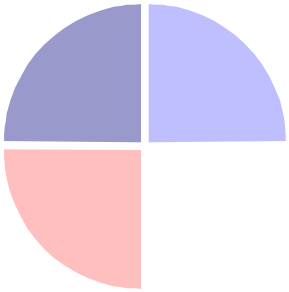

HOUSTON EMA & HOUSTON HSDA CARE CONSORTIUM

NEEDS ASSESSMENT REPORT

Special Study – Undocumented PLWH/A

Prepared for

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

October, 1999
Revised November 17, 1999

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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 Projects, University of Houston (OCP) to conduct a needs assessment and three special studies. The three special studies consisted of a report on the continuum of care, a special study of rural PLWA/H and a special study of undocumented PLWA/H. The needs assessment and the two special population studies identify service needs, gaps, and barriers for persons affected by HIV/AIDS in the Houston Eligible Metropolitan Area (EMA) and HIV Service Delivery Area (HSDA).

The goal of the needs assessment and special studies is to facilitate informed decisions regarding medical and support services for persons living with HIV/AIDS (PLWH/A) that are funded by the Ryan White CARE Act and other sources.

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

2 METHODS

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

Needs Assessment Survey and Focus Group

Process

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

The focus group outline is shown in Attachment 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. The list of barriers were developed based on prior needs assessments conducted by PCH using a multidimensional schema discussed in the Barriers Section, below. The questions related to barriers appear as question 47 of the consumer survey. Respondents also completed open-ended questions where they list needs and barriers.

For analysis purposes, the consumer survey captured demographic information, including stages of HIV infection, mode of transmission, socioeconomic indicators, and location of residency. The survey also measured co-morbidities of HIV with mental illness, sexually transmitted diseases (STDs) and tuberculosis (TB). In addition, the survey included questions related to HIV prevention and behavior.

A total of 24 focus groups were held with participants of different ethnicity/risk category populations. While five groups were “open groups ”, 19 groups were ethnic or risk category, including one group among undocumented PLWH/A. The open groups consisted of participants of diverse ethnic backgrounds and/or various risk categories who were recruited through newspaper advertisements and brochures announcing focus groups and word of mouth. The different ethnic groups were recruited from providers and through outreach. Focus groups were held between April 1999 and June 1999. The consumer surveys were completed between April 1999 and July 1999.

Sampling

<u>PLWH/A Survey</u>

The focus group and survey recruitment strategies were based on an overall sampling plan designed to draw a representative sample of clients from AIDS service organizations and clinics. Respondents of the focus group and respondents to the survey were recruited from 42 agencies

serving PLWH/A, prevention outreach programs, and from organizations and venues known to serve undocumented, including day labor sites. A letter of agreement was created with a service organization serving African immigrants. However, no participant was recruited through this effort. In addition, in order to recruit PLWH/A who may not have accessed the AIDS service agencies, some respondents were also recruited through the outreach efforts of organizations providing HIV prevention services and from community clinics within hospitals.

For the focus groups, the sampling goal was to have ten persons in each of the focus groups representing a broad spectrum of people living with HIV/AIDS. The recruitment of focus group participants represented part of the larger sampling of PLWH/A for the survey that was being conducted simultaneously. Individuals agreeing to participate in the focus groups were asked to complete the needs assessment survey prior to the focus groups. Interviewers were instructed to ask all non-US citizens about their residency status. Undocumented PLWH/A therefore included all participants who reported being undocumented or not having a legal residency status in the United States. Six people, three men, three women, participated in the focus group for undocumented PLWH/A. The focus group was conducted in Spanish by Ms. Lucía Orellana. A total of 31 undocumented PLWH/A completed the survey.

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

Demographic Profile of the Undocumented PLWH/A

Out of 455 people living with HIV/AIDS who completed surveys, 31 participants (5% of the total weighted sample) were undocumented PLWH/A. As this represents a very targeted group they are not comparable to the general sample and because of the sample size the findings should be not considered generalizable to the population of undocumented PLWH/A in Houston.

- The undocumented participants are mostly heterosexuals and not very similar to the overall sample. Thirty-six percent of the undocumented are MSM, 65% are heterosexuals and seven percent are IDUs. This is compared to 62%, 34% and 28% of the total sample who fall within each of the categories, respectively.
- The majority (65%) of the undocumented participants are male, yet, women are still over-represented among this group. The total sample is 82% male and 18% female. .
- Twenty out of thirty-one undocumented PLWH/A are Latinos. Five are either Caribbean black, Indian, or other multi-cultural ethnicity.
- Nearly one third of the undocumented participants have only a grade school education, compared to less than six percent of the total sample.
- Undocumented participants are more likely to be married or living with a partner than members of other target groups. Thirty-nine percent are married or living with a partner, compared to 20% of the total sample.
- Unlike participants in the overall sample with 52% having their own place, less than 20% of the undocumented participants have their own place. More than 60% of the undocumented participants live in a relative's or someone else's place. More than 85%

live with other people and a large percentage (77%) receive some form of assistance in paying the rent.

- Three undocumented participants have an HIV positive partner.
- Less than 13% of the undocumented have been in prison or jail over the past two years compared to about 30% of the overall sample.
- Similarly, less than 14% have been homeless over the past two years, compared to 23% of the participants in the total sample.
- One quarter of the undocumented participants are currently employed in some capacity, part or full time.
- Less than 13% of the undocumented PLWH/A have any form of health insurance. Two people reported having Medicare and two have Medicaid. Three report having some other type of insurance.
- Undocumented PLWH/A receive few benefits or entitlements. The top three benefits received are food stamps (19%), social security income (16%) and rent supplements (16%).
- Seventy-seven percent receive assistance obtaining their HIV medications. Out of those who receive assistance, 65% report receiving ADAP/TDH and 50% receive other type of assistance, namely MAP.
- Fifty-two percent are asymptomatic, forty-five percent have symptoms and three percent are unaware of their HIV status. This is almost the inverse of the overall sample, with 45% asymptomatic and 54% symptomatic PLWH/A. Thirty-five percent of the undocumented participants have an AIDS diagnosis compared to 54% of the overall sample. Seventy-one (71%) of the undocumented participants are currently taking HIV medications compared to 82% of the total sample.
- Less than 20% of the undocumented report any STD. The most common types of STDs are herpes (19%), syphilis and gonorrhea, both at 13%.
- Two undocumented individuals report having active tuberculosis which is being treated.
- The most common substances used by undocumented individuals are the same as those reported by the overall sample but are reported at a lower level. They include alcohol (77%), marijuana (39%) and cocaine (36%).
- Seventy-seven percent of the undocumented PLWH/A report an annual income of less than $6000 compared to about half of the total sample with that income.

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.[1] Responses to the prevention questions are shown in Attachment 4. Graphic representations of several questions are presented and discussed below.

HIV Testing

For the undocumented PLWH/A the most popular places for HIV testing are community clinics, hospital clinics, and counseling and testing centers.

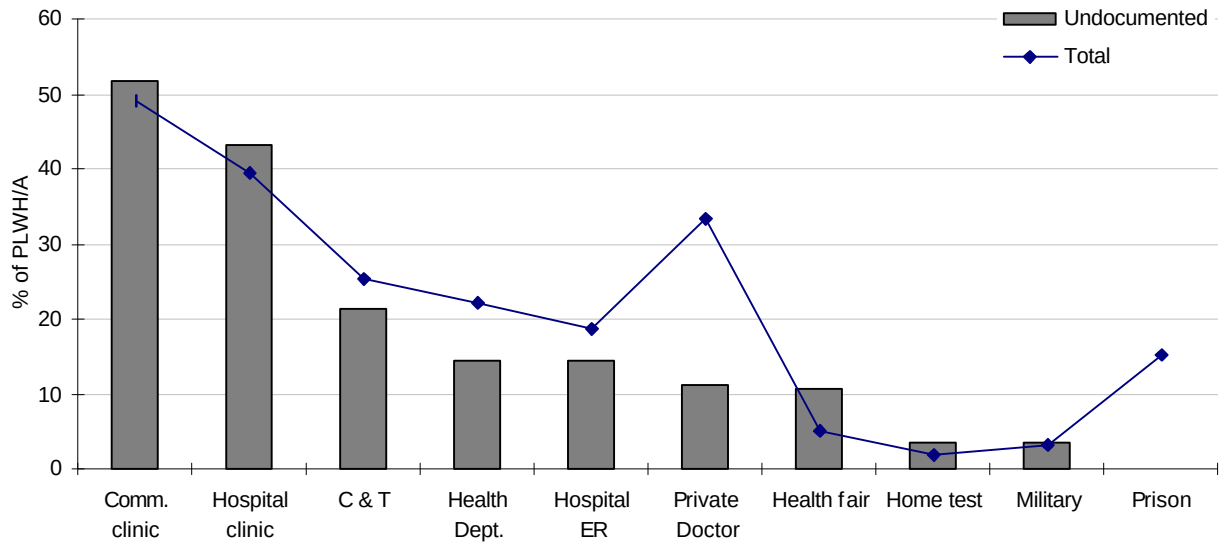
As shown in Figure 3-1, almost 52% of the undocumented participants report receiving their test at a community clinic (black line). This is very similar to the overall total weighted sample who report about 50% using this as their testing site. About 25% of undocumented PLWH/A report being tested at least twice (not shown in graph).

The second most common testing site for undocumented PLWH/A is a hospital clinic. About 43% report being tested in hospital clinics and about 10% say they were tested more than once.

Although reported as the third most common testing site, only slightly over 20% of the undocumented participants were tested in a counseling and testing center. This lower use, as compared to the overall total, may reflect undocumented PLWH/A's lower awareness of these testing sites or their greater concern about confidentiality and being reported to the authorities. Undocumented participants are three times less likely to be tested by a private doctor than are participants in the overall sample.

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

Figure 3-1 Place of Testing



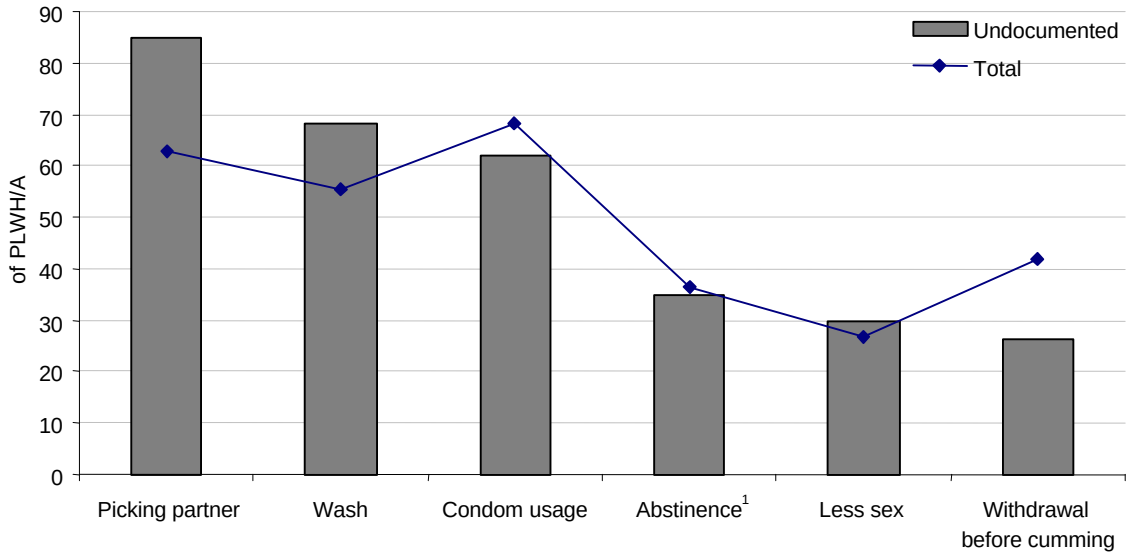
Reported Methods of Reducing Risk for HIV Transmission from Sex

Overall, undocumented participants report much lower sexual activity during the past two years than the participants in the total sample, with the exception of heterosexual undocumented men who report equal or higher sexual activity. From 60% to 100% of the undocumented women have not had sex in the past two years, and 42% to 80% of the men report no sexual activity in the same period of time.

Among the participants who said they had sexual intercourse in the past two years, several ways of trying to reduce risk of re-infection or becoming infected with a sexually transmitted disease are reported. As shown in Figure 3-2, increasing condom use, increasing washing before or after sex and being more careful when choosing partners are among the most popular methods of decreasing the chances of (re)infection or STDs. Although only about 60% say they increased their use of condoms, over 90% say they use condoms all the time with casual partners and close to 70% with regular partners. For undocumented PLWH/A, carefully choosing their sexual partners is the most frequent method reported. With 85% of participants reporting this strategy, this was by far the preferred strategy among undocumented PLWH/A. Increasing the practice of withdrawing prior to ejaculation (cumming) was less used by undocumented than most other groups. From comments made by participants during focus groups or during the administration of the survey this may reflect their already high use of this behavior. An undocumented Latina commented that this is what she and her partner do all the time and there has not been a change in that practice. She noted that they are now more careful about washing after intercourse.

The frequency with which sexually active undocumented PLWH/A had less sex, or increased abstinence is comparable to that reported by the overall sample and is shown in Figure 3-2.

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 undocumented PLWH/A report a much higher frequency of condom use than the total sample, with 67% reporting using condoms all the time as compared to 53% of the total sample. Notably, undocumented PLWH/A (92%) report by far the highest condom use with casual partners than any other group.

On the other hand, as shown in Figure 3-4, when asked why they don't always use a condom, more than 50% of the undocumented PLWH/A report several reasons for not using condoms. The number one reason (82%) is because they "really love" their partner. Also, undocumented PLWH/A are more likely (64%) than the overall sample (44%) to say they don't like using condoms. Tied for the third most common reasons for not using condoms are the belief that their partners do not like condoms, being convinced that they were HIV negative or not caring.

Less than 20% of the undocumented participants say that the reason they did not always use a condom was because there "were none available", " they were high or buzzed on drugs or alcohol", or because "they wanted to have a baby". More than one third say that using a condom is not "real sex", and about 27% say they didn't know how to talk about condoms or they knew the HIV status of their partner. Under 10% say the reason they didn't always use a condom was because they were trying to have a baby.

Figure 3-3 Frequency of Using Condoms

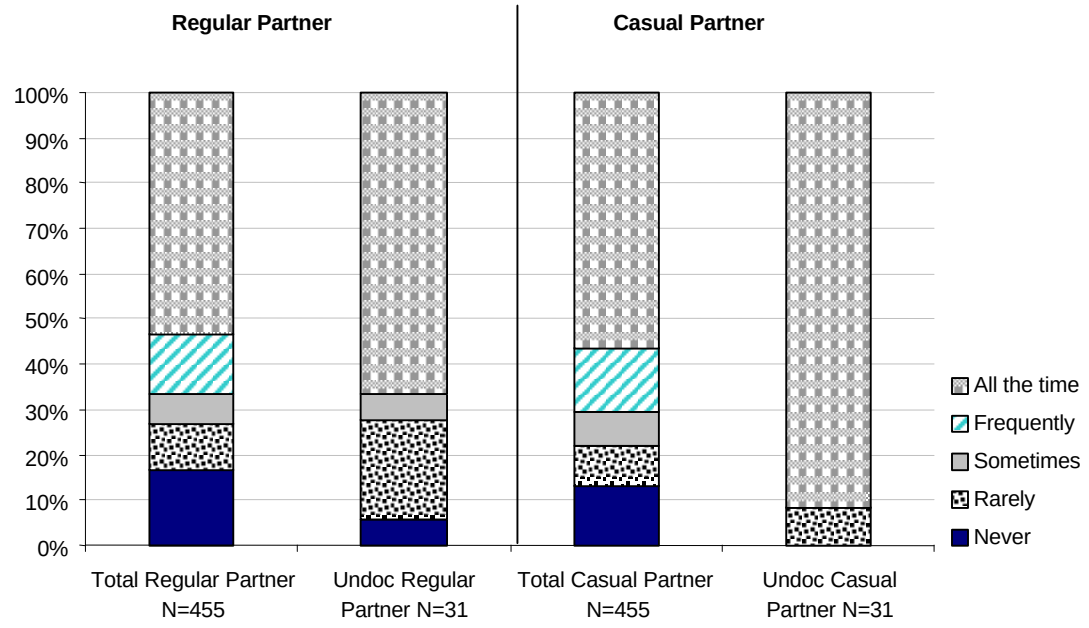
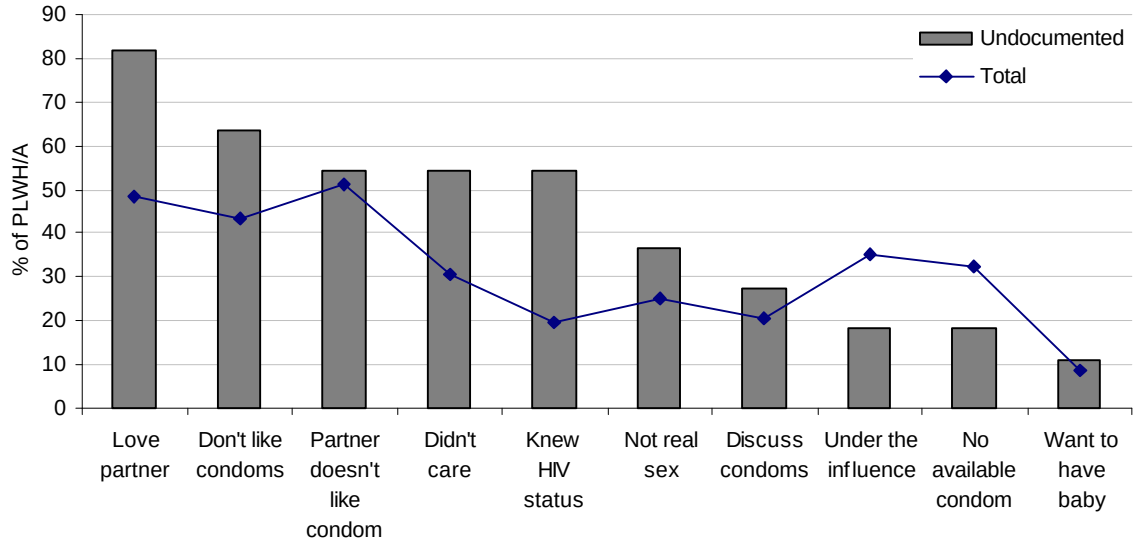


Figure 3-4 Reasons for Not Using Condoms

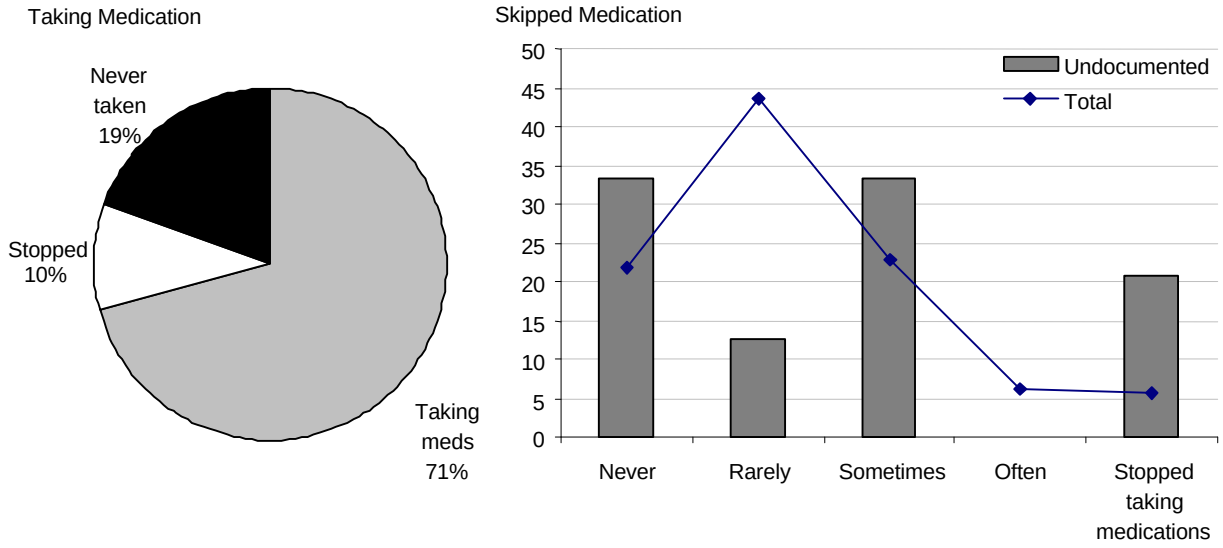


4 MEDICATION AND ADHERENCE

Medication

- As shown in the pie chart Figure 4-1, seventy-one (71%) of undocumented PLWH/A are currently taking medicines for their HIV infection. The in prison (71%) and youth (45%) populations are the only two other groups with equal or lower percentage of participants currently taking medications, but sample sizes are too small to be reliable.
- About 20% of the participants have never taken medication for HIV infection and 10% have taken medications but stopped. The percentage of undocumented never having taken medications is generally higher than most subpopulations, with the exception of 21% of the Hispanic females and youth who report never taking medication for HIV. This finding should be interpreted with caution because of the small sample size of 31.

Figure 4-1 Medications



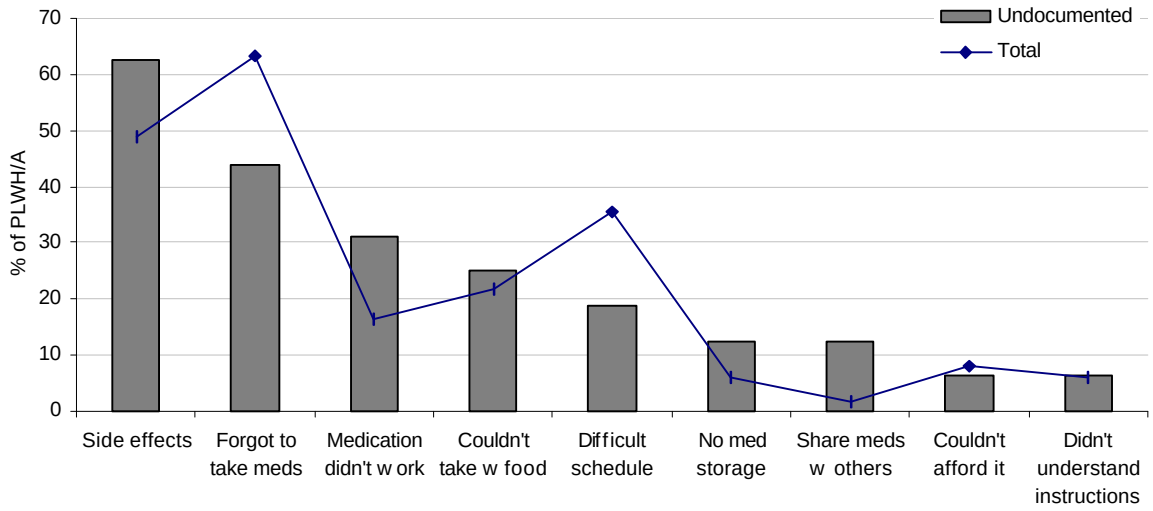
Adherence

- Although, undocumented participants are least likely to being taking HIV medication, once medications are prescribed, they are the least likely to deviate from the medical instructions. More than 75% of all the participants report not taking the medications as prescribed by their doctor compared to about two thirds of undocumented participants. As shown in the bar and line graph in Figure 4-1, over 30% of the undocumented participants report never skipping their medications, compared to less than 25% of the total sample.
- When undocumented participants have discontinued their medication, 25% report having done so with the advice of a doctor – specifically more than the total population.

Undocumented PLWH/A are more likely to report side effects than most groups, with the exception of MSM African Americans.

- Figure 4-2 indicates that over 62% of the undocumented participants and less than 50% of the total sample say they have skipped their medications because of side effects. The next most frequent reason for undocumented participants is because they forgot (44%) followed by the belief that the medication was not working (31%). Figure 4-2 shows that the order for the reasons for discontinuing the medication changes from the undocumented to the overall sample.

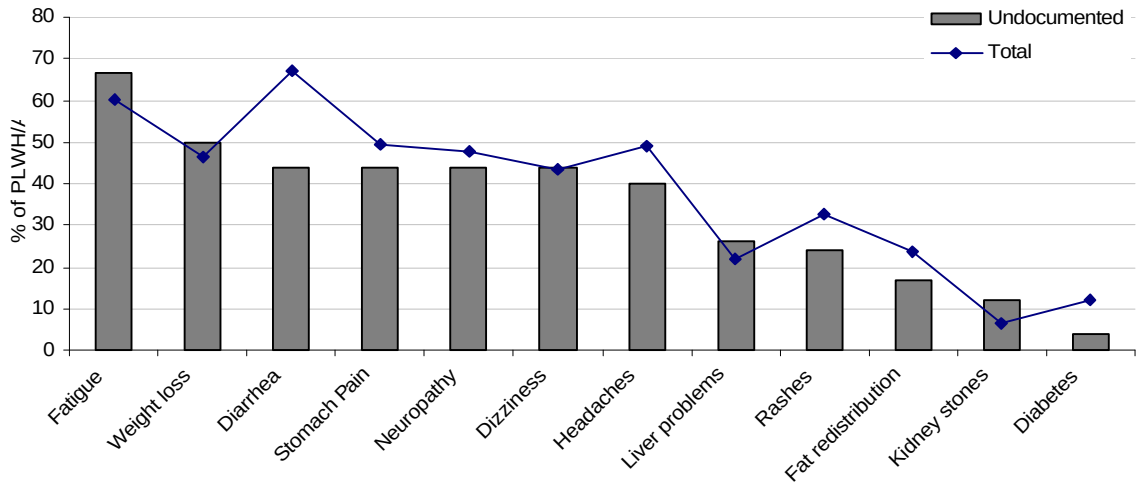
Figure 4-2 Reasons for Stopping Meds



Side Effects

For the most part, undocumented participants report less side effects that the total sample of participants, with the exception of liver problems, kidney stones, and fatigue. Fatigue (67%), weight loss (50%), stomach pain, neuropathy, dizziness and diarrhea (44%) are the most common side effects reported by undocumented participants.

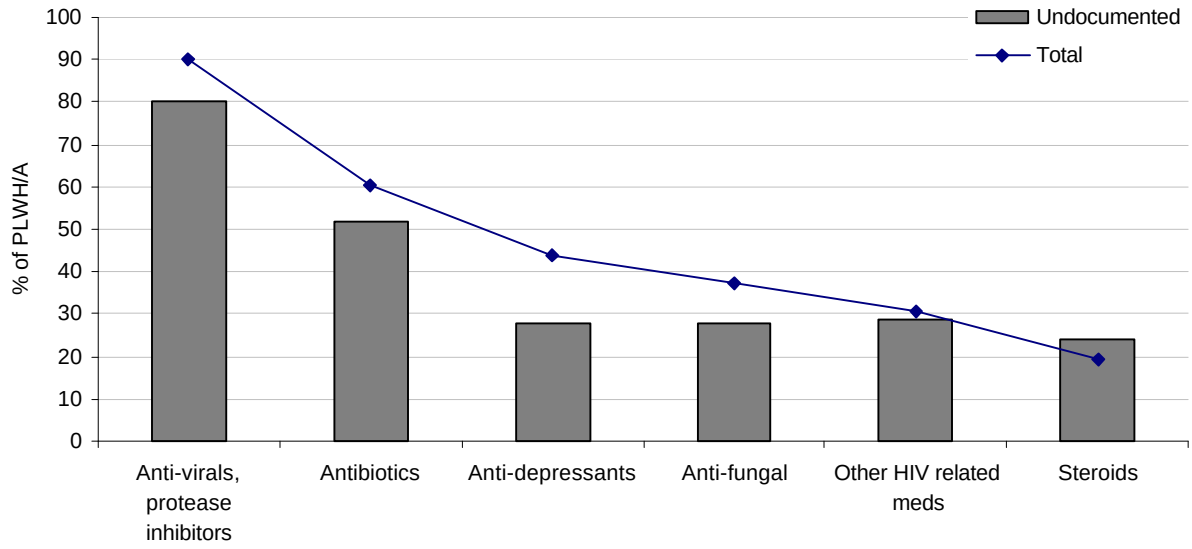
Figure 4-3 Side Effects



Less than two thirds of the undocumented PLWH/A (65%) report taking more than one anti-viral or protease inhibitor compared to 85% of the total sample. For those taking medication, as shown in Figure 4-4, eighty (80%) take anti-virals and/or protease inhibitors.

Antibiotics are the next most commonly taken medication (52%), followed by anti-depressants (28%) and anti fungal medications (28%). As seen in Figure 4-4, there is a difference in the reported use of HIV medications between the undocumented and the total sample, with the total sample more likely to take medication.

Figure 4-4 Medication Taken by Undocumented PLWH/A



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 undocumented participants said they were asymptomatic, about 45% said they have symptoms.

While more than 60% of the asymptomatic undocumented participants report excellent (19%) or good (44%) physical health, asymptomatic participants in the overall sample appear to do even better. More than a quarter of the asymptomatic participants in the total sample report excellent physical health and an additional 50% report good health.

Among the undocumented persons with AIDS, 27% say their health is good compared to 35% of the total sample who say their health is good and 12% who say their health is excellent. Nonetheless, persons with AIDS, both undocumented participants and participants in the overall sample, report better health than those who are HIV positive with symptoms. Less than 15% of the undocumented who are symptomatic or diagnosed with AIDS report being in poor physical health compared to less than 12% in the total sample. . The majority of the undocumented and participants in the overall sample who are symptomatic or living with AIDS report that their health is "fair", with more than one quarter of the undocumented living with AIDS reporting "good" health and more than one third of the total sample reporting good or excellent health.

About 27% of the undocumented living with AIDS say their physical health status has improved compared to 44% of the total sample. HIV positive persons with symptoms are more likely to say that their health is worse than asymptomatic persons living with HIV or those diagnosed with AIDS.

Figure 5-2 reports the current perceived change in emotional health. About 14% of the symptomatic undocumented and about 18% of those living with AIDS report poor emotional health. Similar to participants in the overall sample, more than 50% of asymptomatic undocumented participants report that their emotional health is very good or excellent.

While 38% of the undocumented asymptomatic participants say their emotional health has improved, only 18% of the undocumented participants diagnosed with AIDS, and 14% of those who are symptomatic, say their emotional health has improved. This is in contrast to over 46% of the asymptomatic participants from the total sample, 40% of those diagnosed with AIDS and 33% of the HIV symptomatic participants in the total sample who say their emotional health has improved.

Overall, the perceived physical and emotional health status of the undocumented PLWH/A is notably lower than that reported by the total sample of participants.

Figure 5-1 Quality of Life – Current Physical Health

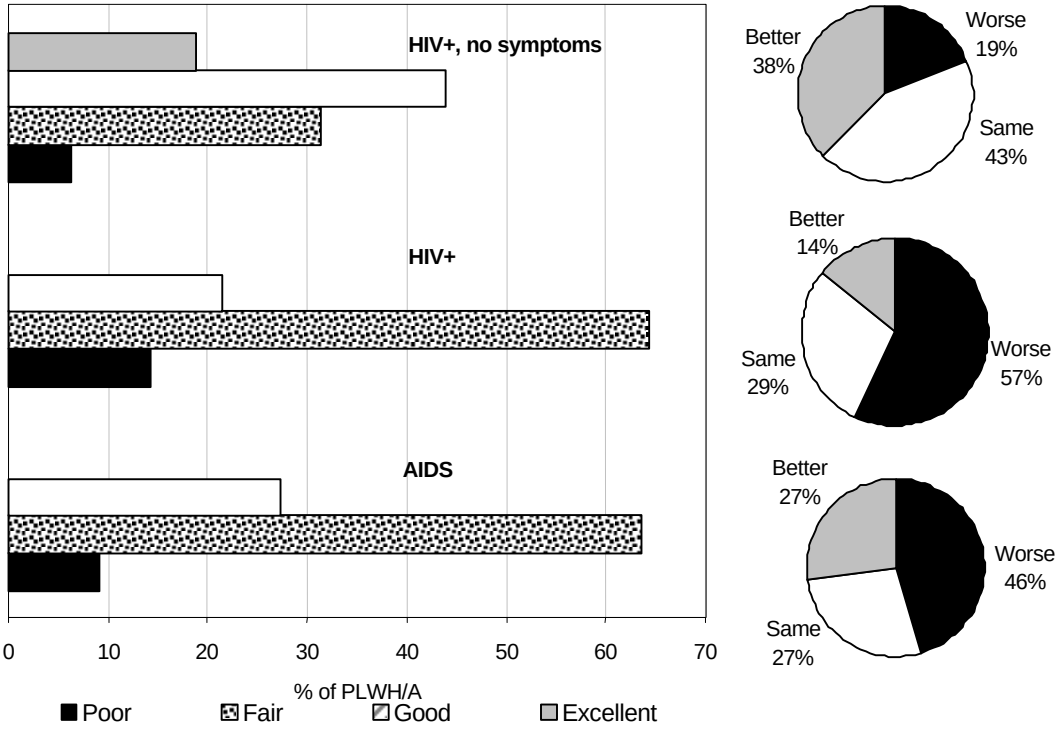
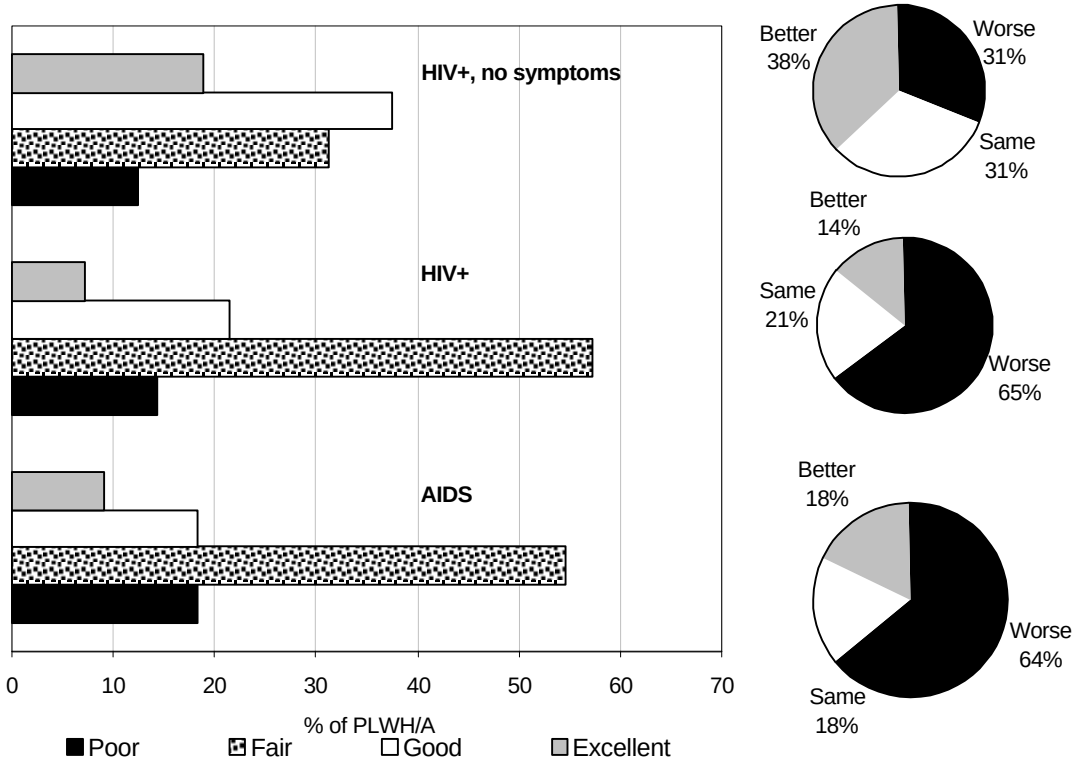


Figure 5-2 Quality of Life – Current Emotional Health



6 SERVICES

Dimensions of Service Need:

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

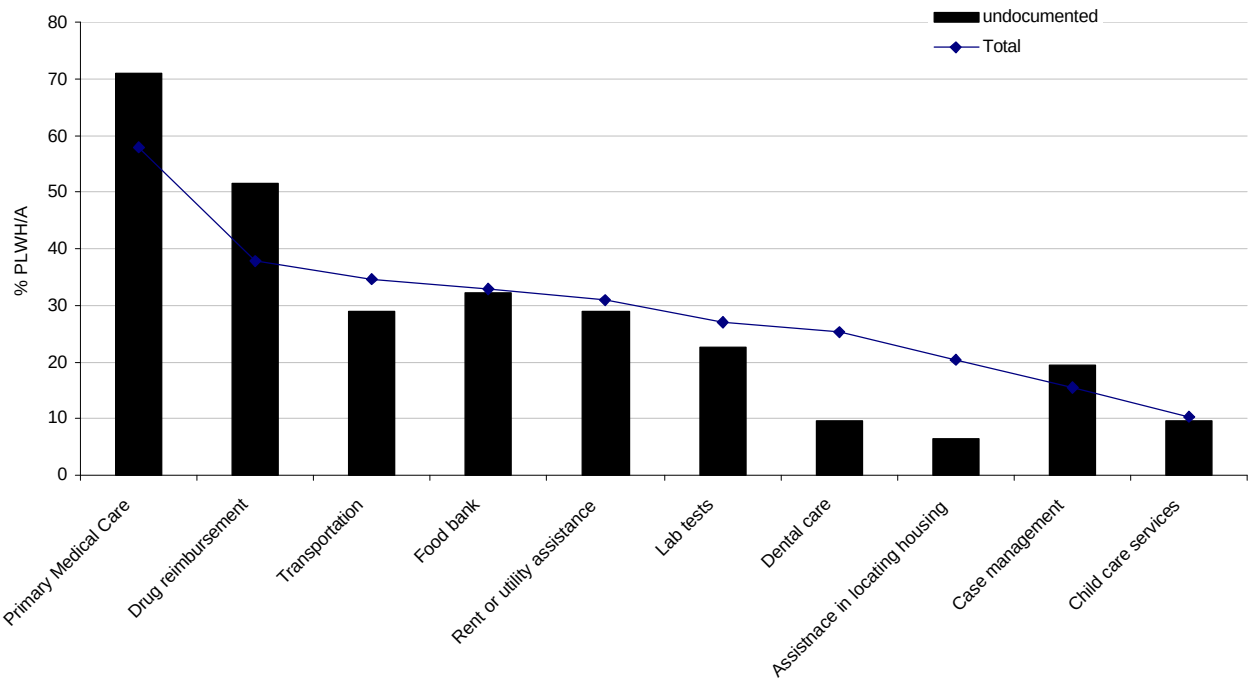
1. The service that was perceived to be most important (each participant ranked the top four services in rank order).
2. Knowledge of the service (Is this service available to you?)
3. Demand for the service (Have you ever asked for this service?)
4. Utilization of the service "ever" and the number of 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 undocumented participants.

Most Needed Services

Participants of the survey were asked to list the four services that “you need the most”. "Top needs" refers to the top four services ranked most important by PLWH/A. Based on this analysis, the rankings of the ten most important services are shown in Attachment 5 and graphically in Figure 6-1. Figure 6-1 shows the top 10 needs for the undocumented. Due to an unrepresentative sample and relatively small sample size of 31, caution should be taken when interpreting the figures. The figure indicates that the undocumented have generally the same pattern of top needs as the total population with slightly ratings higher for out-patient care and drug reimbursement. Undocumented participants tend to have the same or lower rankings than the general population for their other top needs.

Figure 6-1 Top 10 Needs of Undocumented



Medical Services

As found across all populations, outpatient care is the greatest need, with drug reimbursement coming in second. Notably, undocumented participants' need for primary medical care and drug reimbursement is 14% higher than the total sample of participants.

P126, an undocumented male, shared his experience with trying to access medical care. "*After going to [a local AIDS specialty clinic], I was given an appointment for one month. I was told that if I had an emergency to go to the emergency room. I was only taking antibiotics for the pneumonia and the mouth infection, I hadn't started taking medicine to help with AIDS. After one week, I went to the emergency room. They (the people at the hospital) were upset at why [local AIDS specialty clinic] had given me an appointment for one month later instead of treating the problem, especially since they knew the same stuff that the hospital did.*"

<u>Drug Reimbursement FG Comments</u>

Interestingly, while undocumented participants are among the highest recipients of drug reimbursement services, they report among the lowest levels of access. Comments from the focus group added greater insight. For instance, while medication is available to undocumented, it is not anonymous, and that poses a problem. As P126, a male undocumented Hispanic noted, "*Since many of us that are here are not legal, I believe that aid for payment of medication [should be available] whether you are legal or not. I think that if they take away the assistance*

of Medicare or Medicaid or Goldcard that it is going to be very bad... You don't need to be legal to have a Goldcard, but you do need an ID, and just recently in Texas you could get an ID but now you can't if you are illegal."

Basic Services - Food, Rent and Utilities, and Housing

While food bank and rent and utility assistance ranked fourth and fifth overall, they increase in importance among the undocumented participants and move to the third and fourth need. These top ranked services that provide basic needs indicate the growing numbers of PLWH/A who are living longer, but are in or near poverty. For undocumented individuals, who do not receive food stamps, SSI or other supplementary benefits, the need for food and housing assistance are further exacerbated.

P131, an undocumented male, described his situation as follows, *"I don't work now. I don't receive help from the State, I only receive help from [local ASO]. The company I worked for didn't insure me but was going to pay me $200 per week but in the end I didn't receive any help from the company (difficult to understand) I talked to some lawyers (at some agency), but they said they couldn't help me."*

Transportation

Reflecting a need to get to services, transportation is ranked third overall, but drops to fifth among the undocumented. Similar to other participants from other groups, the undocumented participants are well aware of the transportation services available, including scheduled rides through the local transportation provider or use of bus passes.

<u>Transportation FG Comments</u>

P126, an undocumented male, described his experience trying to access services from the local transportation provider. *"I use the Metro bus pass, but I also tried to use the [transportation provider] services, specifically for this meeting, but they never came. When I was giving them my information, I asked them if I needed to confirm and they said that it wasn't necessary and they gave me a number. I waited for them and then I called them and they said that I wasn't in their files so they could not set-up for someone to pick me up."*

Lab Tests

Similar to participants from the overall sample, undocumented participants considered lab test important in their HIV care and rank lab tests as the sixth most important need.

Case Management

Case management usually has an overall rank of ninth, but moves up to 7th among the undocumented participants. For these participants, case managers not only serve as their

interpreters of the English language but also as interpreters of rules and regulations regarding eligibility.

Case Management FG Comments

P130, an undocumented male, discussed his need for a case manger as follows, "*They asked me if I needed a case manager and I said yes because I don't read much so I don't have sufficient information. They told me that a case manager is for people that recently have found out and need the help, it is not long term. So I'm without a case manager, though I think I need one. Like for getting things like the Goldcard, sometimes you don't have the time to get everything you need and it helps to have a case manager to assist in cases like those."*

P126, also an undocumented male, added, "*Since in some places the services differ, it is important to have a case manager not only in the beginning but throughout because they are always informed on the various services offered and the changes that occur."* He added, "*I would like to know how to better navigate myself so that I could make it around like to the different clinics and agencies."*

Dental care

Dental care, ranked as the 8th most important, is a valued service among PLWH/A who find that their existing income levels limit their ability to find dental services elsewhere. It clearly adds to overall health and quality of life of PLWH/A. It is a service that is perceived to be open to all PLWH/A, including the undocumented.

Dental care FG Comments

As P129, an undocumented Hispanic female noted, *"I have dental assistance and am very happy with it. [A local multi-service organization] refers me to dental and optometry clinics where I receive great care. I go to [dental care provider] for dental."*

Mental Health

Mental health therapy is not consistently among the top 10 service needs for all populations, but for the undocumented participants it is tied for the 8th important need with dental care, health insurance assistance, obtaining supportive housing, and newsletters. During focus group discussions, participants often discussed their sense of isolation and loneliness being away from their county and in many cases their families. The fear of being rejected, stigmatized and the lack of information concerning their HIV status made their stay in the US more difficult.

Mental Health Services FG Comments

P131, an undocumented male, explained why he has chosen not to tell his family, "*I'm afraid that if I told my family that they would not trust in me anymore."*

P126, also an undocumented male, added, *"The mentality of people of Latino background is very different from that of American culture, so that is why I have only told some members of my close family and I don't plan on telling others from my distant family. Concerning the rest of society, I don't really care much about what people think."*

P128, an undocumented MSM, discussed his experience when he first found out he was positive. *"I had some symptoms so I went to have some tests done. I was told I was positive. I was really depressed. I was afraid that my partner would reject me, especially because he was my only support that I had, the person I could count on and I didn't want to go to Mexico (to my family) so that they would pity me. I was depressed, but I went on. [Harris County funded hospital] referred me to [HIV/AIDS specialty clinic]. My first appointment was with a psychologist. When they asked me how I felt, I responded by saying "I was entering an unknown world, I felt bad, I felt like no one…. I thought about committing suicide. " I was then referred to [Latino multi-service organization]. I was taking medication."*

P129, an undocumented female, also discussed her depression. *"When I found out all I wanted was to die… I didn't take my medicines or go to the clinic…I got very depressed. I just wanted to die. …If I'm going to have that disease, I just want to die… that disease. No one helped me to be strong. God did."*

Health Insurance Assistance

While less than 10% of PLWH/A say that assistance paying health insurance is among their top ranked service, it emerges among the top ten needs for the undocumented. With less than 13% of the undocumented participants having any form of health insurance, assistance obtaining or paying for health insurance premiums is a great concern.

Assistance Finding Supportive Housing

Close to 10% of the undocumented PLWH/A say that assistance in finding supportive housing is among their top needs. Although more than half of the undocumented participants are unaware of the availability of supportive housing, during focus group discussions a married couple spoke of their success in accessing this service. *"We live in community housing provided by [local CBO]. We qualified for two years, so we have one year left and after, if we still qualify, they will continue to assist us but at a different housing community."*

Newsletters and Information

Newsletters and information are also mentioned by about 10% of the undocumented PLWH/A and appear as one of the top ten needs. Focus group participants from the undocumented group discuss their reliance on oral and written materials for information on various topics including health and immigration matters. As in other focus groups, undocumented participants mentioned having to do their own information gathering because they were not getting enough information from the agencies.

P126, an undocumented male, described how he gets his information about visas and living in the United States as follows, *"I get my information from the news and pamphlets. There are VISA lotteries for people from countries like Mexico and Guatemala, where if selected can apply for a VISA but those that aren't are deported. In [local CBO], I found a book (New York Life) about how one can live here… it gives information…I get information on my own, it was not given to me by an agency."*

Service Awareness, Demand and Utilization

Service awareness, demand, and utilization are presented in Attachment 6 - Attachment 8. In looking at these attachments, the percentages across the different target groups can be compared. For example, in Attachment 6 under the column representing undocumented PLWH/A, 77% said they were not aware of assistance with health insurance premiums. This is in contrast to less than 60% of all the respondents who were unaware of this service. The table percentages can be read within the undocumented participants or compared to the total sample by reading across the rows.

As with the top needed services, a second way to read Attachment 6 is to compare the figures down the column. For example, 6.5% of undocumented participants are not aware that outpatient care is available to them in contrast to 32% that didn't know mental health therapy is available to them.

Attachment 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 different target populations, six special populations and people living with AIDS. They can also be compared down the column to see which services the undocumented participants seek.

Attachment 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 that the undocumented participants used a service over the past year can be compared to that used by the total sample by reading across the rows. The median number of times different services were used by the undocumented participants can be compared by reading down the columns.

Graphic Presentation of Awareness, Demand and Utilization

The graphs shown in the following sections plot the values for the top ten services asked for (level of demand) by undocumented participants. The first section discusses awareness, demand, and utilization. The following section discusses the perceived level of access and satisfaction with each of the services.

- Awareness refers to whether the PLWH/A is aware that the service is available to them, and this is shown as the solid line.

- Demand, shown as the black bar labeled "ask", refers to whether the PLWH/A ever asked for the service.
- Utilization refers to whether the PLWH/A ever "received" the service, and it is shown as the gray bar.

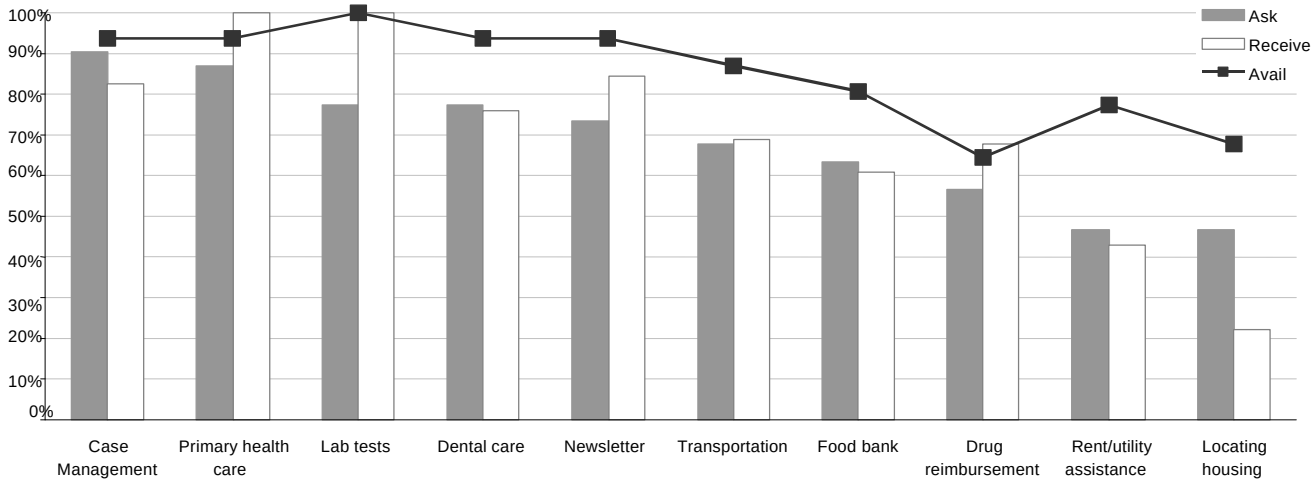
Figure 6-2 displays the awareness, demand and utilization of the top ten services. The services are ordered by the percentage of persons asking for or demanding the services. Demand and utilization follow the same pattern, with the largest percentage of PLWH/A being aware, asking for and receiving primary health care and lab tests.

Services Most Demanded and Utilized

Figure 6-2 shows that case management, primary health care, lab tests and dental care are sought and received by more than 75% of the undocumented participants. Awareness for these services is also among the highest, ranging from 93% to 100% of the undocumented being aware of the availability of these services.

As in the total sample, demand and utilization patterns are somewhat different than the top ranked needs identified by undocumented participants. While drug reimbursement and food bank services are among the top three needs, they drop to 7th and 8th, respectively, of the most sought out services. Dental care, on the other hand, with a rank of 8th tends to rank lower among the most important needs than the fourth rank it was given in relation to demand and utilization.

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



Awareness - Demand Gap

One gap measure is the difference between awareness and demand. The awareness-demand gap measure is calculated by taking the difference between the aggregate percentage of those aware of the service minus those demanding, or seeking the service. For example, while awareness for rent and utility assistance is relatively high (77%) for undocumented PLWH/A, demand and utilization drop to less than 47%. Among the top ten sought services, the awareness-demand gap

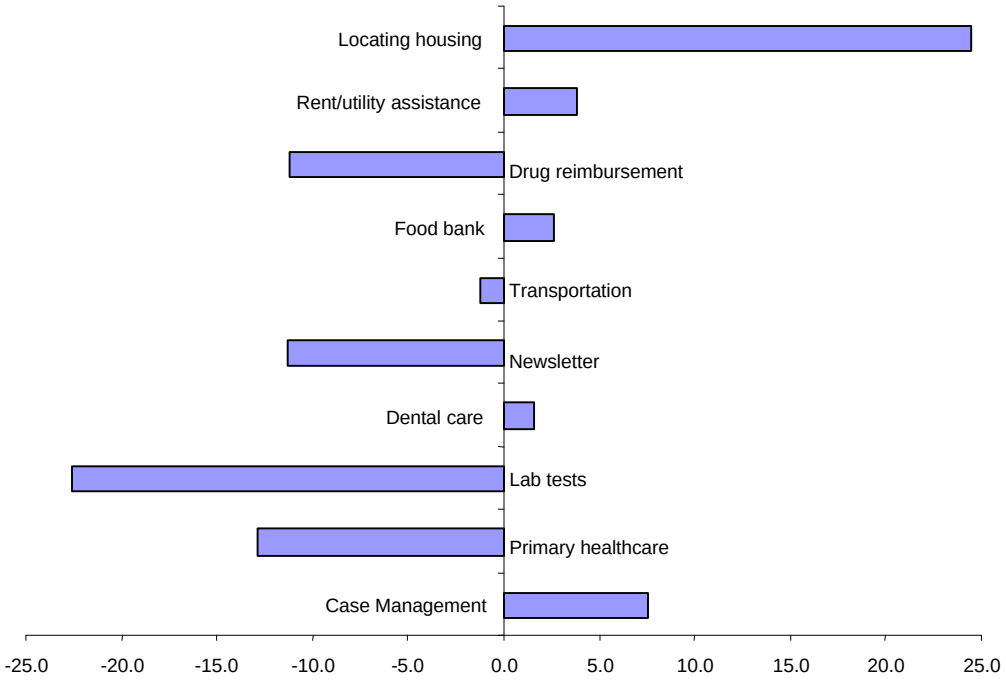
ranges from 3.2% for case management to over 30% for rent and utility assistance. The greatest differences between awareness and demand ranging from 38% to 48% difference are noted for home health care, nutrition counseling, hotline, residential substance abuse treatment, hospice care and peer counseling.

Demand - Utilization Gaps

Another gap measure involves the difference between demand and utilization. As noted above, demand and utilization usually follow the same pattern. However, a gap between what is asked for and what is received suggests an unmet perceived need. The demand-utilization gap measure is calculated by taking the difference between the aggregate percentage of those demanding services minus those who actually receive the service. In the total sample, the demand-utilization gap ranges from 0% to 18%. Among the undocumented this gap ranges from 0% to 36%. Interestingly, undocumented participants report receiving more than asked for of 15 out of the 33 services. Even among the top ten demanded services, five services are received more than they are asked for by undocumented participants. For instance, while undocumented PLWH/A identify the need for more information and identify newsletters among the top services sought, they report getting more newsletters than they actually seek. This may indicate the need for greater information and education about the services offered and their importance in HIV/AIDS care specifically tailored to meet the literacy and cultural needs of the undocumented participants.

Notably, utilization lags behind demand, with a gap greater than 10%, for assistance in locating housing, home delivered meals, peer counseling, and nutrition counseling. Among the services most demanded, the largest unmet demand, with a gap difference of 8%, is case management.

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



Service Satisfaction and Access

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

Attachment 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 the undocumented participants versus the total sample. Similar to awareness, demand and utilization, Attachment 10 consists of a table showing the satisfaction scores for the undocumented participants and the total sample.

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 undocumented participants or across the undocumented participants and the total sample.

Graphic Presentation of Satisfaction and Access

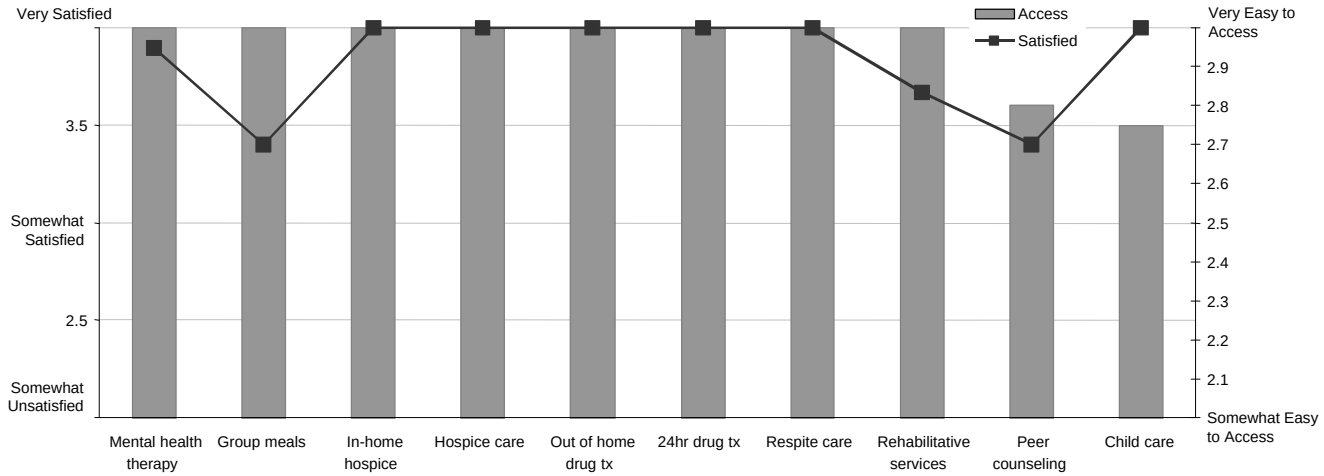
Figure 6-4 displays the perceived access and satisfaction with services for the top ten services, ranked by access, from high to low. In the chart, access is represented by the black bar, with the scale on the right side of the graph, and satisfaction is shown as the line with its scale on the left.

The reason for plotting access and satisfaction together was that they were thought to be related. As seen in the figure, they are related, but access is only one component of satisfaction. Both levels of access and satisfaction were rated high by undocumented PLWH/A, with levels of access ranging from 2.75 to 3.0 and satisfaction levels ranging from 3.4 (somewhat satisfied) to 4.0 (very satisfied). Notably, the undocumented PLWH/A tended to report higher satisfaction ratings than the overall sample for most services.

The services rated as easiest to access by undocumented PLWH/A tend to be the services less demanded or received. These include mental health, group meals, in-home hospice care, hospice care, outpatient substance abuse treatment, residential substance abuse treatment, respite care and rehabilitative services. Undocumented PLWH/A also report being very satisfied with these services.

Even among the services which the undocumented report as hardest to access, only one service, employment assistance, was considered hard to access with a satisfaction score of 1.5, less than somewhat satisfied.

Figure 6-4 Access and Satisfaction with Services - Top 10



Service Future Demand

Participants were asked to indicate whether they would need the thirty-two services previously discussed more, the same or less in the coming year. The anticipated need for each service is shown in the tables in Attachment 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.

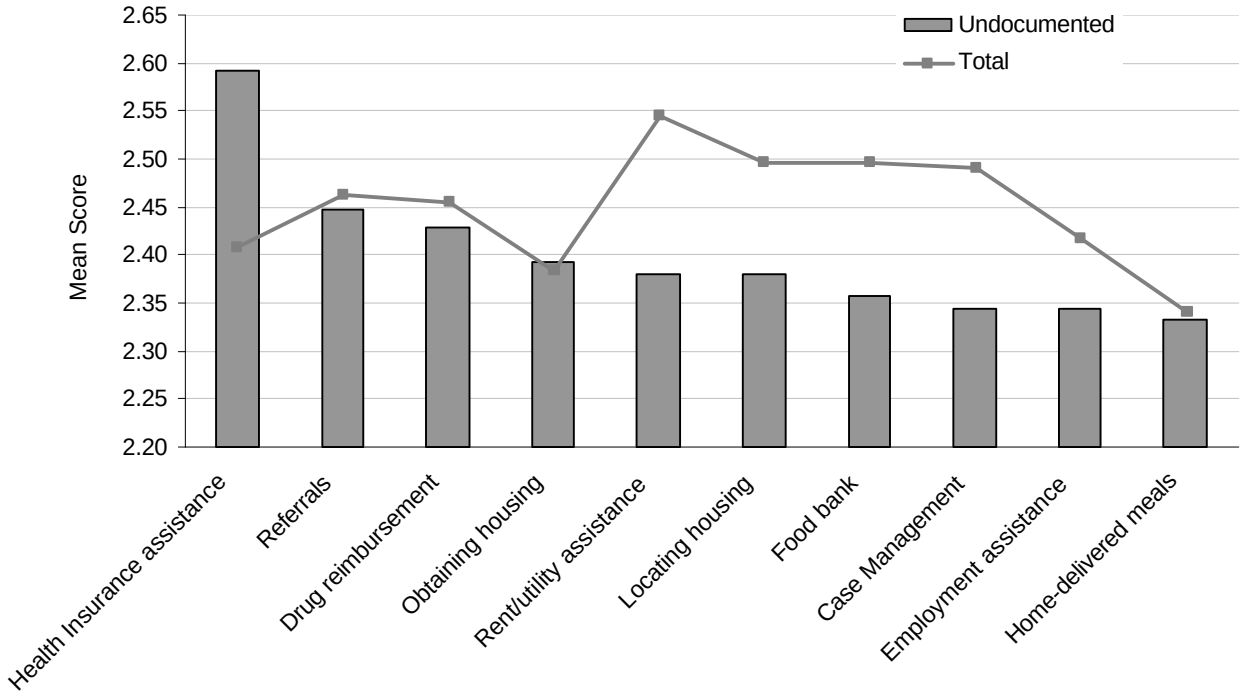
Graphic Display of Anticipated Need

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 of between "needing more" and "needing the same", indicating that, on average, the PLWH/A see an increasing need for services.

The top ten anticipated needed services differ from the top ten most important services previously reported. For the most part, while the most important services include primary care, lab tests and other health care services, the top ten anticipated services relate to services which are coordinated through case management services, including referrals, different forms of financial assistance and housing assistance. The number one anticipated need for undocumented participants is health insurance assistance.

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

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



7 BARRIERS

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

Overall PLWH/A Score for Barriers

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

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

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

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

The determination of the types of barriers was based on a statistical technique called factor analysis.[3] This technique indicates which barriers were most likely to be sorted into the same group by the PLWH/A survey participants. It is as though the PLWH/A were given a deck of cards with each barrier printed on it and asked to sort them into piles reflecting a common underlying theme.

When the ratings of all of the barriers are summed, none of the target groups or ethnic populations reported a big barrier. However, as shown in Attachment 13, the average barrier scores for undocumented PLWH/A (3.1) are somewhat higher than for the overall sample (2.6). This is surprising considering that undocumented participants tend to be the most satisfied and then to rate most services easy to access.

Figure 7-1 Average Barrier Scores for Undocumented PLWH/A – Top Ten

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

[3] A pairwise Pearsons correlation matrix was used as input. A varimax option was selected to better discriminate the factors.

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

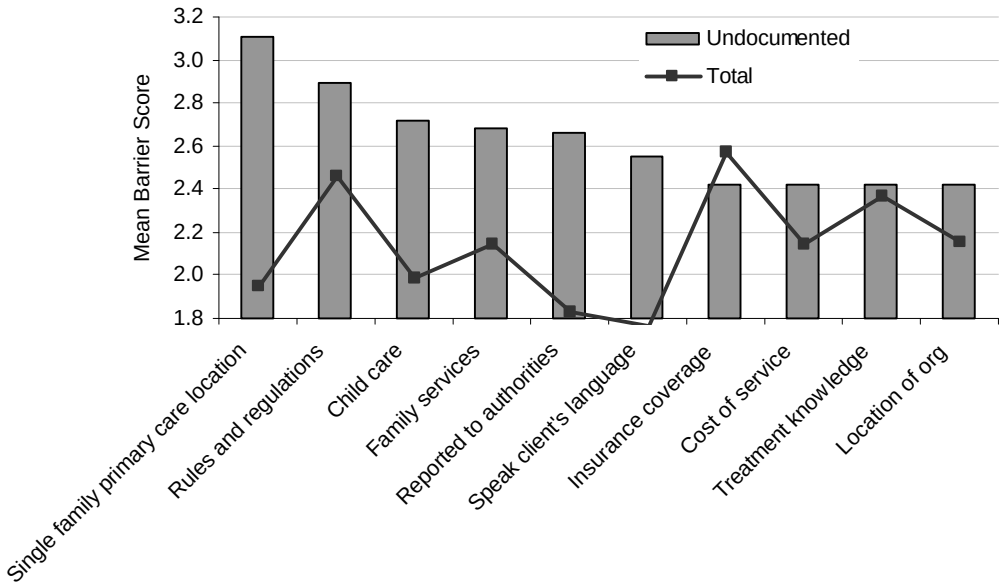


Figure 7-1 shows the top ten barriers for undocumented PLWH/A. Out of the top ten barriers identified by undocumented participants, five are organizational access barriers, three are structural barriers and two relate to the individual. The organizational access barriers include:

- There is no single location where my HIV+ children and I can go for primary care
- The lack of on site child care when I go to get my treatments
- The lack of services for my family
- The chance of being reported to the authorities
- The ability of the person providing services to speak to me in a language that I understand

Organizational Access Barriers

Family Services

The lack of family-oriented services represent the top three organizational barriers for the undocumented participants. This is in contrast to the relatively low ranks assigned by participants of the overall sample to these particular items. For instance, the number one barrier for undocumented participants is the 26th barrier for participants in the overall sample. Similarly, the lack of childcare, the third barrier for undocumented, and lack of services for families, the fourth barrier for undocumented, are the 25th and the 13th barrier for the overall sample, respectively.

Although the majority, 77%, of the undocumented do not live with their children, four out six of the focus group participants are parents, with two of the women having learned about their HIV status when they were pregnant. Also, the top three organizational barriers relate to the lack of

family or childcare services. This may suggest, that although the majority of the undocumented participants do not live with their children they may have children in their native land and are concerned about their well being. For instance, P127, an undocumented female, expressed her concern as follows, *"I'm worried about my children's future. I don't have papers to get medication."* She also described the importance of childcare services and the strategic scheduling that needs to take place when seeking care for herself and her husband. She said, "*We get our appointments made for the same time and in that way the kids can be taken care of by the academy of the agency."*

Reported to Authorities

The fifth barrier identified by undocumented participants is the chance of being reported to the authorities. Participants, however, have figured out ways to manage the fear and look for assistance. P129, an undocumented Mexican female, described how she deals with this fear, "*I'm not worried about obstacles that illegals confront because I can just leave, if you have God in your heart that is all that matters, if I die God will take care of me."*

This is the 28th ranked barrier by participants in the overall sample.

Language - Focus Group Comments

While the ability of the person providing services to speak the client's language is ranked as the 30th barrier among the overall sample, for undocumented participants, this represents the sixth barrier to care. For instance, there were some incidences reported in the focus groups where undocumented participants felt they were not getting the appropriate level of treatment due to a language barrier. P130, an undocumented Hispanic male said, *"Because P157 doesn't speak English they sometimes treat her poorly and speak to her in a rude way.* P129, an undocumented female also added, *"Sometimes the people are very rude and they also don't speak Spanish and there is not one there to translate making it very difficult to communicate. I feel bad because I can't speak the language and people may look down on you but what can you do."*

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

Structural Barriers

In Figure 7-1 the second, seventh and eighth highest barriers are structural. These barriers are more outside of the control of the provider and require changes at the regulatory or legislative level and include:

- Not being eligible to obtain services because of rules and regulation
- Not having enough insurance coverage
- The cost of the service to me

Rules and regulations are identified as the second barriers to care by undocumented PLWH/A. As previously mentioned, undocumented participants rely on case managers to help them interpret and navigate through these rules. Without a case manager these rules and regulations present a small to moderate barrier for undocumented participants. The lack of insurance and cost of service also present a small to moderate barrier.

For undocumented participants these three items are all interdependent. Not having a legal residency status in the United States, undocumented participants have limited access to government-funded programs and therefore the cost of services to them may be higher than for other groups. While some participants reported having a "Goldcard" they expressed concern about what happens once the card expires. For P128, an undocumented male, producing all the required documentation to qualify for benefits becomes a problem. For him, "*The only obstacles I have are proving financial need, residency, how one lives.*"

P130, who has been HIV positive since 1994, has learned how to get by and overcome some of the rules and regulations. He noted, "*I use to worry about proving financial income but not anymore because I now know how to fill out the applications.*"

Individual Barriers

The ninth and tenth barriers for undocumented participants relate to individually based concerns. These include "Not knowing what treatment is available to me" and the location of the organizations. These are also relatively high ranked barriers for participants in the overall sample, with lack of treatment knowledge being the sixth overall barrier and location of the organization being the 12th ranked barrier.

Knowledge of Treatment Information Focus Group Comments

Not being able to communicate with their provider and having little or no access to written information because of their own literacy level or lack of Spanish written materials, undocumented participants face a greater challenge in obtaining treatment information.
P126, a young undocumented male, who has been positive for two months, said he came to the United Sates from Mexico seeking better treatment and medical advice.

Location of Provider Focus Group Comments

For undocumented participants the location of the organizations is their tenth highest barrier to care. While they are aware of the transportation services and report one of the highest use of the transportation service, undocumented participants still find that the distances they have to travel to get to services represent a small to moderate barrier.

8 Summary of Undocumented PLWH/A Needs and Barriers

The undocumented participants were a specifically targeted group for this needs assessment. While the sample size is small and not generalizable to all undocumented PLWH/A in Houston, the findings in this report begin to highlight areas of need for a community which has been traditionally marginalized and underserved.

The undocumented participants in this needs assessment are mostly Latino, male and heterosexual. They are among one of the groups with the lowest annual income, lowest education level and one of the groups most likely to be employed in some capacity.

Focus group comments as well as findings from the survey reveal the importance of the family unit for this group. The family concerns range from emotional support from the family to support for the family, in the form of counseling, childcare and financial assistance.

Undocumented participants report the lowest use of combination therapy, yet, they report among the highest adherence to medications once prescribed.

Being away from their homeland, away from family and friends, and also being less likely to be on medication than members of any other subpopulation, undocumented participants report poorer emotional and physical health. The services and barriers listed below further highlight unmet needs of the undocumented PLWH/A.

Services

Table 8-1 provides a comparison of the top needs of the total sample versus the ratings given by the undocumented participants for most important needs, awareness, demand, utilization, satisfaction, perceived access and anticipated need of these top ten services. The number in the cell is the rank order of each service for each dimension. The top ten for each measure are shown in the table below, however, only the top ten most important services are discussed within the following text. Among the total sample, services beyond the top ten are shown with their respective ranks.

Table 8-1 Top Needs, Rank Order

	Total Sample	UNDOCUMENTED PLWH/A						
		Undocu-mented PLWH/A	Awareness	Demand	Utilization	Satisfaction	Access	Future Need
Primary Medical Care	1	1	2	2	2	23	24	17
Drug reimbursement	2	2	12	8	7	14	25	3
Transportation	3	4	6	6	6	27	26	29
Food bank	4	3	7	7	8	17	27	7
Rent or utility assistance	5	5	8	9	9	24	29	6
Lab tests	6	6	1	3	1	21	21	26
Dental care	7	8	5	4	5	20	18	11
Assistance in locating housing	8	14	11	10	14	9	28	5
Case management	9	7	4	1	4	19	17	8
Mental health therapy	10	9	10	11	10	8	1	15
Health Insurance assistance	11	10	32	17	25	2	19	1

The overall messages are:

- The top ten needs identified by the overall sample are similar to those identified by the undocumented, with slight differences in rank. These are also similar to the services most sought out by the undocumented participants.
- Undocumented participants rate the highest levels of access and satisfaction with services with very little variation from service to service.
- The anticipated needs reported by undocumented participants differ from the top ten services and the most demanded services. This may indicate the anticipated growing need for services which undocumented participants are currently not receiving. The lower anticipated need rankings of the top ten needs may suggest that undocumented participants don't expect to have an increased need for those services, simply to maintain the current need.

– Primary medical care is the top need overall and also ranked as the top need by undocumented participants. While primary care is the second service in terms of awareness, demand and utilization, it drops below 20 in both perceived level of access and satisfaction. Primary care is the 17th ranked anticipated need for undocumented participants.

– Drug reimbursement, the second most important service among the overall sample, is also the second highest service and third anticipated need for undocumented participants. While demand and utilization remain among the top ten, awareness, access and satisfaction drop below the top ten. Again, it most be noted that the reported levels of access and satisfaction for undocumented is very high and therefore an access rank of 25 may still represent a higher score than the overall average.

– Similar to the participants from the overall sample who rank transportation as the third most important service, undocumented participants consider transportation the fourth most important service. Transportation is among the top ten services which

undocumented know about, seek and use. However, undocumented participants rate levels of access and satisfaction with transportation relatively lower than other services. The anticipated need for transportation is also relatively lower than other services.

– The food bank, fourth among the overall sample, is ranked as the third most important service, behind medical care and drug reimbursement. It is also among the top ten anticipated needs.

Barriers

Overall, while none of the groups report "big barriers", undocumented participants identify moderate barriers to care and are the group to report the highest barriers. The highest barrier score for undocumented participants is 3.1 compared to a high total score of 2.2.

Table 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. A "+" beside the number means that the score is greater than the average score.

Table 8-2 Top Ten Barriers - Total vs. Undocumented PLWH/A

	Total Sample	Undocumented PLWH/A
Red tape	1	17
Insurance coverage	2	7
Wait for appt	3	18
Rules and regulations	4	2+
Transportation	5	24
Treatment knowledge [1]	6	9+
Navigate through system	7	15+
Feel like number	8	26
Poor coordination amongst organizations	9	23
Lack of sensitivity	10	21
Location of organization	12	10+
Family services	13	4+
Child care	24	3+
Single family primary care location	26	1+
Reported to authorities	28	5+
Cost of service	14	8+
Speak client's language	30	6+

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

In terms of barriers, the overall messages are:

- The top ten barriers for the total sample are quite different than the barriers for the undocumented participants.

- While some barriers identified by the overall sample drop in rank among the undocumented participants, for many of the barriers the average score is still higher among the undocumented.
- Three out of ten top barriers relate to family-oriented services.
- Fear of being reported to the authorities and language are specific to undocumented participants, and among the top ten barriers identified by this group.
- The three structural barriers of rules and regulations, lack of insurance and cost are among the top ten barriers for the undocumented.
- Similar to participants in the overall sample, lack of treatment information is the number individual barriers for undocumented participants.
- The second individual barrier for undocumented participants is the location of the organizations are their ability to get to those places. While this was the 12th barrier among the overall sample, undocumented participants felt that this was one of the top ten barriers.

9 ATTACHMENTS

Attachment 1 Focus Group Outline

Attachment 2 PLWH/A Survey

Attachment 3 Undocumented 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 Undocumented PLWH/A Barrier