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Communications Meeting 3/24/94

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Steve -

can you figure out
who should get >

Thank you from this
trip? —

Town Meeting Panel Members:

MODERATOR

Don Noel—Political Columnist for *The Hartford Courant*

PANELISTS

Susan Addiss—Commissioner of Health and Addictive Services

Elsie Cofield—Founder AIDS Interfaith, New Haven, CT

Joseph D. Courtney—Co-Chairman Public Health Committee -
CT General Assembly, Hartford, CT

Harlan Dalton, Esq.—Former Member President's National AIDS
Commission; Law Professor, Yale University; Member of
Mayors AIDS Task Force, New Haven, CT

Kristine Gebbie, R.N., M.N., F.A.A.N.—President's National AIDS Coordinator

Shelly Geballe, Esq.—Currently a doctoral student in the Yale School
of Epidemiology-served as Deputy Director of the Civil Liberties
Union

Andrea Germano—AIDS Advocate

Janice Griendel, Ph.D.—Vice President Rabbit Ears Production -
served as Deputy Commissioner in the Connecticut
Departments of Children and Youth Services, Mental
Retardation, and Health Services

Stuart Lane—AIDS Advocate

Alvin Novick, Ph.D.—Professor of Biology, Yale University; Founder
Medical Expertise Retention Program; Co-Founder AIDS
Project New Haven

Donald Pogue, Esq.—Chairman of The Connecticut Hospital and
Health Care Commission

Diane Randall—Executive Director, Connecticut AIDS Residence
Coalition

Rev. Richard Schuster—Executive Director, St. Luke's Community
Services—responsible for operation of McKinney Houses

The Honorable Christopher Shays—4th Congressional District

A TOWN MEETING:

New Visions New Voices

The Health Care Reform Bill and Its Impact on Persons with AIDS

Saint Joseph College
West Hartford, CT
The O'Connell Center
Monday, April 4, 1994
12:30—3:00 p.m.

Co-sponsored by:
The Stewart B. McKinney Foundation
The CT Nurses' Foundation
Saint Joseph College

Kristine M. Gebbie, R.N., M.N., F.A.A.N., is President Clinton's National AIDS Policy Coordinator, and she currently is working to develop the Administration's AIDS Policy. Prior to her appointment, Ms. Gebbie served as Secretary of the Department of Health for the state of Washington.

She has a lengthy career history in the health field and public policy. She has served as a public health official in the state of Oregon, and was a past coordinator of ambulatory care for St. Louis University Hospital. Ms. Gebbie also taught health courses at the University of Washington, the Oregon Health Sciences University in Portland, and St. Louis University.

The Stewart B. McKinney Foundation was established in May 1987 by Lucie C. McKinney, widow of Stewart B. McKinney, a nine-term congressman from Connecticut. Mrs. McKinney's overall goal was simple and straightforward—to carry on her husband's legacy of caring for the disadvantaged among us. The McKinney Homeless Act, which Congressman McKinney co-authored and instituted is one example of his compassion and vision. To follow Stewart's commitment to "the quality of life," Mrs. McKinney's priority became housing; specifically the establishment of residences for homeless people with AIDS (P.W.A.s).

The Foundation's primary role is to fund existing service organizations who are establishing residential programs for homeless P.W.A.s. The Foundation, in collaboration with St. Luke's Community Services, has opened a residence for Walker Clinic in Washington D.C., the Stewart B. McKinney Family Home was dedicated in that city.

Grants have been given to fund residential programs for IV drug users with HIV disease and alliances have been made with other AIDS organizations across Connecticut (Connecticut AIDS Residential Coalition).

Town Meeting Program:

The Health Care Reform Bill and its impact on persons with AIDS

Part I: 12:30 p.m.—1:50 p.m.

Welcome: Winifred E. Coleman,
President, Saint Joseph College

Town Meeting

Moderator: Mr. Don Noel, *Hartford Courant*

Introduction of Kristine Gebbie: Lt. Governor Eunice Groark

Keynote Address: Kristine Gebbie

Panel Exchange with Ms. Gebbie

Intermission: 1:50—2:00 p.m.

Part II: 2:00 p.m.—3:00 p.m.

Audience Exchange with Ms. Gebbie and Panelists

Wrap Up and Summary by Rev. Richard Schuster

Town Meeting Concludes

SILENT VOICES

Orphans of AIDS: An Emerging Human and Policy Problem

The Connecticut AIDS orphan project is a three part initiative to educate the general public, parents, professionals and policy makers about the increasing number of children being orphaned in this country and the world as the result of HIV/AIDS. It is viewed as a fundamental means of supporting The AIDS Orphan Project, under the national direction of Carol Levine and funded by the MacArthur Foundation.

The Beginnings. The AIDS orphan project in Connecticut began during the early fall of 1993, as Janice Gruendel, Ph.D. (Vice President of Rabbit Ears Productions and former State of Connecticut Deputy Commissioner) and Shelley Geballe, Esq. (Yale University School of Epidemiology and Public Health and former Deputy Director of the Connecticut Civil Liberties Union) secured \$50,000 from the San Francisco and Stewart McKinney Foundations to begin a documentary on children being orphaned by AIDS in the United States. Research on this population had convinced Gruendel and Geballe that this growing group of children in the United States and the world required the attention and support of policy makers, professionals and the general public. While numbers within the United States are now estimated to reach 125,000+ (a significant number by any standard), worldwide AIDS orphans will exceed 10 million by the end of this decade. Importantly, with the exception of The Orphan Project in New York City, there has been scant national attention to the needs of these children. Most work on AIDS continues to focus on treatment for *infected* adults and children and on prevention.

The Film Documentary. Also convinced that the stories and the voices of this silent population needed to come to the general public, Connecticut Public Television (CPTV) matched the foundation grants, and the Public Broadcast System documentary was born. Ron Gould, Emmy winning CPTV producer, joined the project as director. Production began with an initial taping of some 30 AIDS parents with uninfected children, grandparents in the family and the professionals who serve them. That these families would participate at all reflects enormous courage, because the stigma which surrounds this disease remains at an extraordinarily high level in this country. Personal and family silence and trauma are still the hallmarks of an AIDS diagnosis, but stories of courage and resilience are there to be told.

The second phase of production involves narrowing the group to three to four families who will allow us film access more deeply into their lives. We are working to be able to include the faces and voices of a number of children orphaned by AIDS, though this is a delicate and difficult challenge. Our broadcast target is sometime during the month of January 1995.

The Book. During the early phases of research on this issue, it became quite evident that there was more information to present than could be included in a 30 minute film and that there were several audiences for this effort. The film is directed at the general public and its goal is to humanize the disease and provide an emotional connection between the general public and these affected

children. However, significant information needs to be available to parents, professionals and policy makers as well.

Dr. Warren Andiman, nationally recognized AIDS pediatrician and Yale faculty member, joined the effort later in the fall of 1993, and a book was outlined and presented to Yale University Press. In January, 1994, Yale Press accepted the proposal. The book will be edited by Andiman, Geballe and Gruendel. Entitled *Silent Voices: Children in Families with AIDS*, the work presents current knowledge and thinking on the medical, developmental, psychological, spiritual and legal aspects of *surviving AIDS* for children whose biological and extended families are dying of the disease. The book also suggests policy and research issues inherent in building effective child and family support systems for this population within the United States, and projects economic implications of an emerging world population of orphans.

Target publication for the book is January 1995. While a limited hard cover version will be published, the book will be predominantly available as a lower cost, soft-cover product. The book and video will be marketed together, based on a multi-media strategy for disseminating information and influencing public policy on this issue.

Radio. Review of early film footage confirmed the power of the stories being told by AIDS infected parents who have uninfected children, and suggested a third element in this multi-media project. While the film is intended for broadcast nationally and will then be available to organizations and individuals at little or no cost, radio provides a more interactive capacity for storytelling and linkages within each community. Also, there is compelling footage from several families who do not wish to be presented visually on television but who have agreed to allow their voices to be broadcast on radio.

The radio component will be based upon production of a series of 3 to 5 minute audio clips in which infected parents and uninfected children talk about living with AIDS. The topical selections will be representative of the issues facing these families. The clips themselves will be drawn both from the film footage and from follow-up conversations. The stories of parents and children will be drawn from natural conversations; they will not be scripted.

The proposed format is for local radio stations to host a "talk show" hour on the topic of children orphaned by AIDS, invite local professionals involved in planning and delivering services, and utilize a selection of real stories from the audio product. In this way, the discussions can be based on real stories without having to locate and identify families with AIDS but can include local service individuals and organizations. In this way, members of local communities can learn about the challenges these children face and can follow up through local resources.

The radio component of this initiative will be developed over the summer of 1994 with the assistance of the national public radio system professionals. Target for broadcast is January-February, 1995.

Distribution. A significant goal of this initiative from the outset has been to reach a broad audience with several levels of information presented in a coordinated way across the print, visual and aural media. To this end, foundation and corporate sponsorship is being sought to underwrite the cost of making the book-video product available to community organizations nationally and making the audio product available to radio stations throughout the country. Additionally, Andiman, Geballe and Gruendel are directing that royalties on the book be used to purchase

additional books for distribution to policy makers and organizations nationally and in each of the 50 states.

Children's Art. An essential element of the initiative involves a search for the "voice of AIDS affected children." While the project can "give voice" to some of these children through their participation in the film or radio footage, the number of children who can and will participate in this way will be quite small. Children's art is another important form of expression. The initiative seeks to identify the words, stories, pictures, poems and songs of children living in families with AIDS as a means of giving voice to this silent population at a much broader level. Permission will be sought to include some of this art in the book. It is our hope that, if enough items can be identified and borrowed, a national traveling exposition can be created.

For further information: Contact: Warren Andiman, M.D.	203-785-4762 (phone) 203-785-7194 (fax)
Shelley Geballe, J.D.	203-481-4923 (phone) 203-483-6153 (fax)
Janice M. Gruendel, Ph.D.	203-857-3760 (phone) 203-857-3777 (fax)
Ron Gould	203-278-5310 (phone) 203-278-2157 (fax)
Barbara Colley Coordinator for Children's Art	203-481-4339 (phone)
Carol Levine	212-925-5290 (phone) 212-925-5675 (fax)

March 1994

SOME QUESTIONS FOR KRISTINE

- 1) Quite simply, why have the Recommendations of the National Commission on AIDS been ignored by this administration? (and) Why have not all the recommendations been implemented?
- 2) The World Health Organization has recently been reporting the deepening of the AIDS crisis worldwide. As a world leader, how does the administration see the United States responsibility to tackle this global pandemic? (and) What initiatives do you foresee to advance the international efforts on AIDS?
- 3) Recently your office intervened in an issue of local interest. In the Microgenesys issue the prevailing decision was for basic research. How does your office intend to further the basic research agenda? (and) How do we stop the drugs-for-profit incentive in AIDS research?
- 4) Last month, at Brooklyn College in New York, President Clinton responded to a question about the AIDS CURE ACT, formerly known as the McClintock Project, by saying he's never heard of, nor seen, the project. Your office has been kept abreast of the project for the past year, with a member of your staff attending a strategy session of the AIDS CURE ACT in January. Are you telling the President what's going on out here, or is he lying? Do you indeed have the ear of the White House, or are you acting as a buffer?
- 5) The Office of AIDS Research, a recent re-organization of NIH AIDS efforts, has been criticized as being yet another level of bureaucracy in an already flawed system. What real changes do you see the new structure facilitating?
- 6) Under the Clinton Healthcare Plan the choice of providers is limited, with the real possibility a PWA could end up having a homophobic or AIDSphobic primary physician as a gatekeeper. How will you insure access to healthcare without regard to sexual orientation or HIV status? How will the plan standardize AIDS treatment accessibility nationwide?
- 7) You are on record as being against the idea of a 'Manhattan Project' on AIDS. Now that the AIDS CURE ACT is pending federal legislation, do you see your role changing? As co-sponsorship for the bill mounts, will you continue to try and repress the concept, or will you proactively pursue it?
- 8) Last World AIDS Day, you and Donna DoNothing announced a new task force on AIDS drug development, despite the fact there currently seems to be no drugs "in the pipeline" to develop. Has this task force met yet? (and) What have they done?

MOST IMPORTANTLY, question what Gebbie is saying here today. Is the agenda being set forth effecting the AIDS crisis? How is healthcare reform going to manage the crisis? By changing our healthcare delivering system are we lessening the crisis of AIDS?

AIDS. It's not just a disease.
It's an industry.





'GO HOME GEBBIE' and tell the president we're pissed. Tell him we want more than hitting the stump for healthcare out of our AIDS Czar. Tell him we want the promised changes. Tell the president you and he are not welcome here, not until progress is made. **'GO HOME GEBBIE' and Put the crisis back into AIDS.**

FOR MORE INFORMATION CALL 732 2229 or 224 7428 ACT UP FIGHT BACK FIGHT AIDS

THE WHITE HOUSE
WASHINGTON

January 6, 1994

Gary Smith, Executive Director
Stewart McKinney Foundation
P.O. Box 338
Fairfield, CT 06430

Dear Mr. Smith:

This letter confirms the visit of Kristine M. Gebbie, National AIDS Policy Coordinator, at the Stewart McKinney Foundation luncheon, on Monday, April 4, 1994.

Ms. Gebbie plans to arrive at 11:30 a.m. to deliver a keynote address, and participate in the subsequent panel discussion. Please call me as soon as possible with the title of the panel and theme of the lunch, so Ms. Gebbie can organize her comments.

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

Enclosure

THE WHITE HOUSE
WASHINGTON

March 10, 1994

Debra Smith
Connecticut Nursing Foundation
292 Woodfield Crossing
Glastonbury, CT 06033

Dear Ms. Smith:

This letter confirms the appearance of Kristine M. Gebbie, National AIDS Policy Coordinator, at the benefit dinner for the Stewart McKinney Foundation co-sponsored by the Connecticut Nursing Foundation, on April 4, 1994.

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

Join us
for a
conversation
with
**Kristine
Gebbie**_{RN, MN,}

National AIDS
Policy Coordinator

**Monday,
April 4, 1994**

**Town Meeting
Saint Joseph College
O'Connell Center
West Hartford, CT
12:30 - 3 p.m.**

**Benefit Dinner
Aqua Turf Club
Plantsville, CT
7 p.m.**

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CT. Nurses' Foundation
377 Research Parkway, Suite 2D
Meriden, CT 06450

Bulk Rate
US Postage
PAID
Permit No. 152
Meriden, CT 06450



**Put
in your
two
cents
!**

Sponsored by
The Connecticut Nurses' Foundation &
The Stewart B. McKinney Foundation

If you have something to say about AIDS prevention and care or would simply like to hear Ms. Gebbie's ideas on the subject, don't miss this unique opportunity. Not only will you gain insights into current AIDS policy, but you'll be a part of the process that shapes future policy. In case you need an added incentive to attend, event proceeds are targeted to extending the education of professionals who work with AIDS patients as well as the care of people with AIDS.

**Come and put in your two cents.
It'll be worth every cent.**



Please respond by March 29.

For further information, please call 232-3882.

Sponsored by

The Connecticut Nurses' Foundation, which is dedicated to the promotion of nursing education and research, and The Stewart B. McKinney Foundation, which is dedicated to caring for patients with AIDS.

Together they are sponsoring the Benefit Dinner plus a FREE Town Meeting earlier on the same day at Saint Joseph College.

Town Meeting Agenda

Topic:
The Health Care Reform Bill & its impact on persons with AIDS

**Saint Joseph College
O'Connell Center
West Hartford, CT
12:30 - 3 p.m.**

Moderator:
Governor Lowell Weicker

Keynote Speaker:
Kristine Gebbie, RN, MN,
National AIDS Policy
Coordinator

Open Discussion Panel Members:

Shelly Gabelle, Esq
Janice Grundel, PhD
Dr. Alvin Novick, PhD
Diane Randall, Exec. Dir.,
AIDS Coalition
Rev. Richard Schuster, Exec. Dir.
St. Luke's Community Service
Hon. Christopher Shays,
Congressman, 4th District

Directions to Saint Joseph College:

I-84 East or West to exit 43. At stop light at end of ramp, turn right, get into left lane, turn left onto Trout Brook Drive. At 4th stop light turn right onto Asylum Street, 1st left into campus.

Directions to Aqua Turf Club:

I-84 East to exit 27 which is 691 connector, to exit 3. Turn left off exit onto Route 10. Proceed straight approximately 3 miles. Turn right at stop light onto Mulberry Street.

I-84 West to exit 29. Turn left at end of exit and then take first right onto Mulberry Street.

Benefit Agenda

**Aqua Turf Club
Plantsville**

6 p.m.
Exclusive Sponsor's
Cocktail Reception with
Ms. Gebbie

7 p.m.
Dinner

8 p.m.
Remarks by
Ms. Gebbie

8:45 p.m.
Q&A moderated
by selected health care
professionals

Yes, I want to put in my two cents.

Monday, April 4, 1994

☐ **Town Meeting, Free**
Saint Joseph College
West Hartford, CT

☐ **Benefit Dinner**
Aqua Turf Club,
Plantsville, CT

Please indicate preferred level of support:

- **\$750 Corporate Table**
Cocktail and dinner admittance for 8
& event program acknowledgement
- **\$250 Event Sponsor**
Cocktail and dinner admittance for 2
& event program acknowledgement
- **\$100 Individual Sponsor**
Dinner admittance for one
& event program acknowledgement
- **\$75 Attendee**
Dinner admittance for one
- **\$ * Supporter**
Event program acknowledgement

*If you are unable to attend, but would like to make a contribution, please indicate amount of your tax deductible donation.

Corporate/Individual Sponsor

Name _____

Address _____

Phone _____

Corporate Attendees Names:

Respond by March 29 to:
CT. Nurses' Foundation
377 Research Parkway
Suite 2D
Meriden, CT 06450

Make checks payable to:
Connecticut Nurses' Foundation

THE WHITE HOUSE
WASHINGTON

Comments of
Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator
before the

Healing AIDS: HIV Primary Care Conference
University of Michigan
Ann Arbor, Michigan
December 2, 1993

HIV Primary Care in the Clinton Health Care Reform Era

Objectives

To review the principles of the Clinton health reform plan

To identify the primary care needs of HIV infected individuals

To discuss the issues in moving toward a reformed system without putting HIV infected individuals at a disadvantage

Discussion

I. Health reform basic principles

- choice*
1. security
 2. simplicity
 3. savings
 4. quality
 5. responsibility

*Private insurance
Choice of Dr
Outlaw abuses
Preserve Medicare
Guaranteed Benefits (2) work*

II. Health reform benefit package

1. primary care
2. diagnostics
3. prescription drugs
4. home care
5. mental health & substance abuse
6. public health system improvement
7. infrastructure development
8. targeted projects

III. Care needs of HIV infected persons

1. get coverage
 - a. comprehensive benefits package
 1. drugs
 2. home care
 3. substance abuse prescriptions
 4. choice
2. equitable continuous coverage
 - a. ~~lifetime limit~~ *out of pocket*
 - b. not treatment specific
 - c. no cancellation
3. early diagnosis
4. planned care *overlpc managed care*
5. appropriate specialty referrals & support
6. participation in research trials
7. supportive services *Ryan White*
8. getting from here to there
 - a. defining outcomes and quality control
 - b. chronic disease
 - c. data management and access
 - d. confidentiality

*essential
providers -*

- IV. Currently insured--plan development and selection
- V. Currently uninsured--finding and enrolling them
- VI. *Building systems of care*
Role of essential providers
 - A. risk adjustment for providers
- VII. Role of Ryan White funding

ST. Joseph College - April 4, 1994
TOWN MEETING
THE HEALTH CARE REFORM BILL AND ITS
IMPACT ON PERSONS WITH AIDS

Workshop - HIV Disease/Healthcare Reform

Conducted by Invitation

Tim Sweeney, AIDS Action Council, Washington. D.C.

9:00 am - 11:15 am

LUNCHEON - Ms. Gebbie, Panelists, Workshop attendees

By Invitation

11:30 am - 12:20 pm

TOWN MEETING BEGINS

Moderator: Mr. Don Noel Hartford Courant

Extends welcome to all, introduces Lt. Governor Groack

12:30 pm - 12:35 pm
(5 minutes)

Lt. Governor Groack introduces Kristine Gebbie

Ms. Gebbie Keynote Address

12:35 pm - 1:00 pm
(25 minutes)

Mr. Noel introduces Mr. Harlon Dalton

(Miss Gebbie joins panel)

1:00 pm - 1:10 pm
(10 minutes)

Mr. Noel poses questions to Ms. Gebbie submitted
in advance by panelists, then opens exchange between
panelists and Ms. Gebbie

1:10 pm - 1:50 pm
(40 minutes)

BREAK

1:50 pm - 2:00 pm
(10 minutes)

Ms. Gebbie, panelists return

Mr. Noel begins second half of Town Meeting

Inviting questions from the audience to respective panelists

2:00 pm - 2:45 pm
(45 minutes)

WRAP - UP

Mr. Noel introduces Rev. Richard Schuster to summarize
Town Meeting

2:45 pm - 3:00 pm
(15 minutes)

TOWN MEETING CONCLUDES

There are no speeches by each panelist, all information flows from questions and responses conducted by the moderator.

MODERATOR

Don Noel
Hartford Courant

PANELISTS

Commissioner Susan Addiss

Elsie Cofield,
Joseph Courtney,
Harlan Dalton,
Kristine Gebbie
Shelley Geballe,
Andrea Germano,
Janice Gruendel,
Dr. Alvin Novick,
Donald Pogue,
Diane Randall,
Richard Schuster,
Christopher Shays,

MODERATOR

Don Noel - Political Columnist for The Hartford Courant since October 1984.

PANELISTS

Susan Addiss - Commissioner of Health and Addictive Services

Elsie Cofield - Founder AIDS Interfaith, New Haven, CT

Joseph D. Courtney - Co-Chairman Public Health Committee - CT General Assembly, Hartford, CT

Harlan Dalton, Esq. - Former Member Presidents National AIDS Commission; Law Professor Yale University; Member of Mayors AIDS Task Force, New Haven, CT.

Kristine Gebbie - Presidents National AIDS Coordinator

Shelly Geballe, Esq. - Currently a doctoral student in the Yale School of Epidemiology - served as Deputy Director of the Civil Liberties Union

Andrea Germano - AIDS Advocate

Janice Gruendel, Ph.D - Vice President Rabbit Ears Production - served as Deputy Commissioner in the Connecticut departments of Children and Youth Services; Mental Retardation; and Health Services

Dr. Alvin Novick - Professor of Biology, Yale University; Founder Medical Expertise Retention Program; Co-Founder AIDS Project New Haven

Donald Pogue, Esq. - Chairman of The Connecticut Hospital and Healthcare Commission

Diane Randall - Executive Director Connecticut AIDS Residence Coalition

Rev. Richard Schuster - Executive Director St. Luke's Community Services - responsible for operation of McKinney Houses

The Honorable Christopher Shays - 4th Congressional District

Daltone
Separate finance

delivery
who is payer / who pays -
care

Velder / Charter
Medicare / Zephyr

Cisneros / HUD conf

1) What will happen to existing cadre of service managers
will they be folded in?
how will fold in happen?
how to package?

? Son credentialing

Ryan White - what will be covered by plan?

Clarity on role / how developed?
inside / outside
relationship.

Interreligious Care Access -

NGO Cutbacks in AIDS services

1) isolated case? vs 2) typical cutbacks
3) what is

Alt Rx?

Care when they can't?

HUD reorg - AIDS not regained ✓

Children affected - mphaus -

AIR BRIDGE?
Hartford tie?

Sub. abuse - MH -
how to incorporate?
"user friendly services"

move to chronic illness model -

Adolescents / AIDS

Bufford -

Action Agenda



1678 Asylum Avenue
West Hartford, Connecticut 06117 (203) 232-4571

*Put in my
file -*

March 10, 1994



Ms. Kristine Gebbie, RN, MN
National AIDS Policy Coordinator
Office of National AIDS Policy Coordination
Executive Office of President
Washington, D.C. 20500

Dear Ms. Gebbie:

I am a social work professor at Saint Joseph College, where you will be speaking at a town meeting on April 4th. I am pleased that you will be here to dialogue with the Connecticut community on AIDS policy issues.

I have enclosed a copy of a paper I co-wrote which has recently been submitted to a professional journal. The paper describes the development of our Certificate Program in the Study of HIV Disease/AIDS. I believe colleges and universities have an obligation to provide education, research, and training on HIV in order to adequately prepare students to enter the workforce, especially those in professional programs such as nursing, social work and teaching.

We hope the program description will give you a feel for one of the ways our small college has responded to the AIDS crisis. I look forward to meeting you when you visit.

Sincerely,

Robert G. Madden, CISW, J.D.
Associate Professor
Social Work Department

RGM/wh
Enclosure

**THE DEVELOPMENT AND IMPLEMENTATION
OF A CERTIFICATE PROGRAM
IN THE STUDY OF HIV DISEASE/AIDS**

Paper Submitted to
Journal of College Teaching
January, 1994

Beverly Spence, Coordinator Weekend College (1992-93)
Robert Madden, Associate Professor of Social Work
St. Joseph College, West Hartford, Conn.

**THE DEVELOPMENT AND IMPLEMENTATION
OF A CERTIFICATE PROGRAM
IN THE STUDY OF HIV DISEASE/AIDS**

Just a few years ago the word "aids" meant persons or things that yield assistance (Webster, 1965). Today that word carries as many emotional associations as cognitive. We know AIDS not only as the name of a chronic and eventually fatal disease (acquired immune deficiency syndrome), but as a term laden with values and judgments. With the explosion of AIDS-related knowledge and research in every field from biochemistry to poetry, colleges and universities are exploring a variety of ways to transmit that knowledge and to respond to a world-wide crisis. Ironically, it is now the original definition of aids that society requires to deal with the AIDS we have come to know.

Higher education is faced with a dual responsibility of meeting the needs of local and global communities and preparing individuals for successful professional lives. We can no longer claim that students have a sufficient base of knowledge and skills to practice in the professions without familiarity with the issues related to HIV disease/AIDS. In addition, colleges and universities have a responsibility to their communities to meet evolving needs for academic study, research and training. As the institution given the role of researching, compiling, processing and communicating ideas and information, colleges are called to respond to our communities' need for education on HIV disease/AIDS.

PROGRAM DEVELOPMENT

It is within this context that Saint Joseph College- a small, Catholic, women's college- developed its Certificate Program in the Study of HIV Disease/AIDS. The idea for the Certificate

Program germinated in a group meeting under the auspices of the McKinney Foundation, a Connecticut-based organization founded by the wife of Congressman Stuart McKinney who died of AIDS-related illnesses. The foundation representatives hoped to spark interest among colleges in developing courses related to HIV disease/AIDS. As a result, several interested faculty members from diverse academic departments met to research what might be done at Saint Joseph College.

We began by considering options for program design. The alternatives were to develop a comprehensive, multidisciplinary program of study; to foster the development of elective courses on AIDS, such as an individual department might offer (Campbell, 1992); to assist faculty in the development of modules on AIDS that could be incorporated into existing courses (Lloyd, 1991); or to improve our general educational efforts on campus to provide students, faculty and staff with information about AIDS (Keeling, 1993; Nevid and Gotfried, 1993). Our deliberations were shaped by examining the mission of the college and possible target populations.

The mission of Saint Joseph College includes the tradition of service to the neediest in society, which reflects the mission of its founding order, the Sisters of Mercy. The establishment of a visible entity that would respond to unmet needs of an underserved population was supported by this mission. The goals of the faculty group were to provide AIDS-specific information to our students, enabling them to be more knowledgeable and effective as they graduate to practice their professions; and to provide academic study for those already working with HIV-positive persons. Also, we hoped to serve not only those people with a personal involvement such as persons with AIDS or caregivers, but anyone interested in learning more about the topic.

After some debate, our choice was to create an undergraduate certificate program. We felt that placing the program on a graduate level would limit the population able to access the courses,

while offering it through continuing education (trainings/workshops) would limit the depth of the offerings. All the courses were designed at a basic level so there would be no prerequisites. This was done to encourage students to take courses outside their area of study, thus broadening their knowledge base and supporting interdisciplinary understanding. Courses were scheduled evenings and weekends to maximize opportunities for working students to participate. Offering the program as a Certificate allowed students completing the program to obtain credentials, and represented a clear statement of the college's commitment to the Program.

PROGRAM IMPLEMENTATION

The original faculty group began by recruiting additional members, incorporating faculty from other professional programs (nursing and nutrition). We then surveyed every department on campus to solicit interest in developing courses related to HIV disease/AIDS. We gave departments the option of choosing the content and number of credits for their courses. We decided departments should be responsible for hiring faculty (some adjunct, some full-time) and monitoring course syllabi for quality assurance.

Perhaps the key issue in program development was the control given to the faculty to design a program that would meet the needs of the community, while not being excessively burdensome to administer. All participation, from steering committee to course development to teaching, was on a voluntary basis. Many faculty have used this program as an impetus for professional development, attending workshops and reading AIDS-related materials. Unlike many initiatives which drain resources from faculty who already feel overwhelmed, this program seems to have energized many of its contributors. Also, the program requires few additional college resources, so it is fiscally responsible in a time of financial retrenchment for most institutions.

PROGRAM DESCRIPTION

The Saint Joseph College

Certificate Program in HIV

Disease/AIDS requires the

completion of eighteen credit

hours of courses from an

interdisciplinary agenda.

Students have seventeen courses

available to them, with most

carrying one or two hours of

credit. The only required

courses are the Introduction to

the Study of AIDS and the

Integrating Seminar. The

introductory course, which uses an interdisciplinary approach, is designed to provide a basic

understanding of HIV disease and an overview of major issues in the field. The Integrating

Seminar, which is taken near the end of the program, provides opportunities for students to

integrate content across the curriculum and focuses on implications for practice, skills for

continued learning, and future direction in AIDS education, policy and treatment. The complete

roster of courses is listed in table 1.

Table 1

CERTIFICATE COURSES

Introduction to the Study of AIDS

AIDS and Social Work Practice

AIDS in Social Context

Basic Nursing Care for People with AIDS/HIV

The Biology of AIDS

Counseling and HIV Disease

Current Developments in the Pharmacology of AIDS

HIV Disease: Special Implications for Children

HIV Infection / AIDS: A Professional Nursing Perspective
Internship

Legal Issues and AIDS

Nutrition of AIDS

Plagues in Human History: From the Black Death to AIDS

Religious and Ethical Issues of AIDS

Representation of AIDS in Contemporary Culture

Adult Populations at Risk (IV Drug Users, Women, etc.)

Integrating Seminar

PROGRAM ADMINISTRATION

Saint Joseph College consists of three major units: The Women's College, The Weekend College and the Graduate School. The Certificate Program is coordinated by the Weekend

College Office under the direction of the Academic Dean. Weekend College serves 400-600 students each semester and is designed for adult learners. It offers four degree programs (American Studies, Business Administration, Nursing and Social Work) and two certificates (Gerontology and HIV Disease/AIDS). While most courses are offered on alternate weekends and carry three credits, courses in the Aids Certificate Program are offered evenings and weekends and carry one or two credits. AIDS courses are offered fall , spring and summer as well as the Weekend College's Term Three (early summer).

The Weekend College office has responsibility for coordination of the program, but oversight functions are shared with faculty members who developed the program. Day to day coordination functions are handled by the program coordinator, who is a half-time faculty member and a half-time advisor/coordinator. The coordinator and the faculty meet on a regular basis as a program steering committee. An advisory council which includes community leaders and teaching faculty has also been formed to give direction to the program.

The Weekend College staff members perform the same services for participants in the AIDS program that they provide to Weekend College students. The administrative assistant responds to phone inquiries, sends materials, and sets up appointments. One marketing/recruiting/advising position has responsibility for developing a marketing plan, while the other is responsible for on-site visits to area businesses and agencies. All advisors are involved in recruiting students, since the advisement of prospective students plays a key role in their decision to enroll.

The advisors work as a cross-functional team with services for adult learners in Weekend College and the AIDS Program centralized in one location. Students come to the office for information, for advisement, for registration. Registration can also be done by phone in the Weekend College office, although new students must meet with an advisor first. In summary,

the strengths of the Weekend College's adult learner orientation have been used to enhance the implementation of the AIDS Program.

The coordinator of the Certificate Program has found that she spends an average of five hours per week on coordination activities for the program. In her role as coordinator, she acts in the following capacities: 1.) the advisor to whom telephone inquiries are referred; 2.) the advisor with whom the initial appointment is made; 3.) the respondent to inquiries from other colleges about the program; 4.) the representative of the College at meetings of the McKinney Foundations's AIDS Education Consortium, and the liaison with the Consortium's director; 5.) a member of the college's AIDS Steering Committee which meets regularly to plan and evaluate the program; 6.) the person who updates the informational brochure and oversees its mailing; 7.) the collector of data on the program including number of students enrolled and their progress; 8.) the overseer of course scheduling for each semester; 9.) the contact person for Saint Joseph College representation at AIDS education events; 10.) the writer of grant proposals; and 11.) the person who arranges internships for students.

ISSUES IN TEACHING

Several interesting issues in teaching in the certificate program have been identified through informal discussions with students and faculty, formal course evaluations, and a brief survey following the first year of the program (nine courses). The most challenging dilemma emerged from the mix of students in the classes. A mixture of traditional age and adult students having little practice experience, with professionals working in the field, many of whom also had advanced degrees, posed difficult classroom management issues. The pedagogical concern has been to provide an entry level of knowledge in each course, while making it challenging for students with experience. Strategies used by faculty to date include operating from an experiential learning

model using cases and exercises to access the readings; using the expertise present in the classroom by creating opportunities for peer instruction and oral presentations; and creating flexible, individually designed papers and projects allowing students to find a level that is challenging yet comfortable. However, each of these has the effect of requiring extensive time commitment from teaching faculty.

A second teaching issue has to do with the demands of keeping current. Although this is true for any course, the rate of change in the area of AIDS is remarkable. This seems, in part, due to the intense interest in the subject and the commitment to go public with each piece of information. In the early days of the disease, much was kept hidden or ignored and many researchers seem determined to reverse that trend. Books and articles used in a course may be outdated by the time the course is offered again, requiring constant revisions of syllabi. Since the AIDS Certificate is an interdisciplinary program, current research and findings must be identified in all relevant disciplines.

Most instructors have invited qualified people from the community to do presentations in class. These have included medical and social service professionals, attorneys, politicians, caregivers, and persons living with AIDS. There have also been field trips to AIDS service organizations and residence programs. Students have responded positively to these learning opportunities, particularly the perspectives of HIV-positive speakers. The role of the instructor is important in these class sessions. Faculty need to assign readings which provide academic and research background to the material presented and must provide opportunities to integrate the readings with perspectives of the presenters. Faculty must also solicit student feedback concerning assignments. Our students have expressed a strong preference for self-designed papers and projects with

application to their professional practice or area of interest, while rejecting evaluation strategies that required testing on specific content.

Related to this issue is the concern about how to handle emotional, personal and values-based material that is raised by the study of HIV disease. One cannot discuss AIDS without also discussing risk behaviors of sexuality and intravenous drug use. Also, many students in the courses have had personal or family experience with HIV disease. These disclosures raise two issues for teaching. First, faculty need to be prepared to establish guidelines regarding confidentiality and reinforce those throughout the course (Campbell, 1992). Second, the sharing of personal information, while important to the learning that occurs in this type of class, needs to be monitored.

Shulman has used the term "the hidden group in the classroom" to describe the potential learning that can occur through mutual aid processes. He warns, however, about the need for faculty to "maintain the educational contract" (1987). Disclosures may be an important part of learning, but there is always the danger that the class sessions can turn into group therapy sessions. Faculty in AIDS courses must be able to relate the disclosure to the course content and to retain control over the extent of the material being disclosed.

All of the teaching issues described above demand extra time, energy, and commitment from faculty. Despite the added responsibility, faculty have reported positive experiences in their courses. One faculty member commented, "It's great to be involved in a course where the students are even more interested and excited about the subject than I am". Another professor was so impressed by student projects that she developed a portfolio of their work to be made available to AIDS educators and the community. Faculty have confessed, however, that the teaching experience can be somewhat humbling since some material is learned with students as new

information arises. On the positive side, this has set up an atmosphere of co-learning, which has been a rewarding experience for both students and faculty.

CONCLUSION

As educators strategically plan for the future and examine the role of higher education in addressing national and global concerns, they must not ignore the AIDS epidemic. Institutions of all sizes have a responsibility not only to teach their students about preventative and remedial measures, but to educate them to teach and help others, and to respond to AIDS in their professional lives. A student in Saint Joseph College's HIV/AIDS Program, wrote the following: "From the suffering of heart, mind and soul may emerge a structure on which to focus on healing, not only the ills of the specific individual, but also the ills of our modern culture. The epidemic may lead us to confirm our mutual commitment to each other as individuals and members of the human race. We could use this crisis as a catalyst and model for our transformation. AIDS challenges our humanity and the very nature of our response may be the basis on which history will judge our generation" (Thomas, 1992). Colleges have an important role to play in this effort. At the very least, we should be teaching caring and compassion.

The program presented above has been effective for a particular institution at a particular time. The basic model of development may prove useful as a catalyst for other colleges and universities to begin the discussion of how they can assume a leadership role in the study of AIDS and its multiple effects on individuals, families and society. As more of our population feels the impact of AIDS, the need for research and education will, no doubt, mirror this increase. The time for program development has certainly arrived.

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