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Folder Title:
PACHA [President's Advisory Council on HIV/AIDS] - Strategic Plan

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WHITE HOUSE COUNCIL ON HIV/AIDS
"SHORT-TERM ACHIEVABLE" PRIORITIES ADOPTED JUNE 17, 1998

Issue/Objective	Votes	Amount of Work: Lots	Amount of Work: Limited	Target(s): White House	Target(s): Administrative Agency	Target(s): Congress (Indirect)
1. Work to advance the call for a State of Emergency in the African American and Latino communities through a variety of strategies, such as the following: • Engage the President by requesting that he convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency • Call for a Special White House conference on the State of Emergency in communities of color	23	X		X		
2. Influence CDC policies and programs related to HIV/AIDS prevention, including: • Establishment of a youth initiative • Ensure that the CDC establishes a national initiative to encourage testing that effectively targets high-risk populations • Ensure that the CDC includes in its HIV Prevention Community Planning guidance language requiring that use of community prevention funds be linked to the local demographics of the epidemic, and that the CDC evaluates compliance with the direction in the guidance	22	X		X	X	
3. Track and advocate for access to care and funding for early intervention through expansion of Medicaid, working at the national policy level (HCFA and the White House) and with regard to State waiver applications	15	X		X	X	

Issue/Objective	Votes	Amount of Work: Lots	Limited	Target(s): White House	Administrative Agency	Congress (Indirect)
4. Work for higher appropriations for HIV/AIDS prevention, services, and research, including the following: • Support NORA's FY 1999 HIV/AIDS appropriations request • Develop an appropriate strategy for 2000 appropriations • Focus on increased funding for substance abuse treatment, building service capacity in communities of color, youth, and international HIV/AIDS programs	11	X		X		X
5. Provide input to the new international strategic plan on HIV/AIDS being developed by the Department of State and help ensure that its provisions are implemented	11		X	X	X	
6. Advocate for attention to women-centered prevention methods (microbicides) [Language of recommendation to come by November]	11	X			X	

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PACHA 1998-99 OBJECTIVES, PRINCIPLES, AND GOALS, BY CATEGORY

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
A	Work to advance the call for a State of Emergency in the African American and Latino communities through a variety of strategies, such as the following: • Engage the President by requesting that he convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency. • Call for a Special White House conference on the State of Emergency in communities of color • Work to advance the call for a State of Emergency. Advocate for increased funding to serve African American and Latino communities. • Engage the President, especially through his interest in race and race relations, to take action on the racial/ethnic implications around HIV/AIDS service delivery.	If the Supreme Court rules that HIV is not a disability under the ADA, work to regain recognition of HIV as a disability.	Seek the alignment of the full range of prevention, medical and social support services (including such basic needs as food and housing) so their funding streams are both equitably available and targeted to special needs and disproportionately affected populations.	Follow through on HIV-positive health care worker guidelines.

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
B	Influence CDC policies and programs related to HIV/AIDS prevention, including: • Establishment of a youth initiative. • Ensure that the CDC establishes a national initiative to encourage HIV testing that effectively targets high-risk populations. • Ensure that the CDC includes in its HIV Prevention Community Planning guidance language requiring that use of community prevention funds be linked to the local demographics of the epidemic, and that the CDC evaluates compliance with the direction in the guidance.	Continue to advocate for a policy that permits the use of federal funds for needle exchange.	Address bigotry, social divisions, and their impact on fueling HIV, and on proposed government remedies.	Convince the President to establish a concrete goal regarding provision of services for people in need, as he has done with vaccine development and infection rates.
C	Track and advocate for access to care and funding for early intervention through expansion of Medicaid, working at the national policy level (HCFA and the White House) and with regard to State waiver applications	Work for legislative repeal of the ban on immigration to the U.S. by HIV-positive individuals.	Put HIV/AIDS prevention at the top of the national agenda.	Work for reauthorization of the Ryan White CARE Act, including reform of ADAP to ensure funding available for providing and maintaining a comprehensive set of therapies (without the need for emergency supplemental appropriations)

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
D	Work for higher appropriations for HIV/AIDS prevention, services, and research, including the following: • Support NORA's FY 1999 HIV/AIDS appropriations request. • Develop an appropriate strategy for 2000 appropriations. • Focus on increased funding for substance abuse treatment, building service capacity in communities of color, youth, and international HIV/AIDS programs.	Support the appropriation of the necessary funds to ensure substance abuse treatment on demand.	Push the microbicide agenda forward by: • Changing the structure of the FDA in terms of toxicity/pharmacology reporting on microbicides. • Addressing liability and access issues. • Obtaining increased funding. [Research Committee will bring specific objectives and recommendations in November]	Follow up on vaccine recommendations.
E	Provide input to the new international strategic plan on HIV/AIDS being developed by the Department of State and help ensure that its provisions are implemented.	Work to establish an effective method for monitoring the epidemic.	Work to improve adherence to treatment guidelines by all providers of care. Includes broader dissemination and education by HRSA related to the treatment guidelines, and their implementation in federal prisons, as well as emphasis on ensuring that underserved populations receive appropriate treatment.	Get the Attorney General to provide a directive to the Bureau of Prisons that mandates pre-discharge planning, including appointments with service agencies, and requirement that medical summaries follow the individual from prison to post-release treatment.

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
F	Advocate for attention to women-centered HIV prevention methods (microbicides). [Language of recommendation to come by November]	Move the research agenda on behavioral interventions -- to learn more about what works and what doesn't work.	Work for the establishment of a longitudinal file for women who received AZT and all anti-retrovirals while pregnant, to monitor them and determine the long-term effects of treatment.	Work for reauthorization of HOPWA.
G		Work to identify and support U.S. leadership in the international arena (within the State Department and other Federal agencies) so that the AIDS issue is raised in all available forums.	Help ensure that the information from HCSUS (HIV Cost, Services, and Utilization Study) is readily available, and that it is used to help federal officials and other entities align services to address the demographics of the epidemic and implement the treatment guidelines [Data not available until after Geneva].	Have the Executive Committee work to increase ONAP staff resources, including both FTEs and the continuity of personnel, with special emphasis on: • Greater involvement in international issues. • A coordinating role on the vaccines issue.

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
H			Ensure that comprehensive services/discharge planning is provided to all individuals leaving prisons, including social services, housing, food, financial assistance, as well as medical care to the extent needed. Includes linkages with available community resources to provide drug treatment, health interventions.	Ensure that the Patient Bill of Rights for Health Care includes clear and explicit reference to HIV care needs, including access to care and implementation of the treatment guidelines.
I			Enhance the federal/ State/local dialogue regarding HIV and prisons, with emphasis on State/local input to the Bureau of Prisons. Address federal guidelines, technical assistance, and funding streams that have policy implications in State and local prisons and jails.	Follow through with ONAP on youth programs status report and plan.
J				Evaluate progress on previous PACHA recommendations regarding HIV surveillance.

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FAX (202) 785-1255 TELEX: 64245

THE MADISON HOTEL
Washington, D.C. 20005
(202) 862-1600

Nick –
We've been thinking about convening a meeting of philanthropists to talk about stepping up support for needle exchange. I'd love your ideas about how to do this, who to invite, etc. Do you think Funders Concerned could help us?

yes → did you ever connect with the Soros/ Told Open Society Institute people?

Nick

Subcommittee on Racial and Ethnic Minority Populations
Tuesday June 16, 1998

A. That the Council embrace as its principal the elimination of disparities regarding HIV prevention, care, treatment, and research across racial/ethnic communities in all Council activities and committee recommendations.

B. Serve as the focal point within the Council for *collaboration with* and *review of* draft recommendations from governmental agencies, national advisory councils, and special initiatives that relate to the HIV epidemic in communities of color **and** provide guidance to the Council for the development of formal Council recommendations.

C. Aide in the coordination of activities within the Council by serving as a repository for policy, surveillance, prevention, care and treatment analysis in racial/ethnic communities.

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

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

DRAFT LETTER

Dear Dr. Sawyer:

We, the members of the Presidential Advisory Council on HIV/AIDS, are extremely concerned about your unwillingness to discuss the use of protective barriers in Federal prisons. We are aware of the many difficult issues that this question poses for you. However, these concerns pale compared to the risk of transmission of HIV, Hepatitis B, Hepatitis C and other sexually transmitted diseases (STDs) in prison. (As reported in the 47.21 MMWR)

We all know that sexual behavior continues among incarcerated individuals. In light of this reality, we must do all we can to prevent life-threatening illnesses. We do know that protective barriers reduce the transmission of HIV and other STDs. Numerous state and international prison experts have recommended the use of protective barriers in the prison setting. Furthermore, several state, county and city prison systems in our country as well as several Federal institutions in other countries have introduced the use of protective barriers in their institutions as one means of preventing the spread of HIV Disease. Of course, this should be part of an overall prevention strategy that includes education, appropriate medical intervention, and other harm-reduction models.

Protective barriers can save lives.

Certainly the lack of protective barriers does not discourage sexual behavior. The lifetime cost of taking care of one new case of HIV Disease is hundreds of thousands of dollars. The prison population offers us a unique opportunity for a comprehensive prevention effort, but protective barriers must be a part of this effort if it is to be effective.

We again request that you meet with our Prison Issues Subcommittee at the earliest opportunity prior to our next Council meeting.

Sincerely yours,

cc: Eleanor Acheson
Janet Reno

PRISON ISSUES SUBCOMMITTEE
Recommendation

DRAFT

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

June 18, 1998

Dear Secretaries Shalala and Reno:

We want to be assured that the PHS AIDS Treatment Guidelines are the standard of medical care in our nation's prisons and jails.

We have the following questions:

- Have those guidelines been put into place?
- Can you provide us with documentation of their implementation?
- How are you assuring that all appropriate providers are being trained in the use of these guidelines?
- How has the use of these guidelines been evaluated?

On behalf of the Presidential Advisory Council on HIV/AIDS, we are requesting a report which specifically outlines the use of the PHS Treatment Guidelines in our Federal corrections system. Please provide us with that information within 90 days. If you cannot do so, please provide us with an explanation as to why this information is not yet available.

Sincerely,

June 16, 1998

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS
PROPOSED RECOMMENDATIONS

Discrimination Committee

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

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

INTERNATIONAL ISSUES

PROPOSED COUNCIL RESOLUTION

(Tabled at December, 1997 Meeting)

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

ASSESSMENT OF THE STRATEGIC PLANNING PROCESS

Please complete this brief assessment form and leave it for the facilitators. Thank you!

1. Overall, how would you evaluate the strategic planning process in terms of:

		Excellent	Very Good	Good	Fair	Poor
a.	Its probable value to the Council?	____	____	____	____	____
b.	Its value to you as an individual Council member?	____	____	____	____	____

2. How would you assess the following aspects of the session:

a.	Objectives and process	____	____	____	____	____
b.	Group involvement and interaction	____	____	____	____	____
c.	Facilitators	____	____	____	____	____

3. What was the best part of the strategic planning process?

4. What was the worst part of the strategic planning process?

5. Do you think the strategic planning will contribute to positive changes in the way the Council operates or what it achieves? ____ Yes ____ No ____ Not sure
If yes, what kind?

6. Please add any other desired comments.

Thank you -- we have enjoyed working with you!

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS
STRATEGIC PLANNING ISSUES AND OBJECTIVES

DISCRIMINATION SUBCOMMITTEE

[Time-sensitive/limited Council effort required]

1. Follow through on the HIV-positive health care worker guidelines.

[Time-sensitive]

2. If the Supreme Court rules that HIV is not a disability under the ADA, work to regain recognition of HIV as a disability.

[Not immediately achievable but morally important]

3. Work for legislative repeal of the ban on immigration to the U.S. by HIV-positive individuals.

[Future; if Committee focus expands]

4. This epidemic is significantly fueled by a lack of self-worth among society's marginalized populations. Government failure to adequately address pervasive racism, sexism, and homophobia -- or worse, government actions that actively promote them -- only serve to create a climate in which the epidemic will flourish. If the Council's self-perceived mandate expands in July 1999, the Discrimination Subcommittee will make it a priority to focus the Council's attention on bigotry, social divisions, and their impact on fueling HIV, and on proposed government remedies.

INTERNATIONAL SUBCOMMITTEE

[Short-term]

1. Provide input to the new strategic plan being developed by the Department of State and help ensure that its provisions are implemented.

2. Work to increase the budget for international AIDS spending, both for United Nations and international NGO programs and for U.S. government programs.

[Longer-term]

3. Work to identify and support U.S. leadership in the international arena (within the State Department and other Federal agencies) so that the AIDS issue is raised in all available forums.

4. Work to increase ONAP staff resources for involvement in international issues.

PREVENTION COMMITTEE

[Broad goal]

1. Putting prevention at the top of the national agenda is a priority for the Presidential Advisory Council on HIV/AIDS (PACHA). To accomplish this goal, the Council will work to: increase funding for prevention; ensure that those funds are appropriately targeted; and promote the cultivation of effective interventions.

[Objectives]

A. Increased Funding
   1) PACHA supports the National Organizations Responding to AIDS (NORA) Fiscal Year 1999 Appropriations Request and will work with the community to develop a FY 2000 budget request. PACHA recommends that part of any new funds must provide increased funding for SAMHSA drug treatment programs and build capacity in racial/ethnic communities (support NRMOs, CDC Race Initiatives).
   2) PACHA will work to advance the call for a State of Emergency and will advocate for appropriate funding.
   3) PACHA recommends the establishment of a CDC youth initiative.

B. Targeting Funds
   1) PACHA will work with the CDC to ensure that funds are more appropriately targeted by racial/ethnic, risk factor, age, gender, and geography.
      a. The PACHA Prevention Committee will work with the CDC in the development of its guidance for HIV Prevention Community Planning.
      b. The PACHA Prevention Committee will work with CDC to evaluate the compliance of State planning groups and health departments.

C. Effective Interventions
   1) PACHA will work with CDC to ensure the cultivation of effective interventions.
   2) PACHA will work to ensure the immediate release of new guidance regarding the content of HIV prevention efforts (content restrictions).
   3) PACHA will work to ensure the expeditious completion of revised infected health care worker guidelines.
   4) PACHA recommends the appropriation of the necessary funds to ensure substance abuse treatment on demand.

2. The PACHA Prevention Committee will evaluate the progress on previous recommendations regarding surveillance and work to establish an effective method for monitoring the epidemic.

3. PACHA recommends and will work with the Administration to ensure that the CDC establishes a national initiative to encourage the knowledge of sero-status that effectively targets at-risk populations.

PRISONS SUBCOMMITTEE

1. Standards of Care: Implementation of Standards of Care in Federal Prisons (including outreach from Department of Health and Human Services to Bureau of Prisons).

2. Discharge Planning: Comprehensive services/discharge planning must be provided to all individuals, including social services, housing, food, financial assistance, as well as medical care to the extent needed.
   a. We must break the spread of HIV and other STDs during and after incarceration through adequate drug treatment, health interventions, and discharge planning with available community resources.
   b. Medical summaries must follow the individual from prison to post-release treatment.

3. Federal/State Dialogue: Federal guidelines, technical assistance, and funding streams have policy implications in State and local prisons and jails. The Federal/State dialogue must be enhanced.

RACIAL AND ETHNIC MINORITY POPULATIONS SUBCOMMITTEE

[Overarching principle/goal]

1. The Council embraces as its principle the elimination of disparities across racial/ethnic communities in all council activities and committee recommendations.

[Council decision on structure and procedures]

2. The Committee will serve as the focal point or clearinghouse within the Council for collaboration with and review of draft recommendations from governmental agencies, national advisory councils, and special initiatives that relate to the HIV epidemic in communities of color and provide guidance to the Council for the development of formal recommendations.

3. Aid in the coordination of activities within the Council by serving as a repository for policy, surveillance, prevention, care, and treatment data and analyses on racial/ethnic communities.

[Time-sensitive objective]

4. Request that the President convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency in the African American and Latino communities.
5. Call for a Special White House conference on the State of Emergency in communities of color at the end of the Council's current term (July 1999).

RESEARCH COMMITTEE

[Achievable objectives]

1. Push the microbicide agenda forward by addressing the following:
   a. Changing the structure of the FDA in terms of toxicity/pharmacology reporting on microbicides (eliminate the requirement that five committees review microbicides)
   b. Liability and access issues (similar to those for vaccines)
   c. Increased funding
   d. Development of methods that empower women to prevent the spread of HIV (will bring recommendations in November)

[Not necessarily achievable in the short term, but very important]

2. Move the research agenda on behavioral interventions -- what works and what doesn't work (cross-committee issue).

3. Support having ONAP assume the role of coordinating the vaccine agenda, and ensure that it has sufficient staff to do so

Follow-up on existing recommendations:

4. Follow-up on vaccine recommendations

SERVICES COMMITTEE

[Overall goal]

1. Seek the alignment of the full range of medical and social services to reflect current and projected needs and demographics, treatment standards, and a realistic assessment of potential resources, both public and private, so that services and supporting funding streams are both equitably available and targeted to special needs populations.

[Short-term]

2. Engage the President, especially through his interest in race and race relations, to take action on the racial/ethnic implications around HIV/AIDS service delivery.

3. Convince the President to establish a concrete goal regarding provision of services for people in need, as he has done with vaccine development and infection rates.

[Legislative]

4. Work for reauthorization of the Ryan White CARE Act, including reform of ADAP to ensure funding available for providing and maintaining a comprehensive set of therapies (without the need for emergency supplemental appropriations).

5. Work for reauthorization of HOPWA.

6. Work on the FY 2000 appropriations process.

[Administrative]

7. Continue to track and advocate for the expansion of Medicaid as a source of funding for early intervention, at the national policy level (HCFA and the White House) and with regard to State waiver applications.

8. Help ensure that the information from HCSUS (HIV Cost, Services, and Utilization Study) is readily available, and that it is used to help federal officials and other entities align services to address the demographics of the epidemic and implement the treatment guidelines.

9. Urge broader dissemination and education by HRSA related to the treatment guidelines, with emphasis on ensuring that underserved populations receive appropriate treatment.

10. Work for the establishment of a longitudinal file for women who received AZT and all anti-retrovirals while pregnant, to monitor them and determine the long-term effects of treatment.

11. Ensure that the Patient Bill of Rights for Health Care includes clear and explicit reference to HIV care needs, including access to care and implementation of the treatment guidelines.

[Structure]

12. Work on the development of a services-focused research agenda (joint effort of the Services and Research Committees).

CROSS-COMMITTEE

1. Increase the FTEs and the continuity of staffing within ONAP so that it has the personnel to fully carry out its roles.

2. Remove ONAP funds from the budget of the Drug Czar.

3. Increase funding for youth-focused and youth-appropriate prevention, services, and research.

June 18, 1998

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS RECOMMENDATIONS ON YOUTH ISSUES

LEADERSHIP RECOMMENDATIONS

- The Council requests that the Office of National AIDS Policy present a detailed status report on the implementation of the recommendations outlined in the White House ONAP report, "Youth and HIV/AIDS: An American Agenda."

- The Council requests that the Office of National AIDS Policy present a detailed status report on the implementation of recommendations from the Presidential Directive.

Disabilities Act Covers State Prisoners, Court Rules

By JOAN BISKUPIC
Washington Post Staff Writer

The Supreme Court ruled unanimously yesterday that state prisoners are protected by a federal law prohibiting discrimination against people with disabilities.

The decision allows a disabled prisoner who was denied a place in a motivational boot camp—and the chance to serve a shorter sentence—to move forward with a lawsuit against Pennsylvania corrections officials. The ruling is likely to force state prisons to provide greater access in a host of operations and programs to disabled inmates.

The 1990 Americans with Disabilities Act forbids any public entity from discriminating against people based on their disability by failing to provide the same kinds of services, benefits or programs that are made available to the rest of the population.

The Pennsylvania Department of Corrections, supported by other states and the District of Columbia, had argued that prisons do not offer "services" in the traditional sense. They also said that states should have control over how they run their prisons and be free of interference from the federal government.

But Justice Antonin Scalia wrote, "Modern prisons provide inmates with many recreational activities, medical services, and education and vocational programs, all of which at least theoretically benefit the prisoners."

Resolving a split among lower courts, Scalia said Congress clearly allowed no exceptions from the ADA for state prisons. He noted in *Pennsylvania Department of Corrections v. Yeskey* that the court was interpreting the statute and not determining whether Congress had unconstitutionally exceeded its power to regulate states' affairs—a question that had not been addressed by lower courts in the case.

June 17, 1998

Dear Fellow Council Members:

Those of you who know my background, know me as a lawyer, a parent, and a long-time friend and supporter of the President. I have been a vocal advocate in expressing my confidence in the President's intelligence and good heart, and the respective roles of those traits in the difficult decisions he would have to make as President of the United States. It was with that degree of confidence that I sought and agreed to accept an appointment to the President's Advisory Council on HIV and AIDS.

Historically, I have always been committed to the interests of the so-called underdog. I consider the "underdog" as the "voiceless"; those citizens who, for a variety of reasons are not well represented in the circles of power and decision-making. Many of the "voiceless" include those whose interests and concerns are not immediately clear, that is, there are issues that "might and could" affect them in the future, but must be addressed and protected now.

Some of the voiceless, as a trial lawyer, are those consumers who would be affected by changes in the liability laws of our states or nation. I recognize that no one knows today if or when they might be a victim of a dangerous drug, negligently designed product, or unsafe medical practice. However, there is a need for someone to speak-out on their behalf today; to defend and protect the civil legal rights of potential "future victims" to be safe from such dangers or harm, and to have the right to a full and complete remedy should the unfortunate occur.

With respect to HIV and AIDS, my concerns are quite similar. I don't know **if** any of my three children will someday become infected with HIV, or **how** it might occur. It could be through heterosexual or homosexual activities, or it may be connected with intravenous drug use. Nonetheless, my personal education over the last four years has taught me that my kids are at risk of becoming infected.

While on the Council, I have focused on prevention issues because I am particularly concerned about these "future victims", and I am acutely aware that "future victims" are not an existing or current constituency, and therefore are "voiceless". I have worked on the Council with a commitment to these "voiceless future victims".

I had previously believed that the President of the United States was committed to protecting that constituency as well, whether they appreciated the need to be protected or not, and notwithstanding their ability or inability to express themselves and their interests to the government. These people could benefit from a sincere, intelligent and coordinated national HIV prevention program. These people could benefit from a sincere, intelligent and coordinated substance abuse treatment and prevention program. These potential future victims deserve to be considered and protected by our government...and by us.

The decision by the White House to approve of needle exchange programs, but refuse to fund them strikes me as an abandonment of acknowledged ability to prevent infections and deaths of "voiceless future victims". It strikes me as completely contrary to the "intelligence" and "good-heart" perceptions I had about President Clinton, and my confidence that if he knew what was the right thing to do, that he would do it.

It also leads me to once again recognize that although the President appointed all of us to this Council to provide useful and insightful advice on how to respond to the epidemic of HIV and AIDS, the White House has consistently failed to heed or accept our advice and counsel on nearly every recommendation we have made. In fact, I don't believe the White House has followed a single one of our recommendations unless they had already decided they were going to do it anyway.

It is with this knowledge and dismay that I submit these remarks today. I feel totally frustrated that my efforts to express, support, and defend the interests of these particular "voiceless future victims" of HIV have not only been fruitless, but have fallen upon incredibly and inexcusably deaf ears.

I believe that the recommendations of this Council are essentially meaningless as far as directly influencing Presidential policy because they are not meaningful to this White House. I am convinced that, on the issue of ending the epidemic, this Administration places great and undue emphasis on rhetoric and fails to pursue proven medical and scientific actions to reduce the infections, suffering, deaths, and economic and social costs resulting from HIV and AIDS.

The needle exchange funding issue, to me, was the litmus test of the government's commitment to the promise "to do all that is necessary to reduce new infections each year until there are none."

To me, resignation from this Council was the most useful and constructive response we could have made to this foolish decision by the White House. To me, continuing to participate on this Council represented an acceptance, if not the condoning of the President's failure to allow federal funds to be used for needle exchange programs. To me, by continuing to "serve" the President on <u>his</u> Advisory Council, we risked complicity for the 33 new infections related to injection drug use which will occur during this meeting.

However, I have repeatedly asked myself if there is anything, anything at all, that could constructively emerge from my continuing on this Council. I have concluded that there are reasons to remain on the Council.

This Council is our "bully pulpit" to various government officials and agencies. And whether they act or not, <u>it can be constructive</u> for us to continue to publicly highlight the errors of their ways from the perspective and authority of a Presidential Council.

This Council is our "media outlet" to identify and expose the errors and omissions of the White House and this Administration. Whether they act or not on our recommendations, it can be constructive for us to use this Council to give our voices added power and volume throughout the nation.

This Council has opportunities to obtain inside information and knowledge, and to share it with non-governmental advocacy groups. This can be constructive as well.

And, while those in the ultimate decision-making positions in the White House may not "allow" all of the lower level governmental agencies to do all that they should or could about HIV and AIDS, there may be some things that we can advocate directly to those agencies that they may be able to do without a specific White House blessing, and to that extent we can be constructive.

So while I fear "complicity" by not publicly resigning, by bypassing the opportunity to be vocal and offensive to the White House about its needle exchange decision, I find some degree of comfort that some how, some way, some day, some of the "voiceless future victims" may benefit from my continued advocacy and participation. I am committed to them, whether they live in the United States or elsewhere in the world; whether they are sick or dying; whether they are infected or not-yet-infected; whether they are my children or someone else's. I hope and pray that in some small way, my efforts will not be completely pointless or in vain.

God bless all of you.

Warmest regards,

Bob Fogel

June 18, 1998

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS RECOMMENDATIONS ON YOUTH ISSUES

LEADERSHIP RECOMMENDATIONS

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- The Council requests that the Office of National AIDS Policy present a detailed status report on the implementation of recommendations from the Presidential Directive.

PACHA 1998-99 OBJECTIVES, PRINCIPLES, AND GOALS, BY CATEGORY

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
A	Work to advance the call for a State of Emergency in the African American and Latino communities through a variety of strategies, such as the following: • Engage the President by requesting that he convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency. • Call for a Special White House conference on the State of Emergency in communities of color • Work to advance the call for a State of Emergency. Advocate for increased funding to serve African American and Latino communities. • Engage the President, especially through his interest in race and race relations, to take action on the racial/ethnic implications around HIV/AIDS service delivery.	If the Supreme Court rules that HIV is not a disability under the ADA, work to regain recognition of HIV as a disability.	Seek the alignment of the full range of prevention, medical and social support services (including such basic needs as food and housing) so their funding streams are both equitably available and targeted to special needs and disproportionately affected populations.	Follow through on HIV-positive health care worker guidelines.

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
B	Influence CDC policies and programs related to HIV/AIDS prevention, including: • Establishment of a youth initiative. • Ensure that the CDC establishes a national initiative to encourage HIV testing that effectively targets high-risk populations. • Ensure that the CDC includes in its HIV Prevention Community Planning guidance language requiring that use of community prevention funds be linked to the local demographics of the epidemic, and that the CDC evaluates compliance with the direction in the guidance.	Continue to advocate for a policy that permits the use of federal funds for needle exchange.	Address bigotry, social divisions, and their impact on fueling HIV, and on proposed government remedies.	Convince the President to establish a concrete goal regarding provision of services for people in need, as he has done with vaccine development and infection rates.
C	Track and advocate for access to care and funding for early intervention through expansion of Medicaid, working at the national policy level (HCFA and the White House) and with regard to State waiver applications	Work for legislative repeal of the ban on immigration to the U.S. by HIV-positive individuals.	Put HIV/AIDS prevention at the top of the national agenda.	Work for reauthorization of the Ryan White CARE Act, including reform of ADAP to ensure funding available for providing and maintaining a comprehensive set of therapies (without the need for emergency supplemental appropriations)

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
D	Work for higher appropriations for HIV/AIDS prevention, services, and research, including the following: • Support NORA's FY 1999 HIV/AIDS appropriations request. • Develop an appropriate strategy for 2000 appropriations. • Focus on increased funding for substance abuse treatment, building service capacity in communities of color, youth, and international HIV/AIDS programs.	Support the appropriation of the necessary funds to ensure substance abuse treatment on demand.	Push the microbicide agenda forward by: • Changing the structure of the FDA in terms of toxicity/pharmacology reporting on microbicides. • Addressing liability and access issues. • Obtaining increased funding. [Research Committee will bring specific objectives and recommendations in November]	Follow up on vaccine recommendations.
E	Provide input to the new international strategic plan on HIV/AIDS being developed by the Department of State and help ensure that its provisions are implemented.	Work to establish an effective method for monitoring the epidemic.	Work to improve adherence to treatment guidelines by all providers of care. Includes broader dissemination and education by HRSA related to the treatment guidelines, and their implementation in federal prisons, as well as emphasis on ensuring that underserved populations receive appropriate treatment.	Get the Attorney General to provide a directive to the Bureau of Prisons that mandates pre-discharge planning, including appointments with service agencies, and requirement that medical summaries follow the individual from prison to post-release treatment.

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
F	Advocate for attention to women-centered HIV prevention methods (microbicides). [Language of recommendation to come by November]	Move the research agenda on behavioral interventions -- to learn more about what works and what doesn't work.	Work for the establishment of a longitudinal file for women who received AZT and all anti-retrovirals while pregnant, to monitor them and determine the long-term effects of treatment.	Work for reauthorization of HOPWA.
G		Work to identify and support U.S. leadership in the international arena (within the State Department and other Federal agencies) so that the AIDS issue is raised in all available forums.	Help ensure that the information from HCSUS (HIV Cost, Services, and Utilization Study) is readily available, and that it is used to help federal officials and other entities align services to address the demographics of the epidemic and implement the treatment guidelines [Data not available until after Geneva].	Have the Executive Committee work to increase ONAP staff resources, including both FTEs and the continuity of personnel, with special emphasis on: • Greater involvement in international issues. • A coordinating role on the vaccines issue.

	1 SHORT-TERM ACHIEVABLE OBJECTIVE	2 SPECIFIC, NOT SHORT-TERM ACHIEVABLE, BUT MORALLY IMPORTANT	3 BROAD PRINCIPLE OR LONGER-TERM GOAL	4 FOLLOW-UP OBJECTIVE: LIMITED OR INDIVIDUAL MEMBER EFFORT
H			Ensure that comprehensive services/discharge planning is provided to all individuals leaving prisons, including social services, housing, food, financial assistance, as well as medical care to the extent needed. Includes linkages with available community resources to provide drug treatment, health interventions.	Ensure that the Patient Bill of Rights for Health Care includes clear and explicit reference to HIV care needs, including access to care and implementation of the treatment guidelines.
I			Enhance the federal/ State/local dialogue regarding HIV and prisons, with emphasis on State/local input to the Bureau of Prisons. Address federal guidelines, technical assistance, and funding streams that have policy implications in State and local prisons and jails.	Evaluate progress on previous PACHA recommendations regarding HIV surveillance.

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WHITE HOUSE COUNCIL ON HIV/AIDS
"SHORT-TERM ACHIEVABLE" PRIORITIES ADOPTED JUNE 17, 1998

Issue/Objective	Votes	Amount of Work: Lots	Amount of Work: Limited	Target(s): White House	Target(s): Administrative Agency	Target(s): Congress (Indirect)
1. Work to advance the call for a State of Emergency in the African American and Latino communities through a variety of strategies, such as the following: • Engage the President by requesting that he convene a special meeting with the Congressional Black Caucus and Hispanic Congressional Caucus to develop a strategy regarding the State of Emergency • Call for a Special White House conference on the State of Emergency in communities of color	23	X		X		
2. Influence CDC policies and programs related to HIV/AIDS prevention, including: • Establishment of a youth initiative • Ensure that the CDC establishes a national initiative to encourage testing that effectively targets high-risk populations • Ensure that the CDC includes in its HIV Prevention Community Planning guidance language requiring that use of community prevention funds be linked to the local demographics of the epidemic, and that the CDC evaluates compliance with the direction in the guidance	22	X		X	X	
3. Track and advocate for access to care and funding for early intervention through expansion of Medicaid, working at the national policy level (HCFA and the White House) and with regard to State waiver applications	15	X		X	X	

Issue/Objective	Votes	Amount of Work: Lots	Limited	Target(s): White House	Administrative Agency	Congress (Indirect)
4. Work for higher appropriations for HIV/AIDS prevention, services, and research, including the following: • Support NORA's FY 1999 HIV/AIDS appropriations request • Develop an appropriate strategy for 2000 appropriations • Focus on increased funding for substance abuse treatment, building service capacity in communities of color, youth, and international HIV/AIDS programs	11	X		X		X
5. Provide input to the new international strategic plan on HIV/AIDS being developed by the Department of State and help ensure that its provisions are implemented	11		X	X	X	
6. Advocate for attention to women-centered prevention methods (microbicides) [Language of recommendation to come by November]	11	X			X	

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Presidential Advisory Council on HIV and AIDS

Telephone Conference Call

Briefing and Discussion on Planned AIDS Vaccine Field Efficacy (phase III) Trials in the United States and Thailand
with
Donald Francis, MD, ScD
VaxGen, Inc.

Date: Tuesday, June 23, 1998

Time: 10:00 - 11:30 am Eastern Daylight Time (7:00-8:30 am PDT)

Call-in no.: 1-888-422-7105

Access Code: 412106

Handouts (tables and graphs to illustrate briefing): Attached

Indications that AIDSVAX Will Protect from HIV-1 Infection

1. Antibody alone is necessary and sufficient to protect from HIV-1 infection

   Passive antibody will protect chimpanzee from 100% infectious challenge
   (Prince, et al, Emini, et al)
   Active immunization with AIDSVAX will protect chimpanzees

   from homologous (IIIB/IIIB) challenge

   from heterologous (MN/SF2 primary) challenge

2. Humans respond better to AIDSVAX than do protected chimpanzees

   Neutralizing antibodies induced in 100% of volunteers

3. "Sieve" analysis of infected vaccinees indicate infections by non-vaccine like viruses

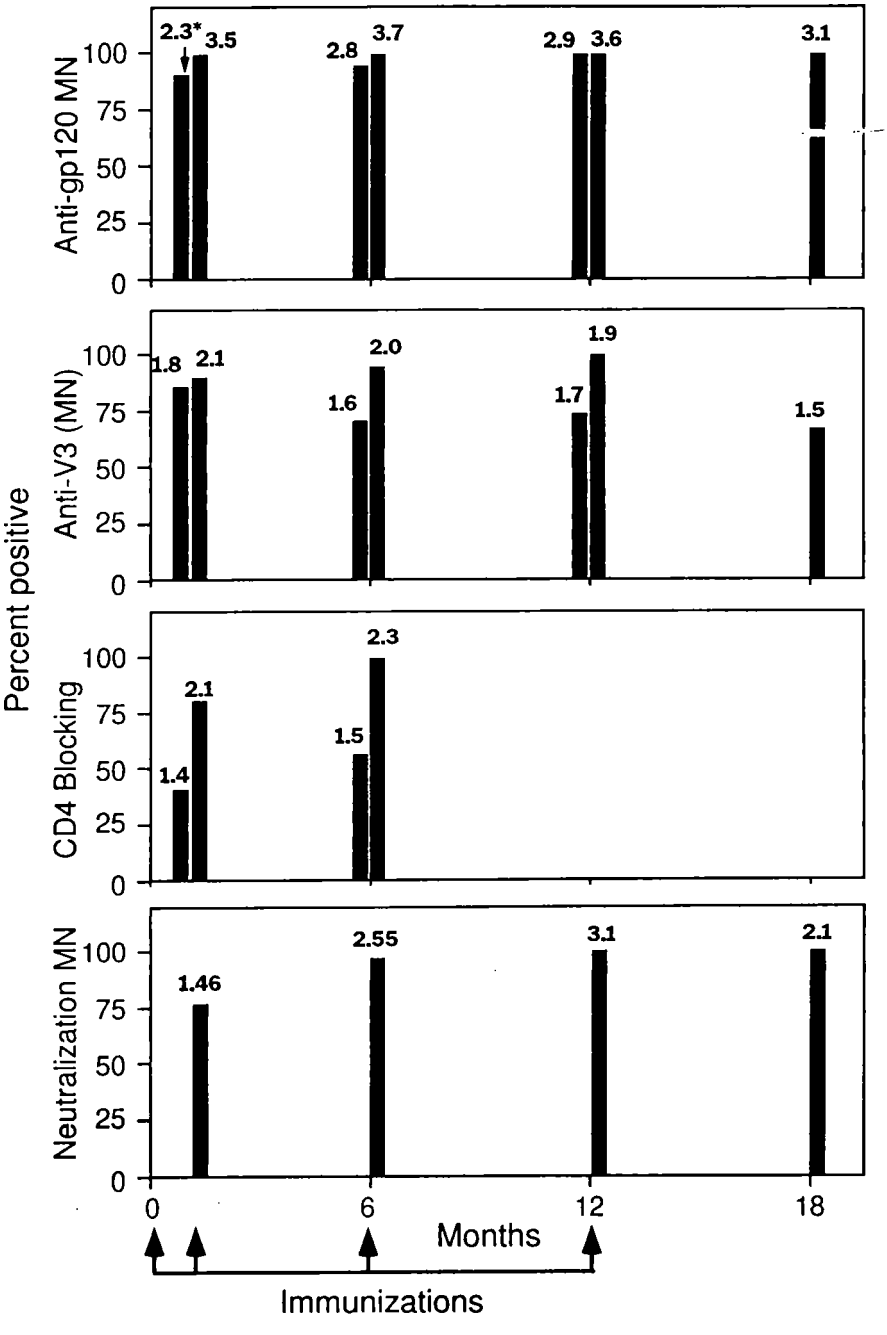
Design of Bivalent AIDSVAX

	GNE8	MN	A244
Tropism	Macrophage	T-cell	Macrophage
Chemokine Receptor	CKR5	CXCR4	CKR5
V-2 Neut Site	RDK	GDK	RDK
V-3 Neut Site	GPGRAF	GPGRAF	GPGQVF
C-4 Neut Site (429)	E	K	G

Immune Response in Vaccinees

IDUs, Bangkok Thailand 1997 n = 22

MN rgp120 (300 µg)



* Geometric mean titer of positives (log_{10})

Summary of VaxGen's Planned Phase III Trials of AIDSVAX

Location	North America	Thailand
Vaccine	AIDSVAX B/B (MN and GNE8)	AIDSVAX B/E (MN and A244)
Sites	30-40	16
Vaccine : Placebo	2:1	1:1
Volunteers	MSM & High-Risk Heterosexuals	Injection Drug Users
Number	5,000	2,500
Start	Summer 1998	Fall 1998 (pending official approval)
Length	3 years + 1 year accrual	3 years + 1 year accrual
Endpoints	Infection & Viral Load	Infection & Viral Load
DSMB	Safety 6 and 12 months Safety and efficacy 24 and 36 months	Safety 6 and 12 months Safety and efficacy 24 and 36 months

Protecting Human Subjects

Maintain high ethical and scientific standards

- Institutional Review Board review, National ethical review (Thailand)
- US FDA review
- UNAIDS ethical review

Informed Consent

- Full written and verbal informed consent
- Knowledge test of volunteer before enrolling (Thailand)

Protection from infection

- Advised not to assume any protection from vaccine
- Risk reduction counseling at each study visit

Protection from social harm

- Clear advice to volunteers of risk of informing others of study
- Support and documentation for false-positive testing

Subcommittee on Racial and Ethnic Minority Populations
Tuesday June 16, 1998

A. That the Council embrace as its principal the elimination of disparities regarding HIV prevention, care, treatment, and research across racial/ethnic communities in all Council activities and committee recommendations.

B. Serve as the focal point within the Council for *collaboration with* and *review of* draft recommendations from governmental agencies, national advisory councils, and special initiatives that relate to the HIV epidemic in communities of color **and** provide guidance to the Council for the development of formal Council recommendations.

C. Aide in the coordination of activities within the Council by serving as a repository for policy, surveillance, prevention, care and treatment analysis in racial/ethnic communities.

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

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

DRAFT LETTER

Dear Dr. Sawyer:

We, the members of the Presidential Advisory Council on HIV/AIDS, are extremely concerned about your unwillingness to discuss the use of protective barriers in Federal prisons. We are aware of the many difficult issues that this question poses for you. However, these concerns pale compared to the risk of transmission of HIV, Hepatitis B, Hepatitis C and other sexually transmitted diseases (STDs) in prison. (As reported in the 47.21 MMWR)

We all know that sexual behavior continues among incarcerated individuals. In light of this reality, we must do all we can to prevent life-threatening illnesses. We do know that protective barriers reduce the transmission of HIV and other STDs. Numerous state and international prison experts have recommended the use of protective barriers in the prison setting. Furthermore, several state, county and city prison systems in our country as well as several Federal institutions in other countries have introduced the use of protective barriers in their institutions as one means of preventing the spread of HIV Disease. Of course, this should be part of an overall prevention strategy that includes education, appropriate medical intervention, and other harm-reduction models.

Protective barriers can save lives.

Certainly the lack of protective barriers does not discourage sexual behavior. The lifetime cost of taking care of one new case of HIV Disease is hundreds of thousands of dollars. The prison population offers us a unique opportunity for a comprehensive prevention effort, but protective barriers must be a part of this effort if it is to be effective.

We again request that you meet with our Prison Issues Subcommittee at the earliest opportunity prior to our next Council meeting.

Sincerely yours,

cc: Eleanor Acheson
Janet Reno

PRISON ISSUES SUBCOMMITTEE
Recommendation

DRAFT

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

June 18, 1998

Dear Secretaries Shalala and Reno:

We want to be assured that the PHS AIDS Treatment Guidelines are the standard of medical care in our nation's prisons and jails.

We have the following questions:

- Have those guidelines been put into place?
- Can you provide us with documentation of their implementation?
- How are you assuring that all appropriate providers are being trained in the use of these guidelines?
- How has the use of these guidelines been evaluated?

On behalf of the Presidential Advisory Council on HIV/AIDS, we are requesting a report which specifically outlines the use of the PHS Treatment Guidelines in our Federal corrections system. Please provide us with that information within 90 days. If you cannot do so, please provide us with an explanation as to why this information is not yet available.

Sincerely,

June 16, 1998

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS
PROPOSED RECOMMENDATIONS

Discrimination Committee

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

PRESIDENTIAL ADVISORY COUNCIL ON HIV/AIDS

INTERNATIONAL ISSUES

PROPOSED COUNCIL RESOLUTION

(Tabled at December, 1997 Meeting)

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

FACTORS TO CONSIDER PRIOR TO SETTING ISSUE PRIORITIES AND OBJECTIVES

1. **What would Council members most like to be able to say about the Council's activities and accomplishments as of the end of July 1999?**

   - That it had accomplished specific results? (If so, what?)
   - That it had engaged the President as an actively involved leader and advocate on HIV/AIDS?
   - That it had increased public understanding/support of HIV/AIDS issues?
   - Other?

2. **Whom should the Council view as its primary and secondary audiences or targets? In what priority order?**

   - The President
   - The Vice President
   - The Secretary of HHS
   - ONAP
   - The Administration
   - The Congress
   - The American Public
   - People with HIV and their Families
   - Other

3. **What are the resources available to the Council to achieve its objectives?**

   - Council staff time
   - Council member time (includes any organizational resources individual members may bring)
   - ONAP personnel time available to help support Council activities
   - Resources of partners on specific issues (e.g., national organizations)

POSSIBLE CRITERIA FOR SELECTING "SHORT-TERM ACHIEVABLE" ISSUE OBJECTIVES

1. **"Achievability"** -- The Council can make measurable? substantial? progress on this issue -- or achieve the specific objective -- within the next year.

2. **Importance** -- Meeting the objective would make a meaningful contribution to the Council's efforts to help address HIV/AIDS.

3. **Appropriateness** -- The issue and objective fall within the scope of the Council's work, and are consistent with the Council's stated positions and priorities.

4. **Responsibility** -- A specific individual or entity is able and willing to take primary responsibility for the work required to this objective; ideally, an individual or group is highly motivated to address this issue and ensure follow-through.

5. **Resource Requirements** -- The resource requirements (time and effort on the part of individual Council members, Council staff, ONAP staff) for meeting this objective are reasonable, in the context of what may be achieved.

6. **Comparative Value** -- When compared with other possible issues and objectives, this one is deserving of time and attention.

7. **Timeliness** -- This is the right time to address the issue.

8. **Other** -- There are other specific reasons for taking on this issue at this time.

POSSIBLE STRATEGIC PLAN FORMAT

I. COUNCIL CHARGE, SCOPE, MISSION

II. OVERVIEW: WHAT THE COUNCIL HOPES TO ACHIEVE IN THE NEXT YEAR

A. Key Issues and Principles
B. Criteria Used to Select Focus Issues and Objectives
C. Overall Strategies

III. SPECIFIC PLANS

A. Primary Focus (Specific Outcomes, Strategies, Responsibilities and Partners)
B. Issues for Continued Public Attention (not readily achievable, but must be kept visible)
C. Additional Issues (to receive more limited follow-up or individual member involvement)
D. Other Activities or Products

IV. LONGER-TERM ISSUES

PLANNING FORMAT

1. **Objective** -- what is the result to be accomplished by July 1999 (or an earlier specified date)?

2. **Decision Maker(s) and Influencer(s)** -- who has the power to make the decisions related to the objective? Who is likely to influence the decision maker?

3. **Strategy(ies) to be Used** -- what are the major approaches the Council should use to help accomplish the objective?

4. **Responsibility and Partner(s)** -- who should have primary responsibility for carrying out these strategies? Who should assist? (Be specific regarding individual Council members, committees, staff.) Identify external partners such as national AIDS organizations.

5. **Timing** -- Identify any key dates or deadlines for action.

6. **Special Concerns** -- Identify any special issues or concerns that may affect achievement of the objective.

SAMPLE COMPLETED PLANNING FORMAT

[EXAMPLE ONLY -- COUNCIL CAN DO MUCH BETTER ON CONTENT!]

1. **Objective** -- what is the result to be accomplished by July 1999 (or an earlier specified date)?

To have the President convene a special meeting with the Congressional Black and Hispanic Caucuses to develop a strategy regarding the State of Emergency regarding HIV/AIDS in the African American and Latino communities.

2. **Decision Maker(s) and Influencer(s)** -- who has the power to make the decisions related to the objective? Who is likely to influence the decision maker?

Decision makers: The President and the Chairs of the two caucuses
Influencers: Sandy Thurman of ONAP, other White House or other Administration personnel (identify key potential allies such as African American and Latino officials)

3. **Strategy(ies) to be Used** -- what are the major approaches the Council should use to help accomplish the objective?

- Agree with ONAP on partners and necessary allies
- Develop action plan with ONAP and key national AIDS organizations
- Arrange meeting with Caucus Chairs (or appropriate committee chairs within each Caucus and get their support
- Prepare briefing materials demonstrating benefits of a special joint meeting
- Set up meeting with X in the White House to discuss possible meeting
  (etc.)

4. **Responsibility and Partner(s)** -- who should have primary responsibility for carrying out these strategies? Who should assist? (Be specific regarding individual Council members, committees, staff.) Identify external partners such as national AIDS organizations.

Primary responsibility: Chair and Executive Director, with help from special ad hoc task force of representatives of Race and Ethnic Minority, Prevention, and Services Committees [specify names]. External partners: Black and Hispanic Caucus Directors, NMAC, X and Y organizations

5. **Timing** -- Identify any key dates or deadlines for action.

Need to hold meeting as soon as possible to give public attention to the State of Emergency and encourage public support for positive action. Determine possible dates prior to the November elections if feasible.

6. **Special Concerns** -- Identify any special issues or concerns that may affect achievement of the objective.

Would be helpful to hold meeting prior to 1998 Congressional elections, since this could provide additional motivation for the meeting. However, due to campaigning and early Congressional adjournment, this could mean a very tight timeline, assuming a Washington, D.C. meeting. Need to weigh benefits of seeking bipartisan support, at least from Caucus members who are Republicans.

E-MAIL FOR PROCESS SUBCOMMITTEE MEMBERS

Date: 4 June, 1998
To: Members of the Process Subcommittee, President's Advisory Council on HIV/AIDS
From: Mosaica
Subj: Questions and Preliminary Framework for the Strategic Planning Session

Based on our conference call and some initial interviews, the Mosaica team has (1) specified several questions to be addressed in telephone discussions with Process Subcommittee members, and (2) outlined an initial, very preliminary framework for the strategic planning session, for further discussion with you individually and at next Tuesday's conference call.

We will try to contact each of you by telephone in the next few days to obtain your reactions to the questions and framework and obtain other input regarding the strategic planning session. If it is more convenient for you, feel free to respond by e-mail (emily@mosaica.org) or fax (202-887-0812).

QUESTIONS

1. What are the two or three most important outcomes of the strategic planning session -- what would you most like to see decided or achieved?

2. Please react to the following as a focus for discussion at the strategic planning session. It has been suggested in initial interviews and the conference call that the Council might want to consider developing a two-phased strategic plan:

   - Between now and July 1999, when the Council's current charter ends, the Council might focus on a small number of "short-term achievable" action items. These action items would be identified at the session, and strategies outlined to address them.

   - Between August 1999 and January 2001, when a new President will take office, the Council might focus on defining a longer-term blueprint or "platform" describing what the next Administration should be doing to address HIV/AIDS. The scope and focus of such an initiative and strategies for accomplishing it would be discussed at the session.

3. Instead of or in addition to the suggestions in #2, what specific questions or issues should the planning session address?

4. Are there any issues you feel should NOT be addressed at the session? If so, what are they, and why not?

5. What other advice or caveats can you offer the facilitators, to help ensure a productive session?

PRELIMINARY FRAMEWORK FOR AGENDA

Following is a VERY preliminary framework for the agenda, reflecting what Mosaica has learned to date, including the idea of a two-phased strategic plan. The times in bold are the periods within the Council meeting agenda that have been set aside for the strategic planning process. Does this approach seem to make sense? If so, are the time frames reasonable?

Monday, June 15, 1:00 - 6:00 p.m.

1:00 - 2:00
- Introduction from the Chair
- Presentation/Discussion of Agenda and Process
- Agreement on Groundrules
- Full-Group Discussion of and Agreement on Desired Session Outcomes
  - ♦ Plan for June 1998 - July 1999: what we can do that will make a difference
  - ♦ Plan for August 1999 - January 2001: what we leave behind
  - ♦ Other

2:00 - 3:00
- Taking the Pulse of the Council (includes "venting" time)

3:00 - 5:45
- Subcommittee Work
  - ♦ Key issues on which the Council needs a briefing
  - ♦ Identification of time-sensitive or "actionable" issues

5:45 - 6:00
- Check-Back following Subcommittee Meetings

Tuesday, June 16, 3:00 - 6:00 p.m.

[During their 9:00 - 11:00 a.m. meetings, the smaller subcommittees are asked to address the same questions the larger subcommittees addressed on Monday afternoon, regarding key issues on which the Council needs a briefing, and time-sensitive or "actionable" issues]]

3:00 - 4:30
- Briefings from the Subcommittees: key issues and time-sensitive issues

4:30 - 6:00
- Discussion: Other Information the Council Needs to Consider as a Basis for Planning
  - ♦ External Factors
  - ♦ Internal Factors

Wednesday, June 17, 9:00 a.m. - 6:00 p.m.

[Most work to be done in the full group, but some use of small groups that include representatives of multiple subcommittees]

9:00 - 10:30 <u>Agreement on a Framework for the Strategic Plan</u>
- Discussion of Key Questions Affecting Strategic Planning
- What Should be the Framework and Scope of the Strategic Plan?

10:30 - 3:00 <u>A Strategic Plan for the Next 13 Months</u>
- Discussion and Decisions
  - ♦ Does the Council want to focus on "short-term achievable"

action items?
- ♦ If yes, what criteria should be used to set action priorities?
- ♦ How should these criteria be applied?

[Lunch break 12:00 - 1:00]

- Process to Obtain Agreement on Action Items
- Strategies for Achieving Action Items

3:00 - 5:30 A Strategic Plan for August 1999 - January 2001

- Discussion and Agreement:
  - ♦ What should the Council seek to accomplish during this period?
  - ♦ What should the Council leave behind or provide to the next Administration?
- Key Objectives and Desired Accomplishments
- Strategies

5:30 - 6:00 Review of Decisions and Plans

Thursday, June 18, 11:15 a.m. - 1:00 p.m.

11:15 - 11:45 • Presentation and Review of Strategic Planning Results
11:45 - 12:30 • Agreement on Responsibilities for Next Steps/Follow-Through
12:30 - 1:00 • Agreement on Content/Format of the Strategic Planning Session Report

We look forward to talking with you.

Emily Gantz McKay, President
Cristina Lopez, Vice President
Kayla Jackson, Senior AIDS Specialist
Mosaica

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4/98

MOSAICA

The Center for Nonprofit Development and Pluralism

Emily Gantz McKay
President

ORGANIZATIONAL CAPACITY AND EXPERIENCE

MOSAICA: The Center for Nonprofit Development and Pluralism exists to encourage the development and effective management of community-based nonprofit organizations in the U.S. and internationally, encourage linkages between the independent sector and other sectors of society, and support ethnic and cultural diversity. A nonprofit, tax-exempt multicultural organization established in February 1994 in the District of Columbia, MOSAICA pursues these purposes through four interrelated types of activities:

1. **PROVIDING CAPACITY-BUILDING ASSISTANCE TO STRENGTHEN NONPROFIT ORGANIZATIONS AND SUPPORT THE DEVELOPMENT OF A STRONG "INDEPENDENT SECTOR," IN THE UNITED STATES AND OTHER COUNTRIES.** MOSAICA assists minority, women's, and other community-based organizations in the U.S. and internationally. Through organizational assessments, evaluation, training, consultation, and self-help guides and informational materials targeting the Boards, staff, and key volunteers of these nonprofit organizations, MOSAICA helps groups improve their planning, program, advocacy, management, governance, resource development, evaluation, and coalition-building skills, so that they can work effectively to provide services, enhance community resources, and alleviate poverty -- and so they can work effectively with other organizations and sectors of society.

   Within the U.S., MOSAICA assists both national and local community-based organizations to carry out organizational and fundraising audits, evaluate their programs, and strengthen management and governance. MOSAICA has provided resource, governance, and organizational development assistance to national Hispanic organizations such as the National Hispana Leadership Institute, Inter-University Program for Latino Research, LULAC, Hispanic Association on Corporate Responsibility, and the National Association of Hispanic Journalists, among other organizations. In addition, MOSAICA has assisted many local groups with organizational and resource development, from a small prevention-focused organization serving Southeast Asian immigrants in Toledo, Ohio to AIDS service providers in communities throughout the nation and organizations in Washington, D.C. Washington area clients include such organizations as the Council of Latino Agencies, the Carlos Rosario International Career Center, the Development Corporation of Columbia Heights, Ayuda, Inc., The Family Place, the Youth Leadership Project of the Indochinese Community Center, and City At Peace. MOSAICA is also active in training community-based organizations to evaluate their programs, with special emphasis on evaluation of HIV/AIDS prevention and treatment services, leadership programs, and multicultural organizations.

   MOSAICA works with minority AIDS service providers as part of a subcontract with John Snow, Inc. (JSI) to provide technical assistance to state and local governments which oversee programs funded through the Ryan White CARE Act, and with prevention programs and community planning groups funded through the Centers for Disease

Control and Prevention as a subcontractor to the Academy for Educational Development (AED). To help make community planning groups for HIV prevention more effective, MOSAICA has developed a manual for community representatives on how to conduct needs assessments and use statistics in planning. MOSAICA has helped to increase the management and resource development capacity of HIV/AIDS service providers in many locations, particularly minority and women's organizations.

Internationally, MOSAICA has provided organizational development assistance to nonprofit organizations in the Middle East, the former Yugoslavia, and Latin America. MOSAICA staff provide ongoing training and individualized assistance in management, governance, and resource development to nonprofit organizations in Israel (Jewish and Palestinian) which are committed to democracy, pluralism, and tolerance, through SHATIL, the capacity-building center of the New Israel Fund. MOSAICA has also trained more than 100 emerging nonprofit organizations in Croatia and in Bosnia and Herzegovina -- most providing mental health and educational services to refugees, displaced persons, and individuals and families affected by the war. NGO training in Bosnia and Herzegovina is now conducted in support of the New Bosnia Fund, a Bosnian-controlled intermediary organization which MOSAICA helped to establish. In addition, staff have provided organizational and resource development assistance to a nonprofit organization in Ecuador, and helped nonprofit groups in Guatemala to begin developing an HIV prevention community planning process.

2. **ASSISTING INITIATIVES WHICH LINK THE NONPROFIT, PRIVATE, AND PUBLIC SECTORS TO ADDRESS COMMUNITY NEEDS AND STRENGTHEN COMMUNITY RESOURCES.** The MOSAICA President serves on the core faculty of the National Hispanic Corporate Council Institute (NHCCI), providing training on strategic community relationships as a component of Hispanic marketing. MOSAICA advises nonprofit organizations on how to develop linkages with corporations, and helps corporations identify appropriate community partners. For example, MOSAICA has assisted the Pfizer Foundation with its Community Health Ventures grantmaking program, offering technical assistance to applicants. Staff have provided training to U.S. Information Agency personnel from the Middle East and South Asia on developing corporate and NGO partnerships for cultural events. MOSAICA works on several major initiatives involving the public, private, and community sectors, providing technical assistance to strengthen HIV/AIDS prevention and treatment services and ensure effective pre-service and in-service training for Corporation for National Service programs.

MOSAICA has a special interest in helping establish nonprofit-private linkages for organizations which benefit individuals and families with limited financial resources, and involve minorities, women, and community-based organizations. MOSAICA also develops self-help guides, training guides, and reports in a variety of program areas involving sector linkages. For example, under contract to the Center for Community Change, MOSAICA prepared a self-help guide on the link between human services and economic development, for use by organizations which are part of the Rebuilding Communities initiative of the Annie E. Casey Foundation.

3. **HELPING TO DEVELOP "CULTURAL COMPETENCE" AND AN APPRECIATION FOR AND EFFECTIVE MANAGEMENT OF DIVERSITY, WITHIN THE NONPROFIT, PUBLIC, AND PRIVATE SECTORS.** MOSAICA provides presentations to associations and organizations, as well as in-depth

analysis, consultation, and training to establish and implement diversity programs. MOSAICA prepared a manual on ways to assure multicultural inclusiveness in states' HIV/AIDS prevention planning processes as part of its work with the National Council of La Raza and the Centers for Disease Control. Diversity issues are addressed in MOSAICA's trainer training for Corporation for National Service grantees. Staff also helped the Division of HIV Services within the Public Health Service in the preparation of its report on communities of color. MOSAICA played a major role in the preparation of *Willful Neglect: The Smithsonian Institution and U.S. Latinos*, the report of the Smithsonian Institution Task Force on Latino Issues, worked with the Latino Oversight Committee to prepare its mid-term report, and prepared its final report, *Towards a Shared Vision: U.S. Latinos and the Smithsonian Institution.*

MOSAICA assisted the National Latino Communications Center with planning for its proposed Latino Channel for Education through facilitating a two-day consultation for Latino educational experts and preparing a detailed report on the results of the meeting. Presentations or training sessions on multiculturalism have been provided for a variety of groups, among them the Farmers Home Administration, National Society of Fund Raising Executives, National School Boards Association, and Partners for the Americas. MOSAICA has developed a variety of training materials to assist individuals and organizations in understanding and appreciating diversity and multiculturalism, and staff have served on several United Way of America diversity committees.

4. **CONTRIBUTING TO THE DEVELOPMENT OF A NEW GENERATION OF COMMUNITY AND ORGANIZATIONAL LEADERS PREPARED TO WORK EFFECTIVELY IN A MULTICULTURAL SOCIETY.** Through a cooperative agreement with the Corporation for National Service, MOSAICA has developed an extensive pre-service guide for use by AmeriCorps national service programs nationwide; additional materials are now being developed and national trainer training provided to prepare AmeriCorps and other national volunteer program personnel to provide effective pre-service and in-service training.

MOSAICA assisted in the documentation of three Hispanic-focused leadership models, and prepared three replication guides and a manual on how to establish a Latino-focused leadership program. The work was carried out as part of the National Council of La Raza's National Hispanic Leadership Initiative.

In all its work, MOSAICA seeks opportunities to provide mentoring, internships, practical experience, and formal and informal training to young adults and natural leaders to enhance their skills and self-confidence and encourage them to work for positive community change -- to reduce poverty and discrimination and provide critical human services for those with the greatest need.

MOSAICA has a small, highly skilled, multicultural Board and staff, and works with consultants from diverse backgrounds. The Board and staff include Hispanic, African American, Asian, multicultural, and white non-Hispanic members who are Christian, Jewish, Muslim, and Buddhist. Several are immigrants. All the staff come from minority and/or multicultural families. MOSAICA training and self-help materials have been translated into Spanish, Bosnian, Hebrew, and Arabic, and the organization regularly provides training in both English and Spanish.

BOARD OF DIRECTORS

Avideh Shashaani, Chair - Chairperson, Fund for the Future of our Children, Chevy Chase, Maryland. Expert in creating multicultural and religious understanding through lectures, training, and writing. Lectures internationally on Sufism and the various aspects of Islam, especially with regard to women's issues, and provides training in stress management and wellness programs. Came to the U.S. as a refugee from Iran.

David G. Hill, Esq., Vice Chair - Attorney, Cleveland, Ohio; many years of experience in anti-poverty programs and civil rights law; directed Pittsburgh anti-poverty agency in late 1960s and served as President of the National Association for Community Development; represents a wide variety of corporate clients in the U.S. and internationally. Trustee, Cleveland State University; member of numerous civic boards. African American.

Irma Flores-Gonzales, Secretary-Treasurer - Consultant, W.K. Kellogg Foundation; Chairperson, National Council of La Raza Board of Directors; Portland, Oregon. Former President, Colegio César Chávez., Mount Angel, Oregon. Board member, Center for Community Change, Washington, D.C. Mexican American.

Phuong M. Do - Training Coordinator, Emigre Community Development, New York Association for New Americans, New York City. Broad experience in training and technical assistance for immigrant community-based organizations. Has directed a national leadership program targeting Southeast Asian community self-help groups, and managed refugee resettlement services. Holds an M.S.W. in Community Social Work. Vietnamese American.

Emily Gantz McKay, President - Sixteen years on the senior staff of the National Council of La Raza, the largest constituency-based national Hispanic organization. Most recently Senior Vice President for Institutional Development and Acting Vice President for Technical Assistance and Constituency Support. Core faculty, National Hispanic Corporate Council Institute. Extensive experience in organizational development assistance; consultation in the U.S. and abroad. Sephardic Jewish American.

LEGAL COUNSEL

Jorge Romero - Fort & Schlefer, L.L.P., Washington, D.C. Cuban American who grew up in Puerto Rico.

TECHNICAL ADVISORS

Phyllis E. Kaye - Consultant, Grantmakers in Health, Healthy Start; expert in health care planning and resource development, conflict resolution, and capacity-building training and materials development. Long-time consultant to National Council of La Raza AIDS Center; collaborates with MOSAICA on varied assignments. Jewish American.

Sima Wali - Executive Director, Refugee Women in Development (RefWID), national organization committed to empowering and developing the leadership skills of refugee women from Third World countries. International advocate for refugee women and children. Came to the U.S. as a refugee from Afghanistan.

EMILY GANTZ McKAY

Emily Gantz McKay is President of **MOSAICA: The Center for Nonprofit Development and Pluralism,** a nonprofit, tax-exempt organization established to provide organizational development assistance to nonprofit organizations in the U.S. and internationally; encourage initiatives which benefit communities and link the nonprofit, private, and public sectors; encourage community-based leadership development; and help organizations to create effective multicultural environments.

Ms. McKay's special expertise is in the management and governance of nonprofit and minority organizations, through organizational development assistance in such areas as program and resource development, strategic planning, evaluation, governance, management, and coalition building; and in helping "mainstream" organizations increase their diversity and multicultural competence and work effectively with community-based groups. She has written numerous organizational development materials, and has trained thousands of nonprofit staff, Boards, and other volunteers. Ms. McKay has worked extensively with Hispanic, Southeast Asian, Middle Eastern, African American, farmworker, refugee, women, and other low-income and minority populations. She provides organizational development assistance to national Hispanic organizations and community-based AIDS service organizations. She also lectures and trains on strategic community relationships and diversity for corporations, public agencies, and mainstream nonprofit groups.

Ms. McKay has provided organizational development training to newly established nonprofit organizations serving refugees and displaced persons in the former Yugoslavia, for the International Rescue Committee's Umbrella Grant for Trauma and Reunification and Oxfam. She assisted in the development of the New Bosnia Fund, a Bosnian-controlled assistance group for the nonprofit sector in Bosnia and Herzegovina, and serves on its Board. Since 1987, she has worked with the New Israel Fund and SHATIL, its capacity-building center, and the social change organizations – Palestinian and Jewish – they assist.

Active with national and local nonprofit groups, Ms. McKay serves as Treasurer of Mary's Center for Maternal and Child Care, Secretary/Treasurer of the Fund for the Future of our Children, Treasurer of AVODAH: The Jewish Service Corps, and Secretary of the New Bosnia Fund. She was a long-time Board member of the Southeast Asia Resource Action Center (SEARAC), and is a former Chair and Vice Chair of Refugee Women in Development, Inc. (RefWID). She has served on other Boards and on the United Way of America Diversity Committee.

From 1978-94, Ms. McKay was associated with the National Council of La Raza (NCLR), the largest constituency-based national Hispanic organization. Most recently Senior Vice President for Institutional Development, she also carried out a special assignment as Acting Vice President for Technical Assistance and Constituency Support. She is a past NCLR Executive Vice President and Vice President for Research, Advocacy and Legislation. At NCLR, Ms. McKay was responsible for development of the Policy Analysis Center, developed and directed NCLR's national leadership initiative, and at various times had oversight responsibility for national initiatives in health, elderly, education, housing and community development, and employment and training. She developed innovative programs, coordinated work on diversity issues, oversaw institutionalization of systems and procedures, coordinated staff development activities, and directed international projects involving Europe and Ecuador.

Before joining NCLR, Ms. McKay worked in various positions in mainstream and minority-owned consulting firms, including as Vice President of CONSAD Research Corporation of Pittsburgh. She began her career with the Pittsburgh anti-poverty program, and has worked as a consultant to nonprofit organizations, the Ford Foundation, Greater Kansas City Community Foundation, and the Cleveland Department of Human Resources and Economic Development, among other groups.

Honors include the I. Pat Rios Award from the Guadalupe Center in Kansas City, Missouri (1988), and the NCLR President's Award (1989). Ms. McKay is listed in *Who's Who in America, Who's Who in the World,* and *Who's Who of American Women.* A native of Ohio, she is a Phi Beta Kappa graduate of Stanford University, holding a B.A. and M.A. in Communication, with emphasis on professional journalism, communication research, and Race and Ethnic Relations.

CRISTINA LOPEZ

Cristina López is Vice President of **MOSAICA: The Center for Nonprofit Development and Pluralism**, a nonprofit organization established to provide organizational development assistance to human service and social change organizations in the U.S. and internationally; support initiatives which link the nonprofit, private, and public sectors; encourage community-based leadership development, and help organizations to create effective multicultural environments.

Ms. López has extensive program and management experience in health programs, education, volunteer initiatives, and services for the elderly and disabled. She works with federal agencies, local health departments, and community-based organizations on the implementation of the Ryan White CARE Act, and with HIV Prevention Community Planning Groups, providing technical assistance and consultation. Ms. López has broad experience in training and organizational development assistance to community-based and national organizations in program and resource development, strategic planning, governance and management, and program evaluation; and provides consultation to mainstream organizations on cultural competency when working with Hispanics. She also has special expertise in research and policy analysis, with special emphasis on Hispanic health and elderly issues, and is the author of several health- and elderly-related publications. An experienced trainer, Ms. López has worked extensively with Hispanics, farmworkers, women, and other low-income minority populations, and with AIDS service providers.

Prior to joining MOSAICA, Ms. López was Director of Leadership Development at the Center for Community Change (CCC), one of the most effective national anti-poverty organizations. While at CCC, she was in charge of national program of grassroots leadership development, and was responsible for CCC's training workshops, conferences, and internal staff development.

From 1988 to 1994, Ms. López was associated with the National Council of La Raza (NCLR), the largest constituency-based national Hispanic organization. Her last position was Vice President for Institutional Development, with responsibility for national initiatives in health, elderly, leadership development, and education and a budget exceeding $2.5 million. She developed the NCLR Center for Health Promotion, and managed projects involving AIDS prevention, immunization and maternal and child health, and community health promotion. While at NCLR, Ms. Lopez also held the positions of Deputy Vice President for Institutional Development, Director of Health and Elderly Services, and Resource Development Director, with responsibility for preparing NCLR's general support and project proposals, as well as funder research, contact, tracking, and reporting.

Internationally, at NCLR and MOSAICA, Ms. López designed and delivered three cycles of training to the Boards and senior staff of eight nonprofit organizations in Ecuador -- some of this work was through a joint project with PACT, with funding through the U.S. Agency for International Development. She investigated possible cooperation between NCLR and the University of Guadalajara through the formation of a medical school exchange program for Hispanic students in the United States. She has provided training in Guatemala to help support the development of AIDS prevention planning efforts.

Ms. López is on the Board of the National Minority AIDS Council and has served on advisory committees for national initiatives such as the U.S. Conference of Mayor's Multilingual Health Assistance Project, the Centers for Disease Control Partnerships in STD Prevention, the National Eldercare Institute on Older Women, and the National Eldercare Institute on Nutrition, among others.

Ms. López holds a Bachelor's in Political Science from the University of South Florida at Tampa, and a Master's in Social Foundations of Education from the University of Virginia at Charlottesville.

MOSAICA
The Center for Nonprofit Development and Pluralism

Emily Gantz McKay
President

MOSAICA CAPABILITY AND EXPERIENCE IN HIV/AIDS SERVICES

MOSAICA has extensive experience in the HIV/AIDS field, working with community-based organizations (CBOs), HIV/AIDS planning bodies, and health departments. MOSAICA's staff have considerable experience in using statistical data to prepare analyses and conduct needs assessments; preparing technical assistance guides and manuals, and policy reports; facilitating focus groups and planning sessions; and providing on-site consultation and training. Capacity-building assistance emphasizes assistance to planning bodies and organizational development for minority-focused AIDS service providers, focusing on resource development, management, governance, needs assessment, and networking. MOSAICA's work includes a wide range of successfully completed assignments for the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau, Centers for Disease Control and Prevention (CDC) contractors, and national and local organizations.

As a subcontractor to the Ryan White Technical Assistance Contract of John Snow Inc. (JSI), MOSAICA:

- **Prepares technical assistance materials designed to assist CARE Act grantees, planning bodies, and service providers engaged in planning and CARE Act implementation.** Materials prepared by MOSAICA include the following: a training guide to assist planning council and consortium members to develop skills needed for full and effective participation in the Ryan White planning process; a Workbook for People Living With HIV/AIDS (PLWH) bringing together materials and lessons learned about effective involvement of PLWHs in CARE Act planning and implementation; a guide for community members of planning bodies on Using Data, Assessing Needs for HIV/AIDS Services and a self-assessment module on priority setting and resource allocation to guide planning bodies in setting program priorities and allocating CARE Act resources.

- **Prepares reports on topics related to CARE Act implementation.** For example, MOSAICA has prepared a number of reports for grantee meetings – including reports on the annual Community Discussion Group meetings with PLWHs, and the 1997 Case Rate EMA Meeting – as well as reports for technical assistance conference calls for the Division of Service Systems. These reports focus on such topics as conflict of interest, comprehensive planning, needs assessment, and managed care and HIV services. Staff have also completed an analysis of grievance procedures within CARE Act programs, an analysis of how farmworkers have been served by CARE Act programs, and a major report on women and Title I and Title II of the CARE Act.

- **Provide on-site assistance and training for Ryan White CARE Act grantees and planning bodies.** MOSAICA has assisted Ryan White planning bodies and grantees in

New Jersey, Texas, Virginia, Connecticut and Puerto Rico; and minority and other community-based providers in the Denver, St. Louis, Washington, D.C., and Kansas City EMAs. MOSAICA also develops curricula and provides training at national CARE Act grantee meetings and other HIV-related conferences. Senior staff have provided training to people living with HIV (PLWHs) on using health services in a managed care setting, as part of the HIV/AIDS Bureau's Managed Care Pilot Project, which provides training and technical assistance to CARE Act-funded programs to address issues of caring for people with HIV in a managed care environment.

MOSAICA'S work in HIV prevention planning includes the following:

- **Providing consultation to HIV Prevention Community Planning Groups**, through the Academy for Educational Development (AED). MOSAICA's staff has provided consultation and facilitated planning sessions and retreats for HIV Prevention Community Planning Groups in Kansas, Louisiana, Michigan, Nebraska, New Jersey, North Carolina, and Puerto Rico. Also through AED, MOSAICA's senior staff has provided technical assistance to HIV prevention groups in Guatemala in implementing the HIV Prevention Community Planning model.

- **Developing technical assistance materials.** MOSAICA developed two manuals for use by HIV Prevention Community Planning Groups, one for community representatives on how to conduct needs assessments and use statistics in planning; and one on methods to ensure multicultural inclusiveness in States' HIV/AIDS prevention planning processes. These manuals were originally developed for the National Council of La Raza (NCLR) as part of a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

- **Evaluating the National and Regional Minority Organization (NRMO) Program funded by the Centers for Disease Control and Prevention.** MOSAICA serves as subcontractor to the Saint Louis University School of Public Health in a national evaluation of the services and effectiveness of the National and Regional Minority Organizations (NRMOs), which provide assistance to minority-focused AIDS prevention projects. MOSAICA's responsibilities include field work to assess program processes and outcomes based on performance indicators and critical success factors related to the 22 NRMOs and the prevention programs they assist.

Other HIV/AIDS-related projects include:

- **Assistance to the National Association of People with AIDS (NAPWA) with its managed care consumer education project,** an initiative to develop Bilingual (English-Spanish) educational materials for PLWHs on how to use health care services in a managed care setting. MOSAICA's responsibilities include conducting Spanish-language focus groups with PLWHs using managed care health services to identify information needs, and developing and testing Spanish language educational materials.

- **Assistance to the National Minority AIDS Council (NMAC) with the CBO National Technical Assistance Needs Assessment Project,** a CDC-funded project to conduct a comprehensive assessment of the technical assistance needs of minority community-based organizations providing HIV prevention and education services in the following six

areas: (1) community planning, (2) use of surveillance and epidemiologic information to target and design HIV prevention programs, (3) use of behavioral science to design prevention programs, (4) evaluation of HIV prevention programs, (5) incorporation of biomedical research findings into prevention programs, and (6) coordination of prevention activities with other providers of preventive care. MOSAICA has lead responsibility for the design and development of the evaluation protocol and instruments, data collection and analysis.

MOSAICA's staff have extensive prior experience in HIV/AIDS. President Emily Gantz McKay helped to develop and oversaw the National Council of La Raza (NCLR) AIDS Center. Vice President Cristina López oversaw the NCLR Center for Health Promotion, which housed a variety of AIDS activities. These included technical assistance to HIV Prevention Community Planning Groups; conferences and workshops on AIDS topics such as farmworkers and AIDS, and other issues of special concern to Hispanics. Other activities include the development of materials, including a variety of statistical summaries and analyses on AIDS, and program planning and evaluation manuals for community-based organizations.

SELECTED HIV/AIDS TECHNICAL ASSISTANCE MATERIALS PREPARED BY MOSAICA

RYAN WHITE CARE ACT MATERIAL

GUIDES AND MODULES

Planning Council Primer: ProvidesTitle I planning council members information about the roles and responsibilities of planning councils and Title I grantees. 1998.

Training Guide: A Resource for Orienting and Training Planning Council and Consortium Members. Rockville, MD: US DHHS HRSA BHRD Division of HIV Services, March 4, 1997.

PLWH Sourcebook. Rockville, MD: US DHHS HRSA BHRD Division of HIV Services, July 1996. Provides information, contacts, and resources related to PLWH involvement in Title I and Title II of the CARE Act.

How to Secure and Maintain PLWH Participation on Consortia and Planning Councils: Putting the Pieces Together. A Two-day Extended Workshop, Ryan White CARE Act National Title I and II Grantee Meeting, June 28 and 29, 1995. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration, August 1995.

Management Standards for Ryan White CARE Act Providers. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration, 1995.

REPORTS

Responding to the Needs of Women with HIV: This report is designed to strengthen understanding of women's issues and service needs, and the ways in which they have been and are being addressed by HRSA. September 1996.

Summary Report on Cost and Outcome Effectiveness, Reauthorization Issues Focus Group, held June 6-7, 1996. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Ryan White Care Act Conflict of Interest Round Table Discussions, Report of Proceedings. Title II Consortia - May 1; 1996, Title II Grantees - May 2, 1996. Title I Grantees and Planning Councils. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Effective Involvement of PLWHs in Ryan White CARE Act Programs/PLWH Sourcebook: Lessons *From the First Five Years - DRAFT*. Compendium of information from many studies and workshops. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration, February 1996.

Grievance Procedures Within Ryan White CARE Act Programs. Provides experiences and "best practice" information for planning councils and consortia concerning how to develop and implement procedures to minimize and to appropriately address client and other grievances. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration, June 1995.

Summary Report on the Fifth Community Discussion Group Meeting with People Living with HIV Disease, June 1997. Report of a two and one-half day meeting with people living with HIV disease from Title I planning councils and Title II consortia nationwide. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Summary Report on the Fourth Community Discussion Group Meeting with People Living with HIV Disease, September 1996. Report of a two and one-half day meeting with people living with HIV disease from Title I planning councils and Title II consortia nationwide. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration. Reports for the three previous community discussion groups also available from the Division of HIV Services.

Summary Report on the Third Community Discussion Group Meeting with People Living with HIV Disease, October 1995. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

TECHNICAL ASSISTANCE CALL SERIES

Adherence to New HIV Treatments, April 8, 1998. Prepared for the Division of Training and Technical Assistance, HIV/AIDS Bureau, Health Resources and Services Administration.

New Tools for HIV Care: STD Services, February 11, 1998. Prepared for the Division of Training and Technical Assistance, HIV/AIDS Bureau, Health Resources and Services Administration.

Statewide Coordinated Statement of Need, October 8, 1997. Prepared for the Division of Training and Technical Assistance, HIV/AIDS Bureau, Health Resources and Services Administration.

HIV Services and Managed Care, May 30, 1997. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Nominations Process for Title I Planning Councils, February 28, 1997. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Grievance Procedures for Ryan White Title I Programs, January 14, 1997. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Effective Integration of Consortium and Planning Council Activities Technical Assistance Conference Call, June 12, 1996. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Needs Assessment: Technical Assistance Conference Call, March 26, 1996. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Comprehensive HIV Health Services Planning: Technical Assistance Conference Call, February 1, 1996. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Roles and Responsibilities of Title I Planning Councils Conference Call, December 6, 1995. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Collaboration Between Titles I and II and CDC HIV Prevention Community Planning Groups Conference Call, September 1995. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Quality Assurance and Improvement: Technical Assistance Conference Call, August 1995. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Collaboration Between Title I Planning Councils, Title II Consortia, and the National AETC Program Conference Call, June 1995. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

Involvement of PLWHS in Title I and II Programs: Technical Assistance Conference Call, December 1994. Prepared for the Division of HIV Services, Bureau of Health Resources Development, Health Resources and Services Administration.

OTHER HIV-AIDS RELATED MATERIALS

1. McKay, Emily Gantz, *Using Data, Assessing Needs: A Guide for Community Members of HIV Prevention Community Planning Groups*. Washington, D.C.: National Council of La Raza Center for Health Promotion, June 1995. A self-help guide prepared to help assure that planning body members, including community representatives, share an understanding of the needs assessment process and a familiarity with terms, format, and concepts of particular importance in understanding statistical reports and evaluations. Developed for the NCLR AIDS Center, for use by HIV Prevention Community Planning Groups, but useful for other planning bodies using AIDS-related epidemiological data and conducting needs assessments.

2. McKay, Emily Gantz, *Do's and Don'ts for an Inclusive HIV Prevention Community Planning Process: A Self-Help Guide*. Washington, D.C.: National Council of La Raza Center for Health Promotion, October 1994. Developed to assist HIV planning bodies recruit and retain minority membership, helpful in designing training related to PLWH diversity.

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