



## HIV Infrastructure Study

Columbia, SC

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## **BACKGROUND |**

The Southern US has been disproportionately affected by HIV/AIDS. CDC epidemiologic data indicate that this region of the US had the highest HIV and AIDS diagnosis rates in the US in 2011.<sup>1</sup> In addition, in 2011 all but one of the metropolitan areas of populations 500,000 or greater with the highest AIDS diagnosis rates were in the Deep South region.<sup>1</sup>

A subset of Southern states is particularly affected by HIV disease and shares characteristics such as overall poorer health, high poverty rates, an insufficient supply of medical care providers and a cultural climate that likely contributes to the spread of HIV.<sup>2-4</sup> These states include Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee and East Texas. Henceforth these states will be referred to as the “targeted states.” HIV and other STDS disproportionately affect individuals in the targeted states and these states share similarities in HIV-related outcomes including the highest HIV case fatality rates in the US.<sup>5</sup> Thirty-two percent of new HIV diagnoses were in the targeted states in 2011 while this region accounted for only 22% of the US population.<sup>1,6</sup>

In order to determine how best to address and improve HIV-related outcomes in communities in the South, we are examining existing HIV-related prevention and care infrastructure and community characteristics of targeted state Metropolitan Areas (MA) that are consistently in the top ten for HIV and AIDS diagnosis rates. Due to high HIV and AIDS diagnosis rates, Columbia SC was selected as one of the communities of study.<sup>7</sup>

## **METHODS |**

In order to gain a more in-depth understanding of the HIV epidemic in the Columbia MA we conducted a community case study using both quantitative and qualitative data sources. This case study examined the infrastructure for HIV prevention and care in Columbia as well as the strengths and challenges for addressing the disproportionate HIV epidemic in the area. This case study included structured interviews with 10 individuals involved in HIV prevention and care, community leaders, advocates, and individuals living with HIV. In addition, a focus group of individuals living with HIV in Columbia was facilitated to gather information on their experiences and perspectives regarding HIV care, HIV prevention, stigma, and factors that influence HIV in their area. Data collection was completed in Spring 2014.

In addition to the qualitative data collection, we identified and summarized existing data sources regarding HIV and STD epidemiology, other health status indicators, community health needs, and service gaps in the Columbia MA. These data sources included community needs assessments, media outlets and state HIV epidemiologic reports.

## RESULTS |

### METROPOLITAN AREA DESCRIPTION

The Columbia SC metropolitan area (MA) consists of 6 counties: Calhoun, Fairfield, Kershaw, Lexington, Saluda and Richland. Richland County contains most of the city of Columbia. According to 2012 US census data, the Columbia MA population was 784,531<sup>8</sup> and the population in the city of Columbia was approximately 131,686.<sup>9</sup> The racial composition of the Columbia MA is 63.4% White, 32.9% African American and the median income for a household in the MA is \$37,051.<sup>10</sup>

Columbia is the state capital and the largest city in South Carolina. It is the only city of substantial size in the MA. In 2010, the racial makeup of the city was reported to be 51.3% White and 42.2% Black. The percentage of the population within Columbia that was Hispanic or Latino of any race was 4.3%. The median income for a household in the city was \$40,550 and 24.3% of residents were living below the poverty level in comparison to 17.6% for the state of South Carolina from 2008-12.<sup>9</sup> Major employers in Columbia include the South Carolina state government, local health care/insurance systems and the University of South Carolina.<sup>10</sup>

***24.3% of Columbia's residents lived below the poverty level from 2008-***

The demographic makeup, poverty level and median income vary among the 6 counties that comprise the Columbia MA. Lexington County, for example, has a population that is 81.3% White, 14.9% Black and 5.7% Latino.<sup>9</sup> The median household income is \$53,644 and 12.4% of the population lives below poverty level. In contrast, Fairfield County's population is 39.6% White, 58.6% Black and 1.9% Latino. The median household income is \$35,452 and the 23.1% of the population lives below the poverty level.<sup>9</sup> Within the Columbia MA, there also exists large variation in population density. For example, several of the counties in the MA, including Calhoun and Fairfield counties, have approximately 34 people per square mile, while Richland County has more than 500 people per square mile.<sup>9</sup> The variation between counties within the Columbia MA may result in challenges to adequately providing services for the entirety of the population and may necessitate different HIV programming tailored to reach and be effective for the various areas within the MA.

| <b>Counties</b> | <b>Population Density (2010)</b> | <b>Race/ethnicity (2012)</b>                 | <b>Median Income (2012)</b> | <b>Persons Below Poverty Level (2008-12)</b> | <b>HIV Prevalence Number (rate)</b> |
|-----------------|----------------------------------|--|-----------------------------|--|-------------------------------------|
| Calhoun         | 39.8                             | White 55.2%;<br>Black 42.8%;<br>Latino 3.2%  | \$39,843                    | 18.2%  | 27<br>(178.3)                       |
| Fairfield       | 34.9                             | White 39.6%;<br>Black 58.6%;<br>Latino 1.9%  | \$35,452                    | 23.2%  | 50<br>(212.1)                       |
| Kershaw         | 84.9                             | White 72.4%;<br>Black 25.1%;<br>Latino 4.1%  | \$44,068                    | 16.1%  | 97<br>(155.8)                       |
| Lexington       | 375.4                            | White 81.3%;<br>Black 14.9%;<br>Latino 5.7%  | \$53,644                    | 12.4%  | 333<br>(124.7)                      |
| Richland        | 507.9                            | White 48.3%;<br>Black 46.8%;<br>Latino 5.0%  | \$48,420                    | 16.4%  | 1719<br>(441.8)                     |
| Saluda          | 43.9                             | White 69.9%;<br>Black 26.3%;<br>Latino 14.8% | \$39,541                    | 18.1%  | 23<br>(115.7)                       |

***Health Indicators:***

Data from the Department of Health and Human Services' Community Health Status Indicators shows that Richland County, which contains the city of Columbia, as well as Calhoun, Fairfield, and Saluda Counties has poorer health indicators than the US average in many categories including low birth weight, infant mortality, and life expectancy, as well as death rates from breast cancer, lung cancer, stroke, and heart disease.<sup>11</sup> On the other hand, although Lexington and Kershaw Counties have lower rates than the US overall in many areas such as life expectancy, these counties had slightly better outcomes on infant mortality and heart disease death rates than the overall US.<sup>11</sup>

A 2013 community health needs assessment conducted by local health care systems for Richland and Lexington Counties indicated that access to health care was a significant concern, particularly for the uninsured. The largest barriers to medical care access and utilization were related to the cost of care and insurance. The assessment also reported extensive use of emergency departments as the primary

medium of health care, particularly for low-income respondents. Qualitative data from community leaders identified that the most commonly identified needs were access to care, diabetes, dental, heart disease, and mental health. HIV/AIDS was only briefly mentioned in the report.<sup>12</sup>

Parts of all counties within the MA were designated as health professional shortage areas by the Health Resources and Services Administration (HRSA) indicating that these areas have too few primary medical care providers, dental providers and/or mental health providers.<sup>13</sup> The shortage areas may be designated for a particular geographic area, demographic area such as low-income populations, or institutional, demonstrating a lack of facilities to provide care. Portions of the MA have HPSA designations for locations, including entire counties or particular neighborhoods, low income populations, and for specified institutions including clinics and correctional facilities in the categories of primary care, dental and mental health. Every county in the MA has at least one form of HPSA designation.

### **Housing:**

In 2010 in the city of Columbia, 33.8% of households were found to be experiencing a housing problem, including cost burden of housing, a physical defect in the housing unit, or overcrowding. Cost burden of housing was the most significant

***30.6% of Columbia's households spend more than 30% of their household income on housing.***

concern, with 30.6% of all Columbia households spending more than 30% of their household income on housing, and 15.4% having a cost burden of more than 50% of income.<sup>14</sup>

The city of Columbia prioritized 7 areas as particular housing needs for 2014-15 based on market analysis, housing needs assessments and community input. Two of the prioritized needs included permanent housing for people living with HIV/AIDS and financial assistance to prevent homelessness within the HIV-positive population.<sup>15</sup> The Columbia MA receives HOPWA funds directly from the Department of Housing and Urban Development (HUD) and has a budget of \$2.3 million for FY 2013-14 to fund housing services for people living with HIV/AIDS (PLWHA) within the MA.<sup>15</sup> These funds are allocated to six agencies in the area to increase affordable housing options and provide emergency housing and supportive services for the HIV-positive community.

According to the South Carolina Plan for Consolidated Housing and Community Development for the years 2011-15, it was estimated in 2009 that 1.1% of the homeless population in South Carolina was HIV-positive. This figure, which is likely underestimated, is three times the rate of positivity in the general South Carolina population, thus indicating a particular need for housing for people living with HIV/AIDS as well as programs targeting the homeless HIV-positive population.<sup>15</sup> The level of homelessness or unstable housing among PLWHA is concerning as it may impede their ability to engage in and maintain care for their HIV as well as any comorbidities. A 2004 housing study of PLWHA that included Richland County and the city of Columbia indicated that 46% of people were unemployed, thus limiting

their access to stable housing. This report, although dated, demonstrated a significant need for affordable, long term housing in South Carolina for PLWHA.<sup>14</sup>

***Unstable housing among PLWHA...may impede their ability to engage in and maintain HIV care...***

## **HIV/AIDS IN THE COLUMBIA MA**

Columbia has consistently been ranked among the US metropolitan areas (with population greater than 500,000) that have the highest HIV/AIDS diagnosis and prevalence rates. Columbia's HIV diagnosis rate has ranked in the top 15 MAs since 2008 for all years with available data and the AIDS diagnosis rate has been in the top ten for the latest two years with available data, 2010 and 2011. For HIV and AIDS prevalence, Columbia has consistently been among the ten MAs with the highest rates from 2008-2011.<sup>1,7,16-18</sup> Columbia's younger population has been particularly affected by HIV. In 2010, Columbia had the highest HIV diagnosis rate among males ages 13-24 and the 9<sup>th</sup> highest diagnosis rate for females 13-24 of any MA in the US.<sup>7</sup> In 2011, Columbia's ranking of HIV diagnosis rate remained high for these younger population groups, ranking 7<sup>th</sup> in HIV diagnoses among 13-24 year old males and 9<sup>th</sup> among males ages 25-34<sup>19</sup> In addition, death

***In 2011, Columbia ranked 7<sup>th</sup> in the country in HIV diagnoses among 13-24 year old males.***

***Columbia had the 10<sup>th</sup> highest death rates for HIV+ men and women in the United States in 2011.***

rates among individuals living with HIV were high in the Columbia MA compared to other regions, as Columbia ranked 10<sup>th</sup> highest in death rates for both men and women who were HIV-positive.<sup>19</sup>

According to the 2013 HIV Epidemiological Profile of South Carolina, 36% of PLWHA in the state were defined as "not in care," meaning that they were known to be HIV-positive but had not received a CD4 or viral load count in the previous year. This figure accounted for the percentage of people who had received an HIV diagnosis, but did not receive their labs in the previous year, therefore it should be noted that there exist a number of individuals who are HIV positive and as yet unaware of their status that are not included in the "not in care" figures. Of those not in care, 41% had a AIDS diagnosis, meaning their HIV disease had progressed to meet AIDS diagnostic criteria set by the CDC. Men accounted for 73% of the individuals not in care and 67% of the individuals out of care were Black, while 26% were White.

The Columbia MA receives Ryan White Part B funding from the state. The Columbia MA does not receive any Ryan White Part A funds. In South Carolina in 2012, 8,180 individuals received Ryan White services out of a total of 14,044 individuals estimated to be living with HIV at the end of 2010. These services included medical

care, medical case management, medications through the AIDS Drug Assistance Program (ADAP), oral care, mental health and substance use treatment, and support services. Of available Ryan White funded services (2012), South Carolinians most often utilized medical case management services, followed by medical care and substance use services.<sup>20</sup>

Medicaid covers HIV-positive individuals in South Carolina that are eligible for this program. To be eligible for Medicaid in South Carolina, individuals must be approved for social security disability and meet the Medicaid income eligibility criteria or be parents of dependent children that subsist at 67% of the poverty level, which translates to an annual income of \$13,084. South Carolina does not have a Medicaid medically needy program, which would allow the state to extend Medicaid coverage to those who have too much income or assets to qualify for Medicaid but have especially high medical expenses. Medicaid coverage in South Carolina allows 12 visits annually to a physician or medical center, including federally qualified health centers and ambulatory care facilities.<sup>21</sup> State approved substance use and mental health services are covered. Prescription coverage includes 4 prescriptions a month, though there may be allowed up to 10 with specific overrides.<sup>21</sup> South Carolina has chosen not to expand Medicaid coverage as a part of the Affordable Care Act (ACA).

## **HIV CARE INFRASTRUCTURE |**

### ***HIV Medical Care:***

HIV medical care resources in the Columbia MA include the University of South Carolina (USC) Infectious Disease (ID) Clinic, the Eau Claire Federally Qualified Health Center (FQHC), which provides primary care and HIV specialty care, and some private Infectious Diseases (ID) physicians in the city of Columbia and outlying counties including Fairfield, Lexington, and Kershaw. HopeHealth Edisto has Ryan White Part B and C funding to provide HIV medical care in Calhoun County, one of the Columbia MA counties, and Upper Savannah Care has Ryan White Part B funding to provide medical care to another one of the Columbia MA counties, Saluda County. While medical care services are available for people residing in the MA counties, Calhoun, Fairfield, Kershaw and Saluda Counties do not have HIV-specific medical care within the county, necessitating travel to find adequate care. Interview participants generally reported that wait times for medical appointments were relatively brief, not longer than 2-3 weeks for new patients. However, some participants reported relatively long waits to see the provider once they arrived at the appointment. In addition, most participants reported that other than for the private physicians, access or waiting times for HIV medical care did not differ by type of medical insurance.

Obtaining HIV medical care was consistently reported to be more difficult for individuals living in areas of the Columbia MA that are outside of the city of Columbia. Although these areas are considered to be metropolitan because they are

included in the Columbia MA, they experience barriers common to more rural areas including lack of qualified health providers and reliable transportation. Individuals with HIV living outside of Columbia are often reluctant to seek care in their immediate area due to fears of being identified as HIV-positive, causing them to travel to Columbia to receive care if possible.

Medications were reported to be accessible through the ADAP program for those who meet the eligibility criteria of income at 300% or lower of the federal poverty level. Some participants reported that although the ADAP formulary covers HIV-related medications, antidepressants, and other commonly prescribed medications, there are medications for psychiatric and medical comorbidities that are not covered so may be difficult for clients to obtain. South Carolina's ADAP program also includes an Insurance Assistance Program (DDP) for insured persons at or below 550% of the federal poverty level that reimburses insurance premiums, copays, and deductibles. ADAP's Medicare D Assistance Program (MAP) assists with Medicare Part D copays and deductibles, including during a coverage gap or doughnut hole.

Interview and focus group participants described a lack of availability of dental care. However, some focus group participants were able to access these services through the Eau Claire FQHC. The FQHC has dentists available to provide dental services for HIV-positive individuals.

### ***Transportation:***

HIV-positive individuals who live in outlying areas of the Columbia MA were consistently reported to encounter significant transportation barriers to obtaining HIV care in Columbia. According to key interview participants, buses are often unavailable outside Columbia city limits. The bus system within Columbia city limits was described as unreliable at times, resulting in difficulty obtaining public transportation for individuals with HIV. Ryan White and Medicaid were reported to provide some limited transportation for those qualifying for transportation services. One key interview participant noted that although Medicaid covers transportation to medical appointments for eligible individuals, there is a requirement for a three-day notice to schedule transportation, resulting in Medicaid transportation not being a viable option for more urgent situations. The Eau Claire clinic is able to provide bus tickets and gas vouchers and has some contracted transportation providers for individuals with HIV. However, funding for these services is often limited due to the demand for the services exceeding the available funding. Several key interview participants discussed a need for telemedicine to address barriers to HIV treatment including transportation for individuals with HIV living in more rural areas and lack of adequately trained medical care providers. They also expressed an interest in working with other areas that have implemented these telemedicine programs in order to begin development of a program in South Carolina.

The South Carolina HIV/AIDS Council maintains two vans that are used to assist selected HIV positive clients facing transportation barriers. During October 2014, the agency received a small grant from a national foundation to assist eligible clients

enrolled in HIV medical care within a local physician’s practice with gas vouchers, cab vouchers, or direct transport to and from place of residence.

### ***Social and legal services:***

Case management services are reported to be available for individuals eligible for Ryan White coverage; however, one key interview participant stated that these services are limited to medical case management and thus may not cover all social service needs a client may experience. An insufficient supply of case managers to meet the demand was also noted as a barrier to receiving these services in all parts of the MA. Targeted HIV case management is covered by Medicaid in South Carolina, though participant experiences with Medicaid differed.<sup>22</sup> Several key interview participants reported that South Carolina Medicaid pays very little for HIV case management services for individuals living with HIV. Some focus group participants reported that Medicaid would not cover their case management services while others said that they did receive case management through Medicaid. For example, one focus group participant said:

***“I don’t have a case manager because I have Medicaid” while another said “I do have a case manager with Medicare and Medicaid. I mean there’s not really much that I really need but when I do need, all I’ve got to do is call my case manager and go in. Every year we do our assessments and what not.”***

In Columbia, HIV case management services are provided by the South Carolina HIV/AIDS Council, Eau Claire FQHC and the USC ID clinic. The USC ID clinic also provides HIV case management in Fairfield, Lexington, and Kershaw Counties in the Columbia MA. HopeHaven- Edisto provides HIV case management services for clients in Calhoun County and Upper Savannah Care Services provides HIV case management services for clients in Saluda County. The HIV case managers assist clients in obtaining services such as prescription medicine coverage through ADAP, transportation, housing, and medical care.

Legal services were reported to be difficult to access for individuals with HIV in the Columbia MA. No legal services were identified that specialize in working with HIV-positive individuals or with any specific HIV-related issues such as discrimination or breach of confidentiality in any of the counties contained in the Columbia MA. Individuals with HIV in need of legal services must try and access an overburdened and under-resourced general public legal aid service. The legal aid organization, South Carolina Legal Services, provides assistance with education, employment claims (though not discrimination cases), housing, family law, public benefits, wills and estates, claims of migrant farmworkers, federal tax problems, and community economic development.

***Individuals in need of legal services must try and access an overburdened and under-resourced general public legal aid service.***

### **Support Groups:**

HIV support groups are available for individuals with HIV through a local AIDS Services Organization, South Carolina HIV/AIDS Council. South Carolina HIV/AIDS Council has support groups available for men, women, and families. Challenges were reported in having consistent attendance at the groups because of stigma, confidentiality concerns, and transportation. Support groups are also available at the USC ID Clinics including a general HIV support group and a group for young adults 18-24 years old. A key interview participant had the following comment about support groups:

***“I think that’s one of the biggest things that we’ve seen, they don’t feel alone. I think that’s been the biggest barrier for a lot of people to get into care. Again, they think that they are the only person who is dealing with this. These support groups have been really -- have taken off and done really well ... One of the topics one time (was a) discussion about disclosure and relationships. I think one of the heterosexual women said, ‘I’ve never had an opportunity to understand what a young, gay man would have gone through. Because I had my own reservations, my own values that kept me from understanding.’ And she said, as we were leaving the group, that ‘people are people and we all have hearts and we all have relationships and our hearts get broken and that’s what I learned today.’ That was quite powerful.”***

### **Substance abuse and mental health care:**

Interview and focus group participants consistently reported that mental health services are often very difficult to access. The USC clinic has a part-time mental health counselor and psychiatrist but study participants believed that this is not enough to meet the mental health needs of all of the patients seen at the clinic. Eau Claire FQHC has a psychiatrist and counselors available for clients who are willing to access these services. Several interview participants described mental health services provided through the counties as difficult to access unless an individual is severely mentally ill. Focus group participants reported the same perceptions regarding the lack of availability of community mental health services. In addition, mental health stigma and lack of education about mental health and mental health services were reported to be barriers to receiving the services that are available in the community.

Interview and focus group participants all described substance abuse services to be limited both for outpatient and inpatient care. Focus group participants reported that copays for substance abuse services are often prohibitive. As one participant stated: ***“There are no free alcohol and drug use services anywhere.”***

**“There are no free alcohol and drug use services anywhere.”**

There is one federally funded program specially for individuals with HIV and substance abuse issues.

Project PACT (***Personal Action Changes Things***) is a Substance Abuse and Mental Health Services Administration (SAMHSA) funded program facilitated by the South

Carolina HIV/AIDS Council in partnership with the Lexington Richland Alcohol and Drug Abuse Council (LRADAC). The program model is designed to enhance early diagnosis and treatment among individuals combatting addiction to alcohol and other drugs. This two-year partnership supports the ability of both agencies to improve quality of life by providing treatment services focused on substance use disorders, mental health diagnoses, and HIV/AIDS and STI risk reduction. The program provides counseling and coaching intervention models to assist clients in implementing change to better their lives and decrease the incidence and prevalence of substance use. The PACT program integrates linkage to HIV/STI medical case management, clinical counseling and mental health into the alcohol and drug setting. Special emphasis has been placed on strengthening LRADAC's capacity to provide culturally competent intervention services to men who have sex with men (MSM)/young MSM (YMSM) communities. Similarly, the South Carolina HIV/AIDS Council is building competencies in alcohol and drug assessment and referral to ensure that individuals that present for services and self-report alcohol use and/or abuse are connected to clinical treatment services.

Federal funding sources such as Housing Options for Persons with AIDS (HOPWA) and SAMHSA were reported to cover some of the costs of inpatient and outpatient treatment for individuals with HIV and to fund some HIV testing for substance users.

## **HIV TESTING AND PREVENTION |**

Key interview participants reported that HIV testing occurs through the local Health Department, although recent restructuring and funding decreases were said to have limited these efforts. Two local ASOs, Palmetto AIDS Life Support Services (PALSS) and the South Carolina HIV/AIDS Council, also provide HIV testing. South Carolina HIV/AIDS Council has a mobile van that is used for testing outreach efforts throughout one urban and five (5) predominately rural counties. During March 2014, the South Carolina HIV/AIDS Council opened the Wright Wellness Clinic, which provides free and confidential HIV/STI screenings and STI treatment for individuals diagnosed through mobile unit outreach. The clinic receives “walk-ins” during selected hours and ensures access to care through a partnership between the South Carolina HIV/AIDS Council and a local physician's practice in Columbia. A triage nurse promotes entry into medical care with individuals who test positive for sexually transmitted infections. Clients can seek treatment two evenings a week and every other Saturday morning. Clients diagnosed with HIV and HCV are referred to local medical providers and selected specialists within the Columbia MSA.

PALSS has a clinic for men that offers HIV testing as well as testing for other STDs and Hepatitis C. PALSS also does testing in outlying counties of the MA. Interview participants reported that statewide HIV testing efforts are now focusing specifically on populations with documented high HIV prevalence including young minority men who have sex with men (MSM) and minority women. One study participant expressed the belief that there was enough testing being done in the region but

thought that the testing efforts could be more efficient by increasing testing in the highest risk communities. In contrast, other participants believed that broader, more saturated testing is needed to help normalize the disease and reduce stigma. The state Department of Health and Environmental Control is initiating plans to provide opt out HIV testing in local emergency rooms, which had occurred in the past but was discontinued.

Other HIV prevention-related activities reported to be provided by community based organizations and/or the health department included community HIV education, condom provision and evidence-based risk reduction interventions with HIV-positive individuals at high-risk of transmitting the disease. The prevention with positives program, Prevention through Action, Care, and Empowerment (PACE) is offered by PALSS and provides counseling to help clients focus on reducing high-risk behaviors.

Most of the funding for prevention was reported to come from the Centers for Disease Control. The South Carolina HIV/AIDS Council was funded by the South Carolina Legislature from FY 2006-FY2011 for Project F.A.I.T.H., (Fostering AIDS Initiatives That Heal), a technical assistance and capacity-building initiative designed to provide HIV health education and risk reduction training, impact HIV stigma, strengthen faith-based health ministries, and open dialogue within African American faith-based institutions and the community at-large.<sup>23-25</sup> After experiencing a veto in funding (FY 2011) the South Carolina HIV/AIDS Council continues scaled-down efforts as funding has been reduced over time. Advocacy efforts continue to re-negotiate revitalization of Project FAITH funding and re-establish momentum within progressive faith-based programs.

Key interview participants reported gaps in prevention efforts including a need for more prevention efforts partnering with black churches, not enough medical care provider education on HIV prevention and treatment, lack of media campaigns (other than on specific occasions such as World AIDS Day), not enough focus on testing and prevention among young minority MSM (including testing for other STIs), lack of ongoing prevention efforts in outlying areas of the MA, and lack of evidence-based comprehensive sexual education in schools. The need for school-based HIV prevention efforts was raised by all key interview participants as well as by focus group participants. Participants consistently reported the belief that evidence-based school HIV education is a critical component in addressing and abating HIV disease in the region, particularly because of the high diagnosis rates among the 13-24 year old age group.

One issue that was raised by several key informant interview participants and focus group participants as potentially contributing to challenges in HIV prevention was an almost fatalistic attitude among some young minority MSM about contracting HIV disease. One key interview participant said that some individuals seem to believe that they were fated to get the disease so were not taking preventive steps. A focus group participant stated that:

***“As a black, gay man, to me a lot of the people who I see who do test positive or when they do come and get tested, even if they’re negative they’ll be like well it doesn’t matter because I’m going to catch it anyway. Like it is what it is. If you catch it, you catch it. It’s like they become so numb to it that they just don’t care.”***

A key interview participant talked about the different community perspectives on HIV and HIV testing, saying: ***“Some of what I’ve heard third party is ‘well I know that I’ll get HIV so I might as well go ahead and get it and get it over with’ ”*** while for others the key interview

***“Some of what I’ve heard third party is ‘well I know that I’ll get HIV so I might as well go ahead and get it and get it over with’ ”***

***--study participant***

***“I don’t want to get tested because I don’t want to know. I don’t want to know the answer.”***

participant reported that they are highly fearful of the stigma attached to HIV, causing individuals to feel that ***“I don’t want to get tested because I don’t want to know. I don’t want to know the answer.”***

Some key interview participants also stated that the advances in HIV treatment that have resulted in HIV being a more chronic disease may have taken away some of the fear that was present when HIV was more of an imminently fatal disease. They believed that education regarding the significant challenges of living with HIV was needed particularly among the younger population who did not witness firsthand the devastation of HIV prior to HAART. Focus group participants discussed the differences in perception of HIV between the younger and older generations with one individual saying:

***“I was at a party and these teens were sitting off to the side of the porch and were talking about HIV as if it was a common cold. Literally. They were talking about it as if it were a common cold but when you talk to somebody who is up in age in their 40s or 50s on up, they look at it as a death sentence no matter what you tell them because they are associating with what they experienced in the past and until things – it’s just going to be time. That’s the way I look at it.”***

Another participant said the perception among many older individuals is: ***“Why do I need to get tested if I’m just going to die?”***

## **BARRIERS TO HIV CARE AND PREVENTION |**

When asked about barriers to engagement and retention in HIV services, the most commonly reported barriers included stigma, housing concerns, lack of

transportation resources, poverty/lack of insurance, educational deficits about HIV disease, treatment, and navigation of care services, as well as lack of adequately trained professionals in the more rural areas. A key interview participant from a medical facility reported that about 60% of their HIV-positive patients present late and cited these barriers as playing a role in this disturbing trend. For example, the participant said:

***“One of the problems in the rural areas, we’ve found, we find them at the same CD4 cell count but still more develop AIDS within a year of diagnosis”***

The key participant attributed this to lack of resources saying:

***“Most of these counties don’t have designated providers so they need to go somewhere else. As you know, it’s difficult to get transportation through Ryan White and stuff like that.”***

Lack of availability of comprehensive or consistent prevention and testing efforts in these outlying areas was reported as a barrier that deters advocates and limits providers’ ability to adequately address HIV in these communities.

#### ***Housing:***

Nearly all key informants mentioned an inadequate supply of housing as a barrier to medical care and health maintenance. Homelessness and lack of housing supply were reported to be a general community problem rather than specific to the HIV-positive population. Several participants stated that the local housing authority in Columbia was no longer maintaining a waiting list for public housing due to housing supply shortages. In addition, it was reported that there were no long-term homeless shelters in Columbia, rather the shelters were primarily emergency/weather shelters. This factor was hypothesized to impede advocacy efforts around housing, as these efforts are most often centered on long-term housing programs. HOPWA funds were said to be available to assist with some emergency housing financial needs for individuals who are HIV-positive. Housing supply and options for individuals with HIV in the outlying areas of the MA were also reported to be a significant concern.

#### ***Stigma:***

Key interview and focus group participants consistently indicated that HIV-related stigma is pervasive in their community. Some participants believed that direct stigma and discrimination have lessened somewhat over time and have become more “covert” and “under the surface.” Stigma was thought to be driven in part by lack of education and fueled by a conservative climate.

One of the drivers of stigma appeared to be the fear of being labeled as gay, as sexual orientation stigma was reported to be extremely high, particularly among those living in poverty, in more rural areas of the MA, and among the African-Americans. Discussing issues of sexuality was often seen as culturally taboo, a factor that was

reported to contribute to continued HIV stigma. One participant stated that women also face stigma and judgment regarding HIV status and often feel that they need to have an “acceptable cover story” about how they contracted HIV to avoid being labeled as “promiscuous or different.”

A common theme among interviews and the focus group was that HIV-related stigma impedes both HIV prevention and care efforts. Several participants indicated that partnering with churches for prevention activities is often difficult because of stigma related to HIV and sexual orientation. Individuals at high-risk for HIV may choose not get tested so as to avoid having to cope with HIV-related stigma. Those who do find out that they are positive may not feel comfortable seeking treatment, as they fear repercussions such as social isolation or loss of employment that may result from being identified as HIV-positive. One key informant described many individuals with HIV as being afraid to disclose HIV to a partner for fear of domestic violence as a consequence of disclosure. Another key interview participant described an example of how stigma can influence medication adherence, saying:

***“So a kid today said he doesn’t take his meds because he thinks he’s so dirty because all his friends that he knows have a very basic education and they hate fags and they hate AIDS patients and he’s sitting there, ‘I thought they were my friends, now I have no friends because they all think -- If I tell them, it’s over.’”***

Stigma was also discussed at length in the consumer focus group. One of the focus group participants expressed the following regarding stigma: ***“For me stigma is just our biggest problem.”*** Another participant added that ***“In the South, nothing is going to change because we don’t talk about sexuality and we’re in the Bible belt and until we have that conversation, nothing is going to change.”*** In follow-up, another participant stated that ***“We need to talk about it in church. They’re not going to talk about it and until we get over that hump because the stigma with sexuality and religion and the Bible belt, HIV is going to stay stagnant.”***

***“We need to talk about it in church.”***

Focus group participants also discussed stigma in areas outside of Columbia saying:

***“...because they are rural areas, what we’re having as a problem is people running their mouth talking, people who they know, people who are the doctors could be their cousins or whoever, running their mouth and we have this stigma about it so we have a lot of people in Orangeburg, Bamberg, if they have Medicaid or a car, they’ll come here and get their services”***

***Participant2: “Or if they’re out there, they do nothing.”***

**Participant1: "Right."**

***Lack of resources and political support:***

Lack of political will to address this highly stigmatized disease was also mentioned as being culpable for the continued spread of HIV. Respondents consistently stated that political support for addressing HIV is very limited. Some even reported that

**Respondents consistently stated that political support for addressing HIV is very limited.**

stigma and misinformation about HIV is not uncommon among lawmakers, which makes the role of advocates even more challenging.

Participants reported that there are a few state and local politicians who are supportive of HIV-related issues, including the Black Caucus, which

has assisted in gaining funding support for HIV education and prevention programs in African-American churches. One key interview participant said that his perception is that a majority of lawmakers have a "pull yourself up by the bootstraps" mentality, which leads to their lack of investment in addressing social problems such as HIV.

Uncertainty about availability and allocation of funds through Ryan White and other funding sources was also cited as a significant concern when trying to plan and implement HIV services. One key interview participant commented about this ambiguity saying that because of delays and uncertainty regarding funding:

***"you can't go forward with your budget, you can't hire confidently, you have faculty or nurse practitioners who can't recruit as well for when you don't really know what your funding will be."***

The perceived lack of support for HIV-related issues as well as broader health issues for individuals with lower incomes was said to translate into a general lack of funding for comprehensive prevention activities and an ongoing strain to meet medical care needs of individuals with HIV. Lack of state and federal funding was consistently said to impact ability to meet the mental health and substance abuse treatment needs of individuals with HIV. One key interview participant discussed frustration with resource insufficiency saying:

***"One of the things that's most frustrating to me is that they expect Ryan White to cover things and then assume that we refer out to services within the community, such as mental health services, dental services, all these other things that are supposed to be out there and they're not there because of state budget cuts."***

In addition, the dearth of resources was reported to contribute to some competition between organizations for the limited resources available. This lack of agency collaboration was discussed by several focus group participants: ***"I want to share***

***with you the biggest barriers that we have here in South Carolina. It's the competition between the organizations." "The competition is because of money."***

However, participants reported some recent improvement in this situation. One stated:

***"I don't know but I think that changes are happening. I think things are starting to take place but of course there's so much further to go but a lot of people who have never even talked before are talking now so that's a step in the right direction."***

Some focus group participants work in either paid or unpaid advocacy roles and reported that they are attending state HIV/AIDS task force meetings and trying to build collaborations amongst themselves and the agencies where they work or volunteer.

In 2010 the Health Law and Policy Clinic at Harvard University issued a report with recommendations for addressing HIV in South Carolina as part of their State Healthcare Access Research Project (SHARP). This report, which was based on extensive community data collection, noted the substantial stigma related to HIV in South Carolina and made several recommendations for state government that could reduce stigma, improve HIV treatment, and reduce the spread of HIV. These recommendations included: 1) restoring full funding to the faith-based stigma reduction program, Project F.A.I.T.H., as well funding other initiatives to increase the participation of churches in HIV prevention activities, 2) expanding Medicaid transportation options to include visits to ASOs and other social and dental services and 3) "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.<sup>26</sup>" To this date, these findings have not been adopted.

## **HIV-RELATED ADVOCACY |**

### ***Advocacy:***

The community has a number of peers, both male and female, who are working with the local ASOs and the USC clinic to provide support, education, and linkage to resources, and to advocate for HIV-positive consumers to obtain services as needed. However, a need for more paid positions for peers was stated. The formal programs to train peer advocates and to engage advocates regarding policy issues were reported to center primarily on women with HIV. There is an advocacy program called Positive Voices that provides leadership training for HIV-positive women who are willing to disclose their HIV status. In 2010, a program for women, the Women's Empowerment Academy, received funds through AIDS United to provide HIV-

positive women with advocacy training and opportunities to advocate such as speaking on the radio, writing materials, and being involved in legislative advocacy.

This program does not require women to disclose their HIV status so is reported to be acceptable to a broader group of women. Approximately 30% of program participants were reported to have been comfortable revealing their status publically although many more are reported to have disclosed to family/friends after participating in the program. One focus group participant said the following about the program:

***“We used to have like two, three, four people coming to the empowerment meetings. We have over thirty people coming to the empowerment meetings. Now we’re thinking about having two empowerment meetings and it’s just being open and concerned and passionate to people”***

Several key interview participants said that there has been interest in creating more structured advocacy opportunities for men. Efforts to create these opportunities were said to be hampered by stigma among men including concerns about being identified as HIV-positive or thought of as gay. Although not specifically advocacy focused, there are several programs targeted toward educating and empowering MSM, particularly minority MSM, that are offered by local ASOs including the CDC’s evidence based 3MV intervention.<sup>27</sup> In addition, the South Carolina MSM Workgroup and other community partners recently offered an MSM HIV Prevention Institute Conference in Columbia. The South Carolina MSM Workgroup was originally a committee of the statewide South Carolina HIV Planning Council and provides educational programs and information to the MSM community in South Carolina including the Columbia MA. The MSM HIV Prevention Institute Conference offered education and support on managing and preventing HIV disease to HIV positive participants and offered education on working in HIV care and prevention to community professionals including a specific track on young MSM.

There is a statewide HIV/AIDS task force, the South Carolina HIV/AIDS Care Crisis Task Force, which advocates for HIV-related issues in the state and includes both agency representatives and people living with HIV. Approximately one-third of the task force participants were reported to be individuals living with HIV, including minority MSM.

## **FACTORS THAT CONTRIBUTE TO HIV DISEASE AND POOR HIV-RELATED OUTCOMES |**

### ***Why does Columbia have relatively high HIV-related rates?***

Study participants were asked for their thoughts about why Columbia has experienced high HIV and AIDS diagnosis rates. Respondents described characteristics of the MA as contributing to the situation including significant

poverty, high population of medically underserved individuals, lack of transportation and other social services, a culture where HIV and sexual orientation stigmas are high and government is not progressive, and unaddressed social problems such as domestic violence. One participant reported:

***“There’s societal factors. There’s epidemiological factors, the southern epidemic being different than the large cities, California, and the northeast. There’s massive health disparities involved here in the South as everybody knows. Those are less likely to be insured, less likely to be able to navigate systems, there are significant comorbidities ... -- it’s difficult to make a change when there’s no political support to make a change.”***

## **COMMUNITY STRENGTHS AND INNOVATIVE PROGRAMS |**

Key interview participants cited an adequate supply of dedicated medical care professionals as one of the significant strengths of the HIV services community in the city of Columbia (although not in the outlying areas of the MA). HIV care was reported as accessible in Columbia without significant waits for new appointments regardless of insurance status, which was also mentioned as a significant strength. Key participants mentioned having strong and comprehensive AIDS Service Organizations in the community as an additional community asset.

Ryan White Part B providers in the Columbia MA were reported to have positive working relationships and to have opportunities to meet and collaborate, including using data collaboratively to improve HIV prevention and care. Additional community strengths included political advocacy efforts, particularly from within the HIV community through the Positive Voices and Women’s Empowerment Academy. Participants believed that the state Capitol’s nearby location offered a greater opportunity for influencing HIV-related policy and allocations than if it were located at a further distance.

A further strength identified through the interviews was that South Carolina’s ADAP program reimburses low-income participants with private insurance for insurance premiums, copays and deductibles thus expanding available health care for PLWHA who could not otherwise afford private insurance.

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### **Columbia Community Strengths**

#### **-At a Glance:**

1. Available HIV medical care in Columbia;
  2. Strong AIDS Service Organizations;
  3. Strong working relationships among Ryan White Part B providers;
  4. Strong political advocacy efforts within the HIV Community;
  5. Use of ADAP funds to help eligible clients access insurance;
  6. Innovative engagement & retention in care program.
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An innovative program that is currently being planned to address engagement and retention in HIV medical care involves the use of state lab data to identify individuals not receiving medical care and to connect them with a bridge counselor if they consent to this service. The bridge counselor will assist these individuals to access medical care services and address barriers to engagement and retention in medical care. This program will expand on an already existing service that uses the evidence-based model, Antiretroviral Treatment and Access to Services (ARTAS) to connect individuals who are newly diagnosed with HIV medical care.<sup>28</sup>

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## CONCLUSIONS

### -At a Glance:

#### **Barriers to HIV Care & Prevention in Columbia**

1. Lack of transportation;
2. Inadequate housing;
3. Lack of legal assistance;
4. Few mental health & substance use services;
5. Few medical providers trained in HIV care in more remote areas of the MA;
6. Inadequate funding for prevention;
7. Lack of political will;
8. Pervasive stigma.

#### **Suggested Strategies**

1. Telemedicine program to address lack of transportation and medical care in more remote areas;
  2. Increased educational efforts for PLWHA, health care professionals, churches, and community to address stigma;
  3. Co-location of HIV care with other services to combat stigma.
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## CONCLUSIONS |

### *Overview:*

Interview and focus group participants indicated that while there are a number of strengths in terms of HIV prevention and care in the Columbia MA including strong ASOs, provider collaboration, and availability of medical care, there are significant resource limitations that likely fuel the HIV epidemic in the area.

### *Barriers to Care and Prevention and Identified Strategies:*

These resource limitations include limited availability of transportation, housing, legal assistance, mental health and substance use services, and general medical care as well as lack of adequate funding for HIV prevention efforts and lack of significant political will to address issues related to HIV.

The Columbia MA includes six counties, which have some heterogeneity in their demographic characteristics and population densities therefore it was not surprising to find disparities in their HIV services and needs. Resource deficits in services such as transportation, case management, mental health care and HIV prevention were reported to be particularly acute in the more sparsely populated areas of the Columbia MA. The more remote areas of the MA also suffer from a lack of medical providers that are trained and experienced in managing HIV care. Thus individuals with HIV in these areas often must travel to Columbia to seek care. Telemedicine, which has been successfully used in less densely populated areas, was suggested by study participants as a potential mechanism for addressing lack of medical care and transportation availability in these more rural areas.

HIV-related stigma was reported to be very high in the Columbia MA, particularly among minorities, and was implicated as impeding both HIV prevention and treatment, therefore fostering the spread of HIV disease. Addressing this significant stigma was said to be paramount to decreasing the impact of HIV in the Columbia area. Increased educational efforts for HIV-positive individuals, health care professionals, churches, schools and the community at large as well as having organizations that co-locate HIV care with other services such as mental health and substance use were suggested as strategies for beginning to combat HIV-related stigma in the community.

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