# Report on the Needs Assessment in Communities of Color

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# Executive Summary

## Introduction

In the fall of 2000, the Houston Ryan White Planning Council conducted a needs assessment to better understand and address disparities being observed in access to HIV care by people of color. Information from the needs assessment was designed to identify barriers and gaps, as well as to prioritize primary care, medications and complementary therapies from the viewpoint of people of color living with HIV/AIDS.

## Methods

Sources of data comprised interviews in November 2000 with 20 agency Executive Directors who had special knowledge and experience regarding people of color, 7 focus groups in December 2000, and 458 client surveys assessed between December 2000 and February 2001. People of color, especially those not accessing primary care, were over sampled.

## Definition

Primary medical care was defined as: "a visit to a nurse, doctor or assistant, to monitor or treat HIV infection in a clinic". PLWH/As were considered "out of care", if they were not getting regular medical care; or if their infection was not being followed up by a doctor or in a clinic.

## Epidemiology

The AIDS epidemic continues to evolve, making new inroads in vulnerable populations. People of color, particularly African Americans are disproportionately at risk. Trends in both gender and exposure are strongly related to the growing impact HIV/AIDS has on the EMAs African American community. The number of AIDS cases diagnosed each year, over the last 2 years shows African Americans, especially the African American women, representing an increasing proportion of the total. It is estimated that African American women account for 76% of new HIV infections among women. By contrast, the impact on Whites and Hispanics has slowed. Basic HIV/AIDS statistics is shown below for Houston/Harris County. A breakdown of these cases by age, sex, and transmission mode, in relation to Hispanics and African Americans, is shown in tables and figures in Section III – Epidemiology Profile.

Cumulative AIDS cases in 6-County Houston EMA through 12/31/00 = 19,263
Cumulative AIDS cases in Harris County reported through 3/31/01 = 18,740
AIDS Cases Alive: PLWA is 42% of Total = 8,084 thru 12/31/00; and 7,778 thru 3/31/01
HIV Disease Prevalence through 12/31/00 = 10,377*
Estimated number of HIV infected in 2001 = 16,127 - 22,439
Total Reported HIV Cases from 1/1/99 through 3/31/01 = 3293
New AIDS cases reported in 2000 = 566: (318 African Americans, 118 Hispanics 130 Whites)
New HIV cases reported in 2000 = 1754: (969 African Americans, 286 Hispanics, 493 Whites)

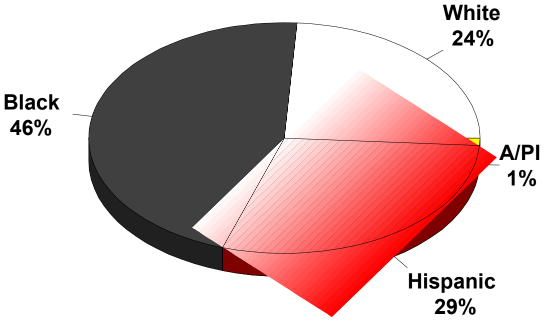
*Source: HIV/AIDS Surveillance Section -- TX Dept. of Health & Houston DHHS*

** See Epi Profile*

Changes in the gender ratio of HIV/AIDS are reflective of changes in modes of exposure. Early in the epidemic, HIV/AIDS was chiefly transmitted through men having sex with men (MSM), followed by injecting drug use (IDU). Infections attributed to these categories, has declined proportionally as exposure through heterosexual sex increases.

## Eligible clients in care vs. not in care

No one knows the specific number of clients not in care in the Houston EMA, however extrapolating from the results of this study of African Americans and Hispanics living in Houston, it was estimated that 64% who know their HIV status are not receiving primary care. The special populations affected comprise ethnic minorities, immigrants, women, youths, gays and WSWs, the homeless, substance abusers and those with mental illness. Various barriers are responsible for this unmet needed. The 2000-2001 service utilization report shows that of 72,841 units of service provided to clients served by Ryan White Title I funded agencies, 46% went to African Americans, 29% to Hispanics and 24% to Whites as shown in below. In comparison with the profile of HIV reporting, 57% of those diagnosed with HIV are African American, 17% are Hispanic and 26% are White.



## Access to Care

In relation to this sample, the following affected access to health care:

- *Location of health services* – Twice as many respondents, preferred HIV medical care outside their neighborhoods, citing confidential reasons.
- *Type of residence* -- In recent past, homelessness was as high as 47%, while 27% had been incarcerated within the last 2 years.

## Introduction

In FY2000, the Ryan White Planning Council (Council) determined that it needed to undertake a Needs Assessment among Communities of Color (COC) in order to better understand and address disparities being observed in access to care -- especially within the African American and Hispanic/Latino communities. It was hoped that a COC Needs Assessment would help the Council in its planning processes to work toward the HRSA goal of "100% access to health care and 0% health disparities".

After a public Request for Proposals failed to elicit an adequate response, the Planning Council directed its Office of Support (OS) to conduct a "Needs Assessment in Communities of Color". Using the available funds, the OS was asked to define and describe service needs and gaps in services for people living with HIV disease in order to plan, establish priorities, and allocate resources within the Houston EMA. The Houston EMA refers to the following counties: Harris, Fort Bend, Liberty, Chambers, Montgomery, and Waller. At the recommendation of the OS, the Council determined to utilize both quantitative and qualitative methodologies, and to utilize secondary data sources wherever possible. All data from the Office of Support studies would be used to achieve the overall project goals:

**RWPC OVERALL PROJECT GOALS**

1) Prioritize fundable services from a consumer point-of-view, including those services found to be needed but not currently offered.
2) Determine funding allocations for those services based on money available within Title I, and information on other funding sources that pay for similar services.
3) Make programmatic recommendations on how to best meet the needs of clients within those services.
4) Help plan a comprehensive system of HIV/AIDS care.
5) Provide the supporting documentation for the annual Ryan White Title I competitive grant application.

The Needs Assessment sub-committee developed the following COC data goals:

**COC DATA GOALS**

1) **What, if any, PLWH/A among Communities of Color (including subgroups like "women", "MSM", "Incarcerated/Soon-to-be-Released", etc.), are underserved and unserved in relation to:**
    a) primary medical care, especially HIV care
    b) medications, especially HIV
    c) complimentary and/or alternative therapies

**When determining numbers and percentages that are underserved and unserved, the following will be used as the reference:**

- The total number of PLWH/A within that community or subgroup who are eligible for services as compared to those who are accessing those services; and/or

- The proportion of PLWH/A within that community or subgroup that are accessing those services as compared to the proportion of Caucasian PLWH/A (using total numbers and stratification based on SES, gender, and risk group).

2) **Among those who are underserved/unserved, what are the reasons for this:**
   a) from the PLWH/A perspective?
   b) from the service provider perspective?

3) **Among PLWH/A who have accessed care in the past, but are no longer accessing those services, why?**

4) **How many PLWH/A within Communities of Color are testing positive for HIV each year (as compared to Caucasians)? Of those:**
   a) How many are entering care? How long did it take for them to enter care from the point of diagnosis? And what made them decide to enter care?
   b) How many aren't entering care? Why aren't they entering care?
   c) What are the improvements that would increase the numbers of PLWH/A who enter care upon diagnosis?

5) **Looking at the current primary care system available to PLWH/A:**
   a) What are improvements that would increase utilization by African-Americans, Hispanics, and other Communities of Color? Especially related to:-
      - Ideal locations of primary medical care programs
      - Primary medical services that should be made available by the programs
      - Community-level and program specific strategies that should be used to engage and keep PLWH/A in care.

## Major Components of the COC Needs Assessment

**1. An updated epidemiological profile**, describing the current status of the epidemic in the service area, specifically the prevalence of HIV and AIDS among the defined sub-populations.

**2. An estimate of Title I eligible individuals** within the EMA compared to the number of clients who are actually accessing Title I services (those in-care vs. those out-of-care). This estimate should include the Medicaid-eligible and financially eligible HIV positive individuals living in the EMA.

**3. An assessment of service needs** among the *affected* populations that explores the perspectives of PLWH, service providers, and community representatives about service needs. There are very few and limited circumstances when *affected* (rather than infected) individuals are eligible for Title I services and these services are always centered around the HIV-infected individual. Therefore, the focus of the assessment is soliciting information from PLWH themselves. Differences between provider and client priorities will be stated and explained.

**4. An assessment of gaps in services** that brings together all of the quantitative and qualitative data on service needs, resources, and barriers to help set priorities and allocate resources.

**5. Recommendations** for the bridging of gaps and/or for the discontinuation of unneeded services. Service, funding and eligibility recommendations will be included in this section.

## Methodology

This needs assessment which was conducted in communities of color by the Ryan White Planning Council, utilized a variety of techniques to gather information from people not accessing primary care.

**As explained to clients, primary medical care was defined as: "a visit to a nurse, doctor or assistant, to monitor or treat HIV infection in a clinic". PLWH/As were considered "out of care", if they were not getting regular medical care; or if their infection was not being followed up by a doctor or in a clinic; or if they were not receiving any mental health service.**

The specific methodology consisted of obtaining data from three sources -- key informant interviews, focus groups and client surveys -- to prioritize primary care, medications, and complimentary therapies from the viewpoint of people of color living with HIV/AIDS.

After a public Request for Proposals failed to elicit an adequate response, informal bids were sought to develop instruments to gather both qualitative and quantitative data. Various investigators were contacted from the following local universities, but the search yielded no results.

In the end, the methodology plan and instruments were developed in-house while an informal bid from Sage Associates was approved to conduct focus groups. In addition, 350 community-based organizations were sought to administer surveys to PLWH/A from their outreach services. Five of these were approved as vendors to assess clients based on willingness, past experience and technical expertise.

## A. Key Informant Interviews

Twenty agency Executive Directors and other individuals who had special knowledge and experience regarding people of color were interviewed in November 2000. Such people gave suggestions regarding methods of assuring inclusion of all appropriate populations in the client focus groups and survey process.

The questions on the interview protocol took into account perceptions of existing gaps in the current provision of services in the community, and available options for dealing with those inactive clients who were still alive. It was important to determine who was not using HIV services, and find out the possible reasons. We sought to find out each agency head's opinion on how clients who were not being actively case managed, could be accessing medications. Finally, we tried to find out the agencies' plans to increase services in the near future.

Two groups of agency leaders were targeted -- Ryan White Title I-funded case management, outreach, food, housing and day care agencies: Also targeted were heads of local community based organizations (CBOs) and religious agencies, known to work directly with communities of color and specifically those working with individuals who are infected with HIV/AIDS. A special effort was made to include a couple of outreach agencies that dealt with MSMs of color. In addition, effort was made to target a pair of primary medical care providers (Title 1 funded outpatient clinics), who may have seen patients for the first visit before these clients went into "inactive status" (have not been seen in 1 or more years). A format of the protocol and a sample letter to agencies are presented in Attachment 1and Attachment 2. Several sources were used to provide information, including Executive Directors and informants from the following agencies:

- American Red Cross (ARC)
- Texas Department of Criminal Justice (TDCJ)
- Amigos Volunteers in Education and Services (AVES)
- Aids Foundation of Houston (AFH)
- Uplift House
- Houston Challenge
- Interfaith Care Partners
- AIDS Housing Coalition Houston, (AHCH)
- St. Hope Foundation
- Houston Area Community Service (HACS)
- Bering Omega Community Services
- The Assistance Fund
- Bread of Life
- African American WSW and Gay Association (AALGA)
- Motherland Inc.
- Donald R. Watkins Memorial Foundation
- Harris County Hospital District -- Thomas Street Clinic
- Northwoods AIDS Coalition
- The Houston Challenge Foundation
- Montrose Clinic

## B. Focus Groups

We contracted with Sage Associates to conduct seven focus groups during the month of December 2000. A total of 25 participants contributed information from their perspective. While not representative of the community, this information together with that from the survey, indicated the perception of PLWH/A. Furthermore, 3 non-HIV service agencies sent representation for an additional focus group to impart potential provider perspective. Attachment 3 depicts the flyer that was used to inform the public about these focus groups. A copy of the format of inquiry, based on open-ended questions, is presented in Attachment 4, with specific probes based on participants' responses. A full compilation report of the opinions and suggestions of these participants is presented in Section II of this document.

## C. Client Surveys

The client survey was developed under the direction of the Needs Assessment subgroup of the HIV Planning Committee. It was constructed to assess 588 PLWH/As, and elicit their views on HIV medical care, on medications and on alternative therapies. A total of 458 participants completed the surveys, making up 78% of the goal.

### Definition

The assessment of people living with HIV/AIDS in communities of color (COC) was primarily focused on those NOT currently accessing medical care. Primary medical care was defined as: “a visit to a nurse, doctor or assistant, to monitor or treat HIV infection in a clinic". PLWH/As were considered "out of care", if they were not getting regular medical care; or if their infection was not being followed up by a doctor or in a clinic; or if they were not receiving any mental health service.

### Sampling Frame

The sampling frame was constructed in such a way to match the basic proportion of surveillance HIV data. To achieve adequate participation of Hispanic PLWH/A in the Houston area, the survey was translated in its entirety into Spanish. Opting to over-sample females and Hispanic populations made it possible for subgroup analyses.

### Pilot testing

Prior to distribution, the survey was pilot tested among a diverse group of persons living with HIV.

### Approved Vendors

The following five vendors assessed client surveys.

- Amigos Volunteers in Education and Services (AVES), to assess Hispanic clients.
- Over the Hill, to assess African American Americans
- Reliable Comprehensive Care Services (RCCS), to assess African American Americans
- Motherland, to assess African and Caribbean immigrants

These vendors were responsible for compensating their interviewers to interview prospective clients. The interviewers consisted of outreach workers, linkage facilitators and support group coordinators. It was often necessary for an outreach worker to assist clients in completing the survey instrument as a result of the client's functional illiteracy or advancing illness.

### Incentive

Contracted agencies provided an incentive to the client.The interviewer first read out a consent page, which was the cover sheet of the survey. The interviewer then explained the purpose of the survey, and had the client verbally consent to continue with the survey (See Attachment 5 for confidentiality statement). The interviewer then extracted information to fill out a unique CPCDMS ID-code, based on the client's Names-DOB-Gender.

### Content

The content of the survey instrument covered 56 questions and spanned 7 pages. A sample is provided in Attachment 6. The survey questions blended themselves more readily to quantitative analyses and measured the following different dimensions:

- Basic demographics
- Access to care including insurance
- Interactions with family and others about care
- Drug use
- STDs, HIV/AIDS diagnoses and stage of infection
- Reasons for seeking and for not seeking care.
- Adherence to medical regimen
- Opinions regarding HIV medications
- Barriers to care

These open-ended questions within the survey provided an opportunity to obtain more "in-depth" information.

The surveys were administered between mid-December 2000 and February 28, 2001 to all segments of the affected community, specifically those not in care. The PLWH/A among communities of color included subgroups of men and women, minority ethnic groups, minority youths, those newly released from incarceration, MSMs and IDUs, all from different economic levels. Attachment 7 is an advertisement that was placed in the following newspapers and magazines, with appropriate Spanish translations where necessary -- *La Voz, La Subasta*, *The Defender*, *The Fort Bend Sun* and *USAfrica*.

# Section I: Analysis of Client Surveys

# TABLES

# FIGURES

# Analysis of Client Surveys

## A. Demographic Characteristics of the Sample

Table 1 shows the race, sex and age distribution of the 458 clients making up the COC sample.

1. Race/Ethnicity: With respect to race/ethnicity, the main focus was on African Americans and Hispanics, in the ratio of 3 to 2. African Americans represented 59% of the sample. There were a total of 183 clients who considered themselves of Hispanic/Latino origin. This comprised 40% of the entire sample.

**Table 1: Race, Sex and Age distribution of the COC Sample**

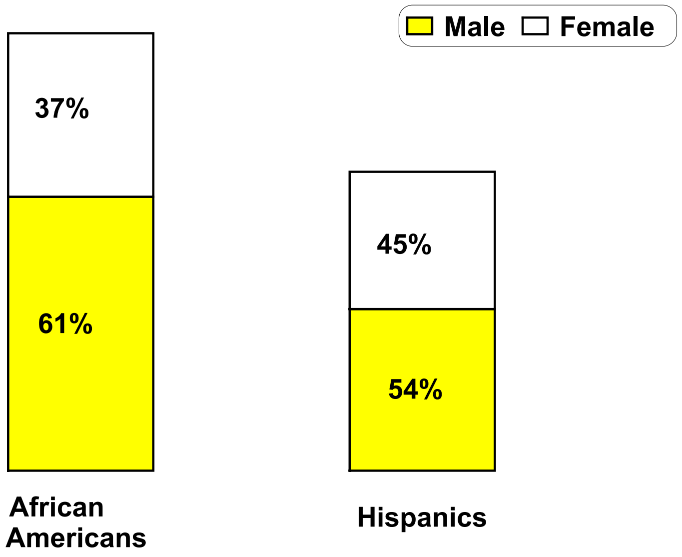
| | Hispanic | Non-Hispanic | Total | % |
|---|---|---|---|---|
| **Race** | | | | |
| **Native American** | 0 | 4 | 4 | **1%** |
| **African American** | 3 | 266 | 269 | **59%** |
| **White** | 179 | 0 | 179 | **39%** |
| **Asian/Pacific Islander /Hawaain** | 0 | 0 | 0 | **0%** |
| **Multi-racial** | 1 | 5 | 6 | **1%** |
| **Sex** | | | | |
| **Female** | 82 | 100 | 182 | **40%** |
| **Male** | 98 | 171 | 269 | **59%** |
| **Transgender** | 2 | 4 | 6 | **1%** |
| **Missing** | 1 | 0 | 1 | **0%** |
| **Age Group (Yrs)** | | | | |
| **13 - 24** | 19 | 21 | 40 | **8%** |
| **25 - 44** | 155 | 166 | 321 | **70%** |
| **45+** | 9 | 88 | 97 | **21%** |
| **Total** | 183 | 275 | 458 | **100%** |
| **%** | 40% | 60% | 100% | |

The proportion of African Americans in this sample closely reflected the EMA's cumulative HIV cases (58%) reported from 1/1/00 to 12/31/00. But because of deliberate over-sampling of Hispanic clients, the proportion of all Hispanics in the COC sample (40%) was significantly higher than that for Hispanic HIV cases, reported cumulatively as 14.9% for the whole EMA.

There were 6 multi-racial clients -- two African American-Native Americans, a White-Native American, a African American (Spanish-speaking) Puerto Rican, a African American Frenchman and a non-Hispanic, non-specified mixed race client.

The Hispanic group consisted of 54% men and 45% women as shown in Figure 1. On the other hand, the ratio of African American men to women was 3 to 2.

**Figure 1: Breakdown by Gender of the African Americans and Hispanics in the**

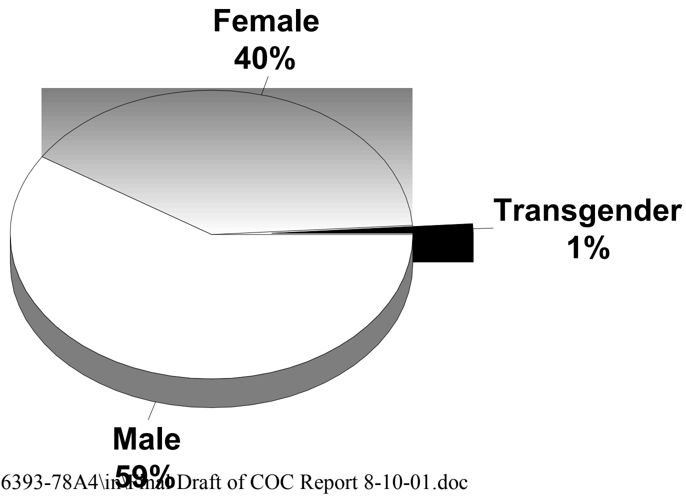


**Sample (N=458)**

## 2. Gender

Overall, females made up 40% of the respondents, and males 59% (Figure 2). There were 6 clients who were transgender (MTF). The proportion of males to females in the sample closely reflected the EMA's cumulative HIV reported cases from 1/1/00 to 12/31/00.

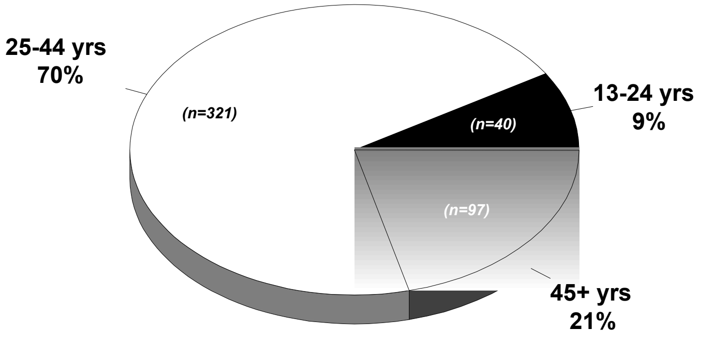
**Figure 2: Gender of 458 Respondents**



## 3. Age

Respondents' ages ranged from 14 years to 70 years, with a median age of 37 years. As expected, the majority of clients (70%), were between the ages 25 and 44 years (See Figure 3). An African American girl, who had recently been diagnosed with HIV, was the only teenager in the sample. Including her, there were 40 youths within the 13-24 year age group. This proportion, which amounted to 16%, was significantly lower than the 25% expected from the cumulative HIV youth cases within the EMA.

**Figure 3: Age of 458 Respondents**



## 4. Type of Residence

Ninety-nine percent of the respondents resided in Harris County, specifically in Houston. There were two clients from Fort Bend County and one from Liberty. The current abode for the majority of clients (71%) was in an apartment or house. Table 2 shows different profiles of living arrangements of respondents, comparing their current abode with other types of residence over the past 2 years. Although 2 clients said they were living in a correctional facility as of now, as much as 27% had been in jail within the last 2 years. Also, homelessness in the recent past was as high as 47%. But currently, less than 7% were on the streets, living in cars or in a homeless shelter.

**Table 2: Type of Residence -- Current vs. the Past 2 years.**

| Abode | Where do you currently live? | Over the past 2 years, have you **ever** been: |
|---|---|---|
| Live in an apartment/house | 71% | -- |
| Jail/Correctional facility | 0.4% | 27% |
| Homeless – on street/In car | 3% | 28% |
| Homeless shelter | 4% | 19% |
| Halfway house | 16% | 20% |
| Drug treatment facility |  | 8% |

## 5. Sexual Orientation

Figure 4 depicts the sexual orientation of the respondents. In all, 57% stated that they were heterosexual, while as much as 15% reported being bisexual. About 25% were homosexual, consisting of MSM 19% and WSW 5%. Sexual identity was further broken down in Table 3 by gender and race. The heterosexual category was higher for females, (73%) as opposed to males (47%). By proportion, there were three times as many homosexual men as women (32% vs. 12%). From a racial/ethnic point of view, 56% of the African Americans were heterosexual, 24% were homosexual and 16% bisexual. No significant differences were observed in the breakdown for Hispanics: 56% reported being heterosexual, while 27% said they were homosexual.

**Figure 4: Sexual Orientation of 458 Respondents**

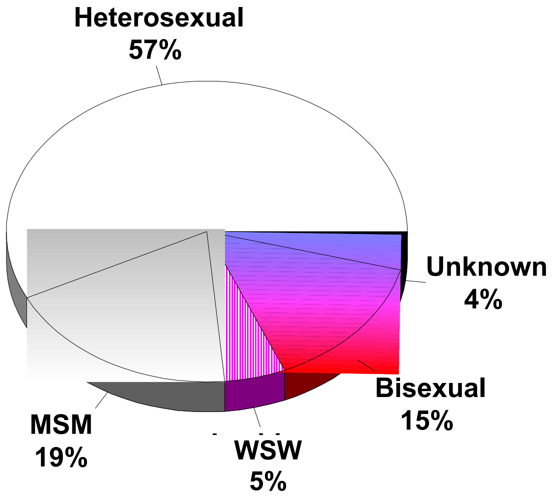


**Table 3: Sexual orientation -- by Gender and Race/Ethnicity**

| Sexual Orientation | Gender | | | Total<br>N (%) |
|---|---|---|---|---|
| | Male | Female | Transgender | |
| Straight/heterosexual | 47% | 73% | | 259 (57%) |
| Homosexual/gay/WSW | 32% | 12% | 83% | 114 (25%) |
| Bisexual | 16% | 13% | 17% | 67 (15%) |
| Unknown | 5% | 2% | | 18 ( 4%) |
| Total33 | 100% | 100% | 100% | 458 (100%) |

| | Racial Background | | | | Total |
|---|---|---|---|---|---|
| | Native American | African American | Hispanic | Multi-racial | |
| Straight/heterosexual | 50% | 56% | 56% | 100% | 259 (57%) |
| Homosexual/gay/WSW | 25% | 24% | 27% | | 114 (25%) |
| Bisexual | 0% | 16% | 13% | | 67 (15%) |
| Unknown | 25% | 4% | 3% | | 18 (14%) |
| Total | 100% | 100% | 100% | 100% | 458 (100%) |

### 6. Residency Status

The majority of respondents (70%) were American citizens. An additional 8% had a visa or legal refugee status. There were 84 undocumented clients, making up 18% of the respondents.

### 7. Marital Status

A little over half the respondents (57%) were single. An additional 27% were either divorced or separated. Less than 1% was widowed or had lost a partner.

## B. Socio-Economic Status (See Figure 5)

### 1. Education

Figure 5 shows the different levels of completed education for the sample. One-third (35%) had achieved a level less than high school, another one-third actually completed high school, while 7% had attended a technical/trade school. A total of 22% had some level of college education. Almost three times as many African Americans as Hispanics had some level of college education (31% vs. 11%)…..{not shown}.

### 2. Employment

In respect to current job situation, half the clients (53%), were not working, while 41% had either a full-time or part-time job. Five respondents claimed a work category of "other" – 3 were on disability, one was a student, while the last reported being a prostitute. Hispanics represent the group with a significantly higher employment rate: 61% of Hispanics had a job, as opposed to 36% of African Americans.

### 3. Income

Twenty-three percent claimed to have an annual household income of zero. As much as 78% was at an income no greater than 300% of the poverty level, See Figure 5. Only 10% had incomes greater than $60,000.

### 4. Insurance Status & Benefits Received

The next 2 figures (6 & 7) show the type of insurance and benefits that these PLWH received. Forty-four percent (44%) of the respondents had no health insurance (see Figure 6). About 14% received government insurance through Medicaid (Gold Card), 6% had Medicare, while another 9% stated they had private insurance.

Figure 5: Social Economic Status of 458 Respondents in COC Sample

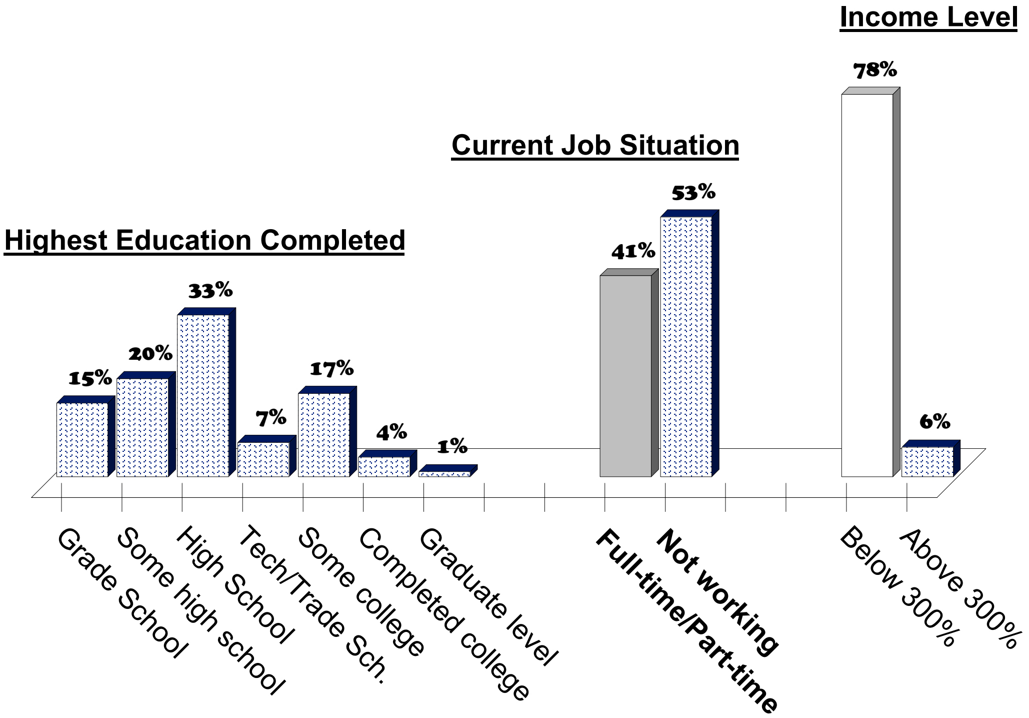
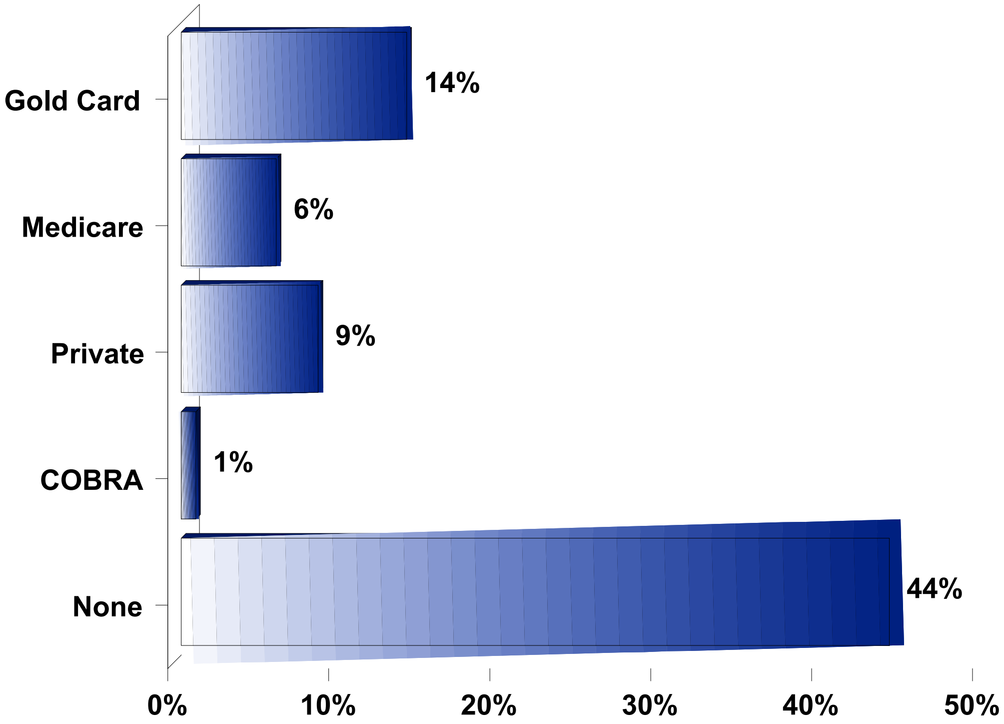
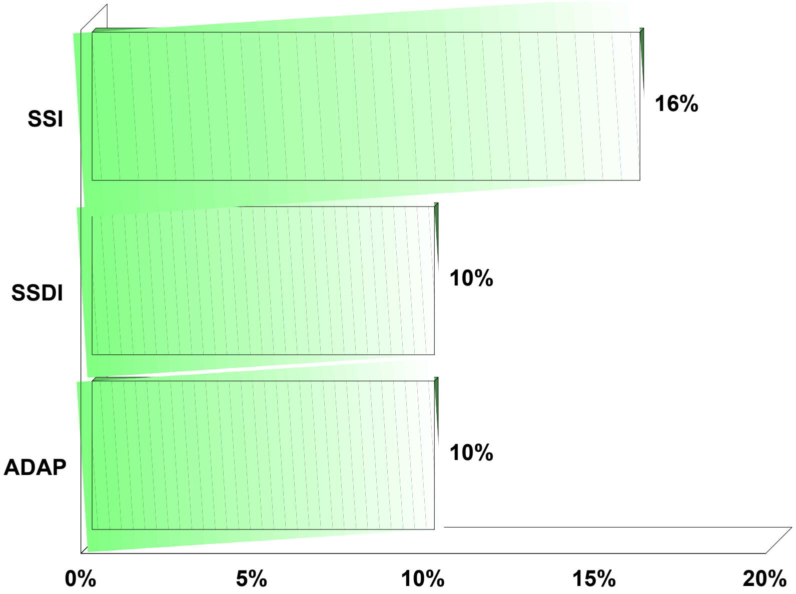


Figure 6: Type of Insurance



Almost half of the PLWH received supplemental benefits from social security -- 16% received SSI while an additional 10% received long-term disability, SSDI. Ten percent utilized the Texas state drug program ADAP, as seen in Figure 7.

**Figure 7: Types of Benefits Received**



## C. HIV Diagnosis & Treatment Characteristics

## 1. Serostatus

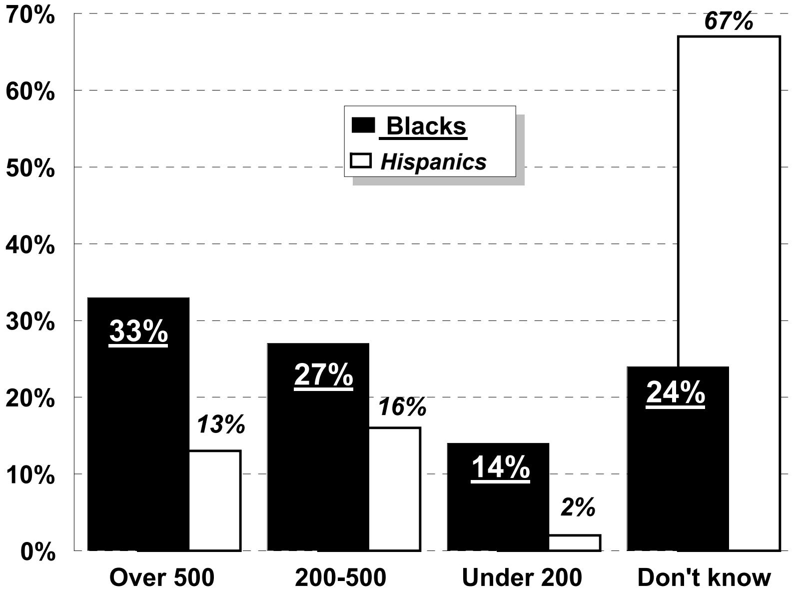
All respondents were HIV-positive. While almost two thirds (62%) were asymptomatic, about 38% were symptomatic. The length of time for which they had been positive ranged from a couple of months to 19 years, with a median of 5 years. Seventeen percent of the sample (n = 78) had already been given an AIDS diagnosis. T4 cell counts covered a wide range, over 500 in 25% of cases and under 200 in 9%. The proportion of those who simply did not know their cell count was as high as 41%. (see Table 4).

**Table 4: T4 Cell Counts of all Respondents**

| T4 Cell Count | % |
|---|---|
| Over 500 | 25% |
| 200 – 500 | 23% |
| Under 200 | 9% |
| Don't know | 41% |
| No response | 3% |

When broken down by ethnicity (Figure 8), significantly more African Americans reported counts over 500, while significantly more Hispanics lacked any knowledge of their T4 counts.

**Figure 8: T4-Cell Count by Ethnicity**



## 2. How Clients found out their HIV status

Various reasons were given as to how PLWH first discovered they were HIV-positive.

Table 5 shows that 43% had specifically requested an HIV test, while 24% found out they were HIV-positive on presenting in hospital for another problem. Eleven percent found out during a physical exam, and 7%, when they donated blood. As part of prenatal care, 4% found out they were HIV positive.

**Table 5: How clients first found out that they were HIV positive**

| | Frequency | Percent |
|---|---|---|
| Specifically requesting HIV test | 196 | 43% |
| Went to hospital for something else | 109 | 24% |
| As part of a physical exam | 51 | 11% |
| During blood donation | 34 | 7% |
| As part of pregnant women care | 20 | 4% |
| Other/No response | 48 | 10% |

### 3. Length of Time before Getting Care/Treatment

As much as 66% of respondents (n=300), said they had received HIV medical care within the first year after being diagnosed with HIV. Of these, (see Table 6), 34% received care within 3 months, 11% within 6 months and 20% within 1 year. Almost 3% (n=12) had delayed seeking care, reporting this to be for as much as 2-10 years after diagnosis. {For those who have never received HIV medical care, see Figure 13}.

**Table 6: Length of Time After Diagnosis, Before Clients Got Treatment.**
(N=300 PLWH who Received Medical Care Within First Year After Diagnosis)

| Time Lapsed | Frequency | % |
|---|---|---|
| Within 3 months | 157 | 34% |
| Within 6 months | 50 | 11% |
| Within 1 year | 93 | 20% |
| Much Later | 13 | 3% |

### 4. Current Health Status

Clients responded roughly equally when asked about their physical and emotional health. Almost 60% rated their physical health as good or excellent, while about 40% rated this status as fair/poor, see Figure 9. The same was also true for emotional health ratings.

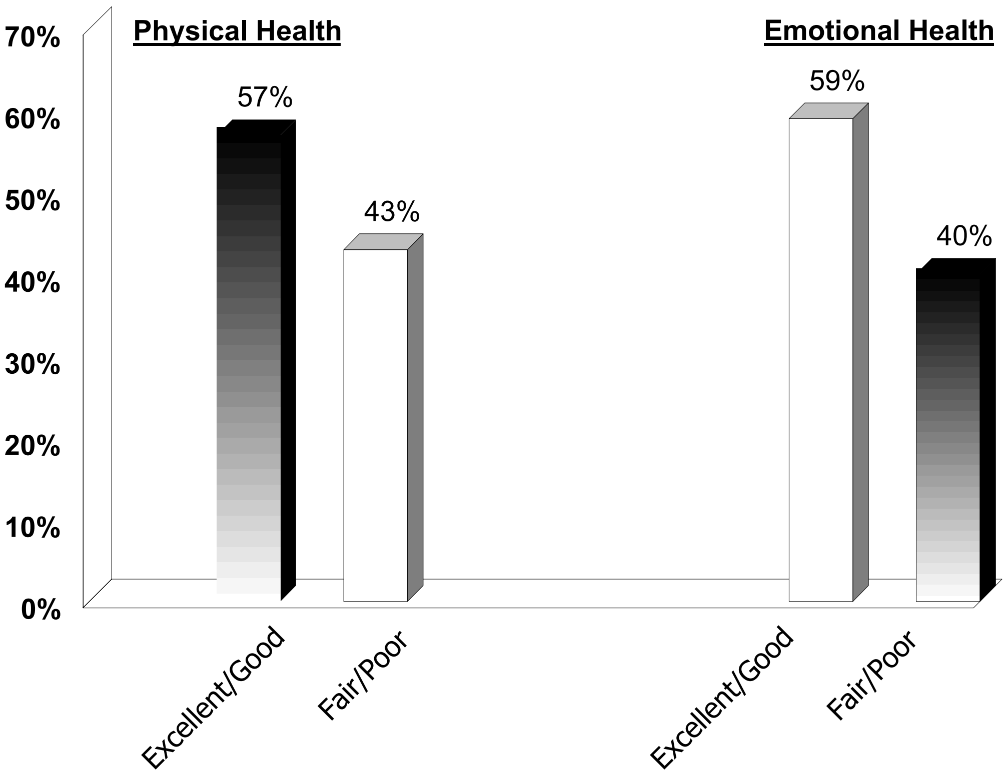


**Figure 9: Physical & Emotional Health Status of Respondents**

However, about half the clients reported they get sick enough to require medical attention. This frequency of illness had a mode of once a year. Table 7 and Figure 10 show that 49% of respondents stated they had never been sick enough form their HIV infection to require medical attention.

**Table 7: Frequency of Illness Requiring Medical Attention**

| Frequency of Illness | # | % |
|---|---|---|
| Once a month | 35 | 7% |
| Twice a year | 95 | 21% |
| Once a year | 102 | 22% |
| Have never been sick | 226 | 49% |

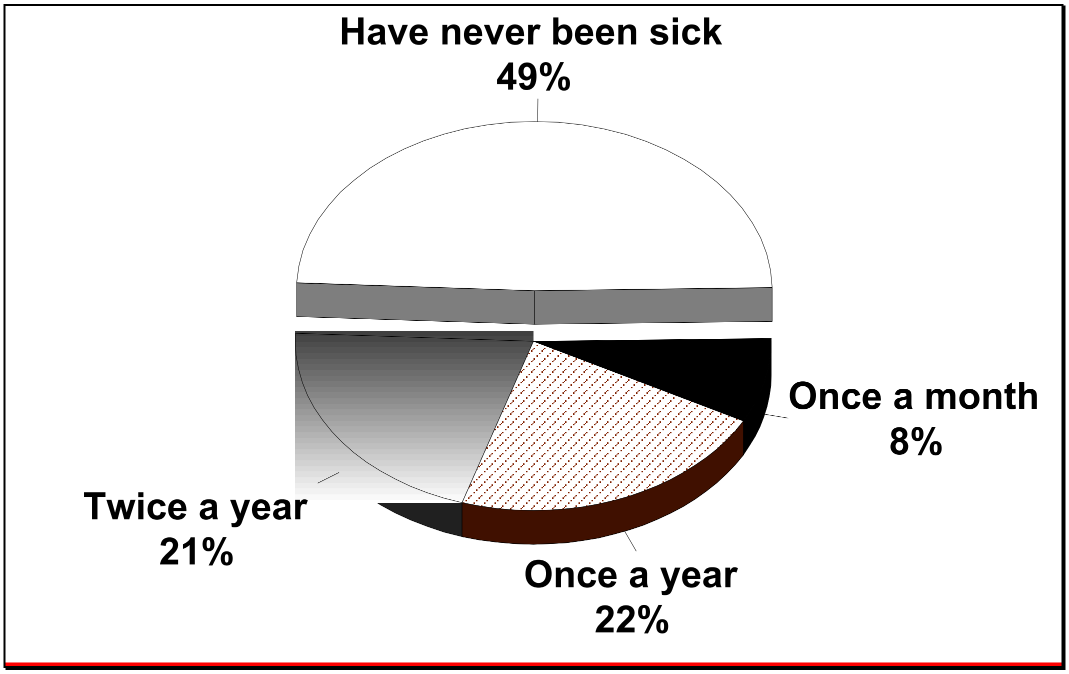


Figure 10: Frequency of Illness Requiring Medical Attention From HIV Infection

## PLWH in Care Vs. Not in Care

Based on the criteria of HIV testing and getting HIV medical care, the COC client survey comprises two of the three distinct populations within the HIV+ community. These 3 stages listed below reflect stages of readiness to change behaviors, which in this case is accessing care.

**∇ Stage I: Those who had not been tested and had not entered care.**
**∇ Stage II: Those who had been diagnosed, but had not entered care.**
**∇ Stage III: Those who had been diagnosed and had entered care.**

Because all survey respondents had already been diagnosed as HIV positive, there were no clients fitting into the Stage I category. The most important inquiry distinguishing stages II and III was the question:

"Are you **currently** getting medical care for your HIV?"

Figure 11 best depicts this distinction. Of the 458 respondents, there where 294 or 64% of the sample who stated they were *not currently* getting medical care for their HIV. **This was the true number of respondents not in care**. One person in this group had an HIV diagnosis of just a few months. The others had been living with HIV for an average of 5 years.

**Figure 11: PLWH in Care Vs. Not in Care**

**Those PLWH who stated they were *in* care were asked why they had sought medical care within the past year. Clients who said they were *not in care* were asked what it would take for them to get medical care for their HIV.**

### 1. Clients in Care

For those already receiving HIV medical care, Table 8 lists the reasons given for seeking care. About 45% reported an HIV-related illness as their main reason for seeking medical care within the past year. An additional 37% went in to have their HIV monitored or get a lab test. Fifteen percent were referred by their case managers. 'Other' reasons stated by the remaining 8 respondents were for seeking care -- during pregnancy (n=2 clients) and presenting for surgery (n=2 clients). The remainder had presented for some other medical conditions such as abdominal pain and diabetes.

**Table 8: Reasons given by 164 PLWH who sought medical care within the past year.**

| | # | % |
|---|---|---|
| Sick or had HIV-related symptoms | 73 | 45% |
| Referred to clinic by case manager | 24 | 15% |
| To monitor HIV infection and get lab test | 60 | 37% |
| Other reason | 8 | 5% |

The frequency of visits shown in Table 9 ranged from once per year to more than 12 times/year. The majority of respondents (62%) had visited 1- 3 times, but only 8% had gone more than 12 times a year.

**Table 9: Frequency of visits within the past year, for 164 PLWH to get HIV medical care**

| | Frequency | Percent |
|---|---|---|
| 1 – 3 times/yr | 102 | 62% |
| 4-5 times/yr | 23 | 14% |
| 6-12 times/yr | 24 | 15% |
| More than 12 times/yr | 13 | 8% |

## 2. PLWH Not in Care

Because of the design of the clients' survey, the most conservative model as to the number of clients out of care would be from Figure 9, where 294 respondents or 64% of the sample said they were *not currently* getting medical care for their HIV. **This was the true number of respondents not in care**. All but one person in this group had been living with HIV on an average of 5 years. The only other person had been diagnosed with HIV only a few months before the survey.

Various responses were given when asked what it would take for these PLWH to get medical care for their HIV infection. Table 10 outlines these. The numbers in parenthesis show how many clients selected the specific themes. Most commonly n=57 (or 19%) of respondents stated that they felt fine and had no symptoms. They felt they would only seek HIV medical care if they were very ill. There were significantly more African Americans in this group, to the ratio of more than 3:1. The next specific reason given was a lack of insurance. Confidential issues though very small in number (n=9), was reported more among Hispanics, specifically Hispanic females.

**Table 10: What Would It Take for 294 PLWH To Get HIV Medical Care?**

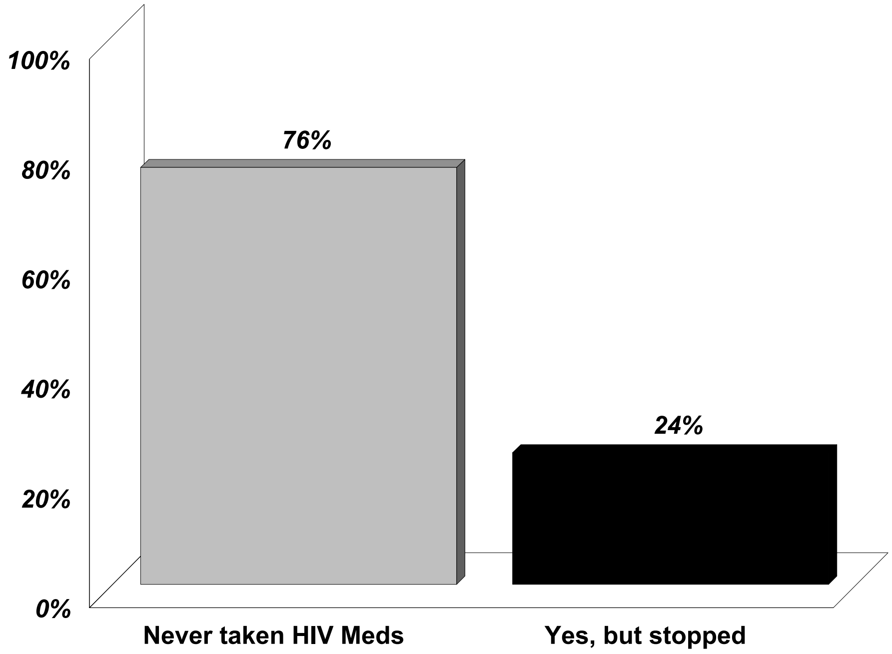
- (57) They currently feel fine and have no symptoms. If they get drastically sick, they will have no choice but seek medical treatment.
- (28) No reason given: they simply do not know what it will take.
- (22) Need a health card, a gold card or insurance.
- (20) Need more information about where HIV services are, about applying for medical services, need info about securing an appointment & info about benefits.
- (16) Transportation to get to services
- (15) Need money to buy medications etc.
- (12) Need motivation -- encouragement from family & support groups. They are just not ready nor do they have the time. Medical care is too much of an effort.
- (9) Anonymity: They need absolute confidentiality, so nobody knows.
- (8) Need good, caring, sensitive and trusting medical staff that will treat clients with respect; make them feel comfortable and take time to explain.
- (6) Time off work for appointments.
- (6) Need to change lifestyle. They do not want to commit to stop using drugs.
- (6) Ensure that HIV meds will not make them sick. They do not believe in the treatment and so do not want to take the HIV meds they are given.
- (5) To have more Spanish-based services.
- (4) A change in immigration status, so that illegal aliens are not deported.
- (4) Education, to understand the disease better.
- (3) Referral or re-application.
- (3) A job
- (3) Simply do not care/not interested in care!
- (4) Housing
- (2) To have meds dropped off at their home
- (1) To fight against their fear.

About 20 of the 294 PLWH who were not seeking care, reported they needed more information about the location of HIV services. They also needed information on how to apply for medical services, how to get benefits and how to secure an appointment. Other issues included a lack of transportation, lack of money to buy medications and a lack of motivation.

Of those PLWH who have accessed care at some point in time, 294 PLWH reported not currently being in care. The majority of those (76%, n=223) had never taken HIV meds (Figure 12).

However, nearly one-fourth, or 24%, (n=71) had previously been on HIV meds at one time, but had now stopped these medications.

**Figure 12: Ever taken HIV Meds?**
**(N=294 PLWH Not Currently Accessing Medical Care)**



Each one of the above two subgroups was asked how soon after being diagnosed HIV-positive did they receive medical care. Figure 11 shows there was very little delay in going for initial medical check up. The proportional responses are depicted in two columns of data. The first column is of the 223 PLWH who had never taken HIV meds. Not surprisingly, the majority of them, 62%, reported they had not received any HIV medical care. The rest of them however, went in for care within 1 year after testing positive. Only 2% said they waited much later, 2 or more years after testing positive. The other column in Figure 13 is of the 71 PLWH who had stopped taking HIV meds.

Almost half of this group (49%) had gone for care within 3 months of diagnosis, and an additional 38% went within 6 months to 1 year.
**Thus the problem does not seem to be a delay in going for initial medical check up. The divergence comes in with other factors that preclude continued medical care.**

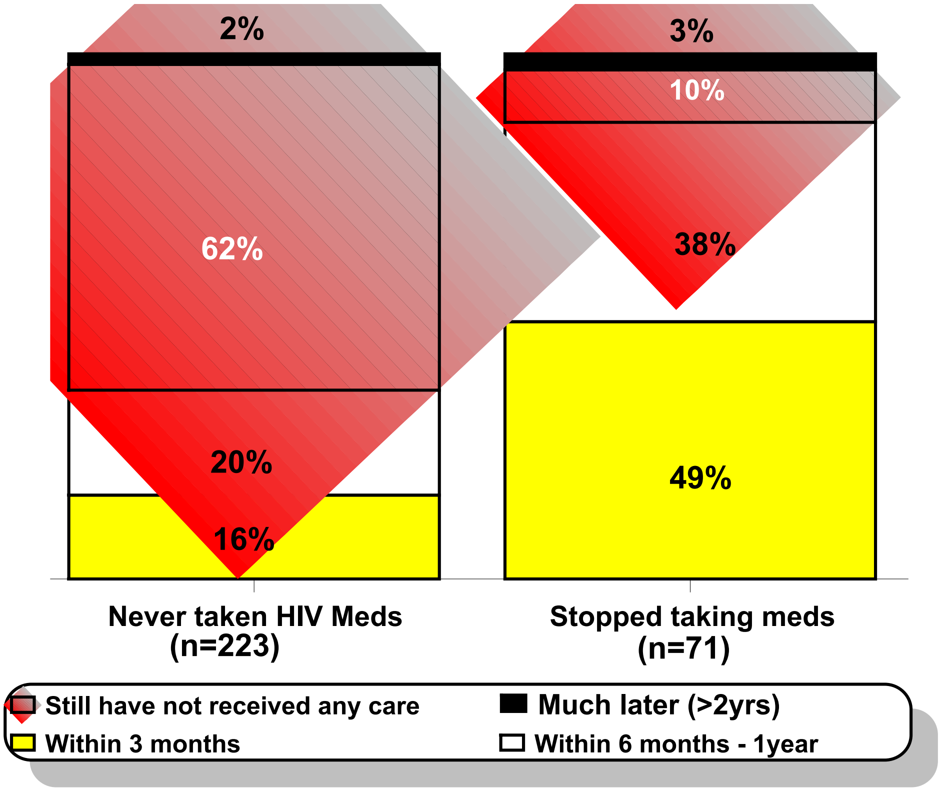


**Figure 13: Length of Time Before Getting HIV Care/Treatment**

### Those who stopped taking HIV Meds

Gender and racial breakdown of the 71 PLWH who stopped taking their medication are shown in Table 11. No gender differences were found among Hispanics; but African American men were significantly more likely to have stopped taking their medication as compared with their female counterparts. Overall, the highest single proportion of those who stopped medication, 45%, occurred among African American males.

**Table 11: Gender and Racial Breakdown of 71 PLWH Who Stopped Taking HIV Meds**

| | Sex | | | Total |
|---|---|---|---|---|
| | **Male** | **Female** | **Transgender** | |
| African American | 32 (45%) | 17 (24%) | 2 (3%) | 51 (72%) |
| Hispanic | 9 (13%) | 8 (11%) | 0 | 17 (24%) |

| | | | | |
|---|---|---|---|---|
| Multi-racial | 1 ( 1%) | 2 ( 3%) | 0 | 3 ( 4%) |
| | **42 (59%)** | **27 (38%)** | **2 (3%)** | **71 (100%)** |

In general, African Americans were 3 times more likely to have stopped taking their medication (72%) than Hispanics (24%). The reasons given for all those who had stopped taking their HIV meds are listed in Table 12.

**Table 12: Reasons given for stopping or skipping medication: ( N=71 PLWH who had previously taken HIV meds, but are currently not accessing HIV medical care)**

| Reason | Freq | % |
|---|---|---|
| • Side Effects | 36 | 51% |
| • Forgot to take meds | 14 | 20% |
| • Difficult schedule/requirements | 17 | 24% |
| • Could not afford meds | 8 | 11% |
| • Medications did not work | 5 | 7% |
| • Didn't understand instructions | 5 | 7% |
| • Couldn't take with food | 2 | 3% |
| • Doctor suggested stopping | 1 | 1% |
| • Other reasons | 7 | 10% |

### 3. HIV and Non-HIV Medications currently being taken

Various medications are currently being taken by PLWH; ranging from anti-retrovirals through anti-depressants. Table 13 outlines these for all 458 PLWH. Twenty-two percent reported **currently** taking anti-retrovirals, while more than one-third of respondents (38%) were not taking any type of medications as of the time of the survey.

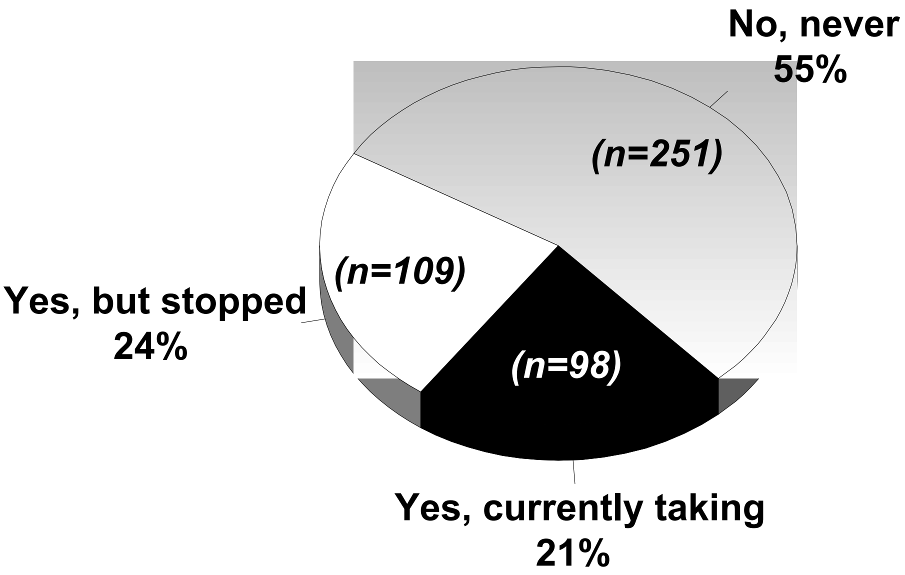
**Table 13: Medications currently being taken by 458 PLWH**

| Type of Medication | Freq | % |
|---|---|---|
| • Anti-retrovirals | 100 | 22% |
| • Antibiotics | 42 | 9% |
| • Anti-fungals | 15 | 3% |
| • Steroids | 6 | 1% |
| • Anti-depressants | 32 | 7% |
| • None | 173 | 38% |

Responses to the more specific question "Have you ever taken, or are you currently taking any medications for your HIV infection" are depicted in Figure 14. Twenty-one percent (21%) were currently on HIV medication, 24% had at one time, taken medication but stopped, while 55% of the entire sample of 458 PLWH, reported they had never taken HIV meds. **Of this latter group, half (51%) had never heard of**

**treatments like protease inhibitors or antiretroviral medications that fight against HIV**.

**Figure 14: Ever Taken or Currently Taking HIV Meds (N=458)**



HIV medications were obtained in the most part by doctor's prescription or in a clinic, e.g. Thomas Street. Other sources were through the pharmacy, the VA hospital, the Assistance fund and ADAP, see Table 14. In one instance, the client said he got his HIV meds from relatives.

**Table 14: Source of HIV Medications for 99 Respondents who are currently taking HIV Meds.**

| Source of HIV Medications | Freq | Percent |
|---|---|---|
| • From prescriptions/clinic | 40 | 40% |
| • Pharmacy | 19 | 19% |
| • VA | 8 | 8% |
| • The Assistance Fund | 6 | 6% |
| • ADAP | 4 | 4% |
| • Relatives | 1 | 1% |

| | | |
|---|---|---|
| - No response | 21 | 22% |

## 4. Opinions about HIV medications

It has already been shown that almost half of those PLWH who were currently not on any medications had never heard of protease inhibitors or anti-retrovirals. Further probes illustrated the PLWH's opinions towards HIV meds. A 3-point likert scale in Table 15 showed that more than half of the respondents (61%) agreed about the availability of drugs to lengthen their lives. In addition, about half agreed that drugs were easy to get if one wanted them. **However, contrary to expectation from past research, very few (16% of the PLWH, felt HIV medications did more bad than good. This gave credence to the conclusion that factors other than the respondents' negative beliefs about HIV meds precluded their accessing HIV treatment**.

**Table 15: Opinions about HIV Meds (N = 458 PLWH/A)**

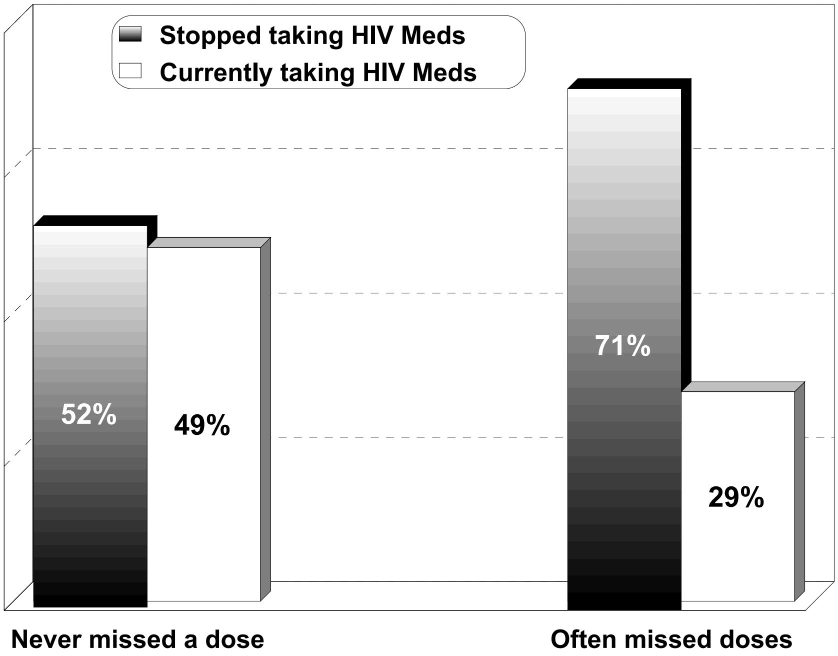
| | Agree | Disagree | Don't Know |
|---|---|---|---|
| - Drugs are available to lengthen lives of PLWH/A | 61% | 10% | 27% |
| - Drugs are easy to get if you want them | 49% | 19% | 29% |
| - HIV meds do more bad than good | 16% | 41% | 40% |

## 5. Compliance with Medication

Irrespective of current access to medical care, a comparison was made of PLWH who had ever stopped taking medications (n=109) and those who are currently on meds (n=98). There was no significant difference in the proportion that had never missed a dose (52% vs. 49%), see Figure 15. However there was a significant difference in the percentage of those who admitted to frequent missed doses.

Among those who often missed doses, 29% were in people currently taking HIV meds, as opposed to 71% in those who has stopped their medication. It is thus apparent how a total drug stoppage could have arisen from frequently missed does.

## Figure 15: Drug Compliance With PLWH



Reasons given for stopping or skipping doses are outlined in Table 16. Respondents could select more than one reason. As the top 3 reasons, clients reported side effects, forgetting to take medications and a difficult drug schedule/requirement.

### Table 16: Reasons given for stopping or skipping medication: Among 207 PLWH who have ever taken HIV Meds: (i.e. currently taking + taken in the past but now stopped)

| Reason | Freq | % |
|---|---|---|
| • Side Effects | 89 | 43% |
| • Forgot to take meds | 58 | 28% |
| • Difficult schedule/requirements | 37 | 18% |
| • Could not afford meds | 14 | 7% |
| • Medications did not work | 11 | 5% |
| • Didn't understand instructions | 7 | 3% |
| • Couldn't take with food | 5 | 2% |
| • Doctor suggested stopping | 4 | 2% |
| • Other reasons | 19 | 9% |

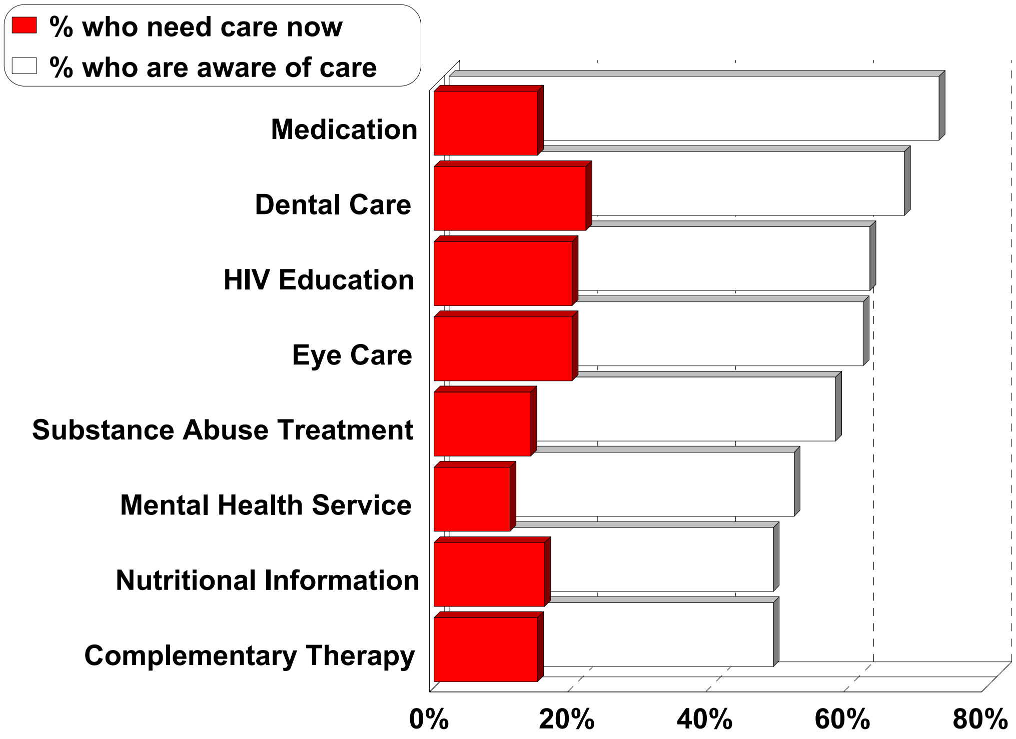
## 6. Unmet Needs for Medical and Social Services

Table 17 shows differences in responses when respondents were asked what services they were aware of and which services they currently needed but could not get. Respondents seemed fairly aware of where to get services like eye care, dental care and HIV education, but only 20% said they currently needed any one of these. Most amazing was the fact that as many as 71% said they knew where to get HIV medication, but only 15% actually felt they needed any medication right now. This awareness issue versus perceived need is again depicted in Figure 16. Respondents were most aware of HIV medication but most in need of dental care.

**Table 17: Medical & Social Services Needed by 458 PLWH**

| Type of Care | Percent who know where to get care | Percent who need care now |
|---|---|---|
| Eye care | 60% | 20% |
| Dental care | 66% | 22% |
| Medication | 71% | 15% |
| HIV education | 61% | 20% |
| Mental health service | 50% | 11% |
| Nutritional information | 47% | 16% |
| Substance abuse treatment | 56% | 14% |
| Complementary therapy | 47% | 15% |

**Figure 16: Service Awareness versus Service Need**



To further quantify service awareness, a continuous variable was created to assess the actual **number** of listed services the PLWH would know how to seek out if needed. The results are depicted in Figure 17. Although 31% of the sample were aware of all 8 of the listed services, as much as 19% reported service awareness of zero, that is they had no idea where to get *any* one of them. On the average, these PLWH lacked information on a mean number of 4.5 services.

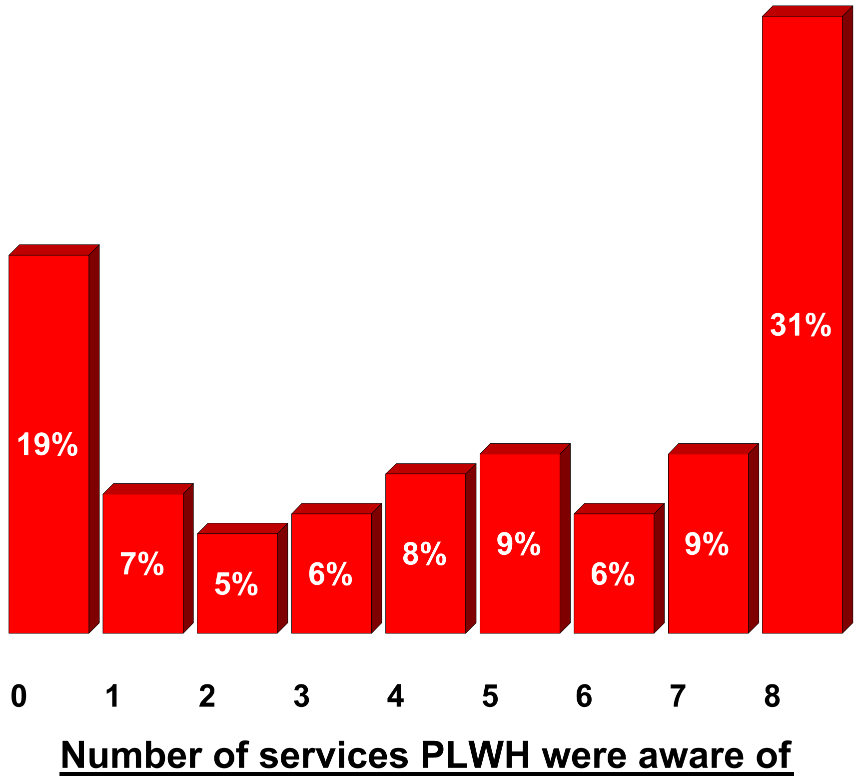
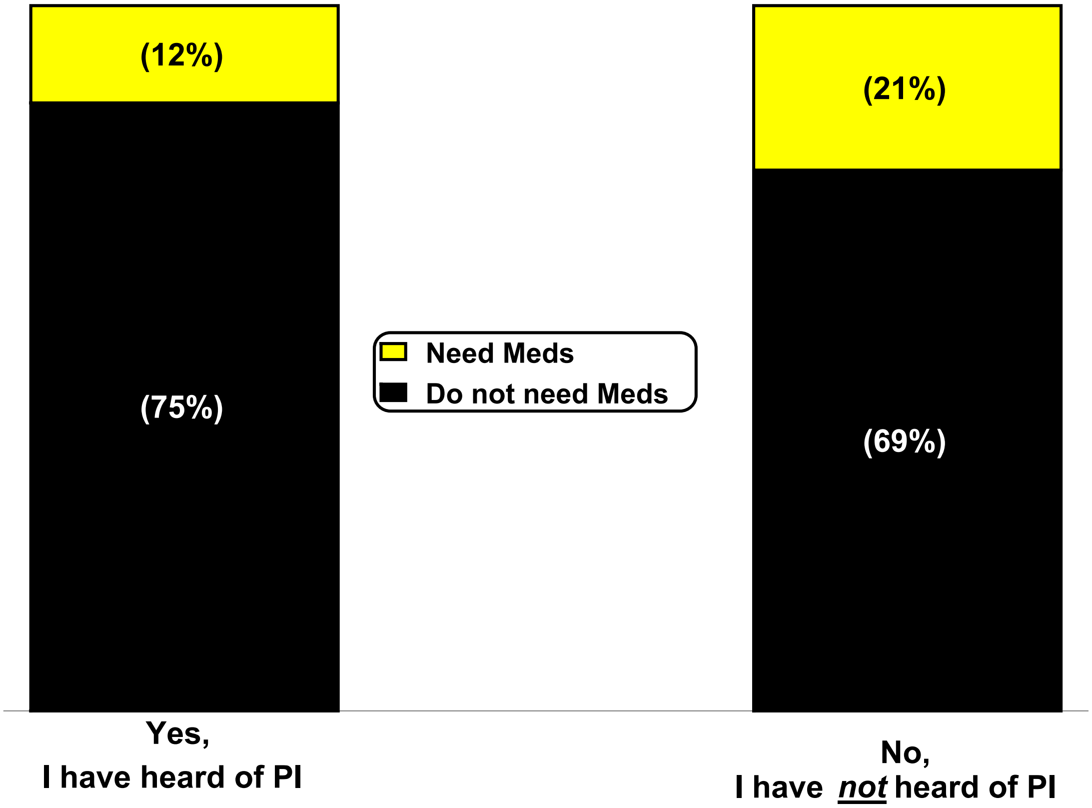


Figure 17: Number of Services of Which PLWH Were Aware

Data from PLWH who had a services need were linked with data on awareness about PI/anti-retroviral treatments. A startling finding resulted, as shown in Figure 18. **It did not seem to matter whether or not these PLWH had heard of anti-retrovirals, they still felt they did not need HIV medication.**

As many as 75% of those who had prior knowledge of HIV medications as well as 69% of those who had none, stated that they did not need HIV medication now.

**Figure 18: Proportion of PLWH Who Felt They Needed HIV Meds, In Respect to Prior Knowledge of Protease Inhibitors or Anti-retrovirals**

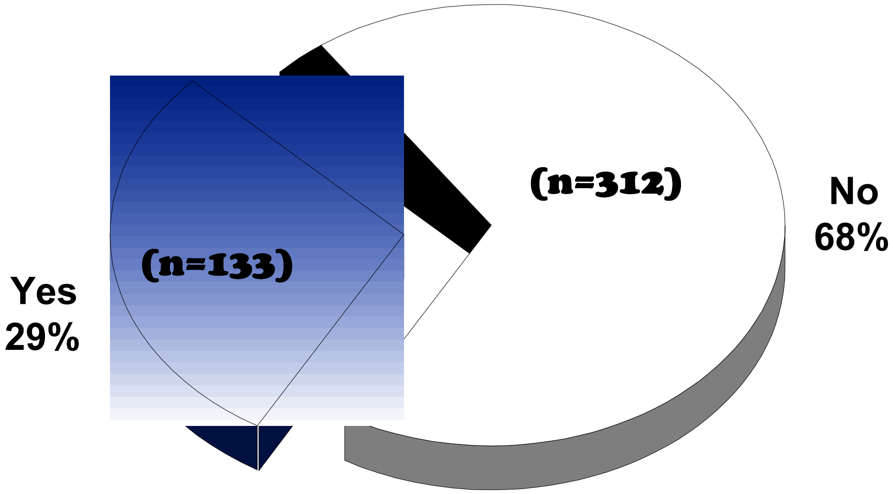


## 7. Barriers to HIV Medical Care

About 29% of respondents said they had, at one time or the other needed HIV care but did not receive it. See Figure 19. Various reasons were given for not getting needed care. These barriers are shown in Table 18. The top 3 reasons were:-

- a lack of information on how or where to get medical care
- lack of transportation,
- confidential reasons – not wanting people to know their HIV status.

## Figure 19: Have you ever-needed HIV Medical care and did not get it?



Those who reported a lack of information as their predominant reason for not getting HIV care were more likely to be African American males. Other clients who reported transportation problems as their main reason were more likely to be female.

### Table 18: Reasons why 133 PLWH did not get HIV care when they needed it

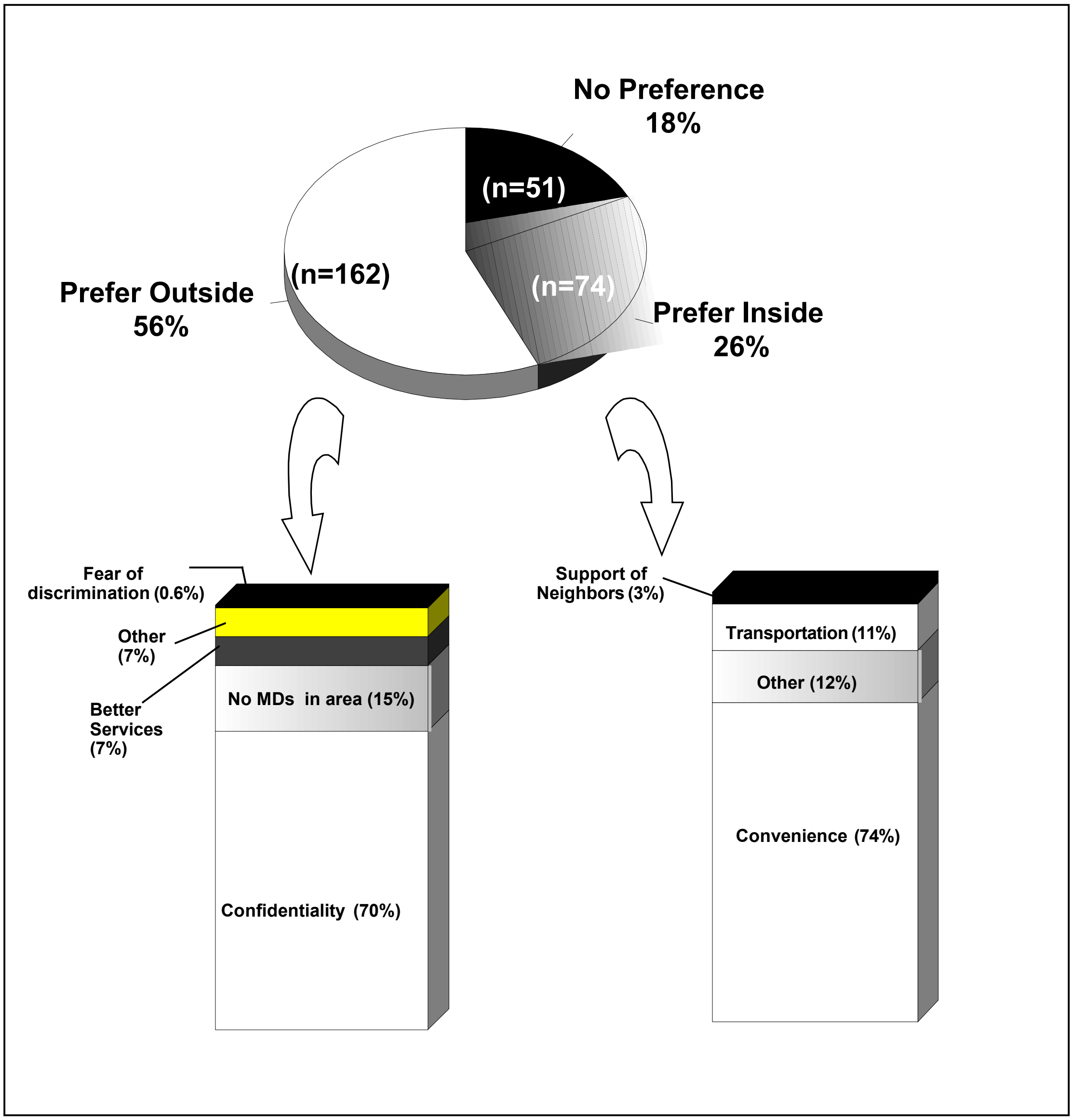
| Reason | Freq | % |
|---|---|---|
| • Lack of info on how or where to get medical care | 52 | 39% |
| • Lack of transportation | 41 | 31% |
| • Confidentiality (not wanting people to know HIV status) | 26 | 20% |
| • Long waiting time (for appointment and to be seen) | 24 | 18% |
| • Missed appointment | 22 | 17% |
| • Did not trust quality of services | 15 | 11% |
| • Could not afford service | 12 | 9% |
| • Was not eligible | 10 | 8% |
| • Suspected medical staff of discrimination | 8 | 6% |
| • Lack of child care | 5 | 4% |

## 8. Preference for HIV Care: In or Outside of Neighborhood

Significantly more clients (twice as many) preferred to get HIV medical care outside their neighborhood. As shown in Figure 20, 56% preferred outside their neighborhood while 26% preferred inside. An additional 18% did not care either way.

Preferences were justified with appropriate reasons, see Figure 20. Majority of clients (70%) who preferred getting HIV care outside, cited confidentiality issues as their main reason -- they just did not want their friends and neighbors to know. Other reasons given to a lesser extent, were that their neighborhoods had no doctors: They stated that all the HIV doctors were in the Houston medical center. About 7% believed that HIV services were better outside their neighborhood with better facilities and faster service.

**Figure 20: Preference of HIV Care: In or Outside of Neighborhood**



Of those who preferred getting HIV care within their neighborhood, the majority (74%) reported convenience to be their main reason. Also reported were the ease of transportation if closer, and the support of neighbors.

## Complementary Health Care Methods

The use of alternative treatments was very infrequent among the PLWH surveyed. Herbal treatment was used by only 14% of respondents, the greatest proportion being among African American males. About 10% of PLWH stated they used massage therapy. To a much smaller extent were the use of chiropractors and acupuncture, 2% each. Biofeedback was reportedly used by only 1 person. A handful of PLWH reported 'other' alternative therapies including penicillin, prayer and exercise.

## Co-Morbidities

### 1. STDs and TB

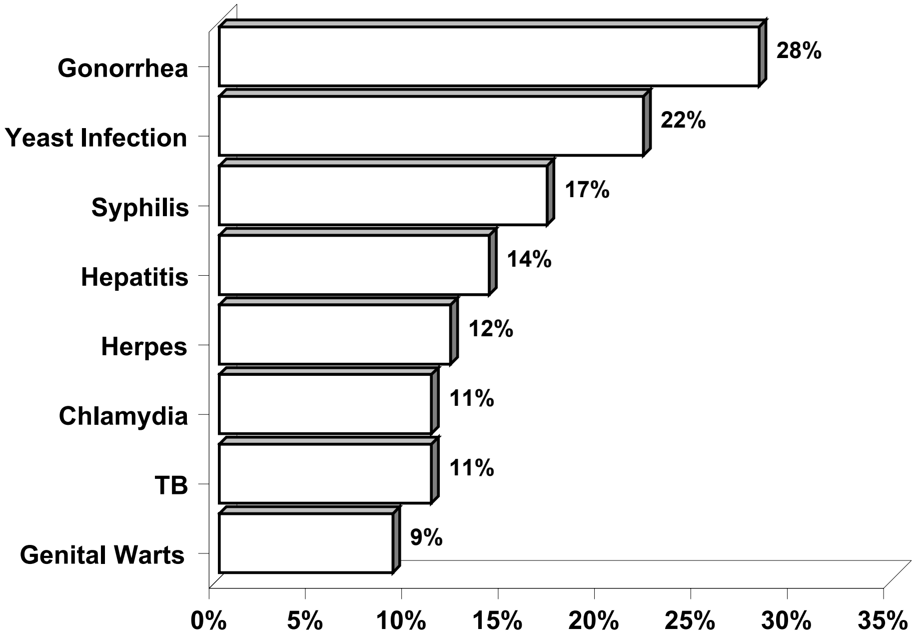
Respondents were asked to indicate any co-morbid infections they had ever had. Over 70% had had a sexually transmitted disease. Table 19 outlines the proportion of co-morbid infections for the entire sample of 458 PLWH. Gonorrhea was the most commonly reported STD (28%). About 22% reported having had yeast infections at one time or the other. This distribution is shown graphically in Figure 21.

**Table 19**
**Percentage of PLWH who had ever had an STD or TB**

| STD or TB | Freq | Percent |
|---|---|---|
| Gonorrhea | 130 | 28% |
| Yeast Infection | 99 | 22% |
| Syphilis | 77 | 17% |
| Hepatitis (A, B, or C) | 64 | 14% |
| Herpes | 54 | 12% |
| Chlamydia | 50 | 11% |
| TB | 49 | 11% |
| Genital Warts | 40 | 9% |

Males had a higher reported rate of co-morbidities (52% vs. 47%). PLWH with STDs were significantly more likely to be African American than Hispanic (66% vs. 33%). Less than 30% (n=132) reported never having had an STD or TB infection.

**Figure 21: Percentage of Co-morbidities in 458 PLWH**



## 2. Substance Use

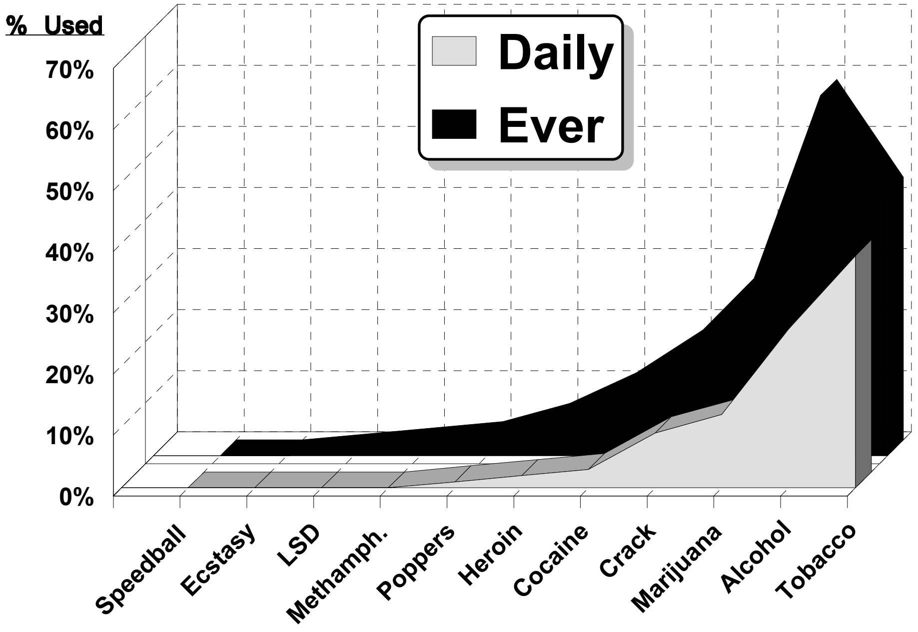
As much as 38% of respondents (n=172), had never used any of the listed substances. However 62%, had used one or the other at varying frequency. The survey indicated a moderately high level of use for alcohol and tobacco, and a much smaller level of use of marijuana and crack see Table 20. More than half of the respondents (59%) had used alcohol, 43% reported ever using tobacco and 29% used marijuana. Of note is the comparison of those who had ever used these substances with those who use them on a daily basis. As shown in Table 20, more than half of respondents who had ever used alcohol, tobacco and marijuana still used it on a daily basis.

Figure 22 again compares ever use with daily use. Alcohol was used by the majority of participants (59%), and almost half of these (26%) still use alcohol daily. On a daily basis, tobacco was the substance most used. This proportion of 38% is so close to the 'ever used' percentage for alcohol, 43%, showing that the majority of those who had started off ever using tobacco were still using it ever day.

## Table 20: Substance Use Among 458 PLWH

| Substance | Not Used | Ever Used | % Ever used | Daily | % Used Daily |
|---|---|---|---|---|---|
| Alcohol | 182 | 268 | **59%** | 118 | **26%** |
| Tobacco | 401 | 197 | **43%** | 175 | **38%** |
| Marijuana | 305 | 131 | **29%** | 54 | **12%** |
| Crack | 352 | 83 | **18%** | 41 | **9%** |
| Cocaine | 382 | 49 | **11%** | 16 | **3%** |
| Heroin | 401 | 27 | **6%** | 10 | **2%** |
| Poppers | 411 | 16 | **3%** | 6 | **1%** |
| Methamphetamine | 422 | 9 | **2%** | 2 | **0%** |
| LSD | 420 | 3 | **1%** | 0 | **0%** |
| Ecstasy | 423 | 2 | **0%** | 1 | **0%** |
| Speedball | 429 | 2 | **0%** | 0 | **0%** |

## Figure 22: Substance Use Among PLWH



## 3. Injecting Drug Use (IDU)

The use of injecting drugs was reported among 32% of all respondents, as shown in Figure 23. When broken down by race (Figure 24), a greater proportion of Hispanics (34%) had a history of injecting drug use than African Americans (29%). This difference however was not statistically significant.

**Figure 23: Drug Use Among 458 Respondents**

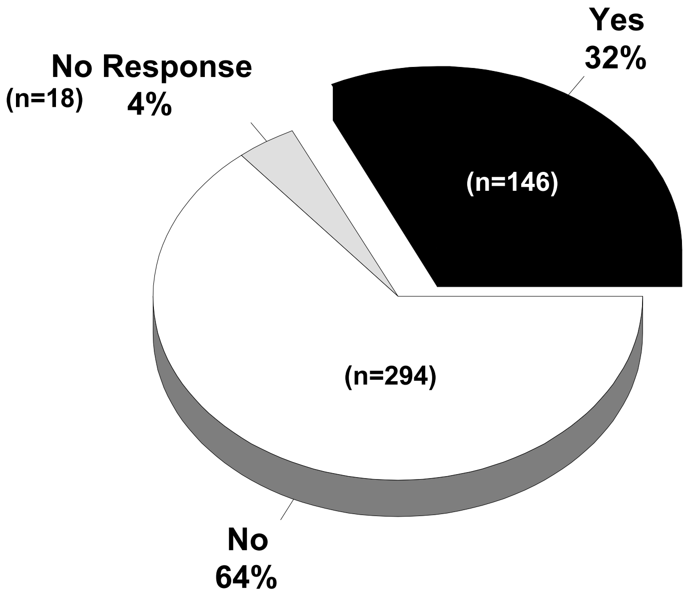
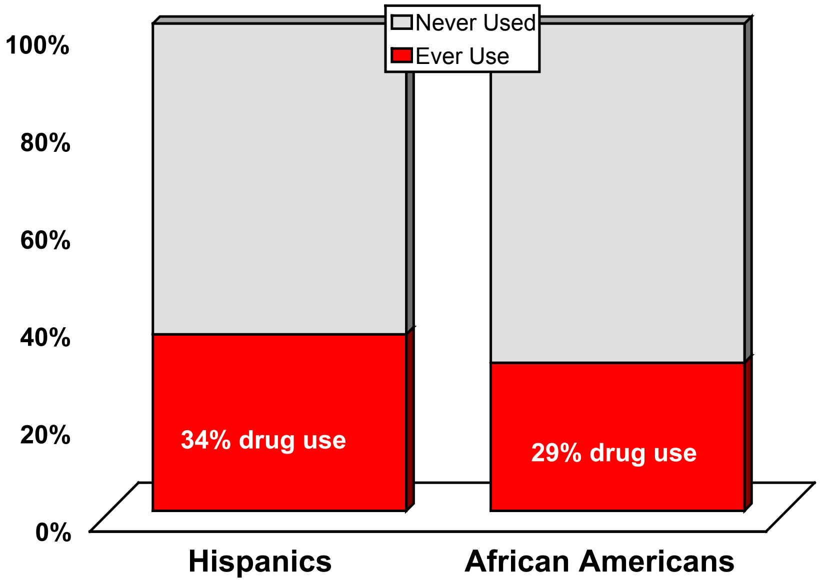


**Figure 24: Proportion of Hispanics and African Americans Who Had Ever Injected Drugs**



## Summary of Analysis of Client Surveys (N = 458)

- With respect to race/ethnicity, the main focus was on African Americans and Hispanics, in the ratio of 3 to 2. African Americans made up 59% of the sample, while 40% of the sample were of Hispanic/Latino origin.
- Females 40%, Males 59%, Transgender 1%
- Median age 37 years, majority in 25 - 44 age group. Sample comprised 40 youths.
- To some extent, the type of residence may have affected access to care: Currently the majority of respondents lived in apartments or houses. In recent past, homelessness was as high as 47%, while 27% had been incarcerated within the last 2 years.
- 25% homosexuality overall – (24% in African Americans, 27% among Hispanics).
- Socio-economic status: Education was used as an indication of literacy: Three times as many African Americans as Hispanics had some college level education, but Hispanics were significantly more likely to be employed (61% vs. 36%). 78% of sample was at 300% poverty level. 44% had no health insurance. 18% were undocumented.
- All 458 were HIV-positive with a mean period of 5 years. 38% symptomatic, while 17% were already diagnosed with AIDS. Significantly more Hispanics lacked any knowledge of their T4-cell count.
- There was very little delay in going for initial medical check up. 66% had received care within first year of being diagnosed. Thus, there seemed to be other factors that precluded continued medical care.
- 64% of respondents are **not** currently getting medical care for their HIV. These had been living with HIV for an average of 5 years. When asked what it would take for them to get into HIV medical care, respondents most commonly cited a severe illness – if they were to get seriously ill they would seek help, but for now, they felt fine and had no symptoms. Other reasons given were a lack of insurance, lack of information on HIV service (location and how to apply), lack of transportation, lack of money and lack of motivation.
- An attempt was made to tease out those PLWH who may have accessed care at some point in time: Considering all responses, about one-fourth (24%) had previously been on HIV meds but had now stopped. It was apparent that a total drug stoppage arose from frequent missed doses. African American were 3 times more likely to have stopped taking their medication than Hispanics (males more than females). 21% are currently on HIV meds, while 55% of all respondents had never taken any medications for their HIV infection. Of this latter group, half had never heard of PI or anti-retrovirals.
- About 29% of respondents said they had, at one time or the other needed HIV care but did not receive it. The major barriers to HIV Treatment were -- a lack of information on how or where to get medical care, (reported more by African American males), lack of transportation (reported mainly by females), and confidential reasons – simply not wanting people to know their HIV status.
- Location of services was used as an indicator of access: Twice as many respondents preferred HIV medical care *outside their neighborhood*, -- citing confidential reasons.

- Most amazing was the respondents opinions about HIV medications: As many as 71% said they knew where to get HIV medication, but only 15% actually felt they needed any medication right now. It did not seem to matter whether or not these PLWH had previous knowledge of HIV meds -- at least 70% of them said they did not need medication **now**. The majority believed that HIV meds were available to lengthen their lives. More than half believed HIV meds were easy to get. While 41% agreed that HIV meds did more good than bad, only 16% disagreed. So, factors other than the respondents' beliefs about HIV meds precluded their accessing HIV treatment. … .. factors like "I feel OK".
- The use of alternative treatments was very infrequent among the PLWH surveyed. Herbal treatment was used by only 14% of respondents, the greatest proportion being among African American males.
- Over 70% had had an STD, significantly more in African Americans than Hispanics (66% vs. 33%). The co-morbid rate was higher in males than in females but not significantly so.
- As many as 38% of respondents had never used any of the listed substances. However, more than half of those who had ever used alcohol, tobacco and marijuana still use it now on a daily basis. The use of injecting drugs was reported among 32%, more so among Hispanics.

# RESULTS OF THE
# COMMUNITIES OF COLOR
# FOCUS GROUPS
# December 2000

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| **Prepared for:** | **Ryan White Title I Planning Council**<br>**Comprehensive HIV Planning Committee**<br>**Needs Assessment Sub-Committee** |
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# RESULTS OF THE
# COMMUNITIES OF COLOR FOCUS GROUPS
# December 2000

## Executive Summary

During the month of December 2000, eight focus groups were held in communities of color as part of the needs assessment activities for the Ryan White Planning council to prioritize primary care, medications, and complimentary/alternative treatment services from a consumer point-of-view. Seven groups, with 25 total participants contributed information from the PLWH/A community perspective and three non-HIV service agencies sent representation to provide the potential provider perspective in an additional focus group.

The report is the compilation of the opinions and suggestions of these participants, and is in no way conclusive. It does provide information on the perceptions and responses of the participants towards the HIV care system. The *General Findings* sections offers discussion from the evaluator regarding the respective issues. While the views may not be transferable across all communities of color, the recurring themes throughout the various conversations provide a source of information for consideration in the needs assessment process. Further research is indicated in several areas to substantiate findings, especially about personal preferences for medical providers in or outside a neighborhood.

## Community Focus Groups

### Reasons for Seeking Primary Care

Of the community members, a significant number (6) reported coming to Houston after an HIV diagnosis or upon release from prison (3). This indicates that Houston may be the end-point destination for people with HIV/AIDS traveling from other geographic locations and supports information from the Texas Department of Criminal Justice that indicates Houston is the city of choice for recently released offenders with HIV. For the most part, males are not diagnosed with HIV until symptomatic and in a system of care. While the greater number of female participants indicated being tested while asymptomatic because of the illness of husband or partner, there were two women diagnosed while pregnant.

### Delays in Seeking Primary Care

The primary problems in getting into care were 1) denial of HIV status and 2) the need for trustworthy information once a decision to enter care had been made. Denial was the overriding issue causing delayed care. In the words of the African American non-HIV service provider, “There is nothing you can do to get them into care if they don’t want it.”

While denial and the social stigma equally impact the Hispanic community, many of them are faced with additional decisions—if undocumented, why bother to test because there are no services and no help. In the monolingual communities, it is also very difficult to find information. Those who are HIV positive do not share information for reasons stated above and there is a reluctance to ask "too many" questions. It is the community norm not to ask for help.

### Factors Supporting Primary Care

Factors supporting access to primary care are transportation and acceptance by one's social support network. The family/social support for individuals entering care makes a tremendous difference, especially within the African American community. Several individuals entered care due to the encouragement of their families and it appears to be a factor in continuing in care.

### Factors Impeding Access to Primary Care

Factors impeding care were lack of money for medication co-pays, gaps in coverage due to re-certification policies, and, within the Hispanic community, difficulty in learning about resources and how to access them because of the language barrier. Participants in all groups reported the difficulty of staying in care and on their medication regimen when faced with $5, $10, and sometimes $15 co-pays for each medication. Those restricted to only three prescriptions per month were forced to pick which prescriptions they would do without. This caused involuntary "drug vacations" in more than one instance. Individuals with transportation reported that parking fees at the Medical Center were an additional cost burden while trying to remain in care. In the Hispanic community, the language barrier impedes the learning process of how to access services.

### Preferences for Neighborhood Care

The preference for clinic locations, in-neighborhood versus out-of-neighborhood, was dependent on the type of neighborhood in which the participants lived. Those in neighborhoods like those around the Medical Center, Montrose and Midtown felt the clinics they attended were in their neighborhoods and they liked the convenience. Those living in more homogenous, culturally exclusive neighborhoods wanted services outside their neighborhoods. All participants reported liking their primary care providers once they entered the system of care. The clinics provided resources and information and helped to create a social support system.

### Activities Managing HIV Disease

The primary activities associated with managing HIV were attending medical appointments and adhering to the medication regimen. There was a self-reported high level of knowledge (18) and of these 15 were taking anti-retroviral medications, eight were on prophylactic antibiotics, and ten were taking antidepressants. It was not clear if antidepressants were being prescribed because of a diagnosis of depression or because these types of drugs alleviate other symptoms or side effects.

### Ability to Access Medication

Participants were aware of the various funding streams for medications including ADAP and the Assistance Fund, however the principle problem with accessing medications was having money for the co-payments. Participants without the funds reported doing without their medications for some period of time. Others reported relying on samples from the physicians' offices to get them by. Those in the Hispanic community reported additional problems when first entering treatment. They were unaware of transportation services and how to pick up their medications.

### Number Discontinuing Medication

When discussing drug vacations and discontinuing HIV medications, three participants reported experimenting with their medications to find out what would happen with their t-cell count. This implies a lack of knowledge about when it is appropriate to stop a medication, such as an antibiotic, and when it is important to continue despite side effects. About half of those stopping medications (4 of 9) did so on the advice of their physician as a result of uncontrollable side effects.

### Challenges Common in Communities of Color

The challenges common in communities of color were denial of the problem of HIV, refusal to discuss issues of sexuality, and fear of disclosure. Within the African American community there is also the need to dispel the widespread belief that AIDS is a government conspiracy to destroy them. For improvements to be made in the treatment of HIV it will be necessary to first deal with these cultural barriers. No group identified any specific HIV services that they needed but were unable to get. While needing services for affected partners and children, no primary care needs went un-addressed.

## Non-HIV Service Provider Focus Group

### Is HIV/AIDS a Problem?

Among non-HIV service providers, there was a general consensus that HIV/AIDS is a problem in the communities of color. Within the African American community there is a sense of frustration that no actions are being directed toward the "State of Emergency" and while African American churches are increasingly aware of the problem, they lack direction and leadership. The problems in the immigrant African and Hispanic communities are compounded by issues about immigration and citizenship, barriers in accessing services and the need for housing. Fear and the stigma of HIV within the minority communities keep people silent. They fear losing family, friends, homes, and jobs if they are known to be HIV positive.

### Is Houston Making Progress?

It was generally agreed that Houston has made some progress in the fight against HIV/AIDS. In the African and African American communities, churches and ministers are beginning to talk about the problems, however participants felt the primary needs of shelter and food would have to be addressed before people would listen to messages about HIV. Within the Hispanic community, the church is not a viable vehicle for communicating about HIV/AIDS because of the unacceptable taboo of discussing sexuality within the Catholic church'.

### Personal Experience with PLWH/A

All participants could give examples of HIV-positive individuals who are not currently in care and offered the following reasons: In the African American community, the fear of disclosure and resulting social stigma is much greater than the need for treatment and people will not seek care if there is the possibility they might be recognized. There is a tremendous gap in service delivery for those who distrust the system and fear disclosure. They distrust the system and do not believe their information is safe.

The African immigrant population is very transient and consequently does not access care.

Hispanics with no documentation do not enter care. Fear and social stigma plays a similar role in this community, however, the undocumented have little motivation to seek testing since subsequent care would be very difficult to obtain.

If individuals are newly diagnosed, they may elect to stay out of care as long as possible to maintain their employment and conserve resources.

### How to Get Individuals Into Care

To get African Americans into care for HIV, issues of trust must first be addressed. The effects of the "Tuskegee Experiment" are still evident through the belief that AIDS was created to destroy them. A prevention approach should target heterosexual African Americans through the churches and case management assistance should be more accessible to those ready to enter the care system.

Housing is a creative way of getting people into care. Treatment and supportive services could be coordinated through housing providers and clients could be linked to services through churches that are providing HIV programs. Information about anonymous hotlines would allow people to maintain anonymity yet obtain information not easily available to them. Many do not understand the difference between confidential and anonymous testing.

In the Hispanic population, the language barriers need to be overcome and appropriate interpreters should be available to assist with office visits and instructions about medications. Case managers should be skilled not only in case management, but also knowledgeable about HIV, medications, and the Hispanic community.

### How Can Small Agencies Collaborate Better

Smaller agencies tend to avoid collaborations with larger entities for fear of losing their identity. Language in the Request For Proposals that specifically required collaboration among small agencies would help. There could also be a forum for the leaders of smaller agencies to meet and discuss the possibilities of collaboration; however some allowance may need to be made to allow smaller agencies to meet requirements about length of time in operation, performing services, etc.

### Services of Providers

All of the non-HIV services agencies were involved primarily in HIV prevention programs within the African American and Hispanic communities. In the African community, the pastor had established a house for PWA/Hs.

## Recommendations

### Demographics

Increase involvement with all agencies that serve the recently incarcerated including: TDCJ, parole officers, halfway houses, and other services for the recently released.

### Reasons for Seeking Primary Care

From this study, there appears to be three distinct populations within the HIV+ community. Those who either have not been tested or have been diagnosed but have not disclosed their status to anyone and have not entered care (Stage I); those who have been diagnosed, have disclosed their status to a few family members or friends, but have not entered care (Stage II); and those who have been diagnosed, disclosed their status, and have entered care (Stage III). These reflect stages of readiness to change behaviors, in this case accessing care. Therefore, the recommendations differ accordingly.

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| Stage I | Address the community issues of social stigma, moral judgment, and the resulting lack of support for those diagnosed with HIV through churches in the African American community and through public information campaigns in the Hispanic community. |
| Stage II | Target a public information campaign to the families of those with HIV to increase social support and encourage treatment. |
| Stage II | Increase the availability of public information about treatment and referral resources, especially within the monolingual Hispanic and immigrant African communities. |
| Stage II | Actively promote HIV/AIDS information hotlines in the immigrant communities. |
| Stage II | Review service provider policies to identify areas for improvement of confidentiality and/or patient anonymity in order to increase community trust. |

### Factors Supporting Access

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| Stage III | Increase public awareness of available transportation programs, especially within the monolingual Hispanic communities. |
| Stage III | Create a category under "Transportation" for parking fees for medical appointments to authorized specialty care providers. |

## Factors Impeding Access to Primary Care

Stage III Increase number and/or training of case managers in both the African American and Hispanic communities.

Stage III Provide properly trained and medically knowledgeable Spanish interpreters at each primary medical service provider site.

## Ability to Access Medication

Stage III Review policies that allow pharmacies to charge handling fees and consider monitoring for discrepancies or abuses of this system.

Stage III Create an inventory of pharmacies willing to work with clients on fixed incomes.

Stage III Provide education/information strategy classes on managing multiple medications under the restrictions of funding limitations.

## Number Discontinuing Medication

Stage III Create information sheets in English and in Spanish, using understandable terminology to explain the general classifications of medications, the effects of terminating drug therapies, and when it is appropriate to self-terminate therapy versus needing the advice of the physician.

Stage III Medication counseling/case management in Spanish and English.

## Other Recommendations

Stage II Provide housing and other supportive services as a part of health care.

Stage III Offer education programs in the clinics with topics such as English, Nutrition, Getting All of Your Medications, etc.

Stages II, III Provide Adult Day Care programs in the minority populations to help foster social support networks (this may be an appropriate activity for community churches rather than AIDS Care Teams).

Stage III Provide employment services that target individuals receiving government sponsored care.

For Providers Create collaboration forums for small, grassroots organizations that are currently providing supportive services, recruiting these organizations through cultural publications, announcements, and flyers.

## Overview of Project

In an effort to identify specific needs and gaps in HIV services with the African American and Hispanic communities of color, the Needs Assessment Sub-committee of the Comprehensive HIV Planning Committee developed a focus group format and a series of questions to be asked of the various community members and non-HIV service providers. This information was collected through a total of seven focus groups with members of the African American (4 groups) and Hispanic (2 groups) communities and one focus group with non-HIV service providers during the month of December 2000.

The community focus groups were held in three locations—The Working Class, a non-profit employment-training agency for people with HIV/AIDS, Amigos Volunteers in Education and Services (AVES) and the Donald R. Watkins' Memorial Foundation. Four groups were with males and three with females. Recruitment for participation was conducted through flyers to agencies and the Learning, Empowerment, Advocacy and Participation (LEAP) class, to the Thomas Street and Donald R. Watkins' clinics and through personal word of mouth. An effort to recruit HIV positive Africans and Caribbeans met with no success, even though the Donald R. Watkins' clinic was identified as the primary medical provider to which Saving Lives Through Alternate Options (SLAO), the primary non-profit agency serving this population referred clients. Staff at SLAO indicated that individuals with HIV in their community were extremely difficult to identify, very closeted about their HIV status and would not be willing to participate in this type of project.

A total of 14 males (12 African American and 2 Hispanic) and 11 females (7 African American and 4 Hispanic) participated in the groups and each received two bus tokens and a $10 gift certificate to Fiesta Mart in appreciation for their assistance. African American and Hispanic individuals were selected to facilitate the respective group discussions.

For the non-HIV service providers' focus group, invitations were sent to approximately 20 non-HIV service agencies that had indicated an interest in participating in community activities. Telephone reminders were made to all agencies to encourage participation in the event. Three representatives from agencies serving communities of color and one interested Caucasian community member ultimately attended the focus group for non-HIV services providers. The staff titles of participants were: health educator for an African American organization, pastor of an African faith-based organization, and executive director of a Latino HIV prevention organization. The number of participants was small and the opinions are not inclusive of all thoughts about HIV/AIDS, however they did represent a wide-ranging view on the problem in their respective communities and indicate possible areas for future needs assessment activities.

## Report Organization

All responses made during the community focus groups have been compiled in one section, *Aggregate Responses of Community Focus Groups* and under the general topic headings of each question. These are presented in the voice of the participants. This section is followed by *General Findings of the Community Focus Groups*. The next section includes *the Responses of the non-HIV Service Providers*, and again *General Findings of the Non-HIV Service Providers.* In the two *Findings* sections of the report, the presented issues and concepts are reviewed by the researcher, incorporating information from additional sources. The *Recommendations* section incorporates the recommendations based on both reports.

## Aggregate Responses of Community Focus Groups

### Demographics

The length of time the participants had been living since their HIV diagnosis ranged from 1982 to 2000. While the majority of individuals were living in Houston at the time of their diagnosis, it is interesting to note that three participants came to Houston upon release from the Texas Department of Criminal Justice in Huntsville, and another six moved to Houston sometime after their diagnosis. Currently, participants lived in a scattered pattern incorporating all quadrants of the greater Houston area.

### Reasons for Seeking Primary Care

22 of 25 participants were reportedly receiving primary care. The two not in care were either newly diagnosed, or had intentionally taken themselves out of care. At least six of the 22 (primarily males) in care were diagnosed while sick or hospitalized with what was probably an opportunistic infection. The males were also more likely to have tested periodically, prior to sero-conversion because they were aware of their risky behavior. While two females were diagnosed during pregnancy, more often the females sought testing when their spouse or partner was ill or suspected of risky behavior.

### Delays in Seeking Primary Care

The reasons for delays in entry to care were attributable to personal issues of denial and fear of disclosure. This period of denial differed by individuals and could range from several weeks to years. Individuals who were diagnosed in other cities or who delayed entering care reported being out of the loop and when ready for care, oftentimes didn't know where to go to get the referral or information about services. This was especially true with the monolingual participants. Those actively involved in substance abuse reported not caring about primary care and only sought it after gaining sobriety.

There also appears to be a strong sentiment or suspicion about HIV, medications, and side effects. Comments from participants in all five African American focus groups as well as from the African American service provider suggested that a segment of the African American community believes that HIV/AIDS was created to destroy their community and the medications prescribed when asymptomatic caused side effects that were another means of creating illness.

## Factors Supporting Primary Care

The leading supportive factor of primary care in all groups was access to transportation, followed by having insurance or money for co-payments. The participants in the African American focus groups indicated that a supportive social network of family and friends was also an important aspect of accessing and maintaining care. The women in both groups also needed reliable childcare and transportation programs for affected children.

## Factors Impeding Access to Primary Care

Problems shared across groups were about accessing "insurance" coverage and the certification/re-certification process for Medicare/Medicaid/Harris County Gold Card, prescriptions exceeding the three per month limit, and perhaps most importantly, lack of finances for medication co-payments. The re-certification process can cause delays in scheduled procedures and result in lost referrals and appointments.

The monolingual Hispanic participants had difficulty in identifying how to access care. This was due not only to language barriers but also to the reluctance of community members to admit knowledge about HIV or HIV services. Participants reported that the lack of knowledge about available transportation services delayed entry into primary care. Once in care, the language barrier continued to be problematic during office visits when medical staff were unable to communicate in Spanish and oftentimes recruited a non-medical, Hispanic employee to act as a reluctant interpreter. This was exacerbated when discussing medication regimens and schedules.

## Preferences for Neighborhood Care

The participants were asked their preference for inside-the-neighborhood versus outside-the-neighborhood primary care and the answers were dependent upon where the participant lived. If living around the mid-town area, the participants preferred services in the neighborhood. If participants lived in culturally distinct communities, or long distances from health care providers, they preferred to receive care outside-the-neighborhood. In both instances, they were talking about the same providers. If the community is too closed or homogenous, there is an intense fear of confidentiality breaches resulting in ostracism, discrimination, and isolation. In some Hispanic communities, an individual sharing housing with others could risk losing his/her home if suspected of having HIV.

Desirable qualities of providers are confidentiality, convenience, quality of care, and an accepting environment, however the fear of patronizing a clinic for HIV treatment was stronger than these needs. An additional problem for those going outside their community for services was inconvenience, distance and travel time. Garage parking fees caused financial strains for those with their own transportation.

## Activities Managing HIV Disease

Across groups, the primary activity in managing HIV disease was adherence to medical appointment schedules and medication regimens.

### Use of HIV Medication

19 of the 25 participants reported to be knowledgeable about HIV medications; and of these, 15 were taking anti-retrovirals; 9 were on prophylactic antibiotics; 11 were taking anti-depressants; and blood pressure medications was the most frequently mentioned non-HIV medication. The Hispanic group participants were more likely to be using alternative forms of therapy, including massage, herbs, counseling/support groups and biofeedback.

### Ability to Access Medication

Participants knew how to access medications, and prescriptions were usually filled at the clinic, or pharmacy and were paid through SSI, Medicaid, ADAP, the Gold Card, and The Assistance Fund.

Barriers to medications were caused by lack of finances. Participants across groups reported that because they didn't have the money for the prescription co-payments, they went without medications, had to select the three "most important" prescriptions to fill, took forced "drug vacations", and so on. They reported problems when trying to order refills if they were not completely out of their medicine, long delays at the Thomas Street Clinic, prescriptions not ready at the appointed times, and in two instances, participants reported receiving someone else's prescription. As discussed earlier, monolingual clients unfamiliar with the transportation system did not know how to pick up their prescriptions.

In two instances, in one male group and one female group, participants reported relying on samples from the doctor's office because they couldn't afford to pick up the prescription.

### Number Discontinuing Medication

Nine of the participants reportedly stopped taking medications, 4 at the recommendation of their physician; and three had taken "drug vacations" at some point in their therapy. The reasons were as follows:

Ceased Medications

- Improved CD4 count -1
- Experimenting to see what would happen - 3
- Medicine ineffective - 1
- Uncontrollable side effects – 3
- Contraindicative with diabetes medicine - 1

Drug Vacations

- No money for medicine – 2
- Just stopped - 1

Across groups, individuals discussed experimenting with their prescriptions. One male was enrolled in a clinical trial and took himself out of it because of the side effects. He later learned from his physician that the study had been stopped due to conflicting findings, confirming his belief that the medications were not helping him.

## Challenges Common in Minority Communities

Within both the African American and Hispanic communities there is a pervading fear of disclosure. HIV positive individuals do not reveal their status and the topic is not discussed. There is shame and social stigma attached to the disease. There is a general *appearance* of a lack of knowledge about HIV, who should be tested, how to get tested, and where to go for treatment. This is more of a “refusal” to learn, attributable again to the stigma of HIV/AIDS. Those who are “too interested” or “know too much” are thought to be HIV positive. In the words of one participant, “If you know too much, you must have it.”

### *D. Other Community Challenges:*

- Problem not the service providers but the people –strong stigma of HIV/AIDS
- People still consider it a gay disease
- Lack of support from the community to stop using drugs
- Lack of acceptance of HIV positive individuals
- Lack of acceptance of homosexuals
- Discrimination against PWA/H
- Moral judgment of PWA/H
- Gays are assumed to be positive

## The African American Community

In the African American community there is a sense of secrecy about sexuality in general and although the community experiences problems with sexually transmitted diseases and incest, it is not discussed within families or among friends. Coupled with the lack of knowledge, there is a low perception of risk and a refusal to listen to information when it is provided. Individuals caught up in a cycle of drug abuse do not value themselves or health care and avoid treatment, even if they know they are HIV positive. Additionally, there is a belief that HIV/AIDS is a contrived disease, developed to kill African Americans.

## The Hispanic Community

Within the Hispanic community, it is the social norm to ***not*** ask for help, which complicates even further problems with communication and identifying sources of information or services. There is also a deep fear of isolation and ostracism from the community. Many working poor and undocumented individuals share housing and living expenses, and fear losing this support if identified as HIV positive. Those who may meet the criteria for changing their legal status are precluded from doing so if they are HIV positive (because this requires an HIV test). They also have many problems in finding employment, and this was a concern for both the men and the women. If they are not eligible for any entitlement funds and cannot work, the problems become overwhelming.

## Challenges Caused by Service Providers

The participants listed only two concerns stemming from service providers, one is the fear of being recognized while in clinic; and the second need is for more bilingual medical staff or trained interpreters.

E. *Challenges Caused by Individuals*

The individual challenges mirror those of the community norms in that there is a lack of information and risk awareness, a denial and refusal of treatment, or the delay of treatment until experiencing symptoms. Those that are HIV do not share information with others who need to know how to access services.

## HIV/AIDS Services Needed but Not Located

Housing and employment were very important to the participants when asked about other needed services. Participants relayed that people with HIV are on a low, fixed income and have trouble identifying affordable and safe housing. Many individuals were interested in working yet needed to remain within entitlement eligibility guidelines. In order to work, there would be the need for educating employers about medical regimens and some allowance in the pre-employment physical. This gap, or need for viable employment appears to be supported when reviewing the number going without medications because they need a little extra money.

While there were no HIV/AIDS services needed but not available to the participants, they did voice the need for supportive services for non-HIV partners and children

## Participants offered the following suggestions as ways to improve HIV health care:

- *Increase transportation programs - 2*
- Provide transportation to support group meetings -1
- ***Offer HIV study groups and/or medication counseling -1***
- Make Medicaid available to all people with HIV -1
- Improve access to medications with help on co-payments, unlimited prescriptions, and expanded formulary to include non-HIV medications -1
- Provide decent, transitional and permanent housing to male and female PWAs -1
- Increase number of specialty clinics in multicultural/open communities -1
- Offer continuum of care in one location -1
- Address the problem of crack cocaine use -1
- Offer English classes in the clinics -1
- Hire more bilingual medical staff -1
- Offer more genotypic and phenotypic testing -1
- Hire more compassionate service providers -1
- Improve communication channels about accessing case management services -1
- Hire more skilled case managers who can address not only services, but also medication issues and questions about the virus. -1
- African American Adult Day Care –1

## General Findings of the Community Focus Groups

A significant percentage of the respondents (6 of 25) reported coming to Houston *after* an HIV diagnosis and another three elected to come to Houston upon their release from the Texas Department of Criminal Justice (TDCJ). This appears to indicate that **individuals with HIV/AIDS living in other geographical regions may be relocating to Houston, and that Houston may be the city of choice for recently released offenders with HIV.** According to the most recent data from the Texas Department of Criminal Justice (1999), Harris County receives the highest number of recently incarcerated individuals--6,934 males or 22.1% of all released males, and 978 females, or 24%. Of these approximately 2.5% are estimated by TDCJ to be HIV positive. This translates to 198 HIV positive, recently incarcerated individuals entering the service care system in Harris County annually.

For the most part, **males are not diagnosed for HIV until symptomatic** and in a system of care. The females were being tested while asymptomatic because of the illness of a husband or partner. Two women were diagnosed during prenatal care.

**The primary problem in getting into care was denial and the second was the need for trustworthy information once a decision to enter care had been made.**
Denial was the overriding issue around delays into care. In the words of the African American non-HIV service provider, “There is nothing you can do to get them into care if they don’t want it.” The denial stems from dealing with the very personal acknowledgement and acceptance of having a terminal illness and is compounded by the community norms, moral judgments and social stigma typified by the statement, “If you’re HIV, you must have done something wrong,” or “If you know too much, you must be HIV.” Those living in culturally distinct communities share core values and beliefs about HIV/AIDS. Individuals feel they are easily recognized within their community and there is no anonymity. This leads to an intense reluctance within the African American community to engage in any behavior that would indicate they were HIV positive, including learning about the disease or visiting any clinic that provides HIV treatment—in or out of the neighborhood.

Periods of denial vary by individual and can last years. At some point, they make the decision to seek care and risk being known as an HIV positive individual. It then becomes an issue of time and space. It can be assumed that many, if not most, have not retained any information received at the time of testing and must seek it anew. They must begin their own data gathering process and good information will be dependent upon who they know and what that individual is willing to share. Realizing that it is not “good” to know too much information, the task becomes more arduous. By providing a strong public identity, an agency may attract calls from individuals ready to enter care.

While the social stigmas are the same in the Hispanic community, many of them are faced with additional decisions—if undocumented, they feel there is no reason to test because there are no services and no help. Knowing their HIV status does not make life easier. In fact, because of close living arrangements, there is the fear of losing one’s home if known to be HIV positive. It is difficult to receive mail or take medications without detection hence the fear of social ostracism is very great. It is difficult to get a job if known to be sick and with no entitlement funding, work is critical for livelihood. In the monolingual communities, it is also very difficult to find information. Those who are HIV positive do not share information for reasons stated above, and there is also a reluctance to ask questions. It is the community norm *not* to ask for help.

**Factors supporting access to primary care are transportation and acceptance by one's social support network.** The family/social support for individuals entering care makes a tremendous difference, especially within the African American community. Several individuals entered care due to the encouragement of their families and it appears to be a factor in continuing in care.

**Factors impeding care were lack of money for co-pays, gaps in coverage due to re-certification policies and within the Hispanic community, difficulty in learning about resources and how to access them because of the language barrier.** Participants in all groups reported the difficulty of staying in care and on their medication regimen when faced with $5, $10, and sometimes $15 co-pays. Those restricted to only three prescriptions per month were forced to pick which prescriptions they must do without. This caused involuntary "drug vacations" in more than one instance. Additionally, those with transportation reported that parking fees at the Medical Center were an additional cost burden while trying to remain in care.

In the Hispanic community, the language barrier impedes the learning process and how to access services.

**The preference for clinic locations—in-neighborhood versus out-of-neighborhood was dependent on the type of neighborhood they lived in.** Those in neighborhoods in close proximity to service providers, such as neighborhoods around the Medical Center, Montrose and Midtown felt the clinics they attended *were* in their neighborhood and liked the convenience. Those living in neighborhoods where they were well known indicated that when they were ready to get medical care, they preferred care outside their neighborhood for fear of recognition. Those living in distant suburbs felt there were no local providers and preferred the care outside their neighborhood for that reason. The clinics provided resources and information and helped to create a social support system and once in the system of care, all participants reported liking their primary care providers no matter where they were located.

**The primary activities associated with managing HIV were attending medical appointments and adhering to the medication regimen.** The Hispanics participants were more likely to be involved with or to have tried alternative types of therapies.

There was a reported high level of knowledge by 19 of 25 participants, and of these 15 were taking anti-retroviral medications, eight were on prophylactic antibiotics, and ten were taking antidepressants. It was not clear if antidepressants were being prescribed because of a diagnosis of depression or because these types of drugs alleviate other symptoms or side effects of other medications.

Participants were aware of the various funding streams for medications including ADAP and the Assistance Fund, however **the principal problem with accessing medications was having money for the co-payments**. Pharmacies are allowed to charge a "handling" fee for filling these prescriptions and the pharmacist makes the decision to charge. While the fee is supposedly set at $5, there were many reports of fees ranging up to $10. Those with private insurance reported a $15 co-payment. This can add up to a sizeable sum if multiple prescriptions are necessary. Participants without the funds reported doing without their medications for some period of time. Others reported relying on samples from the physicians' offices to get them by.

Those in the Hispanic community reported additional problems when first entering treatment. They were unaware of transportation services and had logistical problems in picking up prescriptions from the pharmacy.

When discussing drug vacations and discontinuing HIV medications, **three participants reported experimenting with their medications to find out what would happen with their t-cell count.** This implies not only a willingness to take health risks, but also a lack of knowledge about when it is appropriate to stop a medication, such as an antibiotic, and when it is important to continue despite side effects. About half of those stopping medications (4 of 9) did so on the advice of their physician as a result of uncontrollable side effects.

**The challenges common in communities of color were denial of the problem of HIV, denial and refusal to discuss issues of sexuality, and fear of disclosure.** Within the African American community there is also the need to dispel the commonly held belief that AIDS is a government conspiracy to destroy them.

Finally, **no group identified any specific HIV services that they needed but were unable to get**. While needing services for affected partners and children, no primary care needs went un-addressed.

## Special Focus Group
## Non-HIV Service Providers

**The responses of the representatives of the non-HIV service provider focus group are as follows.**

*How much of a problem is HIV/AIDS a health problem in communities of color?*
All representatives indicated that HIV/AIDS was a health problem in their respective communities.

In the African American community there is anger about the "State of Emergency" and the lack of activity and leadership on the part of city government. While the Houston HIV Prevention Community Planning Group acknowledges that African American women are at the highest risk for HIV, there doesn't appear to be urgency about the situation. Within the community there is a lack of leadership within the African American churches, which are considered the backbone of the community. While there appears to be a growing awareness of the problem of HIV within congregations, there is no insight or direction on how to approach the problem. The only thing the churches currently know is to organize AIDS Care Teams and that is not enough to cope with the growing problems.

While all agencies, regardless of their racial make-up, support the initiative there is the sense within the African American agencies that they do not know what to do to make a difference.

Immigrants with HIV within the community have two primary problems. First, they are immigrants; second, they have no place to stay--and they are coming from everywhere. Members of the African community know that HIV is on the rise, but people try to hide it because there is nothing they can do. There are no services available to them so the church offers prayer. Homelessness within this group is the most critical problem--five people with HIV sought shelter at the church within the past three months. The church is located in a high-crime district and it is hard for people to escape the environment. Additionally, substance abuse is a major problem in the community. The pastor is trying to purchase a group home for people with HIV, however the first effort fell through when the seller learned of the plans for sheltering PWA/Hs.

Hispanics
HIV is one of many needs within the Hispanic community. While working at Ben Taub Hospital, the participant recognized that individuals with HIV have no place to go or family to depend upon when discharged. Within the Hispanic community there is considerable discrimination against people with HIV/AIDS and individuals fear loss of their homes if their families or those they live with find out they are HIV positive. Consequently, they tell no one of their HIV status.

Within the undocumented community HIV is a significant problem. They commonly share housing, live in crowded conditions, and do not want anyone to know their status, again for fear of losing their home.

Participants stated that those with HIV/AIDS need a lot of social support. The Hispanic community needs housing and food first, and then support groups. In order to change the situation, there needs to be constant messages about HIV and acknowledgment of the problem. There also needs to be more education about HIV prevention.

**Do you believe Houston is making progress in the fight against HIV and AIDS?**
The general consensus was that some progress is being made in the fight against HIV/AIDS. The infection rate is not increasing as rapidly as it once was and more community organizations, such as African American churches, are beginning to get involved in educating their congregations. Also, ministers are beginning to talk among themselves, recognizing the emerging needs in their congregations. However, there is a need to expand the focus of HIV prevention by targeting behavioral change and environmental barriers, to focus more on meeting the client where s/he is and providing housing and food as part of HIV prevention.

Ministers in the African Ministry Alliance, an organization of ministers from Gandhi, have been sharing a lot of information and may provide a forum for gathering additional information about the African immigrant community.

Within the Hispanic community, the churches are not at the point of acknowledging the issues around HIV/AIDS such as sex and condom use. If Hispanic youth are to receive this information, schools will have to provide it because it is not available to them through the church or in the home.

*Do you have any personal experience with people with HIV and AIDS who aren't getting medical care?*

A Caucasian community representative knew a number of individuals who currently are not in care and offered the following reasons: 1) financial constraints for those who have been recently diagnosed and do not want to give up their employment nor reveal to their insurance carrier that they have HIV; 2) selection of holistic or alternative treatments to allow for continued employment until they have a greater need to get on medication; and 3) denial of the diagnosis because they are asymptomatic.

African Americans
There are multiple problems that may keep African Americans out of care, the most important being fear of disclosure. The stigma that accompanies an HIV diagnosis is so great that many choose to maintain confidentiality over getting treatment. If the clinic is in their immediate neighborhood, they will not go for fear of being identified. If the clinic is known to provide HIV treatment, even if there is no building signage, they will not go-- including locations like Montrose Clinic, Thomas Street Clinic or any other that can be identified as a treatment center for HIV/AIDS. Individuals may attempt to go out

of the community for care to places like Northwest Clinic, but with that are inherent financial constraints and problems with transportation and child care. If the clinic outside of the community is known as an HIV provider, they will not go.

Many infected African Americans who are gay or substance abusing are not getting care anywhere, not even in gay-friendly clinics. It is socially unacceptable to be gay and people would rather be identified as HIV+. There is a tremendous gap in service delivery for those who distrust the system and fear disclosure. It does not matter what service is offered; if an individual cannot get past the fear, he will not get into care. Individuals do not believe their HIV status information is confidential no matter who runs the agency.

Immigrants

In the African immigrant community, there is still a strong association between being gay and HIV. It is assumed that if you are gay, you are HIV positive. People are very transient; they may be in an area for a couple of months, then move on and never get into a system of care. While some may say they are being treated, it is hard to know if that is true. There are a lot who are infected and continue to have unprotected sex. One church has housed five people in the past three months who claimed to be HIV positive.

Hispanics

The Hispanic participant tested a man two months ago who was HIV positive. Upon seeing him again it was found that he was not in care. Hispanics with no documentation do not enter care because they do not have the proper identification or social security number. Women working in cantinas do not get tested and do not talk about it. They are not in treatment either because they are undocumented or because they do not want to receive treatment for fear of disclosure. Many are infected and simply do not want to know, do not want treatment. They continue to have unprotected sex. The participant reported that the Hispanic community is becoming more accepting of gays.

**What do you think needs to happen in the Houston community to get more African Americans and Hispanics who are HIV+ to go get medical care for their HIV?**

African American
Within the African American community there are many trust issues. There is still the belief that African Americans are being purposefully infected. Even though services are supposed to be confidential, people do not really believe that is true. Anonymous treatment might pull people into care. They would give up the entitlement benefits if they could maintain confidentiality while getting medical treatment and not have to deal with the paperwork. African Americans would rather admit to substance abuse than homosexuality. An effective prevention approach would target heterosexual African Americans through churches.

There is also a problem in accessing case management. The African American agency reported receiving calls daily requesting case management. People knowledgeable enough to request help often cannot get a case manager because the caseloads are too high or the "good" case managers are overloaded. There should be better information about where services are provided and how to access medications, and in the African American community, there are not enough agencies providing case management.

One solution may be to foster smaller organizations that may actually be providing services but are not well known in the funding community and may be overlooked. These agencies are meeting basic client needs such as food and shelter. They may have the capacity but do not know all the players or how to apply for Ryan White funding. To build capacity within smaller organizations, the application process may need to be modified. Many of the smaller agencies need accounting and computer skills and otherwise cannot compete in the funding process.

Housing is a creative way of getting people into care. Treatment and supportive services could be coordinated through housing providers. Clients could be linked to services through churches that are providing HIV programs.

Immigrant
It was suggested that promotion of the toll-free HIV/AIDS hotline to newly diagnosed people, stressing the confidentiality of the service, could be helpful in linking clients to medical care. It is also important to create sufficient structure in a person's life that basic needs are met. Then the individual can focus on medical care and treatment. It is important to have an address, a place to safely receive information and forms without fear of status disclosure.

Hispanics
To make a difference in the Hispanic community the needs are: more accessible services, anonymous services, and more information about existing services promoted at the community level. Also suggested as very important was having trained case managers that "have the soul of a case manager." These individuals should have the skills to communicate and educate about HIV, as well as a thorough knowledge of the

community. Members in the Hispanic community do not understand the difference between anonymous and confidential testing. This must be explained to them.

People in the Hispanic community will not complain about services because they don't want to draw too much attention to themselves. They are afraid to be honest even in one-on-one interviews.

In order to understand about their medications, many Hispanics take someone with them to Thomas Street Clinic to help translate. That is the only way they can be assured that they will understand what is being said. When people are with the doctor, they often do not understand information about the medications and may need written instructions, if they can read. Often, the people used to translate in the clinics are not interpreters and are not knowledgeable about treatments or medications.

It was suggested that it might be possible to use a code number assigned to people wanting care so they would not have to use their names. Access to care must be simplified and explained so that undocumented individuals can receive the care that is available to them. Many people may be eligible to establish residency but will not do so because of the required HIV test. Those that assume they are positive will not test or enter treatment because they fear deportation.

**What has to happen to help small agencies collaborate?**
Ideas to improve collaboration included the suggestion that language in the RFPs require collaboration, especially between small agencies. It was stated that small agencies are afraid to collaborate with the larger agencies for fear of losing "turf" or control, however the smaller agencies should work together. This might require the executive directors of the different agencies to come together in a "collaboration fair" of sorts or a round table discussion. Agencies of similar sizes could match services with needs to coordinate collaboration. Another approach would require a central organization to coordinate all the small agencies and to formulate a policy to support collaboration between agencies, ultimately affording more grant opportunities while offering proof that agencies were true collaborators. Small agencies not recognized by the Health Department may require a more lenient set of measurement criteria with regard to requirements such as length of time in business or history in providing services.

**How do you locate small CBOs who are providing services?**
The most effective way to reach African Americans is to go to the churches. Church newsletters could be used to attract attention to community-based organizations. The most popular radio stations in the African American community are Magic 102 and 97.9.

African Immigrants have several newspapers. US Africa is the most popular one and it was reported that anything put there, people read. Another way to reach the African immigrant community is through announcements and flyers in African stores and posted in African and African American churches.

To reach the Hispanic community the media must be fully utilized. Information would be disseminated more quickly by radio or television than in the newspapers.

Hispanic Newspapers: La Subasta
Hispanic Television Channels: 45 and 48
Radio Station: 93.3

*What is your organization doing to support the fight against HIV in communities of color?*
The African American agency reported that it was conducting HIV prevention programs in substance abuse treatment facilities; outreach/education programs to men, women, and youth; and peer-presented dramas to prisons and other community organizations.

The African American minister had a house for PWAs to assist those coming to his church in need of shelter and care. His is a faith-based organization and they offer prayer and promote an abstinence-based model for HIV prevention.

The Hispanic executive director has been working in HIV prevention and education in the Hispanic community for the past four years. The agency conducts outreach to Hispanic youths in Harris County and has been active in Project Cover-Up, a condom distribution program in targeted areas of Houston.

*Is it possible to put HIV education under another umbrella to promote care? Would community members be more willing to get medical care if it were offered at an STD clinic?*

In the African American community, care at an STD clinic would be more accepted but still a problem. The African American community is afraid of the words HIV and AIDS. If our programs focus on general support and relationship issues, we have no problem getting participants, but if we advertise a class on HIV/AIDS, no one comes.

## General Findings of the Non-HIV Service Providers' Focus Group

***There was a general consensus among focus group participants that*** *HIV/AIDS is a problem in the communities of color.* ***Within the African American community there is a sense of frustration that no actions are being directed toward the "State of Emergency" and while African American churches are increasingly aware of the problem, they lack direction. The problems in the immigrant African and Hispanic communities are compounded by lack of citizenship and access to services and the need for housing.***

**Fear and the stigma of HIV within the minority communities keep people silent.** They fear losing family, friends, homes, and jobs if they are known to be HIV positive.

**Houston is making some progress.** It was generally agreed that some progress has been made in the fight against HIV/AIDS. In the African and African American communities, churches and ministers are beginning to talk about the problems, however participants felt the primary needs of shelter and food would have to be dealt with first before people would listen to messages about HIV. Within the Hispanic community, the church is not a viable vehicle for communicating about HIV/AIDS.

**All participants could give examples of HIV positive individuals who are not currently in care.** When asked why individuals did not seek care, the following reasons were given.

In the African American community, the fear of disclosure and resulting social stigma is much greater than the need for treatment and people will not seek care if there is the possibility they might be recognized. There is a tremendous gap in service delivery for those who distrust the system and fear disclosure. They distrust the system and do not believe their information is safe.

The African immigrant population is very transient and consequently does not access care.

Hispanics with no documentation do not get into care even if positive. Fear and social stigma plays a similar role in this community, however, the undocumented have little motivation to seek testing since subsequent care would be difficult to obtain.

If individuals are newly diagnosed, they may elect to stay out of care as long as possible to maintain their employment.

*What do you think needs to happen in the Houston community to get more Africans, African Americans and Hispanics who are HIV+ to get medical care for their HIV?*
The African American community has many trust issues that need to be addressed before people will feel safe with the available care. The effects of the "Tuskegee Experiment" are still in evident through the belief that AIDS was created to kill African Americans. A prevention approach should target heterosexual African Americans through the churches.

Additionally, case management assistance should be more easily accessible to those ready to enter the care system.

Housing is a creative way of getting people into care. Treatment and supportive services could be coordinated through housing providers. Clients could be linked to services through churches that are providing HIV programs.

Information about anonymous hotlines would allow people to maintain anonymity yet obtain information not easily available to them. Many do not understand the difference between confidential and anonymous testing.

In the Hispanic population, the language barriers need to be overcome and appropriate interpreters should be available to assist with office visits and instructions about medications. Case managers should be skilled not only in case management, but be knowledgeable about HIV, medications, and the Hispanic community.

*What is your organization doing to support the fight against HIV in communities of color?*

The agencies of participants were involved primarily in HIV prevention programs within the African American and Hispanic communities. In the African community, the pastor had established a house for PWA/Hs.

*Is it possible to put HIV education under another umbrella to promote care? Would community be more willing to get medical care if at an STD clinic?*
In the African American community, care at an STD clinic would be more accepted, but still a problem.

**What has to happen to help small agencies collaborate?**
Small agencies avoid collaborations with larger entities for fear of losing their identity. Language in the Request For Proposals that required collaboration among small agencies would help in encouraging collaboration efforts. There could also be a forum for the leaders of smaller agencies to meet and discuss the possibilities of collaboration; however some allowance may need to be made for smaller agencies to meet requirements regarding length of time in operation, performing services, etc.

Channels of Communication in Communities of Color
African Ministry Alliance – ministers from Gandhi
African Newspapers – US African
Flyers to African stores and African and African American churches
Hispanic Newspapers – La Subasta
Hispanic Television Channels – 45 and 48
Hispanic Radio Stations – 93.3
African Americans – church newsletters
African American Radio Stations – 102; 97.9

## Responses by Ethnicity and Gender

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### African American Males
### N = 12

#### Demographics

The participants report the length of time since diagnosis for HIV/AIDS from 1983 to 2000. While most of the participants currently lived in or near midtown Houston, three of the 12 moved to Houston after their diagnosis from places such as Atlanta, Chicago, and Huntsville (released from Texas Department of Criminal Justice).

#### Opportunistic Infections

Three of the 12 were currently experiencing some symptoms or opportunistic infections, however four of them indicated entering the hospital for treatment for a variety of complaints and receiving their diagnosis at that time.

#### Reasons for Seeking Primary Care

Ten of the twelve were currently in primary care. One individual had been recently diagnosed and was trying to figure out the system, and a second individual had taken himself out of care.

While four were diagnosed while hospitalized and referred into primary care, another three were referred into treatment after participating in a health fair, donating blood, or as part of service at SEARCH.
Three others recognized their own risky behaviors, suspected exposure and sought testing. In fact, two routinely got tested for HIV prior to their sero-conversion. Another two entered care because of family pressure, and one entered care while incarcerated.

Even though there was a referral into primary care, the clients delayed entering treatment, primarily to cope with the issues of denial. One participant visited Thomas Street Clinic three different times and sat in the dining room listening to the various conversations before making a decision to enter care. Even though diagnosed while hospitalized, one participant delayed treatment for about a year, and another was so worried about disclosure that he refused to pick up literature or be around anything that would suggest he was HIV positive. He finally found an individual within in ASO with whom he had a comfort level, and then entered medical treatment.

There were other reasons given for delaying treatment, including lack of transportation to a service provider, substance abuse issues overriding the need for medical care, and not least, a suspicion of the treatment. Several comments reflected the belief that people with HIV are being poisoned by the medicine (illness caused by the side effects rather than the infection) and that HIV is a conspiracy to kill African Americans. While on the whole, most participants seemed to understand about the possible side effects of HIV medications, these conspiracy belief constructs pose barriers to entering primary care.

## Factors Leading to Primary Care

Two of the participants discussed the problems in identifying service providers. Those not immediately entering care after diagnosis, for whatever reason, may get lost to follow-up, and after dealing with denial or fear, or the other reasons for delaying treatment, the individual may not know how to re-connect with service providers. For these reasons, they suggested additional outreach and education as possible interventions leading to primary care.

Other important factors enabling primary care were access to transportation, medical insurance, and a support network of family and friends. There is an intense fear of isolation and discrimination because of HIV.

## Inability to Access Care

In the past year, one individual had a problem in getting psychiatric and HIV medication because he had problems with Medicare eligibility and no money for the co-payment.

## Neighborhood Care

There was about an equal number preferring care in their neighborhoods versus outside their neighborhoods. Those living near the Montrose area preferred care in their neighborhoods and those living in more distinct cultural communities preferred care outside their neighborhood.

The reasons for preferring care inside the neighborhood were: convenience, location, and quality of care.
Barriers to care inside the neighborhood were: stigma, care not available, ignorance of community members, and breach of confidentiality.

The reasons for preferring care outside the neighborhood were: quality of care, supportive environment, confidentiality, and avoiding the stigma of being known as having HIV.
Barrier to care outside the neighborhood was: transportation.

## Activities to Manage HIV Disease

Adhering to a medical regimen was the primary activity of participants in managing their HIV disease.

## Use of HIV Medications

Nine of the twelve participants were knowledgeable about HIV medications, specifically anti-retrovirals and prophylactic antibiotics. Six of the twelve reportedly were on anti-retrovirals and two were on prophylactic antibiotics, three were taking anti-depressants and only one reported taking food supplements.

Non-HIV medications included medications for: blood pressure (3), sinusitis (2), pain management, toxoplasmosis, and insomnia.

The reasons for not taking the medications were, in the case of anti-retrovirals, the accompanying side effects, and for prophylactic antibiotics, an improved CD4 count.

## Ability to Access Medications

All those on medications usually had no problems accessing their medications and had their prescriptions filled at the clinic (Thomas Street Clinic or the Veterans' Administration Hospital), picked it up at the pharmacy or had it mailed to their home.

When problems occurred, it was primarily due to lack of finances, or no money for the co-payment. Three of the participants reported going without medications for various lengths of time while trying to pull together the co-payment for their prescription. This was compounded by their reports of not being able to get a refill until they were out of the medication. There was also the report of getting the wrong prescription or that the prescriptions were not ready at the promised time.

In addition to cash for co-payments, the participants used Social Security Insurance, the Assistance Fund program, the Texas ADAP and Medicaid to fund their medications. Additionally, one male reported relying at times on samples of medications from the doctor's office.

## Number Discontinuing Medication

Four participants reported taking themselves off HIV medications, and two reported taking a "drug vacation", one officially sanctioned by the physician. The reasons for stopping the medications were: improved CD4 count; doing own experiment (two participants); and, ran out of medication. One individual taking a drug vacation reported re-experiencing the side effects of the medications.

The frequency of "experimenting" with medications is a point of concern as is the "physician sanctioned" drug vacations. This reinforces the "conspiracy" theory that the medications are another means of making people sick.

## Challenges Due to African American Ethnicity or HIV Status

The male participants reported the following challenges in the African American community:

- HIV positive people refuse to discuss their status because of the stigma and shame associated with the disease.
- There is a sense of secrecy around sex and incest and it is not a topic that is discussed within the family.
- There is a general lack of knowledge about HIV and no perception of risk, coupled with a refusal to listen to information that is provided.

## Challenges of the Community in Receiving Treatment

*Challenges caused by Service Providers*

- *Lack of confidentiality*

## F. Challenges caused by Individuals

- *Active in substance abuse*
- *Fear of services*
- **Not knowing how to access services**
- *Denying HIV status*
- *Delaying therapy until symptomatic*

## G. Challenges caused by Community

- *Problem not the service providers but the people – still a strong stigma attached to HIV/AIDS.*
- *People still consider it a gay disease or think it can't happen to them.*

## HIV/AIDS Services Needed but Cannot Be Located

- **Support groups**
- *Education*
- *Dental Care - Unable to get dental care at Bering because it has been labeled "cosmetic surgery"*
- **Housing – most people with HIV on fixed incomes and difficult to find housing with low incomes**
- *Employment – there needs to be something set up that can assist people that are HIV positive to be able to work and stay within the eligibility ranges – to be able to make extra money and be productive with time*
- *Understanding employers*

## Suggested changes to providing HIV health care in your area

- **Improve transportation**
- *HIV study groups*
- *Make Medicaid available to all people with HIV*
- *Provide transitional and permanent housing to PWA*
- *Provide housing to single men, not just women and children*
- *Provide decent housing, not in areas with lots of drug abuse and run-down buildings*
- *Help people with medication co-pays*
- *Cover costs of non-HIV medications*
- *Adult Day care for African Americans*
- *Unrestricted access to medications*
- *More accessibility in all areas*
- *More personalized care*
- *One-stop care*

## African American Females
## N = 7

### Demographics

The participants reported the length of time since diagnosis for HIV/AIDS from 1989 to 2000 with three of the women reporting a 2000 diagnosis. The participants reportedly resided in all parts of Houston—southwest, northeast, Third Ward and Fifth Ward. When asked about their residency at the time of diagnosis and now, most women were living in that same general community, with the exception of one woman who was in the Texas Department of Criminal Justice (TDCJ) system at the time of diagnosis.

### Opportunistic Infections

Five of the seven participants reported symptoms of an opportunistic infection such as bacterial infections, thrush, fatigue and neuropathy.

### Reasons for Seeking Primary Care

Six of the seven reported receiving primary care. Four were referred to care upon diagnosis, one was receiving care through TDCJ, and one entered care because she feared the disease.

The reasons given for delaying entry into medical care were: fear, denial, and actively substance abusing and didn't care.

### Factors Leading to Primary Care

The African American women reported accessible transportation as the primary factor enabling access to primary care. This was followed by insurance or Medicaid/Medicare coverage, a supportive social network, reliable childcare and information about available services. While discussing transportation, the participants reported on the problems caused by program policies that disallow affected children from transportation services.

### Inability to Access Care

In the past year, three women reported needing but unable to get medical care. Only one woman explained her problem, which was unrelated to service accessibility. (She needed a surgical procedure with a lengthy period of recovery and had no one to care for her children.)

### Neighborhood Care

The women did not live in communities with care and preferred the care outside of their neighborhood. They were generally well pleased with the services at Thomas Street Clinic and Northwest Clinic, primarily because of the quality of care, the confidentiality of the services, and the sense of community within the clinics. (Everyone was there for the same purpose and there was no reason to hide or feel ashamed.)

There were problems associated with receiving care outside of the neighborhood and these were transportation or having the self-motivation for the extra effort it took to travel outside of the community. While there was general discussion about the convenience of having services within the community, the fear of disclosure and stigma attached to patronizing a clinic treating HIV were stronger than the need for the convenience of an easy location.

## Activities to Manage HIV Disease

Adhering to medical regimen was the primary activity of participants in managing HIV.

### Use of HIV Medications

Four of the seven participants were knowledgeable about HIV medications and four of them were taking anti-retrovirals, two were on prophylactic antibiotics, one was on anti-fungal medication and three were taking anti-depressants.

The only non-HIV medication reported was for treating elevated blood pressure.

Alternate therapies included: massage, herbs, and food supplements (2).

Four women reported the reason for not taking the medications were side effects with the anti-retrovirals and that the anti-depressants were not effective.

### Ability to Access Medications

One woman reported problems accessing medications because ADAP had denied her application and she was utilizing the services of the Assistance Fund for her prescriptions.

Barriers to getting medications were due to lack of transportation to pick up the medications; long waits at the pharmacy, prescriptions never ready when promised, and being given the wrong medication.

In addition to cash for co-payments, the participants received medications through the Gold Card (3), Medicaid, the Texas ADAP or help through the Assistance Fund.

### Number Discontinuing Medication

Only one woman reported taking herself completely off HIV medications because she did feel the medications were effective. Another reported taking a “drug vacation” because she did not have the money to pay for the medications.

### Challenges Due to African American Ethnicity or HIV Status

The female participants reported the following challenges in the African American community:

- A fatalistic attitude and the belief that HIV was “made” to get rid of African Americans.
- Drug abuse issues.

## Challenges of the community in receiving treatment

*Challenges caused by Individuals*

- *Drug addiction*
- **Lack of knowledge and awareness about HIV**

**Challenges caused by Community**

- *Lack of support from the community to stop using drugs*
- *Stigma and rejection by own community,*
- *Need to be accepted as a human being and treated with respect*

## HIV/AIDS Services Needed But Cannot Be Located

- *Lack of services for non-HIV partners*

## Suggested changes to providing HIV health care in your area

- *Address the problem of crack cocaine use*
- *More HIV specialty clinics like Thomas Street*

## Additional comments

- *Concern about the new political administration cutting funding*
- **Treat patients like people, not a number**
- *Take the politics out of it.*

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## Hispanic Males
## N = 2

### Demographics

Two Hispanic males participated in this focus group and reported a diagnosis of HIV in 1999.

## Reasons for Seeking Primary Care

Both of the individuals were currently receiving primary care and both were referred into care after being sick with what was probably an opportunistic infection (fever; gum infection).

### Factors Leading to Primary Care

The important factors enabling primary care were 1) transportation. The participants were reliant on friends or family members for transportation.

## Inability to Access Care

In the past year, one participant lost his employment due to excessive absences and when he no longer had insurance coverage, he did not know how to access the public sector service delivery system. He had a friend that guided him through the process and helped him gain access to care.

Both participants discussed the language barriers within the health care delivery system. With a poor command of the English language, they had to wait longer at the medical visit for help in translating the information and in many instances, the person helping them was not appropriate in that it was someone from an ancillary department (cleaning, clerical, etc.) and these individuals would be coerced into helping translate, resented that they were pulled away from their jobs, and offered poor translation service in the process. This especially caused problems for the participants when trying to understand about medication schedules.

### Neighborhood Care

Both participants preferred care within the neighborhood, and one even suggested that care be delivered in-home to help preserve confidentiality. The problem with receiving care outside the neighborhood was again due to problems with transportation.

### Activities to Manage HIV Disease

Both participants reported adherence to medical regimens as well as an exercise program as activities helping them manage HIV disease.

### Use of HIV Medications

Both participants reported knowledge of HIV medications and both were taking anti-retrovirals and prophylactic medications. One of the respondents was also taking anti-fungal medications, steroids, and anti-depressants.

The only non-HIV medication reported was for treating insomnia. Alternative therapies included: massage, herbs, biofeedback, and food supplements (2).

## Ability to Access Medications

Both participants were able to access medications and had their prescriptions filled at the clinic. There were sometimes problems with Gold Card re-certification and miscommunication because of the language barrier.

### Challenges Due to Hispanic Ethnicity or HIV Status

- Unemployment – can't pass employment physicals
- Discrimination within the community
- Ostracism within the community
- Fear of isolation

### Challenges caused by the Service Provider

- Inadequate number of bi-lingual health care providers

### Challenges caused by Individuals

- Refusal of treatment
- Unwillingness to be open and share information

**Challenges caused by Community**
- Lack of acceptance of HIV positive individuals
- Lack of acceptance of homosexuals
- Discrimination against PWA/H
- Rejection by family and loss of home

**Suggested changes to providing HIV health care in your area**
- More transportation
- Transportation to support group meetings
- English classes
- More bilingual medical staff
- More genotypic and phenotypic testing
- More compassionate service providers
- Accessible information about case management services
- Medication counseling
- More skilled case managers who can address not only services, but also medication issues and questions about the virus.

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## Hispanic Female
**N = 4**

### Demographics
**Three of the four participants lived in mid-town Houston and the fourth lived in Pasadena. At the time of diagnosis, the women were in Houston, Pasadena, San Antonio, and Huntsville (TDCJ).**

### Reasons for Seeking Primary Care
Two of the four women were tested for HIV when their husbands were diagnosed, while a third suspected her husband of risky behavior and sought testing. The fourth participant was diagnosed while in TDCJ.

None reported a delay in entry into medical care after diagnosis.

### Factors Leading to Primary Care
**The Hispanic women reported accessible transportation as the primary factor in accessing primary care. This was followed by insurance or money for co-payments, and childcare.**

### Inability to Access Health Care
All four participants reported problems accessing primary care during the past year. One participant had been scheduled for surgery and presented to the hospital the day of the scheduled procedure only to have the surgery cancelled because it was time for re-certification. Another had problems getting help with a pregnancy-related problem.

The women did not get the needed services because: referrals were lost during the re-certification process and delayed treatment; more than the allowable number of prescriptions and had to chose which prescriptions to fill and which to do without; no knowledge of transportation services so went without care until in the case management system; and no child care.

## Neighborhood Care

The women receiving care within their neighborhood were satisfied with the services. The participant living in Pasadena had to travel 20 miles for care because there were no providers in her area (on her insurance program). The distance is problematic and there is no public transportation from Pasadena to the providers in Houston. Those with cars also discussed the barriers caused by parking lot fees – in some instances $8.

### Activities to Manage HIV Disease

The activities used to manage HIV disease included: medical appointments and adherence to drug regimen, peer counseling and support groups, vitamins, exercise, and drama therapy.

## Use of HIV Medications

All of the women were knowledgeable about HIV medications and three of the four were taking anti-retrovirals and prophylactic antibiotics, of these two were also taking anti-fungal medications, anti-depressants, or other non-HIV related medications.

## Ability to Access Medications

All reported that medications were accessible, and usually received through Thomas Street Clinic, a pharmacy, or through doctor's samples.

Barriers to getting the medications are the co-payment for each prescription or if more than three prescriptions a month are ordered. There are also problems in paying for non-HIV medications.

In addition to cash for co-payments, the participants received medications through Medicaid, private insurance, and the Gold Card.

### Number Discontinuing Medication

Three of the four women have discontinued medication at some point and one has taken a "drug vacation". The reasons for discontinuance were: uncontrollable side effects (3); contra-indicative with diabetes medication so participant and physician determined together to forego the HIV medications for the present. When discussing "drug vacations" the respondent experimented with the stopping the protease inhibitor "to see what my t-cells would do."

## Challenges Due to Hispanic Ethnicity or HIV Status

The female participants in the Hispanic focus group were primarily concerned with problems of employment and HIV. Two of them talked about the need to have an employer who wouldn't need to know about the HIV status and would understand about the numerous medical appointments. The other two women haven't disclosed their status to their families and talked about the difficulties of disclosure.

### Challenges of the community in receiving treatment

- *Hispanic immigrant population is scared, there is a lot of shame and fear of opening up;*
- *Fear of discrimination – that's why I didn't get help at first.*
- *Fear of discrimination to be viewed as 'less than'*
- *Don't want to ask for help*

### HIV/AIDS services needed but cannot be located - no

### Suggested changes to providing HIV health care in your area

- *Having to repeat how you got infected to every provider.*
- *More assistance with medications.*
- *Lots of women aren't taking all the medications that they should because they can't afford it*
- *Timely and reliable transportation*

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Responses of All Males

1. African American Males – *12 participants*
   Hispanic Males – *2 participants*

   A. Length of HIV Infection
      *Since 1997, 1991, 1998, 1988, 1996, 1984, 1999, 2000, 1999, 1996, 1996, 1983*
   B. Current Residency
      *9418 Arcola, Montrose, Houston, 5th Ward, Museum District, 249 & Ella Northside, Montrose, Medical Center*
   C. Residency at time of diagnosis,
      *5th War -2, homeless, Atlanta, Huntsville, Riverside, Southside, Northside, Third Ward, Chicago*
   D. HIV symptoms or OI's
      *Depression*
      *Neuropathy -2*

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3. African American Males - Is HIV primary medical care available to you? *Yes-8*
   Hispanic Males - Is HIV primary medical care available to you? *Yes – 2*

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4. African American Males - Number of individuals receiving primary medical care. *Yes - 10*
   4.1 Reasons for seeking primary care

- *Treatment/hospitalization for an OI - 4*
- *Referred at diagnosis – 3*
  *(SEARCH, blood donations, Salvation Army Health Fair)*
- *Engaged in high risk behavior and suspected exposure – 3*
- *Family pressure - 2*
- *Incarcerated*

4.2 Reasons for not getting primary medical care

- *Lack of transportation*
- *No treatment available at time of diagnosis*
- *Substance abuse*
- *Suspicious of treatment*
- *Recently diagnosed*
- *Denial*

4.3 What changes would lead to seeking primary medical care
*More outreach and education*

4.4 Important factors that enable you to get primary medical care

- *Transportation – 3 (Bus tokens from various sources, bus card, taxi rides from Associated Catholic Charities)*
- *Insurance*
- *Support of family and friends*

4. Hispanic Males - Number of individuals receiving primary medical care - 2

4.1 Reasons for seeking primary care

- *Medical visits due to OI, referred into care - 2*

4.2 Reasons for not getting primary medical care

4.3 Important factors that enable you to get primary medical care

- *Transportation*

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5. African American Males - In the past year, number needing but unable to get medical care - *1*

5.1 Specific health problem or need

- *Psychiatric medication*
- *HIV Medication*

5.2 Reason for not getting medical care

- *No money to pay for all co-pays and was refused one medication.*
- *If seeing a specific physician, restricted to appointments on specific days.*
- *Problem with Medicare eligibility.*

5. Hispanic Males - In the past year, number needing but unable to get medical care *- 1*

5.1 Specific health problem or need

- *Lost employment and insurance due to excessive absences – didn't know where to go for services.*

5.2 Reason for not getting medical

- *Problems with language barrier.*

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6. African American Males - Number preferring neighborhood care vs. care outside the neighborhood
    - **In neighborhood-4**
    - *Outside neighborhood - 3*

6.1 Reasons for preference for care outside neighborhood
- *Quality of care*
- *Surrounded by others with HIV (one big family)*
- *Confidentiality*
- *Stigma in the community*

6.2 Barriers to care outside neighborhood
- *Transportation*

6.3 Reasons for preference for care within neighborhood
- *Convenience*
- *Location*
- *Quality care*

6.4 Barriers to care within neighborhood
- *Care not available*
- *Stigma*
- *Ignorance of community members*
- *Breach of confidentiality*

6. Hispanic Males - Number preferring neighborhood care vs. care outside the neighborhood

Reasons for preference for care within neighborhood
- *It's easier and closer*
- *It's better in the area – better to get care at home.*

6.1 Reasons for preference for care outside neighborhood
- *Confidentiality*

Barriers to care outside neighborhood
- *Problems with transportation - 2*

6.2 Barriers to care within neighborhood

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7. African American Males - List of activities to manage and/or treat HIV
    - **Medications-3**
    - *Routine medical care – 3*
    - *Spiritual faith*
    - *Bering Care Center*
    - *Exercise*
    - *Exchange treatment information with other clients*
7. Hispanic Males - List of activities to manage and/or treat HIV
    - *Medical visits 2*

- *Medications regularly - 2*
- *Exercise - 2*
- *Vitamins*
- *Counseling – individual*
- *Massages*
- *Nutritionist, supplements*
- *Chiropractor*
- *Physical therapy*
- *Herbal*

8. African American Males - Use of HIV medications

8.1 Number of those with knowledge about HIV medications – *9*

A. Anti-retrovirals - *8*
B. Prophylactic antibiotics - *4*
C. Anti-fungal medications
D. Steroids
E. Anti-depressants/anti-anxiety medications
F. Other prescription or non-prescription medications
G. Massage
H. Herbal therapies
I. Biofeedback therapies
J. Acupuncture
G. Food supplements

8.2 Number taking each type

A. Anti-retrovirals - *6*
B. Prophylactic antibiotics - *2*
C. Anti-fungal medications - 0
D. Steroids - 0
E. Anti-depressants/anti-anxiety medications - *3*
F. Other prescription or non-prescription medications
  - *Pain meds - 1;*
  - *Toxoplasmosis –1*
  - *Blood pressure -3*
  - *Sleeping medication*
  - *Acid reflux medication*
  - *Sinus -2*
G. Massage – 0
H. Herbal therapies - 0
I. Biofeedback therapies - 0
J. Acupuncture - 0
G. Food supplements - 1

- 8.4 Reasons for not using specific medications
  - A. Anti-retrovirals – *side effects - 2*
  - B. Prophylactic antibiotics – *improved CD4 count*
  - C. Anti-fungal medications
  - D. Steroids
  - E. Anti-depressants/anti-anxiety medications
  - F. Other prescription or non-prescription medications
  - G. Massage
  - H. Herbal therapies
  - I. Biofeedback therapies
  - J. Acupuncture
  - G. Food supplements

8. Hispanic Males - Use of HIV medications
- 8.1 Number of those with knowledge about HIV medications
  - A. Anti-retrovirals -*2*
  - B. Prophylactic antibiotics -*2*
  - C. Anti-fungal medications -*1*
  - D. Steroids - *1*
  - E. Anti-depressants/anti-anxiety medications -*1*
  - K. Other prescription or non-prescription medications
    - *a. sleep aids*
  - G. Massage - *1*
  - H. Herbal therapies - *1*
  - I. Biofeedback therapies - *1*
  - J. Acupuncture
  - K. Food supplements - *2*
- 8.2 Number taking each type
  - A. Anti-retrovirals - *2*
  - B. Prophylactic antibiotics - *2*
  - C. Anti-fungal medications
  - D. Steroids - *1*
  - E. Anti-depressants/anti-anxiety medications - *1*
  - F. Other prescription or non-prescription medications – *1*
  - G. Massage - *1*
  - H. Herbal therapies - *1*
  - I. Biofeedback therapies - *1*
  - J. Acupuncture
  - J. Food supplements - *2*
- 8.3 How do the medications work?
  - A. Anti-retrovirals - *2*
  - B. Prophylactic antibiotics - *2*
  - C. Anti-fungal medications - *1*
  - D. Steroids
  - E. Anti-depressants/anti-anxiety medications - *1*

F. Other prescription or non-prescription medications - *1*
G. Massage - *1*
H. Herbal therapies sometimes
I. Biofeedback therapies – *1*
J. Acupuncture
K. Food supplements – *2*

8.4 Reasons for not using specific medications
A. Anti-retrovirals
B. Prophylactic antibiotics
C. Anti-fungal medications
D. Steroids
E. Anti-depressants/anti-anxiety medications
F. Other prescription or non-prescription medications
G. Massage
H. Herbal therapies
I. Biofeedback therapies
J. Acupuncture
G. Food supplements

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9. African American Males - Ability to access medications

9.1 Are medical treatments available and why not – *Are accessible - all*

9.2 How are medications accessed
- *Pharmacy*
- *Mail*
- *VA*
- *Thomas Street Clinic*

9.3 List of barriers to getting medication
- *Confidentiality*
- *Financial – 3*
- *Can't get straight information from pharmacist regarding when medications will be ready for pick-up*

9.4 Methods of paying for medications
- *Social Security Insurance – 2*
- *Assistance Fund*
- *ADAP*
- *Medicaid*
- *Samples from doctor's office*
-

9. Hispanic Males - Ability to access medications

9.1 Are medical treatments available and why not -available

9.2 How are medications accessed
- *Clinic*

9.3 List of barriers to getting medication
- *Difficulty sometimes in renewing the gold card*

  - *Problems related to language barriers*

9.4 Methods of paying for medications

  - *Gold Card*

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10. African American Males - Number who have discontinued medication

10.1 Number who completely discontinues –*3* vs. "drug vacation" – *1*

10.2 Reasons for discontinuing medication

  - *Improved CD4 count*
  - *Doing own experiment*
  - *Doctor ordered drug vacation*
  - *Stopped and restarted and experiencing symptoms again*
  - *Ran out of meds*
  - *Just stopped – told doctor later and he said it was ok*

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11. African American Males - Challenges and/or difficulties due to ethnicity

- *Refusal to talk about their HIV status- 3*
- *Lack of knowledge about HIV- 2*
- *Stigma - 2*
- *Shame*
- **No perception of risk**

- *Refusal to discuss sex with children and other family members*
- *Secrecy about sex*
- *Incest*
- *Refusal to listen*

11. Hispanic Males - Challenges and/or difficulties due to ethnicity or HIV status

- *Trouble with passing employment physicals – can't get a job.*
- *Discrimination among ourselves, among Hispanics.*
- *Others from my culture will reject me if I share information.*
- *Isolation*

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12. African American Males - Challenges of the community in receiving treatment

*Challenges caused by Service Providers*

- *Bering seems to have a "quota" of African Americans they will help with financial assistance and housing*
- *Lack of confidentiality*

### H. Challenges caused by Individuals

- *Substance abuse*
- *Fear of using services*

- **Don't know how to access services**
- *People don't pay attention to testing locations*
- *May know where to get tested but don't know how to access services (may have tested positive so don't want to retest and don't know how to plug into the system)*
- *People wait too long to get into care.*
- *Know they're HIV positive but push it under the table.*
- *Don't seek therapy until symptomatic*

### I. Challenges caused by Community

- *Problem not the service providers but the people – still a strong stigma attached to HIV/AIDS.*
- *People still consider it a gay disease or think it can't happen to them.*

12. Hispanic Males - Challenges of the community in receiving treatment

**Challenges caused by Service Providers**

- *Language barrier*

Challenges caused by Individuals

- *Sometimes we close up and we don't want treatment. We don't want to receive it.*
- *Problems with holding information close*

*Challenges caused by Community*

- *Lack of acceptance of HIV positive individuals.*
- *Discrimination against homosexuals.*
- *Discrimination against those with HIV.*
- *Rejection by family and loss of home*

12.1 What allows you to go to an organization for help?

- *Friendly, family-like atmosphere*
- *No discrimination or rejection*
- *Available transportation*

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13. African American Males - HIV/AIDS services needed but cannot be located

- **Support groups**
- *Education*
- *Dental Care - Unable to get dental care at Bering because it has been labeled "cosmetic surgery"*

- **Housing – most people with HIV on fixed incomes and difficult to find housing with low incomes**
- *Employment – there needs to be something set up that can assist people that are HIV positive to be able to work and stay within the eligibility ranges – make extra money and be productive with time*
- *Understanding employers*

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14. African American Males - Suggested changes to providing HIV health care in your area
    - **Improve transportation**
    - *HIV study groups*
    - *Make Medicaid available to all people with HIV*
    - *Provide transitional and permanent housing to PWA*
    - *Provide housing to single men, not just women and children*
    - *Provide decent housing, not in areas with lots of drug abuse and run-down buildings*
    - *Help people with medication co-pays*
    - *Cover costs of non-HIV medications*
    - *Less restrictive rules about making appointments at Bering (financial assistance);*
    - *Adult Day care for African Americans*
    - *Unrestricted access to medications*
    - *More accessibility in all areas*
    - *More personalized care*
    - *One-stop care*

14. Hispanic Males - Suggested changes to providing HIV health care in your area
    - *More transportation*
    - *Transportation to meetings*
    - *English classes*
    - *More bilingual people on staff, especially in medical situations*
    - *Interpretation in general – with many languages.*
    - *More genotyping and phenotypic more tests to tell you what is working and not working*
    - *More understanding in service providers – more social workers*
    - *Easily available information on accessing a case manager.*
    - *Medication counseling*
    - *More skilled case managers that can address not only services, but also medication issues, and answer questions about the virus.*

**Responses of All Females**

1. African American Females – *7 participants*
   - A. Length of HIV Infection – *Since 1991, 2000 (3), 3 yrs., 11 yrs.*
   - B. Current Residency – *5th ward, SW, SE, Houston; NE Houston, 3rd Ward*
   - C. Residency at time of diagnosis – *same; Houston, TDCJ*
   - D. HIV symptoms or OI's – *bacterial infections - 2, thrush, fatigue, neuropathy*

1. Hispanic Females - Introductions -4
   - A. Length of HIV Infection
   - B. Current Residency: Pasadena, midtown
   - C. Residency at time of diagnosis: Houston, Pasadena, TDCJ, and San Antonio
   - D. HIV symptoms or OI's

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3. African American Females - Is HIV primary medical care available to you? - *6*
   Hispanic Females – Is HIV primary medical care available to you? – 4

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4. African American Females - Number of individuals receiving primary medical care
   - 4.1 Reasons for seeking primary care
     - *Fear of the disease*
     - *Told to get care when test results were given - 2*
     - *Went to family doctor to confirm HIV test*
     - *Started with prenatal care, didn't want baby to be positive*
     - *TDCJ referred to UTMB but went to TSC an advice of a friend*
   - 4.2 Reasons for not getting primary medical care
     - *What changes would lead to seeking primary medical care*
     - *Fear*
     - *Denial*
     - *On drugs and didn't care*
   - 4.3 Important factors that enable you to get primary medical care
     - *Medicaid/Medicare coverage*
     - *Support of friends and family*
     - *Transportation - 3*
     - *Information about what services are available*
     - **Reliable, quality childcare**
     - *Insurance*

4. Hispanic Females - Number of individuals receiving primary medical care - *4*
   - 4.1 Reasons for seeking primary care
     - *Tested in TDCJ – referred to care*
     - *Husband was ill – 2*

- *Suspected husband of risky behavior*

4.2 Reasons for not getting primary medical care

4.1 Important factors that enable you to get primary medical care –

- *Transportation - 4*
- *Child care*
- *Geographically close (Can still take the bus)*
- *Insurance*
- *Money for co-payments*

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5. African American Females - In the past year, number needing but unable to get medical care – *3*

5.1 Specific health problem or need

- *Therapy for problem unrelated to HIV*

5.2 Reason for not getting medical care

- *Scheduling problem with child care; would need long term child care for major surgical procedure (not HIV related)*

5. Hispanic Females - In the past year, number needing but unable to get medical care - 4

5.1 Specific health problem or need

- *Had gall bladder surgery scheduled and had to reschedule because it was time for re-certification*
- *Pregnancy-related problems*

5.2 Reason for not getting medical

- *Referrals lost during Medicaid re-certification process – delays appointments*
- *More prescriptions than authorized – went without medications*
- *Lack of knowledge about available transportation*
- *Child care*
- *Job conflicts*

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6. African American Females - Number preferring neighborhood care vs. care outside the neighborhood

- *In neighborhood - 0*
- *Outside neighborhood – 2*

6.1 Reasons for preference for care outside neighborhood

- *Quality of care - 2*
- *Confidentiality*

6.3 Barriers to care outside neighborhood

- *Unable to motivate self to go*
- *Transportation*

6.4 Reasons for preference for care within neighborhood - NA

6.5 Barriers to care within neighborhood

- *Breach of confidentiality*

6. Hispanic Females - Number preferring neighborhood care vs. care outside the neighborhood - *1*
   - 6.1 Reasons for preference for care outside neighborhood
     - *All the HIV doctors are in Houston – 20 miles from where I live.*
     - *There are no Infectious Disease doctors on insurance plan in Pasadena.*
   - 6.2 Barriers to care outside neighborhood
     - *Transportation*
     - *Parking – fees are high at medical professional buildings- 3*
     - *Distance is a barrier and there is no bus service from Pasadena*
   - 6.3 Reasons for preference for care within neighborhood - 3
     - *Don't like traveling long distances*
     - *Reduced travel time*
   - 6.4 Barriers to care within neighborhood

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7. African American Females - List of activities to manage and/or treat HIV
   - *Medication*

7. Hispanic Females - List of activities to manage and/or treat HIV
   - *Medical appointments - 3*
   - *Adherence to medications - 3*
   - *Counseling support groups - 2*
   - *Vitamins*
   - *Exercise*
   - *Peer counseling*
   - *Drama therapy – 2*

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8. African American Females - Use of HIV medications
   - 8.1 Number of those with knowledge about HIV medications - *4*
     - A. Anti-retrovirals
     - B. Prophylactic antibiotics
     - C. Anti-fungal medications
     - D. Steroids
     - E. Anti-depressants/anti-anxiety medications
     - F. Other prescription or non-prescription medications
     - G. Massage
     - H. Herbal therapies
     - I. Biofeedback therapies
     - J. Acupuncture
     - G. Food supplements

- 8.2 Number taking each type
    - A. Anti-retrovirals – *4*
    - B. Prophylactic antibiotics - *2*
    - C. Anti-fungal medications – *1*
    - D. Steroids
    - E. Anti-depressants/anti-anxiety medications – *3*
    - F. Other prescription or non-prescription medications
        - *a. Blood pressure*
    - G. Massage – *1*
    - H. Herbal therapies – *1*
    - I. Biofeedback therapies
    - J. Acupuncture
    - L. Food supplements – *2 (1-Isoplus, 1-vitamins)*
- 8.3 How do the medications work?
    - A. Anti-retrovirals – *some side effects*
    - B. Prophylactic antibiotics
    - C. Anti-fungal medications
    - D. Steroids
    - E. Anti-depressants/anti-anxiety medications – *Not effective*
    - F. Other prescription or non-prescription medications
    - G. Massage – *Good for relaxation*
    - H. Herbal therapies – *Nutmeg good for nausea*
    - I. Biofeedback therapies
    - K. Acupuncture – *Reported to be effective for pain relief (Sister reported that deceased client used acupuncture for pain management)*
    - K. Food supplements
- 8.4 Reasons for not using specific medications
    - A. Anti-retrovirals – *Side effects – 4*
    - B. Prophylactic antibiotics
    - C. Anti-fungal medications
    - D. Steroids
    - E. Anti-depressants/anti-anxiety medications
    - F. Other prescription or non-prescription medications
    - G. Massage
    - H. Herbal therapies
    - I. Biofeedback therapies
    - J. Acupuncture
    - K. Food supplements

8. Hispanic Females - Use of HIV medications

- 8.1 Number of those with knowledge about HIV medications
    - A. Anti-retrovirals - *4*
    - B. Prophylactic antibiotics - *4*
    - C. Anti-fungal medications - *2*
    - D. Steroids

- E. Anti-depressants/anti-anxiety medications - *2*
- F. Other prescription or non-prescription medications - *2*
- G. Massage
- H. Herbal therapies
- I. Biofeedback therapies
- J. Acupuncture
- K. Food supplements

8.2 Number taking each type

- A. Anti-retrovirals - *3*
- B. Prophylactic antibiotics - *3*
- C. Anti-fungal medications - *2*
- D. Steroids
- E. Anti-depressants/anti-anxiety medications - *2*
- F. Other prescription or non-prescription medications - *2*
- G. Massage
- H. Herbal therapies
- I. Biofeedback therapies
- J. Acupuncture
- K. Food supplements

8.3 How do the medications work?

- A. Anti-retrovirals
- B. Prophylactic antibiotics
- C. Anti-fungal medications
- D. Steroids
- E. Anti-depressants/anti-anxiety medications
- F. Other prescription or non-prescription medications
- G. Massage
- H. Herbal therapies
- I. Biofeedback therapies
- J. Acupuncture
- K. Food supplements

8.4 Reasons for not using specific medications

- A. Anti-retrovirals
  - a. I quit taking HIV meds a couple of months ago because of other medical problems. Doctor told me to take a vacation from the medication.
- B. Prophylactic antibiotics
- C. Anti-fungal medications
- D. Steroids
- E. Anti-depressants/anti-anxiety medications
- F. Other prescription or non-prescription medications
- G. Massage
- H. Herbal therapies
- I. Biofeedback therapies
- J. Acupuncture
- G. Food supplements

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9. African American Females - Ability to access medications
   - 9.1 Are medical treatments available and why not
     - *ADAP denied eligibility, gets assistance at The Assistance Fund*
   - 9.2 How are medications accessed
     - *Physician*
     - *Pharmacy*
   - 9.3 List of barriers to getting medication
     - *Transportation*
     - *Long wait to get prescriptions*
     - *Prescriptions are "never" ready when promised*
     - *Given the wrong medications*

   - 9.4 Methods of paying for medications
     - *Gold Card –3*
     - *Medicaid*
     - *Cash*
     - *The Assistance Fund*
     - *ADAP*

9. Hispanic Females - Ability to access medications
   - 9.1 Are medical treatments available - *YES*
     - *Some problems coming up with co-pay $10 for each prescription*
   - 9.2 How are medications accessed
     - *Thomas Street Clinic*
     - *Physician samples*
   - 9.3 List of barriers to getting medication
     - *Four HIV medications plus antidepressants and Medicaid only allows three/month*
     - *Problems paying for non-HIV related drugs, requests prescriptions from physician so Medicaid will pay*
   - 9.4 Methods of paying for medications
     - *Medicaid 100%*
     - *Medicaid*
     - *Gold Card*
     - *Private insurance and co-pay*

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10. African American Females - Number who have discontinued medication
   - 10.1 Number who completely discontinues – *1* vs. "drug vacation" - *1*
   - 10.2 Awareness of PCP
   - 10.3 Reasons for discontinuing medication
     - *Medication not effective*
     - *Unable to pay*

10. Hispanic Females - Number who have discontinued medication - *3*

    - *Side effects were not controllable. Stopped all at once and told doctor. He said that was fine, that after I had worked through the other problems then we would go back and find a different combination*
    - *Side effects so I stopped on physicians direction*
    - *Medications made me sick;*
    - *Stopped another time to see what would happen;*
    - *Down to one drug because of diabetes medications*

    10.1 Number who completely discontinues –3 vs. "drug vacation" –1

    - *Experiment to see what my t-cells would do*
    - *Take my medication; good relationship with my physician – together my doctor and I decided I would quit taking a protease inhibitor – want to save options for later.*

    10.3 Reasons for discontinuing medication

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11. African American Females - Challenges and/or difficulties due to ethnicity

    - *People have a fatalistic attitude, believe HIV was "made" to get rid of African Americans*
    - *Drug abuse issues*

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12. African American Females - Challenges of the community in receiving treatment

    *Challenges caused by Individuals*

    - *Drug addiction*
    - **Lack of knowledge and awareness about HIV**
    - *Challenges caused by Community*
    - *Lack of support from the community to stop using drugs*
    - *Stigma and rejection by own community,*
    - *Need to be accepted as a human being and treated with respect*

11. Hispanic Females - Challenges and/or difficulties due to ethnicity or HIV

    - *Employment – would need am employer who I wouldn't have to disclose to, explain doctor's appointments*
    - *Employment and disclosure (hasn't disclosed to family)*
    - *Family wouldn't handle the news well*
    - *Employment – having many medical appointments and not wanting to disclose to employer*

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13. African American Females - HIV/AIDS services needed but cannot be located

    - *Lack of services for non-HIV partners*

13. Hispanic Females - HIV/AIDS services needed but cannot be located - no

14. African American Females - Suggested changes to providing HIV health care in your area

- *Address the problem of crack cocaine use*
- *More HIV specialty clinics like Thomas Street*

14. Hispanic Females - Suggested changes to providing HIV health care in your area

- *Having to repeat how you got infected to every provider.*
- *More assistance with medications. Lots of women aren't taking all the medications that they should because they can't afford it –2*
- *Timely and reliable transportation*

15. African American Females - Additional comments

- *Concern about the new political administration cutting funding*
- **Treat patients like people, not a number**
- *Take the politics out of it.*

## Epidemiological Profile

The HIV/AIDS epidemic has disproportionately affected communities of color throughout the nation, and especially in the Houston area. The African American community, in particular, shoulders a higher proportion of Harris County's HIV/AIDS cases each year. The AIDS incidence and prevalence in Harris County, together with HIV prevalence are distributed by race/ethnicity, gender, age and exposure category, and shown in Table 1.

### AIDS Cases

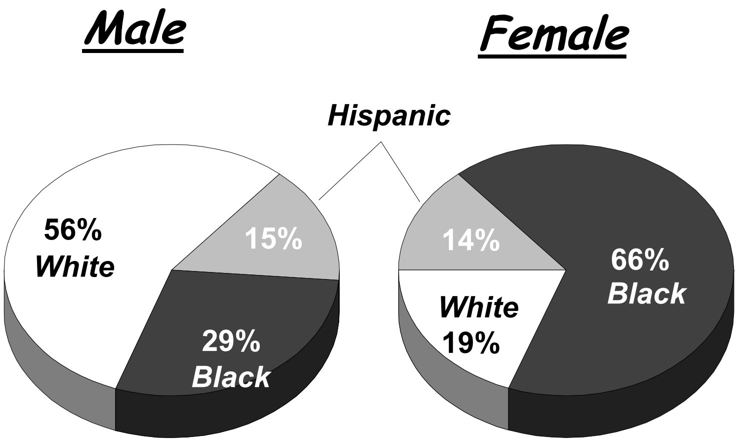
### Cumulative AIDS Cases

In the 6-county Houston EMA, the cumulative AIDS cases through 12/31/00, is 19,263. In Harris County alone, the cumulative number of AIDS cases diagnosed and reported through 3/31/01 is 18,740 with a rate of 15.4 per 100,000 cases. Eighty-nine percent of all AIDS cases in the EMA are reported as Houston residents. Presently, Houston ranks 7th in cumulative AIDS cases in the nation.

Approximately 25% of all AIDS cases diagnosed since 1999 have occurred in women, while 75% have been in men. When broken down by ethnicity as in Figure 1, we find that the proportion of Hispanic males is the same as Hispanic females (about 14%). While more than half of male AIDS cases have occurred in Whites, almost two-thirds (66%) of all AIDS cases reported in females has been in African Americans.

Hispanics account for about 15% of the total number of new AIDS cases reported in Harris County. However, over the last decade, the Hispanic population in Harris County has markedly increased, from 23% in 1990 to about 33% in 2000. As such an increased proportion of Hispanic AIDS cases since 1999 is no longer as noticeable.

**Figure 1**
**Percent of AIDS cases Among Males and Females by Race/Ethnicity: Cumulative AIDS through 03/31/01**

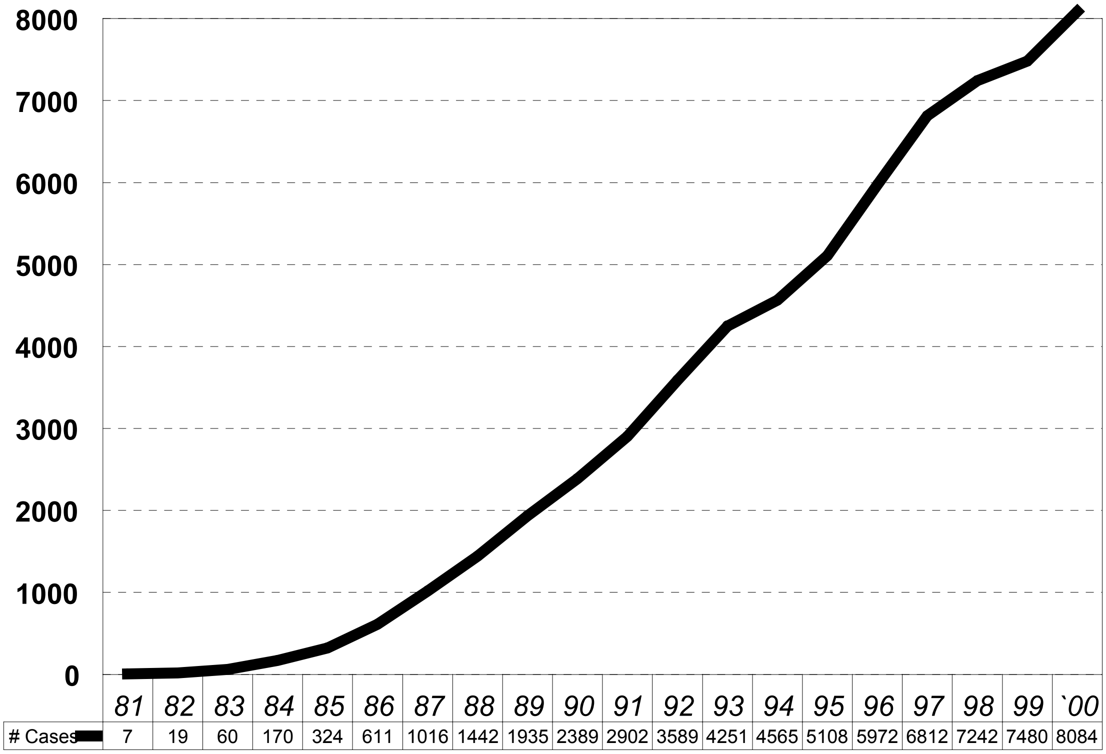


## Living AIDS Cases (PLWA) – AIDS Prevalence

Overall, the cumulative AIDS case fatality rate in the Houston area is 58%. Thus, of the of the total reported AIDS cases (18,740), only 42% are currently living with AIDS (PLWA). This number, which is the AIDS prevalence, amounted to 8,084 as of 12/31/00, and 7,778 through 3/31/01.

While the number of AIDS cases diagnosed in Harris County continues to fall since the mid-nineties, the number of people living with AIDS continues to rise as shown in Figure 2.

**Figure 2: Living AIDS Cases in Houston/Harris County (As Of The End Of Each Year (1981-2000)**



*Source: HIV/AIDS Surveillance Report, CDC, June 2000, + Updates from TDH*

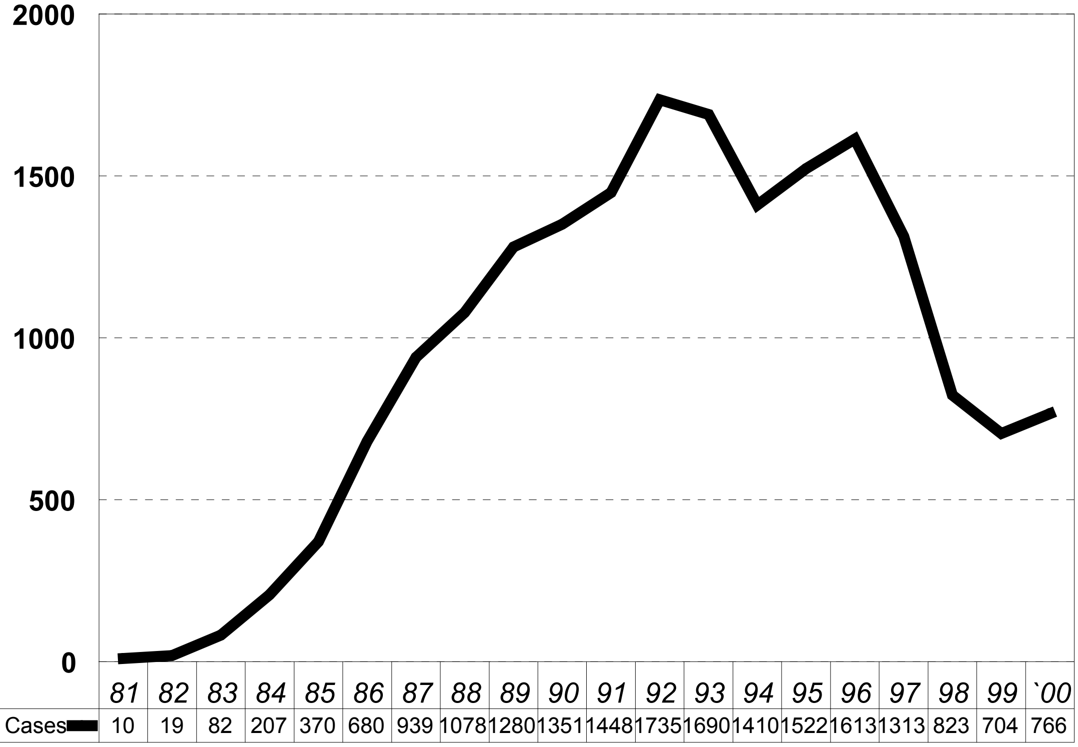
**Table 1: AIDS Incidence, AIDS Prevalence, and HIV Prevalence in the Houston EMA, by Demographic Group and Exposure Category**

| | **AIDS Incidence 1/1/99 to 12/31/00** | | **AIDS Prevalence through 12/31/00** | | **HIV Prevalence as of 12/31/00** | |
|---|---|---|---|---|---|---|
| Demographic Group/ Exposure Category | AIDS Incidence is defined as the number of new AIDS cases diagnosed during period specified. | | AIDS Prevalence is defined as the the number of people living with AIDS as of the date specified. | | HIV Prevalence is defined as the estimated number of people living with HIV, (non AIDS) as of the date specified. | |
| | # | % of Total | # | % of Total | # | % of Total |
| ***RACE/ETHNICITY*** | | | | | | |
| White, not Hispanic | 427 | 29.0 | 3344 | 41.4 | 3956 | 38.1 |
| Black, not Hispanic | 731 | 49.7 | 3239 | 40.1 | 4434 | 42.7 |
| Hispanic | 301 | 20.5 | 1457 | 18.0 | 1743 | 16.8 |
| Asian/pacific Islander | 8 | 0.5 | 37 | 0.5 | 45 | 0.4 |
| Am. Indian/Alaska Native | 2 | 0.1 | 6 | 0.1 | 9 | 0.1 |
| Not Specified | 1 | 0.1 | 1 | 0.0 | 9 | 0.1 |
| **Total** | **1470** | **100.0** | **8084** | **100.0** | **10377** | **100.0** |
| ***GENDER*** | | | | | | |
| Male | 1105 | 75.2 | 6626 | 82.0 | 8079 | 77.9 |
| Female | 365 | 24.8 | 1458 | 18.0 | 2298 | 22.1 |
| **Total** | **1470** | **100.0** | **8084** | **100.0** | **10377** | **100.0** |
| **AGE AT DIAGNOSIS (Yrs)** | | | | | | |
| 0 (0 -11mo) | 2 | 0.1 | 26 | 0.3 | 103 | 1.0 |
| 1 (12-23 mo) | 1 | 0.1 | 13 | 0.2 | 34 | 0.3 |
| 2-4 | 1 | 0.1 | 18 | 0.2 | 39 | 0.4 |
| 5-12 | 5 | 0.3 | 14 | 0.2 | 32 | 0.3 |
| 13 - 19 | 13 | 0.9 | 101 | 1.2 | 244 | 2.4 |
| 20 - 24 | 76 | 5.2 | 452 | 5.6 | 786 | 7.6 |
| 25 - 29 | 198 | 13.5 | 1207 | 14.9 | 1616 | 15.6 |
| 30 - 39 | 612 | 41.6 | 3655 | 45.2 | 4453 | 42.9 |
| 40 - 49 | 396 | 26.9 | 1914 | 23.7 | 2271 | 21.9 |
| 50 - 59 | 123 | 8.4 | 548 | 6.8 | 638 | 6.1 |
| 60 - 69 | 34 | 2.3 | 110 | 1.4 | 129 | 1.2 |
| 70+ | 9 | 0.6 | 26 | 0.3 | 30 | 0.3 |
| Unknown | 0 | 0.0 | 0 | 0.0 | 2 | 0.0 |
| **Total** | **1470** | **100.0** | **8084** | **100.0** | **10377** | **100.0** |
| | # | % of Total | # | % of Total | # | % of Total |
| **Adult/Adolescent AIDS Exposure Category** | | | | | | |
| Men who have sex with men | 601 | 41.2 | 4152 | 51.9 | 4904 | 48.3 |
| Injection drug users | 192 | 13.2 | 1168 | 14.6 | 1458 | 14.4 |
| Men who have sex with men and inject drugs | 68 | 4.7 | 662 | 8.3 | 750 | 7.4 |
| Hemophilia/coagulation disorder | 1 | 0.1 | 19 | 0.2 | 22 | 0.2 |
| Heterosexuals | 316 | 21.6 | 1408 | 17.6 | 1996 | 19.7 |
| Receipt of blood transfusion, blood components, or tissue | 0 | 0.0 | 8 | 0.1 | 9 | 0.1 |
| Risk not reported or identified | 282 | 19.3 | 579 | 7.2 | 1013 | 10.0 |
| **Total** | **1460** | **100.0** | **7996** | **100.0** | **10152** | **100.0** |
| **Pediatric AIDS Exposure Categories** | | | | | | |
| Hemophilia/coagulation disorder | 0 | 0 | 6 | 6.8 | 8 | 3.6 |
| Mother with/at risk for HIV infection | **10** | 100 | 76 | 86.4 | 195 | 86.7 |
| Receipt of blood transfusion, blood components or tissue | 0 | 0 | 5 | 5.7 | 6 | 2.7 |
| Risk not reported or identified | 0 | 0 | 1 | 1.1 | 16 | 7.1 |
| **Total** | **10** | **100.0** | **88** | **100.0** | **225** | **100.0** |

## New AIDS Cases (AIDS Incidence)

Over the last 2 years, there have been 1,470 newly diagnosed cases of AIDS in Harris County – 704 cases in 1999 and 766 in 2000. Figure 3 shows the number of AIDS cases diagnosed since 1981, which has been markedly decreasing since the mid-90s.

Figure 3
Houston/Harris Co. AIDS Cases, Diagnosed from 1981 - 2000



| | 81 | 82 | 83 | 84 | 85 | 86 | 87 | 88 | 89 | 90 | 91 | 92 | 93 | 94 | 95 | 96 | 97 | 98 | 99 | `00 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| # Cases | 10 | 19 | 82 | 207 | 370 | 680 | 939 | 1078 | 1280 | 1351 | 1448 | 1735 | 1690 | 1410 | 1522 | 1613 | 1313 | 823 | 704 | 766 |

*Source: HIV/AIDS Surveillance Report, CDC, June 2000, + Updates from TDH*

In Figure 4, which depicts newly diagnosed and reported AIDS cases over the last 2 years, the burden of the disease is largely on African Americans. While this chart shows a downward trend for each racial group, the decrease in the number of new AIDS cases is least for African Americans (only 15%) followed by Hispanics (19%), as compared to a significant decrease of 33% for Whites.

Since 1999, African Americans were reported with AIDS more than any other racial/ethnic groups. In 1999, they represented 52% of newly diagnosed AIDS cases, but now in 2000 they comprise 59%. This is depicted in Figure 5. Similarly newly diagnosed Hispanic AIDS cases have shown a slightly increased proportion from 20% in 1999 to 23% two years later. In contrast newly diagnosed AIDS cases among Whites have fallen markedly from 27% in 1999 to 17% this year.

**Figure 4: Percent *Decrease* By Race in New AIDS Cases Over the Last 2 years**

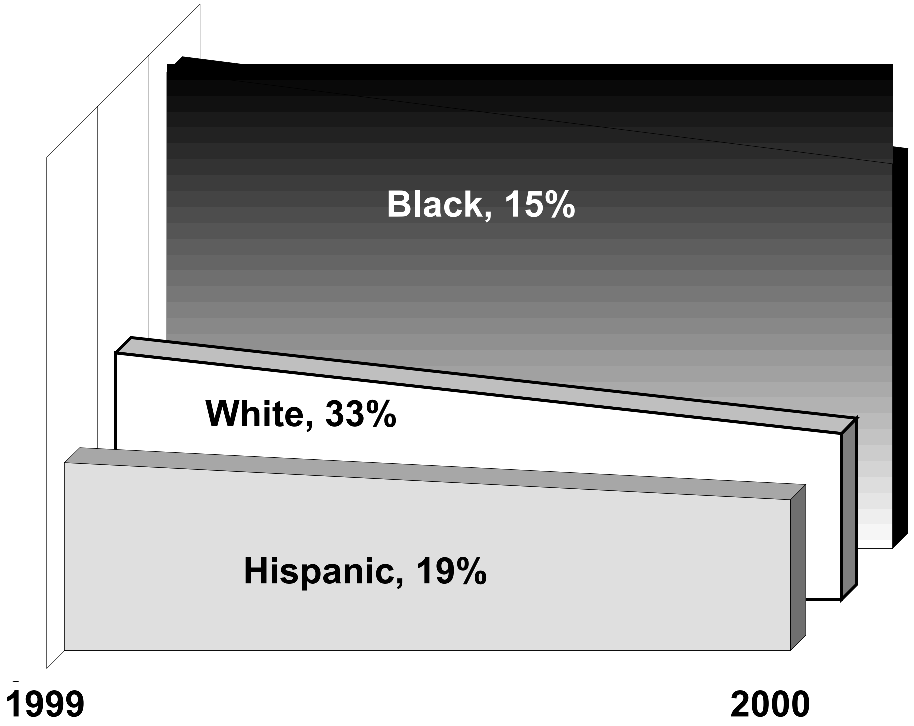
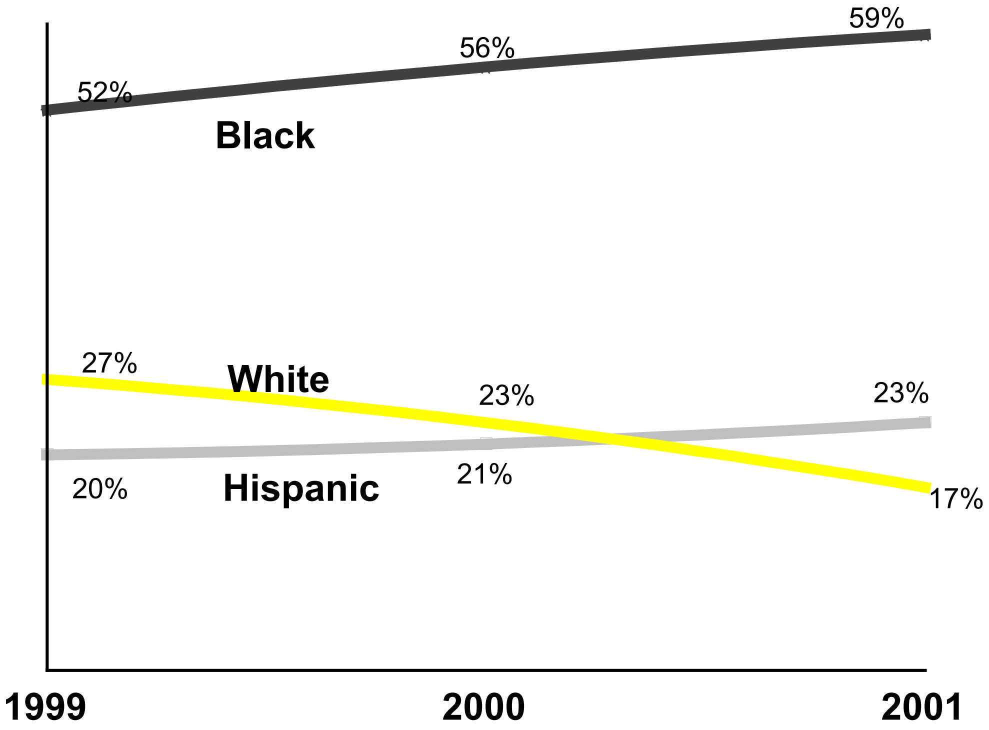


**Figure 5**
**Proportion of AIDS cases diagnosed in 1999, 2000, 2001*, by Race/Ethnicity**



**2001 proportion is based on AIDS reporting data as of 3/31/01*

## Risk Group

Changes in the gender ratio of HIV/AIDS are reflective of changes in modes of exposure. Early in the epidemic, HIV/AIDS was chiefly transmitted through men having sex with men (MSM), followed by injecting drug use (IDU). Currently MSM accounts for a little over 41% of recent AIDS diagnosis and IDU accounts for only 13% (See Table 1 incidence). Infections attributed to these categories, has declined proportionally as exposure through heterosexual sex increases. Heterosexual exposure accounted for 21.6% of reported AIDS cases from 1/1/99 (Table 1 incidence), and an estimated 27% of diagnosed HIV cases (Table 3), compared to 17.6% of living AIDS cases (Table 1 prevalence).

The next two graphs, Figures 6 and 7, show by specific gender, the trend over time for risk factors in newly reported AIDS cases. For males with AIDS, the most common risk behavior remains male to male sexual contact, although as a proportion of all risk behaviors, this continues to decrease. For both males and females, there has been an increase in the proportion of AIDS cases with heterosexual contact as a risk behavior, as well as an increase in 'no reported risk' cases.

### AIDS Percents by Mode of Transmission: Diagnosed in Harris County 1990 – 2000

**Figure 6: Male**

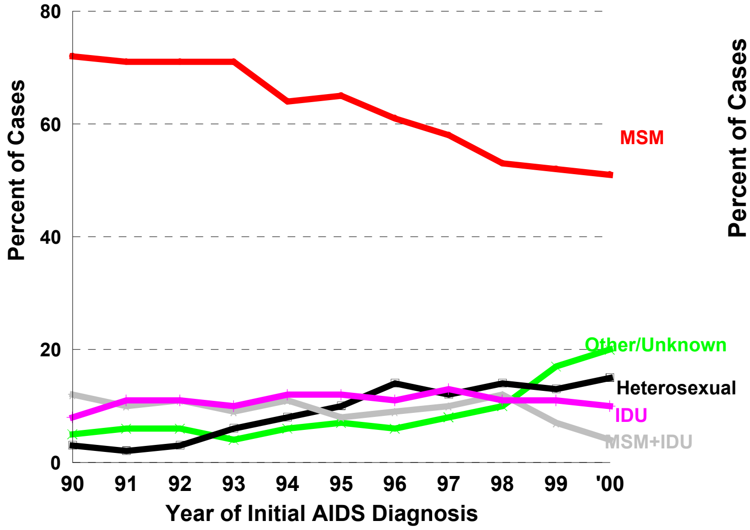
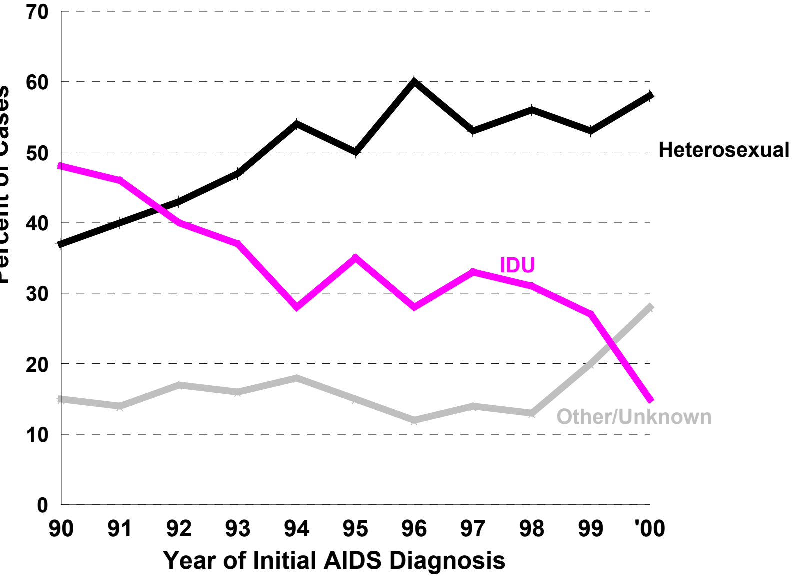


**Figure 7: Female**



## HIV Prevalence

The projected number of HIV infected in 2001 is between 16,127 and 22,439. The CDC estimates that approximately one-third of these people have AIDS, another third are diagnosed with HIV but have not yet developed AIDS, and the remaining third are unaware of their infection. (The client sample size in this document excludes the third group).

Within the Houston EMA, the prevalent cases of HIV disease is 10,377*. "Prevalent cases" here, means all reported living cases of HIV infection and AIDS combined (PLWH/A). The true count of prevalent cases would therefore include all living cases of HIV infection and AIDS which exist in the EMA. We know that AIDS reporting is fairly complete. However, we also know that many HIV-positive people are unaware of their HIV infection, and that their HIV status has not been reported. This number only includes adult and adolescent HIV infection which have been reported by name since 01/01/99. Thus, there are also HIV+ people who are aware of their status, and are not included in this number.

**Texas Department of Health*

The breakdown of HIV prevalent cases by race/ethnicity, gender, age and exposure category are shown in Table 1.

## HIV Reporting

### Population Profile

A comparison is made in Table 2 of the population profile in Harris County, as compared with that of reported HIV cases. Harris County, which makes up 96% of the 6-county Houston EMA is racially and ethnically diverse. Of its 3.4 million residents in 2000, 42.8% are Anglo, 18.5% are African American and 32.9% are Hispanic. New HIV reports show this distribution to be even more pronounced. Using this most current data, we see that African Americans make up more than half (57%) of the HIV cases reported over the last 2 years. Hispanics represent 17% and Whites, 26%.

**Table 2**

**Racial Proportions: Population of Harris County in 2000**
**Campared with Reported HIV Cases in Harris County**
**1/1/1999 - 3/31/2001**

| | Harris County Pop. | | Reported HIV Cases | |
|---|---|---|---|---|
| **Ethnicity/Race** | **No.** | **%** | **No.** | **%** |
| White | 1,432,264 | 42.8% | 853 | 26% |
| Black | 628,619 | 18.5% | 1874 | 57% |
| Hispanic | 1,119,751 | 32.9% | 549 | 17% |
| Other/Unknown | 219,944 | 5.7% | 17 | 1% |
| **Total** | **3,400,578** | **100%** | **3293** | **100%** |

*Source: (1) Census 2000, Harris County*
*(2) Houston HIV/AIDS Surveillance Section, DHHS*

Since HIV reporting commenced in Texas on January 1, 1999, a total of 3293 HIV infections have been reported within Harris County to the Texas Department of Health. This number is broken down by sex, age and ethnicity in Table 3. New HIV infections were higher among African Americans than among any other racial or ethnic groups. Almost half the men who become infected (48%), and 76% of the infected women were African Americans. In addition to suffering disproportionately from AIDS, African American women are also disproportionately infected with HIV.

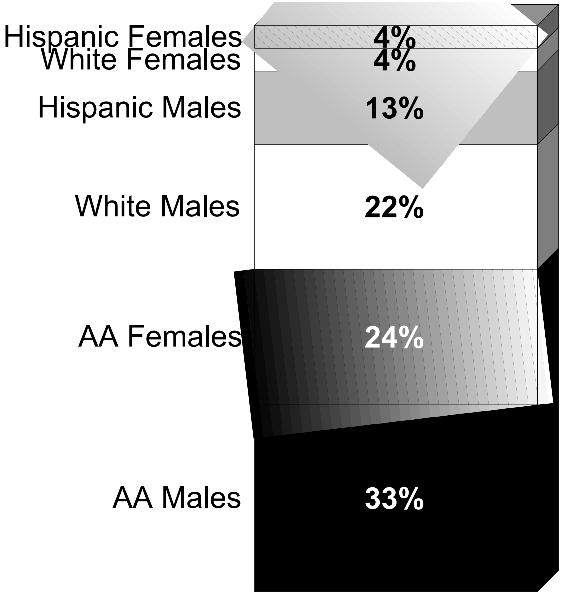
## Table 3

### Cumulative Adult HIV Cases (not AIDS) reported in Houston/Harris County from 1/1/99 through 3/31/01

| | Black, (Not Hispanic) | | Hispanic | | White (Not Hispanic) | | Other | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|
| ***GENDER*** | | | | | | | | | | |
| Male | 1085 | 48% | 426 | 19% | 731 | 32% | 14 | 1% | 2256 | 69% |
| Female | 789 | 76% | 123 | 12% | 122 | 12% | 3 | 0% | 1037 | 31% |
| **Total** | **1874** | **57%** | **549** | **17%** | **853** | **26%** | **17** | **1%** | **3293** | **100%** |
| ***AGE AT DIAGNOSIS (Yrs)*** | | | | | | | | | | |
| 13 - 19 | 137 | 7% | 18 | 3% | 22 | 3% | 0 | 0% | 177 | 5% |
| 20 - 29 | 589 | 31% | 192 | 35% | 229 | 27% | 6 | 35% | 1016 | 31% |
| 30 - 39 | 660 | 35% | 207 | 38% | 381 | 45% | 10 | 59% | 1258 | 38% |
| 40 - 49 | 358 | 19% | 107 | 19% | 160 | 19% | 1 | 6% | 626 | 19% |
| Over 49 | 130 | 7% | 25 | 5% | 61 | 7% | 0 | 0% | 216 | 7% |
| **Total** | **1874** | **57%** | **549** | **17%** | **853** | **26%** | **17** | **1%** | **3293** | **100%** |
| ***Adult/Adolescent AIDS Exposure Category*** | | | | | | | | | | |
| Male to Male | 418 | 22% | 256 | 47% | 543 | 64% | 8 | 47% | 1225 | 37% |
| IDU | 319 | 17% | 37 | 7% | 76 | 9% | 2 | 12% | 434 | 13% |
| Male to male & IDU | 68 | 4% | 17 | 3% | 62 | 7% | 0 | 0% | 147 | 4% |
| Heterosexual contact | 646 | 34% | 144 | 26% | 80 | 9% | 3 | 18% | 873 | 27% |
| Other/Undetermined | 423 | 23% | 95 | 17% | 92 | 11% | 4 | 24% | 614 | 19% |
| **Total** | **1874** | **57%** | **549** | **17%** | **853** | **26%** | **17** | 1% | **3293** | **100%** |

Another way of looking at this is to consider Figure 8, a race-sex combined breakdown of HIV cases reported from 1/1/99 through 3/31/01. Again African Americans, first males, and then females have the highest percentages of all infections reported, while Hispanic females and White females are lowest at 4%. Reported cases among Hispanic males was at 13% of the total, while White males represented 22%.

**Figure 8: HIV Infections by Race & Gender, Reported from 1/1/99 – 3/31/01**



Exposure Category

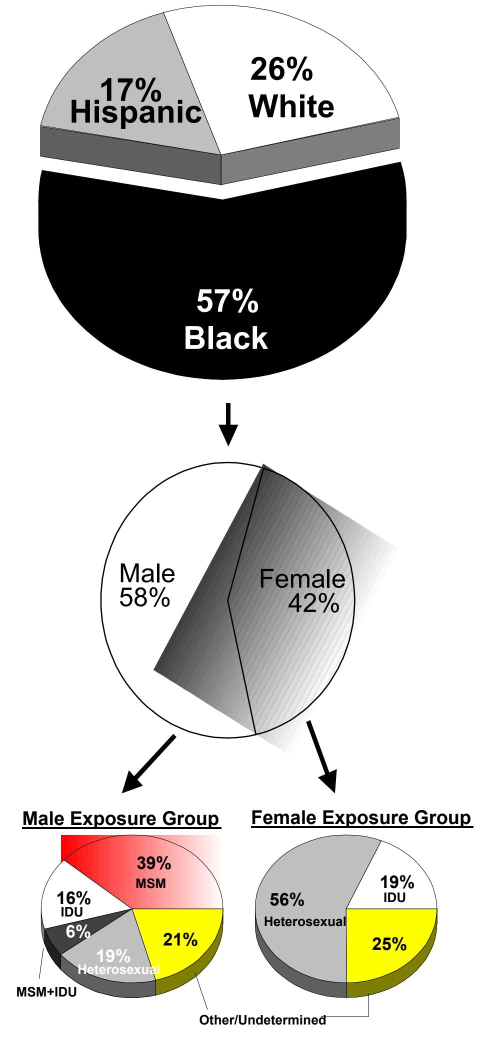
Considering exposure category for all populations, male-to-male sexual contact has been historically the hardest hit. Among White males this risk factor explains 74% of reported HIV infections (See Table 3). In those of color however, this risk factor though emerging still at the top, is at a significantly lower proportion. Figures 9 & 10 depict exposure categories among African Americans and Hispanics respectively. MSM accounts for only 39% in African American males, but 60% in Hispanic males.

The predominant risk factor among females is heterosexual exposure, accounting for 43% in Whites, 56% in African American females, and 68% in Hispanic females (Figs 9 & 10)

# HIV Reported Cases By Gender & Exposure Category, Harris County 1/1/99-3/31/01

**Figure 9**

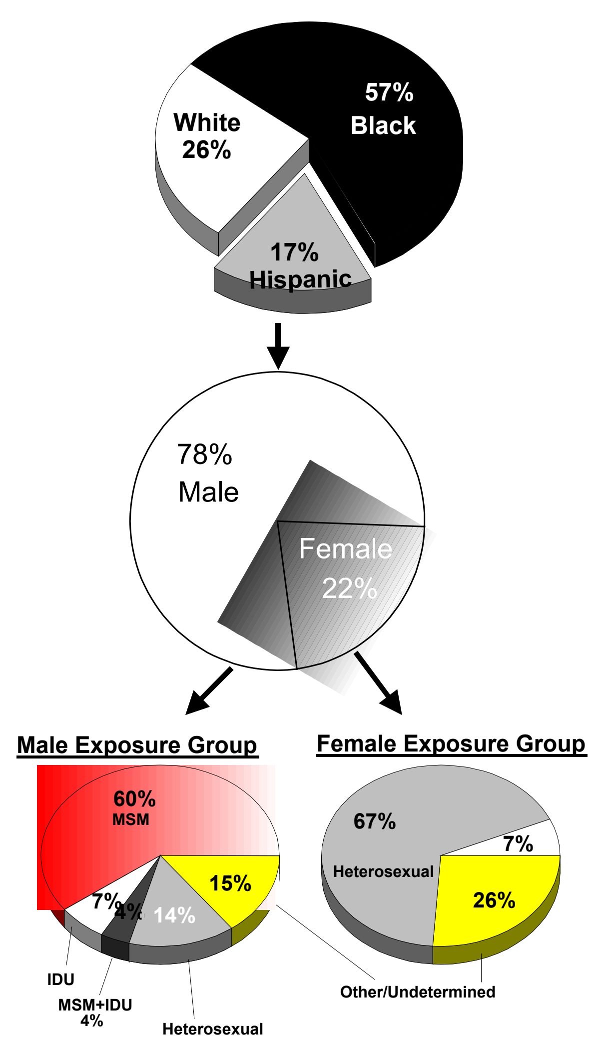
*African Americans,*



*Asian/Pacific Islanders, Native Americans and Alaska Natives represent less than 1% of new HIV Infections

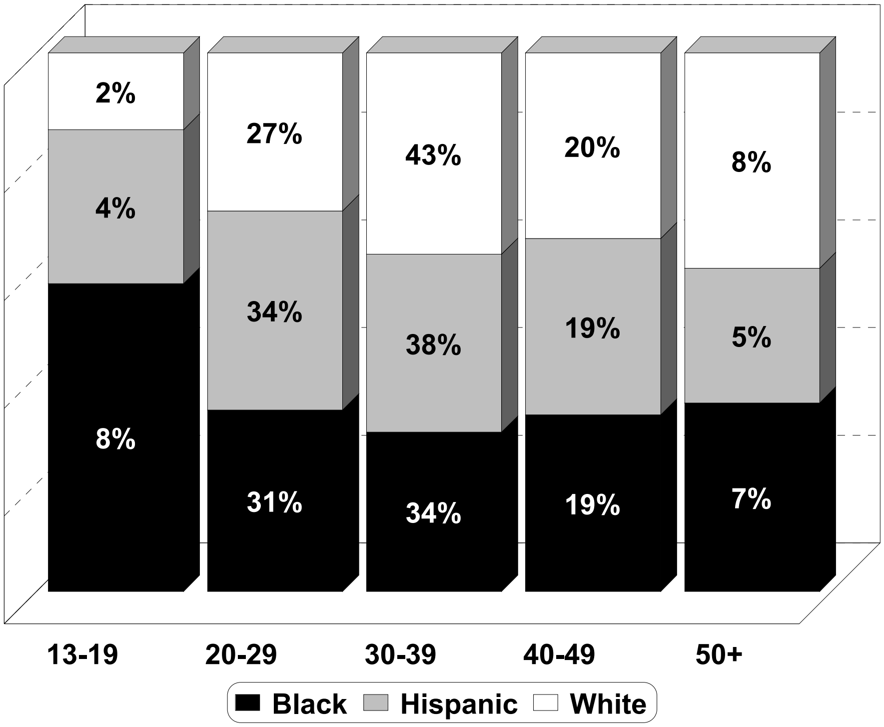
**Figure 10**

*Hispanics,*



Age Group
No significant **racial** differences were noted in overall HIV cases reported by age group. However, the highest percentage (about 38%) for each racial/ethnic population was within the 30-39 year age group (see Table 3). In the younger age groups though, significant differences were found. As shown in Figure 11, teenagers with HIV infections (13-19 years) were 4 times more likely to be African Americans, while young adults (20-29) were more likely to be Hispanic.

**Figure 11**
**HIV infections by Age Group: Reported in Harris County from 1/1/99 to 3/31/01**



Trends in HIV Infection
Though African Americans registered the highest numbers of HIV cases, and Hispanics the lowest numbers, the proportional increase over the last 2 years has been very different. Newly reported HIV cases, increased by 38% in African Americans (from 704 cases in 1999 to 969 cases in 2000) as seen in Figure 12. The increase in Hispanics was at 40% (from 205 to 287). In comparison, Whites had the highest increase of 87% from 263 to 493.

By gender, males registered about twice as many new cases. The increase was about 55% in males, and 35% in females (see Figure 13). Figure 14 shows the trends in reported HIV cases by race/ethnicity and by sex. African American males and African American females are parallel, with the highest number of reported cases each year. Hispanic females and White females have the lowest. The greatest increase though from 1999 to 2000 appears to be among White males.

Figure 12
Trends by Race/Ethnicity in HIV cases Reported in Harris County 1/1/99 –3 /31/01

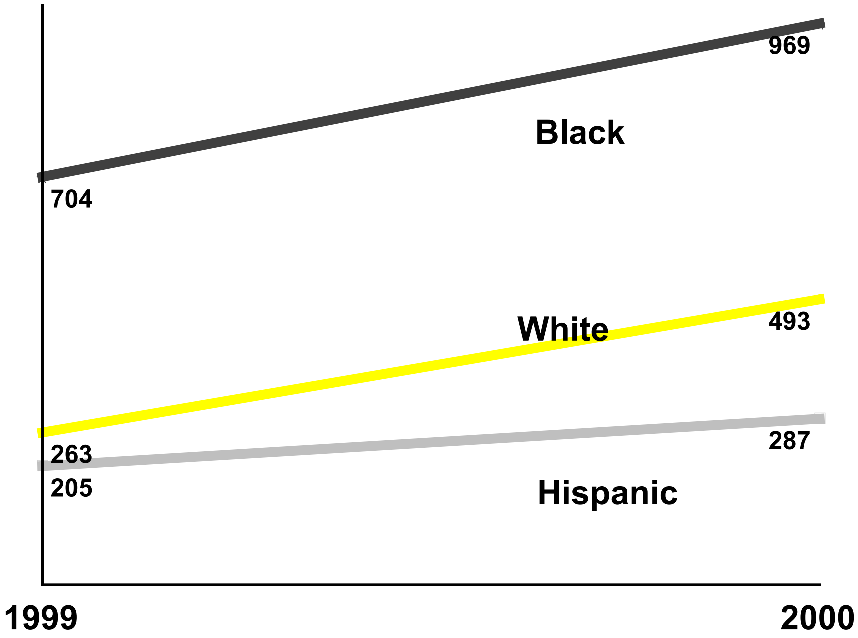


Figure 13
Trends by Gender, in HIV Cases Reported in Harris County 1/1/99-3/31/01

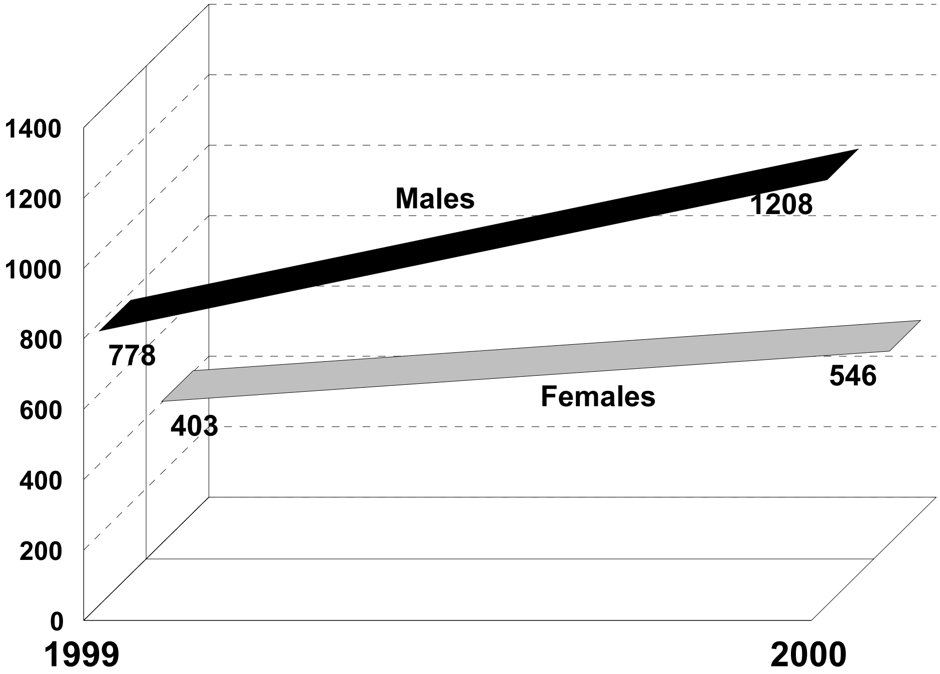
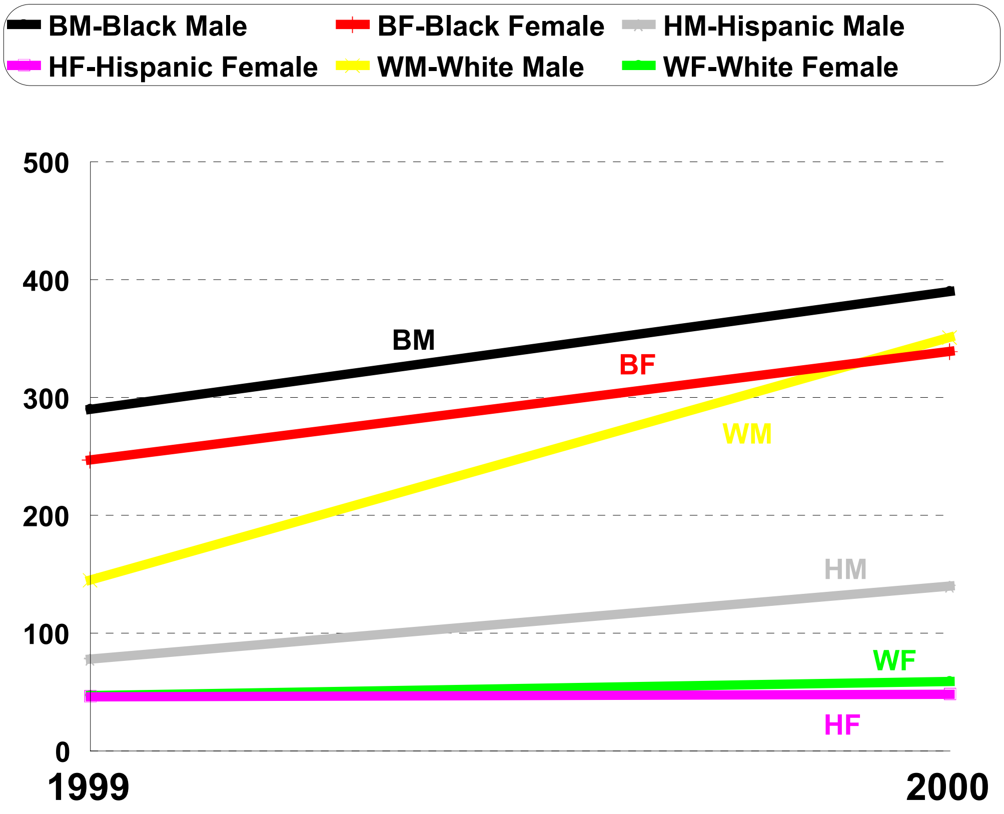


Figure 14

## Trends in HIV Cases Reported in the Houston EMA, during 1999 and 2000, by Race-Sex Categories



*Source: Texas Department of Health*

## COC Report Attachments

# Attachment 1

# Key Informant Interview Protocol

## Key Informant Questions

1. Organization Name: ________________________________________

2. Name of key informant: ______________________________________

3. Position of key informant: ____________________________________

4. Telephone Number: __________________________________________

5. Type of HIV service(s) provided (see list):

| Service | Please Check |
|---|---|
| 1. Case management | |
| 2. Housing Assistance | |
| 3. Outreach | |
| 4. Food Bank | |
| 5. Day Care | |
| 6. Transportation | |

6. Do you target a particular population? (e.g. race, gender, age group, IDU, homeless). For each service mentioned above, what is the number of HIV positive clients who received this service in the previous month -- October 2000. Do you know the total number of HIV positive unduplicated clients?

| Services | Number of *HIV positive* clients served | | | | |
|---|---|---|---|---|---|
| | African American | Hispanic / Latino | Other | Total Number | HIV positive Unduplicated |
| 1. Case management | | | | | |
| 2. Housing Assistance | | | | | |
| 3. Outreach | | | | | |
| 4. Food Bank | | | | | |
| 5. Day Care | | | | | |
| 6. Transportation | | | | | |

7. Over the last 1 year, has there been an overall increase, decrease, or has the need stayed about the same for each service you offer? What percent increase or decrease do you think there has been. Why?

| **Overall** | **% Increase** | **Same** | **% Decrease** | **Why?** |
|---|---|---|---|---|
| 1. Case Management | | | | |
| 2. Housing Assistance | | | | |
| 3. Outreach | | | | |
| 4. Food Bank | | | | |
| 5. Day Care | | | | |
| 6. Transportation | | | | |

8. For two of your services most utilized by HIV positive clients, can you be more specific by subpopulations? Over the past year has there been an increase, decrease, or has the need stayed the same for different subpopulation?. What percent increase or decrease do you think there has been? Why?

| **SERVICE1: ???** | **% Increase** | **Same** | **% Decrease** | **Why?** |
|---|---|---|---|---|
| **African American** | | | | |
| **Hispanic / Latino** | | | | |
| **Women of Color** | | | | |
| **IDUs/drug users** | | | | |
| **MSM** | | | | |
| **Heterosexuals** | | | | |
| **Immigrant** | | | | |

| **SERVICE2: ???** | **% Increase** | **Same** | **% Decrease** | **Why?** |
|---|---|---|---|---|
| **African American** | | | | |
| **Hispanic / Latino** | | | | |
| **Women of Color** | | | | |
| **IDUs/drug users** | | | | |
| **MSM** | | | | |
| **Heterosexuals** | | | | |
| **Immigrant** | | | | |

9. Do you know of any other subpopulations of PLWH/A (defined by age, risk groups, location or other factor) who are not accessing your other HIV or AIDS service, but need to? Who are they? What is preventing them from accessing your services?

| **SERVICE:** | **Sub-population** | **Why?** |
|---|---|---|
| **1** | | |
| **2** | | |
| **3** | | |
| **4** | | |

10. How do you suggest we make contact with these subpopulations listed in questions 8 and 9?

| **Subpopulation:** | **Ways to make contact.** |
|---|---|
| **1** | |
| **2** | |
| **3** | |
| **4** | |

11. After how many months of inactivity are clients living with HIV/AIDS dropped from the "active" to "inactive" list? ______________________________ # months

12. What procedures do you have for tracking and reinstating inactive clients living with HIV and AIDS?

13. Do you think your inactive clients are accessing medication? (Circle answer)....

| | |
|---|---|
| More than active clients | 1 |
| About the same as active clients | 2 |
| Somewhat less than active clients | 3 |
| A lot less than active clients | 4 |
| Not at all | 5 |

**Now I would like to ask a few questions about medication.**

**14**. Tell me whether you think PLWH/A are getting more than they expect, about what they expect, or less than they expect for each of the services I read. For those that are receiving less than they expect, why? (circle the number).

| **SERVICE:** | **More** | **About right** | **Less** | ***(If less)* Why?** |
|---|---|---|---|---|
| **1. Primary Medical Care** | 3 | 2 | 1 | |
| **2. Drug Reimbursement** | 3 | 2 | 1 | |
| **2. Case Management** | 3 | 2 | 1 | |
| **3. Substance Abuse Treatment** | 3 | 2 | 1 | |
| **4. Information & Resources** | 3 | 2 | 1 | |
| **5. Housing Assistance** | 3 | 2 | 1 | |
| **6. Outreach** | 3 | 2 | 1 | |
| **7. Transportation** | 3 | 2 | 1 | |
| **8. Food Bank** | 3 | 2 | 1 | |

15. In what ways are your active clients accessing and paying for their prescription medications?

| | |
|---|---|
| Accessing Prescription Medication | Paying for Medications. |
| | |

16. How much of a part do you think each of the following play, in clients getting HIV medical care: a big barrier, a moderate barrier, a small barrier, or no barrier at all (circle answer)

| BARRIERS | Big barrier | Moderate barrier | Small barrier | No barrier at all |
|---|---|---|---|---|
| **Insurance** | 4 | 3 | 2 | 1 |
| **Eligibility** | 4 | 3 | 2 | 1 |
| **Confidentiality** | 4 | 3 | 2 | 1 |
| **Distrust of the system** | 4 | 3 | 2 | 1 |
| **MORE?** | 4 | 3 | 2 | 1 |

17. Do you currently have any plans to expand your physical facilities or the services you provide?

18. What is the issue on your mind about HIV/AIDS among communities of color?

19. We want to recruit about 15 people for focus groups, from the "hard-to-reach" populations, such as immigrants. Is there anyone in your organization who will be willing to work with us in contacting such clients?

# Attachment 2

# Sample Letter to Agencies

**Houston Area HIV Services Ryan White Planning Council**
**Office of Support**
**2223 West Loop South, Suite 240, Houston, Texas 77027**
**713/572-3724 telephone 713/572-3740 fax**

November 20, 2000

**Katy Caldwell**
Executive Director
Montrose Clinic
215 Westheimer
Houston, TX 77006

Dear Agency Director:

I am writing to request your participation in the HIV/AIDS Needs Assessment in Communities of Color, which is being conducted by the Ryan White Planning Council. The Planning Council is charged with describing service needs and gaps among people who are infected with HIV in order to plan, establish priorities and allocate resources within the six county Houston planning area.

In order to accomplish these goals, part of the assessment is focused on interviewing 22 agency leadership and primary care providers who have the knowledge about people of color seeking HIV and AIDS services. Your knowledge and experience can help us provide enhanced services to your clients.

We want to obtain your suggestions regarding methods of assuring inclusion of all appropriate populations in our client focus groups and survey process. Most importantly we need your input and value your opinion as to why so many ethnic minorities living with HIV /AIDS are not accessing primary medical care. In addition, we wish to record your perceptions on whether people living with HIV or AIDS are getting the services they expect in this community.

Enclosed is a brief protocol, designed to capture this information simply, and with a minimum of time investment on your part. We will be contacting you to set up a confidential telephone interview by the middle of November. We hope you can participate in this important part of the assessment process, and we thank you in advance for your cooperation in this manner.

Sincerely,

Des Ilegbodu

Health Planner

# Attachment 3

# Focus Group Flyer

*The Ryan White Planning Council is asking for input from your clients about HIV/AIDS Services and Care.*
*Here is an opportunity to let their voices be heard.*

There will be a series of focus groups for African American and Hispanic males and females living with HIV/AIDS disease. Bus tokens and a $10 gift certificate will be provided to registered participants.

Seating is limited. If your client would like to attend one of the focus group sessions, please contact Sage Associates to reserve a place --713 861 6667.

**1) Thursday, December 14, 2000**
AVES, 3126 Southwest Freeway, Suite 1310,
(Bi-lingual facilitator)

| | |
|---|---|
| 9:00 a.m. | Hispanic Females |
| 10:30 a.m. | Hispanic Males |

**2) Saturday, December 16, 2000**
The Working Class, 6309 Martin Luther King Blvd, Suite 110

| | |
|---|---|
| 10:00 a.m. | African American Females |
| 11:30 a.m. | African American Males |

**3) Saturday, December 16, 2000**
Donald R. Watkins' Memorial Foundation, 1200 Binz, Suite 120

| | |
|---|---|
| 2:00 p.m. | African American Females |
| 3:30 p.m. | African American Males |

**4) Wednesday, December 20, 2000**
Harris County Health Department, 2223 West Loop S, Auditorium

| | |
|---|---|
| 3:00pm | Non-HIV Service Providers |

# Attachment 4

# Focus Group Format of Inquiry

# Format of Focus Group

## *Introductions*

Moderator introduces (her)himself, then introduces other RWPC Support Staff and Transcriber. S(he) says which company (s)he is affiliated with: Hello, my name is: ______________. I am from________________.

I want to stress to you that this is a completely voluntary meeting and your comments are completely confidential; they will never be associated with your name. In fact, your full name will not be used in this focus group. Instead, you can use an alias, or any name you want to be referred to.

The groups are being taped. The reason for the tape is that we need to go back and listen to your comments for analysis. The tapes will never be heard except by those analyzing this focus group, and they will be destroyed after the completion of the project.

### *Purpose of Focus Group*

What we are doing here is conducting a focus group -- that is, a discussion group where we talk about our opinions and feelings. We will be discussing how you are using services offered to people living with HIV and AIDS and which services you find most important for maintaining your health and quality of life. We particularly want to know which services you may need in the future, but currently can't find.

## ***Ground Rules***

***There are a few ground rules that I would like to cover:***

1. Talk from your own experience and not what you think should be the need of others.

2. This is a discussion group, not a session where I ask you a question and you answer it. So if someone says something and you want to respond directly feel free.

3. However, please speak one at a time, and allow others to finish and express their thoughts.

4. There are lot of views and opinion about HIV and AIDS services, so you may not agree with the experience of another. However, please do not criticize others in the group. If you disagree, simply speak out. Different views are important.

5. There are no right or wrong answers, and everybody's views at this session are equally important. We hope to hear from everyone attending this focus group.

6. Before answering a question I would appreciate it if you would say your first name or alias so that we will be able to keep track of who is saying what.

***Consent***

Since we are not using names, it would be useless to use consent forms. So I am going to say out loud the information usually written in a consent form.

1. This is a focus group for the HIV/AIDS Needs Assessment in Communities of Color, for the Houston EMA Ryan White Title I Funds.
2. You are selected for this focus group because you are living with HIV or AIDS, and you belong to one of the subpopulations.
3. The purpose of this focus group is to get the opinions of people who are affected by HIV/AIDS but not accessing primary medical care.
4. The benefit you may gain from this assessment is to make the Planning Council more aware of how to better serve your needs and allocate resources within the Houston EMA.
5. There are no risks involved in your participation in this focus group. Your names will never be disclosed, and all information you give us will be kept confidential.
6. You may refuse to participate. We accept and respect your decision.
7. We do ask that you fill out the client survey to give us a profile of who you are -- without revealing your name; and also to help us identify where and for whom services are needed.
8. There is no cost to you for participating in this focus group. In fact, you will be provided $____ as a thank you for your participation.
9. Do you understand this information? Do you have any questions? Do you consent to participate? *(Verbally and individually poll the group members).*

__________Moderator                    ___________Transcriber

# Focus Group Questions

*The format of inquiry will be open-ended questions, with specific probes based on participants' responses.*

**Introduction**

1. Let us go around the group and get to know each other better. In order to protect your confidentiality, please introduce yourselves by your first name only and say how long you have known that your were infected with HIV, where you live now, and where you lived when you found out you were HIV infected. Also, please say if you have had any symptoms or opportunistic infections related to your HIV infection?

2. In this discussion we are going to talk about " primary medical care". In your opinion what is primary medical care? What does it mean to you?

**For the purpose of this discussion, we will all be using the same definition. Primary medical care means: Visiting your nurse or doctor or their assistants, to monitor or treat your HIV infection in a clinic. We consider you "out of care", if you are not getting regular medical care; if your infection is not being followed up by a doctor or in a clinic; and if you are not having any mental health service.**

3. Do you know if primary medical care for your HIV infection is available to you? (*PROBE: how did you find out?*)

4. Which one of you is **currently** getting primary medical care for their HIV infection, or any particular symptom? (*MODERATOR SAY THE NUMBER FOR THE TAPE.*)

    4.1. What made you seek care the first time you went?

    4.2. For those <u>not</u> currently seeking primary medical care, what are your reasons for not currently using it? What would it take for you to get health care?

    4.3. For those seeking care, what are some of the important factors that enable you to get primary medical care? (*PROBE: health status, issues of insurance, child care, transportation, advice of friends, etc.*)

5. <u>In the past year</u>, have any of you needed HIV medical care, but were not able to get it?

- 5.1. What was the problem you had for which you did not get care? (*PROBE FOR SPECIFIC SYMPTOM OF NEED SUCH AS ....Acute illness, eye problem, to get a viral load test?*)

- 5.2. Why didn't you get medical care for (*RE-STATE PROBLEMS*?)

6. Which of you prefer to get primary care in your neighborhood and which of you outside of your neighborhood? (*MODERTOR, SAY WHO FOR THE TAPE*)

- 6.1. For those who prefer care outside neighborhood, why?
  (*PROBE FOR REASONS SUCH AS*:
  *<u>Confidentiality</u> -- are you worried that you may be identified by people, those who know you?*
  *<u>Quality of care</u> -- do you believe the services outside your neighborhood are much better?*
  *<u>Reimbursement</u> -- Is the provider in your area not reimbursed?*

- 6.2. What are the barriers to your getting care outside your neighborhood?

- 6.3. For those who prefer to get care in your neighborhood, why?
  *(PROBE FOR REASONS SUCH AS:*
  *<u>Convenience</u>*
  *<u>Quality of care</u>*
  *<u>Sensitivity to my issues, etc.)</u>*

- 6.4. What are the barriers to you getting care in your neighborhood?

**I am interested in discussing how you manage or treat your HIV infection.**

7. What are you doing to manage and treat your HIV infection -- mention everything you are doing including seeing a doctor, taking medication, receiving complementary treatments -- herbal, massage, acupuncture, biorhythms taking food supplements, or doing NOTHING to manage your infection.

8. Medical treatments are known to prolong the lives of those living with HIV and AIDS. On the list on the board there are several types of medication. For each type of medication:

8.1. First, with a show of hands, let me know who knows about each type.

8.2. Then who is taking each type.

8.3. Last, for those who are taking or were taking each medication, how effective do you think each type is in treating the infection or relieving your symptom? What have you heard about its safety or dangers?

(*GO THROUGH* ***the broad*** *LIST*)....

- Are you taking anti-retrovirals and/or protease inhibitors that work against the virus?
- Are you taking antibiotics such as Bactrim that fight infections?
- Are you taking Anti-fungal (such as Diflucan) that are for body rashes or thrush?
- Are you taking steroids which help with your appetite or help you build weight?
- Are you taking anti-depressants for depression or anxiety?
- Are there any other prescription or non-prescription drugs you are taking?
- Are you doing massage?
- Are you taking herbal therapy?
- Are you doing biorhythms? (Biofeedback)
- Are you getting acupuncture?
- Are you taking food supplements?

8.4. For those of you who know about, but are **not** using this specific medication (*SAY EACH TYPE OF MEDICATION*) why aren't you taking it?

(*PROBE FOR REASONS SUCH AS:*

*Side effects.*

*Don't feel it is effective.*

*I feel I should not take it until I really need it.*

*Waiting for something more effective.)*

9. How difficult is it for you to get your medications?

9.1. Do you feel that all the medical treatments you need are available and accessible to you? If no, why not?

9.2. How do you get your medication? (from doctors and pharmacies? from herbalists, from friends, on-the-street, etc.)

9.3. Are there any barriers to getting your medication? (PROBE: transportation, cost, poor instructions, lack of confidentiality, etc.)

9.4. How do you pay for your medication?

10. How many of you have stopped taking your medications? *(MODERATOR SAY THE NUMBER FOR THE TAPE)*

10.1. Did you stop it altogether or just take a drug vacation?

10.2. Did you stop with or without the knowledge of your primary care provider?

10.3. For those of you who have stopped, what is the reason you have stopped taking your medication?

11. What are the specific challenges or difficulties you face because you are ------?

12. Up till now, I have asked you to speak about your own experiences, but now I want you to speak about your "community", *NOTE MAKEUP OF GROUP.* What are the specific challenges you feel your community faces in receiving treatment?

13. Are there any HIV or AIDS services you feel you need but cannot find?

14. If you could change one thing about how health care is provided to people with HIV in your area, what would it be?

15. Is there anything that we have not covered that you may want to add?

# Attachment 5

# Confidentiality Statement

# Houston EMA Survey
# for the Needs Assessment
# in Communities of Color

"I understand that my completion of this needs assessment client survey is strictly voluntary.
If I choose not to complete the survey, it will not affect the services that I receive."

- THIS IS A CONFIDENTIAL SURVEY. RESULTS WILL BE TABULATED ONLY FOR GROUPS, NOT FOR INDIVIDUALS.
- THERE ARE NO RIGHT OR WRONG ANSWERS. LEAVE BLANK ANY QUESTIONS YOU DON'T WANT TO ANSWER OR ANY THAT MAKE YOU FEEL UNCOMFORTABLE.
- Return the survey to the person or agency that gave it to you.
- You may receive other copies of this survey from more than one person or agency. Please fill out and return this survey only one time.
- For a child with HIV disease and/or AIDS, his/her parent, guardian or caregiver may fill out this survey while representing, *as much as possible*, the child's point of view.
- For an individual who is physically or emotionally ill, a friend, family member or caregiver may fill it out while representing, *as much as possible*, that individual's point of view.

Thank you for helping us collect information about what people with HIV/AIDS need. Your input is invaluable and necessary for providing the utmost quality of service. If you have any questions or comments about this survey, please contact the Ryan White Planning Council, Office of Support at (713) 572-3724.

# Attachment 6

# Client Survey Instrument

Today's Date:__ __ __ / __ __ / 2001
Mo Day Year

**Client Code:**

1st ⟷ 3rd letter of firstname
1st ⟷ 3rd letter of lastname
m m ⟷ y y DOB (mm/yy)
sex Male=1 Female=2

1. **What is your current HIV status? Check only one box.**
   - ☐$_1$ HIV positive with symptoms
   - ☐$_2$ HIV positive with no symptoms
   - ☐$_3$ HIV negative
   - ☐$_4$ Don't know

**If you are HIV negative or do not know your HIV status, please return the survey to the person who gave it to you. If you are HIV positive, please answer the following questions.**

2. **Are you:** ☐$_1$ Male ☐$_2$ Female ☐$_3$ Transgender

3. **What is your date of birth?** __ __ / __ __ / 19 __ __
   Mo Day Year

4. **Do you consider yourself Hispanic/Latino?**
   ☐$_1$ Yes ☐$_2$ No

5. **What do you consider your racial background? Check only one box.**
   - ☐$_1$ American Indian/Alaska Native
   - ☐$_2$ Asian or Pacific Islander
   - ☐$_3$ African American or African American
   - ☐$_4$White
   - ☐$_5$Mixed race
   - ☐$_6$Other (specify): ____________________

6. **What is the highest level of education you completed?**
   - ☐$_1$ Grade school or less
   - ☐$_2$ Some high school
   - ☐$_3$ High school/GED
   - ☐$_4$ Technical or trade school
   - ☐$_5$ Some college
   - ☐$_6$ Completed college
   - ☐$_7$ Graduate level
   - ☐$_8$ Other (specify) ________________

7. **Are you currently: (Circle one)**
   - ☐$_1$ Single
   - ☐$_2$ Separated
   - ☐$_3$ Divorced
   - ☐$_4$ Married/living with a partner
   - ☐$_5$ Widowed or lost a partner
   - ☐$_6$ Other (specify) ________________________________

8. **Where do you currently live?**
   - ☐$_1$ In an apartment or house
   - ☐$_2$ In a half-way house, transitional housing or treatment facility
   - ☐$_3$ Homeless shelter
   - ☐$_4$ Homeless -- on the street/in car
   - ☐$_5$ Battered women's/ men's shelter
   - ☐$_6$ Jail/correctional facility
   - ☐$_7$ Other (specify) ________________________________

9. **What is the city, county, and zip code where you live?** ________________, ________________, __ __ __ __ __
   city county zip

**10. How many children are in your household?**

☐$_1$ None
☐$_2$ One child
☐$_3$ Two children
☐$_4$ Three children
☐$_5$ Four or more children

**11. Is there anyone else living with you who has HIV?** **Check all that apply**.

☐$_1$ Nobody
☐$_2$ Husband/wife/partner
☐$_3$ Child: How many children? __________
☐$_4$ Other (specify)_________________________

**12. How many close friends or family members are HIV positive?** ____________

**13. How frequently do you believe that they access outpatient medical care like check-ups, lab tests, or treatment for problems related to their HIV infection?**

☐$_1$ Once a year
☐$_2$ Twice a year
☐$_3$ Three times a year
☐$_4$ 4-5 times a year
☐$_5$ 6-12 a year
☐$_6$ More than 12 a year

**14. How often have you advised your HIV positive friend or family member to seek medical care?**

☐$_1$Never
☐$_2$ Rarely
☐$_3$ Sometimes
☐$_4$ Frequently

**15. How often has your HIV positive friend or family member advised you to seek medical care?**

☐$_1$Never
☐$_2$ Rarely
☐$_3$ Sometimes
☐$_4$ Frequently

**16. Do you consider yourself:**

☐$_1$ Straight/heterosexual
☐$_2$ Homosexual/gay/WSW
☐$_3$ Bisexual

**17. What describes your current job situation**

☐$_1$ Full-time/Part-time job
☐$_2$ Not working
☐$_3$ Other (specify)

**18. What was your annual household income for 1999?** ____________________

**19. What kind of health insurance do you have?** **Check all that apply.**

☐$_1$ Medicaid
☐$_2$ Hospital District Gold Card
☐$_3$ Medicare
☐$_4$ VA
☐$_5$ Private insurance, through work
☐$_6$ COBRA (insurance paid through your last employer)
☐$_7$ Private insurance, not through work
☐$_8$ Other (specify)
______________________________
☐$_9$ None, I have no health insurance

**20. Which of the following benefits do you receive?** **Check all that apply.**

☐$_1$ Supplemental Security Income (SSI)
☐$_2$ Social Security Disability Income (SSDI)
☐$_3$ ADAP

**21. During the last 6 months, how often have you used any of the following?**

| | | If used in last six months | | |
|---|---|---|---|---|
| | Not Used at all | Used Daily | Used Weekly | Used Monthly |
| Alcohol | ☐1 | ☐2 | ☐3 | ☐4 |
| Marijuana or hash | ☐1 | ☐2 | ☐3 | ☐4 |
| Crack | ☐1 | ☐2 | ☐3 | ☐4 |
| Cocaine | ☐1 | ☐2 | ☐3 | ☐4 |
| Crystal Meth or Methamphetamines | ☐1 | ☐2 | ☐3 | ☐4 |
| Ecstasy | ☐1 | ☐2 | ☐3 | ☐4 |
| LSD | ☐1 | ☐2 | ☐3 | ☐4 |
| Speedball | ☐1 | ☐2 | ☐3 | ☐4 |
| Poppers | ☐1 | ☐2 | ☐3 | ☐4 |
| Tobacco | ☐1 | ☐2 | ☐3 | ☐4 |
| Heroin | ☐1 | ☐2 | ☐3 | ☐4 |
| Other substances **(Specify)**<br>______________________________ | ☐1 | ☐2 | ☐3 | ☐4 |

**22. Have you ever injected any substances not prescribed by a medical person?**

☐1 Yes ☐2 No

**23. Have you ever had any of the following? Check all that apply**

☐1 Syphilis
☐2 Genital Herpes
☐3 Gonorrhea
☐4 Chlamydia
☐5 Genital warts
☐6 Hepatitis (A, B, or C)
☐7 TB
☐8 Yeast infections

**24. Over the past 2 years, have you ever been:**

☐1 In prison/jail
☐2 Homeless
☐3 Living in housing provided because you were homeless
☐4 Living in transitional or half-way housing
☐5 Living in drug treatment housing

**25. How would you describe your residency status in the United States?**

☐1 Citizen
☐2 Have a visa (student, temp or permanent)
☐3 Have legal refugee or on asylum status
☐4 Undocumented
☐5 Other (specify) ______________________________

**26. When did you first test positive for HIV?** ___ ___ Month ___ ___ Year

**27. How did you first find out you were HIV positive?**

☐1 When I requested an HIV test
☐2 When I donated blood
☐3 **(For women only)** As part of my care while pregnant
☐4 When I went to the hospital for something else
☐5 As part of a physical exam
☐6 Other (specify) ______________________________

**28. How soon after testing positive for HIV did you receive HIV-related medical care?**

☐1 Within 3 months of being diagnosed
☐2 Within 6 months of being diagnosed
☐3 Within a year of being diagnosed
☐4 Have not received any medical care

**29. Have you been told by your doctor that you have AIDS?**

☐$_1$ Yes
☐$_2$ No

**30.** IF YOU HAVE AIDS, What was the month and year that you were told you had AIDS?

___ ___ Month ___ ___ Year

☐$_1$ Never diagnosed with AIDS

**31. Please check the category that best describes your T4-cell count:**

☐$_1$ Over 500
☐$_2$ Between 200 and 500
☐$_3$ Under 200
☐$_4$ I don't know

**32. Have you ever needed HIV medical care and did not get it?**

☐$_1$ Yes
☐$_2$ No (GO TO QUESTION 34)

**33. If you did not get medical care, why didn't you get HIV medical care? Check all that apply.**

☐$_1$ Did not know how to get medical service
☐$_2$ Did not know where to get care
☐$_3$ Did not have transportation
☐$_4$ Did not want people to find out I am HIV positive
☐$_5$ I missed my appointment
☐$_6$ Still on waiting list
☐$_7$ Could not afford service
☐$_8$ Was not eligible
☐$_9$ Had to wait too long to be seen
☐$_{10}$ Did not have childcare
☐$_{11}$ Did not trust the quality of the services
☐$_{12}$ I felt that the agencies discriminated against me
☐$_{13}$ Other (Specify) ______________________________

**34. How often do you get sick enough from your HIV infection to require medical attention?**

☐$_1$ Once a month
☐$_2$ Twice a year
☐$_3$ Once a year
☐$_4$ I have never been sick

**35. In general, would you say that today your <u>physical</u> health is..**

☐$_1$ Excellent
☐$_2$ Good
☐$_3$ Fair
☐$_4$ Poor

**36. In general, would you say that today your <u>emotional</u> health is..**

☐$_1$ Excellent
☐$_2$ Good
☐$_3$ Fair
☐$_4$ Poor

**37. Are you <u>currently</u> getting medical care for your HIV?**

☐$_1$ Yes
☐$_2$ No

**38. Think about <u>the past year</u>, how often did you get HIV medical care?**

☐$_1$ Never (Go to Q. 40)
☐$_2$ Once a year
☐$_3$ Twice a year
☐$_4$ Three times a year
☐$_5$ 4-5 times a year
☐$_6$ 6-12 a year
☐$_7$ More than 12 times a year

**39. Why did you seek medical care within the past year? (Check all that apply)**

☐1 I was sick or had a symptom related to HIV infection
☐2 I was referred to a clinic or doctor by a case manager
☐3 Monitoring my HIV infection & lab test
☐4 Other reason ____________________
(Specify)

**40. If you are not <u>currently</u> getting medical care, what would it take for you to get HIV medical care?**

**41. Do you prefer to get HIV medical care outside of your neighborhood?**

☐1 Yes → Why do you prefer to get care outside of your neighborhood?

☐2 No → Why do you prefer to get care in your neighborhood?

**42. Have you ever taken, or are you currently taking any medicines for your HIV infection?**

☐1 No, never taken medication for HIV infection ▶ (PLEASE GO TO QUESTION 47)
☐2 Yes, taken medication in the past but stopped
☐3 Yes, currently taking medication

**43. When you need HIV medications, how do you get them?**

**44. What kind of medications are you <u>currently</u> taking? Check all that apply**

☐1 I am not taking medication right now
☐2 Anti-retrovirals and/or protease inhibitors that work against the virus
☐3 Antibiotics such as Bactrim that fight infections
☐4 Anti-fungal (such as Diflucan) that are for body rashes or thrush
☐5 Steroids which help with your appetite or help you build weight
☐6 Anti-depressants for depression or anxiety

**45. How often do you or did you miss a dose of your medication?**

☐1 Never **(Go to Q. 47)**
☐2 Rarely (no more than once a week)
☐3 Some of the time (1 to 4 times a week
☐4 Often (five or more times a week)

**46. Which of the following is a reason you stopped taking, or skipped medication?**
**Check all that apply.**

☐$_1$ Side effects
☐$_2$ Difficult schedule and requirements
☐$_3$ Medication didn't work
☐$_4$ Could not afford it
☐$_5$ Doctor suggested that I stop
☐$_6$ Forgot to take medication
☐$_7$ Couldn't take with food
☐$_8$ Didn't understand instructions
☐$_9$ Other (specify) ______________________________

**47. IF NOT TAKING MEDICATIONS: Have you heard about treatments like protease inhibitors or antiviral medications that fight directly against HIV?**

☐$_1$ Yes ☐$_2$ No

## Please tell me whether you agree or disagree with the following:

| | | | |
|---|---|---|---|
| **48. There are drugs available which can lengthen the life of a person infected with HIV/AIDS** | ☐$_1$ Agree | ☐$_2$ Disagree | ☐$_3$ Don't know |
| **49. HIV drugs are easy to get if you want them.** | ☐$_1$ Agree | ☐$_2$ Disagree | ☐$_3$ Don't know |
| **50. HIV medications do more bad than good.** | ☐$_1$ Agree | ☐$_2$ Disagree | ☐$_3$ Don't know |

**51. Do you use any of the following complementary health care methods? Check all that apply.**

☐$_1$ Massage
☐$_2$ Acupuncture
☐$_3$ Chiropractor
☐$_4$ Biofeedback
☐$_5$ Herbal treatments
☐$_6$ Other (specify) ______________________

**52. If you need any of the following, would you know where to get it?**
**Circle "Yes" or "No" for each item.**

| | | | | | |
|---|---|---|---|---|---|
| Eye Care | $_1$ **Yes** | $_2$ **No** | Mental health services | $_1$ **Yes** | $_2$ **No** |
| Dental care | $_1$ **Yes** | $_2$ **No** | Nutritional information | $_1$ **Yes** | $_2$ **No** |
| Medication | $_1$ **Yes** | $_2$ **No** | Substance abuse treatment | $_1$ **Yes** | $_2$ **No** |
| HIV education | $_1$ **Yes** | $_2$ **No** | Complementary therapy (e.g., massage etc.) | $_1$ **Yes** | $_2$ **No** |

**53. Which of the following do you need *now* but cannot get? Circle "Yes" or "No" for each item**

| | | | | | |
|---|---|---|---|---|---|
| Eye Care | $_1$ **Yes** | $_2$ **No** | Mental health services | $_1$ **Yes** | $_2$ **No** |
| Dental care | $_1$ **Yes** | $_2$ **No** | Nutritional information | $_1$ **Yes** | $_2$ **No** |
| Medication | $_1$ **Yes** | $_2$ **No** | Substance abuse treatment | $_1$ **Yes** | $_2$ **No** |
| HIV education | $_1$ **Yes** | $_2$ **No** | Alternative/ complementary therapy (e.g., massage etc.) | $_1$ **Yes** | $_2$ **No** |

**54. Please list in order, the 3 biggest barriers you have faced when trying to get HIV medical care:**

*1.* (Biggest barrier)

*2.* (Next biggest barrier)

*3.* (Third biggest barrier)

**55. What is the one most important change you think would help people living with HIV, get services?**

**56. Is there anything that we have not covered that you may want to add?**

# Attachment 7

# Advertisement for Client Survey

## Are You A Person Living With HIV/AIDS
## <u>And</u>
## Are you of Hispanic/Latino Origin, African American/African American or Caribbean?

## Do you know someone who is?

**If so, this is your opportunity to participate in a Needs Assessment among Communities of Color.**

***We are especially interested in those who are <u>NOT</u> receiving HIV treatment or service***

Join a confidential group sponsored by the Ryan White Planning Council. Your input will have direct impact on the types of service offered.

**<u>For more information, Please Call:</u>**
**<u>Des at 713-572-3724</u>**

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A. For a FREE book listing services available

**to HIV+ people and their families,**
**call (713) 572-3724 and request**
**a "Blue Book" to be mailed to you.**