



National AIDS Strategy: A Legal Perspective

American Bar Association
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Foreword

Too many Americans are living with chronic diseases without access to necessary care and treatment. Many of our citizens who are infected with HIV fall into that group of Americans.

As we approach the thirty year mark of the HIV/AIDS epidemic, it is appropriate for us as a nation to reflect on the distance we have traveled and the length of the road still ahead. We have made great strides in developing drugs that prolong the lives of those who take them. But, we have a long way to go before all who can be helped by those drugs know that there is help available and have access to that help. Even as public health officials move away from “AIDS exceptionalism,” stigma and discrimination continue to haunt those infected with HIV and limit their access to adequate care and treatment.

For more than 20 years, the American Bar Association has worked to raise the conscience of the bench, bar and public as it pertains to the legal issues raised by the HIV/AIDS epidemic in this country and around the globe. We bring those issues to the fore in 2009 in the hope that the much-discussed initiatives to reform health care in America will include a national response to the continuing domestic HIV/AIDS crisis.

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Introduction

AIDS advocacy organizations have called for a National AIDS Strategy² in response to data released in August 2008 showing a domestic HIV epidemic worse than previously known and to federal funding that is inadequate to the challenge.

According to the Centers for Disease Control and Prevention (CDC), approximately 56,300 new HIV infections occurred in the United States in 2006. This figure, based on improved data collection and analysis, is roughly 40% higher than CDC's former longstanding estimate of 40,000 infections per year.³ Yet while federal funding for the global pandemic has increased markedly in recent years, funding for the domestic epidemic has been flat, cut, or increased only marginally,⁴ with potentially devastating consequences. Indeed, in the U.S. as elsewhere, HIV now affects primarily low-income communities of color, particularly women and youth, who long have experienced more limited access to public health systems, including to HIV prevention, care, treatment, and support services.⁵

Many experts now recognize that law and legal counseling can play a pivotal role in stemming the spread of HIV by ensuring access to public and private resources essential to preventing and managing HIV

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² For more information, see <http://www.nationalaidsstrategy.org/>.

³ See "Estimates of New [HIV] Infections in the United States," CDC Web site, available at <http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/incidence.htm> (August 2008), accessed Feb. 3, 2009.

⁴ See "HIV/AIDS Policy Fact Sheet: U.S. Federal Funding for HIV/AIDS: The FY 2009 Budget Request," Kaiser Family Foundation, available at <http://www.kff.org/hivaids/upload/7029-041.pdf> (April 2008), accessed Feb. 3, 2009.

⁵ The Black community, for example, has been disproportionately affected by HIV/AIDS since the epidemic's beginning, and that disparity has deepened over time. Blacks account for more new HIV infections, AIDS cases, people estimated to be living with HIV disease, and HIV-related deaths than any other racial/ethnic group in the U.S. The epidemic has also had a disproportionate impact on Black women, youth, and men who have sex with men, and its impact varies across the country. Moreover, Blacks with HIV/AIDS may face greater barriers to accessing care than their white counterparts. Today, there are approximately 1.1 million people living with HIV/AIDS in the U.S., including more than 500,000 who are Black. See [Kaisernetowrk.org](http://www.kaisernetowrk.org), *HIV/AIDS Policy Fact Sheet: Black Americans and HIV/AIDS* (October 2008), available at <http://www.kff.org/hivaids/upload/6089-061.pdf> (accessed Jan. 13, 2009).

effectively. In light of this important role, the American Bar Association (ABA) AIDS Coordinating Committee offers this legal perspective on key issues in the development and implementation of an effective National AIDS Strategy.

I. About the ABA AIDS Coordinating Committee

The ABA established the Committee in 1987 to identify, analyze and address legal issues surrounding HIV/AIDS. To ensure a well-rounded, multi-disciplinary approach to the issues, the Committee was and remains comprised of a chair appointed by the ABA president and ‘liaisons’ from more than twenty ABA entities and affiliated organizations, ranging from the Section of Tort, Trial and Insurance Practice to the National LGBT Law Association. In 2006, the Committee invited healthcare professionals to join an advisory committee to inform the Committee’s work in addressing this public health epidemic.⁶

In 1988, the Committee released *AIDS: The Legal Issues*, a comprehensive report and catalogue of policy recommendations.⁷ The ABA House of Delegates, the Association’s policymaking body, adopted all of the recommendations as ABA policy the following year. Since then, the Committee has recommended numerous additional policies; generated multiple publications and reports on specific issues; produced instructional videos for establishing HIV-related non-profits and representing HIV-positive clients; and sponsored hearings, meetings, educational programs, and national conferences on HIV/AIDS law and policy concerns.

The Committee’s current work is both domestic and international in scope, including development of an “HIV Legal Check-up” project to increase access to HIV legal services in Washington, DC, where the domestic epidemic currently is worst; and addressing the global pandemic from a human rights and rule of law perspective. To this end, the Committee is working with the International AIDS Society to develop its Track F programming on “Policy, Law, Human Rights, and Political Science” for the 2010 International AIDS Conference in Vienna, Austria.⁸

⁶ See Appendices A and B for rosters of AIDS Coordinating Committee Members and Healthcare Advisory Committee Members, respectively. The AIDS Coordinating Committee also thanks Donna Futterman, MD, Director, Adolescent AIDS Program, Children’s Hospital at Montefiore Medical Center in New York, and Marsha Martin, DSW, Director of *Get Screened Oakland* in Oakland, California, for their contributions to this paper.

⁷ For a complete listing of ABA policies on HIV/AIDS, visit <http://www.abanet.org/AIDS/policies/home.html>.

⁸ For more information on the 2010 International AIDS Conference, visit <http://www.aids2010.org/>.

II. Historical Overview of HIV/AIDS Law and Policy

In the early years of the U.S. epidemic, law and policy on HIV/AIDS were characterized on one hand by increasingly aggressive public health efforts to treat and care for people living with HIV/AIDS (PLWHA) and, on the other, by discriminatory laws that tended to undermine those efforts. Although the U.S. Supreme Court later held in *Bragdon v. Abbott*, 524 U.S. 624 (1998), that the anti-discrimination provisions of the Americans with Disabilities Act (ADA) cover persons with HIV disease or AIDS,⁹ HIV discrimination persists in multiple sectors, from health care to employment to education, reducing the effectiveness of HIV prevention efforts.¹⁰ An effective National AIDS Strategy will reconcile this conflict in favor of evidence-based policies that eliminate both the appearance and the reality of HIV discrimination.

This policy tension emerged with the first AIDS cases identified in the United States in 1981. Because the epidemic happened to arise among gay men, the Centers for Disease Control and Prevention (CDC) initially labeled the syndrome what it had appeared to be — “Gay-Related Immune Deficiency” or “GRID.” By the time the more accurate term, “Acquired Immune Deficiency Syndrome” or “AIDS” was coined — reflecting the fact that sexual intercourse (gay or straight) is one mode of HIV transmission — PLWHA had become subject to popular contempt for presumably contracting and spreading AIDS through their own “immoral” behavior. As a result, the plight of PLWHA was a subject of political indifference at best and often outright hostility. The public health sector pursued its mission apace, however, consistently calling for science-based public education to about HIV transmission and prevention to address even politically sensitive issues such as condom use, comprehensive sex education, and needle exchange programs, among other interventions. Joined by well organized and committed political activists, the public health sector also called for increased treatment and care resources, culminating in 1990 in the passage of the landmark Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which continues to be the primary vehicle for the authorization of federal funds for community-based care and treatment services.

Despite formidable data supporting these proposed science-based interventions, lawmakers frequently have enacted HIV education and prevention laws and policies that have failed to embrace them or, worse, erected barriers to their implementation. In 1987, the Helms Amendment, for example, forbade the use of federal funds for AIDS education materials that, regardless of evidence to the contrary, could

⁹ The ADA Amendments Act of 2008 has broadened many of these provisions. See discussion *infra* Part IV.

¹⁰ For current examples of HIV-related discrimination in multiple sectors and its potential impact on HIV prevention, see the following Web sites: ABA AIDS Coordinating Committee (<http://www.abanet.org/AIDS/testimonials/home.html>); AVERT (<http://www.avert.org/aidsstigma.htm>); The Body (<http://www.thebody.com/index/legal/discrimination.html>); The Policy Project (USAID) (http://www.policyproject.com/pubs/generalreport/Breaking_the_Cycle.pdf); and the American Civil Liberties Union (<http://www.aclu.org/hiv/discrim/index.html>).

be deemed to "promote or encourage, directly or indirectly, homosexual activities."¹¹ Also that year, HIV was added, without scientific basis, as a "dangerous contagious disease" to the immigration exclusion list.¹² More recent laws and policies also have compromised HIV prevention efforts while purporting to advance them. Federal and many state sex education policies, for example, place an inordinate emphasis on abstinence¹³ despite voluminous scientific data demonstrating that age-appropriate, *comprehensive* sex education, including but not limited to abstinence, reduces the spread of HIV more effectively. In the criminal justice sector, legislative calls to criminalize HIV transmission would effectively label PLWHA as dangerous, stigmatize their having sex and, conceivably, deter HIV testing.¹⁴ Further, most prison systems, despite data showing a higher prevalence of HIV among prison populations,¹⁵ ban prisoners' access to condoms and sterile injection equipment ostensibly because sex and injection drug use among inmates are prohibited.

In sum, many experts believe that laws and policies that discriminate against PLWHA directly or indirectly, or that emphasize perceived "moral" considerations without a basis in evidence or science, contribute to an environment of stigma against PLWHA that impedes their access to HIV prevention, treatment and other vital services.

¹¹ See Peter Lewis Allen, "The Birth of the Helms Amendment: How a Single Pamphlet Started an AIDS War," *available at* FindLaw (http://writ.news.findlaw.com/commentary/20000925_allen.html), accessed Feb. 28, 2009.

¹² See AIDS.ORG, "HIV Travel/Immigration Ban: Background, Documentation," *available at* AIDS.ORG (<http://www.aids.org/atn/a-128-03.html>), accessed Feb. 28, 2009 ("In June 1987 the [Public Health Service], under pressure from President Reagan, added AIDS to the [immigration exclusion] list, but noted that the exclusion was not based on any new scientific knowledge and that 'AIDS is not spread by casual contact which is the usual public concept of contagious.'")

¹³ Also dubbed "abstinence-until-marriage," this policy by definition encourages gays and lesbians legally barred from marriage to never have sex.

¹⁴ See, e.g., Kaisernetwork.org, "Criminalizing HIV Transmission Discourages Testing, Contributes to Spread of Virus, Some Canadian Advocates Say," *available at* http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=56458 (Jan. 15, 2009) ("Mark Wainberg, a Montreal-based physician and former head of the International AIDS Society, said that although his support of the [HIV] anti-criminalization movement might seem 'counterintuitive,' the publicity surrounding criminal HIV cases adds to the negative stigma surrounding the virus and discourages people from testing.") ABA policy since 1989 has held that "[b]ecause existing civil and criminal remedies are available to prosecute the instances in which specific criminal sanctions might apply, HIV-specific criminal sanctions should play a limited role in combating the HIV epidemic. Accordingly, a program of aggressive public education about [HIV] should be implemented as the most effective method of deterring behavior which poses a high risk of transmitting HIV." See n.7, *supra*.

¹⁵ See Susan Okie, M.D., "Sex, Drugs, Prisons and HIV," *New England Journal of Medicine* 105-108 (Vol. 356; No. 2) (Jan. 11, 2007), *available at* <http://content.nejm.org/cgi/content/full/356/2/105> (accessed Mar. 30, 2009). ("Studies involving state-prison inmates suggest that the frequency of HIV transmission is low but not negligible. For example, between 1988 — when the Georgia Department of Corrections began mandatory HIV testing of all inmates on entry to prison and voluntary testing thereafter — and 2005, HIV seroconversion occurred in 88 male inmates in Georgia state prisons. [. . .] In another study in a southeastern state, Christopher Krebs of RTI International documented that 33 of 5265 male prison inmates (0.63%) contracted HIV while in prison. But Krebs points out that 'when you have a large prison population, as our country does . . . you do start thinking about large numbers of people contracting HIV.'" (Internal citations omitted.)

III. ABA Policies on HIV/AIDS

Non-discrimination against PLWHA and evidence-based approaches to the issues are the central themes informing ABA policies on HIV/AIDS. The Committee began developing these policies in 1988 with comprehensive hearings featuring expert testimony from virtually all relevant sectors. As noted, these hearings led to an omnibus package of detailed, Committee-sponsored policy recommendations adopted by the ABA House of Delegates.¹⁶

Taken together, these policies advance the following essential principles, which have informed subsequent ABA policies on a diverse range of issues affecting PLWHA and remain guideposts for national strategy development from a legal perspective:

- A. **Equal access** to health care, employment, housing, education, public accommodations and governmental services regardless of actual or perceived HIV status, and to HIV-related treatment, prevention and research programs regardless of minority status.

This overarching principle is indispensable to the well being of PLWHA as they cope with the virus, for reduced access in any of these areas can cause instability and, by extension, increase chances for HIV transmission and/or HIV drug resistance through inconsistent adherence to treatment regimes.

- B. **HIV testing** that is accessible, confidential, available anonymously, and provided after informed consent is voluntarily given.¹⁷

In general, the right of a legally competent patient to consent to any medical procedure, including HIV testing, resides in the patient and is not subject to waiver or diminution by others. Whether a patient can be deemed legally to have consented to a procedure depends on the extent to which the patient was informed of the nature and foreseeable results and consequences of the procedure, which, as with HIV testing, can encompass both physical and societal dimensions. A National AIDS Strategy should recognize that PLWHA remain subject to stigma and discrimination and that knowledge of this fact and its foreseeable consequences, and the availability of counseling to deal with them effectively, should factor into a determination whether a patient's consent has been informed.

¹⁶ See n.5, *supra*.

¹⁷ ABA policy since 1989 has held that “[a] voluntary HIV test should be conducted only after informed consent, specific to the HIV test, has been obtained and documented.” See n.7, *supra*.

- C. **HIV-specific confidentiality protections** under state and federal statutes and regulations.

Of all HIV-related legal rights, confidentiality of HIV status is most central to ensuring the effectiveness of any National AIDS Strategy, for it gives PLWHA and vulnerable persons confidence to seek prevention, counseling, and testing services. Without these protections, many PLWHA and vulnerable persons will avoid these services altogether, undermining prevention efforts.

- D. **Public health law protections** ensuring minimal risk of unnecessary personal identification and disclosure of HIV status consistent with legitimate public safety concerns.

A key corollary to confidentiality rights is the public health imperative of reducing the spread of HIV by informing sex and/or syringe-sharing partners of PLWHA that they may be at risk of HIV infection. This imperative must be met with the minimum possible threat to the confidentiality rights of PLWHA.¹⁸

- E. Reliable access to **non-discriminatory, comprehensive health care services**, at all stages of HIV disease, in both the public and private sectors, with particular emphasis on ensuring access for minority populations.

This principle includes making Medicaid available to indigent persons with HIV before they become completely disabled; making Medicare available to disabled persons with HIV without the present two-year waiting period; and ensuring access to affordable private insurance for both individuals and small employers. It also means aggressively combating intentional and structural discrimination against people with HIV in all health care settings.

- F. **Insurance coverage** that does not discriminate against persons with HIV and other conditions with higher health care costs.

Insurance plans that sharply limit access to non-generic medications or impose annual or lifetime caps that do not realistically provide coverage for a life-long condition, can have effects as invidious as plans that overtly discriminate based on an HIV diagnosis. Providers who treat people with HIV and other high-cost health care needs must not be excluded from participation in insurance plans. While perhaps

¹⁸ For more information on partner notification issues, see Centers for Disease Control and Prevention, *Recommendations for Partner Services Programs for HIV Infection, Syphilis, Gonorrhea, and Chlamydial Infection* (Nov. 7, 2008), available at http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5709a1.htm#Recommendations_for_Legal_and_Ethical_Concerns (accessed Feb. 9, 2009).

expensive, equal insurance access and coverage for PLWHA ultimately are less expensive than the potential public health and fiscal consequences of exclusion.

G. Reliable access to the legal system and the administration of justice, and non-discrimination under criminal law or in correctional settings based on HIV status.

Free or subsidized legal services protect the rights of low-income and minority populations to health care, housing, employment, and virtually all other opportunities and services that bear on managing HIV responsibly. Doctors as well as lawyers have pointed to the connection between legal assistance and maintaining the health of marginalized persons with HIV and other serious illnesses and disabilities. A National AIDS Strategy must ensure that federal funding for legal services is increased and maintained at a level proportionate to the continuing needs for these services and their centrality to HIV prevention efforts.

IV. Specific Issues, Salient Concerns, and Possible Responses

Consistent with the principles outlined in the previous section, the ABA has adopted additional policy that endorses syringe exchange programs coupled with drug counseling and treatment referral; non-HIV-discriminatory immigration policy; and implementation of legislation, policies, programs, and international agreements relevant to HIV/AIDS in a manner consistent with international human rights law and science-based prevention, care, support, and treatment objectives.¹⁹ Further, the ABA strongly supports increased collaboration between the medical and legal communities in addressing social determinants of health (including HIV infection) through medical-legal partnerships, which place trained lawyers in hospitals and other health care settings to counsel and represent low-income patients on legal issues affecting their health and well being.²⁰

In light of these principles, the following issues, concerns and possible responses, though not exhaustive, merit particular scrutiny in the development of a National AIDS Strategy and may warrant prompt executive or legislative action, as appropriate.²¹

¹⁹ See n.5, *supra*.

²⁰ For more information, including the full policy text and accompanying report, see Medical-Legal Partnerships Pro Bono Support Project: Pro Bono as a Healing Art, at <http://www.abanet.org/legalservices/probono/medlegal/home.shtml>.

²¹ These bills were introduced in the 110th Congress and are included here to explicate further the principles discussed in this paper. Recitation and discussion here of legislative proposals is for informational purposes and should not be construed as formal ABA endorsement of such proposals, in whole or in part, unless and until approved as ABA policy by the ABA House of Delegates.

A. Incarcerated Settings

HIV/AIDS prevalence in incarcerated populations is significantly higher than in the general U.S. population. In 2003, 1.9% of state prisoners and 1.1% of federal prisoners were HIV positive,²² as compared to .47% of the U.S. household population.²³ To reduce incidence rates, public health policies must support behavioral interventions to reduce risk behaviors and provide the means to realize protection, coupled with routine testing and counseling.²⁴

The Stop AIDS in Prison Act²⁵ addresses many of these concerns. It would:

- Direct the Bureau of Prisons to develop and draft regulations to implement a comprehensive policy to provide HIV testing, treatment, and prevention for inmates in federal prisons and upon reentry into the community.
- Require regulations to provide for: (1) testing of inmates upon intake and counseling; (2) pre-test and post-test counseling; (3) improvement of HIV/AIDS awareness and inmate education; (4) HIV testing of inmates annually or upon exposure to HIV; (5) HIV testing of pregnant inmates; (6) comprehensive medical treatment of inmates who test positive and confidential counseling on managing their medical condition and preventing HIV transmission to other persons; (7) protection of inmate confidentiality; (8) testing, counseling, and referral of inmates to health care and social service agencies prior to reentry into the community; (9) the right of inmates to refuse routine testing; (10) mandatory testing after a documented exposure to HIV; and (11) timely notification to inmates of test results;
- Amend the federal criminal code to: (1) require HIV testing for all inmates upon intake regardless of length of sentence or risk factors; (2) allow inmates to decline testing prior to release from incarceration; (3) make HIV test results inadmissible in civil and criminal proceedings; and (4) make HIV testing part of the routine health screening conducted at inmate intake; and

²² *HIV Transmission and Prevention in Prisons*, available at <http://hivinsite.ucsf.edu/InSite?page=kb-07-04-13> (accessed Feb. 3, 2009).

²³ Centers for Disease Control and Prevention press release, "New Report Provides Information on HIV Prevalence in the U.S. Household Population" (Jan. 29, 2008), available at <http://www.cdc.gov/media/pressrel/2008/r080129.htm> (accessed Feb. 3, 2009).

²⁴ See generally *HIV in Correctional Settings: Implications for Prevention and Treatment Policy*, available at http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=2593 (accessed Feb. 3, 2009).

²⁵ H.R. 1943, 110th Cong. (as passed by House, Sept. 25, 2007).

- Direct the Bureau of Prisons to report to Congress: (1) within one year on Bureau policies and procedures to provide testing, treatment, and prevention education programs for hepatitis and other diseases transmitted through sexual activity and intravenous drug use; and (2) annually thereafter on the incidence among inmates of diseases transmitted through sexual activity and intravenous drug use, including specific information on HIV/AIDS.

To be fully effective, any such legislation must be cognizant of prisoners' confidentiality during their period of incarceration and upon their re-entry into the community, and ensure access to ongoing care and treatment after their incarceration.²⁶

The JUSTICE Act of 2007²⁷ also seeks to reduce the spread of sexually transmitted infections in correctional facilities. It would:

- Require the Attorney General to direct the Bureau of Prisons to allow community organizations to distribute sexual barrier protection devices (e.g., condoms) and to engage in sexually transmitted infection (STI) counseling and prevention education in federal correctional facilities;
- Prohibit a federal correctional facility from taking adverse action against a prisoner who possesses or uses a sexual barrier protection device;
- Express the sense of Congress that states should allow for the legal distribution of sexual barrier protection devices in their correctional facilities; and
- Direct the Attorney General to: (1) conduct a survey of all educational, testing, and other programs in federal and state correctional facilities for reducing the spread of STIs; and (2) develop and implement a five-year strategy to reduce the prevalence and spread of STIs in such facilities.

²⁶ See n.17, *supra*. ("In general, if individual social contacts [of HIV-infected persons] are to be recruited for HIV testing, a self-referral approach rather than [health care] provider referral should be used. A provider referral approach should be used only after careful consideration of potential individual and community concerns about privacy and confidentiality.")

²⁷ H.R. 178, 110th Cong. (2007).

B. Injection Drug Use

It is estimated that half of all new HIV infections in the U.S. occur among injection drug users,²⁸ and the CDC estimates that drug users, their partners, and their children comprise one-third of all AIDS cases.²⁹

Interventions targeting risky behaviors particular to injection drug use-related transmission, especially syringe exchange programs, have been proven highly effective in reducing HIV transmission³⁰ by reducing needle sharing among injection drug users.

The Community AIDS and Hepatitis Prevention Act³¹ would allow state and local governments to use federal funds for syringe-exchange programs. The ABA supports this objective and other policies directed toward care and treatment for the underlying addictions that fuel injection drug use.

C. Homelessness and Poverty

Substandard living conditions and limited access to treatment render AIDS a leading cause of death among the U.S. homeless population.³² In addition to delivering prevention services on-site at service settings, preventing HIV transmission in the homeless population requires addressing the survival needs of homeless persons, including housing, employment, substance abuse treatment, and regular medical and mental health services.³³

A National AIDS Strategy therefore should consider whether the Housing Opportunities for Persons with AIDS (HOPWA) program is properly resourced, maximizes access, exercises non-discrimination, and encourages pre-parole planning for incarcerated persons.

²⁸ 2. Holmberg SD. The estimated prevalence and incidence of HIV in 96 large US metropolitan areas. *American Journal of Public Health*. 1996; 86:642-654.

²⁹ *Needle Exchange Questions and Answers – The Body*, available at <http://www.thebody.com/content/whatis/art46390.html> (accessed Feb. 3, 2009).

³⁰ Center for AIDS Prevention Studies fact sheet, “Does Needle Exchange Work?”, available at <http://www.caps.ucsf.edu/pubs/FS/NEPrev.php#2> (accessed Feb. 3, 2009).

³¹ H.R. 179, 111th Cong. (2009).

³² See University of California at San Francisco AIDS Research Institute, Center for AIDS Prevention Studies, “What Are Homeless Persons’ HIV Prevention Needs?” (revised September 2005), available at <http://www.caps.ucsf.edu/pubs/FS/pdf/revhomelessFS.pdf> (accessed Mar. 30, 2009) (“The elevated prevalence of infection combined with limited access to treatment and poor living conditions have contributed to HIV/AIDS becoming a leading cause of death in [the homeless] population.”)

³³ Center for AIDS Prevention Studies fact sheet “What are homeless persons’ HIV prevention needs?”, available at <http://www.caps.ucsf.edu/pubs/FS/revhomelessFS.php> (accessed Feb. 3, 2009).

D. Access to Care and Treatment

Delayed access is another barrier to effective HIV care and treatment. Under current federal law, a PLWHA's Medicaid eligibility becomes effective only after progression to AIDS has occurred or is imminent, thus limiting treatment options and increasing costs dramatically. In response, the Early Treatment for HIV Act (ETHA)³⁴ would amend Title XIX of the Social Security Act to permit states the option to provide Medicaid coverage for low-income individuals when they test HIV-positive, rather than waiting until they have progressed to AIDS.

E. Anti-discrimination — ADA Amendments Act

Under the Americans with Disabilities Act of 1990 (ADA), an individual is considered to have a "disability" if he or she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment. Persons with HIV disease, both symptomatic and asymptomatic, have physical impairments that substantially limit one or more major life activities and are, therefore, protected by the law. Persons who are discriminated against because they are regarded as being HIV-positive are also protected, as are persons who are discriminated against because they have a known association or relationship with an individual who is HIV-positive.³⁵

The Americans with Disabilities Act Amendments Act of 2008 (ADAAA) was signed into law on Sept. 25, 2008, and became effective Jan. 1, 2009. It makes important changes to the definition of the term "disability" in response to several U.S. Supreme Court decisions and portions of ADA regulations promulgated by the Equal Employment Opportunity Commission (EEOC) that had narrowed the ADA's applicability to PLWHA. While retaining the ADA's basic definition of "disability" and emphasizing that it should be interpreted broadly, the ADAAA also clarifies the way statutory terms should be interpreted in several specific ways, including some related to HIV/AIDS. For example, it expands the definition of "major life activities" to include immune system and reproductive functions, and clarifies that an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active.³⁶

³⁴ H. R. 1616, 111th Cong. (2009).

³⁵ See U.S. Department of Justice, "Questions and Answers: The Americans with Disabilities Act and Persons with HIV/AIDS," available at <http://www.ada.gov/pubs/hivqanda.txt> (accessed Feb. 9, 2009).

³⁶ See U.S. Equal Employment Opportunity Commission, "Notice Concerning the Americans With Disabilities Act (ADA) Amendments Act of 2008," available at http://www.eeoc.gov/ada/amendments_notice.html (Oct. 6, 2008) (accessed Feb. 9, 2009).

A National AIDS Strategy should pay close attention to the evolution of EEOC regulations interpreting and implementing the Act's provisions to ensure they address HIV/AIDS consistently with the Act's broad, anti-discrimination purposes.

F. Sex Education

Federal sex education policy developed during the Bush Administration has emphasized abstinence-until-marriage, often (in practice) to the exclusion of providing accurate information about how to prevent contracting HIV and other sexually transmitted diseases through, for example, condom use. Numerous scientific studies³⁷ have found this policy not only ineffective in reducing HIV transmission but counterproductive because youth continue to have sex but do not have access to the information they need to protect themselves from HIV and other STDs. A National AIDS Strategy should emphasize educational approaches to prevention that are consistent with scientific data regarding effectiveness.

The Responsible Education About Life (REAL) Act³⁸ offers one approach. It would:

- Require the Secretary of Health and Human Services to make grants to states for family life education, including education on abstinence and contraception, to prevent teenage pregnancy and sexually transmitted diseases;
- Require the Secretary to provide for a national evaluation of a representative sample of such programs for effectiveness in changing adolescent sexual behavior, including delaying sexual and high-risk activity, preventing pregnancy and disease (including HIV/AIDS), and increasing contraceptive knowledge; and
- Require states receiving such grants to provide for an individual evaluation of the state's program by an external, independent entity.

In addition to reflecting current science with regard to effective sex education curricula, the REAL Act would require ongoing scientific analysis of programs implemented under it to ensure their effectiveness.

G. Minority Populations

³⁷ See, e.g., Sexuality Information and Education Council of the United States (SIECUS) Public Policy Office Fact Sheet, *available at* http://www.siecus.org/data/global/images/research_says.pdf.

³⁸ Responsible Education About Life Act. S. 611, 111th Cong. (2009).

As noted, minority populations generally have had less reliable access to healthcare and bear a disproportionate burden of HIV infection in the United States, with Blacks and Hispanics/Latinos together comprising 66% of HIV/AIDS cases in the U.S. in 2005-06.³⁹

The Health Equity and Accountability Act⁴⁰ would address these disparities as follows:

- Amend the Public Health Service Act to require the Secretary of Health and Human Services to establish the Robert T. Matsui Center for Cultural and Linguistic Competence in Health Care;
- Require health-related programs of the Department of Health and Human Services (HHS) to collect data on race, ethnicity, and primary language;
- Direct each federal health agency to implement a strategic plan to eliminate disparities and improve the health and health care of minority populations;
- Require the Secretary to establish: (1) an Office of Health Disparities within the Office of Civil Rights; and (2) civil rights compliance offices in each HHS agency that administers health programs;
- Reestablish the Indian Health Service as an agency within the Public Health Service of HHS to be administered by an Assistant Secretary of Indian Health;
- Require the establishment of an Office of Minority Health within specified agencies;
- Direct the President to execute, administer, and enforce provisions to address environmental justice in minority and low-income populations;
- Provide for the establishment of health empowerment zone programs in communities that disproportionately experience disparities in health status and health care;

³⁹ See Centers for Disease Control and Prevention, HIV/AIDS Fact Sheets, available at <http://www.cdc.gov/hiv/resources/factsheets/> (accessed Feb. 9, 2009). Since 1989, ABA policy has been that “[p]ublic and private entities should expeditiously develop and implement HIV-related programs targeted to serve minority communities.” See n.7, *supra*.

⁴⁰ H.R. 3014, 110th Cong. (2007).

- Require the Secretary to designate centers of excellence at public hospitals and other health systems that demonstrate excellence in providing care to minority populations and reducing health disparities;
- Make immigrants from certain U.S. territories and possessions eligible for specified federal programs;
- Require the Secretary to expand the Minority HIV/AIDS Initiative;
- Provides for grants for strategies to eliminate racial and ethnic health and health care disparities; and
- Require the Secretary to establish the Rural Health Quality Advisory Commission.

To summarize, the Health Equity and Accountability Act addresses systemic or structural factors that may contribute to persistent disparities in minority healthcare access and HIV infection rates.

H. HIV Testing — Insurance Coverage

Lack of or inadequate insurance coverage of HIV testing is an additional longstanding barrier to HIV prevention. The Routine HIV/AIDS Screening Coverage Act of 2007⁴¹ would address this problem as follows:

- Amend the Public Health Service Act, the Employee Retirement Income Security Act of 1974, the Internal Revenue Code of 1986, and title 5, United States Code, to require individual and group health insurance coverage and group health plans and Federal employees health benefit plans to provide coverage for routine HIV/AIDS screening;
- Amend the Public Health Service Act, the Employee Retirement Income Security Act (ERISA), and the Internal Revenue Code to require a group health plan or a health insurance issuer offering group health insurance coverage to provide coverage for routine HIV/AIDS screening under terms and conditions no less favorable than for other routine screenings;

⁴¹ H.R. 822, 110th Cong. (2007).

- Prohibit such a plan or issuer from: (1) denying eligibility or continued eligibility to enroll or renew solely to avoid these requirements; (2) denying coverage for such screening because there are no known risk factors present or because the screening is not clinically indicated, medically necessary, or pursuant to a referral, consent, or recommendation by any health care provider; (3) providing monetary payments, rebates, or other benefits to encourage individuals to accept less than the minimum protections available under this Act; (4) penalizing or otherwise reducing or limiting the reimbursement of a provider because such provider provided care to a participant or beneficiary in accordance with this Act; (5) providing incentives to induce the provision of care in a manner inconsistent with this Act; or (6) denying a participant or beneficiary continued eligibility to enroll or renew solely because of the results of an HIV/AIDS test or screening procedure; and
- Apply such requirements to health insurance coverage offered in the individual market and coverage offered under the Federal Employees Health Benefits (FEHB) Program.

I. Ryan White Program Changes

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was first enacted in August 1990 to provide Federal funding for HIV-related health services.⁴² The program works with cities, states, and local community-based organizations to provide services to more than half a million people each year who do not have sufficient health care coverage or financial resources for coping with HIV disease. The majority of Ryan White funds support primary medical care and essential support services, while a smaller but equally critical portion is used to fund technical assistance, clinical training, and research on innovative models of care. Federal funds are awarded to agencies located around the country, which in turn deliver care to eligible individuals.

The program was amended and reauthorized for five years in May 1996, for an additional five years in October 2000, and in December 2006 for three years. It is administered by the Health Resources and Services Administration (HRSA), which notes that “[m]uch has changed in the epidemiology and medical management of HIV/AIDS since the Ryan White CARE Act was enacted in 1990. While it used to be that those diagnosed with the disease had little hope, patients today are living longer and healthier lives.”⁴³ Accordingly, the December 2006 reauthorization contains many significant changes, including altering the

⁴² For more information about the Ryan White program, see U.S. Department of Health and Human Services, Health Resources and Services Administration, at <http://hab.hrsa.gov/aboutus.htm> (accessed Apr. 6, 2009).

distribution formulas from estimated living AIDS cases to actual living HIV and AIDS cases, a core services requirement, and provisions regarding non-obligated funds. It also includes a sunset clause, to take effect on September 30, 2009. Many experts believe the impact of these changes has not been fully or sufficiently analyzed and therefore urge that the sunset clause be extended an additional three years.

Given the Ryan White program's critical importance to the effective management of HIV in the United States, and consistent with this paper's emphasis on evidence-based policymaking, extending the sunset date may be warranted until consensus on the impact of the program's changes has been achieved.

V. Summary

Actual or apparent discrimination against PLWHA exacerbates the epidemic by deterring HIV testing, treatment, and prevention counseling. A National AIDS Strategy must be cognizant of this reality.

This means policymakers must recognize, accept, and discuss openly the facts about HIV/AIDS: that it is, fundamentally, a *human* phenomenon driven by the most intimate human behavior — sex — and perhaps the most complex human pathology — drug abuse. And they must do so with humility, acknowledging that these vectors of HIV transmission play out in a broad range of multi-layered and sometimes unfamiliar social, cultural, and interpersonal contexts that require not moral condemnation, which fuels discrimination, nor approbation, which is irrelevant — but clear-eyed adherence to what works.

⁴³ *Id.*

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