

Entering 2011, we have a historic opportunity to change the story about HIV in Illinois and the United States. We are on the cusp of groundbreaking changes, including improved outcomes in the fight against HIV/AIDS thanks to national health care reform and implementation of the National HIV/AIDS Strategy. But the challenges ahead are formidable and demand strategic thinking, creative advocacy, and broad community engagement. Changing the story about HIV/AIDS is possible—but only with your help. The pages that follow explain how.

# 2010 victories inspire hope in the fight against HIV/AIDS.

In March 2010, President Obama signed into law the **Affordable Care Act**, which promises to transform the fight against HIV. In July, President Barack Obama released the **National HIV/AIDS Strategy**, a blueprint for reducing new HIV infections, improving the health of people with HIV, and reducing health disparities. Illinois Governor Pat Quinn also announced that, thanks in part to a six-month advocacy campaign, the **Illinois AIDS Drug Assistance Program (ADAP)** would not see waiting lists or major cost containment in the 2011 state fiscal year. Finally, capping two years of advocacy by the AIDS Foundation of Chicago (AFC) and the Responsible Budget Coalition, the General Assembly passed and Governor Quinn signed into law **state tax reform** to provide short-term stabilization for the state's financial crisis.



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#### But these victories are at risk in 2011.

The new majority in the U.S. House is pressing for repeal of the healthcare reform law. Washington's myopic focus on deficit reductions threatens implementation of the National HIV/AIDS Strategy, expansion of health insurance options, and availability of essential HIV services. ADAPs in 10 states have waiting lists, and Illinois' program will face cutbacks without a major cash infusion. While the state tax increase took the state budget off life-support, the state could have a \$5 billion structural deficit in the foreseeable future.

## **Progress is possible**

Illinois HIV/AIDS Policy Priorities—informed through stakeholder meetings in late summer and fall with people living with HIV, service providers, and advocates statewide—establishes priority changes in public policy to make headway against the HIV epidemic in 2011. Through hard work, concerted advocacy, and renewed commitment, we can make a world of difference in the lives of people with and at risk for HIV/AIDS.

# **Seven Game-Changers: HIV Priorities for Illinois**

AFC's Seven Point Plan is designed to inform policymakers of priority activities needed to combat the HIV/AIDS epidemic in Illinois.

#### 1. Prioritize HIV Prevention

Today, it's estimated that over 45,000 people are living with HIV in Illinois. However, state HIV prevention funding was cut by nearly \$2 million in 2010 to maintain access to life-saving medications through ADAP. State and federal funding is scarce, so Illinois must wring more benefit from every dollar by establishing more formal collaborations between organizations and focusing services on the hardest-hit populations, including gay men of all races, African Americans, and Latinos. Consistent with the national strategy, all funding streams must target populations most at risk for HIV/AIDS.

# 2011-2012 Policy Priorities at a Glance

- 1. Prioritize HIV prevention
- 2. Improve mental health and substance abuse treatment services
- 3. Increase the number of health care professionals offering high-quality HIV primary and specialty care
- 4. Focus on emerging populations
- 5. Reduce the stigma of HIV
- 6. Provide people in prison and jail with high-quality HIV services, including harm reduction and community re-entry services
- 7. Increase access to housing for people with HIV



At the same time, Illinois must maintain funding for interventions that have demonstrated success in reducing infections, such as sterile syringe availability, or risk eroding recent progress slowing infections among injection drug users. Among its highest HIV prevention priorities, AFC and members of the Illinois Coalition for Reproductive Health and Access will work to enact the *Personal Responsibility Education Program (PREP) Act* to require Illinois schools to provide comprehensive and medically-accurate sex education based on evidence. The *HIV Prevention Justice Alliance* (<a href="www.preventionjustice.org">www.preventionjustice.org</a>), a nationwide coalition led by AFC, will focus on structural factors that lead to HIV infection, such as lack of housing, stigma, and incarceration.

#### **Policy Recommendations**

- Consistent with the National HIV/AIDS Strategy, target HIV prevention funding to mostimpacted populations, according to the state's HIV/AIDS epidemiological profile.
- Increase funding for counseling, testing, referral and outreach services and increase public awareness of HIV/AIDS
- Expand school-based HIV prevention tailored for young people, particularly those most at risk of infection
- Champion efforts to establish an Illinois HIV/AIDS Strategy that streamlines all stateefforts involved in the fight against HIV/AIDS to achieved greater outcome with limited state funds available for anti-HIV prevention activities

# 2. Improve mental health and substance abuse treatment systems

Thirty years after the first report of what came to be known as AIDS, untreated substance abuse and mental health conditions continue to drive the HIV epidemic. Chronic or occasional substance users are often unable to negotiate safer sex or condom use. Untreated depression and low self-worth hammer a person's desire to live a healthy life free of HIV. State budget cuts have shuttered treatment programs for people without insurance, further increasing their risk of HIV. State and federal governments must increase mental health funding for people who are uninsured, and make substance abuse treatment available on demand. People who are newly diagnosed with HIV face trauma from their diagnosis; funding should be sufficient to ensure that all newly diagnosed people can access the care they need to manage the emotional and psychological effects of

- Increase mental health access for people newly diagnosed with HIV
- Increase mental health and substance abuse treatment funding
- Recognize untreated substance abuse and mental health conditions as drivers of the HIV epidemic



testing HIV-positive. In the Illinois General Assembly, AFC will advocate for passage of the Emergency Medical Services Access Act, which would offer injection drug users—at high risk of HIV and hepatitis—protection from arrest and prosecution when seeking emergency medical treatment for drug overdose victims. Today, people who overdose are too often abandoned to die because injecting partners fear arrest for drug possession.

#### **2011 FEDERAL FOCUS**

Promote the benefits of the health reform law and focus on implementation: National health reform is a game-changer for people with HIV. Today, nearly half of all people with HIV are uninsured, and rely on the overstretched Ryan White care system for essential clinical and non-clinical services. Thanks to the Affordable Care Act, nearly all low-income people with HIV will have access to comprehensive, affordable health care through Medicaid or subsidized private insurance in 2014. Congressional efforts to repeal health reform, or block its full implementation, would deny people with HIV and other uninsured people from the health services they need and deserve. Illinois will make implementation decisions this year and next year that will shape the future of the state's health care system. Healthcare consumer advocates—including people with HIV—must be educated about the impact of those changes and have a voice at the table when critical decisions are made.

Protect federal funding for essential HIV programs: As Washington focuses on reducing the federal deficit, the rest of the nation is experiencing lackluster economic growth, and unemployment remains at historic levels. While cutting the federal deficit is essential to the nation's future prosperity, people with HIV and other vulnerable populations should not be denied medical care, housing, or medications in the process. We will emphasize the stark tradeoffs presented by the federal budget. We will change the story by rejecting misplaced federal priorities that all too often short-change low-income and middle-income Americans of the health, housing, and support services they need to survive. We will challenge the idea that funding cannot be found, insisting on sacrifices from special interests and powerful lobbies that benefit only a few. AFC's regional ADAP mobilization project will enhance the capacity of state HIV networks to advocate for increased ADAP funding.

**Implement the National HIV/AIDS Strategy:** The National HIV/AIDS Strategy—championed by advocates since 2007—became a reality when President Obama released the plan in July. In 2011, we will hold federal officials accountable—including Congress—for coordinated, bold efforts calibrated to achieve HIV/AIDS targets set by the President, including reducing incidence of HIV.



#### **Policy Recommendations**

- Meet the medical and psychosocial needs of people with HIV who are over 50
- Expand culturally and linguistically appropriate prevention and intervention services for immigrants.
- Increase employment and training for longterm HIV survivors.

## 3. Focus on Emerging Populations

Three decades into the HIV epidemic, specific populations face special needs that are unmet by the current system. Examples include people with HIV who have been living with the disease—and the effects of potent anti-HIV medications—for longer than anyone thought possible, and are now over 50 and aging. Long-term survivors and newly diagnosed people need employment training so they can become economically self-sufficient, thriving members of society who contribute to the nation's economic prosperity. Growing populations of immigrants face legal, linguistic, and cultural barriers to accessing prevention and care services.

# 4. Increase the number of health care professionals who can provide high-quality primary and specialty treatment to people with HIV.

As the United States stands on the brink of a historical transformation of the health care system, too few health care professionals are able to offer high-quality primary medical, infectious disease and other services to people with HIV. In 2014, hundreds of thousands of people with HIV will be newly eligible for care, further stretching providers. AFC will advocate for increased HIV training for primary care doctors, increased access to infectious disease doctors in all areas of the state, particularly in rural areas; cultural competency training to ensure that providers can connect with diverse populations; and education to help providers offer HIV prevention education, link HIV-positive people to care, and make voluntary HIV testing a routine part of medical care. The crisis in dental care access is particularly acute in all areas of the state.

- Increase access to culturally competent infectious disease specialists in all areas of the state.
- Train private and primary care providers to offer prevention education, make HIV testing routine, and link people with HIV to specialty care.
- Expand access to dental care in Chicago and statewide.



#### **ILLINOIS LEGISLATIVE AND BUDGET PRIORITIES**

At the state level, AFC will focus on key budget issues, including adequate **state funding for the AIDS Drug Assistance Program**, which has seen double-digit growth in the past several years. Because of the state's multi-billion dollar backlog of unpaid bills, AFC will join with partners in the Responsible Budget Coalition to support restructuring of debt—including long-term borrowing—to ensure sustainability for agencies that provide vital services on behalf of the state.

In the General Assembly, AFC will advocate for the Illinois Personal Responsibility Education Program (IL PREP), which would require schools to institute comprehensive, age-appropriate, medically accurate sex education. The Emergency Medical Services Access Act would encourage drug overdose witnesses to seek medical assistance by protecting them from arrest or prosecution for drug possession. Another initiative would allow opt-out HIV testing in state prisons, with full pre-test information, implementing recommendations made by the U.S. Centers for Disease Control and Prevention that have been shown to increase HIV testing rates without being coercive. Finally, AFC will advocate for access to harm reduction supplies—including condoms—for incarcerated populations.

## 5. Reduce the stigma of HIV

The stigma of HIV is one of the most insurmountable barriers to HIV testing and treatment today. People at risk of HIV—and particularly in communities of color—fear learning their HIV status because they could be shunned by friends, ostracized by family, or harassed—often illegally—at church, work, or while accessing housing. For people living with HIV, taking medications that can allow them to live a nearnormal, healthy life can also become a daily reminder of external and internalized stigma. AFC will attempt to break down the barriers of stigma by providing accurate information on HIV transmission, highlighting community leaders who are openly living with HIV, and encouraging community members to embrace people with HIV.

- Provide science-based prevention education on the facts about HIV transmission.
- Create community campaigns showcasing people successfully living with HIV.
- Encourage community leaders to embrace people with HIV, both literally and figuratively.



# 6. Provide people in prison and jail with high-quality HIV services, including reentry

Research shows that the HIV rate among people behind bars is 2-3 times higher than among the general population. While Illinois has made great strides in expanding HIV testing among prison inmates, there is more to be done. AFC will work to strengthen re-entry programs throughout Illinois and ensure that the same services are available statewide. In the General Assembly, AFC will advocate for legislation that would allow state prisons to offer opt-out HIV testing, which is recommended by the U.S. Centers for Disease Control and Prevention and often increases HIV testing acceptance. AFC will also advocate for access to condoms and other harm reduction programs for incarcerated individuals.

#### **Policy Recommendations**

- Permit non-coercive and fully informed opt-out HIV testing in Illinois correctional facilities.
- Expand access to harm reduction services in correctional institutions.
- Expand linkage to care and housing for HIVpositive inmates on release.

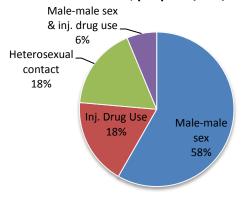
## 7. Increase Access to Housing for People with HIV

Research consistently shows that stable housing is critical to maintaining and improving the lives of people with HIV. While state and federal agencies have thankfully invested in an array of HIV-related housing services, the need for safe, affordable housing continues to outpace available resources. In 2011, AFC will advocate for more funding for long-term housing programs, funding for special populations, including women and families with HIV, and programs for people who are high-cost users of the health care system.

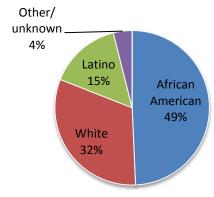
- Increase funding for housing for people with HIV.
- Expand services for women and families with HIV.
- Focus on housing individuals with complex medical needs to reduce health care costs and improve health outcomes



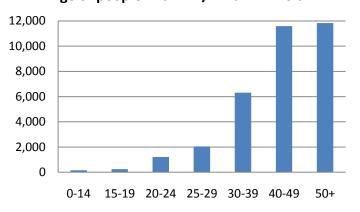
#### Mode of transmisison, people w/HIV/AIDS in Illinois



#### Race/ethnicity of people with HIV/AIDS in Illinois



#### Age of people with HIV/AIDS in Illinois



#### FOR THE RECORD

AFC estimates that 46,000 people are living with HIV/AIDS in Illinois. An estimated 30,000 live in Chicago, 10,000 are in the Chicago suburbs (including Cook County outside Chicago) and 6,000 downstate.

Based on national estimates, 9,000-10,000 of the people living with HIV in Illinois are infected with the virus but don't know it.

Gay men and other men who have sex with men (MSM) continue to be hardest hit by HIV. In 2009, The U.S. Centers for Disease Control and Prevention (CDC) reported that the HIV rate is 50 times higher among gay men and MSM than among other men and women.

In Illinois, African-American women represent more than two-thirds (70%) of women living with HIV/AIDS.

CDC announced in 2008 that an estimated 1.1 million people in the U.S. were living with HIV at the end of 2006; updated numbers will be released in 2011.

The HIV case rate in Cook County (including Chicago) is five times higher than the downstate rate (17.2 cases per 100,000 people compared to 3.1 cases per 100,000).

Sources: U.S. Centers for Disease Control and Prevention, Illinois Department of Public Health, through Oct. 2010. Unless otherwise noted, charts show only individuals with known race or mode of transmission. For more information, visit www.aidschicago.org/statistics.