



**South Carolina
2012 Ryan White HIV/AIDS Statewide
Coordinated Statement of Need and
Comprehensive Plan**



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

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Acknowledgements

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 2012. The Department of Health and Environmental Control (DHEC) staff members that were instrumental in the process are:

Christal Davis, Ryan White Data Manager, STD/HIV Division
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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:

Keisha Alston, BJHCHS	Pat Kelly, A Family Affair
Daisy Arrillaga, New Horizon	LaVonda Johnson, Sandhills Medical Foundation
Valerie Assey, MUSC	Mulamba Lunda, Hope Health
Sallie Bachman, Hope Health Edisto	Jim Manning, PALSS
Gwen Bampffield, ACCESS Network	Pam McKnight, Lowcountry Health Care Systems
Sharon Black, CareSouth Carolina	Hope McQueen, Care South
Troy Bowers, PALSS	Aaron O'Brien, Roper
Bradley Childs, Lowcountry AIDS Services	Tricia Phaup, USC
Aaron Creech, AID Upstate	Nancy Raley, USC DOM
Aishah Foreman, ACCESS Network	Gary Rhett, PALSS
Bambi Gaddist, SCHAC	Rajee Rao, USC
Christine Gordon, HH-Edisto and HH-Lower Savannah	Ralph Rynes, LRADAC
Mahogany Graham, SCHAC	Tyrone Small, USC
Bonetta Graves, Sandhills Medical Foundation	Randy Tarzwell, New Horizon
Andy Hall, AID Upstate	Jacqueline Taylor, Careteam, Inc.
Angel Payton-Harmon, MUSC OPAC	Larry Walton, SC DOC
Adrena Harrison, AETC	Stan Wardlaw, RCHCA
Johanna Haynes, Careteam	Jacob White, SCHAC
Tracey Jackson, Piedmont Care, Inc.	Jason Williams, Upper Savannah Care Services
Latisha Jackson, Catawba Care	Taisha Williams, Upper Savannah Care Services
	Olympia Witherspoon, RCHCA

David Napp of Practical Applications of Public Health, a consultant under contract with the South Carolina Department of Health and Environmental Control, facilitated the process of eliciting input from these stakeholders and writing the SCSN and Comprehensive Plan. The South Carolina DHEC extends many thanks to everyone who contributed in any way to this project.

Executive Summary

The 2012 South Carolina HIV/AIDS Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan (CP) summarizes HIV-related service needs and barriers across South Carolina, and presents goals, strategies and action steps for its evolving HIV service continuum. This document, an update of the SCSN and CP submitted in 2009, has been prepared in accordance with the legislative mandate in the Ryan White HIV/AIDS Treatment Extension Act of 2009 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. Also, a stakeholder survey and a face-to-face stakeholder meeting was held to gather input regarding the barriers and gaps in the current care system. 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 action steps 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 the ninth highest rate of HIV in the United States.

The issues most critically impacting HIV infected persons can be summarized in the following broad categories:

- Societal stigma
- Transportation, housing and unemployment
- Substance abuse and mental health
- Competing health concerns and client fatigue
- Healthcare system limitations
- Poverty and unmet basic needs
- Denial and fear

The Comprehensive Plan includes strategies and action steps in support of two broad goals: 1) Improve client retention in HIV medical care and support services; and 2) Increase the proportion of HIV infected people who know their status and are linked to care when newly diagnosed. The Comprehensive Plan describes numerous strategies to further the achievement of the two overarching goals, as well as a plan for monitoring and evaluating progress in addressing these goals.

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 (CP) for all entities in the state receiving Ryan White assistance.

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. Ryan White legislation requires that the SCSN and CP be developed through a representative process, and that it 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 intent of the SCSN and CP is to assist in the development of a comprehensive and responsive system of care that addresses the needs and challenges of PLWHA as they change over time.

The 2012 South Carolina HIV/AIDS SCSN and CP were developed collaboratively with the input of a broad spectrum of HIV/AIDS stakeholders in South Carolina. A survey was conducted with stakeholders followed by two full-day participatory meetings convened on December 15, 2011, and March 23, 2012, in Columbia, S.C. The survey and first meeting were conducted to identify the needs of PLWHA as they related to people aware of their HIV status and in care, people aware of their HIV status and not in care, and people not aware of their HIV status. The second meeting was used to identify the goals, strategies and action steps described in this plan. An external consultant, David Napp, of Practical Applications of Public Health, administered the stakeholder survey, designed and facilitated both meetings, and assisted in the preparation of the final document. The combined SCSN and CP document was drafted using historical resources, surveillance data, program management experience and all of the community input received from the survey and the two stakeholder meetings.

The format and content of the SCSN and CP document directly follows the structure dictated by HRSA guidance.

I. Where Are We Now?

A. South Carolina HIV/AIDS Epidemic

1. Summary of Epidemiological Profile

The following summary of the local HIV/AIDS Epidemic is based on the 2011 Epidemiological Profile on HIV and AIDS in South Carolina. The complete Epidemiological Profile is in Attachment A.

For the two-year period 2009-2010, 1,572 people were newly diagnosed with HIV in SC. Compared to the 2003-2004 period, there is a 6.5 percent decrease in cases diagnosed and reported in the state. By gender, 76 percent of new HIV/AIDS cases occurred among men; 24 percent are among women. By risk, among the 1,040 people who report risk in SC, men who have sex with men (MSM) represent the largest proportion (72 percent) of recent infections, followed by 22 percent indicating heterosexual sex as their exposure to HIV. Thirty-eight people (four percent of total) were infected through injecting drug use (IDU). Of the people who reported risk, almost 1.5 percent indicated the combined risks of MSM and IDU.

By race/ethnicity, among people diagnosed with HIV/AIDS in SC, 73 percent are African-American; 21 percent are white; four percent are Hispanic. African-Americans have a case rate about eight times greater than whites. Among women recently diagnosed with HIV/AIDS in SC, most are African-American (79 percent); 16 percent are white; four percent are Hispanic. Of the 158 women reporting risk, 90 percent indicated heterosexual sex as their exposure to HIV; eight percent reported IDU. Among men recently diagnosed in SC, 71 percent are African-American; 23 percent are white; four percent are Hispanic. Of the 882 men reporting risk, 85 percent were MSM, 10 percent were exposed through heterosexual sex; three percent were IDU; two percent were both MDM and IDU.

As of December 2010, 14,708 people have been reported living with HIV infection (including AIDS) who are residents of SC. Of these, 10,200 are men and 4,508 are women. Most people (9,096) are ages 25-49; 181 are children and teenagers under 20 years. Similar to new infections, African-Americans are disproportionately impacted. Most (47 percent) of the people living with HIV in SC are African-American men, 25 percent are African-American women, 19 percent are white men and five percent are white women. Three percent of people living with HIV are Hispanic. Most (47 percent) people living with HIV who reported risks are MSM followed closely by men and women exposed through heterosexual sex (38 percent); 10 percent are IDU; four percent are both MSM and IDU.

2. Unmet Need Estimate for 2010

For the purposes of this Plan, HRSA defines unmet need as an estimate of the number of PLWHA who know their status and are not receiving primary care. For this estimation, HRSA indicates that PLWHA who receive at least one CD4 or viral load test annually should be counted as in care and those who do not should be counted as out of care.

However, this method underestimates the number of PLWHA not in care since comprehensive care requires a range of services in addition to an annual CD4 or viral load test.

HARS (HIV/AIDS Reporting System) data was used to review all people diagnosed through December 2010 to determine the number of people living with HIV/AIDS in South Carolina not in care. HARS in South Carolina is a laboratory based reporting system with all CD4 and viral load tests being reportable as of January 1, 2004. People who were deceased as of December 31, 2010 were excluded from the analysis. Only current SC residents were included. A person was reported as being in care if they had a least one CD4 or viral load test report from January 1, 2010 through December 31, 2010. People with no CD4 or viral load test in this time frame were defined as not in care. See Attachment B for Unmet Need Data and Framework. The following describes South Carolina's estimation methods and estimates of persons receiving HIV care during 2010.

Estimation methods: 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 their medical provider not reporting. Persons living with AIDS and HIV at the end of 2010 were determined to be 'in care' if a CD4 or viral load test was performed and reported during 2009.

Population estimates: Number people living with HIV/non-AIDS who know their status = 7,248. Number people living with AIDS who know their status = 9,130. Overall, 38% of people living with HIV/AIDS are in care.

Estimates of people in care: Estimate of number and percent of PLWH/non-AIDS/aware who received HIV primary medical care = 3,525 (49%). Estimate of number and percent of PLWA who received HIV primary medical care = 6,565 (72%).

Estimates of unmet need: Estimate of number and percent of PLWH/non- AIDS/aware who did *not* receive HIV primary medical care = 3,723 (51%). Estimate of number and percent of PLWA who did *not* receive HIV primary medical care = 2,526 (28%).

Data sources: SC HARS; data for unmet need estimates include all known living persons with HIV/AIDS who have a S.C. residence (both persons diagnosed in S.C. and out of state jurisdictions). These data differ from the Epi Profile data which reflects only persons diagnosed in S.C.

Demographics and location of persons who know their HIV status and are not in care: As expected, a larger percentage of AIDS patients seek medical care, 72% versus 49% of HIV/non-AIDS patients. A larger number of females (65%) than males (60%) seek medical care. Blacks seek medical care most often (63%) followed by whites (60%) and Hispanics (49%). Urban patients seek care the slightly more than (61%) rural patients (59%).

Trends associated with the past 5 years regarding Unmet Need: As evidenced in Table 1 the percentages of PLWH, non AIDS and PLWA not in primary care services and thus representing unmet need has decreased each of the last five years. As seen in Table 2, this decrease in the percentage of PLWHA not in care has occurred across gender, race, ethnicity, and geographic groups.

Table 1. Unmet Need Estimate, 2006 - 2010

Year	PLWH, non AIDS	PLWA
2006	58%	34%
2007	56%	32%
2008	55%	31%
2009	54%	31%
2010	51%	28%

Table 2. Percent Unmet Need Estimate by Demographics, 2006 - 1020

Year	Females	Males	Black	White	Hispanic	Rural	Urban
2006	42%	47%	44%	47%	60%	43%	46%
2007	39%	45%	42%	44%	55%	42%	44%
2008	37%	44%	41%	43%	53%	43%	44%
2009	37%	43%	40%	42%	52%	43%	43%
2010	35%	40%	37%	40%	51%	41%	39%

Service needs, gaps, and barriers to care: South Carolina continues to focus on the core services but gaps in the provision of even those services remain due to limited funding. Additional services that encourage those not in care to enter care, such as transportation and outreach services, are becoming more and more difficult to provide. Currently our systems of care have reached capacity. Case managers carry unrealistically high caseloads, making it difficult to provide intensive case management services to those in danger of dropping out of care or those not yet in care.

Efforts to find people not in care and get them into primary care: Despite the lack of resources, providers across the state have been working to review records, touch base with patients and clients who have fallen out of care, and encourage them to reenter the care system. Our comprehensive case management data collection software provides the necessary tools to track clients who have been lost to follow up and allows us to maintain a clean database.

How the results of the Unmet Need Framework were used in planning and decision-making about priorities, resource allocations, and the system of care: Unmet need results are presented to the Ryan White Part B service providers and will be presented annually as numbers are updated. The Service Providers are then able to look for gaps in their service areas and develop local strategies for reaching out to those people who know their status but are not in care i.e. where clinics or outreach activities should be located. The demographics of the unmet need such as race, gender and age have been valuable in program design, to target populations, and geographic areas that demonstrate greatest unmet need.

The unmet need data are concerning to public health and HIV care providers. Persons with HIV who are not in care are more likely to fuel the epidemic because of no education on transmission reduction; poor retention by persons on HIV treatment drugs may be a marker

for non-adherence to HAART and consequent increased drug resistance. Ryan White providers and health departments where persons are first diagnosed need more resources to effectively link persons to early care and to provide ongoing case management for those who do not show up for care or transition through care.

3. HIV/AIDS Unaware Estimate for CY 2009

The Early Identification of Individuals living with HIV/AIDS (EIIHA) initiative is a legislative requirement that focuses on individuals that are unaware of their HIV status, how best to bring HIV positive individuals into care, and refer HIV negative individuals into services that will keep them HIV negative. HRSA prescribes use of a formula to estimate the number of living HIV positive individuals unaware of their status as of December 31st, 2009. Using the prescribed methods (Figure 1), the estimated number of undiagnosed cases in South Carolina is 4,353.

Figure 1. Formula for EIIHA Unaware Estimate

$$\frac{0.21}{0.79} \times 16,378 \text{ (diagnosed PLWHA)} = 4,353 \text{ (estimated number of undiagnosed)}$$

The national estimate of the proportion of people undiagnosed with HIV, as calculated by the Centers for Disease Control and Prevention (CDC), is 21%. This figure provides the basis for the numerator and the denominator used in the formula to calculate the estimate of those who are unaware of their status in South Carolina.

B. Current Continuum of Care

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. DHEC awards Part B contracts to HIV service providers in 11 regions of 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, Catawba Care, 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 two regions (Upper Savannah and Horry-Georgetown-Myrtle Beach) 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. Providers 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 resources have been maximized and the duplication of services has been minimized.

The model of HIV 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 and provides patient transportation to Part C providers in adjacent regions. Care services are coordinated among the providers through MOAs, informal agreements/procedures developed over time by established relationships, or jointly funded Part B and C clinics. The goal is to ensure that a continuum of care is provided by the clinic/provider most appropriate for the client.

There are currently four Ryan White Part D service providers in South Carolina (three regional pediatric/family clinics and one women's clinic). The Part D program also funds one community-based organization that employs a consumer advocate. Without Part D WICY funding for these pediatric providers, South Carolina would have a gap in service coverage for infants, children, and youth. Current Part D WICY services include HIV primary medical care, specialty medical care, and support services. The regional pediatric/family clinics serve families from all counties of the state. No other Part B or C provider serves infants and children with HIV Medical Care Services, ensuring no duplication of other Ryan White supported services. The Part D funds in the Women's Clinic are leveraged with Part B funds to provide services to the large numbers of women and youth.

DHEC also directly provides prevention services and contracts with local organizations to deliver community based prevention services. HIV counseling and testing services are provided by each of the 46 county health departments. Partner counseling/notification services are also offered. Through the CDC Expanded Testing Initiative, South Carolina has established routine Emergency Department HIV testing at four hospitals, thereby reaching many more people. Persons who test HIV positive are informed of HIV care providers in their region and referred to the provider of their choice. This is primarily the Ryan White Part B and C providers for women, male caregivers or older youth and the three regional pediatric/family clinics for infants, children and youth. Community organizations that also provide testing through contracts with DHEC include several Part C funded agencies, 10 other organizations, and 2 CDC directly funded organizations. Other prevention services such as risk reduction counseling and group interventions are provided by two CDC directly funded community organizations and 11 organizations contracted by DHEC. Efforts are targeted to persons at greatest risk of HIV according to the state HIV prevention plan.

Ryan White Section F, AIDS Education and Training Center (AETC) Program provides training for providers serving all populations in South Carolina through the University of South Carolina's Department of Medicine. Medicaid is the major payer of HIV treatment and care and supports almost all HIV exposed/infected infants, children and youth under 19 years old in the state.

Attachment E shows the location of the network of HIV service providers in South Carolina. The distribution of service providers mirrors the epidemic, as more providers are located in the areas with the greatest HIV prevalence.

1. Ryan White funded HIV care and service inventory

The full array of Ryan White eligible services is available to people living with HIV in South Carolina. While not every provider provides every service, the following specific Ryan White services are provided through the Ryan White care system in South Carolina:

Core Medical Services: Outpatient/ambulatory medical care, oral health care, early intervention services, health insurance and premium cost sharing assistance, home health care, home and community based services, hospice services, mental health services, medical nutrition therapy, medical case management and substance abuse services.

Support Services: Case management (non-medical), child care services, pediatric developmental assessment and early intervention services, emergency financial assistance, food bank/home delivered meals, health education/risk reduction, housing services, legal services, linguistics services, medical transportation services, outreach services, permanency planning, psychosocial support services, referral for health care/supportive services, rehabilitation services, respite care, substance abuse services (residential) and treatment adherence counseling.

While support services are critical to connecting and retaining people living with HIV/AIDS to medical care and treatment, the Ryan White providers focus on the provision of core medical services in keeping with HRSA’s policy to spend no less than 75% of funding on core medical services. State support of HIV care and prevention services continues in the form of state funding to the ADAP direct dispensing program and local health department HIV testing programs.

2. Non Ryan White funded HIV care and service inventory

Non Ryan White funded HIV care and services being provided in South Carolina include private medical services for patients with insurance (including Medicaid), HIV prevention services (including HIV counseling and testing) and Housing Opportunities for Persons With AIDS (HOPWA) services. Funding amounts for HIV prevention and HOPWA services are listed in the section below. Many of the services covered by Medicaid and private insurance are provided by Ryan White funded agencies.

3. Funding Sources

Federal and state funding sources for prevention and care for FY 2011 are listed below in Table 3. State and local funding have remained relatively stable over the past several years. However, the epidemic has continued to grow and the net effect is that the needs of PLWHA continue to outpace available resources. Total estimated federal and state prevention and care funding for FY 2011 is \$50,696,807.00.

Table 3. Federal and State Prevention and Care Funding, FY 2011

HIV/STD Prevention Total	\$11,406,833
CDC HIV Prevention	\$4,387,586
CDC HIV Expanded Testing	\$1,111,426
CDC STD	\$1,602,433
CDC Adult Viral Hepatitis	\$69,842

State Funds	\$3,211,414
DAODAS Contract (SAMHSA)	\$283,132
OPA/Title X Family Planning ¹	\$741,000
HIV Care/Support Services Total	\$39,289,974
HRSA Ryan White Part B	\$25,823,345
HRSA Ryan White Part C	\$5,000,000
HRSA Ryan White Part D	\$579,487
HUD/HOPWA ²	\$3,228,286
State Funds (ADAP)	\$4,658,856
Prevention and Care Total	\$50,696,807

In addition to the above listed resources, the state Department of Corrections (DOC) also expends state funds (estimated \$5 million) for HIV testing and care and treatment services for inmates at the state institution. Approximately 450 HIV infected inmates are housed at DOC at any given time. South Carolina also has one organization, the AIDS Benefit Foundation, which conducts fund-raising events and makes small grants available to AIDS service organizations to support services, prevention and capacity –building programs; approximately \$100,000 is distributed annually.

C. Description of Need

This section describes needs for three populations of PLWHA, 1) those who are in care, 2) those who know their HIV status and are not in care, and 3) those who don't know their HIV status. Gaps in care, barriers to care, capacity development needs, and prevention and service needs are also described in this section as those needs are inextricably interwoven with the needs of PLWHA. The needs described below are based on the results of a web-based survey and two full-day meetings with stakeholders in South Carolina, including PLWHA, providers, Ryan White funded programs, and state agencies. The full report from this process is included in Attachment F.

1. PLWHA in Care

Societal Stigma: Persistent societal stigma surrounding HIV/AIDS and its associated risk behaviors has created significant pressures on the HIV/AIDS care system in South Carolina. Stigma is not unique to this state and presents a particularly difficult challenge to HIV care in the Southeastern United States in general due to the prevailing religious, moral, and political views of the region.

Transportation, Housing, and Unemployment: Lack of transportation, inadequate housing, and unemployment have long been recognized as interrelated barriers for PLWHA who are in

¹ HIV counseling and testing in Family Planning clinics

² Includes \$1.5M direct funded cities

care. The current depressed economy has exacerbated these concerns. Many PLWHA struggle to meet short-term basic needs that are more pressing than keeping a clinic appointment or maintaining a medication regimen.

Substance Abuse and Mental Health Needs: Substance abuse and mental health needs are common co-morbidities with HIV infection. Addiction and unmet mental health needs, combined with the demands of maintaining treatment adherence, pose obvious challenges for PLWHA with regard to their ability to stay in care.

Competing Health Concerns and Client Fatigue: Advances in the treatment of HIV infection have led to an increasingly older population of PLWHA. As a result, many PLWHA are now beset with other health concerns common among an aging population, such as diabetes, heart disease, and cancer. These other health concerns may become more pressing for older PLWHA, distracting them from HIV care or complicating their ability to attend multiple appointments with many different providers. Even in the absence of competing health concerns, some PLWHA become fatigued with the effort it takes for long-term management of their infection.

Healthcare System Limitations: Although the HIV care system in South Carolina has provided the best possible care for PLWHA, rising infection rates coupled with chronic inadequate funding has created significant pressures on the care system. There are acknowledged limitations to the care system, some of which are specific to the care of PLWHA and some endemic to the healthcare system in general. These challenges include long wait times for an appointment, long wait times upon arriving at the clinic itself, inadequate staffing, provider turnover, staff that lack cultural competency, and changes in the complexity of eligibility requirements, insurance coverage, and cost reimbursement mechanisms.

2. PLWHA Who Know Their HIV Status and Are Not in Care

Poverty and Unmet Basic Needs: Similar to the challenges described above for PLWHA in care, poverty and unmet basic needs may take precedence over HIV care for PLWHA not currently in the care system. Those previously in care may drop out of care due to the need to work and pay bills, lack of transportation, unstable housing, and other circumstances associated with poverty. These circumstances may also interfere with someone initially entering the care system after their diagnosis. Impoverished clients may not access care or may drop out of care due to concerns about medical expenses.

Denial and Fear: Denial about one's HIV status and the fear of disclosure to others prevents some PLWHA from initially entering the care system. For others who have been receiving care, these concerns may cause them to drop out. Denial and fear are powerful disincentives and can isolate PLWHA from friends, family members, and agencies that might otherwise serve a supportive role.

Substance Abuse and Mental Health Needs: Unmet substance abuse and mental health needs are a significant barrier to PLWHA entering the care system and maintaining their treatment. There are limited resources to address these needs and the some of the providers that are available are either unwilling to treat PLWHA or unfamiliar with the specific needs and context for this population.

Asymptomatic Clients: Asymptomatic PLWHA may not access care because they believe they only need to go to the clinic when not feeling well. This is may be particularly true for those that have been infected for a long time, young adults born with HIV infection, and others who view HIV as a long-term manageable disease. Whereas the public health community has been successful in shaping the public's perception that HIV can be successfully treated, this message may also have unintended consequences as a barrier to maintaining vigilance with clinic appointments.

Healthcare System Limitations: The care system for PLWHA is chronically overburdened and under-resourced. The resulting limitations of the care system are obstacles for PLWHA who had previously received care and have dropped out. These challenges contribute to a further expansion of the epidemic and increasingly unmet care needs. Limited clinic hours, inadequate staffing, and high case loads can be a significant obstacle to receiving HIV care, which in turn lead to lapses in treatment, increases in viral load, declining health, and greater infectivity. In addition, staff that are dispassionate and lack cultural competency, and real and perceived concerns about breaches of confidentiality can create an inhospitable environment that contributes to PLWHA dropping out of care.

3. PLWHA Who Don't Know Their HIV Status

Fear and Denial: There are a variety of barriers to HIV testing for individuals who know they are at risk for HIV infection but don't know their HIV status. Many of these barriers are attributed to attitudes associated with fear and denial, including denial of risk despite knowingly engaging in risk behaviors; fear of the implications of an HIV diagnosis or, conversely, the perception that HIV is not a serious illness; concerns about disclosure of HIV status upon receiving a positive result; and belief that they may be ineligible for care services due to inability to pay.

Societal Stigma: Societal stigma about HIV and risk behaviors shapes the larger context within which fear and denial function as barriers to HIV testing. Some individuals do not get tested for fear they will be judged by society with prevailing negative views about HIV and risk behaviors. Societal stigma can also be an obstacle for linkage to care for newly diagnosed individuals when PLWHA fear that others in their community may learn they are receiving HIV care services.

Unaware of Risk: Some people do not get tested because they are unaware they are at risk for HIV. This may stem from misinformation about risk behaviors, misperception that HIV is only a "gay disease", and from providers who reinforce stereotypes about who is at risk and should be tested. Insufficient community education about HIV and the lack of comprehensive sexuality education in schools have compromised the public's understanding of HIV which, in turn, hinders more widespread testing.

Access to Testing: Limited access to testing services is a barrier to HIV testing. Access to testing is hindered by limited hours, locations, and staffing for HIV testing services. Access is also constrained by providers who resist the trend toward routine testing in medical settings due societal stigma, and their concerns about responsibility for providing positive test results and linking newly diagnosed clients to care. A recent study released by the National Medical Association reported that social stigma is the predominant barrier to routine HIV testing among African-American physicians.

4. Part B Needs Assessment

Ryan White Part B contractors in South Carolina conducted client needs assessment surveys to supplement the needs identified through the process described above. The 11 Ryan White Part B contractors in South Carolina conducted client needs assessment surveys during the period November 2011 through January 2012. A common needs assessment tool was developed and the majority of the providers used the same tool to survey a sample of clients. In order to get feedback from a true representative sample of clients, each of the 11 Part B contractors pulled a random sample of clients from their data system at the beginning of the survey effort. The providers experienced difficulty reaching all of the clients on their randomly selected lists and therefore ultimately relied on some convenience sampling to achieve their required number of completed surveys. It is estimated that 70% of the completed surveys were from those on the randomly sampled client lists while 30% of the completed surveys were achieved through convenience sampling. The survey tool is in Attachment G.

Clients across the state were surveyed regarding their perceptions of their HIV care related needs and how well those needs were being met. Priority needs identified through the survey process were congruent with those identified through the stakeholder survey and meetings, and included oral health care, vision care, medical transportation, housing services, and food bank services. The results of the needs assessments will be used locally in setting priorities for allocation of funds among service needs, developing agency comprehensive plans, and crafting local implementation plans.

D. Priorities for the allocation of funds

Ryan White funding for care and support services in South Carolina primarily comes in the form of Part B (formula funding to the State that is passed on to community providers), Part C (competitive funding that is currently awarded to 10 organizations directly from HRSA) and Part D (competitive funding that is currently awarded to the State and passed on to community providers).

In the past, Part B funds were allocated from the State to providers based only on the percentage of HIV prevalence in a given service area. However, as of April 2012, additional criteria have been used to determine the proportional distribution of funds in the state. The use of additional criteria led to a more equitable distribution of funds. The criteria are: 1) HIV prevalence in the service area; 2) percentage of HIV prevalence served by the service provider in the previous year; 3) percentage of clients served who have no payer source other than Ryan White (Medicaid, Medicare, private insurance); 4) percentage of patients served with medical care and 5) availability of Ryan White Part A dollars. The application of these criteria resulted in some shifting of funding but no one provider received a drastic increase or decrease of funds.

Once funding is determined for each provider there is an allocation prioritization process that is conducted at the local level. The prioritization of funding by each provider considers the presence of other Ryan White funded organizations and the overall availability of community

resources and services. Local input from consumers is encouraged through the use of consumer advisory committees.

E. Gaps in care

Gaps in care are described above in Section I.C, Description of Need, since these gaps are inextricably interwoven with the other needs of PLWHA. As described in Section I.C, gaps in HIV care include long wait times for an appointment, long wait times upon arriving at the clinic itself, inadequate staffing, provider turnover, staff that lack cultural competency, and changes in the complexity of eligibility requirements, insurance coverage, and cost reimbursement mechanisms. Gaps in care also include limited availability of mental health and substance abuse services.

F. Prevention and service needs

Prevention and service needs are described above in Section I.C, Description of Need, since prevention and service needs are inextricably interwoven with the others needs of PLWHA. As described in Section I.C, prevention and service needs include access to HIV testing, and mental health and substance abuse services, as well as access to non-HIV specific supports such as employment, transportation, housing, food, and other basic necessities.

G. Barriers to care

Barriers to care are described above in Section I.C, Description of Need, since these barriers are inextricably interwoven with the other needs of PLWHA. As described in Section I.C, barriers to care include pervasive societal stigma, denial and fear, competing health concerns, client fatigue, poverty and unmet basic needs, availability of mental health and substance abuse services, long wait times for an appointment, long wait times upon arriving at the clinic itself, inadequate staffing, provider turnover, staff that lack cultural competency, and changes in the complexity of eligibility requirements, insurance coverage, and cost reimbursement mechanisms.

H. Evaluation of 2009 Comprehensive Plan

The 2009 South Carolina Ryan White Comprehensive Plan included three focus areas: Access to medical care, quality of medical care and retention in medical area. For each of the three areas, a goal and a set of associated objectives were outlined with specific targets for increasing service levels. Data collection for monitoring of targets continues to be a challenge. As all of the Ryan White providers in South Carolina do not use the same data system, it has been difficult to capture comprehensive statewide data. However, the HIV surveillance system, which captures CD4 and viral load laboratory data on all people living with HIV in South Carolina, provides the necessary data to measure the proportion of people living with HIV/AIDS who are accessing medical care.

Table 4 presents the percentage of PLWHA in care from 2008-2010, using HRSA's definition of in care, i.e., anyone who has accessed medical care in the past 12 months. The percentage of PLWHA in care has increased each year during the three year period. While there is room for

improvement, this is a marker of the success of the care system in better engaging and retaining patients in care.

Table 4. Percentage of PLWHA in Care, 2008 – 2010

Year	Percentage of PLWHA in Care
2008	58%
2009	59%
2010	62%

The South Carolina Ryan White All Parts Quality Management initiative has also provided a mechanism to collect and analyze a limited set of data elements to assess statewide progress. Currently only baseline data is available for two objectives but data will continue to be collected for comparison. The following is a summary of the quality management data for which there is currently statewide baseline data.

- 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. Baseline: 71%
- Increase the proportion of patients who receive a CD4 test every six months by 2%. Baseline: 92%

The Part B Ryan White HIV/AIDS Program Data Report (RDR) provides a mechanism to evaluate progress in meeting the objectives of the 2009 Comprehensive Plan. Table 5 presents the number of clients and services for core medical services for all 17 of the Part B contractors and sub-contractors, 2009 - 2011. RDR data shows an overall increase in the number of clients served and the number of services provided for all categories from 2009 to 2011. However, there is a slight decrease from 2009 to 2010 in the number of medical care visits, clients served with oral health care, and oral health care visits

Table 5. Number of Clients and Services, Core Medical Services, 2009 - 2010

Service Type	2009	2010	2011
Total clients served	7,074	7,514	7,981
Clients served with medical care	4,892	5,064	5,582
Number of medical care visits	24,902	22,927	28,098
Clients served with oral health care	825	584	875
Number of oral health care visits	1,883	1,112	1,657
Clients served with mental health services	770	955	997
Number of mental health visits	2,237	2,734	2,905
Clients served with substance abuse services	407	411	491
Number of substance abuse visits	1,648	1,606	1,799

II. Where Do We Need To Go?

A. Addressing challenges in evaluating the 2009 Comprehensive Plan

South Carolina will continue to collaborate with all Ryan White providers to address the challenges of cross-Parts data collection and de-duplication of data. As HRSA's evaluation of client level data continues to progress we expect to receive a statewide dataset of aggregate, de-duplicated data on client outcomes, which will allow us to further evaluate program progress.

B. 2012 Care goals

The South Carolina 2012-2014 Ryan White HIV/AIDS SCSN and Comprehensive Plan identifies two overarching goals to address the needs of PLWHA:

- Improve client retention in HIV medical care and support services.
- Increase the proportion of HIV infected people who know their status and are linked to care when newly diagnosed.

These goals are responsive to the needs of PLWHA in South Carolina who are in care, those who know their HIV status and are not in care, and those don't know their HIV status. These goals are aligned with the priorities of several national initiatives on HIV care and prevention, including the National HIV/AIDS Strategy (NHAS), Early Identification of Individuals with HIV/AIDS (EIIHA), and Healthy People 2020.

C. Aware of HIV status but not in care

As stated above, there is one overarching goal related to the needs of individuals aware of their HIV status but not in care. This goal addresses the need to retain PLWHA who know their status and are already in care as well as the need to reconnect with care those who know their HIV status and have dropped out of care.

- Improve client retention in HIV medical care and support services.

D. Unaware of HIV status

As stated above, there is one overarching goal to address the needs of individuals who are unaware of their HIV status. This goal is consistent with the expectations set forth by EIIHA, and emphasizes testing individuals who are unaware of their status and linking to care those individuals that are newly diagnosed.

- Increase the proportion of HIV infected people who know their status and are linked to care when newly diagnosed.

E. Closing gaps in care

Strategies to close gaps in care are described below in Section III. B - D as those strategies are also intended to address the needs of PLWHA who know their status but are not in care, those who do not know their HIV status, and the needs of PLWHA who are members of special populations. These strategies include, but are not limited to, integrating the provision of HIV care with other non-HIV related medical care needs of clients, expanding routine HIV testing in health care settings, using a short-term linkage-to-care model to provide intensive case management for newly diagnosed individuals, and establishing a mechanism to transition clients to traditional long-term case management after successful linkage.

Closing gaps in care also requires coordination of services among Ryan White and non-Ryan White funded providers of prevention and care services. As described in Section III.E, below, this coordination is supported by regular Ryan White All Parts Meetings; Quality Management steering committee meetings, which include representation from all Ryan White Parts; ADAP provider advisory meetings, which include representation from a variety of clinical providers; and HIV/AIDS Planning Council, the statewide HIV care and prevention planning body, which includes representatives from all Ryan White Parts and DHEC staff, as well as the work of the South Carolina HIV/AIDS Care Crisis Task Force.

F. Addressing overlaps in care

Similar to closing gaps in care, strategies to address overlaps in care are described below in Section III. A - D as those strategies are also intended to address the needs of PLWHA who know their status but are not in care, those who do not know their HIV status, and the needs of PLWHA who are members of special populations. Enhanced coordination of services also helps to address overlaps in care and is supported through Ryan White All Parts Meetings, Quality Management steering committee meetings, ADAP provider advisory meetings, and the HIV/AIDS Planning Council.

G. Coordinating efforts with care and prevention services

As described in the continuum of care section above, the HIV care and prevention services network in South Carolina operates collaboratively across Ryan White Parts and among other community providers. In the next three years there will be continued collaboration among Ryan White Part B, C, D and F providers with the focus of ensuring the availability of a full array of services in each region and ensuring that there is no duplication of services.

Based on participation in the two stakeholder meetings that were convened, the shared values of the HIV care providers in South Carolina that will be used to guide the collaborative delivery of services are:

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

III. How Will We Get There?

A. Strategies to close gaps in care

Strategies to close gaps in care are described below in Sections B - D as those strategies are also intended to address the needs of PLWHA who know their status but are not in care, those who do not know their HIV status, and the needs of PLWHA who are members of special populations. These strategies include, but are not limited to, integrating the provision of HIV care with other non-HIV related medical care needs of clients, expanding routine HIV testing in health care settings, using a short-term linkage-to-care model to provide intensive case management for newly diagnosed individuals, and establishing a mechanism to transition clients to traditional long-term medical case management after successful linkage.

Closing gaps in care also requires coordination of services among Ryan White and non-Ryan White funded providers of prevention and care services. As described in Section E, below, this coordination is supported by regular Ryan White All Parts Meetings; Quality Management steering committee meetings, which include representation from all Ryan White Parts; ADAP provider advisory meetings, which include representation from a variety of clinical providers; and HIV/AIDS Planning Council meetings, the statewide HIV care and prevention planning body, which includes representatives from all Ryan White Parts and DHEC staff, as well as the work of the South Carolina HIV/AIDS Care Crisis Task Force.

B. Strategies for PLWHA aware of their HIV status but not in care

The section describes strategies and action steps to address the needs of PLWHA who are aware of their status but are not in care, including the need to retain PLWHA who are already in care as well as the need to reconnect with care those who have dropped out of care. These strategies will be implemented during the time period 2012 - 2014 by Ryan White funded and non-Ryan White funded providers of care and prevention services. Collectively, these strategies support the overarching goal of improving client retention in HIV medical care and support services. The strategies were developed collaboratively with input from PLWHA, providers, Ryan White funded programs, and state agencies.

Strategy 1: Retain PLWHA in Care

Action Steps

1. Use peer advocates to assist clients in navigating the care system, and in identifying and addressing barriers to retention in care, particularly when clients are newly diagnosed and/or re-enter care after an absence.
2. Conduct periodic assessments with all clients to identify barriers to retention in care, such as transportation, housing, and employment, and develop individualized plans to address barriers.
3. Develop procedures to ensure clients receive appointment reminders using agreed upon modes of communication, such as cell phone, email, text, and postcard.

Strategy 2: Identify PLWHA Out of Care

Action Steps

1. Run medical appointment compliance reports to identify clients who have dropped out of care and refer those individuals to appropriate staff for follow up, e.g., outreach medical case manager, adherence medical case manager, adherence nurse.
2. Compare URN across providers to determine if clients who have dropped out of care at one agency and still receiving care at another agency.

Strategy 3: Reconnect PLWHA with the Care System

Action Steps

1. Use outreach workers to locate PLWHA who have dropped out of care, assist those clients in addressing barriers to care, and reconnect them with the care system.
2. Re-engage PLWHA upon discharge from jail and/or prison system to support continuity in care.

Strategy 4: Address Non-HIV Related Needs

Action Steps

1. Integrate the provision of HIV care with other non-HIV related medical care needs of clients.
2. Seek additional grant funding through Department of Housing and Urban Development to support housing needs for PLWHA.
3. Increase resources from DHHS for Medicaid transportation services to help improve the availability and frequency of transportation assistance services.
4. Work with Department of Transportation and seek possible grant funds specific for HIV/AIDS.
5. Seek funding sources to provide direct funding for job initiatives for PLWHA.

Strategy 5: Develop Supportive Community

Action Steps

1. Engage faith-based communities to raise awareness about HIV, the impact of stigma, and retention in care issues, thereby reducing stigma as a barrier to care.
2. Reframe terms and definitions used within the HIV care community to describe PLWHA (e.g., consumer) that may inadvertently promote stigma and impact motivation to seek care.

Strategy 6: Utilize Peer Advocates

Action Steps

1. Work within the existing support services infrastructure (HPC Care and Support Services Committee and Part B case management workgroup) to develop a client graduation model that supports the preparation of clients to participate in a statewide peer advocate training program. This work will increase the number of peers advocates involved in outreach initiatives.
2. Seek funding opportunities to support peer advocates within ASO/CBO agencies.

C. Strategies for PLWHA Unaware of their HIV status

The section describes strategies and action steps to address the needs of PLWHA who are unaware of their HIV status, and emphasizes testing individuals who are unaware of their status and linking to care those individuals that are newly diagnosed. These strategies will be implemented during the time period 2012 - 2014 by Ryan White funded and non-Ryan White funded providers of care and prevention services. Collectively, these strategies support the overarching goal of increasing the proportion of HIV infected people who know their status and are linked to care when newly diagnosed. The strategies were developed collaboratively with input from PLWHA, providers, Ryan White funded programs, and state agencies.

Strategy 1: Expand HIV Testing

Action Steps

1. Expand routine HIV testing in health care settings (e.g., emergency department, urgent care clinic, family practice, community health centers).
2. Educate health care providers about CDC's recommendations for routine HIV testing in health care settings, and identify and address providers' barriers to routine testing, such as concerns about reimbursement, stigma associated with testing, and linkage to care.
3. Continue to offer HIV testing in non-traditional settings, such as through mobile vans, at public housing, and during community health fairs.
4. Integrate HIV testing with other services for related risk-factors, such as STD and HCV, reproductive health, substance abuse treatment.
5. Integrate HIV testing with non-HIV related services, such as general health screening offered at community events.
6. Expand testing opportunities for incarcerated individuals (eg., entry and release)
7. Collaborate with American Red Cross and other agencies conducting blood drives to ensure linkage to care for newly diagnosed individuals.
8. Use social media and other targeted communication campaigns to provide education about where testing is provided, why it is important, and to reduce stigma associated with HIV testing.

Strategy 2: Link Newly Diagnosed to Care

Action Steps

1. Use a short-term linkage to care model to provide intensive case management for newly diagnosed individuals (e.g., five sessions in first three months) to support linkage to care, and establish a mechanism to transition clients to traditional long-term medical case management after successful linkage.
2. Employ motivational interviewing and other effective provider-patient communication strategies to identify and address concerns that may hinder linkage to care for newly diagnosed individuals, such as fear of disclosure, stigma, motivation, and other competing concerns.
3. Conduct active referral to support linkage to care, such as when the provider makes the first HIV care appointment and/or accompanies newly diagnosed individuals to their appointment.

4. Connect peer advocates with newly diagnosed individuals to provide emotional support and to help navigate successful linkage to care after initial diagnosis.
5. Establish linkage to care benchmarks for newly diagnosed individuals, monitor linkage to care success rates, and work with providers to address client-level and structural-level barriers for those that have not achieved benchmarks.

D. Strategies for PLWHA who are members of special populations

The section describes strategies and action steps to address the needs of PLWHA who are members of special populations, including the homeless, teens, transgendered individuals, and injection drug users. These strategies will be implemented during the time period 2012 - 2014 by Ryan White funded and non-Ryan White funded providers of care and prevention services. Collectively, these strategies support the overarching goals of improving client retention in HIV medical care and support services *and* increasing the proportion of HIV infected people who know their status and are linked to care when newly diagnosed. The strategies were developed collaboratively with input from PLWHA, providers, Ryan White funded programs, and state agencies.

Strategy 1: Address the needs of the homeless

Action Steps

1. Expand the service portfolio to include housing resources (e.g., HUD), partner with local housing agencies, and outreach and engagement with the homeless population.
2. Refer homeless clients to community and social services providers for life-skills trainings related to education, employment, clothing accessibility, and other basic needs.
3. Identify shelters that are supportive places for PLWHA, and contact shelters known to not accept PLWHA to educate them about HIV issues and, when applicable, inform them of legal requirements to accept PLWHA.
4. Offer cultural competency training to providers working with the homeless population.

Strategy 2: Address the needs of teens

Action Steps

1. Develop transition plans to help teens segue from Medicaid and RW Part D to the adult HIV care system, and to help prepare young clients to become more self-reliant for their care.
2. Identify and utilize youth peer advocates to help support young PLWHA.
3. Develop social media campaigns to educate young people about HIV testing.
4. Expand HIV testing at venues and through services frequented by young people, such as college campuses, youth-focused programs, family court upon release, primary care providers who work with Medicaid patients, and high-risk youth at mental health and substance abuse residential and out-patient centers.
5. Offer cultural competency training to providers working with teen population.

Strategy 3: Address the needs of transgender individuals

Action Steps

1. Collaborate with the SC HPC to review the recent transgender needs assessment and develop strategies to address prevention and care needs.
2. Identify and utilize transgender peer advocates to help support transgender PLWHA.
3. Offer cultural competency training to providers working with the transgender population.

Strategy 4: Address the needs of injection drug users

Action Steps

1. Integrate HIV testing and care services with HCV testing and care services.
2. Collaborate with mental health and substance abuse residential and out-patient centers to offer HIV testing and to identify and link PLWHA to care.
3. Collaborate with harm reduction programs to offer HIV testing to IDUs and to identify and link PLWHA to care.
4. Expand efforts to establish syringe exchange programs and to integrate HIV testing and care services with those programs.
5. Offer cultural competency training to providers working with the IDU population.

E. Coordinating efforts with care and prevention services

Coordination among Ryan White Part B, C, D and F providers and other community providers as described in the previous section will be implemented through the following means:

- Ryan White All Parts Meetings will be convened at least annually.
- Quality Management steering committee meetings, which include representation from all Ryan White Parts, will be convened at least annually.
- ADAP provider advisory meetings, which include representation from a variety of clinical providers, will be convened at least annually.
- Representatives from all Ryan White Parts and DHEC staff will continue to fully participate in the activities of the HIV/AIDS Planning Council (HPC), the statewide HIV care and prevention planning body.
- The South Carolina HIV/AIDS Care Crisis Task Force is an advocacy body made up of a variety of stakeholders and is committed to working throughout the state to increase available fiscal resources dedicated to impacting the HIV/AIDS epidemic.

F. Alignment with Healthy People 2020 Objectives

Healthy People is an initiative of the US Department of Health and Human Services that provides science-based, 10-year national objectives for improving the health of all Americans. Healthy People 2020, launched in December 2010, sets a 10-year agenda for improving the Nation's health. HIV is one of the many topics addressed in Healthy People 2020. There are 18 HIV-related objectives across four areas, including diagnosis, care, testing, and prevention.

Healthy People also identifies evidence-based strategies to achieve these objectives that are focused on clinic recommendations, community-level interventions, and consumer information.

The goals and strategies described in this South Carolina 2012-2014 Ryan White HIV/AIDS SCSN and Comprehensive Plan are consistent with the HIV-related objectives and evidence-based strategies articulated in Healthy People 2020. For example, Healthy People objectives HIV-10 and HIV-13 are to increase the proportion of HIV-infected adolescents and adults who receive HIV care and treatment consistent with current standards, and to increase the proportion of persons living with HIV who know their serostatus. These Healthy People objectives are well aligned with South Carolina's goals (described above) to improve client retention in HIV medical care and support services and to increase the proportion of HIV infected people who know their status and are linked to care when newly diagnosed. Another example of alignment between Healthy People and this Plan related to HIV screening. Under clinical recommendations, Healthy People recommends that clinicians conduct routine screening for HIV for adolescents and adults at increased risk. This evidence-based strategy is consistent with the actions steps in this Plan (described above) to expand routine HIV testing in health care settings, educate health care providers about CDC's recommendations for routine HIV testing in health care settings, and identify and address providers' barriers to routine testing, such as concerns about reimbursement, stigma associated with testing, and linkage to care.

G. Alignment with Statewide Coordinated Statement of Need

This Plan is responsive to the needs described in the South Carolina Statewide Coordinated Statement of Need (SCSN), 2012 - 2014. More specifically, the needs described in this plan (Section I.D), the goals (Section II. B-F), and the strategies and action steps (Section III. A-D) were all based on the results of a web-based survey and two full-day meetings with stakeholders in South Carolina, including PLWHA, providers, Ryan White funded programs, and state agencies. The full SCSN report from this process is included in Attachment F.

H. Responsiveness to the Affordable Care Act

On March 23, 2010, President Obama signed the Affordable Care Act (ACA) and set into place an effort that will help ensure Americans have secure, stable, affordable health insurance and the relief they need from skyrocketing health insurance costs. Historically, PLWHA have had a difficult time obtaining private health insurance and have been particularly vulnerable to insurance industry abuses. PLWHA also face barriers to obtaining care from qualified providers. Consistent with the goals of the President's National HIV/AIDS Strategy, the ACA makes considerable strides in addressing these concerns and advancing equality for PLWHA. Most major provisions of the ACA go into effect in 2014

This Plan describes an approach to addressing the needs of PLWHA that is coordinated with and adapts to changes that will occur with the implementation of the ACA. The AIDS Drug Assistance Program (ADAP), a critical part of the HIV care system, has already adapted to two important provisions. In January 2011, per the ACA, payments made by ADAPs on behalf of patients who had the Medicare Part D prescription drug benefit began counting as a patient's True Out Of Pocket (TrOOP) expense. In order to receive the full benefit of this provision of the ACA, the ADAP rolled out a Medicare Part D Assistance Program (MAP) whereby ADAP shifted

those patients who were eligible for and enrolled in Medicare Part D from the Direct Dispensing program to the MAP. Setting up a separate MAP allowed ADAP to contract with a Pharmacy Benefits Manager (PBM) that facilitates the recording of TrOOP payments and enables MAP patients to leave the Medicare Part D “doughnut hole” thereby reducing their medications costs. The MAP is currently serving about 200 patients and the implementation of the MAP has meant a significant cost savings to the ADAP.

The ACA also provides for the creation of a pre-existing condition insurance plan (PCIP). South Carolina falls under the federally run PCIP and patients with PCIP coverage are accepted into the ADAP Insurance Assistance Program (IAP) based on program eligibility guidelines. Like other types of insurance coverage, patients with PCIP coverage may be eligible for assistance with their insurance premiums, co-pays and deductibles. There are currently about 70 patients with PCIP coverage who are being served through ADAP’s IAP.

Currently, fewer than one in five (17%) people living with HIV has private insurance and nearly 30% do not have any coverage. Medicaid, the federal-state program that provides health care benefits to low-income people and those living with disabilities, is a major source of coverage for PLWHA, as is Medicare, the Federal program for Seniors and people with disabilities. The Ryan White CARE HIV/AIDS Treatment Extension Act of 2009 is another key source of funding for health and social services for this population.

The ACA addresses these problems beginning this year. As early as September 23, 2010, insurers will no longer be able to deny coverage to children living with HIV or AIDS. Insurers also are prohibited from cancelling or rescinding coverage to adults or children unless they can show evidence of fraud in an application, and can no longer impose lifetime caps on insurance benefits. These changes will begin to improve access to insurance for PLWHA and other disabling conditions and help people with these conditions retain the coverage they have.

These changes will provide an important bridge to the significant changes in insurance that will be made in 2014 as the ACA is fully implemented. Beginning in 2014, insurers will not be allowed to deny coverage to anyone or impose annual limits on coverage. People with low and middle incomes will be eligible for tax subsidies that will help them buy coverage from new state health insurance Exchanges. The ACA also broadens Medicaid eligibility to generally include individuals with income below 133% of the federal poverty line (\$14,400 for an individual and \$29,300 for a family of 4), including single adults who have not traditionally been eligible for Medicaid benefits before. As a result, a person living with HIV who meets this income threshold no longer has to wait for an AIDS diagnosis in order to become eligible for Medicaid.

The ACA also phases out the Medicare Part D prescription drug benefit “donut hole,” giving Medicare enrollees living with HIV and AIDS the peace of mind that they will be better able to afford their medications. Beneficiaries who reached the donut hole in 2010 received a one-time rebate of \$250. In 2011, these beneficiaries received a 50% discount on brand-name drugs while they are in the “donut hole,” a considerable savings for people taking costly HIV/AIDS drugs. In addition, ADAP benefits will be considered as contributions toward Medicare Part D’s true Out of Pocket Spending Limit (“donut hole”), a huge relief for low-income individuals living with HIV and AIDS.

The ACA also seeks to make sure that people with public or private coverage have access to the information they need to get the best quality care. This includes:

- Better information. Because of the ACA, people living with HIV and AIDS will also be offered more information and services. With the passage of the new law, plans will be required to provide information in a user-friendly manner that clearly explains what is and isn't covered.
- Quality, comprehensive care. A new comprehensive benefit package that equals that of a typical employer plan will offer all Americans who purchase insurance policies in the individual or small group market a fair and comprehensive set of services that includes prescription drugs, preventive care, chronic disease management, and substance abuse and mental health treatment.
- Preventive care. Beginning September, 2010, some private insurance plans cover recommended preventive services like regular check-ups and certain cancer screenings at no additional cost to eligible people. Comparable provisions apply to Medicare starting of January, 2011. This will help PLWHA stay healthy.
- Coordinated care. The law calls for new investments in community health teams to manage chronic disease. The new law also recognizes the value of patient-centered medical homes (coordinated, integrated, and comprehensive care) as an effective way to strengthen the quality of care, especially for people with complex chronic conditions, and it is proven to be effective as demonstrated by the Ryan White HIV/AIDS Treatment Extension Act of 2009, the pioneer in the development of this model in the HIV health care system.

Despite significant advances in HIV treatment and education, there are over 56,000 new HIV infections annually with significant racial and gender disparities. The health of PLWHA is influenced not only by their ability to get coverage but also economic, social, and physical factors.

- Prevention and wellness. The new law makes critical investments in prevention, wellness, and public health activities to improve public health surveillance, community based programs, and outreach efforts. The new law requires new insurance plans to offer coverage without cost-sharing for HIV screening tests for at-risk individuals. This will enable more people to get access to life-saving treatment more quickly.
- Diversity and cultural competency. The ACA expands initiatives to strengthen cultural competency training for all health care providers and ensure all populations are treated equitably. It also bolsters the federal commitment to reducing health disparities.
- Health care providers for underserved communities. The ACA expands the health care workforce and increases funding for community health centers, an important safety-net for low-income individuals and families. A key recommendation of the National HIV/AIDS Strategy is to increase the number and diversity of available providers of clinical care and related services for people living with HIV. The new law will lead to significant new investments to support critical healthcare workforce expansions to better serve vulnerable populations.

I. Alignment with National HIV/AIDS Strategy (NHAS)

In July 2010, the Office of National AIDS Policy released the National HIV/AIDS Strategy (NHAS). The NHAS articulates three primary goals: 1) reducing the number of people who become

infected with HIV, 2) increasing access to care and improving health outcomes for people living with HIV, and 3) reducing HIV-related health disparities. The strategy also calls for a more coordinated national response to the epidemic. The NHAS outlines action steps to accomplish these goals and to achieve a more coordinated response to the epidemic.

The goals and strategies described in this South Carolina 2012-2014 Ryan White HIV/AIDS SCSN and Comprehensive Plan are consistent with NHAS's goals and action steps. For example, the NHAS goal of increasing access to care and improving health outcomes for PLWHA is aligned with the goals in this plan (described above) to improve client retention in HIV medical care and support services, and to increase the proportion of HIV infected people who know their status and are linked to care when newly diagnosed. Although this South Carolina plan is primarily about HIV care, its attention to early diagnosis, linkage to care, and medications adherence contributes to reduced infectivity and, therefore, is aligned with the NHAS goal of reducing the number of people who become infected with HIV. Lastly, given that South Carolina is in a region of the country that has a growing epidemic among historically underserved minority populations, the goals and strategies in this plan support the NHAS goal of reducing HIV-related health disparities.

J. Response to anticipated state or local budget cuts

State and local funding have remained relatively stable over the past several years. No budget cuts are anticipated. However, the epidemic has continued to grow and the net effect is that the needs of PLWHA continue to outpace available resources.

IV. How Will We Monitor Progress?

A. Monitoring and Evaluating Progress

This section describes plans to monitor and evaluate progress in achieving the proposed goals and addressing the challenges identified in this plan. A set of indicators have been identified for each goal, directionality for each indicator is specified (i.e., increase), and data sources for each indicator are identified. When available, 2010 baseline data for indicators has been calculated. For some indicators, however, 2010 baseline data are not yet available and baseline will be calculated within the first year of this plan. Data for each indicator will be compiled annually and compared to baseline to identify progress during the years for which this plan is in effect.

Indicators were selected based on the following criteria: 1) alignment with the goals stated in this plan, including indicators to assess progress on EIIHA, 2) utilize existing data sources thereby minimizing the reporting burden on Ryan White-funded programs, 3) broad indicators that provide useful benchmarks for statewide progress in achieving goals, and 4) based on reliable data sources to increase accuracy of conclusions drawn from the monitoring and evaluation process. The use of multiple indicators for each goal strengthens the evaluation plan by allowing triangulation across data sources and because each indicator within a goal captures an important facet of achieving the goal.

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

Indicator	Data Source	2010 Baseline
1. Increase the proportion of clients with at least two (2) clinic visits per year, with at least one visit in each six-month period of the year.	Part B Quality Management Data	63%
2. Increase the proportion of adolescent and adult clients \geq age 13 years with HIV/ AIDS CD4 \leq 350 or viral load \geq 100,000 that are prescribed ART.	Part B Quality Management Data	TBD
3. Increase the proportion of female clients with an annual Pap test.	Part B Quality Management Data	42%
4. Increase the proportion of clients seen by an oral health provider annually (i.e., referred and with completed visit).	Part B Quality Management Data	TBD
5. Increase the proportion of clients with an annual syphilis test.	Part B Quality Management Data	64%
6. Increase the proportion of clients tested for Hepatitis C virus infection.	Part B Quality Management Data	32%

7. Increase the proportion of pregnant female clients prescribed antiretroviral therapy.	Part B Quality Management Data	TBD
8. Increase the proportion of clients with a CD4 test every six months.	Part B Quality Management Data	63%
9. Increase the proportion of clients with a viral load test every six months.	Part B Quality Management Data	63%
10. Increase the proportion of clients CD4 ≤ 200 who are receiving <i>Pneumocystis jirovecii</i> pneumonia (PCP) Prophylaxis.	Part B Quality Management Data	53%
11. Increase the proportion of clients with CD4 ≤ 50 (or age adjusted for risk as clinically indicated for children) who are prescribed MAC Prophylaxis (rifabutin, clarithromycin, azithromycin or other).	Part B Quality Management Data	53%

Goal: Increase the proportion of HIV infected people who know their status and are linked to care when newly diagnosed. (EIIHA)

Indicator	Data Source	2010 Baseline
1. Increase the proportion of those people who are tested for HIV within the health department system who test positive.	HIV Surveillance	1%
2. Maintain at 100% the proportion of people who test positive within the health department system who are notified of their results.	HIV Surveillance	100%
3. Increase the proportion of people who test positive who have a documented CD4 or Viral Load test done within three months of their initial diagnosis.	HIV Surveillance	51%

ATTACHMENT A

Epidemiological profile

An Epidemiologic Profile of HIV and AIDS in South Carolina 2011



Division of Surveillance and Technical Support
Bureau of Disease Control
South Carolina Department of Health and
Environmental Control

Executive Summary

In June 1981, the CDC published a report which documented five cases of *Pneumocystis carinii* pneumonia in otherwise healthy young men in Los Angeles, California; these would be considered the first cases of AIDS identified in the United States. That report would prompt AIDS case reports from other areas of the U.S. such as New York, San Francisco, and in 1982, South Carolina.

Since 1986, more than 24,879 people have been diagnosed with HIV infection (including AIDS) in South Carolina through December 2010. During 1985-1990 an average of 860 cases were diagnosed each year. In the subsequent three years (1991-1993), newly diagnosed HIV/AIDS cases averaged 1,306. 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 795. Many more people are infected but have not been tested.

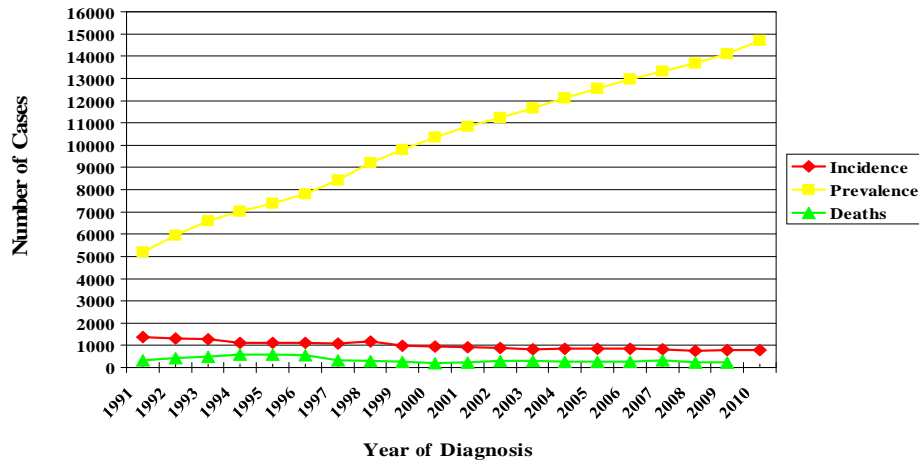
Some of the changes over time in numbers of new cases are largely the result of reporting patterns or targeted testing initiatives. The initial steep rise in the epidemic reflects the early years when less was known about the transmission of HIV and effective medical treatments did not exist. As a result, 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.

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 229 deaths in 2009, a 24 percent drop from the 302 deaths in 1999. 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 people estimated to be living with HIV/AIDS) is significantly increasing. The number of people living with HIV/AIDS at the end of each year has increased 42 percent from 2000 to 2010. 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.

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Figure 1.1 shows total incidence (the number of new cases within a specified time period), deaths and prevalence of HIV/AIDS cases in South Carolina since 1991.

Figure 1.1: South Carolina HIV/AIDS incidence, prevalence, and deaths



Note: number of cases diagnosed in S.C. only; excludes out of state cases returning to S.C.

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.

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Overview of Epidemiologic Profile

The purpose of this Epidemiologic Profile is to provide information to the S.C. HIV Planning Council on the number and characteristics of people becoming HIV infected in order to target and prioritize HIV prevention activities.

This chapter of the S.C. 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:

What are the socio-demographic characteristics of the population?

What is the impact of HIV/AIDS on the population?

Who is at risk for becoming infected with HIV?

What is the geographic distribution of HIV infection? *

What are the patterns of service utilization of people living with HIV/AIDS?

What are the characteristics of people 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.

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 people with HIV infection, as well as those who have progressed to AIDS. Unless noted, most HIV data in this profile includes people diagnosed with AIDS.

HIV Only- Includes only people 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.

Natural Breaks (Jenks) – Is a data classification method designed to determine the best arrangement of values into different classes. This is done by seeking to minimize each class's average deviation from the class mean, while maximizing each class's deviation from the means of the other groups. Natural breaks was used to determine the break point for categories on the maps in this report.

Prevalence- The number or proportion of people 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 people 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 people 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) S.C. 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. The study included interviews completed by residents 18 years of age and older.

Advantages to conducting a telephone survey compared to face-to-face interviews are as follows: 1) phone surveys cost three times less and; 2) are 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 2010 census data, 3 percent of households in South Carolina do not have telephone service available 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 DHEC Clinics

Counseling and testing data, while highly informative about people 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 people 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. People who received multiple tests during the report period are only counted once. It includes people tested in family clinics, maternity clinics, TB, STD clinics and people voluntarily requesting services or referred through partner counseling services. Approximately one third of the total of newly diagnosed and reported people with HIV infection each year are from DHEC counseling and testing sites. People 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. male-to-male sexual contact (MSM), injection drug use (IDU), heterosexual contact with a person at risk for or infected with HIV). 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.

The CDC's hierarchy of risk includes a category for the combined risks of MSM and IDU; in previous HIV/AIDS Epidemiologic Profiles, the combined risks of MSM and IDU have been grouped and reported within the single category of 'Injection Drug Use'. This report leaves the combined risks of MSM and IDU as a stand alone category. 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 percent in DHEC maternity clinics where an estimated 80-90 percent of clients receive HIV testing. This rate is very similar to the blinded childbearing women seroprevalence survey rate of 0.19 percent, which tests a representative sample of all live births in the state.

DHEC, Enhanced HIV/AIDS Reporting Surveillance System (eHARS)

All health care providers, hospitals, and laboratories in South Carolina are required to report people 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. eHARS monitors the incidence and demographic profile of HIV/AIDS; describes the modes of HIV transmission among people 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 people. It includes people 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 people. AIDS surveillance data do not represent people 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 not all HIV-infected people in the population have been 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 (people 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 people seeking or receiving HIV testing early in their infection stages, provide an opportunity to compare people 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 percent 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, people 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”.

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 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 people with these infections have no symptoms or do not recognize symptoms. Most studies of STDs are conducted in health-care settings specifically for people who do recognize symptoms; therefore, these studies usually overestimate the proportion of infected people 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 people 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 people 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 likelihood 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, 2007

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 Community Assessment Network (SCAN)

Its purpose is to provide basic reference data for a variety of users. The primary use of SCAN was 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. SCAN was also used to enumerate and characterize birth attributes.

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 system consists of national, state, and local school-based surveys. In South Carolina, the YRBS consists of questionnaires administered to middle school (6th-8th grade) and high school (9th-12th grade) students in the public school system. A two-stage sampling process is used to provide a state-wide sample at each level. In the first stage, regular public schools with any of the target grades are sampled with probability proportional to the school enrollment. In the second stage, intact classes are sampled randomly and all students in these classes are eligible to participate. The overall response rate is calculated as the percentage of sampled schools that participate multiplied by the percentage of sampled students that complete useable surveys. If this overall response rate is 60% or greater, the resulting data are weighted to be representative of the state as a whole.

There are 367 private K-12 schools in South Carolina (S.C. Statistical Abstract, 2003/04). However, none of them are included in the survey. Also, while schools are randomly selected for participation some may choose not to participate.

The survey includes questions about injury and violence, tobacco use, alcohol and other drug use, sexual risk behaviors, physical activity, and nutrition behaviors (the specific questions can vary from year to year).

This survey is conducted by S.C. Healthy Schools at the Department of Education, and relies heavily on surveillance methods and self-reports; so it depends on how well respondents understand the questions and how well they can accurately and honestly answer the question. However, the questionnaire has demonstrated good test-retest validity and the data are edited, checked and weighted. These data are representative of only public middle school students (grades 6-8) or public high school students (grades 9-12) 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.

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 people 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 linking it with every part of the country, including I-95 extending north-south from New York to Florida, I-26 from Asheville, North Carolina to Charleston, South Carolina, and I-20 extending from Florence, South Carolina to Atlanta, Georgia. Manufacturing is the state’s leading industry, followed by tourism and forestry.

Figure 1.2: Selected demographic information South Carolina and United States

	South Carolina	United States
Population (2010)	4,625,364	308,745,538
Proportion of Persons Living in Non-Metropolitan Areas	30%	20%
Median Age	37.9	37.2
Racial/Ethnic Distribution of Pop. 2010		
% White	66	72
% Black	28	13
% Hispanic	5	16
% Other	2	6
Educational Attainment 2006-2010		
% High school grad. or higher	83	85
% Bachelor’s degree or higher	24	28
Unemployment Rate, 2010	10.9%	9.4%
Median Household Income, 2006-2010	\$43,939	\$51,914

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

Populations

Based on 2010 US Census Bureau data, the total number of South Carolinians was 4,625,364. Of this total, 66 percent were Caucasian, 28 percent were African-American, 0.4 percent were Native American/Alaskan, 1.3 percent were Asian and Pacific Islander and five percent were of Hispanic origin. Fifty-one percent were female and 49 percent were male. Seventy percent of the population distribution in South Carolina is defined as metropolitan, 30 percent is non-metropolitan. The proportion of people who completed a bachelor degree or higher is 24 percent, lower than the U.S. proportion of 28 percent (Figure 1.2).

Education & Earnings

Despite the economic strides made in recent years, South Carolina remains among the states with the highest percentage of people who live below the poverty level (10th of fifty states and District of Columbia). Educational attainment is strongly correlated with poverty, and South Carolina continues to rank low in percent of people over 25 years of age who have bachelor’s degrees or higher (40th of fifty states and District of Columbia). Nearly seventeen percent (16.8 percent) of the population has less than a high school education. By race, 15.5 percent of the white population in South Carolina over the age of 25 had an educational attainment of less than a high school diploma. The same is true for 26.7 percent of the African American population as well as 25.8 percent of other races (other includes Asian, Pacific Islanders and Native Americans).

Figure 1.3: S.C. median income in 2010 by race and Hispanic origin

	Estimate	Relative to African-Americans
For Asian	\$52,406	1.9
For White	\$48,851	1.8
For American Indian/Alaska Native	\$36,750	1.3
For Other Races	\$33,636	1.2
Of Hispanic or Latino origin (of any race)	\$33,592	1.2
For African-American	\$27,643	1.0
For Native Hawaiian/Other Pacific Islander	\$25,446	0.9
S.C. Median income	\$42,018	1.5

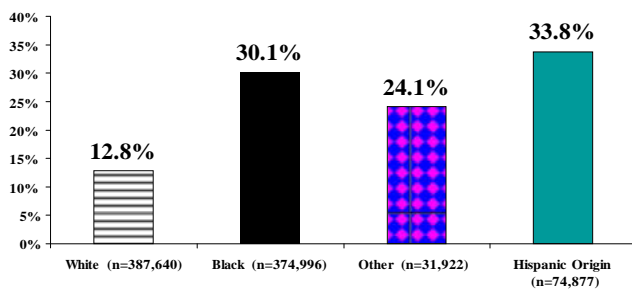
In comparison, Blacks, people of Hispanic origin, and other races have lower median incomes, averaging 25 percent below the state’s median income, while Asian and whites earned 20 percent above the state’s median income (Figure 1.3).

Sources: 2010 American Community Survey 1-Year Estimates

Poverty Level

Based on 2008 Census data, approximately 15.7 percent of South Carolinians lived below the poverty level (ranking 10th in the US); and 11.6 percent of South Carolina families lived below the poverty level.

Figure 1.4: Percent of each racial/ethnic pop. living below federal poverty level; S.C., 2010



POVERTY GAPS

Data Source: U.S. Census Bureau, American Community Survey.

An estimated thirty percent of African-American South Carolinians were below poverty in 2010, compared to 34 percent of people of Hispanic descent, 13 percent among Whites and close to 24 percent of people categorized as other, which includes Asian, Pacific Islanders and Native Americans (Figure 1.4).

Insurance/Access to Primary Care.

Almost eighteen percent (17.5 percent) of South Carolinians do not have health insurance coverage. A significantly higher proportion of people in the state do not have access to a primary care provider (40 percent) compared to the total U.S. population (20 percent) (Figure 1.5). Over 95 percent of counties are designated all or part medically underserved areas and all or part health profession shortage areas (1999).

Figure 1.5: Selected access indicators S.C. and U.S.

	South Carolina	United States
Total Pop. Uninsured, 2010	17.5%	15.5%
Below 200% Poverty Level, 2010	28.1%	27.7%
Counties Designated All/Part Medically Underserved Areas, 1999	95.7%	80.5%
Without Access to Primary Care Provider, 2007	40.0%	20.0%
Women Receiving 1st Trimester Prenatal Care, 2006	67.2%	83.2%

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

Employment

South Carolina’s average unemployment rate for 2010 was 10.9 percent, higher than the US rate of 9.4 percent. The median household income in 2010 was \$42,018 vs. the US median income of \$50,046.

Housing

According to the US Census, in 2010, 69 percent of the state’s homes were owned. The S.C. Council on Homelessness estimates 4,701 people 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.

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 2010. 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 2009, according to the CDC HIV/AIDS Surveillance Report, South Carolina ranked 9th among states, the District of Columbia, and U.S. dependent areas with an AIDS case rate of 15.6 per 100,000 population. During this same time period, South Carolina also ranked ninth among states and the District of Columbia with an AIDS case rate of 11.1 per 100,000 for female adolescent/adult AIDS cases. The epidemic is continuing to grow with an average of 66 cases of HIV infection reported each month during the past year. As of December 31, 2010, 14,708 people have been reported living with HIV infection (including AIDS) who are residents of South Carolina.

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

Gender

Figure 2.1 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 percent of South Carolina’s total population, but comprise 69 percent of people living with HIV (prevalence). HIV-only diagnosed cases during the two-year period 2009-2010 gives an estimate of more recent infections or potentially emerging populations

Figure 2.1: Disproportionate S.C. HIV impact by sex

SEX	No. (%) S.C. Total Population	No. (%) of Total Estimated Living With HIV/AIDS, 2010	No. (%) of Total HIV-Only Diagnosis, 2009-2010
Male	2,250,101 (49%)	10,200 (69%)	804 (77%)
Female	2,375,364 (51%)	4,508 (31%)	236 (23%)
Total	4,625,364	14,708 (100%)	1,040 (100%)

Source: US Census Data; SCDHEC HARS.

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Figure 2.2: S.C. HIV/AIDS case rate per 100,000 for males and females, 2000-2010

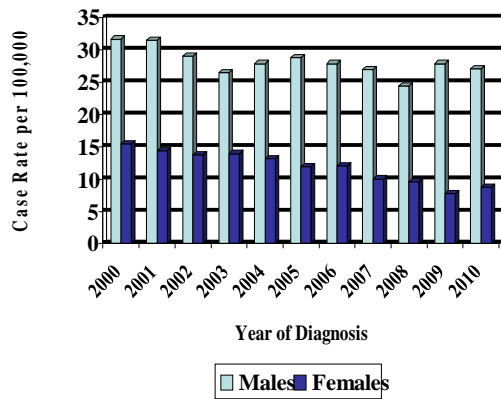


Figure 2.2 shows the rate per 100,000 population for males and females diagnosed with HIV/AIDS each year. During 2000-2010 the case rate for females appears to be slightly decreasing. For males, the rate tends to oscillate, but has a generally downward trend.

Race/Ethnicity

African-Americans are disproportionately impacted by HIV/AIDS in South Carolina. They comprise 28 percent of the state’s total population, yet 72 percent of the total people living with HIV are African-American. Three percent of total cases are Hispanic, who comprise five percent of the state’s population (Figure 2.3).

Figure 2.3: Proportion of persons living with HIV/AIDS by race/ethnicity, 2010

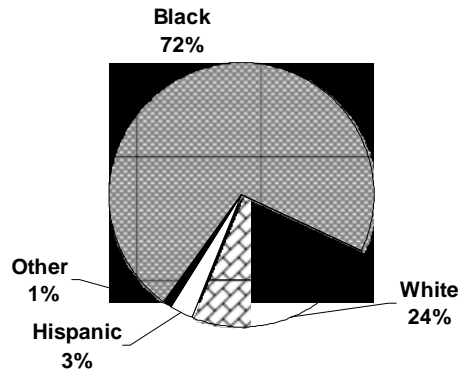


Figure 2.4: Disproportionate HIV impact by race/ethnicity/gender, S.C.

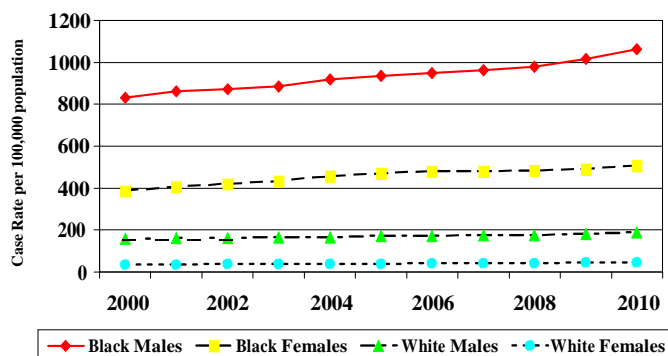
Gender & Race/Ethnicity	No. (%) SC Total Pop.	No. (%) of Total Persons Living With HIV/AIDS, 2010	No.(%) of Total HIV Only Diagnosis, 2009-2010
Black Males	607,917 (13%)	6,893 (47%)	602 (52%)
Black Females	694,071 (15%)	3,679 (25%)	275 (24%)
White Males	1,452,577 (31%)	2,854 (19%)	169 (15%)
White Females	1,516,434 (32%)	679 (5%)	39 (3%)
Hispanic Males	128,098 (3%)	355 (2%)	42 (4%)
Hisp. Females	102,903 (2%)	110 (1%)	8 (1%)

African-American men comprise 13 percent of the state’s population, yet 47 percent of the total prevalent HIV/AIDS cases in 2010. African-American women, similarly, comprise 15 percent of the population, yet 26 percent of prevalent cases. More recent infections (HIV-Only Diagnosis) during 2009-2010 reflect a slight increase among African-American men and a slight decrease among African-American women relative to the proportion of people living with HIV in 2010 (Figure 2.4).

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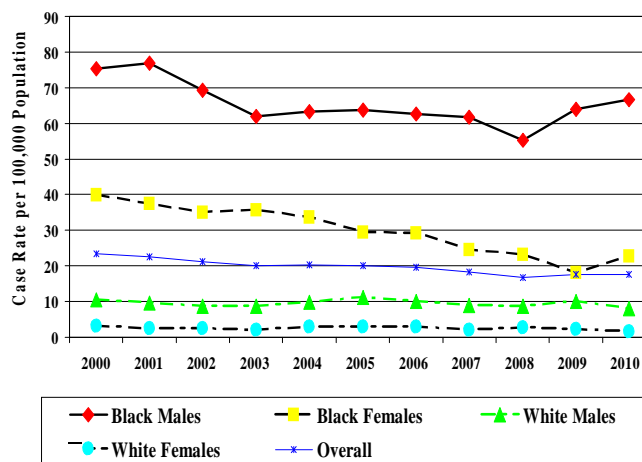
Each year the number of all people living with HIV/AIDS continues to grow. Case rates per 100,000 by race and gender show the disparate burden of HIV among African-Americans. As Figure 2.5 shows, the rate per 100,000 population in 2010 is six times higher for black males than for white males, and twelve times higher for black females compared to white females.

Figure 2.5: S.C. HIV/AIDS prevalence rates by race/gender, 2000 - 2010



While the overall number and rate of newly diagnosed people with HIV/AIDS each year has been declining, there are differences among race/gender populations. The case rate per 100,000 population among white men in South Carolina has on average remained relatively stable during the past five years (2006-2010) (Figure 2.6). The rate for African-American women in S.C. has been steadily decreasing (decreased 22 percent from 2006 to 2010); however, 2010 saw a slight increase over 2009's rate (22.7 in 2010 up from 18.1 in 2009). The rate for African-American males had been relatively stable, but recently is on the rise (increasing 6.1 percent between 2006 and 2010).

Figure 2.6: S.C. HIV/AIDS case rates by race/gender and year of diagnosis, 2000-2010



Age

When looking at age groups, people between the ages of 20 and 44 are disproportionately impacted. They make up 33 percent of the total population yet they represent about 46 percent of prevalent and 69 percent of HIV-only diagnosed cases (Figure 2.7).

Figure 2.7: Disproportionate S.C. HIV impact by age

Age Range	No. (%) SC Population	No. (%) of Total Persons Living with HIV/AIDS, 2010	No. (%) of Total HIV-Only Diagnosis, 2009-2010
< 13 Years	778,429 (17%)	44 (<1%)	1 (<1%)
13 - 19 Years	445,996 (10%)	137 (<1%)	89 (8%)
20 - 44 Years	1,525,842 (33%)	6,818 (46%)	730 (69%)
45+ Years	1,875,097 (41%)	14,708 (52%)	241 (23%)

Figure 2.8: S.C. HIV/AIDS case rate per 100,000 by age by year of diagnosis, 2000-2010

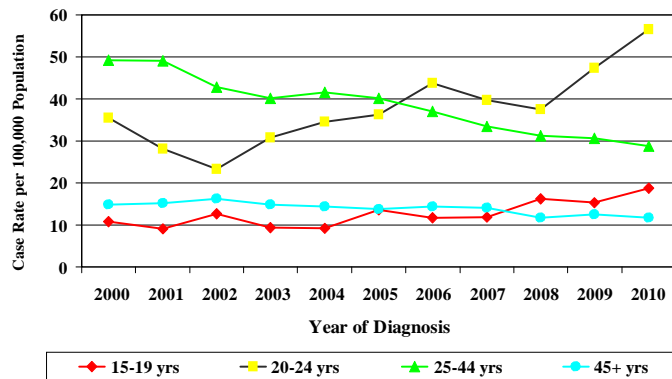
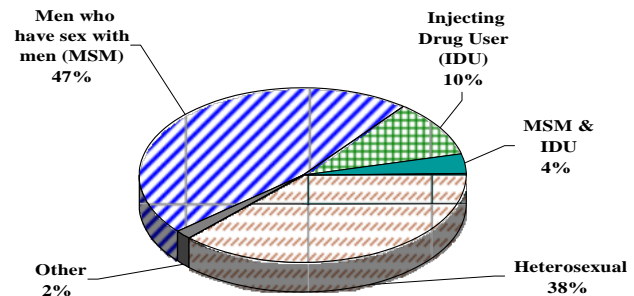


Figure 2.8 shows the HIV/AIDS case rates per 100,000 population by year of diagnosis for selected adult/adolescent age groups for the past eleven years. The rates are highest for people 20-24 years of age, followed by those 25-44 years. Recently, the rate for people 15-24 years of age is on the rise; with the rate for the 15-19 age group increasing 59 percent between 2006 and 2010, and the rate for 20-24 year olds increasing 29 percent over the same time period.

Risk Exposure

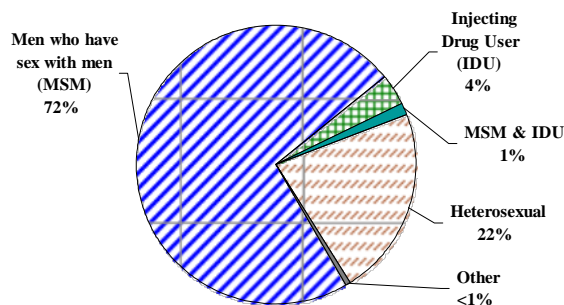
Men who have sex with men (MSM) comprise the greatest proportion of people living with HIV/AIDS at the end of 2010 with known risk factors (47 percent), followed closely by heterosexuals (38 percent). Ten percent are injecting drug users (IDU). Four percent are the combined risks of MSM and IDU. Other risks include blood transfusions, hemophilia, and perinatal transmission. Of the total estimated number of people living with HIV/AIDS in 2010, 24 percent had no risk identified (not reflected in Figure 2.9).

Figure 2.9: Proportion of persons living with HIV/AIDS by risk exposure, 2010
N=11,159



Note: Total excludes cases with no risk identified.

Figure 2.10: Proportion of HIV/AIDS cases by risk exposure, 2009-2010
N=1,040



Note: Total Excludes Cases with No Risk Identified.

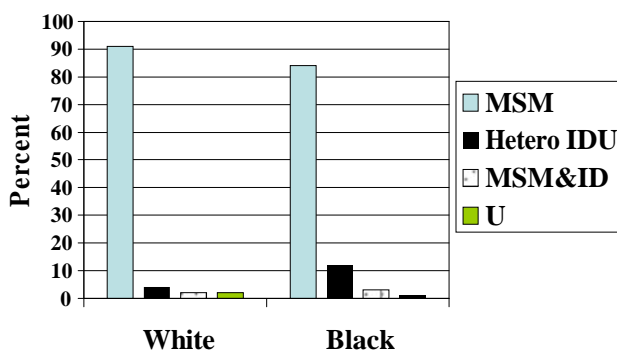
Figure 2.10 shows a slight shift in risk exposure categories among people diagnosed with HIV/AIDS during 2009-2010 with known risk exposures compared to the prevalence cases in Figure 2.9. The proportion of cases due to heterosexual transmission was 22 percent, men who have sex with men accounted for 72 percent, IDUs made up four percent, and MSM and IDU is one percent. Thirty-four percent of these cases had no risk identified (not shown in Figure 2.10).

Note: The primary reasons for risk exposure information not reported were explained in the South Carolina HIV/AIDS Surveillance System section of the introduction. 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 2009-2010 cases originally reported with no risks is relatively close to the total proportion of HIV/AIDS cases by race/gender (Figure 2.11).

Figure 2.11: Comparison of no risk identified cases with total S.C. HIV/AIDS reported cases, 2009-2010

Race/Gender (Adult/Adolescent Cases)	% Total Cases with No Risk Identified, 2009-2010 N=532	% Total HIV/AIDS Cases Reported, 2009-2010 N=1572
Black Male	46%	54%
Black Female	33%	19%
White Male	9%	18%
White Female	6%	4%
Other	7%	6%

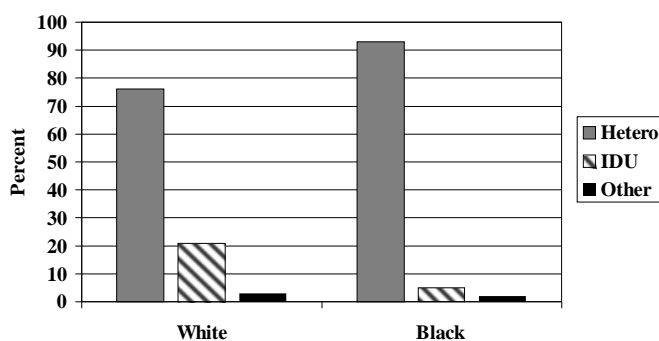
Figure 2.12: Proportion of white and black male HIV/AIDS cases by exposure category, diagnosed 2009-2010



Excludes persons with no risk reported.

During 2009-2010, 71 percent of males diagnosed with HIV/AIDS were African-American. Among white and African-American men with reported risk factors, most cases were attributed to male to male sexual contact (91 percent and 84 percent respectively). Heterosexual risk is more commonly reported among African-American males (12 percent) than among white males (four percent). Injecting drug use and the combined risk MSM & IDU are reported equally (between 1 and 3 percent) for both white and African-American men (Figure 2.12).

Figure 2.13: Proportion of white and black female HIV/AIDS cases by exposure category, diagnosed 2009-2010



Excludes persons with no risk reported.

Among women diagnosed during 2009-2010, 79 percent of cases were among African-American women. Heterosexual contact was the most common reported risk for all women (90 percent).

Figures 2.14 and 2.15 show the proportion of total HIV/AIDS cases diagnosed during four periods from 1999-2010 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 1999-2001 to 2008-2010, there was a 77 percent decrease in the proportion of injecting drug use among men and a 31 percent decrease among women. The proportion of heterosexual risk decreased 64 percent for men and increased five percent for women during the same time periods.

Figure 2.14: Proportional distribution of male HIV/AIDS cases by exposure category, diagnosed 1999-2010

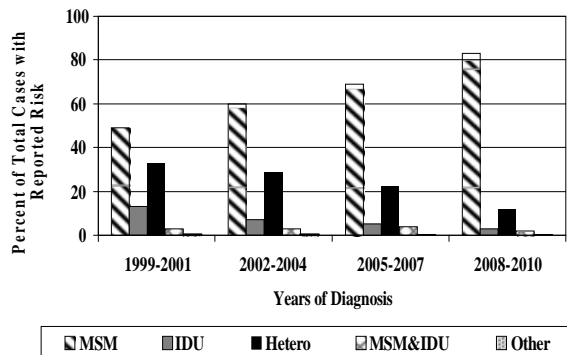
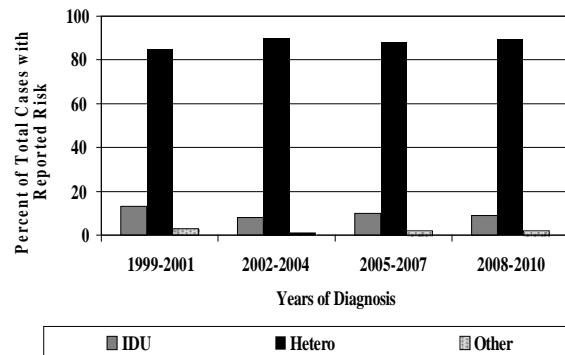


Figure 2.15: Proportional distribution of female HIV/AIDS cases, by exposure category, diagnosed 1999-2010



Residence

People living with HIV/AIDS are widespread throughout the state. Twenty-four percent of counties have prevalence rates ≥ 768 per 100,000 for African-Americans (768.4 is the state rate for African-Americans), as reflected in Figure 2.16. Annual case rates in counties of more recently diagnosed African-American people during 2008-2010 reflect essentially the same counties as highest prevalence rates (Figure 2.17). Richland County has the highest annual case rate (64.7).

Figure 2.16: S.C. HIV prevalence rates (per 100,000 population) cases currently living, 2010 African-American

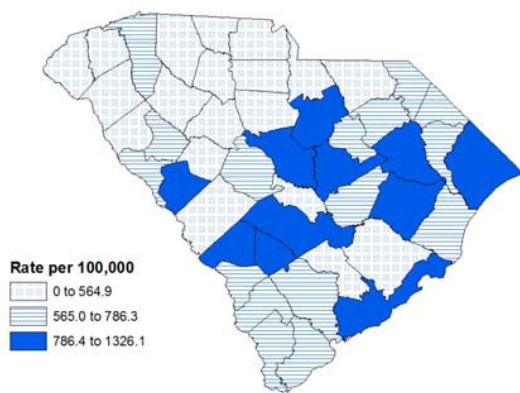
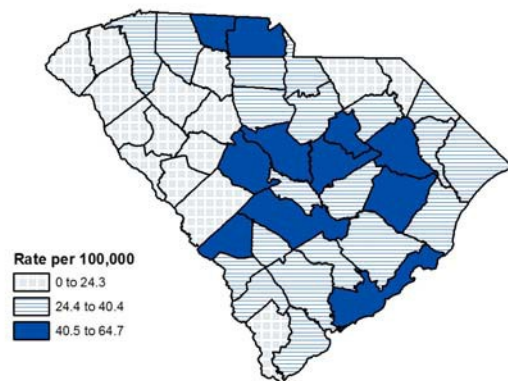


Figure 2.17: S.C. HIV/AIDS incidence rates (per 100,000 population) 2008-2010 average of cases African-American



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Counties with highest prevalence rates among white people include more urban areas of Charleston, Fairfield, Florence, Horry, and Richland; as well as the more rural counties of Colleton, Lee, McCormick, and Marlboro (Figure 2.18). Figure 2.19 shows counties with the highest rates of more recently diagnosed white people are Charleston, Fairfield, Georgetown, Horry, Richland, Sumter, and Williamsburg.

Figure 2.18: S.C. HIV prevalence rates (per 100,000 population) cases currently living, 2010 whites

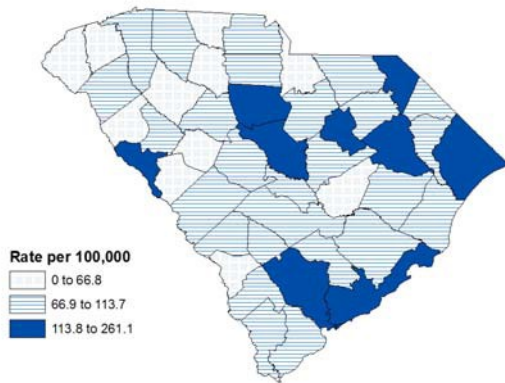
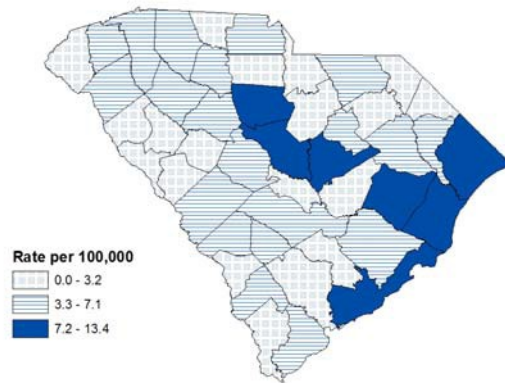


Figure 2.19: S.C. HIV/AIDS incidence rates (per 100,000 population) 2008-2010 average of cases whites



Mortality

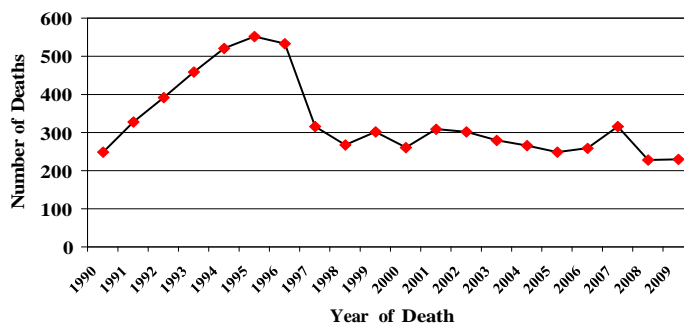
With the advent of combination therapies and the use of prophylaxis, people infected with HIV are living longer and delaying the progression of AIDS, which is the advanced stage of the disease. These medications have also led to the decrease in HIV-related deaths.

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.

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Figure 2.20 shows that the largest decline in deaths in South Carolina was in 1997, dropping to 317 from 532 the previous year. In recent years, death among people 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 2.20: Deaths among persons with AIDS in South Carolina, 1990-2009



Source – Vital Records, S.C. Residence Data.

Figure 2.21: Characteristics of persons who died of AIDS, 2009

	No.	%
Race/Sex		
Black Male	121	53
Black Female	53	23
White Male	41	18
White Female	8	3
Age Group		
<15	0	0
15-24	6	3
25-44	87	38
45+	136	59

Source – Vital Records, S.C. Residence Data.

In addition to representing 47 percent of people living with HIV/AIDS, African-American males accounted for the majority of people dying from AIDS (53 percent) in 2009. African-American females accounted for 23 percent of AIDS related deaths followed by white males (18 percent). By age group, the majority of deaths occurred among people age 45 and older (59 percent) (Figure 2.21).

Figure 2.22: Number of persons who died of AIDS by health region, 2009

Health Region	No.	%
Region 1	8	3
Region 2	32	14
Region 3	65	28
Region 4	42	18
Region 5	22	10
Region 6	23	10
Region 7	27	12
Region 8	10	4
TOTAL	229	100

Region 3 and Region 4 are the areas with the highest number of deaths from AIDS in South Carolina in 2009 (Figure 2.22). These areas are also among those that have the highest prevalence of HIV/AIDS in the state.

Who is at risk for becoming infected with HIV?

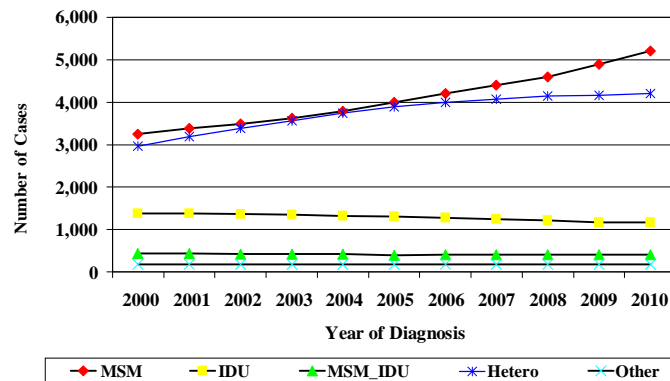
The people most likely to become infected with HIV are those who engage in high-risk behaviors with people in communities with a high number/rate of people living with HIV infection, i.e. prevalence. As mentioned previously, growing numbers of people with HIV in South Carolina are living more healthy 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 people who become newly infected with HIV and people 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 People at Highest Risk

Analysis of characteristics of people with HIV/AIDS helps identify people 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 3.1 shows the number of people 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 people, followed closely by heterosexuals. Injecting drug users (IDU), MSM and IDU, and other risks (e.g. hemophilia, blood transfusion, perinatally acquired infection) comprise fewer numbers.

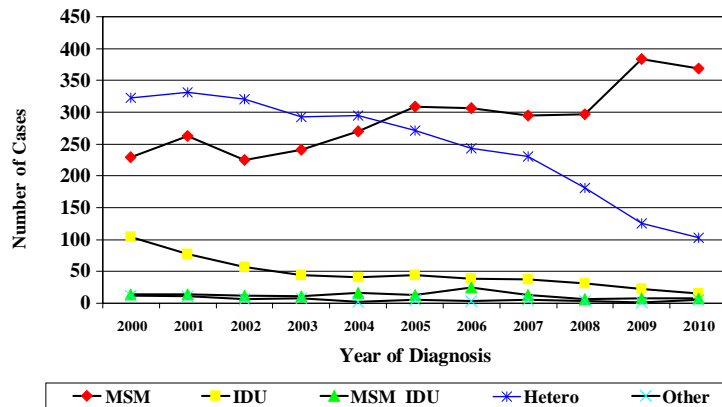
Figure 3.1: Number of persons presumed living with HIV/AIDS at end of year by risk, 2000-2010



Excludes persons with no risk reported.

As with people living with HIV, newly diagnosed HIV/AIDS cases each year indicate that beginning around 2005, more people are reporting their risk as men who have sex with men. As Figure 3.2 shows, this is a change from the earlier part of the decade when heterosexual risk was the most often reported risk. While not validated, many local experts believe 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 declined over the past decade, while the combined risks of MSM and IDU have remained relatively stable.

Figure 3.2: Number of HIV/AIDS cases by year of diagnosis and risk, 2000-2010



Excludes persons with no risk reported.

Based on data in this profile, the following primary populations have been identified as being at the highest risk of HIV/AIDS: men who have sex with men (MSM), high-risk heterosexuals, injecting drug users (IDUs), and men who have sex with men and injecting drug use. Women will be described in the heterosexual and injecting drug user section, and teenagers/young adults will be described within each population category.

Men who have Sex with Men

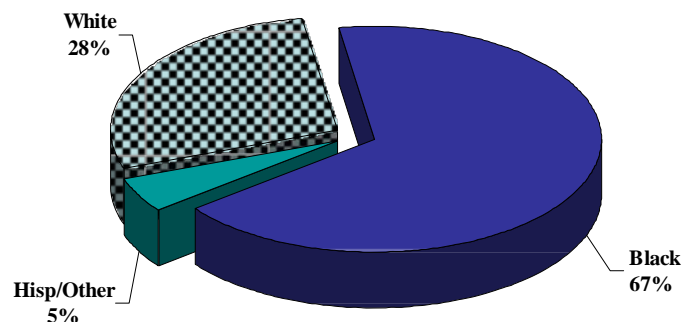
Estimates of Men Who Have Sex with Men Behavior in South Carolina

According to the U.S. Census Bureau, there are approximately 1,520,720 males in South Carolina between the ages of 15-64, which is the age range when people 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 percent to 10.1 percent, with the average at 2.7 percent. This would mean the number of MSM in South Carolina could be estimated to 41,059; although the estimated range is much broader.

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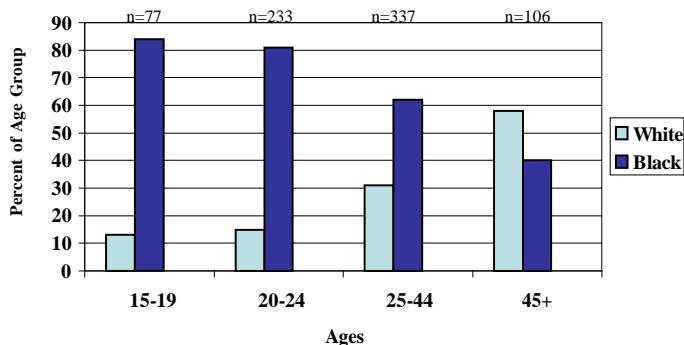
The largest proportion of people living with HIV/AIDS in South Carolina at the end of 2010 was men who have sex with men (47 percent of total prevalent adult/adolescent cases with identifiable risk). MSM accounted for a higher proportion (72 percent) of the more recently diagnosed adult/adolescent cases during 2009-2010. The number of MSM cases diagnosed each year increased 21 percent from 2006 to 2010.

Figure 3.3: Proportion of men with HIV/AIDS who have sex with men by race/ethnicity, diagnosed 2009-2010
N=753



As Figure 3.3 demonstrates, the majority of MSM cases diagnosed during 2009-2010 were African-Americans (67 percent). White men accounted for 28 percent of the new cases and five percent were Hispanic or other races.

Figure 3.4: Percent of MSM HIV/AIDS cases diagnosed 2009-2010 by age group & race
N=753

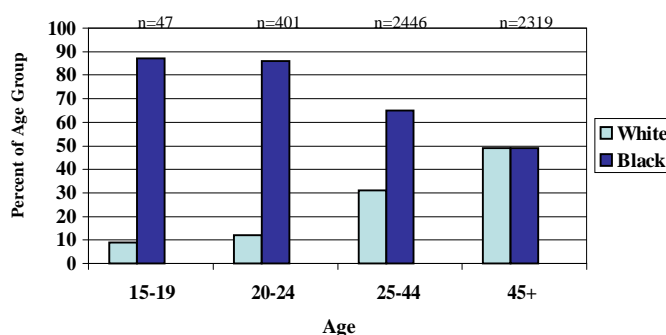


Total N includes 40 other men not included in graph.

The majority of men who have sex with men diagnosed during 2009-2010 were 25-44 years of age (45 percent); 31 percent were 20-24 years old and 14 percent 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 3.4).

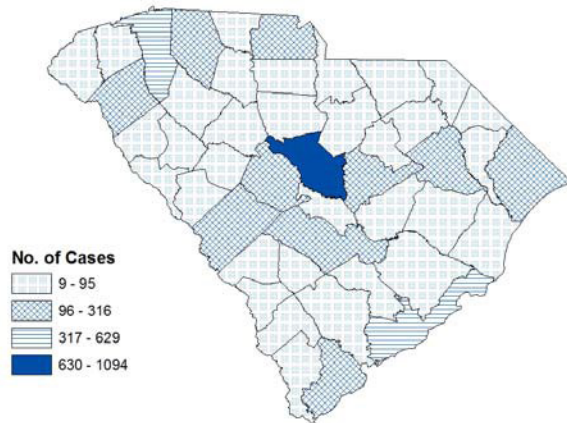
Of the men who have sex with men presumed living with HIV/AIDS in 2010, 59 percent were African-American, 37 percent were white and three percent were Hispanic/other men. As Figure 3.5 shows, for each younger age category less than 45 years, African-Americans comprise the greatest proportion of living MSM. However, among those 45 years and older, the proportion is almost equal for both white and African-American men.

Figure 3.5: Percent of MSM living with HIV/AIDS by age/race, 2010
N=5,213



Total N includes 178 other men not included in graph.

Figure 3.6: S.C. HIV/AIDS prevalence by MSM exposure category, 2010 reported cases by county



Richland County has the greatest number of men who have sex with men living with HIV/AIDS in 2010, with Greenville and Charleston having the next highest numbers. The majority of South Carolina counties had fewer than 100 men who have sex with men living with HIV/AIDS (Figure 3.6).

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 over half the proportion of both living cases (59 percent) and newly diagnosed HIV/AIDS cases (67 percent). 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 available for people 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 people 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 people with HIV/AIDS and the population of those with a non-HIV STD, most experts acknowledge that a diagnosis of an STD would suggest the individual is engaging in unsafe sexual practices. During 2010, 26,837 cases of chlamydia, 7,925 cases of gonorrhea and 160 cases of infectious syphilis were reported in South Carolina. Women with an STD, in particular, indicate high-risk heterosexual activity. 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 reported 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

People with documented high-risk heterosexual contact comprise 38 percent of the total adult/adolescent people living with HIV/AIDS at the end of 2010 and 22 percent of people more recently diagnosed during 2009-2010 (excluding people with no risk identified for both new and prevalent cases). The number of heterosexual cases diagnosed each year decreased 58 percent from 2006 to 2010.

Figure 3.7 shows that African-American men and women comprise a disproportionate 81 percent of recently diagnosed heterosexual HIV/AIDS cases. African-American women account for 50 percent of recent cases and white women account for 10 percent. Thirty-one percent are African-American men while white men account for four percent of recent cases.

Figure 3.7: Proportion of heterosexual HIV/AIDS cases by race/ethnicity, diagnosed 2009-2010
N=228

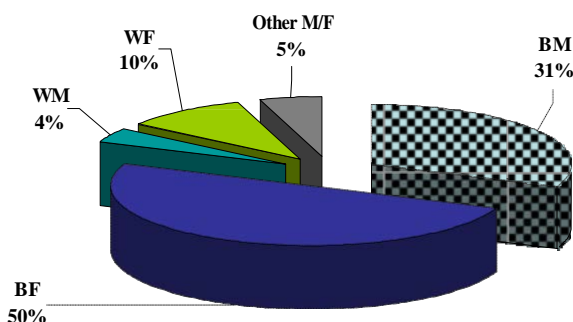


Figure 3.8: S.C. HIV/AIDS cases attributed to heterosexual transmission, by sex and year of diagnosis

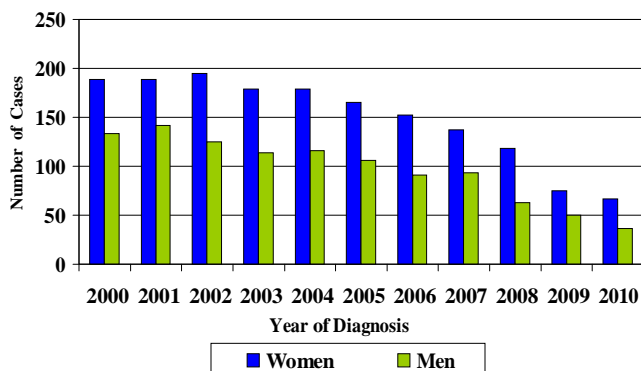
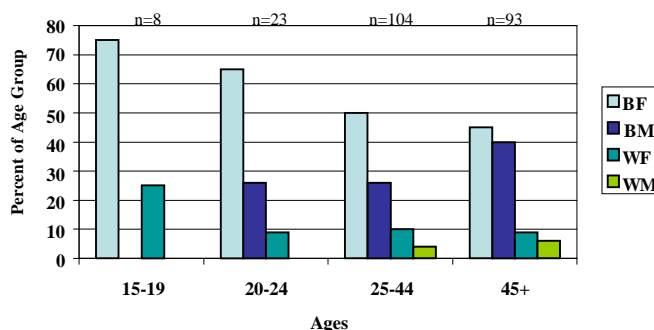


Figure 3.8 shows the number of heterosexually acquired HIV cases in women and men in South Carolina from 2000 to 2010. During most of this period, the proportion of female cases outnumbered the male cases by an average of 58 percent. The number of women reporting heterosexual risk has gradually decreased by 56 percent in the past five years from 2006 to 2010. Likewise, the number of men reporting heterosexual HIV risk has decreased by 60 percent in the same time period.

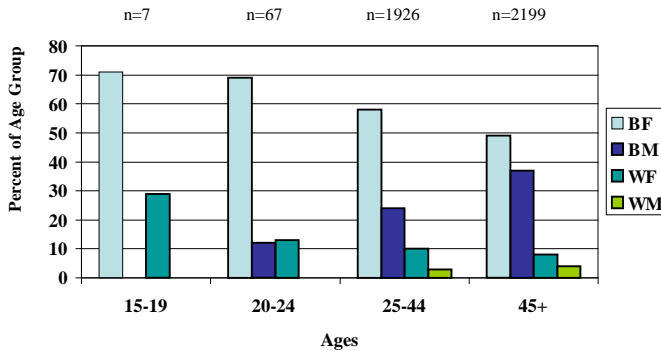
The majority of high risk heterosexuals recently diagnosed were 25-44 years of age (46 percent); 41 percent were 45 years and older and 14 percent under 25 years. With the exception of the 15-19 year old group, African-American women and men comprised the greatest proportion of cases in each age group (Figure 3.9). Among young women less than 45 years of age, over eight out of every 10 are African-American women.

Figure 3.9: Percent heterosexual S.C. HIV/AIDS cases diagnosed 2009-2010 by age/race/sex
N=228



Total N includes 11 other race/sex not included in graph.

Figure 3.10: Percent of heterosexuals living with HIV/AIDS by age group and race/sex, 2010
N=4,199



Total N includes 156 other race/sex not included in graph.

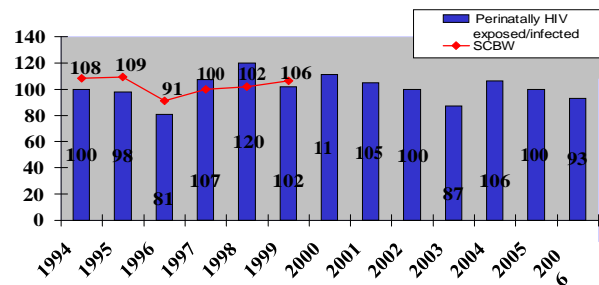
Of the high risk heterosexual people presumed living with HIV/AIDS in 2010, over half were African-American women (54 percent), 30 percent were African-American men, nine percent were white women, and three percent were white men. As Figure 3.10 shows, over eight of every 10 young women under age 25 living with HIV/AIDS were African-American; over one half of people 25-44 were African-American women. Similarly, the proportion of people living with HIV/AIDS 45 years and older is greatest for African-American women

followed closely by African-American men. As with more recently diagnosed people, white women and men account for an average of 12 percent of people 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 women of child-bearing age who have delivered a child, it provides the best overall estimate available for HIV infection among women 15-44 years of age. Figure 3.11 shows that the number of HIV infection cases among all women delivering live births has been stable, averaging nearly 100 per year. The rate, though, is nearly nine times higher among African-American women compared to white women.

Figure 3.11: Perinatally HIV exposed births by year of birth compared to S.C. survey of child bearing women



Source: provisional SC STD/HIV Surveillance Program Data.

Figure 3.12: S.C. HIV/AIDS prevalence by heterosexual contact exposure category, 2010 reported cases by county

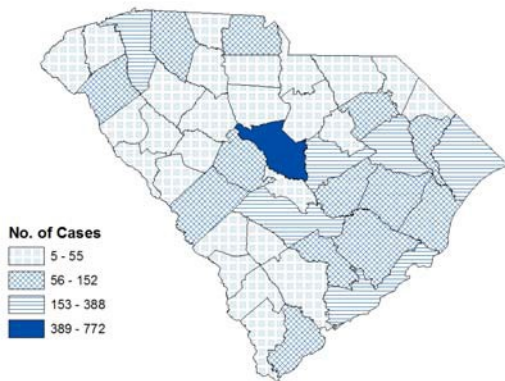
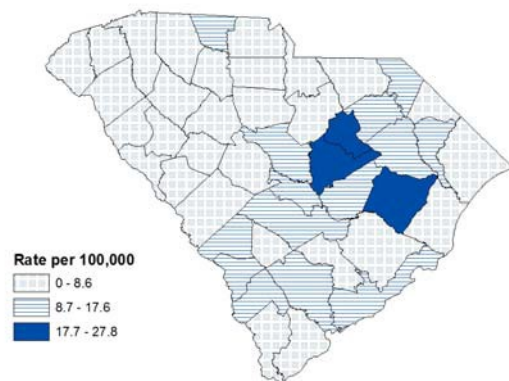


Figure 3.12 shows the counties with the highest prevalence of people living with HIV/AIDS due to heterosexual transmission. Richland has the highest number of reported cases (772), followed closely by Charleston, Florence, Greenville, Horry, Sumter, and Orangeburg. Eighty-five percent of South Carolina counties have less than 152 reported cases each.

Figure 3.13 shows the case rate for 2008-2010 among women, an indicator for more recent heterosexual risk. Lee, Sumter, and Williamsburg have the highest case rates in the state. The majority of counties have case rates below 8.7 (the state rate).

Figure 3.13: S.C. HIV/AIDS incidence rates (per 100,000 population) 2008-2010 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 people 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 people 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

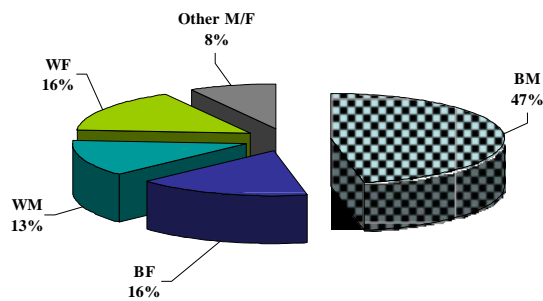
According to the S.C. Department of Alcohol and Other Drug Abuse Services (DAODAS), there are an estimated 4,804 people in South Carolina who are injecting drug users in need of treatment services.

Characteristics of Injecting Drug Users

Injecting drug users (IDUs) account for 10 percent of the people presumed living with HIV/AIDS in 2010 and four percent of people more recently diagnosed with HIV/AIDS during 2009-2010. The number of IDU cases diagnosed each year decreased 62 percent from 2006 to 2010.

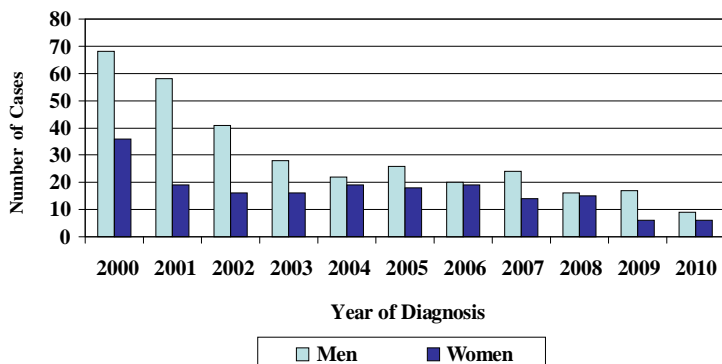
Figure 3.14 shows that 47 percent of recently diagnosed injecting drug use cases are African-American men; African-American and white women each accounted for 16 percent of cases. The least proportion is among white men (13 percent).

Figure 3.14: Proportion of injecting drug users diagnosed with HIV/AIDS 2009-2010 by race/sex N=38



Historically, men have been overwhelmingly impacted by HIV transmitted by injecting drug use, averaging three cases to every one case reported among women each year. Men show a decrease in number of diagnosed IDU cases since 2000, bringing the case numbers for men and women closer together (Figure 3.15).

Figure 3.15: Number of HIV/AIDS cases due to injecting drug use by sex and year of diagnosis, 2000-2010



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Figure 3.16 shows that 52 percent of IDU cases diagnosed in 2009-2010 are from 15-44 years of age; 47 percent of cases are age 45 years and older.

Note: three age groups are used because of small numbers.

Figure 3.16: Percent of injecting drug users diagnosed with HIV/AIDS 2009-2010 by age group N=38

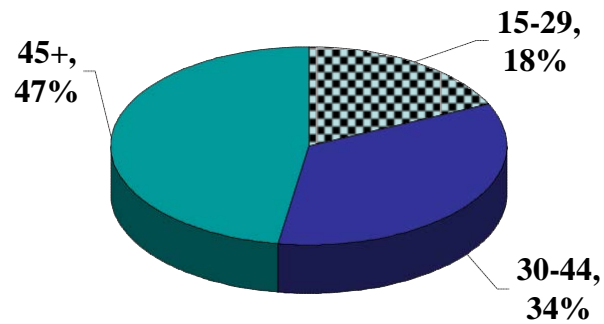
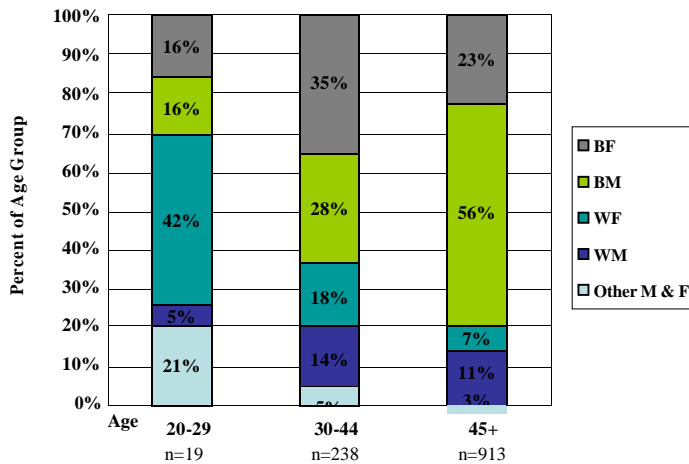


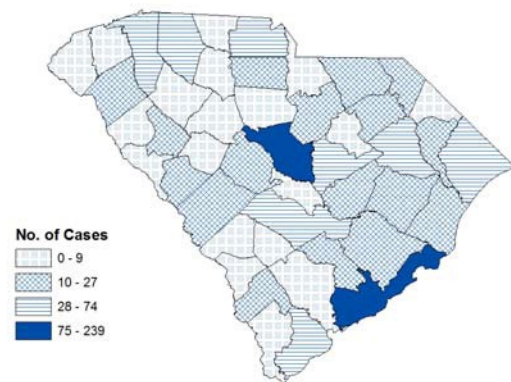
Figure 3.17: Percent of IDU persons presumed living with HIV/AIDS by race/sex and age group, 2010 N=1,170



Of people living with HIV/AIDS due to injecting drug use, most (98 percent) are 30 years of age and older; seventy-eight percent are age 45 and over. Within the 20-29 age group, white females account for the greatest proportion (42 percent). African-Americans account for the greatest proportion of cases over the age of 30, with African-American men accounting for 56 percent of those 45 and older (Figure 3.17).

Figure 3.18 indicates the counties with the highest number of people living with HIV with injecting drug use risk (Richland and Charleston). As with other risks, the more urban counties have the greatest numbers.

Figure 3.18: S.C. HIV/AIDS prevalence by injecting drug users exposure category, 2010 reported cases by county



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 people older than 30 years and those who are predominately in more urban counties including Florence, Greenville, Horry, Spartanburg, Sumter, and York,.

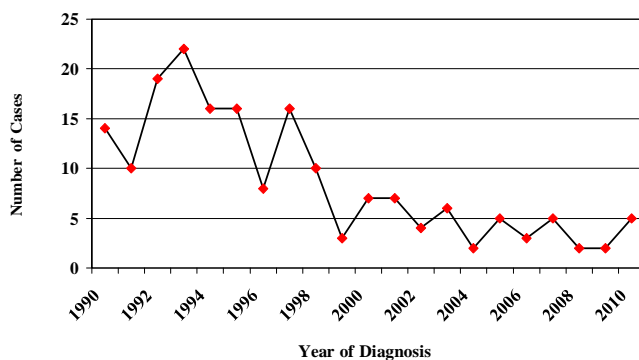
Other Populations at Risk

Other populations at varying risk for HIV are described below and include infants and children, people 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 2010, there were 221 HIV infection cases diagnosed among children less than 13 years of age. This represents one percent of the total reported AIDS and HIV infection cases. The majority of the children with HIV are African-American.

Figure 3.19: Number of children <13 years old diagnosed with HIV/AIDS in South Carolina, 1990-2010



There has been significant progress during the past twenty years in reducing the number of infants with perinatal acquired HIV infection. Figure 3.19 shows the decline in the number of infants diagnosed; from a high of 22 cases in 1993 to 2 cases in 2009. Over the past ten years, the numbers of infants with perinatal acquired HIV infection have fluctuated between 2 and 5 per year.

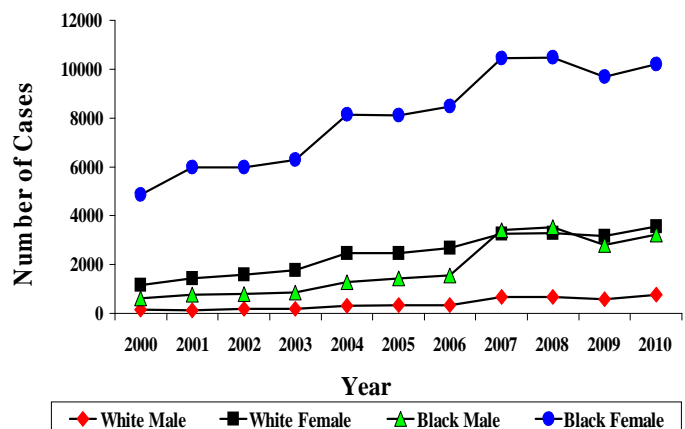
People with Sexually Transmitted Diseases (STDs)

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

Figure 3.20 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. In 2010, there were 26,837 cases of chlamydia diagnosed in South Carolina. Among those cases, 38 percent were African-American women and 13 percent were white women. Thirty-four percent of chlamydia cases have 'Unknown' or 'Other' for race and/or sex; this is attributed to the fact that these conditions are primarily reported by labs, and frequently do not indicate a race.

Figure 3.20: South Carolina reported Chlamydia cases by year of diagnosis, 2000-2010



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Figure 3.21: Proportion of 2010 reported Chlamydia cases by year of diagnosis by age group

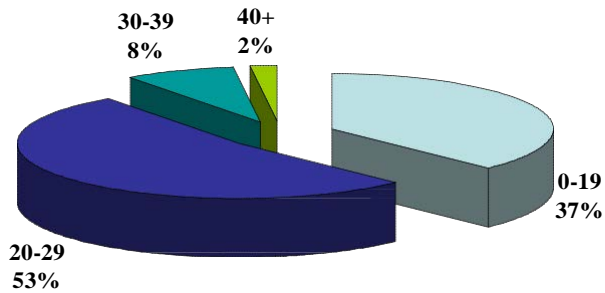


Figure 3.21 shows that in 2010 young adults 20-29 make up the highest proportion of chlamydia (53 percent) in the state. Those age 19 and under make up the second highest proportion of chlamydia (37 percent).

Excludes persons with no reported age.

Gonorrhea

In 2010, 7,925 gonorrhea cases were diagnosed. African-American men and women account for 61 percent of reported cases in 2010. As with chlamydia, thirty percent of reported cases have ‘Unknown’ or ‘Other’ for race and/or sex. Figure 3.22 shows trends among reported race/gender by year.

Figure 3.22: South Carolina reported gonorrhea cases by year of diagnosis, 2000-2010

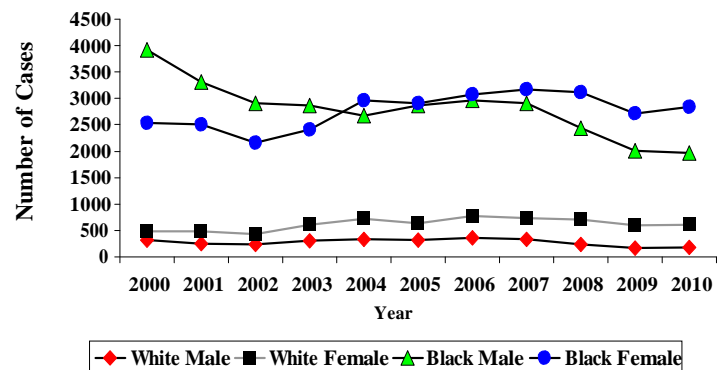
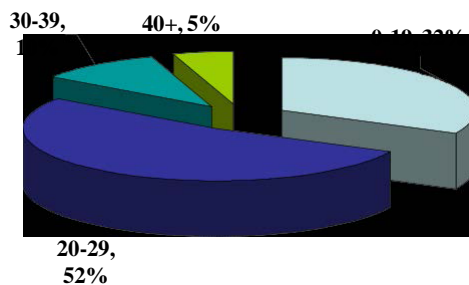


Figure 3.23: Proportion of 2010 reported Gonorrhea cases by year of diagnosis by age group



Like chlamydia, gonorrhea cases most affect young adults under the age of 30 (85 percent of total), with those age 19 and under comprising 32 percent of total, and those age 20-29 comprising 52 percent (Figure 3.23).

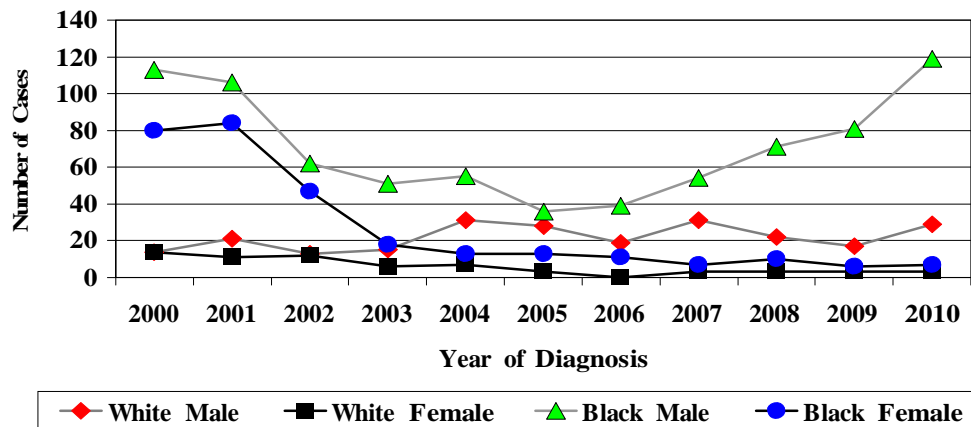
Excludes persons with no reported age.

Infectious Syphilis

In 2010, 160 cases of infectious syphilis were diagnosed; this is up from the 108 cases reported in 2009 and is a 129 percent increase from the number of cases reported in 2006.

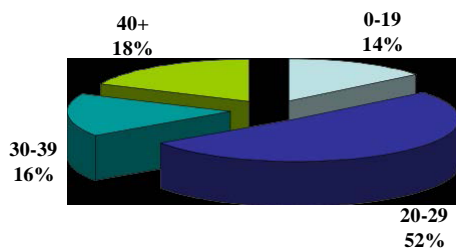
As Figure 3.24 shows, men represent the majority of cases (94 percent). African-American men specifically, are most impacted, accounting for 75 percent of total cases, while white men account for 18 percent of total cases. The number of infectious syphilis cases among white men has increased 53 percent between 2006 and 2010. Over the same time period, the number of infectious syphilis cases for African-American men has increased 205 percent. The number of infectious syphilis cases among both African-American females and white females has dropped significantly between 2000 and 2010. African-American females have seen a 91 percent decrease in the number of cases and white females have seen a 79 percent decrease.

Figure 3.24: South Carolina reported Infectious Syphilis cases by year of diagnosis, 2000-2010



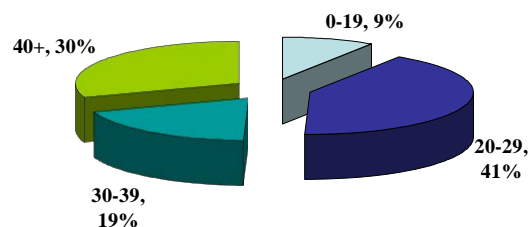
In previous years, the proportion of those impacted by infectious syphilis has been evenly divided among those under the age of 30 and those ages 30 and over (51 percent and 49 percent respectively in 2009). However, 2010 shows a shift in the age range for those most impacted by infectious syphilis. In 2010, those age 29 and under comprised the highest proportion impacted by infectious syphilis (66 percent). Compare Figure 3.25a (2010 infectious syphilis cases) to Figure 3.25b (2009 infectious syphilis cases).

Figure 3.25a: Proportion of 2010 reported Infectious Syphilis cases by year of diagnosis by age group



Excludes persons with no reported age.

Figure 3.25b: Proportion of 2009 reported Infectious Syphilis cases by year of diagnosis by age group



Excludes persons with no reported age.

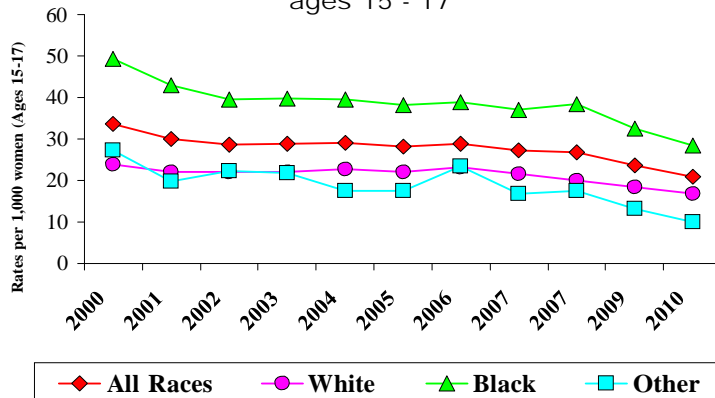
Teenage Pregnancy

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 2.6 in 2000 to 1.1 per 1,000 in 2010, respectively.

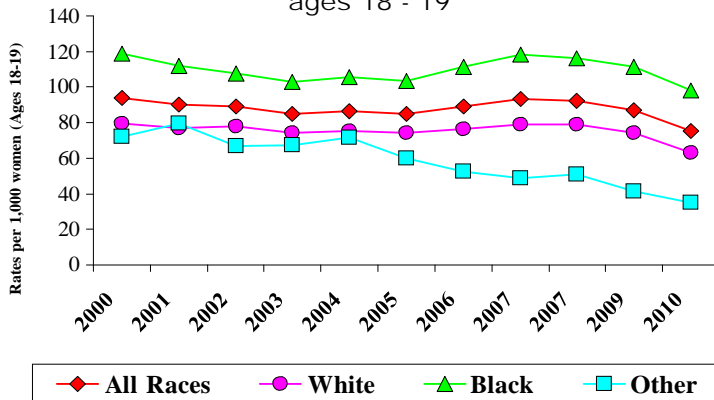
Teenage live births among 15-17 year old South Carolinians have decreased from a rate of 33.6 per 1,000 live births in 2000 to 20.9 in 2010; a 38 percent decline (Figure 3.26). This success is also seen when viewing teen birth rates by racial/ethnic subgroups. The rate for White 15-17 year old teens was 23.9 in 2000 and 16.8 in 2010, representing a 30 percent decline. The rate for African-American 15-17 year old teens declined 42 percent in the same time period from 2000 to 2010. The rate for Others is the only exception to a consistent declining trend where the rate was 27.2 in 2000, dropped to 17.4 in 2004, climbed to 23.3 in 2006 and then down again to 10.1 in 2010, representing a 63 percent decrease in the rate over the 2000 to 2010 period. This fluctuation may be due to small numbers and the trend for this subgroup requires further observation.

Figure 3.26: South Carolina teenage live birth rates, ages 15 - 17



Source – SCDHEC, Vital Records, SC Residence Data

Figure 3.27: South Carolina teenage live birth rates, ages 18 - 19



Source – SCDHEC, Vital Records, SC Residence Data

Figure 3.27 shows the teen birth 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 between 2000 and 2010 than all races, but also as seen in the other age groups their rates have decreased from 118.9 to 98.1, 2000 and 2010, respectively.

People 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 people tested voluntarily in local health departments. This data reflects number of individuals tested, not the number of tests. In 2010, African-Americans comprised 66 percent of the total people tested, but 79 percent of the total positive. Men accounted for 37 percent of people tested but 77 percent of total positive. People 20-39 years of age represented the highest proportion tested (74 percent) and the highest proportion total positive people (66 percent). People over the age of 40 comprised 14 percent of the total people tested, but 29 percent of the total positive.

Public Health regions that accounted for the greatest proportion of people tested who were positive include those with the same urban counties of highest prevalence:

Region 3, (includes Richland County) - 24.1 percent of total positives tested; Region 4 (includes Sumter and Florence counties) – 18.1 percent of total positives; Region 7, (includes Charleston County) – 15.3 percent of total positives; Region 2, (includes Greenville/Spartanburg County) – 12.7 percent of total positives; Region 5, (includes Orangeburg County) – 10.5 percent of total positives; Region 1 (includes Anderson County) – 6.2 percent of total positives; Region 8 (includes Beaufort County) – 4.0 percent of total positives; and Region 6 (includes Horry County) – 4.0 percent of total positives.

Other Behavioral/Risk Data

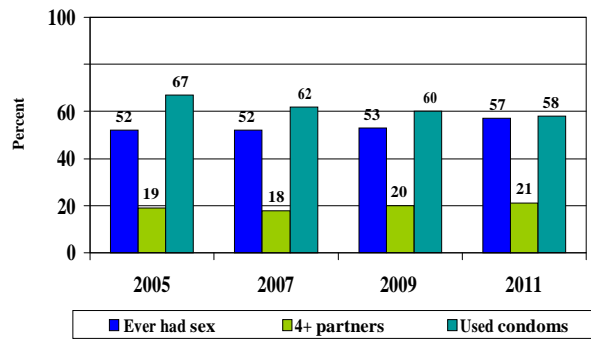
Behavioral Risk Factor Surveillance System (BRFSS)

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 in 1984. Several core questions address knowledge, attitudes, beliefs, and behaviors regarding sexually transmitted diseases, particularly AIDS.

The HIV/AIDS questions for the 2010 survey focused on respondents HIV/AIDS testing history. Results show that when asked about ever being tested for HIV themselves, only 40.8 percent of respondents indicated ever being tested. African-Americans were more likely (59.9%) to have been tested than Caucasians (33.7%). Hispanics are less likely to have been tested, with only 25.1% reporting having ever been tested. Men are only slightly less likely to have been tested than women (39.5% versus 42.0%). Of those reporting having ever been tested, 14.9% reported being tested in 2010 and 59.5% reported being tested between 2005 and 2009.

Youth Risk Behavior Survey (YRBS) The YRBS has been conducted in SC high schools every other year since 1991 and in middle schools since 2005. The survey is part of a national effort to monitor priority health risk behaviors that contribute to the leading causes of death, disability, and social problems among youth and adults in the United States. Figure 3.28 shows that since 2005, the proportion of high school students who have been sexually active, and who report having had four or more lifetime partners, has remained about the same. At the same time, however, the proportion of sexually active students (had intercourse in past 3 months) reporting condom use at last sexual intercourse decreased, showing in an increased risk of exposure to HIV.

Figure 3.28: Proportion of high school students indicating sexual risks, 2005-2011



Source – SC Dept. of Education & CDC

Substance Use

A 1999-2000 household telephone survey of 10,324 adults ≥ 18 yrs was conducted by the S.C. Department of Alcohol and Other Drug Use Services (DAODAS) to assess substance use practices. Results indicated that 37 percent of people used alcohol during past 30 days, three percent used marijuana, and less than 0.5 percent used cocaine and hallucinogens during past month. General patterns of substance use by people 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 (59 percent) and newly diagnosed HIV/AIDS cases (67 percent) among those 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. In particular, interventions also need to be available for people 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 both men and women ages 25 years and up, who account for 86 percent of more recently diagnosed cases and 98 percent of living cases (all races). Efforts also need to target African-American women, who account for nearly half of both living heterosexual cases and more recently diagnosed cases (54 percent and 50 percent respectively). Prevention efforts for African-American men and women should also be tailored to reach those ages 25 to 44, as well as those ages 45 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 (47 percent) of recently diagnosed IDU cases, followed by white men. Efforts should target people 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.

What are the patterns of service utilization of HIV-infected people?

Ryan White Part B

In 1990, Congress enacted the Ryan White CARE Act to provide funding for states, territories and EMAs to offer medical care and support services for people 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 and finally in 2009 with the Ryan White HIV/AIDS Treatment Extension Act.

Ryan White 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 4.1: Characteristics of Ryan White Part B clients compared to S.C. persons living with HIV/AIDS in 2010

	Ryan White Part B Clients, N=9,208	Persons Living with HIV/AIDS, N=14,708
Race/Ethnicity		
White, not-Hispanic	21%	24%
Black, not-Hispanic	74%	72%
Hispanic	3%	3%
Other	2%	<1%
Sex		
Male	65%	69%
Female	35%	31%
Transgender	<1%	---
Age Group		
<13	<1%	<1%
13-24	6%	5%
25-44	43%	42%
45+	51%	52%

During 2010, 9,208 clients received services through the Ryan White Part B funds. Figure 4.1 presents the distribution of Part B clients by race/ethnicity, sex and age as well as for those people living with HIV/AIDS in South Carolina through December 2010. 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) Medical Case Management.

Figure 4.2 shows a break down of Ryan White Part B clients who received six 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 9,208 clients who received services, the majority of clients obtained medical case management services (n=6,780) followed by medical care (n=5,093), mental health services (n=950), dental care (n=557) and substance abuse services (n=405).

Figure 4.2: South Carolina Ryan White Part B Service Utilization by Service Type, 2010

	No. of clients receiving service	Avg. no. of visits per client
Medical Care	5,093	4.5
Medication (ADAP)	3,064	N/A
Oral/Dental Care	557	2.0
Mental Health	950	3.0
Substance Abuse	405	3.8
Case Management	6,780	9.2

Of those services utilized most by clients (visits/clients), medical case management services were among the highest (9.2 visits per clients), followed by medical care (4.5 visits per client), substance abuse (3.8 visits per client), mental health services (3.0 visits per client), and dental care services (2.0 visits per client).

Additional services obtained by clients in 2010 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 (S.C. 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. The S.C. ADAP dispenses medications via mail order through a contracted pharmacy and operates an insurance assistance program located at the Department of Health and Environmental Control. Currently about 80 drugs are on the approved formulary. The S.C. ADAP has an advisory body of infectious disease (ID) physicians and program staff that meets annually to review the S.C. ADAP formulary and make recommendations for program improvements.

In the past, once an antiretroviral medication received FDA approval, it was automatically added to the S.C. ADAP formulary. With the new development of extremely expensive therapies, such drugs are added as appropriate after consultation with the S.C. ADAP Medical Advisory Committee. Fuzeon, Selzentry, abacavir containing medications, 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 for the ADAP direct dispensing program is 300 percent of the Federal Poverty Level (FPL). Eligibility for the ADAP insurance assistance program is 550 percent of FPL. Expenditures are carefully monitored and projections are reviewed monthly.

Figure 4.3 lists the characteristics of clients enrolled in the ADAP program during 2010. Clients served through ADAP have a similar distribution to that of people living with HIV/AIDS in South Carolina. The majority of the clients are non-Hispanic African-Americans/Black (69 percent), male (70 percent) and in the 25-44 year age group.

Figure 4.3: 2010 ADAP Patient Profile Compared to Persons Living with HIV/AIDS

Profile	2010 S.C. HIV/AIDS Prevalence: 14,708	Direct Dispensing Total Served: 3,062	Insurance Program Total Served: 976
Male	69%	70%	67%
Female	31%	29%	33%
African American	72%	69%	66%
White	24%	24%	30%
Hispanic/Latino	3%	5%	1%

In Care vs. Not In Care

Number and characteristics of people who know they are HIV+ but who are not receiving HIV primary medical care?

To analyze the number of people living with HIV/AIDS in South Carolina not “in care,” eHARS (HIV/AIDS Reporting System) data was used to review all people diagnosed through December 2010. eHARS in South Carolina is a laboratory based reporting system with all CD4 and viral load tests being reportable as of January 1, 2004. People who were deceased as of December 31, 2009 were excluded from the analysis. Only current S.C. 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, 2010 through December 31, 2010. People 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.

EPIDEMIOLOGIC PROFILE

Figure 5.1: 2010 S.C. HIV/AIDS cases estimated not in care vs. in care (N=16,378)

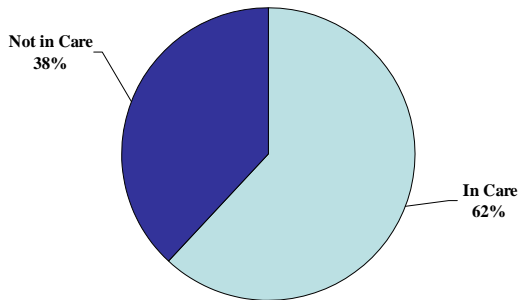


Figure 5.1 shows that of the 16,378 patients diagnosed through December 2010, 38 percent (6,288) patients did not receive a CD4 or viral load test report within the specified time period, therefore are reported as “not in care”. Sixty-two percent are defined as “in care”.

Of the 6,288 clients not in care, 59 percent are living with HIV-only and 41 percent are living with AIDS (Figure 5.2).

Figure 5.2: S.C. HIV/AIDS cases estimated not in care diagnosed through 2010 HIV-only vs. AIDS (N=6,288)

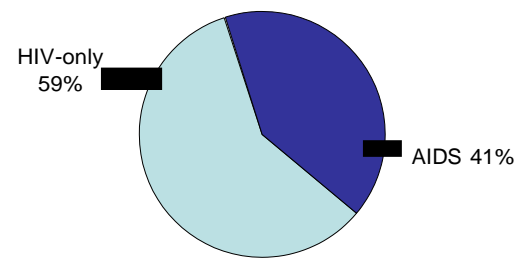
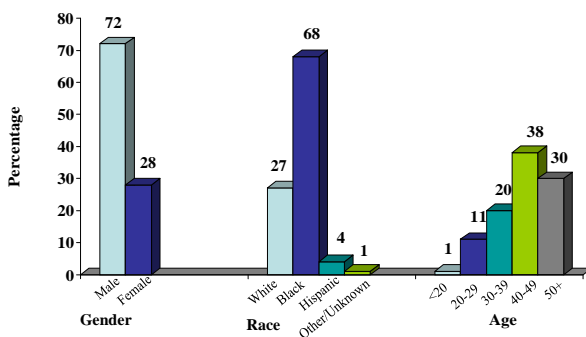


Figure 5.3: S.C. HIV/AIDS cases diagnosed through 2010. Comparison within select demographics of individuals Not In Care

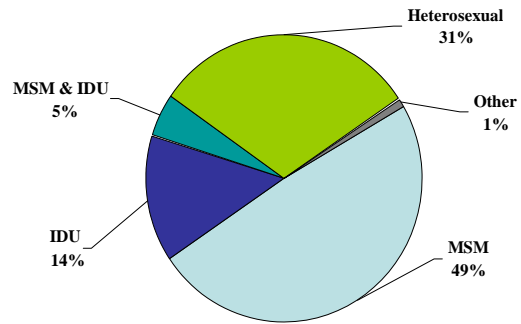


A comparison of individuals Not In Care by gender, shows men account for the largest percentage (72 percent); when compared by race/ethnicity, the majority (68 percent) are African-American; when compared by age groups, sixty-nine percent are between the ages of 20 and 49 (20-29 eleven percent, 30-39 twenty percent, and 40-49 thirty-eight percent). (Figure 5.3)

EPIDEMIOLOGIC PROFILE

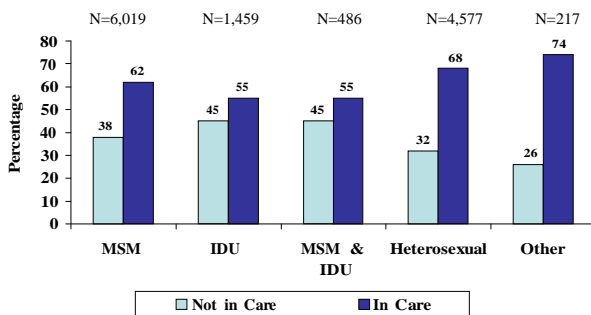
An analysis by mode of exposure of people living with HIV/AIDS indicates most people not in care are MSM (49 percent) and heterosexuals (31 percent) followed by IDUs (14 percent) (Figure 5.4).

Figure 5.4: S.C. HIV/AIDS Cases NOT in care diagnosed through 2010 by mode of exposure



Excludes cases with no risk identified, N = 4,682.

Figure 5.5: S.C. HIV/AIDS cases diagnosed through 2010 comparison within mode of exposure in care vs. not in care



*excludes cases with no risk identified, N = 12,758

Figure 5.5 goes further to compare those in care versus those not in care within each risk category. Among all MSM living with HIV/AIDS, more people are in care (62 percent) than not in care (38 percent). Focusing on those people whose mode of exposure was injecting drug use, the number of those in care (55 percent) is almost equal to the number out of care (45 percent). Likewise, among heterosexuals with HIV/AIDS, 68 percent are in care compared to 32 percent 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 people not in care from urban areas (78 percent) versus rural areas (22 percent) (Figures 5.6 and 5.7).

Figure 5.6: S.C. HIV/AIDS cases estimated not in care diagnosed through 2010 by location (N=6,069)

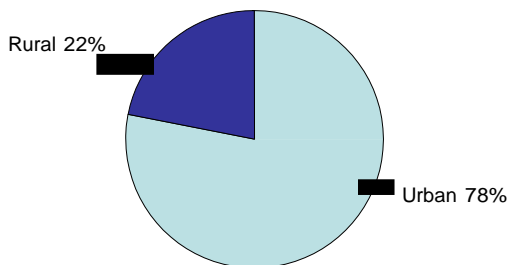
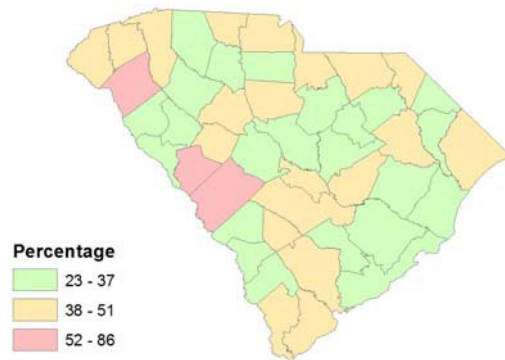


Figure 5.7: S.C. HIV/AIDS Cases NOT In Care Diagnosed through 2010 by County





Division of Surveillance and Technical Support
1751 Calhoun Street Columbia, South
Carolina 29201
www.scdhec.gov/health/disease/stdhiv

ATTACHMENT B

Unmet Need Data

South Carolina Estimate of Unmet Need December 31, 2010

Column 1	Column 2	Column 3	Column 4	Column 5
Population Sizes		Value		Data Source(s)
Row A.	Number of persons living with AIDS (PLWA), for the period of cumulative through 12/31/2010	9,130		HARS
Row B.	Number of persons living with HIV (PLWH)/non-AIDS/aware, for the period of cumulative through 12/31/2010	7,248		HARS
Care Patterns		Value		Data Source(s)
Row C.	Number of PLWA who received the specified HIV primary medical care services during the 12-month period 1/1/2010-12/31/2010	6,565		HARS
Row D.	Number of PLWH/non-AIDS/aware who received the specified HIV primary medical care services during the 12-month period 1/1/2010-12/31/2010	3,525		HARS
Calculated Results		Value	Percent	Calculation
Row E.	Number of PLWA who did not receive primary medical services	2,565	28%	Unmet Need= $2565/9130*100=28\%$
Row F.	Number of PLWH/non-AIDS/aware who did not receive primary medical services	3,723	51%	Unmet Need= $3723/7248*100=51\%$
Row G.	Total HIV+/aware not receiving specified primary medical care services (quantified estimate of unmet need)	6,288	38%	Unmet Need= $6288/(9130+7248)*100=38\%$

NOTE: The data in "Percent" cells of Column 4 Rows E, F, and G is calculated with a formula. Once grantee fills "Value" data in Column 3 Rows A, B, C, and D, the "error" will correct itself.

NOTE: South Carolina completed the HARS/Social Security Death Registry linkage. Cases that were deceased by December 31, 2010 were not included in this analysis.

ATTACHMENT C

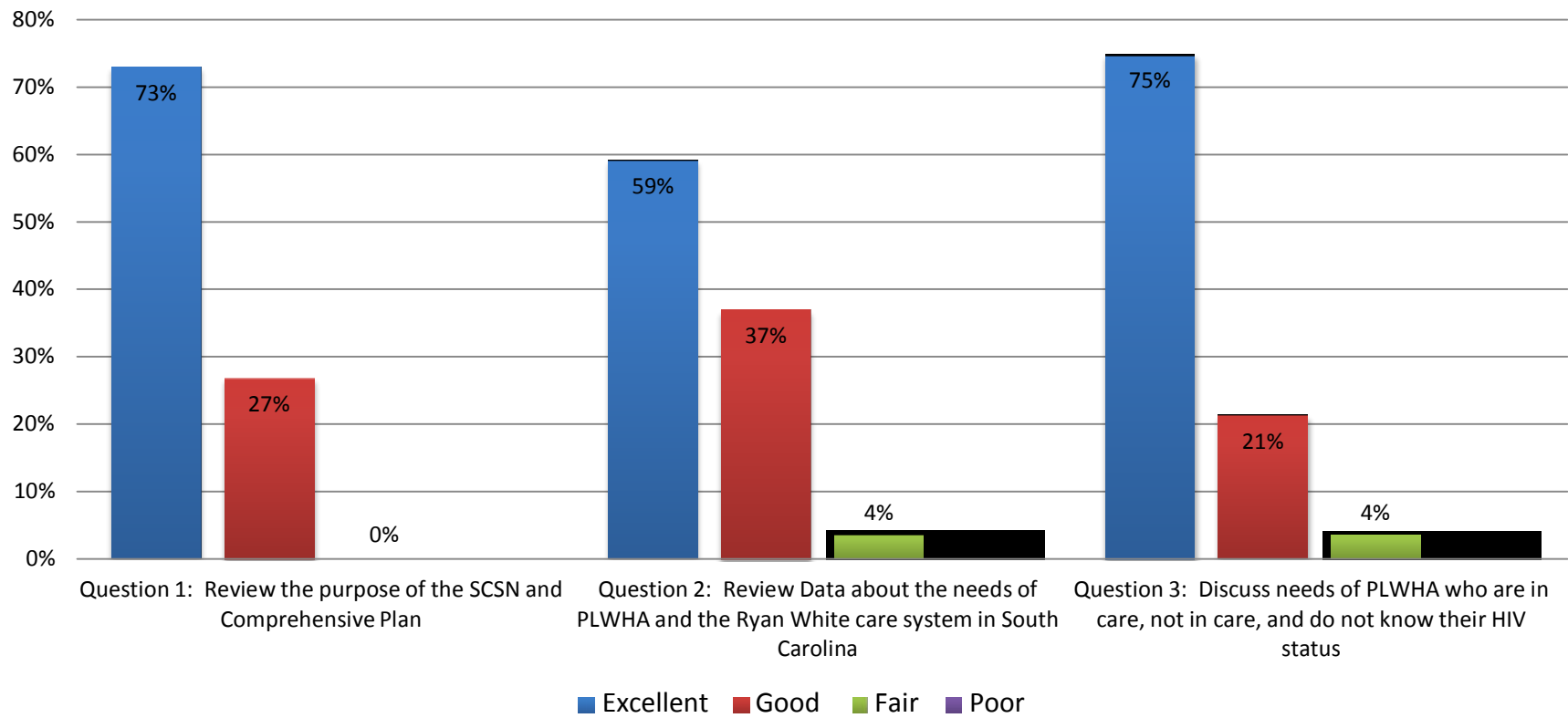
SCSN Meeting Evaluation

SCSN Meeting Evaluation

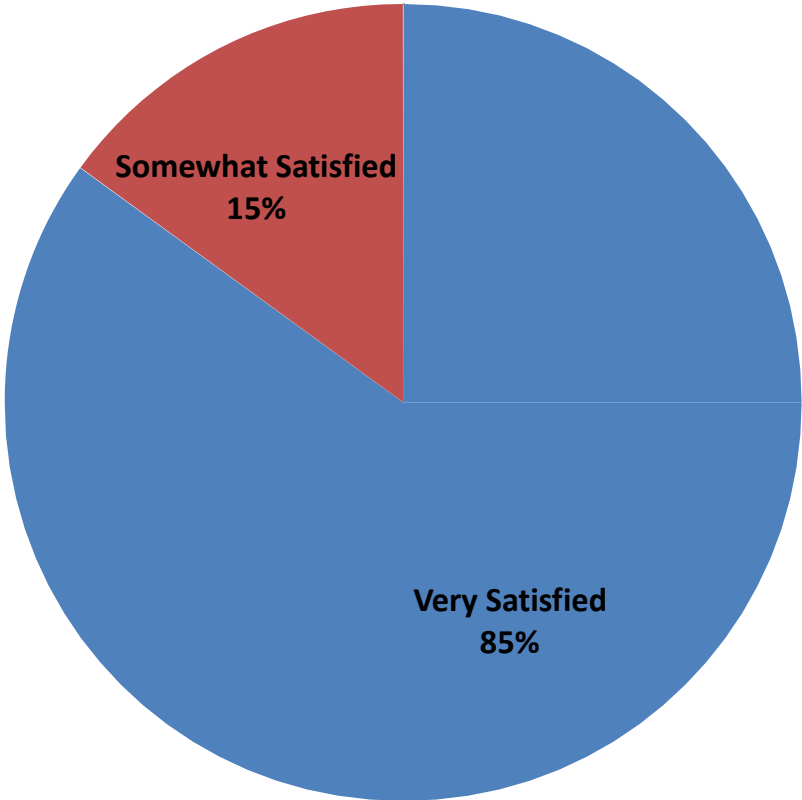
Wednesday, December 14, 2011

	Excellent	Good	Fair	Poor
Question 1: Review the purpose of the SCSN and Comprehensive Plan	73%	27%	0%	0%
Question 2: Review Data about the needs of PLWHA and the Ryan White care system in South Carolina	59%	37%	4%	0%
Question 3: Discuss needs of PLWHA who are in care, not in care, and do not know their HIV status	75%	21%	4%	0%
	Very Satisfied	Somewhat Satisfied	Somewhat Unsatisfied	Very Unsatisfied
Question 4: Overall, how satisfied are you with the meeting	85%	15%	0%	0%

SCSN and Comprehensive Plan Meeting Evaluation December 14, 2011



**SCSN and Comprehensive Plan
Meeting Evaluation
December 14, 2011**



Overall satisfaction with meeting.

Question 5
<i>The most useful part of this meeting was:</i>
1. Data review for SC-Very Good. 2. Prevention in care (there exist a continual bridge to maintain care). 3. Similarities exist across all areas of people-in care, not in care and do not know their HIV status.
1. SCDHEC data update. 2. Outcome of state-wide assessments. 3. Group (small) discussions.
The most useful part of this meeting was:
Discussion.
Group Discussion.
Group Discussion.
Very organized agenda/vision driven.
Breakout groups.
1. Dialogue/networking with other providers, listening to their challenges, accomplishments, etc. 2. Good lunch.
The group discussions allowed me to see some of the same issues that our CHC is experiencing is happening in a lot of other facilities also.
Sharing information of different issues.
Group discussion. Nice touch using slides to present findings.
Group discussion.
Group discussions and group reports.
Having 3 categories (issues) to discuss as opposed to the post-it-notes from last time.
PowerPoint group reports vs. flip chart pages on the wall.
Exchange of information by the "experts."
Discussions with my peers about a range of issues.
Getting to know what other agencies (parts) deal with-negative or positive.
Group breakout sessions.

Group interactions.

Structure, keeping on time, committees recording on laptops instead of charts.

Side discussion of solutions and the identification of a couple of new barriers.

Small group discussions were very useful.

Creative thinking among the break-out group. Also, the food was delicious.

David did a great job facilitating.

Question 6

The least useful part of this meeting:

N/A; however, there is tremendous variance within and among providers. Some need TA.

Meeting was very useful.

I didn't find any part of this meeting to be least useful.

Small group-if prepared could have done this as large groups. Would have preferred to leave building and have lunch out to be better refreshed for afternoon session.

Nothing.

After lunch (and as delicious as it was), it was interesting that I was very alert and attentive as well as enjoying participating.

Could have encouraged topical 2nd groups to skip over the parts already presented by the 1st group with the same topic.

All good.

The length of time.

QM update.

Didn't have a good way to capture the idea for solutions that inevitably rose from the discussion of needs.

Question 7
<i>Something I would really like to see happen at the 2nd planning meeting in early 2012 is:</i>
Need training on impact of immigration law and health care
Focus on the continuum for all individuals in HIV care (prevention to clinical).
Could all presentations be shared with participants?
Recommendations to these problems.
Add training on Medicaid and Affordable Health Care Act. Also, address Latino problem and include Hispanic coalition.
A breakout committee to work on tangible solutions via strategic planning (pilot projects, etc.).
Action versus talking.
1. Ideas to be fleshed out. 2. Begin phasing in a plan. 3. Focus.
New and developing strategies to find solutions to the problems addressed.
Interventions to some of these issues.
Agenda-expectation of what should be accomplished.
Suggestions that work towards collaboration between agencies.
Solutions and agency presentations (brief) on current, successful outreach programs and activities/interventions being implemented.
The plan.
Your track record tells me what you bring will be good.
Data on other disease for comparison (like not in care vs. in care; diabetes vs. HIV). More brownies.
Consideration of Health Care Reform impact for individuals and systems.
Solutions/best practices/what works.
More consumers.

Wi-Fi access; clarification on break-out discussions. Groups wanted to "solve" issues from survey, not discuss.

Seek solutions to the underlying issues to why it is difficult for PLWHA to stay in care, not in care, or unaware of status. Also, how prevention and care can coordinate and pool resources in a stronger, collaborative manner.

Use of trans-theoretical model to examine solutions on where the client may be with denial, grief, loss and personal decision to engage in care.

Same general approach-this time recording solutions- should work.

ATTACHMENT D

Comprehensive Plan Meeting Evaluation

**Meeting Evaluations: SC Ryan White SCSN and Comprehensive Plan Meeting
SC Archives and History Building
Friday, March 23, 2012**

	Excellent	Good	Fair	Poor	Total
Review the report from the first SCSN meeting in December 2011.	20	6	2	0	28
Review summary findings from Part B needs assessment.	16	9	2	0	27
Identify strategies to address the needs for PLWHA not in care, who do not know their HIV status, and for special needs populations.	22	5	0	1	28
Total	58	20	4	1	83
Percentage	70%	24%	5%	1%	

*Please note: a score of 2 was given for the question, "Review the report from the first SCSN meeting in December 2011" because the individual did not have much time to review it during the meeting.

	Very Satisfied	Somewhat Satisfied	Somewhat Unsatisfied	Very Unsatisfied	Total
Overall, how satisfied are you with the meeting?	24	2	1	0	27
Total	24	2	1	0	27
Percentage	89%	7%	4%	0%	

The most useful part of this meeting was:

- Small group discussion: Groups should be shuffled part way through; have more examples of successful strategies.
- Talking with peers and networking.
- Discussing ideas for meeting needs.
- Taking note of things that others are already doing.
- Collaboration of the different parts to produce ideas and strategies.
- The quotes were great and provided ideas of strategies I can implement in my facility.
- Group collaborations and discussions.
- Diverse group of individuals with various degrees of expertise.
- Hearing ideas from others.
- The largest allowed for a number of views which is important for this process.
- Group discussions at the table.
- Report-outs/discussions.
- Networking opportunities.
- Listening to the different presentations were wonderful.
- Small workgroup reports were very helpful and informative, and practical.
- Identifying strategies I hadn't thought of.
- The ideas of the participants.
- Group discussion.
- Everyone working together/brainstorming for idea and solutions.
- Process went well to assess and collect information and strategize for implementation.
- Information provided was very important.
- Each presentation was very helpful.
- Small group sessions and meeting with peers to discuss issues.

Helpful to get recap. Well conducted.
Break out sessions.
All part involvement.
Collaborative presentations.
Small group discussions.

The least useful part of this meeting was:

Tendency to revert to discussion of barriers rather than real solutions.
I didn't find anything that was not useful.
The presentations were good, but too long. Part B needs assessments was not significant to my organization.
This should not be scheduled on a Friday.
Nothing.
N/A...Nothing to be done differently (long day), draining, but worth it.
Having this on a Friday!
The same ideas throughout the years.
All parts at the meeting was helpful.
Very important-many folks are tired but this is always what ASO's and CBO's are up against. Perhaps sodas for afternoon.
N/A. All information was important.
I think all parts were useful but lunch is not useful but necessary.

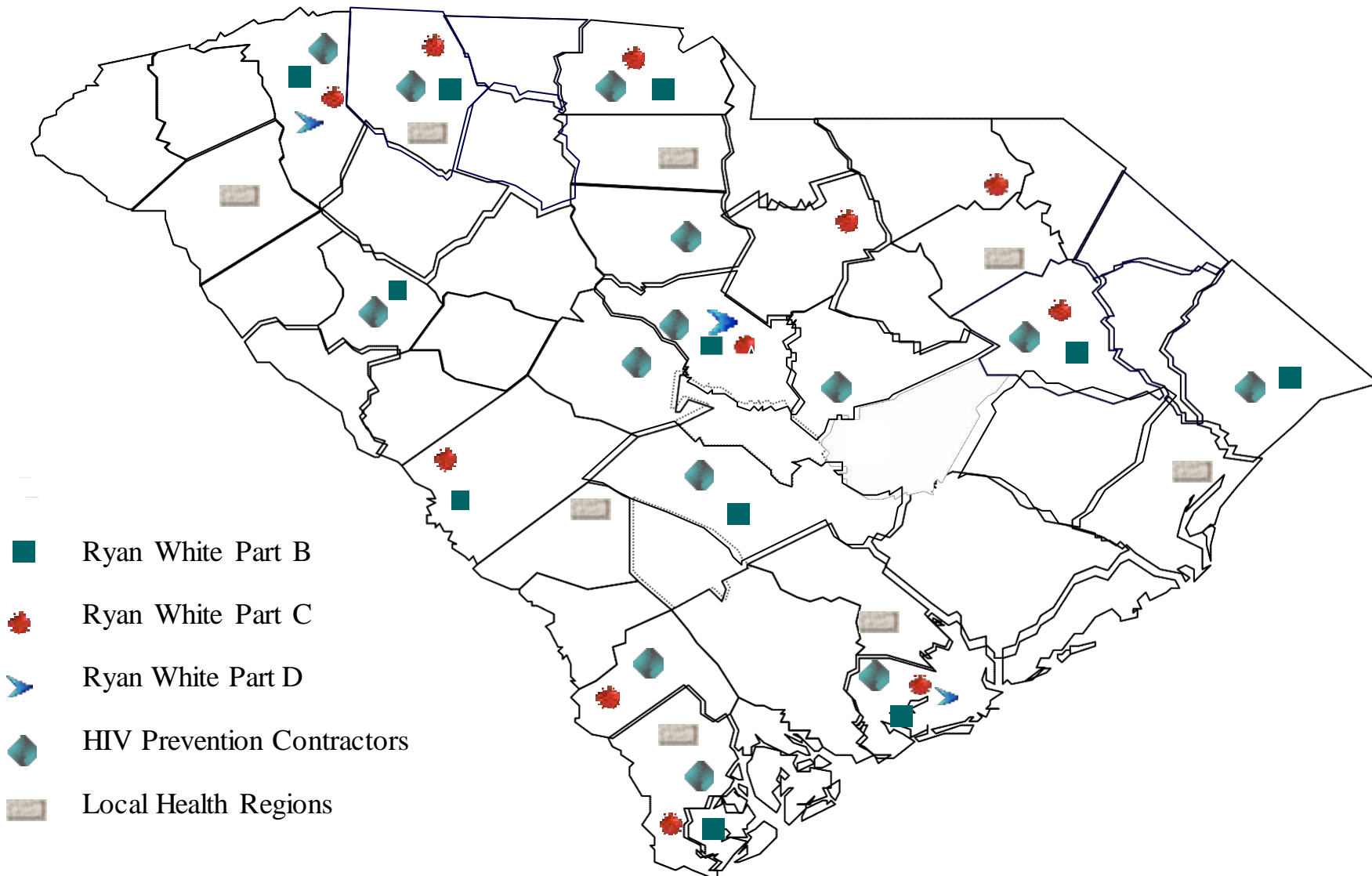
The final SCSN and Comprehensive Plan will be helpful to me if:

We actually use it.
It is specific and is written in a language the general public can.
Strategies for meeting needs are realistic/do-able/not expensive.
Needs and gaps identified.
Resources available or can be found to address the outgoing needs.
Assist with most adequate and effective patient care to our PLWHA.
It involved strategies on the questions presented in the presentations.
I am able to use it for grant proposals.
Yes and lots of great ideas.
Its written in reader-friendly language. The last one was good.
If its comprehensive.
We can gain at least 50% of the plan.
Keep the same group b/c people will understand the flow from previous 2 meetings.
Thanks Noreen and David.
Locally we identify strategies new to us.
All ASO/CBO adhere to the guidance.
It is utilized at all levels: individual, ASO's and CBO's, SC HIV/AIDS Task Force, HPC, etc.
Its used to implement more services.
It was made available in a PowerPoint presentation.
Solutions are reasonable and can be used across all county lines and that the Part B Assessments are included.
It contains strategies that are realistic and achievable and able to be implemented on provider levels as well as agency and health system (advocacy) level.
It incorporates needs of rural health issues.
The strategies are implemented and yield satisfactory results.
Consideration of strategies and align more with most appropriate committees/agencies, etc.

ATTACHMENT E

South Carolina services area map 2012

South Carolina Service Area Map 2012



ATTACHMENT F

SCSN Report

**Summary Report of the
South Carolina Statewide Coordinated
Statement of Need and
Comprehensive Plan Meeting**

Submitted by:

David Napp, MPH

Practical Applications of Public Health

March 19, 2012

Purpose

The Health Resources and Services Administration (HRSA) requires all Ryan White grant recipients, through a representative process, to participate in the development and approval of a Statewide Coordinated Statement of Need (SCSN). The purpose of the SCSN 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. Consistent with guidance from the Department of Health and Human Services, HRSA, this report identifies the needs of PLWHA in care, not in care, and those whose HIV status is unknown.

Process

This SCSN was developed collaboratively with input from a wide variety of stakeholders including PLWHA, providers, Ryan White funded programs, and state agencies. To identify the needs described in this plan, a web-based survey was administered to Ryan White stakeholders in November, 2011. The survey listed needs of PLWHA from the 2009 SCSN and asked respondents to identify current priority needs for PLWHA. A total of 32 people completed the survey for an 89% response rate. A report of survey findings is included in Appendix A.

A one-day meeting was then convened with 40 stakeholders in December, 2011, in Columbia, South Carolina. Survey findings describing priority needs for PLWHA were presented at the stakeholder meeting. A series of concurrent small group discussions then focused on further defining these needs. Small group report outs and the ensuing discussion with the large group was audio taped and transcribed. Transcripts were reviewed to identify the needs of PLWHA described in this report and representative quotes were selected 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.

David Napp of Practical Applications of Public Health, a consultant under contract with the South Carolina Department of Health and Environmental Control, collaborated with an ad-hoc planning committee to conduct the survey and to plan the stakeholder meeting. Members of the planning committee included Noreen O'Donnell and Susan Fulmer, DHEC; Johanna Haynes, Careteam; Pam McKnight, Lowcountry Healthcare Systems; and Angel Harmon, MUSC.

Findings

The findings in this report are organized to answer the following three questions:

1. What makes it difficult for PLWHA who are in care to stay in care?
2. What makes it difficult for PLWHA who know their HIV status and are not in care to get the care they need?
3. What makes it difficult for PLWHA who don't know their HIV status to get tested and linked to care?

All though there are some similarities in the needs of PLWHA across these three domains, the needs for each population are listed separately to help facilitate the development of targeted strategies to strengthen the care system and best meet the needs of PLWHA in South Carolina.

1. What makes it difficult for PLWHA who are in care to stay in care?

Societal Stigma

Persistent societal stigma surrounding HIV/AIDS and its associated risk behaviors has created significant pressures on the HIV/AIDS care system in South Carolina. Stigma is not unique to this state and presents a particularly difficult challenge to HIV care in the Southeastern United States in general due to the prevailing religious, moral, and political views of the region.

There are many ways in which societal stigma functions as a barrier to care for PLWHA. For someone to receive care they must first personally acknowledge and come to terms with their own HIV status, which can be difficult in a society that stigmatizes this illness. Similarly, PLWHA may be concerned about disclosing their status directly or indirectly to others. In an environment of societal stigma, PLWHA may hesitate to disclose their status to partners and family members, ask for assistance with a ride to the clinic to receive care, attend an appointment at a clinic that is known to provide HIV care, or receive copayment assistance that may be recognized by one's employer as associated with the Ryan White program. These are just some of the ways in which societal stigma functions as a barrier to care for PLWHA. The following quotes further describe some of these issues.

"Having to deal with the stigma is hard, for example, in asking for a ride. I know our clinic is kind of in a central area where the hospital is located but some places are not. Some places it kind of tells you what the clinic is. So oftentimes a person is less likely to stay in care because of the stigma associated with those things or with those particular agencies. They don't want to be identified with that clinic and that can be a big barrier for our population right there."

"The stigma associated with staying in care is a big problem. Sometimes with insurance co-pays a lot of people don't want their employer to know and then don't want us to pay that co-pay for them because the employer knows where it comes from. So that can certainly be a barrier to keep a person out of care because they don't want anyone in the HR department to know what medications are being paid for."

Transportation, Housing, and Unemployment

Lack of transportation, inadequate housing, and unemployment have long been recognized as interrelated barriers for PLWHA who are in care. The current depressed economy has exacerbated these concerns. Many PLWHA struggle to meet short-term basic needs that are more pressing than keeping a clinic appointment or maintaining a medication regimen. For example, some PLWHA may feel that they need to choose between taking time off from work for a medical appointment or working so they can pay their bills. For those with unstable housing, it can be difficult for providers to contact clients with appointment reminders and scheduling. Transportation programs, while addressing an important need for many, are reported to have their own limitations, including that PLWHA must plan in advance to schedule a ride and sometimes must wait a long time for their return trip. The following quotes further describe these challenges.

"Housing is always a factor. Thank goodness for HOPA that really helps our patients. Right now there's a job situation where many people are out of work, and, of course, it goes without saying for most of us, a lack of transportation always impacts on our

patients coming to clinic. Difficulty finding time due to work, children, et cetera, can also be a big contributing factor to keeping a person out of treatment. You have to decide do I want to come to care or get paid, pay my bills, and take care of my family."

"Transportation programs oftentimes make a person wait all day. They come pick them up, take them to the hospital, and they end up having to wait all day to get back home. Sometimes the Medicaid van don't even show up, and so, that's been a big issue with some of the folks that we have been dealing with and that can be a barrier as to keeping a person in HIV care. We try to call ahead three days but oftentimes most clients aren't going to do that. It's proactive versus reactive and they end up missing that piece of it. So that is a barrier as far as keeping a person in HIV care."

Substance Abuse and Mental Health Needs

Substance abuse and mental health needs are common co-morbidities with HIV infection. Addiction and unmet mental health needs, combined with the demands of maintaining treatment adherence, pose obvious challenges for PLWHA with regard to their ability to stay in care. The current care system has not been able to fully address these needs. Barriers include too few substance abuse treatment programs, long wait times to enter these programs, and some faith-based programs that exclude individuals based on HIV status or sexual orientation. It was also reported that there are too few mental health providers familiar with treating PLWHA and a fractured system that may require multiple referrals before someone receives mental health care. The following quotes further describe some of these issues.

"I know that here there's not a lot of programs available for people that have substance abuse problems. There are some but not a whole lot that are free. And there aren't a lot available that are treatment facilities for the long-term. And most folks just leaving prison don't want to go back into an inpatient facility. They'd rather just not deal with it, and then we know where that ends up getting them. And there's a very long wait time to get into those programs so that can be another deterrent to keep a person out of HIV treatment."

"Some programs exclude those that are HIV-positive and/or gay. If they have a religion-based substance abuse programs they don't allow them even to come in there. So they have to keep their HIV status and their sexual preference on the low so they can receive treatment."

"Mental health issues can be a big barrier. I had a person that had to go to Columbia Mental Health and they told me to send him to the hospital emergency room and the emergency room said send him back to Columbia Mental Health. Then Columbia Mental Health said send him to the clinic, let them deal with it. So he's been transferred to three different places and the guy has not received any mental health services at all. We have some programs available in our clinic but that has a long wait process. "

Competing Health Concerns and Client Fatigue

Advances in the treatment of HIV infection have led to an increasingly older population of PLWHA. As a result, many PLWHA are now beset with other health concerns common among an aging population, such as diabetes, heart disease, and cancer. These other health concerns may become

more pressing for older PLWHA, distracting them from HIV care or complicating their ability to attend multiple appointments with many different providers. Even in the absence of competing health concerns, some PLWHA become fatigued with the effort it takes for long-term management of their infection. As a result, they may no longer feel they need to see their provider on a regular basis and assume they can simply take their medications without any monitoring. The following quotes further describe these challenges.

"Our population in care is older, and I'll just use my clinic as an example. A large percentage of our patient population is actually well over 50. So we're seeing something different than what we saw in the past, and that is people with other problems. HIV is no longer their main concern because now we have people that have adult onset diabetes, and we also have heart disease now, and we see a lot of cancers as well. So they have these other problems and suddenly other medical problems are getting in the way of their HIV care. So they quit coming to us simply because other medical issues are the stronger need."

"The other issue with this is people have a knowledge deficit. They don't understand that it's important when you have other medical problems along with your HIV that we try to manage all of them together. And therefore they really don't understand this can be quite complicated. You're coming to us, you're going to an endocrinologist, and then you have to go over to the Cancer Institute if you're having to manage cancer. There are a lot of doctors. And so we get into one of the things that was also noted in the survey where you get into that fatigue of this is just overwhelming to someone."

"Ironically, with patients feeling better and living longer they suddenly decide 'Well, heck, the medication is all I need. I get this all the time. I don't need to come to clinic. Just call in my prescription.' This goes back again to a knowledge deficit because if they understood, they would know that the medications are not without side effects. And so we have to monitor their blood work and keep an eye on them and that they just can't keep taking this medication and everything will be fine. Again it just comes back to a lot of times patients not understanding their disease."

Healthcare System Limitations

Although the HIV care system in South Carolina has provided the best possible care for PLWHA, rising infection rates coupled with chronic inadequate funding has created significant pressures on the care system. There are acknowledged limitations to the care system, some of which are specific to the care of PLWHA and some endemic to the healthcare system in general. Long wait times for an appointment and long wait times upon arriving at the clinic itself are both barriers for PLWHA receiving care. Although long wait times are not unique to HIV care, these issues can amplify other barriers to care for PLWHA, such as lack of transportation and unemployment. Inadequate staffing, provider turnover, and staff that lack cultural competency can further exacerbate these concerns, contributing to client frustration and feelings of alienation from the care system. The following quotes describe these issues.

"The structure of the clinic itself a lot of time is a reason that people may not continue in care. People don't like to wait a long time in clinic. I think we've all experienced where if you're running behind people decide they're going to leave. And sometimes it takes us a while to get them back and we have to call and apologize or try to catch them or promise them a meal ticket or some caveat so that they'll keep that

appointment. And for some places maybe they have to wait too long for an appointment and if they have to wait too long to get in they don't come."

"If the support staff lack empathy, or they don't feel like they understand what's going on, or if you don't have enough support staff for people to get what they need, then clients don't feel like they're getting the help that they need when they come. And then for a lot of clinics there's a certain amount of provider turnover. Somebody loves a particular doctor and that doctor leaves. People get really focused on being with that doctor that really understands them. And when the doctor leaves a lot of times the patient leaves as well, and sometimes we lose them to care because of that."

Changes in the complexity of eligibility requirements, insurance coverage, and cost reimbursement mechanisms has created stress for both clients and providers. These challenges manifest in different ways, including insurance coverage that may preclude more than one doctor visit a day, annual Medicaid and ADAP recertification requirements, the need to ensure that providers are in-network for a wide variety of insurance plans, maintaining continuity in coverage when young PLWHA age-out of Medicaid, and managing the administrative demands of verifying coverage for large patients loads. The following quotes further describe these challenges.

"Fragmented medical care can be a problem. In some instances with insurance they can't get their HIV care and see their primary care doctor in the same day because the insurance doesn't cover two medical visits in one day. For others it may be just having to go different places for care."

"Navigating benefit systems can be difficult. Particularly if you couple that with the client moving and changing addresses and things like that. Because with Medicaid for their annual re-certifications they're going to be getting something in the mail that they have to complete and send back in. So if they're not receiving it we're having folks that lose Medicaid. And people lose their ADAP too for the same reason."

"Moving between systems is also an issue. One of the problems that we're having from a Part D perspective in regards to benefits is we're dealing with children who've been HIV-positive all their lives and they've been on Medicaid. And at the age of 19 they're no longer on Medicaid. So they've been compliant with their medication and they've been compliant with coming to medical appointments and then all of a sudden they have no funding. They're not getting medicines anymore and they're afraid of getting a bill. Thankfully, we can cover the visit and they are still in our care. But they still sometimes get a big old fat bill in the mail and that will discourage somebody in a heartbeat when they see a \$1,200.00 bill. And so that's been a problem for us."

"It takes time out of my schedule where I have to go through and verify the type of Medicaid HMO that our patients have. I'm looking at 60-some-odd patients a month that when the first of the month rolls around I have to verify what type of Medicaid they have. If they're out of network with us I have to work with them to either change it and if they're not in that window to change then we're SOL at that point because you cannot bill a Medicaid patient when they don't have Medicaid. So it's a really difficult system to navigate and it makes it harder for providers to do the work that they really need to do as opposed to me sitting around trying to check somebody's Medicaid to see if it's in-network."

2. What makes it difficult for PLWHA who know their HIV status and are not in care to get the care they need?

Poverty and Unmet Basic Needs

Similar to the challenges described above for PLWHA in care, poverty and unmet basic needs may take precedence over HIV care for PLWHA not currently in the care system. Those who had previously been in care may drop out of the care system due to the need to work and pay bills, lack of transportation, unstable housing, and other circumstances associated with poverty. These circumstances may also interfere with someone initially entering the care system after their diagnosis. Even though the HIV care system covers the cost of care for many PLWHA, impoverished clients may not access the care, or may drop out of care, due to concerns about medical expenses. The following quotes describe some of these issues.

"Some of us are blessed to be able to have sick leave, whereas some people living with HIV/AIDS may only be working hourly jobs. And once you're out you don't get paid for that day so they are not wanting to take that particular time off for appointments."

"Poverty and not having enough money to pay the \$3.00 or \$4.00 or \$5.00, whatever it is to be seen, can be a challenge. A lot of times we have patients who come in and they don't have funding and it's a \$50.00 co-pay. And once you kind of hear that once and have to stand by and wait for the discussion to be had in the back room about signing a waiver, a lot of times that's a put-off for people. And eventually they'll end up dropping out of care for that."

"Transportation is a critical issue. Even with incentives they are often inadequate to address the comprehensive challenges, particularly with rural counties. Expense of gas round-trip coupled with time spent on the road is a barrier."

Denial and Fear

Denial about one's HIV status and the fear of disclosure to others prevents some PLWHA from initially entering the care system and, for others who have been receiving care, may cause them to drop out. Denial and fear are powerful disincentives and can isolate PLWHA from friends, family members, and agencies that might otherwise serve a supportive role. For example, PLWHA may hesitate to seek transportation assistance from those in their personal network to whom they have not disclosed their HIV status. Although peer advocates and buddy systems exist to help create a supportive network, some PLWHA do not want to access this resource because they do not want anyone in their community to know their status. Lastly, PLWHA may not access care because of real or perceived concerns about breaches in confidentiality by providers. The following quotes describe these challenges.

"They don't want to disclose their diagnosis to family and friends that might be able to provide transportation or might be somebody that they could talk to about their situation. So they're not accessing different support systems or agencies. For instance, your local ASO, they might not want to go there because acknowledging going to a

particular ASO means I have to acknowledge that I'm positive. So a lot of times that's what's going on."

"With peer advocates and the buddy system, a lot of times when we try to connect positive people together they don't want to be connected together because they don't want anybody else to know that they're positive even though that other person's positive. We try to encourage them to meet or talk because that person could also be their support system, and a lot of times they don't want to do that simply because they don't want anybody to know that they are positive, even though that other person is as well."

Substance Abuse and Mental Health Needs

As documented in previous SCSNs, unmet substance abuse and mental health needs are a significant barrier to PLWHA entering the care system and maintaining their treatment. There are limited resources to address these needs and the some of the providers that are available are either unwilling to treat PLWHA or unfamiliar with the particular needs and context for this population. As a result, many PLWHA with substance abuse and mental health needs are caught in an endless loop of referrals and ultimately fall through the cracks in the care system. The following quote further describes this concern.

"Substance abuse and mental health are big barriers; we've already heard this before. The system issue is there's not enough resources to accommodate the need and people are being passed around. Providers will say 'Oh, you've got this problem. Well, we don't see HIV patients here. Even though you're using, you need to go over here to be seen for that. And you have mental health issues. Well, we don't deal with that here. Go here.' So there's a lot of passing the buck on that and that's it."

Asymptomatic Clients

Asymptomatic PLWHA may not access care because they believe they only need to go to the clinic when not feeling well. This is may be particularly true for those that have been infected for a long time, young adults born with HIV infection, and others who view HIV as a long-term manageable disease. Whereas the public health community has been successful in shaping the public's perception that HIV can be successfully treated, this message may also have unintended consequences as a barrier to maintaining vigilance with clinic appointments. The following quotes describe these concerns.

"A lot of our kids were born with HIV and by the time they're 15 - 16 years old they've been dealing with this all their lives. And I think that goes to the attitude that 'Well, there's nothing wrong with me.' I think a lot of times people have the misperception that somebody living with HIV is somebody that you're going see who has all these things on their face or they look malnourished or they just look sick, and that's not really the case. So I think once you're diagnosed and you don't have that education of why you're being seen by a ID specialist you're going to think 'I look good and I feel good' and then not go to the doctor."

"We're seeing this younger demographic coming through now and I think because for years we've been saying, 'This is a manageable chronic disease. It's not a big deal' and they've heard that and there's some complacency now. So even with a diagnosis they're not accessing care the way they should. "

Healthcare System Limitations

As described earlier in this report, the care system for PLWHA is chronically overburdened and under-resourced. The resulting limitations of the care system are obstacles for PLWHA who had previously received care and have dropped out. These challenges contribute to a further expansion of the epidemic and increasingly unmet care needs. For example, limited clinic hours, inadequate staffing, and high case loads can be a significant obstacle to receiving HIV care, which in turn lead to lapses in treatment, increases in viral load, declining health, and greater infectivity. In addition, staff that are dispassionate and lack cultural competency, and real and perceived concerns about breaches of confidentiality create, an inhospitable environment that contributes to PLWHA dropping out of care. The following quotes further describe these issues.

"A lot of times people are not in care due to work schedules and conflict with clinic appointment availability. We heard a lot about clinic hours and people not being happy with, for instance, the HIV clinic is only on one particular day of the week. I know that is the case where I am now. We only have our HIV clinic one day a week and a lot of our patients have problems with that."

"If they feel like they've gone to a doctor's appointment and they've shared how they felt about taking medications, and during a clinical appointment, if they felt like they've been belittled or spoken to in a manner that they're not accustomed to then they're not going to come back."

"We talked about bad attitude of frontline staff who are a bad fit for a position. And I will tell you I've heard so many stories from different patients, and from the parents of those patients, about their experiences in dealing with the staff of the clinic or staff in other clinics, and their perception of how they've been treated."

"I've had someone share a story about a referral being made on her behalf, and she just felt that the person that was making the referral wasn't respectful of her privacy and was making the referral at the receptionist desk and disclosing to the person on the other end, 'Oh, well, she has AIDS.' Well that's information that's needed to be known but it doesn't need to be disclosed at the front desk where other people can hear and she was very upset about that."

In the context of an overburdened system, some standards for HIV care may inadvertently create barriers to care for PLWHA. For example, requirements that patients must have at least four clinic visit annually can increase lab costs and reduce the availability of appointments for new patients. Similarly, requirements to dispense no more than three months of medications at a time may create additional paperwork and costs. This issue is further described in the following quote.

"I was looking at the Ryan White standard and we've got standards that for reporting that have if we have to have four visits a year, and it creates paperwork and more work and more cost for four appointments a year and four lab draws a year. And then

when you start to look at the medications there's more paperwork generated if you're writing scripts three months at a time versus if you can write them six months at a time, which by law we could do. But the standards keep us from doing that and each of those layers incurs more cost along the way. And the other piece is if you have four visits a year as the standard then you don't have the available openings for the new folks that need to get into get their appointments early."

Lastly, it has been suggested that HIPAA requirements, which are intended to protect the privacy of medical information, may be perceived by some PLWHA as contradicting other messages they hear from providers about the benefits of disclosing their status to friends and family for social support. Although HIPAA requirements and the benefits of personal disclosure are not in fact contradictory, there is concern that this may be confusing to some PLWHA.

"Although we're promoting privacy we're inadvertently promoting secrecy. And where do we find a balance in protecting people's information but encouraging people to share their status or disclose to loved ones or seek support outside of the clinic in their own communities? And maybe we've played a part in that confusion."

3. What makes it difficult for PLWHA who don't know their HIV status to get tested and linked to care?

Fear and Denial

There are a variety of barriers to HIV testing for individuals who know they are at risk for HIV infection but don't know their HIV status. Many of these barriers are attributed to attitudes associated with fear and denial, including denial of risk despite knowingly engaging in risk behaviors; fear of the implications of an HIV diagnosis or, conversely, the perception that HIV is not a serious illness; concerns about disclosure of HIV status upon receiving a positive result; and belief that they may be ineligible for care services due to inability to pay. The following quotes further describe these perceptions.

"A lot of these issues are kind of in quotes because these are the things that we have heard many times, like 'It's not going to happen to me, it's not that big a deal, just take a pill, it doesn't matter if I'm positive or not, it's just not that big a deal, and I can find out later.' That person thinks they are going defy the odds. They want to believe they are the one who's not going to be positive so they just really don't want to confirm that. But if you show up at a testing site you're acknowledging your risky behavior and if you're going in there then that means you did one of the things that you shouldn't be doing anyway."

"Some people think that because they are unemployed that HIV would be a preexisting condition and so it's like that could really be a concern. And they'll say 'Well I'll wait till I get a job and then I'll go be tested and then hopefully it'd be covered.'"

"They don't want to come in and get tested because they say 'Well I don't have no money. I won't be able to go to the doctor. I won't be able to get any kind of healthcare. Where am I going to live?' So they think that if they let everybody know that they're positive then that means that they will be ineligible for a lot of services. So

they think why bother getting tested because if their positive they can't get care anyway."

Societal Stigma

Societal stigma about HIV and risk behaviors has been described previously in this report and shapes the larger context within which fear and denial function as barriers to HIV testing. Some individuals do not get tested for fear they will be judged by society with prevailing negative views about PLWHA and related risk behaviors. For example, people may avoid testing due to concerns that others they know will see them at the testing site or because of concerns that agency staff may divulge personal information about them in other social contexts. Societal stigma can also be an obstacle for linkage to care for newly diagnosed individuals when PLWHA do not follow referrals for fear that others will see them at the "AIDS doctor." The following quotes further describe these concerns.

"There is concern about getting tested in places where staff knows everybody, like the county health department, and people will say 'There's such and such a nurse and she knows everybody and she goes to this big, huge church, and they know everybody.' So there are concerns where the staff are just well-known in the community, which is really a shame."

"When we did consumer surveys a couple years ago folks said they would love it if they could go to one place where they could get all services, and that would be great. Take care of it in one space. And then the next breath they would say they couldn't go to a place like that because that would be the AIDS place. And so the whole stigma about the agency or organization can be a problem. It's kind of like the doctor is known to do AIDS care and then you don't want to go to that doctor because he does AIDS care. So the stigma about the agency, organization, or provider is a problem."

Unaware of Risk

Some people do not get tested because they are unaware they are at risk for HIV. This may stem from misinformation about risk behaviors, misperception that HIV is only a "gay disease", and from providers who reinforce stereotypes about who is at risk and should be tested. In addition, insufficient community education in about HIV and the lack of comprehensive sexuality education in schools have compromised the public's understanding of HIV which, in turn, hinders more widespread testing. The following quotes further describe these concerns.

"Provider judgment that the client isn't at risk can be a barrier to testing. The example I gave was that Miss Junior League doesn't need to be tested and it's kind of like 'Who do I offer tests to, and who do I not offer a test to.' This affects the whole routinization of HIV testing and how that can impact increasing numbers when doctors are still kind of picking and choosing who they perceive needs to be tested or not."

"One of the big things that we recognized was the lack of comprehensive sex education in schools. The Comprehensive Health Education Act mandates CSE but there's a lack of enforcement and appropriately trained staff. And some districts will say, 'Oh, yes, we know that's the law but we don't talk about that.' They will divulge that they

specifically do not do CSE. And that affects everyone's understanding about HIV and risk."

Access to Testing

Limited access to testing services is a barrier to HIV testing. Concerns about access to testing include limited hours, locations, and staffing for HIV testing services. Access is also constrained by providers who resist the trend toward routine testing in medical settings due societal stigma, as well as their concerns about responsibility for providing positive test results and linking newly diagnosed clients to care. A recent study released by the National Medical Association reported that social stigma is the predominant barrier to routine HIV testing among African-American physicians. The following quotes describe these barriers.

"In the last couple months they released a study about black physicians, and one of the outcomes from that is that their self-report says that they're not even offering the test to their mainstream clients. And so that's a major dilemma in 30 years of AIDS that we have providers that don't even offer the test. "

"Lack of appointment times for testing can be a problem. For example, no testing on Fridays was perceived as a problem because if somebody's showing up for testing, or if they're calling about testing, then they may be told that the day they made that big decision is not the day to come or the time to come."

"We hear a lot about provider fear about why people don't want to have routine testing in their facilities. Because then what happens when someone's positive? I got to give them results, and what's my liability, and now what do I have to do, and how do I get them linked to care. And so you have that at the provider level that definitely needs to be addressed."

Appendix A

South Carolina Ryan White SCSN and Comprehensive Plan Meeting Pre-Meeting Survey Results

Overview

A web survey was administered in November 2011 to individuals who would be attending the South Carolina Ryan White SCSN and Comprehensive Plan Meeting on December 14, 2011. The survey asked respondents to identify the needs of PLWHA who are: 1) in care, 2) not in care, and 3) unaware of their HIV status. The survey was conducted to support further discussion at the December 14th meeting about the needs of PLWHA.

Response options for survey questions about the needs of PLWHA in care and not in care were based on the needs identified in the 2009 South Carolina Ryan White SCSN and Comprehensive Plan. Because the 2009 Plan did not list needs of PLWHA unaware of their status, response options for this survey question listed a variety of hypothetical needs for this population.

The survey was created collaboratively by a planning committee, including Noreen O'Donnell, DHEC; Susan Fulmer, DHEC; Angel Harmon, MUSC Pediatrics; Johanna Haynes, Careteam, Inc; Pamela Shepherd McKnight, Lowcountry Healthcare System, Inc.; and David Napp, an independent consultant contracted by DHEC to facilitate development of the 2012 South Carolina Ryan White SCSN and Comprehensive Plan.

Respondents

The survey web-link was sent via email to 36 people. Two booster emails were subsequently sent to further encourage survey completion. A total of 32 people completed the survey for an 89% response rate. Respondent characteristics are summarized below. Multiple responses were permitted so percentages do not add to 100 percent.

Which of the following best describes you? (N=32)

Answer Option	Response Percent
Part B Ryan White provider	41%
Part C Ryan White provider	28%
HOPWA	22%
DHEC staff	19%
Part D Ryan White provider	6%
PLWHA	6%
Corrections	3%
Other	16%

Other = Community Health Center Provider, Medical provider, Prevention Coordinator, PLWHA- ex-offender, CBO Manager

Findings

Web survey findings are presented below. The percent response is listed for each answer option from most to least frequent response. Respondents were asked to select six items for each question and, since multiple responses were permitted, percentages do not add to 100 percent. Verbatim text entries are listed for those who selected "other". Although some text entries were conceptually similar to a pre-defined survey response option, these data were *not* recoded and are *not* reflected in the percentages listed below.

1. What makes it difficult for PLWHA who are in care to stay in care? (N=32)

Answer Options	Response Percent
Lack of transportation makes it difficult for clients in care to reliably get to the services they need.	88%
Societal stigma about HIV and/or risk behaviors makes it difficult for clients to stay in care because they are hesitant to access HIV-related services.	84%
Substance abuse needs makes it difficult for clients to stay in care and adhere to treatment regimes.	84%
Lack of housing makes it difficult for clients to stay in care because of the relative priority they may place on securing safe, stable housing versus seeking health care.	66%
Mental health needs make it difficult for clients to stay in care and adhere to treatment regimes.	66%
Clients have difficulty staying in care because they get fatigued with the long-term process of managing their illness, especially those who have been HIV+ for a long time.	44%
Medication side effects makes it difficult for clients to maintain adherence to treatment regimes.	28%
Clients have difficulty staying in care because they feel confused and burdened by the paperwork and eligibility process to access Ryan White services.	22%
Clients have difficulty staying in care because they feel there are not enough providers like them , such as peers or those of a similar cultural or community background.	22%
Non-English speaking clients have difficulty staying in care because they have a hard time finding language-competent providers or translation services.	13%
Clients have difficulty staying in care when they are incarcerated and do not disclose their HIV status because this disrupts their usual care routine.	13%
Other	38%

Other (PLWHA in care)

- Life complexities make it difficult (reference Maslow's hierarchy) e.g. caring for others such as children, managing appointments without a phone, lacking literacy, etc. Formerly incarcerated people have difficulty finding employment and housing.
- They don't realize the importance of treatment and become despondent.
- Because of denial about their HIV status; and "as long as I'm feeling well, I don't need care"
- Ex-offenders that do not have stable employment upon their release from prison.
- Employment; clients prioritize work over time off to attend medical or case management appointments.
- Low educational attainment, competing needs, lack of self-worth.
- Literacy and job skills are issues. It is hard for clients to find employment without these skills. If they do not have some income, they do not qualify for some housing programs. Individuals who have been incarcerated have a more difficult time securing employment.
- Clients have difficulty staying in care when released from prison because other concerns are first and the stigma of being segregated. First person someone meets in care does not provide cultural and sensitive care.
- Patients feel that the providers do not respect them and their time, have to wait too long for appointments, have difficulty reaching provider by phone.
- Lack of family support due to the stigma associated with HIV and therefore there is no support system in many cases outside a clinic setting.
- I believe that some patients are ashamed, embarrassed and are hesitant because of how they may be treated.
- Clients have a difficult time staying in care because they don't understand the disease and a disease that is not understood is a disease that isn't well managed. Providers have a lot of clients to see and don't have enough time to provide the education that is needed. Case managers have an overwhelming amount of tasks to complete and lots of clients to see and don't have the time to provide intensive education that is needed. Agencies don't have the funding and/or aren't thinking of other creative ways to develop and implement educational tools for case managers to use. All of the above relate to the lack of education that is received by the client.

2. What makes it difficult for PLWHA who know their HIV status and are not in care to get the care they need? (N=32)

Answer Options	Response Percent
Competing issues related to poverty (e.g., food and housing) make it difficult for clients to prioritize accessing HIV care.	97%
Clients denial or fear of disclosing their HIV status to others (e.g. family, partner) discourages them from accessing care.	84%
Substance abuse needs makes it difficult for clients to access HIV care or to recognize that they need care.	78%
Asymptomatic clients don't access care because they feel they do not need HIV care, especially in light of the shift toward thinking of HIV as a long-term chronic illness.	69%
Mental health needs make it difficult for clients to access HIV care or to recognize that they need care.	53%
Clients don't access care because they have had bad experiences with the healthcare system.	53%
Clients have a fatalistic attitude about their illness and are not motivated to access care.	31%
Clients don't access care because they don't feel comfortable engaging with a care system they feel is different from their own culture or community.	25%
Clients who have been in care and dropped out do not reenter the care system due to feelings of personal failure .	22%
Clients don't access care because they believe religion or other "therapies" will heal them.	19%
Undocumented individuals believe there will be personal consequences if they seek care, such as being deported or losing their kids.	16%
Clients don't access care because they find the administrative process to enter the Ryan White system to be burdensome or confusing.	13%
Non-English speaking clients don't access care because they can't find language-competent providers or translation services.	9%
Clients don't access care because they don't know where to go for help.	6%
Other	16%

Other (PLWHA not in care)

- Transportation concerns.
- Transportation.
- For whatever reason, possibly simple denial, clients just aren't interested in being in care.
- There is a need for more counseling services. There is also a lack of Spanish speaking counselors. Personal life issues that lead to stress, anxiety and depression often interfere with care.
- Clients of younger ages, 18-25, are not ready to engage in care and don't have a good understanding of the transition process from youth to adulthood and they don't see medical care as a priority. Competing issues and level of readiness and education are things that keep them from engaging in care.

3. What makes it difficult for PLWHA who don't know their HIV status to get tested and linked to care? (N=32)

Answer Options	Response Percent
People know they are at risk but fear and denial keep them from getting tested.	100%
Societal stigma about HIV and/or risk behaviors keeps people from getting tested.	97%
People don't know they are at risk for HIV and therefore do not get tested.	94%
People are tested, receive results, get referrals, but do not follow through on their first HIV care appointment.	84%
People are tested, receive results, get referrals, and try to follow through on their first HIV care appointment, but waiting times are too long .	34%
People are willing to get tested but don't know where to go for HIV testing.	28%
People are tested but do not receive their results .	22%
People are tested and receive their results, but do not get referrals to HIV care.	22%
Other	28%

Other (PLWHA don't know status)

- HIPAA violation concerns.
- Testing is not part of routine health care.
- People unable to follow through on care due to other priorities (work, child care, etc.)
- They put off testing: they'll get to it later. Misinformed about how HIV is transmitted and if their partner "looks" clean, they must be. People think it's just a disease for black people or for gay people. Misnomers.
- Fear of being tested (or of accessing health care systems) due to immigration issues. Competing priorities (if I'm not sick, my thoughts about getting tested fall by the wayside).
- Lack of self-worth. Low educational attainment.
- Getting tested isn't a priority.
- People often wait until very sick and find out about HIV status at hospital.
- Don't follow thru because of behavior of those they meet at the clinic. Persons tested negative while in prison don't want to know after watching the stigma.

ATTACHMENT G

Part B Needs Assessment Survey

PLEASE COMPLETE THIS SURVEY ONLY IF YOU ARE LIVING WITH HIV, OR HAVE PERMISSION TO ANSWER FOR SOMEONE WHO IS HIV POSITIVE. PLEASE ANSWER THE FOLLOWING QUESTIONS AS COMPLETELY AND ACCURATELY AS POSSIBLE. YOUR PARTICIPATION IS VERY IMPORTANT, AND YOUR INPUT WILL BE USED TO HELP PLAN SERVICES AND PROGRAMS LOCALLY AND STATEWIDE. NO PERSONAL IDENTIFYING INFORMATION WILL BE COLLECTED. IF YOU NEED ASSISTANCE TO COMPLETE THIS SURVEY, PLEASE TALK TO THE PERSON WHO GAVE IT TO YOU. THANK YOU FOR YOUR PARTICIPATION.

PERSONAL INFORMATION

Please check the appropriate boxes and fill in the blanks, if applicable.

- I am completing this survey for myself.
- I am answering the questions for someone other than myself, with his or her permission.

1. Please indicate which of the following condition(s) best describes your HIV/AIDS status. Please provide year of HIV diagnosis, and if status is AIDS please also provide diagnosis date of AIDS.

- HIV positive with no symptoms
 - Living with AIDS
 - HIV positive with symptoms
 - Don't know if I have AIDS diagnosis
- Year HIV diagnosed _____ Year AIDS diagnosed _____

2. Please select the statement that best describes your involvement with HIV medical care services:

- HIV positive and receiving medical services
- HIV positive and not receiving medical services
- A caregiver of a person living with HIV/AIDS receiving medical services
- A caregiver of a person living with HIV/AIDS not receiving medical services
- Don't know

3. Which best describes you?

- Male
- Female
- Transgender
- Other: _____

4. Age Group

- 13-24
- 25-44
- 45-64
- 65+

5. How do you best describe your ethnic background? (Check all that apply)

- White
- Black
- Hispanic
- Asian/Pacific Islander
- Native American/Alaska Native
- Other _____

6. How do you describe your personal relationship status?

- Single
- Married
- Committed Relationship
- Separated
- Divorced
- Widowed

7. Which language are you most comfortable speaking? (Check only one)

- English
- Spanish
- Other: _____

8. In what county do you live? _____

(If you do not know the county, please name the city or town you live in.)

9. What is the highest level of education you completed?

- 8th grade or less
- Some high school
- High school graduate/GED
- Technical or trade school
- Some college
- Completed college
- Graduate level
- Other: _____

10. Please check the best description of where you live most of the time. (*Check only one*)

- In an apartment/house that I own or rent
- At my parent's/relative's/friend's apartment or house
- At a shelter
- At a residential facility (boarding, group, supportive, assisted, skilled nursing, etc.)
- At an institution
- Other: _____

11. Which one of these describes your current job (work) situation? (*Check all that apply*)

- Working full-time job
- Working part-time job → I would work more hours if available
- Working part time on disability
- Not working, receiving full disability
- Not working (not able or not looking)
- Not working, but looking for work
- Full-time Student

12. My personal income per year, before taxes are taken out is:

- \$0 - 10,890
- \$10,891 – 21,780
- \$21,781 – 32,670
- \$32,671 or more

13. How many people are supported by your personal income (Including you)?

- 1
- 2
- 3
- 4
- Other: _____

14. If your income went down by \$100 per month would you have to move?

- Yes
- No

HEALTH AND WELLNESS

15. How did you find out you were HIV positive?

- When I requested a test for HIV
- When I donated blood
- When I went to the hospital or emergency room for something else
- Recommended by my healthcare provider as part of a physical exam or doctor's visit
- When I was in jail or prison
- (For women) As part of care while pregnant
- Other: _____

16. In which state were you diagnosed with HIV?

- South Carolina
- Georgia
- North Carolina
- Other (name) _____

17. When you became aware of your HIV status, please indicate if you received or were referred for any of the following services at that time. *(Check all that apply)*

- Medical care related to the HIV diagnosis
- Medical care for a condition other than HIV
- Substance abuse counseling service
- Mental health services (other than substance abuse counseling)
- If pregnant, for OB/GYN care
- Health/HIV treatment education
- HIV prevention education
- No, I was not referred for services
- Other: _____

18. Once diagnosed with HIV, how long afterwards did you receive medical care related to HIV?

- Immediately 1 – 3 months 3 – 6 months 6 – 12 months 1 yr – 2 yrs
- 2 yrs – 3 yrs 3+ years

19. What would have helped you to begin receiving HIV medical care services sooner?

- Knowing how important early care was
- Not having to take care of family or others
- Knowing who to call or where to go
- Not using drugs or alcohol
- Not being so afraid
- Not being concerned about others learning of my status from being at the doctor's office
- Other: _____
- Nothing, I got help right away

20. In the past year, have you missed your medical appointments more than 2 times?

- Yes No

21. Has it been more than 12 months since you received HIV-related medical care from a doctor or nurse?

- Yes No

If yes, please indicate the reason(s) *(Check all that apply)*

- My doctor or nurse told me that I do not currently need medical care
- I do not believe that I need medical care now because I am not sick
- I do not believe that medical care would do me any good
- I do not know where to go for medical care
- I have not been able to get an appointment
- The medical office is not open at hours I can go
- I use other therapies (herbs, vitamins, acupuncture, massage therapy, or other nontraditional medicine)
- Financial reasons
- I have had bad experiences with the medical office staff
- I do not have transportation
- I do not trust doctors
- I am or have recently been using illegal or street drugs or alcohol
- Lack of child care
- I do not want to receive medical care
- Other: _____

22. Are you taking HIV/AIDS drugs/medications now?

- Yes No

If yes, please describe how your HIV/AIDS medications are purchased? *(Check all that apply)*

- Pharmaceutical drug assistance program
 State drug assistance program (ADAP)
 Medicaid
 Medicare
 Health insurance (other than Medicaid or Medicare)
 Not sure, but my case manager or nurse arranges for me to get my medications
 Other: _____

23. Have you received any of the following within the last 12 months? *(Check all that apply)*

- A. CD4 lab tests Yes No I do not know
B. Viral load tests Yes No I do not know
C. Screening for TB Yes No I do not know
D. (women only) Pap smear Yes No I do not know

24. Do any of the following situations prevent you from getting HIV medical care? *(Check all that apply)*

- No, I keep my appointments
 Medical office is not available at hours I can go
 No way to get there (transportation)
 I don't have a way to pay for medical care
 No help in taking care of my children
 I have other responsibilities
 I'm worried about someone finding out I am HIV positive
 Accessibility barrier (such as wheelchair bound)
 Hard of hearing or deaf
 Visually impaired or blind (not corrected by eyeglasses)
 Chemical dependency (alcohol, street drugs)
 Providers do not speak my language
 Providers don't understand my culture
 I can't get services because of immigrant/legal status
 Fear of being deported
 I don't feel welcome
 Other _____

25. Are you currently taking any medications?

- Yes No (if No, go to question 26)

A. If yes, which of the following best describes the types of medications you are taking? *(Check all that apply):*

- Antiretroviral medications (medications that fight the HIV)
 Medications to treat or help prevent infections caused by HIV
 Medications for medical conditions not related to HIV
 Medications for depression, anxiety, or other emotional/mental health concerns
 I take medications, but I am not sure what they are for.

B. How have you taken your medications in the past 3 months? *(Check all that apply):*

- Daily, on a regular schedule as prescribed.
 Daily, but I miss my prescribed schedule by 1-2 hours.
 I average taking the medications on schedule 4-6 days per week.
 I average taking the medications on schedule 3 days or less per week.
 I take the medications when I am feeling well.
 I take the medications when I am NOT feeling well.

C. Do you understand how you are supposed to take your medications?

- Yes No, I need treatment counseling

D. If there are times that you do not take your medications as directed, please indicate the reason(s) from the choices below. *(Check all that may apply)*

- I always take as prescribed
- Side effects
- Difficult schedule
- Medication didn't work
- Could not afford it
- Did not want to take them
- Forgot to take them
- Afraid others will see my medication/see me taking medication
- I started feeling better
- There were too many pills to take
- There was a language problem. The pill bottles were not labeled in my language.
- Did not understand how to take medicine.
- Other _____

E. If you are taking non-HIV medications, do you have difficulties paying for them?

- Yes No I am not taking any non-HIV medications.

26. Where do you receive your medical care? *(Check all that apply)*

- Emergency Room (ER)
- Name of provider or doctor(s): _____

27. How satisfied have you been when contacting your medical/HIV doctor?

- Not satisfied Somewhat satisfied Very satisfied

28. How satisfied are you with the medical advice you have received from your medical provider(s)?

	Very Satisfied	Somewhat Satisfied	Satisfied	Somewhat Dissatisfied	Dissatisfied	Does Not Apply
HIV Doctor						
Non HIV Doctor						
Nurse						
Case Manager						
Support Staff						
Social Worker						

29. Are you satisfied with the communication between you and your medical provider?

- Yes No If no please explain _____

30. When was the last time that you received dental care?

- In the last 6 months In the last year In the last 5 years Longer than 5 years Never
- I do not receive dental care service
- I do not need dental care

31. Have you received HIV/AIDS education and/or counseling?

- Yes No Yes, but I am still not sure how to best protect myself and/or my partner.

32. Please indicate the sources of information for the following: *(Check all that apply.)*

HIV treatment

- Doctors/Nurse Practitioner
- Internet
- Friends or family
- Support groups
- Case manager
- Newspapers/books/media
- Nurse/other healthcare worker
- Prevention outreach worker
- Other _____

HIV prevention

- Doctors/Nurse Practitioner
- Internet
- Friends or family
- Support groups
- Case manager
- Newspapers/books/media
- Nurse/other healthcare worker
- Prevention outreach worker
- Other _____

33. Of the services listed below, please indicate any that you need, and indicate if you receive those services. Please also indicate the importance of these services to you, regardless if you receive them or not. *(Check all that apply. Skip any that you do not need.)*

Translation/interpretation I need I receive
 Not important Somewhat important very important

Mental health counseling I need I receive
 Not important Somewhat important very important

Help understanding how and why to take my medications I need I receive
 Not important Somewhat important very important

Transportation to medical appointments I need I receive
 Not important Somewhat important very important

Support group I need I receive
 Not important Somewhat important very important

Addictions Counseling I need I receive
 Not important Somewhat important very important

Food pantry I need I receive
 Not important Somewhat important very important

Help with my housing expenses I need I receive
 Not important Somewhat important very important

Help with dental care I need I receive
 Not important Somewhat important very important

Help getting/paying for non HIV medications I need I receive
 Not important Somewhat important very important

Help getting/paying for non HIV medications I need I receive
 Not important Somewhat important very important

Help paying for my health insurance I need I receive
 Not important Somewhat important very important

34. Are there any other services that are not listed that are important to you?

35. What changes would you suggest for improving services for yourself and others living with HIV?

36. Do you have any comments?
