Presidential Advisory Council on HIV/AIDS
Full Council Meeting

November 16–19, 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.; 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; Michael T. Isbell; Ronald Johnson; Jeremy Landau; Alexandra Mary Levine, M.D.; Steve Lew; Miguel Milanes, M.P.A.; Helen H. Miramontes; Rev. Altagracia Perez; Michael Rankin, M.D.; H. Alexander Robinson; 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, and Todd Summers, Deputy Director. Also present were Paul Bouey, Ph.D., National Native American AIDS Prevention Center; Helene Gayle, M.D., Centers for Disease Control and Prevention (CDC); Matthew Murguia, Office on Minority Health; Jeffrey Koplan, M.D., M.P.H., CDC; David Satcher, M.D., Surgeon General of the United States; and staff members Emily Seymour and Kelly Stewart.

Absent: Nicholas Bollman, Debbie Runions, and Charles Quincy Troupe

Monday, November 16, 1998

Opening and General Council Business

Dr. R. Scott Hitt, Chair, opened the Eleventh Meeting of the Presidential Advisory Council on HIV/AIDS (PACHA) with a review of interim activities and meeting goals. He dedicated the meeting to those living with HIV/AIDS, and especially to Drs. Jonathan Mann and Mary Lou Clements-Mann. He stressed the importance of the Council members' striving to achieve as much as is possible in the short time remaining in the Council's charter, which will end in July 1999, and to focus their efforts on those things that can be achieved. He also reminded the members that they are an advisory group, not a lobbying group. Dr. Hitt complimented the committees on their work but suggested that an effort be made to pare down the number of conference calls. In addition, an excess of letters sent to the White House (six recently on the budget, emergencies in communities of color, needle exchanges, etc.) might have reduced their impact, although some positive results are evident. This year's budget, he said, has the largest increase in AIDS funding in any year, and he thanked Ms. Thurman and Mr. Summers of ONAP for their tireless efforts in bringing about this budget.

Dr. Hitt mentioned that, because of expanded work demands, Nicholas Bollman has announced that he must step down as Chair of the Services Subcommittee. Mr. Bollman was unable to attend the November meeting, but will remain on the Council. Dr. Hitt thanked Mr. Bollman for his services and announced that Regina Aragon and Tom Henderson have agreed to serve as Co-Chairs of the Services Subcommittee.

Dr. Hitt praised the work done by Ms. Fraser-Howze, Mr. Robinson, and Mr. Johnson with the Congressional Black Caucus (CBC), and Ms. Fraser-Howze's arrangement of a town hall meeting sponsored by CBC on HIV/AIDS that was broadcast to a network of African-American churches and colleges nationwide. Dr. Hitt thanked the Council members and Mr. Montoya and the ONAP staff and representatives for their ongoing efforts on behalf of the Council. He then welcomed new White House interns working with ONAP: Ms. Seymour from the University of Pennsylvania and Ms. Stewart from the University of Utah.

Dr. Hitt described the role of Executive Director of ONAP on behalf of the Council, which has expanded over the past year. Much time and effort are put into contacting agencies and groups to apprise them of the role of the Council and to make them aware of the Council's recommendations. Mr. Montoya briefly described his responsibilities, stating that he is the designated Federal official, and as such, he oversees the Federal law that affects the Council's activities and makes certain that the information the Council agrees to support reaches the correct Government agencies. As Executive Director, he is the liaison with the NIH Office of AIDS Research (OAR) and provides feedback from the Council on various Government projects.

Dr. Hitt stated that the primary focus of this meeting was to be strategic planning for the period through the end of PACHA's charter (July 1999), with an emphasis on points to be brought up at the White House meeting with President William J. Clinton scheduled for December 18, 1998. This meeting should focus on items that could be accomplished by the end of this Administration (January 2001).

Dr. Hitt asked Council members to review the strategic plan. The Council must organize its efforts and focus to ensure that the plan will be accomplished. To present more than six items at the meeting with the President would be counterproductive. The Executive Committee will finalize the wording of the questions listed below and determine who can best present them. Mr. Montoya suggested that all the questions be worded to fall in the categories of research, prevention, or service.

1. CBC has brought attention to the state of emergency in the black, Latino, and other communities of color. How can the community follow up in all populations at risk?

2. What does CDC plan to do about AIDS prevention? There is little concrete information except that Federal funding for any needle-exchange program is prohibited.

3. Early intervention is vital. More services must be available earlier. What can be done to speed up Medicaid waivers for the States?

4. What is being done to get more funding for AIDS into the Federal budget?

5. What can be done for HIV/AIDS worldwide? What is the policy of the U.S. State Department? Is there a place for community input?

6. What can the Food and Drug Administration (FDA) and OAR do to improve work on a vaccine or a microbicide?

There are other very important issues—getting prevention measures and treatment available in prisons and reaching youth in danger—but all cannot be brought up.

Dr. Hitt reviewed the agenda for the meeting, noting that there would be a full Council presentation on the disparities in HIV/AIDS in health programs for Native Americans, Alaska Natives, and Native Hawaiians. Dr. Satcher and Dr. Koplan are scheduled to address the Council, and he noted that both want to help in this "severe and ongoing" health care crisis. The recent election outcome bodes well for getting appropriations for these purposes. It is important to know how and where the new funds will be spent. HIV/AIDS prevention is receiving the most attention, but needle exchange, specifically, is not a politically acceptable prevention method. Neither the White House nor Congress is very responsive to it, although sound data show that it does prevent the spread of disease.

Update on Activities of the Office of National AIDS Policy

Ms. Thurman, Director of ONAP, thanked Council members for their support and their useful materials in support of common interests. She stressed the importance of the Council's staying focused on deliverable issues, but not to the point where other issues get lost.

The major issues include the following:

1. What role will the Council urge CDC to take?

2. How will the funds in the FY 1999 and FY 2000 budgets be allocated?

3. How should the State Department support the worldwide attack on AIDS?

4. What should be the focus of the Council's December meeting with President Clinton? How can the hot political issue of needle exchange be included?

5. How can the delivery of services to various communities be promoted? How can Hispanics, Native Americans, Hawaiians, and other minorities at risk be reached?

The CBC initiative was introduced on October 26. On October 28, the President declared a "severe and ongoing health care crisis" of HIV and AIDS in the African-American and other minority communities, and announced a $156 million initiative to target this problem. The question is, How will these funds be spent? The agencies and Congress must be convinced that

HIV/AIDS is not a medical problem that affects only gay white men, but a disease with wide social and political implications.

Ms. Thurman acknowledged the tremendous support and assistance of Ms. Fraser-Howze, Representatives Maxine Waters, Louis Stokes, Nancy Pelosi, and John Porter; Senator Arlen Spector; Secretary Donna Shalala; Deputy Secretary Kevin Thurm; Dr. Koplan; and Dr. Eric Goosby in making this initiative happen.

Vice President Al Gore is extremely interested in the HIV/AIDS crisis. He and Ms. Thurman have met with African-American ministers and with members of the National Association for the Advancement of Colored People (NAACP) and the Southern Christian Leadership Conference (SCLC) to get the issues on their agendas. At the insistence of Vice President Gore, Ms. Thurman will meet with African-American ministers in Atlanta to continue the dialogue. The Hispanic community and other minority communities feel they are not fully represented; however, it was noted that CBC took the lead in this effort and was lobbying for help for the African-American *and* other communities of color. The Council will have to work more closely with the Congressional Hispanic Caucus on these issues in the future. President Clinton’s announcement on the CBC initiative indicated his support, and his recognition of Council member Denise Stokes as a person living with HIV/AIDS helped put a face on the statistics.

Needle Exchange. The issue of needle exchange is politically provocative. The Federal appropriations bill for the District of Columbia specifically states that no Federal funds can go to an agency that is using any funds for needle exchange, thereby putting some 100 agencies at risk. Timing is bad for supporting needle exchange; both needle exchange and drug use have been tied to gun use, and the foes of drug use have co-opted the issue. The Administration supports the rationale behind needle exchange and its value in prevention of disease, but there will be a real fight to educate Members of Congress. There is serious concern that insofar as reauthorization of the Ryan White CARE Act is concerned, those in Congress opposed to needle exchange will insist that its ban be included in the reauthorization bill.

Dr. Rankin noted that needle exchange gets some people into drug treatment, and as such it appeals to some more conservative groups, including the military. Rabbi Edelheit suggested that the best way to approach the needle-exchange issue might be to include it as one measure in all preventive programs instead of letting the issue stand on its own.

Federal FY 1999 Budget. The FY 1999 budget has about $500 million in new funds for HIV/AIDS prevention, treatment, research, and services. However, it is spread over a number of programs. With respect to the Housing Opportunities for People With AIDS (HOPWA) increase, the housing appropriations bill contained an increase of only $11 million. An additional $10 million was received through the Department of Labor-Department of Health and Human Services (DHHS) appropriations process. The Office of Minority Health within DHHS gets about $8 million. What makes the budget confusing, however, is that funding was earmarked for HIV/AIDS without new funds’ being added. It is hard to find more than $102 million of the funds claimed by CBC to have been appropriated. Funding for international efforts against HIV/AIDS was increased by $5 million.

Mr. Anderson noted that the total figure appropriated by Congress was more than requested by the President. Ms. Thurman explained that the requested increase was the largest ever, but that if everything had been included, Congress might have cut other items the President wanted. Politically, it was better to leave some leeway for Congress to add funding for special activities.

ONAP will work with the Office of Management and Budget (OMB) on all line items in the FY 2000 budget that affect AIDS prevention, primary care, and support of patients. Prevention funding has been emphasized in the budget, with a targeted focus on spending, particularly getting people of color into HIV testing facilities so that they know their status. ONAP is looking for better ways of integrating sexually transmitted disease (STD), HIV, and maternal-fetal health programs. Additional funds are being sought for the Substance Abuse and Mental Health Services Administration (SAMHSA) for drug treatment and prevention, with increases in block grants and a better delineation of how funds are being spent.

Ms. Thurman spent 2 days in Boston at meetings that focused on care for minority groups. Emphasis at the meeting was on prevention and testing and on integrating them with maternal and child care. Funding has been cut; it was argued that since AIDS deaths are down, less funding is needed. This policy disregards the costs of supporting those living with the disease.

Mr. Summers suggested that the various agencies that received, or are targeted to receive, new funds supply information to the Council about how these funds are being used.

Youth Programs. The December 1996 Executive Order gave DHHS the responsibility to oversee youth programs. World AIDS Day is a program that came out of this Executive Order. The Council should attempt to determine what is being done in all the programs under this Executive Order and whether it can make recommendations. For example, the Selective Service mailing to all males 17 years of age now includes information about AIDS prevention. The Council should look into what can be done to reach females in this age group. Vice President Gore, an outspoken advocate of AIDS prevention and care, will address the problems of reaching youths at risk for HIV/AIDS and housing for those living with AIDS.

Vaccines. Ms. Thurman noted that there has been some progress but not as much as one would like. Dr. Neal Nathanson, OAR Director, is working with an interagency task force to advance vaccine development. Meetings will commence in the near future and will be rotated through the various responsible agencies, which should help in moving vaccine development forward. Building of the new Vaccine Center is progressing, and the work of the Center is continuing under the direction of Dr. Nathanson and Dr. Anthony Fauci, National Institute of Allergy and Infectious Diseases. Search for a director of the Vaccine Center is continuing. President Clinton and Vice President Gore are both interested in vaccine development. Dr. Robert Gallo, University of Maryland, recently announced that an AIDS vaccine will be available within 4 years. Ms. Thurman said that in her opinion this projection is extremely optimistic.

Prisons. Working with the Bureau of Prisons on AIDS prevention is frustrating. Mr. Summers recently met with representatives from the Health Care Financing Administration (HCFA), Health Resources and Services Administration (HRSA), U.S. Department of Justice, and Bureau of Prisons to examine the complicated issues involved. For example, although there is a network of medical care for those who are released from prison and require treatment, people who are in "halfway house" programs are not eligible for other Federal funds because they are considered wards of the Federal Government. The programs are voluntary, and prisoners must sign a waiver stating that they will be self-sufficient. The Bureau of Prisons is obligated to give them only a 30-day supply of medication. Mr. Summers noted that a recent bill, Correctional Officer Health and Safety Act, House Resolution 2070, will change the mandatory testing of prisoners for HIV/AIDS from the time of leaving prison to the time of entering prison for prisoners receiving sentences of 6 months or more. Additionally, there is a requirement that the results of the studies be confidential and that care and services be given. He stressed the need for confidentiality of testing results for those in custody as well as those in the general community.

International Issues. For the first time, the National Security Council (NSC) staff now includes a health care specialist, Dr. Kenneth Bernard of DHHS.

India: The Human AIDS meeting to discuss HIV and AIDS is scheduled for December 1998. A meeting was recently convened in Washington with officials from India and included representatives from the World Bank and DHHS to discuss the issues and how the entities can more effectively coordinate and communicate their efforts. The World Bank has arranged a loan of $200 million for HIV/AIDS control.

South Africa: Technical assistance is needed to address the problem of HIV/AIDS. At the suggestion of Vice President Gore, Mr. Thabo Mbeki, Deputy President of South Africa, will work with ONAP. Representatives from HRSA and DHHS will be sent to South Africa to work with the AIDS program to develop technical assistance programs for HIV/AIDS. A coalition from the AFL-CIO was established to work with South African trade unions in training their members. Industry representatives are to work with the new Business Council on HIV/AIDS to determine what kind of leadership role they want to take.

Uganda, Rwanda, and Kenya: Work continues in these countries, and international financial support is increasing. A delegation will be sent to those countries in early 1999. Considering the current opposition in Congress to any foreign aid, it may be necessary to separate the needs and go after them individually, specifically, the case of AIDS orphans—by the year 2010, there will be nearly 40 million AIDS orphans worldwide. Ms. Thurman noted that there should be support from some conservative Members of Congress to fund programs for children.

AIDS as a Human Rights Issue. The Carter Center recently held a conference on religion and AIDS. The disease increasingly seems to be concentrated on the poor, children, women, and people of color, but it affects everyone. It is important that the Council work with organizations that traditionally work for human rights and ensure that HIV/AIDS is on their agenda and that their issues are on the Council's agenda.

Mr. Hattoy asked if anything could be done to put pressure on the Immigration and Naturalization Service (INS) to eliminate its discrimination against persons with AIDS. Mr. Fogel noted that the State Department was developing a new global AIDS strategy and asked why DHHS and NIH were not offering their cooperation. Ms. Thurman conceded that there had been a lack of cooperation in the past, but this situation seems to be improving. The State Department was slow to distribute its plans, and other agencies had little time to contribute their input.

Where Do We Go From Here? Getting recognition of an AIDS epidemic was the easy part of an ongoing crusade, said Ms. Thurman. Progress will be slower now, but it is important to continue until prevention, treatment, and care are available to all people. She stressed the point that the Council and the country must support the Patients' Bill of Rights, managed care for all persons with HIV/AIDS, the Jeffords-Kennedy bill, which enables those who lose their jobs to keep health benefits, and privacy bills to protect those who are tested for HIV. The Council not only must raise these issues but also must be aggressive to get action on them.

Mr. Robinson noted that the CBC initiative broadened the discussion of HIV/AIDS and suggested that the DHHS Office of Minority Health be included in this effort. The energy level should not be allowed to slow down.

Mr. Henderson commented that the Council's Executive Committee meeting with President Clinton must be more than a photo opportunity, that the Committee must make good use of the meeting. Ms. Thurman assured Council members that the meeting will include all senior staff, and that they will be thoroughly briefed on the issues. It is important to script the meeting to reach the issues.

Ms. Aragon expressed concern that a number of local needle-exchange programs are under attack and are in urgent need of funding. Even though Federal funds are not available, the President and Secretary have said that they support the scientific rationale behind needle exchange. It will therefore be important for the Administration to provide such information to health officials locally in a way that would be helpful, not harmful, to local exchange programs. Ms. Aragon urged the Administration to ask local exchange providers what would be most helpful to them.

Ms. Billings applauded the CBC initiative as a model for AIDS advocacy and questioned what the Council could do now to help Latinos and other at-risk communities. Ms. Thurman noted that Asian Americans, Latinos, and Native Americans have all voiced support of the CBC initiative. Mr. Lew voiced some concerns about the use of the new funds and asked whether strategic plans are in place for their use. How will communities with lower AIDS incidence be reached? How can cultural barriers be breached?

Mr. Montoya said that since members of ONAP would not be able to attend all the committee meetings, it was very important to provide minutes that indicate which issues are most important to the Council.

Mr. Schatz commented that the Council does not always make the best use of its time. He asked whether the Council could do anything to get ONAP a larger support staff. Ms. Thurman replied that ONAP could use more staff but that various agencies provide help for many of ONAP's activities, including very good support from the senior staff at the White House. Unfortunately, support for AIDS programs is low throughout the Government.

Mr. Robinson reiterated that AIDS prevention had been the first item on the Council's agenda from the very beginning, and it continues to be the first. CDC knows some prevention measures that work, but distribution of this information has been minimal. He asked why the best preventive measures have not yet been spelled out and what the spending priorities should be.

Ms. Thurman closed her presentation with a question for the Council, "Given the current political climate, where do we go from here?"

Subcommittee Meetings

Appropriations Subcommittee: Discussion of the FY 1999 and FY 2000 Budgets.

International Issues Subcommittee: Update on "U.S. International Response to HIV/AIDS." Nancy Carter-Foster and David Wagner, U.S. Department of State, invited participants.

Racial Ethnic Populations Subcommittee: National Minority HIV Plan. Matthew Murguia, Office of Minority Health, invited participant.

People of Color Initiatives. Helene Gayle, CDC, invited participant.

Prevention Subcommittee: Needle-Exchange Issues. Marsha Martin, Ph.D., DHHS, invited participant.

Services Subcommittee: "Housing as an Access to Health Care Issue," presentation. Angela A. Aidala, Ph.D., Joyce Moon Howard, Dr.Ph., M.H., and Robert Sember, M.A., Columbia University School of Public Health, invited participants.

"Massachusetts State Medicaid Waiver Planning Process," presentation. Robert Greenwald, Boston AIDS Action Committee; Annette Hanson, M.D., Massachusetts Division of Medical Assistance; and Jeanne McGuire, Massachusetts State AIDS Director, invited participants.

Tuesday, November 17, 1998

Disparities in HIV/AIDS Health Programs for American Indians, Alaska Natives, and Native Hawaiians

Charles Blackwell opened the session by thanking Council members for the opportunity to devote a portion of the meeting to the disparities in HIV/AIDS health programs for American Indians, Alaska Natives, and Native Hawaiians. Mr. Blackwell taught English on the Navaho reservation, received his law degree from the University of New Mexico (UNM), and served on the UNM faculty as Associate Dean of the Law School for 5 years. He has been working in Washington, D.C., for 15 years, 10 of those as the Chickasaw Nation Ambassador to the United States. As the Director of Pushmataha House, he represents 19 tribes in their Washington affairs. He went on to describe the sovereign status of the American Indian tribes: All have, by treaty or Executive Order or Supreme Court decision, rights under the Federal trust relationship as domestic sovereign nations. The American Indian population is approximately 2.1 million. The primary concern of the

Council regarding HIV/AIDS, he said, covers Indian people who are members of federally recognized tribes; however, a large segment of the Native American population—e.g., Hawaiians and Pacific Islanders—are not members of federally recognized domestic sovereign governments, and many are members of State-recognized tribes, as in North Carolina. These groups are no less Native American.

The focus of this meeting, he said, is on deliverables and staying within the Council's Strategic Plan. Mr. Blackwell referred members to the March CDC *Morbidity and Mortality Weekly Report.* The report focused on American Indians, stating that 1,783 cases of AIDS were reported and verified in the American Indian/Alaska Native population. These data reflect only federally recognized tribes—the exact number of American Indians and Alaska Natives infected with HIV/AIDS is not known. The report shows data from 25 States on HIV infection, but no data from the States of Alaska, California, New Mexico, and Washington, all of which have large populations of American Indians and Alaska Natives. Available AIDS data reflect cases dating to 10 years ago. More than half of the American Indian/Alaska Native cases were reported in 5 States: California, 25 percent; Oklahoma, 11 percent; Washington, 7 percent; Arizona, 6 percent, and Alaska, 4 percent. Of the States for which data were available, the following was reported: (1) Native adolescents made up 5.2 percent of HIV cases versus less than 1 percent of the AIDS cases, and (2) 11 percent fewer men are infected from sex with men and 5 percent more people infected from heterosexual intercourse. According to National Center for Health Statistics mortality data, AIDS is the 8th leading cause of death for American Indian and Alaska Native males 10 to 14 years of age, the 10th leading cause for those 15 to 24 years of age, the 5th leading cause for those 25 to 34 years of age, and the 8th leading cause for those 35 to 44 years of age. With respect to the female population, AIDS is the 8th leading cause of death for women 25 to 34 years of age and for infants 1 to 4 years of age. The last seroprevalence survey was conducted from 1989 to 1991 and published in the June 1992 issue of the *Journal on AIDS*.

The American Indian, Alaska Native, and Native Hawaiian communities need the help and support of the Council. It is imperative to ensure that prevention resources are available to these populations through CDC. The disease surveillance system for these groups is less reliable than it was 5 years ago. There is a critical lack of surrogate marker data to help target limited resources in prevention. Misreporting of race and ethnicity is another serious problem. No standardized disease reporting for race and ethnicity exists across all States. Lack of attention to the need for improved disease surveillance for Native populations by CDC suggests that, regardless of the real picture, resources will remain minimal and probably decline for HIV prevention.

The situation has been made more serious by the restructuring and decline of Indian Health Service (IHS) services to a majority of the Indian population and the increased use of PL-93638, the Indian Self-Determination and Education Assistance Act. The IHS is underfunded and in decline, and has not been in tune with the people that it serves.

PL-93638 enables tribes as governments to contract with the Federal Government for their share of the budget to provide services for themselves. They can take the money that the Federal Government spends on those services (i.e., education and health services) and administer those services themselves. Mr. Blackwell commented that, after this process occurs, IHS is not giving information out and not informing tribes about such matters as HIV/AIDS. The Indian population needs the help of PACHA to urge the IHS and CDC to address this problem. IHS, as the primary agency to provide health services to Indians, does not as a policy matter, unless the funds are available, cover the cost of the new AIDS drugs that are available to American Indians and Alaska Natives who are dependent on IHS or tribal health systems for medical care. There is no budget request for this funding. It is a matter of finance and priorities. Congress has made funds available to the States to cover the cost of these drugs through the AIDS Drug Assistance Program (ADAP); Native America, however, was not included in ADAP. Mr. Blackwell quoted the Director of IHS, Dr. Miguel Trujillo, who, in an article in *American Indian Report,* said: “There is no cure for AIDS, and its prevention, ultimately, is an individual responsibility. An unlimited amount of funds for AIDS treatment will, unfortunately, not save a life. Healthy behaviors are what will save our tribes and communities.”

Congress has made provisions in the Ryan White CARE Act for Native American care resources in its Special Projects of National Significance (SPNS) program. The program has a ceiling of $25 million, of which only $1.25 million goes to Native Americans. Mr. Blackwell implored PACHA to work to have the ceiling lifted on the SPNS program and set aside a portion to be directed to Native American AIDS care programs. He referred Council members to the handout listing members of the Congressional Native American Caucus.

Paul Bouey, Ph.D., Director of Research and Surveillance, National Native American AIDS Prevention Center, the longest-standing national organization on American Indian HIV/AIDS issues, then addressed the Council. Focusing on surveillance and statistics, he noted first that the issue of numbers underlies every decision in the health sector as well as in the PACHA Strategic Plan. Numbers are fundamental to discussing CDC policies, to expanding access, to increasing appropriations, and to increasing research. Dr. Bouey stressed three domains in the discussion: denominator, misclassification, and data reporting.

Denominator. This term refers to the U.S. Bureau of the Census and the issue of “who is Indian,” which has become an increasingly complicated problem for American Indians, Alaska Natives, and other groups. The major issue is the increase in the number of American Indians documented, which is attributed to decreases in mortality rates and increases in fertility rates. But what must be considered also is the changing number of federally recognized tribes and the fact that many tribes have changed the criteria by which tribal membership is determined. Mixed ancestry has increased dramatically as well. People have to self-report on the U.S. Census, and the issue then becomes who is attributed as head of household—mother or father—and other demographic issues. At one time American Indians would not identify themselves as such, but in recent years it has become acceptable to identify with marginal populations. The issue of mixed ancestry will continue, and it is estimated that sometime in the next century the proportion of the Indian population that is half to full blood will be less than 8 percent.

Misclassification. A tremendous amount of underreporting occurs. Misclassification applies to fertility, mortality, and morbidity data. According to the literature, individuals filling out census forms do not ask for racial or ethnic identity but make assumptions by observation or by surnames. A cooperative study by CDC and IHS examined racial misclassification of American Indians in Oklahoma pertaining to STD surveillance. Researchers took 1995 State of Oklahoma STD surveillance data and compared them with the IHS User Registry. The findings showed that many of those registered on the State list were not found on the IHS list and that many who self-reported to the State as American Indian were not on the IHS list. Another marker used to determine status as an American Indian was blood quantum, the percentage of Indian blood.

Data Reporting. The problems of data reporting are more serious than misclassification. Two categories are available for understanding such problems—tribal and nontribal. In tribal communities, the issue is not misclassification but a failure to report data either because of insufficient time or resources or as a result of tribal sovereignty. Tribes have a relationship with the Federal Government but not the States. Numbers are not being reported. A recent needs-assessment meeting revealed that two-thirds of tribal communities do not report HIV/AIDS data to the State or to CDC. Regarding nontribal communities, including urban Indian clinics, misclassification is not an issue, but getting good data to the State or CDC is a problem.

Dr. Bouey suggested recommendations for consideration by the Council in each category.

Denominator: The issue has been evident for decades and still has not been resolved. Discussion must continue.

Misclassification: A national standard of classification of race/ethnicity should be promoted, and States should not be given the freedom to develop their own systems. Self-reporting should be promoted. Training should be instituted in the new system.

Reporting: HIV reporting should be promoted in all 50 States. A collaborative team made up of CDC, IHS, and representatives from tribes, States, and local jurisdictions should be instituted to look at States where reporting is working, develop a reporting model, and then implement it in States that do not have a good system.

Following through on these recommendations will involve tremendous cost and time, but the cost of doing nothing will only further the disparities. In reviewing its Strategic Plan, the Council must examine the issue of surveillance.

Discussion ensued, raising the following considerations:

- The IHS has no contact with urban health clinics.

- Sixty percent of the American Indian population is urban; of the total IHS budget, only $25 million goes to 60 percent of the American Indian population, which is less than 2 percent of total IHS funding.

- Tribes see themselves as governmental entities and are reluctant to report to the States.

- The IHS Utilization List does not include all Indians in a given State, and not all Indians use IHS clinics.

Daniel C. Simpson, a Choctaw from Oklahoma, Director of HIV/AIDS Services and AIDS Program Coordinator, IHS, spoke next, offering to respond to PACHA recommendations relating to IHS.

Mr. Simpson referred Council members to the IHS Certificate of Degree of Indian Blood, which is the ticket for health care for Indians. Different tribes require different blood quantums for health care; e.g., the Choctaw require that a person be one-half Indian to receive health care services from the tribe. Regardless of the degree of Indian blood, IHS must abide by the criterion set by each tribe. Mr. Simpson stated that the identification card is for health care, land, education, social services, and in some instances resources. If a person does not meet the criterion for health care and other services of a particular tribe, that person is still recognized as part of the tribe.

Of 543 Indian direct care delivery service units, IHS has 146 facilities and tribally run facilities number 397. Urban programs have 34 facilities. Urban programs advocate for their funds through Title V provisions and get 100 percent of funds appropriated. IHS provided antiretroviral drugs through a memorandum of understanding with CDC until about 1993. After that time, no funds existed to maintain the warehouse for drug storage. Currently, IHS is contracting with the U.S. Department of Veterans Affairs for its drugs, with Indian tribes negotiating with the VA for drugs at cost.

Tribes are becoming more involved in their health programs, and they must be recognized and included in mailings of grant proposals, invitations to HIV/AIDS meetings, and recognition by States, agencies, and programs as sovereign nations capable of providing health care to those with HIV/AIDS. IHS does not provide prevention and health care to all 557 federally recognized Indian tribes. Approximately one-third of tribes run their own hospitals and clinics.

Regarding entitlement issues, Indians often are not recognized as eligible for health care. They have been automatically denied health care by other providers outside of IHS or tribal health programs because of the commonly held belief that IHS provides all services to all Indians. A concerted effort by IHS, tribes, urban programs, other American Indian/Alaska Native organizations, and Government agencies is needed to resolve these discrepancies and overcome this misperception.

IHS data as of December 1997 on AIDS cases show a cumulative total for American Indian/Alaska Natives of 1,783 cases, of which 544 are HIV cases. Of the 1,783 cases, IHS provides services to only 400; of the 544 HIV cases, it provides services to only 350. The remaining receive care from tribal health care programs, urban programs, Medicare, Medicaid, private insurance, and other sources.

Discussion ensued, resulting in the following points:

- IHS clinics provide primary care and prevention services through doctors, nurses, social workers, outreach workers, public health nurses, and other providers.

- Current data do not reflect the use of combination therapy, antiretroviral drugs, or reference to Federal Standards of Care.

- Regarding increased health care services for American Indians under the Ryan White CARE Act, Mr. Simpson will meet with Dr. Joseph O'Neil, Associate Administrator for AIDS, HRSA, to discuss issues, including what has not been done about IHS services and inclusion of American Indians/Alaska Natives in the language of the Ryan White CARE Act programs.

- IHS provides the majority of health services to larger facilities serving this population (37 hospitals, 46 health stations). Tribal operations include 12 hospitals and 233 health stations. Within the next few years, the larger IHS hospitals and the funds involved will go to the tribes.

- Appropriations need to include funding for rehabilitation of hospitals and clinics.

Council Recommendations Addressing American Indian/Alaska Native Issues

II.P.5. Direct the Director of the Indian Health Service (IHS) to develop a comprehensive AIDS prevention and care plan for Indian country (within 90 days) with the input from consumers of IHS services.

The Council requests:

V.P.1. That the President instruct the Secretary of Health and Human Services to reassess the legislative intent of the reauthorized Ryan White CARE Act regarding needs of the Native American community to ensure appropriate support for Native American care, infrastructure development, and coordination on a national level.

V.P.2. That the Secretary of Health and Human Services instruct the Director of IHS to demonstrate within 90 days the adequacy of HIV prevention, care, and treatment, including access to needed drugs, for American Indians and Alaska Natives living on or near reservations. This should include documentation of needs assessments completed, barriers and gaps identified, and proposed solutions. It should also include a discussion of how IHS plans to work with the private nonprofit sector to improve AIDS-related services.

V.P.3. That the Secretary of Health and Human Services instruct the Director of IHS to develop case management oversight guidelines which are appropriately oriented to the specific needs of Native American people with HIV/AIDS and assure the provision of health care and in a safe and culturally appropriate manner.

Update on HIV/AIDS Racial and Ethnic Disparities in Health
Dr. David Satcher, Assistant Secretary of Health and Surgeon General of the United States, U.S. Department of Health and Human Services

Dr. Satcher's presentation centered on three areas of concern: Healthy People 2010, the initiative to eliminate disparities in health, and the HIV/AIDS initiative.

In 1979 Dr. Julius Richmond, Assistant Secretary of Health and Surgeon General of the United States during President Jimmy Carter's administration, issued the Surgeon General's Report "Health Promotion and Disease Prevention," which initiated the Healthy People 1990 objectives. In the late 1980s, the Healthy People 2000 Report was released. More than 60 percent of the Healthy People 2000 objectives have been achieved (e.g., decrease in teenage pregnancy); however, certain objectives have yielded no data, and data on other objectives show that the Public Health Service (PHS) is not making the progress anticipated (e.g., lessening of childhood and adult obesity).

The PHS is in the process of finalizing the plan for Healthy People 2010, which has two major goals: (1) to increase the quality and years of healthy life, and (2) to eliminate disparities in health among different racial and ethnic groups. The current plan includes 500 draft objectives and 26 areas of objectives. Health communication, PHS infrastructure, and disabilities, with HIV/AIDS included as a disability, are new areas of objectives. A community health system has been designed that should allow these objectives to be realized. Dr. Satcher asked Council members to review the objectives and participate in the regional meetings being scheduled.

The initiative to eliminate disparities in health will focus on six areas: the HIV/AIDS epidemic, immunization for both children and adults, infant mortality, cardiovascular diseases, cancer, and diabetes. President Clinton asked for an $80 million budget including $30 million to fund communities to develop model programs, but Congress appropriated only $65 million in the FY 1999 budget, primarily in CDC and HRSA. Only $10 million was appropriated for development of the model community programs. Two types of programs will be funded in FY 1999: some community model programs and some community developmental programs. Dr. Satcher hopes that the HIV/AIDS initiative can be the model program for closing gaps and eliminating disparities.

The Surgeon General referred to President Clinton's October 28 declaration that HIV/AIDS in racial and ethnic minority communities represents a severe and ongoing health crisis. While overall AIDS deaths have declined, AIDS remains the leading killer of African-American men between the ages of 25 and 44 and the second cause of death for African-American women. Eighty percent of new cases occur in African-American and Hispanic women. The PHS plans to unveil a series of initiatives that will invest the $156 million earmarked to address this problem. The Administration intends to outline a comprehensive initiative that includes unprecedented efforts to improve the Nation's health in preventing and treating HIV/AIDS in minority communities. This problem will be addressed in three areas: new prevention efforts, improved access to treatment, and training of health professionals. Strategies for implementation include the following:

- Send crisis response teams—physicians, nurses, epidemiologists, and others—to highly affected areas to assess existing prevention and treatment services and develop new strategies.

- Fund enhanced HIV/AIDS prevention programs in racial and ethnic minority communities, primarily as grants for minority community-based organizations to work with local communities, to make testing and counseling available, and to develop educational programs, community workshops, prevention programs, and treatment programs for African-American and Hispanic women and men at high risk.

- Reduce disparities in treatment and health outcomes for minorities with HIV/AIDS and the problem of access to care and treatment.

- Fund the education of health care providers. CDC started the distance learning (through satellite technology) programs to introduce to health care workers in the field new guidelines for immunization and AZT treatment to reduce maternal-child spread of HIV.

Communication has been enhanced with the advent of satellite downlinks providing access to 30,000 to 40,000 doctors and nurses. A $262 million increase has been seen in the Ryan White CARE Act, which provides primary HIV health care services, treatment, and training for health care professionals on the guidelines. The treatment funds include a more than 60 percent increase for the AIDS drug-assistance program for those who cannot afford the cost of HIV/AIDS drugs. NIH has received a 12 percent increase for HIV/AIDS research.

Dr. Satcher mentioned the programs that were not approved by Congress, namely, the Patients' Bill of Rights and the Jeffords-Kennedy bill to allow people with disabilities to buy into Medicaid and Medicare. These initiatives must be pushed forward at the community level.

The ensuing discussion included the following exchanges:

1. *How does the Administration intend to implement the Race and Health initiative on a broad scale and, in particular, the new funding approved as part of the CBC initiative? How will your Office work with ONAP and within DHHS to implement these initiatives?*

Of the $156 million, $50 million is emergency funding. The PHS must present Congress with specific strategies for using the funds. Whether Congress provides these funds in the future depends on how the funds are used and the projected need for funds. The hope is that funding will be ongoing through the regular budget and that out of the funds model programs for reducing disparities will be developed.

Two-thirds of the $156 million is new funding; the remaining is money set aside by DHHS, e.g., $15 million to HRSA for community health centers to work with the HIV/AIDS strategy. Programs at CDC will work with funds set aside from other sources.

A steering committee has been proposed that will work with the Surgeon General and a representative from ONAP, meeting regularly to review strategies.

2. *What is the Office of the Surgeon General's strategy toward prevention?*
How do you as Surgeon General reconcile the decision by this Administration on the Federal ban on funding needle-exchange programs, and what are your plans to move forward on this issue, especially as it limits prevention of HIV infection?

CDC will take on a special initiative to address the HIV prevention needs of youth, a campaign to promote a wider use of HIV testing and to promote individual knowledge of serostatus, and a more aggressive phase of public accountability regarding leadership in the HIV community. The CDC initiative relates to improving strategies for prevention. CDC will be working with other agencies and looking at what is needed in communities. CDC will have a large portion of the emergency funds to use to improve prevention strategies.

CDC and other agencies looked at several studies on needle exchange, concluding that needle-exchange programs conducted appropriately in the context of community prevention strategies with access to treatment could significantly reduce the spread of HIV, and that no evidence exists that these programs increase the use of drugs. However, it is believed that the Federal Government's funding of needle-exchange programs might send the wrong message to young people, particularly if little or no funding for prevention and treatment of drug abuse was included. The Surgeon General's Office wants to be supportive of local community needle-exchange programs, although Federal funds cannot be used.

3. *As Surgeon General, what do you see as your role in advocating for and using your position to both educate and promote implementation of the PHS standards of care and treatment for HIV/AIDS?*

The Surgeon General's responsibility is clear in terms of the need to communicate clearly with the American people and to educate them. In terms of the standards of care, however, programs must interact with providers on the front line. The Surgeon General's Office must make sure that providers know what the standard of care is and that the Office is pursuing that standard. The Surgeon General's Office also must work with providers to break down the barriers to access.

Education is somewhat broader than the Surgeon General's role, and the Assistant Secretary for Health should be working with the agencies to ensure that quality programs exist to inform, motivate, and mobilize people with respect to guidelines for quality health care.

4. *As Assistant Secretary of Health, what role do you plan to play in ensuring that HCFA does all in its power to determine how to expand Medicaid coverage and to aid the States in applying for and receiving approval of Medicaid 1115 waivers to expand access to early intervention therapies and care?*

DHHS takes its relationship with HCFA seriously and is serious about implementing a broad base for public health, which includes universal access to care, and the role of HCFA. Regarding the Medicaid waivers, the Federal Government is willing to work with States in developing programs in which persons with HIV/AIDS can be covered through Medicaid waivers, but much of the work is at the State level.

Dr. Hitt noted that one of the big problems is that a person must be disabled to receive Medicaid coverage. Some barriers originate at DHHS; for example, at the policy level general pronouncements have been made and general direction given, but the message has not been communicated to those who have the responsibility to determine what should be done.

5. *Is there a mechanism in place to document implementation of a standard of care for HIV health care in Federal prisons, since anecdotal evidence shows otherwise? Do you intend to use your position to encourage State and local prison officials to follow the standards of care for inmates and the transition of ex-offenders to health care providers?*

CDC works with the American Association of Correction Facilities in the areas of HIV/AIDS, tuberculosis, and violence prevention in the prisons. Dr. Kenneth Moritsugu, Deputy Surgeon General, has worked with the Federal prisons and has knowledge of the prison system. His background should help in addressing the many problems relating to health care in prisons.

The Federal prison system has an exemplary program for education, testing, and access to treatment for persons with HIV/AIDS. Major problems exist in prevention, namely, the lack of needle exchange and distribution of condoms. Problems are seen also in following up treatment for prisoners once they are discharged into the community. CDC and HRSA are being asked to coordinate case management of persons in prison and followup care with their transition into the community.

6. *What has been done to follow up on the CBC's People of Color Initiative with other communities?*

The People of Color Initiative has not worked very well for certain minority populations. DHHS is attempting to define the appropriate strategy, part of which will be the crisis response team. A balanced team will be sent into communities requesting assistance to examine the barriers to receiving prevention messages, to testing, and to accessing care. A better job must be done in targeting other resources to communities that are disproportionately affected. CDC is working to assist communities who have the need and commitment but lack the infrastructure to be competitive in attracting grants.

7. *What can be done to strengthen the levels of coordination needed among the many groups working on prevention? What will be done to increase ONAP's and Dr. Goosby's staffs?*

Dr. Satcher will look into the possibility of detailing representatives from CDC, SAMHSA, HRSA, and NIH to ONAP to fulfill its mandate. DHHS is committed to promoting global health and to working with the World Health Organization and the State Department in this effort.

Focus for the Centers of Disease Control and Prevention

Jeffrey Koplan, M.D., M.P.H.

Before Dr. Koplan met with the Council, members discussed the questions they would pose as well as what they hoped Dr. Koplan would gain from this meeting with the Council, specifically realization of their level of frustration with the national prevention strategy and their lack of confidence in the Administration's prevention plan.

Dr. Koplan is working with senior staff at CDC in setting priorities for the agency. The four broad cross-cutting areas that have been established as priorities provide a cohesive, coherent nature to the work of CDC:

- Strengthening science for public health action. Science is what drives public health action, and gaining new knowledge is crucial to this end.

- Collaborating with health care partners, particularly for prevention: private health care providers, organized medicine, business, HCFA, and Medicare/Medicaid. Examples of this priority are reducing racial and ethnic disparities in HIV/AIDS and integrating HIV prevention and treatment programs. CDC can do only so much from a population-based perspective. Much that needs to be done requires coordination with health care providers and other partners.

- Promoting healthy living at every stage in life, broadened to target key health concerns at youth, adolescents, adults, and older adults.

- Broadening CDC's role in international health.

Regarding the role of CDC in the HIV/AIDS arena, Dr. Koplan responded to questions posed by Council members.

1. *What is your vision for how we can reverse the historical failures of our prevention efforts? What principles will guide your efforts in leading the Nation's HIV prevention strategy? Will we move beyond the self-reported behavior surveys and connect prevention efforts with objectives?*

Prevention programs are the appropriate approach with HIV/AIDS and other diseases. CDC's role is to make a case on a scientific basis for what can be done by taking advantage of data from studies, experiences in the field, and literature reviews to demonstrate what will work.

The Administrator cannot set policy for the CDC but can present the case from scientific, public health, and social perspectives. Myriad scientific information will be required to sway public and political opinion. (Tobacco as a health problem is an example of an issue in which the scientific data were available but little public will existed to effect change. The combination of scientific data with public relations, activists groups, and other influences moved public opinion, which in turn moved political opinion.) The questions now concern what measures are still needed to sway opinion and how quickly can they be implemented.

2. *What has been done to follow up the CBC's People of Color Initiative with other communities?*

CDC will expand the groups and community directions, which will allow greater opportunity to reach more groups. Dr. Gayle responded to this question by stating that it is understood that the epidemic is disproportionately affecting some groups, but it is important that information disbursed to communities be relevant to all groups. Efforts will be expanded in the Hispanic/Latino community.

3. *What can be done to strengthen the levels of coordination needed among the many groups working on prevention issues? What will be done to increase ONAP's and Dr. Goosby's staffs?*

CDC will work with agency representatives at the highest levels to ensure that IHS, NIH, and HRSA do what is needed to strengthen coordination among the groups working in the prevention arena. Regarding the need for increased staff in Washington, D.C., Dr. Koplan suggested that the focus be on what is not taking place that needs to take place and what could be done better, and then determine how to best achieve the goals.

4. *CDC's recently issued guidance indicates that States now will be held accountable for documenting that their resources are targeting the epidemic in their jurisdictions. Under community planning, CDC has been reluctant in the past to play a heavy role in directing those resources. What will CDC be doing differently to ensure accountability and enforcement of the new guidance?*

Outcome accountability—e.g., reduction in incidence—determines whether a program continues to receive funding. Many steps in the process take place before outcome is measured. Before outcome accountability can be determined, agreement must be reached on what is to be measured.

CDC is receiving two messages: from communities, the message is "give us the money, and leave us alone"; from agencies, the message is "measure it and do not give funds unless the communities are accountable for the outcomes."

Responding to Dr. Koplan, Mr. Isbell commented that it is CDC's accountability that is in question. At the community planning level, in many cases CDC is largely absent in terms of leadership. CDC has a public health responsibility to ensure that planning bodies that are making decisions about how funds are allocated benefit from CDC leadership. There was some agreement within the group that giving communities funds without leadership does not work. Dr. Gayle responded that CDC needs outside groups such as PACHA to make recommendations. Dr. Hitt commented that PACHA has worked hard to develop consensus recommendations and that CDC should review and evaluate those recommendations.

5. *How will CDC publicly account for the 40 percent of CDC HIV resources in terms of tracking the epidemiology and other aspects of this epidemic*?

Dr. Gayle stated that some of those funds go directly to community-based organizations, and these groups produce good data on targeted populations. Some funds go to State and local health departments for surveillance for tracking the epidemic overall, and some go to school health programs. No funds are not accounted for—some funds are not targeted but go to the general population.

Mr. Schatz commented that the guidelines passed in 1991 by CDC have resulted in many health care workers' losing their jobs. The CDC guidelines have been used recently in court cases to justify discrimination against HIV-infected health care workers. Dr. Gayle has been working to resolve this issue. Dr. Koplan concurred that he is willing to support Dr. Gayle in her efforts and that he will look into the issues posed by Mr. Schatz.

6. *What emphasis will CDC place on primary versus secondary prevention efforts in HIV/AIDS?*

CDC's major concern is primary prevention. Dr. Gayle commented that the interface between prevention and treatment is not clear and that a better job of interfacing prevention with treatment needs to be done. It is important to focus on persons who are HIV positive in order to get them care, but much needs to be done for those already infected with AIDS and to support their prevention needs.

7. *What can be done to get increased funding for CDC in HIV prevention?*

CDC must justify what it does as a public health program that delivers results that the public wants to support. Budget appropriation requests are based on demonstrated results and likely impact if a message is disseminated.

Subcommittee Meetings

Prevention Subcommittee: Discussion on HIV/AIDS Prevention Issues. Helene Gayle, CDC, invited participant.

Services Subcommittee: Update and Discussion on Ryan White CARE Act Reauthorization. Terje Anderson, HRSA Advisory Committee; David Harvey and Miguelina Maldonado, National Organizations Responding to AIDS; John Palenicek, HRSA; and Daphne Long Rankin, National Association of AIDS Education Training Centers, invited participants.

Update on HRSA/Title IV Programs and Focus on Youth. Wayne Saucedo, HRSA, invited participant.

Racial Ethnic Populations Subcommittee: HIV/AIDS Data Policy. Olivia Carter-Pokras, Office of Minority Health, invited participant.

Wednesday, November 18, 1998

Subcommittee Meetings

Racial Ethnic Populations Subcommittee: Update on Healthy People 2000/2010. Deborah Maiese, DHHS, invited participant.

Prison Issues Subcommittee: Overview/Briefing of Prison Site Visit Agenda and National Prisons Meeting. Todd Summers, ONAP, invited participant.

Services Subcommittee: Future Leadership on Access to Care and Treatment Issues. David Beier, Chief Domestic Policy Advisor to the Vice President; Kathy King, HCFA; Marsha Martin, Ph.D., DHHS; Steve Schondelmeyer, Ph.D., University of Minnesota; and Todd Summers, ONAP, invited participants.

Subcommittee meeting in the afternoon focused on HIV Cost Services and Utilization Study, Transition to Co-Chair Model for Subcommittee and Division of Responsibilities, and Review and Update of Subcommittee Workplan.

Research Subcommittee: Update and Discussion on Microbicide Development Recommendations. Penelope J. Hitchcock, D.V.M., and Zeda Rosenberg, Ph.D., National Institute of Allergy and Infectious Diseases, NIH, invited participants.

Thursday, November 19, 1998

Representatives from AIDS Action and the Human Rights Campaign (HRC) were invited to attend this last day’s session. New substantive ideas and a stronger action plan are coming out of the Council, and Dr. Hitt felt that these groups, because they are an integral part of how PACHA deals with the Administration, should be made aware of the Council’s agenda.

Overview of the Strategic Plan

Subcommittee Reports

Racial Ethnic Populations: Reverend Perez reported that the subcommittee revisited the PACHA Strategic Work Plan and came to a consensus that the plan as it stands is appropriate. She pointed out that the following recommendations still need to be implemented and should be addressed at the meeting with President Clinton.

> Instruct the Secretary of Health and Human Services to declare that the rates of HIV infection, compounded by the disparate health outcomes for people with HIV disease in communities of color, constitute a national public health emergency requiring targeted initiatives and additional resources.
>
> Convene a meeting with key civil rights, social justice, youth, and children's advocates as well as health care leaders in communities of color to encourage a communitywide effort to respond to the HIV/AIDS public health emergency.
>
> Meet with the Congressional Black and Hispanic Caucuses to develop a strategy to respond to the urgent HIV prevention and HIV/AIDS health care needs of these communities.

Recommendation 1, Subcommittee Strategic Work Plan. Despite the community's efforts, the President's announcement, and extra funding, these do not comprise an adequate response to the present situation in minority communities. There is a sense, voiced by one Council member, that the President is getting more press for something that he did not do directly, and that most of the funds contributed to the initiative were already in the budget. Ms. Thurman responded that $100 million is new money. Dr. Hitt noted that the Council has a perception that Congress is doing most of the work and the Administration and DHHS are not involved in appropriations, which is not the case. It was noted that the highest priority of the Council is to ensure that racial and ethnic populations in the pandemic do not get overlooked. Also, it is important that the nature of the crisis not be diminished.

Dr. Hitt added that he does not believe that the Council's goal of having the Administration declare the current pandemic a "state of emergency" will be realized. Ms. Fraser-Howze responded that the CBC was still asking for a "state of emergency," regardless of the lack of support earlier from either the Administration or the AIDS community. Had the CBC's request for a state of emergency been granted, 98 percent of its requests would have been granted. A state of emergency allows certain legal events to happen on an emergency basis in the short term, for instance, a limited needle-exchange program. A state of emergency would have permitted movement outside the law; needle exchange could not be overturned by Congress. It becomes the responsibility of the President and the Secretary of DHHS to end the death and destruction immediately.

Responding to concerns that one meeting with the CBC is not sufficient because the issues are ongoing, Ms. Thurman assured the Council that the President has met with both the CBC and the

Congressional Hispanic Caucus and that he meets with the caucuses frequently. Ms. Gutierrez commented that HIV prevention strategy has not been discussed in a comprehensive way by the Hispanic Caucus because it has not been actively involved in this area. Mr. Robinson said that the CBC, although supportive, came forward on this issue because some individuals asked them to. He stressed that declaration of a state of emergency remains the Racial Ethnic Populations Subcommittee's top priority and that it must be the top agenda item at the meeting with the Administration. Ms. Thurman, however, rejoined that the first recommendation as worded, "[the President would] instruct the Secretary of HHS to declare a state of emergency," is not realistic because the system does not work that way. Information is funneled to the President from the Cabinet Secretaries, and it is the Surgeon General's and Secretary's responsibility to make recommendations to the President. Ms. Thurman suggested rewording the recommendation to "the community continues to be very concerned that we have not declared a state of emergency; would he ask the Secretary to report to him on why we have not done so."

Recommendation 2, Interim National Minority HIV Report. At a recent meeting, the National Minority HIV Working Group, composed of veteran and current providers, put together recommendations that direct agencies how to improve services for minorities in their particular systems. Every minority group was represented at the meeting, suggesting a possible consensus. The recommendations have not yet been approved, however, because DHHS wants the working group to review the document and verify that it matches the CBC initiative and other minority goals. The subcommittee will write a letter to Secretary Shalala asking that she support the efforts of the working group and discuss concerns about timing and implementation. Some of the recommendations submitted by the working group are not new but have been on DHHS's agenda for up to 10 years. These will be highlighted in the letter to Secretary Shalala. (Dr. Hitt suggested to the Council members that any letters generated by subcommittees should be reviewed by the Executive Committee. If approved, they can go out under the subcommittee signatures; if altered to include other information, then full Council approval is needed.)

Recommendation 3, CDC's People of Color Initiative. CDC intends to contract with consultants to assess the current programs and their responsiveness to the changing needs of communities of color. The subcommittee in its meeting formulated two responses to this decision to be incorporated in the letter to the Secretary (mentioned above), which will be copied to the various agencies and to Dr. Koplan. The responses are as follows:

> Since the PACHA meeting in Atlanta, the subcommittee was informed that the People of Color Initiative would be responded to, which they interpreted to mean that it would be funded, but it is now an internal assessment. The subcommittee requests CDC's plan for the use of its findings in responding to the state of emergency in communities of color.
>
> The subcommittee would like the dates of the meetings with leaders from the Hispanic, Asian Pacific Islander, and Native American communities.

At the end of the discussion of the Racial Ethnic Populations Subcommittee report, Ms. Fraser-Howze described how the CBC and the conferees produced the CBC HIV/AIDS FY 1999 Appropriations Conference Report Proposal. She distributed to the members the final report language and the Declaration of a National "State of Emergency."

Recommendation 4, HIV/AIDS Data Policy. A report from the Office of Minority Health (Dr. Olivia Carter-Pokras) states that an expanded minimum data set developed by the DHHS Data Council will allow more specific information to be collected on communities of color. Different agencies use different data sets, and the expanded set will provide one data set for all DHHS agencies to use and thereby establish the consistency needed to cross-match the data sets. The recommendations to be included in the letter to Secretary Shalala will be (1) that the DHHS request more specific ethnic/nationality information from more sources, (2) that the impact of undercounting be ameliorated by improved sampling, and (3) that the classification of poor populations and racial ethnic populations living in poor communities be distinguished so that data can be better interpreted. There is concern that $8 million of Office of Minority Health resources has been mistakenly omitted in the final legislation.

Recommendation 5, Disparities in HIV/AIDS Health Programs for American Indians, Alaska Natives, and Native Hawaiians. The subcommittee will include in the letter to the Secretary a request that the resolutions submitted by the Services Subcommittee be addressed more thoroughly and that the Council be apprised of the implementation of the resolutions.

Recommendation 6, Healthy People 2000/2010. The draft plan is out in hard copy, on CD ROM, and on the Internet. The Council has been asked to review it, including those areas that are connected to HIV but are not specific to HIV. The program goal for the years 2000 to 2010 was changed from reducing disparities to eliminating disparities; the sole exception is HIV/AIDS. This exception poses a problem in the message going to communities—allowing disparities to continue insofar as HIV is concerned.

Dr. Hitt asked Jeff Jacobs from AIDS Action and Seth Kilbourn from HRC whether their organizations are doing anything from a grassroots perspective to address this concern. They replied that they were not aware of the Healthy People 2000/2010 issue but would address this problem. It was suggested that all Council members, national organizations, and grassroots organizations make it known that they find this discrepancy unacceptable. The subcommittee will draft a paragraph addressing that concern to be included in the letter to Secretary Shalala.

Regarding the discrepancies in the Healthy People report, Rabbi Edelheit commented that if in the next 10 years a person does not fit in the categories on the scale determined by the CDC, then that person will not be accounted for in the data. Dr. Hitt will draft a followup letter to Dr. Satcher highlighting some of the issues discussed during this meeting. Ms. Thurman suggested that the Council draft a letter to the large national organizations asking them to review these initiatives and respond to the issues. This is an opportunity for the Council to reach out to the community and work together to ensure that everyone is addressing these much larger issues. Mr. Robinson stated that he was outraged by the statement in the report that implied “it was [all right] for African-American men to have the highest rate of HIV infection” and asked Ms. Thurman to discuss this with people at the White House. She responded that the report is sending out a mixed message—on the one hand saying that HIV services must be integrated into the continuum of health care delivery and on the other that the Nation will accept HIV.

A representative from CDC responded to the group’s concerns. When Healthy People 2000 came out, agencies were asked to confirm that they would meet its objectives; most of the objectives were not met. With the Healthy People 2010 initiative, CDC attempted to be more realistic in its goals. The data show that 98.5 percent of the epidemic is among white, African-American, and Hispanic persons, and these data were used to set targets. She suggested that the Council send the message to CDC that it needs to be "the best of the best," but reminded them that representatives from SAMHSA, HRSA, the Office of Minority Health, and the Office of Women's Health as well as community groups were also involved. Dr. Hitt stated that ONAP should have been involved in the process and that this issue would be brought out during the December meeting with President Clinton.

Mr. Milanes addressed the Council. He came to the meeting, he said, with high hopes that the needs of the Hispanic community would be addressed. He felt that he was leaving the meeting not knowing what would happen next or who would take the lead. The African-American community has some organization that is a catalyst for action. He voiced concern that this type of organization does not exist in the Hispanic community, and that unless a recognizable entity such as CDC takes the lead to address the Hispanic community's needs, they will be no further ahead a year from now. Ms. Fraser-Howze responded that the CBC would be meeting with the Congressional Hispanic Caucus and the Native American Caucus next week, and they will request a meeting with President Clinton. They are developing an agenda for congressional action asking for a tripling of the $156 million in funding.

Ms. Fraser-Howze distributed a report entitled "HIV/AIDS and Public Health, African Americans in Crisis, A National State of Emergency" and gave a brief overview of how the initiatives were developed. She thanked Ms. Thurman for the last-minute work to get the White House to agree to present funding for the initiative at the final negotiation meeting.

Appropriations Subcommittee. Ms. Aragon noted that the Appropriations Subcommittee is focusing on the President's FY 1999 and FY 2000 budgets. Three issues arose during their meeting regarding the FY 1999 budget:

> Request from the Administration clarification on the CBC initiative, specifically, the $46 million that is from other sources within DHHS.
>
> The Administration is committed to bringing to Congress the details of how the $50 million of emergency funding will be spent among the various agencies.
>
> Keep track of the $8 million in the Office of Minority Health, in that the Administration requested that it be included as a technical amendment.

The subcommittee will also track the Prevention Subcommittee's recommendation that ONAP be given funding to develop a national testing campaign.

For FY 2000, the overarching concern voiced during the meeting is that the momentum of the FY 1999 appropriations bill in terms of funding and the emphasis on targeted funding to communities of color be maintained. The President's FY 2000 budget must address all HIV/AIDS issues, testing, global health funding, and access to treatment and other services.

Services Subcommittee. As Co-Chair of the Services Subcommittee, Ms. Aragon presented the subcommittee's report. Because of time constraints, she referred Council members to the subcommittee's written report and proceeded with a brief overview of its findings.

Regarding housing as an access to health care issue, recent study findings show that housing is a health care issue that is critical to stabilizing people's lives and encouraging access to and maintenance of treatment. A joint SPNS program from HRSA and the Department of Housing and Urban Development is also being evaluated, and the initial results will be available for reauthorization of the Ryan White CARE Act.

The Massachusetts Medicaid Waiver Planning Process involving cooperation among State public health officials and the advocacy community enabled the development of a 1115 waiver proposal that will be submitted to HCFA before the end of 1998. Two important findings came out of the process:

> The cost differential between a full benefits package and a partial package is 17 percent.
>
> The benefits package could be cost-neutral if it used a 10-year timeframe, if drugs were discounted an additional 10 percent, or if Supplemental Security Income (SSI) or SSI Disability savings were included.

Ms. Aragon noted that although HCFA says the agency encourages State applications, State representatives do not see it that way. Dr. Hitt commented that short of drug-pricing changes, 1115 waivers are the best hope of getting access to care. Mr. Henderson responded that action at the State level is important but the drug-pricing issue is most important. If something is not done about drug pricing, the objective of cost neutrality and access to drug treatment cannot be attained. States are able to move some people to managed care, which allows increased flexibility.

Work is being done on reauthorization of the Ryan White CARE Act, which will not take place until FY 2000. National groups are attempting to identify issues, policy or legislative, to come up with a community consensus. HRSA also is engaged in a detailed planning process to identify issues. HRSA Title IV programs fund the Adolescent Initiative under the Ryan White CARE Act. Funding for youth programs totals $1.9 million, and the Administration hopes to double the funding and the number of programs within the next year.

The issues of leadership and expanding access to care and treatment were discussed by a diverse panel of representatives from the Administration and the University of Minnesota. Pricing of HIV/AIDS drugs, cost-neutral intervention care, expanding coverage, and leadership from the President and Vice President were discussed in terms of access to care.

An update on the Jeffords-Kennedy Work Incentives Improvement Act was given by Connie Garner from Senator Edward Kennedy's office. The goal of the bill is to reduce the disincentives for people with disabilities to enter and stay in the labor force, such as losing Medicaid coverage and SSI/SSDI benefits. A demonstration project in the bill will allow States to create Medicaid "buy-in programs."

The subcommittee discussed the meeting with President Clinton and how to address the issue of Medicaid expansion and drug pricing.

Prevention Subcommittee. Mr. Robinson recounted the subcommittee meeting with Dr. Marsha Martin of DHHS, stating that she recommended that the Administration needed a national strategy for HIV. She did not have an answer when asked how it would differ from the former national strategy; however, she did say that the national strategy is a significant document and is more a national statement of what the Government's response will be. The issue of needle exchange was also discussed. The subcommittee's recommendation is that DHHS provide the Council and the White House (and copy to ONAP) with an executive summary of the scientific research on needle exchange, specifically addressing the Canadian study.

Dr. Hitt explained the importance of being proactive and going into communities explaining what the science is (e.g., on needle exchange) and promoting the science through programs such as rapid response teams. Ms. Thurman responded, saying that legislation is pending to ban Federal funding for any form of treatment for any program that either directly or indirectly supports needle exchange. Dr. Hitt believes there is little likelihood that the bill as written would pass the House of Representatives, but concern was voiced by others that it could pass. The only data in the field at this time are data supplied by General Barry R. McCaffrey, Director of the Office of National Drug Control Policy (ONDCP). The Administration needs to be proactive about promoting the science, and communities need information they can use to convince legislators of the validity of a needle-exchange program.

Subcommittee members reviewed their planned priorities and their belief that CDC is making progress in its efforts to effectively monitor the community prevention planning process. On the recommendation for increased resources, the subcommittee will continue to promote more resources for community planning, but additional resources also need to be made available for testing and counseling and evaluation of existing programs. CDC's process of internal assessment of its effectiveness in reaching communities of color is another area to be included in the letter to Secretary Shalala.

Mr. Robinson directed members to the subcommittee's proposed recommendation on testing. The subcommittee is suggesting that the recommendation be revised to read that the ONDCP model now being used for the national youth antidrug media campaign be adopted for a similar campaign to promote national HIV testing and coordinated within ONAP. It is felt that this campaign would offer the President an opportunity to have a highly visible positive HIV/AIDS message. Dr. Hitt voiced concern over whether broad community support would be available and whether barriers would be raised to doing it. Ms. Fraser-Howze stated that much of the campaign should be targeted to communities of color. However, the issues of whether services are available and whether ONAP will have a policy in place to ensure that services are available must be considered. Ms. Gutierrez responded that the Council should not think twice about pushing this issue. Resistance to delivering the right kind of message should also be expected. Another concern is how the proposed testing campaign will interface with the Administration's policy on reporting HIV/AIDS cases.

The final consensus of the Council was to recommend getting out a coordinated message that stresses promoting knowledge of one's HIV serostatus rather than just being tested for HIV; the promotion should be organized through ONAP. The Executive Committee must be proactive in presenting to the President its concerns about access to care and names reporting. Dr. Hitt mentioned drafting a letter to go to advocacy organizations that would stress the importance of their support regarding FY 2010 issues and the above recommendation.

International Issues Subcommittee. Ms. Billings summarized issues discussed by the subcommittee. Why is there flat funding when the epidemic is increasing internationally? It was suggested that a joint letter be sent from Secretary Shalala and Secretary of State Madeleine Albright to the Appropriations Committee pointing out the enormity of the international health crisis and asking for an increase in global AIDS funding. It was hoped that the update to the 1995 U.S. International Strategy on HIV/AIDS would be ready by World AIDS Day, December 1. The State Department did not go through channels, and as a result received little or no response from the agencies involved. The agency took statements from other documents and presented them as a response to the International Strategy. There is much concern about this approach, as it looks like a compendium of programs with little substance being put forth as a strategy. To solve these problems, it was recommended that the Council request that the U.S. International Strategy and the issue of funding be addressed at higher leadership levels within the State Department.

Ms. Thurman recommended that the Council send a letter to Brian Atwood, Administrator of the U.S. Agency for International Development (USAID) and Secretary of State Albright emphasizing the importance of the international situation and asking for additional funding. A letter will be drafted, reviewed by the Executive Committee, and presented to the full Council for approval. Asked whether the subcommittee had discussed the issue of orphaned children, Mr. Fogel responded that the Administration is taking a proactive stance on this issue.

Prison Issues Subcommittee. Mr. Landau mentioned that the subcommittee was scheduled to go on a site visit to Cumberland Prison. Dr. Hitt noted that because of problems the Council has had with the Bureau of Prisons, the scheduled visit will not proceed as originally expected; rather than including interaction with the prisoners and discussion of their problems, the visit will be an interaction with the prison system.

The subcommittee is attempting to set up a meeting with the director of the Federal Bureau of Prisons, Dr. Kathleen Hawk Sawyer. Dr. Gayle stated earlier that the CDC agreement with the Bureau of Prisons on testing is moving forward and that intervention models are being set up in six States and the District of Columbia. A tentative date for the national meeting on prisons is scheduled for March 11, 1999. Discussion will focus on standards of care, prevention, substance abuse, case management, and compassionate release. The subcommittee is planning to invite Dr. Sawyer as the main speaker. The subcommittee is waiting for a response from ONAP on the March Council meeting date to ensure that there is no conflict between these two events.

Mr. Summers has been convening an interagency meeting to review discharge procedures. The Bureau of Prisons offers a voluntary transition period through transitional facilities for prisoners who are being discharged into the community. Prisoners are given a 30-day supply of medication while in these facilities; however, they are often kept in these facilities for up to 90 days, and no other agency assumes responsibility for providing medication during the period after the initial 30 days. Voluntary consent, compliance, and the potential that these individuals will end up in the community with treatment-resistant HIV need to be addressed and should be included in discussion with President Clinton on inadequate access to care. It was noted that the number of persons involved is quite small.

Research Subcommittee. A paper presenting the subcommittee's recommendations on microbicides was distributed to Council members. Ms. Greenberger commented that the six recommendations listed are the culmination of 3 years of work by the subcommittee. Representatives from NIH and FDA have thoroughly reviewed these recommendations, and it is the impression of the subcommittee that a consensus exists and that the recommendations touch on areas that need to be addressed. It was noted that current annual expenditures for microbicide research are at $25 million.

The Research Subcommittee recommendations were voted on by the Council and unanimously approved as presented.

General Business and Closing

Dr. Hitt mentioned that organizations are sending letters to the Administration with a list of recommendations that include those discussed above as well as others and are requesting that the Council sign on to the letters. The consensus of the Executive Committee is that members as individuals may sign on if they wish; the Council as a unit would agree to sign on only if members have the opportunity to thoroughly review the recommendations and vote on them.
Dr. Levine said that the Research Subcommittee will convene at the next PACHA meeting to discuss the list of recommendations.

When the letter to Secretary Shalala is completed, it will be circulated to the Executive Committee and the full Council, and if approved, the letter will be mailed out. Subcommittee contributions to the letter must be received at ONAP by December 1 in order for Mr. Montoya to coordinate this effort and circulate a draft for review and finalizing by the Council Executive Committee. The issues to be addressed in the letter will include the HIV minority health plan, data issues, Healthy People 2010, IHS recommendations, and an executive summary on needle exchange.

Dr. Hitt reminded members that only five short (2-day) meetings remain for the Council; the goals have been set, and no time is available for new issues to be considered. Some subcommittees or key subcommittee people may be brought to Washington, D.C., once during the year to meet with other organizations to move the Council goals forward as quickly as possible. Conference calls, he said, are to be limited to two calls between now and the March meeting. Members were asked to inform Dr. Hitt when their two conference calls are to take place and to inform Mr. Montoya which dates are best for them for the March meeting and who will not attend the meeting with President Clinton. Mr. Montoya reminded members that Social & Scientific Systems was handling travel logistics for the December meeting and that travel requirements must be in no later than December 1.

Regarding the meeting with President Clinton, Dr. Hitt cautioned that the timeframe will probably be only about half an hour and that it is important that the group remain focused. Also, it is imperative that the Council prepare a background memorandum for the President that is hard hitting and that preempts any anticipated arguments against a given issue. The memorandum will state what is **not** being done, which will allow the President to question whether he is being well advised. Issues to be addressed in the memorandum will include the FY 2000 budget (microbicides, international funding, etc.), people of color and youth initiatives, prevention, access to care including drug pricing, and vaccines. Dr. Hitt will request an interim meeting with the Chief of Staff to discuss the memorandum before sending it to the President. Ms. Thurman suggested that the memorandum be sent to the President on December 13, which will allow him time to review it during his return flight from Israel. Council members will meet the day before the meeting with President Clinton.

Dr. Hitt thanked Council members, Mr. Montoya, Ms. Thurman and the ONAP staff, the conference staff, and guests for their participation. The meeting was adjourned at 12:00.