NATIONAL

COMMISSION

ON AIDS

Report

HIV Disease in Correctional Facilities

March 1991

NATIONAL COMMISSION
ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME

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EXECUTIVE SUMMARY

Introduction

The U.S. Supreme Court, in a key decision in 1976, stated that "[d]eliberate indifference to the serious medical needs of prisoners constitutes the unnecessary and wanton infliction of pain ....proscribed by the Eighth Amendment of the Constitution." The situation today for many prisoners living with HIV disease is nothing if not "cruel and unusual."

In August 1990, the National Commission on Acquired Immune Deficiency Syndrome (AIDS) conducted a site visit and hearing to identify and understand the issues which face the nation and its federal, state and local correctional facilities, in their management of detainees and prisoners living with human immunodeficiency virus (HIV) disease, the continuum of conditions which begins with seroconversion and ends with AIDS. The findings were sobering and troubling. This report will reflect the powerful and often moving testimony of numerous experts, health care professionals, prisoners' rights advocates, educators, correctional personnel, former inmates and prisoners living with HIV disease.

The Commission's findings include:

- Prisoners with HIV infection are rapidly acquiring tuberculosis and many more are at increased risk from the resurgent tuberculosis epidemic in the nation's prisons.
- Prisoners with HIV disease are often subject to automatic segregation from the rest of the prison community despite the fact that there is no public health basis for this practice.
- Lack of education of both inmates and staff creates fear and discrimination toward individuals with HIV disease and unjust policies directed toward inmates living with HIV disease.
- Despite high rates of HIV infection and an ideal opportunity for prevention and education efforts, former prisoners are re-entering their communities with little or no added knowledge about HIV disease and how to prevent it.

The Commission's study also reveals that too many correctional facilities subject inmates to a series of unnecessary, arbitrary indignities which fundamentally affect their basic human rights. As one prisoner wrote:

> "For me, to be a 'prisoner' with HIV infection is a humiliating, distressing, painful, and a potentially life-threatening situation -- more literally a living hell!"

Our nation faces great difficulties in solving the problems of providing HIV-related health care, education, prevention and human rights for all of its citizens, but especially for the young people, women and men with HIV disease who are incarcerated within our correctional facilities. We have an obligation to solve these problems and it can be done.

Living with HIV Disease in Prison

The addition of HIV disease to the already difficult world of prison life has created special problems in three major areas: Health Care; Human Rights; and Education. Lack of adequate health care and often overcrowded conditions subject inmates living with HIV disease to the dangers of tuberculosis and other opportunistic diseases. Lack of education and understanding among officials and other inmates create violations of rights for the inmate living with HIV disease regarding confidentiality and access to prison programs. This report enumerates the problems in these three areas. Immediate action is needed to remedy these glaring injustices.

I. Health Care

Inmates with HIV disease face many of the same difficulties in obtaining adequate health care as do people with HIV disease in the general community. However, due to the lack of mobility and choice which define the life of prisoners, they also face unique problems. These problems include:

- A 1987 study by the Correctional Association of New York suggests that prisoners with AIDS may be dying at twice the rate of nonprisoners with AIDS. The study found that the median time between diagnosis and death was 159 days for prisoners with AIDS who have a history of using intravenous drugs, compared to 318 days for nonprisoners with a similar set of drug using behaviors.
- Doctors and dentists often refuse to treat inmates who have tested positive for HIV and inmates speak often of the difficulty of receiving "hands-on" care for both HIV and non-HIV-related problems.
- Prisoners with HIV infection have much higher rates of tuberculosis and are at increased risk from the resurgent tuberculosis epidemic in the nation's prisons. Immunosuppression fosters progression of dormant tuberculosis to active disease. In 1989, of the 70 inmates with active tuberculosis in New York State, <u>all</u> were HIV positive.
- Due, in part, to the confusion regarding regulations governing clinical research involving prisoners, inmates are often denied access to clinical research programs which could provide opportunities for new HIV treatments available in the general community.
- Inmates living with HIV disease are often denied access to specialists outside the correctional facility who could significantly improve their medical condition.

- T-cell counts, essential for monitoring the progression of HIV disease, are often administered erratically, if at all. Medications are not always available or distributed in a consistent, timely manner.

- Special diets or housing appropriate for those with HIV disease are often lacking.

- Access to voluntary testing with appropriate counseling is in very short supply. Prisoners are often tested without their knowledge and consent and then informed of their seropositive status with inaccurate projections of life spans, treatments, etc.

- Health care, testing and counseling specific to the needs of women and adolescents is virtually non-existent.

II. Human Rights and Confidentiality

> "I feel that incarceration is punishment for the crime I committed, but to be incarcerated and then isolated from all privileges afforded to other inmates who were convicted in the same court room I was convicted in, is above the law." (Excerpted from a letter to the Commission)

The injustices which prisoners with HIV disease are experiencing daily in our correctional facilities are shameful. The ignorance and prejudice which cause so many to mistreat people with HIV disease have, inside prisons, resulted in a loss of human rights for individuals living with HIV disease and lives of isolation and despair. The following are examples of the policies which help to create these injustices:

- Prisoners with HIV disease are often segregated from the rest of the prison community despite the fact that there is absolutely no legitimate public health basis for the practice.

- Segregated inmates often lose access to religious services, work programs, visitation rights, libraries, including law libraries, educational and recreational programs, and drug and alchohol treatment.

- Prisoners with HIV disease are being denied access to early release programs.

- In small prisons, isolation because of HIV positive status can virtually become a sentence of solitary confinement. In larger prisons, inmates with HIV disease, whether from maximum or minimum security facilities, are often grouped together indiscriminately.

- Segregation exposes a confidential fact of prisoners' health status to the rest of the community of inmates and officials.

- In correctional facilities where segregation is not practiced, confidentiality is often violated due to the lack of privacy when meeting with medical personnel and during the distribution of medication.

- Inmates with AIDS are dying inside prisons and hospitals without release, or the support of family, friends or counselors despite the fact that they are not a threat to society.

III. Education and Prevention

Education and prevention programs are in many ways the key to solving some of the most dangerous problems confronting all members of the prison community: inmates, administrators and other officials and staff. These dangers include the risk of continuing to practice behaviors which may lead to HIV infection and the physical danger to inmates with HIV disease noted above. As one prisoner wrote, "you can be hurt or killed if your confidentiality is breached and other inmates find out, especially since this is a dormitory facility and there is not even the security of a locked cell." In the absence of explicit, culturally appropriate education programs for all members of the prison community, both staff and inmates, the following problems will continue:

- Fear and discrimination towards individuals with HIV disease and unjust policies, such as segregation of inmates with HIV disease, will continue without education programs for both inmates and correctional staff.
- Inmates' informed participation in their own medical care, including the decision about whether to seek HIV testing, is not possible without comprehensive HIV education programs.
- Inmates and staff will remain at risk of HIV infection until they are taught how to reduce or eliminate that risk. Without specific education geared towards correctional personnel they will continue to impede their own and inmate's progress toward minimizing risk behaviors.
- Segregation programs are creating a false sense of security about HIV disease among the non-segregated prison community and wrongly suggest that by isolating those individuals who are infected, everyone else is now "safe."
- The means to prevent HIV transmission through the distribution of condoms has been adopted by only a handful of prisons despite the fact that distribution of condoms has resulted in no adverse security incidents thus far.
- Former prisoners are re-entering their communities with little or no added knowledge about HIV disease and how to prevent it.

The Impact of Political, Sociological and Medical Factors

The progress made in medical research and education in the general community has had little effect on improving the situation within prisons. The neglect of health care and

research issues particular to women and adolescents is catastrophic when placed in the context of the HIV epidemic in prisons.

Similarly, political decisions, on both the state and national level, have an immediate and direct effect on the situation within prisons. For example, the national policy of mandatory sentencing for drug offenders (who have very high rates of HIV infection) has placed an enormous burden on the already weak prison health care system.

Persons using injection drugs accounted for 28% of all adult and adolescent AIDS cases reported in the United States from 1981 through 1989. By choosing mass imprisonment as the federal and state governments' response to the use of drugs, we have created a de facto policy of incarcerating more and more individuals with HIV infection. Under the present policy, the percentage of drug offenders in the federal prison system will rise by 1995 from 47 percent to 70 percent. Clearly, we are thus concentrating the HIV disease problem in our prisons and must take immediate action to deal with it more effectively.

Both education programs about HIV disease and drug treatment programs are essential to combatting the spread of HIV infection and must be an integral part of the health programs within correctional facilities. We must also provide drug treatment on demand as a part of the national "war on drugs."

Women and Adolescents

The lack of services for women and adolescents living with HIV disease is another area where the weaknesses in the correctional facilities parallel or exceed those in the general community. Research on HIV disease in women and adolescents is severely lacking. Even though women comprise only nine percent of AIDS cases, they are the fastest growing population to be affected by HIV disease. In studies of the prison community, HIV seroprevalence rates among prison entrants are higher for women than men. Clearly, this demands particular attention. Further, a significant number of women give birth to children shortly before they begin to serve prison sentences, or are pregnant and give birth during their incarceration. These women need prenatal services where confidential HIV testing is offered upon request. Special care to provide education and counseling is essential.

Statistics for the actual rate of HIV infection among adolescents in custody is unknown, but many of them have a history of behavior which places them at a higher risk for HIV infection than adolescents in general. Comprehensive and clear HIV education is absolutely essential for these young people. They often return to their communities after a shorter period of incarceration than their adult counterparts and they must be armed with tools to help them minimize the risk of HIV infection.

Recommendations

> "At times one who is HIV positive just gives up hope. At a time when the Department of Correction and Alabama federal courts say it's alright to treat us/me as lepers, it takes away your feeling of humanity. It leaves one to wonder: what type of human being who is in a position to carry out the constitution of this country, could allow this type of treatment of other human beings to continue, and rest with a clean and clear conscience." (Excerpted from a letter to the Commission)

As a nation, we are responsible for reversing the current situation which exists within our correctional facilities. The job of prison administrators is extremely difficult. Working with insufficient funds and in often difficult conditions they must now deal with an epidemic which the nation as a whole has found extraordinarily difficult to cope with under much less trying circumstances. However, by working in partnership with public health agencies in developing proactive health strategies, and implementing them, correctional officials will be able to deal with these problems and bring successful public health policies to bear in correctional facilities.

The Commission puts forward the following recommendations with the hope that we can move forward a correctional facility environment where humanity will improve and thrive and where the HIV epidemic will not.

1. The U.S. Public Health Service should develop guidelines for the prevention and treatment of HIV disease in all federal, state and local correctional facilities. Immediate steps should be taken to control the subsidiary epidemics of tuberculosis and sexually transmitted diseases. Particular attention should be given to the specific needs of women and youth within all policies.

2. Given the dearth of anecdotal and research information on incarcerated women, incarcerated youth and children born in custody, federal and state correctional officials should immediately assess and address conditions of confinement, adequacy of health care delivery systems, HIV education programs, and the availability of HIV testing and counseling, for these populations.

3. To combat the overwhelming effects which drug addiction, overcrowding and HIV disease are having on the already severely inadequate health care services of correctional systems nationwide, a program such as the National Health Service Corps should be created to attract health care providers to work in correctional systems.

4. The Department of Health and Human Services should issue a statement clarifying the federal policies on prisoners' access to clinical trials and investigational new drugs. In addition, the Food and Drug Administration, in conjunction with the Health Resources and Services Administration and the National Institutes of Health, should initiate an educational program directed toward informing inmates and health care professionals working in correctional facilities of the availability of investigational new drugs, expanded access programs, and applicable criteria for eligibility of prisoners in prophylactic and therapeutic research protocols.

5. Meaningful drug treatment must be made available on demand inside and outside correctional facilities. Access to family social services and nondirective reproductive counseling should also be made available with special emphasis on the populations of incarcerated women, youth and children born in custody.

6. Prison officials should ensure that both inmates and correctional staff have access to comprehensive HIV education and prevention programs. Particular attention should be paid to staff training on confidentiality and educating inmates about the resources available in the prison setting that may be employed to reduce the risk of infection.

7. The burden of determining and assuring standards of care has largely fallen to the courts, due, in part, to the failure of public health authorities to take a leadership role in assuring appropriate standards of health care and disease prevention for our incarcerated populations. Bar associations and entities such as the Federal Judicial Center must, therefore, establish programs to educate judges, judicial clerks, and court officers about HIV disease.

HIV DISEASE IN CORRECTIONAL FACILITIES

Introduction

The HIV epidemic was guaranteed, from the outset, to have a disproportionate impact on the nation's prisons and jails because of the intimate connections between HIV infection, illicit drug use and incarceration. Numerous studies have confirmed that rates of HIV infection among prisoners are high. It can, therefore, be expected that demands on prison health care will continue to grow. However, most public policy debate over corrections issues has focused not on care and prevention, but rather on whether to mandate HIV testing of prisoners. Such discussion is usually predicated on the feared spread of HIV, either among prisoners, or from infected inmates to corrections personnel; yet casual contact does not carry risk and data show that even between prisoners there has been negligible HIV transmission within prisons and jails.

Much more deserving of attention is the disproportionate concentration of persons with HIV disease[1] within correctional facilities, which has resulted, in some areas, in almost intolerable stress on marginal prison health care capabilities. Where once the main reason to seek medical attention was symptomatic respiratory infection, now the sick call rosters are crowded with the complex complaints and manifestations of HIV disease. Furthermore, the serious discontinuity in care for persons with HIV disease that plagues the entire health care system is nowhere more striking than it is for prisoners as they enter and leave custody.

Most troubling of all, prevention efforts have been absent or half-hearted in prisons and jails. When voluntary testing and counseling are made available, their efficacy is often undercut by linkage to categorical denial of privileges for those found to be HIV positive. Because inmates fear stigmatization or loss of privileges if determined to be HIV positive, many avoid testing and counseling. In this way, we are missing opportunities to educate the people at highest risk of HIV infection for prevention of further spread of HIV, as well as other important preventable illnesses. In short, by failing to deal directly with issues of care and prevention in incarcerated populations, we are losing a major public health opportunity.

With these concerns in mind, in August of 1990, the National Commission on AIDS conducted a site visit and hearing to explore the issues confronting the nation regarding HIV disease in federal, state and local correctional facilities. The Commission gained valuable insights into these facilities and systems of prison health care and was impressed with the challenge inherent in meeting even the minimal needs of our incarcerated populations as budgets decrease and overcrowding becomes a desperate fact of prison life.

The Commission heard powerful testimony from health care professionals, prisoners' rights advocates, educators, correctional personnel, former inmates and prisoners living with HIV disease. Their presentations touched on issues ranging from the effects of overcrowding on correctional health care services, to prisoner access to clinical trials and experimental treatments, to HIV education and prevention efforts. Some testimony underscored the inhuman effect of neglect, indifference or policies based on unreasoning fear of prisoners with HIV disease; other witnesses were inspiring in their dedicated determination to provide care despite woefully insufficient resources.

Many of the problems presented to the Commission were present before the HIV epidemic. It was startling to learn the extent to which, in the past decade, the United States has experienced an accelerating expansion of the prison population. As in so many other contexts, the pressures of HIV disease have revealed latent flaws in the system, and have swamped the limited medical resources available. For their part, public health authorities have failed to develop effective programs for reaching incarcerated individuals. As one medical expert told the Commission, "Nationally, a dangerously inadequate prison health care system is being overwhelmed by two epidemics: one, the mass incarceration of poor black and Hispanic drug users and, two, the extraordinary medical demands of the AIDS epidemic" (Cohen 1990).

Neglect of persons imprisoned or otherwise confined cannot be tolerated. Attention to the health needs of persons, whether they are imprisoned or free, should be considered a mandate for a society that professes concern for every individual. Beyond that moral imperative, however, failure to provide adequately for medical and public health needs works to the detriment of the society as a whole; for after temporary incarceration (in most instances months, rather than years) the vast majority of prisoners go back to their communities of former residence. Their health status as they return to society has direct bearing on the health of communities throughout the nation. Moreover, prisoners are entitled to healthful environments and the opportunity to make health care decisions. Federal, state and local policy-makers must give immediate attention to creating a proactive strategy for addressing the health crisis besieging prisons and jails nationwide.

Prevalence of AIDS and HIV Infection

HIV disease is a profound presence in the nation's prisons and jails. As the number of AIDS cases grows, correctional facilities are by necessity transformed. The Commission observed this in New York State, where an estimated 17-20%, or approximately 9,000 of the state's 54,000 inmates, are HIV positive. More than 800 have developed symptoms. According to surveys conducted for the National Institute of Justice (NIJ), through October 1989, there were 5,411 confirmed cases of AIDS reported from the Federal Bureau of Prisons, state prison systems and a sample of 27 to 38 county and city jail systems in the United States.[2] The cumulative number of reported AIDS cases among inmates increased from 766 in November 1985, representing an astounding four year increase of 606%.

Although in 1989, 45 of 50 state correctional systems reported at least one inmate with AIDS, the geographic distribution of AIDS cases in prisons and jails remains remarkably uneven. Seventy-nine percent of inmates with AIDS were reported from seven (14%) of the 51 systems. Eleven (22%) of these systems reported more than 50 AIDS cases each and account for 87% of AIDS cases in inmates. New York, New Jersey, Florida, Texas and California have been particularly hard hit.

HIV transmission in correctional facilities has been a subject of great concern. There is little evidence, however, to show how many prisoners become infected while in prison. Data available to date suggest low transmission rates among incarcerated persons (Horsburgh et al. 1990). The Federal Bureau of Prisons reported that data based on additional time interval tests of a sample of newly committed inmates indicated an extremely small rate of seroconversion, or change in HIV status. Out of approximately 98,000 tests, only 14 demonstrated seroconversion, and all of these cases converted within the first 6 months of confinement. No inmates who tested negative at either the 6 month interval, or at any subsequent testing interval have tested positive at a later time. Due to the latency period of the virus, the fact that all known seroconversion has occurred within the first 6 months of imprisonment suggests the highest probability of exposure prior to incarceration. Additionally, mandatory screening conducted by the Federal Bureau of Prisons of inmates upon release showed lower HIV prevalence rates than among entrants.

Access to Health Care

Historically prisons and jails have been backwaters of health care. As recently as 1973, an American Medical Association survey of 3,000 jails found that 82% had no formal arrangements for medical care; 18% said they called a doctor when needed; 65% had only first aid available on site; and 16.7% had no medical facility, not even a first aid kit (A.M.A. 1973).

This situation of outright indifference to the health needs of the nation's incarcerated populations was transformed in 1973, when the U.S. Supreme Court brought corrections policies under heightened judicial scrutiny, prompting a torrent of litigation challenging prison conditions in general and the lack of adequate health care in particular (Procunier v. Martinez 1973). In 1976, the Supreme Court interpreted the Eighth Amendment prohibition against "cruel and unusual punishment" to require that "deliberate indifference to the serious medical needs of inmates" constitutes a violation of an inmate's protected rights (Estelle v. Gamble 1976).

This decision by the Court distinguishes prisoners as the only individuals in the United States to have an enforceable constitutional right to health care. In accordance, federal courts throughout the 1970's and 1980's have ordered the provision of specific services, facilities and personnel, appointing federal masters to supervise changes in prison conditions and health care. As of 1990, thirty seven states, the District of Columbia, Puerto Rico and the Virgin Islands operate prisons under court orders pursuant to findings of poor

conditions, overcrowding or lack of medical care serious enough to violate constitutional protections.

Protections offered by the courts have been a mixed blessing for prisoners; for although courts have ordered much needed change, prisoners have had to look almost exclusively to the courts for the implementation of medical and public health initiatives. The result of court-ordered interventions has at times been less than positive medical and public health policy, as the standard of care required under the Constitution is not an exalted one. As one legal expert made clear to the Commission, "the law is not readily wielded to order a major social investment in public health" (Burris 1990). Rather,

> The legal system is more open to a claim that a particular medical procedure was improperly denied than that inmates are entitled to the most effective medical care possible, more open to a claim that an inmate has suffered discrimination than a claim that a prison ought to be educating staff and prisoners about HIV (Burris 1990).

The lack of proactive health policies is particularly worrisome as the nation's prison population skyrockets. Approximately one million people are confined in America's prisons and jails. Since 1980, the federal prisons, the District of Columbia, and eighteen states have doubled their prison populations. Four states, including California and New Jersey, have had threefold increases during the same period. In 1988, this growth translated into the need for 800 additional beds each week. Indeed, overcrowding may be the most intractable problem from jurisdiction to jurisdiction. In its wake follow difficulties in delivering health care, further exacerbated by the reality that prisoners tend to come from the most disadvantaged sectors of the population, reflecting the epidemiology of communities where disease is prevalent and access to health care is lacking.

As in its impact on the nation's health care system, the HIV epidemic serves to spotlight serious shortfalls of correctional health care. HIV disease is a particularly complicated condition that can become unmanageable if it arises in a setting where even minor health problems fester without adequate medical intervention. As a witness told the Commission, "It is not possible to graft minimally adequate AIDS services onto a prison health system which cannot provide basic services" (Cohen 1990). And yet, just that must be done, if we are to transform a national attitude of neglect for the health of the incarcerated into proactive public health initiatives that recognize that the health of the nation is inextricably linked to the health of these individuals.

Perhaps the most significant of the recommendations of the Presidential Commission on the Human Immunodeficiency Virus Epidemic on HIV disease in the correctional setting was that, "[c]are and treatment available to HIV-infected inmates in correctional facilities should be equal to that available to HIV-infected individuals in the general community" (Presidential Commission 1988:135) (Recommendation 9-82). The Commission reaffirms this standard and would emphasize, as one witness did, that

> HIV among the incarcerated is not significantly different from the epidemic outside prison walls. It follows that prisoners with, or at risk of, HIV ought to be targeted

for the same basic public health interventions -- voluntary, confidential testing, risk-reduction education, drug-abuse treatment, basic medical care -- that are believed useful outside prison walls. Similarly, protections against discrimination and the publication of private medical information are as or more important to individual lives and the public health effort within prison as without (Burris 1990).

A successful response to HIV disease in prisons applies public health and medical techniques of proven value to meet the medical and psychosocial needs of inmates with HIV disease and to reduce HIV transmission by inmates during and after their imprisonment. In addition, there must be clear recognition of the social dimensions of the epidemic both inside and outside of prison walls, and aggressive interventions must be employed to alleviate existing patterns of fear, neglect and discrimination. HIV disease is increasingly a treatable condition. The ability of health professionals to treat HIV disease before symptoms develop gives individuals new impetus for finding out whether they are HIV-infected. Correctional facilities should have an effective system of early identification of HIV-infected inmates through voluntary, confidential testing, accompanied by pre- and post-test counselling. Individuals who test HIV positive need to be properly examined and regularly monitored by a physician who is knowledgeable about infectious disease and keeps abreast of medical developments in HIV treatment. The full range of approved medications to prevent or treat symptoms of HIV disease must be available in order for the promise of early intervention to be fulfilled.

Because treatments for HIV disease tend to be novel, experimental, and expensive, HIV disease tests the limits of prison health care. Most corrections systems have made zidovudine (AZT) available to inmates meeting approved clinical criteria, although there still is often a considerable lag time between the development of treatment protocols and their availability in prisons and jails. Notably, only 39% of the state and federal systems report administering aerosolized pentamidine to inmates with pneumocystis carinii pneumonia (PCP).

Predictably, when correctional health care has failed to keep pace with developments in the community at large, inadequate care takes its toll on inmates' lives. Thus, a controversial study by the Correctional Association of New York found that the median time between diagnosis and death was 159 days for prisoners with AIDS who have a history of intravenous drug use, compared to 318 days for nonprisoners with similar drug histories. Of the cases of AIDS reviewed in New York prisons, 25% were not diagnosed until autopsy (Potler 1988).

Tuberculosis in Prisons

A resurgence of tuberculosis in corrections facilities is a growing cause for concern (Braun et al. 1989; CDC 1989; Snider and Hutton 1989). Both the National Commission for Correctional Health Care and the Centers for Disease Control (CDC) have called for increased prevention and control efforts. The relationship of HIV infection to tuberculosis and the role of immunosuppression in fostering progression from tuberculosis infection to

active disease have been clearly documented. Unlike HIV, tuberculosis can be spread through the air. Prison overcrowding contributes to a more rapid spread. A CDC survey of 29 states in 1984-85 found prisoners to be three times as likely to develop tuberculosis than age-matched controls who were not incarcerated. Correctional authorities in New York State informed the Commission that in 1989, of the 70 cases of active tuberculosis among inmates, all were HIV positive.

CDC guidelines call for increased vigilance in regard to tuberculosis among both prisoners and staff by skin testing inmates and staff on entry or employment and periodically rescreening. This includes early case findings, reporting, and contact investigations, medical monitoring and isolation of those with active disease, and adherence to medical protocols for prophylaxis and treatment. The link between tuberculosis and HIV infection must be closely monitored. Correctional authorities must move to immediately address a fulminating tuberculosis epidemic among inmates.

Inmate Access to Clinical Trials

Currently, prisoners have little or no access to clinical trials and are not being afforded access to investigational new drugs, although federal regulations do not proscribe such access (Levine 1990). This situation is of some concern in an epidemic where one of the few prospects for prolonging life is the chance that an experimental drug will prove efficacious or prevent permanent disability. As a physician servicing prisoners made clear when she described the following two cases:

> Mr. F., a 30 year-old Black male with cryptococcal meningitis develops severe toxicity to Amphotericin B. The only acceptable alternative, Fluconazole is available only through a clinical trial. Without treatment, the infection is fatal.

> Mr. R., a 25 year-old Hispanic male, has CMV retinitis, unresponsive to Gancyclovir. The only other therapy, Foscarnet, is available only through a clinical trial. Without treatment, the infection will progress and cause blindness (Sharp 1990).

Under the regulations of the Department of Health and Human Services prisoners may be involved in "research on practices, both innovative and accepted, which have the intent and reasonable probability of improving the health or well-being of the subject. In cases in which those studies require the assignment of prisoners . . . to control groups which may not benefit . . . the study may proceed only after the Secretary has consulted with appropriate experts . . ." (45 CFR 46.306 (a)(2)D). Although the regulations do not proscribe access to investigational new drugs, the regulations impose extensive and burdensome requirements on prison officials and investigators.

If prisoners with HIV disease are denied the right to participate in drug trials, they are being denied the opportunity to benefit as those outside the correctional setting may benefit from the trials. Clearly, access to experimental drugs should be a choice for prisoners as it is for nonprisoners with HIV disease. As one expert told the Commission, "We owe it

to our patients not to forget the abuses of the past, but in recalling them, strive to guarantee their rights while facilitating their access to needed treatment -- even if the treatment is in some form still experimental" (Sharp 1990).

A National Institute of Corrections inquiry panel has recommended that prisoners have access to clinical trials of new and innovative therapies (Dubler and Sidel 1988). The panel concluded that under the current federal human subjects regulations prisoners may participate in therapeutic clinical trials, as long as they are not part of a control group that receives a placebo or is otherwise untreated. This same group also concluded that epidemiologic research in prisons, even where serologic data are unlinked to identifiers, should be subject to institutional review board (IRB) scrutiny, despite regulations that might seem to indicate otherwise. As new drugs become approved and available through clinical trials, prisoners should and can be permitted to choose to participate in clinical trials, while remaining protected from coercion and abuse.

Substance Use and HIV Disease

HIV disease is inextricably linked to the medical problem of drug addiction. As one witness testified, "because drug use increases one's risk of incarceration as well as of HIV infection, the inmate population often constitutes a distillate of the infection in the community." Persons using injection drugs accounted for 28% of all adult and adolescent AIDS cases reported in the United States from 1981 through 1989 (IHPS 1990). Presently the United States maintains a de facto policy of incarcerating more and more HIV infected individuals by choosing mass imprisonment as the federal and state government's response to the use of drugs. Under a scheme of mandatory sentencing for drug offenses, the percentage of drug offenders in the federal prison system will rise by 1995 from 47 percent to 70 percent.

A study sponsored by the National Institute of Justice (NIJ) showed that seventy percent of all arrestees (male and female, drug and non-drug charges) in San Diego, New York, Philadelphia, and Washington, D.C. tested positive for one or more drugs, with nine additional cities showing above a fifty percent rate. In New York, 24% of the male and 30% of the female arrestees interviewed reported that they had at some point injected drugs. Twenty-nine percent of male arrestees and 17% of female arrestees who were intravenous drug users (IVDU) reported that they currently shared injection equipment.

Recent studies indicate that drug treatment and HIV education can work symbiotically. Several studies have pointed out that both for HIV infected opiate addicts and for those who are seronegative, methadone maintenance considerably lessens their injection drug use and consequent risk of spreading or acquiring HIV infection through contaminated needles and other injection equipment (IHPS 1990). Correctional facilities must provide drug treatment to as many inmates as can benefit from it. The Commission discourages the practice of segregating inmates who test positive for HIV from the general prison population, whereby they are often denied access to alcoholics anonymous, narcotics anonymous and the few treatment options currently available.

Education and Prevention Strategies

To prevent the spread of HIV infection, inmates and staff need to be taught how to reduce or eliminate their risk of HIV infection. To reduce fear of and discrimination against the infected, an understanding of how HIV infection is detected, how HIV disease develops and how it can be treated must be fostered. Although data show that transmission within prisons is low, comprehensive education and prevention programs will help to prevent any possible spread of HIV infection within correctional facilities, and change behavior to prevent infection once inmates re-enter their communities. The Commission believes that HIV education is also necessary to promote inmates' informed participation in their own medical care, including the decision about whether to seek HIV testing.

As one witness clearly articulated,

> Education must help people begin a process, the end of which is long term behavior change. Risk reduction can only occur when education goes beyond sharing information and helps people find ways to internalize the need for change (Moore 1990).

Accordingly, the Commission believes prevention efforts must help people address the realities of drug use and sexual behavior that take place within prisons. Sex and drug use are realities that cannot be denied. Providing prisoners who engage in high risk behavior with the means of preventing HIV transmission is as important in prisons as it is in the community at large.

The Commission is, thus, distressed to find that only a handful of prison systems distribute condoms. Vermont was the first in the nation to do so. In Mississippi, Philadelphia and New York City condoms are available at institutional infirmaries (Hammett 1990). In the few systems where condoms have been distributed, corrections officials' fears that they might be used as weapons or as containers to smuggle drugs have not materialized. Representatives of the Department of Health Services for the City of New York and the medical care providers for Rikers Island report that "[t]wo years of experience with condom availability in the New York City system have resulted in no adverse security incidents" (Montefiore 1990).

Almost a decade into the epidemic, in many jurisdictions inmates and staff remain substantially misinformed about HIV disease. It may be as one prisoner wrote, that "[i]gnorance is the norm in a place like this . . . ." The consequences of the failure to dispel untoward fears through HIV education may be quite severe for individuals in the correctional setting. As the prisoner went on to write, in the absence of basic HIV education "you can be hurt or killed if your confidentiality is breached and other inmates find out especially since this is a dormitory facility and there is not even the security of a locked cell."

Cause for concern is made all too apparent by the NIJ report which indicated that, although 76% of state/federal and 58% of city/county systems reported decreased or stable

levels of inmate concern about AIDS since 1988, with similar patterns revealed regarding staff concerns, "a number of studies of individual correctional systems reveal continued and substantial concern" about AIDS among inmates and correctional personnel. For example, "[a] 1988 survey of the Federal Bureau of Prisons staff found that almost 40 percent were 'bothered a great deal' by the presence of HIV-infected inmates in the institution, and 14 percent considered leaving their jobs due to the presence of such inmates" (Hammett 1990). Furthermore, prisoners have filed suit seeking the segregation of fellow prisoners with HIV disease. The persistence of these kinds of concerns raises questions about the effectiveness of the HIV education programs in place.

Educational programs vary enormously from jurisdiction to jurisdiction. While many local jail systems rely almost exclusively on written and/or audio visual materials, most state and federal systems offer education sessions where an educator is present. However, the need to monitor the quality and availability of educational programs is evident as reports of inadequacies surface. Consider, for example, this excerpt from the 100th Report of the Office of the Court Monitor, Report on Delivery of Medical and Mental Health Care (1990) regarding HIV education programs in prisons in Puerto Rico:

> On site education to inmates about the symptoms, transmission, and prevention of Human Immunodeficiency Virus (HIV) Infection is virtually nonexistent. Infrequent, poorly attended sessions have been presented in some correctional facilities. The knowledge level of the incarcerated population concerning HIV infection is horribly inadequate. The current system of referring all inmates to "Centro Latinoamericano de Enfermedades de Transmission Sexual (CLETS) for HIV counseling is logistically impossible, burdensome to the correctional staff, and a major barrier to the dissemination of information about AIDS and its prevention to the incarcerated population. Given the enormous problem that HIV infection has caused within the Administration of Corrections and in the Commonwealth of Puerto Rico, the current plan to hire 4 (AIDS) educators to work in correctional facilities is grossly inadequate.

and the following testimony regarding New Jersey:

> Provisions for education and counseling on AIDS is seriously inadequate in both state and county facilities. The state prison system has a limited educational program for Corrections staff and inmates making use of a volunteer corrections staff member and relying largely on videotape; most county facilities distribute pamphlets or nothing at all. While the New Jersey Department of Health provides some training and education services to correctional facilities, there are only two staff positions budgeted to address the state-wide training and education needs of police departments and emergency medical response personnel in addition to corrections. While innovative approaches (such as training or peer counselors and use of a closed circuit television presentation allowing inmates to telephone questions to the educator) have been attempted on a trial basis, the Health Department's efforts in this area necessarily have been limited by budget and staff constraints. One source estimates that the Department annually reaches only 4,000 inmates, or roughly 13% of New Jersey's inmate population on a given day (Hanssens 1990).

HIV education programs are critical to reducing the spread of HIV infection. Education for prevention, however, is of no use if not delivered diligently, clearly, and in the language of the intended listener. As one witness reminded the Commission,

> There are manners of spread of disease within a prison that are not the usual routes. Obviously, sexual activity, IV drug use is one way. Other ways include "spitback methadone," which is . . . where a person basically regurgitates the methadone they've taken in and therefore effectively transmits hepatitis and other such things that way. There's also tattooing that goes on in the prison[.] . . . [I]nmates are very ingenious at finding ways of finding pigment and of tattooing each other. There are many different issues here that really need significant education within the prison with people who are sensitive to the issues that are unique to this environment . . . (Bellin 1990).

Accordingly, particular attention should be given to the special educational needs of prisoners.

The Commission was particularly impressed by the following testimony of an AIDS educator and strongly encourages its use as a model for education programs in correctional systems:

Recommendations for AIDS Prevention Programs in Correctional Settings[3]

Prisons, jails, detention houses and other correctional settings present extraordinary opportunities and challenges for AIDS prevention efforts. On the one hand, no other institution in this society has a higher concentration of people at substantial risk of HIV infection. Moreover, the population in prisons and jails is unlikely to have been reached by other AIDS education programs. On the other hand, formidable obstacles impede effective programs in the correctional system. These include an authoritarian atmosphere, preoccupation with security, inmates' mistrust of public health professionals, violence, discrimination and a high turn over of inmates.

In order to ensure that the public health benefits of reaching this high risk population are achieved, health and correctional officials, AIDS organizations, prisoners' rights groups and other organizations need to work together to develop comprehensive prevention programs in every correctional institution.

Elements of a Comprehensive AIDS Prevention Program

1. All inmates should participate in a mandatory AIDS information and education session upon entry into the system.

Only by mandating correctional systems to provide education to all inmates can it be ensured that all inmates will receive at least some basic knowledge and skills related to HIV risk reduction. Such sessions also reduce the stigmatization that can occur if AIDS education programs are voluntary. These mandatory sessions should include risk reduction information, referral sources within the correctional system, and an opportunity to ask

questions and to request individual confidential counseling. Educators should use language that inmates understand, discuss safe and risky sexual and drug behaviors clearly and explicitly, and should respect the diverse cultures of inmates.

2. All correctional and prison health staff should be required to participate in AIDS education programs.

These programs should provide information on AIDS/HIV, occupational health and safely related to HIV, orientation to prison AIDS policies, information on confidentiality, and an opportunity to voice fears and ask questions. They should familiarize learners with referral sources inside and outside the prison system. These sessions are best provided by health professionals employed outside the correctional system. An educated work force is a critical foundation for an effective AIDS prevention program for inmates.

3. All inmates should have the opportunity to request confidential HIV counseling and testing.

After inmates have had the opportunity to learn information on AIDS/HIV, they should be able to explore individual concerns, plan a personal risk reduction strategy, and opt for HIV testing. HIV counseling and testing should be provided by health professionals with specialized training.

4. Inmates should have the opportunity to participate in ongoing groups that provide information and support about risk reduction.

A single intervention is unlikely to lead to significant changes in risk behavior. Therefore, inmates need the opportunity to raise questions, learn prevention skills, explore feelings, and gain support for risk reduction. Such programs can be integrated into a variety of existing educational, mental health and vocational programs that exist in many prisons.

5. Peer educators can play an important role in prison AIDS prevention programs.

Inmates who want to learn more about AIDS can play a vital role in educating other inmates, making referrals and helping to support those who want to reduce their risk from HIV.

6. Prisons officials need to create a social environment that supports risk reduction and humane treatment towards those with HIV/AIDS.

For some inmates, the prison experience can be a time to make positive life changes. By making drug treatment available to those who want it, by developing effective programs to control sexual violence and discrimination against gay prisoners or those with HIV/AIDS, by providing access to adequate primary care, and by treating diseases such as tuberculosis and syphilis, prison officials can make an important contribution to slowing the spread of HIV both within the prison and outside.

7. Inmates need to learn skills that will protect them against HIV infection both inside and outside the correctional system.

Whether to distribute condoms in prison and whether to teach inmates how to sterilize needles and works have proven to be controversial questions for correctional officers. Both

these questions have important political, social and moral dimensions. From a public health perspective, however, it is clear that where unprotected sexual and drug behavior are known to occur, the availability of condoms and bleach and water can reduce the risk. Prison officials need to decide whether it is more ethical to acknowledge the existence of illegal behavior or to withhold life-saving equipment or skills.

For inmates who are about to be released, providing condoms and teaching how to sterilize needles can protect them and their sexual and drug partners as well as their future children from potential infection. A pre-release counseling session and prevention kit can achieve this goal.

8. Prevention programs need to be closely linked to health and social services for inmates with HIV/AIDS.

Raising awareness about AIDS requires providing the services that people with HIV illness need. These include extensive post-test counseling, medical treatment, access to therapies for HIV infection, support groups, and mental health services.

9. Prevention programs need to address the special needs of female inmates.

Women in prison need intensive education on safer sex and perinatal transmission of HIV. Men need this information too but for women there needs to be an opportunity to discuss gender roles and explore strategies for gaining greater control over sexual decision-making. Pregnant inmates need to have access to HIV counseling and testing with counselors knowledgeable about perinatal transmission and relevant cultural factors. Pregnant women who are HIV infected should have access to a full range of supportive services including prenatal care, support groups, and if desired, abortion referrals. Prison drug treatment programs should be available to women. Female inmates also need to learn about the potential for female-female sexual transmission, especially in those cases where drug using women may already be infected.

10. Prisoners should be included in planning and implementing AIDS prevention programs.

The health education literature suggests that programs in which learners participate in developing the curriculum and the format of educational sessions are more likely to be effective. Prisoners can educate their peers, serve on advisory panels, organize AIDS events, or create educational materials.

11. AIDS prevention programs should be developed for all institutions in the correctional system.

Since most of those arrested do not actually go to prison detention houses and police lock-ups are also important sites for AIDS education. Parole and probation programs offer opportunities for reaching additional populations. AIDS prevention programs in halfway houses and work-release programs are especially important in reaching inmates who will soon re-enter the free world.

12. Correctional systems, prison health services, AIDS organizations, prisoners' rights groups and public health professionals need to work together to create effective AIDS prevention programs in correctional settings.

By themselves, correctional systems often lack the expertise, credibility and resources to develop effective AIDS prevention programs. By joining with other organizations, it is possible to create networks that can have a greater impact than any single group.

The experience of AIDS educators in the first decade of the epidemic suggests that those at risk of HIV infection need ongoing education, support and reinforcement in order to maintain or initiate risk reduction behavior. By developing ongoing relationships and referral systems between correctional and community programs, it will be possible both to help inmates reduce their risk of infection and to prevent transmission to their sexual and drug partners in the free world and to their future children.

AIDS prevention programs remain the single most effective strategy for slowing the spread of HIV infection. Inmates, like others in our society, have the right to be protected from life-threatening illnesses. For legal, moral and public health reasons, correctional and health officials should develop effective and comprehensive AIDS prevention programs in correctional settings.

Screening and Testing

The Commission recognizes that there continues to be considerable debate about the mass screening of inmates for antibodies of HIV. Pressure is on prison administrators from legislators, city and county officials, corrections officers, and inmates themselves for mandatory screening of all prisoners, with subsequent identification of HIV seropositive inmates or those with AIDS. In short, there are a myriad of individuals asserting a "need to know" the confidential medical information of persons in custody in an attempt to limit their vulnerability to HIV infection.

Mandatory screening in a number of jurisdictions has, thus, merely served as a management tool to quell the fears of third parties. In these environments, HIV screening has been used to segregate or otherwise impose restrictions on the activities of seropositive persons; and served a very narrowly drawn public health function of questionable efficacy, as HIV is not casually transmitted.

Paradoxically, the states that have conducted mass screening programs with mandatory, identity-linked testing have been in areas of low seroprevalence. Most of the seroprevalence rates in these mass screening programs were lower than 1.5 percent and all were lower than 3.5%, with the exception of female entrants to the Federal Bureau of Prisons.

Only a few states have recently added mandatory screening programs; others such as New Mexico, South Dakota, Rhode Island and West Virginia have abandoned their screening programs, finding low seroprevalence rates and/or prohibitively high costs. A few states screen on the basis of "risk group," testing intravenous drug users, prostitutes, and self-identified homosexual men (Hammett 1990). None of the five states with the highest cumulative AIDS incidence -- New York, New Jersey, Florida, California and Texas -- currently screen entering inmates for HIV on a mandatory basis. Mandatory screening also raises questions of accuracy and confidentiality of test results; testing in low prevalence populations increases the proportion of false positives. The Commission believes that resources expended for screening would likely be better spent on prevention activities, such as education. There is certainly no point in screening without a clear notion of what is to be done with information uncovered in the screening process.

Housing and Segregation

One recurrent issue in HIV prison policy concerns the advisability of segregating asymptomatic seropositive prisoners or those with AIDS. Arguments for the segregation of inmates have been based on management of inmates, prevention of the spread of HIV through intravenous drug use and sexual activity within the prison, and access to specialized medical care.

Presently, sixteen state prisons segregate all prisoners with AIDS, five segregate those with "ARC" and four, those who are merely seropositive (Hammett 1990). A number of lawsuits have been brought by prisoners challenging the practice of segregation. Lower federal courts have tended to defer to corrections officials' judgment, giving less weight to medical evidence in prisons than it might receive on the outside. A notable recent exception, however, was a consent judgment in a class action filed in U.S. District Court involving inmates at the Connecticut Institute at Somers. The consent judgment declared that "inmates shall not be segregated from the general population solely due to being HIV seropositive or the status of their HIV infection. Inmates may be segregated from the general population when required by their individual security or medical needs, which shall be determined on a case-by-case basis" (Smith v. Meachum 1989).

The Connecticut decree reflects a trend away from blanket policies that segregate prisoners on the basis of serostatus or AIDS diagnosis without regard to individualized clinical or behavioral assessments. In state and federal systems, inmates are more likely than not to be housed on the basis of an individualized determination. In city and county jails, segregation of AIDS cases is still a common practice (36%) but individualized determinations are now the prevailing practice (39%) (Hammett 1990).

The Commission recognizes that HIV disease in prison will only grow larger as a medical and management problem unless it is addressed in a positive and effective way. Systems with large numbers of HIV infected inmates are already finding it impossible to segregate everyone who is infected. New York State, with large numbers of AIDS cases in its prisons, has begun to reintegrate into the general prison population inmates who were

formerly segregated, largely without incident. New York State's attempt to segregate all known HIV positive inmates was enjoined by a court as a violation of the inmates' right of privacy. The court found that the inmates had not been given any choice and that services promised in exchange for the segregation did not materialize (Doe v. Coughlin 1988).

The Commission finds automatic segregation to be wholly without public health merit, often giving rise to dangerous circumstances for the correctional community as a whole. As one medical expert reminded the Commission, segregation of HIV positive inmates may provide a false sense of security for inmates in general population and the correctional staff of these facilities by shifting attention and thus, prevention efforts, away from risk behaviors to risk groups (Maisonet 1990). Where testing for HIV is voluntary or random, many individuals who are indeed positive for HIV may be unidentified. Segregation wrongly suggests that by isolating those individuals who are infected, everyone else is now "safe."

Segregation clearly identifies the infected in a prison population, literally labeling these individuals and rendering them at greater risk for assaults, discrimination, and disparate treatment. In fact, blanket segregation schemes have often resulted in limiting prisoners' access to religious services, law libraries, visitation, educational and recreational facilities, and work. As one witness told the Commission,

> In the New Jersey prison system, AIDS is the great equalizer; a prisoner's AIDS diagnosis substitutes for the system of classification based on the offense, prior record and incarcerations, institutional behavior, staff evaluations and similar factors by which all other offenders, including those with other types of chronic illnesses, are judged. Only one other group of prisoners in the New Jersey state system are subject to automatic segregation without periodic review for consideration of return to general population -- those under sentence of death (Hanssens 1990).

Further, where inmates with HIV disease remain isolated from other prisoners, with few opportunities for respite from idleness, and without the possibility of a chance to return to a less restrictive environment, many report severe depression. As one inmate wrote the Commission, "To be a prisoner with AIDS and HIV is a lonely and scary feeling." The psychological dimensions of segregation were poignantly underscored for the Commission by the plight of a female inmate in New Jersey who remained in virtual isolation for over a year and a half, until a second woman diagnosed with AIDS was placed in the isolation unit. During that time, this inmate was denied even verbal communication with other prisoners, despite her lack of visible symptoms and growing evidence that her continued isolation caused her increasing depression and stress.

The Commission strongly urges recognition that punishing the infected merely because of their HIV status thwarts health promotion and behavioral change efforts, and deters people from seeking testing and medial care. As one advocate made clear, "Automatic segregation of prisoners with AIDS is no more desirable or defensible in an institutional context than it is in the society as a whole" (Hanssens 1990).

The Commission found the following letter from an inmate in Alabama insightful and moving:

On Being HIV Positive in Alabama's Department of Correction

I learned that I'd tested positive for HIV on July 14, 1987. I was immediately removed form trade school (barbering) boarded onto one of the state transportation vans and moved to L.C.F.'s AIDS Unit with all of the other inmates who were HIV+.

Once in the AIDS unit I felt like an animal on display at the zoo. There is a double fence with razor wire atop it separating HIV+ inmates from the general prison population.

I am no longer allowed to take part in trade school, nor am I eligible to take part in any of the D.O.C.'s early release programs. Basically I was placed on a type Death Row and this is where I've been for the last three years.

Inmates who test HIV+ in Alabama are not allowed to take part in any of the work programs and different classifications of inmates are clustered in one dormitory. There are murderers, rapists and to make matters worse, there are men on the unit with life sentence without parole, several life sentences, etc. with men who have 1, 2, 3 & 4 year sentences for petty crimes.

Even the food we eat is served on disposable trays, with ice cream spoons sometimes issued for us to eat meals with (grits, eggs, etc.).

I am serving an 18 year sentence. For 6 years or so I'm expected to just sit around a dormitory with approximately 140 other men and watch T.V.

For those inmates who develop full blown AIDS and require hospitalization, there is no one there for them. No one to clean their cells as needed. No one to bathe them as needed and just to share the agony of the illness that's attacking the body's immune system. It's a very sad situation, when there is no one there to care for you, and it seems you're going to die a lonesome death.

I live in a very tense environment; it can be dangerous when 140 inmates lie around with idle minds.

At times one who is HIV+ just gives up hope. At a time when the D.O.C. and the Alabama federal courts say it's alright to treat us/me as lepers, it takes away your feeling of humanity. It leaves one to wonder, what type of human being, who is in a position to carry out the constitution of this country, could allow this type of treatment of other human beings to continue, and rest with a clean and clear conscience?

I felt that incarceration is punishment for the crime I committed, but to be incarcerated and then isolated from all privileges afforded other inmates who were convicted in the same court room I was convicted in, is above the law.

Frankly, 90 - 95% of the negative treatment I have received has come from D.O.C. officials. I come into contact with inmates in the prison's general population and I have yet to ever be treated indifferently by an inmate. It has always been D.O.C. officials who try and reinforce the idea, myth, fear that AIDS is spread by casual contact.

With the help of concerned citizens, we can stop the madness!!! We too, need human compassion and interaction, if our spirits are to continue on this planet!

Mike Arrington
Alabama HIV Unit
June, 1990

Incarcerated Women

Incarcerated women have been, and continue to be, a forgotten population. This can be attributed, in part, to the historically small numbers of women incarcerated in prisons and jails in the United States. In 1980, there were approximately 13,000 women in federal and state prisons. By the end of 1989, that number had more than tripled, to almost 41,000. In 1989 alone, the female prison population grew by 25%, compared with a 13% growth in the male prison population. In part, the marked increase can be attributed to the advent of mandatory minimum sentencing for drug offenses both at the state and federal level, and the emphasis in this nation's "war on drugs" on interdiction and incarceration rather than prevention and control (Smith 1990).

According to the Federal Bureau of Prisons, about 60% of women in federal custody are serving sentences for drug offenses. A large number of women in prison have alcohol and drug dependency problems. As early as 1979, the General Accounting Office estimated that between 50% and 60% of female prisoners had alcohol and drug dependency problems (GAO 1990). The estimates now ranges between 70% and 80%. Notwithstanding the early identification of this problem, and its rapid increase in seriousness, little has been done in the way of drug and alcohol treatment for women in prison.

The behavior profile of women in prison to a great extent mirrors the profile of those most at risk of contracting HIV infection. The overwhelming majority of female prisoners have multiple drug problems. Many of them are intravenous drug users. Even though women comprise only nine percent of AIDS cases, they are the fastest growing population to be affected by HIV disease. Among prison entrants the HIV prevalence rates are generally higher for women than for men. In New York State the seroprevalence rate for female entrants is 18.8% compared to a seroprevalence rate of 17.4% among male entrants.

Preliminary results from a study of 1,000 consecutive entrants of each of 10 different correctional systems throughout the country conducted by the CDC, Johns Hopkins University and the NIJ, indicate that in general HIV prevalence rates were higher for female than for male entrants. Among males entering prison systems these rates ranged from 2.1% to 5.9%, for females they ranged from 3.2 to 7.8%. Among jail system entrants the rates in men ranged from 2.3% to 7.6% and in females from 2.5% to 14.7%. Additionally, preliminary results from this study indicate that among persons less than 25 years of age, female entrants to correctional facilities had significantly higher rates of HIV infection than male entrants.

Eighty percent of female prisoners have children, and of those 70% are single parents. Prior to their incarceration, 85% of female prisoners, compared to 47% of male prisoners had custody of their children. These women are primarily young, between the ages of 20 and 34 years old. Further, a significant number of women give birth to children shortly before they begin to serve prison sentences, or are pregnant and give birth during their incarceration. The Bureau of Justice Statistics reports that about 25 percent of women in correctional institutions are pregnant or post-partum. In New York City, approximately 8% of female inmates are pregnant at the time of incarceration.

Urgent attention must be given to the special needs of female inmates. As one witness told the Commission,

> While lack of medical care is a problem for most prisons and jails in this country, appropriate medical care for women is even more lacking. Women prisoners have long failed to receive even basic gynecological and medical services, such as detection and treatment of sexually transmitted diseases, routine pap smears and breast exams (Smith 1990).

In addition to the services available to their male counterparts, women in prison are in desperate need of HIV education regarding perinatal transmission and pediatric AIDS, frequent pap smears and other services sensitive to gender and the distinct history of female inmates regarding the conditions of their confinement. In addition, pregnant inmates are in need of prenatal services where HIV testing is offered upon request. Special care to provide education and counseling in a context of freely available reproductive choice is essential.

Adolescents in Custody

The actual rate of HIV infection and AIDS among adolescents in custody is unknown. However, in a 1989 survey of 1,400 public and private juvenile confinement facilities conducted by the National Commission on Correctional Health Care, responding facilities reported 14 confirmed AIDS cases and 2 AIDS-related deaths among juvenile detainees. This figure represents a minimum estimate of the number of AIDS cases among adolescent detainees, as not all facilities were surveyed and of those surveyed only one third responded (Harrison 1990).

While the actual rate of HIV infection among adolescents in custody is unknown, many youth who come under the jurisdiction of juvenile detention facilities have a history of behaviors that places them at higher risk of HIV infection than the general population of adolescents (NRC 1990). There are some 600,000 admissions to public juvenile facilities annually. Over 50,000 adolescents are confined on any given day. Drug crimes account for 5.6% of all offenses. Moreover, recent surveys of juveniles in custody found 63% of these youth used drugs regularly (Bureau of Justice Statistics, cited in the AMA Council of Scientific Affairs, 1990) and that youth in detention are significantly more likely than students of the same age to report ever injecting drugs.

Experts agree that early age of first intercourse and multiple sexual partners may increase the risk of sexually transmitted diseases which may facilitate HIV transmission. In a regional study of inner city detention populations, the average age of first intercourse was 12 years, compared to 16 years for the nation. The average age for group home residents was between 12 and 16 years; some of these are runaways. Most of these individuals have had multiple partners and have little or no knowledge of their partners' prior sexual or drug related behavior, placing them at risk for HIV infection. Seventeen percent of 262 respondents to a survey of 16 to 17 year olds incarcerated in the Los Angeles area reported a history of sexually transmitted disease and 47% reported drinking alcohol in situations that led to unprotected sexual intercourse (Morris et al. 1990). The Commission was, indeed, alarmed to learn that among 184 youth offenders taking advantage of services offered by the San Francisco Youth Guidance Center, 35% reported exchanging sex for drugs or money and 46% agreed with the statement, "Sex without condoms is worth the risk of getting AIDS" (Temoshok et al. 1989). As one witness told the Commission,

> These kids have heard of AIDS, but have many fears and misconceptions and generally suffer from the invincibility that all teenagers feel. A good number of them also feel despair and hatred, and profess no particular interest in protecting themselves or others (Harrison 1990).

While the number of cases of AIDS diagnoses among people age 13-19 remains low, this obscures the far higher number of those infected with HIV who are asymptomatic or whose illness does not meet the CDC definition of AIDS. The more accurate scale of the epidemic in youth is reflected in the number of cases of AIDS diagnosed among persons in their twenties, since an average of ten years passes between infection and progression

to full blown AIDS. Therefore, it is likely that many individuals diagnosed with AIDS in their twenties were indeed infected during adolescence.

Failure to pay close attention to adolescent health, developmental and behavioral issues has resulted in the silent spread of HIV infection among our nation's youth. Because youth in detention are significantly more likely than students of the same age to report engaging in high risk behaviors, the Commission is greatly concerned that little information, empirical or anecdotal, is available on systems of juvenile delinquent agencies regarding health care, education and disease prevention efforts. For the most part, juvenile facilities continue to suffer from extreme inattention. Information regarding access and quality of health care must be obtained and made available.

The need for HIV education programs in juvenile detention facilities cannot be overstated. While most facilities provide some form of health education, these programs are not comprehensive in their discussion of HIV disease. In some cases such programs are offered through a curriculum brought in by the local school district. Local school-based programs, however, may be hampered in their efforts to communicate effectively with incarcerated youth by a reluctance to use clear and open language when discussing controversial behaviors.

HIV education programs for incarcerated youth should recognize the behavioral, social and developmental diversity of the adolescent population. Educational programs should be credible and include accurate, culturally sensitive and linguistically appropriate information. Such programs should ensure that youth are made aware of all effective methods for reducing their risk of contracting or transmitting HIV.

Discharge Planning, Transfer and Early Release

Careful planning for the discharge of prisoners living with HIV disease is a critical aspect of their care. In many cases prisons are hundreds of miles away from the urban centers that are home to many of the inmates, making it difficult for families to visit or to foster the support systems needed to face illness. For inmates who are discharged to the care of families, the families must be offered HIV education to help understand the needs of the inmate and allay any fears they may have about HIV infection and casual household contacts.

Provisions must be made to ensure that inmates with HIV disease on medications continue to receive these drugs. For all inmates who are discharged with HIV disease, referrals must be made to the relevant physicians, clinics, hospitals, hospices, or other health care facilities.

Additional concerns arise for inmates with HIV disease who are transferred from one prison to another. Transfers of inmates between prisons or between prison systems are frequent occurrences. When individuals are transferred, their medical services are disrupted. Since daily monitoring and treatment are necessary for inmates with HIV disease,

delays in forwarding medical records to other facilities and breaches in confidentiality can and do have tragic consequences. As one expert told the Commission, "The days, or weeks, that can be lost in the transfer or release process can be fatal" (Pottenger 1990). The Commission calls upon correctional systems to rigorously evaluate and improve their coordination, information-sharing, and planning processes in this critical area.

The Commission believes that there also needs to be in place in every corrections system a responsive mechanism for the early release of all terminally ill prisoners, including those with HIV disease, who no longer pose a danger to society and whose further incarceration would serve no purpose. Most prison systems lack the nursing care and social support services necessary for dying patients. These services are best provided in a hospital, hospice, or home setting with nursing care support.

In recent years, prison furlough and work release programs have come under attack by politicians, posing difficulties for those seeking early release on compassionate grounds. The politicization of work release programs has held up legislative proposals in some states to provide for "medical parole." A representative of the New Jersey Public Advocates Office testified about the situation in her state:

> [T]here is no readily available mechanism in New Jersey for the release of inmates who are terminally ill. The actual criteria for medical clemency are so stringent, and the process of review so prolonged, that inmates who meet the eligibility requirements frequently die before their application reaches the Governor's desk. There is no early parole available for these offenders; in fact, there is evidence that the Parole Board views disease as an aggravating rather than a mitigating factor (Hanssens 1990).

In most states the Governor has the option of commuting a terminally ill prisoner's sentence by a grant of executive clemency. In the federal system and in some states, there is also the option for a judge to resentence a prisoner because of serious illness. In many states, departments of corrections have the authority to grant a prisoner temporary release or a medical leave of absence to undergo treatment that prison facilities are unable to provide. In some jail systems, detainees who are terminally ill may have their bail reduced to amounts they can afford or be released on their own recognizance.

The Commission encourages the Federal Bureau of Prisons, states, and localities to review the early release options available so that incarceration for persons with HIV disease is not a death sentence. Mechanisms for early release should be streamlined and made readily available for prisoners who are seriously ill and whose release would be unlikely to pose a danger to society. Parole boards, or other bodies with considerable experience in deciding about early release, should make such decisions, and prisoners should be released to an appropriate facility with an adequate discharge plan.

Role of Community Based Organizations

Community based organizations, given the opportunity, can play a significant role in providing support services to the correctional community. Over the last decade, hundreds of community based AIDS service organizations have developed expertise in identifying the needs of persons living with HIV disease and providing highly individualized care and assistance to meet the challenges presented by the epidemic. In the correctional system, community based organizations may be an overlooked resource in the effort to provide appropriate cost effective service interventions. Such organizations exist in every state and, in some instances, offer group and individual programs on a voluntary basis.

Contact with a community based organization may prove valuable to inmates by breaking the pattern of isolation and psychological distress to which so many prisoners with HIV disease are tragically subjected. Inmates with HIV disease experience the loneliness of facing debilitating illness and death in a hostile environment far away from family and support networks. As one inmate wrote in a letter to the Commission,

> Having AIDS in prison is an endless vigil to insure that you receive the medications and treatment that you need. It is dealing with medical personnel who get a thrill out of putting your life and well-being in jeopardy by revealing in sadistic and sinister ways that you are one of the "accused." It is being subject to assaults and "burn-outs" (having your cell set on fire) by other prisoners. It is living with a debilitating fear that someone will find out that you're dying of AIDS and kick you. It is a horrible way to die . . . (Graham 1990).

Community based organizations may provide "buddies," individuals from the local community who are sensitive to issues surrounding HIV disease, with whom an inmate may feel more comfortable discussing his or her concerns about HIV disease. As one witness told the Commission,

> People on the inside often feel that they can't talk about the diagnosis with anyone other than the medical staff whom they see only very briefly. An AIDS buddy and/or case manager from the community gives the individual someone with whom concerns about AIDS can be discussed at length (Forbes 1990).

In addition, community based organizations can play a crucial role in helping to educate family members about HIV disease. Family members may have a difficult time understanding and accepting an individual's seropositive diagnosis. Their own fears and misinformation about HIV disease can make it hard for them to continue to offer support to the incarcerated individual. Staff and volunteers of community based AIDS service organizations can help bridge the gap caused by distance and fear to help maintain relationships between the inmate and his or her family during a very difficult period.

Correctional systems must be encouraged to work cooperatively with community based AIDS service organizations in providing support services and counseling to bridge the gap

between correctional facilities and the community, and to provide follow-up services as inmates return to the community. Community based organizations can also be an important resource for inmates upon release. Persons living with HIV disease who have served to the end of their sentence or are released on parole need immediate access to a broad range of HIV specific services, including appropriate housing in order to make a healthful and successful transition back into their communities. AIDS service organizations can assist by helping persons living with HIV disease and their families plan for their release.

HIV DISEASE IN CORRECTIONAL FACILITIES: A MODEL RESPONSE

GENERAL PRINCIPLES

The National Commission on AIDS recommends that policies with respect to HIV disease in prison be guided by the following basic principles:

1. The HIV epidemic in correctional facilities is part of the same epidemic the nation is experiencing outside prison walls. Interventions among prisoners will save lives and will have a significant impact upon the course of the epidemic in communities to which prisoners will return.
2. Society has a moral and legal obligation to provide prisoners with the means to prevent HIV infection, and to provide adequate medical care to infected prisoners at all stages of HIV disease.
3. Decisions regarding HIV policies should be based on sound medical and public health principles. Interventions employed in the correctional setting should be guided by the same standards of care employed in interventions targeting the general community.
4. Control and prevention of HIV infection must be viewed in the context of the need to improve significantly overall hygiene and health facilities in prisons (WHO 1987).

RECOMMENDED GUIDELINES

I. Medical Care

- Asymptomatic HIV infection is a serious medical condition requiring regular medical attention and in many cases aggressive prophylactic treatment.
- Medical, nursing, inpatient and outpatient services for prisoners with HIV disease should, at a minimum, be equal to prevailing standards of care for people with HIV disease in the community at large.
- Correctional facilities should immediately address the controllable subsidiary epidemics of sexually transmitted diseases and tuberculosis. Infection control protocols established by the U.S. Public Health Service/ Centers for Disease Control should be strictly followed.
- Because of the complex and rapidly changing nature of HIV treatment protocols, quality assurance mechanisms should be implemented to review periodically the adequacy and efficacy of prison medical care.

- Medical information revealed in the course of treatment should be rigorously protected from disclosure to non-treating personnel.
- Treatment of drug addiction should be expanded until all prisoners who request such treatment are able to receive it.

Adequate care includes, but is not limited to:

- meaningful access to HIV testing (see II below);
- regular examinations by physicians with sufficient training to diagnose and treat HIV infection and HIV related illnesses;
- a full physical examination at the time infection is diagnosed, and subsequently as medically indicated;
- access to necessary specialist care where appropriate;
- T-cell monitoring at the intervals prescribed by the U.S. Public Health Service;
- timely, consistent and appropriate access to necessary medications, including prophylactic drug therapies approved by the Food and Drug Administration or recommended by federal health authorities;
- access to dental care;
- access to mental health care;
- access to meaningful drug treatment on demand;
- clean, hygienic housing facilities; and
- appropriate diets.

II. Identification

- Voluntary HIV testing and counseling should be available to all prisoners who request it on a confidential and/or anonymous basis. All HIV tests should be accompanied by individual pre-and post-test counseling conducted by a trained AIDS counselor observing U.S. Public Health Service/ Centers for Disease Control guidelines. Test results should never be made available to any prison employee, even prison medical employees, without the specific, written informed consent of the prisoner.
- Mandatory testing or screening should not be employed.

III. Information and Education

- HIV education should be a high priority for all correctional facilities. Educational programs should include components targeted at reducing behaviors that place individuals at risk, alleviating fear of HIV infection and people with HIV disease, and informing everyone in the correctional setting of available medical care.
- Both inmates and staff need live, interactive HIV education from a credible, properly trained educator at regular intervals. Distribution of written materials and exclusive reliance on video taped educational presentations is not sufficient. All education should be culturally sensitive and linguistically appropriate.
- Education to reduce the risk of HIV infection from intravenous drug use and sexual activity should be explicit, and include clear advice about resources available in the prison setting that may be employed to reduce the risk of infection, even where these behaviors occur in violation of prison regulations or applicable law.
- Condom distribution should be part of an overall health promotion and HIV prevention effort in all correctional systems.
- Because prisoners may discount information provided by prison authorities, outside organizations, including health departments and AIDS service agencies, should be involved in the preparation and presentation of HIV education programs wherever possible. Inmates themselves should be trained and equipped to serve as HIV educators among their peers, with adequate supervision and support from trained HIV educators.
- HIV continuing education programs developed specifically for correctional social service and medical staff should be mandatory and regularly updated. Updated HIV education should be regularly provided for staff of departments of probation and parole as well.
- Support groups for prisoners living with HIV disease should be promoted and encouraged. Correctional systems should work cooperatively with community based AIDS service organizations in providing support services and counseling to bridge the gap between institutions and the community, and to provide follow-up services as inmates return to the community.

IV. Management

- Discrimination and punitive treatment of people living with HIV disease discourages them from seeking education, testing, and treatment, thus, compromising efforts to prevent new HIV infections and to treat persons living with HIV disease.
- Prisoners should not be isolated or housed in special units solely because of their HIV serostatus.

- Prisoners with HIV disease should be permitted to participate in all prison programs and jobs for which they are otherwise qualified, including positions in food or health services in keeping with U.S. Public Health Service/ Centers for Disease Control guidelines.
- HIV-related information in the possession of medical providers should be released only under extraordinary circumstances to prison authorities for the benefit of the patient. Staff should be trained to protect the privacy of inmate medical data. Work rules prohibiting release of HIV-related information should be strictly enforced.
- Jails and prisons should have written HIV management policies and treatment protocols that reflect the most up-to-date medical and scientific information. These policies should be reviewed frequently.
- Universal precautions should be integrated into institutional procedures to limit the health risk to staff and inmates.

V. Release

- HIV disease should not be a reason to punish further any prisoner. Release should not be capriciously denied merely because of HIV status.
- To maintain continuity of care during the transition from prison to the community, every inmate with HIV disease should be assisted in finding medical care and support services in the community. This should include assisting prisoners to register with community based case management services prior to release where such services are available and if the prisoner so desires.
- Prisons and jails should have workable early-discharge and medical furlough programs providing for the timely release of inmates whose incarceration is no longer medically appropriate.

VI. The Role of Public Health Authorities

- Public health authorities must recognize that even though legal and architectural barriers have been erected between institutionalized populations and the community at large, such barriers are often illusory. Individuals move to and from institutions, return to their communities and loved ones, as new waves of entrants await confinement. We must learn that we cannot speak of the health of the nation without also addressing the health of individuals in prisons, jails and other institutions.
- Prisons contain a disproportionate number of people at risk of, or infected with HIV. Public health agencies should make intervention in this setting a high priority, and should work closely with corrections officials to bring successful public health strategies -- for example, education, voluntary testing and counseling, and health care -- to bear in prisons.

RECOMMENDATIONS

In addition to the model guidelines outlined above, the National Commission on AIDS makes the following specific recommendations:

1. The U.S. Public Health Service should develop guidelines for the prevention and treatment of HIV disease in all federal, state and local correctional facilities. Immediate steps should be taken to control the subsidiary epidemics of tuberculosis and sexually transmitted diseases. Particular attention should be given to the specific needs of women and youth within all policies.

2. Given the dearth of anecdotal and research information on incarcerated women, incarcerated youth and children born in custody, federal and state correctional officials should immediately assess and address conditions of confinement, adequacy of health care delivery systems, HIV education programs, and the availability of HIV testing and counseling, for these populations.

3. To combat the overwhelming effects which drug addiction, overcrowding and HIV disease are having on the already severely inadequate health care services of correctional systems nationwide, a program such as the National Health Service Corps should be created to attract health care providers to work in correctional systems.

4. The Department of Health and Human Services should issue a statement clarifying the federal policies on prisoners' access to clinical trials and investigational new drugs. In addition, the Food and Drug Administration, in conjunction with the Health Resources and Services Administration and the National Institutes of Health, should initiate an educational program directed toward informing inmates and health care professionals working in correctional facilities of the availability of investigational new drugs, expanded access programs, and applicable criteria for eligibility of prisoners in prophylactic and therapeutic research protocols.

5. Meaningful drug treatment must be made available on demand inside and outside correctional facilities. Access to family social services and nondirective reproductive counseling should also be made available with special emphasis on the populations of incarcerated women, youth and children born in custody.

6. Prison officials should ensure that both inmates and correctional staff have access to comprehensive HIV education and prevention programs. Particular attention should be paid to staff training on confidentiality and educating inmates about the resources available in the prison setting that may be employed to reduce the risk of infection.

7. The burden of determining and assuring standards of care has largely fallen to the courts, due, in part, to the failure of public health authorities to take a leadership role in assuring appropriate standards of health care and disease prevention for our incarcerated populations. Bar associations and entities such as the Federal Judicial Center must, therefore, establish programs to educate judges, judicial clerks, and court officers about HIV disease.

NOTES

1. The term "HIV disease" encompasses the continuum of conditions that begins with seroconversion and ends with AIDS. In some instances the report refers to HIV infection or AIDS where specifically appropriate, otherwise the term HIV disease is used.

2. It is important to note that this figure represents a minimum estimate of the number of AIDS patients and does not reflect the number of individuals at earlier stages of HIV disease.

3. Developed for the National Commission on AIDS, August 1990, by Nicholas Freudenberg, Professor of Community Health Education and Executive Director, Center for Community Action to Prevent AIDS, Hunter College School of Health Sciences, CUNY; and AIDS Education Consultant, Montefiore Rikers Island Prison Health Services.

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