

# HIV/AIDS POLICY IN THE United States



Monitoring the UNGASS Declaration of Commitment on HIV/AIDS

*A series of reports on HIV/AIDS policy in  
Nicaragua, Senegal, Ukraine, the United States, Vietnam, and Zambia*

**PUBLIC HEALTH WATCH**



OPEN SOCIETY INSTITUTE



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Front cover (clockwise from left) Luke Wolagiewicz, WPN: support group for people living with HIV/AIDS, Ukraine; Donna DeCesare: 16-year-old living with HIV, and his mother, Central America; Gideon Mendel, Corbis: HIV-positive patients at health clinic, Southern Africa; Associated Press, AP: women and children living with HIV and AIDS at a drug rehabilitation center, Vietnam.

Back cover (top to bottom) Associated Press, AP: lab assistant tests blood for HIV, Senegal; Associated Press, AP: coordinator with ACLU National Prison Project talks with people in the HIV/AIDS Housing Unit at Mississippi State Penitentiary.

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# Preface

In June 2001, at the United Nations General Assembly Special Session on HIV/AIDS (UNGASS), 189 national governments, including the United States of America, adopted the Declaration of Commitment on HIV/AIDS. The document commits governments to improve responses to their domestic AIDS epidemics and sets targets for AIDS-related financing, policy, and programming.

The Declaration also stipulates that governments conduct periodic reviews to assess progress on realizing their UNGASS commitments. In recognition of the crucial role civil society plays in the response to HIV/AIDS, the Declaration calls on governments to include civil society, particularly people living with HIV/AIDS, in the review process.

Public Health Watch, established by the Open Society Institute in 2004, supports independent, civil society monitoring of government compliance with international agreements on improving public health. With respect to HIV/AIDS, Public Health Watch is assessing government policies vis-à-vis the UNGASS Declaration. Public Health Watch also supports civil society monitoring of government tuberculosis (TB) and TB/HIV policies, examining compliance with the Amsterdam Declaration to Stop TB and the *Interim Policy on Collaborative TB/HIV Activities* of the World Health Organization (WHO).

For the HIV/AIDS Monitoring Project, Public Health Watch partners in Nicaragua, Senegal, Ukraine, the United States, Vietnam, and Zambia have prepared assessments of national HIV/AIDS policies based on a standardized questionnaire, which facilitates structured review of governmental compliance with key elements of the UNGASS Declaration.

The Public Health Watch methodology incorporates multiple opportunities for dialogue and exchange with a broad range of policy actors during report preparation. Researchers convene an advisory group of national HIV/AIDS experts, activists, and policy actors. They prepare draft reports on the basis of input from the advisory group, desktop and field research, interviews, and site visits. Researchers then organize in-country roundtable meetings to invite feedback and critique from policymakers, academics, government officials, representatives of affected communities, and other key stakeholders. Finally, Public Health Watch supports researchers in conducting targeted advocacy at the domestic and international levels around their report findings and recommendations.

To access the reports of the HIV/AIDS Monitoring Project or to learn more about Public Health Watch, including the TB Monitoring Project to assess compliance with the Amsterdam Declaration to Stop Tuberculosis and the TB/HIV Monitoring and Advocacy Project around the WHO's *Interim Policy on Collaborative TB/HIV Activities*, please see: [www.publichealthwatch.info](http://www.publichealthwatch.info).

# Acknowledgments

This report on United States domestic HIV/AIDS policy was researched and written by Chris Collins, an independent consultant to the Open Society Institute. The staff of Public Health Watch prepared the overview report and provided editing and administrative assistance. Additional editing and production assistance was provided by the Communications Office of the Open Society Institute.

We would like to acknowledge the significant contributions of the U.S. Advisory Board, both in helping conceptualize the U.S. report and reviewing earlier drafts of the document.

Public Health Watch organized roundtable meetings in Washington, D.C., on February 13, 2006, and in Atlanta on March 20, 2006. OSI would like to give special thanks to staff at the OSI-Washington, D.C., office and Dazon Dixon Diallo and Phill Wilson for their assistance in organizing and hosting these meetings. We would also like to thank all the roundtable participants and staff of OSI's Network Public Health Program, whose comments and suggestions were invaluable in finalizing this report.

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**I.**

**PUBLIC HEALTH WATCH**

**Overview**

The Public Health Watch HIV/AIDS Monitoring Project partners with civil society organizations in Nicaragua, Senegal, Ukraine, the United States, Vietnam, and Zambia to monitor and advocate for improved governmental efforts to comply with the UNGASS Declaration of Commitment on HIV/AIDS. This overview report highlights some of the overarching experiences and findings of Public Health Watch partners in these six countries.

Most Public Health Watch researchers found that their ability to participate and provide input into the research and preparation of governments' UNGASS progress reports was limited. On a substantive level, not all countries have adopted comprehensive national strategies in accordance with their UNGASS commitment. There is a lack of sufficient coordination among federal and local governments, the private sector, and civil society (as well as among civil society organizations) in many countries. Prevention efforts often fail to target the most at-risk communities such as injection drug users, sex workers, and racial/ethnic minorities, and there is still insufficient and inequitable access to treatment, care, and support in all six countries.

## **UNGASS Declaration of Commitment on HIV/AIDS**

The 2001 UNGASS Declaration of Commitment represents a milestone in the fight against HIV/AIDS. With the Declaration, 189 governments joined to declare the HIV/AIDS epidemic “one of the most formidable challenges to human life and dignity,” and to state their commitment to “enhanc[e] coordination and intensification of national, regional, and international efforts to combat it in a comprehensive manner.”<sup>1</sup>

The Declaration articulates the need for strong leadership and multisectoral national strategies and financing plans,<sup>2</sup> and sets forth a range of specific targets related to prevention, treatment, care, and support.<sup>3</sup> It emphasizes that an effective response to HIV/AIDS must be grounded in respect for the rights of people living with HIV/AIDS<sup>4</sup> and give priority to vulnerable groups such as women, children, and “other groups at greatest risk of and most vulnerable to new infection” as identified by “public health information.”<sup>5</sup>

Governments also committed themselves to undertake “national periodic reviews with the participation of civil society, particularly people living with HIV/AIDS, vulnerable groups and caregivers, of progress achieved in realizing these commitments, identify problems and obstacles to achieving progress, and ensure wide dissemination of the results of these reviews.”<sup>6</sup>

## **2003 Declaration review process**

The first UN high-level review of government progress on the Declaration was conducted in 2003. Of 189 signatories, 103 submitted national progress reports to UNAIDS for input into

the 2003 UNGASS Global Progress Report. Many civil society organizations expressed dissatisfaction with the level of community participation in the 2003 review, both at the national and the international levels. Some claimed that they were entirely shut out of the process by which governments researched, prepared, and submitted their progress reports. Others expressed dissatisfaction with the role accorded to civil society and people living with HIV/AIDS during the review process, and felt that opportunities to make their voices heard were severely restricted by the relatively “closed” structure and format of the meeting.

## Civil society response

In early 2005, in an effort to respond constructively to these flaws in the 2003 review process, Public Health Watch joined a broad group of civil society organizations from around the world to present a joint proposal to UNAIDS on the need for more substantive civil society participation in the next high-level review in 2006.<sup>7</sup> More specifically, the proposal called for:

- establishment of a formal mechanism by which civil society organizations could present input on implementation of the Declaration in their countries for UNAIDS’ Global Progress Report; and
- development and dissemination of publicly available guidelines encouraging governments to establish clear opportunities for input by a broad range of civil society organizations into the process of preparing and reviewing national progress reports.

UNAIDS responded by inviting the group to provide specific suggestions on civil society participation for inclusion in reporting guidelines for governments. As a direct result of this collaboration, UNAIDS’ *Guidelines on Construction of Core Indicators* for preparation of national progress reports was amended to include the following instructions for national AIDS committees (or their equivalents):

- seek input from the full spectrum of civil society, including nongovernmental organizations (NGOs), faith-based organizations, trade unions, community-based organizations, and people living with HIV/AIDS;
- provide civil society organizations with easy access to their plans for data collection as well as a straightforward mechanism for submitting and evaluating information for the national progress report;
- invite civil society organizations to participate in workshops at the national level to determine how they can best support the country’s reporting process; and
- ensure civil society organizations sufficient opportunity to review and comment on the national progress report before it is finalized and submitted to UNAIDS.<sup>8</sup>

## Civil society monitoring

In addition to Public Health Watch, other civil society organizations are leading projects to support independent civil society monitoring of the Declaration. Of these, Fundar, Gestos, the International Council of AIDS Service Organizations (ICASO), the Latin American Council of AIDS Service Organizations (LACCASO), Panos, and the World AIDS Campaign (WAC) agreed to coordinate their monitoring efforts by sharing methodologies; ensuring broad geographical representation (including both developing and donor countries) and nonduplicative selection of monitoring countries; and collaborating on joint actions and messaging in preparation for the 2006 high-level review.

Together, these organizations have supported the development and presentation to governments of independent “shadow reports” in over 35 countries, and the direct submission of more than 25 reports to UNAIDS as input for the Global Progress Report in advance of UNAIDS’ reporting deadline of December 31, 2005. All of these reports are publicly available at [www.ungasshiv.org](http://www.ungasshiv.org).

## National progress report preparation

All Public Health Watch researchers were encouraged to refer their governments to UNAIDS’ *Guidelines* in requesting opportunities to participate in the development of progress reports in their countries. Many achieved some level of success in participating in the national UNGASS report preparation process; others found their governments unwilling or unable to support a consultative report preparation process.

In **Nicaragua**, Public Health Watch researcher Miguel Orozco, the executive director of Centro de Investigaciones y Estudios de la Salud de la Universidad Nacional Autónoma de Nicaragua (CIES-UNAN), participated in a meeting organized by UNAIDS. The objective of the meeting was to promote exchange of information and to analyze the initial data presented by the government. Orozco and his team were able to present the initial findings and recommendations from his Public Health Watch research. CIES has since organized a roundtable meeting to invite feedback and critique from a wide range of governmental and nongovernmental stakeholders on his draft Public Health Watch report.

The National AIDS Council (NAC) in **Senegal** has been very open to collaboration with Daouda Diouf, a program director at ENDA Tiers-Monde and the lead researcher on the Public Health Watch monitoring project. Representatives from NAC met with Diouf and his team on January 20, 2006, to discuss the initial findings and recommendations of the Public Health Watch research. NAC expressed interest in integrating this and other civil society input into its national progress report. On April 21, 2006, NAC and Diouf presented both the official and civil society UNGASS reports at a workshop to facilitate dialogue about the NGO and government perspectives on Senegal’s progress in upholding the UNGASS commitments

in advance of the high-level review. This meeting also provided an opportunity for Diouf to receive broad feedback on his draft Public Health Watch report.

Andriy Bega, a project manager at the International Center for Policy Studies (ICPS) and the lead Public Health Watch researcher in **Ukraine**, attended the National Conference on Monitoring and Evaluation on September 20-22, 2005, at which a draft of Ukraine's UNGASS national progress report was presented. Participants in the meeting had the opportunity to provide feedback. Though UNAIDS' *Guidelines* were disseminated during the conference, the government did not set forth clear plans for collecting and integrating additional input from civil society groups. The national UNGASS report was presented to select stakeholders on December 16, 2005, and was approved by the National Coordination Council (NCC) on AIDS. The final version of the report is currently available on the Ministry of Health's website.<sup>9</sup> Several members of the NCC have provided written comments on Bega's shadow report, and a few participated in the roundtable discussion on February 24, 2005.

In the **United States**, Public Health Watch researcher Chris Collins has had little success in accessing or participating in the official UNGASS progress report preparation process. To determine the U.S. government's plans for the participation and role of civil society in the UNGASS review process, Public Health Watch sent a letter of inquiry to Mike Leavitt, secretary of health and human services (HHS), in September 2005. Public Health Watch received a response in March 2006 from the special assistant to the secretary of HHS, William Steiger, who indicated that a review report had been submitted, but that due to the "relatively short time frame given for responding on the core indicators" the agency was "unable to engage civil society organizations in the . . . formulation of the report to UNAIDS. . . ." Public Health Watch subsequently sent a copy of the draft Public Health Watch report for review and comment, and requested a copy of the report that had been sent to UNAIDS. No response had been received as of April 2006.

Public Health Watch researcher Oanh Khuat from the Institute for Social Development Studies (ISDS) in **Vietnam** initially faced some challenges in obtaining information from the Vietnam Administration on AIDS Control (VAAC) on civil society participation in the UNGASS review process. She attended a working group meeting uninvited on December 20, 2005. The meeting, chaired by the vice minister of health, included the participation of the director and vice director of the AIDS Administration, the UNAIDS country coordinator, and representatives from UNDP, WHO, USAID, SIDA, and a number of other ministries. Khuat was the only local NGO representative present; people living with HIV/AIDS did not participate in the meeting.

Khuat presented some of her key research findings, and highlighted the fact that there had been no consultation with civil society or people living with HIV/AIDS during report preparation. Both the UNAIDS country coordinator and a representative from USAID spoke up in support of the need for participation by civil society and people living with HIV/AIDS. The Ministry of Health agreed to extend its deadline for input (including from civil society groups)

on the draft progress report. Khuat was thus able to offer specific comments on the draft, which she also shared with UNAIDS, the WHO, the Policy Project, and other organizations.

In January 2006, Khuat received a copy of the final report submitted to UNAIDS by the Vietnamese government. She noted that some of her comments had been taken into consideration and were reflected in the final report. For example, on the basis of her input on the lack of civil society involvement in the national AIDS program, the government lowered its self-assessment rating on civil society participation. The final report acknowledged that substitution therapy was being piloted, not “available,”<sup>10</sup> as the previous draft had indicated, and that there was no antenatal syphilis screening program. Although Khuat believes that the national report should be further revised to more accurately reflect the progress on UNGASS implementation in Vietnam, she is satisfied that inputs from civil society have been accepted and that its participation in the UNGASS process is both recognized by the government and supported by international organizations.

Kaumbu Mwondela, the lead researcher for Public Health Watch in **Zambia** and a board member of the Zambia AIDS Law Research and Advocacy Network (ZARAN), has engaged in extensive consultations with the UNAIDS office. UNAIDS played an active role in coordinating the production of the UNGASS progress report for Zambia and presented the official national report at a strategic planning meeting for the National AIDS Council on January 28-30, 2006, in which Mwondela participated. According to Mwondela, the national report was “off the mark” in certain areas, presenting information that did not reflect the reality on the ground. For example, the official report claimed that antidiscrimination laws protecting people living with HIV/AIDS were sufficient, but failed to acknowledge that these laws are not implemented effectively. Mwondela pointed out these and several other shortcomings in the official report, and scheduled a series of follow-up meetings with key informants to obtain more input for his Public Health Watch report.

Mwondela had difficulty obtaining the final official UNGASS report, but finally acquired a copy in April 2006. His input was not incorporated; the official report still maintains that Zambia has laws and policies that protect people living with HIV/AIDS against discrimination and ensure equitable access to services for all, including vulnerable groups. Mwondela and other civil society representatives feel that they were not consulted adequately during the report preparation process.

## **Global Progress Report**

Public Health Watch presented initial findings, recommendations, and commentary on civil society participation in the UNGASS reporting process from all six countries to UNAIDS in early December 2005 as input for the Global Progress Report. Updated versions were submitted in January and February 2006. Public Health Watch also provided comments on early

drafts of the Global Progress Report. As noted above, Public Health Watch researchers have had the opportunity to review official government reports only when their governments chose to share those reports with them directly or through other sources.

## Initial findings

As noted above, the Public Health Watch methodology provides researchers from very different country contexts with a common framework for assessing implementation of key elements of the UNGASS Declaration, including national strategic plans; political leadership; prevention, care, and support; monitoring and evaluation; and human rights and reducing vulnerability.<sup>11</sup>

In addition to the commentary on opportunities and access for civil society groups in the development and review of national AIDS policy, below is a summary of overarching initial findings identified by Public Health Watch researchers in each of the above areas.

## Strategic plan and financing

*[We declare our commitment to] . . . ensure the development and implementation of multisectoral national strategies and financing plans for combating HIV/AIDS.*

*–UNGASS Declaration of Commitment<sup>12</sup>*

Not all countries participating in the Public Health Watch project have adopted comprehensive national strategies in accordance with their UNGASS commitment.

For example, **Nicaragua** does not have a national policy on HIV/AIDS. As a result, the AIDS initiatives undertaken by different sectors and projects are poorly integrated and coordinated. Information on the status of the AIDS epidemic is not effectively compiled and disseminated, which means that a sound basis for targeted policy development is lacking, and that stakeholders find it difficult to participate effectively in the national response to HIV/AIDS. Absence of governmental leadership and initiative, lack of continuity in national health policies, and frequent turnover among trained health personnel with each change in government are cited as key stumbling blocks to the development of a national policy. Lack of transparency in budgetary allocations and expenditures, including expenditures on antiretroviral (ARV) treatment, is another factor complicating public participation and limiting efforts to ensure government accountability.

**Ukraine** has a national HIV/AIDS program, but implementation has been hampered by significant budget shortfalls. In 2005, combined public and donor resources of \$40 million fell far below actual needs: an estimated \$52 million was required to finance treatment, care, and support alone. The lack of adequate resources is partially due to the program's inability

to mobilize allocation of local resources from regional officials who do not place high priority on HIV/AIDS.<sup>3</sup>

The **United States** does not have a comprehensive national strategy to address HIV/AIDS that covers prevention, treatment, and support services. The U.S. researcher identified the need for better targeting of resources to address racial disparities; increased attention to improving prevention and treatment delivery outcomes; development of an outcomes-oriented strategic plan across federal, state, and local agencies; and increased resources to support evidence-based programming.

In **Vietnam**, a national strategy sets targets to treat 70 percent of people living with HIV/AIDS and to implement comprehensive harm reduction interventions such as provision of safe injecting supplies. However, Vietnam does not yet have an operational plan or a budget to support implementation of its strategy.

In **Zambia**, dependence on donor funding—and therefore vulnerability to heavy donor influence on the articulation and implementation of national HIV/AIDS policies—is a serious issue, and donor programs are not well coordinated with the national HIV/AIDS policy. For instance, the largest line item in Zambia’s prevention program is for school programs that promote sexual abstinence, even though the National HIV/AIDS Communications Strategy recognizes that some sociocultural beliefs run counter to this policy.

## Political leadership and coordination

*Leadership by Governments in combating HIV/AIDS is essential and their efforts should be complemented by the full and active participation of civil society, the business community and the private sector.*

–UNGASS Declaration of Commitment<sup>4</sup>

All Public Health Watch researchers have reported a lack of sufficient coordination between government, the private sector, and civil society. Many countries also reported a marked lack of coordination among civil society organizations.

For example, **Nicaragua** nongovernmental organizations, academic researchers, health workers, and government agencies dealing with AIDS reportedly often work in isolation from, and sometimes at odds with, each other, particularly when competing for limited resources (such as Global Fund monies).

In **Senegal**, HIV/AIDS programming and project implementation tends to be fragmented; very few programs provide a continuum of care—from prevention to ARV treatment to provision of care and support to people living with HIV/AIDS—and impact mitigation. In addition, there has been little attempt to integrate HIV and TB policies and services, though an epidemiological survey in 2003 revealed that HIV prevalence among TB patients in Dakar

exceeded 15 percent and high-level authorities have acknowledged the importance of addressing this burgeoning problem.

On the other end of the spectrum, the **Ukrainian** government's monopoly over provision of public services in Ukraine has led to inefficient utilization of limited resources. For example, the government paid up to 30 times more for antiretroviral drugs than nongovernmental organizations implementing Global Fund projects from 2004 to early 2005, when pressure from the Network of PLWHA and other organizations compelled the government to address the issue. The government delivers services directly through public institutions, and has not given adequate consideration to the potential benefits and cost effectiveness of outsourcing certain services to NGOs. This is particularly relevant for outreach to groups at demonstrably higher risk of HIV infection and transmission, such as injection drug-users.

In the **United States**, political leaders have for years identified HIV/AIDS as an important national challenge. Total funding for AIDS-related programming has increased steadily over the last decade, yet many programs that provide nonmedical support to people living with HIV/AIDS have been "flat funded" or seen only small increases in recent years. A U.S. Institute of Medicine panel concluded in 2004 that the financing system for AIDS care and treatment services in the United States does not allow for "comprehensive and sustained access to quality HIV care."

**Vietnam** has faced particular challenges in managing the relationship between government priorities and those of international donors. For example, the U.S. government limits the use of funding allocated through the President's Emergency Program For AIDS Relief (PEPFAR) for harm reduction activities targeted at injection drug users. But the Vietnamese national strategy, as noted above, aims to provide 100 percent access to safe injecting supplies.

As in Nicaragua and Senegal, Vietnamese NGOs often operate in isolation from one another, with little sense of connection to an overarching policy framework. Their efforts are not coordinated with the national AIDS program, and often do not contribute toward meeting national objectives. Participation of NGOs in development and implementation of HIV/AIDS policy is limited. The same issue has been reported from **Zambia**, where government policies are not well coordinated with or reflected in either the projects of civil society organizations or those of bilateral and multilateral donors.

## Prevention

*Prevention must be the mainstay of our response.*

*—UNGASS Declaration of Commitment<sup>15</sup>*

Comprehensive prevention services as described in the Declaration are not being fully implemented in the six countries in which Public Health Watch has supported research. Government

prevention efforts often fail to develop targeted services to reach the most at-risk communities such as injection drug users and racial/ethnic minorities. In fact, in some cases there are legal barriers to providing services effectively to certain vulnerable groups.

Prevention programs in **Nicaragua** have been limited both in scope and impact. Though efforts have increased in recent years, they are still focused on the general urban population and have not been successful in reaching rural communities and those groups who are most vulnerable to HIV infection, such as sex workers, men who have sex with men, and street children.

The government has been very slow to respond to the HIV/AIDS epidemic with prevention measures in **Ukraine**. Most of the components of a comprehensive prevention package are implemented either incompletely or not at all. For example, prevention programs targeting injection drug users only reach about 60,000 people, just 10 percent of the estimated number nationwide. Substitution therapy, which was declared one of the effective methods of preventing the spread of HIV/AIDS by the government in 2001, was only available to approximately 200 patients as of early 2006. Criminalization of drug use and administrative sanctions on commercial sex workers<sup>16</sup> make these high-risk groups hard to reach with prevention services and programs; members of these groups are reluctant to access existing prevention services for fear of prosecution.

In the **United States**, there has been an erosion of the science and public health basis of the domestic AIDS response. An ongoing disconnect between the evidence of what works and the policy of what is funded has undermined the effectiveness of HIV prevention programming. Funding for HIV prevention has been limited as well. Annual HIV incidence has remained stagnant at an estimated 40,000 for over a decade. AIDS prevention and treatment is needlessly hampered by incomplete information about where new infections are occurring and who is benefiting from services. Many people at elevated risk of HIV infection do not have access to a full range of proven-effective prevention tools.

Drug control laws in **Vietnam** make substitution therapy and needle exchange programs for drug users illegal, posing obstacles for HIV prevention. Possession of needles and syringes can be considered evidence of drug use, and constitute grounds for arrest. These drug control laws contradict the national strategy, which stipulates comprehensive provision of harm reduction interventions. While some provinces have used the national strategy as a legal basis for implementing needle exchange programs for injection drug users, the drug control laws provide a loophole for many provinces that choose not to implement needle exchange programs. Similar inconsistencies exist with condom distribution for sex workers. Possession of condoms can be used as evidence of sex work, which is illegal in Vietnam.

## Care, support, and treatment

*Care, support and treatment are fundamental elements of an effective response.*

*—UNGASS Declaration of Commitment<sup>17</sup>*

Public Health Watch research has found insufficient and sometimes inequitable access to treatment, care, and support in all six countries. Access is often limited to those living in the capital. Repressive policies toward drug users, sex workers, and other groups at risk of HIV/AIDS create obstacles to accessing treatment and other services.

In **Nicaragua**, only people living in the capital, Managua, have access to ARV treatment. For people living in rural areas, practical access to treatment is difficult if not impossible. The Ministry of Health has recognized this issue and is starting to decentralize treatment services, but people living with HIV/AIDS have reported slow progress and persistent lack of access at the community level.

Regional inequalities exist in access to health care and ARV treatment in **Senegal** as well. The majority of health centers and hospitals are clustered around the capital, Dakar, and Senegal's west coast. Inequality in distribution of health centers translates directly into unequal access to ARV treatment: of the 3,622 people living with HIV/AIDS currently on ARVs, 2,368 are in Dakar. There have been efforts to decentralize ARV treatment to make it more accessible to the rural population, but the lack of infrastructure and resources in rural areas have been an obstacle to effective implementation. In addition to poor health infrastructure and resources, remote areas also lack the capacity and training to provide home- and community-based care.

The **Ukrainian** Ministry of Health has significantly scaled up ARV treatment with assistance from the Global Fund—from 135 people receiving ARV treatment at the beginning of 2004 to 3,000 by the end of 2005. However, sustainability is an issue of concern: there is no clear plan to finance ARV treatment after 2008, when the Global Fund grant is scheduled to terminate. Moreover, people living with HIV/AIDS do not have full access to free treatment as stipulated in both the national strategy and legislation. Patients often have to pay for laboratory testing, transportation, diagnosis, and treatment of opportunistic infections, the cumulative costs of which may pose serious obstacles to treatment, particularly since only one specialized AIDS clinic per oblast or region is authorized to prescribe and dispense ARV treatment, requiring some patients to frequently travel long distances they can ill afford.

In both Ukraine and **Vietnam**, repressive policies and discrimination toward drug users and the lack of substitution therapy create obstacles for injection drug users to access medical services, including ARV treatment. There are also significant barriers to accessing treatment in the penitentiary system and drug rehabilitation centers, where HIV prevalence is as high as 50 percent and many inmates are in need of ARV treatment.

In the **United States**, only about half of people living with HIV/AIDS are receiving regular HIV care, and only about half of people who meet government criteria for use of anti-retroviral treatment for HIV are receiving these drugs.

## Human rights and reducing vulnerability

*Realization of human rights and fundamental freedoms for all is essential to reduce vulnerability to HIV/AIDS;*

*Respect for the rights of people living with HIV/AIDS drives an effective response;*

*The vulnerable must be given priority in the response;*

*Empowering women is essential for reducing vulnerability.*

*–UNGASS Declaration of Commitment<sup>8</sup>*

Public Health Watch research indicates that most countries need to do more to reach out to vulnerable and high-risk groups, both as a human rights issue and to increase the effectiveness of their HIV/AIDS policies and programs.

The **Nicaraguan** government has identified sex workers, men who have sex with men, migrant populations, and prison inmates as the groups at highest risk. One local NGO has noted that commercial exploitation of children and adolescents in the Honduras border areas has increased their vulnerability to HIV/AIDS as well. However, little progress has been made in reaching out to these groups with targeted prevention messages or in providing care and treatment to those already infected.

In **Senegal**, AIDS programs are focused on the general population rather than targeting high risk and vulnerable groups such as sex workers (both legal and clandestine), drug users, men who have sex with men, orphans and vulnerable children, migrants, seasonal workers, women of childbearing age, and women living in rural areas. This lack of programmatic focus has persisted despite the fact that the HIV/AIDS epidemic in Senegal is still concentrated, so a more targeted response is warranted to reduce infection rates and to ensure enhanced access to prevention, treatment, and care services among these high-risk groups.

In the **United States**, HIV/AIDS continues to have a devastating impact on communities of color, gay men and men who have sex with men, injection drug users, and the poor. African Americans accounted for an estimated 50 percent of new HIV infections and nearly half of all AIDS diagnoses in 2004. African Americans have more limited access to health care and poorer outcomes for AIDS-related treatment than other groups.

National AIDS policy in **Zambia** does not prioritize marginalized or vulnerable groups; injection drug users and men who have sex with men are not mentioned at all. Even though women and girls are particularly vulnerable to HIV infection,<sup>19</sup> the national policy also fails to specifically address them.

–Public Health Watch

# Notes

1. United Nations General Assembly, Declaration of Commitment on HIV/AIDS, A/RES/S-26/2, adopted at the 26th special session, August 2, 2001. Available at: <http://www.un.org/ga/aids/docs/aress262.pdf>
2. Declaration of Commitment on HIV/AIDS, June 25–27, 2001, Article 37.
3. *Ibid.*, Articles 47-57.
4. *Ibid.*, Articles 58-61.
5. *Ibid.*, Articles 62-67.
6. *Ibid.*, Article 94.
7. For full text of joint proposal and list of more than 50 signatories, see [www.ungasshiv.org](http://www.ungasshiv.org)
8. UNAIDS, *Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators*, Geneva, July 2005. Available at: [http://data.unaids.org/publications/irc-pubo6/jc1126-constrcoreindic-ungass\\_en.pdf](http://data.unaids.org/publications/irc-pubo6/jc1126-constrcoreindic-ungass_en.pdf)
9. The joint statement is available at: <http://www.moz.gov.ua/ua/main/docs/?docID=5194>.
10. The exact language was “YES” in response to a question on whether substitution therapy was available.
11. All of these elements are also reflected in the “national composite policy index” developed by UNAIDS to guide government officials and their partners in developing assessments of progress on UNGASS. See UNAIDS, *Monitoring the Declaration of Commitment on HIV/AIDS: Guidelines on Construction of Core Indicators*, 83-102.
12. Declaration of Commitment on HIV/AIDS, Article 37.
13. Local resources are necessary to fund prevention, care, and support activities. Treatment, including drug procurement, is centralized; shortfalls in financing for treatment are mostly due to the inability of the central government to effectively allocate resources.
14. Declaration of Commitment on HIV/AIDS, preamble to Leadership section, 5.
15. *Ibid.*, preamble to Prevention section, 7.
16. Criminal prosecution of commercial sex workers was repealed in February 2006; sex workers currently are required to pay administrative fines.
17. Declaration of Commitment on HIV/AIDS, preamble to Care, Support, and Treatment section, 8.
18. *Ibid.*, preambles to HIV/AIDS and Human Rights and Reducing Vulnerability sections, 9.
19. For instance, HIV prevalence among 14- to 19-year-old girls is six times higher than boys in the same age group.

**II.**

**Report on**

**U.S. HIV/AIDS Policy**

# Executive Summary

The United States of America, a leader in the international response to AIDS, is failing its own citizens in the response to the epidemic at home. An assessment of AIDS policy and program outcomes finds that the United States is at serious risk of being out of compliance with its obligations to more effectively address the domestic epidemic under the UNGASS Declaration of Commitment on HIV/AIDS.

There are many proud successes from U.S. efforts to address AIDS, including pioneering biomedical research, the provision of high quality care that has saved many lives, and international programs that are reaching millions of people.

Yet needless mortality, inadequate access to care, persistent levels of new infection, and stark inequities continue to define AIDS in America. There has never been a national plan that comprehensively addresses HIV prevention, treatment, and other related needs within the country's borders—and there is no comprehensive strategic plan to address AIDS today. The U.S. public has moved from a sense of crisis about the domestic epidemic to an attitude of complaisance.

The disease we now recognize as HIV/AIDS was identified in the United States a quarter century ago. Within a few years it became clear that the American health care system was not designed, or sufficiently financed, to deliver needed levels of HIV-related medical and support services, particularly in the lower-income, marginalized communities most affected by AIDS. New care and prevention programs were established to fill the gaps, and today federal and state governments sponsor an array of services designed to address the many needs of people living with HIV/AIDS or those at elevated risk of infection.

But in many communities the gaps remain. America has no deficit of dedicated scientists, talented health care workers, or committed prevention and care providers. And yet proven-effective prevention and treatment services have not been delivered to all those in need. Chronic rates of HIV incidence and inadequate care access reveal a shocking level of systems failure.

This is not the fault of any one president or Congress, but an ongoing and shared responsibility. Still, new limitations on Medicaid and flat funding for many federal AIDS programs reflect a federal response that in some ways is becoming even less responsive to demonstrable needs. A new Presidential AIDS Initiative would provide additional resources for prevention, but regrettably focuses on rapid testing to the exclusion of other interventions.

AIDS reveals and exploits longstanding inequities in American society and health care access. The country has failed to come to grips with an interwoven set of social factors—including economic inequality, racial and gender disparities, racial discrimination, and homophobia—that create vulnerabilities to HIV infection and lead to poorer outcomes from health care services.

The epidemic among African Americans is the clearest example of the harsh disparities that characterize AIDS in the United States. No significant progress can be made on national-level outcomes unless policy and programming better meet the needs of this community.

As part of the UNGASS Declaration, the United States made commitments to respond to the global and domestic epidemics and U.S. programs are now playing a crucial role internationally. The American international response has promoted the utilization of national strategies in other countries, infused resources and created health systems where there was limited infrastructure, and focused on outcomes and application of lessons learned. Those touchstones of America's global program could all be applied to make its own domestic AIDS response more effective and equitable.

The UNGASS Declaration commits governments to do the following:

- 1. Allocate adequate resources to address the domestic epidemic**
  - An Institute of Medicine panel has concluded that the financing system for AIDS services in the United States does not allow for “comprehensive and sustained access to quality HIV care.”
- 2. Establish HIV prevention targets and address issues that increase people's vulnerability to infection**
  - The United States failed to meet the 2005 prevention target set by the Centers for Disease Control and Prevention (CDC) and the number of annual new HIV infections has remained at 40,000 for over a decade.
  - HIV prevention resources are not allocated in the most cost-effective manner and research on program effectiveness often does not inform policy.
  - The disproportionate impact of AIDS on African Americans and other communities of color, gay men and men who have sex with men, injection drug users, and the poor continues unabated.
- 3. Achieve the highest attainable standard of AIDS treatment**
  - Only approximately half of people living with HIV/AIDS in the United States are receiving regular HIV-related care.
  - Only approximately half of those people who meet medical criteria for use of antiretroviral (ARV) treatment for HIV are actually receiving the drugs.
  - A significant number of people living with HIV/AIDS are being tested for HIV too late in the course of disease to benefit from early care.

4. **Enact protections to eliminate discrimination against people living with HIV/AIDS**
  - Discrimination and stigma against people living with HIV/AIDS remain a real force in the domestic epidemic and have recently been documented in employment, housing, and other areas.
5. **Develop appropriate program monitoring and evaluation systems**
  - The Institute of Medicine and others have raised concerns that the United States does not adequately measure the quality or utilization of AIDS-related care.

**Findings: Concrete steps to bring the United States into compliance with its UNGASS commitments**

1. **Establish a national HIV/AIDS strategy that focuses on outcomes**
  - Create a true national HIV/AIDS strategy across federal, state, and local agencies that addresses delivery of prevention, treatment, and other services and identifies clear roles, responsibilities, and timelines to achieve measurable results. Use concrete targets and goals as part of an ongoing effort to improve outcomes, systematically assess programming and policy, and hold funders and agencies accountable.
  - Better understand and address personal vulnerability to HIV and barriers to acquisition of HIV care, in part by commissioning an Institute of Medicine study that outlines programmatic and policy solutions. Get better information through improved efforts to monitor epidemic trends and program outcomes.
2. **Comprehensively address racial disparities**
  - Initiate a more integrated, outcomes-oriented, government-wide approach. Launch a vigorous, federally managed effort to test, refine, and deliver innovative programming that improves outcomes for communities of color. Target services to those who are often not reached by the current health system.
  - Acknowledge the structural underpinnings of HIV and AIDS. Expand research to test interventions aimed at reducing stigma, discrimination, and racial and ethnic health disparities.
3. **Dedicate increased resources to proven-effective interventions**
  - Use proven tools to bring HIV incidence down. Increase funding for prevention,

target resources where they can make the most difference, and fund programs based on evidence of what works. Assess how CDC allocates prevention dollars and whether cost-effectiveness research informs spending.

- Act on the proposals made by a distinguished Institute of Medicine panel in 2004 to deliver quality care more widely and equitably. Focus on making Medicaid work for low-income people living with HIV/AIDS, in part by overturning cost-sharing schemes and benefit caps on services. Increase funding for the CARE Act which provides resources for medical and support services and AIDS drugs.
- Address the context of risk and care through increased resources to meet the housing, mental health, and substance abuse prevention and treatment needs of people living with HIV/AIDS. Research and support community level interventions that address structural issues in vulnerability and care access.
- Maintain commitment to a robust research effort to continue to discover ever more effective HIV prevention and treatment strategies.

For over two decades, the response to AIDS has blazed a trail to reforms in broader health care policy. Today, a reinvigorated, evidence-based, and outcomes-oriented approach to the epidemic can enable the United States to live up to its commitments and reach all Americans with proven-effective HIV prevention and life-saving treatment.

# Background

A mysterious new medical condition we now call AIDS was first recognized in the United States in June 1981. Since that time, the AIDS epidemic has become one of the most serious public health concerns in the country and has had a powerful impact on the national discourse on health, human rights, and the involvement of civil society in health policy.

## Baseline statistics

As of July 2005, the estimated population of the United States was 295 million. According to the U.S. Central Intelligence Agency, “The U.S. has the largest and most technologically powerful economy in the world.”<sup>1</sup> In 2004, the country’s gross domestic product was \$11.75 trillion or \$40,100 per capita.

**Table 1:**  
Estimated numbers of AIDS cases by transmission category

	2004	Cumulative
<b>MEN</b>		
MSM	17,691	441,380
IDU	5,968	176,162
MSM & IDU	1,920	64,833
Heterosexual	5,149	59,939
Other	298	14,085
<b>WOMEN</b>		
IDU	3,184	72,651
Heterosexual	7,979	99,175
Other	279	6,636
<b>CHILDREN</b>		
	48	9,443
<b>TOTAL</b>	42,514	944,306

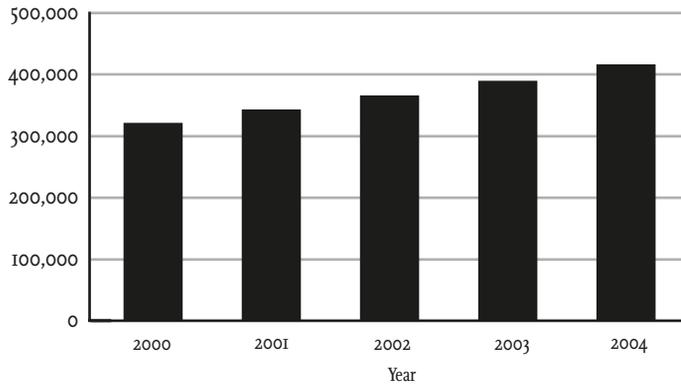
The U.S. Centers for Disease Control and Prevention (CDC) estimates that approximately 40,000 people in the United States are newly infected with HIV each year, or 4.5 new infections each hour. Estimated incidence has plummeted from its peak of more than 160,000 annual infections in the mid-1980s, but has remained at the current level since 1990. CDC estimates that there were between 1.039 million and 1.185 million people living with HIV/AIDS in the United States in 2003. The agency estimated that in 2004 there were 415,193 people living with AIDS in the country.

According to the CDC, the rate of HIV diagnosis in the United States remained “relatively stable overall during 2001-2004,” with 22.8 infections per 100,000 people in 2001 and 20.7 infections per 100,000 in 2004 (in the states using name-based reporting).<sup>2,3</sup> CDC reports that 15,798 people died from HIV/AIDS related causes in

2004<sup>4</sup>—more than 43 deaths each day. An estimated 529,113 have died from the disease since the beginning of the epidemic. AIDS-related mortality rose through the mid-1990s, and then fell dramatically due to the introduction of highly active antiretroviral therapy.

It is difficult to form a detailed and up-to-date picture of HIV incidence because there are no nationally representative surveys of HIV infection in the United States. In its annual Surveillance Report, the CDC only provides information on new HIV diagnoses in the 35 states and other jurisdictions with confidential name-based reporting of infection. Reports from these states generally reflect results from HIV tests, and not necessarily new infections. (California,

**Chart 1: People Living with AIDS**



one of the states with the highest number of new AIDS diagnoses, is excluded from Surveillance Report data because it does not have a name-based reporting system.)

From the beginning of the epidemic in the United States, HIV has had a hugely disproportionate impact on gay men and men who have sex with men, racial and ethnic minorities, injection drug users, and the poor (see Tables 1 and 2). Men who have sex with men accounted for 46 percent of all new AIDS diagnoses in 2004. In 2005, the CDC reported that estimated new HIV diagnoses among these men “remained relatively stable between 2001 and 2003, but increased 8 percent between 2003 and 2004. This trend was consistent across all race categories.”<sup>5</sup> Surveys among young men who have sex with men and those from communities of color show that these groups are at particularly high risk of HIV infection, and that a large percentage of those who are infected do not know it. A recent study found that 77 percent of young men who have sex with men and who tested HIV positive believed they were not infected.<sup>6</sup> Injection drug users accounted for 22 percent of AIDS diagnoses in 2003 and represent approximately a quarter (24 percent) of people living with AIDS.

In 2004, African Americans, Latinos, Asian/Pacific Islanders, and American Indians accounted for 71 percent of new AIDS diagnoses, yet these groups represent only 31 percent of the total U.S. population. The AIDS epidemic has been particularly devastating in the African American community. It has been estimated that about half of all new HIV infections occur among African Americans.<sup>7</sup> Nearly half (49 percent) of new AIDS diagnoses in 2004 were among African Americans, and African Americans have the highest AIDS case rates of any racial or ethnic group.<sup>8</sup> The CDC estimates that the rate of new HIV infections among African Americans in 2004 was 8.4 times that of Caucasians (in the 33 states with name-

**Table 2:  
Estimated numbers of newly  
diagnosed AIDS cases by race**

	2004 Cumulative	
White	12,013	375,155
African American	20,965	379,278
Hispanic	8,672	177,164
Asian/PI	488	7,317
American Indian	193	3,084

### African American community faces heavy burden and disparities in care

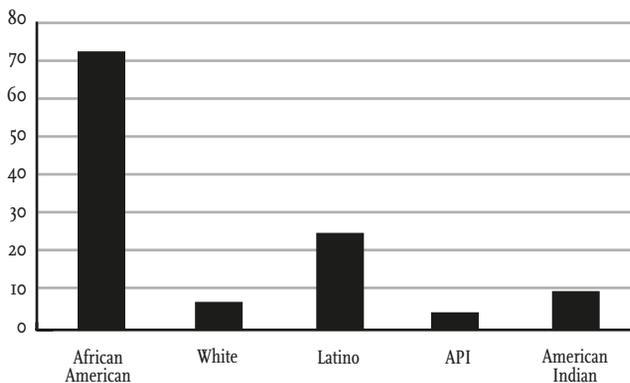
- African Americans accounted for 40 percent of cumulative AIDS diagnoses through 2004, though they represent only 13 percent of the U.S. population.
- In 2004, African Americans accounted for 50 percent of new HIV/AIDS diagnoses in the 35 areas with confidential name-based reporting.
- Survival time after AIDS diagnosis is lower on average among African Americans than it is for other racial/ethnic groups.
- Between 2000 and 2004, deaths among African Americans with HIV declined by 7 percent compared with a 19 percent decline among whites over this period.
- The HCSUS study found that African Americans fared more poorly on measures of access to health care than whites and were more likely to report postponing medical care because they lacked transportation, were too sick to go to the doctor, or had other competing needs.

*HIV/AIDS among African Americans, CDC; CDC, HIV/AIDS Surveillance Report, Vol. 16, 2005; Cunningham, et al, The impact of competing subsistence needs and barriers to access to medical care for persons with HIV receiving care in the US, Medical Care, vol 37, no 12, 1999*

based reporting).<sup>9</sup> HIV was the third leading cause of death among African Americans between 25 and 34 years old in 2001, and the number one cause of death among African American women aged 24–34.<sup>10</sup>

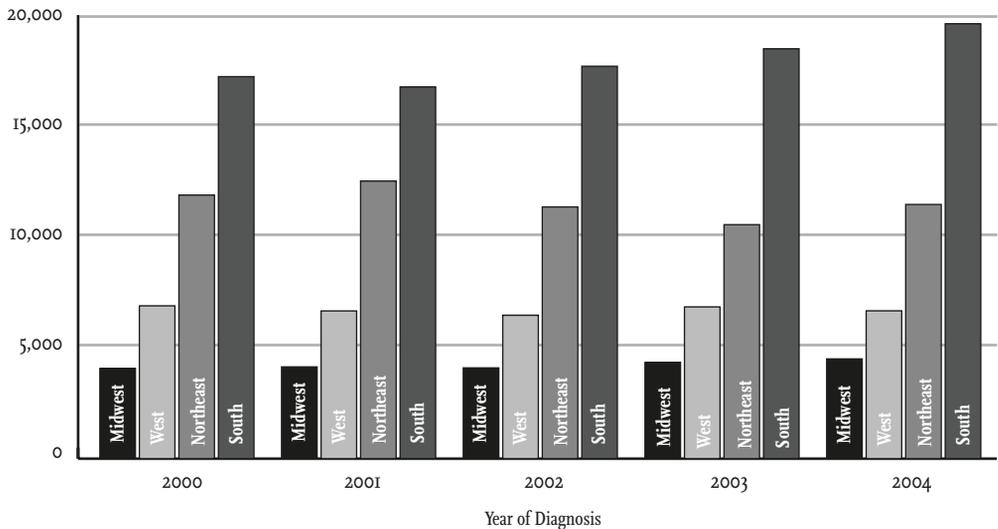
The Latino community has also been hard hit by AIDS. Latinos represented 20 percent of new AIDS diagnoses in 2004, though they comprise only 14 percent of the U.S. population. HIV was the sixth leading cause of death for Latinos aged 25–34 in 2001. Survival after AIDS diagnosis was lower for African Americans and Latinos than for whites or Asians. Women, particularly women of color, are increasingly affected by the epidemic. AIDS diagnoses among women rose from 8 percent of total diagnosis in 1985 to 27 percent in 2004. Among women diagnosed with AIDS in 2004, 64 percent were African American and 18 percent were Latinas.

Chart 2: AIDS Case Rate per 100,000 by Race



Young people, particularly young people of color, bear a heavy burden in the U.S. AIDS epidemic. It has been estimated that half of all new HIV infections are among people under the age of 25.<sup>11</sup> Many of these young people are girls and people of color. Girls represent about half (51 percent) of the HIV infections reported in 2002 among 13 to 19 year olds. In this same age group, African Americans accounted for 65 percent, and Latinos 20 percent, of new AIDS cases reported in 2002.<sup>12</sup> Sharp declines in perinatal HIV transmission have been one of the major successes in the U.S. response to AIDS, with a greater than 90 percent decline in this transmission category between 1992 and 2003.

**Chart 3: AIDS Diagnosis by Region and Year**



### Geographic distribution and trends over time

The yearly number of new AIDS diagnoses is increasing in every region of the country except the West.<sup>13</sup> For years, the South has led other regions in the number of new AIDS diagnoses. In many areas of the South, the legacy of racial discrimination and ongoing poverty and discrimination have put individuals and communities at elevated risk of infection and complicate efforts to deliver appropriate HIV care. It is estimated that nearly four out of ten (39 percent) people living with AIDS reside in the South; 29 percent in the Northeast, 19 percent in the West, and 10 percent in the Midwest.

## TB and HIV

In 2004 14,517 cases of TB were reported to the CDC, a decrease of 2.3 percent from the previous year.<sup>14</sup> Over half (54 percent) of all cases were among foreign-born persons, and Latinos represented 29 percent of all cases. African Americans represented 45 percent of all TB cases in U.S.-born individuals. A significant minority of people living with HIV and AIDS also have TB infection, though the estimated prevalence of coinfection has been gradually declining over the last decade. The CDC estimates that nine percent of all people living with HIV/AIDS, and 16 percent of those aged 25–44 years are coinfecting with TB.

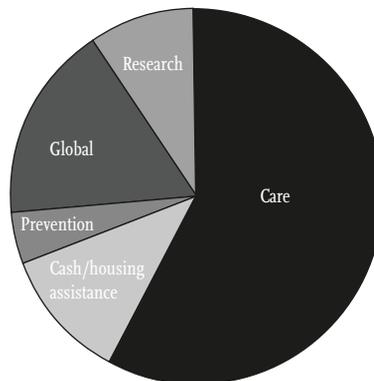
## Health sector budget allocation and spending

In fiscal year (FY) 2006, total U.S. federal spending on domestic and international AIDS is estimated to be \$21.073 billion. The president's FY 2007 budget proposed spending \$22.82 billion on AIDS of which 58 percent would go to care, 12 percent to research, nine percent to cash and housing assistance, four percent to prevention, and 17 percent to address the international epidemic.

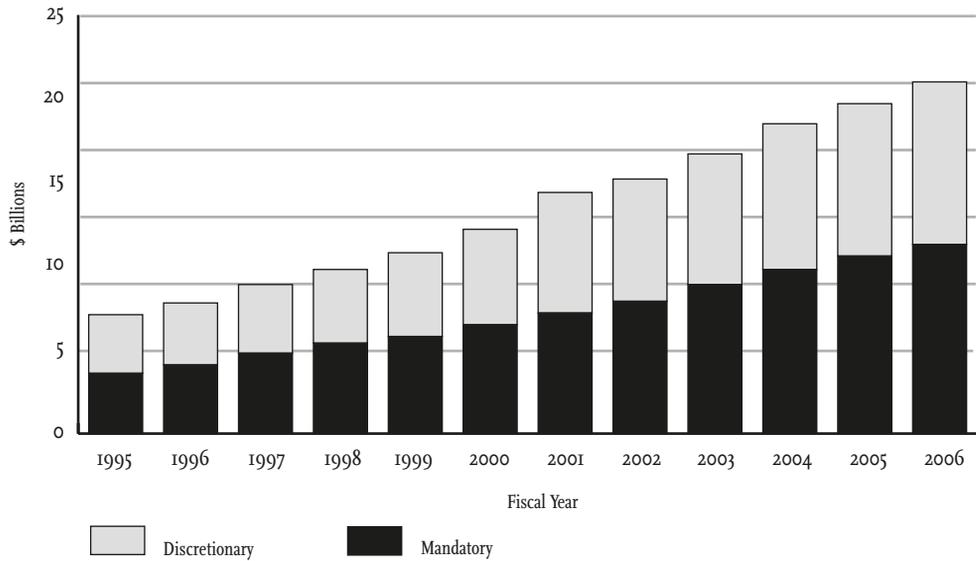
Of the \$17.852 billion devoted to the domestic epidemic in FY 2006, over half is spent for AIDS care through the Medicare and Medicaid programs. These are what are called “entitlement programs” that pay for health services for individuals who meet certain eligibility requirements. Medicaid is the largest single source of federal AIDS funding and provides care largely to lower income individuals who meet state eligibility criteria. Medicare is the second largest source of federal funding for AIDS care. Many people living with HIV/AIDS who are categorized as disabled or who are over 65 are eligible for the Medicare program.

Of the remaining federal funding for AIDS care, most is channelled through “discretionary programs” that are subject to annual appropriations approved by the U.S. Congress. The largest discretionary program providing AIDS-related services is the Ryan White CARE

Chart 4: FY 07 AIDS Budget Request



**Chart 5: Mandatory and Discretionary AIDS Spending**



Act, which supports HIV care, medications, and other services. In FY 2006, CARE was funded at \$2.063 billion, of which \$789.5 million was for therapeutic drugs purchased through the AIDS Drug Assistance Program (ADAP).

### **Socioeconomic factors**

Discrimination and inequality of opportunity continue to plague many aspects of life in America, including health care. Social stratification by race and economic class in the United States has an impact on the HIV epidemic, increasing individuals' vulnerability to HIV infection and inhibiting access to, and utilization of, HIV-related care. A few recent studies demonstrate inequality of opportunity in several areas:

- **Housing:** A March 2006 survey was designed to test whether people of different races who were victims of Hurricane Katrina would be treated equally in the rental housing market. The survey found that white applicants were treated more favorably than African-American applicants two-thirds of the time.<sup>15</sup>
- **Education:** A 2004 study determined that financial support for public schools remains unequal, with the highest-poverty school districts receiving fewer resources per pupil than the lowest-poverty districts in 25 of 49 states studied.<sup>16</sup>

- **Health care:** In 2002, the Institute of Medicine released an analysis of over 100 studies of health care provided to racial minority groups. The IOM analysis concluded that, “The vast majority of published research indicates that minorities are less likely than whites to receive needed services. . . . [E]ven after correcting for access-related factors, such as insurance status. . . . African Americans and Hispanics tend to receive a lower quality of healthcare across a range of disease areas. . . .”<sup>17</sup>

### ***Socioeconomic aspects of HIV/AIDS***

Disease surveillance systems in the United States do not routinely include the collection of income or other economic data. Nevertheless, a wide variety of studies have documented the impact of the domestic HIV/AIDS epidemic on lower income populations. Over a decade ago, the National Research Council’s Panel on Monitoring the Social Impact of the AIDS Epidemic observed that, “instead of spreading out to the broad American population, as was once feared, HIV is concentrating in pools of persons who are also caught in the ‘synergism of plagues’ that include poverty, poor health care, inadequate education, unemployment, and “social disintegration.” This trend has not changed in the interceding years.<sup>18</sup>

The most comprehensive, nationally representative study of people living with HIV/AIDS—the HIV Cost and Services Utilization Study or HCSUS—was conducted in the mid to late 1990s in order to characterize the HIV population and its access to and utilization of HIV-related care. HCSUS found that individuals receiving care for HIV infection differed from the overall U.S. population in that they were disproportionately young, male, African American, poor, unemployed, and underinsured.<sup>19</sup> (It is important to note that the HCSUS study is now dated, particularly as the study was initiated before the wide availability of highly active antiretroviral therapy or HAART.)

The HCSUS study also found a differential in access to care among sub-groups within the study population. For example, African Americans and Latinos received fewer preventive treatments and had fewer outpatient care visits than did whites. Education and income also influenced access to care. Of eligible college graduates, 71 percent had received treatment with the HIV drugs that became available in the last half of the 1990s, while only 51 percent of those who had not completed high school received such care. Lower income individuals had “less favorable patterns of care” as compared to those with higher incomes.

Disparity of health outcomes across socioeconomic lines remains an important factor in today’s epidemic. Research published in November 2005 (based on earlier data) reported that people living with HIV/AIDS who had low socioeconomic status were more likely to die over a five-year period than those with a higher income.<sup>20</sup> The study’s authors suggested that lower rates of private health insurance coverage and lower utilization of ARVs and ambulatory health services among poorer populations could help explain the differential in outcomes.

In 2005, after years without a HCSUS-like assessment of care access and utilization, the CDC launched the Morbidity Monitoring Project (MMP). MMP is intended to “provide nationally representative estimates of clinical outcomes and HIV-related behaviors through medical record abstraction and patient interview,”<sup>21</sup> according to the CDC.

Homophobia, racism, and stigma against people living with HIV/AIDS, drug users, the poor, and others have been powerful forces in the domestic AIDS epidemic from the beginning. The CDC has acknowledged that stigma surrounding HIV/AIDS leads individuals to “deny risk, . . . avoid testing, . . . delay treatment, . . . and suffer needlessly.”<sup>22</sup> The agency has identified a variety of ways in which homophobia affects HIV prevention efforts, “from the individual at risk of infection who may deny his risk because of internal conflicts, to the broader culture, which delivers anti-gay messages, [and] institutionalizes homophobia through . . . laws that regulate intimate sexual behavior, and lags in its support of sensitive and honest prevention for gay and bisexual youth, young adults and older men.”

## **Political commitment**

### ***From “indifference” to institutionalization***

AIDS was recognized as an important epidemic in the early 1980s when Ronald Reagan was president of the United States, yet Reagan did not mention AIDS publicly until October 1987. By the date the president spoke, 27,909 Americans had died of the disease. As a result of advocacy by groups like the AIDS Coalition to Unleash Power (ACT-UP), the leadership of several members of the U.S. Congress, and growing public awareness of AIDS, the disease became a high profile political issue in the late 1980s and early 1990s.

Even with more public attention focused on AIDS, many observers have raised concerns through the years about a lack of adequate political leadership on the epidemic. President Reagan appointed a Presidential Commission on the HIV Epidemic in 1987, but the 600 recommendations made by the commission were largely ignored.<sup>23</sup> In 1991, the National Commission on AIDS appointed by then President Bush released a report lamenting that the United States had responded with “indifference” to the AIDS crisis and calling for a “comprehensive, national HIV prevention initiative” authorized by Congress.<sup>24</sup>

Five years later, the Presidential Advisory Council on HIV/AIDS, appointed by President Bill Clinton, wrote in a progress report that, “The AIDS crisis has generated more than its share of advisory committees. Far too often, the recommendations issued by these committees, commissions, and councils have simply gone unheeded.”<sup>25</sup> More recently, in 2001, a distinguished Institute of Medicine panel reported that, “there is a definite lack of federal leadership with regard to HIV prevention,”<sup>26</sup> and called for a fresh approach to prevention efforts.

There has been a longstanding concern that politics and stigma against various groups

stand in the way of effective domestic and international policies to tackle AIDS. For example, seven federally funded studies demonstrating the efficacy of needle exchange programs (NEPs) to reduce incidence of infection among IDUs have failed to change a federal law prohibiting use of federal funds for NEPs.<sup>27</sup>

The current administration has significantly expanded funding to address the scourge of the global epidemic, and it has pledged concerted efforts on the domestic front as well. In June 2004, as part of a speech announcing increased funding for the ADAP program, President George W. Bush declared AIDS to be “one of the great challenges of our time. . . . We’re committed to ending the plague. . . . America is committed to continue to lead the world in ending the plague.”<sup>28</sup>

Funding for an array of AIDS-related services is now institutionalized in the appropriations process, with Congress annually passing funding legislation that supports AIDS services in numerous federal departments. Since 1998, a federally funded Minority AIDS Initiative has provided dedicated support for prevention and treatment services among people of color.

### ***Lack of a national strategy***

Despite the professed commitments of political leaders and significant overall increases in funding, a quarter century into the epidemic the United States still does not have a true national AIDS strategy focused on measurable outcomes and coordinated responses, and capable of being used to hold government agencies accountable for concrete results.

This is not to say there have never been goals and targets for improving prevention and treatment outcomes. In January 2001, the CDC issued an HIV Prevention Strategic Plan that set a target of halving annual new HIV infections from 40,000 to 20,000 by 2005. The target was not met—in fact, as noted above, CDC estimates annual HIV incidence has remained the same since the agency issued its plan.

Healthy People 2010, a broad-based system of health targets established by HHS, set a variety of HIV-related objectives, from reducing the number of new AIDS cases among men who have sex with men, to increasing the proportion of sexually active persons who use condoms, to increasing the percentage of people living with HIV/AIDS who receive primary medical care and treatment. While these and other targets are laudable, they do not represent a comprehensive and coordinated strategic plan.

In December 2005, the President’s Advisory Council on HIV/AIDS (PACHA) issued a report on the U.S. response to AIDS that called for expanded use of HIV testing, confidential name-based HIV reporting in all states, a major initiative in prisons, more effective distribution of ADAP funds to prevent waiting lines for ARVs, and elimination of anonymous HIV testing.<sup>29</sup>

The PACHA report also affirmed the U.S. commitment to addressing AIDS in less-developed countries through the President’s Emergency Plan for AIDS Relief, initially autho-

rized for five years: “The five-year Emergency Plan is a beginning, and not an end. We have proven that prevention, treatment and care are possible in the developing world.”

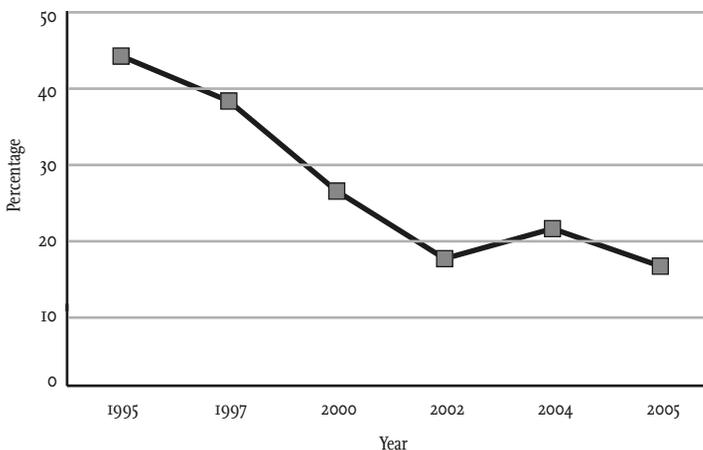
## Public mobilization

The American public has consistently identified HIV/AIDS as one of the most crucial public health concerns in the nation. A survey done by the Kaiser Family Foundation in 2005 found that 16 percent of the public think AIDS is the most urgent domestic health challenge.<sup>30</sup> Survey data from the previous year that grouped responses by race/ethnicity suggested that people’s ranking of the importance of AIDS was related to the impact of the disease in their communities: 43 percent of African Americans and 31 percent of Latinos named AIDS the most important health challenge. Also in the 2004 data, almost one in five people (17 percent) said they are personally “very concerned” about becoming infected with HIV.<sup>31</sup>

There is also support for increased federal funding to address the domestic epidemic. In the 2005 survey, 42 percent of respondents said the U.S. federal government spends “too little” on AIDS and 33 percent said it spends “about the right amount.” Forty-four percent of respondents agreed that spending more on HIV prevention “will lead to meaningful progress in slowing the epidemic,” while another 48 percent said it “wouldn’t make much difference.”

Civil society has been at the center of the response to AIDS since the beginning of the domestic epidemic. For many years, it has been standard practice to include members of civil society on government advisory bodies such as PACHA. The National Institutes of

Chart 6: Percentage Citing AIDS as Most Urgent Health Problem



Health (NIH), the Health Resources and Services Administration (HRSA), and the CDC all have advisory panels that include civil society representatives. Faith-based organizations have been playing an increasing role as providers of federally supported HIV-related services and as representatives on government advisory bodies.

In recent years there has been growing concern about perceived federal harassment of NGOs providing AIDS services that may not reflect the ideological or policy positions of the current administration. For example, in October 2003, Rep. Henry Waxman wrote then HHS Secretary Tommy Thompson of his concern that HHS “may be inappropriately using its auditing authority to penalize groups” that promote comprehensive sex education.<sup>32</sup> A significant share of HIV-related funding to civil society organizations comes from the federal government.

Some observers are also raising concerns about the state of civil society advocacy on AIDS. A comprehensive analysis of federal AIDS advocacy,<sup>33</sup> completed in 2004 and funded by the Ford Foundation, argued that despite the many achievements of the past two decades, some AIDS advocacy organizations were increasingly focusing their work on protecting specific funding streams.

This dynamic “precludes a broader perspective,” according to the report, and risks leaving behind the needs of constituencies not covered by categorical programs (like Medicaid recipients) and issues of concern to the poor and severely marginalized, including substance abusers, people with mental illness, and the prison population. The report called for building on the “strong foundation” of national AIDS organizations with a broader vision that goes beyond individual programs and that can build consensus on an array of issues before the AIDS community and lead to more equitable delivery of AIDS-related services.

Some advocacy organizations have taken issue with the report’s analysis, pointing to important, ongoing work by AIDS lobby groups on behalf of the poor and marginalized. The CARE Act serves primarily low income individuals, many with multiple diagnoses, so advocacy for CARE—a focal point for many AIDS advocacy groups—greatly benefits marginalized populations.

# National HIV/AIDS Policy

## Policy Administration and Financing

### No “Three Ones” for the United States

In many ways, decentralization of decision-making authority is an important strength of U.S. AIDS policy. Local and state HIV/AIDS planning councils are often mandated to include representatives of people living with HIV/AIDS and others from civil society. These committees help make key decisions on the allocation of HIV prevention and treatment resources distributed by the CDC, HRSA, and other federal agencies. Shared decision-making authority means that AIDS programming can be maximally responsive to local needs and informed by the expertise of people responding to the epidemic “on the ground.” Shared authority also places a limit on the ability of the national government to impose programming or policies that may be inconsistent with local standards.

In its response to the global epidemic, the U.S. government has affirmed the value of centralizing some functions of planning and authority through support of the “Three Ones” principles. These principles call for one national AIDS plan, one national decision-making authority, and one system of program monitoring and evaluation.<sup>34</sup> Centralized planning and procurement is an important strategy used by the President’s Emergency Plan for AIDS Relief program to scale up AIDS services in resource limited countries.

The approach is different on the domestic front. The Office of National AIDS Policy (ONAP), located in the White House, provides broad policy coordination for the “domestic efforts to reduce the number of new infections” and its website says it is “working to coordinate an increasingly integrated approach to the prevention, care and treatment of HIV/AIDS.”<sup>35</sup> Yet since its inception ONAP has had a small staff and limited authority, and has never truly coordinated or managed the work of the various federal departments involved in funding AIDS programs and services.

HHS comes as close as any federal agency to providing overall coordination of AIDS services. The CDC, the HRSA, the Centers for Medicare and Medicaid Services (CMS), the National Institutes of Health, the Substance Abuse and Mental Health Services Administration (SAMHSA), and other federal organizations providing AIDS services all come under the authority of the HHS secretary. HHS provides broad oversight of its agencies and sets policy that is implemented in sub-agencies, but several federal programs important in the national AIDS response (including Housing Opportunities for People with AIDS or HOPWA) are not part of HHS’s portfolio and states and localities operate with wide autonomy in several areas

of AIDS policy. HHS's oversight function should be carefully distinguished from true strategic management of the overall federal response.

With no single national AIDS authority, it is difficult for the U.S. federal government to implement a national plan of action across regions or coordinate the efforts of the multiple federal agencies involved in the response to AIDS. This complicates efforts to set meaningful targets and objectives, ensure measures are taken to accomplish them, and hold agencies accountable for their realization.

## Multiple sources of financing

*Increase and prioritize national budgetary allocations for HIV/AIDS programmes as required, and ensure that adequate allocations are made by all ministries and other relevant stakeholders.*

*—UNGASS Declaration of Commitment<sup>6</sup>*

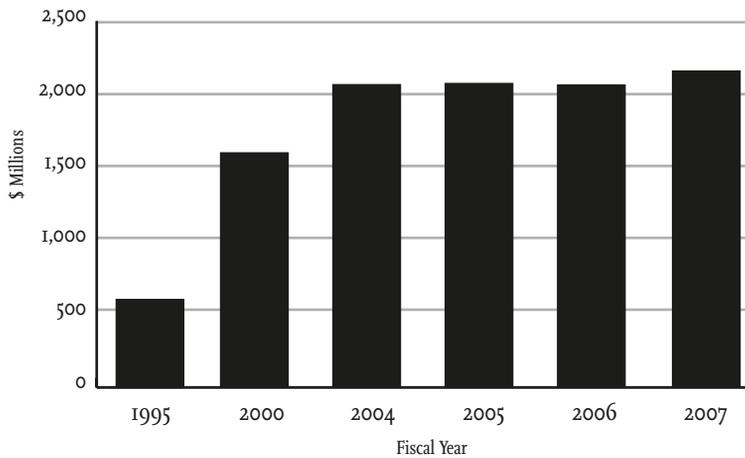
AIDS prevention and treatment services are financed by an array of public and private sources at the federal, state, and local level. Overall spending on HIV/AIDS services in the United States has grown steadily over the last two decades. In recent years, the entitlement programs, primarily Medicaid and Medicare, have been increasing at a faster rate than discretionary programs, including CARE. Within CARE, funding increases have been generally concentrated in the ADAP program. From FY 2005 to FY 2006, ADAP funding increased by 0.25 percent while the CARE Act overall fell by 0.5 percent. Increases to ADAP have been shrinking each year and have been far less than needed to meet growing demand for services.

Funding for HIV prevention at the CDC actually declined from \$731.7 million to \$719.7 million from FY 2005 to 2006. The president's 2007 budget proposal requests the first increase in years—to \$807.7 million—as part of a new Domestic HIV/AIDS Initiative focused

### The CARE Act, Title by Title

- Title I: emergency assistance to severely affected Eligible Metropolitan Areas (EMAs)
- Title II: grants to states and funding for the AIDS Drug Assistance Program (ADAP)
- Title III: Capacity Building Grant program; Planning Grant program; Early Intervention Services program for comprehensive primary health care services
- Title IV: programs targeting women, infants, children, and youth
- The Special Programs of National Significance Program advances knowledge and skills in service delivery
- The AIDS Education and Training Centers (AETCs) Program, a network of regional and national centers that train health care providers to treat persons with HIV/AIDS
- The HIV/AIDS Dental Reimbursement Program supports access to oral health care for individuals with HIV infection.

**Chart 7: CARE Funding**



on expanding rapid HIV testing. Support for housing services for people living with HIV/AIDS has also not increased at the same pace as the number of people living with HIV/AIDS and needing housing services. Funding for the HOPWA program increased by 1.5 percent from FY 2005 to FY 2006, though a 4.8 percent increase is requested for FY 2007.

In sum, those programs that automatically expand (because they are based on eligibility criteria), or that purchase drugs, are growing in the federal AIDS budget, and those that depend on specific appropriations from Congress are remaining relatively flat or actually decreasing.

In 2004, an Institute of Medicine (IOM) panel reviewed the AIDS care financing system and concluded that the current “patchwork” of public financing programs is not well suited to meeting the chronic care needs of the HIV population. The IOM report lamented that, “Fragmentation of coverage, multiple funding sources with different eligibility requirements that cause many people to shift in and out of eligibility, and significant variations in the type of HIV services offered in each state do not allow for comprehensive and sustained access to quality HIV care.”<sup>37</sup>

The growing HIV population is increasingly in need of comprehensive health services from the public sector at a time of mounting fiscal pressures at the federal and state level. The 40,000 people newly infected with HIV each year are now more likely than in the past to be poor, uninsured, or publicly insured.<sup>38</sup> Individuals entering the HIV care system are more likely than before to have comorbidities such as hepatitis C infection, substance abuse problems, or mental illness—conditions that can make treatment and adherence to medical regimens more complex. Several studies reveal that people of color, women, and individuals with substance abuse disorders and mental illness have unequal access to newer drug therapies.<sup>39</sup>

Growing fiscal pressures at the state and federal levels threaten to undermine needed increases in funding for AIDS-related care. As noted earlier, CARE Act funding and other non-entitlement program funding for HIV services has remained relatively flat (with the exception of ADAP) even as the population of people living with HIV/AIDS continues to grow. States are also beginning to impose limits on their Medicaid programs in response to increasing costs.

The Medicaid program will play an even more crucial role in meeting HIV care needs in the years to come as the percentage of people living with HIV/AIDS who are poor and without private insurance increases. It is therefore of particular concern that low reimbursement rates and limited provider availability often interfere with access to Medicaid services,<sup>40</sup> meaning that a greater number of people living with HIV/AIDS will face challenges in accessing quality care. And since states have broad flexibility in setting Medicaid policy, the dramatic variations in the benefits, drug coverage, eligibility, reimbursement levels, and other aspects of the program produce wide disparities in HIV care across the country.

For years the public health community has depended on the CARE program to “back-fill” services not provided through Medicare, Medicaid, or other programs. As of 2003, HRSA estimated that 533,000 individuals were receiving CARE services each year. The role of CARE will become increasingly important as the number of people living with HIV/AIDS grows and states impose new limits on their Medicaid programs. Like Medicaid, there is a wide disparity in CARE funding from state to state. This is a result not of state policy choices, but a multilayered set of CARE funding criteria that can result in up to a 50 percent differential in funding per person between states.<sup>41, 42</sup>

The IOM AIDS financing panel noted with concern that while “the needs of people living with HIV have changed dramatically” these changes are not reflected in locally controlled CARE Title I allocations. (Title I includes funding for 51 eligible metropolitan areas.) In particular, the committee observed that health care services had not received substantial increases in CARE Title I funding in recent years.<sup>43</sup>

With the CARE Act expiring in 2006, reauthorization has sparked widespread debate in the AIDS community. The Bush administration has proposed a set of principles for redesign of the program that include creation of a “severity of need” index for use in allocating resources. The new index would include elements like poverty level, HIV incidence data, and the availability of other resources in the community. The administration would also require that at least 75 percent of funding in Titles I–IV be used for “core medical services.”

The HIV Medicine Association (an organization of HIV medical professionals) has praised the Bush proposals as a constructive approach to redressing wide variations in grant levels across states and localities, and for making “medical care the top priority.”<sup>44</sup> The National Association of People with AIDS (NAPWA) and other advocacy groups have criticized the Bush plan. NAPWA said the plan will “dramatically restrict the ways in which states and cities can use money” and will undermine community-based AIDS services and participatory planning

on the local level.<sup>45</sup> NAPWA called for additional funding for CARE rather than the introduction of a new funding formula that would reduce funding in one region to provide increases in another.

The effort to achieve full access to HIV-care and services extends beyond CARE Act funding and formulas. The IOM AIDS financing committee argued that because CARE is a locally controlled program that depends on annual appropriations from Congress, it “cannot ensure continuity of care from year to year nor ensure all eligible individuals infected with HIV will receive a minimum basic set of services.”<sup>46</sup>

## **IOM’s recommendation for fundamental reform**

After reviewing the financing system for HIV services in the United States, the IOM finance committee looked at a variety of options to achieve broader, more equitable, and more comprehensive services to people living with HIV/AIDS in the coming years. The committee considered several adaptations of current programs, including expansion of the CARE Act and extension of Medicare and Medicaid coverage. Ultimately, however, the committee felt that basing a reformed financing system on changes to these existing programs would “perpetuate major deficiencies in the current financing system.”

Instead of adapting one of the current financing programs, the IOM committee endorsed a fundamental change in the way HIV services are paid for in the country, suggesting the creation of a new federal entitlement program to be administered on the state level and focused on ensuring quality health services for low income individuals with HIV. People living with HIV/AIDS who have incomes at 250 percent of the federal poverty line or below would be eligible, and individuals with higher incomes would be able to buy into the program on a sliding scale basis. Care provided through the program would conform to a uniform, federally defined benefits package that includes primary care services, case management, and prevention services.

In order to attract providers to the program, reimbursement levels would be comparable to those provided under Medicare, rather than the typically lower levels paid by Medicaid. The committee also recommended cost offsets to help fund the new program, including lowering the fees paid for therapeutic drugs by allowing the program to cap payments at the Federal Ceiling Price (FCP), which is based on a reduction of the average price paid to drug manufacturers by wholesalers.

While it is unlikely that Congress will enact a sweeping new federal entitlement program for AIDS, the ambitiousness of the IOM plan points to the many cracks and inefficiencies in the current finance system. At its core, the IOM proposal acknowledges that achieving broader access and more equitable health care outcomes will be a difficult challenge as long as HIV services are subject to differing standards and growing fiscal pressures across U.S. states.

## Good coverage if you can get it

It is estimated that nearly one in three (31 percent) people living with HIV/AIDS are covered by private insurance. Those who receive their insurance through an employer or another “group” policy tend to have the most comprehensive private coverage. And private insurance has its benefits. People with private insurance often have the advantage of being able to start HIV treatment early, but many lose their coverage as their disease progresses (often because they lose their jobs).<sup>47</sup> A RAND study of HIV-related mortality and insurance status found better outcomes (in terms of premature death) among people with HIV with private insurance compared with those on public insurance.<sup>48</sup> The RAND researchers concluded that this difference can be explained by restrictive Medicaid prescription drug policies in some states that limit access to treatment.

An American with HIV who is not already insured or eligible for insurance through an employer often faces a nearly impossible task in trying to find private insurance coverage. One study of the private insurance market determined that people with HIV are “generally considered uninsurable” and are routinely rejected by insurance companies.<sup>49</sup> Even where private insurance is available to people living with HIV/AIDS it may not be affordable. In most cases, there are no limits imposed on the rates insurance companies can charge, and many companies impose annual or lifetime caps on benefits, as well as copayment and deductible requirements that may be prohibitive for many individuals dealing with a chronic, disabling disease.

The health insurance industry is largely regulated at the state level. A decade ago, Congress passed legislation intended to help individuals seeking private coverage. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) established national standards for regulation of health insurance. But HIPAA does not place limits on insurance rates nor does it ensure access to private insurance for those without prior group coverage.

## The importance—and limitations—of private sector giving

Private sector funding from foundations, corporate entities, and other sources has often played a catalytic role in U.S. AIDS services and policy, though total private sector giving is dwarfed by government programs. A survey by Funders Concerned about AIDS found that in 2003, U.S. grantmaking organizations gave an estimated \$394.5 million for HIV-related research and services, representing a 31 percent increase from the previous year.<sup>50</sup>

The vast majority of this funding was dedicated to addressing the global epidemic, with only \$51.9 million going to domestic U.S. AIDS efforts. Nearly three-quarters of the domestically-oriented funding went to HIV/AIDS awareness, prevention, and social services. Private funding focused on domestic needs was concentrated in grants in the Northeast and

West of the country, even though high HIV incidence and poverty rates make the South a compelling candidate for additional support from private funders.

Several government programs are aimed at promoting the engagement of the private sector in the domestic epidemic. The CDC sponsors the Business Responds to AIDS and Labor Responds to AIDS programs, which help businesses and labor unions develop comprehensive workplace programs and work within their communities. For example, United Auto Workers Local 12, in partnership with the American Red Cross, has created award-winning programs, including presentations at high schools and junior high schools on the impact of AIDS, and has hosted HIV Testing Day activities. There are a variety of grant and support programs through the NIH to harness private sector expertise on research and product development of new AIDS treatment and prevention technologies.

### **Experience: the central human resources issue**

While some parts of the country, particularly rural areas, experience shortages of health care personnel, human capacity limitations are not often cited as a critical issue in the U.S. domestic epidemic. The major personnel issue appears to be experience. Because HIV disease is complex to treat, and because the standards of appropriate therapy are evolving rapidly, the experience of health care personnel is critical to the quality of care they can provide. It is also fair to say that effective HIV prevention is equally complex and requires well-trained and experienced practitioners.

The HCSUS study found that HIV patients in rural areas were more likely than urban residents to see physicians who treated few people with HIV.<sup>51</sup> Rural patients were also less likely to have taken the combination ARV therapies that were becoming increasingly available at the time of the HCSUS study. Other studies have identified a link between greater physician and hospital experience with treating HIV to improved patient outcomes and reduced reliance on emergency rooms for care.<sup>52</sup>

# Prevention

## Prevention policy

*By 2003, establish time-bound national targets to achieve the internationally agreed global prevention goal to reduce by 2005 HIV prevalence among young men and women aged 15 to 24 in the most affected countries by 25 percent. . . .*

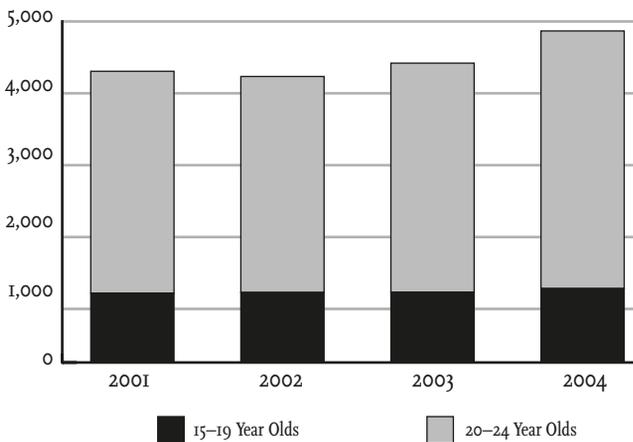
*–UNGASS Declaration of Commitment<sup>53</sup>*

*By 2003, establish national prevention targets, recognizing and addressing factors leading to the spread of the epidemic and increasing people's vulnerability. . . .*

*–UNGASS Declaration of Commitment<sup>54</sup>*

Evidence-based HIV prevention programming has been highly successful in the United States. Annual incidence of infection has fallen from its peak of 160,000 in the mid-1980s and prevention research has exhaustively documented the efficacy of specific interventions with populations at higher risk. Without HIV prevention programming, current incidence would likely be significantly higher. It has been estimated that HIV prevention programs averted between 204,000 and 1.585 million new infections during the period from 1978 through 2000.<sup>55</sup> Several studies have identified HIV prevention interventions that actually save money or are considered cost effective<sup>56</sup> (i.e., the cost per life years saved is considered reasonable when compared with interventions for other diseases).

**Chart 8: Cases of HIV/AIDS among Young Adults (35 areas with name reporting)**



The annual HIV transmission rate, an estimate of the percentage of people with HIV who pass their infection to others, has fallen significantly over the course of the U.S. epidemic. In 1983, the rate was 43.09 percent but within two years had been reduced to 25.23 percent. Many have attributed this dramatic change in large part to community mobilization around HIV awareness and prevention. Today, the transmission rate is between 4 percent and 4.34 percent, meaning that approximately 96 people living with HIV/AIDS do not transmit the virus to others in a given year.<sup>57</sup> As David Holtgrave of Johns Hopkins University has pointed out, this means that the overall U.S. HIV transmission rate has reached approximately the same level as the perinatal HIV transmission rate. This is particularly impressive, since programs to prevent perinatal infection have the advantage of a biomedical intervention (i.e., ARVs) and regular interactions between pregnant women and health providers.

Knowledge of serostatus coupled with appropriate counselling and other prevention interventions is a powerful HIV prevention tool. People who know their HIV status are now highly unlikely to transmit HIV to others. It is estimated that the HIV transmission rate among those who know they are HIV positive is 1.7 percent to 2.4 percent, compared with 8.8 percent to 10.79 percent for those who are unaware of their serostatus.<sup>58</sup>

The important successes of HIV prevention and evidence of the efficacy, cost-savings, and cost-effectiveness of prevention interventions suggests that further, and dramatic, reductions in HIV incidence are within reach. Yet the United States has failed to make progress on reducing annual incidence for well over a decade. Every year, 40,000 Americans are newly infected with HIV—110 people per day, an estimated 55 of them African American.<sup>59</sup> It is therefore a particular concern that funding for domestic prevention has been relatively flat for years. In addition, political concerns stand in the way of applying proven-effective prevention interventions, such as needle exchange, with the result that many people at elevated risk of HIV do not have access to, or information about, the full range of effective prevention interventions. (In the U.S., HIV prevention programming policy is largely determined on the state and local levels. But state policy is influenced by federal funding and policy guidance, which is often driven by national-level political concerns. This paper focuses on federal policy issues.)

**Themes across published scientific reviews of prevention efficacy:**

- Individual, group, and community interventions can effect change in behavior
- Condoms can reduce HIV transmission
- Sterile injection equipment exchanges can reduce HIV transmission and serve as a conduit to drug treatment
- Blood and occupational safety can be effectively safeguarded
- Perinatal infections can be reduced substantially using HIV therapies administered to pregnant women

*Holtgrave, D, Curran J "What works, and what remains to be done, in HIV prevention in the United States," Annual Review of Public Health, 2006.*

Despite ongoing efforts to encourage people to be tested for HIV, it is estimated that one in four people who are HIV positive do not know it.<sup>60</sup> Because the United States does not have an annual, nationally representative survey or other measure of incidence, this figure remains an estimate. Reliance on case reporting of HIV infection in a subset of U.S. states, as opposed to population-based studies, blinds policymakers to true annual incidence and may fail to identify pockets of infection where intensive interventions are needed.

When surveys are done in particular population groups, they sometimes produce deeply troubling findings. For example, in 2004 and 2005 the CDC randomly sampled men who have sex with men at bars, clubs, and other locations in five metropolitan areas.<sup>61</sup> Of the 1,767 men sampled, one in four were HIV positive and nearly half (46 percent) of the African American men were positive. Of those who were infected, nearly half (48 percent) were not aware of their serostatus, even though the majority of these men said they had previously been tested for HIV. Studies like these reveal concentrated HIV epidemics where testing and proven-effective interventions are urgently needed.

## **An ongoing disconnect between research and policy**

Vulnerable groups are consistently identified in federal policies and program documents, but the extent to which the needs of these vulnerable groups are met by current prevention and treatment services in practice is not clear.

Two of the most contentious issues in HIV prevention policy have been sex education and condom availability for young people and needle exchange for injection drug users. The controversy over prevention efforts for youth persists despite a growing consensus about what is effective. A statement published in the *Lancet* in November 2004 and signed by a broad

### **Common Ground on HIV Prevention**

- Ensure prevention activities are grounded in the science of epidemiology, supported at the local level, and respectful of human rights
- Promote abstinence among those young people who are not yet sexually active, encouraging mutual monogamy among sexually active adults, and helping individuals who engage in high-risk activities to stop
- Encourage correct and consistent condom use among individuals who are engaging in high-risk activities and those who are sexually active with a partner whose HIV status is unknown
- Expand prevention programs for young people both in and out of school, supporting parents “in communicating their values and expectations about sexual behaviour”
- Employ community-based approaches

*“The Time has Come for Common Ground on Preventing Sexual Transmission of HIV,” The Lancet, November 27, 2004*

range of religious, political, public health, and science leaders called for an end to the “polarizing debate” on sex education and laid out consensus points for this education (see page 48).<sup>62</sup>

Even so, since 1996 the federal government has allocated almost \$1 billion dollars on abstinence-only-until-marriage programs, and it is estimated that of those school districts that have a sex education policy, 35 percent teach abstinence as the only option outside of marriage, with discussion of condoms either prohibited entirely or permitted only to emphasize its shortcomings.<sup>63</sup> This approach to teaching about sexuality and HIV persists even though a wealth of studies and program evaluations have failed to find abstinence-only programs to be effective.<sup>64</sup> Conversely, an array of individual studies and meta-analyses have determined that comprehensive sex education programs that include information about both abstinence and contraception can be effective in helping young people delay the onset of sexual experience, increase condom use when they do have sex, and reduce their number of sexual partners.<sup>65</sup>

Concern about an abstinence-only approach to sex education is also justified by government surveys that suggest young people need information on safer sex, condom use, and negotiation strategies with sexual partners. The Youth Risk Behavioural Survey (YRBS) consistently reports that approximately half of all high school-aged youth say they have had intercourse at least once.<sup>66</sup> Moreover, nearly a quarter of teenagers who say they have never had sexual intercourse also say they have engaged in oral sex, according to the data released by the National Center for Health Statistics in 2005.<sup>67</sup>

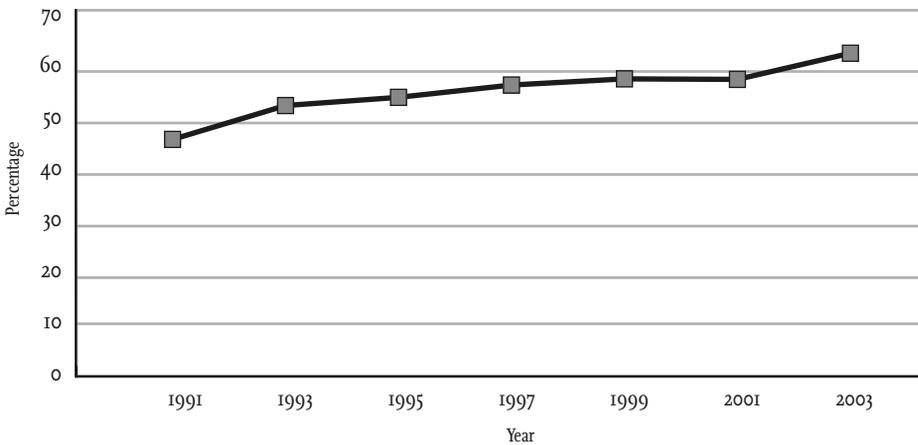
In September 2005, the Sexuality Information and Education Council of the United States (SIECUS) filed suit against the federal government claiming that the curricula commonly used by abstinence-only groups funded by the government provide “inaccurate or incomplete information” and thus violate the Data Quality Act.<sup>68</sup> Also in September, Maine became the third state (after California and Pennsylvania) to reject federal abstinence-only funding because, according to state officials, this funding came with too many content restrictions.<sup>69</sup>

Many high schools do not make condoms readily available to teenagers, even though research has found that in schools where condoms are available students are less likely to be sexually active and more likely to use condoms if they are having sex.<sup>70</sup> In 2003, a CDC fact sheet on condom effectiveness and use was removed from the agency website for an extended time.<sup>71-72</sup> Condom policy debates aside, it is worthwhile noting that young people appear to be increasing their use of condoms. As shown in the chart, reported condom use at last sexual encounter has been increasing over the past several years.

Consistent research findings on the positive impact of needle exchange programs have not succeeded in altering federal policy prohibiting use of federal monies for these programs. A study conducted by Beth Israel Medical Center in 2005 reported that, as of three years earlier, public financing for NEPs had declined and the number of syringe exchange programs in the United States had decreased for the first time in eight years.<sup>73</sup> Still, the study found that the total number of syringes exchanged and total budgets for NEPs (funded largely through private sources) had increased.

In 2003, three members of Congress raised concerns about a new CDC requirement for states to certify that CDC-funded local prevention plans do not violate a statute that prohibits promotion of sexual activity or drug use. Since there was already a process for reviewing these plans, some saw the new CDC requirement as a way of pressuring localities to avoid funding programs that directly address sexual and drug use activity, the primary routes of HIV infection in the U.S. epidemic.<sup>74</sup>

**Chart 9: Condom Use at Last Sexual Encounter—High School-Aged Youth**



## The epidemic in prisons

The nation's prisons are often criticized for providing inadequate HIV prevention and treatment services. People in prison have long been identified as a group particularly vulnerable to HIV, and more recently hepatitis C (HCV) infection, due to the high prevalence of HIV and HCV in prison and the lack of measures within prisons to prevent transmission.

Many people who are incarcerated in the United States are living with HIV. In 2002, 2 percent of people in state prisons and 1.1 percent of people in federal prisons were known to be living with HIV; and in 2002, the overall rate of confirmed AIDS in the prison population (0.48 percent) was nearly three and a half times the rate in the U.S. general population.<sup>75</sup> Risk behaviors are also prevalent in prisons. In a study of men in prison in four regions of the United States, 57.5 percent of those interviewed reported direct knowledge of sexual behavior in prison, and 86.3 percent reported direct knowledge of substance use in prison.<sup>76</sup>

However, preventive measures that are available in many prison systems around the world<sup>77</sup> are rarely available in correctional facilities in the U.S.: condoms are only available in

a few facilities, bleach kits for cleaning needles or needle and syringe exchange programs are generally forbidden, and methadone maintenance therapy is rarely used, although evaluations of programs in the United States<sup>78</sup> and in other countries<sup>79</sup> have shown good results for these interventions.

Care for HIV/AIDS in prisons, long the subject of controversy, may be improving in some cases. A study released by the Bureau of Justice Statistics in August 2005 found that the AIDS-related death rate in jails and state prisons has significantly decreased over the last several years due to improved medical treatment and lawsuits filed by advocacy groups to improve conditions behind bars.<sup>80</sup> Yet there may be important differences in the quality of HIV care in correctional facilities and other settings, such as community-based clinics. In a survey of providers working in correctional settings, published in March 2006, respondents reported that important components of HIV care were not as widely available in correctional settings as they were in community-based clinics.<sup>81</sup>

The CDC Division of Tuberculosis Elimination has developed a variety of guidelines to diagnose and treat TB/HIV coinfection.<sup>82</sup> A CDC survey of TB prevention efforts in large city and county jails revealed that fewer than half of prisons surveyed had policies in place to offer HIV testing to patients who test positive on TB skin tests.<sup>83</sup> When the CDC evaluated medical records, it found that nearly 20 percent of inmates evaluated for TB were also reported to have HIV infection, but that nearly a third of the medical records lacked information on the inmates' HIV status.

When people living with HIV and HCV are released from incarceration, prison health issues necessarily become community health issues. One study found that an estimated 25 percent of all HIV-infected citizens pass through a correctional facility each year.<sup>84</sup> In 2005, Illinois enacted a set of policies to address disturbingly high infection rates among African Americans, with a focus on prison policy. The Illinois law mandates its Department of Corrections and county jails to offer HIV testing on a voluntary basis and at no cost to inmates, and to provide transitional case management and referrals for support services to HIV-positive prisoners in preparation for their release from prison.<sup>85</sup>

## Getting a clearer picture

In 2001, an IOM Committee reviewed U.S. HIV prevention policy and made a series of recommendations. The first was to get better information. The IOM panel said that the United States “needs a surveillance system that can identify new HIV infections and provide more accurate national estimates of HIV incidence.”<sup>86</sup>

Years later, the CDC still relies on name-based reporting of HIV tests, rather than extensive nationally representative surveys. Though the United States uses blinded seroincidence studies to track the epidemic in other countries, CDC makes only limited use of these

studies domestically. Part of the reason is that in the late 1990s Congress passed a law prohibiting HIV testing of newborns unless the results are given to parents, effectively prohibiting blinded seroincidence studies in this population.

## What the evidence suggests about reducing incidence

In addition to doing a better job of surveillance, the IOM panel on HIV prevention policy recommended allocating prevention resources to “prevent as many new HIV infections as possible, guided by principles of cost-effectiveness. . . .” In 2005, the RAND Corporation released a new study comparing the cost effectiveness of various HIV prevention interventions and the implications for domestic prevention policy.<sup>87</sup> RAND researchers Deborah Cohen and colleagues looked at the optimal allocation of \$400 million in HIV prevention resources. (This dollar figure was used because in FY 2004, the CDC provided \$415.5 million to state and local health departments for HIV prevention activities.)

The researchers determined that a mix of targeted and generalized interventions could cut HIV incidence in half—a 20,000 reduction in annual infections, in line with CDC’s stated target. Based on the published research, the interventions that hold the most promise for reducing incidence include community mobilization targeting men who have sex with men, needle exchange in high prevalence areas, partner notification, expanded condom availability, and mass-media campaigns.

The mix of optimally cost-effective interventions identified by RAND researchers is markedly different than the programming emphasized in the CDC’s Advancing HIV Prevention Initiative (launched in 2003).<sup>88</sup> That initiative focuses federal efforts on HIV testing, prevention interventions for people who are living with HIV or AIDS, and prevention of perinatal transmission. In the RAND analysis, the mix of programs emphasized by CDC program falls short of what is possible, holding the potential to reduce annual incidence by only 7,315 infections—12,685 fewer than the “optimal” mix based on cost-effectiveness research. The researchers acknowledged that “political considerations” are involved in selecting HIV prevention strategies, but they advised public health officials to use a “rational allocation scheme” like that in their study to answer political opposition to the delivery of evidence-based interventions.

The president’s new Domestic HIV/AIDS Initiative, announced in his January 2006 State of the Union address, continues the emphasis on testing with additional proposed funding of \$93 million for increased testing activities, including rapid testing. (The proposed FY 2007 increase in CDC funding, visible in the chart on page 53, reflects funding for the new initiative.)

The need for a more strategic HIV prevention approach based on evidence of effectiveness was emphasized by researchers David Holtgrave and former CDC Director Jim Curran, in an article in the *Annual Review of Public Health*.<sup>89</sup> The authors discuss the wealth of

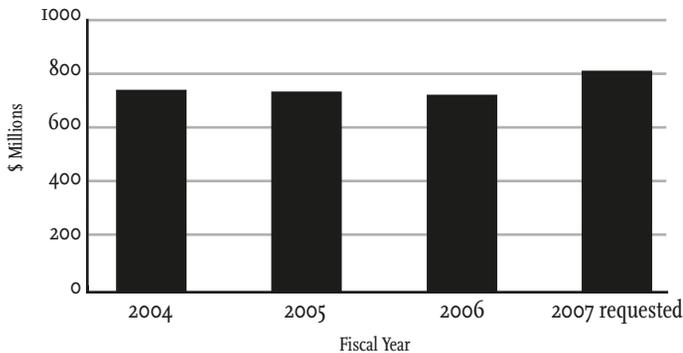
### The President's proposed Domestic AIDS Initiative—2006 State of the Union Address

- \$70 million to states to reduce waiting lists for AIDS treatments
- \$90 million to purchase and distribute rapid HIV test kits (\$20 million to test prisoners and \$20 million to test IDUs)
- \$25 million in grants to strengthen outreach by local community and faith-based organizations

research establishing the efficacy and cost effectiveness of various HIV prevention interventions, and they identify priorities for prevention funding that contrast with the current CDC initiative. Holtgrave and Curran argue that implementation of proven-effective prevention interventions in a comprehensive fashion is “hampered by insufficient funding, imperfect targeting strategies, and a problematic policy environment that creates barriers to the use of some of these life-saving interventions.”

On financing, the authors suggest that an annual incremental increase in HIV prevention funding of \$334 million over four years would be sufficient to address unmet HIV prevention needs. With an estimate of 20,000 infections prevented, the authors note that this increase would be highly cost effective. Finally, the authors call for a policy environment that supports evidence-based HIV prevention, raising concerns about the federal ban on support for syringe exchange and “clear instances in which scientific information [regarding HIV prevention] has been censored in whole or in part” by public agencies.

Chart 10: Funding for HIV Prevention at CDC



## Linkage with treatment and other health services

Counselling and testing play a crucial role as the gateway to treatment for people living with HIV/AIDS and an opportunity to provide prevention services to both HIV-positive and HIV-negative individuals. As noted above, prevention services for HIV-positive individuals have been a major focus of recent CDC prevention efforts. HIV testing is generally available at locations where other sexually transmitted infections (STIs) are diagnosed and treated.

Individuals who test HIV positive are most likely to have been diagnosed in hospital inpatient settings or by a private doctor or HMO medical office.<sup>90</sup> The CDC funds over 11,000 HIV testing sites in the United States, and in 2000 approximately 2 million tests were done at those sites. Nearly a third (31 percent) of people who tested positive for HIV at CDC-funded sites in 2000 did not come back for their test results.<sup>91</sup> It is hoped that greater use of rapid testing will increase the percentage of people who receive their HIV test results. HIV testing is generally available at STI clinics and sites providing antenatal care.<sup>92</sup>

To the extent people receive their HIV test in the context of a health care visit, there is hopefully a direct link to appropriate care. Links to health care through CDC-funded testing sites may be less direct and difficult for CDC to affect, given that the agency focuses on prevention services rather than care delivery or financing. CDC prevention plans have been criticized for not providing sufficient emphasis on the link between testing and access to care.

Of particular concern is that many people are coming forward for testing late in the course of the disease, largely losing the opportunity for early intervention against HIV. In 2003, 39 percent of those diagnosed with HIV received an AIDS diagnosis within a year.<sup>93</sup>

# Treatment

## Access to treatment

*By 2003 ensure that national strategies . . . are developed . . . to strengthen health-care systems and address factors affecting the provision of HIV-related drugs . . . [and] make every effort to provide progressively and in a sustainable manner, the highest attainable standard of treatment for HIV/AIDS.*

–UNGASS Declaration of Commitment<sup>94</sup>

Many people who are able to access HIV care in the United States are likely receiving some of the highest quality care in the world. In numerous urban areas of the country there are scores of doctors and other health care professionals who specialize in HIV/AIDS care as well as many community-based support services. The United States leads the world in HIV treatment research.

Yet the share of people not receiving these high standards of care is shocking. Data from the HCSUS study, published in 1999, indicated that only one-third to one-half of people living with HIV/AIDS were in regular care as of 1996.<sup>95</sup> The most recent estimates are that about half (42 percent to 59 percent) of all people living with HIV/AIDS in the United States are not in regular HIV care.<sup>96</sup>

System failure of this magnitude is not easily explained, but clearly involves both complexities and inequities in the health care system as well as structural issues such as discrimination and poverty, and personal factors—all of which complicate health care seeking and adherence to medical regimens. The IOM financing panel suggested that, “the combination of financing structures and individual characteristics such as race/ethnicity and low income level interact to exacerbate disparities in health care.”<sup>97</sup> The panel cited a number of structural barriers to appropriate care such as cost-sharing requirements (including copayments) and low Medicaid reimbursement rates that discourage providers from treating poor individuals with HIV.

Delayed eligibility for both the Medicaid and Medicare programs are critical issues in care access. Medicaid provides coverage to low-income individuals who meet state-determined income and asset tests. The program also generally requires that individuals meet the federal definition of being “disabled” unless they are eligible through another program (such as transitional assistance to families). The disability requirement means that people in early stages of HIV disease are generally unable to receive Medicaid-funded health care. Medicare provides reimbursement for health care for the elderly and those who have sufficient work history to be

### Using Medicare to Address Racial Disparities in Health Care

The Medicare program has made important contributions to reducing disparities in health coverage in the United States. The National Academy of Social Insurance has identified policy options that would allow the program to make an even bigger impact.

These include the following:

- Reduce or eliminate the Part B premium, deductibles, and copayments
- Enhance the benefit package to pay for additional services
- Increase reimbursement rates for services related to diseases (like HIV) that are more prevalent in communities of color
- Provide incentives to providers who meet targets for reducing disparities

*Eichner, J, Vladeck, B, "Medicare as a catalyst for reducing health disparities," Health Affairs, vol. 24, no. 2, March/April 2005*

eligible for disability services and live long enough to qualify. It takes 29 months after disability is determined for a nonelderly person to begin receiving Medicare-financed care.

State control over their Medicaid programs results in wide disparities across the country in program eligibility and benefits. In addition, fiscal pressures are driving states to place new controls on Medicaid costs. According to a survey done by the Kaiser Family Foundation in 2004, 43 state Medicaid programs were planning to implement controls on pharmacy costs, nine states were planning to reduce or restrict benefits, and nine states were planning to increase copayments.<sup>98</sup>

In October 2005, the federal government gave approval for Florida to make significant changes to its Medicaid program include placing absolute limits on spending and allowing private insurers more room to limit benefits. As Joan Alker at the Health Policy Institute at Georgetown was quoted as saying, "The federal government and the states now decide which benefits people get. Under the Florida plan, many of those decisions will be made by private health plans, out of public view."<sup>99</sup> The federal approval of Florida's Medicaid plan was widely seen as an augur of things to come across the country.

Many barriers to appropriate HIV care involve more personal and structural issues. As noted earlier, approximately one quarter of people living with HIV/AIDS do not know they are infected and so are not seeking care. As the epidemic increasingly affects poor and marginalized communities, a growing number of people living with HIV may feel disenfranchised from health care services generally, or face so many competing emergencies in their lives that seeking ongoing HIV care is not seen as a top priority. According to one study,

people in rural areas may face a variety of barriers to HIV care, including “geographic isolation, poverty, unemployment, lack of education, lack of childcare services, and attitudinal and cultural factors.”<sup>100</sup>

People who have substance abuse or mental health problems also face increased barriers to receiving HIV care and adhering to treatment regimens.<sup>101</sup> U.S. government ARV treatment guidelines acknowledge that lower access to and utilization of HIV care among injection drug users involves several factors, including “active drug use, younger age, female gender, suboptimal health care, not being in a drug treatment program, recent incarceration, and lack of health care provider expertise.”<sup>102</sup>

At the same time, numerous studies demonstrate that many people who face enormous personal hurdles in receiving HIV care and adhering to treatment, including homeless individuals, are able to comply with therapy at rates equal to the general HIV population.<sup>103</sup>

## **Discrimination remains a potent force**

*By 2003, enact, strengthen, or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against and to ensure the full enjoyment of all human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups.*

*—UNGASS Declaration of Commitment<sup>104</sup>*

Federal law prohibits discrimination against people living with HIV/AIDS but such discrimination certainly exists and is one additional factor inhibiting access to care and treatment.<sup>105</sup> In 2003, the American Civil Liberties Union released a report documenting civil rights violations against people living with HIV/AIDS in employment, child custody and visitation, medical care, and housing.<sup>106</sup> In a Kaiser survey released in June 2004, 28 percent of respondents said they would be “somewhat” or “very uncomfortable” working with someone who has HIV or AIDS.<sup>107</sup> The Americans with Disabilities Act is widely interpreted as outlawing discrimination against people living with HIV and AIDS based largely on a 1998 Supreme Court ruling. Yet the ADA does not specifically mention HIV so the extent of these protections at the federal level is not entirely clear.

## ARV Availability and Delivery

### *Who gets lifesaving drugs?*

ARV therapy has proven enormously effective in the United States, dramatically reducing the AIDS death rate and significantly improving the quality of life for hundreds of thousands of people living with HIV/AIDS. But as with HIV-related health care, the estimates regarding access to these drugs is startling. There are no precise measures of ARV access and utilization, but a study by Jim Kahn and colleagues from 2002 indicated that slightly fewer than half of those who need ARVs were receiving the drugs.<sup>108</sup> An analysis by Eyasu Teshale and colleagues published in 2003 suggested that approximately 55 percent of people living with HIV/AIDS who are eligible for ARV treatment according to current guidelines are actually receiving this care.<sup>109</sup>

There are a variety of reasons that help explain why nearly half of the U.S. HIV population is not receiving appropriate drug therapy. Several of these factors, discussed above, have to do with limits and disparities in public and private insurance coverage and access to HIV-related health care generally. Other factors are related to drug access in particular. As of February 2006, 26 state ADAP programs had either implemented waiting lists or other cost-containment measures or were considering these measures, according to the National Alliance of State and Territorial AIDS Directors (NASTAD).<sup>110</sup>

State ADAP programs and drug formularies vary considerably. For example, as of early 2006, 20 states do not provide all FDA-approved ARVs; 11 state ADAP programs did not cover Fuzeon, the one approved fusion inhibitor for treatment of HIV disease.<sup>111</sup> Some states now finance a maximum of as few as three medicine prescriptions per month per beneficiary through their Medicaid programs. This is, of course, highly problematic given that many HIV treatment regimens include many more than three medicines.

Until January 2006, the Medicare program did not pay for prescription drugs. Drug coverage is now being extended to the Medicare population, and Medicare is now required to cover all ARV medications for Medicare eligible people living with HIV/AIDS. The new Medicare drug regulations stipulate that drug purchases funded by ADAP cannot be counted towards the Medicare drug catastrophic coverage threshold, thus potentially requiring thousands of dollars of out of pocket expenditures by people living with HIV/AIDS before Medicare begins paying for their medicines. Commentators are concerned that the new Medicare drug law prohibits the federal government from using its purchasing power to negotiate lower drug prices from pharmaceutical companies.

As noted earlier, cost-sharing schemes and caps on Medicaid spending seriously threaten drug access for the low income population.

## Linkage with prevention and opportunistic infections

Treatment for opportunistic infections is generally available to individuals who have some form of public or private health coverage, but the range of treatments provided may vary. As of February 2006, 22 ADAPs covered 15 or fewer of the 29 drugs highly recommended for treatment of opportunistic infections.<sup>112</sup> Only 26 ADAPs covered drugs for treatment of hepatitis C.

Clinical care obviously presents valuable prevention opportunities, both to provide HIV testing and deliver prevention messages to HIV-positive and HIV-negative individuals. A recent study supported by the Kaiser Family Foundation examines the challenges and opportunities for delivering HIV in clinical care with a focus on HIV services provided through Medicaid and the CARE Act.<sup>113</sup> The Kaiser study concluded that while current law allows for delivery and funding for HIV prevention services through these programs, Medicaid and CARE are not delivering a significant quantity of HIV prevention services. According to the report authors, expansion of prevention through Medicaid and CARE would require policy changes on the state and local level and shifting of current resources.

## Care and Support

No federal law establishes a U.S. federal responsibility to provide health care to all citizens. Instead of guaranteeing universal access to HIV care the government attempts to meet the care needs of the population through a variety of programs that include Medicaid, Medicare, and the CARE Act. An individual's access to diagnostic and treatment services for opportunistic infections (including TB) is subject to all of the complexities involved in access to care discussed earlier.

Hospice services are generally recognized as one area of relative success in the U.S. response to the domestic epidemic. The wide availability of quality hospice care is due largely to the fact that nearly all hospice-related services are reimbursable by Medicare and Medicaid, and by the time individuals need such services they are likely to have become eligible for one of these public plans. Hospice services are one of the areas where faith-based organizations play a particularly crucial role.

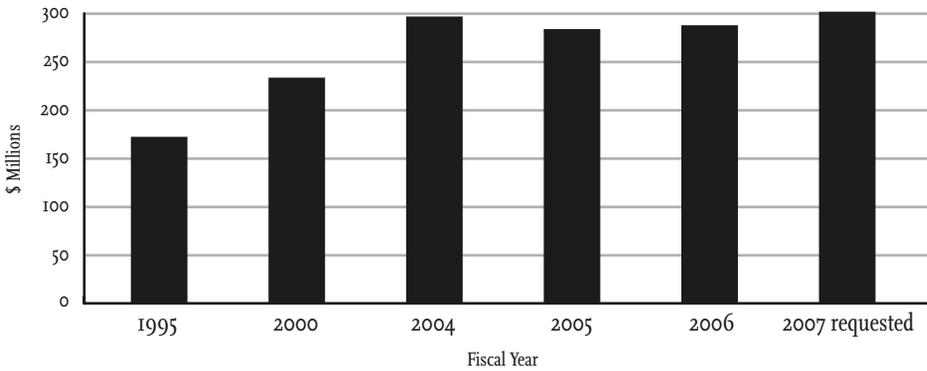
The federal government also provides dedicated resources to address the housing, mental health, and substance abuse treatment needs of people living with HIV/AIDS. HOPWA funds housing assistance and related support services for low income persons with HIV/AIDS and their families. As noted above, HOPWA funding levels have been relatively flat over the last several years, even as the number of low income people living with HIV/AIDS has grown

steadily. HOPWA grew from \$282 million in FY 2005 to \$286.1 million in FY 2006, and the administration has requested an increase to \$300.1 million in FY 2007.

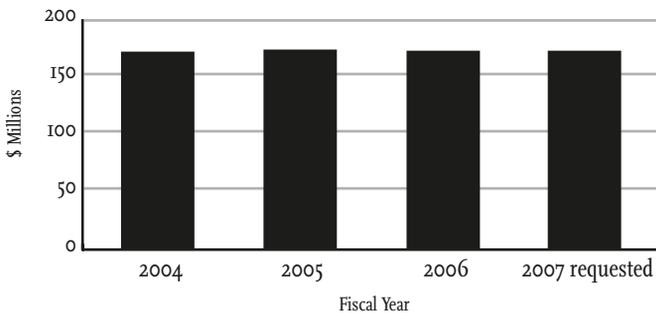
Advocates have raised concerns that most AIDS housing programs actively discriminate against people who use illegal drugs, making it more difficult to bring drug users into care and help them adhere to treatment regimens.

Substance Abuse and Mental Health Services Administration HIV-related programs have also seen stagnant budgets over the last several years, declining from an overall agency figure of \$173 million in FY 2005 to \$172 million in 2006, and with a presidential budget request of \$172 million for FY 2007.

**Chart 11: HOPWA Funding**



**Chart 12: SAMHSA HIV-Related Funding**



# Monitoring and Evaluation

*Develop appropriate monitoring and evaluation mechanisms to assist with follow-up in measuring and assessing progress, and develop appropriate monitoring and evaluation instruments, with adequate epidemiological data. . . .*

—UNGASS Declaration of Commitment<sup>114</sup>

The federal government employs a variety of monitoring and evaluation approaches to track implementation of AIDS-related services. Several gaps in program monitoring have been identified. More information about the specific outcomes of HIV prevention and treatment interventions, and barriers to more effective programming, would help improve the federal response.

In 2004 the CDC introduced the Program Evaluation and Monitoring System (PEMS) to assess the work of CDC HIV-prevention grantees and monitor outcomes from CDC-funded programs. PEMS will ask health departments and community-based organizations to answer questions regarding representation on community planning groups and the correspondence of local HIV prevention programming to CDC priorities identified in the CDC HIV prevention plan. Some advocacy groups have raised serious concerns that the CDC did not adequately consult community organizations during the development of PEMS and that the gathering and reporting of the information required by PEMS will complicate HIV prevention outreach activities.<sup>115</sup> In March 2006, CDC announced that it would suspend implementation of PEMS until the fall in response to community concerns. It will be years before data from the program is available.

The government's program measurement strategies employed in PEPFAR are worth noting here. An assessment of prevention indicators used in the PEPFAR program found that these indicators emphasize measuring activities related to abstinence and faithfulness and give less emphasis to measures of other behavior change, including condom use. The PEPFAR indicators include no measures of prevention interventions for injection drug users—for example, referral of injection drug users to drug treatment.<sup>116</sup>

The Program Assessment Rating Tool (PART) system evaluates the performance of agencies across the government. The FY 2004 PART report on CDC competitive grants for domestic HIV/AIDS prevention concluded that results were “not demonstrated.” The report cautioned that, “The program does have long-term health outcome goals, but not specific targets and timeframes that are consistent with the existing budget. It also has no data on these long-term outcome goals.”<sup>117</sup>

The CARE Act received higher marks from PART. The evaluation found that “the program has contributed to the overall decline in the number of AIDS cases and deaths due to HIV.” However, the PART report noted that, as the CARE statute is written, it allows dupli-

cation of services among providers.<sup>118</sup> The Institute of Medicine HIV financing panel in 2004 raised concerns about insufficient monitoring in the CARE program, noting that absence of nationwide data on individuals served and the services they received “hinders accountability, quality monitoring, and outcomes evaluation” of the program.<sup>119</sup>

Program quality and conformity with congressional mandates are also measured through audits of both federal agencies themselves and federal contractors. As noted above, members of Congress have recently raised concerns about government audit practices, alleging that audits have been used to intimidate some HIV prevention providers.

Federal law includes a variety of requirements to solicit public input. For example, many rules established by federal agencies must be published in the Federal Register. Often new rules are not implemented until after a public comment period.

The U.S. government failed to provide data on its progress toward accomplishing 2003 interim targets for the UNGASS Declaration of Commitment on HIV/AIDS.

# Recommendations

## Concrete steps to bring the United States into compliance with its UNGASS commitments

The U.S. response to the domestic AIDS epidemic has yielded many impressive results. Medical research has produced powerful therapies and effective prevention interventions, comprehensive care and treatment has led to steep reductions in AIDS-related mortality, and prevention activities have reduced annual HIV incidence.

The response to AIDS has driven important changes in health research and care in the United States, from better understanding of viral pathogenesis, to new approaches to health care financing, to changing expectations about the role of patients in managing their own care. AIDS has also revealed again many stark inequities in America—inequities that affect risk for acquisition of HIV and the potential to benefit from treatment. Far too many Americans living with HIV are not receiving appropriate care, and far too many are newly infected each year.

The review of America's response to AIDS in this report suggests that the following actions are urgently needed by the national government, civil society, and the private sector:

1. **Establish a national HIV/AIDS strategy that focuses on outcomes**

- **Develop a national HIV/AIDS strategy** across federal, state, and local agencies that comprehensively addresses delivery of prevention, treatment, and other services and identifies clear roles, responsibilities, and timelines to achieve measurable results. A greater focus on short and long-term outcomes and strategic use of resources is needed in federal AIDS programming. Outcomes targets should be set for HIV incidence, care access and utilization, and treatment quality. Targets should be set across, as well as within, program funding streams. These targets should be part of a comprehensive and systematic effort to evaluate program effectiveness, identify lessons learned, and recalibrate approaches. Federal agencies should be held accountable for achieving outcome goals. HHS should issue an annual report on HIV prevention and treatment outcomes and quality, and identify policy and program modifications based on observed results.
- **Get better information.** AIDS prevention and treatment efforts are weakened by incomplete information about where new infections are occurring and who is benefiting from AIDS care and treatment. It has been several years since the

HCSUS study provided nationally representative data on health care utilization among people living with HIV/AIDS. This kind of information is needed on an ongoing basis in order to improve the reach and quality of treatment services. The CDC's recent support for new surveillance studies, including the Morbidity Monitoring Project, should be encouraged. Funding for surveillance activities at the state and local level is woefully inadequate and must be increased in order for states and community organizations to provide better information to CDC. Surveillance should be included for co-morbid conditions such as hepatitis C as well, which is even more underfunded than HIV surveillance. Surveillance and prevention program monitoring should not create undue burdens on HIV prevention providers. CDC should develop a plan to make better use of available epidemiological tools so that the agency can more fully understand the current dynamics of HIV incidence. HRSA should develop a plan to address concerns of the Institute of Medicine AIDS financing committee with regards to measuring utilization of CARE-funded programming.

- **Better understand barriers to care and treatment.** Barriers to access to HIV care and treatment are complex and combine both system failures and personal and structural issues. Congress should commission an Institute of Medicine study to identify, understand, and make recommendations for addressing barriers to wider access to, and utilization of, HIV care. The HHS annual report recommended above should include an update on implementation of the recommendations identified in the proposed IOM study.
- **Civil society has an enormously important role** in helping design the proposed national strategy and holding the government accountable for setting and meeting new prevention and treatment targets. Advocates will need to closely monitor development of more systematic approaches to racial disparity, prevention and treatment access, and other priorities noted here. Civil society also has a vital role in reviewing federal and state programming and policy to ensure it is based on the best available evidence of what works.

## 2. **Comprehensively address racial disparities**

- **Initiate outcomes-oriented, cross-agency approach:** Addressing racial disparities should be a fundamental component of each element of the federal response. A more integrated, outcomes-oriented, government-wide approach is needed, involving operations research, ongoing assessment of program effectiveness, social level interventions, support for community organizations, supportive services (like housing) and—again—clear targets for improvement tied to systematic assess-

ment and recalibration of policy and programming. Target services to those who are left out of current systems of care. Expand research on behavioral prevention interventions appropriate for diverse African American communities, including gay African Americans and African American men who have sex with men.

- **Acknowledge the structural underpinnings.** The ongoing and pervasive impact of poverty, racism, homophobia, and gender inequality as driving forces in the epidemic must not be underestimated. There are no easy answers to these difficult and complex social problems, but public and private sector leaders who care about better long-term outcomes should acknowledge these challenges and make addressing them part of a comprehensive response to the epidemic.

**The success or failure of US efforts to confront the domestic AIDS epidemic will be determined by how effective they are in addressing the AIDS epidemic in black America. Priorities include:**

- Work with black leaders to build a mass black community movement to end HIV/AIDS
- Expand delivery of proven prevention interventions, including needle exchange and comprehensive sex education
- Expand access to treatment by providing needed financing, adequately funding the CARE Act, and removing policies that shift Medicaid costs to poor families
- End debilitating stigma that helps HIV spread, including homophobia
- Provide resources to build health care and community infrastructure to enable communities to better respond to HIV
- Ensure a more robust outcomes-oriented federal effort to address health disparities
- Provide comprehensive HIV testing, prevention, and treatment services in prisons

*Based on The Way Forward: The State of AIDS in Black America, by the Black AIDS Institute and the NAACP, 2006, and on discussions with the advisory committee for this report*

### 3. Dedicate increased resources to proven-effective interventions

- **Use proven tools to bring HIV incidence down:** HIV prevention interventions have helped bring incidence down sharply but a comprehensive effort is needed to achieve substantial new reductions. Resources for prevention need to be increased. Prevention interventions should be more effectively targeted, and their efficacy should be continually assessed. Funding decisions should be more closely informed by evidence concerning the most cost-effective use of resources. Condom availability in prisons and needle exchange and harm reduction programs are among the effective prevention strategies that should be supported. There are important opportunities to advance prevention efforts by focusing increased attention on evidence-based interventions in jails, prisons, schools, and clinical care settings. Targeted prevention strategies appropriate for different

ethnic and racial communities, gay men and men who have sex with men, girls and women, drug users, sex workers, and others need federal support. Congress should increase HIV prevention funding at the CDC.

- **Follow the (prevention) money:** In the late 1990s the CDC invited a group of academic and community representatives to review how federal HIV prevention resources were allocated among various centers within the agency. It is time for another comprehensive assessment so that Congress and the public can better understand how the CDC utilizes prevention resources. In addition, more information should be available on how states and cities are using prevention funding, particularly with regard to which risk groups are receiving the most attention. The CDC is currently not always able to provide breakdowns on allocation of funds by risk group. Better data and more detailed data collection is necessary, as is more transparent, timely reporting. CDC should create an ad-hoc committee to review HIV prevention spending at the agency and annually present data from states and cities regarding allocation of CDC funds by risk group and intervention.
- **Commit to delivering quality care more widely.** The IOM AIDS financing committee reviewed a variety of options for ensuring the quality and expanding the reach of AIDS-related care and treatment. These included expansion of the Medicaid, Medicare, and Ryan White CARE programs, as well as creation of a new federal entitlement program. The administration and Congress should act on the IOM AIDS financing recommendations, most likely by expanding or modifying existing federal programs to achieve quality and access goals. Consider setting quality standards for HIV care that states and other grantees are required to meet in all federally funded AIDS programs. Access to the Medicare and Medicaid programs should be expanded. A focus on making Medicaid work for low-income people living with HIV/AIDS could have an enormous impact on the reach and quality of AIDS care. Cost-sharing requirements for poor Medicaid recipients should be reduced or eliminated. Congress must appropriate increased resources through all titles of the CARE program, including, but not limited to, ADAP. The administration should not approve state requests to alter the Medicaid programs in a way that would make needed health care less accessible to the poor.
- **Address the context of risk and care.** Increased resources are needed to address the housing, mental health, and substance abuse issues of people living with HIV/AIDS and people at elevated risk for HIV. More research and innovative programming are needed to examine other contextual issues in risk and care

access, including support for behavioral and structural interventions that address environmental risk factors and work to reduce HIV/AIDS stigma, discrimination, and racial/ethnic health disparities.

- **Private sector health care providers should collaborate** closely with public providers and agencies to expand HIV prevention services in the context of clinical care.
- Maintain the commitment to a **robust research effort** (primarily through the National Institutes of Health and the Centers for Disease Control and Prevention) to continue to discover and implement ever-more effective HIV prevention and treatment strategies.

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[We] acknowledg[e] the particular role and significant contribution of people living with HIV/AIDS, young people and civil society actors in addressing the problem of HIV/AIDS in all its aspects, and recogniz[e] that their full involvement and participation in the design, planning, implementation and evaluation of programmes is crucial to the development of effective responses to the HIV/AIDS epidemic.

—UNGASS Declaration of Commitment on HIV/AIDS, Article 33

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Public Health Watch promotes informed civil society engagement in policymaking on tuberculosis and HIV/AIDS. The project's monitoring reports offer a civil society perspective on the extent to which government policies comply with international commitments such as the Amsterdam Declaration to Stop Tuberculosis and the Declaration of Commitment on HIV/AIDS—and on the extent to which those policies have been implemented. HIV/AIDS monitoring reports include assessments of policies in Nicaragua, Senegal, Ukraine, the United States, Vietnam, and Zambia.



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