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.

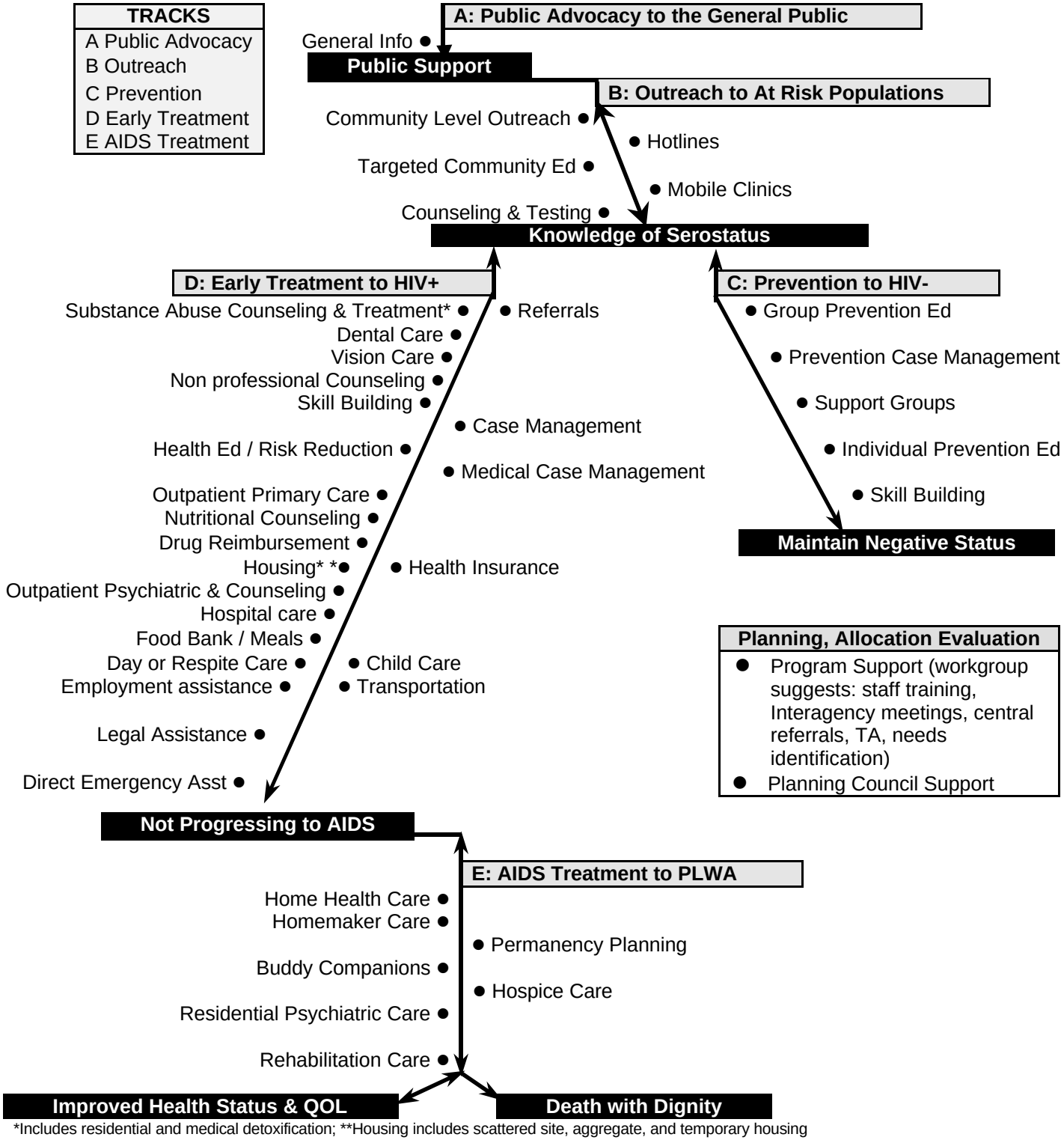
One of the challenges facing the Council and Consortium is the greater integration of tracks in the Continuum of Care. A greater integration of the general public track with early and AIDS treatment tracks is recommended. Many criteria for eligibility to the service system are established by the legislative 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



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

funding from all sources for HIV/AIDS services in the Houston area, including prevention, is

White, TDH, HOPWA, Federal grants and private funding sources for treatment and care services. In the H Omega

recipients of funds. AIDS Foundation Houston reports the most programs (11), followed by HCHD with six, -Omega, Montrose Clinic, and People With AIDS Coalition each with

Figure 2

sources, Ryan White Title I, and Foundations are the top three sources of funding for treatment

client fees, TDH/CDC, and local fundraisers. Other funding sources account for more than 50% or more of the an
Hospital, Montrose Clinic, UT Department of Pediatrics, and Diocesan AIDS Ministry.

Figure 2

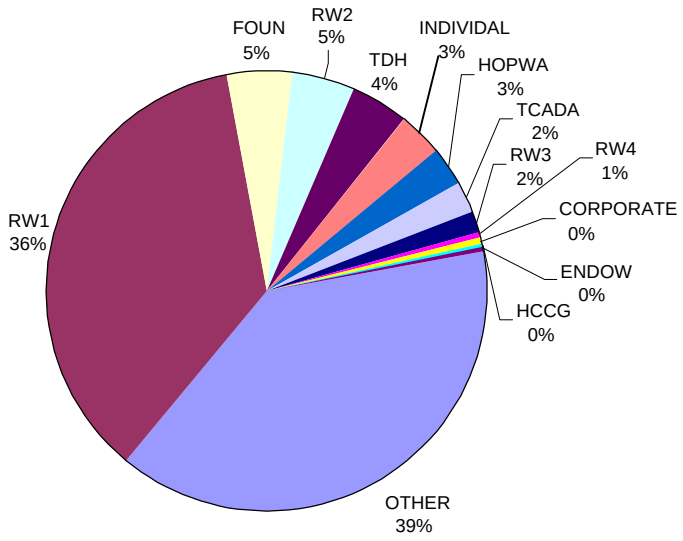


Table 3 indicates how the $21.3 million reported for direct programs was divided among the service categories. Based on Ryan White funds, HOPWA, TCADA and other funds, the services that received over a million dollars were medical care, case management, HIV early intervention and outreach, rental/emergency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

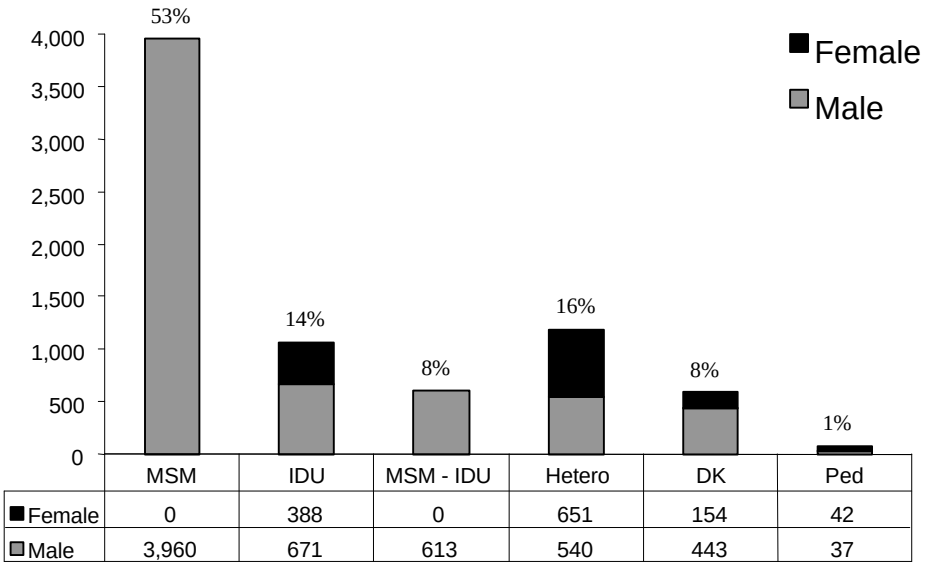
To estimate absolute need and service capacity for HIV/AIDS services, there must be reasonable estimates of those currently utilizing the system of care and the number of PLWH/A who are eligible to access the care system. Based on the epidemiological review, it is estimated by the Texas Department of 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 7$^{th.}$ 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 health	**14**	Nutritional Counseling	**17**	NA	**NA**
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 ranked	Housing Administration	**22**	NA	**NA**
	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

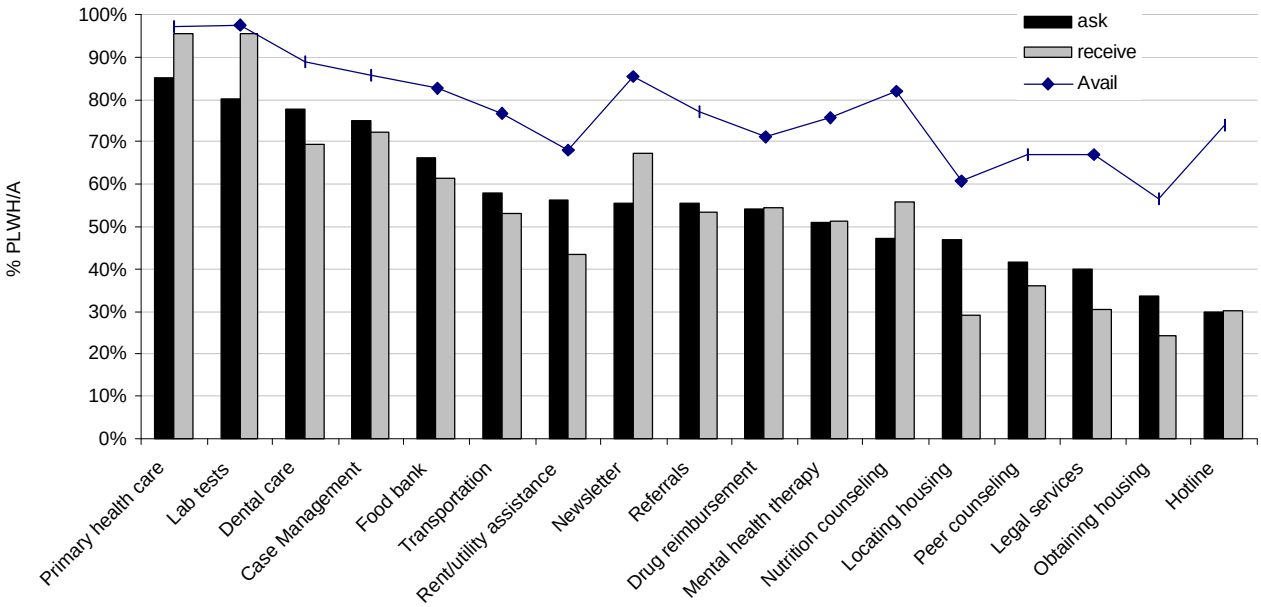
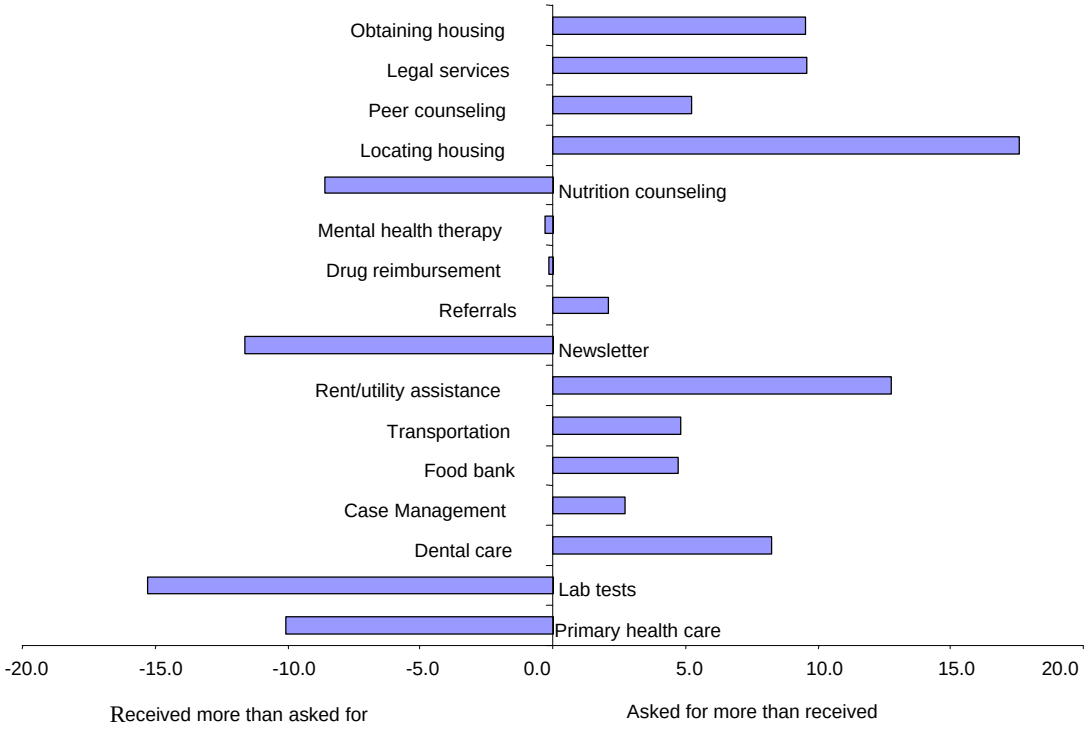


Figure 5 Total Sample Demand- Utilization Gap: Top 16 Services



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).

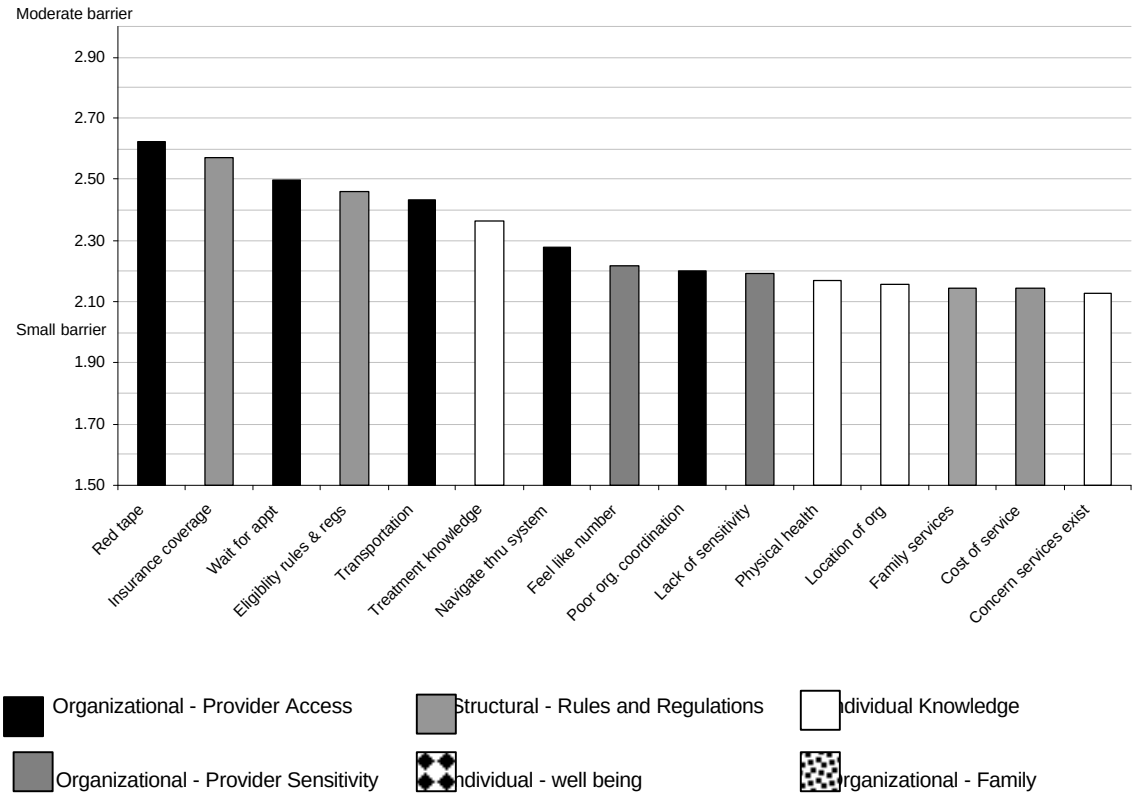
As seen in Figure 6, out of the top nine barriers mentioned, five are organizational access barriers (black bars) and two are structural barriers (dark gray bars). Most relate to the ability to obtain direct services. The organizational access barriers included:

- 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.