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ExOxEmis, Inc.

Corporate Offices
Stephens Building, Suite 1616
111 Center Street
Little Rock, Arkansas 72201
TEL : (501) 375-0940 ; FAX : (501) 375-4171

August 26, 1993

Ms. Kristine Gebbie
AIDS Policy Office
750 17th Street, N.W.
Suite 1060
Washington, D. C. 20201

Dear Ms. Gebbie:

I wanted to thank you again for taking time out from your busy schedule to meet with us last week. It was good to visit with you personally and bring you up to date on the status of our AIDS preventative.

As I indicated in our meeting, we feel that your support for our effort in the area of prevention is crucial. To date, most of the research has focused on a vaccine or cure for AIDS. In the meantime thousands of Americans are contracting this dreaded disease every month.

We plan to continue working with the White House in this effort and look forward to our next meeting with you.

Sincerely,

Jackson T. Stephens, Jr.

ExOxEmis, Inc.

Corporate Offices
One Union Plaza, Suite 1770
Little Rock, Arkansas 72201
TEL : (501) 375-0940 ; FAX : (501) 375-4171

August 11, 1993

Ms. Kristine Gebbie
AIDS Policy Office
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20201

Dear Ms. Gebbie:

I enjoyed visiting with you by phone last week and sincerely appreciate your arranging to meet with us on Monday, August 16, in your office. As we discussed, those attending that meeting will be myself, Mr. Jackson T. Stephens, Jr. and Dr. Nancy Alexander. Mr. Stephens is Chairman of ExOxEmis, Inc., the bio-medical company that has developed the AIDS preventative. Dr. Alexander is Chief of the Contraceptive Branch at the NIH and very familiar with the status of the research dealing with our product at the NIH.

Until your appointment as AIDS Czar, Carol Rasco has been serving as our contact with the Clinton administration. Carol and I have been friends for a number of years and she was familiar with our AIDS research prior to assuming her position in the White House. Additionally, Mr. Stephens and President Clinton have been personal friends for a number of years and the President monitored the progress of our AIDS research while he was still Governor of Arkansas.

We introduced our AIDS killing enzymes to the NIH and FDA under the Bush Administration. In short, our experience with the Bush appointees was disappointing in that we found no fast tracking review process for AIDS related research and a overall lack of enthusiasm in tackling the AIDS problem in general. Since January we have relayed these experiences to Carol Rasco and she has discussed the problems we've encountered with the President. We are extremely excited about your appointment because we understand from Carol that you will be in a position to direct all

efforts involving AIDS research and prevention. We are desperately in need of a "quarterback" in the area of AIDS research. In our meeting next Monday we will share with you the experiences we have had to date and outline our goals for the future. To that end, I am enclosing some material regarding our company and the success we have had to date. Hopefully you will have a chance to look over this before our meeting on Monday. At that time, we will be glad to answer any questions you might have.

Once again I want to congratulate you on your appointment. I look forward to working with you in the fight against this dreaded disease.

Sincerely,

Gary R. Faulkner
Vice President

ExOxEmis, Inc.

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Sincerely,

Gary R. Faulkner
Vice President

Note to Fauci, Kessler, Peter, Fleming

I met today with ~~Dr~~ Jackson Stephens & Gary Walker of GX Oxgenics inc, and Nancy Alexander of NICHD. I ~~believe~~ These men have met before with NIH and FDA officials about their potential product which would be a ~~female~~ controlled spermicide/viricide. Dr Alexander is currently testing some compound of the product through her research program.

There is some question of the process of moving the product along in the process. I indicated that I was available to answer questions or assist them if they hit snags, but that the ordinary process of product review should be workable for them. ~~NIH~~ to be followed.

I also indicated, since they seem inclined to think of lobbying steps, that they might align themselves with groups lobbying for women's health research, & research on women & AIDS.

I'm attaching a copy of their letter to me, for your information. Please call if you have questions.

KRISTINE M. GEBBIE, R.N., M.N., F.A.A.N.
NATIONAL AIDS POLICY COORDINATOR
DEPARTMENT OF HEALTH & HUMAN SERVICES
Room 729H Humphrey Building
200 Independence Ave., S.W.
Washington, D.C. 20201

DAY Monday DATE August 16, 1993

TIME 9:00 a.m. LOCATION 750 17th St., N.W.

SUBJECT Meeting with Stephen Enterprises, Inc.

PARTICIPANTS:

Mr. Stephens, Dr. Alexander, and Mr. Faulkner will be attending. This will be an one hour meeting.

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Ms. Renee P. Wormack-Keels
Executive Director
Social Justice for Women
108 Lincoln Street, 6th floor
Boston, Massachusetts 02111

Dear Ms. Wormack-Keels:

Thanks for your good wishes, and for the information on your programs.

I look forward to meeting you at some point in the not too distant future, when I am in Boston.

I appreciate your efforts, and those of Ms. Buccio-Notaro.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

August 27, 1993

R. Damon Ollerhead
Founder
National AIDS Philanthropic Foundation
90 Paul Revere Road
Needham, Massachusetts 02194

Dear Mr. Ollerhead:

Thank you for writing.

Best wishes in your endeavors. If you will be in Washington, D.C., please call to set up an appointment.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

August 27, 1993

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Needham, Massachusetts 02194

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

Prepared by: APO: KMGebbie: gw: 8/20/93: 632-1090: b:\ollerhea

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

Thanks for writing -
Best wishes in your endeavors. If you will be in DC, please call to set up an appointment

ANS

NAPF

90 Paul Revere Road
Needham, MA 02194
Tel. (617) 449-4578

July 1, 1993

Ms. Christine Geddie
White House
Old Executive Building
Washington, D.C. 20500

Dear Ms. Geddie:

Congratulations and good luck with your new accountabilities.

The Organizations of: Streisand, Jackson, Springstein, et al. are involved with our Foundation. Robert Wagner will be introducing (National Debut), the next Diva of the music world, at the Academy Awards...singing Natalie. She is Barri McPherson...our Spokesperson.

We are considering many to be our Founding Sponsor. Please call me at home (617) 449-4578. Together, with cooperation from all, we will be successful in the eradication of the AIDS epidemic.

Sincerely,

R. Damon Ollerhead
Founder

Enclosure: NAPF Profile

NATIONAL AIDS PHILANTHROPIC FOUNDATION

PURPOSE

The **National AIDS Philanthropic Foundation** is formed as a private non-profit fund raiser to distribute monies to deserving AIDS related organizations throughout the United States.

OBJECTIVE

Each AIDS related organization is chartered to deal with a different medical or social aspect of the AIDS epidemic. Organizations research a cure or vaccine, others educate the immediate and general populations, while others address the growing number of spinoff needs of victims and/or their families. To this end, **NAPF** recognizes the need for greater funding and assumes the role of a funding organization to allow individual organizations to concentrate their primary efforts in the pursuit of their Charters and reduce the time spent in the search of funding. The **NAPF** is a *money engine!*

SELECTION OF FUNDS RECIPIENTS

The **NAPF** Advisory Committee – consisting of Directors and Presidents of selected organizations and experts within the AIDS community – will meet Quarterly to select the most deserving organizations and projects.

PLEDGE

Through those that show their pride and commitment to the **NAPF** cause – all those caring donors and contributors – through the hard work and generous people of all those Organizations; we, together, will be successful in the current care of victims and their families and, more importantly, the future eradication of the AIDS epidemics.

90 Paul Revere Road • Needham, MA 02194 • Telephone (617) 449-4578

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Elysian Hills
P.O. Box 40693
Albuquerque, New Mexico 87196

Dear Elysian Hills Publishing Company:

Thank you for sharing a copy of Just Hold Me While I Cry. The sharing of personal and family experiences has been an important part of our nation's response to the HIV epidemic.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Elysian Hills
P.O. Box 40693
Albuquerque, New Mexico 87196

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

Prepared by: APO: KMGebbie: gw: 8/24/93: 632-1090: b:\elysian

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OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

PRESS RELEASE

July 27, 1993

Albuquerque, New Mexico

For immediate release

For more information contact: Ed Dziczek 505-265-9041

Bobbie Stasey, author of Just Hold Me While I Cry, *a mother's life-enriching reflections on her family's emotional journey through AIDS*, is available for speaking engagements, radio and TV interviews.

Ms. Stasey's son died in 1989 in her home of AIDS. Two years after his death, she began writing a book of her family's experience. Just Hold Me While I Cry was published in February.

Since then, she has lobbied in Santa Fe for the passage of SB91 (see enclosed article from the *Albuquerque Journal*), facilitated talks in Albuquerque, in Birmingham, Alabama, and Los Angeles. Her picture and interview was published in the May issue of *Redbook* magazine (along with several other mothers who have lost children to AIDS). Bobbie Stasey will be a presenter at the National Hospice Conference in Salt Lake City in October.

Bobbie's vision since the book's inception is to share support and information with as many people as possible - support for those who love someone who is HIV-positive, and information for those who have no concept what the emotional and spiritual ramifications are of living with and dying of AIDS. Most people still don't think AIDS can touch their lives.

Her own healing process has allowed her to be able to verbalize her journey with others. There is a crying need for people to hear the heart's expression of the pain and the gifts AIDS offers the world. Hopefully a forum such as yours would help others to overcome their fear of AIDS.

Enclosed is a copy of the book Just Hold Me While I Cry, and a copy of the cassette *The Music* (written and composed by Matthew Seligman, a friend of Jimmy's and a character in the book).

Bobbie Stasey possesses an appealing on-the-air personality. A video of her most recent 30-minute TV interview is available.

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NEW MEXICO'S LEADING NEWSPAPER

ALBUQUERQUE JOURNAL

HOMEOWNER AND HOME BUILDER

113th Year, No. 044 ■ 68 Pages In 6 Sections Saturday Morning, February 13, 1993 ■ Copyright© 1993, Journal Publishing Co. Daily 50¢ ■ Made in USA ★★★★

N.M. Mother Speaks Up For Gay Anti-Bias Bill

By Thom Cole
JOURNAL CAPITOL BUREAU

SANTA FE — More than three years after watching her 26-year-old son Jimmy die of AIDS, Bobbie Stasey-Stubbs on Friday joined the political struggle to end discrimination against homosexuals.

"It's devastating enough to have your son, your family member, your friend die at all under any circumstances, much less to have to contend with the prejudices and the fears because of who that person is," Stasey-Stubbs of Albuquerque said in brief remarks at a rally supporting legislation to prohibit some types of discrimination against gays.

She said being gay is not a matter of choice, as some opponents of the bill, SB91, have argued.

"Jimmy, as sure as I'm standing here, was born gay as sure as I was born heterosexual," Stasey-Stubbs told the 100 to 200 people at the Capitol rotunda rally.

After stepping away from the microphone, she fell shaking and sobbing into the arms of Sen. Tom Rutherford, D-Albuquerque, the sponsor of the anti-discrimination legislation.

Stasey-Stubbs has written a book, "Just Hold Me While I Cry," about her family's experience with AIDS; copies were distributed to senators.

She also wrote a letter to lawmakers telling them that they "are being given the opportunity to choose love instead of fear. ... I believe AIDS is in the world today to teach us how to love unconditionally."

Stasey-Stubbs said after the rally that she needed to grieve and write the book before entering the political arena. "Now it's time to share the story," she said.

Part of her story is the discrimination that her family faced because of her son's sexual orientation.


Stasey-Stubbs

The legislation would outlaw discrimination based on sexual orientation in employment, union membership, public accommodations, credit, and property rentals and sales.

The measure would expand a law that already prohibits discrimination based on race, religion, color, national origin, ancestry, gender, and physical or mental disability.

The Senate rejected the bill in 1991 after a divisive, emotional debate, and the measure may be just as controversial this year.

The split among lawmakers is a reflection of how New Mexicans feel about the issue, according to an Albuquerque Journal poll conducted last week.

The poll — with a margin of error of plus or minus 5 percentage points — showed 50 percent of New Mexicans favored a law to protect homosexuals against discrimination, 39 percent opposed such a statute, and 11 percent were undecided.

The first hearing on the anti-discrimination legislation is scheduled for Monday afternoon before the Senate Public Affairs Committee.

Opponents argue gays choose their sexual orientation and that the bill would condone such a lifestyle choice. They also say the legislation would grant special rights to homosexuals.

Douglas Booth, an attorney for the American Civil Liberties Union of New Mexico, argued against the special-rights argument in comments during the rally.

"Civil rights do not grant special rights to anyone; rather they ensure human rights to everyone," he said. "And when our leaders pass these laws they proclaim unequivocally that all men and women are created equal and that no one need hide behind closed doors any more."

The Santa Fe City Council on Wednesday endorsed the legislation, and Councilor Ouida MacGregor said at the rally that the gay community is "large, active and caring." She said discrimination against it robs society of "a resource we cannot afford to lose."

Secretary of State Stephanie Gonzales said discrimination and bigotry are "toxins" that poison society.

Backers of the bill say they have received endorsements from more than 60 organizations and government and community leaders. They include Navajo President Peterson Zah and 1990 Republican gubernatorial hopeful Frank Bond, as well as labor, business, arts, medical and public interest groups.

"Our allies are growing in numbers," said Neil Isbin, president of the New Mexico Lesbian/Gay Political Alliance, at the rally. But he also warned that opponents of the legislation are formidable.

Rep. Jerry Alwin, R-Albuquerque, is against the legislation and he said his wife, Sharon, is one of the organizers of the opposition.

Literature drops are planned in some Albuquerque neighborhoods and at the Legislature, Alwin said.

He said church groups also are being contacted and there is a possibility of staff and financial support from "The 700 Club," the TV talk show of television evangelist and one-time presidential candidate Pat Robertson.

In a bid to try to soften opposition from fundamentalist churches, the bill was worded so it wouldn't bar religious groups from discriminating on the basis of sexual preference in hiring and in renting property.

Six other states have enacted laws to protect gays from discrimination, backers of the New Mexico legislation say. Voters in Colorado set off a firestorm of controversy last year when they approved a constitutional amendment that prohibits such anti-discrimination laws from being enacted in that state.

The amendment is now on hold because of a legal challenge.

EVERY MOTHER'S WORRY

It's easy to dismiss AIDS until it strikes home. As it could. As it has. As it will.

BY SALLY QUINN

1986 The pediatrician frowned. I knew that frown. I had seen it before. And it made my stomach knot in fear.

My four-year-old son, Quinn, had pneumonia. Again. He'd had a number of infections and viruses that winter—some of them surely because his resistance was still low after his surgery at three months to repair a hole in his heart. Still, he shouldn't have been getting sick so often.

"I don't know how to tell you this," she said. "But I think he should be tested for the AIDS virus." Evidently there had been several incidents where children who'd had blood transfusions in 1982 at Children's National Medical Center in Washington, D.C., had later tested HIV-positive. When Quinn had his open-heart surgery, the country was barely aware of the AIDS virus—and so blood wasn't screened.

I looked at the doctor in horror. I knew what AIDS was. It was a death sentence. After all we'd been through with Quinn, this was a crisis I wasn't prepared for.

She said the test results could take up to ten days.

"I can't wait that long! I need to know *now*."

She managed to expedite the test in two days—the longest two days of my life. How, I kept thinking, was this possible? After all, AIDS was a disease only gay men got. Not children. Not *my* child. It was unthinkable. What would we do? Would we tell anyone? Certainly not! Quinn would be a pariah. He wouldn't be able to go to school. Nobody would play with him.

ROBERT C. BURKE

Sally Quinn knows what it's like to live with the fear of AIDS. Her son, Quinn Bradlee, 11, has been tested twice.

Our friends would shun us. Would my husband, Ben Bradlee, and I get AIDS, too, if we held and kissed him? How would we ever be able to hide our pain while we watched our child die? But what if we didn't tell and he infected another child, and we were responsible? It was all too terrible to contemplate. I walked around like a zombie for two days, telling no one.

The test results turned out to be negative. And strangely anticlimactic. In my mind, my child had had the AIDS virus. I had lived with it. And that changed me dramatically. Instead

of turning my back on AIDS—I was a woman, so it wasn't my problem—I suddenly saw the disease in an entirely new way. It could be my problem. It could be anyone's problem....

1990 The envelope looked innocent enough. It was from Children's hospital. Shortly after Quinn's surgery I had been named to its board of directors, and I was used to getting mail from there. But the letter inside took my breath away: Some of the children who'd tested negative in 1986 had turned up positive. Quinn needed to be tested again.

That old fear engulfed me once more. This time, though, I worried more about the threat of losing my child than about the stigma of the disease. By now, AIDS had reached beyond the gay population—and the issues surrounding it had become more complicated. I'd even been personally involved in some: Like all hospitals, Children's had been grappling with the question of guidelines for doctors and patients. Who should be tested? Should doctors be put at risk by infected patients who refused to be tested? Should patients be put at risk by doctors who wouldn't be tested—or, if they were HIV-positive, wouldn't reveal it? What was right and what was fair? I wrestled with these questions as I waited again through two nightmarish days for Quinn's test results.

Negative! Once again, I had our son back. But now, more than ever, I was made aware that AIDS was a problem we'd all have to deal with sooner or later—if not with a child, then with a parent, a friend, a colleague, a lover. Someday, someone we knew would surely be infected with the AIDS virus.

1993 Quinn was 11 in April. He is healthy and thriving and safe from the virus. For now. But soon he will be a teenager and interested in the opposite sex. How will I protect him then?

AIDS is now a national problem. It is a woman's problem, a children's problem, a mother's problem. As of December, 4,249 American children under age 13 had been diagnosed with AIDS—more than half that number are dead. The statistics for women—the fastest-growing group of victims—are equally staggering: 27,485 AIDS cases, 18,500 deaths. By the year 2000, it's estimated there'll be more than 80,000 American children left motherless by the disease. If, that is, the kids survive: An estimated 1,800 infants a year acquire HIV from their mothers, and that figure is expected to almost double in five years. Twelve- and 13-year-old girls are becoming infected from their first sexual experiences. And while most HIV victims *are* still gay males, drug users, or inner-city residents, doctors are beginning to see mainstream women and teens—from the suburbs and rural areas—who have been stricken.

So, what can we do? As women, as mothers?

Any doctor will tell you that education is the best weapon. And education by the mother is by far the most effective of all. Indeed, according to one expert, the most predictive factor for whether adolescent males will use condoms is having been told to do so by their mothers. *Not by anyone else, but by their mothers.* Increased knowledge hasn't changed behavior yet, but doctors predict that, like with smoking, it will happen. AIDS prevention must be taught at an appropriate age but as early as possible. And it must be personalized, coming from families in the context of their own values, if it is to have an impact.

Families means *us.* We are the women. We are the mothers. We must do everything we can so that no other woman will ever have to experience that knot of fear from being told her child must be tested for AIDS. □

Sally Quinn is a journalist and the author of the novel Happy Endings, *in which the president of the United States tests positive for the AIDS virus.*

MOTHERS'

Some have lost a child to AIDS. Others are infected themselves. Many have been shunned, abandoned—even harassed. Still, they speak out, hoping their stories might yet save lives.

BY BARBARA NEVINS

Carol DiPaolo with her son, Joey, 13, and her mother, Irma Izzo

SIGRID ESTRADA

BROOKLYN, NEW YORK

Carol DiPaolo knew something was wrong immediately after four-year-old Joey's heart surgery in 1984—he kept spiking fevers and getting infections. Finally, in 1988, a doctor suggested an HIV test. Terrified, Carol, 34, sent her husband, her mother, and a friend for the results. One look at her mother's face confirmed her fears. "I grabbed her and said, 'Mommy, I want to go home with you!'" recalls the former secretary. "I wanted to go back to a time that was safe."

For a while, that's what she did. Irma Izzo, 73, moved Carol and her family home with her and, for two months, begged her grieving daughter: "You have to get strong. If you let Joey down, he won't live long." Finally, when doctors warned that Joey had only 18 months left, Carol snapped out of it. She got Joey into an experimental children's program at the National Institutes of Health (NIH) in Bethesda, Maryland, and moved her family home. And she began helping her son—who is now 13—face neighbors who at first didn't want him in school with their kids. No one champions her efforts more than her mother: "I'm proud," says Irma, "that Carol's doing what she's got to do."

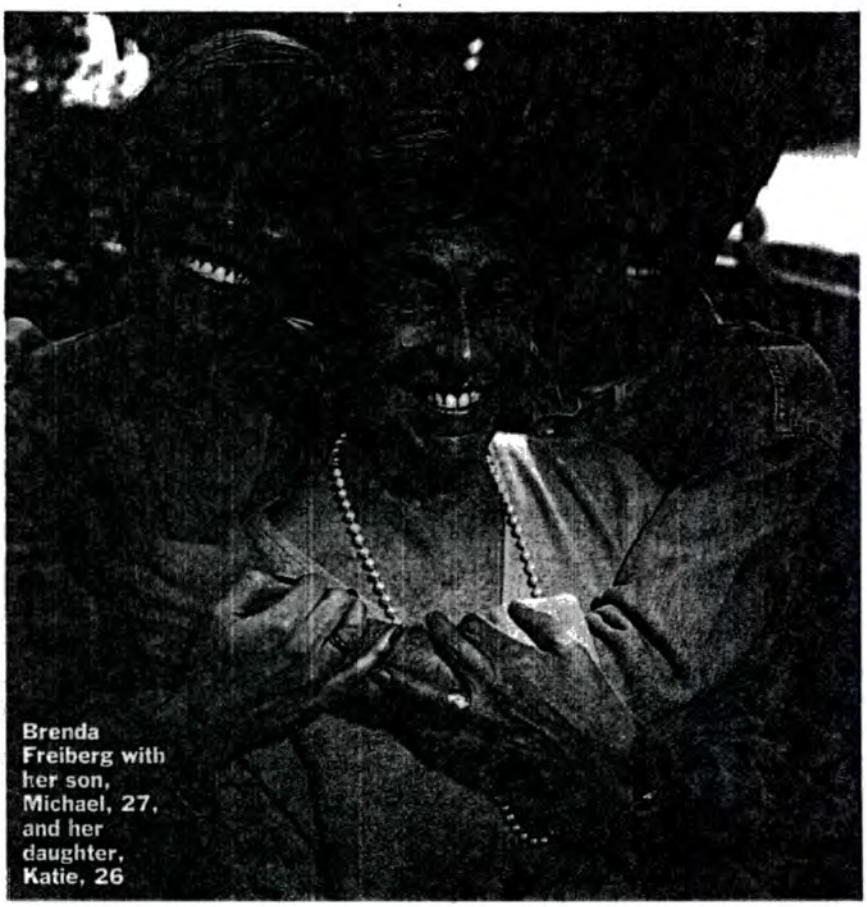
VOICES

SEATTLE, WASHINGTON

People who know 50-year-old Dawn English weren't surprised when, in 1988, the registered nurse brought home a nine-month-old AIDS baby. In the 27 years Dawn had spent raising her own three kids, she'd also cared for 3,000 foster children. "I took Antonia," she says, "because nobody else wanted her."

The baby couldn't sit up or even smile. Doctors said she'd die before her first birthday. But Dawn gave her the drug AZT every six hours and loved her like her own: "Today, she's just a normal, totally obnoxious four-year-old." Now Antonia's legal guardian, Dawn hopes that one new drug after another will keep her alive. She's already lost one AIDS baby—a 19-month-old girl she took in shortly after Antonia—who was very sick and scared by touch. "I bought the softest blankets I could find," Dawn says, "and got her to the point where I could rock and hold her." Three months later, the baby died in her arms.

Dawn English and her foster daughter, Antonia, 4



Brenda Freiberg with her son, Michael, 27, and her daughter, Katie, 26

LOS ANGELES, CALIFORNIA

Six years ago, when Brenda Freiberg first learned that her son Brett, 26, was HIV-positive, she immediately got drunk. "I walked around depressed, feeling sorry for us all," says the 54-year-old business consultant. A year later, when her other son, Michael, then 22, broke the same news, Brenda decided to enjoy whatever time she had left with them both: "It was like a lightning bolt. Something inside me said, 'You're going to miss what's going on if you don't cut it out.'"

One day in 1991, Brenda sensed she should go see Brett at his home in San Francisco. That night, after they had spent the afternoon together, he died in his sleep. Now Michael has come home. "Our life may seem like it's closing down because of our tremendous loss, but it's opened up so much at the same time," Brenda says. "I wish parents realized the love they're missing by rejecting their sons because of homosexuality or AIDS."

SUN PRAIRIE, WISCONSIN

To be safe, Tammy Pheasant decided when she was seven months pregnant to have an AIDS test—a former boyfriend had been an intravenous drug user. It was positive. "My husband freaked out," she says. "He thought we were all going to die."

Neither he nor their baby turned out to be infected. But the marriage eventually disintegrated from the strain, and Tammy, 23, accepted her mother-in-law's invitation to move to Wisconsin with her daughter, who's now three. There, she joined a support group and began speaking out about safe sex. Neighbors shunned her. Several day-care centers refused to accept her healthy daughter. But Tammy doesn't regret her public role. "By the time my daughter understands what HIV means," she says, "I hope there'll be a lot of understanding people around her."

(continued)

LEFT TO RIGHT: NATALIE B. FOBES/GAMMA-LIAISON; GARY MOSS

Bobbie Stasey-Stubbs with a picture of her son, Jim E. Mitchell, and the dog he loved

ALBUQUERQUE, NEW MEXICO

As a bereavement counselor, Bobbie Stasey-Stubbs, 47, helps families face death. But when her son, Jim E. Mitchell, a 26-year-old homosexual, contracted AIDS, she almost forgot her best advice—to honestly share your feelings. "I tried to protect him from *my* fears because I thought he had enough of his own," she says. "I was afraid of building a wall between us. I needed to tell him how much I loved him and how I wished he wasn't going to die."

One morning, her son woke up and said, "I don't think I have much time left." While he could face death, he feared prolonged pain. So with Bobbie's help, he signed a living will declining extraordinary means of life support and spent his final days at home. In August 1989, with his mother at his bedside, he slipped into a coma. His last words were "Mama, Mama."

NEW YORK, NEW YORK

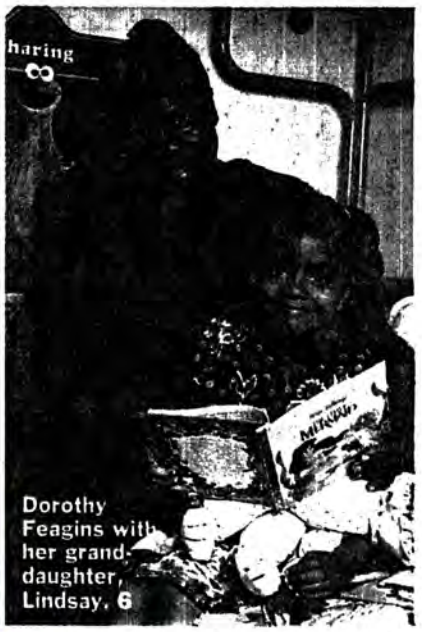
The call came in 1989 while Eileen Mitzman, 58, was in Florida, caring for her dying mother: Her 24-year-old daughter, Marni, had contracted AIDS—via heterosexual sex. The news was almost too much to bear—another daughter, Stacey, 20, had died seven years before in a car accident—and Eileen couldn't face the horror of losing her remaining child. She rushed home, determined to give Marni the will to live.

The illness was immediately debilitating, despite treatment with AZT. Desperate, Eileen begged doctors to try alternate drugs, and began plying Marni with vitamins and books on the power of positive thinking. "But it was a nightmare," she says. "She just kept getting weaker and weaker." Eileen was at her daughter's bedside in 1991 when Marni went into a coma. "All I can do now," she says, "is try to save someone *else*'s child."

DALLAS, TEXAS

Dorothy Feagins, 51, knew that her daughter, Linda, a drug addict, would end up back on the streets after delivering her baby. So in 1987, after raising ten children, Dorothy took in her newborn granddaughter, Lindsay. Five months later, Dorothy and her husband, Tom, learned that both baby and mother had AIDS: "I almost committed suicide. Instead, I told my pastor. He immediately asked me to leave the church before anyone found out and quit."

Within months, word spread through town. Dorothy lost her job as a chef. Her neighbors met to discuss what it meant to have an AIDS baby on their street. Dorothy raced out to confront them: "I yelled, 'Yes, I *do* have a baby with AIDS. And she's here to stay!'"



Dorothy Feagins with her granddaughter, Lindsay, 6

Linda is in and out of hospitals now, but six-year-old Lindsay is still well—thanks to Dorothy's efforts to get her into the NIH program in Maryland, where they fly every month for treatment. And thanks also, perhaps, to Dorothy's determination to infuse their lives with optimism: "I was told from the start that Lindsay wasn't going to live long, but she's still here, happy and stable—love has done a lot for her life." Today, Dorothy manages a day-care and nursing program for AIDS children. "I hope," she says, "to prevent some girl from doing to her mother what my daughter did to me—and to her own child."

LEFT TO RIGHT: GREG SORBER/BLACK STAR; DAVID WOO/GAMMA-LIAISON

Linda Mowrer with her son, Michael Hartranft, 17

EAST PETERSBURG, PENNSYLVANIA

For eight years, Linda Mowrer, 44, kept her secret. She was afraid to tell anyone that her son—a hemophiliac—had AIDS: "We heard about people being burned out of their homes. I didn't want that to happen to my kid. He'd already lost so much."

But last year, Michael Hartranft, her 17-year-old son from a previous marriage, told Linda and her husband that he had to speak out. Though he got AIDS from infected blood, Michael wanted to warn teens about the risks of drug use and unprotected sex. He's frail now, tired, and too sick for school, but Linda supports his cause: "I want him to reach his goals in life, and one of them is to help prevent others from getting AIDS. It's a relief not to have to hide anymore, but I'd give five years of my life not to have to deal with AIDS for just one day."

WHAT YOU CAN DO

Last May, 100,000 special Mother's Day cards were sent to the White House and to Congress, with one message: End the AIDS crisis. This year, Mothers' Voices—a national grass roots organization pushing for more AIDS research funding and programs—has printed 400,000 *more* cards, imploring the new administration to keep its promise of making AIDS a priority.

Founded in 1991 under the umbrella of People Taking Action Against AIDS, Mothers' Voices seeks to mobilize families that have been touched by the disease—and those who fear they may be. The message, according to cofounder Ivy Duneier, is simple: AIDS—like drunk drivers—is everyone's problem. "You don't have to wait to be affected by the loss of someone you love," she says. "As moms, we owe it to the human race to do something about AIDS."

This year's cards are available for free from various AIDS organizations across the country. They can also be ordered in bulk from Mothers' Voices, 150 West 26th Street, Suite 603A, New York, NY 10001. Or clip the card on page 54 and send it to the White House.

DETROIT, MICHIGAN

In 1987, shortly after giving birth to her second son, Michael, Tammy Boccomino discovered—by a random blood test done the day of her delivery—that she was HIV-positive. The source? Her first husband—a known drug addict. Frantic, Tammy had two-year-old Tony tested. Negative. So was her husband, Brian. It was too soon to tell about the baby. "I made promises to God," says Tammy, 31. "I'd say, 'Please, I'll do anything if you'll let him be okay.'" But by the time Michael reached 18 months, it was clear he had AIDS.

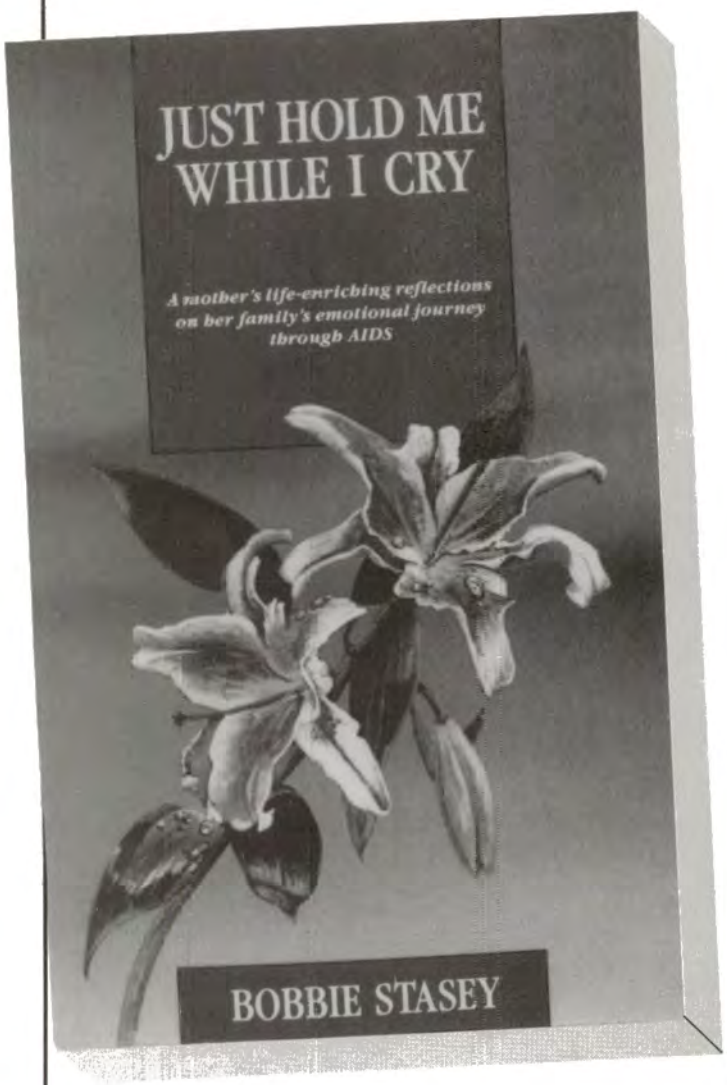
Tammy Boccomino with her sons, Michael, 6, *right*, and Tony, 7

At first, Tammy insisted on secrecy. But she soon realized she couldn't teach her children self-respect if she was also teaching them shame. She began to speak out. "There was a lot of hysteria. Our neighbors wouldn't let their kids play with Tony. You could see people's fear when I took my sons to school," she says. "But I had to decide whether I wanted to allow people to continue thinking you can get AIDS by touching."

Michael's six now—and, miraculously, still well. So is Tammy. "There are days I stay in bed and cry," she says. "But then I do a lot of praying, and get on with life. I'm not going to worry until it's our last trip to the hospital—for me or my son." □

TOP TO BOTTOM: JACK LEONARD/*SUNDAY NEWS*; SANTA FABIO/BLACK STAR

Dialogue Booksigning Meeting



Sharing the experience
of living with
and losing
a loved one to AIDS

Author Bobbie Stasey
discussion moderator

sanctuary
First Unitarian Church
Comanche at Carlisle

Friday
February 26
7 - 9 pm

$5 from each book sold
will benefit
New Mexico AIDS Services

Admission is free

"A safe window to let the pain peer out from behind closed hearts.
A tiny crack in the silence. Light through a shattered pane."

♥

The Outreach

VOLUME 6, NO. 1

MARCH/APRIL 1993

"One Night Stand Up" planned for May 22

Birmingham Aids Outreach is pleased to once again bring you "One Night Stand Up", our annual fund raising and educational event.

This year's gala will take place Saturday, May 22, from 7:30 pm to midnight at the Alabama School of Fine Arts' new facility. The black-tie-optional evening will feature a VIP host reception, a fine arts exhibit, a variety of music from different eras and cultures, as well as dancing and catered food from local restaurants. A display of a small section of the Names Project Memorial Quilt is also planned.

Since its inception in 1990, "One Night Stand Up" has raised more than $200,000 for BAO client services. Our goal this year is to net more than $125,000.

Planning for "One Night Stand Up" is already underway, and volunteers are needed to help solicit corporate sponsors, coordinate education outreach, address invitations to the gala, and sell ads and tickets.

To volunteer for any of the "One Night Stand Up" planning committees, call BAO, 322-4197. Ticket information will be available from BAO after March 15.

AUTHOR BOBBIE STASEY TO VISIT BIRMINGHAM

Author Bobbie Stasey will be the guest at a seminar to share her experiences of losing a loved one to AIDS. Stasey's son – the subject of her book Just Hold Me While I Cry *– died of AIDS in 1989. The seminar is scheduled for Thursday, March 25 at 7:00 pm at St. Luke's Episcopal Church, 3736 Montrose Road, Mountain Brook, in Birmingham.*

Stasey will speak, moderate an audience discussion, and be available afterwards to sign copies of her book.

After her son's death, Stasey began a bereavement support group in New Mexico for survivors of persons who have died of AIDS. She remains active in AIDS support work.

Stasey was a participant in the renowned "Life, Death, and Transition" workshops of Dr. Elisabeth Kübler-Ross, and is the New Mexico contact for the Elisabeth Kübler-Ross Foundation. She won the prestigious Southwest Writer's Workshop Non-Fiction Award in 1988.

Birmingham Aids Outreach is sponsoring Stasey's visit. Admission is free.

Come meet and talk with

Bobbie Stasey,

Author of "Just Hold Me While I Cry"

Share her experiences;

Share your experiences with her.

An afternoon of sharing & conversation.

Sunday, April 18, 1993
12:00 Noon

BEING ALIVE

PEOPLE WITH HIV/AIDS ACTION COALITION

Being Alive
3626 Sunset Boulevard
Los Angeles, CA 90026
(213) 667-3262

Lambda Times

The Newspaper of Lubbock Lesbian/Gay Alliance

APRIL 1993 LAMBDA TIMES PAGE 5 VOLUME 11 NUMBER 4

BOOK REVIEW

"*Just Hold Me While I Cry*"

by Bobbie Stasey

Reviewed by Tony Gregston

While going through the mail for the C.O. Center about a month ago, I came across a letter from a publishing company in Albuquerque asking if we would be interested in reviewing a new book. I didn't know that by responding to this one letter that my whole out-look on life would change and that I could find some answers about AIDS that I wasn't really looking for.

The book is "**Just Hold Me While I Cry**" and the Author is Bobbie Stasey. Bobbie Stasey is a writer, hospice volunteer, and a bereavement counselor. She had no idea that her work was going to hit so close to home. The book is dedicated to Jimmy E. Mitchell, Bobbie's son. Bobbie knew that her son was gay and that AIDS was out there but did not believe that it could effect her. Jimmy was diagnosed with AIDS at the age 23 and the lives of his friends and family were forever changed. "**Just Hold Me While I Cry**" is based on Bobbie's and Jimmy's journey of living and dying with AIDS. We learn from Bobbie that you must be able to take the bad with the good if you are to survive the trauma of terminal illness. Bobbie also shows us that it is o.k. to cry and to need other people to be strong. Bobbie stresses that we must be able to find acceptance in ourselves if we are to be able to accept other people and that acceptance is the key to a happy and fulfilling life.

Bobbie also deals with the terms some people put on "unconditional love". She is very emphatic that unconditional love is just that: no terms, no exceptions, no rules! She shows us that the power of love is the most important force in everyone's life and without love we are all lost. The book made me realize that it is sad that it sometimes takes a tragedy like AIDS for some people to express how they feel about each other. Love may not always be able to move mountains but it <u>can</u> help a terminally ill patient die with dignity.

"**Just Hold Me While I Cry**" is one of those books that will make you feel good while you are bawling your eyes out. It is a <u>must read</u> for anyone who has lost a loved one to AIDS or anyone who knows someone that is living with AIDS. I applaud Bobbie Stasey for bringing her story out and making it available to everyone. Bobbie's story doesn't end with this book. She is tireless in her efforts for equal rights; especially the rights of those afflicted with AIDS. Bobbie Stasey is a woman our community should be proud of and I wish her well with whatever ventures she undertakes.

"**Just Hold Me While I Cry**" can be ordered through Elysian Hills Publishing Co., P.O. Box 40693, Albuquerque, NM 87196. Each copy cost $12.95 plus $2.00 for postage and handling. Copies of the book can also be ordered by calling 1-800-368-3208.

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Tony Gregston,
President, LL/GA

FACTS ABO

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$5 donation or 6 cans food
2:30 pm

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Elyse Hills

Thank you for sharing a copy of Dust. The sharing of personal experiences of families has been an important part of our nation's response to the HIV epidemic.

Sincerely

Book Review

by

Florence Rush

JUST HOLD ME WHILE I CRY by Bobbie Stasey. Publisher, Elysian Hills, P. O. Box 40693, Albuquerque, New Mexico, 87196, 1-800-368-3208. Soft cover, 250 pages with photographs at $12.95 per copy. ($2.00 for handling and postage.)

What's all this nonsense about "family values" when, as a matter of public knowledge, thirty percent of all murders, seventy-five percent of all wife battering and ninety percent of all child abuse (sexual, physical and emotional) takes place within the conventional, heterosexual nuclear family? And what is it today that constitutes a "family" when even the fantasy of the stable intact family unit is dissolving under the impact of an extremely high divorce rate and burgeoning family violence?

A friend of mine once said that a family is whoever you come home to. Today a man comes home to another man, a

woman to gay children to straight parents, straight children to gay parents, children to a single parent, grandchildren to grandparents and step-children to step-parents. Today people come home to their lovers, friends, companions, room-mates, relatives, significant others and a variety of all kinds of human combinations. They come home to where they are wanted and loved. JUST HOLD ME WHILE I CRY is a book about Jimmy who came home to such a family when he had AIDS. He came home to people, related and unrelated, who comprised a list of thirty-five disparate characters who valued him and each other and it was in this homecoming that he found true family values.

Jimmy's story is told by his mother Bobbie Stasey, a divorced, remarried, mother, step-mother and grandmother aged forty-eight. She is a deeply religious woman who has cared for the sick, the bereaved and the needy. In 1981, she learned that her son was gay. She was proud that he trusted her enough to tell her but behind her pride was the fear of "a mysterious disease that is killing homosexuals." In 1988 she learned that her son had AIDS. She said to Frank, her second husband, "If Jimmy gets sick he will be the priority of my life, not you. I will need to focus all my energy on him." Frank understood.

Frank understood because he, too, focused his energy on Jimmy when he was ill and was there in whatever capacity he was needed. When a local church publicly exhibited a disturbing and offensive sign which read, "AIDS is God's punishment to homosexuals" Frank did not hesitate to confront the church officials. He threatened a class action with a final statement, "If you leave that sign up you will find my name on a summons served you by the sheriff." He was there when Jimmy wanted his dog Scarlett to have puppies. Arrangements were made to have her bred, a birthing box was built and Jimmy and Frank were midwives to the blessed event. Jimmy was not strong enough to care for six lively puppies so people arrived from the cast of thirty-five characters and took over. Scarlett's babies were very important and precious to Jimmy:

> Jimmy would sit in a chair next to their box, scoop up a puppy and press it close to his face.... He would put one down among the others and pick up another. He'd do that until he held each one.

Bobbie was her son's primary caregiver but the outpouring of concern, friendship and concrete help, sustained both mother and son. For example, when Jimmy could not hold down his food, Steve-O cleaned up after him.

Kenny and Ronny entertained their friend with a chorus line and "kicked and side-stepped their way from his hospital bed to the door across the room." Rob, Jimmy's ex-lover (who at one time broke Jimmy's heart) filled his hospital room with "pink and red lilies bursting with color and fragrance out of their six-point starts." During a rare visit, Matt interceded to heal the strained relationship Jimmy had with his biological father, Buddy. Jimmy wanted Buddy to accept him for "who he is." He wanted Buddy to know how much the presence of this father, who could never understand his son, meant to him. Matt took Buddy aside, cracked the wall between father and son and reached Buddy:

> Buddy's shoulders sagged. His head dropped. And for the first time ever I saw him cry.....In the space of love shared, the confusion of what a father of a gay son feels, all melted away, washed in tears of sadness. Matt slipped his arm around Buddy's shoulders and hugged him gently..... Suddenly Jimmy opened his eyes a moment, looked at Buddy and said, "I know you love me Dad."

And when Jimmy needed around the clock care and "we couldn't risk turning our back on him for even a minute" many in this wonderful circle of support took shifts watching over him. Bobbie said:

> Jimmy's friends enriched his life. I could not take their place nor did I want to. Jimmy needed all the love he could get. So did we. Those friends who were in his life are now in my life. I've learned to know Jimmy through his friends.

But Jimmy gave as much as he got. While he was still relatively well, he introduced his straight family and friends to his gay life where they learned to embrace and accept a world very different from their own. He took them where they were entertained by the Honeybees, three female impersonators who performed in the style of the Supremes. "They were beautiful and talented" reported Bobbie. "Everybody laughed, whistled and hooted and had a great time. What might have been an oddity before Jimmy's illness was now good clean fun." At a gay club Bobbie said she had never seen "so many people of the same gender dancing with each other." She found that, "It didn't seem strange at all. Everyone was relaxed and happy." The highlight of the evening came when Jimmy and his married brother sashayed on the dance floor together. "I wouldn't have believed how much fun I could have watching my two sons dancing together," she said. Soon after Jimmy died, less than six months after his first hospitalization, Bobbie recalled how people were warmed by the love that emanated from him to

others:

> He could be felt everywhere. His presence was extraordinarily peaceful. His spirit permeated the walls. It was like having one foot in heaven and one foot on earth. The love was that palpable. Everyone who stepped into the space could feel it. What a gift. The love made the pain worthwhile.....I lost my son's body but we all found love.

I said earlier that family is whoever you come home to but, today, more and more of us live alone. I do. The media family of the fifties such as Ozzie and Harriet or the nineties charming Huxtables never existed for me or for anyone I know or anyone I have ever known. Because I live alone does not mean I am alone. Today's rapidly changing family is no longer limited to mommy, daddy and two point five children existing under one roof. I have friends, relatives and neighbors who help in time of need. They offer human contact, friendship and companionship. They are there for dinner, a movie, conversation or just plain bitching and complaining. We fill a variety of needs for each other and are very much a family but, it is the mother's support group (mothers who care for or who have lost a child with AIDS) who reach down, understand and nourish the deepest level of

my emotions. Bobbie Stasey, for all the wonderful list of characters who enriched her life, understood and verbalized the special place her support group had in her life:

> The group was a safe place to talk, cry, yell, complain about doctors, treatment, money, prejudice and fear of old friends and family. In the group we moved from denial, isolation, bargaining, depression and, hopefully, acceptance. Some disappeared from the group never to return but those of us who continued shared our grief, terror, rage and even our laughter. We formed a unique bond and trusting hearts as we listened to each other and witnessed the ways we were living with AIDS and the ways AIDS was a part of our lives.

In my group we unflinchingly face the agony of AIDS. We walk in each others shoes, know each others pain and, as Bobbie Stasey pointed out, we even laugh together. As AIDS has become part of our lives, we exchange love, warmth, friendship, loyalty and courage. This is a family. AIDS has redefined the meaning of "family" for me.

I often wonder what the Regans, Bushes, Qualyes, Buchanans, Robertsons and others of their ilk know of family values. How can they when, under the cloak of church, God and the American flag, they preach bigotry and homophobia--

the very ingredients which foment hatred, distrust and violence. I could suggest that they read JUST HOLD ME WHILE I CRY but have little faith that the message would penetrate their narrow minds. But for all those whose minds are open, I would recommend taking the journey with Bobbie, Jimmy and the wonderful thirty-five; a journey with a family where relationships are built on compassion and understanding. Blood may be thicker than water, but love is more reliable than biological ties.

- * -

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Ms. Jeanetta Richardson
7129 76th Avenue North
Brooklyn Park, Minnesota 55428

Dear Jeanetta:

Thank you for writing and for your deep interest in a better HIV/AIDS education program.

There have been several efforts to make current HIV materials available to schools. In most states, including Minnesota, the State Department of Education and Health work closely in planning educational efforts.

I am sharing your letter with the Department of Health and Human Services, and the Department of Education for their information. All of us in the Federal system need regular reminders of the local results of our work. Your ideas and concerns can be helpful in planning future efforts.

Again, my thanks for your interest.

Sincerely,

Kristine Gebbie

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

cc: Secretary Riley
Secretary Shalala

sent out

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National AIDS Policy Coordinator

cc: Secretary Riley
Secretary Shalala

Prepared by: APO: KMGebbie: gw: 8/20/93: 632-1090: b:\richard.son

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

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There have been several efforts to make current HIV materials available to schools. In most states, including Minnesota, the State Depts of Educ & Health work closely in planning educational efforts.

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Sincerely

Ve Shalala

Riley —

7129 76th Avenue North
Brooklyn Park, MN 55428
August 15, 1993

National Aids Program Office
Office of the Assistant Secretary for Health
Room 728-G, Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear National AIDS Program:

My name is Jeanetta Richardson. I am 14 years old. I go to Northview Junior High School in Brooklyn Park, Minnesota and I am in the 9th grade. I called a 1-800 number and asked for information on AIDS. I was suprised by how much information was sent to me. There was more information for me to know then from the teachers at my school ever told us. The information sent to me was Training Drug Treatment Staff In The Age Of Aids, and Community Based Aids Prevention. I'm writing you to find or come up with some kind of plan for this information to be sent to schools all over the United States. I feel that people need to know more about this disease. Enough to care about there's and

there partner(s). We are not educated enough. Teachers do not know everything. There's the library, but that to many not have all to give - If people in the schools had more access to this information, they wouldn't just educate themselves, but others too. By having guest speakers, (who know all there is to know by the information gathered), coming to our schools every year to talk to us, we would get a better understanding. This would be a perfect plan. People then would know the results of there actions. They know now, but think it's no big deal or it won't happen to them. I would appreciate it if you would reply and tell me what you think. Thank you for listening.

Sincerely,
Jeanette Richardson

THE WHITE HOUSE

WASHINGTON

August 27, 1993

The Honorable Richard W. Riley
U.S. Department of Education
400 Maryland Avenue, S.W., Room 4181
Washington, D.C. 20202

Dear Secretary Riley:

Thank you for meeting with me on Thursday. I look forward to working with you and your staff on our common interest in healthy young people.

I will work with Elaine Holland to coordinate participation of someone from the Deparment of Education in the Healthy People 2000 HIV prevention objectives review, as a first step.

Please let me know if I or my staff can be of any assistance to you.

Sincerely,

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

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National AIDS Policy Coordinator

Prepared by: APO: KMGebbie: gw: 8/20/93: 632-1090: b:\riley

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

KRISTINE M. GEBBIE, R.N., M.N., F.A.A.N.
NATIONAL AIDS POLICY COORDINATOR
DEPARTMENT OF HEALTH & HUMAN SERVICES
Room 729H Humphrey Building
200 Independence Ave., S.W.
Washington, D.C. 20201

DAY Thursday DATE August 19, 1993

TIME 3:00 3:30 p.m. LOCATION Gary Riley Department of Education - 6th & C Streets Entrance

SUBJECT Meeting with Under Secretary Mike Smith

PARTICIPANTS:

Report to RM. 4169 on the 4th Floor. Enclosed is a copy of the draft letter to Senator Kennedy.

Elaine Holland - Key Staff Contact -

talking points for speeches -
Kay Kaylor's office -
use ? & ans -

Research - joint project ?

The Honorable Edward M. Kennedy
United States Senate
Washington, D.C. 20510

Dear Senator Kennedy:

It is my understanding that during consideration of the Elementary and Secondary Education Act this month there may be some discussion of language regarding the range of options available to individual school districts in fashioning their health promotion programs.

The decision about the exact mix of education and services which is best to promote and protect the health of a school population should be a local one. In addition to scientifically sound information presented in an age-appropriate context, activities such as distribution of condoms to sexually active teens can be an important part of the effort. No restrictions should be placed on the right of individual school districts to construct their health promotion or sexuality education programs, even if that may include condom distribution.

I would be happy to meet with you or members of your staff to discuss this issue or answer any questions you may have.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

TO: Howard Paster
White House Congressional Liaison

FROM: Kristine Gebbie, AIDS Policy Coordinator

RE: Draft Letter to Senator Kennedy

I think the following draft letter is self-explanatory. The issue of local control of school board decisions regarding health education is, I think, consistent with the overall administration policy. It seems important to go on record about the issue. I would appreciate an opportunity to discuss this with you. You may contact me at 690-5471, and I will expect your call when you are free. Thanks.

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

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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 M. Gebbie, RN, MN
National AIDS Policy Coordinator

Prepared by: APO: TFox: 9/9/93:202-690-5560:b:\foxlts.gbe\cornell.gbe

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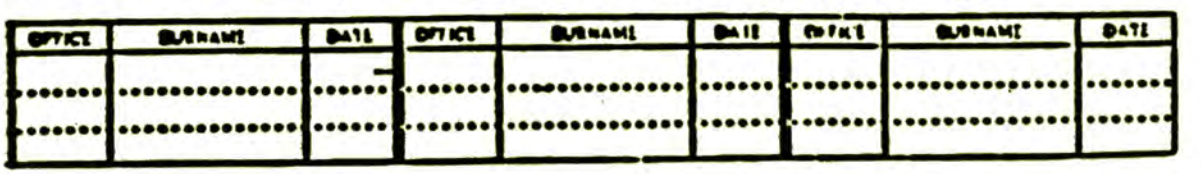


Need >
Congratulations on the
good work --
Keep this office posted
on your efforts "

letter to Cornell-

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

TO: Kristine Gebbie

FROM: Sarah Kovner SSK

SUBJECT: Rockland County Commission on Women's Issues letter of support

DATE: August 12, 1993

I am enclosing a letter and report that was sent to me from Harriet Cornell, a strong advocate for women in all areas whom I have known for some twenty years. The report, which is on the HIV and AIDS Crisis in Rockland County, was prepared by the Rockland County Commission on Women's Issues which Ms. Cornell chairs.

Patsy Fleming and I encourage you to write a letter to Ms. Cornell in the next few weeks supporting the issues raised by the report and the initiative and leadership which went into it. The Secretary will be sending a separate letter of support. Thank you for your time concerning this matter. If you have any questions please feel free to call me, 690-6347.

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) 638-5100
(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

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

Dear Sarah:

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 was mailed to you under separate cover.

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,

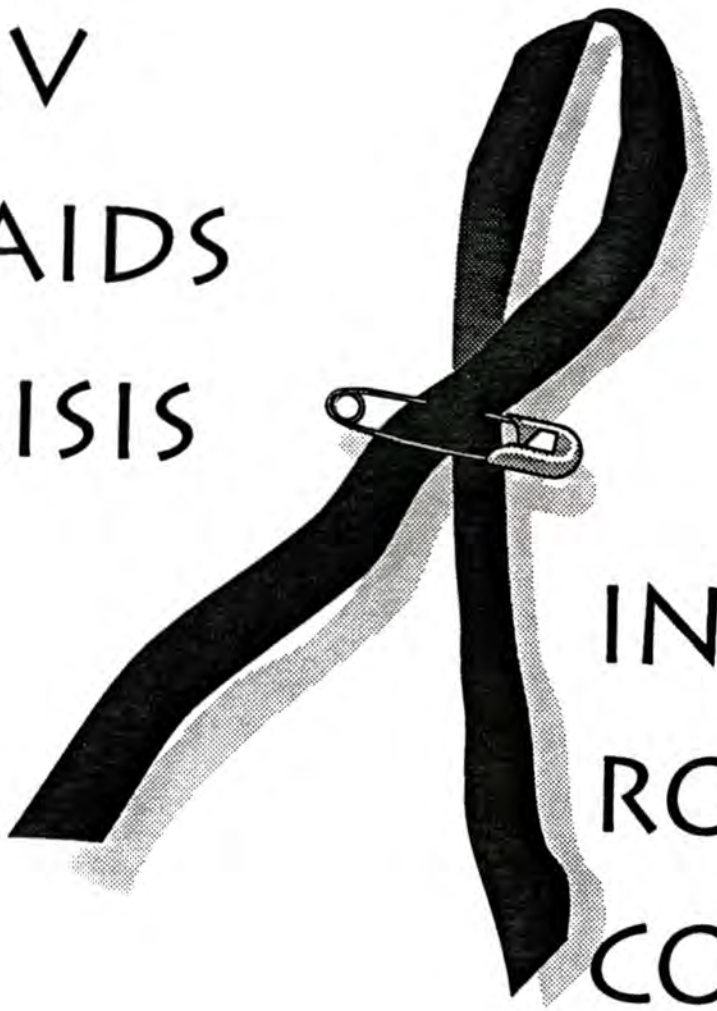
Harriet

Harriet Cornell

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

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
Eve Borzon, R.N.
Jeremy Broun
Dr. Sue Commanday
Dorothy Crapanzano
Marion Curtin
Marge Davitt
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Laura Fasulo
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Julia Thompson
Susan Witte

General Editor: Sue Commanday (Rockland Community College)
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This report was written under the direction of Harriet Cornell. The authors of each section are identified prior to their section.

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The Legislature of Rockland County

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

January 28, 1993

HARRIET D. CORNELL
Chairwoman
Rockland County Commission
on Women's Issues

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

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!

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 outpatient 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

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Ms. Phyllis Buccio-Notaro
Director of Development
Social Justice for Women
108 Lincoln Street, 6th floor
Boston, Massachusetts 02111

Dear Ms. Buccio-Notaro:

Thanks for your good wishes, and for the information on your programs.

I look forward to meeting you at some point in the not too distant future, when I am in Boston.

I appreciate your efforts, and those of Ms. Wormack-Keels.

Sincerely,

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

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

Prepared by: APO: KMGebbie: gw: 8/20/93: 632-1090: b:\buccio.not

FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

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FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

SOCIAL JUSTICE FOR WOMEN

Administrative Offices
108 Lincoln St., 6th Fl.
BOSTON, MA 02111
(617) 482-0747

August 11, 1993

Ms. Kristine Gebbie
National AIDS Policy Coordinator
Office of National AIDS Policy Coordination
Executive Office of the President
Washington, DC 20201

Dear Ms. Gebbie:

I am writing to extend our sincere congratulations on your recent appointment as AIDS Policy Coordinator.

Social Justice for Women is a small non-profit agency in Boston serving the needs of incarcerated women in Massachusetts. In particular, the Women in AIDS Project of SJW responds to the needs of incarcerated women who are HIV positive. I have enclosed a full packet for your review.

It is with much hope that we look forward to your tenure. It has been a crying need that all of the issues and risk groups for HIV receive attention at the federal level in a meaningful, aggressive way.

On behalf of Social Justice for Women, staff, and clients, again congratulations.

Sincerely,

Renee P. Wormack-Keels
Executive Director

Phyllis Buccio-Notaro
Director of Development

PROGRAMS

Women's Health and Learning Center
MCI Framingham
P.O. Box 9007
Framingham, MA 01701
(617) 727-5056 ext. 149

Community Services for Women
108 Lincoln Street
Boston, MA 02111
(617) 482-0747

Neil J. Houston House
9 Notre Dame Street
Roxbury, MA 02119
(617) 445-3066

Women & Aids Project
Primary Location
MCI Framingham
P.O. Box 9007
Framingham, MA 01701
(617) 727-5056 ext. 223

Women in Recovery
Suffolk County
House of Correction
20 Bradston Street
Boston, MA 02118
(617) 635-1000

Dear —
Thanks for your good wishes & for the information on your programs. I look forward to meeting you at some point in the near/distant future.

SOCIAL JUSTICE FOR WOMEN

108 Lincoln Street, 6th Floor
Boston, Massachusetts 02111

SOCIAL JUSTICE FOR WOMEN

Administrative Offices
108 Lincoln St., 6th Fl.
BOSTON, MA 02111
(617) 482-0747

FACT SHEET

About Incarcerated Women

- The average prison sentence for women in Massachusetts is less than one year for non-violent, drug related crimes.
- Most incarcerated women come from poor urban neighborhoods and have limited education and job skills. Many are homeless.
- 70% of all women in prison are mothers with sole responsibility for their children.
- 50% of incarcerated women are white, 30% are black, and 20% are Latina.
- Incarcerated women are often victims of domestic violence and sexual abuse.
- National research on prison health reveals that incarcerated women suffer from illnesses that are chronically undiagnosed and untreated. These health problems are a result of poor preventative health care, substandard living conditions, inadequate diet and substance abuse.
- 90% of all incarcerated women at MCI-Framingham have a history of substance abuse; 54% admit to needle use. This places these women and their babies in the second highest risk group for contracting AIDS.
- Over 4,000 women are incarcerated each year at MCI-Framingham, representing 5% of the total prison population.

About Social Justice for Women

- Social Justice for Women (SJW) was founded in 1985. It administers the **Women's Health and Learning Center**, the **Women and AIDS Project, Community Services for Women** and the **Neil J. Houston House.**
- The **Women's Health and Learning Center** (WHLC) provides substance abuse treatment and education to women at MCI-Framingham. Aside from one part-time counselor employed by the Department of Correction, it is the only source of substance abuse counseling and education for over 530 women on any given day.

PROGRAMS

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MCI Framingham
P.O. Box 9007
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- The Women's Health and Learning Center is responsible for the **Women & AIDS Project** (W/AIDS). The Project provides AIDS education and counseling to incarcerated women. It is the first program of its kind in the country and has recognition by the U.S. Department of Health and Human Services.

- **Community Services for Women** (CSW) develops alternative sentencing plans for prison-bound women at the Boston Municipal and Suffolk Superior Courts. CSW reduces the number of women sentenced to prison and provides alternatives to assist them in breaking the cycle of addiction and crime.

- The **Neil J. Houston House** (NJHH) is a residential substance abuse treatment program that provides an alternative to incarceration for pregnant women and their babies. It is a model program that has received national attention, including President Bush's 38th "Point of Light" and the Peter F. Drucker Award for innovation in Non-Profit Management.

BRIEF AGENCY DESCRIPTION
SOCIAL JUSTICE FOR WOMEN

Social Justice for Women (SJW) is a non-profit private agency dedicated to providing innovative treatment services to women involved with the Massachusetts criminal justice system. The agency's treatment philosophy is feminist and holistic, and focuses on empowerment. SJW designs and advocates for realistic alternatives to incarceration. The agency, via its programs, addresses the root causes of criminal behavior, including substance abuse, incest, sexual assault, family violence, poverty, homelessness, discrimination, and lack of education and job skills.

Each year, approximately 2,700 women are admitted or sentenced to MCI-Framingham or county houses of correction in the state of Massachusetts. Most incarcerated women serve relatively short sentences of one year or less; most have been charged with nonviolent crimes such as prostitution, theft, or possession of controlled substances, to support their poly-drug addiction.

The majority of the women are between the ages of 20 and 35; over 75 percent are mothers with sole responsibility for their children. They are largely from poor urban areas, have limited education and minimal job skills. Fifty percent are Caucasian; 27 percent are African-American; 22 percent are Latina; and 1 percent are other.

Incorporated in 1986, SJW administers five programs to address the needs of these women:

Community Services for Women (CSW) designs and advocates for alternative sentences which address the underlying issues that lead to criminal behavior.

The **Women's Health and Learning Center (WHLC)**, a prison-based program operating out of Massachusetts Correctional Institition-Framingham (MCI-Framingham), the first on-site treatment program for women in prison, provides treatment, counseling, and education services.

The **Women and AIDS Project (W/AIDS)**, located at MCI-Framingham is the first program in the country to bring AIDS education, counseling, and support services inside a prison. It was one of five AIDS education programs commended by the U.S. Department of Health & Human Services.

The **Neil J. Houston House (NJHH)**, another first-in-the-nation model, is a residential pre-release treatment program which offers addicted, pregnant women in prison an alternative to incarceration, pre and post-natal medical services and early intervention services to their infants. The program provides a secure, safe, clean group living environment and serves as a gradual transition for re-integration into the community. NJHH houses 15 women and their infants at any time.

Women in Recovery (W/Recovery), located at Suffolk County House of Correction, is an onsite intensive residential substance abuse treatment program providing group and individual counseling services for incarcerated women (start-up 8/1/93).

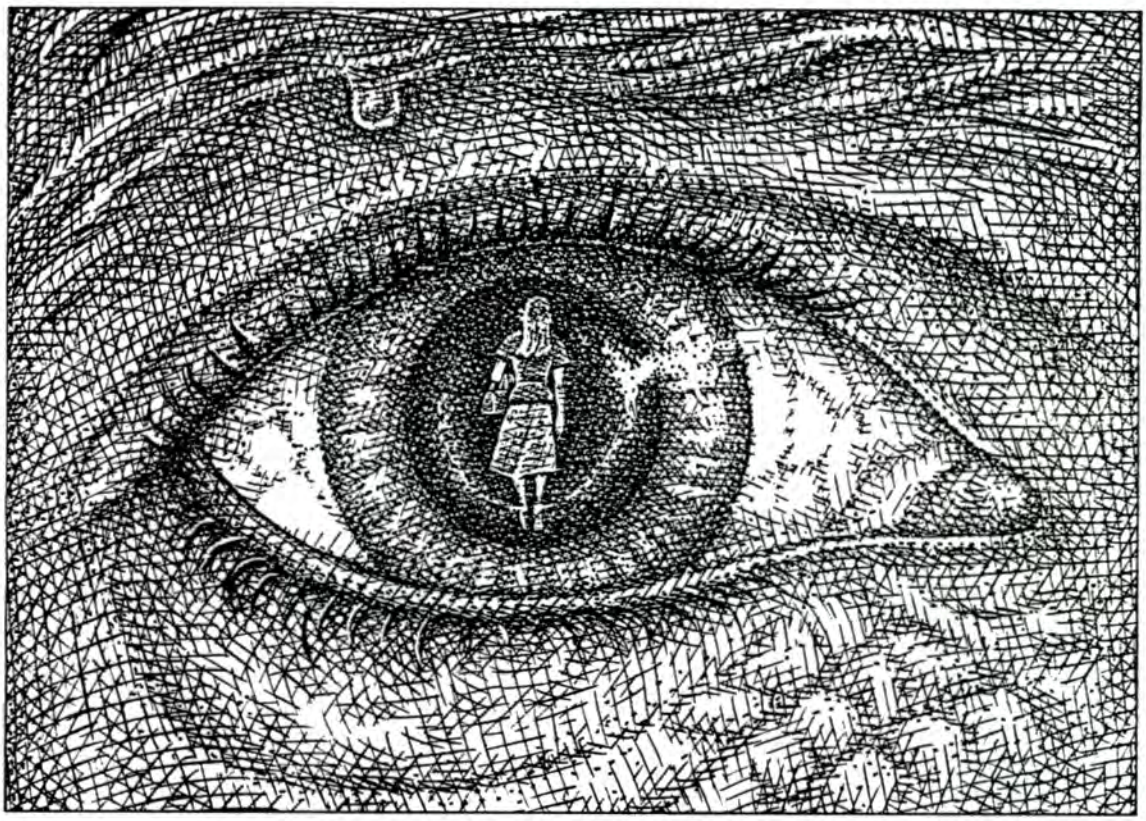
SJW has demonstrated its effectiveness in working with female offenders, and as a result, was recruited by the National Institute of Correction in Washington, D.C. in 1989 to provide technical assistance to agencies across the country. SJW has provided information and assistance to non-profit organizations and state agencies throughout the United States and Canada.

SJW and its programs are committed to empowering women to recover from substance abuse, to regain their health, to believe in their potential to change, to achieve personal growth, and to reunite mothers with their children.

SUNDAY FORUM

STACEY KABAT

Battered women need help, not jail



In the past two months seven women have been murdered in Massachusetts — in every case it is her husband or boyfriend who now stands accused of those crimes.

● April 19 — Mary Ann Montel, 29, of Springfield, mother of three children ages 1 to 7, was stabbed to death. She had earlier fled her home, but returned a day later to pick up some personal belongings. Her husband has been charged with the crime.

● May 2 — Cynthia Reid, 22, of Peabody, died after being stabbed 22 times. Her body was found in her car which had been parked at Logan International Airport. Her boyfriend has been charged in the case.

● May 4 — Susan Kobus, 38, a nurse from Clinton and mother of a 12-year-old son, was shot in the hand and chest, allegedly by her ex-boyfriend.

● May 14 — Nancy Nguyen, 44, of Lowell, and her 7-year-old daughter were stabbed to death with a 10-inch carving knife, their bodies left to burn in a house fire apparently set to cover up the crime. Her husband, suspected of both crimes, died in the fire as well.

● May 30 — Sandra Cintron, 21, of Springfield, mother of children ages 4 and 18 months, was strangled with a cord in front of her two children, allegedly by her ex-boyfriend. Her friend Theresa Moss, 26, survived a strangulation attempt.

● June 7 — Roberta Smart, 34, of North Andover, mother of sons ages 10 and 15 years, was strangled and her body dumped in the woods of New Hampshire. Her husband has been charged.

● June 13 — Alexis Braley, 29, of Somerville, was strangled. Her boyfriend is being accused in the case.

Seven women in two months. This certainly is higher than the statistic we often cite of one victim every 18 days!

There are 10 other women I'd like to tell you about too. They are in prison here in Massachusetts for defending their lives and the lives of their children against their batterers.

They are 10 very strong women — women who, when the system they turned to couldn't protect them, had to protect themselves. They, unlike the seven women you just heard about, are survivors.

Each has her own horrific story of abuse, stories that always start with verbal and mental torture, leading to physical abuse. Stories that include being kicked, beaten, choked, knocked down and dragged in the streets; being beaten with every type of object — billy clubs, bottles, sticks and hammers.

Many tell of being raped. One tells of being cuffed to the bed and being raped, forced to perform various sexual acts, and having objects stuck inside her until she bled. They all have had blackened eyes and teeth knocked out. Two have had all their teeth knocked out. One woman tells of having a knife held to her pregnant belly while her batterer threatened to cut her baby out.

Another recounts tales of having cigarettes put out on her neck and in her hair, and nearly being run over by her husband's van while trying to escape his brutal assaults with her 6-month-old son in her arms. One woman tells of taking a beating so bad that she was rushed to the hospital and was in a coma for two months on life-support and kidney machines.

And yet another recalls being hunted down and attacked while on her job at the MBTA. She had her shirt ripped open, was punched in the gut and spat upon. MBTA Police officers refused her requests to arrest him because it was a "domestic dispute."

Each woman states that it could have been her or her kids who died, and each hopes no woman will ever again have to live with this trauma.

There are some 2,000 women in America who, like these women, are in prison for defending themselves against their batterers. The issue of battered women and self-defense cannot be addressed in a vacuum. It's important to hear and be conscious of the magnitude and type of violence that these women face.

Former Surgeon General C. Everett Koop named domestic violence as the No. 1 health hazard for women in this country. I believe it is not just a serious health hazard, but violence against women is the No. 1 human-rights issue facing the majority of our population — women and their children. The number of women who have died at the hands of their batterers highlights the severity of domestic violence and emphasizes it as a life-and-death issue.

Battered women who have killed their batterers have been doubly victimized: first, by their abusers; and second, by a criminal-justice system that not only failed to protect them from harm, but then failed to recognize the legitimacy of their defense.

This past year in Massachusetts, "An Act to Further Protect Abused Persons" became law. This law communicates that domestic violence will not be tolerated in Massachusetts. It also addresses the current inability of our institutions to protect battered women adequately. This law shows that the Massachusetts Legislature is not only aware of the seriousness of domestic violence in this state, but that it is committed to protecting battered women and their children.

We must remember that the enforcement of this new state law, and the protection of battered women generally, has yet to become a reality for all. The 10 women currently incarcerated in Massachusetts, and the seven women who have been murdered in the last two months, represent the failure of the system to protect battered women.

We, as responsible residents of this state, have the obligation to respond to and remedy, the situation for these 10 women who were not afforded the protection that women today may receive through the law.

These women should be affirmed as survivors, not condemned as criminals. They need our support to help them rebuild their lives.

There are concrete tasks by which we can move forward. We must be vigilant to ensure that the laws already in place are enforced. We need to work for a statewide policy that is tough on domestic violence. We can remedy the situation of the women currently incarcerated in Massachusetts by reviewing each case in light of the new law.

Legally there are a number of possibilities that can be explored to seek their release. They are: traditional legal avenues; early parole consideration; alternative sentencing; or, as we have seen in Ohio and Maryland, the commutations of sentences for women who have killed their batterers. In conjunction with this, we need to examine the gender bias in the present self-defense law and restructure it to provide equal justice for all.

In the words of one of the women imprisoned for defending her life: "In the name of justice and fairness, no woman should continue to be punished for defending herself against an attack on her life." □

Stacey Kabat is assistant director for the Women's Health and Learning Center, a project of Social Justice for Women, which runs programs at MCI-Framingham.

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The Boston Globe

THURSDAY, JANUARY 11, 1990

Program for pregnant convicts receives presidential award

By Tina Cassidy
CONTRIBUTING REPORTER

The Neil J. Houston House has helped to save the lives of 14 babies in less than a year. It has brought many families back together and turned many mothers down a fresh, drug-free path.

The people who live and work at the Roxbury rehabilitation center for convicted mothers did not need a White House award to know their program is a success. But they got one yesterday.

President Bush named the Houston House as one of the "Thousand Points of Light," to which he alluded in his inaugural address.

The renovated laundry building behind the Dimock Community Health Center provides a host of services to convicted women, including prenatal care and drug treatment. It is an alternative that keeps them and their babies – born and unborn – out of jail.

"It's the first program for women that are pregnant, that are addicted, and that are serving jail sentences. It gets the women on the road to recovery from their addiction," said Ruth Smith, director of the Houston House.

The pregnant, convicted women must voluntarily choose to leave the Massachusetts Department of Correction in Framingham for the Houston House, where they can receive counseling and substance abuse treatment.

Most of the 12 mothers and their children are allowed private rooms, equipped with cribs and bathrooms. They also share common areas with televisions, stereos and bottle-warming stations.

All residents have sole responsibility for their babies, and share cooking and cleaning duties. If a mother is sick, one of her peers usually volunteers to watch her baby.

Most women do not enter the house enthusiastically, the director believes, but "we let them unload their baggage. We establish trust and educate them about survival."

Many house residents do not want to leave, although they are encouraged to do so several months after their babies are born.

The program's success has also caught the attention of other states, which hope to create similar rehabilitation centers.

Betsey Smith, executive director of Social Justice for Women, said the Houston House opened its doors less than a year ago to respond to the problems of women delivering their infants in jail.

Social Justice for Women, a nonprofit organization designed to help women in the criminal justice system, has four other programs besides the Houston House.

"Social Justice for Women is encouraged by the prestigious award from the president," Smith said in a statement. "We feel it recognizes a new national awareness of the serious issues of women in the criminal justice system, and recognizes the critical need for community based alternatives to incarceration for women," Smith said.

The New York Times

NEW YORK, WEDNESDAY, AUGUST 30, 1989

Experimental Program For Mothers in Prison

Boston Journal

BOSTON, Aug. 29 — In a red brick house on the grounds of a community health center here, Massachusetts is experimenting with a way to break a cycle of crime and drug use before it is passed on to a new generation.

The Neil J. Houston House in the Roxbury section of Boston is a home for women, some of them pregnant, some of them with newborn babies, all of them addicted to drugs or alcohol and all of them convicted of crimes for which they could have been sent to state prison.

How to deal with the children of parents who are in prison is a problem that has long plagued corrections officials and social service workers.

Some prisons have programs that permit inmates to visit with their older children, and the Bedford Hills Correctional Center in New York has a nursery and allows the women whose babies are born in prison to keep them for up to one year.

• • •

What's different about Houston House is that the mothers and children are never separated from each other and do not live behind bars.

The women in the program volunteer for it, pledging to go through drug and alcohol detoxification programs, to carry the baby through delivery and, after leaving Houston House, to continue to visit it for a year for follow-up care.

Most of the women have been convicted of prostitution or nonviolent drug-related crimes, for which they would have served about five months in state prison.

Eleven women now live in Houston House. So far they have given birth to eight babies who show no sign of addiction. Four more residents are expected soon.

Women usually come to Houston House six months before delivery so they can detoxify before giving birth and receive counseling for their addiction. They also stay there at least two months after giving birth.

They attend classes in parenting and AIDS prevention, go to counseling sessions and get help finding work. They also plan their meals and daily schedules together and baby-sit for each other.

Eventually, they venture out to look for housing, to apply for social service programs and to attend meetings of Alcoholics Anonymous or Narcotics Anonymous.

• • •

Houston House is named for Neil J. Houston, who was a 43-year-old lawyer for the Gardner Howland Shaw Foundation in Boston, a private, nonprofit group that gives grants to programs for women who are imprisoned and to shelters for battered women. Mr. Houston, an advocate of alternatives to prison for women who are criminals, was killed by a drunken driver in 1987.

The house was opened last February after three years of planning by state officials, legislators and a private group called Social Justice for Women that works with prisoners.

The group runs the house in cooperation with Beth Israel Hospital, which is connected with Harvard Medical School, and the Dimock Community Health Center, on whose grounds the house is situated. Money for the project, whose budget is $834,000 a year, comes from the state corrections department, the City of Boston and private foundations.

> The babies at Houston House show no sign of drug addiction.

"Developing a relationship between mother and baby as a service to them and society" is what Houston House is all about, said George A. Vose, the state corrections commissioner.

Because the program is only six months old, it is too early to assess how it is succeeding in meeting one of its goals: making sure that the women do not return to prison.

• • •

One of the women at Houston House is a 29-year-old mother of a three-month-old boy. The woman, who asked that her name not be used out of concern for her son's future, said she had been a medical secretary and had been addicted to cocaine, marijuana and alcohol for 12 years.

The woman said she found that she was pregnant after she had gone to prison on charges growing out of a knife fight. "I imagined being handcuffed to the delivery room bed and then having my son taken away," she said. "By the time I got out he wouldn't have known me."

Expressing fear about "dealing with the real world" after she goes home, she said, "I think I'll call these women every night."

But she said she would overcome her fear, and would succeed because of her son. "Everytime I look at him I feel proud," the woman said. "I'll tell him the truth, within reason, about drugs like my mother never told me."

The New York Times/Rick Friedman

A mother and child at Neil J. Houston House in the Roxbury section of Boston, an experiment in breaking the cycle of crime and drug use.

Sojourner
The Women's Forum
March 1993
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Health Education for Women Prisoners

by Laelia Zoe Gilborn

"People are into drugs or they find out they have AIDS and they want to die. I say it's time to fight for your life!"—Tania, MCI-Framingham

The female prison population is growing rapidly. During the 1980s, the number of women in prison skyrocketed from 14,000 to 40,000, according to the Bureau of Justice Statistics. This growing population is now widely recognized as being significantly "sicker" than its male counterpart. Yet it is served by an overburdened prison system, which historically has neglected the needs of women.

Of the women at MCI-Framingham, the only prison for women in Massachusetts, 80 to 90 percent are addicted to alcohol, cocaine, or heroin. Many suffer from malnutrition and sexually transmitted diseases. Each year, 200 women arrive pregnant. And statistics indicate that 13.1 percent of women in Massachusetts prisons are infected with HIV, the virus that causes AIDS, almost twice the percentage of men.

The Women's Health and Learning Center (WHLC) at MCI-Framingham is a crucial lifeline for women imprisoned there. It arms this needy population with knowledge about health and survival while encouraging them to explore factors leading to substance abuse and incarceration. Founded in 1982 by Social Justice for Women, a Boston-based agency advocating innovative services for incarcerated women, the center provides one-on-one counseling and health education. The centerpiece of the program is a voluntary seven-week certificate program called Living with Recovery, focusing on substance abuse, AIDS education, goal setting, and street survival.

Women and the Drug Culture

Alice has spent most of her adult life in and out of MCI-Framingham on charges of larceny, forgery, shoplifting, assault and battery with a dangerous weapon, and drug possession. She was involved in the drug trade for years and eventually started sniffing cocaine. During her most recent incarceration, she was placed on a methadone treatment plan. But, according to Alice, the treatment blocked up her bowels, tore up her stomach, gave her convulsions, and almost killed her. Terrified of detoxing, she came to the WHLC to give up her addiction to drugs.

Women like Alice are a growing part of the American drug culture. According to the Bureau of Justice Statistics, drug-related arrests in the '80s among men rose 147 percent while for women they rose 307 percent. As women comprise an increasing proportion of our nation's poor, they are drawn by the need for networks and for money to the drug culture—a world fraught with sexual and physical violence, high risk for contracting AIDS, and all the terrors of addiction.

According to its director, Dorothea Keeling, the creators of the WHLC felt that conventional twelve-step programs did not address the interwoven social, political, and legal factors that lead to substance abuse and incarceration for women. Most female criminals are single mothers who are poor, uneducated, and have few job skills. Many experienced neglect or abuse at the hands of family members and ran away only to encounter more violence on the streets. From its inception, the WHLC has used a holistic and feminist approach to focus on substance abuse in the context of this wide range of issues.

For women in prison, drugs and alcohol are linked to hopelessness and shattered self-esteem. By reflecting on their patterns of behavior, exploring their spirituality, and seeking the support of other women, they begin to regain control. "There is a grieving process around drugs," explains Toni Jones, who runs the Women in Recovery workshop. "It's like anyone or anything else you're attached to or have established a relationship with. Recovering addicts have to try to fill that empty space through self-help, counseling, spirituality, and support from other women. We really emphasize support from other women."

For Alice, who says that in her days of dealing drugs she cared only about herself, relying on other women for support did not come naturally. "All women don't trust other women. They are the ones that did things to you in the past. . . . At first people were yelling and screaming. There was no love, no unity. . . . I didn't know there was a lot of love for women. . . . But I found out that other women felt the same way and were going through the same thing. I started opening up."

Like most women in prison, Alice has children but knows that, as a criminal and an addict, she is seen as an unfit mother. For women who view themselves primarily as caretakers, this label causes profound guilt and despair. The pain of separation is heightened by the fact that most female offenders in Massachusetts are incarcerated at MCI-Framingham, no matter how far away their children are. Through the Mothering at a Distance Program at the WHLC, the first mothering group ever to exist in an American prison, inmates make things to send to their children while learning parenting skills.

"Many women have babies to be accepted in society, but they don't know how to care for them," explained Alice, whose son is a straight-A student in high school. "You need to spend quiet, quality time with your child. See where the kid is coming from. Be honest about your situation because people are cruel when they know your mother is in jail. If you tell your child first and explain that you're getting help, they'll know 'my mother didn't leave me because she didn't want me—she had a problem.'"

© Marilyn Humphries/Impact Visuals

Elly Andujar, Dorothea Keeling, and Toni Jones staff The Women's Health and Learning Center at MCI-Framingham.

Demystifying the drug culture is an important first step. In the Women in Recovery workshop, Toni Jones addresses the history of drugs and alcohol in society, stereotypes, myths, barriers to recovery, and laws and medical conditions related to substance abuse. In an intensive group for self-identified addicts, she prepares women to resist the temptation of drugs and alcohol when they return to their communities. "I think relapse is the biggest issue for women recovering from substance abuse," explained Jones. "We try to identify triggers and work on behavior modification. The inmates deal with the situations, people, places, things, and family that may trigger relapse. By the time they get out, there should be no surprises out there."

Of the women at MCI-Framingham . . . 80 to 90 percent are addicted to alcohol, cocaine, or heroin. Many suffer from malnutrition and sexually transmitted diseases. Each year, 200 women arrive pregnant.

The AIDS Epidemic

Alice is now out of prison, living drug-free and being certified as an AIDS educator. She remembers how hard it was for inmates to deal with being HIV positive in the face of limited medical services and stigmatization.

"The girls at Framingham don't have friends to begin with—they certainly won't if they tell people they have AIDS. It's sad because a lot of girls hide it instead of getting the medical care, support, and love they need. They don't realize that if they get help and remove some of the stress in their lives, they can live with HIV."

As they fall below the poverty line and into the drug culture, women will go to prison and contract AIDS at an accelerated pace. Prostitution, IV drug use, increased contact with high-risk males, poor immune systems as a result of malnutrition and addiction, all put women at higher risk for HIV infection.

At the same time, poor prison conditions around the country threaten the lives of inmates with the virus. A 1988 study conducted in New York State revealed that inmates infected with HIV tended to die twice as quickly as nonincarcerated AIDS patients. Another report released in 1991 by the National Commission on AIDS cited discontinuity of care, insufficient prevention efforts, stigmatization and categorical denial of privileges to inmates who are HIV positive as contributing directly to the AIDS epidemic in American prisons. And if prison conditions are bad for men, they are far worse for women. Although their medical needs are greater, women are an invisible part of the American prison population and have historically been denied access to even routine medical care—a catastrophic situation in the face of the large number of women who are HIV positive.

In 1988, Social Justice for Women released a report claiming that conditions at MCI-Framingham threatened the welfare of the inmates, whose immune systems were already compromised by alcohol, drugs, malnourishment, and especially by HIV/AIDS. Meanwhile, inmates complained of long waits for medication, excessive paper work, and a lack of discretion on the part of prison staff. For those who were HIV positive, the intense fear of dying in prison was compounded by the fear of being stigmatized and ostracized by inmates and staff. These conditions were enough to discourage many from confronting the disease and seeking help.

Since then, the WHLC and Emergency Medical Services Associates, which took over prison health care in Massachusetts in 1991, have worked to brighten the outlook for women at MCI-Framingham. Last year, Dr. Anne De Groot of Shattuck Hospital began to visit the prison twice a month to treat inmates infected with HIV. She says that poor nutrition, lack of exercise, and the overall stress of prison life continue to make it hard for inmates to combat AIDS. They wait on long lines five times a day to receive AZT. Often they must choose between a meal and medication despite the fact that taking AZT without food causes nausea.

But De Groot is hopeful and acknowledges many positive developments in medical care at the prison, including improved case management and communication; an onsite AIDS clinic; better nurses and doctors, more of whom are women; and more effective screening for HIV and other STDs. Even women who are not sentenced now have access to testing and information about health care providers in their communities. At the same time, Elly Andujar, a nurse whose position is sponsored by Linkage (an organization that provides medical and social services to drug addicts), has become a critical liaison between the WHLC and the health services unit. She joined the WHLC staff five years ago as a translator for Latina inmates and now assists De Groot. She knows the patients well, works full time, and communicates with De Groot in between visits.

Improved medical services strengthen the impact of the WHLC, which continues to exhibit leadership in addressing AIDS. In 1988, the center launched the Women and AIDS Project, since recognized by the Department of Health and Human Services as a national model. Outreach begins in the Awaiting Trial Unit and continues in the Newly Sentenced Unit and on the prison compounds. The WHLC offers pre- and post-test counseling and sponsors a biannual AIDS speakout. For women who are HIV positive, the WHLC arranges for buddies through the AIDS Action Committee and provides workshops, case management, and one-on-one counseling. The center also advocates early release for women too ill to sustain the prison environment.

Knowledge is power, explains Keeling. Being able to ask the right questions of the medical staff is the best way to access the system. In the Health Empowerment series, experts come in to discuss fetal alcohol syndrome, cirrhosis of the liver, and many other medical conditions affecting the female prison population. AIDS 101, now a required component of the Living with Recovery Program, covers the transmission of the virus, safe sex practices, and the sociopolitical history of the AIDS epidemic.

AIDS outreach is fortified by a new peer education program. Before she invented this program, Keeling, who used to oversee the Women and AIDS Project, was the main source of information and support on AIDS issues. But inmates were hesitant to be seen talking to the "AIDS Lady" for fear of being labeled as HIV positive. Well-informed inmates now serve as more discrete sources of information and support. Unlike the WHLC staff, peer educators are available around the clock and are more likely to witness risky needle use or sexual behavior in the prison. Meanwhile, they are empowered by serving this crucial role.

Andujar points out that having AIDS continues to be especially hard for inmates who do not speak English. Almost no prison personnel speak Spanish, leaving Latina inmates, who comprise 15 percent of the prison population, virtually unable to seek medical or other services. Tania, a 29-year-old inmate from Mexico, tries to provide support to other Latinas, especially when they are going through the HIV test. "I'm glad I was never sick. I cry with them. We have no support." She writes letters to the prison administra-

tion requesting more Spanish-speaking staff but says nothing has changed.

Meanwhile, HIV cannot be fought on an institutional level alone. Fear, guilt, and denial are widespread and must be grappled with by individuals. Andujar runs a group for HIV-positive Latinas called Viviendo Positivo or Living Positively. "My goal for the women is to have them accept their disease to the point that they don't have to worry about confidentiality. To be labeled as HIV positive is horrible to these women; they see themselves as dirty, bad. The fear of coming out about being HIV positive prevents women from getting the services they need. But stress only makes their immune system worse. They need to take care of themselves."

Tania's advice to other inmates embodies the most important message of the Women and AIDS Project: with adequate medical care and support, people can live with the virus for a long time. "If they just found out they have AIDS and can't face reality, I tell them the past is in the past. Focus on the future. There's no difference between a person who does and a person who doesn't have AIDS. Don't think about that. Just take care of yourself so you can live more years."

Preparing for Life on the Outside

Tania was brought up to believe that violence at the hands of men was acceptable. When she was raped as a teenager, she told no one for fear of being blamed. Later she married a man who tried to kill her twice before killing his own son. Now she is in prison for this crime.

Tania spoke with urgency about what she has learned from the WHLC. "I'm in prison because I didn't speak up for myself. Now I speak out about everything."

She may be in prison for a long time, but when she gets out Tania is prepared. "You have to stay away from people who use drugs and you have to use a condom. I love myself too much. I don't want to get AIDS after what I've been through. Just because I have no family and I'm alone—I won't do that. I won't sell drugs or sell my body. I know I can find people, a job. I'm young, I'm smart. I can do it. And I don't have to look for a man either . . . or I'll end up back here."

Most women in prison serve short sentences. Soon they must return to their old communities and encounter all the triggers and circumstances that led to incarceration and addiction in the first place. The WHLC provides inmates with tools, both psychological and practical, to regain control and make better lives for themselves. Inmates leave with resources for finding jobs and housing, access to lawyers and social workers, strategies for regaining custody of their children, interviewing skills, and options for continued therapy. Inmates are again encouraged to seek the support of other women.

But these are women who are used to broken dreams. Many feel that they are failures, bound to fall into the same patterns and traps. Through goal-setting workshops, Jones helps inmates gain control of their lives by identifying realizable short-term objectives, which in turn add up to larger dreams. Through role-playing and worksheets, they practice supporting one another and negotiating potential pitfalls. "It's almost like taking a stroll. We take our goals and our dreams and walk down the block. We walk through all the situations that might come up on the outside."

Once they leave, however, prisoners cannot come back to the WHLC for counseling. Keeling praises organizations like Aurora and Linkage, which serve formerly incarcerated women, but says that more are needed. "It would be helpful to develop a network of former inmates who could serve as counselors and mentors for women when they are released—that's the missing link." As people who know the ropes, former inmates could gain tremendous satisfaction and self-esteem while providing extremely valuable support.

The issues affecting the female prison population are manifold and daunting. The WHLC tackles them comprehensively and head-on. When bolstered by comprehensive medical and social services, programs like the WHLC can turn prisons into sites of reform and empowerment. The center can even serve as a model for community social programs seeking to prevent cycles of poverty, addiction, and illness before they begin.

The greatest testimony to the strength of the WHLC is the desire of women like Alice and Tania to inform and help others, both while in prison and back in their own communities. Alice, who is not infected with the virus, calls herself a walking resource on AIDS and may make a career out of the knowledge and values first bestowed upon her by the WHLC. Concerned that "old folks think they can't get AIDS," she hopes to do AIDS education and outreach to senior citizens. "With my old attitude, I didn't care who I stepped on. I didn't care about anyone except me. But I learned compassion. The Women's Health and Learning Center opened my eyes."

Meanwhile, Tania continues to reach out to other Latina inmates and has overturned her mother's and sisters' acceptance of violence at the hands of male family members. "People ask me why I keep coming back to the WHLC when I never used alcohol or drugs. Well, I have a baby and have eight brothers and sisters and I want to teach them. And also lots of people close to me need to know how to stay away from drugs and AIDS. I want to learn everything and educate myself to help anybody I can."

By encouraging women to look within and to one another as sources of information and support, the WHLC replaces poor self-esteem and despair with strength and knowledge. The impact of this transformation once these women return to their own lives, children, and communities is immeasurable.

Laelia Zoe Gilborn is a freelance writer and works at the Murray Research Center, an archive for studies on women's lives.

Outlook on
JUSTICE
NEW ENGLAND REGIONAL OFFICE • AMERICAN FRIENDS SERVICE COMMITTEE

SUMMER AND FALL ISSUE 1990 VOL. 8 NOS. 3 AND 4

THE WOMEN AND AIDS PROJECT

Women represent the fastest growing group with AIDS in the nation, currently comprising about 9 percent of the total cases - a three-fold increase since 1981.1 According to the Federal Department of Health and Human Services, as of January 1989, over 7,000 women were reported to have AIDS; as of this writing, the actual number of women with AIDS is much higher. By conservative estimates, 100,000 women nationally are infected with the human imunodeficiency virus (HIV).

The profile of the majority of women with the AIDS virus mirrors the profile of women at Massachusetts' only prison for women, MCI-Framingham. Most are in their mid to late twenties; over 75% are mothers with sole responsibility for their children; many are from poor urban areas with histories of drug use; a disproportionate number are African American and Latina women.

According to the Boston AIDS Action Committee, 20 percent of Massachusetts' HIV infected individuals are in correction facilities; a disproportionately high number are women. About 35 percent of the approximately 400 women at MCI-Framingham who volunteered for the AIDS anti-body test in 1988-1989 have tested positive, compared to 13 percent of male prisoners. This disparity reflects a significant characteristic

Feminist Communications / CPF

of Massachusetts' female prisoner population: 90 percent have a history of poly-substance abuse. Sharing contaminated drug paraphernalia accounts for most of the cases of HIV infection.

In response to the increasing number of imprisoned women with HIV infection, Social Justice for Women initiated the Women and AIDS Project in 1988. A national model program, the Women and AIDS Project (W/AIDS) has monitored the medical care, treatment, and aftercare services of scores of HIV-positive women at MCI-Framingham and has reached thousands more women with group education programs and individual counseling.

Social Justice for Women (SJW) is a private non-profit organization dedicated to providing innovative treatment services to women involved with the Massachusetts criminal justice system. SJW designs and advocates for realistic alternatives to imprisonment which address the complex issues in women's lives that lead to conflict with the law, including substance abuse, incest, sexual assault, family violence, poverty, homelessness, discrimination, and lack of education and job skills. SJW is committed to empowering women to recover from substance abuse, to regain their health, to believe in their potential to change, and to achieve personal growth.

Social Justice for Women initiated and administers four programs:

* Community Services for Women designs and advocates alternatives to prison for women that address substance abuse, health care, AIDS education, homelessness, child care, GED, and job training/placement.

* The Neil J. Houston House, a first-in-the-nation model, is a residential treatment program which restores health and hope to incarcerated pregnant women and early intervention services to their infants.

(Continued on page 2)

(continued from page one)

* The Women's Health and Learning Center provides substance abuse treatment, counseling, and education to the over 4,000 women annually sentenced to or detained at MCI-Framingham.

* The Women and AIDS Project, the first program in the country to bring AIDS education, counseling, and support services inside a prison.

Since 1982, SJW has administered the Women's Health and Learning Center, the longest running, non-profit, daily substance abuse program for prisoners in the country. The Women's Health and Learning Center (WHLC) is the only on-site daily substance abuse treatment program inside MCI-Framingham.

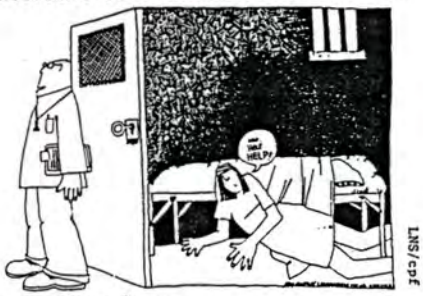
From their position inside the prison, the WHLC staff witnessed and expressed alarm over the increasing incidence of HIV infection among the women who participated in their programs. In June 1988, having secured the Department of Correction's sanction and funding from the Massachusetts Department of Public Health (Center for Disease Control), Social Justice for Women established the Women and AIDS project inside MCI-Framingham. Less than a year later, the project was selected as one of five model programs out of 120 surveyed in a federal Department of Health and Human Services study to identify innovative programs for HIV-positive women.2

The Women and AIDS Project remains the only AIDS-related program inside MCI-Framingham to provide the much needed AIDS services to the approximately 4,000 women confined at MCI-Framingham each year. The W/AIDS team provides educational services to approximately 2,000 women and case management to approximately 350 HIV-positive women each year.

Educational programs and counseling focus on symptomology, treatment and prevention of HIV infection. One-to-one counseling and group workshops address a variety of issues, including crisis intervention, substance abuse treatment, pre- and post-test counselling, institutional prejudice and isolation, denial and grief, and family and parenting.

HIV positive women are seen daily by a member of the multicultural W/AIDS team who assists each woman in meeting her acute needs and designing an aftercare plan. The W/AIDS team works closely with AIDS Action Committee, client family members, parole and probations, and hospice providers to develop appropriate aftercare plans for HIV positive women released from prison.

The W/AIDS team advocates for pre-release of incarcerated women who have become too sick with AIDS to sustain the prison environment. The terror of AIDS is significant enough; it need not be compounded by the terror of dying inside prison, without family, friends, or appropriate medical care. Early release, reunification with family members, and appropriate aftercare services can alleviate that part of the fear.



For all women at MCI-Framingham - especially those with HIV infection - lack of control over medical care is one of the most frightening aspects of prison life. For women experiencing such overwhelming stresses, emotional recovery and health maintenance are extremely difficult.

The Institution's capacity to deliver good health care services to any woman, much less to the increasing numbers with HIV-related illnesses, is severely limited by inadequate facilities, staffing, and equipment; chronic budget cuts to state agencies have had a devastating impact on medical care at Framingham. Even before the Commonweath's present fiscal crisis, the Department of Correction's health service budget began every fiscal year in deficit. In 1989, Framingham's health Services Unit requested 6.5 additional nursing positions and more physician assistant hours; no action has been taken on that request.

Currently, more than 500 women compete for a total of 80 physician assistant and nurse practitioner hours per week. Women at Framingham share 25 physician hours per week with the more than 100 men housed at South Middlesex Pre-Release Center.

All newly sentenced women, regardless of HIV status, are initially confined in the prison's 11-room Health Services Unit where they are screened for hepatitis and other communicable diseases before being transferred to the prison compound. As many as seven women are locked 22 hours per day in a single, dark, poorly ventilated 10' by 16' cell designed to accommodate one or two women. These circumstances are especially health threatening for HIV infected women who should be protected from compounding opportunistic infections.

The shortage of medical personnel at Framingham precludes thorough and accurate record-keeping, comprehensive care plans, and continuity of care. Women are not assigned to a specific physician or physician assistant, and those with on-going or chronic illnesses may be examined by medical personnel unfamiliar with the course of their illnesses.

Women are required to walk from their housing units and stand in "med-lines" to receive medications. For women who are ill, the requirement is an undue hardship, especially in cold and stormy weather; some choose to skip medications

(continued on page 3)

(continued from page 2) rather than endure the discomfort.

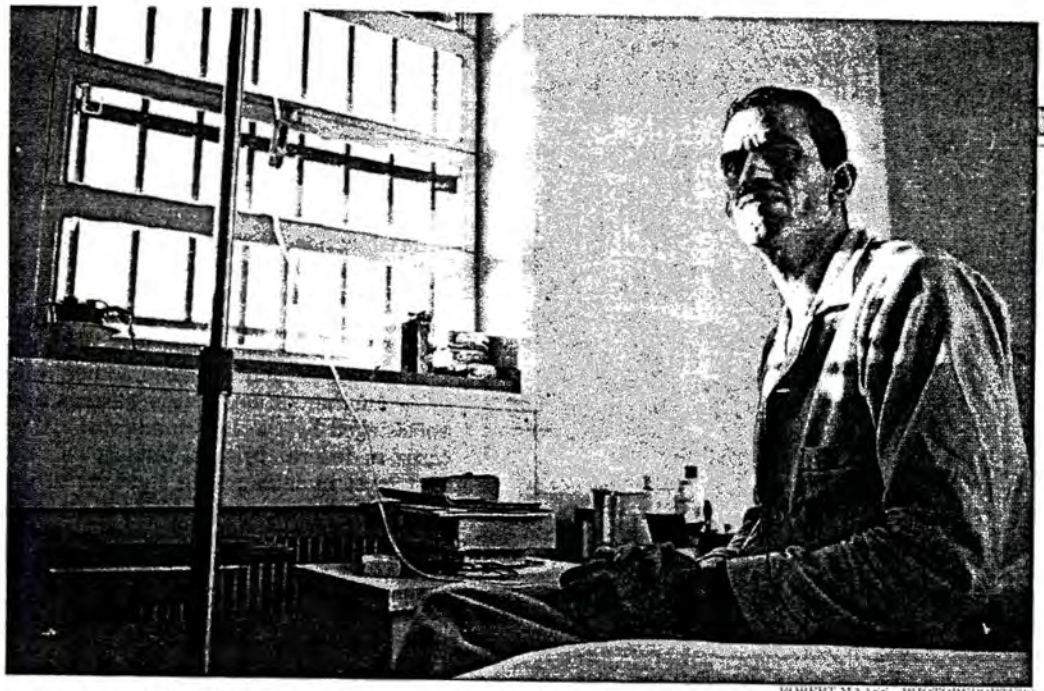
A health Services system ill-equipped to handle medical needs is severely under prepared to manage the growing HIV crisis. As the number of HIV-positive women rises and as more women already infected with HIV get sicker, reassessment of current medical and other treatment services and planning becomes increasingly urgent.

With funding from the federal office for Substance Abuse Prevention, Social Justice for Women in collaboration with Dimock Community Health Center and the Department of Correction has implemented at MCI-Framingham an on-site medical clinic specifically designed to treat sexually transmitted diseases. SJW sees this as a major step forward toward the humane and timely care of HIV positive women; the clinic will be run by an AIDS specialist to monitor women's T-cell counts and AIDS related illnesses and plan timely use of medication (including experimental AIDS drugs). It is anticipated that the clinic will be operational by mid fall of 1990.

....Marianne Galvin, PhD
Director of Administration

Social Justice for Women

1. This articla contains excerpts from The AIDS Epidemic: Impact on Women Prisoners in Massachusetts - An Assessment with Recommendations, by Nancy Waring, PhD, and Betsey Smith, Social Justice for Women, 1990.
2. Cheri Adams Flynt and Jean Cohen, "Identification and Assessment of Coordinated Community-based Programs and Services for Women at Risk for AIDS," prepared by Macro Systems for the federal department of Health and Human Services (April, 1989), p.1.



ROBERT MAASS—PHOTOREPORTERS

Prisons are not the AIDS 'hotbeds' that everyone predicted: *DeMaio at the AIDS unit in Sing Sing*

Learning to Live With AIDS in Prison

Behind bars, there is a new death row, but its inmates are being dealt with in enlightened ways

Inside the walls of American prisons, convicts call it "the package." AIDS, an agonizing, protracted form of execution, has created a new death row, more dreaded than the old. Over the years, cellblock grapevines buzzed with tales of prisoners who were beaten and stabbed by other inmates, or thrown into solitary confinement by guards—just for having AIDS. But now prisons, sometimes prodded by lawsuits filed by prisoner-rights organizations, are beginning to adopt enlightened policies toward convicts with AIDS. In New York state, for example, inmates who are not currently hospitalized with an AIDS-related illness can return to the "mainstream" prison population. To reduce fear among staff and inmates, many prison systems have set up AIDS-education programs (box, page 28). Guards no longer automatically wear masks and gloves when escorting inmates with AIDS. Some states even allow inmates to go home to die.

When the AIDS epidemic hit in 1981, doomsayers predicted prison hospitals would overflow with junkies, homosexual rapists and cellblock "queens." "We're going to see a whopping epidemic," complained one Maryland prison official a few years ago. But to date, this grievous scenario has proved exaggerated. According to a study funded by the Justice Department, there have been only 3,136 confirmed cases of AIDS behind bars, less than 4 percent of the national total. The number of prison AIDS cases increased by 60 percent last year, but on the outside, the rate of increase was 76 percent. Of the 49,414 federal prisoners tested for AIDS antibodies since 1987, only 1,417 inmates tested positive. In 1988 less than 3 percent of new federal inmates coming in from the outside were found to be HIV positive. Says James Riley of the Texas Department of Corrections, "It's a myth that prisons are breeding grounds."

Quarantined: *Prisoners at Vacaville*

JAMES D. WILSON—NEWSWEEK

One reason that the AIDS rate in prison may be lower than expected is caution on the part of the prisoners. Some inmates say that high-risk behavior—unsafe sex in which body fluids are exchanged, sharing smuggled drugs and needles, even tattooing—has dropped off substantially. "It's gone down to a minimum," says AIDS patient Robert DeMaio, 36, who is serving time for second-degree murder in New York's Sing Sing prison.

While the stigma of AIDS has eased, reports of serious abuse continue. In a well-publicized case last year, guards in a federal prison in Richmond, Va., allegedly handcuffed Michael Henson, 33, and tossed him into "the hole" after he tested positive for AIDS antibodies. (The prison denies Henson's charges.) In Nocatee, Fla., Scott Brewer—who later tested negative—told a jailer that he might have been exposed to the virus. "They stuck me in an isolation cell with an AIDS patient," Brewer said. "The officer yelled, 'I've got one with AIDS here'." A bigger problem than abuse is unreliable medical treatment. At the U.S. Medical Center for Federal Prisoners in Springfield, Mo., Michael Lingard had to sue for the right to take regular doses of AZT, the drug that appears to prolong the lives of people with AIDS. Around the country, numerous inmates have died prematurely because prison doctors misdiagnosed their symptoms. A New York state study made last year found the mean survival of AIDS inmates was 128 days—about eight months less than on the outside.

Home to die: But even the most critical AIDS activists concede that some progress has been made. One of the most welcome reforms has been the "compassionate release" parole. California has had the policy for three years, but only two patients have gone home. New York's plan is little more than a year old, and 46 parolees have taken advantage. "Most families accept them," says Ann Quinlan, nurse administrator at Sing Sing. "They see how we deal with patients, and learn by osmosis." Some families still say no. "No one wants to die in jail," said "Lucky," 39, a Georgia convict, "but that's the way it is sometimes." (Last month Lucky died in a prison hospital.)

Allowing prisoners access to condoms for "safe sex" in prison has been the most controversial new policy. Prisons in Vermont and Mississippi, as well as New York City jails, make prophylactics available. But in Bible-belt Mississippi, where sod-

JAMES D. WILSON—NEWSWEEK

Fighting fear and ignorance: *An AIDS counselor visits the San Francisco County Jail*

omy laws are still on the books, church groups protested loudly. Nationwide, prison officials are largely opposed on the ground that free condoms might encourage sexual activity, even rape, as well as create other problems. "Our security people are concerned about this," says Texas administrator Riley. "These things can be turned into slingshots. They can be filled up with a variety of items, and turned into bombs."

Several states, including California, cite the threat of homosexual rape and needle sharing to justify quarantine policies. At the California Medical Facility at Vacaville, healthy HIV-positive inmates are segregated alongside AIDS patients. Some officials fear the situation could erupt into violence. "Parole violators are living with lifers and murderers," says physician Jan Diamond who treats AIDS patients at Vacaville, "and that creates stress." David Wayne Smith, 33, a petty thief housed in the unit, agrees: "Something's not clicking and the tension is mounting all the time," he says. In a recent incident at an AIDS unit in the California Institution for Men in Chino, 15 HIV-positive inmates broke 220 windows to protest their segregation. Elsewhere, even in states that allow AIDS inmates to live in the general population, anyone with a potentially violent nature is isolated: in 1987 a Florida convict laced a guard's coffee with his own AIDS-infected blood.

But at the federal medical center in Springfield, AIDS patients find a potentially positive advantage in being forced to live on a rigid schedule: they welcome being guinea pigs for experimental drugs such as CD-4, which impedes the virus's destruction of the immune system. "You've got inmates in a controlled environment," says Michael Miller, 43, who is HIV positive. "I, for one, would be standing in line for any test."

Prisons sometimes actually involve AIDS activists in policymaking, bringing them in to develop education programs. "We do role playing," says John Egan of the Mid-Hudson AIDS Task Force in White Plains, N.Y. "Inmates act out scenes like being tested or being told they're antibody positive." But some activists say prison officials, reluctant to concede that sex and drug use cannot be controlled, provide too little education. And even when programs exist, the critics say, institutions do not require attendance, rarely offer follow-up sessions and rely on printed material for people with a high illiteracy rate.

If ignorance is one obstacle, complacency is another. Many prison officials are encouraged by the low number of AIDS cases in federal prisons, but they know that most inmates are in state facilities. Only 13 states, largely in areas where AIDS is relatively rare, screen for antibodies. Moreover, the full force of the epidemic may not have hit prisons yet. "There's no hotbed now," says Dr. C. E. Alexander, medical director of Texas prisons. "But what's going to happen in 1995?" Indeed, on the outside, AIDS continues to spread rapidly among i.v.-drug addicts, and in New York state alone, the Department of Correctional Services estimates that between 60 and 70 percent of all inmates have a history of i.v.-drug abuse. Epidemiologists now believe the incubation period for the virus can be more than eight years, maybe as high as 20. Prison officials have to stay vigilant: if the numbers start to climb in the 1990s, the new death row may yet become as overcrowded as was originally feared.

JAMES N. BAKER *with* SUE HUTCHISON *in Boston.* NADINE JOSEPH *in Vacaville.* HOWARD MANLY *in Atlanta.* DANIEL PEDERSEN *in Houston.* KAREN SPRINGEN *in Springfield and* NED ZEMAN *in New York*

For Women: Education and Mutual Support

They tell a parable about "Blackie" at the Bedford Hills Correctional Facility, New York's maximum-security prison for women. Blackie, an inmate who died of AIDS last year, used to say she could always leave her things lying around because she knew no one would dare touch them for fear of being exposed to the virus. Then in 1985 the prison had its first AIDS Counseling and Education program (ACE), and attitudes started to change. "Eventually everyone started stealing [Blackie's things]," an ACE participant recalls. "That was a good sign."

Around the country, some of the most innovative AIDS-education programs have been developed for women behind bars. In San Francisco, Sean Reynolds, an AIDS counselor for the county public-health department, uses tough talk to teach women in the tanks. "Think of condoms as your American Express card, honey," she says. "Don't leave home without it." In Boston, an activist organization called Social Justice for Women developed "AIDS 101" that features "speak outs" where inmates can go to an open mike and say what's on their minds about the disease. "Before, if women tested positive, [inmates] would call them 'AIDS-carrying bitches'," says Francine Melanson, a former drug addict who runs AIDS 101 at the Massachusetts Correctional Institute at Framingham. "Now they're knocking down my door, asking how they can help."

The programs often inspire women to take the antibody test. "I'm going to get tested when I get out," said Michelle Thompson, 23, after one of Reynolds's seminars. "I've been on the streets since I was 11 . . . doing heroin." ACE has stayed in touch with a number of parolees and hopes to set up counseling groups on the outside. But the biggest benefit may be to prisoners who are dying of AIDS. Says Sonya, a frail Bedford Hills inmate who can remember what it was like to be harassed for having AIDS, "These people take care of you."

Our penal system has long failed to address the needs and problems of female offenders. Now, however, there are more creative solutions for a woman in trouble than confining her to a cell.

ALTERNATIVE PATHS

Four years ago, 30-year-old Sandy, mother of two and a heroin addict, served her first prison sentence: six months in MCI-Framingham on drug possession and prostitution charges. When she got out, Sandy (not her real name) was straight for a while. But soon she was on drugs again. And in short order there were more arrests. After she failed to make two court appearances, Sandy knew it was only a matter of time before another arrest, even a routine traffic ticket, uncovered those defaults and she would be Framingham-bound again.

On the advice of a friend, Sandy picked up the phone and called Community Services for Women (CSW), a program that works with court-involved women to find alternatives to prison — alternatives that include supervision as well as services to address the underlying problems that have brought these women into the criminal justice system in the first place.

Sandy is not in jail today. She is enrolled in a methadone program. She is participating in regular family counseling. She has undergone a skills evaluation and may begin a job-training program in the fall. And every week she is in touch, by phone or in person, with CSW client advocate Priscilla Damon, who checks up on Sandy to make sure she is upholding her end of the bargain.

That, essentially, is what alternative sentencing is: a three-way bargain struck among a judge (who agrees to "sentence" the woman to a program other than prison); Community Services for Women (which develops the program with its client's specific needs in mind, goes to court with her to present it, then supervises her participation throughout the "sentence"), and the woman herself (who agrees to stay in touch with CSW while she completes her sentence). Her "sentence" might involve a residential drug treatment program or outpatient treatment combined with frequent, perhaps daily, telephone contact with counselors who monitor her whereabouts and activities.

Those who favor alternative sentencing say it is a bargain in another sense too: It is cheaper than prison and more effective in getting women to make the kind of long-term changes in their lives that make them less likely to be repeat offenders.

PRISCILLA DAMON SPEAKS SOFTLY AND CARRIES A BIG CONVICTION. "PRISONS," says Damon, "are expensive to run, they're overcrowded, and they really don't work."

Damon knows whereof she speaks. From 1983 to 1989 she administered a self-help program called People to People for inmates at MCI-Framingham. Last year Damon left the confines of Massachusetts' only sentencing institution for women, seeking what she calls "a more hopeful solution . . . a chance to work with women before their lives are totally destroyed."

Damon has found that chance at Social Justice for Women, a 4-year-old non-profit organization dedicated to providing treatment and alternatives to incarceration for women in Massachusetts. When Social Justice for Women incorporated in 1986, the organization took over CSW, originally run by

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By Barbara Donlon

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Smith College. Since then, the program has developed alternative sentencing plans for nearly 100 female offenders.

Now Priscilla Damon and her partner, Toni Jones, a certified alcoholism counselor, spend three or four mornings a week in Boston Municipal Court, attempting to interest potentially prison-bound women in their program.

Armed with a list of women being held (either recently arrested and awaiting arraignment or waiting for their trial appearances) and the charges against them, Damon and Jones troll the troubled waters of the BMC holding cell for new clients, passing out their cards and talking to any woman who seems ready to listen.

They are low-key evangelists, spreading a simple gospel. As Jones puts it: "One of my aspirations within the scope of my position is to reach out to younger women [CSW's typical client is in her early 20s] and let them know that there is another path, a different road other than the one that she has chosen."

It is not always an easy sell.

The surroundings, for one thing, are hardly conducive to confidential exchanges. The holding area at BMC might contain as many as 14 women, with charges ranging from common nightwalking to assault and battery.

"It may be high tension, a lot of noise," says Jones. "I go in and try to get a sense of whether these women will talk to me. Most of the time there are some who do want to talk . . . if for nothing else, to find out if [we] can help them get out of this mess. So that's like an opening, and they'll listen. I don't force a woman to talk if she doesn't want to."

Damon and Jones are happy to talk to any woman who wants to talk to them, but they zero in on those facing serious charges and those with additional outstanding warrants, which make the women more likely candidates for incarceration.

On a rainy Monday morning, the second session of Boston Municipal Court is in full swing. First on the schedule are eight or nine driving-under-the-influence cases, all men. Women picked up on disorderly conduct charges (most of which seem to involve impeding the flow of traffic in and around the Combat Zone) will be up next.

Later in the morning, Damon is scheduled to stand up in court for an 18-year-old who has been arrested for disorderly conduct, a violation of her parole on a similar charge.

In the meantime, Damon and Jones look over their list.

There are eight names on it this morning, a couple familiar. The two client advocates repair to a small anteroom outside the holding cell adjacent to the courtroom. There, separated from the women inside by both bars and heavy mesh screening, they scan the sheet and call out the names of women they'd like to talk to. One by one, women who have sitting on a long bench smoking or stretched out on the floor rise and approach the bars.

Sound echoes off the yellow tile walls and Damon and Jones must press their faces close to the wire screen, as if in a confessional, in order to hear and be heard by the women on the other side, their features barely discernible through the thick mesh.

A young-looking blonde in a pink-and-white sweatshirt assures Damon that her problem (a matter involving a stolen purse, complicated by an outstanding warrant) is not drug-related. She is 5½ months pregnant.

"Do you have a safe place to live?" Damon asks.

The blonde says that she is living with her mother.

"Are you getting any prenatal care?" Damon presses.

"What's that?" the woman asks.

Another young woman in a miniskirt and fringed leather-look jacket is here on a disorderly conduct charge. She confidently announces that she is planning to enroll in college. Two minutes later, she admits she has not finished high school.

Damon, with her graying hair, high-necked blouse, and half glasses, looks the motherly part. Jones, in slacks and running shoes, with a cutting-edge haircut adorned with a tiny beaded braid, downshifts effortlessly between the language of the human services professional and slangier street lexicon. Both press their faces close to the mesh screen, trying to make a connection with the woman on the other side. Both know that some of these women will say whatever they think anyone they perceive as being in a position of authority might want to hear.

They are not discouraged, however. Today they plant the seeds. Tomorrow and next week and next month they will be back. In all probability, many of these women will be back too. Some may even be ready to listen.

It is almost 11 a.m., and Damon hurries down the hall to another courtroom where she will shortly present an alternative sentencing plan to Judge Sally Kelly on behalf of the 18-year-old probation violator. The defendant, in tight white jeans and a fluffy sweater, is led into the courtroom with her ankles shackled and sits down next to her attorney.

Kelly is interested in the girl's living arrangements. She has her own apartment in a building her father owns, she says.

The judge inquires as to whether she has brought anyone to court with her this morning. She has not. (She says her father does not know that she has been arrested.)

While the judge does not seem particularly pleased with these responses, she listens to Damon's proposed plan for the girl: regular supervision, the details of which will be worked out between the defendant and CSW, and possible job training and employment pending her return next fall to classes at a local community college. Kelly decides to stay the girl's sentence for a month to give her a chance to show that she can keep to her reporting schedule with CSW.

"If she's arrested again, I'll send her back to Framingham," Kelly promises.

The girl hurries from the courtroom with her attorney. Later, Damon hunts her down in another courtroom to talk to her. Damon isn't sure how she'll do with the program, but says that the fact that she committed herself to longer-term supervision when she could have simply served two months in Framingham and gone free is a hopeful sign. One taste of jail may have been sufficient for this one, she thinks.

According to Damon, after hearing the proposed sentencing plan, a judge will often dispose of the case by granting a lengthy continuance or probation contingent upon the woman's faithful adherence to the plan. Or her sentence could be suspended or a stay of execution of sentence granted — as in the case of the 18-year-old — contingent upon her performance under the alternative sentencing plan. (Unlike a suspended sentence, in the latter case if a client violates the agreement, the state sentence goes immediately into effect, says Damon.)

According to CSW, 93 percent of the alternative sentencing plans they proposed in 1989 were approved by the court. Approximately fifty-five women are currently completing alternative sentences under the CSW program. (Almost all CSW clients have been arrested more than once; at least half have been incarcerated prior to trying alternative sentencing.)

Damon and Jones also find clients in Framingham. Following her arraignment, if a woman is not released on bail or on her own recognizance, she is sent to MCI-Framingham and the Awaiting Trial Unit (ATU). Damon and Jones visit the ATU one day a week to keep in touch with women they have already made contact with and see others who may be interested in an alternative program.

As a former alcoholism counselor, Jones knows that the point at which a substance abuser hits bottom — whatever her particular "bottom" may be — is often the moment when she is most open to intervention. "Prison-bound women may have hit bottom," says Jones. "And maybe this is the time to look at where their substance abuse is taking them."

The substance-abuse issue is critical: More than three-quarters of the women CSW deals with abuse drugs and/or alco-

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is not the only measure of success say Nickerson and Manocchio. For an indigent, homeless woman, sticking with the program for even three months will leave her better off than she was before.

"I get a sense that, with our women, even if they do relapse, they tend to seek treatment [again] a lot sooner than if they'd never been here," says Nickerson.

Women who have been involved in rehabilitation programs offered inside MCI-Framingham, while previously incarcerated, also seem to be able to build on that experience, Nickerson says. "The women just coming out of Framingham [without program participation while inside] didn't do as well."

After eight or nine weeks at Womanplace, says Nickerson, all residents are required to hold a job (and contribute a portion of their earnings to the house) or do volunteer work in the community. The work component is important because, she says, "some of our women have never held down a legal job."

Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) meetings, either afternoons or evenings, are also part of the recovery program. After four months, the women move into what Nickerson terms the "aftercare" component: individual and group counseling to help them cope with their transition back into the community.

While women wait for places to open up in residential programs, many seek services on an outpatient basis. But the problem with some of the most common 12-step recovery programs, like AA and NA "is that [they] leave women with huge amounts of unstructured time during the day when they may get into trouble," says Social Justice for Women's Galvin.

To address the needs of such women for structure and supervision in their lives, in January, CSW, in conjunction with the Crime and Justice Foundation, started a program called Day By Day Alternatives. Funded by a grant from the Public Welfare Foundation Inc. in Washington D.C., it combines support services with a reporting program wherein a woman is closely monitored through daily in-person and telephone contacts with counselors at Boston's Metropolitan Day Reporting Center. Women must also comply with curfews and periodic urine screens.

Although the program is still too new to draw any conclusions about its impact, Galvin is encouraged. "We believe it *is* possible to structure outpatient programs to incorporate the specific needs of women," she says.

If it's possible to develop recovery programs that work for women on the outside, is it not possible to provide the same thing for them while they are incarcerated? There are such services within

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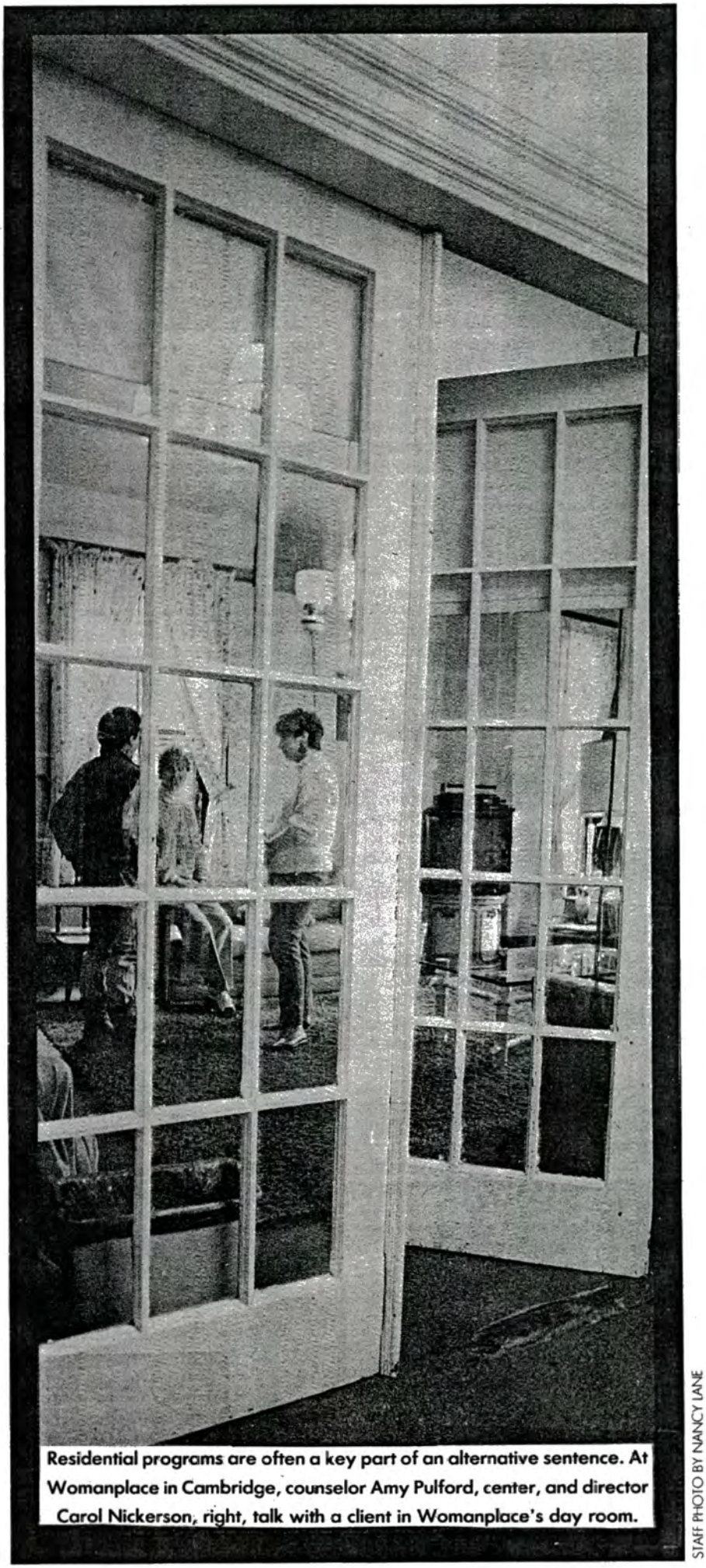

Residential programs are often a key part of an alternative sentence. At Womanplace in Cambridge, counselor Amy Pulford, center, and director Carol Nickerson, right, talk with a client in Womanplace's day room.

STAFF PHOTO BY NANCY LANE

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hol. Over half admit to using needles on a daily basis.

So, for the majority of CSW's clients, gaining some measure of control over their drug and alcohol problems is the priority. For most, a key part of their alternative sentence is their enrollment in a residential treatment facility.

"A significant impact on substance abuse really requires . . . at least six to eight months of residential supervision," says Marianne Galvin, director of development at Social Justice for Women. "The first couple of months of [the] alternative sentence, most of the women are not at the point where they can address education or job training. It is only toward the end of the residential program that they are able to make some concerted decisions about these things.

"Then . . . depending on whether she has certain educational and employment skills, we might channel her towards education or training or community service," Galvin continues.

Once Damon and Jones have helped a woman identify some residential treatment programs in her area that might be suitable, it is up to her to make contact and get herself on a waiting list. (If she is already inside MCI-Framingham, the CSW staff will try to do this for her.)

According to Jones, the wait for admission into one of these centers can be three to six months. While she waits, a woman can count on at least weekly contact with the CSW staff. (Damon and Jones, who each handle about 15 clients at a time, maintain monthly contacts with clients while they are in residential treatment.) The continuing contact and support is critical for women with few constants in their lives, say CSW staffers.

"I think that what is unique about this program is that sense of agreement — that what we [CSW] are agreeing to is that we'll work with [the women] through all the ups and downs of their lives. The fundamental agreement is that they will keep in touch with us at least weekly," says Damon.

Community Services for Women staffers wish there were more substance-abuse treatment programs responsive to the specific needs of female clients. "We strongly believe that traditional treatment is geared towards men, both in structure and timing," states Galvin.

For example, treating recovering men and women addicts together, whether on an inpatient or outpatient basis, is not the best approach, she says.

"The vast majority of women — probably between 70 percent and 80 percent — readily admit that the catalyst for getting them involved in drugs was a man: a father . . . a lover. To put these women into treatment with men essentially sets them up for failure," says Galvin. "They [women] very easily fall back into a pattern of manipulating men . . . roles that they had played out on the street in order to get whatever they needed to obtain drugs."

In addition, says Galvin, "many of the women have been abused sexually or emotionally by men, and it's impossible for them, in treatment with men, to address those issues."

There are about 35 residential treatment centers around the state to which CSW refers clients. One such program is Womanplace, a rambling Victorian house on a quiet side street in North Cambridge, that is home to 20 young women struggling to come to grips with their addictions to drugs and alcohol. It is one of two residential programs — the other being New Day, for pregnant women — run by the Women's Alcoholism Program (part of CASPAR, the Cambridge and Somerville Program for Alcoholism Rehabilitation).

During the first two months, says director Carol Nickerson, the women (who must be alcohol- and drug-free, having gone through "detox" before arriving at Womanplace) concentrate on developing a sense of community with others in the house and on learning to cope with the stresses that often lead to relapse.

This is a highly structured environment in which the women share chores and attend regular house meetings where they work on family issues, parenting skills, self-esteem building, and learn how to handle anger and depression without, as Nickerson puts it, "covering those feelings with the effects of mind-altering drugs."

"The kinds of groups that are set up here have actually evolved over the years to meet the changing needs of the women who come here," says Fran Manocchio, director of the Women's Alcoholism Program that runs Womanplace. As an example, Nickerson cites sessions the staff has instituted to help residents with anorexia and bulimia. "Half of our [clients] have some sort of eating disorder," she says.

Manocchio and Nickerson agree that women addicts have special concerns that must be dealt with if recovery is to be lasting. For example, says Manocchio, "there is a double stigma attached to being a woman and being an addict . . . there's more guilt and shame."

This is particularly important, given what she calls the "sexualized image" of women alcohol and drug abusers. "People automatically assume that if you're an alcoholic or an addict, that you're sexually promiscuous . . ." says Manocchio.

"When women come here, they have lost everything — family, friends, places to live — and in addition to the material losses, there are deep emotional and spiritual losses. They've lost their sense of selves . . . their values and morals."

Helping women overcome feelings of powerlessness and helplessness and take control of their own lives is central to the recovery process, since, as Manocchio notes, "when they come in, the substances have had control over their lives."

Most of the residents at Womanplace are from dysfunctional families — either their own parents have drug and alcohol problems or their partners are substance abusers. Many must also come to terms with the lingering effects of family violence, sexual abuse, or incest.

But there are more everyday issues to deal with, too. "One of the unique aspects of this program," says Manocchio, "is that it provides a comprehensive look at the whole process of recovery . . . vocational issues, daily living skills — shopping, menu-planning — the simple day-to-day tasks that a lot of women have not learned, either because of the adolescent beginning of their substance abuse or [they] come from families where they were not able to learn those skills."

Learning these skills is important, she explains, because a recovering woman can become overwhelmed by the details of managing her life, work, and family — frustrations that can make her revert to the comforts of a needle or a bottle.

Thirty-three-year old Angela (not her real name) had never been in jail, but had been through a rehabilitation program at a private hospital in an effort to kick her drug and alcohol addiction. "But when I got out, I realized in order to keep my sobriety, I needed to do more," she says.

She came to Womanplace and "graduated" from the residential program in November 1987, after which she lived with several other recent graduates in a "sober house," then got a place of her own with another recovering woman. Angela is back at Womanplace now, this time as a counselor. She runs a weekly mothers' group and also provides one-on-one counseling to six residents.

A residential center like Womanplace, "gives you a chance to get away from the isolation . . . the feeling that 'I'm-the-only-one-going-through-this,' " says Angela.

"You get a lot of support here . . . it's a whole new sense of family. It also teaches us how to live — there are commitments and deadlines. There's always someplace you have to be. I think it's important for any recovering person to have that structure," she adds.

Nickerson estimates that 40 to 45 percent of Womanplace's clients complete the six-month program. But "graduation"

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MCI-Framingham, provided either by Department of Correction personnel or by private agencies under contract to the state. Volunteers run AA and NA meetings inside, and Social Justice for Women has a program called the Women's Health and Learning Center that provides substance-abuse counseling and an AIDS education project.

But there are built-in Catch 22s for women seeking recovery behind bars. For one, a correctional institution, with its emphasis on order and need to keep inmates as docile as possible, is hardly the ideal setting to nurture qualities like group cohesiveness and personal self-assurance and assertiveness — the very things a woman needs to build a new life.

Then there is the overcrowding at MCI-Framingham itself — nothing new in the Massachusetts correctional community, but perhaps less heralded in the women's prison than in the men's facilities. Almost all women offenders in the state, including county prisoners and those awaiting trial or serving state sentences, end up at MCI-Framingham.

Built in 1875, the institution was designed to hold 136 sentenced inmates. In early March, the census was 422. The Awaiting Trial Unit was designed to hold 19 women. In March it housed approximately 86.

Damon notes with some amusement the recent uproar over double-bunking at MCI-Cedar Junction maximum-security facility for men. "When I worked at [MCI-] Framingham," she says, "one of the parts of my job was working with long-termers — [women] who had five years or more to serve. The Framingham women have been double-bunked for some time. The last of the single rooms disappeared last spring, just about the time I was leaving there," says Damon. "There were very few of the long-term women who were still in single rooms then. In ATU and some of those areas, there were times when there were six to seven in a room."

Another problem is MCI-Framingham's geographical isolation from most of the community resources that could benefit the women in its care. Because of this isolation, the Female Offender Advisory Report (a DOC-sponsored survey of MCI-Framingham inmates, published in November 1988) noted, "women have great difficulty contacting local resources, such as lawyers, courts, and community agencies involved in job training, housing, or drug treatment programs."

The reality is that most residential drug treatment programs (and some housing subsidy programs) require face-to-face interviews with potential clients. Says Toni Jones: "Treatment facilities are really backlogged — there's a waiting list of three to six months. Those that will come out [to Framingham] to interview ... their waiting lists are even longer. To my knowledge, right now there's only approximately three residential facilities that will interview [women] out there."

Most inmates at MCI-Framingham are serving relatively short sentences. In contrast with the average length of stay for men in the state prison system (four-and-a-half years), most of the women sentenced to MCI-Framingham leave the institution within six months. Over half leave in under 60 days.

But a short sentence can be something of a mixed blessing. It's questionable how much of a lasting impact a drug treatment program is going to have on a woman after only a month or two of participation. (The Women's Health and Learning Center, for example, last fall changed its program from a 10-week cycle to a seven-week cycle to accommodate women with shorter sentences.)

Also, according to the Department of Correction, only 30 percent of women inmates are paroled, meaning that once they return to the community, they will rarely have the regular supervision that a parole officer provides (along with helping former inmates access job training, housing, and mental-health services).

That is why, say CSW staffers, they try to stick with a woman during the vulnerable period when she is first out on her own. For example, they might help her get into a halfway house following residential treatment or help her find an apartment. (Marianne Galvin estimates that about a fifth of CSW clients are homeless when they enter the program.)

Ultimately, of course, the most well-designed program will be useless to the woman who does not reach out for it. "Some women do make a choice to stay in prison rather than go into a substance-abuse program ... because they're not ready to take a look at their substance abuse and start making changes. A lot of them aren't ready to do that," says Jones.

Many women recover only to lapse again, in a pattern that is familiar to those who work with drug and alcohol abusers. But the CSW advocates say they are willing to stick with their clients down the long road to recovery, even if there are detours.

"I lost one at the door of detox," says Jones, sighing. "Yet there's another one out at MCI who seems to be more and more motivated each day ... This is not about giving up.

"That's the beauty of this work ... we are talking about women with a lot of disillusionments, disappointments, and let-downs. To pick them up at the place where we pick them up — at BMC or the Awaiting Trial Unit — that has got to be where the most despair is," says Jones.

"If you can get one that, in spite of all that, will still take your hand and reach out to you ... then you've got something going." ■

STAFF PHOTO BY GEORGE MARTELL

Client advocates for Community Services for Women Toni Jones, left, and Priscilla Damon appear before Judge Sally Kelly. Jones and Damon intercede on behalf of women who want to work out an individual rehabilitative program that will keep them out of prison.

tBf

REPORT

Reclaiming Women's Lives

THE BOSTON FOUNDATION FALL 1989

IT IS AN EARLY MORNING in October, and Priscilla Damon is in Boston Municipal Court hearing the case against a 20-year-old woman who we will call Sheryl. Sheryl has had three prior arrests, but no incarcerations; now she faces charges of unarmed robbery and drug distribution which could lead to a stiff prison term. It is up to Damon, a staff member of *Community Services*, a program of *Social Justice for Women*, to work with Sheryl's lawyer and develop an alternative sentence that will keep her in the community and out of prison.

Sheryl has a lot in common with other *Community Services* clients. She is young, she is pregnant, and her crimes were motivated by the need for money to support her cocaine addiction. "More than 90% of the women in our program are addicted to drugs," says Marian Klausner, Director of *Community Services*. Other common factors among clients, half of whom are women of color, are personal histories which include alcoholic or drug-addicted parents, sexual or physical abuse, lack of education, dependent children, poverty, homelessness, low self-esteem, and, increasingly, exposure to AIDS. "For women whose lives are already in chaos," says Klausner, "AIDS is the final blow."

Klausner and her co-workers try to bring order into these lives in chaos by providing a community-based option to incarceration. It is no easy task. "A successful alternative sentence plan will seek to address all of the woman's needs in a holistic manner by utilizing a range of community-based social service agencies," says Klausner. In addition to community service, alternative sentencing includes residential drug treatment, intensive counseling, and referrals for job training, employment, education and housing. Although *Community Services* is just two years old—and one of the first such programs in the country—it already has success stories to tell. They are inspiring stories about women who are healthy, drug-free, working, and living with their children.

Alternative sentencing is expensive, but Betsey Smith, Director of *Social Justice for Women (SJW)*, points out that prisons are costly too. "And prisons do not rehabilitate or deter because they fail to address the complex underlying needs of women," adds Smith. "Alternative sentencing prevents the separation of families, helps to reduce prison overcrowding, and can effectively assist a woman in breaking out of the cycle of drug addiction, crime and poverty."

Helping women who are already incarcerated to break out of that same cycle is the goal of *SJW's Neil J. Houston House*, a residential program for pregnant incarcerated women. Until *Houston House* opened in March of 1989, women who gave birth in MCI-Framingham were separated from their babies within 48 hours.

But at *Houston House*, which is located on the campus of Dimock Community Health Center in Roxbury, residents are offered substance abuse treatment, perinatal care, and the counseling and referrals that will help them re-integrate into society. So far, eight babies have been born to residents of *Houston House*. All have been drug-free, and, after safe deliveries at Beth Israel Hospital, have come back to *Houston House* in their mothers' arms.

In Suffolk County Courthouse, Marian Klausner and Priscilla Damon of Community Services for Women *confer with a lawyer about an alternative sentence.*

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Mr. Jerry Bell
Executive Vice President
BCK Industries, Inc.
1828 Parkshore Drive #4
Fayetteville, Arkansas 72703

Dear Mr. Bell:

Thank you for writing and sending information about your product. I am sorry you are having difficulty promoting your product but we are not in the position to help you with your marketing efforts.

Best wishes to you in your future efforts.

Sincerely,

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

THE WHITE HOUSE

WASHINGTON

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National AIDS Policy Coordinator

Prepared by: APO: TFox: 8/26/93:202-690-5560:b:\foxltrs.gbe\bell.gbe

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OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

BCK INDUSTRIES, INC.
1828 Parkshore Drive #4
Fayetteville, Arkansas 72703
(501) 442-0886

draft reply

August 16, 1993

Ms. Kristine Gebbie
Director of National AIDS Policy Coordination
Office of National AIDS Policy Coordination
Executive Office of the President
Washington, DC 20500

RE: Viro-Glove, anti-AIDS protective barrier that kills AIDS-HIV on contact for up to six hours.

Dear Ms. Gebbie:

Congratulations with your appointment to a much needed federal position.

To get to the point, BCK Industries is a small business that is experiencing tremendous obstacles in dealing with various federal agencies, except for the Veterans Affairs National Acquisition Center, in trying to promote our product for the various uses of protection afforded against AIDS by our product. Any "at-risk" health care professional would jump at the chance of having Viro-Glove applied to the skin under latex gloves (surgeons, dentists) or for other personnel that are not required to use latex gloves (OSHA) when blood borne pathogens are present (i.e. law enforcement personnel, home care nurse aides, mortuary personnel).

With the V.A. delaying their contract to January 1, 1994 and other federal agencies not even responding, it seems our marketing efforts are impossible. Also, your office must have volunteer agencies that would gladly purchase our product to make their environment more safe.

The question is, is there any coordination that your position could do to help my company get the message out? Is it possible for your office to inform each federal agency that it is available?

Any help would be greatly appreciated. If you have any questions, please call me at the letterhead telephone number above.

Sincerely,

Jerry Bell
Executive Vice President

Encl: Brochure

Are you one of the more than 5.6 million 'at risk' health care workers in the United States?

HERE'S NEWS OF PROTECTION THAT COULD SAVE YOUR LIFE.

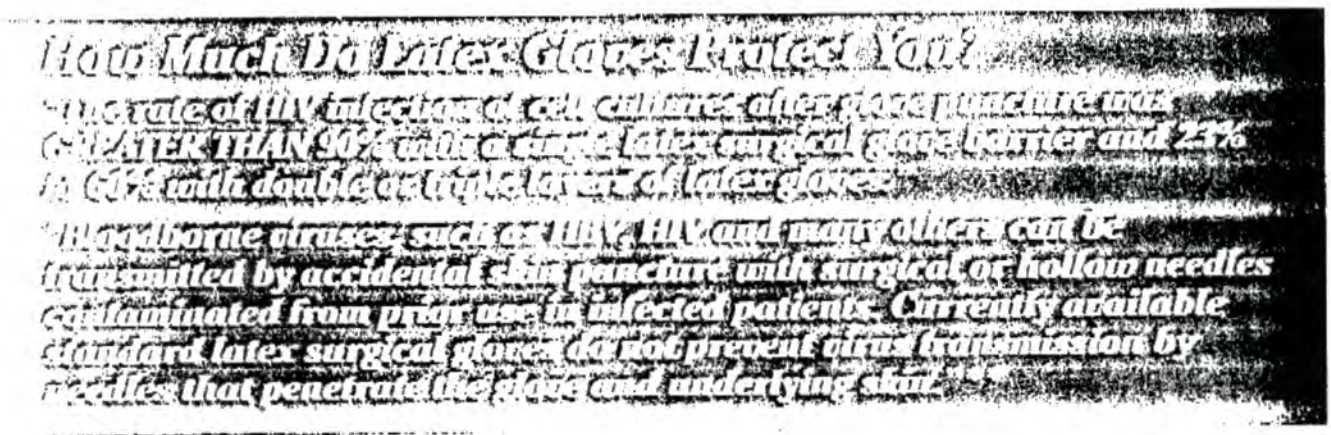
VIRO GLOVE™

Patent Pending

The first proven waterproof, oil and salt resistant product of its kind to kill the AIDS HIV-1 virus on contact for up to six hours in laboratory testing.

VIRO™ GLOVE

Do you feel confident that if you get a patient's blood or body fluids on your skin that you won't contract a serious disease – perhaps, AIDS?



Today the CDC says there are known cases of health care workers who have tested HIV positive and contracted the virus through occupational exposure – either by coming into contact with HIV positive blood or unspecified fluids.*

Research indicates that one, two, or three pairs of gloves become punctured easily by needles, and often become torn without the health care professional realizing it. The truth is, most surgical gloves are made of latex, a semipermeable membrane that allows the passage of gases and fluids. Holes or tears can appear in gloves within 5 to 10 minutes.**

*Centers for Disease Control
**Various sources on file

How can you improve your chances of not becoming infected?

For the first time ever, there is a product that studies show offers you additional protection.

Liquid Glove Derma-film Protection

Forms a Protective Antiseptic Barrier over the Skin for 4 to 6 Hours

VIRO GLOVE™ has been shown through laboratory testing to be a safe and effective prophylactic appliance that forms a protective antiseptic barrier over the skin. VIRO GLOVE™ is the first waterproof, oil and salt resistant product of its kind shown to kill the AIDS HIV-1 on contact along with other pathogens found in blood and body fluids. In today's health care environment, VIRO GLOVE™ is the added protection you deserve. Worn under gloves, VIRO GLOVE™ latches to the skin and lasts for up to six hours.

Similar in feel, texture and scent to many non-oily hand creams, VIRO GLOVE™ is a powerful weapon, that kills a broad spectrum of bacterial, fungal and viral disease producing agents, such as AIDS HIV-1, ARC (AIDS-related complex), Staphylococcus, Streptococcus, Pseudomonas, Trichophyton mentagrophytes, Gonorrhea, Herpes virus, Candida albicans, and Influenza.

In today's health care environment, VIRO GLOVE™ is added protection you deserve.

ACTIVE INGREDIENTS:
Nonoxynol-9.5%, Benzalkonium chloride 0.1%
CAUTION: USE ONLY AS DIRECTED. FOR EXTERNAL USE ONLY. KEEP OUT OF EYES. KEEP OUT OF REACH OF CHILDREN.

GREEN CROSS FOR SAFETY

Patent Pending
* Report available upon request

While no prophylactic can guarantee 100 percent effectiveness, VIRO GLOVE™ is the first product of its kind to achieve 100 percent sterile hands, under latex gloves, for up to four hours. Studies have revealed no toxic or adverse dermatological effects to those who apply the device on their skin. VIRO GLOVE™ is specifically formulated to enhance the texture of the skin.

THE RESIDUAL EFFECT OF VIRO GLOVE™

Field and laboratory testing of VIRO GLOVE™ show dramatic results... a single application of VIRO GLOVE™ will maintain sterile hands under surgical gloves for 4 hours. Testing also shows that VIRO GLOVE™ is activated by moisture. By misting the hands with water, the bacterial counts show a steady decline for an additional two hours!*

VIRO GLOVE™ *Advantages:*

Non-toxic
High Kill Ratio
Moisture Activated
Waterproof, Oil and Salt Resistant
Enhances the Skin
Increases Dexterity
Protects up to Six Hours

DIRECTIONS: Wash application site thoroughly. Apply evenly and generously to all exposed areas where protection is desired, paying close attention to nail and cuticle areas. Reapply every four hours, after glove removal. Use **VIRO GLOVE™** in conjunction with your gloves, mask and other protective wear.

"After thoroughly testing the anti-microbial effect of VIRO GLOVE™, I conclude that VIRO GLOVE™ kills significant amounts of HIV-1 on contact for at least six hours. Health care professionals can make their occupational environment safer by applying VIRO GLOVE™."

Lionel Resnick, M.D., F.A.C.P., F.A.A.P.

Lionel Resnick, M.D., F.A.C.P., F.A.A.P. is medical director of STRATOGEN, a comprehensive outpatient HIV center in Miami Beach, Florida. A physician and research scientist, Dr. Resnick is a principal investigator of research drug protocols. He has been actively involved in AIDS research for the past 10 years, and has authored more than 100 scientific research publications on AIDS. Dr. Resnick is Chief of Retrovirology Laboratories at Mount Sinai Medical Center, in Miami, and is on the research faculty of the University of Miami School of Medicine. He has served as a consultant for the World Health Organization and has been awarded numerous grants for his research from the National Institutes of Health.

Dr. Resnick's Study

September 30, 1992

Table

VIRO GLOVE™ (V1)/Glove-Sweat Anti-HIV Studies

Exp. #1

Time (hrs)	Volume of Sweat/V1	Volume of Sweat/V1	Log Virus Titer Reduction of V1
1 hr	L	0.5	>3.50
1 hr	R	0.3	>3.50
2 hr	L	0.5	>3.50
2 hr	R	0.5	>3.50
4 hr	L	0.6	>3.50
4 hr	R	0.7	>3.50
6 hr	L	0.9	>3.50
6 hr	R	0.8	>3.50
8 hr	L	0.9	1.00
8 hr	R	1.0	0.50
Controls:			
V1 alone			>3.50
V1 + Latex (16 hr)			>3.50
Untreated Hands & Glove/Sweat (1 hr)			0.25 (range 0.00-0.50)
Vaseline-treated Hands & Glove/Sweat (1 hr)			0.50 (range 0.00-1.00)

Exp. #2

Time (hrs)	Volume of Sweat/V1	Volume of Sweat/V1	Log Virus Titer Reduction of V1
1 hr	L	0.2	>3.50
1 hr	R	0.3	>3.50
2 hr	L	0.6	>3.50
2 hr	R	0.5	>3.50
4 hr	L	0.5	>3.50
4 hr	R	0.8	>3.50
6 hr	L	0.8	>3.50
6 hr	R	1.2	>3.50
8 hr	L	1.0	1.33
8 hr	R	1.3	0.72
Controls:			
V1 alone			>3.50
V1 + Latex (16 hr)			>3.50
Untreated Hands & Glove/Sweat (1 hr)			0.25 (range 0.00-0.50)
Vaseline-treated Hands & Glove/Sweat (1 hr)			0.50 (range 0.00-1.00)

Syncytium-Inhibition Assay

Virus stocks were thawed and diluted with PBS to obtain the required amounts of virus necessary for these experiments. Untreated virus served as the TCID50 control for this experiment. After a 1 minute exposure of HIV-1 with the compound, sequential 10-fold dilutions of the treated or untreated virus control were prepared in PBS and each dilution was used to infect MT-2 cells as previously described. Virus expression was monitored by the presence of syncytium formation. HIV-induced syncytium formatin was assessed after 6 days of culture using a syncytium-formation assay as previously described.

Results and Conclusions:

The results of these studies are summerized in the table. V1 under glove occlusion mixed with human sweat led to a reduction in HIV infectivity of >3.50 log 10 TCID50/ml, for up to six hours (two sets of experiments). Untreated or vaseline-treated hands under glove occlusion had no significant anti-HIV activity.

For further information or copies of clinical tests, write or call:

KNIGHT INDUSTRIES, INC.
P.O. BOX 50387
POMPANO BEACH, FL 33074

JERRY BELL, EXEC. V.P. - SALES
BCK INDUSTRIES, INC.
1828 PARKSHORE DRIVE # 4
FAYETTEVILLE, ARKANSAS 72703

THE WHITE HOUSE

WASHINGTON

August 27, 1993

Mr. Michael Weinstein
President
AIDS Healthcare Foundation
1800 N. Argyle Avenue, Suite 304
Los Angeles, California 90028

Dear Mr. Weinstein:

Thank you for your kind words of congratulations on my appointment as the National AIDS Policy Coordinator and for the information about the AIDS Healthcare Foundation. Hospice care is an essential part of a full spectrum of healthcare for persons infected with HIV. I applaud you for the excellent work being done at the Carl Bean AIDS Care Center.

I would like to see your services on a future trip to Los Angeles and will contact you in advance to set up a meeting.

Best wishes in your continuing efforts.

Sincerely,

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

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AIDS Healthcare Foundation
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Sincerely,

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

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FILE COPY

OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE	OFFICE	SURNAME	DATE

AIDS HEALTHCARE FOUNDATION

Formerly AIDS HOSPICE FOUNDATION

July 21, 1993

Kristine M. Gebbie
National Aids Program Office
200 Independence Ave. S.W Room 729-17
Washington, DC., 20201

Dear Ms. Gebbie,

Congratulations on your recent appointment by President Bill Clinton to coordinate the nation's policy and programs on HIV/AIDS. We look forward to working with you in helping to shape a long needed National AIDS strategy.

AIDS Heathcare Foundation's mission is, "to provide a full spectrum of quality and affordable healthcare services to all the Human Immunodeficiency Virus(HIV) infected. In addition, AHF exists to provide strong public advocacy in support of all persons in need of healthcare"

As such, in almost five years of providing medical care for persons with AIDS in our several hospices and clinics, AHF has become the largest communinty-based provider of HIV/AIDS medical services in California. In our two hospices, Carl Bean AIDS Care center and Chris Brownlie, we provide 24 hours of loving care to their residents that emphasize dignity in death. Our clinics, located in Hollywood and Downtown Los Angeles, have served about 2000 patients at all levels of infection.

We take great pleasure in extending an invitation to visit our Carl Bean AIDS Care Center, which serves the South Central Los Angeles Community. We look forward to your visit, and hope this will be the start of a mutual and productive relationship.

sincerely,

Michael Weinstein
President

Enclosures

1800 N. ARGYLE AVE., SUITE 304 LOS ANGELES, CA 90028 (213) 462-2273 FAX (213) 962-8513

Mission Statement

"The mission of the AIDS Healthcare Foundation is to provide a full spectrum of quality and affordable health care services to all the Human Immunodeficiency Virus (HIV) affected. In addition, AHF exists to provide strong public advocacy in support of people with HIV infection and all persons in need of health care."

Address Correction Requested

AIDS Healthcare Foundation
1800 North Argyle Avenue, Suite 304
Los Angeles, CA 90028
(213) 462-2273 Fax (213) 962-8513

AHF

AIDS HEALTHCARE FOUNDATION

"Fight for the living...
care for the dying."

Revision 2.3 by Wim 22 June 1993

The AIDS Healthcare Foundation

AIDS Healthcare Foundation, established in 1987, is the largest community-based provider of HIV Medical care in California. The Foundation has grown from a small group of friends dedicated to the creation of dignified care for people in the last stages of AIDS to a multi-million dollar agency providing excellence in care for people living at all stages of HIV infection and disease.

At the heart of AHF is a simple philosophy: access to care is a human right and should not be determined by a person's income. Therefore, all services at AHF are offered regardless of the ability to pay. AHF accepts private insurance, MediCal and Medicare.

This brochure outlines services available at AHF. We exist to serve you, so please let us know if we can improve any aspect of our care.

AIDS Healthcare Foundation
1800 N. Argyle Avenue # 304
Los Angeles, CA 90028
Tel: (213) 462-2273
Fax: (213) 962-8513

AHF Clinics

Living with HIV can be a challenging, confusing experience. At the AHF Clinics, we provide services necessary to maximize health and well-being at all stages of HIV.

There are three components to the AHF Clinics: one serving the symptomatic patient, one serving the asymptomatic patient and a special Women's Clinic. Patients at the AHF Clinics receive primary care from qualified, compassionate, bilingual professionals. Access to full in-patient and out-patient facilities is available.

The AHF Clinics
Hollywood
1300 N. Vermont Avenue
Los Angeles, CA 90027
Tel: (213) 662-0492
Fax: (213) 662-0196

Downtown
1414 S. Grand, Suite 400
Los Angeles, CA 90015
Tel: (213) 741-9727
Fax: (213) 741-0867

AHF Hospice Program

AHF hospice care is nationally recognized for excellent medical support offered in beautifully designed accommodations. Since a hospice provides the last home residents will know, every effort is made to create as loving and compassionate an environment as possible. A team of dedicated staff and volunteers offers continuous support to residents and their loved ones.

Chris Brownlie Hospice
1300 Scott Avenue
Los Angeles, CA 90026
Tel: (213) 482-2500
Fax: (213) 482-2538

Carl Bean AIDS Care Center
2146 West Adams Boulevard
Los Angeles, CA 90018
Tel: (213) 766-2326
Fax: (213) 730-8244

Thrift Store

The Out of the Closet Thrift Store, located in Atwater Village, offers a wide variety of previously owned clothing and household items at bargain prices. Proceeds from the sale of donated items directly supports medical and residential care to people with HIV/AIDS.

Out of The Clost Thrift Store
3160 Glendale Blvd.
Los Angeles, CA 90036
Tel. (213) 664-4394

Volunteer Resources

As the AIDS Healthcare Foundation spends 93 cents out of every dollar on direct medical care, we depend heavily on volunteers to spend time with hospice residents, work at our thrift store, assist with phones and computer work, staff special events and many other activities. Whether you have a few hours to give or many, we are grateful for your help.

For more information, call Karen Dale Wolman, Director of Volunteer Resources, at (213) 462-2273.

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AIDS Healthcare Foundation
Hospices: For Those We Love

16pgs

AIDS
Healthcare Foundation

HOSPICES

For Those We Love

Comfort Love Dignity Respect Compassion Support