Presidential Advisory Council on HIV/AIDS
Full Council Meeting

June 15-18, 1998

Madison Hotel
Washington, D.C.

MINUTES

Present: R. Scott Hitt, M.D., Chair; Stephen N. Abel, D.D.S.; Terje Anderson; Regina Aragon; Judith Billings; Charles Blackwell, J.D.; Nicholas Bollman; Jerry Cade, M.D.; Lynne M. Cooper; Rabbi Joseph A. Edelheit; Robert Fogel; Debra Fraser-Howze; Kathleen Gerus; Phyllis Greenberger; Nilsa Gutierrez, M.D., M.P.H.; Robert Hattoy; B. Thomas Henderson; Ronald Johnson; Jeremy Landau; Alexandra Mary Levine, M.D.; Steve Lew; Miguel Milanes, M.P.A.; Helen H. Miramontes; Rev. Altagracia Perez; Robert Michael Rankin, M.D.; H. Alexander Robinson; Debbie Runions; Sean Sasser; Benjamin Schatz, J.D.; Richard W. Stafford; Denise Stokes; Bruce Weniger, M.D.; and Daniel Montoya, Executive Director for PACHA within the Office of National AIDS Policy (ONAP). **Present from ONAP:** Sandra Thurman, Director; Todd Summers, Deputy Director; Brad Austin, representative from Substance Abuse and Mental Health Services Administration (SAMHSA); Matthew Murguia, Office on Minority Health (OMH); Robert Soliz, Health Resources and Services Administration (HRSA); J. Todd Weber, M.D., Centers for Disease Control and Prevention (CDC); staff members Julianna Bynoe and Sarah Holewinski; and interns Dory Cohen, Lisa Gonzales, and Mandi Leissoo.

Absent: Michael T. Isbell and Charles Quincy Troupe.

June 15, 1998

Opening and General Council Business

Dr. Hitt, Chair, opened the Tenth Meeting of the Presidential Advisory Council on HIV/AIDS (PACHA) with a review of interim activities and meeting goals. He thanked members, Mr. Montoya, and Office of National AIDS Policy (ONAP) staff and representatives for their ongoing efforts in behalf of the Council. Noting that agency liaisons Mr. Austin, Mr. Murguia, Mr. Soliz, and Dr. Weber will be leaving ONAP soon, Dr. Hitt stressed the need to quickly find replacements to ensure continuity in their projects. He also welcomed new ONAP interns Ms. Cohen, Ms. Gonzales, and Ms. Leissoo.

The primary focus of this meeting was to be strategic and long-range planning through the end of PACHA’s charter (July 1999) and the current Administration (January 2001). Other meeting goals were to study youth issues, review outstanding issues, and decide on the establishment of a PACHA Executive Committee.

Interim Council Activities

Needle exchange: With the President's ban on Federal funds for needle exchange, PACHA and ONAP must formulate appropriate followup. A letter from President William J. Clinton to PACHA defining his response was provided to members, along with media reactions that included editorials from *POZ* and *The Advocate* (by Dr. Hitt). Several members had written Mr. Clinton in protest, and a letter to the President from PACHA has been drafted by Mr. Anderson (see June 18 section).

Vaccine recommendations: Dr. Levine, Ms. Miramontes, and Dr. Hitt attended an ONAP meeting with Dr. Harold Varmus, Director of the National Institutes of Health (NIH), Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases (NIAID), and others involved in the International AIDS Vaccine Initiative (IAVI). NIH is enthusiastic about helping implement the recommendations, including the addition of a key person at ONAP to coordinate vaccine efforts. In response to a letter to *Science* magazine which misstated some of the vaccine recommendations, Dr. Levine and Dr. Hitt drafted a letter to those who signed the letter. The letter of response became the focal point of a new process discussion on June 18.

African-American and Latino issues have been addressed in a call for a State of Emergency and in two Subcommittee conference calls. The issues have been added to all other Subcommittee agendas, and PACHA is monitoring Department of Health and Human Services (DHHS) and Health Resources and Services Administration (HRSA) responses to the emergency.

HIV surveillance: Progress is seen in the CDC's continuing revision of its guidelines, and a draft model confidentiality law with respect to public health information will be issued in the future. New York is proposing an HIV registry with mandatory reporting and partner notification. Ms. Fraser-Howze's and other organizations are working to remove criminalization aspects of the bill. (Ed. Note: Since the meeting, the New York bill passed, and Mr. Johnson was cited by the media on concerns about the program.)

Military HIV personnel policy and HIV-positive health care worker issues are being followed by the Discrimination Subcommittee, with updates to the Council forthcoming.

Appropriations issues will be addressed by a new ad hoc Subcommittee being set up by Mr. Hattoy, who asked for volunteers to serve with the group. Mr. Bollman complied.

Youth issues: Dr. Hitt thanked Mr. Sasser for developing the panel presentation (see June 16 section for further discussion) and recommendations that will be moved into Subcommittees for followup.

Prison issues: The Subcommittee is working on surveillance, a national prison summit meeting, and a Federal interagency meeting on compassionate release.

Services has followed the **HIV Cost Utilization Study (HCSUS)** and development of the CDC National Hotline; Dr. Hitt noted that Ms. Ami Israel of the CDC would be available at Subcommittee meetings to discuss the latter.

Meeting with the Vice President: Dr. Hitt met with Vice President Al Gore during another conference and found the Vice President to be “frustrated” on issues such as needle exchange and HRSA delays on access-to-care action. He is continuing discussion with the pharmaceutical industry on drug costs and vaccine research, however. Dr. Hitt told the Vice President that without his strong leadership, these issues will languish.

Long-range strategic planning: Since the last meeting, the Process Committee began formulating a plan and brought in outside facilitators to help develop a process for setting Council priorities through the end of this Administration. Dr. Hitt introduced facilitators from the firm of MOSAICA—Emily Gantz McKay, President; Cristina Lopez, Vice President; and Kayla Jackson, Senior AIDS Specialist. Several Subcommittees have held conference calls to assess outstanding issues and ongoing objectives for the process.

ONAP Update

Ms. Thurman thanked her staff and outgoing agency representatives and PACHA members for their support, welcomed new interns, and presented an update on recent ONAP activities.

Needle exchange: Saying the refusal of Federal funding for needle exchange was not a total defeat, Ms. Thurman told the Council that it helped move this issue to the front pages for the first time. Seeking a continuance of the debate, ONAP has met with General Barry R. McCaffrey, Director of the Office of National Drug Control Policy (ONDCP). Legislatively, needle exchange has been locked into the Senate Omnibus Drug Bill in a measure to permanently ban the use of Federal funds, and a similar bill has passed in the House of Representatives. She stated that ONAP must be realistic and move forward, but the debate does continue within the Administration. ONAP was urged to keep the Administration and agencies involved, and increased pressure on Gen. McCaffrey was recommended. Dr. Hitt and others thanked ONAP for its strong and brave stand on needle exchange.

Appropriations: ONAP does not believe the current Republican bill will pass, and the Office will monitor all matters involved with HIV/AIDS and keep the Council informed during the summer. Mr. Stafford urged ONAP to include effects of tax cuts on social programs.

International issues: Ms. Thurman said that the international community is willing to work together and is enthusiastic about U.S. goals for vaccines. More involvement is needed by Members of Congress with interest in international affairs to help obtain funding for special projects overseas. To this end, she met with Representative Jim McDermott (D-WA), Chair of the Congressional Task Force on International HIV/AIDS. In addition, Mr. Murguia (OMH) facilitated a meeting of the **Interagency HIV/AIDS Working Group** on international issues, with presentations by representatives from the Department of State on the revision of its HIV/AIDS strategic planning and from the Peace Corps.

Noting that by the year 2010 there will be more than 40 million AIDS orphans, Ms. Fraser-Howze asked if this issue is being addressed in internationally focused meetings. Ms. Thurman said that it is, along with programs on AZT for pregnant mothers. As these figures greatly affect economic, security, and humanity factors in the poorest of nations, conversations are being held with national security agencies as well as health organizations, and money is being sought for programs such as

institutions for the orphans. Other countries, even those most affected, are not willing to own or discuss this problem, especially when they want to talk about economic development, and it is also difficult to convince the American people that this is a real crisis. There is a need to address the issues of orphans, poverty, and unemployment all over the world. A world summit on AIDS orphans was suggested. Mr. Stafford urged the President to stay involved in international issues. Ms. Thurman said that President Clinton is doing so, and ONAP is working to engage Mrs. Hillary Rodham Clinton and Mrs. Tipper Gore in the issue of orphans. It was suggested that the International Issues and Communities of African and Latino Descent Subcommittees address the orphan issue and formulate specific recommendations and strategies.

Vaccines: The meeting with Dr. Varmus was a great first step toward cooperation, Ms. Thurman said. It was noted that there has been positive followup from the meeting participants, including a commitment from Dr. Donald Francis of VaxGen to participate in a Research Subcommittee conference call, open to all Council members, on June 23.

Names-reporting surveillance: Mr. Summers said that ONAP is working with the CDC (Kevin DeCock) and the Office of Secretary Donna Shalala on changes in data collection guidance, and is encouraging a focus on quality of data rather than how they are gathered. ONAP has also met with Kevin Thurm, Deputy Director, and Dr. Eric Goosby, Director of the Office of HIV/AIDS Policy, DHHS, and members of the AIDS community, and has found alarming problems surrounding the linkage of funds to these results and a trend toward mandatory testing. Of concern to the Council is that gaps in the data will affect the true status of AIDS in the African-American and Latino communities, with testing, funding, and care reflecting these gaps. Mr. Summers said the CDC understands both the value and the limitations of the data. Ms. Aragon noted that Mayor Willie Brown of San Francisco had hosted a national conference on the creation of non-names-based reporting that included States (Maryland, Massachusetts, and Hawaii) that have developed such programs.

Women's issues: A session with women leaders and philanthropists was to be held in the White House in June, to help put women and HIV/AIDS on a larger women's agenda. DHHS is holding many informational meetings on these issues as well.

Prison issues: Mr. Summers said that PACHA has played a major role in pushing reforms forward within the Bureau of Prisons (BOP) and the Department of Justice, and ONAP is focusing on prison issues with Administration officials and the community.

Health care worker guidelines: Mr. Summers discussed the results of a conference call between the Discrimination Subcommittee (Mr. Schatz, Dr. Abel, and Mr. Montoya) and the CDC. Mr. Schatz thanked ONAP for setting up the call with Dr. Helene Gayle, Director of the CDC Center for HIV, STD, and TB Prevention, and those writing the new guidelines. An internal working draft is due in August, with the final version possibly available by the end of the year. The CDC will eliminate the requirement for prospective notification of patients by affected health care workers, and special review panels and conformity with the Americans with Disabilities Act may be included.

Council meeting with the President: Ms. Thurman said that the President's Chief of Staff, Erskine B. Bowles, has committed to setting up a full Council meeting with the President, possibly in September (discussed further in the June 18 section).

DHHS Treatment Guidelines: Mr. Robinson noted that the Congressional Black Caucus has supported the call for a State of Emergency and raised questions with DHHS about disparities in health outcomes. The proposed Treatment Guidelines would be an important opportunity to make significant changes, and he asked where they stand. Mr. Summers said that this has stalled at DHHS, partially because of the lack of a method for information dissemination within the medical community. The document is overwhelmingly complex and in constant flux, as rapid changes occur in the disease and treatment science. Underlying this situation is the question of whether it is worthwhile to disseminate information on a mass basis to health care workers who most likely cannot keep up with the changes. The Council insisted that the Guidelines are extremely important, and Ms. Thurman promised to ask for an update.

Council member attendance: Although the Council cannot ask members who do not regularly attend PACHA meetings to resign, Dr. Hitt said that individual members can make known their frustrations and opinions to the persons in question and to the White House.

Long-Range Strategic Planning Introduction and Overview

Dr. Hitt introduced the process to assess past Council accomplishments and determine future desired outcomes and strategies, noting that, although PACHA's charter is up in July 1999, the assumption is that it will be reauthorized for another 2 years. (With a new Administration coming in January 2001, however, a new Council could be chosen.) Ms. McKay gave details about the strategic planning process and summarized consensus points that emerged during a preliminary poll of members: At this stage, it is valuable to focus on a relatively small number of objectives where the Council can make a difference—goals that are achievable by PACHA and/or the Administration—and to concentrate on fewer and more specific recommendations. Achievable issues should be targeted for the first year (through July 1999), and all others assigned to a longer-term segment. This raised concerns about losing momentum on the longer-term issues, but Ms. McKay cautioned members not to assume that the achievable issues are more important than the others or that the latter would be ignored. Other issues needing resolution included the end-of-term Council Progress Report; changes in how members work together, to allow for more effective operations; ramifications of Council member protest resignations; and change in the current direction and structure of the Council. Planning session ground rules were outlined by Ms. Jackson and accepted by the Council.

Two questions were asked to gauge the current feelings of members: (1) How do you feel about the ethics of remaining on the Council versus resigning, and what is your planned response? (2) How should the Council address the tensions regarding response to the changed face of the epidemic and issues of race, power, and influence?

Resignation: Each member was asked to make a personal statement, and the consensus was that, although members feel a strong sense of frustration and disillusionment with the Administration, they will not resign (28 were not prepared to resign; 1 was not sure; 1 did not address the issue). The Council can continue to help by monitoring the Administration (12 mentions); Council

members' role as representatives for millions of people in communities most affected by the epidemic who have no voice is important (9) and can best be achieved through unity, rather than acting as individuals; and resignation even by the entire Council would not make a big enough statement to override the benefits of remaining. Some (8) could identify conditions that might lead to their resignation, for example, if they feel that the Council is no longer effective for the people they represent, or if they believe that no one is listening. Some suggested that the Council is already being ignored by the Administration and that nothing is being accomplished. Others pointed out that, although the Council has not done everything it wanted to, it has made significant progress in bringing such issues as needle exchange; access to treatment for minorities, women, and children; and vaccine development to the forefront, and that it must continue this work. Members who themselves are persons living with AIDS noted that just being able to serve on the Council is a "miracle"; Ms. Stokes, whose grandparents helped start the civil rights movement, said she would not "give up my seat on this bus." (Later in the meeting, Mr. Fogel, who has called for Council resignation several times, said he would not resign but would continue to fight the epidemic.) Dr. Hitt said that the determination of resignation should be based on whether Council members truly are not being listened to and if they have no more creative ways to get their message across.

Response to change in the epidemic: Several cross-committee groups met to discuss Council response to the changes in the epidemic and issues of race, power, and influence. One member of each group summarized what was said.

Ms. Billings: Money and power remain the most influential factors in politics and in determining what the Council can accomplish; communities without these resources cannot do much. Since PACHA cannot bring millions of dollars to the fight to influence the process, all of us, regardless of how we came to the Council and what our experience and biases are, must look realistically at where the epidemic is. We must be willing to put aside personal issues and be driven by reality to refocus and do things differently.

Dr. Gutierrez: The main questions are: (1) How can the Council as a whole operate consistently to put the epidemic in the context of race and class? (2) How can the African and Latino Descent Subcommittee serve to facilitate this? Conclusions were: (1) The Council must recognize that the work of the Subcommittee is changing and expanding. (2) We must look at how people in all Subcommittees can help. The Council must avoid single issues that do not represent the true face of the epidemic and that steer us away from the necessary focus. Structurally, the Council may need an Executive Committee instead of a Process Committee to ensure that the core issues are always addressed and to "deprioritize" recommendations as necessary.

Mr. Hattoy: The concerns are whether all-inclusiveness of particular communities can reflect general diversity and how this will affect other groups with specific needs; whether the Council can educate itself, let alone America, on these issues; and whether all members will feel comfortable attending meetings of a Subcommittee focused on ethnic groups to which they do not belong. The Council must concentrate on African-American and Latino issues, but not all members know how to do that; there must be an all-inclusive, broad picture of race.

Mr. Schatz: Most members have come to this Council table with a sense of exclusion; all concerns of sensitivity and exclusion—race, gender, homophobia, and others—need to be faced by the

membership as a whole. We have to recognize that raising concerns about one group does not mean excluding others; however, things must be put in context so as not to exclude certain groups. We need to recognize that there are tensions among and within groups, and that there is a disparity among members in terms of power and influence. To balance our efforts we must develop mechanisms to help those on the Council who have ideas but not the ability, experience, or confidence to write recommendations or follow through. We must provide an atmosphere in which these people can ask other members for help. Ms. Stokes added that the Council must put principles before personalities and avoid stalling the process with personal problems. Finally, the Council should not make the same mistake the President is making—if something is hard, shy away from it. Mr. Sasser noted that there must be a higher level of trust than now exists within the Council, and resources need to be shifted to accomplish what is needed to stay ahead of the game.

Individuals were then asked to comment on issues of concern, primarily trust within the membership, matters of power imbalance on the Council, and the need for significant changes in structure and thinking. Some saw the Council's problems as universal: Rabbi Edelheit wrote that issues of power and race affecting the Council are indicative of the more pervasive issues in the community at large. Ms. Miramontes said that the racist society we live in has contaminated all of us. First we must acknowledge that and understand that we are trying to do something not seen in the larger society—overcome these prejudices, then help each other do it.

Some saw problems within the Council and its structure: Mr. Robinson said that trust has been betrayed; issues have gotten deprioritized; things agreed upon have not happened. To move forward, trust must be rebuilt and some of those priorities must be carried out. Mr. Anderson reinforced this idea, saying that lip service has been paid to issues focusing on communities of color. Dr. Rankin noted that the best way to defeat a group is to split it into warring camps. The Council must be aware that this could happen within its ranks, and that efforts will be hurt if issues cannot be discussed openly and honestly.

Ms. Aragon seconded the recommendation for an Executive Committee and addressed the dynamic of "formal and informal" power on the Council. The interests of the African-American and Latino communities, as well as the Subcommittee that represents these interests, have been diminished, diluted, or dismissed. Dr. Abel said that cross-committee work is necessary to develop better understanding among cultures and more effective followthrough. The Council has erred in making recommendations it assumed would be understood by and have the same impact on all cultures. The mechanism of recommendations is no longer working well, and the need for an Executive Committee to coordinate issues and actions is indicated.

Dr. Weniger felt that the Council needs to move to a more neutral and facilitative mode of leadership (i.e., Subcommittee Chairs), encouraging ideas to flow up from the grassroots, rather than being dictative. It may be time for the less aggressive members to exert more subtle, healing powers, and for others to recognize that subtlety does not mean weakness. Dr. Levine said that this Council is unique in its openness and its common goals, and that it should be an absolute given that anyone can come to any other member for help at any time.
Ms. Greenberger said that the Council tends to go off on tangents and needs to focus on a very few achievable issues. To accomplish many of its recommendations, members have to trust those with access to resources and the Administration on a regular basis to use these contacts

appropriately. Ms. Fraser-Howze noted, however, that if the Council looks at the issues from a public health perspective, most will be race-related. Dr. Cade felt that the Council has avoided the difficult issues and now must recreate the infrastructure to direct services to the neediest groups in order to address the disease in the next decade.

The consensus was that, although primary focus must be directed toward the African-American and Latino communities, the needs of all other unique groups must not be forgotten. It was pointed out that the Council needs to be mindful of other people of color who are affected in this country. For example, the Native American population, although relatively small, is disproportionately affected by HIV/AIDS. This is not just a matter of race but a legal responsibility of this Government (DHHS and the Indian Health Service), because of the Trust relationship it has with Native Americans, to include this responsibility in all efforts to combat this and other diseases. Mr. Blackwell does not want to be excluded from concerns with other communities of color, or for others who are not Native American to feel excluded from support to his community. Mr. Hattoy said that we all have to trust each other, working together to make sure all groups are considered.

Some members stressed practical issues: Mr. Henderson noted that the Council must realize it cannot resolve these issues in society at large, even if they are resolved within the Council itself. He cautioned against spending too much time working out the process and not addressing the substance of the issues, noting the limits of Council time. Dr. Gutierrez said that, in order to accomplish its goals, the Council needs to understand and use the power and politics issues and the impact of discrimination that exists within the structure in such areas as funding.

Mr. Bollman defined the question at three levels: (1) Personal—How can we make a constructive contribution and draw out the best in everyone on the Council? (2) Political—How can we best present ourselves to the President as a unified but diversified factor? (3) Organizational—How do we operate as a group, between the personal and the political? Changes are needed with respect to resources, how we organize tasks, and how we treat each other to round off sharp edges created by too few resources and too little time.

Reverend Perez made two overarching recommendations: (1) Develop a checklist that will be applied to every issue and recommendation to view it from the perspectives of all unique populations—women, youth, African-Americans, Latinos, Native Americans, white gay men, and others—acting as a prism representing the total face of the epidemic, always in front of our faces. (2) Recreate the Council structure so that every voice is always heard equally.

Dr. Hitt summarized themes in the responses: a need for openness on differences, dealing directly with issues, and awareness that it is OK to pass resolutions that do not name every unique group; developing a process and structure that can more effectively address the issues; and awareness of our time and resource limitations, leading us to focus on a few achievable objectives.

Subcommittee Meetings, June 15

Prevention: Members present were Mr. Robinson, Co-Chair; Ms. Billings; Ms. Gerus; Mr. Landau; Mr. Milanes; Reverend Perez; Ms. Runions; Mr. Sasser; Mr. Schatz; and

Ms. Stokes. Also present were Dr. Weber; Tracy Allaman and Vladimir I. Edmondson, AIDS Action Council (AAC); Ms. Israel; and Ms. Jackson. Discussion focused on long-range planning.

Research: Members present were Dr. Levine, Chair; Dr. Cade; Ms. Greenberger; Mr. Johnson; Ms. Miramontes; and Dr. Weniger. Also present were Mr. Murguia; Sunil Iyergar, *The Blue Sheet*; Monica Le, AIDS Action Council; Margaret Scarlett, DHHS; and Terri Wong, U.S. Department of State (DOS). An update on microbicide development was given to members by Penelope Hitchcock, D.V.M., M.S., NIAID; Ann Marie Corner, President, Biosyn, Inc.; and Polly Harrison, Ph.D., Alliance for Microbicide Development. A full written report—*Topical Microbicides Program Update 1997*—also was provided by NIAID to the full Council.

Services: Members present were Mr. Bollman, Chair; Dr. Abel; Mr. Anderson; Ms. Aragon; Mr. Blackwell; Ms. Cooper; Dr. Gutierrez; Mr. Henderson; Mr. Lew; Dr. Rankin; and Mr. Stafford. Also present were Mr. Montoya; Dr. Weber; Hushel Contes, HIV/AIDS Bureau; Heidi Ecker, *AIDS/STD News Report*; Ernest Hopkins, San Francisco AIDS Foundation (SFAF); and Ryan LaLonde, Native Affairs and Development Group (NADG). The Subcommittee was briefed on the Ryan White CARE Act reauthorization by John Palenick, Ph.D., HRSA; HIV-Positive Health Care Worker Guidelines by Dr. Weber; and Native American issues by Mr. Blackwell.

Subcommittee Meetings, June 16

Discrimination: Members present were Mr. Schatz, Chair; Mr. Henderson; and Mr. Johnson. Discussion centered primarily around priority issues for strategic planning.

International Issues: Members present were Mr. Anderson; Ms. Runions; and Dr. Weniger. Also present were Victor Barnes, CDC/DHAP; Paul Boneberg, Global AIDS Action Network (GAAN); Cowen Devine, SAMHSA; Kate Gorney, American Bar Association (ABA); Susan Kalagher and David Kinch, NCADI/SAMHSA; and Terri Wong, DOS. Nancy Carter-Foster, DOS, briefed the Subcommittee on the revised HIV/AIDS Strategic Plan, saying that the final version was expected by the end of the year.

Communities of African and Latino Descent: Members present were Ms. Fraser-Howze and Reverend Perez, Co-Chairs; Ms. Aragon; Dr. Cade; Rabbi Edelheit; Dr. Gutierrez; Mr. Milanes; and Mr. Robinson. Also present were Mr. Montoya, Mr. Murguia, and Ms. Leissoo; Ms. Ecker; Ms. Israel; Martin Ornelas-Quintero, National Latino/a Lesbian and Gay and Bisexual and Transgender Organization (LLEGO); Eva Seiler, CDC; and Monsanto Alf, National Black Leadership Commission on AIDS (NBLCA). The Subcommittee discussed long-range planning, concerns with the relationship between ONAP and PACHA, a conference call on Latino issues, the Harvard AIDS Institute study, an African-American issues update, and Subcommittee structure. Mr. Murguia reported on the DHHS Race and Health Initiative National Minority HIV Plan and the President's Initiative on Race. In response to Council concerns about focusing attention on all racial/ethnic issues, the group changed its name to Subcommittee on Racial and Ethnic Populations.

Prisons Issues: Members present were Mr. Landau, Chair; Dr. Abel; Ms. Billings; Mr. Blackwell; Dr. Cade; Ms. Cooper; Ms. Gerus; and Dr. Rankin. Others present were Mr. Austin,

Ms. Gonzales, and Rick Lines, Prisoners' HIV/AIDS Support Action Network (PASAN), Toronto. Discussion centered around planning, prison site visits, the Federal Interagency Meeting on Compassionate Release, National Summit Meeting on Prisons, National Minority Health Plan, and assessment of recommendations.

Prevention: Members present were Mr. Robinson, Mr. Anderson, Ms. Gerus, Mr. Landau, Rev. Perez, Ms. Runions, Mr. Schatz, and Ms. Stokes. Also present were Dr. Weber; Renalyn Cuadro, American Foundation for AIDS Research (AmFAR); Mr. Edmondson, Amy Hsu, and Brian Toynes, AIDS Action Council; Mr. Lines; and John Miles and Eva Seiler, CDC/NCHSTD. The Subcommittee developed a list of priorities to be considered in the strategic planning session.

Research: Members present were: Dr. Levine; Dr. Cade; Ms. Greenberger; Mr. Johnson; Ms. Miramontes; and Dr. Weniger. Also present were Mr. Murguia and Ms. Wong. The primary concern was long-range planning and Subcommittee priorities.

Services: Members present were: Mr. Bollman; Dr. Abel; Ms. Aragon; Ms. Cooper; Rabbi Edelheit; Dr. Gutierrez; Mr. Hattoy; Mr. Henderson; Mr. Lew; Dr. Rankin; and Mr. Sasser. Also present were Ms. Gonzales and Ms. Leissoo; Joseph Kelly, National Alliance of State and Territorial AIDS Directors (NASTAD); Ms. Le; and Jane Silver, AmFAR. Samuel Bozzette, M.D., Ph.D., University of California, San Diego, and Martin F. Shapiro, M.D., Ph.D., University of California, Los Angeles, briefed the Subcommittee on HCSUS data, which cover approximately 335,000 persons being treated for HIV/AIDS in the United States.

Panel Presentation on HIV and AIDS Among Youth

Dr. Hitt said HIV and AIDS among youth is an issue we all feel strongly about but have not adequately covered. Mr. Sasser, moderator, noted that this issue is of extreme importance because of the unique devastation that occurs when the young are affected. He thanked Mr. Bollman and the Services Subcommittee, Mr. Montoya, and the AIDS Policy Center for Children and Families, especially Clark Moore, for assistance in assembling the presentation. He recognized young people and other persons involved with youth and HIV/AIDS programs in the audience and introduced the panel.

Donna C. Futterman, M.D., Director of AIDS Programs, Montefiore Medical Center, Bronx, New York, described care and treatment among three primary groups involved in this hidden population: those coming of sexual age, those affected by AIDS through infected family members or friends, and infected youth. Currently, half of the transmissions worldwide are among those under 25 years of age, the majority being youth of color; in the United States, 25 percent of new cases are persons who are under 22 years of age. Of particular vulnerability are young males who have sex with males and young women who cannot identify risk behaviors in partners. Susceptibility factors are behavioral, biological, and socioeconomic, with girls especially vulnerable both biologically and because of gender power imbalances (among teenagers, the highest percentage of cases of HIV are females). Many youth lack health care coverage, sex education is inadequate, communications are poor, and issues of confidentiality are not understood.

A HRSA-funded pilot campaign has been developed in New York to target youth, using language they understand, and funds are being sought to move it into a national arena. Focus is on critical factors in treatment: early intervention (youth being an ideal target), basing treatment on adult guidelines with puberty staging, keeping programs as simple and doable as possible, and obtaining prospective data. Challenges include youth vulnerability, multiple risk factors, immaturity in coping ability, cognitive barriers, and lack of disclosure and family support. Dr. Futterman recommended that the Council advocate for:

- Innovative intervention programs that span the gaps between this group and others infected with HIV/AIDS;
- Outreach and linkage to care for youth;
- Youth-centered programs, including confidentiality/parental notification, adherence and relevant research, and peer and psychosocial support; and
- Funding streams that allow young people to get care in centers of excellence where research is available (not in managed care situations where they may be excluded from access to appropriate levels of care needed and important research programs).

Todd Summers updated the Council on the Presidential Youth Directive to Federal Agencies as to their specific HIV-related youth programs, saying that most of the reports are in and being put into a database. This will be analyzed and followed up with recommendations for integration of youth programs into currently operating HIV prevention, care, and treatment programs and a report to PACHA and the President. In addition, the Vice President has met with a group of young people who either have HIV/AIDS or are involved in care and prevention, which prompted him to request large budget increases in appropriate areas and to include youth and HIV in his agenda. Ms. Thurman also met with participants in a national youth efficacy coalition.

Audrey Smith Rogers, Ph.D., epidemiologist at the National Institute for Child Health and Human Development (NICHD), cited issues presented in the March 1996 ONAP report on research among adolescents: inadequate surveillance, resulting in inaccurate estimates of the scope of HIV in this population, and insufficient attention to influences on behavior, disease progression, effects on immune and reproductive systems as well as interaction, growth, and development around puberty. Factors that could lead to therapeutic benefit remained unidentified. A prime factor to be addressed is how youth interact and become engaged with the health care system and specifically, why adolescents are not in care in greater numbers.

Encouraging news is that the NIH-funded Adolescent Medicine-HIV Research Network has developed a substantial, nationally distributed clinical research infrastructure and a study group called Project Reach (a cooperative agreement between the Government and 15 clinical sites in 13 U.S. cities) to seek answers to HIV disease progression and HIV interaction with adolescent comorbidities. Ryan White Title 4 money helped fund these programs, produce a monograph on clinical management, and launch a drug-adherence initiative. Project Reach has already dispelled some concerns about the capacity of youth to adhere to a program, as more than 90 percent of 375 youth (12 to 18 years of age) have remained in the program since starting 3 years ago. This is due in large part to the use of interdisciplinary teams providing a wide array of adolescent-specific services on site. One-stop settings like this traditionally attract youth to care. Research with adolescents is exceptionally labor-intensive, and funds are needed to adequately support staff to track and encourage subjects. This population may require a clinical trials network of its own and

may not be suited for Phase I and Phase II trials. Reach is establishing normative immunological data that may make future therapeutic drug trials possible; the project has also identified unique adolescent characteristics that allow NICHD to attempt immune reconstitution with aggressive early therapy. Sharing early data with pediatric AIDS clinical trial groups has produced ACTG-381, an adolescent-specific study on immune reconstitution expected to be in the field this summer. Recommendations to the Council were to advocate for:

- Collection of observational data to define and examine population-unique characteristics to identify and implement an array of therapeutic interventions;
- Improved surveillance;
- Additional youth-targeted and effective outreach for HIV counseling and testing;
- Improved linkages between counseling/testing, social service networks, and health care to bring youth into settings where they can participate in research;
- Portability of health coverage to support research participation;
- Effective coordination of an HIV adolescent research agenda, including biomedical, behavioral, and health services; and
- Reallocation of research resources for more targeted funding to expand youth-focused research. Resources and effort must be committed to studying them in settings that can attract, recruit, and retain them as subjects of research.

Bret Rudy, M.D., Director of Adolescent HIV Issues, University of Pennsylvania School of Medicine, Chair of Adolescent Public Policy Committee for the AIDS Policy Center for Children and Families, said youth continue to be underrepresented in epidemiology and care. The need for early intervention, counseling, testing, and treatment is critical, as is research in this group because of adolescents' relative ability for immune reconstitution. Important factors affecting counseling and testing include these: Youth cannot be looked at as adults; they have special needs during stages of psychosocial development; they can be lost easily; and one must understand where they live, what their support system is, and the unique services they need. Prevention is vital, and ordinary risk assessment cannot be used to identify HIV-infected young people. Social factors include homophobia; poor role models, peer support, and self-esteem; lack of choices; poverty; and inability to negotiate. We must be realistic about adolescent sexuality, understanding that abstinence-only programs have little effect on safe sex. Programs that have worked are culturally sensitive, based on cognitive theory of behavior change, social skills, and norms. Recommendations to the Council are:

- Youth need access to free, confidential, age-appropriate, and unrestricted counseling and testing. Advocate to the CDC for youth-targeted funding to develop models in appropriate sites and education. Successful models do exist and can be replicated.
- Look for improved coordination among all services, Government, and the private sector so that youth services are integrated into the whole system (including such programs as family planning, sexually transmitted disease [STD] care, and runaway shelters).
- Advocate for enhanced funding to CDC, HRSA, and NIH to find the most effective strategies around counseling and testing and to get infected youth into care programs based on theory and with outcome measures. Enhance funding to disseminate that information.

- For prevention, seek Federal funding on sexuality programs in schools, starting very early, and for children in the community who are not in school, and call for better support for bisexual, gay, and lesbian youth.

Margaret Campbell, Youth Support Advocate, Multicultural AIDS Coalition, Boston, presented a youth's perspective, saying she would like to see this Council have a long-term commitment to the youth of our country. "I need you to do more—for me, and for the children to come," she said. Key recommendations to help youth include the following:

- Provide comprehensive sex education to every child and young person, starting in the first grade or even kindergarten.
- Have aggressive prevention initiatives that will pull youth into the programs, using their terminology. If you do not use their language, you will not get them to listen.
- Address programs to the real priorities of youth, and make a connection with HIV.
- The term youth cannot be used just as a buzzword. When young people come to the table, their opinions must be validated. (She thanked David Harvey for setting up a forum where policymakers listened to young people.)
- Outreach and access to care are critical, and staying linked to health care is difficult. To decrease the gap between infected youth and the care system, follow and link into other successful social programs for young people, such as YMCA, Boys and Girls Clubs, and violence-prevention programs, that young people access otherwise for help and information. For example, a Boston domestic abuse program is teaching negotiation skills that will help young women use barrier control methods to prevent disease spread.
- In communities of color there is a huge trust issue, especially for males; we need realistic communications about these issues so they will trust the prevention messages.
- Programs need to be highly culture-specific, aiming not just at ethnic populations, but at groups within groups—like the "hip-hop" culture.

Asked what could have helped her in earlier years, Ms. Campbell responded: "education for myself and my mother; knowledge of HIV; knowledge of how to negotiate with an older man for my own protection; honest conversations with adults on these subjects."

David C. Harvey, founder, AIDS Policy Center for Children, Youth & Families, Co-Chair of National Organizations Responding to AIDS (NORA), provided a perspective on Federal policy issues for youth and what PACHA members can do. He thanked important allies of his organization and resources for information on youth issues: Chad Martin and Victor Barnes, CDC; Ms. Silver, AmFAR; Michael Shriver, NORA; Dr. Michael Kaiser, HRSA; Michael Iskowitz, consultant; Ms. Thurman; Mr. Montoya; Dr. Hitt; and Mr. Bollman. He also thanked Mr. Sasser for his long, hard work on youth issues. Organizations doing important work in this area include Advocates for Youth; National Youth Advocacy Coalition; and NORA, which is forming a youth and HIV work group under David Mariner.

To help policymakers understand this population, at the AIDS Policy Center Voices 98 conference youth forums were run by and for youth with HIV. Tough questions were asked, such as, Why can't the Federal Government mandate HIV prevention education programs in all schools? We came away with a lot of work to do. A performance of the rap group TOPS (youth against HIV/AIDS) showed that youth do not "hear" or perceive the world in the same way adults

do. We at the national level have not figured out how to tap into the resources, energy, and brain power of youth; we need to let them drive policy on their issues. Recommendations for moving the Administration, Congress, and the Nation toward solving these issues include:

- Stop studying the issues; put what we already know to be true into action. Remarkable consistency is found among all the documents.
- Push the political will to drive these solutions, remembering that Washington moves slowly.
- Ask in a specific, powerful way for a status report on implementation of the White House Report on Youth and HIV. That report contains a wealth of recommendations.
- On the Presidential Directive, request a detailed report on what has come in and what has resulted—what initiatives have been started and what concrete actions have been taken to allocate more money to implement new programs.
- Take seriously the recommendation to have a youth provider and a person under 24 years of age living with AIDS appointed to PACHA.
- Focus on prevention, counseling, testing, care, and research.
- Use youth (13–24 years) and their unique needs as a filter for all recommendations made by the Council, and for all new programs coming out of CDC, HRSA, and NIH.
- In prevention and services, equitably address targeted funding to youth, especially of color. Look at current funding (for example, under Ryan White, only 2 percent of funds is used for care for youth) to see where we are failing and how we can expand developmentally appropriate services for youth.
- Request information on the new Children's Health Insurance Program passed by Congress. Determine how it is affecting youth. States have much latitude on implementation; what is the Federal Government doing to provide guidance to States?
- In research, develop a coordinated Federal agenda on youth with appropriate funding.

Other general points were made by panelists during discussion: Adolescent-specific programs are lagging because youth came into the epidemic late and because these programs are difficult and expensive to put together. On education efforts, the Federal Government should not be bypassed for other organizations such as the Parent Teachers Association (PTA), because the Government can help prod States into setting up training and model programs. One reason for not doing more to incorporate HIV into existing programs is that other basic social problems must be solved first; we must get the children to school safely, then teach them about AIDS. Sex education has to be accepted before we can move on to HIV/AIDS. One barrier, Dr. Rogers said, is that Americans are living in an era of profound deconstruction, with few consistent structures other than the media. People are extremely anxious, fearful, and cynical about Government, religion, and the social establishment. In discussing the media—where youth is getting its information—Dr. Futterman encouraged the Council to seek help from the corporate world in its advertising to spread messages about methods of safe sex and dangers of HIV. Special areas needing improved understanding include lesbians and HIV, youth and injection drug use, the spread of HIV among youth in rural settings, and legal barriers to providing services to youth.

Dr. Hitt thanked the panel and asked for several things: ONAP for a full briefing on the Presidential Directive at the next meeting; Dr. Rudy for findings in a study on sexual abstinence; Ms. Campbell and others, for updated lists of specific recommendations in writing. Mr. Bollman also thanked the guests and asked that late PACHA member Ed Gould be remembered for his

passion and work on the issues of youth. Mr. Sasser closed the session by introducing Miguel Bustos, co-author of the White House Report on Youth and HIV and currently an advisor to Vice President and Mrs. Gore, who told the Council that PACHA **does** have the power to make things happen and that it is the responsibility of us all to make sure that these issues are addressed.

Long-Range Strategic Planning, Session 2

Members discussed and agreed on the key steps needed in the overall planning process:

- To address sensitive issues (such as resignation, race/ethnicity, power) that may impede the ability of the Council to do its work and resolve them to the extent possible; to help the group work together effectively (begun in Session 1);
- To agree on a small number of short-term, achievable (mostly time-sensitive) action items/objectives and the strategies and structures needed to implement them;
- To identify additional objectives that are extremely important, but which may not be achievable in the short term, and determine strategies to keep them in the public view;
- To agree on the development of a final Progress Report or any other action that should be taken to coincide with the end of the current Council charter in July 1999; and
- To address Council and Subcommittee structure, processes, target audiences, and external relationships to ensure that they maximally help meet Council goals.

Another objective—to outline a plan for August 1999 to January 2001—was shelved until later. Concerns were raised about the definition of "achievable" and the distinction between "short-term" and "not achievable in the short term." Ms. McKay explained that specific evaluation criteria would be established later in the process but that, first, the concepts needed to be approved and all possible priority issues put forward. Each Subcommittee then presented key and time-sensitive objectives it would like to see on a final agenda. (The recommendations given below include revisions given to facilitators after this presentation.)

Racial and Ethnic Populations: Ms. Fraser-Howze said that the primary focus is on HIV/AIDS issues in African-American and Latino communities, with these specific recommendations:

1. The Council should embrace the principle of eliminating the disparities across racial/ethnic communities in all recommendations. (Overarching principle/goal.)
2. The Subcommittee should serve as a focal point (or clearinghouse) within the Council for collaboration with and review of 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. (Internal.)
3. The Subcommittee should aid in coordination of activities within the Council by serving as a data repository for policy, surveillance, prevention, care, and treatment data and analyses on racial/ethnic communities. (Internal.)
4. The Council should request that the President convene a special meeting with the Black and Hispanic Congressional Caucuses to have a discussion on the State of Emergency in these communities. (Time-sensitive, external.)

5. Based on our outlook and the tone we want the President to set for the Nation, the Council should call for a special White House Conference on AIDS within communities of color at the end of the Council's current term. (Time-sensitive, external.)

Discrimination: Mr. Schatz presented two time-specific objectives and two longer-term objectives:

1. Follow through on HIV-positive health care worker guidelines. (Time-sensitive, limited effort. Mr. Schatz and Dr. Abel will be responsible for any action taken.)
2. Having to do with the legal status of HIV: If the Supreme Court rules that HIV is not a disability under the Americans with Disabilities Act (ADA), work to regain recognition of HIV as a disability. (Time-sensitive.)
3. Work for legislative repeal of the immigration ban on HIV-positive visitors and immigrants to the United States. (Not immediately achievable, but morally important.)
4. [Background: 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 perceived mandate expands in July 1999, the Discrimination Subcommittee will make it a top priority to focus the Council's attention on bigotry, social divisions, and their impact in fueling HIV, and on proposed Government remedies. (Future, longer term.)

International Issues: Mr. Anderson presented the Subcommittee's agenda, based on the fact that 95 percent of all HIV infections are outside of North America:

1. To provide input to the new strategic plan of the Department of State and help ensure that its provisions are implemented. (Short-term. The Subcommittee wants to provide input on issues such as vaccine development, orphans, and access to treatment.)
2. Work to increase the budget for international AIDS spending, both for United Nations and international nongovernmental organization programs and for U.S. Government programs. (Short-term, achievable. The U.S. budget regarding foreign issues has been stagnant since 1993, with cuts on AIDS spending. The Subcommittee hopes to ensure that the next budget increases support such programs as UNAIDS and USAIDS, without cutting other health programs.)
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. (Longer-term.)
4. Work to increase ONAP staff resources for international work. (Longer-term.)

Prevention: Mr. Robinson said the Subcommittee's goals and objectives are partially in response to events concerning needle exchange and involve more resources for substance abuse treatment:

1. Putting prevention at the top of the national agenda must be a priority for 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. The following are specific objectives to reach this broad-based goal:
    a. Increased funding—PACHA should:

(1) Support NORA FY 1999 Appropriations Requests, and work with the community to develop an FY 2000 budget request. Recommend that part of any new funds must provide increased funding for SAMHSA drug treatment programs and build capacity in racial/ethnic communities.
(2) Work to advance the call for a State of Emergency in the African-American population and advocate appropriate funding.
(3) Recommend that CDC establish a youth initiative.

b. Targeting funds—PACHA should:
Work with the CDC to ensure that funds are more appropriately targeted by racial/ethnic factors, risk factors, age, gender, and geography. In line with this, the Prevention Committee will (1) work with the CDC in the development of its guidance for HIV Prevention Community Planning and (2) work with the CDC to evaluate the compliance of State planning groups and health departments.

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

2. The Prevention Subcommittee will evaluate the progress on previous recommendations regarding surveillance and work to establish an effective method for monitoring the epidemic.
3. The Subcommittee recommends that PACHA work with the Administration to ensure that the CDC establishes a national initiative to encourage the knowledge of sero-status and effectively targets at-risk populations.

Prison Issues: Mr. Landau presented Subcommittee priorities, as follows:

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, and medical care to the extent needed.
   a. The spread of HIV and other STDs during and after incarceration must be arrested through adequate drug treatment, health interventions, and discharge planning with available community resources.
   b. Medical summaries must follow the individual from prison to postrelease 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.

Research: Dr. Levine discussed one achievable objective on microbicides, for which the Subcommittee will bring specific recommendations to the November meeting, and three longer-term objectives:

1. Push the microbicide agenda by addressing the following:
   a. Changing the structure of the FDA in terms of toxicity/pharmacology reporting on microbicides (eliminate the requirement that microbicides have to be reviewed by five committees).
   b. Issues of liability and access (similar to those for vaccines).
   c. Increased funding.
   d. Development of methods that empower women to prevent the spread of HIV.
2. Move the research agenda forward on behavioral interventions—what works and what does not work. (This is longer-term, extremely important, and all Subcommittees need to be involved. Dr. Levine requested that a panel presentation be considered for the November meeting.)
3. Support having ONAP assume the role of coordinating the vaccine agenda, and ensure that it has sufficient staff to do so. (Longer-term, extremely important.)
4. Follow up on vaccine recommendations. (Long-term.)

Services: Mr. Bollman presented several categories of objectives for the Subcommittee. (Several of the following were added later in answer to Council member concerns about service issues.)

Overarching goal:

1. Seek alignment of the full range of medical and social services to reflect current and projected needs and demographics, evolving treatment standards, and a realistic assessment of potential resources, both public and private. Specifically, services and supporting funding streams must be both equitably available and targeted to special-needs populations (e.g., youth, African-American, Latino, and Native American).

Short-term leadership targets of opportunity:

2. Engage the President, especially through his interest in race issues and 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.

Short-term legislative targets:

4. Work for reauthorization of the Ryan White CARE Act, including reform of the AIDS Drug Assistance Program (ADAP) to ensure funding for providing and maintaining a comprehensive set of therapies (without emergency supplemental appropriations).
5. Work for reauthorization of Housing Opportunities for Persons With AIDS (HOPWA).
6. Work on the FY 2000 appropriations process.

Short-term administrative targets:

7. Continue to track and advocate for the expansion of Medicaid as a source of funding for early intervention, at the national policy level (Health Care Financing Administration [HCFA] and the White House) and with regard to State waiver applications.
8. Ensure that the information from HCSUS 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 antiretrovirals 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, 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 Subcommittees).

Questions were raised about timing, appropriations, and reauthorizations (especially ADAP), and Mr. Bollman said a timetable and more detailed recommendations or other strategies would be developed by the Subcommittee. Regarding ADAP, it will not be ignored, but the feeling is that the Council should not try to reform it in the context of reauthorization.

Facilitators called for discussion on perceived problems or gaps, and the main concerns were how objectives would be prioritized and how elimination of important issues from the agenda could be avoided. The fear was that pressure would be removed from certain important objectives that could not be achieved within the year. To expedite the process of prioritization, facilitators would draft a preliminary list breaking out all Subcommittee objectives into these categories: specific, short-term achievable objectives; specific, not short-term achievable, but morally important objectives; broad principles/longer-term objectives; and followup objectives requiring limited or individual member effort only. The objectives would be assessed as to overall importance in the fight against the epidemic, amount of work each will take, and whether it is actually achievable within the year. Ms. McKay and Dr. Hitt again assured members that no objective would be left out of strategic planning; all would be considered important, even those relegated to longer-term and/or limited effort categories.
Dr. Hitt asked that the Council be realistic about what it can accomplish in terms of resources and suggested that members be as concrete as possible about expected outcomes, to think about new ways of getting things done. Mr. Summers also asked the Council to be mindful of ONAP's staff limitations when it comes to implementation of PACHA objectives.

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Dr. Hitt asked members to complete a questionnaire on the proposed Executive Committee and for Subcommittees to submit conference call schedules to Mr. Montoya. The Council wished

Ms. Thurman and Ms. Holewinski a good trip on the AIDS Bike-A-Thon and thanked Ms. Holewinski, who is leaving ONAP in September, for her work on PACHA issues. Ms. Thurman addressed ONAP considerations in PACHA's strategic planning, asking for a narrower focus on doable objectives because of the agency's limited staff and agenda. She encouraged strong advocation for more ONAP and PACHA staff and for keeping agency representatives for longer periods of time to ensure continuity. HIV/AIDS efforts in progress where the quickest possible movement can be seen include vaccine development and access to care, particularly Medicaid expansion. Other, broader issues in the immediate works deal with racial, women's, and youth goals.

Long-Range Strategic Planning, Session 3

As working documents for the day-long strategic planning session, MOSAICA provided a guide to developing a framework for the plan, a list of Subcommittee objectives, and a preliminary categorization of the objectives. Ms. McKay asked that the Council consider its mandate and scope of activities and determine how broad it wants to be and choose targeted audiences. As part of the framework, members were asked what accomplishments they would like to see attributed to PACHA as of the end of July 1999. The following are a representative selection voiced by Council members:

- The President (and the Administration) is engaged, or reengaged, as an actively involved leader and advocate.
- Public awareness of particular issues and activities is raised.
- The Administration and the Nation respond more rapidly to the epidemic.
- PACHA's role expands from solely advisory to include advocacy and education.
- PACHA helps the CDC streamline its process so it can respond more rapidly to changes in the epidemic and institutionalize those changes.
- The President considers his work on AIDS as part of his legacy and completes some of the work begun by PACHA.
- The point is made in the political arena that this is very much an issue of ethnicity and race, so that the fight against AIDS is linked with the fight against discrimination.
- PACHA broadens its constituency within the Government and the country so that the Council's work becomes a higher priority.
- The Council exerts leadership in the overall community, working more closely with other AIDS organizations to have strength in numbers and to play a greater role in initiatives such as that of the Harvard Institute.
- The Council leaves a clearer understanding of the political process and its importance for local communities.
- Members work more closely in their own communities and with local media to vocalize what the Council is doing and what the issues mean.
- The Council sees the big picture and provides the national vision of what it will take to fight the epidemic.
- It also should be said that the Council sees the small and specific things, that it was responsible for giving one person with AIDS one more year to live.
- The legacy of the Council is that we were unafraid to speak the truth to the American people, not just to the President, and to deal with the consequences.

- This Council recognizes its own accomplishments and continues to work with this Administration and fights to get into the next.

Rabbi Edelheit reminded others that the Council may not be able to measure its accomplishments until the next PACHA or Administration comes into power.

Ms. McKay summarized: The Council wants to focus on and advise the President but sees its targets as broader than the President. There are specific things that can be done in agencies, and there are steps that can be taken to make a difference in people's lives. But the Council also wants to see itself as a conscience, a voice of leadership, taking the high road and speaking out on issues that are not being dealt with, focusing on populations not covered, and making it as hard as possible for the Administration to ignore these issues. "Winning" can mean getting things into the public eye, increasing the debate, making people more aware of the issues. In addition, there is a need to balance the broad picture with some specific battles the Council can win.

Primary audiences: The Council selected the following as audience targets: the President, the Secretary of HHS, ONAP, the media, the Vice President, the Director of ONDCP, the Administration, Congress, the American public (via the media), and people with HIV and their families (via the media).

Resources: Realistically, members understand that their current resources are limited to Mr. Montoya (full time); Council member volunteer time (plus any organizational resources individual members may bring); limited ONAP personnel time to help support and implement Council activities (with the attendant problems of interrupted continuity); and very limited help from Government and national organizational partners on specific issues. The Council has no operational budget. Some members believe it is a waste of time to discuss resources at length rather than address the issues, while others feel it is necessary to fully understand resource limitations so that the Council can make a realistic implementation plan. The general agreement was that the Council must find ways of obtaining more resources to accomplish its agenda. Mr. Bollman suggested that this should be the job of the Executive Committee, with individual members coming forward with any help they can provide to obtain additional outside resources.

During discussion of resources the following views were expressed: (1) too many things get done without a consensus or general knowledge among the full membership, and (2) most things necessarily happen through people involved in the administrative process on a day-to-day basis, through "those on the Council who know the political process and have the Administration contacts." Reverend Perez suggested developing mechanisms for keeping everyone informed and strict strategies so everyone knows who does what. Dr. Hitt pointed out that in the past most recommendations and suggestions were left with the Process Committee, without any strategy being delineated to accomplish them.

Criteria for short-term achievable objectives: The Council agreed on the following general criteria for judging priority objectives for the coming year:

First-tier criteria:
1. Achievability — That measurable progress can be made within the next year.
2. Timeliness/urgency — That this is the right time to address the issue.

3. Comparative value/importance, appropriateness — That the objective is deserving of time and attention.

Second-tier criteria:

4. Responsibility/accountability — A specific individual or entity is able, willing, and highly motivated to take primary responsibility for the work required to accomplish the objective and ensure followthrough.
5. Resource requirements — Know the resource requirements for meeting the objective and evaluate what is available and if it is reasonable, in the context of what may be achieved.

Cross-committee planning: Given a suggested planning format, the Council was divided into cross-committee groups to discuss prioritization of the objectives on the preliminary list. Groups were instructed to look closely at each category and try both to determine top priorities and to move objectives as necessary. At the conclusion of the working session, one person was asked to summarize the priorities for each group. The facilitators then listed those objectives mentioned most often as achievable goals. For each of 13 objectives, members were asked to determine the amount of work involved to accomplish the objective and who the target audience(s) would be. Members were asked to vote for six objectives they considered eligible by these criteria for the short-term achievable priority list. Those objectives chosen are listed below, in abbreviated form, in order of the number of votes cast, and with perceived level of work involved, audience, and Subcommittee(s) that will spearhead each. (The complete list of objectives by types as voted on by the Council is included as Attachments A and B to the Minutes.)

Short-term achievable priorities:

1. Call for a State of Emergency in the African-American and Latino communities and engage the President through meetings with the Congressional Black and Hispanic Caucuses and call for a White House conference on the emergency. (23 votes; much work; within the White House; spearheaded by Ethnic and Racial Populations and Discrimination Subcommittees)
2. Influence CDC prevention activities around youth, high-risk populations, and community participation. (22; much work; within the White House and the CDC; Prevention Subcommittee)
3. Push for Medicaid expansion and State waivers. (15; much work; within the White House and HCFA; Services Subcommittee)
4. Work for higher appropriations for HIV/AIDS programs, services, and research. (11; much work; within the White House and Congress; Appropriations Subcommittee)
5. Provide input to DOS international strategic planning. (11; limited work; within the White House and DOS; International Issues Subcommittee)
6. Advocate for attention to women-centered prevention methods. (11; much work; within administrative agencies; Research Subcommittee)

Other objectives included in the preliminary list and moved to followup, limited-effort columns were:

7. Work for Ryan White reauthorization. (8 votes)
8. Follow through with ONAP on youth programs status report. (6)
9. Work with the Attorney General and the BOP for mandatory discharge planning. (2)

10.	Work for HOPWA reauthorization. (0)

Major points during the discussion revolved around the following:

Suggested new structures and strategies: Strategies for more effective Council work included: allotting more meeting time for the Subcommittees spearheading the main objectives during full Council sessions; using cross-committee working groups and ad hoc subcommittees for specific tasks; using highly targeted letters, meetings, and other methods rather than formal recommendations to get things done; developing standard messages and information for individual members to use in meetings; developing (by Subcommittees) specific, limited-effort strategies for moving issues forward; and advocating for increased resources within ONAP and PACHA.

Ways to keep other issues active: Focus on them through special conference calls and continued monitoring and advocacy by individuals and Subcommittees specifically involved with those issues, calling for Council support when necessary.

June 18, 1998

Establishment of Executive Committee

The proposal to establish a PACHA Executive Committee to supersede the Process Committee resulted in a lengthy discussion on insider/outsider and power issues. Although it was agreed that a small (and wieldy) group was needed for planning and coordination, several members questioned the need for a change. Others felt that the name "Executive Committee" would further enhance the insider/outsider feeling on the Council. Further, it was noted that this proposal was made without preamble; no notice was sent to members prior to the meeting to explain why a change was needed. To some, this was indicative of a current internal problem—that actions are taken in the name of the Council, and many meetings are held by those with power on the Council without full-Council awareness or consensus. Cases in point were the letter to *Science* magazine, Dr. Hitt's meeting with Vice President Gore, and the lack of a written report on the May meeting with Drs. Varmus and Fauci. Dr. Hitt explained that the letter to *Science* was sent from two individuals, not the Council (see discussion below), that the meeting with Vice President Gore was a happenstance at a separate meeting of gays and lesbians with the Vice President, and that the May meeting was ONAP's meeting, and Subcommittee members were simply invited to attend. Ms. Thurman would be asked to submit a report to the full Council membership. Also noted was the perception that Prevention Subcommittee issues had been usurped by others on the Council (e.g., needle exchange). Dr. Hitt agreed that this was a problem, and that an Executive Committee could better monitor and prevent this from happening by following the dictates of the Council.

Ms. Fraser-Howze summarized the history of the PACHA Process Committee, which was established in the early days of the Council as a short-term, ad hoc committee, primarily to facilitate logistics of meetings and intracouncil communications. These duties have since been taken over by Mr. Montoya and the conference planners. The Process Committee, per se, was never intended to last 3 years. Also, to the outside world, an Executive Committee has more meaning as to its functions of coordination and facilitation. It was suggested that having a formal Executive Committee, with clearly defined functions and processes, might enhance intracouncil

communications and bring back some control to the membership through a better flow of information, and that, structured properly, this might ensure that power is shared equally and the perception of insider/outsider is abolished.

It was noted that a primary function of an Executive Committee could be to help the Council get a handle on other resources available to further its causes, particularly important since the Council has adopted an ambitious set of priorities and is underresourced. A formal Executive Committee can represent the changing, diverse face of the epidemic better in the public eye and, finally, can be held accountable.

Composition: The majority of Council members suggested that membership consist of all Subcommittee Chairs and/or Co-Chairs plus others necessary to achieve a balance in diversity. Some felt that Subcommittee designees, rather than Chairs, be appointed; however, Dr. Hitt and Mr. Montoya pointed out that this would make the intracouncil communications more involved, difficult, and duplicative. It was agreed that membership should be open to anyone who was willing to attend all meetings and commit to doing the necessary work of the Executive Committee; some members of the Process Committee (notably Ms. Miramontes and Rabbi Edelheit) pointed out that this was not a matter of having power or privilege, but of doing hard work. All members should be notified of Executive Committee meetings and be able to attend whenever they want.

Functions: Many suggestions were made as to the functions of the new Executive Committee, and Dr. Hitt summarized the responses (both written and verbal): plan meetings, suggest Council policies, follow up on long-term planning and help complete the work plan, review all recommendations through the "filter" of issues affecting special-needs populations (as defined by the Council), help develop strategies for achieving the objectives, and report to the full Council on all that is happening. It should act as a sounding board to make sure the Council is not missing someone or something and help monitor specific issues, along with the appropriate Subcommittees. Other suggestions were that the Executive Committee work with ONAP and Mr. Montoya to move issues forward, monitor implementation of Council recommendations, respond to the media, resolve conflicts, monitor external relationships, monitor adherence work programs, ensure that all Council members' opinions are considered and all individual Subcommittee issues are given equal priority, and seek outside resources for furthering Council causes.

Meetings: It was agreed that the Executive Committee should meet in 1- to 2-hour conference calls every 4 weeks. Agendas should be sent to the full Council in advance, and Mr. Montoya noted that this is possible only if Subcommittees provide him with agenda items in a timely fashion.

Reporting: It was strongly urged that the Executive Committee have someone responsible for taking notes or minutes of its meetings and disseminating them quickly to all Council members. A process suggested was for the note taker to make a preliminary draft for Executive Committee review and revision, then send the approved minutes to the membership.

The New Executive Committee

By a 22 to 8 vote the Process Committee was replaced with a formal Executive Committee comprising the Chairs and Co-Chairs of all Subcommittees, as well as any self-elected member-at-large who would commit for 1 year to be present at **all** monthly conference call meetings and carry out the tasks assigned. The core membership will be able to recruit new Executive Committee members if a gap in Council interests is perceived, and Chairs of any new Subcommittee that may be formed will join the membership. The initial membership will include Subcommittee Chairs/Co-Chairs Mr. Bollman (Services), Mr. Fogel (International), Ms. Fraser-Howze and Rev. Perez (Racial and Ethnic Populations), Mr. Isbell and Mr. Robinson (Prevention), Mr. Landau (Prisons), Dr. Levine (Research), and Mr. Schatz (Discrimination); Dr. Hitt (Chair of the Process Ad Hoc Committee and PACHA); and at-large members Dr. Cade, Rabbi Edelheit, Ms. Miramontes, and Dr. Sasser. Executive Committee conference calls will be open to all members, and the agenda will be provided in advance by Mr. Montoya.

The Executive Committee will have no voting rights and will not make decisions on Council matters (these will continue to be made through full-Council conference calls). Its duties will include: development of Council meeting schedules/agendas (with input from Subcommittees and individuals); filtering all recommendations and suggested actions through special-interest populations; sending out pro forma responses to invitations (to outside meetings, etc.) and thank-you letters as appropriate; facilitating review and adoption (among all members) of proposed full-Council actions, such as recommendations, letters from the Council to the President and others; hearing and resolving, as possible, any conflicts that arise; and reporting back to the Subcommittees on all activities of Council members. If any member is dissatisfied with any action of the Executive Committee, that individual should send a memo to the full Council for deliberation. (See Attachment C for Council responses to Executive Committee options.)

General Business

Letter to President Clinton on needle exchange: Mr. Anderson, at the request of Dr. Hitt and the Prevention Subcommittee, had written a letter to the President presenting the Council's response to the needle exchange action. This preliminary draft had not been reviewed by the Subcommittee or the Process Committee; rather, it should be reviewed at this point by the membership and the new Executive Committee in the context of the overall strategic plan. Members were asked to submit suggestions to Mr. Anderson or other members of the Subcommittee for revision. (Text of the draft is Attachment D to the Minutes.)

Letter to *Science*: A final draft of the letter from Dr. Hitt and Dr. Levine was provided to Council members, and it was agreed that it should be sent as revised. Dr. Hitt explained that this letter had been written as a quick response to misstatements about the vaccine recommendations and was not intended as a letter sanctioned by the Council. Mr. Montoya added that the draft had been reviewed by the Subcommittee at one of its sessions and members not present were later given the opportunity to make corrections to the letter. (This letter appears as Attachment E to the Minutes.)

It was agreed that individuals and Subcommittees must remain sensitive to the fact that any activity that concerns PACHA and its stated priorities should be reported to every member and that any correspondence or activity seen as full-Council action must be voted on by the membership. Activities initiated by individual members (such as correspondence and outside

meetings) should not be attributed to the Council. Mr. Henderson suggested that, when corresponding as individuals, members use their personal stationery to avoid the assumption that the letter has been sanctioned by the Council.

Meeting with President Clinton: The intent of the meeting is for the full Council to sit with the President and convey their concerns about priority issues, particularly in view of the fact that many new members have not had a chance to meet with Mr. Clinton. Dr. Hitt said that a separate meeting would be preferable to one held in conjunction with the fall meeting and he thought that funds could be found for this purpose. The consensus was that the meeting should be held in September, if possible, and that the Council should spend a day in advance preparing the order and substance of the session, and a postmeeting statement should be issued to the press. To most efficiently present the Council's agenda in the time allotted (30 minutes to 1 hour), certain members would be selected to address specific topics. (It was suggested that the Subcommittees also might hold planning meetings during the advance preparation day.)

Subcommittee Reports

Services: Mr. Bollman reported that the Subcommittee had received an excellent introduction to HIV/AIDS issues of the Native American community by Mr. Blackwell, and related materials are available to all members. A request was made for Mr. Blackwell to present to the full Council in November, as this is a population whose special needs must be addressed forthwith. The Subcommittee heard preliminary findings from the HCSUS study by the Rand Corporation and the University of California. Members asked that time be allotted for a more complete report at the next Council meeting, as the data will tell much about where this epidemic is and who is getting services, who is not, and why.

Mr. Sasser presented two leadership youth recommendations requesting reports on results of the 1996 White House Report on Youth and HIV/AIDS and the Presidential Directive. The two recommendations were adopted unanimously (see Attachment B), and Mr. Summers said that ONAP is already working on the requested reports. The recommendation for the appointment of a person under 24 years of age to the Council was shelved, because this is already under way at the White House. (Mr. Bollman said that the Council will ask that this be accomplished before July 1999.) Other youth recommendations are being moved to appropriate Subcommittees for development of strategies.

Research: Ms. Miramontes reported, in Dr. Levine's absence, that the Subcommittee received a full report on microbicides, and that specific recommendations would be presented to the Council in November. Further information must be obtained from the Food and Drug Administration (FDA), DHHS, and NIH. Vaccine issues continue to be monitored, and special attention is being given to behavioral research, especially as regards communities of color and youth. The Subcommittee asked for help on this issue from other Subcommittees and requested time for a full-panel report on behavioral research in November. Dr. Weniger provided an agenda and background material for the conference call with Dr. Donald Francis.

Prevention: Mr. Robinson said that the Subcommittee had formulated three recommendations directed to the CDC: to establish a youth initiative, to establish a national initiative to encourage HIV testing that effectively targets high-risk populations, and to work with the Council in

developing HIV prevention community planning guidance. In line with the new strategic planning results, these issues will go back to the Subcommittee for determination of specific strategies. Other members expressed concern that these important, time-sensitive issues might be delayed by this process, saying that they preferred making general recommendations to losing momentum; all agreed that these should be addressed as quickly as possible as part of the work plan.

Another issue to be included in the working strategy is the need for increased dollars for substance abuse treatment. Mr. Summers said that it will be helpful to ONAP for the Council to consider the mechanisms through which these funds are administered as part of any recommendation it might make, and to stand behind ONAP's efforts in this area.

Prison Issues: Mr. Landau said some progress has been made, with issues on substance abuse treatment, prevention, quality of care, and compassionate release being brought to the attention of the BOP and the Justice Department. There is concern, however, about the lack of effective response from the BOP and because prison issues are not considered among the achievable priorities of the Council. He noted that, since people of color account for more than 80 percent of the population in prisons, this is an issue of race as well. The Subcommittee is trying to increase the pressure and is looking for more information on issues of incarcerated women and youth, managed care in prison settings, the relationship between State and Federal prison issues, and HIV testing. Upcoming activities include participation in the National Meeting on Prisons in October and site visits in conjunction with the November Council meeting.

A Subcommittee recommendation regarding CDC technical assistance for corrections systems surveillance was reviewed and passed unanimously by the Council (see New Recommendations, Attachment B). A letter to Dr. Kathleen Hawk Sawyer, BOP, on protective barriers was tabled until the November meeting, partially at the request of ONAP, which feels that the letter could elevate this very problematic issue above others involved in current agency efforts. It was suggested that the Subcommittee put this issue into context of the overall priorities of the Council. Another letter, to Secretary Donna Shalala and Attorney General Janet Reno on Standards of Treatment, was also tabled until the November meeting. (Both letters are included as Attachments F and G.) Mr. Summers said that ONAP has met with the Assistant Attorney General for Policy, the Superintendent of the BOP, and Surgeon General David Satcher on the status of health care in prisons, and he believes there is a spirit of cooperation and good opportunity for progress. Mr. Landau thanked Mr. Summers and Mr. Austin for their work in moving these issues to the next level.

International Issues: In Mr. Fogel's absence, Mr. Anderson discussed funding for international efforts, a matter that demands attention from the Appropriations Ad Hoc Subcommittee and within the full Council. He presented a resolution, tabled in December 1997, to amend the Embargo Act of 1961. In answer to questions about the timeliness of making this recommendation, Mr. Landau noted that this AIDS-specific issue greatly affects such countries as Cuba. Mr. Bollman pointed out that it affects Africa as well, elevating this to an even higher status, given the increased focus on communities of color by the Council. The recommendation was adopted with two opposed.

Discrimination: There was no formal report; however, Mr. Henderson presented a brief resolution regarding the Americans with Disabilities Act (text in Attachments A and B) which passed with two opposed.

Racial and Ethnic Populations: Ms. Fraser-Howze said that the Subcommittee had changed its name in a desire to be sensitive to all ethnic populations. To round out the diversity of the membership, Mr. Lew and Mr. Blackwell have offered to help out as needed. During this session, the Subcommittee heard a report on the Latino Leadership meeting at Harvard, which produced positive followup and good media attention.

Mr. Murguia summarized information presented to the Subcommittee on the Race Initiatives of the Office of Minority Health (OMH) and the President. The National Minority HIV Plan, he said, under development at OMH for a year and a half, is looking at implementation steps that answer recommendations by community-based minority organizations, the first time that all Public Health Service (PHS) agencies have collaborated with these groups. Currently, the working group (of which Mr. Milanes is a member) is reviewing the final draft, and it is hoped that the Plan will be released in September at the U.S. Conference on AIDS in Dallas. The Subcommittee has been asked to review the document, and OMH hopes it will write a letter of endorsement for the Plan and an encouragement for the Secretary of HHS to ensure its implementation as soon as possible.

On the President's Race Initiative, DHHS has six working groups on various areas, including HIV, where the health status of racial and ethnic populations is vastly different from that of the majority population. The HIV working group, under Co-Chairs Dr. David Holtgrave, CDC, and Dr. Michael Johnson, HRSA, has been given a very wide charge to look at how DHHS addresses HIV/AIDS issues, including funding, services, prevention, research, and information dissemination. The mandate includes making recommendations for any perceived changes needed in the structure and prioritization of programs and funding, and determination as to whether the community is appropriately involved. Ms. Fraser-Howze asked for time at the November meeting for a full-Council update on the two initiatives.

Ms. Fraser-Howze presented a letter from Secretary Shalala to Representative Maxine Waters (D-CA), Chair of the Congressional Black Caucus, indicating that DHHS is responding immediately to the call for a State of Emergency and is reviewing every program on HIV/AIDS within HRSA, SAMHSA, and its other agencies. DHHS will meet with Congresswoman Waters, and the Subcommittee will follow up on this and other activities, including use of available emergency funds for this purpose, and is calling for the CDC to review its programs in terms of the State of Emergency.

Reverend Perez reviewed recommendations calling for a Presidential meeting with the Congressional Black and Hispanic Caucuses and a special White House Conference on the State of Emergency, which were adopted unanimously by the Council (see Attachment A). The Subcommittee will follow up on responses to these and develop specific strategies on all other Subcommittee issues specified as priority goals or objectives.

Ms. Fraser-Howze suggested that, given the major changes in structure, focus, and emphasis on ethnic communities adopted at this meeting, the Council should issue a press release on the new working plan. Ms. Cooper said that such a statement should stress the positive—that PACHA is

concentrating its efforts on communities most affected by the epidemic—rather than on the changes being made within Council structures and operations. Although the Council normally does not issue press statements at the end of its meetings, it was agreed that this could be an exception. Ms. Fraser-Howze was asked to write a first draft of the release and submit it to the Executive Committee for dissemination to the Council for approval.

The question was asked how the White House will be informed of events at this meeting, and Dr. Hitt said that ONAP sends a memo summarizing every meeting to the President, the Secretary of HHS, and other appropriate members of the Administration.

Final Review of the Strategic Plan

The Council received a draft of the list of priority objectives chosen on June 17 (the full text is in Attachment A), and Ms. McKay asked that all members review the document and send any suggested corrections to MOSAICA as soon as possible. The facilitators will draft a final report to the Council. A formal motion was made to adopt the six short-term achievable objectives as priorities for the remainder of the Council's term, and it was passed unanimously. Appropriate Subcommittees were asked to use the planning format provided to develop specific strategies in time for the first Executive Committee meeting (proposed for July 18), where the strategies will be combined in a final working plan for the year. The importance of developing these strategies very quickly was stressed.

It was also agreed that objectives and goals in the longer-term, limited-effort categories would be addressed by the Subcommittees and interested individuals, although it might not be realistic to apply the full planning format to each at this time.

The Executive Committee was to schedule upcoming meetings and develop process strategies for Council communications, activities, recommendations review and filtering, and coordination of strategic plans. Mr. Montoya was asked to provide an orientation to new members, including the important members in the Administration.

Next Meetings and Closing

Next Council meetings. The next full Council meeting is scheduled for November 16–19, 1998, at the Madison Hotel in Washington, D.C. The full schedule of upcoming Executive Committee and Subcommittee conference calls will be sent to all members.

Dr. Hitt thanked Council members, Mr. Montoya, Ms. Thurman and the ONAP staff, facilitators from MOSAICA, the conference staff, and guests for their participation. The Tenth Meeting of PACHA was adjourned at 12:50 p.m., June 18, 1998.

Attachments to the Minutes

A. Strategic Planning Results (Adopted June 17, 1998)

B. New Council Recommendations (Passed)

C. Council Responses to Executive Committee Options

D. Letter to the President Regarding Needle Exchange from the Prevention Subcommittee (Preliminary Draft, In Review)

E. Letter to *Science* Magazine (Revised Draft)

F. Letter to Dr. Kathleen Hawk Sawyer, Federal Bureau of Prisons, from Prison Issues Subcommittee (Tabled)

G. Letter to Secretary Donna Shalala and Attorney General Janet Reno from Prison Issues Subcommittee (Tabled)

H. Private Organizations, Government Agencies, and Media Represented at the PACHA Meeting

A: Strategic Planning Results
Adopted June 17, 1998

Short-Term Achievable Priorities

Six objectives chosen as top priorities were described as to the amount of work each will require ("much" or "limited") and its targeted audiences of action (i.e., the White House, administrative agency, and/or Congress [indirect]), as shown in the following table:

Objectives	Votes For	Amt. Work	Targets
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. (Also mentioned were: advocating for increased funding to serve African-American and Latino communities and calling for the President, through his interest in race and race relations, to take action on the racial/ethnic implications around HIV/AIDS service delivery. Council action will be focused through the Subcommittee on Racial and Ethnic Minorities.)	23	Much	White House
2. **Influence CDC policies and programs related to HIV/AIDS prevention,** including: · Establish 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	22	Much	White House; Admin agency

Objectives	Votes For	Amt. Work	Targets
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. (Prevention Subcommittee)			
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. (Services Subcommittee)	15	Much	White House; Admin agency
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 FY 2000 appropriations. · Focus on increased funding for substance abuse treatment, building service capacity in communities of color, youth, and international HIV/AIDS programs. (Appropriations Ad Hoc Subcommittee, others)	11	Much	White House; Congress
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.** (International Subcommittee)	11	Limited	White House; Admin agency
6. **Advocate for attention to women-centered prevention methods (microbicides).** (Research Subcommittee. Language of recommendation to come by November.)	11	Much	Admin agency

Specific, Not Short-Term Achievable, But Morally Important Objectives

The following objectives are not listed in priority order.

1. If the Supreme Court rules that HIV is not a disability under the ADA, work to regain recognition of HIV as a disability. (Discrimination Subcommittee)

2. Continue to advocate for a policy that permits the use of Federal funds for needle exchange. (Prevention Subcommittee)

3. Work for legislative repeal of the ban on immigration to the United States by HIV-positive individuals. (Discrimination, International Subcommittees)

4. Support the appropriation of the necessary funds to ensure substance abuse treatment on demand. (Prevention, Appropriations Subcommittees)

5. Work to establish an effective method for monitoring the epidemic.

6. Move the research agenda on behavioral interventions -- to learn more about what works and what does not work. (Research Subcommittee)

7. 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. (International Subcommittee)

Broad Principles/Longer-Term Goals

1. 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. (Services Subcommittee)

2. Address bigotry and social divisions and their impact on fueling HIV and on proposed Government remedies. (Discrimination Subcommittee)

3. Put HIV/AIDS prevention at the top of the national agenda. (Prevention Subcommittee)

4. 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.

   (The Research Subcommittee will propose specific objectives and recommendations on this issue in November.)

5. Work to improve adherence to treatment guidelines by all providers of care. This 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. (Prisons, other Subcommittees)

6. Work for the establishment of a longitudinal file for women who received AZT and all antiretrovirals while pregnant, to monitor them and determine the long-term effects of treatment. (Research?)

7. Help ensure that the information from the HIV Cost, Services, and Utilization Study (HCSUS) 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. (Services Subcommittee)

8. 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. This includes linkages with available community resources to provide drug treatment and health interventions. (Prison Issues Subcommittee)

9. Enhance the Federal/State/local dialogue regarding HIV and prisons, with emphasis on State/local input to the Bureau of Prisons (BOP). Address Federal guidelines, technical assistance, and funding streams that have policy implications in State and local prisons and jails. (Prison Issues Subcommittee)

Followup Objectives: Limited or Individual Member Effort

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

2. Convince the President to establish a concrete goal regarding provisions of services for people in need, as he has done with vaccine development and infection rates. (Services Subcommittee)

3. 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).

4. Followup on vaccine recommendations. (Research Subcommittee)

5. 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 postrelease treatment. (Prison Issues Subcommittee)

6. Work for reauthorization of HOPWA. (Services Subcommittee)

7. Work to increase ONAP staff resources, including both full-time employees and the continuity of personnel, with special emphasis on (1) greater involvement in international issues and (2) a coordinating role on the vaccines issue. (Executive Committee)

8. 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. (Services Subcommittee)

9. Follow through with ONAP on youth programs status report and plan. (Mr. Sasser)

10. Evaluate progress on previous PACHA recommendations regarding HIV surveillance. (Prevention Subcommittee)

B: New Council Recommendations

Passed During the PACHA Meeting June 15-18, 1998

Discrimination Subcommittee (Passed with 2 opposed)

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.

International Subcommittee (Passed with 2 opposed)

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.

Prison Issues Subcommittee (Passed unanimously)

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.

Racial and Ethnic Minorities Subcommittee (Passed unanimously)

1. 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.

2. 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).

Leadership Recommendations on Youth Issues (Passed unanimously)

1. 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."

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

C: Council Responses to Executive Committee Options

Number of responses	Response
1. Who should be on the Executive Committee?	
15	Subcommittee Chairs (Process Group), plus several others to achieve diversity and balance
2	The Executive Committee should be elected by the Council
1	Two designees from each Subcommittee (not necessarily Chairs) and Scott Hitt

C: Council Responses to Executive Committee Options	
Number of responses	**Response**
1	Tom Henderson, Joseph Edelheit, Regina Aragon, Nick Bollman, Alexandra Levine, Helen Miramontes, Alexander Robinson, Scott Hitt, Denise Stokes, Mike Isbell
1	A diverse representation of affected communities
1	Council members who are not involved in key decision making opportunities
2. What should the Executive Committee do?	
10	Plan meeting agendas
10	Set political priorities, policies, and the strategic moving of issues
6	Work with ONAP and Daniel to move issues/monitor implementation of Council recommendations
4	Respond to media
4	Resolve conflicts, deal with process issues
3	Ensure communication between ONAP and PACHA
3	Monitor external relationships, delegate requests for information, meetings, and advice to appropriate Committees, Subcommittees, and Council members
2	Advise Chair regarding between-meeting activities (media, meetings with Administration officials)
1	Monitor and report adherence to work programs
1	Ensure all Council members' opinions are considered
1	Ensure all individual Subcommittee issues are given equal priority
1	Makes decisions in absence of the Council
1	Select new Council members
3. Given the above duties, how often should the Executive Committee meet?	
10	Every 2 to 4 weeks, more frequently as meetings get closer, and on an as-needed basis
4	Every other month, or as needed
3	During each Council meeting or before the start of the Full Council meeting. Should visit each Subcommittee
1	As determined by Executive Committee and Full Council
Additional Responses	
3	Meetings should be open to all Council members; however, voting rights maintained by Executive Committee

C: Council Responses to Executive Committee Options	
Number of responses	**Response**
3	Special attention must be given to people of color and youth issues
No Executive Committee should be appointed	
4	

Total Responses Received: 24

D: Letter to the President Regarding Needle Exchange

Preliminary First Draft

(Letter drafted by Mr. Anderson, to be reviewed by the Executive Committee and the Prevention Subcommittee, and submitted to the full Council before sending it to the President.)

Dear Mr. President:

As members of your Presidential Advisory Council on HIV/AIDS, we must convey the profound disappointment, frustration, and anger we feel about the course of action you have chosen to take relative to needle exchange. The belated willingness to certify that needle exchange programs help reduce HIV infection without increasing drug use was an important step forward; unfortunately, the accompanying refusal to allow States and localities to use Federal funds to support this successful intervention represents nothing more than the triumph of political expediency over scientific evidence and compelling human need. Your stated commitment to ending new HIV infections is seriously called into question by this action.

The issue is not resolved—injection drug use continues to drive the HIV epidemic in our country, taking a particularly heavy toll on African-American and Hispanic communities. Your decision on this matter simply accentuates the failure of your Administration (and the country as a whole) to take effective action to stem the twin epidemics of HIV and drug use in our country.

While we continue to strongly believe that allowing Federal funds to be used for needle exchange programs is one vital part of an effective response to the spread of HIV among drug users, failure to take this step must be accompanied by a willingness to take other significant and bold steps to meet this public health challenge.

First, it is not enough to simply talk about drug treatment without taking significant steps to increase and improve drug treatment capacity in this country. It will require a significant investment of resources to create a system where all drug users have immediate access to effective drug treatment, resources your Administration as of yet has failed to put into place. We must set a goal of providing treatment on demand for any drug user in this country. It is our intention to work with members of your Administration and community advocates to shape a national commitment to universal drug treatment access, and to support the resources necessary for these programs.

Second, we must do a better job of coordinating the diverse Federal efforts to prevent HIV infection among drug users and their sexual partners. During the White House Summit on HIV/AIDS in December of 1995, you called for a national meeting bringing together public health and substance abuse providers to address this issue. An August 1997 meeting was held in Tampa, but since that time, no discernible action has taken place on this matter. You must instruct the leaders of the relevant Federal agencies to implement the recommendations that came out of that meeting.

Third, programs to reach out-of-treatment drug users with education, counseling, support, and HIV testing services must be enhanced, including an increased financial commitment to the CDC’s HIV prevention programs. The failure to seek budget increases for these prevention programs is one more serious reason to question your commitment to effective HIV prevention.

Fourth, we have previously urged Federal efforts to change the Model Drug Paraphernalia Act to allow possession of small numbers of syringes, a step that numerous studies have indicated have been highly effective in preventing new HIV infections in those States that have changed their laws. We have yet to see any meaningful action on this recommendation, and we urge you to make this happen.

Fifth, we urge you to instruct the various agencies of the Federal Government to determine ways to effectively link prevention and substance abuse programs with needle exchange programs in communities where they operate. In addition, these same agencies should be instructed to, when appropriate, participate in efforts to advance scientific and public understanding of needle exchange programs, and to study and advance knowledge of successful programs around the country.

Finally, we remind you that the decision not to allow Federal funds to be used for needle exchange programs will result in unnecessary new HIV infections. In response to these many new infections, we urge you to allocate sufficient resources to meet the medical and social service needs of those who are infected. Future budget levels for Ryan White, HOPWA, Medicaid, and other Federal programs funding these services must take into account these new infections.

As your advisors on HIV/AIDS, we must urge you to seriously and effectively address the continuing crisis of HIV among injection drug users and their sexual partners. In light of your decision on needle exchange, action of the items outlined above becomes even more imperative.

Sincerely,

PACHA

August 26, 1998

Floyd Bloom, M.D.
Editor, *Science* Magazine
American Association for the
Advancement of Science
1200 New York Avenue, N.W.
Washington, D.C.

Dear Dr. Bloom:

As members of the Presidential Advisory Council on HIV/AIDS (PACHA), we would like to clarify our position and recommendations made to President Clinton regarding the development of a vaccine against HIV. It is clear from the letter published in *Science* on May 8, 1998, by Agosto et al. that the authors had either not read or not understood the recommendations which we made.

First, under no circumstance did PACHA recommend that the "...responsibility for the development of an HIV vaccine should be removed from the NIH and transferred to other Federal agencies." What we did recommend, in fact, was that the NIH should continue its major responsibility in terms of defining the scientific basis for further vaccine development. We also recommended, however, that other Federal agencies with known experience and expertise in vaccine development be brought onto the team. With the daunting tasks ahead, it would seem obvious that one agency alone, no matter how accomplished, would be less than optimal. Further, since multiple existing agencies—such as the CDC, DoD, and others—have already had years of experience in various aspects of vaccine generation and testing, it appeared clear to us that all existing expertise should be employed, if the President's goal of finding an effective HIV vaccine within a decade is to be realized.

736 Jackson Place, N.W.
Washington, DC 20503

A second major emphasis of our recommendations relates to the fact that no administrative mechanism currently exists to ensure the ongoing communication and collaboration of all existing Federal agencies involved in HIV vaccine work. While the Levine commission recommended such coordination in its report to the NIH, and while occasional and sporadic meetings have been held among members of various Federal agencies, no one, in fact, has been given responsibility for ensuring ongoing coordination of the Federal vaccine effort. Further, multiple complex and interrelated social and political issues also must be addressed for successful implementation of an AIDS vaccine. It is clear, for example, that the pharmaceutical and biotechnology industries must be involved, yet there is no existing mechanism to ensure their ongoing communication and collaboration with the NIH and other Federal agencies. It is clear that representatives of the international community must be involved, including groups such as the World Bank, the United Nations, and the International AIDS Vaccine Initiative. However, no administrative mechanism exists to ensure the requisite ongoing communication among these groups and the NIH and other Federal agencies. After spending years in studying these issues, PACHA has recommended that the role

of administrative coordination of the Federal vaccine effort be placed within the White House, implemented through the Office of National AIDS Policy, which reports directly to the President of the United States.

The authors of the letter to *Science* indicate that PACHA has advocated the widespread testing of existing empiric vaccine approaches. In fact, based upon the continuing increase in HIV-infected persons throughout the world—despite all efforts at behavioral intervention—we have recommended that both empiric and traditional scientific methods be employed in an attempt to develop an effective AIDS vaccine as quickly as possible.

We hope that these comments will clarify the position of PACHA in terms of the Federal HIV vaccine effort. Clearly the goals of PACHA and the authors of the letter are the same: development and implementation of a successful AIDS vaccine as quickly as possible. Toward this end we believe that expertise from all relevant agencies within the Federal Government and administrative coordination on a national and international level will be required to actually achieve this goal.

Sincerely yours,

R. Scott Hitt, M.D.
Chair, Presidential Advisory Council on HIV/AIDS

Alexandra Levine, M.D.
Chair, Research Subcommittee
Presidential Advisory Council on HIV/AIDS

*This letter was never sent.

F: Letter to Dr. Kathleen Hawk Sawyer
Federal Bureau of Prisons

Draft by the Prison Issues Subcommittee

(Letter tabled until the November meeting.)

Dr. Kathleen Hawk Sawyer
Federal Bureau of Prisons

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 47.21MMWR.)

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; 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,

Prisons Issues Subcommittee

cc: Eleanor Acheson
Janet Reno

G: Letter to Secretary Shalala and Attorney General Reno

Draft by the Prison Issues Subcommittee

(Letter tabled until the November meeting.)

Dear Secretary Donna Shalala and Attorney General Janet 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 ensuring 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 that 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,

Prison Issues Subcommittee
PACHA

H: Private Organizations, Government Agencies, and Media Represented at the PACHA June 1998 Meeting

Private Organizations

Advocates for Youth
AIDS Action Council (AAC)
AIDS Policy Center for Children, Youth, and Families
AIDS Vaccine Advocacy Coalition (AVAC)
Alliance for Microbicide Development (AMD)
American Bar Association (ABA)
American Civil Liberties Union (ACLU), National Prison Project

American Foundation for AIDS Research (AmFAR)
Asian and Pacific Islander Wellness Center
Biosyn, Inc.
Children's Hospital of Philadelphia/University of Pennsylvania
Church of Saint Philip the Evangelist
Committee of Ten Thousand (COTT)
DOORWAYS, St. Louis
Drug Policy Foundation
Gay and Lesbian Medical Association (GLMA)
Gay Men's Health Crisis (GMHC)
Global AIDS Action Network (GAAN)
Hilfman and Fogel
HIV/AIDS Bureau
HIV/AIDS Indians
James Irvine Foundation
Midwest AIDS Prevention Project
Montefiore Medical Center
MOSAICA
Multicultural AIDS Coalition
National Alliance of State and Territorial AIDS Directors (NASTAD)
National Association of People With AIDS (NAPWA)
National Black Leadership Commission on AIDS
National Hemophilia Foundation
National Latino/a Lesbian and Gay and Bisexual and Transgender Organization (LLEGO)
National Organizations Responding to AIDS (NORA)
National Youth Advocacy Coalition
Native Affairs and Development Group (NADG)
Pacific Oaks Medical Group
Prisoners' HIV/AIDS Support Action Network (PASAN)
St. Clare's Hospital
San Francisco AIDS Council
San Francisco AIDS Foundation (SFAF)
Sexual Minority Youth Assistance League (SMYAL)
Society for the Advancement of Women's Health Research (SAWHR)
Southern Colorado AIDS Project
Southwest Medical Associates
Targeted Alliances
Temple Israel
Texas General Land Office
University of California, Los Angeles
University of California, San Diego
University of California, San Francisco
University of Pennsylvania School of Medicine
University of Southern California School of Medicine
Washington Center

Government Agencies

Centers for Disease Control and Prevention (CDC)
Department of Children and Families, Miami/Dade County
Department of Health and Human Services (DHHS)
Department of the Interior (DOI)
Department of State (DOS)
Health Care Financing Administration (HCFA)
Health Resources and Services Administration (HRSA)
Indian Health Service (IHS)

National Institute of Child Health and Human Development (NICHD)
National Institute of Allergy and Infectious Diseases (NIAID)
Office of National AIDS Policy (ONAP)
Office of Representative Nancy Pelosi (D-Calif.)
Office of the Vice President
Substance Abuse and Mental Health Services Administration (SAMHSA)

Media

AIDS/STD News Report
Bay Area Reporter
The Blue Sheet