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Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Kristine Gebbie

Subseries:

OA/ID Number: 3774

FolderID:

Folder Title:
Speech Before Rockland HIV/AIDS Forum New York 5/19/94

Stack:	Row:	Section:	Shelf:	Position:
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ROCHESTER AREA TASK FORCE on AIDS, INC.

copy to leads

May 27, 1994

Ms. Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street, N.W. Suite 1060
Washington, D.C. 20500

Dear Ms. Gebbie,

This letter is to thank you for your participation in our town meeting on AIDS in Rochester, NY on May 20, 1994. The feedback from the community has been very positive; you are viewed as sensitive to both human issues as well as the policy issues. Most of us recognize that your office cannot undo the damage done by ten years of neglect. Keep up the good work, and let us know if there is anything we can do to support you in your efforts. We are hopeful that you will have a positive impact on the decisions made by Congress regarding new prevention funds, reauthorization of the Ryan White CARE Act with additional funding, and the research agenda, especially in the social sciences; eg. what works, what does not.

Enclosed you will find the **"AIDS Action Plan for Rochester and the Finger Lakes Region, 1991-1995"** produced by the Finger Lakes Health Systems Agency and the Rochester Area Task Force on AIDS. This is our second AIDS plan since 1987, when we developed one of the first plans in the U.S. Lynne Varricchio from the Finger Lakes Health Systems Agency will send you a copy of the recently completed Pediatric Long Term Care Report you requested under separate cover.

To summarize the meeting on May 20, we urged you to advocate for:

- additional HIV prevention funding;
- better coordination of planning efforts, specifically, substance abuse block grants, Ryan White, and community prevention planning;
- more funding for evaluation of existing prevention programs so that successful models can be replicated;

Finger Lakes Health Systems Agency
1150 University Avenue, Rochester, New York 14607
(716) 461-3520 FAX (716)461-0997

- captioning of the CDC America Responds to AIDS public service announcements to begin outreach to the deaf community;

- inclusion of lesbians living with HIV/AIDS in planning processes and in data collection and reporting; and,

- adequate reimbursement mechanism in health care reform for persons living with HIV/AIDS.

We would greatly appreciate your staff keeping us informed of any new developments regarding the above.

Enclosed you will find a copy of the newspaper article about the meeting. We will send a copy of the videotape as soon as the editing is completed.

On behalf of the Rochester Region Ryan White HIV CARE Network, thank you for your thought-provoking and hopeful message. Maybe you can visit again when you have more time to enjoy the beauty of the lilacs of Rochester.

If you have any questions or comments, please call Kelli at (716) 461-3520.

Sincerely,

Kelli E. McMahon
Coordinator

Rudy Rivera
Chair

THE WHITE HOUSE

WASHINGTON

Comments of

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

before the

Rockland County HIV/AIDS Forum
in
Rockland County, New York

National AIDS Policy: Local AIDS Action

May 19, 1994

I. The components of our national policy
   - A. Research
     1. Breadth in science areas
     2. Applied as well as basic
     3. planned and managed well
   - B. Services
     1. health reform
     2. Ryan White Care services continuation
     3. service system development
     4. awareness of the epidemic in pts/providers
   - C. Prevention
     1. limiting sexual transmission
        a. education that works
     2. limiting substance abuse related transmission
        a. prevention/treatment of addiction
        b. harm reduction
     3. limiting vertical transmission

II. Translation of this policy to local actions
   - A. community acknowledgement of the reality of the epidemic
   - B. involvement of community leaders
     1. in support of those who have been out there already
     2. in partnership with established systems
   - C. attention to making the policies visible at the local level
     1. public support for meaningful research
     2. expectations of access to treatment
     3. commitment to supportive services
     4. leadership on prevention
        a. workplace policies/prevention training

ROCKLAND COUNTY COMMISSION ON WOMEN'S ISSUES:
Its mission is to ensure that women's issues and perspectives are considered in the formation of public policy in Rockland County.

HIV/AIDS COALITION OF ROCKLAND COUNTY:
Its mission is to facilitate and monitor the timely implementation of recommendations set forth in the Women's Commission Report on the HIV/AIDS Crisis in Rockland County. The recommendations outline a comprehensive plan to improve health and support services to HIV+ persons and their families and offer strategies for effective HIV/AIDS education and prevention.

SPECIAL THANKS

AIDS Related Community Services (ARCS)
Joan Amendola
Gerold Bierker
Rick Birnbaum
Clarkstown South High School
Judi DeBiase
Jack Dos Santos
Bill Garbinsky
Barry Gettleman
Dennis La
Maura Mann
Ellen O'Han
Alison Rennie
Retired Senior Volunteer Program
Rockland County Youth Bureau
Rockland County Youth Council
Pauline Sachs
Anthony R. Scaringi
Hy Shuster
Students for a Healthy Awareness
T.O.U.C.H.
Jason Wiles

EVENT PLANNING COMMITTEE

Sal Chiariello
Harriet Cornell
Marianne Furedi
Rachel Grob
Johanna Lee
Sande Lefkowitz
Helen Lipovsky
Marie Lorenzini
Marianne McCarney
June Molof
Peggy Nadell
Donna Pauldine
William Schneider
Carrie Steindorff

PROGRAM

Welcome	***Gerold Bierker***, Principal Clarkstown South High School
Opening Remarks	***Carrie Steindorff,*** Coordinator HIV/AIDS Coalition of Rockland
	Jennifer Flanz, Allison Shinners, Clarkstown North & South High Schools
	The Hon. Harriet Cornell, Chair, Rockland County Commission On Women's Issues
Guest Speaker	***Kristine M. Gebbie, RN, MN,*** National AIDS Policy Coordinator, Executive Office of the President
Panel Discussion	NATIONAL AIDS POLICY, LOCAL AIDS ACTION
Moderator	***Kenneth Packer***, Regional AIDS Education Coordinator for the Lower Hudson Valley

PANELISTS

Andrea Dopwell,
Delta Sigma Theta Sorority,
CEO, Ridgewood Dialysis Center

Johanna Lee, RN, MS
Supervisor, Nyack Hospital
Home Care

Greg Diaz, Community
HIV/AIDS Educator

Marvin Thalenberg, M.D.,
Commissioner,
Rockland County Department of Health

Sal Chiariello, Clarkstown
School District Health Coordinator

Jennifer Flanz, Student

Sherry Berbit, RN, MS
HIV Coordinator,
Good Samaritan Hospital

Donna Pauldine, M. Ed. CRC
Program Dir. Young Adult Center
Rockland County Department of
Mental Health

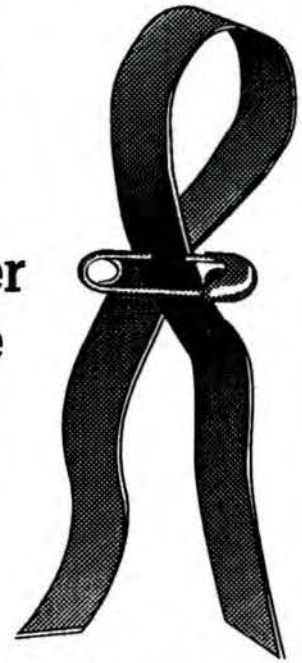
Closing Remarks ***The Hon. Harriet Cornell***

More than 100 Rockland residents are presently serving as members of the HIV/AIDS Coalition, affiliated with the following organizations:

Alliance for Education in Public Policy
ARCS
American Red Cross
Barr Laboratories Inc.
C.A.N.D.L.E.
Clarkstown Central School District
Clarkstown South High School
Cornell Cooperative Extension
Delta Kappa Gamma Society of Rockland County
Rockland Delta Sigma Theta Sorority, Rockland County Alumni Chapter
Dominican College
East Ramapo School District
Education Assoc. of South Orangetown
First Baptist Church of Spring Valley
Good Samaritan Hospital
Grace Episcopal Church
Haitian American Social & Cultural Organization (HASCO)
Helen Hayes Hospital
Martin Luther King Multi-Purpose Center
Mental Health Association of Rockland County
Mid Hudson Health Systems Agency
Nanuet Union Free School District
North Rockland High School
North Rockland High School PTA
Nyack Hospital
Nyack College
Nyack Public School District
Pearl River School District
Pearl River Teachers Assoc.
Planned Parenthood-Westchester and Rockland, Inc.
Ramapo Central School District
Ramapo Counseling Center
Rockland Community Partnership
Rockland County B.O.C.E.S.
Rockland County Commission on Women's Issues
Rockland County Department of Health
Rockland County Department of Mental Health
Rockland County Department of Social Services
Rockland County Guidance Center
Rockland County Nurses Association Dist., 17 of N.Y.S. Nurses Assoc.
Rockland County Probation Department
Rockland County Teachers Association
Rockland Council for Young Children
Rockland County Youth Bureau
Rockland Independent Living Center
Sacred Heart School
South Orangetown School District
Saint Thomas Aquinas College
Stony Point Presbyterian Church
Students for a Healthy Awareness, Clarkstown North & South High Schools
Temple Beth El
Temple Beth Sholom
Thespian Lab Co., Inc.
T.O.U.C.H.
United Jewish Appeal
Volunteer Counseling Services
Westchester Health Center
Westchester Medical Center, Alcoholism Treatment Svc.

HIV/AIDS FORUM:

Strategies to alter the future course of the HIV/AIDS Epidemic



featuring:

Kristine M. Gebbie, RN, MN

President Clinton's National AIDS Policy Coordinator

Thursday, May 19, 1994
9 am - 12 noon
Clarkstown South High School
Demarest Mill Road/West Nyack NY

Sponsored by the Rockland County Legislature's Commission on Women's Issues and the HIV/AIDS Coalition of Rockland County

The Legislature of Rockland County

Allison-Parris County Office Building
New City, New York 10956

Stewart Airport - Newburg, Orange County.

HARRIET D. CORNELL
Legislator, Town of Clarkstown

(914) 638-5100
(914) 634-3304
Fax (914) 638-5675

Chair, Commission on Women's Issues
Chair, Committee for The Arts, Culture & Tourism
Chair, Legislative/Executive Task Force on Transportation
Vice-Chair, Government Operations Committee

March 22, 1994

Ms. Kristine M. Gebbie, RN, M.N.
National AIDS Policy Coordinator
Executive Office of the President
750 7th Street NW, Suite 1060
Washington, DC 20500

Dear Ms. Gebbie:

Thank you for accepting our invitation to speak at the Rockland HIV/AIDS Forum, "Strategies to Alter the Future Course of the HIV/AIDS Epidemic" on Thursday, May 19, 1994, from 9:30 a.m.- 12 Noon, at Clarkstown South High School in West Nyack, NY. We are honored by your recognition of the leadership of the Rockland County Commission on Women's Issues and the HIV/AIDS Coalition of Rockland in initiating a comprehensive approach to combatting this insidious disease.

The agenda of the HIV/AIDS Forum will include:

* Welcome - Harriet Cornell, Rockland County Legislator
* Keynote Speaker Kristine M. Gebbie
* Questions from Panel Members (local health, community and student leaders). These issues will be provided prior to the event.
* 15-30 minute Press Conference with local and regional media. (with your approval)

Sande Lefkowitz of my office has been in contact with Steve Lee and is finalizing arrangements for transportation from LaGuardia Airport to Rockland and into New York City for your next appointment.

I look forward to meeting you on May 19. A great deal of interest and excitement has been generated by announcement of your visit. Your presence will not only heighten awareness of the threat of HIV infection and AIDS in suburban New York but will also demonstrate national leadership and commitment. Thank you.

Very truly yours,

Harriet Cornell

HARRIET CORNELL
Rockland County Legislator

HC:go

THE WHITE HOUSE

WASHINGTON

March 23, 1994

Ms. Sandy Lefkowitz
Town of Clarkston
Legislature of Rockland County
Allison-Parris County Office Building
New City, New York 10956

Dear Ms. Lefkowitz:

This letter is to again confirm the appearance of Kristine M. Gebbie, National AIDS Policy Coordinator, at the "HIV/AIDS Forum: Strategies to Alter the Future Care of the HIV/AIDS Epidemic", on the morning of Thursday, May 19, 1994. The title of Ms. Gebbie's speech will be "National AIDS Policy: Local AIDS Action".

Please call me at (202) 632-1090 with any questions or for further clarification. I am enclosing a biographical sketch and curriculum vitae for your reference.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant
and Scheduler to the
National AIDS Policy Coordinator

Enclosures

THE WHITE HOUSE

WASHINGTON

January 30, 1994

The Honorable Harriet D. Cornell
Legislator, Town of Clarkstown
The Legislature of Rockland County
Allison-Parris County Office Building
New City, NY 10956

Dear Ms. Cornell:

This letter confirms the appearance of Kristine M. Gebbie, National AIDS Policy Coordinator, at the "HIV/AIDS Forum: Strategies to Alter the Future Care of the HIV/AIDS Epidemic", on the morning of Thursday, May 19, 1994. I appreciate the patience and hard of Ms. Sandy Lefkowitz to secure this date, and look forward to learning more about the conference.

Please call me at (202) 632-1090 with any questions or for further clarification. I am enclosing a biographical sketch and curriculum vitae for your reference.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant
and Scheduler to the
National AIDS Policy Coordinator

Enclosures

243

The Legislature of Rockland County

Allison-Parris County Office Building
New City, New York 10956

August 23, 1993

5/19 a.m.

"HIV/AIDS Forum: Strategies to Alter the Future Course of the HIV/AIDS Epidemic"

HARRIET D. CORNELL
Legislator, Town of Clarkstown

(914) 638-5100
(914) 634-3304
Fax (914) 638-5675

Chair, Commission on Women's Issues
Chair, Committee for The Arts, Culture & Tourism
Chair, Legislative/Executive Task Force on Transportation
Vice-Chair, Government Operations Committee

The Hon. Kristine Gebbie
National AIDS Policy Coordinator
Executive Office of the President
750 17th Street NW
Suite 1060
Washington, D.C. 20500

Dear Ms. Gebbie:

Congratulations on your appointment, which has been eagerly awaited by so many. I am writing to you at the suggestion of Sarah Kovner of Donna Shalala's office.

Recent national reports from the Centers for Disease Control about AIDS and its growing transmission among women and teen-agers only confirm what we in Rockland learned three years ago from local statistics. The Rockland County Commission on Women's Issues has worked intensively on this public health threat. After open public hearings, we issued a report with over 70 recommendations, which is enclosed.

The principal recommendation was to form a community-wide coalition to implement the report. Response from the community was overwhelming. Over 90 organizations, including every school district, colleges, churches, synagogues, hospitals, civic organizations responded. The Coalition met for the first time in June and formed seven working committees composed of volunteers.

This local initiative has aroused vocal, well-organized opponents who attempt to block educational efforts through distortions of fact and hysterical right-wing rhetoric. I am sure you are familiar with their arguments which seem to be the same all over the country: they decry condom use, sexuality education (which they call "sex ed for tots,") and any mention of possible needle exchange programs.

I just received a copy of the Final Report of the National Commission on AIDS and was astonished to realize how Rockland's locally inspired efforts exemplify many of the principles called for by the National Commission.

It would encourage continued commitment by local organizations if we were to receive a letter from you applauding our efforts. The report does not presume to mandate any particular path. Rather it is a blueprint for the community. It is certainly not necessary for you to agree with every statement, but rather with the leadership in opening a dialogue and in involving community understanding and action.

Didn't we already get a letter?

I would also like to invite you to be the featured speaker at a symposium of health, education, social services professionals and the public at a date later this year or early 1994, to be arranged at your convenience. We are very close to New York City and all New York airports.

Finally, I would appreciate any information about grants designed to facilitate the coordination of our AIDS Coalition. I look forward to an early response. We need your assistance, and I believe you need us if we are to achieve our common goal of preventing the spread of AIDS. Good luck in your important undertaking.

Very truly yours,

Harriet Cornell

Harriet Cornell
Chair, Rockland County Commission on
Women's Issues

Enclosure

#2

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Ms. Harriet D. Cornell
Chairwoman
Committee on Women's Issues
Allison-Parris County Office Building
New York, New York 10956

Dear Ms. Cornell:

Recently I was given a copy of your Committee's report, *HIV and AIDS in Rockland County*, which was developed by your Subcommittee of Women and AIDS. The report is both informative and timely and you are to be congratulated for producing such an impressive document.

As the AIDS epidemic enters its 13th year, women continue to account for a growing percentage of people infected with HIV in the United States. Many HIV-related issues affect women in a unique and compelling way and warrant special investigation and attention. The issues the Committee's report identifies are indeed important areas for action, and will be receiving my attention.

You are to be applauded for the leadership you have demonstrated in directing the development of this document. Efforts such as yours are an important part of our national effort to stop the spread of the virus and to help care for those infected.

Please keep the Office of the National AIDS Policy Coordinator apprised of future efforts by your organization.

Sincerely,

Kristine Gebbie

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

DEPARTMENT OF HEALTH & HUMAN SERVICES
Office of the Secretary
Washington, D.C. 20201

DRAFT #3

Ms. Harriet Cornell
Legislator, Town of Clarkstown
The Legislature of
Rockland County
Allison-Parris County
Office Building
New City, New York 10956

Dear Ms. Cornell:

Thank you for your letter and the "Report on: The HIV & AIDS Crisis in Rockland County." I apologize for the delay in responding to you.

I applaud your efforts in leading the county's Commission on Women's Issues and encouraging community participation in implementing the subcommittee's recommendations. As the report indicates, AIDS cases reported among women are increasing faster than cases among men. In 1992, AIDS cases reported among women in the United States increased 9.8 percent over 1991. For men, the increase was 2.5 percent. Heterosexual transmission accounted for more than half of the 1992 AIDS cases among women, surpassing drug injection as the major route of transmission. Among women aged 20 to 29 years, this trend is even more dramatic--60 percent of cases among women in this age group in 1992 were attributed to heterosexual transmission, compared with 46.5 percent among women over age 30.

With an estimated 1 in 250 Americans infected with HIV, no community can afford to ignore the HIV epidemic. Preventing HIV infection and AIDS will require great efforts from each of us. AS your experience demonstrates, communities can be intimately involved in the development and implementation of HIV/AIDS prevention activities through the kinds of methods your are pursing in identifying the local situation, noting the available resources, and addressing the most urgent needs.

Ensuring that persons with HIV infection or AIDS continue to lead productive lives as members of their community benefits everyone. More than that, a community mobilized to prevent HIV infection can benefit not only its own citizens, but the entire Nation.

I understand that you have also been in touch with Kristine Gebbie, National AIDS Policy Coordinator, and that you will work directly with her office concerning upcoming events planned in Rockland County later this Fall and Winter.

I commend your commitment to the prevention of HIV/AIDS in women, and I wish you success in this most important endeavor.

Sincerely,

Donna E. Shalala

Ms. Harriet Cornell
Legislator, Town of Clarkstown
The Legislature of
Rockland County
Allison-Parris County
Office Building
New City, New York 10956

Dear Ms. Cornell:

Thank you for your letter and the "Report on: The HIV & AIDS Crisis in Rockland County." I applaud your efforts in leading the county's Commission on Women's Issues and encouraging community participation in implementing the subcommittee's recommendations.

As the report indicates, AIDS cases reported among women are increasing faster than cases among men. In 1992 AIDS cases reported among women in the United States increased 9.8 percent over 1991, compared with an increase of 2.5 percent among men. Heterosexual transmission accounted for more than half of the 1992 AIDS cases among women, surpassing drug injection as the major route of transmission. Among women aged 20 to 29 years, this trend is even more dramatic--60 percent of cases among women in this age group in 1992 were attributed to heterosexual transmission, compared with 46.5 percent among women over age 30.

With an estimated 1 in 250 Americans infected with HIV, no community can afford to ignore the HIV epidemic. Preventing HIV infection and AIDS will require great efforts from each of us. Communities can be intimately involved in development and implementation of HIV/AIDS prevention activities through approaches such as yours--identifying the local situation, the available resources, and the gaps, and then addressing the most urgent needs. Ensuring that persons with HIV infection or AIDS continue to lead productive lives as members of their community benefits everyone. More than that, a community mobilized to prevent HIV infection can benefit not only its own citizens, but the entire Nation.

A copy of your letter has been provided to Christine Gebbie. I assume you will communicate directly with her regarding the invitation to participate in a symposium so that she can consider it in light of her schedule and commitment. In terms of designating an official to participate in a press conference,

I suggest that the most useful person would likely be Marvin Thalenberg, M.D., Commissioner, Rockland County Health Department, Sanitarium Road, Pomona, New York 10970, (914) 364-2512. He would be most knowledgeable of the threats HIV infection presents to the citizens of Rockland County.

Thank you for your commitment to the prevention of HIV/AIDS in women.

Sincerely,

Donna E. Shalala

cc:
Ms. Kristine M. Gebbie
OD
HIV
FMO
CDC/W
ES/PHS
CCU/OS
CLO/OS
ASL/OS
OS Reading File
HHS Official File
CDC Official File (Return to CDC, Atlanta)
Cleared by:CDC:JCurran:HIV:8/27/93
OS No. 9308200069
PHS Tracer No. T59810
CDC ID HCA79521:Doc Name CORNELL.SEC
CDC:WLRoper:da:9/1/93:(404) 639-3291, ERH/9/01/93
Spelling Verifier used by:DAcevedo 9/1/93
Prepared by:WJones, CDC, HIV, (404) 639-0904
Contact: BCoker, CDC, (404) 639-3322

PHS CORRESPONDENCE

159810

REFERRAL DATE: 8-23 **DUE DATE:** 8-25

Faxed 8/24 mb

TO:

- ☑ ASH
- ☐ DEPUTY ASH
- ☐ SG
- ☐ DASH-MO
- ☐ DASH-SE
- ☐ DASH-C
- ☐ DASH-DPHP
- ☐ DASH-IGA / RHA
- ☐ DAS-IH
- ☐ DAS-MH
- ☐ DASH-PA
- ☐ DAS-PHP
- ☐ ADAMHA
- ☐ AHCPR
- ☐ ATSDR
- ☑ CDC
- ☐ FDA
- ☐ HRSA
- ☐ IHS
- ☐ NIH
- ☐ NAPO
- ☐ NVP
- ☐ PCPFS
- ☐ OEEO
- ☐ OEP
- ☐ OGC / H
- ☐ OHL
- ☐ OHPE
- ☐ OM
- ☐ OSIR
- ☑ OWH
- ☑ ES / PHS BB, PAR
- ☐ OTHER

ACTION:

- ☑ SECRETARY'S SIGNATURE
- ☐ ASH SIGNATURE
- ☐ DIRECT REPLY
- ☐ _____ SIGNATURE
- ☐ DRAFT FOR OS SIGNATURE (WHITE HOUSE REFERRAL)
- ☐ REVIEW / CLEARANCE
- ☐ NECESSARY ACTION
- ☑ FOR YOUR INFORMATION

SPECIAL INSTRUCTIONS

URGENT

EXPEDITE

PHS-5175C
Rev. 4/92

PHS / ES
Rm 710H

Phone: 690-7566

Routed by: Wolfhard

The Legislature of Rockland County
Allison-Parris County Office Building
New City, New York 10956

August 9, 1993

HARRIET D. CORNELL
Legislator, Town of Clarkstown

(914) 638-510
(914) 634-330
Fax (914) 638-567

Chair, Commission on Women's Issues
Chair, Committee for The Arts, Culture & Tourism
Chair, Legislative/Executive Task Force on Transportation
Vice-Chair, Government Operations Committee

SPECIAL

Sarah Kovner
Office of the Secretary
Department of Health & Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

Dear Sarah:

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The principal recommendation was to form a community-wide coalition to implement the report. Response from the community was overwhelming. Over 90 organizations, including every school district, colleges, churches, synagogues, hospitals, civic organizations responded. The Coalition is up and running with seven working committees.

Because of the sexual transmission of AIDS and the need for prevention techniques which include condom use, there are vocal opponents who attempt to block educational efforts through distortions of fact and hysterical right-wing rhetoric. The arguments they use, by the way, are the same all over the country: they decry needle exchange programs; condom use; and sexuality education (which they call "sex ed for tots.")

After my conversation with you last week, I believe the Clinton Administration can best support Rockland's grass roots efforts in the following ways:

1. Letters from Donna Shalala and Christine Gebbe applauding the initiative and leadership of the Rockland County Commission on Women's Issues in opening a dialogue about this threat to the public health and developing recommendations which

require community understanding and action. I would like these letters by August 18.

2. A date to be negotiated with Dr. Gebbe for Fall '93 or early '94 to be the featured speaker at a serious symposium of health, education, social services professionals and the public.

3. Attendance by an appropriate Federal official at a press conference with our County Health Commissioner and others to deal with the realities of the AIDS threat and the need for local efforts. If an official is designated, I can work out date and time directly.

Thank you for your help with this important matter. Thank you mostly for being who you are and devoting yourself to the common good. Donna and Bill are very fortunate to have you.

Most sincerely,

Harriet

Harriet Cornell

Best regards.
Hope to see you next time
I'm in D.C.

SPECIAL

930820005

The Legislature of Rockland County

Allison-Parris County Office Building
New City, New York 10956
August 9, 1993

HARRIET D. CORNELL
Legislator, Town of Clarkstown

(914) 638-510
(914) 634-330
Fax (914) 638-567

Chair, Commission on Women's Issues
Chair, Committee for The Arts, Culture & Tourism
Chair, Legislative/Executive Task Force on Transportation
Vice-Chair, Government Operations Committee

SPECIAL

Sarah Kovner
Office of the Secretary
Department of Health & Human Services
200 Independence Avenue, SW
Washington, D.C. 20201

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Most sincerely,

Harriet

Harriet Cornell

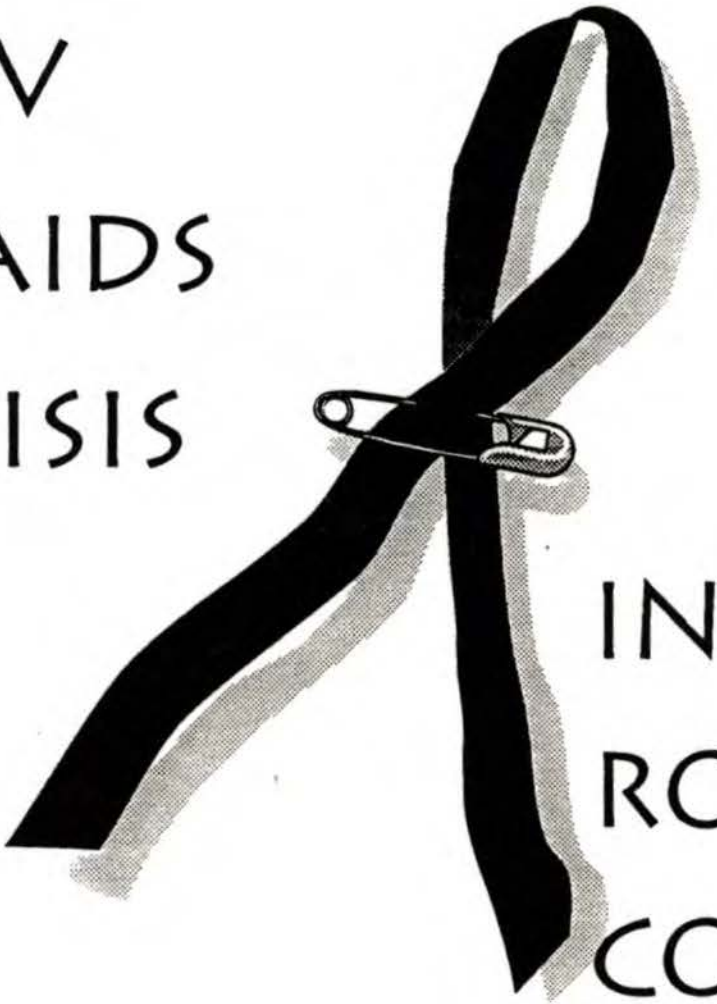
Best regards.
Hope to see you next time
I'm in D.C.

SPECIAL

930820009

Report on:

THE HIV & AIDS CRISIS



IN ROCKLAND COUNTY

Women & AIDS Sub-Committee

ROCKLAND COUNTY COMMISSION ON WOMEN'S ISSUES

Harriet Cornell, Chairwoman

ROCKLAND COUNTY COMMISSION ON WOMEN'S ISSUES

Harriet Cornell, Chairperson

Sande Lefkowitz, Legislative Assistant

Report from the SUBCOMMITTEE ON WOMEN AND AIDS

Co-chairs: Donna Pauldine and Alison Rennie

Members

Sherry Berbit	Laura Fasulo	Peggy Nadell
Eve Borzon, R.N.	Sandy Gitlin	Daisy Pedroza-Balatocan
Jeremy Broun	Carolyn Kaufman	Dr Kathleen Schatzberg
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The Legislature of Rockland County

Allison-Parris County Office Building
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January 28, 1993

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Rockland County Commission on Women's Issues

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Dear Friends:

No place in the world can feel safe from the devastating impact of HIV infection and AIDS. There is presently no global approach, and in this country there has been no national leadership or comprehensive plan to resolve this health crisis. Responses to the epidemic have been largely on the grass roots level. For a long time, a collaborative sense of denial has led suburban areas like ours to behave as if AIDS were not a local problem. Statistics now prove that Rockland County has a very high incidence of HIV infection. We are thirty miles from New York City, the national epicenter of infection; it should not surprise us that Rockland is a site of heavy infection.

In the Spring of 1991, after learning that young women ages 14-24 comprised the fastest growing segment of Rockland's HIV population and that the newborn infection rate was the second highest in the state, outside of New York City, the Rockland County Commission on Women's Issues determined to study the problem of women and AIDS. A subcommittee was formed which discovered almost immediately that it was impossible to separate out completely what affected women from the entire complex of issues surrounding the epidemic. It also discovered that there were some special, additional and unique problems faced by women who are HIV positive. The subcommittee held three public hearings in January 1992, open to all. Summaries of the testimony from these hearings are included in this report, as are selected pertinent statistics and recommendations for action.

The information we have gathered has impressed upon all of us the absolute necessity for this county to create an integrated and comprehensive plan to:

1. Provide a complex of health and support services to HIV positive persons and their families;

2. Provide effective programs of education designed to change people's attitudes and behavior.

Ten years after the AIDS epidemic was recognized, Rockland County is now, for the first time, beginning to establish basic services for infected persons. We are at a crossroads. We can either continue providing superficial and fragmented assistance, or we can seize the opportunity to create a model for other communities.

If we are not sufficiently motivated by altruism, compassion and decency, let us recognize that every penny unspent today is a dollar spent tomorrow for hospital bills and foster care. Our society can ill afford the drain of resources and the waste of human life.

Sincerely,

Harriet Cornell

Harriet Cornell

FOREWORD

This report represents many hours of research and writing undertaken by five task forces, which make up the Subcommittee of **Women and AIDS**. Each task force, staffed entirely by volunteers, studied one facet of the problem in order to present its dimensions, along with recommendations for action. The task forces are: Medical Issues, Non-Medical Support Services Issues, Education, Prevention, and Legal Issues. Each task force wrote its own report.

Rather than attempting to homogenize the five reports into one format, we have preserved the individual styles chosen by each task force. Additionally, those of you who read through the entire report will find some duplication of information. We have permitted this to stand, as we feel some readers might read only selected sections, and therefore, would miss critical data if we eliminated the repetition.

This report, therefore, reflects the complexity of the problem by presenting a constellation of perspectives on the topic of **Women and AIDS**, a collection of various points of view of task force members arrived at after extensive reading, discussion, and reflection. Although there are many voices, they all convey the same urgent message: there is a crisis and the time to work on resolving it is now!

PART I BACKGROUND

Glossary of AIDS Related Terms

ADAP	AIDS Drug Assistance Program. Provides free AIDS-Related medications to eligible persons in New York State.
ANTIBODY	A protein produced by the body in response to infection. Every infection triggers the release of an antibody specific to that disease.
ARC	AIDS Related Complex. HIV infection that is less severe than full-blown AIDS, but which nevertheless may be fatal.
ARCS	AIDS Related Community Services
AZT, ddI, ddC	Antiviral medications, approved for treatment of HIV infection, which slow the progression of, but do not cure, the disease.
CDC	Center for Disease Control
DOH	Department of Health
DOT	Department of Transportation
HIV	Human Immmunodeficiency Virus. Positive Test for HIV antibodies is a sign of HIV infection. As the immune system weakens, persons with HIV infection may develop AIDS.
HIV +	HIV positive - individual's blood contains HIV antibodies, indicating infection.
IMMUNE SYSTEM	A complex network of cells and chemicals in the body that protect it from disease.
IVDU	Intravenous drug user
MMTP	Methadone Maintenance Treatment Program
PWA/PLWA	Person(s) with AIDS/Person(s) living with AIDS.
RCC	Rockland Community College
RCHD	Rockland County Health Department
SSA	Social Security Administration
SSI	Social Security Insurance
STD	Sexually transmitted disease(s)

T-CELL A specialized blood cell which is a primary target of HIV. Declining T-cell numbers indicate immune system degeneration.

TOUCH Together Our Unity Can Heal - Volunteer organization which provides support to PWA, HIV + persons and their families

WCMC Westchester County Medical Center

Statistics

Following are statistical data from a variety of reputable sources which will assist the reader of this report to put into context the severity of the epidemic, the extreme threat it poses to women and their families, and the ever-increasing cost.

Source: Research report by Dr. Jonathan Mann of the Harvard School of Public Health, cited in the NY Times, 6/4/92.

1. Nine million people world-wide are presently infected with HIV. This includes 4.7 million women and 1.1 million children.

2. By the year 2000, the virus will probably infect 40 to 110 million people world-wide.

3. By early 1992 one in five persons infected with HIV developed AIDS, and 2.5 million have died.

4. Of those infected with HIV world-wide, 40% are now women, up from 25% in 1990. Thus the incidence of infection among women is increasing.

5. In the next three years, the number of individuals world-wide who become infected with HIV will be greater than the total that ever developed the disease.

6. The number of children orphaned by AIDS world-wide will double in three years.

7. In the U. S., 40,000 to 80,000 individuals are expected to become HIV infected in 1992.

Source: U. S. Surgeon General Antonia Lovello, cited in Newsweek 8/3/92

The ratio of female to male AIDS patients has doubled in the last four years. In 1987, 17% of those infected in the U. S. were adolescent females. In 1991 that rose to 39%

Source: World Health Organization, cited in NY Times, 7/21/92

1. By the year 2000 most new HIV infections will be in women.

2. Since January 1, 1992, close to half of the one million newly infected adults world-wide have been women.

3. Accompanying the rise of infection among women, is a corresponding rise in the number of children born to them infected with HIV.

Source: Rockland County Department of Health

1. The following table illustrates the most common modes of transmission among patients with AIDS in the U. S. in NY State and in Rockland County.

AIDS INCIDENCE BY RISK FACTORS - NY STATE AND ROCKLAND COUNTY

(EXCLUDING PEDIATRICS AND UNKNOWNS)

RISK (MODE OF TRANSMISSION)*	US	NYS**	ROCKLAND COUNTY***
Homo/Bisexual	62.6%	47.7%	45.5%
IVDU	21.6	40.8	18.8
HOMO/BI/IVDU	7.3	4.5	2.6
Transfusion	3.5	1.3	4.5
Heterosexual	5.2	5.7	28.6****

* As of 1/90 (CDC)
** As of 12/31/89
*** As of 6/31/91
**** Accounts for 18.5% of all male cases and 70% of all female cases. Data indicates high level of HIV infection in heterosexual non-IVDU population of Rockland.

2.. Seroprevalence studies (blood tests) are anonymously performed on newborns to identify the presence of HIV antibody. The Rockland County newborn seropositive rate is the second highest in New York State, excluding New York City.

Source: NY Times 7/23/92

1. The lifetime cost of treating one AIDS patient in the U.S. in 1992 is $102,000. This is up from $85,333 in 1991. The annual cost of treating a U.S. AIDS patient in 1992 is $38,300, up from $32,000 in 1991. The annual cost of treating a U.S. HIV positive person in 1992 is $10,000, up from $5,000 in 1991.

PART II HEARINGS TESTIMONY

Summary of Issues

The following is a summary of the issues raised by the more than 65 individuals who testified during the three hearings held in January of 1992.

This summary of issues was prepared by Peggy Nadell

Medical Issues

* There is a need for more and earlier HIV testing of women.

  Women are diagnosed later in the disease progression because they are more concerned with their roles as family caretakers than with their own health. Women and their health providers are less informed about the differences between men and women in the manifestation of the disease.

* Patients must travel to WCMC for treatment and face many problems.

  -Delays in getting appointments
  -Difficulty in getting transportation
  -Extensive time involved in travel
  -Never see the same doctor twice

* There are needs for:

  -Primary medical and dental work
  -Continuity of medical care
  -Consultative services from specialists
  -Adequate hospital care
  -Increased availability of HIV testing
  -HIV testing for children before they manifest illness
  -Home health care

* Medicaid reimbursement is inadequate to pay for care.

Non-Medical Support Services Issues

* Women of child bearing age are the fastest growing group with HIV infection.

* Cultural and gender roles frequently inhibit the use of condoms and encourage risky sexual behavior.

* Women are heavily represented in the health care professions, and this presents an additional risk to women of contracting HIV on the job.

* Women frequently work in low paying, blue collar jobs that do not have union protection. They often cannot effectuate their rights when they become victims of discrimination because of their HIV status.

* Available statistical data underestimates the number of women infected.

* No child care services are available for women while traveling to, and being treated at, medical facilities.

* Coordinated referral/support services for patient care are needed.

* Respite services for the caregivers of AIDS patients is needed.

* Meal delivery for the homebound patients is needed.

* Lack of action now will result in much greater costs later.

Education

* All populations (children of all ages, parents, teachers, health professionals, social workers, community leaders) need to be educated about HIV/AIDS.

* The "Talking to Kids About AIDS" program, once sponsored by Cornell Cooperative Extension, should be funded again - its elimination is a great loss to the community.

* Education and provision of correct information on HIV/AIDS will counter prejudice.

* There is a need to teach compassion for those who are ill and their families.

* Some health professionals are insensitive to those with HIV/AIDS.

Prevention

* Educational programs for children should include development of their self esteem as the best way to prevent substance abuse, risky sexual activities, pregnancies, and STD in teenagers.

* There is a correlation between substance abuse, early sexual activity and HIV infection.

Legal Issues

* It is expected that more children will be orphaned, with resulting care and custody issues.

* Discrimination exists in housing, schools, medical care, insurance rights, benefit entitlement, employment for PWA's and HIV positive individuals.

* There are legal issues in relation to confidentiality of information.

Excerpts From Testimony

The Director of Planned Parenthood Speaks

In Rockland County one in 200 babies in our area is born HIV +, and 20-30% will remain HIV +. In Rockland, the incidence of AIDS is 70 per 100,000. We have one of the highest rates in the state.

A Rockland Community College Assistant Dean of Instruction and Community Services Speaks

Patients face wide discrimination in schools, jobs, and housing: are disowned by parents; denied medical care; and sometimes, even a respectful funeral.

Rockland Community College Dean of Student Services Speaks

A study at a large university found that of the 80% sexually active students, 29% reported changing to less risky behavior after learning more about AIDS, 12% engaged in more risky behavior, and 59% did not change their behavior. She believes we need to question our assumption that a cognitive approach alone can produce the desired behavior change.

A PWA Speaks

This woman tested HIV + 4 years ago. She receives $508 a month for rent, light, water, transportation, food, clothes. Social Services will pay $1000 a month for a hotel, but not an extra $100 to get an apartment. In an emergency, she cannot get to Westchester County Medical Center as there is no emergency transportation for Medicaid patients. An ambulance will only take her to a local hospital. She can get a doctor's appointment at Westchester County Medical Center for the next day but has to give a week's notice to get transportation. The delay in getting needed medication negatively affects her health. She experiences much prejudice as a PWA even from health care providers, who need more education in working with PWA's. A psychiatrist terminated her treatment in five minutes and refused to shake her hand. "We are human and we are reaching out for help."

The Executive Director of Cornell Cooperative Extension for Rockland County Speaks

He expressed shock that Carrie Steindorff's program, "Talking to Kids about AIDS," was defunded and praised its success. He expects we will see in Rockland increases in numbers of people who are infected and use drugs. The less money allocated, the larger the problem. He is a certified HIV counselor and because of this some people don't want to talk to him and forbid their children to talk to his children.

The President of Rockland County Womens' Bar Association Speaks

Although Federal and State statutes say a person cannot be fired unless he or she is unable to do the job, or presents a health risk to others, women are often fired while still able to carry out their duties, when it is discovered they are HIV + or have AIDS. Women with AIDS are often in blue collar or low paying jobs with no union protection and are unable to enforce their rights. In housing, people are legally protected against discrimination but in reality they have difficulty getting their rights enforced.

A Rockland Community College Paraprofessional Speaks

Initially he thought AIDS didn't affect him, but he began to educate himself. It bothers him now that while he was at college he laughed at the disease when there was so much suffering. He hopes more people will talk about AIDS.

The Nurse Coordinator of Health Services at Rockland Community College Speaks

Students at the college are between the ages of 16 to 60 plus. Each semester she is flabbergasted by students' questions and their lack of knowledge about AIDS.

A Professional Speaks

As a facilitator of womens' groups, she is amazed by professionals and lay people who say women must demand that their partners use condoms. In some cases women get beaten when they make these demands.

Symptoms of infection in women are different than in men, and as a result they are diagnosed as HIV + later in the disease cycle. You can't talk to women about safe sex when they have to turn a trick, not to get money for drugs, but for food and Pampers for their children.

Rockland Community College Nursing Instructor Speaks

She cares for HIV + children in foster care in Rockland County and finds that HIV/AIDS services provided here range from minimal to non-existent. The children are forced to go to New York City or Westchester for care, and transportation is a terrible problem. Everyday care is needed here and Rockland doctors don't want HIV + children in their waiting rooms. These children need to be touched, accepted, and not stigmatized. We must educate health care professionals who don't see PWA as human beings needing care.

The Director of Program Development, Good Council Speaks

Young people are bombarded with images of sex and we need to promote chastity as a health choice. Her definition is "saved sex."

A Head Nurse at the AIDS Unit in Westchester County Medical Center Speaks

She sees very many Rockland County residents at the Center, and sees them when their disease is far advanced. They have to be transferred to other facilities and this leads to problems of transportation for the families. She finds it devastating to call family members to tell them they must come when she knows they have no way to get to Westchester.

A Coordinator of Planned Parenthood Westchester/Rockland Speaks

Planned Parenthood performed 300 AIDS tests in 1991. Requests have doubled since the Magic Johnson announcement, but Planned Parenthood hasn't sufficient staff or time to respond because each test involves pre and post-test counseling. Women ages 14 - 24 are the largest growing HIV + population. She said that aside from Nyack Hospital's North Rockland Center, HIV + women with non-related gynecological problems have difficulty in finding Rockland County physicians who will treat them. This applies to all, not just Medicaid Patients.

An Employee of Ramapo Youth Services and Member of the Rockland County AIDS Awareness Task Force Speaks

In 1986 he conducted a needs assessment on AIDS and found there were no Rockland County services for those with HIV. He is outraged that today there are still no services in Rockland. He says "We need more than compassion; we need official action **NOW**."

A Director of AIDS-Related Community Services (ARC) Speaks

"The longer this problem is ignored, the larger it gets and ultimately the larger the bill." Absolute necessities for Rockland County are:

1. Regional ARCS office
2. Local PWA managed group
3. Department of Health, to act as a key player
4. A proactive commitment from county government
5. Accessible clinic
6. Involvement of other key players, such as Red Cross, school system (present AIDS eduction is a mixed bag at best), and churches.

The Executive Director of TOUCH Speaks

TOUCH recently received their first high school referral. A 17 year old told them, " I just didn't think I could get this." The Director estimates conservatively that there are 1,000 HIV + people in Rockland County, and 14 individuals in and out of hospitals with HIV-related illnesses each month. There are 30 PWA's in TOUCH, and 20 to 30 people TOUCH never sees. He has a 14 year old foster child whose parents both died of AIDS. He could go on with specific cases for an hour, and can't stress enough the urgent need for action.

A Physician, Specialist in Infectious Diseases, Speaks

The attempt to assign blame is the greatest barrier to dealing with HIV/AIDS. We need to educate medical professionals on the issues of HIV and women. More women go undiagnosed until the infection is far advanced. We are near enough to New York City to have large numbers of cases, yet too far to use New York City's treatment centers. There used to be a list of Rockland physicians who would care for PWA's. As the number of patients increased, the number of physicians diminished; now he is the last. These patients are young people who die very slowly, and in great pain. "This is a human problem. We need humane solutions."

The Chief of Pediatrics at Nyack Hospital Speaks

Care for Rockland County children who are HIV + currently takes place at Westchester County Medical Center. Thirty-two HIV + Rockland County children have been reported through the first quarter of 1991 by the Directory of the Pediatric Immunology Clinic at WCMC. We need a facility in Rockland County to care for children with AIDS.

A Nurse at Planned Parenthood Speaks

She is the parent of four children who have had little or no HIV/AIDS education in their schools. She read a statement from a friend who didn't come to testify, because she feared what she said would cause her to lose her job, but wanted her story to be heard.

> She was given an AIDS test, diagnosed HIV +, and told she had two years to live. She was not prepared for the news or provided counseling. She then had a three month wait for her first appointment in Westchester and subsequently never saw the same doctor twice. Her confidentiality was broken by nurses and she felt like a piece of meat. She is living in a hotel room with no cooking facilities, eating such foods as peanut butter, which require no preparation. She is having difficulty getting dental care, and fears doctors will make mistakes in her medical treatment because of their lack of knowledge about AIDS. She feels Rockland County is denying we have HIV/AIDS here, and hopes sharing her experiences will help wake people up.

A PWA Speaks

"I don't see how we can just sit here and not do anything. How can we give up on our kids?"

A Clergyman Speaks

A rabbi admits he is bigoted and wants testing for doctors as he does not want to be jeopardized by a medical professional who may be HIV +. He would be upset if a child with AIDS were in a classroom with his child.

A Physician at the Nyack Health Clinic Speaks

We need services here in Rockland so we don't have to send patients to Westchester. The needs are for: primary care, continuity of care, consultative services from specialists, hospital and tertiary care, and integrated services (medical and health with legal, psychological, housing, dental, etc.). We must educate clergy, teachers, parents, and the leaders of the community.

A Worker at the Methadone Maintenance Treatment Program, Pomona Speaks

One in five new patients on the Program test HIV +. More children are experimenting with drugs, getting addicted, and then using needles as the most effective way to get the drug into their system.

A Health Care Worker Speaks

She thinks of herself as symbolically a PWA although she is HIV negative, because HIV is everyones problem.

A PWA Speaks

As a gay man he is aware of what goes on in gay bars and parking lots. Many of the men there are married and/or bisexual. Their wives, female partners, and unborn children are at risk. Rockland better wake up because AIDS is not only in the city, it is here.

A Female Community Member Speaks

The empty buildings in the Health Complex should be used for long term treatment for PWA's in our community.

A Member of Rockland National Organization of Women (NOW) speaks

"Where are the women tonight? Are women not here even though they have AIDS because they're home as caretakers, poor with no transportation, not encouraged to speak, or minorities who fear they will not be listened to?"

A Registered Nurse Speaks

She has worked for 20 years in New York City and estimates that 50 to 75% of the babies she works with in the Newborn Intensive Care Unit are HIV infected. AIDS is the " bottom rung in health care." The statistics grossly underestimate the severity of the epidemic. The HIV + population has changed and we are now dealing with a middle class disease.

The Director of Young Adult Center, Rockland Department of Mental Health Speaks

We are now seeing AIDS in the mentally ill population, mostly in patients ages 17 to 30. You do not have to be in a high risk group to be vulnerable.

A Member of the Rockland Council on Alcoholism Speaks

Women are less likely to seek treatment because the residential programs require mothers to give up their children for the duration of treatment. Women traditionally are socialized in such a way that they have much lower self esteem than men. This lack of confidence is exaggerated when they are infected with HIV, because of the resulting isolation, guilt, and potential loss of children. We need woman-focused alcohol treatment.

A Founder and Member of the Foster and Adoptive Parents Association Speaks

Foster parents are discriminated against by not being able to participate in support groups, due to issues of confidentiality. HIV + children tend to get very poor medical treatment. This is intolerable when you consider that they make an average of 11 to 20 trips to the hospital every year. Additionally, foster parents and their infected children are isolated and alienated by the prejudices of their work colleagues and neighbors.

A Teacher of Bioethics, and a Housing Director of the Regional Economic Action Committee of Orange County Speaks

He lives in Nyack. "When I say I'm from Rockland County, they laugh." By comparison, Orange County is a haven for people with HIV infections/AIDS.

A Rockland County Public Educator on HIV/AIDS Speaks

She read the following testimony from a PWA; " I moved back to Rockland County with three children to be near my family. After six months in a drug-free community, I found I was HIV +. My husband died of AIDS. I'm on SSI, and get $493 a month, and my rent is $375. I have no transportation, no advocacy, no money for over-the-counter medication. I suffer great pain. Rockland is ignoring the disease and it will spread greatly. Please help me - I don't have much time left."

A Member of the Board of Directors of TOUCH Speaks

She is denied the opportunity to see her grandchildren because she works with people who have HIV infection.

The Executive Director, TOUCH, A PWA Speaks

This disease is about homophobia, racism, sexism, all the prejudices and discrimination. Infected women have not come forward the way men have because they cannot risk it, but that doesn't mean they don't exist.

An Employee of the Rockland County Department of Mental Health, Alcohol and Substance Abuse Services Speaks

We get our statistics from public health records and a large proportion of their patients are people of color. Many private practitioners treat HIV infected people but don't report them. There are more white PWA than official statistics indicate. AIDS is the leprosy of the 90's. Rockland County can become a beacon of humanity and dignity in the fight against AIDS.

An HIV/AIDS Counselor Working in a Methadone Maintenance Treatment Program Speaks

It is important to recognize drug addiction as a disease. We need coordination of services. Rockland is very prejudiced and segregated. Many patients need non-prescription medications to live and these aren't covered by Medicaid. PWA'S often have to choose between eating or getting these medications. We must recognize these people are human beings and need compassion and sensitivity. There are multiple prejudices PWA'S have to deal with in reaction to their HIV status, chemical addiction, and often mental illness.

A Male Community Member Speaks

Unsafe sex is likely to occur in episodes of rape and domestic violence. There is a threat of violence to children, who may be raped by their mother's partners. Due to the stigma of STD in women and children, there is greater likelihood they will go untreated.

A Professional Coordinator of Substance Abuse Prevention Services, Rockland Community College and Chairperson of Rockland Community College AIDS Awareness Committee Speaks

Politicians and people in power must go beyond putting services in place and must be proactive instead of reactive.

A Rockland County Public Educator Speaks

Rockland County has made progress but it is not enough. If you cannot be motivated by compassion and human decency, then be motivated by your pocketbook. Every penny pinched away today is tomorrow's dollar spent on hospital bills and foster care. We need an autonomous planning and quality control board of medical, legal, and social services people, headed by PWA'S - the true experts.

A Paralegal of the Legal Aid Society of Rockland County Speaks

Legal Services has been trying to get the Social Services Administration to change the practices they use to evaluate HIV - related infection, and related eligibility. Now SSA is imposing an unfair and inappropriate functional test on PWA's, a test which requires them to demonstrate that they are physically unable to perform activities of daily living.

An Attorney, Rye, NY

Was an original member of Rye Advisory Council, and has done his own research on AIDS education and presented it to the NYS Senate and Assembly, and NY Board of Education. He read Everett Koop's letter citing abstinence as a choice, and saying safe sex is a fraud. Accidental pregnancies occur even with the use of condoms. He stated that abstinence education should be made an important part of the programs of sex education. He cited research study where this was successful.

PART III ISSUES AND RECOMMENDATIONS

Medical Services

by

Sherry Berbit, Good Samaritan Hospital
Andrea Dopwell, Delta Sigma Theta
Alison Rennie, RCHD

Until very recently, HIV - related medical services in Rockland County were virtually non-existent, forcing persons living with AIDS to seek treatment in Westchester and New York City health facilities. This was inappropriate in that Rockland PWA'S are typically transportation disadvantaged and therefore could not readily access the services. Furthermore, as the PWA population of Rockland continued to increase, the outside care providers became unwilling and unable to assume the additional burdens.

1. On January 22, 1992, the Rockland County Health Department opened an Infectious Disease Clinic to provide comprehensive out-patient HIV care and case management. Current clinic hours are Tuesday from 12:30 to 4:00 p.m., and Wednesdays from 4:00 to 7:00 p.m. Within the initial four months of operation, the I.D. clinic exceeded projected service quotas for the entire year. Clearly, the I.D. clinic as currently constituted is inadequate for the coming demand.

Also, the I.D. clinic provides only the standard treatment modalities. If a patient desires an alternate strategy (i.e. holistic medicines, acupuncture, macrobiotic nutrition, etc.) none is available, nor is there an established referral mechanism. There is also no established referral network for consultation with or treatment by specialists.

Recommendation: Expand outpatient medical services. The Health Department is exploring the feasibility of developing a second clinic site, as Pomona is not accessible to many of those in need. The alternate clinic sites do not currently have the necessary equipment or funding.

Recommendation: Establish a voluntary rotational referral system whereby a service organization (e.g. TOUCH, ARCS) and a physician advisor coordinate referrals of unassigned patients to a pool of practitioners. (See Appendix A. "Peninsula Plan" for details.) This would alleviate the burden on both the I.D. clinic and on the patients who now must travel and/or wait for appointments. Such a system would lay the groundwork for the comprehensive, integrated community-based HIV/AIDS care, which Rockland must develop.

2. Rockland area pharmacies do not accept the reimbursement provided by Medicaid. Those which do take assignment do not ordinarily stock all the necessary pharmaceuticals. The cost of many over-the-counter drugs which are not reimbursed by Medicaid is prohibitive. These drugs, necessary for quality of life, are financially inaccessible for the poor.

Recommendation: Recruit neighborhood pharmacies into the AIDS Drug Assistance Program (ADAP) to expand access to prescription drugs. Actively seek grants or donations from pharmaceutical companies to directly supply non-prescription and non-reimbursable health care products.

3. There is to this date virtually no provision of dental services for PWA's in Rockland County. HIV-related oral infections and diseases must be treated promptly and aggressively because weight maintenance is absolutely vital to survival, and untreated oral infections often make eating solid food impossible.

Recommendation: Establish scatter-site HIV dedicated dental services. The Rockland County Health Department is formulating proposals to establish an HIV-related dental clinic at Pomona. Encourage and support this in every way possible. However, the inadequacies of single-site service have already been demonstrated. There must also be an intensive effort to recruit area dentists into the service network. Incorporate dental services into the "Peninsula Plan." St Clare's Hospital Spellman Dental Clinic in New York City has offered to provide consultation support to Rockland dentists treating PWA's.

4. Approximately 30% of infants born to HIV + women will themselves be HIV + . However, all infants born to infected women may test positive for up to 18 months due to the persistence of maternal antibodies. Standard HIV-antibody testing, therefore, reveals the status of the mother, rather than the status of the newborn. If infected infants cannot be accurately identified, it is impossible to provide appropriate and timely care. Although this issue is not unique to Rockland, local legislation or a lobbied change at the state level would permit the use of more accurate tests that are currently available, such as PCR.

There is no comprehensive pediatric care within Rockland County. The few pediatricians treating HIV-infected infants and children are completely overwhelmed. Doctors cite the low Medicaid reimbursements compounded by excessive paperwork as major obstacles to their accepting disadvantaged patients.

Recommendation: Establish a comprehensive pediatric HIV/AIDS service. Nyack Hospital has submitted a proposal to the New York State Health Department to establish a pediatric HIV service. The State normally demands a high level of concrete community support for agencies seeking to initiate new services. This concrete support must be demonstrated.

5. HIV disease is not reportable until the diagnosis of full-blown AIDS is made. AIDS cases are reported to the New York State Department of Health AIDS Registry, which in turn reports back to the County. There is a significant lag time in reportage; for example, the June 91 Registry Report for Rockland cites 101 cumulative AIDS cases through June 90. The May 92 report cites a total of 155 cases through June 90. Recent national studies have indicated that for every patient officially counted as an AIDS case, there are two more equally ill patients being treated in the same facility who have not been reported. Hearing testimony reveals that although official statistics report a cumulative pediatric case load of nine, there are approximately 40 HIV - infected infants and children being cared for in Rockland County, or residing in Rockland and being treated in Westchester.

Any decisions involving the dedication of health resources must be informed as the overall resource "pie" is finite. State and Federal grant funding levels are based on the reported statistics.

> **Recommendation:** Develop accurate statistics. A comprehensive epidemiological study of the county is vital so we can accurately assess and project needs.

6. Access to home nursing and other in-home support services, as well as access to hospice services, is severely limited. There are no long-term or tertiary care facilities in Rockland County prepared and willing to address the needs of PWA's.

Because individuals with HIV and AIDS are living longer and because care associated with this illness is often complex and intensive, there is a growing need for long term care facilities. The current system, which traditionally serves geriatric patients, is already overtaxed, and is alienating for those who are living with AIDS, as their average ages are between 25 and 35.

> **Recommendation:** Develop and implement a Rockland County long term care facility that is HIV/AIDS specific. Encourage the Rockland County Hospice program to enhance and extend services to be provided to Rockland residents living with AIDS.

Non-Medical Support Services

by

Joseph Lanzone, Ramapo Counseling Center
Linda Sweet, DSS
Susan Witte, ARCS

As rates of HIV infection and AIDS in Rockland County continue to increase, so too does the need for support services enabling individuals to maximize their quality of life living with HIV/AIDS. While primary medical care must take priority in addressing the physical illness, in order to access this care an individual must overcome significant barriers. A broad continuum of support services must be provided to those affected by HIV/AIDS. Following are a number of non-medical problems/needs identified by speakers at the public hearings and corresponding recommendations for ways in which to begin to address them.

Support for Families: Rockland County has one of the highest newborn seroprevalance rates outside of New York City; one out of 256 babies is born to an HIV + mother. Approximately 30% of these children will ultimately be HIV + and in need of primary care and support services. Additionally, since many adults who are currently living with HIV/AIDS are of child bearing age, a great many families are trying to make plans for the future of their children in the face of their own terminal illness. Mothers, fathers, guardians, and other primary caregivers need guidance in how to talk to their children about the problem and how to arrange support for their children after their own deaths.

While official statistics say there are nine cases of full blown AIDS in Rockland, service providers report seeing up to 40 pediatric AIDS cases. This indicates how seriously under-reported AIDS cases are in Rockland County.

RECOMMENDATIONS

1. Provide access for HIV+/AIDS children in all Rockland County service provider settings.

2. Encourage existing children's and family services providers to recognize and become familiar with HIV/AIDS issues, and to access technical assistance in setting up support groups and service referrals for family members. For example, support groups for children whose parents are HIV +; grief and bereavement groups for family members, etc. Encourage the use of more effective and comprehensive family models and counseling and support.

3. Work with Rockland County Foster Care system to:

   a. create a system of flexibility and support in negotiating temporary child placement when a parent is hospitalized.

   b. provide professional support groups for existing foster parents and family members who have an HIV + child placed in their home.

4. Advocate the establishment of locally based HIV-specialized primary care for children and families.

5. Develop and implement support services related to proposed HIV pediatric services at Nyack Hospital, including education and respite care for parents while children are hospitalized or undergoing treatment; support groups for children who are HIV +; a volunteer-based baby holding program; and other services as needed. The National Pediatric HIV Resource Center is an excellent resource for technical assistance in the development and implementation of community-based systems of care for children and families with HIV infection.

Clearing House on HIV/AIDS Resources/Information:

RECOMMENDATIONS:

1. Set up a localized clearing house for information related to both pediatric and adult HIV/AIDS. A local library or service provider may act as the central repository for information to be collected. This information must be made available to those who need it.

2. Provide at this same clearing house, a site for donations of clothing, non-perishable foods, non-medical pharmaceutical and health care products, and other items which are particularly costly to those who are and frequently are not covered under traditional entitlement programs.

Access to Entitlement: Accessing entitlement is a confusing and lengthy process, often complicated by urgent medical and survival needs of individuals. Workers are often not sensitized to the painful emotional issues clients are experiencing.

RECOMMENDATIONS:

1. Provide education/training for existing DSS workers on basic HIV/AIDS information, sensitizing them to client issues and concerns. Review specific criteria for eligibility for benefits related to HIV/AIDS, i.e. enhanced reimbursement for housing, the need to apply for disability first in some cases, etc.

2. Identify a single point of entry for people living with HIV infection to access DSS entitlement and support services. The professional(s), at this point, should also serve as liaisons to outside agencies which can assist the client to access existing services or entitlement.

3. Provide a series of workshops and/or orientation training for service providers on entitlement programs available through DSS, and how to access them most effectively through the above identified point of entry. Provide a component for M.D.'s and R.N.'s which addresses Medicaid issues and access.

4. Publish this information in a "consumers guide/how to" format and make it available through the above-mentioned clearing house.

Food Services: There is a need for preparation and delivery of nutritionally adequate meals to homebound individuals living with HIV/AIDS. Existing services include assorted food pantries such as People to People and soup kitchens and the delivery of non-perishables by T.O.U.C.H. There is also a nutritionist available for consultation at the RCDOH HIV clinic.

RECOMMENDATION:

Develop and implement a Rockland County program similar to these existing models: Gods Love We Deliver, New York City; The Lord's Pantry, Westchester County; The Sharing Community, Westchester County. This program would provide sensitivity training to a corp of volunteers who would prepare and distribute meals on an as-needed basis. Clients may be identified through TOUCH, RCDOH HIV Clinic, ARCS and/or other services organizations.

Housing: One of the most critical needs for individuals living with HIV/AIDS in Rockland county is housing. If a person is homeless, it is virtually impossible to meet his or her other needs.

RECOMMENDATION:

Within the next year, the County must develop and implement a pilot project for HIV/AIDS housing by renovation of unused County-owned building or space (i.e. Bldg.A at the Pomona Health Complex) to provide scattered site housing. These should be developed as 4-6 bed units with a single staff member/case manager to assist individuals to access medical care and support services

Respite Care: Due to the enormous emotional and physical burden faced by those individuals living with HIV and AIDS, respite care is necessary to sustain provision of at-home care.

RECOMMENDATION

Expand existing volunteer-based respite care model programs such as Volunteers of America to meet the needs of caregivers in Rockland County.

SUBSTANCE ABUSE: Since IV drug use remains one of the most common forms of HIV transmission, substance abuse is an integral part of the problem of HIV/AIDS. Active users and their sexual partners are among the fastest growing population with HIV infection. Alcohol and drug abuse complicates treatment of HIV/AIDS patients, inhibits their access to physical and mental health care, and further exacerbates all quality of life issues. In Rockland County, 18% of diagnosed AIDS cases were transmitted through IV drug use.

RECOMMENDATIONS:

1. Mandate basic HIV/AIDS education and risk assessment training for substance abuse treatment providers. Sensitize workers to issues of HIV/AIDS and how these may impact on the success or failure of treatment models and approaches.

2. Provide affordable and accessible substance abuse treatment, more family treatment work in existing provider settings, including inpatient and outpatient accommodations for mothers to have their children close by and/or living with them while in treatment.

3. Encourage the use of a family treatment modality in existing provider settings to integrate HIV/AIDS issues and issues of long term recovery and relapse prevention in the family setting.

4. Encourage existing HIV/AIDS-specific providers and substance abuse treatment providers to run more support groups specifically for substance abusers which address HIV/AIDS in the context of their recovery, early or long term; or which support getting into treatment.

5. Develop and implement a needle exchange program, with a safer sex and treatment referral and linkage component, to prevent the further spread of HIV infection among active IV drug users.

TRANSPORTATION: Access to public transportation or Medicaid-reimbursable transportation has posed a considerable barrier to access treatment and support services for individuals who are living with HIV/AIDS in Rockland County. When individuals are felling ill or weak they are frequently unable to wait at bus stops or to take long bus rides. It is also difficult to negotiate public transportation with small children when one's health is compromised. Money for fares is hard to come by for families on public assistance.

RECOMMENDATIONS:

1. Educate providers and clientele on the criteria for and method of access to Medicaid-reimbursable transportation. Develop a system of advocacy whereby Medicaid transportation providers are held accountable for effective and efficient provision of service.

2. Enhance existing DOT/TRIPS routes to provide more frequent access to HIV/AIDS direct service providers, i.e. Westchester County Medical Center in Valhalla, T.O.U.C.H in Nyack, RCDOH HIV Clinic in Pomona, ARCS Spring Valley.

3. Provide basic HIV/AIDS education to existing transportation providers, sensitizing them to client/passenger issues and ways they may be of assistance.

4. Duplicate and/or expand ARCS model transportation to clients (to begin May 1992). This model utilizes a voucher system where the agency reimburses cab companies for client rides to and from the agency for service, and to and from other appointments where appropriate.

VOLUNTEERISM: Many if not all of the above-mentioned services can be staffed primarily using volunteer support.

1. Due to the very challenging emotional issues associated with HIV/AIDS, i.e. issues of death and dying, sexual orientation, severe physical debilitation and suffering, alienation and isolation, and drug use, it is imperative that any volunteer be provided responsible and appropriate training, sensitization, and ongoing supervision and support.

2. Outreach for volunteer support must reflect the community in which the services will be provided.

Education

by

Susan Commanday, Rockland Community College
Carolyn Kaufman, Planned Parenthood
Kathy Schatzberg, Rockland Community College

HIV/AIDS education is an extremely complex subject which cannot be effectively discussed without reference to topics such as values, drug use/abuse, sexuality, mortality - topics that are controversial and difficult for many people to confront. When a crisis develops in our society, there is a tendency to look toward the schools for solutions; however, with HIV/AIDS, it is clear that no one group or organization can single-handedly provide the comprehensive education that is so desperately needed.

This section of the report includes first a summary of the current state of HIV/AIDS education in Rockland County as reported by those who testified at the hearings, and by school and college administrators. The second section lists recommendations culled from all these sources.

HIV/AIDS Educational Efforts

1. Testimony at the Hearings

Although no public school officials testified at the hearings, there was repeated testimony that educational efforts in public schools are inadequate, vary greatly from school to school, and are subject to community and parental pressures. As a result, many young people are misinformed or ill-informed about HIV/AIDS. Some educational efforts are mounted by various community agencies and organizations, but these too are inadequately funded and are not comprehensive or systematic enough to meet the need.

Cited as a particularly critical loss was the Cornell Cooperative Extension Program "Talking with Your Kids About AIDS" which lost its funding and therefore the efforts of a full-time professional, (Carrie Steindorff). This program was designed to train educators, parents, clergy and other community leaders and addressed the issues of controversiality and denial which make AIDS so difficult for many people to discuss. A local hospital employee is now attempting to deliver this program when requested, but this responsibility is in addition to her other full-time responsibilities.

Rockland Community College officials who testified cited research showing that educational efforts to date have resulted, among both college and high school students, in a fairly high degree of knowledge about HIV/AIDS, its routes of transmission, and the appropriate preventive strategies. Nevertheless, the research indicates that these students have not adopted significant behavioral changes which could protect them from infection.

2. Current Efforts in the Public Schools

At a meeting on April 10, 1992, the Assistant Superintendents of Instruction representing most of the school districts in Rockland County indicated that they had not received the invitations sent to the Superintendents to testify at the hearings. They described the AIDS education programs in their districts as emanating from a New York State mandated health curriculum which included objectives aimed at AIDS education and prevention. The State, they said, has left it to the individual districts to operationalize and implement these objectives, an approach that these Assistant Superintendents felt was appropriate because of differing community sensibilities and values.

In most districts, the professionals responsible for implementing the curriculum and/or for training of the teachers to implement it have been health coordinators or resource counselors whose other duties included substance abuse education and counseling. State budget cutbacks and their impact on staffing were cited as confounding the effort to implement AIDS education. Nevertheless, they believe the districts have implemented a substantial level of educational programming both in traditional classroom format and in special events, such as speakers, health fairs, AIDS awareness days, and the like. Many districts have worked with BOCES and the now defunct "Talking With Your Kids About AIDS" program.

As a group, they agreed that instructional efforts had been extensive and appropriate, but they also agreed that the impact was probably inadequate, not because the instructional programs themselves were deficient but because adolescents tend to believe that "it can't happen to me" and thus do not change their behavior. This factor affects not only AIDS education but also other educational programs aimed at such problems as substance abuse and teen pregnancy.

3. Current Efforts at Rockland Community College

The College's AIDS Awareness Committee coordinates activities which have to date included both faculty workshops and programs for students. Counseling and information about testing and preventive measures are available through the College Health Services Office and the Life, Career and Educational Planning Center. Information about AIDS has been incorporated into various academic courses but future goals include broader inclusion across the curriculum.

RECOMMENDATIONS

HIV/AIDS education is not only information about the disease; it must encompass self-esteem, communication, sexuality education, and drug/alcohol abuse prevention. It must involve a unified message delivered not only by the schools but also by parents, hospitals, clinics, doctors, the media, and community groups such as youth groups, religious organizations, and recreational programs.

I Who needs HIV/AIDS education?

We may think of education as primarily directed at children and teens, but it is clear that many other groups need a variety of educational services: persons with AIDS and their families; health care practitioners, including doctors, nurses, social workers, and counselors; the staff of social service agencies working with such populations as the mentally ill, the developmentally disabled, pregnant teens and women, and alcohol and drug abusers; the clergy; community leaders; teachers and other school workers; parents; and the general population.

II How should AIDS education be delivered?

We may also think of AIDS education as primarily a school function, but it is clear that a sustained effort must include a variety of agencies and modes of delivery. These could include print and audio/visual materials, speakers, and workshops. Following are specific recommendations to be carried out: in the schools, the medical community, and the community at large.

A. In the Schools

1. We need structured, evaluated and monitored programs in which AIDS is discussed throughout the curriculum and at all levels.

2. Self-esteem and sexuality education must be started in nursery school and continued throughout elementary school. Educational programming must take into account child development theory as well as the values and sensitivities of parents and community

3. We must provide opportunities for students to practice assertiveness and communication skills.

4. Education about prevention must stress both abstinence and safer sex practices.

5. We should require HIV/AIDS training for licensure of nursery school teachers and workers and for certification of elementary and secondary teachers.

6. In-service training for all faculty and school staff should be provided at all levels, for all disciplines, and on paid time.

7. We should solicit teacher and student recommendations on how to teach the material.

8. Parents should get age-appropriate educational packets of information whenever a child enters a new school.

9. We should develop peer educator training programs.

10. We must investigate and adopt ways of translating educational efforts into behavioral change.

B. In the Medical Community

1. HIV/AIDS training should be required for licensing and relicensing of all medical practitioners to prevent provider-to-patient and patient-to-provider transmissions.

2. Education of medical practitioners must include not only information about the disease but also development of humane interaction and communication skills.

3. In-service training should be provided for all hospital and clinic staff including doctors, nurses, practical nurses, nurse aides, orderlies, janitors, etc.

C In the Community-at-large

1. Launch an informational print ad campaign (newspapers, billboards and buses).

2. Supplement with media campaign using radio and cable television.

3. Establish a speaker's bureau.

4. Community education should be intentionally and consistently delivered by community groups such as YMCA,YWCA,and YMHA and YWHA: Girl and Boy Scouts; youth groups in churches, synagogues, and elsewhere; support and counseling groups.

5. Establish a county telephone hot-line, staffed by well-informed and well-trained personnel.

6. Restore funds to make the "Talking With Your Kids About AIDS" program a full-time effort.

7. Form a coalition of community groups, parents, and school and college administrators and faculty to initiate, coordinate and evaluate county-wide educational efforts.

D Outreach to the Lesbian and Gay Communities

Stigma traditionally attached to issues of homosexuality have been further compounded by the HIV/AIDS crisis. In Rockland County gay and lesbian communities it has not been safe to organize a formal, visible voice for advocacy due to strong community denial of the existence of other than a heterosexual orientation among our community members. It is vital to address the need for the availability of HIV/AIDS non-medical support services for the lesbian and gay communities in Rockland County. The lesbian community is equally at risk for HIV infection, but is often not addressed in education/prevention literature and by staff of human service agencies not yet aware of and sensitized to the needs of this community. As we become aware that the spread of infection is expanding to the heterosexual non-drug using population and formulate services and programs for this population, we must continue to make outreach services visible and available to the Rockland County gay community.

Sensitization to issues of both the gay and lesbian communities should be provided to the staff of human services agencies, as well as any agency which addresses issues of concern to the Rockland County community as a whole.

Prevention

by

Lois Levine
Marie Lorenzini
Donna Pauldine, Director, Young Adults Center
Clifford Schneider, Cornell Cooperative Extension
Diane Stevenson, Journal News

The incidence of human immunodeficiency virus (HIV) infection and AIDS continues to climb in major cities in the United States, with women and young adults as the fastest growing risk groups. AIDS has become the leading cause of death for women between the ages of 20 to 40 and one of the top five causes of death among women in this age group nationally.

With an estimated 40,000 new cases yearly, it is critical that education and prevention efforts be accelerated, as the only way to curtail the spread of this dread disease.

First, it is important that we recognize that education and prevention are not identical. While education programs can be very effective in stimulating an increase in awareness and knowledge, effective prevention programs lead to behavior change. Successful education programs help to create an environment in which prevention programs can be more effective.

While certain testimony provided at the hearings criticized education and prevention programs as being ineffective in creating real behavioral change, the following recommendations reflect testimony which addressed the need for on-going prevention strategies in the community-at-large, and among adolescents and women.

IN THE COMMUNITY-AT-LARGE

1. Community-based agencies and peers of those being targeted must design and implement prevention programs. For example, education and prevention efforts provided to the male homosexual community by the male homosexual community have been demonstrated to be significantly effective in decreasing the incidence of HIV infection. While there are universal elements in increasing one's knowledge and effecting behavior change, each program must be tailored to a very specific target population, preferably by members of that population who understand it well.

2. We must recognize that people have different reasons for being hesitant to act on the education or prevention interventions they have learned. We must not only understand these barriers to effect behavior change, but develop appropriate strategies to overcome them.

Adolescents/Young Adults

1. The option of abstinence as the only sure way to prevent sexual transmission of the HIV virus must be explored and discussed with adolescents/young adults. In addition, delaying sex, being discriminate in the choosing of a sexual partner, and engaging in monogamous relationships are all pertinent in the teaching of prevention techniques.

2. Should adolescents choose to be sexually active, they must recognize that the use of a latex condom reduces the risk of HIV infection. Clear, direct instruction on the proper use of a condom must also be provided.

3. Adolescents must be made to overcome their feelings of invincibility, (the "it can never happen to me" denial) and be helped to recognize that this "blind spot" has contributed to their age group becoming the fastest growing HIV infected risk group

Women

1. Provide women with non-coercive and non-judgmental counseling to increase their awareness of the need for regular gynecological examination. Alert medical professionals to esophageal and vaginal candidiasis, cervical abnormalities and other reproductive health problems which may signal the presence of HIV infection.

2. Recognize that prevention programs must take into account that, for many women, and especially minority women, prevention activities relating to sexual activities, abstinence, and condom use require the cooperation of their sexual partner. Women need peers to model safer sex and "condom use negotiation skills" as a way of dealing with partners who are recalcitrant in using condoms.

3. Women must be taught to step out of their traditional non-assertive roles in matters of reproductive health and safer sex negotiation.

Conclusion

The effects of missed opportunities for prevention are becoming abundantly clear, with women projected to account for over half of the AIDS cases by 1996. Prevention programs which demonstrate the ability to effect behavioral change are our only vaccine.

Legal Issues

by

Daisy Pedraza-Balatocan, Legal Aid Society of Rockland County
Susan Witte, ARCS

1. Advocacy at the federal, state and local levels is needed to change definition/diagnosis of AIDS adopted by the Centers for Disease Control. The current definition does not reflect the range of disabling illnesses that most frequently afflict women, intravenous drug users, and children. Many entitlement programs, such as those provided through the Social Security Administration and New York State Department of Social Services, require a diagnosis of AIDS for eligibility. Until the definition is more inclusive, women, children, and intravenous drug users living with HIV infection will continue to be ineligible for many of these programs.

2. Significant and aggressive advocacy on a case by case basis is strongly recommended to those affected by HIV/AIDS and seeking entitlement. Many entitlement programs have extremely complicated application processes, and lengthy bureaucratic delays before benefits are received. Applicants are often treated harshly and unsympathetically due to a lack of sensitivity training for entitlement workers. Since entitlement programs are a primary source of health care and financial support for those living with HIV/AIDS, advocacy must be provided to insure that individuals receive the financial and medical services they deserve and need.

3. The Social Security Administration (SSA) recently issued a final rule which changes the procedure for persons seeking Social Security Insurance (SSI) based on their HIV infection. Under the new procedure, SSA may make a finding of presumptive disability for any individual with HIV infection whose symptoms appear on the official CDC list of severe opportunistic infections, not only those who have obtained a CDC-defined AIDS diagnosis, from their physician.

This new ruling sets forth guidelines for assessing the manifestations of HIV infection based on listing impairment and functional limitations. The four general areas of "marked" functioning to be assessed are:

a. Activities of daily living;
b. Social functioning;
c. Difficulties of completing tasks due to deficiencies in concentration, persistence or pace;
d. Repeated episodes of deterioration or decompensation in work or work-like settings.

The ruling identifies additional criteria which are to be taken into account when evaluating children and women infected with HIV, i.e. medical conditions specific to women, such as disabling gynecological complications. The SSA has also proposed a ruling to establish a new listing of impairments entitled, "Immune System," which would include the medical criteria for determining whether adults and children with HIV infection are disabled and therefore eligible for disability benefits.

The most serious problem with the rule is that it adds an overly restrictive functional test as a condition for qualifying for benefits. It also omits debilitating but not totally disabling gynecological complications frequently experienced by women with HIV infection. The new functional test actually makes it far more difficult to qualify for disability benefits with HIV infection than to qualify for disability benefits with a CDC-defined AIDS diagnosis. The functional test makes it nearly impossible for lower income individuals to qualify, because an individual must be seeing a single physician familiar enough with one's medical condition to document and assess the individuals activities of daily living or functional capacities.

4. Confidentiality for people with HIV infection should be mandatory in all aspects of our government, health care, housing, employment, education, and judicial systems. Individuals living with HIV/AIDS also need representation in situations where a breach of confidentiality has occurred, i.e. disclosure of HIV status, taking of bodily fluids to determine HIV status, etc. Another problem in protecting confidentiality for individuals living with HIV/AIDS is that access to an individual's medical records, which often reveal HIV status, has become easier pursuant to the Public Health Law (1986, NY Sessions Laws Chapter 487) and Mental Hygiene Law (1986 Sessions Laws, Chapter 498).

5. Advocacy to obtain adequate and appropriate housing for individuals living with HIV/AIDS is a critical need. Because of discrimination related to HIV/AIDS, many individuals are illegally evicted and locked out of their residences. Many of these individuals then find themselves surviving in inadequate and unhealthy environments, placed temporarily in an overcrowded shelter, or homeless, further exacerbating their medical condition.

Although the New York State Department of Social Services provides a housing supplement for HIV infected individuals, neither DSS workers nor those who are HIV-infected and in need of housing know how to access this supplement. Further, getting DSS to actually pay the supplement is often a problem even when it is ultimately accessed.

6. Individuals in non-traditional living arrangements are often compelled to separate and live independently, or must use up their financial resources in order to be eligible for enough benefit and entitlement income to survive. When a partner dies of AIDS, there is often a legal issue questioning the right of the partner to keep an apartment.

7. Many individuals, including those living with HIV/AIDS, are unaware of their legal rights and their right to receive health care. There should be a service in place which apprises individuals of their rights and opportunities for care. For example, there is a new provision under the Medicaid Community Follow-up program (COBRA) for individuals living with HIV infection. If an HIV + individual has private insurance through an employer, once he or she has left employment, the Department of Social Services will continue payment of their insurance premium rather than placing them on Medicaid, because it is more cost effective. Under this COBRA provision, the individual is insured up to 18 months after job loss.

8. Additional "pro bono" legal support and advocacy is needed for individuals living with HIV/AIDS to prepare health care proxies, conservatorship, power of attorney documents, living wills, regular testamentary wills, estate and trust planning, and other plans for directing assets.

9. Confidentiality around HIV status is critical in child custody cases. A parent living with HIV infection and a drug problem may have to have children placed in foster care. Visitation rights are often refused by the foster parent due to the natural parent's HIV status. Even when the parent gets clean from drug use and may be able to take the children back into his or her home, the HIV-infected parent faces discrimination in the courts in obtaining custody.

10. Family Court should be sensitive to the needs of HIV + parents, as they make plans for the future of their children. Parents should be able to designate a legal guardian for their child(ren) in the event of their death.

11. Better communication and follow through between the legal, social services and medical system is needed to protect children and families living with HIV/AIDS. Often professionals believe that children are being neglected when in fact the parent is neither aware of the child's medical needs nor able to deal effectively with his or her own illness. When parents are found to be neglectful, care guardians are appointed to represent the children who are are placed in foster care. There is no continuity of care for the children or the family. If legal and social service agencies are educated about medical issues related to HIV/AIDS, they will be better able to support parents, children and families living with HIV/AIDS.

12. Appropriate foster placement for children with HIV/AIDS is a serious problem. Few homes are willing to take children with HIV/AIDS, particularly if they require a lot of medical attention. Foster families that will take in an HIV + child are often reluctant to keep the child once full blown AIDS has developed. Families who do take in and care for a child living with AIDS need support for other foster children within the setting who may have a history of abuse and neglect and experience further trauma living with a chronically, terminally ill child.

13. It is important that fathers who have not acknowledged their financial responsibility to their natural children do so before the death of either parent living with AIDS, so that the children can receive any auxiliary benefits they may be entitled to. DNA testing to establish paternity cannot be successfully completed once the father is deceased.

14. We should provide pro bono legal consultation for people living with HIV/AIDS and their families through the Legal Aid Society of Rockland County, similar to the model currently in use by Westchester/Putnam Legal Services or expand the existing program to include a day on site in Rockland to address legal needs of local residents. Westchester/Putnam Legal Services is currently funded under Ryan White Title I ($25,000) to provide low income HIV infected individuals' with advocacy and information/mediation regarding individuals' rights to access to health and human services.

15. Other needs indirectly related to legal concerns:

There is a need in Rockland County for clinical group homes specifically geared for children living with HIV/AIDS.

More educational programs are needed for health care providers, legal advocates, public officials, mental health professionals, day care providers, and virtually anyone who may lack knowledge about HIV/AIDS.

More health care facilities are needed in Rockland County in order to accommodate the growing needs of persons infected with HIV. Clinics are needed to provide proper medical care, which must include a component for gynecological care.

Family planning and birth control concerns should also be addressed. The county needs an HIV/AIDS consortium which will involve groups such as the United Way, Salvation Army, Planned Parenthood, the Centers for Independent Living, Mental Health Clinics and Centers, school representatives, community -based organizations, DSS, and other providers, to plan workshops, training and work on various projects.

We also need an effective way to help persons living with HIV/AIDS to obtain information and assistance in accessing benefits/entitlement.

As a general principal we must recognize that because of the multitude of medical and legal issues involved in HIV/AIDS, we need to provide a unified approach to helping persons with HIV make a life plan.

PART IV RECENT DEVELOPMENTS

Significant developments have occurred during the time required to produce this report based on the Public Hearings convened by the Rockland County Commission on Women's Issues in January 1992. As we go to print, the CDC is preparing to hold forums seeking public response to the most recent proposed revision of the surveillance definition of AIDS. This new definition includes many of the specific diseases manifested by women, IVDU, and people of color. **The Legislative SubCommittee on Women and AIDS** advocated for such inclusions during the last forum and will continue to be a part of the national voice for positive change.

In late October, New York State announced the expansion of the AIDS Drug Assistance Program (ADAP) to provide coverage to eligible applicants, through approved providers, for out-patient medical visits and laboratory tests. The primary care assistance program is called "ADAP PLUS." The Clarkstown Pharmacy in New City recently established a medication delivery service which improves access and reduces patients' difficulties in obtaining prescription drugs.

Rockland County Health Department's weekly out-patient clinic opened in January 1992 providing medical, case management, and nutritional services to adults with HIV disease. In mid-September an evening clinic was added, and there are immediate plans to include dental and respiratory care. The establishment of these vital services greatly alleviates one of the most pressing medical concerns expressed by those testifying at the hearings: the need for HIV positive residents to travel outside Rockland County for basic care. The Rockland County Health Department has also received a grant to renovate space within the Pomona Health Complex to provide a 12 bed emergency housing unit for HIV + homeless men.

AIDS-Related Community Services opened a satellite office in Spring Valley on August 17, thereby making ARCS client support services more readily accessible to Rockland residents. In September, ARCS initiated "Positive Feelings",a support group for children affected by HIV infection in their families.

This spring the **SubCommittee on Women and AIDS** and the **Rockland AIDS Awareness Task Force** co-sponsored a major conference entitled "Facing the Facts, AIDS in our community." Due to the overwhelming response a follow-up conference was held November 10, 1992 with intensive workshops focusing on HIV in women and/or substance abuse and HIV.

While there is some reason for optimism, many critical needs remain to be addressed. The out-patient clinics are an essential service, but it is neither appropriate nor feasible for the Rockland Health Department to be virtually the sole provider of HIV-related health services county-wide. Integrated, shared responsibility is the only long-term solution. A system of improved access to DSS entitlement, supported housing, child care services, and skills development education programs are critical priorities which must be fully implemented within five years.

To this end, the Rockland County Commission on Women's Issues will convene a coalition to facilitate and monitor the timely implementation of these recommendations. Representatives of all services and educational organizations serving Rockland County, as well as consumers, will be requested to participate. Specifically, this coalition should include: TOUCH, ARCS, RCHD, DSS, MMTP, Hudson Valley Health Systems Agency, ROCAC, DMH, MHA, RCC, RC Youth Bureau, Rockland Council for Young Children, Planned Parenthood, Red Cross, Salvation Army, Legal Aid Society, Hospice, Medical and Dental Associations, Regional School Health Coordinators, Student Councils, Clergy, Hospitals, Home Health Agencies, Drug and Alcohol Treatment Facilities, Law Enforcement and Public Transportation. Should it prove necessary, local funding will be sought to provide the coalition a full-time coordinator.

Part V. SUMMARY OF RECOMMENDATIONS

I. The Rockland County Commission on Women's Issues will convene a coalition of service providers, educational organizations and consumers to facilitate and monitor a coordinated approach to the recommendations set forth in this report. Integrated, shared responsibility is essential to prevent the further spread of AIDS.

II. Medical Services Needed:

A. Expand outpatient medical services for better outreach;

B. Establish dental services;

C. Establish a comprehensive pediatric HIV/AIDS service;

D. Establish a voluntary coordinated service to refer unassigned patients to physicians

E. Expand access to needed drugs through pharmacy participation in AIDS Drug Assistance Program (ADAP);

F. Establish a long-term care facility for HIV/AIDS patients;

G. Develop accurate statistics for needs-planning and funding levels;

H. Promote passage of legislation to permit the use of a more accurate test to identify HIV status of newborn.

III. Non-Medical Support Services Needed:

A. Streamline access to entitlement programs and sensitize social workers to HIV/AIDS issues;

B. Provide access for HIV/AIDS children in all service-provider settings;

C. Integrate HIV/AIDS education and training into all aspects of substance abuse work. Establish a needle exchange program and provide safer sex information to prevent further spread of HIV infection among active IV drug users;

D. Encourage family service providers to understand HIV/AIDS issues and to create support groups;

E. Work with foster care system to provide support groups and flexibility in temporary placements;

F. Improve access to public transportation, including information on how to access Medicaid reimbursement for transportation;

G. Establish central repository for HIV/AIDS information;

H Develop a pilot project for HIV/AIDS housing;

I. Expand existing respite care programs;

J. Develop a meal delivery program for homebound HIV/AIDS persons.

III. Education To Increase Awareness of HIV/AIDS Needed:

A. Develop a unified message to be delivered by parents, schools, media, medical community, religious institutions, recreational programs, civic and community groups. The education must encompass self-esteem, sexuality, and drug/alcohol abuse prevention as well as information about HIV/AIDS;

B. Direct the educational services to a wide variety of groups other than children and teens, including those who deliver health and social services, the clergy, community leaders, parents, teachers and the populace at large;

C. Deliver a sustained educational effort using a variety of agencies and techniques. Specific recommendations are detailed for schools, the medical community, and the community-at-large in the report. Successful education programs help to create an environment in which prevention programs can be more effective;

D. Establish structured school programs starting in nursery school, which take into account child development theory as well as the values and sensitivities of parents and community;

E. Require HIV/AIDS training for licensure or certification of certain professionals;

F. Provide in-service training within the medical community which

includes humane communication skills;

G. Launch an informational ad campaign, using print, billboards, radio and cable television.

H. Utilize established community and youth groups to deliver the educational message;

I. Establish a county telephone hot-line, staffed by well-informed and well-trained personnel;

J. Restore funds to make the "Talking With Your Kids About AIDS" program a full-time effort;

K. Establish outreach to the lesbian and gay communities, and make services visible and available.

IV. Prevention Needed:

A. Create strategies leading to behavior changes and to overcome barriers preventing effective change;

B. Promote abstinence for adolescents/young adults as the only sure way to prevent sexual transmission of HIV virus. Help youth understand prevention techniques such as delaying sex and having monagamous relationships. Instruct those adolescents who choose to be sexually active in the proper use of latex condoms for reduced risk of HIV infection;

C. Design and implement prevention programs tailored to specific target populations with help from peers of the target groups;

D. Alert medical professionals to health problems in women which may signal the presence of HIV infection;

E. Increase women's awareness of the need for regular gynecological examinations;

F. Help women acquire the skills necessary to negotiate safer sex with uncooperative sexual partners.

V. Legal Remedies Needed:

A. Advocate for changed definition of AIDS by Centers for Disease

Control;

B. Establish advocacy assistance to enable individuals with HIV/AIDS to access entitlements (their primary source of health care and financial support) and housing, which is often discriminatory;

C. Establish pro-bono legal services to apprise individuals of their rights and their right to receive health care, as well as to prepare health care proxies, power of attorney documents, living wills and other legal papers;

D. Mandate confidentiality for people with HIV infection, including but not limited to health care, employment, housing and child custody issues;

E. Urge revocation of Social Security Administration ruling that imposes a functional test that omits debilitating but not totally disabling gynecological complications. This test also makes it more difficult for lower income persons to qualify for disability benefits;

F. Sensitize the Family Court system and social service agencies to the medical issues of HIV/AIDS so personnel can better support those living with HIV/AIDS;

G. Define appropriate foster placement for children with HIV/AIDS and provide support for the other foster children within the setting to minimize the trauma of terminal illness;

H. Encourage fathers to acknowledge paternity, so children can receive financial benefits if either parent dies.

APPENDIX A

PENINSULA PLAN

From " Community-Based Plan for Treating Human Immunodeficiency Virus-Infected Individuals Sponsored by Local Medical Societies and an Acquired Immunodeficiency Syndrome Service Organization" by Stephen L. Green, MD, Patrick G. Haggerty, MD, Donna Dittman Hale, MHA, Arch Intern Med, Vol 151, 00., 1991, 2061

Individuals infected with human immunodeficiency virus frequently experience difficulty finding medical care from private physicians. Fear of occupational exposure, prejudice, lack of knowledge, and financial loss have all been cited as reasons for the reluctance of primary care physicians to accept patients with acquired immunodeficiency syndrome into their practices. To meet the medical needs of all patients infected with human immunodeficiency virus, this Virginia community adopted a voluntary rotational referral plan to provide primary care for all such individuals. The program required the cooperation of a voluntary pool of internists and family practitioners and an acquired immunodeficiency syndrome service organization with a volunteer physician advisor to coordinate referrals of unassigned patients. No physician received more than three referrals per year. During the two years of operation, 118 referrals were made to thirty physicians. Regular educational seminars were provided with medical updates and consultation support was provided. This locally based program appears to be meeting the acquired immunodeficiency syndrome challenge in this community and may have applicability to other communities as well.

APPENDIX B

PRESENT ON PANELS

Harriet Cornell	Presiding Rockland County Legislator
Greg Anderson	President, Nyack Hospital
Eve Borzon	Vice President, Patient Service, Nyack Hospital
Peter Brante, Jr.	Public Defender
Dr. Paul Bubner	President, Alliance Theological Seminary
Richard Caunitz	Rockland County Legislator
Edward Clark	Rockland County Legislator
Sam Colman	Assemblyman, New York State
George Giacobbe	Commissioner of Hospitals, Rockland County
Stanley Goldstein	Commissioner, Department of Mental Health, Rockland County
Kenneth Gribetz	District Attorney, Rockland County
Alex Gromack	Assemblyman, New York State
Joseph Holland	Senator, New York State
Dr. Frank Medici	Former President, Nyack Hospital
Brian Miele	Rockland County Legislator
Robert Olley	Executive Director, TOUCH
Donna Pauldine	Director of Young Adult Center, Rockland County Department of Mental Health, Co-Chair Women and AIDS SubCommittee
Sister Joan Regan	President, Good Samaritan Hospital
Alison Rennie	Public Educator, HIV/AIDS, Rockland County Co-chair Women and AIDS Subcommittee

APPENDIX C

Professionals Who Testified

William E. Arnold	AIDS Related Community Services, (ARCS) Coordinator of Outreach & Community Development
Daisy Balatocan	Legal Aid Society of Rockland County
Eve Borzon	Vice President, Patient Services, Nyack Hospital
Barbara Braun	Registered Nurse
Shane Bruce	Counselor, Rockland Council on Alcoholism
Sister Marie Buckley	Nursing Instructor, RCC
Annie O'Connor Colwell	RN Clinic Director, Rockland County Methadone Maintenance Treatment Program
Linda Christopher	President, Rockland County Women's Bar Association
Marge Davitt	Rockland County Department of Mental Health, Alcohol & Substance Abuse Services
Taylor P. Dickenson, MD	Infectious Diseases Specialist
Nora Dobbins	Registered Nurse, Rockland County Department of Mental Health, Alcohol and Substance Services
Renne Ferrier	Hudson Valley Title 2 Administrator
Sandy Gitlin	Center Director, Planned Parenthood, Rockland County
Carlla Horton	Deputy Executive Director, Rockland Community Action Council
John Hartigan	Attorney, Coalition of Concerned Clergy & Parents
Kayeton Karowski	Orange County Clinic, Rockland Department of Mental Health, Private Practice
Jane Kerns	Counselor, Rockland Council on Alcoholism
Jerry Klein	FAMILYA, Families of Mentally Ill Young Adults
Beth Koppel	Nurse
Joseph Lanzone	C.S.W., Town of Ramapo Youth Service, Rockland County AIDS Task Force
Dr. Steven Levy	
Helen Lipovsky	Rockland Coordinator, Planned Parenthood, Westchester/Rockland

Mary Luango	Nurse
Judith Merone	ARCS HIV/AIDS Counselor
Robert Olley	Executive Director, TOUCH
Adrienne Orbach	Facilitator, Women's Group
Donna Pauldine	Director, Young Adult Center, Co-chair Women and AIDS SubCommittee
Marianne Pinnel	Nurse, Alcoholism Counselor
Douglas Puder, MD	Director of Pediatrics, Nyack Hospital
Dr. Stanley Ralph	Assistant Dean of Instruction & Community Services RCC
Linda Reisser	Assistant Dean of Instruction, RCC
Alison Rennie	Public Educator, Rockland County Department of Health, Co-chair Women and AIDS SubCommittee
Barry Rosen, MD	
Ellen Sabi	Director of Program Development, Good Council
Clifford Schneider	Former Executive Director, Cornell Cooperative Extension
Paul Seldin	Teacher of Bioethics, Dominican College
Carrie Steindorff	Former Coordinator of "Talking with Kids about AIDS" Cornell Cooperative Extension
Amy Stern	Executive Director, United Hospice of Rockland County
Paul Stolz	Social Worker, HIV Counselor FDR VA, Montrose Medical Center
Scott Sullam	Case Manager, Department of Health
Gillan Swatilla	Westchester Department of Health
Dr. Marvin Thalenberg	Commissioner, Rockland County Department of Health
Jacqueline Williams	Nurse, Planned Parenthood
Susan Witte	Director of Planning & Evaluation, AIDS Related Community Services (ARCS)
Ronnie Zevon	Nurse, Coordinator Health Services, RCC