FOIA Number: 2018-0758-F

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PACHA [President's Advisory Council on HIV/AIDS] - Meetings - 7/97

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PRESIDENTIAL

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HIV/AIDS

Executive Summary
Progress Report

JULY 8, 1996

The AIDS crisis has generated more than its share of advisory committees. Far too often, these committees, commissions, and councils have issued recommendations and detailed reports that have simply gone unheeded.

To avoid this all-too-frequent pattern–and to highlight the frank and continuing interchange between President Clinton and his Advisory Council on HIV/AIDS–we believe it is important to distribute not only our recommendations to the Administration, but also the Administration's responses, with our candid, independent evaluation of their responses.

This first progress report will be followed by others. Because the Council's evaluation process will constantly be evolving, this report is truly a work in progress, as are all of the efforts of the Council itself.

The differences between this report and those issued by previous national and/or Presidential councils addressing the AIDS crisis are illustrative of the differences between the councils themselves. President Clinton's AIDS Council, more than any of its predecessors, reflects the experience and expertise of those most impacted by the epidemic. Forty percent of the Council's members are HIV-positive. One-half are lesbian, gay, or bisexual. One-third are people of color. All Council members have personally been affected by the epidemic.

This Council is different in other ways as well. The Council has had unprecedented access to the President, top-level White House staff, and cabinet officials. To a degree that has surprised many Council members, Administration officials have rapidly addressed and implemented many of our recommendations. Even when the Administration has not been as responsive as we would have liked, our views as a Council, and those of others infected with or affected by HIV, have been heard and taken seriously.

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While our access has been unusually broad, the scope of our mission has been more narrow than that of our predecessors. Our purpose has not been to advise the Nation, or Congress, but to advise the President on what his Administration can and should do to stop the spread of the epidemic; to find a cure and vaccine for HIV; to provide the best possible treatment and care to those who are infected; and to end HIV-related discrimination and intolerance. To augment that advisory role, the Council has established a process, which includes ongoing monitoring and evaluation, to ensure that appropriate Administration departments and agencies respond to our recommendations and are continuously held accountable for their responses.

We recognize that our work to date has yet to address a number of key issues. We encourage suggestions for future recommendations and welcome continued community input, especially from people living with HIV and their advocates. The Council believes that working with this Administration, we now have a significant opportunity to make a positive impact on national HIV/AIDS policy.

Overall, the Council has been impressed with the Administration's strong commitment to key items such as increased funding for the Ryan White CARE Act, vigorous resistance to the proposed dismantling of Medicaid, and support for a strong and well-funded Office of AIDS Research (OAR) at the National Institutes of Health (NIH). We believe that it is remarkable and laudable that the President has, during an era of flat Federal funding, helped to achieve a 43 percent increase in discretionary Federal AIDS funding during his first three years in office. However, the Council is disappointed with the Administration's lack of action on some of our recommendations, particularly regarding some of the more politically charged aspects of prevention and discrimination where greater courage and leadership are required.

This report contains our first two sets of recommendations (issued in July and December of 1995), the Administration's action in response to each recommendation, our evaluation of this response, and our proposed followup. It also includes our third set of recommendations, made in April 1996. We expect, in future months, to update these evaluations and to assess and distribute the Administration's responses to our third set of recommendations as well. We have developed recommendations in five subject areas: Presidential leadership, research, prevention, services, and discrimination. This report is presented accordingly.

Leadership:

The President's personal leadership and commitment in the battle against AIDS is clearly unmatched by his predecessors. By rapidly convening a national summit on AIDS at the Council's request, and by following our recommendation that he discuss HIV/AIDS with other broad audiences, the President has sent a much-needed message about the importance of the issue of AIDS to the American people. However, more visible leadership and direct involvement by the President, Vice-President, and cabinet officials are still needed to combat complacency and inaction wherever they exist, both among the American people and within the Government. For years, various groups have called for a national plan on HIV/AIDS,

and this Administration has expressed its willingness to develop such a plan. However, after almost four years, a National Plan on HIV/AIDS remains in development. The Council eagerly awaits the release of this plan.

Research:

The Council is pleased with the strong commitment made by the Administration in attempting to reorganize all HIV/AIDS research within the various Institutes of the NIH under the leadership and direction of the OAR. We believe that such reorganization ensures a more coordinated, efficient, and ultimately successful research endeavor. The President's strong and consistent support for the OAR is to be commended. However, action by the Congress in FY 1996 makes clear that further work is required to ensure that OAR can exercise its full budget authority in FY 1997 and beyond. The Council is also pleased by the rapidity with which the President called upon Vice President Gore to commence an ongoing dialogue between industry leaders and Government scientists in an attempt to expedite a more coordinated approach to drug, vaccine, and microbicide research and development. Such efforts must be continued, with inclusion of additional constituencies, including the AIDS-affected community, academic scientists, and others. The strong support articulated by the President in the area of microbicide research is greatly appreciated, as we believe such compounds offer significant promise in preventing HIV transmission in a cost-effective and culturally sensitive manner. Further investment will be required in the years ahead. The Council appreciates the Administration's concerns for inclusion of women, children, and all disenfranchised groups infected by HIV into clinical research studies. We look forward to specific actions to ensure that pediatric and gender-specific plans are required at the time of any new drug application to the Food and Drug Administration. In addition, future recommendations will be forthcoming from the Council in the areas of vaccine research and development and in behavioral research.

Prevention:

We were pleased that the President announced during his December 1995 White House Conference on HIV/AIDS his goal of ensuring an annual decrease in the number of new HIV infections in the United States of America. However, the Council continues to have grave concerns that much of the Federal HIV prevention strategy is underdeveloped, lacks focus, and is overly timid. We believe that a bold and carefully conceived plan, including generation of necessary political and societal support, is essential for achieving effective prevention strategies. The Council looks forward to working with the President and his Administration to develop such a plan and support for it.

The Council commends the Administration for its support of the prevention community planning process; its development of more direct public service announcements that discuss condoms and that seek to target high-risk populations such as young people of color and gay and bisexual men; and its opposition to Congressional efforts to decrease access to substance abuse prevention and treatment programs. However, the Council continues to believe that Federal policy regarding needle exchange and the lack of integration/coordination of HIV prevention strategies with substance abuse treatment

programs are not consistent with current knowledge regarding the impact of such programs on HIV prevention. Further, the Council supports increased priority for behavioral research and rapid distribution of key findings to front-line HIV prevention programs.

Services:

The Council is pleased with the Administration's continued support for increased funding for the Ryan White CARE Act. In particular, we applaud the Administration's leadership role in securing a $105 million increase in funding for FY 1996. However, while the President's FY 1997 budget recognizes the continued need for increased AIDS funding, it still does not adequately respond to the growing need for services. Of particular concern to the Council is the Administration's failure to acknowledge in its FY 1997 budget the urgent need for increased funding for AIDS-specific housing through the Housing Opportunities for People with AIDS (HOPWA) Program. Since a growing proportion of people living with HIV/AIDS are homeless or at risk for homelessness, and the needs of this population continue to grow more complex, the Administration must make AIDS housing a higher priority.

The Council commends the President for his consistent leadership in defending the Medicaid program, which is the sole source of health care for nearly 50 percent of PWAs. The Administration has also taken a number of initial steps to develop national guidelines for managed care and Statewide Medicaid waivers, and is committed to using its limited administrative authority to encourage States to offer the broadest possible range of HIV/AIDS services and therapies through the Medicaid program. The Council urges the establishment of more formal managed care guidelines; rejection of managed care waiver applications that provide inadequate care for persons with HIV/AIDS; and the development of policy guidance related to coverage of the newly approved protease inhibitors. The Council cannot overemphasize the importance of the Administration's continued vigilance in this area, as well as in the area of health care provider training and education.

Discrimination:

The Administration's approach in this area has paradoxically been both notably strong and notably weak. The Administration's enforcement of the Americans with Disabilities Act, and the President's public words opposing discrimination based on HIV, race, sexual orientation, and other factors have been valuable and important. The Council particularly commends the President's real leadership in overturning the malicious Dornan Amendment, which would have expelled service members with HIV from the military and denied medical benefits to their families. We also strongly commend his support for the Employment Non-Discrimination Act, which would forbid employment discrimination based on sexual orientation. The Council is profoundly concerned, however, that despite the Administration's positive words, the Federal Government is itself engaged in officially sanctioned HIV/AIDS-related employment discrimination in some departments. Thus, while we commend the Administration for reversing the policy of mandatory HIV testing and discrimination in the Job Corps, we urge the Administration to move swiftly to eliminate similar programs in the military, the State Department, and the Foreign Service, and to

revise its arbitrary guidelines governing HIV-infected health care workers to bring them into accord with current public health consensus.

Conclusions:

In trying to assess the Administration's efforts to respond to the AIDS epidemic, the Council, and all Americans, are confronted with a difficult question: How do we judge and to what do we compare this Administration's efforts? When compared with that of previous administrations, this Administration has clearly made an unprecedented and laudable investment of funding, human resources, and genuine personal commitment. We commend the President's dramatically heightened responsiveness to the urgency of this epidemic. However, when compared with what truly needs to be done, this Administration's efforts are still insufficient. We must not become complacent, given the ongoing nature of this epidemic. The time for increased commitment, along with moral and political courage, is now.

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Copies of the full Progress Report can be obtained by calling the National AIDS Clearinghouse at 1-800-458-5231.