



## HIV Infrastructure Study

Baton Rouge

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## **BACKGROUND |**

Data from the Centers for Disease Control and Prevention (CDC) regarding new HIV diagnoses in 2011, summarized in a Southern HIV/AIDS Strategy Initiative (SASI) manuscript, indicated that the South<sup>1</sup> had the highest HIV diagnosis rate of any US region.<sup>1</sup> In 2011, nearly half (49%) of new HIV diagnoses reported (which includes any new HIV diagnoses regardless of stage of HIV disease) were located in the Southern US, while the South accounted for only 37% of the US population.<sup>1,2</sup>

A subset of Southern states is particularly affected by HIV disease and shares characteristics such as overall poorer health, high poverty rates, an insufficient supply of medical care providers and a cultural climate that likely contributes to the spread of HIV.<sup>3-5</sup> These states include Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee and East Texas. Henceforth these states will be referred to as the “targeted states.” HIV and other STDS disproportionately affect individuals in the targeted states and these states share similarities in HIV-related outcomes including the highest HIV case fatality rates in the US.<sup>6</sup> Thirty-two percent of new HIV diagnoses were in the targeted states in 2011 while this region accounted for only 22% of the US population.<sup>7,8</sup> In addition, in 2011 all 10 metropolitan areas (MA)s with the highest AIDS diagnosis rates were in the Southern region, 9 were in targeted states.<sup>8</sup> Baton Rouge, Louisiana had the highest AIDS diagnosis rate in the US in 2011.

In order to determine how best to address and improve HIV-related outcomes in communities in the targeted states, we are examining existing HIV-related prevention and care infrastructure and community characteristics of targeted state MAs that are consistently among the ten MAs with the highest HIV diagnosis rates. Due to high HIV and AIDS diagnosis rates and HIV mortality rates, Baton Rouge, Louisiana was selected as one of the communities of study.

## **METHODS |**

In order to gain a more in-depth understanding of the HIV epidemic in Baton Rouge we conducted a community case study using both quantitative and qualitative data sources. This case study examined the infrastructure for HIV prevention and care in Baton Rouge as well as the strengths and challenges for addressing the disproportionate HIV epidemic in the area. This case study included 10 structured interviews with individuals involved in HIV prevention and care, community leaders, advocates, and individuals living with HIV. In addition, a focus group with individuals living with HIV in Baton Rouge was facilitated to gather information on their experiences and perspectives regarding HIV care, HIV prevention, stigma, and factors that influence HIV in their area. Data collection was completed in Fall 2013.

In order to gain a more in-depth understanding of available legal services, support groups, and advocacy groups, this case study also included nine structured phone interviews with individuals

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<sup>1</sup> The Census Bureau defines the South as including Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, Oklahoma, North Carolina, South Carolina, Tennessee, Texas, Virginia, West Virginia

working for organizations that provide legal, advocacy, and support group services for people living with HIV/AIDS in Baton Rouge. Data collection for this aspect of the study was completed in spring 2014.

In addition to the qualitative data collection, we identified and summarized existing data sources regarding HIV and STD epidemiology, community health needs, and gaps in services in Baton Rouge and Baton Rouge Parrish. These data sources included community needs assessments and state HIV epidemiologic reports.

## **METROPOLITAN AREA DESCRIPTION |**

Baton Rouge is a mid-size city, with a population of 230,139 in the city and 802,484 in the Baton Rouge metropolitan area.<sup>9</sup> Baton Rouge is located on the Mississippi River and has the 9<sup>th</sup> largest port in the US. Petrochemical production and manufacturing is the largest industry in Baton Rouge.<sup>9</sup> A majority of individuals residing in the city of Baton Rouge are African-American (55%) and 39% are white. One-third of residents have a college education and one quarter live in poverty.<sup>10</sup> According to a 2011 Brookings Institute Report, the city of Baton Rouge had the 5<sup>th</sup> highest concentrated poverty level (defined as neighborhoods where at least 40 percent of individuals live below the poverty line) in the US.<sup>11</sup> In the city of Baton Rouge between 2005-2009, 45% of individuals living in poverty lived in a concentrated poverty neighborhood in comparison to 10.5% nationally, 21% in New York City and 26% in New Orleans. The Brookings Report cites Baton Rouge as one of the cities with the largest increase in concentrated poverty since 2000.<sup>11</sup> Migration from Hurricane Katrina is cited as one of the potential causes of the increase in poverty along with the economic downturn.<sup>12</sup> Living in high concentrated poverty areas may be particularly detrimental as these neighborhoods often have low-performing schools, lack of job opportunities, higher crime rates and poorer health.

***In 2011, the city of Baton Rouge had the 5<sup>th</sup> highest concentrated poverty level in the United States.***

In 2011, a community needs assessment was completed as part of the Mayor's Healthy City Initiative. The community needs assessment process included examination of data from preexisting community assessments and setting of health priorities. Needs assessment findings regarding education and poverty indicated that only 60% of the high school population graduate and the numbers of children in poverty and in single parent households are more than double that of the national statistics.<sup>13</sup> In addition, East Baton Rouge Parish, which includes the city of Baton Rouge, has a low birth weight rate double that of the national benchmark, a teen birthrate almost double the national average, and 6 times more sexually transmitted diseases than the national average. The top 4 health priorities outlined in the community needs assessment included obesity, HIV/AIDS, ER utilization, and mental/behavioral health.<sup>13</sup>

A housing needs assessment conducted in 2010 by the Louisiana Housing Finance Agency found that a full 30% of households were experiencing housing problems, including spending more than 30% of income on housing, overcrowded living conditions, or inadequate kitchen or plumbing facilities. In low income households, 68% were having similar problems.<sup>14</sup> The report concluded that the Baton Rouge metropolitan area had significant need for increases in affordable housing options as well as subsidies and partnerships between housing authorities and social service agencies to accommodate low income housing needs.

## HIV IN BATON ROUGE |

Baton Rouge has consistently been among the US metropolitan areas (population 500,000 or more) with the highest HIV/AIDS diagnosis rates. For example, Baton Rouge was among the five metropolitan areas (MAs) that had the highest HIV diagnoses rates in 2008-2011.<sup>15</sup> In addition, Baton Rouge was among the five metropolitan areas (MAs) that had the highest AIDS

***In 2011, Baton Rouge had the highest AIDS diagnosis rate of any US metropolitan area.***

***34.5% of new diagnoses occurred among women in Baton Rouge in 2010.***

diagnosis rates in 2008-2011. Individuals with HIV are classified as having an AIDS diagnosis if their HIV disease has progressed to the point of meeting certain diagnostic criteria set by the Centers for Disease Control.<sup>16</sup> In 2011, Baton Rouge had the highest AIDS diagnosis rate of any US MA. Women have been particularly affected by HIV in Baton Rouge, as over one-third (34.5%) of new diagnoses occurred among women in 2010 while only 21% occurred among women nationally. In addition, Baton Rouge had the highest

HIV diagnosis rate among females overall and the highest rates among women aged 13-24 of any metropolitan area. Baton Rouge also had the second highest HIV diagnosis rate among men in 2010.

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In 2011, just under one-quarter (24%) of new HIV diagnoses in Baton Rouge were stage 3 (AIDS) at the time of diagnosis.<sup>17</sup> Thirty-one percent were reported to have an AIDS diagnosis within 6 months of their HIV diagnosis. Survival data from the Louisiana Office of Public Health indicate that among those diagnosed with AIDS from 2002-2006, 83% survived 12 months and 70% survived 36 months.<sup>17</sup> The 36-month survival in Baton Rouge was the second lowest of any region in Louisiana and much lower than the national average (83%).

***Only 70% of those diagnosed with AIDS in Baton Rouge survive for 3 years after diagnosis.***

Baton Rouge receives funding for HIV services through the Ryan White Part A program. The majority of this funding is used to cover medical care and medical case management for individuals with HIV.<sup>18</sup> This funding also covers some medical transportation, oral health, early intervention care, and legal services. An analysis of Part A funding per person estimated to be living with HIV revealed no indication that Baton Rouge receives less funding than larger MAs or MAs outside the US South. Funding is available through the Ryan White Part B AIDS Drug Assistance Program (ADAP) to cover HIV medication for individuals meeting financial eligibility criteria (300% of poverty). A growing portion of the federal ADAP award in Louisiana is used to provide funding to purchase and/or continue health insurance coverage for individuals living with HIV. Related cost shares (co-payments and deductibles) are also covered for enrolled clients. In 2013, 1280 individuals living with HIV received insurance continuation assistance in Louisiana.<sup>19</sup>

When the Affordable Care Act (ACA) federally facilitated marketplace (FFM) opened in Louisiana in November 2013, the Ryan White Part B program continued to support the purchase of comprehensive health insurance services to assist eligible clients maintain or obtain health insurance coverage. Four insurance carriers registered to offer various plans through the FFM and during the Open Enrollment period, more than 1700 persons selected a plan for which they sought

Part B assistance in paying premiums and/or cost shares. Without the advent of the FFM and the support of Part B resources, the cost of their comprehensive HIV care would have been absorbed by other federal and state resources. At the end of 2013, there were 447 persons residing in the Baton Rouge area who were enrolled in the Ryan White Part B Health Insurance Program.

Funding from Medicaid also covers medical care for HIV-positive individuals that are eligible. To be eligible for Medicaid in Louisiana, parents of dependent children must subsist at 24% of the poverty level, which translates to \$4,685 annual income, the second most restrictive income eligibility criteria in the country.<sup>20</sup> Medicaid covers 12 physician visits per year regardless of setting, 1 preventive care visit and 3 emergency room visits annually, which count against the physician visit limit. Medicaid in Louisiana does not cover substance abuse services. Additionally, Medicaid covers 5 prescriptions per month, with possible overrides, which may be insufficient for HIV positive individuals on a medical regimen.<sup>21</sup> The Louisiana government privatized the Medicaid system in 2012 and has also been privatizing the state funded hospitals. Under the newly privatized system, traditional HIV case management programs, which generally provided in-person assistance with obtaining medical care and needed resources, are no longer covered by most Medicaid plans.

## HIV CARE INFRASTRUCTURE |

### *Medical Care:*

The key informant interview and focus group participants described a medical care system with several options available for HIV medical care including an Infectious Diseases (ID) Clinic that is part of the Catholic hospital system (formerly part of the LA public hospital system), a community health center clinic, a clinic that is affiliated with a local AIDS Services Organization, and several private ID clinics. With the exception of the private ID practices, the clinics receive some Ryan White funding to provide care for those without health insurance. Study interviews revealed that there are not currently waiting lists to receive HIV medical care at the clinics; however, several participants stated that there were sometimes waits to make appointments and waiting times to receive care once at the clinics. Some study participants perceived that those without health insurance were more likely to experience barriers to medical care such as lengthy paperwork burden or long wait times than those with some type of medical coverage. Participants in the focus group discussed some difficulties stemming from the closing of the public hospital, Earl K. Long hospital, including the time and emotional burden of reapplying to new facilities, additional challenges in filling prescriptions, and lack of condom distribution. These frustrations are illustrated by the following statement by a focus group participant:

***“You have to understand the politics that is going on in this state also... The hospital that (he) was talking about on Earl K. Long, he -- someone just shut it down, so they could happen to merge with Our Lady of the Lake. So the people that were getting help there -- I mean, you have to jump through so many loops and everything and re-apply. Even the nurses that were working there, they had to step down and then re-apply and everything. So patients, it has been tragic, those that were getting their medications easily and everything; now, you have to take a number just to drop your prescription off. That was madness. “***

HIV-positive pregnant women are often seen at a local women’s hospital. The women’s hospital has an innovative program that provides targeted case management for pregnant women who are HIV-positive to increase engagement in care, adherence to medication recommendations and to provide

other services such as education, support, and resource linkage. Since the initiation of this program in 2002, infants contracting HIV are exceedingly rare.

#### *Transportation:*

Transportation to medical care was reported to be a barrier to care for many individuals. Baton Rouge has a bus system but study participants reported that it was often unreliable, particularly for individuals living in more outlying parts of the parish. Participants reported some limited funding available from Ryan White and Medicaid to cover transportation for individuals with HIV qualifying for these programs. The concerns expressed regarding lack of transportation availability were consistent with the findings of a report on access to healthcare for individuals with HIV in Louisiana, which was generated as part of the State Healthcare Access Research Project (SHARP) conducted by researchers at the Health Law and Policy Clinic of Harvard Law School. The study indicated that lack of transportation is a barrier to care for many individuals living with HIV in Louisiana, particularly for more rural living individuals and recommended that advocates “urge the federal Health Resources and Services Administration (HRSA) to change the definition of core service in the Ryan White program to include transportation services.”

#### *Housing:*

Lack of available housing for individuals with lower incomes in the community was also cited as a problem that affects many individuals living with HIV. Housing concerns were said to be particularly problematic for those living in more rural areas of the Baton Rouge metropolitan area. Previous research has consistently identified that individuals who are homeless or unstably housed have poorer HIV outcomes.<sup>22</sup>

#### *Case Management:*

Study participants generally reported greater difficulty with access to HIV case management than they did for medical care. They reported that since the privatization of Medicaid these services are more difficult to access since most of the private Medicaid insurance plans do not cover HIV case management in its traditional form, which included in-home services and personalized care plans. Some private Medicaid plans provide a case manager who is available to talk with enrollees by phone to provide primarily medical-related information, however there lacks consistency in the case manager assigned to a client over time. Certain high-risk populations are reported to have greater access to HIV case management including pregnant women and newly diagnosed individuals. The following provider quote illustrates the concerns regarding telephone case management:

***“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”***

HIV case management paid for through the Ryan White program is reported to be shifting from long-term HIV case management relationships to shorter-term relationships focused on addressing client needs and transitioning clients to self-sufficiency. This was identified to be a difficult shift for some clients as this relationship served to provide support, motivation, and assistance as needed to obtain resources for individuals with HIV who were often experiencing high levels of poverty and HIV-related stigma. Some study participants perceived that these shifts in case management services could be attributed to several factors, including funding limitations and restrictions forcing

agencies to cut provision of case management services, and a shift towards a medical case management model. One focus group participant felt that the client experience in care has deteriorated over time with funding restrictions and limitations on services and time spent with clients:

***“But from my experience, the process is getting worse. It was much better 10 years ago, even though it was in its incubate, its beginnings. But the thoroughness of it, it was more thorough then. Of course, it was one-on-one. You had more intimacy with the individual.”***

#### *Mental Health/Substance abuse treatment:*

When asked about the availability of mental health and substance abuse services, most key informants reported that these services were limited in availability for the general population and that few behavioral services were targeted for individuals with HIV. Ryan White Part A funding data from 2012 indicated that only 2% of Ryan White funding was allocated for mental health services and 3.5% for substance abuse treatment.<sup>18</sup> Focus group participants reported that substance abuse services were generally available in the community but indicated that individuals often are not ready to seek this care. No substance abuse services specifically designed for individuals with HIV were reported.

## **HIV TESTING AND PREVENTION |**

HIV prevention efforts were reported to focus primarily on testing and counseling in the Baton Rouge area. Several community organizations and the local health unit in Baton Rouge receive funding to provide HIV testing. Interview participants reported that these testing endeavors were usually targeted to specific high impact zip codes and risk populations because of requirements by funders. Interview participants indicated that these restrictions have limited their ability to test in areas less impacted by HIV but nevertheless containing individuals at high-risk and unaware of their HIV status such as in more rural areas and on college campuses. The state run hospital that is now closed, Earl K Long, had provided HIV testing in their emergency room (ER). Plans are in process to initiate testing in the hospital ER that sees many of the patients who would have gone to Earl K Long, but this had not been implemented at the time of data collection.

Several key interview participants reported that the State of Louisiana had recently cut all funding for HIV prevention resulting in a greater reliance on CDC prevention funds and increased difficulty in implementing effective prevention strategies. The vast majority of CDC prevention funds are awarded to the state and the state in turn allocates the CDC prevention funds to local organizations. Currently, 6 organizations in Baton receive CDC funding allocated by the state for a total of \$745,000. Condom distribution was reported to be limited in the Baton Rouge area. For organizations receiving funding from the State of Louisiana, condoms are primarily distributed in certain high-prevalence parishes, including East Baton Rouge.<sup>23</sup>

***Participants reported that Louisiana had cut all funding for HIV prevention.***

Interview participants commonly reported lack of funding and available personnel to provide testing and general HIV prevention efforts to be a significant limitation in addressing HIV in the community. One interview participant stated that there needs to be “more boots on the ground” to better implement HIV prevention strategies. A common theme among interview participants and

focus group participants was that there is a lack of prevention and awareness media messaging in the area including billboards and radio announcements. Most participants believed that this type of public prevention campaign is necessary to combat stigma, apathy, and the belief that HIV is not the serious issue that it once was as well as to dispel myths about HIV transmission and disease. Advertising can decrease stigma by increasing the overall visibility of the epidemic and normalizing testing and care seeking behaviors. Some service providers noted the difficulty in publicizing their agencies' available services or testing events, which could also be improved with advertising initiatives. Study participants would like to see saturation media messaging with information in as many public venues as possible such as billboards, buses, barbershops, markets, malls etc. One interview participant stated: ***"There is also the lack of sustained organizational effort to combat the disease as far as sustained advertisement to take this on."***

Some partnerships with African-American churches for prevention were reported but the vast majority of respondents reported that more partnerships in the religious community are needed to adequately address HIV.

Louisiana is a recipient of a federally-funded Care and Prevention in the United States (CAPUS) grant. CAPUS grants were awarded to 6 Southern states and 2 Midwestern states in 2013. The CAPUS grants are designed to reduce HIV-related morbidity, mortality, and related health disparities among racial and ethnic minorities and provide funding to enhance systems for HIV prevention, detection, and linkage to care. Louisiana will be utilizing CAPUS funding to implement evidence-based HIV prevention campaigns in Baton Rouge that will utilize mass media (TV, radio, newspapers, magazines, and the internet) to deliver important HIV prevention messages that align with the High Impact HIV Prevention efforts of the CDC and the National HIV/AIDS Strategy (NHAS).<sup>24</sup>

## **HIV-RELATED LEGAL SERVICES, ADVOCACY ORGANIZATIONS AND SUPPORT GROUPS |**

### *Legal Services:*

The availability of legal services for individuals with HIV was reported by key informants as existent, but limited. The only targeted legal services for people living with HIV/AIDS are provided by AIDSLaw. AIDSLaw offers legal services for people who are HIV positive and whose income falls within the 200% poverty level. AIDSLaw is located in New Orleans, but has had a satellite office in Baton Rouge since 2009. The areas of service provided by AIDSLaw include housing and employment discrimination, government and private benefits, and permanency planning issues including custody, guardianship/tutorship, wills, powers of attorney, and health care powers of attorney. These services are free. However, they require that clients provide a photo ID and proof of HIV status. AIDSLaw does not have the resources to represent all the clients who seek representation.

When a person seeks a service that AIDSLaw cannot handle, they are often referred to either the Southeast Louisiana Legal Services (SLLS) or the LSU Immigration Law Clinic. These organizations provide a wide range of legal services to low-income individuals in addition to those available at AIDSLaw including bankruptcy, mortgage foreclosure, and immigration work. These services are



available to individuals whose income falls within the 200% poverty level and whose assets do not exceed \$8,000.<sup>2</sup> These offices also must turn away prospective clients because of lack of resources.

None of these organizations provide services for confidentiality breaches, private landlord-tenant disputes, or mental health-related issues. These services, and others, are sometimes provided by private attorneys. SLLS reported that it often refers cases to members of the local bar association and that attorneys are generally willing to take the referred cases pro bono, but again, there are insufficient private bar resources to address the full need for legal assistance.

There are several barriers for people living with HIV/AIDS accessing legal services including availability, transportation, and awareness. First, availability of legal service is low because of the inadequate number of pro bono attorneys available compared to the community need. An attorney at AIDS Law explained that ***“for every one social security case we take, there are five more that we could take if we had more resources.”*** The director of a housing community for people living with HIV/AIDS similarly stated that residents in her community are always seeking legal representation. She said that although AIDS Law has been a great help to many of her residents, the one small Baton Rouge office is unable to handle the high need, particularly as the Baton Rouge AIDS Law office serves nine parishes. SLLS has only eleven attorneys providing services to individuals with low incomes in eight surrounding parishes.

This stretching of resources also relates to the second barrier – transportation. Because of the small number of offices, individuals must travel to receive services. Many individuals with HIV lack personal means of transportation and must rely on the bus system or friends and family members to take them where they need to go. SLLS has tried to combat this problem when possible by allowing individuals to apply for their services online or over the phone, and in rare cases making in-home visits.

***“For every one social security case we take, there are five more that we could take if we had more resources.”***

***--AIDS Law Attorney***

The final barrier is lack of awareness. There is no targeted advertising for legal services for people living with HIV/AIDS in Baton Rouge. AIDS Law is strictly a referral service and does not advertise. SLLS similarly gets a high number of clients from referrals but also does some general advertising. None of this advertising, however, is targeted towards the HIV/AIDS community.

All of the interview participants agreed that these barriers stem from a lack of funding. Both AIDS Law and SLLS discussed their desire to increase outreach and to be able to provide more legal services specifically to individuals with HIV/AIDS. Both organizations explained, however, that they can only do so much with their limited budgets.<sup>3</sup> Therefore, there is still a need for more legal

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<sup>2</sup> The asset limit can sometimes be waived by the SLLS executive director.

<sup>3</sup> AIDS Law receives funding from Ryan White Part A. SLLS receives funding from the National Legal Services Corporation, the Louisiana Bar Foundation, and various grants. Both organizations have seen a recent decrease in funding.

services for people living with HIV/AIDS as well as a need to get individuals connected to services that currently exist.

#### *Advocacy Organizations:*

When asked about advocacy organizations for people living with HIV/AIDS, most key informants reported that these organizations are lacking in Baton Rouge. Advocacy organizations were defined to include any organization that advocated for change for the HIV/AIDS community (whether through legislation, funding, education and awareness, prevention, accessibility to treatment, etc.); but specifically focused on programs that involved individuals living with HIV/AIDS in the advocacy work. Considering the latter focus, the only local organizations with advocacy programs for people living with HIV/AIDS were Family Services of Greater Baton Rouge (FSGRB) and the HIV/AIDS Alliance for Region Two (HAART).

The consumer advocacy group at FSGRB is a group of positive individuals who meet once a month to be personally encouraged and to learn how to empower others and advocate for change. The group is free and transportation is provided. A similar program was recently created at HAART in January 2014. This program also empowers and trains individuals living with HIV/AIDS. The end goals are to send these individuals into the community to give educational and inspirational presentations to other persons living with HIV/AIDS, family and friends, employees, and other organizations, and to advocate for change with the Legislature and other key policy makers. This program is also free and transportation is provided. The director explained that HAART wanted to create this program because they realized that ***“advocacy is really lacking in the Baton Rouge area”*** and that in order to make a meaningful difference the agency must focus on ***“empowering everyone.”***

The biggest reported barrier to persons living with HIV/AIDS participating in these programs is stigma. Every key informant had a story about a stigmatized client who didn't want to go to an office associated with HIV, who didn't want to disclose to even a small group, or who didn't want to talk to anyone in the community, including family and friends, about their status.

Yet this barrier is one reason why these advocacy groups are so important – they help empower the community. Or as one interviewee said, ***“they put a face to AIDS, and we need more people willing to do that.”*** Interviewees talked about how these advocacy groups can positively impact a person's life. One program facilitator reported that the clients who participate in her advocacy group are more confident, informed, and care more about what is happening in the community. Another focus group attendee shared her experience of speaking at a youth rally. She said that after she finished speaking someone came up to her and said, ***“It must have been meant for me to come here and hear you speak today . . . I'm four years HIV [positive] myself.”*** The focus group attendee then explained, ***“she hadn't had anybody to talk to, nobody to talk to. That moved me to let me know how I affect people when I do divulge.”***

Another organization, AIDS Law, provides a different sort of advocacy. Though not training people with HIV to advocate themselves, AIDS Law partners with other organizations and consumers to advocate in favor of issues important to the HIV/AIDS community. One attorney at AIDS Law is also the chair of the Louisiana AIDS Advocacy Network (LAAN). LAAN has a liaison at every HIV/AIDS service organization and clinic in East Louisiana thereby connecting AIDS Law to a variety of issues, as AIDS Law has limited resources to provide advocacy.

Interviewees believed that while any advocacy efforts are useful, advocacy has a special power when it comes from individuals who are living with HIV. One focus group attendee explained it this way:

***“They need a committee of HIV positive people to get together, come up with a solution how we can get everybody together in one spot from all these different agencies . . .”***

**--Person living with HIV**

***“They need a committee of HIV positive people to get together, come up with a solution how we can get everybody together in one spot from all these different agencies . . . and if they would implement some of the ideas, that would make a big difference. But see, they go and ask people who don’t know their status, the ones that’s working in big offices downtown. But they don’t ask the people that’s living with it.”***

### *Support Groups:*

The key informant interviews described several support groups available for people living with HIV/AIDS in Baton Rouge. These groups included targeted support for heterosexual men, men who have sex with men, and transgender persons, as well as a mixed gender group. Our interviews did not identify any support groups for women only or youth. Most groups meet twice a month and are provided free of cost. They are facilitated by staff members at the various organizations and funded by Ryan White Part A. The consistent goal across these groups is to bring like-individuals together to support and encourage each other. Discussion topics vary depending on the organization and group members, but typically include topics such as access to services and treatment, medical adherence, depression, self-esteem, relationships, expectations, stigma, and disclosing. Attendance also varies, but usually ranges from 4-15 people per group.

The biggest barrier to individuals attending these support groups is stigma. Representatives from each agency explained that they try to combat stigma by assuring clients that everything is confidential, but many clients fear being seen at an agency associated with HIV and/or don’t want to admit to even a small group of people that they are positive. Every organization had tried something to increase attendance (more advertising, changing times, referrals from peers and case managers, etc.) but stigma remained the biggest reported reason for low attendance.

Another barrier to support group participation is transportation. Although some organizations provide transportation, funding decreases have caused others to cut transportation services. Lack of transportation is directly correlated to lower attendance. For example, after one organization lost the ability to provide transportation, the attendance at its group dropped from 10-12 men down to 4-5. The same decline was observed at another organization, as they had clients wanting to attend support groups but who were without transportation to get there. Transportation used to be provided for one of their groups, but since that stopped the group members were no longer attending the group.

Despite these barriers, support groups are reported to be very beneficial to those who feel comfortable enough and have the means to attend. One focus group attendee explained that his support group ***“strengthened and carried me through.”*** Another person said:

***“What I think, everybody goes through that I-don’t-want-nobody-to-know stage in the beginning. When you first get that diagnosis, you don’t want nobody to know. You really don’t. . But if you don’t have a good support group, you will never be able to get passed that I-don’t-want-nobody-to-know.”***

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

***--person living with HIV***

One interviewee also noted an overall increase in consumer satisfaction when consumers were able to go to support groups. The interviewee said it helped her residents ***“not feel cut off and forgotten.”*** Another group facilitator explained that support groups help people feel more comfortable disclosing their status, and ***“when clients are open about their status they are much more confident and free.”*** Every key informant reported a need for more support groups and/or a need for more clients to attend support groups.

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

When asked about contributors to HIV incidence and poor HIV outcomes in Baton Rouge, study participants described a number of structural, social, and economic factors that are detailed below.

### ***Stigma:***

HIV-related stigma was consistently reported to be pervasive and destructive in its negative influence on protective behaviors, HIV testing, treatment initiation, treatment adherence and willingness to participate in support groups and advocacy. A consistent theme throughout the interviews and focus group was that HIV remains a highly stigmatizing condition, particularly among the African American population and among individuals with lower incomes in general. According to some study participants, incorrect transmission myths persist, creating further fear and shunning of individuals with HIV. Due to this significant negative perception of HIV, individuals often do not want to be tested for HIV or 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 this 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.”***

Those that do know they are HIV-positive may choose not to seek treatment for their HIV disease rather than risk being seen getting treatment and face the potential negative social consequences of exposure of their HIV status. One focus group attendee explained that, ***“because of the stigma surround HIV and AIDS, a lot of people are not interested in getting into care for fear of who’s going to see me.”*** This same fear of being as seen at an agency associated with HIV also stops individuals from participating in advocacy or support groups. A few study participants believed that HIV-related stigma has diminished some over the years resulting in less discrimination against and isolation of individuals with HIV and more family and community acceptance of people with

HIV. However, these participants believed that people living with HIV still experience significant internalized stigma and fear about the consequences of revealing their HIV disease. One key interview participant believed that individuals living with HIV who had more supportive families and friends were often more protected from negative effects of community HIV stigma than individuals who were more socially isolated.

Stigma regarding sexual orientation, which is closely related to HIV-related stigma, is also reported to be highly prevalent in Baton Rouge as it is in much of the Southeastern US.<sup>5,25</sup> This stigma is reported to make it more challenging to reach men who have sex with men (MSM) for HIV prevention and support efforts, particularly among African-American men where sexual orientation stigma is particularly high.<sup>26</sup> This 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. This pervasive stigma was generally thought to be particularly 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 that I would say is very unique to us.”***

Stigma towards transgender persons is also highly prevalent in Baton Rouge. One support group facilitator observed that the impact of stigma was much more prevalent in the transgender support group than in the support group for heterosexual men. This was evidenced by the difference in attendance between the two groups. Both groups meet at the same organization with the same facilitator, and have the same transportation services, but attendance at the heterosexual group is consistently larger than the transgender group. The facilitator reported that she discusses group membership with a lot of transgender persons but that they often fail to attend out of discomfort in disclosing not just their HIV status but also their identity as a transgender individual.

The use of denial as a coping mechanism for individuals with HIV is not new or unique to the Baton Rouge area, however, some participants reported that the substantial levels of stigma in Baton Rouge may exacerbate or increase the propensity for denial-based coping. They argue that individuals may minimize the seriousness of their risk behavior or assert that they do not need to see a medical provider for HIV treatment because they do not want to face significant negative reactions that they fear will occur if they are exposed as HIV-positive. Stigma concerns and denial based coping may both lead to lower likelihood of getting testing and late HIV diagnosis. Among those who have tested HIV-positive, stigma, fears, and denial are reported to contribute to late presentation to care thus placing individuals at higher risk for greater morbidity. One key interview participant reported that very low CD4 counts were common on first presentation for HIV medical care, as are opportunistic infections that are indicative of late presentation to care. This participant implicated stigma and denial as strongly contributing to these poor health outcomes. Below are related quotes from focus group participants:

***“If the stigma wasn’t so bad, I don’t think people would be so ashamed about getting care. “***

***--person living with HIV***

***“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.”***

***“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.”***

#### ***Lack of resources:***

Lack of political support from state lawmakers to address the HIV epidemic was reported as a barrier in adequately responding to HIV in the Baton Rouge community. State funding for HIV prevention has substantially decreased over time thus limiting the availability of effective prevention efforts to those that can be covered through federal funds or through limited private grant availability. Decreased funding has also resulted in limited access to legal, support, and advocacy services either directly or by increasing the barriers to obtaining service. Lack of funding for transportation limits HIV-positive individuals from being able to seek necessary services, and lack of funding for advertising greatly diminishes individual awareness that these services even exist. A number of respondents also reported that coordination of the limited resources available for HIV prevention and care is lacking at times due to not having the time and resources available for interagency coordination. Some mentioned that the situation of very limited resources fosters competition between organizations to secure available funds. The lack of coordination between agencies was noted by both service providers and individuals who receive care in the community. Focus group participants suggested that greater participation by HIV-positive consumers in planning and evaluating HIV care and prevention services would assist in promoting a focus on the needs of individuals with and at high-risk for HIV and creating solutions that would most optimally meet these needs. This is an area where advocacy services could have an impact. Focus group participants had the following comments on these issues:

***Participant 1: “They need a clearinghouse. They need one. Not to say eliminate these other places, but they need a central (place) -- I advocated for this for a long time, that there’d be a one information center where you can get the information and they will direct you where you got to go. These different agencies, some of them are excellent in referring you to where you need to go. But there’s information that they don’t know, because it’s not shared. It’s not shared for fear of one agency developing another...”***

***Participant 2: “Fear of losing out. They’re all competing for the same amount of dollars.”***

***Participant 3: “They need a committee of HIV positive people to get together, come up with a solution how we can get everybody together in one spot from all these different agencies. If they would just sit down, talk and listen to what we have to say, it would make a big -- and if they would implement some of the ideas, that would make a big difference.”***

#### ***High levels of poverty and incarceration:***

High poverty levels and low educational levels are common in the Deep South region of the US, particularly in Louisiana, which has the second highest proportion of residents living under 100% of poverty level and the 5<sup>th</sup> lowest proportion of individuals earning a bachelors degree or higher of

any states.<sup>27,28</sup> Poverty and lack of education have been identified as contributors to higher disease risk and poorer disease outcomes. Poverty contributes to greater individual level risk for disease and also contributes to less tax funding available for states to adequately address community needs including public education and prevention and management of diseases including HIV.

Louisiana has the highest incarceration rates in the US and spends a greater proportion of their state budget on incarceration than the US average.<sup>29,30</sup> The state also has a higher percentage of inmates serving sentences for drug offenses than the US average. Incarceration has been found to disrupt social and sexual networks in minority communities leading to greater infection risks for communities experiencing this phenomenon.<sup>31</sup> A majority of key informants discussed the high incarceration rates in their area and their 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.”***

## **COMMUNITY RESOURCES AND STRENGTHS |**

A number of community strengths in regards to HIV/AIDS prevention and care were noted by study participants. These strengths included committed HIV advocates and service providers who work diligently and creatively to address HIV in their community. These individuals recognize the need to increase availability of services while also combating the barriers that keep HIV-positive persons from taking advantage of those services already in existence. Strong collaboration on the part of providers who receive Ryan White Part D funds (for women and children) was also noted and cited as leading to more successful treatment of HIV-positive individuals eligible for HIV care funded through Part D.

Availability of HIV medical care for individuals in need of this care without substantial waiting time to initiate care was also cited as a critical community strength as was the availability of support groups.

Innovative approaches to addressing HIV in the parish were identified by participants. For example, the women’s hospital HIV pregnancy case management program is unique in imbedding HIV-specific services for HIV-positive pregnant women in an outpatient OB clinic setting in order to improve HIV-related pregnancy outcomes.<sup>32</sup> Innovative partnerships with churches were also described. One organization reported facilitating small group HIV education and prevention messages for pastors at predominantly African-American churches in order to address stigma and raise awareness of HIV in the community. In addition, the state has initiated an innovative linkage to care program for individuals with HIV being released from state

### **Baton Rouge Community Resources and Strengths**

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

- 1.** Committed HIV advocates and service providers,
- 2.** Available HIV medical care,
- 3.** Innovative HIV-specific services for HIV+ pregnant women,
- 4.** Some innovative partnerships with churches,
- 5.** Innovative state linkage to care program for released inmates,
- 6.** Influx of new funding and programs through a recently funded CAPUS grant,
- 7.** Use of Ryan White funds to help eligible clients access insurance through the Affordable Care Act.

prisons that includes the Baton Rouge area. This program provides videoconferencing for the soon to be released individual living with HIV with his/her local ASO organization so that a plan for community transition is in place prior to release.

An additional strength for the Baton Rouge community will be the influx of funding through a recently funded CAPUS grant, which will be utilized to address some of the needs identified by study participants. Specifically, the funding will be used to expand prevention efforts in the Baton Rouge area by using mass media to disseminate prevention messages and increase HIV testing. CAPUS funding will also be used to upgrade surveillance systems and enhance programs to link individuals to medical care who have not previously received these services or who are currently out of medical care. State surveillance data will be used to identify individuals out of care in need of linkage services. Finally, federal Ryan White funding is being used to assist individuals living with HIV who live below 300% of the federal poverty level in Louisiana to access health insurance through the Affordable Care Act by covering premiums and related cost shares (co-payments and deductibles). Through this assistance, utilizing Ryan White Part B resources, clients have portable access to primary medical care, specialty care, diagnostic laboratory services, imaging services and pharmacy benefits that exceed the medications available through the Louisiana AIDS Drug Assistance Program (LA ADAP). By the end of 2013, there were 447 persons living in the Baton Rouge area who were receiving health insurance assistance; this reflects 25% of all clients enrolled in this program.

## CONCLUSIONS |

### *Overview:*

Examination of HIV-related statistics and information provided by study participants portrays an HIV epidemic in Baton Rouge that is highly prevalent, particularly in the area's most vulnerable populations, but existing in the shadows due to pervasive stigma, denial and lack of comprehensive and highly visible prevention efforts. Baton Rouge not only has the highest AIDS diagnosis rate of any metropolitan area in the country, it also has the one of the lowest 3-year AIDS survival of any region in the state of Louisiana – a state that has the lowest AIDS survival in the US.<sup>33</sup>

### *Barriers to Care and Prevention:*

A number of barriers to care and prevention were noted including lack of state prevention funding, lack of transportation options, limited mental health and substance abuse treatment options, and barriers to HIV case management services. More extensive paperwork requirements and some delays in initially accessing medical treatment were reported for individuals without insurance; however, HIV medical care was reported to be generally available for those seeking these services. Fears of the repercussions of HIV disclosure as well as experiences of stigma and discrimination serve to drive HIV underground and lead to reluctance for HIV testing, prevention and treatment among those most vulnerable to the disease.

### *Identified Strategies to Address Baton Rouge Epidemic:*

Additional resources for prevention and comprehensive prevention efforts that raise the visibility of the disease and address stigma as well as greater interagency collaboration, consumer participation in prevention and care planning, and greater resources for HIV case management, transportation, mental health, housing, and legal services were identified as strategies necessary to stem the HIV epidemic in Baton Rouge.



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