A COMMUNITY OF WOMEN ORGANIZE THEMSELVES TO COPE WITH THE AIDS CRISIS: A CASE STUDY FROM BEDFORD HILLS CORRECTIONAL FACILITY

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I. INTRODUCTION

In Bedford Hills Correctional Facility for Women ("Bedford Hills" or "Bedford"), New York State's maximum security prison for women,[1] AIDS has created a crisis. A 1988 study done by the New York State Department of Health showed that almost twenty percent of the incoming women to Bedford were HIV-infected.[2] This statistic does not include all the other women affected by AIDS: those with friends and family members who are sick; those women wrestling with whether to take the HIV antibody test; those who are concerned about how to have safe sexual relationships; the

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[1] Bedford Hills is the only maximum security prison for women in New York State. Approximately 750 women are housed there.

[2] New York State Department of Health, AIDS in New York State 26 (1989). 90 of 480 (18.8%) consecutive inmates entering through Bedford Hills from September 1988 to December 1988 tested positive for HIV. Id. A study done at Downstate Correctional Facility showed that 86 of 493 (17.4%) consecutive male entrants from December 1987 to January 1988 tested positive for HIV. Id. at 28.

many more who are not yet educated or concerned about this; and those with fears and questions about casual contact in an environment which necessitates sharing and close living arrangements.

The situation at Bedford Hills is not unique. A study done by the Department of Correctional Services (DOCS) in November 1987 found the HIV seroprevalence rate in New York State prison entrants to be 17.4%.[3] DOCS officials estimate 60 to 70% of state inmates in New York have a history of drug use, which is one of the main activities that puts people at risk for HIV infection.[4] Statistics also show that HIV has had a devastating impact on low income African-American and Latino communities.[5] African-American and Latino people represent 80% of New York State inmates.[6]

The prison system is faced with deep contradictions in working to meet the crisis of AIDS. On the one hand, studies show that the most effective means for controlling the spread of HIV infection has been grassroots mobilization, community empowerment, and culturally specific organization.[7] This means that prisoners need to be able to organize themselves to educate, counsel, and provide support among their peers.

Prison life, however, is predicated on control by prison administrators and on absolute security. Moreover, in our experience, most prison officials view prisoners as less rational and less capable than others, as people to be "corrected"—in short, as part of the problem. The notion that prisoners could be part of the solution, that they could make a positive difference in a worldwide crisis, appears unimaginable to most correctional authorities. The empowerment of prisoners is viewed as contrary to the needs of security. Furthermore, there is no way to deal with AIDS without engaging issues of sex and drugs. Yet because both are prohibited inside a prison, prison officials have traditionally been loathe to allow open discussion, let alone provide the means to pursue sex or use drugs safely.

There are additional obstacles to addressing the AIDS crisis for women. Women are the fastest growing population becoming infected with

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[3] New York State Commission on Corrections, Acquired Immune Deficiency Syndrome: A Demographic Profile of New York State Inmate Mortalities 1981–87, at 13 (1988).

[4] C. Potler, AIDS in Prison: A Crisis in New York State Corrections (The Correctional Association of New York, 1988).

[5] Harrington, A Fatal Bias: AIDS and Minorities, 14 Human Rights 34 (Summer 1987).

[6] Potler, supra note 4, at 5.

[7] See AIDS Advisory Council, Ad Hoc Committee on AIDS and Correctional Facilities 47 (New York State Department of Health—AIDS Institute 1989).

HIV.[8] Moreover, women bear much of the social burden of the epidemic, particularly in African-American, Latino, and poor urban communities. Yet, the stances of the medical and political establishment have overwhelmingly failed to address this reality. The medical establishment has not extensively studied the particularity of HIV infection in women.[9] Women are excluded from most drug trials.[10] The Center for Disease Control does not track woman-to-woman transmission.[11] Most major medical facilities do not take into account the needs of women arising from their family responsibilities in ensuring access to health care. Invisibility disarms and disempowers women struggling with AIDS.

AIDS Counseling and Education (ACE) is a prison program which is making a difference in the AIDS crisis at Bedford Hills. ACE is an organization initiated and built by women prisoners and officially recognized by the prison administration. It is a program of peer education, counseling, support, and health advocacy. In addition, ACE inspires a spirit of sisterhood and community, encouraging group and individual self-respect and initiative. ACE began as an effort to mobilize the prison community in order to deal with all the ways that AIDS affects it.

In this article, we will examine what we have learned through participating as members of ACE about the effects of the AIDS crisis on women and prisoners, how AIDS organizing can be accomplished in the prison context, and how mobilization around the AIDS crisis has significantly reduced stigma and fear among the women at Bedford Hills.

II. BACKGROUND

In the period from 1985 to 1987, the AIDS situation in Bedford Hills was similar to that experienced in other urban communities. It was characterized by secrecy and denial, shame and fear, ignorance and ostracism, and poor medical care.

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[8] Harrington, supra note 5, at 34.

[9] Report of the Second Public Health Service AIDS Prevention and Control Conference, Women and AIDS, 103 Public Health Reports, J. of the U.S. Pub. Health Service (Supp. No. 1) 88, 89 (Nov. 1988).

[10] According to the AIDS Clinical Trials Information Service, only 10% of the participants in drug trials sponsored by the National Institute of Allergy and Infectious Diseases are women. Nat'l Inst. of Allergy and Infectious Diseases, Demographic Summary of AIDS Clinical Trials Group Study Entries [1986–1991] (Aug. 9, 1991) (available through the AIDS Clinical Trials Information Service).

[11] Chu, Buehler, Fleming & Berkelman, Epidemiology of Reported Cases of AIDS in Lesbians, 80 Am. J. Pub. Health 1380, 1381 (Nov. 1990).

Women with AIDS were placed in the Inpatient Care (IPC) infirmary unit. The unit was dark, dirty, and roach infested, with paint peeling off the walls and sewage occasionally backed up on the floors. Most nurses were afraid to have any physical contact with the AIDS patients. Prison doctors did not know a great deal about AIDS. Women who lived in IPC had no activity programs, no work or education, and no regular access to visits from friends in the prison population. One woman who died of AIDS in 1985 spent her last night alone in IPC, with no nurse or correctional officer willing to attend to her needs.[12]

As prisoners and staff became aware of the AIDS epidemic, fear and stigma spread throughout the prison. Fear of infection through casual contact is heightened in a prison because people share showers, kitchens, and recreation areas. For example, prisoners petitioned the prison administration ("Administration") to get an inmate who was assumed to be HIV-positive off their floor. The inmate had to move because of the pressure. Officers who were packing up the cell of an HIV-positive inmate wore gloves and masks, creating erroneous fears among the inmates that AIDS was spread through casual contact.

III. THE EMERGENCE OF ACE

Attempts to change the situation led to the development of ACE. About twelve women met with the Superintendent of Bedford Hills in 1986 to

[12] The unsatisfactory medical conditions and the death of this inmate were noted in a report by Frank L. Rundle, M.D., a court-appointed special monitor who was overseeing compliance with the judgment rendered in Todaro v. Ward, 431 F. Supp. 1129 (S.D.N.Y. 1977), aff'd, 565 F.2d 48 (2d Cir. 1977), aff'd without opinion, Todaro v. Coughlin, 652 F.2d 54 (2d Cir. 1981) (a class action on behalf of all present and future inmates of Bedford Hills against Benjamin Ward, then Commissioner of the New York State Department of Correctional Services, and others, in which the court held that certain aspects of the medical care at Bedford Hills were constitutionally inadequate and issued orders detailing remedial requirements). See Rundle, Evaluation of Medical Services at the New York State Correctional Facility, Bedford Hills, New York (1987).

> It became increasingly clear that the accelerating incidence of acquired immune deficiency syndrome and related conditions was placing severe additional burdens upon the medical staff, and that a systematic assessment of that burden, with projection of its progressive increase, and a plan to cope with the increased burden were not being addressed by the institution. In April, 1985, an inmate died of AIDS, and detailed review of her medical care over a period of a year raised serious questions of the adequacy of the medical care system in several areas.

Id. at 2.

urge more education of staff and inmates. Because of an agreement with the Superintendent at that meeting, women began to visit people housed in the infirmary in an effort to break down their isolation. One person with AIDS (PWA) contacted the Mid-Hudson AIDS Task Force, and two of its volunteers began visiting the IPC unit. One of the basic literacy classes in the education program wrote and produced a play about some of the personal issues that AIDS raised for them. As more women got sick, many more women in the prison population ("population") became personally involved. Slowly, the reality of AIDS became less about "them" and more about "us." This was dramatized in 1988 when, for the first time, women got together to make quilt squares for sisters from Bedford who had died of AIDS. These squares were sent to be part of the memorial quilt of the National Names Project.[13]

Some of the people with AIDS played the most critical role in opening the struggle to change conditions. One woman, who lived in IPC, fought for the right to get back her job working on the yard crew. At first, she worked alone in the area in front of the hospital. One by one, others on the yard crew joined her. Gradually people were moved by her courage and determination and reembraced her as a friend. Another woman with AIDS, who had been at Bedford Hills for seven years, was someone everyone knew. She came from the infirmary to watch baseball games with the rest of population. Because she was such a popular and widely known person, her diagnosis of AIDS, along with her spirit and openness, made it harder to define people with AIDS as "other."

In December 1987, a group of six inmates submitted a proposal to the Superintendent to create a peer counseling and education program. This initial group was racially mixed and diverse in backgrounds and skills. One woman had been a businesswoman. Another wrote songs and plays and performed in cultural events. Two were active on the Hispanic Committee. Several were in the college program. Two, these authors, had years of experience as political activists and organizers. Several of the women identified themselves as being at high risk for HIV infection, and at least one had a close family member with AIDS. What connected the women of the group was a concern about AIDS and a drive to do something about it.

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[13] Quilt squares are still made when a woman from our community dies of AIDS. We make a square whether she is in Bedford or has gone home already. The Names Project is a San Francisco-based nonprofit organization dedicated to raising public awareness about AIDS. The quilt was begun in 1987 as a vivid memorial to people who died of AIDS. See Bass, Panel by Panel, a Quilt Commemorates the Victims of AIDS, N.Y. Times, Mar. 12, 1989, § 12 CN, at 1, col. 1.

In the proposal we stated that as inmates we had a crucial role to play in dealing with this crisis. It was inmates who could generate the cooperation, trust, self-education, support, and change that women in Bedford Hills needed in order to meet the AIDS crisis. We were confident that there were many women who would respond. We had four goals: (1) to save lives and promote prevention; (2) to create more humane conditions for those already suffering from AIDS and HIV-related problems; (3) to provide counseling and support for people facing the many problems and questions that AIDS creates in our community; (4) to build bridges to outside community groups to ensure that women would have the necessary support when they reentered the community.

Outside the prison, the gay community had become a model of community empowerment in addressing the AIDS crisis. Moreover, within the gay community, PWAs were not allowing themselves to be denied or victimized, but were playing a leading role. The principles of community self-consciousness, peer education, and support had become associated with responding to the AIDS crisis. We sought to use these ideas as some of the guiding principles of ACE.

In the spring of 1988, the Superintendent agreed to allow us to implement the proposed plan for ACE. This was a bold step. In 1988, in the overwhelming majority of prisons throughout the United States, AIDS policy ranged from requiring mandatory testing and subsequent isolation of those testing positive to providing minimal education by outside experts.[14]

The first ACE meeting was attended by thirty-five women who expressed interest in becoming involved with AIDS education and support. We sat around a table, and each woman spoke about what had brought her there. One woman said, "I'm here because I was an IV drug user, and I'm worried that I might have AIDS." Another said, "I'm here because I want to end the ignorance that creates cruelty against us." Another said, "I have a friend who died of AIDS." Suddenly one woman said, "I'm here because I have AIDS. And I think we need a group like this here." There was a stunned silence in the room. No one at Bedford had ever said out loud to a group of women that she had AIDS. Then another woman said, "I just took the test and it turned out positive." She put her arms around the woman sitting next to her and said tearfully, "If she hadn't been here for me, I don't know how I would have gotten through these last days." Her friend was one of the original writers of the proposal for ACE. Then a

[14] See T. Hammet, AIDS in Correctional Facilities: Issues and Options 39–50 (Nat'l Inst. of Justice 3d ed. 1988).

third woman said she had AIDS, and she was here because people had isolated her and treated her with prejudice. These individuals, by speaking openly about their condition, put their trust in the group to build this community of support.

In the initial proposal we had requested training by outside sources. Soon after the first meeting all thirty-five women began an educational process that was empowering. Doctors, nurses, social workers, and a woman with AIDS from Montefiore Hospital came to train ACE members. The four training sessions, each three hours long, incorporated the newest information with role plays, discussion, and sharing of personal experiences. A Bedford Hills staff member and volunteer also led two sessions on counseling.

An informal support network of ACE members developed. The women in population were moved by the spirit of community that was emerging in ACE. On a living unit, one woman who was HIV-positive developed a fever and five women carried her to the shower in the heat of the summer, held her to bathe in the cool water, and then carried her back to bed and massaged her. We held memorials for women who died and made quilt squares for each one. They would not be forgotten. Even if in some cases their own families were too fragmented or too ashamed, people in here would remember them. We claimed each woman who died as our own. Through this, we strengthened our own sense of dignity and self-respect. We chose "Sister" by Cris Williamson as our theme song.[15] The words of this song, "Lean on me, I am your sister," reflected and contributed to the growth of community consciousness.

IV. CONTRADICTIONS BETWEEN PRISONER INITIATIVES AND THE PRISON SYSTEM

By June 1988, we were ready to begin developing outreach programs with the population. The Superintendent announced at an ACE meeting that the New York AIDS Institute had awarded Bedford Hills a quarter of a million dollars to develop a model AIDS program.

However, during the summer months, ACE's work was painfully brought to a complete stop. This was not done formally, but through a series of bureaucratic obstacles. For example, the Administration told ACE we would have to change our regular meeting time in accord with changes in facility schedules. However, they never gave a new meeting time, and

[15] © 1975 Olivia Records, Inc., 4400 Market Street, Oakland, CA 94608.

the weekly ACE meetings could no longer take place. Previously, the Superintendent had attended many meetings and met with individuals to discuss and approve the work. Suddenly, the Administration stopped meeting or communicating with ACE. Because of this, ACE could not get the specific approvals necessary for the work to continue, much less move forward. Because of the lack of communication, it was difficult to understand why such a positive process, which had had the support of the Administration, was suddenly halted.

Months later, the Superintendent explained in meetings, media interviews, and informal discussions some of the thinking that had motivated her actions. In retrospect, we were able to analyze what we experienced and place it in a broader context. It is our hypothesis that the Superintendent's actions reflect contradictions between institutional policies and the needs of ACE. Some of the contradictions are systemic, existing between the prison system and prisoner initiative. Peer education and support combined with self-initiated inmate organization, even for such a positive goal as coping with the AIDS crisis, is seen by the system as a potential threat to prison security and control.

Sometimes ACE's involvement was welcomed by the prison staff; other times, officers or staff raised questions about inmates exercising undue authority or being "out of place." ACE members actively tried to help women who were in crisis and need. This sometimes resulted in members intervening as advocates with medical staff or other staff. At times it meant being in places where inmates were not strictly supposed to be.

ACE gave women the tools to pressure the Administration for better medical care. The Medical Department was already feeling pressure from increased needs arising out of the AIDS epidemic and the *Todaro v. Ward*[16] suit on medical conditions. Inmates are not supposed to pressure prison administrations, in the eyes of many administrators. Ultimately, however, negotiations between the *Todaro* parties resulted in marked improvements in medical staff and procedures, improvements that the administrators as well as the other *Todaro* parties welcomed.

ACE members felt inhibited by an atmosphere of suspicion. A woman in the hospital unit took an overdose of drugs. Because many ACE members spent time visiting and befriending people in IPC, everyone in ACE was put under possible suspicion in the ensuing investigation and was required to take drug tests. No one was found responsible for any wrongdoing, but questions were nonetheless raised about ACE members having such access

[16] 431 F. Supp. 1129 (S.D.N.Y. 1977).

to the hospital area. The work in the hospital, however, was permitted to continue.

The close relationship of sex and drugs to AIDS poses further problems for prison administrations. People must be able to discuss openly their actual sexual experience and confront resistance to changing their practices if the spread of AIDS is to be prevented. Drug use also needs to be openly discussed. Yet in a prison these activities are forbidden. Thus a prison is faced with a dilemma: does creating a safe atmosphere for open discussion and struggle in the interests of public health and saving lives undermine the importance of prisons' rules and views of morality enforced through punishment? In AIDS education work, information is not enough to foster behavior change. It is also necessary to provide the means to enable such change.

Sex does go on in prisons. Thus, administrators are faced with the dilemma of whether to distribute condoms and dental dams in order to prevent the spread of HIV infection. A few jail and prison systems are doing so, including those in Philadelphia, New York City, Vermont, and Mississippi.[17] Most, including the New York State Department of Corrections, oppose such a policy. A recent study by the New York City Bar Association urged that the state prisons adopt a program of condom distribution in order to prevent the transmission of HIV through sex. However, a spokesperson for the prisons said that state prison officials oppose condom distribution because sexual intercourse between prisoners is forbidden by prison regulations.[18]

The control over prisoners is so complete that they cannot take responsibility for themselves unless the authorities permit it. Once we, as prisoners, were given permission to become educated, to take initiative, and to organize our own community, many of us in ACE felt more motivated and empowered than we had ever before in our lives. When this power was taken away, because the need for security and control became overriding, the frustration and anger among the women were greater then ever.

To avoid the above problems, almost all prisons prefer to rely on outside experts to carry out AIDS education and services, rather than on a peer-based process. In an approach used widely in prisons, experts come and do live presentations with question and answer discussions, usually

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[17] Hammet, supra note 14, at 92.

[18] Lambert, Albany AIDS Panel Assails Ban on Condoms to Inmates, N.Y. Times, Sept. 16, 1989, at 30, col. 1.

supplemented by videos and written materials.[19] Before the existence of ACE, this was the form that AIDS education took at Bedford Hills for both inmates and staff. The sessions were carried out by representatives of the New York State Department of Health and other agencies. While the presentations were usually accurate and well meaning, the audience was too large, and the time too short. Many prisoners did not trust the presenters because they were state officials.

Very few prison systems use inmate representatives to deliver AIDS education and instead rely on civilian social workers and medical experts.[20] While in many instances these individuals provide real relief and supportive services to prisons, the experts are the ones doing the work; they do not train and enable prisoners to do it. Experts cannot generate the kind of peer-to-peer engagement, self-initiative, and community involvement that often comes from a grassroots effort. The experts from Montefiore Hospital, however, trained ACE members to do the work themselves. They consciously supported ACE members' efforts toward self-empowerment in order to deal with the AIDS crisis.

When ACE was inactive, arguments and fights increased, provoked by prejudice. During this period, members tried to sustain the group and its work. They continued to press the Superintendent to reactivate ACE. In November 1988, the Superintendent called an ACE meeting and agreed that ACE could begin to work again.

We think that the reactivation of ACE was due to a number of factors. First, the AIDS crisis was getting worse, and the need for ACE could clearly be seen in comparing the conditions when it was active and when it was not active. The Superintendent told ACE that she had gotten a number of letters and reports about fights and problems in the housing units where the newer arrivals lived, and she requested that we do seminars as soon as possible in those buildings to help alleviate the problems. Second, based on the success of the gay community's struggle to deal with AIDS, AIDS professionals increasingly supported the model of a community-based initiative. Third, the *Todaro* settlement brought improvements in the Medical Department, with the addition of new and more responsive medical staff. This enabled the prison to respond to increased medical demands. Lastly, it appeared that a grant from the AIDS Institute would come through.

In retrospect, we can see that particular historical conditions, combined with the prison reality, contributed to the strengths of ACE as a grassroots effort and to some of the problems we encountered. When ACE

[19] Hammet, supra note 14, at 45.

[20] Hammet, supra note 14, at 47–48.

began in 1988, there were almost no structures, programs, staff, or resources to meet the AIDS crisis in prisons throughout New York State and nationally. ACE filled that vacuum at Bedford Hills. The Administration recognized the value of ACE and supported it, but felt that there was a need for full-time civilian staff supervision of ACE. The AIDS Institute grant would serve that purpose. Negotiations over that grant took a long time. In January 1990, the grant from the AIDS Institute was finally secured. This grant will enable the prison to bring in full-time civilian staff, which will provide the Administration with closer supervision and control over ACE. ACE members hope that staff and resources will enable our work to expand, without our losing the power of community mobilization and self-reliance that is at the heart of ACE's success.[21]

ACE members recognize that ACE must function within the limits of policies set by the prison system; however, our work and impact push these limits. This poses a challenge for the prison system, but optimally it can bring about positive changes in prison policy. Indeed, numerous state officials have told ACE members in meetings and have stated publicly that the ACE model should be used in other prisons. There are indications that some type of AIDS peer program will be implemented in other New York State prisons.[22]

V. GROWTH OF COMMUNITY CONSCIOUSNESS AND INITIATIVE

When ACE reconvened in November 1988, one central goal was to create more humane conditions for PWAs. We believed that a commitment had to be made spiritually and materially to those who were infected in order for any other healing to take place. One focus of our energies was the IPC unit where acutely ill women live. We began knitting classes and a weekly bingo night there. We organized parties for the holidays and birthdays. We instituted a donation box. Signs went up on every living unit, and throughout population women donated food and personal items to show support and caring for their sisters in IPC.

The PWAs in ACE who have chosen to speak openly play a special role in our network of support. They are magnets to other women in population who are HIV-positive and seeking comradeship, advice, hugs, and inspiration. Their courage and example of living with AIDS gives others strength. They are key medical advocates and organize support groups. PWAs struggle within ACE to keep the needs of PWAs central to our work.

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[21] See addendum describing ACE's new civilian staff.

[22] See AIDS Advisory Council, supra note 7, at 46.

A common image projected of women who end up in prison is that of drug users, partners of addicts—in short, marginalized, criminal elements. Many women in Bedford are in prison for drug-related crimes. But they are also mothers, caretakers, sisters, and lovers. Many women here grew up in homes headed by mothers and grandmothers who often cared for three generations of children and nursed their elders. ACE encouraged this nurturing capacity by individual example and through the atmosphere that grows out of the group process.

We also arrived at an agreement with the Medical Department for ACE members to be permitted to participate in medical consultations as health advocates, if individual women request it. ACE health advocates do a number of things, including helping women prepare for a medical appointment by defining with them their main questions and working to improve communication between the doctor and the woman.

Our other priority, after reconvening, was to take the knowledge and spirit of ACE into the whole prison population. We decided to run seminars that included education about prevention, transmission, and HIV testing. We work in groups of five or six people: African-American, white, Latina, Caribbean, drug users and those who have not used drugs, college educated and those who did not finish high school, gay and straight, PWAs and non-PWAs. Each woman in the seminar group explains what moved her to get involved in AIDS work.

Together, we are a reflection of the community to whom we speak. We have realized that it is important to examine our differences as well as what we have in common. We have begun to build a Latina sector of ACE. Black and Latina women are looking at ways to address the needs of each distinct community—Puerto Rican, African-American, Caribbean, Latin American—in its own language and based in its own cultural issues. In one of our last workshops we broke up into tables of Black, Latina, and white women to begin that process.

The women see us working collectively in the very process of doing the seminar, which gives them a sense of the power and responsibilities of collectivity in action. We invite all the women to work with us to understand and try to solve the problems AIDS raises for us. We teach what we have learned: safe and unsafe behaviors; what the HIV antibody test is; the issues surrounding whether or not to take the test; and the need to fight stigma and build community support.

Within the seminars we use role plays about real situations we face. The role plays provide a way for us to look at ourselves from a distance, allowing for reflection and giving us all the opportunity to work on the

problems AIDS raises. For example, one role play takes place on the living unit where two people are cooking and a third realizes that one of the women is HIV-positive. She refuses to eat the food and says it should be thrown out. Many of the women identify with the woman who said, "Get rid of that food." We ask, what are the facts in this situation? What are the reasons that even when people know the facts, the fears persist? And then, what would you do? How do we overcome ignorance and how do we challenge stigma?

In another role play, a woman who has just been paroled goes back to her boyfriend or husband. She has learned he should use a condom and tries to persuade him to put one on. When she can't persuade him, we turn to the women and ask, "Does anybody else have an idea of what to do or say?" We then try to look at the social issues underlying the problems.

When the discussion on the HIV antibody test begins, the room becomes silent. The women are not only learning information about the test but thinking about themselves: should they take it or shouldn't they? Anxiety is high. ACE is not pro- or anti-testing, but encourages women to examine the issues for themselves.

ACE members who are PWAs talk about living with AIDS. This is the most emotionally charged and communal moment of the seminar, as they give life to our struggles, needs, fears, and aspirations as a community in crisis and change. We end the seminar by joining hands in a large circle with everyone present, singing our theme song "Sister."

After the seminars, women often approach ACE members individually, with their own stories, problems, questions, and needs. The seminars serve as a starting point for the informal counseling and support that ACE members provide. In the yard, on the living units, in school corridors, the conversations continue.[23]

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[23] Some examples:

...A. has been waiting for four weeks for her test results, and she's beyond tense. Finally she's told to come down to the hospital. She asks her friend, who is in ACE, to come with her for support.

...T. is going on her second furlough. After her first visit, she mentioned to her friend in ACE that she slept with a guy she likes. "Did you use a condom?" "No." After long hours of talks, she's committed to changing things this time, but she seeks her friend out for last minute reenforcement.

...On a living unit, an argument breaks out over who has the use of the stove. One woman calls the other "an AIDS-ridden bitch!" in front of several others. C. intervenes, "Hey weren't you the one in the ACE seminar who said that anyone who would verbally abuse someone for having AIDS is an 'ignorant bitch'?"

The prison reality constrains our counseling work in small and large ways. Because ACE has not had civilian supervisory staff until the present, we have not been able to have an office, and women in population could not reach an ACE member when they needed support and advice. We might begin talking to a woman in the yard who has tested positive and is scared and alone. We reach out to reassure her with a hug. A guard comes over to warn us, "No physical contact! Ladies!" A woman comes to her first support group meeting. It has taken her months to build up the courage to come to a PWA support group. Then two days after she has made that big leap, she is suddenly transferred to another prison.

Despite these problems, the work has flourished. ACE does group orientation sessions with all newly arrived women. We have developed a pre-release program geared towards women who are leaving the prison, either on parole, work-release, or furloughs. We offer an intensive eight session workshop series for women about AIDS.

We wrote a curriculum that we use in our education work and to train new members.[24] Holding memorials and making quilt squares for each woman who dies helps us survive the losses we suffer, as we draw strength from each other as a community.

VI. WOMEN AND AIDS

This is a particular prison community, one of women. By living closely and sharing our lives, separated from men (except for staff), we have a unique opportunity to focus on our own reality and experiences.

In most cities, there is little interaction between the various communities hardest hit by the AIDS crisis. But at Bedford, women from diverse cultures, nationalities, and racial and economic backgrounds find a common bond, as prisoners and as women.

The majority of the women at Bedford Hills are African-American or Latina and/or poor and are from cities racked by homelessness and

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...N. approaches her neighbor in ACE. She's been talking to a woman and likes her, but she's worried because she hears rumors that the woman has AIDS. What should she do?

[24] The curriculum includes orientation materials, seminars, and teaching plans for eight workshops. The workshops include the following: What is AIDS; Stigma; Treatment Strategies and Social Issues; Transmission (Facts and Myths) (which focuses on casual contact transmission, transmission via drug use and blood, and mother to child transmission); Sexual Transmission (Safe Sex Issues and Struggles); Testing; Women and AIDS; and Living with AIDS.

The eight week workshop series is open to anyone from the prison population. Some people take the workshop series purely for their own information.

shrinking social services. These conditions make us even more vulnerable to the impact of AIDS. The statistics indicate this vulnerability; in New York City, eighty-four percent of all people with AIDS are African-American or Latino.[25] A recent study by the New York State Department of Health showed that one in seventy-seven women of child-bearing age in New York City is infected with HIV, but the figures were as high as one in twenty-five in the poorest areas of the Bronx, Brooklyn, and Manhattan.[26] Statistics alone do not adequately convey the reality women at Bedford experience day by day, living through this epidemic. In ACE we have come to understand that developing an analysis of AIDS as a social issue for women is crucial and that acting on those issues is literally a matter of life and death.

One theme which emerges repeatedly in workshops, seminars, and individual conversations is sexuality and how social relations can create passivity and dependence in women, leaving them in a weak position to ask their male partners to use condoms. This increases the vulnerability of women to AIDS. When we ask a group of women if they have ever been pressured into having sex, almost every woman will raise her hand. They speak of rape, date rape, child molestation, and incest in this new light.

We've discovered a tragic irony. On the one hand, women are pressured into sex. On the other hand, when a woman does get infected with the HIV virus via sexual transmission, it's assumed that she did something wrong to get it. In the experience of ACE members, women who get sexually transmitted diseases are stigmatized in a way that men are not.

We discuss why we find ourselves in situations where men won't use condoms and we can't make it happen. We have come up with a list that includes: "I'm too shy"; "Men think they run it"; "He'll think I'm accusing him of cheating"; "I'm afraid he'll get violent"; "Who will support me?"; "I just don't *talk* about sex"; "Condoms don't allow total pleasure."

These problems are underlined by the rise in the percentage of women who have AIDS as a result of heterosexual contact as compared to other modes of transmission.[27] Some of the passivity and reticence to talk about

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Some take it as a first step in joining ACE. ACE members develop their abilities as peer educators by teaching the workshops.

[25] Harrington, supra note 5, at 34.

[26] Evans, Women and AIDS: Fighting for Their Survival, N.Y. Daily News, July 16, 1989, at 30.

[27] See Harrington, supra note 5, at 34.

sex carry over into sexual relationships between women as well, creating obstacles to safer sex between women.[28]

The process of collectively examining our own experience as a community of women has been consciousness-raising. We have developed a sense of commonality as women and an awareness of just how much we are up against. We realize that if we don't strengthen and build solidarity with each other, we will have a hard time doing what we know we should do to save our lives. Out of this consciousness, we are developing a social analysis of women and the AIDS crisis and a greater commitment to action. In workshops and discussions women say, "We have to change things, we have to figure out what to do."

We are urging that the Bedford Hills Medical Department study the particular impact of AIDS and HIV treatments on women in the prison, knowing that this may aid women in other places. We are pushing to make drug trials accessible to women prisoners.[29]

In addition to our work in Bedford Hills, we want to reach out to the larger society and push it to focus more on women's needs in the AIDS crisis. ACE members from inside Bedford have been able to speak at conferences and other events where they are a voice for women, particularly African-American and Latina women, as well as PWAs and prisoners. Our members have spoken at conferences on women and AIDS in New York City, at two conferences on treatment strategies and expanding access to drug trials, and at a conference about AIDS and prisons attended by health and prison officials from around the country. In addition, ACE's work has

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[28] Women are also affected by AIDS as mothers, potential mothers, sisters, and caregivers, as the following examples drawn from the Bedford Hills experience demonstrate:

...T., who is HIV-positive, is a young woman from a large family and has always looked forward to having her own children. Just weeks before she is scheduled to go home on parole, she opens up to an ACE workshop about her inner struggle over whether or not to try to have a baby.

...L. had AIDS. Her mother, who is caring for L.'s HIV-infected baby at home, stayed by L.'s bed during her last weeks in the hospital before she died. She also visits two other children in prison, one of whom is HIV-positive.

...D. is getting ready for a long awaited overnight visit with her two children. "I really need this extended private time with them. Now that they are teenagers, I'm scared to death about them having sex without protection. I never felt very comfortable talking to them about sex, but now I feel it's a matter of life and death."

[29] Drug trials are not available to people in prison. There has been some exploration of the possibility of making them available at Bedford Hills. As of this writing, however, they are not available.

been recognized by the Coalition of Westchester Women's Organizations who gave us their Project of the Year award for 1989.

ACE members getting ready to leave prison want to play a role in addressing some of the contradictions within their own communities (denial, homophobia, the subordination of women), to work with other women around the issue of safe sex, and to build support for PWAs. Two ACE members who have gone home currently have full time jobs in community-based AIDS organizations, and others are in touch with local AIDS networks.

While these accomplishments are significant, many problems persist. Women have learned about their social reality and about safe and unsafe behaviors, but most have not changed their behaviors. Time after time, women going on furloughs talk with us about using condoms, but they do not. In the workshops, where we've succeeded in having the most open and frank discussions, the majority of women say that they can't really imagine adopting safer sex behaviors with either male or female partners.

VII. CONCLUSION

The development of ACE has created many victories. We have experienced a rise in community consciousness at Bedford Hills in times when ACE has been active and a decline in consciousness in times when ACE has been inactive. This is strong evidence that our work has helped to lessen stigmatization of people with AIDS, has lessened people's fears of infection through casual contact, and has promoted an ethic of care and concern. ACE has also been effective in promoting the medical needs and human rights of PWAs through health advocacy: our struggle to improve medical conditions, to improve the infirmary environment, and to create a support network. Numerous medical, counseling, and mental health professionals have told us that ACE has helped them be more effective. Many corrections officers approach us with questions and requests. ACE did one formal educational session of civilian and uniformed staff.

We have learned that if a prison administration is willing to permit a grassroots approach to AIDS work, then the prison context has certain strengths to draw upon. The prison is a small, enclosed community. Its very size and shared living conditions reinforce interdependency, unlike large urban communities. Outside communities face many pressures and devastating problems of survival demanding the attention of both individuals and the community as a whole. In troubled communities, AIDS is only one of many issues. In prison, on the other hand, people are less

pressured by survival concerns and have more time and psychic energy to focus on AIDS and to take advantage of education, counseling, and support groups.

In a women's prison, there is the potential to develop a feeling of sisterhood and solidarity, to focus on ourselves as women in understanding the ways that AIDS affects us and on how we can act together to deal with the crisis. Unfortunately, the dismal climate surrounding AIDS prevention and care in hard-hit communities means that the strength women develop in Bedford Hills can be undercut when they leave. Prisoners will usually return to communities which lack adequate resources to provide health care and where the internal attitudes that create stigmatization are widespread. The situation is bleak in the African-American, Latino, and poor communities that most need to mobilize around AIDS, despite deeply committed efforts by some groups in New York. Without widespread community mobilization, the stigma of AIDS will go unchallenged. The prevention of AIDS cannot rest on individual strength.

The experience of ACE suggests that a grassroots approach to AIDS work can make a difference inside prisons, and that people directly touched by the disease and its consequences are the most effective in fighting it. Communities beyond prison walls should take note that the fight against AIDS is best carried out by those most deeply affected by the crisis. Prisons can be training grounds in which people can become educated, experienced, and committed to AIDS work. They will thus have the tools to make a significant contribution to their communities when they return to them.

VIII. ADDENDUM

In the year since this article was first written, ACE has experienced a number of changes and developments. The $250,000 grant from the New York AIDS Institute, administered by the Women and AIDS Resource Network (WARN) and the Columbia School of Public Health, was finally made available to the Bedford Hills Correctional Facility in January of 1990. An outside director and four-member civilian staff were hired to work with ACE: a coordinator, counselor, community liaison counselor, and administrative assistant. ACE was finally given office space, and twelve of the most seasoned members now work in ACE as a formal prison-approved job.

The office and inmate staffing enabled ACE to be more consistently accessible to all the women in population. We no longer have to search for someone, hoping to find them in the yard or on the corridor. They can come to the office. Informal meetings and video showings, individual

counseling and group discussions happen daily. We can do follow-up counseling with women with whom we come into contact through education and outreach in population. This is especially true among newly arrived women.

The office itself is the center of ACE's energy. It is a place where services are provided, as well as a drop-in center where women can come to talk with ACE members and each other, where PWAs can safely connect to one another and influence others.

The combination of civilian staff and resources and a group of inmates on staff as peer counselors and educators has enhanced ACE's ability to provide services for women in need. For instance, the civilian community liaison counselor works full-time developing resources for HIV-positive women who are leaving prison. Support groups for PWAs and significant others as well as grief groups are available for women. ACE women on staff went through the New York State certified pre- and post-test counseling program and passed the test to become HIV counselors.

ACE has become very much like the community-based service programs that are active on the streets; that is, they are less focused on the mobilization of a community and more on providing education and services. ACE, which started out as an informal, grassroots organization with only inmates, has become a formal structured project, administered by outside agencies and civilian staff, in conjunction with the Administration. Within this structure, there is wide latitude, and need, for all ACE members to develop and carry through on a broad range of work.

A full discussion of the shift in power and emphasis of work is beyond the scope of this article, but we think it is important to note that while the authors were originally hired onto inmate staff, eight months later we were removed by the Administration and WARN director because the Administration felt that we had undue influence. We continued to be active as ACE members. As of September 1991, one of us was reinstated on staff and the other was removed from ACE.

The need for an organization such as ACE has grown since it first began, as the impact of the epidemic has deepened and the number of women coming to prison has spiraled upward.[30] While there have been

[30] From 1980 to 1989 the number of female prisoners under state and federal authorities increased by 202% whereas the number of male prisoners increased by 112%. At the end of 1989, there were 40,556 female prisoners under state and federal authorities, 27,000 more than in 1980. United States Department of Justice, Bureau of Justice Statistics, Special Report on Women in Prisons 1 (March 1991).

no further blind studies to develop exact statistics, we are seeing many more women coming into the prison who are HIV-infected. Many more women are taking the HIV antibody test and testing positive after incarceration. In addition, women are coming to ACE for counseling and support because they have lost one, two, often several close family members to AIDS. Many women worry that their children are infected. The epidemic is devastating whole families across generations.

On the other hand, we are meeting more and more long term survivors: women who have been diagnosed and ill for many years, and continue to struggle to manage the illness and their lives. These women are hungry to know about new treatments.

Most of the original ACE members are gone. Many have left prison; some are no longer active in ACE. Many of the PWAs who took the first steps to speak have left prison. Some have died; many are struggling to survive and thrive. Some continue to be active in AIDS work in the community. Many new women join ACE at the end of each workshop series. Over the years, about 150 women have been active ACE members.