

THE INTERNATIONAL vs. NATIONAL DEBATE:

Is the President's Emergency Plan for AIDS Relief (PEPFAR) international commitment to combating HIV/AIDS succeeding at the expense of those people living with the disease in the United States?

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ADAP Advocacy Association
1501 M Street, NW
7th Floor
Washington, DC 20005

Email: info@adapadvocacyassociation.org
Web: <http://www.adapadvocacyassociation.org>



"Our rates are higher than West Africa, they're on par with Uganda and some parts of Kenya."

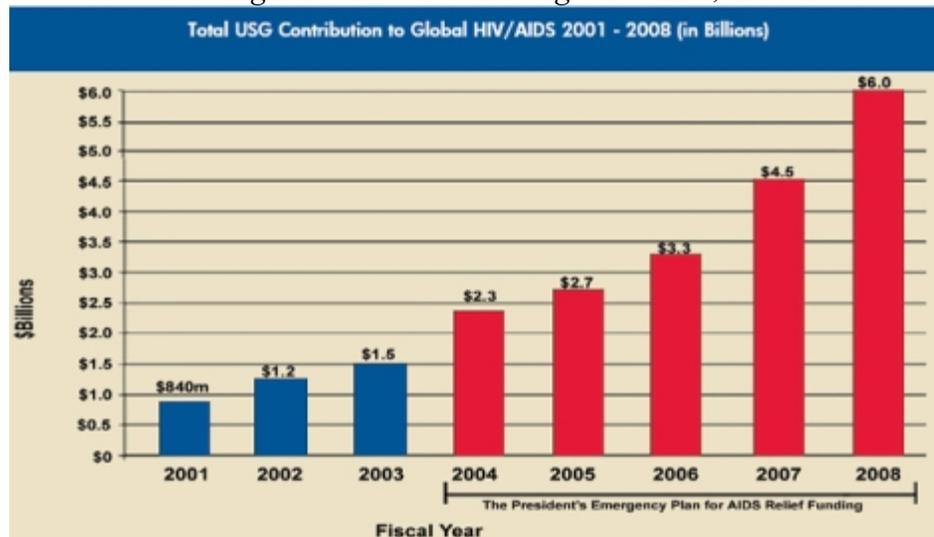
- Shannon L. Hader, director of the District of Columbia's HIV/AIDS Administration, quoted in the Washington Post on March 15, 2009.¹

During his State of the Union speech on January 28, 2003, President Bush announced the Emergency **Plan for AIDS Relief (PEPFAR)**, a five-year \$15 billion plan to fund AIDS care and prevention in the developing world. This ambitious initiative, grown from an earlier program called the "**Global Fund to Fight AIDS, Tuberculosis, and Malaria**" launched in 2001, has been hailed world-wide with near-universal acclaim as an important humanitarian and political effort to stem the tide of global HIV/AIDS. It has been touted as a vital lifeline to millions of people living with HIV/AIDS in the fifteen nations dubbed "Target Countries" ranging from Haiti and Botswana to Vietnam, and though not without some major controversies, it is considered a key piece of Bush's legacy today.

The purpose of this article is not to denigrate the work PEPFAR has accomplished, or to diminish the value of the lives forever changed by the medications and services it has provided to those in need worldwide. Described by former Secretary of State Condoleezza Rice as "transformational diplomacy," it is a strong response to the seemingly insurmountable humanitarian crisis that is the global AIDS pandemic. And for about \$2 billion less in total than what the United States spends in Iraq every month², it's almost a bargain.

But some question whether PEPFAR is an unfit parent who feeds his neighbors as his own family goes hungry. While international efforts are laudable, domestic funding for HIV/AIDS services and supports during the same time period had increased at *less* than the rate of inflation despite an ever-increasing pool of need. While PEPFAR clearly saved lives, it does not negate the fact that lives were lost in the United States. In 2003, eight Americans (five in Kentucky and three in West Virginia) died while on waiting lists for the AIDS Drug Assistance Program (ADAP), which is authorized under Title II/Part B of the Ryan White CARE Act.³ As ADAP funding was being cut by \$2.03 million in Fiscal Year (FY) 2004 and \$2.73 million in FY2005, Congress appropriated \$350 million for PEPFAR. Is this not unconscionable?

Table showing USG contributions to global AIDS, 2001-2008⁴



¹ <http://www.washingtonpost.com/wp-dyn/content/article/2009/03/14/AR2009031402176.html?hpid=topnews>

² http://en.wikipedia.org/wiki/Financial_cost_of_the_Iraq_War#cite_note-2

³ <http://www.dabtheaidsbearproject.com/adwalicrinam.html>

⁴ The President's Emergency Plan for AIDS Relief Funding, Annual Report

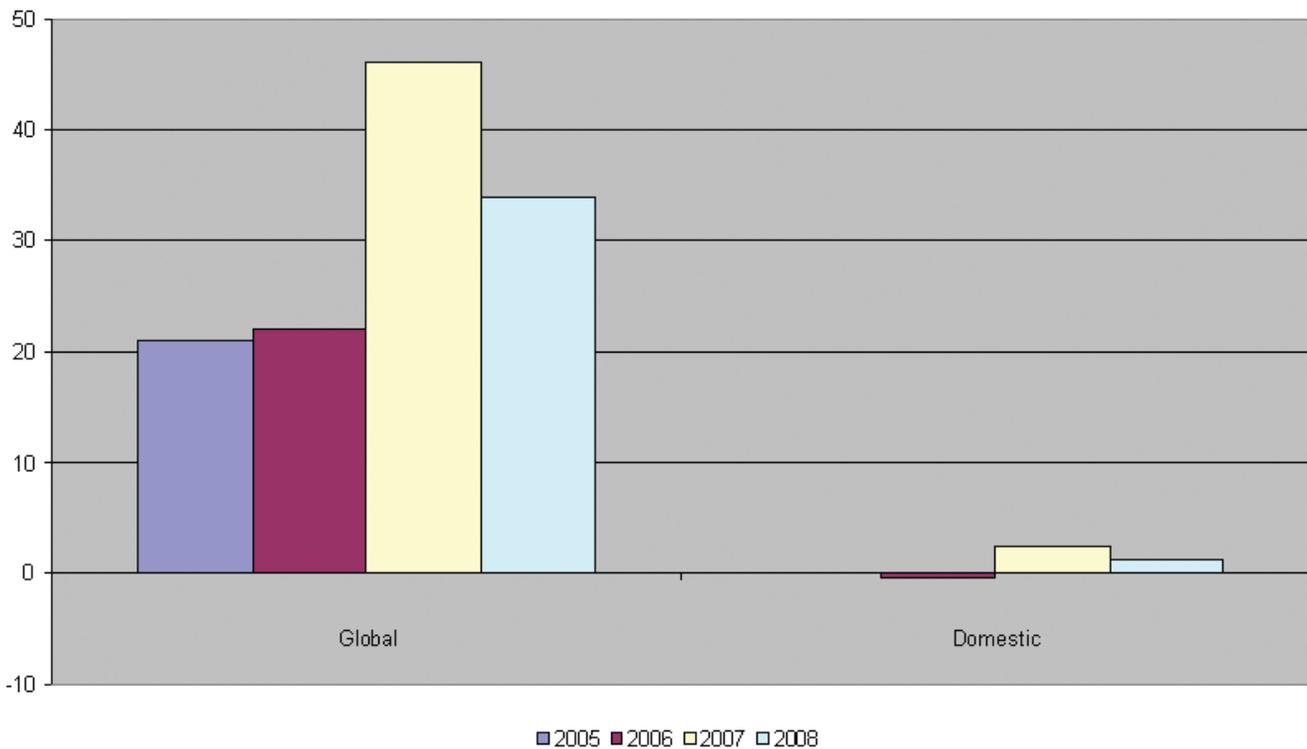
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According to the Center for Global Development, the United States has disbursed \$18.8 billion via PEPFAR since its inception,⁵ and an additional \$5.5 billion is appropriated for FY2009, representing 1/6 of the total State and Foreign operations appropriations.⁶ In comparison, Ryan White funding (including ADAPs) was appropriated at \$2.02 billion in FY2004, \$2.04 billion in FY2005, \$2.04 billion in FY2006, \$2.11 billion in 2007, and \$2.14 billion in FY2008.⁷ The most recent Omnibus spending package approved by Congress included \$2.24 billion for FY2009, which means that the United States has spent one-third (1/3) less on services and supports funded under Ryan White than was sent to combat AIDS abroad!

The large variance in resources committed to combating HIV/AIDS internationally versus here at home are simply staggering, and Americans living with HIV/AIDS have paid a steep price from President Bush’s international generosity – not to mention his other failed policies (e.g., promoting abstinence-only, fighting needle-exchange and abandoning science-based policies). **In 2005, when discretionary spending for domestic AIDS programs remained unchanged from the previous year, and there were 2,187 people on ADAP waiting lists, PEPFAR spending actually jumped 21 percent;** in 2006 there was actually a 0.4% decrease domestically and 1,389 people living with HIV/AIDS nationwide waiting to access ADAP services – including four South Carolinians who died while on that State’s ADAP waiting list, compared to a 22 percent increase for PEPFAR; in 2007, there was a paltry 2.5 percent funding increase and 634 people on waiting lists, compared to PEPFAR receiving a 46 percent increase; and in 2008, PEPFAR funding increased an additional 34 percent compared to 1.2 percent increase for domestic programs as 35 people were on ADAP waiting lists⁸.

Table comparing increases in funding for global versus domestic AIDS, 2005-08⁹



⁵ http://www.cgdev.org/section/initiatives/_active/hivmonitor/pepfardata

⁶ <http://appropriations.house.gov/pdf/SFOFY0902-23-09.pdf>

⁷ National Association of State & Territorial AIDS Directors, “FY2004 – FY2008 Appropriations for the Ryan White Program”, February 2008

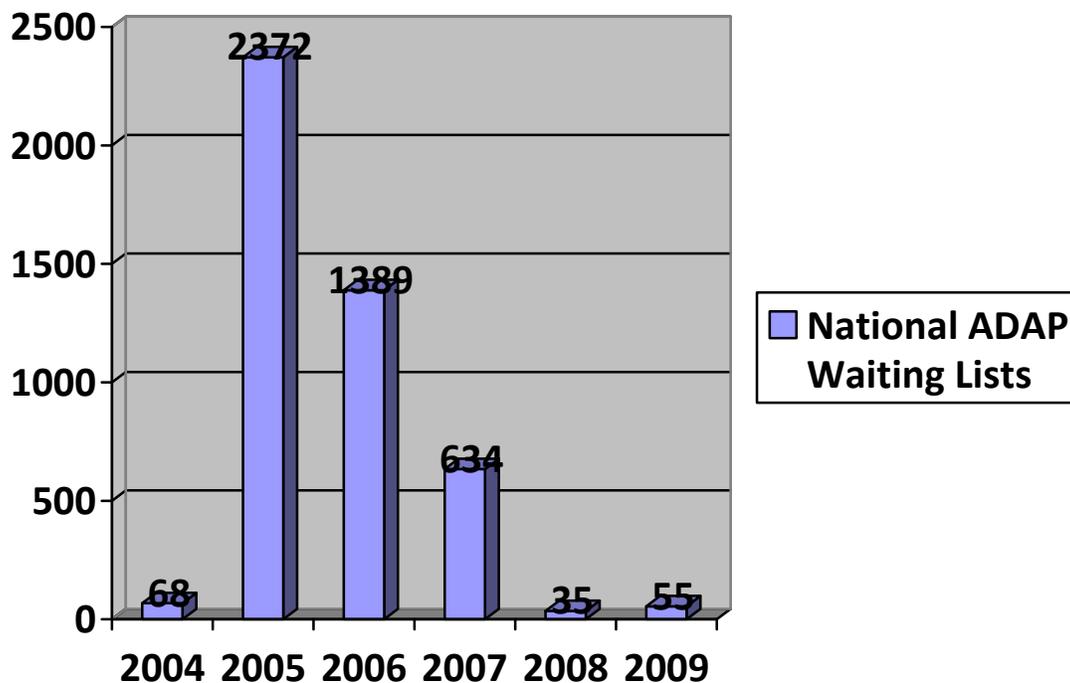
⁸ http://www.blackaids.org/image_uploads/article_575/08_left_behind.pdf

⁹ Ibid

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The domestic expenditures should also be seen in context of need. The population of Americans living with HIV/AIDS was estimated in 2004 to be between 850,000 and 950,000, with a steady increase of 40,000¹⁰ new infections annually (later revised to 56,300 by using a better predictive logarithm). That means that by the end of 2008 the number of people living with the disease had grown by over 28 percent to over 1,000,000, leaving States to cope with this added burden without any meaningful increase in funding for most of the past decade. Terrible stresses have been put on an already overburdened system that has seen drug formularies restricted, essential services slashed and waiting lists occasionally reaching into the hundreds and thousands nationwide (with the attendant deaths), all while \$18.8 billion is being sent overseas. *Is this not unconscionable?*



Drug formularies (or the schedule of medications covered by ADAPs), which vary widely from state to state – from open-ended arrangements still available in a few states to bare-bones basics in others – are often the most tempting target for cost containment and are seen as pragmatically doing less harm than instituting waiting lists. It is important to keep several things in mind, however:

- Until July 1, 2007, there was no minimum standard for ADAP formularies set by the federal government¹¹, and as late as April 2007, one state did not even furnish any Protease Inhibitors (PIs), six ADAPs did not include Fusion Inhibitors, and only four ADAPs covered all twenty-nine of the “A1” drugs highly recommended for the prevention and treatment of opportunistic infections (OIs).¹²

¹⁰ <http://www.kff.org/hiv/aids/upload/Fact-Sheet-The-HIV-AIDS-Epidemic-in-the-United-States-March-2004.pdf>

¹¹ <http://www.survivorshipatoz.org/sub.php?aid=488>

¹² http://www.kff.org/hiv/aids/upload/1584_08.pdf

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- In addition to prophylactic medications used for OIs, there are many other classes of medications, such as Statins used to combat blood-lipid irregularities seen in many patients taking PIs, or anti-depressants, which are urgent accessories to competent HIV treatment.
- Limits on formularies inhibit a physician from prescribing specific medications, which are deemed necessary to his/her patient's well-being, especially as resistance to specific medications begin to appear in more treatment-experienced patients.
- The more basic and limited the formulary, the less likely it is to include the latest advances and refinements such as combination drugs and those with fewer dietary restrictions or indicated side effects. These features help ensure compliance through ease of dosing and absorption, both critical to treatment success.

In addition to medications, many ADAPs provide funds for medical and other support services including ambulatory medical services, case management, laboratory services, and a variety of support services, including transportation to and from medical appointments and pharmacies. Cuts in these areas disproportionately affect people living in rural areas where public transit is difficult where it even exists.

According to a December 2008 report issued by the National Alliance of State and Territorial AIDS Directors (NASTAD):

“As of October 10, 2008, states report that insufficient funding, a lack of providers, difficulties with coordination, and administrative work burden are significant impediments to providing comprehensive client care. Four states report that 266 individuals are on either a medical or support service waiting list for services that include housing, mental health counseling, specialty medical care, and transportation. Five states report that funding is insufficient to ensure that all eligible patients attend medical appointments every three months, which is the standard of care. Eight Part B programs are also considering cost containment measures for their Part B services in light of high demand and reduced funding.

Earlier in the year, the House Labor-HHS Subcommittee provided a \$28.3 million increase for ADAP programs in FY2009 and the Senate Appropriations Committee provided an increase of \$20.1 million. In addition, the House provided an increase of \$14.2 million for Part B programs while the Senate cut the programs by \$6 million. In order to meet the needs of Part B and ADAP programs, NASTAD continues to advocate for the higher amounts in the final appropriations bill which would amount to \$822.7 million for ADAP and \$415 million for Part B Base programs. FY2010 needs are currently being determined.”¹³

But as dire as the current situation is, it has been much worse for American living with HIV/AIDS. In June 2004, when \$2.3 billion was being allocated to PEPFAR, President Bush announced the “Presidential ADAP Initiative” (PAI), a one-time availability of \$20 million for HIV-related drug therapies (though not ancillary care) for ten states with waiting lists to run through March 2006. As needs increased, however, eight more states eventually qualified for an extension of PAI when it was authorized in September 2006 to alleviate their own waiting list troubles.¹⁴

¹³ http://www.nastad.org/Docs/Public/InFocus/20081224_NASTAD%20ADAP%20Watch%20-%202012-08.pdf

¹⁴ Ibid

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Such stop-gap, emergency measures did not begin to cover the needs of domestic AIDS, however. On August 10, 2005, while \$2.6 billion was being allocated to PEPFAR, the Title II Community AIDS Network (TII CANN) sent out a bulletin stating:

“...Enrollment in the PAI [is closed] after FY2005 funding for ADAP did not include resources for the program’s continuation. As a result, states are investigating various strategies to ensure that PAI clients maintain access to their medications once the program expires next month. States include these clients on their ADAP waiting lists, and most do not have the capacity to transition them into their ADAPs when the program expires unless new resources are made available.”¹⁵

On October 5th, TII CANN further stated “without substantial financial support that is both stable and predictable, waiting lists and other cost-containment measures threaten to become a permanent feature of this critical program.”¹⁶ **While AIDS advocates in the United States were requesting an increase of \$197 million in ADAP funding, PEPFAR grew 22 percent, or \$726 million. Is this not unconscionable?**

Interestingly enough, despite the fact that PAI was hamstrung with numerous restrictions, the temporary nature of the initiative was unequal to the full-scale war being waged by the United States against the international pandemic. Not to mention that 866 ADAP clients were not even covered by the emergency funding.¹⁷

Waiting lists, service cuts and formulary restrictions are by no means the only methods of cost containment for ADAP. Cost sharing (co-pays), lowered criteria for financial eligibility, annual expenditure caps, asset assessment (such as precluding home ownership) and twice-yearly eligibility assessment and have all been used to keep ADAP within the limits imposed by budgetary shortfalls.¹⁸ An especially shortsighted way to stretch ADAP dollars across a larger pool of need is something called medical eligibility restriction, where one literally has to get sicker before treatment is started (or, in many cases, continued).

The rates of disbursement for federal AIDS funding are out of synch with the realities of the pandemic as they currently exist in the United States. As the Southern AIDS Coalition (SAC) demonstrated in their 2008 report, “*Southern States Manifesto: Update 2008 – HIV/AIDS and Sexually Transmitted Diseases in the South*,” fourteen southern states (Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia and West Virginia) had 30 percent more AIDS cases in 2005 than the Midwest and West *combined*, yet was dead last in terms of funding for AIDS-related services and supports.¹⁹

The salt in the wound for many of these small, rural communities is that the already-scarce resources mandated abstinence-only prevention messages, which were widely seen as ideology trumping reality at the cost of human lives and untold suffering. The dismal failure of attempts to impose the pious morality of a vocal minority of extreme religious leaders on populations with whom they’ve historically been antagonistic is demonstrated by a continued escalation of infection rates, especially among young MSMs, sex workers and IV drug users, for whom the continued federal ban on needle exchange only increases the likelihood of infection of both HIV and HCV, affecting communities of color, especially in the south.

¹⁵ <http://www.tiicann.org/bmx3/aug05adapwatchpress.pdf>

¹⁶ <http://www.tiicann.org/NASTAD%20ADAP%20Watch%20Oct%2006%20FINAL.pdf>

¹⁷ http://nastad.org/Docs/Public/Publication/2006226_NASTAD%20ADAP%20Watch%20Oct%2005%20FINAL.pdf

¹⁸ <http://www.kff.org/hiv/aids/upload/ADAP-Watch-Report-December-15-2004.pdf>

¹⁹ Ibid

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According to the [Kaiser Family Foundation](#), in 2007, **African Americans accounted for half of all new AIDS cases in the United States, despite representing only twelve per-cent of the population.** Blacks accounted for 45 percent of new HIV infections (24,900 of 56,300 total new infections) and 46 percent of people living with HIV disease in 2006. In another measure of the prevalence of HIV among African Americans, the rates of AIDS diagnoses per 100,000 of various population subgroups were startling: for Blacks the number was 60.3, compared to 20.8 for Hispanics and 6.4 for Whites.²⁰

This disproportional figure is attributable to many factors, among them systemic poverty and a lack of access to health services, so people either don't test as frequently as those with better access to care, or wait too long for treatment, resulting in needless complications and, frequently, higher rates of mortality. The negative stigma associated with the disease presents an entirely different set of sometimes insurmountable circumstances.

Nowhere are the effects of the malignant neglect of domestic AIDS more in evidence than Washington, DC. With a population of just over 590,000 people and an estimated HIV rate of 3 percent of the total population, the number of HIV-positive individuals in the city could range from 15,000 to over 17,500 (or higher).²¹ In comparison, Miami, with a metropolitan population of just over 5,400,000 was estimated to have 12,276 PLWHA in 2004.²² Although some experts suspect in Miami, like many other places the problem is worse.

According to the Washington Post:

"In addition to the epidemiology report, the city is also releasing a study on heterosexual behavior tomorrow. That report, funded by the CDC, was conducted by the George Washington University School of Health and Health Services. Among its findings:

Almost half of those who had connections to the parts of the city with the highest AIDS prevalence and poverty rates said they had overlapping sexual partners within the past 12 months, three in five said they were aware of their own HIV status, and three in 10 said they had used a condom the last time they had sex.

Together, the reports offer a sobering assessment in a city that for years has [stumbled in combating HIV and AIDS](#) and is just beginning to regain its footing. A more accurate accounting of the crisis offers a chance to contain what is largely a preventable disease."²³

Later in the same article Anthony Fauci, director of the National Institutes of Health's program on infectious diseases is quoted as saying: "... remember: The city's numbers are just based on people who've gotten tested," meaning that the actual numbers could well be much higher.

In response to the Washington Post article, Phill Wilson, founder and CEO of the Black AIDS Institute issued a statement beginning with: "*The AIDS epidemic in Washington DC is an unmitigated disaster and a national disgrace. In the capital of the world's richest and most powerful country, HIV prevalence is higher than in Port-au-Prince, the capital of the poorest country in the Western Hemisphere. HIV prevalence among Black men in Washington is 40 percent higher than in sub-Saharan Africa generally. Infection levels among all Blacks in the District of Columbia are higher than in 28 African countries.*"²⁴

²⁰ Kaiser Family Foundation, An Overview of HIV/AIDS in Black America, July 2007

²¹ <http://www.washingtonpost.com/wp-dyn/content/article/2009/03/14/AR2009031402176.html?hpid=topnews>

²² http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2006supp_vol12no3/table2.htm

²³ <http://www.washingtonpost.com/wp-dyn/content/article/2009/03/14/AR2009031402176.html?hpid=topnews>

²⁴ <http://www.thebody.com/content/art50861.html?ic=700100>

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The impact of HIV/AIDS on communities of color in the United States is, to quote the Southern AIDS Coalition's 2008 Manifesto, "**devastating**". The demographics of domestic AIDS has shifted profoundly over the last ten to fifteen years even if the paradigms defining at-risk populations and where they are located remain locked in a mid-1990s mindset that has become anachronistic. Although rates of infection among white gay and bisexual men living in large metropolitan areas still account for a narrow majority of the total, HIV/AIDS is rapidly becoming primarily a disease of black and Hispanic communities living in rural areas of the South, where an infrastructure of care and support simply does not exist, and where cultural barriers discourage its development:

- Despite being 12 percent of the country's population generally, and 19 percent of the South's, 47 percent of new diagnoses nationally and 58 percent regionally, were African-American.
- Five of the ten states with both the highest rates of new infections and highest concentrations of AIDS cases among blacks are in the South, where as many as 50 percent are living below 200% of the National Poverty Line (NPL).
- Seven of the ten states with the highest new Latino infection rates are in the South.
- The greatest population increases in the Latino community are in the rural South. In the 1990s, the growth rate for the Latino community in non-metropolitan areas was more than 70 percent.
- There is a direct correlation between incarceration rates and higher rates of STD infections, including HIV, and poverty. Forty percent of the total incarcerated population is African-American (indeed, in 2005, 12 percent of all black men aged 18-29 were living behind bars). Despite whatever behavior caused them to acquire an STD, well over 95 percent will resume a heterosexual orientation once released.
- In the South, young African-American women are the fastest-growing demographic for HIV infection via heterosexual sex; in 2002, AIDS was the leading cause of death for black women aged 25-34.
- The AIDS case rate for Latinos is second only to African-Americans and is 3.3 times the rate for whites in the United States.

Due to language barriers, cultural and social isolation and a lack of health insurance, Latinos experience a unique set of challenges in accessing health care nationally, but most especially in the South. Because of this, they are frequently diagnosed later than either whites or blacks, resulting in more difficult and expensive specialized treatment.²⁵

The U.S. government, ironically, demands that nations applying to be one of PEPFAR's "Target Countries" be required to develop a National AIDS Strategy, yet the United States itself still doesn't have one of its own. Instead, often people living with HIV/AIDS in the United States are left to navigate through a patchwork of regional, state and local organizations; these organizations are forced to work in competition rather than in cooperation, often to the detriment of people the programs are intended to serve. *Is this not unconscionable?*

²⁵ <http://www.southernaidcoalition.org/Manifesto%20Update%20Final%20pdf%20071408.pdf>

On January 21, 2009, Democratic Congresswoman Barbara Lee (CA-9) introduced H.CON.RES.24, a good first step towards developing a coordinated national AIDS strategy by calling on:

- (1) *The President to develop a national AIDS strategy;*
- (2) *The federal government to partner with African-American communities to develop strategies to reduce and reverse the impact of the epidemic;*
- (3) *The Department of Health and Human Services (HHS) to increase education and outreach regarding HIV prevention, testing, and treatment; and*
- (4) *The people of the United States to educate themselves about HIV infection and the ways in which they can protect themselves.*²⁶

Without a concerted national effort, all the funding in the world will not alleviate the burdens of the increasing number of new infections – especially as they disproportionately impact communities of color.

Additionally, President Obama's appointment of Jeffrey S. Crowley as head on the Office of National AIDS Policy (ONAP) gives many HIV/AIDS advocates all reason to hope that change has actually come to the nation's domestic shortcomings over the last several years. As a Senior Research Scholar at Georgetown University's Health Policy Institute and a Senior Scholar at the O'Neill Institute for National and Global Health Law, Georgetown University Law Center, Mr Crowley is an expert at policy development, and as a former Deputy Executive Director for Programs at the National Association of People with AIDS (NAPWA), he has experience in their proper implementation. Many people living with HIV/AIDS who are frustrated with the system already have placed upon Crowley what can be viewed as unrealistic expectations considering the nation's focus on the international crisis – including the news media.

A National AIDS Strategy represents an opportunity for a call to action, whereby people living with HIV/AIDS in the United States demand that their government properly care for its own citizens before sending scarce resources overseas. ***Ironically, when asked most – if not all – of the people living with HIV/AIDS in America would applaud PEPFAR and the United State's commitment to helping those in need overseas; however, they question why humanitarian efforts, including billions and billions of taxpayer dollars, are going to foreign countries when they see their family, friends and neighbors without access to primary health care, waiting for life-saving medications and in those rare instances, even dying.*** The United States is the last remaining super-power with a vibrant economy (even during these troubling times), so therefore it is incumbent upon its people to lead by example on a devastating pandemic such as AIDS. *But it begs the economic, political and social question of the last six years: Why does the richest nation in the world do so much to help others when its own are left to fend for themselves?*



²⁶ <http://thomas.loc.gov/cgi-bin/bdquery/D?d111:5:./temp/~bdIfBA:@@D&summ2=m&/bss/>

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