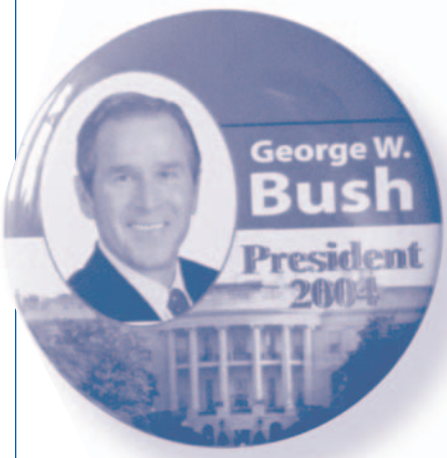
PRESCRIPTIONS FOR REFORM:

A COMPARISON OF THE BUSH AND KERRY HEALTH CARE ACCESS PROPOSALS AND THEIR IMPACT ON PEOPLE WITH HIV/AIDS



BY
LAURA CARUSO, M.P.A.
DIRECTOR OF HEALTH POLICY
GAY MEN'S HEALTH CRISIS

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Executive Summary

For most Americans, especially people with HIV/AIDS, the health care reform proposals that matter most in this year's presidential election are those that will make health care accessible, affordable, and dependable. As we approach the 25th year of the HIV/AIDS epidemic in the U.S., it is critically important for people living with HIV/AIDS and their communities to mobilize voters on Election Day and send a strong message to the next president that the health care access needs of people with HIV/AIDS must be a policy priority.

Issues/ Positions	HIV/AIDS Community	President Bush	Senator Kerry
Supports capped allotments/ capped federal funding for Medicaid	No	Yes	No
Supports Medicaid state fiscal relief	Yes	No	Yes, proposes $25 billion in first 2 years in office
Supports Early Treatment for HIV Act	Yes	Unclear	Yes
Supports implementation of Medicare Modernization Act as passed by Congress	Part D formularies must include all HIV medications; must contain other provisions that will help people with HIV/AIDS	Yes	Yes, with changes to ensure low drug prices for Medicare, prevent retirees from losing coverage, and reduce HMO overpayment
Supports permitting the federal government to negotiate drug prices for Medicare	Yes	No	Yes
Supports reimportation and efforts to reduce cost of prescription drugs by closing loopholes when generics go to market	Yes	No	Yes
Supports increased funding for the Ryan White CARE Act	Yes, CARE Act needs $3.1 billion to deliver services to all people with HIV/AIDS in need of care	Appropriated $2 billion in 2004. Budget calls for $35 million increase in FY 05, which includes a $20 million emergency ADAP allocation	Yes, supports funding to "end ADAP waiting lists and provide an appropriate standard of care;" funding level not specified
Supports tax credits for individuals	Not a priority	Yes	Yes
Supports Health Savings Accounts	No	Yes	No
Supports Association Health Plans	No	Yes	No
Supports new Federal Employees Health Benefits Program pool	Yes	No	Yes
Supports premium rebate pool	Unclear	No	Yes
Cost of plans	N/A	$90 billion–$105 billion over 10 years	$653 billion over 10 years
Number of newly insured Americans	N/A	2 million to 6 million	27 million

Chapter 1: Health Care, the HIV/AIDS Epidemic, and the U.S. Presidential Election

No issue so clearly defines the domestic policy differences between the 2004 Republican and Democratic nominees for President than health care. President George W. Bush and Senator John Kerry offer two very different approaches to "health care reform," an ambiguous phrase encompassing policy changes that range from delivering health insurance to more Americans, to reducing health care costs, to fostering a more efficient and technology-based system of health care administration. Both candidates have made proposals to expand insurance to the uninsured, help make health care more affordable for those who currently have coverage, and reduce health care costs for providers, insurers, and the federal government. Both have made the issue a central part of their domestic policy agendas, and both have organized campaign events focused specifically on health care. While President Bush and Senator Kerry agree that our nation's system of financing and delivering health care needs considerable improvement, the candidates have outlined very different visions for the future of the U.S. health care system and the role of the federal government in achieving reform.

Because health care affects all Americans in one way or another, it is likely to rank as one of the most important issues that voters consider when they cast their votes this November. Nearly everyone experiences the personal aspects of health care at some time or another: caring for a sick child, dealing with the death of a partner or parent, worrying that one's coverage is inadequate or unaffordable, or struggling to navigate a complex maze of bureaucracy to access public health insurance coverage. But beyond the personal experiences, health care's systemic problems continue to worsen: costs are rising, rates of insurance coverage are dropping, and concerns about the quality of care are escalating. As a result, satisfaction with our health system has reached a 10-year low.[1] These factors also explain why 87% of voters rate the candidates' views on health care reform as important in the upcoming election.[2]

The fact that health care has become a centerpiece of our national political debate also stems from its importance to our economy. Health care currently comprises almost 15% of the U.S. gross domestic product, and this proportion is expected to rise to 18% by 2013.[3] Our health economy encompasses not only those who receive care, but also a complex web of purchasers and sellers of health care products and services, including physicians, hospitals, insurance and pharmaceutical companies, organized labor and government. As such, the health care industry accounts for a significant number of jobs in the U.S. and is one sector that has remained economically strong —growing, in fact—during the recent recession. While the strength and size of the industry may help propel the issue to the top tier of the domestic policy agenda, it

1 Washington Post - ABC News Poll: health care. Washington, D.C.: The Washington Post, October 20, 2003.
2 The Commonwealth Fund Biennial Health Insurance Survey 2003.
3 Levit, Katharine, Cynthia Smith, Cathy Cowan, Art Sensenig, Aaron Catlin, and the Health Accounts Team. "Health Spending Rebound Continues in 2002." Health Affairs, January/February 2004, pages 147-159.

also complicates finding solutions to health reform, since any changes will inevitably help some stakeholders more than others and entrenched health care interests may stand to lose if major financing and structural reforms are implemented.

Health reform was a controversial and divisive topic during much of the past century. From the universal health care bills that were introduced in Congress in 1939, to the creation of Medicare and Medicaid in 1965, to the defeat of President Clinton's health reform proposal in 1994, health care is an issue that brings leaders of opposite parties together to achieve policy goals, yet is also used as a political "line in the sand" that helps define the ideological differences between Republican and Democrats. This year, as costs continue to outpace inflation and tens of millions of Americans remain uninsured, the U.S. health care system stands at a dangerous crossroad. The 2004 presidential campaign offers the candidates an unequaled forum to articulate their health policy agendas to the American people.

Health care in America in 2004

The United States spends comparatively more money on health care than any other country in the world: 13.9% of our gross domestic product is spent on health care, and in 2002 costs increased 9%, triple the rate of inflation.[4] Many factors contribute to rising health care costs, including increased health care utilization, more expensive treatments, support and encouragement of medical technology, our government's reluctance to implement price controls on industry, high administrative costs, and waste. It is estimated that at least one quarter of health care dollars are spent on non-medical costs, and a study released in July 2004 by the Blue Cross Blue Shield Association estimated that $85 billion, or 5% of the U.S. health care spending in 2003 was lost to health insurance fraud.[5]

Despite our nation's considerable investment in health care, there are still approximately 44 million Americans without health insurance. These Americans may be unable to access insurance for any of several reasons: they are not offered health insurance through their jobs—or what is offered is unaffordable; they do not have access to or cannot afford some other form of group coverage; individual coverage is either unaffordable or excludes coverage for necessary services; or they do not meet eligibility criteria for public programs.[6] Because out-of-pocket health costs are so high, those who are uninsured tend to forgo preventive care and delay treatment for illnesses until they reach a critical stage.

The majority of non-elderly Americans (i.e. under age 65) are enrolled in employer-based plans and many have seen their share of health care costs grow steadily. Overall, premiums have risen by more than 10% annually since 2001. Employee contributions to employer-based plans have increased as well. Compared to 2000, health insurance premiums in 2003 were 40% higher—$2,700 more, on average, for family coverage.

4 Levit et al., 2004.
5 "Blue Cross and Blue Shield Companies' Anti-Fraud Efforts Result in $240 Million in Savings and Recoveries System Wide." http://bcbshealthissues.com/proactive/newsroom/release.vtml?id=121720 (accessed August 11, 2004).
6 The Institute of Medicine. Insuring America's Health. Washington, D.C.: 2004, pages 35-37.

Over the same period, premiums and deductibles also rose across all types of insurance plans. Furthermore, the number of large firms offering coverage to their retirees and small businesses offering insurance to current employees has dropped.[7] As a result, there has been a decline in the number of employees who are enrolled in employer-subsidized plans; between 1999 and 2002, enrollment in employers' health insurance plans shrank from 90% to 88%.[8] While these statistics do not signal the end of employer-based coverage, they do highlight a disturbing fact: as costs increase in the employer-based market, more Americans will likely become uninsured. Fortunately, public health insurance such as Medicaid has helped buffer the blow for some, but not all, of the increasing number of Americans losing health insurance.

The HIV/AIDS epidemic

Treatment and care for people with HIV/AIDS has improved dramatically since the disease first appeared in the United States. After having leveled off for the last several years, however, the number of new HIV infections in the U.S., according to preliminary data, increased slightly in 2003 and may continue to rise. Today there are roughly 900,000 Americans living with HIV and/or AIDS, of whom approximately 25% may not know they are infected.[9] Thanks to treatment breakthroughs for HIV/AIDS that became available beginning in 1995, HIV disease can be managed with routine care and treatment. The development and distribution of highly active antiretroviral therapy (HAART) in the 1990s has allowed people with HIV and AIDS to maintain their health and stabilize their disease. If taken regularly under medical supervision, HAART can delay or prevent the many health complications associated with HIV/AIDS. Although HIV disease is much more manageable today than it was just a decade ago, it is unclear whether our health system will adapt to provide chronic disease management over a period of many years to those living longer with the disease, as well as to newly diagnosed HIV-positive Americans.

"I believe that the best health care policy is one that trusts and empowers consumers and one that understands the market."

President Bush
New York Times
May 13, 2004

The availability of prescription drugs is critical to the management of HIV/AIDS. HIV medications are some of the most expensive drugs in the world, and the complex combinations (or cocktails) of drugs that are prescribed for individuals cost on average between $10,000 and $30,000 a year.[10] In 1990, the federal government enacted the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act in response to the need for comprehensive HIV/AIDS services, including prescription drugs, for those without access to care. While the law has been reauthorized several times and Congress has modified the structure of the CARE Act, financing for prescription drugs has remained a critical component. Through the AIDS Drug Assistance Program (ADAP), under Title II of

7 "Employer Health Benefits: 2003." The Henry J. Kaiser Family Foundation and Health Research and Educational Trust, 2003.
8 Blanton, Kimberly. "More Find Health Plans Too Costly." The Boston Globe, July 6, 2004.
9 Centers for Disease Control http://www.cdc.gov/hiv/partners/ahp_science.htm (accessed August 10, 2004).
10 Steinbrook, M.D., Robert. "HIV Infection – A New Drug and New Costs." New England Journal of Medicine, May 2003.

the CARE Act, uninsured and underinsured individuals who do not have other sources of coverage for prescription drugs may be able to obtain their drugs at low or no cost through their state's ADAP program.

In addition to routine medical care and prescription drugs, support services are an essential part of HIV/AIDS care. An individual's employment status, housing or lack thereof, nutrition, mental health, and whether he or she uses illicit drugs, are all factors that can positively or negatively influence physical health. Many HIV-positive individuals rely on their physicians, pharmacists, case managers, and counselors to coordinate their care and help assist with other aspects of their lives. According to a study by the U.S. Health Resources Services Administration, support services, such as case management, housing, and adherence services, are important to delivering a quality continuum of care for low-income people who are diagnosed with HIV/AIDS.[11]

An estimated 20% of people with HIV/AIDS are uninsured; unsurprisingly they tend to experience more problems accessing care.[12] People with HIV/AIDS who are uninsured are less likely to have access to antiretroviral (ARV) therapy and are less likely to receive timely care after they are first diagnosed.[13] Although the Institute of Medicine has recommended that health coverage for all Americans be universal, continuous, affordable, sustainable for society, and promote effective, efficient, safe, timely, patient-centered, and equitable care,[14] there is still no mandate or system in place to ensure that all people, including those with HIV/AIDS, have access to the health resources they need.

"We have the greatest health care in the world, the best, but we also have a system in crisis. It's an incredible contradiction."

Senator Kerry
Boston Globe
May 14, 2004

Insurance status not only affects access to care, it limits the HIV prevention interventions among both HIV-positive and HIV-negative people. Individuals with HIV/AIDS who are uninsured are more likely to be unaware that they are carrying the virus than those who have either public or private health insurance.[15] Individuals and their communities are placed at greater risk for HIV infection in areas where lack of insurance is the norm, especially in areas that are disproportionately impacted by HIV, such as low-income areas and communities of color. Since HIV is most easily transmitted at its early stages, early detection of the disease is of paramount importance, but unlikely if an uninsured individual is not receiving regular care.

Men who have sex with men (MSM) have been and remain at the highest risk for HIV infection, and today account for more than half of all the new HIV cases in the U.S. However, the epidemic is growing disproportionately in communities of color, especially MSMs of color, and among women. People of color represent the

11 Levi, Jeffrey, Julia Hidalgo, and Susan Wyatt. "The Impact of State Variability in Entitlement Programs on the Ryan White CARE Act and Access to Services for Underserved Populations." Health Resources and Services Administration, www.hrsa.gov/hab (accessed July 7, 2004).
12 Institute of Medicine. A Shared Destiny. Washington, D.C.: 2003, page 154.
13 Institute of Medicine. Care Without Coverage. Washington, D.C.: 2002, page 64.
14 Institute of Medicine. Insuring America's Health. Washington, D.C.: 2004, pages 111-115.
15 Institute of Medicine. A Shared Destiny. Washington D.C.: 2003, page 154.

majority of new AIDS cases and Americans living with AIDS.[16] Although black and Latino communities represent 12% and 14% of the U.S. population, respectively, they accounted for 50% and 20% of the new AIDS diagnoses in 2002. In 2001, HIV was the third leading cause of death among black Americans between the ages of 25 and 34. Among youth, people of color are likewise disproportionately impacted by HIV. Black Americans represented 61% of new AIDS cases among 13–19 year olds and Latinos represented 21% of infections in this age group.[17] The spread of HIV disease in women is likewise alarming: women account for a disproportionately growing number of new AIDS cases, rising from 7% in 1986 to 26% in 2002.[18] Women are impacted by social factors, like sexism and poverty, that can put them at higher risk for infection, and many are contracting the disease from their partners even though they are in committed relationships.

The disproportionate impact of the HIV epidemic on communities of color and on women unfortunately overlaps with the likelihood that members of these communities will have difficulty accessing health care. Black Americans are twice as likely as non-Hispanic whites to be uninsured, and Hispanics are three times as likely to be uninsured.[19] Although women are more likely to have insurance than men, women have a lower rate of employer-based coverage, tend to rely more heavily on public programs or individual policies, and thus tend to be less stable in insurance status.[20] Because socially and economically disenfranchised populations are disproportionately affected by HIV infection,[21] and because these same communities are less likely to have access to dependable medical care, preventing the spread of HIV disease and caring for those infected is much harder to accomplish in these vulnerable communities.

Understanding the presidential election through the lens of HIV/AIDS

Every presidential election is of critical importance to people living with HIV/AIDS. The platforms of the candidates and the policy proposals developed by each of the parties allow Americans to debate the merits of the HIV/AIDS proposals and identify which candidate better addresses the need for prevention, treatment, funding and health care access for people living with HIV/AIDS.

HIV/AIDS can also be used as an indicator of the types of policy priorities the candidates have for other high-need and high-cost populations. The health care access issues that those who are HIV positive face are similar to those who live with other diseases such as multiple sclerosis, cancer, and people with physical and mental disabilities. HIV/AIDS is one of many chronic illnesses that can best be treated by a system that understands that some people are going to be sicker than others and provisions for high-cost patients must be made.

16 Centers for Disease Control, http://www.cdc.gov/hiv/stats/hasrsupp10.1/table8.htm
17 The HIV/AIDS Epidemic in the United States. The Henry J. Kaiser Family Foundation, March 2004.
18 The HIV/AIDS Epidemic in the United States. The Henry J. Kaiser Family Foundation, March 2004.
19 Institute of Medicine. Coverage Matters. Washington, D.C.: 2001, page 83.
20 Institute of Medicine. Coverage Matters. Washington, D.C.: 2001, page 89.
21 Noring, Sonja, et al. "A New Paradigm for HIV Care: Ethical and Clinical Considerations." American Journal of Public Health, May 2001, page 690.

Finally, the presidential election gives us an opportunity to hold our elected leaders accountable for the pledges they make on the campaign trail. Whoever wins the presidential election will be held to the promises they offered while courting voters. Fulfilling these policy goals is an important test of a president during non-election years.

Why HIV/AIDS advocacy is important during the 2004 presidential election

The HIV/AIDS community—people living with HIV/AIDS, their families, activists, providers, academics, and community-based partners—must educate the presidential candidates about the prevention, treatment, and care needs of people with HIV/AIDS, and the policies that need to be in place in order to stem the epidemic in the United States and the rapidly expanding pandemic in the developing world.[22] Advocacy is needed not only to inform the candidates of the issues around HIV, but to educate ourselves as well about what we collectively need to do to move the HIV/AIDS policy agenda forward. In doing so, we can be one step closer to creating a bipartisan consensus about how to best fight HIV/AIDS.

Advocacy is also needed because HIV/AIDS is one of many policy items that the presidential candidates must address during the election year. While health care is a top focus of the presidential campaigns, so are other issues that are important to Americans like foreign policy, war, the economy, and education. If the HIV/AIDS community does not participate in the political process by making our voices heard, there will be other issues to fill in the void. Helping to push the needs of people with HIV/AIDS higher on the list of policy priorities is not just the candidates' responsibility—it is our responsibility, too.

"It's on the toughest health-care issues—how to best expand access to health care and to restrain cost increases—that the deepest, most revealing differences exist."

David Wessel
The Wall Street Journal
July 8, 2004

The AIDS community has already collaborated to create one of the most visible advocacy projects this election year. *AIDS Vote*, a non-partisan initiative, was conceived and is supported by AIDS organizations across the county that identified the need for an accessible, impartial forum to discuss the presidential platforms and educate voters about where the candidates stand on HIV/AIDS issues. Highlighting topics such as the candidates' positions on funding global AIDS initiatives, expanding the Ryan White CARE Act, and supporting housing and social services, *AIDS Vote* is an excellent example of how community-based advocacy can shape the presidential campaign landscape and encourage Americans to register to vote and become active in the electoral process.[23]

22 This paper does not address the presidential candidates' positions on global HIV/AIDS policy and funding.
23 See *AIDS Vote* at http://www.aidsvote.org.

Chapter 2: The Presidential Campaign Health Reform Proposals

The success of any health care system depends on whether health care is affordable, accessible, promotes quality, offers maximum coverage for its citizens, supports innovation, and provides access to the newest technology. It is by these standards that Americans, especially people living with HIV/AIDS, should judge the Bush and Kerry campaign proposals. The following pages outline the plans offered by the candidates.[24]

Expanding health insurance access and making coverage more affordable

President Bush

- **Offers new health care tax credits for use in the individual market or in state-created pooled purchasing groups:**
  - **Single adults will be eligible for up to $1000 a year if income is below $15,000; the credit phases out by $30,000;**
  - **Families with two or more children could receive up to $3,000 a year in tax credits if income is below $25,000; the credit phases out by $60,000.**
- **Promotes high-deductible individual market insurance linked to Health Savings Accounts (created by the MMA, accounts that allow for virtually tax-free savings for out-of-pocket costs); allows premiums to be tax deductible.**
- **Supports Association Health Plans, which would allow small employers to pool together to purchase health insurance for employees. Such coverage would be exempt from state regulation.**
- **Allows premium payments for long-term care insurance to be fully tax deductible.**
- **Supports tax exemptions for people who take time to care for spouses or parents with long-term care needs.**

Senator Kerry

- **Creates a new pool modeled on the Federal Employees Health Benefits Program (FEHBP) for small and large businesses, individuals, and families that need to purchase health insurance. For the uninsured, tax credits will be available for those who purchase the new group option for premiums exceeding 6% and up to 12%, based on income. In addition:**
  - **Small businesses would be eligible for tax credits up to 50% of premiums;**
  - **Americans ages 55–64 without access to employer-based insurance may receive a 25% tax credit;**
  - **Low-income unemployed would be eligible for refundable tax credits up to 75% for COBRA or the new group option.**
- **Creates a premium rebate pool that would reimburse employee health plans and the new pool for 75% of catastrophic costs above a certain threshold ($35,000 in 2006, $50,000 in 2013) to reduce premiums and make them more predictable. To qualify for this reinsurance, employers would have to pass along savings to workers, cover most workers, and use disease management. Senator Kerry claims this would save approximately 10% of premium costs, or up to $1,000 off a family plan.**
- **Supports Executive Order to ensure participants in the new pool will be guaranteed the right to family health benefits for their domestic partners.**

24 Information from: Collins, Sara R., Karen Davis, and Jeanne M. Lambrew. "Health Care Reform Returns to the National Agenda: The 2004 Presidential Candidates' Proposals." The Commonwealth Fund. Updated March 17, 2004. See also campaign websites www.georgewbush.com and www.johnkerry.com for candidate positions.

Strengthening public programs and maintaining AIDS funding

President Bush

- Implements the Medicare Modernization Act (MMA), to be fully rolled out in 2006, which will:
  - Add a prescription drug benefit to Medicare with safeguards against high out-of-pocket costs for low-income individuals;
  - Provide Medicare beneficiaries with the "choice of individual health plan" as well as a "choice of doctor or hospital" by increasing funding and flexibility for the Medicare managed care program;
  - Provide coverage of disease prevention (cancer screenings, diabetes, osteoporosis).
- Pursues capped federal allotments for Medicaid programs on a state-by-state basis through a Medicaid "reform" proposal as well as waivers of existing federal Medicaid law.[25]
- Temporarily extends the Medicaid transition benefit for families moving from welfare to work.
- Creates a new Medicaid option to allow people with disabilities to have greater flexibility over directing their care in the home and community (New Freedom Initiative).
- Supports modest increases in funding for ADAP, including $20 million to reduce waiting lists in 2004.
- As part of Ryan White Care Act (RWCA) reauthorization, provides Health and Human Services (HHS) with more discretion over RWCA funds and the authority to determine whether groups are making "good use" of their monies, as well as expand the number of religious groups funded to help people with HIV/AIDS.[26]
- Commits to doubling the number of community health centers by 2006, so that they can serve an additional 6.1 million patients.

Senator Kerry

- Addresses perceived problems in the new Medicare law (e.g. aims to reduce the number of retirees losing coverage due to the law, reduce HMO overpayment).
- Expands Medicaid by having the federal government pay for the coverage of all 20 million children on Medicaid if states:
  - Expand Children's Health Insurance Program (CHIP) coverage up to 300% of federal poverty level (FPL) (enrollment bonuses are included);
  - Expand family coverage to 200% FPL (states will get enhanced matching rate);
  - Ensure childless couples and single adults have coverage at or below the poverty level.
- Promotes automatic CHIP enrollment at school, continuous 12 months of eligibility, facilitated enrollment, dropping the five year wait for legal immigrant pregnant women and children, and allowing disabled children to keep their insurance if parents return to work.
- Opposes block granting of Medicaid program, and provides $25 billion for state fiscal relief in first two years of term.
- Supports the Early Treatment for HIV Act (ETHA), which would give states the option to expand Medicaid to cover HIV-positive individuals who are not yet disabled.
- Increases RWCA to end ADAP waiting lists (no dollar amount provided).
- Supports development of federal guidelines that integrate HIV prevention into primary care in Medicaid.
- Supports community health centers (no specific commitment).

25 Office of Management and Budget, Budget of the United States, Fiscal Year 2005, February 2004.
26 Goldstein, Amy. "President Bush Seeks More Control Over AIDS Act." The Washington Post, June 24, 2004.

Reducing health care costs

President Bush

- Reforms the country's medical malpractice system by:
  - Allowing unlimited compensation for economic losses;
  - Capping non-economic damages at $250,000;
  - Limiting punitive damages to "reasonable" amounts;
  - Prohibiting payments from being made in a single lump sum;
  - Reducing amount that doctors must pay if plaintiff has received payments elsewhere;
  - Requiring defendants pay judgments in proportion to fault.
- Reduces Medicaid costs through an anti-fraud policy.
- Expands the use of information technology which could reduce administrative costs (see next page).

Senator Kerry

- Reforms the country's medical malpractice system by:
  - Opposing capped damages;
  - Stopping bad claims unless reasonable;
  - Supporting mandatory sanctions for claims that are presented for improper purposes;
  - Requiring states to have non-binding mediation;
  - Opposing award of punitive damages in medical liability unless proof of intentional misconduct.
- Eliminates loopholes that pharmaceutical companies use to keep generic drugs off the market.
- Requires pharmacy benefit managers that do business with the federal government to be transparent and show savings accrued from industry and bulk purchasing.
- Helps states use Medicaid's ability to negotiate drug prices to cover other populations.
- Provides incentives to states to implement more efficient contracting to leverage better prices.
- Promotes disease management by linking it to new financing increases (see page 8).
- Expands the use of information technology, which could reduce administrative costs (see next page).
- Reduces the amount of uncompensated care in the system by expanding coverage.

Improving quality and promoting a strong health care system

President Bush

- Supports legislation that would implement a Patient's Bill of Rights with a provision that would limit a patient's right to sue.
- Promotes "consumer-driven health care" in which consumers have access to better information about medical treatments and health providers, including the quality of nursing homes.
- Encourages the use of electronic medical records with strong privacy protections. Sets goal of having electronic medical records for most Americans within 10 years.
- Calls for an increase in National Institutes of Health funding that would "improve the prevention, detection and treatment of diseases;" opposes stem cell research except under tightly-constrained circumstances.
- Increases funding for bioterror preparedness efforts.
- Supports legislation that allows medical professionals to work together to share information with the anticipation of fewer medical errors.

Senator Kerry

- Supports legislation that would implement a Patient's Bill of Rights, as well as mental health parity.
- Provides financial incentives, like a "Technology Bonus," for providers to institute electronic medical records, patient registries, and computerized prescribing systems.
- Supports efforts to reduce ethnic and racial disparities in health care.
- Requires private insurers to be using electronic medical record technology by 2008 if contracting with Medicare, Medicaid, or the Federal Employee Health Benefits Program.
- Supports stem cell research.
- Creates "Quality Bonus" that moves toward a "pay-for-performance" system to improve health outcomes and reduce errors.

Cost of plans and number of newly insured

President Bush

According to the U.S. Office of Management and Budget and the Treasury Department, President Bush's health care plan costs $104.3 billion over 10 years including the long-term care policies.[27] The Administration states these initiatives will cover 4 million to 6 million Americans.

According to Ken Thorpe of Emory University, President Bush's plan costs $90.5 billion over 10 years, excluding the long-term care provisions and Medicaid savings, and covers 2.4 million Americans; however, the number of covered Americans will decrease because the dollar value of the refundable credits decline over time.[28]

Senator Kerry

According to Ken Thorpe of Emory University, Senator Kerry's health plan costs $653 billion over 10 years and would increase the number of insured Americans by 27 million. Senator Kerry has indicated that his plan would be financed by repealing the tax cut that President Bush implemented in 2001 for families with incomes above $200,000.[29]

27 Department of the Treasury, *General Explanation of the Administration's Fiscal Year 2005 Tax Proposals*, February 2004; Office of Management and Budget, Budget of the United States, Fiscal Year 2005, February 2004.
28 Thorpe, Kenneth E. "Federal Costs and Newly Insured Under President Bush's Health Insurance Proposals." Emory University, May 2004.
29 Thorpe, Kenneth E. "Federal Costs and Savings Associated with Senator Kerry's Health Care Plan." Emory University, April 2004.

Chapter 3: Will the Plans Improve Access to Care for People with HIV/AIDS?

The fact that the only commonality between the Bush and Kerry health proposals is around peripheral issues such as the need for increased use of medical technology and disease management demonstrates how different the candidates' approaches are in addressing health care reform. In general, President Bush offers a plan that leaves health care decision-making in the hands of the marketplace; in this scenario, private insurers compete for the business of those with the power to purchase, and consumers are given both increased information and responsibility for reducing costs and improving quality. Senator Kerry's plan helps consolidate individuals' purchasing power by expanding both public and private group insurance options. In Kerry's analysis, the problem is that the market is too fragmented, and the lowest income and sickest are left out. The plans highlight the stark ideological differences that exist between the Republican and Democratic plans to address increased access to and affordability of health care in the U.S.

For most Americans, including people with HIV/AIDS, the proposals that matter most are those that will make health care accessible, affordable, and dependable. Yet people with HIV/AIDS have different coverage needs from the average health care consumer. People with HIV/AIDS tend to rely more heavily on publicly-financed insurance because they are low income, disabled, or both. They tend to have less access to insurance in the individual market because their health conditions preclude them from accessing plans that are wary to cover individuals who are high utilizers of health care, especially those who take very expensive medications. The presidential health care proposals should be carefully examined to determine which proposal will best address the needs of people with HIV/AIDS, strengthen the current systems of care that people with HIV/AIDS utilize, and expand coverage to the 20% of people with HIV/AIDS who are uninsured.

Analysis of presidential proposals for Medicaid, Medicare, and the Ryan White CARE Act

People with HIV/AIDS disproportionately rely on public health insurance for their health care. Public insurance programs are the safety net not only for people with HIV/AIDS but for low-income and disabled Americans who have no other access to insurance. They are a vital part of our health care infrastructure in the absence of policies that mandate health insurance for everyone. In fact, the number of non-elderly adults who were uninsured remained stable between 1999 and 2002 because increases in enrollment in public health insurance programs offset reductions in other types of coverage.[30]

30 Zuckerman, Stephen. "Gains in Public Health Insurance Offset Reductions in Employer Coverage Among Adults." Urban Institute, September 2003. http://www.urban.org/url.cfm?ID=310850.

Medicaid

President Bush has previously proposed a major restructuring of Medicaid that would dramatically alter the federal-state partnership in its financing structure, although Congress rejected the proposal in 2003. He supports federal efforts that would encourage states to accept a capped allotment for the federal portion of their Medicaid dollars. By capping the federal share, the federal government would essentially relieve itself of the responsibility of providing additional resources if a state needed to expand its Medicaid program. While the Administration continues to assert that the plan is not a block grant, its "capped allotment" approach contains all of the features of one.[31] In the Medicaid plan that President Bush proposed last year, states would have the ability to establish different eligibility rules for different populations within optional categories, alter the benefits available for optional populations, and impose greater cost-sharing requirements. Unsurprisingly, the President has expressed satisfaction over the "record number" of waivers his administration has granted giving states flexibility over the rules for administering Medicaid and the Children's Health Insurance Program.[32]

Some policy makers endorse the block grant approach to Medicaid because they do not support federal entitlements and do not believe that the federal government can sustain its large and growing open-ended financial obligations under Medicaid. Supporters say that capped Medicaid allotments would save taxpayers money by allowing states maximum flexibility to design programs that meet their state's needs. According to the National Center for Policy Analysis, "one of the merits of block grants is that they encourage states to innovate and to improve the way Medicaid operates."[33] Some states have also been attracted to the block grant approach because it would free them from much of the accountability demanded by meeting minimum federal requirements for benefits and eligibility. Interestingly, the recent debate over block grants has ignored the fact that Medicaid already permits states broad discretion, and states that do not believe they can sustain their Medicaid programs already have flexibility to restrict eligibility and services. Further, the recent debate over Medicaid restructuring has not identified ways that states would "innovate" if they no longer had open-ended financing. Rather, they have identified ways that states could restrict benefits or eligibility in ways that are discriminatory—and impermissible under current law.

Opponents of block granting, including a majority of HIV/AIDS advocates across the country, are concerned that additional state flexibility will lead to cuts, not improvements, in state Medicaid programs, especially in bad fiscal times. Without the automatic federal funding increase that accompanies program expansion, states would have experienced an excessive increase in their own costs during the period of

31 Mann, Cindy. "The Bush Administration's Medicaid and State Children's Health Insurance Program Proposal." Georgetown University, February 2003.
32 Serafini, Marilyn Werber. ""Feeling Better?" National Journal, May 29, 2004, page 1706.
33 Cantwell, James. "Reforming Medicaid." U.S. House Committee on the Budget, August 1995. Accessed from the National Center for Policy Analysis, www.ncpa.org.

2000–2002, when an additional 4 million people enrolled in Medicaid. Capped funding could likewise constrain states' ability to respond to emerging and critical health care needs, like a new AIDS medication coming to market, or a public health disaster. When antiretrovirals became the HIV standard of care in the mid 1990s, people were able to access the drugs through Medicaid, and states were not financially impacted in large part because of increased federal support for these costs.

Senator Kerry has stated that he is opposed to efforts that would block grant the Medicaid program, and he has proposed additional federal funding for Medicaid. He supports the Early Treatment for HIV Act (ETHA), which would offer states an enhanced Medicaid matching rate to cover HIV-positive individuals who are not yet disabled. Studies show that this can both improve the health of HIV-positive individuals by offering them preventive care, and save federal and state dollars by reducing the number of people with AIDS who need treatment. His plan also builds on the Medicaid program by offering states incentives to expand their programs for low-income families and individuals. Senator Kerry proposes making enrollment and recertification in CHIP easier, although he does not offer the same for adults. In total, these proposals may very well increase the number of people with HIV/AIDS who are eligible for public health coverage.

Medicaid	HIV/AIDS Community	President Bush	Senator Kerry
Supports capped allotments/capped federal funding	No	Yes	No
Supports Medicaid state fiscal relief	Yes	No	Yes, proposes $25 billion in first 2 years in office
Supports Early Treatment for HIV Act	Yes	Unclear	Yes

Medicare

President Bush has not proposed major changes to the Medicare program, other than implementing the Medicare Modernization Act that was passed in 2003. Senator Kerry has proposed to reduce drug prices that Medicare pays, stem the loss of retiree health coverage resulting from the Medicare law, and reduce HMO overpayments. Senator Kerry supports closing loopholes in the law that would allow manufacturers of brand-name drugs to keep cheaper generics off the market, and make pharmacy benefit managers more accountable for the prices they charge the government for administering the Medicare Part D drug benefit.

It is unclear exactly how the new Medicare law, which was strongly supported by President Bush, will affect people with HIV/AIDS. However, there are signs that the HIV/AIDS community will have to be vigilant in ensuring the law is implemented

with the community's concerns in mind. The prescription drug discount cards that are currently offered as a result of the law have not proven necessarily beneficial for people with HIV. In 2006, the drug benefit will be administered by private companies that will likely establish formularies based on HHS guidelines. The proposed rules for the new law, however, do not require that ARVs and other HIV-related medications be automatically included in plan formularies. HIV medications aside, plans participating in the Part D benefit will have the ability to design their own formularies, which will affect access to drugs that must be used with HIV medications to treat side effects or other ailments. Plans may also impose high co-payments for selected drugs, require prior authorization and impose dosing limits—all of which would disproportionately affect people with HIV since they typically use many expensive medications. Furthermore, since most Medicare beneficiaries who are HIV positive are dual eligible (i.e. have Medicaid and Medicare), they will need to be educated on how to transition to the new benefit since they no longer can receive drugs through Medicaid. Additionally, the proposed rules recommend prohibiting states from using their ADAP programs to supplement coverage for drugs not available through a beneficiary's plan.

The Medicare law also allows for a six-year experiment in 2010 that would allow private companies to offer Medicare plans and compete with Medicare directly for business. Health insurance plans have an economic incentive to cover healthier, younger people in order to keep their costs down. It is a concern that this demonstration project may weaken the traditional Medicare program for high-need populations by encouraging private plans to "cherry-pick," or draw healthier customers to their plans, leaving a sicker, higher-cost population in traditional Medicare.

Medicare	HIV/AIDS Community	President Bush	Senator Kerry
Supports implementation of Medicare Modernization Act as passed by Congress	**Part D formularies must include all HIV medications; must contain other changes to law that will help people with HIV/AIDS**	**Yes**	**Yes, with changes to ensure low prices for Medicare, prevent retirees from losing coverage, and reduce HMO overpayment**
Supports permitting the federal government to negotiate drug prices for Medicare	**Yes**	**No**	**Yes**
Supports reimportation and efforts to reduce cost of prescription drugs by closing loopholes when generics go to market	**Yes**	**No**	**Yes**

Ryan White CARE Act

For those without insurance, or who are underinsured, Ryan White CARE Act (RWCA) funded programs offer critical drug assistance, prevention and testing, and support services for people with HIV/AIDS. President Bush recently announced a $20 billion increase in the ADAP program—welcome news for the 11 states with people waiting to get on ADAP. However, even though this is "emergency" funding, the Administration has indicated that it will be deducted from the CARE Act's $35 million increase for FY 2005. The CARE Act has grown slightly under President Bush (in 2003 by 6%, in 2004 by 1%[34]) but when ADAP is excluded from the calculation, the remaining titles in the RWCA have experienced cuts over the last four years. HIV/AIDS advocates agree that RWCA funding has not risen to meet the need of growing numbers of people living with HIV/AIDS, the problem compounded by the increasing numbers of the uninsured who have no other insurance and must access RWCA services in order to manage their disease. Senator Kerry supports increasing RWCA funding but has not specified by what amount.

Ryan White CARE Act	HIV/AIDS Community	President Bush	Senator Kerry
Supports increased funding	**Yes, CARE Act needs $3.1 billion to deliver care for all in need of CARE Act services.**	**Appropriated $2 billion in 2004. Budget calls for $35 million increase in FY 05, which includes a $20 million emergency ADAP allocation**	**Yes, supports funding to "end ADAP waiting lists and provide an appropriate standard of care;" funding level not specified.**

Analysis of presidential proposals to insure more Americans through private insurance

Like their proposals for public insurance, President Bush's and Senator Kerry's plans for expanding health insurance in the private market are markedly different. The President's plan is centered on three elements to encourage coverage: tax credits for individual market coverage, health savings accounts, and small-business purchasing pools, also known as Association Health Plans. Senator Kerry relies on the development of a new insurance pool, modeled on the current rules of the Federal Employees Health Benefits Program, which would cover employees of large and small businesses, as well as uninsured individuals and families. Senator Kerry has also proposed picking up high-cost claims in the employer-based market, reimbursing employee health plans for 75% of catastrophic costs above $50,000, as long as employers use the savings to reduce employees' premium costs.

34 Summers, Todd and Jennifer Kates. "Trends in U.S. Government Funding for HIV/AIDS." The Henry J. Kaiser Foundation, March 2004.

Supporters of the President's plan believe the key to making coverage more affordable, and thus increasing the number of insured Americans, is allowing people to have the power to choose their own health insurance. By providing tax credits to purchase insurance in the individual market, consumers will be able to shop around for the best bargain, and producers of health care (i.e. insurance companies) will have to compete for their business, bringing prices down.

For people who are chronically ill, however, the market is difficult to navigate, since insurers are less likely to offer affordable, comprehensive plans to those who are likely to use the benefits the most. For this reason, people who are chronically ill often find themselves in one of two situations: (a) they need insurance, but have no access to a plan that is likely to meet their health care needs; or (b) they purchase a plan that can meet their needs, but pay high out-of-pocket costs and face increased premiums each year. The concept of insurance is supposed to pool risk so that high-cost individuals are balanced out by lower-cost individuals who utilize fewer health services. However, if insurance companies are given the opportunity to "experience rate" their plans, i.e. charge based on an individual's likely utilization of health services, the market is distorted, and higher-cost individuals may be priced right out of it. A 2001 study of a hypothetical person living with HIV with an otherwise perfect bill of health showed that when attempting to obtain individual coverage in regions across the country, the person with HIV was denied coverage from all 60 insurance companies that were approached.[35]

Tax credits for individual market coverage

President Bush's tax credit plan, which offers a refundable tax credit up to $1000 for individuals and up to $3000 for families (depending on income), indexes the credits to the growth in the Consumer Price Index, which the Congressional Budget Office projects will rise by 2.2% a year between 2006 and 2014—below the expected annual rise in health insurance costs. As a result, the value of the credits will fall over time, as will the number of uninsured persons covered under the proposal.[36]

Using a model to predict how employers would respond to policies that affect the health insurance market, a 2004 Kaiser Family Foundation study found that President Bush's tax credit proposal would cover 3.1 million Americans who were previously uninsured, but would only reduce the total number of uninsured by 1.8 million people, because 3.4 million would lose employer-based coverage (employers would stop offering coverage) and switch to non-group health insurance or Medicaid, or become uninsured (estimated at 1.3 million).[37]

Families USA conducted a study that analyzed the out-of-pocket costs associated with tax credit proposals. Using a standard insurance policy that is comparable to the

35 Pollitz, Karen, Richard Sorian, and Kathy Thomas. "How Accessible is Individual Health Insurance for Consumers in Less Than Perfect Health?" Henry J. Kaiser Family Foundation, June 2001, page 19.
36 Thorpe, Kenneth E. "Federal Costs and Newly Insured Under President Bush's Health Insurance Proposals." Emory University, May 2004.
37 "Coverage and Cost Impacts of the President's Health Insurance Tax Credit and Tax Deduction Proposals." Henry J. Kaiser Family Foundation. March 2004.

preferred provider plan within the Federal Employees Health Benefits Program, a 55-year-old healthy woman living at the poverty level paying a $250 deductible and receiving the $1000 tax credit would spend more than half her annual income before she would gain any health insurance benefit. A comparable 25-year-old would spend 28% of her income, assuming in both cases that there are plans available to these women in their states. Studies have shown that the higher the premium, the less likely people are going to pick up a policy. If someone chooses a low-cost insurance policy, the cost sharing thereafter is likely to discourage people from seeking care, and obtaining the prescription medications they need. Families USA concluded that tax credits cause people to choose between two bad options: trying to find sufficient resources to purchase a standard plan that exceeds bare bones coverage, or purchasing a cheap plan and paying high deductibles if they become ill.[38]

Furthermore, the Urban Institute released an analysis that found efforts to increase coverage through premium subsidies or tax incentives may not lead to increased coverage for families that struggle to meet basic food or housing needs. The amount these families are willing to spend for insurance coverage may be substantially less than market premiums, even with tax credits or premium subsidies. The study concludes that "expanding public programs at virtually no cost to the individual, or providing very large subsidies or tax incentives may be the only way to address the needs of families that have needs in other areas."[39]

Finally, the Center for Budget and Policy Priorities cautions against tax credit proposals for purchasing individual market insurance because they invariably will pull healthier people out of the employer-based market, making it harder for employers to maintain affordable plans and causing sicker people to consider enrolling in plans that have limited benefits.[40] For low-income people, the plans' premiums are typically much higher than the $1,000 refund. It seems doubtful that tax credits will indeed allow people with intensive health care needs, such has those with HIV/AIDS, to purchase affordable, comprehensive insurance.

Health Savings Accounts

Health Savings Accounts (HSAs), which were passed as part of the Medicare Modernization Act in 2003, permit employees and employers to make tax-free contributions into savings accounts, allowing individuals to purchase medical services with the funds saved. The account is accompanied by a high-deductible catastrophic health plan that can be accessed once the deductible has been met. A qualified plan must have a deductible of at least $1,000 for a single policy, and $2,000 for a family policy. HSAs, like tax credits, are seen as a way to encourage Americans to be prudent purchasers of their own health care.

38 Families USA. "A 10-Foot Rope for a 40-Foot Hole: Tax Credits for the Uninsured—2002 Update." May 2002.
39 Long, Sharon K. "Hardship Among the Uninsured: Choosing Among Food, Housing and Health Insurance." Urban Institute, May 2003. http://www.urban.org/url.cfm?ID=310775.
40 Park, Edwin. "Administration's Proposed Tax Credit for the Purchase of Health Insurance Could Weaken Employer-Based Health Insurance." Center on Budget and Policy Priorities, April 6, 2004.

HSA deposits are tax deductible, compound earnings on a tax-free basis, and allow tax-free withdrawals. Opponents of HSAs believe that these accounts are designed to shield dollars from taxes, removing money from the tax base and ultimately weakening the economy. Additionally, HSAs can only be used in conjunction with high-deductible health insurance policies, which will attract healthier, younger workers. As they enroll in these plans, those remaining in traditional comprehensive insurance, including older and sicker workers, will cause group health insurance premiums to rise, creating a cyclical effect where more healthy individuals leave the market in search for cheaper insurance. RAND, the Urban Institute and the American Academy of Actuaries have stated that premiums for comprehensive insurance could more than double if HSAs become widespread.[41]

Supporters of Health Savings Accounts refute the notion that only healthy people would open a HSA. They contend that sicker Americans have an incentive to choose a HSA because they would receive money up front to pay for medical expenses, like prescription drugs, and would have direct access to medical specialists and the freedom to choose a doctor.[42]

Association Health Plans

Association Health Plans (AHPs) allow small businesses to band together into groups to buy health insurance at group rates. This differs from other pooling arrangements in that AHPs are allowed to select which firms may join (i.e., they do not have to take all firms in an area) and they are exempt from state insurance regulation. Since AHPs would be regulated under federal as opposed to state insurance laws, they would be exempt from benefit mandates, allowing the plans to keep their benefit packages to a bare minimum, if they choose. A bill to create AHPs is currently pending in Congress. According to the Congressional Budget Office, approximately 330,000 more Americans would be covered through small firms than would otherwise have been the case, although premiums would rise for those remaining in regulated small group plans. That represents a 1.3% increase in coverage through business employers.

While supporters contend that AHPs will give small businesses the help they need to get insurance that is otherwise too costly, opponents are concerned that in an effort to keep costs low, AHPs will have an incentive to target the people who are the cheapest to insure, and could destabilize the small-group market, making it more difficult for less healthy people to find affordable coverage.[43]

41 Greenstein, Robert and Edwin Park. "Health Savings Accounts in Final Medicare Conference Agreement Pose Threats Both to Long-Term Fiscal Policy and to the Employer-Based Health Insurance System." Center on Budget and Policy Priorities, December 2003.
42 Blevins, Sue. "Medical Savings Accounts Give Patients Power." Institute for Health Freedom, www.forhealthfreedom.org/Publications/HealthIns/MSAs.html (accessed July 15, 2004).
43 National Partnership for Women and Families, "Association Health Plan (AHP) Legislation: Myths and Facts." http://www.nationalpartnership.org/Content.cfm?L1=202&TypeID=1&NewsItemID=591.

Creation of new Federal Employees Health Benefits Program pool and creation of premium rebate pool

Senator Kerry's plan to offer health insurance through the Federal Employee Health Benefits Program is designed to pool risk among Americans who are uninsured but not eligible for public insurance. It appears that this coverage will be available to all interested applicants (guarantee issue) and have premium rates spread across the group (some type of community rating). However, since the insurance is not mandatory, it may very well attract a sicker and more high-cost population who need health insurance, causing costs to rise. Opponents of Senator Kerry's plan believe the proposals will fail if implemented since the market cannot sustain an insurance program that will attract the highest cost individuals. Senator Kerry's premium rebate and tax credits are designed to lessen this risk, but these too have come under criticism. Some argue that covering all costs over $35,000–$50,000 in the employer-based market "undermines the basic point of insurance—that is, protecting people from rare and costly events."[44] However, few if any of the more conservative analysts offer suggestions of how to improve health insurance access for people with chronic illnesses and diseases.

Private Insurance	HIV/AIDS Community	President Bush	Senator Kerry
Supports tax credits for individuals	Not a priority[45]	Yes	Yes
Supports Health Savings Accounts	No	Yes	No
Supports Association Health Plans	No	Yes	No
Supports new Federal Employee Health Benefits Program pool	Yes	No	Yes
Supports premium rebate pool	Unclear	No	Yes

44 Gratzer, David. "From HillaryCare to KerryCare." The Weekly Standard, May 24, 2004.
45 As mentioned, tax credit proposals have been criticized for providing support that is insufficient to bridge the gap between premium costs and what the typical individual/family can afford. In the context of HIV/AIDS, individual coverage is generally not available to people living with HIV/AIDS or excludes coverage for HIV as a pre-existing condition exclusion, rendering the coverage effectively meaningless.

Conclusion: What's at Stake for People with HIV/AIDS this Presidential Election Year?

As we draw closer to marking the 25th year of AIDS in the United States, President Bush and Senator Kerry are offering Americans very different visions for the future of our health care system. The candidates have vastly different ideas about how to increase the ranks of the insured while addressing the spiraling costs that have made America's health care system the most expensive in the world.

In the final weeks of the election season, it is important for the HIV/AIDS community to understand exactly how the candidates plan to address the pandemic at home and abroad, and how they aim to improve the delivery of care that is critical to maintaining the health of people living with the disease. As outlined, there are significant differences between the candidates—many of which directly impact the accessibility of health care for people with HIV/AIDS.

It is equally if not more important for advocates to educate themselves, their consumers, and their communities about the differences between the candidates. If we have learned anything from the 2000 election, it is that the adage "every vote counts" is true. All people living with HIV/AIDS should be at the polls from coast to coast on November 2 to vote for the candidate that is best equipped with the ideas and visions to make significant improvements in the lives of people living with HIV/AIDS.

Appendix: Primer on the HIV/AIDS Health Care Coverage Landscape

HIV/AIDS care in the United States consists of a patchwork of programs, insurance plans, and safety-net providers that provide and/or pay for care depending on the age, income, employment status, and health of the individual needing care. These differing sources of coverage are often interwoven to ensure comprehensive and continuous care for people with HIV/AIDS. Both private and public funds pay for our nation's HIV care system through Medicaid, Medicare, the Ryan White CARE Act, and private insurance.

Of the Americans with HIV/AIDS who access care (which is estimated to be only half of those who actually have HIV/AIDS in the U.S.):

- 44% have Medicaid (includes persons who are also eligible for Medicare)
- 6% have Medicare only (excludes those who also have Medicaid)
- 20% are uninsured
- 31% have private insurance[46]

Medicaid

Medicaid is the largest source of financing for HIV/AIDS care and services in the United States. Medicaid is a federal and state program financed by both levels of government and administered at the state level. Each state operates its own Medicaid program, subject to federal law. States that choose to offer Medicaid must follow federal rules and meet minimum federal standards related to eligibility, services covered, and other program features. In exchange, states have a right to receive matching federal payments to finance the Medicaid program. The level of the federal match rate, or federal medical assistance percentage (FMAP), varies based on the per capita income of the state. At a minimum, states are guaranteed that the federal government will cover at least 50% of total Medicaid costs, and the law permits the federal match rate to rise to 83%; currently Mississippi has the highest match rate, with the federal government covering 77% of total Medicaid spending. When analyzing Medicaid's role in providing coverage for health and long-term care services for people living with HIV/AIDS, it is important to remember that different states and territories have different Medicaid rules that will affect access, eligibility and comprehensiveness of care received. There is significant variation among states in how much income individuals can have and still qualify for Medicaid, and in the range of services offered.

Of those in care, 44% of people with HIV/AIDS have Medicaid.[47] It is also estimated that 90% of children with AIDS have Medicaid.[48] Medicaid spending on AIDS care

46 Kates, Jennifer. "Financing HIV/AIDS Care: A Quilt with Many Holes." The Henry J. Kaiser Family Foundation, May 2004, page 2.
47 Kates, page 6.
48 Kates, page 6.

in FY02 was $7.7 billion, including state and federal dollars.[49] According to the Centers for Medicare and Medicaid Services (CMS), an estimated 231,079 people with HIV/AIDS were served by the Medicaid program in FY 2003.[50]

People with HIV/AIDS can qualify for Medicaid in one of several ways. Generally, low-income individuals only qualify for coverage once their HIV has progressed to AIDS, at which point they meet the federal requirement to be considered fully disabled. The Social Security Administration (SSA) determines eligibility for Social Security Disability Insurance (SSDI), Medicare, Supplemental Security Income (SSI), and Medicaid using a single standard of disability that requires individuals to be "unable to engage in substantial gainful activity by reason of a medically determined physical or mental impairment expected to result in death or that has lasted or can be expected to last for a continuous period of at least 12 months."[51] For people who are disabled, they must also meet income and resource standards to qualify for Medicaid. The majority of the HIV/AIDS population is low-income and qualifies for mandatory Medicaid coverage on the basis of receiving cash assistance from the federal Supplemental Security Income (SSI) program. The income support provided by SSI ensures that individuals have income at 74% of the poverty level. People with HIV/AIDS and other people with disabilities can have income above this level and still qualify for Medicaid in 19 states that have extended Medicaid eligibility for people with disabilities up to the federal poverty level.[52] For people living with HIV/AIDS and who contributed to the Social Security system, individuals can receive SSDI income assistance payments. These payments are based on past contributions; the average SSDI payment is approximately 130% of the poverty level. In 35 states plus the District of Columbia, individuals with HIV/AIDS and other disabilities can also qualify for Medicaid through the Medically Needy program, which allows people who are disabled to spend down into Medicaid if they are above Medicaid income levels.[53] In this case, individuals qualify for Medicaid if their income is below a state's medically needy income limit after subtracting incurred medical expenses. In 2001, the median was 55% of the poverty level.[54]

There are federally mandated and optional benefits in Medicaid. Mandatory benefits, which must be offered in a state's Medicaid program, include inpatient and outpatient care, X-rays, home health, and early periodic screening, diagnostic, and treatment services for individuals under 21 (EPSDT). Optional benefits, which states have the option of offering, include case management, physical therapy, dental, and hospice care. Prescription drugs are an optional benefit under Medicaid; all states, however, have chosen to cover drugs through their Medicaid programs.

49 Kates, page 6.
50 Centers for Medicare and Medicaid Services. "Medicaid and Acquired Immunodeficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) Infection." www.cmh.hhs.gov/hiv/hivfs.asp (accessed June 15, 2004).
51 Kates, page 6.
52 Crowley, Jeffrey S. "Medicaid's Role for People with Disabilities." The Kaiser Commission on Medicaid and the Uninsured, August 2003, page 6.
53 Crowley, page 15.
54 Crowley, page 6.

Medicaid has proven its capacity to efficiently deliver a broad array of services to people with complex and extensive health care needs. According to the Kaiser Commission on Medicaid and the Uninsured, Medicaid is actually a lower-cost way to cover a high-need population:[55]

- Medicaid serves a sicker and needier population than the private insurance market.
- Per capita costs are lower in Medicaid for serving comparable populations. When health status is adjusted by excluding disabled adults from analysis, per capita expenditures were lower for Medicaid than in private insurance.
- Neither higher utilization in Medicaid nor the program's more comprehensive benefit structure are key factors driving Medicaid spending.
- Medicaid expansion is an efficient use of public funds. Using public funds to help people purchase private coverage would cost considerably more than building on Medicaid.

While Medicaid is the primary source of coverage for people with HIV/AIDS, there are many more people caught in a catch-22: they could benefit from Medicaid but are ineligible because they are not yet disabled. Waiting for an AIDS diagnosis to be qualified as disabled would trigger Medicaid coverage, but the more serious diagnosis could have been prevented in the first place if preventive care were available through Medicaid. The Early Treatment for HIV Act (ETHA), which is pending in Congress, would allow states the option to receive an enhanced federal match for covering low-income individuals with HIV through Medicaid before they are disabled. Modeled after the Breast and Cervical Cancer program, ETHA could cut the death rate for people with HIV/AIDS in half and save money in the long run, after the costs of AIDS care and years of life lost are taken into account.[56] There is sound evidence that ETHA is good public policy. According to a 2001 study, early antiretroviral therapy "appears to offer good value for resources spent. Some states should consider programs to expand access to early antiretroviral therapy in accordance with current treatment guidelines through Medicaid waivers or other Medicaid demonstration projects."[57]

Likewise, expanding access to antiretroviral treatments, using a hypothetical change in Medicaid eligibility, would improve health outcomes. Researchers estimate that if 38,000 people with HIV had expanded access to HAART, within 5 years more than 13,000 new AIDS diagnoses and 2,600 deaths could be prevented, leading to a savings of more than 5,800 years of life. The net federal cost of the modeled expansion was estimated at $96 to $148 million per year over five years, well below the cost of other public health initiatives.[58]

55 "Medicaid: A Lower Cost Approach to Serving a High-Cost Population." Kaiser Commission on Medicaid and the Uninsured. March 2004.
56 Treatment Access Expansion Project ETHA Fact Sheet, May 27, 2004.
57 Schackman, Bruce et al. "Cost Effectiveness of Earlier Initiation of Antiretroviral Therapy for Uninsured HIV-Infected Adults." American Journal of Public Health, September 2001, page 1462.
58 Kahn, James G. et al. "Health and Federal Budgetary Effects of Increasing Access to Antiretroviral Medications for HIV by Expanding Medicaid." American Journal of Public Health, September 2001, page 1470.

Medicare

While generally perceived to be solely a program for the elderly, Medicare is also a program for non-elderly workers who become disabled and for people with disabilities (spouses and dependent adult children) who are dependent on Medicare beneficiaries. Medicare is actually a very important—and growing—source of coverage for people living with HIV/AIDS. As the second largest source of HIV/AIDS funding, Medicare provides HIV-positive individuals with doctor and hospital coverage. Approximately 19% of people with HIV/AIDS receive Medicare (including those who have Medicaid as well) and use it as their primary source of health insurance. Medicare enrollment has increased among people with HIV/AIDS primarily because they are living longer and are eligible for Medicare because of disability, or because they enroll in Medicare once they turn 65.

Unlike Medicaid, Medicare is financed and administered exclusively by the federal government. Benefits, eligibility and provider payments are uniform across the country, and there is no state variability, except in the services and benefits offered through managed care plans that are offered through Medicare Part C. The Medicare program contracts with regional private contractors to manage the payment of claims for Medicare benefits, however, and there is some regional variation in how regional contractors interpret federal rules.

People with HIV/AIDS who have sufficient work histories can qualify for Medicare if they meet federal SSDI guidelines. Medicare Part A provides people with inpatient hospital services, home health and skilled nursing. Part B, which is optional, pays for physician services and supplies, and the new Part D benefit, which was just passed by Congress in 2003, will provide Medicare beneficiaries with prescription drug coverage, although the scope of benefits and access to antiretrovirals and other HIV medications is still unclear. For those who are dual eligible (have both Medicare and Medicaid), Medicaid has traditionally played a very important role in covering services that Medicare does not cover.

Medicare's importance to people with HIV/AIDS will grow with the implementation of the Part D drug benefit in 2006. The proposed regulation does not require ARVs or other HIV-related medications be automatically included in plan formularies. HIV medications aside, plans participating in the Part D benefit will have the ability to design their own formularies, which will affect access to drugs that must be used with HIV medications to treat side effects or other ailments. Plans may also impose high co-payments for selected drugs, require prior authorization and impose dosing limits—all of which would disproportionately impact people with HIV since they typically use multiple, expensive drugs. The new law prohibits Medicaid from receiving federal matching payments to supplement the Medicare drug benefit, so dual eligible beneficiaries will not be able to wrap one benefit around the other to ensure uninterrupted access to medications. Medicaid programs can, however, receive federal funds to cover drugs excluded from coverage by Medicare, such as barbiturates and benzodiazepines, or over-the-counter medications.

Care for the uninsured through the Ryan White CARE Act and community health centers

The Ryan White Comprehensive AIDS Resources Emergency Act (RWCA) was passed in 1990 to respond to the growing U.S. AIDS epidemic. The funds authorized by the Act go toward several purposes in an effort to provide services to those who are uninsured or underinsured and need access to HIV care. As the third largest source of HIV care in the U.S., the RWCA was funded at $2 billion for the 2003 fiscal year.[59] The Health Resources Services Administration, which administers the CARE Act, estimates that approximately 500,000 people use RWCA-funded services each year.[60]

The Ryan White CARE Act is funded by the federal government; states and local governments are charged with the task of designing programs that receive funding. There are several titles in the RWCA:

Title I
Provides funding for Eligible Metropolitan Areas (EMAs) that are hardest hit by HIV/AIDS. Funds are used for medical and/or support services.

Title II
Half of Title II funding goes to state AIDS Drug Assistance Programs (ADAPs), and the remainder goes to health care and support services, as well as insurance continuation.

Title III
Federal dollars that go directly to organizations providing comprehensive HIV primary care.

Title IV
Funding for medical care, as well as social and prevention services to children and women with HIV/AIDS and their families.

Dental Assistance — Provides funding for dental care for people with HIV/AIDS.

AIDS Education and Training Centers — Funding supports a network of regional centers that provide education and training to providers of HIV/AIDS care.

Special Projects of National Significance — Grants that encourage entities to establish innovative models of care for HIV/AIDS.

The CARE Act has been a critical component of the HIV/AIDS health care infrastructure — when private or public insurance is not available, the Ryan White CARE Act is able to fill in the gaps with services such as dental care, prescription drug coverage through ADAP, case management, housing and transportation services.[61] The CARE Act, unlike Medicaid or Medicare, is a discretionary program, so rising need for services funded by the CARE Act does not automatically translate into additional funding. For example, because of funding shortfalls over the last

59 Kates, page 12.
60 Kates, page 12.
61 Kates, page 14.

several years, there are currently 11 states that have capped enrollment in their ADAP programs, and 9 states that have waiting lists. Others have reduced the number of drugs available on their formularies, or imposed drug dispensing limits.[62]

Community health centers (CHCs) are an important part of the health care safety net system in the U.S. CHCs are funded through federal grants, RWCA dollars, and Medicaid. In 2000, approximately 48,000 people with HIV/AIDS went to a CHC for care.[63]

Private health insurance through the employer-based and individual markets

There are hundreds of thousands of people with HIV/AIDS who, like most Americans, have insurance through their jobs. A much smaller number of people purchase their own insurance in the individual market. Approximately 31% of people with HIV/AIDS in care are covered by some type of private insurance.

For those without access to employer-based insurance and not eligible for public insurance, there are very few choices among health plans available in the individual market. Individual policies are expensive because they tend to attract sicker people who must attain some type of insurance in order to protect themselves from exorbitant out-of-pocket costs. Often people with HIV/AIDS cannot get coverage because plans that are not "community rated" can charge more for people with chronic illnesses, so the market essentially drives them out, or, in some states, explicitly denies them coverage. A 2001 study of a hypothetical person living with HIV with an otherwise perfect bill of health showed that when attempting to obtain individual coverage in regions across the country, the person with HIV was denied coverage from all 60 insurance companies that were approached.[64]

The benefits in employer-based coverage are eroding as the cost of employee health care rises, and employers are increasingly choosing less comprehensive plans to offer their employees, passing more of the costs to their employees, or not offering coverage at all. In 2003, premiums rose in the employer-based market by 13.9%.[65]

Veterans Administration

The Veterans Administration (VA) is a large provider of HIV/AIDS care in the U.S.; in 2001 the VA provided care to approximately 18,500 veterans with HIV/AIDS. In 2002, the VA spent $348 million on AIDS care. There is an HIV/AIDS coordinator in each of the VA's 163 hospitals nationwide, and the VA administers approximately 50,000 HIV tests each year.[66]

62 "AIDS Drug Assistance Programs (ADAPs) Fact Sheet." The Henry J. Kaiser Family Foundation, May 2004.
63 Kates, page 16.
64 Pollitz, Karen, Richard Sorian, and Kathy Thomas. "How Accessible is Individual Health Insurance for Consumers in Less Than Perfect Health?" Henry J. Kaiser Family Foundation, June 2001, page 19.
65 "Employer Health Benefits: 2003." The Henry J. Kaiser Family Foundation and Health Research and Educational Trust, 2003.
66 Kates, page 15.

Institute of Medicine Report

In May 2004, the Institute of Medicine released their long-awaited report entitled "Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White." The Committee was charged with analyzing the current financing and delivery of HIV care in the U.S., and assessing ways to make care more efficient, equitable, and attainable for people with HIV/AIDS. The committee concluded that the U.S. should institute the "HIV Comprehensive Care Program," a new federal entitlement for low-income people with HIV.

Before arriving at their conclusions, the committee found that the current financing system of HIV/AIDS care suffers from:

- Built-in regional disparities, which contradict the principle of a universal standard for HIV care;
- Fragmentation that leads to poor quality care;
- A federal/state partnership that does not acknowledge the national nature of the epidemic;
- Inefficiencies because the federal government is not fully responsible for its financing.

In designing a recommendation, the committee set out the following objectives:

- Ensure that low-income people with HIV have early and continuous access to medical and ancillary services;
- Promote the delivery of high quality services;
- Deliver services with low administrative costs;
- Financing and delivery of HIV services in the U.S. should meet established standards of treatment and promote positive health outcomes.

After considering alternative proposals, the committee recommended a new federal entitlement financed by the federal government and administered by the states:

1. The federal government should establish and fully fund a new entitlement program for the treatment of low-income individuals with HIV that is administered at the state level.
2. The new program should extend coverage for treatment to individuals determined to be infected with HIV whose family incomes do not exceed 250% of the federal poverty level. Individuals with HIV infection whose family incomes exceed this standard should be allowed to establish eligibility for coverage by spending down or by buying in on a sliding-scale basis.
3. The new program should entitle each eligible individual with HIV to a uniform, federally defined benefit package that reflects the standard of care for HIV/AIDS.
4. The new program should reimburse providers who elect to participate at rates comparable to those paid by Medicare for comparable services.
5. To ensure that the new program is a prudent purchaser of drugs used in the treatment of HIV/AIDS, the Congress should implement measures that lower the cost of these drugs, such as applying the Federal Ceiling Price or the Federal Supply Schedule price currently used by some major federal programs. Implementation of this recommendation would allow an estimated discount to Medicaid ARV prices of 9% to 25%.

6. The new program should adequately fund a nationwide demonstration of the effectiveness of Centers of Excellence in delivering covered services to eligible individuals with HIV.
7. The new program should coordinate closely with the Ryan White CARE Act, which should be refocused to meet the needs of low-income individuals who are not eligible to be served by the new program.[67]

The IOM study marks a radical departure from the way HIV services are currently funded and delivered in the U.S. Many questions remain about its structure, benefits, implementation, cost, and political viability; however, it provides a critical benchmark for a conversation about better addressing the health care access needs of people living with HIV/AIDS. It is also significant in that the IOM chose the creation of a new federal entitlement, as opposed to expansions of current systems of care, as the best way to address disparities in treating HIV disease.

Access to prescription drugs

Prescription drugs are arguably the most important part of AIDS care. People with HIV/AIDS access their drugs through many sources, including Medicaid, ADAP, private insurance, state pharmacy assistance programs, and the Veterans Administration. However, according to the Institute of Medicine, there are currently almost 59,000 people with HIV in the U.S. who lack access to HAART.[68]

Since 1990, U.S. spending for prescription drugs has tripled. There are several reasons for the rise in prescription drug costs: increased utilization of drugs, more expensive drugs on the market, and rising retail prescription prices, which have increased an average 7.3% a year from 1992 to 2002, more than double the inflation rate.[69] The pharmaceutical industry spends billions of dollars a year in advertising aimed at consumers and prescribers to maintain and expand its markets, and according to *Fortune* magazine, the industry remains the most profitable in the U.S.

Affordability of and access to prescription drugs has taken center stage at all levels of the health care policy debate. Contentious issues like whether or not the U.S. should reimport drugs from Canada, bargain with pharmaceutical companies for better drug prices, or shine more light onto the true costs of drug research and development are made even more complicated by the reliance of the HIV/AIDS community on drug companies that produce new breakthrough medications to fight HIV.

67 Institute of Medicine, Committee on the Public Financing and Delivery of HIV Care. "Public Financing and Delivery of HIV/AIDS Care." May 2004.
68 Institute of Medicine, "Public Financing and Delivery of HIV/AIDS Care," page 16.
69. "Prescription Drug Trends." The Henry J. Kaiser Family Foundation, May 2003.

Resources

For more information about the Presidential proposals, visit:

http://www.georgewbush.com/HealthCare/

http://www.johnkerry.com/issues/health_care/

"Health Care Reform Returns to the National Agenda: The 2004 Presidential Candidates' Proposals" by Sara R. Collins, Karen Davis, and Jeanne M. Lambrew http://www.cmwf.org/programs/insurance/collins_reformagenda_671.pdf

Gay Men's Health Crisis (GMHC) is a not-for-profit, volunteer-supported and community-based organization committed to national leadership in the fight against AIDS. Our mission is to reduce the spread of HIV disease, help people with HIV maintain and improve their health and independence, and keep the prevention, treatment and cure of HIV an urgent national and local priority. In fulfilling this mission, we will remain true to our heritage by fighting homophobia and affirming the individual dignity of all gay men and lesbians.

For copies of this report, please call 212/367-1228.

For information about our educational materials, please call GMHC Publications: 212/367-1205. For all other information, please call the Hotline or visit our website.

GAY MEN'S HEALTH CRISIS
The Tisch Building
119 West 24 Street
New York, NY 10011

AIDS HOTLINE:
1-800-AIDS-NYC (1-800-243-7692)
IN NYC: 212/807–6655
E-MAIL: hotline@gmhc.org
WEBSITE: www.gmhc.org

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