

# 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**

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# TABLE OF CONTENTS

1	INTRODUCTION	
2	METHODS	
	Needs Assessment Survey and Focus Group	2-2
	Process	2-2
	Sampling	2-2
	PLWH/A Survey	2-2
	Demographic Profile of the Rural PLWH/A	
3	TESTING AND PREVENTION	
	HIV Testing	
	Reported Methods of Reducing Risk for HIV Transmission from Sex	
	Using Condoms with Regular and Casual Partners	
4	MEDICATION AND ADHERENCE	
	Medication	4-1
	Adherence	
	Side Effects	
5	OUTCOMES	
	Quality of Life	
6	SERVICES	
	Dimensions of Service Need:	
	Most Needed Services.	
	Medical Services	
	Transportation	
	Drug Reimbursement	
	Basic Services - Food, Rent and Utilities, and Housing	
	Lab Tests	
	Case Management	
	Case Management FG Comments	
	Dental care	
	Assistance Locating Housing	
	Mental Health	
	Service Awareness, Demand and Utilization.	6-7
	Graphic Presentation of Awareness, Demand and Utilization	
	Services Most Demanded and Utilized	
	Awareness - Demand Gap	
	Demand - Utilization Gaps	
	Service Satisfaction and Access	
	Graphic Presentation of Satisfaction and Access	6-11
	Service Future Demand	6-13
	Graphic Display of Anticipated Need	6-13
7	BARRIERS	
	Overall PLWH/A Score for Barriers	
	Organizational Access Barriers	
	Red Tape - Focus Group Comments	
	Lack of Transportation - Focus Group Comments	
	Family - Focus Group Comments	7-3
	Confidentiality Focus Group Comments	7-3
	Waiting Focus Group Comments	7-4
	Structural Barriers	7-5
	Insurance - Focus Group Comments	7-5
	Rules and Regulations Regarding Eligibility Focus Group Comments	7-5
	Individual Barriers	
	Knowledge of Treatment Information Focus Group Comments	7-6
	Location of Provider Focus Group Comments	7-6
	Concern and that Services Do Not Exist and Knowledge of Services Focus Group Comments	

i



8 Summary of Rural PLWH/A Needs and Barriers	
Services	-
Barriers	
ATTACHMENTS	8-1
TABLES	
Table 8-1 Top Needs, Rank Order	
Table 8-2 Top Ten Barriers - Total vs. Rural PLWH/A	8-4
<u>FIGURES</u>	
Figure 3-1 Place of Testing	3-1
Figure 3-2 Ways to Reduce Risk of HIV Infection	
Figure 3-3 Frequency of Using Condoms	
Figure 3-4 Reasons for Not Using Condoms	
Figure 4-1 Medications	
Figure 4-2 Medication Taken by Rural PLWH/A	
Figure 4-3 Reasons for Stopping Meds	
Figure 4-4 Side Effects	
Figure 5-1 Quality of Life - Physical Health	
Figure 5-2 Quality of Life - Emotional Health	
Figure 6-1 Top 10 Needs of Rural	
Figure 6-2 Services Awareness, Demand, and Utilization - Top 10	6-9
Figure 6-3 Total Sample Demand- Utilization Gap: Top 10 Services	6-10
Figure 6-4 Access and Satisfaction with Services - Top 10	
Figure 6-5 Anticipated Need - Mean Score for Top 10	6-13
Figure 7-1 Average Barrier Scores for Rural PLWH/A – Top Ten	
<u>ATTACHMENTS</u>	
Attachment 1 Focus Group Outline	
Attachment 2 PLWH/A Survey	
Attachment 3 Rural PLWH/A Demographics	
Attachment 4 Condom Use & Prevention Behaviors	
Attachment 5 Top 10 Service Needs	
Attachment 6 Service Awareness	
Attachment 7 Service Demand	
Attachment 8 Service Utilization	
Attachment 9 Frequency of Service Usage	
Attachment 10 Service Satisfaction	
Attachment 11 Service Access	
Attachment 12 Future Demand of Services	
Attachment 13 Rural PLWH/A Barriers	8-1

ii



#### 1 INTRODUCTION

The Ryan White Title I Planning Council and the Houston HIV Service Delivery Area Care Consortium contracted with the Partnership for Community Health (PCH) and the Office of Community Project, University of Houston (OCP) to conduct a needs assessment 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.



#### 2 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 1 and the consumer survey is shown in Attachment 2. 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 2). 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

#### 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 serving rural PLWH/A.

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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 3 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.

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#### 3 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. Responses to the prevention questions are shown in Attachment 4. Graphic representations of several questions are presented and discussed below.

# **HIV Testing**

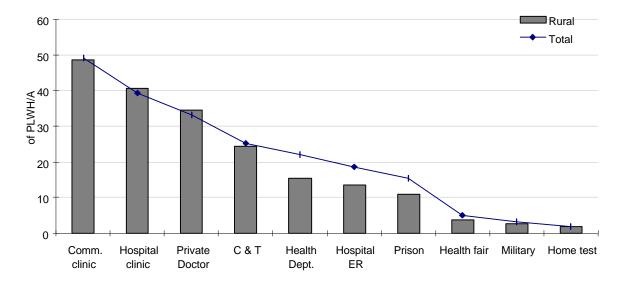
For the rural PLWH/A the most popular places for HIV testing are community clinics, hospital clinics, and private doctor's offices.

As shown in Figure 3-1, 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.





<sup>1</sup> 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.

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## 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 transmitted disease. As shown in Figure 3-2, 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.

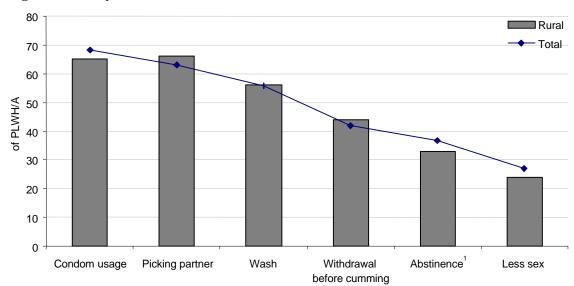


Figure 3-2 Ways to Reduce Risk of HIV Infection

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 3-3 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 3-4, 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 3-3 Frequency of Using Condoms** 

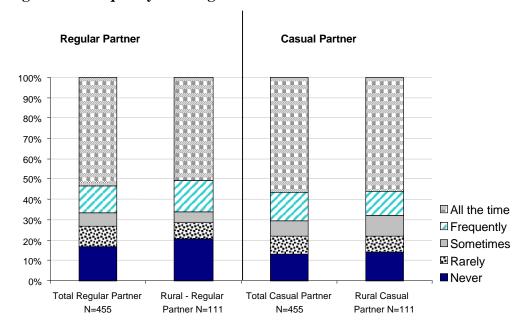
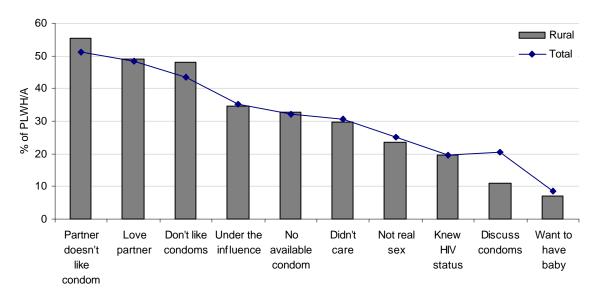


Figure 3-4 Reasons for Not Using Condoms



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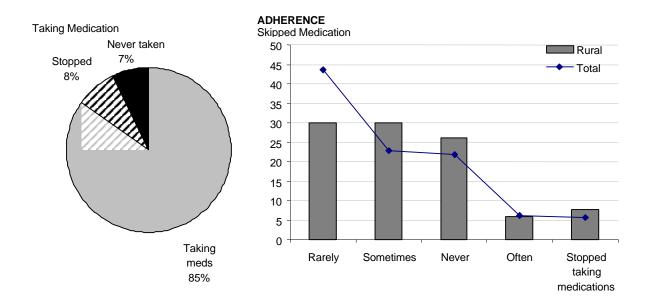


#### 4 MEDICATION AND ADHERENCE

#### Medication

- As shown in the pie chart in Figure 4-1, 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 4-1 Medications** 



For those taking medication, as shown in Figure 4-2, 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 4-2, 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.

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100 Rural 90 Total 80 70 % of PLWH/A 60 50 40 30 20 10 0 Anti-virals, **Antibiotics** Anti-depressants Anti-fungal Other HIV related Steroids protease meds inhibitors

Figure 4-2 Medication Taken by Rural PLWH/A

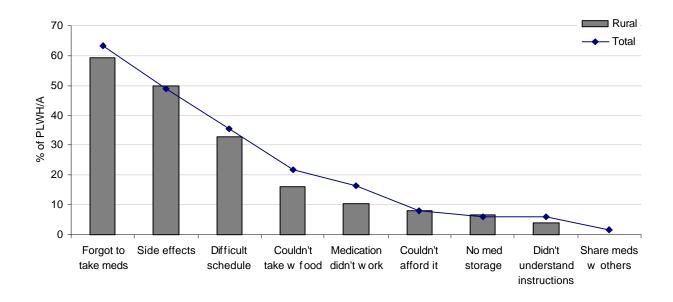
#### Adherence

- As shown in Figure 4-1, 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 4-3 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.



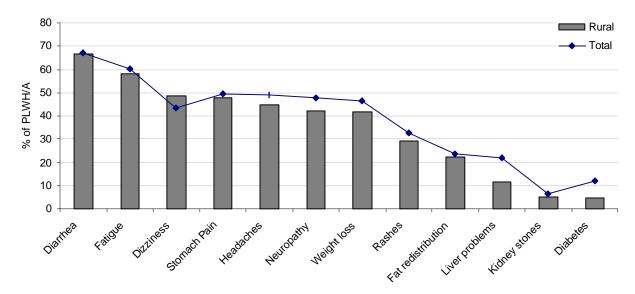
Figure 4-3 Reasons for Stopping Meds



# 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 4-4 Side Effects





#### 5 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 5-1 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 5-2 reports the current perceived change in <u>emotional health</u>. 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 5-1 Quality of Life - Physical Health

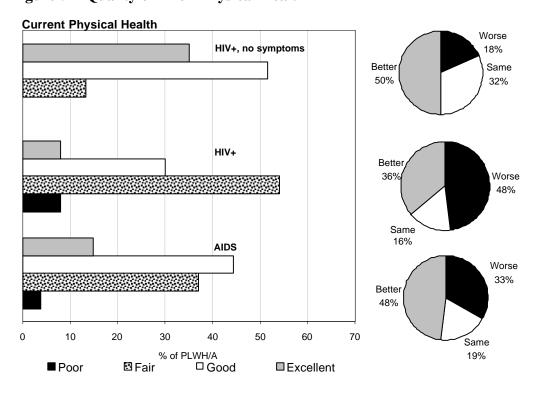
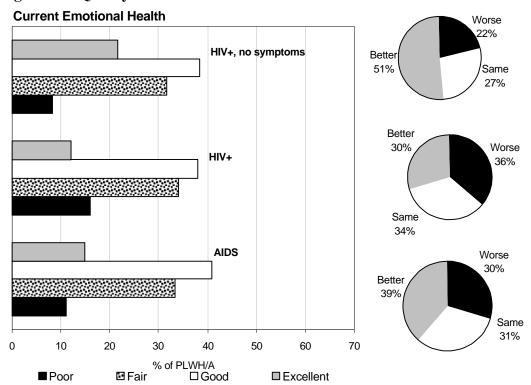


Figure 5-2 Quality of Life - Emotional Health



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## 6 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 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 5 and graphically in Figure 6-1. 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.

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Figure 6-1 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. "The 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 7<sup>th</sup> 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."

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# 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 10<sup>th</sup> 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 6 - Attachment 8. 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 6, 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 6 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 7 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 8 displays the percentage of those who have ever received the services. Attachment 9 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 6-2 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 6-2 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 12<sup>th</sup> and 13<sup>th</sup> of the most sought out services. On the other hand, dental care ranked 8<sup>th</sup> 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

6-8 rural - 11-17 final.doc



demand ranging from 39% to 45% difference were noted for hospice care, in-home hospice, hotline, and out of home substance abuse treatment.

100 Receive 90 Avail 80 70 60 50 40 30 20 10 Primary health Lab tests Case Dental care Transportation Food bank Newsletter Rent/utility Drua Referrals Management assistance reimbursement

Figure 6-2 Services Awareness, Demand, and Utilization - Top 10

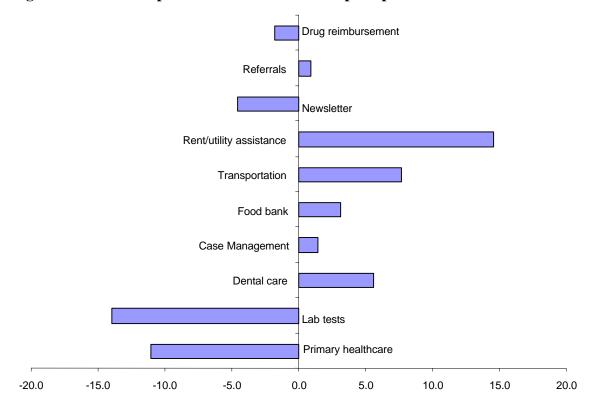
# Demand - Utilization Gaps

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 6-3 Total Sample Demand- Utilization Gap: Top 10 Services



6-10 rural - 11-17 final.doc



#### **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 10 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 10 shows the satisfaction scores for the rural participants.

The table in Attachment 11 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 6-4 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.

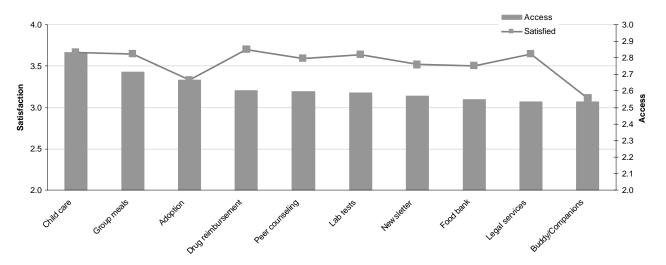
6-11 rural - 11-17 final.doc



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 6-4 Access and Satisfaction with Services - Top 10



6-12 rural - 11-17 final.doc



## **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 12. 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.

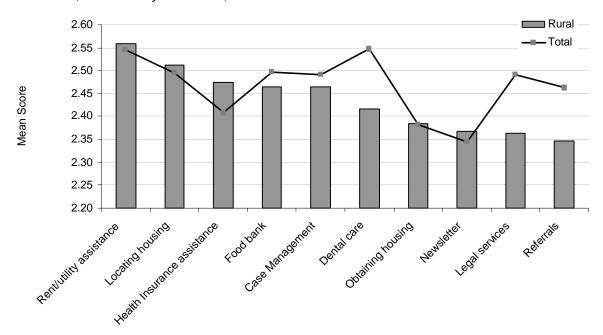
# Graphic Display of Anticipated Need

Figure 6-5 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 6-5 Anticipated Need - Mean Score for Top 10

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



6-13 rural - 11-17 final.doc



## **7 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.<sup>2</sup> 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.<sup>3</sup> 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 13, 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 7-1 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

<sup>2</sup> For exact wording see question 47 in the questionnaire, Attachment 2, and the Barrier section in the focus group outline. Attachment 1.

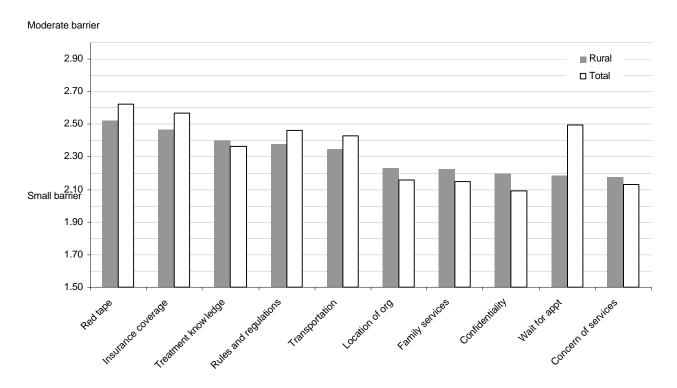
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- Not having transportation
- The lack of services for my family
- My concern that my confidentiality would not be kept
- The amount of time I had to wait to get an appointment or see someone

Figure 7-1 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."

7-2 rural - 11-17 final.doc



# <u>Lack of Transportation - Focus Group Comments</u>

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 7-1, 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

# <u>Insurance - Focus Group Comments</u>

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."

7-6

rural - 11-17 final.doc



# 8 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 8-1 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 8-1 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

8-1 rural - 11-17 final.doc



	Total Sample	Rural PLWH/A	Awareness	Demand	Utilization	Satisfaction	Access	Future Need
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, 11<sup>th</sup> in access and 22<sup>nd</sup> 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 30<sup>th</sup> 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 8<sup>th</sup> overall need and 9<sup>th</sup> for rural participants. Rural participants are not too familiar with the availability of assistance in locating housing.

8-2 rural - 11-17 final.doc



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 9<sup>th</sup> most important service for participants from the overall sample but the 7<sup>th</sup> 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 5<sup>th</sup> anticipated need.
- Mental health service remains, rated as the 10<sup>th</sup> 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 18<sup>th</sup> anticipated need.

8-3 rural - 11-17 final.doc



#### **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 8-2 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 8-2 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 <sup>1</sup>	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+

<sup>1 -</sup> 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.

8-4 rural - 11-17 final.doc



- 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 8<sup>th</sup> most significant barrier for them. For rural participants, this barrier drops just below the top ten. Yet, with a rank of 12<sup>th</sup> it still represents a concern for many of the rural participants.
- Overall, poor coordination among the organizations was seen as the 9<sup>th</sup> 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 12<sup>th</sup> 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.

8-5 rural - 11-17 final.doc



# **ATTACHMENTS**

**Attachment 1 Focus Group Outline** 

**Attachment 2 PLWH/A Survey** 

**Attachment 3 Rural PLWH/A Demographics** 

**Attachment 4 Condom Use & Prevention Behaviors** 

**Attachment 5 Top 10 Service Needs** 

**Attachment 6 Service Awareness** 

**Attachment 7 Service Demand** 

**Attachment 8 Service Utilization** 

**Attachment 9 Frequency of Service Usage** 

**Attachment 10 Service Satisfaction** 

**Attachment 11 Service Access** 

**Attachment 12 Future Demand of Services** 

**Attachment 13 Rural PLWH/A Barriers** 

8-1 rural - 11-17 final.doc