

## **AIDS in the United States: A Secret Epidemic**

by

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### **The Problem**

**AIDS has, unfortunately and increasingly, become a “secret epidemic” in the United States even as it continues to claim lives, compromise and complicate health. It disproportionately affects already marginalized and stigmatized groups and further stigmatizes and marginalizes these groups.**

Many in the United States have been made aware of the devastating assault of the global AIDS pandemic on the populations of developing nations. Celebrities, non-governmental organizations and politicians have taken up the cause for global AIDS awareness and made crucial commitments of funds towards the achievement of global justice and the improvement of health for all. These important global campaigns have had an unfortunate and unintended consequence, however. AIDS has come to be seen as a problem that others face “over there” and its toll right here at home has been slipping under the radar screen.

### **The Research Evidence**

**As reported in 2007 by the Centers for Disease Control and Prevention (CDC), over 421,000 people in the United States are living with AIDS.**

These 421,000 represent only the known and diagnosed cases of people with infections that have progressed to AIDS. Hundreds of thousands more are living with HIV/AIDS and do not know it or have HIV infection but not AIDS. HIV continues to spread in the United States at an alarming rate; the Washington Post has recently reported that the CDC is upping its estimate of the number of new HIV infections acquired in the United States each year from 40,000 to 55,000-60,000. The predicted end of AIDS in America has not come to pass. Americans are still becoming newly infected, still progressing to AIDS and still dying in large numbers.

There certainly is some good news for those in the United States living with AIDS. AIDS is beginning to seem like a chronic, but manageable disease for many. But this doesn't tell the whole story of AIDS in America. Although life expectancy after an HIV positive diagnosis has improved dramatically in the United States in the last decades, AIDS is still ending lives early; life expectancy after an HIV positive diagnosis today is estimated at around 24 years. The increase in life expectancy has been due largely to improvements in antiretroviral therapies (ARVs). But even for those who can afford or find coverage for the very high lifetime cost of the drugs (estimated at over \$450,000), many are battling debilitating side effects of the medicines, struggling with the complications of co-infections like Hepatitis C, and finding the virus resistant to the treatment over time.

As a matter of justice, particularly of concern to us is the impact of the epidemic on already marginalized groups. Those who are most affected by the virus are members of marginalized populations. Amongst the hardest hit are African American and Latino men (over half of men

with AIDS), men who have sex with men (2/3 of men with AIDS), injection drug users (21 percent of people with HIV/AIDS), and African American women (2/3 of new AIDS cases among women). These populations overlap; many with HIV/AIDS are members of more than one of these groups and are made marginal through the intersection of these categories. For example, race and same-gender sexual behavior interact to make African American men who have sex with men a particularly marginalized group. A prevalence surveillance study conducted by the CDC in five U.S. cities in 2004-2005 found that an astonishing 46 percent of African American men who have sex with men were HIV positive—twice the prevalence rate than that for white men who have sex with men.

Further, some groups are doing better than others when it comes to receiving treatment and extending their lives. Despite the advances in treatment and extension of life made possible by ARVs, HIV infection is the leading cause of death for African American women aged 25-34. Two thirds of deaths of persons with AIDS are African American or Hispanic. Among racial groups, survival after an AIDS diagnosis is lowest for African Americans. Among transmission categories, survival after an AIDS diagnosis is lowest for injection drug users. We are clearly failing to address the disproportionate impact on already marginalized groups, thereby only furthering marginalization and injustice.

Why haven't we come to the end of AIDS in America? For one, as attention to the real global problem of AIDS has grown, a general lack of attention to and knowledge about HIV/AIDS as a pressing issue of pandemic proportions in the United States has set in. Our political leaders share this lack of knowledge. Particularly important is misinformation and confusion about the most affected groups in the United States. Spending on the services that work in treatment and prevention of HIV/AIDS has not kept pace with the increases in AIDS cases, treatment costs and new infections. Funding of ineffective abstinence-only prevention programming has diverted scarce resources from the programs that are known to work.

### **What we know about gaps in HIV/AIDS knowledge in the United States**

There continues to be a gap in knowledge between researchers on the one hand and political leadership and the general public. For example, during the 2004 debate between the vice presidential candidates, Mr. Cheney was unaware that HIV was the leading cause of death for young African American women and both he and Mr. Edwards struggled to focus their comments on the domestic AIDS crisis. But to be fair, this incident reflected a general lack of awareness about the U.S. AIDS crisis among the public at large. According to a 2003 Kaiser Family Foundation study, an increase in attention to the global pandemic occurred alongside a decrease in domestic coverage. There has been relatively little focus on those marginalized populations most affected by the epidemic within the United States. Since 61 percent of adults obtain their HIV/AIDS knowledge from the media, it is not surprising to find that there is limited public awareness of what HIV and AIDS are and on the extent of the domestic AIDS situation.

A 2006 public opinion survey conducted by the Kaiser Family Foundation measured attitudes and knowledge about HIV/AIDS in America. The survey found that 43 percent of adults held at least one of the following erroneous beliefs: that HIV could be contracted by kissing, sharing a drinking glass, or via toilet seats. Further, respondents were most likely to associate

homosexuals and injection drug users with HIV and were unaware of the risks faced by people of color. More than fifty percent were unaware that having an STD increases one's vulnerability to HIV infection. The survey results indicate the continuing need for education that targets all adults, but that also especially targets those with less than a high school education and those over fifty years of age. While the survey revealed startling shortcomings in Americans' HIV/AIDS knowledge, we find promise in some of its results. Encouragingly, the survey showed Americans support the kinds of programs that have been shown to be most effective. For example, adults believe that children would benefit from comprehensive sex education (which includes abstinence as one of a series of possible options). Also, most adults support increased domestic funding for HIV/AIDS prevention and testing.

### **What we know about gaps in AIDS treatment in the United States**

We know that ARVs work to extend life and keep people with AIDS healthy. We also know that for the uninsured and underinsured, even when discounted, the cost of ARVs is unaffordable. Since 1990, medications have been provided to people in need in the United States through state-run AIDS Drug Assistance Programs (ADAPs), partially funded through a federal grant under the Ryan White Program. ADAPs are the "payers of last resort," serving low-income people with little other means of access to ARVs. ADAP funding has not kept up with client demand. Waiting lists have amassed in several states. A one-time influx of additional funds for ADAP from President George W. Bush in 2004 and a shift in coverage of some clients to Medicare Part D beginning in 2006 has decreased and even eliminated waiting lists in some states. Still, waiting lists remain in four states. States have increasingly been called upon to pick up the burden and make up for the shortages in their federal ADAP earmarks. States have not been equally successful in doing so. Income eligibility and comprehensiveness of drug coverage vary considerably from state-to-state, creating geographic inequalities in HIV/AIDS care.

### **What we know about what works and what doesn't in HIV prevention**

Twenty-five years into the epidemic, we know a lot about what works in HIV prevention. Successes in prevention came early; in the 1980s, prevention devised by and carried out through gay community activism significantly slowed the tide of the AIDS epidemic. These early efforts are widely regarded as amongst the most successful public health education projects ever undertaken. These early successes have taught us that programs that work come from the perspective, standpoint and values of affected groups. Drawing upon those early successes and working in conjunction with affected communities, public health professionals have continued to develop innovations in HIV prevention programming and have subjected these programs to rigorous evidence-based assessments. The CDC has been working to ensure its funding continues to go to HIV prevention programming that works.

In addition to learning about programs that worked, we've learned a lot about what doesn't work. With more than ten years of federal level sponsorship of abstinence-only education programming for youth, the data evaluating these programs are in and they show these programs aren't working. The most recent research shows that these programs are ineffective in changing sexual risk behaviors, ineffective in delaying the age of first sexual activity, and ineffective at preventing STDs and pregnancy. To date, Congress has spent 1.5 billion on such programs. Not

a single one has been shown to be effective in a scientific evaluation published in a peer-reviewed journal. This 1.5 billion could go a long way if spent on programming that works.

## **Policy Recommendations and Solutions**

An end to the secret AIDS epidemic in America is possible. The good news is that we know a lot about what it would take to get us there. Solutions along these three fronts would go a long way towards this goal:

1. We must seek to address concerns of social justice by providing services to the socially, economically and racially marginalized groups affected.
2. We must refuse HIV prevention and treatment policy that is guided by anti-sex moralizing and demand that policy be guided by evidence and historically effective public health practice. If morality is to play a role in HIV prevention policy, it must be rooted in principles of justice, equity and sexual autonomy.
3. We must institute a program to re-educate the general public on HIV and AIDS in America. Ignorance and complacency must be challenged, as the secret epidemic is brought to light.

Specifically we recommend:

- *Increase funding for domestic treatment programs, through ADAP or other means.* At minimum, we must eliminate waiting lists for AIDS drugs under ADAP. As states seek to cut costs in their ADAP programs by limiting enrollment, restricting eligibility, or cutting back on covered drugs, we must ensure that ARVs are reaching those in need. Beyond the minimum goal of eliminating ADAP waiting lists, we must also look toward increasing the number of people receiving ARVs.
- *Cease funding for abstinence-only based programs; shift to and more fully fund comprehensive and harm reduction programs, appropriate to audience.* Research reveals that Americans support comprehensive sexuality education—an approach that includes the teaching of abstinence as one valid and effective option. Programs must be appropriate and specifically tailored to audience, considering dimensions such as age, sexual identity, culture, language, education, and community context and setting. Where appropriate, harm reduction strategies, such as needle exchange and stepwise sexual risk reduction should be valued. Harm reduction approaches recognize a continuum of risk behaviors and advocate non-judgmental interventions to support any and all reductions in harmful behavior, both small and large. In contrast with abstinence-based strategies, harm reduction hopes to create step-by-step reductions in risk, assisting people with behavior changes that move on a continuum towards safety.
- *Repeal the Helms Amendment so that local content review boards decide appropriateness standards.* The time has come to revise and eliminate the 1988 Jesse Helms Amendment requiring that federally-funded AIDS education materials must not encourage or promote drug use or sexual activity. This rule has allowed intrusive and politicized federal-level reviews of locally appropriate HIV prevention programming. Local content review boards must be fully empowered to determine the cultural appropriateness for their communities. Local control is crucial for the development of innovative programs specifically tailored to

the unique, ever-changing and locally diverse at-risk populations dispersed throughout the U.S.

- *Continue targeted prevention programming to disproportionately at-risk groups and at the same time, reinvigorate a broader sexual health education program.* All Americans should be educated about the impact and contours of the epidemic in the United States, about how HIV is transmitted and about who is most at risk. This broader program must be guided by the principle of sexual autonomy and should recognize that most everyone is at one point in their lives at risk of acquiring HIV or another STD. It is important to recognize that sexual identity and behavior changes over the life course and those at low risk today may become high risk in the future. Such a general program would also help to reduce STD and AIDS stigma—one of the underlying causes for the continuing spread of HIV.
- *Rededicate to the development of innovative media and education campaigns.* Our education campaigns are outdated and do not take advantage of new technologies. We must find ways to utilize the internet, text messaging, music videos, and targeted cable channels, such as Logo, BET, and TV One towards the production of a reinvigorated AIDS education platform.
- *Establish a centralized domestic networking mechanism to systematically provide for information sharing and policy development.* We propose the creation of a network that would connect researchers, private foundations, advocates, and “on the ground” providers from the local through the national level. Throughout the three decade history of the global AIDS pandemic, the open exchange of information has been an essential component of many of the documented successes. The Office of HIV/AIDS Policy is mandated to manage the National HIV Testing Mobilization Campaign, the AIDS.gov information portal, and The Leadership Campaign on AIDS (TLCA). TLCA is specifically focused on targeting marginalized and vulnerable communities of color; but while essential, this focus still excludes some vulnerable communities. The network we propose would be expansive enough to both target all known vulnerable communities and coordinate public-private AIDS partnerships.

## **Conclusion: Learning Lessons from the International Context**

International shifts in how AIDS is both understood and addressed reveals that the kinds of changes we suggest here are feasible. Several of these international shifts might be informative for the U.S. crisis; these include an ideological shift, a new way to facilitate information sharing, renewed commitment to research funding, and protection of the scientific integrity of governmental agencies. For at least the past decade, HIV/AIDS has been seen as symptomatic of broader social justice crises. AIDS is now understood as a human rights issue. As such, strategies employed to protect people’s right to economic security, accessible health care, physical safety, and political enfranchisement are essential for the success of any AIDS-specific policies. Importing such a rationale to a U.S.-specific context would involve an ideological shift that has already occurred among many U.S. AIDS activists and researchers. Researchers now understand that the risk of HIV transmission involves both individual high risk behavior *and* social vulnerabilities such as poverty, racism, gender bias and homophobia. Reducing the risk of HIV transmission requires interpersonal, institutional, and societal means to sustain behavior change.

Monies already earmarked for the AIDS crisis have been redirected for other budgetary needs. This results in delayed or slower implementation of proven interventions. For example, congressional re-authorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has traditionally been characterized by the threat of de-funding or underfunding. The Ryan White CARE Act is the largest federally funded program specifically geared to HIV/AIDS and it provides needed support for many underserved communities in the United States. It includes the AIDS Drug Assistance Program, which provides medical and drug assistance for low-income, underinsured, and uninsured people living with HIV/AIDS in the United States; AIDS Education and Training Center Programs, which facilitate continued multidisciplinary training for providers; Title IV, a series of family oriented programs that benefit mostly minority women with children; and Special Projects of National Significance, which funds initiatives that target hard to reach at-risk populations. Given the scope and effectiveness of this program, such financial tenuousness is problematic. Instead, this series of initiatives could and should receive increased funding which could be utilized to target those populations most immediately affected by HIV/AIDS.

There is a growing body of evidence-based scholarship that has identified what can facilitate the reduction in HIV/AIDS. Therefore, we already know what works: aggressive, community and population-specific education initiatives, top-down governmental support for innovative prevention efforts, sophisticated media campaigns coupled with ones that are age-appropriate and accessible for low-literacy individuals, comprehensive school based sexuality education, easily available barrier methods (male and female condoms plus dental dams), and harm reduction programs such as needle exchange. Above all, what is imperative is the harnessing of public will and the recognition that being a legitimate international voice in the battle to control the AIDS pandemic requires a re-dedication to our own domestic crisis.

### **Key Terms**

AIDS Acquired Immune Deficiency Syndrome  
ADAP AIDS Drug Assistance Programs  
ARV Antiretroviral Medications  
CARE The Ryan White Comprehensive AIDS Resources Emergency Act  
CDC Centers for Disease Control and Prevention  
HIV Human Immunodeficiency Virus  
STD Sexually Transmitted Disease  
TLCA The Leadership Campaign on AIDS

### **Key Resources**

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