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Community Comments 11/12/96 [1]

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MEMORANDUM

TO: Patsy Fleming
Director of National AIDS Policy
FROM: AIDS Action Council
Christine Lubinski/Jay Coburn
RE: National AIDS Strategy document
DATE: November 14, 1996

Thank you for giving us the opportunity to meet with you last week to talk about the priorities of your office for the Administration's second term. We have reviewed the draft "White House National AIDS Strategy 1997" that you gave us at that meeting, and while we wish we had been given more time to review this document, we do appreciate the fact that you sought AIDS Action's input.

We are concerned that the draft document reads much more as a litany of ongoing activities than as a strategic plan for at least the next term of this Administration. The information in the document is not even completely current in terms of accurately reflecting the current funding levels of AIDS programs, and certainly does not reflect a clear articulation of the real challenges that now face us in the context of promising new treatments and their implications for HIV prevention, counseling and testing programs, the whole array of access to care and supportive services programs, including safe and appropriate housing. There is little recognition of the barriers which threaten our progress in the AIDS epidemic from vociferous opposition to the budget authority of the OAR, ongoing efforts to stigmatize and discriminate against people with HIV/AIDS and thereby discourage them from finding out their serostatus and/or seeking care; the increasing fragmentation of the nation's health care systems and cost reduction strategies which threaten quality of and access to health care; and the erosion of any genuine commitment to federal leadership in ensuring that people have housing, just to name a few.

Again, while we appreciate the opportunity to review the draft document, the tight timeline for comments and the absence of any real opportunity for collective dialogue on all of these challenging issues, cannot be construed as real community input. Moreover, the small selection of national groups who received this opportunity, hardly adequately represent the breadth and diversity of the national AIDS community. We thought it was important to review this document and to highlight factual inaccuracies and notable omissions, and have done so (see attached). But we also wish to be clear that even with the integration of the comments provide, it is not our view that this document fulfills its function as a plan for a national AIDS strategy.

Substantive Edits/Suggestions on Draft "White House National Strategy Plan 1997"

Per your request, AIDS Action Council staff have reviewed the draft National AIDS Strategy and are submitting the following editing comments for your consideration:

I. Introduction

- The goal to "reduce the number of new HIV infections..." should refer to "continuing support for effective *HIV* prevention efforts;"
- In the section "An Expanding Public Health Threat" on page 6, second paragraph, *gay and bisexual men of color* should be added to the list of populations that are heavily affected today.

II. Overview of Federal Efforts

- The first paragraph on page 8, second to last sentence, add prevention to read: "In FY 1986 the Federal government expenditures for AIDS research, prevention & **surveillance**, income maintenance, and care were \$508 million."

A. Prevention

- Total number of new infection is estimated to be approximately 40,000 to *60,000* people each year.
- On page 9, under "Sentinel accomplishments," fourth bullet, insert community-based to read: "Due in part to successful implementation of CDC-sponsored *community-based* prevention strategies, a slowing in the growth of the epidemic."
- Also on page 9, first column, last bullet, change to read "Launching the AIDS prevention community planning partnership -- empowering local communities to target resources to innovative prevention efforts for communities at risk." Community planning groups do not develop interventions; they are charged with identifying unmet needs and setting priorities.
- Also on page 9, last paragraph, first sentence strike and add: "... are most effective when designed and implemented ~~at a local level~~ *in partnership with communities to whom they are targeted*."
- The section on "Improving Understanding of Trends in the Epidemic" is very good, particularly the assertion that surveillance can be improved without jeopardizing confidentiality. We insist that you explicitly state strong support for the availability of anonymous testing and opposition to mandatory names reporting.

- The section on "Strengthening Community-Based Programs" is very good.
- The section on "Preventing HIV transmission from the use of contaminated injection equipment" is problematic. While CDC has issued guidelines regarding the use of bleach to clean injection equipment, several studies have seriously questioned the effectiveness of bleach as a realistic prevention strategy. Secondly, is CDC now supporting the removal of restrictions on over-the-counter sale of syringes?
- This document needs to address the issues of partner and spousal notification. We recommend under the section on page 14 "Targeting Vulnerable Populations" a section on partner notification programs. One effective strategy to target vulnerable populations is requiring states to make a good faith effort to notify the spouses of persons with HIV and to have in place voluntary partner notification programs that will protect confidentiality and risk of domestic violence. These voluntary programs should be implemented at the local level and only when they will help change risk behaviors and provide referrals to early intervention and care.

B. Research

- The section, *Contributions of AIDS Research to Research on Other Diseases*, is too general. It would be more powerful if it included more actual and detailed cross-over achievements.
- It should be noted that resistance to OAR and the Consolidated Budget has and will in all likelihood continue to threaten long term planning capacity for all AIDS research at NIH. A clear statement of continued support in the face of that resistance would be helpful.
- In the section detailing the Report of the NIH AIDS Research Program Evaluation Task Force, the recommendation calling for increased research into the causes and treatments of HIV related opportunistic infections should be added.
- On page 18, in the bullet point regarding joint efforts with UNAID, add a commitment to encouraging international efforts in vaccine development and testing protocols.
- On page 19, the last sentence seems to come from nowhere. A sentence should be added that suggests that due to the complexity and expense of new regimens and the damage, over time, caused to an individual's immune system by HIV, even the new therapies and regimens are unlikely to produce positive outcomes for many thousands of people living with HIV/AIDS. Therefore, new drug development must continue to be enthusiastically supported.
- Also on page 19, you state a commitment to the continuation of the CPCRA. If the Levine recommendation regarding the collapse of clinical trial networks is implemented, will the CPCRA continue in its present form?

- The final paragraph in the Research section is unclear. The research conducted at DOD, CDC, and the VA should be defined and the \$4 million for AIDS research government wide should be more clearly characterized.

C. Care

Ryan White CARE Act & Housing

- On page 21, the bullet on Titles I and II needs to include insurance continuations and home and community-based care. On page 22, Title V also supports SPNS, which includes ongoing service delivery for Native American populations.
- There is no mention of targeting care services to communities and populations in greatest need or who require services that are culturally relevant such as people of color, women and adolescents. On page 23 "Future Opportunities for Progress" under *Ensuring Effective Use of Limited Funds* reference to the need to target funding and ensure that services reach marginalized communities should be included. To maximize federal dollars, funds must go to those communities and/or groups bearing the brunt of the epidemic and that are in most need of care services. These federal funds would not only provide immediate care services but also provide funding for the development of basic health care delivery infrastructure and programs that are culturally and age sensitive. Although the CARE Act already includes variables that factor in increased need, greater emphasis on addressing the needs of these communities by HRSA is still needed. These communities include people of color in general, women of color and adolescents. Communities of color currently make up over 53% of the cumulative AIDS case count. Women of color make up over 75.4% of AIDS cases among women yet only represent approximately 20% of all women. More than half of all new HIV infections occur in adolescents and young adults.
- References to FY 97 funding levels for the CARE Act must be revised. On page 24 FY 97 funding for the CARE should be \$996 million and HOPWA should be added at \$196.0 million.
- References to the housing needs of people with AIDS are inadequate throughout the document. The changing demographics of the epidemic are reflected in the growing number of individuals and families living with HIV disease who are homeless or near-homeless. Without stable housing, these people cannot access care or promising drug therapies. Moreover, a significant number of homeless individuals are "dually and triply diagnosed" -- *i.e.*, have chemical addictions and/or mental illness in addition to HIV disease -- and require housing linked with intensive supportive services. In particular, housing should be included on page 5 as a critical component of access to care.
- The list of housing programs on page 22 does not include the McKinney Homeless assistance grants or the Section 8 Rental Assistance programs, both of which are as important (if not more important in some areas) than Section 811 housing.

- The Housing Opportunities for People with AIDS Program (HOPWA) is currently not authorized. Reauthorization HOPWA must be a priority for the Administration. On page 24 "Expanding Support for Housing Services" paragraph insert a commitment to a speedy reauthorization so that program is in place to serve people with HIV/AIDS.

Medicaid

- We have updated statistics from Kaiser on the importance of Medicaid for people living with HIV/AIDS. Currently, approximately 53% (estimated 90,000 in 1994) of adult Americans and more than 90% of children living with HIV/AIDS receive their medical coverage through Medicaid.
- In the "preserving Medicaid" paragraph under "Future Opportunities", we think you should emphasize why people with HIV disease turn to Medicaid. Obviously, Medicaid is the safety net for the poor, but the point is that many people are impoverished by the costs of medical care for HIV disease and have no other alternative but to turn to Medicaid. The inadequacies and inequities of private health insurance coverage for HIV disease -- both managed care and fee-for-service plans -- plays a major role in this scenario. (caps, lifetime limits, restricted access to prescription drug services, etc.)
- The Administration should be actively exploring avenues to provide Medicaid coverage for PLWHIV as soon as they become medically needy, as opposed to requiring them to become completely disabled and/or impoverished.

Medicare

- There should be a separate section on Medicare, which is becoming a payer of HIV care for a growing number of people who are living longer with HIV disease and AIDS. Limitations on what benefits are covered under Medicare (no prescription drugs) and limitations on eligibility for supplementary coverage, which is generally not available to those qualifying for Medicare based on disability (as opposed to age), should be addressed.

SSA Programs

- Language should be included about ensuring that hard-won expansions in the SSDI HIV disability criteria are not undermined. Eligibility criteria must be flexible enough to address the unique nature of disease progression and disability in people living with HIV disease.

Improving Quality of Care

- There should be a discrete sub-heading on **managed care** quality standards and regulations in light of the increase in managed care in Medicaid, Medicare, and the private market and the need to ensure that quality and comprehensiveness of health care for PWLHIV is not compromised. HCFA's oversight of state medicaid waiver applications might be cited as a vehicle for managed care oversight, for example. The Administration should also be advocating for strong consumer protections in all managed care plans. Of particular interest to people living with HIV/AIDS are the following issues: gag rules, confidentiality, grievance procedures/disenrollment, choice of provider, out-of plan options, prescription drug coverage.
- The Improving Quality of Care paragraph could be strengthened to include references to quality of benefits and services available to people living with HIV/AIDS. (For example, supporting efforts to expand access to Medigap to under 65 disabled populations eligible for Medicare as discussed earlier.)
- There should be a discrete sub-heading on **private health insurance** which could outline some of the benefits/limitations of Kennedy-Kassebaum legislation. There should be at least some discussion about exploring avenues to make private health insurance coverage more accessible and affordable for PWLHIV (and other chronic illnesses).

D. Civil Rights

- There is no reference to the reauthorization of the Rehabilitation Act and the important protections it provides in the "Future Opportunities" section.
- This section should also include protecting the privacy of personal health information and medical records.
- There is no reference to the importance of fighting discrimination in housing. Citing litigation to ensure "access to nursing homes" only emphasizes the glaring lack of attention to the importance of housing for accessing care and enhancing the quality and duration of life for people living with HIV/AIDS.
- The reference to the HIV/AIDS education program for Federal workers on page 27 should be changed to indicate that the program contained information on how to manage Federal employees who have HIV infection.
- The section "Protecting Workers" (p. 27) should include reference to unjustifiable restrictions on Federal employees, Foreign Service Officers and members of the armed forces who have HIV. We recommend adding: The Director of the Office of National AIDS Policy will work with Federal Agencies to examine policies and eliminate provisions that permit discrimination in promotion and retention based on HIV status.

E. International Activities

- The vaccine and microbicide sections of the Research section should be repeated in this Section with an explanation that lays out the difficulties of treating HIV throughout most of the developing world.
- In the *Sharing Technologies* sub-section, the Administration should define a commitment to work with a wide range of domestic NGO's through a wide range of programmatic mechanisms. If for example, a community based NGO in Cleveland has a particular expertise in an important prevention technology, the government should look to that NGO as a potential contractee for sharing technology. "Lessons Without Borders", a showcase program with very little funding, limits these interactions. If all domestic NGOs -- and not a few large inside the beltway NGOs -- were considered for all information and technology exchange contracts, the goals of the program could be achieved without new funding.
- The maps detailing the spread of the American epidemic are very effective. Are similar maps available for the international epidemic? It could be very powerful to show entire African or Asian countries that look like New York.

F. Translation of Research Advances into Practice

- Translation of research advances is vital and we commend you for making this a specific area addressed in the National Strategy. We have learned over the past fifteen years that prevention, care and research programs that are grounded in the communities most effected by HIV will be the most successful. However, it is vital that communities have the resources and tools, including cutting-edge research findings, to be effective.

Translation is often achieved by policies and programs that closely link research and practice. However, translation in the context of linkages between researchers and care/service providers is primarily seen as a one way street--getting good science into the hands of community-based providers. We believe that the relationship is and should be more symbiotic. Partnerships between science and practice not only results in better programs, but also better science. The focus of this section should be balanced to incorporate the complimentary goals of translating research advances into practice and incorporating the needs of care/service providers in formulating research questions and setting priorities.

- An additional or substitute example of the importance of translation should be included. The work of NIH, CDC and FDA around the effectiveness of latex condoms in the prevention of HIV is very compelling and highlights action that will prevent the transmission of HIV to millions of Americans. This partnership provided clear guidance on the effectiveness of condoms in preventing HIV, supported the development of PSAs promoting the correct and consistent use of condoms and provided public health experts

with the leadership and science needed to make condoms available in controversial settings such as prisons, and school-based HIV prevention programs.

NATIONAL AIDS FUND

FAX TRANSMITTAL

DATE: November 13, 1996

TO: Patricia S. Fleming

FAX (202) 632-1096

FROM: Callie Gass

TOTAL PAGES INCLUDING THIS COVER:

6

COMMENTS:

NATIONAL AIDS FUND

November 12, 1996

BY FAX
5 Pages

Patricia S. Fleming
National AIDS Policy Director
Office of National AIDS Policy
750 17th Street NW, Suite 600
Washington DC 20503

Dear Patsy:

Thank you for the opportunity to comment on the draft of the proposed National AIDS Strategy. We are very pleased that the Office of National AIDS Policy has developed a strategy to serve as "a foundation for the Administration's response to the epidemic." The strategic plan is a good statement of where we find ourselves at the moment and allows us to take stock of our accomplishments. It also delineates the large territory we must cover as we struggle to stop the spread of this epidemic and to provide appropriate care and service to those who are living with HIV disease.

Staff at the National AIDS Fund has reviewed the document and has prepared both general comments and specific recommendations for changes and edits for your consideration.

PRIVATE SECTOR COLLABORATION

We were very concerned that the draft strategy is silent on the contributions the private sector has made - and is continuing to make - to fighting the HIV epidemic. It seems to us that many of the recent accomplishments were the result of collaboration between the government and the private sector. Moreover, it is our experience that the private sector - particularly private philanthropy - is a key player in many regions of the country, particularly in the field of prevention, and nationwide in supporting research. We also urge you not to overlook the role businesses and unions have played in providing prevention education and in changing the workplace environment to accommodate those living and working with HIV/AIDS.

The following additions to the strategy, which address the ongoing collaboration between the government and the private sector, should be considered:

- o *The Message from the National AIDS Policy Director* should contain a paragraph specifically addressing collaboration with private sector philanthropies and businesses, labor, local communities, and religious organizations, rather than lumping everyone together as "non-governmental." These collaborations have strengthened the effectiveness of federally funded initiatives, created powerful partnerships between the public and private sectors, and generated steady increases in volunteerism and charitable giving; all of which stretches scarce federal resources and improves the climate in which all of us do our work. (Page 4, para. 2)

- o Add a bullet to the "Goals" which establishes collaboration as a goal. *"To harmonize federal initiatives with private sector capacities and commitments to alleviate suffering, reduce infections, and seek practical ways to end the pandemic;"* (Page 5)
- o Add information on the successful use of programs, especially AmeriCorps, to add resources to communities as they fight the epidemic; (Page 9)
- o Add the following bullets to the list of actions since President Clinton took office; (Page 9)
 1. Promoting workplace education through Business/Labor Responds to AIDS;
 2. Attaining FDA approval for home testing.
- o Add the word *workplace* to the third bullet on Page 10 so that it reads *"Strengthening community based and workplace programs;"*
- o Integrate the concept of workplace education and prevention into the discussions on page 12, particularly under the subhead *Prevention Education*
- o *Ensuring Effective Use of Limited Resources* (Page 24) should include a fourth method as follows:
(4) and collaborating with the private sector.
- o The *Record of Accomplishments* should include the BRTA Hotline in the fifth bullet. (Page 33).

A. PREVENTION

The strategy in this section is almost a list of all possible things the Administration could do, many of which are clearly out of ONAP's control, such as increasing access to substance abuse treatment and reducing the availability of illegal drugs. All options are given the same importance in the narrative. We recommend that the prevention section emphasize those things which 1) ONAP can reasonably hope to influence and 2) which have a direct and immediate effect on reducing the numbers of transmissions. We believe this strategy should strongly emphasize preventive interventions, – such as syringe exchange, and the elimination of barriers to those interventions as well as effective prevention education, targeted to vulnerable populations, that results in behavior change/modification – as top priorities. We believe that these remain the most direct routes to reducing transmission. The strategy and intent should be crystal clear on this point.

B. RESEARCH

Future Opportunities for Progress.

While the November 1996 Draft Strategy outlines the need for coordination of the *federal* research effort, (page 17) and supports changes at the NIH to help strengthen the *national* vaccine effort, **development of an HIV vaccine will require international cooperation and coordination and additional participation by the private sector.**

The following additions to the Strategy should be considered:

- **state a role for the U.S., perhaps even the President, in the international effort to develop an HIV vaccine (page 17).**

International cooperation and coordination is needed because:

- multiple efficacy trials will be needed and only 1-2 are likely to be done in the U.S. at any point in time;
 - success will depend on protecting individuals from all HIV strains; most HIV strains are just entering the U.S. population, so trials in other countries will be necessary;
 - the recent success in HIV therapeutics will not be of benefit to many people in this country and the world who do not have access to therapy; prevention through vaccination is a more economically feasible strategy for these populations;
 - U.S. dollars invested in developing countries would be better utilized if the AIDS epidemic could be controlled in those countries
- **set a goal of identifying at least a partially effective HIV vaccine by the year 2005 (page 17).**

This goal is appropriate at this time because:

- re-election has been accomplished;
- there is now scientific consensus that an HIV vaccine is possible;
- the first efficacy trial of an HIV vaccine will likely be initiated during the next 4 years; results from this trial would not be available until after the next election so some movement on this topic is virtually assured;
- the recent success in HIV therapeutics has demonstrated what can be accomplished when substantial public and private sector efforts are made;
- the increased private sector involvement necessary for success would be stimulated by Presidential leadership combined with the generally strong economy;
- time is of the essence; the sooner an effective HIV vaccine is found, the sooner the public health benefits and economic savings would accrue to the U.S. and the world.

- **consider specific actions to demonstrate international leadership, coordination and collaboration.**
 - place HIV vaccine development to the G7 agenda to establish a worldwide commitment and strategy (International efforts);
 - work through the World Bank to guarantee loans to developing countries to purchase HIV vaccines (International efforts)
- **commit to a substantial (50-100%) increase in funding for HIV vaccine R&D at the NIH over the next 4 years.**

While it is commendable that this office has taken a strong interest in microbicide research, it could be severely criticized for not taking as active an interest in HIV vaccine development, since vaccines, not microbicides, are a proven, cost effective means for preventing the spread of infectious diseases (page 18). While there is some re-direction of funds at the NIH into vaccine R&D, re-directing existing funds is slow; new funds are needed to adequately stimulate these efforts. Stimulating HIV vaccine research at the NIH will only be half of a successful formula; stimulating private sector investment is also necessary.

- **consider specific actions to attract more private sector involvement in HIV vaccine development:**
 - work with Congress to address issues that impede private sector investment in HIV vaccine development (e.g. liability, patent issues) (page 17).
 - establish a Forum for Collaborative HIV Vaccine Research (page 18) to promote public-private collaboration on AIDS vaccine development, comparable to the one formed for therapeutics research (pg. 19). A separate Forum seems appropriate since the vaccine developers and the issues and obstacles are different from those in HIV therapeutics and since an international perspective is required;
 - consider new models to provide federal funds to stimulate private sector investment in HIV vaccine development.

E. INTERNATIONAL ACTIVITIES

We believe this section misses a good opportunity to identify the extensive work that has been accomplished on the global impact of the epidemic. The section strikes us as vague and unfocused. The section on USAID would be strengthened by the inclusion of dollar figures and a better description of its cumulative contributions to the global fight. *Future Opportunities for Progress* needs more specific action oriented activities to be useful and given recent events, a commitment to maintain and strengthen the USAID Office on AIDS.

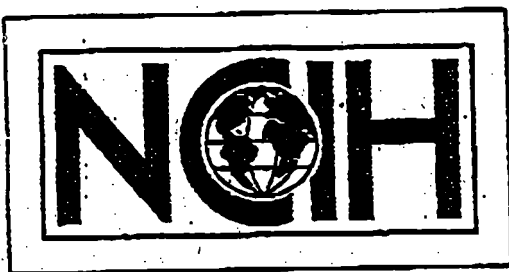
Thank you again for allowing us to comment on your draft document. We hope these comments are helpful as you move towards a final strategy.

If you have any questions or want to discuss these comments further, please give me a call at 202-408-4848, ext 217.

Sincerely,



Callie B. Gass
Deputy Director, Programs and Partnerships



National Council for International Health

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FAX TRANSMITTAL

To: Patsy Fleming
At: ONAP
From: Cynthia Mariel
Dept: AIDS Program

Fax: 202-632-1096
Tel: _____
Date: 13 Nov 96
Ext: 209 Pages: 5

MEMORANDUM



NATIONAL COUNCIL FOR INTERNATIONAL HEALTH

1701 K STREET, N.W. SUITE 600, WASHINGTON, DC 20006, (202) 833-5900, FAX: (202) 833-0075

12 November 1996

Ms. Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, NW
Washington, DC 20503

Dear Patsy:

I would like to thank you again for the recent opportunity to meet with you and your staff and to discuss issues related to global AIDS. I look forward to continuing our history of working together to increase support for and enhanced commitment by the United States government to international AIDS efforts. I greatly appreciate your interest in and demonstrated support for global AIDS issues.

As requested, I have reviewed the draft document, *The National AIDS Strategy*, and have enclosed my comments on the second page to this letter. I very much appreciate the efforts of your office to develop this strategy and congratulate you on the production of such a fine document.

I have prepared a few comments that, of course, reflect my position as an organizational representative working in international AIDS. They do not integrate the political and strategic positioning that is inherent with the work of a White House office. Thus, you will need to weigh my comments against the operational mandate and political context of your own office. Please feel free to contact me if you require additional information and/or review.

In addition, I would also like to take this opportunity to make a special request. I would very much like to include an interview with you for our upcoming issue of *AIDSLink*. The interview would be in a written question and answer format and would focus on the activities of your office in regards to international AIDS during the upcoming Administration.

Based largely on our conversation last week, I have prepared several written questions that are enclosed as a separate page of this letter. Please review the questions and then contact me so that I might know if you are available and agreeable to this interview. For purposes of clarity and efficiency, I am simply asking that you prepare a written response to the questions as well as add any additional comments. In order to meet our press deadline, I would need receive your response to the interview questions no later than 25 November 1996.

Thank you again for the opportunity to work with the Office of National AIDS Policy. I look forward to hearing from you in the near future.

Sincerely,

Cynthia E. Mariel
NCIH AIDS Program



**Comments on the draft copy of
The National AIDS Strategy**

1. Page 3, left column, paragraph 1

Defeating HIV is compared to eradication of smallpox and polio.

Comment: Many would argue that such a comparison tends to medicalize HIV when the issue of HIV/AIDS is multi-faceted and goes well beyond a health problem with a medical solution.

2. Page 5, left column, goal #2

Comment: Because HIV is so closely linked to contextual factors such as socio-economic conditions it might be valuable to include additional wording so that the goal reads, "by providing strong continuing support for effective AIDS prevention efforts and reduction of the socio-economic conditions that contribute to the spread of HIV."

3. Page 7, right column, final paragraph

Comment: The description of the global AIDS epidemic does not cover areas addressed in the previous paragraphs on domestic AIDS. It might be valuable to include some descriptive information that identifies the percentage of HIV infections globally as compared to the number in the U.S., the percentage of global infections that are among women, the percentage of infections that are via heterosexual transmission, and the care related expenditures by the U.S. government related to international AIDS.

4. Page 29, right column, final paragraph

Comment: Does more specific descriptive information need to be added when identifying the United States as the largest contributor to international efforts to combat the pandemic of HIV and AIDS? I have previously heard representatives from USAID describe this role in more specific language.

5. Page 30, right and left column under Future Opportunities for Progress

Comment: In general, the description under this heading focuses on past activities as compared to identification of future commitments. More specifically, in reference to the Paris AIDS Declaration more action oriented language might be included such as, "The U.S. will actively support full enactment of the 1994 Paris AIDS Declaration, of which the U.S. was a signature, through government policies and programs and will encourage other nations to become signatures and supporters of the Paris AIDS Declaration."

6. Page 30, left column, last paragraph

Comment: It is recommended that another statement be added that indicates that the U.S. needs to strengthen support for global HIV/AIDS activities among U.S.-based private voluntary organizations, nongovernmental organizations in developing countries and global HIV/AIDS networks.

Interview questions for *AIDSLink*

1. What do you consider to be the number one priority of your office during the next four years in terms of the US global response to AIDS?
2. How can US-based organizations active in global AIDS efforts assist ONAP in achieving this goal?
3. What contributions can AIDS organizations from developing countries make towards this goal?
4. Why do you think support by the US government to UNAIDS is critical to an effective response to the AIDS pandemic?
5. How can US support for UNAIDS be strengthened?
6. What do you consider the role of your office to be in relationship to major USAID contractors working on international AIDS projects?
7. Why do you think it is important for US-based domestic AIDS groups to become involved in global AIDS?
8. What unique contributions do you believe US-based domestic AIDS groups can make to global AIDS efforts?
9. Based on your knowledge of the US Congress and results of the recent US elections, what are the most effective kinds of educational and advocacy activities that *AIDSLink* readers need to undertake in order to increase support for global AIDS?
10. At present, over 90 % of HIV infection is among developing country populations and yet, approximately only 8 % of global HIV/AIDS funding is spent in developing countries. In addition, per capita health related expenditures by health ministries in many developing countries are less than \$2 per year. How do you reconcile these realities with the strong support you have demonstrated on the issue of equitable access to AIDS treatment and care in developing countries?
11. On World AIDS Day 1994 you were the US representative to the Paris AIDS Summit. At this meeting, the US joined with 42 countries in signing a declaration in which national governments undertook to promote and protect the rights of individuals, particularly people living with HIV/AIDS. To date, the US government still has a travel ban in place restricting people living with HIV/AIDS from entering the country. Will elimination of this restriction be a priority of your office during the next four years?

Additional comments: If the President will be introducing the National AIDS Strategy before December 6, it would be great to include this as an announcement in *AIDSlink* and comments from you on how ONAP will use this strategy in their international AIDS efforts.

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

FACSIMILE TRANSMISSION

to
Patsy Fleming
Jeff Levi

from
Julie Scofield

date
11/12

page/s to follow
3

- ☐ As requested
- ☐ Review and comment
- ☐ As discussed
- ☐ Please respond
- ☐ For your information

If transmission is not
complete, please call
202-434-8090

comments

- Comments / feedback on PRAT
strategy document
- Would like to nail down a meeting
with you soon as well -

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

MEMORANDUM

November 12, 1996

TO: Patricia S. Fleming, National AIDS Policy Director

FR: Julie M. Scofield  and Joseph F. Kelly  NASTAD

RE: Comments on The National AIDS Strategy

Thank you for the opportunity to provide comments on the draft document "The National AIDS Strategy." We look forward to meeting with you in the near future to discuss this document and other issues of importance as the Administration prepares for a second term of office.

Introduction

We have two brief comments on this section. First, the document should include the most recent figures from CDC on the epidemic. Second, we are troubled by the use of disease comparisons in the discussion of the lifetime cost of medical care. The AIDS community is outraged when other organizations use such comparisons. We feel it is divisive to use these kind of comparisons to justify investments in programs and/or public policy decisions.

Prevention

In general, this section adequately lays out a national HIV prevention agenda. We particularly support the references to HIV prevention community planning as the centerpiece of our nation's HIV prevention strategy and recommend that the importance of community planning be recognized throughout this section. Specifically, under the section on primary care, community planning should be referenced in the discussion of our counseling and testing programs. Efforts to target and enhance counseling and testing programs will require discussion and support from community planning groups around the country. In addition, we would like to raise the following concerns with the prevention section.

First, more attention needs to be paid to the prevention of HIV among injection drug users and other substance users. In particular, in the accomplishment section, mention of the Tampa initiative should be included. There should also be a goal specific to prevention of HIV among injection drug users in the section on future opportunities. This is far too important a prevention challenge to be mentioned only within the context of other sections.

Second, there should be a funding initiative for HIV prevention in the section on future opportunities. Additional resources are needed at the local level to implement the high priority prevention programs identified through the community planning process. We do not believe we can accomplish our national HIV prevention goals without additional resources from the federal government.

The reference to the "Congressionally-set goal of reducing perinatal transmission by 50 percent by the year 2000" should be eliminated. This is a glaring oversimplification of the congressional language that fails to recognize the complexity of the issue and the vastly divergent perspectives on the goal itself. This document should not lend credence to language the Administration and other prevention partners had little if any input in crafting.

The language regarding the President's FY 97 budget request should be broadened to include as a priority increasing funding to state and local health departments so that programs benefiting high priority populations, such as those identified by the President, can be implemented.

Care and Services

The strategy is lacking in vision and detail in articulating the future progress needed in HIV/AIDS care and services. Although the statements are clear and important on maintaining as investment priorities the Medicaid program and the CARE Act, there is a very limited strategy described for achieving the goals of affordable, high quality, and responsive care services. In our view, the President's strategy speaks too cautiously about the most recent HIV therapies and disease monitoring technologies. Although we agree that long-term clinical effectiveness of combination therapies and protease inhibitors has yet to be fully demonstrated, there is abundant evidence among researchers, clinicians and consumers that there has been a breakthrough in the way in which HIV disease is treated.

These developments have already changed the routine ways in which HIV care is being delivered and paid for by government programs. The draft White House strategy for AIDS care and services pays little attention to the way in which the newest therapies have altered the treatment opportunities for people living with HIV/AIDS and gives no mention to the way in which the scientific breakthrough represented by viral load testing has changed how HIV disease is attacked by medical intervention.

We believe there needs to be a stronger statement of commitment in the President's strategy that articulates the following points:

- access to the latest developments in HIV/AIDS treatment needs to be a high priority to ensure that these breakthrough therapies are not merely available to individuals

with the ability to pay but are affordable and available to those individuals who are uninsured or underinsured.

- viral load testing represents an important new method for monitoring HIV/AIDS treatment and progression of HIV disease and strategies should be developed to ensure that access is provided in the context of high quality primary care services.
- federal agencies should work with states to ensure that state-of-the-art treatment strategies are employed throughout the public and private sector health care settings, including Medicaid managed care and Ryan White settings.
- the federal government, working in partnership with states and the private sector should develop long-term strategies for examining cost-reduction in terms of the new therapies.

Appendices

We have not had sufficient time to review and comment on the appendices in depth. However, the section of the appendices for HRSA is, in general, woefully inadequate in articulating a vision for delivering HIV/AIDS care for the next several years. The approaches described appear to be a mere fulfillment of the reauthorized CARE Act requirements, and fall short of describing a strategy for ensuring that high quality HIV/AIDS care is affordable, accessible and responsive to the changing treatment dynamics into the next century. The HRSA section could benefit from the kind of goal setting and examination that is described in the section for the Department of Veterans Affairs which appears to reflect a better understanding of the new treatment developments and translating these developments to patients within the VA health system.

Thank you for the opportunity to provide our comments. We look forward to meeting with you as soon as a time can be arranged.

GAAN Global AIDS Action Network

1931 13th Street N.W. Washington D.C. 20009 202-667-6300 202-483-1135-Fax globalaids@aol.com

To: Patsy Fleming
National AIDS Policy Coordinator

— Attn: Jane Sanville

From: Paul Boneberg
Global AIDS Action Network (GAAN)

RE: Draft National AIDS Plan

Date: November 12, 1996

Patsy--

Thank you for the opportunity to comment on the draft national AIDS plan.

Let us begin by again acknowledging the importance of the plan's existence and the inclusion of international issues within it. We recognize that incorporating the complex international aspect is difficult.

We have no objections to what is outlined as the US response to the global pandemic, however we do urge consideration of a few additions and clarifications.

1. Most importantly we urge the inclusion of a statement specifically reiterating the continuing priority of supporting NGOs working in AIDS on the community level. As you know this has been an essential component of US leadership.
2. Also missing is the US commitment to research that has direct impact on our international programs. We urge that our commitment to the development of vaccines, microbicides, and therapeutics that is outlined in the research section be briefly restated in the international program element. To not mention microbicides and vaccines in particular could send the message that the US is lessening its support, which we are sure is not our intent.
3. The section dealing with the skills exchange could be read as limiting domestic NGO involvement to the "Lessons Without Borders" program. We would urge that you make clear that utilizing the expertise of domestic AIDS groups is an element of global AIDS efforts and the "Lessons Without Borders" program is a part--not the entirety-- of that endeavor.
4. The President's quote (again in the research section) on the US commitment for a vaccine and a cure is the heart of the US commitment on AIDS. If that could be reiterated relative to international programs it would be important.
5. Because of the high visibility of this document we think it likely that the graphs showing the spread of HIV will receive great attention in the media. Therefore we urge that a graph showing the international aspect of HIV be included. GAAN believes that such a graphic must exist, but have been unable to identify a good candidate. One option was sent to us by UNAIDS which we attach. We urge that you to contact UNAIDS directly and identify an appropriate graphic for inclusion in the document.
6. It would be useful if the role of the Department of State could be clarified. We assume that they are the lead agency, particularly in coordinating the US's multiple efforts that are referred to in the final paragraph on international programs.
7. It would be helpful if, in the section on "translating research advances into practice", it could be stated that advances in vaccines and therapeutics would be incorporated in future US international activities.

Thank you for the opportunity to provide input on the draft National AIDS Plan. If we can be of assistance please let us know.



AIDS Policy Center
For Children, Youth & Families

MEMORANDUM

TO: Jane Sanville, Daniel Montoya
The White House Office of National AIDS Policy

FROM: David C. Harvey, Executive Director 

DATE: November 15, 1996

SUBJ: White House AIDS Strategy Report

Thank for the opportunity of reviewing the draft White House report titled, "The National AIDS Strategy 1997". Please excuse our delay in responding to the request for comments.

In addition to other comments, I want to suggest a revision to page 22 which describes Title IV of the Ryan White CARE Act. You may wish to consider the following revised language:

Title IV provides support for comprehensive HIV care and access to clinical research programs for children, youth, women and families in community-based family and youth-centered systems of care.

CAEAR Coalition Comments on November 1996 Draft of NAS

As dictated by Alexander Robinson

11/14/96

1. Change Formatting. Matthew said it was hard to find the subject areas like research, prevention, etc.
2. Epidemiological and budget data should be the most current.
3. Concern regarding lack of clinical studies on women and children. There are not a lot of FDA-approved drugs for children. Want more work on pediatric indications and more women included in clinical trials.
4. p. 19. Increase the focus on vulnerable populations. Increase Federal research. In this section you only mention non-Federal programs. This is the only place in the document where non-Federal programs are mentioned. [.. in fact, all the programs cited are Federally-supported]
5. p. 21. You grouped Titles I and II together. Even though services are similar, the focus is different. Ernest Hopkins will send suggested language.
6. First four titles are direct service -- the language in the NAS isn't clear.
7. p. 22 Add bullet on SPNS. Matthew suggests: "SPNS is the Nation's research and development support for innovation and replication in the HIV service delivery." Add information on how SPNS is funded. A commitment to the continuing programs should be included.
8. Making an Investment in Care section. Add language about ensuring adequate support for essential care and services funding by the Federal government especially in the areas of substance abuse prevention and treatment and the Tb prevention and treatment.
9. p. 24 in Ensuring Effective Use of Limited Resources section. Add language: "Enhancing technical assistance to CARE Act grantees, planning councils, and consortia."
10. p. 24 in Improving Program Coordination section. Add language about Tb prevention and treatment among people with HIV.
11. p. 25 Improving Quality of Care section. Add CARE Act programs.
12. p. 25 Evaluating Program Effectiveness section. How will this be implemented?
13. Add SPNS to section on Translation of Research Advances into Practice.

Issues raised by NAPWA

1. Needs a letter from the President to the nation stressing the importance of a continuing, strong national response from government and the private sector.
2. Needs to address the issue of Medicare and Medigap insurance for PLWAs.
3. Needs a greater emphasis on the impact of stigmatization, especially homophobia, racism, and sexism.
4. Wants more emphasis on the quality of life for PWAs.
5. Wants more support for viaticals/accelerated benefits.

EXECUTIVE OFFICE OF THE PRESIDENT

12-Nov-1996 02:29pm

TO: Patsy Fleming
TO: Ursula Sanville

FROM: Jeffrey Levi
AIDS Policy Council

SUBJECT: AmFAR

Jane Silver said AmFAR won't have time for specific comments. However, she did pass along that she thought this version was much improved over the earlier one she had seen (a gazillion drafts ago) and that it was a good first step. (First steps can be divided into many substeps. It all depends where you are sitting.)



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April 29, 1994

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
750 17th Street N.W.
Suite 1060
Washington D.C. 20503

Dear Ms. Gebbie:

Thank you for your request to comment on the National HIV Action Agenda. AmFAR sincerely appreciates this opportunity to participate in an effort to define the nation's HIV strategy.

It is difficult to comment on the April 12, 1994, draft document because it is a combination of specific and general goals and the agenda headings as distributed are not a sufficient starting point for mobilizing and organizing the country's HIV effort. We offer here several broad recommendations related to accomplishing the urgent goal of developing a national HIV action agenda:

- **First**, that you urge the President to act swiftly to name his Presidential AIDS Advisory Committee and that this committee participate in the development of the National HIV Action Agenda;
- **Second**, that an inclusive process, which brings together the federal government, the private sector and the AIDS community, be used to identify and set priorities among goals, objectives, etc. All of these participants have substantial knowledge and experience, and are crucial to the successful implementation of a national HIV agenda;
- **Third**, that the HIV agenda include goals, measurable objectives, action steps, responsibilities, a timeline and budgets;

AMERICAN FOUNDATION FOR AIDS RESEARCH

- Fourth, that in developing the research component of the agenda, the Office of National AIDS Policy (ONAP) consult with and involve the Office of AIDS Research (OAR) Director Dr. William Paul, whose office has just developed the FY'96 AIDS Plan for NIH. The process initiated for the OAR Plan was impressive and should be considered for a broader (NIH, DOD, VA) public/private initiative. Similar discussions need to occur with those having major responsibilities for the prevention and services component of the agenda. Cross cutting goals and objectives among the research, prevention and services components also need to be addressed;

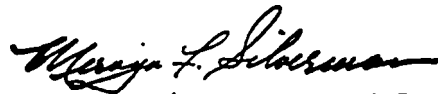
- Fifth, the difficult challenges such as immigration exclusion, syringe exchange, correctional issues, and civil rights, must be addressed if the agenda is to accomplish its mission of mobilizing leadership and serving as a blueprint for action.

The draft document highlights the need to better define the role of ONAP and its relationship to federal departments and agencies. Central to the successful development and implementation of a national agenda is the resolution of questions regarding ONAP's role and responsibilities as they relate to departmental responsibilities and authority.

AmFAR very much appreciates this opportunity to suggest a process for rapidly developing an HIV action agenda necessary both for providing a blueprint for the country to follow and for measuring its successful implementation.

We continue to be available to assist you in any way we can.

Sincerely,



Mervyn F. Silverman, M.D., M.P.H.
President

National AIDS Strategy Community Meetings
Draft - 10/31/96 3:40pm

WEDNESDAY/11-6-96

Human Rights Campaign - 628-1600

Elizabeth Birch-ED

Contact: Don Temple

1-2pm

*No Comments
Rec'd*

AIDS Action Council - 986-1300

Fred Miller-Interim ED

Daniel Zingale-Future ED

Christine Lubinski- Senior Policy Adv.

Contact: Alice Drew x3022

2:30-3:30p

Attached

National AIDS Fund - 408-4848

BJ Stiles-ED

Contact: Adrienne Rice

4-5pm

Attached

THURSDAY/11-7-96

ANIN - 546-0807

Ken South

Contact: Carlos Austina

11am-12pm

*No Comments
Rec'd*

International Group:

1:30-2:30p (T)

GAAN-Paul Boneberg

202/667-6300

202/483-1135 fax

Attached

NCIH-Cynthia Mariel

202/833-5900

202/833-0075 fax

Attached

GNP+-Jairo Pedraza

212/862-9833

No comments Rec'd

NASTAD - 434-8090

Julie Scofield-ED

Contact: Julie Scofield

3:00-4:00pm (T)

Attached

AIDS Policy Center - 785-3564

David Harvey-ED

Barbara Aranda Naranjo-COB

Contact: Heidi Ecker

4:30-5:30pm

Attached

FRIDAY/11-8-96

CAEAR Coalition - 898-0414
Alexander Robinson
Contact: Alexander Robinson

2-3pm (T)

Attached

NMAC - 483-6622
Paul Kawata
Miguelina Maldonado
Contact: Paul Kawata

3-4pm

AMFAR - 331-8600
Jane Silver - Dir. - Public Policy
Dr. Mathilde Krim
Contact: Beth Jones

4:30-5:30pm (T)

Attached

NAPWA - 898-0414
Cornelius Baker
Contact: Mr. Edmond Sylvester

TUESDAY/11-12-96

1:30-2:30pm (T)

Attached

ARC 11/6

98 Budget - HUD, HHS, OMB (housing)

Gordon Adams - PAB - ? DOD

Reauthorizations - NIH, SAMHSA, HAWA.

NIH - Levine Report.

SAMHSA Reauthorization -

Integrate at higher levels.

Research - Forum is up & running.

RS - HCFA is thinking about paying
for clinical trials in
areas beyond HIV.

Microbicides - want them to spend it on microbicides.

Core - 80% of drug market is public, drug pricing.

IL - early intervention has a whole new definition

• Core system built around disability and
late stage.

Demonstrations - Medicaid expansion.

More focus on ITTB - it's going to 1^o care.

IL - Dialogue @ city to move this forward.

In ethical way - don't want to dismantle
end stage until we know these drugs work.

Where is this?

Drugs v. infrastructure -

Drugs - Mayor
African-Americans.

Drich

Office of
Drug Pricing

Adolescent PF
report / fax

out of
Vancouver

What can HRC do?

PF - Nat'l Conference often heated. CSC would fund.

Winnie - we need the #'s to prove it. ??

Rock the Vote, Life Beat, $\Rightarrow$ bring in others.

RS - kept people neutral.

Winnie

H.E.

RS - bring in from other places.

Coburn's prevention bill - what will the strategy do.

RS - Medicaid - $\uparrow$ down to 4%/year. So maybe we
don't ~~want~~ to take a hit on Medicaid.

Elizabeth - dismantling of AIDS infrastructure. [macro funds]

Link to HHS $\sim$ to

trouble shooting / troublemaking.

~~Adrian Christine Lubinski Jay Cohen.~~
Mozzhermes -

Health - NIH, SAMHSA, HHSWA
* Christine - Ad. Rehab Act

Priorities: Prevention, People of color.

Research - Forum (post-marketing strategy trials)
heine

Vaccines + Microbicides

Care. support split between RUCAs, AHA
fighting for HHSWA.

~~Christine~~ → Fair Housing office not a friend of the program.

Availability: SSA and HCEA.

Medicaid - HI - will administration propose a restructuring.
If buying a house and living.

Contributing factors
to ↓ Medicaid base

{ managed care, medical
inflation, economy better }

Will we preserve Medicare too?

How to get the dollars. Development of performance indicators
for HHSWA.

Can we need a health care initiative, Private & Public.

major gap { public → private → pre-existing conditions
health insurance provision of R-K don't apply.

Susan Daniels / _____ - Diana Putina
H-Lopez initiative in NH

Michael Deich)
Housing PAID

~~A~~ - we would fit into the larger fix.

C - Improving Medicare for Medicare ben.

Jack Eelder (ASPE)

Prevention - ~~DC~~ - CDC - how is the \$238 million spent

Gary West / Carmine Jozzi } what's the subtext

Coburn a problem.

Prevention Research — what is the portfolio.

NIH v. CDC.

CDC - 45 FTEs overseeing.

Is CDC holding people accountable.

Jay - 20% should be competitive.

Ch - need R for Q

B - the budget did have this. The \$ is earmarked
for Q, youth, p.o.c. IF talk to Mirella.

H - Title X for planning.

OAR - H - community needs to talk to OAR.
have OAR present to the community.

Goal -

general goals

Start of planning.

implementation process.

DD + HIV policy.

Deployments & promotions

Boards - families & special needs. Precedent.

Antenna
political
value

~~BS~~ Stiles/Califass.

FF - future. Working on 98 budget.

Reauthorizations: NIH, SAMHSA, HOPWA.

Fighting Boman + Coburn.

Prevention - peer education and peer support groups.

QC's 'extra' \$, young people, IDUs
Prevention research important.

Research - Forum.

↑ effort on vaccines.

Microbicides \$100 million over 4 years.

Care

ADAP, J116, SA (training for frontlines people)

↳ BS Stiles - have industry
people @ the table.

Insurance industry at
table. Present

BS - Medicaid - people going home to die,
and they stay there and didn't die.

\$ - having \$ allocated @ point of diagnosis.

Medicaid - 46 billion under balanced budget
period.

Political
Value
Proposition

BS want to take lead
on prevention.

patients have been working
on this.

have you met c. Junders Concerned About AIDS. Want to work c. ~~Richard~~ 

looking for your ^{input} ~~input~~... your antenna... errors of commission/omission.
• There are two parts. Text + appendices

- text → our accomplishments and future opportunities for progress.

Appendices. what we're doing now.

Strategy arranged by policy area - Px.

• It was developed from the Agency-level up. The TAC has also seen it and the version you

Sincerely want your input.

Jiro

International Paul Bomberg, Cynthia Mariel, ~~Ed~~ Pedraza

↑ USAID, support for UNHCR. Promote lessons without borders.

USAID is stepping into care, not just STDs. Need help from domestic groups on the hill. And need their technical assistance. U.S. needs to include the recipients of aid - partnership must be an action. Elaine Daniels shared information with Mexico and Puebla group here.

• Access to Px: important issue. Bomberg put \$ into care issues the U.S. cares about like b, STDs, etc. may to add or to help in to UNHCR. World Bank is a player on the care issue. Jill Cohen is the drug person @ the World Bank. The WFP plan → what does the new science mean to the

U.S. Strategy. What about building plants overseas. Trade/patent overseas. Eric Samper's proposal. Help in accessing the brain power. NRC meeting on AIDS Px in sub-Saharan Africa. Have AID fund.

- PCB - North American Representatives @ JIB.
- last 4 years ^{Bombard} → Bond U.S. AIDS movement to global AIDS movement.
- Shirley Show leadership to other heads of state will/may follow.
- Who's staying going.
- Manuel Paris AIDS summit. How are we living up to this.

11/8 - Sherry Seltzberg / David Harvey.

Thank you. You know what we've achieved. ~~Not~~

Future - 98 budget. Reauthorizations. Pediatric trials.

talk to Sherry.

Seltzberg - Title IV language - how to link to research - meeting legislative. Getting drugs for kids.

HORWA, SAMHSA.

• Coburn bill. Dornan's back.

*** • Prevention. Seltzberg - in NY ~~are~~ coming into mandatory newborn testing. Post-test counseling. Keeping women negative. Opportunity for reaching negative women. Perhaps a new idea. In all cases, they have left the hospital. She will get \$ from Seltzman.

PS - the CDC extra \$. \$34 million.

Technology - have testing in house. And problem of # of false positives.

What about getting companies that do instant testing kits. Demo program.

Rob Jannsen @ CDC is working on it.

• Prevention research. Focus on women, adolescents, POC, young gay men of color.

• Research. Forum, push for vaccines. ^{Fusin} Microbicides.

• Core TBs. HORWA. David Harvey - Title IV ~ 50 million. ↑ here go a long way. Add \$15 million to IV.

Expanding youth. OTG, geographic areas.

OAR reauthorization? living with it.

→ We've made inroads against

neonatal inf - can replicate and leverage the Resources (earmark).

- Counter Coburn, give people color.

① Medicaid. Managed care, medical inflation rate, people (x 2 million)
off the roles, economy good.

Medicare. Rate of growth higher than Medicaid. Absolute \$.

Monkey - had a good meeting c CDC about testing.
community prevention planning.

what A - more inclusive.

② Win in Title IV → ↓ perinatal transmission. Collecting data.
CDC didn't know has been funding their own.

→ competitive set-aside for extra community planning.

* performance measures process →

③ Drug Access - protease inhibitors for women & kids. Secretary
will be submitting Report. PF - runaway youth.

④ Requested DHHS how they will respond to request? [kids +
protease inhibitors.]

⑤ HRSA Administration. AIDS Bureau. Dedicated staff
for Title IV. Issue in MCHB.

{ David will send PF
their board??
research c THB. / 17 re

CLEAR Coalition - Alexander Robinson, Ernest Hopkins,
Thank you. Reaffirmations. Prevention, special pops, Research forum, vaccines,
Rx research. Care-HRW. Medicaid.

Ernest: Medicaid may be going down because we're taking people off
the rolls.

PF have trainings for Medicare Meet c HRCA

Ernest Hopkins: SA has one pager on SA and Alcohol exclusions.
Alexander: What can CLEAR do to help Rx. Why aren't people accessing
care. What makes a difference - color v. non-color Not efficient

Resources in ADAR They've seen ↑ in use of S.A. services (60%)

Also 60% ↑ in new clients, 10 care office visits (94-95)

Trying to make assessments. Priorities informed by changes

Ernest: people on drugs. Drop in the bucket compared to who's in care

It's hard to get, --- process to assess what the new science meant.

Ernest: People really want the conversations about
NE → PF, don't know. Med Marijuana → ^{Gene has a war to fight.}

Alexander - engage those who are opposed in discussion. PF discussions
within the government.

— future conference in these areas.

1/8
Band
revised
#s. for
text
Append
Eva -
updated maps
check
nothing on
international
Latina
international
Chart.
were we
going to top
the issues
raised in
these meetings

NMHC: Moses Agosto, Miguelena Maldonado, Paul Kawata.

FF - Budget. Realignments - NIH, HOPWA, SAMHSA. &
Moses on CARAC - working on the firm curriculum development
project. \$6 million for science aside. 9's issues were perinatal.

RS - 20% ↓ in ped. infections between 94's & 95. OTO announced
in 2/94. Miguelena

Research shift of focus on women. In home Report it doesn't jump out
at you.

Care - Miguelena - Blacks underrepresented in ADP.

SL - Consumer education is a problem. But maybe P.O.C disproportionately
on Medicaid. RS - we'll flip it - HRSA Paul - the consumer education
piece gets bumped around. - who's doing what.

Medicaid - may be off the balanced budget discussion.

Medicaid. Disability + back to work.

Medicare - at \$501 lose cash benefits but can have/buy? Medical
benefits for 39 months + long? for another 11 months.

Med Medicaid.

* PA - Medicaid waiver.

to link domestic + int. PROS/NGOs

Moses - N.E. ~ NASTAD dialogue c ONDCP.

Welfare reform + immigration - what role ONDCP.

1/8
What are
principles.."

AntAR ~>

- intensive education for women.

cross cuts on cost of other diseases. } Would ~~not~~ do
the cross-cut.

- Gramam Amendment

- CCRFA ~>

- drugs for kids.

- NE - looks on books - RW, LHB, & Am/SA.

Strategy Y/N

MEMORANDUM

TO: Patsy Fleming
Director of National AIDS Policy
FROM: AIDS Action Council
Christine Lubinski/Jay Coburn
RE: National AIDS Strategy document
DATE: November 14, 1996

Thank you for giving us the opportunity to meet with you last week to talk about the priorities of your office for the Administration's second term. We have reviewed the draft "White House National AIDS Strategy 1997" that you gave us at that meeting, and while we wish we had been given more time to review this document, we do appreciate the fact that you sought AIDS Action's input.

We are concerned that the draft document reads much more as a litany of ongoing activities than as a strategic plan for at least the next term of this Administration. The information in the document is not even completely current in terms of accurately reflecting the current funding levels of AIDS programs, and certainly does not reflect a clear articulation of the real challenges that now face us in the context of promising new treatments and their implications for HIV prevention, counseling and testing programs, the whole array of access to care and supportive services programs, including safe and appropriate housing. There is little recognition of the barriers which threaten our progress in the AIDS epidemic from vociferous opposition to the budget authority of the OAR, ongoing efforts to stigmatize and discriminate against people with HIV/AIDS and thereby discourage them from finding out their serostatus and/or seeking care; the increasing fragmentation of the nation's health care systems and cost reduction strategies which threaten quality of and access to health care; and the erosion of any genuine commitment to federal leadership in ensuring that people have housing, just to name a few.

Again, while we appreciate the opportunity to review the draft document, the tight timeline for comments and the absence of any real opportunity for collective dialogue on all of these challenging issues, cannot be construed as real community input. Moreover, the small selection of national groups who received this opportunity, hardly adequately represent the breadth and diversity of the national AIDS community. We thought it was important to review this document and to highlight factual inaccuracies and notable omissions, and have done so (see attached). But we also wish to be clear that even with the integration of the comments provide, it is not our view that this document fulfills its function as a plan for a national AIDS strategy.

Substantive Edits/Suggestions on Draft "White House National Strategy Plan 1997"

Per your request, AIDS Action Council staff have reviewed the draft National AIDS Strategy and are submitting the following editing comments for your consideration:

I. Introduction

- The goal to "reduce the number of new HIV infections..." should refer to "continuing support for effective *HIV* prevention efforts;"
- In the section "An Expanding Public Health Threat" on page 6, second paragraph, *gay and bisexual men of color* should be added to the list of populations that are heavily affected today.

II. Overview of Federal Efforts

- The first paragraph on page 8, second to last sentence, add prevention to read: "In FY 1986 the Federal government expenditures for AIDS research, prevention & **surveillance**, income maintenance, and care were \$508 million."

A. Prevention

- Total number of new infection is estimated to be approximately 40,000 to **60,000** people each year.
- On page 9, under "Sentinel accomplishments," fourth bullet, insert community-based to read: "Due in part to successful implementation of CDC-sponsored *community-based* prevention strategies, a slowing in the growth of the epidemic."
- Also on page 9, fist column, last bullet, change to read "Launching the AIDS prevention community planning partnership -- empowering local communities to target resources to innovative prevention efforts for communities at risk." Community planning groups do not develop interventions; they are charged with identifying unmet needs and setting priorities.
- Also on page 9, last paragraph, first sentence strike and add: "... are most effective when designed and implemented ~~at a local level~~ *in partnership with communities to whom they are targeted*."
- The section on "Improving Understanding of Trends in the Epidemic" is very good, particularly the assertion that surveillance can be improved without jeopardizing confidentiality. We insist that you explicitly state strong support for the availability of anonymous testing and opposition to mandatory names reporting.

- The section on "Strengthening Community-Based Programs" is very good.
- The section on "Preventing HIV transmission from the use of contaminated injection equipment" is problematic. While CDC has issued guidelines regarding the use of bleach to clean injection equipment, several studies have seriously questioned the effectiveness of bleach as a realistic prevention strategy. Secondly, is CDC now supporting the removal of restrictions on over-the-counter sale of syringes?
- This document needs to address the issues of partner and spousal notification. We recommend under the section on page 14 "Targeting Vulnerable Populations" a section on partner notification programs. One effective strategy to target vulnerable populations is requiring states to make a good faith effort to notify the spouses of persons with HIV and to have in place voluntary partner notification programs that will protect confidentiality and risk of domestic violence. These voluntary programs should be implemented at the local level and only when they will help change risk behaviors and provide referrals to early intervention and care.

B. Research

- The section, *Contributions of AIDS Research to Research on Other Diseases*, is too general. It would be more powerful if it included more actual and detailed cross-over achievements.
- It should be noted that resistance to OAR and the Consolidated Budget has and will in all likelihood continue to threaten long term planning capacity for all AIDS research at NIH. A clear statement of continued support in the face of that resistance would be helpful.
- In the section detailing the Report of the NIH AIDS Research Program Evaluation Task Force, the recommendation calling for increased research into the causes and treatments of HIV related opportunistic infections should be added.
- On page 18, in the bullet point regarding joint efforts with UNAID, add a commitment to encouraging international efforts in vaccine development and testing protocols.
- On page 19, the last sentence seems to come from nowhere. A sentence should be added that suggests that due to the complexity and expense of new regimens and the damage, over time, caused to an individual's immune system by HIV, even the new therapies and regimens are unlikely to produce positive outcomes for many thousands of people living with HIV/AIDS. Therefore, new drug development must continue to be enthusiastically supported.
- Also on page 19, you state a commitment to the continuation of the CPCRA. If the Levine recommendation regarding the collapse of clinical trial networks is implemented, will the CPCRA continue in its present form?

- The final paragraph in the Research section is unclear. The research conducted at DOD, CDC, and the VA should be defined and the \$4 million for AIDS research government wide should be more clearly characterized.

C. Care

Ryan White CARE Act & Housing

- On page 21, the bullet on Titles I and II needs to include insurance continuations and home and community-based care. On page 22, Title V also supports SPNS, which includes ongoing service delivery for Native American populations.
- There is no mention of targeting care services to communities and populations in greatest need or who require services that are culturally relevant such as people of color, women and adolescents. On page 23 "Future Opportunities for Progress" under *Ensuring Effective Use of Limited Funds* reference to the need to target funding and ensure that services reach marginalized communities should be included. To maximize federal dollars, funds must go to those communities and/or groups bearing the brunt of the epidemic and that are in most need of care services. These federal funds would not only provide immediate care services but also provide funding for the development of basic health care delivery infrastructure and programs that are culturally and age sensitive. Although the CARE Act already includes variables that factor in increased need, greater emphasis on addressing the needs of these communities by HRSA is still needed. These communities include people of color in general, women of color and adolescents. Communities of color currently make up over 53% of the cumulative AIDS case count. Women of color make up over 75.4% of AIDS cases among women yet only represent approximately 20% of all women. More than half of all new HIV infections occur in adolescents and young adults.
- References to FY 97 funding levels for the CARE Act must be revised. On page 24 FY 97 funding for the CARE should be \$996 million and HOPWA should be added at \$196.0 million.
- References to the housing needs of people with AIDS are inadequate throughout the document. The changing demographics of the epidemic are reflected in the growing number of individuals and families living with HIV disease who are homeless or near-homeless. Without stable housing, these people cannot access care or promising drug therapies. Moreover, a significant number of homeless individuals are "dually and triply diagnosed" -- i.e., have chemical addictions and/or mental illness in addition to HIV disease -- and require housing linked with intensive supportive services. In particular, housing should be included on page 5 as a critical component of access to care.
- The list of housing programs on page 22 does not include the McKinney Homeless assistance grants or the Section 8 Rental Assistance programs, both of which are as important (if not more important in some areas) than Section 811 housing.

- The Housing Opportunities for People with AIDS Program (HOPWA) is currently not authorized. Reauthorization HOPWA must be a priority for the Administration. On page 24 "Expanding Support for Housing Services" paragraph insert a commitment to a speedy reauthorization so that program is in place to serve people with HIV/AIDS.

Medicaid

- We have updated statistics from Kaiser on the importance of Medicaid for people living with HIV/AIDS. Currently, approximately 53% (estimated 90,000 in 1994) of adult Americans and more than 90% of children living with HIV/AIDS receive their medical coverage through Medicaid.
- In the "preserving Medicaid" paragraph under "Future Opportunities", we think you should emphasize why people with HIV disease turn to Medicaid. Obviously, Medicaid is the safety net for the poor, but the point is that many people are impoverished by the costs of medical care for HIV disease and have no other alternative but to turn to Medicaid. The inadequacies and inequities of private health insurance coverage for HIV disease -- both managed care and fee-for-service plans -- plays a major role in this scenario. (caps, lifetime limits, restricted access to prescription drug services, etc.)
- The Administration should be actively exploring avenues to provide Medicaid coverage for PLWHIV as soon as they become medically needy, as opposed to requiring them to become completely disabled and/or impoverished.

Medicare

- There should be a separate section on Medicare, which is becoming a payer of HIV care for a growing number of people who are living longer with HIV disease and AIDS. Limitations on what benefits are covered under Medicare (no prescription drugs) and limitations on eligibility for supplementary coverage, which is generally not available to those qualifying for Medicare based on disability (as opposed to age), should be addressed.

SSA Programs

- Language should be included about ensuring that hard-won expansions in the SSDI HIV disability criteria are not undermined. Eligibility criteria must be flexible enough to address the unique nature of disease progression and disability in people living with HIV disease.

Improving Quality of Care

- There should be a discrete sub-heading on **managed care** quality standards and regulations in light of the increase in managed care in Medicaid, Medicare, and the private market and the need to ensure that quality and comprehensiveness of health care for PWLHIV is not compromised. HCFA's oversight of state medicaid waiver applications might be cited as a vehicle for managed care oversight, for example. The Administration should also be advocating for strong consumer protections in all managed care plans. Of particular interest to people living with HIV/AIDS are the following issues: gag rules, confidentiality, grievance procedures/disenrollment, choice of provider, out-of plan options, prescription drug coverage.
- The Improving Quality of Care paragraph could be strengthened to include references to quality of benefits and services available to people living with HIV/AIDS. (For example, supporting efforts to expand access to Medigap to under 65 disabled populations eligible for Medicare as discussed earlier.)
- There should be a discrete sub-heading on **private health insurance** which could outline some of the benefits/limitations of Kennedy-Kassebaum legislation. There should be at least some discussion about exploring avenues to make private health insurance coverage more accessible and affordable for PWLHIV (and other chronic illnesses).

D. Civil Rights

- There is no reference to the reauthorization of the Rehabilitation Act and the important protections it provides in the "Future Opportunities" section.
- This section should also include protecting the privacy of personal health information and medical records.
- There is no reference to the importance of fighting discrimination in housing. Citing litigation to ensure "access to nursing homes" only emphasizes the glaring lack of attention to the importance of housing for accessing care and enhancing the quality and duration of life for people living with HIV/AIDS.
- The reference to the HIV/AIDS education program for Federal workers on page 27 should be changed to indicate that the program contained information on how to manage Federal employees who have HIV infection.
- The section "Protecting Workers" (p. 27) should include reference to unjustifiable restrictions on Federal employees, Foreign Service Officers and members of the armed forces who have HIV. We recommend adding: The Director of the Office of National AIDS Policy will work with Federal Agencies to examine policies and eliminate provisions that permit discrimination in promotion and retention based on HIV status.

E. International Activities

- The vaccine and microbicide sections of the Research section should be repeated in this Section with an explanation that lays out the difficulties of treating HIV throughout most of the developing world.
- In the *Sharing Technologies* sub-section, the Administration should define a commitment to work with a wide range of domestic NGO's through a wide range of programmatic mechanisms. If for example, a community based NGO in Cleveland has a particular expertise in an important prevention technology, the government should look to that NGO as a potential contractee for sharing technology. "Lessons Without Borders", a showcase program with very little funding, limits these interactions. If all domestic NGOs -- and not a few large inside the beltway NGOs -- were considered for all information and technology exchange contracts, the goals of the program could be achieved without new funding.
- The maps detailing the spread of the American epidemic are very effective. Are similar maps available for the international epidemic? It could be very powerful to show entire African or Asian countries that look like New York.

F. Translation of Research Advances into Practice

- Translation of research advances is vital and we commend you for making this a specific area addressed in the National Strategy. We have learned over the past fifteen years that prevention, care and research programs that are grounded in the communities most effected by HIV will be the most successful. However, it is vital that communities have the resources and tools, including cutting-edge research findings, to be effective.

Translation is often achieved by policies and programs that closely link research and practice. However, translation in the context of linkages between researchers and care/service providers is primarily seen as a one way street--getting good science into the hands of community-based providers. We believe that the relationship is and should be more symbiotic. Partnerships between science and practice not only results in better programs, but also better science. The focus of this section should be balanced to incorporate the complimentary goals of translating research advances into practice and incorporating the needs of care/service providers in formulating research questions and setting priorities.

- An additional or substitute example of the importance of translation should be included. The work of NIH, CDC and FDA around the effectiveness of latex condoms in the prevention of HIV is very compelling and highlights action that will prevent the transmission of HIV to millions of Americans. This partnership provided clear guidance on the effectiveness of condoms in preventing HIV, supported the development of PSAs promoting the correct and consistent use of condoms and provided public health experts

with the leadership and science needed to make condoms available in controversial settings such as prisons, and school-based HIV prevention programs.

NATIONAL AIDS FUND

FAX TRANSMITTAL

DATE: November 13, 1996
TO: Patricia S. Fleming
FAX (202) 632-1096
FROM: Callie Gass

TOTAL PAGES INCLUDING THIS COVER:

6

COMMENTS:

NATIONAL AIDS FUND

November 12, 1996

Patricia S. Fleming
National AIDS Policy Director
Office of National AIDS Policy
750 17th Street NW, Suite 600
Washington DC 20503

BY FAX
5 Pages

Dear Patsy:

Thank you for the opportunity to comment on the draft of the proposed National AIDS Strategy. We are very pleased that the Office of National AIDS Policy has developed a strategy to serve as "a foundation for the Administration's response to the epidemic." The strategic plan is a good statement of where we find ourselves at the moment and allows us to take stock of our accomplishments. It also delineates the large territory we must cover as we struggle to stop the spread of this epidemic and to provide appropriate care and service to those who are living with HIV disease.

Staff at the National AIDS Fund has reviewed the document and has prepared both general comments and specific recommendations for changes and edits for your consideration.

PRIVATE SECTOR COLLABORATION

We were very concerned that the draft strategy is silent on the contributions the private sector has made - and is continuing to make - to fighting the HIV epidemic. It seems to us that many of the recent accomplishments were the result of collaboration between the government and the private sector. Moreover, it is our experience that the private sector - particularly private philanthropy - is a key player in many regions of the country, particularly in the field of prevention, and nationwide in supporting research. We also urge you not to overlook the role businesses and unions have played in providing prevention education and in changing the workplace environment to accommodate those living and working with HIV/AIDS.

The following additions to the strategy, which address the ongoing collaboration between the government and the private sector, should be considered:

- o *The Message from the National AIDS Policy Director* should contain a paragraph specifically addressing collaboration with private sector philanthropies and businesses, labor, local communities, and religious organizations, rather than lumping everyone together as "non-governmental." These collaborations have strengthened the effectiveness of federally funded initiatives, created powerful partnerships between the public and private sectors, and generated steady increases in volunteerism and charitable giving; all of which stretches scarce federal resources and improves the climate in which all of us do our work. (Page 4, para. 2)

- o Add a bullet to the "Goals" which establishes collaboration as a goal. *"To harmonize federal initiatives with private sector capacities and commitments to alleviate suffering, reduce infections, and seek practical ways to end the pandemic;"* (Page 5)
- o Add information on the successful use of programs, especially AmeriCorps, to add resources to communities as they fight the epidemic; (Page 9)
- o Add the following bullets to the list of actions since President Clinton took office; (Page 9)
 1. Promoting workplace education through Business/Labor Responds to AIDS;
 2. Attaining FDA approval for home testing.
- o Add the word *workplace* to the third bullet on Page 10 so that it reads *"Strengthening community based and workplace programs;"*
- o Integrate the concept of workplace education and prevention into the discussions on page 12, particularly under the subhead *Prevention Education*
- o *Ensuring Effective Use of Limited Resources* (Page 24) should include a fourth method as follows:
(4) and collaborating with the private sector.
- o The *Record of Accomplishments* should include the BRTA Hotline in the fifth bullet. (Page 33).

A. PREVENTION

The strategy in this section is almost a list of all possible things the Administration could do, many of which are clearly out of ONAP's control, such as increasing access to substance abuse treatment and reducing the availability of illegal drugs. All options are given the same importance in the narrative. We recommend that the prevention section emphasize those things which 1) ONAP can reasonably hope to influence and 2) which have a direct and immediate effect on reducing the numbers of transmissions. We believe this strategy should strongly emphasize preventive interventions, – such as syringe exchange, and the elimination of barriers to those interventions as well as effective prevention education, targeted to vulnerable populations, that results in behavior change/modification – as top priorities. We believe that these remain the most direct routes to reducing transmission. The strategy and intent should be crystal clear on this point.

B. RESEARCH

Future Opportunities for Progress.

While the November 1996 Draft Strategy outlines the need for coordination of the *federal* research effort, (page 17) and supports changes at the NIH to help strengthen the *national* vaccine effort, **development of an HIV vaccine will require international cooperation and coordination and additional participation by the private sector.**

The following additions to the Strategy should be considered:

- **state a role for the U.S., perhaps even the President, in the international effort to develop an HIV vaccine (page 17).**

International cooperation and coordination is needed because:

- multiple efficacy trials will be needed and only 1-2 are likely to be done in the U.S. at any point in time;
 - success will depend on protecting individuals from all HIV strains; most HIV strains are just entering the U.S. population, so trials in other countries will be necessary;
 - the recent success in HIV therapeutics will not be of benefit to many people in this country and the world who do not have access to therapy; prevention through vaccination is a more economically feasible strategy for these populations;
 - U.S. dollars invested in developing countries would be better utilized if the AIDS epidemic could be controlled in those countries
- **set a goal of identifying at least a partially effective HIV vaccine by the year 2005 (page 17).**

This goal is appropriate at this time because:

- re-election has been accomplished;
- there is now scientific consensus that an HIV vaccine is possible;
- the first efficacy trial of an HIV vaccine will likely be initiated during the next 4 years; results from this trial would not be available until after the next election so some movement on this topic is virtually assured;
- the recent success in HIV therapeutics has demonstrated what can be accomplished when substantial public and private sector efforts are made;
- the increased private sector involvement necessary for success would be stimulated by Presidential leadership combined with the generally strong economy;
- time is of the essence; the sooner an effective HIV vaccine is found, the sooner the public health benefits and economic savings would accrue to the U.S. and the world.

- **consider specific actions to demonstrate international leadership, coordination and collaboration.**
 - place HIV vaccine development to the G7 agenda to establish a worldwide commitment and strategy (International efforts);
 - work through the World Bank to guarantee loans to developing countries to purchase HIV vaccines (International efforts)
- **commit to a substantial (50-100%) increase in funding for HIV vaccine R&D at the NIH over the next 4 years.**

While it is commendable that this office has taken a strong interest in microbicide research, it could be severely criticized for not taking as active an interest in HIV vaccine development, since vaccines, not microbicides, are a proven, cost effective means for preventing the spread of infectious diseases (page 18). While there is some re-direction of funds at the NIH into vaccine R&D, re-directing existing funds is slow; new funds are needed to adequately stimulate these efforts. Stimulating HIV vaccine research at the NIH will only be half of a successful formula; stimulating private sector investment is also necessary.

- **consider specific actions to attract more private sector involvement in HIV vaccine development:**
 - work with Congress to address issues that impede private sector investment in HIV vaccine development (e.g. liability, patent issues) (page 17).
 - establish a Forum for Collaborative HIV Vaccine Research (page 18) to promote public-private collaboration on AIDS vaccine development, comparable to the one formed for therapeutics research (pg. 19). A separate Forum seems appropriate since the vaccine developers and the issues and obstacles are different from those in HIV therapeutics and since an international perspective is required;
 - consider new models to provide federal funds to stimulate private sector investment in HIV vaccine development.

E. INTERNATIONAL ACTIVITIES

We believe this section misses a good opportunity to identify the extensive work that has been accomplished on the global impact of the epidemic. The section strikes us as vague and unfocused. The section on USAID would be strengthened by the inclusion of dollar figures and a better description of its cumulative contributions to the global fight. *Future Opportunities for Progress* needs more specific action oriented activities to be useful and given recent events, a commitment to maintain and strengthen the USAID Office on AIDS.

Thank you again for allowing us to comment on your draft document. We hope these comments are helpful as you move towards a final strategy.

If you have any questions or want to discuss these comments further, please give me a call at 202-408-4848, ext 217.

Sincerely,



Callie B. Gass
Deputy Director, Programs and Partnerships



National Council for International Health

1701 K Street, NW - Suite 600
Washington, DC 20006-1503 USA
Tel: 202-833-5900 - Fax: 202-833-0075
E-mail: <ncih@ncih.org>

FAX TRANSMITTAL

To: Patsy Fleming
At: ONAP
From: Cynthia Mariel
Dept: AIDS Program

Fax: 202-632-1096

Tel: _____

Date: 13 Nov 96

Ext: 209 Pages: 5

MEMORANDUM



NATIONAL COUNCIL FOR INTERNATIONAL HEALTH

1701 K STREET, N.W. SUITE 600, WASHINGTON, DC 20006, (202) 833-5900, FAX: (202) 833-0075

12 November 1996

Ms. Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, NW
Washington, DC 20503

Dear Patsy:

I would like to thank you again for the recent opportunity to meet with you and your staff and to discuss issues related to global AIDS. I look forward to continuing our history of working together to increase support for and enhanced commitment by the United States government to international AIDS efforts. I greatly appreciate your interest in and demonstrated support for global AIDS issues.

As requested, I have reviewed the draft document, *The National AIDS Strategy*, and have enclosed my comments on the second page to this letter. I very much appreciate the efforts of your office to develop this strategy and congratulate you on the production of such a fine document.

I have prepared a few comments that, of course, reflect my position as an organizational representative working in international AIDS. They do not integrate the political and strategic positioning that is inherent with the work of a White House office. Thus, you will need to weigh my comments against the operational mandate and political context of your own office. Please feel free to contact me if you require additional information and/or review.

In addition, I would also like to take this opportunity to make a special request. I would very much like to include an interview with you for our upcoming issue of *AIDSLink*. The interview would be in a written question and answer format and would focus on the activities of your office in regards to international AIDS during the upcoming Administration.

Based largely on our conversation last week, I have prepared several written questions that are enclosed as a separate page of this letter. Please review the questions and then contact me so that I might know if you are available and agreeable to this interview. For purposes of clarity and efficiency, I am we are simply asking that you prepare a written response to the questions as well as add any additional comments. In order to meet our press deadline, I would need receive your response to the interview questions no later than 25 November 1996.

Thank you again for the opportunity to work with the Office of National AIDS Policy. I look forward to hearing from you in the near future.

Sincerely,

Cynthia E. Mariel
NCIH AIDS Program



**Comments on the draft copy of
The National AIDS Strategy**

1. Page 3, left column, paragraph 1

Defeating HIV is compared to eradication of smallpox and polio.

Comment: Many would argue that such a comparison tends to medicalize HIV when the issue of HIV/AIDS is multi-faceted and goes well beyond a health problem with a medical solution.

2. Page 5, left column, goal #2

Comment: Because HIV is so closely linked to contextual factors such as socio-economic conditions it might be valuable to include additional wording so that the goal reads, "by providing strong continuing support for effective AIDS prevention efforts and reduction of the socio-economic conditions that contribute to the spread of HIV."

3. Page 7, right column, final paragraph

Comment: The description of the global AIDS epidemic does not cover areas addressed in the previous paragraphs on domestic AIDS. It might be valuable to include some descriptive information that identifies the percentage of HIV infections globally as compared to the number in the U.S., the percentage of global infections that are among women, the percentage of infections that are via heterosexual transmission, and the care related expenditures by the U.S. government related to international AIDS.

4. Page 29, right column, final paragraph

Comment: Does more specific descriptive information need to be added when identifying the United States as the largest contributor to international efforts to combat the pandemic of HIV and AIDS? I have previously heard representatives from USAID describe this role in more specific language.

5. Page 30, right and left column under Future Opportunities for Progress

Comment: In general, the description under this heading focuses on past activities as compared to identification of future commitments. More specifically, in reference to the Paris AIDS Declaration more action oriented language might be included such as, "The U.S. will actively support full enactment of the 1994 Paris AIDS Declaration, of which the U.S. was a signature, through government policies and programs and will encourage other nations to become signatures and supporters of the Paris AIDS Declaration."

6. Page 30, left column, last paragraph

Comment: It is recommended that another statement be added that indicates that the U.S. needs to strengthen support for global HIV/AIDS activities among U.S.-based private voluntary organizations, nongovernmental organizations in developing countries and global HIV/AIDS networks.

Interview questions for *AIDSLink*

1. What do you consider to be the number one priority of your office during the next four years in terms of the US global response to AIDS?
2. How can US-based organizations active in global AIDS efforts assist ONAP in achieving this goal?
3. What contributions can AIDS organizations from developing countries make towards this goal?
4. Why do you think support by the US government to UNAIDS is critical to an effective response to the AIDS pandemic?
5. How can US support for UNAIDS be strengthened?
6. What do you consider the role of your office to be in relationship to major USAID contractors working on international AIDS projects?
7. Why do you think it is important for US-based domestic AIDS groups to become involved in global AIDS?
8. What unique contributions do you believe US-based domestic AIDS groups can make to global AIDS efforts?
9. Based on your knowledge of the US Congress and results of the recent US elections, what are the most effective kinds of educational and advocacy activities that *AIDSLink* readers need to undertake in order to increase support for global AIDS?
10. At present, over 90 % of HIV infection is among developing country populations and yet, approximately only 8 % of global HIV/AIDS funding is spent in developing countries. In addition, per capita health related expenditures by health ministries in many developing countries are less than \$2 per year. How do you reconcile these realities with the strong support you have demonstrated on the issue of equitable access to AIDS treatment and care in developing countries?
11. On World AIDS Day 1994 you were the US representative to the Paris AIDS Summit. At this meeting, the US joined with 42 countries in signing a declaration in which national governments undertook to promote and protect the rights of individuals, particularly people living with HIV/AIDS. To date, the US government still has a travel ban in place restricting people living with HIV/AIDS from entering the country. Will elimination of this restriction be a priority of your office during the next four years?

Additional comments: If the President will be introducing the National AIDS Strategy before December 6, it would be great to include this as an announcement in *AIDSLink* and comments from you on how ONAP will use this strategy in their international AIDS efforts.

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

FACSIMILE TRANSMISSION

to
Patsy Fleming
Jeff Levi

from
Julie Scofield

date
11/12

page/s to follow

3

- ☐ As requested
- ☐ Review and comment
- ☐ As discussed
- ☐ Please respond
- ☐ For your information

If transmission is not
complete, please call
202-434-8090

comments

- Comments / feedback on PRAT strategy document
- Would like to nail down a meeting with you soon as well -

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

MEMORANDUM

November 12, 1996

TO: Patricia S. Fleming, National AIDS Policy Director

FR: Julie M. Scofield and Joseph F. Kelly, NASTAD

RE: Comments on The National AIDS Strategy

Thank you for the opportunity to provide comments on the draft document "The National AIDS Strategy." We look forward to meeting with you in the near future to discuss this document and other issues of importance as the Administration prepares for a second term of office.

Introduction

We have two brief comments on this section. First, the document should include the most recent figures from CDC on the epidemic. Second, we are troubled by the use of disease comparisons in the discussion of the lifetime cost of medical care. The AIDS community is outraged when other organizations use such comparisons. We feel it is divisive to use these kind of comparisons to justify investments in programs and/or public policy decisions.

Prevention

In general, this section adequately lays out a national HIV prevention agenda. We particularly support the references to HIV prevention community planning as the centerpiece of our nation's HIV prevention strategy and recommend that the importance of community planning be recognized throughout this section. Specifically, under the section on primary care, community planning should be referenced in the discussion of our counseling and testing programs. Efforts to target and enhance counseling and testing programs will require discussion and support from community planning groups around the country. In addition, we would like to raise the following concerns with the prevention section.

First, more attention needs to be paid to the prevention of HIV among injection drug users and other substance users. In particular, in the accomplishment section, mention of the Tampa initiative should be included. There should also be a goal specific to prevention of HIV among injection drug users in the section on future opportunities. This is far too important a prevention challenge to be mentioned only within the context of other sections.

Second, there should be a funding initiative for HIV prevention in the section on future opportunities. Additional resources are needed at the local level to implement the high priority prevention programs identified through the community planning process. We do not believe we can accomplish our national HIV prevention goals without additional resources from the federal government.

The reference to the "Congressionally-set goal of reducing perinatal transmission by 50 percent by the year 2000" should be eliminated. This is a glaring oversimplification of the congressional language that fails to recognize the complexity of the issue and the vastly divergent perspectives on the goal itself. This document should not lend credence to language the Administration and other prevention partners had little if any input in crafting.

The language regarding the President's FY 97 budget request should be broadened to include as a priority increasing funding to state and local health departments so that programs benefiting high priority populations, such as those identified by the President, can be implemented.

Care and Services

The strategy is lacking in vision and detail in articulating the future progress needed in HIV/AIDS care and services. Although the statements are clear and important on maintaining as investment priorities the Medicaid program and the CARE Act, there is a very limited strategy described for achieving the goals of affordable, high quality, and responsive care services. In our view, the President's strategy speaks too cautiously about the most recent HIV therapies and disease monitoring technologies. Although we agree that long-term clinical effectiveness of combination therapies and protease inhibitors has yet to be fully demonstrated, there is abundant evidence among researchers, clinicians and consumers that there has been a breakthrough in the way in which HIV disease is treated.

These developments have already changed the routine ways in which HIV care is being delivered and paid for by government programs. The draft White House strategy for AIDS care and services pays little attention to the way in which the newest therapies have altered the treatment opportunities for people living with HIV/AIDS and gives no mention to the way in which the scientific breakthrough represented by viral load testing has changed how HIV disease is attacked by medical intervention.

We believe there needs to be a stronger statement of commitment in the President's strategy that articulates the following points:

- access to the latest developments in HIV/AIDS treatment needs to be a high priority to ensure that these breakthrough therapies are not merely available to individuals

with the ability to pay but are affordable and available to those individuals who are uninsured or underinsured.

- viral load testing represents an important new method for monitoring HIV/AIDS treatment and progression of HIV disease and strategies should be developed to ensure that access is provided in the context of high quality primary care services.
- federal agencies should work with states to ensure that state-of-the-art treatment strategies are employed throughout the public and private sector health care settings, including Medicaid managed care and Ryan White settings.
- the federal government, working in partnership with states and the private sector should develop long-term strategies for examining cost-reduction in terms of the new therapies.

Appendices

We have not had sufficient time to review and comment on the appendices in depth. However, the section of the appendices for HRSA is, in general, woefully inadequate in articulating a vision for delivering HIV/AIDS care for the next several years. The approaches described appear to be a mere fulfillment of the reauthorized CARE Act requirements, and fall short of describing a strategy for ensuring that high quality HIV/AIDS care is affordable, accessible and responsive to the changing treatment dynamics into the next century. The HRSA section could benefit from the kind of goal setting and examination that is described in the section for the Department of Veterans Affairs which appears to reflect a better understanding of the new treatment developments and translating these developments to patients within the VA health system.

Thank you for the opportunity to provide our comments. We look forward to meeting with you as soon as a time can be arranged.

GAAN Global AIDS Action Network

1931 13th Street N.W. Washington D.C. 20009 202-667-6300 202-483-1135-Fax globalaids@aol.com

To: Patsy Fleming
National AIDS Policy Coordinator

— Attn: JANE Samille

From: Paul Boneberg
Global AIDS Action Network (GAAN)

RE: Draft National AIDS Plan

Date: November 12, 1996

Patsy--

Thank you for the opportunity to comment on the draft national AIDS plan.

Let us begin by again acknowledging the importance of the plan's existence and the inclusion of international issues within it. We recognize that incorporating the complex international aspect is difficult.

We have no objections to what is outlined as the US response to the global pandemic, however we do urge consideration of a few additions and clarifications.

1. Most importantly we urge the inclusion of a statement specifically reiterating the continuing priority of supporting NGOs working in AIDS on the community level. As you know this has been an essential component of US leadership.
2. Also missing is the US commitment to research that has direct impact on our international programs. We urge that our commitment to the development of vaccines, microbicides, and therapeutics that is outlined in the research section be briefly restated in the international program element. To not mention microbicides and vaccines in particular could send the message that the US is lessening its support, which we are sure is not our intent.
3. The section dealing with the skills exchange could be read as limiting domestic NGO involvement to the "Lessons Without Borders" program. We would urge that you make clear that utilizing the expertise of domestic AIDS groups is an element of global AIDS efforts and the "Lessons Without Borders" program is a part--not the entirety-- of that endeavor.
4. The President's quote (again in the research section) on the US commitment for a vaccine and a cure is the heart of the US commitment on AIDS. If that could be reiterated relative to international programs it would be important.
5. Because of the high visibility of this document we think it likely that the graphs showing the spread of HIV will receive great attention in the media. Therefore we urge that a graph showing the international aspect of HIV be included. GAAN believes that such a graphic must exist, but have been unable to identify a good candidate. One option was sent to us by UNAIDS which we attach. We urge that you to contact UNAIDS directly and identify an appropriate graphic for inclusion in the document.
6. It would be useful if the role of the Department of State could be clarified. We assume that they are the lead agency, particularly in coordinating the US's multiple efforts that are referred to in the final paragraph on international programs.
7. It would be helpful if, in the section on "translating research advances into practice", it could be stated that advances in vaccines and therapeutics would be incorporated in future US international activities.

Thank you for the opportunity to provide input on the draft National AIDS Plan. If we can be of assistance please let us know.



AIDS Policy Center
For Children, Youth & Families

MEMORANDUM

TO: Jane Sarville, Daniel Montoya
The White House Office of National AIDS Policy

FROM: David C. Harvey, Executive Director *DC*

DATE: November 15, 1996

SUBJ: White House AIDS Strategy Report

Thank for the opportunity of reviewing the draft White House report titled, "The National AIDS Strategy 1997". Please excuse our delay in responding to the request for comments.

In addition to other comments, I want to suggest a revision to page 22 which describes Title IV of the Ryan White CARE Act. You may wish to consider the following revised language:

Title IV provides support for comprehensive HIV care and access to clinical research programs for children, youth, women and families in community-based family and youth-centered systems of care.

CAEAR Coalition Comments on November 1996 Draft of NAS
As dictated by Alexander Robinson
11/14/96

1. Change Formatting. Matthew said it was hard to find the subject areas like research, prevention, etc.
2. Epidemiological and budget data should be the most current.
3. Concern regarding lack of clinical studies on women and children. There are not a lot of FDA-approved drugs for children. Want more work on pediatric indications and more women included in clinical trials.
4. p. 19. Increase the focus on vulnerable populations. Increase Federal research. In this section you only mention non-Federal programs. This is the only place in the document where non-Federal programs are mentioned. [.. in fact, all the programs cited are Federally-supported]
5. p. 21. You grouped Titles I and II together. Even though services are similar, the focus is different. Ernest Hopkins will send suggested language.
6. First four titles are direct service -- the language in the NAS isn't clear.
7. p. 22 Add bullet on SPNS. Matthew suggests: "SPNS is the Nation's research and development support for innovation and replication in the HIV service delivery." Add information on how SPNS is funded. A commitment to the continuing programs should be included.
8. Making an Investment in Care section. Add language about ensuring adequate support for essential care and services funding by the Federal government especially in the areas of substance abuse prevention and treatment and the Tb prevention and treatment.
9. p. 24 in Ensuring Effective Use of Limited Resources section. Add language: "Enhancing technical assistance to CARE Act grantees, planning councils, and consortia."
10. p. 24 in Improving Program Coordination section. Add language about Tb prevention and treatment among people with HIV.
11. p. 25 Improving Quality of Care section. Add CARE Act programs.
12. p. 25 Evaluating Program Effectiveness section. How will this be implemented?
13. Add SPNS to section on Translation of Research Advances into Practice.

Issues raised by NAPWA

1. Needs a letter from the President to the nation stressing the importance of a continuing, strong national response from government and the private sector.
2. Needs to address the issue of Medicare and Medigap insurance for PLWAs.
3. Needs a greater emphasis on the impact of stigmatization, especially homophobia, racism, and sexism.
4. Wants more emphasis on the quality of life for PWAs.
5. Wants more support for viaticals/accelerated benefits.

EXECUTIVE OFFICE OF THE PRESIDENT

12-Nov-1996 02:29pm

TO: Patsy Fleming
TO: Ursula Sanville

FROM: Jeffrey Levi
AIDS Policy Council

SUBJECT: AmFAR

Jane Silver said AmFAR won't have time for specific comments. However, she did pass along that she thought this version was much improved over the earlier one she had seen (a gazillion drafts ago) and that it was a good first step. (First steps can be divided into many substeps. It all depends where you are sitting.)



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April 29, 1994

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
750 17th Street N.W.
Suite 1060
Washington D.C. 20503

Dear Ms. Gebbie:

Thank you for your request to comment on the National HIV Action Agenda. AmFAR sincerely appreciates this opportunity to participate in an effort to define the nation's HIV strategy.

It is difficult to comment on the April 12, 1994, draft document because it is a combination of specific and general goals and the agenda headings as distributed are not a sufficient starting point for mobilizing and organizing the country's HIV effort. We offer here several broad recommendations related to accomplishing the urgent goal of developing a national HIV action agenda:

- **First**, that you urge the President to act swiftly to name his Presidential AIDS Advisory Committee and that this committee participate in the development of the National HIV Action Agenda;

- **Second**, that an inclusive process, which brings together the federal government, the private sector and the AIDS community, be used to identify and set priorities among goals, objectives, etc. All of these participants have substantial knowledge and experience, and are crucial to the successful implementation of a national HIV agenda;

- **Third**, that the HIV agenda include goals, measurable objectives, action steps, responsibilities, a timeline and budgets;

AMERICAN FOUNDATION FOR AIDS RESEARCH

- **Fourth**, that in developing the research component of the agenda, the Office of National AIDS Policy (ONAP) consult with and involve the Office of AIDS Research (OAR) Director Dr. William Paul, whose office has just developed the FY'96 AIDS Plan for NIH. The process initiated for the OAR Plan was impressive and should be considered for a broader (NIH, DOD, VA) public/private initiative. Similar discussions need to occur with those having major responsibilities for the prevention and services component of the agenda. Cross cutting goals and objectives among the research, prevention and services components also need to be addressed;

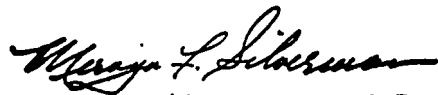
- **Fifth**, the difficult challenges such as immigration exclusion, syringe exchange, correctional issues, and civil rights, must be addressed if the agenda is to accomplish its mission of mobilizing leadership and serving as a blueprint for action.

The draft document highlights the need to better define the role of ONAP and its relationship to federal departments and agencies. Central to the successful development and implementation of a national agenda is the resolution of questions regarding ONAP's role and responsibilities as they relate to departmental responsibilities and authority.

AmFAR very much appreciates this opportunity to suggest a process for rapidly developing an HIV action agenda necessary both for providing a blueprint for the country to follow and for measuring its successful implementation.

We continue to be available to assist you in any way we can.

Sincerely,



Mervyn F. Silverman, M.D., M.P.H.
President

MEMORANDUM

TO: Patsy Fleming
Director of National AIDS Policy
FROM: AIDS Action Council
Christine Lubinski/Jay Coburn
RE: National AIDS Strategy document
DATE: November 14, 1996

Thank you for giving us the opportunity to meet with you last week to talk about the priorities of your office for the Administration's second term. We have reviewed the draft "White House National AIDS Strategy 1997" that you gave us at that meeting, and while we wish we had been given more time to review this document, we do appreciate the fact that you sought AIDS Action's input.

We are concerned that the draft document reads much more as a litany of ongoing activities than as a strategic plan for at least the next term of this Administration. The information in the document is not even completely current in terms of accurately reflecting the current funding levels of AIDS programs, and certainly does not reflect a clear articulation of the real challenges that now face us in the context of promising new treatments and their implications for HIV prevention, counseling and testing programs, the whole array of access to care and supportive services programs, including safe and appropriate housing. There is little recognition of the barriers which threaten our progress in the AIDS epidemic from vociferous opposition to the budget authority of the OAR, ongoing efforts to stigmatize and discriminate against people with HIV/AIDS and thereby discourage them from finding out their serostatus and/or seeking care; the increasing fragmentation of the nation's health care systems and cost reduction strategies which threaten quality of and access to health care; and the erosion of any genuine commitment to federal leadership in ensuring that people have housing, just to name a few.

Again, while we appreciate the opportunity to review the draft document, the tight timeline for comments and the absence of any real opportunity for collective dialogue on all of these challenging issues, cannot be construed as real community input. Moreover, the small selection of national groups who received this opportunity, hardly adequately represent the breadth and diversity of the national AIDS community. We thought it was important to review this document and to highlight factual inaccuracies and notable omissions, and have done so (see attached). But we also wish to be clear that even with the integration of the comments provide, it is not our view that this document fulfills its function as a plan for a national AIDS strategy.

Substantive Edits/Suggestions on Draft "White House National Strategy Plan 1997"

Per your request, AIDS Action Council staff have reviewed the draft National AIDS Strategy and are submitting the following editing comments for your consideration:

I. Introduction

- The goal to "reduce the number of new HIV infections..." should refer to "continuing support for effective *HIV* prevention efforts;"
- In the section "An Expanding Public Health Threat" on page 6, second paragraph, *gay and bisexual men of color* should be added to the list of populations that are heavily affected today.

II. Overview of Federal Efforts

- The first paragraph on page 8, second to last sentence, add prevention to read: "In FY 1986 the Federal government expenditures for AIDS research, prevention & **surveillance**, income maintenance, and care were \$508 million."

A. Prevention

- Total number of new infection is estimated to be approximately 40,000 to **60,000** people each year.
- On page 9, under "Sentinel accomplishments," fourth bullet, insert community-based to read: "Due in part to successful implementation of CDC-sponsored *community-based* prevention strategies, a slowing in the growth of the epidemic."
- Also on page 9, first column, last bullet, change to read "Launching the AIDS prevention community planning partnership -- empowering local communities to target resources to innovative prevention efforts for communities at risk." Community planning groups do not develop interventions; they are charged with identifying unmet needs and setting priorities.
- Also on page 9, last paragraph, first sentence strike and add: "... are most effective when designed and implemented ~~at a local level~~ *in partnership with communities to whom they are targeted*."
- The section on "Improving Understanding of Trends in the Epidemic" is very good, particularly the assertion that surveillance can be improved without jeopardizing confidentiality. We insist that you explicitly state strong support for the availability of anonymous testing and opposition to mandatory names reporting.

- The section on "Strengthening Community-Based Programs" is very good.
- The section on "Preventing HIV transmission from the use of contaminated injection equipment" is problematic. While CDC has issued guidelines regarding the use of bleach to clean injection equipment, several studies have seriously questioned the effectiveness of bleach as a realistic prevention strategy. Secondly, is CDC now supporting the removal of restrictions on over-the-counter sale of syringes?
- This document needs to address the issues of partner and spousal notification. We recommend under the section on page 14 "Targeting Vulnerable Populations" a section on partner notification programs. One effective strategy to target vulnerable populations is requiring states to make a good faith effort to notify the spouses of persons with HIV and to have in place voluntary partner notification programs that will protect confidentiality and risk of domestic violence. These voluntary programs should be implemented at the local level and only when they will help change risk behaviors and provide referrals to early intervention and care.

B. Research

- The section, *Contributions of AIDS Research to Research on Other Diseases*, is too general. It would be more powerful if it included more actual and detailed cross-over achievements.
- It should be noted that resistance to OAR and the Consolidated Budget has and will in all likelihood continue to threaten long term planning capacity for all AIDS research at NIH. A clear statement of continued support in the face of that resistance would be helpful.
- In the section detailing the Report of the NIH AIDS Research Program Evaluation Task Force, the recommendation calling for increased research into the causes and treatments of HIV related opportunistic infections should be added.
- On page 18, in the bullet point regarding joint efforts with UNAID, add a commitment to encouraging international efforts in vaccine development and testing protocols.
- On page 19, the last sentence seems to come from nowhere. A sentence should be added that suggests that due to the complexity and expense of new regimens and the damage, over time, caused to an individual's immune system by HIV, even the new therapies and regimens are unlikely to produce positive outcomes for many thousands of people living with HIV/AIDS. Therefore, new drug development must continue to be enthusiastically supported.
- Also on page 19, you state a commitment to the continuation of the CPCRA. If the Levine recommendation regarding the collapse of clinical trial networks is implemented, will the CPCRA continue in its present form?

- The final paragraph in the Research section is unclear. The research conducted at DOD, CDC, and the VA should be defined and the \$4 million for AIDS research government wide should be more clearly characterized.

C. Care

Ryan White CARE Act & Housing

- On page 21, the bullet on Titles I and II needs to include insurance continuations and home and community-based care. On page 22, Title V also supports SPNS, which includes ongoing service delivery for Native American populations.
- There is no mention of targeting care services to communities and populations in greatest need or who require services that are culturally relevant such as people of color, women and adolescents. On page 23 "Future Opportunities for Progress" under *Ensuring Effective Use of Limited Funds* reference to the need to target funding and ensure that services reach marginalized communities should be included. To maximize federal dollars, funds must go to those communities and/or groups bearing the brunt of the epidemic and that are in most need of care services. These federal funds would not only provide immediate care services but also provide funding for the development of basic health care delivery infrastructure and programs that are culturally and age sensitive. Although the CARE Act already includes variables that factor in increased need, greater emphasis on addressing the needs of these communities by HRSA is still needed. These communities include people of color in general, women of color and adolescents. Communities of color currently make up over 53% of the cumulative AIDS case count. Women of color make up over 75.4% of AIDS cases among women yet only represent approximately 20% of all women. More than half of all new HIV infections occur in adolescents and young adults.
- References to FY 97 funding levels for the CARE Act must be revised. On page 24 FY 97 funding for the CARE should be \$996 million and HOPWA should be added at \$196.0 million.
- References to the housing needs of people with AIDS are inadequate throughout the document. The changing demographics of the epidemic are reflected in the growing number of individuals and families living with HIV disease who are homeless or near-homeless. Without stable housing, these people cannot access care or promising drug therapies. Moreover, a significant number of homeless individuals are "dually and triply diagnosed" -- *i.e.*, have chemical addictions and/or mental illness in addition to HIV disease -- and require housing linked with intensive supportive services. In particular, housing should be included on page 5 as a critical component of access to care.
- The list of housing programs on page 22 does not include the McKinney Homeless assistance grants or the Section 8 Rental Assistance programs, both of which are as important (if not more important in some areas) than Section 811 housing.

- The Housing Opportunities for People with AIDS Program (HOPWA) is currently not authorized. Reauthorization HOPWA must be a priority for the Administration. On page 24 "Expanding Support for Housing Services" paragraph insert a commitment to a speedy reauthorization so that program is in place to serve people with HIV/AIDS.

Medicaid

- We have updated statistics from Kaiser on the importance of Medicaid for people living with HIV/AIDS. Currently, approximately 53% (estimated 90,000 in 1994) of adult Americans and more than 90% of children living with HIV/AIDS receive their medical coverage through Medicaid.
- In the "preserving Medicaid" paragraph under "Future Opportunities", we think you should emphasize why people with HIV disease turn to Medicaid. Obviously, Medicaid is the safety net for the poor, but the point is that many people are impoverished by the costs of medical care for HIV disease and have no other alternative but to turn to Medicaid. The inadequacies and inequities of private health insurance coverage for HIV disease -- both managed care and fee-for-service plans -- plays a major role in this scenario. (caps, lifetime limits, restricted access to prescription drug services, etc.)
- The Administration should be actively exploring avenues to provide Medicaid coverage for PLWHIV as soon as they become medically needy, as opposed to requiring them to become completely disabled and/or impoverished.

Medicare

- There should be a separate section on Medicare, which is becoming a payer of HIV care for a growing number of people who are living longer with HIV disease and AIDS. Limitations on what benefits are covered under Medicare (no prescription drugs) and limitations on eligibility for supplementary coverage, which is generally not available to those qualifying for Medicare based on disability (as opposed to age), should be addressed.

SSA Programs

- Language should be included about ensuring that hard-won expansions in the SSDI HIV disability criteria are not undermined. Eligibility criteria must be flexible enough to address the unique nature of disease progression and disability in people living with HIV disease.

Improving Quality of Care

- There should be a discrete sub-heading on **managed care** quality standards and regulations in light of the increase in managed care in Medicaid, Medicare, and the private market and the need to ensure that quality and comprehensiveness of health care for PWLHIV is not compromised. HCFA's oversight of state medicaid waiver applications might be cited as a vehicle for managed care oversight, for example. The Administration should also be advocating for strong consumer protections in all managed care plans. Of particular interest to people living with HIV/AIDS are the following issues: gag rules, confidentiality, grievance procedures/disenrollment, choice of provider, out-of plan options, prescription drug coverage.
- The Improving Quality of Care paragraph could be strengthened to include references to quality of benefits and services available to people living with HIV/AIDS. (For example, supporting efforts to expand access to Medigap to under 65 disabled populations eligible for Medicare as discussed earlier.)
- There should be a discrete sub-heading on **private health insurance** which could outline some of the benefits/limitations of Kennedy-Kassebaum legislation. There should be at least some discussion about exploring avenues to make private health insurance coverage more accessible and affordable for PWLHIV (and other chronic illnesses).

D. Civil Rights

- There is no reference to the reauthorization of the Rehabilitation Act and the important protections it provides in the "Future Opportunities" section.
- This section should also include protecting the privacy of personal health information and medical records.
- There is no reference to the importance of fighting discrimination in housing. Citing litigation to ensure "access to nursing homes" only emphasizes the glaring lack of attention to the importance of housing for accessing care and enhancing the quality and duration of life for people living with HIV/AIDS.
- The reference to the HIV/AIDS education program for Federal workers on page 27 should be changed to indicate that the program contained information on how to manage Federal employees who have HIV infection.
- The section "Protecting Workers" (p. 27) should include reference to unjustifiable restrictions on Federal employees, Foreign Service Officers and members of the armed forces who have HIV. We recommend adding: The Director of the Office of National AIDS Policy will work with Federal Agencies to examine policies and eliminate provisions that permit discrimination in promotion and retention based on HIV status.

E. International Activities

- The vaccine and microbicide sections of the Research section should be repeated in this Section with an explanation that lays out the difficulties of treating HIV throughout most of the developing world.
- In the *Sharing Technologies* sub-section, the Administration should define a commitment to work with a wide range of domestic NGO's through a wide range of programmatic mechanisms. If for example, a community based NGO in Cleveland has a particular expertise in an important prevention technology, the government should look to that NGO as a potential contractee for sharing technology. "Lessons Without Borders", a showcase program with very little funding, limits these interactions. If all domestic NGOs -- and not a few large inside the beltway NGOs -- were considered for all information and technology exchange contracts, the goals of the program could be achieved without new funding.
- The maps detailing the spread of the American epidemic are very effective. Are similar maps available for the international epidemic? It could be very powerful to show entire African or Asian countries that look like New York.

F. Translation of Research Advances into Practice

- Translation of research advances is vital and we commend you for making this a specific area addressed in the National Strategy. We have learned over the past fifteen years that prevention, care and research programs that are grounded in the communities most effected by HIV will be the most successful. However, it is vital that communities have the resources and tools, including cutting-edge research findings, to be effective.

Translation is often achieved by policies and programs that closely link research and practice. However, translation in the context of linkages between researchers and care/service providers is primarily seen as a one way street--getting good science into the hands of community-based providers. We believe that the relationship is and should be more symbiotic. Partnerships between science and practice not only results in better programs, but also better science. The focus of this section should be balanced to incorporate the complimentary goals of translating research advances into practice and incorporating the needs of care/service providers in formulating research questions and setting priorities.

- An additional or substitute example of the importance of translation should be included. The work of NIH, CDC and FDA around the effectiveness of latex condoms in the prevention of HIV is very compelling and highlights action that will prevent the transmission of HIV to millions of Americans. This partnership provided clear guidance on the effectiveness of condoms in preventing HIV, supported the development of PSAs promoting the correct and consistent use of condoms and provided public health experts

with the leadership and science needed to make condoms available in controversial settings such as prisons, and school-based HIV prevention programs.

NATIONAL AIDS FUND

FAX TRANSMITTAL

DATE: November 13, 1996

TO: Patricia S. Fleming

FAX (202) 632-1096

FROM: Callie Gass

TOTAL PAGES INCLUDING THIS COVER: 6

COMMENTS:

November 12, 1996

BY FAX
5 Pages

Patricia S. Fleming
National AIDS Policy Director
Office of National AIDS Policy
750 17th Street NW, Suite 600
Washington DC 20503

Dear Patsy:

Thank you for the opportunity to comment on the draft of the proposed National AIDS Strategy. We are very pleased that the Office of National AIDS Policy has developed a strategy to serve as "a foundation for the Administration's response to the epidemic." The strategic plan is a good statement of where we find ourselves at the moment and allows us to take stock of our accomplishments. It also delineates the large territory we must cover as we struggle to stop the spread of this epidemic and to provide appropriate care and service to those who are living with HIV disease.

Staff at the National AIDS Fund has reviewed the document and has prepared both general comments and specific recommendations for changes and edits for your consideration.

PRIVATE SECTOR COLLABORATION

We were very concerned that the draft strategy is silent on the contributions the private sector has made - and is continuing to make - to fighting the HIV epidemic. It seems to us that many of the recent accomplishments were the result of collaboration between the government and the private sector. Moreover, it is our experience that the private sector - particularly private philanthropy - is a key player in many regions of the country, particularly in the field of prevention, and nationwide in supporting research. We also urge you not to overlook the role businesses and unions have played in providing prevention education and in changing the workplace environment to accommodate those living and working with HIV/AIDS.

The following additions to the strategy, which address the ongoing collaboration between the government and the private sector, should be considered:

- o *The Message from the National AIDS Policy Director* should contain a paragraph specifically addressing collaboration with private sector philanthropies and businesses, labor, local communities, and religious organizations, rather than lumping everyone together as "non-governmental." These collaborations have strengthened the effectiveness of federally funded initiatives, created powerful partnerships between the public and private sectors, and generated steady increases in volunteerism and charitable giving; all of which stretches scarce federal resources and improves the climate in which all of us do our work. (Page 4, para. 2)

- o Add a bullet to the "Goals" which establishes collaboration as a goal. *"To harmonize federal initiatives with private sector capacities and commitments to alleviate suffering, reduce infections, and seek practical ways to end the pandemic;"* (Page 5)
- o Add information on the successful use of programs, especially AmeriCorps, to add resources to communities as they fight the epidemic; (Page 9)
- o Add the following bullets to the list of actions since President Clinton took office; (Page 9)
 1. Promoting workplace education through Business/Labor Responds to AIDS;
 2. Attaining FDA approval for home testing.
- o Add the word *workplace* to the third bullet on Page 10 so that it reads *"Strengthening community based and workplace programs;"*
- o Integrate the concept of workplace education and prevention into the discussions on page 12, particularly under the subhead *Prevention Education*
- o *Ensuring Effective Use of Limited Resources* (Page 24) should include a fourth method as follows:
(4) and collaborating with the private sector.
- o The *Record of Accomplishments* should include the BRTA Hotline in the fifth bullet. (Page 33).

A. PREVENTION

The strategy in this section is almost a list of all possible things the Administration could do, many of which are clearly out of ONAP's control, such as increasing access to substance abuse treatment and reducing the availability of illegal drugs. All options are given the same importance in the narrative. We recommend that the prevention section emphasize those things which 1) ONAP can reasonably hope to influence and 2) which have a direct and immediate effect on reducing the numbers of transmissions. We believe this strategy should strongly emphasize preventive interventions, – such as syringe exchange, and the elimination of barriers to those interventions as well as effective prevention education, targeted to vulnerable populations, that results in behavior change/modification – as top priorities. We believe that these remain the most direct routes to reducing transmission. The strategy and intent should be crystal clear on this point.

B. RESEARCH

Future Opportunities for Progress.

While the November 1996 Draft Strategy outlines the need for coordination of the *federal* research effort, (page 17) and supports changes at the NIH to help strengthen the *national* vaccine effort, **development of an HIV vaccine will require international cooperation and coordination and additional participation by the private sector.**

The following additions to the Strategy should be considered:

- **state a role for the U.S., perhaps even the President, in the international effort to develop an HIV vaccine (page 17).**

International cooperation and coordination is needed because:

- multiple efficacy trials will be needed and only 1-2 are likely to be done in the U.S. at any point in time;
 - success will depend on protecting individuals from all HIV strains; most HIV strains are just entering the U.S. population, so trials in other countries will be necessary;
 - the recent success in HIV therapeutics will not be of benefit to many people in this country and the world who do not have access to therapy; prevention through vaccination is a more economically feasible strategy for these populations;
 - U.S. dollars invested in developing countries would be better utilized if the AIDS epidemic could be controlled in those countries
- **set a goal of identifying at least a partially effective HIV vaccine by the year 2005 (page 17).**

This goal is appropriate at this time because:

- re-election has been accomplished;
- there is now scientific consensus that an HIV vaccine is possible;
- the first efficacy trial of an HIV vaccine will likely be initiated during the next 4 years; results from this trial would not be available until after the next election so some movement on this topic is virtually assured;
- the recent success in HIV therapeutics has demonstrated what can be accomplished when substantial public and private sector efforts are made;
- the increased private sector involvement necessary for success would be stimulated by Presidential leadership combined with the generally strong economy;
- time is of the essence; the sooner an effective HIV vaccine is found, the sooner the public health benefits and economic savings would accrue to the U.S. and the world.

- **consider specific actions to demonstrate international leadership, coordination and collaboration.**
 - place HIV vaccine development to the G7 agenda to establish a worldwide commitment and strategy (International efforts);
 - work through the World Bank to guarantee loans to developing countries to purchase HIV vaccines (International efforts)
- **commit to a substantial (50-100%) increase in funding for HIV vaccine R&D at the NIH over the next 4 years.**

While it is commendable that this office has taken a strong interest in microbicide research, it could be severely criticized for not taking as active an interest in HIV vaccine development, since vaccines, not microbicides, are a proven, cost effective means for preventing the spread of infectious diseases (page 18). While there is some re-direction of funds at the NIH into vaccine R&D, re-directing existing funds is slow; new funds are needed to adequately stimulate these efforts. Stimulating HIV vaccine research at the NIH will only be half of a successful formula; stimulating private sector investment is also necessary.

- **consider specific actions to attract more private sector involvement in HIV vaccine development:**
 - work with Congress to address issues that impede private sector investment in HIV vaccine development (e.g. liability, patent issues) (page 17).
 - establish a Forum for Collaborative HIV Vaccine Research (page 18) to promote public-private collaboration on AIDS vaccine development, comparable to the one formed for therapeutics research (pg. 19). A separate Forum seems appropriate since the vaccine developers and the issues and obstacles are different from those in HIV therapeutics and since an international perspective is required;
 - consider new models to provide federal funds to stimulate private sector investment in HIV vaccine development.

E. INTERNATIONAL ACTIVITIES

We believe this section misses a good opportunity to identify the extensive work that has been accomplished on the global impact of the epidemic. The section strikes us as vague and unfocused. The section on USAID would be strengthened by the inclusion of dollar figures and a better description of its cumulative contributions to the global fight. *Future Opportunities for Progress* needs more specific action oriented activities to be useful and given recent events, a commitment to maintain and strengthen the USAID Office on AIDS.

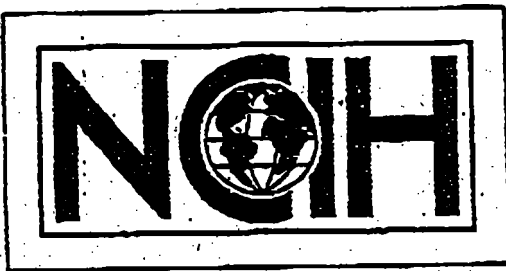
Thank you again for allowing us to comment on your draft document. We hope these comments are helpful as you move towards a final strategy.

If you have any questions or want to discuss these comments further, please give me a call at 202-408-4848, ext 217.

Sincerely,



Callie B. Gass
Deputy Director, Programs and Partnerships



National Council for International Health

1701 K Street, NW - Suite 600
Washington, DC 20006-1503 USA
Tel: 202-833-5900 - Fax: 202-833-0075
E-mail: <ncih@ncih.org>

FAX TRANSMITTAL

To: Patsy Fleming
At: ONAP
From: Cynthia Mariel
Dept: AIDS Program

Fax: 202-632-1096
Tel: _____
Date: 13 Nov 96
Ext: 209 Pages: 5

MEMORANDUM



NATIONAL COUNCIL FOR INTERNATIONAL HEALTH

1701 K STREET, N.W. SUITE 600, WASHINGTON, DC 20006, (202) 833-5900, FAX: (202) 833-0075

12 November 1996

Ms. Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, NW
Washington, DC 20503

Dear Patsy:

I would like to thank you again for the recent opportunity to meet with you and your staff and to discuss issues related to global AIDS. I look forward to continuing our history of working together to increase support for and enhanced commitment by the United States government to international AIDS efforts. I greatly appreciate your interest in and demonstrated support for global AIDS issues.

As requested, I have reviewed the draft document, *The National AIDS Strategy*, and have enclosed my comments on the second page to this letter. I very much appreciate the efforts of your office to develop this strategy and congratulate you on the production of such a fine document.

I have prepared a few comments that, of course, reflect my position as an organizational representative working in international AIDS. They do not integrate the political and strategic positioning that is inherent with the work of a White House office. Thus, you will need to weigh my comments against the operational mandate and political context of your own office. Please feel free to contact me if you require additional information and/or review.

In addition, I would also like to take this opportunity to make a special request. I would very much like to include an interview with you for our upcoming issue of *AIDSLink*. The interview would be in a written question and answer format and would focus on the activities of your office in regards to international AIDS during the upcoming Administration.

Based largely on our conversation last week, I have prepared several written questions that are enclosed as a separate page of this letter. Please review the questions and then contact me so that I might know if you are available and agreeable to this interview. For purposes of clarity and efficiency, I am simply asking that you prepare a written response to the questions as well as add any additional comments. In order to meet our press deadline, I would need receive your response to the interview questions no later than 25 November 1996.

Thank you again for the opportunity to work with the Office of National AIDS Policy. I look forward to hearing from you in the near future.

Sincerely,

Cynthia E. Mariel
NCIH AIDS Program



**Comments on the draft copy of
The National AIDS Strategy**

1. Page 3, left column, paragraph 1

Defeating HIV is compared to eradication of smallpox and polio.

Comment: Many would argue that such a comparison tends to medicalize HIV when the issue of HIV/AIDS is multi-faceted and goes well beyond a health problem with a medical solution.

2. Page 5, left column, goal #2

Comment: Because HIV is so closely linked to contextual factors such as socio-economic conditions it might be valuable to include additional wording so that the goal reads, "by providing strong continuing support for effective AIDS prevention efforts and reduction of the socio-economic conditions that contribute to the spread of HIV."

3. Page 7, right column, final paragraph

Comment: The description of the global AIDS epidemic does not cover areas addressed in the previous paragraphs on domestic AIDS. It might be valuable to include some descriptive information that identifies the percentage of HIV infections globally as compared to the number in the U.S., the percentage of global infections that are among women, the percentage of infections that are via heterosexual transmission, and the care related expenditures by the U.S. government related to international AIDS.

4. Page 29, right column, final paragraph

Comment: Does more specific descriptive information need to be added when identifying the United States as the largest contributor to international efforts to combat the pandemic of HIV and AIDS? I have previously heard representatives from USAID describe this role in more specific language.

5. Page 30, right and left column under Future Opportunities for Progress

Comment: In general, the description under this heading focuses on past activities as compared to identification of future commitments. More specifically, in reference to the Paris AIDS Declaration more action oriented language might be included such as, "The U.S. will actively support full enactment of the 1994 Paris AIDS Declaration, of which the U.S. was a signature, through government policies and programs and will encourage other nations to become signatures and supporters of the Paris AIDS Declaration."

6. Page 30, left column, last paragraph

Comment: It is recommended that another statement be added that indicates that the U.S. needs to strengthen support for global HIV/AIDS activities among U.S.-based private voluntary organizations, nongovernmental organizations in developing countries and global HIV/AIDS networks.

Interview questions for *AIDSLink*

1. What do you consider to be the number one priority of your office during the next four years in terms of the US global response to AIDS?
2. How can US-based organizations active in global AIDS efforts assist ONAP in achieving this goal?
3. What contributions can AIDS organizations from developing countries make towards this goal?
4. Why do you think support by the US government to UNAIDS is critical to an effective response to the AIDS pandemic?
5. How can US support for UNAIDS be strengthened?
6. What do you consider the role of your office to be in relationship to major USAID contractors working on international AIDS projects?
7. Why do you think it is important for US-based domestic AIDS groups to become involved in global AIDS?
8. What unique contributions do you believe US-based domestic AIDS groups can make to global AIDS efforts?
9. Based on your knowledge of the US Congress and results of the recent US elections, what are the most effective kinds of educational and advocacy activities that *AIDSLink* readers need to undertake in order to increase support for global AIDS?
10. At present, over 90 % of HIV infection is among developing country populations and yet, approximately only 8 % of global HIV/AIDS funding is spent in developing countries. In addition, per capita health related expenditures by health ministries in many developing countries are less than \$2 per year. How do you reconcile these realities with the strong support you have demonstrated on the issue of equitable access to AIDS treatment and care in developing countries?
11. On World AIDS Day 1994 you were the US representative to the Paris AIDS Summit. At this meeting, the US joined with 42 countries in signing a declaration in which national governments undertook to promote and protect the rights of individuals, particularly people living with HIV/AIDS. To date, the US government still has a travel ban in place restricting people living with HIV/AIDS from entering the country. Will elimination of this restriction be a priority of your office during the next four years?

Additional comments: If the President will be introducing the National AIDS Strategy before December 6, it would be great to include this as an announcement in *AIDSLink* and comments from you on how ONAP will use this strategy in their international AIDS efforts.

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

FACSIMILE TRANSMISSION

to

Patsy Fleming
Jeff Levi

from

Julie Siegfried

date

11/12

page/s to follow

3

- ☐ As requested
- ☐ Review and comment
- ☐ As discussed
- ☐ Please respond
- ☐ For your information

If transmission is not
complete, please call
202-434-8090

comments

- Comments / feedback on PRAT strategy document
- Would like to nail down a meeting with you soon as well -

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

MEMORANDUM

November 12, 1996

TO: Patricia S. Fleming, National AIDS Policy Director

FR: Julie M. Scofield and Joseph F. Kelly, NASTAD

RE: Comments on The National AIDS Strategy

Thank you for the opportunity to provide comments on the draft document "The National AIDS Strategy." We look forward to meeting with you in the near future to discuss this document and other issues of importance as the Administration prepares for a second term of office.

Introduction

We have two brief comments on this section. First, the document should include the most recent figures from CDC on the epidemic. Second, we are troubled by the use of disease comparisons in the discussion of the lifetime cost of medical care. The AIDS community is outraged when other organizations use such comparisons. We feel it is divisive to use these kind of comparisons to justify investments in programs and/or public policy decisions.

Prevention

In general, this section adequately lays out a national HIV prevention agenda. We particularly support the references to HIV prevention community planning as the centerpiece of our nation's HIV prevention strategy and recommend that the importance of community planning be recognized throughout this section. Specifically, under the section on primary care, community planning should be referenced in the discussion of our counseling and testing programs. Efforts to target and enhance counseling and testing programs will require discussion and support from community planning groups around the country. In addition, we would like to raise the following concerns with the prevention section.

First, more attention needs to be paid to the prevention of HIV among injection drug users and other substance users. In particular, in the accomplishment section, mention of the Tampa initiative should be included. There should also be a goal specific to prevention of HIV among injection drug users in the section on future opportunities. This is far too important a prevention challenge to be mentioned only within the context of other sections.

Second, there should be a funding initiative for HIV prevention in the section on future opportunities. Additional resources are needed at the local level to implement the high priority prevention programs identified through the community planning process. We do not believe we can accomplish our national HIV prevention goals without additional resources from the federal government.

The reference to the "Congressionally-set goal of reducing perinatal transmission by 50 percent by the year 2000" should be eliminated. This is a glaring oversimplification of the congressional language that fails to recognize the complexity of the issue and the vastly divergent perspectives on the goal itself. This document should not lend credence to language the Administration and other prevention partners had little if any input in crafting.

The language regarding the President's FY 97 budget request should be broadened to include as a priority increasing funding to state and local health departments so that programs benefiting high priority populations, such as those identified by the President, can be implemented.

Care and Services

The strategy is lacking in vision and detail in articulating the future progress needed in HIV/AIDS care and services. Although the statements are clear and important on maintaining as investment priorities the Medicaid program and the CARE Act, there is a very limited strategy described for achieving the goals of affordable, high quality, and responsive care services. In our view, the President's strategy speaks too cautiously about the most recent HIV therapies and disease monitoring technologies. Although we agree that long-term clinical effectiveness of combination therapies and protease inhibitors has yet to be fully demonstrated, there is abundant evidence among researchers, clinicians and consumers that there has been a breakthrough in the way in which HIV disease is treated.

These developments have already changed the routine ways in which HIV care is being delivered and paid for by government programs. The draft White House strategy for AIDS care and services pays little attention to the way in which the newest therapies have altered the treatment opportunities for people living with HIV/AIDS and gives no mention to the way in which the scientific breakthrough represented by viral load testing has changed how HIV disease is attacked by medical intervention.

We believe there needs to be a stronger statement of commitment in the President's strategy that articulates the following points:

- access to the latest developments in HIV/AIDS treatment needs to be a high priority to ensure that these breakthrough therapies are not merely available to individuals

with the ability to pay but are affordable and available to those individuals who are uninsured or underinsured.

- viral load testing represents an important new method for monitoring HIV/AIDS treatment and progression of HIV disease and strategies should be developed to ensure that access is provided in the context of high quality primary care services.
- federal agencies should work with states to ensure that state-of-the-art treatment strategies are employed throughout the public and private sector health care settings, including Medicaid managed care and Ryan White settings.
- the federal government, working in partnership with states and the private sector should develop long-term strategies for examining cost-reduction in terms of the new therapies.

Appendices

We have not had sufficient time to review and comment on the appendices in depth. However, the section of the appendices for HRSA is, in general, woefully inadequate in articulating a vision for delivering HIV/AIDS care for the next several years. The approaches described appear to be a mere fulfillment of the reauthorized CARE Act requirements, and fall short of describing a strategy for ensuring that high quality HIV/AIDS care is affordable, accessible and responsive to the changing treatment dynamics into the next century. The HRSA section could benefit from the kind of goal setting and examination that is described in the section for the Department of Veterans Affairs which appears to reflect a better understanding of the new treatment developments and translating these developments to patients within the VA health system.

Thank you for the opportunity to provide our comments. We look forward to meeting with you as soon as a time can be arranged.

GAAN Global AIDS Action Network

1931 13th Street N.W. Washington D.C. 20009 202-667-6300 202-483-1135-Fax globalaids@aol.com

To: Patsy Fleming
National AIDS Policy Coordinator

— Attn: Jane Sanjille

From: Paul Boneberg
Global AIDS Action Network (GAAN)

RE: Draft National AIDS Plan

Date: November 12, 1996

Patsy--

Thank you for the opportunity to comment on the draft national AIDS plan.

Let us begin by again acknowledging the importance of the plan's existence and the inclusion of international issues within it. We recognize that incorporating the complex international aspect is difficult.

We have no objections to what is outlined as the US response to the global pandemic, however we do urge consideration of a few additions and clarifications.

1. Most importantly we urge the inclusion of a statement specifically reiterating the continuing priority of supporting NGOs working in AIDS on the community level. As you know this has been an essential component of US leadership.
2. Also missing is the US commitment to research that has direct impact on our international programs. We urge that our commitment to the development of vaccines, microbicides, and therapeutics that is outlined in the research section be briefly restated in the international program element. To not mention microbicides and vaccines in particular could send the message that the US is lessening its support, which we are sure is not our intent.
3. The section dealing with the skills exchange could be read as limiting domestic NGO involvement to the "Lessons Without Borders" program. We would urge that you make clear that utilizing the expertise of domestic AIDS groups is an element of global AIDS efforts and the "Lessons Without Borders" program is a part--not the entirety-- of that endeavor.
4. The President's quote (again in the research section) on the US commitment for a vaccine and a cure is the heart of the US commitment on AIDS. If that could be reiterated relative to international programs it would be important.
5. Because of the high visibility of this document we think it likely that the graphs showing the spread of HIV will receive great attention in the media. Therefore we urge that a graph showing the international aspect of HIV be included. GAAN believes that such a graphic must exist, but have been unable to identify a good candidate. One option was sent to us by UNAIDS which we attach. We urge that you to contact UNAIDS directly and identify an appropriate graphic for inclusion in the document.
6. It would be useful if the role of the Department of State could be clarified. We assume that they are the lead agency, particularly in coordinating the US's multiple efforts that are referred to in the final paragraph on international programs.
7. It would be helpful if, in the section on "translating research advances into practice", it could be stated that advances in vaccines and therapeutics would be incorporated in future US international activities.

Thank you for the opportunity to provide input on the draft National AIDS Plan. If we can be of assistance please let us know.



AIDS Policy Center
For Children, Youth & Families

MEMORANDUM

TO: Jane Sarville, Daniel Montoya
The White House Office of National AIDS Policy

FROM: David C. Harvey, Executive Director *DC*

DATE: November 15, 1996

SUBJ: White House AIDS Strategy Report

Thank for the opportunity of reviewing the draft White House report titled, "The National AIDS Strategy 1997". Please excuse our delay in responding to the request for comments.

In addition to other comments, I want to suggest a revision to page 22 which describes Title IV of the Ryan White CARE Act. You may wish to consider the following revised language:

Title IV provides support for comprehensive HIV care and access to clinical research programs for children, youth, women and families in community-based family and youth-centered systems of care.

CAEAR Coalition Comments on November 1996 Draft of NAS

As dictated by Alexander Robinson

11/14/96

1. Change Formatting. Matthew said it was hard to find the subject areas like research, prevention, etc.
2. Epidemiological and budget data should be the most current.
3. Concern regarding lack of clinical studies on women and children. There are not a lot of FDA-approved drugs for children. Want more work on pediatric indications and more women included in clinical trials.
4. p. 19. Increase the focus on vulnerable populations. Increase Federal research. In this section you only mention non-Federal programs. This is the only place in the document where non-Federal programs are mentioned. [.. in fact, all the programs cited are Federally-supported]
5. p. 21. You grouped Titles I and II together. Even though services are similar, the focus is different. Ernest Hopkins will send suggested language.
6. First four titles are direct service -- the language in the NAS isn't clear.
7. p. 22 Add bullet on SPNS. Matthew suggests: "SPNS is the Nation's research and development support for innovation and replication in the HIV service delivery." Add information on how SPNS is funded. A commitment to the continuing programs should be included.
8. Making an Investment in Care section. Add language about ensuring adequate support for essential care and services funding by the Federal government especially in the areas of substance abuse prevention and treatment and the Tb prevention and treatment.
9. p. 24 in Ensuring Effective Use of Limited Resources section. Add language: "Enhancing technical assistance to CARE Act grantees, planning councils, and consortia."
10. p. 24 in Improving Program Coordination section. Add language about Tb prevention and treatment among people with HIV.
11. p. 25 Improving Quality of Care section. Add CARE Act programs.
12. p. 25 Evaluating Program Effectiveness section. How will this be implemented?
13. Add SPNS to section on Translation of Research Advances into Practice.

Issues raised by NAPWA

1. Needs a letter from the President to the nation stressing the importance of a continuing, strong national response from government and the private sector.
2. Needs to address the issue of Medicare and Medigap insurance for PLWAs.
3. Needs a greater emphasis on the impact of stigmatization, especially homophobia, racism, and sexism.
4. Wants more emphasis on the quality of life for PWAs.
5. Wants more support for viaticals/accelerated benefits.

EXECUTIVE OFFICE OF THE PRESIDENT

12-Nov-1996 02:29pm

TO: Patsy Fleming
TO: Ursula Sanville

FROM: Jeffrey Levi
AIDS Policy Council

SUBJECT: AmFAR

Jane Silver said AmFAR won't have time for specific comments. However, she did pass along that she thought this version was much improved over the earlier one she had seen (a gazillion drafts ago) and that it was a good first step. (First steps can be divided into many substeps. It all depends where you are sitting.)



AmFAR

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April 29, 1994

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
750 17th Street N.W.
Suite 1060
Washington D.C. 20503

Dear Ms. Gebbie:

Thank you for your request to comment on the National HIV Action Agenda. AmFAR sincerely appreciates this opportunity to participate in an effort to define the nation's HIV strategy.

It is difficult to comment on the April 12, 1994, draft document because it is a combination of specific and general goals and the agenda headings as distributed are not a sufficient starting point for mobilizing and organizing the country's HIV effort. We offer here several broad recommendations related to accomplishing the urgent goal of developing a national HIV action agenda:

- **First**, that you urge the President to act swiftly to name his Presidential AIDS Advisory Committee and that this committee participate in the development of the National HIV Action Agenda;

- **Second**, that an inclusive process, which brings together the federal government, the private sector and the AIDS community, be used to identify and set priorities among goals, objectives, etc. All of these participants have substantial knowledge and experience, and are crucial to the successful implementation of a national HIV agenda;

- **Third**, that the HIV agenda include goals, measurable objectives, action steps, responsibilities, a timeline and budgets;

AMERICAN FOUNDATION FOR AIDS RESEARCH

• **Fourth**, that in developing the research component of the agenda, the Office of National AIDS Policy (ONAP) consult with and involve the Office of AIDS Research (OAR) Director Dr. William Paul, whose office has just developed the FY'96 AIDS Plan for NIH. The process initiated for the OAR Plan was impressive and should be considered for a broader (NIH, DOD, VA) public/private initiative. Similar discussions need to occur with those having major responsibilities for the prevention and services component of the agenda. Cross cutting goals and objectives among the research, prevention and services components also need to be addressed;

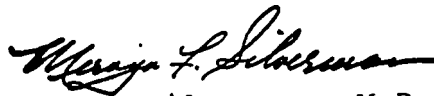
• **Fifth**, the difficult challenges such as immigration exclusion, syringe exchange, correctional issues, and civil rights, must be addressed if the agenda is to accomplish its mission of mobilizing leadership and serving as a blueprint for action.

The draft document highlights the need to better define the role of ONAP and its relationship to federal departments and agencies. Central to the successful development and implementation of a national agenda is the resolution of questions regarding ONAP's role and responsibilities as they relate to departmental responsibilities and authority.

AmFAR very much appreciates this opportunity to suggest a process for rapidly developing an HIV action agenda necessary both for providing a blueprint for the country to follow and for measuring its successful implementation.

We continue to be available to assist you in any way we can.

Sincerely,



Mervyn F. Silverman, M.D., M.P.H.
President

MEMORANDUM

TO: Patsy Fleming
Director of National AIDS Policy
FROM: AIDS Action Council
Christine Lubinski/Jay Coburn
RE: National AIDS Strategy document
DATE: November 14, 1996

Thank you for giving us the opportunity to meet with you last week to talk about the priorities of your office for the Administration's second term. We have reviewed the draft "White House National AIDS Strategy 1997" that you gave us at that meeting, and while we wish we had been given more time to review this document, we do appreciate the fact that you sought AIDS Action's input.

We are concerned that the draft document reads much more as a litany of ongoing activities than as a strategic plan for at least the next term of this Administration. The information in the document is not even completely current in terms of accurately reflecting the current funding levels of AIDS programs, and certainly does not reflect a clear articulation of the real challenges that now face us in the context of promising new treatments and their implications for HIV prevention, counseling and testing programs, the whole array of access to care and supportive services programs, including safe and appropriate housing. There is little recognition of the barriers which threaten our progress in the AIDS epidemic from vociferous opposition to the budget authority of the OAR, ongoing efforts to stigmatize and discriminate against people with HIV/AIDS and thereby discourage them from finding out their serostatus and/or seeking care; the increasing fragmentation of the nation's health care systems and cost reduction strategies which threaten quality of and access to health care; and the erosion of any genuine commitment to federal leadership in ensuring that people have housing, just to name a few.

Again, while we appreciate the opportunity to review the draft document, the tight timeline for comments and the absence of any real opportunity for collective dialogue on all of these challenging issues, cannot be construed as real community input. Moreover, the small selection of national groups who received this opportunity, hardly adequately represent the breadth and diversity of the national AIDS community. We thought it was important to review this document and to highlight factual inaccuracies and notable omissions, and have done so (see attached). But we also wish to be clear that even with the integration of the comments provide, it is not our view that this document fulfills its function as a plan for a national AIDS strategy.

Substantive Edits/Suggestions on Draft "White House National Strategy Plan 1997"

Per your request, AIDS Action Council staff have reviewed the draft National AIDS Strategy and are submitting the following editing comments for your consideration:

I. Introduction

- The goal to "reduce the number of new HIV infections..." should refer to "continuing support for effective *HIV* prevention efforts;"
- In the section "An Expanding Public Health Threat" on page 6, second paragraph, *gay and bisexual men of color* should be added to the list of populations that are heavily affected today.

II. Overview of Federal Efforts

- The first paragraph on page 8, second to last sentence, add prevention to read: "In FY 1986 the Federal government expenditures for AIDS research, prevention & **surveillance**, income maintenance, and care were \$508 million."

A. Prevention

- Total number of new infection is estimated to be approximately 40,000 to **60,000** people each year.
- On page 9, under "Sentinel accomplishments," fourth bullet, insert community-based to read: "Due in part to successful implementation of CDC-sponsored *community-based* prevention strategies, a slowing in the growth of the epidemic."
- Also on page 9, first column, last bullet, change to read "Launching the AIDS prevention community planning partnership -- empowering local communities to target resources to innovative prevention efforts for communities at risk." Community planning groups do not develop interventions; they are charged with identifying unmet needs and setting priorities.
- Also on page 9, last paragraph, first sentence strike and add: "... are most effective when designed and implemented ~~at a local level~~ *in partnership with communities to whom they are targeted.*"
- The section on "Improving Understanding of Trends in the Epidemic" is very good, particularly the assertion that surveillance can be improved without jeopardizing confidentiality. We insist that you explicitly state strong support for the availability of anonymous testing and opposition to mandatory names reporting.

- The section on "Strengthening Community-Based Programs" is very good.
- The section on "Preventing HIV transmission from the use of contaminated injection equipment" is problematic. While CDC has issued guidelines regarding the use of bleach to clean injection equipment, several studies have seriously questioned the effectiveness of bleach as an realistic prevention strategy. Secondly, is CDC now supporting the removal of restrictions on over-the-counter sale of syringes?
- This document needs to address the issues of partner and spousal notification. We recommend under the section on page 14 "Targeting Vulnerable Populations" a section on partner notification programs. One effective strategy to target vulnerable populations is requiring states to make a good faith effort to notify the spouses of persons with HIV and to have in place voluntary partner notification programs that will protect confidentiality and risk of domestic violence. These voluntary programs should be implemented at the local level and only when they will help change risk behaviors and provide referrals to early intervention and care.

B. Research

- The section, *Contributions of AIDS Research to Research on Other Diseases*, is too general. It would be more powerful if it included more actual and detailed cross-over achievements.
- It should be noted that resistance to OAR and the Consolidated Budget has and will in all likelihood continue to threaten long term planning capacity for all AIDS research at NIH. A clear statement of continued support in the face of that resistance would be helpful.
- In the section detailing the Report of the NIH AIDS Research Program Evaluation Task Force, the recommendation calling for increased research into the causes and treatments of HIV related opportunistic infections should be added.
- On page 18, in the bullet point regarding joint efforts with UNAID, add a commitment to encouraging international efforts in vaccine development and testing protocols.
- On page 19, the last sentence seems to come from nowhere. A sentence should be added that suggests that due to the complexity and expense of new regimens and the damage, over time, caused to an individual's immune system by HIV, even the new therapies and regimens are unlikely to produce positive outcomes for many thousands of people living with HIV/AIDS. Therefore, new drug development must continue to be enthusiastically supported.
- Also on page 19, you state a commitment to the continuation of the CPCRA. If the Levine recommendation regarding the collapse of clinical trial networks is implemented, will the CPCRA continue in its present form?

- The final paragraph in the Research section is unclear. The research conducted at DOD, CDC, and the VA should be defined and the \$4 million for AIDS research government wide should be more clearly characterized.

C. Care

Ryan White CARE Act & Housing

- On page 21, the bullet on Titles I and II needs to include insurance continuations and home and community-based care. On page 22, Title V also supports SPNS, which includes ongoing service delivery for Native American populations.
- There is no mention of targeting care services to communities and populations in greatest need or who require services that are culturally relevant such as people of color, women and adolescents. On page 23 "Future Opportunities for Progress" under *Ensuring Effective Use of Limited Funds* reference to the need to target funding and ensure that services reach marginalized communities should be included. To maximize federal dollars, funds must go to those communities and/or groups bearing the brunt of the epidemic and that are in most need of care services. These federal funds would not only provide immediate care services but also provide funding for the development of basic health care delivery infrastructure and programs that are culturally and age sensitive. Although the CARE Act already includes variables that factor in increased need, greater emphasis on addressing the needs of these communities by HRSA is still needed. These communities include people of color in general, women of color and adolescents. Communities of color currently make up over 53% of the cumulative AIDS case count. Women of color make up over 75.4% of AIDS cases among women yet only represent approximately 20% of all women. More than half of all new HIV infections occur in adolescents and young adults.
- References to FY 97 funding levels for the CARE Act must be revised. On page 24 FY 97 funding for the CARE should be \$996 million and HOPWA should be added at \$196.0 million.
- References to the housing needs of people with AIDS are inadequate throughout the document. The changing demographics of the epidemic are reflected in the growing number of individuals and families living with HIV disease who are homeless or near-homeless. Without stable housing, these people cannot access care or promising drug therapies. Moreover, a significant number of homeless individuals are "dually and triply diagnosed" -- i.e., have chemical addictions and/or mental illness in addition to HIV disease -- and require housing linked with intensive supportive services. In particular, housing should be included on page 5 as a critical component of access to care.
- The list of housing programs on page 22 does not include the McKinney Homeless assistance grants or the Section 8 Rental Assistance programs, both of which are as important (if not more important in some areas) than Section 811 housing.

- The Housing Opportunities for People with AIDS Program (HOPWA) is currently not authorized. Reauthorization HOPWA must be a priority for the Administration. On page 24 "Expanding Support for Housing Services" paragraph insert a commitment to a speedy reauthorization so that program is in place to serve people with HIV/AIDS.

Medicaid

- We have updated statistics from Kaiser on the importance of Medicaid for people living with HIV/AIDS. Currently, approximately 53% (estimated 90,000 in 1994) of adult Americans and more than 90% of children living with HIV/AIDS receive their medical coverage through Medicaid.
- In the "preserving Medicaid" paragraph under "Future Opportunities", we think you should emphasize why people with HIV disease turn to Medicaid. Obviously, Medicaid is the safety net for the poor, but the point is that many people are impoverished by the costs of medical care for HIV disease and have no other alternative but to turn to Medicaid. The inadequacies and inequities of private health insurance coverage for HIV disease -- both managed care and fee-for-service plans -- plays a major role in this scenario. (caps, lifetime limits, restricted access to prescription drug services, etc.)
- The Administration should be actively exploring avenues to provide Medicaid coverage for PLWHIV as soon as they become medically needy, as opposed to requiring them to become completely disabled and/or impoverished.

Medicare

- There should be a separate section on Medicare, which is becoming a payer of HIV care for a growing number of people who are living longer with HIV disease and AIDS. Limitations on what benefits are covered under Medicare (no prescription drugs) and limitations on eligibility for supplementary coverage, which is generally not available to those qualifying for Medicare based on disability (as opposed to age), should be addressed.

SSA Programs

- Language should be included about ensuring that hard-won expansions in the SSDI HIV disability criteria are not undermined. Eligibility criteria must be flexible enough to address the unique nature of disease progression and disability in people living with HIV disease.

Improving Quality of Care

- There should be a discrete sub-heading on **managed care** quality standards and regulations in light of the increase in managed care in Medicaid, Medicare, and the private market and the need to ensure that quality and comprehensiveness of health care for PWLHIV is not compromised. HCFA's oversight of state medicaid waiver applications might be cited as a vehicle for managed care oversight, for example. The Administration should also be advocating for strong consumer protections in all managed care plans. Of particular interest to people living with HIV/AIDS are the following issues: gag rules, confidentiality, grievance procedures/disenrollment, choice of provider, out-of plan options, prescription drug coverage.
- The Improving Quality of Care paragraph could be strengthened to include references to quality of benefits and services available to people living with HIV/AIDS. (For example, supporting efforts to expand access to Medigap to under 65 disabled populations eligible for Medicare as discussed earlier.)
- There should be a discrete sub-heading on **private health insurance** which could outline some of the benefits/limitations of Kennedy-Kassebaum legislation. There should be at least some discussion about exploring avenues to make private health insurance coverage more accessible and affordable for PWLHIV (and other chronic illnesses).

D. Civil Rights

- There is no reference to the reauthorization of the Rehabilitation Act and the important protections it provides in the "Future Opportunities" section.
- This section should also include protecting the privacy of personal health information and medical records.
- There is no reference to the importance of fighting discrimination in housing. Citing litigation to ensure "access to nursing homes" only emphasizes the glaring lack of attention to the importance of housing for accessing care and enhancing the quality and duration of life for people living with HIV/AIDS.
- The reference to the HIV/AIDS education program for Federal workers on page 27 should be changed to indicate that the program contained information on how to manage Federal employees who have HIV infection.
- The section "Protecting Workers" (p. 27) should include reference to unjustifiable restrictions on Federal employees, Foreign Service Officers and members of the armed forces who have HIV. We recommend adding: The Director of the Office of National AIDS Policy will work with Federal Agencies to examine policies and eliminate provisions that permit discrimination in promotion and retention based on HIV status.

E. International Activities

- The vaccine and microbicide sections of the Research section should be repeated in this Section with an explanation that lays out the difficulties of treating HIV throughout most of the developing world.
- In the *Sharing Technologies* sub-section, the Administration should define a commitment to work with a wide range of domestic NGO's through a wide range of programmatic mechanisms. If for example, a community based NGO in Cleveland has a particular expertise in an important prevention technology, the government should look to that NGO as a potential contractee for sharing technology. "Lessons Without Borders", a showcase program with very little funding, limits these interactions. If all domestic NGOs -- and not a few large inside the beltway NGOs -- were considered for all information and technology exchange contracts, the goals of the program could be achieved without new funding.
- The maps detailing the spread of the American epidemic are very effective. Are similar maps available for the international epidemic? It could be very powerful to show entire African or Asian countries that look like New York.

F. Translation of Research Advances into Practice

- Translation of research advances is vital and we commend you for making this a specific area addressed in the National Strategy. We have learned over the past fifteen years that prevention, care and research programs that are grounded in the communities most effected by HIV will be the most successful. However, it is vital that communities have the resources and tools, including cutting-edge research findings, to be effective.

Translation is often achieved by policies and programs that closely link research and practice. However, translation in the context of linkages between researchers and care/service providers is primarily seen as a one way street--getting good science into the hands of community-based providers. We believe that the relationship is and should be more symbiotic. Partnerships between science and practice not only results in better programs, but also better science. The focus of this section should be balanced to incorporate the complimentary goals of translating research advances into practice and incorporating the needs of care/service providers in formulating research questions and setting priorities.

- An additional or substitute example of the importance of translation should be included. The work of NIH, CDC and FDA around the effectiveness of latex condoms in the prevention of HIV is very compelling and highlights action that will prevent the transmission of HIV to millions of Americans. This partnership provided clear guidance on the effectiveness of condoms in preventing HIV, supported the development of PSAs promoting the correct and consistent use of condoms and provided public health experts

with the leadership and science needed to make condoms available in controversial settings such as prisons, and school-based HIV prevention programs.

NATIONAL

AIDS

FUND

FAX TRANSMITTAL

DATE: November 13, 1996

TO: Patricia S. Fleming

FAX (202) 632-1096

FROM: Callie Gass

TOTAL PAGES INCLUDING THIS COVER: 6

COMMENTS:

NATIONAL AIDS FUND

November 12, 1996

BY FAX
5 Pages

Patricia S. Fleming
National AIDS Policy Director
Office of National AIDS Policy
750 17th Street NW, Suite 600
Washington DC 20503

Dear Patsy:

Thank you for the opportunity to comment on the draft of the proposed National AIDS Strategy. We are very pleased that the Office of National AIDS Policy has developed a strategy to serve as "a foundation for the Administration's response to the epidemic." The strategic plan is a good statement of where we find ourselves at the moment and allows us to take stock of our accomplishments. It also delineates the large territory we must cover as we struggle to stop the spread of this epidemic and to provide appropriate care and service to those who are living with HIV disease.

Staff at the National AIDS Fund has reviewed the document and has prepared both general comments and specific recommendations for changes and edits for your consideration.

PRIVATE SECTOR COLLABORATION

We were very concerned that the draft strategy is silent on the contributions the private sector has made - and is continuing to make - to fighting the HIV epidemic. It seems to us that many of the recent accomplishments were the result of collaboration between the government and the private sector. Moreover, it is our experience that the private sector - particularly private philanthropy - is a key player in many regions of the country, particularly in the field of prevention, and nationwide in supporting research. We also urge you not to overlook the role businesses and unions have played in providing prevention education and in changing the workplace environment to accommodate those living and working with HIV/AIDS.

The following additions to the strategy, which address the ongoing collaboration between the government and the private sector, should be considered:

- o *The Message from the National AIDS Policy Director* should contain a paragraph specifically addressing collaboration with private sector philanthropies and businesses, labor, local communities, and religious organizations, rather than lumping everyone together as "non-governmental." These collaborations have strengthened the effectiveness of federally funded initiatives, created powerful partnerships between the public and private sectors, and generated steady increases in volunteerism and charitable giving; all of which stretches scarce federal resources and improves the climate in which all of us do our work. (Page 4, para. 2)

- o Add a bullet to the "Goals" which establishes collaboration as a goal. *"To harmonize federal initiatives with private sector capacities and commitments to alleviate suffering, reduce infections, and seek practical ways to end the pandemic;"* (Page 5)
- o Add information on the successful use of programs, especially AmeriCorps, to add resources to communities as they fight the epidemic; (Page 9)
- o Add the following bullets to the list of actions since President Clinton took office; (Page 9)
 - 1. Promoting workplace education through Business/Labor Responds to AIDS;
 - 2. Attaining FDA approval for home testing.
- o Add the word *workplace* to the third bullet on Page 10 so that it reads *"Strengthening community based and workplace programs;"*
- o Integrate the concept of workplace education and prevention into the discussions on page 12, particularly under the subhead *Prevention Education*
- o *Ensuring Effective Use of Limited Resources* (Page 24) should include a fourth method as follows:
(4) and collaborating with the private sector.
- o The *Record of Accomplishments* should include the BRTA Hotline in the fifth bullet. (Page 33).

A. PREVENTION

The strategy in this section is almost a list of all possible things the Administration could do, many of which are clearly out of ONAP's control, such as increasing access to substance abuse treatment and reducing the availability of illegal drugs. All options are given the same importance in the narrative. We recommend that the prevention section emphasize those things which 1) ONAP can reasonably hope to influence and 2) which have a direct and immediate effect on reducing the numbers of transmissions. We believe this strategy should strongly emphasize preventive interventions, – such as syringe exchange, and the elimination of barriers to those interventions as well as effective prevention education, targeted to vulnerable populations, that results in behavior change/modification – as top priorities. We believe that these remain the most direct routes to reducing transmission. The strategy and intent should be crystal clear on this point.

B. RESEARCH

Future Opportunities for Progress.

While the November 1996 Draft Strategy outlines the need for coordination of the *federal* research effort, (page 17) and supports changes at the NIH to help strengthen the *national* vaccine effort, **development of an HIV vaccine will require international cooperation and coordination and additional participation by the private sector.**

The following additions to the Strategy should be considered:

- **state a role for the U.S., perhaps even the President, in the international effort to develop an HIV vaccine (page 17).**

International cooperation and coordination is needed because:

- multiple efficacy trials will be needed and only 1-2 are likely to be done in the U.S. at any point in time;
 - success will depend on protecting individuals from all HIV strains; most HIV strains are just entering the U.S. population, so trials in other countries will be necessary;
 - the recent success in HIV therapeutics will not be of benefit to many people in this country and the world who do not have access to therapy; prevention through vaccination is a more economically feasible strategy for these populations;
 - U.S. dollars invested in developing countries would be better utilized if the AIDS epidemic could be controlled in those countries
- **set a goal of identifying at least a partially effective HIV vaccine by the year 2005 (page 17).**

This goal is appropriate at this time because:

- re-election has been accomplished;
- there is now scientific consensus that an HIV vaccine is possible;
- the first efficacy trial of an HIV vaccine will likely be initiated during the next 4 years; results from this trial would not be available until after the next election so some movement on this topic is virtually assured;
- the recent success in HIV therapeutics has demonstrated what can be accomplished when substantial public and private sector efforts are made;
- the increased private sector involvement necessary for success would be stimulated by Presidential leadership combined with the generally strong economy;
- time is of the essence; the sooner an effective HIV vaccine is found, the sooner the public health benefits and economic savings would accrue to the U.S. and the world.

- **consider specific actions to demonstrate international leadership, coordination and collaboration.**
 - place HIV vaccine development to the G7 agenda to establish a worldwide commitment and strategy (International efforts);
 - work through the World Bank to guarantee loans to developing countries to purchase HIV vaccines (International efforts)
- **commit to a substantial (50-100%) increase in funding for HIV vaccine R&D at the NIH over the next 4 years.**

While it is commendable that this office has taken a strong interest in microbicide research, it could be severely criticized for not taking as active an interest in HIV vaccine development, since vaccines, not microbicides, are a proven, cost effective means for preventing the spread of infectious diseases (page 18). While there is some re-direction of funds at the NIH into vaccine R&D, re-directing existing funds is slow; new funds are needed to adequately stimulate these efforts. Stimulating HIV vaccine research at the NIH will only be half of a successful formula; stimulating private sector investment is also necessary.

- **consider specific actions to attract more private sector involvement in HIV vaccine development:**
 - work with Congress to address issues that impede private sector investment in HIV vaccine development (e.g. liability, patent issues) (page 17).
 - establish a Forum for Collaborative HIV Vaccine Research (page 18) to promote public-private collaboration on AIDS vaccine development, comparable to the one formed for therapeutics research (pg. 19). A separate Forum seems appropriate since the vaccine developers and the issues and obstacles are different from those in HIV therapeutics and since an international perspective is required;
 - consider new models to provide federal funds to stimulate private sector investment in HIV vaccine development.

E. INTERNATIONAL ACTIVITIES

We believe this section misses a good opportunity to identify the extensive work that has been accomplished on the global impact of the epidemic. The section strikes us as vague and unfocused. The section on USAID would be strengthened by the inclusion of dollar figures and a better description of its cumulative contributions to the global fight. *Future Opportunities for Progress* needs more specific action oriented activities to be useful and given recent events, a commitment to maintain and strengthen the USAID Office on AIDS.

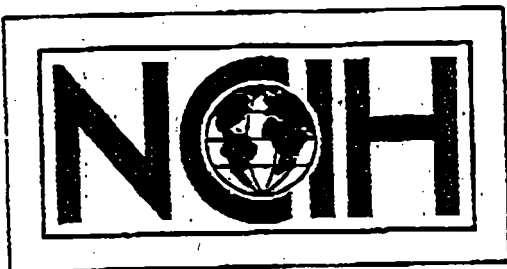
Thank you again for allowing us to comment on your draft document. We hope these comments are helpful as you move towards a final strategy.

If you have any questions or want to discuss these comments further, please give me a call at 202-408-4848, ext 217.

Sincerely,



Callie B. Gass
Deputy Director, Programs and Partnerships



National Council for International Health

1701 K Street, NW - Suite 600
Washington, DC 20006-1503 USA
Tel: 202-833-5900 - Fax: 202-833-0075
E-mail: <ncih@ncih.org>

FAX TRANSMITTAL

To: Patsy Fleming
At: ONAP
From: Cynthia Mariel
Dept: AIDS Program

Fax: 202-632-1096
Tel: _____
Date: 13 Nov 96
Ext: 209 Pages: 5

MEMORANDUM



NATIONAL COUNCIL FOR INTERNATIONAL HEALTH

1701 K STREET, N.W. SUITE 600, WASHINGTON, DC 20006. (202) 833-5900. FAX: (202) 833-0075

12 November 1996

Ms. Patsy Fleming, Director
Office of National AIDS Policy
750 17th Street, NW
Washington, DC 20503

Dear Patsy:

I would like to thank you again for the recent opportunity to meet with you and your staff and to discuss issues related to global AIDS. I look forward to continuing our history of working together to increase support for and enhanced commitment by the United States government to international AIDS efforts. I greatly appreciate your interest in and demonstrated support for global AIDS issues.

As requested, I have reviewed the draft document, *The National AIDS Strategy*, and have enclosed my comments on the second page to this letter. I very much appreciate the efforts of your office to develop this strategy and congratulate you on the production of such a fine document.

I have prepared a few comments that, of course, reflect my position as an organizational representative working in international AIDS. They do not integrate the political and strategic positioning that is inherent with the work of a White House office. Thus, you will need to weigh my comments against the operational mandate and political context of your own office. Please feel free to contact me if you require additional information and/or review.

In addition, I would also like to take this opportunity to make a special request. I would very much like to include an interview with you for our upcoming issue of *AIDSLink*. The interview would be in a written question and answer format and would focus on the activities of your office in regards to international AIDS during the upcoming Administration.

Based largely on our conversation last week, I have prepared several written questions that are enclosed as a separate page of this letter. Please review the questions and then contact me so that I might know if you are available and agreeable to this interview. For purposes of clarity and efficiency, I am simply asking that you prepare a written response to the questions as well as add any additional comments. In order to meet our press deadline, I would need receive your response to the interview questions no later than 25 November 1996.

Thank you again for the opportunity to work with the Office of National AIDS Policy. I look forward to hearing from you in the near future.

Sincerely,

Cynthia E. Mariel
NCIH AIDS Program



Comments on the draft copy of The National AIDS Strategy

1. Page 3, left column, paragraph 1

Defeating HIV is compared to eradication of smallpox and polio.

Comment: Many would argue that such a comparison tends to medicalize HIV when the issue of HIV/AIDS is multi-faceted and goes well beyond a health problem with a medical solution.

2. Page 5, left column, goal #2

Comment: Because HIV is so closely linked to contextual factors such as socio-economic conditions it might be valuable to include additional wording so that the goal reads, "by providing strong continuing support for effective AIDS prevention efforts and reduction of the socio-economic conditions that contribute to the spread of HIV."

3. Page 7, right column, final paragraph

Comment: The description of the global AIDS epidemic does not cover areas addressed in the previous paragraphs on domestic AIDS. It might be valuable to include some descriptive information that identifies the percentage of HIV infections globally as compared to the number in the U.S., the percentage of global infections that are among women, the percentage of infections that are via heterosexual transmission, and the care related expenditures by the U.S. government related to international AIDS.

4. Page 29, right column, final paragraph

Comment: Does more specific descriptive information need to be added when identifying the United States as the largest contributor to international efforts to combat the pandemic of HIV and AIDS? I have previously heard representatives from USAID describe this role in more specific language.

5. Page 30, right and left column under Future Opportunities for Progress

Comment: In general, the description under this heading focuses on past activities as compared to identification of future commitments. More specifically, in reference to the Paris AIDS Declaration more action oriented language might be included such as, "The U.S. will actively support full enactment of the 1994 Paris AIDS Declaration, of which the U.S. was a signature, through government policies and programs and will encourage other nations to become signatures and supporters of the Paris AIDS Declaration."

6. Page 30, left column, last paragraph

Comment: It is recommended that another statement be added that indicates that the U.S. needs to strengthen support for global HIV/AIDS activities among U.S.-based private voluntary organizations, nongovernmental organizations in developing countries and global HIV/AIDS networks.

Interview questions for *AIDSLink*

1. What do you consider to be the number one priority of your office during the next four years in terms of the US global response to AIDS?
2. How can US-based organizations active in global AIDS efforts assist ONAP in achieving this goal?
3. What contributions can AIDS organizations from developing countries make towards this goal?
4. Why do you think support by the US government to UNAIDS is critical to an effective response to the AIDS pandemic?
5. How can US support for UNAIDS be strengthened?
6. What do you consider the role of your office to be in relationship to major USAID contractors working on international AIDS projects?
7. Why do you think it is important for US-based domestic AIDS groups to become involved in global AIDS?
8. What unique contributions do you believe US-based domestic AIDS groups can make to global AIDS efforts?
9. Based on your knowledge of the US Congress and results of the recent US elections, what are the most effective kinds of educational and advocacy activities that *AIDSLink* readers need to undertake in order to increase support for global AIDS?
10. At present, over 90 % of HIV infection is among developing country populations and yet, approximately only 8 % of global HIV/AIDS funding is spent in developing countries. In addition, per capita health related expenditures by health ministries in many developing countries are less than \$2 per year. How do you reconcile these realities with the strong support you have demonstrated on the issue of equitable access to AIDS treatment and care in developing countries?
11. On World AIDS Day 1994 you were the US representative to the Paris AIDS Summit. At this meeting, the US joined with 42 countries in signing a declaration in which national governments undertook to promote and protect the rights of individuals, particularly people living with HIV/AIDS. To date, the US government still has a travel ban in place restricting people living with HIV/AIDS from entering the country. Will elimination of this restriction be a priority of your office during the next four years?

Additional comments: If the President will be introducing the National AIDS Strategy before December 6, it would be great to include this as an announcement in *AIDSLink* and comments from you on how ONAP will use this strategy in their international AIDS efforts.

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

FACSIMILE TRANSMISSION

to

Patsy Fleming
Jeff Levi

from

Julie Siegfried

date

11/12

page/s to follow

3

- ☐ As requested
- ☐ Review and comment
- ☐ As discussed
- ☐ Please respond
- ☐ For your information

If transmission is not
complete, please call
202-434-8090

comments

- Comments / feedback on PRAT
strategy document
- Would like to nail down a meeting
with you soon as well -

NASTAD

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

MEMORANDUM

November 12, 1996

TO: Patricia S. Fleming, National AIDS Policy Director

FR: Julie M. Scofield  and Joseph F. Kelly  NASTAD

RE: Comments on The National AIDS Strategy

Thank you for the opportunity to provide comments on the draft document "The National AIDS Strategy." We look forward to meeting with you in the near future to discuss this document and other issues of importance as the Administration prepares for a second term of office.

Introduction

We have two brief comments on this section. First, the document should include the most recent figures from CDC on the epidemic. Second, we are troubled by the use of disease comparisons in the discussion of the lifetime cost of medical care. The AIDS community is outraged when other organizations use such comparisons. We feel it is divisive to use these kind of comparisons to justify investments in programs and/or public policy decisions.

Prevention

In general, this section adequately lays out a national HIV prevention agenda. We particularly support the references to HIV prevention community planning as the centerpiece of our nation's HIV prevention strategy and recommend that the importance of community planning be recognized throughout this section. Specifically, under the section on primary care, community planning should be referenced in the discussion of our counseling and testing programs. Efforts to target and enhance counseling and testing programs will require discussion and support from community planning groups around the country. In addition, we would like to raise the following concerns with the prevention section.

First, more attention needs to be paid to the prevention of HIV among injection drug users and other substance users. In particular, in the accomplishment section, mention of the Tampa initiative should be included. There should also be a goal specific to prevention of HIV among injection drug users in the section on future opportunities. This is far too important a prevention challenge to be mentioned only within the context of other sections.

Second, there should be a funding initiative for HIV prevention in the section on future opportunities. Additional resources are needed at the local level to implement the high priority prevention programs identified through the community planning process. We do not believe we can accomplish our national HIV prevention goals without additional resources from the federal government.

The reference to the "Congressionally-set goal of reducing perinatal transmission by 50 percent by the year 2000" should be eliminated. This is a glaring oversimplification of the congressional language that fails to recognize the complexity of the issue and the vastly divergent perspectives on the goal itself. This document should not lend credence to language the Administration and other prevention partners had little if any input in crafting.

The language regarding the President's FY 97 budget request should be broadened to include as a priority increasing funding to state and local health departments so that programs benefiting high priority populations, such as those identified by the President, can be implemented.

Care and Services

The strategy is lacking in vision and detail in articulating the future progress needed in HIV/AIDS care and services. Although the statements are clear and important on maintaining as investment priorities the Medicaid program and the CARE Act, there is a very limited strategy described for achieving the goals of affordable, high quality, and responsive care services. In our view, the President's strategy speaks too cautiously about the most recent HIV therapies and disease monitoring technologies. Although we agree that long-term clinical effectiveness of combination therapies and protease inhibitors has yet to be fully demonstrated, there is abundant evidence among researchers, clinicians and consumers that there has been a breakthrough in the way in which HIV disease is treated.

These developments have already changed the routine ways in which HIV care is being delivered and paid for by government programs. The draft White House strategy for AIDS care and services pays little attention to the way in which the newest therapies have altered the treatment opportunities for people living with HIV/AIDS and gives no mention to the way in which the scientific breakthrough represented by viral load testing has changed how HIV disease is attacked by medical intervention.

We believe there needs to be a stronger statement of commitment in the President's strategy that articulates the following points:

- access to the latest developments in HIV/AIDS treatment needs to be a high priority to ensure that these breakthrough therapies are not merely available to individuals

with the ability to pay but are affordable and available to those individuals who are uninsured or underinsured.

- viral load testing represents an important new method for monitoring HIV/AIDS treatment and progression of HIV disease and strategies should be developed to ensure that access is provided in the context of high quality primary care services.
- federal agencies should work with states to ensure that state-of-the-art treatment strategies are employed throughout the public and private sector health care settings, including Medicaid managed care and Ryan White settings.
- the federal government, working in partnership with states and the private sector should develop long-term strategies for examining cost-reduction in terms of the new therapies.

Appendices

We have not had sufficient time to review and comment on the appendices in depth. However, the section of the appendices for HRSA is, in general, woefully inadequate in articulating a vision for delivering HIV/AIDS care for the next several years. The approaches described appear to be a mere fulfillment of the reauthorized CARE Act requirements, and fall short of describing a strategy for ensuring that high quality HIV/AIDS care is affordable, accessible and responsive to the changing treatment dynamics into the next century. The HRSA section could benefit from the kind of goal setting and examination that is described in the section for the Department of Veterans Affairs which appears to reflect a better understanding of the new treatment developments and translating these developments to patients within the VA health system.

Thank you for the opportunity to provide our comments. We look forward to meeting with you as soon as a time can be arranged.

GAAN Global AIDS Action Network

1931 13th Street N.W. Washington D.C. 20009 202-667-6300 202-483-1135-Fax globalaids@aol.com

To: Patsy Fleming
National AIDS Policy Coordinator

— Attn: Jane Sanille

From: Paul Boneberg
Global AIDS Action Network (GAAN)

RE: Draft National AIDS Plan

Date: November 12, 1996

Patsy--

Thank you for the opportunity to comment on the draft national AIDS plan.

Let us begin by again acknowledging the importance of the plan's existence and the inclusion of international issues within it. We recognize that incorporating the complex international aspect is difficult.

We have no objections to what is outlined as the US response to the global pandemic, however we do urge consideration of a few additions and clarifications.

1. Most importantly we urge the inclusion of a statement specifically reiterating the continuing priority of supporting NGOs working in AIDS on the community level. As you know this has been an essential component of US leadership.
2. Also missing is the US commitment to research that has direct impact on our international programs. We urge that our commitment to the development of vaccines, microbicides, and therapeutics that is outlined in the research section be briefly restated in the international program element. To not mention microbicides and vaccines in particular could send the message that the US is lessening its support, which we are sure is not our intent.
3. The section dealing with the skills exchange could be read as limiting domestic NGO involvement to the "Lessons Without Borders" program. We would urge that you make clear that utilizing the expertise of domestic AIDS groups is an element of global AIDS efforts and the "Lessons Without Borders" program is a part--not the entirety-- of that endeavor.
4. The President's quote (again in the research section) on the US commitment for a vaccine and a cure is the heart of the US commitment on AIDS. If that could be reiterated relative to international programs it would be important.
5. Because of the high visibility of this document we think it likely that the graphs showing the spread of HIV will receive great attention in the media. Therefore we urge that a graph showing the international aspect of HIV be included. GAAN believes that such a graphic must exist, but have been unable to identify a good candidate. One option was sent to us by UNAIDS which we attach. We urge that you to contact UNAIDS directly and identify an appropriate graphic for inclusion in the document.
6. It would be useful if the role of the Department of State could be clarified. We assume that they are the lead agency, particularly in coordinating the US's multiple efforts that are referred to in the final paragraph on international programs.
7. It would be helpful if, in the section on "translating research advances into practice", it could be stated that advances in vaccines and therapeutics would be incorporated in future US international activities.

Thank you for the opportunity to provide input on the draft National AIDS Plan. If we can be of assistance please let us know.



AIDS Policy Center
For Children, Youth & Families

MEMORANDUM

TO: Jane Sanville, Daniel Montoya
The White House Office of National AIDS Policy

FROM: David C. Harvey, Executive Director *DC*

DATE: November 15, 1996

SUBJ: White House AIDS Strategy Report

Thank for the opportunity of reviewing the draft White House report titled, "The National AIDS Strategy 1997". Please excuse our delay in responding to the request for comments.

In addition to other comments, I want to suggest a revision to page 22 which describes Title IV of the Ryan White CARE Act. You may wish to consider the following revised language:

Title IV provides support for comprehensive HIV care and access to clinical research programs for children, youth, women and families in community-based family and youth-centered systems of care.



AmFAR

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April 29, 1994

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
750 17th Street N.W.
Suite 1060
Washington D.C. 20503

Dear Ms. Gebbie:

Thank you for your request to comment on the National HIV Action Agenda. AmFAR sincerely appreciates this opportunity to participate in an effort to define the nation's HIV strategy.

It is difficult to comment on the April 12, 1994, draft document because it is a combination of specific and general goals and the agenda headings as distributed are not a sufficient starting point for mobilizing and organizing the country's HIV effort. We offer here several broad recommendations related to accomplishing the urgent goal of developing a national HIV action agenda:

- **First**, that you urge the President to act swiftly to name his Presidential AIDS Advisory Committee and that this committee participate in the development of the National HIV Action Agenda;

- **Second**, that an inclusive process, which brings together the federal government, the private sector and the AIDS community, be used to identify and set priorities among goals, objectives, etc. All of these participants have substantial knowledge and experience, and are crucial to the successful implementation of a national HIV agenda;

- **Third**, that the HIV agenda include goals, measurable objectives, action steps, responsibilities, a timeline and budgets;

- **Fourth**, that in developing the research component of the agenda, the Office of National AIDS Policy (ONAP) consult with and involve the Office of AIDS Research (OAR) Director Dr. William Paul, whose office has just developed the FY'96 AIDS Plan for NIH. The process initiated for the OAR Plan was impressive and should be considered for a broader (NIH, DOD, VA) public/private initiative. Similar discussions need to occur with those having major responsibilities for the prevention and services component of the agenda. Cross cutting goals and objectives among the research, prevention and services components also need to be addressed;

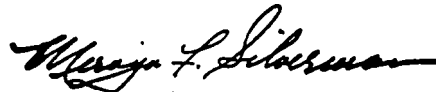
- **Fifth**, the difficult challenges such as immigration exclusion, syringe exchange, correctional issues, and civil rights, must be addressed if the agenda is to accomplish its mission of mobilizing leadership and serving as a blueprint for action.

The draft document highlights the need to better define the role of ONAP and its relationship to federal departments and agencies. Central to the successful development and implementation of a national agenda is the resolution of questions regarding ONAP's role and responsibilities as they relate to departmental responsibilities and authority.

AmFAR very much appreciates this opportunity to suggest a process for rapidly developing an HIV action agenda necessary both for providing a blueprint for the country to follow and for measuring its successful implementation.

We continue to be available to assist you in any way we can.

Sincerely,



Mervyn F. Silverman, M.D., M.P.H.
President

- Patsy will be @ Aaron Diamond
- Tracy Munn - VA.
AAE
- Vaccines - part of "incentives"
discussion
tax/re, patents
- Gramm and me
Jaap Ebler - acting ASPE

CAEAR Coalition Comments on November 1996 Draft of NAS
As dictated by Alexander Robinson
11/14/96

1. Change Formatting. Matthew said it was hard to find the subject areas like research, prevention, etc.
2. Epidemiological and budget data should be the most current.
3. Concern regarding lack of clinical studies on women and children. There are not a lot of FDA-approved drugs for children. Want more work on pediatric indications and more women included in clinical trials.
4. p. 19. Increase the focus on vulnerable populations. Increase Federal research. In this section you only mention non-Federal programs. This is the only place in the document where non-Federal programs are mentioned. [.. in fact, all the programs cited are Federally-supported]
5. p. 21. You grouped Titles I and II together. Even though services are similar, the focus is different. Ernest Hopkins will send suggested language.
6. First four titles are direct service -- the language in the NAS isn't clear.
7. p. 22 Add bullet on SPNS. Matthew suggests: "SPNS is the Nation's research and development support for innovation and replication in the HIV service delivery." Add information on how SPNS is funded. A commitment to the continuing programs should be included.
8. Making an Investment in Care section. Add language about ensuring adequate support for essential care and services funding by the Federal government especially in the areas of substance abuse prevention and treatment and the Tb prevention and treatment.
9. p. 24 in Ensuring Effective Use of Limited Resources section. Add language: "Enhancing technical assistance to CARE Act grantees, planning councils, and consortia."
10. p. 24 in Improving Program Coordination section. Add language about Tb prevention and treatment among people with HIV.
11. p. 25 Improving Quality of Care section. Add CARE Act programs.
12. p. 25 Evaluating Program Effectiveness section. How will this be implemented?
13. Add SPNS to section on Translation of Research Advances into Practice.

Issues raised by NAPWA

1. Needs a letter from the President to the nation stressing the importance of a continuing, strong national response from government and the private sector.
2. Needs to address the issue of Medicare and Medigap insurance for PLWAs.
3. Needs a greater emphasis on the impact of stigmatization, especially homophobia, racism, and sexism.
4. Wants more emphasis on the quality of life for PWAs.
5. Wants more support for viaticals/accelerated benefits.

EXECUTIVE OFFICE OF THE PRESIDENT

12-Nov-1996 02:29pm

TO: Patsy Fleming
TO: Ursula Sanville

FROM: Jeffrey Levi
AIDS Policy Council

SUBJECT: AmFAR

Jane Silver said AmFAR won't have time for specific comments. However, she did pass along that she thought this version was much improved over the earlier one she had seen (a gazillion drafts ago) and that it was a good first step. (First steps can be divided into many substeps. It all depends where you are sitting.)

November 13, 1996

MEMORANDUM FOR PATSY, JEFF, LAHOMA, RICHARD, DANIEL, AND SHERRY

FROM: Jane

SUBJECT: ONAP Review of Community Comments on the National AIDS Strategy

1. Status of comments

- Received from: NCIH
NASTAD
National AIDS Fund
AIDS Action Council
- NAPWA -- written comments pending from Richard. ✓
- AmFAR -- no specific comments will be forthcoming.
- CAEAR Coalition -- pending (phone tag with Alexander Robinson). ✓
- ANIN -- never met, no comments.
- Still Missing: GNP+
GAAN *yes*
AIDS Policy Center
NMAC
HRC
[Anyone else missing?]

2. Please review these comments and assess whether or not the suggestion should be incorporated into the NAS.

We'll meet tomorrow around 5:30 pm to walk through and decide what goes in and what does not.

Thank you for your assistance.

November 13, 1996

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THE CHALLENGES OF HIV/AIDS FOR WOMEN OF COLOR & THEIR FAMILIES

**The Challenges
of HIV/AIDS for
Women of Color
& Their Families**

A PUBLIC POLICY & ADVOCACY INITIATIVE