A large, dashed white outline of the state of Louisiana is centered on the page, serving as a background for the title and subtitle.

Louisiana State Report

An Analysis of the Successes,
Challenges, and Opportunities
for Improving Healthcare Access

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louisiana

PREPARED BY HEALTH LAW AND POLICY CLINIC OF HARVARD LAW SCHOOL
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Louisiana

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foreword




Access to good quality, comprehensive healthcare is critical for people living with HIV and AIDS. Advocating effectively for improved healthcare access requires understanding the underlying legal and policy landscape of a state, the state's fiscal and cultural environment, and existing barriers to healthcare access.

The State Healthcare Access Research Project (SHARP) is researching and analyzing this information and examining states' capacities to meet the care and treatment needs of people living with HIV and AIDS. Working together with community partners, the project is identifying past successes, current challenges, and future opportunities to improve access to care and services for people living with HIV/AIDS. SHARP has three main goals: (1) to improve access to care and treatment, (2) to build advocacy capacity in SHARP partner states and communities, and (3) to share information and effective strategies among partners in the SHARP states. SHARP is currently active in seven states, plus Los Angeles County, California: Alabama, Arkansas, Illinois, Louisiana, Mississippi, North Carolina, and South Carolina. The project will take on additional states or regions in 2011.

Collaboration with community partners is integral to the SHARP process. In the State of Louisiana, the leadership and members of the Louisiana AIDS Advocacy Network were instrumental in connecting us with consumers, healthcare providers, community-based AIDS services providers, agency representatives, and other advocates and researchers as we conducted our in-state research for this report. These community partners have shared their opinions and insights about the successes and challenges faced by people living with HIV and AIDS as they seek care. They have also shared their perspectives on the political, cultural, and fiscal factors unique to Louisiana.




foreword



Our goal is for each state’s SHARP report to be informative and useful. It is our hope and intention that the reports will become a framework for future efforts to expand healthcare access—tools that can be used as part of a broader strategy to bring healthcare to more people living with HIV/AIDS. It is important to note that the reports reflect a snapshot of a state at a moment in time—with national health reform recently passed in Congress and states responding to ongoing economic difficulties, the landscape of healthcare access is changing almost every day. Some of the opportunities discussed in this report may need to be revised accordingly.

SHARP is being conducted by the Health Law and Policy Clinic of Harvard Law School and the Treatment Access Expansion Project (TAEP), with support from Bristol-Myers Squibb. The Health Law Clinic has provided legal services to low- and moderate-income people living with HIV/AIDS for 20 years and actively participates in HIV healthcare access advocacy efforts. TAEP is a national organization focused exclusively on HIV healthcare access advocacy. The mission of both organizations is to help bring quality, comprehensive healthcare to more people living with HIV and AIDS.

acknowledgments

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acronyms

- ACA Patient Protection and Affordable Care Act of 2010
- ADAP AIDS Drug Assistance Program
- ASO AIDS Services Organization
- CBO Community Based Organization
- CDAP Copayment and Deductible Assistance Program
- DHH Louisiana Department of Health and Hospitals
- DOC Louisiana Department of Corrections
- EMA Eligible Metropolitan Area
- ETHA Early Treatment for HIV Act
- FQHC Federally Qualified Health Center
- HAP Louisiana Office of Public Health's HIV/AIDS Program
- HBCP Home Based Care Program
- HHS US Department of Health and Human Services
- HIP Health Insurance Program
- HOPWA Housing Opportunities for Persons with AIDS
- HRSA US Health Resources and Services Administration
- HUD US Department of Housing and Urban Development
- IDU Injection Drug Use
- LAAN Louisiana AIDS Advocacy Network
- LIS Low Income Subsidy
- LPHI Louisiana Public Health Institute
- LSU Louisiana State University




acronyms



- MSM. Men who have Sex with Men
- MSP Medical Savings Program
- OPH Louisiana Office of Public Health
- PAP Patient Assistance Program
- PCASG. Primary Care Access and Stabilization Grant
- PREP. Personal Responsibility Education Program
- SAMHSA US Substance Abuse and Mental Health Services Administration
- SSDI Social Security Disability Insurance
- SSI Supplemental Security Income
- TGA Transitional Grant Area

part I: introduction

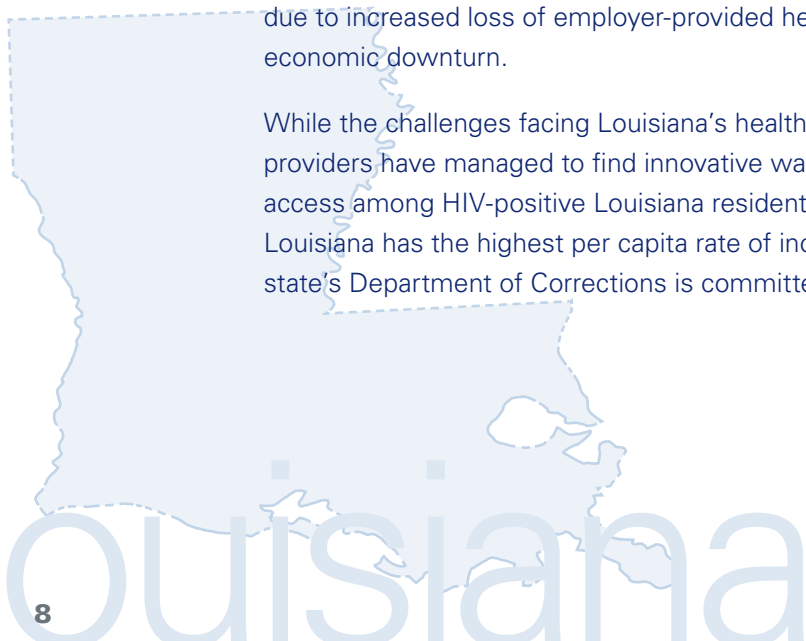


As with other states in the Southeast, Louisiana is a hot spot in the HIV epidemic in the United States. In June 2010, 17,695 Louisiana residents were known to be living with HIV, slightly over half of whom have been diagnosed with AIDS. Among large cities in the United States, Baton Rouge ranked second in its rate of new AIDS cases, and New Orleans ranked third. The HIV/AIDS epidemic poses a tremendous challenge to Louisiana's already strained public health and healthcare delivery systems, but also provides an opportunity for the state to improve its healthcare infrastructure to ensure that all of its residents, including those living with HIV, have access to affordable, high-quality healthcare.

Any efforts to improve healthcare in Louisiana must first acknowledge the state's severe budget crisis. Shortfalls in tax revenues have resulted in mid-year budget cuts, as well as significant uncertainty for those who rely on state-financed healthcare through Medicaid or the Louisiana State University Charity Hospital system. Louisiana has traditionally contributed little or no funding toward its AIDS Drug Assistance Program (ADAP). Although the state does not maintain an ADAP waiting list, enrollment in the program was capped on June 1, 2010.

Nationally, passage in 2010 of the Patient Protection and Affordable Care Act healthcare reform legislation will significantly improve access to care for people living with HIV/AIDS in Louisiana. But many of the statute's key provisions, including its Medicaid expansion and private market reforms, will not come into effect until 2014. That means that uninsured Louisiana residents still face substantial unmet need for healthcare in the meantime. These challenges are compounded by the fiscal difficulties facing the federal government that threaten appropriations for Ryan White programs at the very time that demand for services has increased due to increased loss of employer-provided health coverage during the current economic downturn.

While the challenges facing Louisiana's healthcare system are many, healthcare providers have managed to find innovative ways to continue to improve healthcare access among HIV-positive Louisiana residents. For example, despite the fact that Louisiana has the highest per capita rate of incarceration in the United States, the state's Department of Corrections is committed to providing routine, voluntary



part I: introduction

testing to all inmates upon entry, in addition to ensuring that each inmate who tests positive receives necessary medications while incarcerated and prerelease services starting six months before re-entering the community. Likewise, the Louisiana Department of Health and Hospitals recently secured a Medicaid Section 1115 Research and Demonstration Waiver that will help providers deliver high-quality primary and behavioral healthcare services to low-income, uninsured residents in the New Orleans metropolitan area.

Nonetheless, significant challenges remain, and budget constraints are far from the only barriers to care and treatment services for people living with HIV in Louisiana. Stigma remains a major barrier to prevention and testing as well as access to care; federal policy hinders transportation options for rural residents to access medical and nonmedical services; the political climate at the state House of Representatives means that comprehensive health education legislation faces a steep uphill battle—to name a few. And access to safe, affordable, stable housing is an issue so large, and the need so great, that it is simply beyond the scope of this report. Compounding these challenges are the profoundly different experiences of the northern and southern parts of the state. Regional differences in infrastructure, resources, culture, and politics all contribute to geographic health disparities in the state. While these differences mean that there is no one-size-fits-all solution to securing accessible, affordable, quality care and treatment for all HIV-positive Louisianans, harnessing and coordinating the collective and unique resources of all stakeholders will no doubt lead to new opportunities for change and progress in bringing access to care to more people living with HIV/AIDS in Louisiana.

“Six years ago, I never would have thought I’d be sitting here. But you can either choose to live in ignorance or empower yourself. If you are silent, you give the disease power.”

- SHARP focus group
meeting participant,
Baton Rouge, March 4, 2010

part II: state profile

OVERVIEW OF THE HIV/AIDS EPIDEMIC IN LOUISIANA

Louisiana has a total population of approximately 4.5 million people.¹ As of June 30, 2010, 17,695 persons are living with HIV/AIDS in Louisiana; of these individuals, 9,594 persons (54%) have been diagnosed with AIDS.² Louisiana ranked third in the nation in its rate of new AIDS diagnoses and eighth in its rate of residents living with AIDS in 2008.³ Baton Rouge ranked second for its rate of new AIDS cases among the largest metropolitan areas in the US in 2008; New Orleans ranked third.⁴ In 2009, 1,243 new HIV cases were diagnosed in Louisiana, which represents a slight increase from the 1,154 HIV cases diagnosed in 2008.⁵

Demographics

HIV infections in Louisiana are not evenly distributed among racial, ethnic, or gender groups. Non-Hispanic blacks (32% of the population)⁶ comprise 67% of the reported HIV/AIDS cases (11,847).⁷ Conversely, non-Hispanic whites (63% of the population)⁸ comprise 28% of the reported HIV/AIDS cases (5,017).⁹ Hispanics comprise 4% of the reported HIV/AIDS cases (642)¹⁰ and 3% of the total population.¹¹ In 2009, 75% of newly diagnosed HIV cases and 76% of newly diagnosed AIDS cases were among African Americans.¹² These disparities appear to be intensifying. In 2008, 72% of newly diagnosed HIV cases and 70% of newly diagnosed AIDS cases were among African Americans.¹³

Although females comprise 52% of the state's total population,¹⁴ males constitute a larger portion of the reported new HIV/AIDS diagnoses than females—32% of new HIV cases and 31% of new AIDS cases are among women.¹⁵

Modes of transmission

In Louisiana, the most common mode of transmission for newly diagnosed HIV cases is men who have sex with men (MSM). As of June 2010, 48% of all people living with HIV infection in Louisiana were MSM, and MSM represents the primary risk factor for new HIV diagnoses in the state.¹⁶ In 2009, of the persons who reported a risk factor, 55% reported being MSM, and an additional 3% reported being MSM and injection drug user (IDU).¹⁷ Of newly-diagnosed MSM in 2009, 69% were black, 24% were white, and 6% were Hispanic.¹⁸ The disparate impact of HIV on African American MSM in Louisiana is evident when these figures are compared to national numbers: of newly-diagnosed MSM in 22 states including Louisiana, 46% are white, 35% are black, and 19% are Hispanic. The second most prevalent mode of transmission for males is high-risk heterosexual contact.¹⁹ For females, heterosexual contact is the primary mode of transmission; IDU is the second most common.²⁰

part II: state profile

Geographic distribution

Louisiana is divided into nine public health areas. The vast majority of Louisiana residents living with HIV/AIDS reside in the metropolitan areas of New Orleans and Baton Rouge. In 2009, 32% of newly diagnosed HIV cases occurred in Region I (New Orleans) and 25% occurred in Region II (Baton Rouge).²¹ Approximately 12% of those living with HIV/AIDS in Louisiana reside in rural areas.²² The proportion of people diagnosed with AIDS in rural areas in Louisiana is higher than that for the United States as a whole, where 7% of 2006 AIDS cases were rural, as well as the South as a region, where rural cases accounted for 10% of 2006 AIDS cases.²³

The following table shows the newly diagnosed HIV cases and total case numbers by region.²⁴

Region	New HIV Diagnoses 2009	People Living With HIV/AIDS as of September 30, 2010
I: New Orleans	393	6,355
II: Baton Rouge	312	4,370
III: Houma	40	677
IV: Lafayette	90	1,327
V: Lake Charles	53	962
VI: Alexandria	65	822
VII: Shreveport	123	1,441
VIII: Monroe	76	978
IX: Slidell/Hammond	90	1,010
Louisiana	1,243	17,944

part II: state profile

Unmet need

Unmet need is defined as the proportion of the HIV-positive population not in care in a calendar year. A single test of blood cells or viral load qualifies a patient as in care. Overall in the state, 57% of people living with HIV and AIDS were in care in 2007, leaving unmet need at 43%.²⁵ People with AIDS are more likely to be in care than HIV-positive people without AIDS (70% and 42%, respectively).²⁶ Certain segments of the population have particularly high levels of unmet need: 59% of Hispanic or Latino people living with HIV/AIDS were not in care, compared to 44% of African Americans and 40% of white individuals.²⁷ Even among consumers of HIV/AIDS services in Louisiana, a 2008 survey found that only 78% felt they were receiving enough medical care.²⁸ Certain regions of the state exhibit particularly high levels of unmet need: Public Health Regions I (New Orleans) and V (Lake Charles) both had fewer than half of their HIV-positive populations in care in 2007.²⁹

Federal funding

The total HIV/AIDS federal funding in Louisiana for fiscal year 2009 was \$65,563,295, about 2.1% of the approximately \$3 billion in federal HIV/AIDS funding nationwide.³⁰ The following table shows Louisiana's FY09 federal funding for HIV/AIDS.³¹

Source	Amount
Ryan White	\$46,317,971
Centers for Disease Control and Prevention (CDC)	\$11,508,877
Housing Opportunities for Persons with AIDS (HOPWA)	\$5,976,914
Substance Abuse and Mental Health Services Administration (SAMHSA)	\$1,284,533
Office of Minority Health (OMH)	\$475,000

part II: state profile

STATE ECONOMIC PROFILE

In 2008, the gross domestic product (GDP) of Louisiana was \$222.2 billion.³² The Baton Rouge and New Orleans metropolitan areas contribute a substantial portion of the state GDP; in 2008, these cities comprised 50% of the state GDP.³³ In 2009, Louisiana's per capita personal income was \$35,507, which ranked 32nd in the nation and fell below the national average of \$39,138.³⁴

As of August 2010, Louisiana had an unemployment rate of 7.6%, compared to a national rate of about 9.6% unemployment the same month.³⁵ Like many other states, Louisiana's unemployment rate has risen over the past year, increasing from 5.1% in January 2009.³⁶ Exacerbating the recent uptick in unemployment, Louisiana also experiences a greater concentration of poverty than the rest of the nation, with state poverty levels greatly exceeding the national average. Twenty-three percent of Louisiana residents have income below 100% of the federal poverty level (FPL), compared with 17% nationally.³⁷

Further, in 2008, Louisiana had the second highest poverty rate by household income (18.2%), behind only New Mexico—43% of the state's residents have family income below 200% FPL.³⁸ Indeed, as the Louisiana Office of Public Health (OPH) noted in December 2009, "the full impact of Hurricanes Katrina and Rita, and now Gustav and Ike, continue to affect the poor and the level of poverty and homelessness in the state."³⁹

"The full impact of Hurricanes Katrina and Rita, and Gustav and Ike, continue to affect the poor and the level of poverty and homelessness in the state."

Industries and employers

In 2008, the largest industry in Louisiana was mining, which accounted for 16.4% of GDP.⁴⁰ Nondurable goods manufacturing, the second largest industry, accounted for 14.4% of Louisiana GDP.⁴¹ In 2008, the largest contributor to GDP growth in Louisiana was government, which accounted for 0.55% of the total growth in the state's real GDP.⁴²

In addition to mining, Louisiana has the highest concentration of refineries for crude oil, processing plants for natural gas, and production facilities for petrochemicals in the Western Hemisphere.⁴³ The state, which pioneered off-shore drilling, is America's second largest provider of natural gas and third largest producer and refiner of petroleum.⁴⁴ Although Louisiana has historically produced 25% of the nation's petrochemicals each year,⁴⁵ the April 2010 explosion and subsequent massive oil spill in the Gulf off of Louisiana's coast has resulted in significant uncertainty for the state's oil industry.

part II: state profile

Louisiana also has a strong agricultural economy, ranking second in sugar cane and sweet potato production, third in rice production, and fifth in cotton and pecan production.⁴⁶

Louisiana's commercial fishing industry produces 25% of the nation's seafood, including more shrimp and oysters than anywhere else in the nation.⁴⁷ In 2008, Louisiana's shrimp industry had an economic impact of approximately \$1.3 billion, supported 14,384 jobs, and generated \$91.1 million and \$83.4 million to state and federal revenues, respectively.⁴⁸

Tourism is also an important industry in Louisiana; the state attracts approximately 24 million visitors annually.⁴⁹ In 2007 and 2008, domestic and foreign visitors spent \$9.0 and \$9.5 billion in the state, respectively—up nearly 44% from 2006, but still down 5% from pre-Hurricane Katrina (2004) levels.⁵⁰

In addition to its effects on Louisiana's oil industry, the 2010 Deepwater Horizon oil spill has had a serious negative impact on commercial and recreational fishing and tourism in the state. The long-term impact of the spill on off-shore drilling, fishing, and tourism is unknown at this time.

Louisiana is home to three 2010 Fortune 500 companies: Entergy, ranked 219th, is based in New Orleans; Shaw Group, ranked 309th, is based in Baton Rouge; and CenturyTel, ranked 423rd, is based in Monroe.⁵¹ As of June 2010, Louisiana's civilian labor force consisted of over 2 million people, with approximately 1.94 million employed and 159,000 unemployed.⁵² The most common areas of employment are trade, transportation, and utilities (approximately 368,000 jobs); government (approximately 367,000 jobs); education and health services (approximately 278,000 jobs); and professional and business (approximately 197,000 jobs).⁵³

Revenues (taxation) and expenditures

In 2009, the Census Bureau ranked Louisiana the 23rd highest tax revenue-collecting state; that year, Louisiana collected approximately \$8.5 billion in tax revenue.⁵⁴ The majority of this revenue derived from the individual income tax (\$3 billion), sales tax (\$2.8 billion), and severance tax (\$928 million).⁵⁵

For FY07, Louisiana ranked 21st highest in the nation for total state tax collected per capita and 31st for individual income tax per capita.⁵⁶ Louisiana uses a tiered system of income tax: 2% on the first \$12,500 of taxable income, 4% on income between \$12,501 and \$25,000, and 6% on any income above \$25,501.⁵⁷

part II: state profile

Louisiana has a relatively low property tax rate, ranking 46th nationally.⁵⁸ Its sales tax is set at 4%, which is below the national average (5.4%).⁵⁹ The state levies a \$0.384 per gallon (cpg) tax on gasoline, which includes the federal tax of 18.4 cpg.⁶⁰ This tax is below the national average of 47.3 cpg.⁶¹ Additionally, Louisiana's cigarette tax is \$0.36 per pack, one of the lowest in the nation.⁶²

Louisiana's use of a nominally graduated income tax, coupled with its comparatively high reliance on sales tax and its allowance of an income tax deduction for federal income taxes paid results in an overall regressive tax system (one in which poorer residents pay more of their income in state and local taxes than wealthier residents). A 2009 study of state and local taxes in Louisiana found that:⁶³

- The richest 1% of Louisiana residents pay 5.7% of their income in state and local taxes
- Middle income taxpayers (those earning between \$29,000 and \$46,000) pay 9.9% of their incomes to state and local taxes
- Louisiana families earning less than \$15,000—the poorest fifth of Louisiana nonelderly taxpayers—pay 10.4% of their income in state and local taxes.

Louisiana's expenditures for FY08 totaled nearly \$30 billion.⁶⁴ Of this total, 30.3% was spent on elementary and secondary education, 13.8% on higher education, 7.3% on corrections, and 8.3% on Medicaid.⁶⁵ Louisiana's Medicaid spending as a percentage of its total budget in 2008 was just over half of the US average.⁶⁶

STATE DEMOGRAPHIC PROFILE

According to most recent US Census Bureau estimates, Louisiana had a total population of nearly 4.5 million in 2009.⁶⁷ The median age was 35.1 years, slightly below the national average of 36.7 years.⁶⁸ In 2008, 64.6% of the population identified as white, 32.1% as black, and 3.6% as Hispanic/Latino.⁶⁹ Asians comprised 1.5% and American Indian and Alaskan Native persons made up 0.6%. This compares to a national average of 79.6% white, 12.9% black, and 15.8% Hispanic/Latino.⁷⁰ Louisiana is a primarily Christian state. The majority of Catholics in the state live in the southern parishes, while the central and northern regions are mostly Protestant.

Eighty-five percent of Louisiana residents live in metropolitan areas and only 15% live in rural areas.⁷¹ The largest metropolitan areas in Louisiana are New Orleans, Baton Rouge, Shreveport, and Lafayette.⁷²

part II: state profile

Incarcerated population

Louisiana has the highest rate of imprisonment in the United States and in the world (814 per 100,000)⁷³—in 2007, there were 37,298 offenders incarcerated throughout the state.⁷⁴ Louisiana's incarceration rate is 67% higher than the national rate, and it has grown 285% in the last two decades.⁷⁵ Louisiana also has the third-highest female imprisonment rate in the nation (103 female prisoners per 100,000 female residents).⁷⁶ As of March 2010, 516 persons known to be living with HIV and 167 living with AIDS were incarcerated in the state Department of Corrections system.⁷⁷

Overall health indicators

In its 2009 report, the Commonwealth Fund ranked Louisiana 49th out of 51 (50 states plus the District of Columbia) for health system performance.⁷⁸ The state also ranked 49th in infant mortality, 45th in overweight children ages 10-17, and 49th in nonelderly insured adults.⁷⁹

STD/STI profile

Rates of sexually transmitted diseases in Louisiana are among the highest in the nation: in 2008, Louisiana had the highest rates of primary and secondary syphilis, the second highest rate for gonorrhea, and the fifth highest rate for chlamydia.⁸⁰ According to 2008 Louisiana Office of Public Health (OPH) and Centers for Disease Control and Prevention (CDC) surveillance data for Louisiana:⁸¹

Primary and Secondary Syphilis (P&S) – In 2008, the rate of P&S cases increased over 30% from 2007. Approximately 57% of P&S cases were males. The overall rate of P&S in males was 19.2; the rate in females was 13.66. Males ages 20-24 had the highest gender- and age-specific rate, at 52 per 100,000. Nearly 86% of the 2008 cases were African Americans.

Gonorrhea – Despite decreases in the rate (-14.7%) and number of cases (-1,371) of gonorrhea from 2007 to 2008, Louisiana's gonorrhea rate ranked second highest in the nation in 2008. Females between ages 15-19 had the highest rate (1,221 per 100,000), followed by females aged 20-24 (1,139 per 100,000), followed by males aged 20-24 (849 per 100,000). African Americans represented 75% of gonorrhea cases.

Chlamydia – There was a 21.6% increase in reported chlamydia cases from 2007 to 2008. The rate among women was over three times the rate among men (790.8 compared to 252.1 per 100,000). The highest gender- and age-specific rate was among women aged 15-19 (4,360 per 100,000), followed by women aged 20-24 (3,896 per 100,000). Approximately 65% of chlamydia cases in women were African American, and approximately 74% of cases in men were African American.

part II: state profile

In 2008, the Louisiana Legislature passed a law that authorizes Expedited Partner Therapy (EPT). When treating a patient diagnosed with gonorrhea or chlamydia, a physician, advanced practice registered nurse, or physician assistant may assist other individuals who may have been exposed to gonorrhea or chlamydia by issuing a prescription for the appropriate antibiotic to that partner even in the absence of a physical examination or other physician-patient relationship.⁸² The Louisiana Department of Health and Hospitals (DHH) promulgated the rules necessary to implement this program on February 20, 2009.⁸³

HEALTH SERVICES

Public health regions

The state of Louisiana is divided into nine public health regions (see map, Appendix I).⁸⁴ With the exception of the Ryan White Program, services and funds are generally allocated by region. For purposes of Ryan White funding, the New Orleans Eligible Metropolitan Area (EMA) includes Public Health Region I and three nearby parishes,⁸⁵ and the Baton Rouge Transitional Grant Area (TGA) includes all of Region II as well as Livingston Parish.⁸⁶

Louisiana State University hospital system

Louisiana has an extensive system of public charity hospitals run by the Louisiana State University (LSU) medical schools in New Orleans and Shreveport.⁸⁷ There are 11 public hospitals in all, with the northern 4 falling under LSU-Shreveport and the southern 7 under the LSU Health Care Services Division in New Orleans.⁸⁸ The hospitals serve uninsured, indigent, and underserved communities in the state, and together treat 82% of Louisiana's HIV-positive population.⁸⁹

The two regional systems are independent of each other, although they are both under the LSU umbrella. The public hospital system functions as a quasi-government agency, but is not within the jurisdiction of the Department of Health and Hospitals (DHH).

Medicaid – funding, expenditures, enrollment

The DHH Bureau of Health Services Financing administers Louisiana Medicaid, also known as the Health Network of Louisiana.⁹⁰ A successful Medicaid applicant is entitled not only to benefits going forward but also to retroactive benefits for the time when the application was pending and the three months prior to filing, provided that he or she met all eligibility standards during that time.⁹¹

part II: state profile

In October 2005, Medicaid enrollment was 1,013,151, having passed the million-enrollee mark in the first few months after Hurricanes Katrina and Rita.⁹² Total enrollment in 2006 was measured at 1,090,800,⁹³ roughly 25% of the state population.⁹⁴ The majority of enrollees were children (57.7%), while adults (13.5%), the elderly (10.3%), and the disabled (18.4%) made up the remainder.⁹⁵ Of the HIV-positive population, 60% receive healthcare coverage through Medicaid.⁹⁶

Louisiana's total Medicaid spending for FY08 was \$6.07 billion.⁹⁷ The federal share of Louisiana's Medicaid funding was 69.7%, with the federal government providing approximately \$4.4 billion and the state contributing approximately \$1.7 billion.⁹⁸

Louisiana received approximately \$467 million in American Recovery and Reinvestment Act (ARRA) funding toward Medicaid costs in 2009, and to date in 2010 has received an additional \$777 million (as of August 2010). This represents approximately 1.6% of the total money allocated nationwide.⁹⁹ The addition of those funds increased the federal medical assistance percentage (FMAP) from 71.3% to 80% of total funding for Louisiana Medicaid.¹⁰⁰ Louisiana recently avoided a potentially catastrophic drop in its FMAP due to a calculation quirk that counted post-hurricane aid as income, through a provision in the recently enacted federal health reform law. The so-called "Louisiana Purchase" provision of the law adjusts FMAP calculations for states recovering from major disasters to avoid the artificial and draconian FMAP cuts that Louisiana had previously faced.¹⁰¹

Louisiana Medicaid also operates CommunityCARE, a 1915(b) waiver program that provides case management services to link residents of 20 rural parishes across the state (in Public Health Regions III, V, VI, VII, and VIII) to primary care providers.¹⁰² The Medicaid Act's freedom of choice and statewide requirements have been waived for this program.

Medicaid – eligibility

Louisiana's Medicaid program consists of 30 different eligibility categories, but an applicant applies to the program in general and not any specific subsection. An eligible applicant will receive the same services regardless of the reason for his or her eligibility.¹⁰³ If a Medicaid recipient becomes ineligible under the category for which he or she was originally granted benefits, the agency must confirm that there is no other basis for eligibility before terminating benefits; that is, a person is eligible unless he or she is ineligible under every possible category.¹⁰⁴

part II: state profile

Recipients of Supplemental Security Income (SSI) are automatically eligible for Medicaid.¹⁰⁵ Individuals who do not receive SSI but are eligible for Medicaid based on the income requirements (such as low-income families with children under 18)¹⁰⁶ may apply for benefits directly by mail or in person at a local Medicaid office or application center.¹⁰⁷

If a recipient is deemed ineligible, he or she has the right to continue to receive benefits while a fair hearing request is pending, except in rare instances.¹⁰⁸ Likewise, if a person was automatically granted Medicaid benefits because of SSI eligibility and then lost SSI, he or she would continue to receive Medicaid until the resolution of any appeal.¹⁰⁹ However, Louisiana uses a stricter standard than the federal government requires in that benefits can be terminated immediately if no appeal is pending—the federal standard is to wait until the window for a possible SSI appeal has passed to terminate Medicaid benefits.¹¹⁰

Louisiana Medicaid is automatically available to recipients of Family Independence Temporary Assistance Program (FITAP) funding.¹¹¹ Other individuals may be eligible to apply directly to Medicaid if they are age 65 or older, blind, families with children (defined as “families with a pregnant member, or a child under 18 deprived of the support of at least one parent, or a child under 19, or a woman who needs treatment for breast or cervical cancer”¹¹²), or disabled.¹¹³ Individuals infected with tuberculosis (TB) can receive benefits to cover TB-related services if they meet the financial eligibility standards for SSI.¹¹⁴ Women under age 65 who require treatment for breast or cervical cancer and are diagnosed through the Louisiana Breast and Cervical Health Program (LBCHP) are eligible for Medicaid benefits regardless of income and resources, provided that they do not fall into any other eligibility category and they do not have any other sources of health insurance.¹¹⁵

Pregnant women are presumptively eligible and can qualify for Medicaid funding if they have income below 185% of the federal poverty level (FPL), with no asset limit.¹¹⁶ Children born to eligible pregnant women can receive coverage for up to one year after birth, as long as the mother’s financial status would still qualify her for benefits if she were pregnant at that time.¹¹⁷ Older children up to age 6 may be eligible as well, provided their family’s income does not exceed 133% FPL. Children between 6 and 19 are eligible if the household income is below FPL.¹¹⁸

Parents of eligible children may also receive funds if their income is below 15% FPL, which would be \$182 per month for a single parent of one child or \$229 per month for two parents with a child.¹¹⁹

part II: state profile

In addition to fitting into one of these qualifying categories, otherwise ineligible individual or family applicants may qualify for some Medicaid services through one of several specified programs, including LaMOMS, Louisiana Children's Health Insurance Program (LaCHIP), medically needy program, and others.¹²⁰ These programs provide increased healthcare access for specific at-risk groups, such as pregnant women and children, who are otherwise excluded by Medicaid's eligibility standards.

Medicaid – medically needy spend-down program

Individuals who qualify for Medicaid because they are aged, blind, or disabled but do not meet the financial eligibility criteria may be able to receive assistance if their medical costs are greater than they can pay based on their incomes and assets. Individuals must “spend down” on qualified medical expenses any monthly income in excess of \$100 and assets greater than \$2,000 (\$192 in income and \$3,000 in assets for couples),¹²¹ although these levels are slightly lower for residents of rural areas.¹²² Louisiana's income limits for this program are the lowest of any participating state, and only one other state has a lower asset limit.¹²³ Enrollees through this program cannot receive coverage for some services, such as substance abuse treatment, mental health care, sexually transmitted disease treatment, dental services, and others.¹²⁴ The program provides 90 days of coverage, beginning 30 days prior to the application.¹²⁵

Medicaid – Medicare Savings Program

The Medicare Savings Program is an option through which certain qualified subscribers to Medicare Part A can receive Medicaid assistance in paying their monthly premiums. Individuals who fit the criteria defining Qualified Medicare Beneficiaries (QMB), Specified Low-income Medicare Beneficiaries (SLMB), or Qualified Individuals (QI-1) can have their monthly premiums and possibly deductibles, copayments, and Part D prescription premiums wholly or partly paid for.¹²⁶

For QMB, an individual must have gross income below \$903 per month (FPL) and less than \$4,000 in assets (\$1,215 and \$6,000 for a couple).¹²⁷ For those who qualify, the Savings Program pays premiums, deductibles, and copayments in full and contributes \$35 per month toward the Medicare Part D prescription drug premium.¹²⁸

To qualify as SLMB, an individual cannot have income greater than \$1,083 per month (120% FPL) and the asset limit is \$4,000 (\$1,457 and \$6,000 for a couple).¹²⁹ An SLMB recipient would not need to pay the monthly premium for Medicare Part B and would receive up to \$35 per month for the Part D premium, but would remain responsible for

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his or her own deductibles and copayments.¹³⁰ The benefits and asset limitations are the same for QI-1 as for SLMB, but the income threshold is slightly higher: \$1,219 for an individual and \$1,640 for a couple.¹³¹ All eligible applicants will receive QMB and SLMB assistance, but QI-1 is funded through a block grant and the limited resources are thus awarded on a first-come-, first-served basis and not all eligible individuals will necessarily receive benefits.¹³²

Managed Medicaid

Louisiana began planning a reconfiguration of its Medicaid program in 2010. Plans for a transition to so-called “Managed Medicaid” stalled recently due to mounting criticism, and it is unclear at this time whether the state will ultimately pursue this route.¹³³ Under the plan, the state would transition its Medicaid program from an entirely fee-for-service model to private managed care networks called “coordinated care networks.”¹³⁴ Insurance companies participating in the networks would be able to choose to either receive a prepaid amount per Medicaid recipient or participate in a fee-for-service model, in which reimbursement is tied to delivered care. The proposed program was criticized widely—most notably from LSU System Vice President Fred Cerise, who raised concerns that moving to managed care would cause the state to lose opportunities to maximize federal health care funds (ie, by losing millions of dollars in federal matching funds).¹³⁵ Currently, 70% of all Medicaid beneficiaries nationwide receive services through managed care models.¹³⁶

Medicare

Medicare is a federally-funded program that provides health insurance to people over age 65 who are eligible for Social Security. Disabled adults who are under 65 and who have worked enough years to be eligible for Social Security Disability Insurance (SSDI) also automatically qualify for Medicare after receiving their SSDI benefit for two years. It is possible for a person to qualify for both Medicaid and Medicare (referred to as “dual eligibility”). Medicare covers an estimated 100,000 people living with HIV/AIDS in the US, representing approximately one-fifth of people with HIV/AIDS who are in care.¹³⁷ In Louisiana, 677,880 individuals are enrolled in Medicare in 2010 (approximately 16% of the state’s total population).¹³⁸ Approximately 80% of Medicare enrollees are aged (over 65), while about 20% are disabled. Nationally, 83.7% of Medicare beneficiaries are over age 65 and 16% are eligible through disability.¹³⁹

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Medicare Part D

Medicare Part D helps beneficiaries pay for prescription drugs and requires an additional premium that varies depending on which prescription drug plan is chosen. Part D plans are required to offer a statutorily defined standard benefit. Currently, the standard benefit for 2010 has a \$310 deductible, then coinsurance of 25% up to \$2,830 in total drug costs, followed by a gap in coverage between \$2,830 and \$4,550 (known as the “donut hole”) during which enrollees must pay 100% of the costs of their drugs.¹⁴⁰ After enrollees have incurred \$4,550 in out-of-pocket expenses (including the deductible and coinsurance before entering the donut hole), they qualify for “catastrophic coverage” and pay 5% of drug costs for the rest of the year, with the federal government paying the other 95%.¹⁴¹

The donut hole affects Medicare beneficiaries with income over 150% FPL (\$16,245 per person). Individuals with income below 150% FPL who meet the resources requirements (see following) for the low-income subsidy (LIS) program do not have a donut hole. Part D enrollees taking HIV medications typically are covered for about two months’ worth of medications before falling into the coverage gap. While the AIDS Drug Assistance Program (ADAP) can help people pay for medications in the donut hole, ADAP contributions historically could not count toward the individual’s True Out-Of-Pocket (TrOOP) spending requirement to reach catastrophic coverage. Under the recently-enacted national healthcare reform law, the Patient Protection and Affordable Care Act of 2010 (ACA), ADAP contributions will count toward TrOOP beginning January 1, 2011.¹⁴² This change will help more people reach catastrophic Part D coverage. Notably, the ADAP program that covers copayments is not available in the New Orleans Part A EMA. Contributions by the Part A drug reimbursement program, which is separate from ADAP, will not count toward TrOOP.

Additional changes to the Part D donut hole under the healthcare reform law will phase in over the next several years.¹⁴³ In 2010, beneficiaries who fall into the donut hole will automatically receive a \$250 check from the federal government to help cover medication costs. As mentioned previously, for beneficiaries living with HIV/AIDS, contributions by ADAPs will count toward TrOOP beginning in 2011. Also beginning in 2011, all Medicare Part D enrollees will receive a 50% point-of-sale discount on the cost of brand-name drugs—but the prediscount price will count toward TrOOP. In addition, Part D plans will begin covering greater percentages of enrollees’ generic (beginning in 2011) and brand name (beginning in 2013) medication costs in the donut hole each year until 2019. In 2020, the donut hole will be completely eliminated; enrollees will be responsible for paying the initial deductible, then 25% of medication costs until they reach catastrophic coverage.

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Medicare – Medigap insurance

Federal law does not require that Medigap policies be available to Medicare recipients who are under 65 and disabled, but Louisiana is 1 of 22 states that does require insurance companies to offer at least some Medigap coverage to younger Medicare beneficiaries.¹⁴⁴

In Louisiana, there are 12 options for supplements to Medicare, designated Plan A through Plan L.¹⁴⁵ Plan A provides extended coverage for coinsurance during hospitalizations, hospital expenses beyond what Medicare Part A will pay for, limited charges for bought blood transfusions, and coverage of some coinsurance under Part B.¹⁴⁶ All of the other plans provide all of these benefits along with other optional components.¹⁴⁷ Other plans also include coverage of Part A inpatient deductibles, Part B deductibles, skilled nursing coinsurance, emergency care abroad, home assistance, preventive care, and other benefits in various combinations.¹⁴⁸

State regulations guarantee that Medicare recipients will qualify for Medigap coverage if they fit into one of six categories: Medicare coverage by an employer-sponsored plan, enrollment in a Medicare health plan that ceases coverage, enrollment in other private Medicare plans that cease coverage, preexisting enrollment in Medigap by an insurer who ceases coverage, switch in enrollment from Medigap to a Medicare health plan followed by disenrollment within one year, or new enrollment in a Medicare health plan followed by disenrollment within one year.¹⁴⁹

Louisiana Children’s Health Insurance Program

LaCHIP provides coverage for primary care, preventive and emergency care, immunizations, prescription medications, hospitalizations, home healthcare, and other services for children in poor families. Children under the age of 19 who are not otherwise insured will qualify for free coverage if their parents’ income is below 200% FPL.¹⁵⁰ LaCHIP has two programs, one providing free care to the poorest children and one offering an affordable plan to children whose families have slightly higher income, between 200% and 250% FPL.¹⁵¹ The affordable plan charges a monthly premium of \$50 per family (regardless of the number of children covered) and includes copayments—but with out-of-pocket costs capped at 5% of the family’s income.¹⁵² There is no deductible except for mental health services.¹⁵³ Also, unlike the basic LaCHIP plan, the affordable plan does not include vision or dental coverage.¹⁵⁴

In addition to free or affordable coverage for children, Louisiana provides similar health plans to pregnant women through its LaMOMS program. For women with incomes under 200% FPL, Medicaid will provide free access to prenatal care, delivery, and 60 days of care after delivery.¹⁵⁵

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State high-risk insurance pool

Louisiana provides a state health plan for those who have no health insurance and are unable to qualify for any other coverage because of their health status. In order to join the state pool, an individual must have resided in Louisiana for six consecutive months, have no other coverage (including Medicare, Medicaid, or COBRA), and produce proof of two denied applications for insurance within a single calendar year.¹⁵⁶ If accepted, applicants face a six-month waiting period before their coverage begins. Their premiums are set at 150% of the average of the top five carriers in the area, with a discount for nonsmokers.¹⁵⁷ Applicants can choose from four different coverage plans that have deductibles ranging from \$1,000 to \$5,000.¹⁵⁸

After the deductible has been paid, the insurance plan will pay for 75%-85% of precertified in-patient and out-patient treatment (but only 50% if not precertified), and between 70-90% of prescription drug costs.¹⁵⁹ The program includes an out-of-pocket cap for all expenditures (\$3,500 or \$4,500 depending on the plan chosen) except for medications, for which there is always a copayment.¹⁶⁰ The coverage also has annual and lifetime maximum payouts of \$125,000 and \$625,000, respectively.¹⁶¹ The plan will pay up to \$15,000 in prescription drug coverage annually, but such payments will count against the overall annual expenditure cap of \$125,000.¹⁶²

The state high-risk health insurance pool plan covers most medical treatments, but does not include mental health, substance abuse, obstetric, obesity, or sleep disorder care.¹⁶³ Since the program is funded by discretionary state appropriations, eligibility does not guarantee acceptance and there might be a waiting list for enrollment.¹⁶⁴ Also, there is a six-month waiting period for coverage of preexisting conditions, including prescription drugs.¹⁶⁵ Roughly 1,100 people currently receive health coverage through the pool,¹⁶⁶ and the waiting list is approximately three months long.¹⁶⁷

HIPAA program

In addition to the high-risk pool, the Louisiana Health Plan also includes a HIPAA program through which applicants can continue to be insured after losing group coverage or after losing an individual plan because the insurer ceased coverage overall or in just Louisiana.¹⁶⁸ As long as an application is filed within 63 days of the termination of prior coverage, the new coverage will be renewable and preexisting conditions should be covered.¹⁶⁹ Like the high-risk pool, the HIPAA plan is intended to be a last resort for those who are not eligible for any other group plans, Medicare or Medicaid, and who have already used any COBRA benefits available to them.

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In addition, the state requires 18 months of creditable coverage (the previous 18 consecutively on an individual plan) and that the previous coverage was terminated for reasons other than nonpayment or fraud by the insured.¹⁷⁰ The plan will cover most medical expenses, but does not include mental health services, and provides only limited one-time pregnancy coverage.¹⁷¹ Premiums are set at 200% of the average of the five major carriers.¹⁷² Deductibles and out-of-pocket caps are the same as for the high-risk plan, ranging from \$1,000 to \$5,000 and \$3,500 to \$4,500, respectively; however, the maximum annual and lifetime benefits are somewhat smaller, capped at \$100,000 and \$500,000.¹⁷³

PROGRAMS SERVING PEOPLE LIVING WITH HIV/AIDS

The Louisiana Department of Health and Hospitals (DHH) Office of Public Health (OPH) HIV/AIDS Program (HAP) administers the state's Ryan White Part B program grants, including the AIDS Drug Assistance Program (ADAP), and provides and coordinates several other programs offering services and financial help to those living with HIV and AIDS. The HAP is jointly funded by the state government, the US Department of Housing and Urban Development (HUD), and HRSA (Health Resources and Services Administration, part of the US Department of Health and Human Services [HHS]).¹⁷⁴ These and other programs serving people living with HIV/AIDS in Louisiana are described in the following sections.

Ryan White programs – overview

Ryan White programs serve over 1 million clients nationally, with the vast majority (72% of those who reported their incomes) having income below the federal poverty level (FPL).¹⁷⁵ More than half receive public health insurance, while nearly one-third are uninsured, and only 11% have private health insurance.¹⁷⁶ The Ryan White CARE (Comprehensive AIDS Resources Emergency) Act of 1990, reenacted in 2006 as the Ryan White HIV/AIDS Treatment Modernization Act and reauthorized in October 2009, provides funding to states through five parts and several subprograms, with money from each allocated for different purposes. Of Louisiana's \$40.6 million in Ryan White funds in FY08, \$10.9 million was Part A (24.2%) and \$25.1 million was Part B (55.9%).¹⁷⁷ The remaining 19.9% comprised Part C (primary health and early intervention), Part D (primary care and social services for women and children), AETC (AIDS Education and Training Centers), SPNS (Special Projects of National Significance), and the Community-based Dental Partnership Program.¹⁷⁸ In 2010, New Orleans and Baton Rouge received \$11.64 million in Part A funding,¹⁷⁹ while Louisiana's Part B grant was \$21.68 million.¹⁸⁰ Part C programs in the state were awarded a combined \$2.39 million.¹⁸¹

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In 2008, 40 entities in Louisiana received funding through Ryan White, including community-based organizations, hospitals, health centers, health departments, and others.¹⁸² Approximately 66% of the clients served by CARE Act funding in Louisiana in 2007 had incomes below 200% FPL, with 49% below FPL.¹⁸³ Approximately 43% had no health insurance, with an additional 37% receiving Medicaid or Medicare.¹⁸⁴ Only 6% had private insurance.¹⁸⁵

Part A provides funding to eligible metropolitan areas (EMAs) and transitional grant areas (TGAs), generally large cities with the highest rates of HIV and AIDS cases.¹⁸⁶ Part B funds are allocated to states and territories based on prevalence of AIDS and HIV, taking into account whether parts of the state are already covered under Part A.¹⁸⁷ Part C provides support to public and private organizations providing early intervention services (EIS) and capacity development and planning.¹⁸⁸ Since its reauthorization in 2006, the Act has required that 75% of the funds provided through Parts A, B, and C must be used for core services including “outpatient and ambulatory health services; medications; pharmaceutical assistance; oral healthcare; early intervention services; health insurance premium and cost sharing assistance for low-income individuals; home health care; medical nutrition therapy; hospice services; home- and community-based health services; mental health services; substance abuse outpatient care; and medical case management, including treatment adherence services.”¹⁸⁹ Significantly, transportation is not included.

Part D focuses on organizations that offer services specifically to women, children, and families dealing with HIV/AIDS.¹⁹⁰ Part F includes funding for AIDS Education and Training Centers (AETCs), two dental programs (HIV/AIDS Dental Reimbursement and Community-based Dental Partnership), the Minority AIDS Initiative (MAI), and Special Projects of National Significance (SPNS).¹⁹¹

Ryan White Part A – Eligible Metropolitan Areas and Transitional Grant Areas

Part A of Ryan White Program funds EMAs, those with cumulative total of more than 2,000 reported AIDS cases over the most recent 5-year period, and TGAs, with 1,000-1,999 cumulative reported AIDS cases. Two-thirds of funds are distributed by a formula based on an EMA or TGA’s share of living HIV (non-AIDS) and living AIDS cases; the remainder is distributed via competitive, supplemental grants based on “demonstrated need.” EMAs must establish planning councils, local bodies tasked with assessing needs, developing a plan for the delivery of HIV care, and setting priorities for funding. TGAs are not required to have planning councils (unless they are “grandfathered” EMAs).¹⁹²

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In 2010, Baton Rouge received \$4,083,037 total from Part A, with the vast majority going toward core medical services (such as outpatient service, medical services, oral healthcare, etc.) and support services.¹⁹³ New Orleans received \$7,557,633, with the majority of funds likewise going to core medical and support services.¹⁹⁴ The New Orleans grant is distributed and administered by the City of New Orleans' Office of Health Policy and AIDS Funding. To ensure community input in HIV services planning, the New Orleans Regional AIDS Planning Council determines service priorities and allocates funds to service categories.¹⁹⁵ Roughly one-third of the state population lives in the Part A regions, with the remaining two-thirds in areas that receive Part B funds.¹⁹⁶

Ryan White Part B – states and territories

While Public Health Regions I and II receive Ryan White Part A funding, the rest of Louisiana is funded through Part B, which provides money to all states and territories for core medical services, support services, and ADAP.¹⁹⁷ Base grants and ADAP allocation are calculated based on the number of people requiring services in each state, and supplemental grants are available for “emerging communities,” which have between 500 and 999 new reported AIDS cases over a 5-year period.¹⁹⁸

The HAP has designated seven community-based organizations¹⁹⁹ (CBOs) to oversee treatment and services for people living with HIV and AIDS around the state, with one each in Regions III through IX, and distributes Ryan White Part B funds to each of them. However, since New Orleans and Baton Rouge receive individual grants through Ryan White Part A, HAP does not fund services within the New Orleans EMA or Baton Rouge TGA. Depending on local needs in each region, the CBOs coordinate the provision of outpatient medical care, case management services, dental care, emergency financial assistance, drug reimbursement, food banks and meal deliveries, housing assistance, medication assistance, mental health care, nutritional counseling, substance abuse treatment, and/or transportation assistance.²⁰⁰

Ryan White funding for Regions III through IX from Part B was just over \$25 million for FY08.²⁰¹ Approximately \$18 million of that went toward prescription medication through ADAP, and the rest funded core medical services and support services.²⁰² The 2010 grant was \$21.7 million.²⁰³

After Hurricane Katrina in 2005, an immediate concern was the inadequacy of Part B funding to satisfy the increased demand for services; it was estimated that as many as 8,000 people living with HIV and AIDS in the New Orleans metropolitan area were displaced, with most of those who did not leave the state ending up in Regions III through IX, thus shifting from

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Part A- to Part B-funded localities (without a concurrent shift in funding).²⁰⁴ As of December 2008, however, only about 70% of those living with HIV and AIDS in Orleans parish before the hurricane had returned.²⁰⁵

Due to level or decreased federal funding, increased client utilization rates, and federal funding restrictions regarding core and non core services, OPH recently instituted several cost-saving measures within the Part B program. For example, the allocation to ambulatory/outpatient medical care services was reduced by \$1,230,000 in FY10/11, and two contracts with community-based health providers and four contracts with HIV clinics at the Louisiana State University (LSU) regional medical centers for the provision of primary medical care services were not renewed.²⁰⁶ In addition, the OPH HIV/AIDS Program (HAP) will not dedicate any staff resources to identifying and contracting with community-based agencies to provide Part B home- and community-based care services in Regions III-IX in FY10/11.²⁰⁷ These and several other cost-containment measures represented a total cost savings of nearly \$2.5 million, but OPH projects that this savings will not offset increasing client utilization, and further cost-containment measures are likely during this fiscal year.²⁰⁸

Ryan White Part C – early intervention services

Part C funding accounted for roughly 10% of the Ryan White allocations to Louisiana in 2007.²⁰⁹ Part C funds are meant to provide HIV counseling and testing and other early interventions.²¹⁰ Half of the money given to a state under Part C must be used for such programs and 75% must go toward core services.²¹¹ Capacity development grants are also provided through Part C in order to assist recipients in providing EIS.²¹² In addition, Louisiana's early intervention and primary care programs distribute Part C funds to providers of medical and social services to Louisiana residents with AIDS and HIV. EIS are aimed specifically at those recently diagnosed with HIV, while the primary care section provides longer-term services to those living with HIV or AIDS.²¹³

In 2010, \$2.39 million in Part C funds supported nine clinics in Louisiana: Capitol City Family Health Center; Greater Ouachita Coalition Providing AIDS Resources; LSU Health Sciences Center in New Orleans, Baton Rouge, and Shreveport; Medical Center of Louisiana at New Orleans; NO/AIDS Task Force; and Tulane University Health Sciences Center.²¹⁴

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Ryan White Parts D-F

Ryan White Part D provides funds directly to hospitals and other healthcare providers to support HIV treatment and services specifically for women and children, as well as coordinating clinical trial participation.²¹⁵ The largest Part D-funded program in New Orleans is the Family Advocacy, Care and Education Services program (FACES) administered by the Children’s Hospital.²¹⁶ Since its establishment, the program has expanded beyond case management and education and now works with organizations in four other regions of the state to provide services to women and children.²¹⁷ In addition, LSU operates two recently funded Part D organizations, at Moss Regional Medical Center in St. Charles and Lallie Kemp Medical Center in Independence.²¹⁸

The dental school at LSU is a provider under Part F, which reimburses costs for dental care.²¹⁹ In addition, “Smile Again, New Orleans,” a Part F Special Project of National Significance (SPNS), provides oral healthcare services to the HIV-positive population of the New Orleans metropolitan area on a mobile dental van.²²⁰ The clinical team—including a dentist, hygienist, and dental assistant—provides diagnostic services, preventative services, and simple restorative procedures. The program is led by the LSU School of Dentistry, Interim LSU Public Hospital, and the HIV Outpatient Program/HOP; additional partners include the NO/AIDS Task Force and N’R Peace.

AIDS DRUG ASSISTANCE PROGRAM

Since 1996, Louisiana has received Ryan White funds to provide assistance to people living with HIV and AIDS in paying for prescription medications. The Louisiana ADAP formulary includes all 29 approved drugs for the treatment of HIV/AIDS and 29 of 31 recommended by the HHS for treating associated opportunistic infections.²²¹ States may also use ADAP funds for other medications treating depression, hypertension, diabetes, and other medical problems for beneficiaries, but Louisiana ADAP pays for only three non-HIV-specific medications.²²²

In 2009, Louisiana ADAP had a budget of nearly \$19.4 million,²²³ with the vast majority of those funds paying for prescription drugs for more than 3,000 HIV/AIDS patients who could not afford them.²²⁴ In 2009, the program spent an estimated \$300,000 for insurance purchasing/maintenance for clients.²²⁵ Historically, the state has not contributed at all to ADAP. The 2010 budget contributes no money to ADAP from the General Fund, but does contribute \$4,050 in other state funding, representing approximately \$1.10 per enrollee per year.²²⁶

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In order to qualify for ADAP assistance, individuals must meet financial eligibility criteria and not have any other source of medication coverage such as private insurance or Medicaid.²²⁷ For those who qualify, ADAP provides money to pay for 31 medications recommended by the US Public Health Services for preventing and treating opportunistic infections associated with HIV and AIDS.²²⁸ In order to be eligible, an individual in Regions II through IX must: (1) prove residency in Louisiana (US citizenship is not required), (2) have been diagnosed with HIV, (3) have an income below 300% FPL, (4) have no other prescription medication coverage, (5) have a current prescription for one or more medications on the ADAP formulary, and (6) possess no more than \$4,000 in assets excluding a home and a car.²²⁹ In the New Orleans EMA, residents below 400% FPL may also be eligible for the Part A medication formulary.²³⁰ Eligible individuals who are treated in public hospitals may register through the hospital directly and may also have their laboratory costs covered; patients at other facilities apply to the state for “private ADAP” funding.²³¹

While the ADAP is primarily intended for those who have no other coverage, some individuals who receive Medicare Part D coverage can qualify to use ADAP funds to cover Medicare’s out-of-pocket costs. ADAP will pay for Part D premiums, deductibles, and copays as well as costs associated with the Part D donut hole. A person first must receive benefits through Medicare Part A and/or Part B, enroll in a Medicare Part D prescription drug plan, and apply for a low income subsidy (LIS). If the application for LIS is denied, then he or she may receive ADAP funds to cover the Part D donut hole.²³² If the applicant receives LIS, those funds must be exhausted before ADAP funds become available.

Ryan White funds support ADAP statewide (in the Part A regions as well as the Part B regions), but the Part A funding also covers ARV drugs for consumers with income up to 400% FPL, as well as nonantiretroviral drugs through its pharmacy assistance program. Consequently, medication expenditures per patient outside New Orleans and Baton Rouge are 75% lower than in those cities.²³³

Health Insurance Program (HIP)

The Louisiana Health Insurance Program (HIP, formerly CDAP and HICP) helps people living with HIV and AIDS pay the premiums, deductibles, and copayments associated with their Medicare, Medicaid, COBRA, or private insurance coverage.²³⁴ In order to qualify, an individual must be a resident of Louisiana, have an active health insurance

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policy, have been diagnosed with HIV or AIDS and have an income below 300% FPL.²³⁵ Enrollees in HIP can receive assistance in copayments and deductibles for doctor's visits, laboratory tests, and medications, but not for over-the-counter medications, vitamins, or nutritional supplements.²³⁶

HIP's copayment and deductible assistance is not available to residents of the New Orleans EMA; however, providers in the EMA parishes can provide similar assistance through Ryan White Part A funding.²³⁷

Home Based Care Program

Historically, HAP's Home Based Care Program (HBCP) provided in-home healthcare and/or personal attendant services for people living with HIV and AIDS who need them but do not qualify for other types of coverage that might provide these services. Eligibility requirements included a positive HIV diagnosis as well as a primary care physician's order for in-home care. Additionally, the program required annual income below 200% FPL and assets under \$4,000 (excluding a home and a car).²³⁸ Depending on their individual needs, recipients of services could receive skilled nursing or home health aide care, medical supplies and equipment, physical therapy, and social work.²³⁹ Homebound individuals could also receive assistance with everyday activities in the home.²⁴⁰ Due to dramatic budget cuts in FY10, HAP retracted the allocation for HBCP to bolster resources for ADAP, and anticipates that there will not be funding for the program in FY11.²⁴¹

HOPWA/HUD funding

It is well established that stable housing is associated with decreased risk of HIV infection as well as better health outcomes and greater life expectancy for those living with HIV/AIDS.²⁴² For instance: the literature shows that the HIV/AIDS death rate is 7 to 9 times higher for homeless adults than for the general population; homeless and unstably housed individuals are 2 to 6 times more likely than stably housed individuals to use hard drugs, share needles, or exchange sex or drugs for housing and money; and rates of HIV infection are 3 to 16 times higher among the homeless or unstably housed than in the general population.²⁴³ This growing empirical evidence shows that access to safe, stable, affordable housing is as important for individual positive health outcomes and public health as access to medical care. Indeed, unstable housing situations and homelessness directly complicate medical interventions for the successful treatment of HIV.²⁴⁴

For Regions III through IX, the state DHH administers the federal program Housing Opportunities for Persons with AIDS (HOPWA).²⁴⁵ HUD funds the program and provides money to 29 states and 59 cities nationwide based on prevalence rates of HIV and AIDS

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as determined by the Centers for Disease Control and Prevention (CDC).²⁴⁶ New Orleans qualified for a city grant in 1992, the state received its first grant in 1994, and Baton Rouge qualified for a city grant in 1999.²⁴⁷ New Orleans and Baton Rouge receive money directly from HUD and the Office of Community Economic Development, while DHH distributes the state grant. In FY07-FY09, HUD awarded a total of roughly \$8.7 million to New Orleans, \$4.6 million to Baton Rouge, and \$3.1 million to the rest of the state.²⁴⁸

HOPWA funding is available to individuals with HIV or AIDS with low or moderate income who need assistance paying for housing. Short-term emergency rental assistance is available for up to 21 of 52 weeks based on 3 eligibility criteria: Louisiana residency, HIV-positive status, and an income no more than 80% of the median for the area.²⁴⁹ Applicants must be currently housed but at risk of homelessness because of lack of assets and inability to pay reasonable housing cost; they can then receive assistance in paying rent or mortgage, late fees on back rent, and utility costs.²⁵⁰

HOPWA also offers on-going funding through the Tenant Based Rental Assistance (TBRA) program, which helps people living with HIV who have permanent housing and some income. To qualify for TBRA, an individual must be able to pay 30% of his own living expenses, including rent and utilities.²⁵¹ While the TBRA is not available in the New Orleans Part A EMA, the City of New Orleans recently allocated \$250,000 of its HUD home funds for housing assistance for people living with HIV.²⁵² The funds will be administered by the Office of Health Policy in collaboration with the Office of Community Development. This funding, along with the Housing Authority of New Orleans's (HANO) recent set-aside of 200 Section 8 vouchers for people living with HIV, is expected to secure 250 housing units for people living with HIV in the New Orleans EMA.²⁵³

Additionally, providers of qualified residential facilities can apply for grants for capital improvements or construction and renovation of housing for those with HIV and AIDS. Short-term supported housing funds are available to facilities that temporarily house otherwise-homeless persons living with HIV and AIDS and also provide resources for finding more permanent housing.²⁵⁴ Eligibility of facilities is capped based on capacity (no more than 50 individuals or families at once), duration of stay (no more than 60 days in a 6-month period), and the provision of required housing search services.²⁵⁵

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Another use of HOPWA funding is the competitive grant program, in which local governments and nonprofit entities can apply for grants based on selection criteria such as innovativeness and incorporation into broader long-term plans in areas not eligible for state or city grants.²⁵⁶ Two competitive grants have recently gone to Odyssey House Louisiana and UNITY of Greater New Orleans, a collaborative of 60 to 80 organizations serving the homeless that enables strategic coordination between AIDS services organizations (ASOs) and non-HIV-specific service organizations. Both Odyssey House and UNITY are based in New Orleans and help find housing for displaced residents returning to the city.²⁵⁷

*Louisiana Positive Charge Initiative*²⁵⁸

The Louisiana Community AIDS Partnership (LCAP), an affiliated program of the Louisiana Public Health Institute (LPHI), recently launched a new program, the Positive Charge Initiative, which is a \$1.2 million, 3-year grant program aimed at breaking down the barriers that prevent people living with HIV/AIDS from receiving proper care, treatment, and necessary support. Louisiana's Positive Charge Initiative comprises public-private partnerships that include the HAP, OPH STD Control Program, LSU Health Care Services Division, NO/AIDS Task Force, Acadiana Cares, Capital Area Reentry Program Inc. (CARP), St. John #5/Camp ACE, Interim LSU Public Hospital's HIV/AIDS Outpatient Clinic, N'R Peace, Orleans Parish Prison (OPP), and the Earl K. Long Medical Center's Early Intervention Clinic (EKL-EIC). Louisiana's Positive Charge Initiative will be implemented in New Orleans, Baton Rouge, and Shreveport. All of these locations have high HIV and AIDS case rates, and a large population of HIV-positive persons not receiving care.

Over the course of the next three years, the initiative aims to increase the number of persons living with HIV/AIDS who receive care by improving linkages to medical care and supportive services; work together with the public hospital system, regional STD clinics, and OPP to help individuals who are newly diagnosed with HIV get into care; increase the number of persons living with HIV/AIDS who have disconnected from care get back into a care environment that meets their continuing needs; and provide interventions that are implemented and led by HIV-positive individuals, who will act as peer health case managers.

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OTHER LAWS AND POLICIES

Revised Statutes 14:43.5 Intentional Exposure to AIDS Virus (1987)

This statute makes it a crime punishable by a \$5,000 fine and/or ten years in prison to knowingly expose another person to the AIDS virus through sexual contact or any other means without that person's consent.²⁵⁹ The fine increases to \$6,000 and the prison term to 11 years if the person being exposed is a police officer acting in the line of duty and the person doing the exposing would reasonably know that.²⁶⁰ Although it is not a common criminal charge, cases are prosecuted occasionally. In June 2009, charges were brought against a man arrested in a prostitution sting who had not revealed his HIV status to an undercover police officer.²⁶¹


Revised Statutes 40:1300.11-15 Confidentiality of HIV Test Results (1991)

The state legislature enacted these sections to ensure the confidentiality of patient information concerning diagnoses of HIV and AIDS, and "to encourage the expansion of voluntary confidential testing for HIV."²⁶² The statute provides for, among other things, anonymous coded testing,²⁶³ "opt-out" testing (allowing consent to be provided in response to information provided about the test orally or as incorporated into a general consent form),²⁶⁴ and prohibitions of disclosure of test results without consent (except to certain enumerated healthcare providers and facilities and government agencies including the Departments of Corrections and Social Services).²⁶⁵ The statute does permit disclosure to contacts at risk of exposure, although there is no duty to do so, provided that the identity of the infected individual is not revealed to the contacts.²⁶⁶ In certain cases, a court can order that test results be revealed, if such information is necessary to a criminal or civil trial²⁶⁷ or there is a clear and imminent danger to an individual or the public health,²⁶⁸ but all court records must then be sealed and review of the information provided must be *in camera*,²⁶⁹ with clear instructions on what information can be revealed to whom, in order to maximize patient privacy.²⁷⁰ Although the law deals specifically with the confidentiality of test results, it is applied more broadly to disclosures of "mere HIV/AIDS status...since the only way for anyone to be certain that a person even has the HIV/AIDS virus is as a result of an HIV/AIDS test."²⁷¹

Revised Statutes 40:1064.1 Expedited Partner Therapy (2008)

The Louisiana Legislature passed a law authorizing Expedited Partner Therapy (EPT) in 2008. Under the law, when treating a patient diagnosed with gonorrhea or chlamydia, physicians, advanced practice registered nurses, and physician assistants may issue a prescription for

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the appropriate antibiotic to the partner(s) of the patient who may have been exposed to gonorrhea or chlamydia, even in the absence of a physical examination or other physician-patient relationship. Pharmacy laws and rules require that a prescription be issued only in the context of a legitimate physician-patient relationship. The law does not apply to HIV.

Revised Statutes 37:1747 HIV-Infected Healthcare Workers (1991)

Licensing boards in Louisiana are instructed by this statute to promulgate rules that require licensees and applicants to disclose diagnoses of HIV/AIDS and hepatitis B, in order to protect against transmission to patients.²⁷² The statute provides that such disclosures will be kept confidential.²⁷³

Revised Statutes 15:574.4.2(G) Decisions of Board of Parole; Infectious Disease Testing

A 2010 amendment to the state's parole statute requires parole applicants to submit to and pay for testing for HIV and viral hepatitis.²⁷⁴ The law authorizes the parole board to condition the applicant's parole on the parolee seeking "appropriate" healthcare services, and directs that parole shall be revoked for failure to seek or follow the advice of medical and support services providers. (For the complete language of this new law, see Appendix 2.)

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Access to care in Louisiana varies dramatically by region as well as between urban metropolitan centers and rural areas. In particular, throughout the SHARP research process, in-state community partners noted global differences between southern and northern Louisiana, identifying I-10 as a geographic dividing line of the southern and northern experience. Access to care and the many factors that influence it—resources, geography, transportation, social and political climates, religion and culture, to name a few—look different in New Orleans, Baton Rouge, Lafayette, and Lake Charles than in Alexandria, Natchitoches, Shreveport, and Monroe. Programs that have been successful in urban areas are not necessarily replicable in rural communities. Many of the differences and disparities that exist between southern and northern Louisiana were exacerbated by the population shifts and resource allocations after Hurricanes Katrina and Rita. While Louisiana advocates have long taken a local approach to addressing the needs of people living with HIV and AIDS, in this part of the Louisiana SHARP report, we address several issues that are at play on the statewide level. We recognize, though, that there are no one-size-fits-all solutions to the access to care challenges facing the HIV community.

STATE BUDGET/REVENUE

Significant state budget shortfalls pose a serious threat to access to care for low-income Louisianans today, including people living with HIV/AIDS. With cuts to prevention and testing programs, case management reimbursement rates, and charity hospitals, among others, happening at the same time that the HIV epidemic is growing and more and more people are uninsured due to high unemployment rates, HIV healthcare and support service providers are quite literally having to do more with less. There is no silver bullet for the fiscal crisis facing the state, especially under an administration that has made clear its opposition to using tax increases to raise badly needed revenue, even if that means shutting down essential services. However, HIV advocates will have many allies—particularly in the broader health and education advocacy communities—in undertaking efforts to promote at least some positive change at the state level with respect to the fiscal crisis.

Challenges

The State of Louisiana faces devastating budget shortfalls this fiscal year and in the foreseeable future, as it no longer generates sufficient revenues to fund necessary services—such as education and healthcare. State-wide, agencies have been directed to identify budget reductions up to 35% in the coming fiscal year; this follows mid-year

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budget cuts in FY10 and additional reductions in the FY11 budget already passed. As healthcare and education are the two major budget items left unprotected in the General Fund, these areas inevitably withstand the brunt of cuts because other programs are constitutionally protected.

For instance, in response to the governor's call for across-the-board cuts, Louisiana State University (LSU) proposed eliminating outpatient care for prisoners at its medical centers. As discussed previously, LSU medical centers provide HIV specialty care to HIV-positive inmates. At the time of publication, it is unclear how the Louisiana Department of Corrections (DOC) will preserve inmates' access to necessary medical care, but LSU and DOC are reportedly engaged in discussions to identify strategies to ensure that inmates continue to receive the care they need—including HIV specialty care.²⁷⁵ To avoid further cuts to essential services, Louisiana must identify and undertake either revenue-generating steps or cost-savings measures in nonessential programs.

Opportunities

Reform Louisiana's tax expenditure policies

In addition to the approximately \$8 billion in revenue spending contained in the FY11 state budget, Louisiana coffers will lose over \$7 billion in forgone tax revenues, or "tax expenditures." Over 400 individual pieces of legislation—not contained in the state budget—carve out tax exemptions for groups of individuals, companies, and organizations that cost the state almost as much as it spends each year. Although state revenues are falling, this form of spending has grown 28% since 2006.²⁷⁶ Despite the massive impact tax expenditures have on the state budget, they are not subject to annual review and approval by the legislature—unlike the regular budget, which is proposed annually by the governor; is subject to review, debate, and approval by the legislature; and is available for public scrutiny. In addition, this hidden spending is extremely difficult to rein in, as savings-producing changes to tax expenditure laws require a two-thirds majority vote in the legislature.

Certain kinds of tax expenditures, such as sales tax exemptions for medicine, groceries, and residential utilities, are common to many states and represent sensible (and in Louisiana, constitutionally protected) exceptions to regressive taxes. Many other tax expenditures—especially those enacted years or decades ago that may by now far exceed projected spending when originally passed—may lack justification and need review.

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The Louisiana Budget Project, an independent, nonpartisan policy analysis group, has recently recommended that in order to more efficiently manage its finances and reduce hidden and wasteful spending through tax expenditures, the state should reform its tax expenditure policies in three specific ways:²⁷⁷

- 1) Improve the annual tax spending budget report so that it includes all of the information required by law (how well each expenditure meets its purpose, whether the expenditure is the most fiscally efficient means to meet the purpose, an evaluation of any unintended side effects of each expenditure, and whether the expenditure simplifies or complicates the state tax structure)
- 2) Incorporate an evaluation of tax-side spending in the regular annual budget process
- 3) Change the required vote to reduce or repeal tax expenditures from two-thirds to a simple majority.

A resolution introduced this year by state representative Michael Jackson (No Party–Baton Rouge) represents progress in this direction by requesting the tax-writing committees in both legislative houses to review the goals of Louisiana’s various tax expenditures.²⁷⁸ Both the House and Senate approved HCR187, and it was filed with the Secretary of State on June 30, 2010. As the measure is not binding, advocates should urge their state representatives and senators to actively participate in the review of tax expenditures—especially those who sit on the Ways and Means Committee in the House and the Revenue and Fiscal Affairs Committee in the Senate—and support the additional reforms listed previously.

Raise the state cigarette excise tax

At \$0.36 per pack, Louisiana has the third lowest per-pack state excise tax rate on cigarettes in the country after Missouri (\$0.17) and Virginia (\$0.30); the national average is \$1.45 per pack.²⁷⁹ Revenue from the cigarette excise tax funds the state’s Tobacco Tax Health Care Fund, which provides funding to various cancer research, smoking cessation, addiction disorder, and drug abuse resistance education programs.²⁸⁰ During 2009, 15 states enacted increases to their cigarette excise taxes.²⁸¹ In 2010, three additional states followed suit—including South Carolina, a major tobacco-producing state, where until

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July 2010, when it increased to \$0.57 per pack, the state excise tax on a pack of cigarettes had been only \$0.07—the lowest in the nation—since 1977. In contrast, Louisiana’s cigarette excise tax was last raised in 2002 from \$0.24 to \$0.36 per pack.²⁸² A bill to raise the excise tax by \$1 per pack failed in Louisiana’s House Ways and Means Committee in 2009, despite support from doctors and state and national healthcare advocacy groups and projections that it would raise approximately \$200 million annually for the cash-strapped state.²⁸³

From a public health perspective, increasing the cigarette excise tax is a popular means to raise revenue because it discourages smoking. It is estimated that a \$1 per-pack tax increase in Louisiana would reduce the number of adult smokers by an estimated 26,600 and result in 48,800 fewer youth smokers state-wide.²⁸⁴ Obviously, if the tax successfully reduces smoking rates, revenue raised by the tax will decrease over time. Given Louisiana’s present dire fiscal straits, though, raising the cigarette excise tax would provide much-needed help in the near term—especially if the legislative vehicle set aside some or all of the revenue generated for the General Fund. Another important downside to this proposal is its disproportionate fiscal impact on low-income individuals. Sales taxes generally are one of the least fair revenue-raising mechanisms. However, Louisiana residents already shoulder a significant financial burden associated with the current, low cigarette tax—government health expenditures caused by smoking represent a cost of \$628 to every Louisiana household each year.²⁸⁵

Advocates should work with other health groups to reintroduce legislation to increase the cigarette excise tax, and can look to colleagues in the State of South Carolina—where a try, try again approach was needed—for strategies to move such a bill through the legislature. There, the legislature overcame a veto by the governor to enact a \$0.50 per pack increase in 2010, after failing to secure an increase in 2009.²⁸⁶ In pursuing new legislation to raise the tax, advocates should push for the funds raised not to be earmarked. Allocating the revenue generated to the General Fund would best support state health and education programs, many of which provide essential services for low-income people living with HIV/AIDS.

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AIDS DRUG ASSISTANCE PROGRAM

Successes

Louisiana's AIDS Drug Assistance Program (ADAP) is instrumental in providing access to life-saving medication for low-income Louisiana residents living with HIV/AIDS (See Part II of this report for more detailed information on Louisiana ADAP eligibility, enrollment, budget, and expenditures). Administered by the Office of Public Health's (OPH) HIV/AIDS Program (HAP), ADAP assists not only uninsured individuals, but also Medicare enrollees who cannot afford their Part D premiums and deductibles. Louisiana is one of only 17 states that allows ADAP funds to be used to assist dually-eligible individuals, Medicare beneficiaries enrolled in the Low-Income Subsidy (LIS) program at the full or partial subsidy level, and standard Medicare beneficiaries with these costs. In addition, the state's ADAP is one of 35 that provides medications for eligible individuals who reach the Part D coverage gap (the so-called donut hole).²⁸⁷

Challenges

Past successes notwithstanding, the current stresses confronting Louisiana's ADAP are acute. At the moment, the state's ADAP problems are two-fold. First, the demand for AIDS medications has already outstripped the program's resources for the current fiscal year, forcing OPH to cap enrollment as of June 1, 2010, effectively closing the program to new applicants.²⁸⁸ OPH does not keep a waiting list, but estimates that as of December 17, 2010, ADAP is unable to meet the pharmaceutical needs of over 530 individuals, and the unmet need is expected to continue to grow.²⁸⁹ Second, the state contributes no money to the ADAP; and, as in many states, federal funding is not keeping pace with growing need.²⁹⁰ For instance, the number of individuals served through the Louisiana ADAP has grown 15% since 2008, and the cost of medications in that period rose 33%.²⁹¹

Right now, persons living with HIV/AIDS have the backstop of private patient assistance programs (PAPs) to fill in the gaps created by the ADAP enrollment cap. Some individuals currently unable to access ADAP may not be eligible for the PAPs, which sometimes feature different eligibility requirements and often impose more stringent income caps—though some pharmaceutical companies have recently opened their PAPs to individuals with income up to 500% of the federal poverty level (FPL). In addition, not all consumers who might be eligible for PAPs know that the programs exist or know how to apply. The application

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process for PAPs is well known for the administrative hurdles it imposes on prospective applicants (as well as continuing ones) and case managers. In Louisiana, the Louisiana State University (LSU) Medical Center Pharmacy, Ryan White case managers and social service staff can help individuals apply for PAPs.

Finally, the ADAP crisis affects individuals living with HIV beyond their ability to access medications. While most individuals who are unable to access ADAP can get their HIV medications through PAPs, the ADAP budget strain has resulted in a loss of other essential medical and non-medical services in Louisiana's Part B areas, as the Louisiana Department of Health and Hospitals (DHH) has pulled funding for certain services from Part B programs to support the struggling ADAP program. For example, in Region IV, the state cut funding for one of two nurse practitioner positions at the LSU hospital. In order to preserve this essential position, the Part B provider was forced to direct money away from its food bank program.²⁹² This example highlights the disparate impact that the ADAP funding structure has on the state's non-metropolitan (non-Part A) areas, as the state is forced to find funds within Part B only to cover the ADAP, which is available to residents of the entire state, including Part A areas.

Opportunities

Simplifying the PAP application process

PAPs are playing a larger role in light of the state ADAP crisis. PAPs are designed to support low-income US residents access free or low-cost prescriptions. The programs usually cover brand name drugs only and are administered individually by the pharmaceutical companies that manufacture the drugs. PAPs are administered differently by manufacturer and sometimes even by drugs within the same manufacturer. In most cases the programs are designed around income guidelines. Historically, income limits for most PAPs were below or just above the federal poverty level, but recently, some companies have opened their PAPs to individuals with income up to 500% FPL. The majority of the programs require the patients to be US residents, be uninsured, and meet the income requirements. Income verification in the form of W-2, 1099, pay stub, etc, must generally be provided, as well as any benefits received.

The notoriously complex and time-consuming application process for enrollment in PAPs can be streamlined using application coordination services that maintain a secure, networked database of PAP information and consumer data. Such programs allow case managers and providers to securely store patient and doctor information and supporting documentation in a patient profile. Using the entered data, the program can automatically fill out the majority of PAP application forms and create patient reports and notifications.

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It is possible to link databases across offices for ease of coordination to further eliminate duplication of effort by providers, case managers, and consumers in the process of applying for PAP enrollment.²⁹³ For instance, the Health Department of Kansas City, Missouri, recently launched a system-wide PAP application platform through MedData.

Alternatively, a universal application form for all the PAPs available in Louisiana could be developed for HIV-positive individuals, a strategy currently being pursued by some PAPs in North Carolina.²⁹⁴ Given the extraordinary amount of time case managers in particular report spending on PAP applications, providers and AIDS services organizations (ASOs) are encouraged to explore these options in a coordinated fashion.

Advocate for increased access to Medicaid for people living with HIV to relieve pressure on Louisiana's ADAP

Of course, increased access to PAPs is not a long-term fix to the ADAP funding problem. Although it is not HIV/AIDS-specific, Medicaid is a critical part of paying for healthcare and services for people living with HIV/AIDS in Louisiana, particularly in light of flat funding for Ryan White programs at the federal level and essentially no state funding for ADAP. With the ever-growing need for HIV care and services, access to Medicaid is just as important as having strong Ryan White programs. Cuts to Medicaid—whether in the form of decreased provider reimbursement rates, reduced income eligibility, or cuts to covered benefits—result in more people seeking services from Ryan White programs, including ADAP, which are already overburdened and under-resourced.

The Patient Protection and Affordable Care Act of 2010 (ACA), which is the recently passed national healthcare reform legislation) will eliminate the categorical eligibility requirement for Medicaid. This means that people will be able to receive Medicaid if they are low income (133% FPL or below), rather than being required to fit a particular category, such as disabled or pregnant. This provision will extend health coverage to many HIV-positive Louisiana residents, but does not take effect until 2014. To bridge the gap between the present and expanded Medicaid access in 2014, advocates in Louisiana have two important opportunities.

First, Louisiana's congressional delegation should be encouraged to cosponsor and actively support passage of the federal Early Treatment for HIV Act (ETHA). ETHA is modeled after the successful Breast and Cervical Cancer Act of 2000, and would give all states the option of providing Medicaid coverage to low-income, predisabled people living with HIV by simply choosing the ETHA option on their state plan, with enhanced federal match rates provided to states for the program.

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Second, the state should consider applying for a statewide HIV Medicaid waiver under §1115 of the Medicaid Act. Like ETHA, a waiver would give Louisiana the option of amending its Medicaid eligibility requirements to extend coverage to predisabled poor and low-income people living with HIV. Under the FY11 federal medical assistance percentages (FMAP), the federal government would contribute 70.04% of the cost of providing care under the waiver.²⁹⁵

HIV waivers have been successfully implemented in Massachusetts and Maine. A PricewaterhouseCoopers (PwC) assessment of ETHA (which, as described, would essentially simplify the HIV waiver process) found that early access to Medicaid slows disease progression, increases life expectancy, and is cost effective.²⁹⁶ A study in Alabama found that treating early-stage HIV disease is two-and-a-half times less expensive than treating late-stage illness (\$13,885 vs \$36,532 annually).²⁹⁷ Early access to care benefits public health as well individual health, as people in care have lower viral loads, are less infectious, and are less likely to engage in behaviors that can transmit HIV. (See Appendix 2 for a review of studies on this topic.) ETHA or a §1115 waiver would help to bring Medicaid eligibility rules in line with federal government guidelines on the standard of care for treating HIV.

An HIV waiver would also help to address the unmet ADAP need in Louisiana and allow ADAP to increasingly support premium and copayment obligations, as the majority of ADAP beneficiaries would be eligible for Medicaid-based care and treatment. Medicaid would provide access to a broad range of care and treatment, beyond the HIV medications provided by Louisiana's ADAP.

Louisiana's Department of Health and Hospitals (DHH) recently submitted a successful §1115 waiver demonstration grant application, titled the Greater New Orleans Community Health Connection, that will allow providers in the New Orleans metropolitan area (Orleans, Jefferson, Plaquemines, and St. Bernard parishes) to serve uninsured individuals ages 19-64 with income up to 200% FPL who are not otherwise eligible for Medicaid, LaCHIP, or Medicare.²⁹⁸ The waiver demonstration grant will build on the successful 3-year Primary Care Access and Stabilization Grant (PCASG) that the US Department of Health and Human Services (HHS) awarded to DHH in 2007, under which 25 area not-for-profit and governmental healthcare entities expanded access to primary and behavioral healthcare by stabilizing and growing community-based healthcare delivery systems. (For more information on the PCASG, see Part III section on Access to Healthcare – Successes). Advocates should urge DHH to consider developing a statewide, HIV-specific §1115 waiver, and, in doing so, draw on learnings from the Greater New Orleans Community Health Connection waiver application process.

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ADAP as TrOOP under the ACA

As noted, Louisiana's ADAP provides medications for Medicare beneficiaries who reach the Part D coverage gap and are responsible for 100% of the cost of their medications until they reach catastrophic coverage. Currently, ADAP contributions for Medicare beneficiaries' medications in the donut hole cannot count toward the True Out-Of-Pocket (TrOOP) spending requirement to reach catastrophic coverage. As a result, Louisiana's ADAP, like many states', is essentially stuck paying for medications for eligible Medicare beneficiaries until the end of each year even though they are enrolled in a Part D prescription drug plan.

However, beginning January 1, 2011, ADAP contributions will count toward individuals' TrOOP in Medicare Part D.²⁹⁹ (See Part II for more detailed information on the changes in Medicare under the ACA.) This change results from a provision in the recently enacted healthcare reform legislation and will relieve some of the burden on the Louisiana ADAP, as more Part D-participating ADAP enrollees will reach catastrophic coverage.

Consider formalizing Part A contributions to ADAP

Louisiana's ADAP provides access to medications for residents in the entire state, but is almost entirely funded with Ryan White Part B funds (78% comes from the Part B ADAP earmark, 19% from the Part B ADAP supplemental award, and 3% from drug rebates).³⁰⁰ The New Orleans EMA contributes funds toward ADAP costs for consumers within the EMA, but due to an apparent lack of a mechanism to transfer funds from city to state, the contribution is not formally recognized.³⁰¹ In FY09, the contribution was approximately \$25,000; in FY10 the anticipated contribution is over \$100,000.³⁰² Nationally, approximately one-third of Part A programs contribute to the ADAP in their state(s), with contributions ranging from \$72,794 in Arizona (overall ADAP budget \$4.4 million) to \$8.5 million in New York (overall ADAP budget \$257 million).³⁰³ The Part A program in Massachusetts, where the \$19.3 overall ADAP budget is comparable to Louisiana's, contributes slightly over \$1 million to the state ADAP budget.³⁰⁴

Formalizing the Part A contribution to the state ADAP would carry two significant advantages. First, it would allow copay assistance from Part A to count toward Medicare beneficiaries' Part D out-of-pocket spending requirement in the donut hole beginning in 2011. Under the current contribution structure, copay assistance from Part A's drug reimbursement program does not count toward TrOOP and will not even in 2011 when the healthcare reform provision kicks in that will count ADAP payments toward TrOOP.³⁰⁵ Medicare beneficiaries are generally ineligible for PAPs (eligibility rules usually exclude individuals who have insurance

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coverage); low-income beneficiaries living in the New Orleans EMA who are also ineligible for LIS fall into the donut hole and often need full-pay assistance from Part A. As those contributions will count toward TrOOP, such individuals will reach catastrophic coverage and need Part A assistance for the rest of the calendar year. Needless to say, this arrangement is extremely costly to the EMA Part A program; the cost is exacerbated by the Part A Drug Reimbursement Program's lack of access to manufacturer rebates available to ADAP providers.³⁰⁶ While having its contributions count toward clients' TrOOP in the donut hole is the first advantage of formalizing the Part A contributions to ADAP, access to manufacturer rebates is the second—together, these benefits could realize tremendous cost savings for the Part A drug reimbursement program.

STIGMA

Challenges

HIV/AIDS stigma is a multifaceted and nuanced phenomenon that can manifest in many different ways and is inextricably intertwined with other forms of discrimination, including racism and homophobia. HIV-related stigma in Louisiana—as in other states—is partly due to the association of HIV with behaviors often considered shameful, such as injection drug use (IDU), promiscuity, and male-to-male sex. The state's criminalization of behaviors that are associated with HIV transmission (see Part II for details on Louisiana's criminal statute) also contributes to stigma. Ironically, because culpability under the state's criminal HIV exposure statute is tied to knowing one's status, the law presents a disincentive to testing—thereby contributing to late entry to care and, in all likelihood, further transmission of the virus.

Stigma experienced in family and social settings, as well as the perception that the public harbors widespread fear and negativity toward people living with HIV/AIDS, may lead to greater secrecy and social withdrawal on the part of those living with the virus. In this way, stigma affects people's health-related decisions, including delaying HIV testing, putting off needed care, and not disclosing HIV status to sexual or drug-using partners or medical providers. Stigma impacts both individual and public health. People who do not know they have HIV are more likely to transmit the virus, and people who are late to enter care are often more ill. This can also lead to economic consequences in the form of lost productivity and the need for higher-cost medical

“I was willing to come to this meeting... but I'm not ready to stand on the state capitol steps and let everyone know I have HIV.”

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interventions. Stigma also undermines public education about HIV by discouraging people living with the virus from disclosing their status and participating in education, outreach, and advocacy efforts. In a focus group meeting for consumers in Baton Rouge, one experienced peer educator put it this way: “I was willing to come to this meeting at [a local ASO], but I’m not ready to stand on the state capitol steps and let everyone know I have HIV.”³⁰⁷

Across the state, stigma is consistently identified as a barrier to accessing services. Stigma occurs in all settings, including healthcare facilities, and is particularly a problem in more rural areas of the state, where the “smallness” of rural towns and the fear of others “knowing their business” make people living with HIV/AIDS reluctant to seek care anywhere near where they live. But stigma is not limited to rural areas—consumers in Baton Rouge and providers in Shreveport report that in those cities, stigma contributes to individuals’ reluctance to get tested, attend support group meetings, and seek care; and that stigma is especially a problem in school settings and African American churches. For instance, in Shreveport, commentators recalled a blood bank’s unsuccessful blood drive in local schools—students were reluctant to donate because they associated blood donation with HIV.³⁰⁸ And in Baton Rouge, local advocates noted that while Catholic churches are perceived to be generally open to HIV issues and welcoming of individuals living with HIV, African American churches tend to be more closed—primarily because of homophobia and the perception of HIV as a “gay disease.”³⁰⁹ One focus group participant described her own experience: “In my church, they closed their door to my friend who was gay and positive, but when I learned my diagnosis, they embraced me. It took me challenging their hypocrisy to make them open up to him.”³¹⁰

Successes

Culturally competent outreach initiatives

Because stigma can stem from culturally-specific roots and manifest uniquely in different populations, tailored interventions are crucial in efforts to address it. Across the state, ASOs and providers have made efforts to combat stigma by conducting targeted, relevant outreach within specific populations—teens, men who have sex with men (MSMs), minorities, etc. By using media, language, formats, and even venues that are comfortable for the target audience, educators can maximize the impact of their outreach activities.

For example, staff at the Philadelphia Center, an ASO serving northwest Louisiana with offices in Shreveport and Natchitoches, have developed a Spanish-language education and outreach portfolio that primarily uses a comic strip format to reach Latino immigrants who may have limited reading abilities. The materials—including posters, flyers, and

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computer slide shows—are deployed in the immigrant community in settings that minimize the association of the viewer with the material content. For instance, posters are placed alongside other announcements in entrance/waiting areas in restaurants frequented by the target population, where people can glance at them while waiting to be seated.³¹¹

Similarly, the Keepin' it Real Crew of the Baton Rouge AIDS Society (BRASS) has developed an education and outreach program specific for teens. Members of the Crew perform skits that relate to teens' life experiences and emcee games to test and improve teens' knowledge about HIV and AIDS.³¹² BRASS also offers home health parties, a nontraditional approach to reaching groups that would not be comfortable attending more public education events.³¹³

Opportunities

Support comprehensive health education

In the context of HIV, comprehensive health education is often discussed as it relates to prevention. Indeed, comprehensive health education can help delay the onset of sexual activity and increase consistent condom use for those teenagers who are sexually active.³¹⁴ But it is also a critically important part of reducing stigma associated with HIV disease, and is therefore an essential component of a coordinated strategy to increase testing and promote access to care for people living with HIV and AIDS.

Current Louisiana law allows, but does not require, the provision of sex education in schools.³¹⁵ No sex education may be provided to students prior to grade seven,³¹⁶ except in Orleans Parish, where schools may provide sex education at the third grade level or higher.³¹⁷

In 2010, State Representative Patricia Haynes Smith (D-67) introduced a bill (HB No. 529) to require, rather than merely authorize, the provision of comprehensive sex education in public schools for students in grades 4 through 12. The bill would require the governing authority of each public school to provide “medically accurate, developmentally appropriate, and age appropriate instruction” that includes, among other things, “the benefits of abstinence and delaying sexual activity” as well as “the importance of effectively using contraceptives and barrier methods to prevent unintended pregnancy and to protect against sexually transmitted infections.”³¹⁸ The bill would leave in place the current law’s ban on discussing abortion, and would give parents the opportunity to review the curriculum and materials and then choose whether their children should receive comprehensive health education.³¹⁹

The House rejected the bill by a vote of 23-67. Although it had support from the Louisiana Office of Public Health (OPH) and several health and education advocacy organizations, it was opposed by Governor Bobby Jindal and powerful special interest groups.³²⁰ The nearly three-to-one margin of defeat signals that there is a long way to go before the legislature will pass

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■ a comprehensive health education bill, but the fact that the bill was introduced and garnered as many votes as it did represents not only a positive first step, but a strong foundation on which to grow support for comprehensive health education in schools. HIV advocates should include this bill in their legislative priorities, as comprehensive health education is vital to both HIV (and other STI) prevention and combating stigma.

Other health advocates, educators, and the medical community are natural allies on this issue. The HIV community should reach out to these groups to mount a sustained, visible campaign to support this or similar comprehensive health education legislation within the state legislature. Ensuring that the public as well as all legislators understand what the bill would and would not require is essential to its success. For instance, advocates should highlight that the bill requires parents to have the opportunity to review instruction materials and to decide whether to opt their children out of the curriculum; that it does not abandon the abstinence message; and that it requires all instruction to be medically accurate and age-appropriate.

In the meantime, other opportunities exist to increase the availability of comprehensive health education in schools. Under the current law, local parish school boards have the authority to develop and implement sex education curricula. HIV advocates and other stakeholders should develop relationships with school board officials, and determine on a local level what kind of instruction school boards and school leaders are willing to implement. Anecdotal evidence suggests that in many parts of the state, school boards will not be open to truly comprehensive health education.³²¹ But any curriculum that includes medically accurate information about STI transmission would likely be more effective than no information at all or strict abstinence-only instruction.

Louisiana law prohibits surveying students about their sexual behaviors, so no information is available about the percentage of Louisiana teens who are sexually active, use protection against STIs and pregnancy, etc.³²² But data from neighboring states—Mississippi, Texas, Alabama, Arkansas, and Tennessee—suggest that in Louisiana, at least half of high school students likely are sexually active, many have had multiple sexual partners, and many do not consistently protect themselves from STIs and pregnancy.³²³ The one data point that is collected concerning sexual behavior among high school students in Louisiana is how many were never taught in school about HIV and AIDS; in Louisiana, it is nearly one in four students (23.8%).³²⁴ That rate is higher than in neighboring states, where the percentage of students who had never been taught about HIV and AIDS ranges from about 15% to about 18%.³²⁵

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Given these statistics, advocates should persist in their efforts to bring more comprehensive health education into Louisiana schools and view any progress as a victory. In the current political climate, legislation to repeal the prohibition of surveying students about their sexual behaviors would likely be easier to pass than a substantive bill to require comprehensive health education, and would pave the way to collect data that could help support the call for comprehensive health education in the future.

Partner with lead agencies and organizations in new and expanded comprehensive health education programs

The federal Department of Health and Human Services (HHS) recently awarded Louisiana Office of Public Health's HIV/AIDS Program (OPH HAP) \$769,607 for comprehensive health education under the Personal Responsibility Education Program (PREP) of the national healthcare reform law.³²⁶ In addition, OPH, the Louisiana Public Health Institute, the Institute of Women and Ethnic Studies, and the Central Louisiana Area Health Education Center Foundation received PREP funding totaling over \$4.6 million to deploy teen pregnancy prevention initiatives in the state that replicate evidence-based programs.³²⁷ Under the statute, PREP funds must be used to support "programs that replicate evidence-based teen pregnancy prevention strategies and incorporate other adult responsibility subjects, such as maintaining healthy relationships, improving communication with parents, and financial literacy." Furthermore, the programs must place "substantial emphasis" on both abstinence and contraception for the prevention of pregnancy and sexually transmitted diseases among sexually active youth.³²⁸ HIV advocates should proactively engage HAP, OPH, LPHI, and the other PREP grantees to ensure that all programs supported by this funding incorporate elements to address HIV-related stigma as well as information about HIV and STI prevention, testing, treatment and care. Collaboration around successful implementation of PREP initiatives provides a significant opportunity to continue to grow existing—and build new—partnerships among health, education, and youth advocacy groups across Louisiana. By participating in such partnerships, AIDS services organizations and grassroots advocates can not only ensure accurate and adequate representation of HIV information in health education curricula, but can also develop ready allies for related campaigns at the local, regional, and state levels.

Oppose Title V funding for abstinence-only instruction

Advocates should be aware that although the Obama Administration recently cancelled federal funding for Title V abstinence-only programs, the ACA also reauthorized funding for grants to states to support abstinence-only sex education programs.³²⁹ While there is some new flexibility to Title V abstinence-only program under the ACA, the program continues

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to embrace the abstinence-only-until-marriage definition.³³⁰ Furthermore, states are required to use these funds to promote abstinence to the exclusion of other topics. States cannot use Title V abstinence-only funds to implement comprehensive sex education. Unlike grants under the PREP initiative, which require no state matching, the Title V abstinence-only program requires a state match of \$3 to every \$4 in federal funding.³³¹ Advocates are advised to discourage state officials from applying for this funding.

Combat stigma by increasing the presence of faith leaders at HIV/AIDS-related events and supporting people living with HIV/AIDS

Advocates should urge leaders in Louisiana's faith community who are already supportive of HIV issues to participate in specific activities that combat stigma and promote access to care. Particularly in smaller communities, stigma can negatively influence individuals' willingness to get tested or seek care for HIV infection. Any delays in treatment can be devastating for individual health—and can contribute to the spread of HIV, particularly when infected individuals are not aware of their HIV status.

Faith-based communities can help increase access to care by openly welcoming and supporting people living with HIV and tackling stigma at the pastoral and congregational levels. For example, advocates should urge pastors to participate in testing campaigns by encouraging their congregations to get tested, volunteering at testing events, and getting tested themselves. National HIV Testing Day presents an annual opportunity for faith leaders to get involved. Similarly, supportive faith leaders can attend community events, such as health fairs, along with ASOs. By simply being present at these events, faith leaders can show their support for and decrease stigma about individuals living with HIV/AIDS.

In addition, where pastors are already open to HIV issues, advocates should be proactive in asking them to integrate HIV/AIDS and related issues into worship services and other church functions. Sunday morning is the best opportunity to reach the majority of congregants, and by speaking about HIV from the pulpit, pastors both educate and signal to their congregations that it is acceptable to talk about HIV, health, and sexuality in the church setting. In particular, due to the apparent lack of comprehensive sex education in Louisiana schools, advocates should approach pastors about providing comprehensive health education at church. While some

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pastors may feel strongly about preaching abstinence only, others are willing to discuss sexuality issues—presenting an invaluable opportunity to reach youth who are not receiving adequate information in the school setting.

Continue and expand outreach to faith-based communities

Advocates around the state report that while some faith leaders have been receptive to outreach and education efforts within their churches, many are not. Specifically, commentators have observed that younger pastors are generally more open than older pastors.³³² In faith communities that lack leadership buy-in, advocates should consider focusing education and outreach efforts at the pastor level—rather than the congregation level—first, or if the pastor is not on board, change within the congregation is unlikely.

An important step toward bringing pastors on board in the fight against HIV/AIDS is empowering them with knowledge about the disease and a theological framework for thinking about the issue. Access to HIV experts is essential, as some pastors may not be comfortable starting discussions about HIV in their churches if they lack adequate information. Advocates can plan events at which pastors can learn from public health and medical professionals as well as people living with HIV/AIDS. For this purpose—as well as in the context of theological discussions—clergy-only educational settings are crucial.

Increase the presence of people living with HIV/AIDS within faith-based communities

A key step in the effort to enhance sensitivity, reduce stigma in, and increase engagement of faith-based communities is to increase the presence of people living with HIV/AIDS within faith-based ministries. It can be extremely powerful for congregants to have a person living with HIV or AIDS speak during the worship service or at a church function. For many, that can put a face on the epidemic and help them realize that HIV is real in their communities. In addition to prevention efforts, the church can be a great source of social support and help connect individuals to treatment and other support services. Advocates should convey to pastors the importance of the church being a safe place for individuals to come and discuss their personal issues, which includes the disclosure of their HIV status.

Support federal funding for faith-based initiatives

At the federal level, Representative Elliot Rangel (D-NY) introduced legislation in 2009 that would authorize \$50 million in grants each year from 2010 to 2014 for public health agencies and faith-based organizations to conduct prevention and testing activities as well as outreach

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efforts. The National Black Clergy for the Elimination of HIV/AIDS Act of 2009 (H.R.1964) has 46 cosponsors, including both Democrats and Republicans.³³³ Senator Kirsten Gillebrand (D-NY) introduced the bill in (S.3011) in the Senate in 2010. Currently, Congressman Anh Cao (R-2nd District) is the only representative from Louisiana who has cosponsored the bill in the House; neither senator from Louisiana is a cosponsor. Advocates should contact their representatives to make sure they are aware of this legislation, and urge them to sign on to the bill as a cosponsor.

Encourage state and local health officials to engage with criminal justice counterparts to reduce stigma and barriers to testing caused by Louisiana’s criminal exposure statute

HIV advocates in Louisiana expressed concern about the state’s criminal exposure statute (codified at L.A. R.S. 14:43.5; see Part II for more detailed information on the statute).³³⁴ The law makes criminal the intentional exposure of any person or police officer to “any acquired immunodeficiency syndrome virus.” Connecting HIV exposure to criminal activity contributes to stigma associated with HIV and those who are positive. Even more dangerously, though, by criminalizing “intentional” exposure and thereby hinging culpability on knowledge of one’s HIV status, the law provides a disincentive for individuals to be tested—one cannot be guilty under the law without knowing one’s status.

Testing and early linkage to care are essential to ensure positive individual and public health outcomes. Advocates in Louisiana should address this barrier to testing and take advantage of the growing national movement to reform criminal statutes associated with HIV exposure/transmission. In 2010, national HIV advocacy organizations have engaged the Centers for Disease Control and Prevention (CDC) on this issue, leading the CDC to acknowledge “the risks that criminalization of HIV transmission and exposure may pose to HIV prevention programs and messages,” and conclude that “there is much to be done to address the need for a public health, rather than punitive perspective to drive how people living with HIV/AIDS are approached in the United States.”³³⁵ As a result of this ongoing dialogue, the CDC Division of HIV/AIDS Prevention (DHAP) has committed to developing a communications package that can help local HIV advocates and health departments engage with state and local criminal justice officials.³³⁶ The National Association of County and City Health Officials (NACCHO), the National Association of State and Territorial AIDS Directors (NASTAD), and the Community HIV/AIDS Mobilization Project (CHAMP) are leading this effort with DHAP.³³⁷ Louisiana advocates can look to these organizations for further information and strategy tips as the partnership with DHAP to address this issue evolves.

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ACCESS TO HEALTHCARE

Successes

Nonphysician services

Although Louisiana has a per capita rate of physicians that is lower than the national average,³³⁸ the state has a higher than average rate of registered nurses (898 versus 836 per 100,000 population, respectively).³³⁹ Furthermore, unlike many states, nurse practitioners in Louisiana are allowed to practice without physician involvement and supervision.³⁴⁰ Instead, the state's regulations require use of a written practice protocol, or "collaboration," with a physician when the nurse practitioner exceeds the protocol.³⁴¹ The law also grants nurse practitioners express authority to diagnose and refer patients, as well as to write prescriptions (with physician collaboration or a written protocol).³⁴² Louisiana's relatively high numbers of nonphysician healthcare providers in Louisiana may mitigate some of the problems associated with relatively low numbers of physicians in the state.

Primary Care Access and Stabilization Grant and Medicaid \$1115 waiver

In September 2007, the federal Department of Health and Human Services (HHS) awarded the Louisiana Department of Health and Hospitals (DHH) a 3-year, \$100 million grant to support the already-underway transformation of the regional healthcare delivery system in the greater New Orleans metropolitan area (St. Bernard, Orleans, Jefferson, and Plaquemines parishes) from one that was largely hospital-based to a more community-based system of primary care after Hurricane Katrina.³⁴³ The 25 participating not-for-profit and governmental healthcare entities represented a variety of safety net providers, including federally qualified health centers (FQHCs), academic and hospital-affiliated outpatient programs, faith-based organizations, state entities, and grassroots medical clinics—including NO/AIDS Task Force, a New Orleans-based AIDS services organization (ASO).³⁴⁴ Under the grant, primary services included:³⁴⁵

- Primary healthcare services by licensed primary care practitioners (specialty areas such as internal and family medicine, obstetrics, pediatrics)
- Preventive and well care
- Diagnostic laboratory and radiological services
- Dental and optometric services
- Mental health and/or substance abuse screening, assessment, counseling, referral treatment, and follow-up services

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- Urgent medical and mental healthcare services
- Pharmacy services
- Case management services
- Outreach

In addition, up to 15% of an organization's award could be used to support specialty care.³⁴⁶

The grant supported a 30% increase in the number of clinics operating in the region over 3 years, and its network of participating entities now serves as the primary source of healthcare for approximately 20% of the region's population.³⁴⁷

To bridge the gap between the end of the Primary Care Access and Stabilization Grant (PCASG) in September 2010 and January 2014—when a large portion of the currently uninsured or underinsured clients of PCASG entities will gain access to Medicaid or private insurance under the Patient Protection and Affordable Care Act (ACA)—DHH secured a Medicaid §1115 research and demonstration grant waiver for the region in September 2010. The goals of the new waiver program are to preserve the expanded access to primary and behavioral healthcare achieved through the PCASG; expand use of the medical home model instituted under the PCASG, and transition the participating entities from grant-funded fiscal models to long-term, sustainable programs that are integrated into Medicaid, LaCHIP, and private insurance networks.³⁴⁸ Under the waiver, participating entities will be funded to serve uninsured individuals aged 19-64 with income up to 200% of the federal poverty level (FPL) (that is \$21,660 for an individual in 2010) who are otherwise ineligible for Medicaid, LaCHIP, and Medicare. Among the 25 participating entities, an estimated 75,610 patients fit these criteria.³⁴⁹ The benefits covered will match those provided under the PCASG grant, with the exception of dental, ophthalmology, and pediatric services. For individuals living with HIV, for whom dental and vision services are especially important, access to these services through Ryan White programs will be critical.

Challenges

Provider shortages

In Louisiana, over 34% of the state's medically underserved population live in primary care health professional shortage areas (HPSAs),³⁵⁰ as defined by the HSS.³⁵¹ In the United States as a whole, that figure is only 11.8%.³⁵² A similar disparity exists between the percentages of underserved Louisianans, compared to underserved Americans as a whole, who live in dental

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HPSAs.³⁵³ Traditionally, Louisiana's HPSAs have coincided with its rural parishes, where the average patient-to-physician ratio was more than twice that of Louisiana's urban areas.³⁵⁴ In recent years, however, Louisiana's provider shortage trends have changed, as a number of additional parishes have acquired HPSA designation in the aftermath of Hurricanes Katrina and Rita.³⁵⁵ Thus, Louisiana residents face a high degree of unmet need for medical care, which is at least partially related to the geographic distribution of physicians in the state.

Changes to disproportionate share hospital payments

In addition to challenges associated with post-hurricane rebuilding efforts, like many safety net hospital systems, Louisiana's Charity Hospital system faces significant funding challenges. In addition to significant state funding cuts to Louisiana State University (LSU), new federal audit rules are projected to cost Louisiana \$200 million in disproportionate share hospital (DSH) payments in the coming year.³⁵⁶ And while the ACA will decrease the number of uninsured Louisiana residents by expanding Medicaid eligibility and reforming private market health insurance systems, it also includes significant cuts to DSH payments upon which Louisiana's Charity Hospital system is heavily reliant.³⁵⁷

Provider reimbursement under Medicaid

Provider reimbursement levels pose an additional challenge to healthcare access in Louisiana. When providers receive insufficient reimbursement to cover their overhead costs—much less earn a profit—they will sometimes refuse to accept patients enrolled in Medicaid.³⁵⁸ Case managers across the state report that recent reimbursement changes, including caps on reimbursement and client levels, have made it extremely difficult to meet the demand for Medicaid case management services. Likewise, Medicaid reimbursement for preventative services and hospital care in Louisiana has been generally less than 70% of Medicare reimbursement rates,³⁵⁹ and the state government has instituted multiple additional cuts since 2009. Under the ACA, the federal government will increase Medicaid reimbursement levels for primary care providers to 100% of Medicare rates during 2013 and 2014,³⁶⁰ but the federal government is not obligated to continue to fund those increased rates after 2014. Moreover, the increased reimbursement rates will not extend to the specialists who provide crucial care to patients living with HIV. If the state does not increase provider reimbursement rates to reflect the cost of providing care, continued provider shortages could ultimately render the 2014 Medicaid expansion meaningless for new beneficiaries.

Access to transportation services

Provider shortages and healthcare access issues are closely linked with transportation problems in Louisiana. Across the state, only 39% of people living with HIV who responded to a 2008 survey reported owning their own cars; 71% depend on others (family, friends, volunteers) to

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get them to medical appointments and support services.³⁶¹ Case managers report that clients who live in rural areas often have to travel significant distances to access primary and specialty care.³⁶²

Currently, federal funding restrictions contribute to the barriers that rural patients face in accessing healthcare, because Ryan White providers may allocate only a small portion of their funds for paying for patients' transportation. In rural areas, the lack of public transit options coupled with long distances mean staggeringly high costs for mileage reimbursement for private transportation—and quickly depleted funding. Approximately 12% of Louisiana residents living with HIV reside in rural areas.³⁶³ Given that public transit systems are available in only a few urban centers, the lack of funding for transportation creates a major barrier to healthcare and contributes to dramatic and unfair geographic health disparities.

Opportunities

Federal advocacy to increase access to transportation services

Public transportation options in urban areas make getting to a medical appointment affordable for most patients. However, when a provider has to pay or reimburse mileage for family, friends, or even case management staff who bring rural patients to appointments, transportation becomes a big line item. To increase access to healthcare and essential support services, state advocates should urge the federal Health Resources and Services Administration (HRSA) to change the definition of core service in the Ryan White Program to include transportation services.

Further expand the role of nurse practitioners and physician assistants

Louisiana could improve healthcare access by promoting the training and utilization of physician assistants (PAs). Louisiana has only half as many PAs per capita as the United States on average.³⁶⁴ In Louisiana, PAs are authorized to provide medical services, as delegated by supervising physicians.³⁶⁵ In addition, the state's regulations allow PAs to prescribe drugs after acquiring "prescriptive authority" from the licensing board.³⁶⁶ Licensure requires graduation from an accredited PA training program,³⁶⁷ but there is only one accredited PA training program in Louisiana, located at the LSU Health Sciences Center in Shreveport.³⁶⁸ By expanding and promoting PA training opportunities in the state, Louisiana can further leverage its physician population and decrease unmet need.

Growing the rural healthcare workforce

To address the influence of geography on access to healthcare, Louisiana should also support programs that encourage healthcare providers to practice in underserved communities. One mechanism for incentivizing practice in underserved areas is educational loan repayment. Many states,³⁶⁹ as well as the federal government,³⁷⁰ offer loan repayment to healthcare providers who

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choose to practice in underserved areas. Louisiana currently offers a loan repayment program for providers who choose to practice in Health Professional Shortage Areas (HPSAs).³⁷¹ The state should consider expanding, or otherwise further promoting, that program.

Louisiana should also provide further support to programs that encourage students from rural areas to pursue healthcare provider training. Although students from rural areas often face barriers in establishing careers in medical fields, they are much more likely than students from urban areas to practice in rural communities.³⁷² Louisiana should also continue to utilize its medical schools to encourage and support rural health practice.³⁷³ LSU currently admits 15 students each year into its rural scholars program.³⁷⁴ Tulane Medical School also has a rural medical education program.³⁷⁵ The state should consider studying the results and experiences of those programs to determine how they can be expanded.

Funding opportunities for workforce expansion under the ACA

HHS has set aside \$250 million from the ACA's Prevention and Public Health Fund in 2010 alone for investing in the development of an expanded primary care workforce, with a focus on underserved and particularly vulnerable populations.³⁷⁶ This funding is targeted for initiatives like those suggested previously: supporting PA training in primary care; encouraging students to pursue full-time nursing careers; establishing new nurse practitioner-led clinics; and encouraging states to plan for and address health professional workforce needs, among others. Louisiana's DHH and Office of Public Health (OPH), as well as individual clinics and the medical schools at LSU and Tulane, should consider how they can take advantage of this significant new funding source to expand and strengthen Louisiana's healthcare workforce and address provider shortages and geographic disparities in access to care.

Strategic planning for the future of Ryan White programs

With implementation of healthcare reform, thousands of individuals who previously received care and treatment through Ryan White programs will now access healthcare through Medicaid and new state insurance exchanges. It is clear that despite the tremendous possibilities of healthcare reform for individuals living with HIV and AIDS, major gaps in affordability and access to essential care, treatment, and services will remain. Even after full implementation of healthcare reform, Ryan White programs will be necessary to fill these gaps.

Ryan White programs offer an important blueprint for the expansion of comprehensive health and support services for people with chronic illnesses. In many ways, Ryan White programs serve as a best-practices model for comprehensive and holistic provision of care and treatment. As major healthcare reform provisions go into effect, however, the role of Ryan White will undoubtedly change. Advocacy around integration of Ryan White providers into Medicaid and state exchange provider networks, for instance, will be crucial to ensure seamless access to care for the thousands of people newly eligible for Medicaid and private insurance coverage.

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Integration of Ryan White programs and models of care into Medicaid and private insurance models is also important to ensure a smooth healthcare reform transition for those currently receiving care.

One obvious opportunity for integration is for Ryan White clinics to pursue certification as federally qualified health centers (FQHCs). The healthcare reform law includes billions of dollars in funding and grants for community health centers, including \$11 billion in funding for the operation, expansion, and construction of health centers throughout the nation over the next five years.³⁷⁷ For instance, the federal government recently announced the availability of \$250 million in grants for new access points to support more than 350 new community health center service delivery sites in 2011.³⁷⁸ In light of this significant funding opportunity, advocates should encourage health centers to apply for grants to expand services for people living with HIV and AIDS, and clinics (including Ryan White clinics) that are not in compliance with federal rules regarding qualified health centers should consider bringing themselves into compliance to be eligible for federal grants.

CORRECTIONS

As of 2007, Louisiana had the highest per capita rate of incarceration in the United States.³⁷⁹ While this level of imprisonment creates significant social and economic problems for the state, it also presents an opportunity to impact the health of a segment of the state's population that is at particularly high risk for HIV infection.³⁸⁰

Successes

HIV testing and linkage to care at Department of Corrections facilities

Department of Corrections (DOC) prisons in Louisiana, in collaboration with the state's Office of Public Health (OPH), operate under an "opt-out" model for HIV testing, meaning that the system conducts routine, voluntary testing for HIV of all inmates upon entry.³⁸¹ The DOC positivity rate is estimated at approximately 3%-4%, and the opt-out program has been highly successful in establishing a nearly universal rate of testing upon entry. Based on data from the DOC/OPH prerelease program (discussed in the following section), approximately 32% of the inmates who received prerelease services in 2009 first received an HIV diagnosis while incarcerated.³⁸² In contrast, most parish jails typically offer testing only to those inmates exhibiting clinical indications of HIV infection.³⁸³

Prerelease counseling for HIV-positive inmates at DOC facilities

In addition to offering routine, voluntary testing upon entry, all 13 DOC facilities have offered prerelease counseling to their HIV-positive inmates since December 2008.³⁸⁴ Beginning six

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months prior to release, HIV-positive inmates receive monthly, one-on-one counseling with a corrections specialist from the HIV/AIDS Program in OPH. Prior to the initiation of the AIDS Drug Assistance Program (ADAP) enrollment cap, the prerelease planning program secured temporary ADAP enrollment for DOC inmates that provided 30 days' worth of medicines for released individuals at their local ADAP pharmacy. Now that ADAP is closed to new applicants, the program's correction specialist works with local pharmacies to develop inmates' applications for patient assistance programs (PAPs).³⁸⁵ The correction specialist also helps connect inmates with Ryan White case management services and medical care upon release.³⁸⁶ Each inmate receives a written summary with appointment dates, contacts, and other helpful information upon release to minimize confusion.³⁸⁷ In addition, if the inmate will be initiating community-based HIV medical care for the first time upon release from a DOC prison, the correction specialist will offer to meet him/her at the clinic for the first appointment.³⁸⁸

By planning for and facilitating linkage to healthcare and case management several months prior to release, this program helps ensure that inmates know how and where to access care, allowing them to focus on other priorities such as housing and employment upon release without doing so at the expense of maintaining their health. The current correction specialist cited strong support within the DOC for the prerelease program as a key factor in its success.

Emergency preparedness

Another notable success in the correction context relates to contingency planning. In response to its experiences during Hurricanes Katrina and Rita, the Louisiana DOC has developed a set of sophisticated disaster preparedness plans to ensure continuity of care for inmates living with chronic diseases in the event of an emergency.³⁸⁹ If inmates in a DOC facility need to be evacuated during an emergency, each inmate will be accompanied by a transfer summary, indicating the inmate's medical conditions, medications, upcoming appointments, allergies, PPD status (tuberculosis), and any other specific medical requirements. For evacuations that occur on very short notice, the DOC is prepared to instead send complete medical records for each inmate to the receiving facility. Emergency evacuees will be transferred with all of their medications (on person or sent to the receiving pill call room), and each inmate will receive medical screening upon arrival at the receiving facility. These plans are bolstered by use of an electronic medication record system, and the requirement that pharmacy vendors contracting with the DOC maintain their own emergency preparedness plans, which will allow them to fill large numbers of prescriptions upon short notice. Planning ahead for such events is critical to avoid gaps in treatment and resulting negative health outcomes, such as medication resistance, particularly for

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individuals taking antiretroviral medications.

Challenges

Budget shortfalls affecting treatment options for incarcerated individuals

Despite its high per capita levels of incarceration, Louisiana spends a lower than average percentage of its state budget on corrections.³⁹⁰ Moreover, as in other states, Louisiana's fiscal problems are leading to significant cuts in state agency budgets. DOC officials are preparing for the possibility of a 35% cut to DOC's allocations in the next budget.³⁹¹ Furthermore, because medical care and testing are provided to DOC inmates through collaborations with OPH and Louisiana State University (LSU), those services are vulnerable to budget cuts beyond those that directly affect the funding of DOC. LSU alone is predicting a \$62 million cut in its state funding in the next fiscal year.³⁹²

Access to care at parish jails

The distinction between parish jails and DOC facilities also creates challenges for ensuring access to quality healthcare for incarcerated populations. Healthcare access differs significantly between DOC prisons and parish jail facilities, in part because the inmates in parish jails are confined for an average of six months, while inmates in DOC facilities generally serve a minimum of six years.³⁹³ Although the systems are designed to house different populations of inmates, approximately 21,000 DOC inmates are currently housed in parish jails; as of last year, there are fewer DOC inmates in DOC facilities than in parish jails.³⁹⁴

Parish jails are managed and funded on a local level, reportedly resulting in inconsistent access to treatment and care for inmates living with complex health conditions, such as HIV infection, among different parishes.³⁹⁵ This phenomenon is also likely in part due to the nature of jails versus prisons—parish jails were designed to serve a more transient population than DOC facilities; consequently, fewer healthcare services are available to their inmates. For example, DOC inmates receive opt-out testing for HIV infection, but in most parish jails, asymptomatic inmates are unlikely to be tested. Thus, while the DOC seeks to keep inmates with known physical and/or mental health conditions out of parish jails,³⁹⁶ HIV-positive non-DOC inmates remain in parish jails, and may be unaware of their statuses. In addition, access to medication in parish jails may be inconsistent, particularly in the weeks during which initial arrests and charges are processed. Sometimes, parish jails will release inmates whose medical expenses are too costly.³⁹⁷ Both DOC and parish jails purchase drugs from the LSU system at a discounted rate, but medication for HIV-positive inmates remains a significant cost for both systems, and, as discussed, the system remains vulnerable to funding cuts within the

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LSU system and OPH.

It is unclear what—if any—prerelease planning services are available to inmates leaving parish jails. Providers in Louisiana expressed concern that the quick turnover in parish jails disrupts medical treatment, and may also lead to resistance against first-line antiretroviral treatments.³⁹⁸ Moreover, many parish jails do not allow AIDS services organizations (ASOs) to work with their inmates, often because the jails lack the resources to provide security/supervision according to their internal policies.³⁹⁹

Unfair treatment of HIV-positive and STI-infected individuals under new parole law

During its 2010 short session, the Louisiana Legislature passed an amendment to the state's parole statute that requires each parole applicant to submit to (and pay for) STI and HIV testing, and provide the results of that test to the Board of Parole.⁴⁰⁰ The parole of any inmate who tests positive for a sexually transmitted disease, HIV, AIDS, or viral hepatitis is conditioned upon “the person seeking advice and counseling from the appropriate healthcare and support services.” Under the new law, the parole of a noncompliant parolee must be revoked. (For full text of the law, see Appendix 2.) To be sure, parole is always contingent on a variety of conditions intended to safeguard society and limit risks associated with early release. While there is no evidence for the apparently widely held belief (particularly among the general public and lawmakers) that HIV transmission is rampant within prisons and these offenders infect many more after release, this statute reflects those “public safety” goals as well as recommendations by the public health community for routine testing among high-risk populations.⁴⁰¹ Moreover, linkage to treatment and care is clearly of utmost importance for any individual who tests positive for HIV, in particular. However, as written, this statute raises serious privacy, fairness, and human rights concerns for people living with HIV and other STIs in Louisiana's corrections system—among them, increased stigma, discriminatory enforcement, implications for freedom of choice of medical treatment, unfair punishment where individuals lack access to care, and discrimination against those who cannot afford to pay for testing.

Opportunities

Treatment continuity assurance and linkage to care in parish jails

It goes without saying that lapses in medication adherence due to arrest and detention should be avoided if at all possible. While parish jails may refuse to accept medications brought in by family members or other individuals, anecdotal evidence suggests that jails are likely to be willing to receive medications from ASOs.⁴⁰² ASOs should make sure that clients know to

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call them (instead of family or friends) in the event they are arrested and detained. In addition, ASOs should educate jail staff of the importance of medication regimen adherence, and provide their contact information so that jail staff can contact them when someone who identifies as HIV positive is arrested. This approach obviously does not address the cases where jails lack certified staff to dispense medications. ASOs are encouraged to engage jail management to find a solution for those situations, and may want to consider proposing “keep on person” programs for HIV medications.

A further benefit of maintaining ongoing dialogues and relationships between ASOs and parish jails is the opportunity to link a high-risk population to HIV/AIDS education and services. Linkage interventions like that provide detainees with information about services, and care options in the surrounding community can help increase early access to care. While sustained, in-depth interventions are likely infeasible in most jails simply due to ASO resource constraints, other approaches can increase intervention and education opportunities. For instance, while jails often lack enough staff to accommodate in-house ASO educational programming, HIV education can be integrated into existing programming such as substance abuse support groups or classes. Acadiana CARES, a Lafayette-based ASO, reports having had success with such an approach.⁴⁰³ At the same time, safeguards should be put into place to ensure that the privacy rights of persons living with HIV or AIDS are respected by jail employees and other third parties.

HIV testing

In addition, OPH should consider providing training and funding to parish jails to institute opt-out HIV testing for all arrestees. Opt-out testing has been highly successful within the DOC system, with over 90% of inmates participating in testing upon entry.⁴⁰⁴ Widespread testing allows prison officials to provide necessary healthcare services to inmates living with HIV infection from day one. Given the transitory populations of parish jails, opt-out entry testing is particularly valuable in those facilities, as it can provide status awareness and a point of entry into care for members of a high-risk population who might not otherwise be tested until they fall ill. Thus, the current failure of parish jails to test asymptomatic inmates represents a missed opportunity to have a significant impact on the HIV epidemic in Louisiana. Indeed, in South Carolina—a state that also implements routine, voluntary testing upon entry to state prison but where county jails do not normally test—a recent empirical study showed that many arrestees who are HIV positive but unaware of their status could have been diagnosed earlier through testing at admission and processing at county jails.⁴⁰⁵

Equal treatment for parolees living with HIV/AIDS, viral hepatitis, and other STIs

Finally, advocates in Louisiana should work toward repealing or amending the state’s parole statute that imposes mandatory STI testing on inmates and requires revocation of parole in the

part IV: conclusion

event of treatment noncompliance. At the very least, the law must make testing prior to parole opt-out; should take into account circumstances in which parolees lack access to or have personal grounds for objecting to medical treatment; and should not deny parole to indigent inmates who are unable to pay for testing. Advocates should refocus the efforts of legislators toward creating, funding, and supporting programs that provide fair and effective assistance to HIV-positive inmates and inmates living with viral hepatitis or other STIs as they transition back into their communities.

People living with HIV/AIDS in Louisiana face a number of barriers in accessing comprehensive healthcare and support services. Federal funding for HIV/AIDS programs essentially has been level for several years and the state is slashing its budget for safety net providers—both at a time when need is growing faster than ever due to the economic crisis. In addition, stigma, geographic disparities, and political apathy are major obstacles.

Despite these and other serious challenges, advocates, providers, consumers, agency representatives, and elected officials across the state are fully engaged in improving access to care. While it does not address every barrier that community partners identified throughout the 2010 SHARP research process, this report identifies some practical steps that the HIV community can take to build on its existing successes, leverage the scarce resources that are available, and take advantage of new funding opportunities under the Patient Protection and Affordable Care Act of 2010 (ACA), the National HIV/AIDS Strategy, and other federal legislation. In addition, we identify strategies to continue to combat HIV-related stigma.

Louisianans living with HIV/AIDS and the providers who work with them are practical and creative. They have an impressive ability to make the most out of limited resources, which bodes well for enhancing healthcare and treatment access in the future. The strong collaborative spirit and tireless commitment of the AIDS services provider community—as well as the community of consumer advocates—are key assets in any effort to improve access to care and services in Louisiana.

appendix 2:

Louisiana Revised Statutes 15:574.4.2(G)

 **Decisions of Board of Parole; Infectious Disease Testing**

- (1) Before placing a person on parole, the Board of Parole shall require that person to submit to a test designed to determine whether he is infected with a sexually transmitted disease, acquired immune deficiency syndrome (AIDS), the human immunodeficiency virus (HIV), HIV-1 antibodies, or any other probable causative agent of AIDS and viral hepatitis.
- (2) The procedure or test shall be performed by a qualified physician or other qualified person who shall notify the parolee of the test results.
- (3) If the person tested under the provisions of this Subsection tests positive for a sexually transmitted disease, AIDS, HIV, HIV-1 antibodies, or any other probable causative agent of AIDS and viral hepatitis, he shall be referred to the appropriate healthcare and support services. If the person tested positive, the granting of the parole shall be conditioned upon the person seeking advice and counseling from the appropriate health care and support services. Failure to seek or follow that advice shall result in the revocation of that person's parole.
- (4) The costs associated with this testing shall be paid by the person tested.

appendix 3

Studies Regarding the Cost-effectiveness of Early HIV Treatment

Unmet need and cost of HIV/AIDS care:

Kates J, Levi J. Insurance coverage and access to HIV testing and treatment: considerations for individuals at risk for infection and those with undiagnosed infection. *Clin Infect Dis*. 2007;45(Suppl. 4):S255-S260.

The CDC estimates that there are 1.2 million people with HIV/AIDS in the United States, about 500,000 of whom are not in care and 250,000 do not know their HIV status. The CDC data also indicate that approximately 4 in 10 individuals develop AIDS less than 12 months after an HIV diagnosis. This paper cites a 2003 study that found that of persons who are eligible for antiretroviral therapy, 30% are not receiving medical care.

Schackman BR, Gebo KA, Walensky RP, et al. The lifetime cost of current human immunodeficiency virus care in the United States. *Med Care*. 2006;44(11):990-997.

From the time of entering into HIV care, the projected life expectancy is 24.2 years and the discounted lifetime cost per person is \$385,000 for adults initiating antiretroviral therapy at a CD4 count of less than 350. Antiretroviral drug costs account for 73% of the costs; inpatient costs make up 13%; outpatient costs make up 9%; and other HIV-related medication and laboratory costs make up 6%. The average monthly cost is \$2,000 when patients have a CD4 count of greater than 300 (77% for antiretroviral drugs and 10% for inpatient care). By contrast, those with a CD4 count of less than or equal to 50 have an average monthly cost of \$4,700 (38% for antiretroviral drugs and 49% for inpatient care).

Roberts R, Kampe LM, Hammerman M, et al. The cost of care for patients with HIV from the provider economic perspective. *AIDS Patient Care STDS*. 2006;20(12):876-886.

Researchers analyzed the cost of care for a sample of 280 patients treated at a large urban healthcare facility in the United States over the course of one year. Data indicated an annual average cost of care of approximately \$20,000 per patient. Cost of care varied significantly by CD4 count, with those having CD4 counts between 1 and 50 incurring an average annual cost of care of \$30,000 and those with CD4 counts above 500 incurring an annual cost of care of approximately \$13,000. The greatest variability in cost was the result of inpatient hospitalization rather than outpatient visits or medications.

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Studies Regarding the Cost-effectiveness of Early HIV Treatment

Hutchinson AB, Farnham PG, Dean HD, et al. The economic burden of HIV in the United States in the era of highly active antiretroviral therapy: evidence of continuing racial and ethnic differences. *J Acquir Immune Defic Syndr*. 2006;43(4):451-457.

This study analyzed the lifetime cost of HIV/AIDS resulting from new infections diagnosed in 2002, analyzing both direct medical costs as well as mortality-related productivity losses. The authors found that for the estimated 40,000 new infections that occurred in 2002, the discounted total lifetime cost of illness was \$36.4 billion. This includes \$29.7 billion in mortality-related productivity losses and \$6.7 billion in lifetime direct medical costs. For all persons treated with antiretroviral therapy, medical costs increased by approximately \$1.2 billion; however, productivity losses decreased by \$3 billion. Authors also examined the impact of more effective antiretroviral therapy regimens by increasing life expectancy for persons receiving these regimens. During this scenario, the per person lifetime direct medical costs increased, but decreases in productivity losses more than offset this medical cost increase.

Cost-effectiveness of early intervention as way to avoid more expensive late intervention:

Johnston KM, Levy AR, Lima VD, et al. Expanding Access to HAART: A Cost-effective Approach for Treating and Preventing HIV. *AIDS*. 2010;24(12):1929-1935.

Researchers measured the economic net benefit associated with an intervention to expand HAART treatment in British Columbia, Canada. The study analyzed the relationship of direct medical costs of medications, hospitalizations, physician visits, and laboratory tests to an increase in the proportion of HIV-infected individuals with CD4 counts below 350 receiving HAART from 50% to 75%. Researchers found that increased treatment reduced the incidence of new infections, and despite the up-front costs of increasing HAART use, the expansion was cost-effective within four years.

Chen RY, Accortt NA, Westfall AO, et al. Distribution of health care expenditures for HIV-infected patients. *Clin Infect Dis*. 2006;42:(7):1003-1010.

Researchers analyzed the cost of medical care for patients receiving primary care at the University of Alabama at Birmingham HIV clinic over the course of one year (2000-2001). The study specifically looked at the correlation between CD4 counts and health care expenditures, and found that total annual expenditures for patients with CD4 counts below 50 were 2.6 times greater than total annual expenditures for patients with CD4 counts greater than or equal to 350. The low CD4 group had hospitalization expenditures that were nearly six times greater than the higher CD4 group as well as nonantiretroviral medication expenditures that were nearly eight-fold greater.

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Studies Regarding the Cost-effectiveness of Early HIV Treatment

Krentz HB, Auld MC, Gill MJ. The high cost of medical care for patients who present late (CD4 <200 cells/ μ L) with HIV infection. *HIV Med.* 2004;5(2):93-98.

This study compared the direct costs of medical care in the year following HIV diagnosis for patients presenting with a CD4 count of less than 200 (late presenters) and those who presented with a CD4 count of over 200 (early presenters) in Alberta, Canada. Researchers found that costs for late presenters were significantly higher, with the largest difference in total costs between the two groups attributable to HIV-related inpatient hospitalization. Inpatient hospitalization costs for late presenters were 15 times greater than for early presenters. The cost of antiretroviral drugs for late presenters was over double the cost reported for early presenters.

Hornberger J, Holodniy M, Robertus K, Winnike M, Gibson E, Verhulst E. A systematic review of cost-utility analyses in HIV/AIDS: implications for public policy. *Med Decis Making.* 2007;27(6):789-821.

This paper includes a systematic review of 106 US-based cost-effectiveness studies of HIV/AIDS prevention and management interventions. Specifically, the review looked at the extent these analyses found that prevention and management interventions resulted in cost savings per quality-adjusted life year (a measure that combines length and quality of life). The vast majority of studies compiled in this review found that the approaches analyzed to prevent and manage HIV/AIDS in the US were economically efficient.

Walensky RP, Freedberg KA, Weinstein MC, Paltiel AD. Cost-effectiveness of HIV testing and treatment in the United States. *Clin Infect Dis.* 2007; 45(Suppl. 4): S248-S254.

Researchers reviewed a number of cost-effectiveness studies conducted in the United States and concluded that routine, voluntary HIV testing is a cost-effective intervention, but only when followed by appropriate linkage to care.

Freedberg KA, Hirschhorn LR, Schackman BR, et al. Cost-effectiveness of an intervention to improve adherence to antiretroviral therapy in HIV-infected patients. *J Acquir Immune Defic Syndr.* 2006;43(Suppl. 1):S113-S118.

The objective of this study was to assess cost-effectiveness of a particular nursing intervention designed to improve adherence to antiretroviral therapy. The study found the intervention greatly reduced long-term care costs, largely because the intervention increased treatment adherence to first-line HIV medications, which are more effective and less expensive than second-line regimens.

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Rodgers J, Yip R. PricewaterhouseCoopers. 2003. An analysis of the Early Treatment of HIV Act: Prepared for the Treatment Access Expansion Project.

TAEP retained PricewaterhouseCoopers to assess the effects of early intervention healthcare under the Early Treatment for HIV Act (ETHA), which would have allowed states to expand Medicaid coverage to predisabled people living with HIV. The study found that over 10 years, ETHA reduces the death rate for people living with HIV on Medicaid by 50% and saves the federal government \$31.7 million.

Paul S, Gilbert HM, Lande L, et al. Impact of antiretroviral therapy on decreasing hospitalization rates of HIV-infected patients in 2001. *AIDS Res Hum Retroviruses*. 2002;18(7):501-506.

To determine the effects of advances in antiretroviral therapy on hospital admissions, researchers analyzed clinical information of all patients admitted to New York Presbyterian Hospital-Cornell over four 6-month periods in 1995, 1997, 1999, and 2001. The study found that since the introduction of HAART, there has been a persistent decrease in hospital admission rates. The estimated cost savings in hospitalization due to this decrease was estimated to be \$7,900 per patient per year. Importantly, the study found that these savings alone per patient approached the annual cost of antiretroviral medications per patient.

Schackman BR, Goldie SJ, Weinstein MC, Losina E, Zhang H, Freedberg KA. Cost-effectiveness of earlier initiation of antiretroviral therapy for uninsured HIV-infected adults. *Am J Public Health*. 2001;91(9):1456-1463.

Initiating antiretroviral therapy earlier (at CD4 counts of 500 as opposed to 200) resulted in 51 fewer deaths per 1,000 patients and 72 fewer opportunistic infections per 1,000 patients after 5 years. The study also looked at the financial costs of early antiretroviral therapy paid by federal and state payers. Over the first 5 years, the total costs were \$11,500 higher for early therapy. However, this increase was cost-effective because much of the higher drug costs of initiating treatment earlier were offset by savings from averted HIV-related morbidity.

Gebo KA, Chaisson RE, Folkemer JG, Bartlett JG, Moore RD. Costs of HIV medical care in the era of highly active antiretroviral therapy. *AIDS*. 1999;13(8):963-969.

The study found a significant decrease in inpatient hospital costs associated with treating opportunistic infections and community care costs for patients receiving protease inhibitor-containing regimen compared to those not receiving protease inhibitors. Even with the concurrent increase in medication costs, total healthcare costs remained stable or even lower for patients with access to protease inhibitors.

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Studies Regarding the Cost-effectiveness of Early HIV Treatment

Cost-effectiveness of early intervention as prevention:

Farnham PG, Holtgrave DR, Sansom SL, Hall HI. Medical Costs Averted by HIV prevention efforts in the United States, 1991-2006. *J Acquir Immune Defic Syndr.* 2010;54(5):565-567.

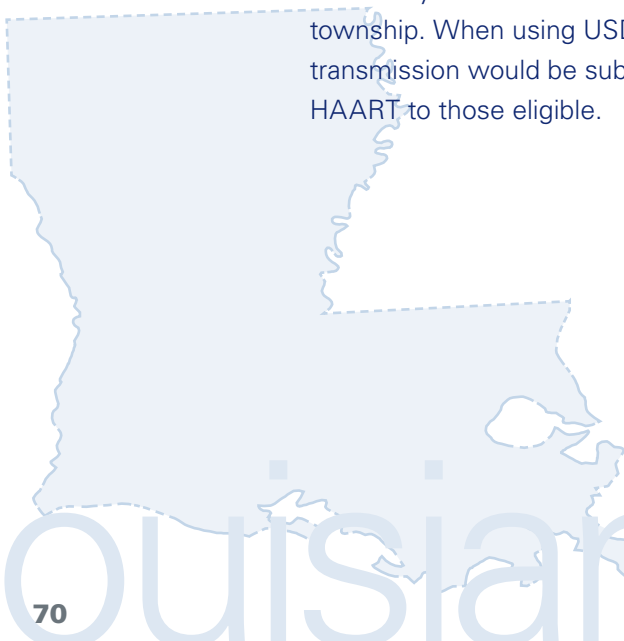
This study analyzed data from several large-scale national surveys to determine the medical costs averted by HIV prevention efforts in the United States from 1991-2006. The authors compared the difference between the number of infections that have occurred with the number of infections that might have occurred in the absence of HIV prevention programs and then analyzed the amount of lifetime treatment costs averted. The study concluded that for the relevant time period, a total of \$129.9 billion in HIV costs was averted.

Porco TC, Martin JN, Page-Shafer KA, et al. Decline in HIV infectivity following the introduction of highly active antiretroviral treatment. *AIDS.* 2004;18(1):81-88.

The study ultimately rejected the hypothesis that infectivity—the probability that an uninfected person will acquire HIV in a partnership with an infected person—was the same in the pre-HAART and post-HAART eras. To the contrary, this study found a 60% decline in infectivity of HIV that coincided with the introduction of HAART. This study supports the effectiveness of early access to HIV treatment as a valuable component of HIV prevention.

Auvert B, Males S, Puren A, Taljaard D, Caraël M, Williams B. Can highly active antiretroviral therapy reduce the spread of HIV? A study in a township of South Africa. *J Acquir Immune Defic Syndr.* 2004;36(1):613-621.

This study looked at the impact of HAART on the spread of HIV in a South African township. When using USDHHS guidelines, the authors found that annual risk of HIV transmission would be substantially reduced by more than two-thirds by administering HAART to those eligible.



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 Fang CT, Hsu HM, Twu SJ, et al. Decreased HIV transmission after a policy of providing free access to highly active antiretroviral therapy in Taiwan. *J Infect Dis.* 2004;190(5):879-885

This study found that since the Taiwan government implemented a policy of providing all HIV-infected citizens with free access to HAART therapy, the rate of new HIV infections has decreased by 53%. The study confirms that early access to treatment is a productive means of reducing HIV transmission.

Velasco-Hernandez JX, Gershengorn HB, Blower SM. Could widespread use of combination antiretroviral therapy eradicate HIV epidemics? *Lancet Infect Dis.* 2002;2(8):487-493.

This study analyzed the impact of antiretroviral therapy on HIV transmission rates in the San Francisco gay community. The authors found that increasing the percentage of individuals receiving antiretroviral therapy would substantially reduce the severity of the HIV epidemic by reducing the rate of transmission. Though antiretroviral therapy coupled with reduction in risky sexual behaviors was found to have an even greater impact on transmission rates, antiretroviral therapy alone had a significant impact on reducing transmission rates.

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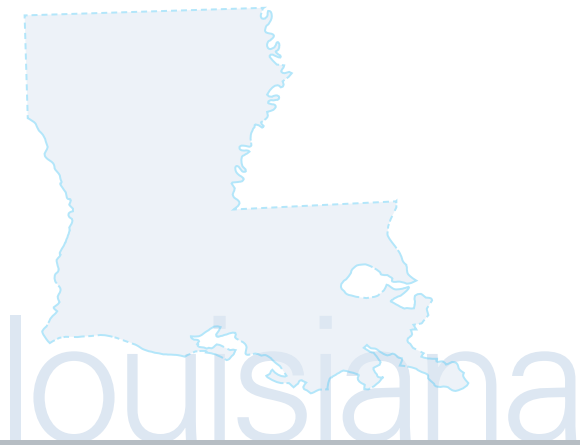
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State Healthcare Access Research Project

About SHARP – A national project of the Health Law and Policy Clinic of Harvard Law School and the Treatment Access Expansion Project, the State Healthcare Access Research Project (SHARP) develops state-level research reports by conducting a series of focus groups and one-on-one interviews with people living with HIV/AIDS, community-based AIDS services providers, healthcare providers, faith leaders, state and federal government officials, and other researchers and advocates. The insights gained from these meetings are supplemented with independent research. SHARP is designed to examine states’ capacities to meet the healthcare needs of people living with HIV/AIDS and has three main goals: (1) improve access to healthcare, treatment, and services; (2) support coalition development and self-sustained, grassroots advocacy capacity; and (3) share information and effective strategies within and among states. This project is conducted in collaboration with and funded by Bristol-Myers Squibb’s WithInSight Initiative. The content of this summary does not necessarily reflect the views or opinions of BMS. **Visit SHARP online at www.taepusa.org or www.withinsightinitiative.org.**



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An Analysis of the Successes, Challenges, and Opportunities for Improving Healthcare Access