



## **HIV/AIDS Care and Prevention Infrastructure in the U.S. Deep South**

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# EXECUTIVE SUMMARY

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## Background

The Southern US has been disproportionately affected by HIV, having the highest HIV diagnosis rates and death rates with HIV as an underlying cause of any US region.<sup>1,2</sup> Nine states in the US Deep South (AL, FL, GA, LA, MS, NC, SC, TN, TX) had especially high HIV diagnosis rates and death rates due to HIV from 2008-2013.<sup>1,3-8</sup> These nine Deep South states contained 40% of HIV diagnoses in 2013, while comprising only 28% of the US population.<sup>1,9</sup> A deeper understanding of the factors that contribute to the disproportionate HIV epidemic in the US Deep South is needed to more adequately address and abate HIV mortality and the further spread of HIV disease. To address this information gap, this study examined HIV care and prevention infrastructures and factors that contribute to the HIV burden and poorer outcomes in the Deep South. Case studies of the HIV-related infrastructures in four metropolitan statistical areas (MSAs) in the region that have pronounced HIV and AIDS diagnosis rates and two control MSAs with similar demographic characteristics but less severe HIV epidemics were conducted.

## Methods

For the six MSAs included in the research (4 “study” MSAs: Baton Rouge LA, Columbia SC, Jackson MS and Jacksonville FL and 2 “control” MSAs: Birmingham AL and Cincinnati OH), we examined preexisting community health data and collected data through interviews and focus groups. Interviews were conducted with individuals providing HIV prevention, care or related services in the MSAs using a standardized format that inquired about availability and structure of HIV care services, prevention services, advocacy, HIV data availability, stigma and other barriers to care, as well as community strengths related to HIV care and prevention. One to two focus groups with persons living with HIV (PLWH) were also facilitated in each MSA following a similar structured interview outline.

## Results

Although the six MSAs varied in population size and composition, they were similar in having higher rates of poverty (with the exception of Cincinnati), STDs, teen pregnancy, diabetes, heart disease, and poorer pregnancy outcomes than the US average. All four study MSAs had high HIV and AIDS diagnosis rates and HIV death rates. However, there were some differences between MSAs in the characteristics of individuals diagnosed with HIV. For example, in 2010, Baton Rouge and Jacksonville had some of the highest proportion of new diagnoses that were female of all US MSAs whereas Jackson and Columbia had high proportions of minority men who have sex with men (MSM) among those diagnosed with HIV. The two control MSAs had AIDS diagnosis rates that were less than half of the rates within the study MSAs in 2013. However, although Birmingham had a lower HIV diagnosis rate than the study MSAs in 2013, this rate was still higher than the overall US rate.

### *HIV Care and Prevention*

In the study MSAs, HIV medical care was most often situated in academic institutions, although some care was also available through other nonprofit organizations and Federally Qualified Health Centers (FQHCs). HIV medical care was reported to generally be available for those able to overcome barriers to care including transportation and stigma concerns. However, medical care was noted to be more difficult to access in the outlying areas of the MSAs primarily because of transportation concerns and a lack of providers located outside of the center city (largest city located in the MSA) of the MSAs. HIV linkage

programs were available in the study MSAs, though they differed in structure and availability. The significant barriers to HIV care participation were consistent across the four study MSAs and included lack of sufficient transportation resources to meet the substantial community needs, lack of quality mental health and substance use treatment, significant HIV-related stigma, inconsistency in support group availability, and an inadequate supply of housing options. Federal Housing Opportunities for Persons living with AIDS (HOPWA) funds were present in each of the communities and were reported to be helpful in meeting some housing concerns. However, HOPWA funds were not sufficient to address the overwhelming housing needs, particularly among MSM and youth. HIV-related stigma was raised as a concern at *all* interviews and focus groups and was said to be pervasive and to deter participation in HIV care as well as HIV testing and advocacy.

HIV prevention services were reported to be concentrated primarily on HIV testing. Testing was noted as mostly available in the MSAs, although some concerns were raised regarding testing funds being directed to high-risk populations, thus resulting in more difficulty accessing testing resources for those not part of these target populations. In the MSAs, HIV testing was offered onsite in places such as STD clinics, Health Departments, and AIDS Service Organizations (ASOs) and through mobile outreach vans. Each community reported some availability of evidence-based HIV prevention interventions but these were very limited. Education and testing programs for minority faith institutions were identified in each MSA, although they differed in scope, organization, and intensity. PrEP availability was also variable in the study MSAs with two MSAs having clinics that provide PrEP while the other two had very limited availability. However, one MSA with limited availability (Columbia) recently secured a grant to enhance PrEP education and availability. Both control communities reported PrEP availability, although PrEP was reported to be underutilized in Cincinnati.

In each community, interview and focus group participants consistently reported needs for more faith based interventions and partnerships with churches as well as a need for more general HIV prevention messaging, particularly through media outlets. Participants reported that there is considerable misinformation and distrust surrounding HIV in their communities, which perpetuates fear and bolsters stigma toward people living with HIV. They believed that more general prevention messages would serve to raise awareness of HIV, dispel myths and ultimately help reduce HIV-related stigma. Lastly, participants universally lamented the absence of comprehensive sex education in schools and believed this factor was contributing to the increase in HIV among youth.

### *Strengths*

Despite the significant challenges and barriers to addressing HIV in the study MSAs, they have considerable strengths that can be built on to better address HIV in their communities. Interview participants consistently reported that their community had some passionate and highly experienced HIV care and prevention providers, leaders, and organizations, and that strong collaborations were in place between some HIV care and prevention organizations, although these collaborations were often dependent on funding and not inclusive of all area providers. Each community had unique situations, strengths, and innovative programs. With adequate resources and technical assistance these innovative programs (outlined in Table 6) may be adapted and implemented in other MSAs.

### *Differences in Control MSAs*

The two control MSAs, Birmingham and Cincinnati, possessed many similarities in HIV care and prevention to the four study MSAs including generally available medical care, lack of adequate transportation resources, high levels of HIV stigma (although more interview participants in Cincinnati thought this was improving than in other MSAs), and lack of adequate behavioral health resources and housing. However, in addition to having similar strengths to the study MSAs, including committed

providers and some interagency collaboration, the control MSAs had additional, unique strengths. Both control MSAs had comprehensive tertiary medical care ID clinics that were the hub of HIV care and research. In addition, UAB has an active Center for AIDS Research and the University of Cincinnati Infectious Diseases Department houses an AIDS Clinical Trial Unit as well as an AIDS Education and Training Center. Both institutions have long standing HIV testing programs in their medical center emergency rooms that included standardized HIV screening, testing, and linkage to HIV care for those newly positive and those who had dropped out of HIV care. In Birmingham, participants lauded the well-organized and active advocacy efforts, particularly those involving individuals living with HIV, along with the consistent and structured collaboration between community organizations and medical practices. The Cincinnati MSA differed from the other MSAs in two significant areas. First is the presence of syringe exchange in the city of Cincinnati, which is unavailable in the Deep South with the exception of some illegal, underground exchanges and a recently funded fledgling effort to lay the groundwork for syringe exchange in Birmingham. The second significant strength unique to the Cincinnati MSA was the presence of Medicaid expansion, which has resulted in a substantial decrease in the number of individuals living with HIV who are uninsured, freeing up some Ryan White funds to pay for services beyond basic medical care.

## **Conclusions**

The case studies of Deep South MSAs disproportionately affected by HIV identify critical resource deficiencies and barriers to HIV testing and treatment that contribute to the disproportionate HIV diagnosis and death rates in the region. Barriers include a lack of adequate transportation, housing, and behavioral health services, as well as a lack of political support and advocacy efforts, and pervasive stigma that strongly impacts participation in HIV testing and treatment. The strengths of the MSAs, including committed providers, agency collaborations, and innovative programs, need to be enhanced to address the significant barriers to care. Study participants identified strategies to reduce barriers and stigma, namely enhancing mechanisms and incentives for collaboration, increasing resources for transportation, housing and behavioral health, enhancing prevention and stigma reduction through saturated media HIV education and collaboration with communities of faith. Resource allocation inequities across regions also need to be addressed.<sup>10</sup>

## BACKGROUND

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The Southern region of the US<sup>i</sup> had the highest HIV diagnosis rate and contained the majority of new HIV diagnoses in 2013.<sup>1</sup> Nine Deep South states (AL, FL, GA, LA, MS, NC, SC, TN, TX), hereafter referred to as the Deep South region, have been particularly affected by HIV, containing 40% of HIV diagnoses in 2013, while comprising only 28% of the US population.<sup>1,11</sup> In addition, eight of the 10 metropolitan areas that contain 500,000 residents or greater with the highest HIV and AIDS diagnosis rates are located within the Deep South.<sup>1</sup> The Deep South region also had the highest death rates among individuals diagnosed with HIV (2010) of any US region.<sup>12</sup> These death rates are higher in the Deep South when compared to other regions even after controlling for demographic characteristics including race, age, gender, and living in a rural or urban area at the time of diagnosis. In addition, the Deep South states had the highest death rates per 100,000 population where HIV was the identified cause of death (2013).<sup>3</sup>

The nine Deep South states share other characteristics that may contribute to their higher HIV diagnosis rates and poorer HIV outcomes including poorer overall health, higher rates of other STDs, high poverty levels, poorer health infrastructures and cultural climates where HIV is highly stigmatized and comprehensive sex education is largely absent.<sup>3,13-16</sup> A deeper understanding of how these and other factors contribute to HIV in the Southern US is needed to better determine necessary steps to more optimally address HIV disparities in the region. This study examined HIV care and prevention infrastructures and factors that contribute to the HIV burden and poorer outcomes in the Deep South by conducting case studies of the HIV care and prevention infrastructures in four MSAs in the region that have pronounced HIV and AIDS diagnosis rates. The study also included an examination of HIV care and prevention infrastructures in two control metropolitan areas with similar demographic characteristics but less severe HIV epidemics. The study findings for these MSAs are synthesized and contrasted to identify themes and determine targets and strategies for intervention.

## METHODS

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Four Deep South MSAs (hereafter referred to as “study MSAs”) with populations of 500,000 residents or greater that were among the 10 MSAs with the highest AIDS diagnosis rates were selected for inclusion in the study (Baton Rouge, LA; Columbia, SC; Jackson, MS; and Jacksonville, FL). Two control MSAs were selected that were similar in size and demographic characteristics to the central cities within the study MSAs. One control MSA was located in the Deep South (Birmingham, AL) and one located outside the Deep South (Cincinnati, OH).

We examined existing demographic and health data for each study MSA and the state containing the MSA including data from community needs assessments, national, state, and county health databases and reports. Whenever possible, MSA-level data were utilized; if these data were not available for the MSA, data for the main city/county for the area were used. Sources commonly examined included data from the US Census Bureau; US Bureau of Labor Statistics; Centers for Disease Control and Prevention; state, county and city health departments and government agencies; and universities and research institutes, among others. These data were used to describe the MSA and state context within which HIV-related services were situated.

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<sup>i</sup> Alabama, Arkansas, Delaware, DC, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia, West Virginia

We also collected data through interviews and focus groups with individuals living with HIV and individuals providing HIV prevention, care or related services in the MSAs between September 2013 and February 2015. In each MSA, information on HIV service providers and other key community informants was gathered through online research and through existing contacts in the community to identify individuals to interview for the study, including those providing direct prevention, care and social services to HIV clients and community and state HIV services leaders. Eight to 10 individuals were identified as potential participants to interview in each MSA and those who agreed to participate and signed the study consent form were interviewed. The interviews consisted of a standardized format that inquired about availability and structure of HIV care services, prevention services, advocacy, HIV data availability, stigma and other barriers to care, and community strengths related to HIV care and prevention. A snowball sampling technique was also utilized, as individuals participating in key informant interviews provided information about other individuals recommended for study participation. Whenever possible, the individuals identified through this sampling technique were interviewed as well. In each MSA, 10 to 15 key informant interviews were completed.

In addition, one or two focus groups with persons living with HIV (PLWH) were facilitated in each MSA. Organizations working with HIV positive clients in each community assisted in identifying and recruiting individuals to participate in the focus groups. Focus groups included a meal and followed a structured guide with questions covering the availability and structure of HIV care and prevention, barriers to care, the availability of other services such as behavioral health and housing, and HIV advocacy efforts. An average of eight to 10 individuals participated in each focus group.

The focus groups were recorded and transcribed. The transcripts were coded thematically and summarized by the research team. The software package ATLAS.ti was used to organize findings. Data from the interviews were also summarized and coded thematically by the research team. A summary of findings from the data gathered for each MSA was included in an MSA-specific report. The report was emailed to key interview participants for comments and the reports were revised accordingly. The six MSA-specific reports were compared by segment (i.e. medical care availability, HIV prevention) to identify similarities, disparities and themes across the six MSAs.

## **RESULTS**

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### **Characteristics of Study MSAs**

The MSAs varied in population size and population size of their center city (largest city located in the MSA), although all MSAs had populations greater than 500,000 residents (Table 1). Jackson was the smallest MSA with a population of approximately 578,000 residents and Cincinnati the largest MSA, at over 2.1 million residents.<sup>17</sup> The center city of each MSA (and its county of location) had a substantially higher percentage of African-American residents than the US average of 12.6 percent.<sup>18</sup> For example, according to 2010 US Census data, 31% of the residents in Jacksonville, 42% of residents of Columbia, 55% of residents in Baton Rouge, 45% of residents in Cincinnati, and 73% of Birmingham residents were African American. Jackson had the highest percentage of African American residents (79%) among the MSA center cities.<sup>18</sup> The MSA center cities generally had much higher proportions of African American residents than the overall MSA (Table 1).

Poverty rates for the MSAs were also higher than the US poverty rate of 14.5% (2013), with the exception of Cincinnati, which also had a poverty rate of 14.5%. Jackson had the highest poverty rate among the participating MSAs, at 22%.<sup>19</sup> Concentrated poverty, defined as share of the poor population living in census tracts with poverty rates of 20% or higher, was a concern in both the study and control MSAs, as

they all had concentrated poverty levels of 40% or more (2008-2012).<sup>20</sup> The concentrated poverty levels ranged from 42.7% in Jacksonville to 63% in Jackson. High concentrated poverty is detrimental to community well-being, as these areas often have depressed home ownership values, higher crime rates, low-performing schools, and poorer physical and mental health outcomes for residents.<sup>21</sup> Four of the MSAs had experienced growth in concentrated poverty in the last decade, while two, Baton Rouge and Jackson, experienced a decrease in concentrated poverty since 2000.<sup>20</sup>

**Table 1: Study and Control MSA Characteristics**

	STUDY MSAs				CONTROL MSAs	
	Baton Rouge	Columbia	Jackson	Jacksonville	Birmingham	Cincinnati, OH-KY-IN MSA
<b>Total Estimated Population Size (2014)</b> <sup>17</sup>	825,478	800,495	577,564	1,419,127	1,143,772	2,149,449
<b>Black or African American (2010)</b> <sup>22</sup>	35.6%	33.2%	47.7%	21.8%	28.2%	12.0%
<b>Overall Poverty Rate (2013)</b> <sup>19</sup>	18.7%	16.6%	22.0%	14.8%	16.9%	14.5%
<b>Concentrated Poverty Neighborhood Rate* (2008-2012)</b> <sup>20</sup>	53.6%	46.4%	63.0%	42.7%	53.1%	46.2%
<b>Distressed Neighborhood Poverty Rate** (2008-2012)</b> <sup>20</sup>	14.8%	10.0%	24.1%	7.1%	14.1%	16.2%

\*Share of Poor Population Living in Census Tracts with Poverty Rates of 20% or Higher

\*\* Share of Poor Population Living in Census Tracts with Poverty Rates of 40% or Higher

### ***Community Health***

Data regarding teen pregnancy, birth outcomes and STDs for the primary counties (county where the center city of the MSA is located) of the four study MSAs generally revealed health outcomes that were worse than US averages (Table 2).<sup>16,23-25</sup> These counties have particularly high STD rates in comparison to the US overall.<sup>16</sup> For example, East Baton Rouge Parish, LA, which contains the city of Baton Rouge, had double the US syphilis rate and Richland County, SC, the county containing Columbia, had a syphilis rate of nearly three times the US average (2013). Hinds County, MS, which contains the city of Jackson, had twice the rate of chlamydia and four times the rate of gonorrhea, as compared to the US overall in 2013. The control MSAs, Birmingham, AL (Jefferson County) and Cincinnati (Hamilton County) also had high STD rates and teen pregnancy rates.

The study and control MSAs also shared poor health outcomes in other chronic disease areas such as cardiovascular disease and diabetes.<sup>26,27</sup> The prevalence of diagnosed diabetes in the central counties of the MSAs were all above the median diabetes percentage among all states (9%).<sup>27</sup> Hinds County

(Jackson) and Jefferson County (Birmingham) had the highest prevalence of diabetes among the MSAs (12.6% and 12.3%, respectively).<sup>27</sup> Additionally, for every central MSA county apart from Hamilton County (Cincinnati), the death rate attributable to heart disease was higher than the US rate for the years 2011-2013 (332.7 per 100,000 population), though rates ranged significantly by county. Hinds County (Jackson) had by far the highest heart disease death rate of the counties of study (419.6).<sup>26</sup>

**Table 2: Study and Control MSA Health Indicators for Counties where Center City is Located**

	Study MSAs				Control MSAs		US Overall
	Baton Rouge (East Baton Rouge Parish)	Columbia (Richland County)	Jackson (Hinds County)	Jacksonville (Duval County)	Birmingham (Jefferson County)	Cincinnati, OH-KY-IN MSA (Hamilton County)	
<b>Percent of live births that are low birth weight (2013)<sup>23</sup></b>	12.3%	11.1%	14.6%	9.2%	11.0%	9.2%	8%
<b>Infant Mortality Rate (2012)<sup>24</sup></b>	11.9	8.8	9.3	8.5	10.4	8.5	6.0
<b>Teen Pregnancy Rate (Births to females 15-19 per 1,000, 2013)<sup>25</sup></b>	29.0	19.5	43.8	32.6	32.6	28.9	26.5
<b>Chlamydia Rate, (2013)<sup>16</sup></b>	608.7	734.3	961.2	650.3	801.5	820.9	446.6
<b>Primary and Secondary Syphilis Rate (2013)<sup>16</sup></b>	10.8	16.3	8.4	4.3	7.9	16.3	5.5
<b>Gonorrhea Rate (2013)<sup>16</sup></b>	160.4	195.0	419.1	233.9	291.7	294.4	106.1
<b>Diagnosed Diabetes (2012)<sup>27</sup></b>	11.5%	10.7%	12.6%	10.8%	12.3%	11.2%	7.0%
<b>Heart Disease Death Rate (2011-2013) per 100,000 population<sup>26</sup></b>	338.5	342.8	419.6	367.8	380.5	325.8	332.7



## HIV Epidemiology and Financing

The four study MSAs all had HIV and AIDS diagnosis rates among the fifteen highest of US MSAs, population 500,000 or greater (2014).<sup>28</sup> These MSAs have consistently ranked among the 15 MSAs of population 500,000 or greater in the US (out of 105 MSAs) for highest HIV and AIDS diagnosis rates.<sup>1,6-8,28</sup> In addition, the study MSAs had HIV death rates higher than the US average.<sup>29</sup> All study MSAs had HIV death rates for females that were among the 10 highest for US MSAs and all but Jacksonville had HIV death rates for males among the 10 highest for MSAs (Jacksonville was 12<sup>th</sup>) in 2011. The death rates in the states containing the study MSAs were also high, particularly Louisiana, which had the highest death rate among individuals living with HIV in 2012.<sup>2</sup>

Although the study MSAs were similar in having a majority of HIV diagnoses occurring among minority populations, there were some differences in demographic characteristics of those newly diagnosed with HIV between the MSAs. Two study MSAs, Baton Rouge and Jacksonville, had particularly high HIV diagnosis rates occurring among adolescent and adult females (Baton Rouge: 24.1 per 100,000 and Jacksonville: 17.0), ranking them first and sixth, respectively, in 2013 for HIV diagnoses among women in US MSAs.<sup>29</sup> In addition, in 2010, Baton Rouge had the highest *percentage* of new HIV diagnoses that were African American females of US MSAs, with nearly one-third of new diagnoses (31%) being part of this population, followed by Jacksonville FL (26%).<sup>30</sup> In contrast, the Jackson and Columbia MSAs had some of the highest proportions of new HIV diagnoses occurring among African-American MSM of any MSA. Nearly one-half of new HIV diagnoses in 2010 in the Jackson MSA (48%) were among African-American MSM, which was the highest percentage of new HIV diagnoses occurring among African-American MSM of any US MSA of population 500,000 or greater (2010).<sup>31</sup> In Columbia, 43% of new HIV diagnoses were among African American MSM in 2010. The study MSAs also had some of the highest HIV death rates of US MSAs. For example, Baton Rouge had the 7<sup>th</sup> highest HIV death rate among males and the 2<sup>nd</sup> highest HIV death rate among females of any US MSA in 2013.<sup>29</sup>

The Cincinnati MSA has consistently had much lower HIV and AIDS diagnosis rates as compared to the study MSAs. For example, Cincinnati was 58<sup>th</sup> among US MSAs for HIV diagnosis rate in 2013.<sup>1</sup> The Cincinnati MSA also had lower HIV death rates than the study MSAs and the US overall and ranked 75<sup>th</sup> among MSAs in HIV death rate among men in 2013.<sup>29</sup> The Birmingham MSA also had HIV and AIDS diagnosis rates lower than the study MSAs. For example, in 2013 Birmingham had the 44<sup>th</sup> highest HIV diagnosis rate of the US MSAs.<sup>1</sup> However, the HIV diagnosis rates consistently remain higher than the overall US average. In 2013, the HIV death rate among males in the Birmingham MSA was also lower than the rates of the study MSAs; however, the HIV death rate in the Birmingham MSA (12.2) among men was higher than the US HIV death rate (10.1) and over 3 times higher than the Cincinnati HIV death rate.<sup>29</sup>

Two of the study MSAs, Baton Rouge and Jacksonville receive Ryan White Part A funds. The remaining study MSAs, Columbia, Jackson and the two control MSAs receive no Part A funds and thus, rely on Ryan White Parts B, C and D to provide funding for HIV medical care and support services.

The states where the four study MSAs are located (LA, MS, SC, and FL) had some of the most restrictive financial eligibility criteria for Medicaid in the US as did Alabama, location of the control MSA, Birmingham.<sup>32</sup> None of these states have chosen to expand Medicaid under the Affordable Care Act (ACA). However, the three states (OH, KY, and IN) that have counties in the Cincinnati MSA have expanded Medicaid, significantly increasing the number of HIV-positive individuals who are covered by Medicaid.

**Table 3: MSA HIV/AIDS Data**

	Study MSAs				Control MSAs		US Overall
	Baton Rouge	Columbia	Jackson	Jacksonville	Birmingham	Cincinnati	
<b>HIV Diagnosis Rate Per 100,000 Population (2014)<sup>28</sup></b>	44.7	25.6	32.2	25.1	14.6	10.3	16.8
<b>AIDS Diagnosis Rate Per 100,000 Population (2014)<sup>28</sup></b>	21.6	12.2	15.2	13.0	9.2	4.6	7.8
<b>HIV Death Rate Per 100,000 Population – Males (2013)<sup>29</sup></b>	23.1	17.7	30.8	15.9	12.2	5.9	10.1
<b>HIV Death Rate Per 100,000 Population – Females (2013)<sup>29</sup></b>	13.1	5.7	12.2	7.8	4.1	1.4	3.4

## **Medical and Social Services Availability (Findings from Interview and Focus Groups)**

### *Medical Care*

Interview and focus group participants in the study MSAs generally reported HIV medical care to be available through academic medical care Infectious Diseases (ID) clinics and/or other medical facilities such as AIDS Healthcare Foundation (AHF) clinics (Figure 1). However, many barriers to accessing and remaining connected with HIV care were described. Most of these barriers were reported consistently across the MSAs including lack of transportation and stable housing and issues related to mental health, substance use, denial/acceptance of HIV, and HIV-related stigma. Concerns about HIV care settings were also noted in some MSAs, including lack of cultural sensitivity and difficulty navigating complex health systems. In addition, although most participants noted the strengths of having a comprehensive HIV care clinic serving as the main source of HIV care in their community, concerns were raised that the clinic was known to provide HIV care; thus, merely walking into the clinic raised fears of being seen by someone in the community and exposed as HIV-positive, which would leave them vulnerable to resulting HIV-related stigma and discrimination.

Greater barriers to medical care were reported in areas of the MSAs outside of the central cities. These outlying areas often lack an adequate supply of HIV care providers, thus individuals living with HIV in these areas frequently must travel long distances to access care. Individuals residing in outlying areas of the MSA also often experience substantial perceptions of stigma surrounding HIV and seeking HIV care.

Programs providing assistance with linkage to HIV care for newly-diagnosed individuals and individuals who have dropped out of care were identified in all four study MSAs. These programs differed in availability and organization across sites. For example, in Jackson, the linkage to care program was funded through a CDC Care and Prevention in the US (CAPUS) grant and was being initiated in a limited capacity at the time of interview. In contrast, in the Jacksonville MSA, linkage to HIV care programs were offered through ASOs and funded by Ryan White Part A funds and were also available through HIV testing programs. In addition, Ryan White funds had recently (at the time of interview) been used to fund an effort to contact and link to care, when possible, all Ryan White Care recipients that had not been in HIV medical care for the last 18 months.

Although not a focal point of data collection, study participants frequently described other types of medical care, including primary and specialty care, as less available than HIV care for individuals with low incomes in their communities. This was particularly the case for adult men under age 65.

### *Control MSAs*

Similar to the study MSAs, HIV care in the two control MSAs was reported to be generally available and barriers to participating in HIV care were consistent with the study MSAs, including HIV-related stigma, lack of adequate transportation, lack of adequate housing, and less accessibility to HIV care outside of the MSA central city. The Birmingham and Cincinnati MSAs both have large infectious disease clinics that are part of an academic teaching and research center: University of Alabama Birmingham (UAB) and University of Cincinnati (UC). Focus group participants had positive comments regarding the UAB 1917 ID clinic and UC ID clinic in Cincinnati including:

*[Appointments or treatments] happen almost immediately because they use it as a priority to take care of you. You know what I'm saying about being affected with this epidemic that we been faced with. Know what I mean, and the clinic that we go to, the staff, the treatment, the medication, all of it is like a plus, and for it to be in the south, I mean, what are we like? Not so much funded here in the south?*

Interview participants at both ID clinics reported that their HIV care programs were strengthened by having very active research institutions at their locations, including the Center for AIDS Research at UAB and the AIDS Clinical Trials Unit at both UC and UAB. The CFAR provides a structure for highly valued medical and social science research and programming and also for HIV education, HIV care organization, and an advisory board of consumers. The ACTUs furnish HIV research and provide the opportunity for inclusion in research trials as well as in advocacy efforts at UC through an active community advisory board. The one negative factor cited about these academic medical center ID clinics was that because of their high profile in the community, there was a perceived stigma attached to obtaining care there, as to be a patient at the clinic was thought to be synonymous with being HIV-positive.

The control MSAs generally had HIV care linkage programs with more longevity and breadth in scope than the study MSAs. For example, in Birmingham, there were linkage coordinators funded by the state as well linkage programs through the UAB ER testing initiative and through local ASOs. In addition, both control MSAs had long standing ER HIV testing programs (located at UAB and UC). The UAB program provides routine opt-out testing while the UC program involves standard HIV risk screening and protocols for when to recommend HIV testing for individuals seeking care in the ER.<sup>33</sup> As mentioned

above, the ER testing programs also included a linkage to HIV medical care component in both MSAs. None of the study MSAs had standardized HIV testing programs in their ERs, although several hospitals had some plans for this in process at the time of interview.

The Cincinnati MSA differed from the study MSAs and the other control MSA regarding health insurance infrastructure, as all three states that have counties in the Cincinnati MSA have instituted Medicaid Expansion. Medicaid expansion has had an impact on the proportion of HIV-positive individuals who are uninsured. For example, one interview participant reported that less than 10% of the client population at UC is dependent on Ryan White funds now that many of those previously without health insurance have been able to access a Medicaid plan. This shift in payer mix has freed up some Ryan White Part A funds that can be utilized for other services in the MSA. In addition, interview participants reported that with more individuals insured through Medicaid expansion, some private ID care providers and hospitals that were not previously providing HIV care were currently expressing more interest in treating individuals living with HIV. Medicaid expansion in Kentucky has also resulted in a decrease in the number of individuals dependent on Ryan White funds to pay for medical care in the Northern Kentucky area of the Cincinnati MSA from 80 clients down to nine, according to a study participant.

However, interview participants noted a downside of Medicaid expansion, as Medicaid expansion has complicated financial systems since there are a variety of insurance plans that cover different services and facilities, even within the same hospital system. Additionally, interview participants reported that many newly-insured clients have difficulty navigating the health care system and there exist significant educational needs in the community regarding the availability of services covered by insurance as well as how to access these services. Consequently, UC is now requiring that ID clinic patients meet with the UC system financial department prior to initiating treatment. Several study participants mentioned that this process had slowed entry to HIV care for some individuals. In addition, one participant discussed changes generated by Medicaid expansion, noting that the changes have sped up linkage to care efforts, as clients no longer have to be connected with a case manager before engaging in medical care due to their new insurance status. While this faster engagement was discussed as a positive development, the decreased engagement in case management was described as detrimental to clients with co-morbidities and other concerns including mental health and substance use. With the streamlined process, these clients who could benefit from a psychosocial assessment and connection with other community resources may not be addressing these needs.

In addition to expanding Medicaid, Ohio has implemented HIPP, the HIV Health Insurance Premium Payment Program, administered by the Ohio Department of Health that directly pays insurance companies for the health care premiums of individuals living with HIV.<sup>34</sup> South Carolina, Louisiana, Florida and Alabama all have Ryan White health insurance payment programs.<sup>35-38</sup> Of the states containing study areas, only Mississippi has no provision for assistance with payment of health insurance premiums and/or copays.

### ***Transportation***

Access to transportation to medical care and other services for PLWH was consistently a challenge across study MSAs. Study participants reported that the public bus systems within their central cities were often unreliable and did not service the outer regions of the city well. In addition, although Ryan White funds were available to assist with bus passes and gas cards for appointments, these funds were reported to be insufficient to meet the needs. Transportation was said to be a particularly challenging issue in the outlying areas of the MSAs. Stigma frequently contributes to transportation challenges, as PLWH may be reluctant to ask for rides to medical care for fear that they will be identified as HIV-positive. The control MSAs were reported to experience very similar transportation challenges, particularly in Birmingham, where the bus situation was consistent with the other Deep South MSAs. Control MSAs also reported

more transportation challenges in the outlying areas of the MSA. However, there were a few exceptions to the greater transportation difficulties in the outlying areas. For example, a federally qualified health center (FQHC) that provides HIV medical care in several counties outside of Jackson MS provides transportation for all their clients in need of these services. The North Kentucky Health District (part of the Cincinnati MSA) was also able to provide transportation to HIV care for all of their clients.

## ***Social Services***

### ***HIV Case Management and Support Groups***

HIV case management services are available within each study MSA. These services are most often provided by ASOs and other non-profit organizations, although some MSAs have case managers located in HIV care clinics. All study MSAs reported concerns about decreased availability of HIV case management services due to declining reimbursements from Ryan White and/or Medicaid. In Baton Rouge and Jackson, Medicaid does not cover any specific HIV case management services. In Baton Rouge, Medicaid covers some general case management services. However, study participants reported that a beneficiary is not assigned a specific case manager so they usually speak with a different person by telephone each time they have a concern and there is variability in the case managers' HIV knowledge. A participant had the following comment regarding the situation:

*They're (clients) having all types of difficulties and problems in getting the things that they need because of this telephone case management... It's all over the phone, and they don't get the same case manager every time... it's hard for people to understand what's going on over the phone, and especially when you get a different person.*

Participants from several MSAs reported that case management services had shifted to a medical case management model, which they believed had resulted in client social services needs not being a priority for case managers. HIV case management services were also generally more difficult to obtain in areas outside the central city, as services were often not situated in these areas requiring travel for the case managers or clients.

In the control MSAs, HIV case management services were generally viewed as available. However, some concerns were expressed regarding high caseloads of case managers in Cincinnati and whether this situation limits the breadth of services that can be provided to each client. In areas outside the central cities of the MSAs, more challenges to acquiring case management services were reported, with the exception of Northern Kentucky, where HIV case management services were readily available.

HIV support groups were available for PLWH in each MSA. The specific types of groups (i.e men only, women, MSM, caregivers etc.) varied across MSAs as did the structure and organization of the groups. Some support groups were offered by ASOs or other nonprofit organizations while others were offered at HIV care clinics. A common theme regarding HIV support groups identified across MSAs was that attendance in the groups was significantly affected by availability of transportation, concerns of stigma/fears of disclosure, and level of awareness about support groups in the community. These barriers contribute to a lack of group stability and inconsistent participation for many support groups resulting in a tendency for groups to come and go. No differences were noted between study and control MSAs on the availability of support groups.

## *Legal Services*

The study and control MSAs varied in access to legal services for PLWH, although legal services were limited by resource constraints in all the MSAs. Study participants in the MSAs stated that public legal services were very limited regardless of HIV status, due to a demand for services that greatly outweighs the availability of providers. There was variability in the availability of legal services targeted specifically for PLWH ranging from no availability (Columbia); very limited availability (Cincinnati, Baton Rouge, Jackson); and more readily available, although still constrained (Jacksonville, Birmingham). In Jackson, there are legal services for cases of discrimination in housing, employment and breach of confidentiality in medical care; however, no HIV-specific services exist to meet other legal needs. In Jacksonville, some legal services were covered through Ryan White, while in Birmingham, the HIV legal services program was primarily funded through AIDS United.

## *Mental Health and Substance Abuse Services*

Interview and focus group participants in all of the study MSAs reported limitations in the availability of public mental health and substance abuse services, usually due to a lack of adequate funding and to other access barriers such as lack of transportation, mental health stigma and lack of willingness/readiness to address mental health and substance abuse. The MSAs differed in the availability of behavioral health care providers that specifically work with PLWH. In Baton Rouge and Columbia, few dedicated behavioral services for individuals living with HIV were identified while in Jackson and Jacksonville, behavioral health providers were available at several ID clinics. However, in each study MSA, participants did not believe that there were enough mental health and substance abuse resources to meet the needs of PLWH. Some participants also questioned the quality of publicly funded services. One said:

*The quality (of services)—that is an issue. The majority of them go through the same clinic, which is a government-run state clinic. They are run through like cattle and given prescriptions. Very little therapy is offered. It takes forever to get an evaluation. Supposedly each one is assigned a case manager. The majority (of case managers) I have never seen.*

In the control MSAs, lack of an adequate supply of mental health and substance abuse services and barriers to accessing the services that were available were also reported, particularly in the Cincinnati MSA. In Birmingham, however, there was greater access to behavioral services through the 1917 ID clinic, where every patient is screened for mental health concerns, and psychiatry is available for individuals found to need these services. In addition, the clinic has an agreement with a local substance abuse treatment provider which offers immediate assessments to 1917 ID clinic patients who are identified by their medical providers as needing substance abuse assessments. However, despite these resources, waiting lists for some services, such as inpatient substance abuse treatment, were reported as problematic.

## *Housing*

Lack of an adequate housing supply for individuals with lower incomes was reported to affect PLWH in all four study MSAs. Public housing systems have long waiting lists in each of the communities. In addition, the MSAs described shelter systems as overburdened and often unable to meet community needs. Housing resources for the young LGBT population, particularly the transgender population, were said to be scarce in the study MSAs. Homeless MSM and transgender youth often end up couch surfing due to limited housing resources.

Housing Opportunities for Persons with AIDS (HOPWA) funds were available to address housing needs for PLWH in the study MSAs. These funds were usually situated at local ASOs and/or other nonprofit organizations and used for services such as short-term rental assistance, utilities and housing deposits. Although the HOPWA funds were not considered to be sufficient to meet the vast housing needs for PLWH, particularly for permanent housing, the funding was widely regarded as a significant asset to the communities. In the Jackson MSA, the program has undergone transitions in recent years and concerns were expressed about the current structuring of services and stringent eligibility criteria. A non-profit organization in Jackson, Grace House, provides residential programs for PLWH; however, the HOPWA funding they have received for these services is through a direct federal HOPWA grant rather than through Mississippi HOPWA funds.

### *Control MSAs*

In the control MSAs, concerns were also expressed regarding an insufficient supply of adequate housing in lower income communities and long waiting lists for public housing programs. In both control MSAs, in addition to providing short-term financial assistance, the HOPWA program funds residential programs. In Cincinnati, HOPWA funds were used for a residential program for HIV-positive individuals with substance abuse problems and for 30 housing vouchers for HIV-positive individuals qualifying for this service. In the Birmingham MSA, AIDS Alabama provides a variety of permanent and transitional housing options (approximately 200 persons housed). Most of the funding used to provide these residential services is through the HOPWA program and McKinney Vento Homeless Programs. AIDS Alabama receives the HOPWA funds for the State of Alabama and City of Birmingham and allocates this funding to organizations throughout the state through a competitive request for proposals process and directly to landlords for clients in need of rental assistance.

*(continued)*

**Table 4: Summary of Services to PLWH in Study and Control MSAs**

<b>MSA</b>	<b>HIV Medical Care</b>	<b>HIV Case Management</b>	<b>Legal Assistance for PLWH</b>	<b>Transportation</b>
<b>Study MSAs</b>				
<b>Baton Rouge</b>	-Several clinic options -Usual waiting time < 1 month for new appointment	-Limited availability -Ryan White covers -Medicaid does not cover HIV-specific case management	-Available but very constrained by funding	- Bus system lacks reliability and coverage -Transportation resources limited
<b>Columbia</b>	-Generally available without a wait -More difficult for those outside the central city	-Generally available although reimbursement declines from Medicaid have occurred	- None identified	-Bus system often not reliable and limited availability for outlying areas -Not enough funding for transportation assistance
<b>Jackson</b>	-Several options for care including one in outlying MSA county -No significant waits to obtain care	-Generally available for Ryan White eligible clients although some funding constraints -No Medicaid HIV specific reimbursement	-Provided in cases of discrimination only	-Limited bus routes -Insufficient financial assistance for transportation
<b>Jacksonville</b>	-Several comprehensive clinic options -Some concerns about consistency of providers	-Reimbursement from Medicaid and Ryan White declining leading to some reduction in availability of services	-Some services are available, through Ryan White	-Bus less available in outlying areas of city -Although resources for transportation exist, not enough to cover need
<b>Control MSAs</b>				
<b>Birmingham</b>	-Services are available -One comprehensive academic tertiary care clinic for adults	-Services generally available on demand – more difficult to access in outlying areas	-Services available but limitations due to high demand	-Bus often not reliable - transportation difficult for outlying areas
<b>Cincinnati</b>	-Services available -One primary academic tertiary clinic -Some private providers	-One ASO providing services -No waiting lists -High caseloads	-No HIV specific services other than legal consultant for agencies	-Available in KY through Ryan White -Some Ryan White and grant resources in Cincinnati – particularly difficult to access in outlying areas of OH and in IN



## *HIV Prevention*

### *HIV Testing*

HIV prevention efforts were primarily concentrated in HIV testing and linkage to care in the four study MSAs. Most participants reported that there were adequate opportunities for testing available, although some lamented that the testing was not always well-advertised. Other participants expressed concerns that testing was usually targeted to the highest risk populations and zip codes, thus individuals who were at risk but not residing in one of these zip codes or falling into specific population targets had greater difficulty accessing testing services. In addition, participants bemoaned that the strong emphasis on targeted testing misses the opportunity to reduce stigma by providing education and testing to the larger community. Standard HIV screening and testing programs in ERs in the MSAs were largely absent, resulting in missed opportunities to identify individuals who are HIV-positive and provide linkage to care services. Testing was said to only be provided to those whose presenting problem to the ER indicated a need to screen for HIV. Baton Rouge, Columbia, and Jackson all had ER testing programs at one time, but these programs have since been discontinued. At the time of the interviews, plans to reinstate programs in Baton Rouge and Columbia were mentioned but no definitive timelines were available.

### *Prevention Interventions*

In each MSA, some evidence-based HIV prevention efforts were underway, such as CLEAR and 3MV, primarily among minority MSM.<sup>39,40</sup> Study participants from the MSAs mentioned that although these efforts were beneficial, much more could be done to provide education and support to the communities at particularly high-risk. In addition, participants in all the study MSAs believed that not enough emphasis was being placed on primary prevention in the general population, particularly among those living in poverty. They believed that there is considerable misinformation and distrust surrounding HIV in these communities, which perpetuates fear and bolsters stigma toward people living with HIV. This stigma serves to further drive people living with HIV underground and discourages engagement in treatment, thus contributing to the spread of HIV. Study participants would like to see funding directed toward community media campaigns such as billboards, and advertisements on buses, radio and television. In MS, some of the CAPUS funding was used for a general education campaign. Jackson MSA participants reported that they wanted to see more resources directed toward these campaigns so they can be ongoing. Study participants discussed the lack of funding available for primary prevention campaigns, particularly from their state governments. Most of the funding for HIV prevention is awarded to their states by the CDC and then allocated to the MSAs by the states, often for specific testing efforts. A few organizations in the MSAs have prevention programs that have been directly funded by the CDC, but rarely have they targeted the broader community.

In all of the study MSAs, participants discussed a need to partner with churches, particularly predominantly African American churches, to provide HIV education and prevention services for these communities and to address issues of stigma. Programs to facilitate these partnerships and prevention efforts were described in each of the communities. These programs were particularly structured and longstanding in the Columbia and Jackson MSAs. In Columbia, there was an endeavor facilitated by the South Carolina HIV/AIDS Council and funded by the South Carolina Legislature from 2006-2013, Project F.A.I.T.H., (Fostering AIDS Initiatives That Heal), which was a technical assistance and capacity-building initiative designed to provide HIV health education and risk reduction training, and impact HIV stigma.<sup>41-43</sup> Although the program demonstrated positive outcomes, the state legislature did not allocate funds for continuation after 2013 and no additional funding sources for the program were identified. Thus the program has largely discontinued activities; however, many of the beneficial effects of the program have remained at participating churches including HIV education efforts and care teams for individuals

living with HIV. In Jackson, the Mississippi Faith in Action program tailors HIV education messages to the needs of the individual churches.<sup>44</sup> In addition to working directly with churches, the program has educational materials for faith communities that are readily accessible on their website for any group to utilize. Several interview participants in Jackson reported that some African American churches and ministers were now more supportive of individuals with HIV and are willing to talk about the issue in their congregations. One participant believed that there were more ministers of African American churches “that are speaking out, well-known pastors,” while another discussed churches and said,

*You have some that’s trying to get on board or starting to get on board. You have some churches that are open to doing (HIV) ministry.*

*“You have some that’s trying to get on board or starting to get on board. You have some churches that are open to doing (HIV) ministry.”*

### *Sex Education in Schools*

Comprehensive sex education in public schools is lacking in the study MSAs. The current education programs are abstinence-based and provide little or no information about sexual orientation and identity and offer incomplete contraceptive information. In Jacksonville, a CDC Division of Adolescent School Health (DASH) grant supports more comprehensive sex education in some schools.<sup>45</sup> The DASH grant, which is administered by Duval County Public Schools and began in 2011, is providing five years of funding for the Duval County Health Department working in partnership with JASMYN, an organization dedicated to addressing the needs of LGBT youth, to administer HIV and STI testing, STI treatment, linkage to HIV care, and comprehensive sex education to students at three family resource centers in Jacksonville. Study participants expressed significant frustration regarding the lack of comprehensive sex education available in schools, particularly in the context of the increase in HIV among youth in the Deep South. One participant stated,

*Lack of education is the biggest stigma that we have. Because we can’t get it in schools. Younger generations, some of them still think that you can contract HIV through mosquitoes. When we did a testing event with a PowerPoint for some students on a college campus but it was high school and middle school students, and they still have that stigma.*

### *PrEP*

Pre-exposure prophylaxis, (PrEP) is available in the Open Arms Clinic in Jackson MS, the state’s only LGBT-focused medical care facility. In addition, the Mississippi Health Department established a PrEP call line for the Jackson MSA to answer related questions and direct callers to facilities providing these services. In Baton Rouge, PrEP is available in Baton Rouge at HAART’s ID Clinic, once a client has met with a provider. Study participants reported little PrEP availability in Jacksonville. Study participants said that very few of the medical providers have been willing to provide this service and reported some confusion in the community about how the costs associated with PrEP would be covered. PrEP availability is also very limited in Columbia. However, the South Carolina HIV/AIDS Council recently received funding from the pharmaceutical company, Gilead, to increase community knowledge regarding PrEP and to improve PrEP accessibility in the area.

### *Control MSAs*

The HIV prevention infrastructures and barriers in the control MSAs were similar to the study MSAs in many ways including a prevention strategy primarily focused on HIV testing, lack of state funds allocated

for HIV prevention efforts, lack of comprehensive sexual education in schools, some partnerships with area churches for HIV prevention, a desire for additional ongoing work in the minority faith communities, and strong interest in broadening HIV prevention activities to include general prevention activities, particularly media related. PrEP is available in both MSAs, although reportedly it is underutilized in Cincinnati.

Despite the similarities between study and control MSAs, there were some notable differences. Both control MSAs had longstanding, standardized testing protocols in place in the ERs of the large tertiary medical center in the MSA (UAB and UC). In addition, the Birmingham MSA had an unparalleled level of collaboration between organizations regarding prevention activities. This collaboration included an HIV prevention network consisting of individuals working across agencies and disciplines for the purpose of increasing HIV awareness and prevention activities. Furthermore, the Cincinnati MSA was unique in the initiation of a syringe exchange program to combat the burgeoning heroin epidemic in the region. The syringe exchange program was available twice a week at two sites in Cincinnati. HIV/Hepatitis C testing was available at the syringe exchange sites and assistance with accessing substance abuse treatment was provided for individuals willing to seek this care. In addition, Birmingham has a fledging program funded by AIDS United. The two-year program is laying the groundwork for advocacy with the Alabama Legislature, Alabama Department of Public Health, Alabama Department of Mental Health, and local law enforcement for access programs.

**Table 5: HIV Prevention Services in Study and Control MSAs**

<b>MSA</b>	<b>PrEP</b>	<b>ER HIV testing program</b>	<b>CDC Evidence-Based Prevention Interventions</b>	<b>Sex education in schools</b>	<b>Faith-Based education</b>
<b>Study MSAs</b>					
<b>Baton Rouge</b>	Available at ASO	None	Sporadic; Limited by zip code	<ul style="list-style-type: none"> <li>• Abstinence-based</li> <li>• No mention of sexual orientation</li> </ul>	Some limited partnerships
<b>Columbia</b>	Limited availability at USC ID clinic; SC HIV/AIDS Council has new grant to enhance knowledge and availability	None	Limited availability through ASOs	<ul style="list-style-type: none"> <li>• Abstinence based; HIV education not required</li> <li>• lack of discussion on sexual orientation</li> </ul>	Project FAITH education initiative – (no longer directly funded but some longer lasting partnerships)

*(table continued)*

**Table 5 (continued): HIV Prevention Services in Study and Control MSAs**

<b>MSA</b>	<b>PrEP</b>	<b>ER HIV testing program</b>	<b>CDC Evidence-Based Prevention Interventions</b>	<b>Sex education in schools</b>	<b>Faith-Based education</b>
<b>Study MSAs</b>					
<b>Jackson</b>	Available through Open Arms Clinic	None	Limited availability through ASOs	Abstinence-only or abstinence plus <ul style="list-style-type: none"> <li>• not required in schools</li> <li>• parental opt-in</li> </ul>	MS Faith in Action –education/ support program for minority churches
<b>Jacksonville</b>	Few options – some availability at ID clinics	None	Limited availability through ASOs	Abstinence or abstinence-plus-for most schools  CDC DASH program provides some comprehensive education	Several organizations provide education at faith organizations
<b>Birmingham</b>	Available at UAB ID clinic	Opt out testing and linkage	Limited availability through ASOs	Abstinence-based. Emphasis that “homosexuality it not an acceptable lifestyle”	Some limited efforts through local ASOs
<b>Cincinnati</b>	Available through ID care providers	Standardized screening, testing and linkage program	Limited availability through ASOs	<ul style="list-style-type: none"> <li>• Decided by local district</li> <li>• Some have abstinence-based, some abstinence plus and some comprehensive</li> </ul>	Local ASO provides education and testing to minority faith organizations

***Stigma***

A consistent theme throughout the interviews and focus groups in each MSA was that HIV remains a highly stigmatizing condition, particularly among individuals with lower socioeconomic status. HIV stigma was reported to be pervasive and extremely detrimental to individuals living with HIV and at-risk for HIV in the study MSAs. Stigma was said to substantially reduce willingness to be tested for HIV, engage in HIV care and participate in HIV support groups and advocacy efforts. According to study participants, incorrect transmission myths persist, creating further fear and shunning of individuals living with HIV. Due to this significant negative perception of HIV, individuals often do not want to be tested for HIV or they delay testing as they fear someone may see them being tested for HIV or they fear the repercussions of a positive test result. One study participant described these concerns as follows:

*I think it's probably more what they feel their friends are going to say if they find out or whatever. I think that's the biggest problem because I think that hinders a lot of people from getting tested because they feel if they get tested, they really don't want to know the result of the test. And if they found out the result of the test, who else is going to know and how can -- I've heard and how can I keep this secret and nobody know.*

Individuals who are aware of their HIV status may choose not to seek HIV treatment rather than take the risk of being seen obtaining treatment and exposed as HIV-positive, which could result in negative social consequences. One focus group attendee explained that,

*because of the stigma surrounding HIV and AIDS, a lot of people are not interested in getting into care for fear of who's going to see me.*

Another participant described similar experiences:

*All these are public buildings where anybody from the public can walk in here and get seen for whatever. Because there is more than just HIV clinics within these places, right? So I'm walking up in there, and when I walk through the door, the first thing I see is three people I know. Instead of me sitting here for my doctor's appointment because I don't want them to know why I'm here. I'm going to walk out that door. Stigma. That's one of the biggest problems surrounding new diagnosis.*

*"Because of the stigma surrounding HIV and AIDS, a lot of people are not interested in getting into care for fear of who's going to see me."*

Another participant shared that:

*If the stigma wasn't so bad, I don't think people would be so ashamed about getting care. It's not even about telling your status or disclose your status. It's about getting into care. That's the thing.*

The same fear of being seen at an agency associated with HIV disease also inhibits individuals from participating in HIV advocacy efforts, support groups and other support services. There were one or two study participants at each MSA who believed that HIV-related stigma had diminished some over the years resulting in less discrimination against and isolation of individuals with HIV. However, these participants believed that people living with HIV still experience significant internalized stigma and thus fear the consequences of revealing their HIV disease. Many participants cited negative experiences with disclosure of their status. Study participants also talked about encountering healthcare and social services providers who still discriminate against individuals who are LGBT, particularly those who are HIV-positive, further reinforcing stigma and fear among individuals living with HIV. These negative experiences were said to deter individuals from seeking care, even if they had attempted at one point to engage.

Stigma regarding sexual orientation, which is closely linked with HIV-related stigma, was also reported to be highly prevalent in the MSAs, as it is in much of the Southeastern US.<sup>13,46</sup> This stigma results in greater challenges in reaching MSM for HIV prevention and support efforts, particularly among African-American men where sexual orientation stigma is especially high.<sup>47</sup> Sexual orientation and identity stigma is often rooted in a religious culture that condemns same sex relationships. Because of this religious underpinning, enlisting the assistance of the churches in providing education and/or other support regarding HIV is reported as challenging. A participant stated that stigma is particularly high for MSM

“especially in the church. People will not disclose. They will not come out as HIV positive. They will not come out about being MSM.”

Another participant stated:

*The health department has a whole initiative to work with the African-American faith community around HIV and so there are churches that do testing and that really there are a few pastors who are really unwelcoming, but they still love the sinner, hate the sin kind of thing and so it doesn't feel as welcoming to a lot of sexual minority folks or the LGBT folks. They go, they are in churches, we are in churches everywhere, but not necessarily feel like fully accepted and so that hiding, that experience of hiding oneself, that breeds problems.*

This pervasive stigma was generally thought to be especially problematic in the South, as illustrated by the following quote from a key interview participant:

*Despite this thing about Southern hospitality, but if it's something that people deem dirty, then there's nothing hospitable about it. So, the stigma that you face and the rejection that you face as a person living with HIV and AIDS in the South is what I would say is very unique to us.*

Another participant added:

*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,

*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.*

*“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.”*

Study participants consistently reported differences in perceptions of HIV and HIV stigma between the younger and older generations. An explanation given for this lower level of concern regarding infection was that many younger MSM believed that they could “just take a pill” if they acquired HIV. Younger people were reported to have less fear of HIV, as they have not seen firsthand the devastation of HIV in the 1980s and 1990s. A focus group participant described the age differences:

*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 or 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?” However, there were a few study participants that described how once young people become positive and experience side effects and/or health issues they become very concerned about their health and espouse more concerns regarding HIV-related stigma.

### *Control MSAs*

HIV-related stigma was reportedly also prevalent and damaging to health care participation and outcomes in the control MSAs. In Cincinnati, stigma was thought to be most prominent in places of concentrated poverty and surrounding issues of sexuality as well as in the less populated areas of the MSA. Several study participants from Cincinnati believed there had been some decline in stigma over time in the area. In Birmingham, despite a strong collaborative care and prevention network, stigma continued to be prevalent and a considerable barrier to effectively stemming HIV disease in the area. One focus group participant in Birmingham said, “*HIV doesn’t kill, stigma does,*” while another talked about how community awareness of the 1917 Clinic as exclusively providing HIV care creates a barrier for linkage and retention in care for some patients, as being seen at the clinic is seen as an act of HIV status disclosure. A focus group member shared:

*[T]here’s only one clinic that most people go to. So being the fact that that one clinic specializes in this one particular disease ... there’s almost an automatic stigma attached to it, which means that if you were diagnosed then you would have to go to this clinic, the last thing you want people to know is that you got to go to the 1917 Clinic cause they know you’re not going there for anything other than HIV. By that same token, it almost forces you to disclose if anybody finds out, and some people may not be ready to disclose at that particular point.*

### ***Political Support and Advocacy Efforts***

Local, state and federal advocacy efforts were described in each MSA but these efforts differed in scope, structure, and consistency among the MSAs. All the MSAs had active state HIV advocacy organizations, however local advocacy efforts varied by MSA. In two of the study MSAs, Jacksonville and Jackson, advocacy efforts, particularly among PLWH, lacked consistent community support and were sporadic. In both MSAs, advocacy efforts were reported to have been more consistent in the past, particularly when HIV was viewed as more of a life-threatening disease. One participant described this situation as such:

*Years ago when I first started here ... we would send busloads of people up to Washington, DC when they do the march on Washington at that time. They were a few Rally in Tally and some people but that hasn’t happened in a very long time. One, none of us have the money. As far as I know, none of us have lobbyists on our staff so there’s really not any of that going on.*

In addition, in both MSAs, the advocacy efforts that were in place were most often concentrated on addressing local HIV services issues and needs rather than on more universal issues, such as funding for prevention or HIV criminalization laws. HIV-related stigma was reported to be a substantial barrier to developing and maintaining advocacy among PLWH in these MSAs.

In Baton Rouge and Columbia, some advocacy opportunities were available for PLWH, although these were limited by lack of resources and significant HIV-related stigma. In Baton Rouge, two organizations have programs that train PLWH in advocacy and provide opportunities for advocacy work when available. In Columbia, advocacy efforts for PLWH were predominantly focused on women. An ASO in Columbia developed and implemented training programs for women interested in advocacy work. Efforts to engage men in advocacy activities have been less successful in Columbia, primarily due to stigma concerns, particularly related to the possibility of being labeled as gay or a man who has sex with men.

### *Control MSAs*

A state HIV advocacy organization exists in Ohio, but few local HIV advocacy efforts were identified in

the Cincinnati MSA. However, participants described more coordinated and targeted activism around the injection drug problem in the area and the need for syringe exchange programs that resulted in creation of the syringe exchange program in Cincinnati. However, advocates in the Northern Kentucky area of the Cincinnati MSA are still working for the initiation of a syringe exchange program in Kentucky.

The advocacy efforts in Birmingham are in sharp contrast to the other MSAs, as there are highly organized advocacy efforts in the MSA for PLWH and others interested in HIV-related advocacy. The Positive Leadership Council, an AIDS Alabama program that is funded through the Elton John Foundation, trains HIV-positive advocates across the state on effective communication with policymakers on HIV/AIDS issues. In Alabama there is also a well-organized annual, statewide campaign to advocate with state legislators for HIV prevention and treatment funding. Organizers produce a white paper focused on collectively identified legislative priorities to guide their advocacy work. ASOs around the state each coordinate a week of the legislative session during which they are responsible for advocacy, and the entire session is typically covered in this way. Additionally, during the legislative session, hundreds of advocates, many living with HIV, attend the annual Media Day event at the Alabama Legislature in Montgomery. A participant described the impact and importance of these efforts:

*We march over to the galleries of the House and the Senate. We fill them up with red shirts and they have to recognize us in the audience. We jam up the elevators, so they know we're there. We have a big event and the state health officer and a lot of legislators come to it ... But I promise you. If we stop doing it one year, we wouldn't get any of the money. It would be gone. Right now, we get about \$5 million for ADAP and the ASOs. We get about that \$394,000 for education. That's what we're doing all this to keep.*

### ***Political Support***

Lack of support from most local and state politicians for addressing HIV-related issues was universally reported, regardless of study or control MSA status. In most MSAs, some supportive politicians were identified but these individuals were in the minority. A lack of political support was not isolated to HIV, rather it extended to issues of poverty and lack of medical insurance. Several participants described a “pull yourself up by your bootstraps” philosophy that was espoused by many politicians.

The lack of political support for addressing issues related to poverty and health inequality was illustrated by the decision of all of the study MSA (and the Birmingham MSA) states not to expand Medicaid under the ACA. One participant quoted research that 75% of those on the AIDS Drug Assistance Program (ADAP) in Alabama would be eligible for Medicaid expansion through ACA if the state of Alabama had selected to accept this provision. Although study participants in Cincinnati reported a lack of political support for HIV-related issues, they lauded the state politicians from Ohio, Kentucky, and Indiana who had advocated for the passage of Medicaid expansion in these states.

### ***Strengths***

There were several strengths related to HIV infrastructure that were reported in the study MSAs. These included dedicated HIV care and prevention providers who work tirelessly to address the needs of individuals living with and at-risk for HIV in their communities. Many of these individuals were reported to have considerable longevity in working in the HIV field. Study participants also described dedicated HIV care and prevention organizations and the significant contributions they make to address HIV in their community. An interview participant remarked,



*It is small enough that providers really know each other and it is southern enough that people kind of get along...here, we may disagree, but we are still going to be civil, friendly, and I think part of being in the Bible Belt is that there is a real earnestness, people really genuinely care and there is a lot of people who really want to make it better. They are like, do the right thing, make it right; there is that element.*

Strong collaborative relationships between some agencies involved in working in HIV care and prevention were also reported in the study MSAs. However, these collaborations were often limited to certain agencies and were frequently dependent on agency leadership, funding, and the specific project they were collaborating on. A participant described the impact of funding requirements for collaboration saying,

*I mean I will tell you what really helps make it happen is funding. So, when the federal government says, collaborate, ... you get points if you address this population and the only way to address is to work with those people. Then we are all at the table together, we are all trying to drop money down, everybody has got a stake in it, it funds staff to work together. That really has been incredible and we have been the beneficiary of that four or five of those kinds of collaborations to build the programs.*

In the Jacksonville MSA, there is a consistent structure for facilitating collaboration regarding Ryan White funding, as the MSA has an HIV prevention planning group and a Ryan White Part A planning group that assists in setting priorities for Ryan White funding.

Another community strength reported in all the study MSAs was that HIV medical care was generally available without a significant wait for individuals willing to seek care and able to secure transportation to care. Other strengths mentioned by study participants were unique to each particular geographic area. These included innovative programs that targeted specific communities and needs such as faith community HIV/STD education, linkage to care programs utilizing peers, and HIV care and prevention among youth. Table 6 presents an outline of unique and innovative programs in the study and control MSAs.

### *Control MSAs*

The control MSAs had strengths that were similar to the study MSAs, including passionate and committed care/prevention providers and agencies, available HIV medical care, and innovative programs. Each control MSA had a few strengths not found in the study MSAs. In Birmingham, participants lauded the well-organized advocacy efforts, particularly those involving individuals living with HIV as a significant strength along with the consistent and structured collaboration between community organizations/medical practices. Although all the MSAs mentioned collaboration between providers as a strength, only Birmingham had a comprehensive and consistent formalized mechanism for collaboration between providers involved in HIV care and prevention. The Jefferson County HIV/AIDS Community Coalition is a coalition of HIV service providers and advocates that meets on a monthly basis to work on improving HIV prevention and care provision in the Birmingham area. A provider described the level of collaboration in Birmingham as being a “true collaboration” rather than a collaboration “in name only” as was seen in other places. Another participant described the collaboration in the MSA as unique and talked about how the AIDS service organizations divvy up services such as housing, legal, and food services to reduce duplication and enhance collaboration. For prevention, the organizations also work to collaborate and avoid competition. There is also a Peer Professional Network in Birmingham, which brings HIV-positive peer professionals together regardless of their agency in order to promote collaboration and provide support for PLWH.

Cincinnati's strengths in HIV care and prevention, as described by study participants, differed from the other MSAs in two significant areas. These included the presence of syringe exchange in the city of Cincinnati and the presence of Medicaid expansion in all three states that are part of the MSA, which has resulted in a substantial decrease in the number of individuals living with HIV who are uninsured.

### ***Factors influencing high diagnosis rates and potential solutions to address these factors***

When asked specifically for their perspectives on why there are higher HIV and AIDS diagnosis rates in their MSA, study participants consistently mentioned significant HIV-related stigma; high levels of poverty; lack of resources, including transportation, housing, and prevention services; and lack of political will and progressive governments. Racial segregation and discrimination were frequently described by participants in Jacksonville as factors that perpetuate stigma and further the spread of disease and the lack of resources for poor, minority communities. Issues of race and discrimination were also mentioned as important factors in other MSAs. In Baton Rouge, racism was frequently discussed in the context of incarceration. Louisiana has the highest incarceration rate in the US and spends a greater proportion of its state budget on incarceration than the US average.<sup>48,49</sup> Incarceration has been found to disrupt social and sexual networks in minority communities leading to greater HIV infection risks.<sup>50</sup> A majority of key informants from Baton Rouge discussed the high incarceration rate in their area and its negative impact on the spread of HIV disease. As one key informant explained:

*Also we have here in Louisiana we incarcerate more people than anybody in the world...and then in the prison system, the testing is voluntary...and you don't have to get tested because they don't really want to know because then they have to provide treatment, and so they don't want to treat, and so we have a large group of incarcerated men coming back home to their women and infecting them, and so that is also contributing to the increase in HIV rate here in Louisiana.*

When asked about strategies to more effectively address HIV in their communities, study participants from all the study MSAs said that they believed that an investment in general awareness prevention messages, particularly through media such as billboards, buses, TV, radio etc., is critical to boost community awareness about HIV, increase competency in understanding risk and testing, and dispel persistent myths about the disease. They believe that this education would have the secondary and crucial effect of alleviating some of the stigma attached to HIV. Participants also wished for additional resources to provide education and support to African American churches to address HIV in their congregations and community.

Participants from all the MSAs also would like to see additional resources to provide essential services including transportation, behavioral health, housing, and comprehensive HIV education to youth. Other strategies mentioned by at least two of the MSAs were greater collaboration and coalition building among community HIV services providers, colocation of services to reduce fragmentation, and increased advocacy efforts, particularly among PLWH.

Study participants in the control MSAs were also asked about strategies to improve HIV care and prevention in their communities. Their answers were similar to those of the study MSAs, as they would also like to see additional resources for critical services, increased collaboration (Cincinnati), stigma reduction interventions, increased general HIV prevention (particularly among youth) and increased advocacy efforts.

## DISCUSSION

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The US Deep South has the highest HIV diagnosis rates and highest death rates among individuals diagnosed with HIV of any US region and also contains eight of the 10 MSAs with the highest HIV and AIDS diagnosis rates.<sup>12,28</sup> This exploration of the HIV prevention and care infrastructures of highly affected Deep South MSAs can inform urgently needed policy and programmatic interventions along the HIV care continuum that are tailored to the needs, populations, and settings in the Southern US.

The four study MSAs were selected based on their high HIV and AIDS diagnosis rates; some similarities in the epidemiology of their HIV epidemics are therefore to be expected, though differences are also apparent. As is true throughout the Deep South, the HIV epidemic is predominantly affecting Black/African American individuals in the MSAs. However, two study MSAs, Baton Rouge and Jacksonville, had higher proportions of HIV diagnoses occurring among women, while Jackson and Columbia had particularly high proportions of HIV diagnoses among minority MSM. It is critical that assumptions of homogeneity of the epidemic in the Deep South are avoided and the local epidemiology of the epidemic be carefully considered when developing appropriate policy and programmatic interventions for states and communities.

While the case studies show that the MSAs have unique aspects to their experiences and challenges in meeting the needs of PLWH and engaging them in medical care, there are numerous commonalities across MSAs. HIV medical care was described as generally available to those willing/able to go, although less accessible to PLWH in more remote areas of the MSAs. Transportation was a major concern cited in all areas, particularly for those living outside of the center city of the MSAs. The availability of mental health and substance abuse services was largely identified as inadequate to meet existing need. Housing for PLWH with low incomes was also seen as lacking across MSAs. The need for additional resources for transportation, mental health and substance abuse treatment, and expanded housing options was immensely apparent across the study and control MSAs.

Stigma was a powerful and widespread issue affecting all aspects of HIV prevention, care, and advocacy across the MSAs. Stigma was seen to vary by age, with youth generally perceiving less stigma regarding HIV and less fear of the ramifications of an HIV diagnosis than older adults. Respondents believed these stigmas were sustained by both lack of HIV knowledge and social conservatism, fueled in part by faith institutions. Efforts to improve HIV prevention and outcomes in these Deep South communities will not reach their full potential until stigma reduction is realized. Study respondents believed that stigma reduction initiatives must include strong collaborations with African American churches, saturating the media with HIV education and anti-stigma messaging targeting the general population, HIV and cultural competency education with care providers and staff particularly in more outlying areas of MSAs, and active peer programs to reduce the isolation and self-stigmatization of PLWH.

In all of the included communities, HIV testing has been the primary focus of HIV prevention efforts. Respondents lamented the lack of comprehensive sexual education in schools and identified this deficiency as a driver of the high rates of HIV infection. The public health of all of the MSAs would benefit from the implementation of comprehensive sexual education in schools, as well as consistent funding of evidence-based prevention programs.

Additionally, insufficient political support for HIV prevention and care efforts was also identified as a primary problem and driver of the lack of resources to address the epidemic. Local advocacy efforts were reported to generally suffer from a lack of consistent support and engagement, particularly those led by and/or involving PLWH. Advocacy efforts need bolstering in order to provide meaningful engagement for PLWH and to effectively engage political leaders in successfully addressing HIV in their community.

Despite significant limitations and challenges to HIV care and prevention, all of the MSAs have critical strengths including committed, passionate, and experienced providers and professionals working within the system. Additionally, strategic partnerships and collaborations between organizations, when in existence, were described in positive terms. These partnerships were credited with enhancing service efficiency, capacity, and attenuating the negative impact of limited resources to address HIV. However, organized collaborations were only structurally supported in one of the study MSAs. Further funding and leadership support is needed to encourage collaborations to maximize the impact of prevention and care efforts.

Each MSA was home to successful, innovative programs developed to meet their local needs. These programs typically had charismatic leaders who worked to ensure the financial sustainability of the organization, the quality and effectiveness of services, and the organization's connection to and visibility within the community. These innovative programs could be replicated in other MSAs with appropriate resources, training and leadership.

The two control MSAs, Birmingham and Cincinnati, had challenges similar to the study MSAs in terms of lack of resources, HIV-related stigma, need for more general prevention efforts, and lack of political support as well as some similar strengths. The primary differences between study and control MSAs were that both control MSAs had comprehensive, tertiary ID clinics that included federally funded research institutions that provided a source of funding, targeted engagement in care, and a center for programmatic and advocacy efforts. The control MSAs also had long-standing standardized ER HIV testing and linkage programs. In addition, the Cincinnati MSA has different demographics than study MSAs, with a lower proportion of the population that are minority; a syringe exchange program; and all three states that comprise the MSA having selected to expand Medicaid. These factors will likely have the consequence of widening the disparity between the Cincinnati MSA and study MSAs. Further, the Birmingham MSA has consistent, well-organized community collaborations around HIV care and prevention, and strong advocacy efforts, particularly with PLWH.

This study has several limitations. Primary data collection occurred in succession for the MSAs, starting with Baton Rouge, LA, in September 2013, through February 2015 for Jacksonville, FL; important changes may have occurred in the infrastructures of the MSAs whose data was collected earlier in this process that are not reflected in this report. Additionally, convenience sampling was used to identify potential focus groups participants, thus they may not be representative of the population of PLWH in the study and comparison communities. Lastly, individuals identified to participate in the key informant interviews do not represent the entire universe of providers and organizations working with individuals at-risk for HIV or HIV-positive in the MSAs so the study may have missed information or views not expressed by individuals included in the interviews.

## CONCLUSIONS

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The case studies of Deep South MSAs that have been hardest hit by HIV identify critical resources deficiencies and barriers to HIV testing and treatment that likely contribute to the disproportionate HIV diagnosis and death rates in the region. These barriers include a lack of adequate transportation, housing, and behavioral health services as well as significant and pervasive stigma and a lack of political support and advocacy for positive change. The strengths of the area, including committed providers, agency collaborations, and innovative programs, need to be bolstered and additional resources allocated to effectively ameliorate the barriers to testing and treatment. Study participants identified strategies to reduce barriers and stigma including enhancing mechanisms and incentives for collaboration, increasing

resources for transportation, housing and behavioral health, enhancing prevention and stigma reduction through saturated media HIV education and collaboration with communities of faith. Resource allocation inequities across the region also need to be addressed.<sup>10</sup>

*(continued)*

**Table 6: Innovative Programs in Study and Control MSAs**

Program Name	Location	Target Population	Description
<p><b>Prison linkage program</b>  <a href="http://www.fsgbr.org/index.php?option=com_content&amp;view=article&amp;id=35&amp;Itemid=5">http://www.fsgbr.org/index.php?option=com_content&amp;view=article&amp;id=35&amp;Itemid=5</a></p>	Baton Rouge	HIV-positive prisoners	Involves videoconferencing for individuals living with HIV that are soon to be released from prison with his/her local ASO organization so that a plan for community transition is in place prior to prison release.
<p><b>HIV Transmission Prevention Program</b>  <a href="http://www.womans.org/giving-and-volunteering/community-programs-and-services/mother-to-child-hiv-transmission-prevention/">http://www.womans.org/giving-and-volunteering/community-programs-and-services/mother-to-child-hiv-transmission-prevention/</a></p>	Baton Rouge	Pregnant Women	Case management program for HIV-positive women and their infants up to a year old. Since 2005, no HIV-positive babies have been born to a mother enrolled in the program.
<p><b>LaPHIE (Louisiana Public Health Information Exchange)</b>  <a href="https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/LaPHIE_Program_Description_12_10_13.pdf?sfvrsn=0">https://effectiveinterventions.cdc.gov/docs/default-source/data-to-care-d2c/LaPHIE_Program_Description_12_10_13.pdf?sfvrsn=0</a></p>	Baton Rouge	Out of care patients; providers	<p>Informational platform between health care entities and HIV surveillance data. Participating health care entities automatically check to determine HIV status and whether they are in care. If out of care, provider is alerted immediately to link to HIV services.</p> <p>In 2013, 78% of patients with an out of care notification were linked to services within 90 days.<sup>51</sup></p>
<p><b>Positive Voices</b>  <a href="http://schivaidsCouncil.org/our-services/p-o-s-i-t-i-v-e-voices/">http://schivaidsCouncil.org/our-services/p-o-s-i-t-i-v-e-voices/</a></p>	Columbia	HIV-positive women	Training program to empower HIV-positive women and involve them in advocacy locally, at the state level and nationally.
<p><b>Women's Empowerment Academy</b>  <a href="http://schivaidsCouncil.org/our-services/p-o-s-i-t-i-v-e-voices/">http://schivaidsCouncil.org/our-services/p-o-s-i-t-i-v-e-voices/</a></p>	Columbia	HIV-positive women	4 week intervention targeting HIV positive women who have experienced stigma and other factors that affected disclosure. Focuses on disclosure, navigating health systems and self-efficacy.

*(table continued)*

**Table 6 (continued): Innovative Programs in Study and Control MSAs**

Program Name	Location	Target Population	Description
<p><b>New Directions</b> (comprehensive PrEP action plan)</p>	Columbia	Individuals at high risk for HIV; providers (facilitated by South Carolina HIV/AIDS Council)	<p>Use multiple strategies to increase knowledge and availability of PrEP including:</p> <ul style="list-style-type: none"> <li>• PrEP education materials and media to enhance community awareness</li> <li>• Popular opinion leader strategies to increase awareness and willingness to engage in PrEP</li> <li>• Extensive training for HIV medical and social services providers to increase PrEP knowledge and accessibility</li> </ul>
<p><b>Grace House</b> <a href="http://gracehousems.org">http://gracehousems.org</a></p>	Jackson	Chronically homeless HIV-positive individuals	Provides 3 phases of housing: independent and tenant-based rental vouchers, permanent housing, and transitional housing. Also provides supportive services including substance use treatment, anger management, transportation
<p><b>Open Arms Clinic</b> <a href="http://oahcc.org/">http://oahcc.org/</a></p>	Jackson	LGBT community	Provides holistic healthcare, including HIV treatment, PrEP, mental health and primary care. (The only LGBT focused clinic in the state)
<p><b>Mississippi Faith in Action</b> <a href="http://commonhealthaction.org/action/item/34-mississippi-faith-in-action.html">http://commonhealthaction.org/action/item/34-mississippi-faith-in-action.html</a></p>	Jackson	Churches	Provides HIV education to churches and church leadership that is tailored to the individual congregation. Also provides online educational materials for use by faith organizations
<p><b>JASMYN</b> <a href="http://jasmyn.org/">http://jasmyn.org/</a></p>	Jacksonville	LGBTQ youth ages 13-23	Provides services and advocacy including STD clinic, HIV care linkage services, case management, transportation, social activities, support groups
<p><b>Jacksonville DASH grant</b> <a href="http://www.duvalschools.org/Page/15694">http://www.duvalschools.org/Page/15694</a></p>	Jacksonville	High school students and their families	HIV and STI testing, STI treatment, linkage to HIV care, and comprehensive sex education to students at three family resource centers located at high schools in Jacksonville.

*(table continued)*

**Table 6 (continued): Innovative Programs in Study and Control MSAs**

<b>Program Name</b>	<b>Location</b>	<b>Target Population</b>	<b>Description</b>
<b>Ryan White Linkage to Care</b>	Jacksonville	Ryan White recipients	Ryan White Part A funds used to provide peer specialists to contact individuals not receiving HIV care in last 18 months and offer linkage services to those willing to accept these services.
<b>Birmingham HIV Coalition</b>	Birmingham	HIV Care and prevention providers and advocates	Network of HIV service providers and advocates that meets monthly. Unique in that they divide up services and collaborate amongst organizations in support services and prevention. Are also working to share data across organizations
<b>UAB ER testing program</b>	Birmingham	Individuals receiving ER services at UAB hospital	Provides opt-op testing and linkage to care services for individuals testing positive for HIV (2 linkage coordinators)
<b>AIDS Alabama</b> <a href="http://www.aidsalabama.org">http://www.aidsalabama.org</a>	Birmingham	Individuals living with HIV or at high risk for HIV	Several innovative programs including: <ul style="list-style-type: none"> <li>• programming specific to Latino populations including outreach, education, testing and case management</li> <li>• Coordinated advocacy program for PLWHA and others in the community – advocate at the local, state and national levels</li> <li>• residential mental health and substance use treatment programs</li> </ul>
<b>ACTU (AIDS Clinical Trials Unit)</b>	Cincinnati and Birmingham	Participants in AIDS clinical trials and Community Advisory Board members	Part of an international network of institutions conducting HIV/AIDS-related clinical trials. Unique community advisory board provides individuals living with HIV to review current research and select clinical trials for the site. Participants also function in peer/mentor capacity for newly diagnosed individuals.
<b>University of Cincinnati Early Intervention Program - ER HIV testing</b>	Cincinnati, OH	Emergency room patients	Started in 1998, program provides testing in the Emergency Department, risk reduction counseling and linkage services for HIV patients who are not in care.



**Figure 1: Study and Control MSA Services and Service Gaps for each Step of the HIV Care Continuum**

Prevent New Infections	Identify Those Infected	Link to Care	Retain in Care	Treat/Suppress Viral Load
<b>STUDY</b>				
<b>Service Strengths</b>				
<ul style="list-style-type: none"> <li>▶ PrEP availability – varied as two MSAs have very limited availability while other 2 have more readily available</li> <li>▶ Evidence-based prevention programs available on limited basis in all MSAs</li> <li>▶ HIV/STD education/testing provided in MSAs – more readily available in MSA center cities</li> <li>▶ HIV prevention/ education in churches in all MSAs – with varied structure, intensity and levels of financial support</li> </ul>	<ul style="list-style-type: none"> <li>▶ HIV/STD testing available through county health departments testing (on-site)</li> <li>▶ Testing services in the community through ASOs (walk-in and outreach)</li> <li>▶ Mobile outreach testing vans</li> </ul>	<ul style="list-style-type: none"> <li>▶ Linkage services available in all communities with varied levels of financial commitment and differences in how the programs are structured.</li> <li>▶ Some funding for transportation to medical appointments</li> <li>▶ Surveillance data used to inform linkage efforts in Baton Rouge and Jacksonville</li> </ul>	<ul style="list-style-type: none"> <li>▶ Bus passes/gas stipends for medical care through local ASOs/medical clinics</li> <li>▶ Some mental health services and support groups available through ASOs and medical care</li> <li>▶ Case management services provided through Ryan White – little specialized case management through Medicaid</li> <li>▶ HOPWA services available in each MSA (some service disruption in Jackson)</li> <li>▶ Some HIV-specialized legal services in Baton Rouge, Jacksonville (discrimination cases in Jackson)</li> </ul>	<ul style="list-style-type: none"> <li>▶ HIV medical care generally available in MSAs although more difficult to obtain in outlying areas of MSAs</li> <li>▶ FQHCs providing some HIV care in Jackson and Columbia MSAs</li> </ul>

*(figure continued)*

**Figure 1 (continued): Study and Control MSA Services and Service Gaps for each Step of the HIV Care Continuum**

Prevent New Infections	Identify Those Infected	Link to Care	Retain in Care	Treat/Suppress Viral Load
<b>STUDY</b>				
<b>Service Gaps</b>				
<ul style="list-style-type: none"> <li>▶ Lack of adequate funding for HIV/STD education and health promotion programs in the community – particularly in the general population</li> <li>▶ Challenges reaching youth with effective prevention programs (i.e. state laws requiring abstinence education in schools)</li> <li>▶ Need for more programs focusing on faith community and anti-stigmatization of PLWH/MSM</li> </ul>	<ul style="list-style-type: none"> <li>▶ Stigma concerns delay testing</li> <li>▶ Lack of information in community about testing locations</li> <li>▶ No standardized ER HIV testing protocols</li> <li>▶ Absence of routine HIV testing by medical providers</li> <li>▶ Some issues of lack of coordination between organizations for testing efforts</li> <li>▶ Testing less available in outlying areas of the MSAs</li> </ul>	<ul style="list-style-type: none"> <li>▶ Lack of consistently available transportation resources</li> <li>▶ Stigma concerns limit effectiveness of linkage efforts</li> <li>▶ Little coordination between ER testing and linkage efforts</li> </ul>	<ul style="list-style-type: none"> <li>▶ Stigma/disclosure avoidance affect client engagement</li> <li>▶ Lack of stable housing</li> <li>▶ Not enough transportation funding to meet the need</li> <li>▶ Clinic-level barriers including care may be perceived as impersonal/not welcoming to clients and staff turnover</li> <li>▶ Limited mental health/substance abuse care</li> </ul>	<ul style="list-style-type: none"> <li>▶ General medical care often difficult to obtain, particularly for men under 65</li> <li>▶ Significant travel is necessary for individuals in many of the outlying areas of the MSAs</li> <li>▶ Stigma is a barrier to care engagement and retention</li> </ul>

*(figure continued)*

**Figure 1 (continued): Study and Control MSA Services and Service Gaps for each Step of the HIV Care Continuum**

Prevent New Infections	Identify Those Infected	Link to Care	Retain in Care	Treat/Suppress Viral Load
<b>CONTROL MSAs</b>				
<b>Service Strengths</b>				
<ul style="list-style-type: none"> <li>▶ PrEP provided at ID clinics</li> <li>▶ HIV/STD partner testing/notification services through multiple sources in MSAs</li> <li>▶ Some evidence-based prevention programs available</li> <li>▶ HIV prevention/education and testing in some churches</li> <li>▶ Syringe exchange program that also provides HIV/HCV testing at 2 sites in Cincinnati (none in Birmingham)</li> <li>▶ Safe Space drop-in program for minority MSM in Birmingham</li> </ul>	<ul style="list-style-type: none"> <li>▶ HIV/STD testing in the community through ASOs – walk-in and outreach</li> <li>▶ County health departments provide testing (on-site)</li> <li>▶ UC and UAB Emergency Rooms provide HIV screening and testing as well as linkage to care</li> <li>▶ Mobile outreach testing vans available for testing</li> </ul>	<ul style="list-style-type: none"> <li>▶ Linkage coordination available through UC/UAB ERs, ASOs and Health Departments (state of AL also provides linkage coordination)</li> <li>▶ Some funding for transportation to medical appointments</li> </ul>	<ul style="list-style-type: none"> <li>▶ Linkage coordinators work with individuals not receiving care to reduce barriers and facilitate re-entry to care</li> <li>▶ ERs able to identify individuals not currently in care who come to ER and offer linkage services</li> <li>▶ Some bus passes/gas stipends for medical care available</li> <li>▶ HIV case management services available</li> <li>▶ HOPWA services available including residential options in both MSAs</li> <li>▶ Legal Assistance available (Birmingham)</li> <li>▶ Some specialized MH/SA care options</li> </ul>	<ul style="list-style-type: none"> <li>▶ Comprehensive HIV care generally available</li> <li>▶ University of Cincinnati and UAB Children’s Hospital provides HIV care for youth</li> <li>▶ In KY and OH, Medicaid expansion has significantly reduced number of HIV-positive individuals without health insurance</li> </ul>

*(figure continued)*

**Figure 1 (continued): Study and Control MSA Services and Service Gaps for each Step of the HIV Care Continuum**

Prevent New Infections	Identify Those Infected	Link to Care	Retain in Care	Treat/Suppress Viral Load
<b>CONTROL MSAs</b>				
<b>Service Gaps</b>				
<ul style="list-style-type: none"> <li>▶ Lack of funding for HIV/STD education and health promotion programs in the community</li> <li>▶ Challenges reaching youth with effective prevention programs due to lack of comprehensive sex education programs</li> <li>▶ PrEP reported to be underutilized in Cincinnati</li> </ul>	<ul style="list-style-type: none"> <li>▶ Stigma and denial result in reluctance to participate in testing</li> <li>▶ Lack of ER testing in Northern Kentucky</li> <li>▶ Absence of routine HIV testing by medical providers</li> <li>▶ Less testing available in outlying areas of the MSAs</li> </ul>	<ul style="list-style-type: none"> <li>▶ Need for travel to care for most living in more remote areas of the MSAs</li> <li>▶ Lack of consistently available transportation resources</li> <li>▶ Some linkage programs do not follow clients long term</li> <li>▶ Surveillance data not used to inform linkage</li> </ul>	<ul style="list-style-type: none"> <li>▶ Stigma/disclosure avoidance affect client engagement</li> <li>▶ Lack of stable housing</li> <li>▶ Not enough transportation available – particularly in more rural areas</li> <li>▶ Complicated service networks</li> <li>▶ Limited mental health/substance abuse care</li> </ul>	<ul style="list-style-type: none"> <li>▶ Stigma regarding receiving care at UC and UAB ID clinic, as they are identified as HIV provider in the area</li> <li>▶ Travel is necessary for individuals in outlying areas</li> </ul>

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