

A Call to Action: **2003 Illinois HIV/AIDS Policy Priorities**

The AIDS Foundation of Chicago (AFC) has prepared this report to inform Illinois lawmakers, community advocates, and the general public of the policies Illinois should pursue in order to adequately respond to the HIV/AIDS crisis in our state.

Making progress against HIV/AIDS is a public health imperative. Since 1981, HIV/AIDS has claimed the lives of more than 15,000 Illinoisans, and as many as 35,000 Illinoisans are believed to be living with the disease. The crisis has most severely affected African Americans and Latinos who account for just 27% of the state's population but more than 60% of all reported AIDS cases. The epidemic will continue unabated unless swift actions are taken to curb new infections and help those living with and affected by the disease.

In ***A Call to Action*** AFC describes a package of state policy reforms and funding provisions designed to dramatically reduce new HIV infections and improve the health, well being, and productivity of Illinoisans living with HIV/AIDS. Endorsing the reforms AFC recommends is a sound and cost-effective investment in Illinois's future; the returns will be measured in HIV infections averted, in lives saved, and in future healthcare costs reduced.

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About the AIDS Foundation of Chicago

The AIDS Foundation of Chicago (AFC) is Illinois's principal advocate for people living with and at risk for HIV disease. Established in 1985 to provide central leadership in the fight against the epidemic, AFC promotes sound HIV/AIDS public policy, funds HIV/AIDS prevention and care projects, and through its Service Providers Council, helps to coordinate the delivery of essential HIV/AIDS services.

AIDS Foundation of Chicago
411 South Wells Street, Suite 300
Chicago, IL 60607
(312) 922-2322
(312) 922-2916 fax

www.aidschicago.org

Executive Summary

In order to reduce the number of annual HIV infections in Illinois, AFC is urging state lawmakers to:

- Help dramatically reduce HIV and hepatitis C transmission by passing legislation allowing adults to purchase and possess sterile syringes without a prescription.
- Restore \$2 million in HIV prevention funding for communities of color that was vetoed by former Governor George Ryan, and increase the appropriation by \$2 million.
- Enhance HIV prevention efforts in Illinois schools by requiring that all health and sex education curricula be comprehensive and medically accurate.
- Support legislation requiring healthcare providers to conduct HIV counseling and offer HIV testing to all patients who are pregnant. HIV counseling would increase awareness of HIV among childbearing women and assist HIV -positive pregnant women in preventing transmission to their children.
- Support a joint House-Senate resolution calling on Congress and the President to increase federal funding for research and development of microbicides.

In order to ensure access to essential health and social services for Illinoisans living with HIV/AIDS, and to offer real hope for those considering HIV testing, state lawmakers should:

- Invest an additional \$6 million in Illinois’s AIDS Drug Assistance Program to avert hundreds of millions of dollars in future healthcare costs.
- Provide Medicaid recipients with the option of prepaying their “spend down” each month in order to reduce red tape and promote continuity of care.
- Protect access to AIDS-related medications in the Medicaid program by passing legislation to ban prior authorization requirements for any AIDS-related medications.
- Fully fund Family Care in order to provide healthcare coverage to more low-income parents, including at least 1,300 living with HIV.

\$10 MILLION INCREASE NEEDED FOR HIV/AIDS

A \$4 million increase is needed for HIV prevention services targeting at-risk communities.

The AIDS Drug Assistance Program needs \$6 million in new state funding to maintain current services, accommodate new clients, and offer new medications.

Introduction

An estimated 1,600 state residents become infected with HIV each year, and some 35,000 Illinoisans are believed to be living with HIV/AIDS. According to the CDC, half of all new HIV infections occur among people under age 25. HIV disproportionately affects African Americans and Latinos—populations already over-burdened by high rates of poverty, substance abuse, and chronic health conditions.

Mirroring national trends, unprotected sexual contact with an infected partner is the leading mode of HIV transmission, followed by injection drug use. In 2001, men who have sex with men accounted for nearly half (46%) of all new AIDS cases in Illinois among men; that year, injection drug use accounted for 21% of new male AIDS cases. While heterosexual contact is the leading mode of transmission for women (49% in 2001), at least half of these cases are believed to have resulted from unprotected sexual contact with a male injection drug user. In 2001, 33% of new female AIDS cases resulted directly from injection drug use. Women accounted for 22% of Illinois's 1,331 reported AIDS cases in 2001.

Recent medical advances have revolutionized AIDS care in the United States, and thanks to new medications and a better understanding of the disease's progression, more people with HIV are living longer and healthier than ever before. This change in the epidemic has made the need for increased funding and support for scientifically proven HIV prevention and care interventions more critical. During the first decade of the epidemic, approximately 100,000 people in the United States were infected with HIV each year. During the second decade of the epidemic, comprehensive HIV prevention programs brought this number down to its current level of 40,000 new infections annually. At this, the beginning of the third decade of AIDS, we must reaffirm our commitment to stemming the spread of HIV by funding and implementing the HIV prevention programs that we know work. We must also ensure that those who live with HIV have the healthcare and support services they need to live fulfilling and productive lives.

Investments in HIV prevention and care that result in transmission reductions and improved health outcomes have direct and compelling benefits for affected individuals, communities, and society as a whole. Targeted and adequately funded prevention and care efforts will reduce state healthcare expenditures and result in improved health outcomes for those populations most affected by HIV/AIDS.

A Call to Action:

Supporting Proven HIV Prevention Approaches

The people of Illinois deserve a comprehensive, science-based, and results-oriented approach to HIV prevention with the goal of dramatically reducing new HIV infections. An extensive body of scientific research has illuminated the policies and programs that work—Illinois has yet to fully embrace these proven strategies.

State lawmakers should help lower rates of HIV in Illinois by pursuing the following legislative and programmatic initiatives:

Pass legislation to allow adults to purchase and possess sterile syringes through pharmacies without a prescription.

- Illinois is one of only five states that has a law requiring a prescription to purchase sterile syringes.
- More than 40 studies and seven federally commissioned reports have proven that increased access to sterile syringes decreases HIV and hepatitis C infections without increasing drug use.
- Allowing pharmacy-based sales of sterile syringes will expand HIV prevention options for injection drug users, and by extension, their partners and children without requiring any additional state funding.

HIV Prevention Priorities

1. Pass legislation increasing access to sterile syringes
2. Restore and increase funding for HIV prevention in communities of color
3. Pass legislation mandating comprehensive and medically accurate sex and health education in Illinois schools
4. Require healthcare providers to conduct HIV counseling and offer HIV testing to pregnant women
5. Support a resolution urging Congress to increase funding for microbicides

Restore HIV prevention funding directed towards communities of color that was vetoed during the last legislative session. Increase the appropriation by \$2 million for a total of \$4 million targeting high-risk communities.

- According to state figures, two of every three reported HIV cases occur among people of color. African Americans and Latinos account for nearly 60% of Illinois' cumulative AIDS cases, but only 27% of the state's population.
- The appropriation, first created in 2001, supported projects serving minority communities at 18 agencies in Chicago, and in Cook, Kane, Madison, Peoria, St. Clair, Will, and

Winnebago counties. Restoring this funding will mean that hundreds of people at high risk for HIV infection will receive the education and support that could save their lives.

Pass legislation requiring that sexuality and health education be medically accurate and comprehensive.

- Such a law will ensure that all public school students receiving sex and health education will be taught in a manner that is age-appropriate, medically accurate, and comprehensive so that they may learn about abstinence, sexuality, risk-reduction activities, HIV/AIDS, other sexually transmitted diseases, and pregnancy prevention in a manner that prepares them to make informed life decisions.
- When teens are given honest information they make more responsible choices. Schools can help all students with a balanced approach that teaches abstinence along with facts about contraception, reproductive health, and responsible decision-making.

Pass legislation ensuring that pregnant women receive necessary HIV counseling during prenatal care to prevent mother-to-child HIV transmission.

- New medical advances have been shown to prevent approximately 90% of all perinatal HIV infections.
- Research shows that when appropriately counseled, up to 95% of pregnant women will consent to HIV testing during prenatal care. If test results come back positive, appropriate medical care can provide women with education about ways to both address their own healthcare needs and prevent transmission to their unborn child.

Pass a joint resolution calling on Congress and President Bush to enact the Microbicide Development Act.

- Microbicides are chemical agents that prevent the transmission of HIV and other sexually transmitted diseases. They are being developed in cream, gel, foam, and other forms for use in addition to or in place of condoms.
- Congress is currently considering a bill to increase funding for microbicide development because the National Institutes of Health has identified microbicide research and development as a priority in their most recent five-year plan. Insufficient funding is slowing the development of these desperately needed HIV/AIDS prevention tools.
- Microbicides will save lives, reduce medical costs, and will help advance the fight against HIV/AIDS in Illinois and throughout the world.

A Call to Action:

Ensure Comprehensive HIV Healthcare in Illinois

State lawmakers should respond to the service needs of the more than 35,000 Illinoisans living with HIV/AIDS by helping to provide medical treatments and other essential services to all who need them. Increasing the availability of HIV medical and social services will help HIV-positive Illinoisans experience improved health outcomes, quality of life, and productivity. Expanded access to treatment and care services would also help prevent costly emergency room visits and hospitalizations and would motivate at-risk individuals to seek voluntary HIV counseling and testing services.

State lawmakers should respond to the medical and service needs of low-income Illinoisans with HIV by pursuing the following legislative and programmatic initiatives:

Increase funding for the AIDS Drug Assistance Program (ADAP) by \$6 million.

- Illinois's ADAP program is currently one of the best in the nation, but that distinction is being threatened by insufficient resources.
- ADAP provides AIDS medications to more than 2,700 low-income, HIV-positive people each month who would otherwise have no access to these life-saving medications. ADAP also reduces healthcare costs by helping people living with HIV/AIDS stay healthier longer.
- The stability of the program is being threatened by both increased enrollment and by the costs of new medications that have recently or will soon become available.

HIV/AIDS Care Priorities

1. Increase funding for the AIDS Drug Assistance Program by \$6 million
2. Pass legislation allowing Medicaid recipients to prepay their "spend down"
3. Promote ready access to AIDS-related medications by banning Medicaid from instituting prior authorization for AIDS-related medications
4. Ensure healthcare to at least 1,300 uninsured HIV-positive parents by fully funding Family Care

Pass legislation to allow Medicaid recipients to pre-pay their spend down requirements.

- Such a law would allow Medicaid recipients to pay their spend down requirements on a monthly basis in the same way that many Illinoisans pay ongoing health insurance premiums.
- Allowing spend down to be pre-paid will ensure continuous healthcare coverage for Medicaid recipients. Currently, coverage can be interrupted by the need for clients to bring their medical bills to a Public Aid office for review.
- This legislation will help reduce the processing times and costs incurred by the Illinois Department of Public Aid, which must individually review each spend down case every month.

Pass legislation protecting all medications used to treat both HIV infection and all opportunistic infections associated with the disease from prior authorization under the Medicaid program.

- Treatment regimens for people living with HIV are complex and subject to change over time. Physicians must have discretion to prescribe medications that are effective against a patient's particular infection and that will not result in harmful drug interactions.
- Many drugs used to treat HIV are new and do not have generic equivalents. Protecting these drugs from prior approval will ensure that all people living with HIV have access to the most effective treatments.

Fully fund the Family Care program.

- Family Care should be fully funded in order to provide healthcare coverage to more low-income working parents who cannot currently afford medical insurance.
- Full funding for Family Care will create access to health care for at least 1,300 parents living with HIV, increasing their ability to stay healthy and provide stable homes for their children.

Overview of HIV/AIDS in Illinois

HIV/AIDS is a Public Health Crisis in Illinois.

- § Illinois ranks 7th in the nation in number of cumulative AIDS cases.ⁱ
- § Since 1981, more than 27,000 Illinoisans have been reported with an AIDS diagnosis; nearly 16,000 have died from the disease.ⁱⁱ
- § An estimated 35,000 Illinoisans are believed to be HIV-positive, including some 12,000 who are unaware of their HIV status.
- § Approximately 1,600 new HIV infections occur each year in Illinois.ⁱⁱⁱ
- § There are people living with HIV in every region of Illinois. Approximately 85% of the HIV/AIDS cases are in the metropolitan Chicago area (Chicago and collar counties) while 15% are downstate.^{iv}
- § The number of reported AIDS cases in Chicago has increased from approximately 4,229 in 1990 to 16,966 in 1999, a jump of 400%.^v

Information is Power

Get the facts about HIV/AIDS at www.aidschicago.org/prevention/faq.html or call the State of Illinois HIV/AIDS Hotline at 1-800-AID-AIDS (1-800-243-2437)

Demographic Changes in the Local Epidemic Mirror Those Trends Observed Nationally.

- § HIV/AIDS continues to affect significantly more men than women, but the proportion of female AIDS cases has increased by more than 40% from 1993 to 1997.
- § Although African-Americans represent only 16% of the state's population, they make up 56.2% of recently diagnosed HIV cases. Latinos account for 11% of the state's population and 11.5% of recently diagnosed HIV cases.^{vi}
- § African-American women account for 64% of all reported female AIDS cases in Illinois.^{vii}
- § Of the total reported AIDS cases in Illinois, male-to-male sexual contact continues to be the predominant mode of transmission (51%) followed by injection drug use (26%).^{viii}
- § African-American men who have sex with men account for nearly 20% of recently diagnosed AIDS cases in Chicago.^{ix}
- § In Illinois, heterosexual contact ranks as the third most common mode of transmission (9%) among the total reported AIDS cases.^x For all AIDS cases reported in 2000, the rate of heterosexual transmission increased by 45% over previous years.
- § A study done last year found that more than one in ten young men who live in urban areas and who have sex with men are infected with HIV. Of the African-American men who were surveyed, 30% were HIV-positive.^{xi}

People with HIV/AIDS Often Have Other Health and Social Factors Affecting Their Health.

- § In the Chicago metropolitan area, nearly 93% of all clients served by the Ryan White CARE Act have annual incomes below \$15,000. Outside the Chicago metropolitan area, 86% of CARE Act clients have annual incomes below this level.
- § 46% of people served in the Chicago area by the CARE Act do not have health insurance. Outside Chicago, the number of uninsured CARE Act clients climbs to 61%.
- § 25% of people with HIV have significant mental illness.
- § Many people with HIV have health care needs that are not covered by CARE Act services (e.g., other health issues, hospitalization, other medications).
- § Many people living with or at risk for HIV are dually or triply diagnosed with serious mental illness, substance abuse or another infection like hepatitis C.

Background on HIV Prevention

HIV Prevention Programs Work

The Institute of Medicine (IOM)^{xii}, National Institutes of Health (NIH)^{xiii}, Joint United Nations Program on HIV/AIDS (UNAIDS)^{xiv} and CDC Prevention Research Synthesis Project (PRS)^{xv} have all completed scientific reviews of HIV prevention programs and all have come to the same conclusion: HIV prevention programs work. The evidence presented in these reviews indicates that successful and effective prevention programs currently exist to meet the needs of a wide variety of populations including men who have sex with men (MSM), injection drug users (IDU), and heterosexuals. Furthermore, a recently published study by a leading HIV prevention researcher estimates HIV prevention efforts in the U.S. have saved 1.5 million lives.^{xvi}

Scientifically Proven HIV Prevention Programs Include:

Syringe Availability—In March 2000, the U.S. Surgeon General prepared a review of all peer-reviewed, scientific studies of syringe exchange programs completed since 1998.^{xvii} The review reaffirmed that there is "conclusive evidence that syringe exchange programs, as part of a comprehensive HIV prevention strategy, are an effective public health intervention that reduces transmission of HIV and does not encourage the illegal use of drugs." Additionally, research from Connecticut and other states have proven that making syringes available through pharmacies without a prescription is an effective HIV prevention strategy.^{xviii}

Syringe access is one component of a comprehensive strategy to prevent HIV transmission among injection drug users, their partners, and their children. This broad-based approach, known as harm reduction, provides the individual with an array of strategies to reduce their risk for HIV. These strategies include syringe access, drug prevention programs, HIV prevention education, and drug treatment on demand.

Correct and Consistent Use of Condoms—For people who are sexually active, condoms provide the best method to prevent the transmission of HIV and other sexually transmitted diseases. When used correctly and consistently, condoms provide an effective barrier, blocking the pathway of HIV during sexual activities. A meta-analysis of several studies conducted by the National Institutes of Health found an 85% decrease in risk of HIV transmission among consistent condom-users.^{xix}

Medically Accurate and Comprehensive Sexuality Education—Research has shown that the most effective sexual health programs are medically accurate and comprehensive. They focus on delaying sexual behavior and provide information on how sexually active young people can protect themselves.^{xx} Research indicates that comprehensive HIV/STD education does not lead to an increase in or early initiation of sexual activity; some studies show a positive association between early HIV/STD education and the delay of sexual activity.^{xxi}

Behavioral Interventions—An extensive body of research exists on how to help individuals change their HIV-related risk behaviors.^{xxii,xxiii} Research has shown that aggressive promotion of safer sexual behavior and prevention and treatment of substance abuse could avert tens of thousands of new HIV infections and potentially save millions of dollars in healthcare costs.^{xxiv} Effective models identified by the CDC include multiple, individual and small group sessions; client-centered, interactive education sessions; peer-led interventions; comprehensive health education; and structural and environmental interventions.

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