

# PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

# AIDS

## No Time to Spare:

The Final Report to the President of the United States  
September 2000

**WARNING:** THE INFORMATION CONTAINED IN THIS REPORT HIGHLIGHTS THE EXPONENTIALLY INCREASING GLOBAL THREAT OF HIV/AIDS. ALL PEOPLES AND COMMUNITIES, REGARDLESS OF OUR MANY DIFFERENCES, ARE CONFRONTED BY THE SAME PERIL OF PHYSICAL AND SOCIAL DEVASTATION. NO LONGER CAN EACH COMMUNITY OR NATION AFFORD TO RESPOND IN ISOLATION. AS A GLOBAL COMMUNITY, WE MUST ACCEPT THE OBLIGATION TO DEVELOP AND IMPLEMENT A SHARED GLOBAL RESPONSE AND ACTION PLAN, ACKNOWLEDGING THAT THE DIFFERENCES OF RACE, SEXUAL ORIENTATION, GENDER, CULTURE, RELIGION AND POLITICS THAT SO OFTEN DIVIDE US DO NOT DIFFERENTIATE THE UNIVERSAL HUMAN EXPERIENCES OF SUFFERING AND HOPE.

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September 2000**

**Washington, DC  
United States**

The Presidential Advisory Council on HIV/AIDS was established by Executive Order on June 14, 1995 for the purpose of providing advice, information and recommendations to the Secretary regarding programs and policies intended to promote effective prevention of HIV disease, and advance research on HIV disease and AIDS. Unless renewed by the appropriate action prior to its expiration, the Presidential Advisory Council on HIV/AIDS will terminate on July 27, 2001.

A copy of this report can be obtained by contacting the Centers for Disease Control and Prevention National Prevention Information Network (CDCNPIN) or by accessing their website at [www.cdcpin.org](http://www.cdcpin.org).

For more information on the Presidential Advisory Council on HIV/AIDS, log onto [www.pacha.gov](http://www.pacha.gov).

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# PREFACE

At the dawn of the new millennium, there is no threat to the global community that demands more urgent leadership and response than HIV/AIDS.<sup>1</sup> The devastation wrought by HIV/AIDS during the past 20 years is almost unimaginable. Globally, nearly 19 million people have died; another 34 million are living with HIV/AIDS, mostly in the poorest regions of the world.<sup>2</sup> In the United States, over 400,000 individuals have died of AIDS and another 700-900,000 are living with the virus.<sup>3</sup>

Yet the tragedy of HIV/AIDS cannot be described merely in terms of the numbers of deaths or infections; in lost productivity and global economic impact; or in the social, political, and cultural havoc created by this ongoing pandemic. The use of historic analogies to the Bubonic Plague, influenza pandemic, or previous World Wars fail to fully illustrate the potential devastation from this disease. The magnitude of escalating statistics causes continuing disbelief of the sheer enormity of human suffering, and such statistics mask the personal struggles, tragedies, and even triumphs of those living with or affected by HIV/AIDS.

Many leaders have used such terms as “state of emergency,” “national security risk,” and “global economic crisis” to describe this pandemic. Globally, the communities with the most significant increases in new infections are most often poor, and in many of Western/developed nations, these are also communities of color. Exacerbating and fueling the HIV/AIDS pandemic are the social viruses of racism, sexism, poverty, and homophobia. People around the world still face both individual and community barriers to honest and open discussions about sexual behavior, sexuality, and substance use/abuse. And we have neither a cure nor a vaccine to protect ourselves from the lethal mixture of disease and apathy.

At this moment in history, the threat of HIV/AIDS challenges the entire human community and thus our global society. In an increasingly interconnected world, there are no safe havens. All peoples and communities, regardless of our many differences, are confronted by the same peril of physical and social devastation. No longer can each community or nation afford to respond in isolation. As a global community, we must accept the obligation to develop and implement a *shared global response and action plan*, acknowledging that the differences of race, sexual orientation, gender, culture, religion, and politics that so often divide us do not differentiate the universal human experiences of suffering and hope.

And it is upon hope that we must build. The struggle to bring an end to HIV/AIDS can be won. Already, investments in biomedical and behavioral research have paid off—we now know how to prevent new infections and treat those living with HIV/AIDS. Though there are enormous disparities in access, the global community has the capacity to expand these life-saving interventions so that all at risk and in need can benefit. Even in heavily impacted

and poor countries, strong leadership and modest investments can have a tremendous impact. Ultimately, it is not an issue of resources, but of will, that keeps us from stopping HIV/AIDS.

The Presidential Advisory Council on HIV/AIDS realizes that this report must look forward, even as it offers final recommendations to President Clinton. We acknowledge and commend the President, Vice President, and other members of their Administration for the many positive actions taken during the past seven years. We especially applaud the leadership of the Office of National AIDS Policy. We also commend members of Congress, who have, with bipartisan spirit, provided critical resources and leadership on many issues. We have been honored to share and to serve in this moment of history. Yet there is still a great deal of unfinished business ahead. Indifference, prejudice, and malaise are still pervasive even as the world slowly awakens to the enormity of the pandemic.

*“Ultimately, it is not an issue of resources, but of will, that keeps us from stopping HIV/AIDS.”*

The Presidential Advisory Council on HIV/AIDS wishes to acknowledge the millions of individuals who have either died or are living with HIV/AIDS, including our own members, colleagues, and friends. Many have witnessed this pandemic and tried to bring messages of hope, but none more urgently than those who struggle to live courageously with this disease.

We stand together with other HIV/AIDS activists from around the globe, echoing the messages of hope from the prophets of all ages, as we say to those who follow: our *global community* must remain steadfast in its collective commitment to act with bold and visionary leadership.

The Honorable Ronald V. Dellums  
Chair

Daniel C. Montoya  
Executive Director

# ACKNOWLEDGMENTS

The Presidential Advisory Council on HIV/AIDS (Council) acknowledges and thanks the large number of dedicated and committed individuals who have supported its efforts. It would be impossible to list out each individual or organization by name; however, their contributions individually and collectively cannot be understated.

Our work would not have been possible without the extraordinary input we received--from ordinary citizens who shared their concerns and stories during public comment periods, community organizations at the local, state and national level, invited presenters, and the many who wrote, e-mailed or communicated with this Council in other forms. Your voice was extremely important for this Council to approach HIV/AIDS and the surrounding complex policy issues from an informed perspective. Your constructive criticism, continued pressure to move the agenda forward, and willingness to discuss and debate policies was extremely important to our mission of providing the President, the Department of Health and Human Services and the Administration with advice on Federal HIV/AIDS-related policies and programs.

The Council recognizes the contributions made by federal agencies regarding funding, travel assistance, staff support and other resources that allowed us to carry out its mission in a professional manner. In addition, the Council would like to acknowledge those who assisted with the planning and logistical aspects of the Council meetings, and their contribution to providing an atmosphere where we as members could focus on the issues.

Most importantly, the Council extends its heartfelt gratitude for the generous contributions of time, knowledge, and spirit from persons living with HIV and AIDS. The Council has worked diligently to honor the memories of those who have died of AIDS, especially Edward S. Gould and B. Thomas Henderson, both members of this Council.

The Council is grateful for the opportunity to serve this nation in confronting the global AIDS pandemic. For that, we extend our sincere thanks to the President, Vice-President and the Administration for not only having the foresight to create this advisory council, but for their willingness, and commitment in having worked to improve the lives for those who are at-risk and living with HIV/AIDS.

# EXECUTIVE SUMMARY

At the dawn of the new millennium, there is no threat to the global community that demands more urgent leadership and response than HIV/AIDS. The devastation wrought by HIV/AIDS during the past 20 years is almost unimaginable. Globally, nearly 19 million people have died; another 34 million are living with HIV/AIDS, mostly in the poorest regions of the world. In the United States, over 400,000 individuals have died of AIDS and another 700-900,000 are living with the virus.

Globally, the communities with the most significant increases in new infections are most often poor, and in many Western/developed nations, these are also communities of color. Exacerbating and fueling the HIV/AIDS pandemic are the social viruses of racism, sexism, poverty, and homophobia. And we have neither a cure nor a vaccine to protect ourselves from the lethal mixture of disease, stigma, and apathy.

No longer can each community or nation afford to respond in isolation. As a global community, we must accept the obligation to develop and implement a shared global response and action plan, acknowledging that the differences of race, sexual orientation, gender, culture, religion, and politics that so often divide us do not differentiate the universal human experiences of suffering and hope.

And it is upon hope that we must build. Ultimately, it is an issue not of resources, but of will, that keeps us from stopping this pandemic. The struggle to bring an end to HIV/AIDS can—and must—be won.

The Presidential Advisory Council on HIV/AIDS (Council) was established in 1995 by Executive Order to advise the President, the Secretary of Health and Human Services, and the Administration regarding policies and programs related to HIV/AIDS. During the last five years the Council has recommended action regarding prevention and care, the search for a vaccine and a cure, and efforts to end HIV/AIDS-related discrimination and intolerance. It has struggled mightily, at times with a deep sense of frustration, to faithfully discharge its responsibilities to the President, his Administration, and most importantly, those here and around the world whose lives have been darkened by the shadow of HIV/AIDS.

The Council has submitted two previous progress reports to the Administration, in July 1996 and December 1997, as well as numerous letters regarding specific issues of particular concern. In August 1998, the Council adopted an internal strategic plan emphasizing the growing impact of the pandemic within communities of color.

This report is the Council's final submission to President Clinton, and an initial challenge to the next Administration. It also emphasizes another signal moment in the history of the HIV/AIDS pandemic: the shift to a "global" perspective. The Council realizes that this report must look forward, even as it offers its final recommendations to the current Administration.

Given the unique historical context of this report, the Council reaffirms several underlying themes:

- HIV/AIDS is a nonpartisan issue.
- HIV/AIDS imperils the entire global community.
- HIV/AIDS threatens national and global security.
- The United States has a responsibility to be a leader and partner in the global fight against HIV/AIDS.
- The response to HIV/AIDS as a public health crisis should be guided by scientific knowledge, not political expediency.
- Addressing the global HIV/AIDS pandemic requires coordinated and sustained political will and financial resources proportionate to need.

This report describes progress, identifies strategies, and makes recommendations for effectively addressing the HIV/AIDS pandemic in both the short and long term. It is divided into two broad sections: prevention and services. It seeks to be inclusive of the broad range of issues both within the United States and throughout the world.

### **Preventing New HIV Infections**

Until a vaccine or cure is found, successful HIV/AIDS prevention interventions remain the sole option available to stop this pandemic. Despite this reality, prevention efforts worldwide have been hindered by the unparalleled stigma associated with HIV/AIDS. Both here and in the rest of the world, new infections take place against a background of poverty, gender and social inequality, discrimination, and limited health infrastructure. The success of HIV/AIDS prevention efforts to date, in the face of these challenges, is commendable if not miraculous.

After nearly 20 years of the HIV/AIDS pandemic it can be said with confidence that:

- Prevention works.
- Prevention is cost-effective.
- HIV/AIDS prevention promotes better overall health.

The Council recommends immediate action in support of the following proven strategies:

- Development of effective and affordable HIV vaccines and microbicides must be prioritized.
- Prevention efforts require renewed and sustained investment.
- Strong leadership and coordination of a multi-sectoral effort are essential to implementation of effective prevention.
- Availability of voluntary, free or low-cost, anonymous and confidential HIV counseling and testing services is critical.
- Factual and truthful education about HIV transmission and how it can be avoided is needed for all.
- The further development and availability of effective prevention products such as condoms, clean syringes, and drugs to prevent HIV transmission are essential.
- A comprehensive, multi-faceted approach is needed to meet the HIV/AIDS prevention needs of drug and alcohol users.
- Behavioral research is critical to the ongoing development of effective HIV/AIDS prevention efforts.
- Ongoing and new structural-level interventions will be key in further reducing new HIV infections.
- Monitoring the HIV/AIDS pandemic on a local, national, and global basis is essential to effectively target resources and assess the impact of HIV/AIDS prevention efforts.

## **Services for Persons Living with HIV/AIDS**

Access to early medical care and treatment remains elusive for many low-income, uninsured people in the U.S., as well as the vast majority of people living with HIV/AIDS in the developing world, where basic public health infrastructure is weak or non-existent. Current treatments are expensive, effective only for some, and often tinged with debilitating side effects. Research must continue to focus on a cure for HIV/AIDS, as well as improving current treatments.

The goal of ensuring access to high-quality and affordable HIV/AIDS care and treatment services in the United States and abroad will require a commitment to leadership, sustained financial support, and a continued reliance upon the many public-private partnerships that currently interact to develop, provide, and fund such care. The ability to confront directly issues of discrimination and stigma, and to encourage and support individuals in their efforts to learn their HIV status and enter and adhere to treatment, will also help ensure ultimate success.

With regard to HIV/AIDS services, the Council knows with certainty that:

- Early care and treatment can dramatically enhance the quality of life and health for persons living with HIV/AIDS.

- Early care and treatment is effective in reducing the cost of HIV/AIDS care over the long term.
- Ensuring access to quality HIV/AIDS care remains a major global challenge.

The Council recommends immediate action in support of the following proven strategies:

- Ensuring early and consistent access to medical care and treatment must be the goal of HIV/AIDS services.
- Support services play a critical role in ensuring access to and retention in care.
- Substance abuse treatment and mental health services must be an integral part of HIV/AIDS-related health care.
- In the United States, eliminating racial and ethnic disparities in health outcomes related to HIV/AIDS requires addressing issues of access, discrimination, and affordability.
- The developmental needs of youth require that they receive age-appropriate services sensitive to their unique circumstances.
- Public health infrastructure is necessary to ensure a sustained response to the HIV/AIDS pandemic.
- Client and community involvement are essential to the establishment of systems of care that are responsive to local needs.
- Government agencies have a particular responsibility to finance HIV/AIDS care and services.

## **Conclusion**

Though the time remaining in the current term is short, the world cannot afford even a momentary lapse in the fight against HIV/AIDS. Each and every day, another 16,000 persons become infected<sup>4</sup>, most in areas of the world where effective treatment is currently not available. The President and his Administration must therefore use all remaining time and authority to implement the Council's recommendations for action during the last 100 days of this Administration, and begin work on the more long-term recommendations offered.

Our shared legacy can be one of determined action fueled by hope, or of mediocrity and ambivalence fueled by resignation. We choose the path of hope, and challenge President Clinton and his Administration, members of Congress and other elected officials, as well as the Presidential candidates, to join us. Together, we can build for our children a world free from the shadow of HIV/AIDS.

# **RECOMMENDATIONS FOR THE LAST 100 DAYS OF THE CLINTON ADMINISTRATION**

In the next few weeks, the people of the United States will determine who will lead U.S. efforts against a global pandemic that is more deadly than any that has preceded it. And while a great deal has been accomplished in the past seven years, important unfinished business remains. With a tremendous sense of urgency, the Presidential Advisory Council on HIV/AIDS urges President Clinton to take the following action in the last 100 days of his Administration:

- Prioritize and fund public- and private-sector vaccine research and development. Begin immediate conversations at the highest global levels regarding the myriad of societal, economic, and regulatory issues that must be solved prior to the wide-scale distribution of any effective vaccine.
- Provide leadership and support for the highest possible funding levels for HIV/AIDS prevention, care and treatment, housing, research, substance abuse treatment, international programs, and the CBC/Minority HIV/AIDS Initiative during final negotiations with Congress on FY 2001 appropriations.
- Work with Congress to reauthorize the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act by the end of this session and do everything possible to ensure that the newly authorized legislation is free of unnecessary and/or harmful testing provisions that interfere with the goal of early care and treatment.
- Support efforts to provide significant debt relief to developing nations hardest hit by HIV/AIDS so that they may devote a greater share of their own resources to fighting the pandemic.
- Eliminate budget neutrality rules that act as a barrier to States' ability to expand Medicaid eligibility to individuals in the earlier stages of HIV/AIDS.
- Work aggressively with Congress to lift the ban on Federal funding for needle exchange programs. Distribute scientific information regarding the efficacy of needle exchange programs to State and local health officials and to Federal HIV/AIDS grantees and sub-grantees in an effort to support local communities' efforts to implement these life-saving programs using non-Federal dollars.

- Support the elimination of U.S. immigration restrictions on people with HIV/AIDS imposed by Congress, and direct the Centers for Disease Control (CDC) to revise the current guidelines for HIV-infected health care workers, which are discriminatory in nature and contrary to sound public health policy and science.
- Participate in World AIDS Day events that highlight the global nature of the pandemic.
- Encourage multi-national corporate leaders to assume a greater role and responsibility in the pandemic given economic and security issues. Urge religious leaders to discuss HIV/AIDS issues openly, and especially to fight sexism, homophobia, and racism, which contribute to high-risk behavior.
- Implement the recommendations of the pending White House Office of National AIDS Policy (ONAP) report on HIV/AIDS and youth, including the development of an interagency plan. Use the release of this report as an opportunity to increase public awareness regarding young people's risk and their unique service needs.
- Direct the Federal Bureau of Prisons to incorporate U.S. Public Health Service Guidelines for Use of Anti-retroviral Agents in Adults and Adolescents in all correctional medical facilities and pre-release planning. Develop and begin implementation of a plan to provide comprehensive substance abuse treatment for all prisoners in need of such services.

# INTRODUCTION

The Presidential Advisory Council on HIV/AIDS (Council) was established in 1995 by Executive Order to advise the President, the Secretary of Health and Human Services, and the Administration regarding policies and programs related to HIV/AIDS. The Council has worked primarily through the White House Office of National AIDS Policy to ensure that HIV/AIDS remains at the forefront of discussion and decision making within the Clinton Administration.

During the last five years the Council has recommended action regarding prevention and care, the search for a vaccine and a cure, and efforts to end HIV/AIDS-related discrimination and intolerance. It has struggled mightily, at times with a deep sense of frustration, to faithfully discharge its responsibilities to the President, his Administration, and most importantly, those here and around the world whose lives have been darkened by the shadow of HIV/AIDS. As the profile and the impact of the pandemic have expanded, so too have the composition and focus of the Council. A voluntary body with diverse affiliations and experience, the Council has sought to raise issues and urge national leaders to address the pandemic in new and more effective ways.

The Council has submitted two previous progress reports to this Administration, in July 1996 and December 1997, as well as numerous letters regarding specific issues of particular concern. In August 1998, the Council adopted an internal strategic plan emphasizing the growing impact of the pandemic within communities of color. (See appendix C)

This report is the Council's final submission to President Clinton, and an initial challenge to the next Administration. It also emphasizes another signal moment in the history of the HIV/AIDS pandemic: the shift to a "global" perspective. While the United States has a responsibility to continue to address HIV/AIDS within its own borders, no longer can the epidemic be split easily into "domestic" and "international" arenas. The *global community*, which includes those living in the United States, is affected by HIV/AIDS. History will judge us harshly if we fail to respond to this entirety of need.

Given the unique historical context of this report, the Council reaffirms several underlying themes:

- **HIV/AIDS is a nonpartisan issue.** The Presidential Advisory Council on HIV/AIDS directs its voice at this Administration because that is its charge. Yet at this time of transition, to focus narrowly on a particular leader or political party is to jeopardize the lives of millions. Our collective future depends on a continued, nonpartisan commitment to ending the HIV/AIDS pandemic. This challenge belongs to political leaders from all parties.

- **HIV/AIDS imperils the entire global community.** Infection rates globally remain largely unchanged or increasing. An estimated 5.4 million people were infected with HIV in 1999, 4.0 million of them in sub-Saharan Africa.<sup>5</sup> Globally, an estimated 60% of all new infections occur in people under age 25, and one-fourth of those living with HIV/AIDS in the U.S. were infected as teenagers.<sup>6</sup> In the 34 countries of Africa, Asia, Latin America, and the Caribbean hardest hit by HIV/AIDS, already almost 25 million children have lost one or both of their parents as a result of AIDS. Without decisive action, the number of AIDS orphans will rise to 40 million by the year 2010.<sup>7</sup> Many of these children no longer attend school because their teachers have died of AIDS. Without intervention, these conditions will most certainly result in serious societal instability, changing the social landscape forever and creating an unprecedented set of child welfare problems.

*“It is our clear national obligation, however, to participate in a global response that is equitable and founded on a fundamental commitment to human rights.”  
AIDS: An Expanding Tragedy the Final Report of the National Commission on HIV/AIDS, 1993<sup>8</sup>*

- **HIV/AIDS threatens national and global security.** The United Nations Security Council has recently characterized the global pandemic as a threat to security and stability, because HIV/AIDS has undermined the economic and political systems of many countries. Vice President Gore, speaking before the first-ever session of that body devoted to a health issue, stated, “No one can doubt that the havoc wreaked and the toll exacted by HIV/AIDS do threaten our security. The heart of the security agenda is protecting lives—and we now know that the number of people who will die of AIDS in the first decade of the 21<sup>st</sup> Century will rival the number that died in all the wars in all the decades of the 20<sup>th</sup> Century.”<sup>9</sup> Echoing that concern, U.S. Ambassador to the United Nations Richard Holbrooke stated, “[AIDS] is the toughest and biggest of all issues, not just in Africa. Africa is just the epicenter...if you ask what is the number one problem in the world today, I would say it is AIDS.”<sup>10</sup>
- **The United States has a responsibility to be a leader and partner in the global fight against HIV/AIDS.** As the world’s most prosperous nation, the U.S. has the resources and capacity to more fully engage in the fight against HIV/AIDS, and the clout to leverage funds from the public and private sectors worldwide. Its global leadership in the search for a vaccine and a cure must continue even as it strengthens research partnerships with other nations. Yet global action must not come at the cost of domestic programs; the U.S. must continue to address domestic issues in the communities most significantly impacted.
- **The response to HIV/AIDS as a public health crisis should be guided by scientific knowledge, not political expediency.** Preventing the spread of HIV/AIDS requires the courage and political will to provide accurate information and apply scientifically sound prevention programs, unfettered by prejudice and stigma.

Global scientific efforts must continue to strive toward the goal of developing an HIV/AIDS vaccine and cure; until then the only effective means of prevention is education. Science must be translated into meaningful knowledge, especially for the young. The lack of basic information can be lethal, especially for young people in developing countries, many of whom are still unaware of even a single method of protecting themselves against exposure and transmission.

- **Addressing the global HIV/AIDS pandemic requires coordinated and sustained political will and financial resources proportionate to need.** Given the magnitude of the crisis, its disproportionate impact on the poor, and the years of work left to develop a vaccine and cure, there can be little doubt that HIV/AIDS will remain a critical issue for years to come. Only through sustained leadership at every level and in every sector of society can this pandemic be successfully ended. Through leadership must come a call to action: to expand research at all levels, to build and integrate systems of prevention and care, and to inspire individual and global action.

*“Today, in sight of all the world, we are putting the AIDS crisis at the top of the world’s security agenda. We must talk about AIDS not in whispers, in private meetings, in tones of secrecy and shame. We must face the threat as we are facing it right here, in one of the great forums of the earth -- openly and boldly, with urgency and compassion.”*  
*Vice President Gore addressing the U.N. SECURITY COUNCIL SESSION ON AIDS IN AFRICA, January 10, 2000*

This report describes progress, identifies strategies, and makes recommendations for effectively addressing the HIV/AIDS pandemic in both the short and long term. The Council recognizes the need for simultaneous action in many areas of prevention, research, and care. Therefore, this document does not offer its recommendations in priority order, nor does it suggest that one need should be forced to compete with another.

# PREVENTING NEW HIV INFECTIONS

## Introduction

HIV is preventable, yet every day nearly 16,000 individuals around the world become infected needlessly. The continued, unchecked spread of this deadly virus will result in the political, social, and economic instability of nations, and is an increasing threat to global survival.

Until a vaccine or cure is found, successful HIV/AIDS prevention interventions remain the sole option available to stop this pandemic. Despite this reality, prevention efforts worldwide have been hindered by the unparalleled stigma associated with HIV/AIDS. The consequences of this chronic stigma are evident in people's denial that HIV/AIDS is their problem; in the fear that prevents people living with HIV/AIDS from disclosing their status; in the reluctance of those at risk to seek testing; in governments' reluctance to participate in science-based HIV/AIDS prevention strategies because they may be seen as endorsing the behaviors that are associated with it; in people's fear to teach their children about the realities of HIV/AIDS; and in the criminalization of the sexual acts of people living with HIV/AIDS.

In the U.S., disproportionate numbers of new infections are found in poor communities of color, among young gay men, among drug users, and among African-American and Latina women-populations who have rarely been embraced by this nation as a whole, and now risk being abandoned or ignored. Both here and in the rest of the world, new infections take place against a background of poverty, gender and social inequality, discrimination, and limited health infrastructure. The success of HIV/AIDS prevention efforts to date, in the face of these challenges, is commendable if not miraculous.

After nearly 20 years of the HIV/AIDS pandemic it can be said with confidence that:

- Prevention works. Until an effective vaccine or cure for HIV/AIDS is found, behavioral change is the only means to stop the expansion of this pandemic. Research and experience have shown that prevention efforts can be successful. A clear example is in Uganda, where a national "AIDS sensitization" effort involved collaboration among scientific, technical, political, medical, social, and communal entities. This massive strategic effort succeeded in reducing the rate of new HIV infections in Uganda from 7.6 per 1,000 person years in 1990 to just 3.2 by 1998.<sup>11</sup> It is essential for HIV prevention programs to target communities at greatest risk for infection.

*"We have to reduce the number of new infections each and every year until there are no more new infections."*

*President Bill Clinton addressing the White House Conference on AIDS Dec. 5, 1995*

- Prevention is cost-effective. In the U.S., studies suggest that the average prevention intervention costs \$40 per person<sup>12</sup> while the average cost of lifetime treatment for an HIV-infected person is \$155,000.<sup>13</sup> Clearly a reduction in the number of new HIV infections would result in significant cost savings.
- HIV/AIDS prevention promotes better overall health. Individuals who benefit from HIV/AIDS prevention efforts not only avoid HIV exposure, but also avoid other diseases that are transmitted sexually or through needle sharing and learn skills that encourage other positive health behaviors. In the U.S., HIV/AIDS prevention efforts have contributed to increases in condom use, reduction in teen pregnancies, and delayed onset of sexual initiation among youth.<sup>14</sup>

Given its effectiveness, its low cost, and its contribution to the betterment of overall health, HIV/AIDS prevention warrants serious and sufficient global investment. This investment must provide ongoing monitoring of prevention effectiveness, prevention-related research, and capacity building for prevention intervention delivery.

## **Prevention Strategies and Challenges**

The Presidential Advisory Council on HIV/AIDS has consistently identified important strategies that must be pursued by the President and by future Administrations if the U.S. is to join other countries that have demonstrated the courage and political will to end this pandemic. At this time in history, all nations must work together to marshal the necessary resources to stop this preventable disease. Following are descriptions of some of the most important prevention strategies that will be necessary to the end the HIV/AIDS pandemic.

*Development of effective and affordable HIV vaccines and microbicides must be prioritized.*

This epidemic will not end without the development of an effective and affordable vaccine. For the past five years, the Council has advocated a strong commitment to vaccine development, and we continue to believe that the unprecedented threat posed by HIV/AIDS requires that extraordinary steps be taken to achieve this goal.

Multiple issues must be addressed related to this effort, including scientific development of such a vaccine, testing of candidate vaccines, and eventual worldwide distribution and use. Important issues that must be dealt with simultaneously include the ethics of participation in clinical trials, determination of who should be vaccinated, responsibility for any liability related to candidate vaccines, pricing and marketing, and ensuring the availability of an effective vaccine for the global community, most of whom will be unable to afford it.

The Council acknowledges and applauds the leadership of President Clinton in the creation of the Dale and Betty Bumpers Vaccine Center at the National Institutes of Health. The Council also urges strong support for enactment of a range of policies designed to encourage vaccine development. We recognize the importance of public-private partnerships and continued U.S. collaboration with our global partners to the success of vaccine development and distribution.

In both the developed and developing world, many women are not empowered to demand that their sexual partners use condoms. For this reason, the development of an effective microbicide (i.e., a topical chemical agent that would kill HIV locally in the vagina or anus) is urgently needed. Since 1995, the Council has made several recommendations regarding microbicide development, with varying degrees of responsiveness on the part of the Administration. In general, scientific study in this area has only recently begun, and global efforts have been slow in focusing on microbicide development. It was not until February 2000 that the first international conference on this topic was convened. While initial studies have been disappointing, an effective microbicide remains an achievable goal, and the Council is heartened by increased activism in this area.

**Recommendations:**

- The Administration should continue to work towards the development of a global plan for vaccine development and distribution based on meaningful collaboration with public- and private-sector partners.
- The Administration should begin immediate conversations at the highest global levels regarding the myriad of societal, ethical, economic, and regulatory issues that must be solved prior to the wide-scale distribution of any effective vaccine. The time to address these issues is now, before an actual vaccine has been developed.
- The Administration should strongly support and work to enact policy reforms that will encourage HIV vaccine development, including tax credits for vaccine research, development, and sales; the creation of international purchase funds; and continued and expanded funding to public-private partnerships that have been established to encourage vaccine development, including efforts such as the Global Alliance for Vaccines and Immunization (GAVI) and the International AIDS Vaccine Initiative (IAVI).
- The Administration should attach high priority to efforts to develop effective microbicides through significantly increased research funding, incentives to industry, and better coordination of microbicide research.

***Prevention efforts require renewed and sustained investment.***

Spending on prevention is truly an investment in the future. Investing in prevention now will help avoid far larger costs for care and services for those who become infected with HIV. Despite the continuing spread of HIV, our nation's commitment to prevention funding has not kept pace with the need. In the past ten years, Federal appropriations for HIV/AIDS prevention have increased by a meager 31%, barely matching inflation.

Even with the enhanced interest in the worldwide pandemic seen in recent years, U.S. spending on measures to prevent new infections in the rest of the world remains at shamefully low levels-total appropriations for the worldwide epidemic are less than the amount allocated to improvements to a highway interchange on the Washington Beltway. But despite that, the United States remains the largest single donor country in global HIV/AIDS efforts. National governments in highly impacted countries have also been slow to allocate resources commensurate with the threat posed by HIV/AIDS. Many of these governments operate under crushing debt burdens, competing demands on limited resources, and a lack of political will, which have hindered appropriate spending.

At home or abroad, U.S. government spending alone will never be sufficient to fully fund all needed prevention efforts. Corporations, voluntary agencies, State and local governments, national governments, international organizations, and the philanthropic sector all have a role to play in supporting efforts to prevent new infections.

**Recommendations:**

- The Administration must work for dramatically increased funding for global prevention efforts consistent with the severity of HIV/AIDS and its importance to U.S. national security. To the greatest degree possible, this should be done in a way that leverages additional funds from other governments, international organizations, and the private sector.
- As part of a global partnership with other leading industrialized nations, the Administration should support current and future efforts to provide meaningful debt relief to developing countries so that they may devote a greater portion of their own resources to fighting HIV/AIDS.
- The Administration should work for meaningful increases in funding allocated to support HIV/AIDS prevention, surveillance and monitoring, and research programs in the U.S., with an emphasis on meeting the needs of communities experiencing new infections. This must include capacity-building assistance to develop and strengthen community-based HIV/AIDS prevention infrastructure in all communities.

***Strong leadership and coordination of a multi-sectoral effort are essential to implementation of effective prevention.***

Around the world, examples from Senegal to Switzerland, from Thailand to Uganda, demonstrate that a well-designed and coordinated multi-sectoral prevention effort with strong national leadership can dramatically reduce HIV transmission. In this country, the Centers for Disease Control and Prevention (CDC) has recognized this need by requiring individual States to develop comprehensive, evidence-based prevention plans utilizing a community participatory process. But while individual States receiving Federal prevention funds are required to have such a plan, no similar, comprehensive prevention plan currently exists at the national level.

The Council has made numerous recommendations concerning the need for a coherent national HIV/AIDS prevention plan and has often been frustrated by the lack of leadership and responsiveness on the part of the CDC. The Council is pleased that efforts are finally underway to develop such a plan. But we are concerned that the multiplicity of planning processes being undertaken (including a Department of Health and Human Services strategic plan, a CDC prevention plan, the eagerly awaited Institute of Medicine report on prevention strategies, and Healthy People 2010, among others) will result in a multiplicity of reports, rather than a clearly focused and well-coordinated national prevention effort.

*“None of are[satisfied], and we won’t be satisfied until we do everything in every community to prevent this disease, and, second, until we make sure everyone who needs care gets it and gets it early enough, which actually has to be our target.”  
Secretary Shalala (presenting to the Council, October 5, 1999)*

The Council recognizes that the challenges of developing a comprehensive approach in one country pale in comparison to the obstacles to effective coordination of the many governmental, business, civil society, development assistance, and other entities that must come together to mount effective responses to the growth of HIV/AIDS globally.

**Recommendations:**

- The President should work for permanent establishment of the Office of National AIDS Policy (or a similar entity) with full authority to increase the efficiency and effectiveness of funding for HIV/AIDS prevention efforts, with appropriate staffing and authority to coordinate all Federal HIV/AIDS prevention efforts.
- The Administration should develop a well coordinated and integrated National HIV/AIDS Prevention Plan to reduce new infections to zero, and ensure cross- departmental and agency participation by empowering an individual reporting directly to the President to oversee the development, implementation, and monitoring of such a plan. All current Federal HIV/AIDS

advisory bodies, committees, and councils should be convened jointly to participate in the coordination, implementation, and monitoring of the plan.

- The Administration should make a concerted effort to engage new and existing partners in HIV/AIDS prevention efforts in this country and worldwide. These partners include State and local health departments, nongovernmental organizations, schools, businesses, labor unions, the faith community, music and media industries, tribal governments and other indigenous organizations, traditional civil rights and civic organizations, and fraternities and sororities.
- The Administration should take concrete steps to remove many of the current barriers that prevent community-based organizations from obtaining funding to support their HIV/AIDS prevention work. This should include steps such as simplified application forms and processes, coordination of grant cycles and applications across funding streams, ensuring participation of more reviewers from minority community organizations, and greater support to build capacity among small minority-based organizations. U.S. global funding efforts should use the same principles to ensure that funding reaches and directly supports the development of appropriate community-based organizations.
- The Administration should make a commitment to use all available avenues for HIV/AIDS prevention, ensuring that all publicly supported systems of services that interact directly with various populations and communities use the point of contact as an opportunity for education or interventions to help prevent HIV transmission.
- The President, his Cabinet members, and other Administration officials must continue and expand efforts to demonstrate U.S. government leadership in the fight against HIV/AIDS by utilizing every opportunity to mobilize public opinion, engage governmental and non-governmental leaders, and encourage multi-sectoral involvement in prevention activities. The U.S. government must take a lead in encouraging development of a global action plan and responses to implement such a plan. Including continued efforts to prioritize AIDS with its G-7 partners.

***Availability of voluntary, free or low-cost, anonymous and confidential HIV counseling and testing services is critical.***

Learning one's HIV status is an important first step in prevention. Research has shown that the vast majority of persons who learn that they are HIV-infected significantly change their behavior to avoid transmitting the virus to others.<sup>15</sup> The CDC estimates that

as many as 300,000 people living with HIV/AIDS in the U.S. do not know they are infected, thus possibly infecting others without knowledge. Globally, only a very small minority of people living with HIV/AIDS have been tested and are aware of their HIV status.

There are multiple and complex reasons that people do not learn their HIV status. Many people are unaware of their risk and see no need for testing. Testing programs may have locations, hours, or costs that make them inconvenient or inaccessible to those at risk. Non-HIV/AIDS health care providers are not always prepared to offer counseling and testing during routine office visits. In addition, concerns about loss of privacy, fears of discrimination, and the unavailability of anonymous HIV testing make some of those at highest risk unwilling to seek such services, and in some cases, HIV care and treatment.

While Federal resources have been used to fund counseling and testing systems at the State and local levels in this country, these systems alone are not sufficient to reach all who need these services. In many other countries, HIV testing is not widely available or affordable for the vast majority of the population. And the Council's previous recommendation for a national campaign to promote HIV testing in the U.S. has yet to be implemented, despite repeated promises that it is in development.

**Recommendations:**

- The Administration should take every step available to it to ensure the continued and expanded availability of both anonymous and confidential, voluntary HIV counseling and testing in Federally funded programs at the State and local levels.
- The Administration should fund and promptly implement a national campaign promoting voluntary counseling and testing, involving both national media and local partnerships.
- The Administration should support the creation and widespread availability of effective, affordable HIV testing technologies in the U.S. and around the world, encouraging innovative practices to overcome barriers to testing.

***Factual and truthful education about HIV transmission and how it can be avoided is needed for all.***

Factual and truthful education is an essential ingredient for effective prevention strategies. It is unrealistic to expect people to take steps to protect themselves if they do not have basic, accurate information about HIV transmission and prevention.

The types of HIV/AIDS education that are needed in this ever-changing pandemic are varied and evolving. There will always be individuals who must learn the basic information about how HIV is transmitted. Others will need specialized education and interventions designed to address their particular risk situations. Successful HIV/AIDS prevention campaigns include candid, culturally sensitive, age- and language- appropriate information that continues to highlight strategies to prevent infection/transmission.

HIV/AIDS prevention messages are most effective when integrated into all “windows of opportunity”, i.e., as part of any health-related program, inside correctional facilities, in all educational institutions, and as part of substance abuse and mental health treatment. They can and should be incorporated within the entertainment industry, as standard corporate/ industry training of the labor force, and as part of any military training.

People of color in the U.S. continue to have disproportionate representation among HIV/AIDS cases, but have not received proportionate targeted HIV/AIDS prevention funding. The Congressional Black Caucus (CBC)/Minority HIV/AIDS Initiative that began in 1999

*“More than 123,000 young adults in the United States have developed AIDS in their twenties. The delay between HIV infection and the onset of AIDS means that most of these young people were infected with HIV as teenagers.”<sup>17</sup>*

is an important step in efforts to address this inequity. The Initiative provides additional dollars to be used specifically to fund research, practice, and capacity building focusing on communities of color, particularly African-American communities-the most represented racial group in HIV/AIDS cases.

Unlike many other nations, the U.S. government has been unwilling to implement systematic, population-wide education that teaches children and adults about sexual and drug-related risks for transmitting HIV. This barrier to explicit sexual and drug-related conversations with young people has had enormous consequences, with at least 50% of new HIV infections in the U.S. occurring among young people under the age of 25.<sup>16</sup> Fears that explicit sexual information would increase sexual initiation among U.S. youth have not been supported by the studies that have evaluated such claims. Yet too many policy makers continue to push to censor the prevention that youth receive by mandating and funding “abstinence only” approaches.

The Administration’s unwillingness to challenge widespread misperceptions concerning HIV transmission risk further hampers the goal of promoting factual HIV/AIDS prevention efforts. This has been demonstrated by the endorsement of nonscientific-based restrictions on the practices of HIV-infected health care workers, as well as implied, if not explicit, endorsement of a congressionally-mandated ban on the immigration and travel of individuals living with HIV/AIDS to the U.S. While providing no real public health benefit, these two policies only serve to contribute to ongoing stigma and discrimination against persons living with HIV/AIDS and further misinformation about transmission risk.

In the 1980s, community organizations and government agencies mobilized to raise awareness and knowledge about HIV/AIDS. Media coverage, public service announcements, and grassroots educational efforts created a social commitment to fighting HIV/AIDS. Today that attention has faded, and the impact of those efforts has slowly worn off in the intervening years. Many observers believe that optimism over treatment advances and the passage of time have allowed a dangerous sense of complacency to set in—a sense that must be addressed and combated directly.

### **Recommendations:**

- The Administration should take immediate steps to remove content restrictions and other barriers to effective HIV/AIDS prevention messages from Federally funded programs.
- The Administration should work to ensure that developmentally appropriate and science-driven HIV/AIDS prevention education takes place in all our nation's schools.
- The Administration should continue to expand funding for communities hardest hit by HIV/AIDS through the CBC/Minority HIV/AIDS Initiative.
- The Administration should provide funding and support for education and prevention that targets the specific needs of gay and bisexual men where rates of infection are increasing substantially, especially among young men and gay and bisexual men of color.
- The Administration should take steps to replace or abolish scientifically discredited policies (such as guidelines restricting HIV-infected health care workers, Congressionally imposed travel and immigration restrictions, the ban on induction of HIV-positive individuals into the military), which feed public misinformation and counteract public education efforts.
- The Administration should work with the broadcast industry to modify existing television and radio “commercial standards” to allow frank and appropriate prevention methods (such as the importance of condom use) to be aired. The Administration should also develop and implement a high profile national media campaign on HIV/AIDS prevention that includes innovative uses of all forms of media (such as television and radio soap operas or “telenovelas”) in delivering general and targeted prevention messages.

*Studies in New York City and Philadelphia found that making condoms available in school does not lead to increases in sexual behavior but does increase condom use among sexually active students.<sup>18</sup>*

***The further development and availability of effective prevention products such as condoms, clean syringes, and drugs to prevent HIV transmission are essential.***

Effective means of preventing HIV transmission exist, yet all too often they are not used simply because they are not available or affordable to those who need them. Male and female condoms are a primary and highly effective means of blocking sexual transmission of HIV. However, many individuals around the world do not have consistent, reliable, and affordable access to condoms. Political opposition often stands in the way of making condoms available to some populations due to claims that condom availability will increase sexual activity, despite scientific evidence to the contrary.<sup>18</sup>

Anti-retroviral therapy (ART) has been shown to significantly decrease the risk of HIV transmission from mother to child (perinatal) and from patient to health care worker. Preliminary data also suggests that effective ART may also lessen the likelihood of sexual transmission of HIV, although there are major unanswered questions about the actual implication of these findings.

The rates of maternal-child transmission have decreased from 8.2 per 100,000 births in 1990, to 2.6 per 100,000 births in 1996, representing a 66% decline in perinatal HIV infection in the U.S.<sup>19</sup> This enormous success is attributed in part to the improved anti-retroviral therapy of HIV-infected children, and most importantly to the use of a three-part preventive drug (AZT) regimen given 12-16 weeks prior to giving birth, during delivery, and for six weeks following delivery.

The treatment approach responsible for the success of perinatal prevention in the U.S. will not be practical to reproduce in resource-poor regions of the world, where 90% of infected infants now reside. However, recent scientific studies have demonstrated that simpler regimens, such as the use of a single dose of nevirapine, given to the mother during delivery and to the infant within the first 72 hours of life, have been associated with 50% reductions in mother-to-child transmission. Provision of these regimens is theoretically feasible in resource-poor regions, but only with the help and assistance of countries such as the U.S.

Availability of clean injection equipment for all individuals who inject drugs is an effective HIV/AIDS prevention intervention. Studies of injection drug users in the U.S. show dramatic reductions in new infections among those who have access to clean needles, with no increase in drug.<sup>20</sup> Needle exchange is an essential part of a comprehensive harm reduction model, through which substance users can learn methods for reducing the harm and risk of infection to themselves and others. The Clinton Administration has the necessary scientific evidence to support and fund the provision of clean needles to those who need them but has chosen not to do so, with deadly consequence.

Research also shows that when legal restrictions on the sale and possession of syringes are eliminated, injection drug users change their syringe-buying and -sharing practices in ways that reduce HIV transmission. Studies conducted by the CDC and the Connecticut Department of Public Health found that needle sharing among drug users fell by 39% after Connecticut passed a law permitting the sale and possession of syringes.<sup>21</sup>

This strategy is also important in nations that have little access to clean syringes for general medical use. As a new epidemic of Hepatitis C is documented among injection drug users worldwide, this particular strategy would have additional health benefits in preventing multiple communicable diseases.

#### **Recommendations:**

- The Administration must work to implement strategies to ensure global access to condoms and other effective barrier methods such as latex gloves to avoid HIV transmission. Condoms must be widely available to all, particularly young people and incarcerated persons—two populations often mistakenly perceived as not sexually active. Strategies must ensure that cost is not a barrier for those in need of these important prevention materials.
- The Administration should work to ensure that health care providers continue to offer voluntary counseling and testing to pregnant women and appropriate treatment to HIV-infected pregnant women. In the U.S., where these treatments are readily available, ART should be part of a comprehensive treatment regimen targeted at both mother and child. Prevention of perinatal transmission should not focus solely on protecting the child while ignoring the mother's health needs.
- The Administration should augment its efforts to make interventions to prevent perinatal transmission available in all parts of the world, including work with the pharmaceutical industry and with global partners to provide these drugs at little or no cost in those areas of the world where they would not otherwise be available.
- The Administration should work aggressively with Congress to lift the Federal ban on funding for needle exchange programs to prevent the further spread of HIV, Hepatitis C, and other blood-borne diseases.
- The Administration should disseminate existing scientific information regarding the efficacy of syringe exchange to State and local elected officials, health officials, Federal HIV/AIDS grantees and sub-grantees, private funders, the

- media, and foreign governments.
- The Administration should actively encourage State efforts to eliminate laws that restrict the sale and possession of syringes, as well as other efforts to broaden pharmacy access to clean syringes. While these laws and regulations are State or local in nature, they are modeled on Federal government guidelines. These Federal standards should be adjusted to reflect scientific evidence and public health needs.

***A comprehensive, multi-faceted approach is needed to meet the HIV/AIDS prevention needs of drug and alcohol users.***

In nations around the world, the use of alcohol and drugs and the sharing of injection equipment have contributed greatly to the spread of HIV/AIDS. There is no single approach to effectively addressing the role of substance use and needle sharing; instead, a variety of interventions are needed to face this challenge. Drug addiction is a chronic, relapsing medical condition: yet all too often our society treats it as an issue of personal failure, deserving of punishment.

The prevention and treatment of drug and alcohol abuse are important mechanisms in reducing HIV/AIDS. In addition to focusing on rehabilitation and recovery through abstinence, substance abuse treatment must adopt new strategies to prevent the transmission of HIV/AIDS to substance users and their sexual partners and children. It is critically important to develop factual, comprehensive HIV/AIDS prevention and primary care services in substance abuse treatment settings. Because most substance abusers will relapse one or more times after initially entering treatment, treatment programs can play an important role in educating alcohol and drug users about HIV/AIDS prevention measures.

For injection drug users who will not or cannot stop using drugs, access to clean injection equipment can make a significant difference in lowering risk of HIV infection. A harm reduction philosophy acknowledges that some individuals will not or cannot abstain from drug or alcohol use or will not enter traditional treatment settings, but that these individuals can change some behaviors that will reduce potential harm.

Much of the current national approach to drugs and drug users has resulted in policies that serve to enhance, rather than decrease, risk of HIV transmission. In recent years, legal changes have eliminated substance abuse as an eligible category for health and income benefits associated with disability status, cutting hundreds of thousands of drug users off from Medicaid coverage. This change is typical of a “war on drugs” approach, which has become, in many ways, a war on drug users.

### **Recommendations:**

- The Administration should develop a plan to expand substance abuse treatment capacity in this country to guarantee treatment access to all who need it, including incarcerated populations. As a part of such a plan, substance abuse prevention and treatment should be funded at levels at least equal to drug interdiction and enforcement efforts.
- The Administration should take steps to ensure the adoption of treatment practices that recognize the likelihood of relapse by including appropriate HIV/AIDS prevention and harm reduction measures.
- The Administration should work to identify and remove legal barriers that prevent drug users from accessing health and social services essential to HIV/AIDS prevention.

### ***Behavioral research is critical to the ongoing development of effective HIV/AIDS prevention efforts.***

Behavior change of any kind is complex. Changing behaviors that are very intimate, involve more than one person, or are related to addiction requires multiple strategies. Continued behavioral research is needed to develop effective HIV/AIDS prevention interventions that can address issues such as perceived self-worth, equity among genders in sexual decision making, and the reduction of sexual coercion and sexual violence.

The cultural context of HIV/AIDS risk behaviors deserves attention around the world. Every nation, every village, and every household has diverse and often unique cultural mores that help or hinder prevention of HIV/AIDS. In certain cultures it may be appropriate to target individual behavior change, but this may be less effective in other cultures where health is viewed as a community issue, not an individual issue. Increased integration of the cultural context of HIV/AIDS prevention is essential in increasing ongoing effective prevention strategies.

Behavioral research is required to identify prevention strategies that are appropriate to the needs of different cultures and communities. Good, relevant behavioral research can assure that prevention resources are being spent on scientifically-proven interventions that will have an impact by reducing new infections.

**Recommendations:**

- The Administration should make a commitment to increased funding for behavioral and prevention research, emphasizing the needs of communities experiencing new infections.
- The Administration should develop and implement mechanisms for widespread and rapid dissemination of usable findings to community-based HIV/AIDS prevention programs.

***Ongoing and new structural-level interventions will be key in further reducing new HIV infections.***

HIV infections are the result of far more than simply individual behaviors. Every new infection happens in an environment that is shaped by social norms, laws, economics, the availability of health care infrastructure, and a range of other factors over which an individual may have little or no control. Rather than focusing entirely on individually-based interventions to combat HIV transmission, effective prevention must also identify and implement those structural changes that will help decrease new infections. These changes range from the treatment of sexually transmitted diseases (STDs), which studies have shown reduces HIV transmission,<sup>22</sup> to ensuring the availability of uncontaminated blood supplies and combating underlying social conditions that contribute to individual or communal vulnerability.

**Recommendations:**

- The Administration should implement activities that help provide funding to guarantee the availability of uncontaminated blood supplies around the world.
- The Administration should provide leadership and funding to support a global effort to reduce the total number of STD infections. This will be achieved only through continued global efforts to develop health service infrastructure vital for the treatment of both HIV/AIDS and STDs. In the U.S., this effort must include a commitment to eradicate syphilis.
- The Administration should continue to support and expand efforts to combat poverty, economic underdevelopment, illiteracy, lack of health care, and economic dislocation due to war, all of which interfere with HIV/AIDS prevention efforts. HIV/AIDS programs should supplement and work with existing development and aid programs to address these issues

- comprehensively.
- The Administration should take all steps at its disposal to combat the social inequities and discrimination in the U.S. and abroad that make entire classes of people marginalized and more vulnerable to HIV/AIDS. This includes efforts to promote economic and social equality between men and women, ending racial and ethnic discrimination, fighting homophobia, and protecting human rights for all.

***Monitoring the HIV/AIDS pandemic on a local, national, and global basis is essential to effectively target resources and assess the impact of HIV/AIDS prevention efforts.***

Accurate and comprehensive information about the incidence, prevalence, and characteristics of HIV/AIDS in communities and countries is integral to developing and assessing prevention programs. Public health officials, community organizations, funders, researchers, and others rely on this data to target resources and determine prevention needs. There are numerous ways to collect this data and different approaches are suited to different environments and accepted by different populations.

Particular attention must be given to improving the quality of data gathered on the Asian and Pacific Islander and Native American populations. State and national surveillance programs lack the subtlety required to identify prevention and care needs of at-risk subpopulations within these large and diverse communities.

*“The pages of history reveal moments in time when the global community came together and collectively found - what President Clinton calls ‘the higher angels of our nature’. In a world living with AIDS - we must reach for one of those historic moments now - or pay the price later.”*  
*Sandra L. Thurman addressing the XIII International AIDS Conference, Durban, South Africa, July, 2000*

**Recommendations:**

- The Administration should place a greater focus on, and provide more financial support for, improving the efficiency and efficacy of the HIV/AIDS behavioral and disease monitoring systems to ensure that the data on which researchers, practitioners, public health officials, and planning groups must depend is accurate and comprehensive.
- In developing and enhancing activities to monitor the epidemic in the U.S. and abroad, the Administration should work to retain community confidence by taking every step to protect individual privacy and human rights. To this end, the State Department should begin to document cases of HIV/AIDS - related human rights abuses. Data collection should always use the least intrusive measures reasonably possible and be designed and implemented in conjunction with affected communities.

- The CDC should establish surveillance systems to identify subpopulations within communities of color that might otherwise be obscured by broad categorizations and to help community prevention planners target prevention resources accordingly.

## **Conclusion**

HIV/AIDS prevention is not a single intervention or “magic bullet” that can be provided to all individuals in all nations. Effective HIV/AIDS prevention is comprehensive and multifaceted, and requires the involvement of all sectors of a given society. It is perhaps this complexity that leads governments to ignore or under-fund HIV/AIDS prevention efforts. Yet, a sound investment in HIV/AIDS prevention today will lead to immeasurable and unquestionable global health benefits for decades to come.

# SERVICES FOR PERSONS LIVING WITH HIV/AIDS

## Introduction

In recent years, HIV/AIDS treatment options have improved enormously, creating hope for longer, more productive lives for many individuals living with the disease. However, existing treatments are expensive, are not effective for everyone, and are associated with many toxicities and side effects. The reality is that access to early medical care and treatment remains elusive for many low-income, uninsured people in the U.S., as well as the vast majority of people living with HIV/AIDS in the developing world, where basic public health infrastructure is weak or non-existent.

The Presidential Advisory Council on HIV/AIDS recognizes that the tremendous disparity in access to care between the United States and developing countries makes it difficult to assess the two situations in a single report. Although experience in this country can inform more recent efforts elsewhere, there are also many examples of how the U.S. could learn from its global partners.

With regard to HIV/AIDS services, the Council knows with certainty that:

- Early care and treatment can dramatically enhance the quality of life and health for persons living with HIV/AIDS. Through early and consistent access to medical care, persons living with HIV/AIDS are best able to make informed decisions regarding their treatment options and to take appropriate steps to delay HIV-related illness.
- Early care and treatment is effective in reducing the cost of HIV/AIDS care over the long term. By helping to protect the immune system, potent anti-retroviral therapy significantly decreases susceptibility to opportunistic infections and other AIDS-related diseases. This, in turn, reduces acute illness, hospitalizations, disability, and lost productivity. While these drugs are costly, they are cost-effective in the long run.
- Ensuring access to quality HIV/AIDS care remains a major global challenge. As the number of persons living with HIV/AIDS continues to grow, public and private funding for essential services must expand accordingly. Substantial new financial resources are also needed to address widening disparities in access to care, both within the U.S. and globally.

## **Service-Related Strategies and Challenges**

In the first 20 years of this pandemic, the United States has identified a number of effective service strategies. The following strategies should guide the action of this and future Administrations:

*Ensuring early and consistent access to medical care and treatment must be the goal of HIV/AIDS services.*

Through regular monitoring and consistent adherence to well-established treatment guidelines, the majority of people living with HIV/AIDS can significantly extend both the quality and length of their lives. Early care is also cost-effective, and has been shown to decrease the risk of HIV transmission to health care workers and from mother to child.

Early diagnosis clearly contributes to the successful outcome of HIV-infected individuals, since care will begin only after one's HIV status is known. Counseling of individuals prior to and after receipt of HIV antibody tests has been shown to be effective in promoting wider utilization of voluntary HIV counseling and testing, and in guiding the way towards more intensive prevention support and medical care.<sup>23</sup>

All people with HIV/AIDS are entitled to quality health care. Unfortunately, even the United States is still far from attaining the goal of universal access to health care.

*The CDC estimates that between 800,000 and 900,000 Americans are living with HIV/AIDS. Of these, one-third do not know their positive status, one-third know their status and are in care, and one-third know their status and are not in care.<sup>24</sup>*

According to the U.S. Department of Health and Human Services, one-half to two-thirds of persons living with HIV/AIDS in the United States are currently not in care.<sup>24</sup> Racial and/or gender disparities in access to care exist and, as a result, disparities in health outcomes also continue.

Globally, only a small fraction of those who require care have access, largely for reasons of affordability. In the United States, the annual cost of providing HIV-related care and treatment to an individual is \$20,000 to \$25,000, an amount that far exceeds total government health spending per person in many developing countries.<sup>25</sup> President Clinton's recent Executive Order on Access to HIV/AIDS Pharmaceuticals and Medical Technologies, the Export-Import Bank's new \$1 billion loan program, as well as the industry's own efforts to provide free or lower-cost therapies in developing nations, are to be commended. However, additional and unprecedented efforts are necessary.

In addition to expanding access to HIV/AIDS therapies, efforts to improve on current treatments are needed. Over the past decade, tremendous achievements have occurred in the development, testing, and licensure of over 15 different anti-retroviral medications, with many additional agents currently in development. Nonetheless, resistance to existing drugs occurs rapidly and predictably, mandating the continued search for new agents.

Furthermore, many of the existing drugs are associated with debilitating side effects and toxicities, requiring research into the development and testing of additional anti-retroviral drugs that are simpler to take and less costly.

Although each individual must decide whether and when to initiate antiretroviral therapy, government programs should do everything within their power to encourage early access to care. Unfortunately, this has not always been the case. In the U.S., for example, current Medicaid eligibility rules require HIV-infected individuals to have a disabling AIDS condition before they are eligible for the program, thus negating the opportunity for early care. Despite growing interest by several States in using Section 1115 waivers to rectify this inherent conflict, only one waiver has been granted to date. The Clinton Administration's continued use of restrictive budget neutrality guidelines to evaluate States' waiver applications poses a significant obstacle to the goal of early care and treatment.

In contrast to the Medicaid eligibility issue, enactment of the Jeffords-Kennedy Work Incentives Improvement Act of 1999 represented an historic effort to reform Federal policy to remove roadblocks to life-saving care. By allowing disabled individuals (including persons living with HIV/AIDS) to maintain their health benefits upon returning to work, and giving States important flexibility in defining disability, this law prevents individuals from being forced to choose between health care and employment. The Council commends the Administration and Congress for their strong commitment to passage of this Act.

#### **Recommendations:**

- The Administration should emphasize the importance of research to develop more effective, less toxic, and easier-to-take medications within the National Institutes of Health and other agencies within the Federal government responsible for the testing, licensure, and regulation of such drugs.
- The Administration, in particular the Office of Management and Budget (OMB), should discontinue use of existing budget neutrality rules to evaluate 1115 waiver applications from States to cover low-income individuals in the earlier stages of HIV/AIDS. The Health Care Financing Administration (HCFA) should continue to work proactively with States interested in pursuing such waivers.
- The Administration should implement promptly the Jeffords-Kennedy Work Incentives Improvement Act and use a portion of demonstration funding provided through the Act to expand access to Medicaid for people in the earlier stages of HIV/AIDS.

- The President and other senior Administration officials should continue to speak out against homophobia and other forms of discrimination that can interfere with access to and quality of health care. The Health Resources and Services Administration (HRSA) should play a proactive role in efforts to educate and train health professionals about discrimination through the AIDS Education and Training Centers and Bureau of Health Professions programs.
- The President and Vice President should use the authority of their offices to push the pharmaceutical industry to minimize the cost of HIV/AIDS treatment, particularly in impoverished regions of the world where substantial price reductions are necessary to ensure access.

***Support services play a critical role in ensuring access to and retention in care.***

In the United States, many people with HIV/AIDS are unable to access care without support services such as housing assistance, transportation, food, child care, legal services, treatment information, interpreter services, outreach, psycho-social services, and case management. These services must be available and provided in a manner that is appropriate for specific populations and cultures.

For example, case managers play a critical role in helping individuals and families with HIV/AIDS to navigate the entitlement system, including Medicaid and welfare to work systems. For women living with HIV/AIDS, the availability of child care and other family-centered services-in which the mother, child, and other family members are cared for at a single facility-can have a direct impact on their ability to receive care.

Assisting people with HIV/AIDS in finding and paying for safe housing similarly improves their ability to access health care and adhere to treatment. Though housing is not traditionally viewed as a health issue, in the case of HIV/AIDS and similar disabling conditions, stable housing is clearly linked to improved access to care and deserves increased support nationally.

In the U.S., one of the most important sources of funding for HIV/AIDS-related support services is the Ryan White (CARE) Act, which expires on September 30, 2000. The CARE Act, as well as the Housing Opportunities for People with AIDS (HOPWA) program, must be reauthorized. It is also essential that funding for these programs increase to meet the needs of the growing population of individuals living with HIV/AIDS in the United States.

In the developing world, services that help address individuals' most basic human needs, such as food and shelter, will substantially improve the quality of life and health for those

living with HIV/AIDS. In developing countries where health services are available, support services will help individuals access care and adhere to complex treatment regimens, which is essential to avoid the development and subsequent transmission of drug-resistant strains of HIV.

**Recommendations:**

- The Administration must work with Congress to reauthorize the Ryan White CARE Act by the end of this session and do everything in its power to ensure that the newly authorized legislation is free of unnecessary and/or harmful testing provisions that interfere with the goal of early care and treatment.
- The Administration must ensure that the Ryan White CARE Act, HOPWA, and other Federal low-income housing programs administered by the U.S. Department of Housing and Urban Development (HUD) recognize and support the critical role of housing in facilitating access and adherence to HIV/AIDS care.
- The Administration should promote “family-centered” care models in which the health care needs of the entire family can be addressed holistically. Cross-agency collaborative planning and funding should be used to more closely integrate services.

***Substance abuse treatment and mental health services must be an integral part of HIV/AIDS-related health care.***

Because a significant percentage of people with HIV/AIDS in the U.S. also have substance use and/or mental health problems, these services must be integrated into the continuum of HIV/AIDS care. Data on prevalence of co-morbidities is not available nationally. However, 25% of new AIDS cases in 1999 were among those who inject drugs, and it is reasonable to assume that a significant percentage of heterosexual transmissions occurred among partners of injection drug users or their children.<sup>26</sup> The need for such services is particularly acute for traditionally underserved populations, including those in prison and the homeless, for whom fewer service options exist.

Unfortunately, the threat posed by HIV/AIDS has done little to inspire increased government funding for substance abuse treatment and mental health services in the U.S. This nation still falls far short of the goal of ensuring the availability of such services for all those who want and need them. The Clinton Administration’s own neglect of substance abuse treatment issues has only exacerbated the situation by creating a vacuum of leadership on these issues. People of color disproportionately bear the cost of this policy of neglect.

*“Nearly two-thirds of all people with diagnosable mental disorders do not seek treatment.”<sup>28</sup>*

The stigma associated with substance use and mental health problems contributes to the lack of integration of these services into the mainstream health care system and limits the ability to serve these groups effectively.<sup>27</sup> Despite previous recommendations from this Council, the President decided in 1998 to maintain a ban on the use of Federal funds for needle exchange programs. This action, which directly defied the scientific validation of needle exchange by the U.S. Surgeon General and other leading public health scientists, has only served to reinforce such stigmatization and contribute to unnecessary new infections. Denying Federal funds to local public health officials to implement these programs stands as an egregious example of politics triumphing over public health and science.

#### **Recommendations:**

- The Administration should develop a five-year plan for increasing funding for substance abuse treatment and mental health service to ensure access to all those in need and parity with other health care services.
- The Administration, in particular the Secretary of Health and Human Services, must identify steps needed to reorganize and revitalize the Substance Abuse and Mental Health Services Administration (SAMHSA) to enable it to provide leadership in the fight against HIV/AIDS and to coordinate its efforts with other Federal agencies.

***In the United States, eliminating racial and ethnic disparities in HIV/AIDS-related health outcomes requires addressing issues of access, discrimination, and affordability.***

In the U.S., people of color are disproportionately represented among individuals living with HIV/AIDS, and these minority groups also experience significantly higher rates of HIV/AIDS-related morbidity and mortality. Effective community-based responses to HIV/AIDS must include culturally and linguistically appropriate programs specifically targeting these high-risk communities.

Recent efforts to expand the service and organizational capacity of minority-run organizations through the CBC/Minority HIV/AIDS Initiative have highlighted the critical role of such agencies. This supplemental funding is helping to bring more people of color into care and to improve the quality of services provided through such organizations. The CBC/Minority HIV/AIDS Initiative will continue to play an important role in the overall system of HIV/AIDS care for years to come.

In addition, the Clinton Administration's goal of eliminating racial and ethnic disparities in six health areas, including HIV/AIDS, is a vitally important public health effort that must continue beyond this Administration. The Surgeon General's efforts in this regard have profound implications in terms of both public health and social justice.

**Recommendations:**

- The Administration should provide strong political, programmatic, and financial support to the CBC/Minority HIV/AIDS Initiative, including support for increased funding in FY 2001 to ensure adequate funding is available to meet the needs of all racial and ethnic groups disproportionately affected by HIV/AIDS.
- The Administration should continue its strong support for the Surgeon General's effort to eliminate racial and ethnic disparities in health outcomes in six areas, including HIV/AIDS.

*The developmental needs of youth require that they receive age-appropriate services sensitive to their unique circumstances.*

HIV/AIDS is increasingly a disease of young people. In the United States, as many as half of all new HIV infections are in people under age 25.<sup>29</sup> Globally, the rates are even more dramatic: UNAIDS recently estimated that in some African countries hardest hit by AIDS, as many as half of all 15 year-olds will eventually die of HIV/AIDS.<sup>30</sup> Statistics such as these demand immediate action.

Youth often face particular barriers to care. These include the lack of financial independence and privacy, as well as the inability to access medical services confidentially and during standard business hours. The White House Office of National AIDS Policy (ONAP) is preparing an updated report on HIV/AIDS and youth. This is an important step in efforts to develop a more focused, cross-governmental initiative focused on the unique care and prevention needs of young people, particularly young gay and bisexual men and young African American and Latina women.

*[I]t is hard to play down the effects of a disease that stands to kill more than half of the young adults in the countries where it has firmest hold—most of them before they finish the work of caring for their children or providing for their elderly parents.”<sup>31</sup>*

Globally, the HIV/AIDS pandemic has had a devastating effect on children and youth. Literally tens of millions of children have been or will be left orphaned by this disease, many themselves also living with the virus. These children require services such as permanency planning, counseling, and education, as well as assistance with basic human needs. It may be difficult for those in the U.S. to grasp fully the social and economic impact of losing an entire generation of parents to HIV/AIDS, but Americans must attempt to do so, both for the sake of our collective humanity and for reasons of national and economic security.

## **Recommendations:**

- The Administration should implement the recommendations of the pending White House ONAP report on youth, including recommendations designed to ensure the availability of family-centered care, access to age-appropriate medical services, and the coordination of youth-focused HIV/AIDS programs provided through the U.S. Department of Health and Human Services. The Administration should also use the release of this report as an opportunity to increase public awareness regarding young people’s risk and their unique service needs.
- The Administration should establish a coherent plan for responding to HIV/AIDS among young people, which includes the efforts of the many Federal agencies that administer programs targeting high-risk youth, as well as State and local governments, philanthropies, businesses, and community-based organizations. The plan should articulate clear goals and identify specific strategies to achieve them.
- The Administration should provide increased financial and programmatic support for permanency-planning programs for children globally who have been or are likely to be orphaned by the death of a parent from HIV/AIDS. These efforts should attempt to enhance the capacity of communities to provide care, and minimize use of more costly institutionally based care.

### ***Public health infrastructure is necessary to ensure a sustained response to the HIV/AIDS pandemic.***

In the United States, the HIV/AIDS pandemic has highlighted gaps in the community-based public health infrastructure. This is particularly true in communities of color, Indian nations, prisons, rural areas, and low-income communities generally. Community health centers and clinics have traditionally been the cornerstone of the public health safety net, and their importance in providing HIV/AIDS care will continue to grow as the number of uninsured people living with HIV/AIDS increases.

*“Each year African countries pay \$15 billion in debt repayments”; 51% of Americans support reducing the amount of debt African nations owe the U.S. so that money owed could be used to deal with AIDS.<sup>32</sup>*

Globally, the ability to provide quality health care for those living with HIV/AIDS is dependent on the ability to improve basic infrastructure in developing countries. In some areas this may mean developing or expanding medical facilities and personnel, and in others it may include providing safe drinking water, decent roads, and electricity. Building capacity where none currently exists will require a substantial infusion of resources from the international community, as well as recognition that, in many developing countries, repayment of international debt is siphoning significant resources away from necessary health spending. Developing such infrastructure will also improve adherence and will reduce the risk of other deadly diseases such as tuberculosis and malaria.

In addition to infrastructure, the availability of appropriately trained personnel is essential to the provision of quality HIV/AIDS care. The Clinton Administration's creation of Public Health Service guidelines for the treatment of HIV disease was a critical milestone in the pandemic, establishing for the first time a standard against which quality can be measured. Given the complex and rapidly changing nature of HIV disease management, ongoing updating and dissemination of these guidelines is essential, as is ongoing provider training. A diverse set of providers who are able to provide culturally sensitive care must be trained in the complexities of HIV/AIDS risk identification, prevention counseling, and disease management. Further, discrimination in health care based on race, ethnicity, gender, and/or sexual orientation must be prohibited, and more rigorous sensitivity training programs are needed.

**Recommendations:**

- The Administration should expand the role of community health centers and clinics to meet the needs of underserved populations living with HIV/AIDS.
- The Administration should support current and future efforts to provide meaningful debt relief to developing countries so that they may devote a greater portion of their own resources to fighting HIV/AIDS. In addition to debt relief, other means of expanding financial support should be explored actively, including international loans, grants, and public-private partnerships. These efforts must be carried out in close coordination with other leading industrialized nations, many of which also provide inadequate global HIV/AIDS relief.
- The Administration should work with other global partners to create a plan for the rapid development of health care and other basic infrastructure in developing nations hardest hit by HIV/AIDS.
- The Administration should challenge institutions of higher education to take leadership roles in the prevention and management of HIV/AIDS by requiring health professions schools, residencies, and internships to develop curricula and programs that ensure high-quality HIV/AIDS training.

*Client and community involvement are essential to the establishment of care systems responsive to local needs.*

HIV/AIDS service needs vary across demographic and geographic boundaries, requiring that efforts to create and sustain systems of care be similarly flexible. Model U.S. programs such as the Ryan White CARE Act and HOPWA reject a “one-size-fits-all” approach to services and instead rely on public-private partnerships at the local level, where service needs are most appropriately identified. This cost-effective model of

community-based care should inform U.S. efforts to assist developing nations. In particular, the important role of not-for-profit nongovernmental organizations in care, prevention, and clinical research must be maintained.

These participatory programs have also demonstrated the importance of developing local leadership among persons living with HIV/AIDS, within diverse minority communities, and among other populations with significant service needs such as the incarcerated, women, substance users, gay and bisexual men, and youth. Consumers and/or community leaders on the front lines of the pandemic are critical partners in the design and implementation of effective HIV/AIDS services.

**Recommendations:**

- The Administration must maintain strong support for the principle of local decision making and control with respect to the planning and delivery of HIV/AIDS care in the U.S. and abroad.
- The Administration should continue to support the development and involvement of community-based leaders, including persons living with HIV/AIDS, as full partners in service planning and delivery.

*Government agencies have a particular responsibility to finance HIV/AIDS care and services.*

Most people living with HIV/AIDS in the U.S. are poor and uninsured. In the past ten years, three critical safety net programs—the Ryan White CARE Act, Medicaid, and Medicare—have emerged as the most important sources of funding for health care for people living with HIV/AIDS. The CARE Act is also an important source of non-medical support services, as are HOPWA and other low-income and disability housing programs.

Although funding for the CARE Act and HOPWA has grown substantially over the past ten years, appropriations have not kept up with the growth in demand for services, including the need for HIV/AIDS treatments through the CARE Act’s AIDS Drug Assistance Program (ADAP). As the number of new cases of HIV/AIDS in the U.S. continues to grow by an estimated 40,000 each year, and as people with HIV/AIDS live longer due to effective treatments, funding for the CARE Act and HOPWA will need to reflect this increased need for services. In addition, as the pandemic reaches farther into already marginalized populations that are often grappling with other significant health issues as well, the need for multidimensional (and often more costly) care will grow.

Since FY 1999, targeted funding through the CBC/Minority HIV/AIDS Initiative has supplemented these larger programs in an effort to expand minority organizational capacity

and improve the quality of HIV/AIDS services for people of color. By recognizing the emergency nature of the pandemic among communities of color in the U.S., the Initiative has led to important new financial and political commitments.

As critical as these discretionary programs will remain, it is also important to look to entitlement programs for longer-term solutions not subject to the annual appropriations process. To that end, expanding Medicaid eligibility to cover persons in the earlier stages of HIV/AIDS will remain an important policy priority, as will ongoing efforts to ensure that those receiving Medicaid services, including those in managed care programs, have access to high quality care. If successful, the Administration's efforts to add a prescription drug benefit to the Medicare program will also have important implications for the significant number of persons living with HIV/AIDS who rely on that program.

The Indian Health Services (IHS) is an essential source of care for many American Indians and Alaska Natives; for those who live on or near reservations, it is the provider of last resort. Unfortunately, the response of tribal governments to the threat of HIV/AIDS has been slow, in part due to the historic under-funding of IHS that has made tribal leaders reluctant to devote limited resources to HIV/AIDS efforts. Begun in 1989, the IHS AIDS program has played only a minor role in funding HIV/AIDS projects for Native Americans, and many Native Americans will not use IHS services due to concerns about confidentiality. In addition, inadequate HIV/AIDS surveillance, the political invisibility of Native Americans, and the complexities of jurisdictional and political issues often place them at a disadvantage for funding. Moreover, a lack of coordination among Federal, State, and tribal governments greatly hinders efforts to deal with the HIV/AIDS epidemic in Native American communities.

Despite this Administration's important efforts to acknowledge that HIV/AIDS is a threat to national security, U.S. funding for global HIV/AIDS efforts remains inadequate. The scope of poverty in the developing world, which is home to 95% of people living with HIV/AIDS, will require a far more significant financial response from the U.S. and from its global partners. The Council, and many millions across the globe, continue to look to the President for leadership on the global HIV/AIDS pandemic. An expanded global role for the U.S. will also require that officials at Federal agencies that have not previously been involved in domestic HIV/AIDS policy receive appropriate authority, training, and funding.

Most importantly, meeting the most critical needs of people living with HIV/AIDS worldwide will require a sustained commitment to financing such care. The resurgence of tuberculosis in the United States in the 1990s following a withdrawal of public health funding for the disease is a dangerous mistake the U.S. and its global partners cannot afford to repeat in the context of HIV/AIDS.

### **Recommendations:**

- The Administration should support the highest possible levels of funding for the CARE Act and HOPWA as the number of persons living with HIV/AIDS in need of these programs continues to grow.
- The Administration should continue its effort to add a prescription drug benefit to the Medicare program and expand efforts within HCFA to monitor and ensure high quality HIV/AIDS care in its programs, including in managed care settings.
- Appropriate agencies within the U.S. Department of Health and Human Services should work more closely with the Indian Health Service, and support increased funding for the IHS-funded health care system so that it may provide high-quality HIV/AIDS treatment for Native Americans/Alaska Natives dependent upon it for medical care. The AIDS Drug Assistance Program funded through the Ryan White CARE Act should cover IHS-funded systems.

### **Conclusion**

The goal of ensuring access to high-quality and affordable HIV/AIDS care and treatment services in the United States and abroad will require a commitment to leadership, sustained financial support, and a continued reliance upon the many public-private partnerships that currently interact to develop, provide, and fund such care. The ability to confront directly issues of discrimination and stigma, and to encourage and support individuals in their efforts to learn their HIV status, and enter and adhere to treatment, will also help ensure ultimate success.

The Council implores the current and future President and Cabinet members to provide the courage, leadership and commitment that are needed to stop the HIV/AIDS pandemic.

## References

- <sup>1</sup>HIV = Human Immunodeficiency Virus; AIDS = Acquired Immunodeficiency Syndrome
- <sup>2</sup>United Nations Joint Programme on AIDS (UNAIDS), Report on the Global HIV/AIDS Epidemic. June, 2000, 6.
- <sup>3</sup>Centers for Disease Control and Prevention. HIV/AIDS Surveillance Report: U.S. HIV and AIDS Cases Reported through December 1999, Year-end edition, Vol. 11, No. 2.
- <sup>4</sup>United Nations Joint Programme on AIDS (UNAIDS), Report on the Global HIV/AIDS Epidemic.
- <sup>5</sup>Report on the Global HIV/AIDS epidemic, June 2000, Joint United Nations Programme on HIV/AIDS (UNAIDS) UNAIDS, Report on the Global HIV/AIDS Epidemic, op. cit.
- <sup>6</sup>Carol Bellamy, Executive Director, UNICEF, Speech to the XIII International AIDS Conference in Durban, South Africa, July 13, 2000.
- <sup>7</sup>Carol Bellamy, Executive Director of UNICEF, Opening Statement to the XIII International AIDS Conference in Durban, South Africa, July 11, 2000.
- <sup>8</sup>National Commission on AIDS, AIDS: An Expanding Tragedy, The Final Report of the National Commission on AIDS, June 1993
- <sup>9</sup>Remarks prepared for delivery by Vice President Al Gore at the United Nations Security Council Session on AIDS in Africa, January 10, 2000.
- <sup>10</sup>Statement made Wednesday, July 13, 2000, in support of a proposed Security Council resolution on AIDS.
- <sup>11</sup>Dr. Sam Mbulaiteye, Uganda Virus Research Institute, Entebbe, in a Presentation to the XIII International AIDS Conference in Durban, South Africa, July 13, 2000.
- <sup>12</sup>Pinkerton, S.D., Holtgrave, D.R., and Valdiserri, R.O., "Cost-effectiveness of HIV Prevention Skills Training for Men Who Have Sex With Men, J AIDS, 11:347-357.
- <sup>13</sup>Holtgrave, D.R., Pinkerton, S.D., "Updates of Cost of Illness and Quality of Life Estimates for Use in Economic Evaluations of HIV Prevention Programs, J AIDS, 16:54-62, 1997.
- <sup>14</sup>Centers for Disease Control and Prevention, 1999 Youth Risk Behavior Surveillance Report, June 9, 2000.
- <sup>15</sup>CDC Morbidity and Mortality Weekly Report 2000, June 16:49(23): 512-15.
- <sup>16</sup>Office of National AIDS Policy, Youth & HIV/AIDS 2000: A New American Agenda, forthcoming, 2000; and Centers for Disease Control and Prevention, "Young People at Risk: HIV/AIDS Among America's Youth," August 1999.
- <sup>17</sup>Youth & HIV/AIDS 2000: A New American Agenda, op. cit.
- <sup>18</sup>Guttmacher, Lieberman, Ward, et al., "Condom availability in New York City public high schools: relationships to condom use and sexual behavior," American Journal of Public Health 1997; 87:1427-1433; and Furstenberg, Geitz, Teitler, et al., "Does condom availability make a difference? An evaluation of Philadelphia's Health Resource Centers," Family Planning Perspectives 1997, 29:123-127.
- <sup>19</sup>CDC Update. "Perinatally Acquired HIV/AIDS in the United States, 1997," Morbidity and Mortality Weekly Report 1997, 46:1086-1092.
- <sup>20</sup>U.S. Department of Health and Human Services, Mental Health: A Report of the Surgeon General, 1999.
- <sup>21</sup>Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, September 1, 1995.

<sup>22</sup>“Prevention and Treatment of Sexually Transmitted Diseases as an HIV Prevention Strategy,” CDC Update, June 1998.

<sup>23</sup>Kamb, M., et. al., “Efficacy of risk-Reduction Counseling to Prevent Human Immunodeficiency Virus and Sexually Transmitted Diseases: A Randomized Controlled Trial. Project RESPECT Study Group.” *Journal of the American Medical Association*, October 7, 1998, vol. 280, No. 13, pp.1161-1167

<sup>24</sup>Estimates as of the end of 1998, Centers for Disease Control and Prevention, “Guidelines for national human immunodeficiency virus case surveillance, including monitoring for human immunodeficiency virus infection and acquired immunodeficiency syndrome,” *Morbidity and Mortality Weekly Report* 1999, 48(RR-13): 1-27; in communications from Faye Malitz, Chief, Epidemiology and Data Analysis Branch, Office of Science and Epidemiology, HIV/AIDS Bureau, Health Resources and Services Administration.

<sup>25</sup>Hellinger, F.J., Fleishman, J.A., “Estimating the National Cost of Treating People with HIV Disease: Patient, Payer, and Provider Data,” *AIDS* 24: 182-188.

<sup>26</sup>Centers for Disease Control and Prevention, “HIV/AIDS Surveillance Report,” 11:12, Table 5.

<sup>27</sup>Kessler, R. C., Nelson, C. B., McKinagle, K. A., Edlund, M. J., Frank, R.G., & Leaf, P. J., “The epidemiology of co-occurring addictive and mental disorders: Implications for prevention and service utilization,” *American Journal of Orthopsychiatry* 1996, 66:17-31; Regier, D. A., Narrow, W. E., Rae, D. S., Manderscheid, R. W., Locke, B.Z., & Goodwin, F. K. (1993), “The de facto U.S. mental and addictive disorders service system. Epidemiologic Catchment Area prospective 1-year prevalence rates of disorders and services,” *Archives of General Psychiatry*, 50:85-94.

<sup>28</sup>Reiger et al., 1993; Kessler et al., 1996, in *Mental Health: A Report of the Surgeon General*, 1999, op. cit.

<sup>29</sup>“Young People at Risk: HIV/AIDS Among America’s Youth,” op. cit.

<sup>30</sup>UNAIDS, *Report on the Global HIV/AIDS Epidemic*, op. cit., 24-25.

<sup>31</sup>*Ibid*, 7.

<sup>32</sup>Quotation from Peter Piot, Executive Director, Joint United Nations Programme on HIV/AIDS, opening statement, Durban, South Africa, July 9, 2000; public support statistic from the Kaiser Family Foundation, “American Views on the AIDS Crisis in Africa: A National Survey. 2000,” op. cit.

# Appendix A: Executive Orders

Executive Order 12963

## Presidential Advisory Council on HIV/AIDS

By the authority vested in me as President by the Constitution and the laws of the United States of America, I hereby direct the Secretary of Health and Human Services to exercise her discretion as follows:

Section 1. Establishment. (a) The Secretary of Health and Human Service (the "Secretary") shall establish an HIV/AIDS Advisory Council (the "Advisory Council" or the "Council"), to be known as the Presidential Advisory Council on HIV/AIDS. The Advisory Council shall be composed of not more than 30 members to be appointed or designated by the Secretary. The Advisory Council shall comply with the Federal Advisory Committee Act, as amended (5 U.S.C. App.).

(b) The Secretary shall designate a Chairperson from among the members of the Advisory Council.

Sec. 2. Functions. The Advisor Council shall provide advice, information, and recommendations to the Secretary regarding programs and policies intended to (a) promote effective prevention of HIV disease, (b) advance research on HIV and AIDS, and (c) promote quality services to persons living with HIV disease and AIDS. The functions of the Advisory council shall be solely advisory in nature. The Secretary shall provide the President with copies of all written reports provided to the Secretary by the Advisory Council.

Sec. 3. Administration. (a) The heads of executive departments and agencies shall, to the extent permitted by law, provide the Advisory Council with such information as it may require for purposes of carrying out its functions.

(b) Any members of the Advisory Council that receive compensation shall be compensated in accordance with Federal law. Committee members may be allowed travel expenses, including per diem in lieu of subsistence, to the extent permitted by law for persons serving intermittently in the Government service (5 U.S.C. section 5701-5707).

(c) To the extent permitted by law, and subject to the availability of appropriations, the Department of Health and Human Services shall provide the Advisory Council with such funds and support as may be necessary for the performance of its functions.

Sec. 4. General Provisions. (a) Notwithstanding the provisions of any other Executive order, any functions of the President under the Federal Advisory Committee Act that applicable to the Advisory Council, except that of reporting annually to the Congress, shall be performed by the Department of Health and Human Services, in accordance with the guidelines and procedures established by the Administrator of General Services.

(b) This order is intended only to improve the internal management of the executive branch, and it is not intended to create any right, benefit, or trust responsibility, substantive or procedural, enforceable at law or equity by a party against the United States, its agencies, its officers, or any person.

WILLIAM J. CLINTON

THE WHITE HOUSE,  
June 14, 1995.

# # #

Executive Order 13009

Amendment to Executive Order No. 12963 Entitled Presidential Advisory Council on  
HIV/AIDS

By the authority vested in me as President by the Constitution and the laws of the United States of America, and in order to increase the membership of the Presidential Advisory Council on HIV/AIDS, it is hereby ordered that Executive Order No. 12963 is amended by deleting the number "30" in the second sentence of section 1(a) of that order and inserting the number "35" in lieu thereof.

WILLIAM J. CLINTON

THE WHITE HOUSE,  
June 14, 1996.

# # #

# **Appendix B: Charter**

## **PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS**

### **PURPOSE**

The Secretary of Health and Human Services is charged in Titles XXII-XXVI of the Public Health Services Act with responsibilities for conducting a variety of activities in connection with the prevention and cure of HIV and AIDS and for ensuring that those infected with HIV or AIDS are provided with quality care.

### **AUTHORITY**

Executive Order 12963, dated June 14, 1995, as amended by Executive Order 13009, dated June 14, 1996. The Council is governed by provisions of Public Law 92-463, as amended, 5 U.S.C. Appendix 2, which sets forth standards for the formation and use of advisory committees.

### **FUNCTION**

The Presidential Advisory Council on HIV/AIDS shall provide advice, information and recommendations to the Secretary regarding programs and policies intended to promote effective prevention of HIV disease, and advance research on HIV disease and AIDS. The function of the Council shall be solely advisory in nature. The Secretary shall provide the President with copies of all written reports provided to the secretary by the Advisory Council.

### **STRUCTURE**

The Council shall consist of not more than 35 members, including the Chair. Members and the chair shall be selected by the Secretary from authorities with particular expertise in, or knowledge of, matters concerning HIV and AIDS.

In addition, the Council shall include ex officio members from relevant HHS components as deemed appropriate by the Secretary or designee.

Members shall be invited to serve for overlapping four-year terms; terms of more than two years are contingent upon the renewal of the Council by appropriate act on prior to its termination. Members shall serve after the expiration of their term until their successors have taken office.

Temporary subcommittees consisting of members of the parent committee may be established to perform specific functions within the Council's jurisdiction. Subcommittees shall make preliminary recommendations for consideration of full council. The Department Committee Management officer shall be notified upon establishment of each subcommittee, and shall be provided information on its name, membership, function, and estimated frequency of meetings.

Management and support services shall be provided by the Office of the Secretary, Office of Public Health and Science.

### **MEETINGS**

Meetings shall be held at the call of the Chair, with the advance approval of a full time Government official, who shall also approve the agenda. A Government official shall be present at all meetings.

Meetings shall be open to the public except as determined otherwise by the Secretary; notice of all meetings shall be given to the public. Meetings shall be conducted, and records of the proceedings kept, as required by applicable laws and Departmental regulations.

### **COMPENSATION**

Members of the Council shall serve without compensation but may, to the extent permitted by law, be paid per diem and travel expenses as authorized by Section 5703, Title 5 U.S. Code, as amended.

### **ANNUAL COST ESTIMATES**

Estimated annual cost for council, including per diem and travel expenses for members but excluding staff support is \$290,000. Estimated annual person-years of staff support required is two (2), at an estimated cost of \$115,000.

### **REPORTS**

In the event a portion of the meeting is closed to the public a report shall be prepared which shall contain, as a minimum, a list of members and their business addresses, the council's functions, dates and places of meetings, and a summary of council activities and recommendations made during the fiscal year. A copy of the report shall be provided to the Department Committee Management Officer.

**TERMINATION DATE**

Unless renewed by the appropriate action prior to its expiration, the Presidential Advisory Council on HIV/AIDS will terminate on July 27, 2001.

**APPROVED**

*Donna Shalala*  
*July 27, 1999*

## **Appendix C: Previous Reports**

## **Appendix D: PACHA Member Biographies**

**Stephen N. Abel, D.D.S., M.S.**, of New York, New York is currently the Director of Dentistry at the Spellman Center for HIV-Related Diseases at St. Clare's Hospital where he is a noted expert in the oral health of HIV patients. Dr. Abel is a co-founder of the Dental Alliance for HIV/AIDS Care and a dental consultant on HIV issues for the American Dental Association.

**Terje Anderson** of Washington, D.C. currently serves as the Executive Director for the National Association of People with AIDS. He has served as the AIDS Program Chief for the Vermont Department of Health and was also the founder of the Vermont Committee for AIDS Resources, Education, and Services. He has chaired the Health Resources and Services Administration's HIV/AIDS Committee and has been the Co-chair for the National Organizations Responding to AIDS. In addition, he has served as the Co-chair for the Vermont Coalition for Lesbian and Gay Rights.

**Regina Aragón** of Oakland, California served as the Public Policy Director for the San Francisco AIDS Foundation, where for nine years she led in developing state and federal policy, including successful campaigns to expand funding for HIV/AIDS, to reauthorize the Ryan White CARE Act, and to decriminalize needle exchange. Ms. Aragon served as the Chair of the Cities Advocating Emergency AIDS Relief (CAEAR) Coalition from 1993-1999. She has a Master's Degree in Public Policy from Harvard University's Kennedy School of Government.

**Barbara Aranda-Naranjo, Ph.D., R.N.** of San Antonio, Texas is an Associate Professor at the School of Nursing at the University of Incarnate Word, San Antonio, Texas. She holds the Brigadier General Dunlap Professorial Research Chair in Nursing, and is also a Clinical Associate Professor in the Department of Pediatrics at the University of Texas Health Science Center. She has worked with women, children, and families living with HIV infection in South Texas for the past 12 years.

**D. Gregory Barbutti, J.D.** of Austin, Texas is the Chair of the Board of Directors of AIDS services of Austin, the largest AIDS service organization in Central Texas. As a long-term survivor of HIV/AIDS and a member on the Board of Directors of the Texas Health Insurance Risk Pool, the Hollyfield Foundation and formerly of the Capital Area AIDS Legal Project, Mr. Barbutti works to educate the public about HIV and strengthen all aspects of the lives of people living with HIV/AIDS in Texas.

**Ignatius Bau, J.D.** of San Francisco, California is the Policy Director at the Asian and Pacific Islander American Health Forum. He has served as the Chairperson of the California Department of Health Services Task Force on Multicultural Health and as a consultant to the Centers for Disease Control and Protection (CDC). He is a member of the Board of Directors of the National Minority AIDS Council and was a founding board member of both the Asian and Pacific Islander Wellness Center: Community HIV/AIDS Services and the Northern California Coalition for Immigrant and Refugee Rights.

**Judith A. Billings, J.D.** of Seattle, Washington has been an educator for 37 years, serving as the Washington State elected Superintendent of Public Instruction for eight years (1989-1997). Diagnosed with AIDS in 1995, she currently chairs the Governor's Advisory Council on HIV/AIDS and the Board of the Northwest AIDS Foundation, and serves on the Board Executive Committee of the National AIDS Fund. She remains active in education, chairing the Board of the Agency for Instructional Technology, co-chairing the Washington State Council on Public Legal Education, and working as the President and CEO of Economics America Washington Council on Economic Education.

**Charles W. Blackwell** of Washington, D.C. is the founding Director of The Native Affairs and Development Group (NADG) at Pushmataha House on Capitol Hill and serves as the Chickasaw Nation's Ambassador to the United States of America. Mr. Blackwell is widely recognized for strongly protecting the federal-tribal trust relationship and the sovereignty of American Indian tribes while developing strong tribal economies. He represents numerous tribes in the state of Washington and many private sector companies in Indian Country.

**Mary Boland, M.S.N., R.N., F.A.A.N.** of Newark, New Jersey is Director of the National Pediatric and Family HIV Resource Center at the University of Medicine and Dentistry of New Jersey in Newark. She is a registered nurse who has worked in the pediatric and adolescent HIV/AIDS wards since 1983 when HIV was first diagnosed in children.

**Nicholas Bollman** of San Francisco, California is the founding President of the new California Center for Regional Leadership. Formerly, Mr. Bollman was the Co-Chair of the Public Policy and Leadership Committee of Funders Concerned About AIDS. Mr. Bollman also served as the Senior Program Director for the James Irvine Foundation, a grant making foundation which provides funding for numerous HIV and AIDS related programs.

**Stephen L. Boswell, M.D.** of Boston, Massachusetts is the Executive Director of the Fenway Community Health Center (FCHC), a national leader in community primary health care for persons living with HIV/AIDS and the gay communities. He is active in various research arenas and is currently a member of the Infectious Disease Unit of

Massachusetts General Hospital and Partners' AIDS Research Center. He helped found the Community Care Alliance, a collaborative enterprise of seven Boston community health centers with historic clinical ties to Beth Israel Deaconess Medical Center.

**Stuart C. Burden** of Chicago, Illinois is a Senior Program Officer at the John D. and Catherine T. MacArthur Foundation. Mr. Burden's grantmaking focus includes reproductive health & rights, sexuality education for young people, and HIV prevention. In addition, Mr. Burden serves on the Boards of the Lambda Legal Defense & Education Fund, the Working Group on Funding Lesbian & Gay Issues, and Funders Concerned About AIDS. Mr. Burden consults on health issues with various foundations and has served on the Scientific Program Committee for the International AIDS Conference.

**Phillip P. Burgess, R.Ph.** of Deerfield, Illinois is currently the National Director of Pharmacy Affairs for Walgreens, and has been involved in responding to the needs of the HIV/AIDS community since the early 1980s. Mr. Burgess is responsible for the recent initiative to certify a large group of Walgreens pharmacists throughout the nation providing pharmaceutical services to HIV/AIDS patients.

**Tonio Burgos** of New York, New York is the President of Tonio Burgos and Associates, Inc., a marketing and public relations firm. He formerly served as Commissioner of the New York and New Jersey Port Authority and as Director of Executive Services for former Governor Mario Cuomo.

**Jerry Cade** of Las Vegas, Nevada operates a private medical practice devoted to the treatment of people with HIV. He is a co-founder and Director of the University Medical Center's AIDS Outpatient Clinic and HIV Inpatient Unit in Las Vegas. He also has served as Executive Director of "Aid for AIDS of Nevada," Nevada's oldest and largest HIV support organization. In 1999, Dr. Cade received the International Association of Physicians in AIDS Care (IAPAC) Heroes in Medicine Award.

**Margaret K. L. Campbell** of Boston, Massachusetts, serves as the project coordinator for "'Politician' with the Sister" at the Justice Resource Institute. This project assists young women in exploring societal systems of gender oppression, racism, sexism, homophobia and other issues, thus reducing risk for HIV. Ms. Campbell has developed many training curricula for youth peer educators and currently serves on the Board of AIDS Alliance.

**Lynne M. Cooper, D. Min.** of St. Louis, Missouri is President of Doorways, an Inter-faith AIDS Residence program, providing housing to 450 people living with HIV/AIDS in the St. Louis region. The Doorways programs have earned local and national awards and Ms. Cooper has been recognized by the Women of Worth, the Deaconess Foundation, the Health Care Financing Administration, and Fontbonne College for service to people living with HIV/AIDS.

**Joseph A. Cristina** of Long Beach, California is currently Vice President of Inventor Relations for Mattel, Inc. As an openly gay HIV positive man, he founded the Children Affected by AIDS Foundation (CAAF). Through Mr. Cristina's leadership as Board Chair, CAAF has been able to provide direct care and services to children affected by HIV/AIDS throughout the nation.

**The Honorable Ronald V. Dellums** of Berkeley, California is President of Healthcare International Management Company and a former member of the U.S. Congress, representing the 9th Congressional District of California for 27 years. As a member and former chairman of the House National Security Committee, he aspired to become an expert on international affairs and to accumulate the knowledge necessary to work on behalf of social justice and human rights. Mr. Dellums led the congressional effort to end U.S. support for the racist apartheid regime of South Africa. The National Health Service Act, introduced by Mr. Dellums in 1977, is still considered one of the most comprehensive, progressive health care proposals ever before the Congress. He is the current chair of this Council.

**Ingrid M. Duran** of Washington, D.C. is the Executive Director of the Congressional Hispanic Caucus Institute (CHCI), a premier national non-profit and non-partisan organization whose mission is to develop the next generation of Latino leaders. Prior to joining the CHCI, Ms. Duran was the director of the Washington, D.C. office of the National Association of Latino Elected and Appointed officials (NALEO).

**Rabbi Joseph A. Edelheit** of Minneapolis, Minnesota serves as the Senior Rabbi of Temple Israel, a 121 year-old, Reform congregation. He has previously led several Jewish and interfaith AIDS coalitions and pastoral service groups. Rabbi Edelheit was the initial rabbinic co-chair of the Reform Judaism's national committee on HIV/AIDS and has written several published essays on topics related to the religious and ethical issues highlighted by the HIV/AIDS pandemic.

**Robert L. Fogel** of Chicago, Illinois is an attorney with the firm of Hilfman and Fogel of Chicago. He is an active supporter of the Chicago House and Social Service Agency which provides housing and services for people with HIV/AIDS.

**Debra Fraser-Howze** of New York, New York is the Founder/President/CEO of the National Black Leadership Commission on AIDS, Inc., founded in 1987. Ms. Fraser-Howze has been widely recognized for her more than two decades of service to African and other communities of color on issues relating to teen pregnancy, HIV/AIDS prevention, and public health.

**Kathleen M. Gerus** of Sterling Heights, Michigan is Chair of the Board of Directors of the National Hemophilia Foundation and serves as a member of the Board of the National Association of People With AIDS. Ms. Gerus is the widow of a man with hemophilia and AIDS.

**Cynthia A. Gomez, Ph.D.** of San Francisco, California is an Assistant Professor in the Department of Medicine at the University of California at San Francisco (UCSF) AIDS Research Institute (ARI) and Center for AIDS Prevention Studies (CAPS). Prior to coming to CAPS, Dr. Gomez spent twelve years working in community mental health settings in Boston. Dr. Gomez also serves on the CDC's HIV & STD Advisory Council, Substance Abuse and Mental Health Services Administration's (SAMHSA) Advisory Committee on Women's Services, and the Scientific Advisory Committee and Board of Directors of the Alan Guttmacher Institute.

**Edward S. Gould** of Encino, California died on November 8, 1996. Before joining the Council in 1995, Mr. Gould had completed a three-year term as Co-Chair of the Board of Directors of the Los Angeles Gay and Lesbian Community Service Center and a member of the Board of Directors of the Center. Mr. Gould was honored in 1994 at the Los Angeles celebration of National Philanthropy Day as the "Outstanding Philanthropist" of the year. He served on numerous boards including the United Way of Greater Los Angeles.

**Phyllis Greenberger** of Washington, D.C. is the Executive Director of the Society for the Advancement of Women's Health Research and since 1993. Ms. Greenberger is a member of The National Advisory Environmental Health Services Council.

**Nilsa Gutierrez, M.D., M.P.H.** is the Medical Director for the Health Care Financing Administration (HCFA). Dr. Gutierrez previously served as a Consultant in Primary Care Delivery Systems where she has reconfigured traditional ambulatory clinic models to primary care delivery systems for hospitals and community-based health care facilities. Previously, Dr. Gutierrez was the Director of the New York State Department of Health's AIDS Institute. Dr. Gutierrez was the Chair of the Latino Commission on AIDS in 1996.

**Bob Hattoy** of Washington, D.C. is a person living with AIDS, who served as a White House Liaison to the Department of the Interior for 4 years and before that as the Deputy Director of White House personnel. Mr. Hattoy came to the Clinton administration from the Sierra Club, an environmental advocacy group. He currently volunteers his time as an advocate with different gay/lesbian and HIV/AIDS organizations as well as working to "Get out the Vote" for various elected Federal, State and local campaigns.

**Thomas Patrick Healy** of New York, New York a writer of poetry and criticism and former contemporary art dealer. He serves as chairman of the public arts organization "Creative Time" and is on the boards of the AIDS Action Foundation in Washington and the New York University (NYU) Art Museum. Mr. Healy is living with HIV.

**B. Thomas Henderson** of Austin, Texas died on December 22, 1999. He previously served as a senior policy advisor to the Texas Land Commissioner and was a former member of the Board of Trustees of the Texas Human Rights Foundation, a statewide organization which seeks to end discrimination based on sexual orientation or HIV/AIDS status. Mr. Henderson was active in fundraising for numerous HIV/AIDS organizations.

**R. Scott Hitt, M.D.**, of Los Angeles, California is a nationally recognized medical doctor who practices with the Pacific Oaks Medical Group, the country's largest private practice health care providers for patients with HIV disease. Dr. Hitt served as Chair of the Council from 1995 through 2000. Dr. Hitt has been recognized for his philanthropic work on behalf of AIDS service organizations. He serves on the Board of Directors of AIDS Project Los Angeles.

**Michael Isbell, J.D.** of New York, New York is currently an independent consultant in the field of public health policy. He formerly supervised the public policy, communications, and education programs at Gay Men's Health Crisis (GMHC), the nation's oldest and largest AIDS service organization. He also directed the AIDS litigation project at Lambda Legal Defense and Education Fund.

**Jack C. Jackson, Jr.** of Washington, D.C. and a member of the Navajo Nation, currently serves as Director of Governmental Affairs for the National Congress of American Indians and as a Board member for the National Native American Indian AIDS Prevention Center. He is originally from Arizona bringing years of experience in federal Indian policy and significant contributions to minority communities.

**Ronald S. Johnson** of New York, New York currently serves as Associate Executive Director of Gay Men's Health Crisis, Inc. (GMHC). In that capacity he manages GMHC's public policy, communications, and community relations. Prior to coming to GMHC, Mr. Johnson served as the Citywide Coordinator for AIDS policy in the Office of the Mayor, City of New York and as the Executive Director of the Minority Task Force on AIDS. Mr. Johnson is living with HIV.

**Carole LaFavor, R.N.**, of Minneapolis, Minnesota is a registered nurse and a member of the Ojibwa Tribe. She is a founding member of Positively Native, a national organization for Native Americans with HIV/AIDS.

**Jeremy Landau** of Santa Fe, New Mexico is the Founder of the National Rural AIDS Network, which provides services and education for people living with the HIV/AIDS virus. He is living with HIV.

**Alexandra M. Levine, M.D.** of Los Angeles, California is currently a Professor of Medicine at University of Southern California (USC), Chief of the Division of Hematology. She also serves as Medical Director of the USC/Norris Cancer Hospital. Dr. Levine's research interests include the hematologic malignancies and HIV disease, where she has published over 150 articles and over 50 book chapters. She began an active program of AIDS research in 1981, focused primarily on the cancers related to AIDS, and most recently on HIV disease in women. Dr. Levine has worked with Dr. Jonas Salk in the development and testing of a therapeutic AIDS vaccine. She formerly served as the Executive Associate Dean of the USC School of Medicine from 1985 to 1990.

**Steve Lew** of San Francisco, California serves as Development Director for CompassPoint Nonprofit Services, based in San Francisco and Silicon Valley. He has been involved in HIV services and advocacy issues over the past fifteen years, co-founding the Gay Asian Pacific Alliance (GAPA) Community HIV project, serving as the Executive Director of the Living Well Project and Asian & Pacific Islander Wellness Center in San Francisco. As a gay man of color living with HIV, Mr. Lew has also participated in local, regional, and national HIV planning and public policy efforts.

**Caya B. Lewis, M.P.H.**, of Baltimore, Maryland is the National Health Coordinator of the National Association of the Advancement of Colored People (NAACP) where she advises on health policy, designs health prevention and education initiatives, and builds partnerships to support the NAACP's 2200 affiliates. During Ms. Lewis' tenure, the NAACP has passed several new policies on HIV/AIDS and implemented an HIV/AIDS film outreach project.

**Miguel Milanés, M.P.A.** of Miami, Florida is the Community/Intergovernmental Affairs Coordinator for the Florida Department of Children and Families-District 11. He previously served as the Director for the Miami-Dade County Health Department's Office of AIDS Services. Before coming to Miami, Mr. Milanés served as a Special Assistant to the Director of the Supportive Housing Demonstration Program at the U.S. Department of Housing and Urban Development.

**Brent Tucker Minor** of Alexandria, Virginia is at Travel Ventures Inc., and currently serves as the Co-chair of the Planning Council for the Washington, D.C. Ryan White Title I Planning Council. Minor also serves on the Northern Virginia HIV Consortium and the Alexandria City Council's Task Force on AIDS among other organizations. Mr. Minor is the former Director of Community Relations for Food & Friends, a community-based organization that delivers meals and groceries to people living with AIDS in the greater Washington, D.C. area. He is living with HIV.

**Helen M. Miramontes, M.S.N., R.N., F.A.A.N.** of Las Vegas, Nevada is a health care professional and an activist focusing on prevention, policy, and provider education. She is the former Clinical Professor and Deputy Director of The International Center for HIV/AIDS Research & Clinical Training in Nursing, School of Nursing, University of California, San Francisco (UCSF), and Nurse Coordinator for the Pacific AIDS Education & Training Center, School of Medicine, UCSF in San Francisco, California.

**Ernesto Ortiz Parra, M.D., M.P.H.** of San Antonio, Texas is both a practitioner at the Centro Del Barrio Community Health Center and a Clinical Associate Professor at the University of Texas Health Science Center in San Antonio where he teaches primary care of HIV patients. Over the past decade, Dr. Parra has been involved in research, medical education, and health care related to HIV infection and prevention. His focus has been on developing early intervention strategies and standards of care for women infected with HIV.

**Reverend Altagracia Perez, S.T.M.** of Los Angeles, California is the Rector of the Church of Saint Philip the Evangelist, Episcopal. Reverend Perez is an active member of HDI Inc., Educational Leadership Council on Latinas and AIDS, and has served as Writer and Consultant for “Teens for AIDS Prevention.”

**John A. Perez** of Los Angeles, California is the Political Director of the California Labor Federation, American Federation of Labor - Congress of Industrial Organizations (AFL-CIO), representing two million unionized workers across all sectors. In addition, Mr. Perez is Co-Chair of the California Democratic Party Finance Committee, a member of the California Managed Health Care Improvement Task Force, and a member of the Board of Directors of the League of Conservation Voters, the Los Angeles County Economic Development Corporation, and the Los Angeles Human Rights Committee.

**Robert Michael Rankin, M.D., M.P.H.,** of San Francisco, California the Chair of the Committee on HIV/AIDS for the Union of American Hebrew Congregations (Reform Judaism) and a consultant on HIV/AIDS for the San Francisco Police and Sheriff’s Department. Dr. Rankin is the former Chief of Psychiatry and Mental Health Services at the Oakland Veterans Administration Medical Center in San Francisco, California. Previously, he served on the Board of Directors of the San Francisco AIDS Foundation.

**Valerie Reyes-Jimenez** of New York, New York is a Board member with Housing Works, Inc. Ms. Reyes-Jimenez was infected with HIV in the early 1980s. She has overcome formidable odds to become a leading AIDS activist and advocate for those living with HIV and AIDS. She has worked side by side with homeless HIV positive individuals and, in particular, those with chemical dependencies and mental disorders.

**H. Alexander Robinson** of Washington, D.C. is President of Robinson & Foster Inc. and Secretary for the Board of the Whitman-Walker Clinic. Mr. Robinson previously served as the President of the National Task Force on AIDS Prevention and the Senior Legislative Representative for the American Civil Liberties Union AIDS and Lesbian and Gay Rights Projects. Mr. Robinson is living with HIV.

**Debbie Runions** of Nashville, Tennessee is a freelance writer and has written a chapter in *AIDS and Women’s Experience: Emerging Policy Agenda* to be published this year. Ms. Runions also serves on Tennessee’s HIV Prevention Community Planning Group.

**Sean Sasser** of Atlanta, Georgia has worked with the San Francisco Department of Health, where he helped create the HIV-Positive Youth Advocacy Project. As an African-American, gay and HIV positive individual, Mr. Sasser is well acquainted with the issues of young people and HIV/AIDS. In addition, Mr. Sasser has served on the Board of Directors of the AIDS Alliance (formerly AIDS Policy Center for Children, Youth and Families).

**Benjamin Schatz** of San Francisco, California is a writer, singer, and performer. He formerly served as the Executive Director of the Gay and Lesbian Medical Association. Mr. Schatz was the first attorney to work full time on issues of AIDS-related discrimination on a national basis by establishing the AIDS Civil Rights Project at the National Gay Rights Advocates.

**Victoria L. Sharp, M.D.** of New York, New York is the Director of the Center for comprehensive Care at St. Luke's Roosevelt Hospital. She serves as the Chair of the Board of Doctors of the World, an international humanitarian organization.

**Richard W. Stafford** of St. Paul, Minnesota is the immediate past State Chair of the Minnesota Democratic-Farmer-Labor Party (DFL). Previously, Mr. Stafford organized the Minnesota AIDS Project, a statewide non-profit organization which provided help for those affected by HIV/AIDS. He currently works as a journalist and consultant.

**Denise Stokes** of Stockbridge, Georgia has been an AIDS educator and activist for eleven years. Her grass roots background is in street outreach, public education, support group facilitation, substance abuse counseling and training other peer counselors. Ms. Stokes sits on the Board of Directors of both Outreach Inc., serving the minority community and All Saints Covenant Community (a men's substance abuse recovery community). She was infected with HIV at thirteen and was not only one of the first people to publicly put a face on heterosexual HIV in the 80's but also instrumental in accessing Southern African-American churches in the early 90's. Ms. Stokes is a frequent presenter to the National Football League on HIV education.

**Todd A. Summers** of Washington, D.C. is a Principal, Progressive Health Partners, Inc. and most recently served as Deputy Director of the White House Office of National AIDS Policy, where he provided policy guidance on a broad range of health, prevention, care, civil rights, housing, immigration, and other issues relating to the AIDS pandemic. In addition, Summers assisted in developing new policy initiatives, preparing briefing materials and speeches, and facilitating multi-agency efforts. Previously, he as co-founder, served as the Executive Director of the AIDS Housing Corporation in Boston, Massachusetts.

**Sandra L. Thurman** of Atlanta, Georgia is the Director of the White House Office of National AIDS Policy, and Presidential Envoy for AIDS Cooperation. For nearly two decades, Ms. Thurman has been a leader and advocate for people with AIDS at the local, state, and federal levels. Ms. Thurman served as the Director of Citizen Exchanges at the United States Information Agency. Before that, she served as Executive Director of AID Atlanta, a community-based nonprofit organization that provides health and support services to people living with HIV/AIDS and offers an array of HIV prevention programs.

**Charles Quincy Troupe** of Jefferson City, Missouri is a Missouri State representative on minority health issues and the impact of AIDS on women and minorities.

**Bruce G. Weniger, M.D., M.P.H.** of Atlanta, Georgia is a medical epidemiologist with international research and training experience on the HIV/AIDS epidemic in Asia and South America. He works at the United States Center for Disease Control and Prevention in Atlanta.

## Appendix E: Correspondence

Date	To	Subject
October 8, 1996	President Clinton	Welfare Reform Bill
December 17, 1996	Secretary Shalala	Needle Exchange Programs
May 6, 1997	President Clinton	Discrimination Issues
July 26, 1997	President Clinton	HIV/AIDS in the Second Administration
August 6, 1997	Secretary Shalala	Meeting re. Council Recommendations
September 11, 1997	Dr. Helene Gayle	Reduction of HIV Infections
October 10, 1997	Secretary Shalala	House Appropriations Bill
December 7, 1997	President Clinton	Needle Exchange Programs
March 16, 1998	Secretary Shalala	Needle Exchange Programs
March 17, 1998	President Clinton	Needle Exchange Programs
April 17, 1998	Dr. David Baltimore	HIV Vaccine Development
August 19, 1998	President Clinton	Medicaid and Drug Therapies
August 19, 1998	President Clinton	AIDS in Racial Ethnic Populations; National State of Emergency in AIDS
September 14, 1998	Dr. Donald Burke, Dr. Daniel Tarantola	Condolence Letter
September 16, 1998	President Clinton	Needle Exchange Funding
September 23, 1998 grams	President Clinton	FY 1999 Funding for HIV/AIDS Pro-
October 28, 1998	President Clinton	FY 2000 Funding for HIV/AIDS Programs
December 8, 1998	Secretary Shalala	HIV/AIDS in Ethnic and Racial Populations

<b>Date</b>	<b>To</b>	<b>Subject</b>
February 17, 1999	President Clinton	Comments on FY 2000 HIV/AIDS Funding
April 7, 1999	President Clinton	Medicaid Eligibility Restrictions
April 7, 1999	President Clinton	Omnibus Appropriations Bill of 1998
April 9, 1999	Secretary Shalala	Invitation to COuncil Meeting
October 7, 1999	President Clinton	Lifesaving Vaccine Technology Act of 1999
April 30, 2000	Secretary Shalala	Scientific Literature on Needle Exchange
May 22, 2000	Secretary Shalala	Final PACHA Report
May 24, 2000	President Clinton	Medicaid Section 1115 Waivers

# Appendix F: Previous Recommendations

## RECOMMENDATIONS (1995-2000)

### DISCRIMINATION

#### I.D.1

Date Passed 7/28/95

#### Description

In talking publicly about HIV, the President should vigorously speak out against HIV-related discrimination and condemn prejudice based on race/ethnicity and sexual orientation, which damage our efforts to combat AIDS. The president should strongly and visibly oppose any amendments to HIV-related legislation that are designed to divide the American people along lines of sexual orientation, substance use history, race/ethnicity, or other factors.

#### II.D.1

Date Passed 12/8/95

#### Description

The Administration should rescind mandatory HIV testing and/or discriminatory policies currently in place in the U.S. Foreign Service, the Peace Corps, the Job Corps, the State Department, and the military, when there is no compelling public health justification.

#### II.D.2

Date Passed 12/8/95

#### Description

The Secretary of HHS should instruct the CDC to (1) review its guidelines that arbitrarily restrict HIV infected health care workers and that lead to discrimination against them, and (2) ensure that these guidelines are consistent with prevailing scientific and public health knowledge on the issue.

#### II.D.3

Date Passed 12/8/95

#### Description

The Administration should oppose any congressional efforts to require that otherwise qualified military service personnel who test positive for HIV be discharged, including a veto of the Department of Defense Reauthorization Act if such a provision is included. In his veto message, the Council recommends that the President state that the veto is, in part, due to the inclusion of this provision.

#### II.D.4

Date Passed 12/8/95

##### Description

The Administration should direct the CDC, Immigration and Naturalization Service (INS), and Department of State to monitor and coordinate the HIV testing of immigrants to ensure informed consent, pre- and post-test counseling, and appropriate legal and health referrals and to ensure that waivers of the HIV exclusion are granted on a priority basis when permitted by statute. Also, when permitted by statute, the INS and the Executive Office of Immigration Review (EOIR) should grant stays of deportation, suspension of deportations, extended voluntary departure, deferred action, and asylum based on the social group category of HIV-positive individuals.

#### IX.D.1

Date Passed 3/15/98

##### Description

The President should work with Congress to create stronger protections for medical privacy, and should veto any legislation that 1) permits law enforcement authorities access to patient records without having obtained a warrant or meaningful and informed patient consent, 2) fails to preserve the ability of the states to enact or maintain stronger privacy protections.

#### X.D.1

Date Passed 7/18/98

##### Description

Regardless of the U.S. Supreme Court determination of the legal rights of those with HIV/AIDS under the Americans with Disabilities Act, the Administration should develop and vigorously pursue a comprehensive strategy to provide the strongest possible protections from HIV/AIDS-based discrimination.

##### LEADERSHIP

#### I.L.1

Date Passed 7/8/95

##### Description

The President himself must engage the American public through a National Summit that encompasses the scientific, medical, social, and political aspects of the AIDS epidemic. This summit, which should be held by the end of this year, should consider the impact of race, culture, poverty, disability, region, gender, sexual orientation, and age on our ability to develop an effective national AIDS strategy.

I.L.2

Date Passed 7/28/95

Description

The President should then proceed with an address declaring the battle against HIV a national health priority and laying out his vision for the ending of this epidemic.

II.L.1

Date Passed 12/8/95

Description

During his State of the Union Address, the President should renew his commitment to ending the AIDS epidemic and to committing our Nation's resources to preventing new infections, caring for people now living with HIV/AIDS, and finding a cure, a vaccine, and effective treatments for HIV. The President should, during this address, announce the immediate release of us updated national strategy of AIDS.

II.L.2

Date Passed 12/8/95

Description

To further accomplish the goals President Clinton outlined at the White House Conference on HIV/AIDS, the Clinton/Gore Administration should ensure that key Cabinet Secretaries initiate and maintain regular face-to-face meetings with HIV service providers, people living with HIV/AIDS, and their advocates to ensure consistent and ongoing communication and partnership with community members on the front lines of the AIDS epidemic.

III.L.1

Date Passed 4/26/96

Description

We urge the President and Vice President to accept the invitation to be National Co-Chairs as well as attend the display of the AIDS Memorial Quilt in Washington, D.C. this October.

IX.L.1

Date Passed 3/8/98

Description

Needle Exchange Resolution: We unanimously express "no confidence" in the Administration's commitment and willingness to achieve the President's state goal of reducing the number of new infections annually until there are no new infections" and the Council urges Secretary Shalala to issue an immediate determination declaring the efficacy of needle exchange programs in preventing the spread of HIV while not encouraging the use of illegal drugs.

IX.L.1.

a

Date Passed 3/15/98

Description

In its ongoing Congressional lobbying related to FY 1999 budget and appropriations, the Council urges the Administration to advocate and fully support increased HIV/AIDS funding levels above those proposed in the President's own FY 1999 budget.

In so doing, the Council urges the Administration's full support for FY 1999 budget and appropriations funding levels proposed by National Organizations Responding to AIDS (NORA), which reflected documented community funding needs across the federal HIV/AIDS portfolio, especially those programs impacting African-Americans, Latinos, Native Americans, and Asian/Pacific Islanders.

IX.L.1.

b

Date Passed 3/15/98

Description

Toward the goal of expanding access to promising new HIV therapies, the Council urges the Administration to consider the critical need for full funding for the ADAP program, as well as for primary medical care and other supported services, including housing, which facilities access to such treatments.

IX.L.1.

c

Date Passed 3/15/98

Description

Considering the goal of reducing the number of new infections, the Council further urges the Administration to support efforts to provide substantial funding increase for prevention programs.

IX.L.1.

d

Date Passed 3/15/98

Description

There is a state of emergency because of HIV/AIDS in African-American and Latino communities. Therefore, the Council urges the Administration's full support for meaningful and sufficient funding levels for prevention and care initiatives targeting these communities.

V.L.1

Date Passed 12/15/95

Description

That in his FY 1998 budget request, the President continue to protect Medicaid and Medicare, and seek increases in funding for research, prevention, care and services including the Ryan White Care Act and HOPWA. In particular, because of the availability of new drug therapies, ADAP funding must be increased, and not in competition with funding for the care system. Increased funding will be essential until new financing systems can be developed among private and public health payers to cover the cost of the new therapies.

In the international arena, the President should seek increases in funding for USAID programs relating to the global epidemic.

V.L.2

Date Passed 12/15/96

Description

That the Vice-President continue the dialogue which he has established with the major manufacturers of HIV/AIDS drugs and that the issue of international provision of basic medications for the prevention and treatment of opportunistic infections and other HIV/AIDS associated medical conditions be added to their agenda.

V.L.3

Date Passed 12/15/96

Description

That the Office of National AIDS Policy create a mechanism for the public sector, the private sector, and the community to engage in a formal, facilitated dialogue process on how to set priorities for HIV care and services that assures the best use of resources and recognizes a context of shifting demands for services. This dialogue should be completed within six to eight months.

V.L.4

Date Passed 12/15/95

Description

That the Office of National AIDS Policy work with the Secretary of HHS and the Secretary of Labor, the co-chairs of the Advisory Council on Consumer Protection and Quality in Health, to assure inclusion of the concerns of people living with HIV and their recommendations.

V.L.5

Date Passed 12/15/96

Description

The Council commends the President and the Office of National AIDS Policy for demon-

strating leadership in developing the Federal Government first national comprehensive strategy for dealing with the HIV/AIDS epidemic. While there are clearly significant issues regarding the epidemic which still must be addressed, the National AIDS Strategy provides a foundation for the Federal Government's response to HIV/AIDS in the year ahead. Specific Implementation tactics and strategies must be developed.

The Council believes that in order to have any realistic chance of achieving the President's stated goals of finding a cure, developing a vaccine, and reducing annual new infections to zero, other important issues such as how to decrease infections among intravenous drug users must be addressed more comprehensively. The Council intends to continue to ensure that all crucial issues are dealt with and to ensure that the actions of relevant Federal Agencies are consistent with the National AIDS Strategy and with the recommendations of this Council.

## **PREVENTION**

### **I.P.1**

Date Passed 12/8/95

Description

The President should make HIV prevention an investment priority during budgetary decision making.

### **II.P.1**

Date Passed 12/8/95

Description

The CDC and the President should direct the Secretary of HHS to produce an annual estimate of HIV incidence based on seroprevalence studies and to work to ensure a reasonable relationship between epidemiological trends and CDC prevention funding. This report should specifically examine the demographic characteristics and geographic distribution of populations that experience disproportionate increases in new infections.

- The CDC should issue to the President an annual estimate of HIV incidence based on seroprevalence studies that provides a geographic and demographic analysis of the populations where there is a continuing disproportionate increase in new HIV infections.
- The President should direct the Secretary of HHS to ensure that resources are allocated to accomplish this task.
- The President should ensure that funding is adequate and responsive to the epidemiological trends, needs, and prevention infrastructure of affected communities.

## II.P.2

Date Passed 12/8/95

### Description

The President should direct the CDC to develop a behavioral surveillance mechanism that will provide an analysis of patterns in risk-taking behavior.

The President should direct the CDC to join with the National Institute on Drug Abuse (NIDA) and other relevant agencies to institute surveillance methods for detecting patterns of risk-taking behaviors in populations that show a continuing disproportionate increase in AIDS cases.

He should direct the Secretary of HHS to coordinate the planning of an early warning system and ensure its ongoing use.

## II.P.3

Date Passed 12/8/95

### Description

The Administration should pursue a comprehensive strategy to decrease HIV transmission related to injection drug use, which accounts for at least 50 percent of new HIV infections. In addition, high-risk sexual behavior while under the influence of drugs and/or alcohol accounts for another significant percentage of new cases of HIV disease. Strategies must explicitly address the sharing of injection drug use paraphernalia, as well as the high-risk sexual behavior associated with drug and/or alcohol use.

## II.P.3a

Date Passed 12/8/95

### Description

Increase access to effective substance abuse prevention and treatment research programs by:

- \* Opposing congressional efforts to cut SAMHSA and other Federal funding for drug abuse treatment and prevention programs in FY 1996 appropriations.
- \* Restoring budget requests for SAMHSA and other Federal funding for drug abuse treatment and prevention programs to at least the FY 1995 levels.
- \* Supporting the continuation of specific funding for NIDA's AIDS demonstration projects.

## II.P.3b

Date Passed 12/8/95

### Description

Revise the Department of Justice Model Drug Paraphernalia Act, which serves as a model for State drug paraphernalia laws, to make it consistent with current reports, studies, and data relating to the access to sterile syringes as an effective intervention to counter HIV transmission among IDUs.

II.P.3c

Date Passed 12/8/95

Description

The President should direct the Secretary of HHS to provide a recommendation (within 90 days) regarding the impact of needle-exchange programs on HIV infection and substance abuse. The recommendation should be based upon current reports, studies, and data on needle-exchange programs, and should include specific recommendations for the programs and demonstration projects to implement needle exchange. The Secretary should develop and execute a plan to carry out the recommendations and indicate what programs and demonstration projects will be started or expanded.

II.P.4

Date Passed 12/8/95

Description

The President should reaffirm his support for community-based planning for prevention activities.

II.P.4a

Date Passed 12/8/95

Description

Direct the CDC to maintain HIV prevention programs independent of any consolidated grant programs, including the currently proposed Performance Partnerships Grants.

II.P.4b

Date Passed 12/8/95

Description

Direct the CDC to continue direct funding to community-based organizations.

II.P.4c

Date Passed 12/8/95

Description

Direct the CDC, with the assistance of existing national minority organizations and other appropriate partners, to structure its technical assistance programs to address the prevention program development and infrastructure needs of populations that are currently experiencing a continued disproportionate increase in new infections.

II.P.5

Date Passed 12/8/95

Description

Direct the Director of the Indian Health Service (IHS) to develop a comprehensive AIDS prevention and care plan for Indian Country (within 90 days) with the input from consumers of IHS services.

### III.P.1

Date Passed 4/26/96

#### Description

We recommend that the President direct the Secretary of HHS, with the NIH, OAR, and the CDC, to develop a coordinated and comprehensive prevention science agenda that includes biomedical, behavioral, and social science interventions.

### III.P.1.

a

Date Passed 4/26/96

#### Description

The NIH and OAR must make an increased commitment to research on sexual behavior and sexuality as indicators of high risk for HIV transmission. Basic research on the underlying mechanisms for sexual and drug-using behavior clearly related to HIV transmission must immediately be solicited and supported at increased levels.

### III.P.1.

b

Date Passed 4/26/96

#### Description

Due to the paucity of data, increased efforts should be made and funded to accurately assess the risk of oral sex. Studies should be funded to assess the potential safety and efficacy of anal usage of insertive condoms.

### III.P.2

Date Passed 4/26/96

#### Description

The OAR should develop research initiatives that seek to identify successful models for behavior change in minority populations. Within communities of color, this population-based research should focus especially on women and gay men, the growing edge of this epidemic.

### III.P.3

Date Passed 4/26/96

#### Description

The limited availability of methadone and other effective substance abuse treatment modalities in many areas, especially rural regions, poses a major challenge for HIV prevention among needle users. The Secretary of HHS should order a formal review of federal regulations concerning access to methadone and other effective substance abuse treatment modalities, to consider ways in which those regulations might be changed to allow greater access to methadone without an adverse impact on substance abuse treatment.

III.P.4

Date Passed 4/26/96

Description

The President should instruct the Secretary of HHS to ensure that federally funded research on HIV prevention interventions include specific mechanisms for rapid dissemination of findings, including resources to allow replication of programs with demonstrated effectiveness.

III.P.4.

a

Date Passed 4/26/96

Description

Allocate funding for training of front-line prevention workers in application of relevant research findings.

III.P.4.

b

Date Passed 4/26/96

Description

The Public Health Service should be directed to establish formal mechanisms for dissemination of accurate and up-to-date information to community and consumers in a way that is rapid, easily understandable, and widely accessible.

V.P.1

Date Passed 4/5/97

Description

The Council requests that the President instruct the Secretary of Health and Human Services to reassess the legislative intent of the reauthorized Ryan White CARE Act regarding needs of the Native American community to ensure appropriate support for Native American care, infrastructure development and coordination on a national level.

V.P.2

Date Passed 12/15/96

Description

That the Secretary of Health and Human Services instruct the Director of Indian Health Services to demonstrate within ninety-days the adequacy of HIV prevention, care, and treatment including access to needed drugs, for American Indians and Alaska Natives living on or near reservations. This should include documentation of needs assessments completed, barriers, and gaps identified and proposed solutions. It should also include a discussion of how IHS plans to work with the private non-profit sector to improve AIDS-related services.

V.P.5

Date Passed 12/15/96

Description

That the Secretary of Health and Human Services instruct the Director of IHS to develop Case Management oversight guidelines which are appropriately oriented to the specific needs of Native American people with HIV/AIDS and assure the provision of health care and in a safe and culturally appropriate manner.

VI.P.1

Date Passed 12/15/96

Description

The Secretary and Health and Human Services should eliminate all regulations and requirements for mandated reviews by citizen review panels of the content of HIV prevention materials. HIV prevention materials produced or distributed with federal funding should be free of restrictions on content, subject only to review for scientific accuracy and cultural appropriateness for the targeted population. Grantees should be given great flexibility in utilizing the least burdensome methods of conducting these reviews.

VI.P.2

Date Passed 4/5/97

Description:

We strongly recommend that the President ensure that the Secretary of Health and Human Services take all necessary steps to promptly certify syringe exchange programs as effective in reducing the incidence of new HIV infections while not increasing substance abuse; thus, the use of federal funds for syringe exchange and substance abuse counseling and treatment programs must be permitted in those communities that determine such programs to be appropriate.

VIII.P.

1.a

Date Passed 12/7/97

Description

That the CDC issue a comprehensive public report on its analysis and scientific documentation of the impact of different surveillance systems on seeking/acceptance of HIV testing and care among and potential discriminatory impacts on, individuals and communities at risk for HIV infection. Such a report should also assess the accuracy, completeness and cost of data obtained under the various reporting systems. We recommend that any move to change reporting systems should not be made prior to the development and release of such a report and following an opportunity for community consultation.

VIII.P.

1.b

Date Passed 12/7/97

Description

That prior to recommending any changes in reporting systems for AIDS and HIV, the CDC be required to provide a comprehensive scientific justification that includes a detailed strategy and implementation plan about how it will obtain and present the data necessary to develop a comprehensive picture of the scope of the current and emerging HIV epidemic.

VIII.P.

1.c

Date Passed 12/7/97

Description

Whatever changes, if any, are made in HIV reporting policies at the national level, we strongly believe that several issues must be addressed. These include the following:

**PRISON**

V.X.1a

Date Passed 12/15/96

Description

The Council requests a comprehensive and specific report be from Federal Bureau of Prisons, and the Department of Defense within 90 days, addressing the inclusion of HIV/AIDS issues in all services of the Federal Bureau of Prisons (including D.C. Jails) and DOD prisons and brigades. This should minimally include the following:

a. Content and frequency of prisons staff educational efforts paying particular attention to issue of women at risk for HIV, substance use, prevention, and the medical management of HIV disease.

V.X.1b

Date Passed 12/15/96

b. Accessibility of all FDA approved HIV/AIDS therapeutic modalities for prison inmates with HIV/AIDS and numbers of prisoners availing themselves of these therapies

V.X.1c

Date Passed 12/15/96

Description

c. Availability of mainstream clinical drug trials for prison inmates, the nature of any access barriers - and means to remove such barriers, and numbers, sites and principal investigators of these programs.

V.X.1d

Date Passed 12/15/96

Description

The Council requests a comprehensive and specific report be from the addressing the inclusion of HIV/AIDS issues in all services of the Federal Bureau of Prisons (Including D.C. Jails) and DOD prisons and brgs. This should minimally include the following:

d. The status of quality assurance criteria and certifications, (including nondiscrimination guidelines) with a demonstrable high level of compassionate care available for the ill and dying.

V.X.1e

Date Passed 12/15/96

Description

e. Description of case management for prison inmates with HIV/AIDS.

V.X.1f

Date Passed 12/15/96

Description

f. Availability of voluntary peer education opportunities for HIV+ inmates. (Please include curriculum participation, site, and frequency statistics.)

V.X.1g

Date Passed 12/15/96

Description

g. Accessibility of condoms and barrier protection against HIV transmission to prison inmates.

V.X.1h

Date Passed 12/15/96

Description

h. Specific details concerning the availability of ongoing (at least every 6 months) educational program for incarcerated individuals regarding all aspects of HIV, including substance abuse issues and sexuality.

V.X.1i

Date Passed 12/15/96

Description

i. Definition of the limits of jurisdiction which differentiate the authority of the federal government in all correctional facilities; District of Columbia, military, federal, state, and local correctional institutions, including federal funding streams.

V.X.1j

Date Passed 12/15/96

Description

j. The scope of implementation of the seven major recommendations of the National Commission on AIDS (March, 1991).

V.X.2

Date Passed 12/15/96

Description

The Administration should direct the Secretary of Health and Human Services to develop oversight language appropriate for discharge planning (including accessing benefits) for ex-offenders with HIV/AIDS designed to assure their continuity of care through Probation Departments in various locales as well as the accessibility of appropriate linkages within the community.

VI.X.1

Date Passed 4/5/97

Description

The President should direct the Justice Department and the Director of the Federal Bureau of Prisons to revise administrative and judicial standards of compassionate release for use in all Federal and Federally-funded prisons. Prisons will do this in accordance with American Bar Association (ABA) Standards. Furthermore, equivalent compassionate release programs should be required in state and local prisons as a condition of these institutions receiving federal funds. The Federal Bureau of Prisons also should be directed to maintain statistical and evaluative records concerning the compassionate release policy and file an annual report to the President, Secretary of Health and Human Services and the Office of National AIDS Policy.

VI.X.2

Date Passed 4/5/97

Description

The President should direct the Secretary of Health and Human Services to develop standards of care to ensure that, prior to release, ex-offenders with HIV/AIDS are provided timely, thorough, and appropriate case management/discharge planning. These standards should address behavioral and social service needs; continuity of care; and appropriate linkages to local community services, medical services, social service benefits, appropriate case management, and housing assistance programs to ensure against homelessness.

### VI.X.3

Date Passed 4/5/97

#### Description

The President shall direct the Federal Bureau of Prisons to incorporate the upcoming Report from the HHS Panel on Clinical Practices for the Treatment of HIV Infections in all correctional medical facilities. It should be required that care providers be adequately trained to implement these standards and all appropriate therapeutic options associated with the management of HIV disease be available.

### VI.X.4

Date Passed 4/5/97

#### Description

The President shall direct the Attorney General to direct the Federal Bureau of Prisons to ensure that condoms and dental dams are made readily available for all prisoners within correctional facilities to prevent transmission of HIV/AIDS.

### VI.X.5

Date Passed 4/5/97

#### Description

The President shall direct the Attorney General to direct the Federal Bureau of Prisons to investigate and report within 90 days on the feasibility of and various options for providing comprehensive substance abuse treatment for incarcerated individuals with a dual diagnosis of chemical dependency and HIV disease.

### VIII.X.

1

Date Passed 12/7/97

#### Description

The Council recommends that the Director of the Office of National AIDS Policy convene a community and government meeting on AIDS in Prisons as soon as possible. Key constituencies should include advocates and experts, exoffenders, representatives of relevant government agencies, correctional health providers and departments, international experts, and other relevant persons or organizations.

### X.X.1

Date Passed 7/18/98

#### Description

The Centers for Disease Control and Prevention should offer technical assistance to Federal and State Correctional systems for the development of data collection instruments on incidence and prevalence of HIV/STD/TB. The CDC should also assist with the assessment of the data collected in order to implement appropriate activities, primary health care, and substance abuse therapies.

## **RACIAL AND ETHNIC POPULATIONS**

### **IX.C.1**

Date Passed 3/15/98

#### **Description**

PACHA endorses the demands of the African-American Consultants to the Centers for Disease Control and Prevention African-American initiative. These demands along with the Council endorsement will be transmitted to the President and the Secretary of Health and Human Services.

### **IX.C.1.**

a

Date Passed 3/15/98

#### **Description**

CDC Director communicate immediately to Secretary Donna Shalala and Surgeon General David Satcher about the HIV/AIDS emergency in the African American community and that the Secretary and the Surgeon General immediately communicate those concerns to President Clinton.

### **IX.C.1.**

b

Date Passed 3/15/98

#### **Description**

The President and Surgeon General declare a state of emergency in the African American community concerning AIDS and public health.

### **IX.C.1.**

c

Date Passed 3/15/98

#### **Description**

CDC Acting Director Clare Broom and Surgeon General Satcher develop an emergency press strategy and implement same "to alert the American public on the present state of HIV/AIDS and initiate a new booklet to the American public on AIDS in communities of African descent."

### **X.C.1.**

Date Passed 7/18/98

#### **Description**

Request that the President convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency in the African American and Latino communities.

X.C.2

Date Passed 7/18/98

Description

Call for a special White House conference on the State of Emergency in communities of color at the end of the Council's current term (July 1999).

IX.C.1.

d

Date Passed 3/15/98

Description

Within 90 days the Directors of the Centers for Disease Control and Prevention, Substance Abuse and Mental Health Services Administration and Office of Drug Control Policy report to Secretary Shalala a new strategy to interrupt the devastation of drug addiction and HIV/AIDS are have on African Americans.

IX.C.1.

e

Date Passed 3/15/98

Description

CDC Director immediately redirect current resources to address the long standing HIV emergency in among African Americans.

IX.C.1.

f

Date Passed 3/15/98

Description

The Administration immediately convene an emergency meeting of national black leaders and organizations to develop their own plan(s) for HIV/AIDS and public health in the African American community.

IX.C.1.

g

Date Passed 3/15/98

Description

Demonstration funding designed to test alternatives to community planning, as well as other program models that meet the needs of the African American community be established immediately.

IX.C.1.

h

Date Passed 3/15/98

Description

The CDC Director will undertake a specific and extensive external research program to identify those factors that cause and promulgate the diversity in reference to the impact of HIV disease on the African American Community.

IX.C.1.

l

Date Passed 3/15/98

Description

The CDC Director will initiate extensive analysis of the correlation of funding and allocation to communities in relation to epidemiologic trends.

## **RESEARCH**

I.R.1

Date Passed 7/28/98

Description

The President should continue to show strong support for a coordinated Federal approach to HIV/AIDS research, including continued support for the Office of AIDS Research (OAR).

I.R.2

Date Passed 7/28/95

Description

The President should continue to show strong support for a coordinated Federal approach to HIV/AIDS research, including continued support for the Office of AIDS Research (OAR).

II.R.1

Date Passed 12/8/95

Description

The Vice President's leadership and technological expertise should be sought to bring together the resources and expertise of various Government agencies, the private sector, community groups, and other nations in the effort to develop HIV vaccines and microbicides and to "reinvent" the Government's involvement in development of these products.

II.R.2

Date Passed 12/8/95

Description

The priority for funding by the OAR for microbicide research and development, as well as such funding within CDC, must be increased substantially, with a concomitant increase of full-time equivalents (FTEs) allocated for this priority.

II.R.3

Date Passed 12/8/95

Description

The Government should develop mechanisms to increase the pool of investigators in microbicide research and development, especially those involved in biomedical and behavioral aspects.

II.R.4

Date Passed 7/18/98

Description

In HIV/AIDS clinical research, the NIH must ensure the early and fundamental involvement of behavioral and social scientists in the process of initial study development, design, and implementation.

II.R.5

Date Passed 12/8/95

Description

HHS should develop ongoing mechanisms to ensure the rapid translation of breakthrough research findings into clinical practice.

II.R.6

Date Passed 12/8/95

Description

A public health policy consensus panel should be convened by the Public Health Service by the end of April 1996 to assess the possible efficacy of available spermicides (e.g., nonoxynol-9) and other licensed products (e.g., chlorhexidine, benzalkonium chloride, diaphragms) to be used in "harm reduction" algorithms to decrease sexual transmission of HIV. The panel should include senior public health policy officials (CDC, FDA, HHS Secretary's Office), research agencies (NIH), community groups (women's health research advocates, commercial sex workers, interested foundations), academia, and industry. The meeting should also feature a review of the entire status of anti-HIV microbicide research.

II.R.7

Date Passed 12/8/95

Description

The Council asks the FDA to comment by January 31, 1996, upon the drugs treatment of

HIV/AIDS in which there is no known evidence of reproductive toxicity. When such toxicity has been documented, alternatives that allow the inclusion of women should be provided.

#### II.R.8

Date Passed 12/8/95

##### Description

The FDA must require a sponsor to file a gender accrual analysis in the annual investigational New Drug (IND) report, as stated in the final version of the proposed regulations published in the Federal Register, Vol. 60, No. 184, at 46794. In addition, for the New Drug Application (NDA) and the product licensing application (PLA), the regulations must require sponsors to analyze clinical data by gender and assess potential differences, including reporting on side effects by gender.

#### II.R.9

Date Passed 12/8/95

##### Description

The Secretary of HHS should publish for public comment by March 1, 1996, the proposed regulations regarding participation of pregnant women in clinical trials, with the following revision: A pregnant woman's ability to obtain written consent from the father of the fetus should not disqualify her from participation in a federally funded clinical trial. This fact should be so stated in the protocol consent form.

#### III.R.1

Date Passed 12/8/95

##### Description

The Administration should require OAR to maintain an ongoing review of the numbers of children enrolled in NIH sponsored clinical trials, to ensure compliance with the right to access.

#### III.R.2

Date Passed 4/26/96

##### Description

A public health policy consensus panel should be convened by the Public Health Service by the end of April 1996 to assess the possible efficacy of available spermicides (e.g., nonoxynol-9) and other licensed products (e.g., chlorhexidine, benzalkonium chloride, diaphragms) to be used in "harm reduction" algorithms to decrease sexual transmission of HIV. The panel should include senior public health policy officials (CDC, FDA, HHS Secretary's Office), research agencies (NIH), community groups (women's health research advocates, commercial sex workers, interested foundations), academia, and

industry. The meeting should also feature a review of the entire status of anti-HIV micro-bicide research.

### III.R.3

Date Passed 4/26/96

#### Description

Research and development for AIDS vaccines should receive a substantial increase in the proportion of funds devoted to it in the Federal biomedical research budget for AIDS.

### III.R.3

Date Passed 4/26/96

#### Description

Research and development for AIDS vaccines should receive a substantial increase in the proportion of funds devoted to it in the Federal biomedical research budget for AIDS.

### III.R.4

Date Passed 4/26/96

#### Description

All agencies of the U.S. Government with experience in various phases of vaccine research and development - including the NIH with its lead role in basic research, DOD, FDA, CDC, and the VA - have valuable roles to play and should contribute their unique institutional expertise, capabilities, resources, and collaborative relationships in a coordinated and expedited Federal effort towards the common goal to produce an effective preventive vaccine for AIDS. In addition - recognizing the need for public-private partnerships and the involvement of other nations in a global effort, and the relative advantage of private-sector, non-profit organizations in rapidly filling gaps in targeted vaccine research, product development, and testing - the concept of an independent international AIDS vaccine initiative should be strongly encouraged and developed.

### VI.R.1

Date Passed 4/5/97

#### Description

The President must declare an urgent goal of developing a vaccine to prevent HIV/AIDS within a decade in order to mobilize public opinion, political will, and international collaboration, and to assign high priority to this effort within each of the governmental agencies involved in HIV/AIDS vaccine research and development. As the HIV/AIDS epidemic has no borders, and a successful vaccine will require international collaboration, the President should work with the leaders of other nations in a global effort to achieve an HIV/AIDS vaccine for all the world.

#### VI.R.2

Date Passed 4/5/97

##### Description

A significant and sustained increase in funds must be made available for HIV/AIDS vaccine research and development. These funds must be derived from NEW sources from both government and industry, and must not be taken from existing programs aimed at prevention, research, care, services, and/or treatment for persons with HIV/AIDS. Innovative use of such funds is essential, as seed money to initiate new and creative hypotheses in vaccine research; to support product development; to expand the proportion of successfully funded grant applications; and to bring additional entities into the HIV/AIDS vaccine field.

#### VI.R.3

Date Passed 4/5/97

##### Description

Participation by non-governmental sectors and organizations is also essential to achieve the goal of expedited vaccine research, product development and use. The Vice President should convene a public-private HIV/AIDS vaccine consultative forum, composed of senior representatives to encourage communication between sectors, to address gaps in the field, and to speed progress towards the President's goal. Participation on this HIV/AIDS vaccine forum should include representation from: US Government agencies, industry, the international community, academia, the World Bank and other funding agencies, the insurance industry, ethicists, and communities most affected by the epidemic.

#### IX.R.1

Date Passed 3/15/98

##### Description

Substantive involvement, coordination, and collaboration among all relevant federal agencies, the private sector, and the international community are critical to the development of an effective AIDS vaccine.

#### IX.R.2

Date Passed 3/15/98

##### Description

Federal leadership at the highest level will be required, through the Office of National AIDS Policy, ensuring that adequate resources are provided for the coordination process necessary to achieve the goal of an effective AIDS vaccine.

IX.R.3

Date Passed 3/15/98

Description

The Office of National AIDS Policy should ensure the development and implementation of a comprehensive federal plan to achieve the goal of an effective AIDS vaccine.

IX.R.4

Date Passed 3/15/98

Description

The process of defining the structure and mission of the proposed (AIDS) Vaccine Center at NIH, and the appointment of a director with the highest level of expertise, should proceed promptly.

IX.R.5

Date Passed 3/15/98

Description

The urgent need for an AIDS vaccine mandates the simultaneous implementation of both basic and empiric scientific approaches.

**SERVICES**

I.S.1

Date Passed 7/28/95

Description

The President should continue his support of the Ryan White CARE Act and should endeavor to prevent the Congress from attaching unnecessary funding restrictions. He should also continue to vigorously support funding levels for the Ryan White CARE Act that are responsive to the rising caseloads and cost of delivering comprehensive services to people with HIV/AIDS and make the CARE Act a budget priority.

I.S.2

Date Passed 7/28/95

Description

The President must maintain a strong commitment to the entitlement status of the Medicaid program, including a willingness to veto any legislation that inadequately funds or transforms Medicaid into a block grant.

I.S.3

Date Passed 7/28/95

Description

The President must continue to demonstrate his strong support for the Housing Opportunities for Persons with AIDS (HOPWA) and other Federal housing programs that serve people living with AIDS. The President should make housing for people with AIDS (PWAs) a FY 1997 priority.

II.S.1

Date Passed 12/8/95

Description

Continue to support and defend the entitlement status and funding for Medicaid and Medicare, and continue to oppose any efforts to restrict eligibility and services for people living with HIV/AIDS.

II.S.2

Date Passed 12/8/95

Description

Direct that any waivers granted to States under the Medicaid program ensures access to a comprehensive continuum of care for people living with HIV/AIDS. To implement this policy, the President should direct the HCFA to establish national criteria by which to assess State waiver applications and to ensure that these criteria be consistent with current health care knowledge. These criteria also should be consistent with the provisions of the Americans with Disabilities Act (ADA), and State plans should be reviewed for this purpose by the HHS Office of Civil Rights.

II.S.3

Date Passed 12/8/95

Description

Direct HCFA to ensure that State Medicaid programs cover HIV testing and counseling.

II.S.4

Date Passed 12/8/95

Description

Direct HCFA to report to the Council, at its next meeting, possible strategies to address the need to ensure that all Food and Drug Administration (FDA)-approved drugs are covered under State Medicaid plans, even when prescribed for "off-label" indications. These strategies should address both policies and vigorous enforcement mechanisms.

II.S.5

Date Passed 12/8/95

Description

The Administration should direct those Federal agencies that either finance or administer health care services (including but not necessarily limited to HCFA, the Department of Veterans' Affairs [VA], the Department of Defense, and the Department of Justice

Bureau of Prisons) to develop oversight guidelines for HIV managed care programs. This will also require effective regulatory enforcement mechanisms.

#### II.S.6

Date Passed 12/8/95

##### Description

The Administration should direct HRSA to develop a coordinated agency-wide approach that provides effective education, training, and technical assistance to HIV/AIDS providers and AIDS service organizations on health care management issues. Such an approach should include active participation by the private sector.

#### II.S.7

Date Passed 12/8/95

##### Description

Because complementary therapies are widely used, the President should direct all appropriate agencies to support investigation of the efficacy of complementary therapies and provide increased financial support for this effort. Therapies shown to have benefits should be reimbursed under Medicaid.

#### II.S.8

Date Passed 12/28/95

##### Description

The President should continue to support full funding to a national network of AETCs, and direct HRSA to ensure that the work of the AETCs is coordinated with community providers and planning groups.

#### II.S.9

Date Passed 12/8/95

##### Description

The Administration should direct HRSA to review and report to the Council at its next meeting the effectiveness of the Bureau of Health Professions' education activities specific to HIV/AIDS.

#### III.S.1

Date Passed 4/5/97

##### Description

The Administration should direct the Centers for Disease Control and Prevention (CDC) to take affirmative steps to ensure that CDC-funded HIV counseling and testing programs in all States and territories offer the option of anonymous testing that is geographically accessible and available to all who wish to be tested anonymously.

### III.S.2

Date Passed 4/26/96

#### Description

The Administration should issue an Executive Directive to the Director of the Office of Personnel Management (OPM) to add nutritional foods to those medical expenses covered under the Federal Employees Health Benefits Program, a fee-for-service plan.

### III.S.3

Date Passed 4/26/96

#### Description

The Administration should direct the Social Security Administration (and other appropriate agencies) to include and add the following reminder to the Social Security Notice of Disability Award: (specific wording to be developed by the Administration - this is our proposal).

If you have extended your medical insurance under Cobra, your employer must be given a copy of this letter no later than----- (date of letter plus 60 days), and sooner in many cases, if you are to take full advantage of your Cobra insurance. You may be eligible for an additional 11 months of coverage after the first 18 months after your Cobra coverage has expired.

### III.S.4

Date Passed 4/26/96

#### Description

The Administration should recommend a substantial increase in the NIH Office of Alternative Medicine (OAM) budget for FY 1997.

### III.S.5

Date Passed 4/26/96

#### Description

The Administration should direct Medicaid and Medicare to determine which alternative/complementary therapies can be reimbursable immediately and directly to qualified health care providers. Medicaid and Medicare also should outline a plan for investigating whether other therapies are reimbursable directly to qualified medical and paramedical practitioners.

### III.S.6

Date Passed 4/26/97

#### Description

The Administration should direct OAM and OAR to act in concert to convene a working group consisting of representatives from countries doing alternative therapy research, HIV alternative therapy practitioners, conventional researchers, representatives from private

insurance and pharmaceutical companies, and HIV-positive people using alternative therapies, to investigate new and innovative ways to research and make available to people therapies that anecdotally are being identified as treatments for HIV.

### III.S.7

Date Passed 4/26/96

#### Description

The Clinton Administration should address the chronic underfunding of Housing Opportunities for Persons with AIDS ( HOPWA) in FY 97 and FY 98 by expanding funding to keep up with the growing demand for housing and related support services in existing HOPWA jurisdictions, as well as the increase in the number of eligible jurisdictions overall. In particular, given the gravity of the situation, the President should include supplemental funds for HOPWA in any budget amendment or emergency supplemental funding request that he may submit to Congress in the next year.

### III.S.8

Date Passed 4/26/96

#### Description

The Administration should demonstrate strong White House leadership and commitment to AIDS housing by convening a series of high-level White House and cabinet level meetings by the Fall of 1996 to develop a coordinated, comprehensive HOPWA Revitalization Plan. At a minimum, these meetings would include representatives from Housing and Urban Development (HUD), Health and Human Services (HHS), Office of Management and Budget (OMB), and the White House. These meetings, and the resulting HOPWA Revitalization Plan, should establish means and timetables to achieve full funding and timely reauthorization of HOPWA as a distinct HUD program, as well as improved interagency coordination and integration of AIDS housing services with other AIDS-related programs.

### V.S.1

Date Passed 12/15/96

#### Description

That the Administration take leadership in working with the states and the private sector to reduce the cost of pharmaceuticals to ADAP and Medicaid programs.

### V.S.2

Date Passed 12/15/96

#### Description

That the Federal Government working with the states expeditiously finance, and evaluate new demonstration projects that (1) enable funds to be used for very early access to HIV care services, and (2) assess the resulting impact on health status, life expectancy, client return to work and earned income, and net health care costs (new expenditures offset by lowered costs), on a lifetime and annual cost-of-care basis. These demonstrations should

be financed with new funds, so as not to diminish access to care and treatment under current funding.

VIII.S.

1

Date Passed 12/7/97

Description

The Council urges the President to include in his FY 1999 budget request to Congress adequate increases in funding for federal HIV/AIDS programs, in order to appropriately address the increasingly complex health and service needs of people living with HIV/AIDS in America.

**OTHER RECOMMENDATIONS**

V.S.1

Date Passed 4/5/97

Description

The President should forcefully oppose the HIV Prevention Act of 1997. Many provisions of this bill, including enforced mandates, interference with State and local control living with HIV/AIDS, will undermine rather than enhance our nations HIV prevention strategy.

VI.M.

2

Date Passed 4/5/97

Description

The Secretary of Health and Human Services should eliminate all regulations and requirements for mandated reviews by citizen review panels of the content of HIV prevention materials. HIV prevention materials produced or distributed with federal funding should be free of restrictions on content, subject only to review for scientific accuracy and cultural appropriateness for the targeted population. Grantees should be given great flexibility in utilizing the least burdensome methods of conducting these reviews.

VI.M.

3

Date Passed 4/5/97

Description

The President should direct appropriate agencies to take all steps necessary to encourage scientific research, including clinical trials, to gauge the potential benefits and/or risks of medical marijuana use (including smoked marijuana) on chronic pain, nausea, glaucoma and other conditions due to illnesses such as AIDS, cancer and other chronic diseases.

Further, the President should direct that, pending the results of such research, the government refrain from any efforts to prosecute doctors who, in good faith, discuss the use of medical marijuana or recommend it for their patients.

## **INTERNATIONAL**

### **X.I.1**

Date Passed 7/18/98

#### Description

The Presidential Advisory Council on HIV/AIDS recommends that the President support efforts in Congress directed at amending the Embargo Authority in the Foreign Assistance Act of 1961 so that any such embargo shall not apply with respect to the export of any food, medicines, medical supplies, or medical equipment, or with respect to travel incident to the delivery of food, medicines, medical supplies, medical instruments, or medical equipment. The embargo of such supplies contributes to the suffering of persons with HIV/AIDS and other diseases.

# **Appendix G: Recommendations for Action to End the HIV/AIDS Pandemic**

## **Preventing New HIV Infections**

- The Administration should continue to work towards the development of a global plan for vaccine development and distribution based on meaningful collaboration with public- and private-sector partners.
- The Administration should begin immediate conversations at the highest global levels regarding the myriad of societal, ethical economic, and regulatory issues that must be solved prior to the wide-scale distribution of any effective vaccine. The time to address these issues is now, before an actual vaccine has been developed.
- The Administration should strongly support and work to enact policy reforms that will encourage HIV vaccine development, including tax credits for vaccine research, development, and sales; the creation of international purchase funds; and continued and expanded funding to public-private partnerships that have been established to encourage vaccine development, including efforts such as the Global Alliance for Vaccines and Immunization (GAVI) and the International AIDS Vaccine Initiative (IAVI).
- The Administration should attach high priority to efforts to develop effective microbicides through significantly increased research funding, incentives to industry, and better coordination of microbicide research.
- The Administration must work for dramatically increased funding for global prevention efforts consistent with the severity of HIV/AIDS and its importance to U.S. national security. To the greatest degree possible, this should be done in a way that leverages additional funds from other governments, international organizations, and the private sector.
- As part of a global partnership with other leading industrialized nations, the Administration should support current and future efforts to provide meaningful debt relief to developing countries so that they may devote a greater portion of their own resources to fighting HIV/AIDS.

- The Administration should work for meaningful increases in funding allocated to support HIV/AIDS prevention, surveillance and monitoring, and research programs in the U.S., with an emphasis on meeting the needs of communities experiencing new infections. This must include capacity-building assistance to develop and strengthen community-based HIV/AIDS prevention infrastructure in all communities.
- The President should work for permanent establishment of the Office of National AIDS Policy (or a similar entity) with full authority to increase the efficiency and effectiveness of funding for HIV/AIDS prevention efforts, with appropriate staffing and authority to coordinate all Federal HIV/AIDS prevention efforts.
- The Administration should develop a well coordinated and integrated National HIV/AIDS Prevention Plan to reduce new infections to zero, and ensure cross- departmental and agency participation by empowering an individual reporting directly to the President to oversee the development, implementation, and monitoring of such a plan. All current Federal HIV/AIDS advisory bodies, committees, and councils should be convened jointly to participate in the coordination, implementation, and monitoring of the plan.
- The Administration should make a concerted effort to engage new and existing partners in HIV/AIDS prevention efforts in this country and worldwide. These partners include state and local health departments, nongovernmental organizations, schools, businesses, labor unions, the faith community, music and media industries, tribal governments and other indigenous organizations, traditional civil rights and civic organizations.
- The Administration should take concrete steps to remove many of the current barriers that prevent community-based organizations from obtaining funding to support their HIV/AIDS prevention work. This should include steps such as simplified application forms and processes, coordination of grant cycles and applications across funding streams, ensuring participation of more reviewers from minority community organizations, and greater support to build capacity among small minority-based organizations. U.S. global funding efforts should use the same principles to ensure that funding reaches and directly supports the development of appropriate community-based organizations.
- The Administration should make a commitment to use all available avenues for HIV/AIDS prevention, ensuring that all publicly supported systems of services that interact directly with various populations and communities use the point of contact as an opportunity for education or interventions to help prevent HIV transmission.

- The President, his Cabinet members, and other Administration officials must continue and expand efforts to demonstrate U.S. government leadership in the fight against HIV/AIDS by utilizing every opportunity to mobilize public opinion, engage governmental and non-governmental leaders, and encourage multi-sectoral involvement in prevention activities. The U.S. government must take a lead in encouraging development of a global action plan and responses to implement such a plan.
- The Administration should take every step available to it to ensure the continued and expanded availability of both anonymous and confidential, voluntary HIV counseling and testing in Federally funded programs at the State and local levels.
- The Administration should fund and promptly implement a national campaign promoting voluntary counseling and testing, involving both national media and local partnerships.
- The Administration should support the creation and widespread availability of effective, affordable HIV testing technologies in the U.S. and around the world, encouraging innovative practices to overcome barriers to testing.
- The Administration should take immediate steps to remove content restrictions and other barriers to effective HIV/AIDS prevention messages from Federally funded programs.
- The Administration should work to ensure that developmentally appropriate and science-driven HIV/AIDS prevention education takes place in all our nation's schools.
- The Administration should continue to expand funding for communities hardest hit by HIV/AIDS through the CBC/Minority HIV/AIDS Initiative.
- The Administration should provide funding and support for education and prevention that targets the specific needs of gay and bisexual men where rates of infection are increasing substantially, especially among young men and gay and bisexual men of color.
- The Administration should take steps to replace or abolish scientifically discredited policies (such as guidelines restricting HIV-infected health care workers, Congressionally imposed travel and immigration restrictions, the ban on induction of HIV-positive individuals into the military), which feed public misinformation and counteract public education efforts.

- The Administration should develop and implement a high profile national media campaign on HIV/AIDS prevention that includes innovative uses of all forms of media (such as television and radio soap operas or “telenovelas”) in delivering general and targeted prevention messages. The Administration should also work with the broadcast industry to modify existing television and radio “commercial standards” to allow frank and appropriate prevention messages (such as the importance of condom use) to be aired.
- The Administration must work to implement strategies to ensure global access to condoms and other effective barrier methods such as latex gloves to avoid HIV transmission. Condoms must be widely available to all, particularly young people and incarcerated persons—two populations often mistakenly perceived as not sexually active. Strategies must ensure that cost is not a barrier for those in need of these important prevention materials.
- The Administration should work to ensure that health care providers continue to offer voluntary counseling and testing to pregnant women and appropriate treatment to HIV-infected pregnant women. In the U.S., where these treatments are readily available, ART should be part of a comprehensive treatment regimen targeted at both mother and child. Prevention of perinatal transmission should not focus solely on protecting the child while ignoring the mother’s health needs.
- The Administration should augment its efforts to make interventions to prevent perinatal transmission available in all parts of the world, including work with the pharmaceutical industry and with global partners to provide these drugs at little or no cost in those areas of the world where they would not otherwise be available.
- The Administration should work aggressively with Congress to lift the Federal ban on funding for needle exchange programs to prevent the further spread of HIV, Hepatitis C, and other blood-borne diseases.
- The Administration should disseminate existing scientific information regarding the efficacy of syringe exchange to State and local elected officials, health officials, Federal HIV/AIDS grantees and sub-grantees, private funders, the media, and foreign governments.
- The Administration should actively encourage State efforts to eliminate laws that restrict the sale and possession of syringes, as well as other efforts to broaden pharmacy access to clean syringes. While these laws and regulations are State or local in nature, they are modeled on Federal government guidelines. These Federal standards should be adjusted to reflect scientific evidence and public health needs.

- The Administration should develop a plan to expand substance abuse treatment capacity in this country to guarantee treatment access to all who need it, including incarcerated populations. As a part of such a plan, substance abuse prevention and treatment should be funded at levels at least equal to drug interdiction and enforcement efforts.
- The Administration should take steps to ensure the adoption of treatment practices that recognize the likelihood of relapse by including appropriate HIV/AIDS prevention and harm reduction measures.
- The Administration should work to identify and remove legal barriers that prevent drug users from accessing health and social services essential to HIV/AIDS prevention.
- The Administration should make a commitment to increased funding for behavioral and prevention research, emphasizing the needs of communities experiencing new infections.
- The Administration should develop and implement mechanisms for widespread and rapid dissemination of usable findings to community-based HIV/AIDS prevention programs.
- The Administration should implement activities that help provide funding to guarantee the availability of uncontaminated blood supplies around the world.
- The Administration should provide leadership and funding to support a global effort to reduce the total number of STD infections. This will be achieved only through continued global efforts to develop health service infrastructure vital for the treatment of both HIV/AIDS and STDs. In the U.S., this effort must include a commitment to eradicate syphilis.
- The Administration should continue to support and expand efforts to combat poverty, economic underdevelopment, illiteracy, lack of health care, and economic dislocation due to war, all of which interfere with HIV/AIDS prevention efforts. HIV/AIDS programs should supplement and work with existing development and aid programs to address these issues comprehensively.
- The Administration should take all steps at its disposal to combat the social inequities and discrimination in the U.S. and abroad that make entire classes of people marginalized and more vulnerable to HIV/AIDS. This includes

efforts to promote economic and social equality between men and women, ending racial and ethnic discrimination, fighting homophobia, and protecting human rights for all.

- The Administration should place a greater focus on, and provide more financial support for, improving the efficiency and efficacy of the HIV/AIDS behavioral and disease monitoring systems to ensure that the data on which researchers, practitioners, public health officials, and planning groups must depend is accurate and comprehensive.
- In developing and enhancing activities to monitor the epidemic in the U.S. and abroad, the Administration should work to retain community confidence by taking every step to protect individual privacy and human rights. Data collection should always use the least intrusive measures reasonably possible and be designed and implemented in conjunction with affected communities.
- The CDC should establish surveillance systems to identify subpopulations within communities of color that might otherwise be obscured by broad categorizations and to help community prevention planners target prevention resources accordingly.

## **Services for Persons Living with HIV/AIDS**

- The Administration should emphasize the importance of research to develop more effective, less toxic, and easier-to-take medications within the National Institutes of Health and other agencies within the Federal government responsible for the testing, licensure, and regulation of such drugs.
- The Administration, in particular the Office of Management and Budget (OMB), should discontinue use of existing budget neutrality rules to evaluate 1115 waiver applications from States to cover low-income individuals in the earlier stages of HIV/AIDS. The Health Care Financing Administration (HCFA) should continue to work proactively with States interested in pursuing such waivers.
- The Administration should implement promptly the Jeffords-Kennedy Work Incentives Improvement Act and use a portion of demonstration funding provided through the Act to expand access to Medicaid for people in the earlier stages of HIV/AIDS.
- The President and other senior Administration officials should continue to speak out against homophobia and other forms of discrimination that can

interfere with access to and quality of health care. The Health Resources and Services Administration (HRSA) should play a proactive role in efforts to educate and train health professionals about discrimination through the AIDS Education and Training Centers and Bureau of Health Professions programs.

- The President and Vice President should use the authority of their offices to push the pharmaceutical industry to minimize the cost of HIV/AIDS treatment, particularly in impoverished regions of the world where substantial price reductions are necessary to ensure access.
- The Administration must work with Congress to reauthorize the Ryan White CARE Act by the end of this session and do everything in its power to ensure that the newly authorized legislation is free of unnecessary and/or harmful testing provisions that interfere with the goal of early care and treatment.
- The Administration must ensure that the Ryan White CARE Act, HOPWA, and other Federal low-income housing programs administered by the U.S. Department of Housing and Urban Development (HUD) recognize and support the critical role of housing in facilitating access and adherence to HIV/AIDS care.
- The Administration should promote “family-centered” care models in which the health care needs of the entire family can be addressed holistically. Cross-agency collaborative planning and funding should be used to more closely integrate services.
- The Administration should develop a five-year plan for increasing funding for substance abuse treatment and mental health service to ensure access to all those in need and parity with other health care services.
- The Administration, in particular the Secretary of Health and Human Services, must identify steps needed to reorganize and revitalize the Substance Abuse and Mental Health Services Administration (SAMHSA) to enable it to provide leadership in the fight against HIV/AIDS and to coordinate its efforts with other Federal agencies.
- The Administration should provide strong political, programmatic, and financial support to the CBC/Minority HIV/AIDS Initiative, including support for increased funding in FY 2001 to ensure adequate funding is available to meet the needs of all racial and ethnic groups disproportionately affected by HIV/AIDS.

- The Administration should continue its strong support for the Surgeon General's effort to eliminate racial and ethnic disparities in health outcomes in six areas, including HIV/AIDS.
- The Administration should implement the recommendations of the pending White House ONAP report on youth, including recommendations designed to ensure the availability of family-centered care, access to age-appropriate medical services, and the coordination of youth-focused HIV/AIDS programs provided through the Department of Health and Human Services. The Administration should also use the release of this report as an opportunity to increase public awareness regarding young people's risk and their unique service needs.
- The Administration should establish a coherent plan for responding to HIV/AIDS among young people, which includes the efforts of the many Federal agencies that administer programs targeting high-risk youth, as well as State and local governments, philanthropies, businesses, and community-based organizations. The plan should articulate clear goals and identify specific strategies to achieve them.
- The Administration should provide increased financial and programmatic support for permanency-planning programs for children globally who have been or are likely to be orphaned by the death of a parent from HIV/AIDS. These efforts should attempt to enhance the capacity of communities to provide care, and minimize use of more costly institutionally based care.
- The Administration should expand the role of community health centers and clinics to meet the needs of underserved populations living with HIV/AIDS.
- The Administration should support current and future efforts to provide meaningful debt relief to developing countries so that they may devote a greater portion of their own resources to fighting HIV/AIDS. In addition to debt relief, other means of expanding financial support should be explored actively, including international loans, grants, and public-private partnerships. These efforts must be carried out in close coordination with other leading industrialized nations, many of which also provide inadequate global HIV/AIDS relief.
- The Administration should work with other global partners to create a plan for the rapid development of health care and other basic infrastructure in developing nations hardest hit by HIV/AIDS.

- The Administration should challenge institutions of higher education to take leadership roles in the prevention and management of HIV/AIDS by requiring health professions schools, residencies, and internships to develop curricula and programs that ensure high-quality HIV/AIDS training.
- The Administration must maintain strong support for the principle of local decision making and control with respect to the planning and delivery of HIV/AIDS care in the U.S. and abroad.
- The Administration should continue to support the development and involvement of community-based leaders, including persons living with HIV/AIDS, as full partners in service planning and delivery.
- The Administration should support the highest possible levels of funding for the CARE Act and HOPWA as the number of persons living with HIV/AIDS in need of these programs continues to grow.
- The Administration should continue its effort to add a prescription drug benefit to the Medicare program and expand efforts within HCFA to monitor and ensure high quality HIV/AIDS care in its programs, including in managed care settings.
- Appropriate agencies within the Department of Health and Human Services should work more closely with the Indian Health Service, and support increased funding for the IHS-funded health care system so that it may provide high-quality HIV/AIDS treatment for Native Americans/Alaska Natives dependent upon it for medical care. The AIDS Drug Assistance Program funded through the Ryan White CARE Act should cover IHS-funded systems.

"The Scriptures say that for everything there is a season. For those of us living with HIV/AIDS, the season for fighting AIDS will continue for the remainder of our lives. But just as the seasons of the year change, bringing new challenges and new perspectives, so too must our "seasons" change in continuing the fight."

B. Thomas Henderson  
Personal Letter to the President  
November 9, 1999