



**State of South Carolina  
2009 Ryan White HIV/AIDS  
Statewide Coordinated Statement of Need  
and  
Comprehensive Plan**

**January 2009**



**STD/HIV Division  
South Carolina Department  
Of Health and Environmental Control**

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January 13, 2009

Andre Rawls, Director  
STD/HIV Division  
South Carolina Department of Health and Environmental Control  
1751 Calhoun Street  
Columbia, SC 29201

Re: Letter of Concurrence  
Ryan White Statewide Coordinated Statement of Need and Comprehensive Plan

Dear Dr. Rawls:

The South Carolina HIV Planning Council (HPC) has completed the review of the combined Ryan White Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan and the voting process for concurrence. Below please find a description of the process and the final results of the vote.

On December 2, 2008, all HPC members were provided with the Ryan White SCSN and Comprehensive Plan for 2009 – 2011, information about the concurrence process, and a voting form. HPC members were instructed to review the SCSN and Comprehensive Plan to determine if it is consistent with programmatic data and identified needs. Opportunities to present questions or concerns about the SCSN and Comprehensive Plan were provided at the HPC meeting on December 2<sup>nd</sup>, with DHEC staff on hand and available to address questions. Additionally, a conference call was scheduled for December 5<sup>th</sup> for any members having additional concerns or questions. A quorum was present at the meeting on December 2<sup>nd</sup> and all members were requested to vote by December 19<sup>th</sup>. A subsequent follow-up contact was made with members who had not yet responded by that date, requesting that they vote and return their forms.

A ballot was provided to every voting member of the HPC and, as of December 31, all but two members had returned their completed ballots. Every member that responded voted for full concurrence with the SCSN and Comprehensive Plan, indicating their agreement that the SCSN accurately describes the needs of PLWHA in South Carolina and the Comprehensive Plan is designed to address those needs.

We believe the process with South Carolina's Ryan White Care Services has been open and cooperative and we look forward to our working relationship continuing throughout 2011. If you have any questions, please feel free to contact us at the numbers listed below.

Sincerely,

*Troy A. Bowers*  
Troy A. Bowers  
HPC Community Co-Chair  
(803) 779-7257

*Susan L. Fulmer*  
Susan L. Fulmer  
HPC Health Department Co-chair  
(803) 898-0684

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Post Office Box 1763 • Columbia, SC 29202 • Phone 803-252-1087 • Fax 803-252-0589

## **Purpose**

The Ryan White legislation requires all recipients, through a representative process, to participate in the development and approval of a Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan. The purpose of the SCSN and Comprehensive Plan is to provide a collaborative mechanism to identify and address significant HIV care issues related to the needs of people living with HIV/AIDS (PLWHA) and to maximize coordination, integration, and effective linkages across the Ryan White Parts related to such issues. The SCSN and Comprehensive Plan must identify broad goals related to the needs of PLWHA, identify critical gaps in life-extending care needed by PLWHA both in and out of care, and describe cross-cutting issues for the Care Act Parts. The Comprehensive Plan portion of the document must describe a plan for the organization and delivery of health and support services in South Carolina. The plan must include appropriate strategies, goals and timelines.

## **Contributions**

Many individuals from a wide variety of organizations across the state of South Carolina contributed to the development of the South Carolina Ryan White Statewide Coordinated Statement of Need and Comprehensive Plan for 2009. The Department of Health and Environmental Control (DHEC) staff members that were instrumental in the process are:

Dr. Wayne Duffus, Medical Director, STD/HIV Division  
Dr. Andre Rawls, Director, STD/HIV Division  
Sonya Bayone, ADAP Director, STD/HIV Division  
Christal Davis, Ryan White Data Manager, STD/HIV Division  
Susan Fulmer, Planning Coordinator, STD/HIV Division  
Katrina Gary, Ryan White Quality Management Coordinator, STD/HIV Division  
Roshan McDaniel, Evaluation Consultant, STD/HIV Division  
Noreen O'Donnell, Ryan White Program Manager, STD/HIV Division  
Jacob Ramsey, Statistical and Research Analyst, STD/HIV Division  
Leigh Williamson, Ryan White Program Coordinator, STD/HIV Division

Professionals from other agencies who actively participated in providing input and feedback into the process and the completed document and who will be essential in the implementation of the plan are:

Karen Bates, SC-C2EA  
Sharon Black, CareSouth Carolina  
Troy Bowers, PALSS  
Lane Brafford, Catawba Care Coalition  
Aaron Creech, AID Upstate  
Luis Cruz, Mecklenburg County  
Teresa Davis, Sandhills Medical Foundation  
Pat Derajtys, University of South Carolina  
Ann Derrick, Cooperative Ministry

Consuela Drayton, Medical University of South Carolina  
Atensia Earp, PALSS  
Wanda Gardner, USC Pediatrics  
Christine Gordon, HH-Edisto and HH-Lower Savannah  
Mahogany Graham, SCHAC  
Andy Hall, AID Upstate  
Adrena Harrison, AETC  
Johanna Haynes, Careteam  
Tracey Jackson, Piedmont Care, Inc.  
Latisha Jackson, Catawba Care Coalition  
Daniela Lembo, BJHCHS  
Lisa L. Lindley, USC School of Public Health  
Mulamba Lunda, Hope Health  
Wood Marchant, MUSC  
Jennifer McDaniel, Catawba Care Coalition  
Pam McKnight, Lowcountry Health Care Systems  
David Napp, Facilitator  
Aaron O'Brien, Roper  
Nancy Raley, USC DOM  
Aishah Rashid, ACCESS Network  
Valetta Rhinehart, Mecklenburg County  
Susan Rodriguez, Lowcountry AIDS Services  
Anna Katherine Rye, University of South Carolina  
Ralph Rynes, LRADAC  
Stacy W. Smallwood, USC School of Public Health  
Randy Tarzwell, New Horizon  
Stan Wardlaw, RCHCA  
Norlica Washington, Sumter Family Health Center  
Jason Williams, Upper Savannah Care Services  
April L. Winningham, USC School of Public Health  
Taisha Williams, Upper Savannah Care Services  
Joanne Wuori, University of South Carolina  
Donna Yutzy, Independent Consultant

The South Carolina DHEC extends many thanks to everyone who contributed in any way to this project.

## **Process**

The SCSN and Comprehensive Plan were developed collaboratively with the input of a broad spectrum of HIV/AIDS stakeholders in South Carolina. Two full-day participatory meetings were convened on September 17, 2008, and November 7, 2008, in Columbia, S.C. The first meeting included a discussion of the SCSN process and purpose. Participants provided input regarding cross cutting barriers and gaps in HIV care. The second meeting was used to identify the goals, objectives, and strategies described in this plan. An external consultant designed and

facilitated both meetings. The actual combined SCSN and Comprehensive Plan document was drafted by DHEC staff using historical resources, surveillance data, program management experience and all of the community input received during the two stakeholder meetings.

## **Introduction**

Part B of Title XXVI of the Public Health Service (PHS) Act, as amended by the Ryan White HIV/AIDS Treatment Modernization Act of 2006 authorizes the federal Health Resources and Services Administration (HRSA) to award formula-based grants to states to improve the quality, availability, and organization of health care and support services for persons and families with HIV disease. Part B of Title XXVI of the PHS Act was previously referred to as Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, the predecessor statute. The legislation governs the Ryan White program, which is administered by the Division of Service Systems (DSS), HIV/AIDS Bureau (HAB), within HRSA. There are five Parts under the Ryan White legislation. The South Carolina Department of Health and Environmental Control (SC DHEC) is responsible for the administration of the Part B program in South Carolina. The Part B program in each state, as designated by the Ryan White legislation, is responsible for the development of a Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan for all entities in the state receiving Ryan White assistance.

## **Executive Summary**

The 2009 Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan (CP) summarizes HIV-related service needs and barriers across South Carolina, and presents goals and strategies for its evolving HIV service continuum. This document, an update of the SCSN and CP submitted in 2006, has been prepared in accordance with the legislative mandate in the Ryan White HIV/AIDS Treatment Modernization Act of 2006 and accompanying guidelines issued by the federal Health Resources and Services Administration (HRSA).

A multi-step process was employed to prepare this document. For the development of the SCSN a comprehensive review of existing Ryan White services in South Carolina was conducted along with a review of the HIV epidemiological data for the state. A stakeholder meeting was held to gather input regarding the barriers and gaps in the current care system. All of the above information is summarized and organized in separate Sections of the SCSN, as outlined in the Table of Contents. Additionally, at the time of this writing, a Ryan White Part B needs assessment effort is in process and this document will be amended to include the information gained from that project.

The Comprehensive Plan was prepared based on the data and information gathered through the SCSN process, a review and understanding of HRSA's Quality Management requirements and input gathered during a stakeholder meeting designed to develop strategies and activities to address the barriers and gaps in care.

The final steps of the process included presenting the draft document to the South Carolina HIV Planning Council (HPC), the integrated prevention and care planning body in the state.

The needs identified in this document are premised on the epidemiological profile of South Carolina, which, according to the Centers for Disease Control and Prevention, has ninth highest rate of HIV in the United States.

The needs most commonly identified for HIV infected persons can be broadly summarized in the following broad categories:

- Comprehensive health care
- Dental care
- Housing and related support services
- Substance/Alcohol abuse-related services
- Mental health services
- Linguistically and culturally competent services in all settings
- Case management and supportive services that enable linkage with and retention in care, and compliance with medication regimens, emphasizing in particular: transportation, food/nutrition services, legal assistance, entitlements/benefits assistance, family support, peer education and support

The Comprehensive Plan, contained in Section III of this document, includes broad goals, principles and strategies for engaging and retaining all HIV infected persons in early, high quality care and services. In general, the goals address the need to: 1) ensure access to medical care 2) ensure quality of medical care and 3) ensure retention in care.

The Comprehensive Plan describes numerous strategies to further all of the objectives associated with the three broad issue areas and goals.

## **SECTION I: Where Are We Now: What Is Our Current System of Care?**

### **Description of the Ryan White Part B Program**

The SC Department of Health and Environmental Control (DHEC) is the state agency responsible for managing and administering the Ryan White Part B program for the state. The STD/HIV Division in the Bureau of Disease Control receives the funding and manages the Program. The Program Manager, the ADAP Director, a Program Coordinator, a Quality Management Coordinator and the Ryan White Data Manager are the key personnel involved in administering the Ryan White Part B program. Contracts are awarded to service providers on a five-year, competitive cycle and once awarded are renewable annually. Fiscal responsibilities are implemented primarily by DHEC's Health Services Operations unit. This includes managing service provider contracts, disbursing funds, monitoring budgets, etc. Using this system, DHEC has been able to process/disburse funds to contractors in a timely manner.

DHEC awards contracts to HIV service providers in 11 regions of the state. The model of service delivery varies by region, depending upon the number and type of community partners within each region. In two regions of the state, the Ryan White Part B providers provide medical and support services through university based medical clinics and CBO partners. In other regions of the state, the Part B providers work in synchronicity with the Part C providers so that the part B provider is primarily tasked with providing supportive services while the Part C provider focuses on medical care, effectively sharing patients between the organizations. In two regions the Part B and the Part C provider are actually the same organization, thereby making available a virtual one-stop shop for PLWHA. Finally, there is at least one region of the state where the Ryan White Part B provider provides all of the supportive services and contracts for medical care with a network of physicians.

The AIDS Drug Assistance Program (ADAP) supplies medications to PLWHA who are income qualified and assists clients in paying health insurance premiums co-pays and deductibles.

DHEC monitors service provider performance, both fiscally and programmatically. Service providers develop budgets based on local prioritization of needs following Ryan White guidelines. The budgets are submitted to the STD/HIV Division for approval. Upon contract award, fiscal reports are required from each service provider on a quarterly and annual basis. Service providers receive fiscal reports from subcontractors on a monthly basis.

Programmatic monitoring is conducted in a number of ways, including mandatory participation in Ryan White Part B Peer Review Committee meetings held at least quarterly. During these meetings, statewide standards and guidelines for activities such as clinical quality management, case management are developed and agreed upon. Programmatic progress reports, based on information collected in HRSA's Ryan White Program Data Report (RDR) and the information necessary to complete the semi-annual progress report to HRSA, are required to be submitted semi-annually.



## **South Carolina HIV/AIDS Epidemiological Profile**

### **Emerging Epi Trends Affecting HIV Care and Service Delivery in South Carolina**

Rising HIV infection rates coupled with inadequate funding, resources and infrastructures have resulted in a disparate situation in our public health care systems in the South, including the state of South Carolina. The impact of HIV/AIDS on populations that also disproportionately reflect vast poverty and inadequate support continues to fuel the challenges of reducing new infections, identifying infections as early as possible and providing adequate care and treatment.

Four out of ten Americans living with AIDS reside in the South. The South has the highest number of people living with and dying from AIDS in the United States, and of the 15 states with the highest rates of new diagnoses, nine are in the South. These facts and trends are reflected in the HIV care system within the state of South Carolina – a care system that has been consistently under-funded throughout the years. Providers in South Carolina are challenged with caring for increasing numbers of patients in the face of reduced budgets and the overwhelming backdrop of the stigma that surrounds HIV/AIDS in the Bible Belt.

In the United States, as well as in South Carolina, the HIV/AIDS epidemic disproportionately affects African-Americans compared with people of other races and ethnicities. In 2007, there were more than 14,600 people reported to be living with HIV infection (including AIDS) in South Carolina. According to recent data, South Carolina ranked third in the country for the proportion of people living with AIDS who are African-American (72%). The rate of people living with HIV/AIDS per 100,000 is almost six times higher for black males than for white males. While race and ethnicity are not themselves risk factors for HIV infection, African Americans are more likely, due to many years of institutionalized racism, to face challenges linked with HIV risk such as poverty, substance abuse, denial and stigma. These factors present challenges to the care providers around cultural competence and sensitivity. All providers within the care system must address these issues in order to promote increased access to and retention in HIV medical care and treatment.

African-American men account for 15% of the state's population. However, in South Carolina African-American men account for 47% of the people living with HIV/AIDS and 49% of the people recently diagnosed with HIV/AIDS. Among African-American men recently diagnosed with reported risks, most cases (68 percent) were attributed to sexual contact among men who have sex with men (MSM). Heterosexual contact accounts for 26% of all newly reported HIV/AIDS cases in men. About six percent of new cases reported injecting drug use (figure 2).

There are more than 6,900 African-American men living with HIV/AIDS in South Carolina. More than 2,600 of those men reported sexual contact with other men as the primary risk factor. The majority of those men (48%) are between 30-44 years of age.

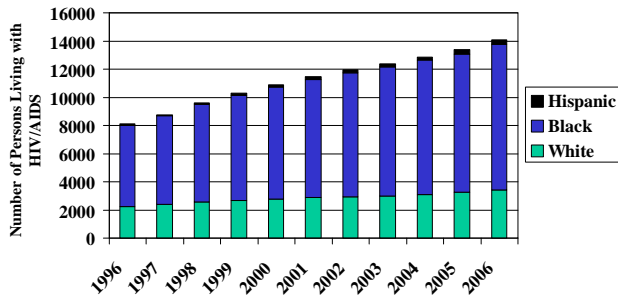
Recent years have revealed a growing Latino population in South Carolina and an increased number of HIV infections among Latinos. Latinos represent 2% of South Carolina's population and they represent 2% of those living with HIV/AIDS in South Carolina. However, Latinos

represent 5% of new HIV infections in South Carolina therefore, despite the relatively small proportion, this increasing trend cannot be ignored. Again, the care system must be enhanced to be able to reach out to the Latino population.

Following is a summary of the South Carolina HIV Epidemiological Profile. It is included in its entirety as Appendix 1.

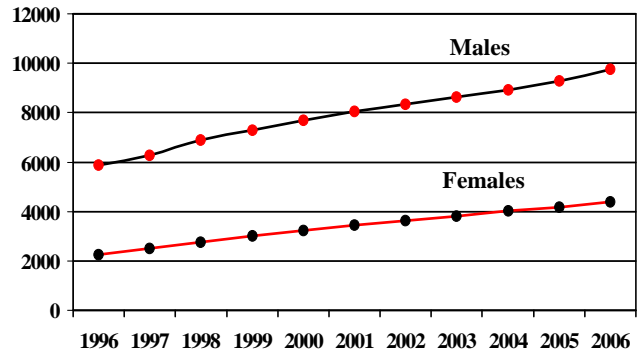
South Carolina has experienced a 5% increase of persons living with HIV/AIDS from the end of calendar year 2005 to 2006. At the end of 2006, there were 14,122 persons estimated to be living with HIV (including AIDS) in South Carolina (Fig. 1), excluding persons diagnosed in other states who now live in the state. At the end of 2006 there were 7,026 people living with AIDS, 6,648 living with HIV (non-AIDS), and 1,329 new AIDS cases diagnosed for 2005/2006. For most demographic categories, the proportion of cases is essentially similar for each these disease indicators. African Americans continue to be disproportionately impacted with HIV, especially African American men. Nearly three of four persons living with HIV, AIDS and newly reported with AIDS are African American, and about 25% are white/Caucasian. Two percent (2%) of persons living with HIV and AIDS are Hispanic, slightly lower than new (incident) AIDS cases (3.5%). Figures 1 & 2 below show the growing number of persons living with HIV disease (including AIDS) by race/ethnicity and gender. *Note: S.C.'s Epi Profile data used for Figures 1 – 5 analyzes HIV disease trends using the total of HIV cases including persons with AIDS, which differs slightly from the data in Attachment 4.*

**Fig. 1 Number of Persons Living with HIV/AIDS in South Carolina by Race, 1996 - 2006**



*\*provisional data; death updates not available*

**Fig. 2 Number of Persons Living with HIV/AIDS in South Carolina by Gender, 1996 - 2006**



*\*provisional data; death updates not available*

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Men comprise the majority of living and incident cases; over one third (34%) of persons living with HIV (non-AIDS) are women, compared to 28% of persons living with AIDS. This may be a result of the past decade shift of the epidemic to women, or more women are being diagnosed in earlier stages of disease than men. The higher proportion of women living with HIV (non-AIDS) compared to incident and prevalent AIDS cases may also be due to more women accessing HIV care and receiving antivirals, delaying or preventing onset of AIDS defining conditions.

More persons in the 20 – 44 year age group are affected with new AIDS diagnosis (64% of total cases) and living with HIV (59%), compared to persons living with AIDS (51%). South Carolina has observed an increasing case rate among persons aged 20 – 24 years for HIV/AIDS cases newly reported during 2005/2006 (Fig. 4).

Nearly 800 persons are newly diagnosed with HIV (including AIDS) in South Carolina annually. Figures 3 & 4 below, from S.C. Epi Profile data, compare the numbers of recently diagnosed cases of HIV (including AIDS) in South Carolina during 2005 and 2006. There are no significant changes noted for most demographic categories for the two years. As noted above, there are more cases diagnosed among younger persons (20 – 24 yrs.); 57% of new cases in this age group are African American men. The predominant exposure category reported was male-to-male sex.

**Fig 3. Number of S.C. HIV/AIDS Cases by Race/Ethnicity/Gender, Diagnosed 2005 & 2006**

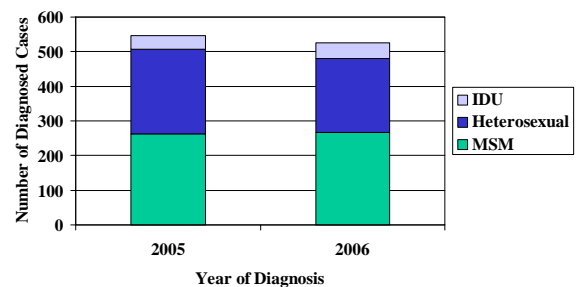
Race/Ethnicity/Gender	CY 2005	CY 2006
Black Men	367	369
Black Women	184	192
White Men	136	136
White Women	43	43
Hispanic Men	27	25
Hispanic Women	5	9

**Fig. 4 Number of S.C. HIV/AIDS Cases by Age, Diagnosed 2005 & 2006**

Age	CY 2005	CY 2006
15 -19 years	28	35
20 - 24 years	100	121
25 - 29 years	86	102
30 - 44 years	343	294
45+ years	203	223

By exposure category, the HIV/AIDS epidemic in South Carolina continues to be primarily men who have sex men and heterosexual (each about 40% of prevalent and incident cases among persons with reported risk). Injecting drug use is not a major transmission category in SC, comprising 18% of persons living with HIV/AIDS. Comparing recently diagnosed HIV/AIDS cases by exposure category (Fig. 5), shows similar proportions for 2005 & 2006. Compared to living cases, injecting drug use accounts for 9% of new diagnosed cases with risk reported.

**Fig. 5 Number of S.C. HIV/AIDS Cases by Exposure Category\*, Diagnosed 2005 & 2006**



\*Excludes cases with no risk identified

## **South Carolina's Response to the HIV Epidemic**

South Carolina first received Ryan White funding in 1991 with an award of less than \$700,000. At that time there were only three Ryan White service providers in the community and an AIDS Drug Assistance Program managed by DHEC. That year the service providers served 193 people living with HIV/AIDS and the ADAP, with a formulary that included only AZT, served 301 people.

The state's care system has expanded and evolved over the past two decades to meet the needs of the changing epidemic. Currently there are 18 Part B service providers, 10 Part C service providers, 6 Part D service providers and an ADAP with over 60 drugs on the formulary. Total HRSA funding in the state for PLWHA is almost \$35 million.

The service providers continually adjust their services in response to the needs of the PLWHA in the state. For example, due to the increased proportion of women infected with HIV, South Carolina's care system responded with the creation of a women's clinic at the University of South Carolina using both Part B and Part D funding. The USC women's clinic also links infants born to pregnant women to pediatric care. Additionally, at the Medical University of South Carolina in Charleston the Part B and Part D programs work together to ensure that women who are bringing their perinatally infected children to the pediatric clinic can be seen in the adult HIV clinic on the same day.

Approximately 30% of the HIV epidemic in South Carolina is located in extremely rural areas with little or no access to public transportation. The care system has evolved to serve the current demographics of the epidemic; Ryan White care providers continue to create innovative ways to address transportation issues – particularly in rural areas. Ryan White care providers assist with transportation through gas vouchers, bus tokens, volunteer drivers, contracts with rural transit authorities and coordination with the Medicaid van services.

Finally, care providers have responded to the disproportionate impact of the HIV disease on African Americans by providing culturally appropriate care. Culturally competent staff are hired and trained in order to provide optimal care and services to various minority and vulnerable populations. Minority AIDS Initiative (MAI) funding was first received from HRSA in 2001 (\$162,085) for the purpose of providing education and outreach services that are intended to increase access for racial and ethnic minorities to ADAP or other prescription drug assistance programs.

While MAI funding has remained steady with only a slight increase by 2008 (\$176,539), through the leveraging of resources South Carolina is able to provide the following MAI services in selected areas of the state: Transitional Case Management to Link Ex-Offenders to HIV Care; Health Promoters for Adherence Support; and Short-Term Case Management to Link Newly Diagnosed to HIV Care.

## **Statewide Coordinated Statement of Need**

### Participation and Input

This SCSN was developed collaboratively with input from a wide variety of stakeholders including PLWHA, providers, public agency representatives, Ryan White funded programs, and state agencies. DHEC is currently working to establish stronger relationships with the state Medicaid agency and the state Mental Health provider.

On October 15, 2008, a consumer Town Hall Forum was held in Columbia, South Carolina as a mechanism for PLWHA to express their needs and voice their opinions about HIV care and prevention services being delivered in South Carolina. The results of that forum are included in the description of need section.

In addition to the information gathered from the stakeholder meeting and the Town Hall Forum, SC DHEC has contracted with Public Consulting Group to conduct a consumer survey of the eleven Ryan White Part B providers that are under direct contract with DHEC. The survey is designed to assess barriers to care and gaps in services for PLWHA who seek care at Ryan White Part B agencies across the state. At the time of this writing the survey team is conducting surveys at agencies across the state. We expect to receive the full results of the survey by February 2009 and these results will be submitted as an amendment to this document.

### Legislative Requirements

As a part of the SCSN, we are asked to describe the efforts we have taken to meet the new Ryan White legislative requirements in our state. The Ryan White care system in South Carolina has long been operating with limited resources and inadequate funding. Therefore, the new legislative requirements of the HIV/AIDS Treatment Modernization Act of 2006 have not had an impact on service delivery in South Carolina. We continue to maximize our resources and prioritize medical care and core services over support services.

South Carolina has developed and implemented a Quality Management program that will allow the measurement of common outcomes for all providers across the state. The Quality Management program is described in detail in Section IV of this document.

### Unmet Need Analysis

An unmet need analysis is conducted each year in South Carolina to determine the number and type of people who are not in care. This data allows us to establish outreach programs that target particularly those who have fallen out of the care system.

The unmet need analysis is conducted using a database of all CD4 and Viral Load tests that were performed throughout the year. South Carolina mandated reporting of all CD4 and viral load tests effective January 2004. During the first six months of 2004, surveillance staff worked to assure that all laboratories were reporting completely. With a laboratory based reporting system, we feel confident that we are not missing any individuals because of failure to report. Each year

we are able to conduct an assessment of the database to determine the number of individuals who accessed care during the year. The following are the results of the assessment for calendar year 2007.

**Population estimates:**

- a) number people living with HIV/non-AIDS who know their status = 6,963
- b) number people living with AIDS who know their status= 8,502

**Estimates of people in care:**

- a) estimate of number and percent of PLWH/non-AIDS/aware who received HIV primary medical care = 3,049 (44%)
- b) estimate of number and percent of PLWA who received HIV primary medical care = 5,760 (68%)

**Estimates of unmet need:**

- a) estimate of number and percent of PLWH/non-AIDS/aware who did *not* receive HIV primary medical care = 3,914 (56%)
- b) estimate of number and percent of PLWA who did *not* receive HIV primary medical care = 2,742 (32%)

To summarize the unmet need data, as expected, a larger percentage of AIDS patients seek medical care, 68% versus 44%. A larger number of females (61%) than males (55%) seek medical care. Blacks seek medical care most often (58%) followed by whites (56%) and Hispanics (45%). Urban patients seek care less often (56%) than rural (58%).

Description of the Ryan White Care System in South Carolina

There are 11 primary Part B service providers throughout the state. There are 46 counties in South Carolina with three primary distinct regions – the Upstate, the Midlands and the Lowcountry. Each county is served by one of the 11 Part B service providers depending on geographic proximity to the service provider. While many patients in the outlying rural areas must travel to receive services, there are more and more options for care closer to home. For example, the University of South Carolina that hosts a full time Ryan White clinic in Columbia also provides medical care in rural Sumter County one day each week. Also, Catawba Care Coalition, the Ryan White service provider based in Rock Hill, offers clinical services at sites in Chester and Lancaster counties.

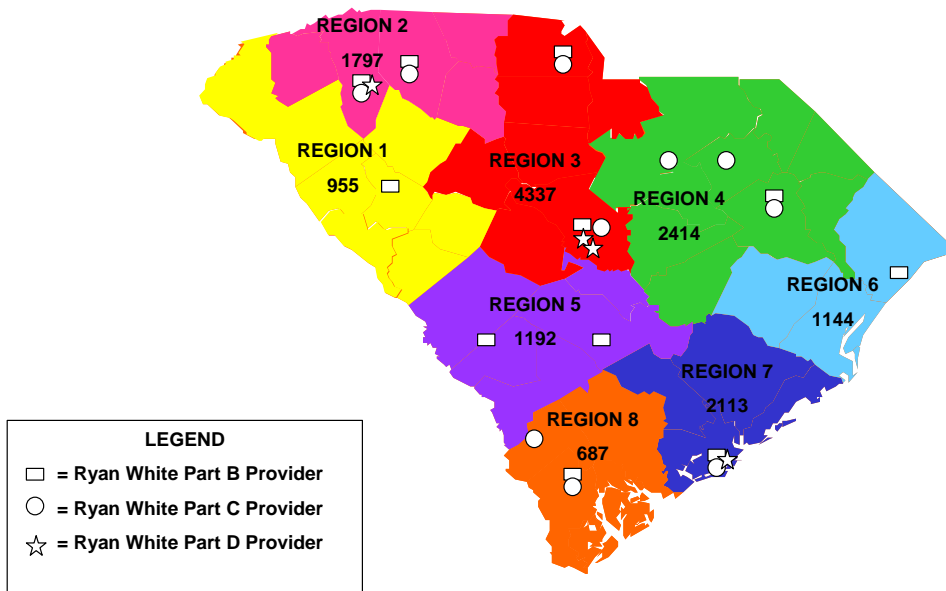
There are currently 10 Ryan White Part C service providers in South Carolina with only one region (Upper Savannah) lacking access to a Part C provider. The Ryan White Part C providers have formed strong partnerships with Part B providers in several regions of the state. We continue to promote effective working relationships among all the Ryan White Parts in each region of the state. As a result of these strong partnerships we have been able to maximize resources and prevent the duplication of services.

There are 6 Ryan White Part D service providers in South Carolina - 4 medical clinics (three pediatric clinics and one women's clinic) and two community-based organizations that employ

consumer advocates. The Part D providers focus on caring for women and children. Services include primary medical care, medical case management and peer advocacy.

The map below indicates the location of each Ryan White provider with an overlay of the number of PLWHA in each region of the state. It should be noted that HIV services have followed the HIV epidemic in South Carolina.

### Ryan White Care Providers in South Carolina and Number of People living with HIV/AIDS by Region, 2007



The AIDS Drug Assistance Program is managed through DHEC and provides medications and insurance assistance to those who are income qualified. The ADAP formulary includes over 60 medications and the program serves over 3,000 clients annually.

Specific local service provider services that have been identified for funding in FY 2009, based on the Needs Assessment efforts and the statewide Comprehensive Plan include (but are not limited to): Ambulatory/Outpatient Medical Care, Medications, Oral Health, Mental Health Services, Substance Abuse Services, Medical Case Management, Treatment Adherence/Compliance, Housing, Nutrition, Transportation, and Health Education/Risk Reduction. During 2008, the program has reviewed service priorities with each Ryan White Part B service provider to demonstrate that at a minimum 75% of funds are being expended on core services.

The services that will be provided in FY 2009 will address the needs of the emerging rural, impoverished, men who have sex with men (MSM) and Hispanic communities in South Carolina. Providing satellite services in the rural areas, including medical care, transportation, medical case management, outreach and education, mental health services and substance abuse services will empower these groups to enter and maintain care services.

The Ryan White Parts B, C and D service providers provide an array of services that will help clients establish and maintain medical care compliance. Treatment adherence counseling is an integral part of medical and supportive services and all Ryan White patients receive treatment adherence messages in the clinical and support services settings. Health Education/Risk Reduction services and Medical Transportation services also ensure that clients will remain engaged in HIV/AIDS primary medical care and adherence to HIV treatments.

South Carolina provides services to women, infants, children and youth in excess of the proportion to the percentage of the AIDS cases represented by each population. Ryan White Part B providers of care have typically exceeded every population with the exception of children ages 2-12 years and youth ages 13-24 since these populations are covered through Medicaid. Data from Medicaid and Ryan White Part D document service provision to this population. The following table illustrates the numbers served in each category and the related expenditures for South Carolina's Ryan White Part B program for 2007.



**Documented State of South Carolina Part B Expenditures by WICY Subgroup in FY2007**

Subgroup	Total Required Expenditures*	Expenditures From ADAP & Part B**	Expenditures From Medicaid*** (CY 2007)	<b>Total</b>
Women	\$ 8,315,022	\$ 8,723,909	\$21,843,985	<b>\$30,567,894</b>
Infants	\$ 2,784	\$29,335	\$372,864	<b>\$402,199</b>
Children	\$ 133,619	\$ 39,701	\$1,307,917	<b>\$1,347,618</b>
Youth	\$ 1,105,143	\$ 709,317	\$4,075,357	<b>\$4,784,674</b>

\* calculated from HRSA/CDC estimates of PLWA in SC

\*\* documented Part B expenditures calculated from number of individuals served by subgroup for FY 2007. Due to recent data system conversion, ADAP numbers represent FY 2006 but will be updated as data becomes available.

\*\*\* data source: South Carolina Office of Research and Statistics

In addition to all of the Ryan White providers in the state, the state Medicaid system serves many PLWHA each year. In calendar year 2007 there were 3,233 PLWHA in South Carolina served by Medicaid with expenditures of almost \$50 million.

A complete chart describing South Carolina’s HIV services network is included as Appendix C of this document.

Ryan White Data Summary

The Ryan White HIV/AIDS Program Data Report (RDR) is an annual report that captures information regarding the services provided by all Ryan White funded entities. The RDR is divided into sections including: service provider information; client information; service information; HIV counseling and testing; and medical information. Providers report on all clients who received services eligible for Ryan White Parts A, B, C or D funding regardless of the actual funding source used to pay for those services. The South Carolina Ryan White Part B contractors complete the RDR forms and submit them to DHEC. DHEC assembles all of the reports and submits the data to HRSA. Ryan White Parts C and D providers submit their RDR data directly to HRSA.

For the purposes of this document, we used 2007 RDR data to produce the following summary data tables.

The first table is a demographic breakdown of people served through South Carolina’s Ryan White care system in calendar year 2007. It should be noted that the demographics of the clients in the RW care system closely mirror the demographics of the HIV epidemic in South Carolina.

<b>Ryan White 2007 Information</b>	
<b>Gender</b>	<b>HIV Positive</b>
Male	5,352
Female	3,385
Transgender	23
Unknown/Unreported	-
<b>Total</b>	<b>8,760</b>
<b>Age (at end of reporting period)</b>	<b>HIV Positive</b>
Under 2 years	171
2-12 Years	112
13-24 Years	479
25-44 Years	4,314
45-64 Years	3,511
65 Years or older	173
Unknown/Unreported	-
<b>Total</b>	<b>8,760</b>
<b>Race</b>	<b>HIV Positive</b>
White (not Hispanic)	1,963
Black or African American (Not Hispanic)	6,346
Hispanic or Latino	268
Asian	17
Native Hawaiian or Other Pacific Islander	2
American Indian or Alaska Native	13
More than one race	131
Unknown/Unreported	20
<b>Total</b>	<b>8,760</b>

**Note:** The data in this table does not include data from Sandhills Medical Foundation and CareSouth Carolina. Both agencies are Ryan White Part C providers that did not respond to this particular data request. It should also be noted that the data is unduplicated among all Part B providers and four of the eight Part C providers that submitted data. There may be some duplication due to the four Part C providers and the 4 Part D providers that do not use the Provide Enterprise data system as endorsed by the South Carolina Department of Health and Environmental Control for its Part B contractors.

The following table shows the number and type of services that were provided through the Ryan White care system in South Carolina during calendar year 2007. It should be noted that outpatient/ambulatory medical care and medical case management are the two services provided most often. We still lack significant services in other areas such as oral health, mental health and substance abuse.

**2007 Ryan White Service Data**

<b>Core Services</b>	<b># Clients</b>	<b># Visits</b>
Outpatient/ambulatory medical care	6,470	31,068
AIDS Pharmaceutical Assistance (local)	105	-
Oral health care	1,035	2,275
Early intervention services (Parts A and B)	-	-
Health insurance premium and cost sharing	229	685
Home health care	3	3
Home and community-based health services	16	20
Hospice services	2	3
Mental health services	660	1,622
Medical nutrition therapy	675	1,412
Medical case management (including treatment adherence)	6,776	44,233
Substance abuse services-outpatient	547	1,106

**Note:** The data in this table does not include data from Sandhills Medical Foundation, a Ryan White Part C provider that did not respond to this particular data request. It should also be noted that the data is unduplicated among all Part B providers and four of the nine Part C providers that submitted data. There may be some duplication of numbers due to the five Part C providers and the 4 Part D providers that do not use the Provide Enterprise data system as endorsed by the South Carolina Department of Health and Environmental Control for its Part B contractors.

## Description of Needs

### ***Stakeholder Meeting***

To identify the needs described in this plan, a one-day meeting was convened with forty (40) stakeholders on September 17, 2008, in Columbia, South Carolina. The table below provides a tally of the types of stakeholders in attendance.

<u>Stakeholder</u>	<u>Attendance</u>	<u>Stakeholder</u>	<u>Attendance</u>
PLWHA	5	Part B + C	3
Part A	1	Part B + D	1
Part B	10	DHEC	8
Part C	6	ADAP	1
Part D	3	Alcohol / Drug	1
		AETC	1

An external consultant, David Napp of Practical Applications of Public Health, was contracted by DHEC to design and facilitate the meeting, and produce this report. During the meeting, participants reviewed the needs identified in the 2006 SCSN and engaged in a series of small group discussions and report outs focusing on two key questions:

1. What makes it difficult for PLWHA who are in care to stay in care?
2. What makes it difficult for PLWHA who are not in care to enter the care system?

Small group reports and the ensuing discussion with the large group was audio taped and transcribed. Transcripts were reviewed by the consultant to identify the issues described in this report and representative quotes were selected for inclusion herein to illustrate key issues. Although the primary purpose of the meeting was to identify needs, participants occasionally offered suggestions for solutions or made observations about how some issues have improved. These comments are also included in this report and provide a springboard for subsequent development of the Comprehensive Plan.

### **Barriers for PLWHA in Care**

The following barriers were identified as being common across services for PLWHA in care. Three categories of barriers are described below. They are not listed in priority order.

1. Client-related barriers: these barriers include characteristics of clients that impeded access to care
2. State and local care system barriers: these barriers describe system characteristics that impeded access to care
3. Federal-level barriers: these barriers include national issues that affect the state and local care system

## 1. Client-Related Barriers

Lack of **transportation** is a wide-spread barrier to health care for many people in South Carolina, including PLWHA. Transportation barriers limit access to and compliance with services for PLWHA, especially in rural areas of South Carolina where the public transportation infrastructure is non-existent. This issue is particularly salient given the recent dramatic increase in gasoline prices, which affects individuals with their own means of transportation as well as agencies that provide transportation assistance.

*“Transportation is actually much bigger than HIV and has to be placed in a much wider context as far as disparity and inequality. We need to be looking at transportation for everybody because that has come up every single year we talk about barriers in care, and if we did the same exercise ten years ago, housing and transportation, I’m sure, would be on the top of the list. But we need to figure out housing for everybody, transportation for everybody, which of course affects our patient population.”*

Lack of **housing** hinders clients’ ability to access and comply with HIV-related services and treatment because of the relative priority and immediacy individuals place on securing safe, stable housing versus seeking health care, especially if they are asymptomatic. Inadequately housed PLWHA have difficulty with receipt and storage of and compliance with medications. As cited in the Universal Declaration of Human Rights, poor living conditions, including overcrowding and in extreme cases, homelessness, undermine safety, privacy and efforts to promote self-respect, human dignity and the attendant responsible sexual behavior. Also mentioned in the Universal Declaration of Human Rights is the fact that the lack of stable housing directly impacts the ability of people living in poverty to reduce HIV risk behaviors and homeless and unstably housed persons are two to six times more likely to use hard drugs, share needles or exchange sex than similar persons with stable housing.

*“It’s not just homelessness that is an issue but back to your Maslow’s hierarchy of needs in that people are looking for a place to live before maybe they’re getting into care.”*

Many clients have unmet **mental health and substance abuse** needs which impact their ability to stay in the care system. These barriers are particularly salient given the limited financial and organizational resources available to address these needs. Ryan White providers have limited resources to provide mental health and substance abuse counseling on site and the overall state system of care for people with mental health and substance abuse issues is lacking. Without an overall change in the statewide system, clients will continue to struggle with these issues that prevent their access to and retention in HIV care.

*“There are times when our clients come out of care and we don’t know about it, and they might be dealing with some mental health issues or substance abuse issues that will force them to be noncompliant and drop out of care.”*

Older clients who have been HIV+ for a long time may be **fatigued** with the long-term process of managing their illness, similar to the way people may tire of managing other chronic illnesses such as diabetes or hypertension.

*“We hear from clients a lot, particularly those clients that are maybe 65 or 70 years old that ‘I’ve been doing this my whole life, I’m just tired of going through the process. I’m tired of going to the doctor all the time. I’m tired of having to worry about it.’ And you can’t blame them in a way. I think it’s the same with other chronic illnesses, like diabetes. That’s why we’ve got fatigue and it can be a barrier to staying in care if they’re tired of it.”*

Clients do not always understand the **administrative requirements** necessary to access Ryan White services and may find the paperwork and eligibility process burdensome and confusing. Other clients may feel a **sense of entitlement** with regard to the types or level of services and assistance they believe should be available to them.

*“It’s hard getting clients to understand why it’s important to go get this form and why this has to be completed and how it has to be completed and to understand the steps of the system to get ADAP or patience assistance.”*

*“We have clients that don’t even know about Ryan White services. But then you have to balance telling them what you can provide versus other clients who feel this sense of entitlement. So it’s a juggling act between telling them what you can provide and making sure that they’re not abusing the system.”*

The client related barriers to care are inadequate transportation, inadequate housing, unmet mental health and substance abuse needs and burdensome administrative requirements. While these needs are not new to South Carolina, they remain strong barriers for individuals living with HIV/AIDS to enter and remain in care.

## **2. State and Local Care-System Barriers**

Lack of **Spanish speaking** providers and translation services makes it difficult to meet the needs of an increasing population of Hispanic clients. Recent statistics have indicated that South Carolina has the fastest growing Latino population in the nation. Latinos represent 2% of South Carolina’s population and they represent 2% of those living with HIV/AIDS in South Carolina. However, Latinos represent 5% of new HIV infections in South Carolina therefore, despite the relatively small proportion, this increasing trend cannot be ignored. Currently available translators may not all have sufficient medical background to convey complex information about HIV care.

*“We have Hispanics that come into care and because of the language barrier we don’t have an interpreter or ability to support their understanding of what’s going on with them and they wind up moving out of care, going maybe somewhere new and we don’t have information on that.”*

*“We have quite a few Hispanic clients and I wonder when I'm speaking if that translator is telling that person what I'm saying. I don't know if they're not understanding because that translator is just basically repeating what I'm saying and not really having the medical background to back that up. To me that seems like the language barrier and that's why they're not understanding.”*

There are insufficient financial and organizational resources to address the **mental health** needs of PLWHA, which impact access to and compliance with many types of services. As mentioned above, the State mental health system is over-burdened and under-funded and only provides care to people with severe and persistent mental illness. For clients who suffer from varying levels of depression (that prevent them from accessing care and remaining in care), Ryan White providers must identify other funding sources to provide adequate mental health services.

*“I know a provider who reached out to the mental health agency and what she's gotten back is that they do not have the time, do not have the energy, don't have the staff, and don't have the personnel. They can barely do what they need to do let alone talk about HIV.”*

*“There is a lack of mental health representation in the HIV care system. We've got people who are doing mental health services, but when it comes to the South Carolina Department of Mental Health, there is not a person who is the HIV person or who can come and represent that agency.”*

Real and perceived **stigma** about HIV, sexual orientation, mental health, and substance abuse impacts the availability and accessibility of services as well as clients' willingness to access care. “Social conservatism is more pronounced in the South compared to the rest of the nation. Shame and fear of stigmatizing reactions on the part of others may lead to reluctance to seek testing and treatment for HIV or other STDs. Men who have sex with men (MSM) may be less likely to be open about their sexual behaviors in such communities and may concurrently be sexually involved with women, who in turn may be unaware of the risk posed to them by their partners' MSM behaviors. Anecdotal evidence across the South indicates that the prominence of the church, with its sexual prohibition, intensifies fear of stigma. (Southern AIDS Manifesto: Updated 2008)” The informants for this report indicated that stigma is the number one barrier to accessing anything to do with HIV.

*“Stigma is just huge about not wanting to come to an AIDS clinic where it says ‘HIV Clinic’ or is perceived as the HIV clinic.”*

*“There's still this undercurrent of homophobia among providers; there's still an undercurrent, or at least a perceived undercurrent.”*

Opportunities for **peer involvement** to serve as adjunct service providers have been limited by the shift toward medical case management. In addition, peers may not always be appropriately matched to opportunities to be involved and their role may not always be valued by all providers

within their care system. Lack of adequate Ryan White funding prevents service providers from being able to provide quality, effective peer-based services.

*“Peer educators are still underutilized and under funded. And the move to medical case management put new standards on anything that was kind of in a case management category, which peers could somewhat have done.”*

**Incarceration** can cause a disruption in care for PLWHA who do not disclose their HIV status and, upon release from prison or jail, clients may not prioritize accessing care relative to their other needs or interests. South Carolina has a discharge planning process for those who are coming out of the state correctional system but the local jail system is fractionated with not one clear policy on treatment and linkage to care for PLWHA.

*“Folks who get arrested while they're in care can have an interruption in services. For some folks, they'll go in there and say, ‘you know, I'm HIV+, and I'm in care’. But a lot of folks will not say anything, and so there's disruption in care.”*

*“For folks in incarceration is there a system in terms of linkage to prepare someone who has all those other things that you have to worry about? Are you really going to go into medical care after release from prison?”*

State and local care systems are rendered less than effective by the shifting demographic and influx of Spanish speaking HIV infected clients. The language barrier in a state that has not previously experienced non-English speaking clients has presented new hurdles. Mental health continues to be a concern as infection in psychiatric consumers continues to rise. The HIV rates among persons with serious mental illness are much higher than the estimated .6% prevalence in the general U.S. population (Meed & Weiss, 2007). The overburdened systems in South Carolina are no exceptions. The institutionalized issues of real and perceived stigma associated with HIV infection continues to be a tremendous barrier to getting and keeping individuals in care. Incongruent opportunities for peer involvement have excluded those individuals that are most likely to be effective treatment adherence coaches. Finally, the corrections systems include a myriad of correlations to the interruption of treatment.

### **3. Federal-Level Barriers**

Federal **emphasis on primary care** has limited the state and local system’s capacity to provide support services such as housing and transportation that are often prerequisite to addressing clients’ medical care needs. South Carolina is bound by the Ryan White legislation to spend at least 75% of Ryan White funds on HRSA’s core services. While South Carolina Ryan White providers have always focused on the core services – even before it was legislatively mandated, this focus has come at the expense of important support services.



*“Administrative barriers come from way above the care providers and one of those issues is the move away from supported services towards primary care services. Of course this is a good thing but it does cut down a lot of these things that are on our list of barriers, such as housing, transportation, and all these huge barriers. HRSA is actually telling us, ‘forget about those, concentrate on primary care.’ Well, how do we do that when we don't address the support needs?”*

**Administrative requirements** from federal funders related to quality improvement and accountability has placed an increasing administrative burden on the care system, which takes time and resources away from addressing client needs. For example, the lack of data infrastructure and personnel dedicated to managing agency data often results in front line staff (case managers and case manager supervisors) becoming over-burdened, stretched and burned out because they are fulfilling both roles. South Carolina has a very streamlined and efficient approach to data collection and reporting but it still requires the dedication of significant personnel resources to manage an agency’s quality initiative and ensure compliance with all of the federal requirements.

*“There's more and more focus on data collection, quality improvement, and getting things to where they're supposed to be that the time spent on actual case management and talking to the patient is diminished. So how the heck are we supposed to do all this extra stuff with less time and less people and less money! It just seems like you're in a rat race, like a hamster going around in a wheel.”*

National **funding and research priorities** are not aligned with the growing epidemic in the Southeast region of the United States. As cited in the Southern AIDS Manifesto: Update 2008, “rising infection rates coupled with inadequate funding, resources, and infrastructures have resulted in a disparate and catastrophic situation in our public health care systems in the South. Characterized by pervasive poverty, lack of adequate services and infrastructures, unemployment and uninsured individuals, the South is faced with a crisis of having to provide medical and support care for increasing numbers of infected individuals without adequate funding.”

*“The money is not following the disease. The epi map of the United States shows that the disease is concentrated in the South, but the funding has not followed that as of yet. So our ability to provide all these services – transportation, housing and on and on – is tied to that funding.”*

*“There's a federal project finding out why people are not in care. There are five states participating. They're all northeast! But people in the Northeast and their barriers are not the same as the barriers in the South. If the majority of the epidemic is in the South and they're finding out the barriers in the North, then there's nothing in the data that's going to be relevant to help me do my job. So right away, you see just how the direction of the federal funding and thought pattern and attitudes are focused.”*

“Flat based funding coupled with CDC rescission for multiple years has resulted in all programs across the country being forced to make choices between needed service. While the funding levels for many southern states has increased and some may argue that is a bit more equitable in terms of distribution, the fact remains that the overall funding for every state is inadequate. The impact of these shortages results in higher cases of HIV and STD and less access to care and treatment. (Southern AIDS Manifesto: Updated 2008)”

## **Barriers for PLWHA Not in Care**

The following barriers and gaps were identified as being common across services for PLWHA not in care. Two categories of barriers are described. They are not listed in any priority order.

1. Client-related barriers include characteristics of clients that impeded access to care
2. State and local care system barriers describe system characteristics that impeded access

### **1. Client-Related Barriers**

Clients who have previously been in care and dropped out may find the **administrative process to re-enter the care system** to be burdensome or confusing. As with many health care programs, there are multiple documentation requirements for clients to access Ryan White care and services. Providers must have enough personnel resources to be able to assist clients in navigating the paperwork requirements.

*“Just dealing with different processes of coming back into care can be hard. If you've been out of care you still have to go through case management and do the forms and stuff and it's like the beginning all over again, so that part can be a problem.”*

*“I've got ten ADAP applications permanently on my desk waiting for that income statement that the client has to get to me. They know where to go and get what they need. But they don't want to turn it in because if their income has changed, they don't want to lose their benefits. And sometimes it may be an unfounded fear. Maybe they actually are eligible for more benefits than they think, but any change is very stressful. Another reason is that Social Security Administration is the most difficult federal agency to deal with that there is, even worse than the IRS. You have to go down there, take a number and wait in line all day.”*

**Feeling of personal failure** may make it difficult for some clients who have dropped out of care to re-enter the care system

*“Sometimes patients may identifying with their case manager or the staff and then when they miss an appointment, they feel like they're letting the clinic staff down or their provider down, so they stay out and say, ‘no, I'll go next time’, and next time turns into one month, three months, and then they're just out of care. That's something that occurred in our clinic. It's not an excuse but it's just they put it on*

*themselves and just stay out.”*

Clients’ **fear** of their diagnosis and **denial** about their HIV status may prevent them from accessing care.

*“When someone tests initially and they don't come back for their results that's another reason why people are not in care, because they don't really know their status. So the barrier is a fear of knowing, basically, if they have HIV or AIDS.”*

**Asymptomatic** clients may not feel compelled to seek services, especially in light of the shift toward thinking of HIV as a long-term chronic illness.

*“Although there is an attitude of fatalism because there is no cure, we think also that because HIV is becoming more of a chronic disease and more manageable and treatable, that the opposite of that may be occurring now; that there's more complacency. Clients think, I don't need them right now, I don't feel bad, and they'll be there when I do need them, so I'm not going worry about getting into care at this point.”*

*“In this country as a whole, as far as healthcare is concerned, prevention's just not a priority. People should know that they shouldn't eat x, y and z because they're going to get heavy and get heart disease and diabetes. Prevention in the HIV community is the same thing. People think, I feel fine now, I'll just wait until later, until I get sick, and then they can take care of me and fix me up.”*

Fear of **domestic violence** may prevent clients from accessing care because they do not want to disclose their status to their partner.

*“Fear of violence and domestic violence can be an issue. For a lot of folks we need to find out if there are any situations that could cause them to avoid coming into care for fear of a domestic violence situation.”*

Clients may not access care because they believe **religion or other “therapies”** will heal them.

*A lot of people will say that, "God will heal me; God will take care of me.”*

Clients may find the **medical system is overwhelming** and drop out of care.

*“The fear of the medical community and the process in general, just that it is an unknown. If you haven't been in medical care, this whole system that you're entering into is unknown, and you're not comfortable with that, so you're less likely to go.”*

**Other issues** identified in the 2006 SCSN that participants felt were still salient include:

- Substance abuse and mental health problems

- Competing priorities, poverty, and homelessness
- Depression with feelings of helplessness and hopelessness
- Attitude of fatalism because there is no cure
- Fear of breaches in confidentiality
- Fear of losing kids or being deported for undocumented individuals
- Client not understanding the difference between HIV, AIDS, and disease management
- Clients not knowing where to go for help
- Language barriers and health illiteracy

As illustrated above, there are a broad variety of reasons an individual may not be in care ranging from paperwork to denial to domestic violence. For every individual not in care there is an unique barrier or set of barriers, real or perceived, keeping them from accessing care. The Ryan White care system in South Carolina must be flexible and creative enough to address these needs in order to ensure optimal health for all PLWHA and the public health of the state.

## 2. State and Local Care-System Barriers

Clients may **not feel comfortable** engaging with a care system that appears to be different from their own culture, race, ethnicity, sexual orientation, and/or language. South Carolina HIV providers must continue to recruit, hire, train and retain culturally competent staff in order to provide optimal and relevant services to those in the care system.

*“We may lose people just because the providers may not mirror the population. Our example was a white person goes into the clinic and everybody in there is black and they think, ‘oh, gosh, I don't feel welcome here,’ and they don't come back. Or the opposite, because you may be a woman, and you go in, they're all male. Or a male goes in and you have a lot of women there.”*

*“Whenever I go for services, as a consumer, whether I'm going to an agency that does case management or I'm going to the doctor, I rarely see any materials out in Spanish. There's a really great supplement for newly diagnosed people that POS released in English and Spanish, and I read the thing, and I thought, ‘God, this is good. I wish somebody had given me this when I was first diagnosed ten years ago’.”*

**Stigma** about HIV among providers and community at large can discourage clients from accessing care. Again, stigma is the backdrop behind all of the issues of access to and retention in care and must be addressed both individually and on local and statewide levels.

*“With the MSM upward trend in infections it could be that people feel there's an underlying homophobia in the community with providers that may be keeping some people out of care.”*

*“In all our clinics we find people that don't come to our specific clinics because they know somebody who works there or they know somebody who's a patient there and they want to be anonymous about being positive.”*

*“Stigma is still the number one barrier to accessing anything to do with HIV.”*

**Other issues** identified in the 2006 SCSN that participants felt were still salient include:

- Lack of transportation to services
- Bad first experience with the care system during post-test counseling or DIS contact
- Poor linkages between receiving a positive test and referral for services
- Poor linkages between jail discharge and the HIV care service system
- Long waiting times for appointments or in waiting room
- Experiences of being treated with disrespect by providers or other agency staff
- Side effect of medications

### **Potential Solutions**

As a pre-cursor to the comprehensive plan, the following is a list of suggestions from meeting participants for solutions to the barriers described earlier as well as observations about how some issues have improved. These comments are included here as direct quotes to provide initial ideas for subsequent development of the Comprehensive Plan.

### **Address language barriers**

*“Maybe they need to have some sort of training for our interpreters that do something about HIV so they can really get the medical background and understand the gist of what we're trying to get across.”*

*“PSA is an interpreter qualification program through DSS. It's three-parts; you have to take a qualification test, two-day class and then a final test.”*

*“We don't speak Spanish, and so one of the things that we try to do is to have them go to Spanish classes for staff to try to train staff in Spanish.”*

### **Use peer educators**

*“Client empowerment is important. If the consumer is educated and empowered to take charge of their own healthcare, then they will ask questions of the physician while they're there and not depend on the doctor to read their mind and know what's going on with them. That's the perfect thing for a peer educator to do.”*

## **Provide mental health services**

*“I have seen in the past three years more and more providers coming up with solutions to mental health and not relying on the state infrastructure and the Department of Mental Health infrastructure. And so I think there have been some success stories in some regions in the state, where they have either done what you're talking about, sharing the provider, or a part-time provider or someone on staff, et cetera.”*

*“We as a group have to come up with some sort of way to organize ourselves to deal with those mental health issues. We have to pool our resources together and contract with a mental health specialist so she's somewhere for two days and then she's somewhere else for another two days.”*

## **Ensure linkage to care**

*“The linkage between general discharge (from prison) and the HIV care service system has been improving and we would like to acknowledge that's one area on this list that we felt like its getting better.”*

*“I will say that also we've made some strides in this area (getting people from testing to care) with some specially funded projects that are just for linkage-to-care. So we're making gains in that area too. “*

## **Reduce turfism**

*“Turfism has improved from 2006 to now. We don't have quite as much turfism in this state, and one reflection of that was the ADAP task force that helped to get more money to end our waitlist from our state government. And another thing is the care and support work through the HIV planning council and working on a case manager best practices sort of thing so that one case manager will be able to benefit from something that another has learned.”*

## **Increase public awareness**

*“All of us as a state need to do something about HIV like some of the bigger states do, like California or New York or whatever. Like get together and have a state AIDS day where everyone can participate all in one day and just get the message out there. Because some of the bigger cities have that, but like in smaller areas where I am, there is nothing like that being done whatsoever. I mean, on World AIDS Day we do try to do stuff but it's not really being done on a really large-scale, community type of effort where it's on TV, where it's on the radio, where it's in the newspaper, where it's in places where people who are at-risk go. Because they're not going to read the newspaper and they're not going to listen to NPR or whatever. We need to get into the community especially in those smaller areas like where I am.”*

## **Improve cultural competence**

*“We need more cultural sensitivity trainings, especially if HRSA directs us to focus more on African American MSM.”*

## **Broaden clinicians’ frame of reference**

*“And that's what we have to do is educate our doctors as well, to be social workers, case managers, to an extent, for the time period that they've got (with their client)”*

The potential solutions articulated by the stakeholders are the foundation for the development of the Comprehensive Plan. While some of the needs and associated solutions do not fit neatly within one particular issue area, improvements in these cross-cutting issues (transportation, language and cultural barriers, linkage to care) will make substantial contributions in refining the current care system for the better.

### ***Consumer Town Hall Forum***

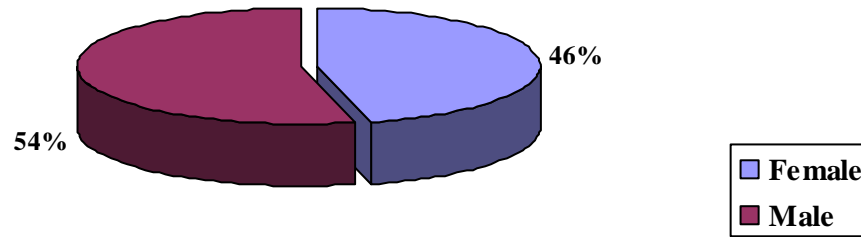
The Consumer Town Hall Forum was held on October 15, 2008, from 6:30-9:00 pm at the Radisson Columbia Hotel and Conference Center. Forum participants were recruited by members of the South Carolina HIV Planning Council through word of mouth, scholarship applications to attend the South Carolina HIV/STD Conference, and a Promotional Flyer. In order to be eligible to participate in the Forum discussion, individuals were required to be HIV positive and reside or be a student in South Carolina.

The demographics of the Town Hall Forum participants differ in some ways from the overall population being served through the Ryan White care system. The participants had higher levels of education and were more likely to be stable housed and work full time than the general Ryan White population in South Carolina. The difference in backgrounds and experiences is the likely explanation for the difference in input. The participants in the Town Hall Forum were more focused on quality of care issues than access to care. The following graphics illustrate the backgrounds of the participants.

### **Gender**

All participants (n=50) responded to this question and are included in Graph 1. Gender was nearly equally divided with twenty-three participants (46%) reported being *female* and twenty-seven (54%) reported being *male*.

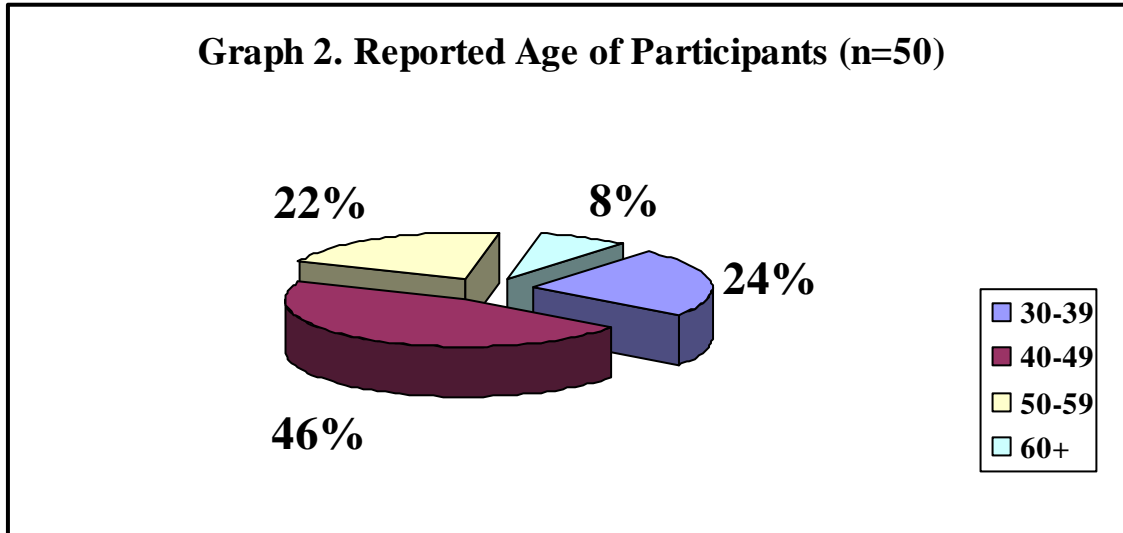
**Graph 1. Reported Gender of Participants (n=50)**





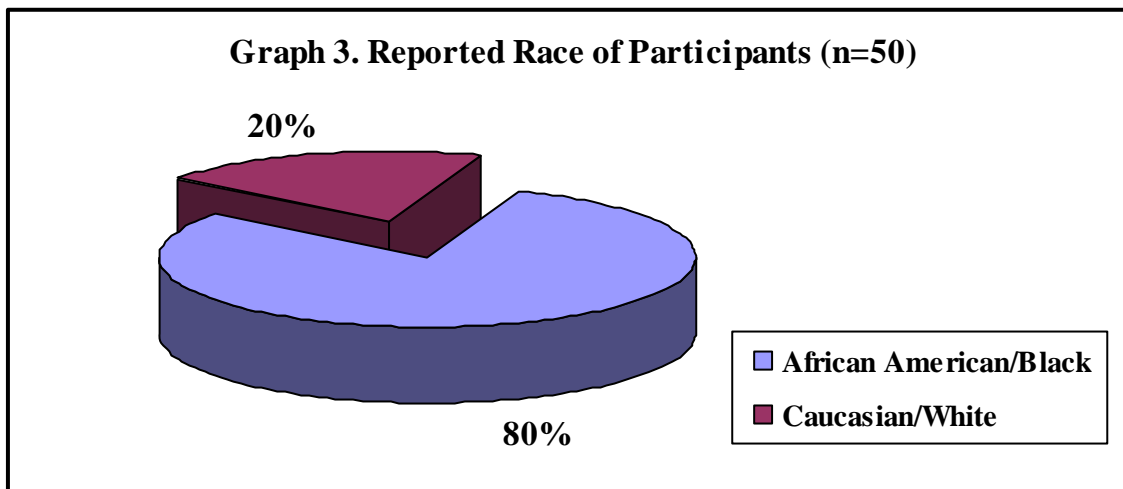
### Age

All participants (n=50) responded to this question and are included in Graph 2. The age of participants ranged from 31 years to 62 years with an average age of 44.8 years. Twelve participants were in their *thirties* (24%), twenty-three in their *forties* (46%), eleven were in their *fifties* (22%), and four were in their *sixties* (8%). None of the participants were younger than 31 years of age.



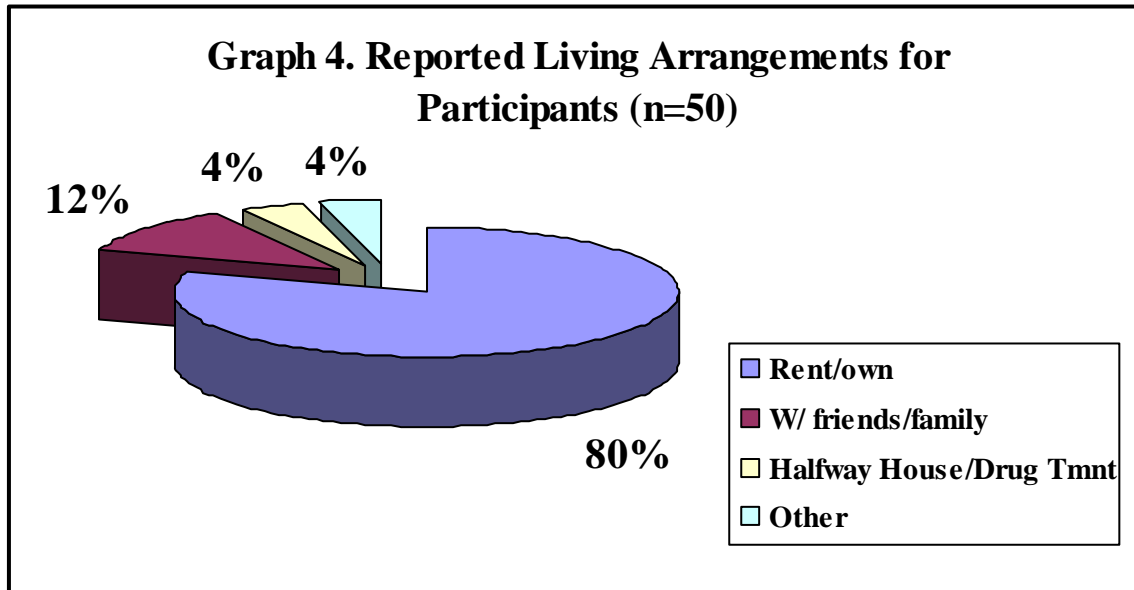
### Race/Ethnicity

All participants (n=50) responded to the question of race and are included in Graph 3. Forty participants reported their race as *African American/Black* (80%) and ten participants reported their race as *Caucasian/White* (20%). Of the thirty-one participants that responded to the question of ethnicity, none reported to be *Hispanic/Latino(a)*.



### Living arrangement

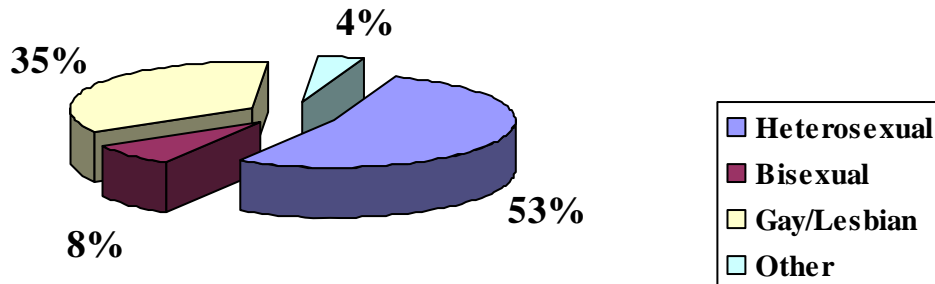
All participants (n=50) responded to this question and results are depicted in Graph 4. Most (n=40) respondents reported that they *rented or owned their own home* (80%). Fewer reported *living with friends/family* (n=6), *living in a halfway house or drug treatment facility* (n=2), and living in *other* arrangements (n=2).



### Sexual orientation

Almost all participants (n=49) responded to the question, "What is your sexual orientation?" with results depicted in Graph 5. More than half of participants (n=26) identified their sexual orientation as *Heterosexual/Straight*. About one-third (n=17) identified themselves as *Gay/Lesbian*. Fewer participants identified as *Bisexual* (n=4) and *other* (n=2). Those that indicated *other* described themselves as "sexual" and "open-minded" in the space provided.

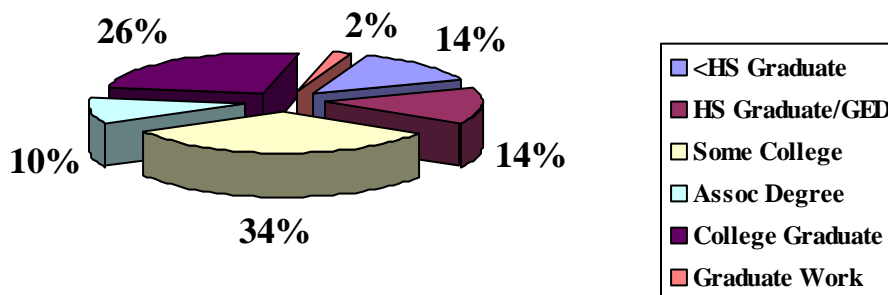
**Graph 5. Reported Sexual Orientation of Participants (n=49)**



**Education level**

All participants (n=50) responded to this question and are included in Graph 6. Nearly three-quarters of participants (n=35) had completed at least *some college*. Seventeen respondents reported having *some college*; five reported having an *associate’s degree*; thirteen reported having *graduated from college*; and one reported completing *graduate work or a graduate degree*. Seven respondents reported having *some high school but didn’t graduate* with another seven reported being a *high school graduate or having a GED (General Education Diploma)*.

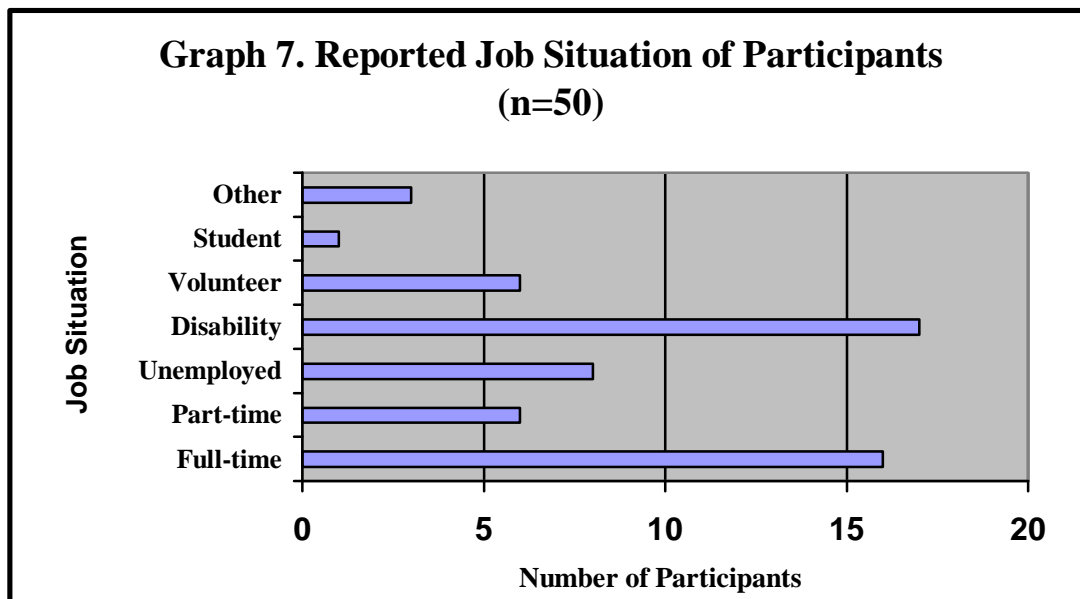
**Graph 6. Reported Education Level of Participants (n=50)**



**Employment status**

All participants (n=50) responded to this question and were asked to “check all that apply,” resulting in fifty-seven total responses being reported in Graph 7. Five individuals checked multiple responses. Seventeen participants reported being on *disability*; sixteen reported working *full-time*; six reported working *part-time*; eight reported being *unemployed*; six reported doing *volunteer work*; and one reported being a *full-time student*. Three participants reported *other* as

their job situation with the following descriptions written in the space offered: *medical leave*, *retired* and *part-time student*.



During the Town Hall forum, three questions specific to HIV care and treatment were posed to the participants. Following are the questions and a summary of the discussion that resulted.

### 1. What HIV care services are most important to you?

Consumers identified medical care, medications, “other” non-HIV specific medications and care, and health insurance as their most important HIV care services. Throughout the Forum discussion, consumers indicated the value of each of these services while also expressing difficulties in obtaining them in various circumstances. Of the “other” non-HIV specific medication and care, mental health care was stressed as an area of great need.

Main Points	Participant Comments
<ul style="list-style-type: none"> <li>Medical care</li> </ul>	<p><i>Medical care...I want to live.</i></p>
<ul style="list-style-type: none"> <li>Medications</li> </ul>	<p><i>A lot of us are taking medications other than our HIV antiretrovirals...and a lot of us are aging...so there's all these other medicines that have nothing to do with HIV. They're new...I don't think enough has been done to see what the long term effects of HIV drugs are and the interactions with these other drugs.</i></p>
<ul style="list-style-type: none"> <li>Other related care services (e.g. diabetes care and medications; mental health care and medications; eye care; oral health care)</li> </ul>	<p><i>I have a problem with depression, and I'm sure a lot of us here do...ADAP doesn't cover those drugs. If I have no insurance, you are where you are and you can't work anymore and it's just hard...</i></p> <p><i>Oral care...your teeth will kill you</i></p>

	<i>Eye care...I have the onset of diabetes and I have to get my eyes examined, not just as a regular reading but they have to examine it to see if I'm losing vision.</i>
<ul style="list-style-type: none"> <li>Health insurance</li> </ul>	<i>Right now I'm trying to hold onto COBRA that I can't really afford and I can't find anybody to pick up the premiums for me...for halfway decent care, I have to have some type of private insurance. If I don't, I have the trouble of being a number on a waiting list.</i>

## 2. What, if any, problems have you encountered in seeking HIV-related care services?

Consumers spent a great deal of time discussing problems they had encountered seeking HIV-related care services in South Carolina. In particular, consumers discussed challenges with their care providers, including being treated or seen by their provider only as a person with HIV, not being treated by the same providers, not trusting their providers, and/or not feeling that their providers were fully knowledgeable about, or forthcoming with them, regarding the side effects of HIV medications. Additionally, consumers expressed frustration with the lack of coverage for “other” medications, access limitations for persons living in rural areas, children aging out of care, and long term community care.

Main Points	Participant Comments
<ul style="list-style-type: none"> <li>Treated only as HIV+ individual and not as whole person</li> </ul>	<p><i>A lot of times, I have found mental health professionals or mental health doctors look at... a person with HIV, the first thing that comes to their mind is that, “oh you’re just depressed because you have HIV”... are they trying to treat the person or trying to treat the person ‘cause they have HIV?</i></p> <p><i>It (examination) seems like it should be more personal, more questions beyond HIV questions</i></p>
<ul style="list-style-type: none"> <li>Lack of continuity in care, lack of time with provider and limited relationship with provider</li> </ul>	<p><i>Every time I went for mental health, I saw a different doctor and how could I build a relationship and become comfortable seeing a different person every time? And how would they know me? So I got tired of going...</i></p> <p><i>Session is only 15 minutes long, they tell me to come back in 5 or 6 months...doesn't do any good.</i></p>
<ul style="list-style-type: none"> <li>Concerns about credibility of provider; lack of trust with provider; and lack of accurate non-HIV-related diagnoses by providers</li> </ul>	<p><i>I appreciate my doctors...but there are times when I do question their credibility...they're not reaching the right diagnosis...are they able to do referrals if they're not sure?</i></p> <p><i>Drug companies help us out, but docs pay more attention to them than us. If they paid more attention to us rather</i></p>

	<p><i>than the drug companies...That's where their money is coming from.</i></p> <p><i>First time I tried to go for disability, each doctor kept on saying, "I don't see anything wrong with you..." and just recently, I was let go from my job...because I couldn't complete my work.</i></p> <p><i>They diagnosed me as depressed for years and come to find out I was bipolar. They (doctors) were confused...</i></p> <p><i>I get treated at the VA and every time I go down there, they give me a different medication for depression.</i></p>
<ul style="list-style-type: none"> <li>• Providers not being knowledgeable or forthcoming about all of the side effects of HIV medications</li> </ul>	<p><i>They don't go in depth to see... what they're doing to the organs in the rest of our body...if you're on the medications too long, they take you off. Why fix something that's not broken? ...They don't tell you about the side effects you're going to go through.</i></p>
<ul style="list-style-type: none"> <li>• Lack of coverage for "other" medications</li> </ul>	<p><i>I was first diagnosed and I was on AZT. Not a month after that I was diagnosed and hospitalized because of diabetes. They said it was an on-set from the medication because it messed up my pancreas. In New York, ADAP covered that. What about on-set illnesses? ADAP says we only cover medication for the HIV antiretrovirals. I don't understand that!</i></p>
<ul style="list-style-type: none"> <li>• Lack of access to medical service alternatives (e.g. health care providers)</li> </ul>	<p><i>What can you do when you're in a community with only one center for you? One infectious disease doctor - what are you going to do if you can't change? Now you have to get transportation to another county to go get a doctor. Who is going to pay for it?</i></p> <p><i>In rural areas, they don't have good docs like some of us do.</i></p>
<ul style="list-style-type: none"> <li>• Children aging out of care services</li> </ul>	<p><i>I have an 18 year old that's pre-natal infected and he's about to turn 19. He's going to exit out of Title 4 and Title 2 services and with budget cuts, my son is going to lose a lot of benefits. Where's that going to leave me?</i></p>
<ul style="list-style-type: none"> <li>• Long-term community care</li> </ul>	<p><i>When I went to sign up for long-term community care, they wanted me to sign over my rights to everything I own in the case of my death. Why should I have to sign over everything to receive their service? I don't think that's right.</i></p>

**3. What would be the single most important change you would suggest in improving HIV care services in South Carolina?**

In order to improve HIV care services in South Carolina, consumers recommended that persons living with HIV, especially in rural areas, have access to the same services as those living in larger cities in the state. In addition, consumers strongly recommended that education/training opportunities regarding HIV meds, how to talk to doctors/health care providers, and how to be “educated consumers” when it comes to their overall health care be provided to persons living with HIV. Consumers also recommended that educational materials that physicians/health care providers use, regarding HIV disease and HIV medications, not include a lot of medical jargon and take into consideration the lower reading/literacy levels of some consumers. Similarly, consumers recommended that providers be trained in how to communicate with their HIV positive patients using less medical jargon, how to be better listeners, and how to “meet consumers where they are.”

<b>Main Points</b>	<b>Participant Comments</b>
<ul style="list-style-type: none"> <li>• Availability of/Access to services</li> </ul>	<p><i>In my agency, x-ray services are not available in our building for our consumers.</i></p>
<ul style="list-style-type: none"> <li>• Education for PLW HIV to become better health consumers/advocates for one another</li> </ul>	<p><i>Education, and we want to be educated.</i></p> <p><i>I didn't have to start taking meds until 16 years into my diagnosis and it floored me. I was not ready and I didn't even know I could say no...I wasn't informed, I was out there speaking all over the place, but there was still a level of information I didn't know about HIV care and I didn't know I had a right to say I'm not ready to do this right now. They scare us so bad...</i></p> <p><i>Complain, but also do...</i></p> <p><i>If you know someone doesn't have a good doc, try to help them get somewhere else.</i></p> <p><i>I decided I wasn't going to let somebody tell me what meds I was going to take. He said this is what you're going to take and this is what you're going to do. No, no, no...I'm a customer, remember, I'm going to tell you what I'm going to do. As a consumer, that's what we must do ...work in a partnership.</i></p> <p><i>We are ultimately responsible for self and I challenge you that if you stay informed and you doctor's know you're informed, you'll get better results. It's ok to change doctors...</i></p>

	<p><i>We let our condition make us feel weak. We were bold before, be bold now. Nobody will take care of you better than you.</i></p> <p><i>About 40% of my clients haven't finished high school. The age range is between 22 and 35...The system has failed that generation, not everybody has the intellectual background to be knowledgeable and even if they had the resources they may not know how to express themselves.</i></p>
<ul style="list-style-type: none"> <li>• Medical-based materials produced in layman's terms; use lay terms with clients</li> </ul>	<p><i>If we can somehow explain in laymen form to doctors that all these medical terms and these medical brochures that doesn't really say what I want it to say...I can't breathe and there's something in there I got to blow out. Together, we can get us and doctors to move to another level.</i></p>
<ul style="list-style-type: none"> <li>• Education for health care providers (including ER doctors) so they can do a better job of "meeting clients where they are" and listen to their clients</li> </ul>	<p><i>Physicians don't recognize where people are coming from. SC has one of the highest rates of illiteracy in this country and they give pamphlet and say this is going to explain everything you need to know. It's not an easy thing to say you have a reading disability, and they'll just take it and say thank you. Same with giving websites, when you live 20 miles out of town and serviced by some rural telephone company you may not even have internet service and where are you going to get a computer when you're living on \$637 per month? You need to reach them where they are. You won't do that if you don't meet them where they are.</i></p> <p><i>How do they think we feel as people that are sick and asking them to help us and they're not listening to nothing that's going on with us?</i></p> <p><i>We as consumers need to have a session with our docs to allow us to sit down and talk to these docs and let them know what's going on. If we can do it as a group. We need to be heard.</i></p>

Overall, the input received was very valuable and the recommendations that resulted from the Town Hall Forum are, in part, incorporated into the Comprehensive Plan.



## **SECTION II: Where Do We Need to Go: What is Our Vision of An Ideal System?**

### **Shared Values and Vision for System Changes**

Throughout the stakeholder meetings that were held in preparation for the development of this document, common themes and ideas around the ideal care system consistently emerged. The following concepts represent the shared values of the South Carolina Ryan White care system stakeholders:

- Comprehensive continuum of care
- Accessible, appropriate, consistent and affordable care
- Collaborative work among service providers
- Services rendered without fear or stigmatization
- Privacy and confidentiality
- Ownership and self determination
- Dignity and respect
- Continuous improvement

Using all of the above concepts as a backdrop, based on local HIV epidemiological trends and considerations of the most vulnerable populations in our state, the shared vision for an HIV care system is to establish and maintain a system of HIV care that provides broad access to quality HIV services including mechanisms that retain people in care. To this end, there are three broad, long-term goals in three primary issue areas. The goals and issue areas, which will guide priority setting, are as follows:

#### 1) Access to Medical Care

Issue Statement: The Health Resources and Services Administration requires providers to address the health needs of persons living with HIV disease, in part, by providing services that enhance *access to care*.

Goal: Improve the ability of PLWHA to access health care in South Carolina.

#### 2) Quality of Medical Care

Issue Statement: The Health Resources and Services Administration is committed to improving the *quality of care and services* and ultimately the quality of life for people living with HIV and AIDS. This commitment is made evident by the requirement of a Quality Management Program in each state.

Goal: Ensure quality of health care services provided for Ryan White patients in South Carolina.

### 3) Retention in Care

Issue Statement: The Health Resources and Services Administration requires providers to address the health needs of persons living with HIV disease, in part, by providing support services that enhance *retention in care*.

Goal: Improve client retention in HIV medical care and support services.

It is important to state that these goals and the resulting program initiatives are contingent on the continuation of dedicated federal, State and local resources that are commensurate with the level of need across the state. If drastic changes in resources occur, extremely difficult choices will need to be made to the overall plan, goals and objectives, resulting in program reductions and service disruption.

The following **principles** guide the development and implementation of program models to achieve the above goals:

- The care and service continuum must be accessible to individuals and families in urban and rural areas regardless of their ability to pay. Funding mechanisms should be creative and focus particularly on the needs of poor communities.
- Methods for routine assessment of the outcome of care and services must be in place for all HIV service providers. Continuous quality improvement facilitates measurement of service outcomes, while fostering on-going self-assessment and improvement.
- Policy and program design must reflect input from a broad range of people affected by HIV/AIDS, including persons living with HIV and health and human service providers engaged in direct care. Communities of color must be central to this collaboration, given the disproportionate impact of HIV on persons of color in South Carolina. Peer education and support is a key component of service delivery and leadership development.
- Confidentiality protections must be in place, providing the basis for assuring personal privacy and anti-discrimination safeguards.

**SECTION III: How Will We Get There: How Does Our System Need to Change to Assure Availability of and Accessibility to Core Services?**

**Comprehensive Plan**

With limited resources available for services for PLWHA in South Carolina, a comprehensive plan (including goals, objectives and activities) has been developed that focuses on three essential issues related to HIV care and treatment: 1) access to medical care, 2) quality of medical care, and 3) retention in medical care. The goals, objectives, and activities for each issue area are outlined below.

<b>1. Access to Medical Care</b>	
<b>Issue Statement:</b> The Health Resources and Services Administration requires providers to address the health needs of persons living with HIV disease, in part, by providing services that enhance <i>access to care</i> .	
<b>Goal:</b> Improve the ability of PLWHA to access health care in South Carolina.	
<b>Objectives</b>	<b>Activities</b>
a. Decrease the proportion of PLWHA who are not in care by 2% annually through January 2012	<ul style="list-style-type: none"> <li>▪ Collect intake data about why clients dropped out of care in the past and are now coming back into care, and use this information to develop individualized agency plans to proactively address barriers to care.</li> <li>▪ Collaborate with other Ryan White Parts in each region to identify clients who have dropped out of care and work together to get them back into care.</li> <li>▪ Increase cooperation between medical case managers and disease intervention specialists (e.g., establish MOA) to identify clients who have dropped out of care and get them back into care.</li> <li>▪ Use Peer Health Navigators to provide transportation, education and outreach to clients.</li> <li>▪ Educate private practitioners about HIV and the Ryan White care system.</li> <li>▪ Incorporate outreach into all job duties (home visits, telephone calls, testing, medical case management, etc.)</li> <li>▪ Increase marketing materials for Ryan White care system.</li> <li>▪ Train/empower consumers to be “educated consumers” regarding their own health care, navigating the health care system and in how to communicate with providers.</li> </ul>
b. Increase the number of Ryan White case managers trained	<ul style="list-style-type: none"> <li>▪ Develop and implement a formal Ryan White Medical Case Management Certification program in South Carolina.</li> <li>▪ Offer training to all Ryan White Parts so medical case</li> </ul>

<p>through the Ryan White case management training system by 2% annually through January 2012.</p>	<p>managers can benefit from learning about other service delivery models.</p> <ul style="list-style-type: none"> <li>▪ Coordinate peer training opportunities among agencies using seasoned, certified medical case managers as mentors.</li> </ul>
<p>c. Increase the number of patient mental health visits by 2% annually through January 2012.</p>	<ul style="list-style-type: none"> <li>▪ Utilize private mental health providers for services for PLWHA.</li> <li>▪ Ensure that ADAP continues to carry anti-depressants on the formulary.</li> <li>▪ DHEC should mandate that a certain percentage of funds provided to Part B provider must be spent on mental health services.</li> <li>▪ Develop a standard mental health screening tool for all service providers.</li> </ul>
<p>d. Increase the number of patient substance abuse treatment visits by 2% annually through January 2012.</p>	<ul style="list-style-type: none"> <li>▪ Develop a standardized substance abuse screening tool for use by all service providers.</li> <li>▪ Provide medical case management training that includes materials on how to conduct a thorough psychosocial assessment.</li> <li>▪ Create a comprehensive definition of substance abuse treatment.</li> <li>▪ Develop better mechanisms to couple mental health and substance abuse counseling services.</li> <li>▪ Establish contracts between service providers and community agencies that can provide substance abuse treatment services.</li> <li>▪ Establish support groups for HIV infected substance abusers.</li> <li>▪ Develop peer outreach programs for PLWHA substance users.</li> </ul>
<p>e. Increase the proportion of clients who are stably housed by 2% annually through January 2012.</p>	<ul style="list-style-type: none"> <li>▪ Increase the number of budgeting and financial workshops for clients.</li> <li>▪ Ensure clients enrolled in housing case management have solid service plans with specific objectives on budgeting and financial management.</li> <li>▪ Develop relationships with local housing experts (providers, landlords, developers) to increase availability / stability of housing for PLWHA.</li> </ul>

## 2. Quality of Medical Care

**Issue Statement:** The Health Resources and Services Administration is committed to improving the *quality of care and services* and ultimately the quality of life for people living with HIV and AIDS. This commitment is made evident by the requirement of a Quality Management Program in each state.

**Goal:** Ensure the quality of health care services provided for Ryan White clients in South Carolina.

Objectives	Activities
<p>a. Achieve 100% participation in the South Carolina Ryan White Quality Management program by January 2010.</p>	<ul style="list-style-type: none"> <li>▪ Identify the benefits to providers of participation in the QM program and “market” the program to providers in these terms so it is not viewed only as an administrative expectation/requirement.</li> <li>▪ Encourage and foster participation on the statewide Quality Management Steering Committee from agencies that in the past have not submitted data.</li> <li>▪ Provide on-going training in QM indicators for all providers.</li> </ul>
<p>b. Increase the number of patients with at least two medical visits per year, one visit in each six month period of the year, by 2% annually through January 2012.</p>	<ul style="list-style-type: none"> <li>▪ Proactively contact clients to remind them of appointments, ensure providers are conducting client follow-up afterwards, and if client is a no-show, then call and/or send letter within three days to reschedule appointment.</li> <li>▪ Increase emphasis on client treatment adherence by decreasing medical case management case loads; case loads may be reduced by allocating sufficient resources to MCM and considering alternative funding sources like HOPWA.</li> <li>▪ Generate buy in from executive directors at provider agencies about the critical need for medical case management.</li> <li>▪ Provide AETC training for providers on PHS guidelines.</li> <li>▪ Develop basic educational materials about primary care, policies, and procedures for all Ryan White clients.</li> <li>▪ Train/empower consumers to be “educated consumers” regarding their own health care, navigating the health care system and in how to communicate with providers.</li> <li>▪ Train providers in how to better meet the needs of consumers, by listening to and effectively communicating (using less medical jargon) with consumers.</li> </ul>
<p>c. Increase the proportion of female patients who receive PAP smears by</p>	<ul style="list-style-type: none"> <li>▪ Integrate women’s health care services into regular HIV clinic visits, educate clients on the need and importance of PAP, prepare women mentally for PAP, implement flow sheet</li> </ul>

<p>2% annually through July 2012.</p>	<p>tracking, ensure adequate time is scheduled for PAP to be conducted during medical visit, and implement an appointment reminder mechanism (e.g., letters, calls).</p> <ul style="list-style-type: none"> <li>▪ Schedule PAP clinic and ID clinic appointments on same day.</li> <li>▪ Contract with provider to provide PAP smears.</li> <li>▪ Ensure transportation assistance is available for clients</li> <li>▪ Collaborate with the Best Chance Network.</li> <li>▪ Include PHS guidelines for care as part of provider contract</li> <li>▪ Obtain medical record if client has PAP with another provider.</li> <li>▪ Have female providers available to treat women.</li> <li>▪ Ensure that PAP smears are entered into the database.</li> </ul>
<p>d. Increase the proportion of patients who receive a CD4 test every six months by 2% annually through July 2012.</p>	<ul style="list-style-type: none"> <li>▪ Ensure case managers assess CD4 test (and all other PHS guidelines) at midyear review with clients and follow up with providers if CD4 test and other needed labs are not being done.</li> <li>▪ Include PHS guidelines for provision of care as part of provider contract</li> <li>▪ Make sure that CD4 test and viral load are included as basic part of monitoring clients with HIV infection.</li> <li>▪ Ensure labs can be performed on site and during medical visit.</li> </ul>
<p>e. Increase the proportion of patients seen by an oral health provider annually by 2% annually through July 2012.</p>	<ul style="list-style-type: none"> <li>▪ Collaborate with community dental and oral health clinics to facilitate client access to oral health treatment and prevention services.</li> <li>▪ Ensure that medical providers and case managers prioritize the assessment of client dental needs and stress the importance of oral health preventive care to avoid costly intensive dental services that strain limited budgets.</li> </ul>

### 3. Retention in Medical Care

**Issue Statement:** The Health Resources and Services Administration requires providers to address the health needs of persons living with HIV disease, in part, by providing support services that enhance *retention in care*.

**Goal:** Improve client retention in HIV medical care and support services.

Objectives	Activities
<p>a. Ensure 75% retention in care rate for Ryan White providers in South Carolina annually through January 2012.</p>	<ul style="list-style-type: none"> <li>▪ Develop a peer-based buddy system and match clients at risk for dropping out of care with a supportive buddy.</li> <li>▪ Address client needs for substance abuse services, mental health care, and other related issues that can improve retention in care.</li> <li>▪ Provide intensive medical case management with new clients.</li> <li>▪ Emphasize that case managers can assist clients staying in care.</li> <li>▪ Educate clients on range of available core and support services.</li> <li>▪ Consider providing one location with bundled services (i.e., one stop shopping) to combine ID visits, PAP clinic, mental health visits, etc.</li> <li>▪ Ensure transportation assistance is available for clients.</li> <li>▪ Contact all clients on caseload monthly to maintain connection.</li> <li>▪ Offer sensitivity/customer service training for providers / staff</li> <li>▪ Reduce turnover in case managers and cross-train staff.</li> </ul>
<p>b. Increase the number of visits for medical case management by 2% annually through January 2012.</p>	<ul style="list-style-type: none"> <li>▪ Schedule medical case management visits to coincide with medical clinic visits so a separate appointment is not need.</li> <li>▪ Encourage active communication between providers and medical case managers.</li> <li>▪ Ensure transportation assistance is available for clients.</li> <li>▪ Increase outreach, targeting clients dropped out of care.</li> <li>▪ Contact all clients on caseload monthly to maintain connection.</li> </ul>
<p>c. Increase the proportion of patients on ARV therapy that receive treatment adherence counseling by 2% annually through</p>	<ul style="list-style-type: none"> <li>▪ Develop and implement the use of a tool providers can use to assess client readiness for medication treatment adherence.</li> <li>▪ Assess and address barriers to case managers providing treatment adherence counseling (e.g., knowledge of ARV drugs, dosing, side effects, and drug interactions; and time required to</li> </ul>

January 2012.	<p>provide education complete applications, and conduct patient assessment).</p> <ul style="list-style-type: none"> <li>▪ Train case managers on medications, side effects, and issues related to treatment adherence.</li> <li>▪ Educate clients about importance of treatment adherence.</li> <li>▪ Hire staff positions dedicated to adherence counseling.</li> </ul>
d. Increase the proportion of clients with a complete annual psychosocial assessment by 2% annually through January 2012.	<ul style="list-style-type: none"> <li>▪ Train case managers to conduct a comprehensive psychosocial assessment with clients.</li> <li>▪ Prescreen charts the day before client visit to see if a psychosocial assessment is needed</li> <li>▪ Ensure case managers remind clients in advance (via phone or letter) of the need to conduct their annual psychosocial reassessment.</li> <li>▪ Reduce the duration of reassessment process by establishing “no changes to report” area on certain parts of form.</li> </ul>
e. Increase the number of clients with a service plan that has been updated in the past six months by 2% annually through January 2012	<ul style="list-style-type: none"> <li>▪ Develop a system for monitoring when service plan reviews are completed, run reports to determine which clients need to update their service plan, and discuss these cases with case managers during supervision meetings.</li> <li>▪ Continue to train MCMs around the approach to using service plans.</li> <li>▪ Encourage client participation and buy-in in developing service plans.</li> </ul>

### **Cross-Cutting Issues/Summary**

During the course of developing this plan, PLWHA, providers, and other stakeholders emphasized the need to address certain cross-cutting issues that do not neatly fit within only one of the above three issue areas. For example, language and cultural barriers, lack of transportation, and stigma associated with HIV infection and HIV-related risk behaviors must be addressed to achieve the above stated goals related to access, quality, and retention in medical care. Improvements in these cross-cutting areas will make substantial contributions to achieving all of the goals and objectives outlined in this comprehensive plan. HRSA’s emphasis on core services, however, does not easily permit use of funds to address these issues as they are somewhat tangential to the direct provision of medical services. It can be challenging to articulate measurable objectives for these issues and data are often not readily available to quantitatively monitor improvements in cultural competency, transportation access, or community-wide dimensions of stigma. Nonetheless, South Carolina is committed to addressing these issues as best as possible and encourages collaboration among care system stakeholders to address these issues in service to achieving the goals of this comprehensive plan.



## **SECTION IV: How Will We Monitor Our Progress?**

### **Using Data For Evaluation**

Monitoring progress in meeting the objectives of the Comprehensive Plan is the key to ensuring access to care, quality of care and retention in care within the Ryan White HIV care system in South Carolina.

All of South Carolina's Ryan White providers currently collect and submit program data to HRSA in the form of a Ryan White HIV/AIDS Program Data Report (RDR). The RDR is an annual report that captures information regarding the services provided by all Ryan White funded entities. The RDR is divided into sections including: service provider information; client information; service information; HIV counseling and testing; and medical information. Providers report on all clients who received services eligible for Ryan White Parts A, B, C or D funding regardless of the actual funding source used to pay for those services. The South Carolina Ryan White Part B contractors complete the RDR forms and submit them to DHEC. DHEC assembles all of the reports and submits the data to HRSA. The Ryan White Parts C and D submit their data directly to HRSA.

Beginning in 2009 all Ryan White providers will be required to submit Client Level Data (CLD) to HRSA in the form of a Ryan White HIV/AIDS Program Services Report (RSR). The RSR includes three components: the Grantee Report, the Service Provider Report and the Client Report. It is the Client Report, or CLD, that requires service providers to submit one de-identified record for each Ryan White client served. Each record will include information on demographic status, HIV clinical information, HIV-care medical and support services received at the service provider and the clients' unique encrypted identifier.

At the same time that Ryan White providers in South Carolina submit their CLD to HRSA, they will submit a similar client level dataset to DHEC as a part of the Quality Management program. Access to all of the data and one hundred percent participation in the data submission process will allow DHEC to monitor the progress made in achieving the objectives of the Comprehensive Plan. DHEC is in the process of developing a secure portal for data submission and a database for analyzing the data once it is submitted.

### **Description of South Carolina's Quality Management Program**

Central to the South Carolina Department of Health and Environmental Control's mission, values, and strategic plan is the goal to improve access to high quality healthcare. The purpose of the quality management program is to set forth a coordinated approach to quality assessment and process improvement within the SC Department of Health & Environmental Control (DHEC), STD/HIV Division, and HIV Care & Support Programs. The STD/HIV Division is dedicated to ensuring the highest quality of HIV medical care and support services for people living with HIV/AIDS in the state of South Carolina. The mission of the HIV Quality

Management Program is to ensure that all people living with HIV/AIDS in South Carolina receive the highest quality of Ryan White funded primary medical care and support services.

During FY 2007 DHEC initiated the statewide Quality Management Program through technical assistance from the National Quality Center in New York. The technical assistance began in December 2006 and since then DHEC has made great progress in developing and implementing a Quality Management Program for the state of South Carolina.

Activities associated with the development of the program include the formation of a Quality Management Steering Committee, the development of a Quality Management Plan that defines the core quality measures for the state, and participation in the NQC Training of the Trainers program in June 2007 in New Orleans in September 2007 in Orlando and in May 2008 in New York City. All Ryan White Parts (B, C, D) are participating in the process and are represented on the Statewide Quality Management Steering Committee. We rolled out the Quality Management Program at a December 2007 SC Ryan White All Parts meeting and our initial data collection period began in January 2008.

The specific statewide indicators that were selected for monitoring are as follows:

1. Number (Percentage) of patients with at least two (2) visits per year, one visit in each six-month period of the year.
2. Number (Percentage) of adolescents  $\geq$  age 13 years & adult clients with HIV/AIDS CD4 <350 or viral load >100,000 that are prescribed HAART.
3. Number (Percentage) of female patients/clients with at least one annual Pap test.
4. Number (Percentage) of patients seen (referred AND with completed visit) by an oral health provider annually.
5. Number (Percentage) of patients with an annual syphilis test.
6. Number (Percentage) of patients with a CD4 and viral load test every six months.
7. Number (Percentage) of patients with CD4 < 200 (or age adjusted for risk as clinically indicated for children) who are prescribed Pneumocystis jirovecii pneumonia (PCP) Prophylaxis.
8. Number (Percentage) of pregnant women prescribed antiretroviral therapy.
9. Number (Percentage) of patients/clients with a complete psychosocial assessment in the past year.
10. Number (Percentage) of clients screened for HIV knowledge every six months.
11. Number (Percentage) of clients with a service plan that has been updated in the past six months.
12. Number (Percentage) of clients with a service plan that has been signed in the past six months.
13. Number (Percentage) of patients with CD4 < 50 (or age adjusted for risk as clinically indicated for children) who are prescribed MAC Prophylaxis (rifabutin, clarithromycin, azithromycin or other).
14. Number (Percentage) of clients with HIV infection who have been tested for Hepatitis B virus infection status.
15. Number (Percentage) of clients with HIV infection who have completed the vaccination series for Hepatitis B.

16. Number (Percentage) of clients with HIV infection who have been tested for Hepatitis C virus infection.
17. Number (Percentage) of clients with HIV infection prescribed antiretroviral (ARV) who receives adherence counseling during appointments 6 months (or less) apart.
18. Number (Percentage) of clients with HIV infection prescribed antiretroviral (ARV) who receives risk reduction counseling during appointments 6 months (or less) apart.

Based on the new HRSA Client Level Data (CLD) requirements that go into effect in January 2009, we have revised the submission date for Quality Management data to July 2009.

The primary Quality Management goal for FY 2009 is to further develop a systematic, state-wide process for planning, designing, measuring, assessing and improving performance with the following components:

1. *Develop a planning mechanism* incorporating baseline data from external and internal sources and input from leadership, staff and patients. Clinical, operational and programmatic aspects of patient care will be reviewed.
2. *Emphasize design* needs associated with new and existing services, patient care delivery, work flows and support systems which maximize results and satisfaction on the part of the patients and their families, physicians and staff.
3. *Evolve and refine measurement* systems for identifying trends in care and sentinel events by regularly collecting and recording data and observations relating to the provision of patient care across the continuum.
4. *Employ assessment* procedures to determine efficacy and appropriateness and to judge how well services are delivered and whether opportunities for improvement exist.
5. *Focus on improving* quality in all of its dimensions by implementing multidisciplinary, data driven, project teams and encouraging participatory problem solving.
6. *Promote communication*, dialogue and informational exchange across the STD/HIV Division and throughout Regional Committees, with regard to findings, analyses, conclusions, recommendations, actions and evaluations pertaining to performance improvement.
7. *Strive to establish collaborative relationships* with diverse stakeholders and community agencies for collectively promoting the general health and welfare of the community served.

With the receipt of statewide data during the summer of 2009 we will be able to establish true baseline data for our Ryan White services. The second cycle of data submission in January 2010 will give us the data we need to determine priorities for service quality improvement by provider, region and state. To date most of our efforts around Quality management have been focused on infrastructure development but with the submission and analysis of data in the coming year we can begin our quality improvement efforts in earnest.

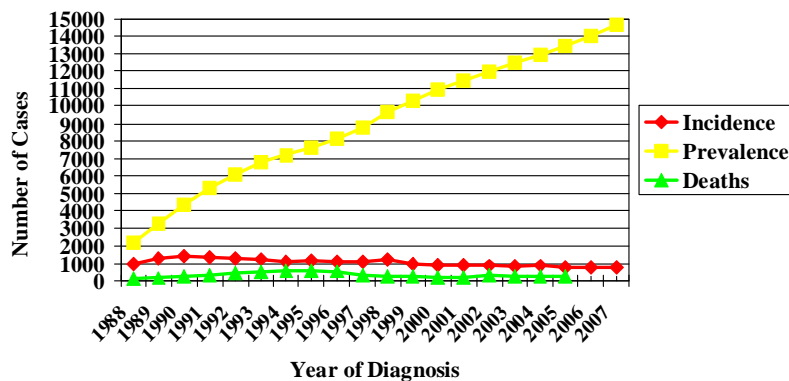
# **APPENDIX A**

## Epi Profile Executive Summary

Since 1986, more than 22,400 persons have been diagnosed with HIV infection (including AIDS) in South Carolina through December 2007. During 1985 – 1990, an average of 848 cases were diagnosed each year. In the subsequent three years (1991 – 1993), newly diagnosed HIV/AIDS cases averaged 1,310. The increase during this period was in part due to the artificial rise in AIDS cases as a result of the change in case definition in 1993. For the past five years, the annual number of new cases has been about 805. Many more persons are infected but have not been tested.

Some of the changes over time in numbers of new cases are largely the result of reporting patterns or targeted testing initiatives. The initial steep rise in the epidemic reflects the early years when less was known about the transmission of HIV and effective medical treatments did not exist. As a result, infection rates increased and more HIV-infected individuals went on to develop AIDS. Most experts believe that when more was learned about HIV and the behaviors involved in its spread, effective prevention strategies reduced the overall number of new infections, and medical treatment, for some individuals, postponed the onset of AIDS. In more recent years, however, there is concern nationally that the epidemic may grow particularly among young men who have sex with men.

**Figure 1. South Carolina HIV/AIDS Incidence, Prevalence and Deaths**



Number of Cases Diagnosed in SC only; excludes out of state cases returning to SC.

Since 1994, new anti-retroviral drugs and strengthened care services have contributed to a decline in overall AIDS deaths. This decline is illustrated by the 249 deaths in 2005, a 58% drop from the 590 deaths in 1994. It is important to note that despite the decline in deaths due to AIDS and the apparent stabilization of the number of new HIV/AIDS cases diagnosed annually, the prevalence of HIV infection (the number of persons estimated to be

living with HIV/AIDS) is significantly increasing. The number of persons living with HIV/AIDS at the end of each year has increased 67% from 1997 to 2007. It is also important to note that there are differences among certain populations in the number and rate of new and prevalent infections, as this profile will indicate. Figure 1 shows total incidence (the number of new cases within a specified time period), deaths and prevalence of HIV/AIDS cases in South Carolina since 1988.

The epidemic in South Carolina is primarily driven by sexual exposure, primarily among men who have sex with men and heterosexuals at risk. Injecting drug use appears to be diminishing as a risk for HIV.

African-Americans are disproportionately affected by HIV/AIDS and are over-represented among all risk populations.

## **Overview of Chapter**

The purpose of this Epidemiologic Profile is to provide information to the SC HIV Prevention Community Planning Group (CPG) on the number and characteristics of persons becoming HIV infected in order to target and prioritize HIV prevention activities.

This chapter of the SC HIV Prevention Plan includes a list of definitions and describes the data sources used, the limitations of each data type, and presents the data in order to answer the following questions:

- 1. What are the socio-demographic characteristics of the population?**
- 2. What is the impact of HIV/AIDS on the population?**
- 3. Who is at risk for becoming infected with HIV?**
- 4. What is the geographic distribution of HIV infection? \***
- 5. What are the patterns of service utilization of people living with HIV/AIDS?**
- 6. What are the characteristics of persons who know they are HIV-positive but who are not in HIV primary care?**

These questions will be explored through analyses of cumulative living (prevalent) and newly diagnosed (incident) HIV/AIDS cases; a description of seroprevalence data from HIV counseling and testing sites and other studies; a summary of other risk behavior profiles and community-based HIV risk assessment information; and a discussion of related sociodemographic, health and risk behavior indicators.

*\*Note: geographic distribution will be discussed within questions 2 and 3 for each population/risk described.*

## **Definitions**

**AIDS** - Acquired Immunodeficiency Syndrome, the end stage of HIV infection characterized by life-threatening or severely disabling disease.

**HIV** - Human Immunodeficiency Virus, the cause of HIV infection.

**HIV/AIDS** - Includes those persons with HIV infection, as well as those who have progressed to AIDS. Unless noted, most HIV data in this profile includes persons diagnosed with AIDS.

**HIV Only**- Includes only persons with HIV infection who did not develop AIDS within 365 days of report of positive HIV test.

**Incidence**- The number of new HIV/AIDS cases newly diagnosed and reported each year. Incidence cases may be combined in two or three year periods.

**Incidence Rate** - Number of new cases occurring during a period of time, divided by the annual average population, multiplied by 100,000. It is a measure of the frequency with which an event (e.g. new HIV/AIDS cases) occurs in a population over a period of time. It is also a measure of risk of getting the disease.

**Prevalence**- The number or proportion of persons estimated to be living with HIV/AIDS at the end of a particular period of time (e.g. year).

**Prevalence Rate** - Total number of living HIV/AIDS cases (both old and new cases) during the year of report, divided by the annual average population multiplied by 100,000. It is the proportion of persons in a population who have a particular disease or attribute at a specified point in time (or specified period of time).

Rates are used to:

- measure the frequency of disease (in this case, HIV/AIDS) or other outcomes of interest,
- describe the distribution of disease occurrence in human populations,
- allow comparison of the risk of disease or burden of disease across populations,
- characterize the risk of disease for a population, and
- identify determinants of disease.

They may also be used to help:

- prioritize prevention programs among competing causes,
- identify target groups for intervention,
- acquire funding for resources, and
- compare events across geopolitical boundaries.

## **TYPES AND QUALITY OF DATA**

Because no one epidemiologic data set will provide a complete picture of HIV/AIDS in the community, or the state for that matter, we have assembled data from several categories and sources. Data from a variety of categories provide a more accurate picture of past, present and future HIV/AIDS infection trends. Keeping in mind that not all data are equal, data sources must be considered in the context of their objectives, strengths and limitations; who the target populations are; how the data were collected; and the validity of the data.

As described above, several data sets are used to illustrate the South Carolina populations diagnosed with HIV/AIDS and to characterize the nature of risk-taking. All of these data sets share limitations or have similar types of bias introduced, in that most are reported by third parties, largely providers, who must seek information from the affected individual as to illness, transmission mode, and demographic characteristics. These reports are limited both by the willingness of providers to ask about these factors and that of clients to report on personal behaviors. These data are also limited in their ability to broadly characterize populations. For instance, STD (sexually transmitted disease) or HIV/AIDS case report data can only characterize persons with STD or HIV who seek treatment, or data on estimated condom use among women can not characterize all women but only those who agree to participate in selected behavioral surveys. Individuals who seek treatment for STD (and who are offered HIV testing) may be very different from those individuals who do not. However, each of the data sets referred to in this profile provide information to describe the relative risk and impact of this disease on the people of South Carolina.

The following summarizes data sources, and limitations, used by the data working group to complete the South Carolina Epidemiologic Profile of HIV/AIDS.

### **Selected Data Source**

#### **Description and Limitations:**

*Department of Alcohol and Other Drug Abuse Services (DAODAS) SC Treatment Needs Assessment: Household Telephone Survey Data*

The purpose of the survey was to collect data on the prevalence of use of alcohol, marijuana, hallucinogens, cocaine, and heroin; to identify treatment needs related to use of these substances; and to determine the background characteristics associated with different patterns of use. The state was stratified into four regions and within each stratum a random sample of telephone numbers were selected using random digit dialing (RDD). The questionnaire was based largely on the National Technical Center's Telephone Substance Dependence Needs Assessment Questionnaire, which is "designed to be the centerpiece of a needs assessment of treatment services that state or territories may conduct as part of their substance abuse planning activities. Trained staff conducted interviews. A total of 10,324 interviews were completed as part of the study by residents 18 years of age and older.

Advantages to conducting a telephone survey compared to face-to-face interviews are as follows:  
1) it costs three times less; 2) able to collect data from a significantly large number of



individuals, resulting in smaller standard errors for the overall estimates of use of various substances and a larger number of individuals with rare characteristics.

Limitations include: population coverage—collecting data by telephone limits the potential respondents to those living in households and excludes individuals, such as the homeless, those in correctional facilities, and those in treatment facilities who may be more likely to experience problems with alcohol and other drugs. Moreover, according to 2000 census data, 4.2% of households in South Carolina do not have telephones and, consequently, had no chance of being included in the study. Secondly, underreporting—in general, respondents’ concerns over confidentiality produce underestimates of reports of sensitive behaviors such as those considered in this study. Despite these limitations, telephone surveys can provide comparatively reliable estimates of substance use and characteristics associated with such use and they have been regarded as an effective means for collecting such data from the general population.

#### *HIV Counseling and Testing Program Data from SC-DHEC Clinics*

Counseling and testing data, while highly informative about persons who seek counseling and testing, does not tell us anything about people who do not seek testing or choose not to test. All states provide HIV counseling and testing services and maintain data to quantify HIV counseling and testing services delivered in publicly-funded sites and to determine the characteristics of persons receiving those services. These data are used by prevention programs to plan and target services for high-risk individuals. The type of data collected in South Carolina include the counseling and testing site type, number of clients tested and number positive for each risk group, number tested, number positive by type of test site, and number tested and number positive by race/ethnicity gender, and age group. Clients receive confidential counseling and testing in each of the 46 county health department clinics.

Note: in 2001 counseling and testing was also provided by community organizations but data from these sites were not available for this report.

The counseling and testing data system is standardized and has been in place for several years. Data in this Epi-Profile reflect number of individual clients tested during a specific period of time. Persons who received multiple tests during the report period are only counted once. It includes persons tested in family clinics, maternity clinics, TB, STD clinics and persons voluntarily requesting services or referred through partner counseling services. Approximately one third of the total of newly diagnosed and reported persons with HIV infection each year are from SC-DHEC counseling and testing sites. Persons tested in other settings, such as physician offices, hospitals, state facilities, etc. are not included in the DHEC counseling and testing database.

To determine a client’s level of risk, each person is assigned a risk status (e.g. injecting drug use, male to male sex, heterosexual with known risk). Since most clients acknowledge multiple risks, risk status is determined by using the CDC’s hierarchy of risk. This process assigns the client’s “highest” risk. The highest possible risk in the hierarchy is sex with a person with HIV/AIDS, while the least significant risk is “no acknowledged risk”. A person is only represented in their highest risk category regardless of how many risks the client acknowledges. This CDC risk hierarchy can limit interpretability of data; it also does not reflect associated risks such as other non-injecting substance use, i.e. crack-cocaine.

Counseling and testing data in South Carolina and nationally is distinct from blinded, HIV seroprevalence surveys which generate an estimate of HIV seroprevalence that is unbiased by client self-selection. The DHEC counseling and testing system only includes clients who seek out counseling and testing services or agree to be tested after consultation with a counselor at a clinic site. However, for those clinic sites in which clients can obtain services other than counseling and testing for HIV, and in which all or nearly all clients actually receive HIV testing, (for example, maternity and STD clinics), data for those sites approximates the reliability of the blinded surveys. For example, the annual percentage of HIV positive tests is consistently 0.1% in DHEC maternity clinics where an estimated 80-90% of clients receive HIV testing. This rate is very similar to the blinded childbearing women seroprevalence survey rate of 0.19%, which tests a representative sample of all live births in the state.

### ***SC-DHEC, HIV/AIDS Reporting Surveillance System (HARSS)***

All health care providers, hospitals, and laboratories in South Carolina are required to report persons diagnosed with confirmed HIV infection and/or AIDS. Each year approximately one-third of new cases are reported from county health departments, one-third from hospitals, one-fifth from physicians, and the remainder from state/federal facilities (including prisons) and laboratories. HARS monitors the incidence and demographic profile of HIV/AIDS; describes the modes of HIV transmission among persons with HIV/AIDS; guides the development and implementation of public health intervention and prevention programs; and assists in evaluating the efficacy of public health interventions. It is the principal source of knowledge regarding trends in the number and characteristics of HIV-infected persons. It includes persons in all age, gender, race/ethnic, and mode-of-HIV-exposure groups; and it provides a historical perspective in trends dating to the earliest recognition of the AIDS epidemic.

This profile primarily presents data on the total infection/disease spectrum: HIV infection including AIDS (not AIDS alone). Because of the long and variable period from HIV infection to the development of AIDS, trends in AIDS cases data do not represent recent HIV infections or all HIV-infected persons. AIDS surveillance data do not represent persons whose HIV infection is not recognized or diagnosed. AIDS cases have declined nationwide; however, because AIDS surveillance trends are affected by the incidence of HIV infection, as well as the effect of treatment on the progression of HIV disease, future AIDS trends cannot be predicted.

Because trends in new diagnoses of HIV infection are affected when in the course of disease a person seeks or is offered HIV testing, such trends do not reflect the total incidence of HIV infection in the population. In addition, because all HIV-infected persons in the population might not have had the infection diagnosed, these data do not represent total HIV prevalence in the population. Interpretation of these data is complicated by several factors, ranging from a person having both HIV then AIDS diagnoses in the same year, varying time between reporting HIV and AIDS cases, and numerous reasons why the number of new HIV diagnoses changed (increased, decreased, or stable).

Some data is provided on HIV infection-only (persons reported with HIV infection who do not have an AIDS diagnosis within 365 days of being diagnosed with HIV). This data, while highly dependent on persons seeking or receiving HIV testing early in their infection stages, provide an

opportunity to compare persons presumably infected more recently with those infected as long as ten or so years ago (AIDS diagnosis).

Risk categories are assigned similar to the methods described above in HIV Counseling and Testing. There are some slight differences in the type of categories between HIV/AIDS surveillance reports and HIV Counseling and Testing reports. In South Carolina, about 33% of adult/adolescent HIV infection/AIDS cases reported in 1998 did not have risk categories reported. These cases are defined as “No Identified Risk”- NIR). The proportion of NIR cases has been increasing nationally as well. The primary reason for incomplete risk information (NIRs) is that reports from laboratories do not include risk, and an increasing proportion of cases result from heterosexual transmission but are not able to be defined in CDC’s definition of heterosexual transmission. For example, persons who report having multiple heterosexual partners or who have sex for money/drugs but the status of their partners is not known, are not classified as “heterosexual”, they are “No Identified Risk”. South Carolina has received funding from CDC to conduct a special project to collect and define indicators of behavioral risk, particularly to define high risk heterosexual behaviors. Indicators include multiple heterosexual and same sex partners, drug use, evidence of blood transfusion or hepatitis, history of sexually transmitted disease, or exchange of money or drugs for sex. This project will provide more useful risk information for prevention planning in the future.

#### ***SC-DHEC, Sexually Transmitted Diseases Management Information System (STD\*MIS)***

Health care providers and laboratories are required by law to report certain sexually transmitted diseases (including syphilis, chlamydia, gonorrhea, chancroid, hepatitis) to SC-DHEC. A sexually transmitted disease, other than HIV infection, represents a visible and immediate health problem that stems from unprotected intercourse with an infected partner. Research from several studies strongly indicates that STDs increase the possibility of acquiring and transmitting HIV infection. The emerging problem of heterosexual HIV transmission in the South closely parallels that of syphilis and gonorrhea. Gonorrhea, syphilis, and chlamydia incidence and prevalence data are used by programs to: 1) monitor local, and state trends; 2) identify high-risk groups and geographic areas in which unsafe sexual behaviors occur, 3) guide the development and implementation of public health intervention and prevention programs; and 4) assist in evaluating the efficacy of public health interventions.

Considering the short incubation periods for these infections, gonorrhea, syphilis, and chlamydia incidence represent recent consequences of unsafe sexual behavior and point to populations who are potentially at very high risk for acquiring and transmitting HIV infection. Unfortunately, an often unrecognized aspect of STDs, including bacterial STDs, is how frequently persons with these infections have no symptoms or do not recognize symptoms. Most studies of STDs are conducted in health-care settings specifically for persons who do recognize symptoms; therefore, these studies usually overestimate the proportion of infected persons who are symptomatic. Studies of STD screening in nonhealth-care settings (e.g., jails, workplaces, and communities) or health-care settings where STD treatment is not the primary function (e.g., family-planning clinics) suggest that most persons with gonorrhea or chlamydia are asymptomatic.

Limitations: STD data lack much information that would help to better understand HIV risk, such as mode of transmission. Also, bias is introduced for some diseases, such as chlamydia,

where screening of asymptomatic persons is done much more frequently in women than in men. For example, all women <25 years attending family planning and STD clinics in county health departments are routinely screened for chlamydia and gonorrhea. Also, there may be bias in that the majority of reports are from public clinics; the personal nature of STD's may affect providers' willingness to report. This may account, in part, for the disparity of some STDs to occur at much higher rates among African-Americans who are more likely to seek care in public clinics, where there is more complete reporting.

#### ***South Carolina Statistical Abstract, 2006***

An annual publication of the South Carolina State Budget and Control Board, Office of Research and Statistics. This state document provides a comprehensive, single-source reference of demographic and economical data pertinent to South Carolina. Statistics providing information on factors impacting the state's social and economical development are compiled from in-house data bases as well as a variety of federal, state, local, and private sources. In order to complete the epidemiologic profile, sociodemographic data from sections State and County Rankings, Education, Employment, Housing, Income, and Population were used. The abstract depends heavily on the US Bureau of the Census data from 2000. As a result of this, data may not represent the current situation in South Carolina.

#### ***South Carolina Vital and Morbidity Statistics, 2006***

Its purpose is to provide basic reference data for a variety of users. The primary uses of the report were to enumerate and characterize mortality attributed to HIV infection. The data were also used to compare trends in HIV infection mortality with other leading causes of death and to characterize the impact of HIV infection on mortality. Data on causes of death are based on information recorded by hospitals, physicians, coroners, midwives and funeral directors. Recorded information may be inaccurate or incomplete due to underreporting of certain causes of deaths, the number of HIV-related deaths and the conditions may be underestimated. Vital statistics data are not as timely as AIDS case reports due in part to processing time.

#### ***Youth Risk Behavior Surveillance System (YRBSS)***

The Youth Risk Behavior Survey (YRBS) was developed cooperatively by the Centers for Disease Control and Prevention (CDC), several federal agencies and state departments of education to measure the extent to which adolescents engage in health risk and health enhancing behaviors. The survey is a 99-item questionnaire administered to 6<sup>th</sup>-12<sup>th</sup> graders in the public school system. Samples are randomly selected based on school size (small, medium and large). Of the 99 items, 11 are on tobacco use, 5 on alcohol use, 4 on marijuana use, 9 on cocaine use, 8 on sexual behaviors for pregnancy, HIV/AIDS and other STD risk, 2 on HIV/AIDS Education, 1 on HIV/AIDS testing and 2 on HIV/AIDS risk perceptions. There are 367 private K-12 schools in South Carolina (SC Statistical Abstract, 2003). However, none of them are included in the survey. Also, while schools are randomly selected for participation some may choose not to participate.

This survey relies heavily on surveillance methods and self-reports; so it really depends on how well respondents understand the question and how well they can accurately and honestly answer the question. However, the data are edited, checked and weighted. These data are representative of only public high school students in grades 6-12 in South Carolina.

### ***Ryan White Program Data Report***

The Ryan White HIV/AIDS Program Data Report (RDR) is an annual report that captures information regarding the services provided by all Ryan White funded entities. The RDR is divided into sections including: service provider information; client information; service information; HIV counseling and testing; and medical information. Providers report on all clients who received services eligible for Ryan White Parts A, B, C or D funding regardless of the actual funding source used to pay for those services. The South Carolina Ryan White Part B contractors complete the RDR forms and submit them to DHEC. DHEC assembles all of the reports and submits the data to HRSA.

### **Question #1: What are the sociodemographic characteristics of the population?**

The HIV epidemic in the United States, and in South Carolina, is a composite of multiple, unevenly distributed epidemics in different regions and among different populations. These populations may comprise persons who practice similar high-risk behavior, such as injecting drugs or having unprotected sex with an infected person. Although race and ethnicity are not risk factors for HIV transmission, they are markers for complex underlying social, economic, and cultural factors that affect personal behavior and health. Low socioeconomic status is associated with increased disease morbidity and premature mortality. Unemployment status is correlated to limited access to health care services, resulting in increased risk for disease. This section provides background information on South Carolina's populations and contextual information, i.e. education, poverty level, housing, etc, for assessing potential HIV impact. The social, economic, and cultural context of HIV infection must be considered when funding, designing, implementing and evaluating HIV prevention programs for diverse populations.

#### **The State**

South Carolina lies on the southeastern seaboard of the United States. Shaped like an inverted triangle, the state is bounded on the north by North Carolina, on the southeast by the Atlantic Ocean, and on the southwest by Georgia. It ranks 40th among the 50 states in size and has a geographic area of 30,111 square miles. South Carolina has a diverse geography that stretches from the Blue Ridge Mountains in the northwest corner to the beaches along the Atlantic coast in the southeast. There are 46 counties and they are divided into 8 public health regions. Columbia, located in the center of the state, is the capital and the largest city. There are 3 metropolitan areas with a population of 500,000 or more: Columbia, Charleston and Greenville areas. The state is crisscrossed by interstate highways that link it with every part of the country, including I-95 extending north-south across the center of the state from New York to Florida and I-26 from Asheville, North Carolina to Charleston, South Carolina, and I-20 that extends east-west across the state from Florence, South Carolina to Atlanta, Georgia. Manufacturing is the state's leading industry, followed by tourism and forestry.

## Populations

Based on projected population estimates, in 2007, the total number of South Carolinians was 4,299,600. Of this total, 65% were Caucasian, 29% were African-American, 0.3% was Native American/Alaskan, 1.1% was Asian and Pacific Islander, and 4% were of Hispanic origin. Fifty-one percent were female and forty-nine percent were male. Sixty-five percent of the population distribution in South Carolina is defined as metropolitan, 35% is non-metropolitan. The proportion of persons who completed a bachelor's degree or higher is 23%, lower than the U.S. proportion of 28%. (Figure 2)

**Figure 2: Selected Demographic Information  
South Carolina and United States**

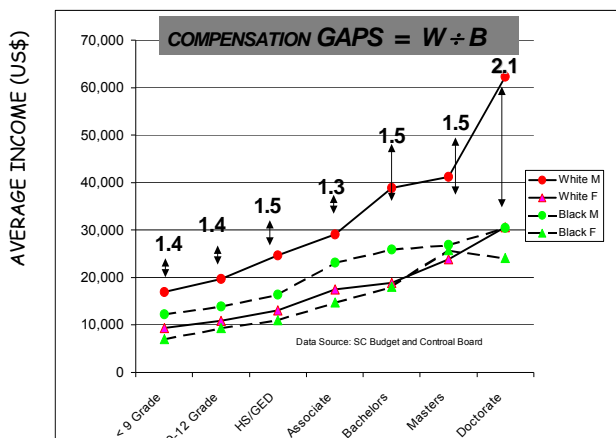
	South Carolina	United States
Population (2007 estimates)	4,299,600	298,215,360
Proportion of Persons Living in Non-Metropolitan Areas	35%	16%
Median Age	37.1	36.4
Racial/Ethnic Distribution of Pop.		
% White	65	66
% Black	29	12
% Hispanic	4	15
% Other	3	7
Educational Attainment		
% High school grad. or higher	81	84
% Bachelor's degree or higher	23	27
Unemployment Rate, November 2007	5.8%	4.7%
Median Household Income, 2007	\$42,561	\$49,901

Sources: U.S. Census Bureau, Kaiser Family Foundation

## Education & Earnings

Despite the economic strides it has made in recent years, South Carolina remains among the states with the highest percentage of persons who live below the poverty level (11th of fifty states and District of Columbia). Educational attainment is strongly correlated with poverty, and South Carolina continues to rank low in percent of persons over 25 years of age who have bachelors' degrees or higher (36th of fifty states and District of Columbia). Nearly twenty percent (19.2%) of the population has less than a high school education.

**Figure 3: Income by Educational Attainment  
by Race & Gender: SC, 1990**



Educational attainment and earnings are directly related. The more education a South Carolinian has, the more money he/she is likely to earn. However, if we compare across gender and racial lines, there are inconsistencies.

White males clearly attain the highest incomes. The income gap between whites and blacks is higher for each education level, but particularly increases for persons with bachelors degrees or more. Income for whites is 1.5 times greater than blacks for persons with bachelors and masters degrees, and is 2.1 times greater than blacks for persons with doctorates. (Figure 3)

**Figure 4: SC Per Capita Income in 1999  
by Race and Hispanic Origin**

	<b>INCOME GAPS</b>	<b>Rel to Blacks</b>
• For Whites	\$22,095	1.9
• Native Hawaiian/ Other Pacific Islander	\$21,638	1.8
• For Asian	\$20,541	1.7
• For American Indian/ Alaskan Native	\$15,325	1.3
• Of Hispanic Origin	\$12,143	1.0
• For Other Races	\$10,473	0.9
• For Blacks	\$11,776	1.0
• OVERALL	\$18,795	1.6

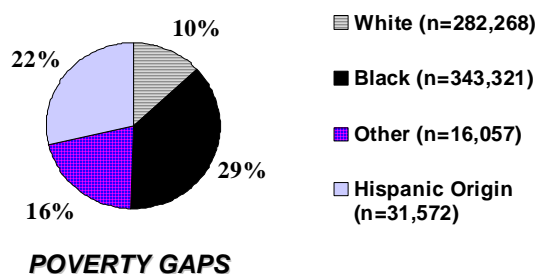
In comparison, Blacks, people of Hispanic origin, and other races earned the least per capita income, averaging 39% below the state's average. Whites earned 18% above the state's average per capita income. (Figure 4)

Data Source: SC-Budget & Control Board, Office of Research & Statistics

### Poverty Level

Based on 2006 Census data, approximately 15.7% of South Carolinians lived below the poverty level (ranking 12th in the US); and 11.9% of South Carolinian families lived below the poverty level.

**Figure 5: Percent of Each Racial/Ethnic Pop Living Below Federal Poverty Level; SC, 2006**



Twenty-nine percent of Black South Carolinians were below poverty in 2006, compared to 22% of persons of Hispanic descent, 10% among Whites and close to 16% of persons categorized as other, which includes Asian, Pacific Islanders, and Native Americans. (Figure 5)

Data Source: 2006 American Community Survey

### Insurance/Access to Primary Care

Sixteen percent (16%) of South Carolinians do not have health insurance coverage. A significantly higher proportion of persons in the state do not have access to a primary care provider (35.8%) compared to the total U.S. population (17.1%) (Figure 6). Over 95% of counties are designated all or part medically underserved areas and all or part health profession shortage areas (1999).

**Figure 6: Selected Access Indicators, SC and US**

	South Carolina	United States
Total Pop. Uninsured, 2006-2007	16.2%	15.3%
Below 200% Poverty Level, 2006	39.5%	34.6%
Counties Designated All/Part Medically Underserved Areas, 1999	95.7%	80.5%
Without Access to Primary Care Provider, 1996	35.8%	17.1%
Women Receiving 1 <sup>st</sup> Trimester Prenatal Care, 2003	83.6%	89%

Source: U.S. Dept. of Health and Human Services, HRSA, Kaiser Family Foundation

### Employment

South Carolina's average unemployment rate for 2007 was 6.9%, higher than the US rate of 6.3%. The median household income in 2007 was \$42,561 vs. the US median income of \$49,901.

### Housing

According to the US Census, in 2007, 70% of the state's homes were owned. The SC Council on Homelessness estimates 6,759 persons are homeless in South Carolina.

### Summary

South Carolina, as many southern states, ranks high for poverty, low educational attainment, and uninsured population compared to other US states. These factors can affect one's ability to access prevention and health care services and adhere to regimens for treatment and care of diseases that may lead to more severe consequences.

## **Question #2: What is the impact of HIV/AIDS on the population?**

In the United States, HIV/AIDS remains a significant cause of illness, disability, and death, despite declines in new AIDS cases and deaths from 1995 to 2007. Current surveillance provides population-based HIV/AIDS data for tracking trends in the epidemic, targeting and allocating resources for prevention and treatment services, and planning and conducting program evaluation activities.

In South Carolina, AIDS cases have been reported since 1981, and confirmed cases of HIV infection have been reportable since February 1986. During the calendar year of 2006, according to the CDC HIV/AIDS Surveillance Report, South Carolina ranked 9th among states and the District of Columbia with an AIDS case rate of 16.3 per 100,000 population. During this same time period, South Carolina also ranked seventh among states and the District of Columbia with an AIDS case rate of 12.5 per 100,000 for female adolescent/adult AIDS cases. The epidemic is continuing to grow with an average of 65 cases of HIV infection reported each month during the past year. As of December 31, 2007, there were 22,489 persons cumulatively reported with HIV, and of them, 17,394 have been diagnosed with AIDS.

South Carolina has experienced a 67% increase of all persons living with HIV/AIDS from 1997 to 2007. More dramatic, there has been an increase of 81% in the number of women living at the end of 2007 compared with the number living in 1997.

This section summarizes the overall toll of the epidemic in South Carolina based on total reported HIV/AIDS cases and deaths.



**Figure 7: Disproportionate HIV Impact by Gender, South Carolina**

SEX	No. (%) SC Total Population*	No. (%) of Total Estimated Living With HIV/AIDS, 2007	No. (%) of Total HIV-Only Diagnosis, 2006-2007
Male	1,948,929 (49%)	10,144 (69%)	675 (69%)
Female	2,063,083 (51%)	4,552 (31%)	299 (31%)
Total	4,012,012	14,696 (100%)	978 (100%)

\*Source: 2000 US Census Data; SCDHEC HARS

Figure 8 shows the rate per 100,000 population for males and females diagnosed with HIV/AIDS each year. During 1997 – 2007 the case rate for females appears to be slightly decreasing. For males, the rate had declined prior to 1998, when the rate increased due to screening in the state correctional facilities. With the exception of 1998, the ratio of men to women has averaged about 2 to 1 during the past three years, where previously it was more than 3 to 1.

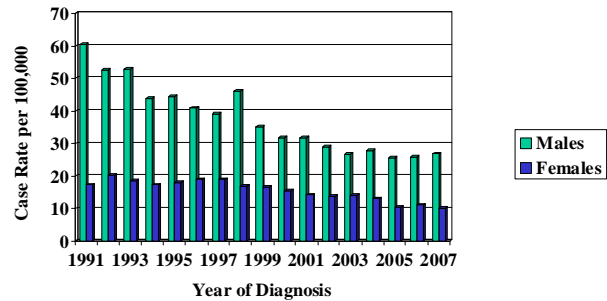
**Race/Ethnicity**

African-Americans are disproportionately impacted by HIV/AIDS in South Carolina. They comprise 30% of the state’s total population, yet 73% of the total persons living with HIV are African-American. Two percent (2%) of total cases are Hispanic, who comprise the same proportion of the state’s population (Figure 9).

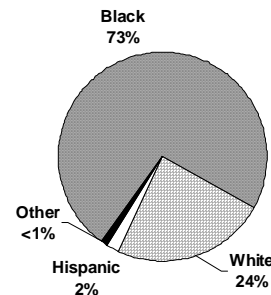
**Gender**

Figure 7 shows the impact of HIV on the men and women in South Carolina. Men unequivocally are disproportionately affected by HIV/AIDS. They make up 49% of South Carolina’s total population, but comprise 69% of persons living with HIV (prevalence). HIV-only diagnosed cases during the two-year period 2006-2007 gives an estimate of more recent infections or potentially emerging populations.

**Figure 8 : HIV/AIDS Case Rate per 100,000 for Males and Females, 1991 - 2007**



**Figure 9: Proportion of Persons Living with HIV/AIDS by Race/Ethnicity, 2007**



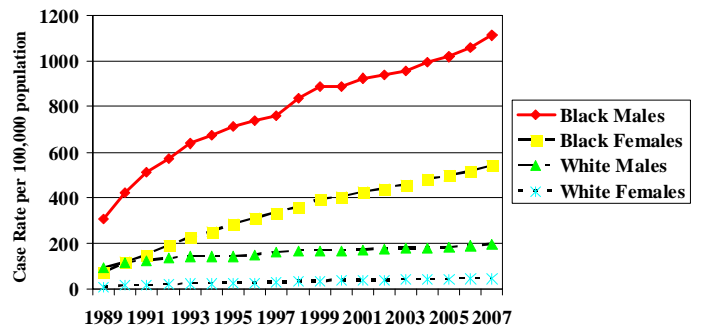
African-American men comprise 15% of the state's population, yet 47% of the total prevalent HIV/AIDS cases in 2007. African-American women, similarly, comprise 17% of the population, yet 26% of prevalent cases. More recent infections (HIV-Only Diagnosis) during 2006 - 2007 reflect a slight increase among African-American men and a slight decrease among African-American women relative to the proportion of persons living with HIV in 2007 (Figure 10).

**Figure 10: Disproportionate HIV Impact by Race/Ethnicity/Gender, SC**

Gender & Race/Ethnicity	No. (%) SC Total Pop.	No. (%) of Total Persons Living With HIV/AIDS, 2007	No. (%) of Total HIV Only Diagnosis, 2006-2007
Black Males	593,707 (15%)	6963 (47%)	486 (50%)
Black Females	668,799 (17%)	3777 (26%)	235 (24%)
White Males	1,355,222 (34%)	2856 (19%)	166 (17%)
White Females	1,394,284 (35%)	669 (5%)	50 (5%)
Hispanic Males	23,978 (0.6%)	282 (2%)	17 (2%)
Hisp. Females	22,296 (0.6%)	79 (.5%)	14 (1%)

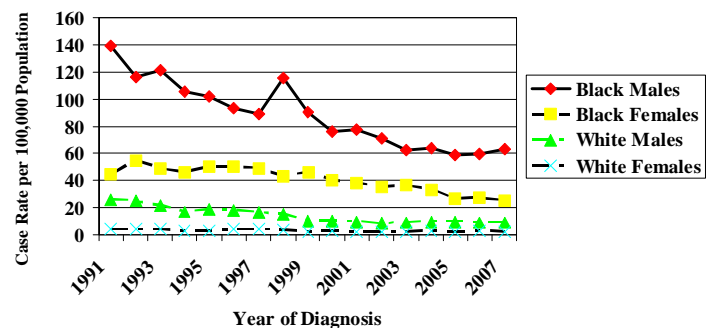
Each year the number of all persons living with HIV/AIDS continues to grow. Case rates per 100,000 by race and gender show the disparate burden of HIV among African-Americans. As Figure 11 shows, the rate per 100,000 population in 2007 is six times higher for black males than for white males, and twelve times higher for black females compared to white females. An increase in the case rate for black men in 1998 reflected a large number of new cases reported as a result of a Department of Corrections screening.

**Figure 11: HIV/AIDS Prevalence Rates by Race/Gender, SC**



While the overall number and rate of newly diagnosed persons with HIV/AIDS each year is stable, there are differences among race/gender populations. (Figure 12) The case rate per 100,000 population among white men in South Carolina has on average remained relatively stable during the past five years (2003-2007). Recently, the rate for African-American women in S.C. decreased 30% from 2003 to 2007. As stated previously, the case rate among African-American males increased in 1998-1999 due to correctional facility screening; however, overall the rate have remained stable during the past five years.

**Figure 12: HIV/AIDS Case Rates by Race/Gender and Year of Diagnosis, SC**



**Figure 13: Disproportionate HIV Impact by Age, SC**

Age Range	No. (%) SC Population	No. (%) of Total Persons Living with HIV/AIDS, 2007	No. (%) of Total HIV-Only Diagnosis, 2006-2007
< 13 Years	724,209 (18%)	52 (<1%)	7 (<1%)
13 – 19 Years	411,579 (10%)	127 (<1%)	54 (6%)
20 – 44 Years	1,467,669 (37%)	7,610 (52%)	677 (69%)
45+ Years	1,408,565 (35%)	6,907 (47%)	240 (25%)

**Age**

When looking at age groups, persons between the ages of 20 and 44 are disproportionately impacted. They make up 37% of the total population yet they represent about 52% of prevalent and 69% of HIV-only diagnosed cases. (Figure 13)

**Figure 14: S.C. HIV/AIDS Case Rate per 100,000 by Age by Year of Diagnosis, 1991-2007**

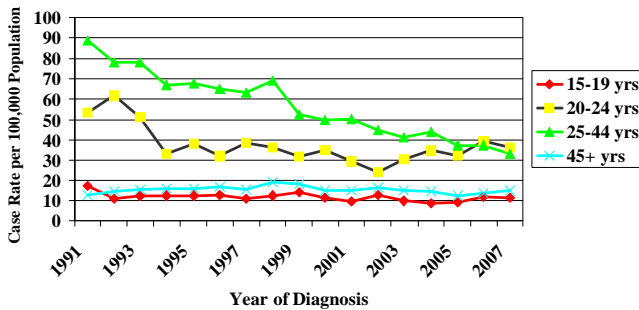
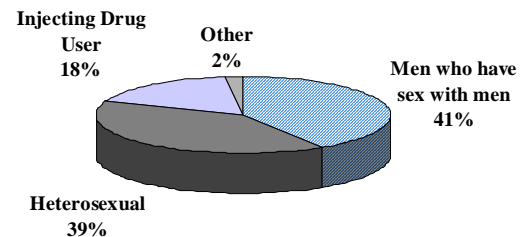


Figure 14 shows the HIV/AIDS case rates per 100,000 population by year of diagnosis for selected adult/adolescent age groups for the past seventeen years. The rates are highest for persons 20-24 years of age, followed by those 25-44 years.

**Risk Exposure**

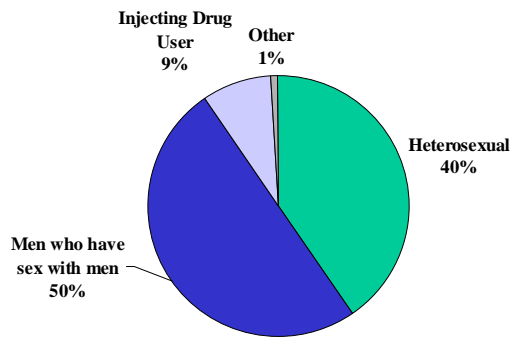
Men who have sex with men (MSM) comprise the greatest proportion of persons living with HIV/AIDS at the end of 2007 with known risk factors (41%), followed closely by heterosexuals (39%). Eighteen percent (18%) are injecting drug users (Figure 15). Other risks include blood transfusions, hemophilia, and perinatal transmission. Of the total estimated number of persons living with HIV/AIDS in 2007, 24% had no risk identified (not reflected in Figure 15).

**Figure 15: Proportion of Persons Living with HIV/AIDS by Risk Exposure, 2007  
N=11,123**



Note: Total Excludes Cases with No Risk Identified

**Figure 16: Proportion of HIV/AIDS Cases by Risk Exposure, 2006-2007**  
N= 1,066



Note: Total Excludes Cases with No Risk Identified

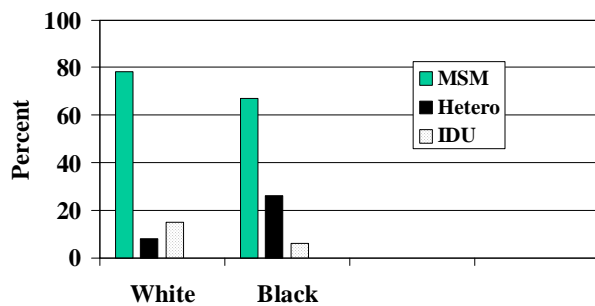
Figure 16 shows a slight shift in risk exposure categories among persons diagnosed with HIV/AIDS during 2006–2007 with known risk exposures compared to the prevalent cases in Figure 15. The proportion of cases due to heterosexual transmission was 40%, men who have sex with men accounted for 50% and IDUs made up 9%. Thirty-two percent (32%) of these cases had no risk identified (not reflected in figure 16).

Note: The primary reasons for risk exposure information not reported were explained in the Introduction, South Carolina HIV/AIDS Surveillance System section. Over time, the proportion of cases with no risk identified in a given year decreases when risks are determined through follow-up surveillance activities. For example, during 2000 there were 312 cases originally reported with no risk; as of December 2001, risks were determined for 249 of the 312 cases. The race/gender profile of 2007 cases originally reported with no risks is relatively close to the total proportion of HIV/AIDS cases by race/gender (Figure 17).

**Figure 17: Comparison of No Risk Identified Cases with Total S.C. HIV/AIDS Reported Cases, 2007**

Race/Gender (Adult/Adolescent Cases)	% Total Cases with No Risk Identified, 2007 N=256	% Total HIV/AIDS Cases Reported, 2007 N=780
Black Male	52%	50%
Black Female	25%	22%
White Male	11%	17%
White Female	5%	4%
Other	8%	6%

**Figure 18: Proportion of White and Black Male HIV/AIDS Cases By Exposure Category, Diagnosed 2006-2007**



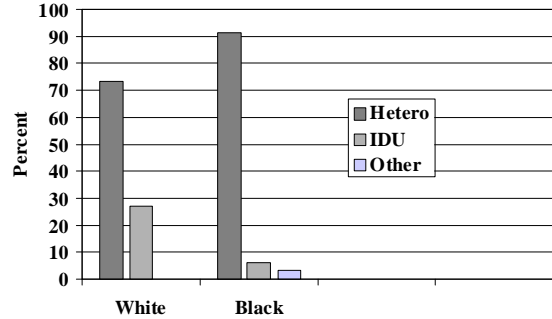
Total Males, All Ages; Excludes Persons with No Risk Reported; N=729

During 2006 – 2007, 70% of males diagnosed with HIV/AIDS were African-American. Among African-American males with reported risk factors, most cases were attributed to male to male sexual contact (67%) and heterosexual contact (26%). Injecting drug use is more commonly reported among white males (15%) than among black males (6%). Among white men,

78% were men who have sex with men. Only 8% reported heterosexual risk (Figure 18).

Among women diagnosed during 2006 – 2007, 79% of cases were among African-American women. Heterosexual contact was the most common reported risk for all women (89%). Injecting drug use is more commonly reported among white women (27%) than among black women (6%). (Figure 19)

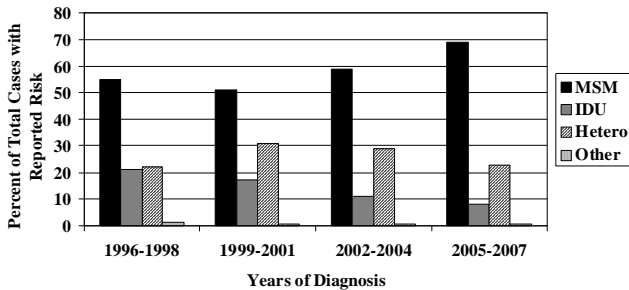
**Figure 19: Proportion of White and Black Female HIV/AIDS Cases By Exposure Category, Diagnosed 2006-2007**



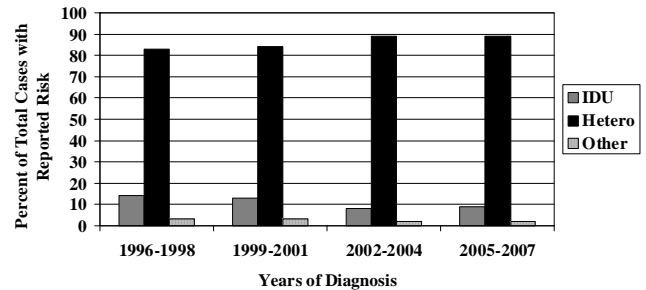
Total Females, All Ages; Excludes Persons with No Risk Reported; N=283

Figures 20 and 21 show the proportion of total HIV/AIDS cases diagnosed during four periods from 1996 – 2007 by sex and risk exposure category for males and females in South Carolina. Both men and women experienced decreases over time in the proportion of total cases with risk reported among injecting drug users. During 1996 – 1998 to 2005 – 2007, there was a 62% decrease in the proportion among injecting drug use among men and a 36% decrease among women. The proportion of heterosexual risk increased 5% for men and increased 7% for women during the same time periods.

**Figure 20: Proportional Distribution of Male HIV/AIDS Cases, by Exposure Category, Diagnosed 1996-2007**



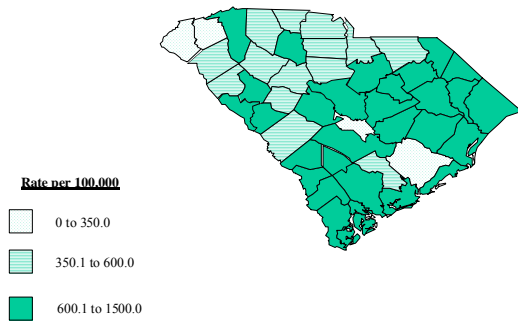
**Figure 21: Proportional Distribution of Female HIV/AIDS Cases, by Exposure Category, Diagnosed 1996-2007**



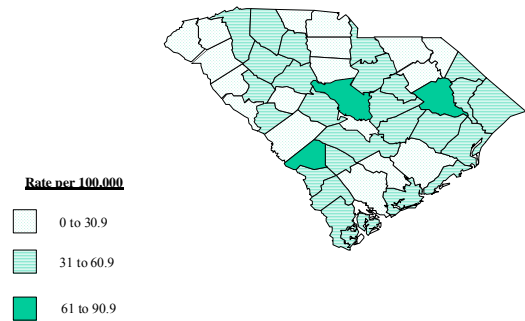
**Residence**

Persons living with HIV/AIDS are widespread throughout the state. Over 60% of counties have prevalence rates >600 per 100,000 for African-Americans, as reflected in Figure 22. Annual case rates in counties of more recently diagnosed African-American persons during 2005 – 2007 reflect essentially the same counties as highest prevalence rates. Richland County has the highest annual case rate (Figure 23).

**Figure 22: SC HIV Prevalence Rates (per 100,000 population) Cases Currently Living, 2007 African-American**

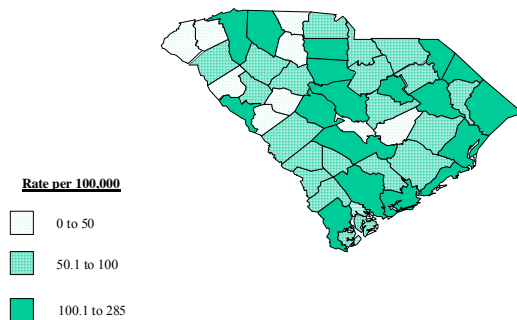


**Figure 23: SC HIV/AIDS Incidence Rates (per 100,000 population) 2005-2007 Average of Cases African-American**

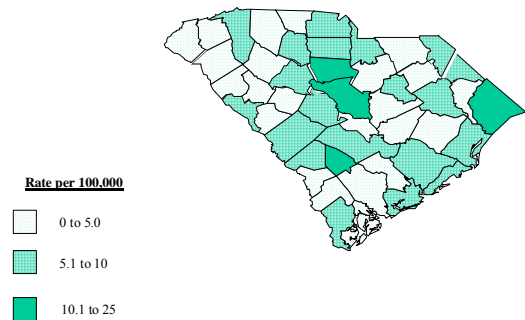


Counties with highest prevalence rates among white persons include more urban areas of Greenville, Spartanburg, Richland and Lexington (Columbia), Charleston, Horry (Myrtle Beach), as well as Orangeburg, Florence, Marlboro, Fairfield, McCormick, Colleton, Jasper, Dillon and Lee (Figure 24). Figure 25 shows counties with highest rates of more recently diagnosed white persons are Richland, Charleston, Horry, Orangeburg, Fairfield,

**Figure 24: SC HIV Prevalence Rates (per 100,000 population) Cases Currently Living, 2007 Whites**



**Figure 25: SC HIV/AIDS Incidence Rates (per 100,000 population) 2005-2007 Average of Cases Whites**



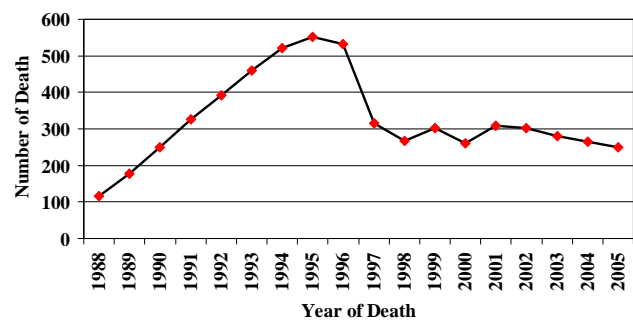
Lee, and Bamberg.

## Mortality

With the advent of combination therapies and the use of prophylaxis, persons infected with HIV are living longer, delaying the progression of AIDS, which is the advanced stage of the disease. These medications have also led to the decrease in HIV-related deaths.

Large declines in HIV mortality nationally essentially occurred during 1996 – 1997. Officials at the Centers for Disease Control and Prevention (CDC) cautiously attributed the sudden drops in deaths to new anti-retrovirals, protease inhibitors, combination therapies, and increased prophylaxis for opportunistic illnesses. However, the initially reported gains were tempered by reports of demographic differentials that suggested only certain groups were benefiting from these new therapies

**Figure 26: Deaths Among Persons with AIDS in South Carolina, 1988-2005**



Source – SCDHEC, Vital Records, SC Residence Data

Figure 26 shows largest declines in deaths in South Carolina were in 1997, dropping to 317 from 532 the previous year. In recent years, death among persons with AIDS has remained fairly stable, which may indicate diminishing efficacy of therapies among some patients. Reasons for this may include delay in diagnosis of HIV infection until severe symptoms arise, difficulty in adherence to prescribed medical treatments, and development of viral resistance to therapy.

**Figure 27: Characteristics of Persons who died of AIDS, 2005**

	No.	%
<b>Race/Sex</b>		
Black Male	128	51
Black Female	65	26
White Male	45	18
White Female	11	4
<b>Age Group</b>		
<15	---	0
15-24	5	2
25-44	124	50
45+	120	48

Although black males represent 47% of persons living with HIV/AIDS, in 2005, they accounted for the majority of persons dying from AIDS (51%). African-American females accounted for 26% of AIDS related deaths followed by white males (18%). By age group, the majority of deaths occurred among persons 25-44 years (50%). (Figure 27)

**Figure 28: Number of Persons who died of AIDS by Health Region, 2005**

Health Region	No.	%
Region 1	18	7
Region 2	41	16
Region 3	55	22
Region 4	49	20
Region 5	18	7
Region 6	16	6
Region 7	35	14
Region 8	17	7
<b>TOTAL</b>	<b>249</b>	<b>100</b>

Region 3 and Region 4 represent the highest number of deaths from AIDS in South Carolina in 2005 (Figure 28). These areas are also among those that have the highest prevalence of AIDS in the state.

### Question #3: Who is at risk for becoming infected with HIV?

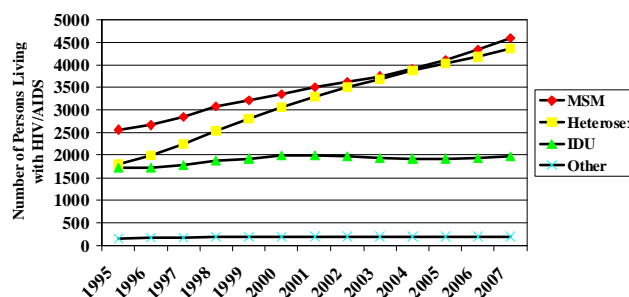
The persons most likely to become infected with HIV are those who engage in high-risk behaviors with persons in communities with a high number/rate of persons living with HIV infection, i.e. prevalence. As mentioned previously, growing numbers of people with HIV in South Carolina are living more healthy lives, including sexual activity. The frequency of high-risk behavior combined with the HIV prevalence in sexual or drug using-networks determines a person’s risk for becoming infected. In order to accurately target STD/HIV prevention and treatment activities, it is important for community planning groups (and program providers) to have information on the number and characteristics of persons who become newly infected with HIV and persons whose behaviors or other exposures put them at various levels of risk for STD and HIV infection. This section summarizes HIV infection among population groups at high risk for HIV infection, sexually transmitted disease data, and behavioral data.

#### Characteristics of HIV/AIDS in Persons at Highest Risk

Analysis of characteristics of persons with HIV/AIDS helps identify persons at greatest risk for becoming infected. Risk for infection can be determined by assessing the frequency of high-risk behavior (e.g., unprotected sex, needle-sharing) in combination with the estimated prevalence of HIV/AIDS and incidence of HIV/AIDS.

Figure 29 shows the number of persons in South Carolina living with HIV/AIDS at the end of each year by reported risk. Men who have sex men (MSM) comprise the greatest number of living persons, followed closely by heterosexuals. Injecting drug users (IDUs) and other risks (e.g. hemophilia, blood

**Figure 29: Number of Persons Presumed Living with HIV/AIDS at End of Year by Risk, 1995-2007**

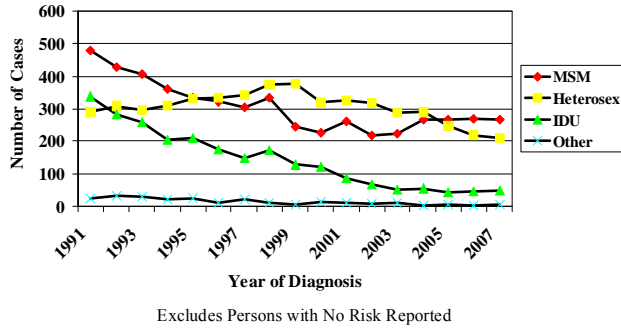


Number Excludes Persons with No Risk Reported; MSM/IDU included in IDU category



transfusion, perinatally acquired infection) comprise fewer numbers.

**Figure 30: Number of HIV/AIDS Cases by Year of Diagnosis and Risk, 1991 -2007**



While men who have sex with men comprise the greater proportion of persons living with HIV, newly diagnosed HIV/AIDS cases each year indicate that beginning in 1997, more persons report heterosexual risk than male to male sex, except in 2004 and 2005 where the number reporting heterosexual risk and male to male sex were almost equal and in 2006, the number reporting male to male sex slightly exceed heterosexual risk.

While not validated, many local experts believe that the number of heterosexuals among African-American men may be artificially high due to fears of discrimination; therefore, men do not reveal male to male sex as a risk behavior. The number of injecting drug users reported each year has remained stable over the past five years (Figure 30).

Based on data in this profile, the following primary populations have been identified as being the highest risk of HIV/AIDS: men who have sex with men (MSM), high-risk heterosexuals, and injecting drug users (IDUs). Women will be described in the heterosexual and injecting drug user section, and teenagers/young adults will be described within each population category. Since African-Americans are disproportionately impacted across each risk category, this impact will be described for each risk population rather than as a separate population. Infants and children and prison populations will be described separately.

## Men Who Have Sex With Men

### Estimates of Men Who Have Sex with Men Behavior in South Carolina

According to the U.S. Census Bureau, there are approximately 1,436,281 males in South Carolina between the ages of 15-64, which is the age range when persons are most sexually active. Review of literature and other state profiles, indicates that the estimated percentage of men who have sex with men (MSM) ranges from 2.1% to 10.1%, with the average at 2.7%. This would mean that the number of MSM in South Carolina could be estimated to be 38,780, although the estimated range is much broader.

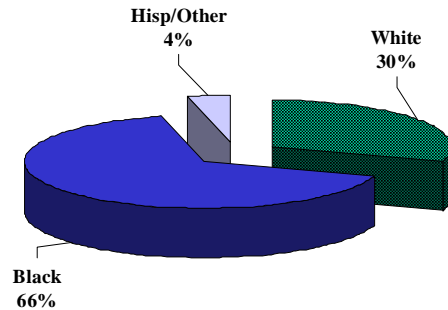
### Characteristics

*Note: for purposes of this analysis, cases that are both men who have sex with men (MSM) and injecting drug users (IDU) are included in the injecting drug user category.*

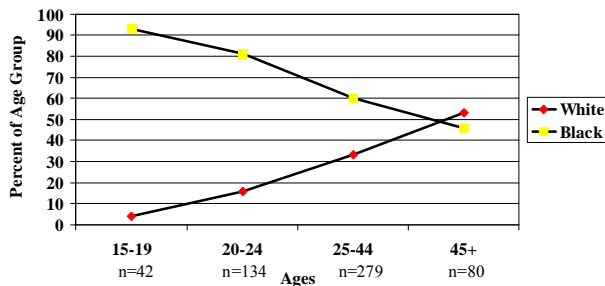
The largest proportion of persons living with HIV/AIDS in South Carolina at the end of 2007 was men who have sex with men (41% of total prevalent adult/adolescent cases with identifiable risk). MSM account for a slightly higher proportion (50%) of the more recently diagnosed adult/adolescent cases during 2006-2007. The number of MSM cases diagnosed each year increased 16% from 2003 to 2007.

As Figure 31 demonstrates, the majority of MSM cases diagnosed during 2006 - 2007 were African-Americans (66%). White men accounted for 30% of the new cases and 4% were Hispanic or other races.

**Figure 31: Proportion of Men with HIV/AIDS Who Have Sex With Men by Race/Ethnicity, Diagnosed 2006-2007**  
N=536



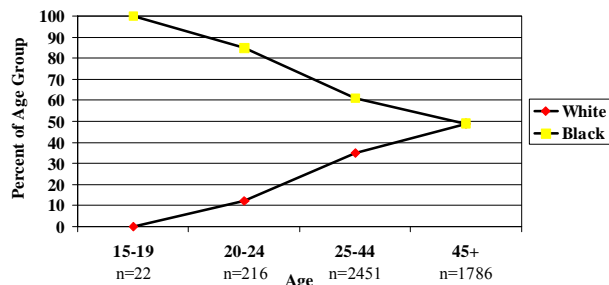
**Figure 32 : Percent MSM HIV/AIDS Cases Diagnosed 2006-2007 by Age Group & Race**  
N=536



Total N includes 24 Other Men Not Included in Graph Due to Small Numbers

The majority of men who have sex with men diagnosed during 2006 – 2007 were 25 – 44 years of age (52%); 25% were 20 – 24 years old and 15% were 45+ years. For men more recently diagnosed, African-Americans accounted for the highest proportion for each age group except for those 45 and older (Figure 32).

**Figure 33: Percent of MSM Living with HIV/AIDS by Age Group & Race, 2007**  
N=4,587

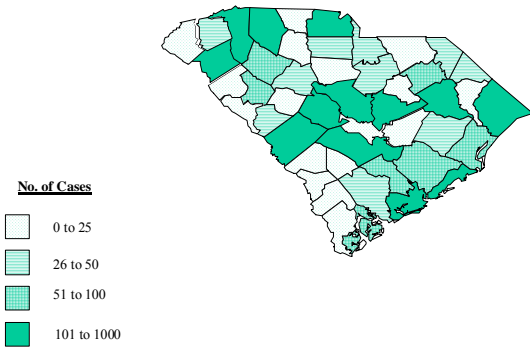


Total N includes 112 Other Men Not Included in Graph Due to Small Numbers

Of the men who have sex with men presumed living with HIV in 2007, 69% were African-American, 28% were white and 3% were Hispanic/other men. As Figure 33 shows, for each younger age category less than 45 years, African-Americans comprise the greatest proportion of living MSM. However, among those 45 years and older, the proportion is

equal for white and African-American men (50%).

**Figure 34: SC HIV Prevalence by Exposure Category, 2007 Reported Cases, by County  
MSM**



The more urban counties of Greenville/Spartanburg, Anderson, York, Richland, Lexington, Charleston, Sumter, Horry, Florence and Orangeburg have the greatest number of men who have sex with men living with HIV/AIDS in 2007 (Figure 34).

Due to small numbers for many counties, portraying the three-year annual case numbers of men who have sex with men by county is not useful.

### Conclusions

These data indicate that prevention efforts targeted to men who have sex with men need to be tailored to both African-American and white men. African-American men account for almost half the proportion of both living cases (47%) and newly diagnosed HIV/AIDS cases (50%). Increased efforts in particular are needed to reach younger African-American MSM <25 years of age; for white men, targeted efforts are needed for those >25 years. Interventions also need to be particularly available for persons living in the more urban areas of the state.

### High Risk Heterosexuals

#### Estimates of High-Risk Heterosexual Behavior in South Carolina

It is difficult to make an assessment of the number of persons in South Carolina who engage in heterosexual contact that puts them at high risk for becoming infected with HIV. While there are some differences in the population of persons with HIV/AIDS than for those with a sexually transmitted disease, most experts acknowledge that a diagnosis of an STD would suggest that the individual is engaging in unsafe sexual practices. During 2007, 26,117 cases of chlamydia, 9,932 cases of gonorrhea and 95 cases of infectious syphilis were reported in South Carolina. Women with an STD, in particular, indicate high-risk heterosexual activity. Among the 2007 cases of chlamydia, 20,542 were among women, and 5,453 women were reported with gonorrhea. More data on STDs, as well as other behavioral indicators such as teenage pregnancy and condom use is described later.

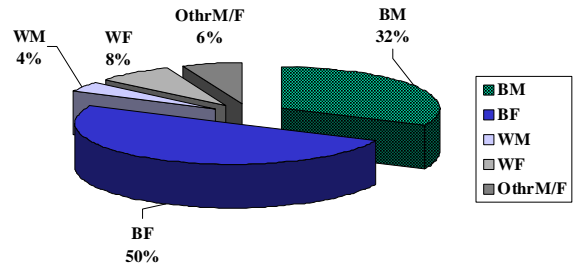
In order for a case of HIV or AIDS to be considered as heterosexual transmission, it must be documented that the individual had heterosexual contact with a person who has documented HIV infection or AIDS, or had heterosexual contact with a person who is in a high risk group for HIV (MSM or injecting drug user).

**Characteristics of High Risk Heterosexuals**

Persons with documented high-risk heterosexual contact comprise 30% of the total adult/adolescent persons living with HIV/AIDS at the end of 2007 and 27% of persons more recently diagnosed during 2006-2007 (excluding persons with no risk identified for both new and prevalent cases). The number of heterosexual cases diagnosed each year decreased 34% from 2000 to 2007 (see Figure 30).

Figure 35 shows that over half (58%) of recently diagnosed heterosexual HIV/AIDS cases are women. African-American women account for 50% of recent cases and white women account for 8%. Thirty-two percent (32%) are African-American men. White men account for only 4% of recent cases.

**Figure 35: Proportion of Heterosexual HIV/AIDS Cases by Race/Sex, Diagnosed 2006-2007 N=429**



**Figure 36: Number of HIV/AIDS Cases Attributed to Heterosexual Transmission, By Sex and Year of Diagnosis**

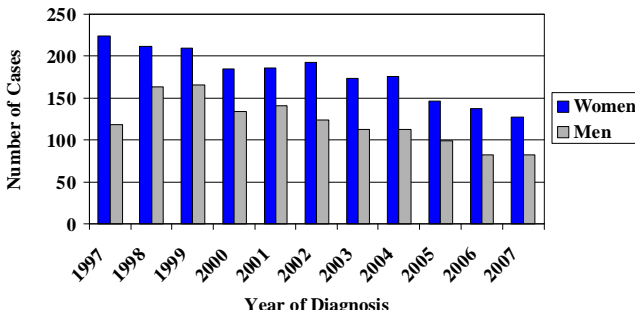
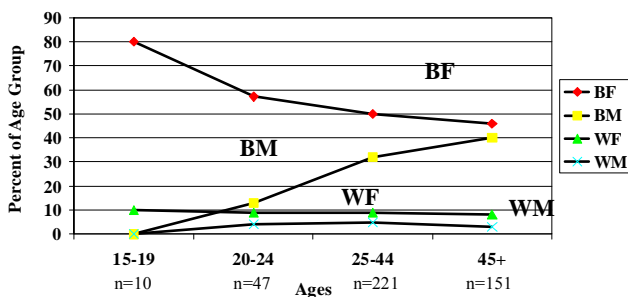


Figure 36 shows the number of heterosexually acquired HIV in women and men in South Carolina from 1997 to 2007. During most of this period, the proportion of female cases outnumbered the male cases by an average of 40%. The number of women reporting heterosexual risk has gradually decreased by 26% in the past five years from 2003 to 2007. Likewise, the number of men reporting heterosexual HIV risk has gradually decreased by 27% in the same time period.

**Figure 37: Percent Heterosexual HIV/AIDS Cases Diagnosed 2006-2007 By Age Group and Race/Sex N=429**

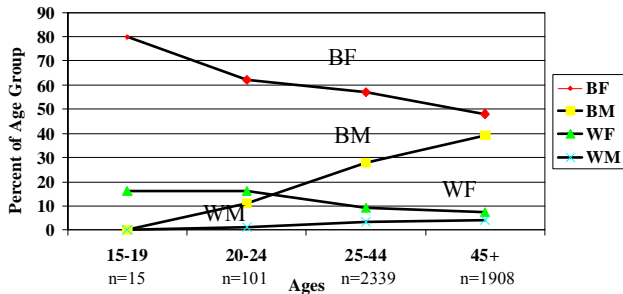


The majority of high risk heterosexuals recently diagnosed were 25 – 44 years of age (52%);

Total N includes 25 Other Race Not Included in Graph Due to Small Numbers

35% were 45 years and older, and 13% under 25 years. With the exception of the 15-19 year old group, African-American women and men comprised the greatest proportion of cases in each age group (Figure 37). Among young women less than 45 years of age, over 8 out of every 10 of the total cases are African-American women. White women and men account for an average of 15% or less of young and older ages.

**Figure 38: Percent of Heterosexuals Living with HIV/AIDS by Age Group and Race/Sex, 2007**  
N=4,363



Total N includes 116 Other Race Not Included in Graph Due to Small Numbers

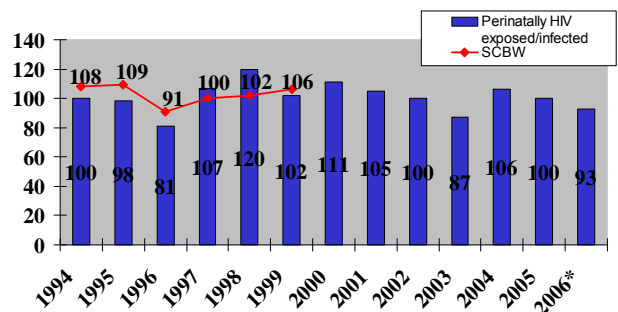
Of the high risk heterosexual persons presumed living with HIV/AIDS in 2007, over half were African-American women (53%), 32% were African-American men; 8% were white women. As Figure 38 shows, over 8 of every 10 young women under age 25 living with HIV/AIDS were African-American; over one half of persons 25 – 44 are African-American women. Similarly, the proportion of persons living 45 years and older is greatest for African-American women followed closely by African-American men. As with more recently diagnosed persons, white women and men account for an average of 12% of persons living with HIV across all age groups.

### Estimates of prevalence of HIV among High Risk Heterosexual Women

Estimates of HIV prevalence among women were obtained during 1990 – 1997 through a population-based seroprevalence survey of women who deliver live births at hospitals throughout the state. Recently estimates are obtained by the pediatric surveillance system using reports of HIV infected women delivering live births. While this prevalence is limited to child-age bearing women who have delivered a child, it provides the best overall estimate available for HIV infection among women 15 – 44 years of age.

Figure 39 shows that the number of HIV infection cases among all women delivering live births has been stable during the past seven years, averaging nearly 100 per year. The rate, though, is nearly 9 times higher among African-American women compared to white women.

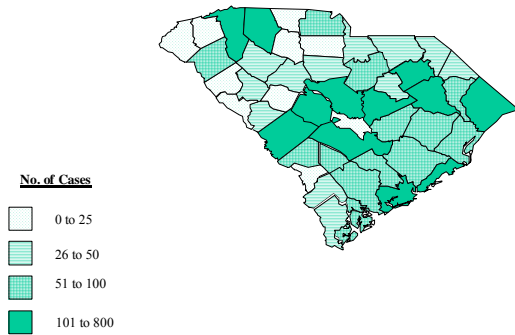
**Figure 39 : Perinatally HIV Exposed Births by Year of Birth Compared to SC Survey of Child Bearing Women**



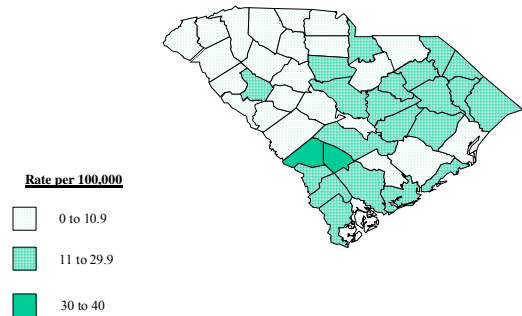
Source: provisional SC STD/HIV Surveillance Program Data

Figure 40 shows the counties with highest prevalence of persons living with HIV/AIDS due to heterosexual transmission. These are the more urban counties of Florence, Greenville/Spartanburg, Richland, Lexington, Sumter, Orangeburg, Horry and Charleston, as well as Darlington and Aiken counties. Figure 41 shows the case rate for 2005-2007 among women, an indicator for more recent heterosexual risk. Richland, Sumter, Orangeburg, as well as rural Marlboro, Marion, Bamberg, Barnwell and Allendale counties had the highest case rates in the state.

**Figure 40: SC HIV Prevalence by Exposure Category, 2007 Reported Cases, by County Heterosexual Contact**



**Figure 41: SC HIV Incidence Rates (per 100,000 population) 2005-2007 Average of Cases Females**



### Conclusions

These data indicate that prevention efforts targeted to high risk heterosexuals need to be tailored to African-Americans, particularly young women under age 25, who account for over six of every ten persons of both living cases and more recently diagnosed cases in this age group. Efforts also need to target African-American men and women 25 – 44 years, who account for over eight out of every ten persons living and more recently diagnosed cases (all ages). Prevention efforts targeting African-American men and women should also be tailored to reach those 45 years and older.

### Injecting Drug Users

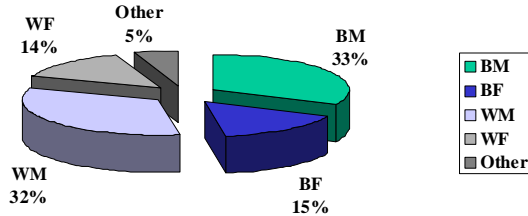
#### Estimates of Injecting Drug Use Behavior in South Carolina

According to 1999-2000 estimates of heroine use provided by the SC Department of Alcohol and Other Drug Abuse Services (DAODAS), there are 8,000 persons in South Carolina who are injecting drug users in need of treatment services.

## Characteristics of Injecting Drug Users

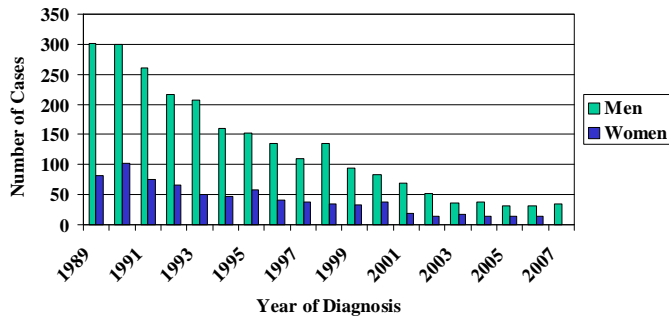
*Note: persons who are categorized as both men who have sex with men and injecting drug users are included in this population description.*

**Figure 42: Proportion of Injecting Drug Users Diagnosed with HIV/AIDS 2006-2007 by Race/Sex N=93**



of cases, and the least proportion is among white women (14%).

**Figure 43: Number of HIV/AIDS Cases Due to Injecting Drug Use by Sex and Year of Diagnosis, 1989-2007**



corrections facilities, identifying more new cases that year. (Figure 43)

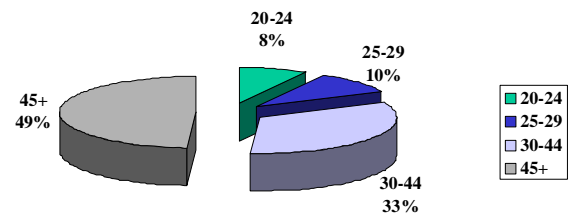
Figure 44 shows that 49% of recently diagnosed IDU cases are 45 years and older; 43% are 25 – 44 years of age. Only 8% of persons diagnosed during 2006-2007 were under 25 years.

Injecting drug users (IDUs) account for 13% of the persons presumed living with HIV/AIDS in 2007 and 12% of persons more recently diagnosed with HIV/AIDS during 2006-2007. The number of IDU cases diagnosed each year decreased 45% from 2001 to 2007. (See Figure 30).

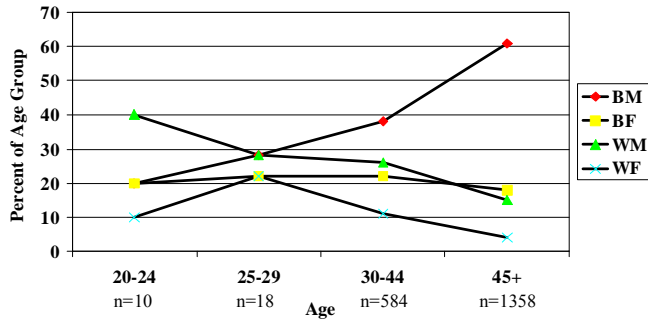
Figure 42 shows that 33% of recently diagnosed injecting drug use cases are African-American men; white men account for 32% of recent diagnoses. African-American women account for 15%

Men are overwhelmingly impacted by HIV transmitted by injecting drug use, averaging 3 cases to every one case reported among women each year. Men show a decrease in number of diagnosed IDU cases since 1998. For most of this same period, the number of diagnosed IDU cases among women was fairly stable. The increase in 1998 cases for men is likely due to targeted screening in

**Figure 44: Percent of Injecting Drug Users Diagnosed with HIV/AIDS 2006-2007 by Age Group N=93**



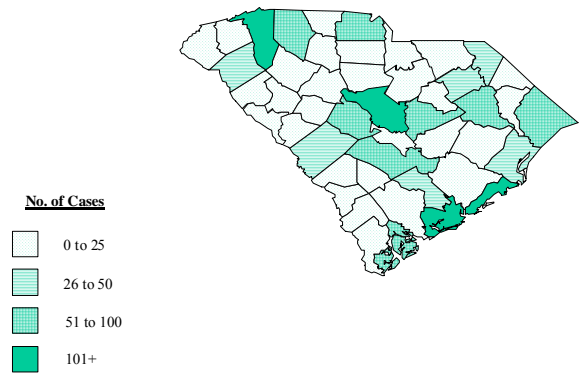
**Figure 45: Percent of IDU Persons Presumed Living with HIV/AIDS by Race/Sex and Age Group, 2007  
N=1,970**



Similarly, persons living with HIV/AIDS due to injecting drug use are largely 25 years of age and older (99%). African-Americans account for the greatest proportion of cases in each age group, with African-American men accounting for over 61% of those older than 25 years. (Figure 45)

Figure 46 indicates the counties with the highest number of persons living with HIV with injecting drug use risk (Richland, Greenville, and Charleston). As with other risks, the more urban counties have the greatest numbers.

**Figure 46: HIV Prevalence by Exposure Category, 2007 Reported Cases, by County  
IDU**



**Conclusions**

Prevention efforts targeting injecting drug users need to be tailored to men, primarily African-American men who comprise a majority of recently diagnosed cases, followed by white men. Efforts should target persons older than 25 years and those who are predominately in more urban counties including Lexington, York, Florence, Spartanburg, Horry, Orangeburg and Sumter.

**Other Populations**

**Other populations at varying risk for HIV are described below and include infants and children, persons with sexually transmitted diseases, and pregnant teen-age women.**

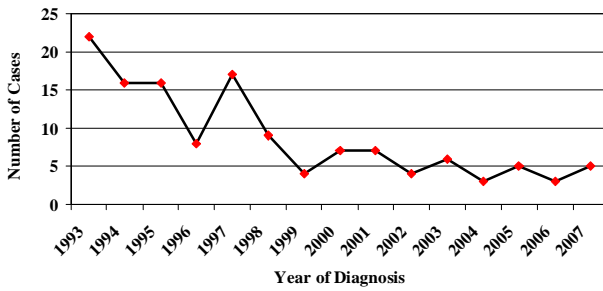
Infants and Children: (Children under 13 years of age)

The majority of infants and children are infected with HIV through exposure to their mother during pregnancy. Through December 2007, there were 105 HIV infection cases



diagnosed among children less than 13 years of age, of which 52 had AIDS. This represents less than 1.0 percent of the total reported AIDS and HIV infection cases. The majority of the children with HIV are black.

**Figure 47: Number of Children <13 Years Old Diagnosed with HIV/AIDS in South Carolina, 1993-2007**



Source: SCDHEC, HARS

There has been significant progress during the past five years in reducing the number of infants with perinatal acquired HIV infection. Figure 47 shows the decline in the number of infants diagnosed from 16 cases in 1997 to 5 cases in 2007.

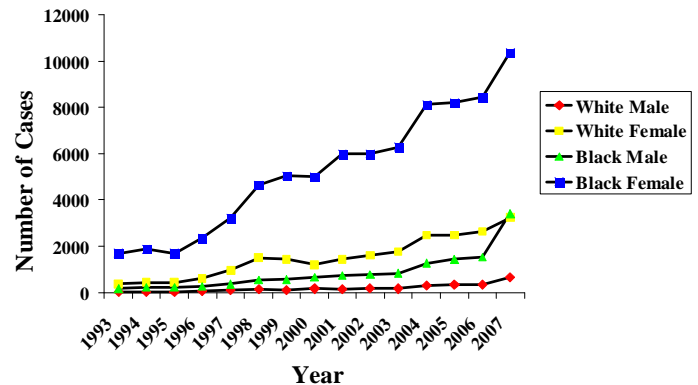
**Persons with Sexually Transmitted Diseases (STDs)**

STDs are primary risk factors for HIV infection and a marker of high risk, unprotected sexual behavior. Many STDs cause lesions or other skin conditions that facilitate HIV infection. Trends in STD infection among different populations (e.g. adolescents, women, men who have sex with men) may reflect changing patterns in HIV infection that have not yet become evident in the HIV/AIDS caseload of a particular area.

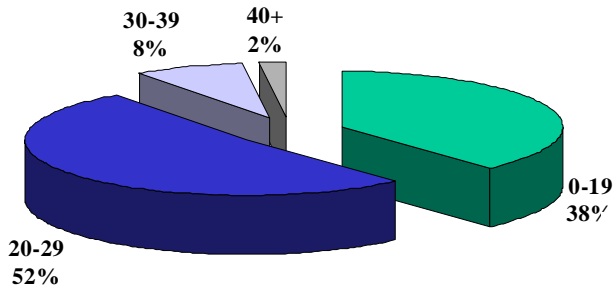
**Chlamydia**

In 2007, there were 26,117 cases of chlamydia diagnosed in South Carolina. Figure 48 shows the increase of chlamydia as a result of initiating routine screening for all young women attending family planning and STD clinics in health departments statewide. Among those cases with reported race/gender, 57% were African-American women; 18% were white women in 2007. Hispanic men and women accounted for 1% of cases in 2007.

**Figure 48: South Carolina Reported Chlamydia Cases by Year of Diagnosis, 1993 - 2007**



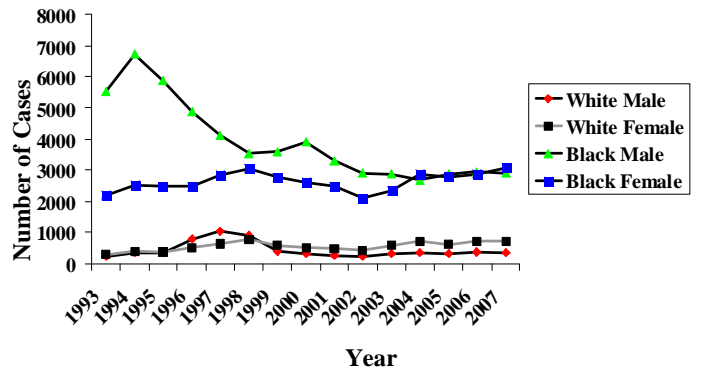
**Figure 49: Proportion of 2007 Reported Chlamydia Cases by Year of Diagnosis by Age Group**



Excludes persons with no reported age

Figure 49 shows that in 2007 young adults 20-29 have the highest proportion of chlamydia (52%) in the state. Counties with highest chlamydia rates per 100,000 population in 2007 were Bamberg (1,460.6), Allendale (1,358.4) and Richland (1,196.9).

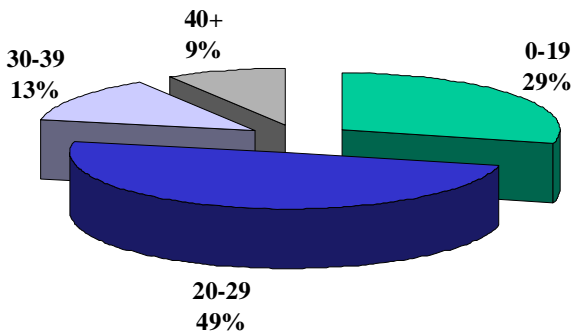
**Figure 50: South Carolina Reported Gonorrhea Cases by Year of Diagnosis, 1993 - 2007**



**Gonorrhea**

In 2007, 9,932 gonorrhea cases were diagnosed. African-American men and women account for 85% of reported cases with known race/gender in 2007. Figure 50 shows trends among race/gender by year.

**Figure 51 : Proportion of 2007 Reported Gonorrhea Cases by Year of Diagnosis by Age Group**



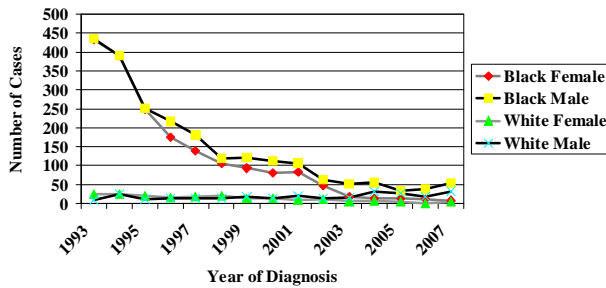
Excludes persons with no reported age

As with chlamydia, gonorrhea cases most affect young adults 20-29 years of age (49% of total) (Figure 51). Counties with highest rates per 100,000 of gonorrhea in 2007 were Lee (481.5); Orangeburg (405.1); and Richland (385.7).

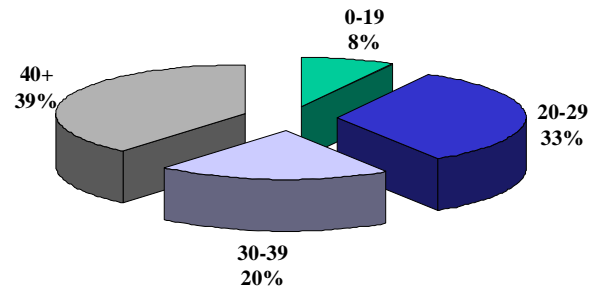
**Infectious Syphilis**

In 2007, 95 cases of infectious syphilis were diagnosed. As Figure 52 shows, significant decreases have occurred during the past ten years for all infectious syphilis cases. As with other STDs, African-Americans are most impacted, accounting for 75% of total cases. Unlike other STDs, syphilis most impacts older adults, 30 years and older (59% of total) (Figure 53). Counties with highest infectious syphilis rates per 100,000 population in 2007 were Lee (9.7), Allendale (9.3), Richland (9.2), and Calhoun (6.7).

**Figure 52: South Carolina Reported Infectious Syphilis Cases by Year of Diagnosis, 1993-2007**



**Figure 53: Proportion of 2007 Reported Infectious Syphilis Cases by Year of Diagnosis by Age Group**



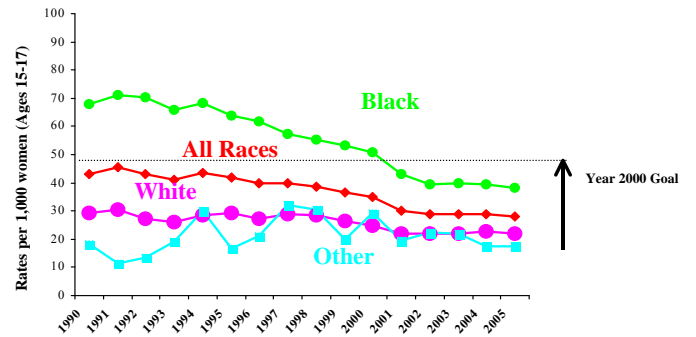
## Teenage Pregnancy

Pregnancy, birth and abortion rates, like STD rates, are indications of the extent of unprotected sexual activity in a population.

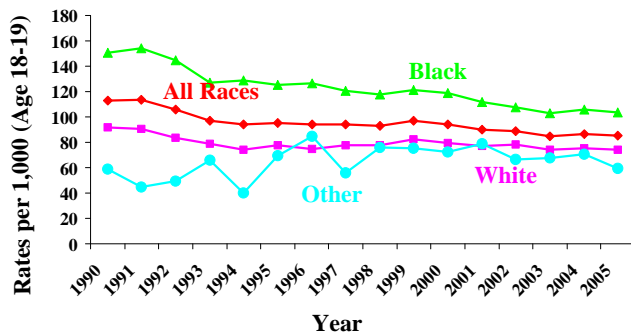
African-American girls between the ages of 10 and 14 have continued to have higher rates of live births than their white counterparts. However, their rates have decreased from 4.2 in 1988 to 1.8 per 1,000 in 2006, respectively.

Teenage pregnancies among 15-17 year old South Carolinians have decreased from a rate of 43.2 per 1,000 live births in 1990 to 28.1 in 2005; a 35% decline (Figure 54). This success is also seen when viewing teen pregnancy by racial/ethnic subgroups. The rate for White 15-17 year old teens was 29.1 in 1990 and 22.1 in 2005, representing a 24% decline. The rate for African-American 15-17 year old teens declined 44% in the same time period from 1990 to 2005. The rate for Others is the only exception to a consistent declining trend where the rate was 21.2 in 1996 and climbed to 30.4 in 1998 and down again to 17.4 in 2005, representing a 18% decrease in the rate over the 1996 to 2005 period. This fluctuation may be due to small numbers and the trend for this subgroup requires further

**Figure 54: South Carolina Teenage Live Births Rates, Ages 15 - 17**



**Figure 55: South Carolina Teenage Live Births Rates Ages 18-19**



Source – SCDHEC, Vital Records, SC Residence Data

observation.

Figure 55 shows the teen pregnancy rates for 18 and 19 year olds. As with the other two age groups, African-American and other teenage girls continue to have higher live birth rates over the 15-year period than all races. But also as seen in the other age groups their rates have decreased from 150.6 to 103.3, 1990 and 2005, respectively.

## Persons Receiving HIV Counseling and Testing At County Health Departments

**Data from local HIV counseling and testing sites (county health departments) generally reflect similar trends as HIV/AIDS surveillance data in terms of who is most likely to be HIV infected, risk category, and county of residence. As stated in the Introduction, the data reflects only those persons tested voluntarily in local**

health departments. HIV infected persons diagnosed through counseling and testing sites account for about one-third of the newly diagnosed persons in South Carolina annually. This data reflects number of individuals tested, not the number of tests. In 2007, African-Americans comprised 64% of the total persons tested, but 77% of the total positive. Men accounted for 38% of persons tested but 70% of total positive. Persons 20-49 years of age had the highest positivity rate and comprised 82% of the total positive persons.

Public Health regions that accounted for the greatest proportion of persons tested who were positive include those with the same urban counties of highest prevalence: Region 3, (includes Richland County)- 28.1% of total positives tested; Region 2, (includes Greenville/Spartanburg County) – 16.2% of total positives; Region 5, (includes Orangeburg County) – 10.8% of total positives; Region 4 (includes Sumter and Florence counties) – 14.3% of total positives; Region 6 (includes Horry County) – 9.1% of total positives; Region 1 (includes Anderson County) – 5.1% of total positives; Region 7, (includes Charleston County)- 9.1% of total positives; and Region 8 (includes Beaufort County) – 4.2% of total positives.

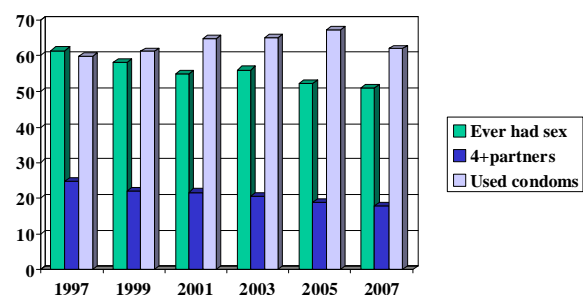
#### Other Behavioral/Risk Data

##### Behavioral Risk Factor Surveillance System (BRFSS)

**Behavior Risk Factor Surveillance System is the world's largest random telephone survey of non-institutionalized population aged 18 or older that is used to track health risks in the United States. In 1981, the Centers for Disease Control and Prevention (CDC), in collaboration with selected states, initiated a telephone based behavioral risk factor surveillance system to monitor health risk behaviors. South Carolina began administering BRFSS since 1984. Several core questions address knowledge, attitudes, beliefs, and behaviors regarding sexually transmitted diseases, particularly AIDS.**

**Results of the 2004 survey suggest most respondents have a fair knowledge of transmission and treatments of HIV/AIDS. Fifty-two percent of respondents said they believed treatments are available to HIV+ women to reduce the chance of transmission to the baby, and 89% believed medical treatments are available to help HIV+ persons live longer. When asked about ever being tested for HIV themselves, only 47% of respondents indicated ever being tested with 67% of those having been tested in the past 4 years. Most respondents who had been tested revealed the main reason for the test was part of a routine check-up or required (51.4%), pregnancy (13.9%), or reasons of personal interest (19.6%). When asked if in the past 12 months if a doctor, nurse, or health professional discussed condom use for preventing**

Figure 56: Proportion of YRBS Students Indicating Sexual Risks, 1997 - 2007



**STDs, a majority (85.1%) said this had not occurred.**

### **Youth Risk Behavior Survey**

The Youth Risk Behavior Survey is administered to students in public high school in South Carolina. Figure 56 shows that over time there have been slight decreases in the proportion of students who have been sexually active, had four or more lifetime partners, and increases in those reporting condom use at last sexual intercourse.

### **Substance Use**

A 1999-2000 household telephone survey of 10,324 adults  $\geq 18$  yrs was conducted by the SC Department of Alcohol and Other Drug Use Services (DAODAS) to assess substance use practices. Results indicated that 37% of persons used alcohol during past 30 days, 3% used marijuana, and less than 0.5% used cocaine and hallucinogens during past month. General patterns of substance use by persons in the state indicate that more men than women use drugs/alcohol; higher use levels are generally among younger respondents (18 – 44 years of age).

### **Summary/Recommendations**

A review of this epidemiological profile indicates the following primary target populations and recommendations for prevention efforts:

#### **Men Who Have Sex With Men**

These data indicate that prevention efforts targeted to men who have sex with men need to be tailored to both African-American and white men. African-American men account for over half of both living cases (58%) and newly diagnosed HIV/AIDS cases (66%) who report MSM risk. Increased efforts in particular are needed to reach younger African-American MSM  $< 25$  years of age; for white men, targeted efforts are needed for those  $> 25$  years. Interventions also need to be particularly available for persons living in the more urban areas of the state.

#### **Heterosexuals**

These data indicate that prevention efforts targeted to high risk heterosexuals need to be tailored to African-American women, particularly young women under age 25, who account for nearly half of both living heterosexual cases and more recently diagnosed persons in this age group. Efforts also need to target African-American men and women 25 – 44 years, who account for over three-fourths of living and more recently diagnosed cases (all ages). Prevention efforts targeting African-American men and women should also be tailored to reach those 45 years and older.

#### **Injecting Drug Users**

Prevention efforts targeting injecting drug users need to be tailored to men, primarily African-American men who comprise just under half (48%) of recently diagnosed IDU cases, followed by white men. Efforts should target persons older than 25 years and

those who are predominately in more urban counties including Richland, Greenville and Charleston as well as Lexington, York, Florence, Horry, Orangeburg and Sumter.

**Question #4: What are the patterns of service utilization of HIV-infected persons?**

In 1990, Congress enacted the Ryan White CARE Act to provide funding for states, territories and Eligible Metropolitan Areas to offer medical care and support services for persons living with HIV disease who lack health insurance and financial resources for their care. Congress reauthorized the Ryan White CARE Act in 1996 and 2000 to support Titles I through IV, Special Projects of National Significance (SPNS), the HIV/AIDS Education Training Centers and the Dental Reimbursement Program, all of which are part of the CARE Act. The legislation was reauthorized again in 2006 when it became the Ryan White HIV/AIDS Treatment Modernization Act. With that reauthorization Titles I-IV were changed to Parts A-D.

Part B funding is used to assist States and Territories in developing and/or enhancing access to a comprehensive continuum of high quality, community-based care for low-income individuals and families living with HIV.

**Figure 57: Demographic Characteristics of CARE Act Part B Clients Compared with Characteristics of Persons Living with HIV/AIDS, South Carolina, 2007**

	CARE Act Clients, N=8,760, %	Persons Living with HIV/AIDS, N=14,696, %
<b>Race/Ethnicity</b>		
White, not-Hispanic	22%	24%
Black, not-Hispanic	72%	73%
Hispanic	3%	2%
Other	2%	<1%
<b>Sex</b>		
Male	61%	69%
Female	39%	31%
Transgender	<1%	---
<b>Age Group</b>		
<13	1%	1%
13-24	6%	4%
25-44	50%	49%
45+	43%	47%

During 2007, 8,760 clients received services through the Ryan White Part B funds. Figure 57 presents the distribution of Part B clients by race/ethnicity, sex and age as well

as for those persons living with HIV/AIDS in South Carolina through December 2007. Clients served through Part B are representative of the population affected with HIV/AIDS in all categories.

HRSA has directed that States should allocate funds for essential core services: 1) Primary Medical Care consistent with Public Health Service (PHS) Treatment Guidelines; 2) HIV Related Medications; 3) Mental Health Treatment; 4) Substance Abuse Treatment; 5) Oral Health; and 6) Case Management.



**Figure 58: South Carolina Ryan White Part B Service Utilization by Service Type, 2007**

Figure 58 shows a break down of Ryan White Part B clients who received five of the core services through funding and the average number of visits per clients. Utilization of HIV related medications is described in the ADAP section. Among the 8,760 clients who received services, the majority of clients obtained medical case management services (n=6,776) followed by medical care (n=6,470), dental care (n=1035), mental health services (n=660), and substance abuse services (n=547).

	No. of clients receiving service	Avg. no. of visits per client
Medical Care	6,470	4.8
Medication (ADAP)	2,887	N/A
Oral/Dental Care	1035	2.2
Mental Health	660	2.5
Substance Abuse	547	2.0
Case Management	6,776	6.5

Of those services utilized more by clients (visits/clients), case management services were among the highest (6.5 visits per clients), followed by medical care (4.8 visits per client), mental health services (2.5 visits per client), dental care services (2.2 visits per client) and clients receiving substance abuse care averaged about 2.0 visits in 2007.

Additional services obtained by clients in 2007 included treatment adherence, counseling, food bank/home delivered meals, health education/risk reduction, referral for health care and supportive services, psychological support services, housing assistance and transportation services.

**AIDS Drug Assistance Program (ADAP)**

The South Carolina AIDS Drug Assistance program (SC ADAP) was established under the Ryan White CARE Act to provide drugs to treat HIV disease and/or to prevent the serious deterioration of health arising from HIV disease in eligible individuals, including measures for the prevention and treatment of opportunistic infections and document the progress made in making the drugs available. The SC ADAP is operated through a centralized pharmacy and an insurance assistance program located at the Department of Health and Environmental Control. Currently 67 drugs are on the approved formulary. During calendar year 2006, ADAP served 2,887 clients. The SC ADAP has an advisory body of infectious disease (ID) physicians and program staff that meets annually to review the SC ADAP formulary and make recommendations for program improvements.

In the past, once an antiretroviral medication received FDA approval, it was automatically added to the SC ADAP formulary. With the new development of extremely expensive therapies, such drugs are added as appropriate after consultation with the SC ADAP Medical Advisory Committee. Fuzeon, pegylated interferon and ribavirin currently require prior reauthorization for approval. No restrictions or caps on the number of other Antiretroviral medications per client exist.

Eligibility in ADAP includes verified HIV positive status, South Carolina residency, and limited income. The financial requirement is measured according to the Federal Poverty Guidelines. Eligibility remains at 300% of the Federal Poverty Guidelines, and the sliding fee scale includes up to 550% of poverty level. Expenditures are carefully monitored and projections are reviewed monthly.

Figure 59 lists the characteristics of clients enrolled in the ADAP program during 2006. Clients served through ADAP have a similar distribution to that of persons living with HIV/AIDS in South Carolina. The majority of the clients are non-Hispanic African-Americans/Black (69%), male (71%), and in the 25-44 year age group.

**Figure 59: 2006 ADAP Patient Profile Compared to Persons Living with HIV/AIDS**

Profile	SC HIV/AIDS Prevalence, 12/31/07: 14,696 Persons	Central Pharmacy Total Served: 2,224	Insurance Program Total Served: 663
Male	69%	71%	69%
Female	31%	29%	30%
African American	73%	69%	69%
White	24%	25%	26%
Hispanic/Latino	2%	4%	4%

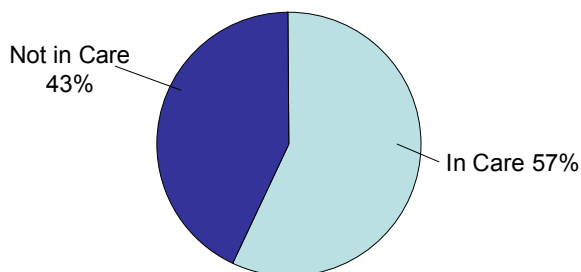
**Question#5: What are the number and characteristics of persons who know they are HIV+ but who are not receiving HIV primary medical care?**

To analyze the number of persons living with HIV/AIDS in South Carolina not “in care,” HARS (HIV/AIDS Reporting System) data was used to review all persons diagnosed through December 2007. HARS in South Carolina is a laboratory based reporting system with all CD4 and viral load tests being reportable as of January 1, 2004. Persons who were deceased as of December 31, 2007 were excluded from the analysis. Only current SC residents were included. A person was reported as being “in care” if they had at least one CD4 or viral load test report from January 1, 2007 through December 31, 2007. Persons with no CD4 or viral report in this time frame were defined as “not in care”.

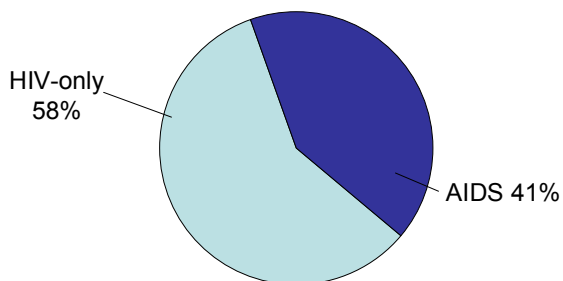
South Carolina conducted the Interstate Duplication Evaluation Project (IDEP) in 2002 assuring that HARS eliminated duplicate cases across states.

**Figure 60: SC HIV/AIDS Cases Estimated Not in Care vs. In Care Diagnosed through 2007 (N=15,465)**

Figure 60 shows that of the 15,465 patients diagnosed through December 2007, 43% (6,656) patients did not receive a CD4 or viral load test report within the specified time period, therefore are reported as “not in care”. Fifty-seven percent are defined as “in care”.



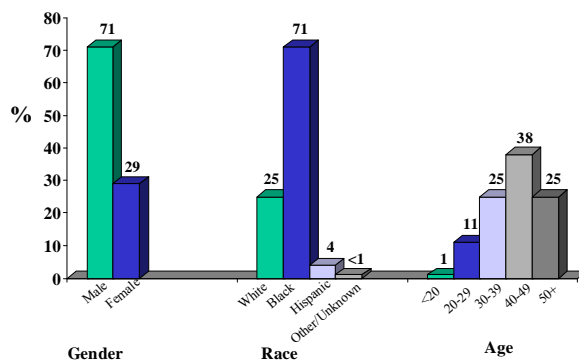
**Figure 61: SC HIV/AIDS Cases Estimated NOT In Care Diagnosed through 2007, HIV-only vs. AIDS (N=6,656)**



Of the 6,656 clients not in care, 58% are living with HIV-only and 41% are living with AIDS (Figure 61).

Figure 62 demonstrates a comparison of persons not in care by select demographics. By gender, the percent of men not in care (71%) is more than double of the percentage of women not in care (29%). Seventy one percent of those not in care are African-Americans. In addition, a comparison by age groups shows that most persons living with HIV/AIDS and not receiving care are between

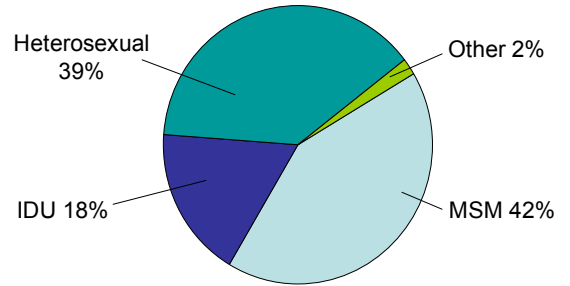
**Figure 62: SC HIV/AIDS Cases Diagnosed through 2007, Comparison within Select Demographics Estimated Percentage Not In Care**



the ages of 30-49 (63%), followed by those who are 50+ (25%) and 20-29 (11%).

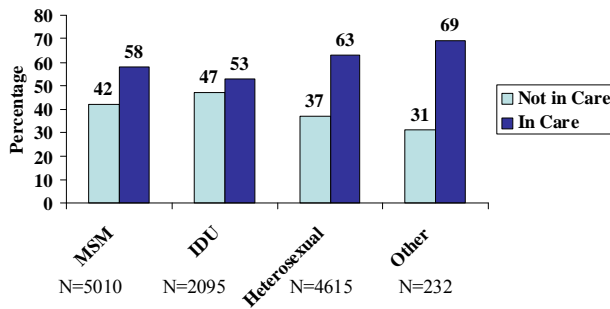
An analysis by mode of exposure of persons living with HIV/AIDS indicates most persons not in care are MSM (42%) and heterosexuals (39%) followed by IDUs (18%) (Figure 63).

**Figure 63: SC HIV/AIDS Cases Estimated NOT in Care Diagnosed through 2007 by Mode of Exposure\***



\*excludes cases with no risk identified, N = 3,513

**Figure 64: SC HIV/AIDS Cases Diagnosed through 2007, Comparison within Mode of Exposure In Care vs. Not in Care\***

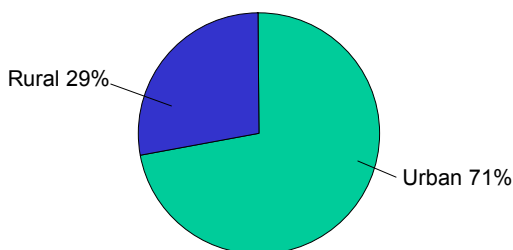


\*excludes cases with no risk identified, N = 3,513

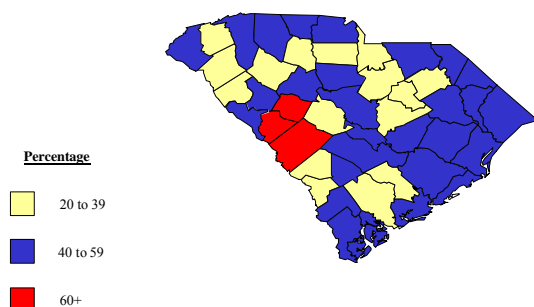
Figure 64 goes further to compare those in care versus those not in care within each risk category. Among all MSMs living with HIV/AIDS, more persons are in care (58%) than not in care (42%). Focusing on those persons whose mode of exposure was injecting drug use, the number of those in care (53%) is greater than the number out of care (47%). Likewise, among heterosexuals with HIV/AIDS, 63% are in care compared to 37% not in care.

The location of a person's residence may have an impact of whether or not they are in care. There are more persons not in care from urban areas (71%) versus rural areas (29%). (Figures 65 and 66).

**Figure 65: SC HIV/AIDS Cases Estimated NOT in Care Diagnosed through 2007, by Location (N=6,656)**



**Figure 66: SC HIV/AIDS Cases NOT in Care Diagnosed through 2007, by County**



# **APPENDIX B**

**Summary Evaluation**  
**South Carolina Statewide Coordinated Statement**  
**of Need and Comprehensive Plan Meeting**  
**SC Archives and History Building**

**September 17, 2008**

**30 out of 41 attendees turned in evaluations**

**Meeting Objectives:**

	<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>	<b>Total # of Evaluations</b>	<b>Evaluation Average</b>
Point Value	4	3	2	1		
Review the purpose of the SCSN and Comprehensive Plan	17	11	2	0	30	3.5
Discuss Ryan White summary data and epidemiological data	13	15	2	0	30	3.4
Identify barriers for PLWHA in and out of care	18	11	1	0	30	3.6
<b>Meeting Average</b>						<b>3.5</b>

	<b>Excellent</b>	<b>Good</b>	<b>Fair</b>	<b>Poor</b>
Review the purpose of the SCSN and Comprehensive Plan	57%	37%	7%	0%
Discuss Ryan White summary data and epidemiological data	43%	50%	7%	0%
Identify barriers for PLWHA in and out of care	60%	37%	3%	0%

**Meeting Satisfaction:**

	<b>#of Evaluations</b>	<b>% of Evaluations</b>
Very Satisfied	21	70%
Somewhat Satisfied	9	30%
Somewhat Unsatisfied	0	0%
Very Unsatisfied	0	0%
<b>Total Evaluations</b>	<b>30</b>	<b>100%</b>

# **APPENDIX C**

**Summary Evaluation**  
**South Carolina Statewide Coordinated Statement**  
**of Need and Comprehensive Plan Meeting**  
**SC Archives and History Building**  
**November 7, 2008**  
**21 out of 31 attendees returned evaluations**

**Meeting Objectives:**

	Excellent	Good	Fair	Poor	Total # of Evaluations	Evaluation Average
Point Value	4	3	2	1		
Elicit feedback on SCSN report	12	9	0	0	21	3.7
Discuss HRSA expectations for SCSN and Comprehensive Plan	11	10	0	0	21	3.5
Review draft goals and objectives for Comprehensive Plan	9	12	0	0	21	3.6
Gather input about activities to address needs of PLWHA	8	13	0	0	21	3.5
<b>Meeting Average</b>						<b>3.6</b>

	Excellent	Good	Fair	Poor
Review the purpose of the SCSN and Comprehensive Plan	57%	43%	0%	0%
Discuss Ryan White summary data and epidemiological data	52%	48%	0%	0%
Identify barriers for PLWHA in and out of care	43%	57%	0%	0%



**Meeting Satisfaction:**

	<b>#of Evaluations</b>	<b>% of Evaluations</b>
Very Satisfied	13	62%
Somewhat Satisfied	7	33%
Somewhat Unsatisfied	0	0%
Very Unsatisfied	1	0%
<b>Total Evaluations</b>	<b>21</b>	<b>100%</b>

# **APPENDIX D**

# South Carolina HIV Services Network Provider Chart

**SC Department of Health & Environmental Control**

**Ryan White Part B Service Providers (RW core services/specialty care\*) Target Pop: Adults/Older Youth**

**Ryan White Part C Service Providers (RW core services/primary care\*) Target Pop: Adults/Older Youth**

- AID Upstate\*\*** (Greenville, Oconee, Pickens & Anderson)
- ACCESS Network (Beaufort, Jasper, Colleton & Hampton)
- Catawba Care Coalition
- CARETEAM (Horry, Williamsburg & Georgetown)
- Catawba Care Coalition (York, Chester & Lancaster)
- HopeHealth (Chesterfield, Darlington, Marlboro, Dillon, Marion & Florence)
- HopeHealth Edisto (Orangeburg, Bamberg & Calhoun)
- HopeHealth Lower Savannah (Aiken, Barnwell & Allendale)
- University of South Carolina** (Richland, Lexington, Fairfield, Newberry, Kershaw, Lee, Sumter & Clarendon)
- Piedmont Care (Spartanburg, Cherokee & Union)
- MUSC Trident Care Coalition/**Lowcountry AIDS\*\* Services** (Charleston, Berkeley & Dorchester)
- Upper Savannah Care Services (Abbeville, Laurens, Greenwood, Saluda, McCormick & Edgefield)

**Regional HIV Pediatric/Family providers (RW core services\*)**

- Greenville Hospital System – Pediatric Infectious Disease** (Greenville)
- University of South Carolina School of Medicine – Dept. Pediatrics** (Columbia)
- Medical University of South Carolina (MUSC)– Pediatric Infectious Disease Dept.** (Charleston)

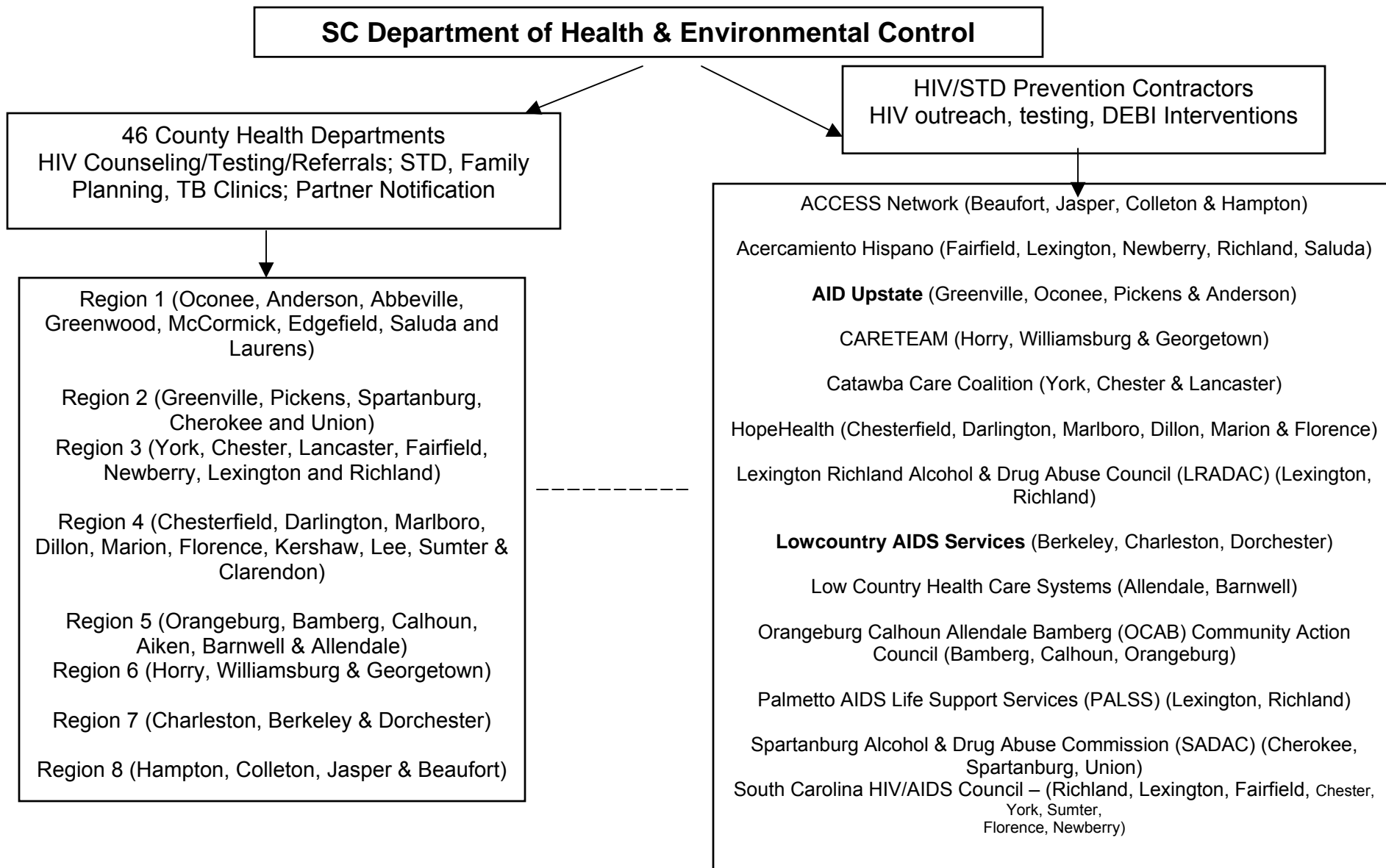
- Beaufort Jasper Comprehensive Health Services, Inc. (Ridgeland)
- CareSouth Carolina (Society Hill)
- Catawba Care Coalition (Rock Hill)
- HopeHealth (Florence)
- Low Country Health Care Systems (Fairfax)
- New Horizons Family Health Services, Inc. (Greenville)
- Richland Community health Care Association (Columbia)
- Roper Care Alliance (Charleston)
- Sandhills Medical Foundation, Inc. (Jefferson)
- Spartanburg Regional Healthcare System (Spartanburg)

**\*Core services: medical, medications, oral health, substance abuse, mental health. case management : \*\*Part D Consumer Advocacy**

**Bolded Text Indicates Part D – Funded Service Providers**

↔ **Indicates joint family** ↔

# South Carolina HIV Services Network Provider Chart Cont.



# **APPENDIX E**

South Carolina

# Ryan White Quality Management Plan



Department of Health and  
Environmental Control

## **Introduction**

The Health Resources and Services Administration's (HRSA) HIV/AIDS Bureau in coordination with HRSA's Office of Performance Review aligned quality measures with performance measures for Part C and D to identify and prioritize quality measures for grantees. These measures are consistent with measures selected by stakeholders of all HIV programs in the state. The overarching purpose of the Quality Management Plan outlined in the following pages is to improve the quality of care for people living with HIV in the state. Through creating an effective and actionable quality management plan, and assuming a direct role in support of quality improvement activities in the state, participants will conceptualize and implement a quality management program, and develop a supporting infrastructure across the defined service area that is consistent with legislative requirements and guidance expectations for all Parts of the Ryan White HIV/AIDS Treatment Modernization Act.

### **Section I: Ryan White Background and History**

The United States Congress enacted the Ryan White Treatment Modernization Act of 2006 (Ryan White Program) in October 2006 with the goal to improve the quality and availability of care for individuals and families infected and affected by HIV disease by providing emergency assistance to regions most severely affected by HIV epidemic. Since 2000 the Ryan White legislation has included specific provisions directing grantees to establish, implement and sustain quality management programs, which include monitoring of access to and quality of health services to ensure that PWHIV who are eligible for treatment receive it.

A major focus of the Ryan White program is not only to eliminate barriers to accessing care, but also to improve the quality of care that its clients receive. New and significant legislative requirements found in the Reauthorization of 2006 direct grantees to ensure that

1. Service providers adhere to established HIV clinical practices;
2. Quality improvement strategies include support services that help people receive appropriate HIV health care (e.g., transportation assistance, case management); and
3. Demographic, clinical, and health care utilization information is used to monitor trends in the spectrum of HIV-related illnesses and the local epidemic.

### **Expectations:**

Emphasized in the Ryan White Program expectations, quality management programs are pivotal in addressing the following key themes:

- Improve access to and retention in care for HIV+ individuals aware of their status
- Quality of services and related outcomes
- Linkage of social support services to medical services
- Ability of the program to change with the epidemic
- Use of epidemiological and health outcome data for priority setting
- Accountability (resources, responsibility, implementation, etc.)

**Definition of Quality**

Quality is defined by HRSA's HIV/AIDS Bureau/Division of Service Systems as the degree to which a health or social service meets or exceeds established professional standards and user expectations. In order to continuously improve systems of care for individuals and populations, evaluation of the quality of care should consider:

1. The quality of inputs
2. The quality of the service delivery process
3. The quality of outcomes

**Section II: Quality Statement**

Central to the South Carolina Department of Health and Environmental Control's mission, values, and strategic plan is the goal to improve access to high quality healthcare. The purpose of the quality management program is to set forth a coordinated approach to quality assessment and process improvement within the SC Department of Health & Environmental Control (DHEC), STD/HIV Division, and HIV Care & Support Programs. The STD/HIV Division is dedicated to ensuring the highest quality of HIV medical care and support services for people living with HIV/AIDS in the state of South Carolina. The mission of the HIV Quality Management Program is to ensure that all people living with HIV/AIDS in South Carolina receive the highest quality of Ryan White funded primary medical care and support services.

The key components of the Ryan White Quality Management Program are:

- Performance and Outcome Measurement
- Data Analysis and Presentation
- Identification of Continuous Quality Improvement (CQI) strategies
- Implementation of CQI initiatives
- Monitoring adherence to the standards of care and performance indicators of the services offered by the agency
- Coordinating data collection for the agency's review by outside organizations
- Identifying processes and procedures for improvement.



## **Section III: Quality Infrastructure**

### **A. Leadership and Accountability**

- **SC Department of Health & Environmental Control:**

- *Health Services Office of Performance Management:*

Health Services has designed a Performance Management System that will enable the deputy area to monitor its performance in all aspects of its operations. Categories for which performance measures have been developed are Management, Human Resources, Public Health Capacity, Data and Information Systems, Customer Focus, Financial Systems and Health Status. All of the indicators are linked to the DHEC Strategic Plan.

STD/HIV Division, HIV Care & Support Services, monthly meetings with division-wide participation including Division Director, Bureau Medical Director, Division Medical Director, Program Managers, Surveillance, Support Staff, Nurse, DIS, Health Education, Financial, Planning and Evaluation Consultants.

Division staff provides oversight and management of the RW Part B & D grants. Staffs monitor all Ryan White funds and sub-contractors to ensure that Ryan White funds are the payer of last resort. The Division leadership is dedicated to the quality improvement process and guides the quality management plan.

- **Quality Management Steering Committee:**

- The Quality Management Steering Committee provides guidance, consultation and input regarding the overall Quality Management Program. Membership consists of ten individuals representing Ryan White Part B, C & D programs, Community Health Centers, local Health Department, and a Community Based AIDS Service organization. Members are also representative of five geographical regions (formerly consortia) of the state; Midlands, Catawba, Upstate (Upper Savannah, Piedmont & AID Upstate), Coastal (Low Country (ACCESS), Trident and CARETEAM), and the HopeHealth (Lower Savannah, Tri-County and Pee Dee) Membership include persons living with HIV.
  - Quality Management Steering Committee members:
    1. Share information regarding quality management plans and processes both within organization and among network partners
    2. Help plan regional meetings as follow-up to technical assistance activities to include developing common sets of quality measures among network partners
    3. Help with cheerleading/buy-in for geographical and HIV and primary care service delivery partners and peers

### **B. Resources**

SCDHEC, STD/HIV Division Director, Infectious Disease Medical Consultants, HIV Care & Support Service Program Director, Part D Coordinator, ADAP Coordinator, Provide Software Consultant, HIV Planning Council, Part B Coordinator, Surveillance Director, HIV

Surveillance Coordinator, and Quality Management (CQI) Coordinator support the Quality Management Steering Committee.

- Regional CQI Committees;
  - The initial development of a statewide Quality Management program included Regional CQI Committees that were initiated in the five geographical areas (formerly consortia) of the state Midlands, Catawba, Upstate (Upper Savannah, Piedmont & AID Upstate), Coastal (Low Country (ACCESS), Trident and CARETEAM), and the HopeHealth (Lower Savannah, Tri-County and Pee Dee). The Regional CQI Committees were designed to promote communication around QM issues and to establish common Quality Improvement goals. After a Quality Management Coordinator was hired it was decided that the groups would be structured in a less formal way. In the absence of formal regional groups, the QM Coordinator will serve as the conduit for regional communication and dissemination of information.
- Part B/D Providers (DHEC Contractors)
  - Part B/D Providers are responsible for ensuring that quality management components of contracts are met.
  - The FY 2008-2009 contract deliverables include the following Quality Management language:
    - Develop and implement a Quality Management plan (i.e., a local Quality Management plan)
    - Participate in All Parts Quality Management meetings
    - Provide information related to the local Quality Management program as requested by the STD/HIV Division

#### **Section IV: Quality Plan Implementation**

- The Ryan White Quality Management Coordinator has the responsibility of management of the QM program.
  - The QM Coordinator is responsible for:
    - Establishing content of and scheduling of meetings
    - Research on best practices
    - Quarterly reports on projects and progress
    - Facilitating consumer involvement in quality improvement and program planning
    - Providing instruction on CQI principles
    - Following up on suggestions by consumers to improve the care they are receiving
- Implementation of the QM Plan includes development of a timeframe for re-measurement that will allow for the tracking of deficiencies and ensure quality care.
- Implementation also includes collection of data from all Ryan White providers in a timely and efficient way that will allow for data analysis and needs assessment throughout the state.

- Finally, there will be a continued focus on promoting provider adherence to highest priority PHS Guidelines for HIV care.

## **Section V: Mechanisms to Promote Quality Care**

### **A. Performance Measurement**

The Quality Management Steering Committee, using priorities identified by Ryan White funded stakeholders, Health Resources and Services Administration's Office of Performance Review measures for Ryan White Part C & D Program and HIVQUAL selected 18 HIV program quality measures to align Ryan White B, C, and D Programs.

### **B. Statewide Quality Measures**

1. Number (Percentage) of patients with at least two (2) visits per year, one visit in each six-month period of the year.
2. Number (Percentage) of adolescents and adult clients  $\geq$  age 13 years with HIV/AIDS CD4  $\leq$  350 or viral load  $\geq$  100,000 that are prescribed ART.
3. Number of female patients/clients with an annual Pap test.
4. Number (Percentage) of patients seen (referred AND with completed visit) by an oral health provider annually.
5. Number (Percentage) of patients with an annual syphilis test.
6. Number (Percentage) of clients with HIV infection who have been tested for Hepatitis C virus infection.
7. Number (Percentage) of pregnant women prescribed antiretroviral therapy.
8. Number (Percentage) of patients with a CD4 test every six months.
9. Number (Percentage) of patients CD4  $\leq$  200 who are receiving Pneumocystis jirovecii pneumonia (PCP) Prophylaxis.
10. Number (Percentage) of patients with C  $\leq$  50 (or age adjusted for risk as clinically indicated for children) who are prescribed MAC Prophylaxis (rifabutin, clarithromycin, azithromycin or other).
11. Number (Percentage) of clients with HIV infection who have been tested for Hepatitis B virus infection status.
12. Number (Percentage) of clients with HIV infection who have completed the vaccination series for Hepatitis B.
13. Number (Percentage) of clients with HIV infection prescribed antiretroviral (ARV) who receives adherence counseling during appointments 6 months (or less) apart.
14. Number (Percentage) of clients with HIV infection prescribed antiretroviral (ARV) who receives risk reduction counseling during appointments 6 months (or less) apart.
15. Number of patients/clients with a complete psychosocial assessment in the past year.
16. Number (Percentage) of clients screened for HIV knowledge every six months.

17. Number of clients with a service plan that has been updated in the past six months.
  18. Number of clients with a service plan that has been signed in the past six months.
- Ryan White Program Data Report (RDR) submitted to QM Coordinator.
  - Review of data for performance measures will occur annually. State health department staff will coordinate these activities. Data reports will be analyzed.

## **Section VI. Annual Quality Goals**

### **A. Overall goals of the Quality Management Program include:**

- A systematic, state-wide process for planning, designing, measuring, assessing and improving performance with the following components:
  - a. *Develop a planning mechanism* incorporating baseline data from external and internal sources and input from leadership, staff and patients. Clinical, operational and programmatic aspects of patient care will be reviewed.
  - b. *Emphasize design* needs associated with new and existing services, patient care delivery, work flows and support systems which maximize results and satisfaction on the part of the patients and their families, physicians and staff.
  - c. *Evolve and refine measurement* systems for identifying trends in care and sentinel events by regularly collecting and recording data and observations relating to the provision of patient care across the continuum.
  - d. *Employ assessment* procedures to determine efficacy and appropriateness and to judge how well services are delivered and whether opportunities for improvement exist.
  - e. *Focus on improving* quality in all of its dimensions by implementing multidisciplinary, data driven, project teams and encouraging participatory problem solving.
  - f. *Promote communication*, dialogue and informational exchange across the STD/HIV Division and throughout Regional Committees, with regard to findings, analyses, conclusions, recommendations, actions and evaluations pertaining to performance improvement.
  - g. *Strive to establish collaborative relationships* with diverse stakeholders and community agencies for collectively promoting the general health and welfare of the community served.

## **B. Multidisciplinary Team and Development of Improvement Plan**

- Once an opportunity for improvement has been identified, a multidisciplinary team will be convened to analyze the process and develop improvement plans. These teams will include those staff members closely associated with the process under study. Every attempt will be made to include individuals from other departments who may be impacted by changes made by the team and to help promote collaboration between departments.

Continuous Quality Improvement Methodology will be utilized and may include, but not be limited to, the following:

### ***PDSA***

- Step 1: Plan
  - Plan a change
- Step 2: Do
  - Try it on a small scale
- Step 3: Study
  - Observe the results
- Step 4: Act
  - Refine the changes as necessary

### ***Flow Chart Analysis***

One of the most useful quality improvement tools as it depicts the sequence of steps performed in a specific process

### ***Cause and Effect Diagrams***

Diagram enables a team to focus of the content of the problem, not the history of the problem.

### ***Brainstorming***

Establishes a common method for a team to creatively and efficiently generate a high volume of ideas by encouraging people to open thinking.

### ***Observational Studies***

An investigational method involving description of the associations between interventions and outcomes.

### ***Activity Logs***

Tracking of activities to help audit and analyze how time is spent on an activity or throughout the business day; helps eliminate time wasting or low-yield jobs.

Quality Committee/Team Meeting Improvement Plans will be developed and implemented by the teams: Improvements may include:

- System Redesign
- Education (Staff, Clients, Stakeholders and Customers)
- Clinical Guidelines review, revision or development
- Procedure and policy changes

- Form development or revision

**C. All improvement plans will be communicated to all appropriate staff and to clients if deemed appropriate.**

**Evaluation**

The QM program will be evaluated annually to assess quality infrastructure and activities to ensure that the quality program is in line with its overall purpose. Based on those findings, the CQI Teams will refine strategies for the following year. Chart audit results, staff and patient comments, effectiveness of CQI activities, and program goals will be used to evaluate the program.

**Capacity Building**

The STD/HIV Division, HIV Care & Support Services received 12 months of technical assistance from the National Quality Center beginning in January 2007. The technical assistance developed the STD/HIV Division, and the Ryan White Programs' capacity and quality management infrastructure. A Quality Management Coordinator was hired in March 2008 and she received training for the NQC in May 2008 and continues to develop the necessary skills to manage the QM program for the Division. Additionally, there are 9 stakeholders statewide who have participated in the NQC's Training of the Trainers.

**Process to Update QM Plan**

- Plan is reviewed and updated annually by consensus by Ryan White staff in consultation with QM Steering Committee.

**Communication**

- Quality Management Steering Committee meetings, and STD/HIV Division bi-annual face-to-face Statewide All Parts meetings with stakeholders, and quarterly HIV Planning Council meetings.