Presidential Advisory Council on HIV/AIDS
Full Council Meeting

March 19-21, 2000

Radisson Barcelo Hotel
Washington, DC

MINUTES

Present:

Ronald V. Dellums, Chair
Terje Anderson
Regina Aragón
Ignatius Bau
Judith Billings, J.D.
Charles Blackwell, J.D.
Stephen L. Boswell, M.D.
Stuart Burden
Phillip P. Burgess, R.Ph.
Lynne M. Cooper, D.Min.
Joseph A. Cristina
Cynthia Gomez, Ph.D.
Thomas Patrick Healy
Michael T. Isbell, J.D.
Ronald S. Johnson
Alexandra Mary Levine, M.D.
Steve Lew
Caya Lewis
Miguel Milanes, M.P.A.
Brent Tucker Minor
Helen H. Miramontes, M.S.N.
John A. Perez
Valerie Reyes-Jimenez
Victoria L. Sharp, M.D.
Denise Stokes

Present from ONAP:

Sandra Thurman, Director
Matthew Murguia
Daniel Montoya, Executive Director, PACHA
Renuka Kher

Absent:

Ingrid M. Duran
Rabbi Joseph A. Edelheit
Debra Fraser-Howze
Robert Hattoy
Michael Rankin, M.D., M.P.H.

Monday, March 20, 2000
Morning General Council Session

Sandra Thurman opened the Fifteenth Meeting of the Presidential Advisory Council on HIV/AIDS (PACHA) by introducing the new chair, Ronald Dellums. She provided a brief overview of Mr.

Dellums' professional accomplishments, noting that he served as a Member of Congress for 30 years. Mr. Dellums thanked Ms. Thurman and welcomed Council members. He said he would approach his duties as Council Chair with pride and humility, and stated that AIDS should not be treated in a vacuum; treatment should address all aspects of human life. Council members then introduced themselves, stating their names and affiliations.

Daniel Montoya, Executive Director, PACHA
and
Sandra Thurman, Director,
Office of National AIDS Policy (ONAP)

Update on Interim Activities

Daniel Montoya read a letter from Vice President Gore welcoming and thanking new and returning Council members for their advocacy of HIV/AIDS issues. The letter offered congratulations to Mr. Dellums on his appointment as Council Chair. Mr. Montoya also spoke about the death of Council member Tom Henderson on December 22, 1999. He said that Mr. Henderson had been integral to the Council's work and a true friend to many Council members. Mr. Montoya said he would enter Mr. Henderson's obituary into the public record so that "people will not forget that even those sitting around this table are still dying from HIV and AIDS."

Ms. Thurman again welcomed Mr. Dellums and said his chairmanship would provide the Council with "an entrance into the halls of power." She noted that Mr. Dellums recently published a memoir, titled *Lying Down With Lions*, and encouraged Council members to read it. Ms. Thurman also recognized the service and leadership of former Council Chair Dr. Scott Hitt, who retired from the Council at the end of 1999. She welcomed new Council members and thanked the ONAP staff for their work. She noted that Dr. May Kennedy from the Centers for Disease Control and Prevention (CDC) and consultant Michael Iskowitz had joined ONAP in recent months.

Ms. Thurman also noted that Todd Summers had left his position as deputy director of ONAP. She recognized Mr. Summers for his service, and told Council members that the deputy director position is vacant and may not be filled by the end of the year. In the interim, Matthew Murguia has taken on many of Mr. Summers' former responsibilities.

Ms. Thurman provided an update of activities in the following priority areas since the Council's last meeting in October 1999.

Minority AIDS Initiative: At the October meeting, the Council called for a state of emergency in the African American and Hispanic communities to address HIV/AIDS. Since that time, ONAP has worked with the Congressional Black Caucus (CBC) to secure $250 million in Fiscal Year (FY) 2000 for the Minority AIDS Initiative. The President has requested $274 million for FY 2001. Ms. Thurman

called this a good increase, though ONAP would like to see more funds requested. ONAP will continue to work with CBC and the Congressional Hispanic Caucus as the budget process proceeds.

Ms. Thurman said it is important to ensure that programs arising from the Minority AIDS Initiative create a continuum of care and achieve maximum impact. She added that ONAP is working to retrofit all programs within the Department of Health and Human Services (DHHS) to include service to traditionally disenfranchised populations. Both President Clinton and Vice President Gore have spoken publicly about the initiative, and it continues to receive "buy-in" from the media. In addition, the Surgeon General has established the Leadership Campaign on AIDS to reach out to minority communities.

CDC's Prevention Programs: ONAP has been working closely with CDC to promote testing and youth initiatives and to develop ways to link prevention funds to health care delivery. CDC has commissioned an Institute of Medicine (IoM) study to evaluate Federal HIV/AIDS prevention services. As prevention funding increases, there is a concern that Federal prevention programs are not reaching the appropriate target populations. The IoM study is being conducted on an "accelerated" basis.

CDC's "Know Your Status" Campaign: The campaign is still a work in progress but appears to be moving forward. ONAP continues to meet with CDC to get the campaign off the ground.

Youth Report: The report will be released this spring; draft copies are available for Council members. Either the President or the Vice President will announce the release of the report. The report outlines the status of the HIV/AIDS epidemic among young people in the United States, and it examines challenges and strategies to address prevention in youth populations. A preliminary youth report was released in 1995; the new report updates relevant statistics from the 1995 version.

Medicaid Access to Care/Funding for Early Intervention: DHHS Secretary Donna Shalala announced the approval of the Maine Medicaid waiver in February. ONAP will continue to work with additional States to facilitate the approval of waivers; a waiver for Massachusetts is pending. ONAP will also continue to work with the Health Care Financing Administration (HCFA) to expand Medicaid.

Appropriations: Ms. Thurman called the recent appropriations season the best ONAP has ever had. Congress approved a $125 million increase for Ryan White CARE programs, a $65 million increase for CDC programs, a $87 million increase for National Institutes of Health (NIH) programs, a $28 million increase in Housing Opportunities for People With AIDS (HOPWA) funding, and a $100 million increase for international AIDS programs.

International Activities: Since the Council's last meeting, the President requested an additional $100 million for international HIV/AIDS programs. The new funding expands Federal HIV/AIDS activities to include the Department of Defense and the Department of Labor. In addition, the Vice President spoke at a January meeting of the United Nations Security Council, which addressed security and economic

development concerns related to HIV/AIDS. As a result of that meeting, the President asked Ms. Thurman and National Security Advisor Sandy Berger to co-chair a working group to determine how ONAP can engage additional Federal agencies to combat AIDS in new ways. This process will examine the role of agencies such as the National Economic Council, the National Security Council, the Department of State, the Department of Defense, and the U.S. Agency for International Development (USAID). Ms. Thurman said the working group will submit its recommendations to the President in late March or early April. The recommendations will be shared with Council members.

Prevention Methods for Women: Ms. Thurman noted that the movement to develop microbicides has drawn increased attention in recent months. She said she met with Congressman Richard Gephardt and UNAIDS Director Peter Piot to discuss efforts to market microbicides once they become commercially available. The group decided to approach cosmetic companies and advertising firms to enlist their help in making microbicides more appealing and user-friendly. A meeting with marketing firms is tentatively scheduled for June.

Miscellaneous Items: Since the Council's October meeting, the Jeffords-Kennedy bill was enacted. ONAP has continued to work with staff at the White House Initiative on Asian Americans and Pacific Islanders and the President's "One America" initiative to include HIV/AIDS in their agendas. The Patients' Bill of Rights is still pending in Congress; the White House is heavily engaged in advocating for this legislation.

The President's Millennium Vaccine Initiative was recently announced; it proposes a $1 billion tax credit for pharmaceutical companies that produce vaccines for HIV, malaria, tuberculosis, and other infectious diseases that affect the developing world. In February, the President met with chief executive officers of major pharmaceutical companies, the president of the World Bank, the director of the World Health Organization, the director of UNICEF, the head of the Gates Foundation, DHHS Secretary Shalala, the Surgeon General, and others to discuss the initiative. The meeting was chaired by the Treasury Secretary and the President's Advisor on Economic Policy.

Questions/Comments: Helen Miramontes suggested that Ms. Thurman include Nancy Padian, a researcher at the University of California-San Francisco, in any discussions about marketing of microbicides. Dr. Padian has conducted several studies on cultural issues affecting acceptability of microbicides in Harare, Zimbabwe, in collaboration with the University of Zimbabwe. Ms. Thurman said ONAP's discussions with advertising and cosmetic companies would address methods of marketing in different cultures as well as how to market microbicides to men.

Ms. Miramontes also asked if any concrete recommendations or "next steps" emerged from the vaccines initiative meeting at the White House. Ms. Thurman said vaccine manufacturers agreed to donate large amounts of vaccine to developing nations, and the Department of the Treasury is currently working with pharmaceutical companies to reach an agreement on the tax credit proposal. She said the President is committed to the issue, and an agreement is expected within the next few weeks. A vaccine

for tuberculosis would be particularly helpful because more than half of AIDS-related deaths in Africa are due to tuberculosis.

Mr. Dellums stated that the vaccine issue is too important to be left solely to the private sector. He asked Ms. Thurman to talk about federally funded vaccine research. Ms. Thurman reported that the Government has allocated more than $200 million to NIH for AIDS vaccine research. She noted that NIH is comfortable with that funding level; the Vaccine Research Center at NIH was dedicated last summer.

Dr. Alexandra Levine noted that better coordination of vaccine research is needed among Federal agencies such as CDC and the Department of Defense. Ms. Thurman said every Federal agency involved in vaccine research was represented at the White House meeting, and it is becoming clearer to the key players that coordination is critical. Ms. Miramontes said the case for improved Federal coordination needs to made to the President and Vice President. Ms. Thurman said the President and Secretary Shalala are aware of the issue.

Steve Lew asked for more information on the Maine Medicaid waiver and who is eligible under the waiver. Mr. Montoya said Tim Westmoreland would provide a detailed update on the Maine waiver later in the meeting.

Michael Isbell asked for clarification on CDC's various strategic planning processes. He stressed that a single national prevention strategy is needed and asked how the planning processes fit together. Ms. Thurman confirmed that DHHS is drafting a 5-year strategic plan for prevention. The CDC strategic plan needs to be integrated into the overall DHHS plan; they are parallel processes. She said the delay in finalizing the DHHS plan may be due to the difficulty of incorporating the CDC piece. Ms. Thurman spoke with Kevin Thurm at DHHS on March 16. He assured her the process is moving forward.

Mr. Dellums reported that, during a March 15 meeting, Secretary Shalala promised ONAP staff and Mr. Dellums that a draft strategic plan would be released to the Council within a week or two.

Ms. Isbell asked about the proposed elements of the "Know Your Status" Campaign. Ms. Thurman said she would let the speakers from CDC address that issue later in the meeting. She said it is "unconscionable" that CDC has not produced a work product after 2 years of discussion about launching the Campaign; this is why an IoM study is needed. Ms. Thurman has met with Mr. Thurm at DHHS and Drs. Helene Gayle and Jeffrey Koplan at CDC to discuss the Campaign, but no details have been forthcoming.

Mr. Isbell said the failure to launch a national prevention strategy after 8 years shows a lack of leadership from Secretary Shalala.

Regina Aragón asked for an update on the proposed guidelines for HIV-positive health care workers.

She noted that one of the Council's first recommendations called for the Administration to take a scientific look at this issue and end discrimination against HIV-positive health care workers. At the October 1999 Council meeting, Secretary Shalala and Dr. Eric Goosby of DHHS stated that new guidelines would be released within weeks; the release is still pending.

Ms. Aragón also asked for an update on DHHS's efforts to disseminate new scientific information on the efficacy of needle exchange. She noted that, on March 17, the Administration responded to a 6-month-old request from Congresswoman Nancy Pelosi for an update on the science, but added that this response is not adequate. The Administration needs to look at how to disseminate the scientific findings to health care practitioners and elected officials at the local level.

Regarding the health care worker guidelines, Ms. Thurman said the White House continues to get the same response from DHHS: the guidelines are still in clearance. She said she has been assured again that the guidelines are forthcoming, but no one at DHHS can give her a date for release. She said she shares the Council's frustration on this issue.

Ms. Thurman confirmed that DHHS released a summary of scientific information on needle exchange on March 17. She said the document appears to be comprehensive but is too long and needs to be distilled for use as an advocacy tool. Ms. Thurman will assign ONAP staff and several Council members to carry out this task in the next 3 to 4 weeks. ONAP will then work with DHHS to determine a plan for distributing the document. Dr. Levine asked for a copy of the 18-page document. Ms. Thurman said she would distribute it to Council members during the meeting.

Caya Lewis asked Ms. Thurman to explain the "Know Your Status" Campaign. She said she had recently received a letter from the CDC about a similar initiative. Ms. Thurman said $10 million in Federal funds had been set aside to target specific populations to encourage them to get tested for HIV. About one-third of all persons with HIV in the United States do not know they are infected, and one-third of those who know they are infected are not in treatment. The challenge is to get people into treatment earlier.

Mr. Dellums commented that he detected a level of cynicism from returning Council members. He said the Council should be mindful of its credibility and should demand that reports due to the Council be submitted in a timely fashion. He added that, during his discussion with Secretary Shalala on March 15, he and the Secretary agreed to meet on a regular basis. He said he will use these meetings to make sure that deadlines are met.

Mr. Montoya clarified that he, Mr. Dellums, Secretary Shalala, Mr. Thurm, Marsha Martin, and other high-level DHHS officials met on March 15 to introduce Mr. Dellums as the new Council chair and to request an update on a list of issues of concern to the Council.

Regina Aragón

Appropriations Overview

Each year, the Council has issued recommendations for Federal funding levels related to HIV/AIDS. Currently, the Council is looking ahead to FY 2001, which starts on October 1, 2000. The Council has and continues to support recommendations for increased funding developed by the National Organizations Responding to AIDS (NORA), a national coalition of AIDS advocacy groups. Each year, NORA looks at each of the major Federal HIV/AIDS programs and identifies how much is needed for prevention and care. Ms. Aragón recommended that Council members read the NORA document for FY 2001, which is included in members' meeting binders.

Ms. Aragón also directed members to look at two letters included in their meeting binders: one from a group of African American advocates and one from a group of Latino advocates. Both letters express support for a substantial increase in funding for the Minority AIDS Initiative in FY 2001. The initiative is currently funded at $250 million. The AIDS community has recommended an increase to $500 million for next year to address all communities of color.

Ms. Aragón added that a statement from Ms. Thurman responding to the President's budget proposal (issued in February 2000) is included in members' binders, along with several charts providing a breakdown of major Federal AIDS programs, the Minority AIDS Initiative, and global AIDS programs.

Ms. Aragón said the President's recent budget release was much better than budgets submitted in the past. NORA's community need numbers are substantially higher than those in the President's budget, but the President's budget is a first step in a long process. Unfortunately, the leadership of the House of Representatives is pushing for a $24 billion cut in domestic spending. Such a drastic cut would translate to a 10 percent across-the-board cut in all Federal AIDS-related programs.

Ms. Aragón noted that, in the past, Congress has not been able to agree on a budget, so the appropriations process has moved forward without a Federal budget in place. She said the Council is hopeful that a budget will not pass this year. Through conference calls and meetings, the Council hopes to continue to be a strong voice for AIDS appropriations within the Administration. Ms. Aragón noted that Jeanne Lambrew of the Office of Management and Budget (OMB) would be making a presentation during the meeting. She is the OMB staff person responsible for health care spending; the Council will rely on her to advocate for high funding levels.

The President's budget proposes a $24 million increase for the Minority AIDS Initiative, which is much less than what NORA requested. Similarly, the President requested only a fraction of what is needed for the AIDS Drug Assistance Program (ADAP). It is critical that the Council not let ADAP slip through the cracks during the appropriations process. Ms. Aragón encouraged Council members to approach her or Terje Anderson with questions about the process.

Questions/Comments: Dr. Levine asked Ms. Aragón to state the amounts requested for ADAP funding. Ms. Aragón replied that the President requested a $26 million increase, and NORA requested a $130 million increase for ADAP. ADAP is currently funded at $528 million.

Mr. Dellums commented that the issue of HIV/AIDS should not be narrowly defined; it cuts across the entire span of human experience. As the Council approaches the appropriations process, it should talk about AIDS in a broader context (i.e., how the disease impacts housing, education, and other social issues).

Mr. Montoya instructed Council members to nominate new co-chairs during subcommittee meetings. Each subcommittee should nominate one new and one continuing Council member as co-chairs.

Joseph O'Neill
Associate Administrator
HIV/AIDS Bureau, Health Resources and Services Administration (HRSA)

Dr. Joe O'Neill provided an overview of the Ryan White CARE Act reauthorization process. He distributed to Council members HRSA's annual progress report on the CARE Act, a policy paper examining the CARE Act's impact on vulnerable populations, and a copy of a newsletter containing recommendations by the HRSA AIDS Advisory Committee regarding the CARE Act reauthorization process.

Dr. O'Neill said there is a lot of controversy surrounding reauthorization, which has intensified over the last 5 or 10 days. He said HRSA and the Council should approach the process with the idea that there are issues that people of good will can disagree on. It is important that advocates remain flexible and creative and pursue robust conversations around the issues.

HRSA began thinking about reauthorization 2 years ago and met with advocates and the agency's AIDS Advisory Committee to develop some broad themes and concepts to guide the process. The challenge is to take these broad themes and transform them into specific measures that will work.

Dr. O'Neill noted that the CARE Act has been tremendously successful; there are many people who have been well served by it. In any given year, 5,000 people receive CARE Act-supported service. In 1997, minorities received 68 percent of services provided under Title I of the Act. That same year, minorities received 64 percent of Title II services, 60 percent of Title III services, and 81 percent of Title IV services. These numbers indicate that resources are being distributed in the communities where they are most needed. The question is: Can the Government do better? Several aspects of the epidemic have changed over the years: AIDS is increasingly a disease of poverty, there is a need for health care systems to provide patients with the right treatment to sustain life, the advent of managed care has influenced health care economics and the organization of health care delivery, and the public now holds Government agencies accountable for how AIDS resources are allocated.

HRSA's conceptual framework for reauthorization includes the following:

Access: Is HRSA doing all it can to achieve maximum access to care? There are about 200,000 to 250,000 people in the United States who have tested HIV-positive but are not receiving any health care. These people are more likely to be recently infected, poor, and a member of a minority community. The CARE Act has done a phenomenal job of reaching underserved communities, but the AIDS community cannot be complacent.

Potential approaches to achieve better access include fostering collaboration between Federal agencies and grantees to provide technical assistance to determine who is not in care. Two U.S. Inspector General studies on the CARE Act concluded that the majority of Federal grantees do not solicit needs information from those outside of HIV care. HRSA staff have discussed working more closely with grantees and points of access in the health care system (e.g., emergency rooms and substance abuse clinics) to identify people out of care, as well as helping grantees to develop plans to address the out-of-care population. HRSA has not advocated more reporting to the Government or increased top-down intervention. The agency is not married to any particular language and does not want to increase the burden on grantees.

Quality: Once a person living with HIV enters the health care system, what happens to him or her? There is a correlation between a person's race, sex, economic status, and area of residency and the quality of care he or she receives. HRSA is not looking for national quality data or standards; it wants to ensure that clinical providers supported by Ryan White funding have a quality improvement program in place. Quality assurance only works from a bottom-up approach. Care has become much more complex, and quality assurance needs to be a priority.

Capacity-Building: A different kind of partnership is required between the Government and the community to enable the Government to allocate resources for activities that are not currently funded. In many isolated rural or inner city communities, there are missing pieces (i.e., establishing medical information systems, training of nurses or physicians, setting up a dental service) that are inhibiting good service delivery. These types of services are not currently funded under Title I or Title II.

Dr. O'Neill noted that there is little disagreement between the NORA recommendations and the Administration's recommendations for reauthorization. Disagreement comes into play when both sides begin discussing *how* to achieve the recommendations.

Questions and Comments: Dr. Cynthia Gomez said she had recently conducted several studies on access to care among men who have sex with men (MSMs) and injecting drug users in San Francisco and New York. Ninety to 100 percent of participants reported they had access to care for HIV, but 50 percent could not name their health care providers. Dr. Gomez said this result may point to a need for standards for quality that take into account the particular sensitivities surrounding HIV/AIDS.

Dr. O'Neill stated that there are national guidelines that set a standard for care, along with a number of related guidelines on prophylaxis. He said the broader question is how to protect and expand social services; these needs vary widely by community. The quality of the system as a whole also needs to be addressed. Health care professionals need to ask: How well is the system serving the broader community, including those not served by the system ?

Dr. Levine noted that 4,000 to 5,000 HIV-positive patients are seen monthly at the Los Angeles County Hospital. In this population, female patients with children are concerned primarily with accompanying their child while that child receives care, and tend to postpone or neglect their own care. Dr. Levine urged HRSA to consider supporting alternative care "environments," such as maternal/child care clinics, that take into account social service needs.

Dr. Lynne Cooper expressed a concern that the new drug treatments for AIDS are consuming more and more of the available resources. She said there is a perception that HRSA does not want to fund housing or food or transportation services. She asked Dr. O'Neill to explain what strategies HRSA is pursuing to convey its desire to expand social services.

Dr. O'Neill agreed that there has been a drain on the system due to the tremendous achievements on the medical side of HIV care. He said HRSA and its local grantees need to make some difficult economic decisions. Grantees should examine the reasons underlying the provision of social services, to ensure that those services contribute to keeping people in care. Partnerships can be created between local and Federal agencies to solve these problems. The bottom line is that more money is needed.

Ms. Aragón asked about funding capacity-building and quality assurance activities. She said it is her understanding that these activities would be funded through an across-the-board shave of AIDS programs. She said it is important to discourage a paradigm that would require local agencies to reduce funding for service. Dr. O'Neill said HRSA would oppose such a paradigm.

Ms. Aragón added that the Administration should look at the two 1 percent shaves that apply to all public health service programs. She explained that there is a 1 percent shave for evaluation and a 1 percent shave for technical assistance. This year, the shaves resulted in a $32 million allocation from the CARE Act that went to the DHHS Secretary for use at her discretion across all programs. She said it is her understanding that HRSA receives only about
$1 million from the shave reallocation.

Dr. O'Neill said the technical assistance piece is not problematic, but HRSA received only $800,000 last year out of a $15 million tap on evaluation. Ms. Aragón suggested that some quality assurance and capacity-building activities could be described as evaluation or technical assistance. She said it seems fair that a greater proportion of the shaves be given back to HRSA to carry out these activities. Dr. O'Neill thanked Ms. Aragón for her comments. He said the evaluation piece is critical, and HRSA has never considered shaving the program. States have indicated to HRSA that they would like to do more

quality assurance activities. HRSA must find a way to approach this outside the administrative cap.

Ms. Miramontes commented that AIDS resources are used first when a patient has several diseases, so there are political issues around capacity-building. She agreed that capacity-building is a priority, but the community needs to figure out how to diffuse conflicts that arise out of pitting one disease against another.

Dr. O'Neill commented that the U.S. health care system is more complicated than is necessary. He reminded the Council that there is tremendous compliance among HIV patients. An analysis of HCSUS data on people receiving care through a Ryan White-supported provider showed that Ryan White patients are more likely to be poor, minority, and less educated. Care provided through the CARE Act is a model; good care is provided to the most vulnerable populations through a community-up approach. The CARE Act is a model for palliative and end-of-life care and for health care systems worldwide. HRSA has only 120 people working on Ryan White — the real work is done at the community level.

Mr. Lew asked if HRSA is looking at quality assurance systemwide, at both the local and national levels, and in services other than medical services. Dr. O'Neill said HRSA is looking at quality of systems and quality of medical care. The latter is a more established discipline, but the systems piece is equally important and will take some time to develop. It is more difficult to figure out how to approach the systems piece.

Ignatius Bau asked Dr. O'Neill to comment on how cultural and linguistic access is incorporated into quality and capacity-building measures. He noted this is an important issue for Latino and Asian populations; traditional health care providers may not have bilingual capacity.

Dr. O'Neill agreed with Mr. Bau and noted that HRSA is supporting activities to broaden cultural and linguistic access. He said Virginia Bourassa of HRSA would talk about a HRSA-sponsored handbook for providers on cultural competency in dealing with Asian/Pacific Islander patients. Quality assurance measures must have buy-in on all levels and must address cultural issues.

Brent Minor commented that the community is looking for greater guidance on developing outcome measures that will satisfy HRSA's requirements. Local planning councils spend millions of dollars on reporting systems, yet it is inevitable that a uniform reporting system for Title I will be applied.

Dr. O'Neill said HRSA is not advocating for a uniform reporting system. The agency is supporting seven demonstration projects that use a uniform reporting system, which have enabled HRSA to use aggregate data to come up with a mathematical model to determine how many people are being served. If a uniform system makes sense, it will be implemented because the community requests it. HRSA is not asking for national standards on quality assurance; locally determined standards should be implemented. However, HRSA will encourage local standards for systems to address service to people

not in care. The Government Performance Act mandates two reporting measures for the CARE Act: one follows units of service provided through the Act, and one sets a target for percentage of minorities served. These outcomes are reported to Congress every year. If better measures are implemented, it will strengthen the CARE Act; it may be important to defend the Act when the economy is not as robust as it is today.

Mr. Dellums asked Dr. O'Neill to clarify why the Ryan White reauthorization process had become controversial over the last 5 to 10 days. Dr. O'Neill responded that the controversy is nothing out of the ordinary for Washington; it has developed around a misinterpretation of HRSA's proposals on access, quality, and capacity-building.

Mr. Dellums asked Dr. O'Neill if HRSA has considered making changes outside of the CARE Act in response to the changing demographics of the AIDS epidemic. Dr. O'Neill said that, ideally, the CARE Act should be flexible enough to serve all populations in need. But he added that broader issues of racism, homophobia, and poverty need to be considered. HRSA is faced with the enormous challenge of providing complicated subspecialty care in communities where basic care has never been provided. This is something that has never been done before.

Ms. Thurman commented that the CARE Act is not enough, which is why the Administration is retrofitting all Federal programs serving vulnerable populations to include HIV/AIDS services. If this does not occur, Federal agencies will continue to "dump" HIV/AIDS patients onto the CARE Act.

Mr. Dellums noted that AIDS has enormous potential for coalition-building but expressed concern that local groups are being pitted against one another as they compete for limited Federal resources. Dr. O'Neill said he subscribes to the "glass half-full" view. He said his experience working in a clinic in Baltimore showed him that remarkable partnerships can occur at the community level.

Thomas Patrick Healy asked Dr. O'Neill to talk about the timeline for reauthorization over the next few months. Dr. O'Neill said reauthorization is now in the hands of Congress; HRSA's role is to provide advice when asked. He said the Senate hopes to mark up the legislation on March 29; the House's plans for the measure are unclear.

Mr. Isbell commented that the lines between prevention and care should be broken down. He asked if HRSA is proposing any measures that would support a more coordinated approach between prevention and care.

Dr. O'Neill said HRSA, CDC, and DHHS have requested that Title I and Title II grantees be allowed to use Ryan White resources for counseling, testing, and outreach when no other resources are available. He noted that African American women receiving primary care through HRSA-funded community and migrant health centers have better access to cervical and breast cancer screening than the average American woman. The same applies for access to diabetes and hypertension screening and

treatment for both men and women using community and migrant health centers.

Dr. O'Neill commented that "the clinic is the door to the community," and HRSA views the CARE Act as a major provider of prevention services. He recounted a recent trip to a 60-year-old Salvation Army hospital in Lusaka, Zambia, that treats AIDS patients. He met with a tribal chieftain who had changed tribal law to lift a requirement that widows have sexual intercourse with their late husbands' brothers. The chieftain explained to other regional chieftains that he had made the proclamation to combat AIDS. Dr. O'Neill remarked that there was a direct relationship between the local hospital and the chieftain's knowledge of AIDS, thus illustrating the idea that providing care affects a community's ability to carry out prevention initiatives on its own.

Afternoon General Council Session

Update on International Initiatives and Overview of the Pandemic

Dr. Paul DeLay, Chief, HIV/AIDS Division, U.S. Agency for International Development

Paul DeLay provided a global overview of the pandemic, focusing on Africa, and spoke about several new Congressional and Administration initiatives that address AIDS worldwide.

He said three patterns of epidemics have emerged in sub-Saharan Africa: 1) the old epidemics that began in the 1950's and 1960's in the Great Lakes region, which have affected between 10 and 25 percent of adults in urban settings; 2) the indolent epidemics in West Africa, complicated by HIV-2, where infections rates hover between 1 and 8 percent; and 3) the six explosive epidemics in Southern Africa, which began after 1990 and have reached the highest infection levels in the world.

Dr. DeLay presented data on seroprevalence rates among antenatal clinic attenders in Africa. In two urban settings in Botswana, HIV infection rates in this group approach 50 percent. Women now account for 55 percent of HIV infections in Africa; infections in girls and young women occur in much younger age groups as compared to boys and men. In some South African provinces, infection rates for pregnant women are at 35 percent. Urban settings, transport routes, routes of military incursions, and migrant routes are the epicenters for HIV.

Successes in combating AIDS in Africa are beginning to be realized. In Uganda, there has been a dramatic decline in HIV prevalence since 1993; a similar pattern is emerging in Zambia in the 15- to 19-year-old age group. Declines in prevalence are also expected in Kenya and parts of India.

Infant mortality due to AIDS has doubled, and childhood mortality has tripled in Southern and Eastern

Africa. For every 5 years of life expectancy lost, there is a .2 percent drop in Gross National Product in Africa nations. Within the next 5 years, negative population growth will begin in South Africa, Botswana, and Zimbabwe. National censuses taken in Malawi and Kenya are showing declines of 1 to 2 million residents. In Zimbabwe, a population drop from 11 to 9 million is expected by 2010, with a steep decline in the number of children and a skew toward boys and young men. China is the only other country that has exhibited a comparable demographic skew. This pattern occurs when girls and young women do not grow old enough to have children.

Dr. DeLay said USAID is active in 22 of 46 sub-Saharan countries. The agency focuses on primary prevention and is increasingly involved in basic medical care, particularly for children with AIDS. The three pillars of USAID's work in HIV/AIDS are as follows: (1) implementing behavior change interventions (focusing on sexual transmission); (2) providing access to barrier methods of contraception; and (3) improving management of sexually transmitted infections.

Newer areas of USAID's activities include: (1) increasing access to testing and counseling (USAID has testing centers in 10 countries); (2) implementing mother-to-child transmission interventions; and (3) implementing a prevention-to-care continuum, particularly in relation to treatment of tuberculosis and survival interventions for children. In addition, USAID supports policy reform and research in the areas of orphan technologies, diagnostics for sexually transmitted diseases (STDs), microbicides, and biological and behavioral surveillance.

Dr. DeLay enumerated several obstacles faced by USAID in implementing its HIV/AIDS programs, including entrenched stigma and denial, lack of resources, poor quality of delivery services, and a minimal role for care with prevention programs. About 6 million new HIV infections occur worldwide every year, 4 million of which occur in sub-Saharan Africa. Until 2000, USAID funding for HIV/AIDS flatlined at $125 million, which was spread across 50 countries. This year, Congress has allocated $200 million to USAID for its AIDS initiatives.

For comparison, Dr. DeLay stated that USAID spends $800 to $900 million per year on prevention programs, while the developing world spends about $500 million. About $200 million of this amount is spent on all of sub-Saharan Africa.

The Leadership and Investment in Fighting an Epidemic (LIFE) initiative provides $100 million spread across an array of Federal agencies, including USAID, the Department of Defense, the Department of Labor, and the Department of Commerce. Vice President Gore announced in January that the White House would request an additional $100 million in AIDS funding, which would triple the U.S. Government's global response to AIDS. The United States is the lead AIDS donor in the world, giving at least four times more money than any other nation.

Under the LIFE initiative, the Department of Defense will look at military-to-military assistance, the Department Treasury will address debt relief and restructuring, the Department of Commerce will

examine worksite-based prevention programs in multinational corporations, and the Department of Labor will work with trade unions. A U.S.-Africa religious leaders summit is being planned, and the State Department is planning a diplomatic initiative. LIFE is focused on 15 priority countries: India and 14 countries in Africa. In 2001, USAID hopes to expand LIFE activities to 20 countries total.

Dr. DeLay concluded by noting that the United States provides one half of the AIDS response in most African countries, while the countries themselves provide about 10 percent, and the World Bank and other bilateral donors contribute the remainder. Current funding levels in most developing countries are not adequate to achieve success in fighting AIDS, though countries like Uganda and Zambia have achieved remarkable changes in behavior and reductions in incident infections.

David Wagner
Office of Emerging Infectious Diseases and HIV/AIDS, Global Bureau,
Department of State

David Wagner summarized the State Department's efforts to combat HIV/AIDS. He said the Secretary of State announced a diplomatic initiative in March that addresses AIDS as an issue that affects global security, economic growth, and politics. Richard Holbrooke, U.S. Ambassador to the United Nations, convened a January meeting of the United Nations Security Council to discuss AIDS, and AIDS has been placed on the agenda for meetings between all major U.S. foreign policy officials and their foreign counterparts. In addition, AIDS has been placed on the multilateral agenda for all global regions, and it is a centerpiece of the G-8 group of industrialized nations meetings.

The Department has incorporated AIDS into its mission program plans, whereby each U.S. embassy or post is assigned certain priority issues and is made accountable for interventions relating to those issues. In particular, ambassadors and country teams are directed to urge foreign leaders to openly address AIDS, urge other governments to consider the adverse economic impact of HIV/AIDS, urge other countries to increase spending for AIDS prevention, emphasize the importance of national AIDS action plans, encourage the support of UNAIDS, and urge the inclusion of AIDS in foreign policy interactions with all government and international organizations.

In February, the Secretary of State issued a new plan that aims to dramatically increase U.S. embassy engagement on AIDS in Africa. State Department officials have met several times with the U.S.-South African Development Community to address AIDS, and the U.S. Government has donated $350,000 to the Community to develop an HIV/AIDS policy and improve coordination on AIDS; the Department is looking to hire a subcontractor to take on this task.

The Department also co-hosted, along with Peter Piot of UNAIDS, a briefing of the foreign diplomatic community in Washington, DC, and has negotiated a United Nations Human Rights Commission resolution on HIV/AIDS. Last fall, the United States issued a statement expressing deep concern and disappointment that the President of Uganda had threatened to arrest several homosexuals in Uganda.

The Secretary of State has become personally involved in the AIDS issue, raising it with each head of state she met with during her October 1999 trip to Africa and at the United Nations General Assembly.

Finally, Mr. Wagner said the Department is drafting a new strategy to promote greater diplomatic intervention and awareness of HIV/AIDS as part of the LIFE initiative.

Gayle Smith
Senior Director for African Affairs, National Security Council
President's Special Assistant on Africa

Gayle Smith began by thanking Ms. Thurman for her efforts to bring attention to AIDS in Africa. She said the Administration's Africa policy is rooted in two goals: 1) to enhance Africa's integration into the global economy; and 2) to counter transnational threats. It is clear how the AIDS epidemic is affecting the Administration's economic policy goals. For example, in Malawi and Zambia, 30 percent of all teachers are infected with HIV, and in Rwanda as many as
35 percent of all citizens with post-secondary education are infected. While Botswana has one of the highest rates of infection in Africa, it is also one of the five fastest growing economies in the world due to a rich supply of diamonds and political stability.

Ms. Smith said AIDS has become a threat to the security of the United States as well as to most African nations. The rate of infection among armies now fighting in the Congo is estimated at between 50 and 80 percent. When these armies return home, they will bring the epidemic with them. AIDS also threatens peacekeepers in Africa; there is a need for basic HIV/AIDS education and condom distribution among troops.

National Security Advisor Sandy Berger treats AIDS as a national security issue and has encouraged other Federal agencies to address the disease. The National Security Council has tried to focus more attention on AIDS, through the LIFE initiative, through Mr. Holbrooke's meeting at the United Nations, and through the President's National Summit on Africa, held in February.

At the U.S.-Africa Partnership Ministerial held in 1999, the Council brought together 88 African ministers from 46 countries to meet with the President and eight members of the Cabinet.
During this event, Mr. Berger and officials from USAID met with African finance ministers to discuss how to craft a national budget to counter the AIDS epidemic.

In addition, the United States established a Bilateral Consultative Commission with Angola last year, which has brought to light a need to measure the scope of HIV/AIDS infection in Angola. Through the LIFE initiative, a baseline survey is being conducted.

The Administration continues to try to institutionalize a response to AIDS across the U.S. Government. For example, the Treasury Department is looking at debt restructuring. In September, the President announced that the United States would forgive 100 percent of bilateral concessional debt to those countries that qualify for the G-7 initiative but who are making their investments in health and social services.

Ms. Smith stressed that the role of the Department of Defense is critical. Through the Africa Crisis Response Initiative and other peacekeeping training programs, the Department hopes to work more closely with African militaries as a good point of entry in countries that have not been able to tackle AIDS adequately.

The Administration is also bringing its economic agencies to the table. Investment in Africa is increasing, but in many African nations, two people must be trained for every job because the AIDS death rate is so high. The private sector needs to be engaged; for example, a German firm just made a huge investment in a condom factory in Kenya. African countries need factories to produce rubber gloves and other basic equipment to fight the epidemic.

The Administration's Interagency Working Group on AIDS coordinates the efforts of 17 Federal agencies and is currently meeting to discuss global AIDS initiatives that can be implemented in advance of the International AIDS Conference in July in Durban, South Africa.

Ms. Smith remarked that President Clinton and several African leaders have successfully brought the AIDS issue "out of the closet." African diplomats now suggest putting AIDS on the agenda of almost every diplomatic exchange between the United States and Africa. She said Africans fear that the media's focus on AIDS in Africa will further the image of Africa as a hopeless continent and will drive investors away. The challenge is to temper news stories of the spread of the epidemic in Africa with the stories of Uganda and other successes.

A stigma persists that Africa is at fault. It is important to be sensitive to the fact that minimal access to health care and poverty have contributed to AIDS in Africa. Dependence on non-governmental organizations also poses problems. The United States needs to impart to Africa greater ownership of the fight against AIDS. This can be achieved through greater investment in research and development capacity in Africa or through bringing more Africans on board in international institutions.

Ms. Smith ended her comments by praising the accomplishments of AIDS activists in the United States and suggesting that they can serve as models for activists in Africa.

Thomas Novotny
Deputy Assistant Secretary, International and Refugee Health, DHHS

Dr. Thomas Novotny stated that HIV/AIDS has been raised as an issue of global importance within the Administration. He noted that the $100 million dedicated to the LIFE initiative in 2000 is a drop in the bucket — the funding must be leveraged.

Dr. Novotny explained that the Office of International and Refugee Health serves to coordinate different parts of DHHS, including CDC, NIH, Indian Health Service, HCFA, and others, to promote the achievement of global health issues for DHHS. As the Deputy Assistant Secretary, Dr. Novotny leads the delegation to the World Health Assembly. His office engages in multilateral activities with the World Health Organization, the World Bank, and parts of the United Nations system to promote DHHS activities in nations such as India, Russia, and South Africa. The Indo-U.S. Vaccine Action Program, for example, is working to develop vaccines that might be applicable in the HIV/AIDS epidemic, including those for tuberculosis. The President plans to highlight this collaboration during his current trip to India. Bilateral relationships have also been initiated with Vietnam, Egypt, Mexico, and Switzerland.

The Office of International and Refugee Health also cooperates with USAID on African health issues, and Secretary Shalala has appointed a committee that includes USAID, the State Department, and the National Security Council, to energize a broader approach to global health.

Dr. Novotny summarized the CDC's role in global AIDS prevention. The agency is active in field-based research collaborations in epidemiology in Botswana, Cote D'Ivoire, Kenya, South Africa, Uganda, India, Thailand, and Vietnam. CDC studies are examining the use of AZT in perinatal transmission interruption and nevirapene, microbicides, and prophylaxis of opportunistic infections. Short-term technical assistance is being provided to Brazil, Latvia, Russia, and the Central Asian nations.

NIH supports basic clinical and behavioral research in more than 100 countries. More than 5,000 NIH research projects focus on AIDS. The Office of AIDS Research coordinates policy, legislative, and budgetary tasks related to AIDS research across NIH's 25 Institutes. Vaccine and therapeutics research is being conducted in Brazil, Haiti, India, Kenya, Malawi, South Africa, Thailand, Trinidad and Tobago, Uganda, and Zimbabwe.

DHHS is involved in two new global AIDS programs. The LIFE initiative is an important opportunity that the President will highlight on his trip to India, Pakistan, and Bangladesh. It focuses on primary prevention, care for children with AIDS, home and community-based care, surveillance, and infrastructure development. The second project — the Global Alliance for Vaccines and Immunization (GAVI) — ensures delivery of vaccines and provides a stimulus to develop new vaccines. Work toward a tuberculosis vaccine could have an important impact on reducing AIDS-related mortality worldwide. GAVI is a partnership funded by the Bill and Melinda Gates Foundation, the International Federation of Pharmaceutical Manufacturers, national Governments, UNICEF, and the World Bank.

DHHS is also collaborating with the U.S. Trade Representative (USTR) to develop a cooperative approach on health-related intellectual property matters consistent with the Administration's goal of helping poor countries gain access to affordable medicines. This initiative allows DHHS to provide information to USTR so that it can make more informed decisions about the pursuit of 301 sanctions on countries that either market or import HIV/AIDS medications.

Finally, Dr. Novotny mentioned that the Intergovernmental Working Group on AIDS is addressing budgetary, legislative, and prevention and care issues. The group is currently drafting several reports.

Questions/Comments: Mr. Anderson commented that stigma still plays a critical role in hampering AIDS treatment and prevention. He challenged the Council and the panel to address the need to combat the stigma of AIDS and make it a higher priority. Mr. Anderson suggested including an assessment of human rights violations directed at persons with HIV/AIDS in the annual State Department report on human rights. He added that the Administration is doing little to support the autonomous development of organizations of people living with HIV/AIDS across the globe. These organizations play a valuable role in combating discrimination and ensuring accountability for spending.

Dr. DeLay responded that USAID will work with UNAIDS over the next 6 months to conceptualize stigma regarding AIDS. Two stigmas surround AIDS: one surrounds modes of transmission, and one surrounds the fact that AIDS is a fatal illness.

Ms. Smith said she would take Mr. Anderson's suggestion about the State Department's human rights report back to her colleagues. She agreed that this is a good idea. Regarding stigma, Ms. Smith said Uganda has been successful with its AIDS prevention program in large part because the president took the issue public by meeting with religious and political groups and producing a video that ran on Uganda's counterpart to MTV. Taking a cue from this example, Administration officials urged President Clinton to speak about the issue in public fora when he travels. In addition, the Administration's Education for Democracy and Development Initiative, which focuses on educating young girls, provides a receptive audience for prevention messages.

Dr. Levine asked whether the National Security Council is addressing AIDS in Southeast Asia. Ms. Smith clarified that the United Nations Security Council meeting in January was not designed to exclude discussion of AIDS in countries outside of Africa; the entire month was dedicated to African issues in the Security Council. Ms. Thurman said AIDS discussions held within the Administration routinely address Asia and the New Independent States as well as Africa. The Central Intelligence Agency has released a report that concludes that the epicenter of the epidemic in the next 15 years will be in Asia and India. Dr. Novotny stressed that CDC is conducting research in Asia and India, and has contributed to the World Bank's work in the region.

Dr. Levine said she finds it interesting that no one on the panel talked about China. She said money funneled into China at this point could perhaps prevent the epidemic from exploding there.

Miguel Milanes asked whether the U.S. Government played a role in supporting Uganda's prevention programs. Can the U.S. role be replicated in other countries ? Ms. Thurman said the United States provided financial support to Uganda, but committed leadership by the Ugandan President and an active USAID mission in Uganda made the difference.

Ronald Johnson asked if the President plans to use his current trip to India, Pakistan, and Bangladesh to bring attention to AIDS. He also asked how the Administration plans to use the Durban conference to advocate for increased political leadership on AIDS. Ms. Thurman replied that President Clinton will talk about AIDS and other health issues in India, despite the resistance of leaders in India to address AIDS openly. She noted that the International AIDS Conference has never attracted political leaders — it is primarily a scientific conference. She welcomed the Council's input on how to handle political involvement in the conference.

Ms. Smith noted that the annual summit of the Organization of African Unity (OAU) will be held in July, just prior to the Durban conference. She suggested that the Administration encourage the OAU to address AIDS in preparation for the conference.

Stuart Burden asked Mr. Wagner to respond to Mr. Anderson's suggestion that persons with HIV/AIDS be included in the State Department's annual human rights report. Mr. Wagner said he appreciated the Council's concerns and would take the request back to his colleagues.

Mr. Burden noted that the State Department played a leadership role in the International Conference on Population and Development, held in Cairo 5 years ago. At that conference, 178 countries issued a consensus statement on reproductive health and rights, and HIV/AIDS was addressed in that document. Mr. Burden asked what the State Department is doing to ensure that the recommendations from the Cairo conference are carried out. Mr. Wagner said the State Department is drafting a "Cairo +5" document and is eliciting comments from overseas posts. Some of the issues raised in that process will overlap with the diplomatic initiative on HIV/AIDS.

Mr. Dellums asked panelists to get back to the Council on unanswered questions, for the record.

Mr. Bau said he is concerned that the discussion on global issues is divorced from the discussion on domestic issues. The panel did not address any linkages between non-governmental organizations in the United States and those abroad. There is also a connection between the epidemic in the United States and the epidemic in Latin America and Asia. Mr. Bau also pointed out that the U.S. policy excluding immigrants based on HIV status contributes to the stigma of HIV/AIDS. He suggested it may be hypocritical of the United States to accuse other nations of discriminating against persons living with HIV/AIDS.

Mr. Dellums noted that there is a difference between the global and international approaches to HIV/AIDS. If the United States views AIDS as a global pandemic, it should see itself as one

component of a global strategy. He said HIV/AIDS has blurred the distinction between the domestic and international sides. It is a threat to the human family.

Ms. Smith said AIDS is in transition from being perceived as an international epidemic to a global one. The Interagency Working Group is attempting to link disparate pieces of the Administration's response. Leon Furth, the Vice President's security advisor, has suggested that the U.S. Government work with other governments to develop a collective effort. Ms. Smith added that launching international exchange programs for health care providers and volunteers might be a good way to attack stigma.

Dr. DeLay said USAID and CDC have funded a "twinning" program for non-governmental organizations for the past 5 years. He said the lack of AIDS non-governmental organizations in Africa is worrisome; USAID needs to build more capacity in this area. In addition, many U.S. non-governmental organizations are not ready to take on an international agenda.

Mr. Burden said he recently learned that USAID is terminating its reproductive health assistance in Brazil because the total fertility rate has declined. He said he questions this decision because of the link between reproductive health and HIV. Dr. DeLay noted that USAID is scrutinized by Congress, which requires that USAID graduate countries when certain conditions are met. However, USAID does have a graduation waiver for HIV/AIDS. In Brazil, the HIV/AIDS program will not close until 2003 or 2004.

Ms. Miramontes asked whether any HIV/AIDS recommendations were adopted at the African Summit held in Washington in February. She noted that participants at the African Regional Summit held last year in San Francisco did not adopt any language related to HIV/AIDS. Ms. Thurman said HIV/AIDS was only mentioned four or five times in the Summit document; no concrete recommendations were adopted. Ms. Smith said the Administration would be drafting a response to the Summit document; she will convey the Council's concern in this area.

Mr. Dellums noted that countries held up as success stories, such as Uganda, still have high AIDS prevalence and mortality rates. The Council should recognize that there is a sense of urgency worldwide, particularly in Africa.

Public Comment
Ellyn Silverman
President, ECS Nutrition Services

Ellyn Silverman stated that she is a registered dietitian and a physician assistant. She urged the Council to support the development of Public Health Service (PHS) HIV/AIDS nutrition-specific guidelines. She said nutritional status is strongly predictive of survival and functional status during HIV infection. She cited a series of statistics indicating that wasting remains a serious problem for adult and pediatric patients with HIV. Little or no guidance is available on appropriate indications and use of nutritional

therapies to prevent wasting. Guidance is also needed to manage side effects, optimize drug absorption, minimize food- and water-borne illness, and help navigate the maze of dietary supplements.

Ms. Silverman said she is a member of a panel of experts on nutrition and HIV disease, convened by the Office of HIV/AIDS Policy at DHHS. The group met in November 1999 to develop recommendations on the need for guidelines to address nutritional and metabolic complications associated with HIV and its treatment. The panel is currently developing an evidence-based needs assessment for Dr. Goosby, and Dr. Shalala and will ask DHHS for support in creating HIV/AIDS nutrition guidelines. She said the need for guidelines is demonstrated by the dramatic impact of PHS treatment guidelines.

Along with urging the Council to support the PHS nutrition guidelines, Ms. Silverman added that nutrition therapy should be added as a medical service in the Ryan White CARE Act. Nutrition information is also missing in the Wellness Act for Medicare. Finally, she recommended that a registered dietitian be included on the Council.

Minority AIDS Initiative

Eric Goosby
Director, Office of HIV/AIDS Policy, DHHS

Dr. Eric Goosby began by stating that inadequacies and inequities in infrastructure have impeded the response to the AIDS epidemic in minority populations over the last 19 years. Disparities in outcome variables — longevity, morbidity, mortality, frequency of hospitalization, and opportunistic infections — correspond with racial, gender, and ethnic lines. These disparities have troubled DHHS since 1992. The Department has attempted to incorporate this theme throughout its various AIDS efforts, including the Minority Initiative, which was developed with the help of the Congressional Black Caucus (CBC).

DHHS has been working on a framework document to define DHHS's goals and objectives on AIDS and minority issues. Dr. Goosby said this document would be distributed to Council members in the next day. He asked for a confidential response from Council members within 1 month. The document has not been distributed to the public.

Dr. Goosby said the document sets forth issues that DHHS and the White House have committed to in prior strategic efforts, such as the 2010 initiative and the Government Performance Review projects. In addition, each Federal agency will respond to the document with its own strategic plan. He said the planning process should highlight an array of issues.

Through the Minority Initiative, DHHS has targeted issues that will enable the agency to better allocate its resources and better position community-based organizations and new grantees to partake of the larger $8 billion amount that DHHS has dedicated to HIV/AIDS programs. DHHS has put a special

emphasis on technical assistance needs. The Department has tried to engage communities that have not previously been involved in Federal programs. New technical assistance efforts are more durable, employ a mentoring approach, and attempt to increase infrastructure. They also attempt to identify problems in the areas of fiscal management, board composition, board development, and linkages with other service organizations targeting high-risk populations.

In choosing grantees, DHHS has tried to identify community-based organizations that have successfully interacted with high-risk populations. Often, these organizations have not received Federal support. The goal is to provide technical assistance that sustains these organizations over time and keeps them well-positioned. The Department has funded four organizations with the first $99 [million?].

Dr. Goosby said DHHS's ability to look at surveillance data gives it a macro-level picture of what is happening in a given community. As populations become more disenfranchised, they do not have the ability to access delivery systems from prevention through care through social support. DHHS is trying to throw this "net" over high-risk populations.

The Department's goals have been facilitated by the crisis response initiated by the CBC. Dr. Goosby said he has been gratified by the responses in Miami, Detroit, and Philadelphia regarding taking known methodologies and using them to inform the community and strengthen community response. Dr. Goosby said he hoped to return before the Council to give a more formal presentation regarding the successes of the rapid response team efforts.

Questions/Comments: Mr. Healy asked Dr. Goosby to explain more fully what is happening in Miami, Detroit, and Philadelphia. Dr. Goosby said DHHS was asked by the mayors and directors of public health in each city to develop a consultation that would allow the community to identify high-risk populations and determine how those populations interface with prevention and treatment modalities. This entailed the identification or work groups made up of persons on both prevention and Ryan White planning bodies, community leaders, and persons using HIV/AIDS services. The groups examined surveillance data and assumptions made in positioning treatment opportunities within high-risk communities. Work group recommendations have been presented to the city directors of public health; they have yet to be presented to the mayors of each city.

Mr. Healy asked about lessons learned. Dr. Goosby said he would make available to the Council an evaluation of the outcomes in all three cities. He said the most significant lesson learned was that researchers' understanding of how HIV moves through a population is only partially reflected in surveillance data. The data do not speak clearly to the decisionmakers. Interviews with high-risk communities may reveal issues such as stigma and prejudice presented at point of entry. Recommendations coming out of the process have addressed issues such as hours of operation, transportation needs, and sensitivity training.

Ms. Lewis noted that she represents the National Association for the Advancement of Colored People

(NAACP). She said the NAACP and other community groups would be interested in becoming involved in the process. Local NAACP chapters do not always know how to get involved in community planning groups. Dr. Goosby thanked Ms. Lewis for her comments.

Mr. Lew asked Dr. Goosby to clarify the four regions that received technical assistance grants. Dr. Goosby said Miami, New York, Chicago, and San Juan received grants.

Mr. Minor asked whether future support for Title I areas will be blocked off into specific measures like the CBC initiative. Because funds from the CBC initiative were commingled with other programs, there is a fear that the goals of the CBC might get supplanted by the mechanism that is already in place. Dr. Goosby said he recognizes the community's frustration but noted that the process carried out in Miami, Detroit, and Philadelphia has led to an easy segue to allocation discussions. In two of the cities, the decisionmaking process for Ryan White was deliberately delayed pending the outcomes of the planning process. In all of the cities, the process has resulted in simply providing another piece of information to allocators; the outcomes have been embraced.

Mr. Minor asked whether an increase in CBC funding to $500 million would affect supplemental awards for Title I areas. Dr. Goosby said there is no direct link between the two, but allocators would take CBC dollars into account. He said the CBC dollars are so small, it is hard to imagine that they would supplant larger processes.

Ms. Aragón said she has been working with an ad hoc coalition of Latino service providers and advocates who have come together to work on the Minority AIDS Initiative and to expand funding for communities of color in FY 2001. The group is looking at a figure of $500 million. Two questions have emerged during the coalition's discussions: 1) Are dollars being effectively targeted to minority community-based organizations? and 2) How has the initiative been expanded to include Latinos, Asian/Pacific Islanders, and Native Americans?

Dr. Goosby responded that the difficulty in targeting minority organizations has been brought to DHHS's attention repeatedly. The definition of a minority organization has been difficult to nail down; HRSA and CDC have different definitions. The fact that the majority of patients served by DHHS agencies tend to be minorities confounds the ability to distribute resources to organizations run by minorities. Dr. Goosby said he does not know how to better target minorities. It is critical that the decisionmaking process remain local. It is difficult for the Federal Government to get too proscriptive about what organizations should look like. DHHS is trying to figure out a way to be more aggressive about this.

Dr. Goosby added that he was gratified that the list of grantees clearly indicates that they serve minority populations.

Dr. Goosby said broadening the CBC initiative has been a top priority for the Surgeon General. DHHS

has attempted to create a dialogue with leaders of different minority communities and is expanding this effort to include the geriatric population, the deaf population, and other populations with limited access to care. The Surgeon General's Leadership Campaign has brought in leaders from a wide range of disciplines, from education to civic service to religion, to discuss how AIDS is spreading within their community and identify strategies to combat it. The campaign has amplified the goals of the CBC's initiative and has increased the level of awareness.

DHHS is actively trying to identify grant application reviewers who are minorities and/or experts on minority issues, and is developing guidance for grant writers that emphasize plain language.

Mr. Lew asked Dr. Goosby to assess the coordination among Federal agencies regarding the CBC funds and their minority portfolios for HIV/AIDS. Dr. Goosby responded that the minority initiative has created new dialogues that he hopes will result in a cultural change among agencies. Mr. Lew asked if there had been a coordination of funding efforts around the relationship between treatment and substance abuse, particularly regarding SAMHSA. Dr. Goosby said no, not to the degree that Mr. Lew was asking about.

Prevention Overview
Eva Seiler, Associate Director for Planning and Policy Coordination,
National Center for HIV, STD, and TB Prevention, CDC
and
David Holtgrave, Director of Intervention Research and Support,
Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, CDC

Eva Seiler provided the Council with an overview of CDC's budget and an update on CDC's planning processes for prevention. She said the CDC Advisory Committee working group on the budget issued a set of recommendations in December, one of which suggests that the agency update its strategic plan. In early February, CDC held a strategic planning meeting; Council members Bau and Isbell attended that meeting. The strategic plan was broken into three domestic goals and one international goal. Working groups were formed around each goal, and meetings are currently being held to draft strategies to implement each goal. The Working Groups will meet May 2 to 3 to draft a 5-year strategic plan document, which will be made public over the summer.

Ms. Seiler reported that CDC contracted with the IoM to develop a national, 5-year vision of prevention. IoM is charged with describing the role that CDC and other agencies can play, along with public and private sector roles, in implementing a prevention strategy. The IoM panel met in January and in early March. A final meeting will be held in Boston April 13 to 15. CDC hopes to get a report from IoM over the summer.

Ms. Seiler said about two-thirds of CDC's budget for FY 2000 will be distributed extramurally for domestic programs. The majority of this allocation goes to State and local health departments,

community-based organizations, State and local education agencies, and other non-governmental organizations. Interventions and program implementation are funding priorities.

CDC received $18 million from the CBC and $21 million from the Secretary's emergency fund to augment efforts to reach minority communities. New projects resulting from this funding include capacity building and technical assistance grants; community development projects to integrate HIV, STD, tuberculosis, and substance abuse; HIV prevention projects for African American faith-based organizations; and direct funding for organizations serving gay men of color. A seven-State corrections project was funded by CDC and HRSA to increase access to care for individuals leaving prison. Finally, CDC funded the Prevention Education and Early Identification Project to increase the number of people who know their serostatus.

David Holtgrave discussed the "Know Your Status" Campaign and other prevention efforts within CDC. He said prevention occurs when a service provider delivers effective interventions to a client or community at risk of transmission or infection. There are three key parts to this framework: service providers, interventions, and clients and communities.

CDC has a longstanding history of conducting HIV counseling and testing, referral, and partner notification, along with health education and risk reduction. Over the last few years, prevention efforts have become more specific, focusing on small-group interventions, community-level interventions, social and prevention marketing, elimination of perinatal transmission, case management, and confronting policy barriers to effective intervention.

Dr. Holtgrave said CDC has produced a compendium that provides a review of what interventions have been found to change HIV-related risk behaviors or disease outcomes. The compendium is included in Council members' meeting binders.

Over the last couple of years, CDC has increasingly emphasized service to communities of color disproportionately affected by HIV/AIDS: African Americans and Latinos, gay men of color, persons living with HIV/AIDS, youth, women, incarcerated persons, and communities with high STD prevalence. The nature of service providers has changed as well; CDC has recently moved toward community-based organizations and coalitions working with communities of color, correctional facilities, and managed care organizations.

In the area of community planning, CDC's program announcements have changed to include more recently tested types of interventions. CDC has used base funding as well as supplemental funds for cooperative agreements, has encouraged partnerships between health departments and community organizations, and has encouraged the use of State funds to develop the capacity of grass roots organizations.

Community planning has led to more grass roots efforts and efforts targeted to health education and risk

reduction. Under cooperative agreements with health departments, $268 million is devoted to community planning; counseling and testing account for 34 percent of this amount, while health education/risk reduction accounts for 39 percent.

Dr. Holtgrave said questions have surfaced in recent years about whether funds allocated through the community planning process are targeted to the appropriate populations. For health education/risk reduction dollars, he noted that funding levels for African Americans and Latinos match AIDS prevalence for each of these communities (40 percent for African Americans and 20 percent for Latinos). CDC needs to do better in allocating proportionate funds for counseling and testing dollars for African Americans and Latinos.

Addressing the "Know Your Status" Campaign, Dr. Holtgrave said there are many individual and public health benefits to early knowledge of serostatus. People tend to change their risk behaviors when they learn they have HIV, and drug therapy can reduce infectiousness. But increases in STD rates and reduced usage of protective measures can also follow. The benefits of new treatments need to be balanced with societal complacency. Whether one tests negative or positive, it is important to receive an array of high-quality prevention services.

Dr. Holtgrave said CDC has used the CBC funds to implement a $7 million prevention project for gay men of color. He said he could provide further information on the specifics of the project to the Council if members are interested.

He concluded his presentation by showing several slides breaking down specific allocations for CDC programs in FY 1999 and FY 2000. In FY 1999, CDC received $18 million from CBC: $9 million went to community-based organizations, $4 million to coalition development, $3 million to capacity-building, and $2 million to faith-related activities. Of the $50 million received in FY 1999 from the Secretary's emergency fund, CDC allocated $7 million for gay men of color, $5 million for corrections activities, $4 million for coalition development, and $5 million for patient identification and education.

In FY 2000, CDC received $72.5 million in new funding: $35 million for LIFE activities, $20 million for community planning activities, $2.5 million for surveillance, and $15 million for both "Know Your Status" and CBC activities.

Ms. Aragón asked the three speakers from CDC to distribute copies of their presentations to Council members. Dr. Holtgrave agreed to this.

Overview of Prevention Marketing Initiative (PMI) Demonstration Project
May Kennedy, Behavioral Scientist, CDC

May Kennedy presented results of the PMI Project, which will be highlighted in the Youth Report that

ONAP is drafting. If Council members are interested in learning more about the process CDC uses to develop prevention marketing programs, they can obtain a free copy of *Applying Prevention Marketing* through the National Prevention Information Network (NPIN).

The 5-year PMI Project used a new form of social marketing to reduce sexual risk of HIV infections among young people in five regions of the United States: Sacramento, California; Newark, New Jersey; Washington, DC; Phoenix, Arizona; and Nashville, Tennessee. Coalitions of local volunteers learned social marketing and behavioral science and, with technical assistance from the Academy for Educational Development and others, planned and implemented marketing interventions themselves. Recruitment and orientation of volunteers took more than 1 year. During the second year, formative research began to frame messages and design materials.

Project participants began the research process by surveying national literature on behavioral determinants in adolescence and compiling teen HIV risk profiles from local epidemiological data (e.g., pregnancy rates). (The project produced a technical assistance book, also available through NPIN, outlining how to compile a local teen epidemiological profile.) Participants also conducted focus groups at the project's five sites and examined the gaps in currently available services for adolescents.

Local advertising agencies were approached with the research and asked to develop draft creative materials, which were then tested by panels of adolescents. Materials and services produced by the project included posters, baseball cards containing role model stories, condoms in key chains, temporary tattoos, information phone lines, a radio soap opera written by teens, and skills building workshops. A workshop curriculum titled "Be Proud, Be Responsible" was used in all five sites.

In addition, a five-timepoint random telephone survey of teens was conducted in 15 zip codes around Sacramento. After 1 year of full implementation of the project, more than 70 percent of Sacramento's teens said they were familiar with the project's prevention messages. For every channel through which adolescents received the message, the odds of having used a condom at last intercourse with main partner rose 26 percent.

Dr. Kennedy stressed that formative research is tedious, expensive, and time-consuming, but it is helpful in coming up with messages that the target audience feels are relevant. She said there have been some interesting solutions developed to the problem of how to undertake formative research in the "Know Your Status" Campaign. Researchers working on the Campaign used a synthesis of AIDS case data and performed a national cluster analysis, yielding information on risk and lifestyle behaviors and media exposure by region. Focus groups were then conducted for the clusters at highest risk for HIV transmission. Dr. Kennedy noted that Melissa Shepherd of CDC was available to answer any specific questions about the "Know Your Status" Campaign.

Questions/Comments: Mr. Isbell asked Dr. Holtgrave if he had information on racial and ethnic targeting of prevention programs by exposure category. He also asked if CDC had done an analysis of

how gay men of color have fared in community planning. Dr. Holtgrave said CDC has community planning budget table slides that break data down by race/ethnicity and risk behavior. There is a close fit in terms of funding matching AIDS prevalence by race/ethnicity. The most dramatic gap in community planning can be seen in programs for gay men, and secondarily for injecting drug users. Dr. Holtgrave suggested that the Prevention Subcommittee address this issue. Over the last couple of years, CDC has started collecting information that compares race/ethnicity and risk. Analysis of gay men of color and risk patterns is next in line. CDC funded specific programs for gay men of color for the first time this year.

Mr. Bau asked Dr. Holtgrave to talk about the barriers CDC has faced in compiling community planning data by State. Dr. Holtgrave said CDC fed community planning data back to States for the first time last year and asked States to explain why their data did not match CDC's data. This year, CDC hopes to take this process a step further to develop profiles for every State that contain epidemiological data and information on directly funded community-based organizations.

Mr. Anderson noted that Dr. Holtgrave committed last year to releasing the State information; this has not happened. Dr. Holtgrave said he thinks that CDC can probably release the information this year. CDC has encouraged every jurisdiction to show its budget table to its community planning groups. After a couple of years of experience with getting information from the budget tables, CDC has a better understanding of the uses of State funding. CDC needs to release the information but also needs to put it in context regarding the sources of funding.

Addressing Dr. Kennedy, Dr. Gomez noted that the OTA [?] report indicated that effective interventions for minority populations had one thing in common: they took the time to learn about the targeted population. Since time is critical in fighting AIDS, she asked what Dr. Kennedy has learned about accelerating the process of formative research. Dr. Kennedy replied that researchers have learned enough to replicate a PMI-type process in much less time. Ms. Shepherd added that CDC researchers have struggled with making the process less time-consuming, but surveying consumers allows researchers to gather a wealth of information. CDC is currently developing technical assistance materials so that others do not have to go through the same step-by-step process. The process takes much more time within Government; in particular, finding the right contractors takes time. She noted that, in emergency situations, Government agencies are occasionally able to circumvent the strict procedures required by Congressional mandate.

Mr. Healy said formative research comes down to one message: prevention works. He asked Dr. Kennedy to talk about what did not work in implementing the PMI Project. He noted that the major issue may be the paltry amounts of money spent on what does work in prevention. Dr. Holtgrave responded that interventions carried out with sufficient intensity are the ones that work. Interventions do not work when researchers sell prevention short. Dr. Kennedy said one surprise emanating from the PMI research was that a large percentage of the target audience listened to news radio while working at night. This kind of research gave CDC a new specificity on potential markets that it had not had

before.

Ms. Shepherd added that it was difficult to combat the assumptions of the creative teams, who thought the main task was to increase teens' perception of risk. The research indicated that there was not a lack of perception of risk. In Nashville, for example, there was a "gift norm": teens had sex in exchange for gifts. Literature indicates that trying to enhance perceived risk among teens is not an effective strategy, though many adults think otherwise.

Dr. Cooper commented that there was a great deal of energy around the "Know Your Status" Campaign when it was first talked about. The White House and the Council discussed involving celebrities such as Oprah Winfrey and Ricky Martin, and the President was supportive of the campaign. She asked where the energy went and if it is still available. She also asked if CDC had identified States and cities that have not put any general revenue into HIV/AIDS prevention.

Ms. Shepherd responded that CDC has looked at recruiting credible spokespeople for the Campaign; Ricky Martin emerged in the research as someone who would be credible. CDC has asked him to participate in an April meeting to discuss the Campaign. Dr. Cooper emphasized that the Council needs to hold the President to his promise.

Ms. Shepherd explained that CDC will convene a meeting on April 10 in Atlanta of 50 partners who can help CDC identify barriers to carrying out the Campaign. She said America Online has agreed to help broadcast prevention and testing messages to the public. Nike, Converse, and drug companies have also been approached to join the Campaign.

Dr. Holtgrave said CDC had funded a project with George Washington University in the early 1990's to examine the uses of State money. At that time, the ratio was one dollar for one dollar, with wide variation across States. IoM has asked this question of the National Association of State and Territorial AIDS Directors (NASTAD), and NASTAD is pulling together some information.

Dr. Levine asked if CDC has longer-term data on condom use. She also asked how many full-time equivalent staff persons (FTEs) are dedicated to the "Know Your Status" Campaign. She commented that it is impossible to convince teens that they are vulnerable; the message should be "It is cool to use condoms."

Dr. Holtgrave said CDC and NIH are now funding much longer term followup intervention studies. Dr. Kennedy said there was a 1-month followup for the PMI Project. Interventions need to be refreshed continually. She said there are outstanding research questions in this area, but there is no money allocated to address them. Dr. Levine commented that the CDC needs to push for better followup.

Ms. Shepherd explained that, in the Office of Communications at the National Center for HIV, STD and TB Prevention, there are four FTEs responsible for fielding all media inquiries, and four additional

FTEs provide communications planning assistance. Currently, two FTES focus solely on communications related to the "Know Your Status" Campaign. Dr. Levine said the Council is being told that the Campaign is a major event. She expressed dismay that there are only two FTEs assigned to it.

Dr. Holtgrave said it is difficult to give a precise number of CDC FTEs devoted to the Campaign. In his division, there are dozens of project officers who devote some of their time to promoting counseling and testing. Ms. Shepherd clarified that CDC has not received its FTE allotment for FY 2000. Dr. Levine suggested that the Council help to get more FTEs assigned to the Campaign.

Mr. Minor expressed frustration that many of the prevention messages coming out of CDC have been watered down. Stephen Boswell noted the rise in STDs among MSMs. He asked what CDC is doing to monitor risky behavior in this area. Dr. Holtgrave replied that CDC could make better use of its STD data.

Tuesday, March 21, 2000
Morning General Council Session

Appropriations Overview

Jeanne Lambrew
Associate Director, Health and Personnel, Office of Management and Budget (OMB)

Jeanne Lambrew noted that is was her second day on the job at OMB. She addressed the Federal budget process and the Administration's agenda on HIV/AIDS. She said the budget process begins in the spring of the prior year, when agencies develop research and policy agendas with input from DHHS and various advisory groups. In early September, the budget goes to OMB, and the negotiation and evaluation process continues through November. The White House, DHHS, and OMB all have a say regarding policy prerogatives. In December, OMB passes the budget back to DHHS for its review, and final decisions are made by the end of December.

Dr. Lambrew noted that there is a high level of interest on HIV/AIDS in this Administration and congratulated her predecessors for making AIDS a priority. In FY 2000, the Administration is spending $11 billion in Federal funding on AIDS, not counting State funding. This amount is about double the

amount devoted to AIDS in 1992 at the start of the Administration. Prevention money has doubled, and treatment money has quadrupled in 8 years. Still, more needs to be done.

The FY 2001 budget provides an increase of $400 million for AIDS, including the international AIDS initiative. The discretionary budget on AIDS is part of this amount. In addition, Medicaid and Medicare have become critical sources of health services for those with HIV/AIDS. The Jeffords-Kennedy bill, known as the Work Incentives Improvement Act, was signed into law in December. It allows disabled persons who are not income-eligible for Medicaid to buy into Medicaid to obtain health services. This is important for people who cannot access private insurance. The Administration also secured funding last fall for a demonstration for people who are not sufficiently disabled to qualify for Medicaid. This is a particular problem for persons with HIV who cannot get Medicaid until they are so sick that they cannot get to treatment. There is a high level of commitment to the demonstration project. The goal is to test and prove that cost-effective care can be implemented earlier.

Dr. Lambrew added that the Jeffords-Kennedy legislation extended Medicare for people with disabilities who return to work. It currently terminates after 4 years; the Act extends eligibility for another 4 years. In this year's budget, eligibility is extended for life.

The Medicare drug benefit will be an important benefit for those with HIV, and the Administration continues its fight for a patients' bill of rights. Dr. Lambrew encouraged the Council to keep an eye on the latter measure because momentum has slowed on Capitol Hill. Finally, a long-term care initiative in this year's budget will take away some of the institutional barriers to Medicaid and offer a $3,000 tax credit to people with activities of daily living disabilities.

Dr. Lambrew stated that OMB is trying to advance policies through administrative actions. The new Medicaid demonstration project is one example. OMB is also implementing performance standards that will apply to funding priorities.

Dr. Lambrew said this year's budget includes an additional $100 million for the global AIDS initiative: $26 million goes to prevention, $54 million to USAID, and $10 million each to the Department of Defense and Department of Labor. Responding to a question from Mr. Dellums, she said there is a $431 million discretionary increase for FY 2000. Of this amount, $100 million is for international programs, and $331 million is for domestic programs. The prevention piece is about $66 million for both sides. An additional $10 million goes to the "Know Your Status" Campaign.

Victoria Sharp asked if the $11 billion amount for FY 2000 includes all Federal programs. Dr. Lambrew said it does.

Dr. Lambrew said the Global AIDS Vaccine tax credit will provide $1 billion in credit over 5 years, beginning in 2006, to provide incentives for vaccine development. This year's budget also includes a 12 percent increase for HOPWA activities.

Dennis Williams
Deputy Assistant Secretary for Budget, DHHS

Dennis Williams summarized several budget tables. Total spending on AIDS jumped from $3.7 billion in 1993 to $9.2 billion (proposed) in 2001. This growth averages out to a 12 percent increase every year. Within that total, discretionary spending has grown from $2.1 billion to $4.9 billion — an average annual increase of 11 percent. Funding for treatment has grown faster than any other functional category beside discretionary programs, at a rate of about 21 percent per year. Research and prevention funding has grown at a rate of 7 to 8 percent per year. For Federal expenditures under entitlement programs, spending has grown from $1.6 billion to $4.3 billion — an average annual growth rate of 13 percent.

In the 2001 budget, total DHHS spending is estimated to grow by $716 million, or 8 percent, over FY 2000. Of this amount, $400 million is for entitlements, and $316 million is for discretionary programs. There is a $125 million, or 8 percent, increase in Ryan White funding; $26 million of this amount will be used to purchase AIDS drugs, and $33 million will be used for early intervention service grants under Title III. The budget also includes $105 million for research on vaccines and to improve treatment efforts at NIH. A total of $267 million will be devoted to AIDS vaccine research.

There is a proposed increase of $66 million for prevention programs at CDC; $40 million will go to expand domestic programs, and $26 million to global programs. Finally, there is a $24 million increase spread over all DHHS programs targeted to HIV/AIDS in minority communities.

Questions/Comments: Mr. Isbell commented that the increase for CDC's domestic programs is slightly misleading. In fact, the national prevention program got much less than a $65 million increase. When the numbers for CDC and NIH are bundled together, it masks the fact that NIH got much larger increases over time than did CDC. Mr. Isbell said he believes the annual increase for CDC has hovered around 3 to 4 percent, and SAMHSA has been flat funded. He noted that prevention funding in the 1990s has flattened out while the epidemic has expanded. Additional funding for prevention is badly needed.

Dr. Williams clarified that the main distinction is between increases in treatment on one hand and research and prevention together on the other. Mr. Isbell said this is a false distinction; the problem lies in lumping research and prevention together. Dr. Williams said that funding for prevention has grown at roughly the same rate as research: 7 to 8 percent per year. Mr. Isbell said the figures produced by the AIDS Action Council indicate that prevention funding has increased at about 4 percent per year.

Dr. Lambrew stated that the Administration is aware of the community's requests for increased prevention funding. This year's budget request includes a significant increase for prevention. Funding increases need to be coupled with a renewed focus on outcomes and management issues.

She added that Ryan White reauthorization is a high priority for the Administration.

Ms. Aragón acknowledged that some of the increases in this year's budget are significant and expressed the Council's gratitude for those increases. She said the Council supports Dr. Lambrew's remarks about the need for administrative reforms within CDC. She asked about funding in the FY 2001 budget for the AIDS Drug Assistance Program (ADAP) and the Minority AIDS Initiative. She noted that proposed funding for both programs is well below what the community has requested.

Dr. Lambrew said the Administration feels quite good about the President's budget. She added that the Administration is willing to work with Congress to find more money. She suggested that the Council put pressure on Congress in coming months to facilitate that process. The CBC initiative is a priority for the Administration.

Dr. Williams stated that ADAP is important, and OMB will work hard to secure maximum funding for it. He noted that Medicaid is also a big source of financing for drugs; the Maine waiver will bring a lot more people into Medicaid and provide additional assistance for residents in that State.

Dr. Williams said 1999 funding for the CBC initiative is only now being put in place. It is important to allow time for the initiative to establish itself. Once that occurs, the pace of growth can increase.

Charles Blackwell asked about the increase for the Indian Health Service (IHS). He said he has worked to get IHS to be more responsive, and IHS has responded that it needs more money. Mr. Blackwell said he does not recall a specific mention of HIV/AIDS funding for IHS in the proposed budget. Dr. Williams said IHS has a large services budget, and HIV/AIDS service is included in that category. Mr. Blackwell asked if any of the IHS increase is specifically earmarked for HIV/AIDS services or activities. Dr. Williams said IHS is working with CDC to be more aggressive in its prevention programs. Mr. Blackwell asked if it would be fair to assume that there is a certain amount of discretion in the use of funds within IHS. Dr. Williams said some discretion is exercised.

Mr. Boswell asked to what extent the number of HIV-positive patients is growing within Medicare managed care. Dr. Lambrew said there were a couple of well-publicized cases last year where managed care plans were acting in bad faith vis-a-vis treatment of HIV-positive patients. Changes in Medicare managed care have led to withdrawals of plans and limitations imposed on drug benefits. This is why the President has proposed a Medicare drug benefit. In this year's budget, the Administration has added $35 billion for catastrophic stop-loss coverage. The Medicare managed care system is not working well; the Administration has developed a proposal to reform the way managed care plans are paid. Under the measure, the plans would be paid based on their costs, with risk adjustment, and split the amount paid by the Government and the beneficiary. This will make Medicare more competitive.

Dr. Lambrew said the risk adjustment will be implemented this year and will apply to 10 percent of

total payments to managed care plans. Congress disagrees with HCFA on this issue.

Mr. Boswell said he is concerned that many providers serving those with HIV/AIDS are seeing a disproportionate number of those patients. They are at particular risk if they are not being reimbursed at adequate rates. What is the timeline for meaningful change?

Dr. Lambrew said Congress is trying to slow the process down, but risk adjustment is supposed to be fully implemented in 2004. She said some basic benefits of managed care should be available to all beneficiaries regardless of whether they are enrolled in a managed care plan.

Mr. Boswell asked Dr. Lambrew to investigate the actual number of HIV-positive patients in Medicare managed care. Dr. Lambrew said she would look into it.

Referring to the Maine waiver, Phillip Burgess asked whether OMB could review the policy that requires waivers be budget neutral. Dr. Lambrew said budget neutrality is an Administration-wide policy, and it has held up well. The goal is to see how the Maine waiver works; it may pave the way for a broader conception of budget neutrality. More evidence is needed. OMB hopes that the Maine waiver can be replicated.

Mr. Burgess asked how much time OMB would need to examine the Maine waiver before moving forward to other States. Dr. Lambrew said Tim Westmoreland could answer that question. Dr. Williams said the Maine waiver is a 5-year demonstration project. Dr. Lambrew said Jeffords-Kennedy demonstrations will serve as a test case; they will not be budget-neutral and should be implemented within 5 years.

Dr. Gomez expressed concern with Dr. Lambrew's comment that the Administration needs to wait on outcome measures before investing further in prevention. She said maintaining 40,000 new infections for the last few years is a powerful outcome measure of the United States' success in prevention. She asked what additional outcome measures would be useful.

Dr. Lambrew said there is a new Government Performance Review goal for CDC to reduce the number of new HIV infections by 5 percent by the end of FY 2001. She clarified that funding is not conditional on outcomes, but CDC is working on additional performance measures. Melany Nakagiri of OMB commented that CDC has talked about measuring the number of people tested for HIV. She added that OMB and CDC would welcome the Council's input on appropriate outcome measures.

Dr. Levine asked OMB to clarify the actual numbers for prevention increases since 1992. She also thanked OMB for its work, and commented that the lack of attention to prevention is frustrating.

Mr. Milanes asked the panelists to explain why the Office of Minority Health (OMH) did not get an increase in the proposed budget. Dr. Williams said the budget numbers represent an effort to maximize

the resources available for programs that actually deliver services to the community.

Ms. Lewis asked where OMH fits into the Federal HIV/AIDS response. Mr. Murguia responded that OMH coordinates minority health activities across DHHS. It is a staff/policy office reporting to the Surgeon General. OMH administers several grants programs that fund minority community-based organizations to carry out prevention or access to services activities. OMH also implements a number of cooperative agreements with national minority organizations. OMH's goal is to get agencies to do as much program work as possible; its major function is to provide policy guidance. Mr. Murguia stated that he has been the AIDS coordinator for OMH for the last 10 years.

Ms. Miramontes asked for clarification on the increase over last year for vaccines research. Dr. Williams stated that there is a 12 percent increase from last year.

HIV/AIDS and the Asian/Pacific Islander Community

Mr. Lew introduced the panel, stating that it was the fourth in a series of presentations to the Council on the impact of the epidemic on different racial and ethnic populations. He said he and Mr. Bau would be participating in the presentations to brief Council members on key policy issues. He noted that the API HIV/AIDS community is a small one, so everyone knows each other. This made it easier to pull together a comprehensive overview. He said the Council had developed a policy paper over the last year identifying key Federal policy issues affecting the API community. Each agency representative on the panel will address these issues.

Mr. Lew said he was pleased that the President recently signed an executive order to increase the participation of APIs in Federal programs, as well as to increase the responsiveness of DHHS programs to APIs. He welcomed Shamina Singh, who was appointed by the President in September 1999 as Executive Director of the White House Initiative on APIs. Ms. Singh oversees the development of an interagency working group and a presidential advisory commission. She has a long history of working with Federal policy initiatives.

Mr. Lew commented that national data does not tell the story of the epidemic in the API community. Surveillance systems are not able to capture the important data. Data collection surrounding APIs did not start until the late 1980s, so the documentation of AIDS cases broken out according to race did not start until then. He said the API community is still in a dialogue with CDC to enable State health departments to report out HIV/AIDS cases by ethnicity. The API epidemic is focused on local communities and is concentrated in certain geographic regions.

Shamina Singh
Executive Director, White House Initiative on Asian Americans and Pacific Islanders

Ms. Singh commended the Council for recognizing the unique needs of APIs with HIV/AIDS. Larger issues facing the API community include barriers to care as a result of inadequate translation services and the citing of insufficient data as a reason for inaction. It is important to remember that APIs comprise more than 30 subpopulations and 100 languages. Such a diverse community runs the risk that its needs may fall through the cracks.

APIs are often perceived as a community of wealthy physicians and engineers, but President Clinton signed the executive order to improve life for APIs because they come from all walks of life. In 1990, APIs comprised just over 4 percent of the population. They are concentrated in California, New York, Hawaii, and Washington, as well as in the six U.S.-associated Pacific island jurisdictions. By 2020, the Census Bureau estimates that 20 million APIs will be living in the United States — a 177 percent increase since 1990.

The dire needs of individual API communities remain invisible. Forty-six percent of Southeast Asian Americans live below the poverty level, compared to 8 percent of whites. Hmong have only a 31 percent high school graduation rate; American Samoans and Palauans have a 50 percent graduation rate. Mortality and morbidity rates in the Pacific Basin are much higher than on the U.S. mainland, and API women have the lowest rates of mammograms and pap smears.

The Administration recognizes that APIs are diverse and have been historically underserved by Federal programs. There is overwhelming evidence that Federal agencies were not taking the necessary steps to identify the needs of APIs through disaggregated data collection. DHHS played a critical role in advocating for the President's executive order on APIs. Ms. Singh recognized Mr. Bau for the role he played in this process.

Ms. Singh said the White House Initiative on APIs is housed within HRSA. The executive order calls for all executive branch departments to increase the participation of APIs in Federal programs where they may be underserved. It also calls for public and private partnerships with community groups and State and local governments, and mandates more research and data collection on API subpopulations. The order establishes a 15-member Presidential Advisory Commission on APIs and an Interagency Working Group, composed of Deputy Secretaries of designated Federal departments, to advise the President, through the DHHS Secretary, on initiative activities.

Ms. Singh said very little data has been collected on APIs as a whole, and even less on HIV/AIDS within the API population. When data is collected, it is almost never disaggregated to separate out the various ethnic groups. This lack of data collection often leads to neglect by the Federal government. Without it, the Administration cannot support requests for programs and funding. Lack of data does not mean that a problem does not exist, and it should not translate into inaction. There are exemplary but underfunded models of prevention and treatment that need support.

Ms. Singh reminded the Council that this week is API Census Week. She attended a kick-off event

yesterday and was reminded of the unparalleled growth of the API population in the last 10 years. She related a story about a Cambodian woman who was asked to testify before the first meeting of the Interagency Working Group on APIs. The woman, whose husband and children were killed by the Khmer Rouge, traveled to Washington but refused to testify on the day of the meeting because of a paralyzing fear of government and authority. This story illustrates the kinds of cultural barriers that prevent APIs from obtaining lifesaving health and social services.

Immigration, whether to flee persecution or to search for economic opportunity, is a major factor in the growth of the API population; two-thirds of APIs are foreign-born. Four of the five top immigrant groups in the United States are from Asia: Vietnam, Philippines, China, and India. APIs, particularly those with language barriers, are underserved by the health care delivery system. Twenty-one percent of API adults have no health insurance; forty-one percent of Korean Americans are uninsured. Forty percent of APIs have limited English proficiency. Existing health policy does not adequately address access to linguistically or culturally competent services.

Ms. Singh said executive orders can serve as a catalyst for action around issues for those who are voiceless and underserved. She said she will do everything possible to engage the necessary stakeholders to tackle the problem of HIV/AIDS in the API community. She asked for the Council's partnership as the White House Initiative on APIs moves forward.

Mr. Lew's comments: Mr. Lew commented that the issues of data collection and proper usage of data are critical. Insufficient capacity at the local level and systemwide is also a problem. Federal agencies need to work to reduce language barriers and provide culturally competent care and prevention.

Mr. Lew introduced Mr. Bau, who has worked with many API health organizations across the United States. Mr. Bau represents the Asian and Pacific Islander American Health Forum, which is the one nationally funded organization that has worked with many API AIDS service organizations in prevention. Mr. Bau also led coalition-building efforts prior to the CBC initiative that called for a state of emergency in the African American and Latino communities.

Ignatius Bau
Council Member and Policy Director, Asian and Pacific Islander American Health Forum

Mr. Bau provided the Council with a demographic overview of APIs and presented data showing how the epidemic has spread among this population. From 1980 to 1990, APIs grew from 1.6 percent of the U.S. population to 2.9 percent of the population: a 95 percent increase. The increase in APIs from 1990 to 2000 is expected to be the highest of any racial/ethnic minority in the United States. It is important to note that APIs identify with their ethnicity or national origin; there is no such thing as an "Asian" or "Pacific Islander." Population increases vary widely among subpopulations. The API population is also highly concentrated: 70 percent of APIs reside in six States (i.e., California, New

York, Hawaii, Texas, Illinois, and New Jersey). Health care strategies specific to the API population need to be driven by State and local agencies. Within States, strategies can be further targeted to specific metropolitan areas where most APIs reside (i.e., Los Angeles, Honolulu, Queens, Santa Clara County, Orange County, San Francisco, Cook County).

The CDC Surveillance Report on HIV/AIDS shows that the cumulative total of API men who have contracted HIV/AIDS through homosexual contact is among the highest of all racial/ethnic groups and is closer to rates found in the white community than it is to rates in other minority groups. In other words, the disproportionate impact of HIV/AIDS is on gay men within the API community. From July 1998 to June 1999, more than half of newly reported AIDS cases among APIs occurred in MSMs. This trend bears out for HIV reporting as well.

There are only 588 cumulative AIDS cases among API women, and 48 percent are due to heterosexual contact. It is important to note that the cumulative percentage of API women who have a risk factor that is not reported or identified is the highest among all racial/ethnic groups. Researchers are not sure why this is the case; it could be due to inconsistencies in data collection.

Dr. Pascale Wortley of CDC recently published an article on APIs and HIV/AIDS. It is the first such article published by the agency. According to the article, the top five States reporting AIDS cases among APIs are California, New York, Hawaii, Texas, and Washington. Seventy-eight percent of cumulative API AIDS cases are found in these five States. The article confirms that the majority of API male AIDS cases from 1992 to 1996 are due to heterosexual contact. Similarly, heterosexual contact is the leading mode of transmission among API women.

CDC was also able to examine data by country of birth. The highest number of API AIDS cases is found among those born in the Philippines, followed by those born in Vietnam, China, Japan, and India.

Mr. Bau noted that health officials in Guam questioned Dr. Wortley's numbers for Guam. They discovered that surveillance reports for Guam had not been sent to CDC; numbers were simply reported through the community planning process. The Guam Health Department is now reporting to CDC, so numbers for Guam will jump in the next CDC surveillance report.

Dr. Wortley concluded that potential misclassification of race/ethnicity among APIs, underreporting of API cases, and cultural barriers must be addressed. She recommended that expanded race/ethnicity information be collected, that the information be self-reported, and that CDC collect more data on specific subpopulations. She also recommended that the data be used for community planning and HIV prevention in subpopulations, and that cultural norms related to sexuality, privacy, and family dynamics be taken into account in prevention programs.

Mr. Bau ended his presentation by displaying AIDS surveillance reports from Oregon and Hawaii, both of which provide breakdowns by mode of transmission and racial/ethnic categories. These are

examples of how data can be presented even when the numbers are small. He also showed a chart produced by the New York City health department in which API and Native American AIDS cases are presented on a scale separate from other ethnic groups. In the latest *Morbidity and Mortality Weekly Report* on gay men of color, the CDC emulated this example.

Questions/Comments: Mr. Lew noted that voluntary-based efforts to address the epidemic in APIs began in the late 1980s in Los Angeles and San Francisco and continued later in New York and Hawaii. Significant networks have emerged in these communities. In San Francisco and New York, there have been efforts to bring elected API officials into AIDS education campaigns. Local delivery systems in these areas have partnered with community organizations to develop primary care services, bilingual case management, and support services to serve APIs.

Mr. Lew pointed out that HRSA has produced a handbook on AIDS prevention and care for APIs. The Asian Pacific Islander Wellness Center worked with HRSA to produce the handbook, which is meant to be a guide for culturally competent care for physicians and nurses working with HIV-positive APIs.

Mr. Milanes asked Mr. Lew to elaborate on how cultural norms can be incorporated into prevention efforts. Mr. Lew said HIV is not in the realm of public or family discussion within the API community, but there is a strong group norm in terms of support. There is often indirect acknowledgment of homosexuality or HIV status. This is an important factor in devising strategy for prevention campaigns, and many community-based organizations are engaging local leaders to encourage family acknowledgment. Confidentiality is an issue, but it does not preclude effective interventions.

Mr. Anderson asked Mr. Bau if he had seen a link between U.S. immigration policy and the willingness of API immigrants to accept counseling and testing services. Mr. Bau said the major concern is that many people are actually excluded from Federal health services due to the 1996 immigration reform laws.

Dr. Levine commented that the issue of translation and language poses a significant barrier to care at Los Angeles County Hospital and asked what is being done to address this problem. Mr. Bau said there is a group called PALS in Los Angeles that provides health interpretation services. There are similar groups in cities with significant API communities. As a fall-back, ATT operates a translation service, but it is not optimal.

Mr. Lew noted that doctors have had to pull maintenance workers out of the hospital to translate for patients, so quality translation is a critical need. Making patient education materials available on the Web in many languages is one opportunity that should be investigated.

Mr. Dellums commented that the Council only has 9 months left to make a difference. He said he feels that a consensus is evolving to embrace AIDS as a global pandemic. He asked Mr. Lew what actions

the Council can take in 9 months to make an impact on the epidemic among APIs.

Mr. Lew said Mr. Bau has developed a workplan in collaboration with organizations in the API and the Native American community. The plan offers a long list of specific recommendations. It is included in Council members' binders.

Virginia Bourassa
Public Health Analyst, HIV/AIDS Bureau, HRSA

Virginia Bourassa said she is new to HRSA; she has spent most of her career working at the grass roots level. She talked about the HRSA API handbook for physicians and nurses, previously mentioned by Mr. Lew. The handbook is meant to be a model to distribute information to places where the API community is smaller than in the major cities.

In addition to developing the handbook, HRSA in FY 1999 examined community planning grants for Title III and funded two API community organizations: the Waikiki Health Center in Honolulu and the Asian Pacific Islander Coalition on HIV/AIDS in New York.

She said the correction of underreporting in Guam had resulted in an increase in Title II funding for Guam. There is never enough data. She said HRSA needs the Council's support to request more support for data collection. HRSA's Office of Science and Epidemiology recently produced a report that looks at client-level data from Orange County, Los Angeles, and San Francisco. With that data, HRSA was able to pull out enough information to examine how APIs access service. The report found that APIs access service later, and the way that APIs look for support is very different.

HRSA also supports Special Projects of National Significance to evaluate innovative service models. Under this project, HRSA funded Abacha [?] in New York to look at one of these models. In addition, HRSA has developed CareWare, a data collection software package that will be distributed for free.

Ms. Bourassa said HRSA increased the number of APIs on its objective review panels from zero to three in 1999. She called this a good start. She encouraged the API community to apply for Title III pre-application technical assistance. She acknowledged that HRSA can do a lot more for APIs.

George Roberts
Special Assistant for Communities of Color, Division of HIV/AIDS Prevention, National Center for HIV, STD, and TB Prevention, CDC

Dr. Roberts commented that CDC recognizes the issues raised around surveillance of APIs and is making some progress in that area. CDC knows that national data do not tell the complete story, but

the agency must start with the national data to make resource decisions. CDC intends to work more closely with State departments to collect more specific data.

CDC is providing funding to API organizations in three major areas: capacity-building, community-based HIV prevention service delivery, and awards to State and territory health departments through the community planning process. This funding amounts to about $7 million. Most of CDC's funding goes to State and local health departments. The agency follows three principles in allocating money to States: 1) Community voices are essential in setting prevention priorities; 2) HIV prevention funding should follow the epidemic; and 3) Intervention should be based on sound science and public health practice.

There has been a shift in community planning from investment in counseling and testing to investment in health education and risk reduction. Most community-based organizations targeting high-risk populations have been funded for the latter. About $4.3 million in State awards is devoted to health education and risk reduction. More than $500,000 goes to Pacific Island territories. CDC held a meeting last year to bring together representatives from these territories to discuss their prevention needs and develop strategies.

For FY 1998 and FY 1999, there was 3 percent API representation on community planning groups. When compared to API AIDS prevalence, which is about 1 percent nationwide, CDC is doing a good job in terms of matching prevalence. CDC's directly funded community-based organization program supplements State resources; $1.6 million has been distributed to eight API organizations through this mechanism. One of these is in Guam. These organizations develop education activities targeted to the entire API community, not just MSMs. Activities include workshops, skits, discussion groups, and translation services.

CDC also distributed $800,000 to the Asian and Pacific Islander American Health Forum and the Asian and Pacific Islander Wellness Center to provide capacity building assistance. The organizations train API leaders to be involved in HIV prevention, enhance community planning efforts, mobilize populations at highest risk, disseminate information on HIV/AIDS, and develop technology transfer programs.

CDC has been working on a communities of color strategy to develop a comprehensive approach to address prevention needs in minority populations. The goal is to reduce transmission of HIV by better characterizing the epidemic, assessing prevention needs, assessing the degree to which CDC-funded activities are appropriate, evaluating staffing resources, and recommending strategies to address shortfalls.

Judith Auerbach
HIV Prevention Science Coordinator and Behavioral and Social Science Coordinator
Office of AIDS Research (OAR), NIH

Dr. Auerbach provided a brief description of how NIH is organized. NIH houses 25 separate Institutes, most of which carry out their own AIDS research programs. OAR was created by Congressional mandate to organize the AIDS research program across NIH in cooperation with all 25 Institutes and to drive the scientific agenda as well as the budget. OAR updates a strategic plan for AIDS research each year. The plan includes a cross-cutting area on racial and ethnic minorities.

NIH has historically organized its AIDS research program into five scientific areas: etiology and pathogenesis, vaccines, natural history and epidemiology, therapeutics, and behavioral and social sciences.

In the area of behavioral and social sciences, that National Institute of Mental Health (NIMH), the National Institute on Drug Abuse (NIDA), and the National Institute on Child Health and Human Development (NICHD) are all supporting AIDS-related projects for APIs. NIMH is supporting researchers in San Francisco who are studying sexuality, culture, community mobilization, and HIV risk among API MSMs. At Columbia University, researchers and community-based organizations are collaborating to evaluate an intervention for transgendered youth in Hawaii. NIMH is also supporting a dissertation at Columbia that is addressing abstinence and condom use among API youth. At the University of California-Los Angeles, researchers are looking at data from San Diego city high schools to investigate health risk behaviors among API youth and to compare those behaviors with those practiced by youth of other racial/ethnic groups in the same community.

NIDA is funding a researcher in San Francisco who is looking at the determinants of drug and hormone use, HIV risk, and protective behaviors among male-to-female transgendered persons who are engaged in the commercial sex trade, with a focus on APIs.

In addition, NICHD is funding a large longitudinal study of adolescent health, which includes an oversample of Chinese youth. The study examines social, environmental, psychological, and genetic influences on health risks and behaviors, including HIV/AIDS.

In the area of secondary prevention, NIMH conducted a grand rounds session at Columbia University that included a community forum on HIV/AIDS in Asian immigrants and refugees. At the University of California-San Francisco, researchers are investigating HIV incidence and prevalence and co-infection among API MSMs who frequent gay venues in San Francisco.

NIH-funded studies on basic biological research include a NIDA-supported study at Johns Hopkins University that is examining the role of genetic HIV diversity and disease progression. At the University of Hawaii, investigators are studying therapy for HIV infection and associated opportunistic illnesses and malignancies among APIs. Several partners have been recruited to this effort, which includes training for minority investigators.

Dr. Auerbach added that many NIH Institutes are conducting international studies on HIV in APIs. She

cited four factors contributing to the limited number of NIH studies on HIV/AIDS among APIs. She said APIs are generally ignored at the Federal level, in part because the API population in Washington, DC, is so small, and because APIs are not well represented in policy arenas. Second, because it appears that HIV infection rates are low in the API community as compared to other racial/ethnic minority communities, there is a resistance to focusing resources on the API community.

Third, Dr. Auerbach pointed out that APIs are not a monolithic community, but they have become a convenient demographic category. Cultural, linguistic, and economic factors that vary among the API subpopulations are lost in this aggregation. This may have implications for the development for culturally appropriate interventions. On the other hand, if the data is disaggregated, the numbers are too small to observe change over time.

Fourth, the dearth of researchers looking at HIV/AIDS among APIs limits the growth of NIH's portfolio.

Dr. Auerbach stated that OAR tries to push the AIDS research agenda with the Institutes. The office involves people from outside the government to implement its research agenda; representation of APIs in these activities has grown. OAR is also looking into the possibility of conducting more workshops and training activities in API communities.

Questions/Comments: Dr. Levine noted that NIH is also funding a Women's Interagency HIV Study site at the University of Hawaii. She commented that NIH might get more "bang for the buck" by going back to each multisite study and asking researchers to pull out data for APIs.

Mr. Isbell asked if there has been any effort to collect data to support prevention services targeted to APIs in the geographic regions where they are clustered. Mr. Bau said his organization conducted a survey of health departments in the top ten States with the largest API populations, asking how much money was targeted to API prevention programs. Texas, Florida, New Jersey, Houston, and Orange County replied that they are devoting no money to API prevention.

Dr. Roberts said CDC is aware that the epidemic among APIs is concentrated in a few regions. Most of the CDC-funded organizations targeting prevention services to APIs are located in California and New York.

Dr. Gomez asked if conducting population-based studies on sexuality would be accepted by the API community. Mr. Bau said he would love to see the kinds of studies that Rafael Diaz has conducted in the gay Latino community replicated for APIs. Mr. Lew added that there is an opportunity to do multisite studies to look at cultural barriers and opportunities.

Dr. Auerbach said the NIH Plan for AIDS-Related Research emphasizes risk and resilience among racial/ethnic communities; this research is appropriate for NIH funding.

Mr. Burden said comparative analyses on incidence rates among API subpopulations in specific geographic areas would be useful. The clearly defined demographics of the API community offers a unique opportunity to conduct these studies.

Dr. Boswell asked what clade of virus is present in the API community. Dr. Auerbach said she is not sure, but it would depend on how native the population is. Mr. Bau noted that 80 percent of the API foreign-born population has been in the United States for at least 10 years, so HIV was likely acquired in the United States for most of this group. Dr. Auerbach said she would inquire about specific clades and would get back to Dr. Boswell.

Nathan Stinson
Deputy Assistant Secretary for Minority Health, DHHS
Director, OMH, NIH

Dr. Stinson said DHHS has carried out several minority initiatives over the last year. Some have been tied to minority institutions of higher learning for Latinos, African Americans, and Native Americans. The Department also initiated the API Action Agenda. These programs allow DHHS to focus on the health needs and potential interventions to elevate the health status of racial and ethnic groups.

About a year ago, DHHS decided to establish a Department-wide steering committee to oversee the management of all minority initiatives. This move created a captive audience of agency heads and their deputies and consolidated all DHHS minority initiatives. Dr. Stinson said he hopes planning and reporting on minority programs becomes second nature within DHHS. The Department needs to have funding targets for minority programs.

A congressional measure passed in 1998 directed OMH to establish an Advisory Committee to advise the Secretary and the Department on the health of racial and ethnic groups. OMH has a budget of only $38 million, so leadership is needed from across the country to hold the Department accountable for programming directed to minorities. Dr. Stinson said the Advisory Committee will serve to voice the community's concerns. Nominations to the committee are still being processed.

OMH is a staff office but has direct grant-making authority, so it can reach directly into the minority community. About $10 million of OMH's budget is directed toward HIV/AIDS-related activities. OMH employs three mechanisms to allocate this funding: 1) Support for community coalitions; 2) Cooperative agreements with national organizations; and 3) Support for capacity- building and technical assistance to regional centers.

Dr. Stinson emphasized that a lack of data should not be used as an excuse for inaction. Collecting broad data obscures where the epidemic is spreading. He said OMH is pleased to be working with the White House Initiative on APIs; this collaboration will make it easier for OMH to accomplish its goals. OMH will continue to be vocal for racial/ethnic groups and their health needs.

Valerie Mills
Associate Administrator for HIV/AIDS, SAMHSA

Ms. Mills noted that SAMHSA is a "new birth" agency when it comes to receiving funding for HIV/AIDS. SAMHSA recognizes that API subpopulations are diverse, and programs directed to these groups must take into account differences in culture and language. SAMHSA is divided into three divisions: the Center for Substance Abuse Treatment, the Center for Substance Abuse Prevention, and the Center for Mental Health Services. Ms. Mills introduced Dr. Tiffany Ho, who has been working on designing mental health programs directed to APIs. Ms. Mills noted that SAMHSA staff is small; she works with three AIDS coordinators, one in each SAMHSA center.

SAMHSA has developed several programs targeting APIs. The Community Mental Health Services (CMHS) block grant program funds transition from homelessness programs in American Samoa and Guam. CMHS has also organized a meeting between SAMHSA, OMH, and API community leaders in Wisconsin, Utah, Nebraska, and Minnesota, to discuss API mental health and substance abuse needs. A national summit on the same topic was held last July.

CSAT has carried out a State treatment needs assessment in American Samoa to describe and qualify problems associated with alcohol and drug abuse, and has supported a study of methamphetamine use in Guam and the Commonwealth areas. Additional CSAT studies have looked at violence and youth in Guam.

SAMHSA has produced a booklet, *Snapshot*, that lists all SAMHSA programs that are up for renewed funding. SAMHSA recognizes that it lacks adequate staff and resources to respond to its knowledge, development, and application programs and the GFAs [?]. SAMHSA is looking at how it can enhance the API application pool. The agency recognizes that there is a lack of data that would aid the API community in applying for these programs, and there is a lack of resources to travel to grantee and technical assistance meetings.

SAMHSA recently held three technical assistance meetings — in Atlanta, Kansas City, and San Diego. Ms. Mills asked for a tally of API participants at these meetings; she was not able to obtain this information.

Last year, SAMHSA received $34 million targeted to racial/ethnic minorities through the substance abuse block grant program. Out of the $34 million, 118 grantees were funded:
34 grantees were located in African American communities, 32 were in unspecified communities, 28 were in African American and Hispanic communities, 9 were in Hispanic communities, and 5 were in other racial/ethnic communities.

SAMHSA recognizes there is a need to bridge the gap. The agency is interested in holding a forum for

API community leaders to speak with senior policy staff members.

Questions/Comments: Mr. Dellums again stated that AIDS requires a global strategy. He said the United States is becoming increasingly racially integrated; this trend has implications for how AIDS is addressed. The API is a small community in the United States, but it provides a window to the rest of the world. If a global approach is adopted, perhaps more research funding can be directed to APIs. In Asia and India, AIDS is a ticking time bomb. The United States has an opportunity to change the paradigm and exploit its own diversity.

Dr. Auerbach agreed with Mr. Dellums' perspective. She said NIH has tried to focus on macrosocial forces that affect health risk and resiliency. NIH's approach is not to focus on a particular ethnic group, but to ask what forces a multiethnic society must contend with when providing health services.

Dr. Roberts said he shares Mr. Dellums' vision. CDC is trying to identify common needs of communities of color to put in place comprehensive strategies that address all communities. Prevention needs can be advanced for the white community as well. CDC has begun using data to arm project officers with the information they need to work better with their State grantees around better targeting of resources. However, Congressional language can limit CDC's ability to act globally.

Mr. Lew said the White House Initiative on APIs is a good opportunity to look at the full participation of API communities within the Federal Government. Data and immigration patterns can be examined as part of this effort.

Dr. Boswell asked Dr. Stinson if OMH is seeking gay, lesbian, bisexual and transgendered membership on its Advisory Committee. Dr. Stinson said the law requires that there be three members from each of the four major racial/ethnic groups. He said it will be difficult to get a wide enough range of expertise among 12 people. OMH will try to be as inclusive as possible. As an alternative, OMH can bring in additional consultants who represent different backgrounds.

Mr. Murguia noted that the cover letters soliciting nominations for the Advisory Committee stated that OMH welcomes nominees to discuss their sexual orientation and HIV status in their applications.

Mr. Lew said the Racial and Ethnic Subcommittee is asking for a response from the various DHHS agencies on its API policy recommendations.

Before her departure, Ms. Thurman thanked Mr. Dellums for chairing the meeting, She reminded Council members to focus on what can be accomplished over the next 9 months. She also thanked Dr. Levine, Debra Fraser-Howze, and Denise Stokes for their service on the Council.

Afternoon General Council Session

Mr. Dellums said several items had been distributed to Council members for their input: 1) the DHHS Draft Strategic Plan, 2) the draft Youth and HIV/AIDS New American Agenda, 3) Targeted Minority HIV/AIDS FY 1999 Grantees, 4) U.S. Department of Housing and Urban Development Office of HIV/AIDS housing information, 5) Secretary Shalala's response to Representative Nancy Pelosi's inquiry on the science regarding needle exchange, and 6) a new Council subcommittee list.

Overview of Healthy People 2010

Mark Smolinski, Senior Clinical Advisor
Office of Public Health and Sciences, DHHS

Dr. Smolinski presented an overview on Healthy People 2010, the nation's prevention agenda launched in January. He distributed copies of the document to Council members and described its different components. The agenda has two goals: 1) to increase the years and quality of healthy life, and 2) to eliminate health disparities. The latter goal is a change from Healthy People 2000, which aimed to reduce health disparities and set forth different targets for different racial/ethnic groups. The 2010 plan expands its target populations to include low-income populations, rural residents, the disabled, and gays and lesbians.

DHHS is trying to focus on factors that determine health (i.e., biology, behavior, environment, access to care). Of the ten leading health indicators listed in Healthy People 2010, four apply directly to HIV/AIDS: responsible sexual behavior, substance abuse, access to care, and mental health. Each indicator is presented as a one-page handout in the plan.

Dr. Smolinski showed a graph on responsible sexual behavior indicating that 15 percent of the sexually active adolescent population does not use condoms. DHHS want to increase the proportion of adolescents who are using condoms or are abstinent to 95 percent of the population.

DHHS has developed national maps that portray the status of leading health indicators in each State. The maps are available on the Healthy People Web site and can be downloaded as slides. DHHS's goal is to make the U.S. public familiar with the leading health indicators within the next 10 years; the Department is discussing marketing and advertising strategies to do this, and Dr. Satcher has made this goal a priority. The final edition of Healthy People 2010 will be released in November at the annual American Public Health Association meeting. The draft document is currently available online and on CD-ROM.

Questions/Comments: Mr. Bau commended DHHS for being so responsive to racial/ethnic communities in drafting the Healthy People 2010 goals and praised the plan for making it clear that one goal applies to all racial groups. He also commended DHHS for breaking out "data not available" into

three categories. Mr. Bau asked what the Department is doing to make sure that other Federal agencies know about the Healthy People objectives.

Dr. Smolinski said DHHS hopes to develop a strategic plan to implement Healthy People 2010 in a more aggressive way than what was done with Healthy People 2000. The Secretary and the Public Health Council will hold a meeting on April 6 to discuss implementation. DHHS wants to make sure that all DHHS agencies use Healthy People measures in addition to Government Performance Review measures. The Department is also trying to get partners to adopt single objectives and work toward achieving those objectives. DHHS will also stage a town hall meeting on implementation during the Prevention 2000 meeting in Atlanta.

Ms. Lewis commented that the NAACP could use Healthy People 2010 in its workshops targeting community groups.

Dr. Gomez suggested that DHHS make slides and graphs available as Powerpoint downloads. Dr. Smolinski said 70 slides can be downloaded off the Web site.

Mr. Anderson asked if Healthy People 2010 includes specific objectives relevant to sexual minorities in areas other than sexual responsibility. Dr. Smolinski said there are many objectives that are relevant to sexual minorities, but there is no data to support reporting out a cell on sexual orientation. The Gay and Lesbian Medical Association published a literature review on science related to gay and lesbian health. There is a minimum template for every Healthy People objective that reports sex, racial/ethnic category, income, and education. Beyond that, there are select population templates. DHHS is going through a process of review to make sure that national data sources support the different objectives. Scientific integrity is a primary concern.

Dr. Gomez said she was a member of the IoM panel on lesbian health research priorities. The IoM report requested that a question identifying sexual orientation be included in Federal research studies.

Dr. Smolinski said his office sent out a memo asking agencies to put sexual orientation into a subset of objectives where DHHS feels it is relevant. The only objectives that DHHS took out were ones that relied on Vital Statistics data. A uniform format needs to be put in place for all data sources. An additional section discussing data collection in small communities will be added to the final draft of Healthy People 2010.

Overview on HIV/AIDS and Medicaid

Tim Westmoreland
Director, Center for Medicaid and State Operations, HCFA

Mr. Westmoreland said he was asked to address a few specific questions before the Council. First, he

addressed the Maine waiver, which was recently approved. He said the Maine waiver should set a new paradigm and pave the way for additional waiver applications. He said he had received only one other concept paper, from the State of Georgia. Maine's application was approved in part because there are so few people with HIV/AIDS in Maine, and in part because Maine agreed to a 14 percent drug discount for people participating in the demonstration project.
HCFA is developing Section 1115 HIV/AIDS demonstration project guidelines. These should be issued soon in the form of a "Dear State Medicaid Director" letter.

Mr. Westmoreland said Council members should encourage States to submit concept papers early. The numbers do not need to be finalized. HCFA can only deal with a State Medicaid agency when approving waivers.

Second, Mr. Westmoreland discussed the Administration's time frame regarding budget neutrality. The issue of budget neutrality has come up with Federal foster care programs as well. It is an ongoing discussion, and Dr. Lambrew is the point person on the issue. There is a possibility of working on a 7-year budget neutrality model instead of a 5-year model. Maine was able to achieve budget-neutrality in 5 years, so a 7-year model was not necessary.

Third, HCFA did not become involved in the Maine drug discount negotiations and does not plan to enter into negotiations in any State. Various States have asked for copies of Maine's terms and conditions.

Mr. Westmoreland said HCFA aims to have two programs related to the Work Incentive Act in place by October 1 (awards will be made October 1). One project will provide $150 million over 5 years for infrastructure, and a second demonstration project will allow States to make people who meet the income and assets standard but are not yet disabled eligible for Medicaid. The second project will provide $250 million over 6 years and is mandatory. Mr. Westmoreland noted that drugs treating depression and breast and cervical cancer drugs might also fall under the demonstration project.

Mr. Westmoreland also addressed how HCFA monitors and ensures quality care, given the disparities that the HCSUS study has identified. He said this process is carried out in the regional offices. After 1115 and 1915 waivers are approved, regional offices are responsible for conducting site visits to ensure quality. HCFA continues to receive incomplete data from State offices. Even with the mandated Medicaid Statistical Information System, 12 States are sending no data, and 15 to 20 States are sending incomplete data. Mr. Westmoreland said he spends a great deal of time trying to improve data collection. Criticisms of quality should be sent to the regional and central offices.

Finally, HCFA is working on regulations resulting from the 1997 Balanced Budget Act that require quality of care for beneficiaries of Medicaid managed care. Proposed regulations have been issued, and the comment period is closed. Counsel has told Mr. Westmoreland that he cannot discuss where the regulations are going. HCFA is also required to produce a report on safeguards for people with special

health care needs enrolled in Medicaid managed care. Some AIDS groups have been involved in that process.

Questions/Comments: Dr. Cooper asked if there is a possibility that HCFA's reluctance to enter into discussions regarding drug discounts may harm smaller, less capable States and developing nations. Mr. Westmoreland said issues around global drug pricing and patent protections should be held in the context of the Medicare prescription drug benefit. Those discussions are ongoing within the Administration and on Capitol Hill. Scientific innovation complicates pricing problems, particularly in the HIV/AIDS realm. Recovery on investment becomes shorter and shorter, not because patent life expires, but because a drug may become obsolete due to innovation. Mr. Westmoreland said he would prefer to take small steps with a few HIV/AIDS drugs in a few States rather than deal comprehensively with drug pricing.

Mr. Lew asked what the time frame would be for larger States applying for waivers. Mr. Westmoreland said in a State with a large number of recently infected HIV-positive persons with little access to drug therapy, 5 years would not be adequate to show budget neutrality using the Maine method. Seven or 10 years may be adequate for other States. It depends on the case mix.

Ms. Aragón said the Council is concerned that Dr. Lambrew stated that the budget neutrality requirement is law and that a 5-year evaluation period for the Maine waiver would be necessary. Mr. Westmoreland said it is his understanding that the budget neutrality requirement is not law, it is a policy decision that is open to administrative interpretation. He added that he is trying to get the 1115 guidelines out so that States will submit concept papers as soon as possible.

Ms. Aragón asked how additional State applications will dovetail with demonstration money. Mr. Westmoreland said this is an interesting question. Dan Mendelson at OMB suggested that some of the demonstration money may be used to tip the balance for States that could not meet the budget neutrality requirement. This possibility is being discussed.

Ms. Isbell said he was confused by Dr. Lambrew's presentation as well. He asked her to clarify her statement. She responded that the Administration welcomed new applications but that OMB wanted to see the Maine data before the standard is revisited. Mr. Isbell said she suggested that the Maine model would be applied to future applications. Mr. Westmoreland replied that he is trying to keep the options open for additional States. The Administration did not discuss many of the outstanding issues during the Maine process because it was not necessary.

Public Comment
Larry Hochendoner
Philadelphia AIDS Consortium

Mr. Hochendoner said he is the executive director of a Title II planning coalition in Philadelphia with a

budget of just under $5 million. He noted that there is much to do in the next 9 months and recommended that the Council hear directly from planning coalitions and larger EMAs [?] throughout the country. Consumers run the coalition in Philadelphia; it is important for consumers to have input into the Federal policy planning process. For example, during the special initiatives program planning process in Philadelphia, there was little communication relative to minority populations and the review within that EMA, so the data used in the three EMA test sites may be something the Council should examine.

Second, Mr. Hochendoner commented that the Administration may want to tap into its national service program to bolster Federal HIV/AIDS programs.

Subcommittee Reports/Other Business

Research Subcommittee: Ms. Miramontes noted that the Subcommittee has been very active over the last 4 years; it has worked on vaccines, microbicides, and inclusion of women and children in clinical trials. Its membership is "largely vetted out" and new members are needed. Ms. Miramontes asked for one representative from each of the other subcommittees. The subcommittee will conduct most of its work by conference call and will conduct meetings during lunch breaks at full Council meetings.

Members are considering drafting a recommendation to bolster the marketing components of the Administration's prevention campaign. The subcommittee is also concerned about the lack of long-term followup on prevention/behavior change initiatives and may recommend that OAR specifically fund studies on long-term outcomes of prevention strategies. Dr. Auerbach gave the subcommittee an encouraging update on microbicides.

Dr. Boswell said he would like to join the subcommittee. The subcommittee made no formal recommendations.

Prevention Subcommittee: Judith Billings said members suggested inserting HIV/AIDS questions into the presidential debates so that both candidates will be forced to make statements on the issue. Another member suggested looking to the private sector (i.e., marketing, advertising agencies) for help with prevention messages. Using "ethnomedia" and the church to send messages to minority communities was also discussed. Subcommittee members also discussed drafting recommendations after reviewing the ONAP youth report, and how to capitalize on national AIDS organizations' interest in expanding prevention advocacy.

During the subcommittee meeting, Mr. Summers suggested that the subcommittee offer input on the IoM study. Ms. Billings asked Mr. Montoya if such input would be appropriate. Mr. Montoya said ONAP would discuss any Council input during future conference calls with IoM. Mr. Murguia stated that the IoM study is scheduled to be completed by May. Mr. Bau suggested that past Council

recommendations on prevention be shared with the IoM panel. Mr. Montoya asked the subcommittee to indicate which recommendations should be sent to IoM under cover. Mr. Murguia noted that Ms. Thurman's written testimony to IoM is available on the ONAP Web site.

Ms. Billings said the subcommittee would look at the letter from Tom Coates to the President that listed ten suggestions for prevention initiatives. The subcommittee will use the letter as a basis for prioritizing prevention issues.

Ms. Aragón reminded the Council that Ms. Thurman suggested that ONAP create a short summary to accompany the DHHS document on needle exchange. Ms. Thurman also agreed to help the Council identify national groups that should receive the document. Ms. Aragón also reminded Mr. Montoya to obtain slides from the three CDC presenters. Mr. Montoya said Ms. Seiler would send him the slides.

The subcommittee made no formal recommendations.

Services Subcommittee: Ms. Aragón announced that Mr. Minor is the subcommittee's new co-chair. The subcommittee has 10 members, with a mix of new and continuing members. The first conference call is scheduled for April 11. The subcommittee will continue to monitor the 1115 waiver process, demonstration funds, and drug pricing. Members will continue to ask about increased funding for housing programs.

Ms. Aragón reminded Council members to review the youth report; comments can be forwarded through the subcommittee. She asked the subcommittee to think about getting more information from DHHS on technical assistance provided through the Minority AIDS Initiative.

Mr. Minor suggested that the Council support the development of the nutrition guidelines outlined by Ms. Silverman. Mr. Montoya said the Council could invite Ms. Silverman to participate in a conference call to discuss a letter to DHHS or the President. Ms. Aragón said she would like to ask Dr. Goosby for comments on the nutrition guidelines. Mr. Minor said the Council should solicit DHHS's help. Ms. Aragón said the Council should invite either Dr. Goosby or Debra Von Zinkernagel to participate in the conference call.

The subcommittee made no formal recommendations.

Closing Comments: Mr. Dellums noted the tremendous commitment and talent present on the Council. He said his role as chair is to facilitate the process, to preserve the rights of each Council member, and to help the Council arrive at a consensus. He noted that he comes to the HIV/AIDS arena with a global viewpoint and would like to get Council members' feedback on that viewpoint. He said he sees the Council as a political group; it can make strong, effective political statements. He said he is deeply appreciative of the opportunity to serve as Chair but understands that it is not his platform alone.

Ms. Miramontes thanked Mr. Dellums for bringing a global viewpoint to the table, but asked the Council to consider the larger issues of human rights and social justice and how they put people at risk for HIV. The Council should look at AIDS in a broad context instead of a narrow, personal context.

Dr. Cooper said she also appreciates the global viewpoint but added that a horizontal view is needed. Looking at how to access mainstream sources of support such as HOPWA, Medicare, and Medicaid is critical.

Mr. Blackwell said he feels a spark of new energy on the Council. He said it is rewarding to see the spirit of camaraderie generated by new Council members. He asked when the next two Council meetings would be held. Mr. Montoya said the Council will meet June 5 and 6, and again in late September or early October. Late September is preferable.

Mr. Perez asked if the Racial and Ethnic Subcommittee could change the time of its next conference call to either earlier or later in the day. Mr. Montoya agreed to change the time.

Dr. Gomez thanked continuing Council members for welcoming new members. She suggested that ONAP schedule time for in-depth discussion at the next Council meeting and limit full Council presentations.

Mr. Lew seconded Dr. Gomez's suggestion. The Council needs an opportunity to discuss how to map out a future vision for the next Administration.

Dr. Gomez said several subcommittees do not make sense as stand-alone committees. She suggested forming two large working groups to address cross-cutting agendas. Task forces could be established within the working groups.

Mr. Anderson agreed that more discussion time at the next meeting would be optimal. He added that it is important for the Council to reconceptualize its work on a more global level, but expressed concern that it might take time away from important domestic issues. The Council needs to think about how it can make an impact in the next 9 months. Mr. Burgess agreed with Mr. Anderson.

Ms. Lewis asked Mr. Montoya to explain how members should review documents and submit comments. Mr. Montoya said members should utilize subcommittee conference calls to discuss their comments on certain documents. The Council then deliberates as a body and submits one response outlining revisions or recommendations. Members also should take documents back to their agency or organization to ask for feedback.

Mr. Burden encouraged the Council to think globally. He noted that the media is paying more attention to HIV/AIDS in recent months, particularly regarding the epidemic in Africa. If the Council has something to say, the Durban conference is the time to do it. Otherwise it might be a missed

opportunity. Mr. Montoya noted that there might be other opportunities to make a public statement because it is an election year. The Council should not feel rushed to put out a document in time for the Durban conference.

Ms. Aragón said the Executive Subcommittee should schedule a conference call to consider Dr. Gomez's suggestion on restructuring the Council's subcommittees. Mr. Montoya said he would schedule a call. He suggested that Council members also consider restructuring the Executive Subcommittee. Ms. Miramontes expressed her support for the restructuring.

Mr. Dellums stated that the Council came to consensus on the following issues:

1. More discussion time should be scheduled into the next Council meeting.
2. Mr. Montoya will schedule an Executive Subcommittee conference call as soon as possible to discuss restructuring.
3. The Council should adopt a more global view on HIV/AIDS but will keep in mind that it only has 9 months in which to further impact Federal policy.

Mr. Dellums thanked returning members for giving new members the benefit of their experience. The meeting was adjourned at 4:00 p.m.