The Comprehensive HIV Services Plan for the Houston Area

Through December 31st, 2005

Under the Ryan White CARE Act, the purpose of comprehensive HIV services planning is to help members of our community develop a detailed picture of the current and future local HIV/AIDS epidemic and to guide decisions about HIV-related services and resources in our region.

This plan is offered as a tool for decision-making. It is designed to be utilized by HIV Planning Groups and any funders of HIV prevention and care

Comprehensive Planning Committee

Mission Statement

We the volunteers of the Houston Comprehensive Planning Committee have come together to develop a Comprehensive HIV Services Plan for the Houston EMA/HSDA guided by the following mission:

> We will provide a plan that will be inclusive of the entire continuum of care to improve the quality of life for those infected with and/or affected by HIV/AIDS in the Houston EMA/HSDA by taking a leadership role in the planning and assessment of HIV resources, resulting in the delivery of prevention and care services that are accessible, efficient, and culturally affirming until the end of the epidemic is realized.

Vision Statement

> Over the next five years, the community will work together to improve and expand a coordinated system of HIV/AIDS prevention and care in order to improve the quality of life for the infected and affected communities.

Shared Values

Shared Values outline the GUIDING PRINCIPLES which planners, service providers, consumers, and community leaders agree will guide the development and delivery of HIV Services within the geographic area.

These are the guiding principles set by the Comprehensive Planning Committee:

1. Better serve the underserved in response to the HIV epidemic's growing impact among minority and hard-to-reach populations.
2. Ensure access to existing and emerging HIV/AIDS prevention strategies and treatments to make a difference in the lives of people at risk for or living with HIV disease.
3. Adapt to changes in the health care delivery system and the role of CARE Act services in filling gaps.
4. Be able to document outcomes.
5. Be driven by and advocate for consumer needs.
6. Acknowledge the value of service provider expertise.
7. Be culturally affirming to the intended audience.

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Letter of Concurrence From the Judge

ROBERT ECKELS
COUNTY JUDGE

November 14, 2000

Dear Elected Officials and all Concerned Citizens:

This *Comprehensive HIV Services Plan* is an important tool to improve prevention, health care and outcomes for people living with HIV/AIDS in the six-county Eligible Metropolitan Area (EMA) and the ten-county HIV Service Delivery Area (HSDA).

The plan was developed with extraordinary cooperation among the many funding streams and agencies involved with the care of individuals affected by and infected with HIV/AIDS. I commend these community volunteers who incorporated goals and objectives that are intended to improve the system so that both HIV prevention and care activities become more effective and better coordinated. The plan also includes a process to continue this critical collaboration.

I encourage elected officials to review the document as you implement your area's HIV care plan. Effective prevention, better care and greater efficiency can be attained if we work together as suggested by the *Comprehensive HIV Services Plan*.

Sincerely,

Robert Eckels
County Judge

ADMINISTRATION BUILDING • 1001 PRESTON, SUITE 911 • HOUSTON, TEXAS 77002
(713) 755-4000 • (FAX) (713) 755-8379

Letter of Concurrence From the Mayor

Lee P. Brown
Mayor

OFFICE OF THE MAYOR
CITY OF HOUSTON
TEXAS

November 13, 2000

Dear Houston Area Citizens:

I offer my support of the 2001 Comprehensive HIV Services Plan developed by the Comprehensive Planning Committee. The Houston area is fortunate to have the expertise of all the volunteers that worked on this plan, and their hard work is well reflected in the document.

This plan allows our community to better address needs of people affected by HIV and provides to us a format to assure an effective, collaborative system that incorporates both prevention and care services.

I encourage other elected officials in the Houston area to use the information in this plan to the greatest extent possible in determining resource allocation and in developing HIV/AIDS policies.

Sincerely,

Lee P. Brown
Mayor

LPB/MdK/gg

901 Bagby, 3rd Floor • Post Office Box 1562 • Houston, Texas 77251-1562 • 713/247-2545 • 713/247-1067 Fax

Letter of Concurrence

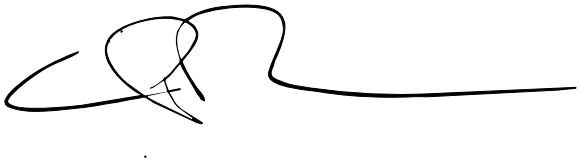
August 10, 2012

Dear Friends,

It is with great pride that we present this five-year Comprehensive HIV Services Plan. Hundreds of people, including individuals with HIV/AIDS, service providers and others have participated in creating this plan. We want to express our deep thanks to all of these people for their dedication and commitment to working together to strengthen and improve our systems of prevention and care.

Please join with us in implementing this important plan.

Sincerely,



Steve DeCorte
Co-Chair, Comprehensive Planning Committee
Ryan White Planning Council

Bruce Turner
Co-Chair, Comprehensive Planning Committee
Ryan White Planning Council

Contributors

This document is the result of countless hours of participation and effort by members of our community who are committed to improving the HIV prevention and care delivery system. Individuals who contributed their expertise included people living with HIV (PLWH) and people who provide services to PLWH.

The diversity of our community in terms of geography, race, ethnicity, sexual orientation, and gender is well reflected among this list of contributors—some who participated in a few instrumental meetings, and others who thought the meetings would never end. Most of the individuals here volunteered their time while some were paid to provide additional expertise or support. Contributors included people familiar with needs assessment methodology, health services planning, and evaluation.

Contributors also included individuals with first-hand knowledge of the gaps in our system…gaps that were confronted as they tried to negotiate a system that can be very confusing and sometimes non-responsive to their needs. All should be acknowledged for their contributions!

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Introduction

H-I-V. Alone, these are three simple letters. Put them together and they identify a disease with an impact of extraordinary proportions. What was once a relatively unknown and concentrated disease has evolved into an epidemic reaching all corners of the globe. It knows no national boundary or division of race, ethnicity, age, sex, or socioeconomic status. Since HIV was identified almost twenty years ago, about 42 million people – men and women, black and white, rich and poor, old and young – have become infected. Over 30 million people have developed AIDS and over 2 million have died from AIDS-related illnesses. In 1997 alone, there were 5.8 million new HIV infections, or approximately 16,000 infections each day.

The HIV epidemic has challenged mankind on all levels of thought – from medical and scientific to social and cultural to economic and political. Clinicians have sought new approaches to treat a disease with new and varying clinical manifestations, while scientists have struggled to find a cure. AIDS advocates have forced controversial subjects like sexuality, drug use, discrimination, sexual inequality, and economic marginalization to the forefront of social and political debate in order to draw attention to the plight of those at risk for and living with HIV. In April 2000, in the wake of catastrophic social consequences of HIV overseas, the United States government declared HIV/AIDS a threat to national security and pledged more resources to battle the disease. Healthcare and social service workers have worked tirelessly to respond to the need for complete, quality HIV care and services. Meanwhile, people and their families living with HIV have fought against sometimes overwhelming social and cultural stigmas simply to live safe, healthy lives.

Countless individuals, organizations, and communities the world over have responded admirably to the challenge of fighting the HIV epidemic. This document represents the efforts of one local community, the greater Houston, Texas area, to prevent the spread of HIV and care for those who are living with HIV and their families.

Comprehensive Planning

The HIV epidemic places a heavy strain on medical and social services. The complexities of the clinical conditions and their impact on the social and economic lives of those who are infected and their families create a confusing maze of services. Adding to the confusion of the care services are those meant to prevent the spread of infection. Organizations and individuals in local communities have needed to come together in order to develop, organize and maintain the most effective, efficient systems of care for people at risk for and living with HIV and their families. One of their most important activities is comprehensive planning, or the creation of a complete picture of the HIV epidemic and available resources with a detailed strategy for action. In the greater Houston area, there are a multitude of people and agencies dedicated to the fight against HIV. While the efforts of all are worthwhile, below is a short description of only four of the major planning groups.

Ryan White Planning Council (RWPC): The RWPC is a 38-member volunteer group of community members who help determine which services are most needed by people living with HIV in six counties of Southeast Texas: Chambers, Fort Bend, Harris, Liberty, Montgomery and Waller. The RWPC prioritizes the services and decides the best way to allocate funds received under Title I (emergency aid to cities) of the Federal Ryan White CARE Act. [For more information about the RWPC, please call 713-572-3724.]

Houston HIV Service Delivery Area (HSDA) CARE Consortium: The Consortium is a group of nonpolitical, nonprofit, nondiscriminatory agencies and individuals pledged to coordinate and deliver HIV services in a compassionate and caring manner to people living with HIV in the six counties noted above plus four more: Austin, Colorado, Walker and Wharton. The Consortium prioritizes services and allocates funds received under Title II (formula funding to the States and territories) of the Ryan White CARE Act and the Texas Department of Health State Services. [For more information about the Consortium, please call 713-526-1016.]

Houston HIV Prevention Community Planning Group (CPG): The CPG is a comprehensive planning group that works toward improving the effectiveness of services at local health departments and community-based organizations as they develop and implement HIV prevention programs. Representatives of affected populations, epidemiologists, behavioral scientists, HIV/AIDS prevention providers and health department staff work together to create an HIV prevention plan for Harris County that will be responsive to the local epidemic. [For more information about the CPG, please call 713-794-9092.]

East Texas HIV Prevention Community Planning Coalition: The Texas Department of Health created six area community planning groups to share in the responsibility for developing a State of Texas Comprehensive HIV Prevention Plan that meets the needs of communities at risk for or already infected with HIV. The Coalition is responsible for a 54-county area of East Texas that stretches from the Oklahoma/Arkansas border to Matagorda County. [For more information on the Coalition, please call 713-767-3441 or 409-258-9317.]

Comprehensive Planning Committee

In 1999, the RWPC led local planning groups and many others in the community in the creation of a Comprehensive Planning Committee (CPC). The CPC served as an *ad hoc* committee of the RWPC, but was composed of the people who plan for, administer, provide, and use HIV care and prevention services in all ten counties of the HSDA (see Section I for a map of the area). Within the designated geographic area, efforts were made to include as many people as possible and to make the CPC as representative of the local epidemic as possible. The first meeting took place in March 1999, with over 100 people in attendance, to discuss the reasons for a comprehensive plan and the structure of the process. The CPC then developed a mission so that the members could clarify the purpose of the CPC and provide a framework for making decisions, a vision that described how the plan was to work, and shared values that were to be the guiding principles that shaped the system of care.

The next step for the CPC was to develop workgroups that would focus on key areas important to the community's service delivery system, or continuum of care. The workgroup areas were: medical services, support services, coordination, client and public advocacy, infrastructure, prevention, and implementation. Members of the workgroups developed and prioritized critical issues based on what are called the "Five A's": affordable, accessible, appropriate, available, and accountable. The idea was to develop a system in which services were *affordable* to all people at risk for or living with HIV and their families, *accessible* to all people, *appropriate* for different cultural and socioeconomic populations, *available* to meet the needs of all people, and *accountable* to the funding sources and consumers for providing services at high quality.

Once the critical issues were reviewed and revised, the CPC developed an ideal continuum of care. That is, they formed a picture of a system that would meet the health and social service needs of all people at risk for and living with HIV and their families. Since not all aspects of this ideal continuum were in existence, the CPC developed a set of goals that, if reached, would result in a realization of the ideal. Each goal had a series of specific objectives and tasks that the HIV community would follow in

order to reach the goals. The final step for the CPC was to develop a way to ensure that the HIV community was making progress in reaching the goals and that these goals continued to make sense to the community.

Conclusion

In short, comprehensive planning helped the Houston-area HIV community make better decisions about changes that may have to be made to the system of care by allowing them to see where they are, where they want to be, how they are going to get there, and what to do once they are there. *The Comprehensive HIV Services Plan for the Houston Area* is a compilation of this information for ten counties of Southeast Texas. It is intended as a living, working guide for those who plan, administer, and provide HIV services in order to improve the quality of life for people at risk for and living with HIV and their families.

Executive Summary

Under the Ryan White CARE Act, the purpose of comprehensive HIV services planning is to help members of our community develop a detailed picture of the current and future local HIV/AIDS epidemic and to guide decisions about HIV related services and resources in our region.

This plan is offered as a tool for decision-making. It is designed to be utilized by HIV Planning Groups, funders of HIV prevention and care, and any individuals or groups who desire to improve health outcomes among people at-risk for HIV infection and those who are already living with HIV in the greater Houston area.

Where We Are Now: A Description of HIV Throughout the Houston area

The land area of the ten-county HIV Service Delivery Area HSDA is 9,415 square miles with a total population of 3,451,112. The Texas Department of Health reports that for the HSDA, through December 31, 1999 as of January 20, 2000, there have been 18,646 cumulative cases of AIDS diagnosed. While treatment for HIV/AIDS is slowing the progression to AIDS in some populations, HIV is still not curable and large numbers of people are continuing to be infected with HIV.

The face of the HIV/AIDS epidemic is changing. As HIV/AIDS moves increasingly into communities of color and into heterosexual populations, HIV care services will need to respond to the changes. The treatment of HIV/AIDS is changing as well. If HIV/AIDS can indeed be turned into a "chronic condition" as opposed to a life-ending disease, the difficult and expensive medical regimes will be a major emphasis in the coming years.

There are currently large numbers of infected individuals who are not accessing the HIV care system. This data suggests that outreach needs to be done for those people, many of whom are African-American or undocumented. Additionally, reports show that those in correctional institutions and those recently released are underserved in medical and support services.

In the future, service demands will most likely be different than they are today. As people live longer, they will have a continuing and growing need for basic services and many of the growing concerns will be the same as those faced by any poor population.

Unless there are major discoveries in medications or vaccines, it is estimated that by 2003 there will be a six to eight percent increase in the number of PLWA/H in the Houston.

The Ryan White CARE system has over 40 organizations that provide various types of care for individuals affected and infected by HIV. There are also numerous agencies that provide prevention services and additional care services. However, there are still numerous barriers to the provision of optimal prevention and care services in the greater Houston area. There are geographic constraints to care, capacity issues, care financing and regulatory issues, jurisdictional/political factors, public health infrastructure constraints and prevention barriers. For example, in a Comprehensive Needs Assessment conducted in 1999, PLWH/A listed "Red Tape" as the overall greatest barrier to care while providers listed the clients' lack of knowledge of the treatments available as the greatest barrier to care. Survey statements include such opinions as a need for the system to provide "more extensive patient medication education."

Where We Are Going: the Ideal System

The Houston area Continuum of Care, or COC, has been recently revised (1999) and is now conceptualized as a sort of "rail system" that identifies and tracks the HIV services deemed necessary to those who are living within the Houston area. This new "rail system" concept will theoretically allow people living in the area to get in or out of the system depending of their general knowledge of the HIV virus including how it is transmitted; their HIV serostatus; their health; and their individual desire to stay within the system. The five tracks on Houston's Continuum of Care are:

A: Public Advocacy to the General Public
B: Outreach to At Risk Populations
C: Prevention of HIV infection
D: Early Treatment of HIV infection
E: AIDS Treatment to PLWA

Over the next five years, the community will work together to improve and expand a coordinated system of HIV/AIDS prevention and care in order to improve the health outcomes and quality of life for the infected and affected communities. The services must be *available* to meet the needs of individuals and families, *accessible* to all populations infected with, affected by, or at-risk for HIV/AIDS, *affordable* to all populations infected or affected by HIV/AIDS, *appropriate* for different cultural and socio-economic populations and prevention/care needs, and *accountable* to the funding sources and clients for providing services at high quality.

The development and delivery of HIV services within the Houston area must:

- Better serve the underserved in response to the HIV epidemic's growing impact among minority and hard-to-reach populations.
- Ensure access to existing and emerging HIV/AIDS prevention strategies and treatments to make a difference in the lives of people at risk for or living with HIV disease.
- Adapt to changes in the health care delivery system and the role of CARE Act services in filling gaps.
- Be able to document outcomes.
- Be driven by and advocate for consumer needs.
- Acknowledge the value of service provider expertise.
- Be culturally affirming to the intended audience.

The Houston Continuum of Care shows the ideal linkages between a full range of client-centered, cost-effective services that would unify the prevention and treatment of the HIV epidemic in the greater Houston area to achieve the following client or individual level outcomes:

- Prevent persons from becoming HIV positive
- Prevent persons who are already HIV positive from progressing to AIDS
- Improve or maintain the health status and quality of life of people living with AIDS
- Provide a dignified death to those who are at the end-stage of AIDS
- Improve linkages to and between services

How We Will Get There

At the local level, participants in the Comprehensive Planning Committee identified the critical issues that are most pressing in the Houston area. This was done by comparing the ideal Continuum of Prevention and Care (or the system of prevention and care that our community ideally wants) against

multiple assessments of the current system. Assessments of the current system utilized PLWH/A and Service Provider input from the Comprehensive Needs Assessment, Focus Groups, and Public Comment.

The Goals, Objectives and Activities through 2005, were identified by the Comprehensive Planning Committee as the local "Critical Issues". They are measurable, time-phased recommendations specific to the following components of HIV Prevention & Care:

- The System of Prevention and Care
- Public Advocacy
- Outreach and Prevention of HIV
- Early Treatment and Prevention of AIDS Progression

The Comprehensive Planning Committee calls upon the community to focus additional resources in these areas to improve health outcomes among those who are at-risk for and living with HIV.

Once We Are There: Implementation, Monitoring & Evaluation

Comprehensive planning does not end with the development of the plan. The components of a comprehensive plan provide a blueprint for decisions about service priorities and resource allocations. Once that blueprint is in place, a monitoring and evaluation plan must monitor progress in achieving short-term and long-term goals and objectives and ensure their continued relevance.

The Comprehensive Planning Committee recommended the creation of a new advisory structure – the Joint Comprehensive Planning Committee (JCPC) to oversee implementation, monitoring, and evaluation. The JCPC will seek to broaden the knowledge base and support of the Comprehensive Plan throughout the Houston area; collect information to monitor progress; and evaluate changes in the environment that affect the system of care, including epidemiology, service needs, provider capacity, resources, and the legislative and regulatory environments. The JCPC will report their findings to the respective planning bodies/funding streams who are in concurrence with the plan. These groups must then use their own processes to achieve the goals and objectives set forth in the comprehensive plan. The JCPC will serve to promote collaboration and information sharing, but is an advisory group only and will not dictate action to the individual planning bodies/funding streams.

The JCPC is an independent group in which *all* members of the community are not only welcome, but also encouraged to participate in order to capture a broad range of knowledge and perspectives. Representatives of planning groups, funding streams, administrative agencies, service providers and people and families at risk for and living with HIV will be invited to join discussions, raise issues and offer recommendations. So that business may be conducted in a timely, efficient manner, the JCPC will be Chaired by three of the major planning bodies and voting membership will be limited.

Once the details of the JCPC have been formalized, it will serve as a mechanism for tracking changes in the HIV environment and determining when and how each component of the plan will be evaluated. The information gathered by the JCPC will be used to make recommendations to the planning bodies/funding streams for any necessary modifications to the plan. Below are some examples of information to be collected. Specific strategies will be determined by the JCPC.

Epidemiologic data: Changes in epidemiology include the distribution of AIDS cases and people living with HIV in the EMA/HSDA. Factors such as age, gender, race/ethnicity, mode of transmission, stage of illness, employment and health insurance status, and housing status also must be considered. All of the planning bodies in the Houston area regularly update epidemiologic information. The JCPC

will serve as a vehicle for integrating this data and presenting it to the community in a standard manner.

Service needs: Information on service needs is collected through needs assessment activities, including consumer and provider surveys, focus groups, interviews and public forums. All of the planning bodies in the Houston area engage in some sort of needs assessment activity on a regular basis. A comprehensive needs assessment, a legislative requirement under Title I of the Ryan White C.A.R.E. act, is conducted every three years. Much of the HIV community already collaborates on needs assessment activities, but the JCPC will serve as the vehicle for bringing more players into the process and for integrating the data that is collected individually.

Service effectiveness: The HIV/AIDS Bureau of the Health Resources and Services Administration has developed six key evaluation questions to guide Ryan White planning bodies in their planning efforts. They are questions that address concerns of other HIV providers as well, and planners are beginning to seek the answers. The questions are:

- To what extent are programs providing underserved minority and vulnerable populations with access to primary medical care?
- To what extent are programs providing clients with primary medical care whose quality meets or exceeds U.S. Public Health Service standards and other care standards?
- To what extent are programs providing services that remove barriers to primary medical care so that individual can enter into and remain in care?
- To what extent are programs reducing morbidity, as indicated by reductions in opportunistic infections and related hospitalizations, increases or slowed rates of decline in CD4 lymphocyte counts, and declines in perinatal transmission of HIV?
- To what extent are programs reducing HIV-related mortality?
- To what extent are programs adapting to a changing service and cost environment?

The JCPC will gather information from the planning bodies/funding streams with regard to these or similar questions and integrate the information into the ongoing comprehensive planning process.

Section I

WHERE WE ARE NOW

A Description of the Houston Area

Chapter One: Geography and HIV Planning Regions

There are multiple funding sources for prevention and care services that are distributed through different agencies at the Federal level. These funding sources are then locally distributed to and overseen by different fiscal organizations, or administrative agencies, and planning bodies. Consequently, the planning and service provision areas are also different. This chapter presents a brief geographic description of the different HIV planning areas that would be expected to benefit from and utilize this Comprehensive Plan.

The Eligible Metropolitan Area (EMA) is the geographic area eligible to receive Title I CARE Act funds, which are passed through the EMA's top elected official. The boundaries of the metropolitan area are defined by the Census Bureau. Eligibility is determined by AIDS cases reported to the Centers for Disease Control and Prevention (CDC). There are over 50 metropolitan areas across the nation that have been designated as eligible to receive Title I funding. Some EMAs include just one city, other EMAs are composed of several cities and/or counties, and some EMAs extend over more than one state. The Houston EMA is a 6-County area that consists of Chambers, Fort Bend, Harris, Liberty, Montgomery, and Waller counties in southeast Texas. The Houston Area Ryan White Planning Council plans for Title I services in the EMA. The land area of the EMA is 5,921 square miles with a population of 3,322,025 for a population density of 561.1 people per square mile (see Map 1.1).

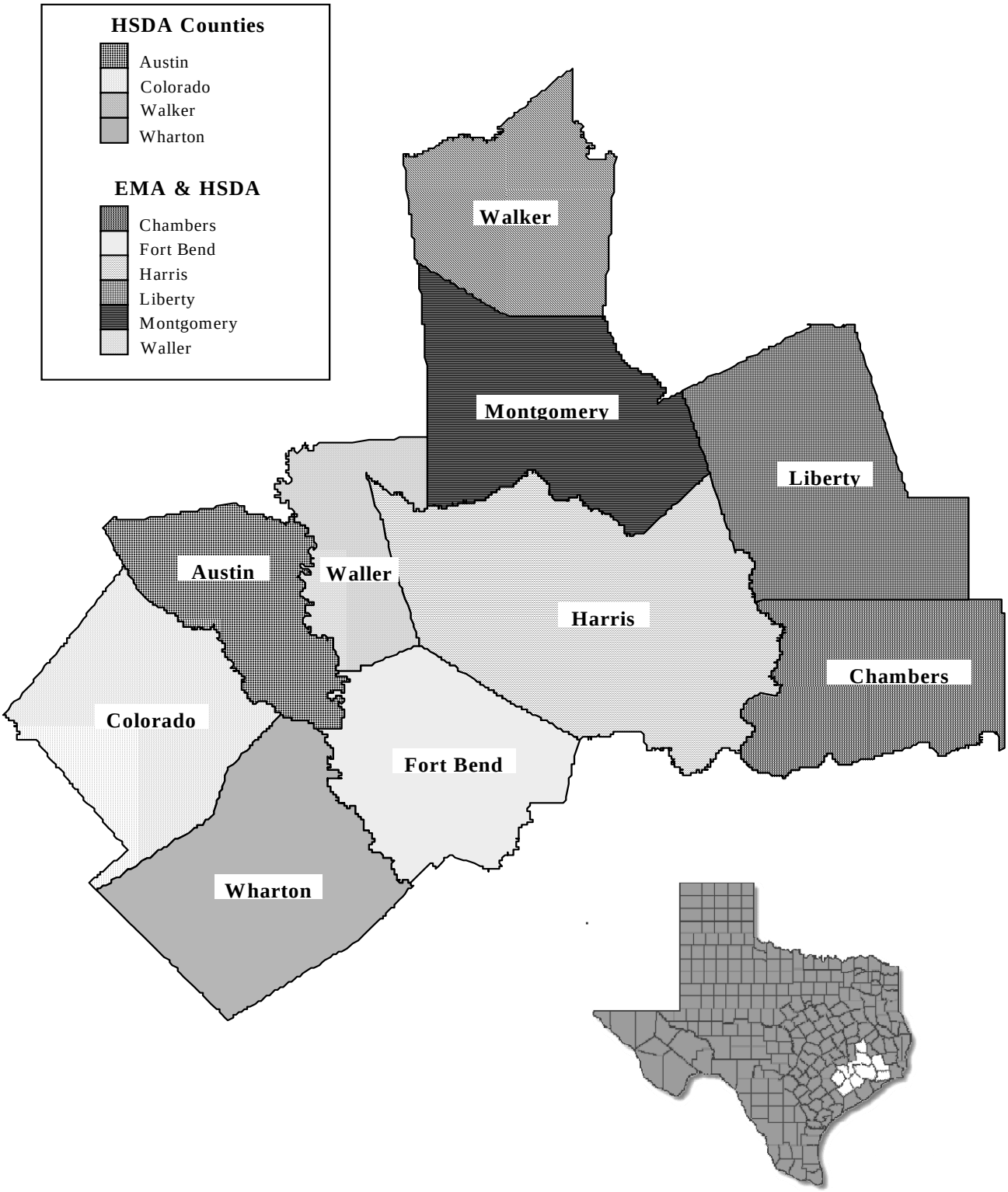
The HIV Service Delivery Area (HSDA) is the Texas geographic area eligible to receive Title II CARE Act funds through the Texas Department of Health (TDH). The Houston HSDA is a 10-County area that contains the six EMA counties plus the adjacent Austin, Colorado, Walker, and Wharton counties. The Houston HSDA CARE Consortium plans for Title II and TDH State Services throughout the HSDA. The land area of the HSDA is 9,415 square miles with a population of 3,451,112 for a population density of 366.6 people per square mile.

Of the total population of 3,451,112 in the ten-county HSDA, 2,818,199 (81.7%) reside in Harris County. The population density of Harris County is 1,630 people per square mile. Harris County is the most populous county in Texas, the third most populous in the nation, and the home of approximately 95% of the HSDA's reported HIV/AIDS cases. The City of Houston in Harris County is the largest city in Texas and the fourth largest in the United States. Houston has 89% of the EMA's reported AIDS cases and is the least densely populated major metropolitan area in the nation. Philadelphia (135 sq miles), Chicago (227.1 sq miles), and Boston (49 sq miles) combined would fit within the city limits of Houston (539.6 sq miles) with room to spare.

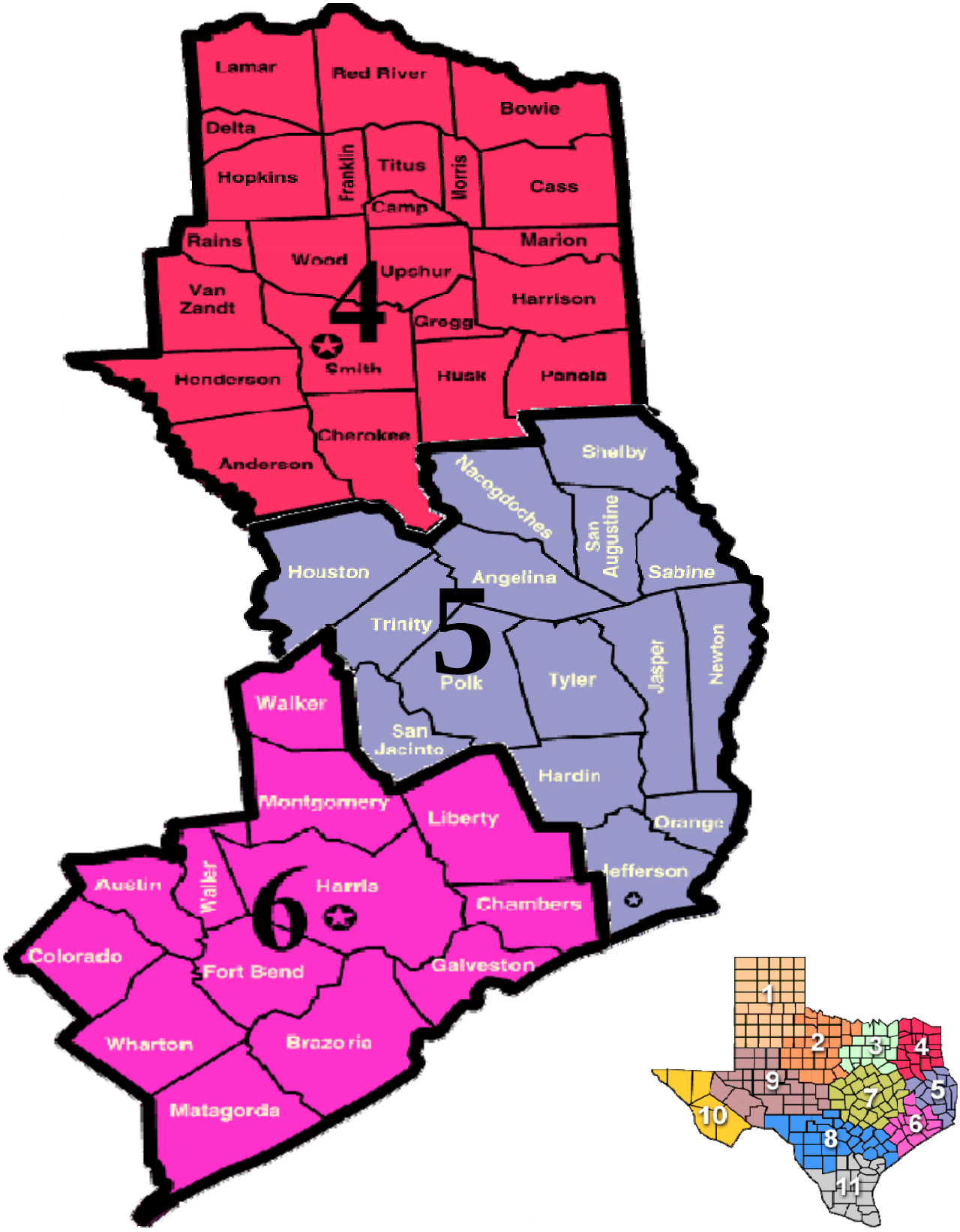
The City of Houston is directly funded by the Centers for Disease Control and Prevention (CDC) for prevention activities in Harris County. The Houston HIV Prevention Community Planning Group (CPG) plans for CDC-funded HIV prevention activities.

The local planning group for the Texas Department of Health (TDH) is known as the East Texas HIV Prevention Community Planning Coalition and they are responsible for prevention planning for the 51 counties of Public Health Regions 4, 5, and 6 in East Texas. The service area stretches from Oklahoma to the Gulf of Mexico and contains one EMA and multiple HSDAs, including the Houston area EMA and HSDA. The Region 4/East Texas Coalition planning area is 51,031 square miles (19.5% of the 261,914 square miles in Texas) with a population of 6,580,177 for a population density of 128.9 people per square mile (see Map 1.2).

Map 1.1: Houston EMA/HSDA



Map 1.2: East Texas Planning Area



Chapter Two: Epidemiological Profile

Epidemiology is the study of infectious diseases that affect large numbers of people, with a focus on preventing more infections. The most important part of epidemiology for comprehensive planning is the distribution of disease, or who is getting it where and when. An epidemiologic profile is a description of the current status of the epidemic with projections for the future.

Physicians in the United States reported the first cases of AIDS to the Centers for Disease Control and Prevention (CDC) in 1981. Since then, the State of Texas has had some of the highest numbers of HIV/AIDS in the United States. According to the CDC, through June 1999, Texas had reported 50,158 cumulative AIDS cases and 23,255 people living with HIV/AIDS.[1] With Houston, the largest city in Texas, at its tip, the 10-county Houston HIV Service Delivery Area (HSDA) was home to 35% of AIDS cases.[2] [Please note: A map of the HSDA can be found in Section I: Geography and HIV Planning Regions.] The number of AIDS cases in Harris County alone was double the Texas average.[3]

With that perspective in mind, what follows is an epidemiologic profile for the HSDA. The information was compiled from the 1999 Needs Assessment conducted for the Houston area[4] and data provided by the Texas Department of Health (TDH). [Please note: Local health authorities collect data from health providers and report their findings to TDH, who compiles the information at the county level and for the State as a whole.] For more detailed epidemiologic information, please see the references listed as footnotes to this chapter, as well as the resources listed in Section VI: Planning Resources.

Cumulative AIDS cases

Perhaps the most commonly recorded and reported statistic on HIV/AIDS is the number of people diagnosed with AIDS since the beginning of the epidemic, or the cumulative AIDS cases. Cumulative case reports show the total number of people ever reported to have an AIDS diagnosis, regardless of whether or not these people are still living. In 1993, the CDC expanded the AIDS case definition to allow reporting of AIDS cases based on a CD4+ T-lymphocyte cell count of 200 cells/microliter, or 14%, or below (prior to that year, a diagnosis of an opportunistic infection was required). [Please note: In December 1999, effective January 1, 2000, the CDC once again expanded the case definition to include detectable viral load as an indicator of HIV infection. This change, however, is not reflected in the data presented in this report.]

TDH reports that for the HSDA, through December 31, 1999, as of January 20, 2000, there were 18,646 cumulative cases of AIDS. The 6-county Eligible Metropolitan Area (EMA) accounted for the overwhelming portion (18,539) of these cases, and almost 96% (17,808) of these cases occurred in Harris County alone.

Table 2.1 presents a breakdown of cumulative cases in the HSDA by race/ethnicity by sex. Table 2.2 presents a breakdown of cases by mode of transmission by race/ethnicity. [Please note: Since there is often a year or more lag in the reporting of HIV/AIDS, the actual numbers for 1999 are likely to increase as more cases are reported over time.]

[1] Centers for Disease Control and Prevention (CDC). *HIV/AIDS Surveillance Report*. 1999; 11(1):5-6.
[2] Texas Department of Health (TDH). *Texas AIDS/STD Surveillance Report*. March 1999.
[3] Greater Houston Consolidated Metropolitan Service Area. *Greater Houston 1999 Community Health Needs Assessment*. Houston: Texas Children's Hospital; 1999.
[4] Partnership for Community Health (PCH). *Houston EMA & Houston HSDA 1999 Needs Assessment Report*. New York: PCH; 2000. Partnership for Community Health (PCH). *Houston HSDA Epidemiologic Report*. New York: PCH; 1999.

Table 2.1: Cumulative AIDS Cases by Race/Ethnicity by Sex in the HSDA

	Female	Male	**TOTAL**
Anglo	490	9,345	**9,835**
African-American (Af-Am)	1462	4,604	**6,066**
Hispanic (Hisp)	302	2,373	**2,675**
Asian/Pacific Islander (API)	4	59	**63**
American Indian/Alaskan (AI/A)	0	7	**7**
Not specified	0	0	**0**
TOTAL	**2258**	**16,388**	**18,646**

Table 2.2: Cumulative AIDS Cases by Mode of Transmission by Race/Ethnicity in the HSDA

	Anglo	Af-Am	Hisp	API	AI/A	Not Specified	**TOTAL**
Men who have sex with men (MSM)	7,402	2,284	1,597	30	5	0	**11,318**
Injection drug users (IDU)	586	1,430	244	4	1	0	**2,265**
MSM/IDU	978	461	183	1	0	0	**1,623**
Heterosexual	404	1,222	394	7	1	0	**2,028**
Blood/blood product	91	25	22	2	0	0	**140**
Pediatric	29	108	42	1	0	0	**180**
Not classified*	345	536	193	18	0	0	**1,092**
TOTAL	**9,835**	**6,066**	**2,675**	**63**	**7**	**0**	**18,646**

* People who could not be interviewed, or who did not divulge their risk behaviors, or who did not know the HIV status or the risk behavior of their heterosexual partners are assigned to this category.

As the tables indicate, over the course of the epidemic, the majority of AIDS cases have been among males (88%), Anglos (53%), and men who have sex with men (61%).

People Diagnosed with AIDS Each Year

Cumulative cases give you an overall picture of AIDS, but rather than just looking at the endpoint, it is important to look at the course of the epidemic over the years. In this way, the community will get a better picture of the current status of the epidemic and an idea of what to expect in the future. [Please note: Because of the lag in reporting, trends are presented through 1998, the latest year for the most accurate data.]

Because the HSDA is a larger geographic area that includes Harris County and the EMA, there are, of course, more AIDS cases diagnosed each year in the HSDA. The trends, however, are very similar for all three areas. The number of cases diagnosed each year in the HSDA dropped from a high of 1,815 in 1992 to 1,760 in 1998, an overall decline of about 3%. However, between 1997 and 1998, there was a 9% increase (from 1,616 to 1,760 cases). The EMA and Harris County saw an overall drop of 3% and 5%, respectively, and an increase in the last two years of 9% and 8%, respectively. [Please note: While the decrease in AIDS diagnoses may be due to the improved effectiveness of drug treatments,

there are some people for whom these treatments are not effective. The latest increase may be a sign that the new drugs are not quite the miracle they were hoped to be.]

While Houston/Harris County may drive the trends for the HSDA, do not be fooled into thinking that HIV does not exist outside of the big city. Since 1992, the nine other counties of the HSDA have bucked the trend, showing an increase of 56% in the number of AIDS cases diagnosed each year. Between 1997 and 1998, these nine counties showed a 13% increase in the number of newly diagnosed cases.

Figures 2.1, 2.2, and 2.3 present the number of newly diagnosed AIDS cases from 1992 to 1998 for the HSDA by sex, race/ethnicity, and mode of transmission, respectively.

Figure 2.1: AIDS Cases Diagnosed Each Year by Sex in the HSDA

Figure 2.2: AIDS Cases Diagnosed Each Year by Race/Ethnicity in the HSDA

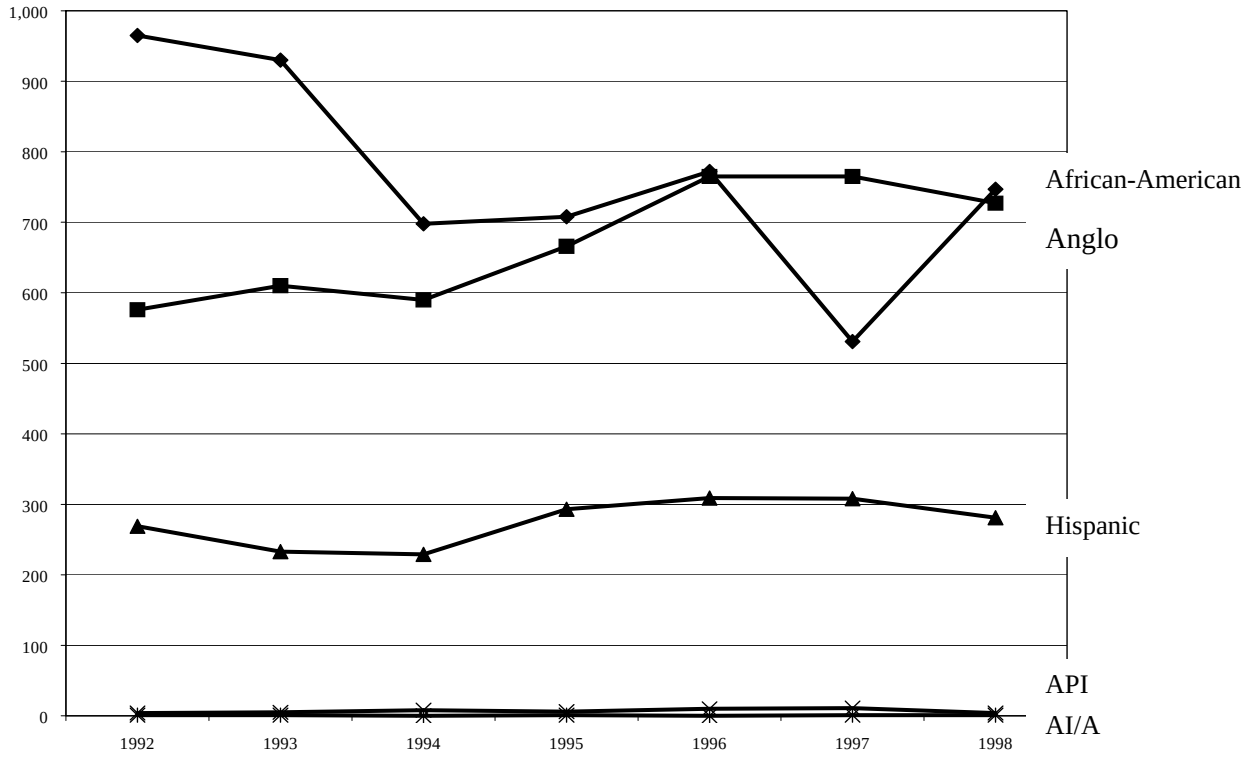
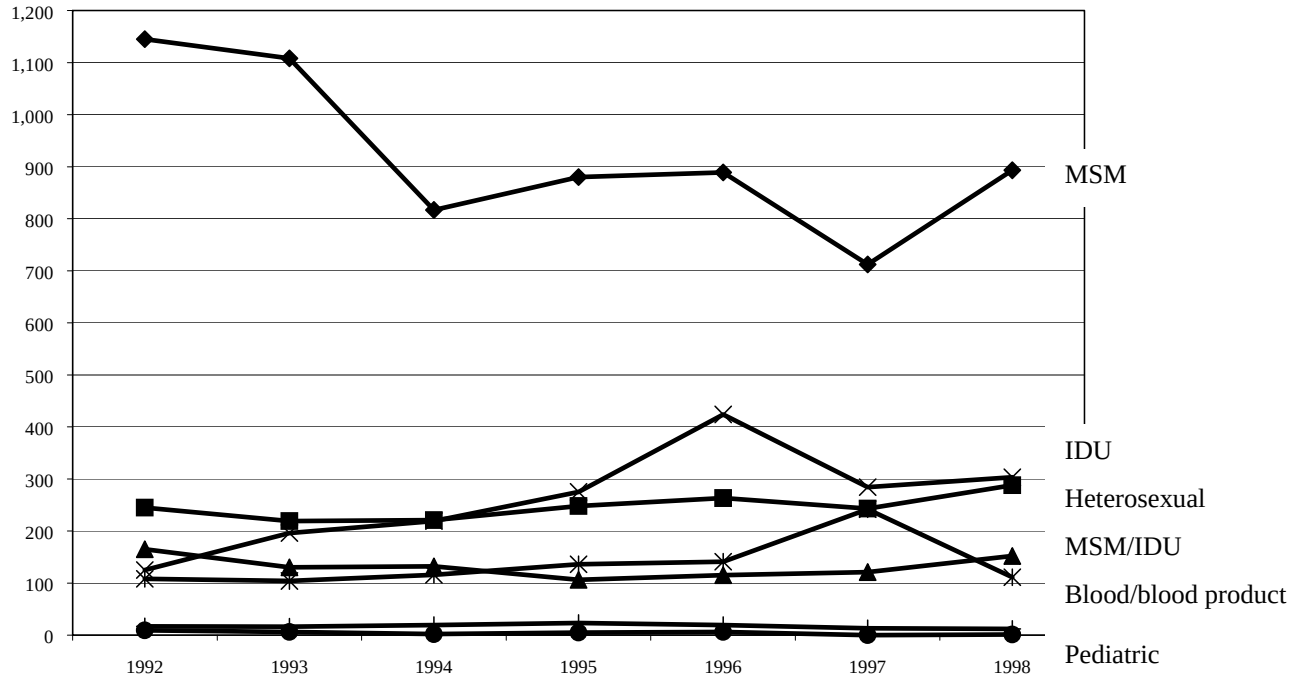


Figure 2.3: AIDS Cases Diagnosed Each Year by Mode of Transmission in the HSDA



The three figures above indicate the changing face of AIDS. While total numbers of cases may not change much, or remain relatively small in comparison to other groups, proportional changes in the mix of the population indicate shifts in the epidemic. Women, heterosexuals, and people of color are becoming infected at alarming rates.

Figure 2.1 shows that while the number of newly diagnosed AIDS cases among males declined by 11% from 1,636 in 1992 to 1,461 in 1998, the number rose among females by 66% from 180 to 299. Figure 2.2 shows that Anglo cases dropped 23% (from 965 to 747), but African-American cases increased by 26% (from 576 to 727) and Hispanic cases increased by 5% (from 269 to 281). In terms of absolute numbers, the number of newly diagnosed African-Americans surpassed the number for Anglos in 1997. Figure 2.3 shows an unequal trend in newly diagnosed AIDS cases by mode of transmission. Men who have sex with men show a significant decline of 22% (from 1,145 to 893), while heterosexuals show an increase of a whopping 142% (from 125 to 303), pushing their share of newly diagnosed cases from 7% in 1992 to 17% in 1998.

A point of interest not included in the graphs is the number of newly diagnosed AIDS cases among children and adolescents in the HSDA. The good news for children (younger than 13 years) is that the number of cases has steadily decreased over the years, from 16 in 1992 to 8 in 1998. This 50% decrease is due, in part, to the use of antiretroviral therapies with women with HIV infection during pregnancy and delivery, and with their children from birth through the next six weeks. Unfortunately, the news for adolescents (aged 13 to 19 years) is not good. The number of AIDS cases diagnosed yearly increased 110% from 10 in 1992 to 21 in 1998.

People living with AIDS

The numbers presented above show the road HIV/AIDS has taken in the Houston area. While they play an important role in HIV planning efforts, they do not take mortality into account. The focus of the continuum of care, or service delivery system, is on the people who are *living* with HIV/AIDS.

TDH reports that for the HSDA, through December 31, 1999, as of January 20, 2000, there were 7,758 people living with AIDS. The EMA accounted for 99.5%, with 95% (7,387) living in Harris County. While the remaining 5% living in the other nine counties may be a small number in comparison, it is important to note that this represents a 430% increase over the figure for 1992.

Table 2.3 shows the number of people living with AIDS in the HSDA by race/ethnicity by sex. Table 2.4 shows a breakdown by mode of transmission by race/ethnicity.

Table 2.3: People Living with AIDS by Race/Ethnicity by Sex in the HSDA

	Female	Male	**TOTAL**
Anglo	256	3,095	**3,351**
African-American (Af-Am)	886	2,141	**3,027**
Hispanic (Hisp)	196	1,143	**1,339**
Asian/Pacific Islander (API)	2	34	**36**
American Indian/Alaskan (AI/A)	0	5	**5**
Not specified	0	0	**0**
TOTAL	**1340**	**6,418**	**7,7587,758**

Table 2.4: People Living with AIDS by Mode of Transmission by Race/Ethnicity in the HSDA

	Anglo	Af-Am	Hisp	API	AI/A	Not Specified	**TOTAL**
Men who have sex with men (MSM)	2,315	984	713	15	3	0	**4,030**
Injection drug users (IDU)	274	734	120	4	1	0	**1,133**
MSM/IDU	357	207	82	0	0	0	**646**
Heterosexual	235	777	279	4	1	0	**1,296**
Blood/blood product	14	3	9	1	0	0	**27**
Pediatric	7	50	26	11	0	0	**84**
Not classified*	149	272	110	1	0	0	**542**
TOTAL	**3,351**	**3027**	**1339**	**36**	**5**	**0**	**7,758**

* People who could not be interviewed, or who did not divulge their risk behaviors, or who did not know the HIV status or the risk behavior of their heterosexual partners are assigned to this category.

Table 2.3 indicates that despite the tremendous increase in newly diagnosed AIDS cases among women, the number of males living with AIDS still far outweighs the number of females: 83% *vs.* 17%. However, women accounted for only 8% of the people living with AIDS in 1992, an increase of over 112%. The majority (66%) of the women living with AIDS are African-American. Data also show that 56% of heterosexuals living with AIDS are women and 60% of heterosexuals are African-American.

In 1998, the race/ethnicity with the highest percentage of all people living with AIDS was Anglo, with 43%, followed closely by African-Americans with 39%. Hispanics were third with 15%. This is in striking comparison to 1992, when Anglos accounted for 62% of people living with AIDS, African-Americans, 25%, and Hispanics, 13%. In other words, the proportion of Anglos decreased by 31%, while the proportion of African-Americans increased by 56% and that of Hispanics by 15%. Another interesting note is that while the proportion of Anglos in the HIV epidemic is less than in the general population (39% *vs.* 60%), it is the reverse for African-Americans (62% *vs.* 38%).

Table 2.4 shows that, at 52%, MSM continue to be the majority of all people living with AIDS. Heterosexuals are the next largest group, with 17%, followed closely by IDU with 15%. In 1992, however, MSM accounted for 66% and heterosexuals for only 5%, a decline of 21% and an increase of 240%, respectively.

Table 2.5 presents the numbers of people living with AIDS within the context of demographic information for each of the ten counties in the EMA/HSDA.

Table 2.5: HIV Service Delivery Area (HSDA) Percent Population and PLWA and AIDS Rate by: County and Population Density, Ethnic Minority Percentage, and Percentage of Population Living in Poverty

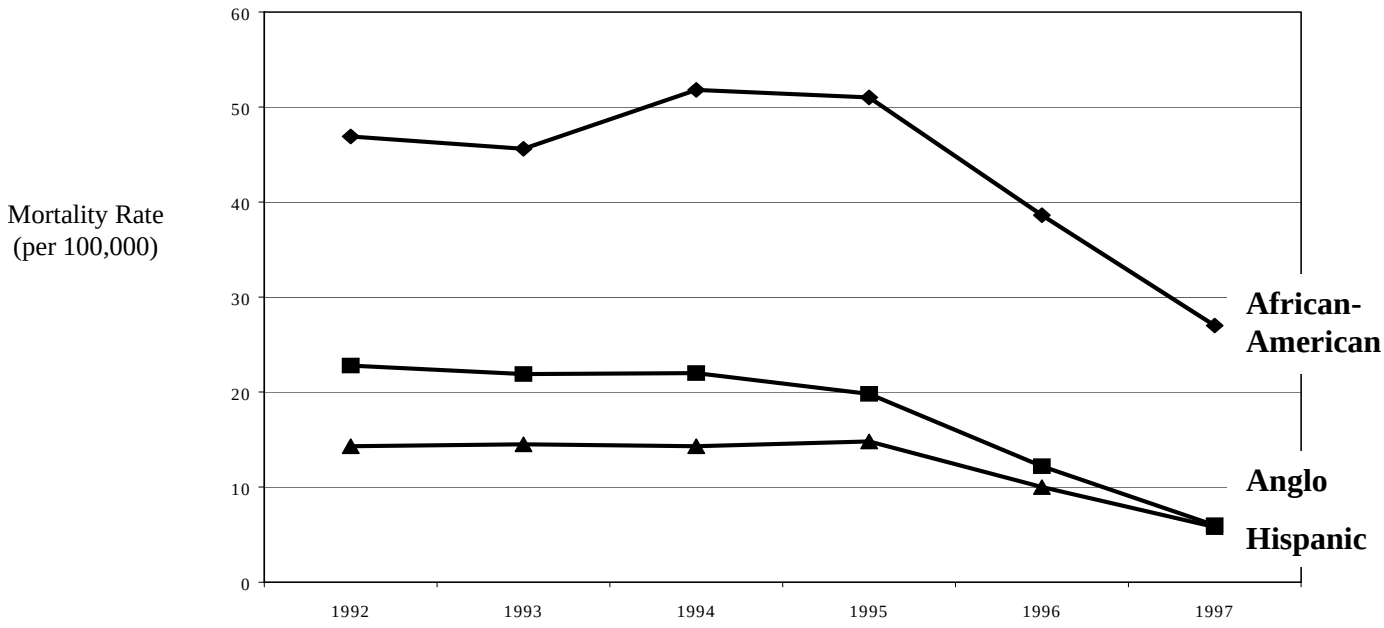
County	*Population*	*% Total Pop*	*% Total PLWA*	*# PLWA*	*AIDS Rate per thou*	*Miles²*	*Pop./M²*	*Minority %*	*Poverty %*
Austin	19,832	0.57	0.063	5	0.25	653	30.4	18.1	14.1
Chambers	**20,088**	**0.58**	**0.038**	**3**	**0.15**	**599**	**33.5**	**16.7**	**11.2**
Colorado	18,383	0.53	0.012	1	0.054	963	19.1	27.4	18.2
Fort Bend	**225,421**	**6.53**	**2.08**	**165**	**0.73**	**875**	**257.6**	**37.4**	**9.4**
Harris	2,818,199	81.7	95.4	7,555	2.68	1729	1630	35.3	19.1
Liberty	**52,726**	**1.53**	**0.44**	**35**	**0.66**	**1160**	**45.5**	**16.5**	**18.8**
Montgomery	182,201	5.28	1.30	103	0.57	1044	174.5	8.8	11.5
Walker	**50,917**	**1.48**	**0.19**	**15**	**0.29**	**788**	**64.7**	**31.4**	**20.4**
Waller	23,390	0.68	0.25	20	0.86	514	45.5	44.5	23.3
Wharton	**39,955**	**1.16**	**0.21**	**17**	**0.43**	**1090**	**36.6**	**27.1**	**19.2**

Totals	*Population*	*%Pop*	*%PLWA*	*#PLWA*	*AIDS Rate per thou*	*Miles²*	*Pop/M²*	*Minority %*	*Poverty %*
EMA	**3,322,025**	**96.3**	**99.5**	**7,881**	**2.37**	**5,921**	**561.1**	**33.64**	**18.00**
HSDA	3,451,112	100	100	7,919	2.29	9,415	366.6	33.41	18.03

Mortality of AIDS cases

Mortality is the occurrence of death in a population during a specific time period and is calculated by dividing the number of deaths by the total population. It reflects everyone recorded by a doctor on the death certificate as dying of AIDS-related disease for a specific year. The mortality rate captures trends in current deaths due to AIDS, whether or not the person was ever reported as having AIDS and regardless of when he or she was diagnosed. As HIV treatment approaches have kept more people from advancing to AIDS and kept those with AIDS alive longer, it is not surprising that the mortality rate for AIDS has declined over the years. What is important to note about mortality is that the death rate for African-Americans is substantially higher than that for Anglos and Hispanics. Figure 2.4 shows the AIDS mortality rate for the EMA by race/ethnicity. [Please note: While data was not available for the HSDA, it is very likely that the trends are identical.]

Figure 2.4: AIDS Mortality Rate by Race/Ethnicity in the EMA



The *Houston HSDA Epidemiologic Report*[5] moderates this information with a report that among a group of people living with AIDS who were receiving care and being tracked by TDH, the mortality rates were generally lower and were very similar across all races/ethnicities. These findings suggest that people living with AIDS, especially African-Americans, must enter the continuum of care as soon as possible after testing positive for HIV.

People living with HIV

The number of people living with AIDS is only the tip of the iceberg. There are others who have not yet progressed to AIDS, but who are living with HIV, the virus that causes AIDS. People living with HIV must be included in the pool of potential service users and sources of infection for others.

Reported HIV cases

As of January 1, 1999, HIV infection (*newly diagnosed*, not retroactive) became reportable by name in the State of Texas. This means that laboratories and health care providers report confirmed cases of HIV infection by name to the local health authority. TDH, which collects this information from across the State, reports that for the HSDA, in 1999, as of January 20, 2000, there were 958 reported cases of HIV infection. The 6-county EMA accounted for most (949), with 96% (918) living in Harris County. Table 2.6 shows the cases of HIV infection in the HSDA by race/ethnicity by sex. Table 2.7 shows a breakdown by mode of transmission by race/ethnicity.

[5] Partnership for Community Health (PCH). *Houston HSDA Epidemiologic Report.* New York: PCH; 1999.

Table 2.6: HIV Infection Cases by Race/Ethnicity by Sex in the HSDA, 1999

	Female	Male	**TOTAL**
Anglo	50	162	**212**
African-American (Af-Am)	271	321	**592**
Hispanic (Hisp)	50	92	**142**
Asian/Pacific Islander (API)	1	5	**6**
American Indian/Alaskan (AI/A)	1	2	**3**
Not specified	3	0	**3**
TOTAL	**376**	**582**	**958**

Table 2.7: HIV Infection Cases by Mode of Transmission by Race/Ethnicity in the HSDA, 1999

	Anglo	Af-Am	Hisp	API	AI/A	Not Specified	**TOTAL**
Men who have sex with men (MSM)	92	99	50	3	1	0	**245**
Injection drug users (IDU)	23	107	9	0	1	0	**140**
MSM/IDU	20	21	7	0	0	0	**48**
Heterosexual	29	192	43	1	1	0	**266**
Blood/blood product	1	0	0	0	0	0	**1**
Pediatric	0	14	3	0	0	2	**19**
Not classified	47	159	30	2	0	1	**239**
TOTAL	**212**	**592**	**142**	**6**	**3**	**3**	**958**

The trends seen in the AIDS data are continued with the HIV data. While the largest reserve of new infections is among males, the proportion of men is decreasing and the proportions of women and minorities are increasing. Now, the majority of newly diagnosed infections is among African-Americans, who account for 62% of cases overall. African-American females and males account for the majority of cases for each sex, 70% and 55%, respectively. Finally, African-Americans account for 72% of all heterosexual cases. Meanwhile, heterosexual transmission also continues to increase in proportion, now accounting for 28% of new infections. [Please note: There is also an increase in the "not classified" category. The Houston Department of Health and Human Services notes that the increasing numbers of females with HIV has led to an increase in the number of not classified cases because the heterosexual contact definition requires more knowledge of the behavior of the sex partner than is available. For a majority of women who fall into this category, the admitted risk is heterosexual sex, but without the detail regarding partners necessary to meet the definition of "heterosexual contact".[6]]

[6] Houston Department of Health and Human Services (HDHHS). *2000 HIV Prevention Comprehensive Plan.* Houston: HDHHS; 1999.

HIV Estimates

While knowing the numbers reported in the previous tables is a significant part of planning, there are some important caveats to remember. Firstly, because of the stigma and discrimination still attached to HIV/AIDS and sexuality, many people do not get tested. Secondly, these are reports of infections captured as a result of *named* testing, that is, they do not reflect the number of HIV positive results found at *anonymous* testing sites. Finally, as mentioned above, these are reports of *new* infections only. We know that there are many more people who were infected before 1999 and are already living with HIV.

Estimating the true number of people who are HIV positive is a good indicator of the number of people who may need care services and the number of people who may be a source of infection for others and at whom prevention measures should be aimed. However, estimating this number is very difficult. "No accurate data on the number of people participating in a certain risk behavior exists"[7]. Recognizing that this true number is hard to pin down, the *Houston HSDA Epidemiologic Report*, using four different approaches, estimates the range for the number of people living with HIV in 1999 as between 13,373 and 20,900[8]. The bulk of these are thought to be living within the 6-county EMA (12,982 to 20,235).[9]

Risk of Reinfection and/or HIV Transmission

Clearly, people continue to be at risk for HIV infection. Almost 28.5% of the people living with HIV/AIDS who were interviewed in the 1997 Greater Houston EMA/HSDA HIV Community Needs Assessment said that they did not use condoms during their last vaginal or anal intercourse encounters. Fifteen percent of those who did not use condoms said their partners were HIV negative and 23% said they did not know the HIV status of their partners. In the 1999 Comprehensive Needs Assessment of PLWH/A, about a third of the 455 survey participants said that the reason they did not always use a condom was there "were none available" or they "didn't care". Many PLWH/A reported that they didn't know how to talk about condoms with their sex partners. Heterosexuals (55%) were more likely to report not always using condoms because they "don't like them" as compared to just under 40% of the men who have sex with men (MSM).

Sexually Transmitted Diseases

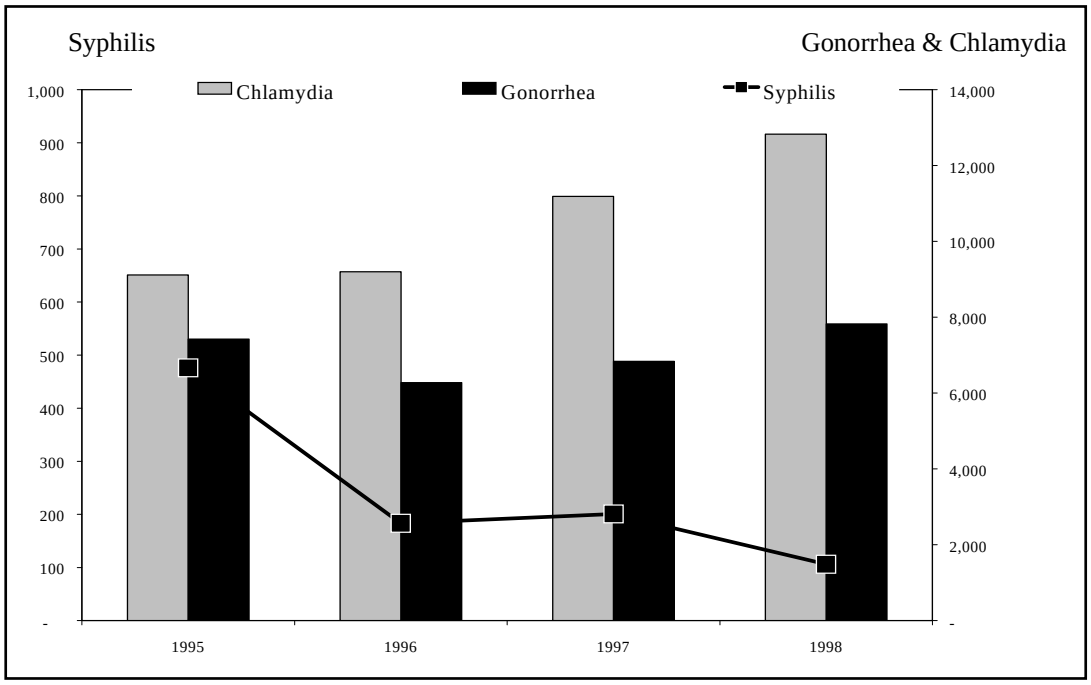
A sexually transmitted disease (STD) is a disease that is spread through intimate sexual (vaginal, oral and anal) contact. HIV is just one of a number of preventable STDs that poses a health risk for Texans. According to TDH[10], in 1998, there were 60,262 cases of chlamydia, 3,876 cases of syphilis and 32,934 cases of gonorrhea, three of the most common STDs in the United States.

People who are infected with STDs other than HIV are at increased risk of HIV infection.[11] STDs are an indicator of sexual activity, and most are an indicator of unprotected sexual contact, a significant mode of HIV transmission. Furthermore, people with a history of STDs are more likely to have a weak immune system, and the open sores/ulcers associated with active STDs increase susceptibility to HIV infection.

[7] *Ibid*.
[8] Partnership for Community Health (PCH). *Houston HSDA Epidemiologic Report*. *Op cit*.
[9] Partnership for Community Health (PCH). *Houston EMA & Houston HSDA 1999 Needs Assessment Report*. *Op cit*.
[10] Texas Department of Health (TDH). *Op cit*.
[11] Houston Department of Health and Human Services (HDHHS). *Epidemiology of sexually transmitted diseases*. Houston: HDHHS; 1999.

In the HSDA in 1998, there were 42,328 cases of chlamydia, 966 cases of syphilis, and 28,349 cases of gonorrhea. According to TDH, in the HSDA, the number of cases of gonorrhea and chlamydia has increased since 1995 and the number of cases of syphilis has decreased (Figure2.5).

Figure 2.5: Cases of Syphilis, Gonorrhea & Chlamydia in the HSDA



The East Texas HIV Prevention Community Planning Coalition (CPC) recently conducted an epidemiologic profile for their catchment area.[12] The CPC divides their data into analysis zones. Table 2.8 presents STD case rates (per 100,000 people) for two of the zones that fall within the HSDA.

Table 2.8: STD Case Rates for Gonorrhea, Chlamydia and Syphilis

Fort Bend, Liberty and Montgomery Counties						
	Anglo		**African-American**		**Hispanic**	
	Male	Female	Male	Female	Male	Female
Gonorrhea	5.5	13.9	99.1	108.8	30.0	56.0
Chlamydia	6.0	56.9	43.6	236.4	37.5	269.5
Syphilis	0.5	0.5	2.0	0.0	1.9	2.1
Harris County						
	Anglo		**African-American**		**Hispanic**	
	Male	Female	Male	Female	Male	Female
Gonorrhea	11.7	21.0	1,024.8	503.0	37.1	274.3
Chlamydia	5.4	48.7	195.4	900.0	46.5	412.6
Syphilis	0.8	0.6	15.9	9.3	1.1	0.8

[12] Health Education Training Centers Alliance for Texas (HETCAT). *Texas HIV Epidemic Profile: East Texas Area*. San Antonio, TX: HETCAT; 2000.

In each analysis zone, STDs are disproportionately affecting communities of color, particularly African-Americans, whose case rates are significantly higher than Anglos. For example, in Harris County, the case rate for chlamydia for Hispanic females is 8.5 times higher than it is for Anglo females (412.6/100,000 *vs.* 48.7/100,000). Even more astounding is the case rate for gonorrhea for African-American males, which is 87 times higher than for Anglos (1,024.8/100,000 *vs.* 11.7/100,000).

Self-reports from consumer surveyed for the 1999 Needs Assessment show that of 300 males living in the HSDA, 30 % had had a diagnosis of syphilis, 30% gonorrhea, 8% chlamydia, 36% hepatitis, and 24% herpes. Of 152 women, 20 % had had a diagnosis of syphilis, 18% gonorrhea, 14% chlamydia, 26% hepatitis, and 15% herpes.

Projections for the Future

AIDS Estimates

According to the *Houston HSDA Epidemiologic Report*:

"There is no agreed upon formula for estimating future AIDS cases... [T]here are many unknown factors that make valid projections of AIDS cases unreliable....Given the great uncertainty, simple projections based on past history, plus some educated guesses about the progression of the disease is likely to be as accurate as more complex models based on equally uncertain assumptions."[13]

The author of the report, using two different models and basing estimates on the assumptions that treatments will continue to be effective and the mortality rate low, projects that there will be 11,388 people living with AIDS in the HSDA in the year 2003 (10,845 of them in the EMA).

HIV Estimates

Clearly, people continue to be at risk for HIV infection. Almost 28.5% of the people living with AIDS who were interviewed for the 1997 Greater Houston EMA/HSDA HIV Community Needs Assessment said that they did not use condoms during their last vaginal or anal intercourse encounters. Fifteen percent of those who did not use condoms said their partners were HIV negative and 23% said they did not know the HIV status of their partners.

While attempting to estimate the numbers of people infected with HIV is an important part of planning, it also is important to recognize the ephemeral quality to this number. The development of a vaccine or the success or failure of particular prevention efforts are just a few examples of what could make these numbers obsolete in a matter of months. With that in mind, what follows is an attempt at some projections reported in the *Houston HSDA Epidemiologic Report*.[14]

The following statistics have been estimated using several models. The seroprevalence estimates from the East Texas CPC, data gathered from various counseling and testing studies, data from studies at clinics throughout Houston, and estimates from CDC statisticians have been compiled and then applied to population estimates of the Houston area. New estimates were then derived from statistical techniques. Given the multitude of unknowns in these computations, however, these numbers should be considered loose estimates at best; at worst, they are numbers "pulled from thin air."

[13] Partnership for Community Health (PCH). *Houston HSDA Epidemiologic Report*. *Op cit*.
[14] Partnership for Community Health (PCH). *Houston HSDA Epidemiologic Report*. *Op cit*.

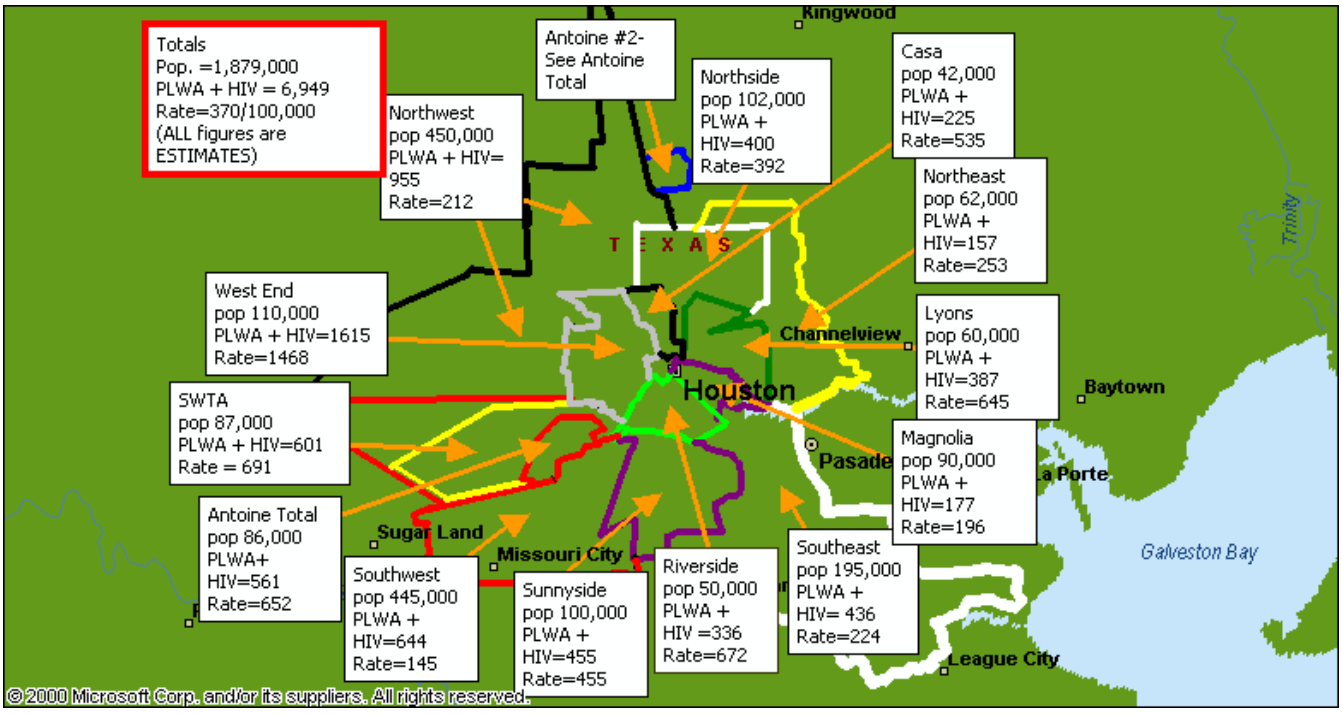
The following assumptions have been made when "guestimating" projected HIV rates:

- The general population in the Houston area will grow from about 3,900,000 in 1999 to 4,200,000 in 2003.
- There will be more gay and bisexual men in Houston and there will be fewer gay men dying from AIDS. However, the number living with HIV is likely to increase.
- If those living with HIV are infectious, there may be an increase in infections among MSM. However, as MSM over the age of 35 tend to be less sexually active than their younger counterparts, their infection rate is likely to decrease.
- The infection rate among young MSM is likely to go up, especially among young African-American men.
- Overall, the infection rate among MSM is likely to remain constant.
- The rate of infection among heterosexuals is likely to increase, especially among African-American females.

The data suggest that the number of people living with HIV in the HSDA in 2003 will range from 14,251 to 22,271. The bulk of these people will be in the EMA (13,811 to 21,584), and if the named reporting numbers continue to fall out as they have done in 1999, the majority of those newly diagnosed cases will be African-American, with a large number of those being female.

Clearly, most of the EMA's cases of HIV/AIDS are within the city of Houston. But even within Houston, cases are not equally distributed across the city. The city is divided into HSA's which stands for "HIV Service Area". HSA's approximate geographic neighborhoods. Using an average rate of 370 cases of HIV (including AIDS) per 100,000 Houston residents, Map 2.1 shows which Houston neighborhoods are disproportionately impacted by HIV according to the proportion of residents estimated to be living with HIV/AIDS.

Map 2.1: Houston HIV Service Areas and HIV Disease Rates per 100,000 Estimated Population (HIV and AIDS combined)



Chapter Three: History of Response to the HIV Epidemic in the Houston Area

Background information on the local response to the HIV epidemic is an important piece of effective comprehensive planning. An outline of legislative actions, funding activities, and past planning efforts will provide a valuable context for current and future planning efforts. A condensed version of the local response in the Houston area is provided below.

Community Response

At the beginning of the chronicled history of people infected with HIV disease, government response was limited or silent. In 1981, there were three AIDS cases reported, and it has since been determined that there were actually ten cases. As relatively little information was known at the time, community response came in the form of grass roots organizations and other community organizations formed for other purposes. The two organizations that were the basis of forming other groups were the Montrose Clinic and Montrose Counseling Center. From these two came such groups as KS AIDS Foundation (later known as AIDS Foundation Houston), and others. Grass roots efforts spawned a number of firsts in the country, such as McAdory House (a residential facility), FIRM (the largest religious response to HIV/AIDS in the country, which provides Care Team support and education), The Assistance Fund (provides money for insurance premiums), Pet Patrol (provides care for the pets of people with AIDS), and others.

As these grass roots organizations took hold, efforts were made in engaging traditional forms of funding. The response in the early eighties was again tepid or non-existent, partly due to an economic depression caused by the collapse of the oil and gas industry. United Way of the Texas Gulf Coast did provide funding for the care of AIDS patients to Visiting Nurses as early as 1986. But, due to the depressed economy, United Way prohibited any new organizations – which most HIV/AIDS organizations were – from applying for funds. Therefore, it was not until 1991 that United Way provided economic support to the Montrose Clinic and Montrose Counseling Center.

On the political scene, the then Mayor of Houston reluctantly agreed in 1985 to support a referendum that would have prohibited the City from discriminating against gay and lesbian individuals in their hiring practices. When the referendum was soundly defeated, gay and lesbian leaders began to feel that key political leaders were distancing themselves from the gay community. Since many of the gay and lesbian leaders were founding board members of agencies like the AIDS Foundation Houston, this began a long period of distrust and finger pointing among local politicians, gay and lesbian leaders, and social service providers. To make matters worse, when mainstream and other types of service providers decided to enter the AIDS arena, they were not interested in working collaboratively with agencies founded by members of the gay and lesbian community for fear of losing their credibility with political leaders. Even gay grass roots organizations did not trust other gay grass roots organizations for fear of being dragged into the political quagmire.

Throughout this whole time, the Mayor, who is responsible for surveillance and prevention, and the County Judge, who is responsible for medical and social services such as the Harris County Hospital District, appointed at least four different task forces to study the problem of HIV/AIDS. Most of the task forces were fraught with discord and ended with few recommendations and no action.

In the mid 1980s, AMI, a privately owned hospital corporation, opened the Institute for Immunology, the first hospital in the country dedicated solely to treating people with HIV/AIDS. It lasted one year, and was closed. Important research projects being conducted through the "AIDS Hospital" came to an

end because no local hospital would assume responsibility for the projects. As a result, AMI returned several million dollars in AIDS research money to the Federal government.

In the late 1980s, the AIDS Foundation was a primary source of social service support for people living with HIV/AIDS. Brown MacDonald, one of the Executive Directors of the foundation was quoted as saying that until the late 1980s, "80% of the foundation's budget came from passing a hat at local gay bars". In an effort to meet the needs of their clients, the AIDS Foundation hired one case manager to provide case management services to over 600 clients. Even with the help of volunteer staff, it quickly became clear that they could hardly provide crisis management to that many clients.

In the midst of the closure of the Institute of Immunology in 1986-87, the Robert Wood Johnson Foundation was awarding case management demonstration grants to cities with large populations of HIV/AIDS patients. In Texas, these funds went to Dallas. Because these demonstration grants proved that case management is a highly effective means of linking clients with medical and social services, the Federal government, through the Health Resources and Services Administration (HRSA), incorporated this service and expanded funding so that AIDS patients throughout the country could receive case management services. (See section on Congressional Response for more information on HRSA.) When Houston became eligible for these funds, distrust among agencies was so high that instead of placing case managers in one organization, Houston designed a "decentralized system" that placed case managers in agencies throughout the geographic area. The first HRSA demonstration grant for case management was awarded to Harris County in 1989.

After closure of the AMI hospital, those patients with private insurance were routed into other hospitals owned by AMI. The rest were referred to the Harris County Hospital District. Overnight, the Hospital District found itself with over 700 AIDS patients on their doorstep. In May 1989, the formation of Thomas Street Clinic, a publicly-funded outpatient clinic for people living with HIV/AIDS, was an important step forward in demonstrating the County's willingness to provide quality healthcare services to PLWH. Today, Thomas Street Clinic is cited as one of the best in the country.

In 1988, then County Judge Jon Lindsay, announced the formation of the Greater Houston HIV/AIDS Alliance (GHHA), a private corporation designed to bring private and public players to the same table to coordinate services for PLWH/A. For example, United Way provided staff support and got a seat on the governing board. Funding streams were still meager, but in 1987, the Texas Department of Health through State Services funding (general appropriations), began a limited amount of funding for community-based organizations. In 1989, they began targeting the highest infection areas, such as Houston, Dallas, Austin and San Antonio.

In the meantime, small groups of individuals were trying to raise private funds, primarily through special events, in an effort to support the cause. The first significant event was "An Evening of Hope," which raised close to $100,000 in 1986 for Bering Foundation. Chaired by Carolyn Farb, this was the first special event to receive mainstream media coverage. "Art Against AIDS" was a collaborative effort between the local arts community and United Way. During the month of September 1987, arts groups, like the ballet, the symphony, local art galleries, and others, dedicated the proceeds from a special performance or the sale of artwork to AIDS. This effort was also effective in heightening the awareness of HIV/AIDS. That same year, the Houston Chapter of the Design Industries Foundation for AIDS (DIFFA) was formed. Between 1987 and 1996, the Houston Chapter of DIFFA raised $2.7 million, making DIFFA/Houston the largest private funder of HIV/AIDS in the Houston area.

On the prevention side, funding to prevent the spread of the infection became available from The Centers for Disease Control (now called The Center for Disease Control and Prevention) in 1985. The

Montrose Clinic was one of the first agencies to receive such funding. Three years later, Over the Hill, an African-American grass roots organization serving the newly released from prison population, received funds to provide testing and counseling.

From 1984 to 1988, the City of Houston received funding for prevention activities as part of the AIDS Prevention and Surveillance Grant, through the Texas Department of Health (TDH). Funding from TDH included support primarily for surveillance activities with and for publication of the monthly AIDS Update. A very limited amount of dollars was spent for education targeted to the general public through information campaigns. Additionally, the City of Houston contributed funding to provide brochures for "AIDS Awareness Week", the general public, and men who have sex with men.

The Perinatal Prevention Project was funded by CDC to the City of Houston in September 1988. This was a pilot program to identify and offer voluntary counseling and testing to women who were high risk or HIV positive and enrolled in family planning, maternity and sexually transmitted disease clinics.

In 1988, the city of Houston received additional funding from TDH to expand the AIDS education activities to develop a citywide HIV/AIDS speakers bureau in conjunction with the AIDS Foundation Houston and to develop AIDS education modules to address each segment of the Houston population in regards to sex, race and income status. Each module consisted of films/videos, pamphlets, risk factor information and a list of speakers who completed training to conduct AIDS presentations. The city also received $3,500 to conduct a minority initiative program targeted to beauty shops, barbershops, and morticians.

In 1989, the City of Houston, one of only six cities in the nation, received funding directly from the CDC specifically for HIV prevention activities. Funds supported health education, HIV counseling and testing, public information and minority initiative campaigns. Funds were also allocated through the grant to fund over 15 community-based organizations and agencies. To date, the CDC has continued funding through this directly funded cooperative agreement.

On the care side, it wasn't until November 1990 that the first Federal funding became available through the Ryan White CARE Act. These funds dramatically changed the grass roots nature of service delivery in the Houston area.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, signed into law by then President George H. Bush, was created in response to the enormous impact the HIV/AIDS was having on the nation at that time. The monies appropriated by this act were to fund HIV/AIDS care services in those areas most affected by HIV/AIDS. Eligibility for Title I funding was and is determined by the number of AIDS cases reported in a given area. Due to the huge impact that HIV/AIDS was having on the Houston area in 1990, Houston and the surrounding counties received funding in the first year of allocation – 1991. That funding amounted to $3.7 million and was a badly needed infusion of stable, comparatively long-term funding.

In early 1990, burgeoning funding, coupled with an increasing number of clients, strained the capabilities of an already fragile system. County Judge Jon Lindsay, who controlled all the money for the GHHA, asked that all funding be moved under the jurisdiction of the County Health Department. There was an investigation and a significant amount of money was returned to the Federal government. The Greater Houston HIV/AIDS Alliance was dissolved in 1993, and the resulting controversy over mismanagement and secrecy caused a redirection of Federal and State funding streams. Title I funding remained with Harris County. Funding from TDH State Services and Title II moved under the newly formed Houston Regional HIV/AIDS Resource Group. Both groups retain that funding to this day.

As all players in the AIDS arena began to rebuild trust, the epidemic began to change. With the advent of new and powerful treatments, the lives of PLWH/A changed as well. People with HIV/AIDS are living longer and functioning better than ever before. The Hospital District continues to receive the largest portion of funds, since medical care is a top priority and since the Hospital District traditionally serves the largest number of clients. As the CARE Act became more responsive to the needs of underserved minorities, primary care sites expanded into alternative locations, resulting in the need for increased ancillary services and medications. With these new medications changing the lives of clients, it also prompted a change in measuring those services. The emphasis is now on medical outcomes, and services have changed in respect to how they can measure that important aspect of clients' lives.

Since the CARE Act was legislated and Houston began receiving Federal funding, much of the financial burden has been mitigated, as many community-based organizations are now able to deliver services to the HIV affected population in the Houston area. Best of all, in many cases, the newer providers are able to outreach into historically underserved/unserved communities and bring people into services while they are still in the earlier stages of the disease. This early intervention is highly important. The use of HAART (Highly Active Anti-Retroviral Treatment) prescribed at the appropriate time has slowed or even halted the progression of the disease in many people, enhancing the quality and duration of life in most cases.

As more people of color, especially African-Americans, became infected with HIV/AIDS, activists at the Federal level began working to ensure that more HIV/AIDS money was specifically targeted to minorities. As a result of the Congressional Black Caucus Initiative 1999, a Title I CARE Act set-aside in the amount of $177,690 was used to target HIV/AIDS care dollars specifically towards services for African-Americans and Hispanics. This amount was in addition to money that the County was already targeting to minority populations. In 2000, the CBC allocation rose to $937,955. On the prevention side, the City of Houston also received CBC money to target minorities in the area of prevention.

However, as unduplicated HIV case reporting numbers became available in mid-1999, resultant to Texas moving to name-based HIV reporting in addition to AIDS reporting, the realization that HIV was disproportionately affecting the African-American community became even clearer. It also became clear that the amount of money set aside in the CBC initiatives were not enough to effectively address the impact of HIV/AIDS in communities of color. Prevention and care advocates pushed their elected officials to declare a "State of Emergency" in the African-American community in the hopes that even more resources and services would be targeted toward communities of color. On World AIDS Day, December 1, 1999, Mayor Lee Brown and County Judge Robert Eckels jointly declared an HIV/AIDS state of emergency in the African-American community.

Congressional Response

On August 18, 1990, Congress enacted Public Law (PL) 101-381, known as the Ryan White Comprehensive AIDS Resources Emergency Act, or the CARE Act. On May 20, 1996, this legislation was reauthorized and amended as PL 104-146, or the Ryan White CARE Act Amendments of 1996.

The CARE Act is intended to help communities and States increase the availability of primary health care and support services in order to reduce utilization of more costly inpatient care (such as hospitals). They are also intended to increase access to care for underserved populations and to improve the quality of life for those affected by the epidemic.

The CARE Act directs assistance to the following areas:

- *Title I* goes to Eligible Metropolitan Areas (EMAs) with the largest numbers of reported cases of AIDS to meet emergency service needs of people living with HIV disease;

- *Title II* goes to all States to improve the quality, availability and organization of health care and support services for individuals living with HIV disease and their families;

- *Title III* goes to public and non-profit entities, such as Community and Migrant Health Center, to support early intervention services for people living with HIV disease. Money is also given for the AIDS Drug Assistance Program (ADAP), which provides medications to low-income individuals with HIV who have limited or no coverage from private insurance or Medicaid.

- *Title IV* goes to clinical research on therapies for children with HIV disease and pregnant women with HIV; it also funds health care to children, youth and their families;

- *Part F* goes to AIDS Education and Training Centers (AETCs), Special Projects of National Significance (SPNS), and the Dental Reimbursement Program.

Figure 3.1: Flow of CARE Act funds

Title I	Title II	Title III	Title IV	Part F
Federal Grants for Emergency Relief to Eligible Metropolitan Areas ⇓	Federal Grants to States and territories ⇓	Federal grants for Early Intervention ⇓	Federal grants to Pediatric/Family Programs ⇓	SPNS, AETCs and the Dental Reimbursement Program ⇓
Chief Elected Official Designates HIV Services Planning Council ⇓	Governor, Administrative Agent (usually the State Health Dept.) ⇓	⇓	⇓	⇓
Governmental Unit (Health Dept.) ⇓	Consortia ⇓	⇓	⇓	⇓
Community-Based Organizations ⇓	Community-Based Organizations ⇓	Community-Based Organizations ⇓	Community-Based Organizations ⇓	Community-Based Organizations ⇓
Services to people living with HIV disease	Services to people living with HIV disease	Services to people living with HIV disease	Services to children, youth, women and families living with HIV disease	Services to people living with HIV disease and training for health care professionals

The Health Resources and Services Administration (HRSA) has the lead responsibility for the implementation of the CARE Act. In 1991 (the first fiscal year of the CARE Act), 16 areas of the nation qualified for funding through Title I. They were:

Atlanta, Georgia
Boston, Massachusetts
Chicago, Illinois
Dallas, Texas
Fort Lauderdale, Florida
Houston, Texas
Jersey City, New Jersey
Los Angeles, California
Miami, Florida
Newark, New Jersey
New York City, New York
Philadelphia, Pennsylvania
San Diego County, California
San Francisco, California
San Juan, Puerto Rico
Washington, D.C.

By 1997, 49 areas throughout the nation qualified for Title I funding and currently there are 51 EMAs. In Texas, in addition to the Houston area, there are four other EMAs that receive funding through Title I – Austin, Dallas, Fort Worth/Arlington and San Antonio.

Including the Houston HSDA, there are currently 26 areas in Texas that receive Title II funding. This HSDA structure has recently been pared down by the Texas Department of Health to seven planning areas: Pan West, Northeast Texas, Northwest Texas, East Texas, Central Texas, South Texas and El Paso. Although it is expected that coordinated regional planning will take place within each of these areas, funding will continue to be earmarked specifically for the existing HSDA areas.

Chapter Four: Assessment of Care and Prevention Needs

A needs assessment is a systematic process of determining the service needs of a defined population. A needs assessment tells us what kinds of services different types of people need and when and where they need them. It should explore the perspectives of people at risk for and living with HIV and their families, service providers, and community representatives. Information is typically collected through surveys, focus groups, interviews, and/or public forums.

Care Needs Assessment *information primarily excerpted from "1999 Comprehensive Needs Assessment" conducted on behalf of the Ryan White Planning Council and the HSDA CARE Consortium.*

The Houston Area HIV/AIDS Services Needs Assessment was conducted by the Partnership for Community Health (PCH) and the Office of Community Projects at the University of Houston. The Needs Assessment identifies, examines, and outlines the needs of, as well as the gaps and barriers to HIV/AIDS services in the Houston area. This effort is made in order to arrive at a series of conclusions about the current and projected capabilities of HIV services to provide for clients' needs.

One of the most difficult elements of both creating and reading a needs assessment is deciphering the complex subjectivity of the seemingly simple word "need". What one person deems a need, another might see as a luxury or simply something that is nice to have. Moreover, ideas about need versus luxury can change in any one individual over time. If an individual moves from a service-heavy area such as San Francisco – where HIV services can include dog walking – to a rural area where even primary medical care might be hard to come by, the client's ideas of "need" are likely to change dramatically. Additionally, what a client might see as a need might be all together different from what a service provider sees as a need.

Thus, the needs assessment attempts to pin down this very slippery term using several refinements of the word and several definitions. They are:

- **Service Need or Absolute Need**
  Based on a model of care, absolute need estimates the number of people who would actually benefit from a service if they were to receive it, regardless of whether they are currently receiving it.
- **Perceived Need or Demand**
  This is the perceived need and demand of PLWH/A and service providers based on qualitative and quantitative data.
- **Service Capacity**
  This is the number of clients who can be served by, or the number of slots available for, a particular service.
- **Fulfilled Need**
  This is the actual demand based on utilization figures, surveys, and other counting mechanisms. These numbers are compiled as individuals with HIV actually seek out and receive a service or identify the service as a future need.

This chapter will discuss the **Perceived Need or Demand** for services by PLWH/A and the needs perceived by the providers. More detailed information can be found in the 1999 Needs Assessment Report (see Section VI: Planning Resources for information on how to get a copy).

Methods

Two methods were employed for gathering confidential information from the clients, including assembling useful focus groups and compiling the results of hundreds of consumer surveys. A total of 24 focus groups were held. These groups were identified by risk category, as in the following list:

- Men who have sex with men (MSM)
- Injection drug users (IDU)
- Heterosexuals
- Those in prison
- Those who live in rural areas
- Adolescents
- Undocumented populations
- Pediatric caregivers

The focus groups were also identified by the participants' ethnicity. An additional five groups were held that were not identified by either risk category or ethnicity. In addition to the 24 focus groups that were held, PCH gathered information from 455 PLWH/A who agreed to provide information and complete surveys.

The focus groups and those surveyed were recruited from various organizations, agencies, and clinics using a strategy that would ensure client confidentiality and a sample of people representative of the community of people living with HIV/AIDS. Forty-two agencies throughout the Houston area were employed in the recruitment of respondents. Additional respondents were contacted through outreach organizations and with the help of community clinics. Both the focus groups and those who were surveyed represent a wide ethnic diversity – including, African-American, Hispanic, Anglo and other ethnicities – as well as a range of risk categories. The total weighted sample of respondents was 81% male and 18% female, which is consistent with the numbers of men and women who are living with HIV.

In order to get information about needs from providers, surveys were sent to 31 Ryan White providers and 13 non-Ryan White providers, and two discussion groups were conducted with a total of 23 provider representatives.

What the Clients Said They Needed

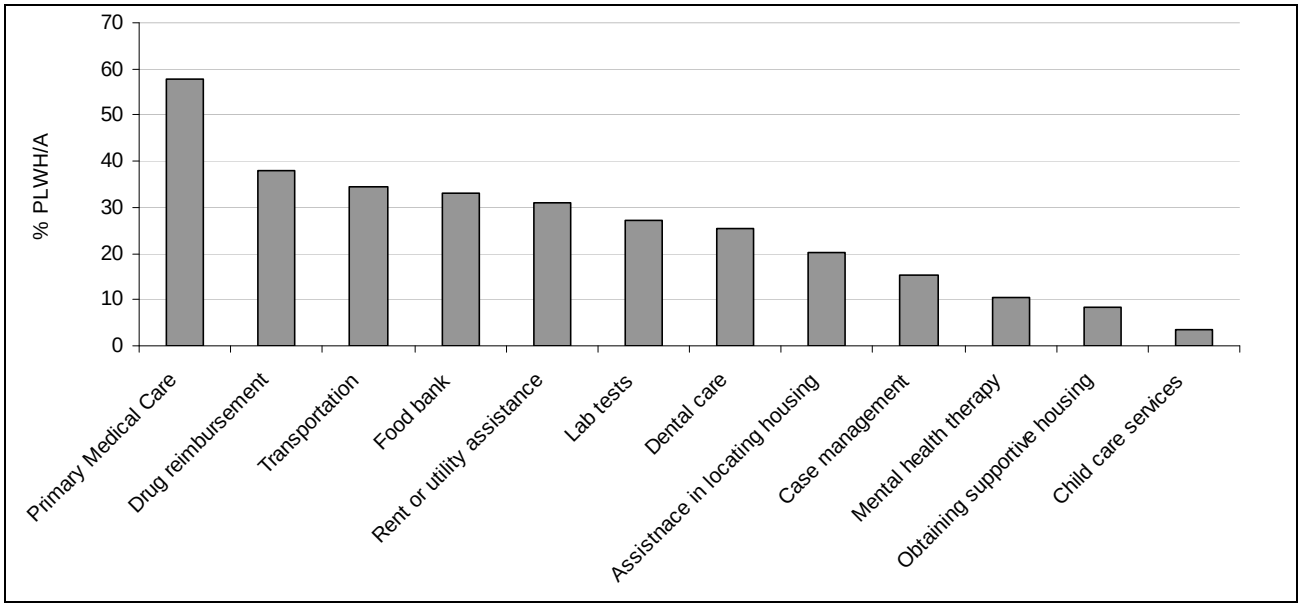
The respondents' answers were gathered and weighted. Responses from groups who were over-sampled, such as women and heterosexuals, were weighted back so that their group of responses more closely represents the estimated size of the affected population. Thus the following information should be considered as an overview of both the entire community of PLWH/A and of several disparate groups of PLWH/A, including:

- MSM
- IDU
- Heterosexuals
- African-Americans
- Hispanics
- Anglos
- Rural Population
- PLWA
- Women

When asked to list the top four services they needed, clients listed a wide variety of services; however, a few services were frequently at the top of the lists of each group of interviewees.

The top ten service needs listed by the overall group in priority of need are listed in Figure 4.1. There are twelve items shown because obtaining supportive housing and child care were not in the top ten for the total population of PLWH/A, but were in the top ten for IDUs and heterosexuals, respectively.

Figure 4.1: Top Care Service Needs



Client Statements

Every population listed outpatient medical care as the greatest need. Most everyone, from the female Anglo IDU, who said "My first concern is medical treatment," to a man in an open session who said, "If you are sick, you should be able to see a doctor," agreed that outpatient medical treatment was their highest priority.

About drug reimbursement, which ranked second overall, clients said such things as, "My first thought was I needed medication." However, for many clients, particularly African-American clients, food and transportation was much more significant than drug reimbursement.

Basic services such as transportation, food, and housing ranked third, forth and fifth overall. The high rankings of these basic service underscores the fact that many PLWH/A are living longer, but these rankings also indicate that many of these people are at or near the poverty level. Their basic needs oftentimes outweigh such necessities as medication. Their statements about these basic services reveal the alarming need many clients have for simple food and housing.

The food bank is very important to many PLWH/A in the system. About it, they say such things as "A place to obtain food is important since I don't receive food stamps," and the "Food bank is the most important [service] for me".

Comments about the need for housing included, "If they [apartment owners] find out you are HIV positive, there are a lot…that discriminate against you," and "In order to access rent/utility assistance, you have to be in the right place at the right time," and "Right now I'm living in independent housing, but I had to go through a whole lot of red tape".

Some people were somewhat satisfied with current transportation options but some felt that there were not enough options. The Houston area sprawls across several miles of very disparate landscapes, including inner city barrios, housing projects, far flung patches of suburban neighborhoods built in the middle of vast open grasslands, and rural trailer parks and bungalows miles away from any public bus line. In the rural counties, there is simply no public transportation. The huge diversity in the Houston landscape coupled with the enormous amount of land included in the area and the weak public

transportation system makes the transportation issue in the Houston an especially thorny problem for some clients.

Many PLWH/A find dental care very important. Overall they ranked it as the seventh greatest need. Because many of the respondents have limited incomes, they cannot get dental care without assistance. Thus, they depend on ASO services for dental care. Comments about dental care were widely varied. Some were extremely positive, such as, "I like their [ASO] services. They don't fool around." Others, on the other hand, were very negative. One heterosexual Anglo man said, "It took me five months to get that [cavities filled] done. Man, I mean, I'm talking pain. [Censored]. What are we, guinea pigs or something?"

Many of the respondents had very strong feelings about the need for case management and improved case management. One man said, "The most important service for me is my case manager." A rural man said, "I've been screwed across the board by case workers since I've been here. I've been here four years." A Hispanic female said, "I get what I need every once in a while, but they gave me a hard time some times. I haven't had one in a year and a half".

Mental health services were not among the top ten services listed for all focus group participants; however, many of those who did list it considered mental health services as essential to their well being. Their plaintive statements about that need speak for themselves. An interviewed adolescent said, "I need my family to understand where I'm coming from because I've been pushing them away because I can't sit down and explain what's wrong with me and how I feel, and, you know, my mom is like . . . she don't know if she can sit on the toilet behind me and [censored] it's so hard for me. I want to go up and hug her but then . . . that's the only thing I really need. I need for me and my family to get together". Some women asked for more women's groups and some rural participants said that it was hard finding groups in their areas. Perhaps one of the most alarming comments came from a bipolar participant who said he was "dumped" from his mental health services because of his dual diagnosis.

Table 4.1 on the following page is a summary of top needs ordered by risk group, ethnic subpopulation, female gender, rural, and recently released populations. The numbers in each cell indicate the ranking of each need under each population. A "+" beside a number indicates that the score is higher than the average score.

Table 4.1: Summary of Top Care Needs

	Total	MSM	IDU	Het	Af Am	Hisp	Anglo	Rural	PLWA	Women	Rec Rel
Primary Medical Care	1	1	1	1	1	1+	1+	1	1	1	1
Drug reimbursement	2	2	4	3	5	2+	2	3+	3	3	2+
Transportation	3	4	2+	2+	2+	6	6	2+	2	2+	3+
Food bank	4	5	3+	4	3+	4	4+	6	5	4+	4
Rent or utility assistance	5	3+	5+	5	4	5	7	4+	4	5	6+
Lab tests	6	6	8	7	8	3+	3+	5+	6	8	10+
Dental care	7	7	7	8	7	7	5+	8	7	7	7
Assistance in locating housing	8	8	6+	6+	6+	9	9	9	9	6+	5
Case management	9	9	9	9+	9	8+	8+	7	8	10	8+
Mental health therapy	10	10	11+	12	12	10	10+	10	10	11	13
Obtaining supportive housing	12	16	10+	11	10+	15	20	15	17	14	9
Child care services	20	32	21	10	11	19	27	19	16	9+	14

The following charts list those needs that selected groups ranked the highest. The overall group is shown as a line in the chart, while the different subgroups are shown as bars. When interpreting these bar graphs, keep in mind that these are relative rankings, and a higher ranking by one population suggests a relative need compared to other services, not the absolute absence of need. Also, because one service is ranked lower by the overall population, it does not suggest that there is not a very important need by a special subpopulation or individual.

Figure 4.2: Top 10 Care Service Needs - Total Sample Compared to Risk Groups

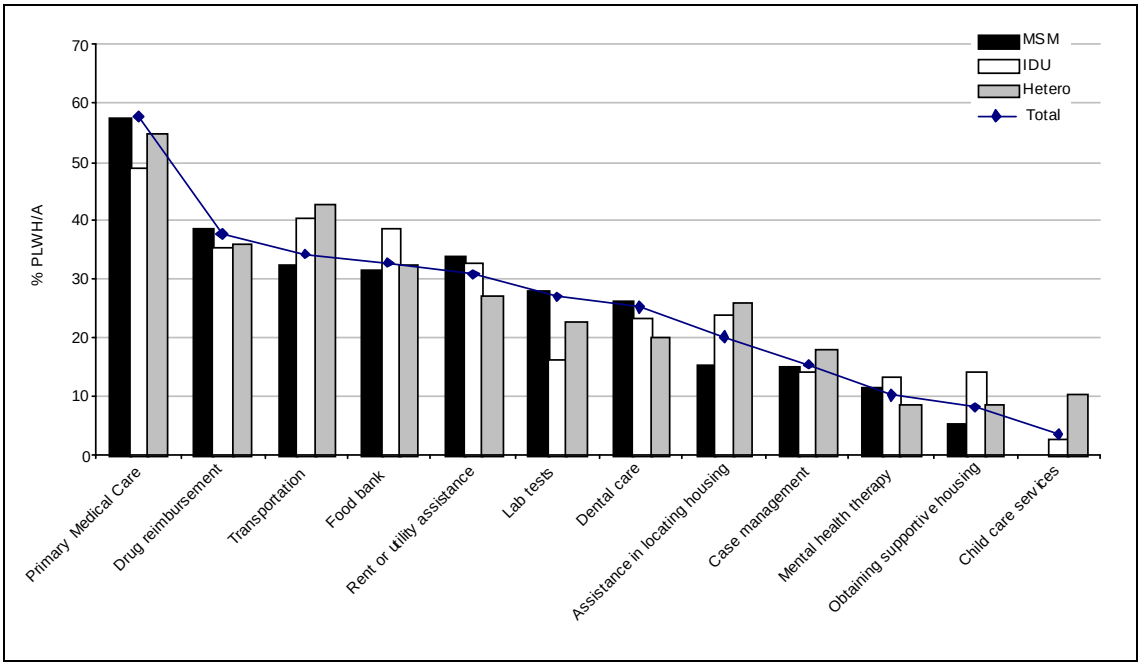


Figure 4.3: Top Care Service Needs by Ethnicity

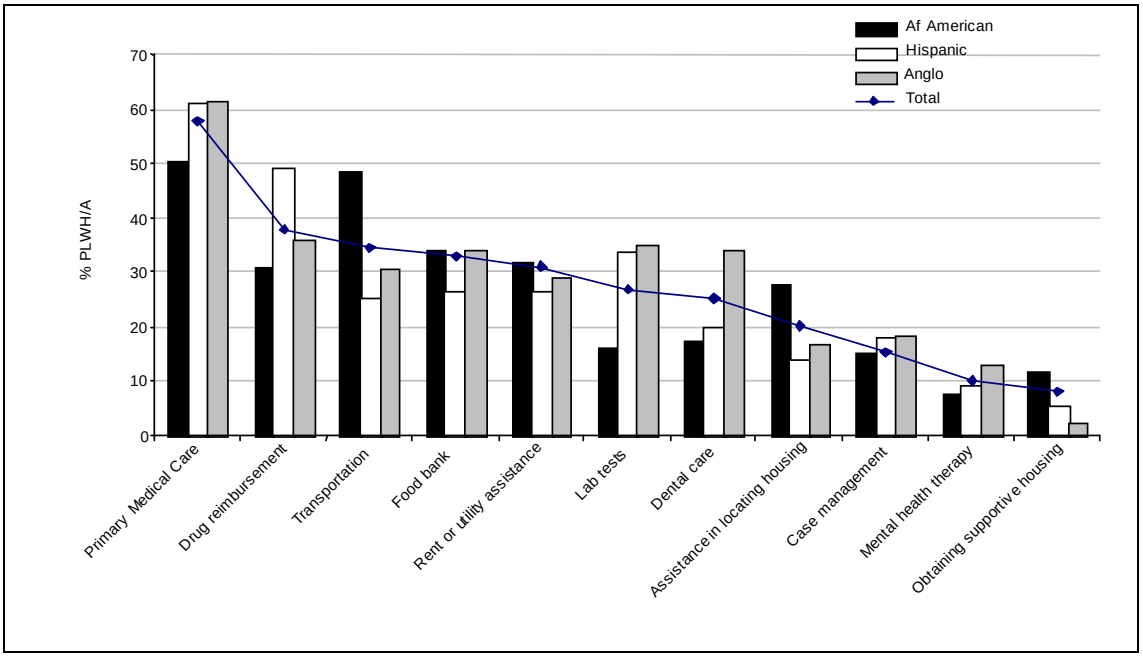


Figure 4.4: Top Care Service Needs by Sex

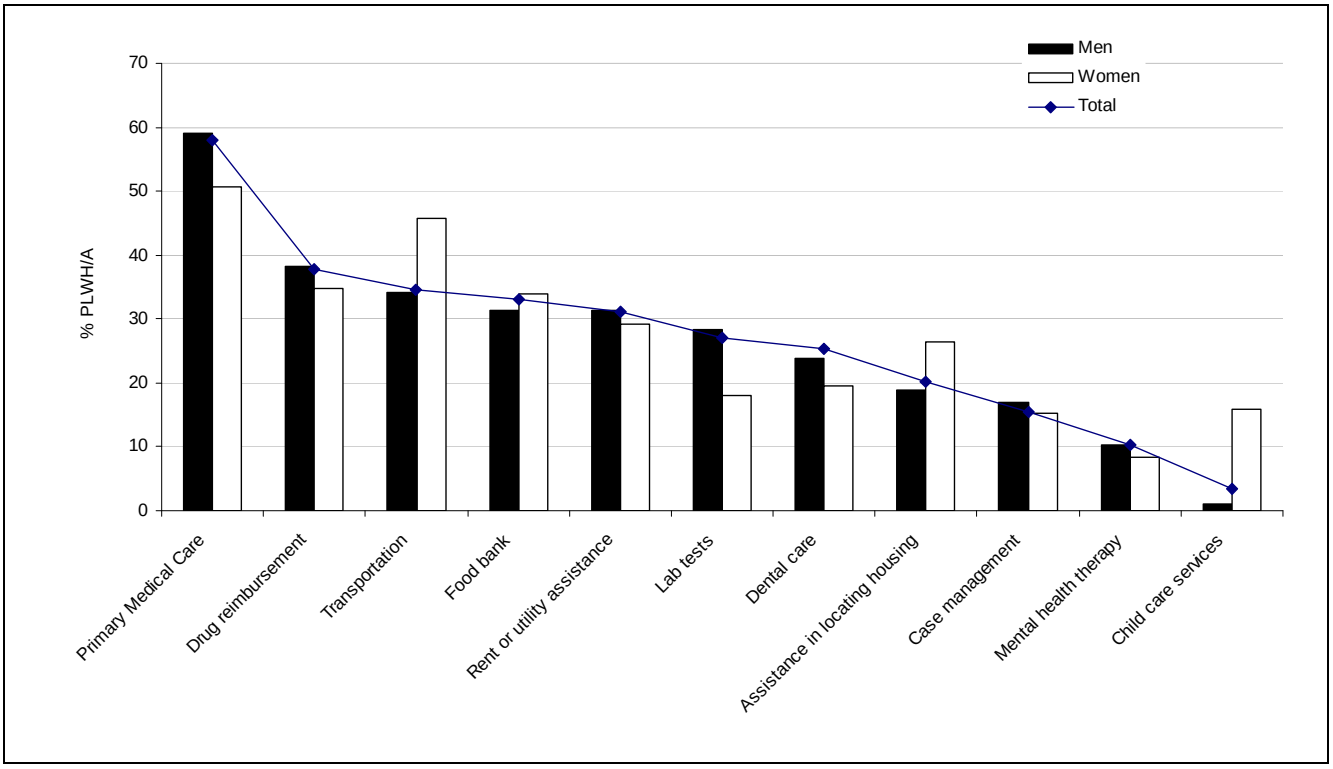


Figure 4.5: Top Care Service Needs by Urban/Rural

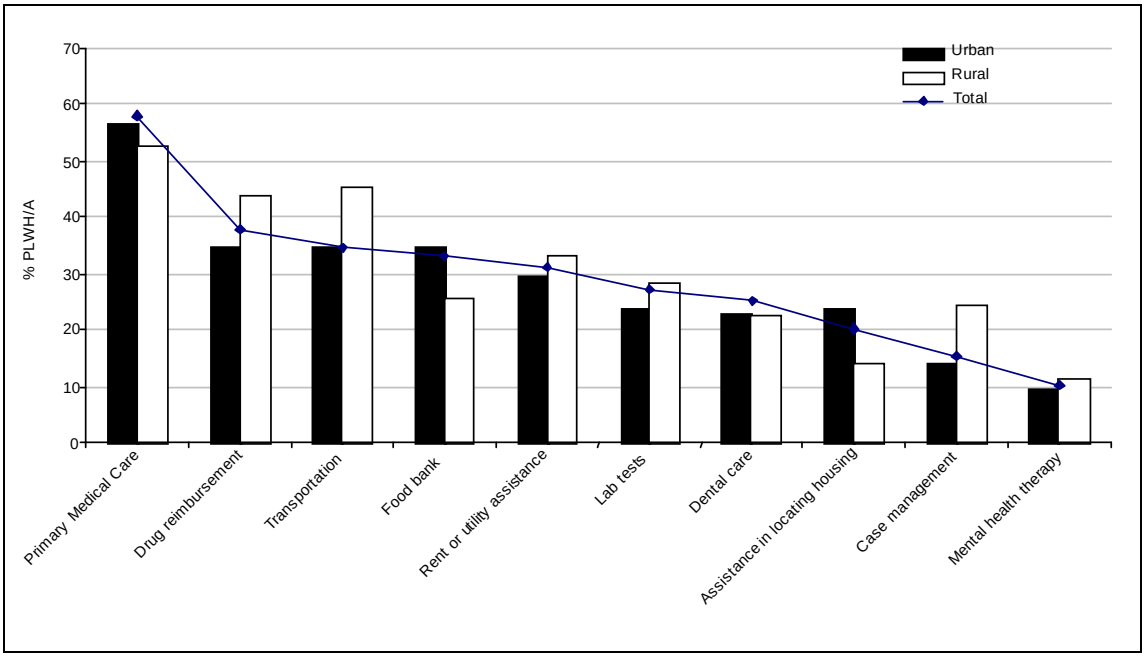
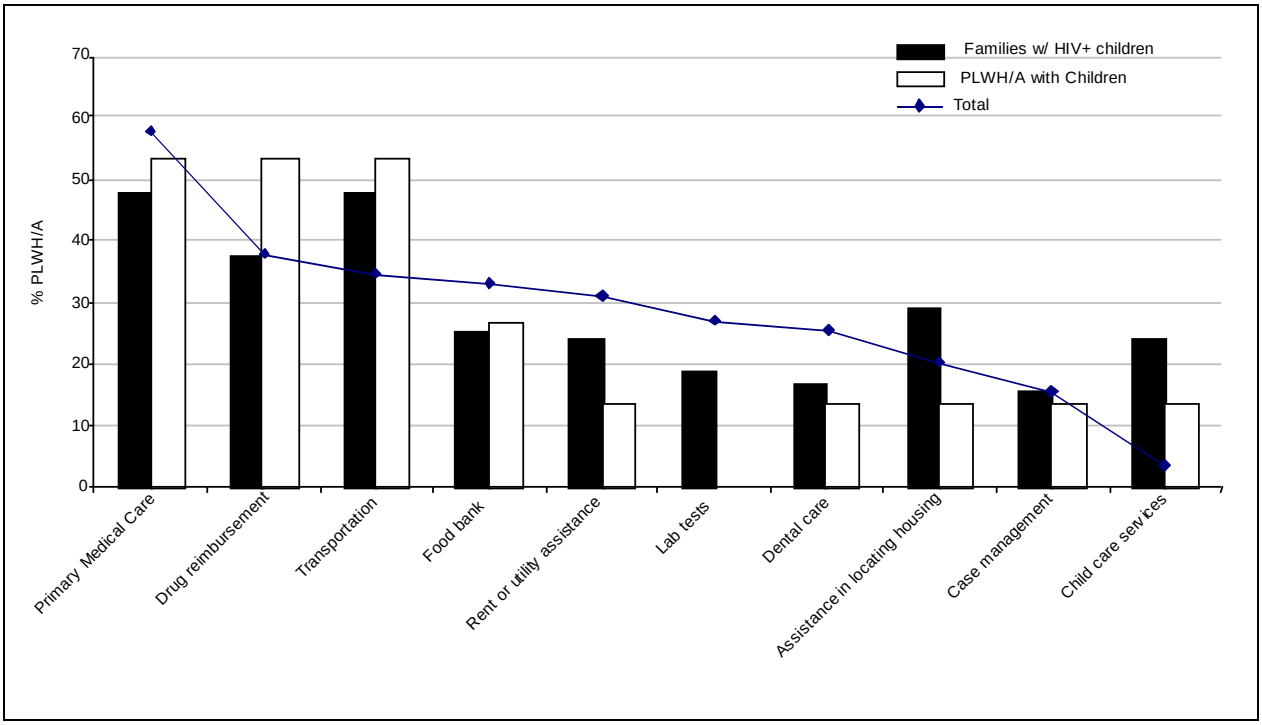


Figure 4.6: Top Care Needs for Families with Children with HIV and PLWH/A with Children



What the Care Providers Say

Providers clearly feel that the greatest overall need of the patients is an increased understanding of both the system of care and the knowledge of treatment. Staff members have said that they feel that it is very important to help clients understand the link between the various systems they will be entering. Additionally, service providers see a great need for mental health care among their clients. Overall, the providers see the greatest need of their clients to be more knowledge of the system and an

increased ability to navigate through the system. (The consumers on the other hand see their greatest need as having to do with the system itself).

Case Managers

In March 1999, the Planning Council's Office of Support conducted a focus group among case managers whose client loads are composed primarily of PLWH/A. The Planning Council selected case managers because their responsibilities bring them into contact with all of the services PLWH/A want, access, and cannot obtain. A total of twelve case managers participated. Their caseloads ranged from 30 clients to 73, with clients representing all of the counties within the HSDA except Chambers.

In addition to speaking about the barriers their clients experience while trying to access current services, case managers were also asked to describe services that their clients need but are not available or which their clients are not able to obtain. These services include:

- Burial/funeral assistance
- Co Pays for various services
- Job training
- Relocation - costs money to move
- Moving assistance
- BIG cleaning - homemaker services only offer light house cleaning
- Ensure
- Food pantries need more perishable foods, clothing, and food vouchers.
- Baby items
- Over the counter meds
- Immigration legal assistance
- Child care

Substance Abuse Providers for PLWH/A

The Planning Council's Office of Support conducted a focus group in March 2000 to solicit comments that were incorporated into a *Service Effectiveness Evaluation of Title I Funded Substance Abuse Services.* Participants felt that people with who receive treatment for their substance abuse problems are more likely to become engaged or stay engaged in ongoing medical care - if they can stay in treatment and stay sober. However, they acknowledged that relapse is high.

The following were identified as needs for more effectively treating substance abuse/chemical addiction among PLWH/A.

- PLWH/A need chemical dependency programs comprised of PLWH/A that specifically address the HIV issue, staffed by individuals who are knowledgeable about HIV and chemical dependency. Beyond HIV issues, providers felt there was need for more "specialized" treatment groups, both in terms of culture and drug/method of choice (i.e., groups for people with HIV who inject drugs).
- Women with HIV need chemical dependency programs that work with schedules that include medical appointments for themselves and their children.
- Need for treatment programs that appeal to adolescents and young adults with HIV.
- Cross training, including cultural sensitivity, to increase communication and understanding among HIV medical providers, substance abuse providers and mental health providers.
- Provide harm reduction information and activities (for example, needle bleaching) to PLWH/A who do not want substance abuse treatment. Provide these activities through Case Management and other services.
- Increase opportunities for Peer Educators who are in recovery to work with PLWH/A who are currently addicted.
- Reduce restrictions and requirements ("red tape") to get into immediate treatment.

Gaps in Care

Results of the 1999 Needs Assessment Report show that the Houston EMA and HSDA have a broad array of services for PLWH/A that are funded through the Ryan White Emergency Act and other funding sources. The positive news from the survey and focus groups is that PLWH/A in care find most services available and accessible and they are generally satisfied with the services. For PLWH/A as a whole, there was not a single barrier to services that was rated as "high".

Outcomes of the system indicate that it works well. Deaths of PLWA have showed a dramatic decline over the past several years. The care system has a track record of improving and stabilizing the physical and mental health of PLWH/A. About 65% of those living with AIDS say their physical health has stayed the same or improved. For those asymptomatic, 46% say their emotional health has improved and over 26% say it has stayed the same. For those with AIDS, over 40% say their health has improved and over 24% say it has improved or stayed the same.

However, the Needs Assessment report also identified areas for improvement. The report identified *gaps in service* by comparing definitions of "need" that included "absolute need" (or theoretical need based on the model of care), client "perceived need", client "demand" and client "fulfilled need". The assessment also evaluated the capacity of the system in terms of the number of clients who are being served, who could be served in the current system, and who theoretically should be served even though they are not currently accessing care.

The gap between those in service and those out of service drives many of the largest gap measures. Before looking at individual services, two estimates are used throughout this section.

- About 5,000 persons are estimated to be in the care system (see below for details).
- About 7,600 are estimated to have AIDS in the Houston Area and another 7,600 are estimated to be infected with HIV.

Summary of Gaps Identified in the 1999 Comprehensive Needs Assessment

The headline from the needs assessment is that there appears to be a large number of people with HIV who are outside the system of care. There may be as many as 10,000 infected persons who do not access Ryan White services. Even allowing for a substantial number of PLWH/A that may see only private physicians, there are likely to be at least 5,000 PLWH/A that are eligible to receive care but who do not.

Gap: Many people living with HIV/AIDS are not accessing early outpatient medical care services. Perhaps the over-riding message in this needs assessment is that a projected two to three times as many people with HIV are outside the care system as those accessing it. Based on the epidemiological data, those not seeking care are likely to be disproportionately African-Americans, who appear to enter the system at a later stage of HIV progression. Women, particularly, African-Americans and Hispanics, are less likely to seek outpatient care. Based on focus group information, undocumented people, largely Hispanic, living with HIV and AIDS also may not be seeking care. Among the needs assessment survey participants, close to 50% of Hispanics, 39% of African-Americans and 28% of Anglos diagnosed with AIDS only learned about their HIV status when they went to the hospital or clinic for some other problem. Nearly 10% of women did not learn of their HIV status until they sought prenatal care.

That so many PLWH/A are eligible to receive care but do not suggests a need for coordinated outreach to those communities most infected but least likely to get services, like African-Americans and

undocumented PLWH/A. The need to develop services and increase capacity will depend less on new infections and more on the success of outreach in attracting those who are infected and in service.

Gap: African-Americans have a higher mortality because they do not access the care system early enough. In the needs assessment, one of the outcomes of the care system measured was mortality. For those in care, the reduction from between 65% to 75% mortality rate in 1992 to fewer than 10% in 1998 is a striking testament to the success of the treatment and care in Houston. When all deaths are considered – those in care and out-of-care – African-Americans have a much higher mortality rate, suggesting that they are entering the system later or not at all.

A second headline from the needs assessment is the large number of PLWH/A who have some contact with the correction system. PLWH/A who are incarcerated could be targeted for care and treatment information, but reports show that those in correctional institutions and those recently released are underserved in medical and support services.

Although it would be expected that the success of new medications would lower the demand for hospice care overall, some service providers have experienced an increase in clients. In discussion, service providers explain the increase because of an increase in PLWH/A who have a history of drug abuse and who are currently abusing substances. They report increases in numbers of African-Americans and women, many of whom were already too sick when they were first diagnosed to enjoy the benefits of HIV combination therapies. Additionally, hospice providers report getting more PLWA released directly from jails and prison who are discharged or given special-needs parole due to advanced illness and the inability of the prison system to care for PLWH/A.

Changing Face of the HIV/AIDS Epidemic

The face of the HIV and AIDS epidemic is changing, and there are constantly new considerations and adjustments in the care system that could be made to improve the health status and quality of life of PLWH/A.

The data strongly suggest the shift in care needs as AIDS evolves from an acute and fatal disease to a severe chronic disease managed by difficult-to-adhere-to and expensive medical regimens. The bottom line for providers is that there will be significantly more clients to serve in 2003 than now, as fewer people die and early HIV treatment becomes the standard of care.

While MSM will continue to be the majority of those living with HIV and AIDS, the profile of the PLWA will change as the numbers of newly diagnosed cases decrease among MSM and increase among heterosexuals. African-Americans have surpassed Anglos in the number of new infections diagnosed each year, and the ethnic profile suggests growing needs within the African-American community.

Before protease inhibitors and combination therapies, the goal of HIV services was to prolong the lives of PLWH/A by educating them about prophylactic treatment, managing opportunistic infections (OIs) and preparing them and their families for the fatal consequences of AIDS. The system had to build capacity for end stage illness, including home and institutional hospice services, home care, home delivered meals and other end-stage services.

Today the goal is to maintain and improve the health status and quality of life of PLWH/A by:

- Educating them about the treatment of a serious chronic disease that requires complex medical regimens and support systems;

- Providing them with quality basic health care and social services;
- Providing coordinated ongoing treatment;
- Monitoring outcomes to assure accountability;
- Modifying, sustaining and enhancing support systems that provide access to care, such as transportation, medical and continuing case management, health insurance, child care and culturally competent personnel.

The demand for future services paints a different picture than rankings of existing services. PLWH/A, say that dental, rent/utility assistance, food bank, and assistance locating housing are their top four anticipated needs. To some degree, this shows they are confident of the continuation of medical care, but it also shows the shift toward the concerns that any poor population confronted with a chronic disease would have. In order to access services, the eligibility criteria for services will keep persons relatively poor, and, not surprisingly, as people live longer they have a continuing need for basic services such as food and housing.

Overall capacity in the delivery system is good. For the critical services of outpatient care, drug reimbursement, and case management, capacity is adequate to meet current demand. If a large number of persons are brought into the care system through outreach, capacity will have to be added. Dental care shows a small unmet demand where more persons request care than receive it, and it is likely to grow because eligibility criteria is low, anticipated need is high, and providers are scarce.

Most of the issues with outpatient care are related to its quality and the dreaded red tape of the system. The process of intake and care could be more efficient and the quality of service could be standardized. Care plans and coordination among providers could be developed to provide a more seamless care plan.

Case management is a service that needs continual review and the mix between service linkage, case management and medical case management needs to be further refined. PLWH/A continue to say that navigating the system and red tape are barriers, and they look to case managers to overcome those hurdles. Ideally case managers will have improved access to client records and can offer more informed advice on their eligibility for services and continuity of care. Training, retention and continuity of case management, and more interactive client contact are suggested by PLWH/A.

Transportation issues are fairly complex. The rural populations and urban populations both expressed a relatively high need. From reported utility and capacity data, it appears that there is unmet need, but the data seems suspect and needs further investigation. What is clear is that the quality of transportation varies, and the sensitivity and concern of the drivers and the expected deportment of riders require additional training or discipline. From the data it is clear that public and private transportation are not well integrated into a single system for the PLWH/A. From an eligibility perspective, having a diagnosis of AIDS may be too rigid for car and taxi service. If a major goal on the continuum of care is not progressing to AIDS, then this criteria might be relaxed. Another issue is making transportation available to families. However, it will be critical to develop infrastructure before inviting greater use.

Housing is identified as a top need by all the stakeholders, and is one of the highest anticipated needs by PLWH/A. The survey indicates a large gap for housing, particularly finding independent housing. Obtaining supportive housing is ranked somewhat lower by PLWH/A. The eligibility criteria for housing is complex, including homelessness in some instances, and housing and drug abuse services overlap. While increasing capacity for independent housing should be a priority, making the housing system more transparent to PLWH/A and changing criteria for eligibility might be considered.

Food is the other basic need that is addressed in the continuum of care. Based on a large waiting list, high anticipated need, and high demand, there is a need to increase capacity. Overall, PLWH/A are satisfied with the service and level of access. The role of the food bank in providing a primary source of nutrition for PLWH/A should be determined and there might be a more variable system of eligibility based on nutritional need.

Direct Emergency Assistance (DEA) with rent and utilities, like food and housing, speak to meeting basic needs. There is a great demand and limited capacity. For PLWH/A the rules are seen as somewhat arbitrary, and access is seen as relatively difficult. The care system might make the process easier and rules clearer. As long as PLWH/A are overwhelmingly poor, the use of DEA will grow to whatever capacity is created. The challenge is determining when services will help improve the status and quality of life of PLWH/A and to decide what level of resource to provide to DEA. Developing an infrastructure to respond quickly to changes in demand would be helpful.

There is little unmet demand for treatment information and risk reduction information. However, the data suggests that information might be designed to be more targeted. Adherence continues to be inadequate and some populations are unaware of available treatment options. The challenge of the care system will be to provide targeted information to populations in need.

While not a top need, insurance continuation deserves special mention in this final section. Insurance coverage is seen as one of the highest barriers by PLWH/A and there is a great perceived gap between the insurance asked for and received. The current insurance assistance is very limited to insurance continuation for those who already have insurance but are unable to pay. The role of insurance, however, might play a significantly greater role in the future. As a large number of PLWH/A are considering returning to work there may be an opportunity to create an insurance "start-up" policy. The recent mandate to require managed care in Harris County may also suggest investigating models of insurance where PLWH/A can obtain insurance to cover health care plans through Medicare or Medicaid or emergency funds.

Care Needs of Subpopulations

Some targeted populations have needs that are different from the general population. Women have a greater need for childcare and are more likely to need referrals. Interestingly, case management is their most anticipated need. They find adult day care, home health care, and health insurance assistance harder to access than other services. Transportation is their highest barrier.

MSM, being the largest group of PLWH/A in Houston, largely follow the needs and barriers of the total populations. In terms of barriers they do not, however, speak in one voice. For example, African-American MSM report the overall highest barrier score in accessing services, while Anglo MSM report the lowest.

IDUs are more likely to need housing than other subpopulations. They have the highest barriers of any group, and are much more likely to mention transportation as a need as well as a barrier.

Heterosexuals are more likely to need childcare services than other subpopulations. They are also more likely to name their own physical health as a barrier to seeking care.

Undocumented PLWH/A are among the poorest PLWH/A and have the lowest educational level. While they have a lower use of medication, once prescribed they are more likely to adhere to a drug regimen. They express a higher than average need for case management and transportation. The

undocumented PLWH/A report the lowest level of access for services. They are more likely to have children than PLWH/A in general and many of the barriers to care relate to family issues.

Rural participants are remarkably similar to all PLWH/A. They report being a little less informed about drug reimbursement. Rural PLWH/A consistently express their need for direct emergency assistance. Not surprisingly with the only dental provider located in central Houston, rural providers say that location of dental care is an issue for them.

Finally the moving of PLWH/A from emergency funds to more sustainable reimbursement streams will become more important in future years. Medicare, Medicaid and State programs offering substance abuse assistance and general medical coverage should continue to be integrated into the overall system of care. While Ryan White Emergency Funds will be available for at least a few more years, eventually AIDS is likely to become a chronic disease whose care will be integrated into the general health care system.

Prevention Needs Assessment

The City of Houston/Harris County planning bodies for prevention and HIV social services both undertook comprehensive needs assessments. Summaries with recommendations follow in this chapter. Needs assessments are essential elements in the planning process. Both the City of Houston and Harris County have worked together to bring all issues and recommendations to the overall planning process in the hopes of ensuring a full continuum of care for persons at-risk, infected and affected by HIV/AIDS.

Needs assessment activities for prevention planning revolve around populations and sub-populations. The Centers for Disease Control, the primary funding source for prevention activities, plans via at-risk populations as a means of decreasing HIV incidence.

Needs assessment activities for HIV social services revolve around care services to promote better health care, improve health status, and ensure standardized health care services. Many times the needs assessment will identify more culturally sensitive services and programs to be developed.

HIV Prevention Planning Needs Assessment Summary *information provided by the HIV/AIDS Bureau of the City of Houston Health Department from their Prevention Needs Assessment.*

As populations affected by HIV disease have changed in recent years, the parties responsible for planning Houston's approach to HIV prevention were in need of more information about how members of affected and at-risk groups perceive HIV disease, and how they might more effectively be reached with prevention messages. This study was intended to provide the Houston Department of Health and Human Services (HDHHS) and the Houston HIV Prevention Community Planning Group (CPG) with data helpful in evaluating the prevention needs of affected and at-risk populations in Houston. More specifically, the study was designed to help identify and describe problem areas in prevention services currently offered, to more clearly describe the needs of at-risk and underserved groups, and to provide recommendations for future program development. The study utilized quantitative data from a 1998 questionnaire, and qualitative data from key informant interviews, provider interviews, and focus groups conducted in the spring of 1999. Results suggest that youth, gay men, HIV-positive persons, and ethnic minority group members are in particular need of expanded, sustained, and more narrowly targeted prevention services. Reported barriers to providing needed services include inadequate childcare and inadequate transportation funds for clients, and a scarcity of chemical dependency treatment programs.

Methodology and Limitations

Qualitative data for this study were collected primarily from structured interviews with key informants who are members of and/or knowledgeable about target populations, and from focus groups with members of target populations. Recent literature related to HIV prevention needs assessment and effective interventions was also reviewed, in order to inform the content of interview and focus group questions. In addition, responses to a resource inventory questionnaire developed by the CPG and disseminated by HDHHS in the spring of 1998 provided limited quantitative data.

Key informants and populations for focus groups were chosen by the principal researcher in consultation with CPG members and HDHHS epidemiology staff, in an effort to ensure that both community involvement and the use of current data about local populations would be maximized. Written guides for key informant interviews and focus groups were developed by the principal researcher. A separate questionnaire was tailored for each key informant. Focus groups were facilitated by the use of identical open-ended questions, with the facilitator using participant responses as the basis for more specific probes. A separate focus group protocol was developed for use with prevention workers.

Eight key informant interviews were conducted by the principal researcher with individuals knowledgeable about the following groups or issues: HIV-infected individuals, African-American men and women, Hispanic populations, men who have sex with men, trends in HIV prevention among various populations, spiritual issues, low-income youth, and prevention workers. (Some interviewees had expertise in more than one of these areas).

Eleven audiotaped focus groups were conducted, either by the principal researcher or by a trained research assistant whose demographic characteristics were compatible with those of focus group members; two CPG members participated in facilitating four of the groups. CPG members were instrumental in providing access to traditionally underserved populations, including African-American women and youth. Focus group populations included African-American women from different socioeconomic categories, youth (African-American, gay, male, female), HIV-negative gay men, recovering substance users, and prevention workers. The focus group facilitator discussed with participants the procedure for conducting the groups, and other matters required for informed consent. All participants initialed a brief informed consent form. A total of ninety-one individuals participated in the focus groups. Data gathered in eleven structured interviews by another community-based research firm, Innovative Thinking Inc., provided information about perceived service barriers from a provider perspective.

Data from key informant interviews and focus groups were analyzed by the primary researcher; data from questionnaires and provider interviews were analyzed by Innovative Thinking Inc. A summary of results of the data analysis is provided in the following section. While findings from the varied sources were remarkably consistent, they cannot be assumed to generalize to all members of target populations in Houston.

It should be noted that an effort was made to collaborate with the Ryan White Planning Council and CARE Consortium, who were engaged in a needs assessment related to care treatment services. The prevention contractor suggested prevention-related questions for inclusion in the survey instrument for treatment services.

Summary of Findings

The remainder of this chapter presents findings of the prevention needs assessment as reported by the City of Houston. Results of the data analysis are reported in two ways: 1) themes found consistently among research participants are described, and 2) observations relevant to specific target populations are provided. Quotation marks indicate the words used by a participant in a focus group or key informant interview. Following the summary of findings, recommendations for modifying current approaches are offered.

General Reported Findings

Perceptions of HIV Disease

HIV continues to be perceived by many individuals in target populations as a disease primarily affecting gay men.

Many people, particularly young men and women and teens, have no first-hand knowledge of HIV/AIDS.

Their information about the illness itself comes primarily from news accounts of current medical treatments and drug advertisements, both of which are thought to present an unrealistically optimistic picture of living with the illness. Participants expressed a clear desire to know "first-hand" about the illness from an infected individual who is willing to discuss his or her own experience.

Except among older gay men, confusion exists about transmission, testing, treatment, and treatment outcomes.

The questions spontaneously raised by participants suggest not only areas of confusion, but also a strong desire to be better informed. One example raised in several focus groups concerns the medical status of Magic Johnson, with some participants expressing the belief that he has been "cured."

Perception of Risk-Taking Behaviors

General reasons reported for putting oneself at risk include:

- Drug and/or alcohol use
- Ignorance about methods of transmission
- Desire to trust one's sexual partner and to be trusted
- Fear that raising the subject of condom use might suggest that "something is wrong" with the person who does so--particularly that the person might have HIV/AIDS or might be gay or bisexual
- Feeling awkward about discussing sex or sexually transmitted diseases: "It kind of kills the moment."
- A belief that that "looking good" or appearing healthy indicates the absence of HIV disease
- The presence of depression, loneliness, low self-esteem, lack of self-respect, or other psychological difficulties
- The influence of social ills such as poverty, homelessness, and domestic violence that may discourage individuals from planning for the future.

Among gay men, a desire or willingness to join the HIV-positive community that is "glorified" by such publications as *Poz* and by upbeat drug advertisements may contribute to unsafe behavior, as does a

lack of social support – in the gay community and in the larger society – for monogamous relationships. Gay men who are HIV-positive are seen by some as achieving a sense of "community" or "identity" that may make contracting a chronic, life-threatening illness seem less forbidding.

Many participants from all groups suggested that fear is no longer a motivator for safer behavior, as younger people have less first hand contact with the illness among peers, and both young and older individuals may be lulled by optimistic accounts of available medical treatment.

Attention to the HIV-Infected

People with HIV are not adequately targeted for prevention.

Not only are individuals in this group the only ones capable of transmitting the virus, they comprise a relatively small and accessible population, compared to the population of HIV-negative persons. While making this population a clear prevention target may have been avoided to insure that infected individuals not be stigmatized, the large numbers of infected persons receiving medical treatment, as well as the various support groups and activities available to them, suggest existing avenues of service delivery that could be utilized in prevention.

People with HIV are not adequately involved in prevention service delivery.

Direct contact with an infected individual is missing from the lives of many members of target populations, particularly youth. Many expressed the conviction that hearing about the transmission and effects of the illness from one who has experienced them would be more likely to leave them with the sort of "fear" that might prompt behavior change – particularly if the infected person's demographic characteristics were similar to those of the listeners. Others noted that their contact with an HIV-infected family member, neighbor, or friend had indeed contributed to their own safer behavior. Some observed that one with the illness is simply a more credible source of information than a "Health Department worker who might put you to sleep".

Current Prevention Education

Inadequate information is provided to school-age males and females.

For a variety of reasons—including ignorance, feelings of invincibility, "raging hormones," lack of good judgment, drug and alcohol use, perceived peer pressure, a lack of focus on the future, schools' ignoring the subjects of HIV/AIDS and homosexuality, and the absence of sufficient family guidance—youth is seen by all groups as being most likely to engage in high-risk behavior, and most in need of prevention information and support.

Much of the material used to educate about HIV/AIDS is either "out of date" or inappropriate to the target audiences.

Research participants were unanimous in calling for more "straightforward," "clear," "explicit" material that does not "sugarcoat" the consequences of HIV infection. There is consensus that written materials developed for gay white male adults who may be well educated do not appeal to all targeted groups, specifically youth who may be gay or straight, women, and minority males who may not self-identify as gay, but fit into the MSM category.

More skills training, with follow-up to encourage continued risk reduction, would enhance the efficacy of prevention programs.

It is important to provide follow-up for those initially reached with prevention messages, to help insure that questions can be addressed and reinforcement for safer behavior provided over time. Current training for prevention workers may be inadequate to foster the "psychological sophistication" needed to address the variety of concerns raised by consumers of prevention services.

Condoms

While availability of condoms in such venues as bars was acknowledged, participants were skeptical that condoms acquired in such a manner were likely to be used; "you find them on the ground outside the bar." In general, providing encouragement and skills to plan to acquire and use condoms is needed. For youth and low-income individuals, easier access to condoms may be helpful.

Testing

The prospect of being tested for HIV is frightening and anxiety-provoking, even more than testing for other STDs. Equally frightening is the idea of requesting that one's partner be tested, or inquiring whether he/she has been. For some, ignorance is bliss, an attitude compounded by anxiety about discussing HIV (considered a "depressing" topic), as well as the desire not to appear suspicious of a partner or to arouse the suspicion of a partner. Fears persist that testing results are not confidential, and, among teens, that the findings will be reported to their parents.

Public Information

A striking finding among the focus group participants was the inability of anyone to cite a memorable piece of publicly available information related to HIV prevention. While participants cited billboards featuring "people with big yellow eyes" as effective at raising their awareness of hepatitis, and "this is your brain on drugs" advertisements related to substance use, comparable examples for HIV were nonexistent. Condom advertisements on television were criticized as trivializing a serious subject; attempts at humor, as with a "condom with feet" scurrying across a bed, or treating a condom as a "fashion accessory" were viewed as ineffective to actually encourage condom use.

Accessibility of Services

Representatives of agencies that provide prevention services tend to see themselves as accessible in terms of parking, staff compatibility with populations served, and proximity to public transportation and to the communities served. However, they note that a general scarcity of funds, particularly for providing transportation or parking money, child care, additional space, and chemical dependency treatment, constitute serious barriers to adequate service delivery.

Perceptions of the Houston Department of Health and Human Services

While no effort was made in the focus groups to obtain information about how target populations view the HDHHS, spontaneous observations during the course of some groups suggest perceptions that may relate to the Department's ability to deliver some prevention services effectively. While the reluctance of some Houston residents to patronize STD clinics in their own neighborhoods is known, participants in this research also expressed displeasure with the "City Health Department" for sending marked cars into their neighborhoods to notify individuals of their possible exposure to STDs. The presence of the cars, as well as the employees "carrying those briefcases," is seen to be a violation of privacy and an

indicator of disrespect. To the extent that these attitudes are thought to characterize the treatment expected at HDHHS clinics, the likelihood that individuals will seek needed medical services, especially those related to HIV prevention and treatment, is diminished.

Reported Findings Related to Specific Populations

Youth

As noted above, the risk-taking behavior of male and female youth was the topic of most consistent concern raised by focus group participants, key informants, and service providers, regardless of age, ethnicity, sexual orientation, or apparent knowledge of HIV disease. The questions raised by the youth themselves during focus groups clearly demonstrated ignorance of basic facts about the transmission and treatment of the illness, as well as a clear desire to obtain more information, preferably from a parent and/or someone infected with the virus. This was true even among those who reported previous exposure to some kind of organized HIV education. Providers note that many at-risk youth are unlikely to be regular consumers of any health care, experience emotional difficulties for which services are not available, and face complicating social problems such as homelessness and poverty.

Without exception, participants observed that HIV prevention should begin with younger males and females – at least by entry into middle school. While sexual abstinence and/or limiting the number of one's sexual partners should be encouraged, intervention programs need to recognize that many youth will need ongoing support to maintain this behavior. In addition, it is crucial to recognize that many youth will be sexually active, and to insure that they are prepared to engage in behavior likely to protect their health. **A strong consensus exists that schools are not doing enough to provide education related to HIV.**

(It may be instructive to view these sobering findings in the context of the report prepared by BenchMark Research in January 1997, for HDHHS. An initial effort to assess the effectiveness of public information programs delivered by funded agencies, the study noted that (1) the Youth at Risk group reported having the least knowledge of HIV and its prevention, (2) a very low (20%) proportion of the Youth at Risk group recalled being exposed to an HIV program in their schools, and (3) the programs offered in junior high schools are rated consistently as less interesting and less informative than other programs. BenchMark noted that these programs are "arguably the most important since only they happen at the time in young peoples' lives when the risky behaviors are being learned" (p. 11). Results of the current needs assessment research suggest that the situation outlined by BenchMark two years ago has not appreciably changed).

African-Americans

African-American participants recognize HIV/AIDS as a growing threat in their community, especially among the young.

Given that the epidemic was initially seen in the United States as a "gay disease," some uncertainty exists about how the epidemic has made inroads into a community where discussion or acknowledgment of homosexuality has not been encouraged. One participant jokingly observed that "in the black community, there are no gays, only bi."

African-Americans need more information about transmission and disease progression, as well as training for safer behaviors.

While the Knowledge, Attitudes, Beliefs, and Behavior (KABB) model may no longer be the most effective in populations where the epidemic has a longer history, the knowledge base and attitudes of many in Houston's black community may be inadequate to encourage safer behavior. To some extent, the community may be in a position comparable to that of gay males at the beginning of the epidemic: in need of developing resources for self-education. Youth and younger females are especially in need of information about risky behavior and skills to behave more safely.

Programs are not adequately directed to the geographic areas where they are most needed.

Neighborhoods, zip codes, or some other geographic designation may provide a more efficient means to organize prevention service delivery.

Partnerships between black community-based organizations (CBO's) and local academic institutions are needed, to enhance the design, development, implementation, and evaluation of programs directed at African-Americans.

It is particularly important to understand how prevention programs are evaluated by the target populations.

Women express particular interest in learning more about HIV infection, and in helping to educate their children about it.

Individuals with low incomes and/or limited employment prospects may be helped most by intervention that include attention to more "basic" needs such as housing, health care, and nutrition, as well as skills-building in such areas as literacy and job training. It is possible that without attention to such needs, many low-income individuals will not feel that they have "something to lose" in contracting a life-threatening illness.

The African-American population should not be viewed as a monolithic group, for which "one size fits all" intervention will be accepted or effective.

Differences in socioeconomic status, employment, education, attitudes toward one's own health and health care in general, and confidence in public agencies are some of the factors to consider in planning appropriate programs.

Hispanic Populations

More specific targeting of at-risk groups is needed.

As noted about African-Americans, Hispanics in the Houston area comprise a diverse population that is not well served by a single approach to HIV prevention.

Socio-economic status (SES) and age should be major considerations in planning interventions. Youth are in need of special attention; while many parents are not averse to their children being informed about sexual matters, the parents are not likely to provide the education themselves. Interventions should begin at a much younger age than currently.

Role models of appropriate behavior are needed, as is ongoing support for appropriate behavior following initial interventions.

More information is needed about the extent to which Hispanic teens may be engaging in unprotected anal intercourse as both a method of birth control and as a way to maintain a "virgin" status.

More information is needed about the behavior of local "labor poolers."

Little "hard" evidence exists about the behavior of this group of workers, which includes migrants from various Latin American countries. Speculation exists that men in this group may be infected through unprotected sex with one another or with male sex workers, and subsequently put their female partners at risk.

While intravenous drug use is not considered a large problem among Hispanics in Houston, excessive alcohol consumption is a likely contributor to unsafe sexual behavior.

Individuals with low incomes and/or limited employment prospects may be helped most by interventions that include attention to more "basic" needs such as housing, health care, and nutrition, as well as skills-building in such areas as facility with the English language and job training.

Gay Men

[Please note: The term "Gay Men" is used here as opposed to "MSM" because research participants self-identified as gay and it is not clear that the observations of "gay men" apply equally to persons in the more general category of men who have sex with men.]

While much progress has been made in educating the gay community about HIV, the epidemic remains a huge problem for this group.

Prevalence rates are highest in the MSM population, so a large group of individuals who can infect others exists. The impression that this group needs less prevention effort is mistaken, in part because the population is not static; rather, it is characterized by constant entry and exit because of such factors as age, geographic mobility, and death of its members. In addition, recent accounts of deliberate participation in unsafe sex ("barebacking") may indicate the coming of a "new wave" of infected individuals, and therefore a heightened need for prevention. Unrealistically optimistic public information about new medical treatments is seldom balanced by more honest and complete information about disease progression and treatment, particularly their impact on quality of life; such supplemental information might help to increase the "fear" that once was a primary motivator to behavior change. Young gay men may be most in need of corrective information about the illness, given that many have not experienced first-hand the multiple deaths that affected an older group.

Risk reduction programs lack adequate depth and follow-up.

To the extent that many at-risk individuals may be depressed, anxious, antisocial, or experience other mental health difficulties, acquiring the skills to engage consistently in safe behaviors is likely to be time-consuming. It is a process best facilitated by interventions that explicitly and over a substantial time period address the difficulties of adopting and maintaining safe behaviors.

Prevention activities do not adequately consider individual and community values, and ethics related to sexual behavior.

While instruction about "safer sex" is fundamental, supplementing it with a consideration of topics such as how sexual decisions are made, what sex means to individuals, and what responsibilities gay men may have to each other may encourage awareness that they live in a community "worth taking care of."

The diversity of the gay community needs more recognition, in order to avoid a "one size fits all" approach to prevention.

While "free sex" and sex as "escape" are accepted by many, many others behave according to different sexual norms. The availability of more venues that don't encourage casual sexual encounters, more opportunities for spiritual development, and more formal social sanctions for stable relationships may serve the purpose of HIV prevention by recognizing the role that social context play in decisions about sexual behavior.

More information is needed about the numbers and behaviors of MSMs not self-identified as gay, particularly African-Americans.

Recommendations

While information in the preceding section suggests obvious areas for change in existing programs, the following recommendations highlight the most crucial topics, and include specific suggestions made by research participants.

A more creative and sustained effort to deliver HIV prevention services to Houston's youth should be made.

Schools are the most obvious and efficient venues for offering HIV prevention information and skills training, and research participants were unanimous in their desire to see schools play an active role in educating boys and girls, beginning at least by age 12; incorporating HIV education into health classes seems most appropriate. There is disparity among local schools with respect to the quantity and type of information presented, and talking with administrators at schools more receptive to frank programs might suggest ways to approach other schools. After-school programs such as those run by the YMCA or local community centers, as well as youth programs sponsored by churches, offer alternate routes of access to youth populations. Churches were frequently mentioned as an "obvious" venue of program development in the African-American community, despite acknowledgment that many clergy continue to deny the existence of an HIV problem in their churches.

All interventions should be delivered by persons "who know what they're talking about, want to talk with us, and lay it on the table." Ideally, an intervention program should include participation of an HIV-positive individual with characteristics similar to those of the target populations, or similar to those of a potential partner of those targeted.

Youth were clear in their desire to receive information and guidance about sexual matters, including HIV. Many indicated their desire to remain "virgins" or return to celibacy, but noted that peer pressure from both males and females, the perception that many peers lead active sex lives, uncertainty about their futures, ignorance about general health matters related to sex, and loneliness are constant challenges for some. HIV prevention programs need to address these social aspects of teens' sexual decision-making, and to foster teens' expressed desire to behave in a "responsible" manner.

Particularly among African-American women, interest was expressed in a "family" approach to intervention. This might include providing information and support to mothers and fathers for talking with their children about facts and decision-making related to sexual behavior and HIV. Several mothers expressed a desire to attend an educational or skill-building event with their children. Women suggested that participation in an instructional program would be greater if it were held in the evening at a local school, or as part of a series of Ladies Health Nights held at a local hotel or multi-service center. Some noted that advertising "relationships" rather than HIV as a theme for an all-female event might enhance attendance. Male African-American youth noted that talking with an older male, such as a "cool uncle," is easier than talking with their mothers.

General awareness of HIV among youth might be raised by public-service advertising on local radio stations, such as 97.9 and 102. Young participants note that many of the songs they hear on these stations are "all about sex," so "why not talk about it?"

Modify the current "B-52 approach" of showering all targets with similar information or programs; tailoring programs to better reach diverse sub-populations may more efficiently utilize scarce resources.

A triage system is needed, to better identify those requiring more intense or prolonged intervention. More individualized assessment, including identification of those with multiple risk factors, is necessary to maximize the effectiveness of interventions designed to modify behaviors. For example, some targeted individuals will need to build assertiveness skills, others may need help in recognizing and countering "triggers" to unsafe behaviors, and others may require attention to specific emotional difficulties such as depression, anxiety, or substance dependence before prevention interventions are likely to be effective. While a relatively small number of individuals will change risky behaviors in response to information only, many will need interventions that are more comprehensive and sustained, with an interactive format that allows a focus on skills acquisition rather than a lecture format that provides only factual information about HIV disease.

For all target groups, supplement information and skill building instruction with opportunities for sustained practice in and support for low-risk behavior.

Opportunities for ongoing follow-up and support in "real life" are needed to reinforce skills taught in workshops. Offering "refresher" courses that allow participants to discuss their difficulties and successes, as well as to raise new questions, is one way to follow up on current multi-session training. (It could also provide an avenue for gathering much-needed data about post-training behavior, and thus be a useful evaluation tool). The need for a more sustained approach may be particularly relevant to youth populations, who are still in the process of developing their intentions about sexual activity, and to MSMs, who may be exposed to mixed messages about the desirability of remaining HIV-negative.

Provide more comprehensive training to prevention workers.

"Front line" service providers would be helped by instruction to enhance their ability to address difficulties that targeted individuals may have in implementing and maintaining desired behaviors. It is especially important for prevention workers to be able to identify those clients likely to need more intensive intervention and/or mental health care referrals. Gatherings of prevention workers from different agencies, perhaps in a structured workshop format, would allow for sharing of common problems and effective strategies, and perhaps help to decrease some duplication of services. Curricula used by prevention workers should be reviewed and updated at least annually, to reflect current research findings and changes in target populations.

Review and update written materials to fit the needs of current target populations, and provide more information orally.

Youths and those who work with them express a preference for oral and deliberately interactive presentations, so that the target audience can ask questions – something that reading a pamphlet does not allow. Inability to ask questions and the perception of the written material as "boring," or requiring "a medical school education" are reasons given for youths' reported disinterest in reading available written material. More straightforward, "street" language should be used. Ideally, each program or presentation would include a brief evaluation component to help assess participants' responses.

Involve more people with HIV in prevention efforts.

No effort should be made to stigmatize those who are HIV positive. Rather, the emphasis should be on countering the cheerful public information about new medications by providing accurate information not only about disease symptoms and treatment, but also the emotional, social, and financial difficulties of living with a chronic illness that currently is incurable.

To the extent possible, HIV-positive persons should be included in prevention service delivery. It may also be possible to enlist more schools in providing volunteer services to agencies caring for the ill, thus giving youth needed exposure to the illness. One participant noted the enormous impact that volunteering had had on his view of HIV disease; hearing one patient ask for toilet paper as a Christmas gift provided a vivid demonstration of the "quality of life" impact of the disease.

Train medical care providers in HIV prevention.

Given that the HIV infected should be a priority target, medical care providers – who are in regular contact with patients and are likely to have credibility with them – could play a significant role in assisting the infected with prevention information, encouragement, and referrals. To be most effective, medical personnel need training in sensitive and frank discussion of sexual matters, identification of emotional difficulties, and knowledge of appropriate referrals.

Consider a public service ad campaign encouraging discussion of safer sex, as well as testing.

One participant suggested an advertisement that would ask something like: "Which conversation would you rather start: the one that says 'have you been tested', or the one that says 'there's something I need to tell you about'?" Another idea was to point out: "If you know him/her well enough to do it, don't you know him/her well enough to talk about it?" Teen participants suggested that some of their peers might respond to encouragement to be tested in the company of a friend ("Instead of the mall, go to the clinic").

Create interventions that acknowledge cultural and other contextual factors that contribute to sexual decision-making.

Individuals do not make sexual decisions in a social vacuum – influences such as perceived support for specific behaviors, expectations about the future, and the sense of belonging to a community of like-minded individuals are only a few of the social contexts that may be important in HIV prevention. Interventions may therefore need to move beyond the individual level to address influences such as community norms related to sexual behavior, economic and educational circumstances that contribute to a sense of hopelessness about the future, and sources that may encourage a sense of responsibility toward oneself and others. Engaging as many "communities" – including neighborhoods, families,

churches, schools, social organizations, and community service groups – as possible in these efforts is desirable.

Utilize existing community resources to address barriers to accessibility.

In the absence of adequate funding, it may be possible to marshal available resources in non-traditional ways. For example, agencies needing more childcare for clients might arrange for a local high school, university, or church youth group to provide child care as a way to fulfill a community service requirement.

Utilize existing community resources for program development.

As this study progressed, it became clear that a number of researchers in Houston, particularly those in academic institutions, could be excellent resources for HIV prevention, functioning either as consultants for program development, as key informants, or as sources of information for CPG members.

Chapter Five: Current System of Care

Continuum of Care

A continuum of care is a model of how a community is using, or would like to use, its resources. In the case of HIV, as defined by the Health Resources and Services Administration (HRSA), a continuum of care is "a coordinated delivery system, encompassing a comprehensive range of services needed by individuals or families with HIV infection to meet their health care and psychological service needs throughout all stages of illness." These services usually include:

- Primary and secondary prevention of HIV infection
- Treatment and prevention outreach to both the general public and to identified at-risk populations
- Medical and social services
- Support services that ensure universal access to medical and social services to all PLWH/A who need service

An ideal continuum of care is a "wish list" of a set of services offered to PLWH/A, identifying all health and social services that may be needed. This wish list then can be compared to the actual system of care, or the resource inventory, so that the HIV community can determine whether the services that are currently available fit the clients' current and projected needs.

The Houston area Continuum of Care, or COC, has been recently revised (1999) and is now conceptualized as a sort of "rail system" that identifies and tracks the HIV services deemed necessary to those who are living within the Houston area. This new rail system concept will theoretically allow people living in the area to get in or out of the system depending of their general knowledge of the HIV virus, including how it is transmitted; their serostatus; their health; and their individual desire to stay within the system. The five tracks on Houston's new continuum of care are:

A: Public Advocacy to the General Public
B: Outreach to At Risk Populations
C: Prevention of HIV infection
D: Early Treatment of HIV infection
E: AIDS Treatment to PLWA

Each track is intended to reach a different audience:

Track A includes general HIV health and prevention messages and is intended for the general population. The ultimate "destination", or goal, of this track is to build public support for HIV prevention and care services.

Track B includes mobile clinics, counseling and testing, community outreach and hotlines and is intended for those populations who have been identified as at risk. The ultimate goal of this track is that people are informed of their serostatus, that is, whether they are HIV positive or negative.

Track C includes audience specific prevention messages as well as support groups and individual prevention counseling and is intended to reach those who choose to test for HIV and then discover that they are HIV negative. The goal of this track is that people maintain their negative status.

Track D outlines an enormous array of services including everything from substance abuse treatment to case management and is intended to reach those who test positive for HIV. The goal of this track is

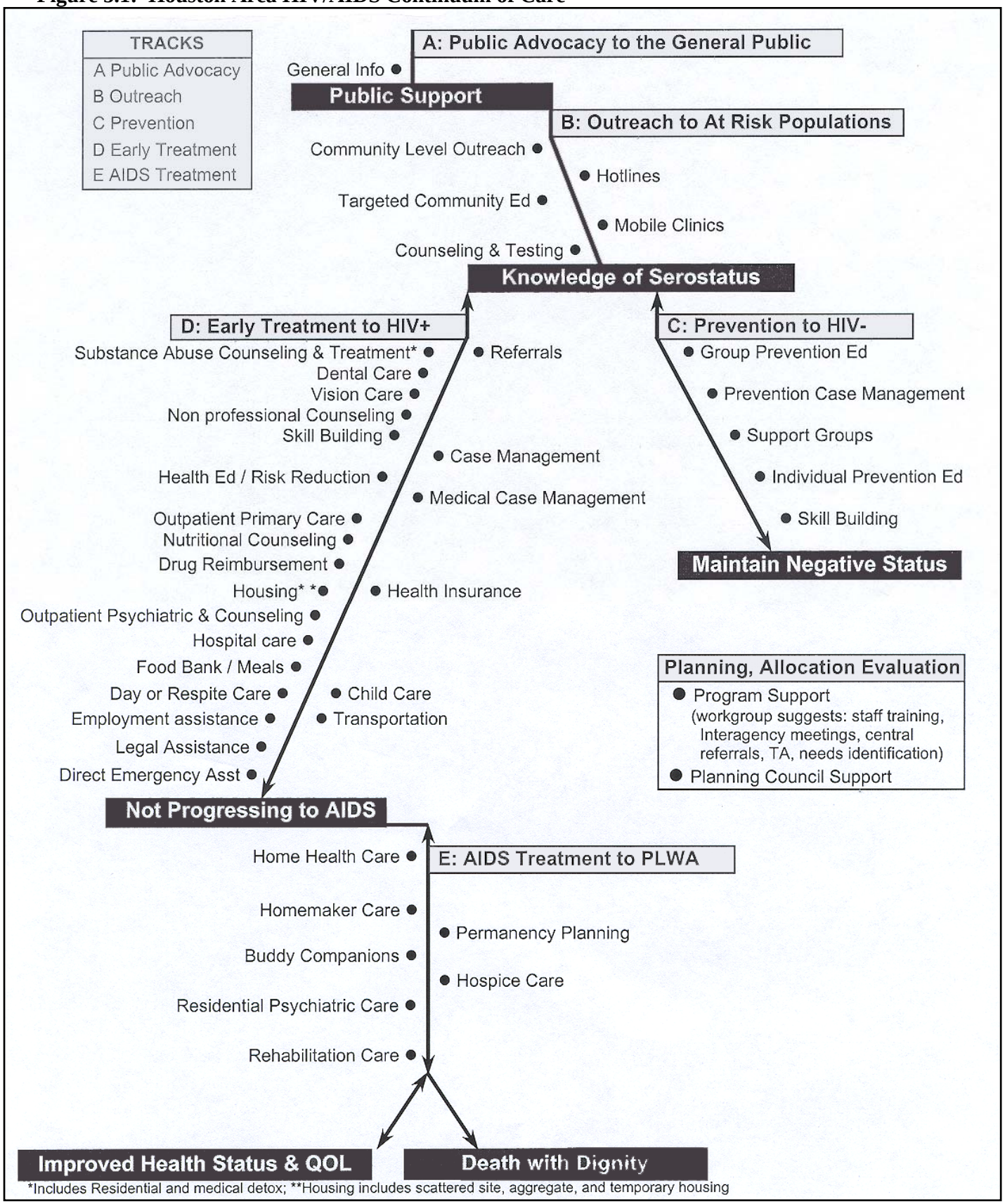
that people with HIV not progress to AIDS (and should a cure develop over the period this document is valid, the "destination" would include moving back to track C or B or A).

Track E includes home health care, hospice care and rehabilitation and is intended for those individuals who receive an AIDS diagnosis. The goal of this track is that people with AIDS improve their health status and quality of life (and hopefully they will return to track D), or, if necessary, to create the conditions that will allow for death with dignity.

This track paradigm allows the continuum of care to be imagined as a system that will easily embrace both individuals who are infected and those individuals who are at risk for infection but test negative. Additionally, the multiple tracks allow movement by clients across the system. As medications become more sophisticated and more successful – at both maintaining the health of recently diagnosed individuals and reviving the health of those individuals whose infections have progressed – the system will need to facilitate a client's ability to get in and out of disparate modes of care with grace, ease, and simplicity.

The image on the following page illustrates the skeletal framework of this "track" system continuum of care.

Figure 5.1: Houston Area HIV/AIDS Continuum of Care



Note: ***This is not an eligibility chart - services that are listed as especially needed by people with AIDS does not mean that people with HIV (not AIDS) are not eligible. And conversely, services listed as especially needed by PLWH to help prevent progression to AIDS, does not mean that PWAs are not eligible for those services.***

The following listing presents information about the HIV service agencies and the services they provide in the Houston area continuum of care. The listing shows the clients each organization services and lists the funding sources (identifying the amounts of those funds by source) for each of the care organizations. The information was gathered from providers who volunteered their information in the 1999 Comprehensive Needs Assessment. For this document, we have linked the agencies to the model of the system of care by describing on which track each agency falls along the continuum of care for HIV prevention and care services (shown in bold next to the service).

Listing of Agencies and Agency-Reported Information

AIDS Foundation Houston, Inc.
Funding FY '98: FEMA, HUD, RW I, Foundation, RW II, TDH, Individual Donations, HOPWA, RW IV – Total Budget $1487,533
Services Provided:

- Residential Housing Services -- **Early Treatment to HIV+**
  Eligibility Criteria: AIDS Foundation Houston provides housing services to several populations all of whom must have HIV infection and be substance free.
- Food Bank -- **Early Treatment to HIV+**
  Eligibility Criteria: 150% or less of the poverty level, HIV infection, live in Houston EMA/HSDA.
- Health Education/Risk Reduction -- **Early Treatment to HIV+**
  Eligibility Criteria: HIV infection, live in Houston EMA/HSDA.
- Support Groups, Non-Mental Health -- **Early Treatment to HIV+**
  Eligibility Criteria: HIV infection, live in Houston EMA/HSDA.
- Volunteer And Buddy/Companion – **AIDS Treatment to PLWA**
  Eligibility Criteria: AIDS Foundation of Houston provides three different Buddy/Companion services including Camps, Phones, Hotlines, Senior Companions, and Creative Arts Healing. Thus, a variety of people are served through these various services including children, teenagers and adults; for general services clients must have HIV infection and live in Houston EMA/HSDA. For Camp HOPE, clients must be 7-16 years of age and have HIV infection. For Camp H.U.G., clients must be 6 or older, be HIV infected or be a caregiver of an HIV infected child, and live in the greater Houston area.
- Referral Services -- **Early Treatment to HIV+**
  Eligibility Criteria: HIV infection, live in Houston EMA/HSDA.
- Employment Assistance -- **Early Treatment to HIV+**
  Eligibility Criteria: HIV infection, live in Houston EMA/HSDA.

Alternate Resources of Texas
Funding FY '98: Unknown
Services Provided:

- Home Health Care -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

Amigos Volunteers in Education and Services
Funding FY '98: RW I, Foundation, RW II, Individual Donations, HOPWA, HCCG – Total Budget $496,230
Services Provided:

- Outpatient Services – **Early Treatment to HIV+**
  Eligibility Criteria: HIV infection, live in Harris or Fort Bend Co.
- Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

- Mental Health Therapy – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

Art League of Houston
Funding FY' 98: Foundation, Individual Donations, HCCG – Total Budget $5,435
Services Provided:
- Art Classes -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, ages 25-35

Assistance Fund, Inc. (The)
Funding FY' 98: Fund Raising, RW I, RW II – Total Budget $1,353,568
Services Provided:
- Drug Reimbursement – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection
- Health Insurance Continuation – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 250% of poverty or below, live in Houston EMA/HSDA, have insurance in place

Baylor College of Medicine
Funding FY '98: Unknown
Service Provided:
- Mental Health Therapy – **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown
- Outpatient Services – **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

Baylor Teen Clinic
Funding FY '98: Unknown
Service Provided:
- Outpatient Services – **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+**
  Eligibility Criteria: Must be 21 or younger, majority of clients are indigent

Bering Omega Community Services
Funding FY '98: Special Events, Interest Misc., RW I, Foundation, RW II, TDH, Individual Donations, Endowment – Total Budget $3,087,166
Services Provided:
- Food Bank -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Income at the federal poverty guidelines, HIV infection, live in Houston EMA
- Direct Emergency Assistance -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

Brentwood Community Foundation
Funding FY '98: RW I, HOPWA – Total Budget $292,655
Services Provided:
- Food Bank -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Income at the federal poverty guidelines, HIV infection, live in Houston EMA

- Direct Emergency Assistance -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

Center For AIDS
Funding FY '98: Unknown
Services Provided:
- Health Education/Risk Reduction -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

City of Houston Department of Health and Human Services
Funding FY '98: Unknown
Services Provided:
- Health Education/Risk Reduction – **Public Advocacy to the General Public, Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Live in Houston area

Coalition for the Homeless of Houston/Harris County, Inc.
Funding FY '98: Unknown
Services Provided:
- Health Education/Risk Reduction -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown
- Referral Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Agency fee of $25, individual fee of $10 to be a member of Homeless Services Coordinating Council

Covenant House Texas
Funding FY '98: RW IV – Total Budget $44,980
Services Provided:
- Adolescent Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: be adolescent, HIV infection, live in Houston/Harris County

Diocesan AIDS Ministry, A Program of Associated Catholic Churches
Funding FY '98: Events, CIK, Diocesan, Foundation, Individual Donations, Endowment – Total Budget $525,502
Services Provided:
- Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in 11 counties of Diocesan of Galveston-Houston
- Direct Emergency Assistance -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in 11 counties of Diocesan of Galveston-Houston
- Health Education/Risk Reduction -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown
- Outreach and Prevention -- **Outreach to at Risk Populations, Prevention to HIV-**
  Eligibility Criteria: Live in 11 counties of Diocesan of Galveston-Houston

Donald R. Watkins Memorial Foundation
Funding FY '98: RW I – Total Budget $803,387
Services Provided:
- Outpatient Services -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Houston EMA, meet other Ryan White I requirements
- Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

- Mental Health Therapy -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown
- Support Groups, Non-Mental Health -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

Family Service Center
Funding FY '98: UWTGC, RW I, RW II – Total Budget $937,546
Services Provided:
- Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection
- Home Health Care -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection
- Mental Health Therapy -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

Fort Bend Family Health Center, Inc.
Funding FY '98: THD EI, RW II – Total Budget $220,136
Services Provided:
- Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Houston HSDA, 500% of Federal Poverty level or for any underserved person
- Mental Health Therapy – **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Houston HSDA, 500% of Federal Poverty level or for any underserved person
- Outpatient Services -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Houston HSDA, 500% of Federal Poverty level or for any underserved person

Foundation for Interfaith Research & Ministry
Funding FY '98: RW I, Foundation, RW II, Individual Donations, HOPWA, HCCG – Total Budget $278,819
Services Provided:
- Volunteer and Buddy/Companion -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, income verification, live in Houston EMA/HSDA

Harris County Sheriff's Dept.
Funding FY '98: Unknown
Services Provided:
- HIV Counseling and Testing – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, in custody of HCSD

Harris County Hospital District (HCHD)
Funding FY '98: Thomas Street HCHD, RW I, RW III – Total Budget -- $9,921,978
Services Provided:
- Health Education/Risk Reduction -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Harris County
- Mental Health Therapy -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Harris County
- Substance Abuse Treatment -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Harris County

- Case Management Services -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Harris County
- Outpatient Services -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

Healthy Lunch Box, Inc.
Funding FY '98: Total budget $109,864
Services Provided:

- Food Bank -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

H.O.P.E. Project
Funding FY '98: Unknown
Services Provided

- Support Groups, Non-Mental Health -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

Houston Area Community Services, Inc.
Funding FY '98: RW I – Total Budget $580,726
Services Provided:

- Case Management Services -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

- Support Groups, Non-mental Health -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown
- Outreach and Prevention -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection

Houston Challenge Foundation
Funding FY '98: Foundation, Individual Contributions, Corporate, Endowment, RW I, RW II, TDH – Total Budget $333,381
Services Provided:

- Food Bank -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, below poverty level, live in Houston EMA/HSDA, not using another pantry, receiving food stamps if eligible

Houston Volunteer Lawyers Program
Funding FY '98: RW I, Foundation – Total Budget $117,633
Services Provided:

- Client Advocacy -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 300% over poverty guidelines, live in Houston EMA/HSDA

Kids in Need of Drug Evaluation & Re-Treatment Clinic
Funding FY '98: RW I – Total Budget $283,000
Services Provided:

- Outpatient Services -- **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Substance high risk, live in Houston EMA/HSDA, exposed in-utero to HIV and/or drugs and/or alcohol

- Case Management -- **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Substance high risk, live in Houston EMA/HSDA, exposed in-utero to HIV and/or drugs and/or alcohol or be a family member of a child exposed in-utero to HIV and/or drugs and alcohol

Life Center, Inc. (The)
Funding FY '98: RW I, Foundation, RW II, Individual Donations, HOPWA, HCCG – Total Budget $500,170
Services Provided:
- Client Transportation -- **AIDS Treatment to PLWA**
  Eligibility Criteria: Low income, 0-70 years of age, AIDS diagnosis, live in Houston EMA/HSDA, sign a rights and responsibilities agreement

Memorial Hermann Home Health
Funding FY '98: RW I – Total Budget $179,307
Services Provided:
- Home Health Care -- **AIDS Treatment to PLWA**
  Eligibility Criteria: AIDS diagnosis, live in Harris County
- Outpatient Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Must be up 500% of poverty, HIV infection

Mental Health Mental Retardation Association of Harris County/PATH
Funding FY '98: Unknown
Services Provided:
- Outreach and Prevention -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Unknown

Montrose Clinic, Inc.
Funding FY '98: Fees, Research Studies, RW I, Foundation, RW II, TDH, Individual Donations, Corporate, HCCG – Total Budget Unknown
Services Provided:
- Outpatient Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 16+ years of age
- Health Education/Risk Reduction -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 16+ years of age
- HIV Counseling and Testing **– Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: 14+ years of age
- Referral Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: 18+ years of age, HIV infection, physician referral

Montrose Counseling Center, Inc.
Funding FY '98: Client Fees, RW I, Foundation, RW II, TDH, TCADA – Total Budget $1,000,227
Services Provided:
- Substance Abuse Treatment -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV+, substance free, live in Houston EMA, 300% of poverty level
- Case Management -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV+, live in Houston EMA, meet DCADA requirements, 300% of poverty level
- Mental Health Therapy -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: 13+ years of age, 500% of poverty level, HIV+, live in Houston EMA

- Health Education/Risk Reduction -- **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: At risk for HIV due to currently using substances or have history with substance abuse, live in Houston EMA
- HIV Counseling and Testing – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: At risk for HIV due to currently using substances or have history with substance abuse, live in Houston EMA
- Outreach and Prevention -- **Outreach to at Risk Populations, Prevention to HIV-**
  Eligibility Criteria: Live in Houston EMA/HSDA, 13+ years of age, at risk for HIV due to currently using substances or have history with substance abuse

NAACP Houston Branch
Funding FY '98: RW I – Total Budget $272,774
Services Provided:

- Support Groups, Non-Mental Health -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 18+ years of age, substance free/abstinence, live in Houston, female
- Outreach and Prevention -- **Outreach to at Risk Populations, Prevention to HIV-**
  Eligibility Criteria: Unknown
- Health Education/Risk Reduction -- **Outreach to at Risk Populations, Prevention to HIV-**
  Eligibility Criteria: 8+ years of age, high risk for HIV/STDs
- Client Advocacy – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection or affected by HIV, adhere to federal poverty guidelines, live in Houston EMA

Nightingale Adult Day Center
Funding FY '98: TDH – Total Budget $75,000
Services Provided:

- Employment Assistance – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Must be over 15 years of age, HIV infection, live in Houston EMA

Northwoods AIDS Coalition, Inc.
Funding FY '98: RW I, Corporate – Total Budget $71,529
Services Provided:

- Food Bank -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, below 500 % of poverty level, live in Houston EMA

People With AIDS Coalition – Houston, Inc.
Funding FY '98: TDHSS, HCHDA, RW I, RW II, TDH, HOPWA – Total Budget $1,047,711
Services Provided:

- Case Management Services -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 300% of poverty guidelines, live in Houston EMA
- Direct Emergency Assistance -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, live in Houston EMA, have emergency need, be at poverty level
- Volunteer and Buddy/Companion -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: 18+ years of age
- Leadership Development – **Public Advocacy to the General Public, Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Live in Houston EMA

Planned Parenthood of Houston
Funding FY '98: Unknown
Services Provided:

- HIV Counseling and Testing – **Outreach to at Risk Populations, Prevention to HIV-**
  Eligibility Criteria: none

Riverside General Hospital
Funding FY '98: RW I – Total Budget $75,000
Services Provided:

- Support Groups, Non-Mental Health -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Federal Poverty Guidelines, 18+ years of age, live in Houston EMA
- Substance Abuse Treatment -- **Outreach to at Risk Populations, Prevention to HIV-, Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Federal Poverty Guidelines, 18+ years of age, live in Houston EMA, have a history of substance abuse and dependency

Sign Shares (DSG, Inc)
Funding FY '98: Unknown
Services Provided:

- Client Advocacy – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 175% of federal poverty guidelines, live in Houston EMA/HSDA, legal issue must by HIV related.

Southeast Texas Legal Clinic
Funding FY '98: Clients, Fundraising, RW I, Foundations, RW II, TDH, Individual Donations – Total Budget $199,658
Services Provided:

- Client Advocacy – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 175% of poverty guidelines, live in Houston EMA/HSDA, legal issue must be HIV related.

Saint John Vianney Catholic Church Social Service
Funding FY '98: Unknown
Services Provided:

- Direct Emergency Assistance – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Low income, HIV infection, be parish member, OR living within zip codes 77077, 770079, 77055, 77043, referred by other agency
- Food Bank -- **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: Low income, HIV infection, be parish member, OR living within zip codes 77077, 770079, 77055, 77043, referred by other agency

Steven's House
Funding FY '98: RW II, Individual Donations, HOPWA – Total Budget $148,154
Services Provided:

- Residential Housing Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, substance free/abstinence

Texas Children's Hospital
Funding FY '98: Federal Grants/CNTRTS, RW IV – Total Budget $1,907,271
Services Provided:

- Outpatient Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, pregnant women 13-55 years of age, pediatrics 0-18

University of Texas Health Science Center for Houston Recovery Campus
Funding FY '98: Other, RW I, Foundation – Total Budget $628,128
Services Provided:

- Rehabilitation Care – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, 18+ years of age, medically indigent, substance use history and status is required, live in HHS Region 6, be homeless

University of Texas Health Science Center of Houston, Women's Immunology Center at LBJ
Funding FY '98: unknown
Services Provided:

- Outpatient Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, must live in Houston EMA/HSDA, Female

University of Texas Houston Health Science Center/Dept. of Pediatrics
Funding FY '98: TDH/CDC, RW I, Foundation – Total Budget $496,230
Services Provided:

- Outpatient Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, meet Ryan White parameters, between 0-21 years of age
- Case Management – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, meet Ryan White income requirements, between 0-21 years of age

UTMB Family Medicine – Conroe
Funding FY '98: RW I – Total Budget $90,000
Services Provided:

- Outpatient Services – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection (symptomatic—above 100 CD4)

Visiting Nurse Association of Houston, Inc
Funding FY '98: RW I, TDH – Total Budget $460,416
Services Provided:

- Home Health Care – **Early Treatment to HIV+, AIDS Treatment to PLWA**
  Eligibility Criteria: HIV infection, doctor's orders, live in Houston EMA/HSDA, medically and financially indigent per federal poverty guidelines

Young Women's Christian Association
Funding FY '98: unknown
Services Provided:

- Health Education/Risk Reduction
- Home Health Care – **Public Advocacy to the General Public, Outreach to at Risk Populations, Prevention to HIV-**
  Eligibility Criteria: School aged youth, Yates High School students

Summary of Service Providers

At this time, each track of the continuum of care is being addressed by the service providers. Below is a quick summary:

Track A: **Public Advocacy to the General Public:** three agencies currently provide public advocacy to the general public.

Track B: **Outreach to At Risk Populations:** 11 agencies currently provide outreach to at risk populations.

Track C: **Prevention to HIV negative:** 12 agencies currently provide prevention messages and support to individuals who test HIV-.

Track D: **Early Treatment to HIV positive:** 39 agencies currently provide early treatment to individuals who are HIV+.

Track E: **AIDS Treatment to PLWA:** 39 agencies currently provide treatment and care to PLWA.

Chapter Six: Inventory of Available Local, State, and Federal Resources

A resource inventory is simply an accounting of all the resources available in a community. These include service providers, the services they offer, and the money available for these services.

The Ryan White CARE Act, the largest sole source of HIV/AIDS funding, cites 25 eligible services categories. These are:

- Adoption/foster care assistance
- Ambulatory/outpatient medical care – Physicians including specialty, care for all stages of HIV infection, lab, pharmacy, and HIV related protocols, on site exams.
- Buddy/companion services – Volunteer program to provide hands on services to clients.
- Case management – Help clients maneuver system while teaching them the skills needed to work through it on their own.
- Client advocacy/legal services – Legal services.
- Complementary (alternative) therapies
- Day or respite care (including child care) – Volunteers who provide social, emotional and physical care.
- Dental care – Provide comprehensive dental care.
- Direct emergency financial assistance – Need for funds (up to $500) within 24 to 72 hours, usually for housing and utilities.
- Drug reimbursement program – Provide drug reimbursement for patients otherwise ineligible for medications through other programs.
- Food bank/home delivered meals/nutritional supplements – Provides food and sometimes food delivery including personal hygiene products and paper products.
- Health education/risk reduction – Provides information about the HIV virus and skill building to keep oneself as healthy as possible.
- Health insurance (continuation)
- Home health care – In home skilled nursing care.
- Hospice Care – Medical, psychosocial support, bereavement services, and spiritual guidance.
- Housing assistance/housing related services – Assist clients in finding both permanent and temporary housing or assist in finding rent and housing subsidies.
- Inpatient personnel costs
- Mental health therapy/counseling – Individual and group therapy including bereavement counseling.
- Nutritional services
- Outreach – Efforts to stop the spread of HIV.
- Referral/hotline
- Rehabilitation care
- Substance abuse treatment/counseling – Provides licensed substance abuse treatment to those not eligible through other reimbursement sources.
- Translation/interpretation services
- Transportation – Provide transportation to those affected and infected with HIV through employee or contract drivers.

For the most current and up-to-date inventory of HIV prevention and care services, please see the Ryan White Title I publication of HIV resources commonly known as the “Blue Book”. (The Blue Book can be viewed online at www.rwpc.org or ordered by calling 713-572-3724.)

The following tables describe and list HIV service expenditures for Calendar Year 1998 in the Houston area. While information was requested from all agencies listed in the Blue Book, the revenue listed in this section comes from self-reported information provided by the 45 agencies and providers who responded to our request for information. However, the agencies that did respond make up the bulk of Ryan White funded agencies. This section does include information on funding sources other than those provided by the Ryan White CARE Act, but it does not include information concerning HIV services provided by private physicians, group practices, PPOs, HMOs, or private hospitals.

The reported figures from the 1999 Comprehensive Needs Assessment suggest that those agencies operating within the Houston area that are currently providing the services listed above are now receiving over $32 million. Those agencies operating within the Houston EMA and those that are receiving Ryan White Funds report receiving about $29 million from various sources, including Ryan White, TDH, HOPWA, Federal grants and private funding sources.

The following tables breakdown funding by agency, funding source and specific amount.

- **Table 6.1** lists the various funding sources by total amount for each reported agency.
- **Table 6.2** breaks down and explains what is meant by the term "other" in the funding sources.
- **Figure 6.1** breaks down total funding for treatment and care by total percentage.
- **Table 6.3** lists the Title I FY '99 Funding in the Context of Other Public Funding.
- **Table 6.4** lists the various funding sources for several agencies that run prevention efforts.

Table 6.1: Reported Care and Treatment funding for FY 98

Sources of funding are found by reading the table from left to right. Funds are ranked by total amount.

AGENCY	# of Programs	Other[1]	RW I[2]	Foundation	RW II	TDH	Indiv. Donations	HOPWA	TCADA	RW III	RW IV	Corporate	HCCG	Endow.	TOTAL BUDGET[3]
TOTAL	**75**	**$11,583,790**	**$11,826,620**	**$1,459,359**	**$1,382,886**	**$1,218,200**	**$1,003,022**	**$858,811**	**$634,383**	**$504,082**	**$150,385**	**$143,422**	**$94,250**	**$55,095**	**$29,914,304**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**	**0%**	**0%**	**0%**	**110%**
Harris County Hospital District (HCHD)	6	$5,400,314	$4,031,662	$0	$0	$0	$0	$0	$0	$490,002	$0	$0	$0	$0	$9,921,978
	8%	54%	41%	0%	0%	0%	0%	0%	0%	5%	0%	0%	0%	0%	110%
Bering Omega Community Services	5	$836,618	$507,145	$1,037,112	$149,957	$191,856	$307,313	$0	$0	$14,080	$0	$0	$0	$43,095	$3,087,166
	7%	27%	16%	34%	5%	6%	11%	0%	0%	0%	0%	0%	0%	1%	110%
AIDS Foundation Houston, Inc.	11	$338,820	$142,176	$17,204	$11,191	$204,951	$562,563	$180,834	$0	$0	$24,372	$5,422	$0	$0	$1,487,533
	15%	23%	11%	1%	1%	14%	38%	12%	0%	0%	2%	0%	0%	0%	110%
Texas Children's Hospital		$1,826,239	$0	$0	$0	$0	$0	$0	$0	$0	$81,032	$0	$0	$0	$1,907,271
		96%	0%	0%	0%	0%	0%	0%	0%	0%	4%	0%	0%	0%	110%
Montrose Clinic, Inc.	5	$750,000	$153,300	$185,000	$21,000	$87,000	$40,000	$0	$0	$0	$0	$135,000	$42,000	$0	$1,413,300
	7%	53%	11%	13%	1%	6%	3%	0%	0%	0%	0%	11%	3%	0%	110%
The Assistance Fund, Inc.	2	$110,000	$495,612	$0	$757,956	$0	$0	$0	$0	$0	$0	$0	$0	$0	$1,353,568
	3%	7%	37%	0%	56%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Montrose Counseling Center, Inc.	4	$37,236	$271,616	$18,270	$9,788	$28,935	$0	$0	$634,382	$0	$0	$0	$0	$0	$1,000,227
	5%	4%	27%	2%	1%	3%	0%	0%	63%	0%	0%	0%	0%	0%	110%
People With AIDS Coalition - Houston, Inc.	5	$86,020	$516,940	$0	$66,704	$355,861	$0	$22,186	$0	$0	$0	$0	$0	$0	$1,047,711
	7%	8%	49%	0%	6%	34%	0%	2%	0%	0%	0%	0%	0%	0%	110%
Family Service Center	3	$383,584	$513,850	$0	$40,112	$0	$0	$0	$0	$0	$0	$0	$0	$0	$937,546
	4%	41%	55%	0%	4%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Amigos Volunteers in Education and Services	4	$0	$196,230	$110,000	$30,000	$0	$30,000	$90,000	$0	$0	$0	$0	$50,000	$0	$496,230
	5%	0%	40%	20%	6%	0%	6%	18%	0%	0%	0%	0%	11%	0%	110%
Donald R. Watkins Memorial Found	1	$0	$803,387	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$803,387
	1%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Houston Area Community Services, Inc.	2	$0	$580,726	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$580,726
	3%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
University of Texas at Houston Health Science Center/ Dept. of Pediatrics	1	$311,735	$291,222	$26,171	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$628,128
	1%	49%	46%	4%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Diocesan AIDS Ministry, A Program of Associated Catholic Churches	4	$466,802	$0	$34,700	$0	$0	$12,000	$0	$0	$0	$0	$0	$0	$12,000	$525,502
	5%	89%	0%	7%	0%	0%	2%	0%	0%	0%	0%	0%	0%	2%	110%

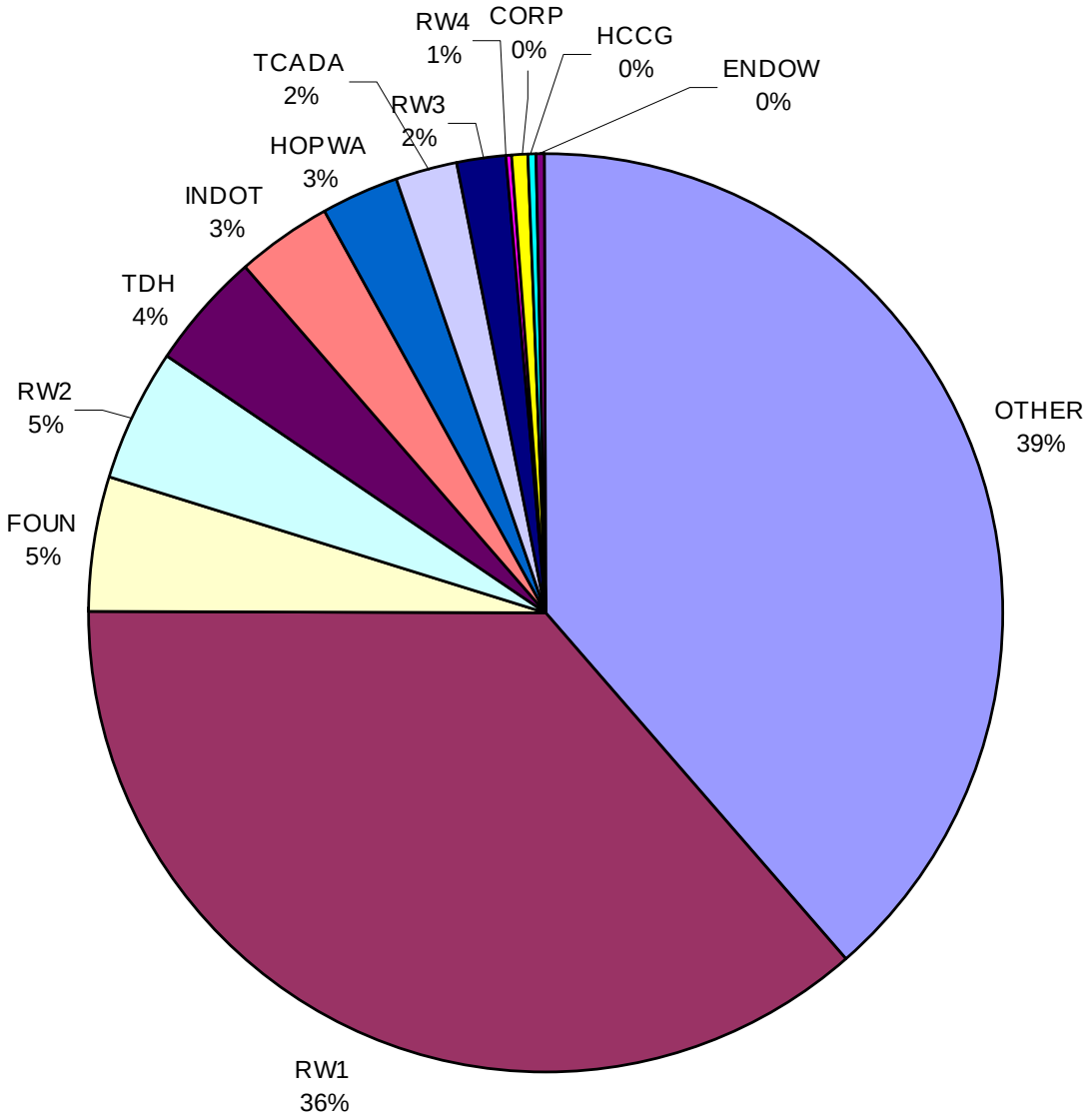
AGENCY	# of Programs	Other[1]	RW I[2]	Foundation	RW II	TDH	Indiv. Donations	HOPWA	TCADA	RW III	RW IV	Corporate	HCCG	Endow.	TOTAL BUDGET[3]
TOTAL	**75**	**$11,583,790**	**$11,826,620**	**$1,459,359**	**$1,382,886**	**$1,218,200**	**$1,003,022**	**$858,811**	**$634,383**	**$504,082**	**$150,385**	**$143,422**	**$94,250**	**$55,095**	**$29,914,304**
		39%	**36%**	**5%**	**5%**	**4%**	**3%**	**3%**	**2%**	**2%**	**1%**	**0%**	**0%**	**0%**	**110%**
Visiting Nurse Assoc. of Houston, Inc.	1	$0	$369,044	$0	$0	$91,372	$0	$0	$0	$0	$0	$0	$0	$0	$460,416
	1%	0%	80%	0%	0%	20%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Houston Challenge Foundation	1	$72,336	$82,302	$0	$72,243	$116,500	$0	$0	$0	$0	$0	$0	$0	$0	$333,381
	1%	22%	25%	0%	22%	32%	0%	0%	0%	0%	0%	0%	0%	0%	110%
The Life Center Inc.		$0	$473,405	$0	$26,765	$0	$0	$0	$0	$0	$0	$0	$0	$0	$500,170
		0%	95%	0%	5%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Brentwood Comm. Foundation	2	$0	$82,303	$0	$0	$0	$0	$211,352	$0	$0	$0	$0	$0	$0	$292,655
	3%	0%	28%	0%	0%	0%	0%	72%	0%	0%	0%	0%	0%	0%	110%
Kids in Need of Drug Evaluation & Re-Treatment Clinic	1	$0	$283,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$283,000
	1%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Foundation for Interfaith Research & Ministry	1	$71,360	$163,882	$0	$0	$43,577	$0	$0	$0	$0	$0	$0	$0	$0	$278,819
	1%	25%	59%	0%	0%	16%	0%	0%	0%	0%	0%	0%	0%	0%	110%
UT Health Science Center for Houston Recovery Campus	1	$0	$0	$0	$0	$0	$0	$275,142	$0	$0	$0	$0	$0	$0	$275,142
	1%	0%	0%	0%	0%	0%	0%	110%	0%	0%	0%	0%	0%	0%	110%
Fort Bend Family Health Center, Inc.	1	$60,000	$0	$0	$160,136	$0	$0	$0	$0	$0	$0	$0	$0	$0	$220,136
	1%	27%	0%	0%	73%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Memorial Hermann Home Health	1	$0	$179,307	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$179,307
	1%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Steven's House	1	$0	$0	$0	$17,860	$0	$50,000	$80,294	$0	$0	$0	$0	$0	$0	$148,154
	1%	0%	0%	0%	12%	0%	34%	54%	0%	0%	0%	0%	0%	0%	110%
Southeast Texas Legal Clinic	1	$7,118	$81,470	$20,878	$19,172	$33,146	$360	$0	$0	$0	$0	$0	$0	$0	$162,134
	1%	4%	50%	13%	12%	20%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Houston Volunteer Lawyers Program	1	$0	$110,000	$17,633	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$117,633
	1%	0%	85%	15%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
UTMB Family Medicine – Conroe	1	$0	$90,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$90,000
	1%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
NAACP Houston Branch	4	$0	$272,774	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$272,774
	5%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Nightingale Adult Day Center	1	$0	$0	$0	$0	$75,000	$0	$0	$0	$0	$0	$0	$0	$0	$75,000
	1%	0%	0%	0%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Northwoods AIDS Coalition, Inc.	1	$0	$68,529	$0	$0	$0	$0	$0	$0	$0	$0	$3,000	$0	$0	$71,529
	1%	0%	96%	0%	0%	0%	0%	0%	0%	0%	0%	4%	0%	0%	110%
Covenant House Texas	1	$0	$0	$0	$0	$0	$0	$0	$0	$0	$44,980	$0	$0	$0	$44,980
	1%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%	0%	0%	0%	110%
Riverside General Hospital	1	$0	$75,000	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$75,000
	1%	0%	110%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	110%
Art League of Houston	1	$0	$0	$2,400	$0	$0	$785	$0	$0	$0	$0	$0	$2,250	$0	$5,435
	1%	0%	0%	44%	0%	0%	14%	0%	0%	0%	0%	0%	41%	0%	110%

1. Funded amounts have been revised by the Administrative agent.
2. Total budget amounts reflect the figures reported by providers, which may not represent the total of all funding amounts shown in the table.

Table 6.2: Other Funding Sources (includes FEMA, HUD, TDHESS, client fees, TDH/CDC, local fundraisers and others)

Agency	Other Funding Source	Amount	Other Funding Source (2)	Amount	Total
AIDS Foundation Houston, Inc.	FEMA	$44,350	HUD	$294,470	**$338,820**
The Assistance Fund, Inc.	Fundraising	$110,000			**$110,000**
Bering Omega Community Services	Special Events	$84,842	Interest misc.	$46,120	**$130,962**
Bering Omega Community Services	Ind. DC Renov.	$685,577	Other Gov Grants	$20,079	**$705,656**
Family Service Center	UWTGC	$383,584			**$383,584**
Fort Bend Family Health Center, Inc.	THD EI	$60,000			**$60,000**
Foundation for Interfaith Research & Ministry	Contributions	$71,360			**$71,360**
Houston Challenge Foundation	Foun., Ind Cont, Corp., Endow	$72,336			**$72,336**
Harris County Hospital District (HCHD)	Thomas St. - HCHD	$5,400,314			**$5,400,314**
Montrose Clinic, Inc.	Fees	$50,000	Research Studies	$700,000	**$750,000**
Montrose Counseling Center, Inc.	Client Fees	$37,236			**$37,236**
People With AIDS Coalition - Houston, Inc.	TDHSS	$36,020	HCHDA	$50,000	**$86,020**
Southeast Texas Legal Clinic	Clients	$5,344	Fundraising	$1,764	**$7,118**
Texas Children's Hospital	Federal Grants/contracts	$1,826,239			**$1,826,239**
University of Texas - Houston Health Science Center/ Dept. of Pediatrics	TDH/CDC	$60,735	University/State	$250,000	**$311,735**
Diocesan AIDS Ministry, A Program of Associated Catholic Churches	Events, CIK	$297,802	Diocesan	$169,000	**$466,802**
TOTAL		**$9,215,739**		**$1,531,433**	**$11,747,172**

Figure 6.1: Funding Sources for Treatment and Care



Dollar Equivalents for Percentages	
Other	$11,583,790
RW I	$11,826,620
Foundation	$ 1,459,359
RW II	$ 1,382,886
TDH	$ 1,218,200
Indiv. Donations	$ 1,003,022
HOPWA	$ 858,811
TCADA	$ 934,383
RW III	$ 504,082
RW IV	$ 150,385
Corporate	$ 143,422
HCCG	$ 94,250
Endow.	$ 55,095
TOTAL	**$ 31.214305**

TABLE 6.3: FY 1999 Title I Funding In The Context Of Other HIV Service Funding (as reported by HIV Services)

Table 6.3 reports on the availability of public funding for HIV-related care services within the EMA from Federal, State and local sources for Fiscal Year 1999 using the five broad service categories as listed below. The row headings in column 1 of Table 6.3 identify the categories of funding available to the EMA which are to be reported as: (1) an aggregate amount for each service category; and (2) as a proportion of the amount of Ryan White Title I, Federal, State, and local funding available for a service category.

Home- and Community-Based Support Services - This service category includes funds available to serve persons/families with HIV/AIDS, by funding source, to provide:

- adoption/foster care
- buddy/companion programs
- case management
- client advocacy
- counseling (other)
- day/respite care (for children or adults)
- outreach
- education/risk reduction
- food services (home delivered meals, food banks, nutritional supplements)
- housing assistance/housing related services
- transportation
- direct emergency financial assistance
- other support services

Ambulatory/Outpatient Medical Care - This service category includes funds available to serve persons/families with HIV/AIDS to provide the following services:

- ambulatory/outpatient medical care
- medications

State AIDS Drug Assistance Program - This service category includes funds available to support the State ADAP program. Included in the first column is the amount of the EMA's Ryan White Title I funding that supports the State ADAP program. Other funding sources on the table would include only the amount of funding supporting people with HIV/AIDS within the Houston EMA.

Other Outpatient/Community-Based Health Care Services - This service category includes funds available to serve persons/families with HIV/AIDS to provide:

- dental care
- home health care
- mental health therapy/counseling
- rehabilitation
- substance abuse treatment/counseling
- other outpatient/community-based health care services not included in the above service categories

Inpatient Care Services - This service category includes funds available to serve persons/families with HIV/AIDS to provide:

- Inpatient personnel costs that prevent unnecessary hospitalizations and/or that expedite discharge as medically appropriate, as specified under Title I of the CARE Act
- Other inpatient medical care services (not fundable with Ryan White funds)

Grantee Administrative Costs, Planning Council Support, and Program Support – This section does not list direct service providers' administrative costs, rather they are included in the allocation to the specific services.

Ryan White Title I Funds - Column 1, reflects FY 1999 formula and supplemental funds allocated to each broad service category. Amount does not reflect any FY '98 funds which were carried over into FY 1999.

Other Federal Funds - Column 3 indicates the total amount of funds available for each broad service category from the following Federal sources: Ryan White Titles II, III, IV, and Special Projects of National Significance (SPNS); HRSA-funded pediatric/family demonstration projects; HOPWA; locally-allocated Community Development Block Grant funding (CDBG); National Institutes of Health (NIH) AIDS Clinical Trials Group (ACTG) and Community Projects for Clinical Research in AIDS (CPCRA); Substance Abuse and Mental Health Services Administration (SAMHSA) HIV funds; and other identifiable Federal funding.

State Funds - Column 5 indicates the aggregate amount of State-appropriated funds allocated to each of the four broad service categories listed in the table.

Local Funds - Column 7 indicates the total amount of local city and/or county general revenue spent on services to persons with HIV/AIDS, for each broad service category. To the extent possible, figures reported reflect all funding supporting persons with HIV/AIDS (e.g., local general assistance or "welfare" payments to this population).

Table 6.3: Title I FY '99 Funding in the Context of Other Public Funding

EMA: HOUSTON									
Services	**Amount and Percent of Public Funding by Source**								
	Ryan White Title I		**Other Federal Funds**		**State Funds**		**Local Funds**		**TOTAL FUNDS**
	(1) $	(2) %	(3) $	(4) %	(5) $	(6) %	(7) $	(8) %	
Home/Community-Based Support Services	4,333,971	9.55	9,583,401	21.13	1,159,900	2.56	0	0.00	**15,077,272**
Ambulatory/Outpatient Medical Care	6,786,051	14.96	837,198	1.85	55,761	.12	11,163,509	24.61	**18,842,519**
AIDS Drug Assistance Program	0	0.00	0	0.00	0	0.00	0	0.00	**0**
Other Outpatient/Community-based Health Care Services	2,418,992	5.33	2,414,199	5.32	290,883	.64	0	0.00	**5,124,074**
Inpatient Medical Care Services	0	0.00	0	0.00	0	0.00	3,623,332	7.99	**3,623,332**
Grantee Administrative Costs, Program Support, Service Activities, Planning Council Support	1,993,110	4.39	595,892	1.31	108,590	.24	0	0.00	**2,697,592**
TOTAL FUNDS	**15,532,124**	**34.23**	**13,430,690**	**29.61**	**1,615,134**	**3.56**	**14,786,841**	**32.60**	**45,364,789**

Table 6.4: Reported Prevention Funding for FY '98

AGENCY	TCADA	HCCG	TDH	Other	CDC	Corporate	Indiv. Contrib	Foundation	RW II	RW III	RW I	Endow.	TOTAL BUDGET
TOTAL	**$722,713**	**$601,180**	**$585,585**	**$419,921**	**$409,429**	**$272,786**	**$142,138**	**$131,351**	**$97,049**	**$78,939**	**$31,348**	**$25,000**	**$3,525,439**
	20%	**17%**	**17%**	**12%**	**12%**	**8%**	**4%**	**4%**	**3%**	**2%**	**1%**	**1%**	**110%**
Montrose Counseling Center, Inc.	$722,713 110%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$722,713** **110%**
Amigos Volunteers in Education and Services	$0 0%	$190,000 32%	$190,000 32%	$0 0%	$211,000 36%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$590,000** **110%**
Montrose Clinic, Inc.	$0 0%	$262,000 46%	$204,000 36%	$0 0%	$0 0%	$110,000 18%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$566,000** **110%**
Planned Parenthood of Houston & Southeast Texas	$0 0%	$0 0%	$0 0%	$278,000 110%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$278,000** **110%**
AIDS Foundation Houston, Inc.	$0 0%	$44,022 11%	$49,134 12%	$0 0%	$112,894 28%	$56,830 14%	$113,920 25%	$9,946 2%	$0 0%	$0 0%	$31,348 8%	$0 0%	**$408,094** **110%**
The Center for AIDS: Hope & Remembrance Project	$0 0%	$0 0%	$0 0%	$96,921 30%	$0 0%	$84,956 27%	$36,718 11%	$116,405 33%	$0 0%	$0 0%	$0 0%	$0 0%	**$320,000** **110%**
NAACP Houston Branch	$0 0%	$49,308 26%	$56,309 29%	$0 0%	$86,535 45%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$192,152** **110%**
Alternate Resources of Texas, Inc.	$0 0%	$0 0%	$86,142 47%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$97,049 53%	$0 0%	$0 0%	$0 0%	**$183,191** **110%**
Kids in Need of Drug Evaluation & Re-Treatment Clinic	$0 0%	$0 0%	$0 0%	$45,000 38%	$0 0%	$31,000 26%	$1,500 1%	$15,000 13%	$0 0%	$0 0%	$0 0%	$25,000 21%	**$117,500** **110%**
Harris County Hospital District (HCHD)	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$78,939 110%	$0 0%	$0 0%	**$78,939** **110%**
Young Women's Christian Association	$0 0%	$35,850 110%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$35,850** **110%**
Mendez Counseling	$0 0%	$20,000 110%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$20,000** **110%**
Riverside General Hospital[2]	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	$0 0%	**$13,000** **110%**

Chapter Seven: Barriers

Barriers

In the needs assessment process, several barriers to care were identified and documented. Of course, until the barriers are identified, little can be done in terms of lowering them and improving access to care.

The questionnaire asked participating PLWH/A to rate and discuss 32 barriers. They rated those barriers on a four-point rating scale that ranged from "big barrier" to "no barrier at all." These barriers were then grouped into three general types of barriers: 1) Individual Barriers – those that include the client's skills, knowledge, and physical and mental health; 2) Organizational Barriers – those the PLWH/A perceive to be related to provider treatment, confidentiality, skill and sensitivity; and 3) Structural – those related to rules and regulations of the overall system of HIV/AIDS care.

The data gleaned from the questionnaires was then examined by using a statistical technique called factor analysis (a copy of the matrix used can be located in the Needs Assessment Document shelved in the Ryan White Council Office of Support). This technique revealed how the PLWH/A would classify each barrier – whether they perceived the barrier to be individual, organizational, or structural.

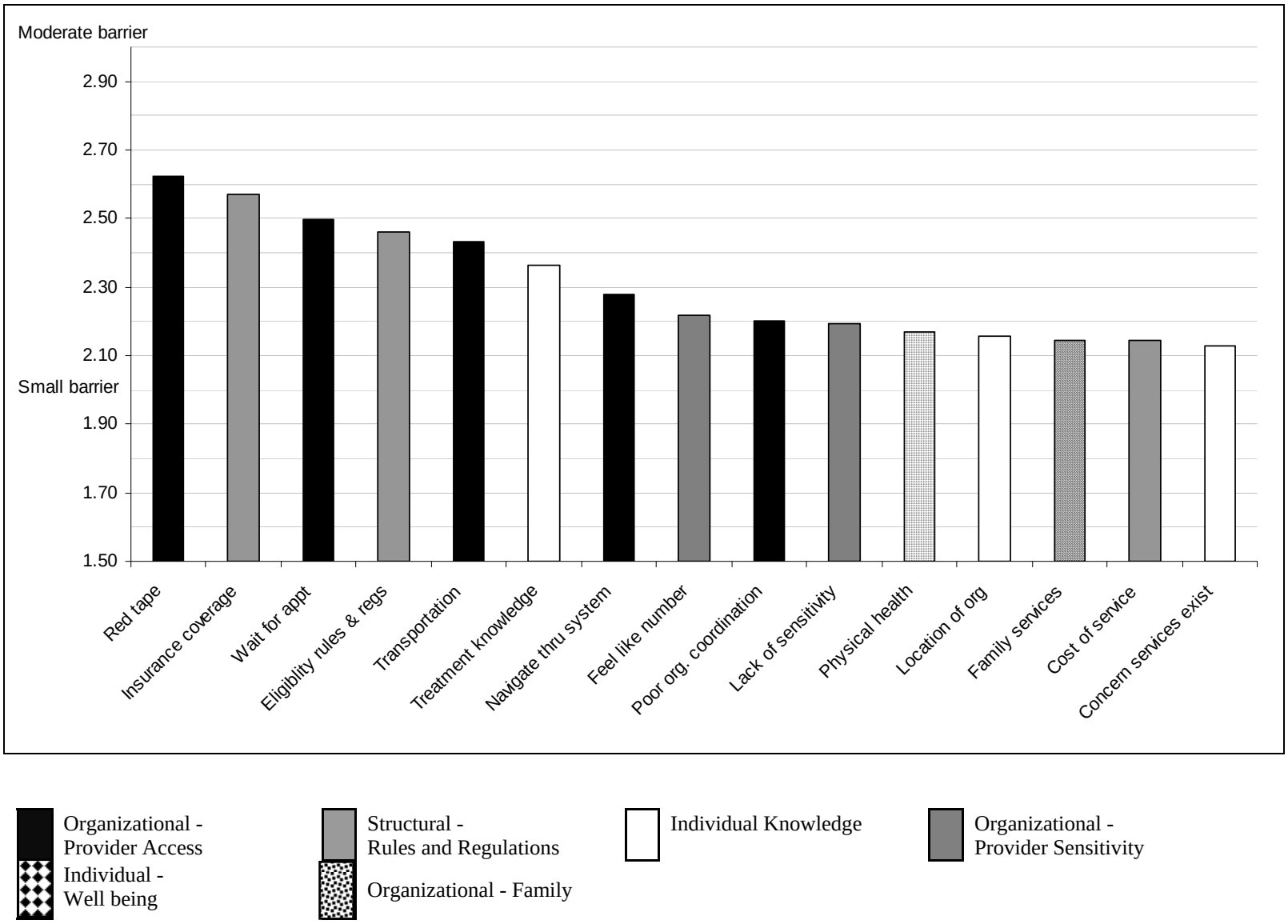
The three categories were then broken down further. Under individual barriers were issues such as a client's knowledge base; organizational barriers were issues such as provider sensitivity; and structural barriers were issues such as cost and insurance. The top five barriers listed by clients were either organizational or structural.

Figure 7.1: Types of Barriers

Individual		**Structural**
Knowledge	***Individual well being***	***Rules and Regulations***
Treatment knowledge	State of mind	Insurance coverage
Knowing services needed	Denial	Cost of service
Location of organizations	Physical health	Rules and regulations
Concern services do not exist		
Organizational		
Provider Sensitivity	***Access***	***Family***
Communication with providers	Poor organizational coordination	Single family primary care location
Lack of sensitivity	Wait for appt	Child care
Sensitivity to beliefs	Red tape	Family services
Feel like number	Navigate thru system	
Discrimination	Transportation	
	Referrals	
Provider skills	***Confidentiality***	***Treatment***
Speak client's language	Confidentiality	No options re-treatment
Provider expertise	Reported to authorities	Understand instructions
Quality of service		Adherence

The top five barriers listed by clients were either organizational or structural. Furthermore, most of the top 15 barriers listed by clients related to their frustrated abilities to obtain services.

Figure 7.2: Individual Barrier Scores - Highest 15 for the Total Population



Focus Group Comments

(Cited from Chapter 10 of the Ryan White Comprehensive Needs Assessment document)

Organizational Access Barriers

Red Tape – highest barrier listed overall

"Paperwork is too hard to fill out, too long…and they start using big words and different words, so I have to use a little paper dictionary" (African-American female).

"They make you reapply every month…I have to get my ID or bus pass before I see my doctor or psychiatrist. I like my doctor and psychiatrist, but it's a pain in the neck, the gold card thing" (Anglo female).

"My . . . recommendation would be to have some type of centralized system" (male unknown ethnicity).

"The biggest barrier for me is going through the red tape. The bureaucracy!" (African-American male).

Waiting – third highest barrier listed overall

Crises care, dental care, transportation and housing were some of the services most noted for long wait times.

"I'm on a waiting list. You call the waiting list and they're like call back [in six months]. . They're like you're on the waiting list and you're like number 1000 and something. You're waiting forever" (African-American female).

"It's a long wait [for services]. That's the worst thing about it...You really do have to practice your patience" (Anglo male).

Navigating the System – third highest organization access barrier

"Sometimes when you call the agencies in the Blue Book, they tell you to have your case manager call them. I keep running into these brick walls" (male unknown ethnicity).

"Most of the referrals I've got have been through other people who have HIV that are either on the street or have been in a program. They [service providers] know about their little job function, but that's about it" (male ethnicity unknown).

"My biggest need is expertise in plugging me into things, like a better case manager" (African-American male).

Coordinating Care and Referrals

"If would help if their were a standardized form that they [service providers] all accepted" (gay male).

"Confidentiality about sharing information is not really a concern. I don't care who knows" (female unknown ethnicity).

Structural Barriers

These barriers are outside the control of the provider and require changes in rules and regulations. They include: 1) Not having enough insurance coverage and 2) Not being eligible to obtain services because of rules and regulation.

Insurance

"My major concern was my family and if I die ... how they gonna have for money. ... I don't know how to get it. I'm scared if I do go get a burial plot, I must just die that day. My kids, I really want to leave them something" (Rural female).

"Biggest barrier - insurance caps, pharmacy caps, HMO's through Medicare. The money is going to have to be shoved out that I don't have for the drugs that the TDH won't cover. I really need those drugs" (Anglo male).

"I have Medicare they allow 3 prescriptions a month. My pills are about 14 pills a day and each of them are about $110 a month apiece and they only pay for 3. I was told the only way I could get the unlimited [coverage] is if I signed over my benefits" (African-American female).

Rules and Regulations Regarding Eligibility Focus Group Comments

"At one point, I couldn't get my meds; they put my Social Security on hold" (African-American female).

"The agencies don't make the rules clear enough. There is no general information that we can all access" (Anglo male).

"I applied there [a ASO community foundation] 2 or 3 times and been denied…I had been clean and sober for at least 8 months. The bad part is that they have 3 brand new group homes and each one is supposed to hold 6 people at any given time, the most they had there was 6 people... The facility is there but they're not putting people in it, so where's the money going? Independent living is virtually impossible because of the income barrier" (African-American MSM).

"The obstacles that are put in front of us are almost impossible to overcome… If you lie, lie your ass off; you do better" (Male).

Individual Barriers

Knowledge of Treatment Information

"I think I need more education on the medication because I'm getting a lot of side effects from medications. I was on AZT and now I'm on a cocktail and it keeps me nauseated, fatigued, diarrhea" (Anglo male).

"I'm starting over again. I need more education on how to take the drugs. That has stopped me from taking the drugs at one time" (Hispanic male).

Concern and that Services Do Not Exist and Knowledge of Services

"There seems to be no central base of information where I could find out where to go. You just kind of learn it as you go along. Sometimes it takes years" (Anglo male).

"I am gay and it is hard to find groups that is for lesbians and HIV positive substance abuse... I'm just not that cool when it's dealing with different issues. They have HIV groups I don't care for, but they need more programs for women's dealing with substance abuse" (African-American female).

"Services are not volunteered. You have to seek them out then you have to go through 12 people to find them" (Male).

Location of Provider Focus Group Comments

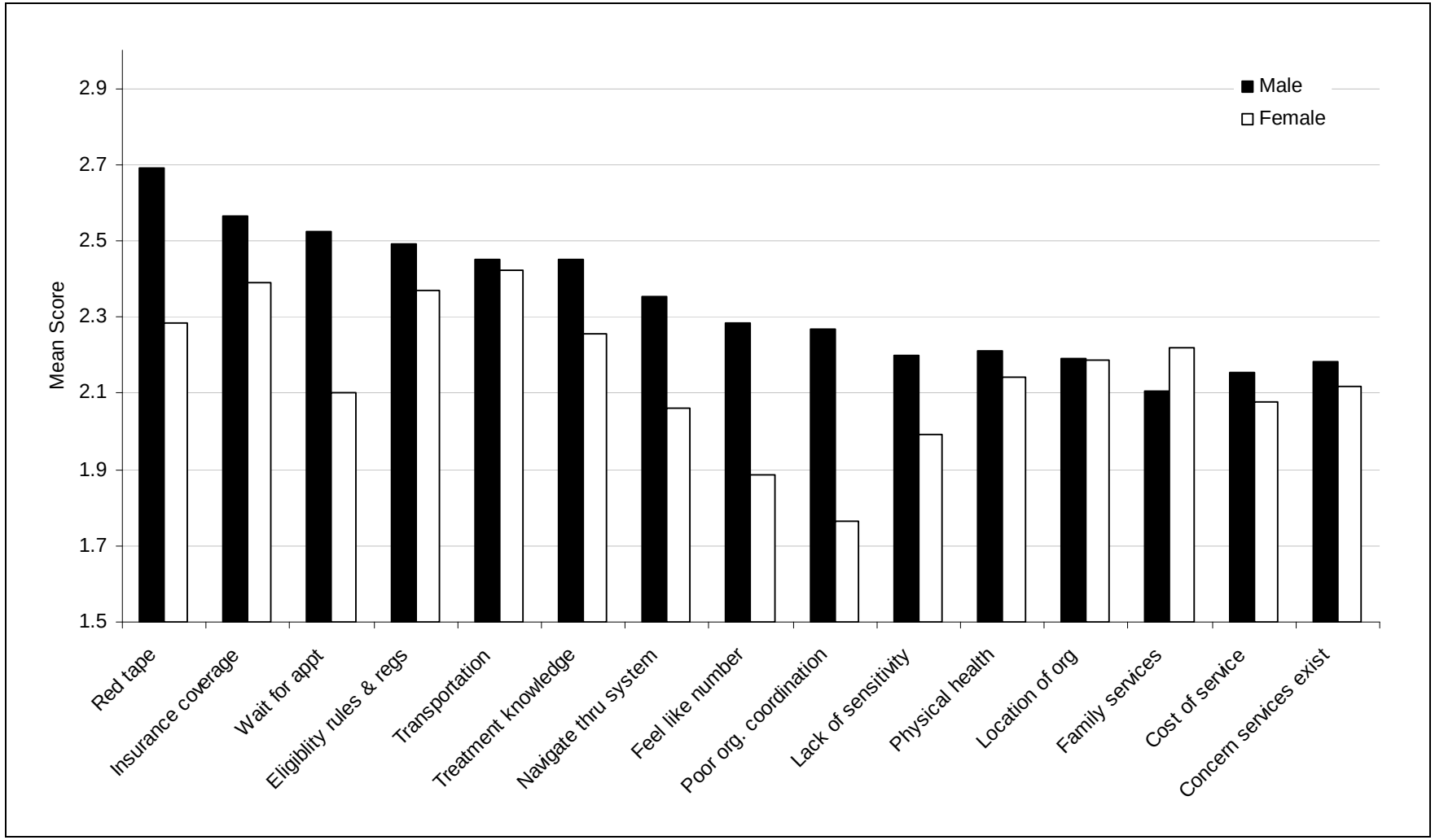
"They [rural PLWH/A] are royally getting screwed now" (Anglo rural male).

"Where I live, Pasadena, it's tough. I can't even get medical treatment for myself, much less for my son. I have to come into town to get treatment" (Anglo female).

Physical Health Focus Group Comments

"They are really being inconsiderate with this HIV stuff for the people, they say we don't need it. I'm mentally and physically sick from this disease... It's not that [I am] living longer healthy, [I'm] living longer sick" (female).

Figure 7.3: Barrier Scores - Highest 15 for Males and Females



Service Providers' Ideas About Barriers as Compared to Clients' Ideas

Interestingly, when service providers were surveyed, they attributed the individual client to be the greatest barrier to care rather than organizational or structural problems.

Clients listed "Red Tape" as the overall greatest barrier to care while providers listed the clients' lack of knowledge of the treatments available as the greatest barrier to care. Their survey statements include such opinions as the system needs to provide "more extensive patient medication education", and "most of the barriers are due to the clients' special needs" (Needs Assessment 10-30).

Figure 7.4: Top Ten Barriers - Providers vs. PLWH/A

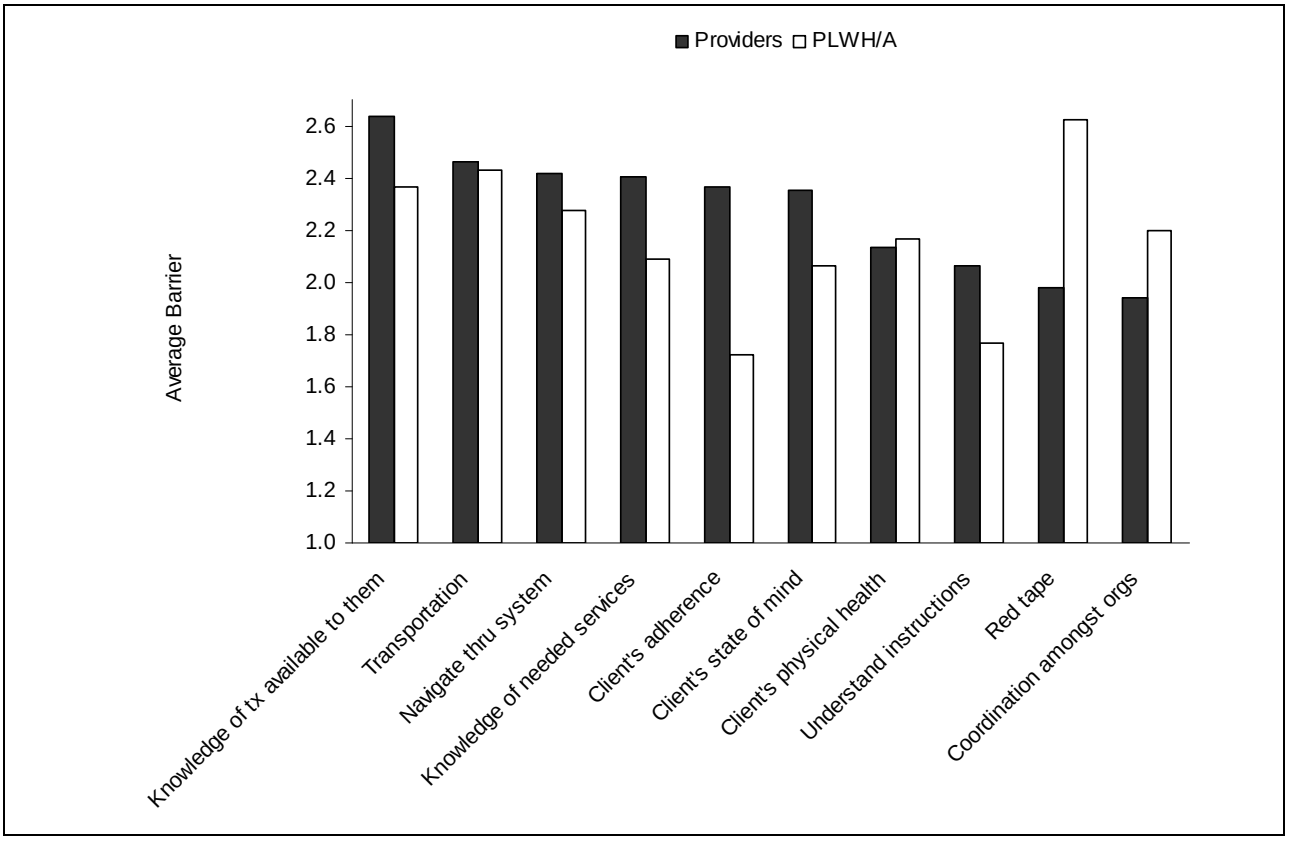


Table 7.1: Provider & PLWH/A Ranking of Barriers

Barrier	Provider Rank	PLWH/A Rank
Knowledge of Tx available to them	1	6
Transportation	2	5
Navigate through system	3	7
Knowledge of needed services	4	17
Client's adherence	5	32
Client's state of mind	6	20
Client's physical health	7	11
Understand instructions	8	29
Red tape	9	1
Coordination among organizations	10	9

Geographic Constraints

Because Houston has a very poor mass transit system and because the Houston area spreads out over several hundred square miles of land, there are many geographic constraints to care. Transportation is the second highest perceived barrier to care ranked by service providers and it is the third most important need for PLWH/A. Moreover, several clients discussed the location of medical services as a barrier to accessing services. Interestingly, according to the statistics, rural participants were no more likely to mention location as a barrier than urban participants were. However, the rural participants often made a special point of mentioning provider location as a troubling aspect of the care and prevention system. Some people living to the north of Houston have to travel as far away as Galveston for some aspects of care.

Coordinating travel for those clients with children is even more difficult, especially from those outlying areas, where there is no public transportation at all. However, while the majority of clients said that they wanted services to be closer, some said they enjoyed the fact that services were outside their immediate area because that distance ensured the confidentiality of services.

Clients who live within or near Beltway 8, a 1,200 square mile highway loop around Houston, can access the Houston Metro bus system. Beltway 8 is almost entirely within Harris County. A daily, unlimited 24-hour bus pass is $2.00. There are fourteen Metro Transit Centers scattered around Houston. These Transit Centers are sheltered. If a client can get to one, bus routes will take them to any of the other Transit Centers. Each Transit Center has a number of other routes for which it serves as a hub. Clients who are debilitated, and call ahead of time, can utilize Metro-lift buses that are equipped for wheelchair access. Urban clients can also access private contractors for transportation services.

Eligible residents of Harris County can access the Harris County Hospital District (HCHD) HIV primary care services, either at the Northwest Health Center or at the Thomas Street Clinic. LBJ Hospital has a specialty clinic for women with HIV. Both of these clinics and the hospital are in the northern part of Houston. Complex or acute care clients generally receive services at Ben Taub General Hospital in the Texas Medical Center in west-central Houston.

Primary care for clients with HIV is also available at community-based clinics. These include the Donald R. Watkins Memorial Foundation, Amigos Volunteers in Education and Services (AVES), and the Montrose Clinic. All these are located within four miles of each other in the west-central part of Houston.

Clients who live in rural areas of the HSDA (outside of Beltway 8) can access transportation services through a private contractor. Rural clients are expected to give the service provider an advance notice of 24 to 48 hours.

Railway service is non-existent in the HSDA.

The distances clients must travel to access primary HIV care in the HSDA can be considerable. For example, it is about 30 miles from Austin County to the clinic in Fort Bend County; 55 miles to the same clinic from Colorado County; 28 miles from Wharton County; and 42 miles from Waller County.

The rural transportation provider reports that fear that their HIV positive status will be revealed in their community remains a major barrier for rural clients, and this barrier has diminished slightly over time. Many clients who could access local service providers (every county has some form of HIV primary care for indigent residents, either clinics or private physicians) prefer to travel to the University of

Texas Medical Branch (UTMB) in Galveston, where their neighbors will not know that they are accessing HIV related services, and where they can expect state-of-the-art treatment.

Clients residing in HSDA counties other than Harris and for whom sophisticated medical procedures are indicated are referred to UTMB at Galveston. The population centers in the eastern HSDA counties (Liberty and Chambers), are 77 miles and 38 miles respectively, from UTMB. From Walker County in the northern part of the HSDA, it is about 121 miles to UTMB. From Montgomery County, it is about 92 miles to UTMB. From Colorado County, in the western part of the HSDA, it is about 120 miles to UTMB in Galveston. Because UTMB cares for clients from counties both inside and outside the HSDA and from the State prison system, an unknown number of residents with HIV of the HSDA receive care at UTMB in Galveston. The Texas Department of Health estimates that approximately 850 people with HIV receive routine care there.

The rural transportation provider reports that 90% of rural clients with HIV use the service to go to UTMB in Galveston. Documentation required to utilize the transportation service includes proof of an HIV positive test result and some proof of residency, usually a utility bill.

Capacity Issues

The needs assessment document indicates that at this time most clients appear to be happy with the amount of services they are receiving. However, the needs assessment document was developed with answers coming from less than ten percent of the Houston area HIV community. When queried in public forums many of those people who were not part of the needs assessment process expressed both surprise and discontent with the idea that the Houston area is currently providing adequate services to its HIV community. Moreover, as PLWH/A live longer lives, the current capacity of the system will be quickly overrun with an ever-increasing client base.

Care Financing/Regulatory Issues

The Comprehensive Planning Committee determined that a confidential interview process would be the best method to collect information from key leaders and experts who might be hesitant to respond in a public forum. The Ryan White Planning Council's Office of Support contracted with SUMA Partners to carry out confidential, semi-structured interviews with key informants. Key leaders were defined as elected officials (City Council members, County Judges, State Representatives and County Commissioners) who could be expected to vote on or exercise authority over broad level decisions relating to HIV/AIDS. Experts were envisioned as administrators, planners, and community advocates who are more likely to be responsible for directing and/or implementing HIV/AIDS programs or decisions. A total of 25 key leaders and 44 experts volunteered to be interviewed. The research was designed to collect data on three major topics related to the provision of HIV/AIDS care and prevention: 1) care financing/regulatory issues, 2) jurisdictional/political factors, and 3) public health infrastructure constraints

If you would like a copy of the entire report titled *Perceptions and Evaluation of HIV/AIDS Care and Prevention in Harris and Surrounding Counties*, please refer to Section VI.

Funding for Prevention Services

When asked about the adequacy of funding for HIV/AIDS prevention, key leaders and experts who felt they had enough expertise about this topic overwhelmingly felt that HIV prevention efforts *are not* adequately funded (64%). When responses were separated between key leaders and experts, key leaders responded in equal numbers between whether they felt funding for prevention is adequate

(14%) or inadequate (14%). Significant was the large percentage (72%) of key leaders that deferred (as compared to 27% deferrals among experts), indicating that this question was outside their expertise.

Funding for Care Services

When asked about the adequacy of funding for HIV/AIDS care, key leaders and experts were more evenly split on whether funding for care services is adequate or not. Forty seven percent indicated that funding is adequate and 53% indicated that funding was not adequate. Responses were for the most part evenly split when the responses for key leaders and experts were separated. Of the key leaders responding, 50% indicated that funding was adequate and fifty percent indicated that funding was not adequate. Forty six percent of the experts indicated that funding for care was adequate and 54% indicated that funding for care was not adequate.

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

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

Regulatory Issues

Respondents were asked whether they found the regulations that apply to the various funding streams to be *helpful* or a *hindrance* in delivering needed services. Thirty eight percent of the total respondents indicated that the regulations were a hindrance. Eleven percent indicated that the regulations were helpful, 5% indicated that the regulations were both helpful and a hindrance and 46% of the respondents deferred and did not answer the question.

Among the key leaders interviewed, 18% responded that the regulations were a hindrance to delivering the needed services and 82% deferred. For the experts interviewed, 48% responded that the regulations were a hindrance and 18% responded that the regulations were helpful. Eight percent (8%) of the experts responded that the regulations were both helpful and a hindrance and 26% deferred.

Verbatim comments:

- *Regulations behind specific funding are a hindrance…they do not allow for emergencies.*
- *For the most part the regulations have a purpose, however some are antiquated. We need to update them and encompass the family.*
- *Title III grants are relatively easy to apply for, but Title I are a nightmare.*
-
- *For housing, regulations are a hindrance; for primary care, they (the regulations) can be very helpful.*
- *I find regulations between different funding sources conflicting -- that is a problem. HUD -- their regulations say one thing. HRSA for housing say another thing. We deal a lot with families and a lot of the regulations prevent us from using funds to help families.*

- *Regulations are not a hindrance. The problem is the lack of technical assistance from the national level or adequate technical assistance to bring us up to speed with the latest techniques in research on what works and doesn't work in AIDS prevention.*
- *I think it's a hindrance because when people are writing regulations, probably they are written around people who lobby the hardest. You have both proponents and opponents who look for strict rules and regulations.*
- *There are barriers for some organizations especially to smaller-based agencies to apply for funding for HIV care services.*
- *Both, they are both helpful and a hindrance. Helpful because they require accountability; they are a hindrance because they slow the delivery process of services.*

Jurisdictional and Political Factors

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

Verbatim comments:

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

Public Health Infrastructure

Most of the respondents referred to the public health system (medically indigent patients) in the generic sense, however, there were specific mentions of the Harris County Hospital District, CDC (as the ultimate public health system), and the Thomas Street Clinic. Respondents cited the following strengths of our public health system with respect to the delivery of HIV/AIDS care and prevention:

1. The overall capabilities of the system, including a valuable database
2. The inherent knowledge available within the system
3. The ability to track and document issues involved with the care and prevention of HIV/AIDS system

4. The ability to provide service to the indigent
5. The strong track record in the area of prevention

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

Verbatim comments:

- *On the whole, there is a lack of information.*
- *No outreach. People have to come to them.*
- *When funds are localized in the inner city and not spread around because then it might not reach the place where the greatest growth of HIV is occurring. An example of such is the aid not reaching the Hispanic population because they don't have Spanish-speaking counselors.*
- *The weaknesses are the ability to bring new clients into care- some of the paper work (eligibility as well as the new system the county has for co-pay).*
- *The weakness is the politics involved. We have a lot of competent and passionate people in this field, but I feel sometimes that their hands are tied.*
- *Lack of funding is the weakness. Funding is not available to reach the lower income minority population who tend to be more disenfranchised and don't take advantage of our services. Therefore, more resource is given to finding them.*
- *Not enough planning experts and not enough people trained academically in Public Health.*
- *It is too big. It gets caught up in itself trying to manage multiple funding streams. He thinks that they commission too much volunteer workers that don't have the proper training to be doing what they are doing. This usually results in special interest needs being addressed and not the main population of those in need. The Texas Department of Health has trouble making sure that all its needs are met through their councils and consortiums.*
- *They don't pay enough attention to the individual needs of people and try to find a one size fits all solution.*
- *Too early to tell. Ratio of HIV/AIDS seems to be rising among minorities. We need to look at that carefully. We need to explain to the public the importance of emphasizing prevention even though this disease is not the leading killer.*
- *Weaknesses include the lack coordination even between the City Health Department and County Health Department. This concerns even the HIV services they provide. The prevention and care services should be a seamless continuum of services that's coordinated. The City Health Department and County Health Department hardly even communicate with one another, let alone coordinated with one another. They duplicate services in some areas and then drop the ball in others.*

Prevention Barriers

During the survey process for the Needs Assessment, several questions were asked of the responding clients about their safer sex practices. The respondents reported several rather alarming ways in which they have attempted to have "safer" sex.

According to the Needs Assessment:

- Over 60% of PLWH/A reported that they were more likely to increase taking care in picking a partner. For IDUs and heterosexuals, the increase was greater than for condom use. African-American MSM and IDUs were more likely to report an increase in being more careful in choosing a partner than Anglo MSM or IDUs.

- Over 55% of the PLWH/A reported increasing washing before sex as a way to protect themselves from (re) infection and STDs. MSM were more likely to report an increase in washing than other risk groups.

Neither washing before sex nor choosing "safe" looking partners are effective methods for preventing HIV infection or STDs. Clearly a great deal of prevention work needs to be done.

It is obviously very important to get prevention messages out to those individuals who test positive for HIV. This sort of primary prevention effort can be stepped up in most every arena. Doctors, caseworkers, and every other HIV/AIDS caregiver needs to become educated as to the ways an individual who is HIV+ can have a satisfying sex life that is as safe as possible. Too often, this enormously important piece of information is left out of the care.

Section II

WHERE WE ARE GOING

Our Ideal Continuum of Care

Chapter Eight: Our Ideal Continuum of Care

In order to identify needs and gaps that must be addressed within our current system of HIV services, the Comprehensive Planning Committee had to first identify what the "ideal" continuum of HIV prevention and care would look like. This ideal could then be used as a measuring stick by which to evaluate the system. The ideal continuum of care is a term that encompasses the comprehensive range of services needed by individuals and families who are at-risk for and living with HIV infection in order to meet their health care and psychosocial services needs. It is a "wish list" set of services and mechanisms for linking these services that the community would like to offer without the constraint of only working with what resources are currently available. The continuum of care outlines an ideal system that would reduce fragmentation between prevention and care, as well as respond to changing individual and family needs in a holistic, coordinated, and timely manner.

The overall goal of this continuum is to provide a framework for care that will be used to inform and guide the planning bodies, providers, and consumers as they establish priorities and fund HIV/AIDS services. It will provide the structure that will enable any adjustments needed to meet continuing and changing needs.

Elements of the Continuum of Care

This continuum of care takes into account several factors. These are: 1) the mission and vision statements of the various planning bodies, 2) the goals and objectives of the planning bodies, 3) the services available in the delivery system, 4) the linkages necessary to ensure efficiency and effectiveness, and 5) the coordinating mechanisms that can be utilized to ensure effective linkages are established and maintained.

System Outcomes

The mission and vision statements note several common system goals that suggest which services should currently be available and which services should be considered in the Houston area continuum of care. These goals and objectives include:

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

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

1. Available to meet the needs of the PLWH/A and their caregivers
2. Accessible to all populations infected or affected by HIV/AIDS
3. Affordable to all populations infected or affected by HIV/AIDS
4. Appropriate for different cultural and socio-economic populations and care needs
5. Accountable to the funders and clients for providing contracted services at high quality

Client Outcomes

In addition to these system goals and objectives, system and client outcomes can be measured to determine its effectiveness. Several client outcomes can be inferred from the goals and objectives above. These address the needs of all of the consumers within the continuum of care. They include: 1) preventing persons from becoming HIV positive; 2) preventing persons from progressing from HIV to AIDS; 3) improving or maintaining health status of PLWA; 4) sustaining or improving the quality of life of PLWA; 5) providing a dignified death to those who are at the end-stage of AIDS; and 6) providing appropriate linkages between services.

The Houston area continuum of care will facilitate the provision of services in a seamless manner so that clients can move easily among the different levels of care. The Houston area has many service providers and in order to provide coordinated services it is important to show how these services can be linked. According to the HRSA guideline, linkages refer to the inter-entity structures.

A New Conceptualization of the Continuum of Care

The goal of the Houston area continuum of care is to show the linkages between a full range of client-centered, cost-effective services that unify the prevention and treatment of the HIV epidemic.

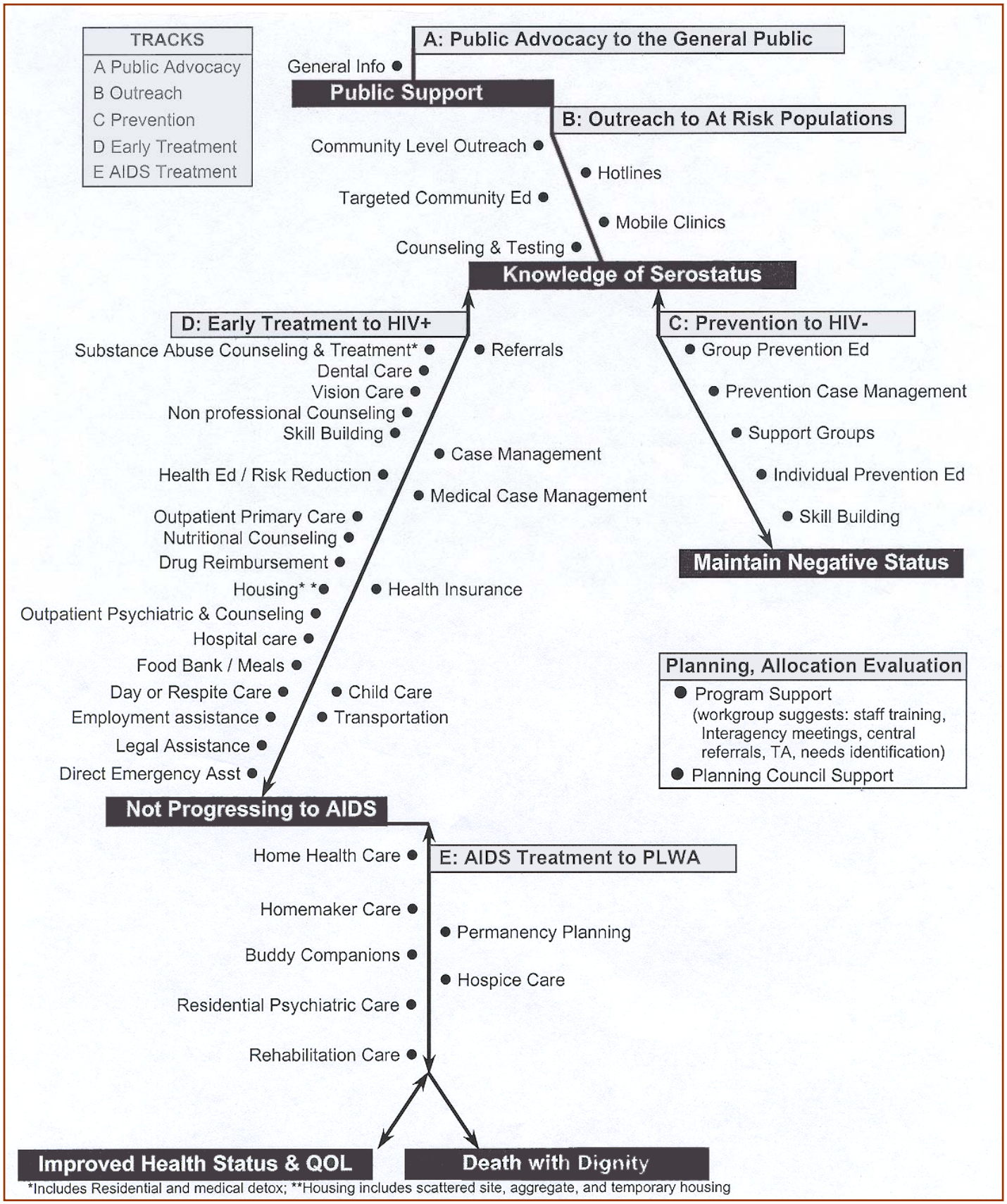
Several models that have a visual representation have been developed by other EMAs. However, none of them suggest outcomes for clients and none clearly delineate the different populations who use the system. Moreover, they all look relatively static and may be more or less difficult to modify, as client needs change along with changing treatment strategies and new advances in care. The Houston area continuum of care, however, has been conceived of as a rail system made up of six tracks that move clients through the system.

Table 8.1 Continuum of Care Tracks

TRACK	QUALIFICATION	START	DESTINATION
A. Public Advocacy	General public	No awareness of AIDS	Support for HIV/AIDS services
B. Outreach	High risk behaviors	No awareness of serostatus	Awareness of serostatus
C. Prevention	Knowledge of negative status	Aware of negative status	Maintaining negative status
D. Early Treatment	Early knowledge of HIV positive status	Awareness of infection	No progression to AIDS
E. AIDS Treatment	PLWA	AIDS diagnosis	Improved health status and quality of life or death with dignity

Figure 8.1, on the following page, shows what that system might look like for Houston. For the HIV positive lines, D and E, the "stations" on the right are those that provide access to the services on the left. Following the figure is a more specific description of the system.

Figure 8.2 Houston Area HIV/AIDS Continuum of Care



Note: ***This is not an eligibility chart - services that are listed as especially needed by people with AIDS does not mean that people with HIV (not AIDS) are not eligible. And conversely, services listed as especially needed by PLWH to help prevent progression to AIDS, does not mean that PWAs are not eligible for those services.***

To summarize the features of this system:

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

Working With the Continuum

The model of the continuum of care is meant to be a framework for decision-making as the Houston area HIV community works toward the following objectives:

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

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

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

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

System Goals and Client Outcomes

In addition to these mission and vision statements, the Comprehensive Planning Committee established three goals to direct their efforts. These goals also help to define the continuum of care in the Houston area. They are:

- Collaborate with and utilize information from all constituencies to plan and deliver high quality and cost effective care.
- Identify and provide services to unserved and underserved populations
- Promote the dissemination of information on HIV prevention, treatment, and resources

Section III

HOW WE WILL GET THERE

Goals, Objectives and Activities through Year 2005

Chapter Nine: Improving HIV Prevention & Care in the Houston Area

Comparing "Where We Are" in HIV prevention and care against our ideal continuum, or comprehensive system of prevention and care, helped identify the needs and gaps that must be addressed while continuing to support what is already in place and working effectively.

At the Federal level on the *prevention* side, the CDC recommends that in order to implement a comprehensive HIV prevention program, State, local, and territorial health departments that receive HIV Prevention Cooperative Agreement funds should assure that efforts in their jurisdictions include all of the following essential components:

1. HIV prevention **community planning**;
2. **Epidemiologic and behavioral HIV/AIDS surveillance**, as well as collection of other health and demographic data relevant to HIV risks, incidence, or prevalence;
3. **HIV prevention counseling, testing, referral, and partner counseling and referral services, with strong linkages** to medical care, treatment, and other needed services;
4. **Health education and risk reduction** (HE/RR) activities, including individual-, group-, and community-level interventions;
5. **Easy access to diagnosis and treatment** of other sexually transmitted diseases;
6. **School-based education efforts for youth**;
7. **Public information** programs;
8. **Quality assurance and training**;
9. **Laboratory support**;
10. HIV prevention **capacity-building activities**, including expansion of the public health infrastructure by contracting with non-governmental organizations, especially community-based organizations;
11. **Evaluation** of major program activities, interventions, and services; and
12. An HIV prevention **technical assistance** assessment and plan.

On the *care* side at the Federal level, HRSA has identified the following critical issues for the effective provision of care to individuals with HIV disease or AIDS and request that those concerned with HIV/AIDS care focus attention on them:

1. **Training and Experience and Their Impact on Quality of Care:** More than ever before, HIV disease requires expert care. But many clinicians do not deliver care that meets current standards because they lack essential experience and training in HIV/AIDS medicine. A response to training needs is a necessary component of improving health outcomes for people with HIV.

2. **Care in Underserved Communities:** Many HIV-positive individuals live in communities with few health care providers in general and even fewer HIV/AIDS clinicians. The lack of both general and specialized care jeopardizes the health of infected individuals. Greater capacity to provide quality care in minority communities is essential for eliminating the health disparities suffered by African-Americans and Hispanics. Locally, the Houston community has also identified PLWH/A living in "rural" areas as an underserved community in need of additional resources for care.

3. **Comprehensive Care:** The incidence of more than one health problem in individuals living with HIV is common. The presence of multiple diagnoses complicates the delivery of health care and increases costs. Of particular concern is that many individuals who have multiple

health problems, especially the poor, currently are not being treated for serious diagnoses like addiction, tuberculosis, and mental health disorders. Without comprehensive health care, the potential for effectively treating HIV is reduced significantly.

4. **HIV-Positive Individuals Not in Care:** Of the 650,000 to 900,000 individuals living with HIV disease in America, up to one-third do not realize they are HIV positive. Many others have tested positive for HIV but are not receiving care regularly. Still others may begin treatment only when they become symptomatic. Poverty, the stigma attached to HIV infection, and multiple health problems are all part of the problem. Lack of information also is a major factor.

5. **Quantifiable Outcomes Data:** A better system for measuring service outcomes is essential for allocating CARE Act resources. The HIV/AIDS Bureau is already responding, but there is much left to be done. Improved outcomes data are needed for all CARE Act programs, but are particularly important for State and local CARE Act planning bodies, which must allocate limited resources to meet the overwhelming need for medical and support services.

6. **Treatment and Adherence:** HAART (Highly Active Anti-Retroviral Therapy) has improved the lives of thousands living with HIV disease, but its costs are prohibitive, its side effects are severe, and its dosing regimens are very complicated. In one test using placebos, even clinicians often failed to take medications as prescribed. As scientists continue to achieve breakthroughs in their labs, we must simultaneously work with clients to make the promise of today's best treatments a reality in the lives of all people with HIV.

7. **Health Insurance and Financing:** In recent years, health care financing has changed significantly, and eligibility for public benefits varies greatly by State. The impact of these changes on quality of care has not always been positive. Managed care, now the country's predominant form of health insurance coverage, also has implications for access to quality care. CARE Act grantees and providers must anticipate and contend with changes in demand resulting from these developments. They must also ensure appropriate care and services for their clients, regardless of the source of payment for the services they provide.

At the local level, participants in the Comprehensive Planning Committee identified the critical issues that are most pressing in the Houston area. They did this by comparing the ideal continuum of prevention and care (or the system of prevention and care that our community ideally wants) against multiple assessments of the current system. Assessments of the current system utilized PLWH/A and service provider input from the 1999 Comprehensive Needs Assessment, focus groups, and public comment.

Some of the critical issues identified by HRSA across the Federal level were not as applicable to the Houston area as they would be in other service areas. For example, it is generally perceived locally that the Houston area has many of the best-trained physicians and one of the best HIV/AIDS medical care systems available in the world. Yet, like many other areas, we as a community need to focus on how to improve getting care to the many thousands of PLWH/A in our area who are not accessing care services, perhaps because they are not aware that they are HIV positive or there are barriers that keep them from getting services.

The following goals, objectives and activities through 2005 have been identified by the local Comprehensive Planning Committee as our local "critical issues". The Comprehensive Planning Committee calls upon the community to focus additional resources in these areas to improve health outcomes among those who are at-risk for and living with HIV.

Client Intake and Linkage

A primary concern expressed by clients currently accessing the HIV system has historically been their difficulties navigating the system. Clients have said that the "paperwork [is] too hard to fill out" and "too long"; additionally the paperwork is simply too complicated. One woman said that she had to carry a "paper dictionary" around with her just so that she could read the "big words" on the forms. Clients have called the current system a "pain in the neck" while complaining about the frequency with which they have had to reapply for services. In addition to clients, service providers also ranked "the clients ability to navigate through the system" as the third greatest barrier to the system. PLWH/A ranked red tape as the highest barrier to the system.

Thus the suggestion made by one client, to have "some type of centralized computer system" that will intake and coordinate client information, is actually a primary goal of the HIV community. This centralized system will alleviate many of the complaints clients have that include having to fill out "700 pages worth of questionnaires and stuff". It will answer one man's call for "one standardized form that they [service providers] all accepted".

Additionally, a centralized system will help both staff and clients become more aware of the various services available. One of the primary barriers to individuals getting services has been the fact that many simply don't know what is available to them; moreover, many have said they don't know the location of the service providers. One rural man complained that the only type of case management available to those living outside the city was "The Blue Book". He added that he knows "more [about available services] than the case managers". Still another man described his experience with the current system this way: "You have to go all the way in town. You have your blood work done here, up-to-date; You have to make sure you've been pre-approved where you're still on the system up there. Then you have to go in there. They look at you. You have to go back and then you have to go back again. You have to make at least 2 to 3 trips". This kind of discouraging repeated legwork on the part of the clients (legwork that ultimately discourages many from staying in the system and thus, indirectly, encourages clients to drop out of the system) will be eliminated once a centralized system is in place. As one client put it, "if it were more of a universal thing to where you can be plugged into all the services", clients would not be so likely to "fall through the cracks and loop holes".

GOAL A: By February 28, 2005, 100% of the clients who participate in the HIV service system in the Houston area will more easily understand the system and how to navigate through it, will experience a minimum of repetition and complication in the intake and eligibility process, and will be linked to all needed services as efficiently as possible.

Objective A1: By September 1, 2004**,** all Houston area HIV services will use a single data management system for all clients, and with proper security, will allow participating service providers access to basic client information while providing the administrative and planning bodies with unduplicated client level information across all service categories that will be consistent with administrative reporting requirements for all RW Titles and will enhance planning activities.

Activity A1.1: Complete the development of the Centralized Patient Care Data Management System (CPCDMS) including a standardized intake form for data collection.

Tasks

a. Involve representatives from all funding streams in the development process;

b. Identify all data needed from all funding sources to gather basic client information to establish Ryan White eligibility, to be enrolled in all HIV/AIDS medical and social services (including indicators of disease level and income factors), to be used for planning and reporting, and to provide an indication of service needs and the service plan of a client;
c. Create all forms and materials needed to implement the CPCDMS.

Activity A1.2: Beginning June 1, 2000, initiate a pilot testing of the CPCDMS for Title I clients.

Tasks
a. Ensure computer capacity and capabilities for all Title I providers;
b. Educate Title I providers regarding administering and recording the standardized intake process;
c. Print and distribute final tools and instructions;
d. In June 2000, implement the CPCDMS with Title I case management agencies;
e. In September 2000, implement the CPCDMS with primary medical care providers;
f. By March 2001, implement the system fully for all Title I providers;
g. Monitor and make changes as needed.

Activity A1.3: By January 1, 2002, implement the data system with other Ryan White Titles.

Tasks
a. Evaluate the implementation and stability of the system within the Title I system and make changes as needed;
b. Ensure computer capacity and capabilities for all Ryan White providers;
c. Work with the administrative bodies of each Title to establish agreements and timetables for implementation;
d. Make any changes to the system and standardized intake form as required to incorporate other Titles.

Activity A1.4: As the system becomes operational, use data provided by CPCDMS to fulfill reporting requirements and carry out planning.

Tasks
a. Seek and gain approval from TDH for Houston area agencies to discontinue use of COMPIS and substitute CPCDMS as the source of data for the Houston area for COMPIS;
b. Create report formats and organize data accordingly;
c. Use data to understand service utilization in the system of care as one element in information used for annual planning cycles.

Activity A1.5: By September 1, 2003, implement the data system with other HIV treatment funding sources.

Tasks
a. Continue to evaluate the implementation of the system within the Ryan White Titles and make changes as needed;
b. From the beginning work with the administrative agencies of all funding sources to understand the advantages and efficiencies of an area wide data management system for all HIV clients;
c. As needed make any changes to the system required to accommodate the data needs of all funding sources;

d. Create agreements and timetables for implementation with the administrative agencies of each funding source and provide technical assistance as needed.

Activity A1.6: Expand the use of the data management system to clients who receive Texas Commission on Alcohol and Drug Abuse (TCADA) and/or HIV prevention and education services in the Houston area.

Tasks

a. Meet with TCADA and prevention providers and administrators to help them understand and accept the standardized data management system;
b. Adapt the intake form as needed to meet program needs of all HIV/AIDS clients and services;
c. Ensure computer capabilities of providers;
d. Educate all providers regarding administering and recording the standardized intake process;
e. Implement data management system with all HIV clients;
f. Monitor, evaluate and make changes as needed;
g. Continue outreach and incorporation of new points of entry as possible.

Objective A2: By February 28, 2005, a standardized intake, eligibility and linkage process including the data management system will operate throughout the Houston area. At a minimum, the process will include the following elements:

- Provide on-site intake services at key points of entry into the system of care;
- Ensure security and confidentiality of any personal data from the consumer;
- Have the capacity to authorize basic Ryan White eligibility for all services within the Ryan White system of care;
- Ensure that each client has an identified primary care provider;
- Prepare with the client a linkage plan that outlines all appropriate services throughout the Houston area, identifies a specific set of services that the client needs, addresses ways to overcome barriers to receiving services, and includes a referral to professional case management services as need and client interest indicate.

Activity A2.1: Concurrent with the development of the data management system, design and implement a model of a process for universal intake, eligibility and linkage for people living with HIV in the Houston area.

Tasks

a. Convene a working group made up of representatives from all relevant constituencies—planning bodies, government agencies, consumers from different HIV subpopulations, medical and social service providers and administrators, HIV/AIDS policy and planning agencies, and other experts;
b. Provide a method for ongoing communication and input from the broad network of clients, providers and other appropriate policy and planning bodies and funders;
c. Establish and agree to system design outcomes;
d. Determine the parameters of the intake, eligibility and linkage system including the possible use of an electronic card system;
e. Establish areas of commonality and compatibility
f. Identify possible problem areas and identify ways to address the problems;
g. Garner agreements in concept from all participating planning bodies and administrative agents;

h. Develop any tools, policy statements and instructions needed;
i. Gain final agreements at all levels;
j. Begin implementation starting with Ryan White Titles I and II and adding others as soon as practical.

Coordination of Service Providers and Resources

There are many people providing services to individuals with HIV within the Houston area. These hard working agencies provide an enormous variety of services ranging from legal assistance to food pantries to housing to medical services (just to name a few). Currently, however, both consumers and providers rate the lack of coordination among these agencies as one of the top ten barriers to good care, even though many providers feel that the communication between agencies is of the utmost importance to the success of their programs.

One surveyed client reported, "It seems like none of the agencies work together at all"; another said, "I need more continuity of care. One agency refers you to certain things, and another agency refers you to other things". Yet a third participant in an open forum said to an agency, "I want to know why your case managers can't work with all the other agencies", and a forth said simply, "They [agencies] need to coordinate this stuff".

Some clients believe that inter-agency politics subverts coordination between agencies. While others see the lack of coordination between agencies as simply an outcome of muddled communication. Whether the reason is politics, personality clashes, or weak communication, the current level of coordination between providers will be greatly enhanced by providing several tools and procedures that will increase the communication between service providers. Increased communication will keep providers up to date on what is out there for their clients so that they will be better able to direct their clients to the services needed. Increased communication will also serve to lesson tensions that will naturally occur between providers as each works to provide the best possible services for their clients. The outcome of all this communication between providers will hopefully be better educated clients who are better able to navigate a large and much facetted system.

GOAL B: By February 28, 2005, services for clients will be improved through increased cooperation and coordination of service providers and improved administration functions.

Objective B1: By February 28, 2001, there will be a structure for on-going communication and coordination among HIV agencies.

Activity B1.1: Organize interagency meetings of all agencies that serve and support people with HIV.

Tasks:

a. Convene main organizers to establish areas to be addressed by the group - methods for quality assurance, outreach, and system wide changes; explore possible incentives for active participation;
b. Develop a means for paying for this activity either through shared costs or capacity building funds;
c. Hire a coordinating group with the experience and objectivity to organize and facilitate meaningful meetings;
d. Develop a list of provider contacts including representatives from agencies that do not receive HIV funding but have the programs or services relevant to people with HIV including Medicaid, Texas Department of Criminal Justice (TDCJ), Texas Commission on Alcoholism and Drug Abuse (TCADA), Mental Health and Mental Retardation Authority (MHMRA), Housing and Urban Development (HUD), Metropolitan Transit Authority (METRO), Coalition for the Homeless, etc. and ensure key people attend;
e. Set measurable outcomes for interagency meetings and service improvement;
f. Plan and hold first meeting;

g. Establish a structure for on-going operation;
h. Hold meetings quarterly;
i. Monitor and evaluate outcomes.

Objective B2: By June 30, 2001 the most efficient and effective way for service providers to carry out administration and reporting requirements will be determined and changes implemented as needed.

Activity B2.1: Assess and realign, as needed, the administrative responsibility placed on service agencies.

Tasks:
a. Define current administrative and reporting requirements;
b. Assess Federal, State and local government mandatory procedures;
c. Evaluate the cost and effort required to meet administrative responsibilities;
d. Compare and contrast agencies' administrative methodologies;
e. Develop recommendations for making changes;
f. Educate planning bodies regarding agency administrative requirements to allow proper assessment of provider and consumer concerns;
g. Make a plan to implement the recommended changes;
h. Monitor implementation and adapt and change as needed.

Objective B3: By June 30, 2002, all funding available to provide prevention, treatment and care for people living with HIV/AIDS in the Houston area will be used as efficiently and effectively as possible and that Ryan White money will be used as a last resort, as required by law.

Activity B3.1: Compare and contrast all of the different funding streams used to fund HIV services in the Houston area.

Tasks:
a. Identify overlaps and intersection of funds;
b. Do cost analysis studies to determine costs of services;
c. Identify barriers and gaps reimbursement and funding;
d. Advocate for a more user-friendly Medicaid system;
e. Expand or redevelop a quality assurance system regarding eligibility and service use;
f. Make adjustments to coordinate funding streams;
g. Report findings to appropriate planning bodies.

Quality of Care

The SUMA report (a report of the perceptions and evaluations of HIV/AIDS care and prevention in Harris and surrounding counties) included in this plan indicates that many administrators, community advocates, and planners have expressed a need for a system of accountability that will quantify the successes of the systems of prevention and care. This report also suggests that the HIV planning bodies work toward developing a methodology and a set of guidelines that will help track the uses of Title I and Title II funding.

Moreover, while there are many successes within the system, there is an indication from some clients that the quality of care needs more pro-active monitoring. Some clients have complained that care service staff does not know enough about the system, saying, "They know about their little job function, but that's about it". One African-American male summed up his biggest complaint with the system saying, "my biggest need is expertise . . . like a better case manager".

Setting clear standards for all people working within the care system, as well as providing all the training and monitoring needed to make sure those standards are adhered to will alleviate many of the complaints voiced by those clients who feel that they "know more than the case managers".

GOAL C: By February 28, 2005, the quality of care for people living with HIV/AIDS in the Houston area will be improved by clear standards for operation.

Objective C1: By August 30, 2001 there will be standards of care and prevention guidelines for every direct service in the Houston area continuum of care.

Activity C1.1: Beginning in January 2000, a participatory process will be operational to create and/or update standards of care or prevention guidelines for each service category, including medical case management.

Tasks:

a. Establish a process for creating, monitoring and updating standards of care and prevention guidelines;
b. Review or develop treatment standards and prevention guidelines;
c. Gain approval for and implement guidelines within the system of care;
d. For each new standard/guideline, and with any changes, notify all providers of that service regardless of funding source;
e. Review and update standards/guidelines on an annual basis.

Activity C1.2: Create a set of training policies, procedures, and activities to ensure that each person providing direct services to clients has achieved the required skill level.

Tasks:

a. Establish standards for the minimum knowledge and level of expertise that is needed for all staff and volunteers who provide direct client services;
b. Review and evaluate which services, in addition to case management, need to have training and what training is needed;
c. Establish levels of expertise and experience for all trainers;
d. Ensure that all agencies are monitoring and documenting the necessary continuing educational activities for licensed personnel;
e. Identify continuing educational needs for non-licensed professional personnel;

f. Develop a centralized training system that offers required basic skills training for staff and volunteers that includes education on HIV and AIDS, sensitivity to clients and cultural differences, and awareness of the continuum of care and other more advanced topics as needed.
g. Establish policies and procedures that allow staff and volunteers who have the appropriate levels of training and experience areas to be exempted from basic training activities;
h. Provide and require periodic updates on the HIV/AIDS epidemic and new or enhanced methods for care and treatment;
i. Identify existing training opportunities within the local community or on a State and national basis, publicize these activities to all staff and volunteers, and encourage agencies to establish training policies for all staff and volunteers.

Public Advocacy

Public Policy Advocacy

As PLWH/A live longer, great care needs to be given to ensure continued proactive funding of care services. It is only through continued funding that the care system will be able to assure all clients attentive and innovative services. Moreover, demand for services will undoubtedly rise as treatment regimes continue to improve the lives and the health of PLWH/A. Thus, advocating for strong public policies that will ensure for the continued well-being and health of individuals who are HIV positive will become increasingly important in the coming years.

Even now, many believe funding for HIV services to be inadequate, as is clearly stated in the previously mentioned SUMA report – a document that reports the findings gleaned from a series of semi-structured interviews with key informants made up of 25 key leaders and 44 experts. In fact, 54% of the experts interviewed for the SUMA report said that they believed that at the present time there is not enough funding for care. Furthermore, experts as well as key leaders said that year-to-year uncertainty about funding is a weakness in the public health system. The consensus from both experts and leaders is that the public health system needs to be provided with more, and more consistent, funding for care.

GOAL D: By February 28, 2005, all HIV care, prevention, and research will be fully funded, including new and innovative services.

Objective D1: Through December 2000, advocate and monitor the Ryan White reauthorization and funding process.

Activity D1.1: All planning bodies will monitor the reauthorization and appropriations process and keep their respective community groups advised of progress and problems.

Tasks:

a. Each administrative agency establishes a method and timeframe to monitor and report to their planning bodies.

Activity D1.2: Encourage provider and consumers to participate in national advocacy efforts.

Tasks:

a. Community-based organizations (CBOs) and consumers become participating members in national advocacy groups such as National Minority AIDS Council (NMAC), Cities Advocating Emergency AIDS Relief Coalition (CAEAR), Urban Coalition of HIV and AIDS Supervisors (UCHAPS), National Association of People with AIDS (NAPWA), and AIDS Action;
b. CBOs and consumers schedule visits to local Congresspersons and Senators to advocate for Ryan White reauthorization and funding;
c. Each planning body appoints a member to monitor and report on the reauthorization process.

Objective D2: Through each Congressional session, advocate for increased funding for care, prevention, and research.

Activity D2.1: All planning bodies will monitor the reauthorization and appropriations process and keep their respective community groups advised of progress and problems.

Tasks:

a. Each planning body establishes a method and timeframe to monitor and report back to their planning bodies.

Activity D2.2: Encourage provider and consumers to participate in national advocacy efforts.

Tasks:

a. CBOs and consumers become participating members in national advocacy groups such as AIDS Action, National Minority AIDS Coalition (NMAC), Cities Advocating Emergency AIDS Relief Coalition (CAEAR), Urban Coalition of HIV and AIDS Supervisors (UCHAPS), and National Association of People with AIDS (NAPWA);
b. CBOs and consumers schedule visits to local congresspersons and senators to advocate for increased funding;
c. Each planning body appoints a member to monitor and report on the legislative process.

Objective D3: During each two-year session of the Texas Legislature, advocate for full funding of prevention, care, and research services.

Activity D3.1: All planning bodies will monitor the reauthorization and appropriations process and keep their respective community groups advised of progress and problems.

Tasks:

a. Each planning body will establish a method and timeframe to monitor and report back to their planning bodies.

Activity D3.2: Encourage provider and consumers to participate in Statewide advocacy efforts.

Tasks:

a. CBOs and consumers become participating members in statewide advocacy groups;
b. CBOs and consumers schedule visits to local State Representatives and Senators to advocate for increased funding;
c. Each planning body appoints a member to monitor and report on the legislative sessions.

Objective D4: On an ongoing basis, ensure that the Texas Board of Health policies and AIDS Drug Assistance Program (ADAP) policies and procedures meet client needs.

Activity D4.1: Planning bodies will monitor activities of the Texas Board of Health and advocate for specific policies and procedures as becomes necessary.

Tasks:

a. Provide appropriate information to Health Commissioner and Board Members;
b. Report, as necessary, to planning bodies.

Activity D4.2: Monitor activities of ADAP Advisory Board and staff and advocate for specific policies and procedures as becomes necessary.

Tasks:

a. Provide appropriate information to Advisory Board members and ADAP staff;
b. Report as necessary to planning bodies.

Objective D5: By March 2003, more non-Ryan White County monies will be allocated to fund client services by planning bodies.

Activity D5.1: Advocate for funding increases at Harris County Commissioners Court and the Harris County Hospital District.

Tasks:

a. CBOs and consumers schedule visits to the County Judge and County Commissioners to advocate for increased funding;
b. Provide appropriate information to Commissioners and Hospital District Board members as necessary;
c. Report as necessary to planning bodies.

Objective D6: By the end of Fiscal year 2004, more non-CDC money will be allocated by the City of Houston for HIV prevention and education activities.

Activity D6.1: Advocate for funding increases at Houston City Council.

Tasks:

a. CBOs and consumers schedule visits to the Mayor and City Council members to advocate for increased funding;
b. Provide appropriate information to City Council members and the Mayor as necessary;
c. Report as necessary to planning bodies.

Objective D7: In the 2001 Legislative Session, advocate for decriminalization of needle exchange programs using studies that demonstrate the effectiveness of this strategy to significantly decrease HIV transmission.

Activity D7.1: Work with other statewide groups to scientifically demonstrate whether needle exchange is effective in reducing HIV transmission (and) if shown to be effective, work with other statewide groups to coordinate efforts to pass legislation that would allow needle exchange.

Tasks:

a. CBOs and consumers join as participating members of Statewide group;
b. CBOs, consumers and Statewide groups collect statistical and other relevant information and/or advocate for needle exchange research;
c. CBOs and consumers schedule visits to local State Representatives and Senators to explain findings and advocate for increased funding if effectiveness is demonstrated.

Activity D7.2: If the effectiveness of needle exchange is demonstrated, build public sentiment in favor of needle exchange programs.

Tasks:

a. Meet with editorial boards of newspapers to present information and solicit support of needle exchange programs.

Outreach and Prevention of HIV

Because HIV is one of the few diseases that can be prevented by behavior modification, prevention and education are two of the most important jobs in the HIV community. That being said, behavior remains one of the hardest pieces of the human condition to affect and change. Guided by a complex set of variables - including individual history, cultural norms, substance abuse issues, momentary circumstances, age, religious beliefs, and countless other issues - high risk behavior can be extremely difficult to modify.

Still, HIV educators throughout the Houston area continue to work at developing effective programs that will help individuals develop strategies that will eventually modify risky behavior. Moreover, in their efforts to be effective and proactive these educators work at creating curriculum that is tailored to the many disparate cultures living throughout the community, oftentimes targeting those populations that appear to be at the greatest risk given the epidemiological data.

In an effort to develop successful HIV prevention strategies, the Centers for Disease Control and Prevention (CDC) codified a way for diverse organizations to come together with local health departments so that they might work collectively toward improving the efficacy of local HIV prevention efforts. The resulting document of this CDC recognition, entitled the Supplemental Guidance on HIV Prevention Community Planning for Non-competing Continuance of Cooperative Agreements for HIV Prevention Projects, mandates flexible directives to organizations, cities and states that receive HIV prevention funding. Part of those directives call for the creation of Community Planning Groups. Community Planning Groups are made up of individuals who have been affected and/or infected by HIV. These groups meet periodically and review the epidemiological data along with programmatic successes and failures and attempt to establish some guidance as to where prevention efforts should go.

The Houston area has two Community Planning Groups (CPG), one for the Houston area and one for the outlying counties. Both groups have written prevention plans that capture epidemiological data and use that data to delineate those populations who appear to be at greatest risk for HIV. The plans then suggest appropriate prevention strategies given the population. If you would like to obtain a copy of the most current edition of either the East Texas Prevention Plan or the City of Houston Prevention Plan, please refer to the contact information in Section VI.

One of the many goals of the HIV prevention community planning process is to develop an HIV prevention plan that will guide local prevention efforts. Because resources are limited, an important task involved in creating this plan is the process of identifying both current and emerging populations who appear to be at high risk for HIV infection; for though it is risky behavior, rather than membership in any population, that increases the risk of HIV transmission, the CPG attempts to be both responsive and proactive. It is therefore important that emerging trends in the seroprevalence rates of HIV be located so that the CPG can build prevention strategies that are informed, intelligent, and culturally effective.

Several steps involved in the creation of the plan are outlined and clarified. The priority-setting criteria is examined and explained. The priority-setting process must be scientifically based and utilize certain planning factors, such as riskiness of behavior, HIV seroprevalence rates and unmet needs.

The plan also presents an epidemiological profile for the city of Houston and the surrounding areas. Prevalence studies, behavioral risk studies, and studies concerning the cofactors for HIV are presented in tandem with the profile. Interventions developed during previous years, including community outreach, individual level counseling, peer outreach/support, small group counseling, CTRPN/E and

community leader endorsement, are explained. Each plan includes a resource inventory that lists the funded prevention services and agencies currently targeting at risk populations. Recommendations as to the sort of referrals and linkages that should occur between prevention workers, care/treatment facilities, and service providers are also made in the HIV prevention plans.

The HIV prevention plan also presents guidelines for an evaluation and data collection process that will enable the CPG to document and keep track of the various prevention strategies being implemented throughout the city with the intent of discovering the impact of those strategies on the community.

As is the case in many planning processes, not every person, issue, and effort is addressed in these plans. During this planning, the Comprehensive Planning Committee discovered some gaps in the two plans and discussed the potential for this document to address those gaps, most notably among those who are already infected with HIV. Therefore, in an effort to plan for and support a continuum of care for the Houston area, this comprehensive plan addresses the need to provide prevention services within other entities.

Where goals and objectives refer to effective "prevention strategies", those strategies are inclusive of interventions recommended by the Centers for Disease Control and Prevention (CDC).

CDC Defined Prevention Interventions

Public Information: Mass media announcements that will increase public awareness as to which communities are being most affected, which prevention methods are most effective, where to find prevention information and services, where to access free condoms and what sort of scientific breakthroughs are and are not happening.

Community Level Intervention: Create peer and social groups that will effectively teach community members how to modify their behaviors. These groups along with community leaders will work to change cultural attitudes that stigmatize discussion of risky behavior and safer sexual practices.

Street and Community Outreach: Reach marginalized and stigmatized community members who are not getting sound prevention information.

CTRPN/E (Counseling, Testing, Referral and Partner Notification/Elicitation): Create community based, culturally and linguistically effective Outreach Programs that will encourage testing and partner notification as well as change and modify risky behaviors whatever the testing outcomes.

Group Level Counseling: Create groups that can and will openly discuss their risky behaviors and ways that they can change and affect those behaviors and thus save their own lives.

Individual Level Counseling: Provide one-on-one counseling and extensive information on safer sex options and practices as well as impact the sexual activities, communication and negotiation skills and self-esteem of individuals who are participating in the counseling.

Prevention Case Management: Track and counsel at risk individuals who come through any State, city or private agency, thus gleaning information that will help in creating more effective interventions as well as supporting individuals struggling to make positive choices in their own lives.

HIV Prevention

HIV prevention is an ongoing activity throughout the Houston area. Most prevention activities are considered and monitored through the Houston HIV Prevention Community Planning Group and the East Texas HIV Prevention Community Planning Coalition, two Federally-mandated organizations made up of HIV infected and affected individuals who have a vested interest in stopping the spread of HIV in the diverse communities throughout the Houston area. These groups make recommendations to the various agencies (including city and county health departments) that create and fund prevention activities. In order to make sure that prevention monies are being spent wisely, the two groups spend time tracking the epidemiology of HIV and other STDs. Using epidemiological data as well as their own anecdotal experiences, the members of the groups are able to create a list of priority populations – populations that appear to be at the greatest risk for HIV infection. This list of priority populations ensures the smart expenditure of the limited resources currently allotted for prevention activities.

The HIV community continues to push prevention messages forward. This plan advocates for increased prevention messages and activities meted out to those individuals who are HIV positive as well as to the entire population of the Houston area. The HIV services community is in the unique position of being able to advocate for prevention messages being communicated to every individual who is HIV positive who comes into the service system. All individuals who care for the HIV positive community must become knowledgeable of those prevention strategies that are most effective and caregivers need to communicate those strategies to their clientele.

GOAL E: By February 28, 2005, reduce transmission of HIV by 25%.

Objective E1: By February 28, 2002, utilize proven effective and innovative primary prevention strategies to decrease new HIV infections.

Activity E1.1: Implement HIV prevention strategies that best meet the needs of those people and communities who are at the highest risk for HIV infection.

Tasks

a. Utilize prevention plans developed through the Houston HIV Prevention Community Planning Group and East Texas HIV Prevention Community Planning Coalition;
b. Conduct prevention strategies that are culturally and linguistically appropriate to decrease cultural barriers to HIV prevention knowledge and behavior;
c. Conduct prevention strategies that best meet gaps identified through needs assessment activities;
d. Conduct non-HIV STD prevention activities in populations with high rates of non-HIV STDs;
e. Conduct harm-reduction prevention strategies to high-risk substance use populations;
f. Develop and utilize program curriculum developed with scientific efficacy and practical implementation.

Activity E1.2: Implement HIV prevention strategies that best meet the needs of identified emerging populations who may be at increased risk of HIV.

Tasks

a. Utilize regional epidemiological profiles to identify emerging populations who may be at risk of HIV;
b. Utilize regional STD surveillance profiles to identify high-risk, non-HIV rates that may indicate possible increases in HIV infection;
c. Conduct prevention strategies that are culturally and linguistically appropriate to decrease cultural barriers to HIV prevention knowledge and behavior;
d. Conduct harm-reduction prevention strategies to high-risk substance use populations;

e. Develop and utilize program curriculum developed with scientific efficacy and practical implementation.

Activity E1.3: Create HIV prevention education programs for professional administrators, faith communities, health professionals, and school administrators.

Tasks

a. Develop, distribute and utilize program curriculum developed with scientific efficacy and practical implementation.

Objective E2: By February 28, 2002, utilize proven effective and innovative secondary prevention strategies to promote wellness and safer sex practices and decrease re-infection among people who are HIV positive.

Activity E2.1: Implement HIV risk-reduction strategies that best meet the needs of people with HIV.

Tasks

a. Utilize prevention plans developed through the Houston HIV Prevention Community Planning Group and the East Texas HIV Prevention Community Planning Coalition;
b. Conduct risk-reduction strategies that are culturally and linguistically appropriate to decrease cultural barriers to HIV prevention knowledge and behavior;
c. Conduct risk-reduction strategies that best meet gaps identified through needs assessment activities;
d. Conduct harm-reduction prevention strategies to HIV+ substance use populations;
e. Develop and utilize program curriculum developed with scientific efficacy and practical implementation.

Activity E2.2: Implement HIV risk-reduction strategies for identified emerging populations.

Tasks

a. Utilize regional epidemiological profiles to identify emerging populations who may be at risk of HIV;
b. Conduct risk-reduction strategies that are culturally and linguistically appropriate to decrease cultural barriers to HIV prevention knowledge and behavior;
c. Conduct harm-reduction prevention strategies to HIV+ substance abuse populations;
d. Develop and utilize program curriculum developed with scientific efficacy and practical implementation.

Activity E2.3: Create HIV prevention education programs discussing secondary prevention efforts for professional administrators, faith communities, health professionals, and school administrators.

Tasks

a. Develop, distribute and utilize program curriculum developed with scientific efficacy and practical implementation;
b. Maintain up-to-date information on treatment education and utilize this information in the curriculum.

Objective E3: Starting March 1, 2000, continue HIV prevention planning through the community planning process.

Activity E3.1: Ensure that the planning process is inclusive and representative of the local epidemic.

Tasks

a. Utilize epidemiological surveillance data to identify the local epidemic profile for membership;
b. Ensure that all planning members are educated and knowledgeable in pertinent planning issues;
c. Allow the planning process to be conducted with open and respectful dialogue;
d. Ensure that the planning group membership is ethnically diverse.

Activity E3.2: Create a mechanism to share information acquired through needs assessment, epidemiological studies, scientific literature, prevention providers, non-HIV service providers, and other planning bodies.

Tasks

a. Ensure scientific expertise is participating in the planning process, such as epidemiologists and behavioral scientists;
b. Assign an individual to monitor literature for pertinent information and to share the information gathered with appropriate policy-setting entities;
c. Review on-going sero-incidence studies to keep abreast of where new infections are occurring;
d. Review and monitor the effectiveness of needle exchange programs occurring in other jurisdictions;
e. Maintain the possibility of implementing needle exchange programs in the Houston area.

Activity E3.3: Conduct evaluation of HIV prevention programs and the HIV prevention planning process.

Tasks

a. Develop and implement an evaluation process to monitor program effectiveness, behavioral change, or changes in knowledge, attitudes, or beliefs;
b. Conduct evaluation of the community planning process.

Activity E.3.4: Ensure cooperation between care providers and prevention providers.

Tasks

a. Ensure that members of the Ryan White Planning Council and CARE Consortium are present at all prevention planning meetings and that the information is reported back to theirs and other planning bodies;
b. Require representation from care planning bodies to serve on prevention planning bodies and that prevention representation is placed on care planning bodies.

Early Treatment/Prevention of AIDS Progression

Increase and Maintain PLWH/A in Medical Care

Many PLWH/A are not getting into the system of care, and even more are not getting into the system in a timely fashion. As medications and treatments become increasingly more successful, it becomes increasingly paramount that all people living in the Houston area who are and who will become HIV positive access the system of care now in place. Current treatment protocols emphasize early intervention. Thus, an expanded effort needs to be made in order to gather all persons needing treatment into the system. Currently, about 5,000 people within the area receive services; however, there are an estimated 10,100 people who need services. That gap of over 5,000 people - most of whom are African-American, Hispanic and undocumented people — is one that will be closed over the next five years through expanded outreach programs and education campaigns (special focus on the linkages between counseling and testing and care services will be a part of getting more of those testing positive into the system).

The average 14-day waiting period many people report experiencing to get into outpatient care and the wait lists for care suggests that the system could improve its efficacy. This improved efficacy would help to reduce the number of people who don't show up for appointments (35% of all appointments are currently no shows), as many of those who don't show up complain about the red tape and long waits involved in getting services. One client stated, "The system in Harris County is overrun and ill managed". Still another put it this way: "It's 3 months to see the doctor…right now I can't get my medications. I have to see the doctor; I missed my appointment. There is no medication until July. He won't prescribe it until I see him". Once cultural barriers and red tape are eliminated, the system will be easier to access and many more people will more easily access the system that is currently available.

Still, as increasing numbers of people are living with HIV, more and more individuals will need care. The current system will most likely not be able to sustain services to the increasing population of PLWH/A. Thus, the system needs to be measured and the capacity of the current system needs to be tallied. As the system becomes increasingly efficient, current capacity will shift; however, the current system needs some sort of barometer or gauging mechanism in place with which to measure capacity, thus creating a quicker response time to the epidemic as it changes over time.

GOAL F: By February 28, 2005, increase the number of people who are receiving early and ongoing medical care for HIV/AIDS, in an attempt to close the gap between those testing positive or previously known to have tested positive and those in medical care.

Objective F1: By February 28, 2003, implement a strategy to reach the currently underserved PLWH/A. The strategy will increase the number of PLWH/A in trackable medical services by 25% over March 1, 2000 numbers.

Activity F1.1: By June 30, 2000, a working group will be established that is representative of all HIV funding sources/planning bodies that has the responsibility to explore and create strategies for disseminating information on HIV disease and how to access the available medical care services.

Tasks:

a. Identify structure and participation for group;
b. Identify and secure staff support and other needed resources;
c. Review all current information being distributed on these subjects;

d. Fund an education campaign by which information on Early Intervention, HAART, and the necessity of ongoing laboratory tests can be disseminated.

Activity F1.2: By March 1, 2001, implement a targeted education campaign to reach the populations of greatest need as identified through the City of Houston's epidemiological report for the year 1999.

Tasks:
a. Divide the strategy between planning groups, according to area, funding, etc.;
b. Monitor the dissemination of information;
c. Monitor statistics as developed from Thomas Street Clinic, CBOs etc.;
d. Report results to planning bodies and Joint Comprehensive Planning Committee.

Objective F2: By February 28, 2003, ensure that the proportion of people who test positive that move from testing and counseling into medical care within three months of test is at least 75%.

Activity F2.1: Develop a linkage between prevention/testing staff and entry into medical care.

Tasks:
a. Incorporate "care-focused" linkage worker staff into HIV counseling and testing clinic sites to form primary relationships that help the newly tested enter medical care;
b. Incorporate care-focused service linkage workers into quality discharge-planning activities for the soon-to-be-released incarcerated;
c. Incorporate care-focused service linkage workers into quality discharge planning at private/public hospitals;
d. Provide service linkage workers with incentives they are able to offer the newly diagnosed, to be available at entry into medical care, e.g., fast track dental, or eye care;
e. By February 28, 2001, ensure there is a method in place to track the positive tests and new clients entering trackable medical service.

Objective F3: By February 28, 2001, ensure that the system of care maintains and supports people in care.

Activity F3.1: Reduce cultural barriers to treatment and services.

Tasks:
a. Increase peer counseling programs and opportunities in communities to be targeted;
b. Increase the ability of medical service providers to perform outreach and provide care in multiple languages (not just English/Spanish);
c. Increase education of non-HIV service providers in where and how to access care;
d. Evaluate the clinic system for geographic accessibility to emerging populations;
e. Increase the ability of medical providers to provide alternative therapies.

Activity F3.2: Ensure that all primary care providers include high quality medical case management that helps individuals maintain medical treatment adherence.

Tasks:
a. Define and set care standards for medical case management within the primary care service category;
b. Require that medical case management is offered as part of primary care outpatient services;
c. Review and evaluate effectiveness of medical case management services and make changes as needed.

Objective F4: By July 2001, identify the capacity needed in the health care system to effectively serve the projected increase in the patient population.

Activity F4.1: Conduct an area-wide assessment of the health care system to determine accurately the capacity currently filled, available, or overburdened.

Tasks:

a. Evaluate the current capacity of each health system component including inpatient, primary and specialty care, hospice and home health services;
b. Project the capacity needed for each component including an evaluation of the numbers of doctors trained to treat HIV professionally;
c. Recommend to planning councils, hospital district, universities, and AETC what needs to be done to have sufficient capacity to increase care.

Activity F4.2: Perform cost analysis and evaluate the reimbursement method for HIV primary care in the Houston area.

Tasks:

a. Planning bodies need to allocate resources to have administrative agencies contract/ perform Analysis.
b. Evaluate payment method of RW Care Act recipients;
c. Evaluate payments received through Medicaid, Medicare and HMO's and advocate to the State Government changes deemed beneficial;
d. Evaluate payments received through Medicaid, Medicare and HMO's and advocate to the Federal Government changes deemed beneficial.

Medication Issues

The epidemiology report shows clearly that new HIV medications and treatments are having a profound effect on the lives of many PLWH/A. However, the science shows that these medications must be taken as prescribed. Skipping or neglecting to take a round of medication can have dire consequences. The virus can mutate out of the range of current medications, thus rendering the medications impotent. Currently, 40% of PLWH/A skip their medications and as many as 10% skip their meds often – most without the advice of their doctor. The top reported reason for clients skipping medication is that they simply "forgot" to take it. The second greatest problem reported by clients concerning their medications was the side effects of the meds. These responses suggest that clients need a greater understanding of the way their medications are working as well as a better understanding of medication choices that are available to them.

In fact, service providers report that the biggest barrier to treatment is the clients "lack of knowledge"; they have said "more extensive patient medication education" is needed.

Clients themselves have also expressed a need for more information, saying such things as "I needed information right away as far as my T-cells and things . . . and it was hard for me to find that out." Another client said, "I know enough information about the virus and how it affects my body. I think I need more education on the medication because I'm getting a lot of side effects from my medications." Still another client said, "I need more education on how to take the drugs. That [lack of information] has stopped me from taking the drugs at one time".

Beyond a lack of understanding among clients of the treatments available to them is the fact that there are about 3,000 persons who receive drug reimbursement services and an estimated 8,500 who could benefit from drug reimbursement, leaving a gap of about 5,500 persons. This enormous gap indicates a need to educate HIV services clients about the medication services available to them.

GOAL G: By February 28, 2005, people with HIV/AIDS who are in the Houston area system of care will have improved understanding of and access to all available therapeutic and treatment medications, including nonprescription drugs.

Objective G1: By March 2002, there will be increased awareness of the medication programs available in the Houston area.

Activity G1.1: Establish and implement methods to improve awareness of medication programs available to people with HIV/AIDS.

Tasks

a. Create and provide information and education on how to use medication programs for clients entering the system;
b. Identify and provide information and education for clients who are in the system but are not participating in medication programs;
c. Work with the local AETC to ensure that local physicians and other non-Ryan White health care providers are knowledgeable about all HIV related programs, including ADAP;
d. Ensure the AETC markets the medication program to clients, physicians, medical schools, and hospital districts in rural areas;
e. Create and/or improve methods to screen for eligibility and actively link clients with ADAP services.

Objective G2: By February 29, 2002, there will be improvements in medication programs in the Houston area system of care.

Activity G2.1: Identify gaps and barriers in services and advocate for changes.

Tasks

a. Evaluate services for effectiveness and make recommendations for improvements;
b. Review pharmaceutical buying and distribution policies and procedures and make recommendations for improvements;
c. Bring regional groups together to advocate with drug companies for easier access and an increase in resources.

Section IV

ONCE WE ARE THERE

Implementation, Monitoring & Evaluation

Chapter Ten: Implementation, Monitoring & Evaluation

The comprehensive planning process provides HIV planning groups, service providers, funders, and consumers a picture of the local HIV epidemic and the continuum of care that is in place to meet the challenges of the epidemic for people and families at risk for and living with HIV. It helps the community make better decisions about how to organize and maintain an effective, efficient continuum of care by showing where we are, where we are going, and how we are going to get there.

But comprehensive planning does not end with the development of the plan. Comprehensive planning is a journey, rather than a destination. It is worth the time, effort, and expense only if it helps ensure that a comprehensive system of prevention and care is in place and maintained or reconfigured over time to meet the essential health and support needs in a changing environment.

While Ryan White Title I is legislatively responsible for developing, following, and updating a comprehensive plan for the organization and delivery of HIV services, the Houston Area HIV Services Ryan White Planning Council realizes that there are goals and objectives outlined within this plan for which it has no legislative or funding oversight. The Planning Council also recognizes that in order for the plan to be truly effective, the community must work together. The Planning Council started the comprehensive planning journey as a cooperative effort between the various funding streams and planning bodies. Continuing on that route means that the community must work together to show what to do once we are there, that is, how to implement, monitor, and evaluate the plan. In order to accomplish this, the community Comprehensive Planning Committee recommended a new structure – the Joint Comprehensive Planning Committee.

Joint Comprehensive Planning Committee

The comprehensive plan is a document intended to embody the goals of, and for, the entire HIV community, that is, the people who plan for, provide, and receive HIV care and prevention services in the Houston area. The complexity of the HIV disease and the people it affects, in addition to the complexity of the funding and administration of HIV prevention and care programs, has produced a system that is diverse and many times fragmented. Service providers and planning groups are bound by different funding and legislative requirements and, therefore, focus their efforts on separate pieces of the continuum of care (e.g., prevention *vs.* care or the EMA *vs.* the HSDA). Added to the mix are individuals who may or may not share cultural or social backgrounds, sexual orientation, HIV status, or work styles. On top of that, the planning process is a long and demanding road that requires a great amount of time and effort. By accepting the comprehensive plan, the respective parties commit to a collaborative effort to implement the plan through the use of the resources available through the various funding streams. The Joint Comprehensive Planning Committee (JCPC) is intended as a liaison group with the hope of bringing all the pieces together and addressing the challenge of a coordinated, collaborative approach to monitoring and evaluation.

In 1999, members of the HIV community joined with the Community Training and Assistance Center in a project designed to build the capacity of the Houston community to respond to the HIV epidemic. Part of the project was the Funding Stream/Planning Group Collaboration Task Force, which produced a report with recommendations for strengthening the working relationships among and between the service providers, planning groups, and affected populations.[15] The report was met with enthusiasm from a broad range of community members, most of whom expressed the desire for a clear and ongoing commitment to the spirit and intent of the recommendations. The JCPC meets those criteria

[15] Community Training and Assistance Center (CTAC). *Report and Recommendations: Strengthening Houston's Response to HIV/AIDS*. Boston: CTAC; 2000.

by providing "a stronger base of ongoing relationships, strong and reliable communication processes, and experience working together collegially on targeted objectives."[16]

It is important to remember, though, that the JCPC is an advisory coalition made up of a diverse group of individuals who, for the most part, represent organizations and groups that are far more complex than these single individuals. It is natural that the JCPC follow a progression of incremental growth that will start with issues concerning formation and end with the actual performance of activities.[17] While it appears that the HIV community has passed the first stage by agreeing to work as a collective body around an identified concern, caution must be exercised not to proceed too quickly. In order to establish and maintain the JCPC as a viable, effective force, the committee will first need to build both an internal structure and a clearly defined role for itself in the community.

In so doing, the overriding theme must be one of cooperation. The JCPC should serve as an impetus to a meaningful collaboration between funding streams, planning bodies, service providers, consumers and others as a result of efforts made to achieve the goals and objectives set forth in the Comprehensive Plan. It should NOT, however, be confused with the idea that this group will dictate commands to individual funding streams. This group will act as a caretaker of the plan so that dialog may begin, but each funding stream will remain responsible for their own decisions. If this can be achieved, the quality and quantity of services available in the Houston area will demonstrate a strong, viable response to HIV in our community over the next five years. The following information more clearly identifies structures and processes as they are currently being planned.

Structure

The JCPC is an independent group on which *all* members of the community are not only welcome, but also encouraged to participate in order to capture a broad range of knowledge and perspectives. Representatives of planning groups, funding streams, administrative agencies, service providers and people and families at risk for and living with HIV will be invited to join discussions, raise issues and offer recommendations. However, as is the case for all large groups, it is important to have a more formalized structure in place so that business may be conducted in a timely, efficient manner. What follows is a structure that the JCPC members created at their first two meetings.

JCPC meetings will be held once every three months in an open forum at accessible locations within the community. In order to coincide with meetings of the major planning bodies, the JCPC will meet on the first Monday of the month. Meeting times and locations will be scheduled in advance and publicized through such means as mailouts, website announcements, advertisements in local newspapers and announcements at meetings of the planning groups. Materials will be made available to voting members at least one week before the meetings, with extra copies provided at the meetings. A single point person will handle coordination of the meetings and materials (see below. The Houston Regional HIV/AIDS Resource Group has offered to seek funding on behalf of the JCPC to provide administrative support for JCPC activities, including personnel (a JCPC coordinator), meeting costs (e.g., location fees, refreshments, copying), and consumer incentives (e.g., mileage reimbursement).

The chair of the JCPC will be shared by three of the major planning bodies in the Houston area: the Houston HIV Prevention Community Planning Group (CPG), the Houston HSDA CARE Consortium (the Consortium), and the Houston Area HIV Services Ryan White Planning Council (RWPC). The chairs, who will share responsibilities on a rotating basis, will help ensure the productivity of meetings by keeping the discussion to the agenda and recognizing speakers so that everyone may be heard.

[16] Personal communication with Janice Litwin, Community Training Assistance Center.
[17] Texas Department of Health (TDH). *Coalition Building: A Healthy Community is Everyone's Business.* Austin, TX: TDH; 1996.

Business will be conducted by majority vote, with voting rights given to the following:

- Voting rights will be held by service provider representatives from the Consortium, the RWPC, and the Title IV Advisory Council who are appointed by the respective bodies. Because the plan is intended to direct changes in the continuum of care, those who are expected to implement and sustain those changes must be involved in the monitoring and evaluation. These are the organizations that provide HIV services.
- Voting rights will be held by people living with HIV (PLWH). Again, because the plan will affect the continuum of care, it is important that those people who are most likely to receive the services be directly involved in the monitoring and evaluation. In order to ensure that all communities affected by the epidemic are represented, five voting positions will be held for PLWH. Preference will be given to those people living with HIV who use the services offered in the continuum of care, particularly primary care, and to those who are not employed by HIV service providers. The JCPC will take steps to preserve the confidentiality of its members and to help ease financial the burden of participation. [Please note: The JCPC has asked three PLWH to assist in the recruitment of PLWH representatives. If you would like to make a nomination, please contact The Resource Group at 713-526-1016.]
- Voting rights will be held by (non-service provider) representatives from the Consortium, the RWPC, the CPG, the East Texas HIV Prevention Community Planning Coalition, and the Title IV Advisory Council. Voting rights also will be held by representatives from local Title III Early Intervention Services grants, Housing Opportunities for People with AIDS, the Houston Regional HIV/AIDS Resource Group, and HIV Services of the Harris County Department of Health. One way to direct changes to the continuum of care is to fund services that respond to the desired change. Another way is to provide technical assistance to service providers to help them implement the change. Therefore, it is important that funding streams, planning bodies, and administrative agents are involved in the monitoring and evaluation. Representatives will be appointed by the respective agencies/bodies.

Official business will be conducted only after a quorum of 50% of voting members plus one is reached. Each voting member will be given equal voice in making decisions and will be given the opportunity at the onset to designate an alternate member who will attend meetings in the event that the primary member is unable. The composition of the voting members will be reviewed quarterly and will change as needed to meet the changes that may occur in the environment (e.g., funding is shifted from one provider to another), comply with voting rights criteria, and maintain the diversity of members.

Implementation

The first step in implementing the plan is acceptance of the plan by the HIV community. The very creation of the JCPC indicates that most of the major players, at least, agree in theory with the idea of a comprehensive plan and are interested in seeing it carried out. The comprehensive planning process, from the beginning, included a diverse segment of the Houston area community, but the distribution of the draft of the plan will allow more of the community to see all segments of the plan in one piece for the first time. After public comments are received and the plan is finalized, it is hoped that members of the community will "sign on" as participators in the plan and that the plan will receive votes of concurrence from the funding streams and planning bodies and will become a part of their formalized structure. The RWPC, for instance, has already created a new standing committee, the Comprehensive HIV Planning Committee, that will serve as the connection to the JCPC.

Once the plan is finalized and accepted, those that sign onto the plan will bear the responsibility to broaden their knowledge base and work for the success of the plan throughout the Houston area. The plan must be promoted within traditional (HIV providers) and non-traditional (non-healthcare

community organizations) communities so that all stakeholders have a better understanding of how the system of prevention and care works. The JCPC will be a venue for this collaborative effort.

However, the planning bodies and funding streams will have to move beyond mere acceptance of the plan. They also will need to independently use their planning resources to ensure that programs and activities are moving the community toward reaching the goals and objectives set forth in the comprehensive plan. The JCPC will serve to further promote collaboration to help inform planning bodies of potential areas of need and, hopefully, led to an improvement in decision making about expanding, reducing, adding, eliminating, or refining services.

Monitoring

Perhaps the biggest impetus behind comprehensive planning is the desire to organize and deliver services within an ideal continuum of care. The core of the finished plan is the goals and objectives developed to reach that ideal. As such, implementation of the plan requires monitoring the community's progress in achieving these goals and objectives. Monitoring allows early recognition of problems so that barriers to progress can be identified and reported to the planning bodies.

Table 1, at the end of this chapter, presents a suggested initial framework for monitoring performance. One of the first tasks of the JCPC may be to develop monitoring factors, baseline data and monitoring tools and timeframe. Once the framework is complete, the JCPC can begin to monitor progress and identify barriers to reaching the goals and objectives of the plan. The JCPC will then report their findings to the respective planning bodies/funding streams that are in concurrence with the plan. These groups must use their processes to assist in removing the barriers to progress. If they are unable to remove the barriers, it will be necessary to make recommendations back to the JCPC about the need to evaluate the plan and make appropriate amendments to the timeline and/or objectives and activities. In addition to monitoring the progress of the comprehensive plan, the JCPC will collect information that will assist the planning bodies in maintaining a clear picture of the make up of both the HIV community that we serve and the programs and services available to these constituents.

Evaluation

Because a comprehensive plan makes sense only if it improves the quality of life for people and families at risk for and living with HIV, it is important that the plan keep pace with the changing dynamics of HIV. For example, the epidemiology of HIV, the legislative and funding environments, treatment protocols, and the health service delivery system may all change over time. Therefore, in addition to monitoring the progress toward attaining the goals, a comprehensive plan must also address evaluation strategies to assess the continued relevance of the goals and objectives. These strategies will provide an ongoing process for ensuring that the plan remains a viable working document.

The JCPC will serve as the mechanism for tracking changes in the environment and determining when and how each component of the plan will be evaluated. The information gathered by JCPC will be evaluated and used to determine any report to the planning bodies/funding streams any needed modification to the comprehensive plan. Below are some examples of information to be collected; specific strategies will be determined by the JCPC.

Epidemiologic data: Changes in epidemiology include the distribution of AIDS cases and people living with HIV in the EMA/HSDA. Factors such as age, gender, race/ethnicity, mode of transmission, stage of illness, employment and health insurance status, and housing status also must be considered. All of the planning bodies in the Houston area regularly update epidemiologic information. The JCPC

will serve as a vehicle for integrating this data and presenting it to the community in a standard manner.

Service needs: Information on service needs is collected through needs assessment activities, including consumer and provider surveys, focus groups, interviews and public forums. All of the planning bodies in the Houston area engage in some sort of needs assessment activity on a regular basis. A comprehensive needs assessment, a legislative requirement under Title I of the Ryan White CARE Act, is conducted every three years. Much of the HIV community already collaborates on needs assessment activities. It is hoped that the JCPC will serve as a vehicle for bringing more players into the process and for integrating the data that are collected individually.

Service effectiveness: The HIV/AIDS Bureau of the Health Resources and Services Administration has developed six key evaluation questions to guide Ryan White planning bodies in their planning efforts. They are questions that address concerns of other HIV providers as well, and planners are beginning to seek the answers. The JCPC will gather information from the planning bodies/funding streams with regard to these or similar questions and integrate the information. The questions are:

- To what extent are programs providing underserved minority and vulnerable populations with access to primary medical care?
- To what extent are programs providing clients with primary medical care whose quality meets or exceeds U.S. Public Health Service standards and other care standards?
- To what extent are programs providing services that remove barriers to primary medical care so that individual can enter into and remain in care?
- To what extent are programs reducing morbidity, as indicated by reductions in opportunistic infections and related hospitalizations, increases or slowed rates of decline in CD4 lymphocyte counts, and declines in perinatal transmission of HIV?
- To what extent are programs reducing HIV-related mortality?
- To what extent are programs adapting to a changing service and cost environment?

Overlooked Issues: By all accounts, the comprehensive planning process is an incredible endeavor. It is a great challenge for members of a diverse community to come together and work effectively in developing the best plan of action. Tremendous efforts were made to recruit participation in the process from service providers, administrators, planners, people and families at risk for and living with HIV, and the community at large. As is the case with any large planning effort, however, some issues or points of concern may have been lost in the process or simply not captured at all. In addition, although the Comprehensive Planning Committee (CPC) encouraged questions and comments throughout the process, because of funding and legislative requirements, they have had to balance openness and inclusiveness with the timely creation of a final product. It is inevitable and recognized that some omissions will occur. Finally, while there are many individual areas of concern, the plan is an attempt at a *global* improvement in the quality of life for people at risk for or living with HIV. As such, it is important to realize that some specific issues may not be addressed.

In recognition of these factors, and as an attempt to leave no stone unturned and meet the needs of as many people at risk for or living with HIV as possible, the CPC has expressed a need to make a concerted effort to revisit overlooked issues. Comments received from previously held public forums and from the release of a draft version of the plan will be forwarded to the JCPC, which will determine if and how issues will be included in a revised plan. Further input from the community will be sought at the time of discussion. Examples of issues already raised include: rehabilitation, financial planning, services for men and women who are incarcerated, greater community linkages/publicity, linkages to HMOs, and improved inclusion of affected family members in the continuum of care.

Objective	Monitoring factors	Baseline data	Monitoring tools	Monitoring timeframe
Goal A: By February 28, 2005, 100% of the clients who participate in the HIV service system in the Houston area will more easily understand the system and how to navigate through it, will experience a minimum of repetition and complication in the intake and eligibility process, and will be linked to all needed services as efficiently as possible.				
By September 1, 2004, all Houston area HIV services will use a single data management system for all clients and, with proper security, will allow participating service providers access to basic client information while providing the administrative and planning bodies unduplicated client level information across all service categories that will be consistent with administrative reporting requirements for all Ryan White Titles and will enhance planning activities.				
By February 28, 2005, a standardized intake, eligibility and linkage process including the data management system will operate throughout the Houston area. At a minimum, the process will include the following elements: provide on-site intake services at key points of entry into the system of care; ensure security and confidentiality of any personal data from the consumer; have the capacity to authorize basic Ryan White eligibility for all services within the Ryan White system of care; ensure that each client has an identified primary care provider; prepare with the client a linkage plan that outlines all appropriate services throughout the Houston area, identifies a specific set of services that the client needs, addresses ways to overcome barriers to receiving services, and includes a referral to professional case management services as need and client interest indicate.				
Goal B: By February 28, 2005, services for clients will be improved through increased cooperation and coordination of service providers and improved administration functions.				
By February 28, 2001, there will be a structure for on-going communication and coordination among HIV agencies.				
By June 30, 2001, the most efficient and effective way for service providers to carry out administration and reporting requirements will be determined and changes implemented as needed.				
By June 30, 2002, all funding available to provide prevention, treatment and care for people living with HIV/AIDS in the				

Objective	Monitoring factors	Baseline data	Monitoring tools	Monitoring timeframe
Houston area will be used as efficiently and effectively as possible and Ryan White money will be used as a last resort, as required by law.				
Goal C: By February 28, 2005, the quality of care for people living with HIV/AIDS in the Houston area will be improved by clear standards for operation.				
By August 30, 2001, there will be standards of care and prevention guidelines for every direct service in the Houston area continuum of care.				
Goal D: By February 28, 2005, all HIV care, prevention, and research will be fully funded, including new and innovative services.				
Through December 2000, advocate and monitor the Ryan White reauthorization and funding process.				
Through each Congressional session, advocate for increased funding for care, prevention and research.				
During each 2-year session of the Texas Legislature, advocate for full funding of prevention, care and research services.				
On an ongoing basis, ensure that the Texas Board of Health policies and ADAP policies and procedures meet client needs.				
By March 2003, more non-Ryan White County monies will be allocated to fund client services by planning bodies.				
By the end of Fiscal Year 2004, more non-CDC money will be allocated by the City of Houston for AIDS prevention and education activities.				
In the 2001 Legislative Session, advocate for decriminalization of needle exchange programs.				
Goal E: By February 28, 2005, reduce transmission of AIDS by 25%.				
By February 28, 2002, utilize proven effective and innovative primary prevention strategies to decrease new AIDS infections.				
By February 28, 2002, utilize proven effective and innovative secondary prevention strategies to promote wellness and safer sex practices and decrease re-infection among people who are AIDS positive.				
Starting March 1, 2000, continue AIDS prevention planning through the community planning process.				

Objective	Monitoring factors	Baseline data	Monitoring tools	Monitoring timeframe
Goal F: By February 28, 2005, increase the number of people who are receiving early and ongoing medical care for AIDS/AIDS, in an attempt to close the gap between those testing positive or previously known to have tested positive and those in medical care.				
By February 28, 2003, implement a strategy to reach the currently underserved people living with AIDS/AIDS. The strategy will increase the number of PLWH/A in trackable medical services by 25% over March 1, 2000 numbers.				
By February 28, 2003, ensure that the proportion of people who tested positive for HIV that move from testing and counseling into medical care within three months of the test is at least 75%.				
By February 28, 2001, ensure that the system of care maintains and supports people in care.				
By July 2001, identify the capacity needed in the health care system to effectively serve the projected increase in the patient population.				
Goal G: By February 28, 2005, people with HIV/AIDS who are in the Houston area system of care will have improved understanding of and access to all available therapeutic and treatment medications, including nonprescription drugs.				
By March 2002, there will be increased awareness of the mediation programs available in the Houston area.				
By February 29, 2002, there will be improvements in medication programs in the Houston area system of care.				

Section V

GLOSSARY OF TERMS

Access to Services: The extent to which clients can get or receive the service. Assumes that service was available to clients. Numerous factors may influence access to services even though the service is deemed available to the client.

ADAP: see AIDS Drug Assistance Program.

Administrative Agency: A lead, or administrative, agency is authorized to receive funds and distribute them according to service priorities established in the HIV care plan. An administrative agency may be a State or County health department, a community foundation, a public trust, a community-based organization, an AIDS service organization, or an incorporated non-profit agency. In the Houston area, the administrative agency for Title I of the Ryan White CARE Act is HIV Services, Public Health and Environmental Services, Harris County Department of Health; for Title II, the administrative agency is The Houston Regional HIV/AIDS Resource Group.

AETC: see AIDS Education and Training Center.

AI/A: American Indian/Alaska Native.

AIDS Drug Assistance Program (ADAP): The ADAP was created as part of the Ryan White CARE Act and is administered under Title II. ADAP provided medications to low-income people living with HIV/AIDS that are uninsured or under-insured and lack coverage for medications.

AIDS Education and Training Center (AETC): The AETC was created as part of the Ryan White CARE Act and is administered under Part F. The AETC program is a network of regional centers that conduct targeted, multi-disciplinary education and training programs for health care providers.

API: Asian/Pacific Islander.

ASO: AIDS service organization

Availability: Primarily concerned with whether the service was offered to the client/community.

Barriers: A number of factors or circumstances that prohibit or inhibit access and/or use of services. The reason for and source of barriers are diverse.

CARE Act: see Ryan White CARE Act.

CAEAR: Cities Advocating Emergency AIDS Relief Coalition

CBO: Community-Based Organization.

CDC: see Centers for Disease Control and Prevention.

Centers for Disease Control and Prevention (CDC): The Centers for Disease Control and Prevention is a Federal agency of the Department of Health and Human Services. The CDC mission is to promote health and quality of life by preventing and controlling disease, injury and disability. The CDC is the Federal agency responsible for tracking diseases that endanger public health, such as HIV.

Community Forum or Public Meeting: A small-group method of collecting information from community members in which a community meeting is used to provide a directed but highly

interactive discussion. Similar to but less formal than a focus group, it usually includes a larger group; participants are often self-selected (i.e., not randomly selected to attend).

Community Planning Coalition/Group: The CDC started a program in which people from at-risk communities and those who are HIV positive utilize data from scientists and other professionals in order to decide the most effective HIV prevention programs and methods for stopping the spread of HIV infection in their area. In the Houston area, the groups are the Houston HIV Prevention Community Planning Group (covering Harris County) and the East Texas HIV Prevention Community Planning Coalition (covering 51 counties stretching from Matagorda to Texarkana).

Comprehensive Planning: The process of determining the organization and delivery of HIV services; strategy used by a planning body to improve decision-making about the services and maintain a continuum of care.

Consortium: Title II of the Ryan White CARE Act created and authorized consortia. A consortium is an association of public, private non-profit, and community-based organizations operating within an HSDA and individuals who are community leaders, persons representative of populations affected by HIV, people infected with HIV, and family members/caregivers of people with HIV. The consortium determines how Federal and State grant funds will be used in its geographic area to treat and provide services to people with HIV/AIDS. In the Houston area, the consortium is the Houston HIV Service Delivery Area CARE Consortium.

Continuum of Care: A set of services and linking mechanisms that responds to an individual or family's changing needs for HIV prevention and care. A continuum of care is the complete system of providers and available resources (CARE Act and others) for people at risk for or living with HIV and their families within a particular geographic service area, from primary care to supportive services.

CPC/CPG: see Community Planning Coalition/Group.

CTRPN/E: Counseling, Testing, Referral and Partner Notification/Elicitation

Eligible Metropolitan Area (EMA): A designation used by the Ryan White CARE Act to identify an area eligible for funds under Title I (aid to metropolitan areas hardest hit by HIV). The Houston EMA consists of the following six counties: Chambers, Fort Bend, Harris, Liberty, Montgomery, and Waller.

EMA: See Eligible Metropolitan Area.

Epidemic: The spread of an infectious disease through a population or geographic area.

Epidemiologic Profile: A description of the current status, distribution, and impact of an infectious disease or other health-related condition in a specific geographic area.

Epidemiology: The study of factors associated with health and disease and their distribution in the population.

Focus Group: A method of information collection involving a carefully planned discussion among a small group led by a trained moderator.

HAART: Highly Active Anti-Retroviral Treatment

Health Resources and Services Administration (HRSA): The Health Resources and Services Administration directs national health programs that improve the Nation's health by assuring equitable

access to comprehensive, quality health care for all. HRSA works to improve and extend life for people living with HIV/AIDS, provide primary health care to medically underserved people, serve women and children through State programs, and train a health workforce that is both diverse and motivated to work in underserved communities. HRSA administers the Ryan White CARE Act.

HIV Service Area (HSA): A designation used by the City of Houston Health Department within the city limits. HSA's approximate neighborhood boundaries.

HIV Service Delivery Area (HSDA): Also known as Health Service Delivery Area. A designation used by the Ryan White CARE Act to identify an area eligible for funds under Title II (formula funding to States and territories). The Houston area HSDA consists of the following ten counties: Austin, Chambers, Colorado, Fort Bend, Harris, Liberty, Montgomery, Walker, Waller, and Wharton.

Housing Opportunities for People with AIDS (HOPWA): HOPWA is a Federal program of the Department of Housing and Urban Development. HOPWA provides housing assistance and supportive services for low-income people with HIV/AIDS and their families.

HOPWA: see Housing Opportunities for People with AIDS.

HRSA: See Health Resources and Services Administration.

HSA: See HIV Service Area.

HSDA: See HIV Service Delivery Area.

IDU: Injection drug use(r).

KABB: Knowledge, Attitudes, Beliefs and Behaviors. Typically used to describe survey instruments which measure those particular variables in relation to a particular behavior.

Need for Service: The extent the service was requested. May encompass terms such as was the service wanted, desired, necessary to address health problems/concerns.

Needs Assessment: A process of collecting information about the needs of people at risk of or living with HIV and their families (both those receiving care and those not in care), identifying current resources (CARE Act and others) available to meet those needs, and determining what gaps in care exist.

Part F: Part F of the Ryan White CARE Act administers several programs: 1) Special Projects of National Significance (SPNS), which supports the development of innovative models of HIV care and is designed to address special care needs of individuals with HIV/AIDS in minority and hard-to-reach populations; 2) AETC, program is a network of regional centers that conduct targeted, multi-disciplinary education and training programs for health care providers; and 3) HIV/AIDS Dental Reimbursement Program, which assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health treatment to patients with HIV.

Planning Council: Planning Councils are volunteer planning groups composed of community members who prioritize services and allocate funds under Title I of the Ryan White CARE Act. In the Houston area, the planning council is known as the Houston Area HIV Services Ryan White Planning Council.

PLWH/A: People (or person) living with HIV/AIDS; PLWH and PLWA also are used.

Prevention Services: Interventions, strategies, programs, and structures designed to change behavior that may lead to HIV infection or other disease. Examples of HIV prevention services include street outreach, educational sessions, condom distribution, and mentoring and counseling programs.

Public Health Service Area (PHSA): Service area used for public health planning.

MSM: Men who have sex with men.

Ryan White CARE Act: On August 18, 1990, Congress enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. Reauthorized in 1996, the CARE Act is designed to improve the quality and availability of care for individuals and families affected by HIV/AIDS. The CARE Act includes the following major programs: Title I, Title II, Title III, Title IV, and Part F. The CARE Act is now the largest sole source of HIV funding in the nation.

SES: Socio-economic Status. Social and Economic indicators like income and education. SES is consistently correlated with differences in health outcomes.

Sexually Transmitted Disease (STD): A disease that is spread through intimate sexual contact, such as HIV, herpes, syphilis, and gonorrhea.

Special Projects of National Significance (SPNS): SPNS is administered by Part F of the Ryan White CARE Act. This program supports the development of innovative models of HIV care and is designed to address special care needs of individuals with HIV/AIDS in minority and hard-to-reach populations.

SPNS: see Special Projects of National Significance.

TDH: Texas Department of Health.

Title I: Under the Ryan White CARE Act, funding is given to eligible metropolitan areas hardest hit by the HIV/AIDS epidemic. In the Houston area, Title I funding is given to the Harris County judge, administered by the Harris County Health Department, and guided by the Houston Area HIV Services Ryan White Planning Council.

Title II: Under the Ryan White CARE Act, funding is given by formula to States and territories to improve the quality, availability, and organization of health care and support services for people living with HIV/AIDS. There is an emphasis on rural populations. In the Houston area, Title II funding is given to the Texas Department of Health, administered by Houston Regional HIV/AIDS Resource Group, and guided by the Houston HSDA CARE Consortium.

Title III: Under the Ryan White CARE Act, funding is given to community-based organizations for outpatient early intervention services. In the Houston area, the Title III grant recipient is the Harris County Hospital District.

Title IV: Under the Ryan White CARE Act, funding is given to public and non-profit entities to coordinate services to, and improve access to research for, children, youth, women and families. In the Houston area, the Title IV grant recipient is the Houston Regional HIV/AIDS Resource Group.

Section VI

PLANNING RESOURCES

The following reports are available from the RYAN WHITE PLANNING COUNCIL OFFICE OF SUPPORT:

1999 NEEDS ASSESSMENT REPORT:

- **MAP OF HOUSTON EMA/HSDA**
- **EXECUTIVE SUMMARY**
- **SUMA REPORT: PERCEPTIONS AND EVALUATION OF HIV/AIDS CARE AND PREVENTION IN HARRIS AND SURROUNDING COUNTIES**
- **1999 HOUSTON EMA EPIDEMIOLOGICAL REPORT**
- **NA REPORT: SURVEY AND FOCUS GROUP REPORT OF CONSUMERS AND PROVIDERS**
- **ATTACHMENTS FOR THE NA REPORTS**
- **IDENTIFICATION AND DESCRIPTION OF THE CONTINUUM OF CARE**
- **NA REPORT: SPECIAL STUDY - RURAL PLWH/A**
- **NA REPORT: SPECIAL STUDY - UNDOCUMENTED PLWH/A**
- **HIV/AIDS SERVICES, ELIGIBILITY & OUTCOMES: REPORT FROM THE 1999 PROVIDER SURVEY**

The Needs Assessment reports are available individually at: *www.rwpc.org/Publications/NA_Report/1999_houston_needs_assessment_index.htm* or you may request a hard copy or CD-Rom to be mailed.

Contact: Ryan White Planning Council Office of Support, 2223 West Loop South, Suite 240, Houston, TX 77027, Phone: 713-572-3724, Fax: 713-572-3740, TTD: 713-572-2813, Web: www.rwpc.org.

The following report is available from the HOUSTON REGIONAL HIV/AIDS RESOURCE GROUP:

1999 HOUSTON HSDA EPIDEMIOLOGICAL REPORT
Contact: Houston Regional HIV/AIDS Resource Group, 500 Lovett Blvd., Suite 100, Houston, TX 77006, Phone: 713-526-1016, Fax: 713-526-2369, Web: *www.hivresourcegroup.org*

The following reports are available from the CITY OF HOUSTON:

HIV SURVEILLANCE INFORMATION FROM CITY OF HOUSTON HEALTH DEPARTMENT
Contact: Kaye Reynolds, HIV Surveillance, 8000 N. Stadium Drive, Houston, TX 77054, Phone: 713-794-9441, Fax: 713-794-9391

CITY OF HOUSTON PREVENTION NEEDS ASSESSMENT REPORT, 1999
Contact: Glenda Gardner, HDHHS, Bureau of HIV/STD, 8000 N. Stadium Drive, Houston, TX 77054, Phone: 713-794-9092, Fax: 713-798-0830

2000 HIV PREVENTION COMPREHENSIVE PLAN
Contact: Glenda Gardner, HDHHS, Bureau of HIV/STD, 8000 N. Stadium Drive, Houston, TX 77054, Phone: 713-794-9092, Fax: 713-798-0830

EPIDEMIOLOGY OF SEXUALLY TRANSMITTED DISEASES
Contact: Glenda Gardner, HDHHS, Bureau of HIV/STD, 8000 N. Stadium Drive, Houston, TX 77054, Phone: 713-794-9092, Fax: 713-798-0830

The following reports are available from the TEXAS DEPARTMENT OF HEALTH:

HIV SURVEILLANCE INFORMATION FROM THE TEXAS DEPARTMENT OF HEALTH
Contact: Dianna Highberg, TDH HIV/STD, 1100 West 49th Street, Austin, TX 78756, Phone: 512-490-2560, Fax: 512-490-2536

TEXAS HIV EPIDEMIC PROFILE - EAST TEXAS AREA
Contact: Susan Rokes, TDH Region IV/East Texas Coalition, 5425 Polk Avenue, Suite J, Houston, TX 77023, Phone: 713-767-3441, Fax: 713-767-3295

EAST TEXAS REGIONAL ACTION PLAN - TDH REGION IV
Contact: Susan Rokes, TDH Region IV/East Texas Coalition, 5425 Polk Avenue, Suite J, Houston, TX 77023, Phone: 713-767-3441, Fax: 713-767-3295

The following reports are available from the HRSA-HIV/AIDS BUREAU:

OUTCOMES EVALUATION TECHNICAL ASSISTANCE GUIDE
(Available for download at: *www.hrsa.gov/hab/evaluation)*

NEEDS ASSESSMENT SELF ASSESSMENT MODULE FOR PLANNING COUNCILS AND CONSORTIA

COMPREHENSIVE HIV SERVICES PLANNING SELF ASSESSMENT MODULE FOR PLANNING COUNCILS AND CONSORTIA

Contact: HRSA-HIV/AIDS BUREAU, 5600 Fishers Lane, Rm. 7-46, Rockville, MD 20857, Phone: 301-443-6652, Fax 301-443-0791, Information Center Phone: 1-888-ASK-HRSA (1-888-275-4772), Web: *www.hrsa.dhhs.gov/hab/publications.html*