

Introduction and Methodology

INTRODUCTION AND BACKGROUND

Needs assessment is an essential tool for planning. The purpose of the 2005 Houston Area HIV/AIDS Comprehensive Needs Assessment is to provide accurate and reliable information about the level of use, perception of need, experience of barriers, and analysis of gaps in services to those affected with HIV/AIDS. This information is used by community-based planning bodies in order to:

- ⌘ Prioritize fundable services from a consumer point-of-view, including needed services not currently offered;
- ⌘ Determine funding allocations for those services based upon money available within the various partner organizations, and to inform other funding sources which pay for similar services;
- ⌘ Make programmatic recommendations on how to best meet the needs of clients within those services;
- ⌘ Support efforts to plan a comprehensive system of HIV/AIDS care; and
- ⌘ Provide the supporting documentation for annual Health Resources and Services Administration (HRSA) and Department of State Health Services (DSHS) grant applications.

Legislative mandates dictate that such an assessment include:

- ⌘ Consultation with People Living With HIV/AIDS (PLWHA);
- ⌘ Consultation with HIV/AIDS service providers and others;
- ⌘ Identification of populations with severe needs and co-morbidities as indicated from epidemiological data; and
- ⌘ Evaluation of the effectiveness of available resources and services in meeting needs.

In addition, the 2000 CARE Act Reauthorization placed additional emphasis on identifying people with HIV/AIDS who know their status and are not receiving primary medical care and engaging these individuals in care. Throughout the document these individuals are described as being “out-of-care”. Determining needs of out-of-care PLWHA and developing and/or funding services to meet these needs is critical to fulfilling these legislative mandates.

The following Needs Assessment was conducted for the Houston Eligible Metropolitan Area (EMA) and the Houston Health Services Delivery Area (HSDA) designated by the Texas Department of State Health Services (DSHS). The EMA is designated by the Health Resources and Services Administration (HRSA), a division of the United States

Department of Health and Human Services, to receive Ryan White CARE Act funds to provide services to People Living with HIV or AIDS (PLWHA). The Houston EMA is a six-county area in southeast Texas that consists of Chambers, Fort Bend, Harris, Liberty, Montgomery and Waller counties. The Houston HSDA consists of these same six counties and four others - Austin, Colorado, Walker and Wharton. The land area of the combined EMA/HSDA is 9,415 square miles and the 2000 Census showed the population to be slightly more than 4.3 million.

The Houston EMA receives Ryan White Title I funding, which provides emergency relief to metropolitan areas that are disproportionately affected by HIV/AIDS. This funding is awarded to the Harris County Judge's Office and administered by the HIV Services Division of the Harris County Public Health and Environmental Services Department. As the administrative agency for these Title I funds, \$19 million in fiscal year 2004, HIV Services subcontracts with more than 26 agencies to provide health and support services to PLWHA. HIV Services relies on the Ryan White Planning Council, a volunteer collaboration comprised of people affected by HIV, service providers and community leaders, to establish service definitions, set priorities and allocations and to direct long-range planning for Title I funds.

The Houston HSDA is the area designated by the state to receive Ryan White Title II and DSHS State Services funding, which is intended to improve the quality, availability and organization of health care and support services for PLWHA, with an emphasis on rural populations. In Texas, Title II and DSHS State Services funding is channeled through the Department of State Health Services to the Houston Regional HIV/AIDS Resource Group, Inc. The Resource Group is also the administrative agency for several other funding sources that provide HIV/AIDS services in the area, including Ryan White Title III (funding to community-based organizations for outpatient early intervention services) and Title IV (services for children, youth, women, and families) and some of the funds from Housing Opportunities for Persons with AIDS (HOPWA) for a total of more than \$7.2 million in 2004. The planning body for the HSDA is the State of Texas Assembly Group East (STAGE).

Other partners in the development of this assessment include the: City of Houston HIV Prevention Community Planning Group, East Texas Community Planning Group, City of Houston administered Housing Opportunities for Persons with AIDS (HOPWA), Harris County Hospital District, and Coalition for the Homeless of Houston/Harris County.

The 2004 Integrated Epidemiological Profile identified 15,591 PLWHA in the EMA and 15,690 in the HSDA. These figures are understated, however, since HIV reporting did not begin in Texas until 1999. The epicenter of the HIV epidemic is Houston/Harris County, home to nearly 95% of the infected population.

HRSA has identified priority populations that are disproportionately impacted by HIV

OVERSIGHT OF THE NEEDS ASSESSMENT PROCESS

disease across the country. These are the focus of this needs assessment and include:

- ⌘ Pediatrics (0 - 12 years)
- ⌘ Injecting drug users
- ⌘ African-Americans
- ⌘ White/Anglo MSM
- ⌘ Youth (13 - 24 years)
- ⌘ Other substance users
- ⌘ Latinos
- ⌘ Men of color who have sex with men (MCSM)
- ⌘ Women of child-bearing age (13 - 44 years)

Other priority populations identified by the partners producing the document include:

- ⌘ Recently released
- ⌘ Homeless
- ⌘ PLWHA with co-morbidities of tuberculosis (TB) or sexually transmitted infections (STI)
- ⌘ Rural clients
- ⌘ PLWHA with Mental Health Conditions

Information about undocumented immigrants was also sought, but it was found that these consumers are often reluctant to admit or discuss undocumented status. Instead of undocumented immigrants, therefore, Latinos became a priority population. When possible, information about undocumented Latino consumers was gleaned from the consumer survey and focus group discussions.

METHODOLOGY

OVERSIGHT OF THE NEEDS ASSESSMENT PROCESS

The Joint Needs Assessment Group (NAG) guided the needs assessment process and was made up of representatives of all partner organizations, consumers, service providers and other community members. The tasks of the NAG were distributed among four working groups:

Joint Epidemiology Group—Responsible for collecting epidemiological data from the City, State and other sources which was used, among other things, to determine the number of consumers to be sampled in each of the subpopulations. These “cell numbers” were used to develop a work plan for data collection. This group also reviewed and provided input for the Epi report before being presented to the full planning bodies for approval.

Joint Data Collection Group—Responsible for consumer data collection including oversight of both the consumer survey and all focus groups. This included: identifying priority populations for the study, consumer survey development and approval, determining sample size requirements, identifying agencies for survey administration, monitoring survey returns based upon consultant report, and determining populations to include in focus group discussions.

Joint Resource Inventory Group—Responsible for the provider survey, including development of survey instrument. In order to improve provider survey response, members personally contacted agencies to solicit cooperation in completing the survey. This significantly improved the response rate compared to previous years.

Joint Gap Analysis Group—Responsible for planning data presentation and reviewing the needs assessment report for content and accuracy before being presented to the NAG and full planning bodies for approval.

CONSUMER SURVEY

A survey of 654 people living with HIV disease was conducted during April and May 2004. This included 452 consumers receiving HIV medical care and 202 (30.9%) who were not receiving it.⁴ These percentages approximate the Centers for Disease Control and Prevention (CDC) estimate that one third of PLWHA are outside the care system.

Survey Design

The Texas Statewide Coordinated Statement of Need (SCSN) Project developed a consumer needs assessment survey instrument for use throughout the state. This survey was the foundation for the 2004 Houston-Area Comprehensive Needs Assessment consumer survey. Questions were added to the SCSN survey to gather additional information about the needs of out-of-care, homeless, recently released and substance users/injecting drug users. New questions were designed to be consistent with the existing survey format, and additions were made with concern for the overall length of the survey. This survey was translated into Spanish.

The survey was modified for administration to caregivers of pediatric patients. Changes for homebound clients were considered, but it was felt that the general survey was acceptable for that population.

All consumer surveys used in this study are included in Appendix 1.

Survey Sampling Approach

Methodology

A pure random sample is not feasible since each PLWHA in the Houston region would have to have an equal probability of selection. Therefore, a stratified convenience sample was used. A sampling plan was developed by the Joint Epi Group and is presented in Appendix 2.

A weekly sample profile was produced that examined the number of respondents in each priority population and evaluated conformance to the sampling plan. Agencies surveying in-care consumers and field team members surveying out-of-care PLWHA were informed of sample requirements and directed to survey specific

⁴ “Receiving medical care” and “in-care” are defined as having any of the following in the last 12 months: a CD4 test, a viral load test or being on antiretroviral therapy.

groups of consumers in order to adequately sample the priority populations.

Field Team Recruitment and Training

A 29 member field team was used for survey administration. The field team was comprised of outreach workers, counselors, PLWHA and others. The field team was recruited and managed by Families Under Urban and Social Attack (FUUSA). FUUSA is a non-profit social service organization with ties to both Houston and the surrounding rural areas. An application was used to screen and select field team members. In order to avoid conflict of interest, field team members could not be employees of any partner funded organizations.

Field team members were instructed in the goals of the needs assessment, candidate selection, interviewing techniques and proper completion of the survey form during a six-hour training session. The SCSN Project Director conducted the first training with New Solutions, Inc. (NSI) support. A second group was also trained by NSI consultants. Two weeks into the survey process, a follow-up training and debriefing session reinforced the training and clarified questions relating to proper completion of the survey tool.

Survey Administration

Three approaches were used for survey administration. In-care consumers were surveyed at agencies they use for services, out-of-care PLWHA were identified in the field and surveyed, and homebound and outlying rural consumers were interviewed via telephone.

In-care PLWHA were surveyed at provider agencies throughout the HSDA. A surveying schedule was developed by members of the Joint Data Collection Group with the help of FUUSA representatives. In order to enhance the diversity of the sample, the schedule targeted smaller, diverse agencies early in the process, and included large providers toward the end of the field work. In this way, larger providers recruited participants in a targeted manner to meet sampling goals. Field team members were scheduled at agencies based upon the projected number of consumers to be surveyed. At least one Spanish speaking field team member was present at all survey locations.

Field team members administered surveys at provider locations under the supervision of a representative from the Office of Support for the Ryan White Planning Council. This provided field team members with constant supervision and additional familiarity and training on survey administration.

Field team members conducted surveys of the out-of-care independently or under the supervision of a FUUSA outreach worker. Team members were originally hired because of connections with out-of-care PLWHA, and these networks were tapped for surveying. Before being approved for out-of-care interviewing, field team members gained experience with the survey instrument at in-care agency sites. The FUUSA HIV

Program Director determined when field team members were ready to administer surveys to out-of-care individuals in the field. To ensure proper completion, submitted out-of-care surveys were checked by the FUUSA program director.

Homebound, rural or PLWHA with other situations that limited ability to participate in the survey at provider locations were surveyed via telephone. Key case management and home health agencies were contacted throughout the HSDA to solicit telephone survey participants. Case managers were asked to contact appropriate PLWHA and those consenting to participate completed the survey with an NSI representative over the telephone. Since a rural focus group was not considered feasible, additional phone surveys with rural consumers were conducted at the end of the survey period.

Consumer Stipends and Field Team Payment

Upon completion of the survey, both in-care and out-of-care PLWHA were given a gift card for their participation. Homebound and rural consumers received their gift card via the mail.

Field team members were paid hourly for work at in-care agencies. For out-of-care surveys, field team members were paid for each completed survey submitted. Upon completing either five out-of-care surveys or six hours at in-care agencies, field team members qualified to be paid for attendance at the field team training.

Data Analysis

Due to the complexity of the survey instrument, optical scanning could not be used for data entry. Data was entered manually using an NSI-developed database containing more than 600 data fields. A data checking system ensured accuracy of data entry.

As mentioned above, weekly respondent profiles were run in order to monitor the sample. These profiles included the number surveyed from each priority population, sample demographics, transmission mode and county of residence.

One month into the field work, an abbreviated report of findings was submitted to the Joint Data Collection Group in order to support decision-making about populations to target with focus group discussions.

Once the field work was completed, data was cleaned in order to minimize inconsistencies, and “other” responses were re-categorized when possible. Statistical analyses were conducted including frequencies and cross tabulations for in-care, out-of-care and priority populations. Total service need, met and unfulfilled need calculations were performed along with detailed information on barriers to care and are included in this report. This same information shown as a table or graph is available on CD-Rom from the Office of Support for the Ryan White Planning Council.

Respondent Overview

People living with HIV, not AIDS, are overrepresented in the survey sample when compared to epidemiology data. People living with AIDS are 60% of the Houston-area epidemic and 40% of the survey sample.⁵

Based upon gender, the survey sample includes 63% male respondents and 34% female. This compares to 74% males and 25% females infected in the region.

- ⌘ The survey's gender distribution is more closely aligned with HIV diagnoses which include two-thirds men (66.4%) and one-third women (33.6%).

By age, the survey sample has a slightly younger profile than the regional epidemic overall.

- ⌘ The sample is made up of 2.1% children 12 years of age and under, compared to 1.2% infected in the region. Even with this percentage, however, the pediatric survey sample is small, n=14.
- ⌘ The sample includes 9.2% youth ages 13 to 24, compared to 4.8% in the overall epidemic. Since youth was a population of focus, this age group was targeted for oversampling with a resulting n=66.
- ⌘ A total of 56% of the sample is in the 25 to 44 year age range, compared to nearly 60% of the epidemic.
- ⌘ More than 29% of the sample is in the 45 to 64 age range, compared to 32.4% of the regional epidemic.

Racial variations between the sample and the regional epidemic include:

- ⌘ Hispanics are over-represented in the sample, comprising 23% of the sample and 18% of PLWHA in the EMA/HSDA.
- ⌘ White, non-Hispanics are under-represented in the sample, comprising 22% of those surveyed and 33% of PLWHA in the EMA/HSDA.
- ⌘ Black, non-Hispanics are 50% of the survey sample and 48% of the regional epidemic.
- ⌘ The survey sample included 14% monolingual Spanish-speaking respondents.

Survey Limitations

As is the case with the administration of large-scale surveys, some data limitations were identified. These include:

- ⌘ The possibility of selecting contradictory responses;

⁵ In comparing the consumer survey sample to the epidemiology in the EMA and HSDA, it should be remembered that HIV reporting did not begin until 1999. The result is that people living with HIV that have not converted to AIDS who were diagnosed before 1999 have not been tested since that time will not be included in surveillance statistics.

FOCUS GROUP DISCUSSIONS

- ⌘ Use of terms that may have been unclear to participants, particularly those with lower reading levels;
- ⌘ Forced selection of responses without the options of “not applicable,” “don’t know” or “refused”;
- ⌘ Confusing formatting of questions; and
- ⌘ Long survey instrument leading to participant fatigue.

In order to minimize these limitations, the following were undertaken:

- ⌘ A staff member from the Office of Support for the Ryan White Planning Council supervised survey administration at all survey sites. She also checked surveys for completeness and consistency. The same staff member attended almost all survey sites, increasing consistency.
- ⌘ Field team members read the survey questions and completed the form for out-of-care consumers. They were available for reading assistance and to answer questions at in-care sites. Spanish speaking field team members were available at all in-care surveying.
- ⌘ FUUSA representatives checked all out-of-care surveys - in the field when possible, or afterwards.

Comparisons of ambiguous responses with other questions to clarify meaning were made whenever necessary.

FOCUS GROUP DISCUSSIONS

Eleven focus group discussions were conducted during June and July. Nine were with consumers and two were with providers. The overall goal was to expand the depth of understanding of consumer needs and barriers to care. Focus groups typically included eight to ten consumers. The largest included 12 substance users while the smallest was made up of five Men of Color who have Sex with Men (MCSM).

Methodology

Consumer Focus Groups

Consumer focus group recruitment was conducted through partner funded agencies. Applications were distributed by the agencies, and FUUSA scheduled qualified participants for the discussions. Although groups targeted specific priority populations, consumer participants often met criteria for more than one group. Since similar questions were asked across groups, the total number of consumer participants for each group and for the priority populations is presented below.

In order to promote effective, open discussion, consumer focus group moderators racially and culturally matched the participants. The two Latino focus groups were conducted in Spanish with a transcriptionist/translator present. Both the African-American and Latina moderator have worked extensively with PLWHA and in the

AIDS community and are familiar with issues confronted by consumers.

Focus groups were conducted at four locations throughout the community. Consumer participants were given a gift card for their attendance.

Groups ranged in length from 90 minutes to 135 minutes. A general focus group guide with targeted questions for populations was used to direct the discussion. (Guides are included in Appendix 2)

Provider Focus Groups

One provider focus group was conducted with case management supervisors and the other with non-HIV-specific providers. The former were recruited from an existing group with the goal of identifying service needs and barriers of their clients. The non-HIV-specific providers were recruited from large Houston-based agencies and organizations in order to discuss improving service integration and linkage to care. An NSI consultant facilitated these groups which were conducted at the Office of Support for the Ryan White Planning Council.

For both consumer and provider focus groups, verbatim transcriptions were made from the voice recorders. All transcripts were grouped by theme and commonality of response.

Consumers Who Delayed Care Focus Group

Knowing that out-of-care generally will not attend group discussions, it was thought that a focus group with consumers who have recently (within the last six months) begun HIV medical care after delaying access for at least a year after diagnosis would provide information about barriers to care and approaches to overcome those barriers. Four Ryan White Title I funded medical providers were asked to solicit participation from their clients fitting this profile. When first attempts at recruiting were unsuccessful, the group was postponed. When the second date arrived, five participants were confirmed, but only one attended. Subsequently it was decided to perform telephone interviews with consumers meeting these criteria, but few participants came forward, and only three interviews were conducted.

FOCUS GROUP DISCUSSIONS

Consumer Focus Group Participant Profile – All Consumer Groups (n=77)

		# Attending Group*	# Meeting Profile**
African-American Straight Men	African-American men who report they are heterosexual	8	14
African-American Women	African-American women between ages 18 and 44	11	17
Diagnosed since 2002	Included in all groups	na	18
Homeless	Currently homeless or living in transitional housing	10	11
Latino Men	Spanish speaking Latino men, recent immigrant status preferred	6	9
Latina Women	Spanish speaking Latina women, recent immigrant status preferred	12	12
Men of Color Who have Sex with Men	The group targeted African-American MSM. This figure reflects African-American, Latino and Asian participants who report being homosexual or bisexual	5	13
Recently Released	Released from jail or prison in last 12 months	6	7
Substance Users	Active substance user with in the last 12 months	10	18
White MSM	White men who report being homosexual or bisexual	9	10
Provider Focus Group Participants n=20			
Case Management Supervisors	Case Management Supervisors from Ryan White funded agencies	11	11
Non-HIV-Specific Providers	Representatives of Large Organizations that Reflect HRSA's Key Points of Entry	9	9

* Attended this focus group.

** Attended any focus group *and* fit profile for this focus group.

PROFILE OF PROVIDER CAPACITY

A detailed provider survey was conducted in order to evaluate services delivered to PLWHA throughout the region.

Survey Design and Sample

The SCSN developed a comprehensive profile of provider capacity survey which served as the basis for the Houston-area survey. In order to meet study objectives, questions were added to the SCSN instrument which focused on funding streams by service, staffing levels, staff qualifications, waiting times for appointments, multilingual staff and cultural competency training and available capacity at current resource level.

The survey was sent to all agencies listed in the Blue Book, the Houston area HIV resource directory published by the Office of Support for the Ryan White Planning Council. In order to enhance the response rate, members of the Joint Resource Inventory Group called upon their contacts at key agencies and personally requested support in completing the survey. In addition, NSI contacted every non-responding provider twice to solicit completed surveys. This process yielded a total of 83 completed surveys during the survey period and five late submissions. The data from this latter group has been included wherever possible. Response rate by service category is presented below. In some cases the rates are greater than 100%, indicating the Blue Book does not have a complete service listing for all agencies returning surveys.

Survey Limitations

Limitations associated with the Profile of Provider Capacity include:

- ⌘ A long and detailed survey that was perceived to focus exclusively on services for PLWHA, discouraging completion by non-HIV-specific providers.
- ⌘ The survey did not ask if a service was provided, it only asked for number of HIV positive clients and the funding directed to their services. Therefore, the true provision of service was not identified since non-HIV-specific services and services not used by PLWHA were omitted.
- ⌘ Some questions were not asked in a yes/no format, so all respondents had to be considered in calculating percentages.
- ⌘ Analyses by service category were often based on small numbers of respondents.
- ⌘ Responses relating to agency attributes (i.e., waiting time for appointment, funded services, etc.) were not specific to services.

Data Analysis

A database was developed for data entry. Data was divided into responses using a number, such as client counts and dollar values and responses using a character, such

as yes-no or a word.

- ⌘ Frequency analysis was conducted for character variables. Percentages were calculated based upon the sample.
- ⌘ Numeric variables were analyzed using the mean.

These analyses were conducted for the total sample and for each service category.

Several gaps analysis methodologies were considered. Due to the data limitations by service category associated with the provider survey, most of the information for the gaps analysis was extrapolated from the consumer survey.

PROFILE OF PROVIDER CAPACITY

Profile of Provider Capacity Respondent Comparison

Service	Total Respondents	<u>Blue Book</u> Total	Respondent % of <u>Blue Book</u>
Ambulatory Outpatient Medical Care			
Primary Care	9	12	75.0%
Vision Care	5	5	100.0%
OB/GYN	4	7	57.0%
Pediatric Care	4	12	33.0%
Treatment Adherence**	5	3	166.7
Buddy/Companion Services**	6	1	27.3%
Case Management	17	42	40.5%
Client Advocacy	5	6	83.3%
Referral Services	7	7	100.0%
Childcare	6	6	100.0%
Day/Respite Care	5	10	50.0%
Drug Reimbursement	6	12	50.0%
Early Intervention Services**	7	2	350.0%
Emergency Financial Assistance	10	38	26.0%
Food Services	7	43	16.0%
Nutritional Supplements**	5	2	250.0%
Health Education/Risk Reduction	11	19	57.9%
Health Insurance**	6	3	200.0%
Home Healthcare	5	11	45.5%
Hospice	4	8	50.0%
Housing Assistance	9	21	42.9%
Housing Related Services	9	33	27.3%
Legal Services	7	10	70.0%
Child Welfare Services**	4	27	14.8%
Mental Health Counseling	8	33	24.2%
Support Groups		21	
Nutritional Counseling**	8	1	57.1%
Oral Health (Dental)	6	6	100.0%
Outreach**	11	20	55.0%
Psychosocial Support**	4	19	21.1%
Rehabilitation	4	8	50.0%
Substance Abuse	10	43	23.3%
Transportation	9	11	81.8%

** This service is not listed as a category in the Blue Book but may be included in an agency's description of services provided.

