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**Subseries:** National AIDS Strategy

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**Folder Title:**
Crosswalk of Community Comments 12/12/96

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December 12, 1996

Patsy and Richard --

Attached are the materials regarding the community comments on the National AIDS Strategy. I have noted how each suggestion was handled in writing on the organizations' comments.

Bottom line -- we incoroporated a lot of comments. We can in good faith tell each organization that many of their suggestions were incorporated into the final document.

Any questions let me know.

==========

**1. NMAC**

No written comments were provided. Daniel called them to remind them.

Major concerns raised in the meeting were:

- re-authorizations for NIH, HOPWA, SAMHSA
  NS: only mention NIH re-authorization, p. 19

- NIH's revamping of the prevention science agenda (Moises is now on the NIH committee)
  NS: specific mention of NIH's implementing Levine report findings, including the prevention science agenda, p. 19

- research should focus on women
  NS: special section on vulnerable populations, p. 20

- Blacks underrepresented in ADAP (fyi, my notes say RS promised to follow-up with HRSA)

- Medigap, disability and back to work
  NS: p. 24

- increasing the dialogue with ONDCP
  NS: ONDCP mentioned on p. 15, issue of dialogue not mentioned

**2. National AIDS Fund**
See attached sheets.

**3. NAPWA**
See attached sheet.

**4. AIDS Action Council**
See attached sheets.

**5. AmFAR**
No comments added. See attached sheets.

**6. CAEAR**
See attached sheets.

**7. NASTAD**
See attached sheets. NB: They didn't meet with us -- some comments reflect lack of understanding about text/appendices differences.

**8. Human Rights Campaign**
No written comments were provided. Daniel called them to remind them.

Major concerns raised in the meeting were:

- Need more focus on IIIB.
- New optimism is great but we don't want to dismantle the service structure for end-stage disease until we know if these drugs work.
- Need more dialogue on the drugs v. infrastructure dilemma.
- Needle exchange -- how can we move this forward.
- Don't want mandatory testing for pregnant women.

**9. ANIN**
Never met with them. No comments provided.

**10. GAAN**
See attached sheet.

**11. NCIH**
See attached sheet.

**12. AIDS Policy Center**
See attached sheet.

# 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

changed, p. 7

- The goal to "reduce the number of new HIV infections..." should refer to "continuing support for effective ***HIV*** prevention efforts;"

added, p. 8

- 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

No. Did not agree & OMB.

- 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

It's made consistent

- Total number of new infection is estimated to be approximately 40,000 to ***60,000*** people each year.

No

- 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."

language changed. P. 11

- 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.

language changed P. 12

- 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.

Support Community planning P. 13

- 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? CDC Research indicates that such approaches may work.

Bleach language removed. P. 15

- 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.

No language added.

**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.

No Δ. Approved by NIH.

- 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.

Stated on P.19

- 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.

No Δ. Would have had to go back to NIH.

- 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.

P.20, 21, 30 language added on HIV-1 vaccines.

- 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.

Forum for Collab. HIV P. 20

Continued support for Research P.21

- 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?

OAR supports the CPCRA. Form to be decided. CPCRA has better follow-up than ACTG.

No change. NAS not that specific.

- 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

Added. P. 22-23

- 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.

SPNS added. P. 23

Language added. P. 24

- 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.

Budget #'s ranged as per OMB. P.25

- 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.

Third national goal A'd to include housing P.7

- 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.

housing added to Civil Rights, P. 27

- 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.

Added, p. 23

Not added.

- 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

Want C HCFA stats.

- 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.

language added, P.24

- 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.)

Not added.

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

Sections on Medicare and SSA added, P. 24, 25

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

Section on SSA added, P. 25

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

Part of larger managed care issue. Added language on P. 26

- 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.

No added. Medicare addressed

- The Improving Quality of Care paragraph could be strengthen 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.)

Added, p.22

- 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**

Not added. Would have had to go back.

- There is no reference to the reauthorization of the Rehabilitation Act and the important protections it provides in the "Future Opportunities" section.

Part of bigger issue - will fight on all fronts. p.27

- This section should also include protecting the privacy of personal health information and medical records.

Housing added p.27

- 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.

No, too specific.

- 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.

Language is in there about the Director working with Depts. p.28

- 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:**

1400 I Street NW Suite 1220 Washington DC 20005-2208 (202) 408-4848 Fax (202) 408-1818

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

Added to PF letter

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:

- *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 in PF letter, p. 6 One sentence in POTUS letter

- 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)

- Add information on the successful use of programs, especially AmeriCorps, to add resources to communities as they fight the epidemic; (Page 9)

- 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.

- Add the word *workplace* to the third bullet on Page 10 so that it reads *"Strengthening community based and workplace programs;"*

- Integrate the concept of workplace education and prevention into the discussions on page 12, particularly under the subhead ***Prevention Education***

- ***Ensuring Effective Use of Limited Resources*** (Page 24) should include a fourth method as follows:
  *(4) and collaborating with the private sector.*

- 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, (page17) 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.

Didn't get this specific in NAS pp. 20, 21, 30 highlight U.S. Commitment

- **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

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.

other added

2. Needs to address the issue of Medicare and Medigap insurance for PLWAs.

added p. 24 + 25

3. Needs a greater emphasis on the impact of stigmatization, especially homophobia, racism, and sexism.

added p. 12. Also existing language on p. 27

4. Wants more emphasis on the quality of life for PWAs.
Alluded to in 3d national goal. P-7

5. Wants more support for viaticals/accelerated benefits.
Nothing added.

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

1828 L STREET, N.W., SUITE 802
WASHINGTON, D.C. 20036-5104
TEL (202) 331-8600
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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

***CAEAR Coalition Comments on November 1996 Draft of NAS***

*As dictated by Alexander Robinson*

*11/14/96*

Formatting Changed. 1. Change Formatting. Matthew said it was hard to find the subject areas like research, prevention, etc.

Data updated 2. Epidemiological and budget data should be the most current.

Language Added to section on vulnerable populations. p. 21 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.

Entire section devoted to vulnerable pops. p. 20 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 ....] → incorrect, all are Federal programs.

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. [No language sent.]

Language added, pp. 22-23. 6. First four titles are direct service -- the language in the NAS isn't clear.

language added, p. 23 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.

Addressed in prevention p. 16. 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. Also addressed in program coordination, p. 25. language added p. 25.

Language added, p. 26 9. p. 24 in Ensuring Effective Use of Limited Resources section. Add language: "Enhancing technical assistance to CARE Act grantees, planning councils, and consortia."

Added, p. 25 10. p. 24 in Improving Program Coordination section. Add language about Tb prevention and treatment among people with HIV.

Added, p. 26 11. p. 25 Improving Quality of Care section. Add CARE Act programs.

12. p. 25 Evaluating Program Effectiveness section. How will this be implemented? Working c agencies, GPRA, part of implementation process.

13. Add SPNS to section on Translation of Research Advances into Practice.

Not added. But, OHAP charged with coordinating.

FEB 07 '02 04:40

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 Saville

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. More language on NGOs added. P. 30-31.

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. More language added on PP. 20, 21, 30.

3. The section dealing with the skills exchange could be read as limiting domestic NGO involvement to the "Lessons Without Boarders" 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 Boarders" program is a part--not the entirety-- of that endeavor. language modified, P. 30-31

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. Importance of int'l approach to vaccines - language added, PP 20, 21, 30.

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. Excellent idea. Figure ~~Chart~~ added → P. 38

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. Not added.

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. Sharing advances in int'l section, P. 30.

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

NCIH

**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.

Did not change language.

**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."

Did not change language

**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. Expanded section on international epidemiology, p. 9. Added int'l figure, p. 38.

**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. language on U.S. role in research expanded, pp. 20, 21, 30.

**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." Support for Paris declaration in document. No further language added.

**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.

More language on NGOs added, p. 30

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.

Added more general language about SPNS, AETCs, p. 23.

Did address their concerns about children & access to research/drugs in research section, p. 20-21.

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December 12, 1996

Patsy and Richard --

Attached are the materials regarding the community comments on the National AIDS Strategy. I have noted how each suggestion was handled in writing on the organizations' comments.

Bottom line -- we incoroporated a lot of comments. We can in good faith tell each organization that many of their suggestions were incorporated into the final document.

Any questions let me know.

Jane

==========

**1. NMAC**

No written comments were provided. Daniel called them to remind them.

Major concerns raised in the meeting were:

- re-authorizations for NIH, HOPWA, SAMHSA
  NS: only mention NIH re-authorization, p. 19

- NIH's revamping of the prevention science agenda (Moises is now on the NIH committee)
  NS: specific mention of NIH's implementing Levine report findings, including the prevention science agenda, p. 19

- research should focus on women
  NS: special section on vulnerable populations, p. 20

- Blacks underrepresented in ADAP (fyi, my notes say RS promised to follow-up with HRSA)

- Medigap, disability and back to work
  NS: p. 24

- increasing the dialogue with ONDCP
  NS: ONDCP mentioned on p. 15, issue of dialogue not mentioned

**2. National AIDS Fund**
See attached sheets.

**3. NAPWA**
See attached sheet.

**4. AIDS Action Council**
See attached sheets.

**5. AmFAR**
No comments added. See attached sheets.

**6. CAEAR**
See attached sheets.

**7. NASTAD**
See attached sheets. NB: They didn't meet with us -- some comments reflect lack of understanding about text/appendices differences.

**8. Human Rights Campaign**
No written comments were provided. Daniel called them to remind them.

Major concerns raised in the meeting were:

- Need more focus on IIIB.
- New optimism is great but we don't want to dismantle the service structure for end-stage disease until we know if these drugs work.
- Need more dialogue on the drugs v. infrastructure dilemma.
- Needle exchange -- how can we move this forward.
- Don't want mandatory testing for pregnant women.

**9. ANIN**
Never met with them. No comments provided.

**10. GAAN**
See attached sheet.

**11. NCIH**
See attached sheet.

**12. AIDS Policy Center**
See attached sheet.

# 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

changed, p. 7

- The goal to "reduce the number of new HIV infections..." should refer to "continuing support for effective ***HIV*** prevention efforts;"

added, p. 8

- 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

No. Did not agree & OMB.

- 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

Is made consistent

- Total number of new infection is estimated to be approximately 40,000 to ***60,000*** people each year.

No

- 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."

language changed. P. 11

- 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.

language changed P. 12

- 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.*"

Support Community planning P. 13

- 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? CDC Research indicates that such approaches may work.

Bleach language removed. P. 15

- 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.

No language added.

**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.

No Δ. Approved by NIH.

- 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.

Stated on P.19

- 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.

No Δ. Would have had to go back to NIH.

- 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.

P. 20, 21, 30 language added on Int'l Vaccines.

- 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.

Forum for Collab. HIV P. 20

Continued support for Research P. 21

- 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?

OAR supports the CPCRA. Form to be decided. CPCRA has better follow-up than ACTG.

No change. HAS not that specific.

- 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

Added. P. 22-23

- 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. SPNS added. P. 23

Language added. P. 24

- 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.

Budget #'s changed as per OMB. P.25

- 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.

Third national goal Δ'd to include housing P.7

- 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.

Housing added to Civil Rights, P. 27

- 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.

Added, P. 23

Not added.

- 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

Need CHFA stats.

- 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.

language added, P.24

- 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.)

Not added.

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

Sections on Medicare and SSA added, P. 24, 25

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

Section on SSA added, P. 25

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

Part of larger Medicaid care issue. Added language on P. 26

- 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.

No added. Medicare addressed

- The Improving Quality of Care paragraph could be strengthen 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.)

Added, p. 22

- 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**

Not added. Issues have had to gone back.

- There is no reference to the reauthorization of the Rehabilitation Act and the important protections it provides in the "Future Opportunities" section.

Part of bigger issue - will fight on all fronts. P. 27

- This section should also include protecting the privacy of personal health information and medical records.

Housing added. P. 27

- 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.

No, too specific.

- 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.

Language is in there about the Director working with Depts. p. 28

- 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:**

1400 I Street NW Suite 1220 Washington DC 20005-2208 (202) 408-4848 Fax (202) 408-1818

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

Added to PF letter

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:

- *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)

10 in PF letter, p. 6
One sentence in POTUS letter

- 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)

- Add information on the successful use of programs, especially AmeriCorps, to add resources to communities as they fight the epidemic; (Page 9)

- 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.

- Add the word *workplace* to the third bullet on Page 10 so that it reads *"Strengthening community based and workplace programs;"*

- Integrate the concept of workplace education and prevention into the discussions on page 12, particularly under the subhead ***Prevention Education***

- ***Ensuring Effective Use of Limited Resources*** (Page 24) should include a fourth method as follows:
  *(4) and collaborating with the private sector.*

- 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, (page17) 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.

Didn't get this specific in NAS. pp. 20, 21, 30 highlighted U.S. commitment

- **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.

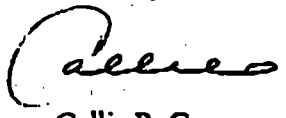
## E. INTERNATIONAL ACTIVITIES

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

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.

ltr added

2. Needs to address the issue of Medicare and Medigap insurance for PLWAs.

Added P. 24+25

3. Needs a greater emphasis on the impact of stigmatization, especially homophobia, racism, and sexism.

added P. 12 Also existing language on P. 27

4. Wants more emphasis on the quality of life for PWAs.
Alluded to in 3d national goal. P-7

5. Wants more support for viaticals/accelerated benefits.
Nothing added.

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;

- **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

*CAEAR Coalition Comments on November 1996 Draft of NAS*

*As dictated by Alexander Robinson*

*11/14/96*

Formatting Changed. 1. Change Formatting. Matthew said it was hard to find the subject areas like research, prevention, etc.

Data updated 2. Epidemiological and budget data should be the most current.

Language Added to section on vulnerable populations. P. 21 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.

Entire section devoted to vulnerable pops. P. 20 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 ....] → incorrect, all are Federal programs.

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. [No language sent.]

Language added, pp. 22-23. 6. First four titles are direct service -- the language in the NAS isn't clear.

Language added, P. 23 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.

Addressed in prevention P. 16. 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. Also addressed in program coordination, p. 25. language added p. 25.

Language added, p. 26 9. p. 24 in Ensuring Effective Use of Limited Resources section. Add language: "Enhancing technical assistance to CARE Act grantees, planning councils, and consortia."

Added P. 25 10. p. 24 in Improving Program Coordination section. Add language about Tb prevention and treatment among people with HIV.

Added P. 26 11. p. 25 Improving Quality of Care section. Add CARE Act programs.

12. p. 25 Evaluating Program Effectiveness section. How will this be implemented? Working ⅁ Agencies, GPRA, part of implementation process.

13. Add SPNS to section on Translation of Research Advances into Practice.

Not added. But, OHAP charged with coordinating.

FEB 07 '02 04:40

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. More language on NGOs added. P. 30-31.

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. More language added on PP. 20, 21, 30.

3. The section dealing with the skills exchange could be read as limiting domestic NGO involvement to the "Lessons Without Boarders" 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 Boarders" program is a part--not the entirety-- of that endeavor. language modified, P. 30-31

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. Importance of int'l approach to vaccines - language added, PP 20, 21, 30.

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. Excellent idea. Figure ~~Chart~~ added → P. 38

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. Not added.

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. Sharing advances in int'l section, P. 30.

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

NCIH

**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.

Did not change language.

**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."

Did not change language

**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.

Expanded section on international epidemiology, p. 9. Added int'l figure, p. 38.

**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.

language on U.S. role in research expanded, pp. 20, 21, 30.

**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."

Support for Paris declaration in document. No further language added.

**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.

More language on NGOs added, p. 30

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

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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.

Added more general language about SFNS, AETCs, p. 23.

Did address their concerns about children & access to research/drugs in research section, p. 20-21.

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