Executive Summary

INTRODUCTION

The 2005 Houston Area Comprehensive HIV/AIDS Needs Assessment was designed to provide accurate and reliable information about people living with HIV/AIDS (PLWHA) service use, perceived need, access barriers and service gaps. The partner agencies[1] supporting this needs assessment will use the information to prioritize fundable services, allocate resources, develop programmatic recommendations to best meet the needs of PLWHA and enhance the continuum of care. These partner agencies provide services to a ten-county region, designated by the State as a Ryan White Title II Health Service Delivery Area (HSDA). Six of these counties comprise the federally defined Eligible Metropolitan Area (EMA) that receives Ryan White Title I funding.[2]

This needs assessment presents information gathered from surveying 654 PLWHA, 85 service providers and 97 individuals participating in eleven focus groups. In addition throughout the needs assessment, focus was placed on 13 priority populations that include:

- Pediatrics (0 - 12 years)
- Youth (13 - 24 years)
- Injecting drug users (IDUs)
- Other Substance Users
- African-Americans
- Latinos/Hispanics
- White/Anglo men who have sex with men (MSM)
- Men of color who have sex with men (MCSM)
- Women of childbearing age (13 - 44 years)
- Rural Residents
- Recently released from jail/prison
- Homeless PLWHA
- PLWHA with mental health conditions and with co-morbidities of TB or STI

The consumer survey sample was slightly younger, included more women and more minorities than the overall epidemic in the region. This was due to the need to adequately sample each of the priority populations. Of the focus groups, nine were conducted with consumers and two with providers. Consumer groups included: African-American men, African-American women, recently released, white/Anglo men who have sex with men (MSM), minority MSM, homeless, substance users, Latino men and Latina women. Both Latino groups were conducted in Spanish. Provider focus groups included case management supervisors and non-Ryan White providers.

[1] Partner agencies include Houston Area Ryan White Planning Council, Harris County Public Health and Environmental Services Department, Houston Regional HIV/AIDS Resource Group, State of Texas Assembly Group East (STAGE), City of Houston HIV Prevention Community Planning Group (CPG), East Texas CPG, Housing Opportunities for Persons with AIDS (HOPWA), Harris County Hospital District, and the Coalition for the Homeless of Houston/Harris County.

[2] EMA counties include Chambers, Fort Bend, Harris, Liberty, Montgomery and Waller. The HSDA includes these six plus Austin, Colorado, Walker, Wharton.

CHARACTERISTICS OF OUT-OF-CARE PLWHA

Information about out-of-care PLWHA should be used to expand and develop services that will promote entry into the care system and encourage service utilization. Key characteristics of out-of-care consumers include:

- More frequently male or transgendered individuals in comparison to women.
- Younger than in-care consumers, including 60% of youth respondents.
- Less likely to have an AIDS diagnosis than in-care PLWHA. The most frequent reason for being out-of-care was, "I do not believe I need medical care currently because I am not sick."
- More recently diagnosed with HIV than those receiving medical care.
- More than 80% are uninsured compared to 48% of those in-care and 25% of all EMA/HSDA residents who are uninsured. "I don't have a way to pay for it" was a frequently identified barrier to care for both in-care and out-of-care PLWHA.
- History of drug use is similar for both in-care and out-of-care consumers, but different in the percentage of current users with nearly 40% of out-of-care PLWHA reporting current IV or other substance use vs. 11% of those receiving HIV medical care.
- In comparison to in-care consumers, a larger percentage of out-of-care consumers did not receive service referrals when diagnosed, 24% of out-of-care versus 15% of in-care.
- Out-of-care PLWHA are difficult to locate in rural counties. The survey sample included 15% rural out-of-care compared to 30% out-of-care for the total sample.
- Out-of-care PLWHA report a wide range of unfulfilled service needs including: rental assistance, primary medical care, health insurance, oral health and utility assistance with more than 60% of respondents citing each of these.

Attributes of the out-of-care priority populations that are different from the total out-of-care sample include:

- Out-of-care African-Americans more frequently report treatment for sexually transmitted infections (STI) or tuberculosis (TB) than their in-care counterparts.
- Out-of-care Latino PLWHA are employed either full-time or part-time to a greater extent than in-care Latinos and other out-of-care populations. Out-of-care Latinos' frequently identified barriers to care included "fear of being deported" and "I can't get services because of immigrant/legal status."
- 40% of IDUs identify commercial sex work as a transmission mode.
- Out-of-care PLWHA recently released from jail/prison are more frequently homeless, active drug users, and unemployed. This population is 30% white/ Anglo, compared to 21% of the out-of-care sample.

- Out-of-care substance users are younger than the total survey sample and other out-of-care populations. Although they typically went farther in school than other out-of-care populations, they tend to be unemployed with low incomes and no insurance.
- Out-of-care women tend to be working and incomes are somewhat higher than other groups. Women are more recently diagnosed than other out-of-care populations, and 35% entered medical care and then dropped out, compared to 29% of the total sample.
- Youth tend to be out-of-care to a greater extent than other populations. According to the survey results, out-of-care youth tend to be male or transgendered and a larger percentage are white than found in other out-of-care populations.

CHARACTERISTICS OF IN-CARE PLWHA

A total of 452 consumer survey respondents are receiving HIV medical care. Most of these surveys were conducted at provider agencies throughout the EMA/HSDA.

Primary medical care, vision care, oral health care, case management and food bank were the most widely needed services among in-care PLWHA. In general, these needs are being met.

- Primary medical care is the most needed service among in-care PLWHA, and more than 90% report the need is being met. Of those identifying barriers to primary care, the most frequently identified is access (i.e., far away, inconvenient hours, long waiting times, etc.) followed by information (i.e., didn't know it existed, where to go, how to qualify, etc.)
- Vision care is in-care consumers' second most frequently needed service, with 85% citing this need, and oral health care (dental) is third, with need reported by 79% of in-care respondents. In both cases, two-thirds report their needs are being met while one-third of those needing the services report their needs are not being fulfilled. For both services most frequently identified barriers are access followed by information.
- Case management is needed by 79% of in-care consumers, and 84% of these PLWHA are having this need met, with almost all reporting it is "easily" met.
- Food bank is needed by nearly three-quarters of in-care PLWHA, and 80% report this need is being met.

Services with the largest number of in-care PLWHA reporting their needs not being met are supportive in nature and include: rental assistance, utility assistance, housing-related services, household items and legal services.

Although the increased availability of bus passes has yielded positive results,

transportation is an ongoing need for in-care PLWHA.

- Two-thirds report a need for bus passes, and more than 73% are having this need met.
- Both gas/taxi vouchers and van transportation are needed by 46% of in-care consumers. These needs are not as easily met with nearly 60% reporting unfulfilled needs for gas/taxi vouchers and 50% reporting unfulfilled needs for van transportation.

The impact of unfulfilled transportation needs can be seen on the number of in-care PLWHA reporting missed medical appointments due to transportation: more than one-quarter of respondents report missing between one and five medical appointments in the last 12 months due to "transportation problems", and another 5% have missed more than five medical appointments for this reason. Transportation was also identified as something that keeps 12% of in-care PLWHA from "getting needed HIV medical care."

Other identified general barriers to accessing HIV medical care include "I don't have a way to pay for it" for 13% of in-care respondents and "I don't feel welcome" for 5%.

SIGNIFICANT FINDINGS AND RECOMMENDATIONS

Linking PLWHA with the HIV medical care system and maintaining them in care is an overarching goal of the CARE Act. As EMAs and HSDAs accomplish this goal, current care systems will be required to expand to accommodate additional capacity. The rate and timing of this expansion will be dependent upon the success of early intervention services and outreach in effectively linking PLWHA with the care system and provider agencies' effectiveness in maintaining PLWHA in the care system.

The consumer survey identified PLWHA service needs, including needs of the total sample, in-care, out-of-care and the 13 priority populations. The extent that needs were being fulfilled or not fulfilled for each group was also determined. These results were projected to the population of PLWHA living in the EMA/HSDA in order to consider the *total* potential demand on the care system if *all* consumer needs were fulfilled. Results for each service are published in the report. The actual demand for services, however, will be determined by the Houston EMA/HSDA's success in linking PLWHA with the care system and maintaining them in care.

Effective initial linkage with the service system upon diagnosis is a critical determinant of in-care or out-of-care status. Seventy percent of out-of-care PLWHA *never* entered the care system after diagnosis while 58% of in-care consumers *immediately* began medical care after diagnosis. Therefore, effectively moving newly diagnosed PLWHA into medical care upon diagnosis is the critical first step to accessing and maintaining PLWHA in the system of care. Individualized, culturally appropriate approaches to making these linkages during post-test counseling is critical. Identify the most effective approaches with targeted populations and replicate them.

HRSA defined six core services[3] that are critical to accomplishing the goal of providing HIV medical care for all diagnosed PLWHA. The first core service is HIV primary medical care. Current providers have limited capacity to serve large volumes of additional patients. Through targeted development, new and expanded programs should reduce perceived barriers to care for those who are currently outside the care system. Consider funding model programs that combine targeted outreach and medical care for specific out-of-care populations. In addition, the feasibility of expanding capacity through a continuum of HIV medical care should be evaluated. This would include care for "well" PLWHA in community or neighborhood clinic settings progressing to specialty infectious disease care for those with more advanced disease. OB/GYN services for female consumers should be co-located with HIV medical care when possible, and community providers should be trained to care for these women in their local settings.

Focus group results demonstrated that a fine line exists between "empowering" consumers and consumer perceptions that case managers are "not doing their jobs." While empowerment is a goal, accomplishing it can be challenging for case managers. Case management support, including such things as training, standards of care and outcomes evaluation tools, should promote consumer/case manager relationships that foster empowerment. Specific case management guidelines or acuity scales should be developed for supporting consumers though the first year of diagnosis. Expansion of targeted case management services for consumers with intensive needs, such as recently released or youth, should be considered.

The availability of drug reimbursement services needs to be better communicated to both consumers and providers, using targeted messaging. Ideally information should be integrated from all drug reimbursement funding sources and providers in order to reduce duplication. Options to increase drug reimbursement funding for both HIV and non-HIV medication should be evaluated. This includes, but is not limited to, reimbursement for non-HIV medication and reimbursement for co-payments and payments to augment insurance that does not adequately cover HIV medication.

Mental health therapy and counseling may be expanded in order to promote the development of model programs for targeted populations. These may include programs for newly diagnosed PLWHA that promote diagnosis acceptance and linkage with the care system, services for youth, women, recently released, Latinos and PLWHA with dual diagnoses of substance abuse and mental disorders. Mental health therapy should be integrated with counseling and testing, HIV medical care and case management services. Literature about mental health services should inform, promote and de-stigmatize the service. Consider using testimonials or consumers' verbatim remarks, similar to those made in the focus groups, attesting to the benefits obtained from mental health services.

[3] Core services include: primary medical care, case management, drug reimbursement, mental health therapy and counseling, substance abuse treatment, and oral health care.

The consumer survey and focus group discussions present a picture of substance abuse treatment that is available, but not always optimal for diverse populations. Provider information reveals available services, but not these are not always targeted to PLWHA. These services may also be limited for the uninsured. Identify opportunities to leverage funding through partnerships with substance abuse treatment programs. Explore alternative models of providing mental health and substance abuse counseling at primary care sites. Continue to educate substance abuse treatment providers to more effectively treat HIV positive consumers.

In order to most effectively meet PLWHA service needs and leverage the purchasing power of HIV-specific funds, develop collaborative services/programs with other funding sources. Services may blend HIV care or supportive services, housing, substance abuse treatment, etc, and may target specific populations. Consider beginning with a visible, beneficial, low-cost intervention that can be accomplished within the first year. Build upon successes with the ultimate goal of an integrated, balanced HIV service continuum with non-HIV specific agencies and funding sources contributing at least as much as HIV-specific funding.

Safe, affordable permanent housing is an ongoing need for impoverished PLWHA. While some consumers find dedicated housing for PLWHA appealing others are concerned about disclosure by association with PLWHA-specific housing. Therefore, both options should be considered as housing is developed. Partner with local organizations to expand housing options for PLWHA. Consider collaborative activities in which housing organizations provide facilities and HIV-specific funding provides core and supportive services.

Low income PLWHA have unfulfilled basic needs that can pose significant barriers to care. For many of these services, non-HIV specific organizations are available and accessible throughout the EMA/HSDA. As resources are expended on core services, reductions in CARE Act funding may be appropriate if services are provided by other community organizations. PLWHA will need to access these non-HIV specific funded services for such things as food, emergency financial assistance, housing assistance, some types of vision care, etc. Case managers and others directing PLWHA must have complete information about these community resources in order to make appropriate referrals, including service location, hours of operation, qualification requirements, approval process and bus route access.

The stigma of HIV disease is a significant barrier to care within the Houston EMA/ HSDA. Stigma prevents people from seeking proper medical and psychological care for HIV disease. A comprehensive approach to combating stigma in the EMA/HSDA is needed. This may be one component of a public relations plan that is undertaken by the partners of this needs assessment.