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National Action Agenda Meeting 2/9/94

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THE WHITE HOUSE

WASHINGTON

National Action Agenda
To Stop HIV

INTRODUCTION

The National Action Agenda to Stop the HIV Epidemic has three interactive areas; research, care, and prevention. Within each are critical action steps to be taken by the nation.

In the pages that follow, multiple action steps--an HIV action agenda--are proposed for each of the interactive areas. Each proposed action agendum has been recommended in a report from the National Commission on AIDS and by at least one, often several, community, advocacy organizations.* These agenda ultimately strive to form a framework of national action that is coordinated and focused.

Also proposed with the National Action Agenda are steps to improve collaboration among all HIV activities across the board, to mobilize resources and forces heretofore under exploited, and to deal more forthrightly with the difficult and potentially divisive issues of inclusion, discrimination, and legislative remedy.**

HIV ACTION AGENDA

I. Priority Area One: RESEARCH--Research findings are the foundation for action. The National Action Agenda attempts to drive the nation to resolve questions of cure and prevention, of drugs and behavior, by suggesting action that will better organize the effort and enhance communications among researchers engaged in the effort, between researchers and care givers, and between researchers and the prevention effort.

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* Community, advocacy organizations from which suggestions outlined in the National Action Agenda are drawn include the Black Leadership Commission on AIDS, Inc., the Federal AIDS Agenda '93 Delegates, Funders Concerned About AIDS, and the National Hispanic/Latino AIDS Coalition.

** Further discussion of the specific recommendations made by the National Commission on AIDS and the various community, advocacy organizations can be found in the companion document: "Recommendations Found in Reports from the National Commission on AIDS and Community, Advocacy Organizations."

- Organization, Communication Within Research Community
  - Actively investigate models for innovative research projects that could more quickly facilitate the discovery of a cure or a vaccine
  - Work to speed the full implementation of the new Office of AIDS Research reforms which centralize all AIDS research planning and communications at NIH
  - Form formal linkages between agencies and departments throughout the federal government that are engaged in AIDS-related biomedical or behavioral research or in the dissemination of research findings
  - Work to maintain strong support for HIV/AIDS research in the federal budget
  - Ensure strong community participation in the development of federal research plans and policies
  - Evaluate possible legal, regulatory, and financial obstacles to the development of HIV vaccines

- Development of Drugs
  - Work with HHS to ensure that the deliberations and progress of the Drug Development Task Force (DDTF) are made public in a timely manner
  - Solicit comments from individuals and groups regarding drug develop; offer to assist and serve DDTF
  - Ensure that reforms implicit in the mission of DDTF are vigorously implemented

- Dissemination/Translation
  - Collaborate with affected Federal Departments and Agencies to issue a policy statement that all HIV service and prevention programs receiving federal funds should have evaluation and technical assistance components
  - Encourage organizations that sponsor research and pilot projects to undertake and publish meta-analyses that identify program design and implementation characteristics
  - Encourage that the results the meta-analyses (from above) be published in the non-technical literature
  - Encourage that work (such as in 2 and 3 above) already completed for publication be rewritten for the non-technical literature
  - Develop guidance for local action, particularly in education and prevention, through collaboration between Federal health and education agencies
  - Encourage PHS agencies (most notably, AHCPR, HRSA, and NIH) to coordinate the dissemination of information, to target physicians who practice in communities of color,

and to work with schools and professional associations that train minority health professionals

- Request that Federal Departments, particularly PHS agencies, develop detailed plans to integrate appropriate behavioral and social science research into each component of the treatment and prevention effort
- Encourage PHS to revive its process to determine the information dissemination programs maintained under its auspices and the needs of the American public for HIV data and information
- Collaborate with other government, government-sponsored, and nongovernment database owners to make their information accessible to all via the mechanism developed with PHS described above

II. Priority Area Two: CARE--Action steps within the cure area aspire to better ensure infected people receive necessary care and support; that effective therapies are available, and that the period between infection and disease manifestations is maximized.

- Health Care Reform
  - Incorporate prevention services associated with substance abuse and sexual activity into a comprehensive benefit package with adequate incentives to ensure their delivery
  - Work with the Administration's health care reform entities, other federal agencies responsible for relevant categorical programs, the Congress, and the community to ensure that the health care and supportive services needed by persons with HIV are accessible

- The Ryan White C.A.R.E. Act
  - Assist the HRSA AIDS Advisory Committee to convene its planned public forum to discuss issues regarding the reauthorization of the Ryan White C.A.R.E. Act, and lend the name of the Coordinator to the process, if requested
  - Work with community groups to ensure all issues and voices are represented

- Housing
  - Issue a document that briefly describes the housing needs of HIV-infected people, the federally sponsored housing programs that are available to them, new legislation that explicitly makes housing programs for the disabled open to people with HIV disease, and a short list of relevant principles and assumptions

- Convene a work group with representation from CDC, HRSA, and SAMHSA from PHS and HUD to discuss the concept of housing-based prevention programs
- Convene the newly formed, national coalition on housing and HUD to discuss the litany of issues raised by the National Commission on AIDS and community, advocacy organizations

- Children
  - Link and coordinate community-based, academic, and legislative efforts
  - Coordinate the care for HIV-infected people with relevant "orphan services" (custody, foster care, adoption) and consideration of juvenile justice, education, and institutionalization
  - Identify the major programmatic components of a program to fully address HIV in children and identify a lead Department for each component
  - Encourage the lead Departments and the vital players to develop a plan
  - Facilitate a coordinated review of the complete national effort to prevent HIV transmission among women so as to describe an effective program

- Testing
  - Issue a policy statement regarding testing for HIV infection that addresses confidential and anonymous testing, pretest and post test counseling

- Health Care Worker Guidelines
  - Ask the Assistant Secretary for Health if the Public Health Service is still comfortable with its published guidelines

III. Priority Area Three: PREVENTION--The prevention agenda seeks to better focus efforts to interrupt transmission of the virus by improving the educational effort, widening efforts to reduce the risky behaviors associated with transmission, and by increasing the application of the science base in planning and program implementation.

- Prevention Marketing
  - Ensure that clear, explicit messages are consistently incorporated into all current and future prevention activities

- Work with CDC and other federal government components to ensure that HIV prevention activities are integrated into other federal government activities
- Work with State and local governments, non-governmental organizations, private businesses and communities in general to encourage them to join in prevention marketing initiative effort to reach individuals at risk

- Drug Abuse

  - Form a discussion group to articulate current policy and begin, from the HIV perspective, to develop government-wide policy toward substance abuse and to define agency responsibilities
  - Initiate discussion of "harm reduction"--currently used as an underpinning for needle exchange strategies--as an umbrella or unifying strategy to reduce transmission of the virus

- General "Wellness"

  - Encourage and facilitate joint activity between CDC and the Department of Education (DOE) to explore the issue of a comprehensive health curriculum that includes HIV prevention, discussions of sexuality and the teaching of general prevention skills
  - Facilitate CDC, HRSA, SAMHSA, and HUD collaboration to implement HIV prevention activities among public housing residents and recipients of housing support
  - Document collaboration between NIH and those involved in substance abuse prevention and treatment activities and between NIH and those who provide services to HIV infected people
  - Assist CDC to enhance or create linkages that will be required as a result of its external review process
  - Review the CDC external review findings with the objective of applying those findings to other activities and to other Departments and agencies
  - Form interdisciplinary teams or discussion groups to explore opportunities in the broad areas of wellness and the translation of behavioral and social science research findings into program
  - Use these teams, or some portion of them, as the nucleus for planning teams for specific or general projects

- Materials

  - Develop a government-wide policy statement on the content of materials, consistent with the new CDC conditions announce the Federal Register and consistent

with the stipulations expressed in the "Federal AIDS Agenda"*

IV. CROSS CUTTING ISSUES

- Buy in and Collaboration
  - Articulate a national policy with following provisions:
    a. All HIV-related advisory boards and commissions must include HIV-infected people and must reflect the ethnicity, gender, geography, and risk factor profiles of the impacted populations
    b. Community-based recipients of Federal funds for HIV activity must have staff and boards reflective of the clientele they serve
    c. HIV program design, development, implementation, and evaluation must include HIV-infected people and participants must be reflective of the ethnicity, gender, geography, and risk factor profiles of the populations targeted
  - Open discussions with Philanthropy and others in the private sector about joint projects
  - Continuously offer White House speech writers, as well as speech writers in the various Federal Departments, suggested text regarding the epidemic for inclusion in public talks
  - When events relevant to the responsibilities of a specific Department are anticipated or unfold, text for public or professional announcement should be provided to affected officials
  - Develop a structure for ensuring broad community involvement and communications from the community to the Coordinator are facilitated and unimpeded
- Legislation
  - Review various suggestions to determine if there are legislative efforts the Administration may wish to champion
  - Pros and cons for each potential initiative should be documented, and, when appropriate, affected Departments should be asked to prepare an initiative
- Discrimination

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* Federal AIDS Agenda '93 Delegates. Federal AIDS Agenda '93. May 1993.

- Encourage the Justice Department to state its commitment to enforce and vigorously investigate violations of the Americans with Disabilities Act
- Encourage the civil rights divisions of the various Departments to state their commitment to enforce and investigate civil rights complaints and to routinely issue press releases whenever they have taken action or caused action (legal or programmatic) to be taken to improve conformance with the Americans with Disabilities Act, other law, or policy that restricts or forbids discrimination against HIV infected people
- Encourage the Small Business Administration to designate a person (or component) within its structure to review existing policy regarding HIV
- Convene representatives from the National AIDS Clearinghouse, community, advocacy organizations, and others (e.g., the legal profession and drug manufactures) to discuss the needs, review what is currently available, and develop mechanisms to increase the availability of existing materials to assist HIV infected people to recognize and avoid fraud

CONCLUSION

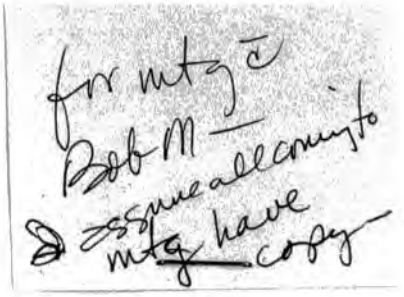
As this American tragedy continues, the death toll exceeds a quarter of a million people. More than 40,000 new infections occur annually, and from the pool of an estimated one million Americans already infected, 50,000 to 60,000 develop the devastating manifestations of HIV disease--AIDS--each year. And the epidemic continues to expand and evolve, touching ever more communities and populations; destroying, killing, and ravaging the lives of individuals and families. To respond, the nation must be nimble. It must address the current realities, the emerging issues, and it must anticipate tomorrow.

With the counsel of involved and concerned individuals and groups across the nation, the National AIDS Policy Coordinator will work with the Presidential HIV/AIDS Advisory Council to set the immediate priorities and to continuously review the status of the epidemic and the national response to it. As the epidemic evolves, the National Agenda will change. Priorities within the National Agenda will be rearranged, action items will be dropped, new opportunities will be pursued.

With the aid of community, religious, business, and political leaders, the goal--to stop HIV--can be achieved. As the President said, when he charged Kristine Gebbie to provide the leadership to stop this epidemic, "AIDS is terrifying. It inflicts tragedy on too many families. But ultimately, it is a disease; one we can defeat...with commitment and courage and

constancy, and with vocal and responsible leadership from our nation's government."*

* Clinton, WJ. Remarks by the President in Announcement of Kristine M. Gebbie as AIDS Policy Coordinator. June 25, 1993.



Attachment Three

National Action Agenda
To Stop HIV

SUGGESTIONS FOR REVISION

The National Action Agenda to Stop the HIV Epidemic has three interactive areas; research, care, and prevention. Within each area are critical action steps to be taken by the nation, including the private sector and government at all levels.

- Research findings are the foundation for action. The National Action attempts to drive the nation to resolve questions of cure and prevention, of drugs and behavior, by suggesting steps to enhance the organization of the effort and to improve communications among researchers engaged in the effort, between researchers and care givers, and between researchers and the prevention effort.
- Action steps within the ~~cure~~ Care area aspire to better ensure infected people receive necessary care and support; that effective therapies are available, and that the period between infection and disease manifestation is maximized.
- The prevention agenda seeks to better focus efforts to interrupt transmission of the virus by improving the educational effort, widening efforts to reduce the risky behaviors associated with transmission, and by increasing the application of the science base in planning and program implementation.

In the pages that follow, multiple action steps--an HIV action agenda--are proposed and described for each of the interactive areas. Each proposed action agendum has been recommended in a report from the National Commission on AIDS and by at least one, often several, community, advocacy organization.* These agenda ultimately strives to form a framework for national action that is coordinated and focused.

Also proposed with the National Action Agenda are steps to improve collaboration among all HIV activities across the board, to mobilize resources and forces heretofore under exploited, and to deal more forthrightly with the difficult and potentially divisive issues of inclusion, discrimination, and legislative remedy.

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* Clinton, WJ. Remarks by the President in Announcement of Kristine M. Gebbie as AIDS Policy Coordinator. June 25, 1993.

Meeting 2/9 @ 8:00 a.

NOTE TO KRISTINE M. GEBBIE

SUBJECT: Text for the Introduction to the National Action Agenda

Per your instruction I have transcribed (attachment 1) the handwritten text you supplied (attachment 2) to replace the transmittal memorandum from me to you. The are two places where I need clarification or guidance. These are noted with shaded text in attachment one.

Based on the concepts in your handwritten text, I am providing you with alternative text (attachment 2) for your consideration. This suggestion for revision endeavors to (a) keep faith with the message in the handwritten text, (b) maintain consistency with the style of the main document, and (c) focus on the document's content and your plans for its use.

Robert D. Moran
Planning Officer

Attachments (2)

CC: Dr. Barrer
Dr. Lawrence

National HIV Action Agenda

TRANSCRIBED TEXT

The National Action Agenda to stop HIV infection has three interactive areas, research, care, and prevention. For each area there are critical steps to be taken by the Federal Government, by state and local governments, and by those in the private sector.

Research is the foundation of action as it has been. It is essential that a well-organized research effort aggressively drive toward the answer to questions of cure and prevention, of drugs and behavior.

While that research continues, we must assure that any individual infected with HIV is receiving appropriate care and support, allowing for a maximum period of symptom-free activity, and assuring that available, effective therapies are made available.

It is also essential that we prevent further spread of this epidemic using all available outreach mechanisms. We have the tools. We need to stop the spread of HIV. With more effort we will be more successful in our goal.

On the following pages actions in each policy area are identified.* These will form the framework for national action. With the advice of the Presidential Advisory Council, the National AIDS Policy Coordinator will keep us moving.

Mobilization and Ownership

No action taken within the three areas can be effective without the full mobilization energy, based on a national acknowledgment of HIV, the toll it is taking, and the [sentence breaks off here; no further text.]

The Board and the National AIDS Policy Coordinator will direct personal efforts to enlisting the community, religious, business, political leadership in the effort. [I am directed at this point to quote from the state of union address on community. Community reference in the state of the address is specific. I cannot find a quote that fits.]

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* They are actions which have been identified by a wide range of groups, including the Black Leadership Commission on AIDS, Inc., the Federal AIDS Agenda '93 Delegates, Funders Concerned About AIDS, the National Commission on AIDS, and the National Hispanic/Latino AIDS Coalition.

Attachment Two

The national ~~policy on AIDS~~ action agenda to stop HIV infection has 3 (interactive areas) ~~major areas~~ parts:

~~1) a vigorous strong Research agenda~~

2) research, services CARE and prevention.

For each area, there are critical ~~action~~ steps to be taken ~~some~~ by the federal government ~~and~~ by state & local governments, communities, and by those in the private sector.

Research is the ~~building~~ foundation of action as it has been. ~~We must find a way to "curing" the disease will require drugs to stop.~~ ~~The nation~~ It is essential that a well-organized research effort aggressively drive toward the answers to ~~the~~ questions ~~of~~ of cure and prevention, of drugs and behavior, which will ~~allow us~~

While that research continues, we must assure that any individual ~~infected~~ (infected) diagnosed with HIV is receiving appropriate care & support, ~~throughout. With the the length of symptom free life as~~ allowing for ~~optimum~~ a maximum period of symptom free

$ 317 million overall
140 million in title I fy 93 to fy 94 title
115 to 230 title X

activity, and assuring that all available, effective therapies are made available.

It is also essential that we prevent further spread of the epidemic, ~~communities must collaborate so that they~~ using all available outreach mechanisms.

539
348
234

On the following pages ~~within the~~ sections in each policy area ~~that~~ are identified,* These will form the framework for national action. ~~In the coming months,~~ with the advice of the President's Advisory Council, the NAPC will ~~focus the attention~~ keep us moving.

We have the tools we need to stop the spread of HIV. With more effort we will be more successful

* They are actions which have been identified by a wide range of groups, including

~~Attitude across all areas the~~

~~Aside~~

Mobilization and Ownership

No actions taken within the 3 areas can be effective without the full mobilization ~~of nation~~ energy, based on a national acknowledgment of ~~the~~ HIV, the toll it is taking and the

The Bd & the NAPC will direct personal ~~attention~~ efforts to enlisting the community, religion~~s~~, business political leadership in the effort, quotes from state of the Union on community ...