Access to HIV/AIDS Services in Florida

2007 marks the 25th year of the AIDS epidemic

The HIV/AIDS pandemic is a global concern. The disease is now the leading cause of death for adults (age 15-59) worldwide. First documented in the 1980’s in isolated populations, HIV/AIDS has grown to become a disease which adversely affects the poor, both globally and domestically. Furthermore, the cost of care for HIV/AIDS has risen significantly over time. This issue brief seeks to explore the current status of health services for HIV-positive Floridians, and also touches briefly on coverage for HIV prevention services. The intention of this brief is to inform policy makers, providers, and health care advocates in their efforts to support quality health care and healthy populations in our state.

Historical and Epidemiological Context

Human immunodeficiency virus (HIV) is most often transmitted through sexual intercourse or sharing of injection drug needles; occasionally the infection is transmitted during birth from mother to infant, but new treatments have reduced this type of transmission to a relative handful of cases each year. Once infected with HIV, persons are initially asymptomatic for many years. Such persons are not considered to have AIDS. Over time, however, the virus’ relentless attack on specific components of the immune system results in a decrease in the body’s ability to fight off infections. AIDS is defined when the immune system becomes sufficiently impaired, or when persons begin to get sick with AIDS-related conditions.

The first cases of HIV/AIDS were diagnosed twenty-five years ago. Overall incidence of HIV has fallen since a peak in the 1980’s, however incidence is rising within certain subpopulations, including some racial and ethnic minorities, women, men who have sex with men, and youth. The introduction of effective HIV/AIDS treatments in the 1990s has reduced morbidity and mortality and as a consequence life expectancy has increased. However, roughly half of Americans currently infected with HIV are not in care or receiving these treatments. Managing the treatment of HIV is further complicated by comorbid conditions, substance abuse,
and lack of compliance resulting in drug-resistance. Additionally, although the US relies on advanced surveillance and data collection to track the spread of HIV/AIDS, one quarter of all people currently living with the disease do not know their health status, highlighting the need for increased testing and preventive services.

HIV/AIDS Trends in Florida

The emergence of AIDS in Florida was sudden. According to Florida’s Bureau of HIV/AIDS, at the end of 1980 there were 10 diagnosed cases of HIV/AIDS in Florida, resulting in 10 deaths and by 1984 there were 471 cases and 434 deaths. Today, approximately 10% of U.S. HIV positive persons (100,000 people) live in Florida, one in 229 Floridians is HIV positive, and 4,000 new cases are diagnosed each year.

Health Disparities

The National Institutes of Health define health disparities as “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.”

Race and Ethnicity: Since the beginning of the HIV/AIDS epidemic, racial and ethnic minorities have borne a disproportionate share of the disease burden. Nationally, Blacks and Latinos make up the majority of new diagnoses and existing cases. Of all racial disparities, the sharpest is between Blacks and Whites. In fact, Blacks account for over half of all HIV deaths in the United States, and alarmingly have lower survival rates upon diagnosis, indicating a lack of appropriate health care.

Gender and Age: Although three-quarters of HIV positive Floridians are male and over half of these cases result from male-to-male sexual contact, the prevalence of HIV/AIDS has slowly and steadily risen among females, who now account for almost one-third of all cases in the US. In Florida, the percentage of female AIDS cases rose ten percent in ten years, reaching 31% by 2005. Sixty-six percent of female HIV cases in Florida are among blacks. The primary mode of transmission to women is heterosexual contact.

Legal Status and Geography:

Documenting HIV rates among undocumented immigrant populations is a continuing challenge. However, population mobility increases the risk for HIV/AIDS and with Florida’s high rate of immigration, focusing on this high-risk and hard to reach group of Floridians will increasingly become more important. Disparities also exist geographically between rural and non-rural counties. It is presumed that some rural/urban disparities stem from average socioeconomic status of residents, education level, and/or lack of access to health care. More research into causes of inequality is needed, especially in relation to rural women and HIV.
Health Insurance and the Uninsured: Of all the trends so far discussed, disparities between insured and uninsured HIV/AIDS patients are the most directly tied to health care access issues. A regular source of care is essential to appropriate HIV/AIDS treatment, which calls for disease management and complex drug regimens. Correlations between insurance status and HIV/AIDS point to a lack of access to care for those without appropriate insurance coverage, whether public or private. The lack of a regular source of health care can lead to delayed treatment, irregular drug therapy, and even increased mortality. The benefits of being insured for HIV-positive persons were greatly increased with the introduction of antiretroviral therapy, an effective but difficult-to-afford treatment option. In fact, health insurance has lowered the probability of six-month mortality by about three-fourths. Although the majority of insured HIV/AIDS patients are covered through Medicaid or other programs, roughly 20% of HIV-positive people are uninsured.

HIV/AIDS Care: Access and Financing

Research has shown that 42% to 59% of people living with HIV/AIDS in the US are not receiving regular care. Ensuring access to appropriate care and emphasizing prevention must remain a top priority for the state of Florida in order to maintain control over a growing epidemic.

Without private coverage, how do HIV-positive Floridians access health care?

A large network of federal, state, and local programs, both governmental and non-governmental, provide health care and support services to HIV/AIDS patients in Florida. These services are invaluable, but the lack of a cohesive system continues to represent a barrier to appropriate care.
Many patients obtain care and financing through multiple sources, a practice which inevitably leads to gaps in care or coverage. Below, several of the largest sources of financing and provision of HIV/AIDS care for Floridians are reviewed. Many patients receive care through more than one of the following programs.

**Ryan White and the AIDS Drug Assistance Program (ADAP)**

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act (Ryan White Program) is the United States’ largest federally funded program financing HIV/AIDS care after Medicaid and Medicare, and the only disease-specific program of its kind. In 1990, when it became apparent that many urban hospitals were struggling to keep up with the growing HIV/AIDS epidemic, the CARE Act was enacted to fill gaps in care and to improve the quality and availability of care for low-income, uninsured, and underinsured individuals and families affected by HIV/AIDS. CARE Act clients are typically the most disadvantaged HIV patients, coming from low socioeconomic status and from racial and ethnic minorities. In 2004, more than 59 percent of clients served by the CARE Act were people of color.

Nationally, one in five (20%) HIV-positive people is uninsured. Many of these receive care through programs sponsored by the Ryan White CARE Act. Unlike Medicaid, Ryan White is not a public insurance program. Instead, the Health Resources and Services Administration’s HIV/AIDS Bureau funds grantees nationwide, who, in turn, deliver care to half a million people every year. Ryan White has been reauthorized three times since it was first passed, and is composed of five Parts. The program is named after Ryan White, a teenager whose struggle with HIV/AIDS and AIDS-related discrimination brought the disease to public attention.

Florida ranks third in the nation, after New York and California, in its total Ryan White funding, estimated at over $210 million per year. Over half of this funding goes towards Part B of the Act, which covers ambulatory health care, home-based health care, insurance coverage, medications, support services, outreach to HIV-positive individuals who know their HIV status, early intervention services, and the AIDS Drug Assistance Program. One-third of Florida’s Ryan White resources fund Part A of the Act, which provides emergency assistance to Eligible Metropolitan Areas (EMAs) most severely affected by the HIV/AIDS epidemic.

The AIDS Drug Assistance Program (ADAP) is a key component to the Ryan White program. ADAP provides...
its clients with medications, disease management training, and information. To qualify for ADAP assistance, the recipient cannot receive these same services through Medicaid, Medicare, or another insurance program. In Florida, the ADAP Wrap-Around Pilot Project provides select Medicare eligible clients with assistance in the payment of their out-of-pocket Medicare Part D pharmacy and deductible expenses.\(^{21}\)

Another program funded by the Ryan White program is the Minority AIDS Initiative (MAI), established to help to identify and assist people of color who are HIV-infected but not receiving any medical care. MAI uses the Antiretroviral Treatment Access Study (ARTAS), a short-term intervention, which places an emphasis on identifying an individual’s strengths and using these strengths to achieve goals. Most of the MAI clients suffer from substance abuse and/or mental health illness and are referred appropriately. Although the target population is minorities, MAI does serve non-minority individuals who know their HIV status and are not under care.\(^{22}\)

It is important to recognize that the CARE Act was established to *fill gaps in care*, not to be a primary provider of HIV/AIDS care in the US. The program is strained as the HIV/AIDS epidemic spreads, with some states enacting cost-containment strategies to stretch their Ryan White dollars and others establishing waiting lists for HIV/AIDS treatments. High utilization of Ryan White programs then, is an indicator of wide-spread lack of access to HIV/AIDS care. In a report entitled, “Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White,” the Institute of Medicine calls for an overhaul of the current HIV/AIDS health system.\(^{23}\)

Under the direction of the 1997 Legislature, the Agency for Health Care Administration (AHCA) established a Medicaid disease management initiative to control costs and improve health outcomes for its chronically ill recipients. In 1999, AHCA awarded a contract to the AIDS Healthcare Foundation (AHF)\(^{26}\) to provide disease management services for Medipass HIV-positive recipients. This contract brought thousands of Floridians under AHF’s disease management program, ‘Positive Healthcare.’ In a 2004 report, Florida’s Office of Program Policy Analysis and Government Accountability (OPPAGA) indicated that AHF’s program was effectively cutting costs and had

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**Insurance Coverage Among Persons With HIV/AIDS in Care, United States, 1996**

![Insurance Coverage Chart](chart.png)

reached the majority of recipients who were eligible for its services.\textsuperscript{27}

Under Florida Medicaid Reform in some counties, operation of disease management programs is being transitioned to contracted health plans and MediPass is being discontinued. It is still too early to measure the effects of this transition on Florida’s HIV/AIDS population. A recent debate over the discontinuation of AHF services has not yet been resolved, as advocates and patients continue to appeal the decision. The action by AHCA has prompted AIDS Healthcare Foundation to file a lawsuit against the agency.\textsuperscript{28} Post-reform assessment of HIV/AIDS patient satisfaction and quality is recommended.

HIV-positive Floridians who do not qualify for Medicaid may be eligible for the Medically Needy Program. After incurring a pre-determined amount of medical bills each month (based on income and household size) a Floridian can apply for Medicaid to cover additional costs. This supplemental coverage is applied for and granted on a month-by-month basis.\textsuperscript{29} For high-utilization clients such as HIV/AIDS patients, tracking and submitting medical bills could represent a significant barrier to accessing this program.

Florida’s Project AIDS Care (PAC) is a waiver program authorized under federal legislation enabling state Medicaid agencies to provide home and community-based services to AIDS patients as a more humane and more cost-effective way to ensure appropriate care.\textsuperscript{30} PAC is a ‘special enhancement’ of Florida Medicaid, which pays for certain services not covered under the standard Medicaid benefit package. These services are often delivered in the home and go beyond health care to include social services. Other states have implemented Medicaid waivers to expand services and eligibility, a policy issue that will be discussed further below.

\textbf{Florida Department of Health}

The Florida Department of Health’s Bureau of HIV/AIDS is a champion of public health and prevention, but also facilitates certain aspects of HIV/AIDS care and financing. The AIDS Insurance Continuation Program (AICP) is a state program for persons who are diagnosed with AIDS or are HIV-symptomatic, and who cannot afford to pay their private insurance premiums. The program makes direct payments (up to $750/month) to participants’ employers or insurance companies for continuation of medical, dental, and vision coverage.

AICP is funded by Florida’s Department of Health (via federal and state dollars) and managed by the Health Council of South Florida, Inc., a private nonprofit agency. It is administered through regional community-based organizations. The program is designed to save Florida money by keeping HIV/AIDS patients insured and out of other public programs.\textsuperscript{31} Additionally, the DOH offers confidential and anonymous testing and counseling to the general public through any of its county health department locations.\textsuperscript{32}

\textbf{Medicare}

Medicare is a federal health insurance program that covers people over 65 years of age and Americans with a permanent disability. Medicare accounts for just over one-quarter of federal spending on HIV/AIDS care in the US and is an important source of coverage for people living with HIV/AIDS who qualify for Social Security Disability Insurance (SSDI). Only a small fraction of HIV-positive Medicare recipients qualify on the basis of age only, as just 3% of HIV-positive Americans are over the age of 65.\textsuperscript{33}

Since the 2006 approval of a new prescription drug benefit, Medicare’s
stake in HIV care has risen. As discussed above, pharmaceuticals comprise a large and costly portion of HIV care based on current standards. According to the Department of Health and Human Services, all drug plans contracted through Medicare are required to cover all anti-retroviral drugs. However, some research shows HIV-positive recipients having problems filling prescriptions. In a recent survey, seventy-five percent of HIV medical providers reported that they had patients who went without medications.34

Medicare beneficiaries are required to join Medicare plans, however the Ryan White Program’s ADAP has supported Medicare beneficiaries during their transition to new drug plans, helping to cover plan premiums, co-pays, and medication costs.35,36 Dual-enrollment in Medicare and Medicaid is common, with roughly two-thirds of HIV-positive Medicare enrollees also covered by Medicaid.37 However, as of January 2006, Medicaid drug coverage terminated for any dual eligibles, and Medicare Part D picked up full prescription coverage. The effects of Medicare Part D on HIV/AIDS care will be an ongoing focus of research.

Veteran’s Affairs (VA)
The VA health care system, widely known for its large-scale integration, is both a payer and provider of HIV care, making it the largest single provider of HIV care in the US. As a federal program, the VA serves almost 20,000 HIV-positive veterans annually. The VA’s National HIV/AIDS Program provides testing, treatment, and counseling for veterans, and is a resource of disease-related information, guiding patients through all steps of the health care process: getting tested, adjusting to diagnosis, and making treatment decisions. There are sixty-seven VA locations in Florida providing care to an important segment of our population.38

HIV/AIDS Prevention and Public Health Services: Access and Financing

The national leader in HIV/AIDS prevention is the Centers for Disease Control and Prevention (CDC). The CDC estimates that approximately 40,000 new HIV infections occur in the United States each year. Prevention of these new infections is extremely cost effective, compared to the expense of treating the

Table 1. HIV (not AIDS) and AIDS cases, top ten reporting states, 2004. (2005 data not available)

<table>
<thead>
<tr>
<th>Reporting States**</th>
<th>Number of AIDS Cases</th>
<th>% US AIDS Cases</th>
<th>Number of HIV Cases***</th>
<th>% US HIV Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>New York</td>
<td>7,641</td>
<td>17%</td>
<td>6,033</td>
<td>18%</td>
</tr>
<tr>
<td>Florida</td>
<td>5,822</td>
<td>13%</td>
<td>5,107</td>
<td>15%</td>
</tr>
<tr>
<td>California</td>
<td>4,679</td>
<td>10%</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Texas</td>
<td>3,290</td>
<td>7%</td>
<td>4,143</td>
<td>12%</td>
</tr>
<tr>
<td>New Jersey</td>
<td>1,848</td>
<td>4%</td>
<td>1,704</td>
<td>5%</td>
</tr>
<tr>
<td>Illinois</td>
<td>1,679</td>
<td>4%</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Georgia</td>
<td>1,640</td>
<td>4%</td>
<td>2,124</td>
<td>0%</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>1,629</td>
<td>4%</td>
<td>1,330</td>
<td>4%</td>
</tr>
<tr>
<td>Maryland</td>
<td>1,451</td>
<td>3%</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>North Carolina</td>
<td>1,137</td>
<td>3%</td>
<td>1,099</td>
<td>3%</td>
</tr>
<tr>
<td>Remainder of US*</td>
<td>13,913</td>
<td>31%</td>
<td>11,993</td>
<td>36%</td>
</tr>
<tr>
<td>**Total Cases</td>
<td>44,747</td>
<td>100%</td>
<td>44,747</td>
<td>100%</td>
</tr>
</tbody>
</table>


**Remainder of states where HIV is reportable as of 12/02: Alabama, Alaska, Arizona, Arkansas, Colorado, Idaho, Indiana, Iowa, Kansas, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Mexico, North Dakota, Oklahoma, South Dakota, Utah, W. Virginia, Wisconsin and Wyoming.

Connecticut has confidential HIV infection reporting for pediatric cases only.

Washington reports symptomatic infection and name-to-code-based system. California, District of Columbia, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Rhode Island and Vermont report HIV on a code based system. Delaware, Maine, Montana, and Oregon report on a name to code based system. New Hampshire has other type of reporting.

Data only from those states where HIV is reportable.

Includes only persons reported with HIV infection who have not developed AIDS.

disease. HIV prevention services include diagnostic testing for HIV and other STDs, and interventions to reduce transmission, such as counseling, condom distribution, prevention case management, substance abuse treatment, and mental health services. These HIV prevention services can be delivered in a variety of clinical settings, and the reduction of barriers to early diagnosis of HIV and access to other prevention services is critical. The CDC has endorsed a strategy called the ‘Advancing HIV Prevention (AHP) Initiative’ which aims (1) to make HIV testing a routine part of medical care, (2) to increase diagnosis outside of medical settings, (3) to prevent new infections, and (4) to decrease perinatal transmission. In response to the CDC’s Initiative, the Florida Department of Health’s Bureau of HIV/AIDS has established teams to tackle each of these four goals.

Because disparities persist and HIV does not affect all communities equally, the effectiveness of prevention efforts can be maximized by targeting specific populations and implementing programs at the local level. Recognizing this, Florida’s Department of Health (DOH) has stepped up its commitment to addressing HIV/AIDS prevention in minority populations and has established an enormous range of projects related to the issue. For example, the DOH established a statewide media campaign entitled, “We Make the Change” as well as community mobilization meetings which involve the grassroots organizations in the work of the HIV/AIDS Minority Network. The network was created to build capacity and develop links between community organizations and the DOH, and to provide peer-based support and mentoring.

Another program, the HIV/AIDS Prevention Education Project, works to strengthen HIV/AIDS prevention education and school health education in Florida. The Perinatal HIV Program works to prevent mother-to-child HIV transmission by educating women and health care providers on the importance of HIV testing for pregnant women and the availability of treatment to prevent perinatal transmission. The number of newly diagnosed HIV and AIDS cases in infants has declined 96 percent since 1992, less than two percent of HIV-infected women deliver an infected infant each year.

Financing for HIV prevention services varies according to type of service and type of payer. The major providers of funding for HIV/AIDS care (Medicaid and Ryan White) also allocate funding for most HIV prevention services. However, these services generally are optional services and therefore must be supported by legislative or other administrative decisions. Some HIV prevention decisions are controversial due to disagreements regarding the best methods to reduce risky sexual behavior and shared injection drug use. It is also difficult for providers to document and bill for HIV prevention services such as counseling. Financing organizations may

Factors Affecting HIV/AIDS Disparities:

- Late diagnosis of HIV.
- Access to/acceptance of care.
- Delayed prevention messages.
- Stigma.
- Non-HIV STD’s in the community.
- Prevalence of injection drug use.
- Complex matrix of factors related to socioeconomic status.

be able to identify new methods to provide incentives to encourage more access to HIV prevention services.

Conclusion

Florida has the 2nd highest number of persons with HIV/AIDS in the nation. The majority of these persons do not have private insurance; rather, they receive care through a variety of publicly funded service programs. Treatment for HIV is available and effective, but very expensive. In 2007, the system continues to evolve, with Medicaid Reform changing the financing and organization of care for a large number of Floridians with HIV infection. Although the Reform effort has resulted in numerous complaints from various parties, it is still too early to determine the actual impact of Reform on health outcomes.

Funding for HIV prevention programs is likely to be cost effective but often difficult to implement due to competition for funding from programs providing direct care for persons who are already infected. HIV prevention programs are likely to reduce costs related to HIV over the long run, but require initial funding and societal acceptance. More data on the impact of financing options on healthcare outcomes and utilization should be available in the near future.

Prepared by:
Lisa Chacko, MPH
Robert Cook, MD, MPH
Melisa Foronda, BHS

Endnotes


5 Florida Department of Health: Bureau of HIV/AIDS Home Page www.doh.state.fl.us/disease_ctrl/aids/index.html


7 The Kaiser Family Foundation, statehealthfacts.org. Data Source: Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention-Surveillance and Epidemiology, Special Data Request, November 2006.

8 Florida Department of Health. The Perinatal HIV Program www.floridashealth.com


EmAs must have reported at least 2,000 AIDS cases during the previous 5 years and have a population of at least 500,000.


‘Positive Healthcare’ was the first disease management program designed specifically for HIV-positive Medicaid recipients US, and the first DM organization to receive accreditation from the National Committee for Quality Assurance (NCQA).


AIDS Healthcare Foundation. www.aidshealth.org

Florida Department of Children and Families. www.dcf.state.fl.us/ess/medicaid.shtml


Florida Department of Health, AIDS Insurance Continuation Program. www.doh.state.fl.us/disease_ctrt/aids/care/aicp.html


