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National Alliance of State and Territorial AIDS Directors

## Health Disparities and the Role of Policymakers: A Prevention Commentary

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### Introduction: What Does "Health Disparities" Mean?

For the past 25 years, public health practitioners have grappled with a complex web of social factors in order to create comprehensive programs that reduce – and ultimately seek to eliminate – the spread of HIV/AIDS, viral hepatitis and sexually transmitted diseases (STDs) among racial and ethnic minority communities in the U.S. While there have been significant strides, e.g., targeted funding for specific populations, innovative cross-governmental programs, and refined approaches to disease prevention and treatment, these efforts have shown minimal success in decreasing disease burden.

Critical questions continue to emerge in the country's debate on the role of health disparities in disease proliferation. Despite enhanced efforts, why do African Americans currently represent more than half of all HIV cases in the U.S.? Are changing immigration and disease trends in the Latino population, coupled with issues of acculturation, creating demands on service delivery systems nationwide? Is public health prepared to respond to the unique HIV, viral hepatitis and STD prevention needs of Asian American, Native American and Native Hawaiian, and Pacific Islander communities? Questions like these, and a myriad of others, have demanded that the tripartite system of federal, state, and local public health agencies explicitly acknowledge health disparities and begin to address the factors that contribute to negative health outcomes in marginalized populations. In their ongoing efforts to positively impact health and wellness of minority communities, public health is faced with an environment that is often politically charged and disconnected from the daunting influences that run far beyond the realm of public health's reach.

A 2002 Institute of Medicine (IOM) Report entitled, *"Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,"* asserts that "a person's health may be affected by factors related to the health care system, such as the appropriateness of care, access to care, health insurance, and language and cultural barriers between physicians and their patients. It may be affected by factors beyond the control of the system, such as a person's level of education, living environment, preferences with regard to medical care, and socioeconomic status."<sup>1</sup> The report acknowledges gaps in traditional systems of care and begins to frame multilayered structural factors that contribute to poor health overall. Building on the IOM report as a framework for identifying the systemic roots of health disparities, the development and implementation of U. S. policy initiatives intended to improve the health of diverse and unarguably resilient populations across race

and ethnicity require robust examination.

Last month's [HIV Prevention Bulletin](#) focused on syndemics—two or more afflictions, interacting synergistically, contributing to excess burden of disease in a population.<sup>2</sup> This month's *Bulletin* focuses broadly on health disparities and the roles racism and policy—at all levels of government—plays in alleviating or compounding structural factors that widen the health disparity gap in the U.S. Conversations involving health disparities *and* syndemics must be combined in order to effectively examine the spread of HIV/AIDS, viral hepatitis, and STDs in racial and ethnic minority communities.

We will examine three policy initiatives that have had significant influence, either intended or unintended, on the spread of HIV/AIDS in racial and ethnic minority communities. While the policy initiatives we selected are, by no means, the only noteworthy drivers of health disparities, they clearly articulate and underscore the intersection between health disparities and policy as it pertains to HIV/AIDS. For example, needle exchange programs effectively prevent transmission of HIV. Still, policies prevent the distribution of clean needles and syringes in many parts of the country. Minority populations disproportionately fill America's jails and prisons and, at the same time, have the highest rates of HIV and STDs. What policies contribute to this link? Additionally, abstinence-only before marriage programs have not been proven effective in reducing the onset of sex—and, subsequently the spread of disease—in young people. Even so, current policies divert funding from comprehensive sexuality education to support these ineffective programs. So, what roles do racism and policy play in promulgating disease?

### **Racism, Policy and Health: A Lethal Recipe**

*"Let me just put this in perspective. If HIV/AIDS were the leading cause of death of white women between the ages of 25 and 34, there would be an outraged outcry in this country."*

**— Senator Hillary Rodham Clinton, Howard University, June 2007**

Before a thorough analysis of U.S. policy design, implementation, and evaluation affecting racial and ethnic communities can occur, one must admit that racism has persistent effects in our society. Racism did not originate and does not continue in an impenetrable construct. On the contrary, and despite gains in equality throughout the years following the Civil Rights Movement, racism is still pervasive in the U.S. To this end, we must be mindful of the biases, learned stereotypes, and attitudes about race that we bring to the metaphorical "policy drafting table."

In terms of exploring health among racial and ethnic groups, researchers now hypothesize that negative health outcomes are in fact due to the effects of racism.<sup>3</sup> Health disparities, at their genesis, are rooted in a lack of acknowledgement or unwillingness to explore complex differences across racial and ethnic groups, as no one group is monolithic. This is racism. Ignoring the causes of group differences impedes the advancement of scientific knowledge, perpetuates ideas of biologically-determined differences between races, and, ultimately, limits efforts at primary prevention.<sup>4</sup>

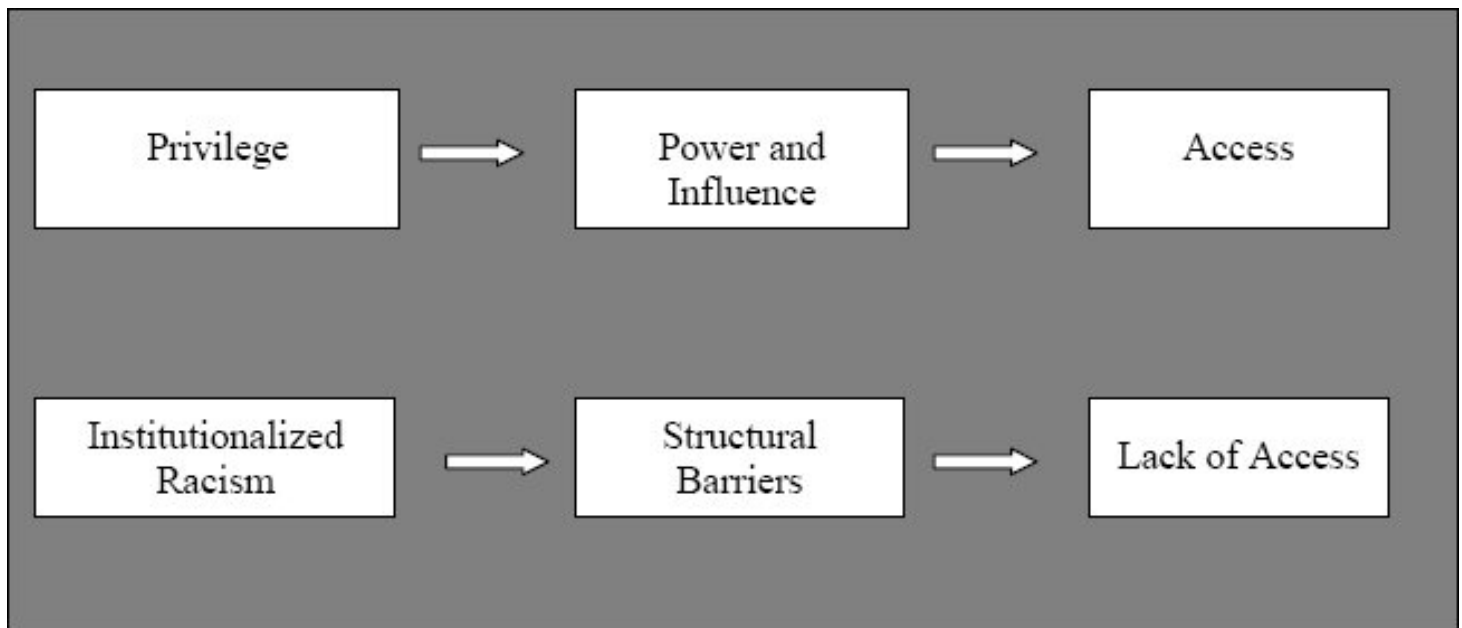
Researcher Camara Phyllis Jones developed a framework for understanding racism on three levels: institutionalized, personally mediated, and internalized. This framework is useful for raising new hypotheses about the bases of race-associated differences in health outcomes, as well as for designing effective interventions to address these differences. For the purposes of this discussion, we will focus on institutionalized racism as it relates to this framework. Jones asserts:

*"Institutionalized racism is defined as differential access to goods, services, and opportunities of society by race. Institutionalized racism is normative, sometimes legalized, and often manifests as inherited disadvantage. It is structural, having been codified in our institutions of custom, practice, and law, so there need not be an identifiable perpetrator. Indeed, institutionalized racism is often evident as inaction in the face of need."<sup>5</sup>*

Jones further notes that institutionalized racism has its origins in discrete historical events but persists because of contemporary structural factors that perpetuate those historical injustices.

Building upon Jones' concept of institutionalized racism and its affect on access to health care and prevention programs, we present a conceptual framework in Figure 1 below. The model demonstrates how institutionalized racism contributes to structural barriers in health care systems that ultimately result in lack of access for certain communities. In a parallel system, privilege leads to power and influence and, ultimately, results in access to healthcare and prevention programs. The model is meant to demonstrate the role of racism in the proliferation of health disparities and to illustrate the need for consideration of racism in the development of strategies to address health disparities.

**Figure 1. Conceptual Framework**



### **Examining the Layers of U.S. Policy Initiatives**

While many health departments, community based organizations, and front-line staff sort through the issues discussed above during design and delivery of public health services, to what degree do policymakers consider the intricate details of these issues when conceptualizing or reauthorizing policy geared towards reducing health disparities, including HIV/AIDS, viral hepatitis and STDs in racial and ethnic minority communities?

For example, in December 2003 the Department of Health and Human Services (HHS) released its own National Healthcare Disparities Report<sup>6</sup>. Unlike the 2002 IOM Report (*Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*), HHS did not describe healthcare disparities as a national problem. In fact, the final version, which was cleared by political appointees, hardly mentioned the word "disparity" and highlighted how racial and ethnic minorities are in better health than the general population. The original draft of the report, however, had been consistent with the findings of the IOM report, with scientists describing disparities as "national problems" that are "pervasive in our health care system" and that disparities carry a significant "personal and societal price." The final version of the report contained none of these conclusions.

As we have discussed, the political landscape at all levels of government has a very real impact on the structural factors that widen or narrow the health disparities gap in the U.S. To help articulate and underscore the intersection between health disparities and policy, we will examine three policies that clearly have implications for the health outcomes of racial and ethnic minority communities as they pertain to HIV/AIDS: needle exchange, corrections, and abstinence-only sexuality education.

*Needle Exchange: What's Left to Know? It works!*

*"A meticulous scientific review has now proven that needle exchange programs can reduce the transmission of HIV and save lives without losing ground in the battle against illegal drugs."*

**— Donna Shalala, Former Secretary of Health and Human Services,  
April 1998**

As we asserted in the April 2007 [HIV Prevention Bulletin](#), using clean needles reduces the likelihood of HIV transmission.<sup>7</sup> Despite key scientific findings that underscore the effectiveness of needle exchange programs in reducing new HIV infections in injection-drug-using (IDU) populations, the Clinton Administration decided to let stand a nine-year-old ban on federal funding for needle exchange. Clinton's own advisors articulated the reason: lifting the ban might motivate conservatives to strip federal resources thereby usurping local AIDS prevention projects that provide needle exchange. The decision was political, not scientific. The ongoing ban on the use of federal funds to support needle exchange programs impedes effective HIV and viral hepatitis prevention efforts for IDUs and their sexual and needle sharing partners. Simply put, policy contributes to new HIV infections.

Taking it a step further, the policies that prevent access to clean needles and syringes disproportionately impact racial and ethnic minorities. Blacks, Hispanics, Asian/Pacific Islanders, and Native Americans account for just over half of all reported AIDS cases in the U.S. Yet, among AIDS cases traced directly or indirectly to injection drug use, non-Whites account for nearly 80 percent of the cases. Furthermore, 85 percent of pediatric AIDS cases traced to injection drug use have occurred among racial and ethnic minorities.<sup>8</sup> Using Jones' model as a framework, the lack of access to effective HIV prevention tools, like clean needles and syringes, is directly related to structural barriers, like federal and state laws. These structural barriers are aligned with the reality of the epidemic where HIV disease burden in racial and ethnic minority communities is highest. What role has institutionalized racism played, consciously or unconsciously, in this missed opportunity?

While issues of race, coupled with socioeconomic status and the politics of needle exchange, may seem obvious, what is most notable is the manner in which race continues to be nonexistent in discussions within both Congress and the Administration. Despite the fact that the HIV epidemic among IDUs is overwhelmingly an epidemic of those who are poor and non-White, this fact is rarely mentioned when policymakers debate needle exchange. Is this a result of the generalized discomfort in the American political system about matters of race—a phenomena that warrants further exploration? Could it reflect a decision on the part of supporters to avoid associating the discussion of HIV/AIDS and needle exchange with a population that invokes more fear than compassion among the broader electorate?

Policymakers should be guided by evidence-based data when considering controversial programs such as needle exchange that seek to reduce new infections. Health departments can be meaningful agents of change surrounding the efficacy and implementation of needle exchange policy. Furthermore, health departments and communities must reframe the debate around needle exchange by using epidemiological information to garner support of leaders, policymakers and the community at large. Discussions should undoubtedly include the faces of the epidemic, including current and former substance users.

Policy change regarding needle exchange can reduce new HIV infections among IDUs and, ultimately, begin to address health disparities among minority populations. The policy is straightforward and is clearly based in science. Perhaps an even greater challenge is an examination of correctional policies involving a complex set of structural-level issues at both the state and federal levels, and their impact on health disparities.

*Corrections and Communities: The Domino Effect*

*"The result of this war [on drugs] has been a massive increase in incarceration rates for minority men. This "epidemic of incarceration" of males, both young and old, has had profound effects on the fabric of families in urban minority communities and has resulted in increased rates of female-headed households."*

**— Robert Aronson, et al., *American Journal of Public Health*; May 2003**

U.S. corrections and law enforcement policy asserts tremendous influence on the health outcomes of racial and ethnic minority communities nationwide. Moreover, the interconnectivity between the incarcerated and those most impacted by health disparities overall has been thoroughly examined, as definitive and researched conclusions are well documented. Considering the aforementioned, we know that: 1) Some prisoners arrive in correctional facilities already infected with HIV and/or STDs; 2) Some prisoners engage in high-risk behaviors and become infected while incarcerated; and 3) Health consequences of incarceration have significant impacts on prisoners and on the communities to which they will ultimately return.<sup>9</sup>

In 2004, the Bureau of Justice Statistics (BJS) reported approximately 1.1 million incarcerated individuals in state and federal correctional facilities. Of those incarcerated, approximately 60 percent were Black or Hispanic. Indeed, in the same report, the BJS reported that the HIV seropositivity rate among Blacks and Hispanics was nearly two percent of the inmate populations, while it was less than one percent for Whites, clearly indicating a disproportionate impact on minority prison populations.<sup>10</sup>

But beyond the startling statistics, one should consider the resulting effects of incarceration in ethnic and minority communities and the connection to HIV, viral hepatitis and STD risk. For example, given that inmates are overwhelmingly male, incarceration disproportionately reduces the ratio of minority men to minority women in the general population.<sup>11</sup> This paradigm has the potential to impact a woman's ability to be discriminating in partner choice and in negotiating safer sex practices. As a result, a woman may encounter more men who engage in high-risk behavior and, at the same time, who have increased bargaining power in partner selection. Together, these characteristics could lead to less fidelity in partnerships and less stable relationships overall. This example underscores the unintended consequences and "domino effect" nature of myopic policy.

Overall, policymakers must strive to advance legislation that seeks to address the disproportionate impact of HIV, viral hepatitis and STDs on racial and ethnic minorities in jails and prisons across the U.S. At the source is a need to remedy draconian laws which place racial and ethnic minority communities at greater risk for incarceration, e.g., national drug control laws.

Additionally, public health practitioners should work to establish meaningful relationships with correctional facilities. These partnerships can be fruitful in delivering critical core public health functions, including HIV, viral hepatitis and STD prevention education and screening, vaccination against hepatitis A and B, and in the most preferred of situations, distributing condoms in correctional facilities.

Like laws and correctional policies that influence the health status of minorities, abstinence-only sex education policy limits the meaningful impact of comprehensive sexuality education for minority youth. And the effect of abstinence-only until marriage on gay youth and minorities in communities where marriage rates have dramatically fallen cannot be underestimated.

*Abstinence-only Until Marriage Education vs. Comprehensive Sexuality Education – the Evidence is Clear!*

*" . . .there was already a policy in place that didn't want to hear the science, but wanted to quote, unquote, preach abstinence, which I felt was scientifically incorrect."*

**— Former Surgeon General Richard Carmona,  
House Government Reform Committee, July 2007**

Statistics demonstrate that, through 2001, African Americans and Latinas accounted for 84 percent of cumulative AIDS cases among women ages 13 to 19 and 78 percent of cases among women ages 20 to 24. Through 2001, African Americans and Latinos accounted for 62 percent of cumulative AIDS cases among men ages 13 to 19 and 60 percent of cases among men ages 20 to 24.<sup>12</sup> In addition, the chlamydia rate among women ages 15 to 19 was nearly seven times higher among African Americans than among Whites (8,483 and 1,276 per 100,000, respectively). Among males aged 15 to 19, chlamydia rates were 12 times higher among African Americans than among Whites (1,550 and 128 per 100,000, respectively).<sup>13</sup> In the same year, 75 percent of all reported cases of gonorrhea occurred among African Americans for whom the gonorrhea rate was 782 per 100,000 population, compared to 114 among Native Americans, 74 among Latinos, and 29 among non-Hispanic Whites.<sup>14</sup> These statistics illustrate a simple point: young racial and ethnic minorities are engaging in sex and, at the same time, are bearing a disproportionate burden of disease. What effective skills building are they receiving to protect themselves and others?

Even with epidemiological data that clearly makes the case for sexuality education that appropriately engages sexually active youth; the emphasis over the last six years has been on abstinence-only until marriage education. The impact leaves little doubt that some sexually active youth in the U.S. do not have knowledge of or access to methods for protecting themselves.

Recently, a multiple-year study by Mathematica Policy Research Inc., commissioned by HHS, showed that young people who graduate from abstinence-only programs are no more likely than their peers to wait for sex.<sup>15</sup> On the other hand, comprehensive sex education has been demonstrated to lead to less risky behavior, ultimately fewer HIV, viral hepatitis, and STD infections, and therefore fewer health disparities among young people.<sup>16</sup>

One of the most important landmarks in the ongoing debate about abstinence-only education occurred in October 2006, when a report was released by the non-partisan Government Accountability Office (GAO). This report documented that HHS wasted millions of taxpayer dollars by delivering abstinence-only-until-marriage programs with minimal oversight and review for scientific accuracy.<sup>17</sup> Proponents of comprehensive sexuality education hope the GAO report will result in increased oversight of these programs, including standardized and rigorous measures to determine the effectiveness of abstinence-only education.

The other pivotal document released last year came from the Society of Adolescent Medicine, which unveiled findings from an extensive review of federally-funded abstinence policies and programs. The report, *Abstinence-only Education Policies and Programs: A Position Paper of the Society for Adolescent Medicine*, stated:

*"...abstinence-only education programs provide incomplete and/or misleading information about contraceptives, or none at all, and are often insensitive to sexually active teenagers."*<sup>18</sup>

Another major development occurred when New Jersey rejected federal funding to provide abstinence-only-until-marriage programs. In a letter from New Jersey's Commissioners of the Department of Health and Senior Services and the Department of Education to HHS Secretary Michael Leavitt, the state informed the federal government of its decision, explaining that the "abstinence-only-until-marriage guidelines contradict the core curriculum content standard in comprehensive sex education that New Jersey has had in place for more than 25 years."<sup>19</sup> Moreover, the governor's office cautioned that accepting federal abstinence-only funds may, in fact, cost the state money because students may require additional sex education to clarify the partial and misinformation taught in abstinence-only-until-marriage programs.<sup>20</sup> As of April 2007, eight states (California, Connecticut, Maine, Montana, New Jersey, Ohio, Rhode Island and Wisconsin) have rejected Title V federal funding.

Since 1982, the U.S. government has spent over a \$1.5 billion on unproven abstinence-only-until-marriage programs through three major funding streams. These funding streams are: Title V, passed as part of the 1996 Welfare Reform Act; Community-Based Abstinence Education (CBAE) Grants; and the Adolescent Family Life Act (AFLA). Of that money, over \$800 million has been spent during just the current administration. Under the leadership of President Bush there has been a continued expansion of investment in these programs with more than \$175 million allocated for Fiscal Year 2007 alone.

In 2006, the flat funding of federal funds for abstinence-only until marriage programs, the continued push for the accuracy and evaluation of abstinence-only until marriage programs by the public health and medical communities, and the bold statement made by New Jersey's leadership in their decision to turn back Title V funding, demonstrated a shift towards effectiveness and medical accuracy in the landscape of sexuality education. However, in their FY2008 funding bill, the House Appropriations Committee includes a \$28 million increase for Community Based Abstinence Education grant—the first increase in three years.

In light of the evidence that abstinence-only programs are not effective in delaying sexual activity among young people, policymakers must examine their role in limiting the access of sexually-active young people to the vital information necessary to help them prevent HIV, viral hepatitis, and STD infections, and, ultimately, to impact health disparities among them. Legislators, particularly those in the tri-caucuses (Black, Hispanic and Asian/Pacific Islander) should be mindful of, and clearly articulate, the role these policies play on the impact of health disparities among youth. Health and education agencies should carefully consider the role of both abstinence-only and comprehensive sexuality education, taking into account the scientific evidence that supports and/or refutes the effectiveness of these programs. Ultimately, the goal should be to provide youth, and particularly youth of color, the ammunition they need to make informed decisions about their sexual behaviors. A decision not to do this is political, not scientific.

## Conclusion

NASTAD has prioritized addressing racial and ethnic health disparities as an overarching strategic goal of all its programming, setting the stage for continued movement toward policies and programs that seek to reduce health disparities in vulnerable, yet resilient populations. In this month's *Bulletin*, we examined policies that contribute to continued health disparities in the U.S. This examination is intended to open a dialogue to explore differing perceptions of new or current policies and practices. Simply viewing these policies as we have in the past is no longer sufficient. A re-framing of the discussions and policies must take place with a renewed sense of evidence-based thinking. Political ideology must no longer be the basis for the creation of policies and laws that ultimately affect the health and wellness of our nation's citizens and residents—in many cases the underserved, ethnic and racial minority populations, who are most often the populations at most risk for HIV, viral hepatitis, and STDs.

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### **Errata**

The story from California on social networks, "Using Social Networks: California's Satellite Syringe Exchange Program Experience," that appeared in the June [HIV Prevention Bulletin](#), was written by Valorie Eckert, Tom Stopka and Alessandra Ross.

### **Meeting and Planning Calendar**

Capacity Building Opportunities: For a searchable database of CDC-supported capacity building trainings and events, please visit: the Capacity Building Branch's [Group Events Management System](#) site.

August 23-26, 2007

[Staying Alive 2007](#), Cleveland, OH. National conference by and for people living with HIV/AIDS sponsored by the National Association of People With AIDS (NAPWA)

August 23 - 24, 2007

National AIDS Education & Services for Minorities Capacity Building Assistance Summit 2007, Oakland, CA. Focus is to orientate, educate, inform, and build skills of those involved in prevention planning. For more information, visit the [conference website](#).

September 27-28, 2007

19th Annual Denver STD/HIV Clinical Update, Denver, CO. For information contact by calling (303) 436-7226; or visit the [website](#).

October 15, 2007

[National Latino AIDS Awareness Day](#).

November 2-6, 2007

[American Association for the Study of Liver Diseases Conference](#), Boston, MA

November 3-7, 2007

[American Public Health Association Conference](#), Washington, DC

November 7-10, 2007

[United States Conference on AIDS](#), Palm Springs, CA.

December 1, 2007

World AIDS Day.

December 2-5, 2007

[2007 National HIV Prevention Conference](#), Atlanta, GA.

December 4, 2007

[Michigan Hepatitis C Conference](#), Plymouth, MI

February 3-7, 2008

15th Conference on Retroviruses and Opportunistic Infections, Boston, MA. For more information, visit the [conference website](#).

February 7, 2008

National Black HIV/AIDS Awareness Day. For more information, visit the [event website](#).

February 25-26, 2008

2008 National Conference on African Americans and AIDS, Philadelphia, PA. Sponsored by Minority Healthcare Communications, Inc. For more information, visit the [conference website](#).

March 10, 2008

National Women and Girls AIDS Awareness Day. For more information, visit the [event website](#).

March 20, 2008

National Native HIV/AIDS Awareness Day. For more information, visit the [event website](#).

March 28-29, 2008

17th Annual HIV Conference, Orlando, FL. Sponsored by the Florida/Caribbean AETC. For more information, visit the [conference website](#).

May 19, 2008

National Asian and Pacific Islander AIDS Awareness Day. For more information, visit the [event website](#).

May 22-25, 2008

20th Annual National Conference on Social Work and HIV/AIDS, Washington, D.C. For more information, visit the [conference website](#).

July 28-29, 2008

2008 National Conference on Latinos and HIV/AIDS, Miami, FL. For more information, visit the [conference website](#).

August 3-8, 2008

XVIII International AIDS Conference, Mexico City, Mexico. For more information, visit the [conference website](#).

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NASTAD's production of the *Bulletin* is made possible through funding provided by CDC's Division of HIV/AIDS Prevention (DHAP) in the National Center for HIV, Viral Hepatitis, STD, and TB Prevention.

If you have an idea or program relative to any of these topics that you would like to include in the *Bulletin*, please contact [Dave Kern](#) or [Lynne Greabell](#) (202) 434-8090. NASTAD's *HIV Prevention Bulletin* is written and edited by NASTAD staff and participants of community planning and prevention efforts around the country.

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The logo for NASTAD, featuring the word "NASTAD" in a light purple, sans-serif font. To the left of the text are three vertical dots of the same color, arranged in a column.

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