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Report

White House Discussion on Women and HIV/AIDS

Sarah T. Holewinski
1552 33rd Street, NW
Washington, DC 20007
(202) 395-1441

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Responding to the Needs of Women with HIV

Title I and Title II Ryan White CARE Act

March 1997

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
HRSA
Health Resources & Services Administration
Bureau of Health Resources Development

UCSF Center for AIDS Prevention Studies
AIDS Research Institute

what are women's HIV prevention needs?

updated 8/98

are women at risk?

Yes. In 1997, women comprised 22% of all AIDS cases in the US. Heterosexual contact is the leading risk exposure category for all women (38%), and 29% of those are due to sex with an injection drug user (IDU). Injection drug use accounts for 32% of all cases.[1] The majority of women who have sex with women (WSW) acquired HIV via drug use or sex with a man, although a few women have been identified infected via same-sex contact.

Women are one of the fastest growing populations being infected with HIV, and the number of AIDS cases among women increases steadily each year. Women under 30 made up 22% of AIDS cases among women in 1996. Because the time from HIV infection to developing AIDS can be long, many of these women acquired HIV in their teens.[2]

African American and Hispanic women have been disproportionately affected by AIDS. AIDS rates for African American and Hispanic women are 17 and 6 times higher than for white women. In 1997, African American women made up 60% of all female AIDS cases, Hispanics 20% and Whites 19%.[1]

what places women at risk?

Male-to-female transmission is estimated to be eight times more likely than female-to-male;[3] in 1997, 38% of women contracted HIV through heterosexual contact, as opposed to 7% of men. Reasons for this are twofold: there are more men than women in the US infected with HIV, which increases the likelihood that women would have an infected sex partner; and HIV is more easily transmitted from men to women due to the greater exposed surface area in the female genital tract.[1]

Sexually transmitted diseases (STDs) other than HIV can increase the risk of new HIV infections at least two to five times. Genital ulcers and immune response associated with STDs make it easier for HIV to enter the body. There are an estimated 12 million new cases of STDs every year, and populations at highest risk for HIV infection also have disproportionately high rates of other STDs.[4] Treatment of STDs can be an effective HIV prevention strategy.

Injection and non-injection drug use puts women at increased risk for HIV infection and is strongly linked to unsafe sex. In one study, female IDUs reported sharing needles 32% of the time, and obtained used needles from their regular sex partner 71% of the time.[5] Women who smoke crack cocaine, particularly women who have sex in exchange for money or drugs, are at high risk for HIV infection via sexual transmission.[6]

Sexual abuse and coercion places many women at risk. In one study, physical and sexual abuse were "disturbingly common" throughout life among women at high risk for HIV infection. Childhood sexual abuse (42%) and physical abuse (42%) was also common. Women who have been abused are more likely to use crack cocaine and have multiple sex partners.[7] Public health agencies need to raise public awareness about sexual abuse and coercion and help women and men develop the skills needed to prevent it.

what are barriers to prevention?

Women do not wear the condom. For women to protect themselves from HIV infection, they must not only rely on their own skills, attitudes, and behaviors regarding condom use, but also on their ability to convince their partner to use a condom. Gender, culture and power may be barriers to maintaining safer sex practices with a primary partner. HIV prevention strategies must target both women and men in heterosexual couples and address gender norms in sexual decision-making.[8]

Women are disproportionately represented among the poor. Because of this, women are less likely to have health insurance and access to health care services. Many minority women living in poverty are also disproportionately affected by HIV. For these women, the struggle for daily survival may take precedence over concerns about HIV infection, whose impact may not be seen for several years.[9]

Like many people in committed relationships, women may find intimacy in their relationship to be more important than protection against HIV. Unsafe sex may be linked to emotional and social (not necessarily financial) dependence on men. The ideal of monogamy, including assuming their partner's fidelity, may increase AIDS risk denial.[10]

Says who?

1. CDC. HIV/AIDS Surveillance Report. 1998;9:10.

2. CDC. Update—HIV/AIDS and women in the United States. Fact sheet prepared by the CDC. July 1997.

3. Padian NS, Shiboski SC, Glass SO, et al. Heterosexual transmission of human immunodeficiency virus (HIV) in Northern California: Results from a ten-year study. American Journal of Epidemiology. 1997;146:350-57.

4. Wasserheit JN. Epidemiological synergy. Interrelationships between human immunodeficiency virus infection and other sexually transmitted diseases. Sexually Transmitted Diseases. 1992; 177:167-77.

5. Leonard LE, Baskerville B, Hotz S. Risk factors for needle sharing in women who inject drugs. 11th International Conference on AIDS, Vancouver, British Columbia. 1996. Abstract #TuC2503.

6. Edlin BR, Irwin KL, Faruque S, et.al. Intersecting epidemics: Crack cocaine use and HIV infection among inner-city young adults. New England Journal of Medicine. 1994; 831:1422-7.

7. Vlahov D, Wientge D, Moore J, et al. Violence among women with or at risk for HIV infection. 11th International Conference on AIDS, Vancouver, British Columbia. 1996. Abstract #TuD135.

8. Gomez CA, Marin BV. Gender, culture, and power: Barriers to HIV-prevention strategies for women. The Journal of Sex Research. 1996;33:355-362.

4ER A publication of the Center for AIDS Prevention Studies (CAPS) and the AIDS Research Institute, University of California, San Francisco. Thomas J. Coates PhD, Director. Funding by the National Institutes of Mental Health. Special thanks to the Kaiser Family Foundation.

UCSF Center for AIDS Prevention Studies
AIDS Research Institute

what are the methods for protection?

Women are more likely to protect themselves from pregnancy using methods that do not depend on partner cooperation, such as oral contraceptives. However, oral contraceptives like the pill do not protect against STDs and HIV. Female-controlled methods to prevent HIV transmission are needed. Traditionally, abstinence, condoms and dental dams have been the main methods of protection. In 1993, Reality®, a female condom, was introduced on the market but to date, results have been mixed as to its efficacy, affordability and interest in use.

Vaginal microbicides that would prevent STD transmission but allow for pregnancy have been developed and piloted in some prevention programs. Further efforts need to include large-scale efficacy trials and to increase scientific interest and support from pharmaceutical companies to develop microbicides that prevent HIV infection.[11]

what is being done?

Recruiting women as community leaders was the basis for an effective HIV prevention program among low-income urban women living in housing developments. Women opinion leaders were trained to lead risk reduction workshops, provide HIV educational materials and condoms, and conduct HIV education through community events. The women effectively mobilized their residential community through tailored prevention messages and activities.[12]

Because women at risk are not always visible as a specific population or community, programs must strive to be where women are. A program provided HIV prevention services for women visiting their incarcerated male partners at San Quentin State Prison. The program, based at the visitor's center, trains women visitors as HIV educators, and the educators provide group and individual peer education. The program is low cost and has been well-accepted by visitors and by the prison.[13]

Interventions that promote HIV counseling and testing for both members of a couple should be considered. The California Partner Study provided couple counseling in combination with social support to serodiscordant heterosexual couples (where one partner is HIV positive and the other HIV negative). As a result, condom use increased and no new HIV infections were reported among the couples.[14]

Most drug treatment programs are staffed by men and oriented towards male clients. Allowing pregnant women to enroll in drug treatment, and allowing women to bring children with them would be helpful. In San Francisco, CA, a women-only needle exchange program was well accepted and used by female drug users. The number of needles exchanged and number of visits was similar between women who attended the women-only exchange versus mixed gender exchanges. However, women who visited the women-only exchange were more likely to receive health care and to receive additional health promotion services such as food, vitamins, coupons and clothing.[15]

what needs to be done?

Because women are more likely to be infected by men, and AIDS cases due to heterosexual contact are increasing, programs that specifically target men (especially IDUs) will have a beneficial impact on women. Needle exchange and drug treatment are important strategies, since almost half of all infections in women are due to injection drug use. Encouraging women to seek STD diagnosis and treatment should also be a part of effective HIV prevention strategies.

More research needs to be done on modes of HIV transmission and risks for women, including woman-to-woman transmission. Innovative, women-specific interventions need to be evaluated. A comprehensive HIV prevention strategy uses many elements to protect as many people at risk for HIV as possible. Interventions that address sexuality, family, culture, empowerment, self-esteem and negotiating skills, as well as interventions located in varying community settings are especially important.

PREPARED BY KATHLEEN QUIRK, MA* AND PAMELA DECARLO*
*CAPS

9. Farmer PE, Connors MM, Simmons J., editors. Women, poverty, and AIDS: Sex, drugs, and structural violence. 1996. Common Courage Press, Monroe, ME.

10. Sobo EJ. Choosing unsafe sex: AIDS-risk denial among disadvantaged women. 1995. University of Pennsylvania Press, Philadelphia, PA.

11. Phillips DM. Microbicide development: progress and obstacles. Third Conference on Retroviruses and Opportunisitic Infections. 1996.

12. Coley BI, Sikkema KJ, Perry MJ, et al. The role of women as opinion leaders in a community intervention to reduce HIV risk behavior. National Conference on Women and HIV, Pasadena, CA. 1997; Abstract #206.3. Contact: Brenda Coley 414/456-7746

13. Collaborative programs in prison HIV prevention. Contact: Barry Zack, Centerforce, Health Programs Division, San Quentin, CA: 415/456-9980.

14. Padian NS, O'Brien YR, Chang Y, et al. Prevention of heterosexual transmission of human immunodeficiency virus through couple counseling. Journal of Acquired Immune Deficiency Syndrome. 1993;6:1043-1048.

15. Lum PJ, Guydish JR, Brown E, et al. An innovative needle exchange program exclusively for women is well accepted by female injection drug users in San Francisco. International Conference on AIDS, Geneva, Switzerland. 1998. Abstract #43261. Contact: Paula Lum (415) 597-4965.

HEALTH RESOURCES AND SERVICES ADMINISTRATION
BUREAU OF HEALTH RESOURCES DEPARTMENT
DIVISION OF HIV SERVICES

To the Title I and Title II network of grantees, planning councils, consortia, administrative agencies, providers, and clients:

Across the globe, an estimated 5.8 million people were infected with HIV in 1997, approximately 16,000 new cases every day. Of those, 14,000 are adults and 40% of them are women. In the United States, between 120,000 and 160,000 women are estimated to be infected with HIV. Women are the most rapidly growing segment of the population at risk for AIDS in the United States. The rates for African-American and Hispanic women are especially alarming. AIDS rates for these women are 17 and 6 times higher than for white women. In 1997, African-American women made up 60% of all female AIDS cases, Hispanics 20% and whites 19%. Yet as these percentages proceed to climb, women continue to face inequities in treatment, care and prevention.

These are all things that you, who work and live in this epidemic, have heard before.

Supportive services for women with HIV is clearly an important component of a comprehensive and effective health care system. The Health Resources and Services Administration (HRSA) designed this report as an important review and analysis of how Title I and Title II of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act have responded to the needs of women with HIV. Congress recently reauthorized the CARE Act, administered by HRSA. Significant refinements are under implementation by HRSA's Bureau of Health Resources Development (BHRD). As in the past, the Division of HIV Services (DHS) will be responsible for implementation oversight for Title I of the Act, which directs AIDS services funding to metropolitan areas with the largest number of reported AIDS cases, and Title II which provides formula grants to the States, the District of Columbia, Puerto Rico and eligible territories.

The report examines HRSA's guidances and expectations regarding women's issues, the development of data and experience on women's needs and services, the extent of women's services and involvement in planning processes in selected metropolitan areas and states, current accomplishments and challenges and the refinements of the new Act. It is designed to strengthen the understanding of women's issues and service needs, and the ways in which they have been and are being addressed by HRSA, Title I and Title II grantees, planning bodies, service providers, and women with HIV/AIDS. Over the years, the attention to women's issues and the capacity of Title I and Title II programs to identify and meet women's service needs have grown. Grantees and planning bodies are recognizing the changing face of the epidemic in their service areas and modifying their processes and structures to respond to new needs and demands. The process has not been easy and challenges will continue.

Women with HIV/AIDS have special needs and face special barriers to services. They need services which focus on them as individuals, not only as mothers of unborn babies or children, or

as caregivers for other people living with HIV infection (PLWHs). Like Title I and Title II grantees throughout the Nation, HRSA is committed to providing appropriate, high quality services for women with HIV/AIDS.

The new legislation provides opportunities for us to strengthen efforts to serve and involve women through the CARE Act. We hope that this report will support, motivate and assist you as you work to provide HIV care services to women.

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TABLE OF CONTENTS

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Divider Title: _____

These conference materials were created with the help of Todd Summers, Deputy Director, Office of National AIDS Policy. Each participant received a binder containing these pages in color.

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Divider Title: _____

This briefing paper was faxed to each participant before the discussion:

June 23, 1998

DISCUSSION ON WOMEN AND HIV/AIDS

DATE:	**June 25, 1998**
TIME:	**11 a.m. - 3 p.m.**
LOCATION:	**Old Executive Office Building**

I. PURPOSE

AIDS is increasingly a disease of women, particularly women of color. Each and every day, here in the United States, and across the globe, thousands of women are infected with HIV. This meeting will provide an opportunity for women leaders in private industry, philanthropy, advocacy, and government to begin a dialogue about how we can integrate HIV/AIDS into the broader women's agenda.

II. PARTICIPANTS

Moderator:
Veronica Biggins

Confirmed Participants:

LaVerne Alexander
Director, Government Relations
Girl Scouts of the USA
(202) 659-3780

Veronica Biggins
Partner
Heidrick & Struggles
(404) 577-2410

Margaret Campbell
The Multicultural AIDS Coalition
(617) 442-1622

Mary Anderson Cooper
Associate Director
National Council of Churches
(202) 544-2350

Gloria Feldt
President
Planned Parenthood Federation of America
(212) 261-4601

Mary Fisher
Founder and Chairman of the Board
Family AIDS Network
(703) 243-8242

Phyllis Greenberger
Executive Director
Society for the Advancement of
Women's Health Research
(202) 223-8224

Steve Gunderson
Managing Trustee
Family AIDS Network
(703) 243-8242

Michael Iskowitz
Children's Defense Fund

Ingrid Saunders Jones
Vice President Corporate External Affairs
The Coca-Cola Company
(404) 676-3525

Wanda Jones, PhD
Deputy Assistant Secretary for Health
US Dept. of Health and Human Services
(202) 690-7650

Felicia Lynch
President
Women and Philanthropy
(202) 887-9660

Marsha Martin
Special Assistant to the Secretary
Dept. of Health and Human Services
(202) 690-5400

Prema Mathai-Davis
Chief Executive Officer
YWCA of the U.S.A.
(212) 273-7801

Victoria A. McEneney
President
Women's Bar Association of D. C.
(202) 496-7637

Eileen McGrath
Director
American Medical Women's Association
(703) 838-0500

Dr. Marjorie Muedee
President
The Ford Foundation
(212) 573-4961

Francess Page
Senior Public Health Advisor
US Dept. of Health and Human Services
(202) 690-6373

Ann Rosewater
Counselor to the Secretary
Dept. of Health and Human Services
(202) 260-9923

Elisa Sanchez
President
MANA, A National Latina Organization
(202) 833-0060

Margaret Scarlett
Senior Health Policy Analyst
Dept. of Health and Human Services
(202) 690-5560

Susan Schomaker
Family AIDS Network
(703) 243-8242

Jane Silver
Director of Public Policy
American Foundation for AIDS Research
(202) 331-8600

Ester Silver-Parker
President
AT&T Foundation
(212) 387-4113

Evelyn Tomaszewski
Project Director
National Association of Social Workers
(202) 336-8390

Deborah Vonzinkernagel
Deputy Director for Policy
Office of HIV/AIDS
Dept. of Health and Human Services
(202) 690-5560

III. AGENDA

11:00 a.m. *Welcome and Introductions - Conference Room 476*
Audrey Haynes - Director, White House Office of Women's Initiatives
Sandra Thurman - Director, White House Office of National AIDS Policy

11:15 a.m. *Introduction of Participants*
Veronica Biggins

11:30 a.m. *Update on HIV/AIDS in Women*
Wanda Jones

12:00 p.m. *Lunch - Indian Treaty Room*
Keynote Speakers: Mary Fisher, Margaret Campbell

1:15 p.m. *Discussion*
How do we more effectively integrate HIV/AIDS into the larger womens agenda?

3:00 p.m. *Adjourn*

IV. LOGISTICS

Transportation:

- **From National Airport**

  By Taxi: Taxi service is available from National Airport. The cost is approximately $10. Taxis are located outside the baggage claim area. Allow approximately 20 minutes from National Airport to the White House.

  By Car: Take the George Washington Memorial Parkway North approximately 1.5 miles to the 14th Street Bridge exit (Route 1). Take this exit and cross the 14th street bridge, staying in the left hand lane. Follow 14th street to K Street. Make a left on K and follow to 17th. Make a left on 17th. There are multiple parking garages along 17th street. If you have not found parking by the time you reach Pennsylvania Avenue, make a right on Pennsylvania. There will be parking garages on either side of the street. Parking cost is estimated at $10.

- **From Dulles International Airport**

  By Taxi: Taxi service is available from Dulles Airport. The cost is approximately $45. Taxis are located outside the baggage claim area. Allow approximately 40 minutes from Dulles Airport to the White House.

  By Car: Take the Dulles Access Road toward Route 66 east and Washington, DC. Take Route 66 East to the Theodore Roosevelt Memorial Bridge. Cross the bridge and take the Constitution Avenue exit. Follow Constitution Avenue to 17th Street. Turn left on 17th Street and follow to Pennsylvania Avenue. Turn left on Pennsylvania. There will be parking garages on either side of the street. Parking cost is estimated at $10.

- **From Union Station**

  By Taxi: Taxi service is available from Union Station. The cost is approximately $5. Allow approximately 10 minutes from Union Station to the hotel.

Old Executive Office Building

- The Old Executive Office Building is located at the corner of 17th Street and Pennsylvania Avenue, next to the West Wing of the White House. You should enter into the Pennsylvania Avenue side entrance with photo ID ready for clearance. Proceed to the guard desk. Elevators are located to your right and Conference Room 476 is on the 4th Floor.

V. Contact information

Sarah Holewinski
WH Office of National AIDS Policy
P: (202) 395-1441
F: (202) 456-2438
E: Sarah_T._Holewinski@oa.eop.gov

RSVP Form:

White House Discussion on Women and HIV/AIDS
Thursday, June 25, 1998
11:00 AM to 3:00 PM
Room 474 (Indian Treaty Room)
Old Executive Office Building

Information Sheet

PLEASE RSVP BY 5:00 PM (EST), TUESDAY, JUNE 16, 1998
BY FAXING THE FOLLOWING INFORMATION TO THE
OFFICE OF NATIONAL AIDS POLICY
AT (202) 456-2438; INQUIRIES MAY BE MADE TO (202) 456-2437

NAME (Last, First):_____
PROFESSIONAL AFFILIATION:_____
WK ADDRESS:_____
DAY PHONE:_____ DAY FAX:_____
DATE OF BIRTH (MMDDYY):_____ SOC.SEC.#:_____

Attendee Lists:

LaVerne Alexander	Director, Government Relations, Girl Scouts of the USA	1025 Connecticut Ave, NW, Ste 309 W DC 20036	202-659-3780
Veronica Biggins	Partner, Heidrick & Struggles	303 Peachtree, Ste 3100, Atlanta, GA 30308	404-577-2410
Margaret Campbell	The Multicultural AIDS Coalition	801B Tremont St., Boston, MA 02118	617-442-1622
Mary Anderson Cooper	Associate Director, National Council of Churches	110 Maryland Ave., NE, #108 WDC 20002	202-544-2350
Gloria Feldt	President, Planned Parenthood Federation of America	810 Seventh Ave. New York, NY 10019	212-261-4601
Mary Fisher	Founder and Chairman of the Board, Family AIDS Network	1611 N. Kent St., #1003 Arlington, VA 22207	703-243-8242
Phyllis Greenberger	Executive Director, Society for the Advance-ment of Women's Health Research	1825 L St., NW, Ste 625 WDC 20036	202-223-8224
Steve Gunderson	Managing Trustee, Family AIDS Network	1611 N. Kent St., #1003 Arlington, VA 22209	703-243-8242
Michael Iskowitz	Children's Defense Fund		
Ingrid Saunders Jones	Vice President Corporate External Affairs, The Coca-Cola Company	Post Office Drawer 1734 Atlanta, GA 30301	404-676-3525
Wanda Jones, PhD	Deputy Assistant Secretary for Health (Women's Health), US Dept. Of HHS	200 Independence Ave., SW, Rm 730B WDC, 20201	202-690-7650
Felicia Lynch	President, Women and Philanthropy	1015 18th St., NW, #202 WDC 20036	202-887-9660
Prema Mathai-Davis	CEO, YWCA of the U.S.A.	Empire State Bldg., 350 5th Ave., Ste. 301, NY, NY 10118	212-273-7801

Victoria A. McEneney	President, Women's Bar Association of D. C.	1900 K Street, NW WDC	202-496-7637
Eileen McGrath	Director, American Medical Women's Association	801 N. Fairfax St., Ste 400 Alexandria, VA 22314	703-838-0500
Dr. Marjorie Muedee	President, The Ford Foundation	320 East 43rd St. NY, NY 10017	212-573-4961
Francess Page	Senior Public Health Advisor, Office on Women's Health	200 Independence Ave., SW, Rm 730B WDC, 20201	202-690-6373
Valerie Rochester		633 Pennsylvania Ave., NW WDC	202-737-0120
Elisa Sanchez	President, MANA, A National Latina Organizaiton	1725 K St., NW, #501 WDC 20006	202-833-0060
Susan Schomaker	Family AIDS Network	1611 N. Kent St., #1003 Arlington, VA 22209	703-243-8242
Jane Silver, MPH	Director, Public Policy, American Foundation for AIDS Research	1828 L St., NW, #802 WDC 20036	202-331-8600
Ester Silver-Parker	President, AT&T Foundation	32 Avenue of the Americas, Rm 2606 NY, NY 10013	212-387-4113
Evelyn Tomaszewski	Project Director, National Association of Social Workers	750 First St., NE, Ste 700 WDC 20002	202-336-8390

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June 23, 1998

Margaret Campbell
Member
Board of Directors
AIDS Policy Center for Children,
Youth and Families

Dear Ms. Campbell:

It is with great pleasure that we invite you to participate in a White House discussion on women and HIV/AIDS. The meeting will be held on Thursday, June 25th, 1998 from 11 AM - 3 PM (EST), with arrival at 10:30 AM. (Lunch included).

Because of your proven leadership on many important issues, we believe you can galvanize others by raising awareness about the dramatic increases in HIV/AIDS among women. Invitees include a diverse group of leaders representing the HIV/AIDS community, prominent women's advocates, and national public health officials. Ms. Veronica Biggins, former director of White House Personnel, will facilitate the discussion.

We hope you are able to join us. Should you have any questions, please feel free to call Sarah Holewinski at (202) 395-1441.

Sincerely,

Sandra L. Thurman
Director
Office of National AIDS Policy

Letter to confirm Mary Fisher's participation:

June 17, 1998

Mary Fisher
1611 North Kent Street, Suite 1003
Arlington, VA 22209

Dear Mary,

I am so happy that you will be attending the upcoming meeting on women and AIDS. I would like to invite you to make the keynote comments for about 10 to 15 minutes during the lunch (12:00 to 1:00). Your personal perspective on why those concerned with the needs of women and families need to address HIV/AIDS would be most helpful. I also hope that you will stay for the discussion that will follow (1:00 to 3:00).

This meeting will be very helpful in our efforts to get the AIDS epidemic included as part of the broader women's agenda. Veronica Biggins, former Director of White House Personnel, will be moderating the meeting. Joining you will be a small, select group of women leaders.

I appreciate that your availability for these events is very limited, and wanted you to know how very much I appreciate your willingness to join us.

Very truly yours,

Sandra L. Thurman
Director
Office of National AIDS Policy

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Divider Title: _____

This is a draft of what will be sent out to the WH Discussion participants. It was created with the help of Margaret Scarlett of the Office of HIV/AIDS, Department of Health and Human Services:

August 7, 1998

Dear Participants,

Thank you for attending the recent White House Discussion on Women and HIV/AIDS. This discussion is prompted by the challenge of how to include the growing epidemic of HIV/AIDS among U. S. women among an already lengthy list of concerns about other women's issues . Because your organization is already addressing other women's issues, your timely contribution in developing the best ways to most effectively work together in addressing women and HIV/AIDS issues was critical.

Attached is the summary of the June 25th discussion. Continued, open dialogue must continue, especially on determining ways in which the government and private sector can most effectively collaborate in addressing HIV/AIDS among women. Within the next few months, we plan to develop a comprehensive communication strategy to deliver the message about HIV/AIDS among American women. This strategy will include how to reach those medium sized towns and cities and rural areas in which HIV/AIDS among women is dramatically increasing.

In the near future, another meeting will be held with an expanded group of participants to continue our productive discussion about how to better integrate women and HIV/AIDS issues within a broader women's agenda. In the next few weeks, Sarah Holewinski will be contacting you about your availability for such a meeting. She can be reached at (202) 395-1441. We also want to follow-up with you about particular policies or programs, and your interest in becoming part of our next steps in addressing the challenge of HIV/AIDS among women in the U.S.

We look forward to your continued participation and our work together to face this challenge.

Sincerely,

Sandra Thurman
Director
Office of National AIDS Policy

Summary of White House Discussion on Women and HIV/AIDS
June 25, 1998

Since AIDS is increasingly a disease of women, particularly women of color, in the United States, women leaders were invited to participate in a discussion about the impact of HIV/AIDS among women across the United States. The purpose of the meeting was to provide an opportunity for women leaders to dialogue about how HIV/AIDS can become integrated into the broader American women's agenda. Participants included representatives from women's organizations, private industry, philanthropy, religious institutions, policy, and government. The list of participants is attached.

This dialogue was initiated by the two co-sponsors, Ms. Audrey Haynes, Director, the White House Office on Women's Initiatives and Outreach Director and Ms. Sandy Thurman, Director, White House Office of National AIDS Policy. The moderator was Ms. Veronica Biggins, a partner with Heidrick and Struggles, and former director of Office of White House Personnel. Dr. Wanda Jones, Deputy Assistant Secretary for Health, U.S. Department of Health and Human Services, presented an update on the status of the epidemic of HIV/AIDS among women in the United States.

Two luncheon keynote speakers followed. They were Ms. Mary Fisher, Founder of the Family AIDS Network, and Ms. Margaret Campbell, an HIV Treatment Advocate and African American HIV/AIDS Health Outreach Educator. Both eloquently discussed their personal experiences in addressing the challenges of HIV as a woman, in their communities, with health providers, within organizations and the impact on friends, loved ones and colleagues.

Following the luncheon speaker, participants were asked to address the question, "How do we more effectively integrate HIV/AIDS into the broader women's agenda?" In response, the following issues were identified by participants:

1. The number one issue identified by participants was the need to develop a comprehensive communication strategy to increase awareness of the growing problem of HIV/AIDS among U.S. women. To date, much of the media coverage about heterosexual transmission and the epidemic among women has focused on international, not national, issues.

Any proposed communication strategy which focuses on the challenges presented by women and HIV/AIDS issues should focus on the national situation, rather than the international. Media should be made aware of the newer statistics regarding women and HIV/AIDS and use them. The communication strategy should be addressed at the national level, and also, at the grass roots level. This strategy should also target multiple media outlets, such as newspapers like the N.Y. Times, Washington Post; magazines, such as Essence; include spokespersons such as Oprah

Winfrey or Dick Gregory; and be inclusive of women's organizations, especially those not yet involved in HIV/AIDS issues. Another critical role of women's organizations is to identify specific strategies for different communities, which should be part of the communication strategy. Ms. Biggins asked if participants concurred with this approach; all agreed that the development of a communication strategy was a top priority for women and HIV/AIDS issues.

The need for a specific strategy to target messages to youth, particularly young women, was also addressed. One current challenge is how to get the word out about HIV/AIDS to youth, as well as how to get HIV/AIDS back in the media headlines to capture their attention. Some of the "hope messages" from progress with new antiretroviral drugs appear to have drowned out messages about the continued need for HIV prevention. Youth and others should understand that new drugs are not a cure for HIV, and that the diminishing numbers of HIV/AIDS among certain populations is not true among young people. The strategy can include methods to engage various media outlets, such as MTV, radio, or newspapers, as well as to go beyond these traditional methods to reach youth to use other innovative ways. These ways include communication with various teen music groups, teen organizations, artists, and mid-level media. In the future, any new communication messages about HIV/AIDS must be relevant and inclusive of women.

2.A specific coalition of women's organizations is needed to "gender the disease." Such a coalition would include existing organizations already involved in HIV/AIDS issues, as well as those addressing AIDS policy issues. The purpose of the coalition would be to put a "gender lens" on AIDS. Also, this coalition would focus on programs for women and girls, moving beyond policy related issues, perhaps including groups connected to each other by funding sources. Overall, women's coalitions are important in addressing issues relevant to women's health; this means that multiple groups must be addressed when delivering messages about the growing epidemic of HIV/AIDS among American women..

3. Provider education, specifically physician education, is now needed to train those providers to recognize signs and symptoms of AIDS in women. Anecdotal reports suggest that physicians need information about referrals, testing issues, as well as training on how to be sensitive to lifestyle issues to ensure appropriate risk assessment. There is also an acute need for a more integrated health service delivery model or system for women, which includes family planning, pediatric, and other health services.

4. General education about HIV/AIDS issues should be refined and based on prevention. In particular, special needs of youth issues should be addressed, as well as those topics such as prejudice, ignorance and any other "they are not like me" issues. An educational approach must include broad based women's organizations, women's magazines, and advocacy approaches.

5. Youth support and parenting issues should also be addressed as part of education; the feeling was expressed that this must be a BIG effort, with more than education alone . Focus should be on better targeting children at risk and working with organizations such as boys' and girls' clubs, and building self-esteem and hope for a future, as well necessary training in decision-making.

6. Advocacy for HIV/AIDS among women needs to be strengthened at all levels. Advocacy issues should address the role of women in society, which may increase their vulnerability, and should include their unrecognized role in caregiving of loved ones. Enrolling women's organizations and women's magazines in advocacy efforts will strengthen efforts to enhance advocacy; one approach suggested was highlighting visits to organizations that provide direct services to persons with HIV/AIDS in the media. Another suggestion was to have a very high level governmental official, such as the President or Vice-President, address women and HIV/AIDS issues. Multiple, concurrent efforts are needed to develop a comprehensive approach to advocacy. This strategy should include "putting a face on women and HIV/AIDS" in different communities across the U.S.

There is a need to build constituencies or "political capital". Many spoke of the lost leadership from earlier days of the HIV/AIDS epidemic; new leadership, with national state and local legislative initiatives, are needed. Innovative ways must be found to integrate HIV/AIDS issues into existing services, with service providers including HIV/AIDS into their routine client communication and counseling. These service providers may be in housing, nutrition, reproductive care or other sectors. Another approach is to ensure that decision-makers at the national, community and grass roots organization level become a priority for receiving the new information about women and HIV/AIDS issues among women. Those leaders may need technical assistance about how to best advocate on women and HIV/AIDS issues because women's issues may be different than those of gay men, and because traditional approaches to prevention and treatment are also different for women. Any advocacy efforts should be focused on the special needs of women.

7. The important role of the faith communities was addressed, especially with regard to its critical impact within the African-American community. The challenge of determining the best way to engage ministers in HIV/AIDS issues was discussed. The mid-level tier of the faith communities may be a strong resource for a compassionate and caring approach to community advocacy. Many participants also emphasized that religious-affiliated organizations provide an array of services to and for women, including food, clothing and shelter, as well as child care. Faith communities have ongoing programs, such as substance abuse prevention and recovery groups. These programs can include HIV/AIDS issues.

8. The key role and significant resources of the corporate world was noted for their potential role in addressing women and HIV/AIDS. Many noted that corporate assistance is available and plentiful, especially in the context of their experience in marketing new and emerging issues. One strategy to investigate would be to work with certain types of businesses, such as condom manufacturers or other businesses, that provide products related to prevention of HIV/AIDS. The urgent need for an effective microbicide was noted so that women could use this to prevent HIV or other sexually transmitted diseases when condoms are not an option.

9. In general, the crisis of women and HIV/AIDS can be recognized as an opportunity , and an effective communication strategy might be to utilize mid-level media markets, which are smaller than national media markets to alert Americans about this issue. Such an approach would have the advantage of reaching women in communities in which HIV/AIDS is becoming a problem

among women. This approach would include middle tier mass media, such as smaller cities and town newspapers, and include innovative ways in which to deliver messages where people live and work, such as beauty salons.

Ms. Thurman closed the meeting, expressing gratitude to participants in the dialogue. She stated that there would be press releases about women and HIV/AIDS issues at the XII International Conference in Geneva. In addition, she stated that delivering messages about women and HIV/AIDS in middle tier media sounded like an excellent idea and would be explored further. Participants were invited to continue the dialogue that was begun within their own organizations, so that these might be incorporated into next steps. Ms. Thurman thanked the participants and stated that many more organizations must be involved. She proposed another dialogue among a larger group of participants to continue this productive discussion, as well as challenging others to continue to find new ways to include HIV/AIDS among the broader women's agenda.

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Original Proposal:

Women's Leadership Conference on HIV/AIDS
Round-table Draft

I. Background

The recent report by the Center for Disease Control, emphasizing the skyrocketing numbers of new HIV infections among the female population, has brought national attention to the health of American women, and specifically to the problems they face when dealing with this epidemic. In response to reports with similar findings, AIDS community concern, and civil rights groups for equality in the health care system, the Director of the Office on National AIDS Policy, Sandra Thurman, has asked that this office address the issues surrounding women and HIV/AIDS through a round-table discussion. As this issue ties into the Ryan White Care Act, as well as the White House Office of Women's Initiatives, we are in a position to gather some of the nation's most influential and well versed participants on this critical issue.

Ryan White Care Act, Title IV

Though the Ryan White Care Act in general is a service to women and men, Title IV pertains specifically to women living with HIV/AIDS and in turn, is what will be focused on in greater detail both here and in the round-table discussion. The Title IV program, which is administered by the Maternal and Child Health Bureau, focuses on the health services both primary and community based, that provide medical and social support for women, children, youth, and families affected by the HIV/AIDS epidemic. Of the 59 projects during FY 1996, 7 funded womens' initiatives sites, and 45 Title IV Grants went to funding Coordination of HIV Services and Access to Research for women, children, youth, and families. In addition 53% of the Title IV grantees were either adolescent or adult women in FY 1995. The majority of Title IV clients enrolled are mothers over the age of 25 years and children under the age of 24 years, and therefore still dependent upon the family, the majority of which are single parent house-holds headed by women.

The Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission (WIN) Program focuses on counseling and testing for women of childbearing age, to engage and maintain pregnant women and their children in care, and to promote the education of perinatal transmission. During the last half of 1995, WIN sites reported reaching more than 5,000 women through outreach efforts, supported HIV counseling activities for more than 17,000 and enrolled almost 360 pregnant women with HIV care. Other services for women under the Ryan White Care Act, Title IV include:

- Clinical care and management
- Mental health
- Substance abuse
- Disclosure issues
- Mandatory HIV testing/counseling
- Peer outreach
- Support groups, maintenance of groups, establishing groups for affected children
- pregnancy planning
- Cultural diversity/sensitivity
- Program evaluation, including outcome measures and ways to assess cost effectiveness
- Information dissemination, e.g. models that work, linkages/collaboration. clinical management of HIV disease

II. Tentative Issues:

The issues surrounding Women and HIV, as in most health care topics, cover a vast amount of information stemming from womens' role in our society through the years, their education, and the taught messages on prevention, and proceed up through the treatment they receive after acquiring HIV. Obviously, issues such as discrimination and economic status do not contain themselves within the boundaries of this epidemic but rather are evidence of a larger problematic environment for women in our society. Some of the issues from Ryan White (listed in background) will be used in the agenda of the round-table discussion, as they are specific to and vitally important to womens' lives and those living with HIV/AIDS. In addition, the implications stemming from a woman living with HIV reach issues surrounding pregnancy, and entire populations such as children and adolescents, both of which are included in Ryan White, Title IV.

The round-table format is certainly conducive to exploring the larger problems associated with womens' health and HIV. Passing these issues by, either because of their complexities or because of their wide ranging and difficult ramifications, would only make the discussions surrounding HIV/AIDS seem superficial. Below is a very broad list of probable issues to be discussed either in a formal agenda, or in the conversations that will undoubtedly arise in other contexts; each of the following relate to the above listed Title IV programs:

- Ryan White Care Act - special considerations, funding, general focus on current programs and initiatives;

- Support groups and peer outreach - building community (i.e. stress in womens' lives as they play a dual role as mother and worker, and the compounding effects that it has on HIV treatment and care);

- Substance abuse in women (i.e. IV drug use) and the solutions that are currently available

- The burdens placed on both children and adolescents in the increasingly common single-parent household, and the specific programs designed to overcome them as they relate to Title IV;

- Prevention and education, including pregnancy planning and education of perinatal HIV transmission;

- Testing (i.e. mandatory testing), counseling, treatment, and care as well as current initiatives that pertain to these issues;

- Discrimination in all facets, especially those of living with HIV, caring for children, and being a woman in our society;

- Employment issues focusing on HIV and the workplace, economic status, and discrimination;

- Managed care as it pertains to barriers to access including current Ryan White initiatives that are designed to overcome them.

In addition to those Title IV issues mentioned above, early intervention services as stipulated in Title III of the Ryan White Care Act for persons at high risk for HIV infection, also have a significant impact on women and will be discussed in the round-table.

III. Tentative Participants could include:

- womens' rights advocates
- women of color
- lesbian communities
- federal representatives involved in womens' issues
- nongovernmental organizational representatives
- women and HIV activist groups
- prominent researchers and medical care providers
- childrens' rights advocates and representatives

IV. Scope of Work:

- Coordinate and act as a liaison between the AIDS Program Office at HRSA and the Office of National AIDS Policy with the expressed purpose of conducting a Leadership Round-table to focus on the topic of Women and HIV/AIDS;

- Assist in developing the concepts that should be presented and discussed, those including

Ryan White as well as other programs and issues surrounding the complications women face with HIV/AIDS;

- Act as a liaison between the AIDS Program Office at HRSA and the Office of National AIDS Policy concerning the desired outcome of the round-table as well as possible consumer materials resulting from the conference;

- Act as a liaison between the HRSA AIDS Advisory Committee, the Presidential Advisory Council on HIV/AIDS, other officials of the federal government, as well as other public/private organizations involved in issues surrounding women and HIV;

- Provide follow-up correspondence and appropriate action pending the outcome of the conference, with HRSA, the AIDS Community, and participants;

- Plan and implement the logistics of the event including:
    - Participants/Participant availability
    - Dates for round-table and follow-up action
    - Location that is conducive to the conference and its participants
    - Travel, lodging accommodations, transportation
    - Provide briefing and research materials as requested; and

- Assist in scheduling for possible resulting future round tables and meetings among ONAP, HRSA, the participants of the conference, and the AIDS community.

V. Period of Performance:

The period of performance in order to complete the Women's Leadership Conference on HIV/AIDS will be from, on, or before August _, 1997 through December 31, 1997.

Draft

Women's Leadership Summit

This summary is to serve as an update on the progress made in developing a Women's Leadership Summit under the direction of the White House Office of National AIDS Policy.

- *Target dates*

  Though originally planned for the second week in January, February has proved to the most feasible time in which to gather the desired participants as well as to obtain an appropriate site.

- *Site*

  The Indian Treaty Room of the Old Executive Office Building as part of the White House Complex is decidedly the most appropriate site for this event.

- *Briefing materials/evaluation*

  Prior to the Summit, each participant will receive briefing books including: background information on the issues to be discussed, participant biographies, meeting agenda, and any other pertinent information to be decided upon at a later date. Approximately six weeks after the Summit, the Office of National AIDS Policy will issue an evaluation report on the proceedings and brief the participants on any follow-up items that result from them.

- *Press*

  One of our goals in deciding to hold this Women's Leadership Summit was to bring the issue of 'Women and HIV' to the forefront of our national women's agenda. The issues that surround women's health in general such as barriers and access to care, discrimination, and lack of participation in clinical trials are no more hard hitting than in the cases of HIV and AIDS. The media will play an important role in helping to publicize the link between women and HIV and health care as well as to communicate that these issues are a top priority.

- *Participants*

  We are in the process of putting together a list of approximately 40 participants that would include representatives not usually found o panels that concern

health and HIV. By including a diverse crowd, representatives from academia, media, corporate and business leaders, and health officials, we will bridge the gap between the HIV health agenda and the ongoing agenda to better improve womens' lives. Invitations will be sent to participants with the strict understanding that substitutes will not be accepted.

- *Potential format*
  (subject to change after further discussion)

  Welcome and introductions will be given by Sandra L. Thurman, Director, White House Office on National AIDS Policy. Up to four panels will follow, each including three presenters who will be given approximately 10 minutes. We will either end each panel with a discussion period, or as an alternative, end the entire Summit with a more broad and open discussion. This core part of the event will be followed by a press conference and a reception that should include a broader list of attendees.

- *Budget*

  In order to keep both costs to a minimum, participants will be expected to arrange travel and lodging on their own accord. Our budget will include only briefing materials, which should not require any significant commitment of funds, and the costs associated with holding a small reception.

- *Summit co-planners*

  We will continue to work closely with the White House Women's Initiatives Office in order to bring together both the national women's agenda and the HIV agenda.

April 27, 1998

Ms. Anne Marie Rakovic
Project Director
John Snow, Inc.
44 Farnsworth Street
Boston, MA 02210-1211

Dear Ms. Rakovic:

As per your letter dated April 10, 1998, I wanted to provide you with an update on the White House discussion on women and HIV/AIDS as well as other services I have provided the Office of national AIDS Policy.

As I am sure you are aware, the issue of federal needle exchange funding has taken to the forefront of our agenda at ONAP recently. In order to prepare Director Thurman and Deputy Director Todd Summers for the impending decision on this issue by the Clinton Administration, I was called upon to obtain and coordinate statistics and other information relevant to women and needle exchange. This included the effect of IV drug use and subsequent HIV infection among women and their children as well as the impact of existing needle exchange programs on lowering the rate of HIV infection.

Though the decision made by the Administration and President Clinton was not quite the outcome we had all worked so hard for, I am confident that the information compiled on women, children and HIV will continue to serve the Office of National AIDS Policy well into the future.

As for the discussion on women and HIV/AIDS at the White House, the date has again been pushed back to that of June 6, 1998. Dealing with the issue of needle exchange imposed significant setbacks not only on my work with the White House discussion, but also with Director Thurman's involvement - as she is the major driving force behind the event.

Details have been finalized in terms of format, issues, and invited guests (attached for your records is that list of attendees). The participant list has been a matter of some debate, as Director Thurman decided that we must include more women with experience on this subject - a change that required a careful evaluation of previous invitees. Now that the list is finalized, invitations are being sent out this week and follow up calls will be made shortly. I am encouraged by the fact that we have already received positive feedback.

I am certainly looking forward to seeing this discussion happen; I know that the delays in getting it up and running will only serve to improve the outcome. As always, thank you for your patience and if there is any further information you may need, I will be happy to provide it.

Sincerely,

Sarah T. Holewinski
Consultant

Sarah T. Holewinski

06/30/98 02:34:50 PM

Record Type: Record

To: dlebel @ jsi.com @ inet

cc:
Subject: It's done!

---------- Forwarded by Sarah T. Holewinski/OPD/EOP on 06/30/98 02:38 PM ----------

Sarah T. Holewinski

06/30/98 01:26:32 PM

Record Type: Record

To: Ann Marie Rakovic <annmarie_rakovic @ JSI.COM>

cc:
Subject: It's done!

Hello Anne Marie -

I apologize for the lapse in communication.

The White House Discussion on Women and HIV/AIDS was absolutely wonderful. It took place last Thursday (June 25th) with about 30 people from business, government, philanthropy, etc. (see attendance list attached).

We began at 11 AM with an overview from Wanda Jones, Director of Women's Health at HHS. Discussion followed with Ms. Veronica Biggins moderating. I gave out a briefing book at the meeting including: Background on women and HIV/AIDS, agenda, participant list, glossary, and bios on the speakers. I will send you that briefing book this week for your files.

The keynote speakers were Mary Fisher and Margaret Campbell, a young African American woman living with HIV. Both were incredible - most of the particpants had tears in their eyes during the entire hour they spoke. We had the event catered by B&B Catering, who the White House uses for most of their smaller events. Between making sure the food was correct, getting the crew set up in the Indian Treaty Room , staffing Sandy for the event, making sure all of the participants were there, and staffing Mary Fisher (the highest profile guest), I had little time to be involved in the actual discussion.

I do know however, that we had some hard-hitting ideas come out of the discussions - ideas that we will be following up with in the coming weeks. It was decided, first and foremost, that the

public does not see the AIDS epidemic among women as a crisis. The women came up with several suggestions, all of which I will send to you in a follow-up report.

Margaret Scarlett from the DHHS will be sending me a transcript of the event within the next week or so. And I, in turn, will forward you an entire report outlining the details of my work, the event, and the follow-up activities that are to take place. Please let me know if you need any more specifics before that time.

All in all it was a great event and I believe that we here at ONAP and the women who came got a lot out of it. Thanks for your patience and understanding in the process of planning this discussion. We got it done right - the way we wanted it done - and I am more than pleased with the outcome.

Talk to you soon!
Sarah Holewinski

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