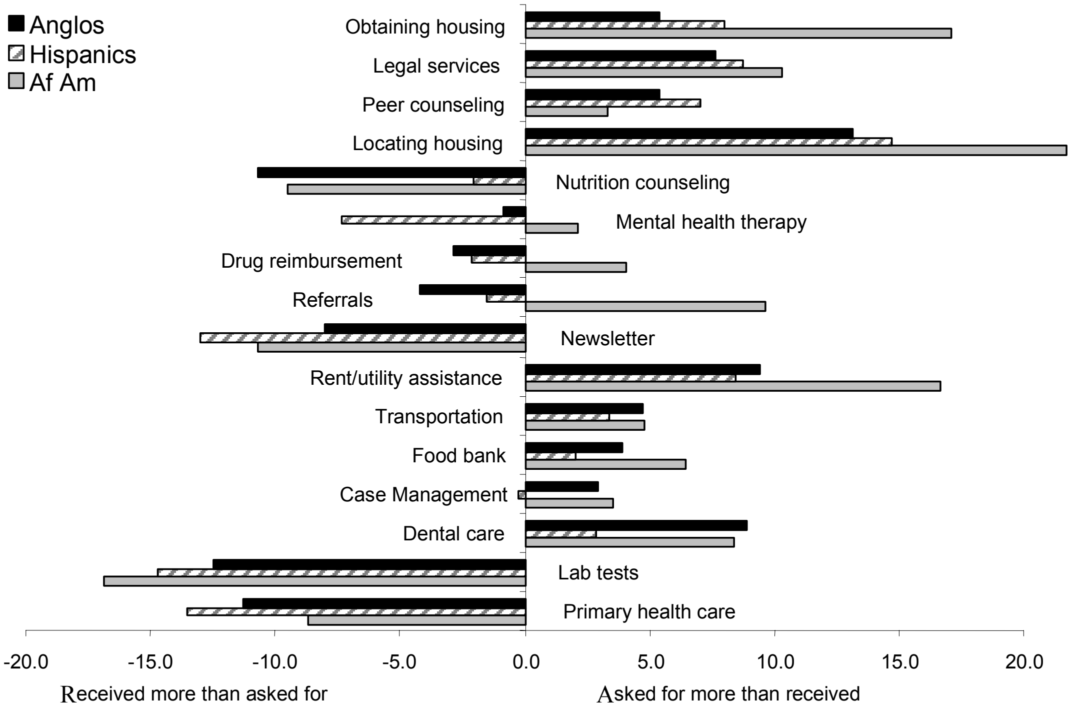
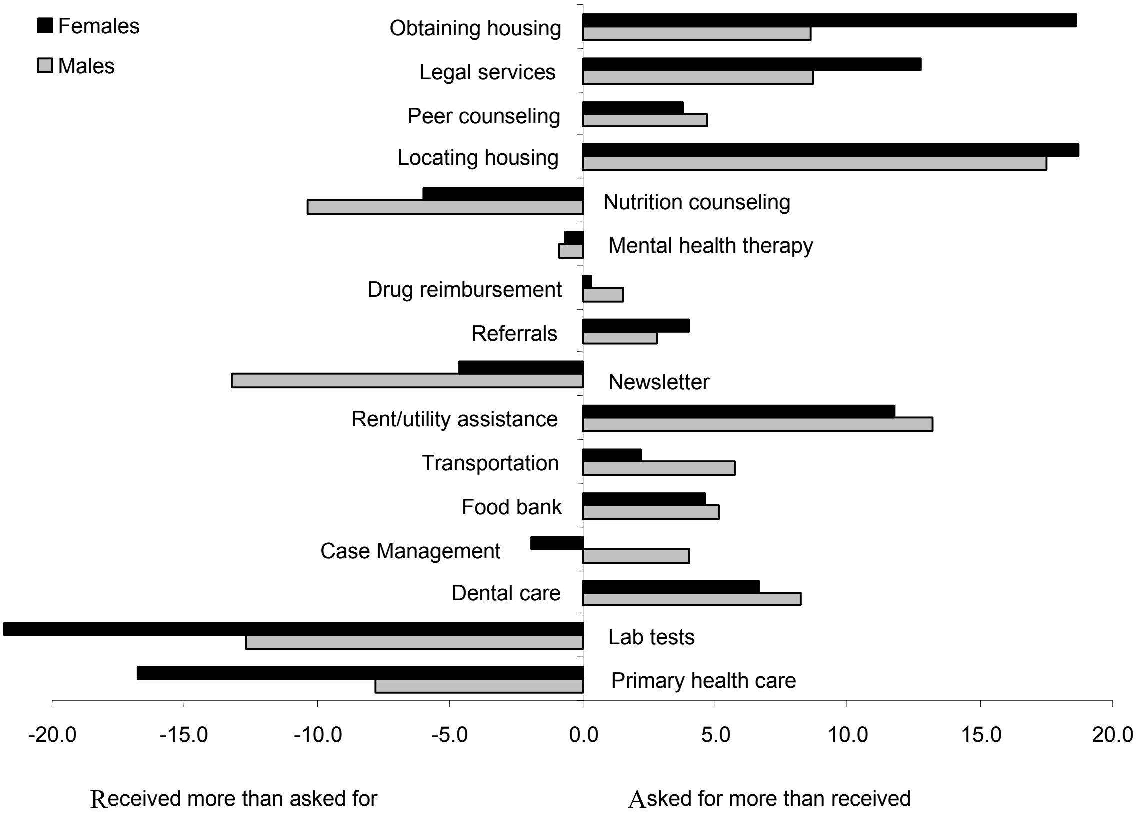


Figure 0-16 Demand Utilization Gap by Gender- First 16 Services



Services Less Demanded and Utilized

Figure 0-17 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 0-18 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 0-18, group meals, out-of-home substance abuse treatment, and hotline services were received by PLWH/A more than they were solicited.

Figure 0-19 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 0-20 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 0-21 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 17, Attachment 18, and Attachment 19 there were some notable differences between subpopulations for awareness and demand.

Figure 0-17 Services Awareness, Demand, and Utilization -Last 16

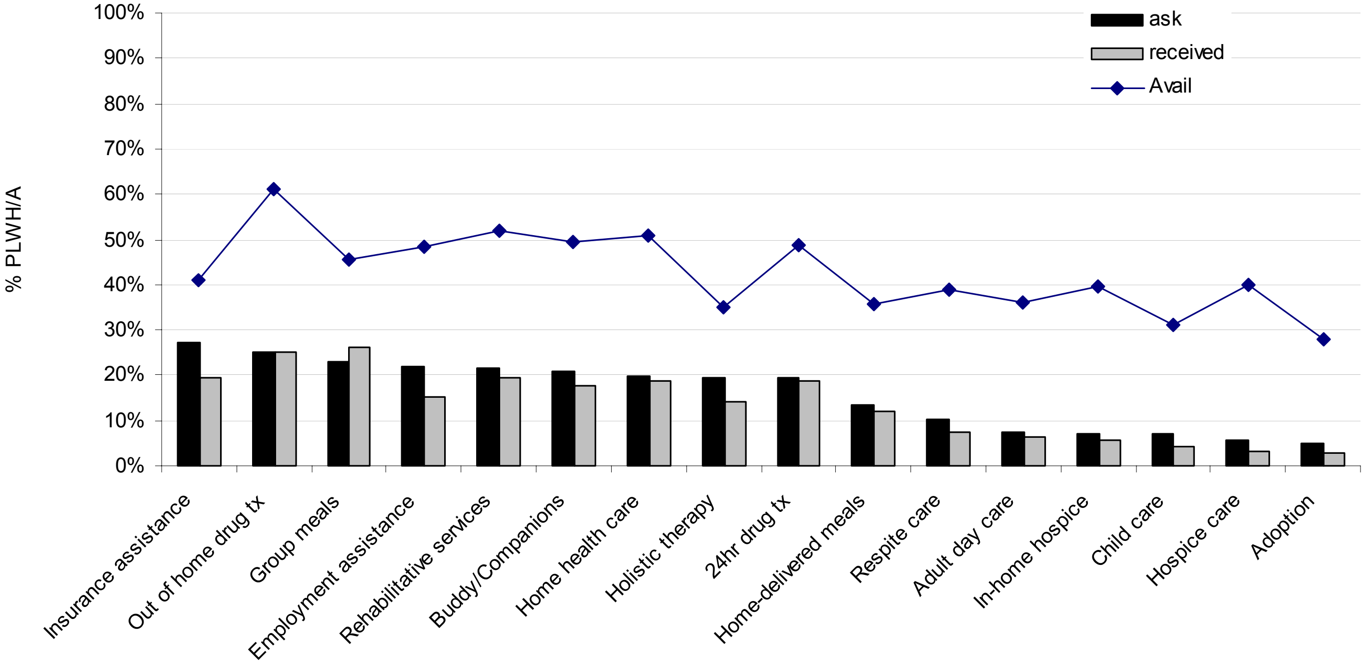


Figure 0-18 Total Sample Demand Utilization Gap - Last 17 Services

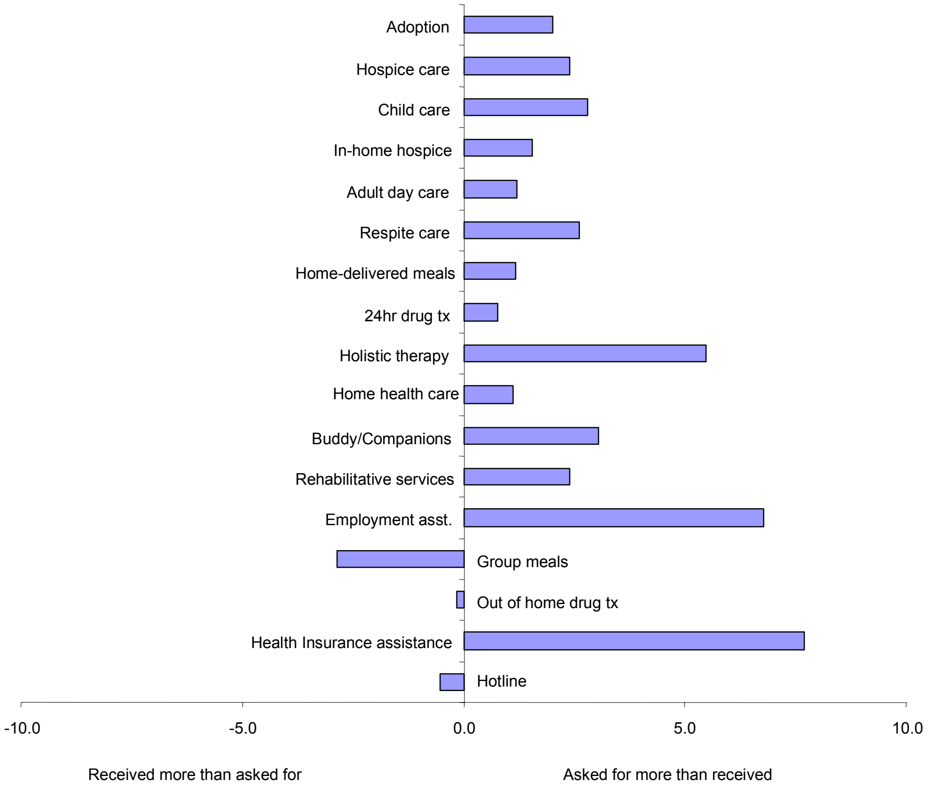


Figure 0-19 Demand Utilization Gap by Risk Group- Last 17 Services

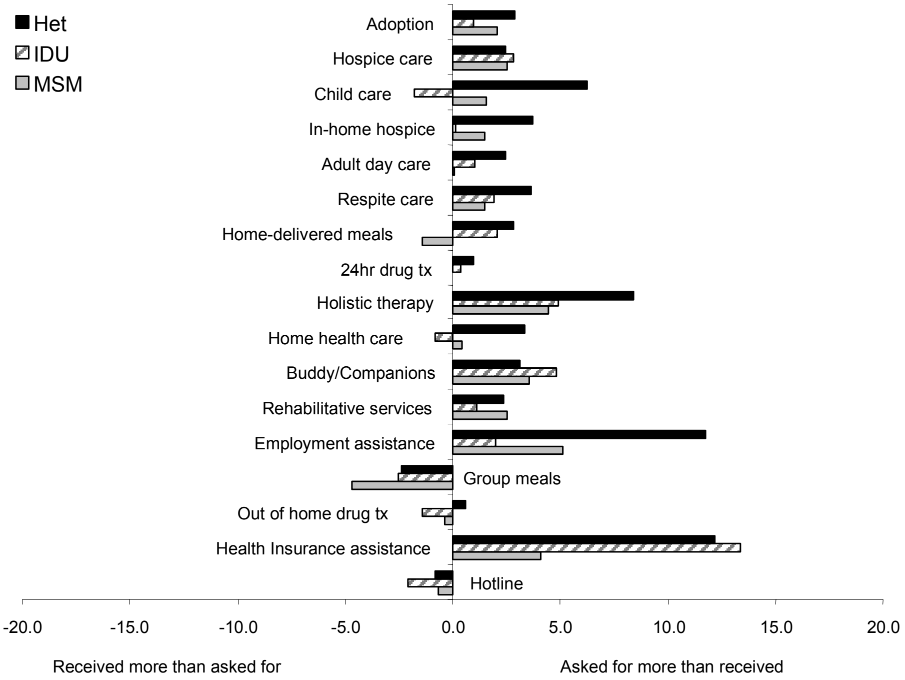


Figure 0-20 Demand Utilization Gap by Ethnicity - Last 17 Services

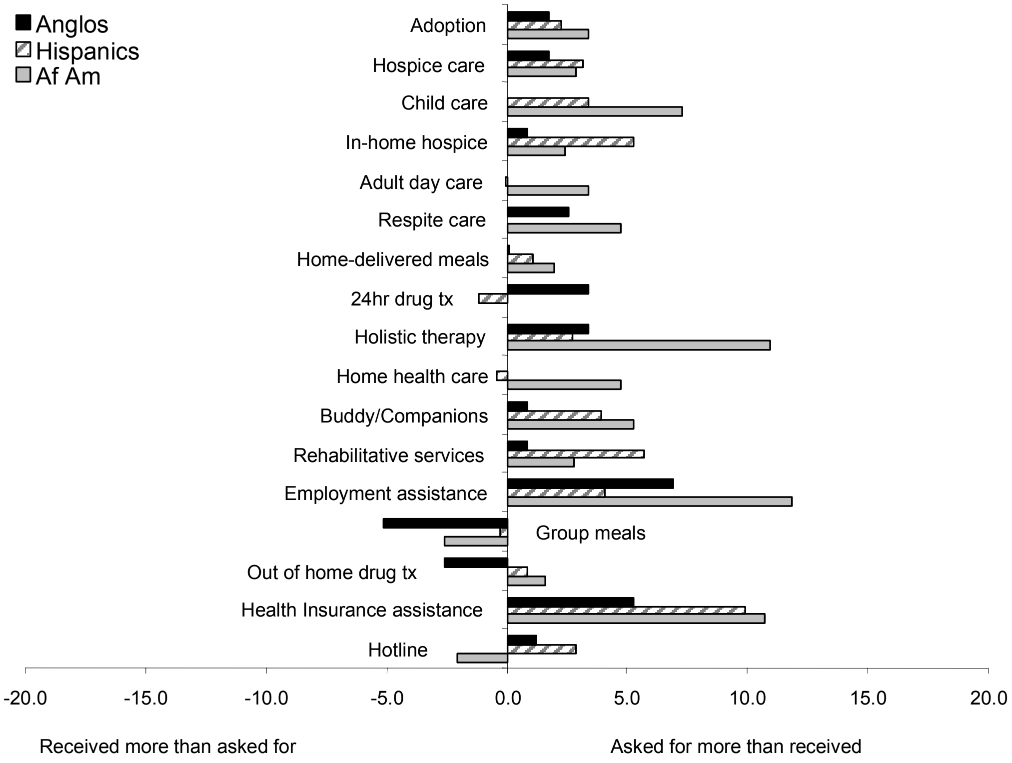
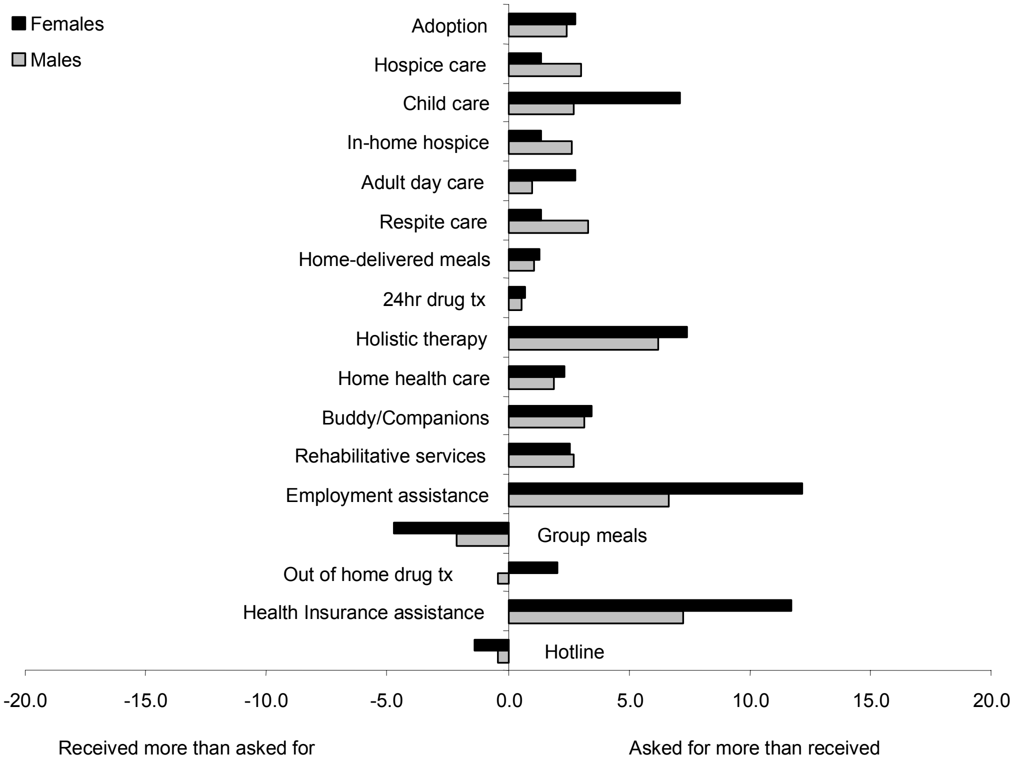


Figure 0-21 Demand Utilization Gap by Gender- Last 17 Services



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 21 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 21 consists of a series of three tables showing the satisfaction scores for different subpopulations.

The series of tables in Attachment 22 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 0-22 and Figure 0-23 display the perceived access and satisfaction with services. Figure 0-22 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 0-23 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 0-22 and the corresponding Attachment 21 and Attachment 22 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 0-22 and Figure 0-23 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 0-22 Access and Satisfaction with Services - Top 17

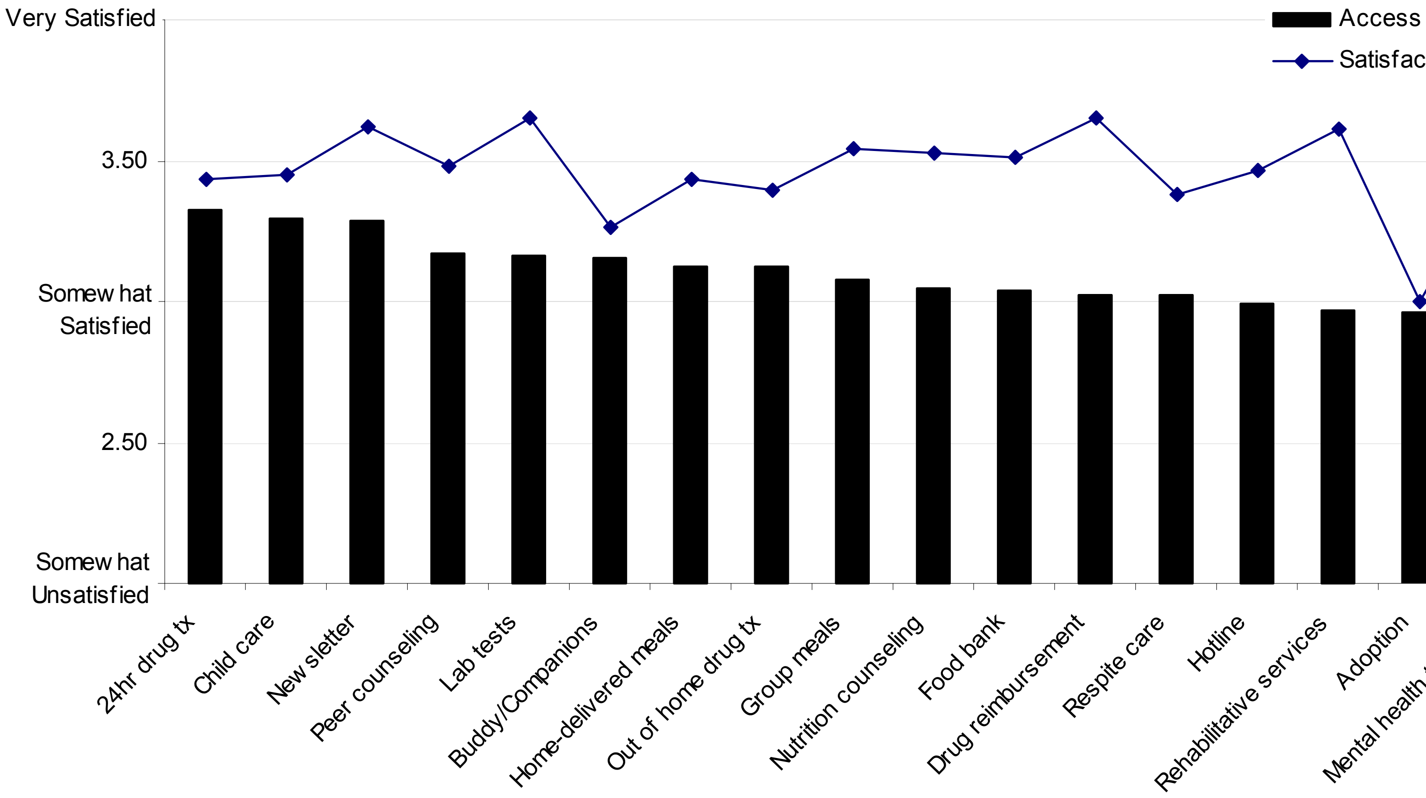
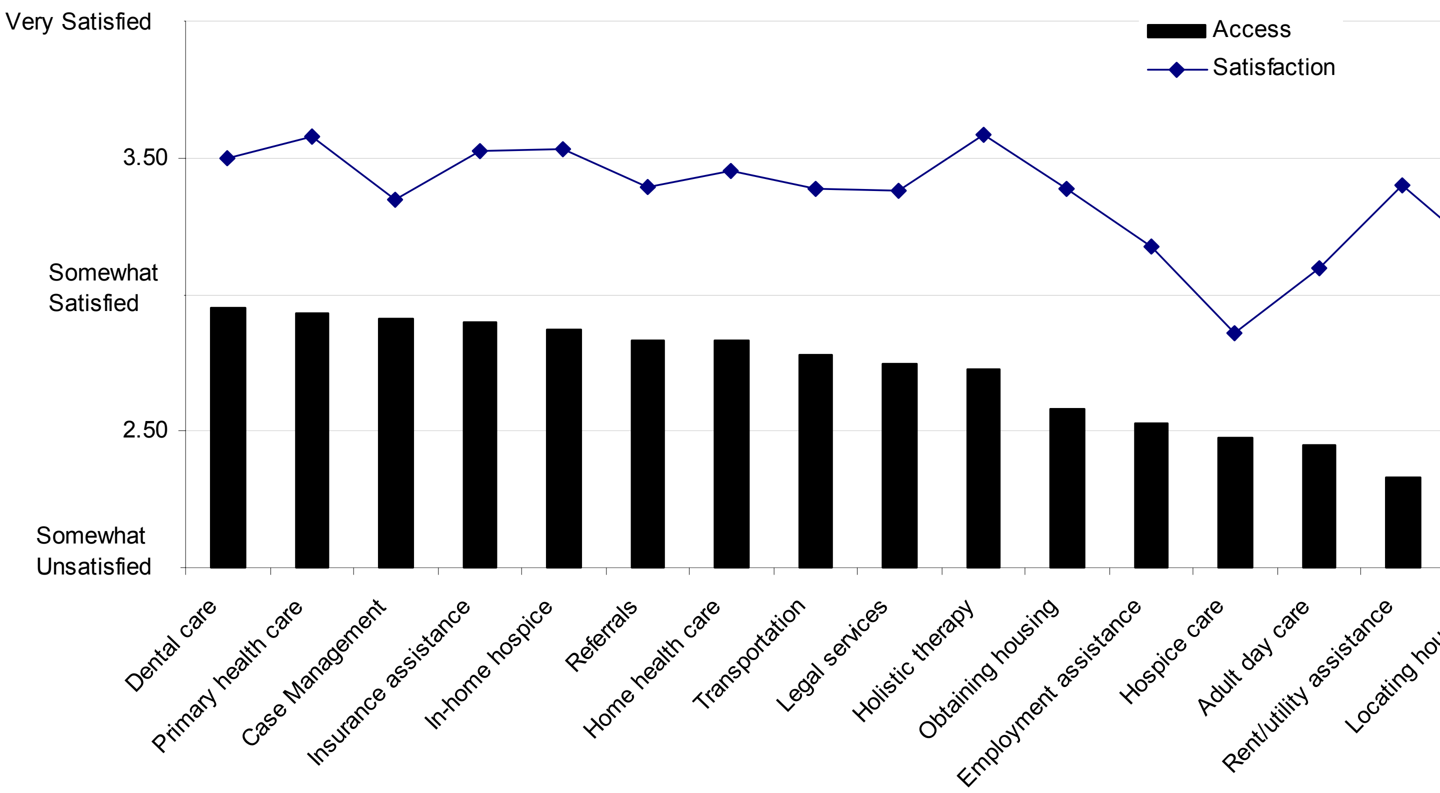


Figure 0-23 Access and Satisfaction with Services - Last 16



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 28. 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 0-24 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 28, 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 28. 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 0-25 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 0-25 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 28.

Figure 0-24 Anticipated Need - Mean Score for Top 13

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

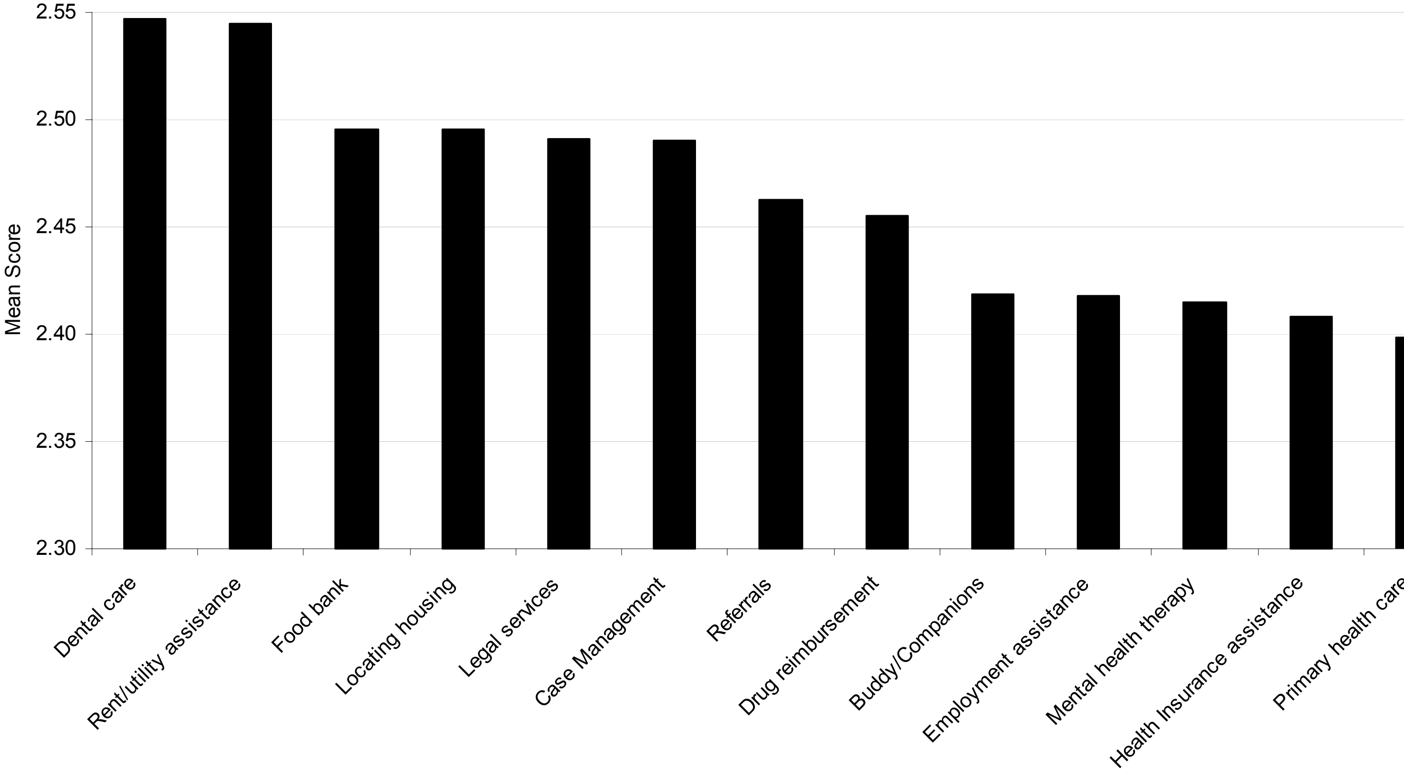
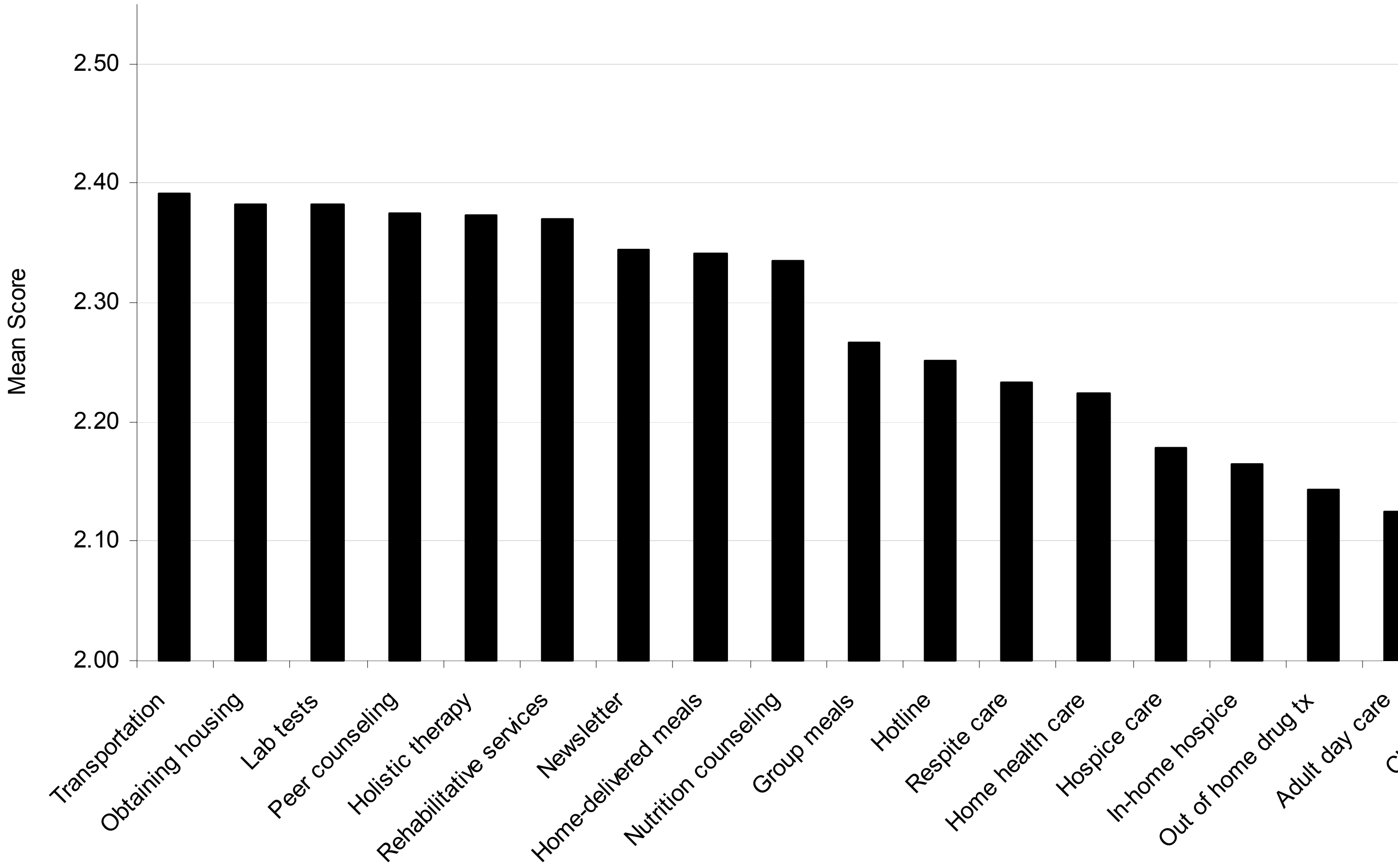


Figure 0-25 Anticipated Need - Mean Score for last 20 Services

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



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.[29] 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.[30] 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 0-1 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 0-1, 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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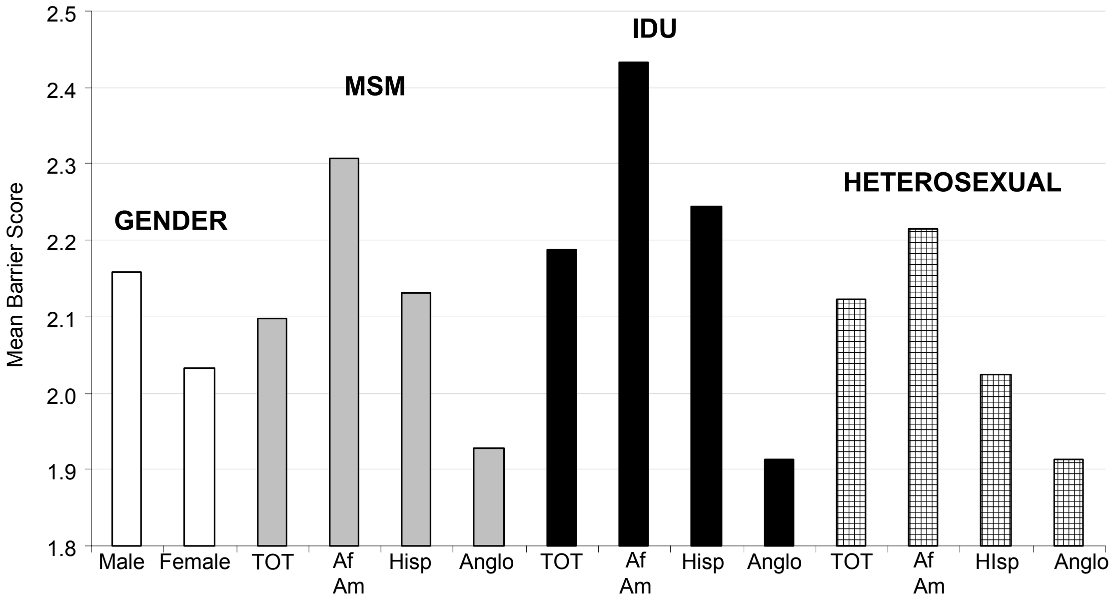
[29] For exact wording see question 47 in the questionnaire, Attachment 6, and the Barrier section in the focus group outline, Attachment 5.

[30] 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 24.

As seen in Figure 0-1, 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 0-1 Average Barrier Scores by Risk Group

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



In Figure 0-2, 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 0-2 Average Barrier Scores by Special Populations

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

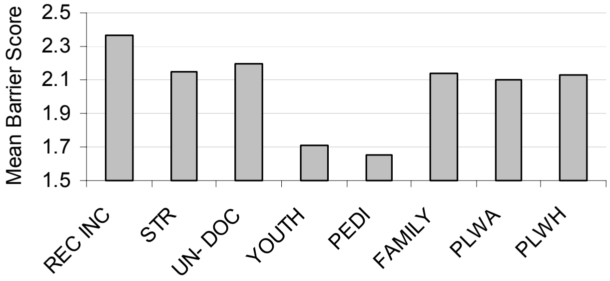
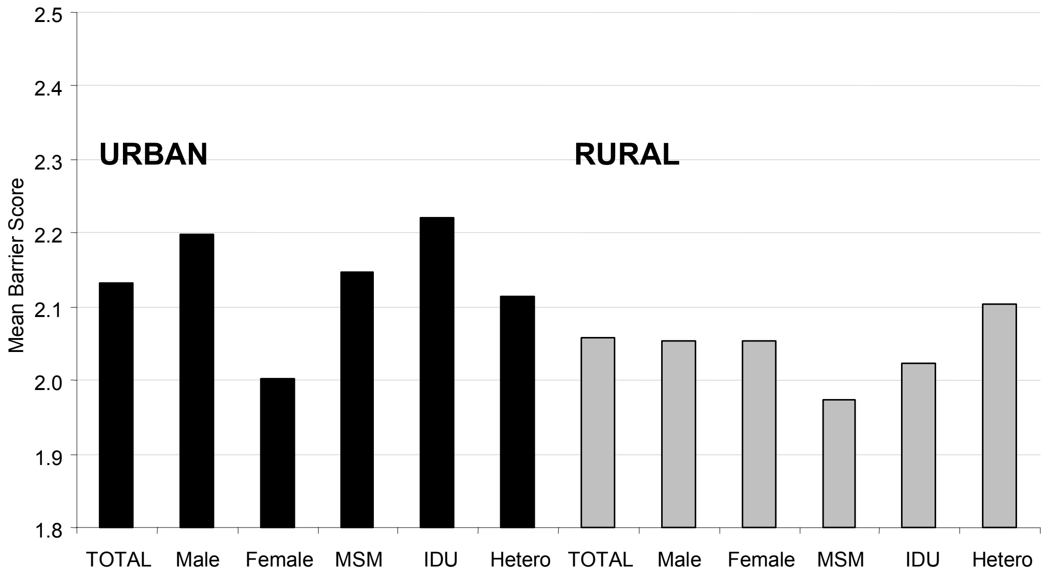


Figure 0-3 shows the barriers for the urban and rural PLWH/A. It is further divided by gender and risk group. Urban females living with HIV and AIDS report the lowest overall barrier scores. In the rural areas, the heterosexuals indicate the highest overall barrier, but no group indicates a very high overall barriers.

Figure 0-3 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 0-1 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 0-4. 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.[31]. Thus the difference between "red tape" (2.62) and "insurance coverage" (2.57) is not significant, but the difference between "red tape" and "eligibility rules and regulations" (2.50) is significant.

Table 0-1 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	

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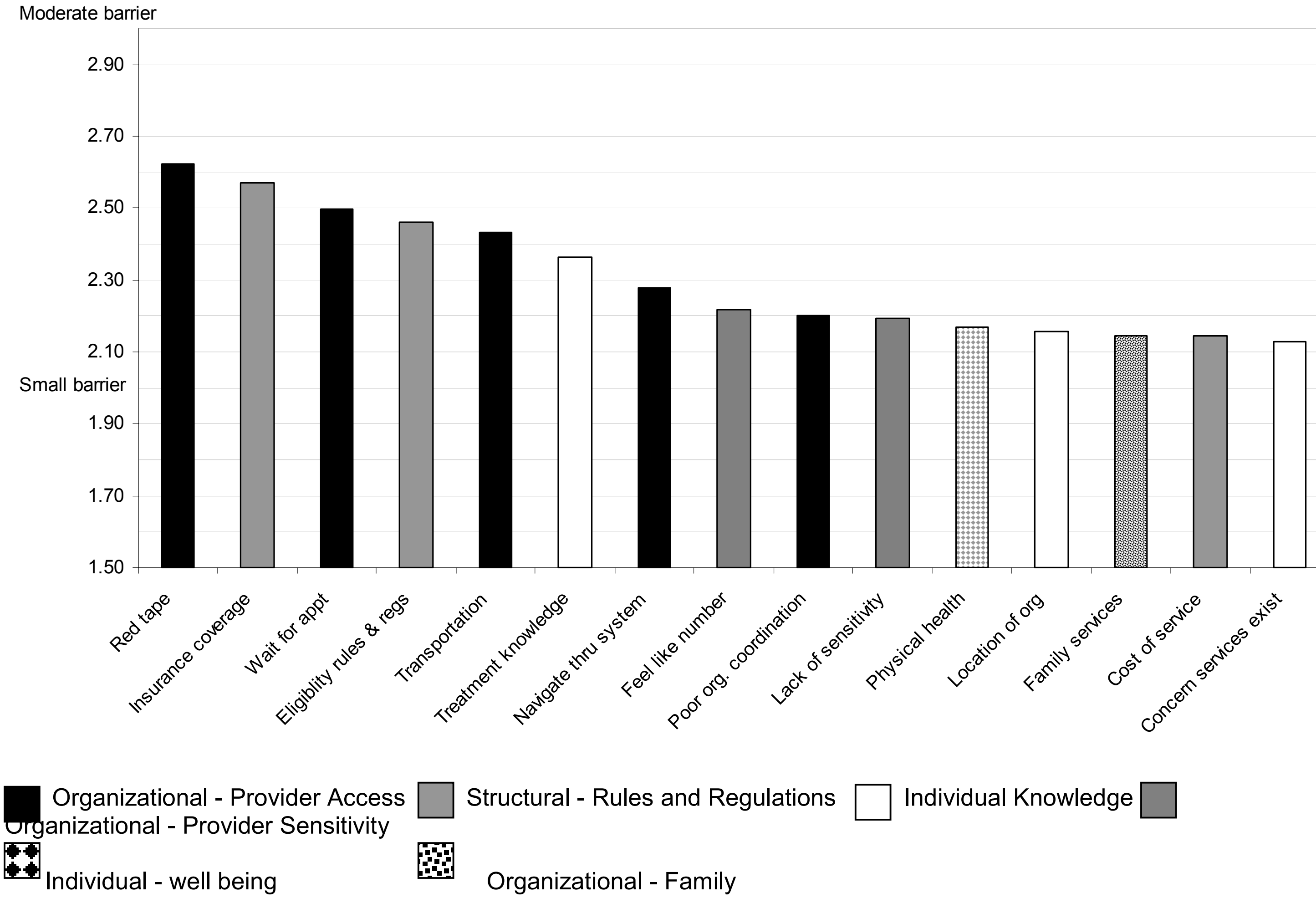
[31] Based on two-tailed t-test, with a confidence interval of 95%. This will vary somewhat for each barrier because of missing data (those persons said it was "not appliable" or left the iterm blank.

	27 Single family primary care location 28 Child care 29 Family services	

Figure 0-4 Individual Barrier Scores - Highest 15 for the Total Population



As seen in Figure 0-4, 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 0-4 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 0-5 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."*

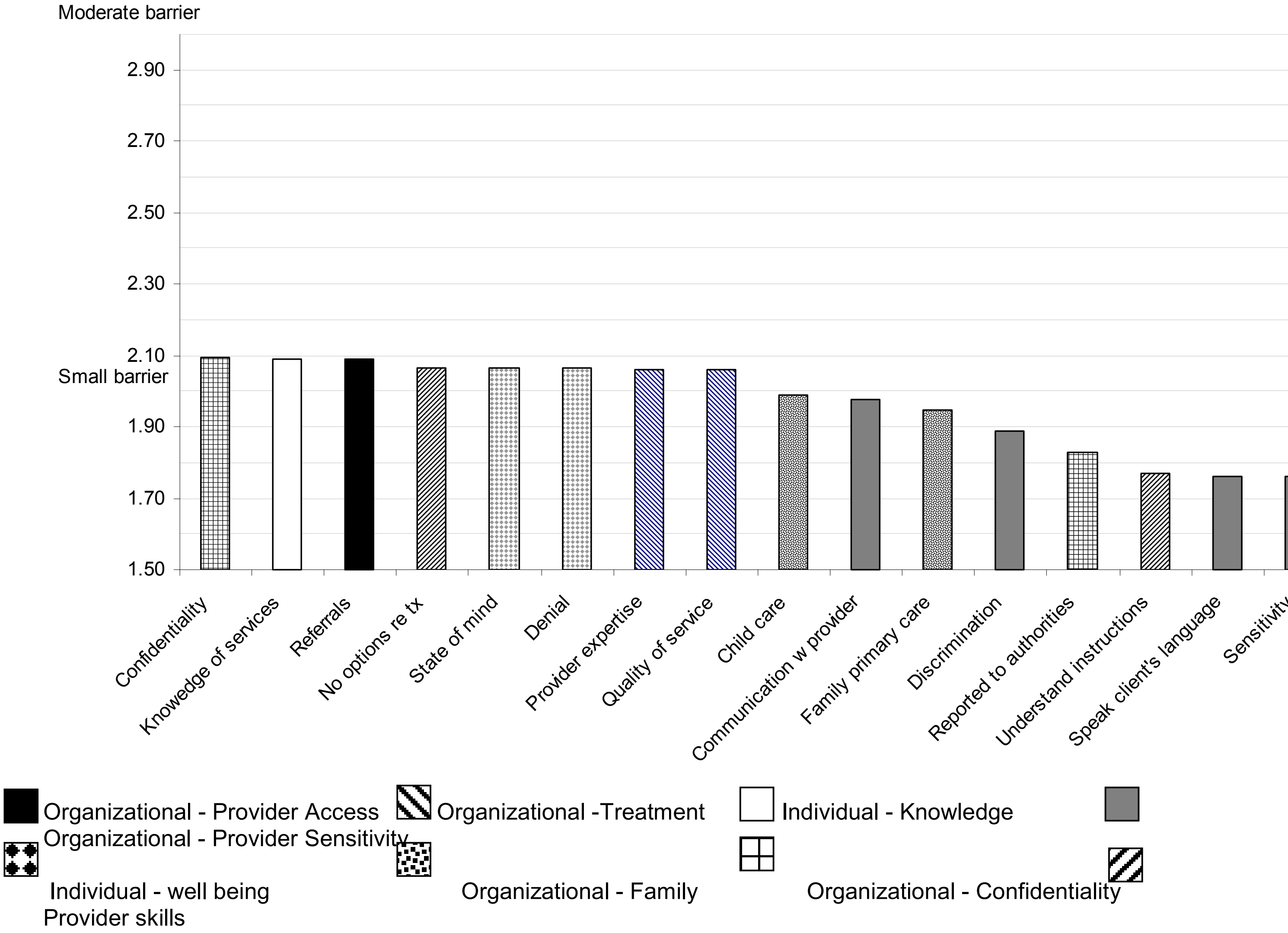
For others it was an unwillingness to keep difficult regimens or laziness. P7, an African American female adolescent, said, *"I'm just lazy (regarding medical treatments)…it's just that the regiment is so hard to follow."* P51, an Anglo MSM, said, *"I don't feel any different when I take them than when 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 0-5 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

Not all subpopulations have the same ranking. Generally, as shown in Figure 0-6, 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 25. Attachment 25 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 0-6 Individual Barrier Scores - Highest 15 for Males and Females

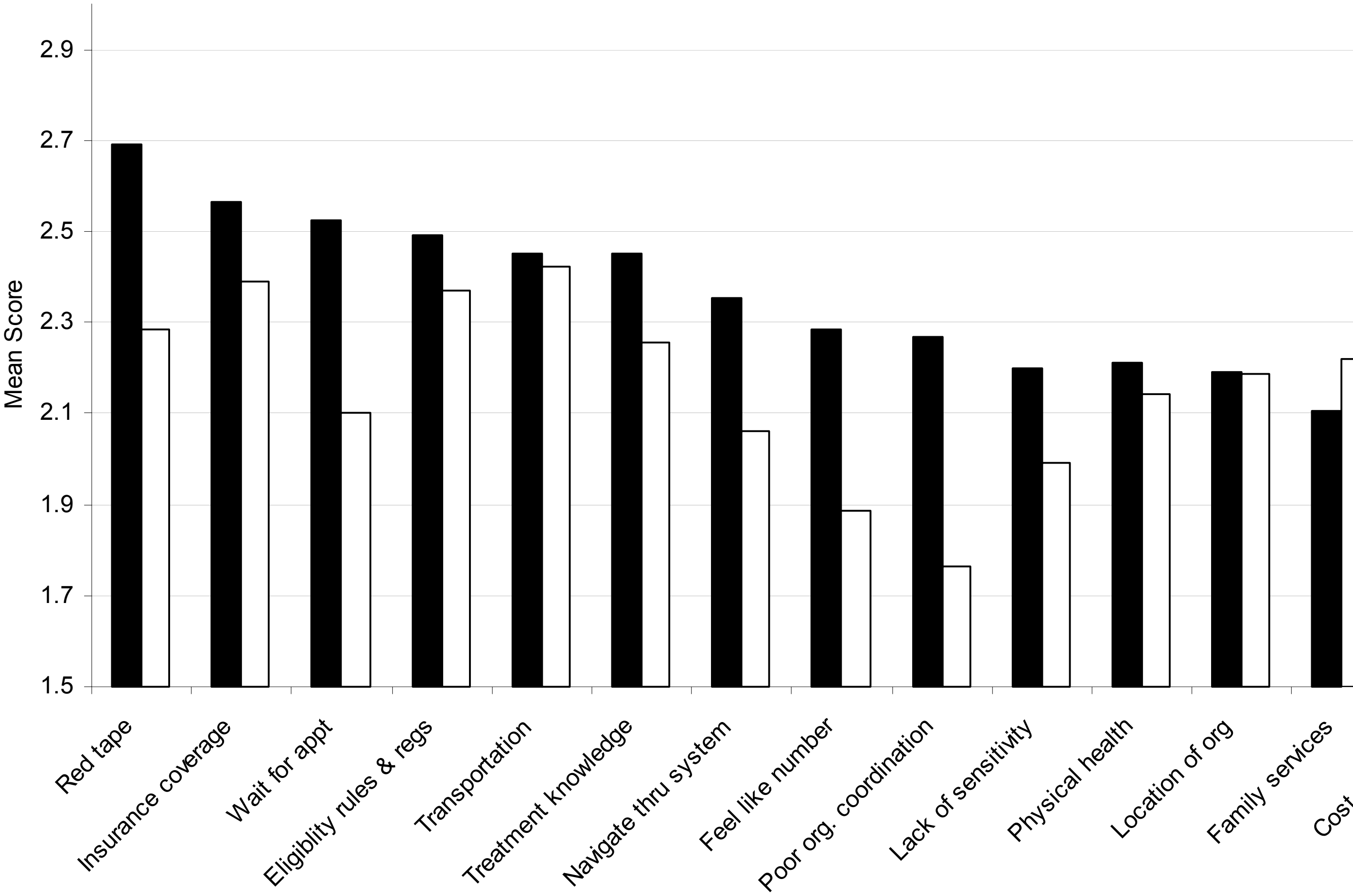


Figure 0-7 Individual Barrier Scores - Highest Barriers for MSM

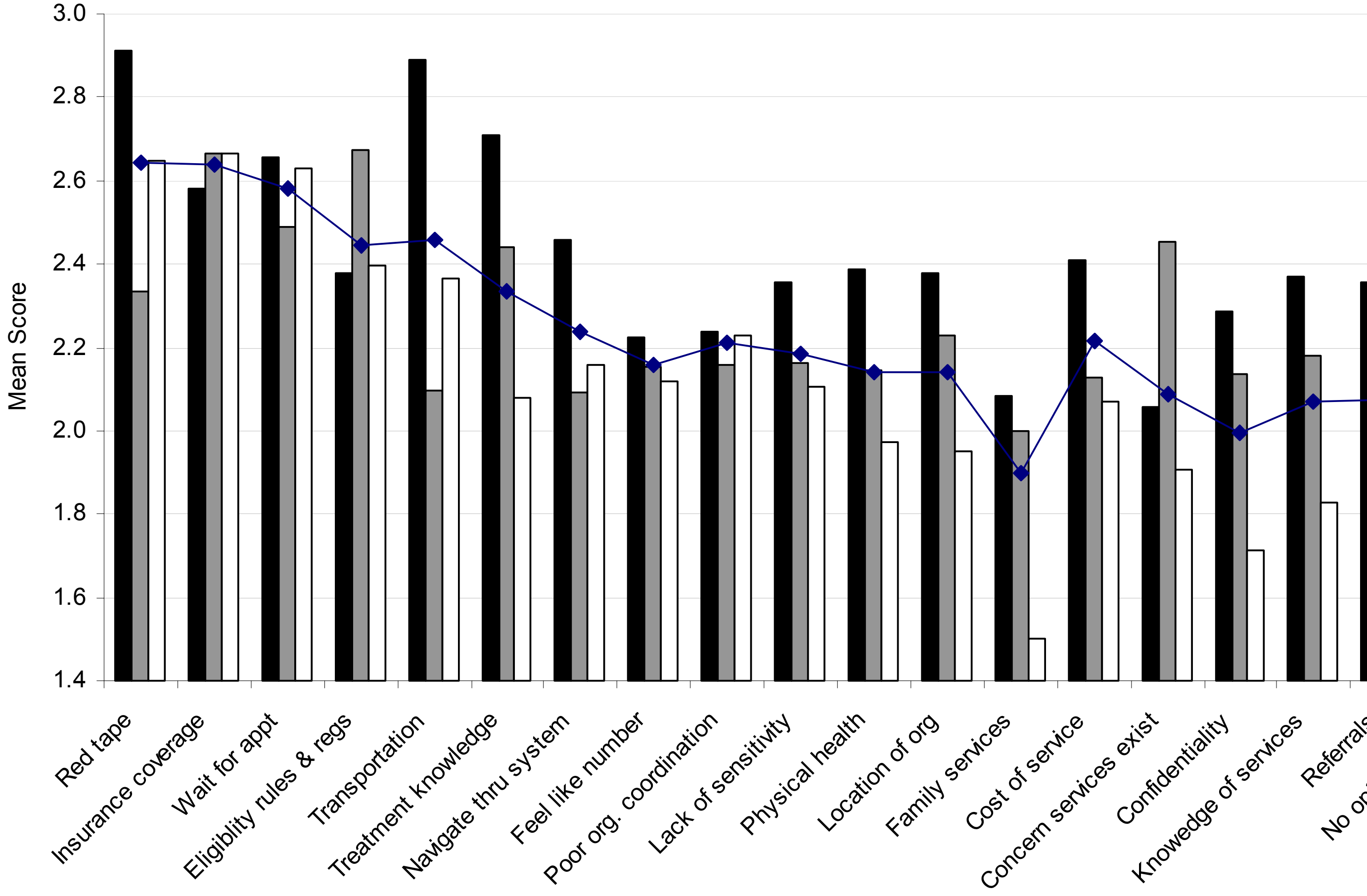


Figure 0-8 Individual Barrier Scores - Highest Barriers for IDU

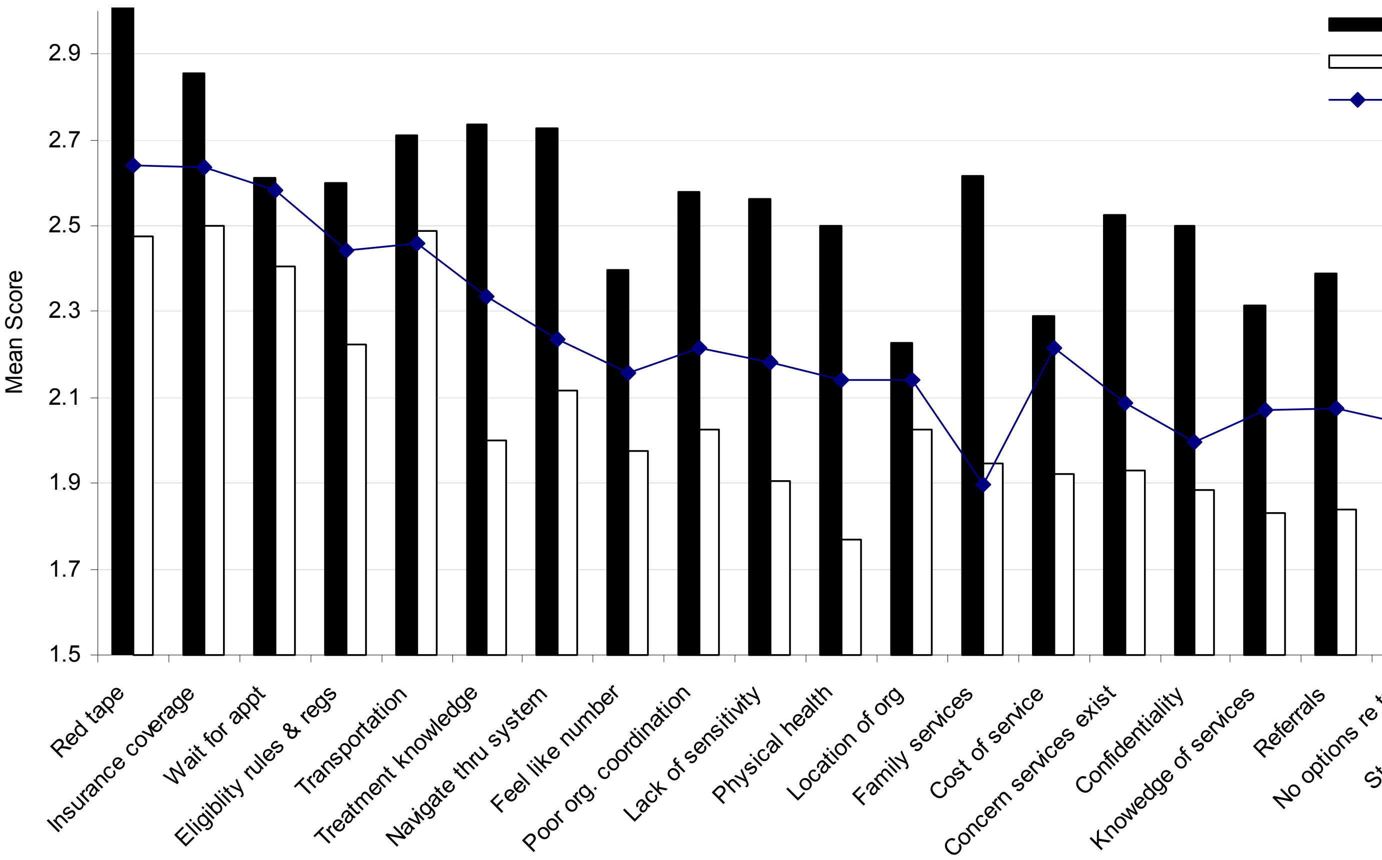


Figure 0-9 Individual Barrier Scores - Highest Barriers for Incarcerated & Recently Incarcerated

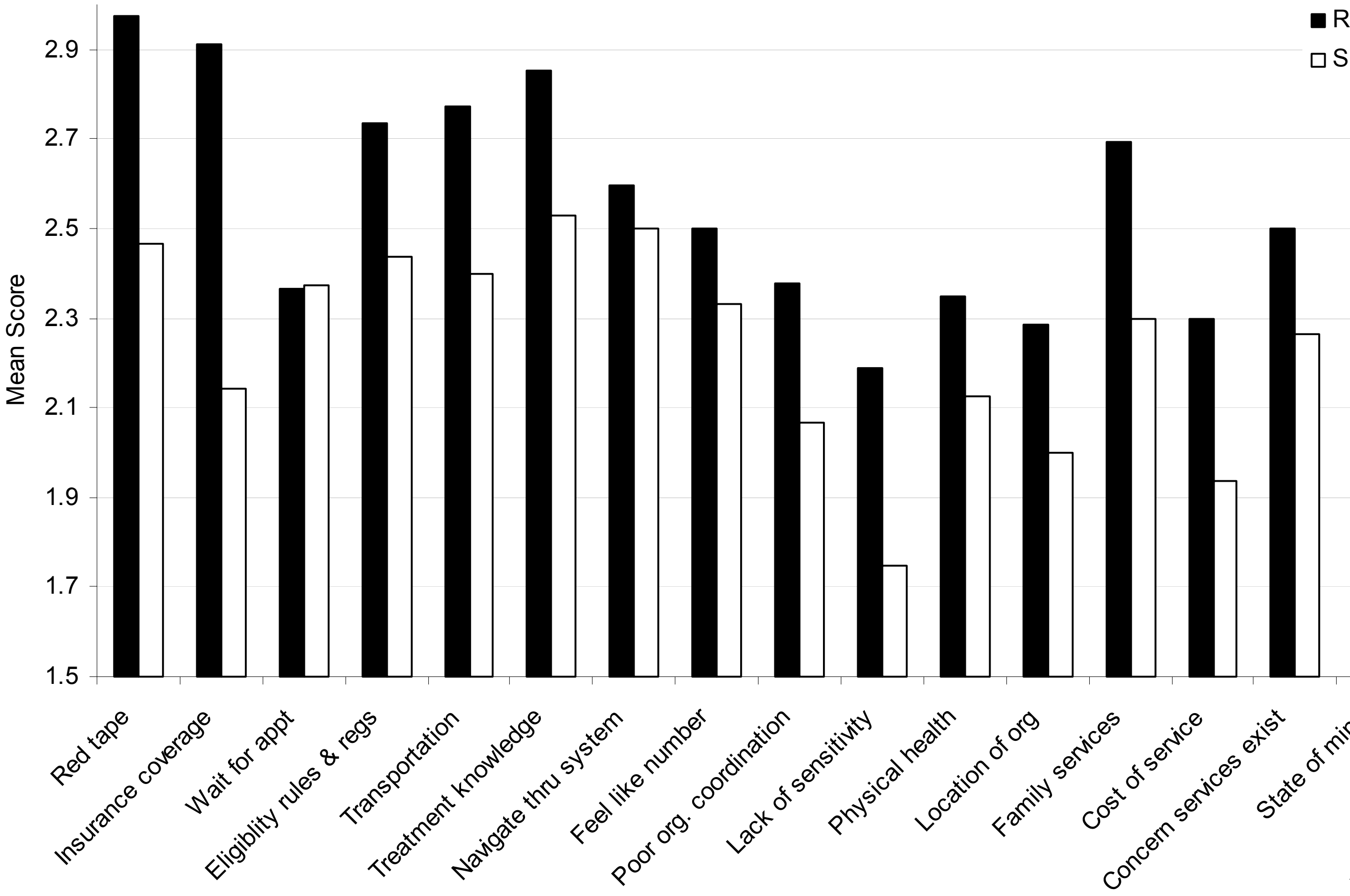
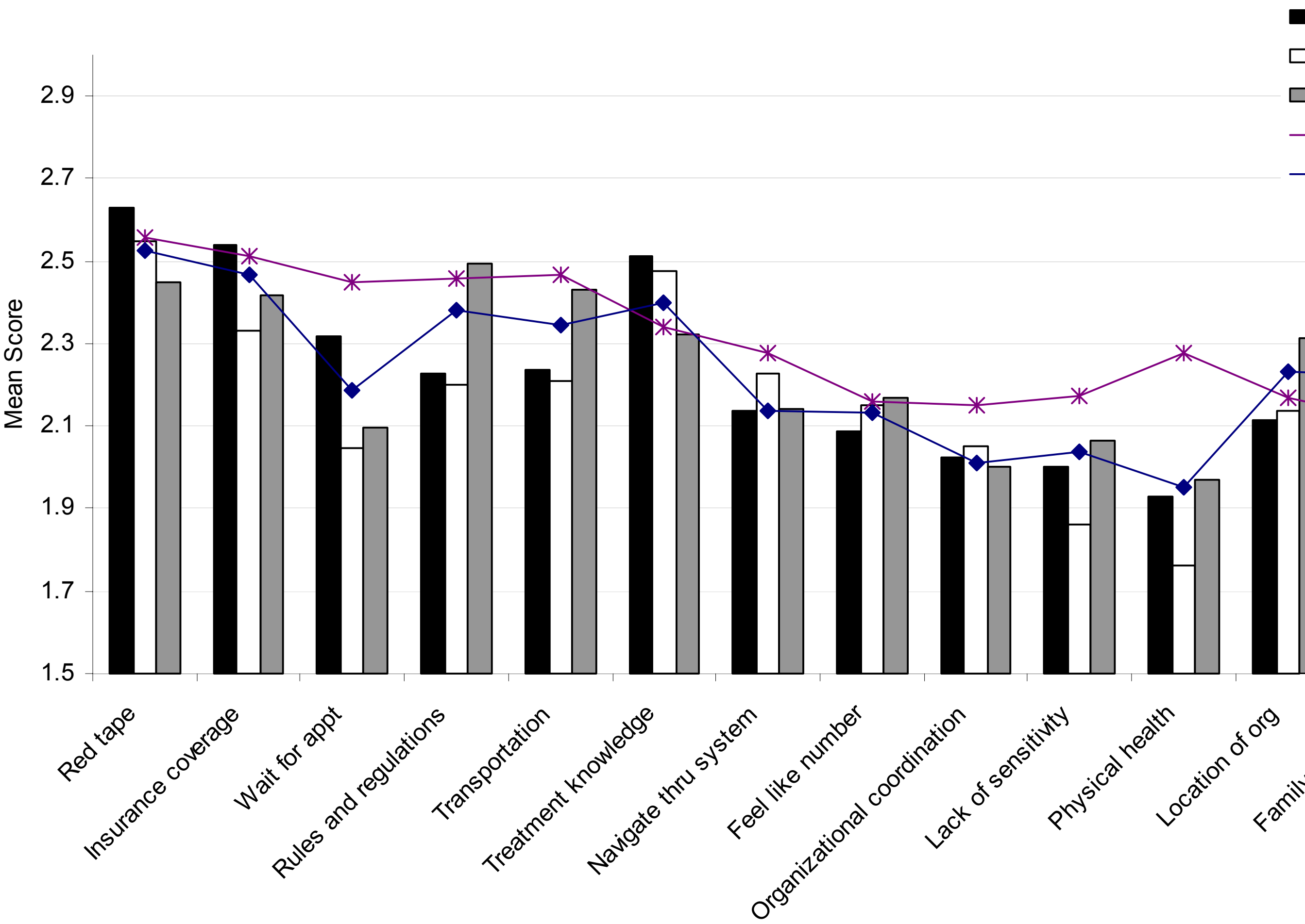


Figure 0-10 Individual Barrier Scores - Highest Barriers for Urban-Rural



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.[32] 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 26 illustrates the reported barriers to care as rated by the staff from 45 participating agencies. Attachment 26 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 26, 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 26 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 26 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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[32] For exact wording see page 5 in the provider survey, Attachment 7. 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 26, 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 26, 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 0-11 and Table 0-2. 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 0-11 Top Ten Barriers - Providers vs. PLWH/A

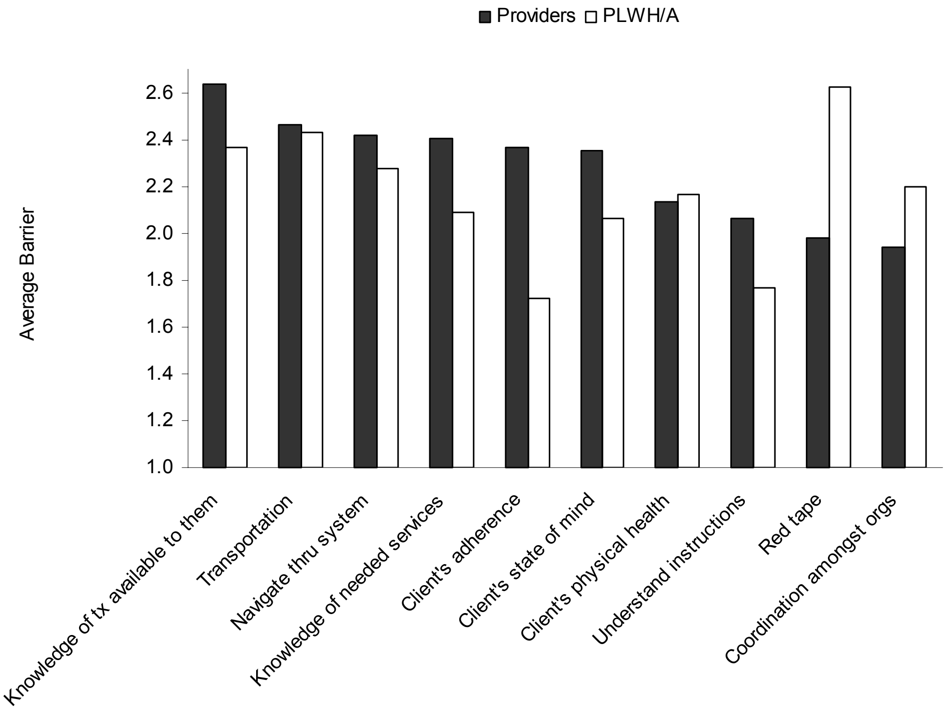


Table 0-2 Provider & PLWH/A Ranking of Barriers

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.

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 0-1. 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 0-1. “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 0-2, 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 0-3 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 0-4 shows the "other" funding sources for prevention.

Table 0-1 Reported Care and Treatment funding for FY 98

AGENCY	# of Programs	Other[1]	RWI[2]	Foundation	RWII	TDH	Indiv Donations	HOPWA	TCADA	RWIII	RWIV
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**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**
Harris County Hospital District (HCHD)	6	$5,400,314	$4,031,662	$0	$0	$0	$0	$0	$0	$490,002	$0
	8%	54%	41%	0%	0%	0%	0%	0%	0%	5%	0%
Bering Omega Community Services	5	$836,618	$507,145	$1,037,102	$149,957	$191,856	$307,313	$0	$0	$14,080	$0
	7%	27%	16%	34%	5%	6%	10%	0%	0%	0%	0%
AIDS Foundation Houston, Inc.	11	$338,820	$142,176	$17,204	$11,191	$204,951	$562,563	$180,834	$0	$0	$24,372
	15%	23%	10%	1%	1%	14%	38%	12%	0%	0%	2%
Texas Children's Hospital		$1,826,239	$0	$0	$0	$0	$0	$0	$0	$0	$81,032
		96%	0%	0%	0%	0%	0%	0%	0%	0%	4%
Montrose Clinic, Inc.	5	$750,000	$153,300	$185,000	$21,000	$87,000	$40,000	$0	$0	$0	$0
	7%	53%	11%	13%	1%	6%	3%	0%	0%	0%	0%
The Assistance Fund, Inc.	2	$100,000	$495,612	$0	$757,956	$0	$0	$0	$0	$0	$0
	3%	7%	37%	0%	56%	0%	0%	0%	0%	0%	0%
Montrose Counseling Center, Inc.	4	$37,236	$271,616	$18,270	$9,788	$28,935	$0	$0	$634,382	$0	$0
	5%	4%	27%	2%	1%	3%	0%	0%	63%	0%	0%
People With AIDS Coalition - Houston, Inc.	5	$86,020	$516,940	$0	$66,704	$355,861	$0	$22,186	$0	$0	$0
	7%	8%	49%	0%	6%	34%	0%	2%	0%	0%	0%
Family Service Center	3	$383,584	$513,850	$0	$40,112	$0	$0	$0	$0	$0	$0
	4%	41%	55%	0%	4%	0%	0%	0%	0%	0%	0%
Amigos Volunteers in Education and Services	4	$0	$196,230	$100,000	$30,000	$0	$30,000	$90,000	$0	$0	$0
	5%	0%	40%	20%	6%	0%	6%	18%	0%	0%	0%
Donald R. Watkins Memorial Found	1	$0	$803,387	$0	$0	$0	$0	$0	$0	$0	$0
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Houston Area Community Services, Inc.	2	$0	$580,726	$0	$0	$0	$0	$0	$0	$0	$0
	3%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
University of Texas at Houston Health Science Center/ Dept. of Pediatrics	1	$310,735	$291,222	$26,171	$0	$0	$0	$0	$0	$0	$0
	1%	49%	46%	4%	0%	0%	0%	0%	0%	0%	0%
Diocesan AIDS Ministry, A Program of Associated Catholic Churches	4	$466,802	$0	$34,700	$0	$0	$12,000	$0	$0	$0	$0
	5%	89%	0%	7%	0%	0%	2%	0%	0%	0%	0%
Visiting Nurse Association of Houston, Inc.	1	$0	$369,044	$0	$0	$91,372	$0	$0	$0	$0	$0
	1%	0%	80%	0%	0%	20%	0%	0%	0%	0%	0%
Houston Challenge Foundation	1	$72,336	$82,302	$0	$72,243	$106,500	$0	$0	$0	$0	$0
	1%	22%	25%	0%	22%	32%	0%	0%	0%	0%	0%
The Life Center Inc.		$0	$473,405	$0	$26,765	$0	$0	$0	$0	$0	$0
		0%	95%	0%	5%	0%	0%	0%	0%	0%	0%
Brentwood Community Foundation	2	$0	$82,303	$0	$0	$0	$0	$210,352	$0	$0	$0
	3%	0%	28%	0%	0%	0%	0%	72%	0%	0%	0%

AGENCY	# of Programs	Other[1]	RWI[2]	Foundation	RWII	TDH	Indiv Donations	HOPWA	TCADA	RWIII	RWIV
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**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**
Kids in Need of Drug Evaluation & Re-Treatment Clinic	1	$0	$283,000	$0	$0	$0	$0	$0	$0	$0	$0
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Foundation for Interfaith Research & Ministry	1	$71,360	$163,882	$0	$0	$43,577	$0	$0	$0	$0	$0
	1%	25%	59%	0%	0%	16%	0%	0%	0%	0%	0%
UT Health Science Center for Houston Recovery Campus	1	$0	$0	$0	$0	$0	$0	$275,142	$0	$0	$0
	1%	0%	0%	0%	0%	0%	0%	100%	0%	0%	0%
Fort Bend Family Health Center, Inc.	1	$60,000	$0	$0	$160,136	$0	$0	$0	$0	$0	$0
	1%	27%	0%	0%	73%	0%	0%	0%	0%	0%	0%
Memorial Hermann Home Health	1	$0	$179,307	$0	$0	$0	$0	$0	$0	$0	$0
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Steven's House	1	$0	$0	$0	$17,860	$0	$50,000	$80,294	$0	$0	$0
	1%	0%	0%	0%	12%	0%	34%	54%	0%	0%	0%
Southeast Texas Legal Clinic	1	$7,108	$81,470	$20,878	$19,172	$33,146	$360	$0	$0	$0	$0
	1%	4%	50%	13%	12%	20%	0%	0%	0%	0%	0%
Houston Volunteer Lawyers Program	1	$0	$100,000	$17,633	$0	$0	$0	$0	$0	$0	$0
	1%	0%	85%	15%	0%	0%	0%	0%	0%	0%	0%
UTMB Family Medicine – Conroe	1	$0	$90,000	$0	$0	$0	$0	$0	$0	$0	$0
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
NAACP Houston Branch	4	$0	$272,774	$0	$0	$0	$0	$0	$0	$0	$0
	5%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Nightingale Adult Day Center	1	$0	$0	$0	$0	$75,000	$0	$0	$0	$0	$0
	1%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%
Northwoods AIDS Coalition, Inc.	1	$0	$68,529	$0	$0	$0	$0	$0	$0	$0	$0
	1%	0%	96%	0%	0%	0%	0%	0%	0%	0%	0%
Covenant House Texas	1	$0	$0	$0	$0	$0	$0	$0	$0	$0	$44,980
	1%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%
Riverside General Hospital	1	$0	$75,000	$0	$0	$0	$0	$0	$0	$0	$0
	1%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Art League of Houston	1	$0	$0	$2,400	$0	$0	$785	$0	$0	$0	$0
	1%	0%	0%	44%	0%	0%	14%	0%	0%	0%	0%

1. Other” funding sources include FEMA, HUD, TDHSS, client fees, TDH/CDC, local fundraisers, and others. Table 0-2.
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 27.
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 0-2 Other Funding Sources

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

Figure 0-1 Funding Sources for Treatment and Care

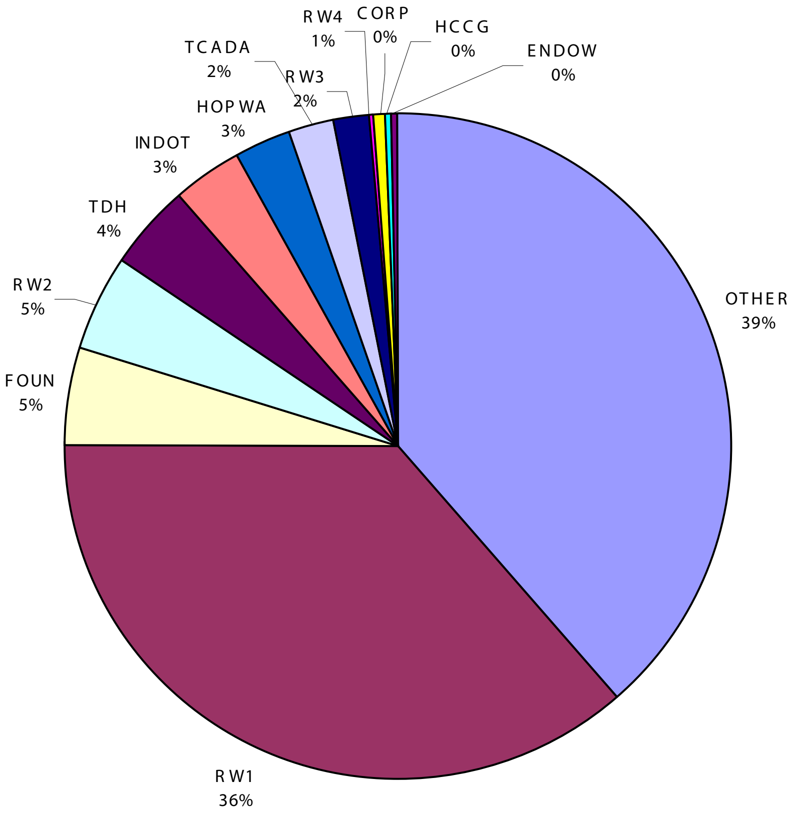


Table 0-3 Reported Prevention Funding for FY98

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

[2] Funding source not specified.

Table 0-4 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 0-2 Funding Sources for Prevention Services

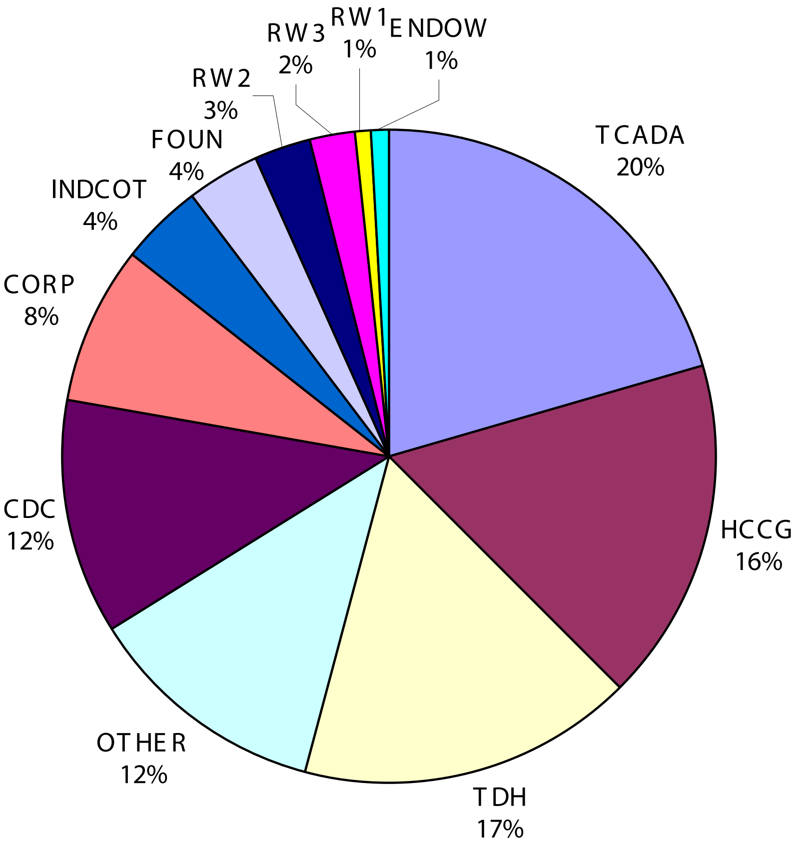


Table 0-5 indicates how the revenues reported in the survey were divided among the service categories. Based on Ryan White Funds, HOPWA, TCADA and other funds, the services that receive over a million dollars are medical care, case management, HIV early intervention and outreach, rental/emergency housing assistance, and dental.

Table 0-5 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 0-6, 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 0-6 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

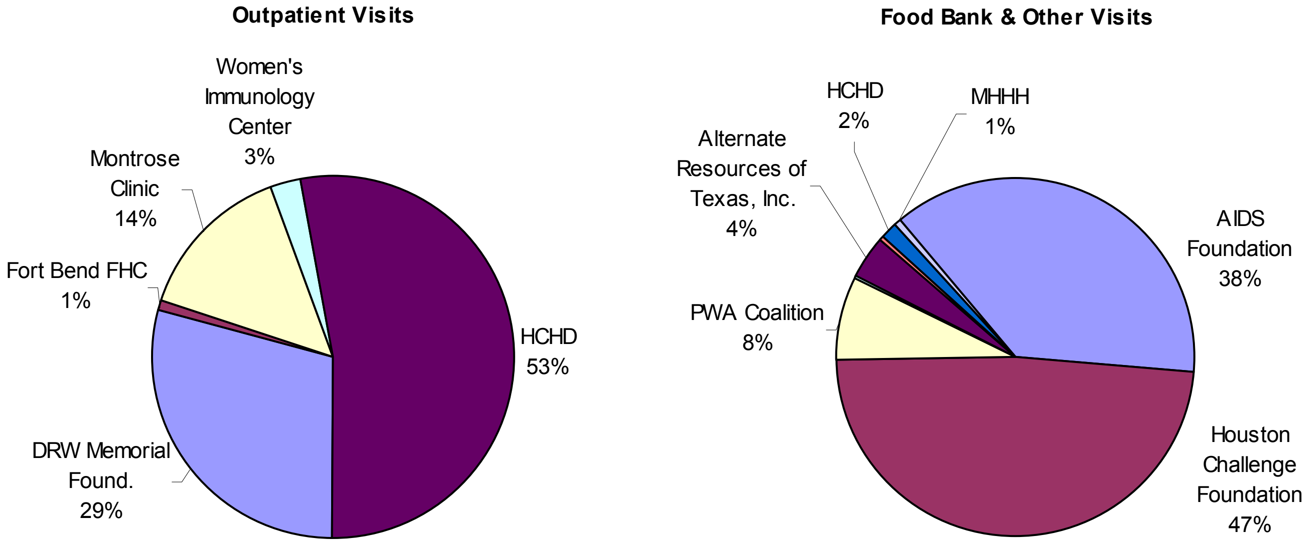
Providers	Unit of Service	Total Clients served	1998 Units provided	Budget	Cost per visit	Type of Visits
AIDS Foundation Houston	1 Visit	17	21	$1,259	$59.95	Spirit Wellness Center
Alternate Resources of Texas	1 Visit	159	1277	$65,500	$51.29	Skilled Nursing
Alternate Resources of Texas	1 Visit	7	34	$2,399	$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 0-3 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 0-3 Percent of Total Visits Delivered by Provider



Sessions – Mental Health, Substance Abuse Counseling and Wellness Education

Table 0-7 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.

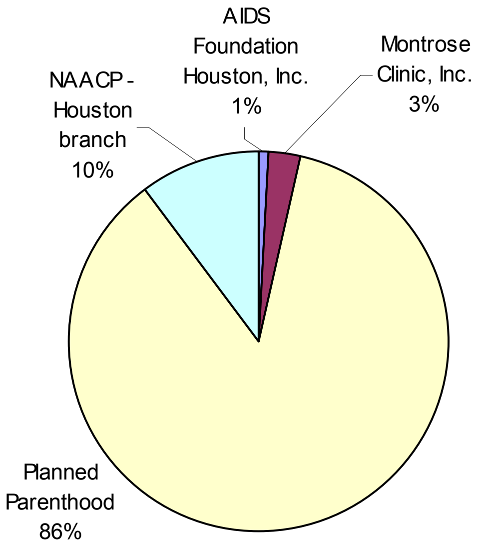
Table 0-7 Sessions Provided

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 0-4 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 0-4 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 0-8 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.

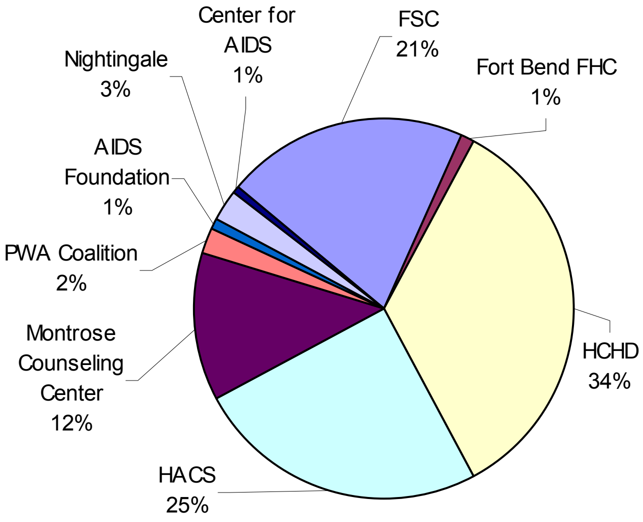
Table 0-8 15-Minute Increments Provided

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 0-5 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 0-5 15- Minute Increments



Days – Respite, Hospice and Residential Services

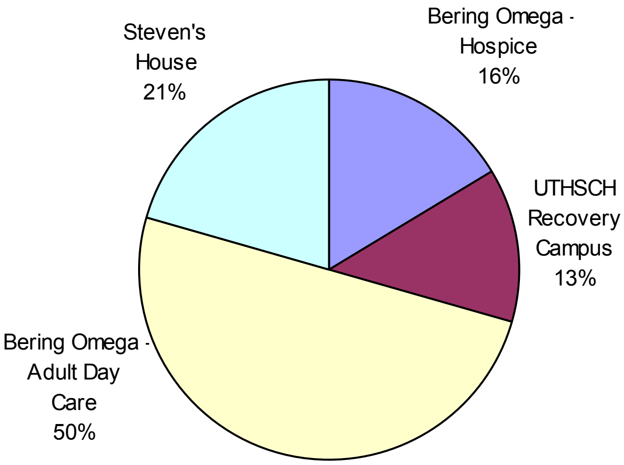
Hospice, adult day care, housing, and rehabilitation services are all measured in days. Table 0-9 shows that in 1998, 7,907 days of care were provided to 353 clients at a cost of $105 dollars per day. The cost of adult day care at $40.00 per day is substantially lower than the cost of hospice care at $189.00 per day.

Table 0-9 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 0-6 shows that Bering-Omega's adult day care combined with the hospice care program account for 40% of the total days provided.

Figure 0-6 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 0-10 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 0-10.

Table 0-10 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 0-11 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 0-12, 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 0-12 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 0-13 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 0-13 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 0-14, in 1998, they served 516 clients and provided reimbursement for 1550 prescriptions.

Table 0-14 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 0-15. 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 0-15 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 0-16 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 0-16 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 0-17 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 0-17 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 0-17 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 0-18 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 0-18 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 0-19 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 0-19 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 0-20 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 0-20 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 0-21 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 0-21 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 0-22 shows that among the 45 reporting service providers, there are 557 full-time equivalent staff members.

Table 0-22 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 0-7 Number FTE by Position, Male & Female

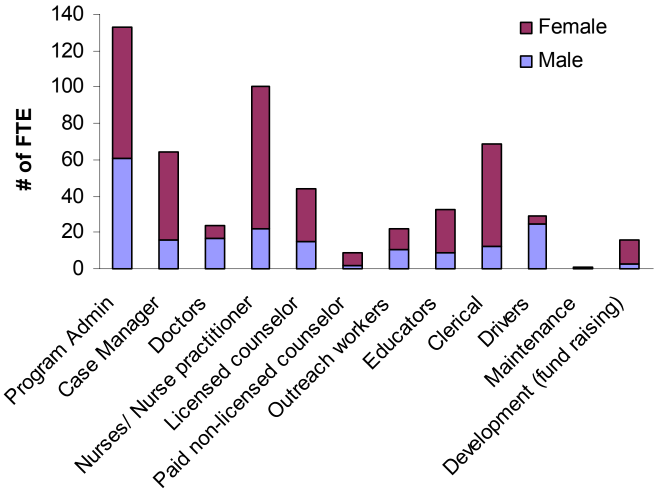
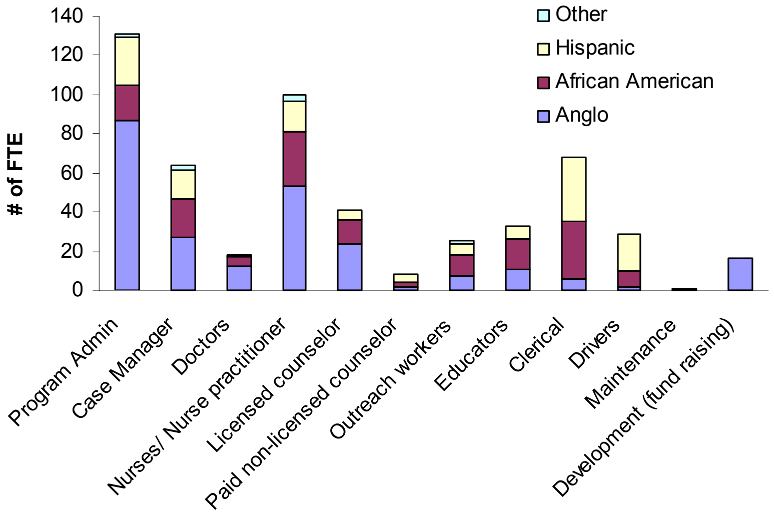


Figure 0-8 Number FTE by Position, Ethnicity



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 0-1. The outcomes and the populations they most directly affect are shown in Table 0-1.

Table 0-1 Outcomes and Populations They Impact

OUTCOMES	POPULATIONS
6. Public support for HIV/AIDS services	General population
7. Awareness of serostatus for at-risk populations	At risk population; DK serostatus
8. Maintaining negative status for those who know their HIV negative status	HIV negative
9. No progression to AIDS for those who are HIV positive	HIV positive, symptomatic or asymptomatic

10. 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.

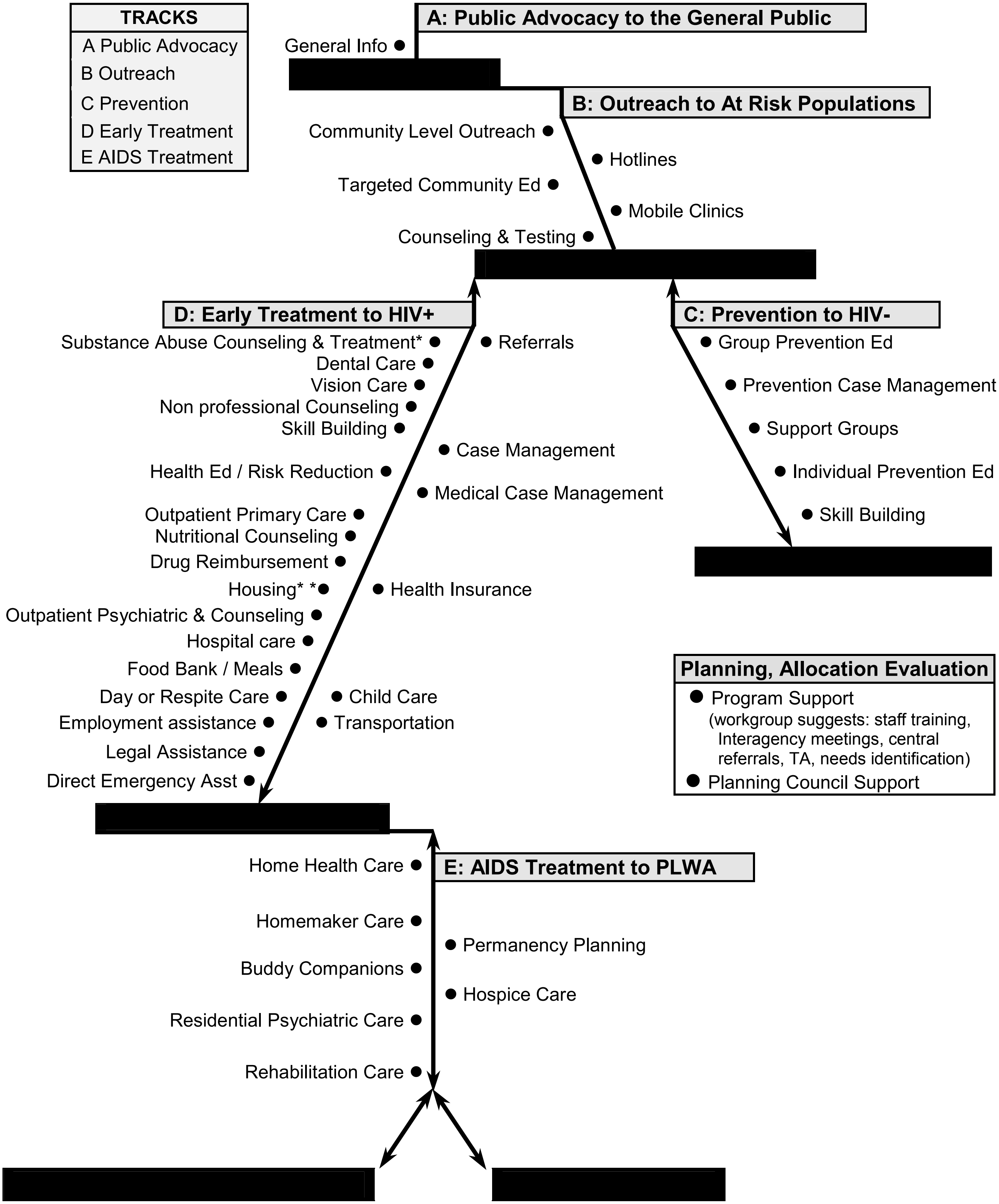
One of the challenges facing the Council and Consortium is the greater integration of the goals as part of the overall provision of services within the Continuum of Care. Two basic facts are essential in developing this integration. First is the awareness that funding and rules and regulations governing 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 0-1 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 0-2. 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 0-2 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.[33] 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

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

eligible to receive ADAP and local drug reimbursement is between 2,700 and 3,500. While there will be more 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[34]. 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.

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

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[35]. Of those about half would be living with AIDS and have a 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.

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

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 if everyone eligible who demanded access received it. The exact number will depend on the success of outreach in bringing those not in care into the system.

Perceived Need or Demand

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.

Fulfilled Need

The reported number of unduplicated clients served are fewer than the epidemiological estimate would suggest. Based on reports from TDH[36] 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.

Capacity of the System

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[36] Personal conversation with John Allen, TDH.

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.

Unmet Absolute Need

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.

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."[37] 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 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.

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

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.[38] 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 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

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[38] 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.

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 if everyone who could benefit did.

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 if everyone eligible requested this service. 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.

HOUSTON EMA & HOUSTON HSDA

IDENTIFICATION AND DESCRIPTION OF THE CONTINUUM OF CARE

Prepared for

HOUSTON AREA HIV SERVICES RYAN WHITE PLANNING COUNCIL AND THE HOUSTON HSDA CONSORTIUM

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IDENTIFICATION AND DESCRIPTION OF HOUSTON EMA CONTINUUM OF CARE: INTERIM REPORT

Prepared for the
Houston Area HIV Services Ryan White Planning Council and The Houston Health Services Delivery Area Consortium

April 1999 (Final revision June 1999)

Submitted by the Partnership for Community Health, Inc.

INTRODUCTION

The Houston Area HIV Services Ryan White Planning Council (Council) and the Houston Health Services Delivery Area Consortium (Consortium) have placed a high priority on describing the current continuum of care (COC) for people living with HIV/AIDS (PLWH/A) in the Houston EMA. The Partnership for Community Health (PCH) and the Office of Community Projects (OCP) at the Graduate School of Social Work, University of Houston started this project in January 1999 and completed a community meeting on February 24, 1999. This document is a report of the background research and the outcome of that meeting.

Goal

The overall goal of this project is to provide a framework for a continuum of care that will be used to inform and guide the Council, Consortium, providers, and consumers in establishing priorities and funding HIV/AIDS services. It will provide the information that will enable planners to make the adjustments necessary to meet the continuing and changing needs of PLWH/A.

Objectives

The work plan established by the PCH/OCP project team and approved by the Council and the Houston HSDA Care Consortium is described below.

1. Provide a theoretical framework within which to describe the Houston EMA COC.
2. Identify and gather information from other EMAs around the country.
3. Facilitate a community meeting to present the theoretical framework, describe the types of models from around the country, select a model prototype for the Houston community, and begin to discuss how the full COC should be represented for the Houston EMA.
4. Review the results of this work with the participants at the community forum.

Concurrent with the COC effort, PCH/OCP, as part of the overall needs assessment, will:

1. Gather information from existing resource guides about the number and kinds of services that exist in the Houston EMA related to the provision of HIV services.
2. Through survey instruments, focus groups and provider interviews, suggest how the continuum of care reflects the current service needs, gaps and barriers in the Houston area.

In the final recommendations of the needs assessment, the discussion of the continuum of care will emphasize service needs, gaps and barriers as well as the necessary linking mechanisms to ensure the system works as efficiently and effectively as possible.

FRAMEWORK FOR THE CONTINUUM OF CARE

A continuum of care (COC) is defined by HRSA[39], as "a coordinated delivery system, encompassing a comprehensive range of services needed by individuals or families with HIV infection to meet their health care and psychological service needs throughout all stages of illness."

Most Eligible Metropolitan Areas (EMAs) serving PLWH/A include in their system of care:

- Primary and secondary prevention of HIV infection
- Outreach to the general and at-risk populations to promote prevention and treatment
- The delivery of medical and social services
- The delivery of support services to assure that PLWH/A can access medical and social services.

The COC speaks to several constituencies:

- The general public, whose support is needed for the continued community support of the HIV and AIDS prevention and care systems.
- At-risk populations who are HIV negative and a subset of the general public. They are the targets of prevention efforts.
- PLWH/A who are consumers of the HIV and AIDS services.
- The service providers.
- The administrative agents for the Ryan White Care Act.
- The local, State and Federal funders who require accountability for service systems and provide the resources and governing regulations for the entire system of prevention and care.

These constituencies are in a reciprocal relationship. They plan for the continuum of care, utilize HIV/AIDS services, and monitor the effectiveness of the services.

In addition to these various constituencies, the COC includes the set of services and linking mechanisms that the Ryan White Planning Council, the Consortium, and the community feel should be available to reach their vision for the community.

ELEMENTS OF THE CONTINUUM OF CARE

A continuum of care must take into account several factors in order to truly reflect the needs of the communities infected and affected with HIV and AIDS. These are:

1. The mission and vision statements of the various planning bodies
2. The goals and objectives of the planning bodies
3. The services available in the delivery system

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[39] Self Assessment Module, JSI, 1998.

4. The linkages necessary to insure efficiency and effectiveness
5. The coordinating mechanisms that can be utilized to ensure effective linkages are established and maintained

Mission and Vision

Houston is a complex service environment with several different planning bodies, each with their own mission and vision statement. These statements allow the public, staff and governing boards to determine what the focus of service provision will be, what guiding principles will determine how those services are provided and, in a broad sense, what the expected outcomes are for the system. The mission and value states of the Council, Consortium, and Prevention Planning Group are shown in Attachment 1.

System Outcomes

The mission and vision statements note several common system goals that suggest what services should currently be available and what services should be considered in the Houston Area COC. These goals and objectives include:

- Identifying and addressing the needs of unserved and underserved populations.
- Including prevention and treatment services.
- Providing services in an efficient and effective manner.
- Providing services in a seamless manner as a person moves among the different levels of care.
- Providing high quality and culturally appropriate services.
- Advocating for the service needs of PLWH/A.
- Encouraging cooperation necessary for the coordination and delivery of services.
- Assuring that the community in need is aware of available prevention and treatment resources.
- Promoting the dissemination of information to all constituencies.
- Identifying service needs, gaps and barriers.
- Planning capacity to meet needs.
- Improving the quality of life of PLWH/A.
- Assuring that the system is free of discrimination based on race, color, creed, gender, religion, sexual orientation, disability, or age.
- Assuring that PLWH/A, the general public, and providers are included in the process.

Five attributes summarize the system goals and objectives. Referred to as the 5 A's, the delivery system must be:

1. Available
2. Accessible
3. Affordable
4. Appropriate

5. Accountable

The services must be *available* to meet the needs of the PLWH/A and their caregivers, accessible to all populations infected or affected by HIV/AIDS, *affordable* to all populations infected or affected by HIV/AIDS, *appropriate* for different cultural and socio-economic populations and care needs, and *accountable* to the funding sources and clients for providing contracted services at high quality.

Client Outcomes

In addition to these system goals and objectives, system and client outcomes can be measured to determine its effectiveness. Several client outcomes can be inferred from the goals and objectives above. These address the needs of all of the consumers within the COC. They include:

- Preventing persons from becoming HIV positive.
- Preventing persons from progressing from HIV to AIDS.
- Improving or maintain health status of PLWA.
- Sustaining or improve the quality of life of PLWA.
- Providing a dignified death to those who are at the end-stage of AIDS.

Linkages

Continuums of Care ideally provide services in a seamless manner as a person moves among the different levels of care. The Houston area has many service providers and in order to provide coordinated services, linkages are critical. According to the HRSA guideline for developing a continuum of care, linkages refer to those inter-entity structures that result in:

- Better client care coordination. Clients with multiple needs or those who move from one intensity level to another should have a well-coordinated treatment plan understood by all involved.

- Integrated information systems where one client record that combines financial, clinical and utilization information is available for multiple users, without breaching the confidentiality of the clients.

- Integrated systems of financing that allow for access to all aspects of the system through some mechanism of financial support.

While not all continuums of care will incorporate all of these elements, they are guideposts for improving service integration, efficiency, and effectiveness.

Mechanisms for Providing Inter-entity Linkages

Some of the mechanisms presented in the HRSA guidelines for establishing the necessary linkages include:

1. Participation on councils,

2. Joint planning meetings,
3. Joint prioritization activities,
4. Contractual arrangements,
5. Joint case conferences,
6. Standardized practice procedures,
7. Uniform intake forms,
8. Shared client information,
9. Shared staff arrangements.

The Houston area already engages in several of these activities and the challenge for the Houston area is to develop those mechanisms that will best meet the goals and objectives of the continuum of care.

Summary of the COC Framework

In summary, the COC in the Houston area needs to focus upon the mission and vision of the Council, Consortium, and Prevention Planning Group. It has to have concrete system and client outcomes to the services provided within the system. The COC is more than a list of services, however, it is a plan for maintaining, improving and adding the strategic linkages that promote efficient and effective service delivery.

REVIEW OF THE EXISTING CONTINUUMS OF CARE

In specifying and modifying the Houston Area COC, the project team reviewed and documented lessons learned from the continuum of care of other EMAs.

Methodology

In reviewing the existing COCs throughout the nation, 49 eligible metropolitan areas (EMAs) were found to receive Title I funding. Of those 49, 45 in the contiguous United States were contacted to send the team information about the COC. Multiple attempts were made to contact these EMAs, either through the designated contact person, the Planning Council Chairperson, or other Ryan White personnel. The project team was able to reach 23 of the EMAs. All of the EMAs had comprehensive plans and some kind of description of their service delivery system, but only six provided a visual representation or model of their existing COC.[40] This visual model provides a snapshot of how planners can delineate and arrange services and linkage mechanisms within an HIV/AIDS system of care. These visual models were provided by:

1. Cleveland, Ohio
2. Hudson County/Jersey City, New Jersey
3. Austin, Texas
4. Riverside/San Bernadino, California
5. New York City, New York
6. Orange County, California

Demographics

The demographics related to a number of variables in both these six sites and in the Houston EMA are noted in Tables 1 – 5 at the end of this section.

Table 1, on page 9, summarizes population figures along with growth, projected growth and migration figures for each EMA. The Houston EMA includes six counties: Chambers, Fort Bend, Harris, Liberty, Montgomery, and Walker. Table 1 indicates that:

- Of the seven EMAs reviewed, Houston had the second largest land area, behind Riverside/San Bernadino.
- Houston was second behind New York City in population.
- The Houston EMA is currently ranked eighth in national population, and has experienced a 21.2% population growth between 1990 and 1996. Austin was the only EMA reviewed with a higher percentage of population growth (24.7%).
- Only Houston, Riverside/San Bernadino, and Austin experienced a positive net migration between 1990 and 1996. Houston's population is expected to continue growing, with an anticipated 12.6% projected population growth for 1996 through 2002.

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[40] It is important to distinguish between the service delivery system and the existence of a visual presentation of the COC. Further, the existence of a COC model does not assure that it is implemented or descriptive of the actual service system.

Table 2, on page 10, takes a look at the racial and ethnic make-up of each community included in this study.

- In general, the population of the Houston EMA most resembled that of the New York and Hudson County/Jersey City EMAs in racial breakdown. These three EMAs had a larger percentage of African Americans than the other EMAs. New York had the highest percentage at 21%, followed by Houston with 18% and Hudson County/Jersey City at approximately 16%.
- The Orange County EMA had the highest percentage of Asians/Pacific Islanders, with about 12% of the population, while this racial group only comprised 2.4% of the Houston EMA population.
- All the EMAs had approximately 1% or less of the population American Indian, Eskimo, or Aleut.
- In the breakdown by ethnicity, Hudson County/Jersey City had the highest percentage of the population with Hispanic origin, with 37% of the population. The Austin, Riverside/San Bernadino, and Orange County EMAs had between 25% and 30% of the population of Hispanic origin. The Houston EMA had 13% of the population of Hispanic origin.

Client Profiles

Table 3, on page 11, details client characteristics of recipients of Ryan White CARE Act (RWCA) funding. Approximately 25% of the clients served by the Houston EMA in FY 1996 were female. This gender breakdown is most similar to the Austin EMA, which had about 22% female clients served. Both the New York and the Hudson County/Jersey City EMAs served a higher percentage of female clients, with 43% and 39% female clients, respectively.

With respect to race/ethnicity, both African American and Hispanic clients were disproportionately represented among clients served by the RWCA in the Houston EMA. African Americans comprised approximately 18% of the population in Houston in 1996, but were 43% of clients served. Houston’s Hispanic population is also over represented among RWCA clients: Hispanics were 18% of the clients served but only comprised 13% of the general population in 1996. These figures concur with overall trends in the epidemic. According to the Centers for Disease Control and Prevention (CDC), African Americans have the highest rate of HIV infection: 92.9 per 100,000 in 1995. Hispanics had the second highest rate: 46.2 per 100,000 in 1995 (CDC, 1998).

The breakdown of the age of RWCA clients in the Houston EMA is similar to the other EMAs that were identified for comparison. Approximately 96% of the clients served in the Houston EMA were 20 years of age or older. Only about 2% of the clients were adolescents, and 2.5% were children under age 13. The Hudson County/Jersey City EMA had the largest percentage of children under 13 served, with approximately 8% of clients served. The New York EMA had both the largest percentage of adolescent clients in FY 1996, with about 11% of the clients served, and the largest percentage overall of children and adolescents under age 20, with about 17% of the clients served.

Table 4, on page 12, looks at information related to exposure category. Almost half of the clients served by the RWCA in the Houston EMA were in the category of men who have sex with men (MSM). This percentage is more than double that of both the New York and Hudson County/Jersey City EMAs.

Approximately 17% of Houston clients were in the injection drug use (IDU) exposure category. While this figure is about double that of both the Austin and Riverside/San Bernadino EMAs, it is less than half of the percentage of IDU exposure of the New York and Hudson County, New Jersey EMAs. With approximately 8% of clients in the exposure category of heterosexual contact, Houston also has approximately half as many clients as the New York and Hudson County/Jersey City EMAs in that category. It is significant to note that the Houston EMA had the highest percentage of clients in the combined MSM/IDU exposure category, with 17.5% of clients served.

RWCA Funding[41]

Table 5, the final table at the end of this section, details the Title I and Title II expenditures for several of the EMAs. In FY 1996, the combined Title I and Title II Ryan White CARE Act funding for Houston was $9,706,735. This amount represented 32% of the total funding for HIV services in the community. Therefore, approximately 68% of HIV services in the Houston EMA were funded through other sources. This percentage was comparable to that of the Austin and Hudson EMAs, with 38% and 35% of total funding from Titles I and II, respectively.

Both the New York and Riverside/San Bernadino EMAs had a higher percentage of RWCA funding, with approximately 50% of HIV services funded through Titles I and II for both EMAs.

Table 3 indicated that 27,080 clients were served through the RWCA in the Houston EMA in FY 1996. Approximately 39% of these clients, or 10,490 people, were new clients. By contrast, in the other four EMAs, approximately half of the clients served were new clients.

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[41] Statistical information for Ryan White CARE Act clients and providers was not available for the Cleveland and Orange County EMAs, therefore these two EMAs are not included for comparison in Tables 3 through 5.

Table 3 EMA Demographics

EMA	**Houston TX**	**Cleveland OH**	**New York NY**	**Austin TX**	**Riverside/ San Bern. CA**	**Hudson County/ Jersey City NY**	**Orange County CA**
Land Area	5,921 Sq. miles	2,708 Sq. miles	1,148 Sq. miles	4,226 Sq. miles	27,270 Sq. miles	47 Sq. miles	790 Sq. miles
Population	3,791,921	2,233,288	8,643,437	1,041,330	3,015,783	550,789	2,636,888
National Population Rank	8	21	2	55	11	88	5
Population Growth 1990-96	21.2 %	4.8 %	2.9 %	24.7 %	16.9 %	-0.4 %	9.4 %
Projected Pop. Growth 1996-2002	12.6%	0.6 %	-0.3 %	14.2 %	14.7 %	-0.4 %	5.3 %
Net Migration 1990-96	+ 36,250	- 59,448	- 976,137	+ 113,773	102,585	- 69,855	- 177,332

Source: American Community Network

Table 4 EMA Population Breakdown by Ethnicity

EMA	Houston TX	Cleveland OH	New York NY	Austin TX	Riverside/ San Bern. CA	Hudson County/ Jersey City NJ	Orange County CA
White*	79.0 %	92.0 %	72.0 %	89.0 %	87.0 %	75.9 %	85.4 %
Black	18.4 %	7.0 %	21.2 %	8.8 %	7.2 %	15.7 %	1.9 %
Asian or Pacific Islander	2.4 %	0.7 %	6.1 %	1.3 %	4.7 %	8.1 %	12.1 %
American Indian, Eskimo, or Aleut	0.3 %	0.2 %	0.3 %	0.4 %	1.2 %	0.3 %	0.6 %
Hispanic	13.0 %	2.0 %	19.1 %	25.7 %	29.8 %	37.0 %	26.1%

Source: American Community Network

*All federal record keeping and data presentation is required to use four race categories (White, Black, American Indian and Alaska Native, Asian and Pacific Islander) and two ethnicity categories (Hispanic and non-Hispanic). Race and ethnicity are treated as separate and independent categories.

Table 5 Ryan White CARE Act Client Statistics

EMA*	Houston TX	New York NY	Austin TX	Riverside/ San Bernadino CA	Hudson County/ Jersey City NJ
Clients served	27,080	101,510	3,260	3,740	9,170
Gender					
Male	20,450 (75.5%)	57,600 (57.6%)	2,540 (77.9%)	3,160 (84.5%)	5,620 (61.3%)
Female	6,630 (24.5%)	43,210 (42.6%)	710 (21.8%)	570 (15.2%)	3,550 (38.7%)
Ethnicity**					
White	10,350 (38.2 %)	15,040 (14.8%)	1,650 (50.6%)	2,210 (59.1%)	1,890 (20.6%)
Black	11,510 (42.5%)	43,570 (42.9%)	910 (27.9%)	580 (15.5%)	4,110 (44.4%)
Hispanic	4,900 (18.1%)	38,250 (37.7%)	620 (19.0%)	800 (21.4%)	3,020 (32.9%)
Asian/PI	100 (0.4%)	1,510 (1.5%)	10 (0.3%)	40 (1.1%)	50 (0.5%)
Native Amer.	220 (0.8%)	380 (0.4%)	20 (0.6%)	50 (1.3%)	6 (0.06%)
Age**					
Under 13 y/o	680 (2.5%)	5,330 (5.3%)	90 (2.8%)	20 (0.5%)	770 (8.4%)
13-19 y/o	480 (1.8%)	11,570 (11.4%)	10 (0.3%)	30 (0.8%)	320 (3.5%)
20 y/o & older	25,910 (95.7%)	83,200 (82.0%)	3,150 (96.6%)	3,680 (98.4%)	8,060 (87.9%)

Source: Health Resources and Services Administration, HIV/AIDS Bureau
* Data unavailable for Cleveland, OH and Orange County, CA
** Percentages may not equal 100 due to missing data

Table 6 Ryan White CARE Act Percentage of Clients by Exposure Category

EMA*	Houston TX	New York NY	Austin TX	Riverside/ San Bernadino CA	Hudson County/Jersey City NJ
MSM	48.2%	18.2%	37.7%	48.1%	13.6%
IDU	16.8%	38.2%	9.3%	7.7%	44.3%
MSM/IDU	17.5%	1.8%	4.8%	5.8%	0.1%
Heterosexual Contact	8.3%	25.9%	6.8%	2.4%	27.8%
Other/Undetermined	9.1%	15.9%	41.5%	36.0%	14.2%

Source: Health Resources and Services Administration, HIV/AIDS Bureau* Data unavailable for Cleveland, OH and Orange County, CA

Table 7 Ryan White CARE Act Provider Statistics

EMA*	Houston TX	New York NY	Austin TX	Riverside/ San Bernadino CA	Hudson County/ Jersey City NJ
# new AIDS cases for 1995 (% national total)	1,158 (1.62%)	10,496 (14.70%)	323 (.45%)	768 (1.08%)	760 (1.06%)
CY 1996 Title I funding	$9,035,644	$66,786,341	$1,709,019	$3,918,274	$5,031,492
CY 1996 Title II funding	$671,091	$6,578,542	$634,130	$632,829	$166,687
% total HIV Service Funding from Titles I & II	32%	50%	38%	47%	35%
Clients served	27,080	101,510	3,260	3,740	9,170
New clients	10,490	52,320	1,500	1,980	4,600
Estimated % with HIV**	35.8%	53.8%	54.1%	46.2%	36.7%
Estimated % with AIDS**	62.3%	37.1%	34.8%	51.9%	57.0%

Source: Health Re sources and Services Administration, HIV/AIDS Bureau
* Data unavailable for Cleveland, OH and Orange County, CA
** Not all providers report HIV status

ASSESSMENT OF CONTINUUMS OF CARE

Types of Continuums of Care

For the purpose of this report, the model COCs received from the six EMAs have been categorized into four basic types. These are the *linear*, the *client-need centered*, the *hierarchical* and the *functional.*[42] Categorizing models into four different types is somewhat arbitrary and there is some overlap between the various models. However, it provides a way to delineate the major characteristics of each model and assist in deciding which model or features of each model are most suitable for the Houston community.

Table 6 summarizes the four types of models. The visual presentations of the COC models are found in Attachment 2.

Table 8 Continuum of Care Model Typology

Type	Definition	Example
Linear	- Straight line - Uses disease trajectory to define service delivery system	Cleveland, OH
Client-need Centered	- Client is focus - Flexible structure - Movement defined by client needs	Hudson County/Jersey City, NJ
Hierarchical	- Relational classification - Organized around core set of services	Austin, TX
Functional	- Represents functional categorization of client needs - Services are placed together because they represent similar functions	Riverside/San Bernadino, CA New York, NY Orange County, CA

Linear Model

The linear model suggests that services travel along a single line from entry into the system to, usually, death. The Cleveland model is an example of this type of representation. The client's entry into the service system is determined by the client's stage of disease, as defined by T-cell count. Movement within the system goes in one direction only, following the progression of the disease toward death. The client starts with the initial positive test and ends with a T-cell count of 0 to 50. Services are categorized according to this progression. For example, a client may start with referral to care, which becomes primary care in the early stages of infection and then ongoing care, medical care, intermittent disability, and then hospice services as ability for independent living decreases and the need for professional health care increases.

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[42] It is important to keep in mind that models assessed are visual representations of much more complex processes and systems. In addition, the snapshot view of the continuum of care as presented in these one-page models does not delineate how planners might go about arranging services and linkage mechanisms to make the model an actuality.

This model has several positive features. It demonstrates that many services are needed throughout the disease process, and that the *character* of the services may change as the disease progresses. For instance, legal issues are generally different at stage one than they are at the final stages.

The biggest drawback to this model is that it presents a dated notion of HIV and AIDS services. Today, the health and well-being of PLWH/A do not usually follow a linear progression from health to death. In addition, as a working model, it presents two particular problems:

1) The model does not emphasize the linkages that might be necessary throughout a system to make it most accessible and flexible to those who need it.
2) The format creates a fair amount of redundancy in the listing of services. For example, transportation is listed four different times.

Client-Need Centered Model

The client-need centered model has the client as its focus. The premise of the model allows for a flexible structure, but the organization of and movement within the model are defined by client needs and characteristics, and it is designed for direct client use.

The Hudson County/Jersey City, NJ, model is a good example of a client-need centered model. Hudson County refers to its model as a Care Map, and it is a step-by-step guide of where to go for HIV/AIDS services. If a client is concerned about getting tested, he or she can find out which services are available by going to Care Map I and following the arrows. It is the client's individual situation and needs that drive the structure of the model. The same is true of Care Map II. Once a test is positive, the client goes in one direction if they are a child or adolescent, another if they are an adult, and another if they are an adult with special needs.

This type of model's greatest strength is in providing the user with a clear entry point into the system and a clear path to the outcomes of care. The Care Maps are also good tools for case managers, giving them a cursory view of how the system works and allowing them to coordinate care and express the direction of care relatively easily to their clients.

However, while it is important for COCs to be responsive to client needs, this particular representation is not as helpful a tool for planners in designing and modifying the system. It does not show the system as a whole and does not demonstrate how the system needs to be designed, evaluated, or modified over time. This is particularly true in relation to portraying the linkages and coordinating mechanisms that are necessary to keep a complex system of care functioning efficiently and effectively.

Hierarchical Model

The hierarchical model is arranged by a relational system of classification organized around a core set of services. The model presumes that until a basic set of needs related to physical health, or survival, are met, the next level of need, which may be more related to quality of life, cannot be realized.[43]

The Austin model is an example of the hierarchical type of model. The core of the model is the basic needs category, or those services a PLWH/A needs for survival. The independence and life skills categories are the successive steps in the hierarchy reaching toward optimum emotional and physical well-being. At the bottom of the model are the resources, infrastructure, case management, and outreach functions that are required to maintain the system. They serve as integrating mechanisms for the delivery of services across all categories. With good resources, a sound infrastructure, and case management and outreach systems in place, a client can move from one service to another and one category to another.

Unlike in the linear model, there is no element of time implied. A client is not held to a particular service at a particular stage of disease. It is organized with the goal of living with HIV/AIDS and is flexible to meet the needs of the individual. The model is also a useful tool for planners because it represents all necessary parts of a well functioning system.

One problem with the model, however, is the relative arbitrary placement of services, which may not reflect the values of the PLWH/A who are using the services. For example, what one client sees as a service to reach a higher level of independence, another may view as a basic need. To the extent that the hierarchical arrangement might determine resource allocation, this placement of services could be a potential problem. It is likely that services needed by smaller target groups will be viewed as less "basic" and possibly under- or un-funded.

Functional Model

The functional model represents a planner's best understanding of how a system addresses a client's needs. Services are placed together because they represent like functions or serve similar functions within the overall system. Three of the models in this report fall into the functional category. They are New York, Riverside/San Bernadino, and Orange County, CA.

The Riverside/San Bernadino model organizes services into three categories: core, ancillary, and access. Core services address the basic needs of PLWH/A, that is, food, housing, safety/security, and health care. Beyond that are the ancillary and access services, which support health care and social needs and allow PLWH/A to address barriers to care.

The New York model uses four intersecting circles to describe its system. Each contains its own set of services: targeted, access, physical and life sustaining, and capacity building. This model was developed with the New York Planning Council in

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[43] It is similar in concept to the model of psychological health and growth articulated by Maslow, in whose schema the primary level relates to safety needs and the highest level encompasses the need for self-actualization and expression.

mind, referring to specific funding categories and work groups within the system that address the various resource issues and needs within their designated area.

The Orange County, CA, model uses a three-column chart with the following service categories: medical and healthcare, practical, and supportive. Placement of services in each category is defined by actual practice - vision care is a medical service, a food bank is a practical service, and respite care is a supportive service. This is a flat representation with no demonstration of a relationship between the services. What is interesting, however, is the use of italics to show services that are available but not funded by Ryan White.

The functional models serve as good tools for guiding councils and planners. They help to conceptualize the service delivery system and its various aspects, which enables these groups to focus on how to prioritize resource allocation and improve service delivery and integration.

On the other hand, the models are more or less static and they may not anticipate future client needs. The nature of the categories may not allow for the inclusion of new or emerging services that are necessary to the well-being of the client group. While they serve to address individual needs, they may not be very helpful to the everyday lives of PLWH/A because the total context of their need may not be addressed.

A second disadvantage is that the models are not user-friendly in their presentation. The New York model, for example, uses language unfamiliar to the general consumer. In addition, while the inclusion of services geared to specific populations is commendable, the wording and placement leads to a fair amount of redundancy in the listing of services and the uncertainty of where they are most appropriate.

Service Categorizations in the Models

There is little agreement on what should be basic or secondary services within the COCs. In the six models presented, there are over 100 services listed. As shown in Table 7, Riverside/San Bernadino lists 21 services as basic needs. Austin includes some of these but not others, adds some new ones, and comes out with a total of 14 "basic services". New York includes 11 "basic services". Austin, New York, and Riverside agree on three as basic: ambulatory care, dental care, and drug reimbursement. There are over 15 services that only one EMA includes as basic. Whether these categorizations reflect unique needs in each of the EMAs or whether they tend to indicated the somewhat arbitrary nature of categorizations is unknown.

Table 9 Functional Models Service Categories

	EMA		
1.1.1.1.1 Services	Austin	New York	Riverside/ San Bernadino
Ambulatory care	X	X	X
Dental care	X	X	X
Drug reimbursement	X	X	X
Adult day care		X	X
Buddy services		X	X
Emergency shelters	X		X
Food bank	X		X

Home care/skilled nursing	X	X	
Home-delivered meals	X		X
Hospice care	X		X
In-patient medical services	X		X
Mental health treatment	X		X
Rental/utility assistance	X		X
Emergency financial assistance	X		
Emergency medical care	X		
Emergency response			X
Food and nutrition		X	
Food – grocery vouchers			X
Housing / Apartments			X
Housing referral coordination		X	
Housing - Single room occupancy units			X
Housing - supportive housing			X
In-home supportive services			X
Skilled nursing facilities			X
Spiritual care			X
Substance abuse treatment	X		X
Supportive counseling		X	
TB services		X	
Treatment education		X	

Additional Continuum of Care Information

In addition to the six models presented above, information related to three additional EMAs has been gathered. In Sacramento, CA, a clearly defined continuum of care exists within the Ryan White Title I application. The system is built around Core Services, or those "essential to the infected person's health, longevity, and quality of life." These are augmented by Primary Linking Services and Support Services, which enable people affected by HIV/AIDS to obtain the core services and stay in care. The entire system is enhanced by Community Capacity Building Services designed to continually improve the system of care.

In New Haven, CT, the continuum has the goal of "sustain[ing] a seamless provision of services to safeguard the quality of life throughout all stages of the life cycle of this disease." The services are grouped into four categories: 1) health care, 2) psychosocial (including case management), 3) social service (food, transportation, etc.), 4) substance abuse treatment, and 5) extended care services. Case management with extensive collaboration and well-developed referral systems among all service providers is a key element.

In the New Haven model, there are three additional notable features: 1) Clinic Coordinators who oversee aspects of the clinic operations, including maintaining relations with clients and linking with case managers, 2) Early Linkage, a program designed to help transition a client from prevention services into the care delivery system and diminish the gap between testing positive and entry into primary care service, and
3) Interagency collaboration as a condition of funding through the Planning Council.

Detroit, MI, has developed a booklet that discusses the continuum of care. There are five elements: 1) Coordinating and Integrating Mechanisms, 2) Medical Care, 3) Mental

Health Care, 4) Population Concerns, and 5) Social Services. Under each element, they discuss the ideal for different types of services and the plan to reach that ideal. The goal is a functional continuum of care that will allow clients to “directly access care services at any point.” Individual (between providers, case managers and clients) and systemic (between payors, policy makers, and public officials) coordination is key to a seamless continuum of care.

DEVELOPING THE HOUSTON CONTINUUM OF CARE

Goals of the Houston Continuum of Care

The goal of the Houston COC is to specify and show the linkages between a full range of client-centered, cost-effective services that unify the prevention and treatment of the HIV epidemic in the greater Houston area.[44]

The objectives discussed within the Houston community have been:

1. To coordinate an innovative, complete continuum of care to meet the needs of the HIV infected and affected communities.

2. To ensure that the service model is client-centered and community supported.
   - 2.1 Develop and implement a system to bring clients into the planning and evaluation process.
   - 2.2 Develop a grievance procedure for clients.
   - 2.3 Develop marketing/communication strategies that ensure community participation.
   - 2.4 Develop reporting methods.
   - 2.5 Provide viable financial and administrative resources for the continuum of care to maximize service dollars.
   - 2.6 Streamline financial and administrative resources.
   - 2.7 Develop and implement strategies to secure ongoing funding.

3. To ensure accountability and quantitative evaluation of the continuum of care.
   - 3.1 Ensure that evaluation recommendations are addressed.
   - 3.2 Implement summative evaluation of the process.
   - 3.3 Implement an outcome-based system of evaluation.
   - 3.4 Disseminate results of evaluation process.

Process Outcomes

The process outcomes for a comprehensive coordinated delivery system include that services be:

1. Client centered: Clients must have input into defining their needs, assessing services, and modifying/changing services to meet their needs. This is achieved by assuring the:
   - 1.1 Participation of PLWH/A in the planning process.
   - 1.2 Feedback from PLWH/A through needs assessment and consumer satisfaction surveys and an accessible grievance procedure.

2. Proactive: The Consortium, Council, Prevention Planning Group, and providers must anticipate the changing needs of PLWH/A and the system has to be flexible to meet new needs.

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[44] This goal is based on the synthesis of Houston information.

3. Comprehensive: A comprehensive continuum of care for HIV/AIDS services often includes more than services funded by the Ryan White Care Act. A comprehensive system:
   3.1 Encourages the general public to provide continuing support to PLWH/A through supporting public programs that provide services.
   3.2 Promotes awareness of HIV status to those at risk so that they can receive early care and protect others from infection.
   3.3 Provides prevention services to those who are HIV negative.
   3.4 Provides treatment to those who are at all stages of HIV infection.

4. Dynamic: The system should suggest movement of persons from one service to another. Consumers move about in the system depending on their needs.

A New Conceptualization of the Continuum of Care

Several models that have a visual representation have been developed by other EMAs. Their characteristics, strengths, and weaknesses are outlined in the preceding section of this report. Most COCs have lists of services organized in linear, client-centered, and hierarchical or functional systems, as described above. However, none of them suggest outcomes for clients and none clearly delineate the different populations who use the system. In addition, all look relatively static and may be more or less difficult to modify as client needs change along with changing treatment strategies and new advances in care.

PCH/OCP suggests a new way to conceive the continuum that includes these elements. Often times, analogies help in understanding a model. In this instance, conceive of the Continuum of Care as a rail system made up of six rail tracks that move passengers up and down the lines to different stations. As shown in Table 8, the tracks are defined by their starting and ending points.

The tracks represent the general type of services. The qualifications refer to the types of consumers who generally take the different lines. The starting points define the key identifying factor for the passenger. The destination is the outcome for the consumers.

Think of the passengers as being in three classes:

1. Ambassador class: those with private insurance.
2. Business class: those with Medicaid or Medicare.
3. Coach class: those with no insurance or who are uninsured or under-insured.

Between the starting point and destinations are several station stops representing services. The consumer can choose to stop or skip that station. They can get on and off at different times and go back and forth on the line. If they have the right qualifications, they can move between lines.

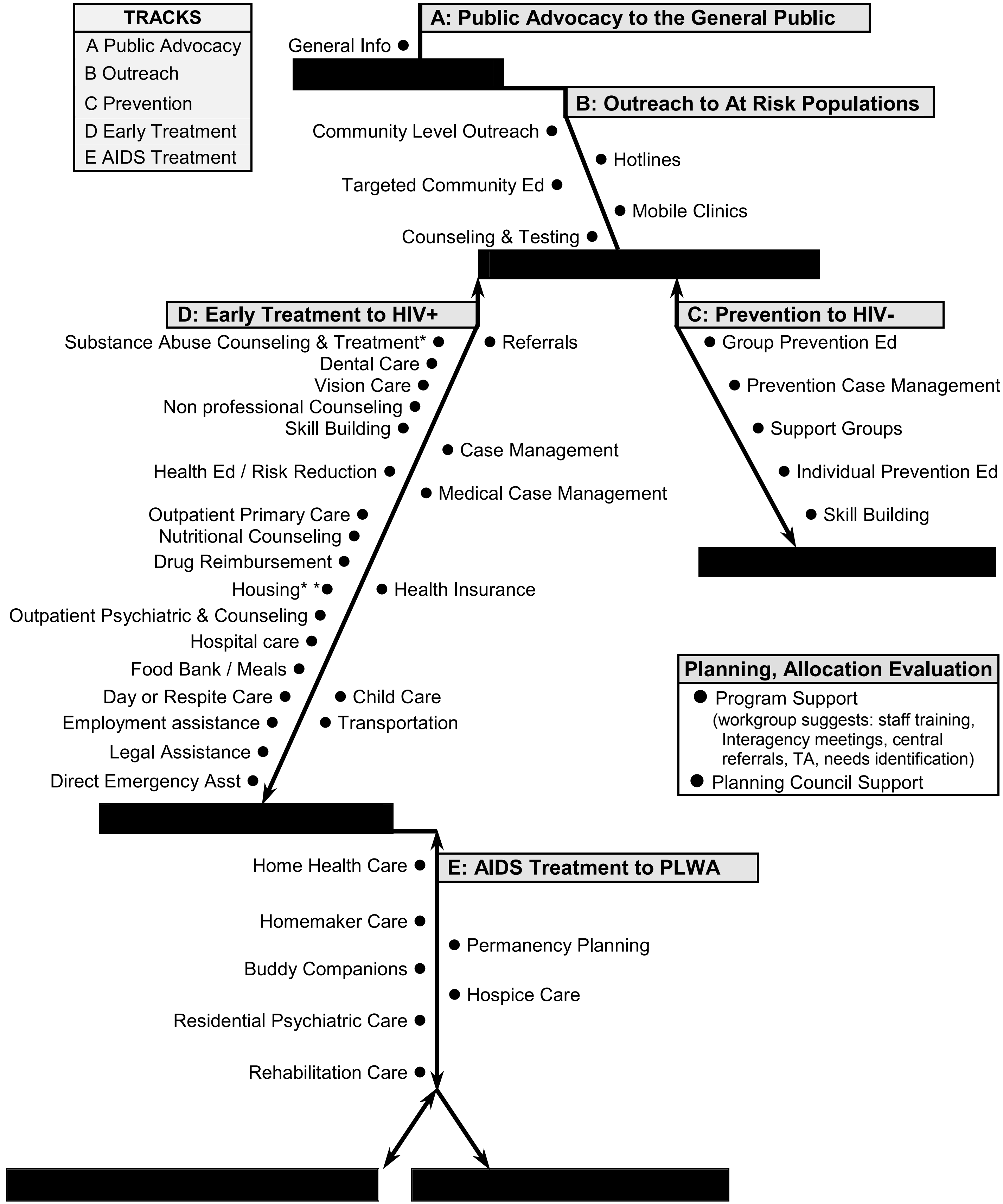
Table 10 Continuum of Care Lines

TRACK	QUALIFICATION	START	DESTINATION
A. Public Advocacy	General public	No awareness of AIDS	Support for HIV/AIDS

B. Outreach	High risk behaviors	No awareness of serostatus	Awareness of serostatus
C. Prevention	Knowledge of negative status	Aware of negative status	Maintaining negative status
D. Early Treatment	Early knowledge of HIV positive status	Awareness of infection	No progression to AIDS
E. AIDS Treatment	PLWA	AIDS diagnosis	Improved health status & quality of life (QOL) (or) Death with Dignity.

Figure 1, on the following page, shows what that system might look like for Houston. For the HIV positive lines, D-E , the “stations” on the left are those that provide access to the services on the right. The numbers in parentheses present the 1999 priorities. Following the Figure is a more full description of system.

Figure 2 HIV/AIDS CONTINUUM OF CARE



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

To summarize the features of this system:

- It has several tracks, each defined by its outcomes.
- Consumers can enter the system at any point on the track, provided they are qualified.
- Consumers can travel up or down the line.

Working with the Continuum

At this point, the continuum of care presented in this report is a framework, but it is not the recommended Houston Continuum of Care. Rather, it is a place to start. There are several tasks to be completed, including:

Defining the Services

The first task is reviewing the services and their placement on the system. Are the services on the right track? For Ryan White services, this is particularly relevant for the HIV positive tracks (D-F) that feed into the PLWA1 (initial stages) and PLWA2 (late stages) tracks. The service stops along these tracks are largely predetermined. While some adjustments may be necessary, HRSA and the past history of the Houston EMA have determined the services and the eligibility of the consumers. The largest challenge is to set the terms of eligibility between HIV and AIDS.

Defining the Consumer

The second major task is to review who the consumers are and project who they are likely to be in the future so as to ensure that the system has the capacity to meet their needs. This is done by reviewing the existing and projected profile of consumers in the epidemiological review. For each of the different populations, estimates can be made regarding their utilization and the capacity of the system to serve them.

A well-operating system will not have a lot of excess capacity, but at the same time also will not have huge waiting lines. In addition, a well-operating system will ensure that there are adequate ways for people to feed into the system. Several factors need to be considered and figures will be available after completion of the needs assessment:

1. Knowledge of the potential number of consumers in the system so we can start to determine the capacity of the system. These include:
    1.1. General population
    1.2. Targeted population
    1.3. HIV positive in the system
    1.4. HIV positive out of the system
    1.5. PLWA early stages
    1.6. PLWA late stages
2. Knowledge of the insurance status of the consumer in order to determine how many seats of the different classes to install in the system. How many will be full-paying consumers (How many with insurance)? How many will be subsidized (Medicare, Medicaid, State or Federal drug reimbursement, etc.)? How many will be nonpaying (uninsured)?

3. For those subsidized consumers, it will have to be decided if there are more efficient ways to

have them access the system. What services can be provided to those who have Medicaid and Medicare? Will managed care provide the access to needed services? How can those with private insurance best use the system to obtain the best treatment?

4. The planner of the system should have a good profile of the consumers in order to determine if the services will meet their different needs and demands. Consumers might be divided by:
    - 4.1. Ethnicity
    - 4.2. Special situation
    - 4.3. Risk population
    - 4.4. Sex
    - 4.5. Co-morbidities

5. The planners of the system should make sure that the consumer has direct input into the systems through the use of needs assessment surveys and participation on the various planning bodies.

Creating the Linkages

When planning the placement of service, and the opening of new services, the linkages between services are equally as important as the services themselves. There are competing objectives:

1. Reduce redundancy of administrative burden and services in the system while ensuring adequate access to those who live in distant areas.

2. Provide adequate input of services through multiple points of access. Think of this as designing a ticketing facility. For HIV and AIDS services, we need not only direct outlets (testing), but adequate links to emergency rooms, drug treatment, STD clinics, and acute care facilities.

3. Facilitate services while not overburdening the staff and capacity of the system.

4. Ensure continuity of services so that consumers find that they are able to move around the system and will not be stuck at any one station.

Training the Providers

Training providers and their staff is key to having a well-running system. Without trained staff and assurances that they have adequate benefits, any system will break down. Is there adequate formal and informal training? What is the benefit structure for the staff?

Informing and Training the Consumers

Informed consumers are the best consumers. What efforts are made to have them informed? Are the efforts coordinated?

Assessing the System

Every system should have standards. They might be divided into two basic areas:

1. How the system provides the services. For example common criteria include:
    1.1. Waiting times
    1.2. Quality of services
    1.3. Consumer satisfaction
    1.4. Ability to spend the allocated funds on the contracted services

2. Did the system have the desired outcomes?
    2.1. Health status: mortality and morbidity
    2.2. Quality of life

INPUT FROM THE COMMUNITY[45]

On February 24th, 1999 the PCH/OCP project team facilitated a community meeting to review the theoretical framework, present the models from other EMAs, and outline a proposed model for the Houston community. As a starting point, the group agreed to use the proposed model for discussion related to how this community would like to see the continuum of care represented.

In discussing the Houston COC, two groups were formed. One centered on prevention services and one on services to those who were infected or affected by HIV. Several questions were posed to the groups. These related to appropriate services, special populations, linkages, and training and support for providers and administrative agents.

The information from these groups will be used in conjunction with data from the consumer surveys, focus groups, and provider surveys in developing the final recommendations for the Continuum of Care.

What Should Be Modified on the Proposed Model Continuum of Care?

General comments from the participants indicated that the concept of viewing the continuum of care as service tracks that served six population groups (defined by their risk, exposure to, or point of HIV disease progression) was well received. There was some concern, however, that the track system as delineated suggests that services are time-linked in a linear fashion with one following the other. While the intent of the system is to show that it is nonlinear (people can get on or off the system at different stops and at any time), this was not clear from the analogy. Some participants also felt that the hierarchical Austin model made more sense for the Houston EMA.

Within the context of the "track" system, some participants felt that a better method would be to show the services grouped together (particularly for D and E) with entry to the universe of services at many different points. This would prevent the model from unintentionally misrepresenting how services are needed by, or available to, consumers who are HIV positive or diagnosed with AIDS. While the level of need may differ with the different diagnoses, the service itself is still required. Others felt that the tracks should only be seen as a reference point and should not be interpreted literally and also pointed out that some services do indeed have eligibility criteria based on severity of illness.

Several comments noted the linear "look" of the system and suggested more intersecting "stations" and highlighting the major junctions and overlap of the "tracks." This change will be presented in the final recommendation.

There was also some concern expressed with the outcome "Death with Dignity" if the model were to be useful in working directly with clients. The consensus was that this

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[45] A revised continuum of care reflects comments that the suggested continuum of care was too linear and the lined too "vertical". In addition, the difference between early and late treatment is visually closer. The outcome "death with dignity" was not revised after the Council felt that it best reflected the "end point" of late treatment. The services are limited to those funded under the existing Ryan White. Suggested additional services will be discussed in the forthcoming Needs Assessment.

designation should be changed if such use was anticipated. If the model is to be used as a planning tool only, it could be acceptable to leave the outcome as stated.

These issues will be addressed in the final model. Comments related to specific tracks on the model or targeted populations groups were also provided by the two groups. These are categorized according to the Tracks that are affected.

Specific comments regarding the tracks included:

Track A. Public Advocacy/Information: In addition to what is already represented on Track A, the population at large should receive general information through the media and mass marketing, as well as hotlines, that could provide basic information.

Track B. Outreach: In addition to the services mentioned as additions to Track A, the participants mentioned the need for:

1. Mobile clinics
2. Outreach workers and transportation services to allow persons to have post-exposure prophylaxis (PEP)
3. Counseling and testing
4. Health education risk reduction (HERR) services
5. Preventive case management
6. Individual and group preventive education
7. Support groups
8. Skill building opportunities
9. Job training
10. Education and housing assistance
11. Classes offered to couples with sero-discordance so that they may maintain their status and preserve their health
12. Needle exchange programs for high risk groups

Several participants noted that while many of these services were listed on Track C, they should be started earlier.

Track C. Prevention: The new services identified in B (job training, education, housing assistance, PEP, HERR, preventive case management, transportation services, mobile clinics, outreach workers) should be continued on this track. An HIV/AIDS vaccine would be appropriate here.

Track D. Early Treatment, Track E. AIDS Treatment, and Track F. End Stage Treatment: These tracks should be combined with multiple depots for entry into the system.

The services between D and E in particular should not be separated, as they are needed by both groups. In addition, access to services such as childcare (infected and affected children) and mobile clinics should be included. Other services to include:

1. HERR
2. Permanency planning
3. Support groups (non professional - peer counseling)
4. Housing assistance (rent, locations)
5. Job training, education and employment assistance
6. Skill building to include empowerment and self advocacy
7. In-house recovery counseling
8. Transitional, scattered-site, congregate, or temporary housing (focus on women with children and consumers outside Harris county)
9. Nursing, social, and family-centered, as well as medical, case management
10. Medical detoxification and stabilization services

What Are the Primary Issues Related to Special Populations?

Prison Population

There is no consistent care in the penal system. Currently, there is no case manager at the Sheriff's Department to meet the needs of the HIV positive prisoners and soon-to-be-released population. Issues relate to mistreatment, being burned out on medicines, treatment complications, and many psychosocial problems. When they are released, there is no continuity of care or transfer of services. A serious gap in the delivery system exists between the time of release and when they are connected to a case manager and can apply to the Thomas Street Clinic.

HIV Negative Children of HIV Positive Adults

As this population is underserved, it is not clear how many children fall into this category. Both the HIV positive adults and the children are affected when there are no services that can handle the needs of parents with children. This includes providing day care when the parent is in treatment and offering suitable transportation for both the children and the parent. Women often sacrifice their care in the long run in order to meet the needs of their children. These issues go back to the intake/assessment process in that the case manager needs to be able to refer outside of the system to take care of the children - a dual referral process. These children lose services after the death of their parent/s although some programs do have a grace period.

Older Adults

Older adults who have not become eligible for Medicare often cannot access the system. There is a need to have geriatric case managers to support this population group.

Adolescents

Adolescents, particularly those who are homeless, have special needs. Services that should be targeted to this group include peer groups, information on safer coming out and general counseling services regarding HIV status.

Recreational Drug Users

This group is particularly prone to indulging in risky sexual behaviors. They have a need for prevention services, including needle exchange programs, to ensure that they do not become HIV positive, or, if they are already positive, from passing the infection onto others.

Undocumented Persons

This group has been identified as one of three special studies to be included in the needs assessment. There are several major issues that impact this group of persons. First, the language and cultural barriers often preclude someone from seeking services. While Title I does not require documentation of citizenship, some agencies are confused about this. In addition, persons hesitate to approach agencies for fear of losing their anonymity and worry about the confidentiality of the information that they share with the agency. Building trust is a key issue and should be emphasized with all service providers. Providers also need to understand how cultural barriers other than language can impede the provision of services. Cultural competency extends beyond learning a new language.

Gay Males

Special attention should be paid to gay males for prevention services. These should include, prevention case management, skill building for safe behaviors, and relapse prevention services.

MSM/IDU

The Houston EMA, in comparison to the other EMAs described earlier (see Table 4), has a large percentage of clients in the MSM/IDU exposure category. Of particular importance is the need for needle exchange programs.

Sex Workers

Sex workers have special needs related to the frequency of potential risky behaviors. Prevention services are extremely important for this particular group.

Women of Color

This population group often does not seek services for a number of reasons: lack of access, fear of identifying self as HIV positive, limited resources, and all of the issues that impact parents of HIV negative children mentioned earlier.

Persons Returning to Work

Persons who have returned to work as their health status improves will often forego their health care because they do not want to take off work for doctor and/or clinic appointments.

Heterosexual Minority Men

This group may choose not to get services because they do not want to be identified as HIV positive. Special outreach efforts may be required.

How Do Linkages Work within the System?

Prevention Services

In the prevention discussion group, several issues were noted to improve linkages within the system on Tracks A and B. First, there should be transportation services that could get interested individuals to educational events. As clients come into the system, there should be a prevention case management system to ensure services are targeted and appropriate. A mobile outreach service could help identify potential at-risk clients who could benefit from prevention services. In addition, there should be better identification for referral services for the general public and at-risk populations.

Intervention and Treatment Services

The intervention discussion group noted the ***Centralized Patient Care Data Management System (CPCDMS***) as the new database that will facilitate access to integrated client record management. It was noted that there has been misunderstanding and lack of communication about how the system will work. All Ryan White services will be connected to the system and other entities can purchase the software to become a part of the system. While the protocols for these linkages have not been established, this system is viewed as a potential solution to the ongoing issue of client record keeping. The further development and testing of the system over the next year will be an important step in building effective linkages in the Houston EMA.

A lengthy discussion was held about the advisability of having the client records reside with the client and moving from site to site with that person. However, issues of record loss and replacement make this an inadvisable method of client tracking and reporting.

Cross contracts between service providers have worked well to facilitate collaboration. However, there are several issues. It is often difficult to get like service providers to the table to collaborate. Competition over limited funding can be a barrier. Because of access to funding streams, alliances change from contract year to contract year. In order to do effective collaboration, one must know the agencies well, trust their intentions, and know their various agendas. There needs to be better methods of having this occur in order to facilitate more collaboration and joint case planning.

Single year funding is noted as a strong disincentive to collaboration, case planning, coalition building, and evaluation. Group members noted that multi-year funding is necessary for continuity of service alliances as well as client care. While it was recognized that HRSA mandates the project length, many felt that multi-year funding should be advocated for. There was a recommendation for 5-year funding with an end to the RFP process as it currently exists.

Planning, building effective services and ensuring quality care all require multi-year endeavors. Clients are often hurt as one agency loses funding and another picks up the client base. In competitive funding, when an application is not accepted for renewal, valuable information is often lost and valuable time is spent in reinventing the wheel to recreate the client's service history. Clients are often loyal to case managers, not the agency. Information is lost in the transition to new services. Under current rules, this transition must take place in too short a time frame - the current 30 day Title I time period needs to be extended if multi-year contracts are not a possibility. Clients often abandon the system in these transition periods. It is not appropriate to ask case managers to make up for dysfunctional systems. Rather, these complex linkages must be improved.

There was a recommendation to explore a **voucher system** that would allow money to go to a client who could then purchase services when and where needed rather than having the funds go to the agencies through a competitive bid process. In addition, not enough clients are applying for Medicaid. They are often in the Ryan White system because it is easier to sign them up for those services. There are outside funds and State tax funded services that could be available to clients if they would access them. Better linkages between all types of services would facilitate more appropriate utilization of both treatment services and funding streams.

One additional issue was noted: There needs to be continued efforts to develop **standards of care** and to ensure that services actually reach these standards. Follow-up and quality of care evaluations are needed to ensure that the service delivery system is working well on behalf of clients - both the individual services within the system as well as the linkages that are developed to integrate the many and varied service categories.

What Services Should the COC Include for Providers and Administrative Agents?

Benefits and Perks

A primary need identified by both discussion groups was a benefits and perks package to include health insurance, retirement, and workmen's compensation. By doing this as a pool of providers, premiums could be reduced and there would be less likelihood that workers would lose benefits as they transferred from one agency to another.

Staff Training

Another area identified by all participants relates to staff training. This is needed in several different areas. First, bereavement training - the cost of caring - to help identify and mitigate the stress of working with a population that often experiences death. There was a recognition that there is a difference between those providers who live with AIDS themselves and those who do not and how they relate to clients and handle client issues and their own mortality.

Additional training should be offered in the area of cultural competency, enhancing the quality of care, fund raising, supervision skills, good management practices, and resource and referral issues, such as using Medicaid and accessing United Way services. It was noted that the Council has just approved an allocation of funds for case management training. In addition, there should be contract requirements to provide ongoing staff development training.

Interagency Meetings

Participants suggested that more meetings among agencies would not only improve linkages for clients, but also provide the opportunity for developing individual and organizational skills through joint in-service training and case collaboration.

Integrated Funding Streams

Individual funding streams often lead to fragmented care as an agency may be covered for one type of service but not another. While some agencies might have the expertise to provide the additional services, they often do not have the resources or may not wish to assume the liability of taking on the additional work without reimbursement or contractual authority to do so.

Technical Assistance

A technical assistance program that would allow agencies to call for specific help in addressing a time-limited, discrete problem could help improve service delivery and client outcomes.

Central Referral System

When agencies identify a problem or issue with a client that they themselves cannot address, it is not clear who they should call to get the appropriate service for that client. A central referral source that has access to client records and care plans would facilitate effective service provision for both service providers and their clients.

Geographical Coordination of Services

Case management is about more than just race/gender/family type, etc. It is also about community. If services were more geographically coordinated, there would be fewer transportation problems and better linkages. Originally, the service delivery system was developed from an emergency response, and it still does not reflect a client-needs perspective. Resources began as a cluster around a central area and 15 years later it remains the same. Retooling the system could improve quality of care and client access.

Provider Survey

It was noted that a provider survey to identify provider needs would be very helpful in identifying what issues need to be addressed. The surveys that have been done often go to top level management who may not understand the needs of line staff. The survey should be broad based to identify needs at all levels within the service provider system.

NEXT STEPS

This is a working document in the continued development of a Houston Area HIV/AIDS Continuum of Care. This document will be submitted for review to the community for their review and comments.

Comments will be incorporated into the final draft, and if the community is interested in working with the recommended framework, a second community workgroup will be facilitated by the consultants.

The recommended framework will be used as a context for the information being collected in the needs assessment consumer and provider surveys and focus groups. To the degree possible, as suggested in Working with the Continuum, page 24, the service needs, gaps and barriers will be quantified for the continuum of care. The final model will then be developed and presented along with the full needs assessment report.

Attachment 28 Mission and Vision Statements

Missions

The mission of the Ryan White Planning Council is to "improve the quality of life and advocate for those infected and/or affected with HIV/AIDS by taking a leadership role in the planning and assessment of HIV resources."

The Houston HSDA Care Consortium has the following as its preamble: "We, the members of this Consortium, commit to each other that we will endeavor to provide the highest quality services to our patients and clients. We pledge to cooperate together through honest debate and discussion in order to coordinate and deliver the funded services in a most efficient and effective manner. This Consortium does not tolerate prejudice in any form. No member of this Consortium shall discriminate on the basis of one's race, color, creed, gender, religion, sexual orientation, disability, or age."

The Community Planning Group (CPG) Mission: "Our mission is to develop a comprehensive prevention plan (the plan) to present to the Houston Department of Health and Human Services (HDHHS) as a guide for their HIV prevention efforts. Our task is to study the issues surrounding the HIV epidemic and provide input to HDHHS through the development of the plan. The plan addresses specific HIV prevention needs of various populations based on their 'high-risk' sexual and drug using behaviors. The CPG recognizes that BEHAVIORS put people at risk, not their particular race, ethnicity, or sexual orientation."

Visions

The vision of the Ryan White Planning Council is stated thusly: "We envision an educated community where the needs of all HIV/AIDS infected and/or affected individuals are met by accessible, effective, and culturally sensitive health and psychosocial services that are part of a full coordinated system. The community will continue to intervene responsibly until the end of the epidemic."

System Goals and Client Outcomes

In addition to these mission and vision statements, the Ryan White Planning Council has established three goals to direct their efforts. These goals also help to define the COC in the Houston EMA. They are:

1) Collaborate with and utilize information from all constituencies to plan and deliver high quality and cost effective care

2) Identify and provide services to unserved and underserved populations

3) Promote the dissemination of information on HIV prevention, treatment and resources

Attachment 29 Visual Models of Continuums of Care

HOUSTON EMA & HOUSTON HSDA CARE CONSORTIUM

NEEDS ASSESSMENT REPORT

Special Study – Rural PLWH/A

Prepared for

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

October, 1999
Revised November 17, 1999

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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 and three special studies. The three special studies consisted of a report on the continuum of care, a special study of rural PLWA/H and a special study of undocumented PLWA/H. The needs assessment and the two special population studies identify 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 and special studies is to facilitate informed decisions regarding medical and support services for persons living with HIV/AIDS (PLWH/A) that are funded by the Ryan White CARE Act and other sources.

This supplemental report describes the findings of the special study among rural participants and presents information obtained through the survey and focus groups of rural PLWH/A and specifically addresses their perceived needs, demands, and barriers to care.

METHODS

Focus groups, and a consumer survey were the major components of the special study among rural PLWH/A. The focus groups and consumer survey were sampled and recruited through the service providers serving rural PLWH/A and through word of mouth among participants.

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.

The focus group outline is shown in Attachment 3 and the consumer survey is shown in Attachment 4. The lists of services developed by PCH/OCP and the Needs Assessment Committee were derived from the list of funded services and services priorities set by the Planning Council. They are shown in question 46 of the consumer survey (Attachment 4). The list of barriers was developed based on prior needs assessments conducted by PCH using a multidimensional schema discussed in the Barriers Section, below. 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.

A total of 24 focus groups were held with participants of different ethnicity/risk category populations. While five groups were “open groups ”, 19 groups were ethnic or risk category, including three groups with rural PLWH/A. 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 and word of mouth. The targeted groups were recruited from providers and through outreach. Focus groups were held between April 1999 and June 1999. The consumer surveys were completed between April 1999 and July 1999.

Sampling

<u>PLWH/A Survey</u>

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 serving rural PLWH/A.
In addition, 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. Two focus groups were conducted in Conroe and one in Fort Bend. A total of 22 PLWH/A participated in the focus groups for rural PLWH/A. A total of 111 rural PLWH/A completed the survey. Due to the large distances respondents may have had to travel several interviews were conducted over the telephone.

For a full description of the logistics and methodology of the focus groups and survey refer to the full needs assessment report.

Demographic Profile of the Rural PLWH/A

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. Attachment 5 which presents the table of demographics for rural PLWH/A compared to the total sample shows that the populations are similar in many respects. When looking at these figures it is important to note that the sampling design included an overrepresentation of women, heterosexuals and people of color. As such, the rural sample under-represents MSM, Anglos and men. Also, the sample may be biased toward participants who were able or willing to travel the distances to get to the focus group facilities or the designated survey sites.

- Forty-one percent (41%) of the rural PLWH/A are MSM, 59% are heterosexuals and 20% report being IDUs. This is compared to 62%, 34% and 28% of the total sample who fall within each of the categories, respectively. The overrepresentation of heterosexuals and IDU compare to the 56% MSM, 19% heterosexual and 13% IDU in the epidemiological report of the rural counties.
- The rural participants are 67% male, 33% female. As compared to 82% male and 18% female in the total sample and 80% male and 20% female in the epidemiological profile.
- Thirty-nine percent are African American, thirty-seven percent Anglo, eighteen percent Hispanic and six percent other ethnicity. This is a very similar ethnic breakdown as seen in the total sample. There's slightly more African Americans in the rural sample (39%) compared to the total sample (35%). There is also an under representation of Anglos which account for 51% in the epidemiological profile.
- With about 44% of the rural participants having some level of college education, the level of education among the rural participants and the total sample (46%) is very similar.
- More than three quarters of the rural PLWH/A as well as participants from the total sample are single, divorced, separated or widowed.

- The larger percentage of rural participants live in their own place or a relative's place compared to what is reported by participants from the total sample.
- 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.
- A slightly lower percentage of rural participants have been in jail than participants of the total sample. 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.
- A much smaller percentage (12%) of rural participants than participants from the total sample (23%) total have been homeless for some length of time during the past two years.
- Twenty-two percent are currently employed in some capacity, part or full time and thirty-eight percent are on full-time disability. This is about the same percentage of PLWH/A from the total sample that is employed.
- Similar to the total sample, 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 the total sample as well as by rural participants are SSDI (49%), social security income (32%), and food stamps (32%). Over 80% receive assistance paying for their HIV/AIDS medications. ADAP pays for HIV medications for three quarters of the rural participants.
- Rural participants are more likely to be asymptomatic than participants from the total sample. Fifty-four percent of the rural participants are asymptomatic and less than half have an AIDS diagnosis.
- Eighty-five of the rural participants are currently taking HIV medications and more than one-quarter say they never skip a dose. These percentages are similar to those reported by the total sample.
- Among diseases that can be sexually transmitted, hepatitis, gonorrhea and syphilis are the most common types of infections among rural participants as well as participants from the total sample
- Slightly over 10% report having some form of tuberculosis, active or inactive. This is somewhat less than what is reported by the overall sample with about 16% reporting some form of tuberculosis.
- Similar to urban and the total sample populations, alcohol (78%), marijuana (56%) and cocaine (41%) are the top three substances used by rural participants.
- The income distribution for rural participants is similar to that of the overall sample. More than one third of the rural participants make between $6,000 and $25,000 a year.

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.[46] Responses to the prevention questions are shown in Attachment 6. Graphic representations of several questions are presented and discussed below.

HIV Testing

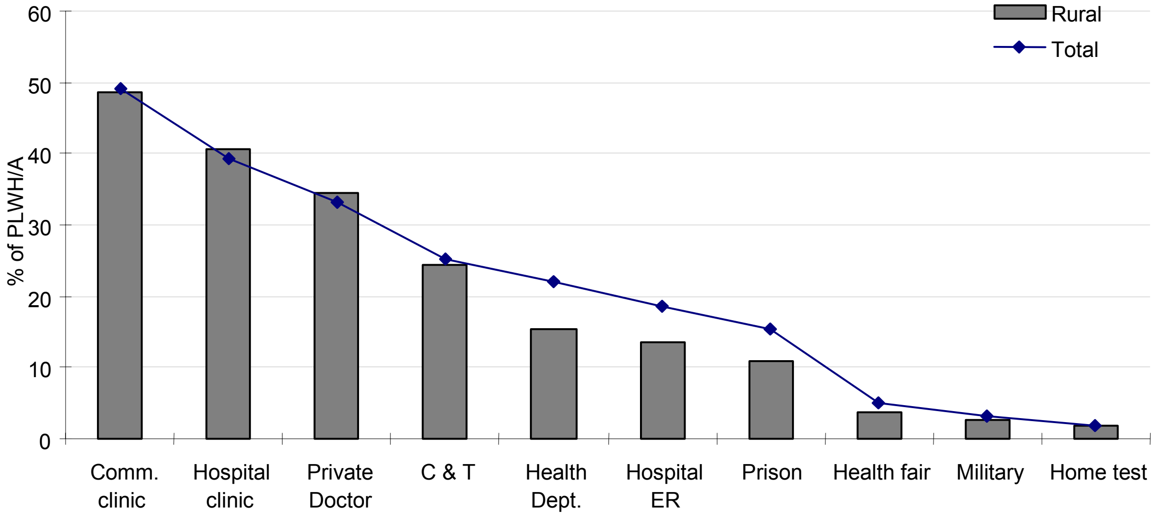
For the rural PLWH/A the most popular places for HIV testing are community clinics, hospital clinics, and private doctor's offices.

As shown in Figure 0-1, almost half of the rural participants reported receiving their test at a community clinic (black line). This is very similar to the overall total weighted sample who also report about 50% using this as their testing site. About 25% of rural PLWH/A reported being tested at least twice (not shown in graph) in a community clinic.

The second most common testing site for rural PLWH/A is a hospital clinic. About 41% reported being tested in hospital clinics and about 15% said they were tested more than once.

Reported as the third most common testing site, more than one third of the rural participants were tested in a private doctor's office.

Figure 0-1 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 several ways of trying to reduce risk of re-infection or becoming infected with a sexually

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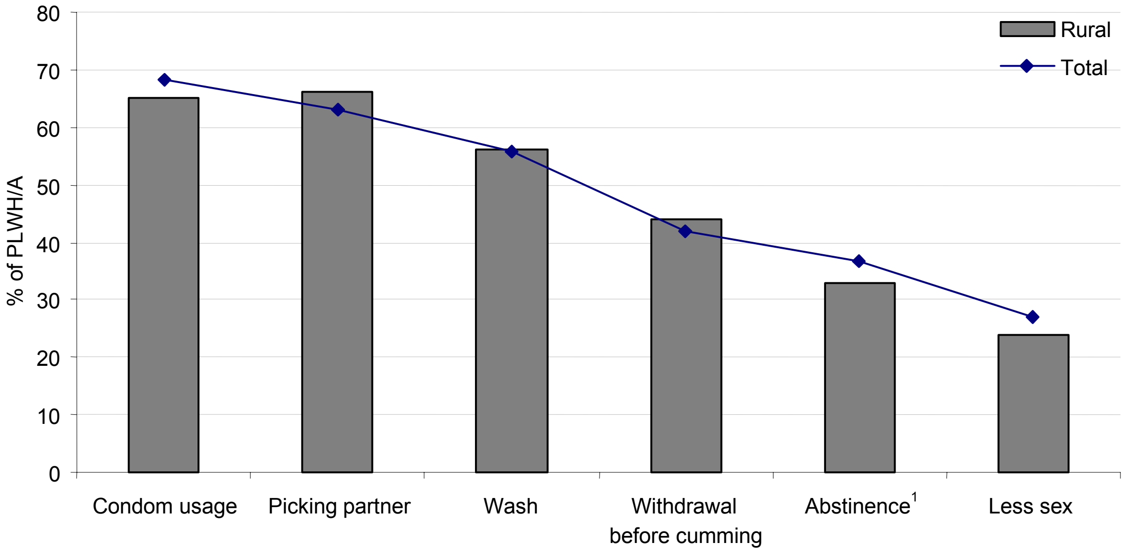
[46] The questions in the survey were of interest to the Prevention Planning Group, but should not be interpreted as a comprehensive examination of prevention behavior.

transmitted disease. As shown in Figure 0-2, being more careful when choosing partners, increasing condom use, and increasing washing before sex were methods that were the most popular to decrease the chances of (re)infection or STDs. More than 65% of the rural PLWH/A said they were now more careful when choosing a partner and also increased their use of condoms. Condom use among the rural PLWH/A is comparable to the overall sample population, with slightly more than half of the participants reporting using condoms all the time with their regular partner or a casual partner. Having sex less often or abstaining from sexual intercourse were the least strategies used for prevention of (re)infection or STDs.

Figure 0-2 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 0-3 indicates that rural PLWH/A report a similar frequency of condom use with both regular and casual partners as that reported by the total sample.

As shown in Figure 0-4, when asked why they don't always use a condom, more than 50% of the rural PLWH/A report several reasons for not using condoms. The number one reason (56%) is because they have the belief that their partners do not like condoms. The second and third reasons are because they "really love" their partner and they don’t like using condoms. Wanting to have a baby was a reason for less than 10% of the rural PLWH/A.

Figure 0-3 Frequency of Using Condoms

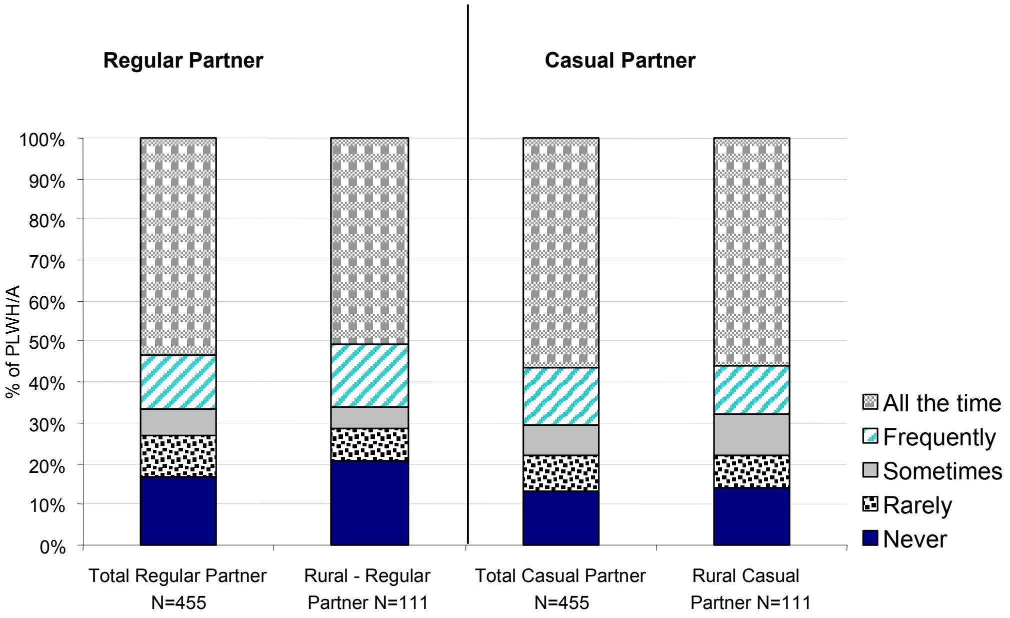
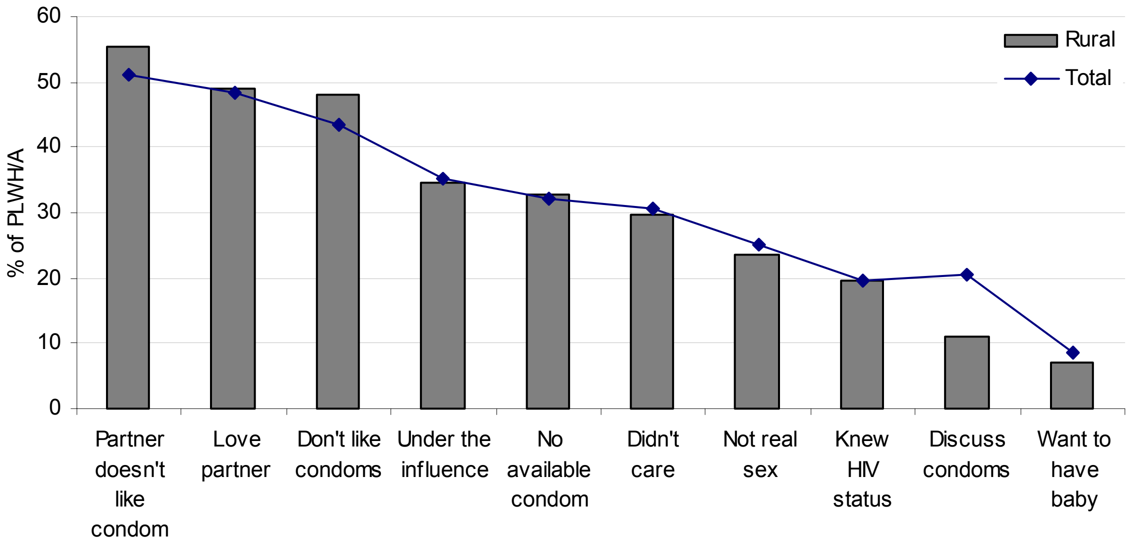


Figure 0-4 Reasons for Not Using Condoms

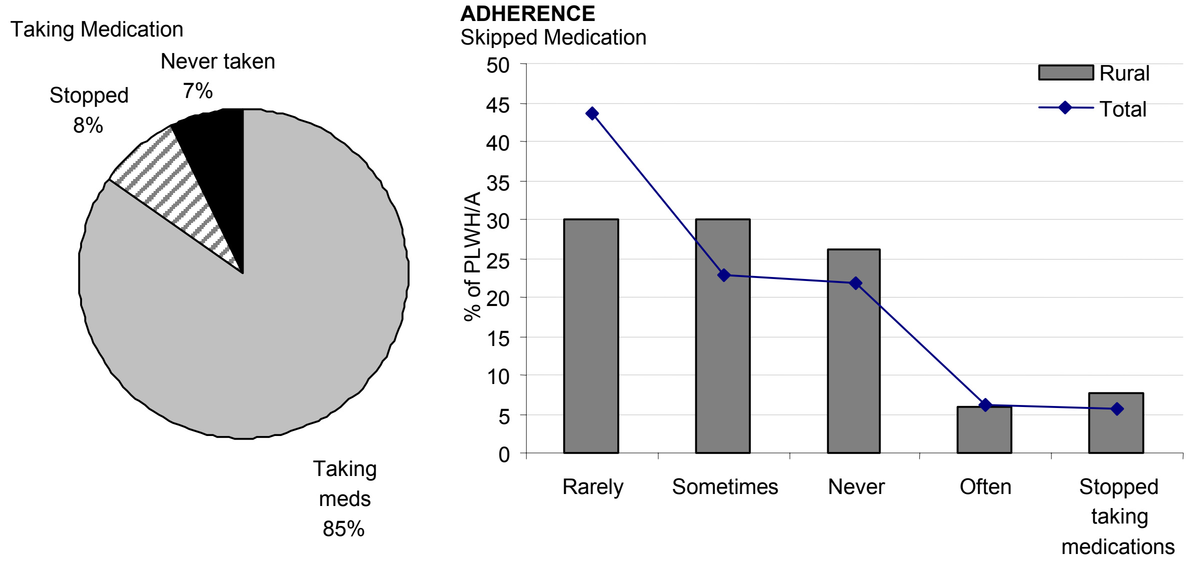


MEDICATION AND ADHERENCE

Medication

- As shown in the pie chart in Figure 0-1, eighty-five (85%) of rural PLWH/A are currently taking medicines for their HIV infection. Only pediatric caregivers (88%) and PLWA (87%) report a higher use of medications.
- The bar and line graph shows that less than 10% of the rural participants have never taken medication for HIV infection or have taken medications but stopped.

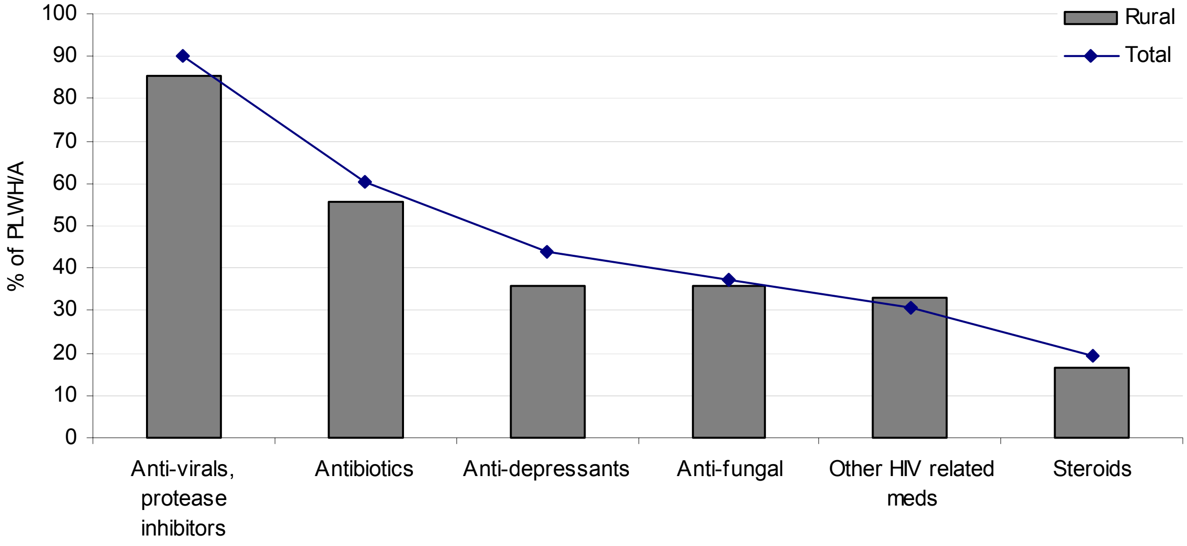
Figure 0-1 Medications



For those taking medication, as shown in Figure 0-2, over eighty-five (85%) take anti-virals and/or protease inhibitors. Similarly, over 85% of the rural PLWH/A report taking more than one anti-viral or protease inhibitor.

Antibiotics are the next most commonly taken medication (56%), followed by anti-depressants (36%) and anti-fungal medications (36%). As seen in Figure 0-2, there is not a big difference in the reported use of HIV medications between the rural and the total sample. The biggest difference is noted in the use of anti-depressants. About 36% of the rural participants report using anti-depressants compared to 44% of the overall sample.

Figure 0-2 Medication Taken by Rural PLWH/A

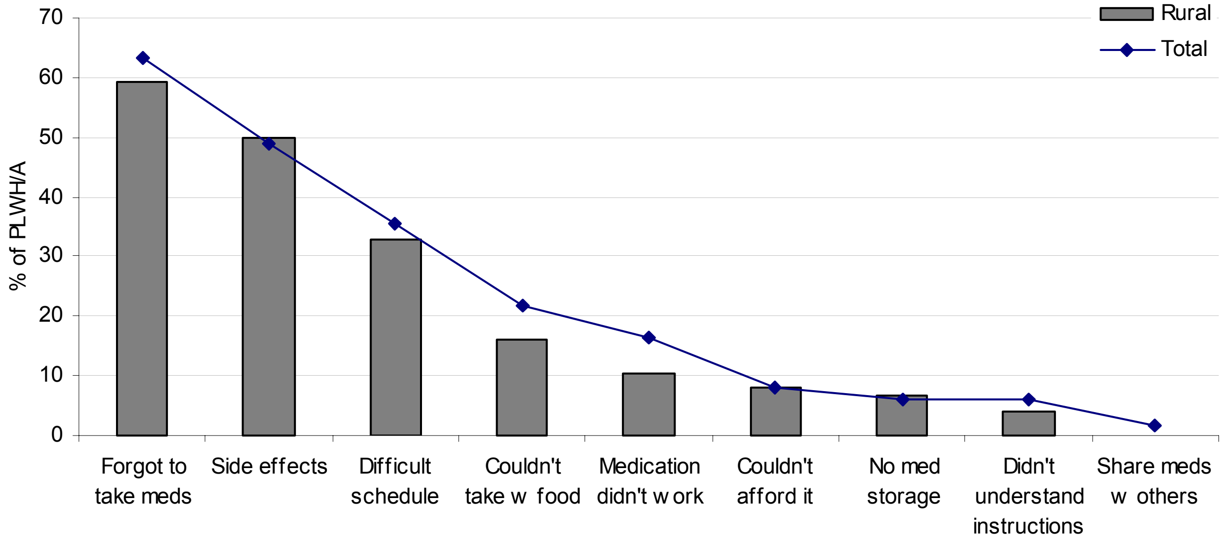


Adherence

- As shown in Figure 0-1, rural participants report similar levels of adherence with their medications as do members of other groups. More than a quarter of rural participants say that they never skip their medication, while about 36% report skipping the medications sometimes or often.
- Similar to other groups and the overall sample, when rural participants have discontinued their medication close to 85% have done so without the advice of a doctor.
- Fifty percent of the rural PLWH/A have experienced side effects associated with their use of HIV/AIDS medications.

Figure 0-3 indicates that close to 60% of the rural participants say they have skipped their medications because they have forgotten to take it. The second most frequent reason for skipping medications is the side effects associated to the use of the medications. Also, about one-third of the rural participants report skipping their medications because of the difficulty of the schedule. These are the same top three reasons reported by the overall sample.

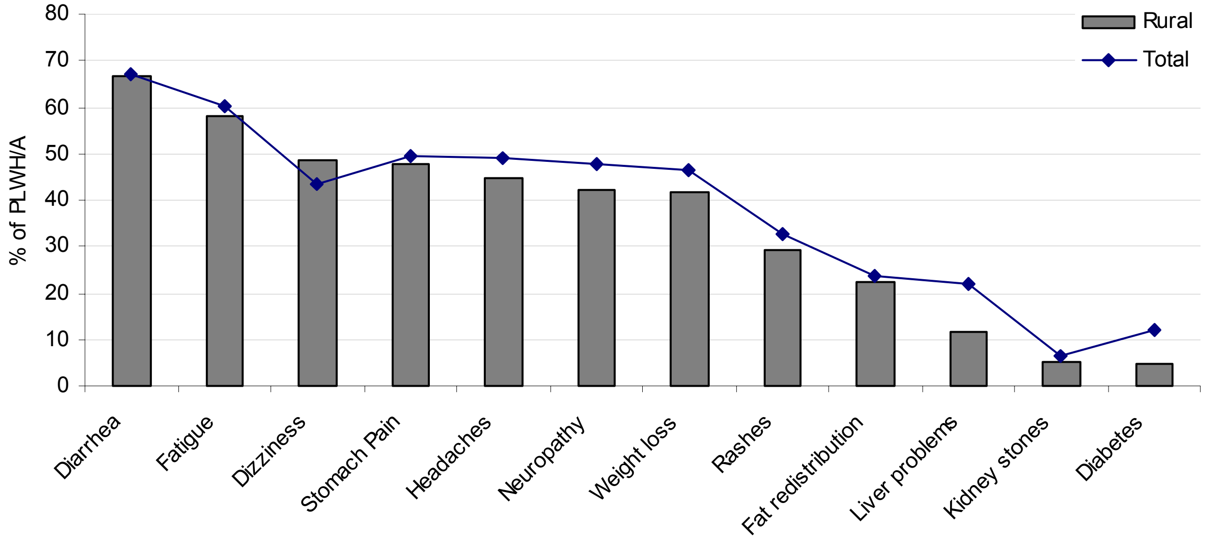
Figure 0-3 Reasons for Stopping Meds



Side Effects

On the most part, rural participants report about the same number and type of side effects as do the total sample of participants. Two exceptions are diabetes and liver problems. Less rural participants experience these side effects than the percentage reported by the overall sample.

Figure 0-4 Side Effects



OUTCOMES

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 0-1 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 the rural participants said they were asymptomatic, about 45% said they have symptoms.

Notably, more than one-third of the rural participants with no symptoms report excellent physical health and an additional 52% report being in good health. This is by far the healthiest feeling group among the participants. Even among the rural participants diagnosed with AIDS, close to 60% report good (44%) or excellent health (15%). Less than four percent of those diagnosed with AIDS and eight percent of those with symptoms report poor physical health.

About 50% of those living with AIDS say their physical health status has improved. HIV positive persons with symptoms are more likely to say that their health is worse (48%) than asymptomatic persons living with HIV or those diagnosed with AIDS.

Figure 0-2 reports the current perceived change in emotional health. Remarkably, 50% or more of the rural participants, regardless of their stage of infection report good or excellent health. Less than 12% of the rural PLWA and asymptomatic rural participants report poor emotional health and about 16% of those with symptoms report poor emotional health.

Similar to the overall sample, from 30% to 50% of the rural participants say their emotional health has improved. Symptomatic rural participants fair out slightly better than the overall sample, with 36% reporting worse emotional health compared to 41% of the overall sample.

The fact that the vast majority of those living with HIV/AIDS do not report poor physical or poor emotional health, and that a sizable minority say they have improved their physical and/or emotional health, suggest that the system is making a positive impact on the lives of PLWH/A.
Moreover, for rural PLWH/A improved or sustained quality of life is more clearly noted than among other populations.

Figure 0-1 Quality of Life - Physical Health

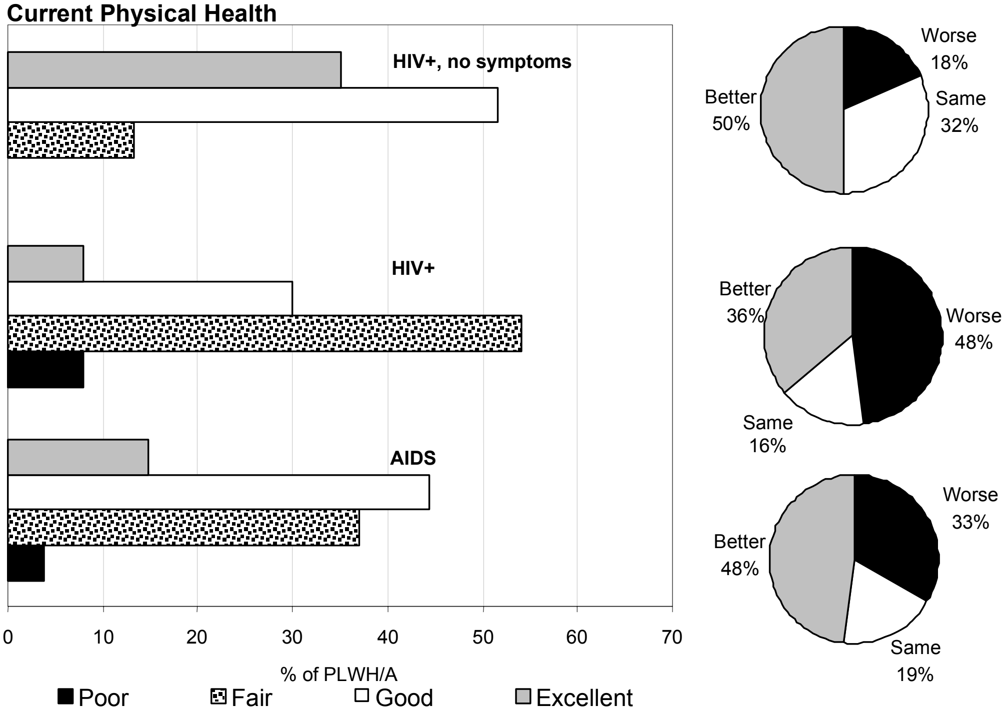
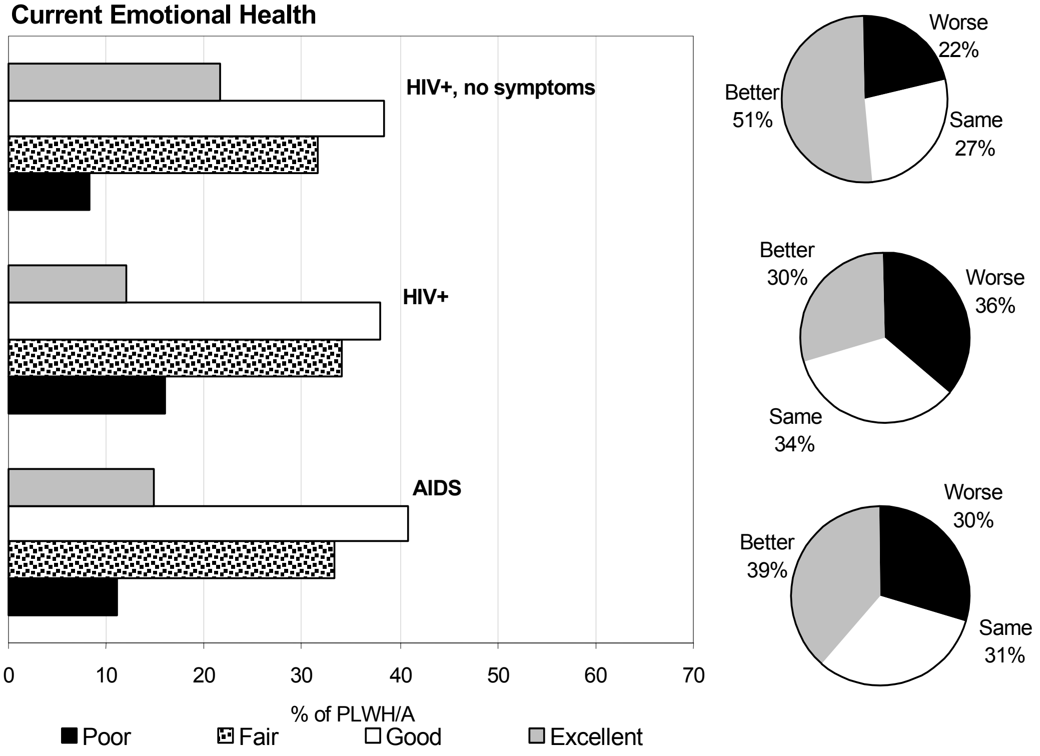


Figure 0-2 Quality of Life - Emotional Health



SERVICES

Dimensions of Service Need:

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

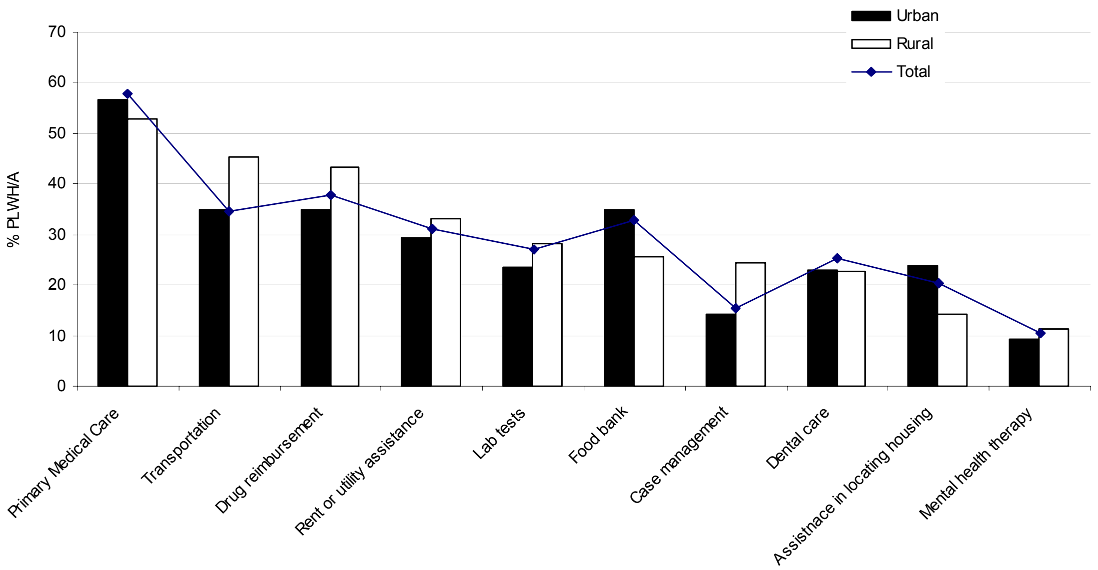
8. The service that was perceived to be most important (each participant ranked the top four services in rank order).
9. Knowledge of the service (Is this service available to you?)
10. Demand for the service (Have you ever asked for this service?)
11. Utilization of the service "ever" and the number of times in the last year
12. Satisfaction with the service
13. Ease of access
14. 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 in greater depth in the Houston Needs Assessment report. The section below highlights the top ten needs for the rural participants.

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 Attachment 7 and graphically in Figure 0-1. The figure indicates that although the services identified as the top ten most important are the same for rural participants as they are for the participants in the overall sample, the relative rankings assigned by each group differ slightly. For instance, while drug reimbursement was the second most important service for the overall sample, transportation was the second most important for rural participants.

Figure 0-1 Top 10 Needs of Rural



Medical Services

As found across all populations, out-patient care was the most important service for rural participants, with more than 50% of rural participants rating this as the number service. .

P1, a rural man who has been positive for four years compared his experienced in Harris County to his experience in the rural areas, "*"I was sick…and waited 35 days to see a doctor in Harris County. I came out here and I had a doctor's appointment in the same week. The system in Harris County is overran and its ill managed."*

P111, a rural man who has been positive since 1997 also spoke of the importance of continuity of medical care." *I like to have a regular doctor. Like all these people around here. You come in here, you have certain many doctors but they don't know what the hell's going on. They get your work and stuff, and then they say, what are you here for? I like one doctor to be here and help me with what I got and to follow up. I don't need other doctors to know what's going on, and they don't even know nothing about what's going on."*

P117, rural woman felt that what was important for her was to get to see the doctor. "T*he drugs for the medication the state pays for that. Another thing is to see the doctor more. It's 3 months to see the doctor. It's not like [local HIV specialty clinic]. Right now I can't get my medications, I have to see the doctor, I missed my appointment. There is no medication until July, he won't prescribe it until I see him*.

Transportation

Transportation was rated as the second most important service for rural participants.

P4, a rural 50-year-old man felt that, " *Transportation is a major concern for rural people living with HIV/AIDS. There are no buses at all. We are royally getting screwed now*"

P120, also a rural man described one of the problems that can go wrong with the transportation service. "*I sit on my doorsteps waiting for transportation. After about 2 hours, I guess they're not coming. When I went to call the, they showed up and left a note on the door. I had to get scheduled all over again. It was a miscommunication between me and them."*

P122, a rural Latina added "*Sometimes I don't have transportation, because sometimes [multi-service 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."*

Drug Reimbursement

Ranked as the third most important service, more than one-third of the rural participants reported drug reimbursement as a top service. This is comparable to the overall rating by the total sample.

Basic Services - Food, Rent and Utilities, and Housing

Rent and utility assistance was ranked fourth by the rural participants and fifth overall. Food services, also ranked among the top ten needs, indicate that as participants stop working or wait on the processing of entitlements and benefits their need for assistance with basic living expenses increases.

P123, a rural man described his need for utility assistance as follows, *"I've had one problem back when I first put in for my SS/- SSD. I had no income for five months because I had to wait. It put a burden on my roommate. All the bills were on him. "*

P122, a rural Latina also described how she uses her benefits to make ends meet, "*I've used the food banks. I pay my parents each month $60 from the TANF I get for my son."*

P120, a rural Anglo man has explored the different benefits that may be available to him. His situation is as follows, " *I'm currently using utility assistance and food banks. I did try and get assistance for affordable housing.'*

Lab Tests

Similar to participants from the overall sample, rural participants considered lab tests an important part of their HIV care and ranked lab tests as the fifth most important need.

For P124, an Anglo rural woman, said having her lab tests done is important to keeping herself informed about her infection. *"I needed to check my viral loads and CD cell 4 counts. And to see how progressive it was. And to get my Medication. I'm still learning about that but the information I'm getting is good."*

Case Management

Case management, with an overall rank of ninth, moved up to 7th among the rural participants. While some rural participants felt that there were no case management services in the rural areas others emphasized the need for quality case management.

Case Management FG Comments

P1, a rural man described his perception of how case management functioned in the rural areas. He said, "*The Blue Book is the only thing that we've got that's case management out here. There are not many pamphlets or printed materials in the rural areas and there is no hotline." He* added, *"I know more than the case managers. Word of mouth is it [how things get done]."*

P119, another male rural participant, described the importance of case managers as follows, "*Your services are pivotal around who your case worker is. I've heard good things about [specific case manager]. I've been screwed across the board by case workers since I've been here, I've been here for 4 years."*

Dental care

Dental care, ranked as the 8th most important, was a valued service among rural PLWH/A who found that it was not readily available to them.

As P4, a rural man, noted, *" Dental care is needed out here. We have to go all the way to Houston."*

Similarly, P1, another rural man, added, "*I've got dental work that needs to be done right now. What's keeping me [from getting it done] is I don't want to make that 52 mile drive."*

P144, a rural resident, felt that the single, most important service missing in his area was dental. He described his current dental care routine as follows, *" You have to go all the way in town, you have your blood work done here up-to-date, you have to make sure you've been pre-approved where you're still on the system up there. There you have to go in there, they look at you, you have to go back, and then you have to go back again. You have to make at least 2 to 3 trips."*

Assistance Locating Housing

More than 20% of the rural PLWH/A said that assistance in locating suitable housing was among their top ten needs. Rural participants found that housing was more limited in the rural areas.

In one of rural focus groups, P110, a rural resident, said, *" I would have moved back into Houston, because there're more services. In fact I thing I'm going to have to because there's more housing available."*

Mental Health

Mental health therapy was not consistently among the top ten service needs for all populations, but for the rural participants it was the 10th most important service.

P118, a female rural resident, described her need for additional mental health support that she felt was not being addressed by her case manager. She described her interaction with her case manager as follows, *"I want somebody to help me because I don't know what to do. This is new for me. Sometimes I'm on the phone with her, we are arguing and fighting on the phone. I don't need that. I don't need her to tell me what to do with my body. She don't have the disease that I have. She don't understand how I feel. It makes you angry. It makes you like, like you want to go kill somebody. Make you want to kill yourself. She doesn't understand. She thinks it's her way, not mine."*

Service Awareness, Demand and Utilization

Service awareness, demand, and utilization are presented in Attachment 8 - Attachment 10. In looking at these attachments, the percentages between the overall sample and the rural participants can be compared by looking across the columns. For example, in Attachment 8, under the column representing rural PLWH/A, 22% of the participants said they were not aware of newsletters. This is in contrast to less than 15% of the respondents from the overall sample who were unaware of the service. The table percentages can be read within the rural participants or between the rural participants and the overall sample by reading across the rows.

A second way to read Attachment 8 is to compare the figures down the column. For example, less than one percent of rural participants were not aware that outpatient care was available to them in contrast to 24% that didn't know mental health therapy was available to them.

Attachment 9 displays 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 rural participants versus the overall sample. They can also be compared down the column to see which services the rural participants seek.

Attachment 10 displays the percentage of those who have ever received the services. Attachment 12 shows 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 the rural participants used a service over the past year can be compared to that of the overall sample by reading across the rows. The median number of times different services were used by rural participants can be compared by reading down the columns.

Graphic Presentation of Awareness, Demand and Utilization

The graphs shown in the following sections plot the values for the top ten services asked for (level of demand) by rural participants. 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 0-2 on the following pages display the awareness of services (the line), the percentage of the rural participants asking for services (demand), and the percentage of the rural PLWH/A who reported receiving services. The services are ordered by the percentage of persons asking for or demanding the services.

Services Most Demanded and Utilized

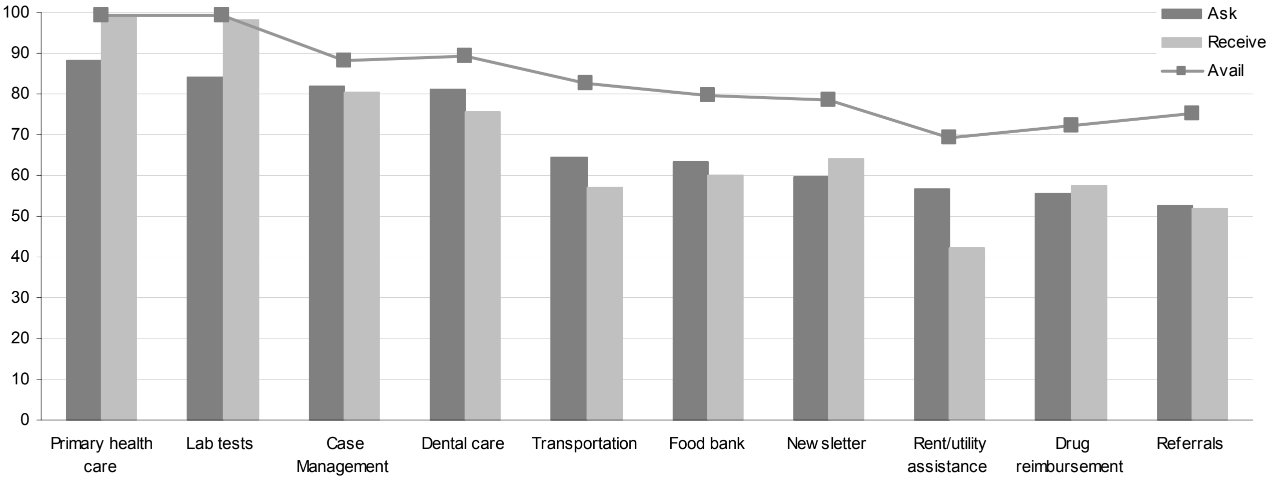
Figure 0-2 shows that primary health care, lab tests, case management, and dental care were sought and received by more than 75% of the rural participants. Awareness for these services was also among the highest, ranging from 88% to 99% of the rural participants being aware of the availability of these services.

As in the total sample, demand and utilization patterns were somewhat different than the top ranked needs identified by rural participants. While most of the top ten services remained the same, their relative ranks shifted. For instance, while mental health therapy and locating housing were among the top ten most important services they fell to 12th and 13th of the most sought out services. On the other hand, dental care ranked 8th among the most important needs for rural participants was ranked as the fourth most demanded service.

Awareness - Demand Gap

One gap measure is the difference between awareness and demand. The awareness-demand gap measure is calculated by taking the difference between the aggregate percentage of those aware of the service minus those demanding, or seeking the service. For example, while awareness for mental health was relatively high (76%) for rural PLWH/A, demand and utilization dropped to less than 53%. Among the top ten sought services, the awareness-demand gap ranged from 6.5% for case management to 22.5% for referrals. The greatest differences between awareness and demand ranging from 39% to 45% difference were noted for hospice care, in-home hospice, hotline, and out of home substance abuse treatment.

Figure 0-2 Services Awareness, Demand, and Utilization - Top 10

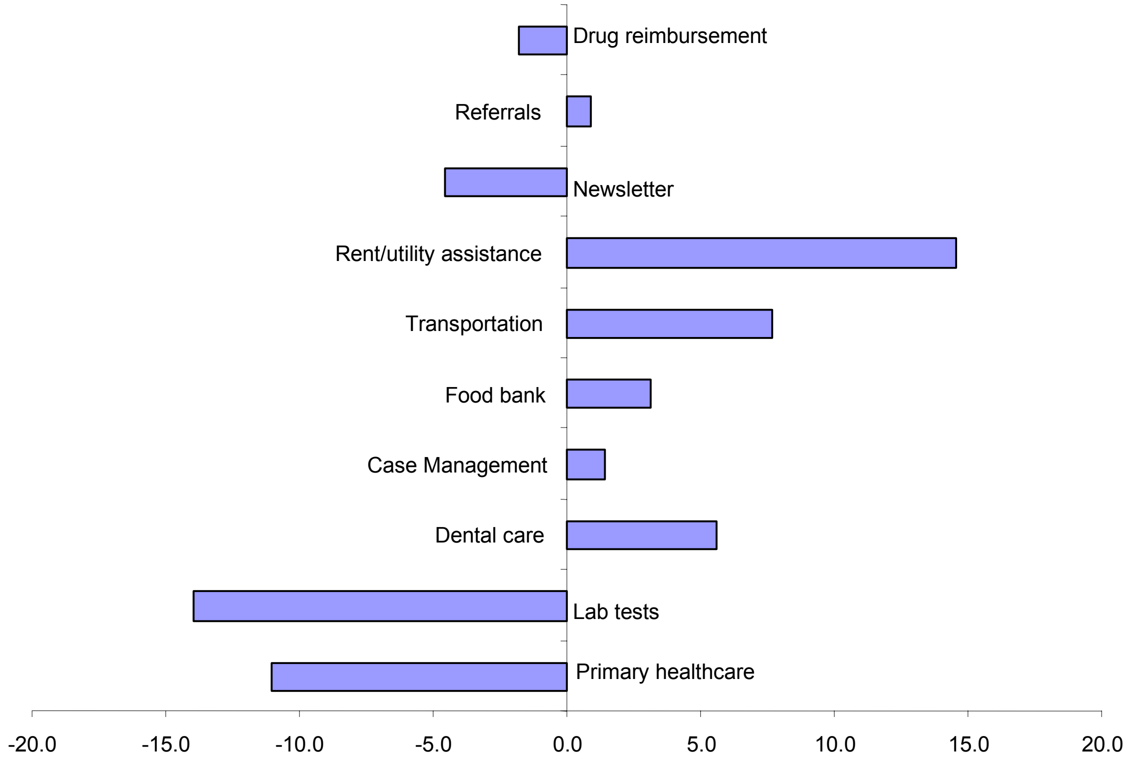


Demand - Utilization Gaps

Another gap measure involves the difference between demand and utilization. Demand and utilization usually follow similar patterns. However, a gap between what is asked for and what is received suggests an unmet perceived need. The demand-utilization gap measure is calculated by taking the difference between the aggregate percentage of those demanding services minus those who actually receive the service. In the total sample, the demand-utilization gap ranged from 0% to 18%. Among the rural participants this gap ranged from 0% to 21%.

Among the services most demanded, the largest unmet demand, with a gap difference of 15%, was rent/utility assistance. Among the top ten most demanded services, rural participants reported receiving more primary care, lab tests, newsletters, and drug reimbursement than they asked for. The greatest difference between services sought and services actually received were noted in legal services, employment assistance, obtaining housing, rent/utility assistance and assistance locating suitable housing. This gap ranged from 11% to 21%.

Figure 0-3 Total Sample Demand- Utilization Gap: Top 10 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 14 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 14 shows the satisfaction scores for the rural participants.

The table in Attachment 15 shows 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 the rural participants or between the rural participants and the total sample.

Graphic Presentation of Satisfaction and Access

Figure 0-4 displays the perceived access and satisfaction with services for the top ten services, ranked by access, from high to low. 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.

The reason for plotting access and satisfaction together was that they were thought to be related. As seen in the figure, they are related, but clearly access is only one component of satisfaction. Both levels of access and satisfaction tended to be were rated lower by the rural participants than by participants overall. Among the ten easiest services to access the rating ranging from 2.5 for legal services and buddy/companion services to 2.8 for childcare. The satisfaction levels ranged from 3.0 for adoption services to 3.7 for drug reimbursement.

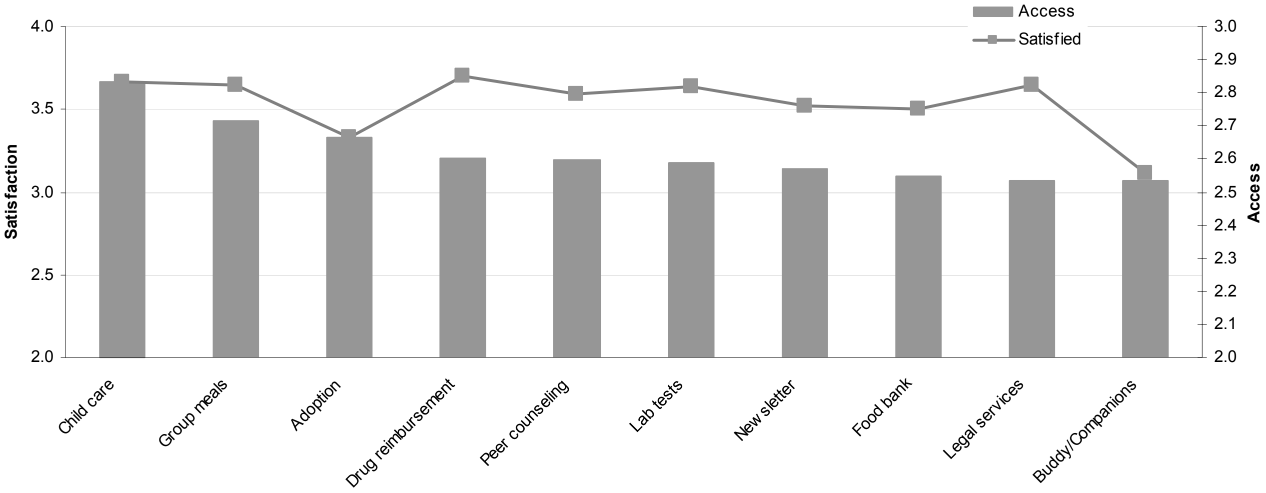
Unlike participants from the overall sample, rural participants rated some of the top demanded services as relatively easy to access. Rural participants rated lab tests, drug reimbursement and the food bank among the top ten easiest services to access.

The hardest services to access tend to be the services less sought. However, for rural participants locating housing and rent/utility assistance were among the top ten services most sought and among the top ten services hardest to access. Rural participants felt that locating housing was the hardest service to access, with an access score less than 2.0. Rent/utility assistance was also considered to be only somewhat easy to access.

Rural participants were generally somewhat to very satisfied with the services they considered easy to access. Satisfaction ratings for the top ten easiest services to access ranged from 3.1 for buddy/companion service to 3.7 for drug reimbursement.

Among the ten hardest services to access, rural participants were least satisfied with hospice care (2.7), followed by assistance locating housing (2.8).

Figure 0-4 Access and Satisfaction with Services - Top 10



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 16. 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.

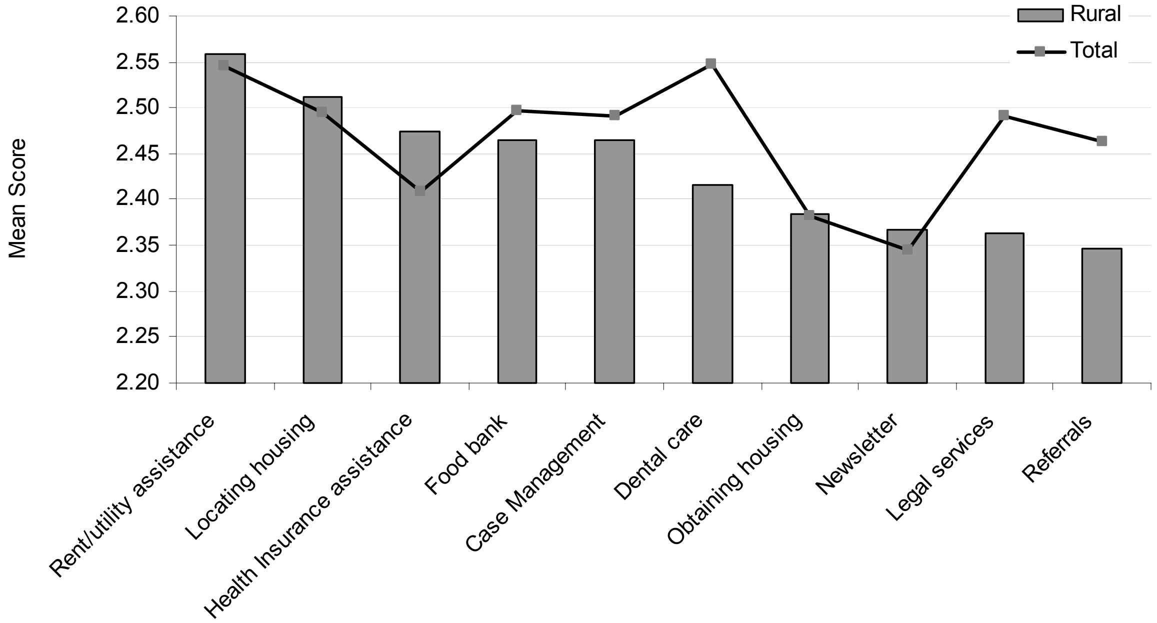
Graphic Display of Anticipated Need

Figure 0-5 shows the top ten services for which PLWH/A feel they have the greatest future need. Notably, all of these services have an average score higher than 2.0 and fall between "needing more" and "needing the same." This indicates that, on average, the rural PLWH/A see an increasing need for all services.

For rural participants, the top ten anticipated needed services differed from the top ten most important services previously reported. On the most part, while the most important services included primary care, lab tests and other health care services, the top ten anticipated services related to services which are coordinated through case management services and provide financial security or stability. For instance, the top five anticipated services were rent/utility assistance, assistance locating housing, health insurance assistance, food bank and case management. Interestingly, rural participants included legal services, newsletters and referrals among their top ten anticipated services. These have much lower rankings among the overall sample.

Figure 0-5 Anticipated Need - Mean Score for Top 10

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



BARRIERS

Rural people living with HIV and AIDS (PLWH/A) identified several barriers that could be lowered in order to improve the access and quality of services provided. In many instances PLWH/A felt that the "system" was responsible for the barriers and did not attribute the barriers to agencies or staff. In general, as suggested by the overall high marks for satisfaction, PLWH/A felt that services were 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.[47] 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.[48] 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.

When the ratings of all of the barriers were summed, none of the target groups or ethnic populations reported a big barrier. Overall, as shown in Attachment 17, the average barrier scores for rural PLWH/A were similar to those of the total sample, yet, the scores for the rural participants tended to be lower. While the highest barrier score reported by the total sample was 2.6, the highest score for the rural participants was 2.5.

Figure 0-1 shows the top ten barriers for the rural PLWH/A. Out of the top ten barriers identified by rural participants, five were organizational access barriers, two were structural barriers and three related to the individual. The organizational access barriers included:

- The amount of red tape and paperwork I had to fill out to get the service
- Not having transportation
- The lack of services for my family
- My concern that my confidentiality would not be kept
- The amount of time I had to wait to get an appointment or see someone

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[47] For exact wording see question 47 in the questionnaire, Attachment 4, and the Barrier section in the focus group outline, Attachment 3.

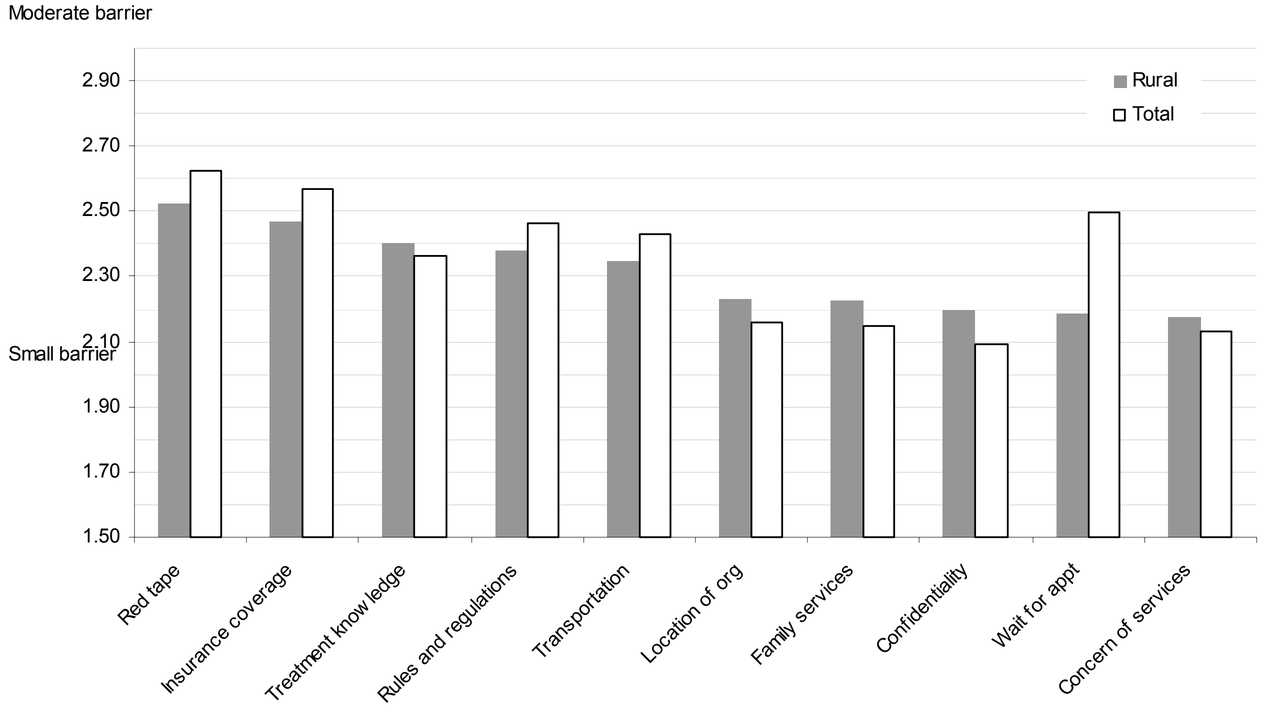

Figure 0-1 Average Barrier Scores for Rural PLWH/A – Top Ten

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

Organizational Access Barriers

Red Tape - Focus Group Comments

The highest barrier reported by all PLWH/A as well has rural participants was red tape. P119, an Anglo male rural resident, feels that his life is going by with him having to go through many different steps before obtaining the necessary services. He said, *“Obviously life span is your first concern. I was admitted to the hospital, that's how I found out on New Year's Eve. It's a process of going through that particular visit, then the red tape can drag for weeks and weeks and weeks. You get your initial admission into the clinic, but then you have to go through...[self-censored] then you start services immediately...”*

Similarly, for P112, a rural resident who has been infected for seven years, the thought of the amount of red tape he had to go through was daunting. He said, “*My major concern was the red tape was too much and it took too much.”*

Lack of Transportation - Focus Group Comments

The second highest organization access barrier is lack of transportation. Transportation was previously discussed as one of the top services needed and it also comes up as one of the top barriers to accessing care. For instance, for P124, an Anglo rural woman, the distance she has to travel for care is a problem. She said, “*Accessibility of the transportation and the doctor needs to be closer. I drive 40 miles round trip now.”*

P118, a Hispanic female, also has difficulty getting to her appointments. Her situation is as follows, *"It's like me, I'm having problems. I barely got someone to take me to Houston to go get my glasses and to go to the dental. Some of them [transportation providers] don't go as far as 2 hours drive."*

Family - Focus Group Comments

Most PLWH/A with HIV positive children were receiving services, and knew of medical services. While lack of services for families was not perceived as a large problem, it was the seventh ranked barrier by rural participants.

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 [HIV specialty hospital clinic] started advertising childcare there and I think that's great. When you are first diagnosed, you should be sent to a Next Step clinic."*

P117, a female from the rural areas 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."*

A number of participants with HIV negative children said they felt they did not have services. 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."*

Confidentiality Focus Group Comments

While confidentiality was considered a small barrier, it was often referred to in the focus groups and it was ranked as the eighth barrier for rural participants. Among many participants there was a feeling that one cost of being HIV positive means a loss of confidentiality. P2, an Anglo rural 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."*

There was also the fear that other rural residents were not tolerant of or sensitive to people living with HIV/AIDS. P1, a rural gay male, conveyed this feeling as follows, "*I don't want to come home one night and find my house burned down because my redneck neighbor found out that I am the AIDS-infested queer next door. That is a very, very real fear out here."* P2, also added his experience, *"We [at rural CBO] were approached by the fire chief here, who said he wanted a list of our clients so that if he ever came to the building he would know who his people could and could not save."*

Waiting Focus Group Comments

Waiting for services was the ninth highest ranked barrier by rural participants. They described different junctures in their HIV care history when they've had to wait to be treated or even to be scheduled for an appointment. These junctures may have happened early in their seeking of are or later on as they try to manage their illness.

For example, P118, a female rural resident, described her experience when first trying to access services. She said, "*My major concern when I found out was my son and my husband. I was worried about them. It took about 3 1/2 months when I could come in as a walk-in. I sought services right away, but it took that long to get an appointment.*"

Another example is P119 who has been infected for four years and has had several frustrating experiences trying to seek care. He described one of these situations as follows, "*I've spoken to several other people, I've been here for 4 years so there's 4 years of history. When you have an assistant physician come in that's here for 2 days out of the month, you have to sit there for 4 hours, trying to explain to them everything you've been through for 4 hours. Then they run back to you regular physician. Can't they have HIV day on Tuesday or something and have the same doctor every Tuesday. Or you'll sit here for 4 or 5 hours, you walk in, and it's "well Dr. X." Well then, why the hell am I here. I've sat here for 4 hours. And then they're, "well, why are you here?" Well Dr. X wanted a follow-up. "Follow-up what?" I don't know. I tried to sign in as a walk-in this morning during break, then they said, "no, you have to sign up at 1:00." It's crap like that.*

Rural participants also complained about the length of time people have to spend traveling to get services and then having to wait on top of that becomes very difficult. For P2, an Anglo rural man, having to travel long distances and then being turned away is very aggravating. In his opinion, "*Medical services aren't available. People have to go a 100 miles to [university medical center] when they're sicker than dogs, wait 5,6,7 hours to be seen and then told, "You can't get your medication today, sorry.* "

Both P5 and P6 have had to wait a long time to see some service providers and see this as a barrier. At {dental care provider], P6 had to wait for hours only to have the visit canceled.

Neither P5 nor P6 like the length of time they have to wait, nor the confusion over appointments that sometimes happens. These problems are compounded by the distance they have to travel for their care.

Structural Barriers

In Figure 0-1, 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 groups revealed 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.

For P117, a female rural resident, her concern was the welfare of her family once she died, She said, "*My major concern was my family and if I die that today, how they gonna have for money.* "

P114, a male rural resident, described the problems he faced because of lack of insurance. He said, "*My major concern was how long I had to live. 2 yrs, 4 yrs, 10 yrs? I was working in Houston so I tried to go through [Houston based hospital] because I had no health insurance. They told me I had to go to the County. It took me 3 to 4 days to find out where, when, and how."*

Rules and Regulations Regarding Eligibility Focus Group Comments

The second highest structural barrier concerned rules and regulations regarding eligibility. The focus groups revealed several barriers that PLWH/A face regarding eligibility. Some of these regulations affect the type service a person is entitled to receive as well as who, or what agency provides it. For example P125, a rural African American man, stated, *The only problem I have is since I'm so close to the Belt, this transportation services will not come get me. And since I'm inside the belt, this transportation service will not come get me."*

The difficulties in qualifying and maintaining SSI were mentioned by several participants. For example, P114 described what he's had to go through and what he has had to learn about the system. He said, *"But then you can't own anything. I'm not going to give up what I worked hard for. Now I have to give it up and live in a $500/month apartment in order to get SSI if I apply for it, if I can. You can't apply for SSI until you show 2 signs of infection."*

Individual Barriers

The third highest barrier, "Not knowing what treatment is available to me" was an individual level barrier. "The location of the organization providing services " and "my concern that the services I need do not exist," were also individual barriers identified by rural participants.

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. P2, an Anglo rural resident, felt that *"People don't have options."*
Similarly, P118 felt he needed more information. He said "*That's why I'm having problems with [case worker]. I want somebody to help me because I don't know what to do. This is new for me."*

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 the rural focus group participants made a special point of mentioning transportation.

As one P116, a female rural resident, complained, *"you have to go to 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 rural resident, 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."* P6 echoed the sentiment. P6 lives in Needville and goes to Richmond for glasses, Houston for dental work and to Fort Bend. Fort Bend is 35-40 minutes from his home.

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

As noted above, rural PLWH/A rely on their case managers for information. Yet, rural participants felt that there are gaps in the information they have available to them. Both P5 and P6 have a lot of questions about the services they need and the services that exist.

Several focus group participants wanted to know more about specialized groups. For example, P119, a male rural resident, noted, *"Services are not volunteered. You have to seek them out then you have to go through 12 people to find them."*

Summary of Rural PLWH/A Needs and Barriers

Overall, rural participants are very similar to participants in the overall sample. The demographic profile shows that in many areas, rural participants and total sample participants share common characteristics. A noticeable difference, however, is the perceived quality of life. Rural participants as a whole report much higher physical and emotional health than do participants in the overall sample.

This higher physical and emotional status can help explain the relative rankings of services as well as the lower barrier scores. For example, the anticipated needs for rural participants have less do to with medical and mental health and more to do with financial stability. Similarly, rural participants report lower barriers to care. This perhaps reflects their greater ability to gain access to services, despite the distances and rules and regulations they need to overcome.

Services

Table 0-1 provides a comparison of the top needs of the total sample versus the ratings given by the rural participants for most important needs, awareness, demand, utilization, satisfaction, perceived access and anticipated need of these top ten services. The number in the cell is the rank order of each service for each dimension. The top ten for each measure are shown in the table below, however, only the top ten most important services are discussed within the following text. Among the total sample, services beyond the top ten are shown with their respective ranks.

Table 0-1 Top Needs, Rank Order

	Total Sample	Rural PLWH/A	Awareness	Demand	Utilization	Satisfaction	Access	Future Need
Primary Medical Care	1	1	1	1	1	8	11	22
Drug reimbursement	2	3	11	9	7	2	4	13
Transportation	3	2	5	5	8	28	23	16
Food bank	4	6	6	6	6	13	8	4
Rent or utility assistance	5	4	13	8	12	22	30	1
Lab tests	6	5	2	2	2	7	6	19
Dental care	7	8	3	4	4	15	18	6
Assistance in locating housing	8	9	16	13	17	32	33	2
Case management	9	7	4	3	3	21	16	5
Mental health therapy	10	10	9	12	11	10	14	18
Health Insurance assistance	11	12	27	18	18	24	27	3
Obtaining housing	13	18	18	16	21	31	29	7
Legal services	14	13	14	15	15	5	9	9
Nutrition counseling	15	14	7	11	9	16	17	12
Referrals	16	21	10	10	10	17	21	10
Peer counseling	18	16	15	14	13	9	5	17
Newsletter	19	19	8	7	5	11	7	8
Rehabilitative services	20	22	20	23	23	3	26	26
Child care	21	17	32	28	28	4	1	27
Holistic therapy	22	28	28	24	25	1	19	21
Group meals	31	32	22	19	16	6	2	15
Adoption	32	27	33	31	31	18	3	32

The overall messages are:

- The top ten services for rural participants mirror the top ten needs reported by participants from the overall sample.
- Primary medical care is the top need overall and also ranked as the top need by rural participants. While primary care is the number one service in terms of awareness, demand and utilization, it drops to number eight in satisfaction, 11th in access and 22nd in terms of future need for rural participants.
- Drug reimbursement, the second most important service among the overall sample, is generally among the top ten services, but drops in terms of awareness and anticipated need by rural participants.
- While participants from the overall sample rank transportation as the third most important service, rural participants consider transportation the second most important service, second only to primary care. Rural participants are well aware of transportation services, demand them and use them. However, they find that access is not easy and their satisfaction drops to 28 out of 33. Surprisingly, transportation is not among the top ten anticipated needs for rural participants.
- The food bank, fourth among the overall sample, is ranked as the sixth most important service, sixth in awareness, demand and utilization. The access level remains within the top ten but satisfaction drops to 13. Rural participants anticipate a growing need for food bank services and rate it as the fourth highest anticipated need.
- Throughout the focus groups and through the survey findings, rural participants consistently expressed their need for rent and utility assistance and their dissatisfaction with the current access level. This is the fourth most important service for rural participants, yet awareness and utilization levels drop below the top ten. Access, ranked 30th out of 33, and satisfaction are relatively low for rural participants. It is the number one anticipated need for rural participants.
- The importance of lab tests remains relatively high for rural participants as well as participants from the overall sample. The anticipated need is the only measure which falls below the top ten for rural participants. The anticipated need for lab test is relatively low for rural participants.
- Dental care is an important service for rural participants which they feel is not adequately available to them as revealed by the survey findings and comments from the focus groups. While rural participants are well informed about the availability of dental care they rate both access and satisfaction relatively low.
- Assistance in locating housing is the 8th overall need and 9th for rural participants. Rural participants are not too familiar with the availability of assistance in locating housing. Therefore they seek the service, don’t use it, perceive it as the most difficult service to access and are dissatisfied with the service. Nonetheless, this is the second most anticipated need for rural participants.
- Case management is the 9th most important service for participants from the overall sample but the 7th most important service for rural participants. Participants awareness, demand and utilization of case management services is high. Yet, rural participants felt case management is not as easily accessible as other services and are relatively less satisfied with this service. Rural participants rate case management as the 5th anticipated need.
- Mental health service remains, rated as the 10th most important service for rural participants and the overall sample, ranks among the top ten in awareness and

satisfaction. However, it is not one of the top ten sought or used services, and rural participants rated it as the 18th anticipated need.

Barriers

When the ratings of all of the barriers are summed, none of the risk groups or ethnic populations reported a big barrier. For the most part, rural participants rate barriers to services lower than participants from the total sample. The highest barrier score for rural participants is 2.52 compared to a high total score of 2.62. However, among the top ten barriers reported by rural participants, five out of ten are rated higher by rural participants than by the total sample.

Table 0-2 provides a summary of the top ten barriers for the total sample compared to the rural participants. The number in the cell is the rank order. The number in the cell is the rank order. A "+" beside the number means that the score is greater than the average score.

Table 0-2 Top Ten Barriers - Total vs. Rural PLWH/A

	Total Sample	Rural PLWH/A
Red tape	1	1
Insurance coverage	2	2
Wait for appt	3	9
Rules and regulations	4	4
Transportation	5	5
Treatment knowledge [1]	6	3+
Navigate through system	7	11
Feel like number	8	12
Poor coordination amongst organizations	9	18
Lack of sensitivity	10	32
Location of organization	12	6+
Family services	13	7+
Confidentiality	16	8+
Concern of services	15	10+

1 – In the consumer survey, participants were asked to indicate how big a barrier “not knowing what treatment is available to me” represented to them.

In terms of barriers, the overall messages are:

- Red tape is the number one barrier for participants in the total sample as well as rural participants.
- Insurance coverage is also a concern and perceived as the second highest barrier to care by the overall sample and rural participants.
- While waiting time was discussed as a barrier by several focus group participants in the rural groups, its relative importance drops to nine among rural participants. It is the third barrier among the overall sample.
- Rules and regulations are equally important for all the participants and rural participants.
- Transportation, named as an important service for rural participants, is also a top barrier. Rural participants and participants in the overall sample agree in the rank order of lack of transportation as a barrier.
- Knowledge about treatment is the number one individual barrier for both the overall sample and rural participants. However, for rural participants the lack of knowledge represents an even greater barrier, with a rank of number three.

- Navigating through the system, ranked as the seventh barrier to care among the overall sample, drops slightly below the top ten to number 11 among rural participants. Yet, this rank supports the need of additional information and case management services for rural PLWH/A as previously discussed.
- Overall participants said that they were made to feel like a number and this represented the 8th most significant barrier for them. For rural participants, this barrier drops just below the top ten. Yet, with a rank of 12th it still represents a concern for many of the rural participants.
- Overall, poor coordination among the organizations was seen as the 9th barrier. This lack of coordination is less evident to rural participants who perhaps see less providers and less service providers. Coordination among fewer providers is the rural setting may be less problematic.
- While participants in the overall sample felt that lack of sensitivity from their provider was a top barrier, rural participants rated this as the lowest barrier to care. Although rural participants had several complaints about the rules and regulations and levels of access to care, very few had criticisms about the way they were treated or made to feel by service providers.
- While location of the organizations ranked as the 12th barrier among the overall sample, rural participants who had to travel several miles for services felt that this was one of the top barriers.
- While participants in a more urban setting fear that their confidentiality would be kept is less of a concern for PLWH/A, for rural participants this rates among the top ten barriers. Living in the rural areas, participants want to safeguard their confidentiality.
- Finally, the concern that services they need may not exist represents a greater barrier for rural participants than for participants from the overall sample. The lack of access to information and to a variety of services makes rural participants fearful that the services they may need do not exist. Greater outreach efforts and access to newsletters would help sustain the perceived higher quality of life in the rural areas.

ATTACHMENTS

Attachment 30 Focus Group Outline

Attachment 31 PLWH/A Survey

Attachment 32 Rural PLWH/A Demographics

Attachment 33 Condom Use & Prevention Behaviors

Attachment 34 Top 10 Service Needs

Attachment 35 Service Awareness

Attachment 36 Service Demand

Attachment 37 Service Utilization

Attachment 38 Frequency of Service Usage

Attachment 39 Service Satisfaction

Attachment 40 Service Access

Attachment 41 Future Demand of Services

Attachment 42 Rural PLWH/A Barriers

NOTE: *All attachments are from the Needs Assessment Report: Survey and Focus Group Report of Consumers and Providers.*

HOUSTON EMA & HOUSTON HSDA CARE CONSORTIUM

NEEDS ASSESSMENT REPORT

Special Study – Undocumented PLWH/A

Prepared for

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

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Revised November 17, 1999

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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 Projects, University of Houston (OCP) to conduct a needs assessment and three special studies. The three special studies consisted of a report on the continuum of care, a special study of rural PLWA/H and a special study of undocumented PLWA/H. The needs assessment and the two special population studies identify 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 and special studies is to facilitate informed decisions regarding medical and support services for persons living with HIV/AIDS (PLWH/A) that are funded by the Ryan White CARE Act and other sources.

This supplemental report describes the findings of the special study among undocumented participants and presents information obtained through the survey and focus groups of undocumented PLWH/A and specifically addresses their perceived needs, demands, and barriers to care.

METHODS

Focus groups, and a consumer survey were the major components of the special study among undocumented PLWH/A. The focus groups and consumer survey were sampled and recruited through the local service providers serving undocumented PLWH/A and through word of mouth among participants.

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.

The focus group outline is shown in Attachment 3 and the consumer survey is shown in Attachment 4. The lists of services developed by PCH/OCP and the Needs Assessment Committee were derived from the list of funded services and services priorities set by the Planning Council. They are shown in question 46 of the consumer survey. The list of barriers were developed based on prior needs assessments conducted by PCH using a multidimensional schema discussed in the Barriers Section, below. 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 residency. 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.

A total of 24 focus groups were held with participants of different ethnicity/risk category populations. While five groups were “open groups ”, 19 groups were ethnic or risk category, including one group among undocumented PLWH/A. 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 and word of mouth. The different ethnic groups were recruited from providers and through outreach. Focus groups were held between April 1999 and June 1999. The consumer surveys were completed between April 1999 and July 1999.

Sampling

<u>PLWH/A Survey</u>

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, including day labor sites. A letter of agreement was created with a service organization serving African immigrants. However, no participant was recruited through this effort. In addition, 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. Interviewers were instructed to ask all non-US citizens about their residency status. Undocumented PLWH/A therefore included all participants who reported being undocumented or not having a legal residency status in the United States. Six people, three men, three women, participated in the focus group for undocumented PLWH/A. The focus group was conducted in Spanish by Ms. Lucía Orellana. A total of 31 undocumented PLWH/A completed the survey.

For a full description of the logistics and methodology of the focus groups and survey refer to the full needs assessment report.

Demographic Profile of the Undocumented PLWH/A

Out of 455 people living with HIV/AIDS who completed surveys, 31 participants (5% of the total weighted sample) were undocumented PLWH/A. As this represents a very targeted group they are not comparable to the general sample and because of the sample size the findings should be not considered generalizable to the population of undocumented PLWH/A in Houston.

- The undocumented participants are mostly heterosexuals and not very similar to the overall sample. Thirty-six percent of the undocumented are MSM, 65% are heterosexuals and seven percent are IDUs. This is compared to 62%, 34% and 28% of the total sample who fall within each of the categories, respectively.
- The majority (65%) of the undocumented participants are male, yet, women are still over-represented among this group. The total sample is 82% male and 18% female. .
- Twenty out of thirty-one undocumented PLWH/A are Latinos. Five are either Caribbean black, Indian, or other multi-cultural ethnicity.
- Nearly one third of the undocumented participants have only a grade school education, compared to less than six percent of the total sample.
- Undocumented participants are more likely to be married or living with a partner than members of other target groups. Thirty-nine percent are married or living with a partner, compared to 20% of the total sample.
- Unlike participants in the overall sample with 52% having their own place, less than 20% of the undocumented participants have their own place. More than 60% of the undocumented participants live in a relative's or someone else's place. More than 85% live with other people and a large percentage (77%) receive some form of assistance in paying the rent.
- Three undocumented participants have an HIV positive partner.

- Less than 13% of the undocumented have been in prison or jail over the past two years compared to about 30% of the overall sample.
- Similarly, less than 14% have been homeless over the past two years, compared to 23% of the participants in the total sample.
- 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/TDH and 50% receive other type of assistance, namely MAP.
- Fifty-two percent are asymptomatic, forty-five percent have symptoms and three percent are unaware of their HIV status. This is almost the inverse of the overall sample, with 45% asymptomatic and 54% symptomatic PLWH/A. Thirty-five percent of the undocumented participants have an AIDS diagnosis compared to 54% of the overall sample. Seventy-one (71%) of the undocumented participants are currently taking HIV medications compared to 82% of the total sample.
- 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 but are reported at a lower level. They include alcohol (77%), marijuana (39%) and cocaine (36%).
- Seventy-seven percent of the undocumented PLWH/A report an annual income of less than $6000 compared to about half of the total sample with that income.

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.[49] Responses to the prevention questions are shown in Attachment 6. Graphic representations of several questions are presented and discussed below.

HIV Testing

For the undocumented PLWH/A the most popular places for HIV testing are community clinics, hospital clinics, and counseling and testing centers.

As shown in
Figure 0-1, almost 52% of the undocumented participants report receiving their test at a community clinic (black line). This is very similar to the overall total weighted sample who report about 50% using this as their testing site. About 25% of undocumented PLWH/A report being tested at least twice (not shown in graph).

The second most common testing site for undocumented PLWH/A is a hospital clinic. About 43% report being tested in hospital clinics and about 10% say they were tested more than once.

Although reported as the third most common testing site, only slightly over 20% of the undocumented participants were tested in a counseling and testing center. This lower use, as compared to the overall total, may reflect undocumented PLWH/A's lower awareness of these testing sites or their greater concern about confidentiality and being reported to the authorities. Undocumented participants are three times less likely to be tested by a private doctor than are participants in the overall sample.

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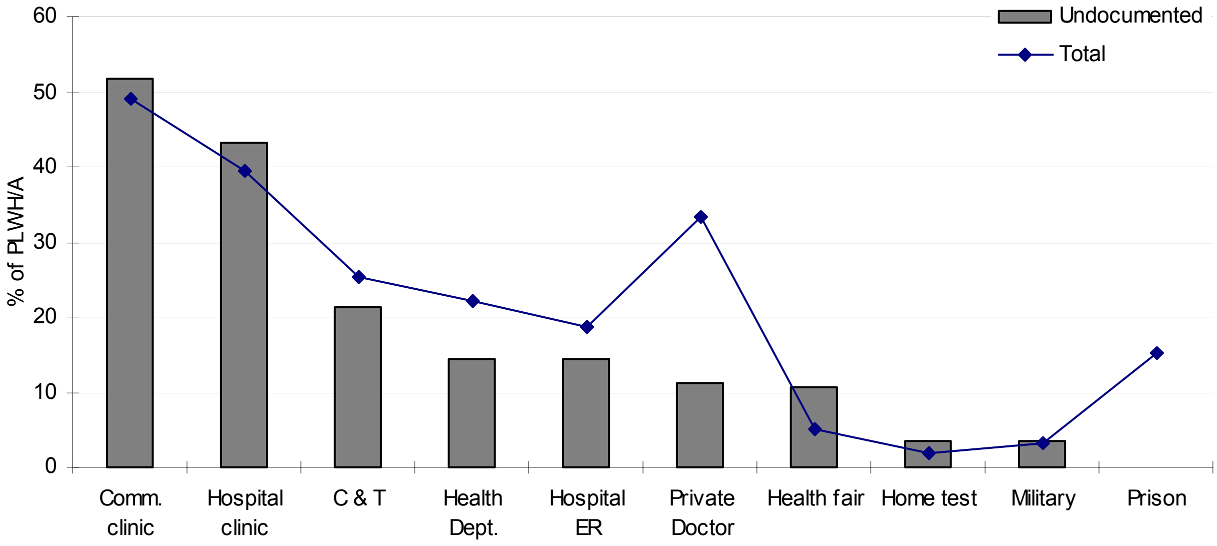
[49] The questions in the survey were of interest to the Prevention Planning Group, but should not be interpreted as a comprehensive examination of prevention behavior.

Figure 0-1 Place of Testing



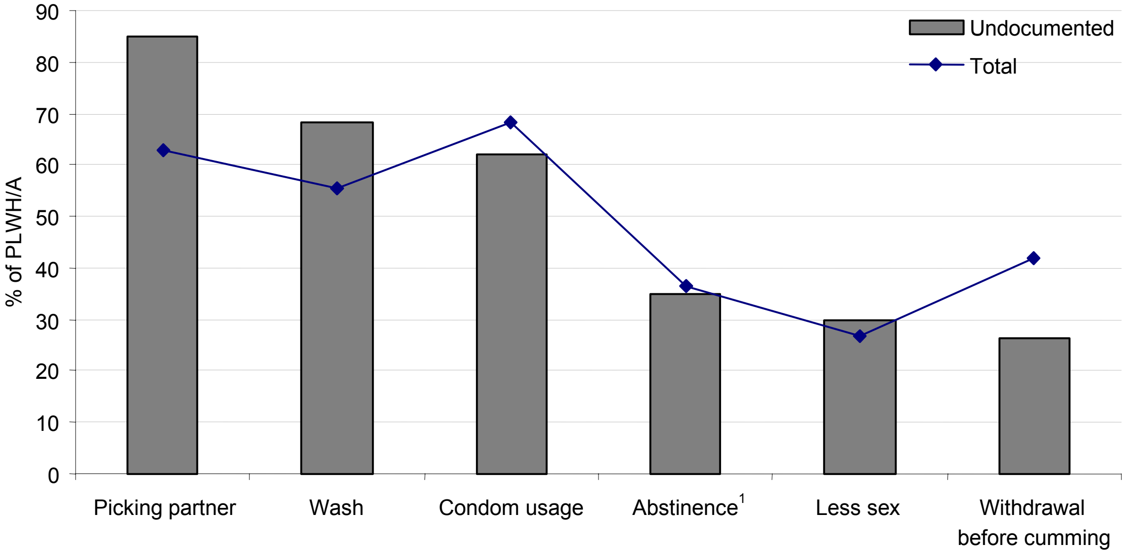
Reported Methods of Reducing Risk for HIV Transmission from Sex

Overall, undocumented participants report much lower sexual activity during the past two years than the participants in the total sample, with the exception of heterosexual undocumented men who report equal or higher sexual activity. From 60% to 100% of the undocumented women have not had sex in the past two years, and 42% to 80% of the men report no sexual activity in the same period of time.

Among the participants who said they had sexual intercourse in the past two years, several ways of trying to reduce risk of re-infection or becoming infected with a sexually transmitted disease are reported. As shown in Figure 0-2, increasing condom use, increasing washing before or after sex and being more careful when choosing partners are among the most popular methods of decreasing the chances of (re)infection or STDs. Although only about 60% say they increased their use of condoms, over 90% say they use condoms all the time with casual partners and close to 70% with regular partners. For undocumented PLWH/A, carefully choosing their sexual partners is the most frequent method reported. With 85% of participants reporting this strategy, this was by far the preferred strategy among undocumented PLWH/A. Increasing the practice of withdrawing prior to ejaculation (cumming) was less used by undocumented than most other groups. From comments made by participants during focus groups or during the administration of the survey this may reflect their already high use of this behavior. An undocumented Latina commented that this is what she and her partner do all the time and there has not been a change in that practice. She noted that they are now more careful about washing after intercourse.

The frequency with which sexually active undocumented PLWH/A had less sex, or increased abstinence is comparable to that reported by the overall sample and is shown in Figure 0-2.

Figure 0-2 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 0-3 indicates that undocumented PLWH/A report a much higher frequency of condom use than the total sample, with 67% reporting using condoms all the time as compared to 53% of the total sample. Notably, undocumented PLWH/A (92%) report by far the highest condom use with casual partners than any other group.

On the other hand, as shown in Figure 0-4, when asked why they don't always use a condom, more than 50% of the undocumented PLWH/A report several reasons for not using condoms.
The number one reason (82%) is because they "really love" their partner. Also, undocumented PLWH/A are more likely (64%) than the overall sample (44%) to say they don't like using condoms. Tied for the third most common reasons for not using condoms are the belief that their partners do not like condoms, being convinced that they were HIV negative or not caring.

Less than 20% of the undocumented participants say that the reason they did not always use a condom was because there "were none available", " they were high or buzzed on drugs or alcohol", or because "they wanted to have a baby". More than one third say that using a condom is not "real sex", and about 27% say they didn't know how to talk about condoms or they knew the HIV status of their partner. Under 10% say the reason they didn't always use a condom was because they were trying to have a baby.

Figure 0-3 Frequency of Using Condoms

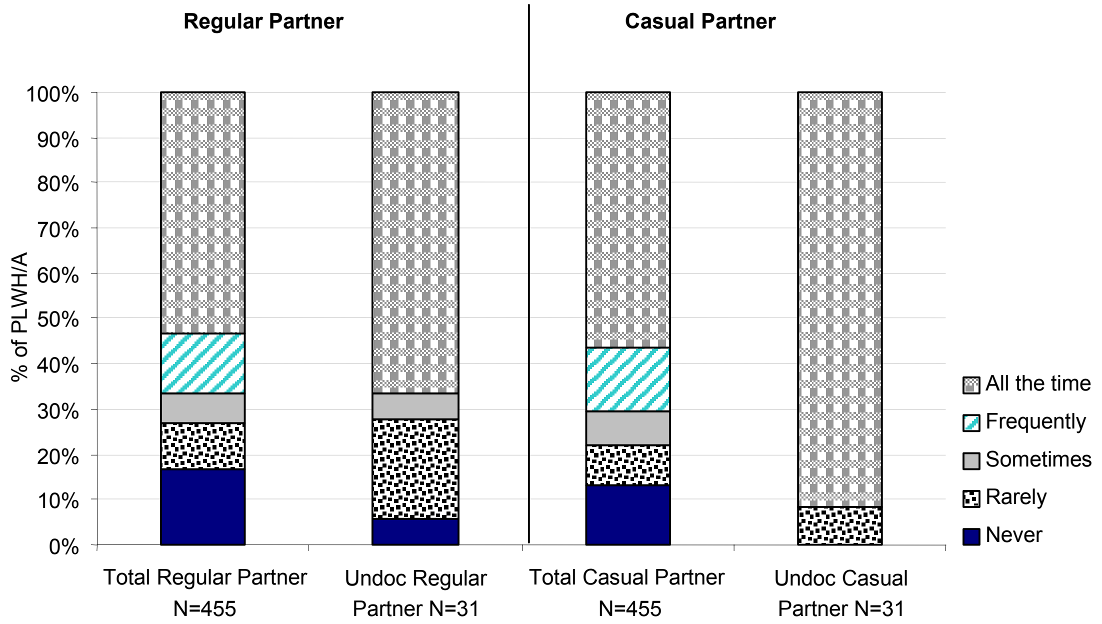
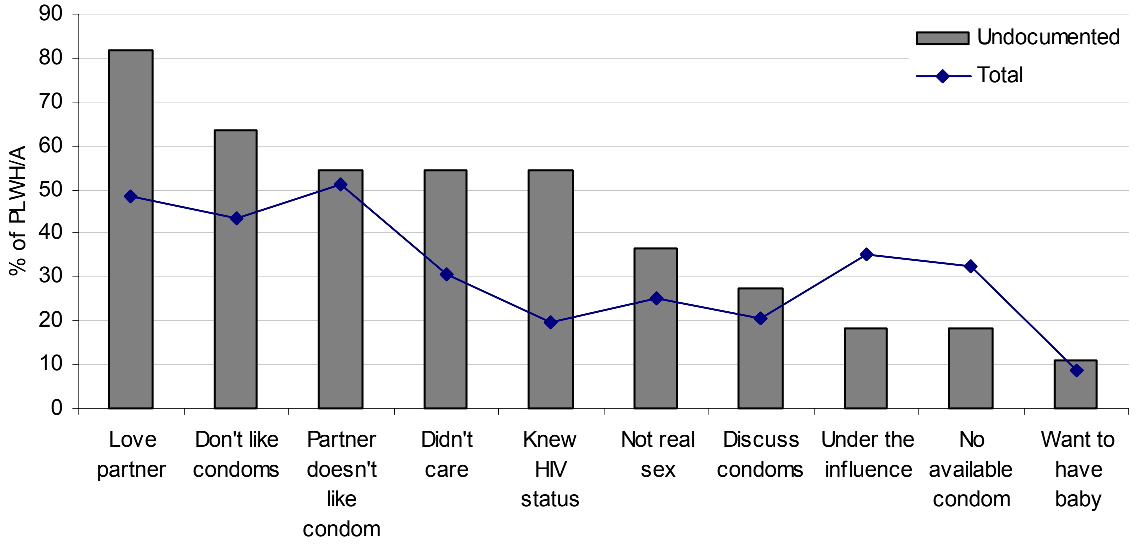


Figure 0-4 Reasons for Not Using Condoms

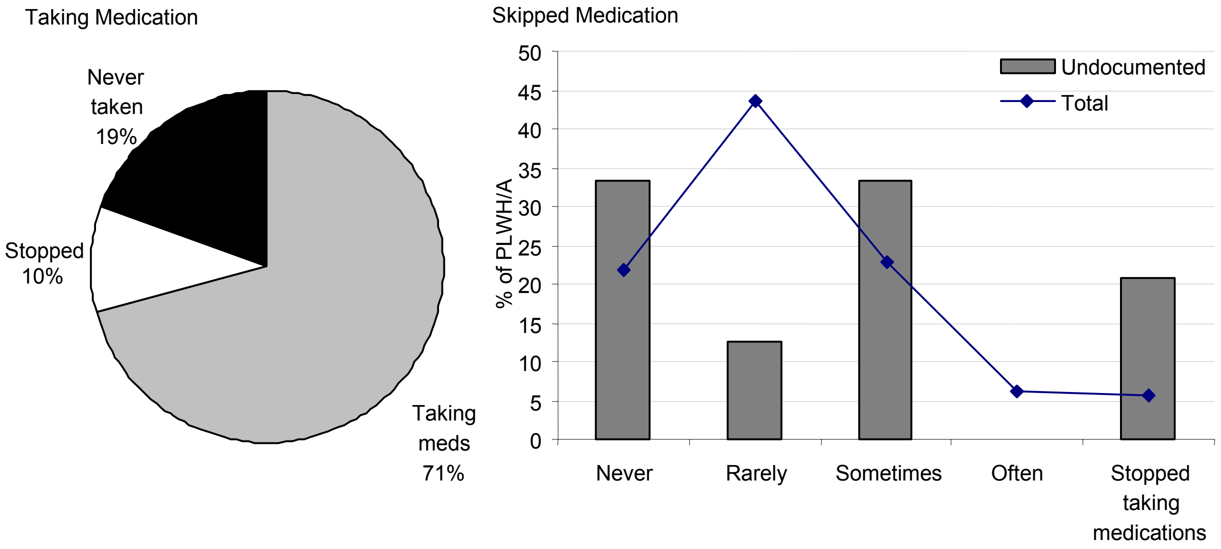


MEDICATION AND ADHERENCE

Medication

- As shown in the pie chart Figure 0-1, seventy-one (71%) of undocumented PLWH/A are currently taking medicines for their HIV infection. The in prison (71%) and youth (45%) populations are the only two other groups with equal or lower percentage of participants currently taking medications, but sample sizes are too small to be reliable.
- About 20% of the participants have never taken medication for HIV infection and 10% have taken medications but stopped. The percentage of undocumented never having taken medications is generally higher than most subpopulations, with the exception of 21% of the Hispanic females and youth who report never taking medication for HIV. This finding should be interpreted with caution because of the small sample size of 31.

Figure 0-1 Medications



Taking Medication

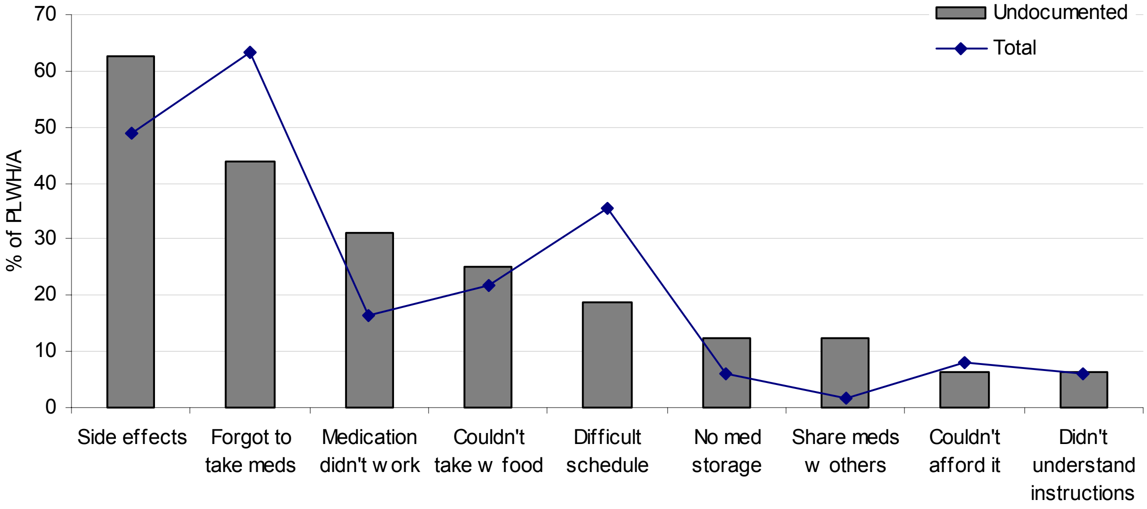
Skipped Medication

Adherence

- Although, undocumented participants are least likely to being taking HIV medication, once medications are prescribed, they are the least likely to deviate from the medical instructions. More than 75% of all the participants report not taking the medications as prescribed by their doctor compared to about two thirds of undocumented participants. As shown in the bar and line graph in Figure 0-1, over 30% of the undocumented participants report never skipping their medications, compared to less than 25% of the total sample.
- When undocumented participants have discontinued their medication, 25% report having done so with the advice of a doctor – specifically more than the total population.
- Undocumented PLWH/A are more likely to report side effects than most groups, with the exception of MSM African Americans.

Figure 0-3 indicates that over 62% of the undocumented participants and less than 50% of the total sample say they have skipped their medications because of side effects. The next most frequent reason for undocumented participants is because they forgot (44%) followed by the belief that the medication was not working (31%). Figure 0-3 shows that the order for the reasons for discontinuing the medication changes from the undocumented to the overall sample.

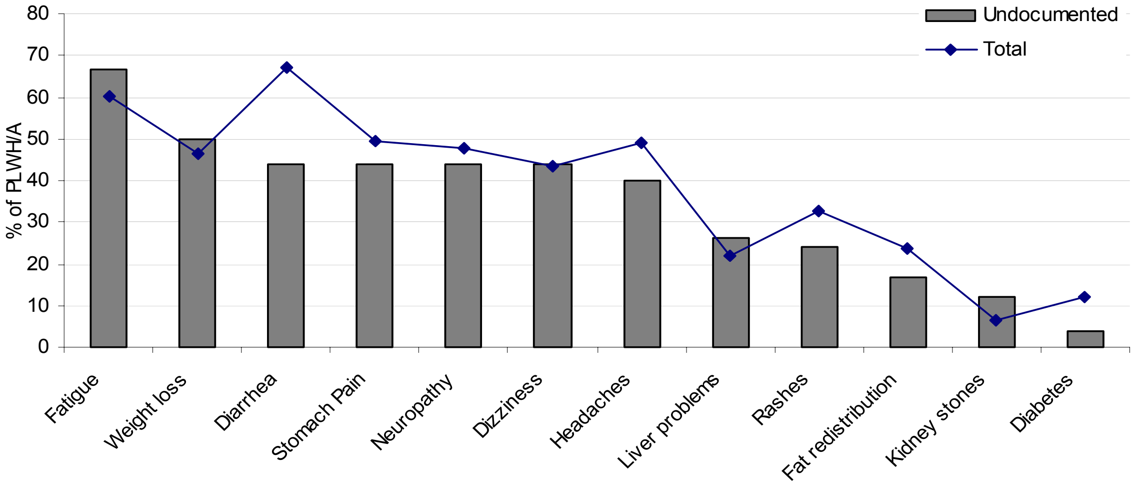
Figure 0-2 Reasons for Stopping Meds



Side Effects

For the most part, undocumented participants report less side effects that the total sample of participants, with the exception of liver problems, kidney stones, and fatigue. Fatigue (67%), weight loss (50%), stomach pain, neuropathy, dizziness and diarrhea (44%) are the most common side effects reported by undocumented participants.

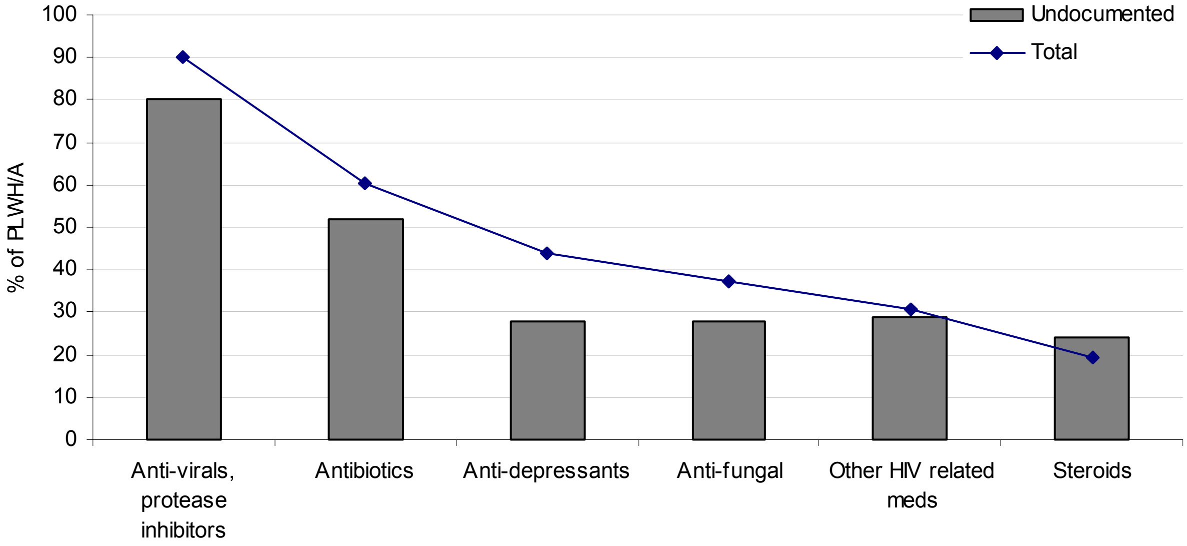
Figure 0-3 Side Effects



Less than two thirds of the undocumented PLWH/A (65%) report taking more than one anti-viral or protease inhibitor compared to 85% of the total sample. For those taking medication, as shown in Figure 0-2, eighty (80%) take anti-virals and/or protease inhibitors.

Antibiotics are the next most commonly taken medication (52%), followed by anti-depressants (28%) and anti fungal medications (28%). As seen in Figure 0-2, there is a difference in the reported use of HIV medications between the undocumented and the total sample, with the total sample more likely to take medication.

Figure 0-4 Medication Taken by Undocumented PLWH/A



OUTCOMES

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 0-1 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 the undocumented participants said they were asymptomatic, about 45% said they have symptoms.

While more than 60% of the asymptomatic undocumented participants report excellent (19%) or good (44%) physical health, asymptomatic participants in the overall sample appear to do even better. More than a quarter of the asymptomatic participants in the total sample report excellent physical health and an additional 50% report good health.

Among the undocumented persons with AIDS, 27% say their health is good compared to 35% of the total sample who say their health is good and 12% who say their health is excellent. Nonetheless, persons with AIDS, both undocumented participants and participants in the overall sample, report better health than those who are HIV positive with symptoms. Less than 15% of the undocumented who are symptomatic or diagnosed with AIDS report being in poor physical health compared to less than 12% in the total sample. . The majority of the undocumented and participants in the overall sample who are symptomatic or living with AIDS report that their health is "fair", with more than one quarter of the undocumented living with AIDS reporting "good" health and more than one third of the total sample reporting good or excellent health.

About 27% of the undocumented living with AIDS say their physical health status has improved compared to 44% of the total sample. HIV positive persons with symptoms are more likely to say that their health is worse than asymptomatic persons living with HIV or those diagnosed with AIDS.

Figure 0-2 reports the current perceived change in emotional health. About 14% of the symptomatic undocumented and about 18% of those living with AIDS report poor emotional health. Similar to participants in the overall sample, more than 50% of asymptomatic undocumented participants report that their emotional health is very good or excellent.

While 38% of the undocumented asymptomatic participants say their emotional health has improved, only 18% of the undocumented participants diagnosed with AIDS, and

14% of those who are symptomatic, say their emotional health has improved. This is in contrast to over 46% of the asymptomatic participants from the total sample, 40% of those diagnosed with AIDS and 33% of the HIV symptomatic participants in the total sample who say their emotional health has improved.

Overall, the perceived physical and emotional health status of the undocumented PLWH/A is notably lower than that reported by the total sample of participants.

Figure 0-1 Quality of Life – Current Physical Health

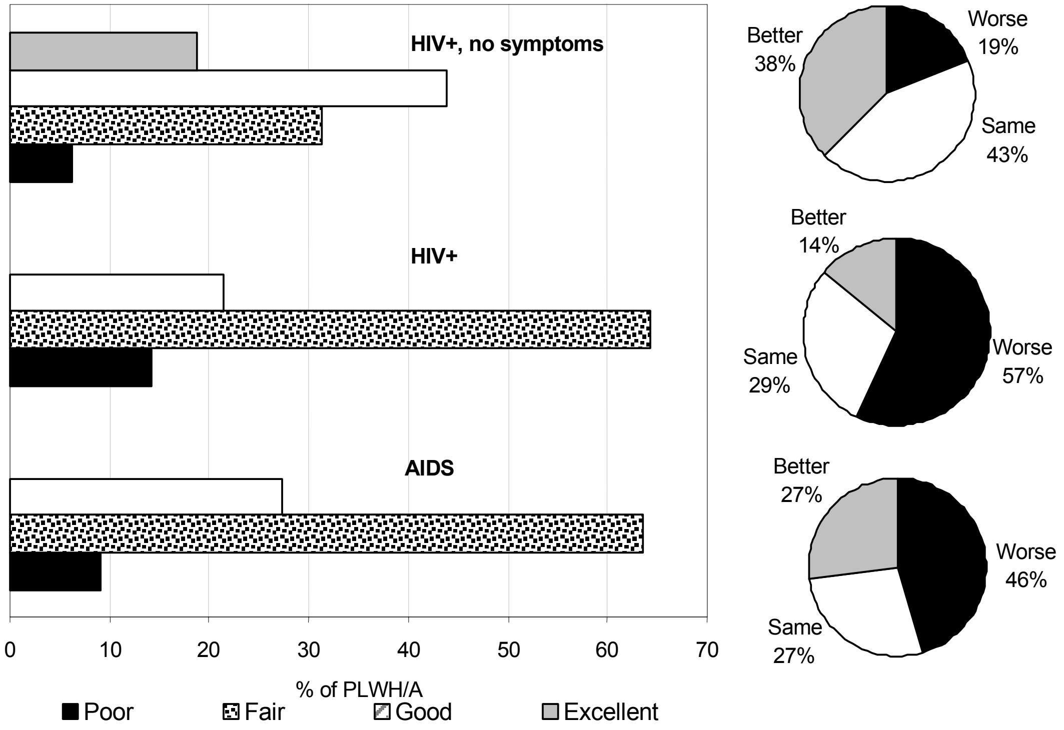
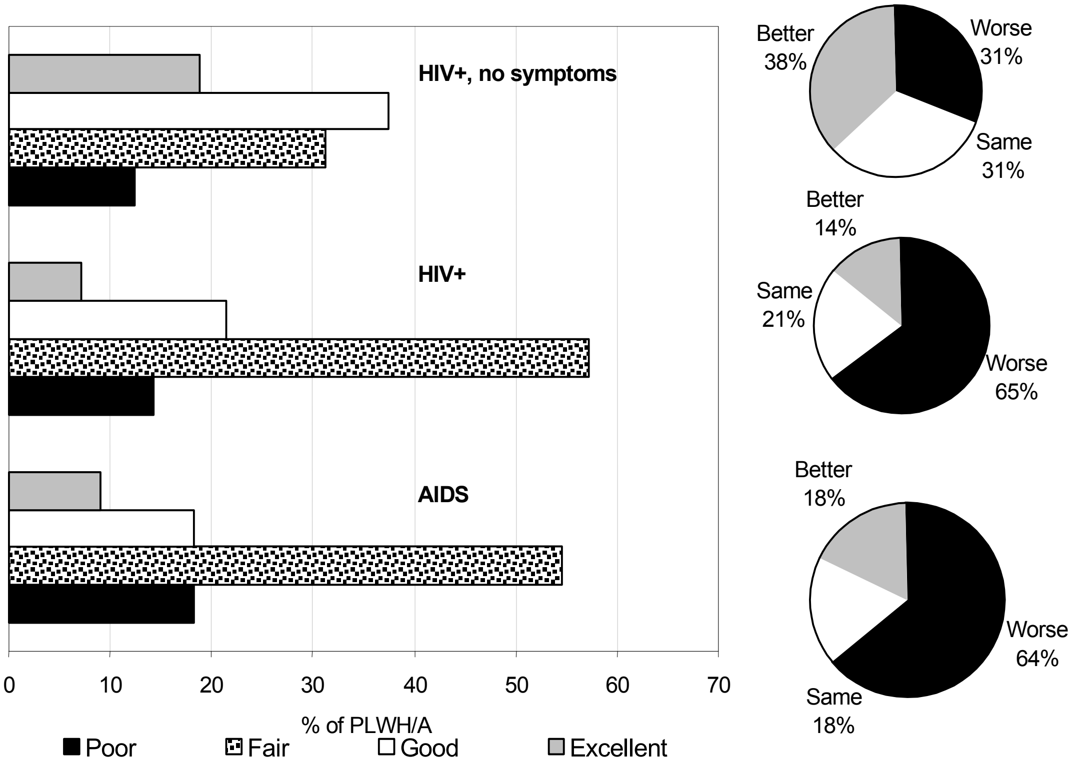


Figure 0-2 Quality of Life – Current Emotional Health



SERVICES

Dimensions of Service Need:

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

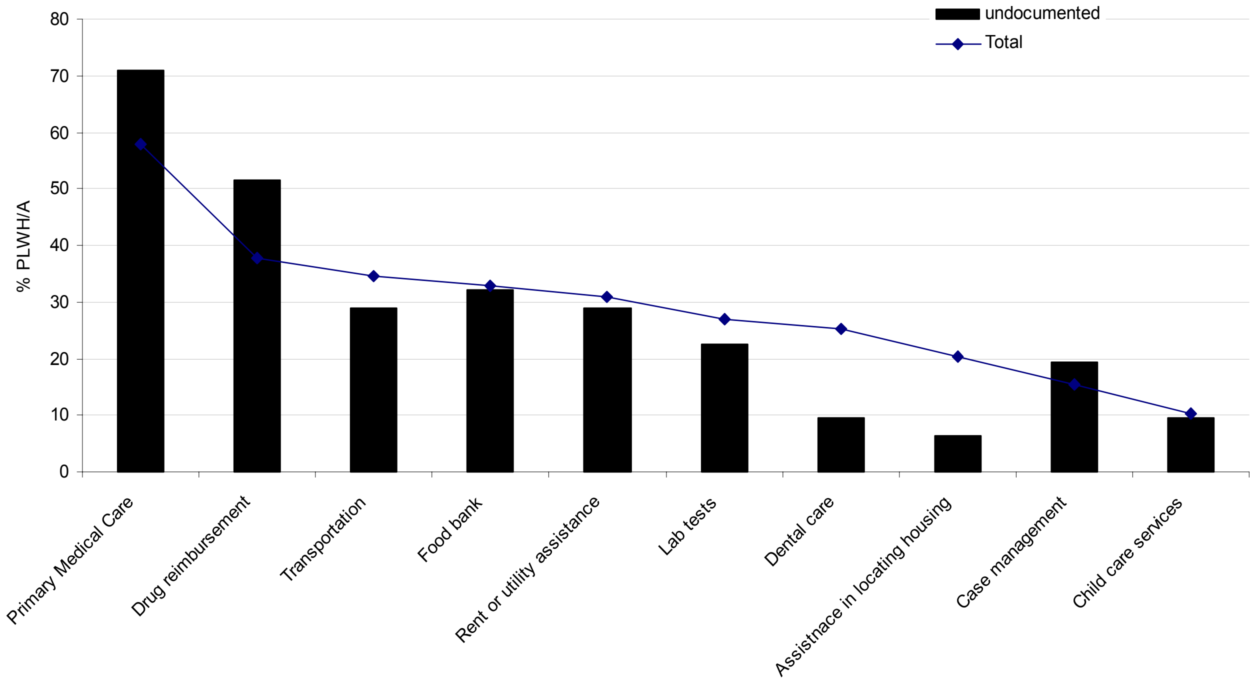
15. The service that was perceived to be most important (each participant ranked the top four services in rank order).
16. Knowledge of the service (Is this service available to you?)
17. Demand for the service (Have you ever asked for this service?)
18. Utilization of the service "ever" and the number of times in the last year
19. Satisfaction with the service
20. Ease of access
21. 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 in greater depth in the Houston Needs Assessment report. The section below highlights the top ten needs for the undocumented participants.

Most Needed Services

Participants of the survey were asked to list the four services that “you need the most”. "Top needs" refers 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 Attachment 7 and graphically in Figure 0-1. Figure 0-1 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 with slightly ratings higher for out-patient care and drug reimbursement. Undocumented participants tend to have the same or lower rankings than the general population for their other top needs.

Figure 0-1 Top 10 Needs of Undocumented



Medical Services

As found across all populations, outpatient care is the greatest need, with drug reimbursement coming in second. Notably, undocumented participants' need for primary medical care and drug reimbursement is 14% higher than the total sample of participants.

P126, an undocumented male, shared his experience with trying to access medical care. "*After going to [a local AIDS specialty clinic], I was given an appointment for one month. I was told that if I had an emergency to go to the emergency room. I was only taking antibiotics for the pneumonia and the mouth infection, I hadn't started taking medicine to help with AIDS. After one week, I went to the emergency room. They (the people at the hospital) were upset at why [local AIDS specialty clinic] had given me an appointment for one month later instead of treating the problem, especially since they knew the same stuff that the hospital did."*

Drug Reimbursement FG Comments

Interestingly, while undocumented participants are among the highest recipients of drug reimbursement services, they report among the lowest levels of access. Comments from the focus group added greater insight. For instance, while medication is available to undocumented, it is not anonymous, and that poses a problem. As P126, a male undocumented Hispanic 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."*

Basic Services - Food, Rent and Utilities, and Housing

While food bank and rent and utility assistance ranked fourth and fifth overall, they increase in importance among the undocumented participants and move to the third and fourth need. 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. For undocumented individuals, who do not receive food stamps, SSI or other supplementary benefits, the need for food and housing assistance are further exacerbated.

P131, an undocumented male*,* described his situation as follows, *"I don't work now. I don't receive help from the State, I only receive help from [local ASO]. The company I worked for didn't insure me but was going to pay me $200 per week but in the end I didn't receive any help from the company (difficult to understand) I talked to some lawyers (at some agency), but they said they couldn't help me."*

Transportation

Reflecting a need to get to services, transportation is ranked third overall, but drops to fifth among the undocumented. Similar to other participants from other groups, the undocumented participants are well aware of the transportation services available, including scheduled rides through the local transportation provider or use of bus passes.

Transportation FG Comments

P126, an undocumented male, described his experience trying to access services from the local transportation provider. *"I use the Metro bus pass, but I also tried to use the [transportation provider] services, specifically for this meeting, but they never came. When I was giving them my information, I asked them if I needed to confirm and they said that it wasn't necessary and they gave me a number. I waited for them and then I called them and they said that I wasn't in their files so they could not set-up for someone to pick me up."*

Lab Tests

Similar to participants from the overall sample, undocumented participants considered lab test important in their HIV care and rank lab tests as the sixth most important need.

Case Management

Case management usually has an overall rank of ninth, but moves up to 7th among the undocumented participants. For these participants, case managers not only serve as their interpreters of the English language but also as interpreters of rules and regulations regarding eligibility.

Case Management FG Comments

P130, an undocumented male, discussed his need for a case manger as follows, "*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."*

P126, also an undocumented male, added, *"Since in some places the services differ, it is important to have a case manager not only in the beginning but throughout because they are always informed on the various services offered and the changes that occur."* He added, "*I would like to know how to better navigate myself so that I could make it around like to the different clinics and agencies."*

Dental care

Dental care, ranked as the 8th most important, 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. It is a service that is perceived to be open to all PLWH/A, including the undocumented.

Dental care FG Comments

As P129, an undocumented Hispanic female noted, *"I have dental assistance and am very happy with it. [A local multi-service organization] refers me to dental and optometry clinics where I receive great care. I go to [dental care provider] for dental."*

Mental Health

Mental health therapy is not consistently among the top 10 service needs for all populations, but for the undocumented participants it is tied for the 8th important need with dental care, health insurance assistance, obtaining supportive housing, and newsletters. During focus group discussions, participants often discussed their sense of isolation and loneliness being away from their county and in many cases their families. The fear of being rejected, stigmatized and the lack of information concerning their HIV status made their stay in the US more difficult.

Mental Health Services FG Comments

P131, an undocumented male, explained why he has chosen not to tell his family, *"I'm afraid that if I told my family that they would not trust in me anymore."*

P126, also an undocumented male, added, "*The mentality of people of Latino background is very different from that of American culture, so that is why I have only told some members of my close family and I don't plan on telling others from my distant family. Concerning the rest of society, I don't really care much about what people think."*

P128, an undocumented MSM, discussed his experience when he first found out he was positive. "*I had some symptoms so I went to have some tests done. I was told I was positive. I was really depressed. I was afraid that my partner would reject me, especially because he was my only support that I had, the person I could count on and I didn't want to go to Mexico (to my family) so that they would pity me. I was depressed, but I went on. [Harris County funded hospital] referred me to [HIV/AIDS specialty clinic]. My first appointment was with a psychologist. When they asked me how I felt, I* *responded by saying "I was entering an unknown world, I felt bad, I felt like no one…. I thought about committing suicide. " I was then referred to [Latino multi-service organization]. I was taking medication."*

P129, an undocumented female, also discussed her depression. *"When I found out all I wanted was to die… I didn't take my medicines or go to the clinic…I got very depressed. I just wanted to die. …If I'm going to have that disease, I just want to die… that disease. No one helped me to be strong. God did."*

Health Insurance Assistance

While less than 10% of PLWH/A say that assistance paying health insurance is among their top ranked service, it emerges among the top ten needs for the undocumented. With less than 13% of the undocumented participants having any form of health insurance, assistance obtaining or paying for health insurance premiums is a great concern.

Assistance Finding Supportive Housing

Close to 10% of the undocumented PLWH/A say that assistance in finding supportive housing is among their top needs. Although more than half of the undocumented participants are unaware of the availability of supportive housing, during focus group discussions a married couple spoke of their success in accessing this service. "*We live in community housing provided by [local CBO]. We qualified for two years, so we have one year left and after, if we still qualify, they will continue to assist us but at a different housing community."*

Newsletters and Information

Newsletters and information are also mentioned by about 10% of the undocumented PLWH/A and appear as one of the top ten needs. Focus group participants from the undocumented group discuss their reliance on oral and written materials for information on various topics including health and immigration matters. As in other focus groups, undocumented participants mentioned having to do their own information gathering because they were not getting enough information from the agencies.

P126, an undocumented male, described how he gets his information about visas and living in the United States as follows, "*I get my information from the news and pamphlets. There are VISA lotteries for people from countries like Mexico and Guatemala, where if selected can apply for a VISA but those that aren't are deported. In [local CBO], I found a book (New York Life) about how one can live here… it gives information…I get information on my own, it was not given to me by an agency."*

Service Awareness, Demand and Utilization

Service awareness, demand, and utilization are presented in Attachment 8 - Attachment 10. In looking at these attachments, the percentages across the different target groups can be compared. For example, in Attachment 8 under the column representing undocumented PLWH/A, 77% said they were not aware of assistance with health insurance premiums. This is in contrast to less than 60% of all the respondents who were unaware of this service. The table percentages can be read within the undocumented participants or compared to the total sample by reading across the rows.

As with the top needed services, a second way to read Attachment 8 is to compare the figures down the column. For example, 6.5% of undocumented participants are not aware that outpatient care is available to them in contrast to 32% that didn't know mental health therapy is available to them.

Attachment 9 displays 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 the undocumented participants seek.

Attachment 10 displays the percentage of those who have ever received the services. Attachment 12 shows 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 that the undocumented participants used a service over the past year can be compared to that used by the total sample by reading across the rows. The median number of times different services were used by the undocumented participants can be compared by reading down the columns.

Graphic Presentation of Awareness, Demand and Utilization

The graphs shown in the following sections plot the values for the top ten services asked for (level of demand) by undocumented participants. The first section discusses awareness, demand, and utilization. The following section discusses the perceived level of access and satisfaction with each of the services.

- 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 the black bar labeled "ask", refers to whether the PLWH/A ever asked for the service.
- Utilization refers to whether the PLWH/A ever "received" the service, and it is shown as the gray bar.

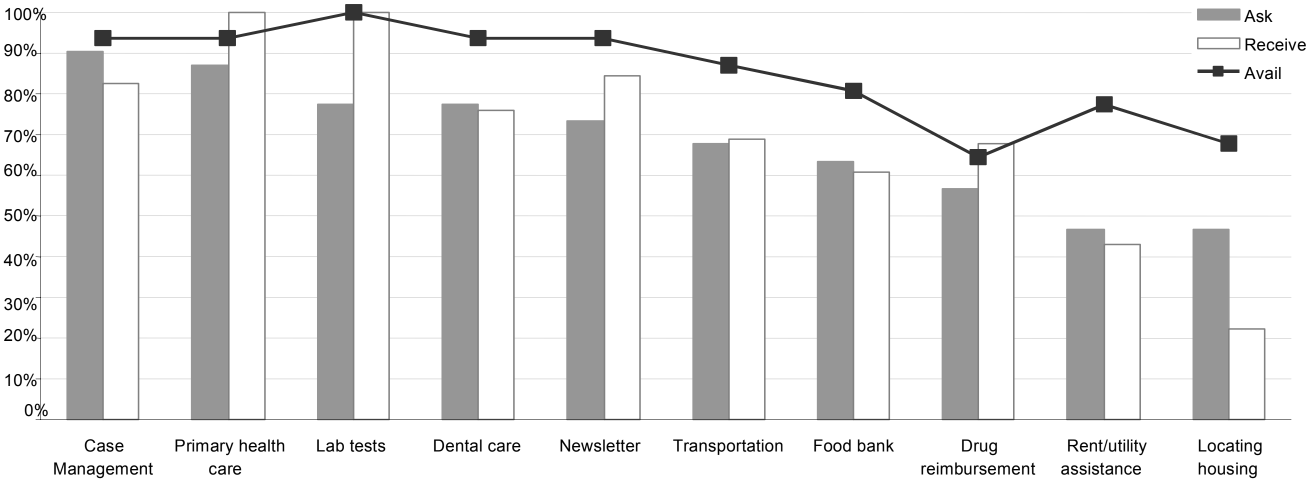
Figure 0-2 displays the awareness, demand and utilization of the top ten services. The services are ordered by the percentage of persons asking for or demanding the services. Demand and utilization follow the same pattern, with the largest percentage of PLWH/A being aware, asking for and receiving primary health care and lab tests.

Services Most Demanded and Utilized

Figure 0-2 shows that case management, primary health care, lab tests and dental care are sought and received by more than 75% of the undocumented participants. Awareness for these services is also among the highest, ranging from 93% to 100% of the undocumented being aware of the availability of these services.

As in the total sample, demand and utilization patterns are somewhat different than the top ranked needs identified by undocumented participants. While drug reimbursement and food bank services are among the top three needs, they drop to 7th and 8th, respectively, of the most sought out services. Dental care, on the other hand, with a rank of 8th tends to rank lower among the most important needs than the fourth rank it was given in relation to demand and utilization.

Figure 0-2 Services Awareness, Demand, and Utilization - Top 10



Awareness - Demand Gap

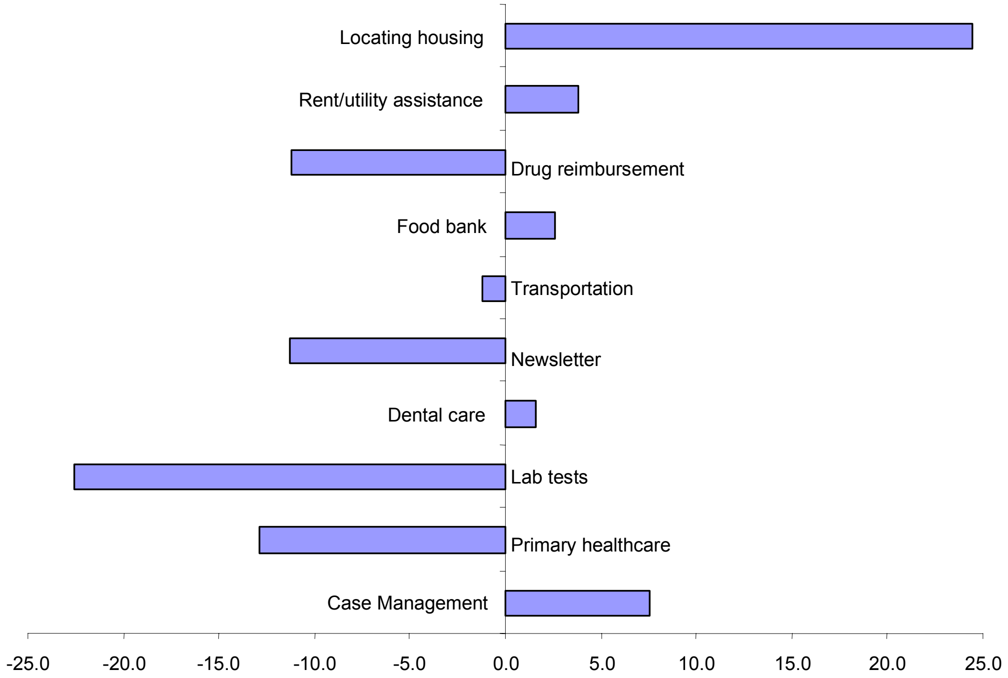
One gap measure is the difference between awareness and demand. The awareness-demand gap measure is calculated by taking the difference between the aggregate percentage of those aware of the service minus those demanding, or seeking the service. For example, while awareness for rent and utility assistance is relatively high (77%) for undocumented PLWH/A, demand and utilization drop to less than 47%. Among the top ten sought services, the awareness-demand gap ranges from 3.2% for case management to over 30% for rent and utility assistance. The greatest differences between awareness and demand ranging from 38% to 48% difference are noted for home health care, nutrition counseling, hotline, residential substance abuse treatment, hospice care and peer counseling.

Demand - Utilization Gaps

Another gap measure involves the difference between demand and utilization. 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. The demand-utilization gap measure is calculated by taking the difference between the aggregate percentage of those demanding services minus those who actually receive the service. In the total sample, the demand-utilization gap ranges from 0% to 18%. Among the undocumented this gap ranges from 0% to 36%. Interestingly, undocumented participants report receiving more than asked for of 15 out of the 33 services. Even among the top ten demanded services, five services are received more than they are asked for by undocumented participants. For instance, while undocumented PLWH/A identify the need for more information and identify newsletters among the top services sought, they report getting more newsletters than they actually seek. This may indicate the need for greater information and education about the services offered and their importance in HIV/AIDS care specifically tailored to meet the literacy and cultural needs of the undocumented participants.

Notably, utilization lags behind demand, with a gap greater than 10%, for assistance in locating housing, home delivered meals, peer counseling, and nutrition counseling. Among the services most demanded, the largest unmet demand, with a gap difference of 8%, is case management.

Figure 0-3 Total Sample Demand- Utilization Gap: Top 10 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 14 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 the undocumented participants versus the total sample. Similar to awareness, demand and utilization, Attachment 14 consists of a table showing the satisfaction scores for the undocumented participants and the total sample.

The table in Attachment 15 shows 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 the undocumented participants or across the undocumented participants and the total sample.

Graphic Presentation of Satisfaction and Access

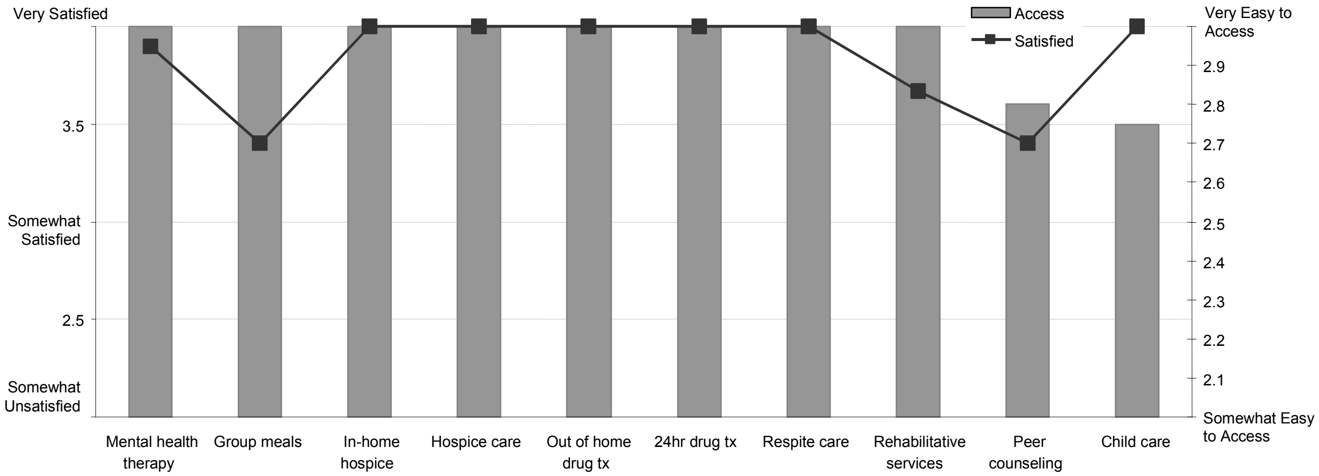
Figure 0-4 displays the perceived access and satisfaction with services for the top ten services, ranked by access, from high to low. In the chart, access is represented by the black bar, with the scale on the right side of the graph, and satisfaction is shown as the line with its scale on the left.

The reason for plotting access and satisfaction together was that they were thought to be related. As seen in the figure, they are related, but access is only one component of satisfaction. Both levels of access and satisfaction were rated high by undocumented PLWH/A, with levels of access ranging from 2.75 to 3.0 and satisfaction levels ranging from 3.4 (somewhat satisfied) to 4.0 (very satisfied). Notably, the undocumented PLWH/A tended to report higher satisfaction ratings than the overall sample for most services.

The services rated as easiest to access by undocumented PLWH/A tend to be the services less demanded or received. These include mental health, group meals, in-home hospice care, hospice care, outpatient substance abuse treatment, residential substance abuse treatment, respite care and rehabilitative services. Undocumented PLWH/A also report being very satisfied with these services.

Even among the services which the undocumented report as hardest to access, only one service, employment assistance, was considered hard to access with a satisfaction score of 1.5, less than somewhat satisfied.

Figure 0-4 Access and Satisfaction with Services - Top 10



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 16. 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.

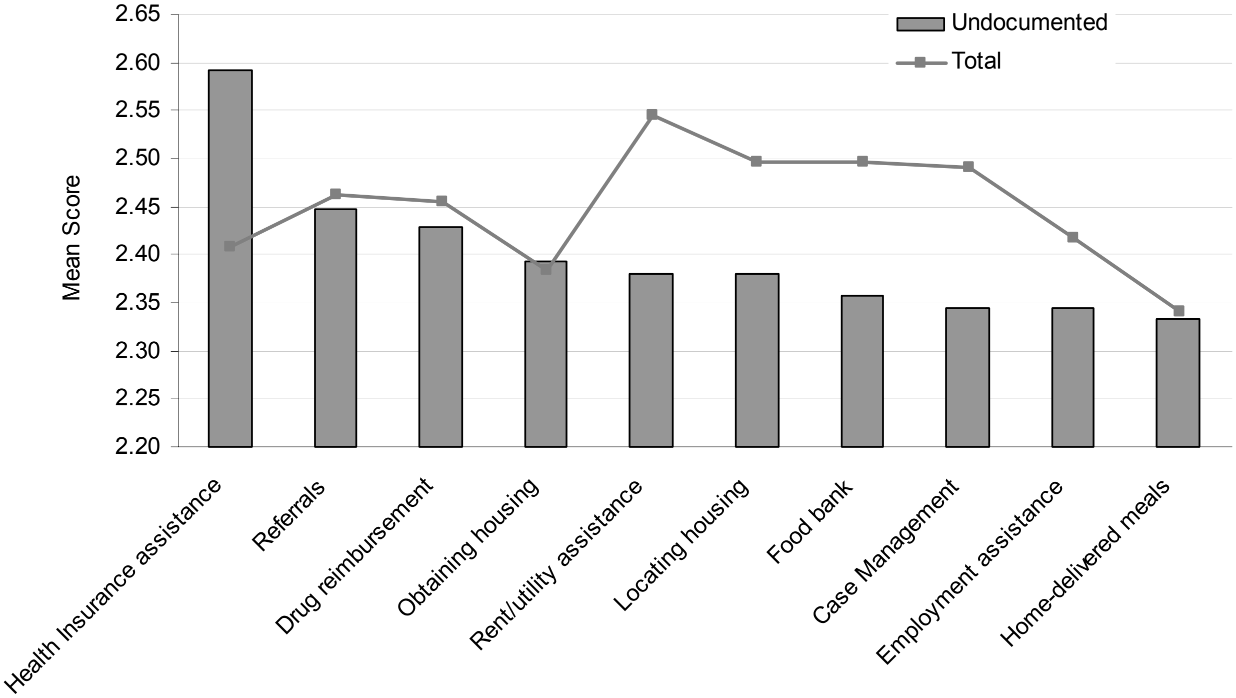
Graphic Display of Anticipated Need

Figure 0-5 shows the top ten 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.

The top ten anticipated needed services differ from the top ten most important services previously reported. For the most part, while the most important services include primary care, lab tests and other health care services, the top ten anticipated services relate to services which are coordinated through case management services, including referrals, different forms of financial assistance and housing assistance. The number one anticipated need for undocumented participants is health insurance assistance.

Figure 0-5 Anticipated Need - Mean Score for Top 10

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



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.[50] The thirty-two barriers can be grouped into three general types of 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.[51] 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.

When the ratings of all of the barriers are summed, none of the target groups or ethnic populations reported a big barrier. However, as shown in Attachment 17, the average barrier scores for undocumented PLWH/A (3.1) are somewhat higher than for the overall sample (2.6). This is surprising considering that undocumented participants tend to be the most satisfied and then to rate most services easy to access.

Figure 0-1 Average Barrier Scores for Undocumented PLWH/A – Top Ten

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

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[50] For exact wording see question 47 in the questionnaire, Attachment 4, and the Barrier section in the focus group outline, Attachment 3.

[51] A pairwise Pearsons correlation matrix was used as input. A varimax option was selected to better discriminate the factors.

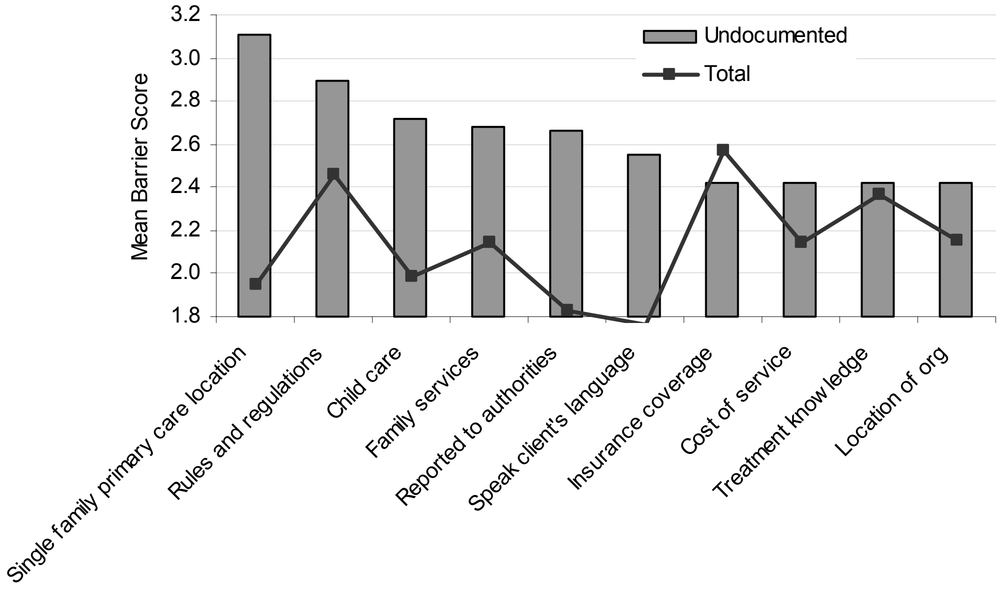

Figure 0-1 shows the top ten barriers for undocumented PLWH/A. Out of the top ten barriers identified by undocumented participants, five are organizational access barriers, three are structural barriers and two relate to the individual. The organizational access barriers include:

- There is no single location where my HIV+ children and I can go for primary care
- The lack of on site child care when I go to get my treatments
- The lack of services for my family
- The chance of being reported to the authorities
- The ability of the person providing services to speak to me in a language that I understand

Organizational Access Barriers

Family Services

The lack of family-oriented services represent the top three organizational barriers for the undocumented participants. This is in contrast to the relatively low ranks assigned by participants of the overall sample to these particular items. For instance, the number one barrier for undocumented participants is the 26th barrier for participants in the overall sample. Similarly, the lack of childcare, the third barrier for undocumented, and lack of services for families, the fourth barrier for undocumented, are the 25th and the 13th barrier for the overall sample, respectively.

Although the majority, 77%, of the undocumented do not live with their children, four out six of the focus group participants are parents, with two of the women having learned about their HIV status when they were pregnant. Also, the top three organizational barriers relate to the lack of family or childcare services. This may suggest, that although the majority of the undocumented participants do not live with their children they may have children in their native land and are concerned about their well being. For instance, P127, an undocumented female, expressed her concern as follows, *“I’m worried about my children’s future. I don’t have papers to get medication.”* She also described the importance of childcare services and the strategic scheduling that needs to take place when seeking care for herself and her husband. She said, "*We get our appointments made for the same time and in that way the kids can be taken care of by the academy of the agency."*

Reported to Authorities

The fifth barrier identified by undocumented participants is the chance of being reported to the authorities. Participants, however, have figured out ways to manage the fear and look for assistance. P129, an undocumented Mexican female, described how she deals with this fear, "*I'm not worried about obstacles that illegals confront because I can just leave, if you have God in your heart that is all that matters, if I die God will take care of me."*

This is the 28th ranked barrier by participants in the overall sample.

Language - Focus Group Comments

While the ability of the person providing services to speak the client's language is ranked as the 30th barrier among the overall sample, for undocumented participants, this represents the sixth barrier to care. For instance, there were some incidences reported in the focus groups where undocumented participants felt they were not getting the appropriate level of treatment due to a language barrier. P130, an undocumented Hispanic male said, *"Because P157 doesn't speak English they sometimes treat her poorly and speak to her in a rude way.* P129, an undocumented female also added, *"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. I feel bad because I can't speak the language and people may look down on you but what can you do."*

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."*

Structural Barriers

In Figure 0-1 the second, seventh and eighth highest barriers are structural. These barriers are more outside of the control of the provider and require changes at the regulatory or legislative level and include:

- Not being eligible to obtain services because of rules and regulation
- Not having enough insurance coverage
- The cost of the service to me

Rules and regulations are identified as the second barriers to care by undocumented PLWH/A. As previously mentioned, undocumented participants rely on case managers to help them interpret and navigate through these rules. Without a case manager these rules and regulations present a small to moderate barrier for undocumented participants. The lack of insurance and cost of service also present a small to moderate barrier.

For undocumented participants these three items are all interdependent. Not having a legal residency status in the United States, undocumented participants have limited access to government-funded programs and therefore the cost of services to them may be higher than for other groups. While some participants reported having a “Goldcard” they expressed concern about what happens once the card expires. For P128, an undocumented male, producing all the required documentation to qualify for benefits becomes a problem. For him, “*The only obstacles I have are proving financial need, residency, how one lives.”*

P130, who has been HIV positive since 1994, has learned how to get by and overcome some of the rules and regulations. He noted, “*I use to worry about proving financial income but not anymore because I now know how to fill out the applications.”*

Individual Barriers

The ninth and tenth barriers for undocumented participants relate to individually based concerns. These include “Not knowing what treatment is available to me" and the location of the organizations. These are also relatively high ranked barriers for participants in the overall sample, with lack of treatment knowledge being the sixth overall barrier and location of the organization being the 12th ranked barrier.

Knowledge of Treatment Information Focus Group Comments

Not being able to communicate with their provider and having little or no access to written information because of their own literacy level or lack of Spanish written materials, undocumented participants face a greater challenge in obtaining treatment information.

P126, a young undocumented male, who has been positive for two months, said he came to the United Sates from Mexico seeking better treatment and medical advice.

Location of Provider Focus Group Comments

For undocumented participants the location of the organizations is their tenth highest barrier to care. While they are aware of the transportation services and report one of the highest use of the transportation service, undocumented participants still find that the distances they have to travel to get to services represent a small to moderate barrier.

Summary of Undocumented PLWH/A Needs and Barriers

The undocumented participants were a specifically targeted group for this needs assessment. While the sample size is small and not generalizable to all undocumented PLWH/A in Houston, the findings in this report begin to highlight areas of need for a community which has been traditionally marginalized and underserved.

The undocumented participants in this needs assessment are mostly Latino, male and heterosexual. They are among one of the groups with the lowest annual income, lowest education level and one of the groups most likely to be employed in some capacity.

Focus group comments as well as findings from the survey reveal the importance of the family unit for this group. The family concerns range from emotional support from the family to support for the family, in the form of counseling, childcare and financial assistance.

Undocumented participants report the lowest use of combination therapy, yet, they report among the highest adherence to medications once prescribed.

Being away from their homeland, away from family and friends, and also being less likely to be on medication than members of any other subpopulation, undocumented participants report poorer emotional and physical health. The services and barriers listed below further highlight unmet needs of the undocumented PLWH/A.

Services

Table 0-1 provides a comparison of the top needs of the total sample versus the ratings given by the undocumented participants for most important needs, awareness, demand, utilization, satisfaction, perceived access and anticipated need of these top ten services. The number in the cell is the rank order of each service for each dimension. The top ten for each measure are shown in the table below, however, only the top ten most important services are discussed within the following text. Among the total sample, services beyond the top ten are shown with their respective ranks.

Table 0-1 Top Needs, Rank Order

	Total Sample	UNDOCUMENTED PLWH/A						
		Undocu-mented PLWH/A	Awareness	Demand	Utilization	Satisfaction	Access	Future Need
Primary Medical Care	1	1	2	2	2	23	24	17
Drug reimbursement	2	2	12	8	7	14	25	3
Transportation	3	4	6	6	6	27	26	29
Food bank	4	3	7	7	8	17	27	7
Rent or utility assistance	5	5	8	9	9	24	29	6
Lab tests	6	6	1	3	1	21	21	26
Dental care	7	8	5	4	5	20	18	11
Assistance in locating housing	8	14	11	10	14	9	28	5
Case management	9	7	4	1	4	19	17	8
Mental health therapy	10	9	10	11	10	8	1	15
Health Insurance assistance	11	10	32	17	25	2	19	1

The overall messages are:

- The top ten needs identified by the overall sample are similar to those identified by the undocumented, with slight differences in rank. These are also similar to the services most sought out by the undocumented participants.
- Undocumented participants rate the highest levels of access and satisfaction with services with very little variation from service to service.
- The anticipated needs reported by undocumented participants differ from the top ten services and the most demanded services. This may indicate the anticipated growing need for services which undocumented participants are currently not receiving. The lower anticipated need rankings of the top ten needs may suggest that undocumented participants don't expect to have an increased need for those services, simply to maintain the current need.
- – Primary medical care is the top need overall and also ranked as the top need by undocumented participants. While primary care is the second service in terms of awareness, demand and utilization, it drops below 20 in both perceived level of access and satisfaction. Primary care is the 17th ranked anticipated need for undocumented participants.
- – Drug reimbursement, the second most important service among the overall sample, is also the second highest service and third anticipated need for undocumented participants. While demand and utilization remain among the top ten, awareness, access and satisfaction drop below the top ten. Again, it most be noted that the reported levels of access and satisfaction for undocumented is very high and therefore an access rank of 25 may still represent a higher score than the overall average.
- – Similar to the participants from the overall sample who rank transportation as the third most important service, undocumented participants consider transportation the fourth most important service. Transportation is among the top ten services which undocumented know about, seek and use. However, undocumented participants rate levels of access and satisfaction with transportation relatively lower than other services. The anticipated need for transportation is also relatively lower than other services.

– The food bank, fourth among the overall sample, is ranked as the third most important service, behind medical care and drug reimbursement. It is also among the top ten anticipated needs.

Barriers

Overall, while none of the groups report "big barriers", undocumented participants identify moderate barriers to care and are the group to report the highest barriers. The highest barrier score for undocumented participants is 3.1 compared to a high total score of 2.2.

Table 0-2 provides a summary of the top ten barriers for the total sample compared to the rural participants. The number in the cell is the rank order. A "+" beside the number means that the score is greater than the average score.

Table 0-2 Top Ten Barriers - Total vs. Undocumented PLWH/A

	Total Sample	Undocumented PLWH/A
Red tape	1	17
Insurance coverage	2	7
Wait for appt	3	18
Rules and regulations	4	2+
Transportation	5	24
Treatment knowledge [1]	6	9+
Navigate through system	7	15+
Feel like number	8	26
Poor coordination amongst organizations	9	23
Lack of sensitivity	10	21
Location of organization	12	10+
Family services	13	4+
Child care	24	3+
Single family primary care location	26	1+
Reported to authorities	28	5+
Cost of service	14	8+
Speak client's language	30	6+

1 – In the consumer survey, participants were asked to indicate how big a barrier "not knowing what treatment is available to me" represented to them.

In terms of barriers, the overall messages are:

- The top ten barriers for the total sample are quite different than the barriers for the undocumented participants.
- While some barriers identified by the overall sample drop in rank among the undocumented participants, for many of the barriers the average score is still higher among the undocumented.
- Three out of ten top barriers relate to family-oriented services.
- Fear of being reported to the authorities and language are specific to undocumented participants, and among the top ten barriers identified by this group.
- The three structural barriers of rules and regulations, lack of insurance and cost are among the top ten barriers for the undocumented.

- Similar to participants in the overall sample, lack of treatment information is the number individual barriers for undocumented participants.
- The second individual barrier for undocumented participants is the location of the organizations are their ability to get to those places. While this was the 12th barrier among the overall sample, undocumented participants felt that this was one of the top ten barriers.
-

ATTACHMENTS

Attachment 43 Focus Group Outline

Attachment 44 PLWH/A Survey

Attachment 45 Undocumented PLWH/A Demographics

Attachment 46 Condom Use & Prevention Behaviors

Attachment 47 Top 10 Service Needs

Attachment 48 Service Awareness

Attachment 49 Service Demand

Attachment 50 Service Utilization

Attachment 51 Frequency of Service Usage

Attachment 52 Service Satisfaction

Attachment 53 Service Access

Attachment 54 Future Demand of Services

Attachment 55 Undocumented PLWH/A Barrier

NOTE: *All attachments are from the Needs Assessment Report: Survey and Focus Group Report of Consumers and Providers.*

HOUSTON EMA & HOUSTON HSDA CARE CONSORTIUM

HIV/AIDS SERVICES, ELIGIBILITY AND OUTCOMES:

A report from the 1999 Provider Survey

Prepared for

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

November 1, 1999
Revised November 18, 1999

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SERVICES

INTRODUCTION

This document reviews all services reported by Title I and Title II. Each service is described and the report shows the unit of service reported, eligibility criteria and outcomes. The data reported is from the provider survey conducted in 1999. The methodology for the Provider Survey is fully discussed in the "Needs Assessment Report: Survey and Focus Group Report Of Consumers and Providers."

SERVICE CATEGORIES AND UNIT OF MEASURES

The service categories used in Houston and their corresponding units of care are shown in Table 3 below, based on Consortium ranking. Table 4 shows the differences in Consortium and Council services and rankings of services for 2000-2001. A brief description of each service follows, including a description of the services offered by each provider and their expected outcomes. The information presented is based on the 1998-1999 Ryan White Title I service category definitions, descriptions provided in the Blue Book and information obtained from the 1999 provider survey. In some instances, provider names are given for a service but the description is blank. This indicates that records show that they provide the service, but no provider survey was submitted or information was left blank/incomplete.

Table 3 Services & Unit of Measurement
(Based on Consortium 2000- 2001 Priorities)

SERVICES AND SUBSERVICES	UNIT OF SERVICE
1. Outpatient Medical Care	
1.1. Appointments with a doctor, nurse or their assistants in an office or clinic for a problem or to monitor HIV infection	Visit
1.2. Lab tests for infections such as viral loads, t-cell counts	Test
1.3. Nutritional Counseling	Visit
1.4. Women's Primary Care	Visit
1.5. Vision Care	Visit
2. Drug Reimbursement	Per treatment or prescription and per visit
2.1. Drug reimbursement - Assistance in paying for HIV related drugs – ADAP & HIV HOPE	
3. Case Management	15 min increments
3.1. Case management – someone who helps a client coordinate HIV/ AIDS health care (intake, follow-up, other)	
3.2. Medical case management (only funded as case management)	
4. Transportation	
4.1. General Transportation – assistance to access physical or mental health care on a regular or emergency basis	One way
4.2. Transportation Voucher Program – including Metro bus tokens, passes and gas vouchers	Token, pass
5. Housing Assistance	
5.1. Assistance in location or obtaining suitable housing	
5.2. Obtaining housing in a supportive housing facility	
5.3. Long-term or short-term housing	Per month
6. Dental care	Procedure
7. Food Bank	
7.1. Food Pantry	Visit
7.2. Meals at Thomas Street	Per person/per meal
7.3. Nutritional Supplements	
7.4. Home-delivered meals	Per person/per meal
8. Direct Emergency Assistance	
8.1. Direct financial emergency assistance – including rent, utilities, telephone, relocation allowance	Month
8.2. Household items	Visit
9. Substance abuse treatment / counseling, advocacy and outreach	

SERVICES AND SUBSERVICES	**UNIT OF SERVICE**
9.1. Substance abuse treatment (not in a residential setting)	Day
9.2. Substance abuse treatment in a 24 hour a day residential setting	Day
10. Home health care	
10.1. Home health care from nurse or professional home health agency that is provided through a case manager	Hour or Visit
10.2. Homemaker care	Hour
11. Mental Health Therapies	
11.1. Professional counseling – Mental health therapy with a psychologist or social worker in individual or group sessions	15 min increments
11.2. Outpatient Psychiatric Services	Visit
12. Respite Care	
12.1. Child Day Care – in-home reimbursement system	Half day (4 hr max)
12.2. Child Day Care – medically managed child day care	Day
12.3. Adult Day Care	Day
12.4. Volunteers/Respite care teams	Hour
13. Client Advocacy	
13.1. Legal services	Hour
13.2. Permanency Planning – adoption/foster care assistance	Hour
13.3. Communication Services	2 Hours
14. Health Education / Risk Reduction 14.1. Health Education / Risk Reduction Sessions 14.2. Newsletters, leaflets or booklets about HIV/AIDS treatment 14.3. Hotline or telephone information	Course Newsletter
15. HIV Counseling and Testing	
16. Health Insurance Continuation	Per payment
16.1. Assistance paying health insurance premiums, co-payments, and deductibles	
17. Counseling Other	
17.1. Support groups/non-mental health	15 min increments
18. Rehabilitation Care	Physical Therapy Session
19. Volunteer Programs 19.1. Volunteers or peers who assist in household or personal tasks and provide support (Buddy/Companions) 19.2. Volunteers providing direct client services	Hour
20. Hospice care / Home hospice care	
20.1. In-home hospice care or intensive care at home by a nurse and home care assistants during the end stage of HIV infection	Per day
20.2. Hospice care**,** out of the home, where terminally ill PLWH/A live during the end stage of AIDS	Per day
21. Referral	Per referral
22. Outreach	Contact
22.1. Street outreach	
23. Holistic or complementary therapy – including acupuncture, massage or chiropractic care from licensed practitioner	Session
24. Employment assistance / vocational counseling and training	15 minutes
25. Leadership Development	Program

Table 4 Houston Consortium and Council Priorities for FY 2000-2001

CONSORTIUM	Consortium Priority	Council Priority	COUNCIL
Primary Medical Care, Rural	**1**	**1**	Outpatient/Ambulatory/Nutritional Services
Medication Assistance	**2**	**2**	Drug Reimbursement
Transportation, Rural Non-rural gas vouchers (new)	**3**	**4**	Transportation
Housing	**4**	**5**	Housing
Food Pantry Food Pantry, Rural	**5**	**7**	Food Bank/ meals / nutritional supplements.
Case Management Case Management, Special Needs Primary Care Case Management Adolescent Services	**6**	**3**	Case Management
Day Care, Pediatric	**7**	**12**	Day or Respite Care
Dental	**8**	**6**	Dental Care
Counseling Counseling, Rural	**9**	**11**	Mental Health
Health Insurance Premiums	**10**	**15**	Health insurance
Legal Legal Rural	**11**	**13**	Client Advocacy / Legal / Permanency Planning
Hospice	**12**	**21**	Hospice Care
Household Items	**13**	**8**	
Home Health Home Health, Rural	**14**	**10**	Home Health Care
EMI/HERR	**15**	**14**	Health Education / Risk Reduction
Volunteerism	**16**	**19**	Buddy / companion
Nutritional Counseling	**17**	**1**	Outpatient/Ambulatory/Nutritional Services
Assisted Living	**18**	*	
Day Care, Adult	**19**	**12**	Day or Respite Care
Employment Assistance	**20**	**	
Interpreter Services	**21**	**	
Housing Administration	**22**	**5**	Housing
Peer Counseling	**23**	**16**	Counseling (Peer / Other)
		8	Direct Emergency Assistance
	*	**9**	Substance Abuse
	*	**17**	Program Support
	*	**20**	Planning Council Support
	*	**22**	Referral
	*	**23**	Outreach

DESCRIPTION OF SERVICES

Ambulatory/Outpatient Medical Care

Clinic-based and Community Primary Care

Primary health care services include on site physician, physician extender, nursing, phlebotomy, radiographic, laboratory, pharmacy, intravenous therapy, home health care referral, licensed dietitian, patient medication education, and patient care coordination. The agency/clinic must provide continuity of care with inpatient services and subspecialty services (either on-site or through specific referral to appropriate agencies). Services by all providers are provided in rural communities outside Harris County directly or through sub-contract

Services provided

- Continuity of care for all stages of adult HIV infection;
- Laboratory and pharmacy services including intravenous medications (either on-site or through established referral systems);
- Access to the Texas ADAP program (either on-site or through established referral systems);
- Access to compassionate use HIV medication programs (either directly or through established referral systems);
- Access to HIV related research protocols (either directly or through established referral systems);
- On-site pelvic exams as needed with appropriate treatment and referral.

Qualifications

All services are provided by State licensed physicians, registered nurses, nurse practitioners, pharmacists, physician assistants, State licensed dietitian, social workers and ancillary health care providers in accordance with appropriate State licensing and/or certification requirements and with knowledge and experience of HIV disease. The providers and system are Medicaid/Medicare certified.

Women's Primary Care

Women's Primary Care provides a continuum of HIV medical services for eligible, indigent clients with HIV disease. These services include on-site physician, physician extender, nursing, phlebotomy, radiographic, laboratory, pharmacy, intravenous therapy, home health care referral, licensed dietitian, patient medication education, and patient care coordination. The provider provides continuity of care with inpatient services. The provider ensures that subspecialty physician, primary care nursing or ancillary health care provider services are available on-site or by specific established referral protocols to appropriate agencies upon primary care physician order.

Services Provided

- Continuity of care for all stages of adult HIV infection;
- Laboratory and pharmacy services including intravenous medications (either on-site or through established referral systems);
- Access to the Texas ADAP program (either on-site or through established referral systems);
- Access to compassionate use HIV medication programs (either directly or through established referral systems);
- Access to HIV related research protocols (either directly or through established referral systems);
- Complies with the Adult Standards for HIV Primary Medical Care Components of Medical Practice and provides state-of-the-art HIV-related primary care medicine in accordance with the most recent National Institute of Health (NIH) HIV treatment guidelines.
- On-site pelvic exams as needed with appropriate treatment and referral.

Qualifications

The provider is responsible for ensuring that services are provided by State licensed physicians, registered nurses, nurse practitioners, pharmacists, physician assistants, State licensed dietitian, social workers and ancillary health care providers in accordance with appropriate State licensing and/or certification requirements and with knowledge and experience of HIV disease.

Patient Medication Education

Program Description

- Educators are RNs or a Master level Mental Health Professionals.
- Clients are able to form an ongoing relationship with the assigned staff member doing the patient medication education.
- Clients who prescribed ongoing medical regimens (i.e. protease inhibitors) are assessed for adherence. Clients with adherence issues related to lack of understanding, must receive more education regarding their medical regimen. Clients with adherence issues that are behavioral or involve mental health issues are referred to counseling.

Vision Care

Services are provided at an eye care clinic or Optometrist's office. The service sub-categories include appointments with a doctor, nurse, or their assistants in an office or clinic for a problem or to monitor HIV infection and lab tests for t-cell counts and infections such as viral loads.

Services Provided

Services include but are not limited to:

- External/internal eye health evaluations;
- Refractions;
- Dilation of the pupils;
- Glaucoma and cataract evaluations;
- CMV screenings;
- Prescriptions for eye glasses and over the counter medications;
- Provision of eye glasses (contact lenses are not allowable);
- Referrals to other service providers (i.e. Primary Care Physicians, Ophthalmologists, etc.) for treatment of CMV, glaucoma, cataracts, etc.

Outpatient Care Providers, Eligibility and Outcomes

Amigos Volunteers in Education and Services, Inc., Baylor College of Medicine Health Care – Pediatric, Donald R. Watkins Memorial Foundation, Inc., Fort Bend Family Health, Harris County Hospital District, Montrose Clinic (including Vision Services), UTMB – Conroe Clinic, UT Health Science Center of Houston – including Women's Immunology at LBJ Hospital & Pediatric), and KINDERx Clinic (Kids In Need of Drug Evaluation and Re-treatment clinic).

The services offered by each provider and their expected outcome are described in Table 5.

Table 5 Outpatient services

OUTPATIENT SERVICES		
Amigos Volunteers in Education (AVES)		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Harm reduction approach 3) Live in Harris or Fort Bend Co.	Outpatient medical care-for women, men and adolescents (1.1-1.4). Treatment, education and advocacy – our clients receive education sessions during each doctor visit and are invited to our on-going workshops.	

OUTPATIENT SERVICES, cont…		
Baylor Teen Clinic		
Eligibility	**Service Description**	**Outcomes**
1) Must be 21 years or younger 2) The majority of clients are indigent.	Well trained multi-disciplinary staff provides gender neutral, culturally sensitive services in a confidential setting. The programs are no cost to clients and target adolescents who are at high risk for school dropout due to lack of primary health care, chemical abuse, violence, and/or teen pregnancy. The clinics network with various community groups to address adolescent medical care needs. Services offered in the Teen Health Clinics include: family planning, HIV screening/pre-post test counseling, STD screening, treatment and test of cure; prenatal care, evaluation for contraception, individual counseling, crisis intervention, complete medical exam, comprehensive lab profile, sports physicals, screening for substance and alcohol abuse, parenting education, self-esteem coaching, Early Periodic Screening Diagnosis and Treatment, and case management.	Current patient profiles identify the high-risk teen clients as primarily African-American (65%) with Hispanic (29%) and Anglo (11%). However, the proportion of Latino teens in the clinics is consistently growing, reflecting the changing population trends in Texas and the Southern region. In 1998, the clinics saw over 12,000 adolescent patients. Of this group, 20% were males. During this time period, the clinic diagnosed 11 HIV positive teens, screened approximately 3,000 patients for HIV and also found 2,730 cases of STDs. There was an increase in the number of adolescents served by the clinics, number of referrals to our clinical programs, and an increase in Hepatitis B, immunizations and physical examinations. There was a reduction in the prevalence of STDs and HIVs, number of counseling sessions for individuals at risk for HIV infections, number of individuals agreeing to be tested for HIV, and decrease in participates in HIV pre/post test counseling

OUTPATIENT SERVICES, cont…

Donald R. Watkins Foundation

Eligibility	Service Description	Outcomes
1) HIV infection symptomatic or asymptomatic or diagnosed with AIDS 2) Must live in Houston EMA 3) Must meet other Ryan White Title I requirements	Provide primary care visits to eligible clients, which may include site physician, physician extender, nurses, phlebotomy, radiography laboratory, pharmacy, intravenous therapy, home health care referral, dietitians, patient medication education, and patient care coordination.	Improvement of health and living status for 750 unduplicated clients with limited or no income. Donald Watkins provided at least 10,000 units of primary care visits to persons living with HIV.

Fort Bend Family Health

Eligibility	Service Description	Outcomes
1) 500% of Federal Poverty Level or underserved for any person 2) All stages of HIV 3) Live in Houston HSDA	Offers primary health care, medical case management, labs, imaging, specialty care, medications.	Treatment adherence lead to maintenance or improvement of health.

Harris County Hospital District

Eligibility	Service Description	Outcomes
Must be HIV + or with AIDS diagnosis	**Primary Medical Care -** Provide direct outpatient primary medical care services to people living with HIV and AIDS at Harris County Hospital District facilities and coordinate other services needed by clients that are not accessible in our facilities. Services provided on site in our facilities include appointments with a doctor, nurse or their assistants for a client specific problem or monitoring the progression of the infection, lab tests, women's primary care, drug assistance, physical therapy, and pain management.	HCHD expected to be able to delay the progression of the infection and allow clients to have an extended productive quality of life. The number of clients that have been able to return to a meaningful productive life and helping others in the community to deal with the infection increased.
Must be HIV + or with AIDS diagnosis	**Early Intervention Program -** Early intervention, primary care, linkages to other community services, dental care, outreach, and HIV counseling/testing.	Newly diagnosed clients remained as healthy as possible.

OUTPATIENT SERVICES, cont…

Montrose Clinic

Eligibility	**Service Description**	**Outcomes**
1) Must be up to 500% of poverty 2) HIV infection symptomatic or asymptomatic	Provide outpatient primary care, nutritional counseling, and vision care.	Achieved lower viral load, higher t-cell, and fewer opportunistic infections. Early detection of CMV. An increase in the ability of clients to return to work. Unexpectedly, no matter how much work is invested with clients, they are not compliant with meds.

Texas Children's Hospital

Eligibility	**Service Description**	**Outcomes**
1) Pregnant women (13-55 yrs old) and Pediatrics (0-18 years old) 2) HIV+ or with AIDS diagnosis	Pediatric and adolescent outpatient medical care, case management, referrals, direct emergency assistance, transportation, HIV testing for children and adolescents, AIDS clinical trials for children with HIV and pregnant women with HIV.	Increased # of research participants (greater than 100). Decreased # of perinatal transmission (maintained less than 5%). Decreased # of adolescent/adult women STDs. TCH has developed a camp as a new outreach program, and has developed a liaison with a pharmacy to assist in medication non-compliance. Unfortunately and unexpectedly, recognition of patient noncompliance hindered funding available for transportation assistance.

UTMB – Conroe Clinic

Eligibility	**Service Description**	**Outcomes**
1) HIV infection, symptomatic (above 100 CD4) 2) Harm reduction approach	Offers primary health care.	The management of patient's HIV infection slowdown/reverse progression of the disease. UTMB worked in a socially complex population. Some clients made their healthcare difficult to manage.

OUTPATIENT SERVICES, cont…

UT Health Science Center of Houston, Dept. of Pediatrics

Eligibility	Service Description	Outcomes
1) Must meet Ryan White income parameters 2) Between ages 0-21 3) HIV infection symptomatic or asymptomatic	UTHSC provides primary and subspecialty medical care to 80 HIV infected children and 100 HIV exposed newborns each year. The 100 exposed infants are not included in these numbers.	

UT Health Science Center of Houston, Women's Immunology Center at LBJ Hospital

Eligibility	Service Description	Outcomes
1) Must live in Houston EMA/HSDA 2) HIV infection symptomatic or asymptomatic	Women's Primary Care and Case Management	UTHSC served 300 women, adolescents, and children. UHSC lost a considerate amount of patients because of managed care. UTHSC is doing same work for same money but not being reimbursed at same rate.

KINDERx Clinic (Kids In Need of Drug Evaluation & Re-Treatment Clinic

Eligibility	Service Description	Outcomes
1) HIV exposed in- utero 2) Substance high risk 3) Live in Houston EMA/HSDA 4) Exposed in-utero to drugs, alcohol, and/or HIV/AIDS.	Provides medical care, case management, and social services to children exposed to drugs, alcohol and/or HIV/AIDS, and their families. When funding is available, KinderX also provides nutritional counseling and education to HIV/AIDS infected men and women.	Kinderx Clinic one-stop-shop has seen a 90% immunization rate and an increase compliance with appointments. It was able to provide availability of staff on their main-site and more outreach.

Drug Reimbursement

Local (Houston EMA only) drug reimbursement program provides pharmaceuticals to patients otherwise ineligible for medications through private insurance, Medicaid/Medicare, State ADAP or other sources. Medications available are those in the State ADAP (Levels I and II) and local Medication Plus formularies. Patients must have income no greater than 500% of the Federal Poverty Index and are limited to a maximum of $1,500.00 per month in medications through this program.

Drug Reimbursement Providers, Eligibility, and Outcomes

The Assistance Fund (TDH administers the ADAP program).

Table 6 Drug Reimbursement

DRUG REIMBURSEMENT		
The Assistance Fund		
Eligibility	**Service Description**	**Outcomes**
1) Income must be 500% of poverty 2) All ages eligible 3) HIV infection symptomatic or asymptomatic 4) Must live in 6 county or 10 county depending on program 5) Valid Rx from doctor	Provide long & short-term help with HIV related meds for those with no insurance.	This service was able to keep clients from getting debilitating infections and hospitalization.

Case Management

Case Management is provided at no cost to HIV/AIDS infected persons who are not able to access services without assistance. Case managers can link their clients to appropriate services and help them develop the skills and resources they need to access services on their own. A single agency may have one targeted and one untargeted team.

Case Management Team

Case management provides both case management, service linkage, and outreach activities. Case management is a working agreement between a client and a case manager for a defined period of time based on the client's assessed needs. The purpose of case management is to assist clients with the procurement of needed services so that the problems associated with living with the disease are mitigated. Case management is primarily home and community-based. Service linkage is a working agreement between a client and a service linkage worker for a variable period of time, based on client need, during which information, referrals and service linkage are provided on an as-needed basis. 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.

Key Activities

- Identifying and screening clients;
- Assessing each client's medical and psychosocial history and current service needs;
- Developing and regularly updating a service plan based upon the client's needs and choices; and implementing the plan in a timely manner;
- Providing information, referrals and assistance with linkage to medical and psychosocial services as needed;
- Monitoring the efficacy and quality of services through periodic reevaluation;
- Advocating on behalf of clients to decrease service gaps and remove barriers to services is helping clients develop and utilize independent living skills and strategies.

Services target low-income individuals with HIV/AIDS who demonstrate multiple medical and psychosocial needs. This includes, but is not limited to: primary care; specialized care; alternative treatment; medications; placement in a medical facility; emotional support; mental health counseling; substance abuse treatment; basic needs (including food, clothing, and shelter); transportation; legal services; and vocational services. Services also target clients who cannot function in the community due to barriers. This includes, but not limited to: extreme lack of knowledge regarding available services; inability to maintain financial independence; inability to complete necessary forms; inability to arrange and complete entitlement and medical appointments; homelessness; deteriorating medical condition; psychiatric illness; illiteracy; language/cultural barriers; and/or the absence of speech, sight, hearing, or mobility.

Case Managers are to serve eligible clients, especially those underserved or unserved population groups which include: African American, Hispanic/Latino, Women and Children, Veteran, Deaf/Hard of Hearing, Substance Abusers, Gay/Lesbian/Transsexual, Homeless.

Services Delivered

Case Management/Service Linkage services are integrated into the Houston Regional HIV Care Management System (HIV/CMS). They comply with HIV/CMS Case Management/Service Linkage Standards for Care and policies and procedures as they are completed and/or revised including linkage to the Houston Case Management Uniform Reporting System (URS) database.

One of the Team Members must function as the designated F.T.E. Supervisor. The designated Supervisor is required to have at least 10% direct service time with the clients of the Team. Case Managers/Service Linkage Workers spend at least 50% (1,040 hours per FTE) of their time providing direct case management services. Direct case management services include any activities with a client (face-to-face or by telephone), communication with other service providers or significant others to access client services, monitoring client care, and accompanying clients to services.

Case Managers are required to have at least one (1) face-to-face encounter per month with all of the Team's active clients in the clients' natural environment. Indirect activities include travel to and from a client's residence or agency, staff meetings, supervision, community education, documentation, and computer input. Direct case management activities are documented in the URS according to the Case Management/Service Linkage Standards of Care.

Populations are served in their natural environment and in a culturally competent manner. Culturally competent services include, but are not limited to: services that are provided in a language and format the client understands; interpreter services; communications devices for the deaf/hard of hearing; and staff with documented prior experience, training and/or education regarding the underserved/unserved populations.

Personnel Qualifications

Providers comply with the Houston HIV/CMS Case Management/Service Linkage Standards of Care and Position Descriptions. At least one (1) of the Case Manager FTE positions on the Case Management/Service Linkage Team are fluent in both English and Spanish (both oral and written). Case management/Service Linkage staff have at least one year of paid HIV/AIDS experience.

Rural Case Management Team

Same as above, except services to be provided in Houston EMA counties other than Harris.

Hispanic/Monolingual Team

Same as above, except services to be provided by staff who are bilingual and bicultural.

Children/Adolescents Team

Same as above, except staff must have prior experience with children and adolescents.

Medical Case Management Team

Same as the above, with the following differences. The focus of the Medical Case Management Team concept is to provide short-term intensive intervention by a team of case managers which will address service linkage, medical needs and psychosocial needs depending on client need followed by long-term availability of information, referrals and intermittent interventions, if required. Clients at all levels of need are served.

Medical Assessment and Consultation

Medical Assessment and Consultation is performed through the participation (either directly or via consultation) of the Registered Nurse member of the Team. It includes:

- Client assessments;
- Develop a medical service plan for each client and ensure its implementation;
- Home visits;
- Interaction and advocacy with medical providers on behalf of clients;
- Monitor medical services accessed by clients and follow-up as needed;
- Transition clients out of medical case management upon completion of medical service plan and medical stabilization;
- Medical Assessment and Consultation.

Case Management Service Providers, Eligibility, and Outcomes

Amigos Volunteers in Education and Services, Inc. (provider survey not submitted), Covenant House Texas – Adolescent Case Management, Donald R. Watkins Memorial Foundation, Inc. (provider survey not submitted), Family Service Center (urban and rural), Harris County Hospital District, Houston Area Community Services, Montrose Clinic, Montrose Counseling Center, People With AIDS Coalition, UT Health Science Center at Houston, and Diocesan AIDS Ministry – A Program of Associated Catholic Churches.

Table 7 Case Management Services

CASE MANAGEMENT SERVICES

Amigos Volunteers in Education and Services, Inc.

Eligibility	Service Description	Outcomes

Covenant House Texas – Adolescent Case Management (Title IV)

Eligibility	Service Description	Outcomes
1) Must be an adolescent 2) HIV infection symptomatic or asymptomatic 3) Must live in Houston/Harris County	Case Management for adolescents, male and female.	Provided case management to 45-48 adolescents. Increased enrollment into clinical trials and par-ticipation in HIV+ support groups. Unexpectedly, Covenant House had some clients with a reluctance to participate in clinical trials and support groups.

Donald R. Watkins Memorial Foundation, Inc.

Eligibility	Service Description	Outcomes

Family Service Center

Eligibility	Service Description	Outcomes
HIV infection symptomatic or asymptomatic	The program provides case management services to HIV/AIDS persons which include assisting clients with procurement of needed services so that problems associated with living with the disease are mitigated. Services are primarily home and community based.	Provide case management services to 410 clients and 6,240 direct service hours.

Harris County Hospital Clinic

Eligibility	Service Description	Outcomes
1) Must live in Harris Co. 2) HIV infection, symptomatic or asymptomatic	Provide the help clients need to coordinate their HIV/AIDS health care regimen. Services provided include: client's needs assessment, intake, refer clients in the direction where they can receive the needed care, follow up to see how clients are doing and help clients to be compliant with their care regimen.	

CASE MANAGEMENT SERVICES, cont…		
Houston Area Community Services		
Eligibility	**Service Description**	**Outcomes**
Must be HIV + or diagnosed with AIDS.	Intensive case management services and service linkage to HIV+ persons.	HACS was able to stabilize clients thus fostering independence.

Montrose Clinic **Eligibility**	**Service Description**	**Outcomes**
1) Must be 16+ 2) HIV infection symptomatic or asymptomatic	Provide case management services to PWAs who are deaf, hard of hearing, visually impaired, and/or mentally retarded.	27 clients received case management services which provided advocacy and referral for clients in the hearing world throughout their needs. Several service providers were educated on dealing better with the deaf/hard of hearing populations for improved service delivery. Unexpected outcomes: 1). At times, the client's dependency on the case manager, who is hearing but can sign, exceeded appropriate levels resulting in the need for the case manager to work harder on empowering the client. 2). Increased the awareness that other disabled groups, such as with mental retardation, have increase need for services.

Montrose Counseling Clinic **Eligibility**	**Service Description**	**Outcomes**
1) 300% of poverty level 2) HIV infection symptomatic or asymptomatic 3) Must live in Houston EMA 4) Must meet TCADA requirements	General case management and case management specifically for substance users.	Expected outcome: an increase in quality of life, an increase in medication adherence, and decrease in homelessness.

CASE MANAGEMENT SERVICES, cont…

People With AIDS Coalition

Eligibility	Service Description	Outcomes
1) Must be at 300% of poverty guidelines 2) HIV infection symptomatic or asymptomatic 3) Live in Houston EMA	Case management provides advocacy between it and the service system to ensure quality and continuum of care.	PWA provided over 11,485 units of service to the Houston EMA.

UT Health Science Center of Houston, Pediatrics Dept.

Eligibility	Service Description	Outcomes
1) Must meet Ryan White income requirements 2) HIV infection symptomatic or asymptomatic	Provide case management services to families affected by HIV/AIDS. Ours is a family service model. One third of our cases are pediatric cases.	

KINDERx Clinic (Kids In Need of Drug Evaluation & Re-Treatment Clinic

Eligibility	Service Description	Outcomes
1) HIV exposed in-utero 2) Substance high risk 3) Live in Harris Co. & surrounding area 4) Exposed in-utero to drugs, alcohol, and/or HIV/AIDS.	Provides medical care, case management, and social services to children exposed to drugs, alcohol and/or HIV/AIDS, and their families. When funding is available, KinderX also provide nutritional counseling and education to HIV/AIDS infected men and women.	Improvement of quality service. A one-stop-shop with a 90% immunization rate and an increased compliance with appts.

Diocesan AIDS Ministry, A Program of Associated Catholic Churches

Eligibility	Service Description	Outcomes
1) HIV infection symptomatic or asymptomatic 2) Must live in 11 counties of Diocesan of Galveston-Houston	**General case management -** Diocesan AIDS Ministry assists HIV+ clients to access Houston Care System and other social services. It moves clients toward self sufficiency in maintaining care regimen.	Case managers provided service to 80 clients per year.
1) HIV infection symptomatic or asymptomatic 2) Must live in 11 counties of Diocesan of Galveston-Houston	**Case management for women & children –** Provides intensive case management, decreasing financial assistance and support groups focused on building life skills that lead to self-sufficiency. This is a 6-month program.	As a new program twelve single, female head-of-household clients participated.

Transportation

General Transportation

General Transportation service is defined as transportation service provided through the use of individual EMPLOYEE or CONTRACT drivers with vehicles/vans to eligible individuals. Taxi vouchers are used only in emergency situations. General Transportation service hours are from 7am to 10 p.m. on weekdays (non-holidays), and coverage must occur for Saturday social services and medical appointments.

Services Provided

To provide General Transportation services to access medical and/or support services for eligible individuals. Transportation will include round trips to single destinations and round trips to multiple destinations. Taxi vouchers are provided to eligible clients only for identified emergency situations. HIV/AIDS affected others may accompany the HIV/AIDS diagnosed clients as necessary.

Transportation Vouchering Program

Transportation Voucher service is defined as providing vouchers for the essential transportation of eligible clients. Vouchers consist of METRO bus tokens and passes, and gas vouchers.

Taxi vouchers cannot be purchased under this service category. Transportation Voucher service hours are from 8am to 5pm on weekdays (non-holidays), with exceptions noted under agency requirements.

Services Provided

The intent of this funding is to provide transportation services to access medical and/or support services for eligible individuals. Clients receiving METRO bus passes are ineligible for tokens. Gasoline Voucher services are authorized for use only after reasonable alternative transportation sources have been exhausted.

Table 8 Client Transportation

CLIENT TRANSPORTATION		
The Life Center		
Eligibility	**Service Description**	**Outcomes**
1) Must have low income 2) 0-70 years of age 3) Diagnosed AIDS 4) Must live in Houston EMA 5) Must agree to and sign consent for transportation, rights and responsibilities.	General Transportation – to medical and support services by auto.	Better access to providers/reduction to distance, time, money and barriers. Improved quality of life. The program achieved 348.977 units of service. 800 HIV+ individuals received transportation services. More people were able to access services because of the hours of service.
1) Must have low income 2) 0-70 years of age 3) Diagnosed AIDS 4) Must live in Houston HSDA 5) Must agree to and sign consent for transportation, rights and responsibilities.	Rural Transportation – to medical and support services	The program achieved 35,687 units of service. 100 HIV+ individuals received transportation services. Unexpectedly, denial of transportation services to the affected populations occurred. Also there were not enough funds to cover cost of transportation to UTMB.

Housing Assistance

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. Rental and utility assistance are not part of this service. (This service is not currently funded by Title I but other funding sources available.)

Housing Assistance Service Provider, Eligibility and Outcome

AIDS Foundation Houston and Steven's House

Table 9 Housing Assistance

RESIDENTIAL HOUSING SERVICES		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Substance free/abstinence 3) Live in HSDA/EMA	**Tenant-Based Rental Association -** long-term rental assistance.	Decreased homelessness and increased independence.
1) Income eligibility is established by Housing Authority 2) HIV infection symptomatic or asymptomatic 3) Substance free/abstinence 4) Live in HSDA/EMA	**Beecher Wilson -** Long-term project based rent assistance.	Offered permanent housing for a minimum of 30 clients.
1) HIV infection symptomatic or asymptomatic 2) Substance free/abstinence 3) Live in HSDA/EMA	**Life Road -** Housing and support services for homeless HIV+ men/women/children.	Decreased homelessness and substance abuse. Increased adherence, permanent housing, income/skills, and independence.
1) Must be female w/ HIV infection symptomatic or asymptomatic 2) Substance free/abstinence 3) Living in HSDA/EMA	**A Friendly Haven -** Comprehensive housing, support, case management, mental health services for homeless HIV+ women and children.	Decreased: substance abuse, homelessness, hospital visitation, emergency room visitation, and # of hospital days. Increased: adherence, skills/income, employment, transport, and childcare.

RESIDENTIAL HOUSING SERVICES, cont…		
Steven's House **Eligibility**	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Substance free/abstinence	Intermediate care facility, room and board, support groups in house, C.D. support groups, 24-hour supervision, males and females, free.	Enabled residents to return to independent living. A family atmosphere was created with many previous residents visiting for dinners, special occasions or just drop-ins.

Dental Services

Dental services include restorative dental services, oral surgery, root canal therapy, fixed and removable prosthodontics; periodontal services include subgingival scaling, gingival, curettage, osseous surgery, gingivectomy, provisional splinting, 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.

Services Provided

- Individual comprehensive treatment plan;
- Diagnosis and treatment of HIV-related oral pathology, including oral Kaposi's Sarcoma, CMV ulceration, hairy leukoplakia, xerostomia, lichen planus, aphthous ulcers and herpetic lesions;
- Diffuse infiltrative lymphocytosis;
- Standard preventive procedures including oral hygiene instruction, diet counseling and home care program; oral prophylaxis; restorative care; oral surgery; root canal therapy; fixed and removable prosthodontics; periodontal services, including subgingival scaling, gingival curettage, osseous surgery, gingivectomy, provisional splinting, laser procedures and maintenance.

The provider has mechanism in place to provide oral pain medication as prescribed for clients by the dentist.

Agency Qualifications

The dental provider has prior experience treating HIV disease and/or on-going HIV educational programs that are documented in personnel files and updated regularly.

Dental Service Providers, Eligibility, and Outcomes

Amigos Volunteers in Education and Services, Inc. (provider survey not submitted) and Bering Omega Community Services.

Table 10 Dental Care

DENTAL CARE		
Bering Community Service Foundation w/ Omega House		
Eligibility	**Service Description**	**Outcomes**
1) Must be 17 years of age and above 2) Must be without dental insurance except for oral medicine	Provide comprehensive dental services for HIV+ individuals including standard preventative procedures, HIV related oral pathology, dentures, tooth extractions, and denture repairs.	Provided 10,000 dental visits for the improvement of HIV+ client health. Unexpectedly, Bering has met clients with a number of unique diagnoses.

Food Bank

Food Pantry

A facility that provides food and related grocery items to include personal hygiene, paper products, cleaning supplies and diapers. This service does not provide food to affected persons and individuals who are caregivers for HIV/AIDS infected persons. Up to 90% of funds can be used for the wholesale purchase of food and specialty items. In addition an agency has an option of purchasing food vouchers in an amount up to 10% of its award. Agencies planning to use this option must provide the County a copy of written guidelines for the issuance, recording and safeguarding of food vouchers and receive approval of these guidelines prior to issuing food vouchers.

Services Provided

Operation of a food pantry for residents of the Houston EMA. Food vouchers must be issued and recorded in the name of the client only. Tobacco, liquor and pet food or pet products may not be purchased.

Meals At Thomas Street Clinic

One light meal, which includes some combination of fresh fruit, sandwiches, prepackaged snacks and beverage appropriate for PLWH utilizing the Harris County Hospital District's Thomas Street Clinic.

Services Provided

The provision of light meals at Thomas Street Clinic. The District will provide and maintain a walk-in refrigerator for storage of light meals. The District also provides staff to distribute the food daily (Monday-Friday). Provider agency is responsible for the delivery of food by 10:00 a.m. each morning the Clinic is open and for the pick of unused (if any) food by 2:00 p.m. each afternoon. Unused food is delivered to an appropriate HIV/AIDS service provider for distribution to Ryan White eligible clients.

Nutritional Supplements

Up to a 90-day supply at any given time, per client, of the following nutritional supplements: L-Glutamine; Supplemental Protein Powder; Acidophilus; Multi-Vitamins; Milk Thistle; Alpha-Lipoic Acid.

Services Provided

The provision of the eligible nutritional supplements to clients at no more than 300% of poverty with a written referral from a physician or licensed dietitian which specifies frequency, duration and amount. The per client cap may not exceed $1,000.00 annually. A request to exceed the cap may be made to the administrative agent based on demonstrated need by client. Information on this service will at least be communicated to health care providers funded by Titles I and II.

Food Bank Service Providers

AIDS Foundation Houston, Brentwood Economic Community Development Corp., Healthy Lunch Box, Inc. (provider survey not submitted), Houston Challenge Foundation, the Northwood AIDS Coalition, Riverside General Hospital (provider survey not submitted).

Table 11 Food Bank

FOOD BANK		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) 150% or less of poverty level 2) HIV infection symptomatic or asymptomatic 3) Live in Houston EMA/HSDA	Food pantry services (Stone Soup) and a rural voucher program.	Decreased hunger, served a minimum of 1200 clients, and improved nutrition knowledge.

Brentwood E.C.D., Inc.		
Eligibility	**Service Description**	**Outcomes**
1) Income eligibility is based on Federal Poverty Guidelines 2) All ages are eligible 3) HIV infection symptomatic or asymptomatic 4) Live in Houston EMA	Provides food and related items to include cleaning supplies, personal hygiene items, paper products and diapers to HIV-infected persons.	By the end of the contract period, Brentwood provided at least 500 unduplicated eligible clients with food and related grocery items by means of a food pantry program for HIV-infected individuals.

Health Lunch Box, Inc.		
Eligibility	**Service Description**	**Outcomes**

Houston Challenge Foundation		
Eligibility	**Service Description**	**Outcomes**
1) Below poverty level 2) Must live in Houston EMA/HSDA 3) Must not be using another pantry and get food stamps if eligible 4) HIV infection, symptomatic or asymptomatic	Food pantry for indigent clients affected/infected with HIV/AIDS.	Served 1287 people with quality and compassionate pantry service

FOOD BANK, cont…

Northwood AIDS Coalition

Eligibility	Service Description	Outcomes
1) Must be below 500% poverty level 2) HIV infection symptomatic or asymptomatic or w/ AIDS diagnosis 3) Live in Houston EMA	Provision of food/hygiene supplies and household cleaning products.	Served 84 unduplicated clients with a 90%+ satisfaction rating. Unexpectedly, Northwood AIDS Coalition goals exceeded 25%.

Riverside General Hospital

Eligibility	Service Description	Outcomes

Direct Emergency Assistance

Direct Emergency Assistance

The term “emergency” is defined as a need for funds within 24 hours to 72 hours. Agency is required to acknowledge receipt of the assistance request within 24 hours. Emergency 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.

Services Provided

- Rent (late rental payments are excluded)
- Utilities (gas, water and electricity)
- Telephone bills/TTY, including long distance charges up to $25.00
- Relocation allowance not to exceed $200.00. (This one time allowance may be given to clients relocating out of the Houston EMA.) This relocation allowance is to be included in the $500.00 overall limit. Clients are limited to utilizing this assistance once per contract year for each individual service need unless extreme hardship is documented by the contracting agency.

The following guidelines exist in providing these services:

- Assistance must be in the form of vouchers made payable to vendors, merchants, landlords, etc. No payments may be made directly to individual clients or family members.
- Agency must operate during regular business hours, Monday through Friday from 8:00 a.m. to 5:00 p.m.
- Agency must provide services to homebound clients.
- Agency may not require a client to have a case manager as a prerequisite for assistance.

Household Items

To provide HIV/AIDS infected persons with household items to support their independent living. No more than 20% of these funds can be used for the purchase of household items.

Services Provided

Pickup, delivery, and storage of donated household items including, but not limited to, furniture, small appliances, kitchen utensils, bathroom accessories, and linens; purchase of basic household items that are not donated including but not limited to mattresses, etc. Contractor will make appropriate provisions (on site or voucher) for clothing to eligible indigent clients.

Direct Emergency Assistance Service Provider, Eligibility, and Outcomes

Brentwood E.C.D., Inc., People With AIDS Coalition, and Diocesan AIDS Ministry - A Program of Associated Catholic Churches.

Table 12 Direct Emergency Assistance

DIRECT EMERGENCY ASSISTANCE

Brentwood E.C.D., Inc.

Eligibility	Service Description	Outcomes
HIV infection symptomatic or asymptomatic	Brentwood provides short-term rent, mortgage, and utility assistance to a minimum of two hundred (200) unduplicated, HIV/AIDS clients, who met the eligibility standards.	By the end of the contract period, Brentwood provided housing and supportive services to a minimum of 200 unduplicated HIV/AIDS infected clients. The program outcomes provided more assistance to clients in rent, mortgage, and utility assistance to prevent homelessness.

People With AIDS Coalition

Eligibility	Service Description	Outcomes
1) HIV infection symptomatic or asymptomatic 2) Live in Houston EMA 3) Have emergency need	**Direct Financial Emergency Assistance –** includes rent, utilities, telephone & relocation allowance in the form of vouchers not to exceed $500 on an annual basis.	The DEA program served 411 clients with financial assistance with 181,843 in vouchers.
1) Must be at poverty level 2) HIV infection symptomatic or asymptomatic 3) Live in Houston EMA	**New Beginnings Household Restart -** provides furniture and household items to eligible clients in the Houston EMA.	Provided services to over 6,500 clients in the Houston EMA.

Diocesan AIDS Ministry - A Program of Associated Catholic Churches

Eligibility	Service Description	Outcomes
1) HIV infection symptomatic or asymptomatic 2) Must live in 11 counties of Diocesan of Galveston-Houston	Provides emergency financial assistance to secondary clients with HIV/AIDS.	Provided emergency financial assistance to 400 secondary clients with HIV/AIDS.

DIRECT EMERGENCY ASSISTANCE, cont…

St. John Vianney Catholic Church Social Service

Eligibility	Service Description	Outcomes
1) Low income 2) HIV infection, symptomatic or asymptomatic 3) Must be member of parish and living in following zip codes: 77077, 77079, 77055, 77043 4) Referred by other agencies	St. John Vianney provides emergency services to many people including a small number of persons with AIDS, and have an AIDS care team. Emergency assistance includes case management, buddy/companion services, direct financial assistance, household items, and food bank.	

Substance Abuse Treatment

Substance Abuse Treatment/Counseling (Level 1 & 4)
A unit of service is defined as one (1) hour of substance abuse treatment.

Services Provided

Services for all eligible HIV/AIDS patients with substance abuse disorders. Client must not be eligible for services from other programs/providers (i.e. MHMRA of Harris County) or any other reimbursement source (i.e. Medicaid, Medicare, Private Insurance) unless the client is in crisis and cannot be provided immediate services from the other programs/providers. In this case, clients may be provided services, as long as the client applies for the other programs/providers, until the other programs/providers can take over services. All services must be provided in accordance with the Texas Commission on Alcohol and Drug Abuse Chemical Dependency (TCADA) Treatment Facility Licensure Standards. Specifically, regarding service provision, services must comply with §148.202. *Services Required In All Programs,* §148.211 *Level I Treatment* and §148.214. *Level IV Treatment*. Providers of Level I Treatment must make such treatment available, either directly or through sub-contract, to all Title I eligible clients (including rural).

§148.202. *Services Required In All Programs* states:

- Members of the client's treatment team shall demonstrate effective communication and coordination.
- Every residential client shall have a medical history and physical examination.
- Chemical dependency education shall follow a course outline that identifies lecture topics and major points to be discussed.
- The program shall provide education about the health risks of tobacco products and nicotine addiction.
- The program shall provide HIV education based on the Model Workplace Guidelines for Direct Service Providers developed by the Texas Department of Health.
- Clients shall have access to HIV counseling and testing services directly or through referral.
- Services shall be voluntary, anonymous, and not limited by ability to pay.
- Counseling shall be based on the model protocol developed by the Texas Department of Health.
- The program shall make testing for tuberculosis and sexually transmitted diseases available to all clients unless the program has access to test results obtained during the past year.
- Services may be made available directly or through referral.
- If a client tests positive, the program shall refer the client to an appropriate health care provider and take appropriate steps to protect clients and staff.
- The program shall: provide access to appropriate health care and mental health services directly or through referral; refer pregnant clients who are not receiving prenatal care to an appropriate health care provider and monitor follow-through; and refer clients to ancillary services necessary to meet treatment goals.

§148.213. *Level I Treatment* states:

- All clients admitted to Level I Detoxification programs shall be in need of detoxification.
- Every client shall have a medical history and physical.
- Residential clients shall have the medical history and physical within 24 hours of admission. If the facility cannot meet this deadline because of exceptional circumstances, the circumstances shall be documented in the client record. Until a client's medical history and physical is complete, staff shall observe the client closely and monitor vital signs.
- Outpatient clients shall have the medical history and physical before admission.

- The program shall provide continuous supervision for clients.
- In residential programs, direct care staff shall be awake and on site 24 hours a day.
- During day and evening hours, at least two awake staff shall be on duty for the first 12 clients, with one more person on duty for each additional one to 16 clients.
- At night, at least one awake staff member shall be on duty for the first 12 clients, with one more person on duty for each additional one to 16 clients.
- In outpatient programs, direct care staff shall be awake and on site whenever a client is on site. Clients shall have access to on-call staff 24 hours a day.
- If the program accepts clients with acute detoxification symptoms or a history of acute detoxification symptoms, the program shall have: a licensed vocational nurse or registered nurse on duty during all hours of operation; and a physician on-call 24 hours a day.
- Level of observation shall be based on medical recommendations and program design.
- A physician shall approve all medical policies, procedures, guidelines, tools, and forms, which shall include: screening instruments (including a medical risk assessment) and procedures; treatment protocol or standing orders for each chemical the program is prepared to detoxify; and emergency procedures.
- The clinical supervisor shall be a physician, physician assistant, advanced practice nurse, or registered nurse.
- The program shall: ensure continuous access to emergency medical care; provide clients access to mental health evaluation and linkage with mental health services when indicated; and use written procedures to encourage clients to seek appropriate treatment after detoxification.
- Direct care staff shall complete training as described in §148.114 of this title (relating to Special Training Requirements).
- Staff shall help each client develop an individualized post-detoxification plan that includes appropriate referrals.

§148.213. *Level IV Treatment* states:

- All clients admitted to intermediate programs shall be medically stable; and able to function with minimal structure and support.
- The program shall have enough staff to provide clients with adequate support and guidance.
- The program shall set limits on counselor caseload size that ensures effective, individualized treatment and rehabilitation. Criteria used to set the caseload size shall be documented.
- The program shall be adequately staffed during hours of operation to ensure effective service delivery.
- In residential programs, the awake direct care staff-to-client ratio shall be at least 1:16 during the hours clients are awake.
- For clients transferred from Level I or admitted directly to this level of treatment, counselors hall complete a comprehensive client assessment within five individual service days of admission in residential programs; and 45 calendar days of admission in outpatient programs.
- All clients hall have an individualized treatment plan within seven individual service days of admission in residential programs; and 45 calendar days of admission in outpatient programs.
- The facility shall deliver an average of two hours of structured activities per week for each client, including at least one hour of chemical dependency education or counseling. These activities shall be designed to help clients establish a healthy, independent lifestyle.
- The program shall offer chemical dependency counseling services.
- The program design and application shall include increasing levels of responsibility for clients and frequent opportunities for clients to independently apply knowledge and practice skills in non-structured settings.

Agency Qualifications

The facility must be licensed by the Texas Commission on Alcohol and Drug Abuse with Level I and Level IV treatment designations.

Substance Abuse Treatment/Counseling (Levels 3 & 4)

A unit of service is defined as one (1) client visit for substance abuse treatment.

Services Provided

Services for all eligible HIV/AIDS patients with substance abuse disorders. Client must not be eligible for services from other programs/providers (i.e. MHMRA of Harris County) or any other reimbursement source (i.e. Medicaid, Medicare, Private Insurance) unless the client is in crisis and cannot be provided immediate services from the other programs/providers. In this case, clients may be provided services, as long as the client applies for the other programs/providers, until the other programs/providers can take over services. Services provided must be integrated with HIV-related issues which trigger relapse. All services must be provided in accordance with the Texas Commission on Alcohol and Drug Abuse Chemical Dependency (TCADA) Treatment Facility Licensure Standards. Specifically, regarding service provision, services must comply with §148.202 *Services Required In All Programs,* §148.213 *Level III Treatment* and §148.214. *Level IV Treatment.*

§148.202. *Services Required In All Programs* states:

- All services shall be delivered according to a written plan.
- The program shall be culturally appropriate for the population served.
- Members of the client's treatment team shall demonstrate effective communication and coordination.
- Every residential client shall have a medical history and physical examination.
- Chemical dependency education shall follow a course outline that identifies lecture topics and major points to be discussed.
- The program shall provide education about the health risks of tobacco products and nicotine addiction.
- The program shall provide HIV education based on the Model Workplace Guidelines for Direct Service Providers developed by the Texas Department of Health.
- Clients shall have access to HIV counseling and testing services directly or through referral.
- Services shall be voluntary, anonymous, and not limited by ability to pay.
- Counseling shall be based on the model protocol developed by the Texas Department of Health.
- The program shall make testing for tuberculosis and sexually transmitted diseases available to all clients unless the program has access to test results obtained during the past year.
- Services may be made available directly or through referral.
- If a client tests positive, the program shall refer the client to an appropriate health care provider and take appropriate steps to protect clients and staff.
- The program shall provide access to appropriate health care and mental health services directly or through referral; refer pregnant clients who are not receiving prenatal care to an appropriate health care provider and monitor follow-through; and refer clients to ancillary services necessary to meet treatment goals.

§148.213. *Level III Treatment* states:

- All clients admitted to Level III shall be medically stable; and able to function with limited supervision and support.
- The program shall have enough staff to meet treatment needs within the context of the program description.
- Counselor caseloads shall not exceed 1:16.
- Direct care staff shall be awake and on site during all hours of program operation. The direct care staff-to-client ratio shall be at least 1:16 during the hours clients are awake in residential programs; and all hours of operation in outpatient programs.
- For clients transferred from Level 1 or admitted directly to this level of treatment, counselors shall complete a comprehensive client assessment within five individual service days of admission.
- All clients shall have an individualized treatment plan within seven individual service days of admission.
- The facility shall deliver an average of ten hours of structured activities per week for each client, including at least five hours of chemical dependency education and/or counseling.
- The program design and application shall include increasing levels of responsibility or clients and frequent opportunities for clients to apply knowledge and practice skills in structured and non-structured settings.

§148.213. *Level IV Treatment* states:

- All clients admitted to intermediate programs shall be medically stable; and able to function with minimal structure and support.
- The program shall have enough staff to provide clients with adequate support and guidance.
- The program shall set limits on counselor caseload size that ensures effective, individualized treatment and rehabilitation. Criteria used to set the caseload size shall be documented.
- The program shall be adequately staffed during hours of operation to ensure effective service delivery.
- In residential programs, the awake direct care staff-to-client ratio shall be at least 1:16 during the hours clients are awake.
- For clients transferred from Level I or admitted directly to this level of treatment, counselors hall complete a comprehensive client assessment within five individual service days of admission in residential programs; and 45 calendar days of admission in outpatient programs.
- All clients hall have an individualized treatment plan within seven individual service days of admission in residential programs; and 45 calendar days of admission in outpatient programs.
- The facility shall deliver an average of two hours of structured activities per week for each client, including at least one hour of chemical dependency education or counseling. These activities shall be designed to help clients establish a healthy, independent lifestyle.
- The program shall offer chemical dependency counseling services.
- The program design and application shall include increasing levels of responsibility for clients and frequent opportunities for clients to independently apply knowledge and practice skills in non-structured settings.

Agency Qualifications

The facility must be licensed by the Texas Commission on Alcohol and Drug Abuse with Level III and Level IV treatment designations.

Substance Abuse Treatment Service Providers, Eligibility, and Outcomes

Harris County Hospital District, Montrose Counseling Center, Inc., and Riverside General Hospital.

Table 13 Substance Abuse Treatment

SUBSTANCE ABUSE TREATMENT		
Harris County Hospital District		
Eligibility	**Service Description**	**Outcomes**
1) Must be HIV + or with AIDS diagnosis 2) Must live in Harris Co.	Level I substance abuse treatment (outpatient detoxification) and Level IV substance abuse treatment (2 x weekly group therapy). Baylor College of Medicine is subcontracted to provide substance abuse treatment services to the Harris County Hospital population.	No program outcome measurements were in place at the time this program was operated by HCHD.

Montrose Counseling Center		
Eligibility	**Service Description**	**Outcomes**
1) Must be 300% of poverty level 2) Must be 17 years of age or older 3) All stages of HIV 4) Substance free / abstinence 5) Must live in Harris Co. & EMA	Level III and IV outpatient treatment. Level III – 10 hrs group and 1-hour individual per week. Level IV – 2 hrs of group and 1-hour individual per week.	MCC expected to assist in risk reduction, relapse prevention, and harm reduction. Unexpectedly, some clients needed level II residential. Since there was no one in Houston that was sensitive to or trained to do HIV, Montrose reported taking some people that might be better served in residential

SUBSTANCE ABUSE TREATMENT, cont…

Riverside General Hospital

Eligibility	**Service Description**	**Outcomes**
1) Federal Poverty Guidelines for income eligibility 2) Must be 18 and older 3) Must live in Harris and surrounding counties 4) Have a history of substance abuse and dependency	Substance Abuse/Dependency Treatment for clients with HIV/AIDS. This was a 60-day Treatment Program from 8am-1pm. Clients were also allowed to access other services not funded by Ryan White (support group facilitated by a counselor x2 evening every week.)	Expected to give 21 clients substance abuse/dependency treatment; for three or less clients to relapse and return to treatment. Only two clients relapsed and returned to treatment. Riverside was not able to reach 21 client's goal; clients did not want to stay in treatment 60 days, thus unable to use $75,000 total grant.

Home Health Care

In-home Skilled Nursing

A unit of In-Home Skilled Nursing care is defined as one (1) skilled nursing visit. Physician ordered skilled nursing care provided by a Licensed Vocational or Registered Nurse for HIV patients in their place of residency.

Services Provided

- Medication administration;
- Medication supervision;
- Central line dressing changes;
- Starting intravenous lines;
- Intravenous line and wound dressing changes;
- Phlebotomy services;
- Palliative care services;
- Nutritional support and training (including tube feedings);
- Foley catheter insertion;
- Restorative nursing, training of family/significant others in patient care techniques;
- Ongoing monitoring of patient's physical condition and communication with attending physician(s).

Provider Qualifications

Skilled Home Health Nursing Care is provided by a Licensed Vocational or Registered Nurse. Services are initiated within 48 hours of receipt of physician's order. Services are available on a 24-hour basis. Provider must coordinate patient referrals with Harris County Hospital District Thomas Street Outpatient Home Care Coordinator and other outpatient/ambulatory health care providers, including inpatient discharge planners.

In-home Intravenous Therapy

A unit of In-Home Intravenous Therapy care is defined as one (1) in-home intravenous therapy visit. Physician-ordered intravenous medication therapies administered by a registered nurse in the patient's home or residential facility.

Services Provided

- Intravenous line initiation (including med-line catheter insertion);
- Management of central lines, administration and supervision of intravenous therapies;
- Monitoring of patient's physical condition;
- Collaboration with referring physician(s).

Services are available on a 24-hour basis. Services are delivered within 48 hours of receipt of a physician's order. Provider must have a licensed pharmacist on staff or provide pharmacy services via contract. Provider must coordinate patient referrals and supplies with Harris County Hospital District Thomas Street Outpatient Home Care Coordinator and other outpatient/ambulatory health care providers, including inpatient discharge planners.

Home Health Aide Care

A unit of Home Health Aide care is defined as one (1) hour of home health aide care. This service is defined as a home visit by a Home Health Aide for the purpose of performing specific tasks to allow the patient to remain in their place of residency. Phone contact is made with the patient by the agency within 24 hours of the date of the referral, as a part of the service delivery process. A home visit with the patient by the Registered Nurse is required within 72 hours of the referral. The care plan and consent for service are to be signed during the initial home visit. Services are re-evaluated every 60 days by the Registered Nurse, or more often if necessary, to determine the adequacy of the care plan. Services are authorized by a physician.

Services Provided

- Personal care assistance includes bathing, grooming, oral hygiene, shampooing hair and reminders to take medication;
- Personal immediate environmental care includes changing bed linens and light laundry (2 loads);
- Meal preparation/feeding/serving/clean-up;
- Basic communication skills include talking, listening, recording and observation;
- RN assessment/monitoring, supervision of the Home Health Aide.

Guidelines for Termination of Services

1) The goal of the service has been attained and the patient has been rehabilitated to a point where the patient is able to manage without agency assistance. 2) Three visits by the Home Health Aide to the patient's home and the patient is not available for service (does not include hospitalization, medical appointments) and the patient fails to notify the agency to cancel or to reschedule the home visit. 3) Patient's behavior becomes abusive, unpredictable or a threat to the employee's health and safety. 4) Maintenance of the patient's care can be assumed by the willing and able adult family members or other service providers (TDH, etc.). 5) Patient or patient's family, guardian (power of attorney) requests termination of services. Referring agency is notified when and the reason why the patient is terminated from service.

Qualifications

Services are performed by individuals appropriately trained and certified in the provision of home health aide, skilled nursing and intravenous therapy services including infection control to HIV patients. The providing agency is licensed by the Texas Department of Health as a Home and Community Support Services Agency. The acceptable documentation for licensure is a copy of the agency’s current Home and Community Support Services Agency license from the Texas Department of Health.

Homemaker care

A unit of service is defined as one (1) hour of homemaker care. Homemaking services are specific tasks provided to HIV patients to facilitate their maintaining independent living and to remain in his/her home.

Patients are assessed according to the Homemaker Assessment Form by the homemaker supervisor to determine the client's level of needs. The assessment process will include the development of a service plan by the professional staff member in collaboration with the patient and his/her significant other/adult family members. The service plan will outline the duties of the Homemaker. A copy of the service plan is placed in the patient's home during the initial in-home assessment. The service plan is be revised as needed, and will include a supervisory visit.

Services Provided

- Environmental care includes light housekeeping, light furniture dusting sweeping/ mopping/vacuuming floors, changing bed linens and light laundry (2 loads);
- Shopping;
- Meal preparation/serving/clean-up;
- Basic communication skills include talking, listening, and recording.

Guidelines for Termination of Services

1) The goal of the service has been attained, and the patient is able to manage without agency's assistance. 2) Maintenance of patient's care can be assumed by the patient's adult family or others (TDH, etc.). 3) Patient’s or family’s written request for termination of service. 4) Three visits by the homemaker to the patient's home to deliver service; patient not available for service. 5) The patient's behavior becomes abusive, unpredictable or a threat to the employee and service cannot be delivered in a safe environment. The referring agency is notified if the patient is terminated from service. Reason for termination must be communicated. A patient may receive a maximum of twenty (20) hours of care per seven-day period. Contractor must receive written approval from Administrative Agency to provide additional services.

Qualifications

Services are performed by individuals appropriately trained in provision of homemaker services to HIV patients and must have professional supervision. The providing agency is licensed by the Texas Department of Health as a Home and Community Support Services Agency. The acceptable documentation for licensure is a copy of the agency’s current Home and Community Support Services Agency license from the Texas Department of Health.

Home Health Care Service Providers, Eligibility and Outcomes

Alternate Resources of Texas, Family Service Center, Memorial Hermann Home Health Care, and Visiting Nurse Association of Houston.

Table 14 Home Health Care

HOME HEALTH CARE

Alternate Resources of Texas

Eligibility	**Service Description**	**Outcomes**
HIV infection symptomatic or asymptomatic	Home health care includes skilled nursing, infusion therapy, home health aide, and homemaker services.	Experienced a reduction of hospital visits and length of stay; and improved quality of care which helped improve the client's quality of life

Family Service Center

Eligibility	**Service Description**	**Outcomes**
HIV infection symptomatic or asymptomatic	The program provides homemaking services to HIV/AIDS persons. To assist them, FSC performs activities of daily living in their home. This assists and facilitates the ability of clients to maintain independent living.	1) The program outcome was to provide 10,039 units of homemaker service to 150 clients. 2) 93% reported being helped in maintaining independence. 3) High satisfaction rates

Memorial Hermann Home Healthcare

Eligibility	**Service Description**	**Outcomes**
1) Must be diagnosed w/ AIDS. 2) Live in Harris Co.	Our business line is home health skilled nursing care in the home.	Provided quality patient care in the home.

Visiting Nurse Association of Houston

Eligibility	**Service Description**	**Outcomes**
1) Medically and financially indigent per Federal Poverty Guidelines 2) HIV infection or w/ AIDS diagnosis 3) Live in Houston EMA/HSDA 4) Requires doctor's order	Home Health Care, including skilled nursing, Infusion Therapy, and Home Health Aide Services; and homemaker services.	Provided 17,711 hours of Home Health Care and Homemaker services to HIV+ clients in EMA and 3,148 hours of Home Health Care services to HIV+ clients in HSDA, in order to maximize quality of life, prevent or delay institutionalization, and provide care in a culturally appropriate manner. Unexpectedly, VNA has seen a decline in utilization of these services by HIV+ clients, due to new drug therapies preventing or delaying onset of symptoms.

Mental Health Therapy

Professional Counseling

All Title I eligible clients living in the EMA are provided access to this service. A unit of service is described as an individual counseling session lasting a minimum of 45 minutes or one group session lasting a minimum of 90 minutes. Support Groups are defined as professionally-led (licensed therapists or counselor) groups that comprise HIV positive individuals, family members, or significant others for the purpose of providing emotional support directly related to the stress of caring for an HIV positive person. Bereavement Counseling is individual counseling which assists clients in resolving grief and mourning associated with the death of a parent/partner/family member. Counseling must be initiated within 12 months of the death of the parent/partner/family member and is provided for a short-term duration to a Title I eligible affected child, partner or other family member.

Target Population

HIV/AIDS infected and affected individuals living within the Houston Eligible Metropolitan Area (EMA).

Client Eligibility

For individual therapy sessions (office and non-office based):

- Client must be HIV positive or the affected significant other of an HIV positive person.
- HIV positive client must have a DSM-IV Axis I diagnosis eligible for reimbursement under the State Medicaid Plan.
- Affected significant other is eligible for services only related to the stress of caring for an HIV positive significant other or for bereavement counseling.
- Client must have an income at or less than 500% of the Federal Poverty Level.
- Client must not be eligible for services from other programs/providers (i.e. MHMRA of Harris County) or any other reimbursement source (i.e. Medicaid, Medicare, Private Insurance) unless the client is in crisis and cannot be provided immediate services from the other programs/providers. In this case, clients may be provided services, as long as the client applies for the other programs/providers, until the other programs/providers can take over services.
- Medicaid/Medicare, 3rd Party Payer and Private Pay status of clients receiving services under this grant must be verified by the provider prior to requesting reimbursement under this grant.

For support group sessions:

- Client must be either an HIV positive person or the significant other of an HIV positive person.
- Affected significant other is eligible for services only related to the stress of caring for an HIV positive significant other.

Outpatient Psychiatric Services

All Title I eligible clients living in the EMA are provided access to this service. A unit of service is defined as one client visit for Outpatient Psychiatric Care.

Services Provided

- Diagnostic Assessments: comprehensive evaluation for identification of psychiatric disorders, mental status evaluation, differential diagnosis which may involve use of other clinical and laboratory tests, case formulation, and treatment plans or disposition.
- Emergency Psychiatric Services: rapid evaluation, differential diagnosis, acute treatment, crisis intervention, and referral. To be available on a 24-hour basis, emergency room referral is permitted.
- Brief Psychotherapy: individual, supportive, group, couple, family, hypnosis, biofeedback, and other psychophysiological treatments and behavior modification.
- Psychopharmacotherapy: evaluation and medication treatment of psychiatric disorders, including, but not limited to, anxiety disorders, major depression, pain syndromes, habit control problems, psychosis and organic mental disorders. Access to an on site pharmacy must be available.
- Rehabilitation Services: some, but not necessarily all, of the following: physical, psychosocial, behavioral, and cognitive training.

Mental Health Therapy Service Providers, Eligibility and Outcomes

Amigos Volunteers in Education and Service, Inc. (provider survey not submitted), Baylor College of Medicine – Outpatient Psychiatric Care (provider survey not submitted), Donald R. Watkins Memorial Foundation, Inc. (provider survey not submitted), Family Service Center, Harris County Hospital District, and Montrose Counseling Center

Table 15 Mental Health Therapy

MENTAL HEALTH THERAPY		
Amigos Volunteers in Education and Service, Inc.		
Eligibility	**Service Description**	**Outcomes**

Baylor College of Medicine – Outpatient Psychiatric Care		
Eligibility	**Service Description**	**Outcomes**

Donald R. Watkins Memorial Foundation, Inc.		
Eligibility	**Service Description**	**Outcomes**

MENTAL HEALTH THERAPY, cont…

Family Service Center

Eligibility	Service Description	Outcomes
Must be HIV+.	The program utilizes solution oriented counseling to enable an individual or family to be its own source of support during times of crisis by reactivating existing coping skills or developing new ones to solve their problems.	1) 10% decrease in symptoms after 30 days of treatment. 2) 3% increase in functioning at close of treatment. 3) #Of unduplicated cases opened in 1998: 2,041. 4) # Of hrs of clinical services provided in 1998: 12,947. 5) 93% of clients reported their presented problem as resolved.

Harris County Hospital District

Eligibility	Service Description	Outcomes
1) Must be HIV + or with AIDS diagnosis 2) Must live in Harris County	Basic psychiatry services including traditional psycho-pharmacotherapy, emergency and routine diagnostic assessments, brief psychotherapy, rehab and other non-pharmacologic services, stress management, EMG/EEG-based biofeedback, cognitive restructuring, memory retraining, and sleep hygiene education. Baylor College of Medicine is subcontracted to provide psychiatric services to the Harris County Hospital District population.	No program outcome measurements had been developed at the time this program was operated by HCHD.

Montrose Counseling Center

Eligibility	Service Description	Outcomes
	Individual professional counseling. Group counseling with people living with HIV disease and caregivers.	Stress reduction, medication adherence, coping skills, and support network.

Day/Respite Care

Volunteers/Respite Care Teams

The use of volunteers to provide social, emotional and physical care to HIV/AIDS infected individuals which includes training these volunteers to provide in-home bedside care/support services and providing supervision and support for respite care teams dealing with the stress of caring for these clients. The intent of all the volunteer programs is to provide direct "hands on" volunteer services and not volunteers for agency administrative assistance.

Services To Be Provided

The provider recruits, trains, coordinates and supports a pool of volunteers to service a broad geographical area. An agency may not provide outreach or case management services under this category (See Case Management Section).

Day/Respite Care Service Providers, Eligibility, and Outcomes

Bering Omega Comm. Services

Table 16 Day/Respite Care

DAY/RESPITE CARE		
Bering Community Service Foundation w/ Omega House		
Eligibility	**Service Description**	**Outcomes**
Must be 18 years or older.	**Adult day care -** Up to 10 hrs of adult day care w/ services including the provision of nursing care, physical therapy, exercise programs, art groups, individual & group nutritional counseling, instructional workshops, healthy socialization, field trips, peer support groups and transportation.	Bering expected to empower the clients and provide an average of 16 adult day care visits per day. Unexpected was the high number of clients in assisted living.
1) Can be a caregiver or 2) HIV infection symptomatic or asymptomatic	**In-home respite care –** Bering provides volunteer services to clients in their home. These services will provide socialization, companionship, and emotional support.	Bering provided self-sufficiency and self-esteem to clients and relief to the client's caregivers; but, was surprised at the number of clients that live alone.

Client Advocacy

A unit of service is defined as one (1) hour of comprehensive legal service provided to HIV/AIDS infected individuals and/or their legal representatives by an Attorney licensed to practice in Texas. Only time spent by the Attorney working on a client's case may be billed under contracts issued under this RFP. Attorney time billed to the contract must be recorded in 1/10th of an hour increments (i.e., 6 minutes is 0.1 hours). Travel time to and from a client's residence is not billable.

Communication services are listed as a client advocacy program because the service is built into the cost of the service the client who needed the communication assistance was receiving (e.g. included in the cost of a primary care visit, or cost of a professional counseling session).

Services Provided

Comprehensive legal assistance includes but is not limited to estate planning, permanency planning, discrimination, entitlement, and insurance disputes. Criminal matters are not eligible for Ryan White funded legal assistance.

Client Advocacy Service Providers, Eligibility, and Outcomes

Houston Volunteer Lawyers, Inc., N.A.A.C.P., Sign Shares, and Southeast Texas Legal Clinic.

Table 17 Client Advocacy

CLIENT ADVOCACY		
Houston Volunteer Lawyers, Inc.		
Eligibility	**Service Description**	**Outcomes**
1) Must be 300% over poverty guidelines 2) HIV infection symptomatic or asymptomatic 3) Must live in Houston EMA Title II counties	Legal services such as representation in family law matters, landlord tenant disputes, consumer contracts. Social security and creditor problems. Houston Volunteer Lawyers provide medical directives, wills, powers of attorney, etc.	Expected to provide 2,014 hours of service to 350 clients. Unexpectedly, there was an increase in requests for legal seminars on topics such as returning to work, immigration and family law. Houston Volunteer lawyers do not have funding for such education.

Client Advocacy, cont…		
N.A.A.C.P.		
Eligibility	**Service Description**	**Outcomes**
1) Adhere to Federal Poverty Guidelines 2) HIV infection, symptomatic or asymptomatic, AIDS diagnosed, or affected/effected by HIV 3) Live in Houston EMA	This program provides client advocacy by way of legal services. Offering representation in administrative hearings, estate planning, and other legal issues/matters.	The desired outcomes of the last funding cycle were accomplished with 1159 units of service provided to 120 unduplicated clients. All clients served were satisfied with the benefits incurred as a result of legal assistance being provided. Unexpectedly, some clients had legal matters that the N.A.A.C.P. program did not have the monetary resources to handle and these matters were referred out to private attorneys.

Sign Shares (DSG, Inc.)		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic or w/ AIDS diagnosis 2) Substance free/abstinence or w/ harm reduction status	Communication Services – For those with a hearing impairment or who are deaf or hard of hearing – Sign Shares bridges the gap between all direct service providers and patients.	Interpreter services were subcontracted to medical care providers, employers, educational facilities, and virtually all programs for reasonable accommodation. HIV/AIDS direct care providers were comfortably and successfully offered the same program to deaf and HOH persons.

Client Advocacy, cont…		
Southeast Texas Legal Clinic		
Eligibility	**Service Description**	**Outcomes**
1) 175% Poverty Federal Guidelines 2) HIV infection, symptomatic or asymptomatic 3) Live in 10 County Houston HSDA 4) The legal issue must be HIV related	Direct legal assistance by a licensed attorney to an eligible client. Services range from estate planning to litigation matters.	STLC must provide approximately 2000 units of service to eligible clients under the current funding sources. The number of unduplicated clients will vary based upon the types of legal issues presented. STLC reduced the number of unduplicated clients has been noted because more litigation issues are being presented as opposed to the usually large number of estate planning requests. A positive result was a greater impact in addressing discrimination issues facing the target population.

Health Education/Risk Reduction/Nutritional Services & Information about Treatments & Medications

Definition/Service

A unit of service is defined as one (1) course lasting a minimum of two (2) hours in health education and risk reduction and provided to a minimum of five (5) HIV+ infected individuals.

Services Provided

Services for all eligible HIV/AIDS infected individuals. This service is defined as the provision of information about medical and psychosocial support services and counseling. The services also includes the preparation and distribution of materials in the context of medical and psychosocial support services to educate clients with HIV about methods to reduce the spread of HIV. Services include, but are not limited to, health education on understanding and communicating about HIV infection; its effects on the body, emotions and interpersonal relations; and risk reduction on the transmission of HIV. Also included is information on complimentary/alternative therapies.

Health Education/Risk Reduction/Nutritional Service Providers, Eligibility, and Outcomes

AIDS Foundation Houston, Amigos Volunteers in Education and Services, Inc. (AVES) (provider survey was not submitted), Donald R. Watkins Memorial Foundation, Inc. (provider survey was not submitted), H.O.P.E. Project, Harris Country Hospital District, Montrose Clinic, Montrose Counseling Center, N.A.A.C.P., Coalition for the Homeless of Houston/Harris Co., Inc., Diocesan AIDS Ministry – A Program of Associated Catholic Churches, Young Women's Christian Association, and City of Houston Department of Health and Human Services.

Table 18 Health Education/Risk Reduction / Nutritional Service Providers

HEALTH EDUCATION/RISK REDUCTION		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Must live in Houston EMA/HSDA	**Project IMPACT -** Comprehensive HERR workshops targeting persons living with HIV.	Provided at least 87 workshops with a minimum of 5 HIV+ consumers in each workshop. Unexpectedly, AFH had to reduce # of workshops due to mobility to secure appropriate documentation by clients in order to participate in workshop. A revision in documentation protocols is needed.

HEALTH EDUCATION/RISK REDUCTION, cont…

Harris Country Hospital District

Eligibility	Service Description	Outcomes
1) Must be HIV + or with AIDS diagnosis 2) Must live in Harris Co.	**Health Education / Risk Reduction -** An 11-week curriculum which was offered in four day cycles and four night cycles. It covered reducing the risk of transmitting the virus, dealing emotionally with being HIV+, physical impact of HIV, maintaining health, managing medications, psychosocial meds and support services, and HIV-related illnesses.	

Montrose Clinic

Eligibility	Service Description	Outcomes
1) Must be 16 years of age or older 2) HIV infection symptomatic or asymptomatic	**Next Step -** Health Education/ Risk Reduction sections.	A 30% increase in knowledge about HIV was obtained. 300 clients received Next Step services. Appropriate referrals were given. Unexpectedly, some clients desired to have viral load testing, but funding was not available. And, the Next Step educator became a short-term case manager to help clients procure services.

Montrose Counseling Center

Eligibility	Service Description	Outcomes
	Courses in residential tx and prison re: HIV, HIV/CD, STD, TB, Hep B, Case Management.	Montrose Counseling did not have a # of presentations it was required to do. Education programs were used to enhance case management. The expected outcomes were risk reduction, harm reduction, and identify positive people.

N.A.A.C.P.

Eligibility	Service Description	Outcomes
1) 8 years and older 2) High risk for HIV/STDs	**P.O.W.E.R. Program -** HIV Education and prevention to at-risk African American women.	The N.A.A.C.P. prevented the spread of the HIV virus and/or its transmission.

HEALTH EDUCATION/RISK REDUCTION, cont…		

Coalition for the Homeless of Houston/Harris Co., Inc.

Eligibility	Service Description	Outcomes
	HSCC is a forum of Homeless Service Providers that meets once a month to network and set priorities and actions to address homelessness in Houston/Harris Co.	Homeless service providers were able to collaborate for funding and increase services. Needs of homeless were met.

Diocesan AIDS Ministry – A Program of Associated Catholic Churches

Eligibility	Service Description	Outcomes
	Provides intensive case management, decreasing financial assistance and support groups focused on building life skills that lead to self-sufficiency. This is a 6 month program	This was a new program. Twelve single, female-head-of-household clients participated.

HEALTH EDUCATION/RISK REDUCTION, cont…

The Center For Aids: Hope & Remembrance Project

Eligibility	Service Description	Outcomes
Must be HIV + or with AIDS diagnosis	**Information Center** - Free printed and bulk subscriptions to national AIDS newsletters and other literature from basic to advanced, free Internet access, an extensive scientific and medical reference collection are provided on a walk-in basis. Treatment counseling by appointment is available. Also serves as a referral to social service providers.	The information center is designed to be as unintrusive as possible so there is no client intake process. While the Center does not know who 48% of our callers and visitors were in 1998, it knew that 30% identified themselves as PWAs and/or ASOs. By utilizing the treatment information resources at the information center, service providers were able to optimize service provision to clients and help empower them to procure the best health care available. PWAC used the info center for monthly meetings; AIDS Mastery used the space some weekends. A volunteer treatment advocate buddy training program with AIDS Foundation Houston is conducted at the Center. Both AFH and AVES have had staff rotations at the Center. A journal club is now taking place twice a month at noon.
Must be HIV + or with AIDS diagnosis	**Research Initiative/Treatment Action (RITA!) -** Provides a primary source of HIV/AIDS treatment and research information free of charge to PWAs, AIDS service providers, clinics, hospitals, and doctors' offices.	Provided a broader knowledge base for decision-making purposes regarding treatments. Unexpectedly, RITA! was not included in POZ's review of treatment newsletters. The newsletter is indexed in AIDSLine.

HEALTH EDUCATION/RISK REDUCTION, cont…

The Center For Aids: Hope & Remembrance Project

Eligibility	Service Description	Outcomes
Must be HIV + or with AIDS diagnosis	**Community Forums -** The forums provide medical updates for PWAs who are heavily treated and most in need of new options and research information.	Allowed patient access to and dialogue with medical and scientific thought leaders in the field in order to increase knowledge base for making decisions about treatments. The Center for AIDS is now part of the program planning committee for the annual Houston Conference on AIDS in America. We also have a formal working agreement with Harris County Hospital District's HIV Projects division.

Young Women's Christian Association

Eligibility	Service Description	Outcomes
1) School-age youth 2) Students attending Yates High School	To increase the number of low-income teens receiving education for enhancing their knowledge on HIV/STD, utilizing school-based settings.	Conducted 510 group sessions for a minimum of 11 people in school settings. The YWCA of Houston's HIV/STD program experienced positive outcomes in the past 10 months. High school students attending Yates High School have stated they are knowledgeable about HIV/STD illnesses and feel more comfortable discussing it.

HEALTH EDUCATION/RISK REDUCTION, cont…		
City of Houston Department of Health and Human Services		
Eligibility	**Service Description**	**Outcomes**
1) Harm reduction approach 2) Must live in Houston MSA	**Counseling/Testing, Referral & Partner Notification (CTRPN) –** provide client centered prevention counseling, referral, partner notification, and screening for HIV and other STDs in HDHHS, community based organizations (CBO) clinical and outreach settings. **HERR –** provides individual, group and community level interventions designed to increase knowledge and influence behaviors for persons at risk for HIV. **Early Intervention –** provide empowerment and educational activities in individual and group settings to clients newly diagnosed with HIV. **Public Information –** provide mass media and other campaigns to provide awareness of HIV to the general public and communities at increased risk for HIV.	By Dec. 31, '99 - **CTRPN** will - *reach a minimum of 2,500 MSMs over age 25 and 2,500 MSM under 25; *reach a min. of 1,500 AfAm, 1,000 White and 500 Latino IDU/substance users; *reach a min. of 6,000 AfAm, 5,000 Latino and 4,000 White het females & 5,000 male hets at risk for STDs; *reach a min. of 150 male & 150 female sex workers; *achieve a 1.5-partner/cluster index from partner notification interviews conducted by HDHHS personnel w/ new HIV + clients; and *75% of new partners of HIV infected persons initiated for follow-up will receive prevention counseling. **Early Intervention Prog.** - % of new HIV+ clients attending the Next Step workshop will increase from 75% to 80; *% who access case management will increase from 66% to 80%; *all HIV+ clients will be offered viral load testing at the completion of the results counseling session; *95% of HIV- counseling & testing clients w/ an identified social, medical, or other need will be provided w/ an appropriate referral for services; and *95% of HIV- counseling & testing clients who are referred for other services will be offered prevention case management.

HIV Counseling and Testing

Program Description

If someone thinks they have been exposed to HIV, they should consider taking an HIV test. This medical test is the only way to tell if someone is infected with the virus. The test can be done at a doctor's office or clinic. At many public clinics, the individual does not have to give their name, and often the test is free or at a very low cost. Typically, the testing sites give results to the individual in 10-14 days.

HIV Counseling and Testing Service Provider, Eligibility, and Outcomes

Harris County Sheriff's Dept., Montrose Clinic, Montrose Counseling Center, and Planned Parenthood of Houston

Table 19 HIV Counseling and Testing

HIV COUNSELING AND TESTING		
Harris County Sheriff's Dept.		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection, symptomatic or asymptomatic 2) In custody of HCSD	The project offers HIV counseling, testing and education through PCPE counselors. It also offers HIV/STD education prevention and referrals to Early Intervention. The HERR education counselors do not specifically target the PLWH/A, in fact there is not documentation as to whether or not the client is (+). The targeted audience is women at high risk, i.e. drug users, sex workers, or partners of drug users, etc. The PCPE counselors provide pre-test and post-test HIV counseling. The HERR sessions include education about STDs, and negotiation skills.	Harris Co. Sheriff's Dept. had at least 7,000 PCPE Counseled and 2,200 HERR Education sessions.

Montrose Clinic		
Eligibility	**Service Description**	**Outcomes**
Must be 14 years or older	Provide pre & posttest counseling and HIV test.	If someone tests positive, Montrose Clinic helps that person seek early medical intervention.

HIV COUNSELING AND TESTING, cont…

Montrose Counseling Center

Eligibility	Service Description	Outcomes
1) 500% of poverty level 2) 15 years of age or older 3) HIV infection, symptomatic or asymptomatic 4) Must live in Houston EMA	Testing in residential tx and on street.	Montrose Counseling did not have a # of presentations they were required to do. Education programs are to enhance case management. The expected outcomes were risk reduction, harm reduction, and identify positive people.

Planned Parenthood of Houston

Eligibility	Service Description	Outcomes
No requirements	Prevention counseling to identify & reduce risks, HIV testing & boost test counseling & referral to providers. Partner elicitation.	Increased clients self-perception of risk. Helped the client negotiate plans to reduce risk and learn serostatus. Helped get positive clients to early intervention and case management.

Health Insurance Continuation

The money in this category is provided to one contractor to pay for the State's high-risk pool insurance for eligible HIV+ individuals within the EMA. Unit of service is one month of insurance coverage.

Health Insurance Continuation Provider, Eligibility, and Outcomes

The Assistance Fund.

Table 20 Health Insurance Continuation

HEALTH INSURANCE CONTINUATION		
The Assistance Fund		
Eligibility	**Service Description**	**Outcomes**
1) Income must be 250% of poverty or below 2) All ages eligible 3) HIV infection symptomatic or asymptomatic 4) Must live in 10 county area in/around Houston 5) Must have insurance already in place	Offer assistance with co-payments, deductibles and insurance premiums for up to 29 months. No cap on services, no waiting list.	Provision of units of service kept clients from being patients of Harris County Hospital Dist. Unexpectedly, financial resources were outstripped by demand – i.e. could pay for more services, but limited due to funding.

Support Groups/Non-Mental Health

A unit of service is defined as one (1) support group session. Support groups (non-mental health) for Persons Living with HIV (PLWH) who are in need of support with issues secondary to recent developments in HIV-related treatment. Groups have at least 5 and no more than 15 participants, not including agency staff and/or facilitators. Groups meet at least weekly throughout the term of the contract year. The groups focus on changes PLWH face since the introduction of protease inhibitor (PI) class medications and multiple drug therapies.

The changes in attitudes and behaviors of PLWH who may have been preparing for terminal stage AIDS and are now healthier include: loss of disability income eligibility; returning to the workforce and the implications that may have in benefit eligibility; family and personal relationships (increased stress, questions about one's absence from the workforce for an extended period of time, etc.,); and coping with changes in personal health brought on by PI medications.

Agency Qualifications

Qualified agencies have a Registered Nurse (RN) with at least 2 years HIV-related experience on staff or available as a contractor to provide coordination and consultation to the group participants and facilitator in regards to medication and health issues. Groups may be facilitated by a layperson who has personal knowledge of HIV/AIDS related issues (PLWH preferred). Qualified agencies have has at least 2 years experience in the provision of HIV/AIDS related services in the greater Houston metropolitan area. Support groups are provided in community based locations which are convenient to the attendees' residence (community centers, churches, etc.).

Support Group Service Providers, Eligibility and Outcomes

AIDS Foundation Houston, Art League of Houston, Donald R. Watkins Memorial Foundation, Inc. (provider survey not submitted), H.O.P.E. Project, Houston Area Community Services, Inc. (provider survey not submitted), the N.A.A.C.P., and the Riverside General Hospital (provider survey not submitted).

Table 21 Support Groups, Non-Mental Health

SUPPORT GROUPS, NON-MENTAL HEALTH		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Living in HSDA/EMA	The provision of peer facilitated support groups which focus on treatment issues, including compliance, adherence, back to work issues, credit counseling, and quantity/quality of life issues.	Completion of at least 51 support groups attended by a minimum of 3 HIV+ individuals per group. Unexpectedly, AFH had to adjust number of groups due to mobility to secure needed HIV+ documentation.

SUPPORT GROUPS, NON-MENTAL HEALTH, cont…

Art League of Houston

Eligibility	Service Description	Outcomes
1) Must be between ages 25-35 2) HIV infection symptomatic or asymptomatic or w/ AIDS diagnosis	**Art Classes –** Free weekly art classes year round funded by the city of Houston through CACHH, the Art Colony Association. A light which is provided by the National Council of Jewish Women.	Participants created individual works of art which were exhibited, used, given as gifts or sold by the students; paintings, mosaic furniture, birdhouses, decorative items.

Donald R. Watkins Memorial Foundation, Inc.

Eligibility	Service Description	Outcomes

Houston Area Community Services, Inc.

Eligibility	Service Description	Outcomes

N.A.A.C.P.

Eligibility	Service Description	Outcomes
1) 18 years and older 2) HIV + 3) Substance free/abstinence 4) Live in City of Houston 5) Women at high-risk	**Women Developing Solutions -** Support groups/nonmental health.	Program was expected to serve 1,094 and served 1,000. The positive aspect was the changing attitude of the clients.

Riverside General Hospital

Eligibility	Service Description	Outcomes

H.O.P.E. Project

Eligibility	Service Description	Outcomes
Must be HIV + or with AIDS diagnosis	**Treatment Mixer -** A revolving group of men heavily treated attend this loosely structured meeting facilitated by the R.N. to exchange information about treatment.	PWAs came to the mixer with scientific questions in advance of or immediately after a visit to their physician. The mixer empowered the PWA in the decision-making process. Unexpectedly, attendance at the mixers dropped off in 1998. Newly diagnosed men have also attended.

Rehabilitation Care

A unit of service is a physician-ordered physical therapy and/or skilled rehabilitation service provided to HIV patients in community-based organizations, health care facilities, and/or patient's home.

Services Provided

Diagnostic evaluations, pain management and training/rehabilitation in the following areas: activities of daily living, neuromuscular rehabilitation, gait, mobility, speech, language and cognitive abilities.

Rehabilitation Care Provider, Eligibility and Outcomes

UT Health Science Center for Houston Recovery Campus

Table 22 Rehabilitation Care

REHABILITATION CARE		
UT Health Science Center for Houston Recovery Campus		
Eligibility	**Service Description**	**Outcomes**
1) Must be medically indigent 2) 18 years or older 3) HIV infection symptomatic or asymptomatic 4) Substance use history and status is required 5) Must live in HHS Region 6 6) Must be homeless	Stabilization (medical, drug abuse, and mental health) for homeless HIV+ persons prior to entry into residential substance abuse treatment. Service initiation.	Decreased the number of people recycled through the system after they were released from Ben Taub, HCPC, etc. and helped prevent them from returning to the streets. 324 will receive stabilization; 100 will receive treatment; 25% will maintain stable housing 6 months subsequent to tx; 25% will have maintained sobriety. Unexpectedly, it has been impossible to get HIV case management organizations (except MCC) to participate in multi-disciplinary staffing; although Consortium agencies state need for service. Such a task requires intensive on-going outreach.

Volunteer and Buddy/Companion

Volunteers/Other

Volunteer programs provide innovative programs to benefit HIV/AIDS infected individuals. The intent of all the volunteer programs is to provide direct “hands on” volunteer services and not volunteers for agency administrative assistance.

Services Provided

The provider has demonstrated a capacity to recruit, train, coordinate and support a pool of volunteers to service a broad geographical area. The services funded in this service category are used to provide respite care or “buddy” programs. These are not outreach or case management services.

Volunteers/Community

The use of volunteers to support a variety of volunteer programs to provide support services for HIV/AIDS infected individuals which may include, but are not limited to, buddy programs, spiritual and emotional support and companionship. The intent of volunteer programs is to provide direct “hands on” volunteer services and not volunteers for agency administrative assistance.

Services Provided

The provider has a capacity to recruit, train, coordinate and support a pool of volunteers to service a broad geographical area.

Volunteer Service Providers, Eligibility, and Outcomes

AIDS Foundation Houston, Foundation for Interfaith, and PWA Coalition.

Table 23 Volunteer and Buddy/Companion

VOLUNTEER AND BUDDY/COMPANION		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic. 2) Must live in HSDA or EMA.	**Volunteer services** – Provides direct client service through 7 specific programs. These include Camp, Creative Arts Healing, Hotline, Pediatric, Phone Buddy, Senior Companion, Hospital, and Stone Soup Food Pantry.	Recruited and trained a minimum of 150 volunteers to produce 19,000 hours of service to 1,000 unduplicated clients through direct client service. New programs were created late in 1998 based on a review of client needs focusing on treatment adherence.

VOLUNTEER AND BUDDY/COMPANION, cont…

AIDS Foundation Houston

Eligibility	Service Description	Outcomes
1) Must be between the ages of 7-16 years 2) HIV infection symptomatic or asymptomatic	**Camp HOPE -** Gives children living with HIV/AIDS the chance to experience the outdoors in a safe and supportive manner – and simply to have fun.	For most of the children, these were first-time experiences. Not only did they have a good time, they also increased their self-esteem and learned what camaraderie is all about. The camp, which won Leadership Houston's 1996 Leadership in Action Award by taking top honors in the Health and Human Services category, has been enormously successful. Initial response was so positive that Camp Hope entered into collaboration with the Camp for All Foundation to extend the annual event to a full week.
1) Must be 6 or older 2) Can be a caregiver or symptomatic / asymptomatic 3) Must live in greater Houston	**Camp H.U.G. -** the first and only camp program in the greater Houston area specifically designed for HIV+ children, their siblings, and their parents or caregivers. It provides nurturing environments in which children with HIV/AIDS can experience life as "normal kids". Also, parents and caregivers are invited to attend an afternoon psychosocial workshop led by an expert on children and families living with HIV/AIDS.	Recreation has been the main purpose of Camp H.U.G. – children can enjoy an afternoon of horseback riding, team sports, fishing, canoeing, arts and crafts, nature studies, swimming and other water sports.

Foundation for Interfaith

Eligibility	Service Description	Outcomes
1) Income verification is necessary 2) HIV infection symptomatic or asymptomatic 3) Live in Houston HSDA	Provide 36,000 hours to 170 unduplicated clients and supervise 605 volunteers organized into Care Teams.	

VOLUNTEER AND BUDDY/COMPANION, cont…		
People With AIDS Coalition – Houston, Inc.		
Eligibility	**Service Description**	**Outcomes**
Must be 18 years of age or older	Provide support for HCHD/TSC as well as host special events for clients.	PWA expected to provide 16,000 units (hours) of service throughout the Houston EMA.

Hospice Care/Home Hospice Care

Services Provided

Services must include, but are not limited to:
- Medical and nursing care,
- Palliative care,
- Psychosocial support,
- Spiritual guidance, and
- Bereavement services for the patient and surviving family members.

Physical therapy services can be made available on a subcontract basis.

Agency Qualifications

Providers are licensed by the Texas Department of Health as a hospital, special hospital, special care facility or Home and Community Support Services Agency (with Hospice Designation). Agency must be Medicaid and Medicare certified.

Hospice Care Service Provider, Eligibility, and Outcomes

Bering Omega Community Services.

Table 24 Residential Hospice

RESIDENTIAL HOSPICE		
Bering Community Service Foundation w/ Omega House		
Eligibility	**Service Description**	**Outcomes**
1. Must be 18 years of age and older 2. Less than 6 months prognosis	Hospice to PWAs in the terminal stage of their illness in a serene and attractive surrounding while offering spiritual and psychosocial support for resident families and partners.	Provided 24 hr nursing assisted by 90 highly trained patient care volunteers. Unexpectedly, Bering saw an increase in clients the last several months.

Referral

Program Description

Referral Service Providers, Eligibility and Outcomes

AIDS Foundation Houston, Coalition for the Homeless of Houston/Harris Co., Inc., and Montrose Clinic.

Table 25 Referrals

REFERRAL SERVICES		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Living in HSDA/EMA	Referrals, needs assessment, advocacy, benefits counseling, and follow-up.	Increased access to available, appropriate, affordable and acceptable services.
Coalition for the Homeless of Houston/Harris Co., Inc.		
Eligibility	**Service Description**	**Outcomes**
	Data/Network – Coalition provides I & R for call-in agency staff or individual requesting services to avoid becoming homeless or emergency shelter when homeless. Referral is also made to substance abuse programs when requested.	Individuals received assistance in what they requested, i.e. food, clothing, shelter, utility or rent assistance, etc.
Agency fee of $25, individual fee of $10 to be member of HSCC.	**Homeless Services Coordinating Council (HSCC) –** Same as Data/Network + HSCC is a forum of Homeless Service Providers that meets once a month to network and set priorities and actions to address homelessness in Houston/Harris Co.	Same as Data/Network - homeless service providers collaborated for an increase in funding and services. Needs of homeless were met.
Montrose Clinic		
Eligibility	**Service Description**	**Outcomes**
1) Must be 18 years of age or older 2) Various disease state criteria 3) Must have physician referral	**HIV Research –** Provide clients access to clinical drug trials. Clinical trials are a way for PLWH/A to help advance research and have access to "cutting edge" treatments. All drugs used now are only available because others participated in clinical trials.	Clients had positive health outcomes. New drugs were approved by FDA.

Outreach and Prevention

Program Description

Outreach and prevention, in the sum of all efforts, intended to stop the further transmission of HIV; education that is intended to prevent transmission of HIV to non-infected persons. Activities provide relevant information in a way that is understandable to the individual, including offering advise and suggestions, identifying alternatives and their probable consequences, modeling behaviors, teaching problem-solving techniques, or clarifying perceptions. (Not currently or previously funded with RW Title I funds in Houston, part of Service Linkage Worker responsibilities under Case Management).

Outreach includes programs which have as their principal purpose as identifying people with HIV disease so that they may become aware of and may be enrolled in care and treatment services. It does not include HIV counseling and testing nor HIV prevention education.

Services Provided

- Planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort;
- Targeted to populations known through local epidemiology data to be at a disproportionate risk of HIV infection;
- Be conducted at times and in places where there is a high probability that HIV-infected individuals will be reached;
- Be designed with quantified program reporting that will accommodate local effectiveness evaluation.

Outreach Service Providers, Eligibility and Outcomes

Houston Area Community Services, Montrose Counseling Center, N.A.A.C.P., Diocesan AIDS Ministry – A Program of Associated Catholic Churches, and MHRA of Harris Co.

Table 26 Outreach and Prevention

OUTREACH AND PREVENTION		
Houston Area Community Services,		
Eligibility	**Service Description**	**Outcomes**
HIV + or diagnosed with AIDS.	Provide outreach services to engage persons who never used the HIV system of Care to utilize it.	Served at least 800 people of HIV infection. One negative outcome was that many clients had already been in the HIV/CMS at one point in time.

OUTREACH AND PREVENTION, cont…

N.A.A.C.P

Eligibility	Service Description	Outcomes
	HIV/AIDS and STD education. Self-esteem empowerment.	

Montrose Counseling Center

Eligibility	Service Description	Outcomes
1) Must be 13 years of age or older 2) Must be at risk for HIV 3) Currently using substances or have history 4) Live in Houston EMA/HSDA	Montrose Counseling does street outreach in Fort Bend Co.	Montrose Counseling did not have a # of presentations they were required to do. Education programs are to enhance case management. The expected outcomes were risk reduction, harm reduction, and the identification of positive people.

Diocesan AIDS Ministry – A Program of Associated Catholic Churches

Eligibility	Service Description	Outcomes
1) Targets faith-based groups 2) Must live in 11 counties of Diocesan of Galveston - Houston	Developing and maintaining Parish outreach to promote education and information related to Diocesan AIDS Ministry and HIV/AIDS.	Provided outreach services to at least 6 parishes, 2 St. Vincent de Paul Conferences, 6 faith-based organizations in Galveston and 2 interfaith activities. The Interfaith Planning Committee did an outreach project through several pantries and food programs. 600 educational flyers went out.

MHMRA of Harris Co./PATH

Eligibility	Service Description	Outcomes
	Outreach to homeless mentally ill, psychiatric services, rehab, case management, dual diagnosis services, substance abuse programming, housing referrals.	Served approximately 840 clients during FY98. Contacted 2100 homeless during FY98. Total funds for FY98 $369,000. Stabilized homeless mentally ill population both through psychiatric and through housing.

Employment Assistance/Vocational Counseling and Training

Program Description

For someone living with HIV, staying productive and active is important for both financial and emotional reasons. Several agencies in the Houston area have programs that will train, counsel, and refer people looking for jobs. If able to work, a person with HIV can benefit from a steady paycheck, possible health insurance, improved self-esteem and more choices.

Employment Assistance/Vocational Counseling & Training Service Providers

AIDS Foundation Houston and Nightingale Adult Day Center

Table 27 Employment Assistance

EMPLOYMENT ASSISTANCE		
AIDS Foundation Houston		
Eligibility	**Service Description**	**Outcomes**
1) HIV infection symptomatic or asymptomatic 2) Living in HSDA/EMA	**Spirit Wellness Center -** Outreach, employment resources, job search and to place clients in employment services. The do nutrition counseling to increase knowledge.	Helped 50% of clients become employed. Discovered that 50% of clients that take classes increase their knowledge.
Nightingale Adult Day Center		
Eligibility	**Service Description**	**Outcomes**
1) Must be over age 15 2) HIV infection symptomatic or asymptomatic 3) Live in Houston EMA	Vocational counseling, job seeking assistance and job placement.	Provided 8,000 units of service to 123 unduplicated clients with 94 clients finding employment. Have found that people completing classes are finding employment. Large number of clients has not fully completed classes.

Leadership Development

Program Description

Leadership Development Service Provider, Eligibility, and Outcomes

People With AIDS Coalition (PWA)

Table 28 Leadership Development

Leadership Development		
People With AIDS Coalition		
Eligibility	**Service Description**	**Outcomes**
Must live in Houston EMA	Project L.E.A.P. is a 96-hour training program that teaches infected and affected individuals how to advocate for funding for HIV/AIDS.	Upon completion, 30 people (25 HIV+) should seek to serve on committees, councils, and Boards of Directors that determine resource prioritization and allocation for HIV/AIDS related funding. A 4 fold increase in participation by graduates in advocacy related programs and activities occurred.