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Meeting with Women and AIDS Coalition 2/9/94

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From HC War Room
20-30 folks.

CAMPAIGN FOR WOMEN'S HEALTH

BY FAX

5998255

January 24, 1993

Charlotte Hayes
Scheduling Dept.
Health Care War Room
The White House
Fax: (202)456-2362

Dear Charlotte,

The Women and AIDS Coalition(WAC), an alliance of organizations convened to ensure that the concerns of women with HIV/AIDS are addressed in public policy, is planning a meeting to discuss how these concerns are addressed in health care legislation. I am writing as a WAC representative to formally request that a representative from the Clinton Administration attend this meeting to speak about how the Clinton Health Security Act deals with HIV/AIDS health concerns for women.

The meeting will be held on **Wednesday, Feb. 9, from 1:00 until 2:30 PM in the Universal North Building, 1875 Connecticut Ave. NW**. I spoke with Christine Heenan this morning regarding her availability for this event. She referred me to you and recommended that I specifically request her or some other spokesperson who is considered expert on HIV/AIDS and women's issues. As of today, other scheduled speakers for this event include Christine Lubinski of AIDS Action Council and Cindy Pearson of the National Women's Health Network. Cindy Hall of Rep. Connie Morella's office also plans to attend. We would like to have the Administration's perspective in this discussion and hope that you will be able to provide a representative.

Thank you in advance for your assistance in this matter. Please feel free to call me at (202)783-6686 if you have any questions. I look forward to hearing from you this week.

Sincerely,

Alice M. Weiss
Campaign for Women's Health

A Project of O.W.L.
666 Eleventh Street, NW, Suite 700, Washington, DC 20001 (202) 783-6686 FAX (202) 638-2356

WOMEN AND AIDS COALITION

A Task Force of the National Organizations Responding to AIDS (NORA)

Monthly Meeting Agenda

DATE: Wednesday, February 9, 1994

TIME: 1:00 pm

PLACE: 1875 Connecticut Avenue, NW
Third Floor Conference Room
Room 310

I. Policy and Strategy Discussion on Women at Risk and HIV Positive Women and Health Care Reform.
   A. Speakers
      1. **Christine Lubinski, AIDS Action Council**
      2. **Cindy Pearson, National Women's Health Network**
      3. **Kristine Gebbie, National AIDS Policy Office**
   B. Question: Looking at all provisions, how will Health Care Reform effect women at risk for HIV and HIV positive women? What recommendations can be given to ensure the health care needs of these women?

II. Continued Discussion on WAC's Strategy with Health Care Reform
   A. Letter written to House and Senate committes to testify
   B. Presentation and discussion of the policy paper and testimony
   C. Discussion of further action and strategy

III. Continued Discussion on WAC Diversity and Participation
   A. Presentation and discussion of letter
   B. Discussion about the list of five organizations asked of individuals at last meeting
   C. Discussion of further suggestions for diversity and participation

IV. Revisit and Brainstrom Project Ideas from December Meeting
   A. Media project
   B. Briefing book
   C. Adolescent HIV prevention summit
   D. Kristine Gebbie's office
   E. Congressional briefing
   F. AIDS Watch 1994

NEXT MEETING: Wednesday, March 9, 1994
Ryan White Care and Womens Programs

THE WHITE HOUSE

WASHINGTON

Health Care Reform and the HIV Epidemic
Top Ten Issues

For those infected with HIV, the assurance of comprehensive health insurance is an essential public health goal.

The Office of the National AIDS Policy Coordinator has provided advice on policy formulation during the development of the Health Security Act (HSA). These efforts were directed towards assuring adequate care and services for people with HIV/AIDS. As the Congress now debates the HSA, the Administration is making every effort to assure that modifications to the President's proposal maintain equity and sensitivity to the special needs of HIV-infected individuals.

Private insurance companies, like other businesses, seek to maximize profits by choosing only "acceptable" insurance risks. Under the HSA, universal coverage is guaranteed. Universal means everyone! What does Health Security mean to you?:

* **Universal coverage - HIV status or other health conditions do not prevent you from getting coverage.**
* **Community ratings prevent persons with HIV infection from being charged more for premiums.**
* **Prescription drugs will be covered.**
* **Ryan White CARE Act services will not be lost.**
* **Any form of discrimination is prohibited.**
* **Essential providers - specialists in treating HIV and AIDS will be available to all people who need them.**

Based on a series of focus groups with people with AIDS and HIV/AIDS service organizations, a list of "top ten" concerns for the HIV community were identified. Information regarding these concerns is attached for your review.

I hope this information will be helpful to you. If I can be of further assistance or provide any additional information, please contact me or Andrew E. Barrer, Ph.D. at (202) 632-1090. Thank you.

Kristine Gebbie

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

1. Premium Financing and Risk Adjustment

Issue: Will the risk adjustment mechanism prevent "redlining" for persons with HIV/AIDS or other life threatening illnesses?

Summary: Yes. Redlining, or any attempts to limit access to people with HIV or AIDS is clearly prohibited. The HSA provides mechanisms which require states to spread the financial risks associated with special communities by adjustments which would take into account such factors known to affect utilization of services, such as age, sex, health status and services to disadvantaged populations. The health plans have to meet specific rules on enrollment, community rating, information, and grievance procedures.

2. Availability of HIV Specialist, "Essential Providers"

Issue: Will HIV positive persons be able to continue using their local HIV medical specialist?

Summary: The Health Security Act establishes a special category of health care provider which is referred to as an "essential provider". Any health care provider or organization can make application to be certified as an essential provider. Within the HSA, a Ryan White grantee or subgrantee can be automatically certified as an essential provider. Each health plan must enter into a written agreement with each essential provider located within its service area.

3. Long-term Care and Home Health Care

Issue: Persons with HIV/AIDS often need home health care and long-term care services. Will the Health Security Act provide those needed services?

Summary: Home health care is included in the nationally guaranteed comprehensive benefits package. A new long-term care initiative will expand coverage of home and community-based care. This will make it possible for more elderly and disabled persons, including persons living with HIV/AIDS to live in their homes and communities while receiving long-term care. The Act will improve

Medicaid coverage for persons in nursing homes.

The HSA will improve the quality and reliability of private long-term care insurance and provide tax incentives for persons to buy it; and tax incentives to help individuals with disabilities work.

4. Availability of Mental Health and Substance Abuse Services

Issue: Mental health needs in the HIV/AIDS community tend to be greater than the average. What will HSA do to provide these services? Injecting drug users, at high risk of HIV infection and transmission, currently have inadequate treatment and preventive services available to them. Will adequate services be available to treat these individuals in order to ameliorate their additive disease and halt the epidemic?

Summary: A base level of mental health services will be provided to all persons through the Health Security Act. We know that viable mental health services are part of a good program of health care and especially beneficial to HIV infected persons.

In order to make a significant difference in the rate of new infections in the injecting drug use population and their sexual partners, the HSA will provide substance abuse treatment to everyone.

5. Health Care Reform and the Ryan White CARE Act

Issue: Will the financial restructuring of the health care system assure the delivery of health care services appropriate to the needs of vulnerable populations whose access problems go beyond lack of insurance?

Summary: The comprehensive benefits package provided by the HSA may not provide all essential services for persons with HIV/AIDS. Conversely, a variety of services currently provided by the CARE Act would be covered under the HSA benefits package. These would include primary care services, medications, assistance for health insurance coverage, home-based services, case management,

transportation, and outreach. It may be necessary to utilize Ryan White CARE Act funds "freed up" by the provision of these services under HSA to subsidize the supplemental and client's share of insurance premiums, co-payments, deductibles, and expenditures that exceed spending caps.

The CARE Act is not a "band-aid" that can be discarded after health care reform. The Act will serve as a critical resource to sustain health care delivery systems and insure the continued delivery of essential and comprehensive health and support services to those infected with HIV.

6. Medicaid and Medicare Funding and Program Transition Issues

Issue: What impact will the HSA have on funding for the Medicaid and Medicare programs? What programs will be available during the transition from the old system to the one provided under the HSA?

Summary: Under the HSA adult Medicaid recipients who now receive cash supplements (currently 9 million beneficiaries) would be enrolled in the new system, but would not have to pay premiums. Further, they would be entitled to join a new state and federally-matched program providing wrap-around services similar to those now available under the Medicaid program. Children less than 18 years of age who are currently eligible or would be Medicaid recipients, with eligibility for wrap-around services (primarily based on poverty level), would be provided those services through a new federally funded (but state administered) program, ***regardless of their cash assistance status.***

The Medicare program will be preserved and strengthened under the HSA, which will add new coverage for prescription drugs and expanded coverage of home and community-based care.

7. Health Security Act (HSA) and Confidentiality Issues

Issue: What safeguards are envisioned for the handling of health information on HIV affected persons under the Health Security Act ?

Summary: The HSA addresses the issue of how information will be handled and what penalties will be imposed for misusing information. The HSA will provide guidance level information on creation of the oversight board, users and uses of information, privacy standards, enrollee rights, outright prohibitions, training of information handlers, and comprehensive health information privacy protection. The development of the Comprehensive Health Information Privacy Protection Act will be implemented within two years from the date of passage.

8. Grievance Procedures

Issue: How can individuals ensure that their health plan will provide the health benefits and services they require?

Summary: The HSA is intended to provide adequate health care coverage for all citizens and legal residents of the United States. The Act requires States to approve each health plan before it can engage in providing health care under the Act. The law prohibits exclusions because of pre-existing conditions or through "red-lining," the practice of excluding a particular group of individuals because of perceived high risk.

The Health Security Act includes a comprehensive grievance process for any person aggrieved by acts or practices which result in denial or delay of benefits or payments. Individuals must work within the individual plan's grievance process before going to adjudication through the Complaint Review Offices set up in each state. If there is a question as to an individual's eligibility for a plan, subsidies or cost sharing, the individual may go directly to court and all costs can be reimbursed if the court finds for the individual.

The complaint office must rule in under 30 days, although a 24 hour appeal is available in cases of emergency. Appeals must be processed within 60 days. There are means of appealing, with the national board being the ultimate administrative appeal.

9. "State Options"

Issue: What impact will "State Options" have on coverage under the HSA? What impact will it have on services, availability, and affordability?

Summary: Some states cover additional services under federally matched Medicaid programs. Under the HSA, a number of programs will become available at each state's option. To assure that there is not a loss of services to the person with AIDS, Ryan White will continue to act as the safety net to assure needed services reach all people in need. The expanded use of case management, will help follow individual needs and assure services are provided.

10. Public Health System Core Functions

Issue: What is the nature of the funding for research on behavior, health services and Core Functions of Public Health Programs?

Summary: The Health Security Act will provide funding for AIDS specific research and public health initiatives that will have to be provided under the authority of the Public Health System. Behavioral research into those behaviors that may cause or contribute to disease will be conducted by the National Institutes of Health. The Act will also provide funding for strengthening the public health core function of states, including those components related to diseases of public health significance. This support will allow communities to maintain strong programs to prevent the spread of HIV, tuberculosis, and other conditions of public health importance.

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