OBAMA-BIDEN TRANSITION PROJECT

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NATIONAL AIDS STRATEGY

www.nationalaidsstrategy.org

November 19, 2008

Dear Presidential Transition Team:

Thank you for President-Elect Obama's leadership on health reform and, specifically, in calling for a National AIDS Strategy for the United States.

In his AIDS platform, then-candidate Senator Obama pledged that:

> "… in the first year of his presidency, he will develop and begin to implement a comprehensive national HIV/AIDS strategy that includes all federal agencies. The strategy will be designed to reduce HIV infections, increase access to care, and reduce HIV-related health disparities. His strategy will include measurable goals, timelines, and accountability mechanisms."

We look forward to working with you to help your Administration develop and implement a National AIDS Strategy that can bring needed coordination, accountability, and results-orientation to our national response to the epidemic.

The attached Framework document discusses the need for a Strategy, provides guiding principles to make a Strategy effective, and suggests a process for establishing a Strategy. Consistent with this document, we very much hope the new Administration will act, *within its first 100 days*, to appoint a National AIDS Strategy panel and establish a White House-level office and coordinator to provide leadership in developing and implementing the Strategy.

We are ready to help you consider how to begin the National AIDS Strategy process. Please feel free to contact us through Chris Collins of the Coalition for a National AIDS Strategy at ChrisCSF@aol.com or by phone at 845.701.0158.

Sincerely,

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FRAMEWORK FOR DEVELOPING AN EFFECTIVE NATIONAL AIDS STRATEGY FOR THE UNITED STATES
October 2008

Preamble

We call on the President-elect to exercise leadership in the fight against HIV/AIDS at home by creating a National AIDS Strategy for the United States, and we are eager to work with him to move forward on this historic effort.

Enormous progress has been made in the effort to control the HIV/AIDS epidemic in the United States since those first tragic years when entire communities were devastated by illness and death. HIV infection rates have fallen from their early 1990s peak, and advances in antiretroviral therapy have prolonged the lives of many thousands of Americans. But despite the investment currently made by federal and state governments, as well as a large and generous private sector, progress on the domestic epidemic has stalled badly in recent years.

The Centers for Disease Control and Prevention (CDC) announced in August of this year that the annual HIV incidence is 40% higher than previous estimates, and that a new HIV infection occurs in the U.S. every nine minutes. HIV infection rates are increasing among some of the most vulnerable populations in the epidemic. Fully one-half of people living with HIV are not receiving care and treatment in this wealthiest of nations. Disparities in health outcomes among people of color and women are profound. For a nation with our intellectual and financial resources, the current deficiencies in America's response to HIV/AIDS are completely unnecessary and unacceptable.

Most federal HIV/AIDS programs have been flat funded for several years, but while we must increase resources committed to the domestic response, we must also use these resources more strategically and effectively. We must move from a patchwork response to a coordinated effort. We must focus on tracking and improving outcomes rather than simply launching more programs. We need a National AIDS Strategy that refocuses the domestic response to AIDS on achieving lower HIV incidence, increased access to care, and reduced racial, ethnic, and gender disparities.

Presidential leadership is essential to create and implement the National AIDS Strategy we need. The President is in the best position to convene stakeholders and ask them to come to agreement about the specific set of targeted initiatives required to significantly improve the nation's response to the epidemic, demand that responsible government and non-governmental organizations coordinate their efforts, and make the federal government and recipients of federal funding accountable for steadily improving results of their efforts.

The goal of moving the United States from simply managing the HIV/AIDS epidemic—which is what we are doing today—to truly eradicating it requires a bold, innovative National AIDS Strategy capable of moving all people with HIV/AIDS into comprehensive, high-quality care and treatment and reducing new cases of HIV infection to their lowest possible levels. It will require a sense of urgency, and levels of cooperation, coordination, and discipline that have not been seen in the epidemic in nearly a decade.

Only the next President can bring together the intellect and resources needed to make the United States an example to the world of how HIV/AIDS can be controlled. In this document, we recommend a framework for him to do so. We look forward to a dialogue with the President-elect's Transition Team about how we can work together to achieve this vital goal.

The Need for a More Effective Response to AIDS

U.S. investments in HIV/AIDS continue to produce powerful results: preventing thousands of new HIV infections each year, delivering antiretroviral treatments that improve the longevity and quality of life of tens of thousands of Americans, and breaking new ground in biomedical, behavioral, and social research. However, over 1.5 million HIV infections and over half a million deaths into its 27-year-old HIV/AIDS epidemic, the United States still does not have a comprehensive, strategic national plan to eliminate HIV/AIDS within its own borders.

The U.S. government is spending over $17 billion in Fiscal Year 2008 on the domestic epidemic. Allocation of those funds is determined by a variety of uncoordinated federal laws, policies, and programs, as well as state and local decision-making processes. Indeed, decentralization of decision-making authority is one of the hallmarks of HIV/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/AIDS prevention and care funding streams. In addition, the AIDS Drug Assistance Program, Medicaid, and other programs that provide services to people living with HIV/AIDS are funded and managed at least partly at the state level. This diffused authority means that HIV/AIDS programming can be responsive to locally defined needs, but it also complicates any effort to conduct comprehensive national planning and initiatives or hold any particular level of government accountable for improved results.

While the federal government requires the states to develop plans for the use of funds, no national-level plan guides the strategic use of federal AIDS-related dollars. No plan requires the myriad federal agencies that have a role in addressing HIV/AIDS to coordinate their efforts in order to maximize outcomes, or holds federal agencies accountable for steady progress in reducing new infections and increasing rates of care and treatment for already infected individuals. A roadmap is urgently needed at the national level to better coordinate the work of

federal, state, and local agencies and focus policy and programming on achieving improved outcomes.

While it is laudable that a vast array of non-governmental organizations—including businesses, foundations, and religious and civil rights organizations, as well as non-profit health and human service providers—have responded to the epidemic, their efforts are not well coordinated among themselves or in collaboration with government.

Finally, HIV/AIDS biomedical and behavioral research, while robust, suffers from a lack of prioritization, coordination, and focused application to meet the practical needs of community-based service providers.

Government and non-government assessments 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." In 2004, an Institute of Medicine 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."

Several persistent facts point to the need for a more strategic and effective response:

- One quarter of Americans who have HIV do not know it. CDC has recommended routine HIV screening of all Americans aged 13 to 64, but has thus far failed to provide specific policies, guidelines, programs, and resources to achieve this goal.
- 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 and are therefore at greater risk for opportunistic infections, other HIV-related conditions, and faster progression to AIDS.
- Approximately half of all people living with HIV/AIDS are not receiving regular HIV-related health care, and approximately half of those who meet U.S. government medical criteria for use of antiretroviral treatment for HIV are not receiving that treatment.
- People of color, particularly women of color, and men who have sex with men (MSM), especially young MSM of color, suffer much higher rates of infection than other populations at risk for HIV. People of color and women experience much poorer health outcomes than the general population of people living with HIV disease. Racial and ethnic disparities in HIV infection rates are exacerbated by similar disparities in incarceration rates. High levels of incarceration of people of color result in poor health outcomes not only for those who cycle in and out of prisons and jails but also for their partners, family members, and communities left behind.

- CDC's estimate of the number of annual new HIV infections remained at 40,000 between 1997 and 2007. In August of 2008, CDC increased its estimate of new infections to 56,300 in 2006 and, with back calculation, to 55,400 per year from 2003 to 2006. In part this increase was due to more accurate case reporting methodology. However, the increase also reflected a recent rise in new infections in certain groups, including gay and other men who have sex with men, particularly young MSM of color, and women of color.
- Stigma and discrimination still serve as barriers to more effective treatment for and prevention of HIV.

The unsatisfactory outcomes from our country's response to AIDS have serious human and economic costs. A study published in 2003 found that failure to meet the government's then goal of reducing HIV infections by half would lead to an additional $18 billion in expenses through 2010.

Guiding Principles of an Effective National AIDS Strategy

As of October 2008, approximately 350 organizations and 1,200 individuals have signed a Call to Action for a National AIDS Strategy that addresses the urgent need to:

- Improve prevention, care, and treatment outcomes through reliance on evidence-based programming;
- Set ambitious and credible prevention, care, and treatment targets and require annual reporting on progress toward goals;
- Identify clear priorities for action across federal agencies and assign responsibilities, timelines, and follow-through;
- Include, as a primary focus, the prevention and treatment needs of African Americans and other communities of color, women of color, MSM of all races and ethnicities, and other groups at elevated risk for HIV;
- Address social, economic, and structural factors that increase vulnerability to HIV infection;
- Promote a strengthened and more highly coordinated HIV prevention and treatment research effort; and
- Involve many sectors in developing the Strategy, including government, business, community, civil rights organizations, faith-based groups, researchers, and people living with HIV/AIDS.

The Process for Developing a National AIDS Strategy

The President of the United States, through the Domestic Policy Council, should appoint a panel of experts on HIV/AIDS from every Department of the United States Government with responsibilities for responding to the epidemic, representatives of key non-governmental and civil society organizations, people living with and at risk for HIV, and other stakeholders to develop a National AIDS Strategy. This panel must reflect the diverse communities affected by HIV/AIDS. It should hold at least one meeting at which it receives public input into the development of the Strategy, and at least two meetings at which its deliberations are open to the public. The panel should take into account stakeholder input—gathered in multiple ways—and the best available evidence on effective strategies to achieve HIV prevention, care, and research goals. The Strategy should be fully developed no later than January 20, 2010, and be operational until December 31, 2014.

The President should reinvigorate a White House–level AIDS Office (like the Office of National AIDS Policy) to provide staffing to the panel and establish the AIDS Office Director as the individual holding authority for oversight and coordination of all government and federally funded non-governmental organizations required to implement the Strategy.

Congress must appropriate sufficient sums for Fiscal Year 2009 to the White House–level AIDS Office to plan and implement a National AIDS Strategy. The President must commit to continued funding in his subsequent budget requests to assure the development, implementation, and evaluation of the Strategy.

The National AIDS Strategy should not repeat or recreate the exhaustive set of goals that have characterized previous planning efforts to respond to the epidemic (see Appendix A), though many of the goals these plans have described are important. Instead, the National AIDS Strategy must:

- Describe a limited and focused set of strategic initiatives that will increase to the highest possible levels the number of Americans who know their HIV status and the number of HIV-positive Americans who are engaged in comprehensive, high-quality care and treatment for HIV and related conditions; reduce to the lowest possible levels the disparities in health outcomes that are experienced by gay and other men who have sex with men, communities of color, and women; and reduce to the lowest possible levels the number of new cases of HIV infection that occur annually;
- Prioritize initiatives targeting populations or jurisdictions with the highest prevalence and incidence of HIV/AIDS in the nation (consistent with current epidemiological data), with emphasis on outcomes related to African Americans and other communities of color, women of color, and gay men of all races and ethnicities;

- Describe the legislation, policies, and programs that are necessary to carry out those initiatives;
- Set specific outcomes by which each of the initiatives will be evaluated, along with timelines for implementing them;
- Assign responsibility for implementation of each of the action steps to appropriate government agencies and create mechanisms to facilitate collaboration between these agencies and non-governmental organizations;
- Determine the annual cost and financing mechanisms necessary for implementing each initiative, along with recommended sources of funds. Sources may include the re-direction of existing federal resources to the action steps contained in the Strategy, as well as additional resources that should be sought by the President from the Congress; and
- Develop a mechanism by which existing sources of federal funding for HIV/AIDS will be made consistent with participation in the initiatives described in the Strategy.

Once developed, the National AIDS Strategy should be submitted by the Director of the White House–level AIDS Office to the President for implementation, and a report should be provided annually to Congress on progress toward the goals articulated in the Strategy.

APPENDIX A

Previous Attempts at National Planning to Address HIV/AIDS in the United States

Since the late 1980s, numerous high-profile advisory committees have made well-reasoned—and 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. As a progress report from President Bill Clinton's Presidential Advisory Council on HIV/AIDS observed, "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."

The Presidential Commission on the HIV Epidemic, appointed by President Ronald Reagan in 1987, issued a report with 600 recommendations that were largely ignored.

The Clinton Administration produced its own National AIDS Strategy in 1997, outlining overarching goals in prevention, treatment, and a variety of other areas, and listing specific goals, objectives, and action steps for numerous federal agencies. Yet many of the action steps were vague, with no office identified to carry them out, and no timelines set for completion of tasks. It has therefore been impossible to assess the plan's effect on the domestic epidemic.

Healthy People 2010 is a "framework" of national goals for improved health as 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. Likewise, 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 did not cite specific action steps or plans.

The National Institutes of Health (NIH) has had a detailed plan for AIDS research across the agency, orchestrated by the Office of AIDS Research (OAR), since 1993. The plan is mandated by law, and is updated annually in a complex process that includes a range of stakeholders, including internal NIH researchers and grant program managers, external scientists, community advocates, and representatives of other Health and Human Services agencies that engage in research-related activities (e.g., CDC and the Food and Drug Administration). The *NIH Plan for HIV-Related Research* identifies scientific priorities in a number of key areas, and drives the NIH AIDS research budget—that is, dollars are allocated through the various NIH Institutes and Centers according to the ranked priorities developed across them. The effectiveness of this approach lies in the statutory budget authority given to the OAR by Congress.

The NIH/OAR plan and process are considered a model in the government for linking priority setting and budget allocation. However, the ability to monitor outcomes from the AIDS research programs is limited. Given the nature of basic science (as "discovery"), it is difficult, and not always appropriate, to attempt to monitor outcomes in epidemiological terms (e.g., how many new infections are averted as a result of a particular study). Applied, or intervention,

science does affect HIV risk and/or disease outcomes, but for only the study sample, which is necessarily a small number of people. It is the application of the research—its implementation in medical care and prevention service organizations—that will produce such outcomes more broadly, and this application is performed by agencies other than NIH. There is a strong need to develop mechanisms to better ensure that outcomes from NIH-funded research are disseminated and implemented by these agencies.

Also, while NIH is the largest funder of AIDS research in the U.S. (and the world), its programs are not well coordinated with those of other federal science agencies, private research organizations, and foundations to avoid redundancy and duplication of effort.

CDC also has developed a detailed and well-publicized HIV-related plan. The agency's *HIV Prevention Strategic Plan*, issued in 2001, set several clear and ambitious goals, including an overarching goal to halve HIV incidence by 2005. It included an assessment of HIV incidence in the U.S. and reviewed elements of successful HIV prevention programming.

The CDC/Health Resources and Services Administration Advisory Committee on HIV and STD Prevention and Treatment, created in 2002, reviewed CDC's *Strategic Plan* and identified several barriers to its implementation:

- Lack of community and national-level endorsement, resulting in minimal coordination and collaboration;
- Weakly 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 MSM); and
- Disconnect between systems that support HIV prevention, counseling, testing, and care.

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 has said that over 1,000 action steps were developed to follow up on their plan, but because these steps have not been made public, it is impossible to gauge the effect 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, CDC has issued a new strategic plan that has less ambitious targets, fails to integrate approaches with other federal agencies, and provides no clear path to reducing HIV incidence.

APPENDIX B

Key Resources Supporting the Case for a National AIDS Strategy

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Centers for Disease Control and Prevention. Subpopulation estimates from the HIV incidence surveillance system—United States, 2006. *Morbidity and Mortality Weekly Report* 57(36):985–89. September 12, 2008.

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Collins, C. *Improving Outcomes: Blueprint for a National AIDS Plan for the United States.* New York: Open Society Institute. May 2007.

Committee on Oversight and Government Reform Hearing. The domestic epidemic is worse than we thought: a wake-up call for HIV prevention. U.S. House of Representatives. September 16, 2008. Washington, D.C. Available at http://oversight.house.gov/story.asp?ID=2171. (See especially the testimony of Dr. Julie Gerberding, Director, Centers for Disease Control and Prevention.)

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Institute of Medicine. *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White.* Washington, D.C.: National Academies Press. 2005.

APPENDIX C

Framework Document Working Group Members

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