



Policy Brief: Critical Policy Challenges in the Third Decade of the HIV/AIDS Epidemic

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On June 5, 2001, the Kaiser Family Foundation and the Ford Foundation jointly sponsored a daylong Symposium to mark the 20th year of the HIV/AIDS epidemic and focus on the key challenges facing the United States at home and abroad in the epidemic's third decade. This policy brief continues the process begun that day by highlighting some of the challenges and approaches to addressing the epidemic, with a focus on the U.S. role. To access the web cast, agenda, and transcripts from the June 5 symposium, please go to www.kff.org/AIDSat20.

On June 5, 1981, the United States Centers for Disease Control and Prevention (CDC) reported the first cases of what would later be called acquired immunodeficiency syndrome, or AIDS.¹ Since that time, 774,467 cases of AIDS have been reported in the United States (U.S.), including more than 42,000 cases in the last year alone. There have been almost 450,000 AIDS-related deaths in the U.S.² An estimated 800,000 to 900,000 Americans are living with HIV, including over 320,000 who are living with AIDS, the most advanced form of HIV disease.³ With the introduction of more effective AIDS treatments, and resulting declines in AIDS deaths, an increasing number of people are living with HIV/AIDS in the U.S. However, new data from the CDC suggest that the era of sharp declines in AIDS deaths and new AIDS diagnoses in the U.S. has come to an end, raising concerns about the need to “re-energize” efforts to prevent new cases and to expand access to treatment.⁴

While HIV/AIDS is a national epidemic, it has had an especially severe impact on certain population groups, including gay and bisexual men⁵, injecting drug users and their sexual partners, young people, and racial/ethnic minority communities. People of color now represent the majority of new HIV infections (74%) and people living with AIDS (62%).^{2,3} The epidemic is also increasingly affecting

women and economically disadvantaged communities.⁶ Women represent an increasing proportion of new AIDS cases each year, with African American women making up 64% and Latinas making up 18% of new infections among women.³ Half of all new HIV infections are estimated to be among those under the age of 25.⁷ Moreover, there is mounting evidence that the geographic areas most severely affected by HIV/AIDS are communities with high poverty rates.^{6,8}

Globally, the epidemic has already claimed almost 25 million lives.^{9,10} Around the world, 40 million people are estimated to be living with HIV/AIDS, with most living in the developing world.¹⁰ HIV is now the number one cause of death in Africa and the fourth leading cause of death globally.¹¹ By 2020, HIV is expected to cause more deaths worldwide than any other infectious disease in world history.¹² In addition to this enormous public health impact, HIV/AIDS presents a development crisis for many nations and has been recognized as a security threat by the United Nations, the U.S., and other governments around the world.

The multiple threats posed by the epidemic have led to both domestic and global responses that have produced some significant progress. Despite

this, however, numerous challenges remain. This policy brief seeks to highlight some of the critical challenges and decisions that face the U.S. at home and abroad in the third decade of the epidemic:

Domestic Challenges:

- Reducing the number of new HIV infections in the U.S.
- Increasing the number of people with HIV/AIDS who are in care
- Paying for HIV/AIDS drugs and addressing rising drug expenditures
- Addressing the disproportionate impact of HIV on racial and ethnic minorities
- Stimulating research and development in pursuit of better treatments, effective vaccines and a cure
- Maintaining attention to the U.S. epidemic while also responding to the global crisis

Global Challenges:

- Identifying appropriate forms and amounts of U.S. assistance
- Balancing priorities: prevention, care, research, and infrastructure development
- Shaping the new Global Fund to Fight AIDS, Tuberculosis & Malaria to be effective, accountable for large resource commitments, and responsive to national and regional needs
- Promoting access to treatment in developing nations while also addressing U.S. intellectual property interests

Introduction

The U.S. has seen both a public and a private sector response to HIV/AIDS. The epidemic has required action by the federal government, states, cities and localities, school boards, and others. Private organizations – including community-based organizations, foundations, religious organizations, and individuals – have played a central role in the nongovernmental response. Of special importance has been the role played by people living with HIV/AIDS. People affected by the epidemic, particularly the gay and lesbian community, pioneered early efforts to build and support an infrastructure for responding to HIV.

The U.S. began appropriating federal funds to respond to HIV/AIDS in 1982 and by FY 2000, estimated spending totaled \$10.8 billion. Of this total, 71% went to care and assistance, 19% to research, 8% to prevention, and 2% to the global response.¹³ (See Exhibit 1). Apart from providing resources, Congress has also enacted a series of laws to address the epidemic (see Exhibit 2).

President Bush’s FY 2002 Budget proposed to increase funding for HIV-related research at the National Institutes of Health (NIH) by 12% over FY 2001 levels. The budget proposed a 3% increase in HIV-related prevention programs at the CDC, including a 1% increase in domestic prevention and an 11% increase in global prevention efforts. There was a proposed 10% increase for the major global AIDS activities conducted by the U.S. Agency for

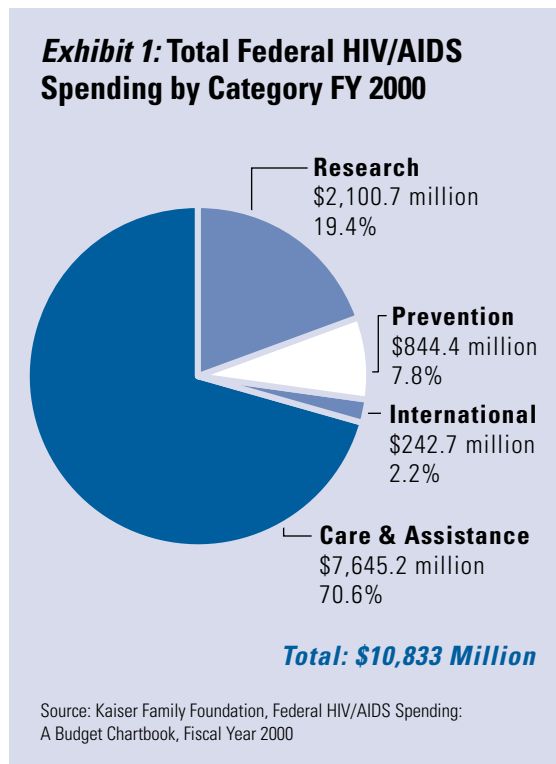


Exhibit 2: Key HIV/AIDS Related Laws

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 (Public Law 101-381) authorizes funds to “improve the quality and availability of care for individuals and families with HIV disease.” The CARE Act provides funding to cities, states, and other public and private non-profit entities to develop, coordinate, and operate systems of care. Congress has twice reauthorized the Act, which is currently authorized through September 2005.

The Americans with Disabilities Act of 1990 (Public Law 101-336) prohibits discrimination against any qualified individual with a disability – including people living with HIV/AIDS – in employment, public services, telecommunications, and public accommodations.

The Housing Opportunities for People With AIDS (HOPWA) Act of 1991 (Public Law 101-625) provides housing assistance to low-income people living with AIDS. Funds are allocated to states and cities.

The National Institutes of Health Revitalization Act of 1993 (Public Law 103-43) provides authority for a permanent, independent Office of AIDS Research at NIH and requires the director of that office to “act as the primary Federal official with responsibility for overseeing all AIDS research conducted or supported by NIH.”

The Ricky Ray Hemophilia Relief Fund Act of 1998 (Public Law 105-369) mandates a single payment of \$100,000 to any individual infected with HIV if the individual has any blood-clotting disorder and was treated with blood-clotting agents between July 1, 1982 and December 31, 1987.

The Ticket to Work/Work Incentives Improvement Act of 1999 (Public Law 106-170) enables states to create new Medicaid buy-in programs for working individuals with disabilities and authorizes state demonstration programs to provide Medicaid to workers with potentially severe disabilities, including HIV/AIDS, who are not yet disabled.

The Global AIDS and Tuberculosis Relief Act of 2000 (Public Law 106-264) authorizes funds for U.S. participation in the global response to HIV/AIDS, TB, and malaria.

International Development (USAID). No increase was proposed for the Ryan White CARE Act, which provides care and services to underserved families and individuals affected by HIV in the U.S.^{14, 15, 16, 17} (this brief was prepared before Congress took final action on FY2002 appropriations).

After two decades, the combined public and private sector effort has resulted in significant progress in the fight against HIV/AIDS including the identification of the viral agent that causes AIDS; the introduction of combination therapy, or highly active antiretroviral therapy (HAART), resulting in dramatic declines in AIDS-related mortality in the U.S. and elsewhere; the development of therapies that prevent and treat the many opportunistic infections that affect people with HIV; and the development of biomedical and behavioral interventions that can prevent the spread of HIV through sexual contact, needle sharing, and from mother-to-child during pregnancy and birth.

Despite these successes, many policy challenges remain. These challenges are complex and interrelated, domestic and global, and cut across the areas of prevention, care, and research. In some instances, policy options have been developed or are being considered.^{8,18,19,20,21} In other areas, the course of action is not yet clear. Some of the critical challenges and decisions facing the U.S. include the following:

Domestic Policy Challenges

Reducing the Number of New HIV Infections in the U.S.

Efforts to raise awareness about HIV/AIDS and change risky behaviors have helped to slow the number of new HIV infections in the U.S. from more than 150,000 per year in the mid-1980s to 40,000 today. Yet the U.S. has continued to experience about 40,000 new infections each year

since the early 1990s, a figure the CDC and others have called “unacceptably high.”¹⁸ The recent stabilization in the decline of AIDS cases and deaths is also of concern. CDC has set a national goal of reducing new HIV infections to 20,000 by 2005, with a particular focus on eliminating racial and ethnic disparities in HIV incidence.¹⁸

One underlying challenge to prevention efforts is that HIV transmission primarily involves sex and drug use, subjects with which many people – policymakers included – are uncomfortable. As a result, many prevention interventions have evoked controversy, perhaps best illustrated by the issues of sex education and syringe access policies in the U.S (see Exhibit 3).

Strategies for addressing prevention challenges include:

Targeting At-Risk Populations and Tailoring Interventions. Successful HIV prevention efforts have targeted at-risk populations with messages tailored to their cultural and social environment. In addition, there is increasing recognition of the critical importance of targeting prevention efforts to those who are HIV positive.¹⁸ The CDC recently launched the Serostatus Approach to Fighting the Epidemic (SAFE), aimed both at those who are already HIV-positive, as well as those who are uninfected.²² Targeted prevention efforts need to be sustained and continually assessed. With the advent of more effective treatments and the lessening of the fear of death, for example, the impact of earlier campaigns may be showing some signs of lessening, especially among younger men who have sex with men.²³

Reducing Stigma. Stigma associated with HIV disease, and the related stigmas of homophobia and negative attitudes toward drug users, persist. A third of Americans (33%) say they would be concerned that people would think less of them if they found out they had been tested for HIV and 28% say they would be uncomfortable working with someone who has AIDS.²⁴ Individuals who fear rejection or discrimination if their HIV status

were known may delay getting tested or seeking care. There is also evidence that stigma may contribute to risky behavior (e.g., unsafe sex and drug use).^{18,23} Public health experts have called for the expanded use of public education campaigns to raise awareness and reduce stigma.²¹

Integrating Prevention and Treatment. A recent Institute of Medicine report recommends integrating HIV prevention services into the clinical setting, particularly as a way to target prevention efforts to those who are already HIV positive.⁸ As with other preventive services, HIV prevention is often inadequately reimbursed by most public and private insurance programs. Primary care practitioners have few incentives to provide prevention counseling and services in their interactions with patients. Strategies for addressing the need for better integration of prevention in the clinical setting include mandating or encouraging the provision of HIV prevention services in public programs, such as Medicaid, and encouraging private purchasers to expand access to prevention services through the development of federal guidelines and purchaser education initiatives on the value of prevention.⁸

Prevention Research. Research into methods to provide new behavioral and clinical prevention strategies to people at risk for or living with HIV also are underway. These include behavioral research interventions designed to help people reduce their risk of infection, and research into the development of new methods of protection such as microbicides. Microbicides, a synthetic or natural substance designed to kill or neutralize HIV during sexual intercourse, could be especially important for women, who could initiate microbicide use on their own (unlike condoms).³¹

Increasing the Number of People with HIV/AIDS who are in Care

An estimated one-half to two-thirds of the 800,000 to 900,000 Americans living with HIV/AIDS are not in regular care. This is driven primarily by two

Exhibit 3: Prevention Politics: Sex Education and Sterile Syringe Access

Sex Education. Young people continue to be at risk for HIV and other STDs. School-based sex education is key way in which young people receive information about HIV/AIDS. A recent report on sexual health by Surgeon General David Satcher notes: “School education is a vital component in providing equity of access to information.”²⁵ Sex education in the U.S. primarily is guided by state and local policies with limited federal government involvement. State laws range from general mandates that some form of sex education be taught to more specific requirements about what messages should be included. Because state laws about sex education are fairly broad, the specifics of what is included in the curriculum often are left to local school districts or individual schools. Many communities continue to wrestle with the question of whether to provide “abstinence only” or more “comprehensive” sex education messages. Thirty-four states and the District of Columbia require schools to provide STD/HIV/AIDS education, with two limiting such education to abstinence only; of the sixteen that do not require sex education, three require that if sex education is offered, it must teach abstinence. According to national surveys, most Americans support a comprehensive approach to sex education.²⁶

Most direct federal funding for sex education has focused on the promotion of abstinence-only education. The Adolescent Family Life Act of 1981 provides funding for abstinence-only education and the welfare reform act of 1996 offers states \$50 million to fund abstinence-only programs. CDC has provided funding for HIV/AIDS education since 1988, and its guidelines emphasize a more comprehensive approach to sex education. However, five states recently signaled that they might not accept such funds because they do not promote an abstinence-only message, including one state that voted to return the funds.²⁷

Sterile Syringe Access. Injecting drug users, their partners, and their children account for at least 36% of all AIDS cases in the U.S. reported through 1999.¹⁸ A variety of approaches have been explored to reduce infection rates in this population including relaxing state laws restricting the possession and sale of clean syringes and establishing syringe exchange programs. As of 1998, there were 131 syringe exchange programs (SEPs) in the U.S. in 33 states, up from 68 in 1995.²⁸ Public opinion polls indicate that a majority of Americans support syringe exchange programs.²⁴ Ten states have laws that explicitly authorize the operation of syringe exchange programs.²⁹ Since 1988, the federal government has prohibited the use of federal funds to support SEPs, due to concern about that SEPs could lead to increased drug use. In 1998, after a review of the scientific literature, the Department of Health and Human Services concluded that syringe exchange reduced HIV transmission without increasing drug use but the ban on federal funding for SEPs was maintained.³⁰

factors: many Americans with HIV – up to one-third – do not know they are infected and, therefore, are not seeking needed care; and many people with HIV do not have access to insurance coverage or care to help them afford the high cost of HIV treatment and services, averaging as much as \$20,000 a year. HIV increasingly affects those who are poor, outside the workforce, and have a history of barriers to access. Even among individuals who have resources, the costs of HIV care can exhaust their assets and may leave them impoverished. As a result, people with HIV/AIDS increasingly are likely to rely on the public sector for their care.³² Strategies for addressing these issues include:

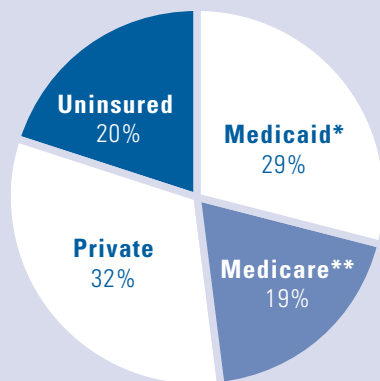
Increasing the Number of People who Know their HIV Status. U.S. Public Health Service guidelines call for voluntary and confidential counseling and testing for HIV in a variety of settings including private physicians’ offices,

clinics, and dedicated HIV testing sites. Yet recent CDC data indicate that a significant proportion of HIV positive Americans are first learning their status in the very late stages of infection, suggesting that they have gone for several years without appropriate treatment.³³ Seventy percent of Americans say they have not talked to their doctor about HIV/AIDS, and many report wanting more information about HIV testing.²⁴ A recent survey of teens found that many would not know where to go to get tested for HIV.³⁴ In addition, despite federal guidelines calling on doctors to routinely offer HIV testing to all pregnant women, a recent report showed that 40% of pregnant women were not offered HIV tests by their physicians.³⁵ Efforts to provide more information to the public about the benefits of testing, the types of tests available, and where to go to get tested may facilitate testing opportunities, as would targeted

provider education. New testing technologies, particularly rapid testing, may also facilitate testing in a variety of environments. Finally, efforts to reduce stigma and discrimination may also encourage people to learn their HIV status.

Increasing Access to Care and Coverage for People with HIV/AIDS. People with HIV/AIDS obtain care and coverage from a patchwork of public and private sources.³² About one-third of those in care have private insurance, more than half rely on public programs, and roughly a fifth are uninsured (see Exhibit 4).³⁶

Exhibit 4: People Living with HIV/AIDS in Regular Care: Estimated Insurance Coverage, 1996



*Does not include those who are also covered by Medicare.
**Includes those with other insurance, primarily Medicaid.
Source: Bozzette, S.A., et al., "The Care of HIV-Infected Adults in the United States", NEJM, Vol.339, No.26, 1998.

Public programs, particularly Medicaid, Medicare, and the Ryan White CARE Act, are critical sources of coverage and care for people with HIV/AIDS, especially those who are low-income. Policymakers are considering an array of approaches to expand public and private coverage. Some are specific to people with HIV/AIDS while others represent broader changes that stand to benefit many people

with access barriers including people with HIV/AIDS. Public approaches include expansion of entitlement programs (e.g., Medicaid and Medicare), in which spending for eligible individuals is based on the need for and cost of services, and discretionary programs (e.g., Ryan White), where the availability of services depends on the amount of money appropriated each year by Congress. Other options include market-based approaches to expand access to private insurance and coverage of the uninsured (see Exhibit 5). Some options for expanding access specific to people with HIV/AIDS have raised concerns about the equity of disease-specific expansions. In addition, proposals to expand public programs (e.g., Medicaid and Medicare) will be evaluated within the context of the overall costs of these programs.

Addressing the Disproportionate Impact of HIV on Racial and Ethnic Minorities

HIV/AIDS has disproportionately affected racial and ethnic minorities since the beginning of the epidemic, and that impact is growing. HIV is the leading cause of death for African Americans between the ages of 25 and 44 and the 3rd leading cause of death for Latinos in this age group.⁴¹ African Americans and Latinos represent approximately 12% and 14% of the U.S. population respectively, but 47% and 19% of new AIDS cases (see Exhibit 6).^{2,42}

The increasing concentration of the epidemic among minority Americans is due to many complex factors including social inequalities (related to income and race) and stigma associated with being gay or bisexual that exists within minority communities as well as in the larger society. These contextual forces may operate at the individual level to increase high risk behaviors or at the societal level by compromising community infrastructure for responding to the epidemic. There is a critical need to better understand where and why disparities occur, how these interrelated factors affect receptivity to prevention messages

Exhibit 5: Options for Expanding Coverage and Care to People with HIV/AIDS

Entitlement Approaches

Medicaid Coverage. Medicaid is a Federal-State program that provides health and long-term care coverage to three main groups of low-income Americans: the elderly, parents and children – particularly pregnant women – and the disabled. In addition to meeting these categorical requirements, individuals must also meet income requirements that vary from state to state. Medicaid is the single largest source of public financing for HIV/AIDS care in the U.S., covering more than half of all people with AIDS. For most low-income people with HIV, eligibility is limited to those who are already disabled. This presents a “Catch-22” for many people with HIV/AIDS, whose eligibility is postponed until they become disabled despite the availability of treatments that may prevent disability. Several options are being considered including:

- **Section 1115 Waivers.** Several states have applied for or are considering Medicaid Section 1115 waivers to expand eligibility to people with HIV prior to disability. Maine, Massachusetts, and the District of Columbia had been awarded waivers, but only Massachusetts’ program is operational. A major barrier to this strategy is that 1115 waivers must be “budget neutral” (i.e., the costs of the expansion over a designated period of time cannot exceed the costs to Medicaid in the absence of the expansion).
- **The Ticket to Work/Work Incentives Improvement Act of 1999.** The Ticket to Work/Work Incentives Improvement Act (TWWIIA) of 1999 included an option for states to launch demonstration projects to expand Medicaid benefits to workers with potentially severe disabilities, including HIV/AIDS, who are not yet disabled. Mississippi and the District of Columbia have been awarded approval for HIV-related demonstrations under the Act.
- **The Early Treatment for HIV Act.** Because of many of the barriers faced by states through the 1115 process and the limited nature of the TWWIIA demonstrations, Congress is considering The Early Treatment for HIV Act (ETHA). ETHA would create a new state option to expand Medicaid coverage to low-income people living with HIV who have not yet been classified as disabled, similar to legislation passed last year by Congress that gave states the option to provide Medicaid coverage to women diagnosed with breast and cervical cancer.³⁷

Medicare Coverage. Medicare is an increasingly important source of coverage for people with HIV/AIDS who are disabled and have sufficient work history to qualify for disability insurance. One challenge to accessing the Medicare program for people with disabilities, including HIV/AIDS, is the 29-month waiting period for benefits after disability has been determined. Proposals have been made to either waive or reduce the waiting period for people with HIV/AIDS. Congress took similar action last year for people suffering from Lou Gehrig’s Disease. Another challenge within the Medicare program is the lack of an outpatient prescription drug benefit in the Medicare program. Lawmakers have debated options for adding a prescription drug benefit to the Medicare program.

Discretionary Approaches

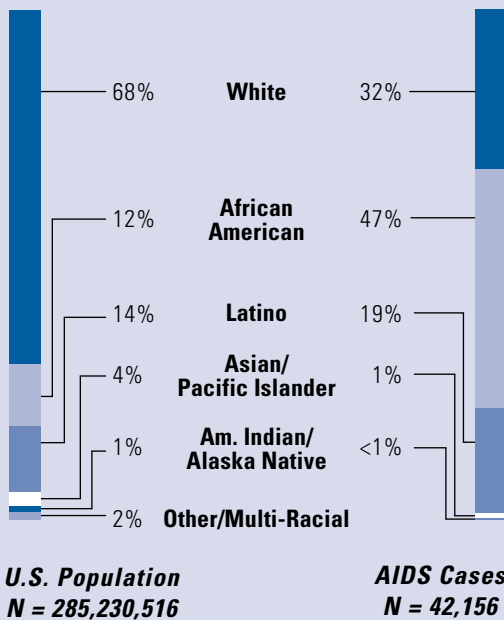
Ryan White CARE Act. The Ryan White Care Act is a vital source of care for people with HIV/AIDS who are uninsured and underinsured. As the number of people living with HIV/AIDS continues to grow and the cost of care increases, demand for CARE Act services is also increasing. In FY 2001, Congress appropriated \$1.8 billion for the Act, an increase of more than \$200 million from FY 2000. The President’s FY 2002 budget proposal did not include an increase for Ryan White.

Market-Based Approaches

Covering the Uninsured. One fifth of people with HIV/AIDS in care are uninsured.³⁶ Policymakers are considering several approaches to reducing the overall number of people who are uninsured, including people with HIV/AIDS, such as offering refundable tax credits or direct subsidies to assist consumers in purchasing private insurance coverage.³⁸

Private Insurance Coverage. People with HIV often have a difficult time obtaining or retaining private coverage unless they are employed. A recent study of the individual insurance market indicated that people with HIV are considered “uninsurable” and routinely rejected when they apply for coverage.³⁹ The Health Insurance Portability and Accountability Act of 1996 established basic national standards for insurance regulation in the small group market and to a lesser extent in the individual insurance market, but many barriers remain. Some states have enacted laws limiting insurers’ underwriting practices by requiring insurers to sell policies to anyone who can pay the premium and by utilizing community rating or rating bands to limit premium increases.^{32,40}

Exhibit 6: U.S. Population by Race/Ethnicity and Newly Reported AIDS Cases, 2000



* May not total 100% due to rounding.
 NOTE: White, African American, Asian/Pacific Islander, American Indian/Alaska Native, and other/multi-racial groups do not include those of Hispanic origin. In the 2000 Census, individuals were allowed to report more than one racial category. In this Exhibit, individuals who reported more than one racial category are included in "other/multi-racial."
 SOURCES: Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, Year-End Edition Vol. 12, No.2; U.S. Bureau of the Census, Profile of General Demographic Characteristics: 2000; U.S. Bureau of the Census, Profile of General Demographic Characteristics: 2000 - Puerto Rico

and health care access, and whether people of color are being adequately served by public programs, particularly Medicaid and Ryan White.

Understanding the views of minority leaders and minority communities toward HIV/AIDS is important for informing the response to the epidemic. A recent survey of Black Elected Officials (BEOs) found that BEOs see HIV/AIDS as a more urgent problem in their communities than in recent years and support the involvement of all sectors in responding to the epidemic including all levels of government, religious organizations, schools, and parents.⁴³ A national survey of Americans found that African Americans and Latinos were more likely to express a sense of urgency and concern about the epidemic than whites, and also

supported involvement by the public and private sectors. However, the proportion of African Americans, Latinos, and whites ranking AIDS as the number one health problem facing the nation has declined somewhat over time, although African Americans still ranked AIDS as number one.²⁴

Several federal initiatives have been created to specifically address the disproportionate impact of HIV on racial and ethnic minorities, including the Minority HIV/AIDS Initiative (MHAI), the Leadership Campaign on AIDS (TLCA) and Crisis Response Teams (CRT). Adopted by Congress in 1999, the MHAI provides funds to community-based organizations, faith communities, research institutions, minority-serving colleges and universities, health care organizations, state and local health departments, and correctional institutions to help them address the HIV/AIDS epidemic within the minority populations they serve.⁴⁴ A key purpose of the MHAI is to enhance community capacity and infrastructure to respond to the epidemic. In FY 2001, Congress appropriated \$350 million for these efforts, an increase of nearly \$100 million from FY 2000. President Bush's FY 2002 budget called for a 1% increase. The Congressional Black Caucus called for a \$540 million, or more than a 50% increase, over the current year.

In recognition of the importance of involving leaders, The Leadership Campaign on AIDS is designed to galvanize minority community leadership to address the epidemic by building partnerships with minority communities and organizations in an effort to educate and mobilize public and private sector leaders. The Crisis Response Teams Initiative provides technical assistance to cities where racial and ethnic minorities have been hard hit by HIV/AIDS and works with these communities to quickly develop programs to address the epidemic's impact.

Paying for HIV/AIDS Therapies and Addressing Rising Drug Expenditures

Spending on prescription drugs is one of the fastest growing components of U.S. health care spending.⁴⁵ Spending on HIV-related therapies – both therapeutic and prophylactic – is no exception. Rising spending on these therapies is due to three main factors: increasing utilization of medications as more people are living with HIV/AIDS and seeking access to medications; the move to more complex, multi-drug treatment or drug mix; and rising prices. Because access to medications is critical for people with HIV/AIDS and these drugs are expensive, concerns about rising expenditures and the price of prescription drugs have been raised. Several questions face policymakers including: Are there mechanisms for purchasing drugs at lower prices, such as purchasing in bulk or through rebate programs? Should government be involved in limiting or controlling drug prices? Should the public and private sectors' respective investments in drug research be considered in determining drug pricing (several AIDS drugs, including AZT, have been developed as a result of significant public investment)? Are there ways to use existing resources more efficiently, such as purchasing or continuing private insurance coverage for people with HIV? These issues are of primary concern to the two major programs that provide medications to people with HIV/AIDS in the U.S. – Medicaid and the AIDS Drug Assistance Program (ADAP) of the Ryan White CARE Act:

Medicaid. Medicaid is a critical source of medications for people with HIV/AIDS. Forthcoming data from the Kaiser Family Foundation indicate that Medicaid spending on antiretrovirals represents a small but significant portion of overall Medicaid prescription drug spending and expenditures have risen rapidly over the past decade.⁴⁶ A recent report by the HHS Office of the Inspector General (OIG) found that Medicaid pays more for AIDS drugs than other government programs (e.g., Ryan White and the Department of

Veterans Affairs) and recommended that Medicaid have access to lower federal prices and that states review payment approaches.⁴⁷ A number of states are trying to negotiate additional drug price discounts for their overall Medicaid programs, and some specifically for AIDS drugs. Maine has actively sought additional AIDS drug price discounts from pharmaceutical manufacturers in order to help pay for an expansion of Medicaid eligibility; the District of Columbia is seeking access to federal Department of Defense pricing in an effort to do the same thing.

ADAP. A key part of the Ryan White CARE Act pays for AIDS drugs through state-run AIDS Drug Assistance Programs (ADAPs). In recent years, Congress has sharply increased ADAP funding to \$589 million in FY 2000. Still, increasing demand and expenditures have caused some states to limit access to ADAPs through waiting lists, formulary restrictions, and other mechanisms. Strategies for limiting costs include restructuring drug purchasing and distribution systems, better coordination with Medicaid, seeking voluntary manufacturers' rebates, negotiating discounts with pharmacies, and using funds to purchase or continue private health insurance coverage.^{40,48,49}

Stimulating Research and Development of Vaccines, Therapeutic Drugs, and Other Interventions

Despite significant public investment and progress in HIV research, there is no cure for HIV, no vaccine against the virus, and available treatments, while effective for many, do not help everyone and often have severe side effects. There is a great deal to learn about how to use existing pharmaceuticals safely and appropriately; about long-term toxicities of the multiple medications that are being prescribed for people living with HIV; and about the development of drug resistance. Priority research areas include vaccine, prevention, microbicide, and therapeutic research (See Exhibit 7). Congress, in recent years, has shown a strong commitment to

increasing appropriations for research, including for HIV/AIDS. HIV/AIDS research at NIH received \$2.24 billion in FY 2000. President Bush has proposed increasing that to \$2.5 billion in FY 2002.

Policymakers are faced with a complex array of decisions and choices concerning research and development: What is the role of the federal government in conducting therapeutics research vis à vis private pharmaceutical and biotechnology companies? What is the best way to allocate public research dollars for basic science research versus clinical research? Are public dollars – or public policies – leading to research that can answer some of the questions about long-term toxicities, resistance, etc.? Since barriers prevent private firms from aggressively conducting vaccine research, should federal policymakers fund this research directly or try to incentivize private research (e.g., through tax credits)?

Maintaining Attention to the U.S. Epidemic while also Responding to the Global Crisis

The scope of the global pandemic and its affect on nations, communities, families, and individuals throughout the world have not been seen in modern times. Both the public and private sectors continue to be challenged with the need to step up efforts to respond to the global pandemic. At the same time, maintaining attention to the epidemic in the U.S., including public awareness and concern, remains critical. A recent national survey found some limited signs of “AIDS fatigue”. Although Americans still rate AIDS as a top health concern for the nation, the proportion of Americans citing AIDS as the number one health problem has declined over the past few years.²⁴ In addition, a recent report on the role of private philanthropy in responding to the epidemic found that while philanthropic support of global AIDS efforts is on the rise, support for domestic efforts has not increased.⁵¹ It is within this context that attention

Exhibit 7: HIV/AIDS Priority Research Areas

Vaccine Research. The U.S. government spent an estimated \$240 million on AIDS vaccine research in FY 2000 and President Bush has proposed increasing that to \$357 million in FY 2002. To date, over 60 phase I/II trials of 30 candidate vaccines have been conducted worldwide, but an effective vaccine is still several years away.⁵⁰ In addition to research challenges to finding effective vaccines, there are also questions related to the need to stimulate the R&D process, pricing, distribution, and liability. Lawmakers are considering offering tax credits to vaccine manufacturers to aid in the R&D process. Some have called on Congress to begin debating these issues now so that solutions are ready if and when vaccines are approved for use in humans.

Prevention Research. Prevention research priorities include research into the management of sexually transmitted diseases; perinatal prevention, including enhancing understanding of breast-feeding risk; and the development of topical microbicides (see below). In addition, understanding how to assist people in changing behaviors that place them at risk for HIV infection is a critical priority.

Microbicide Research. The development of topical microbicides – a synthetic or natural substance that can kill or neutralize HIV during sexual intercourse – is a high priority for many researchers. Spending on microbicide research was \$28 million in FY 1999. Legislation pending in Congress – the Microbicides Development Act – would increase microbicide funding to \$100 million a year by 2003.³¹

Therapeutic Research. A significant proportion of people with HIV/AIDS have not benefited from current HIV therapies. In some cases, the drugs do not appear to work at all; in others, the drop in HIV viral load is temporary and appears to wear off. Among those who are able to tolerate the drugs, there are a growing number of complications including lipodystrophy (re-distribution of fat cells within the body and the deposition of dangerously high levels of fat in the trunk), heart and liver ailments, and other conditions. Development of new therapies, therefore, continues to be important.

to the domestic epidemic must be considered, including questions about whether public and private sector entities – the different levels of government, faith-based groups, corporations, schools, health care providers, private philanthropies – should be doing more to respond to the epidemic in the U.S.

Global Policy Challenges

This section focuses specifically on the U.S. role in responding to the challenges presented by the global epidemic. Addressing the many challenges that also face international organizations and individual nations is beyond the scope of this policy brief.

The global effort to fight AIDS needs both leadership and resources (human and financial). In FY2001, the U.S. allocated \$622.5 million to global HIV/AIDS programs, making it the largest contributor to these efforts (see Exhibit 8). Other nations have, however, contributed more in terms of spending as a proportion of their gross national product.⁵² The role of foundations has been significant and philanthropic support for global AIDS efforts has risen over the past several years.⁵¹

In its first few months, the Bush Administration has announced its desire to play a leadership role in fighting HIV/AIDS in the developing world and in devoting increased resources to global efforts. Among the challenges facing the U.S. in responding to the global epidemic are:

Identifying Appropriate Forms and Amounts of U.S. Assistance

The U.S. allocates funding and other resources used to address the global epidemic in several ways, including direct financial assistance to other countries, support for multilateral organizations such as the Joint United Nations Programme on

HIV/AIDS (UNAIDS), broader forms of development assistance, debt relief, loan programs, technical assistance, and in-kind support (see Exhibit 9). To date, the bulk of U.S. foreign assistance to the global pandemic has been in the form of bilateral assistance to other nations, through U.S. Agency for International Development (USAID).

While the level of spending and other resources made available is clearly a fundamental component of the U.S. response, others include the mechanisms by which resources are allocated and the services, programs, and issues to which they are targeted.

One of the major barriers facing many developing nations' ability to respond to the epidemic is their foreign debt. UNAIDS has stated that annual debt servicing obligations have displaced spending on HIV/AIDS and other health and poverty reduction programs.⁵³ As a result, many developing nations consider grants and debt relief to be more viable options than loans. Last year, for example, when the U.S. Export-Import Bank announced plans to provide \$1 billion in loans per year over a five-year period to support the purchase of HIV/AIDS medications made

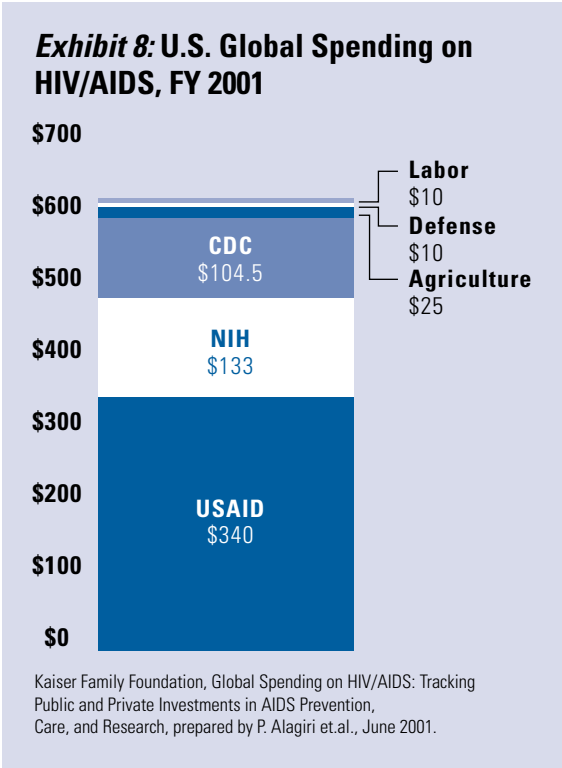


Exhibit 9: Forms of U.S. Foreign Monetary and Other Assistance for HIV/AIDS

U.S. Agency Activity. Several U.S. agencies oversee and engage in global AIDS activities and programs, including the State Department, USAID, CDC, NIH, and the Peace Corps. The State Department provides overall direction for U.S. global HIV/AIDS policies, including policy guidance to USAID, an independent agency. USAID implements U.S. foreign economic and humanitarian assistance programs, and provides the bulk of bilateral assistance for addressing the epidemic in developing countries. The CDC supports HIV/AIDS prevention and prevention research activities around the world as part of the U.S. response to the global pandemic. Much of CDC's activities involve technical assistance conducted in partnership with USAID. NIH conducts and funds international HIV/AIDS research efforts. The Peace Corps, which places volunteers around the world, recently launched a new education effort to train volunteers to provide HIV prevention and care services.

Direct Assistance Through Government-to-Government Agreements and Bilateral Aid. A key strategy of USAID is to form bilateral working relationships with governments around the world to cooperatively conduct prevention, care, and research programs. This approach to development assistance is based on promoting broad-based economic growth through policy analyses, technical assistance, and training. In addition, emergency relief is structured to help nations make the transition to sustainable development. In addition to developing working relationships, the U.S. also provides bilateral support directly to governments to address HIV/AIDS.

Contributions to Multilateral Programs. The U.S. also contributes to multilateral programs, such as UNAIDS, the World Bank, and the Pan American Health Organization. The newly proposed Global Fund represents the creation of a new multilateral program. The Global Fund has received pledged contributions from the U.S. and other country donors as well as the private sector.

Loans to Developing Countries. Loans are another mechanism used by the U.S. and others to provide international assistance. Last year, the U.S. Export-Import (Ex-Im) Bank announced plans to provide \$1 billion in loans per year for five years to support the purchase of HIV/AIDS medications made in the U.S. The Ex-Im Bank also announced that it would increase the standard repayment terms for HIV/AIDS pharmaceutical sales in these countries from six months to five years.

Debt Relief. According to the World Bank, 33 of the world's 41 most heavily indebted countries are in Africa with a total debt of \$230 billion.⁵⁴ There is a growing movement on the part of developed nations to forgive all or part of that debt. Debt relief can enable developing nations to spend more of the resources on health programs addressing HIV/AIDS. Such efforts are also focusing on ways to ensure that debt relief results in commitments by host countries to use resources for health-related initiatives. Last year, Congress approved nearly \$450 million in debt relief for developing nations, primarily in sub-Saharan Africa. Pending legislation – the Debt Cancellation for HIV/AIDS Response Act (H.R. 1567) – would allow the U.S. to instruct its directors at the World Bank and the International Monetary Fund to advocate for debt relief efforts.

Direct Assistance to Non-Governmental Organizations (NGOs). Non-governmental organizations (NGOs) play a critical role in many nations' response to the epidemic. Providing financial and non-financial assistance to such organizations enhances their ability to respond to local needs and ensures more accountability for U.S. resources. Many of USAID's activities, for example, target NGOs either directly or through other organizations in an effort to build their capacity and provide technical assistance. Some U.S. NGOs have also begun to form partnerships with NGOs in other nations.

in the U.S., many developing nations expressed reluctance to seek such loans because of their already high levels of debt. More recently, the Bush Administration and others have called on the World Bank and other multilateral lending organizations to increase the proportion of funding available in the form of grants. There is also a growing move on the part of developing countries to forgive debt, and options are being explored to connect debt relief

efforts to specific health programs, including those addressing HIV/AIDS.

Other forms of support, including technical assistance, knowledge-transfer (e.g., in terms of research advances), identification of best-practice interventions, and capacity building at the local level, including with non-governmental organizations (NGOs), are important strategies for

helping developing nations respond to the epidemic. USAID currently supports several activities that provide these types of support to developing nations, NGOs, and the organizations that work with them.

As the U.S. makes decisions about providing assistance, there is also a need to understand the social and political context in which the epidemic occurs among different populations, regions, and countries. As part of this assessment, the response to the epidemic can be informed by lessons learned from the broader field of international development. Finally, there is a need to assess how other policy decisions may affect the response to the epidemic. For example, critics have suggested that the Administration's reinstatement of the "Mexico City Policy," barring the use of U.S. family planning funds by organizations that "promote abortion" may have adverse consequences for organizations that also provide HIV-related services in the developing world.

Shaping the Global Fund to Fight AIDS, Tuberculosis & Malaria to be Effective, Accountable for Large Resource Commitments, and Responsive to National and Regional Needs

In April 2001, U.N. Secretary-General Annan laid out a plan to create a Global Fund of \$7 billion to \$10 billion to mobilize and coordinate resources in the fight against HIV/AIDS, tuberculosis (TB) and malaria.⁵⁵ In May, President Bush made the first formal pledge to this Fund, promising an initial \$200 million in FY 2002 funds.⁵⁶ Congress already appropriated \$100 million as part of a FY 2001 supplemental appropriations bill that the President signed.⁵⁷ While the Global Fund presents a highly significant development, many details must still be resolved, including its mission and scope, its governance structure, accountability issues, guidelines for the use and targeting of funds, and the level of funding needed. U.S. policymakers, foundations, and research and community

organizations are playing important roles in helping to define the parameters of the Global Fund working through a Temporary Working Group (TWG). Key decisions and issues include:

Mission & Scope: Discussions are underway to identify the mission and scope of the Global Fund. In his initial proposal, U.N. Secretary-General Annan laid out five objectives: 1) To ensure that people everywhere know how to prevent infection; 2) To stop mother-to-child HIV transmission; 3) To provide care and treatment for all persons infected; 4) To redouble the search both for a vaccine and a cure; and 5) To protect persons made most vulnerable by the epidemic, especially children orphaned by AIDS. Largely at the request of the U.S. and the European Union, the scope was broadened to include tuberculosis and malaria.

Governance/Structure: Decisions are being made about how the Global Fund will be governed. Preliminary plans call for the Fund to be governed by a small, independent board made up of governments from donor and developing countries, non-governmental organizations, the private sector, and the U.N.⁵⁸ Another key issue will be the representation of people living with HIV, TB, and malaria in the governance of the Global Fund.

Amount and Sustainability of Funds: To date, the Global Fund has received more than \$1.4 billion in pledged contributions from nations, individuals, and private sector entities, including foundations.⁵⁹ Efforts to obtain additional pledges continue, and will need to be sustained over time.

Accountability: A key to winning financial support is the ability of the Global Fund to demonstrate that its funds will be well spent. Initial plans call for transparency and accountability, but mechanisms for achieving these principles have not yet been finalized.

Allocation, Eligibility and Use of Resources: Additionally, questions remain regarding what types of entities will be eligible to receive funding. Will funds be available to governments, NGOs, or both? Should donors be able to earmark funding?

Stakeholders also are discussing how funds will be allocated across prevention, treatment, and infrastructure development. A critical consideration will be whether to allow resources from the Global Fund to purchase, or provide grants to purchase, generic drugs and whether to allow the Global Fund to support bulk purchasing efforts.

The Role of the Global Fund in the Context of Other Global AIDS Efforts: Finally, there are important questions about the role of the Global Fund in the larger context of other global AIDS and development efforts. The U.S. government and other donors, including corporations and foundations, provide support to global efforts through several mechanisms. Some stakeholders have raised concerns that money committed to the Fund be new money, rather than funding redirected from other health and international development budgets. Some donors have expressed a desire to fund global AIDS efforts directly or outside of the Global Fund, again underscoring the importance of viewing the Global Fund within the broader context of international HIV/AIDS funding. U.N. Secretary-General Annan and interim leadership of TWG have responded by calling for the Global Fund to be additive to current bilateral and multilateral efforts, and by clarifying that the Fund is not intended to be the only mechanism for responding to these three diseases.

Balancing Priorities: Prevention, Care, Research, and Infrastructure Development

Research, care and prevention are integral components of an effective global or national HIV/AIDS strategy, and understanding the often complex relationships between them is critical to responding to the epidemic. For example, care and treatment can play a fundamental role in helping to make HIV prevention strategies more effective, both by providing opportunities to encourage safer behavior among those who are already infected and by offering hope and an incentive to get tested to those who do not know their HIV status.

However, some studies indicate that the availability of more effective therapies in the U.S. may have led some individuals to engage in risky behaviors, due to their perception that treatments are available if they become infected. Further analysis can offer important lessons for introducing therapies in other countries.

In pledging U.S. support for the new Global Fund, President Bush advocated “an integrated approach that emphasizes prevention and training of medical personnel as well as treatment and care.” The President noted, “Prevention is indispensable to any strategy of controlling a pandemic such as we now face.”⁵⁶ This approach has been echoed by a broad range of international leaders, including U.N. Secretary-General Annan. A recent international leadership forum on HIV prevention, sponsored by the Kaiser Family Foundation, the Ford Foundation, and the Gates Foundation, concluded that: “The global community must pursue a comprehensive strategy to fight AIDS. Prevention, care and treatment, and research are all essential components of an effective global response to AIDS.”⁶⁰ To date, the majority of U.S. government spending on HIV/AIDS in developing countries has been for prevention, with few resources allocated to care.⁶¹ As the U.S. seeks to promote an integrated approach to the global pandemic, it will need to look at ways to foster public-private partnerships that support care and research in developing countries.

The issue of health care infrastructure is fundamental to these considerations. Definitions of “infrastructure” include such elements as the availability of health centers and facilities, roads, equipment, supply systems, water, security, and stability of government. There has been some reluctance on the part of the U.S., other nations, and the private sector to provide increased or new support for certain interventions, particularly treatment interventions, in developing countries due to concerns about existing infrastructure. Even if treatment and prevention interventions become broadly available in developing countries, limited

infrastructure may hinder delivery in some areas. Some have argued that providing low-cost or free drugs should wait until infrastructure issues are addressed. Others note that while many developing nations may not have Western-style health care delivery systems, they can deliver needed services. Some believe that the availability of treatment would encourage infrastructure development. These conflicting views point to the need to improve the understanding of the role of infrastructure in delivery of prevention and treatment interventions in the developing world and to identify ways to support infrastructure enhancements. It will be important to gain experience in implementing infrastructure development initiatives—and to assess the level of infrastructure needed for different types of interventions. The experience of Brazil's National HIV/AIDS Program, as well as other pilot programs throughout the world, demonstrate models for effectively delivering HIV medications and primary health care in resource-poor settings.

Promoting Access to Treatment in Developing Nations While Addressing U.S. Intellectual Property Interests

The last year has witnessed important progress in removing barriers to access to treatment for people living with HIV in developing countries.

Nonetheless, the cost of antiretroviral and other medications far exceeds what is affordable for most individuals in these countries. High costs are in part related to intellectual property rights laws, which provide twenty years of market exclusivity to manufacturers. Pharmaceutical manufacturers have said that this period allows them to recoup research and development costs. Others argue that this period allows drug makers to earn large profits. This has raised concerns about the need to balance these protections with greater access to medications especially in poor nations in the developing world. Because many pharmaceutical manufacturers are U.S.-based companies or have

substantial operations in the U.S., the role of U.S. trade policy has become central to discussions about enhancing access in developing countries.

The U.S. position in this area is not yet fully resolved and decisions are still being made regarding how these interests will be balanced. In February 2001, President Bush signaled his intention to maintain a Clinton Administration Executive Order, first signed in May 2000, which clarifies U.S. policy with regard to intellectual property rights and drug access in sub-Saharan Africa. Under that policy, the U.S. will not invoke its trade laws concerning patents for pharmaceuticals. Instead, the U.S. will hold sub-Saharan African countries to standards set by the World Trade Organization (WTO).⁶² The recent White House statement about the Global Fund, however, indicated the U.S. belief that the Fund must respect intellectual property rights as an incentive for research and development.⁶³ The most recent annual review of intellectual property protection, released by the U.S. Trade Representative (USTR), emphasized the need for both protection of property rights and the need for responding to health emergencies.⁶³

Within this context, several strategies are being explored to enhance access to treatment including the purchasing of generic drugs, bulk purchasing, parallel importation, compulsory licensure, and tiered pricing. Many major pharmaceutical manufacturers do not support these strategies, although several have announced plans to offer reduced drug prices in developing countries. As these questions are unresolved, it is anticipated that intellectual property issues will continue to arise as new programs are implemented to make HIV pharmaceuticals available in the developing world.

Conclusion

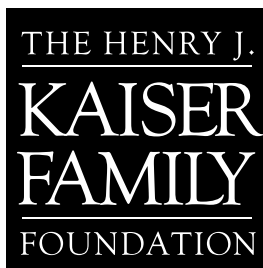
Despite significant progress in addressing the HIV/AIDS epidemic over the past two decades, policymakers, public health experts, communities, and advocates continue to be faced with tremendous challenges. These challenges traverse both the domestic and foreign policy arenas, and include long-standing questions about care and treatment, prevention, and research as well as new ones introduced by the changing nature of the epidemic itself and the need to balance demands for more limited resources. This policy brief has sought to highlight some of the most critical challenges facing the U.S., in an effort to inform current discussions about resources, leadership, and direction in responding to the epidemic at home and abroad over the next decade.

Prepared by Richard Sorian and Jeffrey Crowley of the Georgetown University Institute for Health Care Research and Policy and Jennifer Kates of the Kaiser Family Foundation

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The Henry J. Kaiser Family Foundation

2400 Sand Hill Road
Menlo Park, CA 94025
Tel: (650) 854-9400
Fax: (650) 854-4800

Washington office:
1450 G Street, N.W., Suite 250
Washington, DC 20005
Tel: (202) 347-5270
Fax: (202) 347-5274

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