
IMPROVING OUTCOMES

BLUEPRINT FOR A NATIONAL AIDS PLAN FOR THE UNITED STATES

PUBLIC HEALTH WATCH



OPEN SOCIETY INSTITUTE
Public Health Program

IMPROVING OUTCOMES

BLUEPRINT FOR A NATIONAL AIDS PLAN FOR THE UNITED STATES

Chris Collins

PUBLIC HEALTH WATCH



OPEN SOCIETY INSTITUTE
Public Health Program

Copyright © 2007 by the Open Society Institute

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form by any means without the prior permission of the publisher.

Published by

Open Society Institute

400 West 59th Street

New York, New York 10019 USA

www.soros.org

For more information:

Public Health Watch

Open Society Institute

Email: phwinfo@sorosny.org

Website: www.publichealthwatch.info

Design by Andiron Studio

Printed in the United States by Prestone

Contents

Summary	5
The Need for a More Effective Response to AIDS	7
Lack of Comprehensive Planning	9
Characteristics of a Strategic National AIDS Plan	13
The Development of an Effective National Plan	23
Acknowledgements and Notes	26

New approaches are needed to achieve steady progress against the complex challenges of the domestic AIDS epidemic.

Summary

The United States has allowed its domestic AIDS epidemic to become a chronic public health problem characterized by persistent levels of new infection, needless mortality, insufficient access to care, and disturbing racial disparities. Too many citizens continue to be denied the benefits of AIDS prevention and treatment programs that have already saved thousands of lives and prevented many more infections.

New approaches are needed to help Americans hold their government, and themselves, accountable for steady progress against the complex challenges involved in the domestic AIDS epidemic. It is time the United States develops what it asks of other nations that it supports in combating AIDS: a national plan that provides a roadmap for concrete and equitable results.

In the 26 years since the AIDS epidemic was recognized, a variety of advisory bodies have proposed ways to improve the nation's response to AIDS. Yet in many cases solid recommendations have been met with inaction and worthy goals have been forgotten. Few of the country's AIDS blueprints have been plans of action that set clear objectives, identified responsibilities and timelines, and included strategies to assess and refine efforts.

A national AIDS plan that transforms the way America addresses the epidemic would do the following:

- 1. Focus increased attention on concrete outcomes through reliance on evidence-based and cost-effective programming.**

2. Set ambitious, visible, and credible targets for improvement in a limited number of areas.
3. Identify clear priorities for action on the selected targets.
4. Set out specific objectives for multiple sectors, including government, civil society, community organizations, and business.
5. Make the prevention and treatment needs of African Americans a primary focus.
6. Promote and test innovative ideas about how to overcome structural barriers to more effective prevention and treatment.
7. Improve methods of measuring progress.
8. Make federal agencies responsible for coordinating the collaborative efforts of government, business, and civil society.
9. Require the Secretary of Health and Human Services to report regularly on the status of progress toward targets in the national plan.

America needs a national AIDS plan that is ambitious, visionary, and practical—a true plan of action that lays out specific steps to make progress in the near term while identifying more fundamental systems changes that can lead to significant and sustained improvements. An inclusive process that produces a plan with clear goals—backed by strategies and increased funding—could produce important results. And to the extent a national strategy helps demonstrate new and effective approaches to AIDS programming it could serve as a model for broader efforts to improve health care services for all Americans.

No comprehensive plan guides strategic use of AIDS-related dollars or holds government agencies accountable for steadily improved outcomes.

The Need for a More Effective Response to AIDS

Over 1.5 million HIV infections and over half a million deaths into its 26-year-old HIV/AIDS epidemic, the United States still does not have a comprehensive strategic national plan to tackle AIDS within its own borders. The United States will spend over \$16 billion on the domestic epidemic in fiscal year 2007. Allocation of those funds will be determined by a variety of federal laws, agency policies, and state and local decision-making processes. Many of the programs will be evaluated for effectiveness and prudent fiscal management. But no comprehensive plan will guide strategic use of AIDS-related dollars or hold government agencies accountable for steadily improved outcomes for people living with HIV/AIDS or at risk of infection.

Mediocre Outcomes

U.S. investments in HIV/AIDS continue to produce powerful results: preventing thousands of new HIV infections each year, delivering antiretroviral drug treatment that lengthens and improves the quality of life for tens of thousands of Americans, and breaking new ground in biomedical and other research. However, several stubborn facts about the AIDS epidemic in the United States point to the need for a more effective response:

- ▶ The number of annual new HIV infections has remained at an estimated 40,000 for over a decade.

- ▶ One quarter of Americans who have HIV do not know it.
- ▶ A significant percentage of people living with HIV/AIDS are tested for infection too late in the course of disease to benefit from early medical care.
- ▶ Approximately half of people living with HIV/AIDS are not receiving regular HIV-related health care.
- ▶ Approximately half of those who meet U.S. government medical criteria for use of antiretroviral treatment for HIV are not receiving this treatment.
- ▶ African Americans and other communities of color bear a severely disproportionate burden in the epidemic. Though blacks represent 12 percent of the U.S. population, between 2001 and 2004 they accounted for 51 percent of newly diagnosed HIV infections in the 33 states that had used confidential, name-based reporting of HIV and AIDS since 2001.¹ Black Americans living with HIV have not seen equal benefits from AIDS treatment: from 2000 to 2004, deaths among whites living with HIV declined 19 percent compared to 7 percent for blacks. Survival time after an AIDS diagnosis is lower on average for blacks than for other racial/ethnic groups.²

Fragmented and Uncoordinated Response

Government and private studies have consistently recognized the need for a more effective domestic response to AIDS. A government rating system found that domestic HIV prevention efforts are “not performing” and that “results [are] not demonstrated.”³ In 2004, an Institute of Medicine (IOM) panel reviewed the U.S. financing system for AIDS-related care and concluded 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.”⁴ Several states have waiting lines for their AIDS Drug Assistance programs (ADAP) that support access to antiretroviral therapy.

Decentralization of decision-making authority is one of the hallmarks of AIDS programming in the United States. Local and state advisory bodies that include people living with HIV/AIDS, community representatives, public health leaders, elected officials, and others make decisions about how to allocate an array of federal HIV prevention and care funding streams. In addition, Medicaid, ADAP, and other programs that provide services to people living with HIV/AIDS are funded and managed at least partly on the state level. This diffused authority means that AIDS programming can be responsive to locally defined needs, but it also complicates any effort to do comprehensive national planning or hold any particular level of government accountable for improved results.

Previous AIDS plans generally lacked clear goals, strategies, and actions—and very often good recommendations were not implemented.

Lack of Comprehensive Planning

There are many ways to define what “strategic planning” can mean in the context of a country’s AIDS policy and programming. A UNAIDS guide for national AIDS planners offers three ways of understanding strategic planning:

A strategic plan may be conceived as a general framework for implementing the national response. Such a strategic framework sets fundamental principles, broad strategies, and the institutional framework, and is the basis for a subsequent formulation of more operational priority projects and programmes. In the second option, the strategic plan would not only include the strategic framework as defined above, but also the more detailed strategies necessary to change the current situation, and the successive intermediate steps needed to reach the stated objectives. The third option takes the level of detail still a step further: the priority actions contain not only operational plans, but also detailed alternatives for each strategy, to overcome potential obstacles.⁵

Over the years, the United States has had numerous AIDS plans that meet the first definition—frameworks developed by advisory bodies, advocates, and government agencies that set out basic principles. Since the late 1980s numerous high-profile advisory committees have made well-reasoned—sometimes politically courageous—recommendations for improving the federal AIDS response. Yet these plans generally lacked clear goals, strategies, and actions. And very often good recommendations were not implemented.

The Presidential Commission on the HIV Epidemic, appointed by President Ronald Reagan in 1987, issued a report with 600 recommendations that were largely ignored.⁶ A progress report from President Bill Clinton's Presidential Advisory Council on HIV/AIDS observed 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."⁷

The Clinton White House produced its own National AIDS Strategy in 1997.⁸ The plan outlined overarching goals in prevention, treatment, and a variety of other areas, and listed specific goals, objectives, and action steps at numerous federal agencies. The strategy was notable in that it set very specific objectives and listed steps to achieve them. Yet many of the action steps were vague, with no office identified to carry them out, and no timelines set for completion of tasks.

Healthy People 2010 is a "framework" of national goals for improved health that has been established by the Department of Health and Human Services. It includes a variety of HIV-related goals but offers no specific plan for achieving them. The *Healthy People 2003* progress review on HIV-related goals provided a list of general "approaches for consideration" to make improvements in the response to AIDS, but does not cite specific action steps or plans.⁹

The CDC is to be applauded for developing the most detailed and well-publicized attempt at HIV-related planning. The agency's *HIV Prevention Strategic Plan*, issued in 2001, set several clear and ambitious goals, including an overarching goal to decrease by 50 percent the number of new annual HIV infections by 2005. It included an assessment of HIV incidence in the country and reviewed elements of successful HIV prevention programming. The CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment (or CHAC, created in 2002) reviewed the CDC's *Strategic Plan* and identified several barriers to its implementation:

- ▶ Lack of community and national-level endorsement, resulting in minimal coordination and collaboration
- ▶ The plan's less than well-defined scope and relevance to other federal agencies
- ▶ Neglect of macro-level and structural factors that influence HIV transmission
- ▶ Lack of effective preventive interventions for communities of color, especially African Americans (including men who have sex with men)
- ▶ Disconnect in systems that support HIV prevention, counseling, testing, and care¹⁰

The CDC *Strategic Plan* promised that "detailed action steps will be added to the operational plan" and that it would "serve as the basis of a yearly 'report card' to the public on the activities of CDC and its grantees." CDC staff have said that over 1,000 action steps were

developed to follow up on their plan,¹¹ but since these steps have not been made public it is not possible to gauge the impact of the plan's recommendations. CDC says no report card was developed, though a meeting was held for various agency divisions to report on implementation of action steps.

Since the *HIV Prevention Strategic Plan* lapsed in 2005, the agency has not created a new strategic plan, though the CHAC has passed a resolution extending the previous plan through 2010. Though the CDC plan set ambitious targets, missing from the planning effort was a clear link between objectives, strategies, and accountability—and acknowledgement of the need for additional resources. Bringing these elements together is a challenge for future federal HIV planning efforts.

This paper suggests characteristics of a new, comprehensive national AIDS plan that could make it more effective than those that have come before.

A national plan should both identify practical short-term strategies to achieve improved outcomes and provide a vision for broader, systemic reforms.

Characteristics of a Strategic National AIDS Plan

If the U.S. response to the domestic AIDS epidemic were a well-run business, it would have a strategic plan that includes 1) objectives, 2) strategies to accomplish those objectives, and 3) processes to assess progress and make refinements along the way. Below are priorities in each of these three areas that should be considered as a national AIDS plan is developed.

Setting Objectives

Priority #1

A national AIDS plan should focus increased attention on outcomes through reliance on evidence-based and cost-effective programming.

Much of today's discussion on domestic AIDS policy is concentrated on issues such as funding levels for critical programs like the Ryan White program and hot-button policy debates such as school-based sexuality curriculum. These are crucial issues that must continue to be primary areas for advocacy. A credible national plan should build on this national discussion in productive ways, concentrating on the results of programming and continually prompting the question about what is and is not working and how to do better.

On prevention, an outcomes-centered plan would focus increased attention on questions such as the following:

- ▶ Where are the highest incidence areas?
- ▶ What are the best opportunities to affect incidence?
- ▶ How can local and state programs be encouraged to use prevention resources to maximize impacts on incidence?
- ▶ How can interventions that have been shown to reduce risk behavior be brought to scale in a way that demonstrates clear impact on incidence?

On treatment, an outcomes-centered debate would focus the attention of policymakers on opportunities to use all the major treatment financing programs (including Ryan White, Medicare, and Medicaid) in integrated, innovative ways to increase the percentage of people living with HIV/AIDS receiving care. Greater attention to better outcomes and a more holistic vision of HIV-related health care provision could lend additional support for the longstanding effort to extend Medicaid eligibility to people early in the course of HIV disease (principally through the Early Treatment for HIV Act).

An increased orientation around outcomes could be useful in supporting evidence-based policymaking and cost-effective use of resources. There is an ongoing disconnect between evidence of what is effective in HIV prevention and where resources are allocated. For example, Congress has prohibited federal resources from being spent on needle exchange programs, despite the proven effectiveness of such programs in preventing the spread of HIV. A Rand study released in 2005 determined that if CDC's HIV prevention funds were allocated based on cost-effectiveness research, total annual HIV infections could be reduced by half.¹²

The more federal government employees and others involved in the response to AIDS believe that outcomes will be measured and that progress will be expected, the more they will be able to obtain internal agency and political backing for utilizing evidence-based approaches and allocating resources in a cost-effective manner.

Priority #2

A national AIDS plan should set ambitious, visible, and credible targets for improvement in a limited number of areas.

Targets can be powerful because they can bring clarity about the ultimate goals to all those engaged in the response. The World Health Organization's "3 by 5" initiative¹³ illustrated this point. The WHO goal of providing 3 million people with AIDS treatment by 2005 was not met. But the campaign had an important impact, sending a clear message to national governments and international aid agencies that AIDS treatment in low income countries was a top priority. The campaign also helped galvanize advocacy at the country level and internationally.

Missing from 3 by 5 was a connection between the ambitious target and specific strategies and sufficient resources that would have made the goal achievable. The lesson for a U.S. national AIDS plan is that highly visible goals for reduced incidence and expanded treatment delivery could be effective, but targets cannot simply be slogans—they have to be tied to strategic planning, sufficient resources, and willingness to act on evidence of what is working and what is not.

Limiting the number of targets provides clarity about the top priorities in the response to AIDS. Creating 25 targets sends a message that none are primary. Establishing a small number of targets can encourage the various complex public and private systems involved in prevention, care, and treatment to collaborate to achieve a few shared principal objectives.

A forthcoming paper by David Holtgrave, Jean McGuire, and Jesse Milan¹⁴ suggests several goals as a basis for national planning, such as a lower number of new annual infections, increased number of people who know their serostatus, and higher percentage of people receiving appropriate treatment services. Other outcome measures worth considering involve the quality of HIV-related care. For example, the HIV Cost and Services Utilization Study (HCSUS) used measures such as regularity of care, utilization of outpatient services, and access to medicines as quality measures. As noted below, goal setting also needs to bring special attention to reducing incidence and increasing care access among African Americans.

Milestones and interim markers are also important, particularly if the timeline for goals is set several years in the future. A lesson from the CDC 2001 *HIV Prevention Strategic Plan* is that interim measurement of (limited) progress toward the five-year goal could have been useful in motivating new and improved strategies to make the goal achievable.

Strategies to Realize Goals

Priority #3

A national AIDS plan should identify clear priorities for action on the selected targets.

A vast field of services, policies, and agencies are involved in domestic U.S. AIDS programming. No one plan can encompass every aspect of this diverse response, and federal, state, and local laws and policies limit the options available to planners working on a national level. A national plan needs to identify the best opportunities to make measurable impact through the public and private sectors and through civil society.

An AIDS plan for the United States should be informed by the entirety of AIDS programming, but identify a fairly limited number of discrete areas where there is particular need for improvement. The plan might, for example, identify these areas:

- ▶ The top five priorities to expand treatment coverage in a particular region, assign responsibilities among government and other actors to do specific things to

address these priorities, and set a timeline for assessment of progress in each area by each actor.

- ▶ Several “hot spots” where HIV incidence is particularly high and dedicate significant increased resources, and identify specific initiatives, to bring infection rates down.

Setting priorities is far more difficult (and politically challenging) than listing all the things that ideally should be done, but priority setting could be one of the most additive aspects of the planning process. Some degree of flexibility and mid-course correction must be built into the national plan to accommodate learning and new opportunities that emerge.

Priority #4

A national AIDS plan should set out specific objectives for multiple sectors, including government, civil society, community organizations, and business.

The federal government has a responsibility to lead the fight against AIDS, one of the greatest public health challenges facing the nation. Government brings more financial resources to bear on the problem than any other sector. And the history of the AIDS epidemic is full of examples where governments—for example, Australia and Thailand—acted decisively and made significant positive impacts on their AIDS epidemics.

But AIDS is everyone’s responsibility, not just the government’s. No national AIDS plan, even if vigorously implemented by federal, state, and local authorities, can change the course of the epidemic unless the private sector, faith-based institutions, community-based organizations, and others also participate. A national AIDS plan needs to be multisectoral, spelling out specific objectives, strategies, and tactics for civil society and the private sector to build on government efforts to address AIDS more effectively.

Priority #5

A national AIDS plan should make the prevention and treatment needs of African Americans a primary focus.

The disproportionate impact of the epidemic on African Americans means that no major progress can be made on overall outcome numbers for the nation unless the prevention and treatment needs of African Americans are met more successfully. This recommendation is consistent with a CHAC proposal that calls for prioritizing racial and ethnic minority populations, particularly African Americans, within the national-planning and goal-setting process. (In March 2007, the CDC announced plans to expand and improve HIV prevention and treatment programming for African Americans, but these plans do not represent the full scale effort that is needed.¹⁵)

One way to ensure a major focus on African Americans is to set specific subgoals for blacks within the national HIV incidence and care access targets. As a matter of political (and perhaps legal) reality, it may be necessary to create subgoals for several racial/ethnic groups, as well as other groups at elevated risk including gay men and men who have sex with men, injection drug users, and young women. However the subgroup issue is handled, a relevant national AIDS plan will need to promote an intensified, evidence-based, and well-funded effort to prevent and treat HIV infection among African Americans.

Addressing HIV in the black community will require continued and increased involvement of national, state, and local black institutions, including civil rights, social, faith, academic, media, and other organizations. A companion national plan, in addition to the one outlined in this paper, could be developed by black leaders and focused on the civil society response to AIDS in the black community. The black national AIDS plan could help catalyze increased involvement of black institutions, encouraging specific commitments for action in the community and making demands of government. Other communities might be interested in developing tailored plans as well.

A more comprehensive and effective approach to AIDS in the black community must attend to the prevention and treatment needs of the diverse range of African Americans, including black men who have sex with men. According to the CDC, men who have sex with men represent the largest HIV transmission category among men of all races who are living with HIV or AIDS.¹⁶ A report released by the Black AIDS Institute and the National Association for the Advancement of Colored People¹⁷ in 2006 called for an end to “debilitating stigma that helps HIV spread” in the black community. The report notes that stigma undermines prevention and treatment efforts, “particularly in the South and among gay and bisexual men.” Additional behavioral and psychosocial research is needed in order to inform and pilot behavioral and structural interventions that can be effective in the black community, including among black men who have sex with men.

Priority #6

A national AIDS plan should promote and test innovative ideas about how to overcome structural barriers to more effective prevention and treatment.

There is a growing realization that improving HIV-related outcomes will require interventions that address the systemic, social, and economic underpinnings of risk and health care utilization in the country.

A report by Robert Fullilove issued by the National Minority AIDS Council in November 2006 argued that, “the HIV/AIDS epidemic in African-American communities results from a complex set of social, individual, and environmental factors.”¹⁸ The report calls for a variety of interventions to address the “root causes” of the epidemic among blacks, includ-

ing support for strengthening African American communities by addressing the need for affordable housing and reducing the impact of incarceration “as a driver of new HIV infections.” It identifies the need for reform of prison policy to ensure voluntary HIV testing with truly informed consent, HIV prevention education, substance abuse programs, and comprehensive discharge programs.

A study published in the *American Journal of Public Health* in January 2007 underscores the need for community-level interventions to advance HIV prevention. Denise Hallfors and colleagues reviewed nationally representative data on sexual and drug behavior to understand the degree to which behavioral differences account for racial disparities in HIV and sexually transmitted disease (STD) prevalence. The researchers found that while risk for HIV and STD acquisition is heightened among young white adults when they engage in high-risk behaviors, black young adults are at elevated risk whether or not their personal behaviors are “high-risk.” This research points to the importance of structural-level interventions which have the potential to have a population-level impact.¹⁹

There are many potential structural interventions in the response to AIDS, from making the blood supply safe to addressing the economic and social foundations of vulnerability and health care utilization. Some of these interventions can have rapid impact; some will take much longer to demonstrate effectiveness. One essential point for national planners is that multiple strategies are needed.

More effective prevention will require a combination of approaches that includes greater investment in proven-effective behavioral interventions and longer term strategies to tackle vulnerability. Appropriate interventions are needed to reduce transmission in sex venues, shooting galleries, and via sexual connections made over the Internet. This will need to be done through a range of structural and behavioral interventions.^{20 21} A major initiative is needed to improve prevention and treatment in the prison and jail system; it should include transition programs that help those leaving incarceration.

Improved access to AIDS treatment will require research on, and implementation of, new approaches to promoting care utilization in populations that are poor and marginalized and may be estranged from the health care system. Some examples:

- ▶ Partners in Health has adopted a model of HIV care for the poor it has used in resource-limited countries to provide quality care to lower income people living with HIV/AIDS in the Boston area.²²
- ▶ In 2004, an Institute of Medicine panel proposed 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 people living with HIV/AIDS.²³
- ▶ In 2005, Rep. Donna Christensen introduced *The Health Empowerment Zone Act* to allow poor communities to utilize federal resources to address environmental issues in community health.

- ▶ Referring to the President’s Emergency Plan for AIDS Relief (PEPFAR), Steve Wakefield, a leading African-American AIDS advocate, has called for a “PEPFAR for the United States”—a program that would establish health care infrastructure and human resources capacity in lower income communities that have been hard hit by AIDS.

These kinds of creative approaches need to be given a full hearing in the context of national strategic planning.

Numerous public programs provide important opportunities to improve HIV prevention and care outcomes. National planners should consider the potential to leverage the resources of other federally supported programs, including the following:

- ▶ public housing
- ▶ youth jobs programs
- ▶ Veterans Administration health facilities
- ▶ prisons and jails
- ▶ Vista and Americorps programs
- ▶ publicly funded vaccine and other HIV prevention clinical trials
- ▶ Medicare- and Medicaid-funded managed care organizations
- ▶ public programs to address racial disparities in health care generally

Many rules of the game are already set in the U.S. AIDS response. Federal and state laws dictate how funds are allocated; decisions are made in diverse settings around the country. A national plan needs to start with the legal and policy environment as it exists today, identifying concrete opportunities for fully mobilizing the current system and also inspiring new thinking, and broader support, for systems change over time. Ideally, a national plan will both identify practical short-term strategies to achieve improved outcomes, and provide a vision for broader, systemic reforms—like the entitlement program proposed by the IOM—which need to be considered by federal lawmakers and may take longer to accomplish.

Assessing Progress

Priority #7

A national AIDS plan should improve methods of measuring progress.

Current government data-gathering mechanisms are not adequate to provide regular and reli-

able measurement of prevention outcomes and treatment access goals. The call for improved measures echoes similar recommendations over many years. In 2001, when an IOM committee studied domestic HIV prevention policy, one of the chief recommendations it made 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.”²⁴ Better surveillance also needs to be more directly tied to prevention strategy, rapidly informing resource and intervention targeting as trends in incidence change.

Measuring progress on infection rates, HIV transmission rates, and other markers will necessitate more regular and thorough surveys of HIV positive and negative populations. Reliable measurements of access to care will require ongoing research of care access and utilization by the HIV positive population, similar to the HCSUS study which was supported for a relatively brief period in the 1990s. The federal Agency for Healthcare Research and Quality is engaged in several studies on HIV-related care cost, quality, and access, but the agency’s research would need to be expanded to yield timely, ongoing data on care utilization by the overall HIV positive population. The CDC’s Medical Monitoring Project is collecting data on care utilization among the HIV positive population and may be able to provide valuable information on care access and barriers to care starting in 2008.

Priority #8

A national AIDS plan should make federal agencies responsible for coordinating the collaborative efforts of government, business, and civil society.

Progress on most of the remaining challenges in the domestic AIDS epidemic cannot be accomplished by one government agency working in isolation. CDC’s current reliance on testing as a prevention strategy is one example of why government agencies must be pushed to coordinate efforts more effectively. Success of the CDC policy depends, in large part, on better collaboration between that agency, the Health Resources and Services Administration (HRSA), and other government and nongovernment providers.

While better interagency collaboration is clearly needed, it is important to remember that coordination is not an end in itself. A national plan that concentrates on interactions between agencies will be mired in questions of bureaucracy. Instead, an outcomes-oriented plan should challenge agencies to demonstrate better collaboration by achieving measurable prevention and care results, and working together to identify and address barriers to progress.

For accountability to have meaning, it needs to rest with a limited number of responsible actors. Federal agencies cannot control the work of all public and private actors, but federal agencies can be held responsible for leading the effort to implement the national

AIDS plan: identifying barriers to progress, mapping strategies to address these challenges, providing direction and incentives to state and federal actors, and reporting on remaining challenges and stumbling blocks at every level.

Priority #9

A national AIDS plan should require the Secretary of Health and Human Services to report regularly on the status of progress toward the plan’s targets.

Annual or biennial reporting would help drive accountability and remind the public, policymakers, and the media about the importance of improving outcomes from HIV-related services. Annual reporting on progress—or lack thereof—toward targets would also provide advocates with a recurring opportunity to focus on successes and shortfalls in the domestic AIDS response. A goal-oriented plan that is tied to ongoing monitoring and can demonstrate concrete results would buttress arguments for increased investments in AIDS and other health care priorities.

Regular reports from Health and Human Services should be part of an ongoing effort to assess progress and refine approaches based on evidence of what is working. In this way, the national plan should be a living document—something that is changed and adapted over time. For example, a broadly representative planning group might be brought together annually to assess progress on outcomes measures and refine aspects of the national AIDS plan based on measured progress and new research.

The goal is not an official plan on paper but a sustained process of learning what works, refining efforts, building public support, and steadily improving outcomes.

The Development of an Effective National Plan

A national plan that is “owned” only by federal agencies will mean little. When the CDC plan to halve the number of new HIV infections had run its course, there was little attention to the failure of the plan to produce any perceptible results in terms of lower infection rates. What would make the national AIDS plan proposed in this paper any different? Several elements are important in developing a credible plan that can have impact. The plan has to have the following:

- ▶ **Buy-in from a range of stakeholders**, including people living with HIV/AIDS, providers, advocates, AIDS service organizations, public health and business leaders, and high ranking government officials.
- ▶ **A strategic orientation**. Top priorities for action should be clearly articulated. Areas of flexibility in national policy and programming need to be identified so that meaningful action items can be developed. (This does not preclude longer term proposals for structural change from also being included in the plan.)
- ▶ **Assignment of responsibility**. Each actionable item should have an office, organization, or individual in charge of follow-through. The plan should identify clear timelines and responsibilities for implementation of proposals.

- ▶ **Accountability measures**, such as the annual reporting and achievable targets, discussed above.
- ▶ **Acknowledgement of the need for additional resources**, including proposals for use of new funding, and, in some cases, reallocation of existing resources.

The process of developing a credible national plan must engage a diverse range of stakeholders. Yet the plan must be much more than a list of priorities identified by multiple constituencies. It must include ranked priorities, objectives, and action steps for government and civil society institutions. In addition, the development process for the plan should “do no harm;” it should not be divisive or undercut support for evidence-based programs; it must not simply add a layer of bureaucratic reporting.

There are many ways to create an effective and credible national AIDS plan. In December 2006, the CHAC sent a letter to Health and Human Services Secretary Michael Leavitt calling on him to “initiate the development of a multi-sectoral National Plan...,” proposing that the president impanel a committee to develop such a plan.²⁵ This committee might nominate 30 to 40 people from government, policymaking bodies, affected communities, NGOs, providers, and others. To build support from the broader society and incorporate lessons from other fields, many of those nominated should come from outside the world of AIDS, including other areas of public health and business. Training and other support would be offered to committee participants who may not have experience with strategic planning, AIDS policy, or epidemiology to ensure all those involved are able to participate in an informed manner.

This group would be “locked away” with experts in strategic planning for several days or a week. Their mandate would be to produce a plan that establishes priorities, identifies responsibilities and accountability mechanisms, and sets definite targets for steady progress. This draft could then be discussed at regional public hearings in several locations in the country.

The plan would be revised in consultation with the presidential committee, which would be charged with reflecting input from public hearings while maintaining aspects of the plan that can make it effective: focusing on clear outcomes, identifying priorities for action, promoting evidence-based interventions, and assigning responsibilities and timelines. As the CHAC working committee on national planning has pointed out, “Success of the updated Plan will depend on taking different approaches, clearly defining a road map, and implementing a detailed mobilization strategy.”

Ultimately, the goal is not an official plan on paper but a sustained process of learning what works, refining efforts, building public support, and steadily improving outcomes over many years. Strategic planning will not provide a quick fix to the complex challenges involved in the U.S. AIDS epidemic, including deficiencies in the nation’s overall health care system and

vulnerabilities exacerbated by longstanding social inequities. But a credible national planning process that sets priorities and targets and promotes accountability could have a valuable and lasting impact on America's response to AIDS.

There is renewed support for efforts to secure health care access for all Americans. AIDS-related policy and programming reforms that demonstrate success at reaching more people more effectively with quality health services can lay the groundwork for fundamental improvements in the way all Americans are served by the nation's health care system.

Acknowledgments

Improving Outcomes: Blueprint for a National AIDS Plan for the United States was researched and written by Chris Collins, an independent consultant to the Open Society Institute. It follows from *HIV/AIDS Policy in the United States*, a report issued by the Open Society Institute in May 2006, which provided a comprehensive assessment of U.S. domestic AIDS policy. The report, based on extensive review of published research and HIV-related statistics, was developed in consultation with an advisory body of AIDS policy and programming experts. It is available online at http://www.soros.org/initiatives/health/focus/phw/articles_publications/publications/hivaids_20060523. Public Health Watch, a project of OSI's Public Health Program, funded and produced both publications.

The author would like to thank the many people who helped with development of this paper, including Maureen Baehr, Cornelius Baker, Sean Barry, Helena Choi, Julie Davids, John Fleshman, Debra Fraser-Howze, David Gilden, Rachel Guglielmo, Rebecca Haag, David Holtgrave, Ernest Hopkins, Ronald Johnson, Jen Kates, Dave Kern, Ari Korpivaara, Jesse Milan, Murray Penner, Steve Wakefield, Phill Wilson, and Toni Young. Particular thanks to Dan Wohlfeiler for his formative comments and suggestions.

Public Health Watch and the Public Health Program

Public Health Watch promotes informed civil society engagement in policymaking on HIV/AIDS and tuberculosis. The project's monitoring reports offer a civil society perspective on the extent to which government policies comply with international commitments such as the UNGASS Declaration of Commitment on HIV/AIDS and the Amsterdam Declaration to Stop Tuberculosis. The Public Health Program aims to promote health policies based on social inclusion, human rights, justice, and scientific evidence. The program works with local, national, and international civil society organizations to combat the social marginalization and stigma that lead to poor health, to facilitate access to health information, and to foster greater civil society engagement in public health policy and practice.

Open Society Institute

The Open Society Institute works to build vibrant and tolerant democracies whose governments are accountable to their citizens. To achieve its mission, OSI seeks to shape public policies that assure greater fairness in political, legal, and economic systems and safeguard fundamental rights. On a local level, OSI implements a range of initiatives to advance justice, education, public health, and independent media. At the same time, OSI builds alliances across borders

and continents on issues such as corruption and freedom of information. OSI places a high priority on protecting and improving the lives of marginalized people and communities.

Investor and philanthropist George Soros in 1993 created OSI as a private operating and grantmaking foundation to support his foundations in Central and Eastern Europe and the former Soviet Union. Those foundations were established, starting in 1984, to help countries make the transition from communism. OSI has expanded the activities of the Soros foundations network to encompass the United States and more than 60 countries in Europe, Asia, Africa, and Latin America. Each Soros foundation relies on the expertise of boards composed of eminent citizens who determine individual agendas based on local priorities.

Notes

1. Centers for Disease Control and Prevention (hereafter CDC), "Disparities in HIV/AIDS Diagnosis, 33 States, 2001-2005," *Morbidity and Mortality Weekly Report*, vol. 56, no. 9 (March 9, 2007).
2. CDC, *HIV/AIDS Surveillance Report 2005* (Atlanta: December 2006).
3. U.S. Office of Management and Budget, <http://www.expectmore.gov> (accessed January 2007).
4. Institute of Medicine, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White* (Washington, DC: 2004): 9.
5. UNAIDS, "Guide to the Strategic Planning Process for a National Response to HIV/AIDS," *Strategic Plan Formulation* (Geneva: 1998).
6. *San Francisco Chronicle*, "AIDS Panel Accustomed to Neglect: National Commission's Recommendations Are Rarely Carried Out" (September 26, 1992).
7. Presidential Advisory Council on HIV/AIDS, *Progress Report* (July 8, 1996).
8. http://clinton2.nara.gov/ONAP/nas/ns_toc.html (accessed February 2007).
9. http://www.healthypeople.gov/data/2010prog/focus13/HIV_ProgressReview.pdf
10. McGuire, J. and Roberts, G., co-chairs, "CHAC Work Group on Updating the HIV Prevention Strategic Plan: Report on Work Group's Findings" (November 13, 2006).
11. Email communication with CDC staff (January 16, March 21, and March 22, 2007).
12. Cohen, D., et al., "Cost-effective Allocation of Government Funds to Prevent HIV Infection," *Health Affairs*, vol. 24, no. 4 (July/August 2005).
13. Launched in 2002 by WHO and UNAIDS, the "3 by 5 Campaign" set the international goal of reaching 3 million people living with HIV and AIDS with antiretroviral treatment by the end of 2005.
14. Holtgrave, D., McGuire, J., and Milan, J., *The Magnitude of Key HIV Prevention Challenges in the United States: Implications for the New National HIV Prevention Plan* (forthcoming).
15. In March 2007, CDC released its plan for a "Heightened National Response to the HIV/AIDS Crisis among African Americans." Though increased agency focus on HIV in the black community is a welcomed development, community advocates have been quick to point out that the new CDC plan fails to address structural factors in vulnerability to infection among black Americans, does not insist on increased resources to support needed prevention efforts, and fails to provide targeted strategies

to address AIDS in the black, gay community. For more information, see Community HIV/AIDS Mobilization Project, "Bush Administration's Long-Awaited African-American HIV Prevention Plan Involves No New Money, No New Strategies, and Ignores Gay Men," Press Release (March 8, 2007), <http://www.champnetwork.org/index.php?name=CDC-African-American-initiative> (accessed March 13, 2007).

16. CDC, *HIV/AIDS Surveillance Report 2005*, vol.17 (Atlanta: December 2006): 19 and 22.
17. Wright, K., *The Way Forward* (Baltimore: NAACP, February 2006).
18. Fullilove, R., *African Americans, Health Disparities, and HIV/AIDS* (Washington, DC: National Minority AIDS Council, November 2006), http://www.nmac.org/nmac2/PDF/NMAC%20Advocacy%20Report_December%202006.pdf
19. Hallfors, D. D., et al., "Sexual and Drug Behavior Patterns and HIV and STD Racial Disparities: The Need for New Directions," *American Journal of Public Health*, vol. 97, no.1 (January 2007): 125-132.
20. Wohlfeiler, D. and Poterat, J., "Using Gay Men's Sexual Networks to Reduce Sexually Transmitted Diseases (STD)/HIV Transmission," *Sexually Transmitted Diseases: Journal of the American Sexually Transmitted Disease Association*, vol. 32, no. 10 (October Supplement 2005): s48-s52.
21. Wohlfeiler, D. and Ellen, J.M., "The Limits of Behavioral Interventions for HIV Prevention," in Cohen, L., Chavez, V., Chehimi, S., eds., *Prevention Is Primary: Strategies for Community Well Being* (San Francisco: Jossey-Bass, 2007): 329-347.
22. <http://www.pih.org/where/USA/USA.html>
23. Institute of Medicine, *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White* (Washington, DC: 2004).
24. Institute of Medicine, *No Time to Lose: Getting More from HIV Prevention* (National Academy Press, 2001).
25. McGuire, J. F. and Milan, J., co-chairs, "Letter to the Honorable Michael Leavitt, CDC/HRSA Advisory Committee on HIV and STD Prevention and Treatment" (December 19, 2006).

Over 1.5 million HIV infections and over half a million deaths into its 26-year-old HIV/AIDS epidemic, the United States still does not have a comprehensive national plan to guide strategic use of AIDS-related dollars or hold government agencies accountable for steadily improved outcomes for people living with HIV/AIDS or at risk of infection.

Improving Outcomes: Blueprint for a National AIDS Plan for the United States offers policymakers concrete recommendations for a more strategic approach to HIV/AIDS programming and policy, with the goal of making measurable progress in HIV infection rates, access to AIDS-related care, and racial disparities. This report follows from *HIV/AIDS Policy in the United States*, a report issued by the Open Society Institute in May 2006, which provided a comprehensive assessment of U.S. domestic AIDS policy.

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 TB 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, and Vietnam.



OPEN SOCIETY INSTITUTE