Presidential Advisory Council on HIV/AIDS
Full Council Meeting

September 21–22, 2000

Madison Hotel
Washington, DC

MINUTES

Present:
Ronald Dellums, Chair
Regina Aragon
D. Gregory Barbutti
Ignatius Bau
Judith A. Billings, J.D.
Charles W. Blackwell
Stephen L. Boswell, M.D.
Stuart C. Burden
Philip B. Burgess. R.Ph.
Margaret K.L. Campbell
Lynne M. Cooper, D.Min.
Joseph A. Cristina
Ingrid M. Duran
Rabbi Joseph A. Edelheit
Cythnia Gomez, M.D.
Michael T. Isbell, J.D.
Ronald S. Johnson
Alexandra Levine, M.D.
Steve Lew
Caya B. Lewis
Miguel Milanes, M.P.A.
Brent Tucker Minor
Ernesto Parra, M.D., M.P.H.
Valerie Reyes-Jimenez
Michael Rankin, M.D., M.P.H.
Victoria L. Sharp. M.D.
Denise Stokes
Todd Summers

Present from ONAP:
Sandra Thurman, Director
Renuka Kher
Matthew Murguia
Daniel C. Montoya, Executive Director, PACHA

Thursday, September 21, 2000
Morning General Council Session

Mr. Dellums opened the Seventeenth Meeting of the President's Advisory Council on HIV/AIDS by stating that the focus of the 2-day meeting would be the Council's final report entitled AIDS—No Time to Spare: Final Report to the President of the United States. After referring to talking points he would address, he suggested that Drafting Committee members be identified and that Ms. Aragon, who edited the final version, clarify its overall approach. Mr. Dellums expressed his appreciation to Drafting Committee members and commended them for articulating the sense of urgency required to confront the global dimensions of the HIV/AIDS pandemic.

Ms. Aragon thanked members of the Drafting Committee as well as members of the Council who provided comments. A substantial amount of committee work from PACHA's June meeting went into the report, and major themes from both Prevention and Services Committees were identified. Of particular importance was the recognition of the role of the United States and the current Administration in addressing the worldwide as well as domestic implications of HIV/AIDS.

Ms. Aragon named Drafting Committee members: Rabbi Joseph Edelheit, Dr. Cynthia Gomez, Mr. Greg Barbutti, Mr. Brent Minor, Mr. Daniel Montoya, Mr. Gregory Smiley, and Sarah Auld, an intern from ONAP. She outlined the process that evolved to generate the report, acknowledging review assistance from Ms. Miramontes and Dr. Levine, former co-chairs of the Research Committee, as well as several staff from the Clinton Administration.

Mr. Dellums opened the floor to comments.

Update of Interim Activities

Mr. Montoya said that the final report represents 5 years of work on the part of Council members, many of whom were involved from the Council's first meetings, the first of which was held at the Madison Hotel in Washington, D.C. He had attended on behalf of Tom Henderson, who was in the process of being appointed a PACHA member.

Mr. Montoya said that Ms. Thurman would inform them of whether a meeting would be scheduled with President Clinton and that Friday afternoon would be an optimal time to meet him. Mr. Montoya had made public comments in this regard to bring pressure to bear on White House schedulers.

In commenting on the final report, Mr. Montoya said that the report is forward thinking, direct, and acknowledges that the current Administration has been more progressive than any other in putting the issue of HIV/AIDS forward. He urged that time would be best spent in reviewing what still needs to be accomplished. To that end, the report provides both recommendations for the Administration's last 100 days in office in relation to HIV/AIDS policy and provides a road map for the next Administration.

Mr. Dellums said that the Council has been successful in bringing a global perspective to AIDS prevention and treatment, which is now resonating in the broader community. He expressed his pride at being able to serve the Council and lauded the report as perhaps the most progressive document written on this subject to date.

Mr. Summers commended Ms. Aragon's commitment to the Council and to the report. He said that he had re-read reports submitted by the National Commission on AIDS and noted that many of the issues discussed in early reports have not been resolved. He encouraged members to work toward actualizing as much of the report as possible.

Discussion ensued regarding the possible meeting with the President and what the Council should do if this did not materialize.

Mr. Dellums thanked members of the ONAP staff, including Greg Smiley and Renukah Kher as well as MOSAICA in coordinating the production of the report. Mr. Montoya echoed appreciation for his staff, particularly ONAP interns. He then outlined the agenda for the rest of the day. He invited those present to sign up for public comment to be scheduled at 3:30 p.m. prior to the conversation about the roll out and progress report.

Dr. Gomez mentioned that the IOM report is scheduled for release the week of September 25–29, 2000, and that, depending on press coverage of the PACHA report, IOM would also solicit coverage. She suggested taking advantage of the timing, rather than being overshadowed by release of the IOM report.

Mr. Dellums introduced Ms. Thurman in her new capacity as Special Envoy for AIDS Cooperation.

Office of National AIDS Policy (ONAP) Update

Ms. Thurman began by discussing the upcoming congressional appropriations process and expectations that the Congress would meet all of the Administration's requests to expand the budget for both international and domestic programs. She said that the possibility is that Congress would adjourn as scheduled on October 6 or 12, and then return after the November elections to engage in the appropriations process. Ms. Thurman said that there are still significant funding gaps—amounting to $22 billion—in terms of the President's overall budget request and what the Congress is working with. Strong advocacy is required to ensure that HIV/AIDS spending priorities are addressed.

On a more encouraging note, she said that the Ryan White CARE Act will be reauthorized. Getting the bill passed the first time was difficult and reauthorization even harder. This time has been even tougher, but it should move in the House on September 25 or 26 and in the Senate hopefully during the same week. President Clinton has only 10 days to sign it once it comes to the White House. If an event can be planned in conjunction with the Ryan White CARE Act, supporters within Congress could be pursuaded to slow the reauthorization process. She said that the bill contains few surprises or mandates that were initially discussed in conjunction with the "hold harmless."

In terms of other funding, the AIDS Drug Assistance Program (ADAP) Working Group has asked for $134 million for ADAP funding. The President's request for ONAP funding was $26 million. Ms. Thurman assured the Council that ONAP would work through the next several weeks to reduce that significant gap and that they will work with the Congress to meet that objective, while meeting the President's priorities. Another large difference is evident between the Minority AIDS Initiative request at $350 million and the ONAP request of $274.5 or $275 million.

Mr. Dellums asked Ms. Thurman to comment about the AIDS-Tuberculosis Relief Act.

She replied that what is being referred to as "the Global AIDS bill" and the Tuberculosis Relief Act is authorized at $300 million. Ms. Thurman said that it is too early to assess the outcome, but she believes that funding would be within range of the requested figure. Negotiations are proceeding, but ONAP is authorized to request $300 million. These budget items would be discussed in more detail on Thursday afternoon.

Ms. Thurman said that the youth report should be ready for release by October 2, 2000, at the National AIDS Conference in Atlanta and that a school would be used as a venue to focus on youth and their participation in the fight against AIDS.

World AIDS Day is a few months away. Religious leaders from throughout the world will be at the White House and Ms. Thurman said she is not certain whether President Clinton would participate. The important role that leaders from communities of faith have to play in the epidemic, both domestically and internationally, would be a major theme of the event. PACHA members were invited to participate and were welcome to submit names of people who should be invited.

Ms. Thurman informed the Council of the AIDS event held in Nigeria during President Clinton's visit 3 weeks prior to the Council meeting. The President of Nigeria, the head of the National Association of People With AIDS (NAPWA), and a peer educator all participated. Ms. Thurman remarked that it was extraordinary that only these four participants were on the stage, given the fact that world leaders were present.

She commented that after both presidents spoke about AIDS, the President of Nigeria asked the wife of the president of NAPWA—who is also HIV-positive—to come up on stage. She described the Nigerian President as a large, military man with a booming voice who then walked across the stage and embraced this woman, who is living with AIDS. This was a tremendous event in a country where stigma is still so apparent.

Ms. Thurman then reviewed topics for the afternoon presentation. She said that a final schedule for the meeting at the White House has not been set and that the President's schedule is very full. She said the President is anxious for the meeting and that hopefully there would be word within the next hour.

Ms. Cooper asked whether funding requests would be met for Housing Opportunities for People With AIDS (HOPWA). Ms. Thurman said budget requests would be granted. Ms. Cooper also asked how the Department of Housing and Urban Development (HUD) is doing, in general, because of HUD funding areas that provide AIDS support. Ms. Thurman responded that HUD is having a variety of problems in this regard, and that those specializing in housing would be more appropriate to consult for information. Although other housing programs vital to PWA are possibly losing ground and strategies should be discussed for approaching HUD and members of Congress, Ms. Thurman felt the problem was not insurmountable.

Ms. Aragon underscored Ms. Thurman's comments that the Administration's budget for HIV/AIDS-related programs can be improved and that although few officials would be involved in the final stages of the appropriations process, it is a given that both President Clinton and Mr. Jack Lew, representing the Office of Management and Budget (OMB), would be at those meetings.

Ms. Aragon wanted to echo Ms. Thurman's comments and stressed the Council's expectation that the President's budget will be exceeded during final stage discussions, given that significant funding is available and should be allocated for HIV/AIDS programs. She said that, having prepared the report, Council members are aware that urgent issues loom both globally and domestically that must be addressed. She enjoined Ms. Thurman to take this message back to the Administration.

Dr. Levine and Ms. Thurman exchanged several questions and answers regarding budget-related questions, the first concerning the dollar amount of the Ryan White CARE Act and whether $26 million for ADAP is the current amount. Ms. Thurman responded that that figure represents the requested increase. Dr. Levine then asked for the actual funding total. Ms. Thurman replied that the ADAP total is $554 million. She said that the community has asked for an additional $135 million and that the $26 million should be exceeded.

Dr. Rankin strongly urged Ms. Thurman to do her utmost to see that the meeting with the President is scheduled. Ms. Thurman assured Dr. Rankin and the Council that the President understands their position, and she emphasized that the President is commited to HIV/AIDS policy and is "doing battle" with his schedulers.

Discussion ensued regarding several budgeting items that relate to AIDS, including the Global AIDS and Tuberculosis Relief Act. Ms. Thurman anticipated dramatic increases in HIV/AIDS budget requests.

After discussion about various budget issues, Ms. Thurman said the same challenge with regard to development of innovative vaccines and microbicides still confronts AIDS researchers and has involved an ongoing struggle with NIH and others whose position is that sufficient research is being conducted. Ms. Thurman pointed out that the epidemic is now disproportionately affecting women and developing countries. Although much more needs to be accomplished, the President, Secretary Summers, and the national economic advisor have been involved in bringing CEOs of health care-related corporations into the fight against AIDS. She said that the Administration has made significant progress in creating this huge shift in orientation.

Mr. Dellums thanked Ms. Thurman, and said that he hoped Dr. Rankin's comments reflecting Council members' feelings about the urgency of their meeting with the President would strengthen her hand in her later discussions with him.

He then introduced Dr. Helene Gayle.

The CDC HIV Strategic Plan

Dr. Gayle greeted the panel and congratulated Ms. Thurman regarding her new appointment as Special Envoy for AIDS Cooperation. Dr. Gayle informed the Council that the CDC's draft strategic plan, to be in effect for 5 years, is currently available on their Web site and invited feedback. She said that Michael Isbell and Ignatius Bau participated in drafting the plan and that Dr. Cynthia Gomez served on CDC's Advisory Committee.

Dr. Gayle reviewed the CDC's strategic plans, which date back to 1992 before major breakthroughs in treatment had occurred. Demographics have changed since the early 90s so that HIV/AIDS is having greater impact on women, communities of color, and young people. Fifty percent of new infections are occurring in people under 25 years of age and 30 percent of new infections are among women. More than 70 percent of new HIV infections are in communities of color, particularly African American and Latino.

A review in 1998 found that although current strategies have "met the mark" in many ways, a better long-term plan is necessary to guide strategy so that it does not become a year-by-year, ad hoc approach. The review has been instrumental in prompting the CDC to develop a more codified strategic plan.

Among the CDC's major goals is the over-arching issue of policy with regard to reducing new HIV/AIDS infections. Although the CDC has explored strategies such as behavioral change and its impact on transition rates, quantifying transmission is a new approach that involves setting national goals to reduce new infections. The CDC's goal is to reduce the number of new, yearly infections from an estimated 40,000 to 20,000 by the year 2005 (reducing by half the number of new HIV infections over the next 5 years). Two related goals are increasing the number of those who are aware of being infected from 70 to 95 percent by 2005 and ensuring their linkage to appropriate prevention and care and support services. A fourth domestic goal is to reduce HIV transmission and to improve HIV/AIDS care and support through partnership with resource-constrained countries. Dr. Gayle then discussed these goals in more detail.

Dr. Gayle then spoke of putting the CDC's Strategic Plan into operation. The strategy will be a guiding document for research, defining unmet needs, allocating new resources, assisting with public-private collaboration, and supporting the CDC in being accountable through defining measurable goals.

Public meetings are currently being held, and the Plan is scheduled for completion by December 2000.

Dr. Gayle was asked to assess how long it takes for goals to be implemented through CDC's cooperative agreements with States and whether State funding levels would be tied to meeting CDC goals.

Dr. Gayle said the CDC commissioned a report from the Institute of Medicine (IOM) to assess where the United States should go with regard to HIV/AIDS prevention. This is scheduled to be released September 27, 2000. Resource allocation with regard to cost effectiveness and goals is addressed within that report, as well as incentives for States to implement effect approaches to reducing new infections, such as immunization programs.

Questions and Comments

Mr. Summers thanked Dr. Gayle, acknowledging the CDC's work in producing the report and for "knocking heads" with the FDA on rapid testing approval. He also recognized the CDC's promotion of research regarding needle exchange. He voiced concerns about whether broad-based programs are being designed for youth at increased risk in all sectors of the population, rather than more targeted efforts in school-based programs.

Dr. Gayle said that the CDC will be prioritizing those approaches that have the greatest impact for people at risk. Although school-based sex and HIV/AIDS education is important, she questioned whether the schools are necessarily the best environments in which to learn negotiation skills and issues that lead to behavioral change.

Dr. Levine expressed concerns that two recent negative trials on Nonoxynol-9 may possible dampen this approach to research. She said that she doesn't believe NIH will take the lead in this area but that it will be necessary for CDC to do so, and asked Dr. Gayle for her comments. Dr. Gayle said the CDC is limited by resources available for research and that increasingly prevention dollars have been earmarked, which limits CDC's range with regard to possible areas of exploration. Although the CDC and NIH have different roles, it appears that anything that involves research should only fall within the purview of NIH.

She said that prevention represents a broad spectrum that should include research and that there is a role for an agency such as CDC, which can perform field-based research and that is more geared toward immediate program implementation, versus an agency that does research at the early end of the disease progress. She said that this should be regarded as an "either-or" dichotomy and that researchers within the CDC are actively involved in research on microbicides and collaborating with both federal and nonfederal partner agencies.

Dr. Levine asked whether there is anything PACHA members can do to support this process.

Dr. Gayle said that most reports she has seen view NIH as synonymous with research and that with regard to prevention, the CDC and other agencies can contribute.

Dr. Levine said that trials are ongoing, looking at post-exposure prophylaxis. She said that she is worried that youth throughout the country are getting the "wrong message" that they can do whatever they want to do, regardless of consequences, because they can

"just sign up and get their AZT." She asked Dr. Gayle if is aware of whether anyone within the CDC is focusing on this issue.

Dr. Gayle said that the CDC has put out an factsheet and that as the CDC continues targeting more messages to youth, this issue would be taken into consideration. In general, young people appear to be thinking that the epidemic is not serious and that drugs can be taken if they get it, or to keep from getting it (HIV), and have a kind of "quick fix" mentality. A broad reeducation is required to alert youth to the fact that AIDS is a serious disease and that there is no "morning after" pill.

Mr. Burden thanked Dr. Gayle for her presentation and inquired about the international arena. Dr. Gayle said that the more detailed breakdown of the Strategic Plan includes discussion of non-government organizations (NGOs). Targets included in the report reflect those of UNAIDS and other international agencies, such as reducing new infections by 25 percent. Specific objectives include reducing sexually transmitted HIV infections and developing capacity, which includes strengthening surveillance programs through technology and other goals.

She said that CDC is not the lead prevention agency internationally and therefore its role is somewhat different in the global fight against HIV/AIDS than in the domestic one. The CDC is consulting with each country to augment its own national strategic plan, so that, for example, if that country is already making progress in treatment of sexually transmitted diseases but needs help in expanding voluntary counseling and testing programs, the CDC would lend its expertise in this area.

Mr. Bau complimented the CDC on its efforts, noting that organizational challenges still exist to implement this model as CDC's baseline in responding to the HIV/AIDS pandemic, rather than maintaining the current structure, in which programs are split across different centers and in different divisions and where budgets are not necessarily aligned. Staffing and budgeting patterns will need to be redesigned, which presents a formidable challenge.

Dr. Gayle said that the Strategic Plan should be meaningful and that CDC's "buy in" of the Plan has been extremely important. The Office of the Director of the CDC has been supportive in the effort to align priorities to most effectively implement the Plan.

Dr. Boswell also commended Dr. Gayle and the CDC for creating specific goals that will facilitate progress in combatting the epidemic. He asked how the Plan is being coordinated with Healthy People 2010 and whether the Plan's goals reflect those of Healthy People 2010.

Dr. Gayle said that the CDC worked to ensure consistency between Healthy People 2010 and the Strategic Plan and asked Ms. Eva Seiler, who has been the liaison between two documents, to respond to this question.

Ms. Seiler said that the Healthy People 2010 goals focus on racial and ethnic groups in terms of reducing HIV/AIDS. By reducing rates of infection by 50 percent, the Healthy People 2010 goal to reduce HIV/AIDS among particular minority populations can be achieved. This objective was kept in mind while framing the Plan, but a specific effort was not made to blend the two reports.

Dr. Boswell commented that chemotherapy can be effective in terms of long-term prognosis for those with acute infections. In October, a group in Boston will present a study in Nature that suggests that treatment during acute infection with antiretrovirals, followed by intermittent withdrawal of these drugs, can result in control of the virus in 100 percent of cases where this is effectively done. He asked Dr. Gayle whether the CDC is considering coordination of a conference to discuss the implications of this treatment approach and identifying individuals who are acutely infected in clinical settings.

Dr. Gayle responded that increasing the number of HIV-positive people who know their status early will be a major objective of the CDC. By eliminating the barriers that currently exist to knowing HIV status, it will be easier to immediately link patients to services. She said this is an area in which it is critical for the CDC, the Health Resources and Services Administration (HRSA), and other agencies to coordinate outreach to managed care and other health care organizations to make sure people receive services and are not just being identified as HIV-positive.

Dr. Boswell encouraged the CDC and HRSA to not only stress early identification of those infected with HIV but to take specific action, including public campaigns, to make providers facilitate treatment.

Dr. Gayle said that the Know Your Status campaign is recommending the targeted campaigns in areas where new infections are occurring and coordinating media campaigns and public information regarding barriers to testing. This should be done on a national level and as rapidly as possible.

Mr. Summers asked Dr. Boswell to define “acute infection” as referred to in the Nature study.

Dr. Boswell said that studies have been done in early infection (i.e., more than 3 months after the onset of acute infection) that indicate that less benefit occurs than in early cases where acute infection has been identified due to flu-like symptoms. He said that Harry Rosenberg and Bruce Walker have done much of this work in Boston and believe that this timeframe is within the first 6 weeks to 3 months of the onset of the infection.

He said that these data are based on a study of eight patients that were treated for acute infection for flu-like symptoms. When viral loads dropped to a low, pre-specified level, therapy was withdrawn. When the viral load climbed, in some cases back to a level of 10,000, therapy was reinstituted and the viral loads dropped again. This was repeated three times for all eight patients. Each patient is now completely off drugs with viral

loads of less than 500. Dr. Boswell said that this is a markedly different situation from what was evident 10–18 years ago.

Dr. Gayle agreed with this perspective and that the CDC might consider how the data may relate to public health service guidelines, although the agency is less involved in clinical recommendations. The CDC should focus on improving prevention efforts by early identification and treatment of those newly infected with HIV. She said that one other benefit of this strategy is increased coordination with other key agencies that provide care. The care-prevention continuum should be made as seamless as possible.

Mr. Burgess asked Dr. Gayle to speak about the potential role of community pharmacists in the effort increase counseling and testing. He said that particularly in the inner city, the pharmacist is the most readily available health care professional.

Dr. Gayle said that there is no specific mention in the Plan regarding interventions by pharmacists and agreed that this is an important area to reinvestigate.

Dr. Gomez asked Dr. Gayle whether the CDC has considered ways to respond to barriers to counseling and testing. A demonstration project in San Francisco produced a 30-second media piece, called "HIV Starts With Me," that urges HIV-infected individuals to take responsibility for not transmitting the virus. She said that the targeted audience was invited to provide feedback on the PSA. She referred back to the "America Responds to AIDS" campaign that prohibited the airing of ads about condom use and expressed concern that these types of barriers will again interfere with CDC's creative approach to educating the public. Ultimately what CDC can do alone is limited, and higher level political leadership is required on some of these issues.

Ms. Campbell asked what the CDC is doing to involve the entertainment industry.

Dr. Gayle said this is another area requiring broad partnerships and that people at higher levels of authority than hers have tried taking on some of these difficult issues. She said that the CDC's strategy has been to engage entertainers and NBA players such as Magic Johnson who are responsible role models in the "Know Your Status" campaign. Her hope is that these messages will work toward balancing the counterproductive ones sanctioned by an industry concerned about huge profit margins.

Ms. Cooper expressed the hope that more "grumbling and gnashing of teeth" would occurr within the CDC regarding needle exchange because it is a clearly proven strategy in combatting HIV/AIDS and should not continue to be held up in political debate.

Dr. Gayle said that PACHA has been heroic in promoting needle exchange. She said that she has suggested to her staff that cooperative agreements soliciting proposals on needle exchange be sent out to see whether they are even noticed. She said that the CDC is not silent internally and will continue to do what it can to promote needle exchange, but they

are not allowed to implement needle exchange programs and resolution of this issue must be externally driven.

Ms. Cooper said that policies have been repeatedly requested regarding HIV-positive health care workers.

Dr. Gayle said that policies have been drafted and bringing them "into the light of day" will require further research.

Mr. Summers remarked that the Council is concerned about the delay in putting out more scientifically based health care worker guidelines and that PACHA expects the Administration to live up to its commitment, made in person to the Council, that this would be done expeditiously.

Dr. Gayle said that the CDC would like to move forward on this issue and welcomed the Council's continued support.

Mr. Jackson commended the CDC for furthering the presidential mandate to consult with tribal governments and asked how the Strategic Plan would be implemented as part of CDC's outreach.

Dr. Gayle said that a meeting of division directors was held recently during which a CDC representative of Native American descent spoke about improving outreach efforts to this community. She said that data would be provided that would help better evaluate where tribal efforts as compared with the Indian Health Service (IHS) would be the better resource and which urban areas should be targeted for services for those who no longer live on reservations. She said that one of her senior staffers has been to several recent meetings in areas with high Native American populations.

Dr. Levine said that emergency departments are the place to begin educating clinicians about early prevention and treatment for HIV infection. With regard to needle exchange, she said that not only does it not lead to more drug use, but that it leads to getting people off drugs by aligning drug users with social workers and methadone clinics who then could provide programs to support drug abstinence.

Dr. Gayle said the prohibition is very clear about contributing resources to any program that would support needle exchange, but that perhaps Substance Abuse and Mental Health Services Administration (SAMSHA) would be the more appropriate venue for this type of approach. She said that the issue should be dealt with straightforwardly because so much more progress could be made.

Mr. Lew said that prevention services are now included as linkages for people with HIV. He said that it seemed as if the percentage of people with HIV linked to prevention services is probably lower than those for people linked to care and that a push is needed to coordinate more effectively with HRSA and the SAMHSA. He asked what efforts are being made to promote immediate coordination of interventions and asked whether

allocations are being discussed for interventions that HRSA or SAMHSA could implement. Mr. Lew asked also about monitoring of HIV-positive individuals to promote access to prevention services.

Dr. Gayle said cross-agency programming must be accelerated, and CDC has worked on some smaller projects with HRSA, particularly for correctional populations. Adequate evaluation and monitoring systems are not yet in place. These are not "resource-neutral" activities, and these types of ancillary services require diversion of funds from those earmarked from other priorities.

Mr. Lew said that concerns have been raised about what services providers are being asked to link HIV-positive patients to, particularly with inadequate interventions in place.

Ms. Miramontes asked whether the Strategic Plan addresses ways to operationalize collaboration. She said that one of the biggest barriers in the Federal Government is the lack of inter-agency cooperation and resulting competition for funds.

Dr. Gayle said that the Plan does not specifically address this issue. She said that Earl Fox and senior staff from HRSA came to speak with CDC about inter-agency collaboration. She said that prevention needs to be discussed in the context of primary care across the board, but that a "memorandum of agreement" may be necessary that would help to avoid turf battlers through seamless integration of prevention and care components. Others have been exploring how the National Institutes of Mental Health (NIHM) research findings can improve cooperative efforts and funding and then translate and implement research findings to the community so that prevention services can be expanded.

Dr. Parra asked whether new initiatives have been developed to address prevention needs of minority communities.

Dr. Gayle said that both the first and second goals address populations of greatest risk and that communities of color are clearly highlighted.

Dr. Parra referred to an article published in AIDS Patient Care about pregnant women in south Texas, in which they were asked about barriers to testing. A primary barrier was that they would be perceived as sexually promiscuous, so that it is clear that stigmatization is the overriding issue.

Mr. Minor said that he has sat on community planning groups in Richmond, Virginia, and characterized the process has often long and laborious. He said that he felt CDC had done a poor job in its prevention efforts, particularly in light of aggressive and targeted campaigns by other nations that may not be as "sophisticated" as the United States but that have achieved significant reductions HIV infections.

He said he is anxious to know what stigmatization really means and that as more people are moved into care, it would appear that many agencies are already working to capacity.

His fear is that "if past is prologue," many of goals may be reduced to no more than verbiage. He said community activists regard the CDC as "Oz" and that the perception exists that they do not effectively engage at the community level. One-on-one actions at the local level are called for in reducing HIV infections.

Mr. Minor advocated an aggressive stance on the part of the CDC and urged the agency to allow PACHA members and others in Congress to fight the relevant political battles that allow for effective public health interventions.

Dr. Gayle appreciated Mr. Minor's candid remarks. She said that the CDC is a Federal agency and that its role has been to work with States in supporting their local affilliations, setting a tone and standards that can be applied throughout the community level. She acknowledged that the impediments are very real and that there are constraints that limit CDC initiatives.

Mr. Summers said he felt that the CDC's work in community prevention planning has been some of its best, although improvement is needed. He commended Dr. Holtgrave's leadership in this area. He then asked Dr. Gayle whether consideration could be given by her colleagues at both HRSA and CDC to moving the Ryan White Title I and the community prevention CDC processes from annual to 2-year cycles for applications. He said the interim year could then be spent doing joint prevention and care planning. He said that this could be done without statutory change and provide a more comprehensive system of care and prevention.

Dr. Gayle said that internal discussions had been held at CDC regarding the feasibility of 2-year funding cycles for joint community planning.

Ms. Stokes said that she appreciated the language in the CDC draft regarding comprehensive adolescent education about HIV as well as the section on needle exchange, although the case for this issue could always be stated more strongly. She expressed the concern that there are not enough programs for adolescents who are already addicted.

Dr. Gayle suggested that the full document may already contain reference to specific allocations. She said that SAMHSA was involved in developing these aspects of the Plan and that sometimes it is difficult to assess where one agency's responsibilities end and another's begins.

Ms. Stokes said that she was actually suggesting an increase in the number of beds provided for adolescents in drug treatment.

Dr. Gayle confirmed that this is definitely a SAMHSA issue.

Ms. Stokes addressed the need for a greater push toward educating HIV-positive patients, in terms of knowing their treatment options, such as genotyping, to determine whether patients are resistant to certain drugs, rather than suffering for months while getting sick

from taking the drug. She also mentioned that many people with HIV are not getting vaccinated for Hepatitis B, and that the number of Hepatitis C diagnoses is increasing.

Dr. Gayle responded that this is an issue of treatment and care rather than one that would pertain to the CDC, although information is put out through CDC clearinghouses such as the MMWR, which are public health service guidelines.

Ms. Stokes suggested that these issues may be incorporated in something like the "Know Your Status" campaign so that patients would know their options.

Dr. Gayle said that these issues have to be worked out with CDC's sister agencies to avoid battles over turf. Also, CDC does not yet have sufficient resources to design an adequate "Know Your Status" campaign. This information is necessary and should be taken up with CDC's colleagues. Linkage of hepatitis and HIV services is being explored within the CDC, particularly with regard to drug substance abusing populations.

Mr. Dellums thanked Dr. Gayle for her contribution and her availability to the Council on such short notice. He then told the Council that a meeting with President Clinton had been scheduled for Friday, September 22 at 1:45 p.m. and that there would be an update later in the afternoon.

Mr. Montoya reminded PACHA members that as such, they cannot lobby Congress on any legislation. However, this does not hold for their constituents, and he urged members to contact their communications directors to get the word out.

Mr. Summers then informed the Council of a copy of a letter to Vice President Gore that he had e-mailed to all of the PACHA members. The objective is to send a letter to both campaigns outlining a progressive strategy and agenda on AIDS, ideally to be sent out Thursday (9/22) afternoon., and signed "member of PACHA" with a note specifying "for reference purposes only." He asked members to indicate their interest in being included on the letter.

The question was raised as to whether the letter could be signed on behalf of the entire Council.

Mr. Montoya said he would check into the possibility of signing the letter as a group rather than as individuals. He then introduced and thanked May Kennedy, who has assisted Ms. Thurman and Mr. Murguia with the youth report at ONAP in interfacing with CDC, and Sandy Perlmutter, Executive Director of the President's Council on Physical Fitness and Sports. Ms. Permutter has worked with Mr. Montoya to explore ways their respective offices can interrelate with regard to the impact of HIV/AIDS on people involved with sports and fitness.

Dr. Levine suggested that those who prefer not to have their names on the letter to Vice President Gore mention this to Mr. Summers.

Mr. Dellums then adjourned the meeting until 2:00 p.m.

Thursday, September 22, 2000
Afternoon General Council Session

Mr. Burden opened the afternoon session by introducing Ms. Thurman.

Global Overview and HIV/AIDS

Ms. Thurman commented that there are currently more than 34 million people infected with HIV worldwide, and in only four and one-half years there will be 100 million. She said that 16,000 people become infected each day, and 11,000 are in Africa. This amounts to one person being infected every 8 seconds. The epicenter of the epidemic is now shifting from Africa to Asia and other regions of the world, and although percentages may not be as high because of the large concentrations of population in Asia, the overall numbers of those infected will exceed those in Africa.

There are seven countries in sub-Saharan Africa that have 20 percent of the adult population infected with HIV. Seventy percent of infected people live in the world's poorest countries. The term "pandemic" has been used lightly, partially because nothing of this magnitude has been experienced within the past several centuries. Although it is difficult to reflect on the fact that we know the proportions of the pandemic, with no prior history it is difficult for many people to grasp what it would look like. A dramatic shift has occurred in the perception of both the public and political leaders in the last 18 months, including better press coverage.

She said the President requested an additional $100 million to expand programs globally. Congress has appropriated the funds, and strides have been made by USAID and CDC. This year's budget request goes further, given the awareness that AIDS is a fundamental development, economic, gender, poverty, and security issue, not just a health issue. President Clinton has requested $10 million to expand Department of Defense (DOD) programs in military sectors around the world, because military and police are disproportionately affected in the developing world. Another 10 million has been requested for the Department of Labor (DOL) to work with organized labor around the world, particularly in sub-Saharan Africa, where migrants and mine workers are vulnerable. One out of four mine workers is infected in many mining communities and among migrant farmers.

The workplace can be used to educate and provide care and services to people with HIV/AIDS, particularly in areas where no other infrastructure exists. Increases have been requested for CDC to perform surveillance and prevention and to increase USAID support to community-based programs. Seventy percent of funds allocated to USAID goes to community-based organizations "on the ground," as this is where the fight against AIDS will be most successful.

Ms. Thurman then reviewed various funding and budgeting items, commenting that there is a growing understanding that the developed world has the responsibility not only to provide debt relief, but to help in building the infrastructure required for health care delivery, for roads, for education, and for other resources needed to enable greater access to care and treatment.

Ms. Thurman then spoke of recent travel by Government officials to speak with leaders of various nations about the impact of disease on their countries and the need to examine spending priorities, mentioning that this was a first in terms of the personnel involved.

At President Clinton's request, ONAP, USAID, and the State Department are planning a trip to Asia at the end of October to ensure that past mistakes do not retard the effort to combat AIDS in Asia. According to the National Intelligence Center (NIC), the AIDS epicenter in 15–20 years will be in Asia and the former Soviet Union, and that as this Administration leaves, sufficient momentum is created to raise awareness that AIDS is a global pandemic. She then reviewed President Clinton's upcoming travels and the inclusion of HIV/AIDS in discussions with world leaders in Asia, India, and Vietnam.

Ms. Thurman then described her new position, Special Envoy for AIDS Cooperation, as being a point person to work with other Governments on the AIDS issue. She will be working closely with UNAIDS to help bring visibility to the issue of HIV/AIDS in capitals around the world. The position will be staffed out of ONAP. This is an exciting approach to creating energy and dialogue around the U.S. response to HIV/AIDS as well as that of other countries.

Ms. Thurman then introduced Mr. R. P. Eddy, a staff member of Ambassador Holbrook at the United Nations, who has worked closely with ONAP for the past year to 6 months on HIV/AIDS issues.

Presentation by Mr. R. P. Eddy, U.S. Mission to the United Nations

Mr. Eddy first spoke of the framework for the Special Envoy position as most likely being the program coordinating board at UNAIDS; it is not attended by a political process, although the issue is clearly monumental. He expounded on the framework them, noting that it entails meetings among high-level officials once or twice per year so that resources are not squandered. This body would also be mandated to adopt the aggressive goals of UNAIDS and other agencies toward resolving the HIV/AIDS crisis. It can also be a forum to review resource allocation and burden sharing, as well as for confronting nations that should be contributing more capital or those that are recalcitrant in creating national plans to combat the pandemic.

Mr. Summers asked about ONAP staff assisting with this effort, about internal coordination within the State Department to keep step with the Africa Bureau, and about staffing positions for HIV/AIDS within the NSC and other foreign policy agencies.

Mr. Eddy said that he has not been aware of any robust planning for future infrastructure within these agencies. Ms. Thurman added that these offices are currently understaffed and underfunded, and that more coordination should occur within the State Department regarding the integration of an HIV/AIDS agenda.

Ms. Thurman noted that during the Millennium summit, Secretary of State Madeleine Albright held her annual dinner for female Ministers of State, and that HIV/AIDS was the topic of discussion. The 15 women Foreign Ministers sent a letter to UN Secretary Kofi Annan, asking him to increase UN engagement in the fight against AIDS. Ms. Thurman noted the significance of this event and that it speaks to Secretary Albright's dedication to the issue.

Ms. Cooper asked about the potential for a paternalistic mentality that may emerge as the social and economic fabric of African countries frays due to the pandemic.

Ms. Thurman said that this discussion has not occurred thus far, but what has been discussed is the need for responses to the pandemic to be "homegrown" and that the United States should be a facilitator for sustainable health care delivery programs. She said that there is a tendency to spend time training groups of American consultants who are ultimately disconnected from local communities. She then spoke of the economic difficulties faced by many African countries, especially Nigeria.

Dr. Gomez asked Ms. Thurman's impression of how domestic issues will coexist with the global dimensions of the pandemic.

Ms. Thurman said that these dimensions of the crisis are not mutually exclusive and that the vast majority of national resources are spent on the domestic battle against AIDS. She said that the United States is spending only $225 million internationally and between $8–11 billion at home.

She said that focusing on the international front helps reframe considerations of U.S. policy domestically, particularly given that the evolution of the epidemic in the United States now "mirrors" those throughout the world, with rates of infection increasing among women, youth, and people of color.

Mr. Burden said the issue of international versus domestic spending was of concern, given the U.S. GDP. He asked what Ms. Thurman's position is on the issue of debt forgiveness and pointed out that African countries are refusing to take on more debt, which they see as contributing to the problem of escalating HIV infection. He also expressed concern about how efficiently funds are being spent on HIV/AIDS internationally.

Ms. Thurman said that the United States has been by far the largest donor to the international fight against AIDS, contributing 50 percent of the funding, even though the amount is not sufficient. She said that debt forgiveness is essential as many countries are spending four times more on debt service as they are on health care service delivery,

which then cannot sustain. Funding is being monitored by USAID programs. If the $65 million the agency was allocated for AIDS programs is divided 15 ways, the totals may be relatively negligible for individual community-based organizations with whom USAID has had long-standing relationships. She added that members of Congress have also been of this opinion after seeing the programs in operation.

Mr. Burden said he was also referring to funds that are channeled through the World Bank, to which the United States is contributing.

Ms. Thurman said that the United States, as one donor, does not have control over World Bank spending. However, these funds are being internally monitored and pressure could be brought to bear on the World Bank. The HIV/AIDS advocacy community has not had a long history of engagement with the World Bank, although this is beginning to change.

Mr. Isbell asked Ms. Thurman to speak about the status of the HIV/AIDS epidemic in Russia and the former Soviet Republics, particularly with regard to U.S. domestic policy on needle exchange.

Ms. Thurman said that Russia and the former Soviet Union have seen the highest increases in new infections of HIV in the last year. Eighty percent of new cases are associated with IV drug use. These countries do not have drug treatment available and she was pessimistic about change.

Mr. Isbell said that these conversations are occurring in countries where no public health infrastucture exists. He is aware that G-8 cooperation would be a first line of approach but asked what official policies are recommended to countries dealing with a health crisis that is veering out of control.

Ms. Thurman said that most of these governments are not taking on HIV/AIDS as a problem. The first challenge is to reverse this problem and then to shift the approach to policy recommendations.

Mr. Isbell said that USAID was doing aggressive condom distribution in Uganda when this was not occurring in the United States, and that “hope springs eternal.”

Ms. Thurman said it might be possible to be more creative internationally than on the domestic front, but again, said that the United States is not even at a point to engage world leaders in this discussion.

Dr. Levine said that she had spoken with various Ministers of Health. The pandemic must be foremost for all officials in countries affected by HIV/AIDS. As an example, fresh needles are not available in Russian hospitals. She asked that one of the first meetings of Envoys be held in Africa or whereever these officials can have first-hand experience of the dimensions of the pandemic.

The comment was made that the Caribbean basin and Latin America are often treated as "after thoughts" with regards to HIV/AIDS. Given the rates of infection in Guiana, Honduras, Haiti, and other countries in this region, the question arises as to whether organizations such as the Pan American Society (PAS) and Special Envoy to Latin America, Buddy McKay, can raise the problem to the same degree as the Administration's efforts in Africa, Russia, and other parts of the world.

Ms. Thurman is planning on going to South America in December. She has met with the Vice President of Brazil to talk about how to include South and Central America and the Caribbean basin region in these dialogues.

Mr. Minor asked whether the United States may be linking foreign aid with prevention programs and whether this policy may be effective.

Ms. Thurman said that although this is not currently U.S. policy, attention is paid to how a particular country responds to the health needs of its citizens. A caveat is inserted into debt relief programs that some funds be used for health and social programs, although not necessarily for AIDS programs. There are many constraints imposed on U.S. aid that debt-burdened nations are further strained in their efforts to comply.

Ms. Miramontes said that she is concerned that the United States tends to take the position that it is supplying the expertise to battle HIV/AIDS, which smacks of a "new colonialism." True partnerships are necessary in countries where many people have already found ways of coping with and surviving profound challenges.

Ms. Thurman agreed that this was an important point. She said that USAID has been doing fundamental development work in partnerships for decades. It is important to be culturally sensitive in our own country and as an example, referred to the disappointing outcomes regarding the Ryan White CARE Act allocations that were originally designated to be spent by people representing communities in America. Existing mechanisms should be used to coordinate response so that energy and time can be efficiently and effectively dedicated.

The question was raised whether migrant health care issues have been the object of attention internationally for communities affected by HIV/AIDS and if so, whether there are similarities with regard to provision of services.

Ms. Thurman said that rates of infection among migrant workers are much higher than they are in the United States, even though there are increased rates domestically. For the most part, service delivery systems to migrant workers do not exist in the developing world. Exceptions include the organizing of mine workers and the growing awareness of companies that health care and education in the work place are economically advantageous. A question was raised as to whether former Council members would be permitted to attend the meeting with President Clinton. Mr. Dellums said that Mr. Montoya would be consulted about this process and that an effort would be made to include them. He said that public comment would be held at 3:30 p.m.

Mr. Dellums then thanked Ms. Thurman and appreciated her clear understanding that AIDS is a global pandemic. He said that although many people give "lip service" regarding their awareness of AIDS as a pandemic, the level of this awareness is thin, as compared with the substance and texture in Ms. Thurman's remarks. He also said that what frightens him about his role as PACHA chairman is that he is "learning too much." He said that he originally joined the Council, not to become an "expert" on AIDS but to dramatically raise awareness about the fact that millions of people are dying throughout the world, particularly in Africa, and that neither the United States or other countries in a position to respond were doing so. He does not want to lose that focus by becoming an "expert." Mr. Dellums expressed the concern that if he becomes overly immersed in data regarding specific issues, he will not be able to function as creatively or effectively.

Mr. Dellums expressed his appreciation and affection for colleagues on the Council and for former Council members, and said that he will continue to use the report in his capacity as AIDS activist. Mr. Dellums added that he would see the transition through to the new Administration.

After further discussion about the need for more AIDS awareness and its impact on immigration restrictions, Mr. Dellums and Mr. Montoya adjourned the meeting for a 15-minute break.

Meeting with the President: Preview

After a 15-minute break, Mr. Montoya described the afternoon's presentation of the roll out so that PACHA members would be clear on their respective roles. He explained that a "roll out" is a preparation to ensure that all communications efforts are synchronized with regard to their meeting with President Clinton.

He said that the meeting time has been moved up to 12:10 p.m., before the end of the day's press cycle. The Friday meeting would adjourn soon after Tim Westmoreland's discussion of Medicaid funding, and members should go directly to ONAP and meet there by 11:00 a.m. Council members would then walk to the White House to be processed in, which always takes more time than expected. The group should be in the West Wing waiting room 20 minutes prior to the meeting.

He said that unfortunately only current PACHA members would be able to attend the meeting and that it was still unclear whether he and Ms. Thurman would be included.

At most 10–20 minutes would be available for the meeting. Comments directed to President Clinton must be clear and concise. Only Mr. Dellums, as chair, should present the report, along with some brief comments. Often President Clinton does not meet his schedule because he often stays longer in meetings than expected. This may mean that members would have more time than planned, but it was important to plan as if time were only available for brief comments.

Mr. Montoya then reviewed the press kits that were sent to supportive organizations.

Mr. Dellums suggested that he not be the only speaker during the White House meeting and made alternate suggestions.

Mr. Summers agreed that it was important to acknowledge that there were people in the meeting who are living with HIV and that Tom Henderson should also be mentioned, because he was a friend of the President's.

Mr. Dellums agreed and asked Mr. Montoya to contact White House staff Thursday evening to communicate the group consensus not to spend time with photographs.

Ms. Aragon expressed appreciation for the opportunity to speak during the meeting at the White House, but advocated for Mr. Dellums because he has the relationship with the President and has the stature to be able to re-engage him into the conversation. She said that at least 3 to 5 minutes of essential remarks should be planned and although Mr. Dellums might be the only one in a position to deliver them, someone else should be ready to back him up.

Mr. Dellums said he would prepare a succinct statement and commented that if the President is rushed to attend another event, this would present a perfect segue in terms of their theme of "no time to spare" to address the AIDS crisis. He asked the Council to agree on nominating someone with HIV/AIDS to speak.

Mr. Montoya asked self-disclosed HIV-members to consider whether they would be interested as individuals in speaking during the meeting.

Mr. Montoya then reviewed what would transpire after the meeting with the President. Further discussion ensured about the meeting, what should be emphasized in the time allotted, and other areas of concern. He also noted that Council members would be able to have copies of the report and poster.

Friday, September 22, 2000
Morning General Council Session

Mr. Dellums opened the session and briefly reviewed times and places for the meeting with President Clinton.

Mr. Dellums then introduced Dr. Tim Westmoreland, an official with HCFA, who would speak on a range of issues, including early access to HIV/ADS health care through Medicaid.

Overview of Early Access to HIV/AIDS Health Care Through Medicaid

Dr. Westmoreland said that mandatory spending programs—specifically Medicaid and Medicare—continue to be the overwhelming source of HIV financing in the United

States, with a projection this year of $2.2 billion in Medicaid funds and a total of $1.9 billion in state matching funds, for a total of $4.1 billion out of an overall Medicaid total of approximately $210 billion for the coming fiscal year; $1.7 billion is allocated for HIV services from Medicare.

Dr. Westmoreland said that Medicare funding appears to be slightly declining while Medicaid continues to rise; with the aging of the population, Medicaid will surpass Medicare within the foreseeable future. Many people forget that Medicare is a huge source of AIDS health care financing, because people are living long enough to qualify for SSDI (Social Security Disability Insurance), the route into Medicare and once there, they receive better hospital and physician reimbursement rates. Low-income patients can also be dual-eligibles, receiving both Medicare reimbursement for doctor and hospital visits and Medicaid prescription drug benefits, which are not linked with the Medicare package.

To the extent those with HIV/AIDS can navigate their way through these "antiquated" categorical eligibility systems of SSI and SSDI, they can end up with a fairly comprehensive package; an increased number of patients are in this group.

Dr. Westmoreland then discussed the Work Incentives Act, also known as the "Ticket to Work" Act, in which there are buy-in options for Medicaid so States could allow people with higher income or whose health has improved to stay on Medicaid and not lose eligiblity because of higher income or improved health status. Eligibility will begin on October 1, 2000. A minimum of 45 States have attended conferences to determine how they might implement Work Incentive Act eligibility for Medicaid in either of the two categories—improved income or health care status.

In addition, demonstration projects have allowed states to receive grant money, for a total of $300 million over 5 years, or $50 million a year and escalating, to provide optional Medicaid eligiblity on a demonstration basis for people who are HIV positive but not yet ill or manifesting symptoms. Dr. Westmoreland said this applies not only to HIV patients but to anyone who would become disabled without health care interventions.

Dr. Westmoreland said the first round of applications have been closed out with a disappointing number of State applications—currently only one State has applied for HIV activities. Two other States have applied for funding for depression, which is classically suited to this program with the advent of new pharmacology that allows potential patients to avoid the disabling symptoms of depression. This is a positive step for HIV coverage because the stronger the case for early intervention with regard to other health care issues, the easier it will be to obtain HIV/AIDS coverage.

New applications will be held to accommodate those States that did not already apply. Dr. Westmoreland said that ideally some of the grants would be "out on the street" by Monday, October 2, 2000, so that HCFA could meet the President's commitment to implement these grants as soon as funds are available in the coming fiscal year.

Dr. Westmoreland said that it has been interesting to coordinate Medicaid and Medicare funding with the Ryan White package for the first time in such a substantial way. He said that he has held discussions with HRSA officials about sharing Medicaid data sources and ensuring that benefits do not overlap as well as that mandatory dollars are spent before discretionary funds. He said that Ryan White CARE providers now must apply for reimbursement rather than simply using grant funds, which is a "hard lesson" for those who write checks out of grant money. However, using mandatory dollars will allow many more people with HIV/AIDS to be served.

Dr. Westmoreland then spoke of the difficulities being experienced in the State of Maine regarding pharmaceutical pricing caps and that the Pharmaceutical Research and Manufacturers Association is in the process of suing the State to try to overturn the waiver. He also mentioned the State of Wisconsin, which is seeking a budget neutrality waiver for HIV early intervention. A concept paper from the District of Columbia has suggested creative options for using other sources of federal funding for HIV/AIDS. Dr. Westmoreland said it was hoped the waivers could be accomplished before the end of the calendar year.

He encouraged PACHA members to urge their state Medicaid representatives and AIDS groups to submit concept papers to HCFA, because this is necessary to begin the process of working with the State on funding allocations. There is a clearer understanding of what budget neutrality calculations will be, for purposes of these waivers, with the Office of Management and Budget (OMB), and that OMB is interested in working with HCFA. Even if budget neutrality figures do not quite add up at the time of submission, HCFA may be able to assist with balancing budgets.

Mr. Lew asked whether HRSA or HCFA have estimates of how much Ryan White providers are already receiving from Medicaid reimbursement.

Dr. Westmoreland did not have the figures available but could get them. Numbers dramatically vary from State to State, depending on the relative generosity of Medicaid programs. A State that only provides three prescriptions a month will only provide a limited amount of reimbursement through Medicaid. Another issue is that providers are used to asking for grant money rather than pursuing third-party liability against Medicaid, which is always the last payer; providers must look in other directions before receiving funds, other than Ryan White, for which Medicaid is a primary payer. Few programs can seek this type of third-party reimbursement from Medicaid. Also, some State reimbursement levels are so low, for example, $12.50 for a physician visit, that the doctors prefer to be reimbursed from the Ryan White program.

Mr. Lew asked whether a creative approach might be a partial reimbursement through Medicaid and then the balance through Ryan White and whether any of Maine's innovative approaches to cost savings apply to other States as well.

Dr. Westmoreland said that he knows some of the strategies that Maine is considering but they have not yet been announced. Once Maine finishes its proceedings, he would be

happy to circulate their findings pertinent to cost savings as well as Wisconsin's approaches.

Mr. Isbell said that he has worked with Georgia on submitting a concept paper but that the reaction among those he has talked to about the possibility of swift approval is fairly cynical. Dr. Westmoreland asked whether this was true at the Federal level; Mr. Isbell said it was. Mr. Isbell said that he was encouraged by Dr. Westmoreland's indications that the concept papers could be approved on a more timely basis and asked him about a timeline for approval.

Dr. Westmoreland said that 4 months to get an 1115 waiver from start to finish is "breakneck" speed, and many people would say that it often takes HCFA 2 years. Although not an AIDS waiver, HCFA has solicited this because it improves health care rather than rationing health care. States should be asked whether their 1115 or 1915 waivers that took longer to process were trying to cut back on benefits that were guaranteed under the statute. He is optimistic that the current waiver would be accomplished in 4 months, or that the glass is "one-fifth" full, although January 20, 2001, is the deadline, at the earliest, to accomplish these objectives. However, he is encouraging States in this regard because of mutual agreements that have come out of recent meetings with HCFA actuaries and the OMB.

Ms. Aragon said that one of the recommendations in the final report to be presented to President Clinton concerns budget neutrality. When the report was prepared, the waivers received exclusive focus. However, at the reception held last night, staff indicated that an opportunity exists to move legislation by the end of the session that would allow States to get around waivers by mandating under law that poor people with HIV under a certain income level would be eligible for Medicaid. This is clearly a more comprehensive and easier solution. Ms. Aragon then asked Dr. Westmoreland for an indication of the Administration's position on a more comprehensive solution to AIDS funding.

Dr. Westmoreland estimated between $40 and $60 billion will be spent on health care over the next 5 years, of which $1.6 billion is to be directly used for making new people eligible for Medicaid as opposed to paying providers for uncompensated care, without regard to insuring new enrollees.

Ms. Aragon said that after learning this information about Medicaid reimbursement for HIV/AIDS, the press release was amended to move the Medicaid issue to the first page.

Dr. Westmoreland said that there is active discussion within Congress about expanding Medicaid to include women with breast and cervical cancer who are diagnosed at a CDC screening site but are uninsured. He said that he has been a long-time advocate of the need to serve all people who are not able to receive treatment by virtue of the disability standard. He stressed the unreasonableness of requiring a woman with breast or cervical cancer to be disabled by the disease before she can qualify for Medicaid, just as it is unreasonable for people with HIV/AIDS to have to be disabled to receive treatment.

Dr. Westmoreland commented that it was somewhat ironic that the breast and cervical cancer advocates got this idea from the HIV bill and are not ahead, having moved the bill past the House and Senate, but stressed the fairness of asking for the same policy to be applied with regard to the disability requirements for breast and cervical cancer sufferers.

He said that the breast and cervical cancer bill had a 75 percent Federal share, with only a 25 percent State match. If this route were also pursued for HIV/AIDS, the CBO score would be dramatically reduced. Dr. Westmoreland commented that the breast and cervical cancer advocates have been successful in moving both early intervention and enhanced matching, which could not be accomplished at this stage with the HIV bill.

Mr. Bau said that at the end of August the Office of Civil Rights (OCR) within HHS issued policy guidance on access for limited English-speaking populations and is following up on President Clinton's Executive Order mandating that Federal agencies follow Title VI rather than imposing it on grantees. He asked Dr. Westmoreland whether HCFA has addressed this issue with regard to Medicaid and Medicare benefits for limited English proficiency (LEP) individuals. He said that struggles have been endemic not only with grantees but in trying to obtain information from Medicaid and Medicare.

Dr. Westmoreland said that he has spoken with Tom Perez at OCR extensively regarding this issue. The guidance that OCR sent out is called "Safe Harbours," which specifies that the recipients of Federal funds can be assured that the OCR will not investigate or sue them. As such, he believes that the standards are higher than most courts might have found would be required, and he understands President Clinton's order to be that the Federal Government should live up to that higher standard.

He said that a letter had been sent to State Medicaid directors on LEP that tries to offer guidance with regard to what he characterized as a "terrible problem" in terms of dealing with applications, managed care enrollment forms, disenrollment forms, and appeals forms for LEPs.

The larger issue with regard to LEP in the health financing programs is with Medicare. Medicaid publishes very few Federal publications, and those are intended for state bureaucrats. He urged publication of more consumer-friendly forms and information, but said that HCFA usually relies on the States to put out their own material because it varies so much from one State to the next.

Dr. Westmoreland said that it is important that as State plans and waivers are approved, they must take into account LEP, literacy levels, and disability. Managed care forms that are illegible do not allow for informed consent or choice. Because this is a new issue for State Medicare programs, it continues to be a struggle that will take years to solve. Medicaid has a responsibility to ensure that State grantees and recipients of Federal funds live up to the effort to resolve the problem for patients with LEP.

Mr. Dellums thanked Dr. Westmoreland. He then reviewed the previous day's discussion during which items were prioritized for the Council's meeting with the President. He said

that he was not planning to present a "dissertation" to the President but to highlight the main issues reviewed by the Council. He asked the Council to comment on other items that should be on the agenda.

Mr. Lew urged more time be devoted during the meeting to the Medicaid legislation.

Ms. Aragon agreed that the Medicaid package is essential and suggested that President Clinton might be reminded that his friend, Tom Henderson, stressed the importance of expanding Medicaid eligibility to cover people in the earlier stages of HIV infection during the PACHA meeting 2 years ago. The Council could express its hope that President Clinton would strongly support pending Medicaid legislation.

Mr. Summers said that Vice President Gore committed to Medicaid expansion 4 years ago and that this is still an unfulfilled promise. Furthermore, the Administration is working closely with Congress on the breast and cervical cancer bill; thus, there is no justification to pursue this bill and not to follow through on their stated commitment to HIV/AIDS.

Ms. Aragon said that the final report states that the budget neutrality obstacle should be corrected because now there is an actual opportunity of getting this legislation passed. The issue should be presented.

Mr. Montoya said there would not be sufficient time to discuss general themes in detail but that if President Clinton poses any questions, particularly about Medicaid legislation, a Council member would respond. Mr. Dellums emphasized that follow-up mechanisms exist to expand issues relevant to PACHA beyond the immediate opportunity to meet with the President.

Ms. Aragon suggested that within the context of appropriations, it could be stated that the opportunity now exists to pass legislation to expand Medicaid eligibility to those in early-stage HIV status, which will significantly impact available resources. This would allow Tom Henderson's name to be mentioned as a former mutual friend and colleague who had already spoken to President Clinton about this issue 2 years ago.

Mr. Dellums said he would express gratitude to the President for what he and his Administration have accomplished.

Mr. Summers agreed that early care should be stressed to President Clinton, that there is an opportunity to extend care to everyone with HIV/AIDS in the United States with a relatively nominal amount of money, and that it could be done through Medicaid.

With the Council poised to adjourn and meet at the ONAP office, Rabbi Edelheit asked Mr. Montoya what PACHA's formal status would be after the Council's meeting with the President.

Mr. Montoya said that PACHA was created by an Executive Order from the President and is chartered through July 2001 or beyond the election. He clarified that once the new President assumes office, he can rescind the Executive Order, allow it to expire, or create another advisory body.

Rabbi Edelheit asked whether another meeting is planned.

Mr. Montoya said that ONAP is exploring dates and hopes to schedule another meeting, although spring is a busy season, with the inauguration and new Administration arriving.

Mr. Dellums asked PACHA members who could reconvene after the meeting at the White House to do so at ONAP. In the event the Council did not meet again in its official capacity, he wished to extend his appreciation to all of the members on the Council, who had been so effective and committed to producing the final report.

The seventeenth meeting of the President's Council on HIV/AIDS was adjourned.