

State Healthcare Access Research Project (SHARP)

*An Analysis of the Successes, Challenges, and Opportunities
for Improving Healthcare Access in Northern Florida*

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Foreword

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Acronyms

ACA	Patient Protection and Affordable Care Act of 2010
ADAP	AIDS Drug Assistance Program
AHCA	Agency for Health Care Administration
AICP	AIDS Insurance Continuation Program
ASO	AIDS Services Organization
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
CMS	Centers for Medicare and Medicaid Services
DOH	Florida Department of Health
EMA	Eligible Metropolitan Area
EPT	Expedited Partner Therapy
FHAAN	Florida HIV/AIDS Advocacy Network
FQHC	Federally Qualified Health Center
HAB	HIV/AIDS Bureau
HCBS	Home and Community Based Services
HHS	US Department of Health and Human Services
HOPWA	Housing Opportunities for Persons with AIDS
HPSA	Health Professional Shortage Area
HRSA	US Health Resources and Services Administration
HUD	US Department of Housing and Urban Development
IDU	Injection Drug Use
LIS	Medicare Part D Low Income Subsidy
MSM	Men who have Sex with Men
MUA	Medically Underserved Area
MUP	Medically Underserved Population
PAC	Project AIDS Care
PAP	Patient Assistance Program
PCIP	Pre-existing Condition Insurance Plan

PREP	Personal Responsibility Education Program
SAMHSA	Substance Abuse and Mental Health Services Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
TGA	Transitional Grant Area

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Part I. Introduction

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Part II. State Profile

Overview of the HIV/AIDS Epidemic in Florida

Florida is the fourth most populous state in the United States and has the third most cumulative reported cases of AIDS, behind California and New York.¹ As of March 31st 2011, 98,897 people were presumed living with HIV/AIDS in Florida.²

Florida has the highest number of new HIV diagnoses and the 2nd highest number of new AIDS diagnoses in the country. Jacksonville has the 3rd highest AIDS incidence rate in the country.

According to data from the Centers for Disease Control and Prevention, there were an estimated 6,120 new cases of HIV diagnosed in Florida in 2009, representing a rate of 33.0 per 100,000 population—the highest in the nation.³ In the same year there were an estimated 4,392 new AIDS diagnoses, representing a rate of 23.7 per 100,000 population—3rd highest in the nation.⁴ Miami (including Miami, Fort Lauderdale, and West Palm Beach), Jacksonville, Orlando, and Tampa have AIDS diagnosis rates among the top 20 metropolitan areas (MSAs) in the United States in 2009.⁵ At 37.2 per 100,000 population, Miami's rate of AIDS diagnosis in 2009 was the highest in the nation among MSAs. And northern Florida's largest

urban center, Jacksonville, had the third highest AIDS diagnosis rate (29.1 per 100,000 population) of MSAs in 2009.⁶

CDC data show that approximately 4.2% of new AIDS cases in Florida in 2006 were reported in rural areas.⁷ This is a lower percentage than the nation as a whole (7.2%) and the South as a region (10.3%), and is likely reflective of the magnitude of the epidemic in Florida's urban centers rather than particularly low case rates in rural areas.⁸ Broward, Miami-Dade, and Palm Beach Counties in South Florida accounted for nearly half (46.4%) of the 3,461 new AIDS cases reported in the state in 2010.⁹ Nonetheless, HIV/AIDS is a statewide concern, with some of the highest AIDS case rates (cases per 100,000 population) in 2010 occurring in Union (29.7), Gadsden (29.3), Baker (28.2) and Duval (28.2) Counties, all of which are located in North Florida.¹⁰

Demographics

The incidence and prevalence of HIV/AIDS in Florida are not evenly distributed among different racial, ethnic, or gender groups. As in much of the rest of the country, communities of color are disproportionately affected by HIV/AIDS.

Of the cumulative reported cases of HIV/AIDS through March 31st, 2011 non-Hispanic blacks account for 48.69% of adult cases and 76.33% of pediatric cases, even this group represents only 16% of the state's overall population.¹¹ Hispanics, representing 22% of Florida's population, account for 19.7% of adult cases and 12.3% of pediatric cases.¹² Whites, representing 57.9% of the overall population in Florida, account for 29.9% of adult cases and 8.8%, of pediatric cases.¹³ Among new HIV cases, 47% of individuals diagnosed were black, 22% were Hispanic, and 29% were white.¹⁴

As is the case throughout the United States, men account for a large proportion of the HIV/AIDS cases in Florida. Of Floridians with living with HIV/AIDS, 69.9% are male and 30.1% are female.¹⁵ In the most recent data for newly reported HIV diagnoses in the state in 2010, men accounted for 75% of adult diagnoses.¹⁶

Of all people in Florida living with HIV/AIDS, the greatest proportion are between the ages of 40-49 (35.7%), followed by 50-59 (26.0%).¹⁷

Modes of transmission

For all Floridians diagnosed with HIV in 2010, male-to-male sexual contact was the most frequently-reported mode of exposure (47%). Heterosexual contact was reported as the mode of exposure in 27% of new HIV diagnoses, and 3% were attributed to injection drug use (IDU).¹⁸

State Demographics, Economic Indicators, Education, and Health

Demographics

According to the United States Census Bureau, Florida is the fourth most populous state with an estimated population of 18,801,310 in 2010.¹⁹ Of Florida's total population, approximately 25.4% (4,779,445 people) is located in northern Florida,²⁰ a predominantly rural area.²¹

For the state as a whole, 57.9% of the population identified as non-Hispanic white, 22.5% as of Hispanic or Latino origin, 16.0% as black, 2.4% as Asian, and 0.5% as American Indian or Alaskan Native.²² In North Florida, 71.9% of the population identified as non-Hispanic white, 16.6% as black, 6.0% as of Hispanic or Latino origin, 1.2% as Asian, and 0.5% as American Indian or Alaskan Native.²³ Florida's population of noncitizens, 9%, is higher than the national average of 7%.²⁴ Indeed, the Census Bureau estimates that about a third of the increase in Florida's population between 2000 and 2010 was due to international migration.²⁵

The median age of Florida's populace is 40.7 years,²⁶ and 41.3 years in North Florida²⁷—significantly higher than the national average of 37.2. years²⁸ Recently, both Florida's elderly population and youth population have been growing rapidly, with a corresponding decline in the working age population.²⁹

Economic indicators

In 2009, Florida's per capita income was \$37,780, ranking 24th in the nation.³⁰ That total was slightly slower than the national average of \$39,138.³¹ Similarly, the state's median household income of \$44,755 was below the national average of \$50,221.³² Given these figures, it is unsurprising that Florida has a higher percentage of people living in poverty than the nation as a whole (16.0% versus 15.2%).³³ The state's average weekly wage of \$871 is significantly below the national average of \$971.³⁴ Florida has the 24th lowest cost of living in the country, but has higher than average grocery and transportation expenses.³⁵

As in most other states, there is a disparity in the economic well-being between those living in the urban and rural areas of Florida. The estimated poverty rate in rural areas of the state is 19.4%, compared to 14.7% in urban areas.³⁶ Nationally, the poverty rate in rural areas was 16.5%, compared to 14.9% in urban areas, indicating that the rural-urban divide is greater in Florida than other parts of the country.³⁷

Over half of the counties in northern Florida have poverty rates greater than 20% and the average working wage in the region is \$200 less than the state average.

The major job sectors in northern Florida are healthcare and social assistance, retail and trade, accommodation and food services, public administration, and education services.³⁸ There are also large agricultural, construction, and manufacturing sectors.³⁹ According to the most recent data, the unemployment rate in North Florida was 10.0%,⁴⁰ which is slightly higher than the national average of 9.1%, but lower than the 10.7% rate statewide.⁴¹ In 2009, over half of the counties in North Florida had poverty rates greater than 20%.⁴² The average working weekly wage in northern Florida is \$685,⁴³ compared to \$871 statewide.⁴⁴ The rural-urban contrast is equally stark when looking through the lens of per capita income, with urban Floridians having incomes over \$10,000 higher than their rural counterparts.⁴⁵ In the near future, this discrepancy may narrow due to the disproportionate impact of the housing crisis and high unemployment on urban areas.⁴⁶

Revenues (taxation) and expenditures

The state legislature passed a \$70.5 billion budget for FY2011, an increase of \$4 billion over FY2010, with \$24.05 billion from General Revenue, \$27.1 billion from federal funds, and \$19.4 billion from state trust funds.⁴⁷

Generally, Florida has lower tax rates than the national average. In 2009, Floridians paid 9.2% of their income in the form of state and local taxes, compared to 9.8% paid by Americans on average.⁴⁸ Corporations are assessed a 5.5% tax on income, while individuals do not pay any state income tax.⁴⁹ Each sale, admission charge, storage, or rental is subject to a general sales tax of 6%.⁵⁰ In addition to the state sales tax, most counties impose a discretionary sales surtax.⁵¹ Certain items, such as food and drink for human consumption, farm equipment, and certain prescription medications are exempt from Florida sales tax.⁵²

Property taxes are assessed by local governments and vary by county.⁵³ All property tax revenue is reserved for local governments by the Florida Constitution and the state government receives no revenue from the assessment of property taxes.⁵⁴

Education

The state of Florida is at par with the national average for educational attainment. The US Census Bureau estimates that 84.9% of Floridians ages 25 and over are high school graduates, compared to 84.6% of the national population.⁵⁵ Similarly, 25.6% of Floridians age 25 and over have bachelor's degrees compared to 27.5% of the U.S. population.⁵⁶ Within the state, there are geographic and racial

disparities in educational attainment. In 2009-2010, 85.4% of white students enrolled in high school graduated, while the numbers for blacks and Hispanics were 68.4% and 75.3%, respectively.⁵⁷ Students in rural areas are slightly less likely to graduate from high school. In northern Florida, the four-year high school graduation rate is only 77%.⁵⁸ Since much of northern Florida is characterized as rural, the shortfall in educational attainment is an important local factor. Despite educational shortcomings at the secondary school level in the region, three of the largest institutions of higher education in the state (University of Florida, Florida State University, and Florida State College at Jacksonville) are all located in northern Florida.

State healthcare capacity, facilities and infrastructure

The healthcare industry contributed 648,180 jobs to Florida's economy in 2010, accounting for 9.1% of total employment.⁵⁹ There are 31,610 physicians in the state⁶⁰ and 25.8 active physicians per 10,000 people, which is lower than the national average of 27.7.⁶¹ There were 158,390 registered nurses,⁶² (842 per 100,000 people)⁶³ and 12,237 nurse practitioners⁶⁴ (65 per 100,000 population).⁶⁵ Florida law requires that nurse practitioners must have physician supervision for diagnosing and treating patients and for prescribing.⁶⁶

Approximately 2.8 million Floridians live in primary care health professional shortage areas (HPSAs).⁶⁷ A primary care HPSA is an area where there is less than one primary care physician per 2,000 people and where primary medical professionals in contiguous areas are overutilized, excessively distant, or inaccessible.⁶⁸ This number amounts to 15.3% of the state's population, well above the 11.8% of the national population that lives in HPSAs.⁶⁹ Approximately 9% of the population lives in mental health HPSAs.⁷⁰ Access to dentists is also limited, with 15.8% of the Florida population living in dental HPSAs.⁷¹

Florida has 143 rural health clinics (RHCs)^{72,73} and 40 federally qualified health centers (FQHCs).^{74,75} These FQHC delivered care to 997,110 underserved patients in 2009.⁷⁶ There are 210 hospitals in the state, 25 of which are run by the state or local government, 82 are non-profit, and 103 are for-profit.⁷⁷

Rates of insured/uninsured individuals

In 2010 there were 3,854,000 uninsured people in Florida.⁷⁸ Florida's 20.8% uninsurance rate is significantly higher than the national average of 16.3%.⁷⁹ Thirty percent of the state's population relied on public sources for insurance, which is in line with the national average of 29%.⁸⁰ Among private employers in the state, 46.2% offered health insurance to their employees, which is well below the national average of 53.8%.⁸¹

The poor are disproportionately represented among the uninsured. In 2008-2009, 54% of Floridians living below 139% of the FPL were uninsured.⁸² Thirty-seven percent of those between 139-250% of FPL were uninsured.⁸³ For adults at or above 400% of FPL, only 9% were uninsured.⁸⁴

People identifying as non-Hispanic blacks make up 16.1% of the state's population, but account for approximately 19% of uninsured.⁸⁵ Hispanics bear an even more disproportionate burden, accounting for 22.5% of the population, but 32% of the state's uninsured.⁸⁶ Together, the two primary minority groups in the state account for approximately 38% of the state's population, but account for over 51% of the state's uninsured.⁸⁷

Florida has the highest rate of uninsured children in the country.

In 2009, only 82% of children ages 18 and under were insured, leaving 18% (756,700) uninsured.⁸⁸ In this respect Florida shares with the state of Texas the dubious distinction of having the lowest insured rate for children in the country.⁸⁹ Across the country, an average of 90% of children are insured.⁹⁰ Some counties in Florida opt to use local funds to provide coverage to children regardless of their immigration status.⁹¹ In addition, children who do not meet the Medicaid or CHIP immigration status criteria can buy coverage at full cost under the Healthy Kids and MediKids programs.

Reproductive health

Nearly half of all pregnancies (46.0%) in Florida are unintended.⁹² In Duval County, where Jacksonville is located, that rate is 56.1%.⁹³

In North Florida, the average teen birth rate is 51.5 live births per 1,000 females aged 15-19.⁹⁴ This rate is significantly higher than the Florida Department of Health's Long-Term Program Plan goal of 37.0 live births per 1,000 females aged 15-19.⁹⁵ The teen birth rate exhibits significant racial disparities: the rate for white teens was 25.9, while the rate for black teens was 34.5.⁹⁶ Data was not reported for teens of other races.

At 7.9 per 1,000 live births,⁹⁷ northern Florida's infant mortality rate is higher than the national rate of 6.8.⁹⁸ There are significant racial disparities in infant mortality as well. The rate of nonwhite infant deaths (14.8 per 1,000 nonwhite live births) is more than double the rate of white infant deaths (6.1 per 1,000 white live births).⁹⁹ Nonwhites were nearly twice as likely to give birth to babies of low birth weight as whites (12.7% compared to 7.2%).¹⁰⁰

Nearly one million women in Florida need publicly supported contraceptive services because their income is below 250% of the federal poverty level (FPL) or because they are sexually active teens.¹⁰¹ Within the state, over 320 publicly funded family planning centers provide contraceptive care to approximately 345,500 women.¹⁰² Of these clients, 27.6% were teenagers.¹⁰³ Sixty-eight percent of women in need of publicly supported contraceptive care either do not receive it or must find private means.¹⁰⁴ Nearly 32% of mothers in Florida lacked any kind of health insurance (private or Medicaid) at the time of pregnancy.¹⁰⁵ The need for reproductive health services likely contributes to the state's relatively poor performance on indicators on measures such as infant mortality, teen birth rates, and birth rates.

Minors in Florida are permitted to consent to sexually transmitted infection (STI) services; however, a parent must be notified before an abortion can be performed.¹⁰⁶ Medical professionals and medical institutions may refuse to provide abortion services for medical or religious reasons.¹⁰⁷ In one recent

study, 72% of Florida counties had no abortion provider and 25% of Florida women lived in these counties.¹⁰⁸

Among Florida public high school students, 50.6% report having ever had sexual intercourse.¹⁰⁹ Of the high school students who had sex within the past 3 months, 65.1% of these students used a condom the last time they had sexual intercourse,¹¹⁰ but 82.2% of teens did not use birth control pills or Depo-Provera before the last time they had sexual intercourse.¹¹¹ Failure to use birth control seems widespread among Floridians; fifty-nine percent of new moms who did not intend to get pregnant failed to use contraception.¹¹²

Nutritional assistance

An estimated 2.6 million Florida residents participated in the Supplemental Nutrition Assistance Program (SNAP) (food stamps) in 2010, the third highest total in the nation.¹¹³ The state has seen participation more than double since 2007.¹¹⁴ Several counties in North Florida have seen increases in enrollment of greater than 70% since 2007, with the region's largest city, Jacksonville, experiencing a 60% increase in the last three years.¹¹⁵

In 2010, the average monthly SNAP benefit per person in Florida was \$141.40, which is higher than the national average of \$133.79,¹¹⁶ and the eighth highest of any state.¹¹⁷ Spending on food stamps in Florida totaled \$4.42 billion, representing 6.8% of the \$64.7 billion spent nationally.¹¹⁸

Incarceration

Florida's incarceration rate is well above the national average: in 2009, there were 559 incarcerated people per 100,000 residents in the state compared to a national rate of 502 per 100,000 residents.¹¹⁹ There are 108 jail facilities in Florida, with a combined capacity of 60,589.¹²⁰ The state's prison system consists of 121 facilities that house 89,766 inmates.¹²¹ Federal prisons in Florida house 13,811 inmates.¹²² Additionally, the Office of Community Corrections within the Florida Department of Corrections (DOC) oversees 279,760 probationers and 4,528 parolees.¹²³

In FY 2009-2010, the state spent approximately \$415 million on health services for inmates in state facilities.¹²⁴ That amount represents approximately 18% of the DOC budget.¹²⁵ More than 2,300 health services staff members that provide health care to inmates at state institutions.¹²⁶ It is estimated that HIV/AIDS rates in correctional facilities are three to five times higher than in the general population.¹²⁷ In 2006, approximately 66,780 inmates were tested for HIV in DOC facilities and 1,185, or 1.77%, tested positive.¹²⁸ Overall, there are an estimated 4,464 people living with HIV/AIDS in DOC custody or otherwise institutionalized.¹²⁹

Pre-release care

The DOC has implemented a pre-release program to counsel HIV positive inmates about post-release disease management. Approximately 100 HIV-positive inmates leave Florida's prisons each month.¹³⁰ The Department's Pre-Release Planning Program (PRPP) provides planning services to infected inmates during the six months prior to their return to their communities.¹³¹ There are five pre-release planners

who are responsible for providing pre-release planning to all of the state's HIV positive inmates.¹³² In addition to educating inmates generally about the disease, the planners help connect inmates with social service agencies and medical care providers in their communities post-release. Inmates are also given a 30-day supply of medicine upon release.¹³³ The PRPP has been moderately successful, with nearly 72% of inmates receiving PRPP services keeping their post-release medical or social service appointments.¹³⁴

Overview of Programs and Services for People Living with HIV/AIDS

National HIV/AIDS Strategy (NHAS)

In July 2010, the Obama Administration released the National HIV/AIDS Strategy, the first-ever comprehensive coordinated HIV/AIDS roadmap, which outlined goals and targets for the nation's HIV/AIDS policy. The overarching goals of the HIV/AIDS Strategy are threefold: to reduce new HIV infections; to increase access to care and improve health outcomes for people living with HIV; and to reduce HIV-related health disparities.¹³⁵ To facilitate the achievement of these goals, the Administration also released an implementation plan, which outlined short-term actions to be taken by federal agencies to execute the NHAS's recommendations.¹³⁶ The strategy acknowledged the critical importance of collaboration between the federal government and state, local, and tribal governments, as well as the role of non-profits and the private sector. A year after the release of the NHAS, many federal agencies have created new initiatives and have focused resources on issues affecting people living with HIV/AIDS,¹³⁷ but it is too soon to tell if the Strategy's goals will be met by its 2015 timeline.

Florida Bureau of HIV/AIDS

In Florida, the Bureau of HIV/AIDS within the Department of Health is the primary state agency responsible for developing and coordinating HIV/AIDS programs and policy initiatives. The Bureau focuses much of its effort on community initiatives. For example, the Department of Health funds 14 Ryan White Part B HIV Care Consortia.¹³⁸ Each consortium acts in an advisory capacity to the Bureau for planning and prioritizing the service needs of individuals with HIV. Five of the 14 consortia are devoted wholly or in part to counties in northern Florida.¹³⁹

Ryan White programs

The Ryan White Program is the country's largest federally funded program for people living with HIV/AIDS. Part A provides funds for eligible metropolitan areas (EMAs) and transitional grant areas (TGAs), including Fort Lauderdale, Jacksonville, Miami, Orlando, and Tampa-St. Petersburg. In 2010, these areas received \$74, 571,821 in Part A funding.¹⁴⁰ The state as a whole received \$118,435,571 for Part B programs, such as HIV testing, education and prevention, home and community-based care, medications, assessment, and direct health support services.¹⁴¹ It also received \$4,421,554 through Part C for early intervention outpatient care.¹⁴² Of the total Ryan White award for the state of Florida in 2010, \$5,873,586 was specifically targeted to the North Florida region.

AIDS Drug Assistance Program (ADAP)

Florida's ADAP is administered by the HIV/AIDS Bureau (HAB) within the Florida Department of Health.¹⁴³ In order to participate in Florida's ADAP, applicants must: be a Florida resident; have a laboratory test documenting confirmed HIV infection; not be receiving services or be eligible to participate in local, state, or federal programs that provide similar services;¹⁴⁴ have an income at or below 400% of the Federal Poverty Level (FPL);^{145, 146} submit a completed application; and cooperate with staff during the eligibility process.¹⁴⁷

In 2010, Florida received about \$92 million in federal Ryan White funding for ADAP.¹⁴⁸ In 2009, the Florida legislature cut state ADAP funding by \$1 million to \$10.5 million. No additional funding was appropriated in 2010.¹⁴⁹ Since then, a host of cost-containment measures have been instituted in the program due to the fiscal pressures of reduced funding and increased client enrollment.

In June 2010, HAB instituted a waiting list for enrollment in the ADAP.¹⁵⁰ As of September 16, 2011, 4,175 people were on the ADAP waiting list.¹⁵¹ This is an increase of 1,585 individuals since December 31, 2010¹⁵² and accounts for slightly under half of the individuals on ADAP waiting lists nationally.¹⁵³ The waiting list applies to all new applicants and clients whose cases were closed as of June 2010. Pregnant women, children, and adolescents are exempt from the waiting list and are immediately enrolled in ADAP. The HIV/AIDS Bureau expects to move approximately 1,500 individuals off the wait list and in to ADAP by early October, 2011 subsequent to the disbursement of federal funding for the program.¹⁵⁴

ADAP in Crisis:

4,175 people were on Florida's ADAP waiting list in September 2011, accounting for nearly half of all individuals on waiting lists across the country.

Other cost-containment-based ADAP policies in 2010 required all new applicants (not re-enrollments) to have a prescription for an antiretroviral medication covered by the ADAP formulary;¹⁵⁵ required Medicare Part D enrollees to enter the donut hole prior to enrolling in ADAP;¹⁵⁶ and suspended new enrollments in the hepatitis C program.¹⁵⁷ Additionally, the state dramatically reduced the ADAP formulary. Florida's ADAP formulary currently covers only antiretroviral and opportunistic infection medication.¹⁵⁸ But prior to August 1, 2010 the formulary also covered medications for co-occurring conditions such as schizophrenia, diabetes, Hepatitis B, high cholesterol, depression, and influenza.¹⁵⁹ Patients are now referred to patient assistance programs (PAPs) to obtain these medications.¹⁶⁰

In January 2011, ADAP administrators announced that the program faced an extreme budget shortfall, rendering it unable to provide any medication from the beginning of February until the new round of federal Ryan White funding became available in April.¹⁶¹ Welvista, a large mail-order pharmacy that distributes donated pharmaceuticals, stepped in to provide medications to two-thirds of Florida's ADAP clients until new federal Ryan White funding became available in April 2011.¹⁶²

AIDS Insurance Continuation Program (AICP)

The AIDS Insurance Continuation Program is a statewide program for individuals who, because of their HIV/AIDS status, are unable to maintain private health insurance coverage. The program makes direct payments (up to \$750/month) to each client's employer or insurance company for the continuation of medical, dental, mental health and optical coverage. The AICP does not pay for disability or life insurance. The program also pays co-payments and deductibles depending on the availability of funds. Individuals can apply for the program through local county health departments or through certain community-based organizations.¹⁶³ In July 2009, the program was forced to institute a waiting list.¹⁶⁴ As of August 31st, 2011, there were 332 people on the waiting list, including 21 residents of northern Florida.¹⁶⁵

Centers for Disease Control and Prevention (CDC) Prevention Initiatives

CDC provides additional federal funding to local nonprofits and state governmental agencies for specific prevention initiatives including counseling, testing programs, health education/risk reduction activities, and surveillance/monitoring activities.¹⁶⁶ In 2010, nonprofits and state and local health agencies in Florida received \$36,297,048 in CDC prevention funding.¹⁶⁷ Of these awards, \$755,886 went to institutions whose work focused on populations in northern Florida.¹⁶⁸

Housing Opportunities for Persons with AIDS (HOPWA)

HOPWA is the U.S. Department of Housing's program to provide housing assistance and related supportive services for people living with HIV/AIDS. There are currently three competitive grant awards operating in Florida, which fund model projects or programs that address the specific needs of persons living with HIV/AIDS and their families in innovative ways.¹⁶⁹ One of these, the I.M. Sulzbacher Center for the Homeless, is located in North Florida. There are also eight other formula awards to the State and eligible metropolitan areas to address the specific needs of persons living with HIV/AIDS and their families. HOPWA funding for Florida programs totals \$42.6 million.¹⁷⁰

Overview of federal funding sources

Federal funding to support HIV/AIDS programs in Florida in 2010 totaled approximately \$314.7 million.¹⁷¹ The federal Ryan White program contributed the majority of that amount (\$226.2 million).¹⁷² Within the Part B allocation, \$92.2 million went toward ADAP.¹⁷³ CDC contributed \$36.3 million for HIV prevention efforts.¹⁷⁴ The remaining federal funding came in under the Housing Opportunities for People Living with AIDS Program (HOPWA) (\$42.7 million), the Substance Abuse and Mental Health Administration (SAMHSA) (\$8.4 million), and the Office of Minority Health (OMH) (\$1.1 million).¹⁷⁵

Sources of Federal Funding for Florida HIV/AIDS Programs (2010)

Source	Amount (in millions)
Ryan White Program Funding	\$ 226.2
CDC	\$ 36.3

HOPWA	\$ 42.7
SAMHSA	\$ 8.4
Office of Minority Health	\$ 1.1

Medicaid

The Agency for Health Care Administration (AHCA) is responsible for administering Medicaid in Florida.¹⁷⁶ AHCA is also the lead agency for the Children’s Medical Insurance Programs (Title XXI–SCHIP), the state’s health insurance program for uninsured children.¹⁷⁷

Medicaid is funded by both federal and state contributions. The federal medical assistance percentage (FMAP) is used to calculate the federal contribution to state Medicaid programs. Florida’s FMAP was temporarily increased from 55.4% to 68.8% due to federal stimulus funds provided for in the American Recovery and Reinvestment Act of 2009 (ARRA).¹⁷⁸ The enhanced FMAP program expired June 30, 2011, despite continued high need due to ongoing heightened unemployment and uninsurance rates combined with state budget woes.

Generally, Medicaid is available to pregnant woman, disabled adults, caretakers of children under age 18, adults over age 65, and children under age 19 who meet low-income requirements. Supplemental Security Income (SSI) recipients typically automatically receive Medicaid.¹⁷⁹ The Patient Protection and Affordable Care Act of 2010 (ACA) expands Medicaid eligibility to children, parents and childless adults who are not entitled to Medicare and who have family incomes up to 133% of the federal poverty level (FPL) beginning on January 1, 2014.¹⁸⁰

Florida does not have a §1115 waiver in place to provide Medicaid coverage to non-disabled people living with HIV/AIDS.¹⁸¹ Thus, an applicant must demonstrate disability before applying for Medicaid and cannot use Medicaid to access therapies that might prevent disability.

Florida Medicaid enrollees who have been diagnosed with AIDS may be eligible to enroll in the §1915(c) Project AIDS Care (PAC) Medicaid waiver program for home and community based services (HCBS). Florida originally received federal approval for this program in 1990; the current waiver is set to expire December 31st, 2012.¹⁸² The program is capped at 5,900 enrollees. To be eligible, an individual must be otherwise eligible for Medicaid; must show documentation of an AIDS diagnosis and the presence of AIDS related opportunistic infections; must have been determined to be at risk of hospitalization or institutionalization in a nursing facility; must not be enrolled in another Medicaid HCBS waiver program; and be capable of remaining safely in the home and community.¹⁸³

Working disabled persons whose income is less than 250% FPL and who would be eligible to receive SSI benefits if not for their earned income may obtain Medicaid through the Medicaid for the Working Disabled Program. In 2011, this means an individual must make less than \$2,268 per month (\$27,225 annually) or a family of four must have an income of less than \$4,656 per month (\$55,875 annually).¹⁸⁴

Medicaid managed care pilot program

In addition to the state's traditional Medicaid program, in 2006 Florida obtained a §1115 waiver to launch an experimental Medicaid pilot program in Duval and Broward counties.¹⁸⁵ Through this program, traditional Medicaid was replaced with a managed-care model, in the hopes of reducing costs and improving efficiency by allowing beneficiaries to enroll in any available plan, including capitated managed care plans (HMOs) and provider-sponsored networks (PSNs). The managed care program was eventually expanded to Baker, Clay, and Nassau counties, enrolling over 288,000 consumers in those areas, about ten percent of Florida's statewide Medicaid enrollment.¹⁸⁶

Independent research on the show that the pilot program's efficiency and cost-saving impacts have been mixed at best.¹⁸⁷ Nevertheless, the Florida legislature passed a bill in April 2010 directing the Florida Agency for Health Care Administration to seek approval of a three year waiver extension for the pilot program.¹⁸⁸ While federal consideration of the extension was pending, the state also notified CMS of its intent to expand the waiver statewide, and the legislature passed a sweeping Medicaid reform bill during the 2011 session that includes statewide expansion of the waiver.¹⁸⁹ As of September 2011, the state and federal government continue negotiations regarding the waiver and the legislature's proposed expansion of the waiver across the state.

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 age 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 living with HIV/AIDS who are in care.¹⁹⁰ In Florida, 3.3 million individuals were enrolled in Medicare in 2010 (18% of the state's total population).¹⁹¹ Approximately 86% of Medicare enrollees in Florida were aged (over 65), while about 13% are disabled. Nationally, 84% of Medicare beneficiaries are aged and 16% are disabled.¹⁹²

Medicare Part D

Originally launched in 2006 and intended to help beneficiaries pay for prescription drugs, Medicare Part D requires an additional premium that varies by plan. Part D plans are required to offer a statutorily defined standard benefit, which currently 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").¹⁹³ 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%.¹⁹⁴

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 for the Low Income Subsidy (LIS) program (see below) do not have a donut hole. Low-income individuals who are not

enrolled in a Part D drug plan may receive assistance through the Florida Discount Drug Card Program, which helps to lower the cost of prescriptions.¹⁹⁵

Historically, Part D enrollees who entered the donut hole were required to pay 100% of the cost of their prescription drugs until they reached catastrophic coverage; third-party payments to assist with drug costs could not count toward an enrollee’s “True Out-Of-Pocket” spending requirement (TrOOP). For Part D enrollees taking HIV medications, who are typically are covered for about two months worth of medications before falling into the donut hole, this meant that contributions by the state AIDS Drug Assistance Program (ADAP) to help people pay for medications in the donut hole could not count toward TrOOP. Consequently, these individuals could not reach catastrophic coverage and ADAP paid for their drugs until the next year, when their plan was reset. However, under the Affordable Care Act (federal healthcare reform), ADAP contributions now count toward TrOOP,¹⁹⁶ presumably helping more people reach catastrophic Part D coverage.

Under federal healthcare reform, ADAP contributions now count toward TrOOP in the donut hole, and Part D plans cover a greater percentage of brand name and generic drug costs. These changes are effective in Florida despite the state’s ongoing litigation challenging the constitutionality of the Affordable Care Act.

Additional changes to the Part D donut hole under the healthcare reform law will phase in over the next several years.¹⁹⁷ In 2010, beneficiaries who entered the donut hole automatically received a \$250 check from the federal government to help cover medication costs. Since January 1, 2011, all Medicare Part D enrollees receive a 50% point-of-sale discount on the cost of brand-name drugs—but the pre-discount price counts toward TrOOP. In addition, Part D plans cover greater percentages of enrollees’ generic (effective 2011) and brand name (effective 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 and then 25% of medication costs until they reach catastrophic coverage.

In Florida the Part D plan with the lowest monthly premium charged \$14.80 per month in 2011. Of the 27 private prescription drug plans in Florida, ten offer at least some gap coverage. The plans vary in their coverage of generic drugs.¹⁹⁸ It is worth noting that most antiretroviral medications that treat HIV/AIDS do not have generic equivalents.

Low Income Subsidy (Extra Help)

The Extra Help/LIS program provides financial support for people with especially limited income and resources. LIS covers approximately 33% of Part D enrollees in Florida.¹⁹⁹ The program pays for all or part of the monthly premiums and annual deductibles and provides lower prescription copayments for Medicare prescription drug plans. The LIS income limit is 150% FPL. The program also has a resource limit of \$12,510 for individuals and \$25,010 for married couples who live together.²⁰⁰ LIS beneficiaries with income between 135% and 150% FPL pay a sliding-scale-based Part D premium and have a \$60 annual deductible.²⁰¹ Recent changes in the law mean that life insurance is not counted toward the

resource limit and help received from a third-party to pay for household expenses (food, utilities, mortgage or rent payments, or property taxes) does not count as income.

Individuals with Medicare and full Medicaid (“dual eligibles”) are automatically enrolled in LIS. Nonduals with income less than 135% FPL also receive LIS automatically if they receive SSI. Individuals who are not dual-eligible, do not receive SSI, and who have income less than 135% FPL must apply for LIS.

To ensure that Extra Help will pay for the entire Medicare drug coverage premium, individuals must pick drug a plan that has a premium equal to or lower than the Extra Help premium amount for their state and offers only basic coverage. Basic coverage is coverage that does not exceed the drug benefit outlined in Medicare law. In Florida, the Extra Help premium amount is \$25.41 in 2011. Nationwide, the 2011 premiums range from \$22.62 in New Mexico to \$40.68 in Idaho and Utah.²⁰² Five Part D plans have a premium of \$0 for people who qualify for LIS.²⁰³

Federal Pre-Existing Condition Insurance Plan (PCIP)

Florida residents with pre-existing health conditions can obtain health insurance coverage through the Pre-Existing Condition Insurance Plan (PCIP) established under the Affordable Care Act.²⁰⁴ The state of Florida opted to have its PCIP be administered by the federal government. Nationally, 24 states have federally-run PCIPs,²⁰⁵ while the remaining 26 states administer their own plans. In order to qualify for PCIP coverage, an applicant must: be a U.S. citizens or lawfully present in the U.S.; have been uninsured for at least the last six months before applying; and have a pre-existing condition or have been denied coverage because of a medical condition.²⁰⁶

Individuals in the federally administered PCIP program can choose between three plan options: the Standard Plan, the Extended Plan and the Health Savings Account eligible plan. The 2011 Standard plan has a \$2,000 medical deductible and \$500 drug deductible, which is expected to help individuals who must take maintenance medications.²⁰⁷ The Standard Plan monthly PCIP premium rates vary by the age of an enrollee, ranging from \$196 per month for persons 18 and younger to \$626 per month for persons 55 and older.²⁰⁸ (For more information about the PCIP, see Part III and Appendix 2 of this report.)

Access to care for immigrants

The Affordable Care Act (ACA) improves access to care for documented immigrants but does little to address the lack of health care treatment options for undocumented immigrants. Documented immigrants are subject to the law’s requirement that all individuals carry creditable health insurance coverage (the so-called “individual mandate”), and may purchase health insurance through state insurance exchanges.²⁰⁹ (See Part III for more information about state exchanges.) Those who meet financial eligibility requirements and purchase health insurance through a state exchange may qualify for tax credits to help offset the cost of premiums as well as additional cost-sharing assistance.²¹⁰ The ACA left in place the existing five-year waiting period required for documented immigrants to be eligible for Medicaid.²¹¹

In contrast, undocumented immigrants are entirely excluded from the ACA's healthcare reforms. Individuals with undocumented immigration status are exempt from the law's individual mandate because they are ineligible to purchase private health insurance through the state insurance exchanges.²¹² Similarly, this population cannot receive financial assistance to help defray the cost of purchasing insurance. Undocumented immigrants will remain ineligible for Medicaid even after the program's eligibility rules are expanded in 2014.²¹³

Community health centers

Community health centers are "non-profit, community-directed health care providers serving low income and medically underserved communities."²¹⁴ These community-based centers help overcome barriers to care by being located in federally-identified high-need areas, being open to all residents regardless of insurance status, offering supportive services to help their patients access care (e.g., transportation, case management), and providing linguistically- and culturally-appropriate services. There are over 300 community health centers located in Florida, facilitating access to care for needy and underserved local populations.²¹⁵ The U.S. Department of Health and Human Services recently awarded \$479,190 in funding under the Affordable Care Act to six nonprofits in northern Florida so that they can become community health centers.^{216, 217} These funds will help the organizations expand their offering of services as well as enable them to serve a larger patient population.

Relevant State Laws and Regulations

Testing and reporting

Florida permits anonymous HIV testing. Clinic sites in every county offer STD services on a reasonable and/or no cost basis to adults and adolescents, regardless of their citizenship status. All clients, including adolescents are assured confidential STD clinical services.²¹⁸

STD reporting requirements, including HIV/AIDS reporting, are described in the Florida Administrative Code. Section 3 of Chapter 64D of the Code addresses reportable diseases and sets out detailed confidential name-based reporting requirements for medical providers and laboratories with respect to positive HIV results.²¹⁹ Practitioners must report an AIDS diagnosis within two weeks, and laboratories must report a positive HIV test result within three days.²²⁰

At 48.4%, the percentage of individuals aged 18-64 who in 2010 reported ever having been tested for HIV in Florida was higher than the national average (40.3%).²²¹ This success is attributed to the state's aggressive testing campaign over the past several years.²²²

Florida is one of 27 states that requires pretest counseling.²²³ Florida law requires those who perform HIV tests in county health departments and other registered testing sites to obtain informed consent, make private counseling available both before and after the test, and confirm positive preliminary results with a supplemental test before informing the subject of the result.²²⁴ Minors may

receive confidential testing and treatment for STIs and HIV, and providers may not reveal that testing or treatment has occurred without the minor's permission.²²⁵

Though shown to be effective, expedited partner therapy (EPT) is likely prohibited in Florida by statutes that require physicians to conduct a physical exam prior to prescribing drugs. EPT involves offering a prescription medication to the diagnosed patient for their sexual partners(s).²²⁶ State Senator Oscar Braynon filed a bill during the 2011 regular legislative session to create an EPT pilot project in two North Florida counties, however the bill died in committee.²²⁷

Florida law does not require notification of a person's known sexual contacts and intravenous drug use contacts upon a positive HIV test result.²²⁸ Medical practitioners are protected against civil and criminal liability, however, if they disclose confidential information to a sexual partner or needle-sharing partner where: a patient diagnosed with HIV has identified such partners to the practitioner; the patient refuses to notify the partner of the diagnosis and to refrain from activity that is likely to transmit HIV; the practitioner informs the patient of his or her intent to inform the partner(s); and the practitioner reasonably and in good faith informs the partner(s) of the diagnosis out of a perceived civil duty or professional obligation.²²⁹

Criminal exposure statute

Florida is one of 32 states with a criminal statute related to HIV exposure.²³⁰ Under state law, it is illegal for a person who is aware of his or her positive HIV status and is aware that HIV is communicable by sexual intercourse to knowingly engage in sexual intercourse with another person without first informing them of his or her HIV status and having that person then consent to sexual intercourse.²³¹ Violation of the statute constitutes a third degree felony and is punishable by not more than a \$5,000 fine and not more than 5 years in prison.²³²

To date, we are only aware of three prosecutions under this law, dating back to 1937 when it addressed venereal diseases generally.²³³ Of these, two of the prosecutions occurred in the past ten years. The most recent conviction under the statute was overturned by the District Court of Appeal, on the grounds that the statutory definition of "sexual intercourse" was limited to actual contact of male and female sex organs.²³⁴ The statute has been cited for support in a few civil suits, as well.²³⁵

Physician extender law and regulations

Florida law allows physicians to delegate certain health tasks to licensed physicians' assistants (PAs).²³⁶ Physicians assistants can enhance access to care by allowing a doctor to see a larger number of patients while best-utilizing her medical expertise. A physician may supervise up to four PAs and is ultimately responsible and liable for the PAs' performance, acts, and omissions.²³⁷ PAs may assess patients and prescribe and dispense medications other than controlled substances, anesthetics, and radiographic contrast materials.²³⁸

Sex education

Since 2007, Florida high school students are not required to complete any credits in sex education in order to graduate.²³⁹ If a school district decides to offer sex education, it must teach “abstinence from sexual activity outside of marriage as the expected standard for all school-age students while teaching the benefits of monogamous heterosexual marriage.”²⁴⁰ It is also left up to the district’s discretion to provide instruction on HIV/AIDS as part of its health education curriculum.²⁴¹

In 2009, there were 33 organizations in Florida that received federal funding to provide abstinence-only-until-marriage programming.²⁴² Of these, sixteen were faith-based organizations. In total, the state received over \$13 million dollars to support abstinence-only-until-marriage programs, over the twice the amount it received for such programming in 2007.²⁴³ Notably, these programs are targeted towards urban areas and minority communities.

Harm reduction policies

Harm reduction refers to a range of public health policies intended to reduce the negative consequences associated with drug use and other high-risk activities. These programs include sterile syringe access, support/counseling, housing, and homeless services. It is illegal under Florida law to deliver drug paraphernalia where one knows or has reason to know that it will be used to introduce a controlled substance into the body.²⁴⁴ Consequently, the state Department of Health does not operate a formal needle exchange program.²⁴⁵ However, a needle exchange program exists in Miami; the director acknowledges that the police are aware of his operations.²⁴⁶

According to the National Alliance on Mental Illness, there are inadequate mental health support programs in the state. Community mental health services are typically only available to individuals who are in crisis.²⁴⁷ State plans that cover uninsured residents exclude mental health and substance abuse treatment.²⁴⁸ However, these services are covered under the Pre-Existing Condition Insurance Plan (PCIP), a program established by the Affordable Care Act.²⁴⁹

Resources for the homeless are relatively strong in Florida. For example, 10 Healthcare for the Homeless (HCH) grantees provide primary care, mental health, and substance abuse counseling and services at free-standing medical centers, mobile health units, schools, food pantries/kitchens, and homeless shelters in the state.²⁵⁰ However, most of these resources are focused on the southern part of the state; only one center is located in northern Florida (Jacksonville).²⁵¹

Recent Legislative Activity

During the 2011 legislative session there were a number of bills introduced related to HIV/AIDS. The bills primarily addressed prescription drugs and sex education:

- Senator Sobel (D-31) proposed, for the second time, SB 180, a proposal to prohibit limitations on prescribing antiretroviral drugs for treating HIV.²⁵² The bill was referred to the Banking and Insurance Committee and died in committee.
- Senator Flores (R-38) introduced SB 1492, requiring parental permission to participate in education on reproductive health or sexually transmitted diseases.²⁵³ The bill was referred to the Education Pre-K-12 Sub-Committee and died in committee.
- Senator Margolis (D-35) introduced SB 1648, which required high schools to provide students with medically accurate education in human sexuality and AIDS.²⁵⁴ The bill was referred to the Education Pre-K – 12 Sub-Committee and died in Committee.

The House of Representatives also addressed HIV/AIDS, though there were fewer proposed bills directly addressing the issue.

- Representatives Bileca (R-117) and Corcoran (R-45) introduced HB 1077, requiring parental permission to participate in education on reproductive health or sexually transmitted diseases, paralleling SB 1492.²⁵⁵ The bill was referred to the K-20 Competitiveness Sub-committee and died in committee.
- Representatives Steinberg (D-106) and Kriseman (D-53) introduced HB 1181, requiring high schools to provide students with medically accurate education in human sexuality and AIDS, paralleling SB 1648.²⁵⁶ The bill was referred to K-20 Innovation Sub-committee and died in committee.

In May 2011, the Florida Legislature passed a bill, SB 2144, relating to administration of the state's Medicaid program.²⁵⁷ Of note is a provision requiring all Medicaid recipients with HIV/AIDS who reside in Broward, Miami-Dade, or Palm Beach counties to be assigned to a managed care plan that specializes in treating persons with HIV/AIDS. The bill was signed into law at the end of May.

Notable legislative supporters

A number of Florida's elected officials have addressed the state's HIV epidemic. For instance, U.S. Senator Bill Nelson has publicly called on President Obama and Governor Rick Scott to make ADAP a priority.²⁵⁸ He has also urged his colleagues in the Senate Appropriations Committee to fill the ADAP funding gap.²⁵⁹ Within the U.S. House of Representatives, Representative Alcee Hastings introduced legislation in February 2011 to provide an additional \$42 million for the ADAP program, which ultimately passed.²⁶⁰ Another Florida Representative in the U.S. House, Debbie Wasserman Schultz, has long been an advocate for ADAP and promoting the rights of people with HIV and AIDS.

Part III. Successes, Challenges, Opportunities

Stigma

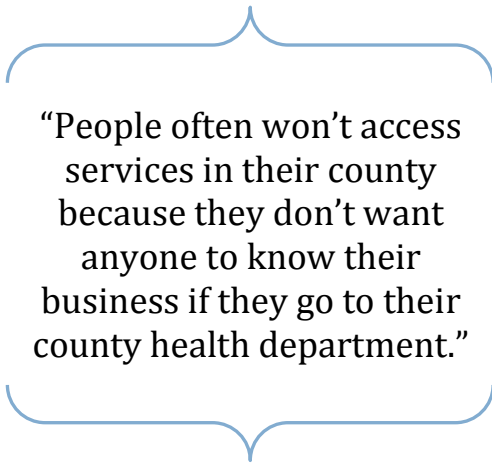
Challenges

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 northern Florida—as in other states—is partly due to the association of HIV with behaviors considered shameful or even blameworthy, such as sexual promiscuity, male-to-male sex, and drug use. The state’s criminalization of behaviors associated with HIV exposure (see Part II for details on Florida’s criminalization statute) also contributes to stigma. Ironically, because culpability under the criminal HIV exposure statute is tied to knowing one’s serostatus, the law presents a disincentive to testing—thereby contributing to late entry to care and, in all likelihood, further transmission of the virus.

Across northern Florida, stigma is consistently identified as a barrier not only to accessing treatment and care for people living with HIV and AIDS, but to all services along the prevention-treatment continuum.²⁶¹ Consumers, case managers, healthcare providers, health officials, and community organizers and advocates describe stigma as having a chilling effect on the willingness of those living with or at risk of HIV to access services. “Internalized stigma” is a powerful and harmful deterrent in rural areas in particular, where the smallness of communities and fear of others “knowing their business” or being recognized by family members or acquaintances at offices or agencies that offer HIV testing or treatment services makes people living with HIV/AIDS reluctant to access services near where they live.²⁶² But stigma is not limited to rural areas—HIV advocates, consumers, providers, and health officials in Jacksonville, Gainesville, Tallahassee, Panama City, Fort Walton Beach, and Pensacola all describe stigma as a major factor in their communities as well.²⁶³

When stigma affects people’s health-related decisions—such as delaying HIV testing, putting off needed care, or not disclosing HIV status to sexual or drug-using partners or medical providers—negative individual and public health outcomes result. People who do not know they are infected with HIV are more likely to transmit the virus, and people who are late to enter care are more often ill. This can lead to economic consequences in the form of lost productivity and the need for higher-cost medical 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.

Stigma stands not only as a significant barrier for individuals to access services, but it can also affect to some extent what services are available in a given community. For example, in



“People often won’t access services in their county because they don’t want anyone to know their business if they go to their county health department.”

“Black, gay, poor,
uneducated, and HIV
positive are what you don’t
want to be in Jacksonville.”

the Jacksonville metropolitan area, where HIV stigma connected to racism, homophobia, and hostility toward youth and poor and low income individuals was reported to be especially pervasive, providers cite a lower level of support from the private sector—businesses and churches, in particular²⁶⁴—than is evident in other parts of northern Florida.²⁶⁵ One provider observed that after six years, only 16 restaurants city-wide participated in the community’s annual Dining Out for Life event.²⁶⁶ Stakeholders in some northern

Florida communities identified widespread apathy about HIV disease within faith-based communities in northern Florida. For instance, commentators in Panama City and Jacksonville noted that while some faith leaders are open to HIV educators having a table at a church-based health fair, pastors are unwilling to talk about sexual health and HIV on Sunday mornings or even include HIV in their health ministries.²⁶⁷

At a time when public sector funding for HIV services is falling well short of need, lack of private sector and faith community involvement due to entrenched stigma within communities can seriously handicap agencies, clinics, and health departments that need not just financial support, but also in-kind support and partnerships to maximize their effectiveness in the community.

Opportunities

Susan Walch, Associate Professor of Psychology at the University of West Florida in Pensacola, has documented a quantifiable relationship between homophobia and fear of AIDS on one hand, and personal contact with someone who is gay or has AIDS, on the other.²⁶⁸ Her 2010 study found that “[p]ersonal contact with someone who is homosexual or someone who is living with HIV/AIDS was associated with both lesser homophobia and lesser fear of AIDS.”²⁶⁹ In contrast, evidence from other sources indicates that HIV education alone does not significantly reduce stigmatizing attitudes.²⁷⁰ These studies suggest that one of the best strategies to fight stigma is to maximize opportunities for people living with HIV and AIDS to openly engage with members of their community—and vice-versa. While the literature does not appear to address the effect on stigmatizing attitudes of personal contact with HIV negative advocates and allies, anecdotal evidence suggests that this is also an effective strategy, as discussed below.

Integrate in to the community

Efforts to mainstream or normalize HIV disease and people living with HIV within the community can serve to combat stigma while building networks of allies for future advocacy collaboration. Integrating in to the community by participating on other organizations’ boards and supporting their community-based efforts, joining the local Chamber of Commerce, and partnering with other health and disability organizations are all strategies that agency leaders across northern Florida are already using. For example, Putnam County School District Migrant Education Program coordinators Lucia Robles and Linda Osborne note that by sitting on the board of directors of a local federal credit union, the county

board of zoning adjustment, and Healthy Families (a community-based, voluntary home visitation program to prevent child abuse and neglect), they have forged invaluable relationships within their community and have gained support for their own programming with essential community allies.²⁷¹ Pursuing opportunities such as these can help build familiarity and trust in the broader community—a foundation that not only can help reduce stigma but can pay dividends when it comes to maximizing shared resources and launching effective advocacy campaigns.

“We can be a part of the community where we live.”

Implement stigma-combating strategies to engage the private sector

When businesses see HIV related stigma as pervasive in their communities, it is hardly surprising that many are uncomfortable participating in highly visible ways to support HIV/AIDS issues out of worry that in doing so, they might alienate their customer or client base. Indeed, many businesses might not be ready to hang a red ribbon on their door or openly display HIV/AIDS educational materials in their establishments. But, given the opportunity, they might consider supporting the HIV community with financial or in-kind support to local organizations, for example by providing volunteer manpower at events or donating meals or meeting space for events or meetings. HIV/AIDS services organizations and county health departments should consider maximizing such low-profile opportunities for businesses to get involved. Staff at JASMYN, a nonprofit youth services organization for lesbian, gay, bisexual, transgender and questioning (LGBTQ) youth in Jacksonville, report having had significant success with this approach. Their organization receives frequent support from members of the local business community who volunteer to chaperone social events and bring in hot meals for youth meetings at the JASMYN office.²⁷² These opportunities are an important step in reducing stigma by educating members of the business community about HIV/AIDS and providing opportunities for personal interactions, with the broader goal of ameliorating concerns they might have about the consequences to their business interests of more openly supporting the HIV community.

To build on that approach, a second step is to emphasize how important business leaders are to shaping the community. When approaching potential allies in the business community to ask for their more visible and vocal engagement, consider using the following messaging points, which were developed by the CDC for its Business Responds to AIDS initiative and subsequently adopted by the Florida HIV/AIDS Bureau in its We Make the Change initiative:²⁷³

- Community business leaders have tremendous influence within their communities.
- HIV/AIDS affects us all, but many people are uninformed or misinformed about the nature of HIV/AIDS and how to prevent the spread of the disease. Stigma and silence about the disease fuel the epidemic.
- The key to stopping the spread of HIV is to break the silence around the disease. We must begin talking about HIV/AIDS where we live, work, play, and worship. Having conversations about

HIV/AIDS allows for opportunities for raising awareness and educating communities on how they can protect themselves from HIV.

- As a business leader in our community, you can help start the conversations where people work and play. You have the opportunity to impact the lives of members of our community by simply supporting HIV prevention/education efforts.

Increase the presence of faith leaders at HIV/AIDS-related events and provide support to clergy

Northern Florida's location in the so-called Bible Belt amplifies the influence, and as a result, the importance of faith community. Given the central role that religion and the faith community play in the lives of many residents of northern Florida—and particularly among minority communities that are disproportionately impacted by HIV disease—it is important to engage the faith community as part of a comprehensive approach to eliminating stigma in the region. In many communities, advocates and organizations are already working with faith leaders. For example, in Putnam County, Health Department staff participate in the Community Coalition, a group of faith community leaders who volunteer to do community outreach.²⁷⁴

Advocates should urge leaders in the faith community who are already open to 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 unaware 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 and health departments. By simply being present at these events, faith leaders can show their support for and decrease stigma about individuals living with HIV and AIDS. These are important first steps, especially given that many faith leaders in northern Florida are reportedly open to HIV issues but unwilling or unready to integrate HIV/AIDS and related issues into worship services and other church functions.

A critical step toward bringing pastors on board in the fight against HIV/AIDS—and one that could help move pastors toward Sunday morning talks about the disease—is empowering them with knowledge and a theological framework for thinking about HIV. Access to HIV experts is essential, as some pastors may be uncomfortable 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 and AIDS. For this purpose—as well as in the context of theological discussions—clergy-only educational settings are crucial.

Support federal funding for faith-based initiatives

At the federal level, Representative Elliot Rangel (D-NY) and Senator Kristin Gillibrand (D-NY) introduced legislation in 2011 that would authorize \$50 million in grants in 2012, and additional funding from 2013 to 2016 for public health agencies and faith-based organizations to conduct prevention and testing activities as well as outreach efforts.²⁷⁵ The National Black Clergy for the Elimination of HIV/AIDS Act of 2011 (H.R. 1462, S.795) currently has 44 cosponsors, including four representatives from Florida: Corrine Brown (FL-3), Kathy Castor (FL-11), Alcee Hastings (FL-23), and Frederica Wilson (FL-17).²⁷⁶ Specifically, the bill would provide funding for the following initiatives:

- Department of Health and Human Services (HHS) Office of Minority Health (OMH) grants to public health agencies and faith-based organizations to conduct HIV/AIDS prevention, testing, and related outreach activities to reduce HIV/AIDS in the African-American community.
- Substance Abuse and Mental Health Services Administration (SAMHSA) grants to: (1) public health agencies and faith-based organizations to conduct HIV/AIDS and sexually transmitted disease outreach, prevention, and testing activities and substance abuse testing and mental health services targeted to the African-American community; and (2) faith- and community-based organizations to provide services to youth who are HIV positive or at risk for HIV/AIDS and who have run away from home, are homeless, or reside in a detention center or foster care.
- Centers for Disease Control and Prevention (CDC) grants to faith-based organizations for public health intervention and prevention activities in the African-American community to reduce HIV/AIDS, sexually transmitted diseases, tuberculosis, and viral hepatitis.
- CDC actions to: (1) expand and intensify HIV/AIDS activities in African-American communities and educational activities targeting black women, youth, and men who have sex with men; (2) expand funding to build the capacity of African-American communities to respond to HIV/AIDS; and (3) implement a national media outreach campaign on getting tested.
- National Institutes of Health (NIH) research on behavioral strategies to reduce the transmission of HIV/AIDS in the African-American community.
- National Center on Minority Health and Health Disparities grants for the study of biological and behavioral factors that lead to increased HIV/AIDS prevalence in the African-American community and for behavioral and structural network research and interventions.
- Health Resources and Services Administration grants for: (1) training health care providers in HIV/AIDS prevention and care, (2) developing policies for providing culturally relevant and sensitive treatment to individuals with HIV/AIDS, (3) HIV/AIDS telemedicine programs, (4) certification programs for providers in HIV/AIDS care, (5) establishment of comfort care centers for people with HIV/AIDS, and (6) incentive payments to health care providers to implement HIV/AIDS testing.

Although the bill has support from some members of the Florida Congressional delegation, advocates should consider contacting their representatives and senators to make sure they are aware of the legislation, and urge them to sign on to the bill as a cosponsor.

Comprehensive Health and Sexuality Education

Commentators throughout northern Florida describe the lack of comprehensive health and sex education in public schools as a major problem in their communities. Furthermore, they explain, school officials in many communities are in fact averse to the provision of information about HIV/AIDS within schools by staff and volunteers from CBOs and local health departments.²⁷⁷ For instance, one school official in Area 1 rebuffed an offer from the Escambia County Health Department (Pensacola) to have a speaker who was HIV positive present information in a school there, saying “we wouldn’t want a smoker to come tell kids not to smoke.”²⁷⁸

Challenges

The state of Florida’s “stress abstinence” policy regarding sexuality education and instruction on HIV and AIDS directs that “[t]roughout instruction in acquired immune deficiency syndrome, sexually transmitted infections, or health education, when such instruction and course material contains instruction in human sexuality, a school shall:

- (a) Teach abstinence from sexual activity outside of marriage as the expected standard for all school-age students while teaching the benefits of monogamous heterosexual marriage.
- (b) Emphasis that abstinence from sexual activity is a certain way to avoid out-of-wedlock pregnancy, sexually transmitted infections, including acquired immune deficiency syndrome, and other associated health problems.
- (c) Teach that each student has the power to control personal behavior and encourage students to base actions on reasoning, self-esteem, and respect for others.
- (d) Provide instruction and material that is appropriate for the grade and age of the student.”²⁷⁹

Previously, Florida high school students were required to complete one-half credit in “Life Management Skills”—courses that included instruction in the prevention of HIV/AIDS and STDs—in order to graduate. Since the 2007-08 school year, however, students are no longer required by Florida law to take any health education course. Instead, school districts have the option to require students to complete one-half credit in “Health Opportunities through Physical Education” (HOPE), which integrates personal fitness and life management skills, and includes instruction on HIV/AIDS and other STD prevention.²⁸⁰ However, state law provides that any health education must include “an awareness of the benefits of sexual abstinence as the expected standard.”²⁸¹ Furthermore, “[a]ny student whose parent makes written request to the school principal shall be exempted from the teaching of reproductive health or

any disease, including HIV/AIDS, its symptoms, development, and treatment,” and “[c]ourse descriptions for comprehensive health education shall not interfere with the local determination of appropriate curriculum which reflects local values and concerns.”²⁸² Anecdotal reports from across northern Florida confirm that school districts in this region are in fact implementing either no sexuality education at all or abstinence-only instruction, consistent with state law.²⁸³

“Everybody has tried to get sex education into Duval County schools. It never works. We have to ramp up the underground approaches.”

The state of Florida recently applied for and accepted \$2.6 million in federal funding for Title V (abstinence-only) sex education made available under the national healthcare reform law.²⁸⁴ The state also applied for and was awarded nearly \$2.8 million in Affordable Care Act (ACA) funding for comprehensive health education, but has since rejected that funding.²⁸⁵ (Notably, the Title V funding requires three state matching dollars per four federal dollars received, whereas funding for comprehensive health education under the ACA requires no state matching dollars.)

Despite the focus on abstinence in Florida schools, data from the CDC’s most recent biannual high school Youth Risk Behavior Surveillance report reveal that a higher percentage of Florida’s high school students than high school students across the U.S. have ever had sexual intercourse, had sexual intercourse for the first time before age 13, or have had sexual intercourse with four or more persons in their lifetime.²⁸⁶

High school students who have...	Florida 2009	Duval County 2009*	United States 2009
Ever had sexual intercourse	50.6%	53.9%	46.0%
Had sexual intercourse for the first time before age 13 years	8.3%	10.1%	5.9%
Had sexual intercourse with four or more persons (during lifetime)	16.6%	17.6%	13.8%

Source: CDC Youth Risk Behavior Surveillance—United States 2009 (June 4, 2010).

*Duval County is one of 20 local surveys conducted in addition to surveillance in 50 states; data provided here for local interest.

Lack of comprehensive health education in schools combined with unreceptive school boards and administrators may be a significant contributing factor to anecdotal reports of a growing number of positive young people seeking agency and/or clinic services, including youth and young adults getting an AIDS diagnosis simultaneous to their first positive HIV test.²⁸⁷

Successes

In the face local school officials’ apathy and even hostility regarding the provision of comprehensive, accurate health and sexuality education that includes instruction in the prevention of HIV/AIDS, many CBOs and local health departments across northern Florida have implemented alternative strategies to reach and educate youth. Many use the peer educator model, training core groups of youth volunteers to serve as liaisons in the youth community broadly as well as in settings such as health fairs, church

functions, and juvenile detention centers.²⁸⁸ Others take advantage of outside-the-classroom school settings in which staff members can integrate educational messaging; for instance, in mentorship roles as sports coaches or student organization advisors.²⁸⁹

Opportunities

Support comprehensive health education policy initiatives

As discussed previously, Florida state policy requires educators to stress abstinence and heterosexual marriage as expected behavior standards within health education curricula. In addition to the state's growing HIV epidemic, data showing that Florida teens are more likely than teens across the U.S. to be sexually active strongly suggest that alternative educational approaches are needed. Comprehensive health education can help delay the onset of sexual activity and increase consistent condom use for those teenagers who are sexually active.²⁹⁰ 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.

In 2008 and 2010, state legislators in both houses of the Florida legislature introduced the Florida Healthy Teens Act, a bill to require schools that already teach information about sexually transmitted infections, family planning, and pregnancy to provide age-appropriate, medically-accurate and comprehensive sex education, including facts about abstinence and methods of preventing unintended pregnancy and the spread of diseases.²⁹¹ The proposed law defined comprehensive sex education as information about: responsible decision-making; goal setting, negotiation, and communication; self-esteem and positive interpersonal skills; abstinence; and, starting in the 6th grade, the risks and benefits of contraception and methods of preventing sexually transmitted infections, including HIV and AIDS. It specifically required that any comprehensive sex education curriculum teach that abstinence is the only certain way to avoid pregnancy or sexually transmitted diseases.

Importantly, the Healthy Teens Act provided for enforcement by parents or guardians, stating that “a parent or guardian of a student enrolled in a school that is subject to the requirements ... who believes that the school is not complying with those requirements may file a complaint with the district school superintendent.”²⁹² The bill provided two further levels of enforcement by parents if this initial complaint did not result in a satisfactory response: parents can file an appeal to the district school board and then an appeal to the commissioner of education, requiring the commissioner to undertake an investigation and take corrective action. The lack accountability for the implementation of comprehensive health education laws long in place in other states—notably, South Carolina²⁹³—underscores the importance of parental enforcement rights provisions in any comprehensive health education law that Florida advocates consider pursuing.

Although the Healthy Teens Act died in committee and seems unlikely to pass the Florida legislature in the near future, it is important to note that there is strong public support for comprehensive health education in the state. Surveys in 2007 and 2008 revealed that 73% of Florida voters believe that public schools should teach a comprehensive sex education program.²⁹⁴

Apply for federal funding to support local comprehensive health education programming

The state of Florida recently rejected nearly \$2.8 in federal funding for comprehensive health education under the Personal Responsibility Education Program (PREP) of the national healthcare reform law. While PREP is primarily intended for state implementation of evidence-based comprehensive health education programming, Florida's HIV and youth advocates should be aware that beginning in 2012, the law provides PREP grant opportunities to community- and faith-based organizations in states that did not apply for funding under the program in 2010 and 2011.²⁹⁵ For entities that already provide, or are interested in providing comprehensive health education to youth in their communities as part of HIV/AIDS education and outreach programming, PREP represents a potentially significant new source of funding. The program ends in 2014.

Outreach and Linkage to Care

In the context of HIV, outreach—including education and testing—is often discussed as it relates to prevention. 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. Commentators across northern Florida describe a variety of obstacles to effective HIV outreach.

Challenges

Funding

Diminishing local, state, federal, and private funding in the past two years has meant fewer staff at health departments and other agencies to do more work as the epidemic continues to grow in virtually every community.²⁹⁶ Reduced funding has led some northern Florida agencies to rely more heavily on volunteers; others have essentially halted some or all of their services and programming. For every agency affected by financial strain, the irony is that they must dedicate more time and resources than ever to searching for alternative funding sources simply to continue their existing level of work—which itself takes away from resources for programming.

Restrictive state policies

State policies such as employee background check requirements and restrictions on the use of social media tools on state computers hamper health departments' ability to use strategies they know to be effective in their communities.²⁹⁷ For example, staff at the Alachua County Health Department (Gainesville) lamented the prohibition on using Facebook as a tool to reach individuals who test positive for follow up and linkage to care, noting frequent instances of phone numbers being disconnected by the time test results are available.²⁹⁸ And in Pensacola, staff at the Escambia County Health Department (Pensacola) note that the very people whose relevant life experiences make them excellent outreach workers and peer educators are often difficult to hire due to background check requirements. As a

result, the agency terminated its state-funded peer program and has transitioned it to an informal initiative.²⁹⁹

Barriers to reaching and serving Hispanic communities

Outreach and linkage to care within Hispanic communities is complicated by unique cultural, logistical, and even political barriers.³⁰⁰ HIV-related stigma manifests somewhat differently in Hispanic communities. One commentator described HIV as being “taboo” in Hispanic communities, and observed that this form of stigma stems in part from gender-based cultural attitudes—the machismo complex among Hispanic men on one hand, including a fervent non-recognition of male-to-male sexual activity; and a “God will protect me” outlook among Hispanic women on the other hand.³⁰¹ One strategy to circumvent lack of willingness to talk about HIV that reportedly has been successful at least in some communities is to integrate HIV/AIDS outreach with other health education and testing services such as diabetes, blood pressure, smoking cessation, heat stress, and pesticide exposure.³⁰²

Even when initial outreach has succeeded, other barriers can stymie access to care for members of northern Florida’s Hispanic communities. Perhaps most obviously, language can present a barrier to accessing health education and health care services, particularly at smaller health departments and community-based organizations that might lack Spanish-speaking staff.³⁰³ As one commentator in Area 3/13 pointed out, many rural health departments refer Spanish-speaking clients to the health department in Gainesville, where Spanish-language health services are available—but these clients often lack transportation, and in any event are not free to take time off from work to travel to Gainesville.³⁰⁴ Lack of linguistic cultural literacy can also significantly hamper record-keeping functions. Anecdotal reports suggest a widespread lack of knowledge among health department and services organization staff regarding Hispanic surname conventions,³⁰⁵ a problem that is apparently compounded by the lack of data entry protocols for names in CareWare. As a result, tracking an individual’s health history can require pulling multiple records—and knowing what names to search under in the first place.³⁰⁶

Successes

Community culture-based outreach initiatives

As discussed previously section, stigma presents a major barrier across the HIV prevention-care continuum. Because stigma can stem from culturally-specific roots and manifest uniquely across different populations, tailored interventions are crucial in efforts to move beyond stigma and achieve meaningful outreach and linkage to care. Across northern Florida, ASOs and providers have made efforts to conduct targeted, relevant outreach within specific populations—teens, minorities, men who have sex with Men (MSMs), immigrant communities, etc. By using media, language, formats, and even venues that are comfortable for the target audience, educators and clinicians can maximize the impact of their outreach activities.

For example, in the Gainesville area, the Rural Women’s Health Project (RWHP) has developed Spanish and Spanish-English *fotonovelas* as a tool to model positive health choices and support HIV

“It’s a matter of knowing what the needs are and taking advantage of how the community works.”

prevention.³⁰⁷ RWHP’s *fotonovelas* present accurate information in a culturally relevant context showing realistic situations for women, men, and young people. In addition, the *fotonovelas* use minimal text, popular language, and visuals that render them easily read across literacy levels. These elements make RWHP’s *fotonovelas* an excellent educational tool for outreach workers, youth, and discussion groups. While the *fotonovela* format has largely been used to reach Hispanic immigrant communities, this type of tool could also be highly

effective for outreach within non-Hispanic communities. Indeed, in Panama City, BASIC NWFL has—with input from youth advisors—also begun using print materials that emphasize visual representation to reach African American youth as well as Hispanic youth.³⁰⁸

In a more urban setting, the Leon County Health Department (Tallahassee) takes strategic advantage of the diversity of its staff and volunteers to reach different populations in different community settings. They focus on practical approaches to community outreach that take in to account how they are perceived by different communities—which includes acknowledging race and gender biases. This means, for instance, that a white female staff member does outreach at the Rotary Club, while African American staff members and volunteers do outreach in the black community at family reunions, college dorms, etc. Health department staff point out that gaining the trust and confidence of the populations in which rates of transmission are highest is essential to effective intervention—but that process can take years, and demands novel approaches that are tailored to the unique culture of neighborhood communities. For example, the department has developed strategies and programming to reach community gatekeepers in its “Into the Night” initiative, which operates on the streets from 10 PM to 2 AM to reach high-risk populations—drug users and dealers; prostitutes and johns.³⁰⁹

“A lot of initiatives that come from CDC or even HAB just don’t work in our communities.”

These programs’ successes highlight the need for deployment not just of nationally-recognized prevention strategies, but—perhaps even more importantly—locally-produced strategies that respond to specific community needs and culture. Indeed, as one commentator observed, “a lot of initiatives that come from CDC or even HAB just don’t work in our communities.”³¹⁰

Access to Healthcare, Treatment, and Support Services

Transportation

Challenges

Nearly every provider, consumer, health official, and advocate surveyed for this report cited transportation as one of the main barriers to access to care and support services for people living with HIV and AIDS in northern Florida.³¹¹ As in other southern states, inadequate transportation affects rural areas disproportionately northern Florida. Staff at WellFlorida Council in Gainesville noted, for instance, that public transit options exist in only four counties or municipalities in all of Area 3/13, which covers 15 counties.³¹² Furthermore, they observed, the Medicaid transportation program in that region saddles riders with so many requirements and limitations that the program itself has become a barrier.³¹³ For example, patients may only bring one other person on the van—essentially excluding those caring for young children—and beneficiaries who have a car registered in their name are excluded regardless of their ability to pay for gas or the operability of the vehicle. Even when enrollees meet the requirements for transportation services, Medicaid only provides transportation for beneficiaries' medical ("medically necessary and Medicaid compensable") appointments, which represent only a portion of the range of services that are critically important to whole-person care, including meetings and support groups at HIV/AIDS services organizations. And in 2011, the Florida legislature enacted legislation that directs the Agency for Health Care Administration (AHCA) to require copayments for transportation services—imposing yet another barrier for those who need transportation.³¹⁴

Opportunities

Given the climate around Medicaid in Florida today, opportunities to reform or expand Medicaid transportation services are unlikely. As an alternative, advocates should consider looking to the federal Ryan White program—especially in light of the National HIV/AIDS Strategy's goal of reducing health disparities—as a target for reform around access to transportation. Currently, federal funding restrictions in the Ryan White program severely limit the ability of rural patients to access healthcare, because providers may allocate only a small portion of their funds for paying for clients' transportation. In rural areas, the lack of public transit options coupled with long distances mean staggeringly high costs for mileage reimbursement for private transportation—and quickly-depleted funding. As profoundly rural counties (those with a population density of less than 100 individuals per square mile)³¹⁵ account for 26 of the 38 counties in northern Florida,³¹⁶ and public transit systems are available in only a few communities, the lack of funding for transportation creates a major barrier to healthcare and contributes to geographic health disparities. HIV/AIDS advocates in Florida 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.

Many—if not most—other southern states struggle with this issue as well, making it one that is ripe for collaborative advocacy. A multi-state effort around changing the Ryan White definition of core service could be an attractive cause for the newly-formed bipartisan Congressional HIV/AIDS Caucus,³¹⁷ given

that this change would mark a victory for the new Caucus without necessarily representing a new outlay of federal funds. (Seven members of Florida’s Congressional delegation are currently members of the Caucus; the only member from a northern Florida district is Corrine Brown (D, FL-3).)³¹⁸

Provider Shortages

Challenges

Local commentators across northern Florida identified access to providers—and specialists in particular—as a major challenge for people living with HIV and AIDS in this part of the state.³¹⁹ For instance, in Area 2A, it was noted that no dentists accept Medicaid, forcing consumers to travel to Gainesville—a trip in the neighborhood of 150 miles each way—for dental care.³²⁰ Similarly, commentators in Area 1 and Area 3/13 noted that access to non-HIV specialty consult services and medical care (e.g., gynecology, eye care, diabetes care, heart disease) is limited, again because specialists are unwilling to accept Medicaid patients (or in some cases, out-of-county Medicaid patients) due to inadequate reimbursement rates.³²¹

Formal data support these anecdotal observations concerning lack of access to healthcare providers. Much of northern Florida’s area and populations are identified by the federal Health Resources and Services Administration (HRSA) as health professional shortage areas (HPSAs).³²² HRSA has also identified Medically Underserved Populations (MUPs) or Areas (MUAs) across northern Florida. The MUA designation is used to identify a whole county or a group of contiguous counties, a group of county or civil divisions, or a group of urban census tracts in which residents have a shortage of personal health services; MUPs identify groups of persons who face economic, cultural or linguistic barriers to health care.³²³

The following table shows that all of the 38 northern Florida counties included in this report have federally designated HPSAs or Medically Underserved Populations/Areas (MUPs/MUAs) in one or more category:³²⁴

Quick Facts: HPSAs

Health Professional Shortage Areas may be designated as having a shortage of primary, dental, or mental health providers. HPSAs may be urban or rural areas, population groups, or public or medical facilities.

For primary care, a shortage means a population to provider ratio of greater than 2,000:1.

For dental care, a shortage means a population to provider ratio of greater than 3,000:1.

For mental health care, a shortage means a population to provider ratio of greater than 10,000:1.

See HRSA, Shortage Designation: Health Professional Shortage Areas & Medically Underserved Areas/Populations, <http://bhpr.hrsa.gov/shortage/>.

County	Primary Care HPSA	Dental HPSA	Mental Health HPSA	MUP	MUA
Alachua	LIMFP, WC, RHC	RHC, CI	RHC	LIMFP	
Baker	RHC, CI	CI, LIP, WC, RHC	RHC		WC
Bay	LIP, WC, CHC	LIP, WC, CHC	CHC, GA, WC		GA
Bradford	LIP, WC, RHC	LIP, WC	GA, WC, CI		WC
Calhoun	LIP, WC, CI	LIMFP, WC, CI	CI, GA, WC	LIP	
Citrus	LIP, WC, RHC, CHC	LIP, WC, CHC	CHC, LIP, WC	LIP	
Clay	GA, LIP	--	--		GA
Columbia	LIMFP, WC, CHC, RHC, CI	LIMFP, WC, CHC, CI, RHC	GA, WC, CHC, RHC	LIP	
Dixie	WC, CI	CI, LIP, WC	WC, CI		WC
Duval	LIP, CHC	CHC, LIP	CHC	LIP	GA
Escambia	GA, LIP, CI, CHC	LIP, WC, CI, CHC	CI, CHC	LIP	GA
Franklin	WC, CI	LIP, WC, CI	WC, CI	LIMFP	
Gadsden	WC	LIMFP, WC	LIMFP, WC		WC
Gilchrist	LIMFP, CI, WC, CHC	LIMFP, WC, CHC, CI	WC, CHC, CI	LIMFP	
Gulf	CI, LIP, CHC, RHC	LIP, WC, CI, CHC	CHC, GA, WC, CI	LIP	
Hamilton	WC, CI	LIMFP, WC, CI	GA, WC, CI		WC
Holmes	LIP, WC, RHC, CI	LIMFP, WC, CI	GA, WC, CI	LIP	WC
Jackson	LIP, CI, WC, RHC	LIMFP, WC, CI	CI, GA, WC	LIMFP	
Jefferson	LIP, CI, WC	LIMFP, WC, CI	WC, CI	LIP	
Lafayette	WC, CI	CI	GA, WC, CI		WC
Lake	LIMFP, WC, CI	LIMFP, WC, CI	WC, CI	LIMFP	
Leon	LIP, WC, CHC, CI	CI, LIP, WC, CHC	CHC, LIMFP, WC, CI	LIP	
Levy	LIMFP, WC, RHC	LIMFP, WC, RHC	RHC	LIP	
Liberty	WC, CI, CHC	WC, CHC, CI	WC, CHC, CI		WC
Madison	WC, RHC, CI	LIMFP, WC, CI, RHC	WC, CI, RHC		GA
Marion	LIMFP, WC, CI, RHC, CHC	LIMFP, WC, CHC, CI	CI, CHC, LIP, WC	LIMFP	
Nassau	GA	--	--		WC
Okaloosa	LIP, CI	LIP, CI	CI		GA
Putnam	LIMFP, WC, CHC, RHC	LIP, WC, CHC, RHC	WC, CHC, RHC	LIMFP	
Santa Rosa	CI, LIP	LIP, CI	CI		GA
St. Johns	LIP	LIP	WC, CHC	LIP	
Sumter	WC, CHC, RHC, CI	CI, CHC, LIP, WC, RHC	WC, CI, CHC, RHC		WC

Suwannee	WC, RHC	LIMFO, WC, RHC	GA, WC, RHC		WC
Taylor	LIP, RHC, CI, WC	LIP, WC, CI	WC, CI		WC
Union	LIP, WC, CI	LIMFP, WC, CI	GA, WC, CI		WC
Wakulla	WC, CI	LIMFP, WC, CI	WC, CI		WC
Walton	LIP, WC, CI	LIMFP, WC, CI	WC, CI	LIP	
Washington	WC, CI	LIP, WC, CI	GA, WC, CI		WC

LIMFP: Low Income/Migrant Farmworker Population **LIP:** Low Income Population **WC:** Whole County
CI: Correctional Institution **CHC:** Comprehensive Health Center **RHC:** Rural Health Clinic **GA:** Geographic Area
MUA: Medically Underserved Area **MUP:** Medically Underserved Population

Successes

Direct access to oral hygiene healthcare

Until this year, Florida was in the minority of states that required authorization by a dentist prior to a dental hygienist initiating treatment of a patient. A December 2010 report by the Florida Legislature’s Office of Program Policy Analysis and Government Accountability (OPPAGA) addressed this issue. While it avoided making a specific recommendation, OPPAGA concluded that “statutory changes to supervision requirements for dental hygienists may also provide hygienists the ability to serve patients in settings that focus on underserved areas.”³²⁵ Subsequently, during the 2011 regular session, the Florida legislature passed legislation expanding the permitted practice settings for dental hygienists to include “health care access settings,”³²⁶ a departure from existing law that limited practice settings for dental hygienists to the offices of licensed dentists and public health programs and institutions. The new legislation also expanded the scope of practice of dental hygienists to include fluoride application, dental charting, and prophylaxis as well as supervising the oral hygiene care of patients and instructing patients in oral hygiene.³²⁷ Florida now joins 31 other states with laws in place to allow direct access to dental hygiene services, meaning that a dentist need not examine or authorize dental hygiene services in at least some settings outside the office.

Opportunities

Improving access to oral healthcare services

In spite of some local successes, several providers and consumers in both urban and rural communities in northern Florida note the lack of access to dental care as a major obstacle for people living with HIV and AIDS.³²⁸ To improve access to dental care, advocates in Florida should consider the feasibility of a variety of policy and practice options, including:

- **Increasing awareness among nondental healthcare providers of the importance of dental care in managing HIV disease.** With proper training, nondental health care professionals can acquire the skills to perform oral disease screenings and provide other preventive services. The Institute

of Medicine (IOM) and National Research Council (NRC) recently issued a report³²⁹ on access to oral healthcare for vulnerable and underserved populations in the U.S. that recommended development of multidisciplinary core oral health competencies for nondental health professionals. The report emphasized the importance of involving a variety of stakeholders to ensure that they are appropriately broad.³³⁰ In this context, the importance of input from the HIV community cannot be overstated. While a national initiative such as that promoted by the IOM report may take years to launch and implement, this strategy could at least begin be deployed at the local/regional level by promoting dialogues between dental associations and HIV providers (medical and non-medical), and identifying training opportunities for nondental health providers.

- **Working with dental schools to expand opportunities for dental students to care for patients with complex oral health care needs**, including those living with HIV and AIDS, in community-based settings in order to improve the students' comfort levels in caring for vulnerable and underserved populations. Such an approach is currently in practice in Region 2A, where for \$3, clients of BASIC Northwest Florida have access to regular dental screenings and cleanings at Gulf Coast Community College.³³¹
- **Increasing Medicaid reimbursement rates**, especially in light of reports that in some health regions in northern Florida, there are no dentists who accept Medicaid patients. This problem is exacerbated by the statewide shortage of dentists, which makes it economically feasible for dentists to refuse to accept Medicaid patients.

ADAP Crisis

Successes

Florida's HIV/AIDS community has faced a massive challenge in avoiding gaps in treatment for consumers since the state's Bureau of HIV/AIDS was forced to institute a waiting list for the AIDS Drug Assistance Program (ADAP) in June 2010, and closed the program altogether for approximately six weeks in early 2011 before the 2011 funding year began. Using a sustained, coordinated, statewide approach, advocates successfully negotiated with industry and state health officials to secure and deploy an essentially gap-free drug access program (the Welvista ADAP Waitlist Solution Program) to cover 5,912 existing ADAP enrollees through the 2011 shut-down.³³² In addition to the massive effort that went in to securing the Welvista program, considerable resources were required to ensure that patients were seamlessly enrolled in the program and, for thousands on the ADAP waiting list, applying for Patient Assistance Programs (PAPs). While in many states, the administrative burden of PAP application documentation falls on the shoulders of already taxed case managers, some agencies in northern Florida reported that partner clinics stepped in to that role to streamline the process—another example of highly effective collaboration.³³³ Ultimately, commentators noted, few or none of their clients experienced gaps in treatment attributable to the ADAP crisis.³³⁴

Challenges

While multiple stakeholders around the state succeeded in a remarkable effort to avoid treatment gaps for those already enrolled in ADAP and to secure access to medications for those on the waiting list through PAPs, the ADAP crisis in Florida is far from over. First, and perhaps most troubling, is the trend of state and federal funding for ADAP simply not keeping pace with growing need. In spite of a national epidemic that continues to grow at a steady pace—roughly 50,000 new infections annually³³⁵—federal funding for the Ryan White program, which includes ADAP funding, has essentially flat-lined over the past several years at around \$2.1-\$2.2 billion.³³⁶

Second, Florida (along with all other states) experienced a several-month delay in the notice of final awards and disbursement of federal funding for 2011. By June 30th, the state had received only \$57.9 million—48% of its 2010 Ryan White award amount, with no indication of what the final award total would be for 2011. Of that amount, the state earmarked \$41 million for ADAP.³³⁷ By mid-September, the state had received notice of the final award amount, but not before the state's waiting list grew to 4,175 individuals—representing approximately 47% of the total number of people on waitlists nationally.³³⁸ (As of late September, HAB anticipated moving approximately 1,500 individuals off the waiting list and in to the program.)³³⁹

Third, Florida has not received a proportionate share of federal emergency ADAP funding in 2011. The final FY2011 continuing budget resolution passed by Congress in April allocated \$50 million in emergency ADAP funds to states. But despite Florida's having nearly half of the nation's wait-listed population, the federal government initially sought to limit each state's emergency award eligibility to \$3 million—a restriction that likely would have resulted in the state's inability to continue to provide medications for at least some ADAP enrollees.³⁴⁰ Largely in response to a joint effort by members of Florida's Congressional delegation, this restriction was lifted and states' eligibility was raised to allow states to receive at least as much in emergency funding as they received in the prior year (Florida received \$7 million in federal emergency ADAP funds in 2010).³⁴¹ However, while HRSA has not announced the final emergency funding award, it is not expected to reflect Florida's share of the wait list burden one-for-one; HRSA also appears to be taking in to account the need to address other cost-containment related program restrictions states have implemented over the past year, such as restricted formularies and reduced eligibility.

Opportunities

Maximize enrollment in the Pre-existing Condition Insurance Plan (PCIP) to alleviate pressure on ADAP

To assist individuals—including people living with HIV and AIDS—who have traditionally been unable to secure affordable, comprehensive health insurance coverage in the private market obtain meaningful coverage prior to the nationwide expansion of Medicaid and launch of state health insurance exchanges in 2014, the Affordable Care Act (ACA) provided for the establishment of temporary pre-existing condition health insurance plans in every state

PCIP Tip:

Find the PCIP application instructions and materials in both English and Spanish at <https://www.pcip.gov/Apply.html>.

beginning in 2010.³⁴² Under the ACA, each state could choose whether to administer such a plan on its own or allow the federal department of Health and Human Services (HHS) to do so on its behalf. Florida is one of 24 states that opted for a federally-administered PCIP.³⁴³

Florida’s PCIP was in place by August 1, 2010, and as of July 31, 2011, there were 1,454 individuals enrolled in the program statewide. Nationally, enrollment and spending for both federal- and state-administered PCIPs remains far lower than officials initially projected: “Before the program was implemented, the Congressional Budget Office estimated the program could cover an average of 200,000 individuals each year with the \$5 billion appropriation. The Office of the Actuary within the Centers for Medicare & Medicaid Services (CMS) projected enrollment of 375,000 by the end of 2010 and that funding would be exhausted by 2011 or 2012.”³⁴⁴ In fact, total enrollment in both state- and federally-run PCIPs as of July 31, 2011 was only 30,395.³⁴⁵

To encourage enrollment, the federally-run PCIPs have lowered premiums twice within the first year and expanded the program from one to three plan options. The following table shows the current monthly premiums—which vary by age, but not health status, tobacco use, geography, or gender—as well as deductibles and cost-sharing for the three plan options in Florida’s PCIP:³⁴⁶ (See Appendix 2 for the 2011 Summary of Benefits.)

Age	Standard Plan Monthly Premium	Extended Plan Monthly Premium	HSA Plan Monthly Premium
0 – 18	\$118	\$158	\$122
19 – 34	\$176	\$237	\$183
35 – 44	\$211	\$284	\$220
45 – 54	\$270	\$363	\$280
55+	\$376	\$505	\$390
Medical deductible	In-network: \$2,000 Out-of-network: \$3,000	In-network: \$1,000 Out-of-network: \$1,500	Combined medical and Rx deductible: \$2,500 (in-network) / \$3,000 (out-of-network)
Rx deductible	Formulary: \$500 Non-formulary: \$750	Formulary: \$250 Non-formulary: \$375	
Co-insurance rate for covered medical services after deductible met: 20% (in-network)* / 40% (out-of-network)			
<i>*Exceptions: \$25 copay for in-network primary and specialty care office visits; free in-network preventive services</i>			
Maximum annual out of pocket cost to consumer: \$5,950 (in-network) / \$7,000 (out-of-network)			

In addition, the federally-run PCIP relaxed the process used to determine eligibility. Until June 30, 2011, applicants were required to provide proof of denial or an offer of coverage with an exclusionary rider from another insurance carrier. Beginning July 1, 2011, HHS added a third option, which allows applicants to demonstrate their pre-existing condition by submitting a letter from a provider indicating a current or past diagnosed medical condition. (See Appendix 2 for a template provider letter that meets the HHS application requirements). In addition to documenting a pre-existing condition, an applicant must be a U.S. citizen (or be lawfully present) and have been without creditable insurance coverage for at least six months to be eligible for enrollment.

The PCIP provides comprehensive benefits coverage with no waiting period once an applicant is deemed eligible.³⁴⁷ In fact, federal regulation³⁴⁷ requires that an eligible individual who submits her complete

application before the 15th day of the month must be covered on the first day of the following month.³⁴⁸ The following benefits are covered: hospital inpatient and outpatient services; mental health and substance abuse services; professional services for the diagnosis or treatment of injury, illness or condition; non-custodial skilled nursing services; home health services; durable medical equipment and supplies; diagnostic x-rays and laboratory tests; physical therapy services (occupational therapy, physical therapy, speech therapy); hospice; emergency services; prescription drugs; preventive care; and maternity care.³⁴⁹ Notably, preventive care services are covered at no cost to the consumer if obtained in-network.³⁵⁰

Several unique administrative and logistical concerns attach to the enrollment in the PCIP of people living with HIV and AIDS who are current Ryan White program clients or ADAP enrollees. With respect to this population, it is important to note the following:

- **Ryan White funded medical care is not considered “creditable coverage” for purposes of PCIP eligibility.** Therefore, receipt of medical care services from a Ryan White HIV/AIDS Program funded clinic does not disqualify an individual from being eligible for the PCIP.³⁵¹
- **Program grantees may subsidize premiums and out-of-pocket benefit costs (annual deductibles, coinsurance requirements, and copayments) of Ryan White program beneficiaries who are enrolled in the PCIP program.**³⁵² Should nationwide enrollment increase dramatically, HHS may revise the rule on third-party premium payments to be more restrictive. However, current enrollment data suggests this will not be necessary.
- **Individuals with creditable insurance coverage, even if it is paid for with Ryan White HIV/AIDS Program Grant funds or another source, are ineligible for the PCIP program.**³⁵³ Creditable coverage includes, but is not limited to: COBRA, job-based coverage, individual market coverage, State high risk pools, and most other public programs (e.g., Medicaid, Medicare). Therefore, AIDS Insurance Continuation Program (AICP) enrollees are ineligible for the PCIP.
- **Providers can petition to be included in the PCIP provider network.** Maintaining provider continuity is an important concern for many people living with HIV and AIDS. To ensure that enrolling in the PCIP does not mean that consumers must change providers—and therefore dissuade eligible applicants from enrolling—it is important that current primary care and specialty care providers apply to be included in the PCIP provider network. This can be accomplished online at <http://www.pciplan.com/Providers/index.html> (click on “Network application”). According to CMS officials, the credentialing process can take a couple of months.³⁵⁴

A pilot program is underway in Area 11B to enroll certain high-cost Ryan White program clients in the PCIP and track costs for comparison. Anecdotally, it is reported that since the most recent decrease in PCIP premiums, it has been cheaper for the Ryan White grantee to pay for clients’ PCIP premiums and out-of-pocket costs than to keep them on full ADAP and pay for their medical care with Ryan White dollars.³⁵⁵

ADAP as TrOOP under the ACA to save state ADAP dollars and help Medicare beneficiaries

Historically, ADAP contributions for Medicare beneficiaries' medications in the Part D donut hole could not count toward the True Out-Of-Pocket (TrOOP) spending requirement to reach catastrophic coverage. As a result, Florida's ADAP, like many states', would essentially fall in to the donut hole along with those beneficiaries, and ended up paying for their medications until the end of each year even though they were enrolled in a Part D prescription drug plan.

However, beginning January 1, 2011, ADAP contributions by law count toward individuals' TrOOP in Medicare Part D. This change results from a provision of the national healthcare reform law and will relieve some of the burden on the Florida ADAP, as more Part D-participating ADAP enrollees will reach catastrophic coverage, under which Part D-covered drugs are available at nominal cost.³⁵⁶ (See Part II for information on other changes in Medicare under the ACA.) While the logistics of this change, including identification of a Pharmacy Benefits Manager (PBM), caused a bit of a delay in its on-the-ground rollout in Florida, a mechanism to track ADAP payments for Part D enrollees was in place in the state starting January 1, 2011.³⁵⁷ As a result, the state's ADAP should realize savings in the first year of this reform initiative.

Expanded Access to Care under National Healthcare Reform

Recent Census Bureau data shows that 49.9 million people (16.3% of the U.S. population) were uninsured in 2010—up from 49.8 million people (16.1%) in 2009.³⁵⁸ In Florida, approximately 3.9 million people were uninsured in 2010, representing 20.8% of the state's population.³⁵⁹ Two provisions of the Patient Protection and Affordable Care Act (ACA), the nation's healthcare reform law that was enacted in 2010, are expected to dramatically decrease the number of uninsured Americans: the launch of state health insurance exchanges, and the expansion of Medicaid eligibility. Both provisions take effect on January 1, 2014.

Challenges

State failure to plan for health insurance exchange

The ACA requires that by January 1, 2014, all states must have in place a health insurance exchange through which consumers and small businesses can

Spotlight on Florida's 2011 anti-healthcare reform legislation:

[H 1193](#), passed House and Senate and signed by Governor Scott on June 2, 2011 ([Chapter No. 2011-126](#)). This law prohibits a person from being compelled to purchase health insurance except under specified conditions, including dangerous occupation, voluntary enrollment in public benefits or contracts between private parties.ⁱ

[S 2](#), passed Senate and House; sent to the Secretary of State on May 4, 2011. This joint resolution proposes a state constitutional amendment to prohibit laws or rules from compelling any person, employer, or health care provider to participate in any health care system, permit any person or employer to purchase lawful health care services directly from health care provider, or permit health care provider to accept direct payment from person or employer for lawful health care services. Requires voter approval or disapproval on the November 6, 2012 ballot.ⁱⁱ

ⁱ insert citation

ⁱⁱ insert citation

Find more information on these and other 2011 bills at the National Conference of State Legislatures website at <http://www.ncsl.org/?tabid=18906>.

compare plans and purchase high quality, affordable health insurance coverage.³⁶⁰ Individuals and families purchasing health insurance through exchanges may qualify for premium tax credits and reduced cost-sharing depending on their income. Exchanges are not themselves health insurance plans; their function is to certify plans that meet ACA reform requirements and to serve as easily navigable, competitive marketplaces for individuals and small businesses to buy insurance.

The ACA provided for, and HHS has distributed, grants to states for the purpose of planning and establishing exchanges.³⁶¹ Florida applied for and received a \$1 million exchange planning grant in 2010, and is eligible for additional implementation grant funding from HHS in 2011.³⁶² However, Governor Scott and the Florida legislature have announced the return of the planning grant to the federal government, and it is assumed that the state will not apply for implementation grant funding³⁶³—which in other states has ranged from \$4 million (Nevada) to \$39.4 million (California).³⁶⁴

Florida's decision to defer planning and implementation of a health insurance exchange represents not only a loss of millions in federal funding for the state, but also a missed opportunity to create a marketplace uniquely tailored to the needs of Florida's consumers. Under the ACA, states have significant flexibility to determine the design of exchanges, for instance in deciding whether to participate in multi-state or regional exchanges, whether to establish subsidiary exchanges to serve distinct geographic areas, what additional benefits (if any) plans offered through the exchange must cover beyond the federally-required Essential Health Benefits Package (EHBP), and whether to allow issuers of large group plans to offer health insurance through the exchange.³⁶⁵ Florida's decision to forgo planning its own exchange also represents a lost opportunity for community involvement in shaping the exchange, because the ACA requires that in executing its decision-making authority, a state must consult with a range of stakeholders—including consumers, representatives from the small business and self-employed community, and advocates for hard to reach populations.³⁶⁶ Instead, if the state has not initiated meaningful exchange planning by January 1, 2013, HHS is required by law to commence establishing a federally-run exchange in the state to ensure that a functioning exchange is in place by January 1, 2014.³⁶⁷

State failure to plan for Medicaid expansion

In addition to creating state health exchanges, the ACA addresses the nation's high rate of uninsurance by eliminating the categorical eligibility requirements in Medicaid and expanding eligibility for the program to most individuals and families with income up to 133% of the federal poverty level (FPL) beginning January 1, 2014.³⁶⁸ An across-the-board 5% income disregard for Medicaid eligibility determination under the new law means that the effective income eligibility will be 138% FPL. Based on 2009 and 2010 Census Bureau data on poverty and uninsurance rates in the state, it is estimated that approximately 1.5 million individuals will be newly eligible for Medicaid in Florida under the expanded rules in 2014.³⁶⁹ (This figure does not account for future population growth or changes in rates of poverty or uninsurance, or the percentage of currently uninsured Florida residents whose immigration status is undocumented.) However, Florida health officials note that the state has not undertaken concerted planning for the Medicaid expansion.³⁷⁰

Opportunities

Exchange navigators

Despite the state's failure to initiate planning for new healthcare access opportunities under the ACA, Florida's HIV/AIDS community should be prepared to take steps to help ensure that the 2014 transition is a smooth one for people living with HIV/AIDS who will become eligible for Medicaid or who might qualify for subsidized private insurance through the exchange.

Creation of a health insurance exchange in Florida—whether it is ultimately state- or federally-administered—will increase access to much needed health services and prescription drug coverage for millions of Floridians. For many people living with HIV and AIDS— population that has historically been shut out of the private health insurance market—the exchange will allow access to affordable and reliable health insurance coverage for the first time; thousands of currently uninsured people living with HIV and AIDS will be moving in to a new health system. It is important to learn from the implementation of the Medicare Part D program and avoid the coverage interruptions and enrollment delays created by the program's complexity, the lack of sufficient assistance with navigation, and an overabundance of plan choices that did not offer meaningful differences in terms of coverage or mechanisms for plan comparison. Coordination with existing HIV/AIDS programs, including integration of Ryan White providers into exchange provider networks and culturally competent outreach and navigation assistance to current Ryan White consumers, is essential to ensure uninterrupted access to care.

To this end, existing agencies that provide case management and/or other support services to people living with HIV and AIDS should consider becoming officially designated exchange “navigators” by applying to the exchange for grants to provide navigation services. Under the ACA, entities eligible for navigator grants include community- and consumer-focused nonprofit groups that have existing relationships with uninsured and underinsured consumers who are likely to qualify for enrollment in a health plan through the exchange.³⁷¹ Navigator duties include:³⁷²

- Conducting public education activities to raise awareness of the availability of plans through the exchange
- Distributing information about enrollment in the exchange, including the availability of premium tax credits and cost-sharing assistance for those who are income-eligible
- Facilitating enrollment in health plans offered through the exchange
- Making referrals to appropriate agencies for enrollees with questions, grievances, or complaints regarding their health plan
- Providing information in a manner that is culturally and linguistically appropriate to the needs of the population being served

Advocacy

HIV/AIDS advocacy is a truly multi-faceted endeavor. Advocacy means different things to different people. In one sense, advocacy can mean asserting and defending one's own needs around access to care, support and treatment as a person living with HIV, whether in a health care setting or on the capitol steps. This section will discuss a broader, yet related, kind of advocacy. As members of and allies to the HIV/AIDS service and healthcare community, readers of this report are uniquely positioned to undertake local, regional, state, and even federal level policy advocacy strategies that seek to achieve systemic improvements for access to care, especially for poor and low income people living with HIV and AIDS. Importantly, advocacy strives not only to influence government policies, but also to shape public opinion and community and institutional norms. Even—and especially—at a time when the political and economic climate make the day-to-day aspects of serving the community and simply staying afloat more and more difficult, advocacy is an essential component of the portfolio of community-based organizations, healthcare providers, and consumers.

Challenges

“The politics in this town are totally ‘good-old-boy.’ Sometimes it works for us, and sometimes it really hurts us.”

Commentators across northern Florida note that with diminishing resources and overstretched staff, many organizations simply lack the capacity to undertake much advocacy activity. In Panama City, for instance, staff at BASIC NWFL described a loss of opportunities for case managers to talk about the need for advocacy with clients due to increasing case loads and reporting requirements that mean less one-on-one time with clients.³⁷³ Others lament a disengaged consumer base, and cite stigma, lack of awareness, and a changing population as factors that

currently contribute to that disengagement.³⁷⁴ Concerns about restrictions on lobbying activities for tax-exempt organizations also seem common, and may be a big reason why some community-based HIV/AIDS organizations are not active in advocacy networks. Finally, Florida's conservative political climate—both at the local and state levels—presents another obvious obstacle to successful HIV/AIDS advocacy today.

Successes

Florida HIV/AIDS Advocacy Network (FHAAN)

While many commentators across northern Florida noted a paucity of advocacy in the region today, the state has a long and rich history of successful HIV/AIDS advocacy. Florida's first HIV/AIDS advocacy group, The AIDS Institute (TAI), organized in the mid-1980s and incorporated in 1992 as a grassroots mobilization effort in response to the early HIV crisis. Over the next decade, TAI developed a strong working relationship with the Bureau of HIV/AIDS (HAB) in the Florida Department of Health. As issues came up in Florida, the group's leadership worked with HAB to address them. While this relationship

proved effective for HIV/AIDS programming at the state level, some speculate that it also contributed to grassroots disengagement and apathy, as concerted community-level actions and responses were rarely needed to achieve favorable results. With state resources shrinking over the past several years, TAI identified the need to reinvigorate Florida's advocacy community, and launched the state's current state-wide advocacy network, the Florida HIV/AIDS Advocacy Network (FHAAN), in 2008. Today, FHAAN has a base of over 1,200 participants, with over 300 active participants across Florida. The network is comprised of grassroots advocates, healthcare providers, and support services providers (e.g., case managers and outreach coordinators).³⁷⁵ FHAAN leaders note, however, that stakeholders in northern Florida are underrepresented within the network, despite ongoing efforts to activate and mobilize potential HIV/AIDS advocates in the region.

Activate U

One of the Florida HIV/AIDS community's biggest advocacy successes has been the Activate U Advocacy Academy, a program funded by AIDS United (and formerly, the National AIDS Fund) to promote grassroots advocacy training. Home-grown out of Okaloosa AIDS Support and Informational Services (OASIS) in Fort Walton Beach, Activate U trains hundreds of consumers annually through the Positive Living conference in addition to conducting workshops for grassroots advocates throughout northern Florida during the year. Topics include the basics on how to effectively advocate on HIV/AIDS issues and how to locate, and contact elected officials. Attendees are provided talking point data sheets on AIDS Drug Assistance Program (ADAP), AIDS Insurance Continuation Program (AICP), housing concerns for people living with HIV and AIDS, Medicaid updates, and issues relating to HIV prevention needs and funding.³⁷⁶

Opportunities

Build advocacy capacity and reach

There are a number of strategies that can serve to increase the northern Florida region's collective advocacy capacity even at a time when individual community-based organizations' staff and financial resources are stretched extremely thin.

First, it is crucial for agency leaders to understand that they have significant flexibility to undertake advocacy and lobbying without jeopardizing their organizations' tax-exempt 501(c)(3) status. Helpful overviews of the applicable federal and state laws and rules concerning lobbying are available in "non-legalese" formats from sources such as Alliance for Justice,³⁷⁷ AIDS Foundation of Chicago,³⁷⁸ and Independent Sector.³⁷⁹ Sharing this information with staff and board members will go a long way toward making everyone more comfortable with their roles as HIV advocates.

Second, the HIV community can take advantage of the work that other organizations and coalitions are already doing around advocacy. Adding voices from northern Florida's HIV/AIDS community to ongoing state and federal efforts will help ensure that the unique issues facing the region are not overlooked, and will help policy makers from the region to realize they must be accountable to their constituents. Doing so takes less time than one might think. Many state and federal coalitions of HIV and other health and disability advocacy organizations provide easy-to-complete advocacy action opportunities such as sign-on letters, template email messages that can be personalized, and talking points for making

Tips: Advocacy and Lobbying by Nonprofits

Non-profit organizations often shy away from advocacy because they are unsure what activities are permitted and what activities are restricted under tax law. In fact, most of what community-based organizations might consider undertaking with respect to policy actions is permissible advocacy—not lobbying.

Even activities that do qualify as lobbying are permitted within certain requirements. Federal law recognizes lobbying as an entirely proper function of nonprofits. Congress passed landmark legislation in 1976 to clarify and expand the extent to which nonprofit organizations could lobby without jeopardizing their tax-exempt status under Section 501(c)(3) of the Internal Revenue Code.

Permitted advocacy actions include issue education such as reports and fact sheets. Other actions that count as advocacy are non-partisan voter education, convening stakeholders, building relationships with legislators and regulators, polling, and building advocacy capacity. Notably, under IRS rules, advocacy relating to regulations, executive orders, litigation, and enforcement of current laws is *not* considered lobbying.

Lobbying, which is permitted within certain limitations under IRS rules, consists of communication that expresses a view about specific legislation *and* includes a call to action. (If directed at the public, the communication's call to action might be to contact legislators; if directed at legislators, the communication's call to action would be to vote a specific way on the piece of legislation.) But to qualify as lobbying, there must also be an expenditure of funds. Therefore, signing on to a letter prepared by another organization does not constitute lobbying, even if the letter takes a position on a specific piece of legislation. That's because lobbying occurs only when there is an expenditure of funds for an activity that meets the other criteria for lobbying.

Find more information about advocacy and lobbying in The Nonprofit Lobbying Guide, available online at http://www.independentsector.org/lobby_guide. (See chapter 9 in particular.)

phone calls or public comments. Often, the same coalitions and organizations also provide up-to-date information on federal and state policy issues of concern to the HIV/AIDS community. For example:

- In Florida, the [Florida HIV/AIDS Advocacy Network](#) (FHAAN) hosts monthly network calls and produces a weekly electronic newsletter to update the statewide HIV/AIDS community about program and funding developments at the state level regarding access to care and related issues (e.g., ADAP, AICP, Medicaid managed care, the Pre-existing Condition Insurance Plan).³⁸⁰
- At the federal level, healthcare access groups such as the [Treatment Access Expansion Project](#), [AIDS United](#), [Families USA](#) and [Community Catalyst](#), as well as groups with broader poverty justice missions such as the [SAVE for All](#) campaign of the Coalition on Human Needs, are excellent sources of information and action alerts, including social media actions.³⁸¹

HIV/AIDS organizations in northern Florida are encouraged to sign up for alerts from these groups—and to help clients sign up as well. The importance of consumer involvement in advocacy simply cannot be overstated. As more and more lawmakers use and pay attention to social media, participating in advocacy through social media outlets such as Twitter and Facebook can be a good first step for consumers who might be reluctant to engage more publically in advocacy.

Third, consider partnering with other disease- and program-specific organizations and coalitions in Florida. Policy matters relating to access to care for people living with HIV and AIDS often have implications for the broader health and disability community, and combining voices across interest groups can effectively amplify constituent messaging to lawmakers. Organizations that focus on mental health issues, Medicaid, immigrant rights, poverty, reproductive rights, justice for youth, and even legal services would be natural allies for the HIV/AIDS community at the local and state levels.

Finally, HIV/AIDS organizations should tap in to an often overlooked internal resource: boards of directors. Because they hail from a wide range of backgrounds and often have personal or professional contacts throughout communities, board members are an invaluable resource when it comes to building advocacy capacity. As constituents, personal letters or phone calls from board members to policy makers that explain why an issue is important to them and how it affects the organization and local community can add depth to direct actions from coalitions, particularly where the board members have direct or indirect relationships with the recipient of the message. It is important to keep board members informed of current policy matters that might affect the organization, to identify opportunities for them to take action, and clearly communicate expectations as to their involvement in advocacy efforts.³⁸²

Upcoming policy advocacy opportunities

Although the policy landscape is constantly changing, a few specific advocacy opportunities are worth mentioning here given the scope of the issues involved and the relatively long time frame during which opportunities for action will continue to arise:

- Florida Medicaid reform and managed care expansion—the Florida legislature passed sweeping Medicaid overhaul legislation in the 2011 session that would, among other things, essentially

expand the state's two existing Medicaid managed care pilot projects to the entire state.³⁸³ This change requires federal approval to implement, which to date has not been issued.

Transitioning to managed care is not necessarily a negative development for Florida. However, observers and stakeholders have reported some significant problems with the existing pilot programs, including increased fiscal strain on providers due to lower reimbursement rates; increased delays in patients' access to services due to prior authorization delays and lack of provider participation in managed care networks; and high rates of plan turnover.³⁸⁴

Consequently, advocates are advised to closely monitor new developments and participate in FHAAN efforts to ensure consumers' rights and meaningful access to care are protected throughout any transition process.

- Southeastern States National HIV/AIDS Strategy Initiative (12 Cities Expansion Project)—this new initiative will develop policy and strategy recommendations aimed at securing a federal commitment for implementation of the National HIV/AIDS Strategy (NHAS) in the parts of the Southeastern United States most impacted by the HIV/AIDS epidemic. The NHAS's 12 Cities Project, for example, will support comprehensive HIV/AIDS planning and cross-agency response in 12 urban communities with the highest estimated AIDS prevalence. While the 12 Cities Project is an important strategy for addressing the epidemic in these high-prevalence cities, there must be a corresponding strategy for addressing the epidemic in communities with the highest estimated incidence rates. The South is at the epicenter of the current HIV epidemic in the United States with the highest rates of new infections, the highest death rate from AIDS, the greatest number of people living with HIV/AIDS, the largest percentages of persons with HIV who are not in care, and the fewest resources. The NHAS has identified the South as a "geographic hot spot," and acknowledges that the South is disproportionately impacted by HIV. This campaign seeks to focus national resources where the epidemic is growing fastest.
- Healthcare reform implementation—advocates can look to national organizations for information about opportunities to participate in healthcare reform implementation. Although the state of Florida has essentially chosen not to participate in implementation planning activities for new initiatives under the Affordable Care Act, there are ongoing opportunities for individuals and organizations to weigh in on proposed federal implementing regulations (e.g., regulations for state health exchanges and details of the Essential Health Benefits Package (EHBP) that will be required under the Medicaid expansion for new beneficiaries as well as in state exchanges). In addition, broad-based efforts are needed to protect the health reforms already underway, including important Medicare Part D reforms (see Part II) and funding for programs supported by the new Prevention and Wellness Fund.

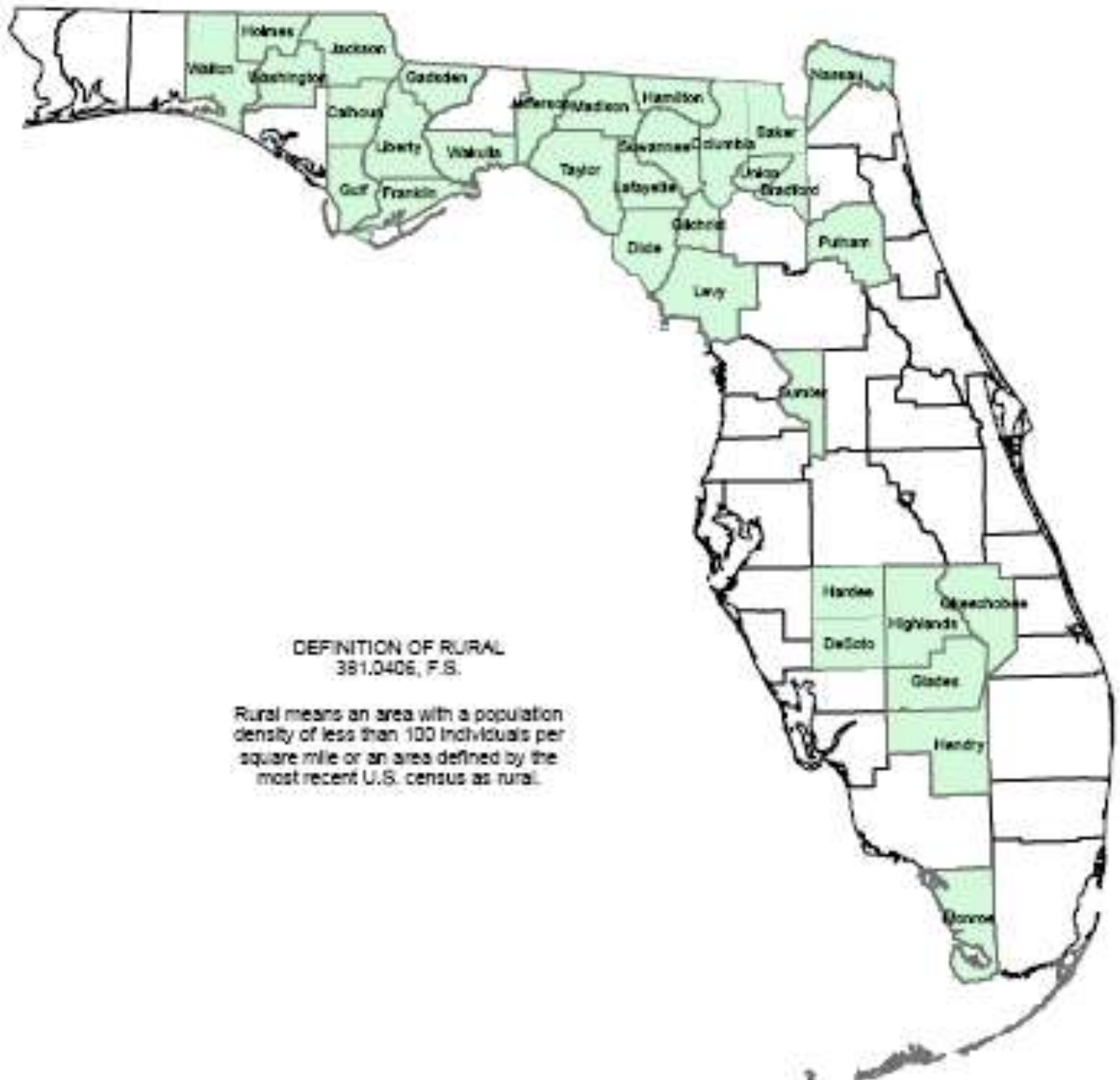
Part IV: Conclusion

[content under development]

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Appendix 1—Maps

Florida's Rural Counties

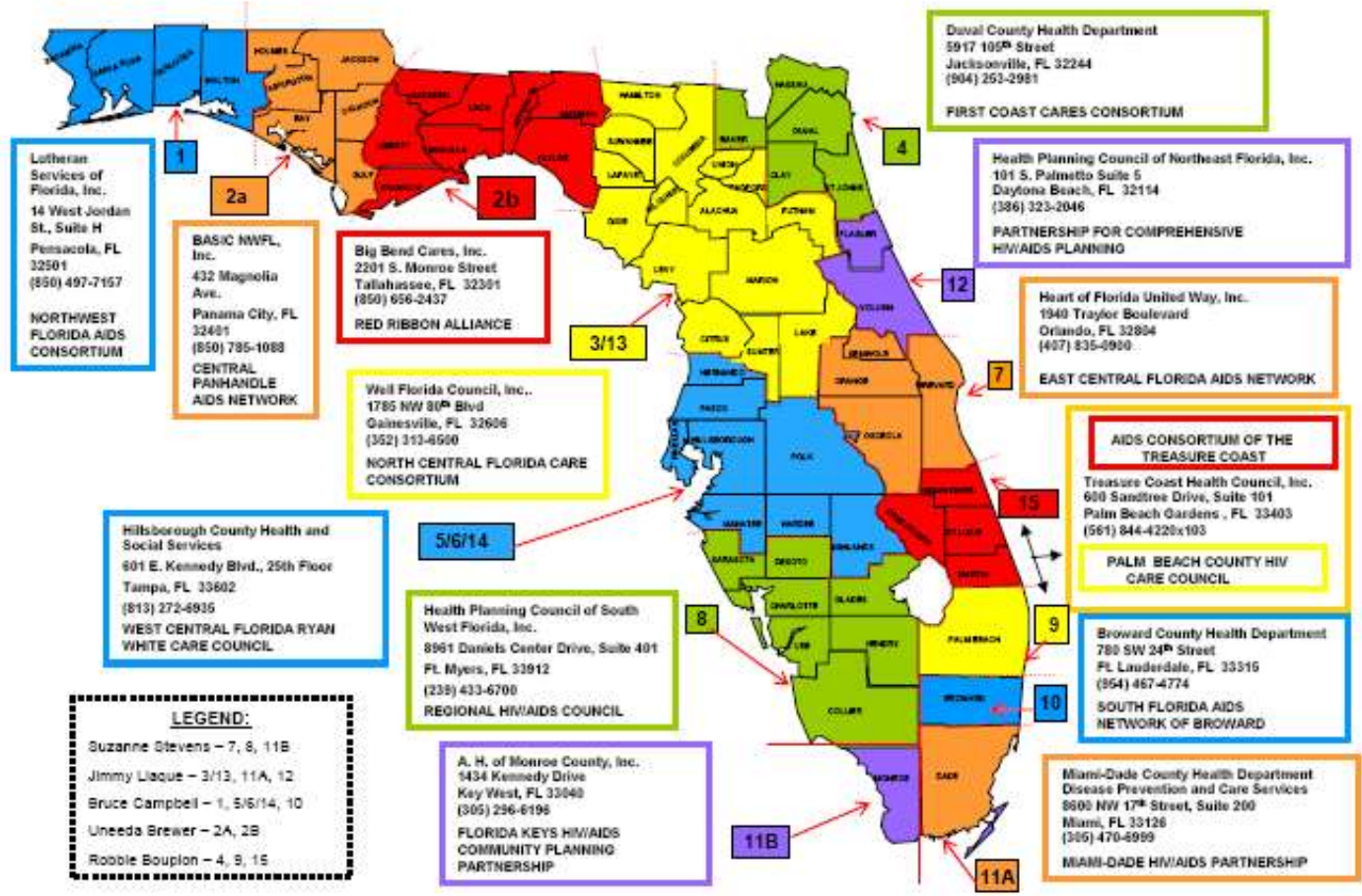


Source: Florida Department of Health, Office of Rural Health

http://www.doh.state.fl.us/workforce/ruralhealth/PDFs/Rural_Counties_Map.pdf

Appendix 1—Maps

State of Florida Ryan White CARE Act Part B Service Areas Consortia – Lead Agencies – Community Programs Coordinators



Source: Florida Department of Health

http://www.doh.state.fl.us/disease_ctrl/aids/care/RW_Consortia_Lead_Agencies_10_5_09rb2.pdf

Appendix 2—PCIP in Florida (Benefits Summary)

What you pay for care	Standard Option		Extended Option		HSA Option	
	In-network	Out-of-network	In-network	Out-of-network	In-network	Out-of-network
Deductible type	Separate medical & prescription deductibles		Separate medical & prescription deductibles		A combined medical & prescription deductible	
Deductible (medical)	\$2,000	\$3,000	\$1,000	\$1,500	\$2,500	\$3,000
Coinsurance (medical)	20%	40%	20%	40%	20%	40%
Catastrophic (or Out-of-Pocket) Maximum*	\$5,950	\$7,000	\$5,950	\$7,000	\$5,950	\$7,000
Inpatient Hospital Services [†]	20%	40%	20%	40%	20%	40%
Outpatient Surgery	20%	40%	20%	40%	20%	40%
Primary Care Office Visit	\$25 copay	40%	\$25 copay	40%	\$25 copay	40%
Specialty Office Visit	\$25 copay	40%	\$25 copay	40%	\$25 copay	40%
Annual Preventive Care Office Visit	Nothing	40%	Nothing	40%	Nothing	40%
Preventive Care – Other	Nothing	40%	Nothing	40%	Nothing	40%
Emergency Room	20%	40%	20%	40%	20%	40%
Lab – Outpatient	20%	40%	20%	40%	20%	40%
X-Ray ^{††} & Other Diagnostic Tests	20%	40%	20%	40%	20%	40%
Maternity & Newborn Care ^{†††}	20%	40%	20%	40%	20%	40%
Therapy Services ^{††}	20%	40%	20%	40%	20%	40%
Durable Medical Equipment (DME) ^{††}	20%	All charges	20%	All charges	20%	All charges
Skilled Nursing Facility ^{††††}	Benefits limited to \$700 day		Benefits limited to \$700 day		Benefits limited to \$700 day	
Home Health Care – skilled nursing, IV therapy ^{††} (limited to 25 in-home visits per calendar year)	20%	All charges	20%	All charges	20%	All charges
Hospice (combination inpatient & outpatient)	Benefits limited to \$15,000		Benefits limited to \$15,000		Benefits limited to \$15,000	
Mental Health/Substance Abuse	Same as medical conditions.		Same as medical conditions.		Same as medical conditions.	
Prescription Drugs:	Formulary	Non-formulary	Formulary	Non-formulary	Formulary	Non-formulary
Rx Deductible	\$500	\$750	\$250	\$375	NA	NA
Retail – up to a 30-day supply each fill						
Generic – First Two Fills	\$4	\$4	\$4	\$4	\$4	\$4
Generic – 3rd Fill & After	Greater of \$4 or 50%	Greater of \$4 or 50%	Greater of \$4 or 50%	Greater of \$4 or 50%	Greater of \$4 or 50%	Greater of \$4 or 50%
Brand – First Two Fills	\$40	\$80	\$30	\$60	\$30	\$60
Brand – 3rd Fill & After	Greater of \$40 or 50%	All charges	Greater of \$30 or 50%	All charges	Greater of \$30 or 50%	All charges
Specialty	25%, \$150 max	50%, \$300 max	25%, \$150 max	50%, \$300 max	25%, \$150 max	50%, \$300 max
Mail Order – 90-day supply						
Generic	\$10	\$10	\$10	\$10	\$10	\$10
Brand	\$100	\$200	\$75	\$150	\$75	\$150
Specialty	25%, \$350 max	50%, \$500 max	25%, \$350 max	50%, \$500 max	25%, \$350 max	50%, \$500 max

* In-network deductibles, copays and coinsurance apply to the in-network out-of-pocket maximum, but do not satisfy the out-of-network catastrophic (out-of-pocket) maximum.
[†] Pre-certification for these services is required. Therapy services include Physical & Occupational (up to 60 visits/calendar year); Speech (up to 30 visits/calendar year) and Cardiac or Pulmonary Rehab.
^{††} Only certain radiology procedures require pre-certification.
^{†††} Care of a newborn during the covered portion of the mother's maternity stay.
^{††††} Inpatient stay at a skilled nursing facility is covered for the first 14 days following transfer from acute inpatient stay, when skilled care is still required.

Additional information on prescription coverage:
 Under the Standard and Extended Options, you receive prescription benefits after just meeting the prescription deductible. Preferred Step Therapy and Prior Authorization rules apply to some medications. For a list of drugs on the formulary, go to www.pciplan.com. Non-preferred step therapy drugs are not a covered benefit. If you choose a brand-name drug for which a generic drug exists, you will pay the generic copay and the difference between the cost of the brand-name drug and the cost of the generic drug, unless your physician has provided clinical necessity for the brand-name drug which will require preauthorization. Only the generic copay will apply to your deductible and out-of-pocket maximum. The difference between the cost of the brand-name drug and the generic will not be applied to the deductible or annual out-of-pocket maximum. Specialty medications are those used to treat some severe, chronic medical conditions and are usually administered by injection or infusion.

For complete details on benefits, please see the 2011 PCIP brochure.

Source: Government Employees Health Association, Pre-existing Condition Insurance Plan 2011 Benefits Summary, <http://www.pciplan.com/forms/pdfs/2011BenefitsSummary.pdf>.

Appendix 2—PCIP in Florida (Sample Provider Letter)

[content forthcoming]

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²⁹⁷ Interview with Jennifer Findley, MSW, HIV/AIDS Program Coordinator – Area 1, Escambia County Health Dept. (June 2, 2011); Interview with Bobby Davis, HIV/AIDS Program Director, Alachua County Health Dept. (March 31, 2011); Interview with Leroy Jackson, Area 2A HIV/AIDS Program Coordinator, and Samuel Carter, Early Intervention/Contract Manager, Leon County Health Dept. (May 31, 2011).

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