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Subseries: National AIDS Strategy

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Advisory Council Comments - Fall 1996

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Debbie Runions
Schatz letter [Kathy Genus, Tom Henderson, Ron Johnson]
Mike Isbell
Ed Gould
Mike Rankin

8

Mike Isbell

FIRST IN THE FIGHT AGAINST AIDS
GMHC

FAX MEMORANDUM

to: Ms. Patsy Fleming
fax #: (202) 632-1096
re: National AIDS Strategy (Draft)
date: September 25, 1996
pages: 6, including cover sheet.

Jane – Some excellent comments. (I checked the ones I like.)

From the desk of...

Michael T. Isbell
Associate Executive Director
Gay Men's Health Crisis
129 West 20th Street
New York, NY 10011

(212) 337-3351
Fax: (212) 337-1220

MEMORANDUM

To: Members, Prevention Subcommittee
Presidential Advisory Council on HIV/AIDS

From: Mike Isbell

cc: S. Hitt
A. Levine
E. Gould
P. Fleming
J. Levi

Re: [Draft] National AIDS Strategy

Date: September 23, 1996

I'm circulating my preliminary thoughts on the Draft National AIDS Strategy in advance of the Prevention Subcommittee's upcoming conference call. Most of my comments focus on the prevention components, but I've also taken a look at other sections of the Strategy and have included my thoughts on them, as well.

Message from the National AIDS Policy Director

* The introduction should make clearer precisely what the Strategy is and what it isn't. This was, of course, a topic of extensive discussion at our September meeting. Even after all of that discussion, though, I must admit that I'm still a little unclear about what the document is intended to be. When I see the title "National AIDS Strategy," I assume that this represents the federal plan for responding to the epidemic. If that's not what's intended, that should be made plain in the introduction.

* Although the introductory session ends with visionary statements about bringing an end to the epidemic, I'd begin with this idea. Thus, while I'd certainly emphasize the goal of bringing "focus and direction" to the federal AIDS effort, I'd note in the first paragraph that the purpose of everything the federal government is doing is to the speed the day when AIDS will be a thing of the past. A more hard-hitting introduction might help mitigate the inevitable response at the community level to some of the more bureaucratic language within the document.

* The prevention goal (i.e., the second bullet) on page 3 is actually more timid than it need be. The President himself has established the goal of reducing new infections each year, until there are no new infections. On page 11 of the draft, the document refers to "the national goal of no new infections." If that's our goal, we ought to say it up front.

* In fact, I think all of the goals should be sharpened somewhat to indicate the administration's sense of urgency in responding to the epidemic. For example, I'd reframe the third bullet to focus on the goal of ensuring that "*every* person with HIV has meaningful access to the affordable, high-quality services which he or she needs." While it may be unlikely that this goal can ever be achieved, I would assume we all agree that that is our actual objective.

* Although it's unlikely that the administration will incorporate this idea into the national strategy, I believe the Council should go on record urging better coordination of federal AIDS efforts. While the Office of National AIDS Policy plays an important coordinating and consensus-building role within the executive branch, it should be invested with greater authority to ensure accoutability among the federal agencies whose job it will be to effectuate the national strategy.

I. Introduction

* The Introduction states that "AIDS is a costly disease." That's true, of course, and the cost is probably increasing with the advent of new therapies. Moreover, the point is important for the document, since any national strategy statement must justify substantial federal outlays for AIDS prevention, treatment and research.

The document, however, fails to provide additional information to enable the reader to place AIDS-related costs in their proper context. First, while AIDS is expensive, it is not *inordinately* expensive in comparison with other chronic diseases. Second, many of the federal programs mentioned in the document are extremely cost-effective because they help *reduce* HIV-related medical costs. HOPWA, for example, funds a continuum of housing programs that provide far less costly alternatives to institutionalization. Similarly, by reducing the epidemic's long-term burden, HIV prevention services represent an immediate and future economic savings for the country. (In other words, AIDS isn't an endless drain on public resources; rather, the federal government has developed excellent strategies for reducing the epidemic's economic impact.)

I'm not sure that these points belong in the Introduction, which currently has a singleminded focus on AIDS/HIV epidemiology. Somewhere, though, the document should make these points, which might help combat the growing sentiment that "AIDS gets more than its fair share."

II. Overview of Federal Efforts

A. Prevention

* Under "Future Opportunities for Progress," the document should set forth the goal of enhanced coordination of federal HIV prevention efforts, in order to ensure that prevention programs are grounded in behavioral and ethnographic research and based on the latest epidemiologic data. Currently, there is insufficient coordination between the various federal agencies performing prevention science research; similarly, there has historically been inadequate coordination between prevention programs and epidemiology.

* Under "Future Opportunities for Progress," I would reformulate the first bullet as follows: "Improving understanding of trends in HIV transmission, seroprevalence and risk behaviors." (Better understanding of risk behaviors is briefly addressed in the text on page 12 but is ignored in the objective.)

* Our "Future Opportunities for Progress" also depend on addressing policy barriers that impede effective HIV prevention, including the failure to formally remove longstanding restrictions on the content of federally-funded HIV prevention materials, the federal ban on funding for needle exchange programs, State needle prescription laws, and the timidity of State and local education officials to ensure appropriate HIV education for at-risk youth. While the federal government lacks actual control over some of these issues, the need for federal leadership is clear.

* The document does not address the role of counseling and testing in HIV prevention, which is curious, given its historic prominence at the CDC. While I believe the Council should reject the simplistic (and inaccurate) notion that testing itself should be the centerpiece of our prevention efforts, it is equally clear that the nation's laissez faire approach to testing effectively squanders countless opportunities to intervene with effective HIV prevention services.

Research on Effective Prevention Strategies

The document's emphasis on prevention research is greatly appreciated. I'd flesh it out, though, in the following ways:

* In addition to behavioral research, I would at least mention the need for enhanced support for ethnographic and qualitative research on community cultures, social networks, etc.

* Given the potentially important impact on prevention of viral load, genetic mutations and drug resistance, some mention should be made of the need to link prevention science with the ongoing basic science research agenda.

* The emphasis on evaluation is great. My experience of evaluation components included in most government prevention contracts, however, is that they don't wind.up telling us very much. If we truly want to emphasize evaluation, the government is going to have to pay for it. Thus, I'd move beyond the goal of merely including evaluation components in HIV prevention contracts to a recognition of the need to greatly enhance government support for program evaluation, with particular emphasis on replicable, cutting-edge community-based interventions.

* While I agree with the document's support for the community planning process, I'd like to see a commitment to a comprehensive evaluation of the impact of community planning on HIV prevention services. Based on my experience in New York, I remain deeply skeptical that the community planning process is having the impact envisioned by its original proponents.

Program Integration and Collaboration

* The section on substance abuse places undue emphasis on the intersection of HIV prevention with the nation's drug abuse control efforts. Completely missing is the need to greatly enhance programs for out-of-treatment drug users. In New York and elsewhere, community-based organizations have experienced remarkable success with peer-based programs targeting drug users. The document should call for greater support for these and other programs.

* Better coordination is needed at the federal level among the multiple agencies that address substance use and/or HIV.

* I would imagine that the sentence about needle exchange on page 14 was hard to come by, and I'm certain that Patsy and Jeff deserve praise and thanks for getting even this much into the document. The Council, though, should go on record urging the administration to lift federal restrictions on funding for needle exchange, on the basis of the overwhelming (and growing) body of data demonstrating the effectiveness of needle exchange.

Targeting Vulnerable Populations

* I applaud the inclusion of this objective in the document. In my opinion, however, there is insufficient accountability at the CDC to ensure that sufficient funding is targeted at the populations in greatest need. Some plan to require CDC to account for funding allocation is called for.

Research

* The document appropriately recognizes the need for federal "leadership and coordination" on AIDS research. I'd also add the need for *strategic planning*, since this is the essence of the NIH reforms that led to the Office of AIDS Research (as well as the philosophy of the Levine Commission Report).

Translation of Research Advances Into Practice

* The document repeatedly emphasizes the government's success in speeding the development and approval of new drugs. Little mention, however, is made of the need to perform followup studies to give providers and consumers the information they require to make informed treatment decisions. On its own, industry clearly isn't going to take on this task. Federal leadership is essential. As I understand it, the primary purpose of the Keystone process is to develop strategies for performing critical standard-of-care studies. Given how important federal leadership will be to the success of this effort, I would place emphasis on this item in the national strategy.

Already in the research section.

* The document appropriately stresses the need for provider education, but it fails to note the overwhelming need for consumer education programs. At GMHC, our experience suggests that the doctor's office is not always the best place for consumers to get the information they need or desire. In light of the potential public health consequences of widespread drug resistance, the country should invest in programs that provide consumers with the information they need (a) to make treatment decisions and (b) to comply with their medical regimens.

* Whenever the issue of provider education is mentioned, the universal default mode seems to be clinical practice guidelines. In the case of HIV disease, however, given the rapid changes in therapeutic and diagnostic approaches, I'm dubious of the meaningfulness of clinical care guidelines. The consensus process for government-sponsored guidelines is so arduous that the guidelines are obsolete as soon as they're published. While clinical guidelines probably have some role in provider education, I think there are numerous other strategies that could be as useful, such as comprehensive professional and public education campaigns. (With regard to people currently in care, the most pressing public policy challenge is probably not how to optimize use of triple-drug combination therapy, but to ensure that patients receive first-generation treatments such as PCP prophylaxis.)

To: The Prevention Sub-Committee
& Patsy, Jeff and Jane at ONAP
Terje Anderson
Judith Billings
Bob Fogel
Kathy Gerus
Mike Isbell
Scott Hitt
Jeremy Landau
Altagracia Perez
Alexander Robinson
Ben Shatz
Denise Stokes

RE: The National AIDS Strategy Report
Date: Oct. 3, 1996
Pages: 2 including this one

Dear Y'all:

This is my attempt to address the absence of any mention of HIV/AIDS prevention in schools. I think that the educational element should be mentioned somewhere in the "Record of Accomplishment." My suggestion is just that. The second portion I think belongs under Future Opportunities for Progress—Program Integration and Collaboration

Jeremy, Terje, Ben, Mike, Alexander you know how to do this stuff. Please look at it and tell me what language to use to strengthen it. I haven't been at this as long as you all have. And Judith, this is your expertise. I'd welcome your insights. (By the way you look fabulous in POZ!) I've got additional information here if any of you have questions.

I also think that in our move to bring Prevention to equal footing with Services and Research that we might be thinking of a recommendation in December to make funding the Comprehensive School Health Education Program in all states a priority. The cost is rather small in comparison to other programs.

Talk with you all on Monday.

2600 Hillsboro Pike #11-1 Nashville, TN 37212 (615) 298-5069 or 226-4764

Insert on Pg. 11 just after the one line sentence fragment ending the paragraph begun at the bottom of page 10.

"Adolescents and youth are one of America's most under served populations in terms of access to health care services and health education. The Division of Adolescent and School Health (DASH), a program of the Centers for Disease Control and Prevention, addresses the prevention of priority health risks (including HIV/AIDS) among adolescents and youth.

DASH provides support to national, state and local agencies and organizations with the capacity to help address adolescent health. CDC provides fiscal support and technical assistance to the education agencies in every state, six territories, Washington, DC, and 18 large cities to help schools implement effective health education to prevent the spread of HIV.

Insert on Pg. 13 after the introductory paragraph under the heading ***Program Integration and Collaboration.***

Prevention Education. The Center for Disease Control and Prevention's Guidelines for Effective School Health Programs to Prevent the Spread of AIDS state the Nation's public and private schools have the capacity and responsibility to help assure that young people understand the nature of the HIV epidemic and the specific actions they can take to prevent HIV infection.

In addition, the guidelines recommend that "Education about AIDS may be most appropriate and effective when carried out within a more comprehensive school health education program that establishes a foundation for understand the relationships between personal behavior and health."

CDC's Division of Adolescent and School Health (DASH) currently supports Comprehensive School Health Programs in thirteen states. The model uses an eight component program that is a planned, sequential, Kindergarten through grade 12 approach that integrates important categorical topics such as HIV, STDs, unintended pregnancy, alcohol, drugs, tobacco and intentional and unintentional injury.

Comprehensive School Health Education is one of the more efficient means of preventing risk behaviors. These activities have been accomplished by funding infrastructure at the state level in departments of health and education. It must be expanded into every state in the nation.

(The cost would be $25 million each year to expand the CSHE to all 50 states.)

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: G 3411

Date Rcvd: 10-17-96

From: Benjamin Schatz, JD, Chair
Gay and Lesbian Medical Association

Staff Action:

Reviewed By Jeff: _____ **Reviewed By: Patsy** ✓

Assigned To: ① ~~Copy for Jane~~ ② PF

RCVD: _____ **DONE:** _____

Recommendations/Instructions:

Jane - see starred sections

To Support Staff: _____

Date of Response: _____

n:\corresli

GLMA

Gay and Lesbian Medical Association

211 Church St., Suite C ▾ San Francisco, CA 94114
Ph: 415-255-4547 ▾ Fax: 415-255-4784 ▾ Email: gaylesmed@aol.com
Founded in 1981 as the American Association of Physicians for Human Rights

October 8, 1996

Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, Suite 1060
Washington, DC 20500

Dear Patsy,

As members of the Discrimination Committee of the Presidential Advisory Council on HIV/AIDS, we are writing to offer some feedback concerning the civil rights section of the draft National AIDS Strategy. We offer suggestions about both the text and appendices.

We are pleased by the strong anti-discrimination language in the draft and by the impressive list of accomplishments enumerated. We are concerned, however, that the focus of the section may be unduly narrow. Thus, in addition to addressing such issues as employment discrimination and discrimination in access to health care facilities, we would urge that the Strategy emphasize combating discrimination in education, housing, service establishments, and other areas covered by federal law.

In addition, we would urge that the Strategy promote a broader and more proactive federal approach to combating HIV-related discrimination. For example, the draft section on "providing leadership" should emphasize devoting agency resources to proactive initiatives designed to aggressively address systemic problems of discrimination — e.g. refusal by dentists, physicians, and other health care workers to provide care for patients with HIV — in addition to the bully pulpit role described.

We believe another "future opportunity for progress" would be to provide leadership in advocating reasonable legal/policy approaches on discrimination issues not specifically addressed by federal law. As one possible example, the Justice Department, or the HHS Office of Civil Rights, might issue advisory opinions on such issues as HIV discrimination in the contexts of family law (e.g. denials of child custody and visitation privileges) or criminal law (e.g. charging HIV+ people who spit with attempted murder). Reasoned advisory opinions on such matters by the DOJ or HHS OCR, while not legally binding, could prove to be extremely helpful to courts that are grappling with these issues.

We would also advocate a significant expansion of the "Appendices" section of the Strategy. Several Departments and agencies which are (or should be) addressing issues of HIV discrimination — HHS, HUD, the State Department, the Department of Education, DOD, the VA, the Peace Corps, and others — have not included an entry in the civil rights section. The paucity of reports in the civil rights section, and especially the failure of HHS to include a report, may create the unfortunate impression that HIV discrimination issues are not taken seriously by all relevant agencies.

made note OCR/HHS

We are grateful to have the opportunity to share our concerns with you, and for the enormous amount of work you and your staff have done to put together this groundbreaking document. Thank you for all of your hard work. If we can be of further assistance, please do not hesitate to contact us.

Sincerely,

Benjamin Schatz, JD, Chair
Kathy Gerus
Tom Henderson
Ronald Johnson

October 9, 1996

To: Jeff Levi
National Office of Aids Policy

From: Ed Gould

Re: Services Sub-Committee Comments on
National Aids Strategy Draft

Please excuse the "cryptic" nature of these notes. In the interest of getting this to you quickly, I decided not to worry about being "artful" in my presentation.

Our committee met by telephone last week. Those who had specific comments agreed to put them in writing to me. Given that I have only received a note from Mike Rankin, I am writing this memo based on my thoughts. I will also attempt to "capture" of others although these will be my words not those of the committee. To the extent that these are not complete, I tried. Mike Rankin's letter of two pages follows this memo.

In the introduction by Patsy Fleming, the group would ask for a stronger introduction providing that in bullet 2 in column 1 the rate of new infections reach zero, in the third bullet reflecting a goal that "all" people have access, in the last bullet rather than better we have enhanced care, that a goal of taking HIV out of the political arena be sought and lastly that HIV is a "public health" crisis affecting everyone.

On page 8 where the discussion of cost is found, the group felt a need to reference that AIDS is far from the only "costly" disease and many persons receive substantial support for those illnesses from Federal and State Government.

On page 12, behavioral research, the group is encouraged by the statement and would actually suggest the lack of this research be presented even stronger as a barrier to HIV prevention.

On page 13, the group would recommend a stronger statement that the research and public health data suggests in the absense of treatment for substance abuse on demand, or at least funded much more adequately, "needle exchange" should become a part of the Strategy.

I am not sure where the following comment fits as its seems fairly global - that is as we continue to see improvements in drugs and knowledge about treatment, the time between the development of the information and its dissemination needs to be shortened.

p24. The second full bullet in column 1 should we be thinking about the implications of people who have previously been disabled because of HIV that now feel well enough to at least begin to work again, they not be faced with having to "remain disabled" in order to continue to receive treatment and care.

p25. the emphasis on the difficulty in coordination of some many different programs that help people with HIV/AIDS should have even more emphasis and a way needs to be found to do a better job with that effort.

p.25 We need to find away to help people understand the importance of integrating HOWPA into the broader system of care and treatment for people with HIV if HOWPA is to be fully effective in its purpose.

p. 25 the paragraph at the very end of the second column the thought was that the guidelines need to be broad and flexible given the rate of change being experienced. This is illustrated by the fact that so many HIV patients often know more than their MD. Further, the uneven knowledge often leads to less than "state of the art" care in many parts of the country.

p. 28. We would broaden the "bully pulpit" to include many more people in the Administration than the President.

VA MENTAL HEALTH CENTER
427 13th St.
Oakland, CA 94612
October 3, 1996

Mr. Ed Gould
16655 Calneva Drive
Encino, CA
91436

Dear Ed,

As promised, these are my comments on the VA section of the document.

In a number of VA centers, care for veterans living with HIV/AIDS is excellent. But all too often this is so because there are committed physicians and other clinicians who have chosen to make it so--not because of any clear mandate from DVA Central Office.

In the past, the VA has offered excellent training programs for its clinicians. I don't believe these have been held in several years. This may be because of budget constraints, but that only tells me HIV/AIDS doesn't have a sufficiently strong advocate in the Department. They still provide training for other disorders--they should for AIDS as well.

So this is what I'd like the document to say, vis a vis the DVA:

1. There should be a statement from Secretary Brown to all DVA VISN Directors, Regional Directors, and Chiefs of Staff of medical centers, that he personally considers outreach to, and treatment of veterans living with HIV/AIDS to be a top priority.

To that end, medical centers and clinics, whenever possible, should identify

2. To that end, medical centers and clinics, whenever possible, should identify clinicians with special expertise in the treatment of HIV/AIDS. Those clinicians should be supported in establishing AIDS clinics and prevention programs.

3. The DVA should provide training conferences for physicians, nurses, and other clinicians, on a regular basis. Those attending these conferences should be expected to return to their various centers with skills and knowledge they can transmit to their colleagues.

4. The DVA should direct those in the field to have regular contact with veterans organizations, public and private hospitals and clinics, and with community HIV/AIDS organizations, with the goal of identifying veterans living with the virus, and bringing them into VA treatment centers if they so desire.

These are the main issues I'd like to see covered, Ed. If I think of others, I'll let you know. There are some absolutely first rate clinicians in the VA, offering the best possible care to vets with HIV--but we have to make sure that's the case in every VA hospital and clinic. And that will take leadership from the top. I hope our Council can help make that happen.

Sincerely,

Mike

Robert M. Rankin, M.D.
Chief, MHC, Oakland VAOPC

To: The Prevention Sub-Committee
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Terje Anderson
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(The cost would be $25 million each year to expand the CSHE to all 50 states.)

Patsy. Here's the crosswalk.
Any comments on the agenda? Jane

Crosswalk between PACHA Comments on National AIDS Strategy and Incoporated Text

PACHA Comments on National AIDS Strategy	*NAS Text Changes*
Message from the National AIDS Policy Director. Need stronger introduction. Define the strategy. Begin with Ms. Fleming's ending statements on ending the epidemic.	Changed order, added text about the strategy, and added letter from President. (p.2, pp. 5-6).
Introduction. Sharpen all goals to indicate the Administration's sense of urgency.	Goals were changed to: The President has identified the following national goals to guide our efforts to end the epidemic of HIV and AIDS: ■ **To develop more effective treatments, a preventive vaccine to protect the uninfected, and a cure for those currently infected through strong, continuing support for HIV-related research;** ■ **To reduce the number of new HIV infections in adults and children in the U.S. until the rate of new infections reaches zero by providing strong, continuing support for effective HIV prevention efforts;** ■ **To ensure that all people living with HIV have access to services, from health care to housing and supportive services, that are affordable, of high quality, and responsive to their needs;** ■ **To ensure that all people living with HIV are not subject to discrimination;** ■ **To provide strong, continuing support for international efforts to address the HIV epidemic; and,** ■ **To ensure that research advances are translated into improved HIV prevention programs and enhanced care for HIV- positive persons.** (p.7)

Make prevention goal stronger to reflect President's quote in beginning of prevention section.	The goal was changed to match the President's quote: ■ **To reduce the number of new HIV infections in adults and children in the U.S. until the rate of new infections reaches zero by providing strong, continuing support for effective HIV prevention efforts.** (p. 7)
There should be quality care for all in the goals.	The goal was changed: ■ **To ensure that all people living with HIV have access to services, from health care to housing and supportive services, that are affordable, of high quality, and responsive to their needs.** (p.7)
A goal should be added emphasizing that HIV should be taken out of the political arena and viewed as a public health crisis affecting everyone.	The six goals match the 6 sections of the text and appendices. The importance of viewing HIV/AIDS as an international public health crisis is addressed in the President's letter (p. 2), and the Introduction (pp. 7-9).
Introduction states that AIDS is a costly disease... [but] AIDS is not inordinately expensive. Many federal programs mentioned in the document are extremely cost-effective because they help reduce HIV-related medical costs. HOPWA funds a continuum of housing programs that provide far less costly alternatives to institutionalization. Similarly, by reducing the epidemic's long-term burden, HIV prevention services represent an immediate and future economic savings for the country. AIDS isn't an endless drain on public resources; rather the federal government has developed excellent strategies for reducing the epidemic's impact. The document should make these points to combat the growing sentiment that "AIDS gets more than its fair share."	Text was modified to emphasize the cost of care and the role of Federal programs in reducing the economic impact: The average lifetime cost of medical care after an HIV diagnosis is $119,000. People living with HIV are often dependent on the public sector for their health care, particularly in the later stages of HIV disease. More than 50 percent of people living with AIDS are enrolled in Medicaid, including more than 90 percent of children with AIDS. In FY 1996, the Federal government spent an estimated $1.8 billion on Medicaid benefits for people living with HIV and AIDS and another $690 million on Medicare benefits. Social Security benefits for people disabled by HIV/AIDS totaled nearly $980 million in FY 1996. Many Federal programs such as Housing Opportunities for Persons with AIDS (HOPWA) and CDC's prevention efforts contribute to reducing the short- and long-term economic costs of the epidemic. (p. 9)

Prevention. Adolescents and youth are one of America's most underserved populations in terms of access to health care services and health education. The Division of Adolescent and School Health (DASH), a program of the Centers for Disease Control and Prevention, addresses the prevention of priority health risks (including HIV/AIDS) among adolescents and youth.	Language on schools was added: Federal efforts have shown that HIV prevention programs can b. effective. CDC's prevention projects, many in partnership with states, loc.l governments, schools, and community-based organizations, have demonstrated that prevention programs are most effective when designed and implemented in partnership with communities to which they are targeted. (p.12) The following section on prevention education was also added: ***Prevention Education.*** Collaboration with communities and sc! ›ols is a critical factor in communicating HIV prevention messages to our youth. The Centers for Disease Control and Prevention's *Guidelines for Effective Schoo! Health Programs to Prevent the Spread of AIDS* helps assure that young people u.derstand the nature of HIV transmission and the specific actions they can tak· to prevent HIV infection. Support for these programs should and will continue. (p.14)
Document does not address counseling and testing. ... while testing should not be centerpiece of our prevention efforts, it is equally clear that the nation's laissez faire approach to testing effectively squanders countless opportunities to intervene with effective HIV prevention services.	Counseling and testing are addressed in the following text: New and promising medical interventions make it critical to im› ›ove our approach to HIV counseling and testing -- creating a critical bridge betwe n prevention and primary care. CDC is committed to improving the follow-up se.vices for those counseled and tested at publicly-funded sites including the quali›y of referral to services for those who test HIV-positive. (p. 15) Primary care providers must learn to incorporate a person's sex.al and drug-using history when a medical history is taken, offering HIV-related c› ›nseling and voluntary testing, and providing prevention education to HIV-p› sitive individuals as part of the provider-patient relationship. (p. 15)

Add goal of enhanced coordination of federal efforts in order to ensure that prevention programs are grounded in behavioral and enthnographic research and based on the latest epidemiologic data. Currently there is insufficient coordination.	Basing prevention interventions on research is addressed in the following text: Effective interventions must be based on sound research findings and evaluations. In response to the recommendations from the Report of the NIH AIDS Research Program Evaluation Task Force, NIH is developing a comprehensive HIV prevention science agenda. NIH and CDC are committed to increasing future support for basic research on behavior, interventions, social marketing, and program evaluation. (p. 13) Improving program coordination and integrating prevention is addressed in the following text: ***Improving Program Coordination.*** Integrating HIV-related services is an important step in assisting communities to build seamless systems of support for the most vulnerable persons in our communities. Organizations receiving Federal funding to provide AIDS-related care often require support from several Federal Agencies. For example, creating a comprehensive community-based program that integrates primary care, substance abuse treatment and prevention, sexually transmitted disease screening, Tb prevention and treatment, HIV prevention, access to clinical trials, and housing assistance requires separate applications to SAMHSA, HRSA, CDC, NIH, and HUD. (p. 25)
Change this bullet to read "Improving understanding of trends in HIV transmission, seroprevalence, and risk behaviors."	The text was changed to read: • Improving understanding of trends in HIV transmission, seroprevalence, and risk behaviors. (p. 12)

Make a statement that would actually suggest the lack of this research be presented even stronger as a barrier to HIV prevention.	One of the major goals for HIV prevention states: • Improving scientific knowledge about effective prevention models and strategies. (p. 12) Text states: Effective interventions must be based on sound research findings and evaluations. In response to the recommendations from the Report of the NIH AIDS Research Program Evaluation Task Force, NIH is developing a comprehensive HIV prevention science agenda. NIH and CDC are committed to increasing future support for basic research on behavior, interventions, social marketing, and program evaluation. (p. 13)
Given the potentially important impact on prevention of viral load, genetic mutations and drug resistance, some mention should be made of the need to link prevention science with the ongoing basic science research agenda.	This concern is addressed in the research section, where NIH will: • Develop a comprehensive NIH HIV prevention science agenda, combining biomedical, behavioral, and social interventions. (p. 19)
Mention the need for enhanced support for ethnographic and qualitative research on community cultures, social networks, etc.	Language regarding community cultures was added: Intervention research focuses on individual and community-level interventions that result in modified sexual and drug-using behaviors and, as a consequence, reduced HIV transmission. There have been significant accomplishments in this area, but, as this portfolio expands, it will be critical to assess interventions in the context of community cultures and social networks that are relevant to the growing number of populations that must be reached by HIV prevention programs. This research should be designed by a broad range of scientists, public health, and community experts to assure its relevance. (p. 13)

There is a need to greatly enhance government support for program evaluation, with particular emphasis on replicable, cutting-edge, community-based interventions. ... I'd like to see a commitment to a comprehensive evaluation of the impact of community planning on HIV prevention services.	Language on cutting-edge programs was added to the evaluation and dissemination section: ***Evaluation and Dissemination.*** To ensure that prevention programs actually are working -- and to ensure that scarce resources are spent on the most effective interventions -- all Federally-funded prevention activities routinely will include evaluation components. Funding Agencies will share widely the knowledge gained about what works and what does not work to ensure promotion of innovation and best practices in the field. In addition, as part of the Federal government's compliance with the Government Performance and Results Act, CDC and SAMHSA will continue to work with their grantees to develop appropriate performance measures for HIV prevention programs, including those developed under the community planning process. (p. 14)

Add the following: ***Prevention Education.*** The Center for Disease Control and Prevention's Guidelines for *Effective School Health Programs to Prevent the Spread of AIDS* state the Nation's public and private schools have the capacity and responsibility to help assure that young people understand the nature of the HIV epidemic and the specific actions they can take to prevent HIV infection. In addition, the guidelines recommend that "Education about AIDS may be the most appropriate and effective when carried out within a more comprehensive school health education program that establishes a foundation for understanding the relationships between personal behavior and health. CDC's Division of Adolescent and School Health (DASH) currently supports Comprehensive School Health Programs in thirteen states. The model uses an eight component program that is planned, sequential, Kindergarten through grade 12 approach that integrates important categorical topics such as HIV, STDs, unintended pregnancy, alcohol, drugs, tobacco, and intentional and unintentional injury. Comprehensive School Health Education is one of the more efficient means of preventing risk behaviors. These activities have been accomplished by funding infrastructure at the state level in departments of health and education. It must be expanded into every state in the nation. (The cost would be $25 million each year to expand CSHE to all 50 states.)	A section on prevention education was added: ***Prevention Education.*** Collaboration with communities and schools is a critical factor in communicating HIV prevention messages to our youth. The Centers for Disease Control and Prevention's *Guidelines for Effective School Health Programs to Prevent the Spread of AIDS* helps assure that young people understand the nature of HIV transmission and the specific actions they can take to prevent HIV infection. Support for these programs should and will continue. (p. 14)

The section on substance abuse places undue emphasis on the intersection of HIV prevention with the nation's drug abuse control efforts. Completely missing is the need to greatly enhance programs for out-of-treatment drug users. In New York and elsewhere, community-based organizations have experienced remarkable success with peer-based programs targeting drug users. The document should call for greater support for these and other programs.	The document addresses the need for continuing community-based planning to develop locally-designed prevention priorities. (p. 14)
Include a stronger statement that the research and public health data suggests in the absence of treatment for substance abuse on demand, or at least funded more adequately, "needle exchange" should become part of the Strategy. There is a need federal leadership to lift ban on needle exchange and address policy barriers ... Better coordination is needed at the federal level among the multiple agencies that address substance use and/or HIV.	Language on needle exchange programs is: • *Preventing HIV transmission from the use of contaminated injection equipment.* The sharing of needles and syringes among injecting drug users is a major means of HIV transmission in the drug-injecting population. Abstinence from drug use is always the preferred means of HIV prevention. The CDC recommends using sterile or never-used injection equipment. CDC-supported research has indicated that removal of restrictions on over-the-counter sale of syringes resulted in decreased reported needle sharing. Current Federal law restricts the use of Federal funds for syringe exchange programs; however, a number of communities across the country have undertaken these programs with local resources. NIH-supported research on existing needle exchange programs is identifying the characteristics that influence program success as an HIV prevention strategy. (p. 15)

There is insufficient accountability at the CDC to ensure that sufficient funding is targeted at the populations in greatest need. Some plan to require CDC to account for funding allocation is called for.	The text section on targeting vulnerable populations states the importance of providing funding for those at greatest risk: The HIV epidemic continues to have a disproportionate impact on certain populations where infection rates are rising at a rapid pace. A fifth and final challenge for prevention programming is to pay particular attention to groups that traditionally receive fewer services, but where the risk of infection is greatest. These include adolescents (especially young gay men), women, minorities, gay men of color, substance abusers, and prisoners. Many Federally-funded HIV prevention activities already target these populations. The additional $32 million appropriated in FY 1997 for the CDC will provide new funds specifically intended for programs and research targeting adolescents, women, and substance abusers. To ensure that prevention programs, including community planning efforts, are as effective as possible all Federally-funded prevention activities routinely will include monitoring and evaluation components. (p. 16)
Research. The document appropriately recognized the need for federal leadership and coordination on AIDS research. I'd also add the need for strategic planning, since this is the essence of the NIH reforms that led to the Office of AIDS Research (as well as the philosophy of the Levine Commission Report).	Text on strategic planning was added: Developing and implementing the Federal government's AIDS research agenda presents both scientific and logistical challenges that require leadership, coordination, and strategic planning, first among the 24 institutes, centers, and divisions of the NIH, and second among the various Departments and Agencies throughout the government that support HIV research. (p. 18-19)

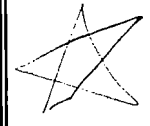
Care and Services. We should be thinking about the implications of people who have previously been disabled because of HIV that now feel well enough to at least begin to work again, they are not faced with having to "remain disabled" in order to continue to receive treatment and care.	Text on Medicare and assessing SSA programs was added: Medicare is also becoming an increasingly important source of health care coverage for people living with HIV/AIDS. Individuals who receive Social Security Disability Insurance (SSDI) benefits for 29 months, including a 5 month waiting period, are eligible to receive Medicare benefits. As the life expectancy of people living with AIDS has increased, a greater number of those individuals have begun to qualify for Medicare. While this provides an important additional source of benefits, there are limitations on benefits -- in particular, the absence of prescription drug coverage -- that may be problematic for persons living with AIDS. Supplementary medical coverage, known as Medigap insurance, is often difficult for a person living with AIDS to obtain. The Administration is exploring options to make Medigap policies more accessible. (p. 24) ***Assessing Social Security Administration Programs.*** With the improved quality of life realized by many people due to the advent of protease inhibitors and combination therapy, it is important to assess programs such as Supplemental Security Income and Social Security Disability Insurance regarding their flexibility in meeting the needs of individuals as they seek to move off and on to disability. The current system of disability programs, which assures continued access to health insurance, often places obstacles in the way of individuals who want to return to work. The Administration is exploring mechanisms to ensure that Federal programs support people with disabilities who want to work or return to work. (p.25)

The emphasis on the difficulty in coordination of so many different programs that help people with HIV/AIDS should have even more emphasis and a way needs to be found to do a better job with that effort. We need to find a way to help people understand the importance of integrating HOPWA into the broader system of care and treatment for people with HIV if HOPWA is to be fully effective in it purpose.	Language on improving program coordination has been expanded: Integrating HIV-related services is an important step in assisting communities to build seamless systems of support for the most vulnerable persons in our communities. Organizations receiving Federal funding to provide AIDS-related care often require support from several Federal Agencies. For example, creating a comprehensive community-based program that integrates primary care, substance abuse treatment and prevention, sexually transmitted disease screening, Tb prevention and treatment, HIV prevention, access to clinical trials, and housing assistance requires separate applications to SAMHSA, HRSA, CDC, NIH, and HUD. The Agencies funding HIV-related services are committed to simplifying and improving the application process for Federal funding and to facilitating service integration. HRSA and SAMHSA have issued joint program announcements, and HUD and HRSA have issued a joint program announcement for the Special Projects of National Significance (SPNS) program. These concerted efforts to improve integration will be continued and expanded, with special attention to linking HIV and substance abuse prevention and services. Improving collaborative efforts with the private sector is yet another opportunity for strengthening the effectiveness of current public-private partnerships and developing new ones. Combining resources and innovation makes more efficient use of scarce public and private resources. We must work to strengthen existing partnerships and seek innovative approaches for developing new collaborations. (pp. 25-26)

Quality care guidelines need to be broad and flexible given the rate of change being experienced. This is illustrated by the fact that so many HIV patients often know more than their MD. Further, the uneven knowledge often leads to less than "state of the art" care in many parts of the country.	Text regarding quality of care includes: ***Improving Quality of Care.*** Federally-supported efforts such as Medicaid, Medicare, Ryan White CARE Act programs and the health care delivery systems at the Department of Veterans Affairs (VA) and the Department of Defense (DOD) can and should consistently provide high-quality care. Ensuring consistency in care delivery requires increased training for health care professionals and greater accountability through the use of performance measures for quality care. It may also require enhanced technical assistance to CARE Act grantees, planning councils, and consortia. Having access to quality care within the context of managed care is an important emerging issue for all Americans including those living with HIV. The President has established the Advisory Commission on Consumer Protection and Quality in the Health Care Industry to examine changes in the industry and make recommendations. It is also essential that practical information on research advances for practicing clinicians and their patients be provided in a timely manner. (See Section on Translation of Research Advances into Practice.) HRSA and HCFA will continue to offer guidance to grantees and the States in regards to maintaining the quality and standard of care appropriate for people living with HIV. To this end, during FY 1997, the Office of HIV/AIDS Policy at HHS is undertaking a program to develop clinical practice guidelines in conjunction with other government Agencies such as the NIH, VA, and DOD and private-sector clinicians. (p. 26) There is also text in the Translation of Research Advances into Practice section: ***Increasing Education and Training.*** As we continue to expand our base of knowledge about AIDS care, efforts to educate and train health care professionals in state-of-the-art care for people living with HIV and AIDS must be maintained. (p. 33)

(1) There should be a statement from Secretary Brown to all DVA VUSN Directors, Regional Directors, and Chiefs of Staff of medical centers, that he personally considers outreach to, and treatment of veterans living with HIV/AIDS to be a top priority. (2) To that end, medical centers and clinics whenever possible should identify clinicians with special expertise in the treatment of HIV/AIDS. Those clinicians should be supported in establishing AIDS clinics and prevention programs. (3) The DVA should provide training conferences for physicians, nurses, and other clinicians on a regular basis. Those attending these conferences should be expected to return to their various centers with skills and knowledge they can transmit to their colleagues. (4) The DVA should direct those in the field to have regular contact with veterans organizations, public and private hospitals and clinics, and with community HIV/AIDS organizations, with the goal of identifying veterans living with the virus, and bringing them into VA treatment centers if they so desire.	Text on the importance of quality care at VA facilitates was added: Federally-supported efforts such as Medicaid, Medicare, Ryan White CARE Act programs and the health care delivery systems at the Department of Veterans Affairs (VA) and the Department of Defense (DOD) can and should consistently provide high-quality care. ..... It is also essential that practical information on research advances for practicing clinicians and their patients be provided in a timely manner. (See Section on Translation of Research Advances into Practice.) HRSA and HCFA will continue to offer guidance to grantees and the States in regards to maintaining the quality and standard of care appropriate for people living with HIV. To this end, during FY 1997, the Office of HIV/AIDS Policy at HHS is undertaking a program to develop clinical practice guidelines in conjunction with other government Agencies such as the NIH, VA, and DOD and private-sector clinicians. (p. 26)
Civil Rights. The focus [of the civil rights section] is unduly narrow. Should also emphasize combating discrimination in education, housing, service establishments, an other areas covered by Federal law.	Language to broaden this section was added: The fourth goal of the National AIDS Strategy is to fight discrimination on all fronts, including employment, access to health care, education, housing, service establishments, and other areas covered by Federal law, and to provide national leadership in erasing the stigma associated with HIV and AIDS. (p. 27)

.. the Strategy should promote a broader federal approach to combating HIV-related discrimination. ... the section on providing leadership should emphasize devoting resources to proactive initiatives designed to aggressively address systemic problems of discrimination -- e.g. refusal by dentists, physicians, and other health care workers to provide care for patients with HIV ...	Language to broaden the section was added: ***Enforcing Rights.*** Efforts to protect the civil rights of people with HIV and AIDS must be ever-vigilant. The Federal government will continue to exhibit strong leadership on this issue through its enforcement of the Americans with Disabilities Act and public condemnation of discriminatory acts or statements. Active steps are being taken to prevent discrimination in the areas of employment, access to health care, education, housing, and service establishments. A joint effort by the Department of Health and Human Services and the Department of Justice aimed at access to nursing homes is a significant step forward in protecting the rights of people living with HIV. (p. 28)
Broaden the bully pulpit to include many more people in the Administration than the President.	Text was added to included all members of the Administration: ***Providing Leadership.*** Leaders of government have an obligation to use the power of their elected office to speak out against acts or words of discrimination against any group of people. President Clinton and members of his Administration have used and will continue to use their positions to oppose discrimination against people living with HIV and AIDS. (p. 28)
Add an Opportunity for Progress -- Provide leadership in advocating reasonable legal/policy approaches on discrimination issues not specifically addressed by federal law. As one possible example, the Justice Department, of the HHS Office of Civil Rights, might issues advisory opinions on such issues as HIV discrimination in the contexts of family law (e.g. denials of child custody and visitation privileges) or criminal law (e.g charging HIV+ people who spit with attempted murder). Reasoned advisory opinions on such matters by the DOJ or HHS OCR, while not legally binding, could prove to be extremely helpful to courts that are grappling with these issues.	The government will continue to protect the civil rights of people living with HIV and AIDS. There is a concern that requests for advisory opinions could result in unfavorable policy decisions.



Expand Appendices to include other departments that should be addressing civil rights issues	There should be some modification of the civil rights section of the Appendices. However, it is too late to make the changes for the 1997 version.
Translation of Research Advances into Practice. There is little mention of the need to perform follow-up studies needed to perform follow-up studies to give providers and consumers the information they require to make informed treatment decisions. .... would emphasize this in national strategy. The document stressed the need for provider education, but fails to note the overwhelming need for consumer education programs. At GMHC, our experience suggests that the doctor's office is not always to best place for consumers to get the information they need or desire. In light of the potential public health consequences of widespread drug resistance, the country should invest in programs that provide consumers with the information they need (a) to make treatment decisions and (b) to comply with their medical regimens. ... I'm dubious of the meaningfulness of clinical care guidelines. ... While clinical guidelines probably have some role in provider education, I think there are numerous other strategies that could be useful, such as comprehensive professional and public education campaigns.	Added language on the need for consumer education: Consumer education efforts are also important. In light of the potential public health benefits that could result from the proper use of a wide range of therapies, it is vital to support programs that provide consumers with the information they need to make treatment decisions and comply with therapeutic regimens. (p. 33) Language about the need for rapid translation of research results was also added: It is essential that practical information for practicing clinicians and their patients be provided as quickly as possible. To this end, during FY 1997, the Office of HIV/AIDS Policy at HHS is undertaking a program to develop clinical practice guidelines in conjunction with other government Agencies and private sector clinicians. (p. 33)
As we continue to see improvements in drugs and knowledge about treatment, the time between the development of the information and its dissemination needs to be shortened.	Language about the need for rapid translation of research results was added: It is essential that practical information for practicing clinicians and their patients be provided as quickly as possible. To this end, during FY 1997, the Office of HIV/AIDS Policy at HHS is undertaking a program to develop clinical practice guidelines in conjunction with other government Agencies and private sector clinicians. (p. 33)

CROSSWALK FOR ONAP STAFF

PACHA Comments	NAS Text Changes
Message from the National AIDS Policy Director. Need stronger introduction. Define the strategy. Begin with Ms. Fleming's ending statements on ending the epidemic.	Changed order and added letter from President. (p.2, pp. 5-6).
Introduction. Sharpen all goals to indicate the Administration's sense of urgency.	Goals were changed to: The President has identified the following national goals to guide our efforts to end the epidemic of HIV and AIDS: ■ **To develop more effective treatments, a preventive vaccine to protect the uninfected, and a cure for those currently infected through strong, continuing support for HIV-related research;** ■ **To reduce the number of new HIV infections in adults and children in the U.S. until the rate of new infections reaches zero by providing strong, continuing support for effective HIV prevention efforts;** ■ **To ensure that all people living with HIV have access to services, from health care to housing and supportive services, that are affordable, of high quality, and responsive to their needs;** ■ **To ensure that all people living with HIV are not subject to discrimination;** ■ **To provide strong, continuing support for international efforts to address the HIV epidemic; and,** ■ **To ensure that research advances are translated into improved HIV prevention programs and enhanced care for HIV- positive persons.** (p.7)

Make prevention goal stronger to reflect President's quote in beginning of prevention section.	The goal was changed to match the President's quote: ■ **To reduce the number of new HIV infections in adults and children in the U.S. until the rate of new infections reaches zero by providing strong, continuing support for effective HIV prevention efforts.** (p. 7)
There should be quality care for all in the goals.	The goal was changed: ■ **To ensure that all people living with HIV have access to services, from health care to housing and supportive services, that are affordable, of high quality, and responsive to their needs.** (p.7)
A goal should be added emphasizing that HIV should be taken out of the political arena and viewed as a public health crisis affecting everyone.	Not added. 6 Goals match 6 sections of the Report. PH addressed throughout Report -
Introduction states that AIDS is a costly disease... [but] AIDS is not inordinately expensive. Many federal programs mentioned in the document are extremely cost-effective because they help reduce HIV-related medical costs. HOPWA funds a continuum of housing programs that provide far less costly alternatives to institutionalization. Similarly, by reducing the epidemic's long-term burden, HIV prevention services represent an immediate and future economic savings for the country. AIDS isn't an endless drain on public resources; rather the federal government has developed excellent strategies for reducing the epidemic's impact. The document should make these points to combat the growing sentiment that "AIDS gets more than its fair share."	Text was modified: The average lifetime cost of medical care after an HIV diagnosis is $119,000.[1] People living with HIV are often dependent on the public sector for their health care, particularly in the later stages of HIV disease. More than 50 percent of people living with AIDS are enrolled in Medicaid, including more than 90 percent of children with AIDS. In FY 1996, the Federal government spent an estimated $1.8 billion on Medicaid benefits for people living with HIV and AIDS and another $690 million on Medicare benefits. Social Security benefits for people disabled by HIV/AIDS totaled nearly $980 million in FY 1996. Many Federal programs such as Housing Opportunities for Persons with AIDS (HOPWA) and CDC's prevention efforts contribute to reducing the short- and long-term economic costs of the epidemic. (p. 9)

Re language on schools was

Prevention. Adolescents and youth are one of America's most underserved populations in terms of access to health care services and health education. The Division of Adolescent and School Health (DASH), a program of the Centers for Disease Control and Prevention, addresses the prevention of priority health risks (including HIV/AIDS) among adolescents and youth.	Added language (in grey): Federal efforts have shown that HIV prevention programs can be effective. CDC's prevention projects, many in partnership with states, local governments, schools, and community-based organizations, have demonstrated that prevention programs are most effective when designed and implemented in partnership with communities to which they are targeted. (p.12) Added the following section: ***Prevention Education.*** Collaboration with communities and schools is a critical factor in communicating HIV prevention messages to our youth. The Centers for Disease Control and Prevention's *Guidelines for Effective School Health Programs to Prevent the Spread of AIDS* helps assure that young people understand the nature of HIV transmission and the specific actions they can take to prevent HIV infection. Support for these programs should and will continue. (p.14)
Document does not address counseling and testing. ... while testing should not be centerpiece of our prevention efforts, it is equally clear that the nationas laissez faire approach to testing effectively squanders countless opportunities to intervene with effective HIV prevention services.	Counseling and testing are addressed in the following text: New and promising medical interventions make it critical to improve our approach to HIV counseling and testing -- creating a critical bridge between prevention and primary care. CDC is committed to improving the follow-up services for those counseled and tested at publicly-funded sites including the quality of referral to services for those who test HIV-positive. (p. 15) Primary care providers must learn to incorporate a person's sexual and drug-using history when a medical history is taken, offering HIV-related counseling and voluntary testing, and providing prevention education to HIV-positive individuals as part of the provider-patient relationship. (p. 15)

Add goal of enhanced coordination of federal efforts in order to ensure that prevention programs are grounded in behavioral and enthnographic research and based on the latest epidemiologic data. Currently there is insufficient coordination.	Basing prevention interventions on research is addressed in the following text: Effective interventions must be based on sound research findings and evaluations. In response to the recommendations from the Report of the NIH AIDS Research Program Evaluation Task Force, NIH is developing a comprehensive HIV prevention science agenda. NIH and CDC are committed to increasing future support for basic research on behavior, interventions, social marketing, and program evaluation. (p. 13) Improving program coordination and integrating prevention is addressed in the following text: ***Improving Program Coordination.*** Integrating HIV-related services is an important step in assisting communities to build seamless systems of support for the most vulnerable persons in our communities. Organizations receiving Federal funding to provide AIDS-related care often require support from several Federal Agencies. For example, creating a comprehensive community-based program that integrates primary care, substance abuse treatment and prevention, sexually transmitted disease screening, Tb prevention and treatment, HIV prevention, access to clinical trials, and housing assistance requires separate applications to SAMHSA, HRSA, CDC, NIH, and HUD. (p. 25)
Change this bullet to read "Improving understanding of trends in HIV transmission, seroprevalence, and risk behaviors."	The text was changed to read: • Improving understanding of trends in HIV transmission, seroprevalence, and risk behaviors. (p. 12)

Make a statement that would actually suggest the lack of this research be presented even stronger as a barrier to HIV prevention.	One of the major goals for HIV prevention states: • Improving scientific knowledge about effective prevention models and strategies. (p. 12) Text states: Effective interventions must be based on sound research findings and evaluations. In response to the recommendations from the Report of the NIH AIDS Research Program Evaluation Task Force, NIH is developing a comprehensive HIV prevention science agenda. NIH and CDC are committed to increasing future support for basic research on behavior, interventions, social marketing, and program evaluation. (p. 13)
Given the potentially important impact on prevention of viral load, genetic mutations and drug resistance, some mention should be made of the need to link prevention science with the ongoing basic science research agenda.	This concern is addressed in the research section, where NIH will: • Develop a comprehensive NIH HIV prevention science agenda, combining biomedical, behavioral, and social interventions. (p. 19)
Mention the need for enhanced support for enthographic and qualitative research on community cultures, social networks, etc.	Language regarding community cultures was added: Intervention research focuses on individual and community-level interventions that result in modified sexual and drug-using behaviors and, as a consequence, reduced HIV transmission. There have been significant accomplishments in this area, but, as this portfolio expands, it will be critical to assess interventions in the context of community cultures and social networks that are relevant to the growing number of populations that must be reached by HIV prevention programs. This research should be designed by a broad range of scientists, public health, and community experts to assure its relevance. (p. 13)

There is a need to greatly enhance government support for program evaluation, with particular emphasis on replicable, cutting-edge, community-based interventions. ... I'd like to see a commitment to a comprehensive evaluation of the impact of community planning on HIV prevention services.	Language on cutting-edge programs was added to the evaluation and dissemination section: ***Evaluation and Dissemination.*** To ensure that prevention programs actually are working -- and to ensure that scarce resources are spent on the most effective interventions -- all Federally-funded prevention activities routinely will include evaluation components. Funding Agencies will share widely the knowledge gained about what works and what does not work to ensure promotion of innovation and best practices in the field. In addition, as part of the Federal government's compliance with the Government Performance and Results Act, CDC and SAMHSA will continue to work with their grantees to develop appropriate performance measures for HIV prevention programs, including those developed under the community planning process. (p. 14)

Add the following: ***Prevention Education.*** The Center for Disease Control and Prevention's Guidelines for *Effective School Health Programs to Prevent the Spread of AIDS* state the Nation's public and private schools have the capacity and responsibility to help assure that young people understand the nature of the HIV epidemic and the specific actions they can take to prevent HIV infection. In addition, the guidelines recommend that "Education about AIDS may be the most appropriate and effective when carried out within a more comprehensive school health education program that establishes a foundation for understanding the relationships between personal behavior and health. CDC's Division of Adolescent and School Health (DASH) currently supports Comprehensive School Health Programs in thirteen states. The model uses an eight component program that is planned, sequential, Kindergarten through grade 12 approach that integrates important categorical topics such as HIV., STDs, unintended pregnancy, alcohol, drugs, tobacco, and intentional and unintentional injury. Comprehensive School Health Education is one of the more efficient means of preventing risk behaviors. These activities have been accomplished by funding infrastructure at the state level in departments of health and education. It must be expanded into every state in the nation. (The cost would be $25 million each year to expand CSHE to all 50 states.)	A section on prevention education was added: ***Prevention Education.*** Collaboration with communities and schools is a critical factor in communicating HIV prevention messages to our youth. The Centers for Disease Control and Prevention's *Guidelines for Effective School Health Programs to Prevent the Spread of AIDS* helps assure that young people understand the nature of HIV transmission and the specific actions they can take to prevent HIV infection. Support for these programs should and will continue. (p. 14)
The section on substance abuse places undue emphasis on the intersection of HIV prevention with the nation's drug abuse control efforts. Completely missing is the need to greatly enhance programs for out-of-treatment drug users. In New York and elsewhere, community-based organizations have experienced remarkable success with peer-based programs targeting drug users. The document should call for greater support for these and other programs.	Not added. The language on S.A. was not changed.

Include a stronger statement that the research and public health data suggests in the absence of treatment for substance abuse on demand, or at least funded more adequately, "needle exchange" should become part of the Strategy. There is a need federal leadership to lift ban on needle exhchange and address policy barriers ... Better coordination is needed at the federal level among the multiple agencies that address substance use and/or HIV.	Language on needle exhange programs is: • *Preventing HIV transmission from the use of contaminated injection equipment.* The sharing of needles and syringes among injecting drug users is a major means of HIV transmission in the drug-injecting population. Abstinence from drug use is always the preferred means of HIV prevention. The CDC recommends using sterile or never-used injection equipment. CDC-supported research has indicated that removal of restrictions on over-the-counter sale of syringes resulted in decreased reported needle sharing. Current Federal law restricts the use of Federal funds for syringe exchange programs; however, a number of communities across the country have undertaken these programs with local resources. NIH-supported research on existing needle exchange programs is identifying the characteristics that influence program success as an HIV prevention strategy. (p. 15) • *Integrating HIV prevention into substance abuse treatment and prevention programs.* In August 1996, at the request of President Clinton, the Public Health Service Agencies jointly co-sponsored a national meeting of State and local officials, researchers, and community experts from the fields of HIV and substance abuse to develop an action plan to more effectively integrate HIV and substance abuse prevention efforts. PHS Agencies are committed to implementing this strategy in the year ahead. • *Enrolling substance abusers into drug treatment.* Substance abuse treatment is a major form of HIV prevention. This Administration will continue to support funding for substance abuse treatment. Further, through outreach, research, and demonstration programs, SAMHSA, NIH, and CDC will work to enroll more people in treatment and to find more successful interventions to accomplish this end. • *Reducing the availability of illegal drugs.* The White House Office of National Drug Control Policy (ONDCP) is leading this fight on two fronts: reducing demand for drugs through treatment and prevention programs and reducing the availability of drugs through supply reduction programs.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

23-Sep-1996 02:27pm

TO: Ursula Sanville

FROM: Kimberly Farrell

SUBJECT: Re: PAC attendance

We have a record of attendance for the entire meeting...the only difference would be Bob Hattoy who only attended on Monday afternoon ..would you like me to fax it to you?

Of the members, those absent on Sunday were:
Aragon, R.
Boland, M
Fraser-Howze, D.
Hattoy, R.
laFavor, C.
Stafford, R.
Thurman, S.
Troupe, C.

From: Ursula Sanville
To: ksf
Subject: PAC attendance
Date: Thursday, September 19, 1996 2:48PM

Hello Kimberly --

Do you have a roster of which Council members attended the Sunday session at
the
last meeting? Please let me know, thanks,

Jane

Draft

MEMORANDUM TO ALL MEMBERS OF THE PRESIDENT'S ADVISORY COUNCIL ON HIV/AIDS

FROM: Dr. R. Scott Hitt, Chair

SUBJECT: Review of Draft National AIDS Strategy

At our September 1996 meeting, the Council agreed to review the preliminary draft copy of the National AIDS Strategy prepared by the Office of National AIDS Policy. The Council also agreed to offer our comments and suggestions to ONAP by no later than November 15, 1996. Release of a final draft to national, regional, and community organizations involved in the national response to the epidemic will follow in December.

To maximize our ability to influence the final product, it is imperative that we honor our commitment to maintain an embargo on this document. No copies -- or excerpts -- of this document can be shared or discussed with non-Council members. This includes your employers, colleagues, and associates.

In order to meet our deadline, I will need comments from Council members and/or subcommittees by no later than close of business November 1. These suggestions will then be collated and delivered to ONAP by November 15. All comments and suggestions must be provided in written form.

Please let me know if you have any further questions. Thank you.

Review of the National AIDS Strategy

The President's Advisory Council on HIV/AIDS has been asked by the Office of National AIDS Policy to review a preliminary draft of the National AIDS Strategy. The Council has requested until November 15 to complete its review and offer its comments and suggestions to ONAP. A final draft Strategy will be released to the public in December.

Why is the preliminary draft being kept confidential?

The President's Advisory Council on HIV/AIDS has requested an opportunity to review the preliminary draft and offer its detailed comments and suggestions. Until that time, this is this is an incomplete document. We have been assured that input will be sought from the broader public following the Council's review.

What is your preliminary impression of the document?

It would be unfair for me to offer any comment until I and my colleagues have an opportunity to fully review the document and discuss our reactions and suggestions.

Does the Strategy contain any new initiatives?

It would be inappropriate for me to comment on the document. I would say that it is clear that a great deal of work went into the preparation of this preliminary draft.

Isn't this a cover-up until after the election?

No. The Council requested this review period to make sure that we have an opportunity to have real input into this important document. It is much more important to do this right than to do it fast.

Nick Bollman's comment —

The Administration should be congratulated for developing the 1st-ever National AIDS Strategy, and consulting the PAC & others in its development.

JS - review please

Draft

MEMORANDUM TO ALL MEMBERS OF THE PRESIDENT'S ADVISORY COUNCIL ON HIV/AIDS

FROM: Dr. R. Scott Hitt, Chair

SUBJECT: Review of Draft National AIDS Strategy

? Did we send more out to those who weren't there?

Each of you has now received a preliminary draft copy of the National AIDS Strategy at the September 1996 meeting prepared by the Office of National AIDS Policy. ~~The~~ Council ~~has~~ agreed to review this preliminary draft and offer ~~our~~ comments and suggestions to ONAP by no later than November 15, 1996. Release of a final draft to ~~national, regional, and local~~ organizations involved in the national response to the epidemic will follow in December.

To maximize our ability to influence the final product, it is imperative ~~that we honor~~ our commitment to maintain an embargo on this document. No copies ~~of~~ excerpts ~~of~~ this document can be shared with any non-Council members ~~provided to other individuals or organizations~~. This includes your employers, ~~and~~ colleagues, and friends.

In order to meet our deadline, I will need comments ~~by~~ from all Council members by no later than close of business November 1. These suggestions will then be collated and delivered to ONAP by November 15. All comments and suggestions must be provided in written form.

Please let me know if you have any further questions. Thank you.

? Scott is going to do this? Thought process was through sub-committee

Other stuff -- (RS - let's discuss... ideas...)

Suggested talking points — ?

Instructions on How to handle inquiries, press questions?

Really bold - thanking Administration for its efforts and this opportunity to review...

JS - review please

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E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

03-Oct-1996 12:03pm

TO: Jeffrey Levi

FROM: Ursula Sanville
AIDS Policy Council

SUBJECT: services subcommittee

FYI --

The services subcommittee had some comments but nothing too out there. The comments were:

- Beef up the national goals;
- Add language about how far we've come and how far we need to go and what are the implications of the good news;
- Document needs to capture the dynamism of the epidemic;
- More language on cost of drugs;
- Much more on how to get information out to MDs;
- This a Federal Strategy .. need to incorporate and challenge other partners;
- For AIDS is a costly disease paragraph -- want more detailed comparisons of HIV to other chronic diseases;
- want stronger needle exhchange language;
- specifics about how to integrate HOPWA into care;
- more about the "Notch Effect" and how it affects social security;
- for civil rights, the entire administration should show leadership, not just the President.

Process -- subcommittee will get comments to Ed who will send draft to us and committee. Then final will come to ONAP.

Prevention Conference Call 10/7/96

Strategy

1. Process for putting comments together
   - do it separately to ONAP
   - make group statement for emphasis.

Illicit Substance
Back up - future opportunities to match goal.

Billings - want to begin with all young children. ? common statement
Hendau - funding priority was something that was done
   - youth - common message.
Hendau - p. 11 the nation has also combatted...
   not true. Cannot support.
   - Clearer definition of what this strategy is about
   - Put the tag line up front.

2. Letter from Helene Gayle

10/3/96 Services Subcommittee

Reaction to the Strategy —

Where it can be added, deleted, modified.

Border in initial statements about the goals. Make them sound more grand.
? Take AIDS out of political arena and make more a medical arena.

Rankin - VA was meaningless drivel.
Only good stuff where there are gay + lesbian docs. Otherwise nothing.

Tom - w

Ed - 2nd bullet →
PP's letter
- Reduce # of infections to ZERO
- Ensure that all people with HIV have access to care.

- look how far we've come and how far we need to go. Implications of the good news.

Ballman - Document needs to capture dynamism. So it doesn't seem out of date.

Issues
- Cost of drugs
- Info out to medical community
- Patients know more that MDs.

Services will be increasingly difficult.
Project Inform's Vancouver - assessment of what it means for Rx.
(September)

This a Federal Strategy - challenge to other printer.
Clarified
- give me your specific comments.
Need to make AIDS a public health issue.

What is this document about.

How to convey dynamism and moving target nature.

Introduction:

P.1 liked adolescents and racial + ethnic minorities.
P.8 Like other chronic diseases, AIDS is costly.
What distinguishes this is dependence on Medicaid because of life.
Putting peopl

Ed will have comments

Overview of Federal Efforts

Substance abuse + prevention together.
stopping

want better needle exchange language

Research

Care + Services Section

Integrating housing.
Future opps - prog
① - systematic way of integrating HOPWA into care
- add a bullet on this. / Tonio Burgos will do language

② How do the treatments reach the pops. @ risk
Educate clinicians.
BIG ISSUE

③ Social Security →
- What are opportunities when people feel better.
- How do we work within the existing Rules.
The Notch effect → * literature. Antonio Burgos.

Civil Rights
p. 28 leadership. The entire Administration has a role.

Process → comments to Ed.
draft letter to ONAP.
then final draft.

DRAFT

Dear Patsy,

As members of the Discrimination Committee of the Presidential Advisory Council on HIV/AIDS, we are writing to offer some feedback concerning the civil rights section of the draft National AIDS Strategy. We offer suggestions about both the text and appendices.

We are pleased by the strong anti-discrimination language in the draft and by the impressive list of accomplishments enumerated. We are concerned, however, that the focus of the section may be unduly narrow. Thus, in addition to addressing such issues as employment discrimination and discrimination in access to health care facilities, we would urge that the Strategy emphasize combating discrimination in education, housing, service establishments, and other areas covered by federal law.

In addition, we would urge that the Strategy promote a broader and more proactive federal approach to combating HIV-related discrimination. For example, the draft section on "providing leadership" should emphasize devoting agency resources to proactive initiatives designed to aggressively address systemic problems of discrimination — e.g. refusal by dentists, physicians, and other health care workers to provide care for patients with HIV — in addition to the bully pulpit role described.

We believe another "future opportunity for progress" would be to provide leadership in advocating reasonable legal/policy approaches on discrimination issues not specifically addressed by federal law. As one possible example, the Justice

Department, or the HHS Office of Civil Rights, might issue advisory opinions on such issues as HIV discrimination in the contexts of family law (e.g. denials of child custody and visitation privileges) or criminal law (e.g. charging HIV+ people who spit with attempted murder). Reasoned advisory opinions on such matters by the DOJ or HHS OCR, while not legally binding, could prove to be extremely helpful to courts that are grappling with these issues.

We would also advocate a significant expansion of the "Appendices" section of the Strategy. Several Departments and agencies which are (or should be) addressing issues of HIV discrimination — HHS, HUD, the State Department, the Department of Education, DOD, the VA, the Peace Corps, and others — have not included an entry in the civil rights section. The paucity of reports in the civil rights section, and especially the failure of HHS to include a report, may create the unfortunate impression that HIV discrimination issues are not taken seriously by all relevant agencies.

We are grateful to have the opportunity to share our concerns with you, and for the enormous amount of work you and your staff have done to put together this groundbreaking document. Thank you for all of your hard work. If we can be of further assistance, please do not hesitate to contact us.

Sincerely,

Benjamin Schatz, JD, Chair
Kathy Gerus
Tom Henderson
Ronald Johnson

FIRST IN THE FIGHT AGAINST AIDS

GMHC

FAX MEMORANDUM

to: Mr. Jeff Levine
fax #: (202) 632-1096
re: National AIDS Strategy (Draft)
date: September 25, 1996
pages: 6, including cover sheet.

From the desk of...

Michael T. Isbell
Associate Executive Director
Gay Men's Health Crisis
129 West 20th Street
New York, NY 10011

(212) 337-3351
Fax: (212) 337-1220

MEMORANDUM

To: Members, Prevention Subcommittee
Presidential Advisory Council on HIV/AIDS

From: Mike Isbell

cc: S. Hitt
A. Levine
E. Gould
P. Fleming
J. Levi

Re: [Draft] National AIDS Strategy

Date: September 23, 1996

I'm circulating my preliminary thoughts on the Draft National AIDS Strategy in advance of the Prevention Subcommittee's upcoming conference call. Most of my comments focus on the prevention components, but I've also taken a look at other sections of the Strategy and have included my thoughts on them, as well.

Message from the National AIDS Policy Director

* The introduction should make clearer precisely what the Strategy is and what it isn't. This was, of course, a topic of extensive discussion at our September meeting. Even after all of that discussion, though, I must admit that I'm still a little unclear about what the document is intended to be. When I see the title "National AIDS Strategy," I assume that this represents the federal plan for responding to the epidemic. If that's not what's intended, that should be made plain in the introduction.

* Although the introductory session ends with visionary statements about bringing an end to the epidemic, I'd begin with this idea. Thus, while I'd certainly emphasize the goal of bringing "focus and direction" to the federal AIDS effort, I'd note in the first paragraph that the purpose of everything the federal government is doing is to the speed the day when AIDS will be a thing of the past. A more hard-hitting introduction might help mitigate the inevitable response at the community level to some of the more bureaucratic language within the document.

* The prevention goal (i.e., the second bullet) on page 3 is actually more timid than it need be. The President himself has established the goal of reducing new infections each year, until there are no new infections. On page 11 of the draft, the document refers to "the national goal of no new infections." If that's our goal, we ought to say it up front.

* In fact, I think all of the goals should be sharpened somewhat to indicate the administration's sense of urgency in responding to the epidemic. For example, I'd reframe the third bullet to focus on the goal of ensuring that "*every* person with HIV has meaningful access to the affordable, high-quality services which he or she needs." While it may be unlikely that this goal can ever be achieved, I would assume we all agree that that is our actual objective.

* Although it's unlikely that the administration will incorporate this idea into the national strategy, I believe the Council should go on record urging better coordination of federal AIDS efforts. While the Office of National AIDS Policy plays an important coordinating and consensus-building role within the executive branch, it should be invested with greater authority to ensure accoutability among the federal agencies whose job it will be to effectuate the national strategy.

I. Introduction

* The Introduction states that "AIDS is a costly disease." That's true, of course, and the cost is probably increasing with the advent of new therapies. Moreover, the point is important for the document, since any national strategy statement must justify substantial federal outlays for AIDS prevention, treatment and research.

The document, however, fails to provide additional information to enable the reader to place AIDS-related costs in their proper context. First, while AIDS is expensive, it is not *inordinately* expensive in comparison with other chronic diseases. Second, many of the federal programs mentioned in the document are extremely cost-effective because they help *reduce* HIV-related medical costs. HOPWA, for example, funds a continuum of housing programs that provide far less costly alternatives to institutionalization. Similarly, by reducing the epidemic's long-term burden, HIV prevention services represent an immediate and future economic savings for the country. (In other words, AIDS isn't an endless drain on public resources; rather, the federal government has developed excellent strategies for reducing the epidemic's economic impact.)

I'm not sure that these points belong in the Introduction, which currently has a singleminded focus on AIDS/HIV epidemiology. Somewhere, though, the document should make these points, which might help combat the growing sentiment that "AIDS gets more than its fair share."

II. Overview of Federal Efforts

A. Prevention

* Under "Future Opportunities for Progress," the document should set forth the goal of enhanced coordination of federal HIV prevention efforts, in order to ensure that prevention programs are grounded in behavioral and ethnographic research and based on the latest epidemiologic data. Currently, there is insufficient coordination between the various federal agencies performing prevention science research; similarly, there has historically been inadequate coordination between prevention programs and epidemiology.

* Under "Future Opportunities for Progress," I would reformulate the first bullet as follows: "Improving understanding of trends in HIV transmission, seroprevalence and risk behaviors." (Better understanding of risk behaviors is briefly addressed in the text on page 12 but is ignored in the objective.)

* Our "Future Opportunities for Progress" also depend on addressing policy barriers that impede effective HIV prevention, including the failure to formally remove longstanding restrictions on the content of federally-funded HIV prevention materials, the federal ban on funding for needle exchange programs, State needle prescription laws, and the timidity of State and local education officials to ensure appropriate HIV education for at-risk youth. While the federal government lacks actual control over some of these issues, the need for federal leadership is clear.

* The document does not address the role of counseling and testing in HIV prevention, which is curious, given its historic prominence at the CDC. While I believe the Council should reject the simplistic (and inaccurate) notion that testing itself should be the centerpiece of our prevention efforts, it is equally clear that the nation's laissez faire approach to testing effectively squanders countless opportunities to intervene with effective HIV prevention services.

Research on Effective Prevention Strategies

The document's emphasis on prevention research is greatly appreciated. I'd flesh it out, though, in the following ways:

* In addition to behavioral research, I would at least mention the need for enhance support for ethnographic and qualitative research on community cultures, social networks, etc.

* Given the potentially important impact on prevention of viral load, genetic mutations and drug resistance, some mention should be made of the need to link prevention science with the ongoing basic science research agenda.

* The emphasis on evaluation is great. My experience of evaluation components included in most government prevention contracts, however, is that they don't wind up telling us very much. If we truly want to emphasize evaluation, the government is going to have to pay for it. Thus, I'd move beyond the goal of merely including evaluation components in HIV prevention contracts to a recognition of the need to greatly enhance government support for program evaluation, with particular emphasis on replicable, cutting-edge community-based interventions.

* While I agree with the document's support for the community planning process, I'd like to see a commitment to a comprehensive evaluation of the impact of community planning on HIV prevention services. Based on my experience in New York, I remain deeply skeptical that the community planning process is having the impact envisioned by its original proponents.

Program Integration and Collaboration

* The section on substance abuse places undue emphasis on the intersection of HIV prevention with the nation's drug abuse control efforts. Completely missing is the need to greatly enhance programs for out-of-treatment drug users. In New York and elsewhere, community-based organizations have experienced remarkable success with peer-based programs targeting drug users. The document should call for greater support for these and other programs.

* Better coordination is needed at the federal level among the multiple agencies that address substance use and/or HIV.

* I would imagine that the sentence about needle exchange on page 14 was hard to come by, and I'm certain that Patsy and Jeff deserve praise and thanks for getting even this much into the document. The Council, though, should go on record urging the administration to lift federal restrictions on funding for needle exchange, on the basis of the overwhelming (and growing) body of data demonstrating the effectiveness of needle exchange.

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To: The Prevention Sub-Committee
& Patsy, Jeff and Jane at ONAP
Terje Anderson
Judith Billings
Bob Fogel
Kathy Gerus
Mike Isbell
Scott Hitt
Jeremy Landau
Altagracia Perez
Alexander Robinson
Ben Shatz
Denise Stokes

RE: The National AIDS Strategy Report
Date: Oct. 3, 1996
Pages: 2 including this one

Dear Y'all:

This is my attempt to address the absence of any mention of HIV/AIDS prevention in schools. I think that the educational element should be mentioned somewhere in the "Record of Accomplishment." My suggestion is just that. The second portion I think belongs under Future Opportunities for Progress—Program Integration and Collaboration

Jeremy, Terje, Ben, Mike, Alexander you know how to do this stuff. Please look at it and tell me what language to use to strengthen it. I haven't been at this as long as you all have. And Judith, this is your expertise. I'd welcome your insights. (By the way you look fabulous in POZ!) I've got additional information here if any of you have questions.

I also think that in our move to bring Prevention to equal footing with Services and Research that we might be thinking of a recommendation in December to make funding the Comprehensive School Health Education Program in all states a priority. The cost is rather small in comparison to other programs.

Talk with you all on Monday.

2600 Hillsboro Pike #11-1 Nashville, TN 37212 (615) 298-5069 or 226-4764

Insert on Pg. 11 just after the one line sentence fragment ending the paragraph begun at the bottom of page 10.

"Adolescents and youth are one of America's most under served populations in terms of access to health care services and health education. The Division of Adolescent and School Health (DASH), a program of the Centers for Disease Control and Prevention, addresses the prevention of priority health risks (including HIV/AIDS) among adolescents and youth.

DASH provides support to national, state and local agencies and organizations with the capacity to help address adolescent health. CDC provides fiscal support and technical assistance to the education agencies in every state, six territories, Washington, DC, and 18 large cities to help schools implement effective health education to prevent the spread of HIV.

Insert on Pg. 13 after the introductory paragraph under the heading ***Program Integration and Collaboration.***

Prevention Education. The Center for Disease Control and Prevention's Guidelines for Effective School Health Programs to Prevent the Spread of AIDS state the Nation's public and private schools have the capacity and responsibility to help assure that young people understand the nature of the HIV epidemic and the specific actions they can take to prevent HIV infection.

In addition, the guidelines recommend that "Education about AIDS may be most appropriate and effective when carried out within a more comprehensive school health education program that establishes a foundation for understand the relationships between personal behavior and health."

CDC's Division of Adolescent and School Health (DASH) currently supports Comprehensive School Health Programs in thirteen states. The model uses an eight component program that is a planned, sequential, Kindergarten through grade 12 approach that integrates important categorical topics such as HIV, STDs, unintended pregnancy, alcohol, drugs, tobacco and intentional and unintentional injury.

Comprehensive School Health Education is one of the more efficient means of preventing risk behaviors. These activities have been accomplished by funding infrastructure at the state level in departments of health and education. It must be expanded into every state in the nation.

(The cost would be $25 million each year to expand the CSHE to all 50 states.)

Office of
National AIDS Policy

Correspondence Routing Slip

Tracking Number: G 3411

Date Rcvd: 10-17-96

From: Benjamin Schatz, JD, Chair
Gay and Lesbian Medical Association

Staff Action:

Reviewed By Jeff: _____ **Reviewed By: Patsy** ✓

(1) Copy for Jane

Assigned To: (2) FF

RCVD: _____ **DONE:** _____

Recommendations/Instructions:

Jane - see starred sections

GLMA

Gay and Lesbian Medical Association

211 Church St., Suite C • San Francisco, CA 94114
Ph: 415-255-4547 • Fax: 415-255-4784 • Email: gaylesmed@aol.com
Founded in 1981 as the American Association of Physicians for Human Rights

October 8, 1996

Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, Suite 1060
Washington, DC 20500

Dear Patsy,

As members of the Discrimination Committee of the Presidential Advisory Council on HIV/AIDS, we are writing to offer some feedback concerning the civil rights section of the draft National AIDS Strategy. We offer suggestions about both the text and appendices.

We are pleased by the strong anti-discrimination language in the draft and by the impressive list of accomplishments enumerated. We are concerned, however, that the focus of the section may be unduly narrow. Thus, in addition to addressing such issues as employment discrimination and discrimination in access to health care facilities, we would urge that the Strategy emphasize combating discrimination in education, housing, service establishments, and other areas covered by federal law.

In addition, we would urge that the Strategy promote a broader and more proactive federal approach to combating HIV-related discrimination. For example, the draft section on "providing leadership" should emphasize devoting agency resources to proactive initiatives designed to aggressively address systemic problems of discrimination — e.g. refusal by dentists, physicians, and other health care workers to provide care for patients with HIV — in addition to the bully pulpit role described.

We believe another "future opportunity for progress" would be to provide leadership in advocating reasonable legal/policy approaches on discrimination issues not specifically addressed by federal law. As one possible example, the Justice Department, or the HHS Office of Civil Rights, might issue advisory opinions on such issues as HIV discrimination in the contexts of family law (e.g. denials of child custody and visitation privileges) or criminal law (e.g. charging HIV+ people who spit with attempted murder). Reasoned advisory opinions on such matters by the DOJ or HHS OCR, while not legally binding, could prove to be extremely helpful to courts that are grappling with these issues.

We would also advocate a significant expansion of the "Appendices" section of the Strategy. Several Departments and agencies which are (or should be) addressing issues of HIV discrimination — HHS, HUD, the State Department, the Department of Education, DOD, the VA, the Peace Corps, and others — have not included an entry in the civil rights section. The paucity of reports in the civil rights section, and especially the failure of HHS to include a report, may create the unfortunate impression that HIV discrimination issues are not taken seriously by all relevant agencies.

made note OCR/HHS

We are grateful to have the opportunity to share our concerns with you, and for the enormous amount of work you and your staff have done to put together this groundbreaking document. Thank you for all of your hard work. If we can be of further assistance, please do not hesitate to contact us.

Sincerely,

Benjamin Schatz, JD, Chair
Kathy Gerus
Tom Henderson
Ronald Johnson

October 9, 1996

To: Jeff Levi
National Office of Aids Policy

From: Ed Gould

Re: Services Sub-Committee Comments on
National Aids Strategy Draft

Please excuse the "cryptic" nature of these notes. In the interest of getting this to you quickly, I decided not to worry about being "artful" in my presentation.

Our committee met by telephone last week. Those who had specific comments agreed to put them in writing to me. Given that I have only received a note from Mike Rankin, I am writing this memo based on my thoughts. I will also attempt to "capture" of others although these will be my words not those of the committee. To the extent that these are not complete, I tried. Mike Rankin's letter of two pages follows this memo.

In the introduction by Patsy Fleming, the group would ask for a stronger introduction providing that in bullet 2 in column 1 the rate of new infections reach zero, in the third bullet reflecting a goal that "all" people have access, in the last bullet rather than better we have enhanced care, that a goal of taking HIV out of the political arena be sought and lastly that HIV is a "public health" crisis affecting everyone.

On page 8 where the discussion of cost is found, the group felt a need to reference that AIDS is far from the only "costly" disease and many persons receive substantial support for those illnesses from Federal and State Government.

On page 12, behavioral research, the group is encouraged by the statement and would actually suggest the lack of this research be presented even stronger as a barrier to HIV prevention.

On page 13, the group would recommend a stronger statement that the research and public health data suggests in the absense of treatment for substance abuse on demand, or at least funded much more adequately, "needle exchange" should become a part of the Strategy.

I am not sure where the following comment fits as its seems fairly global - that is as we continue to see improvements in drugs and knowledge about treatment, the time between the development of the information and its dissemination needs to be shortened. [TRIP]

p24. The second full bullet in column 1 should we be thinking about the implications of people who have previously been disabled because of HIV that now feel well enough to at least begin to work again, they not be faced with having to "remain disabled" in order to continue to receive treatment and care.

p25. the emphasis on the difficulty in coordination of some many different programs that help people with HIV/AIDS should have even more emphasis and a way needs to be found to do a better job with that effort.

p.25 We need to find away to help people understand the importance of integrating HOWPA into the broader system of care and treatment for people with HIV if HOWPA is to be fully effective in its purpose.

p. 25 the paragraph at the very end of the second column the thought was that the guidelines need to be broad and flexible given the rate of change being experienced. This is illustrated by the fact that so many HIV patients often know more than their MD. Further, the uneven knowledge often leads to less than "state of the art" care in many parts of the country.

p. 28. We would broaden the "bully pulpit" to include many more people in the Administration than the President.

VA MENTAL HEALTH CENTER
427 13th St.
Oakland, CA 94612
October 3, 1996

Mr. Ed Gould
16655 Calneva Drive
Encino, CA
91436

Dear Ed,

As promised, these are my comments on the VA section of the document.

In a number of VA centers, care for veterans living with HIV/AIDS is excellent. But all too often this is so because there are committed physicians and other clinicians who have chosen to make it so--not because of any clear mandate from DVA Central Office.

In the past, the VA has offered excellent training programs for its clinicians. I don't believe these have been held in several years. This may be because of budget constraints, but that only tells me HIV/AIDS doesn't have a sufficiently strong advocate in the Department. They still provide training for other disorders--they should for AIDS as well.

So this is what I'd like the document to say, vis a vis the DVA:

1. There should be a statement from Secretary Brown to all DVA VISN Directors, Regional Directors, and Chiefs of Staff of medical centers, that he personally considers outreach to, and treatment of veterans living with HIV/AIDS to be a top priority.

2. To that end, medical centers and clinics, whenever possible, should identify clinicians with special expertise in the treatment of HIV/AIDS. Those clinicians should be supported in establishing AIDS clinics and prevention programs.

3. The DVA should provide training conferences for physicians, nurses, and other clinicians, on a regular basis. Those attending these conferences should be expected to return to their various centers with skills and knowledge they can transmit to their colleagues.

4. The DVA should direct those in the field to have regular contact with veterans organizations, public and private hospitals and clinics, and with community HIV/AIDS organizations, with the goal of identifying veterans living with the virus, and bringing them into VA treatment centers if they so desire.

These are the main issues I'd like to see covered, Ed. If I think of others, I'll let you know. There are some absolutely first rate clinicians in the VA, offering the best possible care to vets with HIV--but we have to make sure that's the case in every VA hospital and clinic. And that will take leadership from the top. I hope our Council can help make that happen.

Sincerely,

Robert M. Rankin, M.D.
Chief, MHC, Oakland VAOPC

Mike Isbell

FIRST IN THE FIGHT AGAINST AIDS

GMHC

FAX MEMORANDUM

to: Ms. Patsy Fleming
fax #: (202) 632-1096
re: National AIDS Strategy (Draft)
date: September 25, 1996
pages: 6, including cover sheet.

Jane - Some excellent comments. (I checked the ones I like.)

From the desk of...

Michael T. Isbell
Associate Executive Director
Gay Men's Health Crisis
129 West 20th Street
New York, NY 10011

(212) 337-3351
Fax: (212) 337-1220

MEMORANDUM

To: Members, Prevention Subcommittee
Presidential Advisory Council on HIV/AIDS

From: Mike Isbell

cc: S. Hitt
A. Levine
E. Gould
P. Fleming
J. Levi

Re: [Draft] National AIDS Strategy

Date: September 23, 1996

I'm circulating my preliminary thoughts on the Draft National AIDS Strategy in advance of the Prevention Subcommittee's upcoming conference call. Most of my comments focus on the prevention components, but I've also taken a look at other sections of the Strategy and have included my thoughts on them, as well.

Message from the National AIDS Policy Director

* The introduction should make clearer precisely what the Strategy is and what it isn't. This was, of course, a topic of extensive discussion at our September meeting. Even after all of that discussion, though, I must admit that I'm still a little unclear about what the document is intended to be. When I see the title "National AIDS Strategy," I assume that this represents the federal plan for responding to the epidemic. If that's not what's intended, that should be made plain in the introduction.

* Although the introductory session ends with visionary statements about bringing an end to the epidemic, I'd begin with this idea. Thus, while I'd certainly emphasize the goal of bringing "focus and direction" to the federal AIDS effort, I'd note in the first paragraph that the purpose of everything the federal government is doing is to the speed the day when AIDS will be a thing of the past. A more hard-hitting introduction might help mitigate the inevitable response at the community level to some of the more bureaucratic language within the document.

* The prevention goal (i.e., the second bullet) on page 3 is actually more timid than it need be. The President himself has established the goal of reducing new infections each year, until there are no new infections. On page 11 of the draft, the document refers to "the national goal of no new infections." If that's our goal, we ought to say it up front.

* In fact, I think all of the goals should be sharpened somewhat to indicate the administration's sense of urgency in responding to the epidemic. For example, I'd reframe the third bullet to focus on the goal of ensuring that "*every* person with HIV has meaningful access to the affordable, high-quality services which he or she needs." While it may be unlikely that this goal can ever be achieved, I would assume we all agree that that is our actual objective.

* Although it's unlikely that the administration will incorporate this idea into the national strategy, I believe the Council should go on record urging better coordination of federal AIDS efforts. While the Office of National AIDS Policy plays an important coordinating and consensus-building role within the executive branch, it should be invested with greater authority to ensure accoutability among the federal agencies whose job it will be to effectuate the national strategy.

I. Introduction

* The Introduction states that "AIDS is a costly disease." That's true, of course, and the cost is probably increasing with the advent of new therapies. Moreover, the point is important for the document, since any national strategy statement must justify substantial federal outlays for AIDS prevention, treatment and research.

The document, however, fails to provide additional information to enable the reader to place AIDS-related costs in their proper context. First, while AIDS is expensive, it is not *inordinately* expensive in comparison with other chronic diseases. Second, many of the federal programs mentioned in the document are extremely cost-effective because they help *reduce* HIV-related medical costs. HOPWA, for example, funds a continuum of housing programs that provide far less costly alternatives to institutionalization. Similarly, by reducing the epidemic's long-term burden, HIV prevention services represent an immediate and future economic savings for the country. (In other words, AIDS isn't an endless drain on public resources; rather, the federal government has developed excellent strategies for reducing the epidemic's economic impact.)

I'm not sure that these points belong in the Introduction, which currently has a singleminded focus on AIDS/HIV epidemiology. Somewhere, though, the document should make these points, which might help combat the growing sentiment that "AIDS gets more than its fair share."

II. Overview of Federal Efforts

A. Prevention

* Under "Future Opportunities for Progress," the document should set forth the goal of enhanced coordination of federal HIV prevention efforts, in order to ensure that prevention programs are grounded in behavioral and ethnographic research and based on the latest epidemiologic data. Currently, there is insufficient coordination between the various federal agencies performing prevention science research; similarly, there has historically been inadequate coordination between prevention programs and epidemiology.

* Under "Future Opportunities for Progress," I would reformulate the first bullet as follows: "Improving understanding of trends in HIV transmission, seroprevalence and risk behaviors." (Better understanding of risk behaviors is briefly addressed in the text on page 12 but is ignored in the objective.)

* Our "Future Opportunities for Progress" also depend on addressing policy barriers that impede effective HIV prevention, including the failure to formally remove longstanding restrictions on the content of federally-funded HIV prevention materials, the federal ban on funding for needle exchange programs, State needle prescription laws, and the timidity of State and local education officials to ensure appropriate HIV education for at-risk youth. While the federal government lacks actual control over some of these issues, the need for federal leadership is clear.

* The document does not address the role of counseling and testing in HIV prevention, which is curious, given its historic prominence at the CDC. While I believe the Council should reject the simplistic (and inaccurate) notion that testing itself should be the centerpiece of our prevention efforts, it is equally clear that the nation's laissez faire approach to testing effectively squanders countless opportunities to intervene with effective HIV prevention services.

Research on Effective Prevention Strategies

The document's emphasis on prevention research is greatly appreciated. I'd flesh it out, though, in the following ways:

* In addition to behavioral research, I would at least mention the need for enhanced support for ethnographic and qualitative research on community cultures, social networks, etc.

* Given the potentially important impact on prevention of viral load, genetic mutations and drug resistance, some mention should be made of the need to link prevention science with the ongoing basic science research agenda.

* The emphasis on evaluation is great. My experience of evaluation components included in most government prevention contracts, however, is that they don't wind up telling us very much. If we truly want to emphasize evaluation, the government is going to have to pay for it. Thus, I'd move beyond the goal of merely including evaluation components in HIV prevention contracts to a recognition of the need to greatly enhance government support for program evaluation, with particular emphasis on replicable, cutting-edge community-based interventions.

* While I agree with the document's support for the community planning process, I'd like to see a commitment to a comprehensive evaluation of the impact of community planning on HIV prevention services. Based on my experience in New York, I remain deeply skeptical that the community planning process is having the impact envisioned by its original proponents.

Program Integration and Collaboration

* The section on substance abuse places undue emphasis on the intersection of HIV prevention with the nation's drug abuse control efforts. Completely missing is the need to greatly enhance programs for out-of-treatment drug users. In New York and elsewhere, community-based organizations have experienced remarkable success with peer-based programs targeting drug users. The document should call for greater support for these and other programs.

* Better coordination is needed at the federal level among the multiple agencies that address substance use and/or HIV.

* I would imagine that the sentence about needle exchange on page 14 was hard to come by, and I'm certain that Patsy and Jeff deserve praise and thanks for getting even this much into the document. The Council, though, should go on record urging the administration to lift federal restrictions on funding for needle exchange, on the basis of the overwhelming (and growing) body of data demonstrating the effectiveness of needle exchange.

Targeting Vulnerable Populations

* I applaud the inclusion of this objective in the document. In my opinion, however, there is insufficient accountability at the CDC to ensure that sufficient funding is targeted at the populations in greatest need. Some plan to require CDC to account for funding allocation is called for.

Research

* The document appropriately recognizes the need for federal "leadership and coordination" on AIDS research. I'd also add the need for *strategic planning*, since this is the essence of the NIH reforms that led to the Office of AIDS Research (as well as the philosophy of the Levine Commission Report).

Translation of Research Advances Into Practice

* The document repeatedly emphasizes the government's success in speeding the development and approval of new drugs. Little mention, however, is made of the need to perform followup studies to give providers and consumers the information they require to make informed treatment decisions. On its own, industry clearly isn't going to take on this task. Federal leadership is essential. As I understand it, the primary purpose of the Keystone process is to develop strategies for performing critical standard-of-care studies. Given how important federal leadership will be to the success of this effort, I would place emphasis on this item in the national strategy.

* The document appropriately stresses the need for provider education, but it fails to note the overwhelming need for consumer education programs. At GMHC, our experience suggests that the doctor's office is not always the best place for consumers to get the information they need or desire. In light of the potential public health consequences of widespread drug resistance, the country should invest in programs that provide consumers with the information they need (a) to make treatment decisions and (b) to comply with their medical regimens.

* Whenever the issue of provider education is mentioned, the universal default mode seems to be clinical practice guidelines. In the case of HIV disease, however, given the rapid changes in therapeutic and diagnostic approaches, I'm dubious of the meaningfulness of clinical care guidelines. The consensus process for government-sponsored guidelines is so arduous that the guidelines are obsolete as soon as they're published. While clinical guidelines probably have some role in provider education, I think there are numerous other strategies that could be as useful, such as comprehensive professional and public education campaigns. (With regard to people currently in care, the most pressing public policy challenge is probably not how to optimize use of triple-drug combination therapy, but to ensure that patients receive first-generation treatments such as PCP prophylaxis.)

GLMA

Gay and Lesbian Medical Association

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Founded in 1981 as the American Association of Physicians for Human Rights

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October 8, 1996

Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, Suite 1060
Washington, DC 20500

Dear Patsy,

As members of the Discrimination Committee of the Presidential Advisory Council on HIV/AIDS, we are writing to offer some feedback concerning the civil rights section of the draft National AIDS Strategy. We offer suggestions about both the text and appendices.

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We are grateful to have the opportunity to share our concerns with you, and for the enormous amount of work you and your staff have done to put together this groundbreaking document. Thank you for all of your hard work. If we can be of further assistance, please do not hesitate to contact us.

Sincerely,

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Kathy Gerus
Tom Henderson
Ronald Johnson