

A Meta-Evaluation of Area HIV/AIDS Needs Assessments

Submitted by:

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Executive Summary

Ryan White Title I and II service areas conducted local needs assessments during the 2001-2002 years. The reports provide valuable quantitative and qualitative data on the extent of the disease in the local communities and the extent that the local areas are meeting the needs of those people living with HIV infection and/or AIDS. Needs assessment data include analysis of both secondary data sources and primary data sources. Secondary data include epidemiologic and demographic data while primary data includes information collected by a planning committee through methods such as surveys, interviews and focus groups. This meta-needs assessment is a synthesis of needs assessment and the results of fourteen service areas within the state of Florida. Analysis and synthesis also provides a foundation for development of a consistent format that could be used for local needs assessment as well as providing information for the statewide needs assessment.

Demographics

Five of the fourteen service areas provided demographic information on their regions. Demographic issues contained in the needs assessment reports included factors such as race, age, poverty levels, and unemployment rates. Demographic information appears to be essential for effective HIV/AIDS planning efforts as many of these factors are directly related to health care access.

Epidemiology

Epidemiology was also not provided by all service areas. This information would appear to be an important foundation for the assessment of needs and allocation of health services resources. These data provide important insights into the regional variations in the spread of the disease and how the disease is treated. It becomes even more important for the integration of secondary prevention efforts with treatment efforts. This information would appear to be an important foundation for the assessment of needs and allocation of health services resources at the local level.

Methods

Methods of primary data collection varied to some extent. Eleven service areas utilized client surveys, 5 utilized focus groups, 5 utilized provider surveys and 3 utilized “expert” surveys for primary data collection. “Expert” is synonymous with key informant in this context. Additionally, public hearings, case manager interviews/surveys and primary care provider surveys were conducted. Areas varied extensively in the use of different methods. Populations of interest for the service areas influenced these variations.

Findings

Many of the findings from the different surveys and interviews reflect the same general issues. It is notable however, that clients’ perceptions of their needs vary somewhat from providers’ perceptions of their clients’ needs. Client based focus groups found a need for more support systems, but providers, reported medical care followed by pharmaceuticals as the most requested services.

Service needs were reported with consistency across the areas. The following are the highest reported service needs in descending order: **Case management, Pharmaceuticals, Dental, Outpatient medical care, Housing, Transportation, Specialty medical care, Food bank/pantry, Mental health counseling, Laboratory testing, and Substance abuse treatment.**

Based on provider responses, the most readily available services include **Counseling, Medical care, Alternative therapies, Dental care, Substance abuse treatment, Prevention, Pharmaceuticals and Housing.** Few of the providers indicate that services such as pastoral care, legal, peer support, optical care and referral services are available. Top service needs appear to be well covered by providers. The four service needs that are not provided but are reported as needs are case management, transportation, food bank/pantry and laboratory testing.

Available resources cover only a few of the identified service gaps. Some of the service gaps may be due to ineligibility for Ryan White funding. Other gaps are unique to specific service areas and may be addressed through reallocation of funds.

Barriers

Findings suggest that clients and providers agree on barriers to care and service. Personal experiences that tend to create difficulty for clients include lack of money, lack of strength/energy, applying for benefits, qualifying for benefits, lack of community resources for persons who are HIV positive and lack of assistance from family members.

Barriers were split into different types: barriers to obtaining information, access barriers, barriers to care, barriers to service provision and barriers in providing care. Transportation and lack of information were the two most identified barriers to care. Among barriers to service provision, transportation and language/cultural issues were the most often identified. When broken down by whom is doing the reporting, consumers identified lack of information most often as the barrier to care. Providers identified both transportation and lack of information equally and case managers or key informants identified transportation, followed by red tape. Transportation appears to be the most common reported barrier as reported by both consumers and providers.

Conclusions

Standardized data collection and reporting would facilitate more effective use of area assessment for benchmarking, comparison, and compiling a statewide assessment. Recommendations for the epidemiological profile include reporting of both HIV and AIDS prevalence, providing a demographic breakdown of both the HIV and AIDS cases to include gender, race, and mode of exposure. Other risk indicators (e.g. STDs) should also be reported.

Guidance for primary data collection may be particularly useful. In general, qualitative techniques such as focus groups and open-ended semi-structured interviews may be best for developing insights concerning issues of complexity and context. More quantitative data collection such as closed ended interviews or surveys are more valuable for

generalizing results across populations.

Client surveys and focus groups appear to be the most common methods of ascertaining clients' points of view. Focus groups of subpopulation are useful for obtaining more in depth information. Some identified populations of special interest, such as the elderly, the homeless, or migrant workers, did not receive the attention that area identification seemed to require. As indicated by HRSA, providers are probably best reached through surveys and interviews. Follow up phone calls to providers who fail to respond or complete the funding portions of surveys maybe critical to obtain valid results. It appears that service areas will need to be persistent in ascertaining provider funding sources, capacity and capabilities in order to comply with HRSA guidelines and to have accurate information. This may stress area planners but this information will be helpful to consistently assess the extent needs are met and where services might need to be expanded.

Recommendations related to findings include the need for state and local areas to address the discrepancy between client and provider perceived needs for substance abuse treatment programs and mental health services. Also providers are criticized by for their lack of language and culturally sensitive services and materials. Additional resources or policies to support enhanced linguistically and culturally appropriate services are indicated. An assessment of clients' access to and use of education and information received for HIV/AIDS in each area also appear to be needed since both providers and clients alike consistently cite lack of information as a barrier to care.

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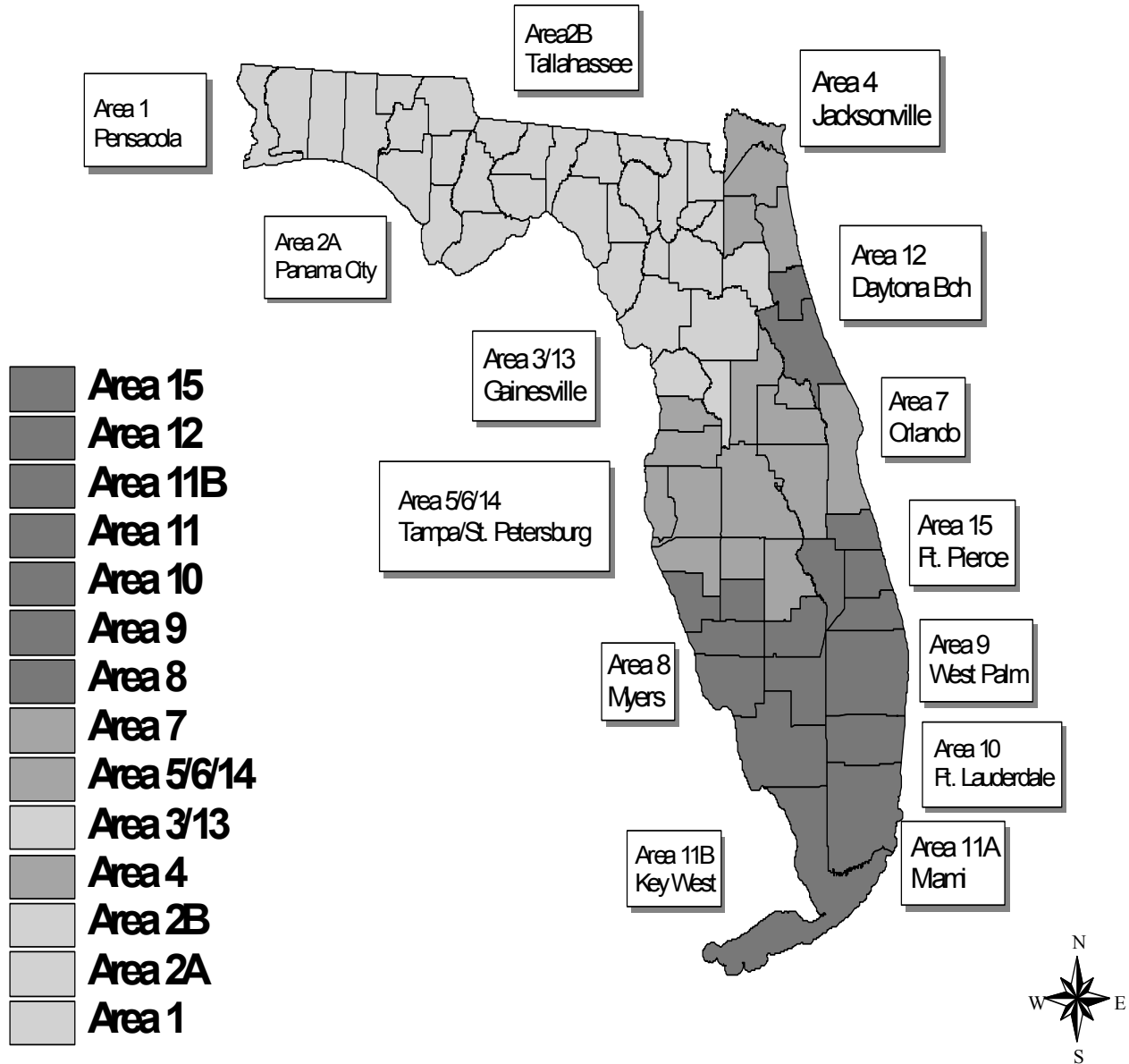
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Figure 1. HIV/AIDS Patient Care Service Areas



Source: Florida Department of Health/Bureau of HIV/AIDS
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Introduction

Ryan White Title I and II areas conducted local needs assessments during the 2001-2002 years. These reports were collected over the course of a year in both hard copy and electronic formats. Report size varied from approximately 80 pages to well over 300 pages. The reports provide valuable quantitative and qualitative data on the extent of the disease in the local communities and the extent that the local areas are meeting the needs of those people living with HIV infection and/or AIDS. Identifying the extent and types of existing and potential care service needs are also the purposes for conducting this area needs assessment. This process involves an analysis of disease trends and the relation of the current service delivery system to the disease within a good perspective. The extent of unmet needs or underutilized resources is also examined. This includes an analysis of the trends in service utilization, priorities, gaps and access barriers.

Needs assessments are usually obtained through analysis of secondary data and primary data. Primary data includes information collected by a planning committee through methods such as surveys, interviews and focus groups. The analysis of each area's methods also provides a foundation for development of a consistent format that could be used for local needs assessment as well as the format for the state report.

The US Department of Health and Human Services, Health Services and Resources Administration (HRSA) has recommended the types of information that should be included in HIV/AIDS needs assessment reports. These recommendations provide important benchmarks for guiding state and local needs assessments. This report includes an assessment of how the area needs assessments conform to the HRSA guidelines.

This meta-needs assessment is a synthesis of needs assessment and the results of fourteen service areas within the State of Florida. The following sections include a summary of the service area reports, including the demographics, epidemiology, methods and results sections. In addition, an analysis of the utility of the methods and findings for the reports is provided. Based upon this information, recommendations for statewide data collection methods will also be addressed.

Meta-Evaluation Methods

Ryan White Title I and II service areas conducted local needs assessments during the 2001 - 2002 years. These fourteen reports were collected over the course of a year in both hard copy and electronic formats. Report size varied from approximately 80 pages to well over 300 pages. Whenever the electronic formats were incomplete, the hard copy format was used as a reference. In a few cases when the electronic format was unavailable, hard copies were scanned at the Institute for Health, Policy and Evaluation Research and stored electronically.

The reports were first segmented by the major themes of Demographics, Epidemiology, Methods, Findings and Recommendations in Microsoft Word. Each major theme was analyzed by area. Then recurrent and atypical themes were identified electronically. Additional thematic analyses were performed by identifying and extracting recurrent and atypical themes. Comparing the content of the area reports to the HRSA guidelines provided additional levels of analyses. The Guidelines formed benchmarks for comments of local needs assessments. The extent the local needs assessment compiled with HRSA guidelines are noted and findings are reported. Themes such as service needs and barriers to service were identified quantitatively by recording the number of times they were reported. The relationship of need to local economic conditions was analyzed by mapping reported needs and comparing the map to the 2001 Florida Price Level Index. Other themes were simply qualitatively reported. After completing the analyses, the reports were finally summarized for reporting purposes.

Demographics

Of the fourteen service areas, five provided demographic information on their regions. Service areas had some items in common. For instance, whites comprised the majority of most service areas with general population estimates reported as growing in most areas as well. Adults over the age of 65 ranged from 12.9 percent to 30 percent of the population of the different service areas. Poverty levels for these service areas ranged from 6 percent to 17.6 percent while the poverty levels of female-headed households and the poverty level of children were especially high. Along with poverty levels, unemployment rates were also of particular concern.

AREA 1

The Northwest Florida Community Planning Partnership (NWFCPP) is comprised of four counties. These include Escambia, Okaloosa, Santa Rosa, and Walton Counties. These counties make up the Department of Health Area One.

Area One has 3,673 square miles and is largely rural. Area One is home to approximately 620,011 residents of which approximately 517 AIDS cases and 199 HIV cases have been reported.

Table 1. Area 1 Demographics

| County | Total Population | Caucasian | Black | Asian & Pacific Islander | Other | Female | Male |
|------------|------------------|-----------|--------|--------------------------|-------|---------|---------|
| Escambia | 291,007 | 207,025 | 69,609 | 8,730 | 5,616 | 150,072 | 140,935 |
| Santa Rosa | 115,566 | 105,858 | 5,663 | 2,254 | 1,791 | 58,361 | 57,205 |
| Okaloosa | 174,298 | 145,121 | 18,859 | 7,059 | 3,259 | 86,818 | 87,480 |
| Walton | 39,140 | 34,169 | 3,707 | 309 | 955 | 20,004 | 19,136 |

Source: University of West Florida, HAAS Center for Business Research and Economic Development

AREA 2A

The Central Panhandle Planning Partnership is comprised of six counties set in the Big Bend Area of the Florida Panhandle, encompassing 3,875 square miles. The counties included in the planning area are Bay, Calhoun, Gulf, Holmes, Jackson, and Washington.

By July 1999, the area was estimated to have a population of 269,920, or 1.7 percent of the total state population, with Bay County having the largest share of residents. Almost 53 percent of the population was male, and just over 47 percent were female residents. A majority of the residents were white (77.5 percent), with non-whites comprising 22.5 percent of the district's residents, a higher percentage than the state average of 15.7 percent. 23.7 percent of residents are below the age of 17 and only 12.9 percent of residents in the area are 65 years or older.

This planning area has several subpopulations, or special populations, which are noteworthy, either because of an increased risk of HIV infection, and/or because of factors that may have special bearing in their care and treatment. Several major military bases make the planning area their home including Tyndall Air Force Base and Naval Coastal Systems Station. There are also two Federal Bureau of Prisons facilities located in Jackson County. It is estimated that approximately 0.23 percent of the population planning area are homeless on a daily basis. Also, approximately 4.3 percent of the total residents of the planning area are disabled. An additional population that needs special mention is the migrant worker population. According to an unpublished report from the Florida Department of Children and Families (DCF), migrants face health problems that are neither simple nor easy to address, and in some instances are similar to conditions which are faced in third world countries.

In 1999, 17.6 percent of the planning area's population was living below the poverty line. Within the counties of the planning area, 22.3 percent of children under 17 lived in poverty. Households headed by females are another population that is especially susceptible to the danger of living in poverty. In the planning area, 53.5 percent of all female households lived in poverty. Additionally, all counties of the planning area have unemployment rates higher than the stage average of 4.8.

AREA 2B - Demographics not provided

AREA 3 - Demographics not provided

AREA 4 - Demographics not provided

AREA 5 - Demographics not provided

AREA 7 - Demographics not provided

AREA 8

Area 8 is comprised of four coastal counties (Charlotte, Collier, Lee and Sarasota), bordered on the west by the Gulf of Mexico and three inland counties. The area covers approximately 6,633 square miles, which is approximately 12.2 percent of Florida's geographic landmass. As in most of Florida, the majority of Southwest Florida's population is concentrated within its coastal counties. Of the 1,166,894 persons estimated to reside in Area 8 in 1999, 89.2 percent were white, 7.3 percent were black and 3.5 percent were Asian/Pacific Islander or other racial background. In terms of ethnicity, 8.7 percent are estimated to be of Hispanic heritage.

Persons 65 years and older comprised 27 percent of the population in 1999, and 28 percent of the population are projected to be 65 years and older by 2010. Not all counties had a high proportion of elderly persons. In 1999, 11 percent of Hendry County residents were estimated to be 65 years or older, a lower proportion than Area 8 and the State of Florida (18 percent).

Compared with all Florida residents, average household income is greater in Area 8's coastal counties and less in the inland counties. Median household income for Area 8's inland counties is also lower than the median household income for all Florida residents (\$28,230).

In 1997, more persons were employed in services (132,742) than any other category in Area 8. The second largest employment sector was retail trade, which employed 101,216 persons. It is noteworthy that 67 percent were employed in lower paying jobs that offer fewer benefits, such as health insurance. Area 8's unemployment rate followed the State's trend, decreasing slightly from 1995 to 1997. There were approximately 30,818 seasonal and migrant farm workers and 34,208 of their dependents living in Southwest Florida in 1998.

During 1996 -1997, 9.5 percent of Area 8 residents received Medicaid. Residents of Hendry and DeSoto counties were far more likely to receive Medicaid benefits than any other county in the Area. Area 8 received 5.4 percent of Florida's Medicaid dollars, and 3.6 percent of Florida's SSI dollars.

Based on 1990 Census data, Area 8 had a lower rate of poverty than the State of Florida. Likewise, among children, 15.6 percent of residents 0 -17 years old live in poverty versus 18.7 percent of children residing in the State of Florida. Among families, 6 percent in Area 8 live in poverty versus 9 percent of families residing in the State of Florida. Approximately 0.4 percent of Area 8 residents are homeless.

AREA 9

Palm Beach County is 2,200 square miles, including thirty-eight municipalities and vast agricultural areas. The county is comprised of expensive coastal communities; centrally located suburban neighborhoods, emerging downtown business and cultural centers and Western agrarian settlements. Population estimates generated by the Bureau of Economic and Business Research (1999) estimate that Palm Beach County is projected to grow from 1,057,796 in 1999 to 1,157,342 in 2004. This county is now the third fastest growing county in the state of Florida and the 16th fastest growing county in the United States.

The county's racial composition consists of 78 percent white, 13 percent black, 9 percent Hispanic and <1 percent other. Thirty percent of Palm Beach County residents are over 60; nearly 10 percent of the residents reside in poverty. Nearly 46 percent of female-headed households live in poverty along with 30 percent of children. The mean household income is \$61,223 with a median of \$35,833. The predominant language spoke at home is English followed by Spanish, French or French Creole and then other. Over one-quarter of the residents have a college degree and less than one-quarter are without a high school diploma. In Palm Beach County, 8.3 percent of the residents are unemployed.

AREA 10

Broward County, situated along Florida's southeast coastline between Dade and Palm Beach Counties, is the second largest metropolitan area in the state. Encompassing 30 municipalities and unincorporated areas, it is home to 1,623,018 residents - approximately 10 percent of Florida's total population.

Service industries and retail trades provide 57 percent of all jobs. Average wages are slightly higher than those paid throughout the state, and the cost of living is the third highest in Florida. Unemployment has consistently been close to the state average.

According to the 2000 census, about 21 percent of the population is black. In addition, many people who told census takers that they belong to "some other race" are of Haitian or Caribbean descent. Hispanics, primarily of Puerto Rican, Cuban and Columbian descent, currently represent 17 percent of the total population.

AREA 11 - Demographics not provided

AREA 11B - Demographics not provided

AREA 12 - Demographics not provided

AREA 15 - Demographics not provided

Findings

Some, but not all service areas, provided demographics which could help inform local planning efforts. Knowledge of special subpopulations might account for higher incidence and/or prevalence of HIV/AIDS and could help planning and allocation of resources. For example, the inmate population in one of the service areas may account for a larger number of cases. In addition, the transient population of the military stations may impact estimates of HIV prevalence in that area. Migrant worker population estimates are also of interest for analyzing those who are classified as 'unconnected'. These transient populations may contribute to underreporting. A recent study indicated that migrant workers who leave families behind in other countries are more likely to engage in atypical behaviors which make them at higher risk for HIV infection (Hirsch, 2002).

The need for tailored programs based on demographic information directly relates to the delivery of health services. Providers and clients alike have cited language and culture as barriers to care. Population language usage estimates would then also be another useful variable for determining if materials made in only English would be sufficient. It is not clear from reports if all service areas are making materials, or even focus groups, available to speakers of other languages.

Information on medical concerns would be useful. Only one area included Medicaid data information. More information is needed on the number of uninsured in a service area.

Disparities in funding would be better resolved by knowing which areas have higher rates of uninsured.

Most importantly, demographic information should be linked to HIV/AIDS planning efforts. It wasn't clear why women of childbearing age, and numbers of household by income were provided. Other data that was provided was not analyzed in later sections. For example, why identify the number of migrant laborers if no assessment of service for migrant laborers is presented? Local needs assessments should specify how they are addressing special populations, including issues related to language and cultural competence.

Epidemiology

HRSA states in its Title I manual, "Epidemiologic profile, which describes the current status of the epidemic in the EMA, specifically the prevalence of HIV and AIDS overall and among defined subpopulations. The profile should also describe trends in the epidemic." Epidemiology was not provided by all service areas.

AREA 1

In Area 1, Sixty-five percent of the HIV cases were men and 35 percent were women. The proportion of cases by race/ethnicity was 41 percent White, 56 percent Black, and 2 percent Hispanic. Cases reported with no identified risk (NIR) represent 18 percent of the total HIV cases. Nearly 28 percent of all cases were reported with MSM as a risk. Approximately 12 percent were reported with IDU as a risk. Nearly 37 percent were reported with a heterosexual risk.

Fifty-eight percent for the HIV cases were from publicly funded sites and 37 percent were privately funded sites. Among Males, 63 percent of the cases from publicly funded sites were among minorities, compared with only 34 percent of the cases from privately funded sites. Among females, 78 percent of the cases from publicly funded sites were among minorities, compared with only 34 percent of the cases from privately funded sites.

At a minimum, 16 percent of the adult female HIV cases were known to be pregnant. By race/ethnicity, among adult female HIV cases, at least 21 percent of whites and 15 percent of blacks were known to be pregnant; there were no Hispanic female HIV cases. There were 10 pediatric HIV cases of which 10 percent were white, 90 percent were black, and none were Hispanic.

As of June of 1999, there were 716 adults living HIV and AIDS. Men made up 78 percent of this group; 57 percent were white, 39 percent black and 2 percent Hispanic. Twelve percent of these men were aged 50 or older. In the female cases, 29 percent were white, 69 percent black and 1 percent Hispanic. Eight percent were aged 50 or older. There were 15 living pediatric HIV and AIDS cases as June 1999, of which 20 percent were white, 80 percent black, and none were Hispanic.

AREA 2A

A majority of AIDS cases reported between 1996-98 occurred among males, (who had a rate per 100,000, over seven times the rate among women), with the majority of cases among black males, 59.5 percent in contrast to 37.5 percent among white males. Men Having Sex with Men (MSM) accounts for the highest number of cases reported during the three year time period, followed by Heterosexual Contact as the second leading transmission cause. A total of 45 cases are included in the category of Risk Not Reported/Other.

Finally, it is important to note that within the Central Panhandle planning area there have been no reported cases of pediatric AIDS for the time period 1981 through 1998. Testing and counseling data from the period 1996-98 indicate that a few tests have been given to children of HIV infected mothers, none of whom tested positive.

A total of 372 persons with HIV/AIDS are presumed to be alive in the planning area, with 320 of these males, and 52 females. Almost 60 percent (58.9 percent) are black, 36.6 percent are white, 4.0 percent are Hispanic, one person presumed alive is Asian, and one is a Native American. The largest group of survivors is between the ages of 30 and 39 years; the smallest group (1) is over 60 years.

Ninety-one cases of HIV infection were reported during July 1997 and June 1999. Of these, 67 percent were among black residents, with 29.7 percent of cases among whites. 82.4 percent occurred among males. The greatest number of infections was reported with heterosexual contact as the cause of transmission.

A total of 22 individuals reported with HIV were under the age of 30; 73 percent of these were male, 77 percent were black, and one case was a male Hispanic. Slightly over 36 percent did not identify a risk factor, while 27 percent of cases were attributed to MSM, and 14 percent to heterosexual contact.

A total of 69 individuals reported with HIV were over the age of 30; 85.5 percent of these were males, 63.7 percent were black, and two were Hispanic males. Slightly over 37 percent did not identify a risk factor, while 27.5 percent of cases were attributed to MSM, 18.8 percent to Heterosexual Contact, and 14.5 percent to IDU.

AREA 2B - Epidemiology not provided

AREA 3 - Epidemiology not provided

AREA 4 - Epidemiology not provided

AREA 5

There were 4,513 AIDS and 2,372 HIV cases in this service area. Among males with AIDS, the most prevalent mode of exposure was MSM followed by IDU and heterosexual contact. Sixty-two percent of the cases were among whites followed by 28 percent among blacks and 9 percent among Hispanics. Less than one percent of the total AIDS cases identified themselves as other. Among the male HIV cases, risk not specified replaced heterosexual contact as the third risk factor. In this group, 49 percent of the men were white, 41 percent black, 9 percent Hispanic and 1 percent other.

Among females, heterosexual contact, intravenous drug use and risk not specified were the top three modes of exposure for AIDS. Over half of this group was black; 33 percent were white and 12 percent Hispanic. Less than 1 percent identified themselves as other. Risk not specified was first, followed by heterosexual contact and then intravenous drug

use among the HIV cases. There was a bigger gap between blacks and whites among the HIV cases. Here 63 percent were black, 27 percent white, 9 percent Hispanic and 1 percent was other.

AREA 7

Among all five of the Central Florida counties, male AIDS cases outnumber female AIDS cases. In the 1996 to 2000 period of time, male cases decreased each year, except for 1999, while female cases remained relatively stable.

The most prevalent mode of exposure in all five counties for the years 1996 to 2000 was MSM. IDU was the second highest mode of exposure for three counties, while heterosexual contact was the second highest mode for the remaining two counties. For a very large number of cases, the source of exposure was documented as 'others/unknown.'

In Partnership 7 counties, AIDS cases are higher in number for whites in each age subgroup, except 13 to 19 year olds. Blacks ranked first for 13 to 19 year olds and second for all other age groups. MSM is the highest mode of exposure for all of the age subgroups, except for 13 to 19 year olds. While heterosexual contact ranked second for 20 to 29 year olds and those over 50, IDU ranked second amongst 30 to 39 year olds and 40 to 49 year olds.

During July 1997 through December 2000, the total combined number of HIV cases is reported as being 1,952 for the five counties. Males account for a higher number of cases among most of the counties. Among ethnic groups, African Americans have the highest number of HIV cases in four of the five counties. Whites have the second highest number of HIV cases in all five Central Florida counties.

MSM is the most frequent HIV transmission mode in four of the counties; heterosexual contact is the most common mode of exposure in the remaining county. Heterosexual contact ranks second among the most frequent modes of transmission in the four counties while MSM is second in one county. In all five counties, IDU is the third most frequent mode of exposure.

Blacks had the highest number of HIV cases in all age subgroups during the time period studied. MSM was the most frequent mode of exposure to HIV among all age subgroups except 13 to 19. Heterosexual contact ranked higher than IDU among all age groups except 40 to 49 year olds.

AREA 8

The seven counties that make up Area 8 account for 3,113 of Florida's 75,101 AIDS cases cumulative through June 2000. This figure represents about four percent of Florida's total AIDS cases reported through the HIV/AIDS Reporting System (HARS). The rate of AIDS in Area 8 is 19.9 per 100,000 persons, varying across the seven counties.

The number of adult/adolescent AIDS cases reported per year from 1981 through 2000 in Area 8 is shown. Compensating for the spike in 1993 (which reflects the change in AIDS case definition), the reported adult/adolescent AIDS cases increased steadily in Area 8 from 1991 to 1995. From 1995 through 1997 there was a substantial drop in reported AIDS cases. Reported adult/adolescent AIDS cases decreased 21 percent between 1995 and 1996, and 28 percent between 1996 and 1997. From 1998 to 1999 Area 8 saw an 18 percent increase in reported AIDS cases. The reason for this increase is uncertain and should be monitored closely.

Fifty-three percent of AIDS cases in Area 8 are white versus 40 percent for the State of Florida. Nine percent of AIDS cases are Hispanic versus 15 percent for the State of Florida. The percentage of AIDS cases according to sex, mode of exposure, and age distribution is very similar between Area 8 and the State of Florida.

Of the 516 HIV cases reported in Area 8, 228 persons or forty-four percent were white, 234 persons or 45 percent were black, and 52 persons or 10 percent were Hispanic. For the State of Florida, 26 percent were white, 58 percent were black, and 15 percent were Hispanic. Thus, Area 8 had a higher proportion of white persons reported with HIV than the state and a lower proportion of black persons. In Area 8, 317 or 61 percent of reported HIV cases were male and 199 or 39 percent were female; for the State of Florida, 60 percent were male and 40 percent were female. Thus, Area 8 has a similar proportion of male and female reported HIV cases as the State of Florida.

People aged 30-39 represented 40 percent of the reported HIV cases. People aged 20-29 represented 23 percent of all cases, followed by persons 40-49 who represented 22 percent of all cases. Similarly, for the State of Florida, persons aged 30-39 represented 39 percent of the reported HIV cases. Persons aged 20-29 represented 23 percent of all cases, and persons aged 40-49 represented 23 percent of all cases.

For 121 cases (or 23 percent of all reported HIV cases), the mode of transmission was reported as homosexual male contact. Among these men, 91 (75 percent) were white, 19 (16 percent) were black, and 11 (9 percent) were Hispanic. For 311 cases (or 60 percent) the mode of transmission was not specified.

AREA 9

The Palm Beach County statistical area ranked seventh in 1997 in AIDS case rates among the 97 metropolitan areas in the United States with populations of 500,000 or more. The rate of reported AIDS cases in the Palm Beach County EMA was 73 per 100,000 population. The age adjusted leading causes of death in Palm Beach County suggested that HIV/AIDS is the third highest after heart disease and cancer.

Overall, men account for the majority of reported AIDS cases in Palm Beach County through 1999 (68 percent), while females accounted for 32 percent of the cumulative number of cases. The majority of AIDS cases occurred among blacks, accounting for an

average of 64 percent. The average has remained consistent from 1994 to 1999. Two times as many cases of all reported cases through 1999 were between 20 and 39 years old. Also, there is an increase in the percentage of adults over 50 contracting the virus.

Among the cumulative adult/adolescent category, 31 percent were men having sex with men, 17 percent were injection drug users, 3 percent reported having combined categories of being injection drug users and men having sex with men, 30 percent reported heterosexual transmission, 1 percent contracted through receipt of blood and 17 percent identified no identifiable risk. Cumulatively, through 1999, there were a total of 202 pediatric AIDS cases in Palm Beach County. There were in total, 6 white cases, 181 black cases, and 15 Hispanic cases. Ninety-six percent of those cases were due to perinatal transmission of HIV/AIDS.

From mid-1997 until December 1999 there were 1,214 new HIV cases reported in Palm Beach County. The data reveals that of the new HIV cases, 53 percent are males and 47 percent are females. Approximately 87 percent are less than 50 years old with 50 percent between 20 and 44 years. 70 percent of the new HIV cases in the county were black, not Hispanic, 22 percent white, not Hispanic and 7 percent were Hispanic. Twenty-three percent of the new HIV cases report heterosexual sex as their exposure category, while 20 percent report men having sex with men. The category 'no identifiable risk' had the overwhelming majority with 52 percent. As of 2000, there are no population-based trends available in Palm Beach County for directly and accurately approximating rates of HIV infection.

AREA 10

Broward County has consistently ranked second only to Dade County in the number of AIDS cases in Florida. Its high AIDS incidence rate (54.8 per 100,000) places it third in the nation among metropolitan areas with a population of 500,000 or more. The first documented case of AIDS in Broward County was reported in 1982. Since then, Broward has accounted for 16.2 percent of the AIDS cases reported in Florida and 1.7 percent of all cases nationwide. According to the Florida Department of Health, Bureau of HIV/AIDS, a cumulative total of 12,676 cases of AIDS had been reported in Broward County through December 31, 2000 (excluding Department of Corrections). Of these, more than half (55 percent) are known to have died.

The Centers for Disease Control and Prevention (CDC) estimates that there are 800,000 to 900,000 people living with HIV in the United States. By applying the 1.7 percent proportion of AIDS cases reported to date in Broward County, it was assumed that 13,600-15,300 people in this EMA know they are HIV-positive. The CDC also believes that one-third of PLWH are unaware that they are carrying the virus. By adjusting for this remaining portion, it was estimated that HIV prevalence in Broward County ranges from 20,400 to 22,950. The mid-range point estimate was approximately 21,675. This translated into about 1.3 percent of the County's overall population. During the year 2000, a total of 832 new AIDS cases and 942 new HIV cases were reported to the Department of Health. Using a combination of statistical models, local epidemiologists

project that, at a minimum, demand for HIV/AIDS services will double again within the next five years.

Of the 726 positive test results recorded at Broward's registered HIV counseling and testing sites during 2000, a total of 214 tests (29 percent) were performed anonymously. Most anonymous tests were conducted at community-based organizations (66 percent) or private doctor's offices (13 percent). Gay/bisexual men (particularly white men) most frequently chose anonymous testing. During 2000, women accounted for 44 percent of the positive tests conducted at confidential sites, compared to only 28 percent of the tests performed anonymously. Similarly, only 39 percent of anonymous tests were among African Americans, compared to 76 percent at confidential sites.

Although HIV/AIDS is no longer considered a disease exclusive to the gay community, the epidemic continues to disproportionately affect gay and bisexual men in this area. Blacks in Broward County have also been disproportionately affected by the HIV/AIDS epidemic. For example, although they comprise only 21 percent of the population, they account for 48 percent of people living with AIDS as of 12/31/00. Immigration from the Caribbean and Latin America, where HIV infection rates are much higher than in the United States, has had a significant impact on the demand for HIV services in Broward County as well. Additionally, since tuberculosis (TB) is one of the most common complications of HIV infection, TB patients as a group have a higher prevalence of HIV infection than the general population. According to State testing data, about 12 percent of new HIV infections in Broward County are attributed to the sharing of HIV-infected drug injection equipment. Another 4 percent indicated IV drug use (IDU) in conjunction with homosexual/bisexual behavior. Furthermore, Broward County has a significant homeless population, drawn by the region's pleasant climate and sound economic conditions. Behaviors that increase a homeless person's HIV risk include unprotected sex with multiple partners, injection drug use, sex with an IDU partner, and exchanging sex for money or drugs. In most cases, several risk factors are involved. Lastly, the Broward County Sheriff's Office reports that, during the first half of 2000, HIV tests were administered to more than 1,600 inmates who were considered to be at high risk for HIV/AIDS. Of these, approximately 10 percent tested positive.

AREA 11

Miami ranks fourth in the nation in the number of AIDS cases from 1981 through June 30, 2000, after New York City, Los Angeles, and San Francisco. Miami-Dade County has the second highest rate of AIDS at 58.3 per 100,000 residents, just after New York City. For the first time, the number of AIDS cases reported in Miami-Dade County has dropped.

For many years, Miami-Dade County has had a higher proportion of AIDS in the African American population as well as the substance abuse population than has been reported for the nation as a whole. This is also true for women. The county has had the highest number of pediatric AIDS cases, after New York, but efforts to reduce perinatal transmission have dramatically reduced the number of children diagnosed with AIDS. In

1999 one percent of all HIV cases were pediatric infections.

More than 31,500 people were estimated to be living with HIV/AIDS in Miami-Dade County as of the end of 2000. Roughly one-third has AIDS. However, when a person is tested anonymously, the results are not reported to the state. Reporting occurs only when the person consents and opts for confidential testing. Therefore these numbers do not represent the total number of HIV cases, and may not reflect accurately the demographics of the population with HIV infection.

Over half (57 percent) of the HIV/AIDS population is estimated to be Black Non-Hispanic or Haitian. This proportion is higher than shown in the number of AIDS cases, indicating a growing rate of HIV infection in this group. In fact, estimates provided to Miami-Dade County by the CDC show nearly two-thirds of the HIV-only population being Black non-Hispanic. Twenty-one percent of those living with HIV are Hispanics. Thirty percent of the estimated number living with HIV/AIDS are women. This is an increase of three percent over the previous year. No estimates are made by age, though it appears from reported HIV infections that the population is getting younger. Nationally, more adolescents are being infected than previously.

Miami-Dade County continues to be troubled by the high rate of cases of unknown infection route. These cases are labeled as NIR, or No Identified Risk. Based on current data and work by the Florida Department of Health to reclassify cases, it is known that heterosexual sex is a major contributor, accounting for up to half of the infected population. However, it is also clear that most cases are related to substance abuse: sex with an injection drug user, high-risk sex while under the influence of drugs or alcohol, or other means. Thus the connection between substance abuse and HIV/AIDS in the community is rather clear.

AREA 11B - Epidemiology not provided

AREA 12

Since July 1997, positive results from confidential HIV testing have been reported to the state public health office. These figures provide a more current view of who is getting infected and the way they are getting infected. Reported HIV cases by race/ethnicity show that 48 percent are African Americans, 43 percent are white and 8 percent are Hispanic and less than one percent are of another race. It is important to recognize that of the total 347 reported HIV cases, 42 percent were reported in women.

For males, of the 201 reported HIV cases, the leading mode of transmission was males having sex with males (MSM) at 50 percent (n=101), followed by no identified risk reported (NIR/Other) at 20 percent (n=41), then heterosexual contact at 13 percent (n=28), IV drug users (IDU) at 11 percent (n=23), and combined MSM/IDU at 3 percent (n=6). For the female population who have tested positive for HIV during this time period, the leading mode of transmission was heterosexual contact at 50 percent (n=73), followed by no identified risk reported at 38 percent (n=55), and IV drug use at 12

percent (n=17).

Cumulatively through June 30, 2001, in Volusia and Flagler Counties there have been a total of 1,167 AIDS cases reported. Of these AIDS cases, 522 persons are presumed to be living with AIDS in the area. Of the persons presumed to be living with AIDS, 25 percent are women and of the women living with AIDS 49 percent are African American.

The most reported mode of exposure in males is MSM followed by IDU, heterosexual contact, NIR and by transfusion. In females, the most reported mode of exposure is heterosexual sex followed by IDU, NIR and transfusion. The high number of those with AIDS classified under the no identified risk exposure category tends to obscure actual trends. Statewide trends in the analysis of NIR cases have shown that the majority of the NIR cases are attributable to heterosexual contact.

The distribution of cumulative AIDS cases by age show that 45 percent of the cases in Area 12 were in the 30 - 39 age group, followed by 27 percent of the cases between 40 - 49 years of age. The smallest percentage of AIDS cases was seen in the 13 - 19 age category.

AREA 15

The current local epidemic is characterized by poverty, less education, economic disadvantages, larger unemployment and reliance on public assistance. Eighty-four percent of needs assessment survey respondents had an annual household income of less than \$16,000. The local epidemic disproportionately affects the black, Non-Hispanic population accounting for 70 percent of Presumed Alive HIV/AIDS cases in Area 15 as compared to the total black, Non-Hispanic population of 10.4 percent in Area 15.

The cumulative HIV cases (July 1, 1997-June 30, 2001) for blacks in Area 15 were 76 percent (475) of total cases (628). The cumulative AIDS cases (1983-June 30, 2001) for blacks in Area 15 were 66 percent (1,372) of total cases (2,076). Twenty-eight percent of the Presumed Alive HIV/AIDS cases in Area 15 are white. The cumulative HIV cases (July 1, 1997-June 30, 2001) for whites in Area 15 were 19 percent (122) of total cases (628). The cumulative AIDS cases (1983-June 30, 2001) for whites in Area 15 were 28 percent (591) of total cases (2,076).

Five percent of the Presumed Alive HIV/AIDS cases in Area 15 are Hispanic. The cumulative HIV cases (July 1, 1997-June 30, 2001) for Hispanics in Area 15 were 5 percent (31) of total cases (628). The cumulative AIDS cases (1983-June 30, 2001) for Hispanics in Area 15 were 5 percent (106) of total cases (2,076).

Findings

Epidemiological data on HIV/AIDS in each county in the service area was reported by most, but not all of the service areas. This information would appear to be an important foundation for the assessment of needs and allocation of health services resources. These

data provide important insights into the regional variations in the spread of the disease and how the disease can be treated. It becomes even more important for the integration of secondary prevention efforts with treatment efforts.

Some of the area needs assessments provide information on STDs and other comorbidities. As HIV is sexually transmitted and as having an STD can increase ease of transmission, (by increasing viral load or by offering HIV an ulcer through which to transmit) knowing the rates of STD in population can help understand HIV risk further. Although STD incidence does not reflect all high-risk subpopulations (e.g. IDU) it can provide insights about other important high-risk populations. These comorbidities have implications for health care services and prevention.

Methods

Eleven service areas utilized client surveys, 5 utilized focus groups, 5 utilized provider surveys and 3 utilized “expert” surveys for primary data collection. “Expert” is synonymous with key informant in this context. Additionally, public hearings, case manager interviews/surveys and primary care provider surveys were conducted. The following will provide evidence for the variation in methods utilized. Populations of interest for the service areas influenced these variations.

AREA 1

Background

During a technical advisory meeting/discussion among the three Ryan White Title II consortia of northwest Florida, the consultants from the firm of John Snow & Associates, suggested that because of the similarities in the geographic area, a regional assessment would be a less time-consuming and more productive way of carrying out this process. During a follow-up meeting of the 3 consortia, the Northwest Florida AIDS Consortium (NoFLAC), Central Panhandle AIDS Network (CPAN) and the Panhandle AIDS Network (PAHAN), representatives decided to contract with the Northwest Florida/Big Bend Health Councils to conduct a needs assessment on a regional basis, essentially in two phases.

Surveys

After analyzing the needs assessment instruments of many different consortia and Title I Planning Councils in the state of Florida, an advisory committee comprised of at least 2 or 3 representatives from each consortia developed and approved a final survey instrument which would be distributed through the Northwest Florida/Panhandle region. The instrument was given to lead agencies of the three consortia for distribution to clients and prospective clients within the service area. A total of 208 surveys were returned, representing slightly under 10 percent of the midline projected number of PLWH disease (2500) in the region, according to the State of Florida Department of Health.

AREA 2A

Surveys

Three distinct needs assessment components, completed over a two-year period, are summarized in the needs assessment summary. The first component, the client survey, was completed in September 1999. As a second component of the general needs assessment, case managers, whose primary task is to facilitate client access to services, were involved in an interview and survey process. As a complement to the PLWH survey and the case manager survey/interview processes, a survey of primary care providers was initiated.

Each of these components was selected and agreed upon so that a comprehensive picture of need in the Central Panhandle AIDS Network (CPAN) Planning Area could be developed. In this sense, the unique components were designed to be complementary, providing information from different points of reference, and

completing information when necessary. Additional information was abstracted from interviews with select key informants in the service area.

AREA 2B

Surveys

Client surveys are merely one part of a general needs assessment and the consortia were well aware that it would be impossible to have all components of a fully comprehensive needs assessment completed by a specific date. Therefore, it was decided that during the second year, the client survey information would be supplemented by a series of either public hearings, focus groups, key informant surveys, case manager interviews and/or surveys, or similar mechanisms to develop additional information specific to the service areas.

AREA 3

Surveys

From March through May of 2000, an eight-page survey was mailed to 461 active, case-managed Ryan White clients residing throughout the 15 counties covered by the Consortium. An active client is defined as one who received at least one Ryan White funded service during the six months preceding commencement of the survey. The survey asks clients for general information about themselves; their experiences with health care, case management, and other Ryan White services; the impact of personal experiences; and their assessment of priority needs.

AREA 4

Background

The committee decided that information from several instruments would be combined and modified to meet the needs of the local area. It was also decided that data would be collected in three ways: surveys, focus groups and public hearings.

Surveys

It was decided that in order to obtain a representative sample, all provider agencies would be asked to administer the surveys. Case managers would administer surveys when clients came in for services and Ryan White staff would survey clients as they waited for doctor appointments. Because the survey instrument was quite lengthy, it was decided that the survey would be administered as an interview if needed, rather than filled out by the participant. Ryan White staff provided training for anyone involved in conducting the surveys. To avoid duplication, respondents were asked to fill out only one survey, and where possible, their unique client identification number was recorded. It was indicated on the survey that all information was anonymous and confidential. Surveys were administered to consumers only. However, the last page of the survey, which asked the respondents to rank a list of services, was also given to providers during their focus group.

Focus Groups

Decisions were made concerning who should be involved, which target groups should be included, and facilitator training. It was agreed that the focus groups should be composed of the following: Men having Sex with Men (MSM), females, adolescents, substance abusers, mental health clients, incarcerated, homeless, and providers, and where possible, more than one group to include various demographic characteristics. In order to increase participation, it was agreed to offer an incentive of a \$25 food certificate, paid for out of General Revenue funding. Flyers advertising the focus groups were distributed to the providers. Facilitator training was held for those who were interested in being a focus group facilitator. A total of 15 focus groups were conducted, one of which was composed of 16 providers, and the remainder were composed of consumers from the various risk and demographic categories mentioned above.

For the focus groups, the sampling goal was to have at least 6 and no more than 12 participants per group. Recruitment of participants for the focus groups was accomplished with the assistance of case management agencies, other service providers, and posting of flyers in various agencies and facilities. Individuals agreeing to participate in the focus groups were asked to complete the same demographic survey that was being completed in the survey process prior to the focus group. Participants were also asked to identify if they were aware of services available on a separate sheet at the conclusion of the focus group. A \$25.00 incentive in the form of a local grocery store gift certificate was provided for all focus group participants, with the exception of the service providers who participated.

Public Hearings

Two public hearings were held, one in St. Johns County and one in Duval County. Because of the low turnout in previous years, it was decided to have the public hearings in a more informal setting than in the past. The public hearing in St. Johns County was held at St. Paul's AME Church. Transportation from Clay County was provided and participants were offered refreshments. The public hearing in Duval County was held at noon at Touching Lives Ministry, a faith-based outreach and health information facility. The public hearing was held in conjunction with a fish fry. Both public hearings were advertised on the radio and in the local newspaper, and members of the planning council were present to listen to the comments of the public.

AREA 5

Surveys

The needs assessment utilized a variety of techniques to gather information from relevant sources. The FY 2001 client survey involved surveying PLWH residing throughout the Care Council's total service area (TSA). A total of 654 clients completed the questionnaire. In addition to general demographic questions (i.e., age and gender) the questionnaire contained multiple and short answer questions about the need for all Ryan White funded services as well as more detailed

questions on housing and transportation needs.

The surveys were distributed at various service sites to insure diversity and a representative sample. The sites consisted mainly of primary care providers (both public and private) and AIDS Drug Assistance Program's offices. Additional sites were chosen to allow the harder-to-reach PLWH to participate and included food banks, drug treatment providers, homeless shelters, PLWH support groups, community based AIDS coalitions, and HIV housing programs.

A fourth component of the needs assessment involved surveying 87 "experts". "Experts" were defined as members (voting and non-voting) of the Care Council and/or its ten standing committees. Questionnaires were mailed to 44 Care Council and 43 committee members requesting their input on the service needs of PLWH in their respective county. A cover letter from the Care Council Chair and an addressed, postage-paid envelope were included. Reminder postcards were mailed five days after the initial distribution of the surveys. Sixty surveys were completed, which is a 69 percent return rate.

The survey instrument gathered demographic data about the respondent (e.g., county and category represented), perceived need at the county-level of 20 HRSA service categories, perceived availability at the county-level of 20 HRSA service categories, perceived quality of PLWH life, barriers to improving quality of life, impression of PLWH services on six quality measures, and projected service needs for 2005.

Surveys were mailed or faxed to community agencies to gather information about the services provided as well as the availability and appropriateness of those services for HIV+ clients. The focus of the FY 2001 analysis was to reach out to new resources that had not responded to previous attempts, or that had been newly identified. In addition, existing resource information was updated. The total number of resources identified for the inventory was 222 for the TSA.

Focus Groups

A second component of the needs assessment involved conducting focus groups among client populations that are typically under-represented (as compared with the epidemiology data) in previous needs assessment efforts. The under-represented populations were identified as adolescents, blacks, elderly, hearing impaired, inmates, intravenous drug users (IVDU's), migrants and rural residents. The focus group approach was intended to elicit the participation of these groups because it was felt that case management agencies and other service providers could assist in the identification and solicitation of the participants, while maintaining the client's confidentiality.

Care Council and committee members in all eight counties of the TSA participated in the scheduling and conducting of focus groups. Members volunteered to be site sponsors and/or facilitators for the focus groups. Twenty-

five facilitators were trained by Health Council staff, and were instructed to utilize a script designed to identify current and future needs, perceived availability of services, and prioritization of needs. The use of the script assured comparability between the focus groups. Health Council staff co-facilitated each session, generally serving in the role of recorder.

Persons attending focus groups were asked to complete a participant information sheet that gathered demographic information (e.g., county of residence, gender, age, race and mode of transmission). Sixteen persons participated in five focus groups.

Another component of the needs assessment involved conducting focus groups among case managers who work with HIV+ clients.

Six focus groups involving 69 staff were conducted as part of case management training supported by the Ryan White Care Council. Health Council staff facilitated the sessions utilizing a script designed to identify current and future needs, perceived availability of services and effectiveness of the service delivery system, and prioritization of needs. The use of the script assured comparability between the focus groups.

Persons attending the focus groups were asked to complete a participant information sheet that gathered demographic information (e.g., county of work, gender, age, race, and case management experience). Participants were asked to provide their perceptions on six quality measures for PLWH services in the community including convenience, coordination, client focus, overall quality, staff, and collaboration.

The needs assessment conducted focus groups among service providers who did not have contracts for Ryan White services. Care Council and committee members in all eight TSA counties were requested to participate in hosting provider groups. In response, members from four counties (Hillsborough, Manatee, Pinellas and Polk) developed lists of potential participants for the non-Ryan White provider focus groups and agreed to serve as hosts. Each individual on the list represented one of the twenty HRSA service categories. Letters were mailed to the invitees indicating that a specific Care Council member had identified them as having expertise that would be valuable to the needs assessment process. Invitees were asked to respond whether they or their representative would attend the focus group.

The 41 persons who attended the five focus groups were asked to complete a participant information sheet which gathered demographic data (e.g., county represented, experience as service provider, services provided, gender, race). The facilitator followed a script to insure comparability between the focus groups. The script allowed participants to identify service needs, perceived availability of those services, impressions of PLWH services on six quality measures and

barriers to improving the service delivery system.

AREA 7

Focus Groups

In order to accomplish these objectives, interviews with PLWH outside the medical care system and focus groups with providers were conducted. Specifically, two focus group discussions were conducted. One was with eight outreach workers and case managers, and a second included 10 executive directors of Title I funded agencies. In both groups barriers to care were discussed as well as suggested strategies to overcome these barriers.

Client Interviews

Twenty-six in-depth consumer interviews identified barriers to care, service needs and suggested strategies to overcome barriers. Interviews averaged approximately 30 minutes in duration. Participants discussed experience with service linkages at the time of diagnosis, past HIV service utilization, requirements/motivation to move into HIV medical care, and prioritized service needs. A card sort technique was then used to prioritize service needs. Thirty-one potential Ryan White Title I funded services were presented on cards. Participants were asked to select the 10 services that they most need, and then rate their importance.

A field team comprised of outreach workers and case managers was used to do case finding and schedule interviews. These “recruiters” attended a training session outlining their responsibilities and providing tools for support of their recruitment activities. They identified consumers for interviews, scheduled appointments and assured the consumers were present for appointments. In many cases the recruiters transported the consumers to the interviews.

Consultants conducted the confidential interviews at locations in Orange and Seminole Counties. Locations were selected based upon confidentiality and convenience for consumers. Interviewed PLWH were compensated for their time and participation, and recruiters received a stipend for each interview they facilitated.

AREA 8

Surveys

Providers throughout Area 8 were asked either in person, via e-mail or telephonically to relate what they believe to be the gaps in services for HIV/AIDS clients.

AREA 9

Surveys

The needs assessment process utilized several strategies to solicit input. The centerpiece of the process was the creation and distribution of written surveys to persons living with HIV/AIDS (PLWH/As) and receiving case management

throughout Palm Beach County. Other components of the needs assessment process included a written provider survey, focus groups of targeted consumer sub-populations and an administrative review of services.

The 2000 Consumer Survey targeted persons living with HIV/AIDS throughout Palm Beach County. The survey was based on ones developed for Three Year Comprehensive Needs Assessments by Boston, Baltimore and Seattle EMA's and the Palm Beach County CARE Council. Staff members from the CARE Council and five participating providers were responsible for distributing and collection of the survey. Staff from the CARE Council performed the analysis and interpreted the results.

The HIV CARE Council sought to collect information on a wide spectrum of persons living with HIV/AIDS in Palm Beach County, ranging from individuals who were HIV positive yet not symptomatic to persons with end-stage illness. The process emphasized traditionally underserved populations, including people of color; White men having sex with men; men of Color having sex with men; injection drug users; women; adolescents and Hispanics. Survey forms were produced in English, Spanish and Creole.

The survey questionnaire inquired about 43 types of HIV/AIDS related services offered in the Palm Beach County Continuum of Care. Consumers identified each service as either ones they needed and used, did not need, needed but could not get or, could get but did not use. Additionally, comments were solicited to provide a depth of understanding and identify barriers of care. Consumers were also asked to choose up to seven of the services that they would consider to be most important for them. The survey also collected basic demographic information including information specific to HIV/AIDS health status and current living situations. Survey instructions explicitly stated that consumers should not include their names, addresses or phone numbers on completed surveys. To safeguard respondent's confidentiality, the surveys were pre-addressed to the "Planning Council", rather than the "HIV CARE Council." Surveys were bar coded for pre-paid reply.

Consumers were invited, by mail, to participate in the survey entitled "Speak Out, Be Heard." enclosed in the mailed package were a cover letter operating as an invitation, the questionnaire instrument, a pre-paid return envelope and an insert containing instructions. Consumers could mail the survey in after a self-administration, call a help-line for help in taking the questionnaire and then mail, or bring the survey to their case management agencies for "hands on" aid, and then mail it in or turn it in to their case management agencies;

Posters were displayed at the five participating case management agencies encouraging consumers to come in and take the survey during a designated time with help from other PLWH/A's. The surveys were administered by trained data collectors and brought to the CARE Council or mailed in; or consumers could

also pick up a survey from either their case manager or their case management agency lobby. They were invited to take it home and fill it out by themselves; utilize phone aid; come to their agency for a face-to-face administration; or mail it in after a self-administration.

Twenty-five PLWH/A's data collectors were drawn from the five participating case management agencies. These individuals received word of the data collection by flyers posted in their respective agencies. The trainees were paid \$25.00 to attend a two-and-one-half-hour training relating to this project. The participants received training on confidentiality and signed a State of Florida Confidentiality Statement. The survey instrument was read aloud and questions were solicited to clarify the data collection procedures. Eighteen individuals were selected to participate in the Needs Assessment Survey. These individuals were paid \$10.00 an hour for five hours per day for five days. They earned a total of \$275.00; including the \$25.00 for training. This process of training through data collection generated excitement throughout the participating data collectors. Anecdotally, they spoke of wanting to more fully participate in the functions of the Palm Beach County HIV CARE Council as an unanticipated benefit of data collection involvement.

The Palm Beach County HIV CARE Council created and distributed "key informant" provider surveys to each agency supplying HIV/AIDS case management services in Palm Beach County. One aim of the "key informant" provider interview sought to gather information from administrators. Also, a key informant provider survey went to one case manager per agency to gather information from those closer to consumers. The council's aim was to gather service priority and service gap data through written provider surveys from two tiers of agency employees.

The survey collected data from agencies providing case management to persons living with HIV/AIDS in Palm Beach County at all of their sites. This direction emerged from the Palm Beach County HIV CARE Council: Needs Assessment Sub-Committee. The provider survey distribution list was identical to the provider-site distribution roster used for consumer surveys. The Palm Beach County Department of Health included surveys from three employees from three sites; the Comprehensive AIDS Program (CAP) included surveys from seven employees from three sites; the Haitian Center for Family Services distributed three surveys to three employees at one site; Hope House of the Palm Beaches distributed two surveys to one site, and Compass, Inc. distributed three surveys at two sites. There were a total of five participating agencies and 18 employees at 10 sites.

The survey inquired about the types of services offered by the provider, the total number of persons with HIV/AIDS on the provider's current caseload, identified trends or changes that they observed in their clientele and a brief categorical health indicator breakdown regarding the provider's HIV/AIDS clientele. Using

the same list of 43 HIV/AIDS-related services that appeared on the consumer survey, providers were asked to identify up to seven services that they believed were most important for their client populations. The survey presented the same list again so that the providers could check off each service that they felt was needed by a substantial number of their clients, but that clients were having trouble accessing. The second list created a lack of access or gap identification by providers: 30 surveys were distributed across providers and the Palm Beach County HIV CARE Council received a total of 18 valid responses, for a return rate of 60 percent.

In order to capture quantitative and descriptive information pertaining to providers, a review tabulation and analyses were completed to view service inventory, utilization and basic clientele demographics. The survey collected information from fourteen providers of services delivered to persons living with HIV/AIDS in Palm Beach County. These included primary medical care providers, case management agencies, mental health and substance abuse professionals and housing providers in Palm Beach County. Forty-two variables relating to client demographics, provider descriptors, service inventory, number of clients served, and funding comprised this component of the data collection.

Focus Groups

The needs assessment process included five focus groups to gather in-depth qualitative information from specific sub-populations of persons living with HIV/AIDS in Palm Beach County. The questions posed to participants focused on consumer needs, utilization patterns, gaps in services, barrier issues and overall impressions of the HIV/AIDS care and service delivery system in Palm Beach County. Focus groups were held with the following sub-populations: men having sex with men; Hispanics; adolescents; women; injection drug users. A total of 25 people attended the five focus groups, with a median of 5 participants per group. Respondents received \$25.00 each for their time as well as reimbursement for transportation or childcare expenses incurred. In addition, an observer took written notes at each group to assist with final transcription.

Key service providers assisted in disseminating information about the focus groups within the targeted communities. The first sixty minutes of each group included questions about the overall continuum of HIV/AIDS services in Palm Beach County; the final half-hour was devoted exclusively to questions regarding each groups specific requirements relating to accessibility and appropriateness and availability-related issues.

AREA 10

Surveys

Council staff and the Comprehensive Planning Committee designed the 1999 HIV/AIDS Client Survey. The survey was printed in pamphlet format, so that it could be folded in thirds. One panel displayed the Council's mailing address, and served as an address label for those who wished to fill the form out at home and

mail it in. The questionnaire requested basic demographic data (i.e., gender, race/ethnicity, age, zip code, primary spoken language) and information regarding their health status (i.e., length of time since HIV diagnosis, where they were living when first diagnosed, co-occurring conditions, insurance coverage, referral sources, and current treatment regimen).

Clients were also asked to indicate if they were members of various sub-populations, including gay or bisexual, Haitian, blind or visually impaired, deaf or hearing impaired, homeless, substance abusers, or recently incarcerated, and co-infected. They were then presented a list of services that are currently eligible for funding under Ryan White Title I or Title II. In order to be as specific as possible about clients' needs, several service categories (e.g., medical care, dental care, day/respite care, food services) were broken down into sub-headings.

For each service category, respondents were asked whether, during the past year: they 1. had used the service, 2. needed the service, but could not get it, 3. did not need the service. On the back panel, clients were presented with a list of fifteen potential problems/barriers and were asked to check all that made it difficult for them to get need services. A final section was reserved for written comments or statements of unmet needs. No names were requested and they were assured that all information would remain confidential. The questionnaire was translated into Spanish and Creole, and these versions were distributed upon request.

AREA 11

Surveys

In 2001, the Miami-Dade County HIV/AIDS Partnership, as part of its annual needs assessment, undertook a project to identify who and where the unconnected are, and barriers to entering into care. The Miami-Dade team decided on an ethnographic approach for its first effort to identify and interview the unconnected.

At a meeting with providers of Ryan White Title I outreach services, supervisors were asked to participate in the study by permitting their outreach workers to administer the surveys, either while on their appointed rounds or after work hours. The team stressed the importance of reaching people at all times of day and in varied locales. Eleven organizations helped with the survey, including eight Ryan White providers. Finally, several individuals were recruited for their special knowledge of certain populations (such as sex workers) or areas. In all, at least 25 outreach workers and others worked on the study. To the extent the survey relied on outreach service providers and their outreach workers, the survey was conducted in places they said they conducted their own outreach activities. Other volunteers relied on acquaintance sampling at certain high-risk areas to identify potentially unconnected people. These special recruits were indigenous to the HIV/AIDS population, knew people who were unconnected to care, and knew where to find some of them.

The workers distributed surveys at more than 40 locations, focusing primarily on areas known to be gathering places for people who might be at high risk of being HIV positive or unconnected to medical care, and which may not have been surveyed previously. In addition, one Haitian church and an inner city high school was visited to attempt to gain some baseline information on those thought to be unconnected, whether or not they are HIV positive.

A brief survey was created to elicit information on whether people get medical care, use alternative medicine or religious support, whether the respondent had HIV positive acquaintances, and perceived barriers to care. Questions on HIV testing and serostatus were left to the end in order to achieve the best possible returns.

The volunteer outreach workers were trained at their locations by staff from WSA. All surveyors signed confidentiality statements at the training. They were instructed on how to give and get back the surveys, to check for completeness, and other elements. The volunteers and WSA worked out approximate locales where the questionnaires would be given out in an effort to avoid duplication of effort. Finally, they were given small denomination food coupons as incentives for the respondents. During the process, several individuals were given referrals and connected to services.

Focus Groups

From February through April 2001, Williams, Stern & Associates conducted a series of focus groups and key informant interviews throughout Miami-Dade County. The purpose of the focus groups and key informant interviews was to assess the needs of persons living with HIV/AIDS in the County. Due to the diverse populations of persons affected and infected with HIV/AIDS, focus groups and key informant categories for the 2001 Needs Assessment were chosen based on perception of unmet needs in certain HIV/AIDS populations. The areas of perceived unmet needs were issues related to the following populations: adolescents, sex workers, substance abusers, the incarcerated, the homeless, migrant farm workers, children, and the elderly. Other topics of interest were adherence, case management, immigration and legal issues and the unconnected. A total of 12 focus groups and 15 key informant interviews were conducted in an effort to identify unmet needs. Participants were assured of confidentiality and consent was given to providers of origin for participation where appropriate.

Williams, Stern & Associates conducted six focus group sessions with adolescents of several ethnic, social and economic backgrounds. The groups included infected and affected teens, peer counselors, and at risk youths.

AREA 11B

Surveys

Members of the survey committee of 2000, representing the Monroe County Health Department, AIDS Help, Inc., the Florida Keys HIV/AIDS Community

Planning Partnership, and individuals of the HIV/AIDS community met with the consultant on numerous occasions to prepare the client survey. It was decided by the Planning & Priorities Committee members that the original eight-page client survey used in 2000 should again be used without amendment, providing a more efficient statistical response. This is the third joint effort by the Consortium (The Florida Keys HIV/AIDS Community Planning Partnership), the lead agency (Monroe County Health Department) and the sole provider (AIDS Help, Inc.) to produce one written client survey benefiting each organization. Three hundred forty-eight (348) surveys were mailed to HIV/AIDS clients/patients of AIDS Help, Inc., and the Monroe County Health Department HIV/AIDS Clinic.

The client survey was designed in four sections. Section I requested personal information, Section II client needs, Section III medical care, and Section IV case management. A letter from the appropriate participating organizations was included requesting their client's assistance with the survey. Surveys were mailed with a stamped return envelope. Surveys were returned to a post office box and collected by the consultant.

AREA 12

Surveys

The Needs Committee of the newly formed PCHAP designed the 2001-2002 HIV/AIDS Client Needs Survey. Beginning in May 2001, the committee began their work with an in-depth review of the needs assessment process. This review included purpose of a needs assessment, components of a needs assessment, review of the 2000-2001 needs assessment process, components, and results.

The Planner identified various surveys from throughout the state and provided each member of the committee with copies for review. After reviewing various surveys and methods to administer surveys the committee members adapted the client survey used by Broward County Ryan White Title I to be used in Area 12. The survey format chosen was one that was easy to read, complete, and return by the clients in Area 12.

The survey was printed in pamphlet format, so that it could be folded into thirds. The questionnaire requested basic demographic data (i.e., gender, race/ethnicity, age, zip code, primary language spoken) and information regarding their health status (i.e., year tested HIV positive, where they were living when first diagnosed, co-occurring conditions, receiving of other benefits, type of setting of majority of medical care, and current treatment regime).

Clients were also asked to indicate if they were members of various sub-populations, including gay or bisexual, blind or visually impaired, deaf or hearing impaired, homeless, drug or alcohol problems and use in last year, and incarceration during the current year. They were then presented a list of services that are currently eligible for funding under Ryan White Title II funds. For each service category, respondents were asked whether, during the past year they had

used the service; needed the service, but could not get; or did not need the service.

On the back panel, clients were presented with a list of fifteen potential problems/barriers and were asked to check all that made it difficult for them to get needed services. Also on the back center panel clients were presented with a list of Ryan White Title II services that are eligible for funding and clients were asked to rank 10 services that are the most essential for the health and social service needs. Finally, a comment section was also included on the back panel for written comments or statements of unmet needs. No names or client identifies were requested to assure anonymity.

The survey was pilot tested during a PCHAP Client Lunch and Learn. Based on comments from the participants of the Lunch-n-Learn a few wording changes were made in the survey configuration and then finalized by the Needs Committee and the survey was presented during the PCHAP Membership Meeting in July 2001.

The survey was designed to be self-administered. A caregiver could complete survey forms for HIV-positive children or individuals who were very ill. A question on the survey form asked each respondent whether their questionnaire was completed by a (1) person living with HIV, (2) caregiver, or (3) interviewer.

Surveys were also distributed during PCHAP meetings, to other providers, and during the Lunch-n-Learn. The surveying process took place from July through the end of August. The surveys were returned to the Health Planning Council of Northeast Florida's main office in Jacksonville, Florida.

The 2001 - 2002 Provider Survey was adapted from various surveys gathered from around the state and previously used survey in Area 12. Recognizing that providers are busy seeing clients the intent of the survey was to be quick and user friendly for the provider. The survey was designed to obtain information concerning area served, population served, perceived barriers to care for a client, program information, perceived service priorities rankings and need for expansion of the service. A list of service definitions as defined by HRSA was also included.

AREA 15

Surveys

During the months of March 2001 through June 2001, Consumer Surveys of Need were distributed to PLWH/As residing in Okeechobee County and the city of Indiantown with the assistance of the Ryan White Case Management Agency. The surveys were distributed in English and Spanish. These areas were targeted due to the low representation of PLWH/As residing in these locations during the Comprehensive Survey of 2000/2001. The two communities are located in a rural setting and are set apart from the mainstream system of care.

During the months of June through August 2001, a medical provider survey was

distributed to physicians serving PLWH/As in Area 15. The survey focused on collecting information related to capacity and utilization, data collection systems, the continuum of HIV-care services including primary care, specialty care, emergency room and inpatient hospital services, coordination of services including service linkages, standards of care, treatment adherence/compliance and barriers to delivery of HIV-care.

Findings

A majority of service areas used client surveys as a data collection tool. This method for collecting information regarding HIV allows respondents to fill surveys out at their own convenience and in confidentiality. Unfortunately, response rates from the surveys were often very low. Methods for improving response rates or conducting non-respondent surveys appear to be essential for the data to be more valid. Additionally, none of the service areas addressed the issue of informed consent or Human Subjects Protection. Although the data being collected will not be used for research, the need for considering meeting the minimum requirements for human subjects protection, beyond confidentiality, should be addressed. In some areas, to protect confidentiality, survey reply envelopes were pre-addressed to a non-HIV identifying address, such as a post office box, or to an attention line that did not include “HIV” or “AIDS”.

Less than half of the areas utilized focus groups. While focus groups have the advantage of determining a shared view or a diversity of views quickly, it has been suggested that controversial and highly personal issues are poor topics for this method (Patton, 2002). Also, Kitzinger (1995) states “The idea behind the focus group method is that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one to one interview.” Some service areas used focus groups as a primary data collection method, resulting in generalizing results based on a small convenience sample. In the reports, when focus groups were used as a supplement, they did tend to expound upon information already obtained in the client surveys while bringing attention nuances that were not identified in the surveys. For example, this client makes a strong point: “Receptionist at _____ (major medical care provider) was not sure it was me even though I had a letter from the prison doctor and from Harbor House. She halted all paperwork and said I needed to go back and get more identification. It was more or less like I was lying. When I went back (a second time) they drew blood for viral load and screening. After a month, I still have not seen a doctor.” Not only has a service barrier been identified, the client provides more in depth insight into the nature of the barrier and what might need to be done to reduce the barrier.

Notably, while in focus groups, participants tended to request peer-led support groups more than was indicated in client surveys. Adolescents were underrepresented in client surveys, but when interviewed via focus groups, they too identified a need for support groups. The consensus was that they want to talk to someone but don’t know who to trust or how to form support groups. The interaction and synergy of the focus group appeared to trigger more in depth understanding of this need.

Of note were a few procedures which were uncommon to typical data collection methods. For instance, PLWA were used to conduct focus groups. It was an opportunity for them to earn money and consumers may be more comfortable with their peers. However, concern has been raised that these PLWA facilitators may have personal agendas that could influence some focus group results. PLWAs could have strong opinions and biases about issues since they have personal involvement. Unbiased facilitators of focus groups may be necessary to effectively use the focus group as a source of valid information . Incentives were often motivation for participating in the focus groups. \$10, \$25, \$25 plus reimbursement for transportation or childcare, and food gift certificates have been offered. Some service areas also had surveys translated into other languages and available upon request.

Results

These results are the results as reported by the fourteen service areas. As evidenced in the previous section, some areas conducted the needs assessment based on a comprehensive data collection method. As a result, these areas tended to be able to provide more extensive products. Other areas succinctly described their results.

AREA 1

Clients

Barriers to Care/Service

The five most frequently mentioned problems in accessing treatment from their current provider in decreasing order were scheduling, waiting time, transportation, money for medication and doctor with limited HIV/AIDS experience. Other problems mentioned by one or two persons were distance, co-pay, getting in to be seen, too many changes, getting to the appointment, poor message relay system, problem with hours, small clinic parking lots, insensitive nurse, calling to see the doctor, no childcare and too much medication. Barriers in receiving routine care included needing services not available, transportation, long waiting list, cost of medications, fear my HIV status would be known and confidentiality issue.

Needs

The most frequently reported needs in this area were regular medical care, medications, food, eye care and dental care. The most frequently reported unmet needs were dental care, financial assistance, eye care, legal assistance and nutritionist services.

AREA 2A

Providers/Case Managers

Client Needs

It should also be noted that case managers, survey respondents, and key informants all agree that the most frequently requested service which can be provided through Ryan White and other funding sources is medical care followed by pharmaceuticals.

Case managers were asked to talk about the services which are most frequently requested by their clients and which can be provided through Ryan White Title II funding. As might be expected there are a variety of answers, but it would appear that medical assistance, pharmaceuticals, and diagnostics were the top three most frequently mentioned. This perspective was quite similar to that which PLWH responding to the clients needs survey indicated. When asked what services were received, over 82 percent of PLWH responding to the survey indicated medical care, approximately 80 percent indicated medications, and slightly more than 62 percent mentioned eye care and care in an emergency room. The latter is not necessarily the most appropriate location for receiving medical care, but in this service area, it has become a necessity.

Comments from the case managers who were interviewed indicated that providers have varying levels of knowledge of HIV/AIDS, as well as experience in treating this disease, and as a result, there also would be considerable variation in the services provided to clients. For example, some physicians do not routinely screen for various forms of hepatitis, some may not have a quarterly schedule for blood work, pap smear, etc. Therefore, any conclusion that client needs are being satisfactorily met should be reached with caution.

The current system appears to be meeting the needs of PLWH, except for a few minor situations. Drugs for the treatment of mental illness, psychotropic drugs, or drugs for enhancing mental health are not included on the ADAP formulary. The consortium also has restrictions on prescribing some specific mental health drugs. Pain medications on a sustained or prolonged basis are also accessed with restrictions to prevent abuse. Problems arise if clients from other states move into the area and have expectations from previous service delivery systems. There appears to be some genuine need for antidepressant medications, though this should be framed within the context of general discussions on mental health needs of clients in the service area.

Case managers estimate that between 85-90 percent of their clients adhere to their drug regimens, though other concerns, such as housing, paying utility bills, etc., overshadow the adherence issue for clients with fewer socio-economic resources. Unfortunately, these same clients may take HIV/AIDS less seriously in general because of their immediate concerns with financial resources. As has been already mentioned, financial assistance was one of the top three priorities listed by respondents to the PLWH survey.

Case managers were also asked several questions relating to frequently requested services which could not be provided. While there was some variation in responses, it is clear that transportation, dental care, and mental health care rank as the top three priority needs, at least among those which can be addressed through the use of Ryan White Title II funds. At least two of these needs were also indicated as priority needs through the PLWH survey, where dental care was the most frequently cited unmet need mentioned by 42 percent of respondents, and transportation was mentioned by 17 percent of respondents. Other service needs such as financial assistance, help with housing, and legal assistance were frequently mentioned by respondents to the PLWH survey as well as by case managers, but these are services which cannot be provided through Title II.

Mental health also emerged as a priority need as a result of the case manager interview/survey process, though, as has been indicated above, this was not among the top needs as prioritized through the PLWH survey. Case managers described a number of their clients in terms, such as overwhelmed, isolated, denial, inability to cope, irresponsible, and others, that suggested a need for counseling, and emotional assistance in dealing with this disease on a daily basis. A number of other comments made by case managers suggested that in part they

are currently trying to fill in the gap made by the unavailability of mental health services. Frequently, case managers feel that they are asked to provide the emotional support which many clients need to face the reality of the disease. At other times, they are asked to be the ones to enable clients to accept the day to day responsibility for dealing with disease, including drug adherence, keeping medical and dental appointments, maintaining a healthy diet, avoiding bad habits such as smoking and alcohol consumption, adopting healthier lifestyles in general, avoiding secondary infection, and also preventing the spread of the virus to others. In being asked to fill these many roles, case managers are being asked to actually serve in the role of mental health counselor, a role that may be more successfully filled by a professional licensed in that area of expertise. Support groups conducted by independent professionals, and substance abuse counseling were also suggested as being unmet needs of a small, but important client population.

Clients

Needs

PLWH respondents to the client survey felt that eye care and emergency room care were services easily obtained. Roughly fourteen percent of survey respondents indicated a need for specialty medical care. Normally the need for specialty services coincides with more advanced conditions related to HIV or the diagnosis of AIDS, when clients are also eligible for Medicaid. As additional effects secondary to HAART, Highly Active Antiretroviral Therapy, become apparent, the need for medical care, including specialty services, may also become more apparent.

Next to medical care, access to medications was the most frequently listed service received by clients (approximately 80 percent) who responded to the needs assessment survey. Strangely, while individuals responding to the client survey did not list medications as one of the top five needs, other information obtained from the same survey indicates that the fourth most frequently mentioned problem in accessing care and treatment is the lack of money for medicines. It also became evident that prisoners released from incarceration with only a thirty-day supply of medications may need medications on an interim basis as they wait to become eligible for the ADAP or other programs. This is only one of several problems for recently released prisoners who are transitioning into the local community. It is evident that medications are being heavily utilized by the client population, and survey information as well as comments from the case managers indicate that clients feel that they are adhering to their drug regimes (roughly 40 percent of survey respondents indicated that they never miss a dose).

Respondents to the client survey listed dental care as the most frequently requested service (41.6 percent of respondents). It was also frequently mentioned during the case manager and key informant interviews.

Slightly over 26 percent of respondents to the client survey indicated that they are

currently receiving mental health services and an additional 29 percent indicated that they are participating in support groups. Fewer respondents, less than 2 percent, indicated that they are receiving substance abuse treatment. Less than 5 percent indicated a need for mental health services, and no respondent indicated a need for substance abuse interventions. Both the case manager and the key informant interviews indicated a larger, perhaps unrecognized, need.

Respondents to the client survey listed financial assistance as the second top priority (22.0 percent). It also emerged as a concern during the various interviews. It was listed as the eleven most requested services which could be provided in the internal client services tracking system discussed earlier.

Slightly over 17 percent of survey respondents listed transportation as a priority need. It was also cited as the top priority need by the case managers. Obviously, lack of transportation was listed as one of the principal obstacles to accessing services, particularly in the counties outside of Bay, and even for the poorer clients residing in Bay County. Lack of transportation was the most frequently listed obstacle to services on the client survey. Transportation continues as an unmet need, in part, because of the lack of available providers.

Twenty two percent of respondents to the client survey expressed their need for housing assistance, though it was apparent that participants did not fully understand what services were available, nor how those services were restricted by federal and other guidelines. It is obvious that there continues to be a need for clients to understand service availability, eligibility, and limitations since expectations appear to far outweigh available resources. Housing for persons with HIV/AIDS is sometimes complicated by the lack of appropriate housing within the general community. HIV/AIDS only adds additional complicating factors which can make placement more difficult. There appear to be frequent housing emergencies, and a need for transitional housing at isolated times.

Providers/Case Managers

Client Attitudes

Interviews with case managers identified fear of being identified as HIV positive, client denial, guilt, various forms of social and geographic isolation, fear of being disowned by family and friends, and similar factors, as principal obstacles to accessing care, and adhering to a care and treatment regime. For minority persons with HIV/AIDS, several of these factors may have even more severe consequences. This insight was validated through comments of participants in the focus groups, and it was evident that there were many unspoken issues that were preventing individuals from completely dealing with the disease. In at least one focus group, there was discussion about the need for being able to talk to other persons with the disease and draw support from each other in facing its daily consequences. Talking with others might also provide new lines of information on services available and how to effectively access them.

Information from interviews also suggests that many additional client problems such as a lack of responsibility for taking care of oneself, non adherence to medical and drug regimes, failure to practice primary and secondary prevention, and hostility toward providers and others could be alleviated through both formal and informal counseling and support. In fact, these services may also be necessary before individuals can understand their need for other related services such as substance abuse intervention.

In some respects, client expectations far exceed the possible available resources, and there is a need to refocus these requests to more reasonable expectations. For a minority of clients, it was evident that an unhealthy “entitlement” attitude was shaping their expectations. For others, the need for additional financial assistance was based on very understandable human needs and wants. It was clear from various interviews and discussions that clients do not understand that the Care Act was not intended to provide for every medical, social, and other need that an individual may have simply because he/she happens to be HIV positive. Providing this needed perspective to services under the Care Act may reduce client frustration with the system, and direct the assessment of need to more healthy expectations.

Barriers to Care/Service

An important part of any needs assessment is identification of obstacles to accessing services. Several of these obstacles in the service area have already been mentioned in the discussions about services thus far. These include; lack of transportation, particularly for low income, minority clients and clients in counties surrounding Bay, lack of knowledgeable and experienced providers, particularly dental professionals, and the lack of specialized services within the community at large.

Obstacles specific to certain subpopulations were also identified. For African Americans, the possibility of being label as HIV positive is a very significant obstacle to accessing services, beginning with the need to be tested for the virus. This personal fear combined with the community’s general lack of appreciation for how the HIV epidemic is impacting the African American population, and a lack of accurate information about the disease makes it extremely difficult for clients to access services and follow through with care and treatment. For migrant or homeless clients, illiteracy and the lack of proper food, shelter, and clothing may be additional obstacles. For women, providers’ under-appreciation of the way in which HIV affects women can undermine comprehensive medical care of infected women, and also erode a woman’s confidence in her physician. For women who have young children who are not infected, problems of providing for the affected children’s care while the mother is keeping medical and other types of appointments can be a significant obstacle. These include the availability and a funding source for day care and transportation. Case managers unanimously agreed that clients were comfortable in accessing services at Children’s Medical Services, and that CMS was providing good care to clients when needed. For HIV

infected prisoners, there is a general lack of orderly transition programs from state prison medical care to community programs. Adherence to drug regimes can be problematic.

Physicians were also asked if there were any services or other forms of assistance that would help them in delivering care to PLWH. The most frequently mentioned service (named by 7 respondents) was periodic updates on HIV care and treatment. This was followed by sufficient reimbursement mentioned by 4 respondents. Outside case management and other support services was mentioned by 3 respondents and enhanced opportunities for consultation was mentioned by 2 respondents. One additional comment asked for additional assistance when patients are hospitalized.

AREA 2B

Clients

Needs

Of those who identified their county of residence, 75 were from Area 2B. Sixty-four percent of respondents were black, 34.2 percent were white and 1.3 percent were Hispanic. This corresponds to 75 percent, 22.6 percent and 2.4 percent of the reported AIDS cases respectively. In Area 2B, the age range of the survey respondents was similar to the age range of reported AIDS cases in the area. The 40-49 age group was slightly smaller, and the 20-29 age group was slightly larger than the region.

78.2 percent of respondents use a private doctor as a place to see a doctor. This was followed by percent using "Other", 7.7 percent using the county health department, 3.8 percent using the ER and 1.3 percent use children's medical services. The majority of respondents traveled less than 10 miles to see the doctor. Sixty-two percent indicated that they believed the protection of their confidentiality was excellent. The biggest problems in accessing treatment were money for medication, scheduling, transportation, doctor with limited HIV/AIDS experience and waiting time. The most frequently cited unmet needs in this area were financial assistance (29 percent), dental care (21.3 percent), help with housing (18.8 percent), eye care (16.3 percent) and transportation (15 percent).

AREA 3

Clients

Needs

Respondents indicate they use Ryan White case management, HIV clinical services, and Ryan White vendor services most frequently. Respondents report using the following vendor services most frequently within the last year: dental (67 percent); medications (44 percent); transportation (18 percent); and optical (14 percent). Herbs, acupuncture, and massage are vendor services which between four and five percent of the respondents indicate that they used during the past year.

It is interesting to note that in the 1999 survey, only seven percent of respondents indicated that they used the Housing Opportunities for Persons with AIDS (HOPWA) program, while slightly more than 28 percent indicate using HOPWA on the 2000 survey. This may be indicative of an increased emphasis on the HOPWA program and a shift during the 1999 - 2000 contract year to independent case management agencies for the Ryan White and HOPWA programs.

Of the 186 individuals who indicate source of payment of medical bills, 21.0 percent report that Medicaid pays their medical bills. In addition, nearly 17 percent indicate that both a combination of Ryan White and public insurance (either Medicaid or Medicare) pays for their bills, while slightly more than 16 percent indicate that a combination of Medicaid and Medicare is the payor of their medical bills. Nearly 12 percent of the respondents reveal that Ryan White is the only source of payment for their medical bills, while only three percent indicate a combination of Ryan White and private insurance. A high percentage of *other* is also indicated as responses with three, four, and five sources of pay were tabulated as *other*. This high percentage of *other* payors is indicative of the often-complex array of payor sources that a client must negotiate to obtain services. In addition, this may also be an indication of lack of client awareness of the actual source of payments for the medical care that they receive. Education and advocacy programs may be ways in which to improve these two situations.

Overall, written comments of respondents regarding their medical care are exceedingly positive. However, some respondent comments indicate fear over running out of eligibility or no longer being eligible for other reasons for continued medical care. Again, expanded education and advocacy programs could help to allay these client fears, and give them a better understanding of how the Ryan White program works, what services are available to them, and under what conditions or guidelines the services will be rendered.

On the survey, clients are asked if during the past year, their needs were met when they thought that they needed a service. Needs which are identified by a larger number of respondents are more often *always* or *usually* met. This does not hold true for every service need, but it does for many of them. In general, this may be explained by the fact that the highly demanded services often have an ample supply of vendors, therefore, making it easier for a service need to be fulfilled. However, special consideration should be given to acupuncture; massage; herbs; chiropractic; and consumable medical equipment for their high percentages of *sometimes/never* responses. Each service has its own unique service delivery and availability issues and fulfillment of perceived needs should be judged on a service-by-service basis.

The presence of dental care, case management, access to medicines, and transportation in the top eight needs (those which 30 percent or more of the clients indicate as needs in the coming year) validate the Consortium's current spending priorities. However, the client responses also point out some areas that the

Consortium should consider for future funding allocations. Housing assistance has moved up from the eighth most indicated need in the 1999 survey to the fourth most indicated need in 2000. In addition, financial counseling has dropped out of the top eight and has been replaced by massage therapy.

Upon reviewing the written comments of the respondents, there are additional considerations as well. Many of the comments explain a specific dental care need confirming the identification as dental services as the number one need of respondents. Other clients indicate that they need help negotiating the “red tape and rules” of available programs, or that there needs to be more of a concern to get people on Ryan White. A few client comments indicate a need for assistance with a substance abuse or mental health problem. One client indicates that he or she is judged by case-managers as completely self-sufficient though that self-sufficiency depends on current health status, which is ever changing.

Barriers to Care/Service

Personal experiences for which the highest percentage of respondents indicate *always* or *usually* create difficulty include: lack of money (65.1 percent); lack of strength/energy (46.4 percent); applying for benefits (34.0 percent); qualifying for benefits (32.4 percent); lack of community resources for persons who are HIV positive (32.4 percent); and lack of assistance from family members (30.3 percent). Again, expanded education and advocacy programs may help in the areas of applying and qualifying for benefits (which also addresses the lack of money or resources) as well as directing clients to other resources for HIV positive individuals. Enhanced client/consumer networks may also help to minimize the impact of the lack of assistance from family members.

Confidentiality is also a personal issue. Of the 169 respondents who answered the question on confidentiality, slightly more than 13 percent indicate that during the past year, they have been concerned that their confidentiality has been broken. Respondents offer few comments concerning these confidentiality breaches, and the comments that have been made do not directly address a confidentiality issue or incident or any Ryan White case manager or provider. In the 1999 survey, nearly 24 percent of the respondents indicated that their confidentiality had been compromised, and again the comments generated by these respondents had little to do directly with any confidentiality breach concerning the Ryan White program.

Confidentiality is a major issue in health care, especially for those individuals with HIV disease, which still carries a big stigma in society. In its current form, the question on confidentiality does not provide the specific insight into client confidentiality concerns that was hoped when the question was originally included in the survey. Because guarantee of client confidentiality is not just an issue of ethical healthcare delivery, but also of the quality of healthcare delivery, the questions should be re-tooled to provide better information.

AREA 4

Clients

Needs

Two hundred and eighty surveys were returned. Survey results indicate that the percent of clients' ranking of the priorities placed the following services in the top five, in order of highest priority: primary medical care (90 percent), pharmaceuticals (82 percent), case management (75 percent), dental care (71 percent) and alternative therapy (35 percent).

A comparison of the top five services that clients said they needed the most in the 2000 survey compared to the services they needed the most in 1994 was performed. Overall, there was a general increase in percentage of clients indicating a need for all fourteen services, compared to 1994. Three services in particular showed a greater prioritization of need according to the 2000 survey. Ninety percent (90 percent) of clients stated primary medical care is needed the most compared to 50 percent in 1994. Pharmaceuticals was needed most by 82 percent of clients in 2000, compared to 38 percent in 1994, and dental care was needed most by 71 percent of clients in 2000, compared to 52 percent in 1994. Clients were asked if they had used each of the services in the past year. If they answered no, they were then asked to give a reason why. The most frequent reason given was "Did not need the service", followed by "Did not know about the service" and "Did not qualify for the service".

The survey asked the clients to make additional comments on their needs if they wished to do so. The overwhelming majority of responses referred to transportation. Not only did they want it to be more readily available, but also they wanted improvements, especially with regard to the transportation being on time. Another comment expressed frequently was the need for better information on availability of services. Other comments included the need for financial assistance for basic needs, more empathy and understanding, increased awareness of the disease, more funds for housing, increased dental care, better education and information on how to live with HIV, improved medical services, increased preventive measures, less waiting time at doctor's office, less paperwork/bureaucracy, more case managers, and counseling for the families of infected individuals.

In addition to the providers' focus group, 14 focus groups consisting of a total of 101 PLWHA were held over a two-month period. The participants included clients from outlying counties as well as those in Duval County, and included mostly African-American men and women, a smaller number of white men and women, and a small number of Hispanics. The focus groups also included people with a variety of special needs, such as those receiving treatment for substance abuse, mental health issues, ex-homeless people, adolescents and a group of caregivers representing the needs of pre-adolescents. As a general rule, most of the participants expressed a need for services that they had difficulty obtaining; therefore the need for transportation was often expressed as more important than

the need for medical care. While transportation is available, there was an overwhelming concern that the transportation was often late. This would result in the client being late for an appointment, which would then be canceled. The clients expressed difficulty in scheduling appointments within a short period of time, and complained of long waiting times before being seen. They also complained of the lack of respect and empathy from service providers in general.

Another need that was expressed frequently during the focus groups was for more information about what services were available and how to access them. It was said that they often find out from discussions with other PLWHA what services are available, and felt that the case managers should be more knowledgeable and provide the clients with more information. Several clients expressed the need for basic personal items, saying they could not afford to buy them because they did not have a job. They said many employers discriminated against them, so they were not able to get a job. They recommended that some form of job service program be initiated with a list of employers who would be willing to hire someone with HIV. Many clients said that red tape was often a barrier, making it difficult to access services quickly and that the eligibility criteria should be changed. The reason for this was that many of them felt sicker even though their CD4 counts were higher, and that their CD4 count should not be used as the primary basis to determine whether they should be allowed to access services. They also felt that more should be done to educate the public because they live in fear that someone will find out they are HIV+ and will discriminate. They feel that if HIV/AIDS is discussed more openly in public, and people are better educated, there will be less fear and more acceptances of those who are affected by the disease.

The group of adolescents expressed an overwhelming need for support groups. They are afraid their friends will reject them if they find out that they are HIV+, so they keep it to themselves, and therefore they feel isolated and lonely. They expressed a need for people to talk to, but did not know who they could trust and therefore did not know how to go about forming a support group.

In each group session, participants cited many of the same services. Overwhelmingly, medical care was cited as the most needed service with case management, dental services, medication or transportation following closely behind. The most cited needs follow, in no particular order:

- Medical Care
- Pharmaceuticals
- Transportation
- Housing/Transitional Housing (including financial assistance to get it)
- Case Management
- Food Bank
- Nutritional food (not just fillers)
- Mental Health/Substance Abuse Treatment

- Dental Care
- Counseling, Education & Information for accessing services
- Child Care

“You have to be able to get to the doctor to go to the doctor” Female, April 11, 2000

“You have to have a house to take a shower, stay out of the weather, take care of personal hygiene issues, and stay healthy.” Female, March 21, 2000

“Transportation needs to be more reliable, they know they are picking up someone with HIV, so they just take their time” Male, March 27, 2000

There were many common barriers identified in the focus groups. Many of these common barriers had to deal with confidentiality issues, transportation, physical illness, and clinic/doctor issues some of which include:

- Appointments get canceled without notice.
- Inconvenient hours for clients that work normal hours.
- Only one place to go to for primary health care.
- Transportation is unreliable.
- Not a lot of consistency with doctors.
- Not comfortable with receptionist.
- No privacy in the waiting room.
- Too long of a wait between diagnosis and first appointment.

In almost all of the focus groups, the lack of information, education and/or awareness of some of the following were cited as barriers:

- Services available
- The disease process
- Living with HIV
- Medication side affects
- How to access services
- Participants felt that in some cases, case managers needed to be better informed or educated on the same issues.

Another barrier consistently identified was too much “red tape” or bureaucracy to gain access to various services such as housing, food bank, and other services. Also, in most of the focus groups, many participants discussed a barrier as having HIV and not AIDS because of many services being available for those diagnosed with AIDS. Many focus group participants also stated that their illness or not feeling well was a barrier, some contributing factors included depression, too sick, stress, and anxiety.

“Doctors make you wait hours for an appointment.... even when you’re on time -

like I have nothing else to do” Male, March 13, 2000

*“Some doctors and nurses are just nasty.... they need to be more sensitive” Male
March 9, 2000*

*“There is not enough information provided to clients on how to access services”
Male, April 20, 2000*

*“The pharmacy gave me refills for three months but my next appointment wasn’t
for six months!” Male, March 9, 2000*

*“Educate clients to medication reaction and offer solutions to
reactions...sometimes you can never get a straight answer” Female, March 27,
2000*

*“Transportation is unreliable, you have to wait and wait, then you miss your
appointment, then its hard to get another one.” Male, March 7, 2000*

*“Staff needs to educate more on HIV and living with HIV” Female, April 20,
2000*

*“ Everyone knows what you go to BCCC for, I am afraid someone will find out I
have HIV” Female, March 9, 2000*

*“The current requirements are too strict, you have to have AIDS to access most of
the services.” Male, March 7, 2000*

Participants of the focus groups identified the lack of transportation, housing, too much bureaucracy, lack of awareness/education on HIV/AIDS, and clinical/doctor issues as barriers to accessing services. Unmet needs included the lack of transportation and housing.

In the majority of the focus groups, job services were cited as an unmet need. Participants had many concerns surrounding the ability to get a job without being discriminated against or without losing some, if not all, of the services available to them. Many participants expressed the desire to go back to work and/or the desire to be educated to provide them with training to enable them to return to work.

*“When I apply for a job, they check on my medical history & then tell me the job
is not available...The case managers tell me to get a job because my CD4 count is
too high, but I can’t get a job because employers discriminate” Female, March 7,
2000*

*“They need to create a job service for those infected with HIV/AIDS because
some of us are strong enough to work, but when the employer finds out we’re*

HIV+ they won't hire us because they say their insurance would go up." Male, March 7, 2000

Another unmet need that was identified in many of the focus groups was the need for more support systems including mental health and other support groups for PLWHA's, in the form of peer-led support groups for family members, care givers, youth/adolescents living with HIV/AIDS and other PLWHA's.

Some other common themes that came out of the focus groups regarding unmet needs included having an "advocate" who only dealt with PLWHA issues, more access to food stamps and/or the food bank, lessen the load on the case managers by increased hiring, childcare while at appointments, options for medical care other than BCCC, and more health education concerning adherence, nutrition, and staying healthy as a person living with HIV/AIDS.

Overwhelmingly, the response to this question was to provide more outreach and education using PLWHA, peers, or other "trusted" community members.

Increasing the community awareness of what services are available, where to get tested, and where to go for services, was also cited in the majority of the focus groups. When increasing awareness, do it in a "clear" understandable presentation (flyer, bill board, poster, radio, etc.). Increasing community awareness should decrease stigma and fear about HIV/AIDS.

"Link up to a buddy right after diagnosis to help with denial and help walk them through the system." Female, March 9, 2000

"Get the message out that having HIV is not a death sentence." Female, April 20, 2000

When asked what is the single most important change you would make, the clients responded:

- Better counseling when results are given.
- Change criteria for eligibility.
- Criteria for eligibility should be assessed individually (You can be sicker with a higher CD4 count than when its lower).
- Train case managers on services available and educate better on HIV issues.
- Medical staff needs to be more sensitive to needs of patients.
- Get more case managers.
- Greater community awareness and individual education.
- Simplify the bureaucracy.
- Have more providers in outlying counties.
- Need more providers of all kinds, especially those who are more culturally sensitive.

- Need better ob/gyn services for women.
- Need more options for medical care.

Providers

Client Needs

Sixteen providers participated in focus groups. In addition to the focus group discussion, the providers were also asked to fill out the prioritization page on the survey instrument, and rank the services based on what they individually thought the clients' needs were. The providers felt the five most important needs of the clients were primary medical care (94 percent), pharmaceuticals (88 percent), case management (81 percent), substance abuse treatment (40 percent) and health education/information & referral (38 percent). During the focus group discussion, the providers were asked to come to a consensus on the ranking of services they felt the clients needed the most. As a result of the consensus process, the five services that were ranked by the group, in order of greatest need, included primary medical care, pharmaceuticals, case management, substance abuse treatment and transportation.

AREA 5

Clients/Providers/Case Managers

Client Needs

The Needs Assessment Committee reviewed each of the eight components of the FY 2001 needs assessment separately during the January, February and March meetings. At the March meeting of the Committee, each report was weighed and a score was developed for each service. Based on these weights all 20 HRSA defined services were scored and a prioritized list of services was developed. The Committee recommended that the Care Council adopt the following priority recommendations:

Service Priority Recommendations (in rank order)

Core Services

Ambulatory/outpatient medical

Medications

Case management

Planning council support

Additional Services

Transportation

Emergency financial assistance

Dental care

Housing assistance/housing related

Mental health therapy/counseling

Food bank/home delivered meals

Client advocacy

Nutritional services

Substance abuse treatment/counseling

- Counseling (other)
- Home health care
- Day care or respite
- Buddy/companion
- Other support services
- Rehabilitation care
- Hospice Adoption/foster care
- Program support

Barriers to Care/Service

Participants were asked to identify barriers that keep agencies/services from reaching the highest level of quality on the six indicators. The groups were also asked to recommend possible solutions to overcome those barriers. The Needs Assessment Committee reviewed the input of the case managers and non-Ryan White providers. The Committee decided that the barriers and proposed solutions merited further attention and recommended they be referred to the appropriate committees/organizations.

Case managers recognized several barriers to service provision. The first is that funders don't recognize the changing face of the epidemic. Clients live longer and they need different services. Case managers also recognized problems with client knowledge or participation. For instance, there seems to be a lack of knowledge by clients of the disease, eligibility vs. entitlement, and available services. Also, education/literacy levels of clients can sometimes prevent understanding of information. There is an indifference of the disease due to "the cocktail" and as a result non-adherence by clients. Clients are also concerned about confidentiality being protected. Clients can't pass background/credit checks for housing/job programs. Case managers identified cultural/racial insensitivity to evolving population of clients. Funding is another problem; there is a shortage of funds and also limited eligibility for Medicaid.

Under the heading of coordination/continuum of care, case managers recognized that there is inaccessibility to some services (e.g., alternative therapies). There is also a lack of a continuum of care, clients are unable to receive all services that they need and poor communication between providers. There is an unwillingness of providers to work together and this results in fighting over clients. Waiting lists make access to some services difficult in a timely manner and part of this problem is attributed to difficulty getting providers to accept Ryan White funds.

There is a lack of quality assurance system. Non-compliance by some agencies with rules results in inconsistencies between agencies and clients jumping between providers. The rules are constantly changing yet there is inconsistency on part of Grantee in rules enforcement. There is also excessive and repetitive documentation of payor of last resort when it is the only resort. Focus on billable hours not client needs.

Staff stress and burnout results from restrictions on what a case manager can do and the fact that agencies have outdated equipment. The problem is compounded by a shortage of physicians, ARNPs, etc. experienced in HIV. For clients, transportation is inadequate, inefficient and women with children have additional needs for services such as day care, transportation.

Barriers to service provision was also ascertained for non-Ryan White providers and many of the same problems were identified. Of note is that this group of providers recognized there is community resistance regarding HIV/AIDS service and education. Specifically, schools and other social institutions do not want to discuss HIV.

AREA 7

Clients

Needs

Consumers were asked to identify services they need. Their unprompted responses identify the needs that are of particular importance since they are the things that immediately come to mind for these consumers. As might be expected for generally poor people, the most frequently identified services fill basic needs-food, shelter, employment and financial support. Medical care was identified, particularly by those PLWH who are ill.

In order to establish service needs and their importance, consumers were asked to consider their need for Ryan White Title I funded services using a “card sort” technique. From this list of needs, they prioritized the services in order of importance. As the epidemic spreads among the poor, basic needs take priority. The card sort substantiated this. Emergency financial assistance, groceries/food vouchers, housing assistance and dental care were among the services identified by the largest number of consumers and considered the most important. Other highly rated services included HIV medical care and medication assistance.

Barriers to Care/Service

Providers identified PLWH barriers to care based upon their experience, and consumers discussed their reasons for not seeking care. Providers explained the *interconnectedness* of barriers, with individual consumers experiencing a variety of barriers that come together to prohibit them from accessing care. The PLWH interviewed demonstrated this convergence of barriers, limiting access.

Poverty is an example of a multifaceted barrier cited by providers and evidenced by consumers. For these consumers, the basic necessities for survival are priorities with health care assuming less importance. Identified service needs reflect consumers’ impoverished lifestyles with housing, groceries/food vouchers and emergency financial assistance among the most frequently identified and highest priority service needs.

Concern about HIV medication was the most frequently identified barrier to care

among those interviewed. Over half expressed reluctance to take HIV medication. Many PLWH receive their information about HIV medication *on the street*. They have seen others' conditions deteriorate after beginning medication or have heard about others' bad experiences. None had information related to positive outcomes. Concerns include: potential side effects, having seen others' conditions deteriorate after beginning medication; reluctance to take a large number of pills daily; the complexity of regimens; and confidentiality issues when regimens require taking pills in public. PLWH believe that if they are in HIV medical care, physicians will require them to take medications, and they are reluctant to do so.

Providers discussed consumers' reluctance to take medication, focusing on cultural issues, particularly among African-Americans. Executive directors pointed out that African-Americans typically don't go to the doctor for preventive care, only going for those things that cannot be treated at home, and they don't take all the medicine they are given. They discussed adherence issues including unwillingness to take medication daily and the tendency not to take an entire prescription, even when limited amounts of medication are prescribed. When interviewing PLWH, it became clear that those who were feeling well were less inclined to seek medical care than those who were not. Some of the consumers did not access counseling and testing until their health began failing.

Twenty years into the epidemic, the stigma of HIV disease continues to be a significant barrier to care. The stigma is the root cause of many of the barriers to care that were evidenced in this study. Providers made the point that the severity of the stigma varies by family and by culture. The stigma among Haitian and Latino communities is reportedly very severe. It affects both consumer attitudes and the availability of services. Some consumers living in those counties do not want to access services locally and county officials reportedly deny the need for HIV services, stating, "We don't have that problem." The stigma of the HIV disease leads to delaying counseling and testing, denial after diagnosis, fear of disclosure and confidentiality concerns.

Most PLWH who are not receiving care do not want others to be aware of their HIV-positive status. PLWH, particularly those who are not receiving HIV services, are very concerned about others *knowing their business*. Many consumers interviewed had not disclosed their status to others, including family and close friends. One executive director stated, *People don't want to admit they are positive due to the losses associated with it. If you tell your family you have to be ready to lose everything*. Consumer comments confirmed these provider perceptions and the ongoing stigma associated with HIV. In order to avoid disclosure, a common practice among PLWH in the Orlando EMA is traveling to another county or area of the EMA to access services.

Similarly, confidentiality concerns are a significant barrier to care. Services with the "AIDS" label in the community will often be minimally utilized. In order to

promote optimal utilization providers must develop and deliver services with an emphasis on confidentiality. Service location, facilities that maintain privacy, and provider attitudes are all critical components of confidentially delivering services. Ryan White Title I funded services must be required to promote confidentiality and conform to confidentiality standards. Both provider focus group participants and consumers interviewees expressed concern about breaches in confidentiality by Title I funded providers.

Providers must understand the background and cultures of each population group they work with in order to appropriately address their clients' needs. Provider focus group participants discussed the need for culturally competent services. The point was made that most providers are *culturally sensitive*, but *they are not educated to be culturally competent. People get offended because someone does something unintentional.* Providers suggested offering uniform cultural competence training for Ryan White Title I funded agency personnel and expanding diversification among both professional and paraprofessional staff. They advocated employing personnel that reflect the racial, ethnic and sexual identity profiles of the population(s) served. The comment was made, *Clients need to see someone like them.* Providers made the point that cultural competence must extend beyond racial, ethnic and sexual identity to include appropriate treatment of the illiterate. The point was made that providers should consider literacy levels in paperwork and written materials. It was felt that staff should be trained to recognize the signs of illiteracy and help consumers as necessary.

Providers discussed consumer attitudes as a barrier to care. Their description of *an entitlement attitude* demonstrates the barrier between consumers and providers. Providers feel that consumers place unrealistic demands and expectations upon the care system and when these are not fulfilled consumers are disappointed. This can lead to negative relationships between providers and consumers that can cause PLWH to exit the care system. Providers advocated uniformly educating consumers in order to promote realistic expectations of the care system. With the goal of empowerment, providers supported an approach that encourages consumers to access the system appropriately, and educates them about their roles and responsibilities in care. Providers felt that this may be accomplished through both dialogue and consequences for inappropriate or disruptive actions. A provider reported that her agency has dramatically decreased no shows after implementing a policy that if you do not come to an appointment without canceling three times, you are out of the service for 30 days.

Providers also reported significant turnover among outreach workers and case managers. Not only an agency liability related to recruitment and training, turnover is a significant barrier to care for the consumer. If that employee resigns, the PLWH is at risk for exiting the system. Case manager and outreach worker turnover also results in an information gap. New employees initially may not have the background and expertise of the person they are replacing. The learning curve may be limit effective service delivery at the expense of their clients.

Lack of information about HIV services is a barrier to care, and it is a service need. When discussing reasons for not receiving services, several PLWH stated they *don't know what's available*. Another said, *I want to start seeing the doctor, but I don't know where to go*. Half of the consumers interviewed expressed a need for information about HIV services

Consumers described lifestyles that limit or prohibit service access. These include poverty (described above), conflicts with employment, commercial sex work, substance use, homelessness, transgendered identities and spiritual belief systems.

Housing is a critical service need for consumers outside the care system. Without stable housing, it is very difficult for PLWH to consider accessing medical care and almost impossible to follow a complex medication regimen.

Providers discussed the influence of traditional religion as well as witchcraft, voodoo and alternative belief systems in refusing HIV medical care. Some PLWH interviewed confirmed these barriers. Several stated that they have put themselves *in God's hands*. PLWH perceive access barriers related to the bureaucracy and "red tape" associated with service delivery as significant barriers to care. The majority of consumers described an experience with "the system" that resulted in difficulty accessing services. Enhancing service coordination and collaboration among providers will offer a partial solution to reducing the systemic bureaucracy. This was advocated in both provider focus group discussions.

Transportation is a barrier to care, particularly in the outlying counties of Seminole, Osceola and Lake. An outreach worker made the point, *Getting people where they need to be when they need to be there with the number of providers we have is a difficult task. We need to consider other alternatives such as reimbursing for gas money, reduced fare bus passes*.

Only two of the PLWH interviewed had any type of insurance, and several consider this a barrier to care. Many consumers are unaware of the free care available through Ryan White Title I. One consumer felt that he was not tested for HIV when he went to the emergency room because he did not have insurance and *they don't want to treat me*. Provider comments confirm that deductibles and co-payments are more than PLWH can afford, so they do not access services. In addition, the point was made that undiagnosed PLWH with insurance do not want to be tested due to concerns that a positive outcome will affect their insurance.

Four of the consumers interviewed were diagnosed with HIV in jail or prison. Two of these consumers received referrals to care on the outside, and two did not. Upon release, former inmates are faced with many challenges as they re-integrate into society, often relegating HIV treatment to a low priority. Since PLWH

require intensive services and support when released from jail or prison, an provider suggested offering collaborative training to improve transition services for the recently released.

Based on their experiences, providers identified gaps in the service continuum. These included a wide range of services in outlying counties, medical care, specialty medical care and outreach. Outreach workers describe limited services across the continuum in outlying counties. Executive directors report waiting lists for medical care. Providers report spending hours or even days on the telephone trying to find specialists who are willing to provide treatment with limited compensation. Effective outreach is very labor intensive. Outreach workers discussed the time required to gain a consumer's confidence and bring him/her to testing.

Subpopulations

The following presents findings related to three special populations: men of color who have sex with men, women of childbearing age, and youth. Among MSM of color, the most frequently mentioned service need of greatest importance was HIV medical care. The MSM of color reporting the need for medical care included both newly diagnosed PLWH as well as those who had been diagnosed for many years whose health is beginning to fail. The MSM of color who were feeling well and those who were concerned about the side effects of medication were reluctant to seek medical care. Nonetheless, medication assistance was also identified as needed by the majority of this population.

Other services frequently mentioned as needed and considered important included: housing assistance, emergency financial assistance, dental care and groceries/ food vouchers. In addition, a small number of consumers identified a need for transportation. This is noteworthy since all who considered it a need rated it highest in importance.

Four women of childbearing age were interviewed for this study. None of the women interviewed have health insurance. All have very limited incomes with three reported earning less than \$500 per month and the fourth earning between \$500 and \$1,000 month. As might be expected from their income levels, all of the women interviewed report a need for emergency financial assistance. Three women ranked this need among their top four priorities. Three women identified medical care as a needed service, and on average it was the second most important service need. Case management and information about HIV services were also highly rated service needs. The two women that identified a need for housing assistance awarded it their highest importance rating.

The four HIV-positive youth interviewed provide an overview of the difficulties that are encountered in overcoming barriers to care among this population. All of the youth reported recurring depression since their HIV diagnoses, and the three men of color report hiding and denying the condition. This denial is a central to

their refusal to access care, since medication and medical care serve as reminders of HIV-positive status, and they do not want their contacts on the street to be aware of their conditions. Concern was also expressed about the potential side effects caused by medication, with reports of having seen friends' conditions deteriorate rapidly after initiating therapy. Other needs these youth identified included housing assistance, emergency financial assistance and dental care.

AREA 8

Providers

Client Needs

A review of all complaints reveals that there is a general misunderstanding regarding the roles and responsibilities of clients and providers, as well as regarding the procedures related to service access and provision. Providers found lesser instances of complaints regarding rudeness of providers and/or lack of knowledge or denial of services. Additionally, systems issues resulting in grievances were related to frequent staff turnover, inadequate training of staff and lack of a procedures manual.

The following needs were identified by staff at the Hendry/Glades Health Department who implement the Title III program:

Mental health family counseling and treatment;

Substance abuse counseling and treatment;

Transportation: Medicaid only pays for transportation to medical appointments during the workweek; no transportation is available over the weekend.

Communication and language barriers: (a) Most of the women seen at the clinic cannot afford telephones and live in isolated areas-they depend on visits from Title III nurses, (b) there is a need for Spanish speaking medical nurses;

Training for regular physicians and practitioners to offer HIV testing and counseling since many do not want to go to the health department (for fear of recognition, even though the service is free);

Nutrition: The current nutritionist travels from Sanibel and due to travel constraints is in the area infrequently;

Respite housing for day and over night stays: most women (infected or caregivers of the infected) put their own needs last and there is a great need for respite.

Assistance with housing: The women they see need more than rent payment; many are victims of domestic violence and have to move out of the house and area. Some places that will house the women do not understand the nature of HIV/AIDS. This leads to a secondary need of educating those willing to take in infected or affected women and their children.

Coordination: Need a list of potential housing that's not related to HOPWA. This is for immediate need and due to unforeseen circumstances such as violence and homelessness.

Barriers to Care/Service

Language differences are major barriers to patient care service in Area 8,

especially for the Haitian population. There is a growing number of HIV/AIDS infected and affected persons in this community scattered throughout the region. They are a close-knit community that has beliefs and customs different to their new home in the United States. In order to be adequately treated for HIV/AIDS, those infected must comply with medications and appointments. Without having a trusted interpreter who speaks Creole, adherence levels are low or non-existent. Most Haitians do not want to converse about intimate issues with someone from their own community; they believe gossip will spread when this occurs. Therefore it is recommended that Creole interpreters not from the local Haitian community be solicited to provide culturally pertinent information to patients at clinic and doctor appointments.

Other identified barriers/services gaps include the following:

- Lack of coordination between case management and clinical management meetings of the SWAN Consortium;
- Inadequate communication flow system regarding roles and responsibilities of partners;
- Lack of adequate needs assessment subcommittee members who reliably attend meetings to work on the needs assessment;
- Surveillance records show more people are infected than the number of those receiving care, especially in minority communities; therefore more innovative minority outreach initiatives are needed;
- Inadequate coordination of events or initiatives in Area 8;
- Inadequate number of specialty providers, especially dental, dermatological and infectious disease;
- Inadequate transportation for those who do not have a way to go to appointments;
- Poor adherence and compliance by patients once in care;
- Low communication between mainstream and culturally diverse patients is difficult due to illiteracy and language differences;
- Limited ability of case management to adequately perform job because of client overload (one case manager for 100-200 clients);
- Lack of coordination to apply for additional grants as a region to address items not covered by Medicaid and Ryan White;
- Fear or uneasiness of patients to go to the health department because they don't want others to recognize them and realize what they may be going to the clinic for treatment;
- Inadequate continuing education of providers to keep them wanting to see Ryan White patients;
- Inadequate access to doctors at all clinics;
- Inconsistent and inadequate continuity of care;
- Inadequate advocacy or ombudsman to assist individual patients with their needs;
- Complacency in Person Living With AIDS (PLWA) community.

Currently, there are a lack of dental and specialty providers in Area 8. Of those specialty providers that do participate, most do not accept Medicaid and have

stated they would not accept Medicaid rates. Furthermore, providers contacted in regards to their interest in participating in the Ryan White program have stated they have no interest in doing so at Medicaid rates. Thus, the Council is working with providers to see what rates are acceptable in order to retain them, would comply with terms of the contract and would be lucrative enough to attract new providers.

AREA 9

Clients

Needs

The consumer survey inquired about 43 types of HIV/AIDS-related services offered in the Palm Beach County Continuum of Care. Consumers identified each service either as one they needed and used, did not need, needed but could not get or could get but won't use. Utilization rates were calculated based on services which consumers checked as "need and use." Consumers reported moderately high of utilization for medical services. Fifty-nine percent of respondents reported current use of outpatient medical care. There was a higher utilization of case management services (68 percent) yet, a low reporting of counseling/support services. There was a low utilization rate for housing, food services and utilities. There was a minimal utilization rate for alternative therapies, nursing, insurance, home health, transportation and employment-related services. Utilization increased with level of illness.

The consumer survey included a one-page list of the 43 types of HIV/AIDS-related services offered in the Palm Beach County Continuum of Care. The survey asked consumers to identify up to seven services that they considered as most important to them. Responses were ranked by overall percentage of response. Consumers ranked drug prescription programs (ADAP/Drugs/Medicine) as their highest priority, followed by outpatient medical care, dental services, laboratory testing, help paying for rent/mortgage, case management and assistance in paying for utilities.

Level of illness did appear to have an impact on the ways in which consumers prioritized the services. This applies both to the rank order of the services, as well as the relative importance of the service based on the percentage of those who report it as a priority.

Providers/Case Managers

Client Needs

The CARE Council received a total of 18 valid responses, for a return ratio of 60 percent from providers. The majority of participating providers indicated that their clients do not adhere to medication protocol 61 percent; whereas 33 percent indicate they observe an improved adherence to medication schedules; 28 percent providers report improved health status; 22 percent report consumers are mainly AIDS diagnosed vs. HIV positive; 5 percent report barriers due to language and observe more complications due to Hepatitis C; and 11 percent observe increased

incidence of HIV positive among women.

While 28 percent of the providers report more mental health clients, more complications due to mental health issues and more observed depression, 22 percent; 17 percent of the same providers report a difficulty in accessing mental health services, a refusal by consumers to accept mental health counseling and a consumer population that exists in denial about mental health problems related to HIV/AIDS. Additionally, 17 percent of providers indicate a need for psychiatric services.

Thirty-three percent of providers report that substance abuse is an ongoing problem and 28 percent indicate that their clients who are substance abusing are most likely not to adhere to medication protocol and resist substance abuse treatment. 11 percent of those surveyed have reported improved substance abuse treatment access; complimenting the 17 percent who have observed a decrease in substance abuse among their HIV/AIDS clients.

The provider survey included the same one-page list of 43 types of HIV/AIDS-related services as was included in the consumer version. The survey asked each responding provider to identify up to seven services that they considered as most important for the clients they served. Providers ranked case management and medical outpatient services as the highest priorities for their HIV/AIDS clients, followed by drugs/medicine/ADAP, transportation, housing assistance, foods and laboratory tests.

Comparison between consumer and provider responses yields numerous differences in both priority rankings and percentages. In general, providers were more likely to prioritize clinical services, while consumers were more likely to prioritize ancillary services, particularly those that provide financial support.

Barriers to Care/Service

Consumers identified several service gaps in the Palm Beach County Continuum of Care as being grossly deficient. Consumers consider lack of access (lack of access=gap) to groceries as the number one service gap. Over one-third of survey respondents noted this gap. A companion of this service category is payment of rent/mortgage. Almost one-third of survey respondents also consider there to be a lack of access in this category. Other service categories that were ranked as gaps by one-third, or nearly one-third, of survey respondents were: utilities, housing, rent (as mentioned previously), private insurance continuation and massage therapy.

In most service categories, no pattern emerged regarding specific access barriers, with consumers reporting a mix of different barriers. The services that consumers identified as having the greatest amounts of barriers were substance abuse treatment, counseling, peer support, buddy/companion services, clinical trials, spiritual counseling and dental services. Of the aforementioned barriers, the most

prominent obstacle was lack of information. The services that reported the fewest service barriers were: transportation, rent, medical referrals, groceries, translation/interpreter services, telephone referrals, laboratory tests, help filling out government forms and outpatient medical care. The consumers did not generally assign a comment to these service categories.

Higher percentages of providers identified gaps in services (e.g., transportation, etc.) than did consumers. This is probably due to the fact that providers were asked to consider a service as a gap if a substantial number of their clients had trouble accessing a service, while each consumer vote represents the response of one individual.

Providers identified transportation as the number one gap for the clients they serve. Translation and home health aid were identified as gaps by half of responding providers. Other services that providers ranked among the top service gaps for their consumer populations were: rent/mortgage payments, vocational rehabilitation, substance abuse treatment (outpatient), substance abuse treatment (residential), legal services, respite care, direct emergency assistance and child care.

Subpopulations

Qualitative data were collected from five (5) specific sub-population focus groups with the purpose of gathering more in-depth information to provide a deeper understanding of the following subsets: (1) Men who have sex with men; (2) Hispanics; (3) Women; (4) Injection Drug users; (5) Adolescents. Anecdotally, the participants of the “men who have sex with men” focus group report the following:

There is a growing sense of apathy and disinterest among men who have sex with men regarding HIV/AIDS. This applied to both white males and men of color. These men disclosed that they learned their most useful information about how to access services from peer-referrals. To that end, the groups loudest protest was that there weren't enough support groups specific to their needs.

Telephone referrals to dental and medical care are difficult. In fact, a few group participants choose not to disclose their sero-status when seeking private medical and/or dental treatment to expedite care.

All group participants state that case management services are very good across the Continuum of Care.

The men stated that they would like alternative models of substance abuse treatment to be available, need more spiritual counseling, and different and more mental health services.

Medical and related services all seem to be more than adequate for this group.

In-home services were not a high priority for these men. In fact, they reported not being interested at this time.

Financial help had the most barriers to care. The men in need of housing reported long waiting lists, ridiculous housing rules (i.e., sex is forbidden for all adults in

HIV/AIDS funded housing communities); the need to “jump through hoops” to obtain housing and the requirement of being completely abstinent to retain housing.

Additionally, there appears to be a gap in transitional employment services, job skills training and help finding new jobs.

The final word was again about lack of support particularly, with regard to lack of support among the HIV/AIDS infected/affected gay community.

The Hispanic participants of the *Needs Assessment Survey* indicated service utilization (need and use) in the following areas: dental, primary medical, laboratory tests, prevention, vitamins and health foods, and case management. The one barrier that was pronounced (need, won't use) was ADAP. There does not appear to be enough medical information pertaining to HIV/AIDS in Spanish. There is a dearth of interpreter services, therefore case management and related services are difficult and counseling is nearly impossible. Spiritual and religious counseling however is widely available and utilized.

The Hispanic group underscored the need for Spanish-speaking public health workers (i.e., doctors and nurses) and stated that outreach and testing in vulnerable Spanish and rural communities is non-existent. Additionally, the Spanish culture relies heavily upon non-western therapies and our current system doesn't financially support such expenditures (no reimbursement). Finally, there is no “Farmacia” in our system of care and our Hispanic focus group is requesting this service. In-home services are not occurring in the Hispanic communities according to focus groups participants.

The focus group members stated that the Spanish get less help and attention in terms of financial support. The Hispanic participants report great difficulty finding suitable housing and get very little assistance paying for rent, utilities and groceries. The members of the Hispanic focus group also report that there is no formalized network for Hispanics and therefore, services such as food bank, child care, transportation, job skills training, legal and respite care are not readily available.

Generally, the IDU focus group suggested that the low indication of substance abuse treatment utilization on the Needs Assessment Survey was a reflection of poor substance abuse treatment provision in our Continuum of Care coupled with denial of substance abuse problems. The low service utilization was enhanced by fear of reprisal from providers and authorities. They clearly stated that substance abuse is an issue yet, continues to be hidden. The group also stated that there is an information and prevention gap relating to HIV and injection drug use. Additionally, this group hastened to add that while using, HIV infection is simply not a priority; drugs are.

Women in Palm Beach County are estimated to account for 32 percent of the cumulative number of AIDS cases and 47 percent of the HIV cases since 1997.

Heterosexual contact with an infected partner remains the highest transmission route for this population. Injection drug use among females is considered to be minimal. Black women report that they “know” their incarcerated partners engage in same-sex behavior while in prison yet continue to place themselves “at risk” when their partners are released. Many women with HIV/AIDS are living in poverty and do not have health insurance. Some are substance abusers. Women with children tend to enter the service system much later in the progression of their disease, placing the needs of their children before their own.

The estimated number of adolescents with HIV/AIDS in Palm Beach County is approximately 200. 96 percent of these cases are due to vertical transmission of HIV/AIDS (i.e., mothers having HIV/AIDS). There are several risks associated with this population such as: the refusal of social and educational institutions to educate teens about sexual behavior and condom use, young teens having few “positive” role models, gay teens experimenting with “bare backing” and “Russian Roulette” (engaging in unprotected sex with multiple partners, some of whom are HIV infected). Some teens regard this high-risk behavior as a rite of passage.

AREA 10

Providers/Case Managers

Client Needs

A total of 42 providers furnished general information in response to this survey’s request. The majority of providers felt that although the problem of HIV/AIDS is continuing to worsen for the community they serve, access to health and social services is improving. Providers were asked to rank the ten services they considered most essential to the well being of their clients. In response, they gave primary importance to the need for medications, outpatient medical care, and case management. More than half of the providers surveyed identified a further need for expanded dental care, medication reimbursement, and transportation. The need for additional substance abuse treatment and housing assistance programs also continue to rank high. Some providers indicated that expanded services should be targeted towards specific sub-populations.

This survey asked local providers whether they feel that the HIV/AIDS Delivery System in Broward County is adequately meeting their clients’ needs. Responses reflect two general trends: the need for more effective and efficient delivery of currently funded programs, and the need for further service expansion to meet growing demands.

Barriers to Care/Service

Dental care, both general (27 percent) and specialty (23 percent), and financial concerns, including help finding affordable housing (24 percent) or emergency help paying rent to prevent eviction (20 percent) presented the greatest obstacles to services clients said they wanted but were unable to get. Approximately one-fifth of the sample population also said that they were unable to get legal services

or alternative/complimentary therapies, or needed help finding services, either through client advocacy or referral. The homeless and immigrant populations had the highest percentage of unmet needs, while children, seniors and those under the care of a private physician indicated that their needs were being met most effectively.

Asked to identify system wide factors that prevent their clients from receiving needed services in an efficient and timely manner, the most frequently cited response, cited by 85 percent of those sampled, was “clients’ lack of knowledge about the availability of services”. In addition, at least half felt lack of adequate funding prevented needed service expansion, or identified “drug or alcohol addiction” or “lack of transportation” as serious barriers. Thirty out of thirty-nine providers (77 percent) were concerned that their current funding levels would not cover their HIV-related costs through the end of this fiscal year.

AREA 11

Clients

Needs

Summary of findings from focus groups

| POPULATION | KNOWLEDGE AND AWARENESS | ATTITUDES | PERCEPTION | PERSONAL AND FAMILY ISSUES | SOCIAL ISSUES | BARRIERS TO MEDICAL CARE | COMMUNITY ISSUES/UNMET NEEDS |
|--|--|---|--|--|---|---|---|
| Adolescents | Limited by School Curriculum | It Can't happen to me. | HIV is a MSM and substance abuse problem | Parents are barrier to Care. | Morality | Confidentiality | Radio-Ads Concert advertisement. Peers as Educators |
| Elderly | Limited | Don't think about it | Young and gay disease | Don't talk about sex openly | Unprotected sex | Physicians don't discuss | Education of medical providers on elderly risk |
| Incarcerated & Recently Released | Limited Information | Refuse to comply | Sex with MSM while in jail is ok | Not disclosing status to family | Unemployment | Continuum of care | Continuum of care needed. Revolving door of HIV |
| Migrant farm workers & Undocumented Immigrants | Limited Information Literacy Barriers | Fear of the INS & Family disclosure | HIV positive people are Deported | Stigma Blame Isolation | Language barrier Isolation Literacy | Confidentiality Culturally competent providers Local clinics | Few services Isolation Substance abuse Transportation |
| Sex-Workers Who Smoke Crack Cocaine | Limited | Preoccupied with drugging. Don't think about HIV when High | Not high risk | Rejection Disclosure | Stigma | Substance abuse | Stigma Substance abuse Housing |
| Substance Abusers/Mental Illness/ Homeless | Limited information | Shame Hopelessness | “Dying so why not get high” Denial No one cares | Dysfunctional Disclosure Rejection | Stigma Identification Unemployment | Relapse Homelessness No place to keep medications Providers are judgmental | Transitional housing Transportation Longer treatment Easier access |

Providers/Case Managers

Client Needs

Providers did not frequently mention a lack of services, but rather mentioned difficulties in connecting clients with services. Information provision was a theme that ran throughout the answers provided:

- HIV positive individuals need to be made aware that they are eligible for free medical care and other services.
- Families need to be involved and educated in regard to HIV, adherence, etc.
- Providers need information on what other providers have available and how clients can access services.

Ways need to be found to get and keep clients in care:

- Outreach was mentioned.
- Transportation problems need to be addressed.
- The need for continuity of care.

Most providers already have formal agreements with other providers in regard to HIV service provision, but many expressed the need for more service coordination, interagency communication, and the need for regular provider meetings.

AREA 11B

Clients

Needs

Twenty-three items were rated on a four-point scale in an effort to determine if the needs of clients were being met. The ratings were as follows: 1) Need and Get; 2) Need but Do Not Get; 3) Do Not Need; 4) Unfamiliar with Services. The analysis shows that Monroe County HIV/AIDS clients are seeing an increasing number of their needs being met. Case management services being received reflected 90 percent and optical care & eye exams received a 62 percent response. These numbers represent a significant increase over last year. Eighty-eight percent of respondents are receiving prescription medicine service, which is a 3 percent increase, and eighty-four percent receive primary medical care. Sixty-four percent of respondents need and are receiving dental services. This is a solid fourteen percent increase over last. Twenty-six percent of respondents expressed they now receive the AICP Insurance program, which is a six percent increase over last year.

Clients who have been hospitalized in the past year totaled 27 percent. While hospitalized 44 percent reported they received excellent care, 30 percent received good care, 18 percent received average care and 8 percent received poor care. According to the hospital chart it would appear that these numbers reflect a substantial improvement in services at the Lower Florida Keys Medical Center.

Ninety eight percent of the respondents are clients of AIDS Help, Inc. Of the 98 percent receiving services from AIDS Help, Inc., sixty-one percent rated services as very good and 25 percent rated them as good. Current case managers received a rating of very good from their clients. Eighteen percent rated their case manager as good, with 12 percent rating their current case manager as average and 5 percent rated them as poor.

Of the four volunteer services surveyed, transportation and legal assistance were questioned in section II - Client Needs. Twenty-six percent of clients need and receive transportation services. Fifty-two percent of those clients find the service to be very good and 28 percent find the service to be good. The remaining 20 percent of clients find the service to be average to poor. With regard to the legal services, ten percent reported in section II to receive the service and 17 percent reported to need the service but did not receive it. Of the 10 percent receiving legal services, 40 percent indicated the service is very good, 23 percent stated the service is good, while 37 percent stated the service to be average to poor.

The other two volunteer services questioned were the buddy program and moving assistance. With regard to the buddy program, 41 percent reported it to be very good, 27 percent reported it to be good, 8 percent reported it to be average and 24 percent reported it to be poor. Forty-one percent reported the moving assistance very good, 30 percent reported the service to be good, 8 percent reported it as average and 18 percent ranked the service as poor

The clients surveyed gave high ratings to their case managers in coordinating between their primary care providers and AIDS Help, Inc. - 44 percent very good; 26 percent good; 21 percent average and 9 percent poor. The AIDS Help Health Educator(s) appears to be under-utilized by the responding clients. Only 17 percent of the clients have consulted with an educator and 83 percent report no contact. Fifty-six percent of AIDS Help, Inc. clients who responded to this survey stated they would be interested in serving as a volunteer. This is up 8 percent over last year's survey.

AREA 12

Clients

Needs

Forty-four percent of survey respondents indicated that they currently receive benefits from Medicaid. Approximately one-third of the respondents indicated that they receive Medicare. Services that were provided under other included, ADAP, SSI/D, employee disability insurance, and CHAMPUS. Twenty-five percent of survey respondents indicated having private insurance or belonging to an HMO. Whites were more likely to have private insurance coverage or belong to an HMO than minorities. Men were also more likely than women to have private coverage. Twenty-five percent of survey respondents indicated that they were responsible for the care of a child under the age of 18. The majority of the respondents were female and minorities.

To gather more information on clients health care needs and to identify where clients were getting their health care questions were asked concerning this. The Needs Committee also felt that in order to bring people into care it was important to identify where clients were getting their HIV information. Following is a description of the survey responses to the questions asked. The majority of respondents (47 percent) indicated that they received their medical care at a public clinic. Thirty-eight percent indicated receiving most of their medical care through a private doctor. Three percent indicated receiving most of their medical care through the emergency room, and nine percent indicated other. Those who marked "other" responded with HMO, just moved to area, and named the Care Centre. Thirteen percent of respondents indicated that they had been hospitalized for an HIV/AIDS condition during the year. The most reported location for learning about HIV/AIDS services in Area 12 was in the Doctors office or clinic. Forty-three percent of the survey respondents identified this response. The next most identified source of service information was from an AIDS Organization or advocacy group over 30 percent of responses. Other sources of service information in rank order friend or family member, Newspaper/radio/TV, other, and church. No responses were made for community festival. There was no space left for the "other" response the respondent to list the source.

The five most reported needed and used service were 1) outpatient medical care (83 percent); 2) medications (80 percent); 3) case management (75 percent); 4) specialty medical care: visits to a eye or skin doctor (46 percent); and 5) general dental care (44 percent). The five services that were reported needed and used the fewest times were 1) Buddy/companion services (6 percent) ; 2) rehabilitation care (4 percent) ; 3); child day care (2 percent); 4) foster care /adoption (2 percent); and 5) adult day care (1 percent). The most reported service that survey respondent indicated as "needed but could not get" was general dental care followed by outreach/referral, alternative therapies, client advocacy, and legal.

Providers/Case Managers

Client Needs

A total of 34 provider surveys were returned. Providers indicated that they were funded through various sources. All respondents were Ryan White Title II providers. The majority of providers indicated that they expected their services to increase. A few providers felt that their services would stay the same and no providers indicated that their services would be decreased. The only referral problems providers identified were for specialty doctors such as ear, nose and throat (ENT) and orthopedics. The other problems identified for referrals were from agencies on the west side of Daytona and they indicated that transportation was a problem for their clients.

An equal (48 percent) amount of providers felt that HIV/AIDS has become more severe in the community they serve or had stayed about the same. One provider felt that HIV/AIDS was becoming less severe in the community. Providers'

perception of access to services was once again split between improving and staying about the same (37 percent). Twenty-five percent of the providers felt that access to services was becoming more difficult for clients.

Service providers were asked what services should be expanded in the upcoming year. The most frequently identified service for expansion identified by over half of the respondents was substance abuse treatment followed by housing assistance, health insurance continuation, medications, transportation, client advocacy, and health education/risk reduction.

Due to the growing diversity of those infected with HIV expansion of services is necessary and will benefit all populations. However, some providers indicated specific populations for services to be expanded for minorities, specifically African American women and their children, were most often cited by providers for the above services and others to be expanded to.

Barriers to Care/Service

Survey respondents were asked to identify any problems they have encountered that made it hard to get a service. They were also asked to identify the service that they had a problem getting. The majority of the services that clients referred to having problems getting were not funded by Ryan White such as food stamps, Medicaid, Medicare, SSI/D HUD applications, and affordable housing. The Ryan White funded services that respondents did identify the most were dental, case management, and legal services. Legal services were identified most often as the service that respondents did not know how to apply for. Case management issues that were identified include trouble communicating, site too far away, and had to wait too long for services. Dental services were identified as being too high of cost and the service site was too far away. The most identified barrier was transportation. Twenty-six people identified transportation as a barrier to receiving services followed by 20 people who identified that they did not want people to know that they had HIV. Fifteen survey respondents indicated that they had housing problems.

Providers were asked to identify barriers that they feel prevents their clients from accessing needed HIV-related services in an efficient and timely manner. Lack of knowledge of both the client and the provider were the largest barriers. For clients it was how to access services and for providers it was lack of knowledge of services and how to refer to these services.

AREA 15

Clients

Needs

The ten most utilized services (and the percentage of survey respondents who utilized the service) were:

1. Telephone Referrals to Medical or Dental Care (92 percent)

2. Having a Professional help you get Services (92 percent)
3. Outpatient Medical Care (88 percent)
4. HIV Related Laboratory Testing (88 percent)
5. Medical Information about HIV/AIDS (88 percent)
6. Transportation/Rides to medical and social service appointments (75 percent)
7. Vitamins/Health Foods (71 percent)
8. Food Bank Boxes (67 percent)
9. Medical Referrals (67 percent)
10. Help Filling Out Government Forms (67 percent)

There are some services that consumers said they needed and could get but wouldn't use indicating barriers to use of this service such as dislike of available providers or mistrust of the service itself. The single most frequently cited service was dental care. 12.5 percent of respondents stated they could get but would not use this service. Second most frequently cited service was Inpatient Hospital Care.

The seven leading service priorities for survey respondents were the same as reported by survey respondents of the Needs Assessment Survey of 2000/2001 with the exception of transportation services. Transportation was a top priority for survey respondents living in Okeechobee and Martin Counties during both surveys (2000/2001 and 2001/2002) as compared to a ranking of 11th place by All Respondents in the 2000/2001 Survey.

Providers/Case Managers

Client Needs

The Medical Provider Survey was distributed to twelve physicians serving persons with HIV/AIDS in Area 15 (Indian River, Martin, St. Lucie and Okeechobee counties) during the month of June 2001. *Five out of six physicians reported having a data collection system in place to collect health status indicators.* One provider reported using quality assurance forms in each chart listing everything from allergies to dates of paps, chest, TB, Hepatitis, CMV, wasting, etc.; two providers reported using flow sheets and Health Pro; and two providers reported collecting CD4, HIV UL, CMV, AFB and PPD.

According to survey respondents, the estimated percent of patients who did not show for their scheduled appointment in the past twelve months (prior to the time of this survey) was approximately 10-15 percent. *The estimated percent reported by survey respondents is the perceived percentage of missed appointments. The information provided is not based on a validated data collection system and may underestimate the actual percentage of missed appointments.*

Survey respondents were asked to identify the primary care services provided to HIV/AIDS patients in the past twelve months (prior to the survey) by placing a check mark in the box that corresponded to each service provided from a list of

services. The services that were NOT checked by each respondent (thereby representing a service not available by that provider) are listed. *Three out of six survey respondents listed prenatal care as a service NOT available.*

The two most reported chronic conditions were Diabetes and Anemia. The top three medical specialty referrals made by each respondent during the past twelve months (from the time of this survey) are also listed. The two most referred medical specialties listed were Dental and Neurology.

Barriers to Care/Service

The top five service gaps (percent reported as needed but could not get) were:

1. Help Finding Affordable Housing (38 percent)
2. Support Groups (38 percent)
3. One-to-One Peer Support (21 percent)
4. Massage Therapy (25 percent)
5. Alternative Therapies (21 percent)

Findings

Service needs were reported with consistency across the areas. The following are the highest reported service needs as indicated by clients, providers and experts, in descending order: **Case management, Pharmaceuticals, Dental, Outpatient medical care, Housing, Transportation, Specialty medical care, Food bank/pantry, Mental health counseling, Laboratory testing, and Substance abuse treatment.**

Based on provider responses, the most readily available services include **Counseling, Medical care, Alternative therapies, Dental care, Substance abuse treatment, Prevention, Pharmaceuticals and Housing.** A few of the providers indicate that services such as pastoral care, legal, peer support, optical care and referral services are available. Top service needs are generally well covered by providers. The four service needs that are not readily provisioned are case management, transportation, food bank/pantry and laboratory testing.

Many of the findings from the different surveys and interviews reflect the same general issues. What is notable however is that clients' perceptions of their needs do vary somewhat from providers' perceptions of their clients' needs. Generally, indigent people frequently identify service needs that fulfill basic needs. These include food, shelter, employment and financial support. Those PLWH who are ill identify medical care.

Client based focus groups found a need for more support systems. These include peer-led support groups for family members or caregivers and for youth/adolescents living with HIV/AIDS. Additionally, focus group participants felt that the best way to get infected people to access service was to provide more outreach and education using PLWHA, peers or other trusted community members.

According to providers, however, among the most frequently requested service that can be provided through Ryan White and other funding sources, is medical care followed by pharmaceuticals. Dental care is also frequently mentioned during case manager and key informant interviews. Furthermore, very few clients indicate they are receiving substance abuse treatment or have a need for substance abuse interventions. In focus groups, however, providers tend to rank the need for substance abuse treatment as high. This disparity could be an assessment of the problem by providers or it may reflect a more “pre-contemplative” state or denial state of clients related to substance abuse. This disparity in perspectives between providers and clients deserves attention.

Clients also did not indicate a need for mental health services. However, both case manager and key informant interviews indicate a larger, unrecognized need. In fact, client problems such as lack of responsibility for taking care of oneself, non-adherence to medical and drug regimes, failure to practice primary and secondary prevention and hostility toward providers and others could be addressed through counseling and support. Some case managers find that they are inadequately providing this role in lieu of licensed, professional counselors.

Findings suggest that clients and providers do agree on barriers to care and service. Personal experiences that tend to create difficulty for clients include lack of money, lack of strength/energy, applying for benefits, qualifying for benefits, lack of community resources for persons who are HIV positive and lack of assistance from family members. Providers identified a phenomenon of the interconnectedness of barriers to care based on their experiences. In other words, a variety of barriers come together to prohibit consumers from accessing care, for example, poverty. The perceived service needs of these consumers include housing, groceries/food vouchers and emergency financial assistance.

Additionally, clients are fearful about confidentiality. One service area found that thirteen percent of respondents indicated that during the past year they had been concerned that their confidentiality had been broken. Also, services with the “AIDS” label in the community are minimally utilized. Service locations, facilities that maintain privacy and provider attitudes were identified as critical components of confidentially delivering services. Providers recognized these same issues. Fear of being identified as HIV positive, client denial, guilt, social and geographic isolation, fearing of being disowned by families include some of the principle obstacles to accessing care. The severity of the stigma of having HIV disease varies by family and culture. Reportedly, the stigma among Haitian and Latino communities is very severe. This stigma leads to delaying counseling and testing, denial after diagnosis, fear of disclosure, and confidentiality concerns. Some PLWH had a feeling they were HIV positive for months or even years before they were actually tested.

Red tape is a barrier for accessing services quickly and many felt that eligibility criteria should be changed. Having HIV and not AIDS was discussed in a focus group as being a barrier. The consensus was that many of the services being offered are available for those with AIDS.

Lack of information about HIV services is consistently cited as a barrier to care. A few interviewed PLWH do not have any type of insurance and were not aware of the free care available through Ryan White programs. Some interviewed PLWH expressed their opinions regarding medication, benefits, and care services were attributed to information from friends. This information appears to be as inaccurate as it is accurate.

Language differences are major barriers to patient care. Hispanic participants of a focus group reported that there does not appear to be enough medical information pertaining to HIV/AIDS in Spanish. Additionally, interpreter services are lacking, thereby affecting case management and related services.

Providers indicated that reporting requirements, oversight procedures, and eligibility requirements could reduce the overall effectiveness of programs. They also increase the number of caregivers interacting with a single client. There is also a problem in securing funding and personnel. This includes a lack of minority providers and a lack of multiple providers within service categories.

Job services were cited as being an unmet need in a collection of focus groups. Participants questioned the ability to get a job without being discriminated against or without losing some or all of the services available to them. Many participants would like to go back to work or have training to enable them to return to work.

One service area reported that employee turnover is a significant barrier to care for the consumer. When an employee resigns, PLWH are at risk for exiting the system. Case manager and outreach worker turnover also result in an information gap.

Undocumented immigrants or those who are awaiting resident status often encounter barriers to care. These people tend to be wary of government-sponsored services and services offered in government buildings.

In a focus group of MSM, the men in need of housing reported long waiting lists, ridiculous housing rules (e.g. sex is forbidden for all adults in HIV/AIDS funded housing communities); the need to “jump through hoops” to obtain housing and the requirement of being completely abstinent to retain housing.

Only one service area specifically focused on the elderly population. The attitude of this group is that HIV is a young and gay person’s disease and the elderly don’t think about it. Physicians also do not discuss HIV prevention with this group.

The results of the client surveys are reflected in the findings of the different focus groups. Clients’ needs are an extension of their financial and/or health status. Clients who are classified as being in a subpopulation also identified issues that are specific to them. For instance, it has been demonstrated that persons for whom English is a second language are in need of translators and translated materials.

Providers seemed to identify needs that reflect upon their own agendas. Transportation is identified readily as a barrier to service as missed and late appointments reflect poorly for providers. However, not all barriers or needs are self-serving. Providers identified lack of information as a barrier that prohibits care as clients don't know where to go for help and providers do not know how to refer them for that help.

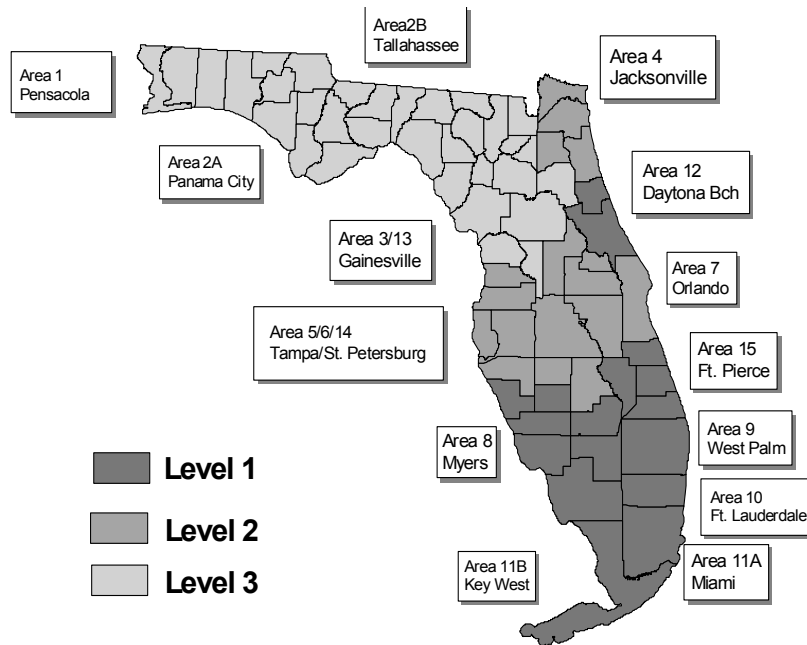
Barriers were split into different types: barriers to obtaining information, access barriers, barriers to care and barriers in providing care. Among responses to barriers to care, transportation and lack of information were the two most identified. Among barriers to service provision transportation and language/cultural issues were the most identified. When broken down by whom is doing the reporting of barriers in general, consumers identified lack of information most often as the barrier to care. Providers identified both transportation and lack of information equally and case managers or key informants identified transportation, followed by red tape. Overall transportation is the greatest reported barrier.

Following HRSA guidelines, a resource inventory was assessed. It is evident that the available resources cover few of the identified service gaps. Some of the service gaps will need to be solved internally; Ryan White apparently does not fund some of the other services, such as specific alternative therapies. The remaining gaps seem to be a condition of the service area and may need to be addressed through reallocation of funds.

Analysis of Crosscutting Themes

Geography

A comparison of unmet needs in the state shows that there is a clear line of demarcation in types of needs vs. the cost of living of the service area. In service areas with cost of living indices in the top third for the state, need requests revolve around payment of living expenses including rent/mortgage, utilities and insurance. Additionally, these areas were the only ones to report alternative medicine/therapies as unmet needs. Service areas where cost of living indices average in the lower third of the state, needs revolve around basic needs, such as food pantries or housing assistance. Those areas within the middle tier are more likely to need case managers or client advocates, medications and transportation. As can be seen in the map below, the four service areas that comprise the panhandle have the lowest costs of living for the state. The bottom half of the state has the highest costs of living.



Source: 2001 Florida Price Level Index
Prepared by Center for Health Statistics, Duval County Health Department, April 9, 2003

Table 1. Reported Unmet Needs by Area

| | Level 3* | | | | Level 2 | | | Level 1 | | | | | |
|---------------------------------|----------|----|----|------|---------|--------|---|---------|---|----|------|----|----|
| | 1 | 2A | 2B | 3/13 | 4 | 5/6/14 | 7 | 8 | 9 | 10 | 11** | 12 | 15 |
| Alternative medicine/Therapies | | | | | | | | X | X | X | | X | |
| Benefits information | | | | | | | | | X | | | | |
| Buddy/Companion | X | X | X | | | | X | | | | | | |
| Case managers/ Client advocates | | | | | X | X | | | | X | X | X | |
| Childcare | X | X | X | | | | | | | | X | | |
| Dental | X | X | X | | | X | X | | X | X | X | X | |
| Domestic violence services | | X | X | | | | | | | | | | |
| Drug/Alcohol treatment | X | | X | | | | X | | | | X | | |
| Emergency financial assistance | | | | | | X | | | | | | | |
| Emergency rent | | | | | | | | | | X | | | |
| Eye care | X | X | X | | | | | | | | | | |
| Food bank/Pantry | X | X | X | X | X | X | | X | X | | | X | |
| Grocery payments | | | | | | | | | X | | | | |
| Help with insurance | | | | | | | | | X | | | | |
| Housing assistance | X | X | X | | | X | X | | X | X | | X | |
| Insurance payment | | | | | | | X | | X | | | | X |
| Job training/Job hunting help | X | X | X | | | | | | X | | | | |
| Legal services | X | X | X | | | | | | X | X | | X | |
| Medications | X | X | X | | | X | | X | | | X | | |
| Meds co-payment | | | | | | | | | | | | X | |
| Mental health counseling | X | X | X | | | X | X | | | | X | | |
| Nutritional counseling | X | X | X | | | | | | | | | X | |
| Outreach/referral | | | | | | | | | | | | X | |
| Peer advocacy | | | | | | | X | | X | | | | |
| Peer education | | | | | X | | | | | | X | | |
| Physical therapy | | | | | | | | | X | | | | |
| Rent/Mortgage payment | | | | | | | X | | X | | | | X |
| Residential care | | | | | | | X | | | | | | |
| Specialty treatment | X | X | X | | X | | | X | | | | X | |
| Spiritual care | X | | X | | | | | | | | | | |
| Supplemental money | X | X | X | | | | | | X | | | | |
| Support groups | X | X | X | | | | X | X | | | | X | |
| Support services | | | | | | | | | X | | | | |
| Transportation | X | X | X | | | X | | X | X | | | | |
| Utilities payments | | | | | | | X | | X | | X | | X |
| Vitamins/Health foods | | | | X | | | | | X | | | | |
| Water filters | | | | X | | | | | | | | | |

Providers vs. Clients

Providers and clients have different perceptions regarding the needs of clients. One service area succinctly described the situation: providers tend to place more priority on clinical services and clients place more priority on ancillary services. Substance abuse treatment was consistently cited by providers as a service that clients needed. Other frequently mentioned service needs included outpatient medical care, case management, pharmaceuticals, and transportation. Of those reports that distinguished unmet needs, mental health care, transportation, specific pharmaceuticals, and continuity of care were among the services identified. After combining “needs” and “unmet needs”, transportation was listed the most often; seven times out of eight reports. This was followed by pharmaceuticals, cited six times, medical care and case management, each cited five times, and substance abuse treatment, which was cited four times.

Clients listed their needs to include primary medical care, case management, pharmaceuticals and dental care. Clients also specifically listed their unmet needs to include information regarding services, transportation, dental care, housing assistance, support groups or peer support, and client advocacy. Combining “needs” and “unmet needs” as definitions, in eight out of ten reports, both medical care and dental services were cited. In six reports housing assistance, pharmaceuticals and transportation were each cited.

While substance abuse treatment made the top five in the provider’s list, it was only mentioned by one report as a client indicated need. Also, while providers identified 13 different categories that represent client needs and unmet needs, clients identified 20 categories. Not considered by providers were alternative therapies, client advocates, more information of services, legal services, optical care, outreach services, and peer support/support groups.

Barriers

In twelve reports that provided information on barriers to service or care, transportation, listed in nine reports, was the most often cited. This lack of information was witnessed in both providers and clients. Lack of information followed, cited eight times, with confidentiality and lack of continuum of care, each listed six times. This was followed by cultural/racial insensitivity which was cited four times. Out of the thirty-three barriers listed, staff turnover/stress was listed three times. Despite the high ranking for substance abuse treatment among providers as a client need/unmet need, only two reports listed substance abuse as a barrier to service/care.

Some service areas also identified barriers to care to specific subpopulations. For African-Americans, the stigma of being HIV positive is a barrier to seeking care. In addition, providers find that this group of people tends to not seek preventive care or adhere to medications. For migrant and/or homeless populations, illiteracy, lack of proper food, shelter and clothing are barriers to care. This situation lends to the concept of the

interconnectedness of barriers to care previously mentioned.

Ryan White Title I vs. Ryan White Title II Funding

Six of the service areas report receiving Ryan White Title I (RWI) funds, five report receiving both Ryan White I and Ryan White II (RWII) and the remaining seven report receiving only Ryan White Title II funds. Eighty-three percent of RWI funded areas collected data on needs using two or methods (e.g. client and provider surveys) versus fifty-seven percent of RWII funded service areas. Notably, however, RWII reports were more likely to indicate that clients' needs were almost always being met.

Subpopulations

A disappointing number of reports identified subpopulations that should be studied in depth, yet these same reports failed to provide information on the specific needs of these populations. MSM and IDU were consistently the most frequently reported methods of exposure, yet little analysis of the care complications for either of these groups was provided. In particular, the needs of IDU who may be willing to undergo substance abuse therapy is of importance. Some providers and clients noted that for IDU, it would appear they are more concerned with obtaining drugs than with their health. One comment from an executive director: "They don't want to take medication; they don't care about dying; they don't want the doctor or anyone to find out. They just want to get high."

Some service areas have populations where particular nationalities are predominant. For example, Cuban, Haitian and Caribbean populations have ideologies distinctive to their groups. In addition, these cultures may have an influential role in defining client attitudes towards their HIV positive status and the related treatment. While attention has been paid to the barriers of language and cultural differences, of importance is determining the particular needs of these groups. For instance, as pointed out by a couple of reports, some of the people in these groups subscribe to "alternative religions". Is there a service gap in obtaining pharmaceuticals that forces clients to choose alternative therapies for relief or is it that these clients put more faith in alternative therapies than in Western medicine? These are but two examples of questions that could be answered by these populations.

Fortunately, a few service areas did obtain information from the formerly incarcerated regarding their needs. Often cited is the need for a strong transition from the prison medical care to community programs. While incarcerated, medications are provided. Upon release, obtaining housing and transportation is difficult. In addition, adherence to drug regimes tends to be problematic. One service area noted that former inmates were faced with many challenges as they re-integrate into society which relegates HIV treatment to a low priority.

Also underreported were the unmet needs of women. For those women with young children who are also affected, the problem of providing care is an obstacle. It was reported that lack of availability and funding for day care and transportation served to amplify the problem. Other client groups that were identified, but for which relatively little information was collected, includes commercial sex workers, the homeless, and migrant workers.

Findings

The top ten unmet needs, in descending order, were reported as **Dental, Food bank/pantry, Housing assistance, Transportation, Support groups, Specialty treatment, Mental health counseling, Medications, Legal services, and Case managers/client advocates**. Specific needs of clients appear to be somewhat dependent upon where the client lives in the state. Differing opinions between clients and providers illustrates the need for local areas to utilize several methods of data collection in order to obtain a comprehensive depiction of needs. As some areas have already recognized, special subpopulations tend to have needs that differ from the general population of HIV/AIDS clients. In order to ensure generalizability of results, collecting data from these special subpopulations will also need to be performed.

Analysis of Area Reports Using HRSA Guidelines

The U.S Department of Health and Human Services, Health Resources and Services Administration (HRSA) has established recommendations for a comprehensive HIV/AIDS Needs Assessment. The comprehensive needs assessment should have at least five important components: 1) an epidemiologic profile, 2) an assessment of service needs, 3) a resource inventory describing services available, 4) a profile of provider capacity and capability, and 5) an assessment of service gaps and unmet need based on an analysis of the aforementioned information. Following is a summary of the information as provided by each area and an analysis of how the area needs assessment reports conform to the HRSA guidelines.

Assessment of Service Needs

AREA 1

As indicated by client surveys, the services most indicated as needed, but couldn't get were financial assistance, dental care, eye care, legal assistance and nutritionist services. The most frequently identified reasons for difficulties in receiving routine care as indicated by clients were needed services not available, transportation, long waiting list, fear HIV status would be known, confidentiality issue and cost of medications

AREA 2A

Clients indicated in their surveys that the services most indicated as needed, but couldn't get were dental care, help with housing, financial assistance, legal assistance and transportation. The most frequently identified reasons for difficulties in receiving routine care also indicated by clients were transportation, needing services not available, fear HIV status would be known, cost of services, and confidentiality issue.

AREA 2B

The services most indicated as needed, but couldn't get were financial assistance, dental care, help with housing, eye care and transportation. The most frequently identified reasons for difficulties in receiving routine care as indicated by clients were needing services not available, transportation, fear HIV status would be known, cost of medications and cost of services. Through surveys clients identified these service needs and barriers.

AREA 3

Services most needed by respondents to the client survey were: CD4 count/viral load test (92 percent); dental x-rays/cleaning (87.1 percent); medical case management (82.8 percent); pharmacy/emergency drug assistance/ADAP (79/7 percent); and dentures/fillings/extractions/tooth repair (76.7 percent). Services least needed by survey respondents are: alcohol or substance abuse detoxification (2.8 percent); babysitting at

agency/clinic (2.9 percent); kinship care (3.5 percent); special services for child with HIV or other disabilities (4.6 percent); and respite care (5.6 percent). Top five services identified as needed but not received include: food vouchers (45.2 percent); emergency medical care (43.4 percent); food pantry (40.1 percent); water filters (38.9 percent); and vitamins/Ensure/Sustacal (36.0 percent).

Providers indicate that the most important need of PLWH is counseling/support services. Information/education/referrals about their disease and receiving/taking medications are the next most important needs. Other reported needs are transportation, financial assistance, basic needs (food, clothing, housing) and good medical care.

In response to a barrier in receiving needed services: respondent's income is too high for SSDI; amount received from SSI is not enough and respondent has a long wait for approval for food stamps. The three biggest barriers faced when trying to obtain HIV/AIDS related services: travel and/or transportation to services; services no longer being available in their area; lack of information about services; obtaining SSI/SSDI; receiving food stamps; and phone calls not being returned from service providers. The single most important change to improve services is the need for better access to information about services.

According to providers, the top three barriers to care for consumers are lack of money, lack of transportation and lack of information on services and care. Other barriers indicated include limited space and time for counseling/care, 'red-tape' associated with financial assistance, anonymity, referrals and medications.

AREA 4

Consumer surveys ranked the following services in the top ten, with the highest priority listed first: primary medical care, pharmaceuticals, case management, dental care, specialty care, housing assistance, alternative therapy, counseling (other than mental health), legal assistance, transportation. Focus groups ranked the following services in the top ten: primary medical care, housing, financial assistance, pharmaceuticals, case management, transportation, dental, drug/alcohol treatment, health education/information, specialty care.

Primary barriers, as indicated through focus groups, surveys, public hearings, etc., include medical adherence/organizational/service, geographic, capacity, policy/regulatory, individual/client barriers, infrastructure constraints, and funding barriers.

According to key informant interviewees, the biggest barriers in providing care to clients when they need a service they do not provide is lack of funding which directly affects services like transportation, numbers of beds for clients and transitional housing for clients. Also, getting through the barriers within the system was a listed barrier. The biggest barriers to providing services to clients included transportation, availability of services, convincing clients that services are needed, payors sources, and distance

between outlying counties and Duval County.

AREA 5

The results of the client survey, case manager focus group, expert survey, client focus group, and provider focus group were each assigned a weight. Based on these weights 20 HRSA defined services were scored and a prioritized list of services was developed.

Service priority recommendations (in rank order):

Ambulatory/outpatient medical
Medications
Case Management
Planning council support
Transportation
Emergency financial assistance
Dental care
Housing assistance/housing related
Mental health therapy/counseling
Food bank/home delivered meals

According to case managers, barriers to service provision include changing epidemic of the disease, client knowledge/participation, cultural environmental appropriateness, funding, coordination/continuum of care, quality of services, staff issues, transportation and women's issues. According to non-Ryan White providers, barriers to service provision include addictions/mental health programs, adherence, caregiver burnout, child care, client knowledge/participation, community resistance, confidentiality, coordination/continuum of care, cultural competency/sensitivity, data/tracking, employment, food, funding, housing, legal services, managed care, mental health, prison services, rules, staff issues, substance abuse, and transportation.

AREA 7

Top ten needed services as reported by clients are primary care, medications, case management, nutritional services, dental care, food, treatment education, information & referral, rent/utilities, and peer support. The top ten unmet needs were informed neighborhoods, drug/alcohol treatment, rent/utilities, residential care (hospice), private insurance assistance, buddies, housing (getting help, e.g., locating), mental health, dental care and peer support. Unmet needs were also examined with four subpopulation groups in mind: race/ethnicity, gender, age, region.

Common themes as described in focus groups with regards to weaknesses in the HIV/AIDS resource system include unavailable or ineffective case management, roadblocks to medical coverage through social security, unfilled or delayed prescriptions, inadequate transportation, lack of clients' awareness of resources and the service delivery system, insufficient housing opportunities, deficient and discriminatory medical care,

inaccessible and overly-conspicuous service organizations, and disrespectful provider attitudes toward PLWHs particularly in the medical profession.

Respondents in the focus groups specified thirty-seven barriers to service provision. The top ten were as follows: lack of cooperation from case management, difficulty in locating eligible clients, insufficient clinic hours, transportation unavailable, agency turf guarding, language barriers, having a lengthy MOA for referral providers, case management is not provided, people's fear of AIDS and fear of employees getting AIDS.

AREA 8

The following needs were identified by staff at the Hendry/Glades Health Department who implement the Title III program:

Mental health and family counseling and treatment;
Substance abuse counseling and treatment;
Transportation: no transportation is available over the weekend;
Communication and language barriers: (a) most of the women seen at the clinic cannot afford telephones and live in isolated areas (b) there is a need for Spanish speaking medical nurses;
Training for regular physicians and practitioners to offer HIV testing and counseling since many do not want to go to the health department (for fear of recognition, even though the service is free);
Nutrition: the current nutritionist, due to travel constraints, is in the area infrequently;
Respite housing for day and overnight stays: most women put their own needs last and there is a great need for respite;
Assistance with housing: the women they see need more than rent payment; many are victims of domestic violence and have to move out of the house and area;
Coordination: need a list of potential housing that's not related to HOPWA.

AREA 9

The top ten services that were reported as needed and used by consumers were laboratory tests (75 percent), case management (68 percent), primary medical/outpatient (59 percent), medical information (59 percent), medical referrals (58 percent), dental (58 percent), vitamins and health foods (55 percent), ADAP (53 percent), Help getting support services (52 percent), and benefits information (46 percent). The top ten service priorities from consumer surveys were ADAP/drugs/medicine (58 percent), outpatient medical care (55 percent), dental (51 percent), laboratory testing (48 percent), help paying for rent/mortgage (44 percent), case management (35 percent), help paying for utility bills (34 percent), housing assistance/finding a place to live (29 percent), help paying for groceries (28 percent), and vitamins and health foods (27 percent). Prioritizing services was impacted by level of illness as reported by consumers.

Service priorities as indicated by providers were case management and outpatient medical care (72 percent), each equally ranked as number one. ADAP/drugs/medicine

(761 percent), transportation (56 percent), housing assistance (50 percent), food/pantry (39 percent), laboratory testing (33 percent) ranked two through six. Utilities payments, rent/mortgage payments, counseling/support services, legal services, and medical/hospital (28 percent) all ranked equally at number seven.

Both groups assign similar importance to ADAP, outpatient medical, laboratory tests, rent/mortgage payment, utility bills, housing assistance, groceries, legal assistance, insurance continuation and inpatient hospitalization.

The survey asked all consumers to identify services as ‘can get, won’t use’ to represent access barriers. Substance abuse services and support groups were ranked first and second, respectively. 1 to 1 emotional peer support, buddy/companion, clinical trials, and spiritual counseling ranked third. Dental ranked fourth and physical therapy, acupuncture and mental health tied at ranking fifth. Of these barriers, the most prominent obstacle was lack of information. Estimates of consumer needs by service category and estimates of unmet need were also provided.

AREA 10

The top ten service needs as indicated by clients are outpatient medical care, medications, general dental care, case management, specialty medical care, food bank, nutritional counseling, client advocacy, outreach/referral and support groups. The top ten unmet needs reported by this group are general dental care, housing assistance, specialty dental care, legal services, alternative therapies, client advocacy, emergency financial assistance, outreach/referral, medication co-payments and insurance continuation. Three of the high-ranking service needs are also an unmet need.

The top ten service categories as prioritized by providers are medications, ambulatory/outpatient medical care, case management, housing assistance, specialty medical care, transportation, substance abuse treatment, health insurance continuation, mental health counseling and direct emergency financial assistance.

The major problems that made access to services difficult for survey respondents were lack of knowledge, housing problems, fear of disclosure, transportation problems and unnecessary delays in the provision of services. Additionally qualifying criteria is too strict; clients may not be poor enough, sick enough or US citizens. With regards to barriers to care, the most frequently cited response, cited by 85 percent of providers sampled, was ‘clients’ lack of knowledge about the availability of services’. In addition, at least half felt that lack of adequate funding prevented needed service expansion, or identified ‘drug or alcohol addiction’ or ‘lack of transportation’ as serious barriers.

AREA 11

Service needs were not ascertained in this area, however through the use of numerous focus groups, barriers to care were identified. For adolescents, barriers to care include health care providers are insensitive to gay and transgender issues; healthcare curriculum in public schools does not engage conversation on gay and transgender lifestyles; lack of

support services for gay and transgendered youth in public schools; gay and trans gender youth have fatalistic attitudes; stigma among African American adolescents that AIDS is a Haitian and gay disease; transgender and gay youth experience emotional and psychological stress because of lack of support and fear of rejection from family members; more services are needed in minority communities for inner city gay youth. According to key informants, with regards to adolescents, transgender youth have few services available to them; most transgender youth are immigrants and may end up homeless or living with friends; there is a lack of culturally sensitive materials targeted at young Hispanic gay males.

The greatest barrier to medical care by those who are substance abusers and/or are mentally ill is substance abuse. Several participants experienced difficulty getting into treatment because they had to be cleared by a psychiatrist before admission. Clients in residential treatment often miss scheduled medical appointments because group activities take priority over outside appointments. Key informants felt that many encounter barriers to treatment because they are dually diagnosed and that most treatment centers do not address substance abuse, HIV/AIDS and mental illness together. Also, adolescent substance abusers have few programs available to them

AREA 11B - Not provided

AREA 12

According to clients, the five most reported needed and used service were outpatient medical care (83 percent), medications (80 percent), case management (75 percent), specialty medical care: visits to an eye or skin doctor (46 percent) and general dental care (44 percent). The most reported service that survey respondents indicated as 'needed but could not get' was general dental care (30 percent), followed by outreach/referral (26 percent), alternative therapies (24 percent), client advocacy (24 percent), legal (20 percent), and nutritional counseling (20 percent).

According to providers the top ten service needs were outpatient medical care for HIV, medications, substance abuse treatment, health education/risk reduction, case management, health insurance continuation, mental health counseling, food bank, dental care, and emergency financial assistance. One of the biggest differences is the service category substance abuse where clients ranked this service as 23 and providers ranked it as 3. There is also a large variance in the service category of mental health counseling where providers ranked this service 7th and clients as 13th.

According to providers, lack of knowledge of both the client and the provider were the largest barriers to care. For clients, it was how to access services and for providers it was lack of knowledge of services and how to refer these services.

AREA 15

The ten most utilized services were telephone referrals to medical or dental care (92

percent), having a professional help you get services (92 percent), outpatient medical care (88 percent), HIV related laboratory testing (88 percent), transportation/rides to medical and social service appointments (75 percent), vitamins/health foods (71 percent), food bank boxes (67 percent), medical referrals (67 percent), help filling out government forms (67 percent). Four out of six providers listed transportation as one of the top barriers in the delivery of primary care to HIV/AIDS patients.

Table 2. Itemization of Barriers

| Barriers to Obtaining Information | Barriers to Care | Barriers to Providing Care | Barriers to Service Provision | Barriers to Access |
|---------------------------------------|-----------------------------------|----------------------------|-------------------------------|---------------------|
| Travel | Transportation | Lack of funding | Changing epidemic of disease | Lack of information |
| Lack of information | Lack of information | Rape Tape | Client knowledge | Housing |
| Phone calls not returned by providers | Limited time spent with providers | Transportation | Cultural environment | Fear of disclosure |
| | Red tape | Lack of available services | Funding | Transportation |
| | Anonymity | Payors sources | Continuum of care | Lengthy wait times |
| | Referral problems | Travel distance | Quality of services | Qualifying criteria |
| | Problems receiving medication | | Staff issues | |
| | Inadequate funding | | Transportation | |
| | Substance addiction | | Women's issues | |
| | Cultural sensitivity | | Case management problems | |
| | Lack of adolescent services | | Eligible clients | |
| | Cost of medications | | Insufficient clinic hours | |
| | Cost of services | | Agency turf guarding | |
| | Fear HIV status would be known | | Language barriers | |
| | Needing services not available | | Red tape | |
| | | | AIDS stigma | |

Resource Inventory & Profile of Provider Capacity and Capability

AREA 1 - Not provided

AREA 2A - Not provided

AREA 2B - Not provided

AREA 3

When providers were asked to describe their organizations, pharmacies and county health departments were the highest indicated responses. Pharmacy, 17.6 percent, county health

department, 16.5 percent, dental clinic, 12.9 percent, community-based organization, 10.6 percent, substance abuse/mental health treatment facility, 9.4 percent, massage clinic, 5.9 percent, AIDS service organization, 3.5 percent, optometry clinic, 3.5 percent, hospital-based clinic, 2.4 percent, health clinic, 2.4 percent, chiropractic clinic, 2.4 percent, hospital, 2.4 percent. When asked about the type of services provided, medical care (29.1 percent) and mental health counseling (19.8 percent) were the most indicated responses. Substance abuse treatment, 16.3 percent, dental care, 16.3 percent, pharmacy, 15.1 percent, non-mental health counseling 7.0 percent, complementary/alternative therapy, 5.8 percent, massage, 5.7 percent, optical care, 4.7 percent, transportation, 3.5 percent, referral services, 2.3 percent, food distribution/nutrition, 2.3 percent, pastoral care, 2.3 percent, child care, 2.3 percent, chiropractic, 2.3 percent, housing, 1.0 percent, food/fun, 1.2 percent, prison ministry, 1.2 percent are also provided. More than 70 percent of the provider respondents indicated they accept Ryan White reimbursement and 20 percent indicate they provide some kind of charity care.

Each county has its own health department that provides preventive and primary care. A few agencies host Ryan White funded ARNPs to provide primary care and patient education for HIV and AIDS patients. A limited number of private primary care providers also see HIV-positive patients.

The Alachua CHD functions as provider of Title II Ryan White case management services for this area. Florida's Medicaid AIDS waiver program's case management is provided by two county health departments and by AIDS Resource Alliance in Lake County. HOPWA is provided through Catholic Charities, Inc. In addition, there are only a few AIDS service organizations serving this area and several known community-based organizations supporting HIV/AIDS programs. Case management is provided to 79.5 percent of the total presumed living PLWH, 18.8 percent of housing case management, 49 percent of ambulatory HIV care and 47.2 percent of vendor services.

HRSA provides funding through the Ryan White CARE Act Title II. These funds support the Ryan White Title II Consortium, ADAP and AICP. The CARE Act requires states to match federal funding dollars to support HIV/AIDS patient care services. This general revenue allocation supplements ADAP, AICP and CHDs that provide HIV/AIDS patient care.

Over 40 percent of survey respondents indicate they have taken the 4-hour AIDS 104 training class and 27 percent indicate their staff has taken the 1-hour AIDS 101 training class. Ninety-seven percent indicate that they are accepting new HIV-positive patients. All respondents indicate they speak English, almost 30 percent have someone in the office that speaks Spanish, and no provider indicated they speak Haitian Creole. Most survey respondents 94 percent indicate they target adults, 92 percent indicate they target males, and 90 percent indicate they target females. Of the providers that responded to the survey, 76 percent indicate they are Ryan White service providers, 21 percent indicate they were not Ryan White service providers and 1 percent indicated they did not know if they were Ryan White service providers.

AREA 4

Agencies in area 4 described themselves as being one or more of the following: AIDS service organization, health clinic, community based organization, hospital, county health department, substance abuse agency, mental health agency, HIV primary care provider, HIV prevention organization or other. The majority of these were not-for-profit. Medicaid, Ryan White and self-pay/uninsured were the most often-cited payment sources. Clients in these agencies are estimated to be 56 percent African American, 42 percent white, 1 percent Asian/Pacific Islander, 1 percent Alaskan/American Indian, 1 percent other; 51 percent male, 49 percent female and 39 percent children. State, federal and local government respectively provided the most grants or special funding to these agencies.

Several HIV counseling and testing sites are co-located with a primary care clinic. In response to the epidemic infecting a larger proportion of African Americans in area 4, comprehensive HIV early intervention services are targeted towards African Americans through a partnership, known as the Jacksonville AIDS Comprehensive Services (JACS). Primary specialty medical care is offered by one agency and substance abuse treatment services can be accessed through two agencies in Area 4. Mental health counseling and treatment, as well as dental care can be accessed through several agencies.

AREA 5 - Not provided

AREA 7

Nineteen agencies participated in the provider survey. Three organizations that are strictly HIV/AIDS service agencies represent 15.8 percent of the responding resource system. Two agencies (10.5 percent) are multi-service, including HIV/AIDS, organizations. Five organizations (26.3 percent) are non-AIDS/HIV type agencies. Two agencies are substance abuse focused organizations that also service PLWHA. Five health organizations comprise a large part (31.3 percent) of this system. Two agencies did not specify their major function. Services most often provided by these agencies include medical care, substance abuse and access (e.g. child care, transportation).

Most agencies did not provide client capacity data. However, of those that provided that information, the range for medical care services is 100 to 1,650. Dental care service ranged from 325 to 650; complementary/alternative therapy services ranged from 0 to 100; case management service ranged from 774 to 1,692; access service ranged from 10 to 1061; housing service ranged from 20 to 560; benefits/financial service ranged from 250 to 929. Only one agency provides family services, which is respite care, with a client capacity of 20.

Six of the respondents indicate that their organizations target a particular racial or ethnic group; all six target African Americans. Two organizations target a specific gender; both target females. Six providers target a particular age group; five of these targets adults and one targets children under 12. Eight organizations attempt to provide service for a

‘special needs group.’ These groups include homeless and at-risk people, the poor, children over age 13 with special needs, substance abusers, and incarcerated people over age 50.

AREA 8

Input was limited in the provider capacity survey. As a result, provider feedback was incorporated into the QA/QI monitoring process.

AREA 9

Forty-one provider sites are identified in the report; the majority of these being other community-based service organizations. Half of these fourteen providers do not have diverse staff. The total number of clients served is over 8,000, with just under 3,500 being new clients. Males make up slightly more of the clientele than females, with blacks being the majority race. Additionally, the majority of clients are over the age of 20. Of the services listed, counseling was the only one not being received by any of the clients. The gross majority of providers receive Title I funding, followed by state/local, public (other than Medicaid) resources, then Title II funding, and lastly ADAP.

Of the 18 key informants responding to the survey, 83 percent indicated they provide case management; 55 percent provide treatment/education/outreach counseling; 33 percent provide counseling; 28 percent provide peer support; 28 percent provide housing; 22 percent provide prevention; 22 percent provide referrals; 22 percent provide medical services, 17 percent; provide financial assistance; 17 percent provide food pantry; 11 percent provide nursing; 11 percent provide ADAP; 6 percent provide legal services, home health aid or assistance filling out government forms.

AREA 10 - Not provided

AREA 11

Of the 26 participating providers, the majority of them see between 750 and 1500 clients annually. Sixty-five percent of them have provided HIV services for more than 10 years. The types of agencies represented include HIV/AIDS service organizations, health centers or clinics, multi-service agencies that includes HIV/AIDS, community based organizations (not HIV/AIDS), hospitals, a university medical center, substance abuse provider and DME provider.

Of nineteen substance abuse treatment providers, thirteen offer both residential and outpatient services, with the majority of clients receiving outpatient treatment. 520 clients were known to be HIV positive and over 1100 are estimated to be positive. Most of the providers served less than 499 clients per year and none had a waiting list for outpatient substance abuse treatment. Five of the thirteen providers of residential substance abuse treatment had waiting lists. 68 percent of providers offer HIV testing and counseling and 717 clients get HIV testing each month.

Medicaid provides more than half of the estimated AIDS funding in Miami-Dade County. This was followed by Ryan White Title I, ADAP, Medicare, General Revenue, Others and finally Veterans Administration.

AREA 11B - Not provided

AREA 12

Thirty-four providers that responded to the survey indicated that they were funded through various sources. All respondents were Ryan White Title II providers.

AREA 15

Of six providers responding to the survey, an estimated number of patients served ranged from 13 to 615. Five out of the six physicians reported having capacity to serve additional patients by as many as double the current number of patients served. Of the patients who have health insurance, the number or percent that have managed care plans was estimated to be less than 10 percent by five out of six survey respondents. When asked about the top three chronic conditions that were common among HIV/AIDS patients, the two most reported chronic conditions were diabetes and anemia. Respondents described the strength of their relationships with other HIV/AIDS providers in the System of Care. The weakest relationships were reported to be with mental health and substance abuse treatment providers. Four out of the six respondents reported these relationships to be weak or non-existent.

Identification and Assessment of Gaps in Services

AREA 1 - Not provided

AREA 2A - Not provided

AREA 2B - Not provided

AREA 3 - Not provided

AREA 4 - Not provided

AREA 5 - Not provided

AREA 7 - Not provided

AREA 8

In last year's needs assessment "unsuccessful health outcomes due to inadequate quality of care and discrimination" was identified as a service gap. To assess and solve this

deficiency, a Quality Assessment tool was developed.

Other identified service gaps include: lack of coordination between case management and clinical management meetings of the SWAN Consortium; inadequate communication flow system regarding roles and responsibilities of partners; lack of adequate needs assessment subcommittee members who reliably attend meetings to work on the needs assessment; more innovative minority outreach initiatives are needed; inadequate coordination of events or initiatives in area 8; limited ability of case management to adequately perform job because of client overload; lack of coordination to apply for additional grants as a region to address items not covered by Medicaid and Ryan White; inadequate continuing education of providers to keep them wanting to see Ryan White patients; inconsistent and inadequate continuity of care; in adequate advocacy or ombudsman to assist individual patients with their needs; and complacency in PLWA community.

AREA 9

Each service that a consumer identified as ‘needed, but could not get’ is considered a service gap. The top ten service gaps were help paying for groceries (35 percent), help paying for utilities (34 percent), help paying for rent (33 percent), help finding affordable housing (31 percent), help getting or maintaining insurance (30 percent), massage therapy (29 percent), finding a new job/learning job skills (25 percent), benefits information (24 percent), help paying for insurance (22 percent). Tied for tenth place were vitamins/health foods, alternative medicine, physical therapy and transportation (21 percent). Five of the top ten consumer priorities also ranked among the top ten gaps. The top ten services which consumers listed as both a priority and a gap were rent/mortgage payments, dental, utility payments, grocery payments, housing assistance, case management, vitamins and health foods, massage therapy, insurance continuation and transportation.

Responding providers were asked to check of the services which a substantial number of their clients needed but had difficulty accessing. Transportation (50 percent), translation/interpretation (44 percent), home health aid (39 percent), help paying for rent/mortgage (33 percent) were ranked one through four. Tied for fifth place were housing assistance/finding a place to live, vocational rehabilitation, and help paying for utility bills (28 percent). Finally, substance abuse outpatient counseling, residential substance abuse treatment, legal services, respite care/adult day health, direct emergency assistance and child care (22 percent) all ranked sixth.

AREA 10 - Not provided

AREA 11 - Not provided

AREA 11B - Not provided

AREA 12 - Not provided

AREA 15

The top five service gaps were help finding affordable housing (38 percent), support groups (38 percent), one to one peer support (21 percent), massage therapy (25 percent) and alternative therapies (21 percent). There are some services that consumers said they needed and could get but wouldn't use indicating barriers to use of this service such as dislike of available providers or mistrust of the service itself. The single most frequently cited service was dental care. 12.5 percent of respondents stated they could get but would not use this service. The second most frequently cited service was inpatient hospital care.

Findings

Ten of the thirteen service area reports included an epidemiologic profile. In the provided information, we find that one service area reported on HIV prevalence only and one service area reported HIV estimates. Two of the service areas used "HIV/AIDS" as their reporting definition while the remaining six service areas reported on both HIV and AIDS prevalence. As both HIV and AIDS are reportable in the state of Florida and both have major implications for health care services planning, both the area and the statewide needs assessment reports should reflect prevalence estimates for both conditions.

The second component of the needs assessment, an assessment of service needs, was provided by most of the service areas. This section includes identifying those barriers that prevent PLWH from receiving needed service areas. First, it must be clarified there exists a difference between 'needs' and 'unmet needs.' Needs are those service needs currently being addressed through existing services available to target populations. This may be more accurately described as 'met needs.' Unmet needs, on the other hand, refer to service needs of those not currently in care as well as those in care whose needs are only partially met or not being met. The distinction between met needs and unmet needs was not always apparent upon review of several reports. Without this distinction, determining statewide unmet needs is severely hindered.

The third component necessary is a resource inventory which provides a comprehensive depiction of the continuum of care. This resource inventory should include for each provider a description of the types of services provided, the number of clients served, and funding level and their sources. Most of the service area reports did not provide this type of information. In fact, one service area reported that they were unable to obtain funding information from many agencies as the participants viewed themselves as being in a competitive funding market; they felt threatened by divulging this data. The majority of service areas instead focused on finding out from their clients where they obtained services. This may be the only viable solution to assessing resources when providers are unwilling to provide the appropriate information.

A profile of provider capacity and capability, the fourth section, should describe the extent to which the services in the resource inventory are offered by providers, are

accessible to populations in need of services, and are appropriate for PLWH and specific subpopulations. This section relies heavily upon the information provided by the providers for the previous section in addition to data from sources that provide insight on access and appropriateness. As a result, performing this analysis is limited to what types and how much information providers are willing to give.

The final component of the comprehensive needs assessment is an assessment of service gaps and unmet need. This is based on all of the data about service needs, resources, and barriers already ascertained in the other portions of the needs assessment. As this was viewed as a fundamental segment of the needs assessment, consequently the overwhelming majority of service areas provided this information. However, HRSA recommends that the unmet needs and gap analysis provided here should include both PLWH in care as well as those not currently receiving CARE Act or other HIV services. The vast majority of service areas only collected data from those clients already in care.

Of the HRSA component guidelines, obtaining the provider information seems to present the greatest challenge. While having this information would be an immediate indicator of which services are lacking in a particular area, a well-planned client survey may be just as indicative of what services are not available.

Future needs assessments at the local level will need to address each of the five HRSA guidelines. Alternative solutions for obtaining hard to find data for those guidelines will also need to be adopted. There seems to be relative consistency in reporting needs and unmet needs for clients throughout the state. However to ensure uniformity, there needs to be a clear distinction between “met needs” and “unmet needs” by the service areas. It’s important to continue to obtain opinions from both providers and clients as far as needs, for a complete picture. Barriers to care seem to also be consistent throughout the state. One recommendation in this area is to also distinguish between providers’ and clients’ perceptions of barriers, which was not always previously done.

Recommendations

Local HIV needs assessment reports have limitations as a formulation for a statewide needs assessment such as incompleteness of reporting, methodological variability and inconsistent quality. Nevertheless, several benefits have been identified. First, despite the different methodologies, many service area reports had findings that were similar to the findings of other service areas. Second, the reports identified specific prevention services needed and requested by both target and emerging populations. Lastly, the reports documented many barriers to service and care in the state.

Recommendations for consistent data collecting and reporting data are substantial. These recommendations are a result of the comparison and synthesis of the area reports and an assessment of the area reports in light of the HRSA guidelines. Recommendations for the epidemiological profile include reporting of both HIV and AIDS prevalence, providing a demographic breakdown of both the HIV and AIDS cases to include gender, race, and mode of exposure, and other risk indicators (e.g. STDs), if available, should also be reported. Client surveys and focus groups appear to be the most common methods for ascertaining clients' points of view. Focus groups by subpopulation are useful for finding out more in depth information. Some identified populations of special interest such as the elderly, the homeless or migrant workers, did not receive the attention that area identification seemed to require. As indicated by HRSA, providers are probably best reached through surveys and interviews. Follow up phone calls to providers who fail to respond or complete the funding portions of surveys is also advisable. Additionally, service areas will have to be diligent in ascertaining provider funding sources, capacity and capabilities. Additional recommendations include areas providing reports in electronic format, preferably in rich text format (.rtf), which facilitates handling. There also needs to be clarification of common terms (e.g. met needs, unmet needs).

Recommendations related to findings include the need for state and local areas to address the discrepancy between client and provider perceived needs for substance abuse treatment programs and mental health services. Also providers are criticized by for their lack of language and culturally sensitive services and materials. Additional resources or policies to support enhanced linguistically and culturally appropriate services are indicated. An assessment of clients' access to and use of education and information received for HIV/AIDS in each area also appear to be needed since both providers and clients alike consistently cite lack of information as a barrier to care.

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