

**State of Florida
Statewide Coordinated
Statement of Need (SCSN)**

2006-2009

Submitted to:

**U. S. Department of Health and Human Services,
Health Resources and Services Administration,
HIV/AIDS Bureau**

Submitted by:

**Florida Department of Health,
Division of Disease Control,
Bureau of HIV/AIDS, Patient Care Resources
Section**

**Prepared by the Quality Management Institute
Bureau of HIV/AIDS**

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PLWH/As, service providers, HIV/AIDS program coordinators, Ryan White administrative staff, other public agency representative, Ryan White Title I grantee, Title I Planning Council, Title II grantee, Title II consortia, Title III, Title IV, Part F AIDS Education Training Center, Part F dental reimbursement program, Part F SPNS grant, providers of substance abuse treatment and mental health treatment, Medicaid, Medicare, Veteran's Administration, community health centers, and correctional facilities.

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I. Introduction

The Statewide Coordinated Statement of Need (SCSN) is a mechanism for addressing key HIV/AIDS care issues and enhancing coordination across CARE Act programs and titles. Section 2617(b)(5) of the 1996 Ryan White CARE Act requires: “an assurance that the public health agency administering the grant for the State will periodically convene a meeting of individuals with HIV disease, representatives of grantees under each part of this title, providers, and public agency representatives for the purpose of developing and implementing a statewide coordinated statement of need.” The State Title II program is responsible for coordinating the SCSN, but all titles and grantees are expected to participate.

Florida’s SCSN has been an ongoing collaborative and representative process to identify significant issues, gaps and recommended strategies related to the needs of persons living with HIV/AIDS. The SCSN process which was initiated in 1996 in response to the Ryan White CARE Act requirement and as described in this document reflects the activities which were broadened over the years to include more representation and reflect the changing needs of Florida’s HIV/AIDS population.

Originally, the Bureau of HIV/AIDS, as the Title II grantee, convened and hosted annual All Titles Coordination Meetings for the purpose of developing the SCSN. In 1998, in order to increase participation in the process of developing and implementing the SCSN, the Florida HIV/AIDS Community Planning Group (FCPG), accepted the responsibility of developing and implementing the SCSN. The FCPG (which has since reorganized into the HIV/AIDS Community Planning Network, with a section known as the Patient Care Planning Group) is Florida’s most comprehensive and representative HIV/AIDS prevention and patient care planning body, and is well represented by Titles I, II, III, IV and Part F programs, prevention Community Planning Groups as well as Persons Living With HIV/AIDS (PLWH/As), and other representatives of Florida’s HIV/AIDS population. The support of the SCSN as a component of the FCPN has been very successful in the continued coordination, integration and linkage efforts across the CARE Act Titles.

Other SCSN initiatives by the Bureau of HIV/AIDS have included the planning coordination for the AIDS Insurance Continuation Program and the AIDS Drug Assistance Program with Ryan White Title I Eligible Metropolitan Areas and the Titles III, IV and Part F programs. This has proven to be a positive cross-Title initiative and has resulted in a uniform advocacy for these Title II programs.

In 2003 the Statewide Coordinated Statement of Need (SCSN) was updated and the process began with a meeting of the Florida CARE Act Coalition held on August 25, 2003. The Florida CARE Act Coalition is a statewide partnership of Titles II and I grantee representatives. The meeting was organized by Florida’s Ryan White Title II grantee, the Bureau of HIV/AIDS, Florida Department of Health. In attendance were the representatives from the six Title I grantees in Florida, the Title II grantee for Florida, and some representatives from Titles III and IV. Technical assistance for this meeting was provided by staff from the Quality Management Institute and the Institute of Health, Policy and Evaluation Research located in the Duval County Health Department. Input for the first draft of the 2003 SCSN was obtained at this meeting in a workshop facilitated by staff from the Quality Management Institute. This workshop provided the platform for beginning the development of the Statewide Coordinated Statement of Need for 2003 as specified in the 1996 Re-authorized CARE Act legislation.

Prior to the workshop, the staff of the Quality Management Institute reviewed Statewide Coordinated Statement of Need reports from the states of New Jersey, Texas, Delaware, Oregon,

Michigan, and Idaho in an effort to identify best practices. Staff utilized the information garnered from this review to develop a template for the process of producing the Florida SCSN.

The workshop began with legislative and policy updates and a review of the following information:

- The 2001 Statewide Coordinated Statement of Need for Florida
- The 2002 Epi-profile for Florida
- The final report of the Statewide Needs Assessment Study of Care and Support Services Access for Floridians Living with HIV Disease & AIDS published in 2002 by the Institute of Health, Policy and Evaluation Research at Duval County Health Department.
- Section VI, Chapter 4 of HRSA's Ryan White Care Act Title II Manual
- A Synthesis of Year 2002 Pilot Implementation of the Rapid Assessment Response and Evaluation Methodology in Selected Florida Counties

The second component of the workshop was an interactive dialogue among participants to identify significant statewide care issues in the following areas:

- Existing service delivery and care needs
- Unmet needs
- Emerging trends (underserved, co-existing conditions, economic, etc.)
- Gaps in care services
- Cross cutting issues (transportation, data management, communication among providers, etc.)
- Challenges (access, linkages, quality management, etc.)

The final module of the workshop was the development of a work plan for the Florida SCSN including goals, activities, responsibilities and timelines for achieving the goals.

Input of the Title I and Title II grantees was obtained to develop a draft document. The draft document was then forwarded to all of the Title III, Title IV and Part F Grantees in the state for review and recommendations. All of the Title III, IV, and Part F grantees were invited to participate on a conference call to discuss their recommendations. All comments were incorporated into another draft document by the staff of the Quality Management Institute.

The last step in the process of developing the SCSN was to present the final draft to the Florida HIV/AIDS Community Planning Group (FCPG). The SCSN revised draft was presented to the body of the FCPG at the quarterly meeting held in Tampa, Florida, from September 24 to September 26, 2003. FCPG members were offered an opportunity to review the document and provide input with their recommendations for changes that were incorporated upon consensus acceptance by the membership.

In developing this update for the 2006-2009 SCSN, the process was again restructured. Health Resources and Services Administration (HRSA) guidance regarding the update for the SCSN was presented and discussed at Florida's Patient Care Planning Group meeting, held in July 2005. Several hurricanes, both in Florida and in neighboring states, and the associated deployment of staff to provide disaster assistance, impacted our ability to conduct state-wide meetings as intended, and therefore the development of this document was expedited through the use of an on-line survey. More details of the process to develop the updated 2006-2009 SCSN are provided in Section II below.

This report is organized within the following five (5) sections. Following this introductory section is Section II which describes the 2005 process for updating Florida's SCSN. Section III, Epidemiologic Profile of HIV/AIDS in Florida, presents characteristics and trends of the HIV/AIDS

epidemic in Florida, including co-morbid diseases. Section IV, Findings from Needs Assessments and Other Related Documents, describes the findings from all needs assessments conducted in each of the regional areas, the statewide needs assessment, and other information gathered from a statewide assessment conducted by the Quality Management Institute. Section V, Standards and Quality of Care, includes standards and quality of care for the six core services identified in the SCSN and the emergent treatment issues. Finally, Section VI, Identified Statewide Concerns, identifies issues and concerns with goals and strategies to address statewide system unmet needs, emerging trends, cross-cutting issues, challenges, and critical gaps.

Information gathered during the SCSN process was incorporated into the development of the goals and objectives of the state's Comprehensive Plan for 2006-2009 which was updated in November, 2005.

II. Process for Updating Florida's SCSN for 2006-2009.

To prepare for the update process, the staff of the Quality Management Institute reviewed the latest guidance from HRSA regarding the SCSN update requirements, and SCSN reports from the states of New Jersey, Texas, Delaware, Oregon, Michigan, Idaho and Colorado in an effort to identify best practices. Staff utilized the information garnered from this review to develop a template and action plan for the process of producing the 2006-2009 Florida SCSN. After the review, a survey developed by the state of Colorado was adapted for use for Florida. The survey asked participants to identify significant statewide care issues in the following areas:

- Existing service delivery and care needs
- Unmet needs
- Emerging trends (underserved, co-existing conditions, economic, etc.)
- Gaps in care services
- Cross cutting issues (transportation, data management, communication among providers, etc.)
- Challenges (access, linkages, quality management, etc.)

This survey was placed on the Quality Management Institute's website using Survey Monkey software, so participants could provide feedback on-line. A memo with instructions for completing the survey was sent via e-mail to the HIV/AIDS program coordinators in all planning areas in the state, asking them to solicit participation from representatives from all Titles in their planning area. A list of targeted participants was provided, which included representatives from the Title I grantee and planning council, Title II grantee and consortia, Title III, Title IV, Part F AETC, dental reimbursement and Special Project of National Significance (SPNS) grantees. In addition, a list of specific target participants was provided, which included representation from substance abuse providers, mental health providers, Medicaid, Medicare, Veteran's Administration, community health centers and correctional facilities. In addition to the instructions for completion of the survey, two attachments accompanied the memo (1) the 2003 SCSN to use as a reference, and (2) the findings of the 2005 statewide consumer needs assessment, which was conducted using a standardized needs assessment survey tool.

Participants were given three weeks to complete the survey. In most areas of the state, representatives participated by completing the survey individually. In the Orlando area, an area-wide meeting was held to discuss the SCSN before participants completed the survey. In addition, two participants filled out the survey on paper and faxed their responses to the QMI. After the three-week data input period, the data were extracted into an Excel file for analysis. A total of 115 people responded to the survey from every area of the state. Some of these participants filled out the survey on behalf of one or more other people they were representing (such as a

consortium), and some participants represented more than one of the target categories. At least one representative from every category on the list of target participants submitted input and comments.

The data and comments were incorporated into a draft SCSN document and presented to all HIV/AIDS program coordinators (HAPCs) at a statewide meeting on January 5, 2006. Feedback was solicited to determine whether the comments reflected statewide concerns, unmet needs and gaps, and whether any additional state-level concerns existed that had not been identified to date. Feedback comments were incorporated into a final draft document, which was then reviewed by Bureau staff and the HAPCs for final concurrence.

The findings of the SCSN are located in Table 1, Section VI of this document. The statewide concerns, gaps and issues have been incorporated into the goals and objectives of the statewide Comprehensive Plan for 2006-2009, and the Bureau of HIV/AIDS, Patient Care Section is in the process of developing action plans in order to implement any changes and/or improvements that need to occur in response to the findings in this document. A link to the appropriate goal from the Comprehensive Plan is listed in Table I, next to the concerns that have been identified during the SCSN process.

III. Epidemiologic Profile of HIV/AIDS in Florida

The Surveillance Section of the Bureau of HIV/AIDS, Florida Department of Health, provides an overview of data on HIV and AIDS for the state of Florida.

In 2003, New York reported the largest number of reported acquired immune deficiency syndrome (AIDS) cases (6,684) California ranked second, and Florida ranked third, reporting 4,666 cases in 2003 (Table 1).

Florida ranked second among the states that report human immunodeficiency virus (HIV) with 5,467 cases in 2003. New York, which started reporting HIV in December of 2000, reported 8,403 cases (25%), followed by Florida, then Texas with 4,292 cases (13%). Pennsylvania ranked fourth with 2,665 cases (8%) for the same time period (Table 1).

Table 1. HIV (not AIDS) and AIDS cases, top ten reporting states, 2003. (2004 data not available).

Reporting State**	Number of AIDS Cases	% US AIDS Cases	Number of HIV Cases***	% US HIV Cases
New York	6,684	15%	8,403	25%
California	5,903	13%	N/A	N/A
Florida	4,666	10%	5,467	16%
Texas	3,379	8%	4,292	13%
Illinois	1,730	4%	N/A	N/A
Maryland	1,854	4%	N/A	N/A
Pennsylvania	1,895	4%	2,665	8%
Georgia	1,907	4%	52	0%
New Jersey	1,516	3%	1,361	4%
Louisiana	1,041	2%	787	2%
Remainder of US*	14,388	32%	10,274	31%
Total Cases	44,963	100%	33,301	100%

Source: CDC HIV/AIDS Surveillance Report, Vol. 15.

Table 2. AIDS cases, top ten reporting MSA's in the United States, December 2003 (2004 data not available).

Metropolitan Statistical Area	Number of Cases	Percent of US Cases
New York City, NY	5,580	12.5%
Los Angeles, CA	2,558	5.7%
Washington, DC	1,743	3.9%
Chicago, IL	1,527	3.4%
Houston, TX	1,324	3.0%
Philadelphia, PA	1,288	2.9%
Atlanta, GA	1,212	2.7%
Miami, FL	1,072	2.4%
Baltimore, MD	1,028	2.3%
San Francisco, CA	767	1.7%
Remainder of US MSAs	26,670	59.6%
Total Cases	44,769	100%

Among metropolitan statistical areas in the United States, Miami ranked eighth (1,072) in the number of AIDS cases reported in December 2003 behind New York City, Los Angeles, Washington D.C., Chicago, Houston and Philadelphia. During this same time period, New York City had the highest AIDS case rate in the nation with 59.2 per 100,000 population, followed by Miami (45.8) and San Francisco (45.2)

Figure 1: HIV & AIDS Cases and Rate by Gender. Florida, 2004

HIV and AIDS Cases in Men by Race/Ethnicity. Rate per 100,000 Population*, Florida, 2004

Race/Ethnicity	AIDS		HIV	
	Cases	Rate*	Cases	Rate*
White, non-Hispanic	1,408	29.4	1,550	32.3
Black, non-Hispanic	1,804	184.7	1,791	183.3
Hispanic	793	62.4	960	75.5
*Other	51	33.8	61	40.4
Total	4,056	56.4	4,362	60.7

*Other includes Asian/Pacific Islander or American Indian/Alaskan Native, Multiracial or other race.

HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the

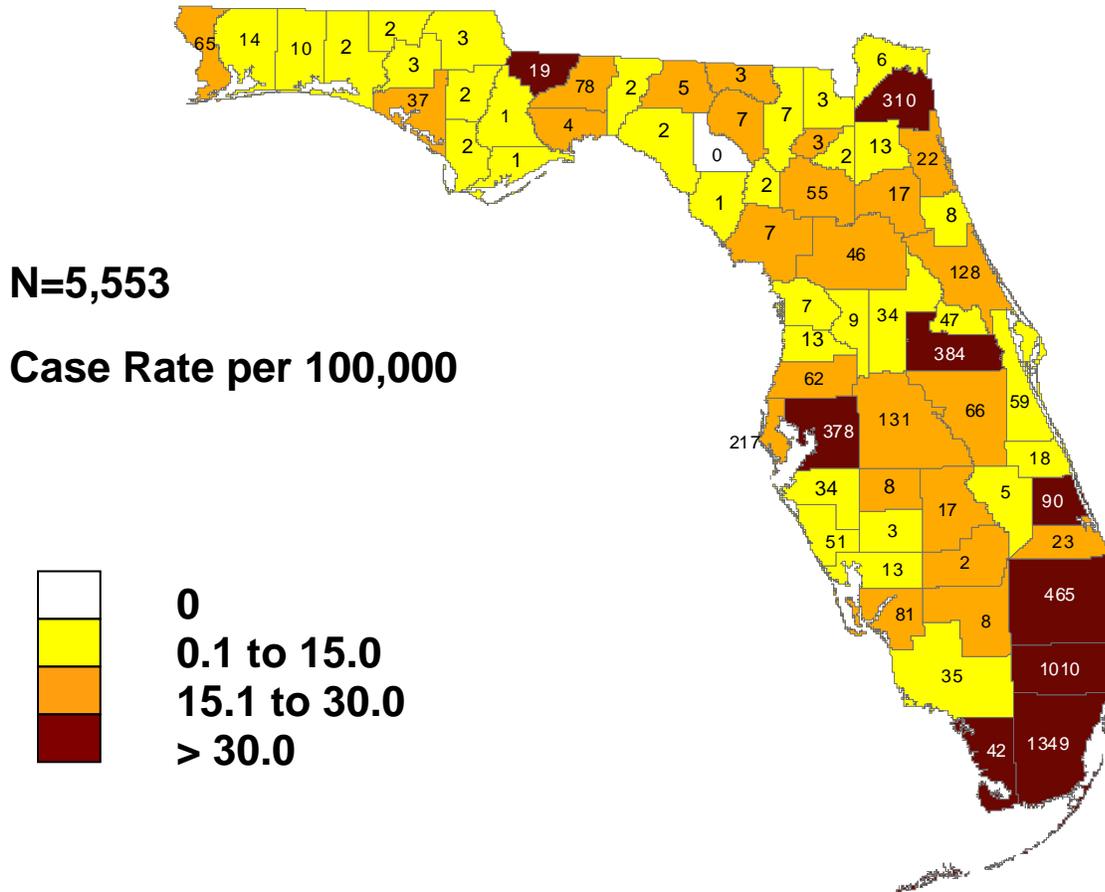
HIV and AIDS Cases in Women by Race/Ethnicity. Rate per 100,000 Population*, Florida, 2004

Race/Ethnicity	AIDS		HIV	
	Cases	Rate*	Cases	Rate*
White, non-Hispanic	282	5.5	345	6.8
Black, non-Hispanic	1,219	112.9	1,299	120.3
Hispanic	211	16.6	263	20.7
*Other	29	17.2	34	20.2
Total	1,741	22.9	1,941	25.5

AIDS Rate ratios: Black-to-White – 6.3:1
 HIV Rate ratios: Black-to-White – 5.7:1

Hispanic-to-White – 2.1:1
 Hispanic-to-White – 2.3:1

Figure 2: AIDS Rates per 100,000 Population Reported by County of Residence. Florida, 2004

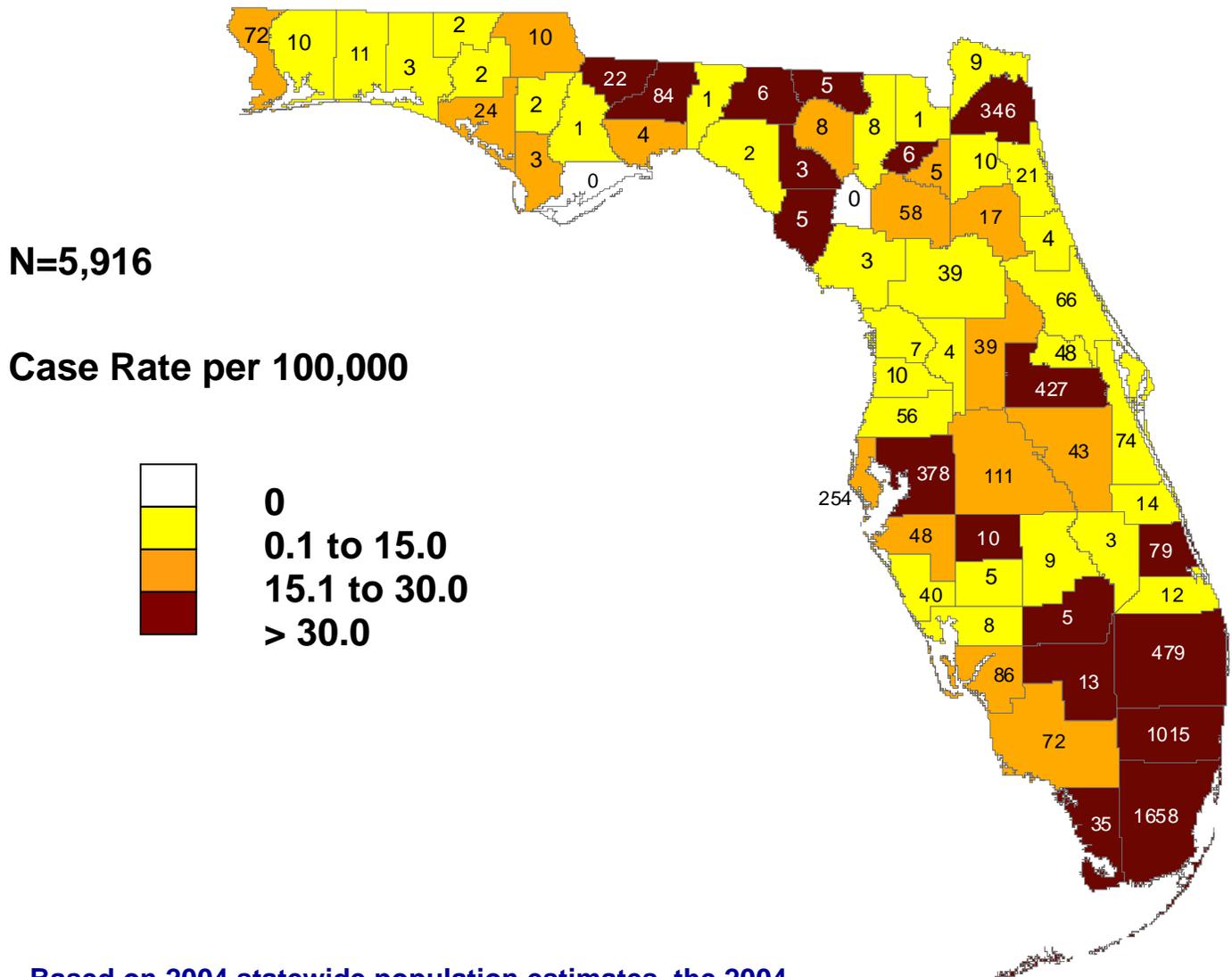


The count of cumulative AIDS cases reminds us of the overall burden of HIV/AIDS on the community. The epidemic has dispersed from 6 major epicenters to suburban and rural areas. No county has been spared.

In 2004, at least one AIDS case was reported in all but one of Florida's 67 counties (Figure 2). Although the AIDS epidemic is widespread throughout Florida, the majority of cases were reported from the seven most populous counties: Broward, Duval, Hillsborough, Miami-Dade, Orange, Palm Beach, and Pinellas. These seven counties reported a combined total of 4,113 cases, or 71% of Florida's total reported cases in 2004. The greatest numbers of AIDS cases were reported from three counties located in the southeastern part of the state, Broward, Miami-Dade, and Palm Beach. These three counties reported a combined total of 2,824 cases in 2004, or 48% of the statewide total.

Analysis of county-specific AIDS case rates per 100,000 population for 2004 indicate that Broward County ranked the highest with a rate of 58.0, followed by Miami-Dade (56.5), Monroe (52.2), St. Lucie (41.1), Gadsden (40.5) and Orange (37.8) Counties

Figure 3: HIV Cases (regardless of AIDS status) Reported by County of Residence. Florida, 2004

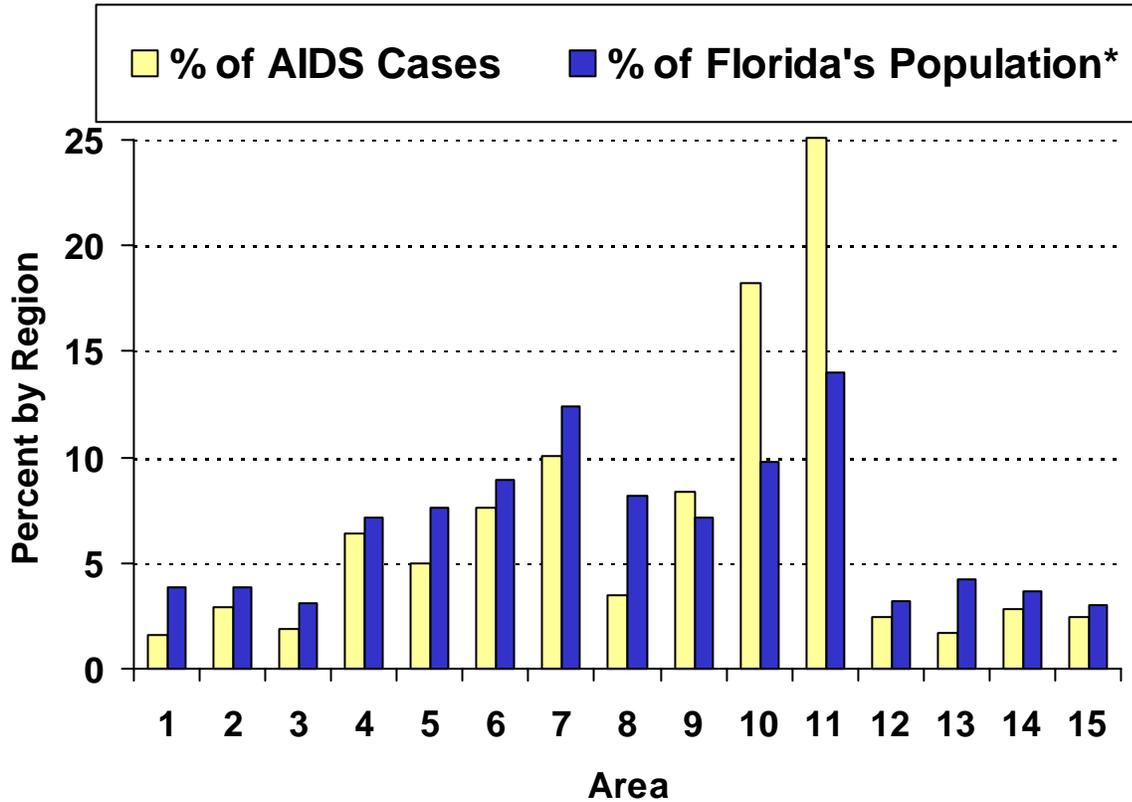


Based on 2004 statewide population estimates, the 2004 state rate is 36.2 per 100,000 population.

*County totals exclude Department of Corrections cases (N=425). Numbers on counties are cases reported.

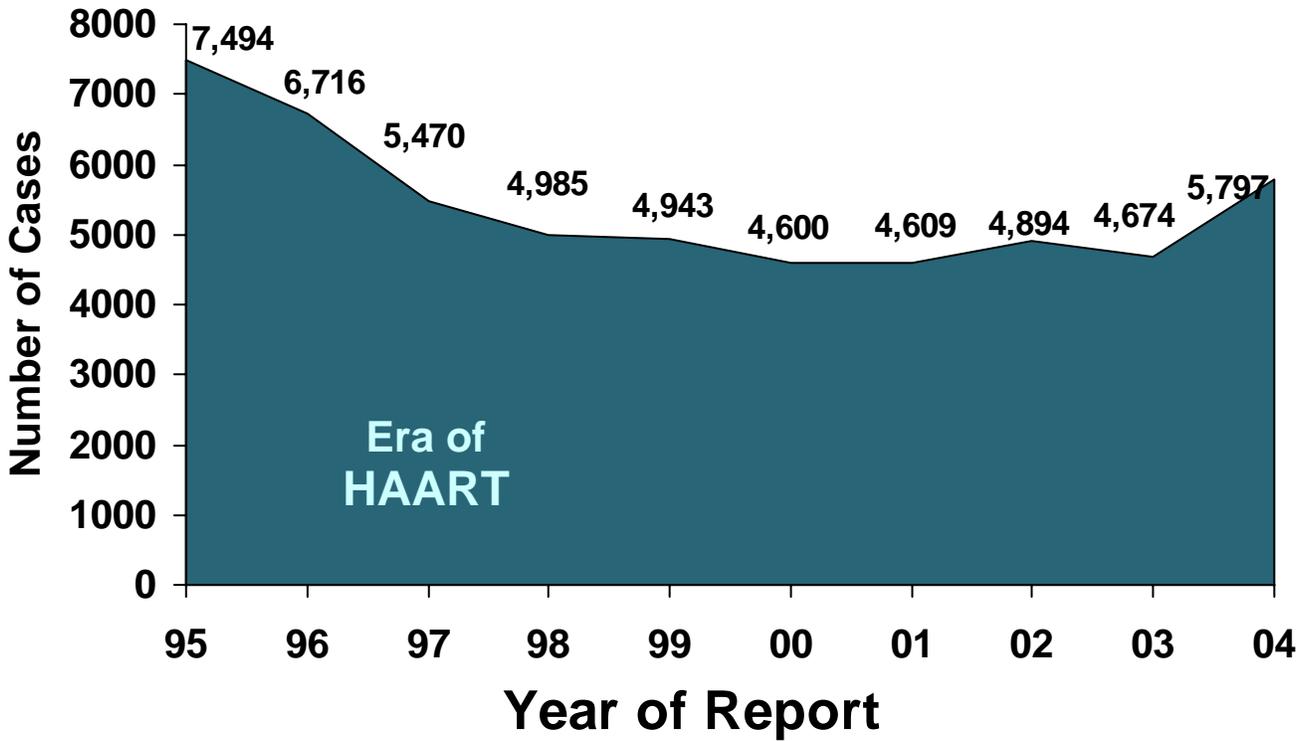
This map does not reflect HIV incidence. HIV data include those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.

Figure 4: Percent of Reported Living HIV/AIDS Cases* and Population by Area. Florida as of 01/31/03



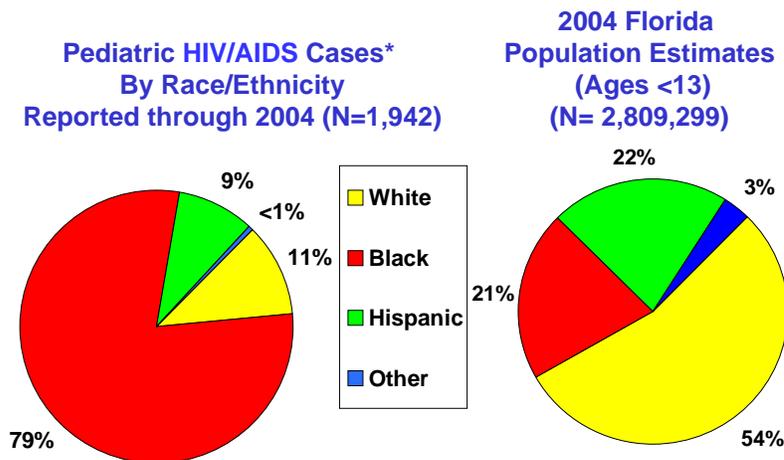
As can be seen in Figure 4, a disproportionate percent of AIDS cases, compared to the percent of people in the population, exists in Florida's southern counties. The greatest proportion of AIDS cases are in Area 11 (Miami and the Keys), followed by Area 10 (Broward County) and Area 9 (Palm Beach County).

Figure 5: AIDS Cases by Year of Report. Florida, 1995-2004*



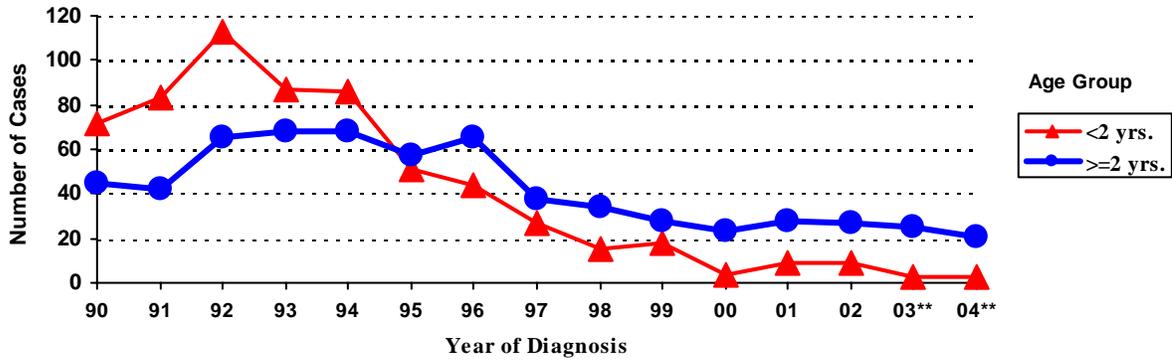
(* In a preliminary report, 2005 reported AIDS cases showed a decrease to 4,908).

Figure 6: Percent of Pediatric HIV/AIDS cases and percent of population, Florida.



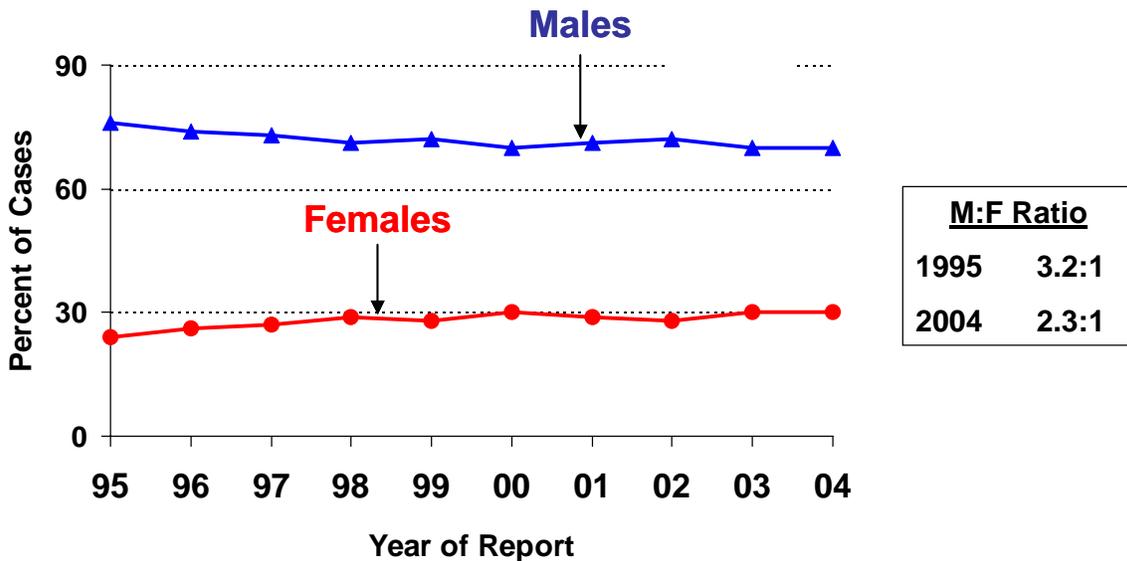
*Include cases in persons aged >12 yrs. at HIV or AIDS diagnosis with a ped risk aged <=12.
2004 data are provisional. 2004 Population Estimates, DDH, Office of Planning, Evaluation and Data Analysis

Figure 7: Pediatric AIDS Cases by Age Group & Year of Diagnosis. Florida, 1990-2004
N= 1,258



Pediatric AIDS cases have shown a continuous decline due to the availability of anti-retroviral therapies. (Figure 7)

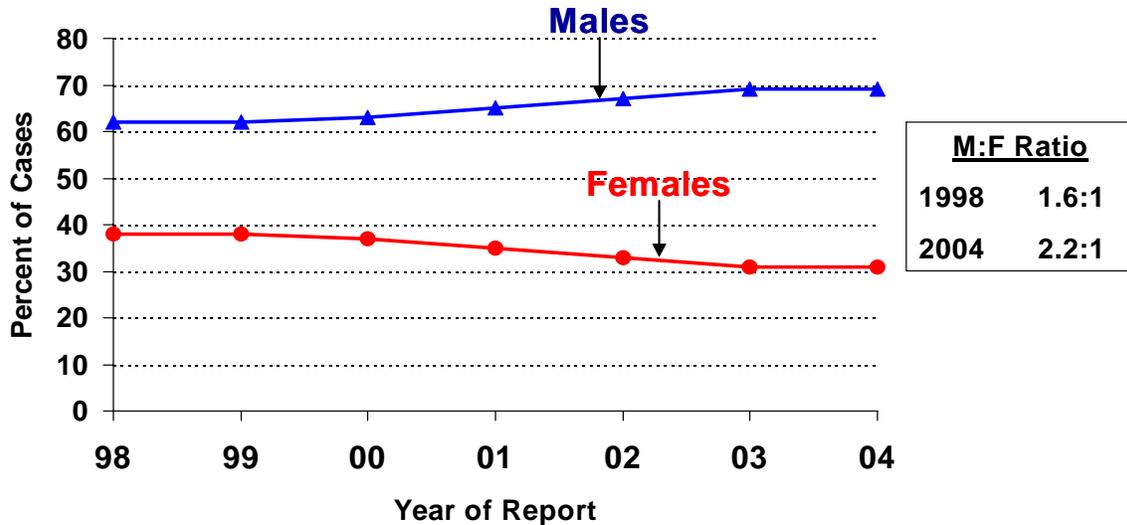
Figure 8: Percent of Adult AIDS Cases by Sex and Year of Report. Florida, 1995-2004.



Comment: AIDS cases tend to represent HIV transmission that occurred many years ago. The relative increases in female cases reflect the changing face of the AIDS epidemic over time.

In 1995, 24% of the AIDS cases reported in Florida were female (Figure 8). Over the past ten years, the proportion of AIDS cases among women has increased steadily. This has resulted in a decline of the male-to-female ratio, from 3.2:1 in 1995 to 2.3:1 in 2004. In 2004, the case rate per 100,000 population was 56.4 among adult males and 22.9 among adult females, indicating that AIDS cases in this period were still more likely to be reported among males than females in Florida.

Figure 9: Percent of adult HIV cases (regardless of AIDS status) by sex and year of report, Florida, 1998–2004.*



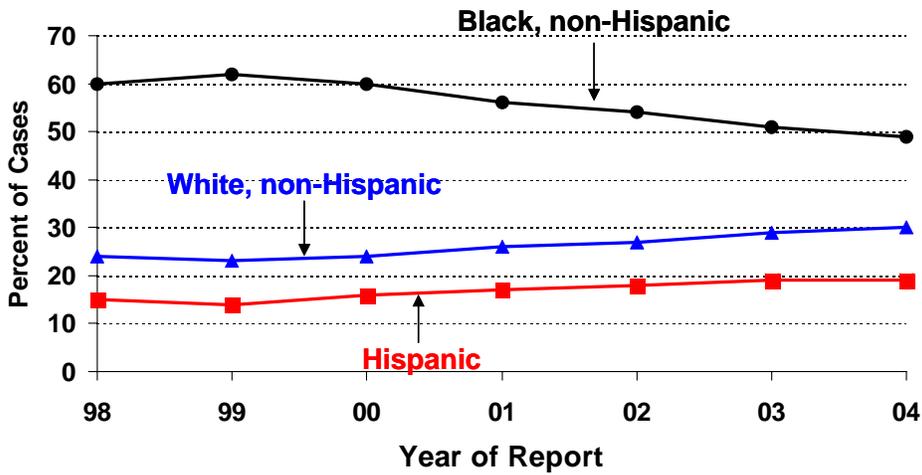
Comment: The relative increases in male HIV cases might be attributed to recent increases in HIV transmission among men who have sex with men (MSM), which may influence future AIDS trends. HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.

The relative increase in male HIV cases illustrated in Figure 9 might be attributed to recent increases in HIV transmission among men who have sex with men (MSM), which may influence future AIDS trends. It might also be attributed to a greater proportion of males in this population getting tested compared to females. This warrants further study to determine which is the case.

AIDS cases tend to represent HIV transmission that occurred many years ago. The relative increases in female cases reflect the changing face of the AIDS epidemic over time. In 1993, the male to female ratio of AIDS cases was 4.0:1; however, by 1995 it was 3.2:1 and in 2004 this ratio had narrowed to 2.3:1. Other things being equal, the trend of an increasing male percentage of HIV positivity will translate into a widening gap in AIDS in future years, unless women proceed to AIDS more rapidly than men.

(*HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.)

Figure 10: Percent of Adult HIV Cases (regardless of AIDS status) by Race/Ethnicity and Year of Report. Florida, 1998 - 2004

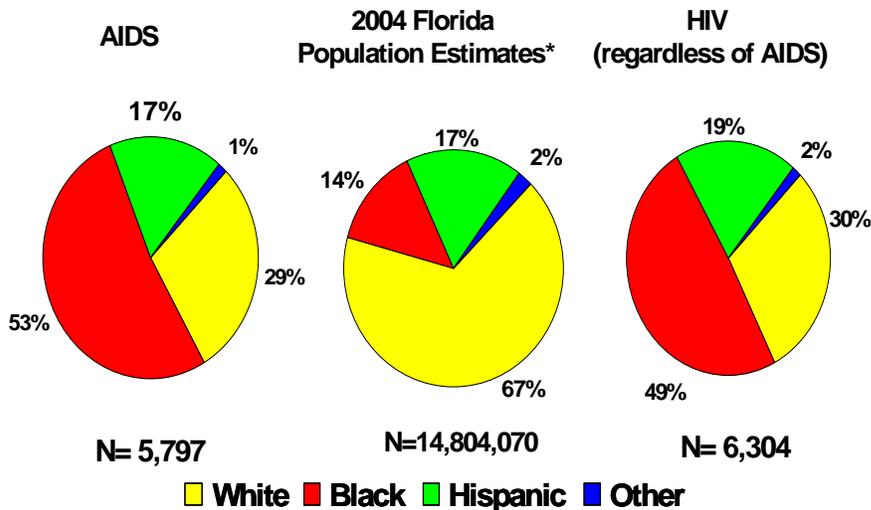


*Other races represent less than 2% of the cases and are not included.
 HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.

Throughout the 1980's, AIDS cases among whites predominated. In 1993, AIDS cases in blacks surpassed whites.

Figure 11: Comparison of Adult Population (2000 Census) and Total AIDS Cases by Race/Ethnicity.

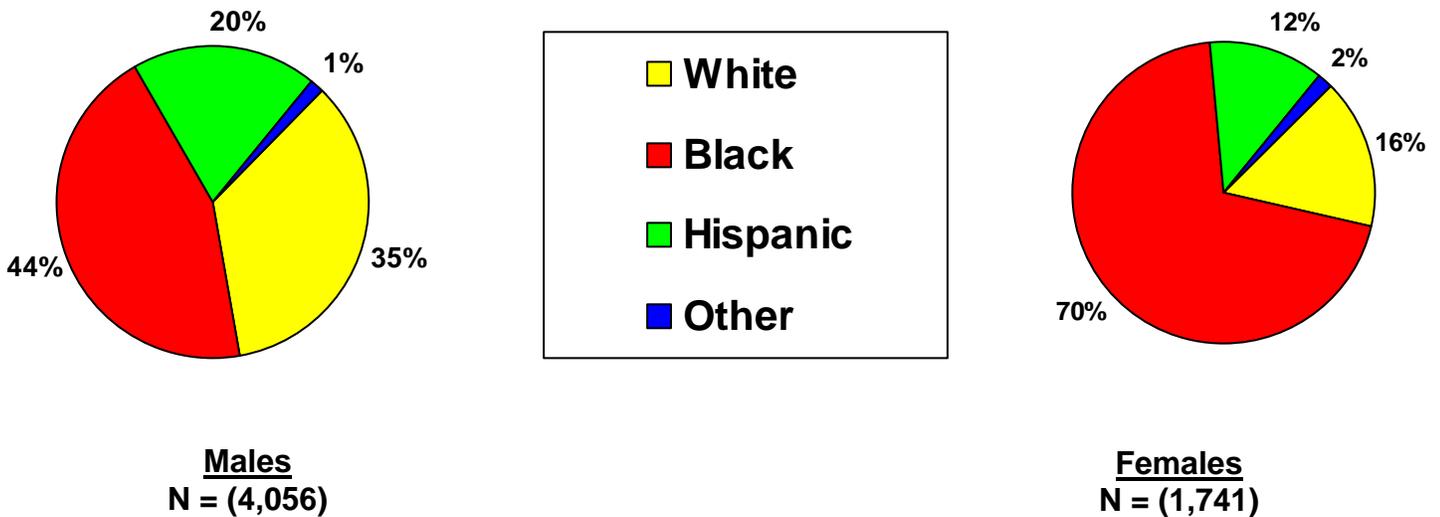
While blacks make up 14% of the population in Florida, they constitute 49% of the HIV cases and 53% of the AIDS cases for 2004.



Other includes Asian/Pacific Islander, or American Indian/Alaska Native, Multiracial or Other race.
 HIV data includes those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.
 *2004 Florida Population Estimates, Adults (Ages 13+), DOH, Office of Planning, Evaluation and Data Analysis

Disparities are even more evident among women: Annually, more than 70% of female AIDS cases have been reported among black women since 1988. (See Figure 12). HIV case reporting, implemented in mid-1997, has shown a very similar distribution of cases by race/ethnicity and sex.

Figure 12: Reported Adult AIDS Cases by Sex and Race Ethnicity. Florida, 2004

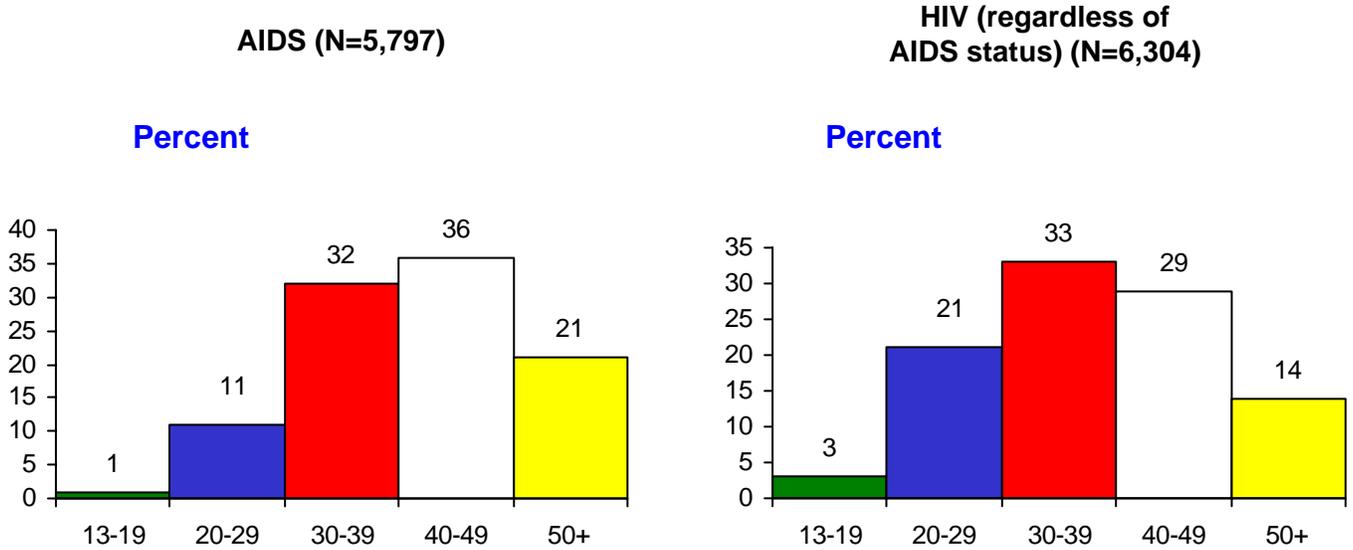


Among black males, the AIDS case rate is 8 times higher than among white males. Among black females, the AIDS case rate is 24-fold greater than among white females. Hispanic male rates are 2 times higher and Hispanic female rates are 3 times higher than the rates among their white counterparts. (Population data are based on 2000 Census.)

Factors that have been attributed to increasing disparities include the following:

- Late diagnosis of HIV,
- Access to, or acceptance of, care,
- Delayed prevention messages,
- Stigma,
- Non-HIV STDs in the community,
- Prevalence of injection drug use,
- Complex matrix of factors related to socioeconomic status.

Figure 13: Percent of Adult Cases by Age Group. Florida, 2004



HIV data include those cases that have converted to AIDS. These HIV cases cannot be added with AIDS cases to get combined totals since the categories are not mutually exclusive.

Figure 14: Adult Male AIDS Cases by Exposure Category and Year of Report (NIRs redistributed). Florida, 1995-2004

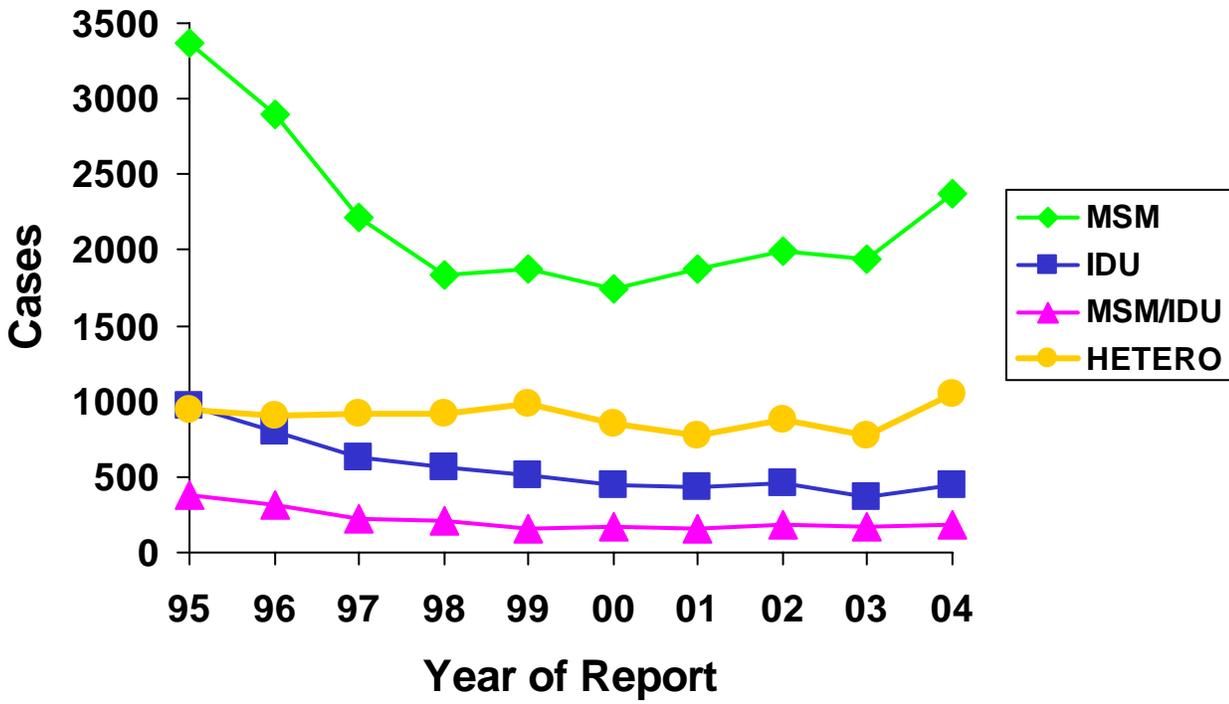


Figure 15: Adult Female AIDS Cases by Exposure Category and Year of Report, (NIRs redistributed). Florida, 1995-2004

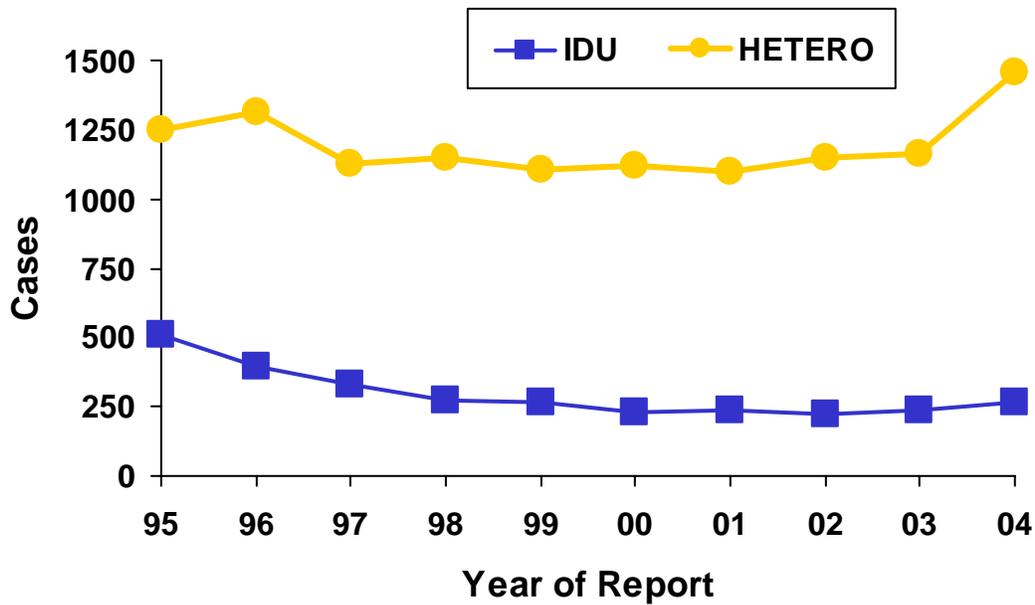


Figure 16: Adult Male HIV Cases (regardless of AIDS status) by Exposure Category and Year of Report, (NIRs redistributed). Florida, 1998-2004

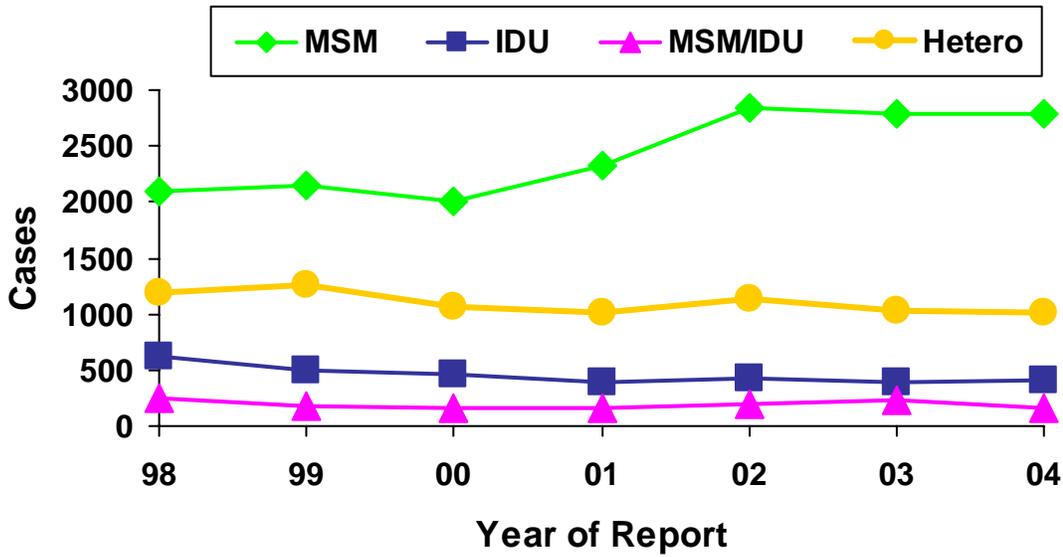


Figure 17: Adult Female HIV Cases (regardless of AIDS status) by Exposure Category and Year of Report, (NIRs redistributed). Florida, 1998-2004

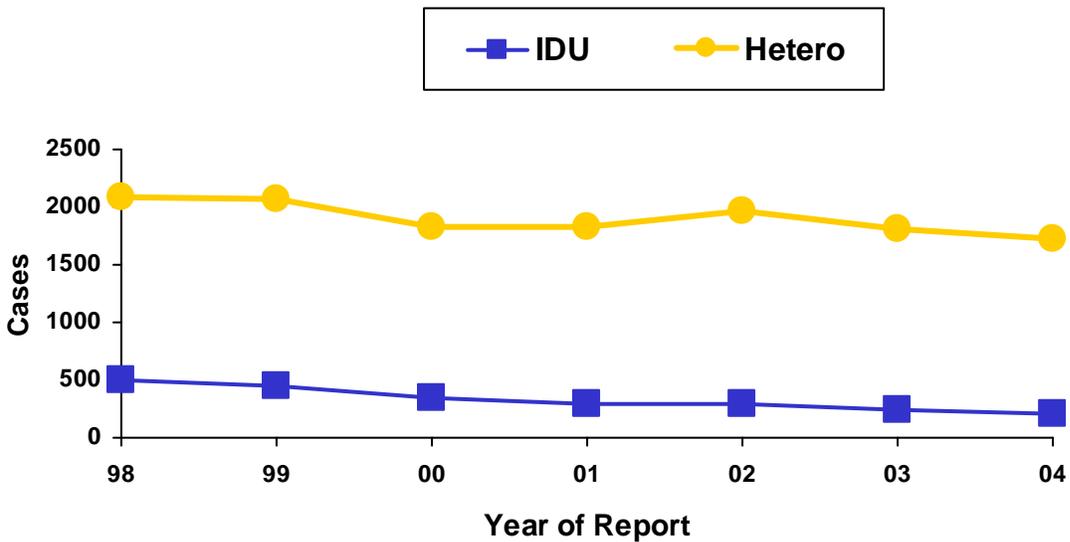
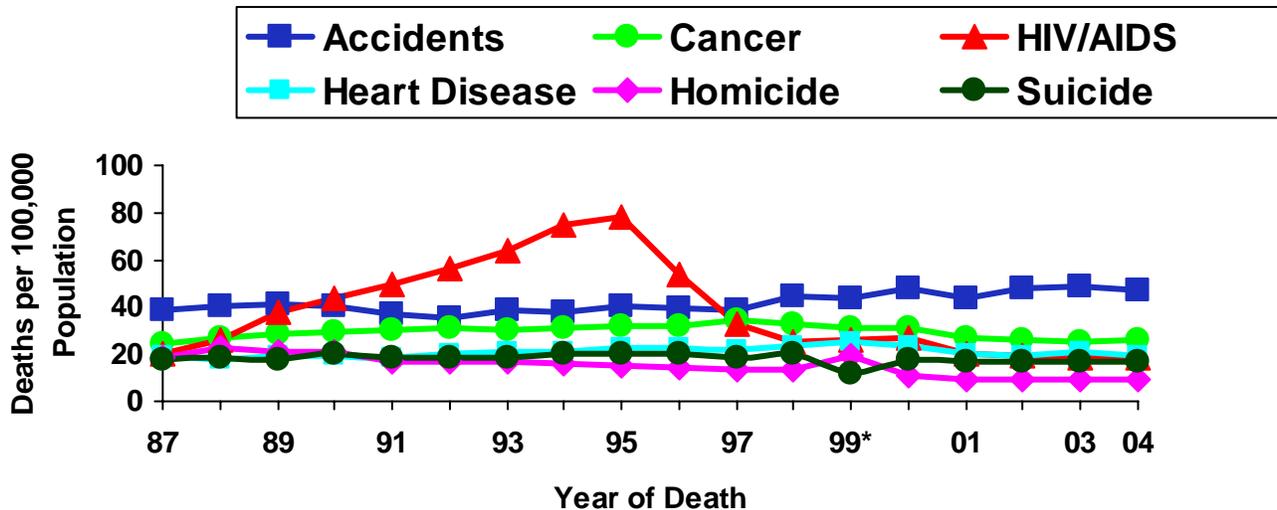


Figure 18: Death Rates From Leading Causes of Death Among Persons 25-44 Years of Age By Year of Death. Florida, 1987-2004*



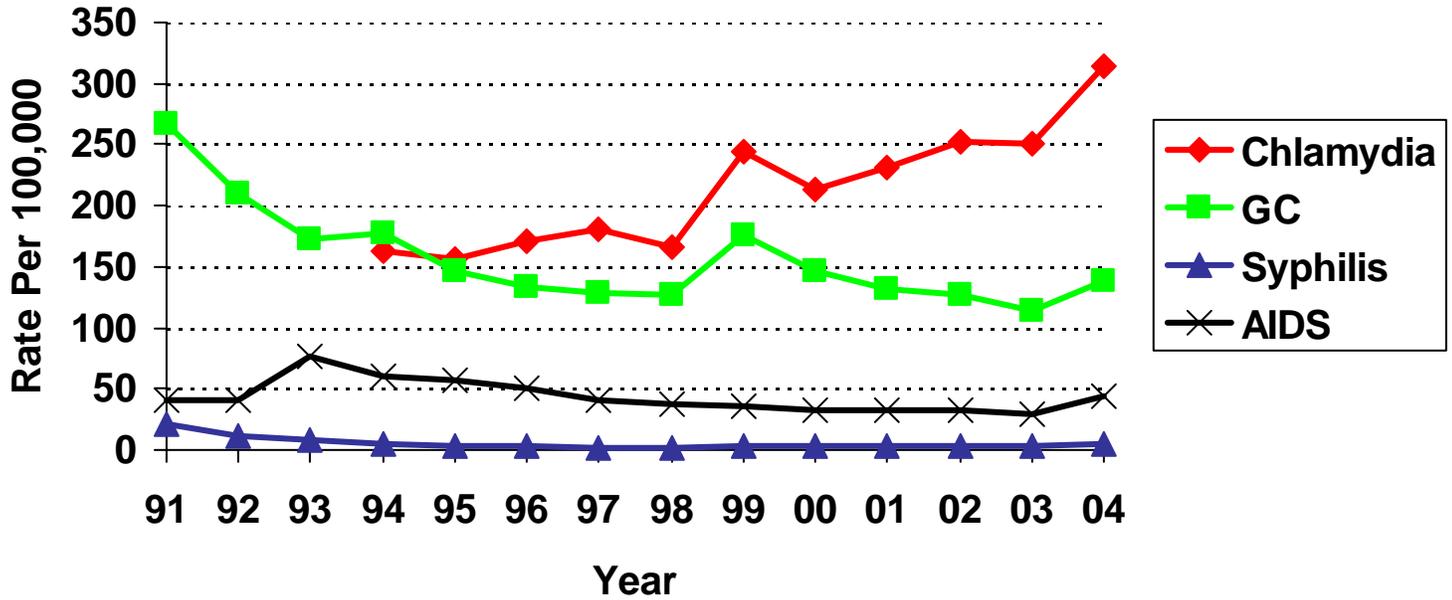
*Rates are expressed as deaths per 100,000 population.

**A new national system for coding death certificates began in 1999, which resulted in an increase of approximately 14% in the annual number of HIV/AIDS deaths.

Figure 18 shows that the death rate among 25-44 year olds due to AIDS increased rapidly during the 1980s and early 1990s compared to deaths due to other causes. HIV/AIDS deaths decreased markedly from 1996-1998, associated with the advent of HAART in 1996. Overall HIV/AIDS deaths, regardless of age, have shown a similar decline since 1995, however there was a slight increase from 2001 to 2002, with an increase from 1658 deaths per 100,000 in 2001 to 1705 deaths per 100,000 in 2002. This change may reflect factors such as viral resistance, late diagnosis of HIV, adherence problems, and lack of access to or acceptance of care. Racial/ethnic disparities are evident in the death rate data.

Other diseases can serve as surrogate indicators for risk of HIV infection. This is particularly true of other Sexually Transmitted Diseases (STDs), since they represent a measure of sexual behavior. Figure 19 shows that Chlamydia rates have increased steadily during the 1990s.

Figure 19: Syphilis, Chlamydia, Gonorrhea and AIDS Rates per 100,000 Population. Florida, 1991-2004



In conclusion, several trends have been identified and are summarized below:

- Increases in MSM and heterosexual transmissions
- Disparities in race/ethnicity & economic status
- Disparities in geographical areas
- Individuals are coming into treatment later, resulting in sicker patients
- Increase in death rate
- Disproportionate impact on MSMs, women and minorities
- Emerging populations include seniors, migrating populations (farm workers, tourists, aliens, and teenagers).

IV. Findings from Needs Assessments and Other Related Documents

In 2002, Dr. William Livingood et al of the Institute for Health, Policy, Evaluation, and Research were contracted by the Bureau to conduct a meta-evaluation of local areas' needs assessments throughout the state of Florida. The four major components of the meta-evaluation included:

- An analysis of existing sources of surveillance data
- Meta Evaluation of regional Needs Assessments
- Meta Evaluation of Rapid Assessment, Response and Evaluation (RARE) studies
- Qualitative studies of 3 selected populations

Major findings of the meta-evaluation are summarized as follows:

- There is a need for greater emphasis on confidentiality and privacy (Clients do not want to visit a testing site, clinic or other agency that is dedicated to providing HIV/AIDS services out of fear of being identified as having HIV, which creates a barrier to care.
- There is a need for standardization of Needs Assessments throughout the state
- There is a need for incorporating awareness of culture and context. It is important to gather qualitative information as well as quantitative in order to gather a depth of information to provide better insight into what works.
- There is a need for more integration of prevention with patient care along a continuum of care. Prevention activities need to be planned and coordinated as part of the continuum of care, rather than viewed as distinctly separate. Gaps in service can be more easily addressed when these activities are planned together.
- Great variation in types of services and funding sources
- Categorical funding streams contribute to fragmentation of services, and make analysis of funding difficult (example Substance Abuse Treatment – there is a difference between those funded directly and those funded through RW)
- Separate funding streams require different reporting & requirements
- Areas with more whites utilize AICP more, since they tend to have a higher proportion with insurance, while areas with more black and Hispanics tend to utilize ADAP more. (For example, Miami-Dade has highest rates for uninsured (24.6%) compared to state average (16.8%))
- There is a need for greater integration of other services (substance abuse treatment and mental health)
- Need to plan and deliver health care services from ecological perspective (Social environment)
- There is a need for evaluation
- Geographical distribution of funding around the state appears to be imbalanced. Rural areas tend to have higher proportion of funding per PLWHA, and when cost of living is considered, many urban areas appear to be under-funded. However, it must be taken into consideration that the overhead and administrative costs of small rural areas are greater per person, and the difficulties with transportation leads to a greater need to fund transportation.

In 2002, staff of the Quality Management Institute, Bureau of HIV/AIDS, conducted an assessment of the 14 local Needs Assessments conducted by each of the local planning bodies around the state compared to the latest Needs Assessment Guidance produced by HRSA. The findings of this assessment include the following:

- Many of the 14 areas included most of the information asked for in the HRSA Guidance, but NO area included everything.
- Only a few areas provided general demographics for the entire population, which makes it difficult to determine whether disparities exist.
- Epi Profile – 71% (10/14) had an Epidemiology section, but only one area broke the data down completely into HRSA-defined sub-populations.
- Co-Morbidities identified in the needs assessments:
 - 21% (3/14) addressed STDs
 - 57% (8/14) addressed substance abuse
 - 14% (2/14) addressed TB
 - 14% (2/14) addressed Mental Illness
 - 0% addressed Hepatitis
 - 14% (2/14) addressed Homelessness
 - Only 1 area identified surrogate markers, such as pregnancy rates
- Assessment of Service Needs discussed:
 - 14% (2/14) areas included information regarding individuals who know their status, but are not in care
 - 42% (6/14) areas included some, but incomplete, information in a Resource Inventory
 - 50% (7/14) partially addressed provider capacity and capability
 - 78% (11/14) indicated coordination with other programs
 - 100% identified barriers to care
 - 50% (7/14) areas discussed unmet need
 - 93% (13/14) partially addressed service gaps
 - 57% (8/14) discussed disparities in access
 - 100% identified trends and/or common themes
 - 78% (11/14) identified client perception of service quality and appropriateness
 - 86% (12/14) assessed needs based on HRSA-approved service categories
- Cross cutting themes from this assessment include the following:
 - There is a statewide need for training on conducting needs assessments, based on HRSA's latest guidelines
 - There is a need for standardized collecting and reporting of data that can be compared and contrasted for statewide planning purposes. This need has been addressed through the Comprehensive Plan Guidance that was sent out to the local areas in July 2003.

As a result of this study, a work group was formed to develop a statewide, standardized needs assessment survey for consumers. The survey was implemented in the spring of 2005 and eight of the fifteen HIV/AIDS Planning Areas provided data online, six areas submitted written reports of recently conducted needs assessments, and one area submitted an Excel data file which had some questions similar to the standardized survey.

The needs assessment questions on service utilization identified service gaps and barriers to care. Some of the most needed and used services identified through this process were food bank/food vouchers, emergency financial services, and Health Education and Risk Reduction. Service gaps, which identified services that were needed, but not received, included dental care, emergency financial assistance and food bank/food vouchers. The desire to keep one's HIV status

private, lack of transportation, lack of knowledge of where to apply for services, and being ineligible for services were major barriers of access to services.

Cross-cutting issues that were common to all Planning Areas include poverty—as indicated by need for emergency financial and housing assistance, and homelessness—drug use, lack of transportation, lack of private insurance, lack of knowledge about where services were available, perceptions of some staff as lacking compassion, and co-morbidities.

In addition to the findings already mentioned, several needs, gaps and challenges were also identified. They include the following:

- Need for integrated, interdisciplinary approaches to care & support services
- Increased costs associated with multiple diagnoses (Hepatitis, TB, STDs diabetes)
- Increased costs of new treatments – people living longer adds to the financial burden
- Misperceptions of the treatment as a cure leads to risky behavior
- Education regarding treatment adherence
- Housing and transportation is problematic
- Attitude of entitlement
- Shortage of dentists & doctors who accept Medicaid
- Impact of shift in funding and policies
- Provider capacity & capability – need for more trained specialists, Medicaid providers, dentists
- Impact of distrust and stigma
- Linkages between prevention & care – referrals and retention
- Links to the incarcerated and newly released inmates
- Provider & program staff education on culture and social issues
- Review of funding allocation mechanisms
- Coordination & collaboration
- Data management systems
- Quality Management & Evaluation

V. Standards and Quality of Care

During the years 1999 and 2000, members of the Florida Community Planning Group (FCPG), Patient Care Section, develop and implemented standards of care for the following: general, or common, standards of care, medical care, pharmaceuticals, dental, case management, substance abuse, and mental health services. The standards of care were revised in November of 2001, and a subsequent revision of the case management standards occurred in 2002. Reference is made to the August 3, 2001 document prepared by the Florida Community Planning Group, “Standards of Care,” which define in specific detail each of the standards of care for the six (6) core services:

The core services that HRSA has identified include:

1. Medical Care
2. Pharmaceuticals
3. Dental Care
4. Case Management
5. Substance Abuse Treatment/Counseling
6. Mental Health Treatment/Counseling

During the SCSN meeting of August 25, 2003, members of the Coalition had a lengthy discussion regarding whether the six (6) core services should be expanded and other standards of care should be developed, as well as what does Florida’s continuum of care address. Additional services for emerging need include the following: outreach, food bank, housing, transportation, legal, health education and risk reduction, medication co-pays, health insurance continuation, psycho-social treatment, treatment adherence, home health, early intervention, and buddy companion services. These are not necessarily in any priority order at this time, but will be considered for prioritization during the next year. As a result of the discussion, particular goals and strategies were identified and are included in Section VI, under the heading of Cross-cutting Issues and Challenges.

In 2005, the Patient Care Planning Group held a discussion relating to the Standards of Care, and a workgroup was formed to study the current standards to revise and update them. Because the Public Health Service has Clinical Guidelines as standards for medical care, it was decided that standards for medical care would refer to these Clinical Guidelines.

VI. Findings of the 2005 SCSN On-Line Survey

Tables 6-9 illustrate the various categories that participants identified with when they filled out the survey for the updated SCSN.

Table 6. Participants by Category.

Category	Number	Percent
PLWH/A	17	17%
Service Provider	44	44%
HAPC	5	5%
Ryan White Administrative Staff	17	17%
Public Agency Representative	10	10%
Other (please specify)	6	6%
Total Respondents	99	100
(skipped this question)	16	

Table 7: Representation by Ryan White Program

Representation of one or more of the following Ryan White programs	Number	Percent
Title I Grantee	14	17%
Title I Planning Council	16	19%
Title II Grantee	29	35%
Title II Consortia	33	40%
Title III	15	18%
Title IV	13	16%
Part F AETC	9	11%
Part F Dental Reimbursement	3	4%
Part F SPNS Grant	1	1%
Total Respondents	83	100%
(skipped this question)	32	

Table 8: Representation by Agency Type.

Representation of one or more of the following agencies:	Number	Percent
Substance Abuse Treatment	10	28%
Mental Health Treatment	14	39%
Medicaid	6	17%
Medicare	3	8%
Veteran's Administration	2	6%
Community Health Center	18	50%
Correctional Facilities	4	11%
Total Respondents	36	100%
(skipped this question)	79	

Table 9: Representation by Planning Area*

Representation from Consortium/Planning Area	Number	Percent
1	8	10%
2A	2	2%
2b	1	1%
3/13	2	2%
4	4	5%
5/6/14	23	28%
7	13	16%
8	12	14%
9	5	6%
10	2	2%
11A	4	5%
11B	1	1%
12	2	2%
15	4	5%
Total Respondents	83	100%
(skipped this question)	32	

***Note: Some people indicated that they were representing their group, rather than respond as an individual.**

Table 10: Responses to Question Regarding Who is Infected.

WHO IS INFECTED?	Number of Responses			
	Important Emerging Trend	Somewhat important	Not an Issue in Florida	Response Total
Increases in infection among women	88	22	2	112
Increases in infection among minorities	87	24	1	112
Increased incidence of dual diagnosis	79	34	0	113
Persons who know their status but are not in care (Unmet need)	78	35	0	113
Increased incidence of young gay men with HIV infection	73	38	1	112
Large increases of newcomers with HIV/AIDS to Florida	66	45	2	113
Late diagnosis	64	45	3	112
Total Respondents	114			
(skipped this question)	1			

Table 11: Responses to Question Regarding Service Delivery Challenges.

SERVICE DELIVERY CHALLENGES	Number of Responses			
	Important Emerging Trend	Somewhat important	Not an Issue in Florida	Response Total
Increased economic challenges	92	21	0	113
Underserved counties within rural areas	85	21	4	110
Housing	78	34	1	113
Barriers to care for underserved populations	76	33	4	113
Need for dental care	67	46	0	113
Unmet need and gaps in CORE services for persons both “in” and “out” of care	64	45	1	110
Access and adherence to medications while incarcerated	62	40	8	110
Improving CARE entry and access points	61	43	6	110
Increasing access to medications (prescription drugs)	61	43	7	111
Linkages with prevention services	60	38	12	110
Coordination of services (e.g. coordination between Titles)	57	45	9	111
Linkages to other disease conditions (Such as STDs Hepatitis Tuberculosis)	56	48	8	112
Underserved counties within Metro areas	40	56	11	107
Total Respondents	113			
(skipped this question)	2			

Table 12: Responses to Question Regarding PLWH/A Issues.

PLWH/A ISSUES	Number of Responses			
	Important Emerging Trend	Somewhat important	Not an Issue in Florida	Response Total
Substance abuse (e.g. Meth use)	88	22	0	110
Insurance issues	77	30	1	108
Effects of long term use of medications	76	33	1	110
Impact of the failure to disclose on infection rates among women	69	41	0	110
Total Respondents	110			
(skipped this question)	5			

Table 13: Responses to SCSN Question Regarding the Rank of Top Ten Priority Services

Rank	Services ranked by priority	% of responses
1	Primary care	98
2	Prescription drugs	98
3	Dental care	98
4	Case management	93
5	Mental health	90
6	Substance abuse services	86
7	Transportation	83
8	Emergency housing assistance	79
9	Health insurance continuation	75
10	Food bank	55
11	Emergency financial aid	49
12	Client advocacy	31
13	Home health care	31
14	Hospice	12
15	Other	8

It is important to note that HRSA’s guidance indicates that the services need not be listed in priority order; however, for planning purposes, the number of responses and ranking provides helpful information. It is also important to note that the participants in this survey were mostly providers and program administrators (83% vs. 17% PLWH/A). Aggregated findings from the statewide Needs Assessment related to consumer-perceived needs, ranked by importance, are provided below for comparison:

Table 14: Responses to Statewide Needs Assessment Question Regarding the Rank of Top Ten Priority Services

Rank	Service ranked by priority	% of responses
1	Case management	85
2	Medications	84
3	Outpatient medical care	70
4	Food bank/food voucher	56
5	Dental	52
6	Health education risk reduction	49
7	Referrals	47
8	Client advocacy	46
9	Nutritional counseling	42
10	Mental health counseling	41
11	Emergency financial assistance	40
12	Psychosocial support	39
13	Substance abuse treatment	21

More detailed information regarding the findings of the consumer needs assessment can be obtained by contacting Andrea Davis at Andrea_Davis@doh.state.fl.us or calling (850) 245-4444 ext. 2549.

In addition to objective survey questions, the SCSN survey provided participants with an opportunity to provide open-ended comments related to unmet needs, emerging trends, cross-cutting issues, challenges and critical gaps. The issues identified through this process can be found in Table 15, along with a linkage to one or more goals found in the 2006-2009 Comprehensive Plan.

VI. Identified Statewide Concerns: Unmet Needs, Emerging Trends, Cross-cutting Issues, Challenges, and Critical Gaps.

Based on an examination of the statewide needs assessment conducted by the Institute for Health, Policy & Evaluation Research, the local needs assessments conducted in the 14 regional planning areas, the standardized consumer needs assessment and the SCSN survey, a number of concerns in the areas of unmet needs, emerging trends, cross-cutting issues, challenges, and critical gaps have been identified with respect to HIV/AIDS service delivery systems throughout Florida. Goals and strategies have been developed to address these issues, and are found in the 2006-2009 Florida Comprehensive Plan. The unmet needs, trends, issues, challenges and critical gaps are presented in Table 15 below, along with a link to the Comprehensive Plan Goal. These should be considered in a statewide context and may not apply to all regions and locales in the state.

Table 15. Identified Statewide Concerns with Linkage to Comprehensive Plan Goal(s)

<p>1. Unmet Needs:</p>	<p>Link to Comprehensive Plan Goal (Refer to the 2006-2009 Comprehensive Plan for objectives and strategies)</p>
<p>1.1. There is a need to improve on methods to assess the shifting HIV/AIDS demographics throughout the state and regional areas to better allow those care systems to respond to needs of emerging communities and populations, as well as to identify people living with HIV who know their status but are not receiving regular HIV-related primary health care.</p> <p>1.2. Trends in the epidemic show that disparities still exist with respect to race/ethnicity, economic status, and in geographic areas of the state.</p> <p>1.3. There is an increase in the number of men and women who are in the jail or corrections system, which impacts their levels of care. There is a need to continue to improve transition to primary medical care for this population in some areas of the state.</p>	<p>Goal 1: Improve access and reduce barriers to HIV-related health care services statewide.</p> <p>Goal 2: Eliminate disparities among disproportionately affected sub-populations and historically underserved communities.</p> <p>Goal 3: Improve the quality of health care and health outcomes</p> <p>Goal 7. Establish standardized eligibility standards for primary health care and support services</p> <p>Goal 8: Improve planning processes throughout the state.</p> <p>Goal 10. Enhance our collaboration with partners in the state.</p>

2. Emerging Trends:	Link to Comprehensive Plan Goal (Refer to the 2006-2009 Comprehensive Plan for objectives and strategies)
<p>2.1. Shifts in co-morbidities influence care and treatment, which impacts the HIV/AIDS systems of care by creating the need for integrated and interdisciplinary team approaches. These shifts include, but are not limited to, the following:</p> <ul style="list-style-type: none"> • The increase and impact of Hepatitis (i.e., HAV, HBV, HCV; STDS (i.e., syphilis, Chlamydia, etc.); and tuberculosis on HIV/AIDS systems of care • The increase and impact of substance abuse and mental health concerns. There is an inadequate number of treatment providers available around the state. • The rise in patients using crystal methamphetamine who are not receiving treatment is causing disruptions in the health care of these patients. This issue does not appear to have reached a sufficient level of awareness by physicians and dentists. There is a need for improved coordination with SAMHSA- funded mental health/substance abuse treatment providers. • There is a need for improved specialty care provider coordination; i.e., Cardiologist, Nephrologists, Gastroenterologists and Gerontologists. <p>2.2. An increase in the number of people who are negotiating for sexual encounters via the internet enables them to remain anonymous. This makes it difficult to reduce transmission and bring them into care.</p> <p>2.3. Shifts in the populations affected by the disease influence care and treatment and impact the HIV/AIDS systems of care. There is an increasing need for integrated and interdisciplinary team approaches, including the following:</p> <ul style="list-style-type: none"> • The increase in MSM and heterosexual transmissions. • The increase in emerging populations such as seniors, migrating populations (farm workers and tourists), teens, women, minorities, and the incarcerated. 	<p>Goal 1: Improve access and reduce barriers to HIV-related health care services statewide.</p> <p>Goal 2: Eliminate disparities among disproportionately affected sub-populations and historically underserved communities.</p> <p>Goal 3: Improve the quality of health care and health outcomes</p> <p>Goal 8: Improve planning processes throughout the state.</p> <p>Goal 9. Improve data collection systems throughout the state</p> <p>Goal 10. Enhance our collaboration with partners in the state</p>

<ul style="list-style-type: none">• Florida is a major refugee relocation center. There are increasing numbers of new residents who are coming from countries that are heavily impacted with HIV/AIDS or are victims of human trafficking, which places a greater burden on the system.	
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3. Cross-Cutting Issues and Challenges:	Link to Comprehensive Plan Goal (Refer to the 2006-2009 Comprehensive Plan for objectives and strategies)
<p>3.1. Transportation issues present challenges in both rural and urban areas of the state.</p> <p>3.2. Major Medicaid reform in Florida will lead to new challenges to care and drug coverage systems as the changes take effect.</p> <p>3.3. The coordination of services across funding sources and providers continues to present challenges throughout the state.</p> <p>3.4. Staff turnover and related need for continual training and education.</p> <p>3.5. Data management is a continual challenge within the state and regional areas. Challenges related to this issue include:</p> <ul style="list-style-type: none"> • Education regarding the sharing of client information to improve coordination of care across providers • Additional requirements for quality and performance measures place stress on staff and systems of care • Multiple data bases and the need for consistent, standardized methods for managing, collecting, and reporting of data • A need for better information systems to track people who drop out of care, follow-up on referrals, or who cross county lines in order to receive duplicate services. <p>3.6. There continues to be misunderstanding on the part of some clients related to their eligibility for services, which indicates a need for greater client education regarding the services.</p> <p>3.7. There is a need to strengthen the planning, delivery and integration of prevention and patient care services across the continuum of care so that service gaps can be more easily addressed.</p>	<p>Goal 1: Improve access and reduce barriers to HIV-related health care services statewide.</p> <p>Goal 2: Eliminate disparities among disproportionately affected sub-populations and historically underserved communities</p> <p>Goal 3: Improve the quality of health care and health outcomes</p> <p>Goal 4. Improve and enhance resource management and financial accountability.</p> <p>Goal 5. Create and maintain a high-performance workplace environment through the development and implementation of an effective human resource management system.</p> <p>Goal 6. Create an environment of quality and performance management</p> <p>Goal 7. Establish standardized eligibility standards for primary health care and support services</p> <p>Goal 8. Improve planning processes throughout the state</p> <p>Goal 9. Improve data collection systems throughout the state</p>

	Goal 10. Enhance our collaboration with partners in the state
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4. Critical Gaps:	Link to Comprehensive Plan Goal (Refer to the 2006-2009 Comprehensive Plan for objectives and strategies)
4.1. There is a limited availability of specialty providers, including dental providers, in some areas of the state.	Goal 1: Improve access and reduce barriers to HIV-related health care services statewide.
4.2. Improved collaboration at the federal level (i.e., SAMHSA) and state level mental health and substance abuse agencies (i.e., state of Florida Department of Children and Families) would help with providing integrated services to address the needs of some clients dealing with issues related substance use.	Goal 2: Eliminate disparities among disproportionately affected sub-populations and historically underserved communities.
4.3. Decreasing numbers of providers who accept Medicaid reimbursement.	Goal 3: Improve the quality of health care and health outcomes
4.4. Limited availability of childcare options for women with children that may need residential treatment or may require regular medical care visits.	Goal 8. Improve planning processes throughout the state
4.5. Limited availability of a continuum of care for HIV-infected adolescents in some areas of the state.	Goal 9. Improve data collection systems throughout the state
4.6. Continued stigma associated with HIV/AIDS status, which impedes access to care and/or services for some clients.	Goal 10. Enhance our collaboration with partners in the state
4.7. There is a need for coordinated mental health (psychiatry, psychology) services to be integrated as a standard part of HIV care.	

V. Summary and Conclusions

Much progress has been made in Florida since the initial SCSN in working toward achievement of the identified goals and objectives, however the HIV/AIDS epidemic is shifting to new population groups, which poses new challenges to the state. Women, persons with low socioeconomic class, minority populations, incarcerated and other marginalized groups are inequitably becoming infected. These are people who have other more pressing needs, making their ability to follow complex medical treatments less of a priority.

Ryan White planners, administrators, service providers, and consumers continue to be actively engaged in ongoing work within the various collaborative partnerships established in Florida. Collaboration between different service providers by coordinating direct care produces synergistic effects, reduces duplication of services and is both effective and efficient. Collaboration is also occurring with respect to quality management, fiscal and administrative tasks of the respective grants. This type of collaboration is becoming more necessary as the HIV/AIDS epidemic grows; the needs of the clients increase and become more complex, and reductions are made in HIV funding.

Over the past year, greater effort has been made in the collaborative planning efforts between grantees within the state of Florida. The networks of care developed as a result of the Ryan White CARE Act, while comprehensive in scope, have not eliminated all the barriers and gaps within the service delivery systems. The issues identified in this SCSN have been incorporated and integrated into goals and objectives in the 2006-2009 Florida Statewide Comprehensive Plan for Patient Care Services and form the ideal around which local programs and services need to be developed. It is the intent of this document that barriers and gaps identified through this process in collaboration with other grantees and partners, may be reduced through a sincere application of the recommended goals and strategies identified in the Comprehensive Plan. The process and outcome of the Florida Statewide Coordinated Statement of Need is in compliance with the guidance from HRSA and is inclusive of the participation by all Ryan White CARE Act grantees in Florida, including those from the Part F programs.

HIV/AIDS community stakeholders are challenged with drawing from the generality found here while filling in the specifics particular to their local areas' needs. In that spirit of collaboration and proactively moving from the conceptual to the real, HIV/AIDS stakeholders throughout the state of Florida may be ensured of steady improvement in the continuum of care for their communities.