STRUGGLES FOR JUSTICE

Community of Women Organize Themselves to Cope with the AIDS Crisis: A Case Study from Bedford Hills Correctional Facility

Judy Clark and Kathy Boudin

Introduction

IN BEDFORD HILLS CORRECTIONAL FACILITY, New York State's maximum security prison for women, AIDS has created a crisis. A recent study showed that almost 20% of the incoming women were HIV infected (New York State Department of Health, 1989). 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 concerned with having safe sexual relationships and the many not yet educated or concerned about this; those with fears and questions about casual contact in an environment that 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% (New York State Commission on Correction, 1988: 13). In 1987, 58% of the deaths among New York State prisoners were due to HIV-related illnesses (*Ibid.*: 7). DOCS officials estimate 60% to 70% of state inmates have a history of drug use, one of the main activities that puts people at risk for HIV infection (Potler, 1988). Statistics show that HIV has had a devastating impact on low-income Black and Latin communities. In both New York State and New York City, over 50% of the people with AIDS are Black and Latin. Black and Latin people represent a disproportionately high 80% of New York State inmates (*Ibid.*: 6). These statistics point to the need for AIDS work in the prisons to challenge the unnecessary fears and stigmatization of PWAs (people with AIDS), and to promote programs of support, prevention, and medical care.

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 grass-roots mobilization, community empowerment, and culturally specific organization (Sy, 1989),[1] as is true for other health-related problems (AIDS Advisory Committee, 1989). This means that prisoners need to be able to organize themselves to educate, counsel, and provide support among their peers (*Ibid.*). Yet prison life is predicated on absolute security and control by prison administrators. The empowerment of prisoners is viewed as contrary to the needs of security. Moreover, most prison officials view prisoners as less rational and less capable beings, 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, is unimaginable to most authorities. Furthermore, there is no way to deal with AIDS without engaging issues of sex and drugs. Yet because both are illegal inside a prison, prison officials are loathe to allow open discussion, let alone to provide the means to pursue sex or drug use more safely (Hammet, 1988).

There are additional obstacles to addressing the AIDS crisis for women. Women are the fastest-growing population becoming infected with HIV (Santee, 1989). Moreover, women bear much of the social burden of the epidemic, particularly in Black, Latin, and poor urban communities. Yet the prevailing attitudes of the medical and political establishments have overwhelmingly denied the impact of this reality. Often, when AIDS is discussed in the media and by public health officials, the majority of women with AIDS are labelled as "IV drug users or their partners," "prostitutes," and "crack users." Alternatively, women are defined as "vectors": transmitters of the virus to their babies or, in the case of prostitutes, a threat to middle-class heterosexual men. Women's own humanity and needs are rendered unimportant. The medical establishment has not studied the particularity of HIV infection in women. Women are excluded from most drug trials. The Center for Disease Control does not track women-to-women transmission. Most major medical facilities

JUDY CLARK and **KATHY BOUDIN** have been active in social and political movements for over 25 years. They are currently in prison serving life sentences at Bedford Hills Correctional Facility for Women in New York State. Correspondence can be sent to: Judith Clark, 83–G–313, Kathy Boudin, 84–G–171, Box 10000, Bedford Hills, NY 10509–2499.

The authors wish to thank Gilda Zwerman for her encouragement and ongoing input into the writing of this article, and for her editorial work. We wish to thank the following people for their comments: Jean and Leonard Boudin, Kim Christensen, David Gilbert, Suzanne Kessler, Debra Levine, Eve Rosahn, and Karen White. Although the authors are solely responsible for the opinions and analysis in this article, the lessons and experiences described are the product of the efforts of more than 75 women who have been members of ACE. In particular, we wish to thank Rosa Barbot, Katrina Haslip, Maria Hernandez, and Carmen Royster for their comments and encouragement.

do not take into account the needs of women arising from their family responsibilities to ensure access to health care (ACT-Up, 1989; Santee, 1989). No wonder the phenomenon of women with AIDS has been called "the silent epidemic" (Santee, 1989). Their invisibility serves to disarm and disempower women struggling with AIDS.

ACE (AIDS Counseling and Education) is a prison program that is making a difference in the AIDS crisis at Bedford Hills Correctional Facility. 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 is a spirit of sisterhood and community, encouraging group and individual self-respect and initiative. It has as its broadest goal the empowerment of 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 ways in which the AIDS crisis affects 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 fears among the women at Bedford Hills.

The Period before ACE

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

Women with AIDS were placed in the In-Patient Care (IPC) — the infirmary unit. The unit was dark, dirty, 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 there had no programs, no recreation, 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 (CO) willing to attend to her needs.

A report from a court-appointed Special Monitor overseeing a medical-conditions court case for Bedford Hills (*Todaro* v. *Ward*, 1977) referred to this woman:

> 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 (Rundle, 1987: 2).

The report also summarized the general situation concerning AIDS:

> It also 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 (*Ibid.*).

As prisoners and staff became aware of the AIDS epidemic, fear and stigma spread throughout the prison. Fears of infection through casual contact are heightened because people share showers, kitchens, and recreation areas. Here, as in any closed institution, rumors, tensions, and confrontations had fertile territory in which to spread, fanned by prisoners, officers, and civilian staff. For example, prisoners petitioned the administration to remove an inmate who was assumed to be HIV positive from their floor and the inmate was compelled to move because of the pressure. Officers who were packing up a cell of an HIV-positive inmate wore gloves and a mask, creating fear among the inmates through the erroneous notion that AIDS is spread through casual contact.

Attempts to change the situation helped create conditions for the development of ACE. About 12 women met with the Superintendent in 1986 to urge more education of staff and inmates. Out of an agreement with the Superintendent at that meeting, women began to visit people housed in the infirmary to break down their isolation. One PWA contacted the Mid Hudson AIDS Task Force and two 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 and problems that AIDS raised for them. As more women got sick, many more women in the 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.

The greatest challenge to the AIDS crisis was proposed by some of the people with AIDS themselves. One woman who lived in IPC struggled for the right to get her job back, 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 re-embraced her as a friend. Another woman, who had been at Bedford for seven years, was someone everyone knew. She came from the infirmary to watch baseball games with the rest of the population. Because she was such a popu-

lar and widely known person, her diagnosis of AIDS, along with her spirit and openness, made it harder to define people with AIDS as "other."

The Emergence of ACE

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 their backgrounds and skills. One woman had been a businesswoman. Another wrote songs and plays and performed in cultural events. Two were active in 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 were their feelings about how they, their families, and communities were affected by AIDS and by their drive to do something about it.

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 inside 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 dealing with the many problems and questions that AIDS creates in our community; and
4. To build bridges to outside community groups so that women would have the necessary support when they re-enter 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 instead were playing a leading role. The principles of community self-consciousness, peer education, and support all became associated with responding to the AIDS crisis.

How could we apply this model in our situation? Women at Bedford Hills Correctional Facility started out with many obstacles. We are prisoners: 75% are Black and Latin, many are IV drug users, and all are women (Nuttall, 1988). Along with being oppressed and marginalized, people internalize society's negative attitudes. Self-deprecation is manifested when people cease to care about their own personal survival on many levels and lack respect for others in their community. Being in prison makes a person even more dependent and less able to take initiative. Although we share our lives inside, there

was no existing consciousness of community. Women had to build that to help in the fight against AIDS.

We brought certain strengths as women. There is a tradition of nurturing and caring that can be drawn on for AIDS work. Women take an interest in each other's personal problems. They give each other advice as part of friendships. Women can establish deep emotional-support systems. Women in prison seek relationships and bond with each other. There is less homophobia and denial of homosexual relations within a women's prison than in a men's prison. Consequently, there was a more open atmosphere to deal with issues of sexuality, which is imperative in AIDS work. It also meant that we could easily identify with and draw upon the example of the gay community outside.

After several months, in the spring of 1988, the Superintendent agreed to allow us to implement the proposal for ACE. This was a bold step since in the overwhelming majority of prisons throughout the U.S., policy ranged from one requiring mandatory testing and isolation of those testing positive to, at best, one providing minimal education by outside experts (Hammet, 1989). In several instances, male prisoners in New York State who have tried to initiate AIDS work were restrained and sometimes transferred (Gilbert, 1989; Lown, 1989).

The first meeting of ACE was attended by 35 women who expressed interest in becoming involved with education and support around AIDS. We sat around a table and each woman spoke about what 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 here had ever said out loud to a group of women that she had AIDS. Then a 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. Then a third woman said she had AIDS and she was here because of how people had isolated her and treated her with prejudice.

These individuals, by speaking openly about their condition, put their trust in the group that day. Their trust and others' positive responses are what began to build this community of support.

In the initial proposal we had requested training by outside sources. Soon after the first meeting all 35 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 of three hours each incorporated the newest information with role plays, dis-

cussion, and sharing of personal experiences. A Bedford staff member and a volunteer also led two sessions on counseling.

Although ACE carried out no formal outreach programs in this period, the ripple effect of this group of women began to transform awareness and attitudes about the situation of AIDS throughout the facility. Over and over one could see the fear and stigma being overcome by information seeking, caring, and nurturing. 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 at the stage of ARC 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, making 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 Chris Williamson as our theme song. The words of this song, *Lean on Me, I Am Your Sister...*, reflected and contributed to the growth of community consciousness of women.

Contradictions between Prisoner Initiative and the Prison System

By June 1988 we were ready to begin developing outreach programs with population. The Superintendent announced to an ACE meeting that the New York RIDS Institute had awarded Bedford Hills Correctional Facility a quarter of a million dollars to develop a model AIDS program. This was largely due to ACE's work. We looked forward to a period of growth.

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 that 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 the weekly ACE meetings could no longer happen. Previously, the Superintendent attended many meetings or met with individuals to discuss and approve the work. Suddenly, the administration stopped meeting or communicating with ACE, which meant that ACE could not get the specific approvals necessary for the work simply to 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 some of her thinking and actions in meetings, media interviews, and informal discussions. In retrospect, we were able to analyze what we experienced and place it in a broader context. Some of the problems we reflected on included the following:

- Inspired by the sense of having a mission, ACE members actively tried to help women who were in crisis and need. Sometimes this resulted in members intervening as advocates with medical staff or other staff. Sometimes it meant being in places where they weren't strictly supposed to be. After all, this is a prison, where movement is supposed to be strictly controlled. Sometimes staff welcomed ACE's involvement; but other times, officers or staff raised questions about inmates exercising undue authority or being "out of place."
- As women became more educated, they helped each other to try to get better medical care. This put pressure on the Medical Department, which was already feeling pressure from increased needs arising from the AIDS epidemic and from the *Todaro* v. *Ward* law suit about medical conditions. Ultimately, negotiations between the parties of the suit resulted in marked improvements in medical staff and procedures that all parties welcomed. But no prison administration likes being pressured by inmates and lawsuits.
- A woman in the hospital unit took an overdose of drugs. Because many ACE members spent time visiting and being buddies to people in the IPC area, everyone in ACE was put under possible suspicion in the ensuing investigation and had to take drug tests. No one was found responsible for any wrongdoing, but questions were nonetheless raised about ACE members having such access to the hospital area. The work in the hospital was permitted to continue, but ACE members felt pressured by the atmosphere of suspicion.

The relationship of sex and drugs to AIDS poses further problems for prison administrations. People must be able to openly discuss their actual sexual experience and confront resistance to changing their practices if the spread of AIDS is to be prevented. The same need for open discussion holds true for the use of drugs. Yet in a prison these activities are illegal. Thus, a prison is faced with the dilemma of whether creating a safe atmosphere of open discussion and struggle in the interests of public health and saving lives also undermines the prisons rules and views of morality enforced through punishment. In AIDS education work, information is not enough to foster behavioral change. It is also necessary to provide the means to enable such a change (DesJarlais and Friedman, 1988). Because sex does go on in prisons, administrators are faced with the dilemma of having to distribute condoms and dental dams in order to prevent the spread of HIV infection. A few jail and prison systems are doing so; Vermont, Philadelphia, New York City, and Mississippi are examples (Hammet, 1989). Most, including the New York State Department of Corrections, oppose this policy. A recent study by the New York City Bar Association urged that the state prisons adopt a program of condom distribution to prevent transmission by sex. However, a spokesman for the prisons said that state prison officials oppose condom distribution because sexual intercourse between prisoners is forbidden by prison regulations (Lambert, 1989).

It is our view that these and other problems reflected built-in contradictions between the prison system and prisoner initiative: peer eduction and support combined with self-initiated inmate organization, even for a positive service-oriented goal such as coping with the AIDS crisis is seen by the system as a potential threat to prison security and control. Two ACE members, participating in a conference on prison and AIDS, observed a federal prison administrator recoil as he vehemently disagreed with the approach of a peer-based program such as ACE.[2] Furthermore, in subsequent conversations with staff and administration, they acknowledged that ACE's freewheeling energy and activity, which helped build the supportive and engaged process, also made them nervous.

Thus "empowerment" within a prison is severely limited. The control over prisoners is ultimately so total that they cannot take responsibility for themselves unless the authorities permit such a process. But, of course, "empowerment" is something people create for themselves. Once we, as prisoners, were given permission to become educated, to take initiative, to organize our own community, many women in ACE felt more motivated and empowered than they ever had before in their lives. When it was taken away because the need for security and control became overriding, the frustration and anger among the women was all the greater, "like a dream deferred."

To avoid the problems described above, almost all prisons prefer to rely on outside experts to carry out AIDS education and services rather than on a peer-based process. In the most widely used approach, experts come to give live presentations with question-and-answer sessions, usually supplemented by videos and written materials (Hammet, 1988). Before the existence of ACE, this was the form that AIDS education took at Bedford Hills Correctional Facility for both inmates and staff. The sessions were carried out by representatives of the New York State Department of Health and other agencies. Although the presentations were usually accurate and well-meaning, the audience was too large, the time too short, and many people did not trust the presenters because they were state officials.

In some prisons, civilian social workers and AIDS experts have been hired to do ongoing work (*Ibid.*). Although in many instances they provide real relief and supportive services to individual 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 and self-initiative and community involvement that can only come from a grass-roots effort. The experts from Montefiore Hospital 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.

Without ACE's active presence among population, arguments and fights again broke out, provoked by verbal and physical attacks on women suspected

of being HIV positive. A positive community consciousness cannot be sustained without constant reinforcement. Without an inmate-organized form for building this consciousness we witnessed the re-emergence of fear, stigma, shame, and all the accompanying behaviors.

During this period when ACE was demobilized, members tried to sustain the group and work. They continued to press the Superintendent to reactivate the group. 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 several factors. First, the crisis in AIDS was getting worse, and the need for ACE could clearly be seen in comparing the conditions when ACE 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 these buildings to help alleviate these problems. Second, the model of a community-based initiative was the approach increasingly supported by AIDS professionals, based on the success of the gay community's struggle to deal with AIDS. Third, the *Todaro* v. *Ward* 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 the AIDS Institute grant would come through and a potential staff member began to attend meetings.

In retrospect, we can see that particular historical conditions combined with the prison reality to create the context for both the strengths of ACE as a grass-roots effort and some of the problems we have encountered. When ACE began in 1988, there existed almost no structure, programs, staff, or resources to meet the AIDS crisis in prisons throughout New York State and nationally. ACE filled that vacuum at Bedford. The Superintendent recognized the value of ACE and supported it. In general, the Bedford Hills Correctional Facility administration supports programs that rely on inmates, exemplified by the Children's Center and the Family Violence Program and the South Forty Pre-Release program. It was obvious to the administration, however, that there was a need for full-time staff supervision of ACE and the AIDS Institute grant served that purpose. Negotiations over that grant took a long time. Although ACE has functioned and grown in the year and a half since the summer of 1988, we have also experienced additional crises when our work and organization have been disrupted and curtailed. ACE had less day-to-day supervision than a prison administration can tolerate for such a mass-based program. As of this writing (January 1990), the grant from the AIDS Institute has finally been secured. This 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 the staff and resources can enable our work to ex-

pand, without our losing the power of community mobilization and self-reliance that is at the heart of ACE's success.

ACE members recognize that ACE must function within the limits of the policies set by the prison system. Nevertheless, our work and impact push these limits. This poses a challenge for the system, but optimally it can bring about positive changes in policy. Indeed, many state officials have told ACE members in meetings and publicly that the ACE model needs to be utilized in other prisons, and there are indications that some level of peer AIDS organization will now be implemented in other New York State prisons.[3]

Growth of Community Consciousness and Initiative

When ACE reconvened in November 1988, one central goal was to create more humane conditions for PWAs. The commitment had to be made spiritually and materially to those who were HIV infected in order for any other work to develop. One focus of our energies was the IPC unit where acutely ill women live. We began knitting classes and a weekly bingo night. We organized parties for the holidays and birthdays. We started a donation box; signs went up on every living unit, and throughout the population women donated food and personal items as one small way to show support and care for their sisters in IPC. We intensified our informal buddy work as friends and spent hours with women who were ill, sharing love, humor, and caring.

A common image projected of women who end up in prison is of drug users, partners of addicts, marginalized and criminalized elements. Many of the women in Bedford are in prison for drug-related crimes. But they are also mothers, caretakers, sisters, and lovers. Many of the women in here grew up in homes headed by mothers and grandmothers who often cared for three generations of children and nursed their elders. Women in prison, like women in oppressed communities on the outside, are moved to take care of people in need. The same hard, boisterous, selfish "taker" in one situation, when faced with an ill, needy, frightened woman becomes a nurse, a sister, a friend willing to bathe, rub, soothe, sing, and hug. ACE encouraged this capacity through example, and by pointing it out in others and giving it a social meaning.

An agreement with the Medical Department was reached that enabled ACE members to participate in medical consultations as health advocates in cases where individual women requested it. Among the services provided by ACE health advocates to women are: to help them prepare questions for medical appointments, to help improve communication between the doctor and the woman, and to provide emotional support for the woman. This encourages more holistic medical care through focussing on social and emotional factors affecting the woman in addition to the purely physical ones.

This supportive atmosphere forcefully challenged the stigmatization of HIV-positive persons. It benefitted PWAs because it reduced stress and made it more likely that women would seek medical care.

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 the population who are HIV positive, seeking comradeship, advice, hugs, and inspiration. Their courage and example of living with AIDS give 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.

Our other priority 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: Afro-American, white, Latin, 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 states what moved her to get involved in AIDS work. Together, we reflect the community to whom we are speaking. The women see us working collectively in the very process of doing the seminar, which gives them a sense of the power and possibilities 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, and the issues surrounding whether or not to take it; the need to fight stigma and build community support. Our seminars are more than a presentation of facts, the approach usually taken by experts.

In the seminars we use role plays about the real situations we face. This provides a mirror for us to view ourselves from a distance, which allows for reflection; and it allows all of us 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 has just been paroled and goes back to her boyfriend or husband. She has learned that 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 anyone else have an idea of what to do or say?" We try to look at the social issues underlying the problems. How, as women, we are faced with real obstacles because of our social and personal disempowerment, so that taking responsibility can only happen through collective and individual empowerment.

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 levels are high. ACE is not pro- or anti-testing, but instead 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 and singing our theme song, *Sister*.

While some of us in ACE have been public speakers, organizers, or teachers for years, many have never spoken before a group or thought of themselves as teachers. By working to meet the needs of our community, ACE members have developed and grown. This community-based approach to AIDS work unleashes enormous potential in women that affects not only their work in AIDS, but also every area of their lives. There is a real connection between the experience of working to meet the needs of our community and the self-development of individuals who engage in that process.

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.

Counseling, support, and health advocacy are woven into our daily lives in this community. Primarily, we do not seek to develop a professional model; our relationships and work do not create an "us-them" dichotomy. In the yard, on the living units, and in school corridors, conversations take place. Some vignettes from this process are:

- "A." has been waiting for four weeks for her test results and she is beyond tense. Finally she is 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, she raised to her friend in ACE that she slept with a guy whom she likes. "Did you use a condom?" "No." After long hours of talks, she is committed to changing that this time. But she seeks her friend out for last minute reinforcement.
- 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 our ACE seminar who said that anyone who would verbally abuse someone for having AIDS is an 'ignorant bitch'?"

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

The prison reality constrains our counseling work in large and small ways. Because ACE has not had civilian supervisory staff until now, we have not been able to have an office, and often women in the population could not reach an ACE member when they needed support and advice. We might be 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 the problems, however, 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 interested in joining ACE or who want to learn more in depth about AIDS. We wrote a curriculum that we use in this work and in the training of new members. 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.

Women and AIDS

This is a particular prison community: one of women. By living closely together 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. At Bedford, however, women from diverse cultures, nationalities, and racial and economic backgrounds find a common bond, as prisoners and as women.

Most women at Bedford are Afro-American, Latina, or poor and are from cities racked by homelessness and shrinking social services. These conditions make us even more vulnerable to the impact of AIDS. The statistics indicate this vulnerability: in New York City, 84% of all women with AIDS are Black or Latin. Over 90% of the infected children under five are Black or Latin (Santee, 1989: 3). A recent study by the New York State Health Department showed that 1 in 77 women of childbearing age in New York City is infected with HIV, but the figures were as high as 1 in 25 in the poorest areas of the Bronx, Brooklyn, and Manhattan (Evans, 1989: 30). Statistics alone do not adequately convey the daily reality experienced by women at Bedford in attempting to live 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 that emerges repeatedly in workshops, seminars, and individual conversations is sexuality and how the dominant view of women as sexual objects for men affects our vulnerability 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 discuss why we find ourselves in situations where men won't use condoms and we can't make it happen. We 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"; "fear of violence"; "Who will support me?"; "I just don't *talk* about sex"; and "Condoms don't allow total pleasure." What is suggested by these answers is that the social relations that enforce a women's passivity and dependence leave women in a weak position to ask their male partners to use condoms. These problems are underlined by the rise in the percentage of women who have been diagnosed with AIDS as a result of heterosexual contact as compared to other modes of transmission: from 11% in 1984 to 29% in 1989 (Santee, 1989: 2). Some of these attitudes of passivity and reticence to talk about sex carry over into sexual relationships between women as well, creating obstacles to safer sex between women.

We have identified a basic and tragic irony: on the one hand, women are pressured into sex. On the other hand, when a woman does get infected with HIV through sexual transmission, it is assumed that she did something wrong.

Women who contract sexually transmitted diseases are stigmatized in a way that men are not. Women are affected by AIDS as mothers, potential mothers, sisters, and care givers.

- "T.," who is HIV positive, is a young woman from a large family, who has always looked forward to having her own children. Just weeks before she is scheduled to go home on parole, she opens up in an ACE workshop about her painful internal struggle over whether 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, two-day overnight visit with her two children:

> I really need this extended private time with them. Now that they are teen-agers, I'm scared to death about them having sex without protection. I never felt very comfortable telling them about sex, but now I feel it's a matter of life and death.

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 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 both 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 have begun to build a Hispanic sector of ACE, and Afro-American and Latina women are looking at ways to address the needs of each community — Puerto Rican, Afro-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, Hispanic, and white women to begin that process.

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 help women in other places. We are pushing to make drug trials accessible to women prisoners.

Besides our work in Bedford, women want to reach out to the larger society for more of a focus on women's needs in the AIDS crisis. ACE members from inside have been able to speak at conferences and other events where they are a voice for women, particularly Afro-American and Latina women, PWAs and prisoners.[4] Our members have spoken at conferences on women and AIDS in Albany and New York City, at two conferences on treatment strategies and expanding access to drug trials, and at a conference about AIDS and prison, which was attended by health and prison officials from around the country. In addition, ACE's work has been recognized by the Coalition of Westchester Women's Organizations, which gave us their Project of the Year Award of 1989.

Women preparing to leave prison wish 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 in promoting safe sex and building 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.

Although 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 have succeeded in having the most open and frank discussions, most women say that they can't really imagine adopting safer sexual behaviors with either male or female partners.

Conclusion

Certain gains have been won from the development of ACE. We have experienced the rise of community consciousness in Bedford Hills Correctional Facility in times when ACE has been active, and the decline of consciousness when ACE was inactive. This is strong evidence that our work has helped to lessen the stigmatization of people with AIDS, as well as people's fears of infection through casual contact, and to promote an ethic of caring concern. ACE has also been effective in promoting the medical needs and human rights of PWAs through health advocacy, through our struggle to improve medical conditions, and by improving conditions of life in the infirmary and through our support work. Numerous medical, counseling, and mental health staff have told us that ACE has helped and encouraged them to be more effective and many COs 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 grass-roots process of prisoners doing AIDS work, then the prison context has certain strengths to draw upon. The prison is a small, enclosed community; the very size and shared living conditions reinforce an interdependency. This is very unlike large urban communities. Also, outside communities face many pressures and devastating problems of survival demanding the attention of both individuals and communities; AIDS is only one among many issues. In prison, people are less pressured by survival issues, and we have more time and psychic energy to focus on AIDS, 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 to consider how we can act together to deal with the crisis.

However, the very isolation of this women's prison also creates limitations for the effectiveness of AIDS-prevention work. How effective can it be to educate women about safe sex if that same education is not taking place among men, inside and outside of prison? Without interaction between women and men, struggling together to reach new norms, new practices, and new relations, the new consciousness developed by women in prison will be limited in impact.

The dismal climate for AIDS prevention and care in the hardest hit communities means that the strength and support that women develop in prison can be undercut when they leave. Bedford Hills Prison is an environment that provides HIV-positive women more support, emotional bonding, and a self-consciousness about self-respect for themselves as women than they are likely to encounter outside. Unfortunately, they will usually re-enter communities where there are inadequate resources for health and other support services and

where the internal contradictions that create stigma are flourishing. In spite of deeply committed efforts by some groups such as Women and AIDS Resource Network (WARN) in New York, the situation is bleak in the Black, Latin, and poor communities that most need to mobilize around AIDS. Without widespread community mobilization, the stigma cannot be challenged. The prevention of AIDS cannot rest on individual strength.

The experience of ACE suggests that a grass-roots approach to AIDS work can make a difference inside prisons. ACE is a model for other communities in that the fight against AIDS is best carried out by those people most deeply affected by it. Prisons can be training grounds in which people can become educated, experienced, and committed to AIDS work and they can return to their communities where they can make significant contributions. Within those communities, as in Bedford, women are living with AIDS, affected by all aspects of the epidemic. In ACE we have seen that women can become a motive force in the battle against AIDS.

NOTES

1. Although these authors promote peer education among recovered addicts, women, PWAs/ARCs, youth, and minorities, they do not extend this principle to prisoners. In the recommendation for correctional systems, they merely recommend education and counseling programs that are sensitive to the audience. We hope that programs such as ACE and *other* articles such as this can break down the barriers that keep the more progressive health and education policies from being implemented in prisons.

2. This occurrence was reported on by the two ACE members, Katrina Haslip and Carmen Royster, who participated in the conference entitled "HIV/AIDS for Prison Health Professionals." It was presented by the Columbia University School of Public Health on June 20, 1989, at Horton Memorial Hospital in New York. The agenda included a presentation and discussion of ACE as a model program by Nereida Ferran, M.D., Director, Health Services, Bedford Hills Correctional Facility, and by Carmen Royster and Katrina Haslip.

3. In a paper issued by the New York State Department of Health AIDS Institute entitled "Management of HIV Infection in New York State Prisons," it is stated that prisoners should be involved in developing inmate HIV curricula, in teaching other inmates about HIV, and in peer counseling programs (AIDS Advisory Council, 1989: 46). The paper further states:

> Inmate peer educators/counselors may be most effective because prisoners are more likely to listen to and trust other prisoners. Counselors can provide extra support for behavior change from their own experience and may be able to change attitudes towards prisoners with AIDS through setting an example. The AIDS Counseling and Education program at Bedford Hills Correctional Facility provides an example of a successful, prisoner-initiated program of peer counseling and education (*Ibid.*: 47).

On many occasions in meetings and in informal discussions with ACE members, New York State and City officials have spoken of the need for the ACE model of a peer process to be used in other prisons. These officials include people from the New York State AIDS Institute; State Division of Women, the governor's office, New York; New York Commission on Human Rights for

AIDS Discrimination Unit; New York State Department of Health; and New York State Division of Alcoholism and Alcohol Abuse.

4. Some of the conferences in which ACE members have participated on panels include:

a. "Through the Eyes of Women and Children: Strategies for Prevention and Treatment of AIDS," May 5, 1989 in Albany, New York. Sponsored by the AIDS Council of Northeastern New York, Albany Medical Center, and Russell Sage College.

b. "Organizing Community-Based Clinical Trials: Models for the AIDS Epidemic," held at Columbia University, New York City, from July 7–9, 1989. Sponsored by Community Research Initiative (CRI), New York, and County Community Consortium (CCC), San Francisco.

c. "HIV/AIDS for Prison Health Professionals," held at Horton Memorial Hospital, New York on June 20, 1989. Presented by the Columbia School of Public Health.

d. Women and AIDS Conference 1989: The Impact of AIDS on Women, held November 8, 1989, in New York City. Chaired by representatives of the New York City Department of Health.

e. "ACE members accepted the award for Project of the Year for Women's Equality Day," held on Friday August 25, 1989, at the Westchester County Courthouse in White Plains, New York.

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