

SUMMARY OF FINAL REPORT

Statewide Needs Assessment Study Of Care and Support Services Access for Floridians Living with HIV Disease & AIDS

Submitted by:

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Introduction

The purpose of the Statewide Needs Assessment was to conduct a comprehensive statewide study and analysis of the needs of the infected and affected HIV/AIDS population for the Florida Department of Health, Bureau of HIV/AIDS, using a) existing data and information, and b) supplementary studies in selected areas to provide a representative assessment of communities throughout Florida. The Statewide HIV/AIDS Health Care Needs Assessment was designed to provide the Florida Department of Health, HIV/AIDS service providers and other HIV/AIDS planning entities with information to:

1. establish resource allocation priorities and to implement positive changes in service delivery,
2. correct service delivery gaps in various client need categories throughout the state of Florida,
3. formulate culturally competent service responses in the form of new or revised programs or initiatives,
4. identify unmet needs, those service needs of individuals not currently in care as well as those who are in care but whose needs are only partially met or not being met, and
5. determine major barriers to accessing services.

A challenge in developing the overall needs assessment was to build on existing data or information. The challenge was to assimilate, synthesize and present the large volumes of data and information in a form that could effectively be used for planning purposes. For example, DOH has comprehensive HIV/AIDS surveillance data. Each of the regions receiving federal grants (Ryan White Titles I & II) have conducted extensive needs assessments for their respective regions, covering all of Florida's geographic boundaries. A small number of areas, predominantly urban areas in either southeastern or northeastern Florida have conducted federally sponsored ethnographic studies of communities with large high-risk populations. Other studies had also been conducted throughout Florida, primarily in response to local community interests and available resources.

The Statewide Needs Assessment is comprised of four major components:

- 1) An analysis and report on existing sources of surveillance data, providing an HIV/AIDS epidemiological profile of the state of Florida
- 2) A Meta Evaluation of the Regional needs assessments conducted by the HIV Planning Councils and the HIV Planning Consortia covering the Title I and Title II regions of Florida
- 3) A Meta Evaluation of the federally funded RARE studies completed in Southeastern and northeastern urban areas of Florida.
- 4) Qualitative studies using extensive ethnographic methods of three selected populations in different regions to provide more representative geographic and demographic characteristics of the state.

This report attempts to summarize the results of the major components of the Statewide Needs Assessment and present overall findings and conclusions to help guide the HIV/AIDS planning process. The report is organized into 7 major sections, this introduction, brief summaries of each of the major components of the Statewide Needs Assessment (Patient Care Epidemiologic Profile, Area Needs Assessments, Recommended Protocol, Qualitative Studies of Selected Populations, Secondary Analysis of Selected Studies and Reports, and a section on Conclusions. The large volumes which make up the specific components of the Statewide Needs Assessment are published as separate documents. The Statewide Needs Assessment Final Report is simply a summary and synthesis of the large amounts of both quantitative and qualitative information contained in the various components. Readers interested in greater details are invited to review the Reports of the Specific Components identified in this Report.

Patient Care Epidemiologic Profile Analysis of Quantitative Data Bases & Reports

The purpose of this Patient Care Epidemiologic Profile was to analyze the currently available and accessible data for patient care within the context of the HIV/AIDS surveillance data. Section A of the report provides an overview of the most recent and pertinent HIV/AIDS surveillance information as a foundation for analysis of the patient care data. (The Bureau of HIV/AIDS Surveillance Section recently completed an exceptionally thorough and comprehensive epidemiologic assessment, providing a strong foundation for this report. That surveillance report is available from the Bureau of HIV/AIDS and it is not the purpose of this report to reflect the details of that epidemiologic assessment). Section B contains a comprehensive overview of the available and accessible data for multiple patient care support systems.

This Epidemiological Profile is a major component of a statewide needs assessment of care and support services accessed by Floridians living with HIV disease & AIDS. The Epidemiologic Profile for the Patient Care Needs Assessment primarily concentrated on the quantitative data that are available and accessible in the various statewide data systems. Other major components that are complementary to this Epidemiological Profile include a synthesis and summary of the local area needs assessments and a report on ethnographic (primarily qualitative) studies of selected communities in Florida.

Prevalence and Incidence of HIV/AIDS in Florida

Prevalence data is based on a comprehensive overview of the HIV/AIDS epidemic in Florida over the past twenty years which is chronicled in the *Epidemiologic Profile for HIV Prevention Community Planning* by the Surveillance Section of the Bureau of HIV/AIDS. HIV/AIDS are a major public health threat in the state of Florida. In 2000, Florida ranked second among states in the number of reported AIDS cases and ranked first in the number of HIV cases. Miami ranked sixth among all cities in the number of reported AIDS cases in 2000 and had the highest case rate in the nation (58.0 per 100,000).

The impact of HIV/AIDS was analyzed in detail and included the following analyses: mode of exposure groups, racial/ethnic groups, pediatrics (0-12), young adults (13-25), men and women, seniors, geography, partnerships, rural and non-rural counties, prevalence, mortality, SHAS (Supplemental to HIV/AIDS Surveillance), BRFSS (Behavioral Risk Factor Surveillance System), and HIV/AIDS among the incarcerated, military applicants, health care workers, and the homeless. The report also includes information on co-infection of HIV and TB and ancillary data. The Patient Care Epidemiologic Report contains on selected data from the more comprehensive *Epidemiologic Profile for HIV Prevention Community Planning*, which should be consulted for greater detail.

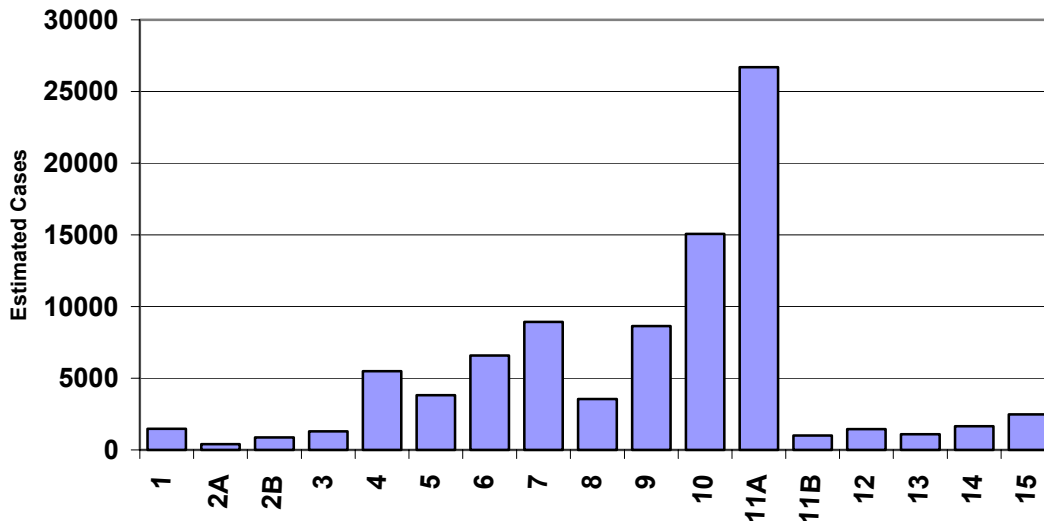
Much of the incidence and prevalence reporting is based on the HIV and AIDS Reporting System (HARS). The Florida Department of Health records HIV and AIDS cases into HARS. All cases are reported to the Centers for Disease Control (CDC) using a uniform

case definition that all states use. Effective January 1, 2000, the surveillance case definition for HIV infection was revised to reflect advances in laboratory HIV virologic tests. The definition incorporates the reporting criteria for HIV infection and AIDS into a single case definition for adults and children (MMWR 1999;48[no.RR-13]:29-31). Diagnosis and demographic information for HIV and AIDS cases are collected in the HARS system. The completeness of the AIDS case information is estimated to be 85%, but the completeness of HIV case reporting has not yet been established.

The first AIDS case was reported in Florida in 1981. AIDS reporting became mandatory in 1984, and HIV reporting became mandatory much later (July, 1997). The CDC expanded the AIDS surveillance case definition for adults and adolescents in 1993, which subsequently caused a dramatic increase in cases for that year. HIV cases represent those persons who tested positive for HIV in a confidential setting (anonymous HIV tests are not reportable) since July 1997 and do not yet meet the case definition for AIDS. HIV and AIDS cases are mutually exclusive in the HARS system. Once an HIV case does meet the case definition for AIDS, it is considered an AIDS case. In addition to the conversion of HIV to AIDS, the database is also updated for new information related to risks or causes of the HIV/AIDS infection. This information is updated and applied to data collected in previous years, creating a dynamic database for previous years, in addition to the current year of data collection. It is the changing nature of the database with interactive updates for previous years which leads to the term “Living Database.”

HIV/AIDS is very unevenly distributed throughout Florida. Partnership areas located within Florida have very different rates of HIV and AID prevalence as illustrated in Figure 1.

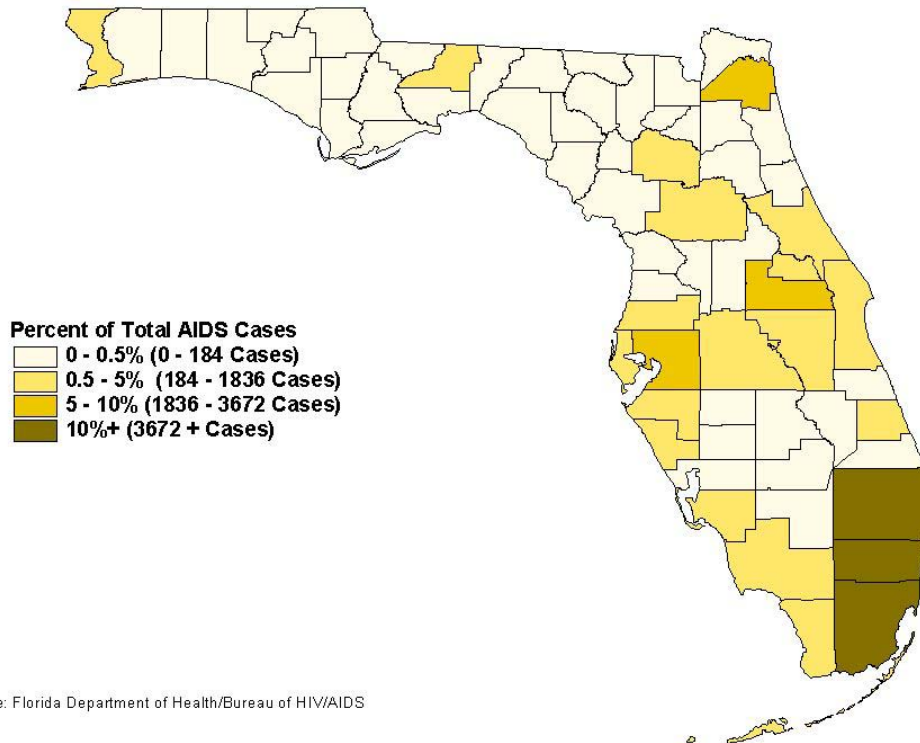
Figure 1. HIV/AIDS Prevalence Estimates by Partnership Area, Florida, 2002



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

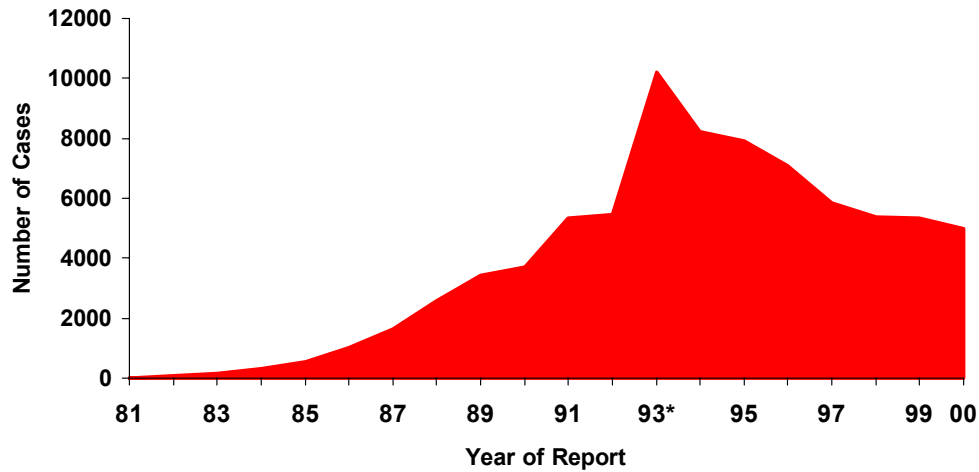
The variance in distribution can be illustrated with a map of Persons Living with AIDS (PLWA) in Florida (Figure 2). Clearly, the more urban areas of Florida, those more heavily populated counties designated as metropolitan statistical areas, tend to have the higher number of PLWAs

Figure 2
Persons Living with AIDS, Florida, through 2001



The trend for reported new AIDS cases has steadily decreased since 1993 overall. The changing rate of new AIDS cases is reflected in Figure 3. However, adult non-Hispanic Black male cases have been steadily increasing, as have non-Hispanic Black female cases. Black women with heterosexually acquired HIV are the fastest growing group with AIDS.

Figure3. Adult AIDS Cases By Year Of Report, Florida, 1981-2000

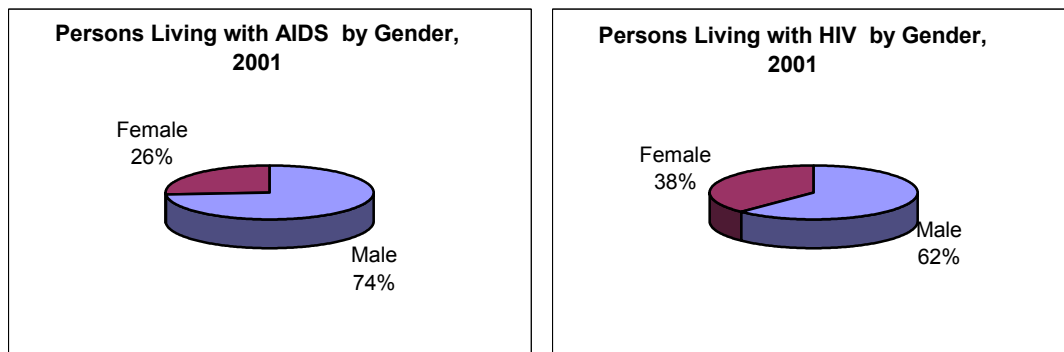


*The AIDS surveillance case definition was expanded for adults/adolescents in 1993.

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

The general population broken down by gender is approximately equal between males and females (slightly higher female population). However, almost seventy percent of the estimated number of persons living with HIV/AIDS are male. Approximately, three-fourths of the AIDS cases are male and 62% of the HIV cases are male (See figure 4). Although women are a smaller proportion they have become substantially impacted by the HIV/AIDS epidemic which was thought to be primarily a male disease. This high proportion of women has important implications for patient care delivery, particularly as it relates to the heavier burden of child care that women tend to experience.

Figure 4. Persons Living with AIDS and HIV by Gender, Florida, through 2001



Whether analyzing prevalence estimates, rates, actual numbers of persons living with HIV/AIDS, or differentiating by disease status, Blacks are disproportionately affected by the HIV/AIDS epidemic in Florida. The general population of Florida (2000 Census) is 65% non-Hispanic White, 14% non-Hispanic Black, 17% Hispanic, and 4% other races. The racial percentages of persons infected with HIV differ greatly from this general population profile, except for Hispanics (16% of the prevalence estimates; 17% of general population). Over 50% of the estimated prevalent cases are Black and 32% of the estimated cases are White. Reported AIDS cases are steadily increasing for both Black males and females. Black women with heterosexually acquired HIV are the fastest growing group with AIDS. The HIV/AIDS epidemic is clearly affecting the Black population at a much higher magnitude than any other race.

Figure 5. Demographic Summary Table, HIV/AIDS Prevalence, Florida

	General Population	HIV Prevalence Estimates (% of total)	Persons living with AIDS (% of total)	Persons living with HIV (% of total)
Race: <i>White</i>	65%	32%	35%	27%
<i>Black</i>	14%	52%	48%	57%
Other	3%	1%	0%	1%
<i>Hispanic</i>	17%	16%	17%	15%
Gender: <i>Male</i>	49%	69%	74%	62%
<i>Female</i>	51%	31%	26%	38%

*Totals may not equal 100% due to rounding.

Source: Florida Department of Health, Bureau of HIV/AIDS, US Census

Years: General Population (2000), Prevalence Estimates (2002), PLWHA (through 2001)

Florida HIV/AIDS Patient Care Systems

An extensive system, HIV/AIDS patient care operates in the state of Florida across many funding streams. The AIDS Drug Assistance Program, AIDS Insurance Continuation Program, Ryan White Title I, Title II, Title III, Title IV, general revenue resources, and Medicaid claims are major components of this HIV/AIDS Patient Care system. These are actually multiple publicly funded systems serving individuals accessing public support. These systems do not reflect how all of the people with HIV/AIDS in the state of Florida are accessing services, since services are also provided through public systems. However, because AIDS becomes such an extensive burden, far out stripping the private resources available to individuals, the public resources become of paramount importance in caring for Persons Living with HIV and AIDS. Each of these public programs has differing eligibility requirements, limiting the ability to fully assess the gaps in services. Because the surveillance data do not reflect poverty levels and programs have different

financial eligibility requirements, data are separate for each program and were not able to be integrated for this report.

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act

Title I provides emergency assistance to Eligible Metropolitan Areas (EMAs). EMAs have populations over 500,000 and have reported at least 2,000 AIDS cases over the last five years. Title I funds are used to provide a continuum of care for persons living with HIV. Title I services include: outpatient/ambulatory care, early intervention such as testing and counseling, support services such as hospice, housing and transportation and inpatient and outpatient case management. During Service Year 2000-2001, the six EMAs awarded Title I funds were Ft. Lauderdale, Jacksonville, Miami, Orlando, Tampa/St. Petersburg and West Palm Beach.

Title II provides grants at the state level. States may then provide patient care directly or subcontract with Title II HIV Care Consortia (as is in the case of Florida). Title II funds may be used for ambulatory care, home health care, insurance coverage, medications, support services, outreach and early intervention. In the service year 2000-2001 Florida funded fourteen consortia.

Title III provides funds for outpatient care of newly diagnosed HIV individuals to health care centers, private not-for-profit primary care centers particularly those providing care to underserved populations such as migrant workers and the homeless. Services can include risk reduction, testing, medical and dental care, nutrition and psychosocial services.

Title IV provides funding for programs serving the particular needs of children and women and their families. Services include primary and specialty medical care, psychosocial services, logistical support, outreach, and case management.

Special Projects of National Significance (SPNS) – provides funding to evaluate current healthcare models, develop innovative new models of care, and implement and duplicate effective health care models.

State Funding

General Revenue funds are used in Florida to supplement federal funding and provide care via county health departments (with at least 50 recorded cases of AIDS) and patient care networks. A comprehensive range of services are provided by both county health departments and patient care networks, including: medical and dental, drug reimbursement, home health care, nutritional services, rehabilitation, hospice, case management and other support services. Patient care networks may also provide inpatient care, emergency care, nursing home care and residential services. In addition, the Florida Legislature appropriates special contracts to geographic areas in need of specific services.

Combined State and Federal Funding

Medicaid

The Agency for Health Care Administration (AHCA) administers the Florida Medicaid program. Medicaid is a jointly funded, federal and state program designed to provide health care for Floridians with income and assets below specified poverty levels. The Florida Medicaid Program has special programs for persons living with HIV and AIDS.

AIDS Drug Assistance Program (ADAP)

The AIDS Drug Assistance Program is administered through the Florida Department of Health, Bureau of HIV/AIDS, Patient Care Resources Section. It is funded by Ryan White II funds and supplemented with general revenue funds appropriated by the legislature. This program provides assistance to HIV positive individuals with the purchase of HIV prescribed medication.

AIDS Insurance Continuation Program (AICP)

The AIDS Insurance Continuation Program is funded through Title II of the Ryan White CARE Act and general revenue funds allocated by the Florida legislature. AICP is administered by the Health Council of South Florida. This program pays insurance premiums for HIV-positive individuals who are unable to maintain their private health coverage.

Children's Medical Services

Funds appropriated by the Florida Legislature to Children's Medical Services are used for medical, social and health support services for HIV-exposed infants, children, and adolescents, from birth to age 21.

Persons served by Patient Care Systems

The HIV/AIDS epidemic in Florida disproportionately affects males and the Black population as compared to the general population of Florida. Blacks make up over half of the estimated HIV/AIDS cases, but only 14% of the general population. The patient care systems operating in Florida designed to provide services to the HIV infected population have differing client demographics as illustrated in the table below. Approximately half of all Medicaid, General Revenue and Ryan White Title II clients are non-Hispanic Black, which is consistent with the racial breakdowns of the prevalence estimates. Over forty percent of ADAP clients are Black. Hispanic clients make up a larger proportion of the total ADAP clients as compared to other programs (26% of ADAP total). Approximately, seven to eight percent of Medicaid and Ryan White Title II programs are of Hispanic ethnicity. The majority of AICP clients are White and male.

Medicaid served more HIV/AIDS clients than any other patient care system in Florida. Nearly 20,000 unduplicated clients accessed Medicaid services in FY 00-01. Ryan White Title II served nearly 12,000 clients and ADAP and General Revenue dollars assisted over 8,000 clients each. AICP paid insurance coverage for nearly 1,500 clients.

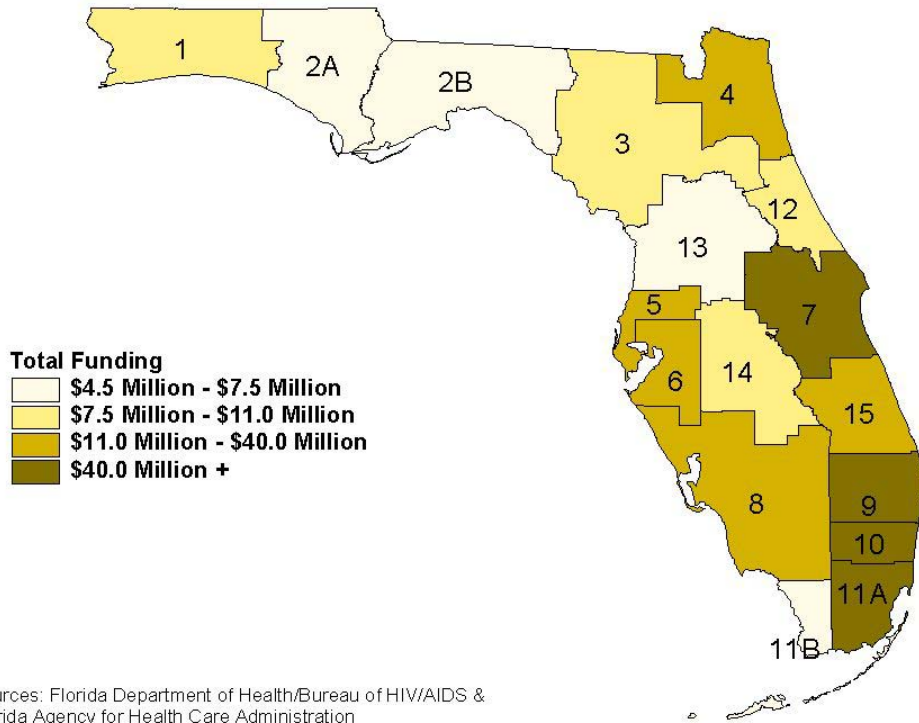
Figure 6. Summary Demographics (Surveillance Data and Funding Streams)

	General Population	Medicaid Clients	Gen. Rev. Clients	ADAP Clients	AICP Clients	RWT2 Clients	HIV Prevalence Estimates	PLWA	PLWH
	N=15,982,378	N=19,991	N=8,694	N=8,307	N=1,498	N=11,688	N=95,000	N=38,419	N=22,609
Race - Ethnicity									
White (Non-Hispanic)	65%	30%	34%	28%	67%	39%	32%	35%	27%
Black (Non-Hispanic)	14%	49%	52%	44%	16%	51%	51%	48%	58%
Hispanic	17%	7%	12%	26%	16%	8%	16%	17%	15%
Other	4%	15%	1%	2%	1%	1%	1%	0%	0%
Gender									
Female	51%	43%	34%	28%	15%	37%	30%	26%	38%
Male	49%	57%	66%	72%	85%	63%	69%	74%	62%

Sources: US Census 2000, Agency for Health Care Administration, Florida Department of Health, Bureau of HIV/AIDS, Health Council of South Florida

Figure 7

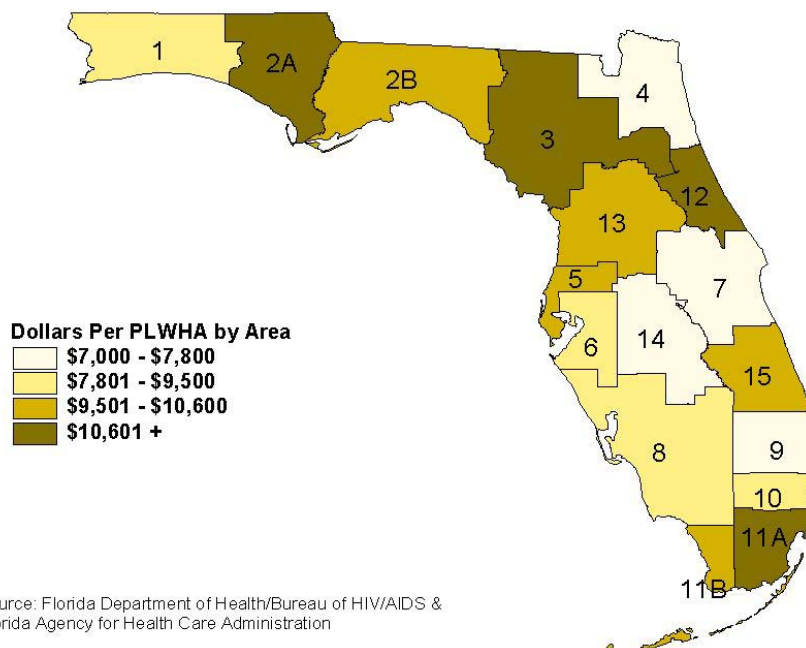
Total HIV/AIDS Funding by Area, Florida, FY 00-01



Areas 11A, 10, 9, and 7 all receive more than \$40 million in funding. The areas with the smallest amount of funding are 2A, 2B, 11B, and 13 with \$4.5 million - \$7.5 million each. When analyzed by dollars per persons living with HIV/AIDS, however, Areas 2A, 3, 12, and 11A receive the most funding with over \$10,600 per person living with HIV/AIDS each. Areas 4, 7, 9, and 14 have the least amount of total dollars per person living with HIV/AIDS, with only \$7,000-\$7,800 per person.

Figure 8

Total Funding Per Person Living With HIV/AIDS, Florida, FY 00-01



Conclusions

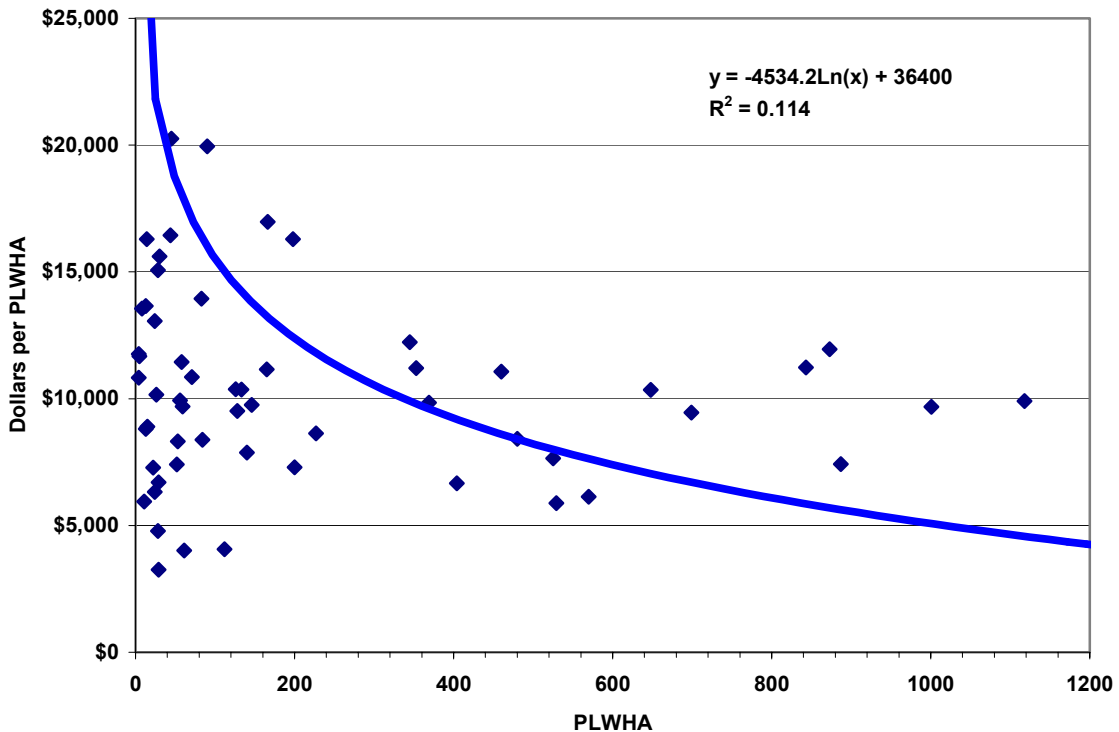
1. Types of Services and Funding:

HIV/AIDS patient care services vary in their dependence on sources of funding. For example, HIV/AIDS related substance abuse services tend to be much more dependent on general revenue as a source of funding. Clearly, federal support for substance abuse services tends to have very different funding streams than funding for services more specifically linked to HIV/AIDS. These categorical funding streams undoubtedly contribute to fragmentation of services and make analysis of funding for services difficult. Substance abuse services that were not directly linked to HIV/AIDS (not included in one of the major HIV/AIDS funding streams) were not included in this report.

2. Variation in funding by population density:

Rural areas tend to have a higher proportionate funding per PLWHA than Urban areas, but this does not consider economy of scale. Regression analysis of the cost and size of the population of PLWHAs provides a mechanism for analyzing the cost of services within the context of the higher cost associated with smaller populations. This analysis (Figure 8) shows that most rural areas fall below the curve created by the regression coefficient based on the data. The logarithmic regression trendline shown ($R^2=0.114$) does not, however, reveal a clear relationship between county prevalence distribution and dollars per PLWHA. This line was the best fit available for the data and is intended to be a reference or approximation of a norm in order to consider economies of scale. When using this logarithmic trendline as a point of reference, most rural areas appear relatively under funded. On the other hand, the data does not take into account the higher cost of living that may drive costs up for the urban areas. Techniques for factoring cost of living would show that many more urban areas are comparatively under funded.

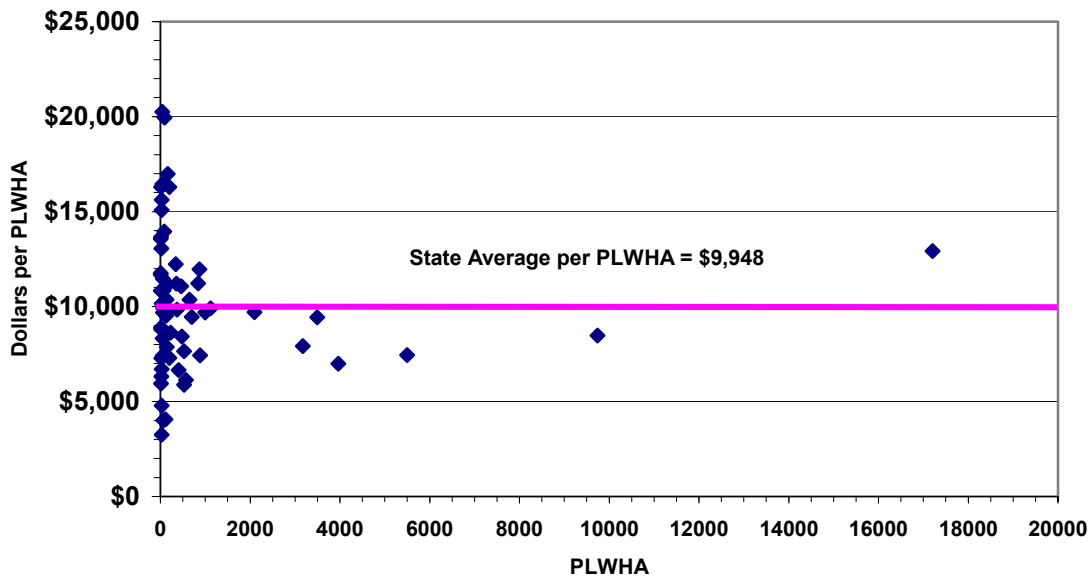
Figure 9: Average Dollars per PLWHA by County and Prevalence Distribution, Florida, FY 00-01



Some of the variations are not explained by the data. In particular, the data do not show why some areas are funded in much greater proportion to the prevalence of HIV/AIDS, but there may be very plausible explanations. Funding for some areas may be higher because of a greater proportion of high risk factors in the community. Clearly, a few atypical situations may be responsible for creating needs far outside of the norm, and thereby creating high costs for services in some of the smaller communities. Public

funding (the primary focus of this report) for some areas may be lower because of substantially higher amounts of private funding, for which data were unavailable for inclusion in the analyses for this report.

Figure 10. State Average per Person Living with HIV/AIDS, Florida, FY 00-01



3. Other Geographic disparities in funding:

Analysis of the data for the different types of HIV/AIDS care services funding shows an imbalance of specific types of funding for the different areas. In addition to population density, these variations are at least partially explained by the demographic make up of the areas. For example, some areas have higher rates of private insurance than others. In particular, an examination of data from the *Florida Health Insurance Study* indicates that Miami-Dade has one of the highest rates for uninsured (24.6 percent) in the state, compared to the state average of 16.8 percent. This high rate of uninsured, with particularly high rates of uninsured among some racial/ethnic groups, at least partially explains the high rate of ADAP funding in some areas compared to others.

4. Racial/Ethnic funding variations:

Variations in funding are at least partially linked to combinations of factors such as the prevalence of the disease and other factors such as race/ethnicity and insurance coverage. It should not be surprising that Whites, who have relatively high rates of insurance, are more likely to use AICP. Data from the *Florida Health Insurance Study* indicate that Broward, Miami Dade, and Palm Beach have much lower rates of uninsured Whites than most counties in the state. Those three counties ranged from 9 percent to 11.4 percent uninsured Whites in comparison to the State mean of 13.2 percent and the state range of 9 percent to 22.8 percent uninsured Whites. The high rate of AICP is at least partially

explained by the relatively high rate of Whites with insurance, since the program specifically targets people who are insured.

While Miami-Dade has high rates of insured Whites (creating greater potential for AICP funding), it also has some of the highest rates in the state for uninsured Hispanics and African Americans (creating greater potential for ADAP funding). Over half of the total uninsured Hispanic under age 65 population and approximately one-third of the uninsured African American under age 65 population in the state are in Miami-Dade. This data showing high rates of insured Whites and high rates of uninsured Hispanics and African Americans explains how Miami-Dade would have high utilization rates for both programs for the insured as well as programs for the uninsured.

5. Evaluation:

Major programs that provide funding for HIV/AIDS care services have limited evaluations. An evaluation of these programs could include an assessment of all major stakeholder expectations for the programs followed by an assessment of the program's success in meeting those expectations. Stakeholders might include PLWHA, case managers, care providers, and DOH staff. AICP has surveyed some stakeholders, in particular, the clients of that program. All programs may benefit from systematic data collection with case managers who have critical insights about program implementation. Data from this type of evaluation is critical for more substantive analysis of the relationship of the HIV/AIDS epidemic to the funding and delivery of health care services. A third-party evaluation could also help to increase the credibility of any evaluation results.

Area Needs Assessment

Ryan White Title I and II service areas conducted local needs assessments during the 2001-2002 years. The reports provided 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 assessments and the results for 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 some 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 can be categorized as: 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 assessments for benchmarking, making area comparisons, and compiling a statewide assessment. Recommendations for the epidemiological profile include reporting of both HIV and AIDS prevalence, and 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.

The various forms of primary data collection used for the area needs assessments have strengths and weaknesses. 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. However, poor response rates, which tended to be common, seriously undermine the generalizability of survey results.

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 and information that may not be readily accessible through direct questioning. Some populations of special interest identified in the demographic sections, such as the elderly, the homeless, or migrant workers, did not receive the attention in the form of any additional data collection or identification of their specific needs that seemed to be indicated by their specific recognition in the demographic sections.

Providers are probably best reached through surveys and interviews. Follow up phone calls to providers who fail to respond or complete portions of surveys may be 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 appears to be important to consistently assess the extent that needs are met and where services might need to be expanded.

Recommended Protocols

A standardized needs assessment process and report process for areas in Florida would facilitate benchmarking, comparisons, and compilation of a statewide report. The analysis of area needs assessment reports including the extent that they complied with HRSA Guidelines for Needs Assessments provided a substantial foundation for recommending a statewide needs assessment protocol for future reports.

HRSA Guidelines

According to HRSA, 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. The epidemiological profile describes the current status of the epidemic in the service area. AIDS prevalence data and HIV prevalence data are used to document the status and impact of HIV/AIDS among defined subpopulations and trends in the epidemic. The second section, the assessment of service needs, includes identifying those barriers that prevent PLWH from receiving needed services. The third recommended component is a resource inventory which provides a comprehensive depiction of the continuum of care. This resource inventory should include a description of the types of services provided for each provider, the number of clients served, and funding levels and their sources. 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 in the previous section in addition to data from sources that provide insight on access and appropriateness. 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.

Local Area Needs Assessments

Upon review of the needs assessment provided by the local service areas, it was apparent that the content of any one report was determined by that individual area. For instance, some areas had the resources to provide extensive follow-up as part of their data collection methods, while others were forced to rely on scanty response rates. High non-response and poor response rates limited the validity of findings in all areas. Additionally, use of terms seemed to vary from area to area. Clarification of a few common terms (e.g. met needs, unmet needs) would facilitate greater uniformity of the local area needs assessments.

Recommendations for the Area Needs Assessment Reports closely followed HRSA Guidelines. Specific Recommendations included :

- Organization of Reports
 - Epidemiologic Profile
 - Resource Inventory & Profile of Provider Capacity and Capability
 - Estimating Unmet Need
- Data Collection Process
 - Consumer Survey
 - Provider Survey
 - Outreach Survey
 - Focus Group Interviews
- Examples of data collection instruments and data reporting
 - Tables for reporting demographic and epidemiologic data
 - Consumer Survey
 - Provider Survey
 - Focus Group Facilitator Guide
 - Resource Inventory
 - Definitions

Qualitative Studies of Selected Populations

Introduction

These studies involved two distinct in time, yet coordinated phases of the qualitative data collection and analysis. These two phases are: 1.) the focus group study of the FCPG care and prevention stakeholders and key informants (November 2001), and 2.) The formative development, implementation and analysis of each of the three ethnographic interview studies of the selected populations (Summer/Fall 2002). Together, these two coordinated data collection and analysis efforts provide the in-depth understanding of context and complexity for which qualitative studies are primarily designed.

The focus group studies of the prevention and care groups of the FCPG and the qualitative studies of three selected populations serve two main functions. First, these projects yield in-depth insight into and understanding of the patterns of the use of health care services by specific communities identified as being potentially underserved. These groups were identified as outside the cultural mainstream of society or outside the stereotypical culture of people who are at high risk for HIV/AIDS. Second, the studies were designed to provide some geographic and demographic balance to earlier federally funded Rapid Assessment, Response, and Evaluation Project (RARE) studies that were conducted in the larger urban areas on the Eastern side of the state.

The studies of selected populations were conducted within the Northwest, Central and Southwest regions to provide regional balance to recent qualitative information provided through the RARE method funded by the Office of Public Health and Science, and the Office of HIV/AIDS Policy. These RARE projects were conducted in the Jacksonville, the Northeast area of the state, in Palm Beach County, and in Miami Dade, the Southeast area of the state.

Focus Group Study

The specific populations to be used for the three ethnographic interview studies were selected through this focus group study of the FCPG stakeholders. In keeping with the assumptions that must be met to conduct focus group research, these individuals are people particularly knowledgeable about the situation and able to articulate their knowledge. These are people whose insights can be particularly useful in helping observers understand what is happening and why (Patton 2002: 321). In this case, this large group of HIV/AIDS providers, consumers and activists who meet quarterly to engage in statewide HIV/AIDS planning, served as the stakeholders or gatekeepers for the selected populations.

The FCPG is made up of two sets of participants, the prevention focused group and the care focused group. To conduct the focus groups the larger group was split into the care and prevention subgroups. Then three focus groups were conducted with each of these subgroups.

The findings of the focus groups were developed in two stages. The initial analysis of the focus groups, conducted by the researchers who conducted the focus groups, was used to select the populations to be the focus of ethnographic interview studies. Young adults, the formerly incarcerated and migrant laborers were the three groups that were identified. This initial analysis process also provided a framework for the types of questions to be asked. The second stage of the analysis provided more in-depth investigation of the richness of information obtained through the focus group interviews. This analysis process complemented the ethnographies and provided a thematic foundation for the analysis of the population specific interviews. The following themes emerged from this analysis: Groups of people who are overlooked for care, barriers to treatment or care, concerns about testing, prevention issues, areas where additional training is needed, and, integration of substance abuse and mental health care.

Studies of Selected Populations

In each region, northeast for the Young Adults 18-25, central for the Formerly Incarcerated, and the southwest for the (Spanish speaking) Migrant Laborers, it was necessary to engage in separate rounds of reconnaissance work in order to determine the most likely sites for encountering and gaining access to the populations. After identifying possible key locations for contacting the subject populations, it was then necessary to identify the on site gatekeepers of those locations. These gatekeepers were able to provide/facilitate access to the study populations.

Using *snowball sampling*, multiple gatekeepers were probed for insight into what problems might be encountered while trying to interview people from the selected groups. In addition, they were asked if they knew other locations and methods for contacting the key informants of the selected populations. Using the snowball approach the original circle of contacts became bigger and bigger and eventually overlapped. Soon a number of people or sites had been mentioned repeatedly, this allowed for the convergence of search efforts for appropriate sites. A log was kept for each segment of the study, detailing interaction with gatekeepers. This process supported the dependability audit built into the studies to ensure trustworthy results.

Data collection processes initially involved getting informed consent from each volunteer interviewee. Face to face interviews were conducted by another interviewer, sometimes with support of interpreters. Interviews were recorded and transcribed. Data analysis was a multistage process which emphasized dependability, triangulation and trustworthiness.

Findings and Conclusions

1. Stigma and the Fear of Stigma

One of the strongest themes that surfaced throughout the meta-analysis of these interview studies was the stigma the participants of these studies perceive is associated

with HIV/AIDS and the fear that the stigma could impact them individually or impact their professional efforts. This theme includes many dimensions. Some examples are the following: the general fear of stigma, the fear of being disowned, the fear of letting people down, the fear of being injured because someone finds out, the fear of rejection for your sexuality, and the embarrassment that would go with any or all of these if someone knew you had HIV/AIDS. The fear of stigma motivates people differently and for different reasons, and results in different outcomes. But, it is clearly a very critical motivator of people's behaviors (or lack thereof).

2. Desire for Confidentiality

Another important concern across all populations was the issue of confidentiality. Closely associated with the potential for stigma and discrimination, the desire for confidentiality was a recurring theme. People who might get tested, might engage in prevention activities, get health or medical care, get HIV/AIDS treatment or attempt to prevent the spread of the disease will not do so if they can not trust the confidentiality of the situation. They will also not go to treatment if they perceive that going to a specific location or attending a special clinic or seeing a specific case manager will remove their perceived sense of confidentiality. The ability to trust in confidentiality and perceived threats to confidentiality are powerful influences that need to be better understood.

3. The Concept of Prevention

Examination of the focus group data indicates that prevention is an organizing construct that does not have shared meaning within the broader public health and medical care communities. The focus group participants highlighted this in their many quotes and passages that reflected the perceived need for prevention, secondary prevention and training. A problem noted is that there is a persistent belief that prevention is 'the sharing of information' and that, if provided, information will, by itself, change behavior. This belief system is seen as a barrier to effective implementation of prevention.

These interviews and focus groups produced a plethora of suggestions for prevention and intervention methods. The focus groups documented multiple barriers to the perceived need for community empowerment-focused prevention. Strategies need to be developed to capitalize on and enhance the capacity of these groups through empowerment-focused prevention. Though experts have asked their opinion before, without a clearer understanding of what community prevention is and what it can do, community participants cannot contribute at their best level. Training for community participatory processes, both for the professionals and community members, is greatly needed.

4. The importance of understanding culture and context

Recent literature has reported that when needs are assessed for the populations impacted by the HIV/AIDS epidemic these needs should be characterized as "evolving" needs. The ever changing context of their lives was clearly demonstrated in the analysis of the interviews of these populations and the focus groups. Perhaps the strongest and most important theme that emerged from the data analysis across all three selected population groups and the focus groups is how very different these groups and their needs

are - both within the individual population groups and between the selected population groups.

Though there was a great deal of similarity in the responses of women in the migrant worker populations, the many differences between the groups seemed overwhelming. Their styles of communication, the knowledge bases from which they worked, their perceptions of health and medical care, their ways of looking at the world and their expectations were all strikingly different. For this reason one of the most important things that can be learned from this theme is that there will be contrasts both within and between populations of concern and that continually understanding cultures and contexts is necessary to effect change.

5. Interwoven sets of complex issues and needs: Co-morbidities, disengagement, disempowerment, denial, fear, and, frequently, poverty.

Each of the three selected populations displayed a differing array of complex realities. They did not share the same constellation of substance abuse problems (though most groups had substance abuse issues). They did not share the same types of fear of being diagnosed with HIV (though all groups described different reasons for fear). All three selected groups did display an assortment of interwoven, complicated problems. Some of these problems were behavioral, some were social, and some issues were environmental. All of these problems and were all interactively connected.

The focus group participants clearly documented the complexity of the issues, noting that drugs, basic survival concerns and other realities greatly complicate efforts to control the epidemic. When the findings of these studies are considered from an ecological perspective it is possible to find various and varying intrapersonal, community, organizational and policy-related problems that synergistically impact these populations (and the systems of care and prevention). However, the constellation of issues would differ for each individual and will clearly change over time.

The message from this theme is that public health practitioners and health care providers will be most successful if they keep their focus on a broad spectrum of possible issues.

Barriers to accessing medical care and HIV testing

Many of the issues relayed in the earlier findings and themes have an impact on efforts to access medical care. These include the stigma, the embarrassment, the denial, the effect of the co-morbidities, the culture and context of peoples lives, the fear of the loss of confidentiality, the focus by medical care on the biomedical model of the epidemic, the availability of transportation, the cost or availability of adequate insurance, the sense of invulnerability or that lack of concern for one's own well being, the negative impact of marketing, the lack of depth of understanding of science and the relationship of a virus to well-being, etc.

What is unique about the themes that emerged from the meta-analysis of these studies is the diversity in the ways that these issues synergistically impact the desire to access medical care. No two interviewees conceptualized barriers or availability of medical care in the same way. There seems to be little perceived overlap between client realities and

provider assumptions. The focus group participants documented the many missed opportunities as well as some examples of how things could be done differently.

Summary of the Research Process

Needs assessments can be proactively designed to cast a “wide net” and involve the multiple stakeholders in the process of highlighting issues (L and G FGE). Or, they can be more traditionally developed to measure and compare only “rigidly-defined,” preconceived indicators. Assessments can highlight the unexpected, complex, contradictory realities of the lives and communities of vulnerable, overlooked populations or they can document problems in ways that reinforce the belief systems of experts (which reifies a narrow, stereotypical viewpoint). Assessments can focus on hearing and seeing through the eyes of the community while simultaneously developing processes to improve the system. Assessments can accomplish this if they incorporate strategies to include the voices and values of overlooked or unheard populations and the involved stakeholders.

It was the goal of the processes described in this report, the focus groups and the studies of selected populations, to highlight the complexity, contradiction and unexpected realities of overlooked populations. It was also the goal of the processes used to provide the richness and depth of understanding that could provide insights into opportunities to link communities and people to care that could facilitate policy development and provide opportunities for training and program changes. In addition, this series of studies has provided the format and context for understanding the various components of this FL HIV/AIDS needs assessment. The final recommendations in the final assessment report will be offered within the context of the findings from these studies.

Secondary Analysis of Selected Studies and Reports

In addition to secondary analysis on available quantitative data sets containing epidemiological and patient care data, secondary analysis was also conducted on a number of qualitative studies that were conducted in Florida. These studies provided a comprehensive perspective of patient's need for care among persons living with HIV and AIDS (PLWH/A).

RARE Projects

Three HIV/AIDS RARE projects were completed in Florida. Duval, Palm Beach, and Miami-Dade counties participated in these RARE Projects. The purpose of the RARE Projects was to examine the determinants of access to HIV/AIDS treatment and prevention services with selected high-risk populations.

The Rapid Assessment, Response, and Evaluation (RARE) methodology came out of the U.S. Department of Health and Human Services, Office of HIV/AIDS Policy. RARE philosophy and methodology are described in greater detail in documents titled, "Rapid Assessment, Response, and Evaluation Project RARE: RARE Field Assessment Methods Training Workbook" and "Rapid Assessment, Response, and Evaluation Project RARE: A Guide for Conducting Community-Based Rapid Assessment, Response, and Evaluation." RARE is a rapid reconnaissance, mixed method data collection strategy for understanding human health behaviors in their social and cultural contexts. This strategy uses five approaches that include a) Rapid assessment surveys, b) Cultural expert interviews, c) Focus Groups Interviews, d) Direct observation, and e) Geo-mapping. A brief description of each method follows.

Rapid Assessment Surveys: These surveys consist of short, closed ended questionnaires. These questionnaires are used with small groups of individuals.

Cultural Expert Interviews: These interviews consist of in-depth, one-on-one consultations. Participants include policy makers and community leaders, service providers, and individuals from vulnerable subgroups..

Focus Groups Interviews: These groups are an extension of cultural expert interviews and use a small group of three to five persons. Individuals include community activists, gatekeepers, or community "movers and shakers," who participate in a focused discussion. A facilitator who should remain value neutral moderates the discussion.

Direct Observation or Fieldwork: This is a surveillance technique for examining social environmental processes. Observers may utilize different approaches in conducting public health surveillance. These include a) complete observation, b) complete participation, or c) a mixture of observation and participation.

Geo-Mapping: This technique is used to analyze spatial data and present a visual display of the findings. Data inputs include geographic explanations of health or disease such as arrest rates or hospital admissions, prevalence rates, or socio-demographic factors. These data are subsequently translated into visual maps, which spatially identify high, moderate, and low risk locations.

Findings

Underutilization of HIV/AIDS care is a summary concept that reflects multiple etiologic and/or contributory factors. The most universal concern that emerged from all three major studies was violation of confidentiality and privacy associated with locating HIV/AIDS services in HIV/AIDS designated clinics. Other findings included:

- a) Reservoirs of inaccurate knowledge about HIV transmission,
- b) Negative attitudes about susceptibility to HIV infection,
- c) Faulty beliefs about the origin of HIV/AIDS,
- d) Chronic use of illegal drugs,
- e) Participation in survival sex,
- f) Lack of visible disease prevention and risk reduction education in high-risk communities, and

Unmet Need Studies

State and local Title I HIV Health Services Planning Councils have responsibility for assessing unmet needs of PLWH (Buchanan, 2002). Unmet needs have been defined as not receiving viral load tests, CD4 cell counts, or antiretroviral therapy in a 12-month period (Janney, Kahn, and Franks, 2002). The point prevalence of people diagnosed with HIV (s) and the proportion of HIV positive/aware people who are receiving primary medical care for HIV (p) allows for estimation of unmet needs by taking $(1-p) \times s$. This quantitative assessment not only identifies "...populations not in care for HIV [but also allows for qualitative assessment of] the reasons for their lack of service utilization" (Parham & Conviser, 2002). The objective of the cluster evaluation of Unmet Need Studies was to identify methodologies and summarize key findings and recommendations. Two studies of unmet needs that were conducted in the Orlando (Lake, Seminole, Osceola, and Orange Counties) and Jacksonville, Florida EMAs are reported here. Although other studies of unmet need were considered for reporting, these were the only two discrete studies completed as this report was being prepared.

Procedures

Data collection used field research and investigative methodologies. In the Orlando EMA, Focus groups (N = 18) and interviews (N= 26) included 44 respondents. One focus group had eight outreach workers and case managers, the other had 10 Executive Directors of Title I funded agencies. The 26 in-depth, open-ended, face-to-face, field interviews were conducted with PLWH. Outreach workers and case managers conducted the field interviews after completing basic training. Training sessions covered responsibilities such as identifying potential interviewees, scheduling appointments, providing or arranging transportation to the interview cite, and probing. Both interviewers and interviewees (PLWH) received compensation. Interviews lasted less than one hour and were conducted in convenient and semi-private locations in Orange and Seminole Counties. PLWH were asked about their: a) Experiences with service linkages at the time of diagnosis, b) Previous use of HIV service, and c) Motivation to move from diagnosis to HIV medical care.

In the Jacksonville EMA, a consortium of health, social, and faith-based organizations launched an investigative process of client tracking. Nine steps summarized this process: 1) Searching the local computerized HIV database for people diagnosed and registered with HIV between January 1st, 1998 and July 1st, 1999 who did not access services between July 1st, 1999 and July 31st, 2000, 2) Sending a letter by certified mail to the last known residential address, 3) Calling the last known residential address, 4) Visiting the last known residential address, 5) Asking caregivers, friends, and neighbors for relocation address, 6) Calling the last known medical provider agency, 7) Contacting City of Jacksonville emergency financial assistance services, 8) Searching Corrections Offender Information (www.dc.state.fl.us/activeinmate), Social Security Death Index (www.ancestry.com), and property owners websites, and 9) Using small media (flyers and public service announcements) to generate information on clients. Consortia members trained in field research administered 32 closed ended, in-person surveys. Surveys were self-or interviewer administered. Referrals to services were also completed during the data collection and reassessment process.

Data Analyses

Narrative data across all sites were summarized by content analysis. In Orlando EMA, respondents identified 31 needs unprompted. These were summarized using percentages, averages, and rankings. A card sort technique was used to narrow the list of 31 needs to 19, which included Ryan White Title I funded services. Next, each need was ranked using a 10 point scale where one (1) signified most important and 10 least important. Ranked scores for each need were averaged across all raters to obtain mean scores. If these scores are grouped into three categories representing the lower, middle, and upper thirds of the overall distribution then specific patterns emerged.

In the Jacksonville EMA, summary statistics used frequencies and rankings. Frequencies were used to tally the number of conditions that respondents identified that limited their access to treatment. Numerical ranks were used to prioritize the importance of services perceived useful for PLWH. Rankings extended from one (1) to 14, where smaller values indicated greater importance.

Findings and Conclusions

The assessments of unmet needs have limitations. Purposive and availability sampling were used to draw respondents who were willing to participate. Consequently, the samples had few Hispanics and women. Because respondents were predominantly Black/African American, the data lack the perspectives of other groups that are affected by HIV.

Strategies for assessing unmet needs differed by EMA. In the Orlando area, data collection was primarily qualitative. Focus groups and interviews were used to assess why PLWH were not in HIV medical care. In the Jacksonville EMA, a mixed method approach was used. Client tracking identified half of the 238 PLWH who were not in medical care and a survey was used to understand reasons for not being in medical care. The two different approaches yielded very different results.

Reasons for not accessing HIV medical care also differed by subgroups of PLWH. The large group of interviewees from the Orlando EMA included MCSM, WCBA, and YYA. As a whole, interviewees identified primary needs as HIV medical care, transportation, mental health counseling, assistance with medication, housing, and emergency financial assistance. In contrast, interviewees identified secondary needs as case management, substance abuse treatment, food vouchers, information about HIV services, dental care, services after normal working hours, and support groups. When needs were examined by subgroups, HIV medical care, medication and housing assistance remained top priorities, but MCSM identified transportation, emergency financial assistance, and dental care as priority issues. In contrast, WCBA identified case management and YYA identified mental health therapy/counseling as priority concerns. Similar needs have been reported Mark, Hirozawa, Soskolne, Liu, and Katz (2001). Thus, these data cannot be easily dismissed because they have implications for planning early intervention services to support increased access to HIV medical care.

Jacksonville used a census approach to identify everyone who was not utilizing publicly available HIV/AIDS care during a specific period of time. This technique yielded very different results and perspectives compared to the Orlando approach. According to the Jacksonville study, major reasons for non-use of HIV/AIDS public health system included:

- Incarceration (14%),
- Death (16%),
- Private health insurance (17%),
- Knowledge (had insufficient information about where to locate care), attitudes (dissatisfaction with quality care), and beliefs (perception of little benefit of care) (24.5%),
- Relocation to another city (27%), and
- Other less prevalent conditions such as drug use, not keeping scheduled appointments, and receiving services in a county different from place of residence, among others.

The assessments of unmet needs in the Orlando and Jacksonville EMAs were important first steps for understanding how to improve access to health care for low income, uninsured, and under-insured PLWH. Clearly, public health practitioners have opportunities to understanding the complexity of living with HIV/AIDS and take action to align treatment and support services with the values, needs, and preferences of PLWH. This approach holds promise to ease clients' apprehension about medication intake and privacy of access to services as well as providers' concern with inter-agency collegiality and cooperation, duplication of services, and transformation of the entire system of HIV medical care into a more user friendly and responsive entity for PLWH. The two different approaches used for these studies produced very different results. The Orlando process used qualitative methods. Thus the data provided insights rich in explanations regarding why some people may have difficulty accessing HIV/AIDS care. And although the sampling method does not allow readers the luxury of generalizing the results to all PLWH/A, the data is useful for planning participatory action oriented co-

laboratories with the community to facilitate empowerment and justice for PLWH/A. In contrast, the Jacksonville approach was effective in providing a comprehensive picture of how much of the problem was due to barriers to access in the form of knowledge, attitudes, and beliefs versus factors that do not constitute barriers such as: having private insurance, availability of care in private less obvious settings, relocation to another city, and death. Clearly non-users of publicly available HIV/AIDS care in Jacksonville present a diverse set of conditions that characterized the group. This suggests that program planners who assume a one-size-fits-all proposition will develop programs that have limited potential to attract and retain the majority of PLWH/A who present for HIV/AIDS services. It also provides considerable evidence that it cannot be assumed that people who are not accessing public care are not getting any care.

General Conclusions

This Statewide Needs Assessment was composed of a number of sub-studies. Each of these components yielded conclusions. The following conclusions were the most important that emerged from across the various components. For more detailed conclusions, the reader should consult the sections of this report related to each component and the more detailed reports for each component.

1. Privacy & Confidentiality

The results of this statewide needs assessment indicate that providing HIV/AIDS health care through distinctly identifiable HIV/AIDS clinics presents a number of problems. It is clear from the findings of many of the needs assessment studies that this process creates a barrier for many PLWH/A to accessing care. Linked to the barrier issue, but a problem in itself, is the violation of the PLWH/A's privacy and confidentiality that occurs when one must enter a clinic, testing center or other types of care that is dedicated to or known to be for HIV/AIDS. This situation presents moral and ethical problems. It may also be violating the spirit of the Health Insurance Portability and Accountability Act (HIPAA). This problem is further discussed in various contexts in a number of sources including areas of this needs assessments, the RARE studies, and the Qualitative studies of Selected Populations.

2. Standardized Needs Assessments

The planning areas currently develop their Health Care Needs Assessments using very inconsistent approaches, with varying levels of validity. Because of this inconsistency and, in some cases, lack of documented validity, it is difficult to assess how some areas are providing services to meet needs. This is particularly relevant to issues identified in the HRSA guidelines. Extensive resources have been used to develop these needs assessments, but, due to their lack of comparability, they have limited value for compiling a statewide needs assessment. They are also not developed in a way that would support comparisons over time for benchmarking the many key issues.

3. Importance of Culture & Context

The importance of culture and context is a very central finding of various dimensions of this overall needs assessment. The importance of avoiding the use of stereotypes about people or avoiding the tendency to reduce complex information to "risk factors" as a way to identify these populations was made particularly clear. Emphasizing a simplistic view of marginalized populations results in a continuation of missed "understandings" of culture and context that could make a difference in the effectiveness of our efforts. Consequently, the assumptions, research methods and best practices employed would be most effective if validated by or informed by an accurate understanding of the specific populations, contexts or individuals of concern (rather than taken from generalized assumptions made about these populations). Briefly, qualitative data collection appears to be critical to adjust to the continually changing epidemic and the changing populations impacted by the disease. It is imperative that the individuals responsible for the needs

assessments acquire training on the many phases of doing qualitative research and the appropriate methods of analyzing the data.

4. Integration with Other Services

Substance abuse and mental health services appear to be a major unmet need. Though consumers may be in denial about the need for substance abuse treatment services in particular, it is clear that this, along with mental health interventions, remains a major contributor to the evolving epidemic of HIV/AIDS. Other issues that appear to create barriers for use of these services are accessibility to these services, the lack of integration of these services with HIV/AIDS services, the lack of cultural awareness and sensitivity and the lack of integration with other non-stigmatizing health care services.

5. Ecological Model for Health Care Planning

There also appears to be a need to plan and deliver health care from a more ecological or holistic model of health care. Approaching individuals or groups from a biomedical perspective, reducing their concerns to a disease model and emphasizing our own expertise does not appear to be the most successful approach to control this evolving epidemic. The multifaceted realities of the lives of people and the complexity created by their situations require more integration of care and more emphasis on client-focused resource decision-making. The studies involving members of the FCPG, the recently incarcerated individuals, migrant workers and young adults all documented how the current system of care and prevention is organized around the experts and the biomedical model, not around the people and communities of concern. Recent recommendations to promote health social environments and recommendations for linking the social environment to health from the Task Force on Community Preventive Services would be an organizing construct for greater emphasis on these issues (American Journal of Preventive Medicine: Supplement. Interventions in the Social Environment to Improve Community Health; A Systematic Review. April 2003). Another important resource would be to provide more training in the ecological model and how it is most effectively applied to assess needs, assets and plan change (Brownson 2003).

6. Prevention & Care Continuum

Separation of health care and prevention may undermine successful planning and delivery of effective interventions. It may be helpful to conceptualize prevention and care as a continuum rather than distinct aspects of the efforts to stop the epidemic. Recent research has shown that an integrated approach that simultaneously implements complementary processes for primary prevention, secondary prevention and early medical intervention, tertiary care and tertiary prevention may have good potential. These strategies are especially effective when developed in a collaborative fashion with clients and community. Using this concept as an organizing construct could significantly impact planning and implementation efforts. Using this construct to organize efforts will require significant additional training for all people involved across the continuum. It will also require that the clients and community members become trained in how to participate in collaborative assessments and participatory research.

7. Program Evaluation

Major programs that provide funding for HIV/AIDS care services have limited evaluations. An evaluation of these programs could include an assessment of all major stakeholder expectations for the programs followed by an assessment of the program's success in meeting those expectations. Stakeholders might include PLWHA, case managers, care providers, and DOH staff. AICP has surveyed some stakeholders, in particular, the clients of that program. All programs may benefit from systematic data collection with case managers who have critical insights about program implementation. Data from this type of evaluation is critical for more substantive analysis of the relationship of the HIV/AIDS epidemic to the funding and delivery of health care services. A third-party evaluation could also help to increase the credibility of any evaluation results.

8. Geographic Distribution of Funding

Analysis of the data for the different types of HIV/AIDS care services funding shows an imbalance of specific types of funding for the different areas. In addition to population density, these variations are at least partially explained by the demographic makeup of the areas. For example, some areas have higher rates of private insurance than others. In particular, an examination of data from the *Florida Health Insurance Study* indicates that Miami-Dade has one of the highest rates for uninsured (24.6 percent) in the state, compared to the state average of 16.8 percent. This high rate of uninsured, with particularly high rates of uninsured among some racial/ethnic groups, at least partially explains the high rate of ADAP funding in some areas compared to others. Variation in funding should be examined and similar justification provided, or reallocation of funding considered.