



Understanding public opinion toward HIV/AIDS

Foreword by Sean Cahill

Public perceptions of HIV/AIDS and people living with HIV/AIDS have changed significantly since the 1980s, in most instances for the better. In the early years of the epidemic, people with HIV/AIDS were often refused service at restaurants and barber shops—the reason Gay Men’s Health Crisis (GMHC) started offering hot meals and haircuts to clients. Many people living with HIV/AIDS were shunned by family members. Even some gay men who were HIV negative suffered from HIV related stigma and prejudice, because of the association of AIDS with homosexuality in public opinion.

In the paper that follows this forward, noted Political Scientist and Pollster Ethel Klein, Ph.D. provides a summary of recent polling on HIV/AIDS. She provides some analysis of racial differences in perceptions of risk and whether the epidemic is getting better or worse. Klein also examines how people’s attitudes have changed since the 1980s, and what has not changed.

While most Americans have become more educated and enlightened about HIV/AIDS, an examination of public opinion polling data from recent years indicates that HIV-related stigma remains high. In fact, in 2006 half of Americans believed that HIV/AIDS contributes to anti-gay bias, the same proportion that believed this two decades earlier in 1986. Many Americans do not want to work with an HIV-positive person, share an apartment with one, or have an HIV-positive individual teaching their children.

At GMHC we know that HIV-related stigma remains strong and is a major structural driver of the epidemic. Gay men report that HIV stigma is stronger than a decade or so ago; when they tell

people they recently got diagnosed, some respond, “How could you not know better?” Very few people active in the New York City House and Ball community, which is comprised largely of black and Latino gay men, are open about their HIV-positive status. Many GMHC clients report not being out to their own siblings about their HIV status, for fear they won’t be allowed to continue their relationships with their nieces and nephews. And fear of deportation, as well as stigma, keeps many immigrants from getting tested and diagnosed with HIV, leading to significant health disparities between foreign-born and native-born people living with HIV/AIDS. For example, in 2007 foreign-born New Yorkers were more likely (33%) than native-born New Yorkers (22%) to be dually diagnosed with HIV and AIDS.¹

Yet some policy makers question this reality of HIV stigma, claiming that HIV/AIDS is no different from diabetes or heart disease. Some have argued that written informed consent for HIV testing should be ended because the HIV stigma extant in the 1980s is not longer an issue. Polling data, however, support the claim that HIV stigma remains strong.

Throughout the HIV/AIDS epidemic, the disproportionate impact of HIV on gay and bisexual men has contributed to anti-gay bias; likewise anti-gay bias has also led to punitive and counterproductive governmental responses to HIV. These include the HIV travel and immigration entry ban, adopted in 1987, and restrictions on HIV prevention education, such as the federal restrictions on the “promotion” or “encouragement” of homosexual activity initiated by Senator Jesse Helms (R-NC) that same year.

GMHC frequently receives written communication that highlights the realities of current HIV stigma and its persistent anti-gay bias. The following are examples are responses that individuals voluntarily submit to GMHC.

- “If you guys would stop butt f**king each other you wouldn’t have this problem.”
February 2008
- “Do not ever send me your fag garbage again. I can’t believe the millions of dollars spent on medication to give the fags and junkies both of which choose to get the virus by engaging in their filthy activities.”
June 2008
- “AIDS is a result of sin.”
June 2008
- “Die, Fags, Die! Thank nature for AIDS”

- *May 2007*
“Fags are to blame.”
- *September 2006*
“Go enjoy your self inflicted disease.”
- *September 2006*

Americans remain concerned about HIV, with black and Latino Americans more concerned than whites. Young people are very concerned as well. A plurality of respondents of all races say AIDS is more of a problem in their communities than a few years ago. More than four in five Americans say AIDS is a problem. While Americans view cancer as the top health issue facing the country, HIV and heart disease are virtually tied for second most important health issue.

It is understandable why African Americans and Latinos are disproportionately concerned about HIV/AIDS, as the epidemic disproportionately affects their communities. Although African Americans are 13% of the US population, according to the 2000 Census, they represented 49% of the new HIV/AIDS diagnoses reported in 2005 from 33 states with name-based reporting.² Latinos are 15% of the US population, but were 18% of the new HIV/AIDS diagnoses reported in 2006 in the 33 states with name-based reporting.³

Nearly two thirds of Americans support higher government spending on HIV prevention and care, even as local and state governments slash spending in this area due to the fiscal and economic crisis. The public also has significant concerns about the confidentiality of HIV testing and written, informed consent.

Over the past decade the US has greatly expanded its role in fighting global AIDS. This is true of the government’s President’s Emergency Plan for AIDS Relief (PEPFAR), which has placed 1.7 million people onto antiretroviral treatment, mostly in Africa. These governmental efforts are complemented by funders like the Gates and Clinton Foundations, which have placed millions more on AIDS medications. However, even as Americans have rightly focused attention on global AIDS, here at home the HIV/AIDS epidemic is worse than we thought, with nearly 60,000 new infections a year, a number 40% higher than previously thought. The number of annual new diagnoses has remained steady for most transmission categories, but for MSM the

number of new diagnoses has been on the rise since the early 1990s. In 2003 the CDC estimated that as many as 1.2 million Americans were living with HIV or AIDS.⁴

Under the Bush-Cheney Administration, funding for HIV prevention dropped 19% in real dollar terms. Federal funding for HIV care services was level funded, again not keeping up with inflation. Over the past year New York City and State have slashed funding for HIV prevention and care by millions of dollars, even as the number of people getting newly diagnosed and in need of services increases steadily.

It is GMHC's hope that the 111th Congress and the Obama-Biden Administration will significantly increase funding for HIV/AIDS prevention and care, both to make up for Bush-Cheney era cuts in inflation-adjusted terms, and to make up for the local and state cuts occurring across the US. Critics of increased federal funding for HIV/AIDS prevention and treatment argue that public support for these programs is not very deep. They argue that people do not want to throw any more money at the problem. According to these naysayers, Americans believe there are other health problems, such as cancer and heart disease, which take precedence over HIV/AIDS funding.

The finding that a significant percentage of Americans support obtaining written, informed consent before testing someone for HIV is a very significant finding, given that government leaders at CDC, in Albany and in New York City are strongly urging the abolishment of written, informed consent. Clearly a significant share of the American public thinks that getting an HIV test is different from getting a cholesterol or blood pressure test, and that written informed consent should be sought by medical providers.

These polling data demonstrate widespread public support for increased government funding for HIV prevention and treatment programs. Federal funding for CDC HIV prevention has remained flat-funded for years. Congress and the new Administration can act swiftly to ensure an increase in HIV prevention funding in fiscal year 2010. In addition, HIV related stigma remains strong, and is connected to anti-gay bias. Government and other social institutions should increase

efforts to combat both kinds of stigma. Finally, more effective sex education is required to reach young people with the message that they are at risk.

U.S. public opinion toward HIV/AIDS: Perceptions of risk, bias, and government spending

By Ethel Klein

MYTH: AMERICANS ARE NO LONGER WORRIED ABOUT AIDS

Overall, HIV/AIDS continues to be a serious concern for most Americans, both as a personal worry and as a problem facing their children and their communities. HIV/AIDS is not an invisible problem. In 2006, more than four in ten Americans (42%) said they knew someone who had HIV or AIDS, or someone who had died of AIDS. African Americans (63%) were most likely to know someone, followed by whites (41%) and Latinos (37%).

AIDS continues to be on people's agendas. In 2007 a health survey found that 35% of Americans said that AIDS was a health problem that concerned them a great deal. Some 28% said they were somewhat concerned, while 22% were not concerned at all.⁵

While the number of people who said they feared getting infected with HIV/AIDS has declined since the mid-1990s, nearly three in ten Americans (29%) said they were worried about becoming infected with HIV in 2006—15% were very concerned. African Americans (34%) and Latinos (31%) were significantly more likely than whites (9%) to say they were very concerned about becoming infected.

This level of worry increased when parents were asked if they were concerned about their children becoming infected with HIV. In 2006, most parents of children ages 21 or younger were

at least somewhat concerned about a son or daughter becoming infected with HIV. African American (79%) and Latino (78%) parents were more likely to express apprehension than white parents (52%).

AIDS is also acknowledged as posing a problem to local communities. African Americans and Latinos have been particularly hard hit by the HIV epidemic, so it is not surprising that they are more likely than whites to say that the problem of HIV/AIDS has gotten worse in their local communities in recent years. In 2006, nearly half of African Americans (49%) and Latinos (46%) said AIDS was a more urgent problem for their communities than it was a few years ago, compared to 15% of whites. Still, 51% of whites acknowledged that AIDS was a problem affecting their local community today.

Thinking about the way AIDS is affecting your local community today, do you think the problem of AIDS is a more urgent problem for your community than it was a few years ago, a less urgent problem, is about the same, or has AIDS never been a problem in your community?

	More	Same	Less	Never a Problem	Don't Know
All	23%	34%	10%	23%	10%
African Am	49%	24%	6%	15%	6%
Latino	46%	27%	7%	10%	10%
White	15%	36%	10%	28%	10%

Another 2006 survey of the African American community found that 56% said HIV/AIDS was a big problem for black men as a group.⁶ Many fewer (27%) were worried about they themselves or a family member getting HIV/AIDS.

When asked if they had personal concerns about getting AIDS, most (70%) teens said no. In contrast, 60% felt AIDS was a serious problem facing their friends—44% said it was a very serious problem according to a 2004 Gallup Youth Survey of 13-to-17-year-olds.⁷ The level of perceived seriousness increased with age; 38% of teens between the ages of 13 and 15 said AIDS was a very serious health issue among their friends, compared with 52% of teens aged 16 to 17.

In 2004 13% of new HIV/AIDS diagnoses from Guam, Virgin Islands, and the 33 states with name-based reporting occurred among 13- to 24-year-olds.⁸ It is estimated that many more people are infected as youth and diagnosed later. According to the CDC, “Young men who have sex with men, especially those of minority races or ethnicities, were at high risk for HIV infection.”⁹ In New York City new HIV diagnoses among young men who have sex with men 13-29 increased 33% from 2001 to 2006. Seventy-seven percent of these young men who have sex with men were black or Latino.¹⁰

MYTH: AIDS IS NO LONGER A PRESSING NATIONAL PROBLEM

Some argue that Americans don't view AIDS as a major problem, as they did in the 1980s. Those who assert that HIV/AIDS is no longer perceived to be a major problem appear to misunderstand the public's views. A 2007 PEW poll found that 82% of Americans said that the spread of HIV/AIDS was at least a moderately big problem in our country—39% said it was a very big problem.¹¹ Moreover, 42% felt that the issue of HIV/AIDS was a bigger problem in our country today than it was five years ago, compared to 15% who said it was a smaller problem.

The perception that the country is making progress in dealing with HIV/AIDS has also changed in the last decade—and not for the better. In 1997, 52% of adults said we were making progress in dealing with the disease¹²; in 2006 that number was down to 40%. Whites (41%) and Latinos (39%) were more likely to see continued progress when compared with African Americans (30%). African Americans were by a five-to-three margin more likely to say the nation was losing ground (49%) rather than making progress (30%).

Thinking about the way the problem of HIV/AIDS affects the United States today; do you think the problem is about the same as it has been, that the US today is making progress in this area, or that the US today is losing ground?

	Progress	Losing	Same
1997	52%	27%	14%
2006	40%	29%	22%

African American	30%	49%	13%
Latino	39%	30%	14%
White	41%	25%	24%

HIV/AIDS is not merely perceived as a problem in its own right; it is also seen as high on the list of *urgent* problems. In 2006 34% of Americans ranked cancer as the most urgent health problem facing the nation, with HIV/AIDS (17%) virtually tied with heart disease (18%) for second place. African-Americans ranked HIV/AIDS at the top of the list, with 39% identifying it as the nation's most urgent health problem. Almost one in four Latinos (23%) said this was the nation's most urgent health problem. The perception of urgency about HIV/AIDS was significantly less among whites (13%).

Young people ages 18-29 were even more likely to focus on HIV/AIDS. Nearly three in ten (28%) named it as the most urgent health problem facing the nation, compared to 16% of people ages 30-64 and 10% of those 65 and older. In 2004 a Gallup Youth Survey of 13 to 17 year olds found that 15% of teens thought that HIV/AIDS was the most urgent health problem facing the US, ranking with cancer and obesity as the most common response.

MYTH: THERE IS NO LONGER A STIGMA ASSOCIATED WITH HAVING HIV/AIDS

Americans continue to believe that there is discrimination against people infected with HIV/AIDS. Acknowledgement of this prejudice and discrimination remained largely unchanged in the 20-year period from 1986 to 2006. In 1986 half of Americans told a CBS News poll that there is a lot of discrimination against people with AIDS. In 2006, the Kaiser Foundation found 45% of Americans believed that there is a lot of prejudice against people living with AIDS. In another poll conducted by Kaiser in 2007, 80% said people living with HIV/AIDS faced discrimination—40% said people with HIV/AIDS faced a lot of prejudice.¹³

		<i>How much prejudice and discrimination do you think there is against people infected with HIV and AIDS in this country today?</i>				
		A lot	some	a little	none	Don't Know
2007	Pew/Kaiser	40%	40%	12%	3%	5%
2006*	Kaiser	45%	36%	11%	3%	5%
2004*	Kaiser	45%	38%	9%	2%	--

2000*	Kaiser	51%	33%	8%	2%	6%
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*In these years the question was worded “How much prejudice and discrimination do you think there is against people living with HIV and AIDS in this country?”

A plurality of Americans believes that concerns about HIV/AIDS infection increase prejudice against gays and lesbians. In 2006 50% of Americans believed that the HIV/AIDS epidemic made people more likely to discriminate against gays and lesbians.¹⁴ This is not very different from a 1986 Newsweek poll reporting 49% of the public thought fear of infection was causing discrimination against all homosexuals.¹⁵

People were much more comfortable with working with someone who had HIV (41% saying very comfortable) compared to having a roommate who was HIV positive (25% very comfortable.) When parents of children ages 21 or younger were asked how comfortable they would be if their child had a teacher who was HIV-positive, only 29% said they would feel very comfortable.

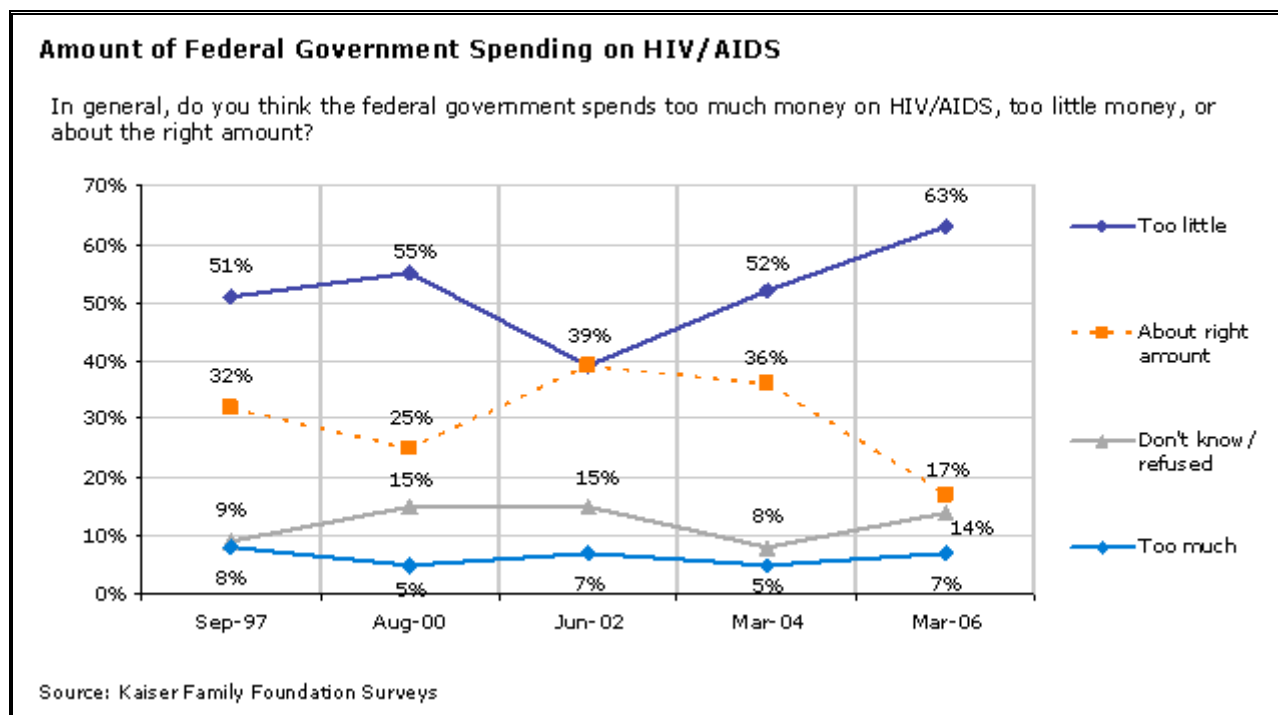
In general, how comfortable would you be, personally...working with someone who has HIV or AIDS--very comfortable, somewhat comfortable, somewhat uncomfortable, or very uncomfortable?

	Very Comfortable	Somewhat Comfortable	Not Comfortable	Don't Know
2006 Kaiser	41	30	21	8
2004 Kaiser	35	35	28	3
2000 Kaiser	33	35	28	4
1997 Kaiser	32	33	33	2

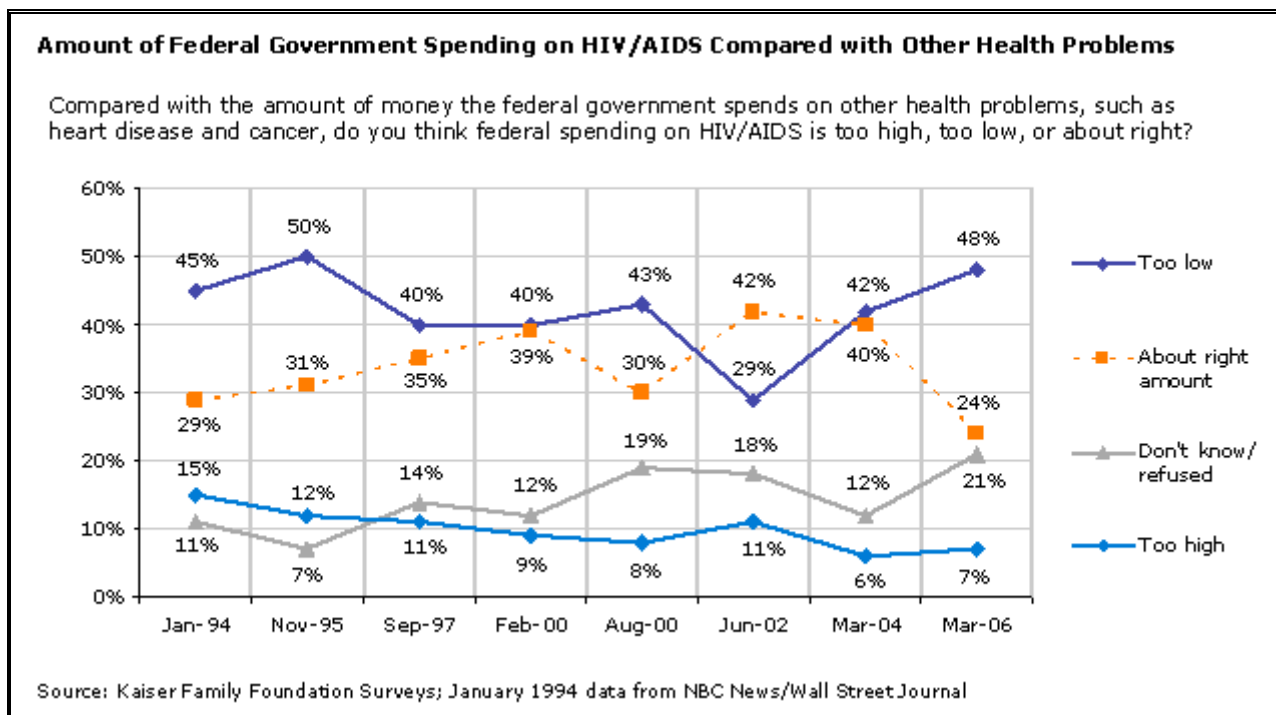
MYTH: HIV/AIDS IS NOT A FUNDING PRIORITY FOR MOST AMERICANS.

Not only is the public very supportive of increasing federal spending on HIV/AIDS, but that support has in fact been growing. A 2007 survey commissioned by Trust for America's Health found that 65% of Americans said we needed to spend more than we were currently spending on infectious diseases like AIDS. A third of these respondents wanted the federal government to spend much more than it was currently allocating to address research, prevention and treatment

of AIDS.¹⁶ The percentage of people who support more spending in a Kaiser survey increased steadily from 39% in 2002 to 52% in 2004, and to 63% in 2006.



When asked to compare the amount of money the federal government spends on HIV/AIDS to the amount spent on other health problems, such as heart disease and cancer, the pattern remains the same. The percent who think the amount of federal spending on HIV/AIDS should increase even *relative* to the amount spent on heart disease and cancer also grew, rising from 29% in 2002 to 42% in 2004 to 48% in 2006.



Even more significant is the fact that most Americans are optimistic that spending more money on HIV prevention and testing will lead to meaningful progress in slowing the epidemic. In 2006, about six in ten said that spending more money on both HIV/AIDS prevention (62%) and testing (59%) will lead to meaningful progress in this country. About three in ten say such spending won't make much difference.

MYTH: AMERICANS OPPOSE PROTECTING PRIVACY OF HIV TESTING

Testing has proven to be central to HIV prevention and treatment. Americans have gotten the message. The number of adults who report having been tested for the disease increased substantially from 37% in 1995 to 48% in 1997, where it leveled off. In 2006, about half of adults in the U.S. (48%) said they had been tested for HIV at some point, including about one in five (19%) who reported they were tested in the past year. Among those who were tested, 51% asked to be tested, 24% were told by a nurse or doctor to be tested, and 18% were under the impression it was a routine part of the examination. The CDC now recommends that all adults, aged 18-64, be tested for HIV at least once annually.

Getting an HIV test is partly a function of age. As people get older, they are less likely to get tested. In 2006, six in ten adults aged 18-39 reported having an HIV test, compared to about one in two (51%) of 40-64 year olds, and dropping to two in ten (21%) people aged 65 and older. The share of non-elderly adults who said they had been tested increased slowly but steadily from 43% in 1997 to 55% in 2004. Since then, however, the percentage getting tested has leveled off.

African Americans and, to a somewhat lesser extent, Latinos seem to have gotten the message that HIV testing is important, given the striking racial disparities affecting both groups. For example, black women are 23 times as likely as white women to get an AIDS diagnosis; black men are 8 times as likely as white men to get an AIDS diagnosis.¹⁷ In 2006, both groups were much more likely than whites to report having had an HIV test in the last year.

In 2006, most Americans (70%) knew that it is not standard practice to perform a test for HIV; you have to ask your doctor to perform the test (or consent to have the test performed). The most common reason people reported for not being tested is that they didn't feel at risk (61%). Prejudice was also a factor. About one in five adults (21%) believed people would think less of them if they found out they had been tested for HIV. And while most people who did not get tested said they had not felt at risk, 13% said worries about confidentiality was the reason they had not been tested.

A significant number of people expressed the need to protect individuals' privacy in connection with testing. Four in ten Americans surveyed said they wanted to have more information about how to protect their privacy when getting an HIV test, independent of whether they had in fact been tested. This is an increase from 2004, when about a quarter (24%) said they wanted more information about whether HIV test results were confidential. Nearly three in ten (28%) believed that HIV testing required a different approach than the routine screening protocol used for most infectious diseases, including requiring written permission from the patient in order to perform the test.

An even more telling indicator of the need for privacy is the difference in the tenor of the responses people gave when they were asked about themselves compared to what they felt was

needed for society in general. When survey respondents to the 2006 Kaiser survey were told the FDA had recently been discussing a new oral HIV test that people could buy over-the-counter, about one out four (26%) said they would prefer to use a home test rather than have the test done in a doctor's office or clinic. A much larger percentage (65%) felt this was a good development because it would encourage people who might not get tested otherwise because they were afraid or ashamed to go to the doctor to learn about their HIV status.

Most adults believe that it is beneficial to have free and confidential testing. In 2004, nearly two-thirds (65%) said they and their community benefited from free and confidential AIDS/HIV testing and counseling.

¹ Ellen Weiss Wiewel. HIV/AIDS in Foreign-Born New Yorkers 2001-2006. HIV Epidemiology & Field Services Program. *New York City Department of Health and Mental Hygiene*. Power point presentation. Epi Seminar, Bureau of HIV/AIDS Prevention and Control. Feb. 19, 2009.

² Centers for Disease Control and Prevention (CDC) Fact Sheet, HIV/AIDS among African Americans, Revised August 2008, www.cdc.gov/hiv, accessed March 20, 2009.

³ CDC Fact Sheet, HIV/AIDS among Hispanics/Latinos, www.cdc.gov/hiv/, accessed March 20, 2009.

⁴ CDC Fact Sheet, HIV/AIDS in the United States, Revised August 2008, www.cdc.gov/hiv, accessed December 12, 2008.

⁵ Survey by Pew Global Attitudes Project (Pew 2007) conducted by Princeton Survey Research Associates International, April 23-May 6, 2007 and based on telephone interviews with a national adult sample of 2,026. There were parallel surveys in 46 other countries. <http://pewglobal.org/reports/pdf/256.pdf>

⁶ Survey by Henry J. Kaiser Family Foundation, Harvard University, Washington Post conducted by ICR-International Communications Research, March 20-April 29, 2006 and based on telephone interviews with a national adult sample of 2,864, including an oversample of blacks. The sample included a total of 1328 African American men and 507 African American women. Results are weighted to be representative of a national adult population. http://www.kff.org/spotlight/hivus/upload/HIV_US_Epidemic_outline.pdf

⁷ Gallup, Teens Still Views AIDS as Urgent Health Problem. March 23, 2004. The Gallup Youth Survey of 785 respondents aged 13 to 17 was conducted via Internet between January 22 and March 9, 2004 by Knowledge Networks. <http://www.gallup.com/poll/11071/Teens-Still-View-AIDS-Urgent-Health-Problem.aspx>

⁸ CDC Fact Sheet, HIV/AIDS among Youth, Revised August 2008, www.cdc.gov/hiv, accessed March 20, 2009.

⁹ Ibid.

¹⁰ Gay Men's Health Crisis, City Policy Agenda 2008, New York: GMHC, 2008.

¹¹ Pew 2007, op. cit..

¹² Survey by Henry J. Kaiser Family Foundation conducted by Princeton Survey Research Associates, September 17-October 19, 1997 and based on telephone interviews with a national adult sample of 1,205. <http://www.kff.org/hivaids/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14580>

¹³ Pew 2007, op. cit.

¹⁴ Survey by Henry J. Kaiser Family Foundation. Methodology: Conducted by Princeton Survey Research Associates International, March 24-April 18, 2006 and based on telephone interviews with a national adult including oversamples of African Americans and Latinos sample of 2,517. A total of 378 African Americans and 447 Latinos were interviewed. Results were weighted to be representative of a national adult population. <http://www.kff.org/kaiserpolls/upload/7513.pdf>

¹⁵ Newsweek poll conducted by Gallup Organization, November 5-November 6, 1986 and based on telephone interviews with a national adult sample of 756.

¹⁶Trust for America's Health. conducted by Greenberg Quinlan Rosner Research, January 18-January 22, 2007 and based on telephone interviews with a national adult sample of 1,015.

<http://healthyamericans.org/reports/files/2007HealthPriorities.pdf>

¹⁷ CDC Fact Sheet, HIV/AIDS among African Americans.