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Meeting with National Pediatric Family HIV/AIDS 11/9/93

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NATIONAL PEDIATRIC
HIV
RESOURCE CENTER

OCT 28 1993

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900 Second Street, NE
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October 13, 1993

Kristine Gebbie, R.N.
Federal AIDS Policy Coordinator
The White House
750 First Street, NW
Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

Thank you for agreeing to speak on health care reform at the Ryan White CARE Act Title IV project directors meeting in Baltimore on November 9, 1993, from 11:00-12:00 noon. The conference will take place at the Hyatt Regency Baltimore On the Inner Harbor, 300 Light Street, Baltimore (410-528-1234). I will confirm the room location with you prior to the event.

I have spoken to Retina Holmes on your staff who assures me that this time period meets your scheduling limitations. I understand that you need to be at Johns Hopkins University at 12:30pm. If you have further scheduling limitations, please let me know as soon as possible.

As you know, Congress recently completed the transfer of the Pediatric/Family AIDS Demonstration Program within Title IV of the CARE Act. Title IV has now become an important focus of providing funds to deliver specialized pediatric, adolescent and family HIV services throughout the United States. Approximately 60 project directors and staff members of projects that are located through the United States will attend the meeting.

I look forward to seeing you on November 9th. Please contact me with any questions.

Sincerely,

David C. Harvey
Coordinator of Public Policy
Washington Office



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FAX COVER SHEET

Washington Office

TO: Steve Lee

FIRM: Nat Hlth Pol. office

FAX NUMBER: 632-1096

FROM: David C. Harvey, Coordinator of Public Policy

TOTALNUMBEROFPAGES 10

DATE: 10-29-93 TIME: 11AM

NOTES: I am on my way to
New Orleans and I would
review talking points because
I never finished. But use
as you will and apologize
to Krishne. Thanks.

Also, The letter is wrong.
There will be 150 people.

National Pediatric/Family HIV/AIDS Project Meeting
Hyatt Regency, Baltimore, MD
DRAFT AGENDA

Tuesday, November 9, 1993

- 7:30 - 8:30 a.m. *Registration and continental breakfast*
- 8:30 - 8:45 a.m. *Welcome* Beth Roy, M.S., Chief, Hemophilia and
Pediatric AIDS Branch, Maternal and Child
Health Bureau
- 8:45 - 10:00 a.m. *Plenary: Demonstrating Program Impact Through Research and
Evaluation*
- ° Overview of the Issues
Mary Boland, R.N., M.S.N., Director,
National Pediatric HIV Resource Center and
Children's Hospital AIDS Program
 - ° Demonstration project evaluation studies

Julia Hidalgo, Sc.D., Chief, Center for
AIDS Services Planning and Development,
AIDS Administration, Maryland Dept. of
Health and Mental Hygiene

Jean R. Setzer, Ph.D., Assistant Professor,
The University of Texas Health Science
Center at San Antonio

Marilyn G. Crain, M.D., M.P.H., Assistant
Professor of Pediatrics and Microbiology,
University of Alabama School of Medicine
 - ° MCHB Evaluation Study
Pernell W. Crockett, M.S., Public Health
Analyst and Project Officer on Study,
Hemophilia and Pediatric AIDS Program
Branch
 - ° Responding to Policy-makers (Ryan White Program Evaluation
Studies)
Katherine M. Marconi, Ph.D., Director,
Office of Science and Epidemiology, Bureau
of Health Resources Development

10:00 - 10:15 a.m. *Break*

10:15 - 11:15 a.m. *Plenary: Maternal & Child Health Bureau Presentations*

- ° FY 1994 funding and grant process

- ° Update on other Federal AIDS programs

Beth Roy, M.S., Chief, Hemophilia and
Pediatric AIDS Branch

11:15 - 12:00 noon *Plenary: HIV/AIDS and the Health Care Reform Proposal*

Kristine Gebbie, R.N., M.N, F.A.A.N.
National AIDS Policy Coordinator
The White House

12:30 - 1:30 p.m. *Networking Luncheon: Research and evaluation*

1:30 - 3:00 p.m. *Plenary: Older Children with Perinatal HIV*

Moderator: James Oleske, M.D., M.P.H.,
Francois Xavier Bagnoud Professor of
Pediatrics, UMDNJ-New Jersey Medical
School

- ° Older children with perinatal HIV: experience from two
sites

Samuel Grubman, M.D., Assistant Professor
of Pediatrics, UMDNJ-New Jersey Medical
School

Gwendolyn B. Scott, M.D., Professor of
Pediatrics, University of Miami School of
Medicine

- ° Learning from the experience of children with hemophilia
and HIV

Kevin Cwayna, M.D., Project Coordinator,
Sentinel Project, Comprehensive Hemophilia
Program, University of Minnesota

- ° Family perspectives
Parent

- ° Ethical dilemmas: disclosure, assent for care

Jenny Grocz, A.C.S.W., Co-Director,
Deevelopmental and Family Services Unit,
Rose F. Kennedy Center, Bronx

3:30 - 5:00 p.m. *Break-out Discussion Groups: Older Children with Perinatal HIV*

° Disclosure issues

Moderator: Sandra Y. Lewis, Psy.D., Assistant Professor of Pediatric and Psychiatry, UMDNJ-New Jersey Medical School

° Quality of life considerations

Moderator: Mary Mallory, M.S.N., P.N.P., Coordinator, Dallas Pediatric HIV Health Care Demonstration Project

° Family concerns

Moderator: Parent

° Long term medical management

Moderator: James Oleske, M.D., M.P.H.

° Transition from childhood to adolescence

Moderators: Kevin Cwayna, M.D.

Fran Pursell, B.C.S.W., Resources for Adolescents Program, New Orleans

Wednesday, November 10, 1993

8:30 - 10:30 a.m. *Plenary: Women and HIV: Issues in Care Delivery*
Moderator: Elaine Gross, R.N., M.S., Nurse
Educator, National Pediatric HIV Resource Center

° Comprehensive care for women: counseling, testing and
early intervention
TBA

° Psychosocial issues for women with HIV infection
Patricia O. Loftman, C.N.M., M.S., Director,
Midwifery Service, Harlem Hospital Center

° A woman's perspective
Linda Horton

° Reproductive rights: ethical issues
Nancy Kass, Sc.D., Assistant Professor, School of
Hygiene & Public Health, Johns Hopkins
University

10:00 - 10:30 a.m. *Break*

10:30 - 12:00 noon *Plenary: Ryan White Act Reauthorization and Title IV
Implementation*

° Reauthorization and the political process
David Harvey, M.S.W., Coordinator for Public
Policy, National Pediatric HIV Resource Center

° Ryan White reauthorization
G. Stephen Bowen, M.D., M.P.H., Associate
Administrator for AIDS, Health Resources and
Services Administration

° Title IV reauthorization and implementation
Lauren Deigh, M.P.A., Deputy Chief, Hemophilia
and Pediatric AIDS Branch, Maternal and Child
Health Bureau

1:30 - 3:00 a.m. *Discussion Groups: "Think tanks" on Title IV issues*

- Collaboration between care and research
Moderators: Janet Squires, M.D., title, University of Texas, Southwestern Medical Center
Shari Saltzberg, M.P.A., Associate Director, Brooklyn Pediatric AIDS Demonstration Project
- Evaluation
Moderator: Jean R. Setzer, Ph.D., Assistant Professor, The University of Texas Health Science Center at San Antonio
- Barriers to clinical trials and potential solutions
Debbie Allen, Bureau of Family and Community Health, Massachusetts Department of Public Health
- Adolescents with HIV: issues under Title IV
- Reauthorization of Ryan White: legislative issues

3:00 - 4:00 a.m.

Reports from Discussion Groups and Wrap-up: Legislative Issues for Ryan White Title IV

Moderators: Beth Roy, M.S.
David Harvey, M.S.W.

Ryan White Reauthorization
Discussion Group Goals

Purpose

- o The purpose of the discussion groups will be to contribute participants' clinical expertise and service system design concerns to a discussion of policy recommendations for reauthorization of the Ryan White CARE Act. Although we will focus on Title IV, there may be relevant issues to consider for other Titles of the CARE Act.
- o Moderators should lead the discussion on their assigned topic areas with a focus on clinical and service system design concerns. From these discussions, recommendations can be developed for reauthorization consideration.
- o Assign a member of your discussion group the task of recording major items of discussion so that a report may be presented during the wrap-up.

Questions to Consider in Discussion Groups

1. Discuss successful clinical, service or evaluation models and cite examples. Discuss problem areas and unmet needs as well as areas of success.
2. Cite any existing data that may be present in relation to the issues you identify above. Identify areas of data needs that can be easily obtained either through brief surveys by the Resource Center or other research.
3. Relate discussion to federal policy and the current statutory authority of Title IV. Identify areas in the statute that meet your service system's needs and where it does not. Compare this discussion to your understanding of how Title I, II and III are implemented and whether these Titles meet the needs of your service system in identified areas.

Wrap-Up Session

During the wrap-up session, we will review the results of the discussion groups and attempt to relate the issues that get identified to the following areas:

- o Financing mechanism of Title IV (formula vs. grant allocation).
- o Unique justification for Title IV and what it does differently from other Titles of Ryan White, including a discussion of health care reform in relation to Ryan White reauthorization.
- o Enforcement mechanism for Title II 15% set-aside and possibly mandating cooperation with Title IV.

- o Broadening authority of Title IV to build comprehensive care systems and link to an expanded definition of NIH research programs.
- o Examining population specific needs in the statute which include adolescents, pregnant women, children, and families.
- o Administrative issues related to interagency cooperation between MCHB, NIH and HRSA, and issues related to evaluation.

Resources

1. Facilitators may refer to the conference notebooks which will contain the Title IV statutory language, the NPHRC summary of the Senate report language, the model legislation developed last year by the public policy committee, and other summaries of issues related to reauthorization of Titles I-III and health care reform.

United hospital
fund outline 10/15
research-

HIV & Health Care Reform -
Both good & worrisome

Security
simplicity
choice
savings
quality
responsibility

1) get coverage
affected population = $\rightarrow$ uninsured

~~fears of loss of coverage~~

comp. benefit pkg - (problem when state is generous)

2) equitable continuous coverage

lifetime limit
not dx specific
not cancellable

or private
cov.
Rx drugs
home care
substance abuse Rx
choice

the question of
adequate providers
to dx
to manage care

3) need adjustment for providers
the shift from grant to client contracting.

4) quality & outcomes

how to define

the chronic disease worry
(correlate study Oregon)

5) data/confidentiality

"the perfect is the enemy of the good"

Coverage
for prisoners?

commitment to transition -

subsidies for low income -

Jim Tallor
call from Pres?

Don't
9/7/06
400
3424