
Chapter 6

Focus Group Analysis

FOCUS GROUP ANALYSIS

In order to provide a means to validate the findings of the survey and to gain greater access to the opinions and service recommendations of people affected with HIV/AIDS and providers of services to them, sixteen focus groups were conducted between January 28 and February 1, 2002. Groups were held for the following populations:

Client Groups:

1. African American men who have sex with men
2. Anglo men who have sex with men
3. People with disabilities
4. Incarcerated women
5. Long-term survivors of HIV (diagnosed before 1992)
6. Older Adults, age 45 years or older
7. Residents of northern rural regions
8. Residents of southern rural regions
9. Substance users
10. Women of childbearing age (self-reported as pregnant at time of focus group)
11. Women of childbearing age (self-reported as not pregnant at time of focus group)
12. Youth, ages 13 - 19 (2 groups)
13. Youth, ages 20 - 24

Provider Groups:

1. Providers of services to people affected with HIV/AIDS
2. Providers of services to immigrants and refugees with HIV/AIDS

The focus groups were semi-structured interviews with several topics explored in each. Participants were asked about their perceptions of factors and services that supported them in their efforts to maintain health and factors that may inhibit their efforts. Though each group quickly developed a unique character, several themes were consistently expressed. Among these:

- Participants' assertion that access to medical care and medications was essential
- Perception of increasing social isolation since HIV diagnosis
- Housing, transportation and access to food were often significant challenges
- The importance of support groups to participants, in their attempts to:
 - Adhere to medication regimens
 - Combat isolation and loneliness
 - Learn about HIV and services for PLWH/A

The following discussion briefly summarizes the focus groups. A chart of service category gaps, generated by the survey phase of the Needs Assessment, and analyzed by focus group population, accompanies the summaries, as a means of further validation.

NOTE: Interpretation of data for Hospice, Home Health Care and Adult Day Care is limited by 2 factors: 1- the population surveyed was primarily ambulatory and relatively healthy; 2- the questions on the survey were inadequate to accurately assess the need for these services.

Rehabilitation, Research and Long-Term Care were terms that survey respondents may have found confusing, which may have influenced their response. During the validation process, several told facilitators that they interpreted rehabilitation to refer to such services as substance abuse treatment or post-incarceration services, such as employment training.

AFRICAN AMERICAN MEN WHO HAVE SEX WITH MEN

The participants in this group were primarily young men, most of who identified as homosexual, and approximately one-third as bisexual. The men were savvy about services and offered generally positive comments about medical and social service providers, with minor complaints about infrastructure issues, such as the burdens of paperwork.

The men discussed the importance of education services to the African American community, and especially prevention services to women, as seen in the following excerpts.

“Educate the public that HIV is not a death sentence. Help them know it’s not fatal. I don’t know how to bring that together.”

“A lot of people fear that they will get negative attention and will feel shame. Many think they are positive but would have to give up a lot of things they’re doing if they were identified.”

Table 6-1: GAP ANALYSIS – AFRICAN AMERICAN MSM

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	41%	1
Ambulatory/Outpatient Medical Care	36%	2
Emergency Medical Services	32%	3
Inpatient Services	24%	4
Rehabilitation*	19%	5
Mental Health Therapy/Counseling	12%	9
Home Health Care *	11%	11
Long-Term Care*	17%	6
Patient Education Services	13%	7
Prevention Education Services	13%	8
Nutritional Services	11%	10
Medications and Therapeutic	8%	13
Research*	9%	12
Dental Care	4%	15
Social Case Management	3%	17
Substance Abuse Treatment/Counseling	5%	14
Hospice*	3%	16

*See note on page 176 regarding these service categories.

A detailed analysis of the issues faced by African American MSM can be found in Chapter 9.

ANGLO MEN WHO HAVE SEX WITH MEN

Participants in this group were quite familiar with systems of care, and demonstrated great familiarity with Ryan White funded programs. Concerns of the participants were housing, transportation and relationships with case managers.

Although at least one participant owned his home (*“I’m one of the lucky ones”*), most indicated that they were struggling with finding and maintaining stable housing. One individual reported that he only *“lives well when [he] lives with someone else”* but such situations are short-term and unpredictable. Interwoven with the concern for housing was a reported need for transportation.

The most intensely discussed topic in the group was the relationship with case managers. Participants were conflicted about their perceived dependence on their case managers, simultaneously chiding themselves and restating the crucial role the workers play in their lives from assistance in service access to interpersonal support.

“I’ve been positive for 20 years. I don’t really need a caseworker, but in other ways, I really do. I’m sometimes lost... If any of us were to walk in and ask for a caseworker, they’d say ‘OK, we’ll get you an appointment sometime next month.’ Since you’re doing okay, you walked in here, you’re fine.”

Table 6-2: GAP ANALYSIS – ANGLO MSM

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	43%	1
Ambulatory/Outpatient Medical Care	34%	2
Emergency Medical Services	24%	3
Inpatient Services	15%	4
Rehabilitation*	11%	5
Mental Health Therapy/Counseling	8%	7
Home Health Care*	9%	6
Long-Term Care*	7%	9
Patient Education Services	4%	13
Prevention Education Services	8%	8
Nutritional Services	4%	12
Medications and Therapeutic	4%	11
Research*	5%	10
Dental Care	1%	15
Social Case Management	3%	14
Substance Abuse Treatment/Counseling	1%	17
Hospice*	1%	16

*See note on page 176 regarding these service categories.

PEOPLE WITH DISABILITIES

Participants in this group of both men and women who self-identified as disabled, reported physical disabilities, substance abuse and mental illness, in addition to HIV. As might be expected, participants were almost unanimous in listing medications and medical providers as 2 of their top 3 needs, with the third a variation of social or spiritual support.

As was found in other groups, participants cited transportation and housing as severe needs fraught with barriers to access. These range from perceptions of overt discrimination to lack of accommodations for physical disabilities. An especially poignant conversation emerged in which participants discussed their experiences of marginalization and loneliness. According to the group, many individuals face increased social isolation because of the combination of HIV and other disabilities. Participants recounted incidents when family members refused to serve them food on the family dinnerware and others of abandonment by friends.

One participant summarized the attitude of the group as shown by the following:

“Doubly isolated having HIV/AIDS and a handicap. We are either pitied or shunned and can’t get people to just treat us as folks. We work hard to be accepted but can be very prickly when we get rejection and we’ll be rejecting people first with sharp words, actions, avoidance.”

Table 6-3: GAP ANALYSIS - DISABLED

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	52%	1
Ambulatory/Outpatient Medical Care	35%	2
Emergency Medical Services	26%	3
Inpatient Services	18%	4
Rehabilitation*	16%	5
Mental Health Therapy/Counseling	11%	7
Home Health Care*	11%	6
Long-Term Care*	9%	9
Patient Education Services	10%	8
Prevention Education Services	7%	10
Nutritional Services	7%	11
Medications and Therapeutic	5%	13
Research*	5%	12
Dental Care	3%	15
Social Case Management	3%	14
Substance Abuse Treatment/Counseling	2%	17
Hospice*	2%	16

*See note on page 176 regarding these service categories.

INCARCERATED WOMEN

The participants in this group were inmates in a state prison for women. In order to protect their confidentiality, these interviews were conducted individually. Each of the women recounted, without prompting, that they were incarcerated for a drug-related offense. The participants were scheduled for release from one week to 11 months from the time of the interviews. All had children who were currently living with relatives.

None of the women indicated that her HIV status was her most pressing concern, as was the case in many of the other groups. Rather, they were most concerned about their ability to structure a lifestyle that allowed them to refrain from drug use.

Affordable, safe, independent housing for themselves and their children was determined to be the core of that lifestyle. Most also anticipated finding adequate employment and some spoke of job training. When pressed about their health concerns, they spoke of concerns that they would be able to afford medications. At least one woman also spoke passionately about the need for prevention education so, *“my daughter doesn’t end up like me.”*

Table 6-4: GAP ANALYSIS - INCARCERATED WOMEN

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	53%	1
Ambulatory/Outpatient Medical Care	39%	2
Emergency Medical Services	29%	3
Inpatient Services	19%	4
Rehabilitation*	12%	8
Mental Health Therapy/Counseling	8%	11
Home Health Care*	10%	9
Long-Term Care*	14%	5
Patient Education Services	12%	7
Prevention Education Services	13%	6
Nutritional Services	4%	14
Medications and Therapeutic	8%	10
Research*	6%	13
Dental Care	3%	15
Social Case Management	2%	16
Substance Abuse Treatment/Counseling	2%	17
Hospice*	6%	12

*See note on page 176 regarding these service categories.

LONG-TERM SURVIVORS

The selection criterion for this group was a diagnosis with HIV prior to 1992. Participants were men and women ranging in age from approximately mid-40s to mid-50s. None indicated a current AIDS diagnosis. Two individuals discussed comorbidities, one man was diabetic and a woman cited a physical disability related to an injury from an automobile accident.

Most commonly mentioned needs, in addition to medical care and medications, were for transportation, housing and food pantry services. Difficulties with transportation service providers and the belief that public transportation offered more options, encouraged several of the participants to try to gain access to bus passes. Though they stated a clear preference for public transportation, affordability was a major barrier, as one participant explained:

“They [transit service] have changed their policies, and sometime 40 cents is hard to come by. My daughter rides with me, since I don’t have the Freedom Pass. It is hard for me since it would be \$1.40 going and \$1.40 coming back, that is \$2.80 I could use for food or rent.”

For a few participants, limited access to safe, affordable housing was classified as a deterrent to medication adherence and medical treatment. This is consistent with the information provided in many of the groups. Three of the participants were Hispanic and stressed the importance of bilingual, bicultural staff in medical and support service agencies. An example came in the discussion of food assistance. Participants requested not only that additional food pantries be established in a wider range of locations, but also that providers consider stocking more ethnic foods.

Table 6-5: GAP ANALYSIS - LONG-TERM SURVIVORS

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	45%	1
Ambulatory/Outpatient Medical Care	36%	2
Emergency Medical Services	28%	3
Inpatient Services	19%	4
Rehabilitation*	14%	5
Mental Health Therapy/Counseling	8%	11
Home Health Care*	9%	7
Long-Term Care*	9%	9
Patient Education Services	9%	8
Prevention Education Services	10%	6
Nutritional Services	8%	10
Medications and Therapeutic	4%	13
Research*	6%	12
Dental Care	2%	16
Social Case Management	4%	14
Substance Abuse Treatment/Counseling	2%	17
Hospice*	3%	15

*See note on page 176 regarding these service categories.

NORTHERN RURAL RESIDENTS

Participants in this group were men and women who live primarily in Montgomery County, an area north of Houston. The critical needs reported by the participants were the need for satellite service sites, especially for dental, medical and food pantry¹ services; transportation and community-based information campaigns and prevention education.

According to participants, rural medical and dental providers are not only ill equipped to assist clients in health maintenance and treat them for HIV-related conditions, but also quite reluctant to do so. In contrast, participants expressed much satisfaction with agencies that offer satellite services locally, but they indicated that these are limited. Many, therefore, chose to seek healthcare in Houston. Transportation then becomes a barrier to accessing care. Policies of providers that permit little flexibility in keeping appointment times or who have policies that require appointments to be made to complete paperwork, were noted to be burdensome for rural clients.

The recommendations for community information and prevention education were particularly strident in this group. Participants recounted incidences where they were shunned or directly discriminated against because of their HIV status. They further reported that community awareness of HIV risk and prevention behaviors was lacking and that few venues were available for this information to be presented.

Table 6-6: GAP ANALYSIS (NOT DIFFERENTIATED SOUTH VS NORTH)

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	40%	1
Ambulatory/Outpatient Medical Care	32%	2
Emergency Medical Services	27%	3
Inpatient Services	12%	4
Rehabilitation*	4%	11
Mental Health Therapy/Counseling	4%	15
Home Health Care*	9%	5
Long-Term Care*	8%	6
Patient Education Services	4%	10
Prevention Education Services	7%	8
Nutritional Services	5%	9
Medications and Therapeutic	7%	7
Research*	4%	14
Dental Care	4%	12
Social Case Management	0%	17
Substance Abuse Treatment/Counseling	0%	16
Hospice*	4%	13

*See note on page 176 regarding these service categories.

¹ While food pantry service is critical and is reported in several groups, it is also noteworthy that the group was held in a site where a food pantry was about to close and there was an anticipated 4 - 6 week interval before a new provider would be operational.

ADULTS OVER 45

This group of men and women reported that the most crucial needs related to their healthcare were access to medication, medical providers and financial assistance. The need for medical care was particularly important in this group, all but one participant also reported significant comorbidities that included: bipolar disorder, CMV, diabetes, AIDS-related asthma, hypertension and stroke. One participant had also been diagnosed with AIDS. In their discussion of the need for medical care, they were especially articulate about the necessity for providers to be adequately informed and to treat them in a compassionate and respectful manner. Participants noted that issues of competence and provider attitude were more likely problematic when they sought care from a provider not accustomed to treating PLWH/A, as the following passage illustrates:

“The attitudes of people towards those receiving HIV care in settings that are not just for AIDS patients is very bad. The ignorance of many health care professionals, treating us like we are contagious or wicked is a hurtful thing to our mind frame, at a time when we can not afford stress in our lives.”

The group also addressed the importance of social support. One of the participants told of his experiences as an informal mentor to a younger, newly diagnosed patient. He stressed the sense of isolation one feels at the time of diagnosis, which was exacerbated in this case, since the young patient was also monolingual in Spanish. When told he had AIDS, he felt terrible. [Mentor] met him at [provider] and told him “You might die of something else, this you can live with”. He was better after that.

Table 6-7: GAP ANALYSIS – OLDER ADULTS

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	38%	1
Ambulatory/Outpatient Medical Care	26%	2
Emergency Medical Services	19%	3
Inpatient Services	11%	5
Rehabilitation*	10%	7
Mental Health Therapy/Counseling	13%	4
Home Health Care*	9%	8
Long-Term Care*	10%	6
Patient Education Services	5%	12
Prevention Education Services	3%	14
Nutritional Services	6%	9
Medications and Therapeutic	6%	10
Research*	1%	16
Dental Care	1%	15
Social Case Management	5%	11
Substance Abuse Treatment/Counseling	4%	13
Hospice*	1%	17

*See note on page 176 regarding these service categories.

CURRENTLY PREGNANT WOMEN

While the women in this group asserted that medical care and access to medications were essential needs, especially as they affected their pregnancies, the central theme of the group was the importance of their relationships with their providers. Participants spoke of the critical importance of case managers and medical staff in assisting them with medication adherence, maintaining emotional health and hope and coping with their fears related to the health status of their children. The following is reflective of several comments.

“I thought of not taking my medications, when I went to [provider], they make me feel so happy and comfortable, even tranquil that I make sure I stay on my treatment.”

The medical concerns of the group were significant. Ranging in age from 39 to 45, their risks associated with pregnancy were higher and all but one reported a comorbidity including: stroke, diabetes and paranoid schizophrenia. Nonetheless, when they spoke of their healthcare needs, they focused exclusively on their hopes and fears for their children.

“We all worry—we’ve been in treatment for 2 years and then find out new things about how strong this disease is. My main worry is for my baby to not be affected.”

“I worry about my baby being HIV positive, it’s a 50/50 chance of my baby being affected by medicine. This is a happy but scary time.”

Table 6-8: GAP ANALYSIS – WOMEN (NOT DIFFERENTIATED BY PREGNANCY STATUS)

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	40%	1
Ambulatory/Outpatient Medical Care	28%	2
Emergency Medical Services	16%	3
Inpatient Services	11%	4
Rehabilitation*	8%	6
Mental Health Therapy/Counseling	7%	9
Home Health Care*	8%	7
Long-Term Care*	6%	11
Patient Education Services	8%	5
Prevention Education Services	8%	8
Nutritional Services	6%	10
Medications and Therapeutic	5%	12
Research*	2%	15
Dental Care	4%	13
Social Case Management	3%	14
Substance Abuse Treatment/Counseling	1%	16
Hospice*	1%	17

*See note on page 176 regarding these service categories.

SOUTHERN RURAL RESIDENTS

All participants indicated that medical care, access to medications and dental care were their most essential needs. Their requests for medical care included not only access to clinics, but equally to medical personnel who are well informed and accessible. Several of the participants were treated in Houston, which is located more than 30 miles from the site of the focus groups and as much as 90 miles from the home of at least one of the participants. Access to medications required, for participants, adequately informed medical personnel and financial assistance to purchase the drugs. Currently, all participants are under regular medical care, and all expressed general satisfaction with most of their providers, although there was discussion about the “attitudes of some of them.” Their dissatisfaction appeared to be much less prominent than it was in the northern counties.

Dental care was considered an essential need both because of the paucity of dentists in their hometowns and because of the lack of training about care of HIV+ patients among these providers. All participants found that transportation was quite problematic in the area. As in many other groups, participants stressed the importance of community education and the impact that an informed and compassionate community has on the quality of their lives.

“The more information you get out to the community, the better people deal with stuff. There are family members, of course, that are not able to deal well with the issues for lack of knowledge. A lot of times it’s very uncomfortable. It’s very important for them to get together using the Ryan White funding, to get the information to the communities.”

Table 6-9: GAP ANALYSIS – RURAL (NOT DIFFERENTIATED SOUTHERN VS NORTHERN)

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	40%	1
Ambulatory/Outpatient Medical Care	32%	2
Emergency Medical Services	27%	3
Inpatient Services	12%	4
Rehabilitation*	4%	11
Mental Health Therapy/Counseling	4%	15
Home Health Care*	9%	5
Long-Term Care*	8%	6
Patient Education Services	4%	10
Prevention Education Services	7%	8
Nutritional Services	5%	9
Medications and Therapeutic	7%	7
Research*	4%	14
Dental Care	4%	12
Social Case Management	0%	17
Substance Abuse Treatment/Counseling	0%	16
Hospice*	4%	13

*See note on page 176 regarding these service categories.

SUBSTANCE USERS

Each of the participants in this group self-reported use of drugs, most often cocaine, heroin and either marijuana and/or alcohol. Participants discussed limitations of medical services, lack of affordable housing and the particular challenged faced by those with a history of incarceration, especially in finding housing. The link between housing and substance abuse recovery is described as follows:

“The location of halfway houses is in the drug-infested neighborhoods. This makes it difficult to recover. The success rate of the houses needs to be checked.”

These participants reported numerous threats to their health, in addition to possible chemical dependency, including episodic or chronic homelessness, repeated incarcerations and difficulties in maintaining medication adherence as well as refraining from HIV risk behaviors.

Table 6-10: GAP ANALYSIS – SUBSTANCE USERS

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	50%	1
Ambulatory/Outpatient Medical Care	32%	2
Emergency Medical Services	29%	3
Inpatient Services	19%	4
Rehabilitation*	13%	6
Mental Health Therapy/Counseling	11%	8
Home Health Care*	15%	5
Long-Term Care*	12%	7
Patient Education Services	10%	9
Prevention Education Services	10%	10
Nutritional Services	6%	13
Medications and Therapeutic	6%	12
Research*	8%	11
Dental Care	4%	15
Social Case Management	3%	16
Substance Abuse Treatment/Counseling	4%	14
Hospice*	3%	17

*See note on page 176 regarding these service categories.

WOMEN NOT CURRENTLY PREGNANT

Comprised of women in their 40s, this group, more than any other, described their HIV status in terms that suggested that their diagnosis reflected on their sense of identity. Though they listed their three highest needs for health maintenance: medical care, case management and housing, they stressed that they wanted to communicate the impact of the diagnosis. That discussion centered on the shame and ostracism that they believed their diagnosis caused them. Although never asked the question, four of the six participants volunteered that they were infected through blood transfusion, all after 1990, which seemed unlikely, but underscores the fear of judgment that was repeated throughout the Group.

Each recounted the story of her diagnosis. Four indicated that they were not told they were HIV positive, but rather were given indirect comments that hinted at the situation. All reported that the quality of care from the private physicians who had treated them prior to diagnosis deteriorated so much so that they transferred to a clinic specializing in HIV care. The group reported their initial reactions to their diagnosis: depression, alcohol abuse treatment avoidance and passivity. For one woman, the experience was sufficiently disconcerting, that she had not sought care since her diagnosis 6 months prior to the group. At the conclusion of the session, the women concurred that support groups would be very useful to them.

Table 6-11: GAP ANALYSIS - WOMEN (NOT DIFFERENTIATED BY PREGNANCY STATUS)

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	40%	1
Ambulatory/Outpatient Medical Care	28%	2
Emergency Medical Services	16%	3
Inpatient Services	11%	4
Rehabilitation*	8%	6
Mental Health Therapy/Counseling	7%	9
Home Health Care*	8%	7
Long-Term Care*	6%	11
Patient Education Services	8%	5
Prevention Education Services	8%	8
Nutritional Services	6%	10
Medications and Therapeutic	5%	12
Research*	2%	15
Dental Care	4%	13
Social Case Management	3%	14
Substance Abuse Treatment/Counseling	1%	16
Hospice*	1%	17

*See note on page 176 regarding these service categories.

YOUTH (AGE 13 - 24)

Two groups were held for youth. Although recruiting efforts were targeted toward segregating 13 - 19 years old and 20 - 24 year olds, participants in both groups ranged from 14 - 24. The participants in these groups were African American adolescents and young women, most of whom were also mothers of toddlers or infants. In both groups, the participants adamantly emphasized the need for consistent and persistent prevention efforts directed toward adolescents and young adults, most especially toward females.

The participants detailed that lack of information about HIV risk and naiveté about their sexual partners had placed them in jeopardy. They spoke of their current efforts within their social networks to inform friends and family about risks and protection factors. Similar to accounts from older women, these participants reported the importance of their health care providers in supporting their adherence to medications regimens and risk reduction. Those with children indicated their perceptions of the importance of maintaining their health in order that they might better care for their children.

Table 6-12: GAP ANALYSIS – YOUTH (AGE 13 – 24)

SERVICE CATEGORY	% Indicating Gap	Rank
Support Services	17%	1
Ambulatory/Outpatient Medical Care	15%	3
Emergency Medical Services	12%	4
Inpatient Services	15%	2
Rehabilitation*	0%	0
Mental Health Therapy/Counseling	0%	0
Home Health Care*	0%	9
Long-Term Care*	5%	10
Patient Education Services	7%	7
Prevention Education Services	7%	8
Nutritional Services	0%	0
Medications and Therapeutic	7%	6
Research*	0%	0
Dental Care	7%	5
Social Case Management	2%	11
Substance Abuse Treatment/Counseling	0%	0
Hospice*	0%	0

*See note on page 176 regarding these service categories.

Chapter 7

Provider Survey Findings

PURPOSE

The Health Resources and Services Administration (HRSA), the federal agency that funds programs to care for people with HIV/AIDS (PLWH/A), describes the continuum of care (range of services) that a community must provide. It includes:

- Primary and secondary prevention of HIV infection;
- Outreach with particular emphasis to prevent and treat at-risk or special needs populations;
- Delivery of medical care and social services;
- Services directed at supporting adherence to treatment, care and prevention goals;
- Provision of support services that assist PLWH/A in meeting practical needs and in obtaining access to medical and social care.

In order to better determine the community's capacity to address the continuum of care and more effectively meet the needs of clients with HIV/AIDS, the Needs Assessment included a survey of providers of services to those clients. The survey, adapted from the Statewide Coordinated Statement of Need (SCSN) Provider Survey (see Procedures) included questions that generated the following types of descriptive information:

- Types of agencies offering HIV-related services
- Demographics of client population
- Range of services offered
- Barriers to service

The survey also polled providers for their recommendations to improve the system of care for clients and to foster collaboration and cooperation among agencies.

In addition to the survey, provider input was solicited through two focus groups: one open to all providers of HIV services and one for providers of services to immigrants.

PROCEDURES

Administration

Upon completion of the survey and approval by the Joint Resource Inventory Group and the Joint Needs Assessment Group (See Procedures), a notification was sent to all providers listed in the Houston Area Resource Guide (the Blue Book) inviting them to participate in the provider survey. Respondents were given the opportunity to complete the survey online through a secure website or as a paper survey. Online surveys were submitted directly to the analysis team. Paper surveys were sent via fax or mail to either the analysis team or to the Ryan White Planning Council Office of Support, who forwarded them to the analysts. Fifty providers completed the survey.

Providers were informed of focus groups through telephone solicitation and information presented at meetings of planning bodies. Ten providers attended the general focus group

and 7 attended the immigrant providers group. Data from these groups enhance both the client and provider survey data in the Needs Assessment.

Limitations

The provider survey was adapted from the mandated Statewide Coordinated Statement of Need (SCSN) instrument. Because this Needs Assessment was the first large-scale administration of the Survey, it involved challenges similar to those encountered in the client survey. Respondents reported difficulties in determining appropriate time periods in requests for funding and budget information and found questions about client counts at times unclear.

In addition, respondents encountered difficulties in selecting options from a table in Question 8 (see Appendix C). The table included headings and subcategories, both, either or neither of which could be selected, as illustrated in Table 7-1.

Table 7-1: QUESTION 8. DOES YOUR AGENCY PROVIDE THE FOLLOWING?

Service	Check if the service is provided to persons living with HIV	Amount of your total budget
AMBULATORY/OUTPATIENT MEDICAL CARE	<input type="checkbox"/>	\$
Primary Care	<input type="checkbox"/>	\$
Vision Care	<input type="checkbox"/>	\$
OB/GYN	<input type="checkbox"/>	\$
Pediatric	<input type="checkbox"/>	\$
Specialty	<input type="checkbox"/>	\$
Psychiatric Treatment	<input type="checkbox"/>	\$
Infectious Diseases	<input type="checkbox"/>	\$
Medical Case Management	<input type="checkbox"/>	\$

Providers reported that they were unclear whether checking a category heading (service category), as in this example, checking Ambulatory/Outpatient Medical Care meant that they provided all individual services in the category (i.e., primary care, vision care, etc.) and were equally unclear whether checking a service, such as primary care, required selecting the Ambulatory/Outpatient Medical Care option. The issue was addressed in the analysis. Service category levels were calculated by tallying responses at the heading category level. Any check mark for any of the services was counted as a check in the heading category. Only one check per heading category was counted. The number of check marks for that line item determined individual services. For example, Ambulatory/Outpatient Medical Care totals were calculated by the number of checks on the header line and/or if any of the individual services in the category (primary care, vision, etc.) were checked. For Vision Care only check marks on that line were tallied.

Profile of Responding Agencies

The discussion that follows highlights the features of the agencies described by survey respondents. A listing of participating agencies, their services, funding sources and client demographic profiles are briefly discussed and illustrated.

Of the 50 providers that responded to the survey, 19 represented organizations whose services are offered either exclusively or primarily to PLWH/A or are perceived by the community to be ASOs. These were self-reported or later classified as AIDS Service Organizations (ASO). Thirty-one organizations were self-reported or later classified as non-ASO in that their client populations extend beyond PLWH/A. Agencies “later classified” as ASOs target PLWH/A for services, but do not serve only these individuals. A list of the agencies represented in the survey is found in Appendix J.

Type of Agency

Among respondents, 17 (34%) reported that their agencies were community-based organizations, 7 (14%), were exclusively ASOs, 6 (12%) were multi-service organizations, and the remaining 7 were identified as health clinics, hospitals or hospital districts. Thirteen (25%) of the organizations indicated “other” in response to type of structure, though which type is not specified. According to respondents, 60% of the organizations do not specialize in treating PLWH/A, as seen in Table 7-2 below.

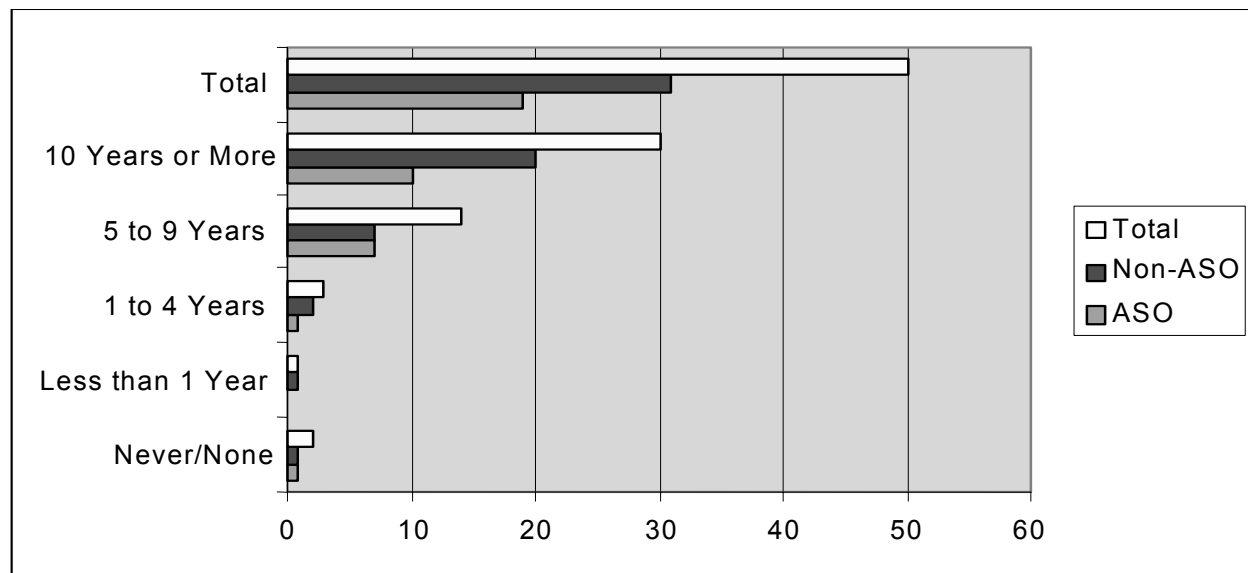
Table 7-2: ORGANIZATIONAL STRUCTURE

Structure	ASO	Non ASO	Total	Percent
Community-based Organization	5	12	17	34%
AIDS Service Organization	7	0	7	14%
Multi-service Organization	1	5	6	12%
Health Clinic	2	1	3	6%
Hospital	0	2	2	4%
Hospital District	0	2	2	4%
Other	4	9	13	26%
TOTAL	19	31	50	100%

Duration of Service

Non-ASOs have a longer tenure of service than do ASOs. Of ASOs 53% have been in existence for at least 10 years, compared to 63% of non-ASOs. Figure 7-1 shows the number of agencies that have been in existence for each of the time periods listed.

Figure 7-1: PROVIDER SERVICE TENURE



Funding Sources

Ryan White CARE Act funding is the predominant source of support for HIV-related services reported by both ASO (84.2%) and non-ASO (58%) respondents. The non-ASOs were more likely to report funding from private insurance (22.6%) and client fees (29%), while ASOs report more foundation support and contributions (57.8% for both). ASOs were also far more likely to receive funding from public sources. The complete list of the sources of funding reported by agencies is found in Appendix G.

Services Offered

According to the respondents, social case management is the most frequently offered service (32%), followed by ambulatory medical care, prevention education and patient education (each 28%). Of the respondent sample, minimal variations exist between ASOs and non-ASOs in the services they offer, with the exception of ambulatory outpatient medical care. Four of the 19 ASOs make this service available to clients compared to 10 non-ASO organizations.

These data do not show a particularly high concentration of agencies in any one category. This may reflect a combination of factors, such as, but not limited to:

- The attempt among providers to minimize unnecessary duplication of services;
- Limits in the funding available for services regardless of need; and/or
- Possible limits in the availability of other resources, such as staff or facilities, that are required to provide a given service.

The services offered cover a range of categories and might indicate factors such as:

- Community commitment to meet a broad range of client needs
- Community effectiveness in communicating a broad range of needs to providers

In Table 7-3, the numbers of providers in key service categories are listed by individual service.

Table 7-3: SERVICES PROVIDED – ASO VS. NON-ASO

SERVICE CATEGORY	# ASO	# Non ASO	Total	% of Total respondents
Social Case Management	7	9	16	32%
Ambulatory/Outpatient Medical Care	4	10	14	28%
Prevention Education	7	7	14	28%
Patient Education	6	8	14	28%
Mental Health Services	4	7	11	22%
Transportation	4	7	11	22%
Medical Case Management	4	6	10	20%
Support Services	4	4	8	16%
Substance Abuse Treatment	4	3	7	14%
Substance Abuse Counseling	2	3	5	10%
Drug Reimbursement Program	1	4	5	10%
Housing	3	2	5	10%
Home Health care	0	2	2	4%
Dental Care	1	0	1	2%
Hospice	1	0	1	2%

Demographics of Populations Served

Although respondents did not delineate the specific demographics of their clients, several reported efforts to target client populations. Seven agencies targeted female clients; six male; and one transgendered clients.

Of those agencies that specified the race and ethnicity of their client populations, 9 indicated African American clients; 3 agencies, American Indian; 2 agencies, Pacific Islander/Hawaiian; two agencies, Anglo, and 1 agency Asian. Six agencies indicated that they focused on services to Hispanic clients.

Using age as a criterion, 10 agencies served clients less than 12 years of age, 5 agencies served adolescents; 5 young adults age 20 – 39; and 8 listed clients 40 and older.

Providers also categorized their clients using HRSA definitions of populations with special needs. Table 7-4 lists these categories in addition to the number of respondents who reported offering services to them.

Table 7-4: CLIENT POPULATIONS SERVED

Population Served	# Of Agencies Responding
Monolingual (non-English)	45
Men of color who have sex with men	43
Women of Childbearing Age	42
Incarcerated/ Recently released	42
Homeless	39
Youth (13 - 24)	38
Undocumented immigrants	36
Substance users (non-IDU)	33
Deaf/Hard of hearing	28
Anglo MSM	26
Rural residents	25
Injection Drug Users	24
Children (under 13)	14

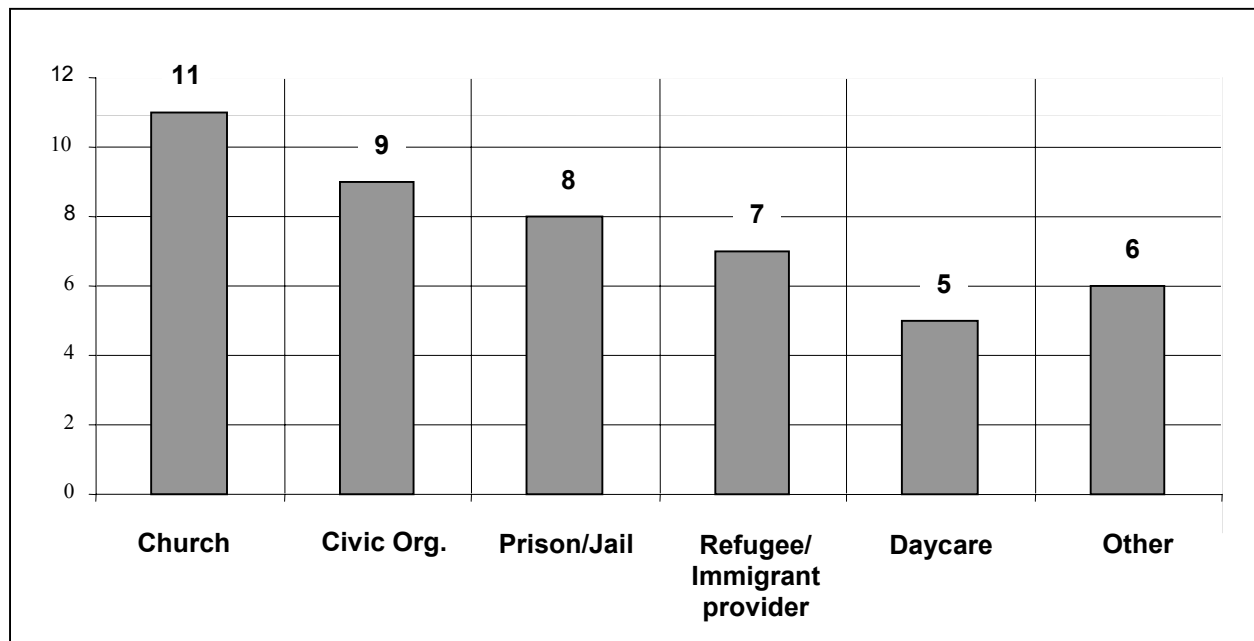
Of the 6 client populations most frequently served, 4 also have been identified in the local community as groups with especially high service needs. These are African American men who have sex with men, Women of Childbearing Age, Incarcerated/Recently Released individuals and Youth, ages 13 - 24. (See Chapter 8, Special Studies, for a more in-depth discussion of the service needs of each of these groups.) Focus groups with both providers and clients as well as the current body of research related to HIV/AIDS cite that these groups appear to have increasing incidence of HIV infection, are at greater risk of comorbidities and may experience more frequent and more severe barriers to care.

It is noteworthy that nearly half of the respondents indicated their agencies served clients who do not speak English. As several participants in the provider focus groups noted, the community has witnessed significant increases in the number of African, Asian as well as South American immigrants. Participants stressed their concerns about the limitations that language and cultural barriers place on non-English speaking clients and on the agencies committed to offering care to them.

Collaborations

In order to determine the nature of collaborations among agencies, providers were asked whether their agencies engaged in verbal agreements, commitment letters, letters of collaboration, binding agreements, or signed Memoranda of Understanding (MOU's) with other agencies related to the provision of HIV-related services. The most frequently reported collaborations are shown in Figure 7-2.

Figure 7-2: MOST FREQUENTLY REPORTED COLLABORATIONS



Comparison of Client and Provider Responses: Service Barriers

Service barriers were computed from the responses in the client survey, which elicited information about the services that clients believed were difficult to access. The provider survey; however, elicited more specific information about what those barriers to access might entail. What follows is an analysis of client and provider responses.

In Table 7-5, client survey respondents ranked the services in which they encountered barriers.

Table 7-5: CLIENT-REPORTED BARRIERS

Service Category	% of Clients Reporting Barrier
1. Support Services	33.7%
2. Ambulatory/Outpatient care	18.4%
3. Emergency Medical Services	12.3%
4. Rehabilitation Services*	11.3%
5. Long-Term Care*	10.4%
6. Inpatient Services	9.4%
7. Social Case Management	9.3%
8. Patient Education	9.2%
9. Home Health Care*	8.7%
10. Mental Health	8.2%

*See note on page 176 regarding these service categories.

Providers were asked to indicate what barriers clients encountered, as shown in Table 7-6.

Table 7-6: PROVIDER REPORTED BARRIERS

Provider-identified Barrier	% of Providers Reporting
Transportation to services	44%
Sharing of client data	11%
Issues in medication adherence	11%
Client substance use/abuse	11%

The findings were quite consistent between providers and clients, as evidenced by information gathered in focus groups. Transportation as a barrier was cited in each of the client focus groups, and often as the most significant barrier in accessing medical and support services. Transportation was also identified as a barrier on the client survey. For a more thorough discussion, see Chapter 5, Targeted Findings: Transportation and Housing.

Limited data sharing is perceived by clients, according to focus group information, as “excess paperwork.” Especially in the groups for Anglo MSM and African American MSM, many clients reported a perception that they were required to supply each new provider to whom they might be referred with information that they had given previous providers. They indicated that they are “already in the system” (referring to either COMPIS or CPCDMS) with this replication reported as burdensome. Other clients reported that the sharing of any data among providers was unacceptable as it might lead to a breach in confidentiality.

Client inability or refusal to adhere to medication regimens was self-reported in focus groups and reiterated in provider groups and in responses to the client survey as a significant barrier to continuing in medical care. Many focus group participants offered anecdotes that medication side effects or the rigors of medication scheduling were significant barriers to seeking or maintaining medical care. Among self-reported out-of-care clients, 46% indicated on the survey that they chose not to seek medical care. In contrast, 33% cited provider advice and 21% access to care as the primary barrier.

Focus group and street interview participants offered additional explanations of the personal choice not to seek care that is consistent with the provider report. Several reported that initially after diagnosis, they were stunned and tended to conceptualize their HIV status as either an indication of immediately impending death or as something of no significance, which could be denied. With these attitudes they indicated that the rigors of treatment were perceived to be useless or of no significance.

For many clients, eventual contact with service providers corrected these notions and treatment began. However, according to both providers and clients, once the physical and emotional stress and side effects of medication adherence is experienced, clients

are again at risk of reverting to the more extreme positions. These notions and client reactions are documented throughout the HIV-related professional literature as well as that focusing on other serious, chronic diseases.

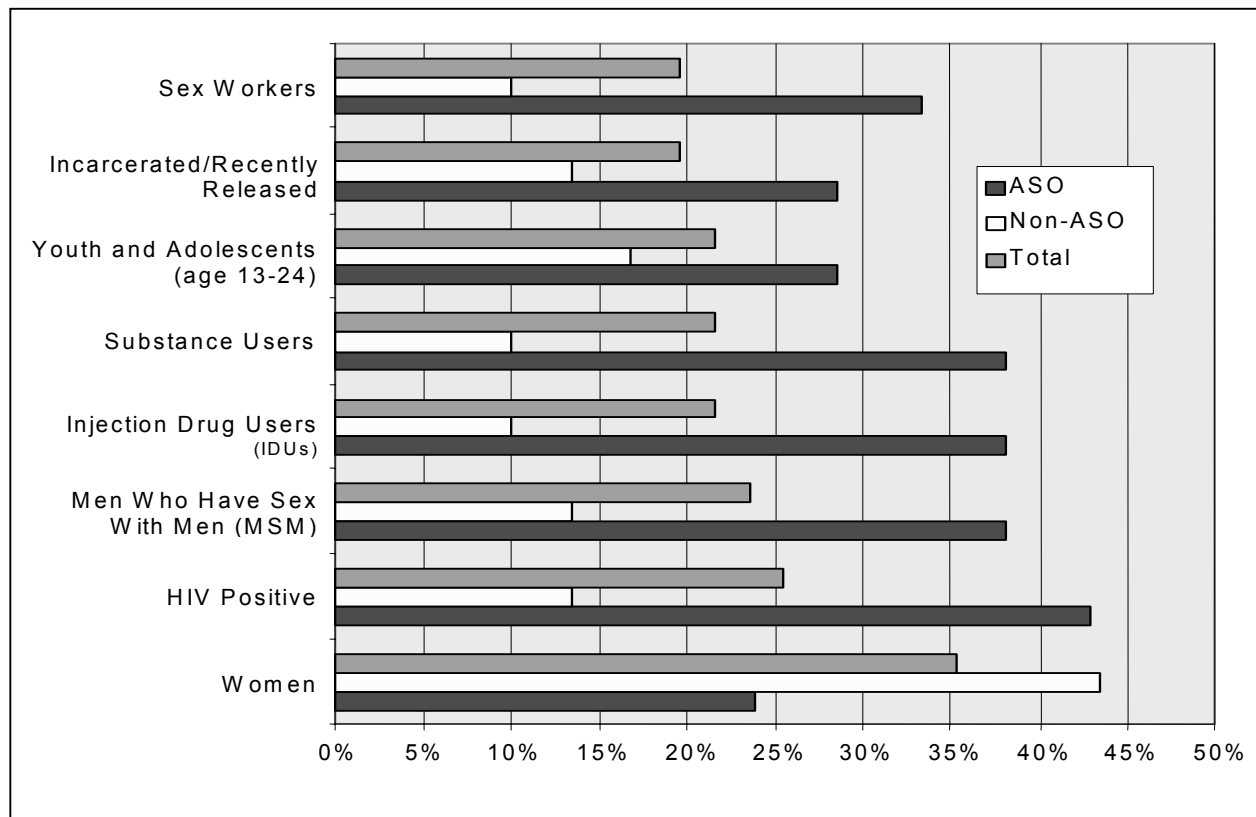
The inhibiting effect of substance abuse on care-seeking behaviors was also substantiated in all phases of the needs assessment. This factor is significant in that the presence of diagnosed and undiagnosed substance abuse among PLWH/A has been shown to be substantial. (See Substance Abuse Treatment/Counseling, for additional information)

PREVENTION ACTIVITIES

Populations Served:

Both on their survey and in focus groups, providers detailed their efforts in HIV prevention. More than 40% of the ASO respondents indicated that they provided prevention services most often to those who are HIV positive, as well as to MSM, injection drug users (IDUs) and individuals who use and/or abuse other substances. Programs for sex workers and individuals who are currently incarcerated or recently released tended to be in the scope of service of ASOs. Women of childbearing age were more likely to be served by non-ASOs. Figure 7-3 shows the percentage of agencies that offer services to clients in each of the listed categories.

Figure 7-3: PREVENTION SERVICES: POPULATIONS SERVED



Populations Targeted:

In addition to listing the client populations that they were serving, providers were asked if they had identified categories of clients on whom they specifically focused services. ASOs indicated that their primary focus on prevention was with PLWH/A (43%), followed equally by women, MSM, IDUs and substance users (38% each). Among non-ASOs, the reported primary target populations were women and youth (17% each). See Table 7-7 for a complete list.

Table 7-7: POPULATIONS TARGETED FOR PREVENTION SERVICES

Population	% of ASO	% of Non ASO	% of Agencies
Women	38%	17%	25%
HIV Positive Individuals	43%	13%	25%
Men Who Have Sex with Men	38%	13%	24%
Injection Drug Users	38%	10%	22%
Substance Users	38%	10%	22%
Youth Adolescents	29%	17%	22%
Incarcerated	29%	13%	20%
Sex Workers	33%	10%	20%

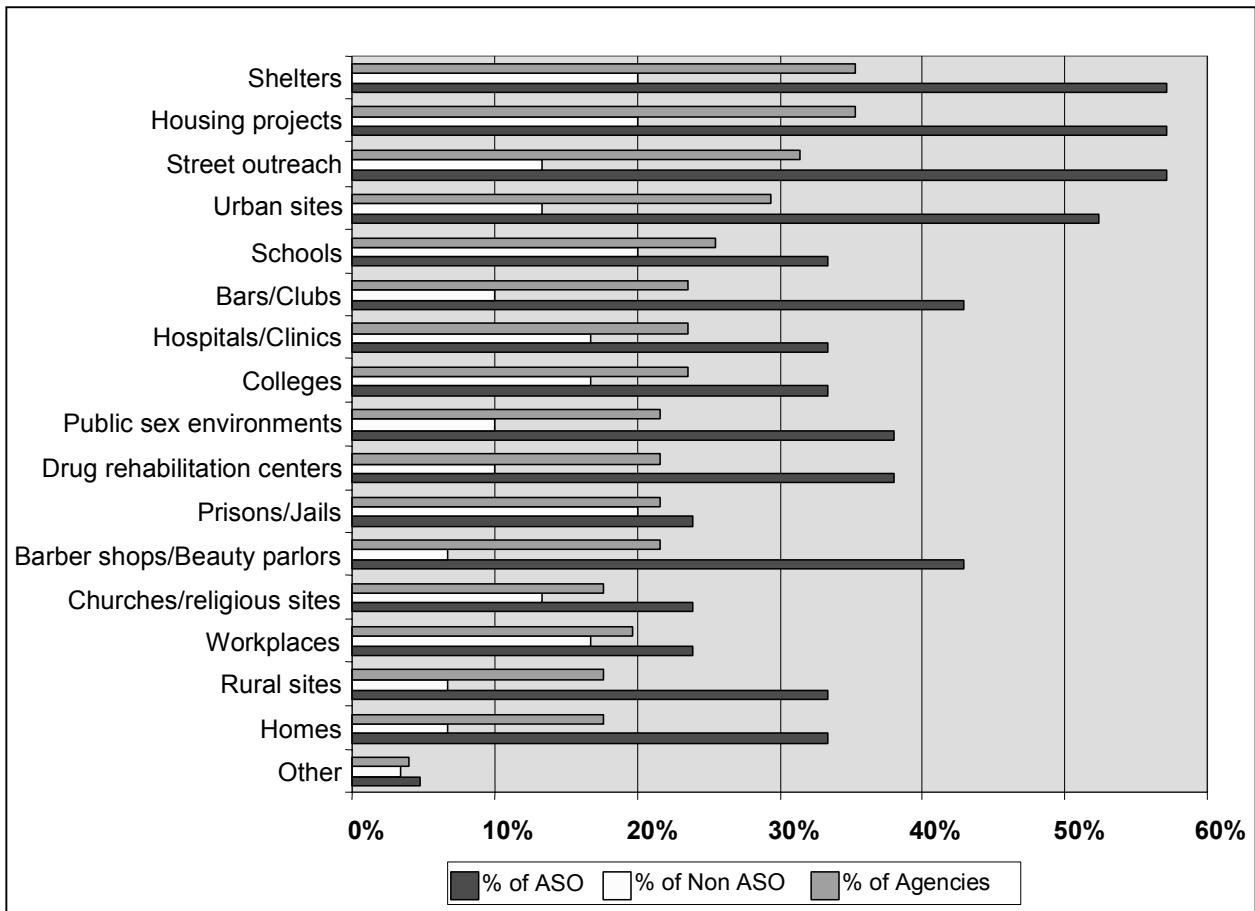
Sites Where Prevention Services are Offered:

In the provider survey, respondents indicated where they conducted outreach and other prevention activities. ASOs offered more prevention services in neighborhood sites such as homeless shelters, housing projects, street outreach, urban sites and bar/clubs, and barber shops/ beauty parlors. Non-ASOs were more likely to host institutional preventive efforts including jails, schools, churches and workplace prevention efforts. Client focus group, street outreach and survey data corroborate the effectiveness of the site selection.

For example, in street interviews, which were conducted in many of the sites where prevention activities occur, most respondents indicated at least some familiarity with outreach workers and were able to list HIV testing sites and basic information about HIV risk factors and protective measures. However, in focus groups, participants consistently cited the need for more prevention services, aimed not only to those at highest risk, but to the community at large. Further, survey respondents reported high rates of use of shelters, approximately 17% of the respondents had been incarcerated within the prior 2 years and 33% had been treated for substance abuse.

Figure 7-4 compares ASO and non-ASO prevention service delivery sites.

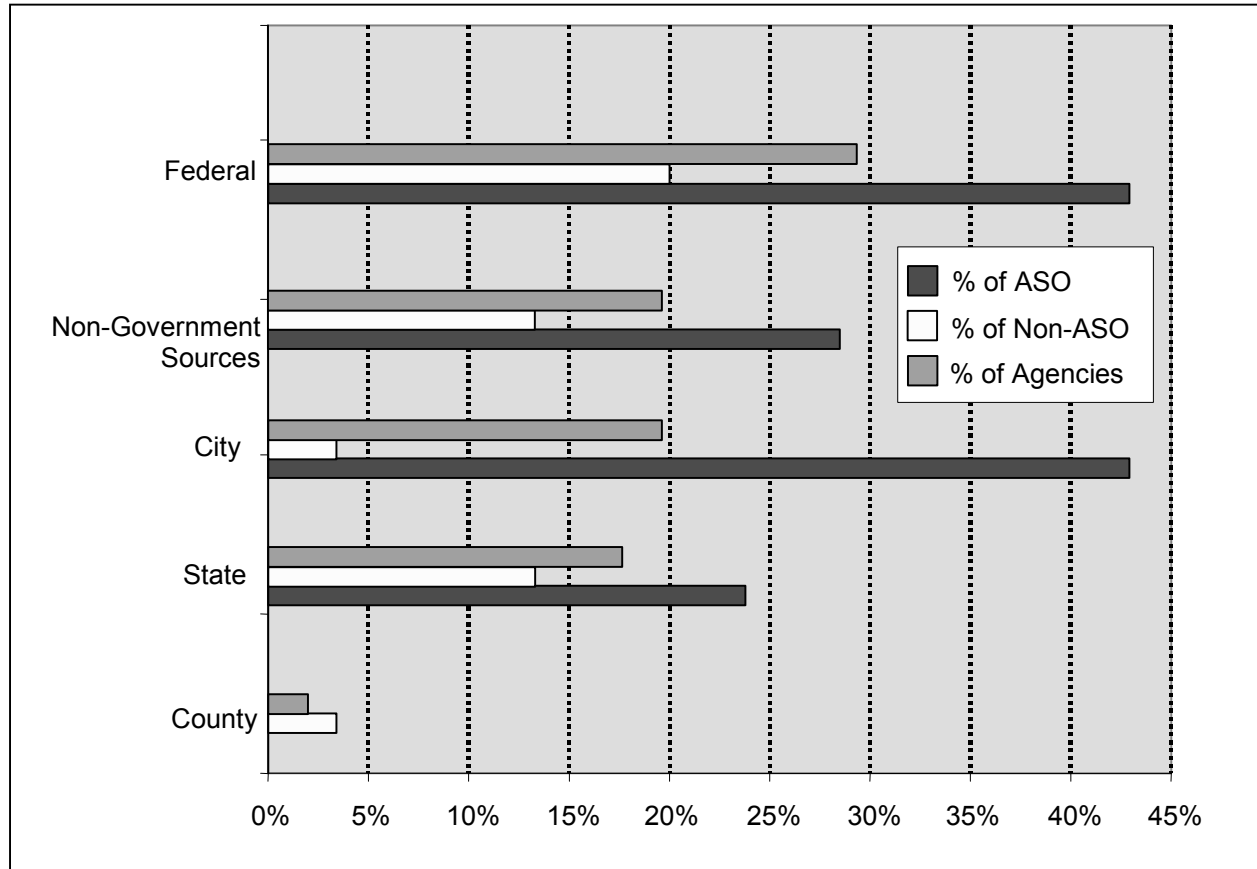
Figure 7-4: PREVENTION SERVICE SITES: ASO VS NON-ASO



Funding of Prevention Efforts:

Federal and municipal sources of funding dominate for AIDS service organizations. Non-ASOs also rank federal funding as their primary source of funds, with non-government services second, closely followed by State funding sources as Figure 7-5 illustrates.

Figure 7-5: FUNDING SOURCES FOR PREVENTION



SUGGESTED SERVICE IMPROVEMENTS

When asked to recommend features or programs that might enhance service delivery, ASO and non-ASO providers were quite consistent. The noteworthy exception was in the recommendation for multicultural training, designated by 16% of ASO and only 7% of non-ASOs as shown in Table 7-8.

In focus groups, providers explained that among their clients are immigrants and refugees from all parts of the globe. Although Texas is associated with predominantly Hispanic/Latin immigrant populations, Houston is also home to an increasing number of Asian, Central European and African immigrants.

To truly assist these clients, providers must be able to access interpreter services. In addition, they must understand which customs enhance access and adherence to treatment and

which inhibit or even prevent clients from seeking, adhering to and benefiting from treatment. Participants in the focus group for providers of services to immigrants indicated that their request for networking, language training and advocacy as well as multicultural training centered on improving their competence with the range of clients that they seek to serve.

Table 7-8: AGENCY SUGGESTIONS TO BETTER SERVE CLIENTS

Recommendation	% ASO	% Non-ASO
Provider Networking	24%	24%
HIV Specific Training	14%	15%
Advocacy Training	14%	15%
Multicultural Training	16%	7%
Language Training	11%	10%
Increased Convenience	8%	10%
Prevention and Early Intervention Training	5%	10%
Other	8%	8%

FOCUS GROUP CENTRAL THEMES

Within the 2 provider focus groups several themes emerged. Reviewing these adds context to the survey findings and can be used to support the community's efforts to enhance the service delivery system.

Service Needs:

- Similar to clients, providers expressed the importance of ambulatory outpatient medical care and support services.
- Providers rank mental health and preventive services higher than do clients, although both groups list them as essential.
- Focus group participants added that their clients are reporting an increasing need for dental and vision care. Dental care needs consist of prevention, treatment and prosthodontics. In vision care, needs include preventive care, corrective lenses and CMV screening. This may be related to the disparities between Medicaid coverage and the availability of these services to those in the HIV continuum of care.
- Rural clients indicated a need for satellite service centers in both the northern and southern communities in the EMA/HSDA, which was confirmed by providers.

Service Barriers:

- Participants in the focus groups corroborated the survey respondents' description of service barriers.
- According to participants, the system-related services, transportation and client data sharing, are being addressed by the community. New transportation options are being created, including increasing the number of providers and developing options to using transportation services.

-
- Client data sharing methods will continue to improve as region-wide data systems are upgraded and as the issue is addressed through provider collaborations.
 - Providers recognize the special needs that accompany clients with substance use/abuse issues and are attempting to incorporate those needs into care delivery systems.
 - Providers also stressed the need for multicultural competence in the delivery of services.
 - Both clients and providers report that limited access to insurance further compromises access to care for many clients.

Prevention Services:

- Providers indicated they are diversifying their prevention efforts to include more targeted populations, more sites and a wider range of methods. Secondary and tertiary prevention efforts were especially noted.
- Clients, especially African American women, were adamant about the need for primary prevention services to women of color.
- Rural clients requested community-wide prevention and general HIV-related information.

RECOMMENDATIONS

Based on the findings of the provider survey and focus groups, the following recommendations are offered:

- Use Standards of Care and contractual negotiations to ensure consistent provider adherence to cultural sensitivity policies.
- Determine balance between client choice of provider and provider capacity.
- Continue to communicate with client base regarding frequently misunderstood services:
 - Substance abuse short-term treatment does not equal housing
 - Dental services and spectrum of offerings, link to transportation issues
 - Vision care/Cyto Megalo Virus (CMV) testing available at [provider] - clarify payer qualification criteria
 - Housing can be supported using multiple funding sources for client not only HOPWA.
- Focus on expanding the network of agencies and organizations that can serve as points of entry to the HIV continuum of care and provide them with information about the HIV/AIDS system of care.
- Develop and enforce protocols for referrals to the appropriate provider and level of care.

MEETING THE UNMET NEED - A POSSIBLE FORMULA

Effective continuum of care systems improve the health status of populations by accurately assessing client needs and increasing access to care by reducing barriers and gaps in required services. In the current needs assessment, 19% of survey respondents indicated that they either were not currently under medical care or had never been in care. The following section discusses the impact of effective recruiting of the out-of-care on provider capacity.

The formula assumes a goal of bringing the out-of-care/never-in-care into care, lists the specific services that these entrants will require of the service delivery system and proposes a method to analyze the impact on provider capacity. The formula does not provide guidance on how to increase the number of entrants into care. Rather, it offers a method for calculating the capacity of the HIV continuum of care to meet the needs of those who do enter care.

Based on the Needs Assessment findings, it is anticipated that the initial requests of the “never-in-care” group will be for basic medical care, while the “out-of-care” group will request not only medical care, but also social and mental health services.

Description of the Targeted Populations

HRSA defines the “out-of-care” group as those who do not receive primary medical care within a six-month period. The individuals know their HIV status and may even use support services. The “never-in-care” is a second group who may or may not know their HIV status, but who has not presented for HIV-related medical care.

The Centers for Disease Control estimates that 25% - 30% of individuals infected with HIV are not currently in regular medical care. Reasons suggested for this trend include factors that are often contradictory such as:

- The increasing incidence of the disease in populations who are underrepresented in general health care,
- A perception among some individuals that HIV is of less consequence due to antiretroviral therapy
- Difficult medication regimens
- Medication side effects
- Lack of awareness of HIV status.

These trends result in increasing percentages of people outside or at the fringe of care. Two groups of those “not-in-care” can be described:

1. “Out-of-care” (12% of client survey respondents). Research shows that the reasons for their care status include:
 - a. Personal choice (skepticism or mistrust of medical systems, personality factors, religious beliefs, skepticism about effectiveness or intent of care delivery system, etc.),

-
- b. Lack of resources needed to seek and maintain participation in care
 - c. Misunderstanding of medical advice or need for care
 - d. Cultural issues
 - e. Insurmountable system barriers
2. “Never-in-care” (7% of client survey respondents). According to research, the “never-in-care” group is unlike the “out-of-care” or “in care” constituents. They are homogenous with an alternative title of ‘unconnected’. They are heavily comprised of recent immigrants, many of whom have extensive comorbidities in addition to HIV/AIDS. They tend to be homeless or in highly shifting housing situations, be living in poverty, have high degrees of mental health comorbidities and are profoundly distrustful of authority. Many are undocumented residents, with such fear of the immigration system that this prevents them from accessing any system of care.

Approach

- Using the database developed through the needs assessment along with integration of other complementary efforts determines demographic and service details associated with the not-in-care respondents. These will be further subdivided into the “out-of-care” and “never-in-care” subgroups. Analyze the demographic, utilization and narrative data, where available, to better inform the planning bodies of the profiles and composition of these two groups.
- Establish policy goals for reducing the “not-in-care” percent. It is not reasonable to assume that all affected will enter care. It is desirable, however, to systematically develop approaches over the three-year period addressed in the needs assessment, or bringing more of these two groups into treatment.
- Determine the provider capacity to offer the specific services that these new entrants will require. Provide projections of how services might evolve over this three-year period (2003 - 2005).
- Outline an action plan to address impact.
- Review the success of these efforts on an annual or semi-annual basis and refine the approach based on progress.

Calculation

- Apply the “out-of-care” (12%) and “never-in-care” (7%) percentages to the entire PLWH/A population in the Houston EMA/HSDA.
- Determine what subset of these groups is likely to enter care given successful outreach efforts, and what goal the planning bodies wish to set per year. [For example: if the goal for Year 1 (2003), is to reduce “out-of-care” by 2% to 10%, then determine what impact that would have on the number of new PLWH/A accessing services = 22,000 x 2% = 440 new entrants].

- Through research into the needs assessment database and other complementary surveys, determine what services these groups are likely to access. [Using the example above, 440 new entrants x 32.2 service utilization rate (utilization quoted from CPCDMS data for FY 2002) = 14,168 additional visits].
- Compare the number of new entrants into the delivery system and the capacity of providers to provide those services with a plan to better match availability. [Compare 14,168 additional visits in example to current capacity of the system, with weighting to areas that “out-of-care” are likely to access—inner city, bilingual services].
- Use the CPCDMS and COMPIS systems to monitor utilization as these new entrants start to use the delivery system and adjust accordingly.
- Revisit the percentage reduction goal for “out-of-care” and “never-in-care” on a semi-annual (every six months) basis.

Derivation of Provider Capacity vs. Client Need

- From the Houston 2002 Epidemiological Profile, use 7,636 living reported AIDS cases and apply to “in-care”, “out-of-care”, “never-in-care” from client survey:

Estimated PLWH/A “in-care”	81%	8,951
Estimated PLWH/A “out-of-care” re: HRSA definition	12%	1,326
Estimated PLWH/A “never-in-care”	7%	774
		11,050

Houston Area 2002 Epidemiological Profile

Estimated PLWH/A “in-care”	81%	18,392
Estimated PLWH/A “out-of-care” re: HRSA definition	12%	2,725
Estimated PLWH/A “never-in-care”	7%	1,589

22,706

(weighted sample)

- Take CPCDMS data and use to determine Title I reported utilization by major categories deriving and applying utilization COMPIS for other Titles.
- Triple tier apply percentages from the client survey for “in-care”, “out-of-care” and “never-in-care”.
- Subtract the difference and estimate capacity:
 - By Title I providers
 - By Title II providers

Range of Estimate of Provider Capacity/Unmet Need

Unweighted Sample:

Estimated PLWH/A “in-care”	81%	8,951
Estimated PLWH/A “out-of-care” re: HRSA definition	12%	1,326
Estimated PLWH/A “never-in-care”	7%	774
		11,050

Conclusion (11,050):

The sum of Title I provider reports and CPCDMS data from 3/01/01 to 2/28/02 = 7,820 registered clients and 250,240 encounters = 32 encounters/client.

- “In-care” (8,951 x use rate (unduplicated encounters/client) = Total encounters – CPCDMS total encounters = baseline capacity.
- Cumulative “in-care” + “out-of-care” = (8,951 + 1,326 = 10,277 x use rate) = Total encounters required in ‘optimal’ system – actual CPCDMS reported encounter = ‘achievable’ capacity.
- Cumulative total of “in-care” + “out-of-care” + “never-in-care” = (11,050 X use rate) = total encounters in ‘ideal’ system – CPCDMS total encounters = ‘optimal’ capacity.

FOR TITLE I providers only, the deficit in provider capacity ranges from 6,994 to 19,939 encounters or 14% to 41%.

Weighted Sample:

Estimated PLWH/A “in-care”	81%	18,392
Estimated PLWH/A “out-of-care” re: HRSA definition	12%	2,725
Estimated PLWH/A “never-in-care”	7%	1,589
		22,706

Conclusion (22,706):

- “In Care”: (18,392 x use rate (unduplicated encounters/client) = total encounters – CPCDMS total encounters = baseline capacity
- Cumulative “in-care” + “out-of-care” = (18,392 + 2,725 = 21,117 x use rate) = total encounters required in ‘optimal’ system – actual CPCDMS reported encounter = ‘achievable’ capacity
- Cumulative total of “in-care” + “out-of-care” + “never-in-care” = (22,706 X use rate) = total encounters in ‘ideal’ system – CPCDMS total encounters = ‘optimal’ capacity

FOR TITLE I providers only, the deficit or provider capacity ranges from 65,312 to 91,973 encounters or 35% to 90%.

Interpretation

This algorithm assumes that the goal of the planning bodies of the Houston EMA/HSDA is to ensure that the baseline or foundation premise is for the “in-care” population to be totally served by provider resources (consistent with the HRSA Goal: “100% access, 0% disparity”).

- An achievable situation is one in which the majority or all of “not-in-care” are also able to access resources.
- An optimal situation allows coverage of the entire PLWH/A, including the sum of “never-in-care” although this may not be realistic, given their decision to not access services.

Assessing the provider capacity vs. client need at either end of the estimated PLWH/A spectrum displays that:

- At the 11,050 level, PLWH/A needs are met by Title I providers alone for all “in-care” with either other Titles, Texas Medicaid and or the private system covering the remaining 10 - 14% (health planning norm is to provide 85% of capacity for the entire population.)
- The cumulative “in-care” and “out-of-care” result in a 25% deficit.
- The entire PLWH/A estimate of 11,050 results in a 30 - 35% deficit in the existing system provided by Title I agencies ONLY.
- At the 22,706 level, PLWH/A needs are not met (using the 85% ‘capacity’ level or 15% deficit by Title I providers alone) at even the “in-care” levels with an estimated deficit of 20%
- Cumulative amounts for the optimal care capacity of “in-care” and “out-of-care” result in a 30% deficit
- Including all populations (“in-care” + “out-of-care” + “never-in-care”) results in an unbalanced system of deficit approaching 50%.

Chapter 8

Special Study Populations: Themes and Recommendations

THEMES AND RECOMMENDATIONS:

AFRICAN AMERICAN MSM

Theme 1: AA MSM are better educated more likely to carry employer-sponsored or private/ Insurance or COBRA and have Drug Assistance from those payers than All Respondents or other Special Study Groups.

Recommendation: This socioeconomic group can better access resources yet is slightly less likely to be 'In Care' at 77% than All Respondents. This may demonstrate cultural beliefs or misperception or unawareness of Providers. Respondents reported that providers advised against aggressive Primary Care despite a tendency for AA MSM to be unaware of their Viral Load. This suggests that either the Providers for AA MSM need to be educated regarding more aggressive primary care or at a minimum, more proactive education of their clients regarding viral load needs to occur.

Theme 2: AA MSM admit in 'Sexual Orientation' and qualitative comments from both focus groups and the RARE street interviews to hustling with both sexes whether they are truly bisexual or not. They openly express concern about transmission to African American Women.

Recommendation: Proactive and open communication and education among the African American community needs to occur about protection (condoms) and/or education of African American women about rejection or refusal techniques.

Theme 3: Comorbidities are of particular concern for AA MSM due to their ethnic propensity to be at higher risk for high blood pressure and diabetes. The interaction of these two conditions to antiretroviral therapy is most concerning.

Recommendation: Ensure that providers to AA MSM are aware of the complications and risks associated with antiretroviral medication and conditions to which African Americans are predisposed. Fully alert all providers, including non-ASO's who may be less aware of these complications than AIDS Service organizations.

THEMES AND RECOMMENDATIONS:

YOUTH

Theme 1: Youth consistently demonstrated a desire for more education, information at an earlier age. This extends to risk factors such as unprotected sex and drug use. Early grade school seems premature, but specific comments about sex education not starting until the 6th grade as far too late show the need to start these efforts early.

Recommendation: Continue to provide prevention education at increasingly earlier ages in school systems, churches and day care. Extend patient education programs targeted to young mothers and female teens.

Theme 2: Youth are among the most likely to be uninsured. Several lose coverage when they turn 18 years old.

Recommendation: Further target those PLWH/A Youth who are turning 18 to ensure continuity of care and funding.

Theme 3: Youth are vulnerable to being unconnected to any care system due to their lack of means to pay for care, lack of awareness to find out what services are offered, belief that they are not at high risk and their probability of being uninsured.

These vulnerability factors are stressed when many young women have children at an early (under 20 years) age. Lack of employment or under-employment further stresses their situation.

Recommendation: Coordinate AIDS prevention efforts with other social service agencies (immigrants, schools, after-school programs, YMCA and YWCA/Boys & Girls Clubs) that cater to youth. Develop risk profiles to have these staff use in assessing and referring those youth most vulnerable to risk of developing HIV.

Consider a peer outreach program to inform and educate Youth regarding risk factors and areas for testing/treatment.

Theme 4: 16.7% of Youth stated that they were born HIV positive. Of the “out-of-care” Youth, 7.2% also stated that they were HIV positive at birth. This may indicate either their early aggressive treatment and appropriate medical advice to not receive primary care in the past 6 months or a fatalistic attitude towards the disease.

Recommendation: Continue to assess any difference in the care needs of perinatally infected youth.

Theme 5: Surveillance data suggest that the rate of new infection among youth is increasing and that as many as 25% - 30% of those infected may not know their HIV status.

Recommendation: Expand outreach, testing and early intervention programs to youth. Explore the opportunities for assistance in these efforts from the NIH-funded Adolescent Trial Network, which was created to “develop effective methods of enhanced case finding for Youth living with HIV/AIDS, and to develop and test prevention efforts for the most vulnerable youth.” [Ellen, JM, Adolescents and HIV. May 2002. *The Hopkins HIV Report.*]

THEMES AND RECOMMENDATIONS:

WOMEN LIVING WITH HIV/AIDS

Theme 1: A high percentage of women (56.6%) were diagnosed as HIV positive incident to other testing (did not seek out direct test to confirm HIV). Women were the special study group least likely to be diagnosed following a visit for HIV testing. Pregnancy testing is a unique means of detection with 13.9% determining their HIV status at this point.

Recommendation:

Communicate with points of entry conducting pregnancy testing about developing protocols for care since this is a frequent locus for HIV diagnosis.

Aggressively refer or treat these women.

Ensure that sensitive handling of females occurs in regards to their being informed of their diagnosis.

Theme 2: Females were less likely to use ADAP or other drug reimbursement benefits despite their high use of antiretroviral therapy (expensive medications with co-payment currently averaging \$105).

Recommendation: Review females' awareness of drug reimbursement benefits, particularly ADAP.

Theme 3: Females represented a higher 'out-of-care' population than the population (15% v. 12%) with 41% of the 15% 'out-of-care' reporting that they did not seek primary care within the past 6 months due to physician advice.

Recommendation: Further explore the report that providers advise females against actively accessing primary care services. A high percentage of 'out-of-care' was reported yet current viral load most resembles highest viral load.

THEMES AND RECOMMENDATIONS:

INCARCERATED/RECENTLY RELEASED

This special study group represented the highest risk factors:

- 50% uninsured (highest)
- Over 50% disabled
- 53% self-reported substance abuse, 45% injected drugs 'ever'
- 19% Out-of-care

This was the only group who did not place their HIV/AIDS diagnosis as their most pressing concern. They unanimously stated that staying free of drugs was their #1 mission. Their children tend to live with relatives, with their key concerns being finding housing, employment and basic resources to stay 'clean' of drugs.

Theme 1: The incarcerated/recently released were notable in their service category rankings in the higher value placed on substance abuse and mental health services. According to experience reported by providers of substance abuse services, very few individuals receive any substance abuse treatment while incarcerated.

Recommendation: Work to develop more transition programs including those inside prisons to ease the transition of the high (53% self-reported) rate of substance abuse. The Texas Department of Criminal Justice (TDCJ) has established a program of halfway houses for individuals who are identified or who request transition opportunities that incorporate substance abuse treatment.

Theme 2: In-prison and transitional HIV medication adherence is a significant issue with recently released often reporting being issued a 10-day supply of drugs. Lack of permanent address is a confounding obstacle to being 'in care' and continuing adherence to a strict medication regimen.

Recommendation: Develop a comprehensive transitional program that allows clinics to 'adopt' recently released, with prior resources provided including a permanent address if none is otherwise available, ongoing medication regimen and basic resources (nutrition and basic medical care).

Theme 3: Transportation is frequently mentioned as a limitation to accessing other needed services. In addition, many individuals, upon release, do not have a valid identification, such as a driver's license, which is also a barrier to accessing transportation and other services.

Recommendation: Incorporate transportation as a resource provided before release.

Theme 4: High disability and low employment rates make this group vulnerable to remain “out-of-care” (19% vs 12% for all respondents). Among those recently released from prison, there is a high rate of uninsured.

Recommendation 4: Within the comprehensive transition program, incorporate job retraining, insurance eligibility and other efforts to economically support the recently released. These efforts need to be anticipated well before release (up to 1 year prior).

Theme 5: A substantial percent of incarcerated/recently released individuals are in care and express concerns about medication availability and service coordination. A smaller but important subset of incarcerated/recently released appears disinterested in care. Several focus group interviews with incarcerated/recently released revealed that this disinterested population exists and may be difficult to reach. This is true despite the presence of comorbidities disproportionate to the full population (neuropathy, thought/memory disorders, liver disease, pulmonary disease) as illustrated in Table 8-1.

Table 8-1: COMORBIDITIES - INCARCERATED/RECENTLY RELEASED VS. ALL RESPONDENTS

Type of Comorbidity	All Respondents	Incarcerated
Hypertension	29%	30%
Neuropathy	25%	33%
Thought/Memory	23%	34%
Lung	18%	22%
Cholesterol	18%	22%
Liver	17%	21%
PCP Pneumonia	14%	17%
Diabetes	9%	8%
Kidney	9%	5%
Heart	8%	10%
Cancer	6%	7%
Don't Know/None	26%	26%

Recommendation 5: More comprehensive screening on intake and release of these individuals from incarceration, both for HIV and comorbidities. From these efforts, a more thorough assessment of treatment needs can be determined.

Theme 6: Releasees with felony drug offenses are not eligible for food stamps leaving them vulnerable and straining food banks.

Recommendation: Work with providers to insure access to service.