Organizing Inside

Against all odds, inmates have emerged as their own best AIDS educators and advocates. Why don’t prison wardens, ASOs and health departments get it?

November 1, 1998 By Esther Kaplan

It’s a sweltering August afternoon. A single fan tries unsuccessfully to kick up a breeze in an airless room at New York State’s only maximum-security prison for women, Bedford Hills Correctional Facility. One or two at a time, women filter in, emerging from the afternoon count. Here, surrounded by wilting potted plants and loose stacks of HIV prevention pamphlets, the prison’s PWA support group convenes gradually, as the conversation slides from lunchtime chatter to discussion of a mysterious rash; soon, two women have rolled up their sleeves to compare notes. This is ACE, AIDS Counseling and Education, the oldest inmate-run HIV program in the nation.

At today’s gathering, all the women happen to be mothers, and their children quickly eclipse health concerns once one woman confesses her biggest fear: that she won’t make it out alive. The conversation heats up. Pearl Richardson, a mother of five whose youngest is HIV positive, says the state is seeking to terminate her parental rights. From across the table, Karen “KK” Loftin, a mother of two and one of the group’s charismatic leaders, issues a challenge: “My attitude is, ’I’m not dead yet!’ and I plan to live and take care of them.” Richardson shakes her head and says, “I admire KK because she has the determination that I strive to achieve. I just haven’t found the heart or courage yet.” One woman in the group, Vanessa Morgan, has just signed her exit papers after seven years. As she begins to reflect on what this program has meant to her, she leans her head against Loftin’s shoulder. “I haven’t had a disciplinary ticket in two years because of ACE,” she says. Everyone around the circle knows this is no mean feat, since, having lashed out at a guard after testing positive, Vanessa spent most of 1994 and 1995 in a Special Housing Unit, where prisoners deemed unmanageable are locked down for 23 hours a day. More than a few of those present have spent time there since their diagnosis. Twenty-three-year-old Karisa Santiago, a sweet-tempered workshop leader, nods. “Without ACE,” she says, “we’d all be locked down.”

In its 11 years at Bedford Hills, ACE has created the space for dozens of women, furious and closeted about their status, to become proud, outspoken leaders. Founded and run by inmates, ACE offers in-depth HIV education, pre- and post-test counseling, new inmate orientation and support groups; its members do everything for PWAs from explaining protease-related lipodystrophy to changing bedpans. At Bedford, as in New York’s other two women’s prisons, one of every five women is HIV positive -- one of the highest rates of any community in the nation. ACE members constantly circulate among them, recruiting and training new prisoners, both positive

and negative, to join what many call their “family.” Michael Haggerty, executive director of the Correctional HIV Consortium, which provides staff training and program development services to prisons and jails in 41 states, says educators with programs like ACE have a “cultural competency” that outside experts lack, and are respected and listened to for their experience. Last July, a Department of Justice study gave its imprimatur to prisoner leadership, calling inmate peer education programs an “effective and promising ... [way] to address problems of HIV/AIDS.”

But ACE has rarely been replicated. According to a 1997 study by the National Institute of Justice, only 13 percent of state and federal institutions have peer-led HIV programs; even among these, says Jackie Walker, AIDS coordinator of the ACLU’s National Prison Project, “there’s a real range in terms of how much input from prisoners is allowed.” Almost 25,000 inmates are known to be HIV positive in this country’s state and federal prisons (the rate of AIDS inside is six times higher than for the US population as a whole), and by all accounts, sexual activity and drug injection are widespread behind their walls. But prison administrations have generally responded to inmate initiatives by cracking down, and state health departments have been slow with funds, preferring to send in the occasional AIDS expert for a lecture. Even when it comes to AIDS, the national prison trend is toward punishment, not rehabilitation. As longer drug sentences increase the likelihood of jailhouse transmission, severe cutbacks in education programs generally, combined with longstanding bans on condoms and bleach to clean needles, cripple attempts to confront the central crises of the prison epidemic: discrimination, lack of prevention and inconsistent, often negligent, care. Education and advocacy on these fronts has overwhelmingly been left to those most strapped for resources -- the inmates themselves. “There are some organizations on the outside raising the issues,” says Romeo Sanchez, coordinator of the Alliance for Inmates with AIDS, a New York-based coalition with a former-prisoner work group, “but they need to give inmates a more active voice in identifying their concerns and priorities. The prisoners themselves have so much to offer in terms of insights, approaches and ideas about what works.”

The first known inmate AIDS death in the US was in 1981, and by the mid-’80s, coinciding with a nationwide explosion of AIDS activism, prisoners began to respond to the growing crisis. In New Hampshire, an HIV positive inmate staged a hunger strike over the lack of AIDS counseling, part of a prisonwide work stoppage over poor food and medical care. In Alabama, saying they were housed “like animals being held for slaughter,” HIV positive inmates, too, went on strike. In California, HIV positive inmates broke hundreds of windows to protest their segregation. And in several states, inmate protesters coordinated with ACT UP chapters on the outside -- most famously, staging a series of prison-gate demonstrations and behind-the-walls hunger and medication strikes at facilities in Chowchilla and Vacaville, California, that resulted in an investigation into prison health care for PWAs by the state legislature. Jimmy Magner began to publish his *PWA RAG,* a widely read newsletter by and for inmates with HIV, from inside a federal prison in Georgia. Prisoners with HIV filed grievance upon grievance about discrimination, abuse and lack of treatment, often forwarding them to outside advocates. These consistent missives, along with lawsuits crafted by inmates themselves, led to class-action suits in New York, New Jersey, California, Florida and elsewhere. According to Jack Beck, supervising attorney for the Legal Aid Society’s Prisoners’ Rights Project, which filed the New York suit, “The problems with HIV began to expose the fundamental flaws in the prison health care system.”

These efforts provoked significant changes. Whereas inmates in New York state were once treated only with aspirin or AZT, Beck says three-drug combination therapy is now standard. A consent decree signed in 1992 in New Jersey eliminated the segregation of prisoners with AIDS in that state. Following ACE's lead, scattered peer education programs have sent down roots. And with all its continuing faults, care at the Vacaville men's facility is now considered among the best in the country. Yet no gain came easily for the inmates involved.

"For many years we didn't have any real assistance from the outside," says Yusuf Shakoor, who had a hand in one of the earliest attempts anywhere to develop an inmate HIV program, Prisoners Educating Prisoners on AIDS (PEPA) at Auburn Correctional Facility in upstate New York. If AIDS organizations recognized the problem at all, he said, "all they did was have seminars among themselves -- they never came into the prisons." This was back in 1987, when if you were rumored to have HIV you were shunned -- inmates wouldn't even steal your cigarettes. Chances are, your cell would be burned out; guards would look the other way, at best. In some facilities, they would lock you down as if you'd committed an act of violence; in others you'd get relegated to an HIV unit that was, in the words of one inmate, "basically a dungeon." According to Ruben Rodriguez, a former inmate activist who tested positive while incarcerated in New York, "friends would turn into enemies." Ignorance ruled, and HIV education, if it existed at all, was usually limited to an out-of-date health-department pamphlet.

Shakoor is now an inmate at Sullivan Correctional Facility, a maximum-security prison in the heart of New York's Catskill Mountains, where he is serving a 25-to-life sentence for murder. This state's prison system has been called one of the largest AIDS practices in the country, with 7,500 of its inmates known to be positive in 1997. Once the director of a youth program in Brooklyn, Shakoor, himself HIV negative, has used every method in the book to advocate for PWAs while incarcerated: He has filed grievances and organized letter-writing campaigns over lousy medical treatment, run support groups through pastoral care programs, even circulated prevention literature covertly in the prison yard. For his efforts he's been put in administrative segregation, charged with infractions -- inciting a riot, threatening an officer -- that are never upheld in disciplinary hearings. Shortly after PEPA held its first organized activity in early 1987 at Auburn, an HIV class led by the Central New York AIDS Task Force, all 30 participants got transferred to other facilities. Though prison administrators will never say it on the record, says Shakoor, "any time they feel you're an influence, an advocate, an activist, they'll ship you out." Inmates call it "diesel therapy."

It's a five-hour drive from New York City to Comstock, New York, a slip of a town far enough from Lake George, the area's main tourist attraction, to lack even a single hotel. As you drive into town on Highway 6, Great Meadows Correctional Facility -- "Compliance to the Max" -- looms above you. If it weren't for the rows of razor wire, the gothic stone building could be a turn-of-the-century orphanage. This "punishment prison" is the kind of facility you're sent to if you're deemed a troublemaker or a security risk. Behind its walls, David Gilbert, who is HIV negative, has built his second HIV program from scratch. Gilbert, whose manner is affectingly gentle, even birdlike, is what Rodriguez would call "a militant," serving 75 years to life for his involvement in a 1981 Brinks truck robbery to support underground black activists, a botched attempt that left three officers dead. When his codefendant Kuwasi Balagoon died of AIDS in 1987, Gilbert turned his organizing

abilities -- forged in the radical Students for a Democratic Society and Weather Underground -- to the epidemic. With Shakoor, Gilbert was a driving force behind PEPA, respected enough to break through the extreme panic over the issue to get key leadership on board from each of the inmate communities -- the Muslims and Rastas; the Cubans, Dominicans and Puerto Ricans; the Italians and the bikers -- to hold the first, controversial HIV forum.

There are rules against more than six inmates gathering at once, so he and Shakoor would pull together six here, six there, with someone shouting back and forth to communicate; they surreptitiously got letters of support from outside groups and managed to hand in a polished proposal to the Auburn administration without ever having officially “met.” Gilbert calls those early efforts to start PEPA “the first steps towards blunting AIDSphobia”; he and his cohorts had to intervene in their cellblocks to avoid burnouts of HIV positive inmates or make a show of walking in the yard with someone who’d just tested positive, in part to offer counseling, but mostly to send a message not to mess with him. After PEPA, at that time an unheard-of inmate initiative, was shut down by the administration, Gilbert did a circuit of the most restrictive facilities in the state before landing at Comstock, “the hardest place to organize,” where he was told he’s staying. But, says Rodriguez, who was sent “around the horn” a few times himself and now works at an alternative to incarceration program in New York City, “All that transferring backfired on them, because everywhere we went, we just created more programs.”

The first to gain a permanent foothold in a men’s facility in New York was PACE, Prisoner AIDS Counseling and Education; there are now PACE programs at eight of the state’s 70 prisons. Rodriguez was instrumental in PACE’s founding at Eastern Correctional Facility in 1989, with only the volunteer support of a receptionist from a nearby agency, AIDS Related Community Services (ARCS). “Before that,” says Cesar Loarca, who took over prisoner services there in 1990, “inmates were an invisible community to ARCS.” Now, like ACE, the program is well established, with a small, crowded office to call their own, and an accomplished slate of programs that includes a hospital buddy system, an AIDS 101 unit for GED classes, and an intensive 12-week educational cycle covering everything from prevention to new treatments that even the occasional corrections officer is apt to listen in on. Arquelio Gonzalez, an HIV positive inmate and PACE’s Spanish-language coordinator, is working to institute a translation program that would allow bilingual PACE members to accompany Spanish-speaking prisoners to their medical appointments. With Latinos making up 40 percent of HIV-infected male inmates in New York, and few Spanish-speaking medical staff in the rural, white communities where most prisons have been built, services for Spanish speakers is a cutting-edge issue. It is a testament to PACE’s impact that such a proposal would even be on the table. Yet the group still lacks the most basic prevention tools.

As in every prison in America, sex and drugs are prohibited at Eastern -- even masturbating can get you a disciplinary ticket for degeneracy. Condoms are illegal in all but two state systems, Vermont and Mississippi. And bans on bleach for cleaning needles have remained immovable, despite data that show an estimated 80 percent of inmates nationally are incarcerated on drug-related offenses. According to the Correctional HIV Consortium’s Haggerty, “there are as many drugs in prison as on the street, and they’re just as easy to obtain.” Sexual activity is far less documented, but a recent study by the Latino AIDS Commission in New York found that 17 percent

of former inmates said they'd had sex while in prison; 64 percent had directly observed it. To be caught engaging in sex or using drugs could mean anything from loss of "good time" to several months in lockdown, so there's intense pressure to do things quickly, before a guard swings by. These restrictions create some awkward silences as the men of PACE discuss their work in the narrow yellow classroom that houses their classes and support groups.

"We say, 'All right, cool, there's no condoms here, that's a given,'" says Allen Simon, at 52 PACE's elder statesman. "'So if someone offers you something that looks pretty good, what are you going to do?' And that starts them thinking." Simon, who has two brothers who died from the virus, says PACE members are explicit about safer sex and drug use, though it all has to be framed as lessons for "the street" or information to share with your family. While they can't recommend using contraband, PACE members still explain how to clean a set of works and say (hypothetically of course), "If you can get drugs, you can get bleach. So go out of your way and get it." Staff coordinator Charles Pierra, a former musician who's been at Eastern for more than 10 years, brings to his job a marked sense of humility, a quality he says AIDS organizations who've come to train PACE members often lack. "This group is far ahead of any on the outside in terms of their preparation, their effectiveness, their sense of urgency," says Pierra. "People have left this facility and started groups based on the knowledge they gained here." Several collaborations had to be cobbled together for the New York state prisons' peer-education programs to become models cited in Department of Justice reports. ACE, for example, got off the ground -- and has endured -- because of the organizing skills of founders like Kathy Boudin and Judy Clark, codefendents of Gilbert's and former members of the Weather Underground; supportive coordinators from outside community groups (the latest, Liz Mastroieni of the Women's Prison Association, brings her down-to-earth Bronx style to interactions with the women); a warden, Elaine Lord, who has been behind the program from day one, an unusual occurrence, to say the least; and vocal PWAs, like Katrina Haslip, who died seven years ago, and KK Loftin, who doesn't plan to die anytime soon. Mastroieni, staff coordinator for the past four years, talks about what it has taken to keep the program alive.

"As a civilian," she says, "I do the dance," meaning the balancing act required to represent her community organization on Department of Corrections territory while being paid by the Department of Health but answerable to the inmates. In any given moment, she says, if she is seen as breaking a rule, she could be escorted out in handcuffs. "You can't come in here full of vinegar," Mastroieni says. By being diplomatic, says Boudin, ACE has managed to become "a network throughout the prison," with 40 or 50 "walking counselors" who, in addition to their formal duties as leaders of HIV workshops or support groups, are each approached informally several times a week by inmates looking for private advice. The group has a reach that outside AIDS organizations could never begin to replicate.

No other program in the country has achieved ACE's level of autonomy. Walker, of the ACLU's Prison Project, says that "most prison wardens don't want prisoners to play active, decision-making roles while they're in the facility." And some prison HIV efforts that had enjoyed years of progress have faced severe obstacles of late. Tales abound of doctors and community volunteers getting kicked out of prisons for being too outspoken. In the wake of rebellions that shook the federal prisons two years ago -- the response to a racially divisive bill establishing disparate

penalties for crack and cocaine -- some facilities banned inmate organizations outright. This sounded the death knell for HIV programs like one at a women's facility in Dublin, California, built up by inmates over a period of four years. In late 1997, at a men's state prison at Corcoran, a few hours south, a vocal committee of PWAs in the infectious-disease segregation unit was shut down, after a year of successful advocacy over discrimination and inadequate treatment.

Crucial outside advocacy projects -- Prisoners Legal Services in New York and the HIV/AIDS in Prison Project of Catholic Charities in the Bay Area, founded by Judy Greenspan ("hated by wardens across America," said one inmate, for her relentless activism) have faced budget cuts so severe this year that they've had to close their doors. Loarca, who was himself downsized from ARCS, the upstate New York AIDS group, last year, sees a pattern: "In the last few years money has decreased for HIV services, and one of the first things to go is -- guess what -- prison programs." Whereas in 1990, when panic over the prison epidemic was at its height, 96 percent of state and federal systems had HIV education in at least one facility (a number less impressive than it appears, since a large state may have upward of 50 prisons), that number fell to 75 percent in 1996.

Even though, as Gilbert says, "you *can* create conditions that foster these programs," state bureaucrats, prison administrations and AIDS agencies alike have balked. State prison wardens are usually appointed for life; they have limited accountability, and their prime charge is security, which is at odds with inmate-led advocacy or education. State prison commissioners, on the other hand, are political appointees, worried more about being seen as condoning sex, suggests Thomas Powell, director of clinical services for the Vermont Department of Corrections, than about public health. Powell says he's approached all the time by prison staff who want to replicate his state's condom-distribution program, but their commissioners won't give the green light. When pushed, corrections departments claim condoms pose a security risk, but, says Powell, whose program has operated for 12 years without incident, "I've lost my ability to respect that position." And prisoners and advocates alike say that most AIDS organizations have not made prisoners, despite their high infection rates, a priority. Loarca said prison work isn't popular with funders; his organization, ARCS, was happy to get Ryan White funds using the prison numbers in their district, but only a bit of that money ever trickled into the facilities.

Haggerty, of the Correctional HIV Consortium, sees these responses as short-sighted, to say the least. Sooner or later, he says, 90 percent of inmates with HIV will return to their communities. According to a study by his group, most inmates said their first priority within two hours of being released was to get high; their second was to have sex. "Corrections see themselves in a void," Haggerty says; on the other hand, Loarca says, inmates are "invisible" to community AIDS organizations. Between the two, the larger public health picture has yet to be systemically addressed. This doesn't have to be the case. Building on the success of New York's pervasive peer-education programs -- a pioneering initiative from the state's AIDS Institute -- just completing its first year of community funding, will provide HIV prevention and transition services to the entire state system. And according to an August 1998 report, these efforts may have begun to bear fruit: Inmate infection rates dropped from 13.9 percent in 1995 to 10.7 percent in 1997. Still, in New York and elsewhere, what Haggerty calls "a growing bunch of excellent leaders who are

incarcerated” remain the most persistent network of advocates challenging the crises of the prison epidemic nationwide.

“Prison is a time when people who are doing drugs and living the fast life slow down, and you can reach them,” says Gilbert, whose new group at Comstock has reached over 300 inmates this year. “Outside organizations can help a little, but they can’t deal with prisoners in their daily lives.” Though prisoners are prohibited from sharing their models directly with inmates in other prisons, ACE, in typical can-do fashion, found a way around that rule. Last month, Overlook Press published *Breaking the Walls of Silence,* a book by the women of ACE chronicling the history of their program that just happens to include a complete HIV peer-education curriculum.

Says Greenspan, who now conducts her HIV advocacy, almost without funding, through California Prison Focus, “Without prisoners willing to risk everything, nothing can happen. The challenge for us on the outside is to respond boldly, to show our support in whatever way we can.” Back in the cluttered ACE office, Kathy Boudin leans forward in her plastic chair as she talks about the ambition ACE has sparked among the women here. “Peer support, community involvement, can be taken other places,” scaling not only the high fences of Bedford Hills but
those of prisons all around the country. “That,” she says, “was our dream.”

“One nurse told me, when he was four hours late with my dose, ’Stop complaining, it’s not going to kill you.’ I said, ’Forget about $17,000 a year. Just buy me a shovel and I’ll go dig my own grave.’”

-Paul J. Kelly, ACI Cranston, Cranston, Rhode Island

“The worst is if you’re HIV positive and caught in a sex act. You have to do 90 days to a year in administrative control, locked away in segregation. Negative people do 30 days to six months in local control.”

-Lawrence Owens, Southern Ohio Correctional Facility, Lucasville, Ohio

“Being transferred to another prison takes from six to 12 hours, and we rely on transportation officers for our meds. Sometimes they forget, other times they simply will not give them to us.”

-Jimmy Feliciano, Clinton Correctional Facility, Dannemore, New York

Research assistance: Dana Gornitzki and Karen Pantelides

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