

HIV and AIDS:

A Spartanburg County Perspective



30 YEARS OF AIDS
Sixth Edition - 2012

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Piedmont Care, Inc. is the nonprofit organization providing HIV and AIDS care, prevention and advocacy in our community. Donations to Piedmont Care, Inc. are tax-deductible. To make a donation, please contact:

Tracey L. Jackson, Executive Director
Piedmont Care, Inc.
101 North Pine Street, Suite 200
Spartanburg, SC 29302
(864) 582-7773
tracey@piedmontcare.org
www.piedmontcare.org

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Community Long Term Care (DHHS)
Piedmont Care, Inc.
Region II Public Health District
Spartanburg Alcohol and Drug Abuse Commission
Spartanburg County Community Development Department
Spartanburg County HIV/AIDS Committee
Spartanburg Regional Healthcare System

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INTRODUCTION

On June 5, 1981, the Centers for Disease Control and Prevention (CDC) published their Morbidity and Mortality Weekly Report first mentioning what would later be named HIV – the Human Immunodeficiency Virus. Thirty years into this pandemic, people continue to be infected and die from HIV/AIDS (Acquired Immunodeficiency Syndrome).

In the early years of this epidemic, HIV/AIDS was a death sentence. There was no treatment and no cure. Patients, families, and doctors were helpless against the rapidly progressing disease that claimed so many lives in painful and horrifying ways.

Since the last publication of this report in 2008, some things surrounding HIV and AIDS have changed. The U.S. has a national AIDS strategy. There are 29 HIV/AIDS drugs on the market and at least 7 in the development pipeline (www.thebody.com). And, according to UNAIDS, at least 56 countries have either stabilized or achieved significant declines in rates of new HIV infections. Unfortunately, some things have remained the same. The stigma and fear surrounding this disease continues to impair prevention and care efforts. Sadly, no cure or vaccine has been found.

This report uses a global perspective to examine the constantly growing impact of the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) on Spartanburg County, South Carolina. Much of this document is applicable and beneficial to surrounding counties.

The Spartanburg County Community Development Department and the Spartanburg County HIV/AIDS Committee set several goals for this report:

- Describe the impact of HIV/AIDS in Spartanburg County.
- Educate the community about HIV/AIDS.
- Make recommendations to Spartanburg County government.
- Create a sense of urgency to spur local response to the epidemic.

EXECUTIVE SUMMARY: STATISTICS NOT TO BE IGNORED

Spartanburg County, like communities worldwide, is impacted by the HIV/AIDS epidemic. Of the 46 counties in the state, Spartanburg ranks 31st in HIV/AIDS case rates and has more than 950 people living with HIV/AIDS (SCDHEC surveillance reports).

HIV/AIDS is a global epidemic. According to the Kaiser Family Foundation, the HIV/AIDS epidemic has already claimed more than 25 million lives. HIV/AIDS has been reported in all regions of the world. HIV is a leading cause of death worldwide and the number one cause of death in Africa.

- 33.3 million people worldwide are living with HIV/AIDS.
- There are an estimated 16.6 million orphans worldwide due to HIV/AIDS.
- Every 12 seconds another person contracts HIV, up from 13 seconds in 2008.
- Every 16 seconds someone dies from AIDS.

According to the Centers for Disease Control (CDC):

- An estimated 1.2 million people are living with HIV/AIDS in the U.S.
- Approximately 56,000 new HIV infections occur in the U.S. annually.
- Approximately 21% of people infected with HIV do not know they have the virus.

HIV/AIDS: THE FACTS

- HIV is the virus that causes AIDS (a result of HIV infection). HIV is an acronym for Human Immunodeficiency Virus. Currently, there is no cure for HIV.
- AIDS is an acronym for Acquired Immune Deficiency Syndrome. AIDS is a condition that results from HIV infection. The condition is caused by the weakening of the immune system as a result of the virus. Currently, there is no cure for AIDS.
- People can find out if they have HIV by getting counseled and tested. Using a sample of blood, urine, or fluid from the mouth, a test can show whether people have antibodies to HIV.
- People with AIDS or HIV often show no outward signs of infection. HIV can be active in the body before it starts to reveal symptoms. The only way to determine if a person has HIV is to be tested.
- Good medical care can dramatically extend and improve the quality of life for people with HIV infection, including people with AIDS.
- HIV spreads through unprotected vaginal, oral and anal sex and blood-to-blood contact with people who have HIV. HIV can also spread from a mother with HIV to her baby during pregnancy, birth, or through breast feeding.
- The body fluids that transmit HIV are blood, semen, vaginal fluid, breast milk and other body fluids containing blood.
- HIV cannot spread from person to person by casual everyday contact. People cannot get HIV from just being around someone with HIV or from sharing utensils, office space, bathrooms, handshakes or phones. In addition, the virus is not spread by hugs, touches, massages or even kisses on the cheek.
- Condoms are not 100% effective. However, when used correctly and consistently, latex or polyurethane condoms greatly reduce the spread of HIV and some other sexually transmitted diseases.
- HIV is not spread through mosquito or insect bites.
- The risk of becoming infected with HIV from a blood transfusion in the U.S. is extremely low. The blood supply has been tested for HIV since 1985.

A GLOBAL EPIDEMIC

HIV/AIDS is a global pandemic of catastrophic consequences that not only affects public health, but our social and economic well-being. HIV infection is disproportionately related to wealth. We will never truly address the epidemic without a more equitable distribution of resources.

UNAIDS, the Joint United Nations Programme on HIV/AIDS, in cooperation with the World Health Organization (WHO), releases an annual report on the status of the global AIDS epidemic.

The 2010 UNAIDS report estimated:

<p>33.3 million people are living with HIV/AIDS worldwide. 2.6 million people were newly infected with HIV. AIDS deaths in 2009 totaled 1.8 million.</p>
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There is good news in the global fight against HIV/AIDS. According to UNAIDS, “new HIV infections have fallen by nearly 20% in the last 10 years, AIDS-related deaths are down by nearly 20% in the last five years, and the total number of people living with HIV is stabilizing.” AIDS remains the leading cause of death in Sub-Saharan Africa. Worldwide, HIV is primarily transmitted heterosexually, although risk factors vary within and across populations. Declines in global AIDS related deaths over the last couple years may be attributable to better access to antiretroviral treatment services.

Human rights issues continue to diminish the success of the global HIV/AIDS fight. In some countries, “punitive laws continue to hamper access to AIDS-related services” (UNAIDS). However, addressing human rights issues such as stigma and discrimination are more likely to be incorporated into national AIDS strategies.

HIV/AIDS IN THE UNITED STATES

Despite scientific advances, the HIV/AIDS epidemic is far from over. In the U.S. someone contracts HIV every 9.5 minutes. Every American is affected by the HIV/AIDS epidemic and almost half of all Americans know someone living with HIV/AIDS. In June 2010, President Barack Obama unveiled his *National AIDS Strategy*.

Vision for the National HIV/AIDS Strategy

“The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.”

The goals of the *National HIV/AIDS Strategy* are:

- 1) reducing the number of people who become infected with HIV,
- 2) increasing access to care and optimizing health outcomes for people living with HIV,
- 3) reducing HIV-related health disparities.

Where we stand:

- Approximately one in five people living with HIV are unaware of their status, placing them at greater risk for spreading the virus to others.
- Roughly three-fourths of HIV/AIDS cases in the United States are among men, the majority of whom are gay and bisexual men.
- One-fourth of Americans living with HIV are women, and the disease disproportionately impacts women of color. The HIV diagnosis rate for Black women is more than 19 times the rate for White women.
- Racial and ethnic minorities are disproportionately represented in the HIV epidemic and die sooner than Whites.
- The South and Northeast, along with Puerto Rico and the U.S. Virgin Islands, are disproportionately impacted by HIV.
- One quarter of new HIV infections occur among adolescents and young adults (13 to 29).
- Twenty-four percent of people living with HIV are 50 or older, and 15 percent of new HIV/AIDS cases occur among people in this age group.

HIV/AIDS IN THE SOUTH

The Southern AIDS Coalition promotes accessible and high quality systems of HIV and STD prevention and care throughout the Southern states and the District of Columbia. These states include: Alabama, Arkansas, Delaware, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia and West Virginia. According to the Coalition, “Southern states continue to report the highest number of new AIDS cases, the highest newly reported HIV cases, and the smallest decrease in deaths due to AIDS.”

SOUTH CAROLINA'S HIV/AIDS SCENE

South Carolina was recently described as “the buckle of the AIDS belt.” (www.AIDSVu.org) This label indicates grim news. South Carolina is “one of only eight states to feature an infection rate of at least 354 HIV diagnoses per 100,000 citizens.” Other states with similar epidemics are: Delaware, Florida, Georgia, Louisiana, Maryland, New Jersey, and New York. The same data source notes that of the 46 counties in South Carolina, “32 have been assigned the highest level of infection (at least 249 HIV diagnoses per 100,000 citizens.”

The 2010 epidemiological profile prepared by South Carolina DHEC reports:

In South Carolina approximately 15,000 people are living with HIV/AIDS.

69% of persons diagnosed with HIV/AIDS are men.

31% of persons diagnosed with HIV/AIDS are women.

73% of persons diagnosed with HIV/AIDS are African American.

3% of persons living with HIV/AIDS are Hispanic.

24% of persons diagnosed with HIV/AIDS are white.

South Carolina ranks 10th among states for AIDS case rates.

Men are disproportionately affected by HIV/AIDS. They make up 49% of South Carolina's total population, but comprise 69% of persons living with HIV. African Americans are disproportionately impacted by HIV/AIDS in South Carolina. They comprise 29% of the state's total population, yet 73% of the total persons living with HIV. HIV-only diagnosed cases give an estimate of more recent infections or potentially emerging populations. This data shows an increasing proportion among females (38%) compared to the prevalence data (31%). The same data reflects a slight decrease among white men and increase among African American women relative to the proportion of persons living with HIV. Approximately 30% of those infected in South Carolina live in extremely rural areas.

Of people living with HIV/AIDS in South Carolina, only 59% are receiving appropriate medical care. Those people living with HIV/AIDS who are not in care (41%) are either receiving no care or inadequate care.

At the time this report was written, in South Carolina, some people living with HIV/AIDS are on a waiting list for free or low-cost life-saving medications. The program that provides these medications - the AIDS Drug Assistance Program (ADAP) - is predominantly funded through federal funds. However, state funds are required to make this program work. South Carolina continues to underfund this critical program. In fiscal year 2011, South Carolina reduced

SOUTH CAROLINA'S HIV/AIDS SCENE continued

funding for ADAP by more than 50% from the previous year. The South Carolina HIV/AIDS Crisis Task Force, a collaboration of AIDS service organizations, government agencies, and advocates, continues to educate lawmakers about the severity of the HIV/AIDS epidemic in South Carolina.

People with another STD (sexually transmitted disease) are at higher risk for HIV infection. Of serious concern in the fight against HIV/AIDS is the impact of STDs in South Carolina. According to the South Carolina Department of Health and Environmental Control (SCDHEC), South Carolina ranks 4th for chlamydia, 3rd for gonorrhea, and 22nd for syphilis of the 50 states.

SPARTANBURG COUNTY'S STORY

Spartanburg County, like communities worldwide, is impacted by the HIV/AIDS epidemic. Of the 46 counties in the state, Spartanburg ranks 31st in HIV/AIDS case rates (SCDHEC surveillance reports). The demographics of the HIV/AIDS epidemic in Spartanburg County mirror the State epidemic.

Data provided by the South Carolina Department of Health and Environmental Control (SCDHEC), cumulative through December 31, 2009, shows that Spartanburg County reported 972 HIV and AIDS cases, an increase of 88 since 2007, with a population of 284,307. According to SCDHEC, between 40 and 59% of people living with HIV/AIDS in Spartanburg County who know they are infected are not receiving medical care. There is an increased burden on the care and prevention communities as HIV positive people are living longer and the number of HIV infections rise.

Census data from 2010 indicates that the population of Spartanburg County has increased nearly 11% since 2000. African Americans make up 20% of the population, but 60% of HIV infections (prevalence data 2009). Almost six percent of the population is Hispanic or Latino, which is slightly higher than the percentage for the state and is an increase of three percent in the last decade. It is estimated that almost 15% of the county's residents live below the poverty level. The median household income is estimated to be \$40,000. Men make up slightly less than half of Spartanburg County residents yet they account for approximately 70% of HIV/AIDS cases.

Two organizations serving Spartanburg County residents living with HIV/AIDS are funded through the Ryan White Program, formerly the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The Ryan White Program works with cities, states, and local community-based organizations to provide HIV-related services to more than half a million people each year. The program is for those who do not have sufficient health care coverage or financial resources for coping with HIV disease. Ryan White fills gaps in care not covered by these other sources. Piedmont Care, Inc., the nonprofit organization providing HIV and AIDS care, prevention, and advocacy in our community, currently serves approximately 400 people living with HIV/AIDS. Approximately 75% of those reside in Spartanburg County. Since inception in 1994, Piedmont Care has served over 1100 people living with HIV/AIDS and their families. Each year Piedmont Care serves approximately 60 new HIV-positive clients and provides more than 100 free HIV tests. The Spartanburg Regional Healthcare System Ryan White clinic serves approximately 350 people of which 79% reside in Spartanburg County.

LOCAL RESOURCES

Community Long Term Care (DHHS) – (864) 587-4707

Community Long Term Care (CLTC) offers a waiver program for people living with HIV and AIDS. After meeting Medicaid eligibility criteria, individuals with AIDS can be offered services including personal care aides, home delivered meals, incontinence supplies, nutritional supplements, private duty nursing, home management services, environmental modification, and attendant care services. Registered nurses complete the evaluation process to determine level of care, and functional and medical criteria. Social Workers serve as case managers to assist clients and caregivers coordinate needed services.

Mary Black Health System LLC (MBHS) – (864) 573-3000

Mary Black Hospital employs an infectious disease specialist who treats patients in both inpatient and outpatient settings. In addition to serving hospital and office patients, the physician serves at the Spartanburg Regional Healthcare System Ryan White Part C clinic.

Piedmont Care, Inc. – (864) 582-7773 – www.piedmontcare.org

Piedmont Care, Inc., an educational and advocacy organization, coordinates and provides medical, social and psychological services for individuals and families affected by or at risk for HIV. Piedmont Care provides the following services for people living with HIV and AIDS:

- Case Management
- Dental care
- Food Bank
- Health education/risk reduction
- Housing assistance
- Medical Insurance continuation
- Language services
- Medication assistance
- Mental Health
- Nutritional supplements
- Outpatient medical care
- Transportation

Ryan White Comprehensive AIDS Resources Emergency (CARE) Act federal funds were secured in 1994 to establish Piedmont Care, Inc.

Piedmont Care provides the following HIV prevention services to the community:

- HIV testing and counseling
- Prevention education, *The Facts: HIV 101*
- Awareness services, speakers, health fair participation
- Condom education and distribution

LOCAL RESOURCES continued

Social Security Administration – (864) 583-8223

Persons living with HIV and AIDS may be eligible for Social Security, Supplemental Security Income, and Medicare. The Spartanburg County Department of Social Services offers Aid to Families with Dependent Children, Food Stamps, and Medicaid.

Spartanburg Alcohol and Drug Abuse Commission (SADAC) – (864) 582-7588

The mission of Spartanburg Alcohol and Drug Abuse Commission is to reduce human suffering from alcohol, tobacco and other drug use abuse and addiction by providing and promoting quality prevention, education, intervention and treatment services in Spartanburg County. SADAC's clinical treatment staff provides individual and group level counseling for drug users and other chemically dependent clients. Prevention staff provide HIV/AIDS education to clients in treatment and the general community. Referrals are made to support services.

Center for Integrated Prevention Practices. SADAC's Prevention Department provides the latest evidence/science-based curriculums that target alcohol, tobacco and other drug abuse, and HIV infection prevention. These programs have multiple sessions with pre/post testing that show knowledge gained and risk behavior changes. Available programs also include educational trainings to parents, school personnel, civic, religious and business groups.

HIV Education and Risk Reduction Services. Individuals who use alcohol and other drugs are placing themselves at risk for becoming addicted and/or infected with diseases such as TB (tuberculosis), HIV and other STIs (Sexually Transmitted Infections). Alcohol, tobacco and other drug use reduces the body's ability to fight off diseases and impairs one's judgment and decision-making. This program provides prevention and interventions through education and confidential HIV counseling and testing. These programs encourage personal development to lower risk of infectious diseases, encourage behavior change, and provide services to help people live a healthier lifestyle. These programs are science/evidence-based and are available to Spartanburg, Cherokee and Union County residents.

Spartanburg County Government – (864) 595-5300

Spartanburg County government supports the HIV/AIDS Committee and other HIV/AIDS initiatives in the county in a variety of ways. The County has been actively involved in addressing housing issues, providing meeting space, and offering staff support to assist in communication and coordination of interested organizations. Minimal financial assistance is given for the publication of service brochures and this document, *HIV and AIDS: A Spartanburg County Perspective*.

LOCAL RESOURCES continued

Spartanburg County Health Department – (864) 596-2227

The Spartanburg County Health Department has played a major role in the identification, prevention, and treatment of HIV/AIDS since the first case was identified locally. It has been involved in educational efforts through the media, speaking to various groups and organizations, distributing literature, and providing community outreach. The Health Department provides confidential HIV testing and counseling, coordinates a partner notification (contact tracing) program, and houses an STD clinic. All positive HIV test results must be reported to SCDHEC.

Spartanburg County HIV/AIDS Committee – (864) 595-5300

The purpose of this committee is to focus attention on the issue of HIV/AIDS in our community. The Spartanburg County Health Planning Commission established the HIV/AIDS Committee in 1987. This committee serves as a coordination and communications tool for participating organizations. Among the Committee's activities are: creation and distribution of this report, publication and distribution of an HIV/AIDS service brochure, and implementation of World AIDS Day activities. This Committee provides critical linkage between local policy makers and those organizations focused on preventing and treating HIV/AIDS.

Spartanburg Regional Healthcare System (SRHS) – (864) 560-6806

SRHS has cared for those with HIV/AIDS since 1985. An Adult Infectious Disease Clinic was organized within the Regional Internal Medicine Clinic in 1990. Since 2002, SRHS has received federal funds through the Ryan White Remodernization Act (formerly the Ryan White CARE Act) to expand primary and HIV specialty care services provided to individuals living with HIV/AIDS. Services provided through this program include outpatient medical treatment, mental health counseling, nutritional counseling, transportation services, and pharmaceutical assistance services.

Upstate Homeless Coalition – (864) 595-5304

The Upstate Homeless Coalition is a collaborative organization dedicated to ending homelessness through programming, advocacy, and building safe and affordable housing. The Upstate Homeless Coalition coordinates the programs and initiatives throughout a 13-county area, helping to find gaps in services for homeless people and develop strategies to close the gaps.

Other Services

Other agencies that play a role in the provision of services to people with HIV/AIDS include the Spartanburg Area Mental Health Center, the Spartanburg County Housing Authority, local ministries, shelters, Piedmont Community Actions, Mobile Meals, the Salvation Army, and ReGenesis Community Health Center.

CRITICAL ISSUES

Although these issues are organized by topic, they do not exist in a vacuum but are inter-related. When considering this list, please remember that HIV/AIDS affects all aspects of our society and our culture. Individuals do not live in isolation and these critical issues can neither be discussed nor addressed without acknowledgement of their interconnectedness.

HEALTH CARE REFORM – AFFORDABLE CARE ACT

Uncertainty surrounding the Affordable Care Act, of which many provisions are set to go into effect in 2014, causes distress to both people living with HIV/AIDS and those serving them. Political debate surrounding the Act, including provisions and threats to repeal, leave vulnerable populations with questions that currently must go unanswered.

According to the Obama Administration, “The 2010 Affordable Care Act puts in place comprehensive health insurance reforms that will hold insurance companies more accountable, lower health care costs, guarantee more health care choices, and enhance the quality of health care for all Americans. The Act could help as many as 32 million Americans who have no health care today receive coverage.”

For people living with HIV/AIDS, who have historically been denied health insurance coverage and lacked access to qualified medical providers, the Affordable Care Act could change much about the care system. The Affordable Care Act is designed to:

- Improve Access to Coverage – Under the Act people living with HIV/AIDS cannot be denied health insurance coverage, be given caps on coverage, or have their coverage rescinded. The Act will also provide more access by broadening Medicaid eligibility and eliminating the Medicare Part B donut hole.
- Ensure Quality Coverage – Health plans will be required to provide information in a user-friendly manner. A new comprehensive benefit package will offer all Americans who purchase insurance policies in the individual or small group market a fair and comprehensive set of services. There is an increased focus on preventive services such as check-ups and screenings. Community health teams, proven effective through the Ryan White CARE Act, will help patients manage chronic disease.
- Increase Opportunities for Health and Well-Being – The Act requires critical investments in prevention, wellness, and public health. There will be expanded initiatives to strengthen cultural competency for health care providers and expansion of the healthcare workforce in underserved communities.

What is certain is that those organizations and advocates dedicated to fighting HIV/AIDS through care, prevention, and education remain vigilant and ready to adapt to changes in health care provision.

CRITICAL ISSUES continued

ECONOMIC IMPACT

In a 2010 letter to editors of newspapers around the state, Harvard advocate and author Dorothee Alsentzer wrote, “untreated HIV is associated with emergency room treatment and hospitalizations costing on average about \$33,000 annually per individual — not to mention the cost of lost productivity and revenue when a person is too sick to work. Absent insurance coverage, the cost of treatment is borne by the state.”

Based on data presented in this document, the Spartanburg County HIV/AIDS Committee estimates that approximately \$1.75 million could be spent annually in Spartanburg County to provide HIV/AIDS treatment to HIV positive people (972 people at \$18,000 each). This cost estimate reflects medical care only and does not include psychological and support services such as case management, transportation, counseling, and housing.

Dr. Kent Stock, an infectious disease specialist practicing in Charleston, South Carolina, completed a study of the economic impact of the HIV epidemic in South Carolina. “HIV disproportionately affects South Carolina. The state consistently ranks in the top 10 nationally in AIDS case rates per 100,000 people. While the demographic statistics are well-characterized, the economic impact of HIV is not well-known. In 2004, a study estimated the economic impact of HIV on the state. The findings suggested that the economic impact is substantial, and a crisis has emerged. Direct cost analysis suggested \$151 million was spent on behalf of 12,604 HIV-infected patients in 2002. \$72 million (48%) was spent on hospitalizations and Medicaid paid the largest percent of hospitalization charges (43%). A ‘cost of illness’ estimate examines an epidemic’s true cost to society. HIV’s cost exceeded \$6.5 billion in 2002. The estimated foregone earnings of people living with HIV who were too ill to work exceeded \$5.7 billion in 2002. The data also suggested that HIV is adversely affecting our state’s gross state product – growth rate, wages, individual and household per capita income and worker productivity. Left unchecked, the HIV epidemic could drain the state’s hospital systems, particularly in rural areas, and weaken a work force vital to attracting new business to the state. The disease remains the single greatest public health threat to contemporary society and has the potential to financially cripple an economically vulnerable state such as ours. If we do not come together as a state and immediately address the health and economic issues precipitated by the HIV pandemic, we may bankrupt the future of a generation of South Carolinians.”

The cost of treating HIV/AIDS is staggering and would impoverish most individuals. There are an estimated 47 million Americans without health insurance coverage. The Kaiser Family Foundation reports, “Combination therapy alone costs between \$10,000 and \$12,000 per patient per year depending on the regimen and payer. When additional medical expenses for doctor’s visits, laboratory tests, and drugs to prevent or treat HIV-related opportunistic infections are taken into account, average annual costs rise to approximately \$18,000 to \$20,000 per patient, with even higher expenses for those with more advanced HIV-related illness.” “According to recent research, three-drug combination therapy for AIDS, in spite of its

CRITICAL ISSUES

ECONOMIC IMPACT continued

expense, is a cost-effective use of resources. If states offered more instead of less generous ADAP benefits – for example, few or no limits for drug prescriptions per patient, total monthly costs would fall a significant 30%. Much of the decline in costs could be attributed to a reduction in average hospitalization costs from \$750 to \$395” (Manifesto).

Since one quarter of new HIV infections occur among adolescents and young adults (13 to 29), the HIV/AIDS epidemic will impact our population during the most productive years of their life. The Southern States Manifesto states, “Combination therapy was associated with a near doubling in life expectancy for patients with advanced AIDS thereby reducing the average cost of potential life lost. This leads to a figure of \$23,000 per quality-adjusted year of life saved, a measure of the costs to improve and extend life.” According to The Kaiser Family Foundation, U.S. federal funding for HIV/AIDS was expected to total \$22.8 billion in 2007, an increase of 4 billion from 2004. Of this, 57% was designated to care, 12% to research, 9% to cash and housing assistance, 4% to prevention and 17% to combating the international epidemic.

HOUSING

The Centers for Disease Control and Prevention (CDC) estimates that over one million Americans are living with HIV and AIDS. Throughout many communities, persons living with HIV or AIDS risk losing their housing due to compounding factors, such as increased medical costs and limited incomes or reduced ability to keep working due to AIDS and related illnesses. Stable housing is the cornerstone of HIV/AIDS treatment, allowing persons with HIV/AIDS to access comprehensive healthcare and adhere to complex HIV/AIDS drug therapies.

The affordable housing stock in Spartanburg County is limited which affects all low or very low income residents. Increasing access to affordable, stable and safe housing would benefit all underserved and vulnerable populations.

Without stable housing, people living with HIV/AIDS may be unable to focus on treatment and prevention of the disease.

MEDICAL CARE

Early Treatment: Treatment advances have substantially reduced AIDS-related mortality. Treatment has extended the lives of many and in some cases improved their quality of life. Current treatments are not a cure and may not work for all HIV positive people. Treatment with powerful HIV/AIDS drugs can have a dramatic impact on the disease, including slowing the progression of HIV to AIDS. Powerful treatments may come with debilitating side effects impacting the ability to work and take care of day to day living.

Early HIV care and treatment keeps people healthier, working longer, prevents new infections, lengthens and improves lives, and saves money. According to the Southern AIDS Coalition’s 2009-2010 recommendations, “evidence exists proving that a person with HIV/AIDS who is in care and/or on treatment is less biologically able and less behaviorally likely to transmit the virus to others.” Care and support services can increase productivity through fewer sick days due to untreated HIV. Keeping people in care can prevent the development of drug-resistant

CRITICAL ISSUES

***MEDICAL CARE* continued**

strains of HIV. HIV medications can reduce the amount of the virus in the body, which reduces the level of infectiousness, and the transmission of the disease to others. Early treatment for pregnant women almost eliminates mother-to-child transmission.

Numerous academic studies show early treatment of HIV disease is cost effective. Researchers in British Columbia, Canada analyzed the relationship of direct medical costs of medications, hospitalizations, physician visits, and laboratory tests to an increase in the proportion of HIV-infected individuals...”Researchers found that increased treatment reduced the incidence of new infections, and despite the up-front costs to increase HAART (Highly Active Anti-Retroviral Therapy) use, the expansion was cost effective within four years.” Studies also show that medical costs for individuals entering care late in their disease process is significantly higher than for those entering early with the largest difference in cost attributable to HIV-related inpatient hospitalization (SHARP Report).

Access to Medications: The South Carolina AIDS Drug Assistance Program (ADAP), a part of the South Carolina Department of Health and Environmental Control’s HIV/STD division, provides free/low-cost HIV/AIDS medications to eligible individuals, including measures for the prevention/treatment of opportunistic infections. ADAP serves more than 3000 people annually with a formulary of close to 70 medications. As of April, 2012, this program has a waiting list of approximately 400 people. South Carolina continues to struggle with funding for the ADAP program. Each year the S.C. HIV/AIDS Task Force brings attention to the need for these life-saving medications at the state legislative level.

“Proper treatment is essential for suppression of the virus. ADAP shortfalls can lead to restrictions such as stiffer eligibility requirements, stricter clinical requirements, limited formularies, waiting lists and gaps in coverage. These restrictions can lead to dangerous treatment interruptions, which encourage drug resistance and discourage patient retention in care, both of which have profound effects on public health. Since near perfect adherence to drug regimens are required for successful treatment, it is important to ensure the consistency of state ADAPs” (www.tiicann.org).

MENTAL HEALTH

Mental illnesses affect more than 57 million Americans. They can strike individuals from all walks of life no matter what age, race, education, gender or income. They can affect the person's ability to think clearly, their behavior and how they relate to others. Mental illnesses are medical illnesses just like diabetes, high blood pressure or heart disease. Today, according to ongoing research, 80-90% of people with mental illnesses will improve or recover if they get appropriate treatment. An accurate diagnosis by a doctor or mental health professional is critical. According to research by the American Psychiatric Association, HIV prevalence among people with severe mental illness is greater than the general population and HIV risk behaviors are common among people with severe mental illness.

CRITICAL ISSUES

MENTAL HEALTH continued

A high adherence rate to advanced therapy for HIV, HAART, is required to adequately suppress the virus, limit drug resistance, and reduce transmission. Mental health issues, such as depression, can make adhering to a complicated medication regimen extremely difficult. “Like other serious illnesses such as cancer, HIV often can be accompanied by depression, an illness that can affect mind, mood, body and behavior. Treatment for depression helps people manage both diseases, thus enhancing survival and quality of life...Although as many as one in three persons with HIV may suffer from depression, the warning signs of depression are often misinterpreted...Some of the symptoms of depression could be related to HIV, specific HIV-related disorders, or medication side effects...Whatever its origins, depression can limit the energy needed to keep focused on staying healthy, and research shows that it may accelerate HIV’s progression to AIDS” (National Institute of Mental Health).

According to Heather Ravnan, LISC-CP, “research consistently shows that talk therapy in combination with medication achieves better outcomes than medication alone for the treatment of depression and other mental health conditions. Thus, the availability of talk therapy for people living with HIV/AIDS can be an important part of their treatment by helping them cope more effectively with the stressors of managing a chronic illness.”

PREVENTION

In the United States, investments in HIV prevention have paid off. The rate of new HIV infections has slowed from more than 150,000 in the mid-1980s to 55,000-58,500 per year now. Despite the substantial decline, the rate of new infections is still unacceptably high, making prevention as important as ever (CDC). The goals of HIV prevention are:

- to decrease those persons who are at a high risk for acquiring HIV,
- to change and maintain behaviors to keep them uninfected,
- to provide skills for a behavioral change and
- to prevent new infections by working with persons diagnosed with HIV.

Education

HIV education raises fundamental issues and addresses taboo subjects such as sex, gender, drugs, and death. HIV/AIDS educators are often limited in the information they can provide which makes accurate information difficult to access. Effective HIV education programs promote the facts about HIV/AIDS, dispel myths, and provide linkage to related programs. Comprehensive sex education may not only help to prevent the spread of HIV, but could help eliminate future stigma and discrimination.

Testing

The CDC estimates that 850,000 to 950,000 persons in the United States are living with HIV and of those, an estimated 21% are unaware of their infection. Early testing allows people to take necessary precautions to prevent spreading HIV to others. The earlier the start of treatment, the greater the delay in the onset of serious complications associated with HIV/AIDS.

CRITICAL ISSUES

PREVENTION continued

The Centers for Disease Control and Prevention recommends routine HIV testing of patients 13 to 64 years of age. Because early detection is crucial in maintaining health, these new guidelines are meant to identify and bring to treatment the estimated 250,000 Americans living with undiagnosed HIV infection (Johnson). Confidential HIV counseling and testing is available at Piedmont Care, the Spartanburg County Health Department, and the Spartanburg Alcohol and Drug Abuse Commission.

Condom Distribution

Consistent and correct use of male latex condoms can reduce (though not eliminate) the risk of HIV and other STD transmission, as well as unintended pregnancy. Laboratory studies have demonstrated that latex condoms provide an essentially impermeable barrier.

According to the South Carolina Campaign to Prevent Teen Pregnancy, “Over half of all South Carolina high school students have had sex (53.4%) and only 60% of sexually active high school students in South Carolina used a condom at last sexual activity. Abstaining from all sexual behaviors is the only way to completely protect against sexually transmitted infections, HIV and pregnancy.”

Reports by the CDC show that condom distribution programs are cost-effective and cost saving. These programs are effective in increasing condom use, increasing condom acquisition or condom carrying, promoting delayed sexual initiation or abstinence among youth, and reducing incident STIs. Condom distribution programs can increase condom use among a wide range of populations.

STIGMA

According to Dr. Theodore de Bruyn stigma is associated with HIV/AIDS because, “it is a life-threatening disease; people are afraid of contracting HIV; it is associated with behaviors that are considered deviant; a belief that HIV/AIDS has been contracted due to unacceptable lifestyle choices; and, some believe it is the result of a moral fault which deserves punishment.”

Stigma exists worldwide, but may have a unique role in HIV/AIDS care and prevention in our community. According to the 2009-2010 South AIDS Coalition HIV/AIDS Health Care Policy Brief and Recommendations, beliefs labeled as “conservative” that are predominant in the South,

“have often resulted in the documentation of a culture that blames those with HIV/AIDS due to supposedly sinful behavior, which is especially true for MSMs (men who have sex with men) and persons who use or abuse drugs. These ideologies contribute to an environment that is indifferent or hostile to all persons living with HIV/AIDS, regardless of how the disease was contracted.”

The stigma surrounding HIV/AIDS affects how we prevent and treat HIV. Stigma prevents some people from seeking HIV testing. It prevents people from disclosing their HIV-positive status to their friends and family. It disenfranchises people with HIV/AIDS and oftentimes their supporters, as well. It even discourages people living with HIV/AIDS from getting the

CRITICAL ISSUES

STIGMA continued

medical care they need to save their lives.

We cannot solve the HIV/AIDS problem without first creating an environment where HIV/AIDS stigma is not tolerated. Education initiatives such as South Carolina's Comprehensive Sexual Health Education Act could curtail future stigma and discrimination.

TRANSPORTATION

Lack of accessible, low cost, and reliable transportation is a barrier to health care throughout South Carolina. People living with HIV/AIDS who are in treatment must visit their physician often for monitoring and follow-up. Approximately 30% of the HIV epidemic in South Carolina is located in extremely rural areas with little or no access to public transportation. Reliable transportation has a positive impact on linkage to and retention in care, as well as compliance with medication regimens.

Transportation is also a challenge for those seeking HIV prevention services such as community-based counseling and testing.

The Ryan White Program does not consider the provision of transportation services a priority demonstrating a program bias toward urban settings. Rural communities in the South are hardest hit by this epidemic; therefore, transportation services and the development of efficient public transportation options are critical.

PROJECTIONS AND TRENDS

HIV/AIDS does not lend itself easily to projections, particularly in an area as small as Spartanburg County. The Spartanburg County HIV/AIDS Committee is comfortable making the following statements which may relate to Spartanburg County:

- A. There will be an increasing impact on business, industry, and government in terms of costs and productivity.
- B. HIV/AIDS will continue to spread into schools and colleges demonstrating the need for strong prevention education programs.
- C. New drugs to treat HIV/AIDS will continue to be developed.
- D. Community awareness will increase as more people become personally acquainted with someone with HIV/AIDS.
- E. Housing, including long term care, temporary shelters, residential care facilities, and foster care will continue to be needed.
- F. Transportation and mental health services for low income clients will continue to be an urgent need.
- G. The debate over abstinence based education versus abstinence only education will continue.
- H. Health Care Reform will greatly impact the HIV/AIDS care and prevention landscape.

RECOMMENDATIONS

The Spartanburg County HIV/AIDS Committee supports the following recommendations of the *State Healthcare Access Research Project: South Carolina State Report: (SHARP)*

#1. Increase testing, linkage to care, and treatment adherence by combating HIV-related stigma – Stigma is a major barrier for individuals to get tested for HIV and access healthcare and support services after an HIV diagnosis. To address this barrier:

Engage faith-based communities in HIV testing and treatment campaigns, and support federal and state funding for faith-based initiatives.

South Carolina's location in the Bible Belt carries a rich history of religious devotion and social conservatism. As church is the focal point of life for many African Americans, and African Americans are disproportionately affected by the HIV/AIDS epidemic in South Carolina, engaging faith-based communities is essential to reduce HIV-related stigma, increase awareness about HIV/AIDS, and connect HIV-positive individuals to medical care and support services.

- Faith leaders should actively participate in testing campaigns by encouraging their congregations to get tested, volunteering at testing events, and getting tested themselves.
- Advocates should empower faith leaders by putting them in touch with experts and people living with HIV who can educate them about HIV, stigma and related issues.
- South Carolina's Congressional delegation should support funding for public health agencies, nonprofit organizations, and faith-based organizations to conduct prevention and testing activities as well as outreach efforts.

Enforce South Carolina law and pursue federal and state funds to support comprehensive health education.

In the context of HIV, comprehensive health education is often discussed as it relates to prevention. But it is also a critically important part of reducing stigma associated with HIV, and is therefore an essential component of a coordinated strategy to increase testing and promote access to care for people living with HIV and AIDS. In South Carolina, enforcing the state's existing Comprehensive Health Education Act – on the books since 1988 – will help address stigmatizing attitudes about HIV and AIDS. The state is responsible for ensuring that local school districts comply with the Act's requirements, which afford flexibility in the design of comprehensive health education curricula. Historically, enforcement has been lax; consequently, many South Carolina middle school and high school students today do not receive comprehensive health education. To correct this situation and combat stigma by improving health education:

- Health advocates should work with the Department of Education to launch a campaign to enforce the Comprehensive Health Education Act and support local districts that need assistance coming into compliance with providing funding, technical assistance, and curriculum development support.

RECOMMENDATIONS continued

- HIV advocates should work with the Department of Health and Environmental Control (DHEC) and the South Carolina Campaign to Prevent Teen Pregnancy to ensure that federal funds awarded to the state through the new Personal Responsibility Education Program (PREP) are used to support local school districts' implementation of comprehensive health education curricula that address HIV-related stigma and include medically-accurate sexual health and HIV/STI prevention information.

#2. Promote access to comprehensive care and increase access to lifesaving medications.

Emergency federal funding recently reduced the waiting list for South Carolina's ADAP Drug Assistance Program (ADAP) from 290 individuals to 88, but the list is already back over 700 and will continue to grow unless other measures are taken to relieve pressure on the program.

Pursue a statewide HIV waiver for the state's Medicaid program – States can apply for a 1115 waiver from the Centers for Medicare & Medicaid Services (CMS) to expand eligibility for their Medicaid programs to pre-disabled individuals living with HIV. By allowing the state to move people under an income level set by the state into Medicaid prior to the general expansion of Medicaid under the Affordable Care Act in 2014, a waiver would maximize federal funding for healthcare for South Carolinians living with HIV and allow ADAP funds to be used to assist other uninsured and underinsured individuals.

Deploy coordinated Patient Assistance Program (PAP) application software that maintains a secure, networked database of information and consumer data – Such programs allow case managers and providers to securely store patient and doctor information and supporting documentation. Using the entered data, the program can automatically fill out the majority of PAP application forms and create patient reports and notifications. It is possible to link databases across offices to further eliminate duplication of effort by providers, case managers, and consumers in the process of applying for PAP enrollment. This technology will greatly reduce the amount of time case managers and providers spend on PAP applications for consumers who are waitlisted or ineligible for ADAP and help avoid dangerous gaps in treatment.

#3 Continue linkage to care and promote treatment adherence in the corrections context.

The corrections system presents an important opportunity to test and provide treatment for HIV. To ensure that HIV-positive individuals receive comprehensive, uninterrupted treatment and care during and after incarceration.

- **Ensure that routine opt-out testing and linkage to care upon entry remains in place.** Should policies regarding segregation based on HIV status within the South Carolina Department of Corrections (SCDC) change in the future, it is essential that routine, voluntary testing and linkage to care—including HIV specialty care—continue.
- **Secure access to substance abuse and harm reduction services.** HIV-positive inmates currently lack access to substance abuse and harm reduction services, putting them at significant risk of relapse once they are released. Providing substance abuse and harm reduction services for HIV-positive inmates should be a priority for SCDC.

RECOMMENDATIONS continued

- **Provide access to work-release opportunities for HIV-positive inmates.** Current policy denies equal employment opportunities to HIV-positive inmates. Providing additional opportunities for inmates to earn income while developing skills is critical to helping those who are released find employment, which can reduce recidivism, treatment lapses, and risk behaviors that contribute to the spread of HIV. Community advocates should work with SCDC to change current policy and expand employment opportunities for inmates living with HIV—thus improving both individual and public health outcomes.

4. Increase access to quality healthcare and support services – Lack of transportation is a barrier to care and support services for many South Carolinians living with HIV. To address this problem:

- **End geographic disparities in access to transportation and healthcare services.** Currently, federal funding restrictions severely limit the ability of **rural** patients to access healthcare, because providers may allocate only a small portion of their funds for paying for patients' transportation. In rural areas, the lack of public transit options coupled with long distances mean staggeringly high costs for mileage reimbursement for private transportation—and quickly-depleted funding. As profoundly rural areas represent over 30% of South Carolina and public transit systems are available in only a few urban centers, the lack of funding for transportation creates a major barrier to healthcare and contributes to dramatic and unfair geographic health disparities. State advocates should urge the federal Health Resources and Services Administration (HRSA) to change the definition of core service in the Ryan White program to include transportation services.
- **Expand Medicaid transportation options.** South Carolina Medicaid only pays for transportation to medical appointments; it does not pay for HIV-positive individuals' transport to HIV/AIDS service organizations, support groups, dental services, or other basic needs. Expanding transportation options should be a priority for the South Carolina Department of Health and Human Services. Support services are essential to maximize positive health outcomes of individuals living with HIV/AIDS, but lack of adequate transportation means many cannot take advantage of these services.
- **Collocate and synchronize medical and service providers.** Lack of transportation can be a major barrier for consumers who need access to nonmedical services. In some parts of the state, medical and service providers are either one and the same or have effectively collocated. Not only can collocating address the transportation problem by allowing clients to piggyback nonmedical services appointments onto medical appointments, physical proximity can also facilitate smoother provision of care by increasing the dialogue between medical and service providers. This is especially true if the offices share file management software. This arrangement allows case managers to retrieve viral load and other information required for ADAP and other program

applications without having to visit medical offices in person to pull the file or wait for the medical office to provide it.

GLOSSARY

Acquired Immune Deficiency Syndrome (AIDS) - AIDS can affect the immune and central nervous systems and can result in neurological problems, infections, or cancers. It is caused by the human immunodeficiency virus (HIV).

Antiretroviral therapy - Treatment with drugs designed to prevent HIV from replicating in HIV infected persons. Highly active antiretroviral therapy (**HAART**) is an antiretroviral regimen that includes multiple classifications of antiretroviral drugs.

Confidentiality – Pertains to the disclosure of personal information in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the original disclosure.

Confidential HIV test – An HIV test for which a record of the test and the test results are recorded in the individual’s chart.

ELISA – Enzyme-linked immunosorbent assay. A commonly used screening test to detect antibodies to HIV.

High-risk behavior - Those behaviors that increase the chance of harm to one's body including the chance of being infected by the AIDS virus.

Human Immunodeficiency Virus (HIV) - The virus that causes AIDS. It destroys the immune system by invading and attacking T-cells, the white blood cells that attack infection.

Incidence – The number of new cases in a defined population within a certain time period. Used to measure disease frequency.

Injection drug user – Someone who uses a needle to inject drugs into his or her body.

MSM – Risk category for HIV-infection representing “men who have sex with men.”

Prevalence – The total number of cases of a disease in persons not known to have died in a given population at a particular time.

Risk factor – Behavior or other factor that places a person at risk for disease.

Ryan White Treatment Remodernization Act – (Formerly the Ryan White CARE Act) The Federal Ryan White Program was enacted in 1990 to improve the quality and availability of care for low-income, uninsured, and underinsured individuals and families affected by HIV disease.

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INTERNET RESOURCES

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AIDS Map: www.AIDSVu.org

American Foundation for AIDS Research: www.amfar.org

Centers for Disease Control and Prevention: www.cdc.gov

Community Access National Network: www.tiicann.org

Doctors of the World – USA: www.doctorsoftheworld.org

Joint United Nations Programme on HIV/AIDS: www.unaids.org

Kaiser Family Foundation: www.kff.org

Kaiser Network: www.kaisernetwork.org/dailyreports/hiv

National Association of People with AIDS: www.napwa.com

National Minority AIDS Council: www.nmac.org

Piedmont Care: www.piedmontcare.org

S.C. Department of Health and Environmental Control: www.scdhec.gov/

Spartanburg County Alcohol and Drug Abuse Commission: www.sadac.org

The Body: An AIDS and HIV Information Resource: www.thebody.com

The Pandemic: Facing AIDS project: www.pandemicfacingaids.org

U.S. Census Bureau: <http://quickfacts.census.gov/qfd/index.html>

U.S. Department of Health and Human Services: www.dhhs.gov

U.S. Health Resources and Services Administration: www.hrsa.gov

U.S. White House: www.whitehouse.gov

World Health Organization: www.who.org