The New York State AIDS Advisory Council

REPORT
on
HIV/AIDS SERVICES
in
NEW YORK STATE CORRECTIONAL FACILITIES

February 1999
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HIV/AIDS SERVICES
in NEW YORK STATE
CORRECTIONAL FACILITIES

EXECUTIVE SUMMARY

Inmates in New York State prisons, like inmates elsewhere, are dependent on health services provided by the state. In New York, the Department of Correctional Services (DOCS) has responsibility for health care in state prison facilities. Of the more than 105,000 people incarcerated in New York’s state, city, and county corrections facilities, approximately 70,000 are inmates in 73 New York State prisons. About 8,000, conservatively estimated, are HIV-positive.

In 1989, increasing numbers of inmates with HIV/AIDS prompted the New York State AIDS Advisory Council to examine HIV services in state facilities, with inevitable attention to inmate health services in general. In its report, “Management of HIV Infection in New York State Prisons,” the Council concluded that there were serious deficiencies in prison health services, particularly for inmates with HIV, and that substantial improvements should be undertaken immediately. Principal among the report’s recommendations were two: the Department of Health should monitor progress; and failure to effect the needed changes within 18 months should result in transfer of authority for inmate health services to the Department of Health.

In 1996, in view of high rates of HIV infection among inmates and reports of inadequate inmate access to HIV prevention and treatment services, inappropriate care, and insufficient improvement in HIV services, the Council determined that renewed and intensified attention to this issue was required. The Criminal Justice Subcommittee of the New York State AIDS Advisory Council was constituted in late 1996 and charged with review of New York State inmate HIV services and publication of a report and new recommendations.

The Subcommittee, consisting of 13 members, was chaired initially by Lambert King, M.D. and subsequently for virtually all of its work in this report by Victoria Sharp, M.D. It met nearly monthly from October 1996 through November 1997 and periodically thereafter, together with AIDS Institute staff members, observers, and invited guests.

Deliberations of the Subcommittee were guided by the following premises concerning HIV care in a prison setting:

1) Every inmate should be considered to be at risk for HIV and should be encouraged to learn
his or her HIV status.

2) Inadequate health care is not a condition of punishment. The state has particularly stringent obligations to provide access to health information, prevention measures, and medically appropriate treatment to people who are confined and unable to seek other medical opinions or health care providers. People with HIV in prisons should be accorded treatment that meets the same standards of care as people with HIV in any other setting.

3) Maintaining confidentiality and continuity of treatment is more difficult in prisons than in other settings but is no less critical. Confidentiality is essential to encourage HIV counseling, testing, and initiation of care for individuals, which in turn help to prevent HIV transmission, hospitalizations for acute crises, and release into the community of inmates who do not know their HIV status or how to obtain care. Continuity of treatment is an essential component of clinical care and crucial in preventing the development of HIV drug resistance from missed doses of medication.

4) The state has public health responsibilities to monitor the quality of prison health care, collect and make data publicly available, and ensure collaboration among state departments, agencies, and providers.

The Subcommittee requested information from the New York State Department of Correctional Services, from HIV service providers and other organizations who work with inmates, from the State Department of Health, including the AIDS Institute, from the New York City Department of Health, from health department HIV directors and prison medical directors in other states, and from inmates. The Subcommittee conducted focus groups and site visits, invited speakers, considered medical and legal issues in provision of services, examined proposed legislation, and gathered many types of documents for review.

The Principles and Recommendations of the Subcommittee, presented in full at the end of this report, were submitted to the full Council in December of 1997 and approved unanimously at the Council’s January 1998 meeting. Supporting data in this report have been updated through December 1998.

Although information about many important issues was not made available to the Subcommittee, the group was nevertheless able to identify a number of significant problems in the provision of HIV services in correctional facilities and to design recommendations to address them. Since it was the intent of the Council to identify to the extent possible the full range of problems preventing exemplary HIV education, testing, and treatment in correctional facilities and to address each with detailed recommendations, nine principles and 26 subdivided recommendations are presented in this report. Following is a summary by type of service:

I. Administration of HIV and Health Care Services (see page 10).
Health services are provided directly by DOCS staff in prison clinics, infirmaries, and Regional Medical Units, and to a limited extent through telemedicine. Outside organizations under contract to DOCS provide off site specialty care and hospital services. New York State Department of Health AIDS Institute (AI) contractors provide HIV education, counseling, testing, peer training, support services, and transitional planning in correctional facilities. AIDS Institute staff also provide anonymous counseling and testing, and additional testing is done by DOCS. The Subcommittee found that DOCS has experienced difficulties maintaining consistent contractor services. There are delays in access to specialty care and highly variable and inadequate provision of services among and within facilities by both DOCS and AI contractors.

Among the Subcommittee’s most serious concerns was the relationship between the Departments of Health and Correctional Services. These departments should have, in the view of the Subcommittee, a mutual interest in the assurance of inmate health services that meet contemporary standards. Currently, there is no central role for the Department of Health (DOH) in designing, monitoring, coordinating, or improving health care in prisons and no other consistent oversight mechanisms.

- The Subcommittee listed its concerns as: uneven, uncoordinated services; lack of a single standard of care; lack of oversight; and inadequate health care staff and training.
- The report’s principal recommendation (number 1) is that the Department of Health assume overall responsibility for health services in correctional facilities and, until legislative and regulatory authority is in place, that DOH have a major oversight role in assuring appropriate health care in prisons. Additional relevant recommendations address staffing and training (2, 3, 4), standards (10), data collection and analysis (20), quality of care and accountability (21), and funding (24).

II. HIV Education and Prevention (see page 16).
HIV prevention education is offered at intake by DOCS medical personnel and provided thereafter by AIDS Institute staff and contractors, and by contractor-trained peer educators. Educational sessions are voluntary. The Subcommittee again noted that many facilities lack services and the extent of service varies greatly by facility. Contractors experience substantial problems arranging access to prisons and training staff. Inmates have no access to condoms or other prevention measures and little access to information about treatment options. There are insufficient education materials in Spanish and other languages.

- Specific Subcommittee concerns are: lack of universal HIV education, contractor difficulties gaining access to facilities, insufficient use of peer educators, lack of acknowledgment of high risk inmate behavior, and subsequent unavailability of condoms and other prevention methods.
- The Subcommittee has urged that HIV education be mandatory at intake and at least annually for all inmates (in appropriate languages by trained instructors), that greater use be made of peer educators, that condoms and harm reduction information be made available (recommendations 5, 6), and that inmates receive comprehensive information about treatment options (7).
III. HIV Counseling, Testing, and Seroprevalence (see page 20)
All HIV testing in New York State prisons is voluntary, a policy which the Subcommittee strongly supports. Confidential testing is provided by DOCS medical staff and AI contractor personnel. AI staff also provide anonymous testing. Although HIV rates among newly incarcerated inmates have decreased for men, they remain high (about 7% in 1996-97) and have not decreased for women (18%). Many inmates do not know their HIV status. Further, there is a large discrepancy between HIV infection rates reported in confidential and anonymous testing programs compared to those in blinded seroprevalence studies, indicating that insufficient numbers of inmates at risk for HIV elect testing.

- The Subcommittee listed as concerns these discrepancies in rates and the lack of confidentiality and other barriers that discourage counseling and testing.
- Recommendations listing specific ways to improve confidentiality (8) and encourage testing (9) address these concerns.

IV. HIV Treatment Services (see page 24)
DOCS is aware of one third to one half of the estimated 8,000 inmates with HIV. Although antiretroviral therapy is available to the great majority of known HIV-positive inmates, there is evidence of substantial variation in access to treatment by facility. There are no system-wide comprehensive guidelines for HIV care. There are major shortages of staff and inadequate HIV staff training. Treatment education and clinical monitoring, especially critical with new HIV therapies, are seriously deficient. There are no uniform systems for access to specialty care or chronic care management. Interpreters trained in confidentiality principles are needed for non-English speaking inmates.

- The Subcommittee listed as concerns: inadequate identification of HIV-positive inmates, inadequate HIV training of primary care providers, uneven inmate access to HIV therapies, insufficient access to specialty care, lack of coordination of primary and specialty care, and inadequate treatment education and attention to continuity of care.
- Recommendations address staffing and training (2, 3, 4); treatment education (7); confidentiality (8); standards (10); acute, chronic, inpatient, specialty, and hospice care (11 through 17); and possible use of empty New York City hospital beds for inmate care (25).

V. Transitional and Support Services (see page 31)
Transitional planning and support services (counseling, support groups, and buddy services) are provided by AIDS Institute contractors. DOCS staff also provide referrals for discharged inmates. Contractors do not provide services to all facilities or to all discharged or transferred inmates in a facility and sometimes do not have access to needed documents. There is no standard system for seeing that inmates are referred to either DOCS staff or contractors for transitional planning and none for routine follow-up after discharge.

- The Subcommittee cited insufficient inmate access to transitional planning, inadequate
provisions for follow-up, and uneven provision of support services.

- The Subcommittee recommended (19) that transitional planning with information on treatment maintenance be provided to every inmate released for discharge, parole, medical parole, probation, work release, or transfer to another facility.

### VI. Terminal Care and Compassionate Release (see page 32)

AIDS deaths in prisons have shown a steady decrease since 1995 both in absolute numbers and as a percent of total deaths. Hospice care exists in two DOCS facilities, which care for only a small percent of the inmates with HIV who die while incarcerated. Compassionate release, including medical parole, is available but has benefitted a small and decreasing percent of eligible terminally ill inmates.

- The Subcommittee expressed concern about inadequate inmate access to hospice care and compassionate release.
- Terminal care and compassionate release recommendations (17, 18) address this.

### VII. Quality Assurance (see page 34)

Despite legal and statutory mandates and a number of critical reports and audits over the past ten years, no statewide quality assurance mechanisms for prison health services have been established, although DOCS has begun discussions about the AIDS Institute’s Quality of Care program. Health services in prisons are not covered by Department of Health regulations for health facilities, and despite Memoranda of Understanding and other attempts to increase collaboration between the Departments, there has been little coordination of efforts or resources to address quality improvement. There are no existing systems for routine monitoring of care, for data collection and reporting, or for computerized medical records. Gaps in all types of services and DOCS failure to adequately implement past recommendations strongly support the Subcommittee’s view that a quality assurance program be designed promptly in partnership with the Department of Health and other appropriate agencies.

- The Subcommittee cited the lack of statewide quality assurance mechanisms, DOCS failure to correct longstanding problems, inadequate oversight of correctional health services, and lack of public information about inmate health services.
- The recommendations on a DOH role (1), data collection and analysis (20), and quality of care (21-23) address these concerns.

Regarding funding, the Subcommittee was unable to determine whether DOCS funding allocations are adequate. Some of DOCS AIDS program costs include expenses for non-AIDS care. In addition, nearly one quarter of the $45.8 million allocation for FY 1996-97 came from commissions paid by long distance phone companies to the State on collect phone calls made by inmates to families and friends. This constitutes, in the Subcommittee’s view, an unfair tax on inmates’ families and friends for HIV services. Inmates should not be charged in any way, including co-payments, for health services. The AIDS Institute’s Criminal Justice Initiative is funded by nearly $3 million in state and federal sources, in addition to more than $800,000 for anonymous counseling and testing. This amount seems inadequate...
to provide comprehensive AI services to all DOCS facilities. The Subcommittee anticipates that some of its recommendations will require additional financial resources, although some could be implemented at no cost. Recommendations 24 and 25 address funding.

Finally, the Subcommittee concluded that it is incumbent upon state officials from all divisions and departments providing services to incarcerated or former inmates to work together to significantly improve HIV disease prevention and treatment for this population. It is not only possible, but urgent, given long-standing deficiencies and high HIV infection rates, that New York State design and administer uniform quality health services in correctional settings. Although the Subcommittee recognizes that security is the paramount concern in prisons, both security and health are enhanced by the administration of a quality health care system.

It is the hope of the Council that this report will be carefully and promptly considered. The Subcommittee’s final recommendation (26) calls for a mechanism to review the implementation of its recommendations, remove barriers to change, and ensure corrective action. A review should occur within one year of public dissemination of this report.
INTRODUCTION

Mandate for appropriate medical care
Incarceration necessarily involves the surrender of basic freedoms. The paramount concern of prisons, equally self-evident, is the maintenance of security and order. While these axioms are the legitimate foundation for policy and organizational structure in correctional facilities, they cannot justify lack of appropriate medical care.

Since, by law, denial of health care cannot be made a condition of punishment, and since inmates are not free to secure their own health services, states must assume complete responsibility for health and medical services for inmates. It is, therefore, incumbent upon state agencies to provide care that meets current medical standards and to monitor this care through an effective quality assurance program. Correctional health services must be open to public scrutiny and accountable to public regulation.

The advent of the HIV/AIDS epidemic has increased the stringency of these requirements. Reducing rates of HIV infection in all populations is a critical public health goal. The cost and complexity of HIV treatment makes coordination and quality of care essential. There is strong medical and public interest in ensuring that released inmates know their HIV status and continue treatment regimens. These considerations demand that HIV education, prevention, and appropriate HIV/AIDS treatment in prisons be among the state’s highest public health priorities. Unfortunately, in New York, as in most states, that has not generally been the case.

The provision of health services in prisons is, in truth, a difficult task. Corrections systems are administratively unwieldy and traditionally outside the purview of health agencies. Intractable health problems resulting from substance abuse, mental illness, poor nutrition, and other factors are concentrated in inmate populations. However, with rapid advances in HIV treatment and ever increasing numbers of incarcerated people, there is new urgency to the need for improvements in prison health services in general and HIV/AIDS care in particular.

AIDS Advisory Council Criminal Justice Subcommittee
In New York, letters from activists and legislators, interagency agreements, and critical reports concerning inadequate health services for inmates have thus far had limited impact. In 1996, in view of high rates of HIV infection among inmates and reports of inadequate inmate access to HIV prevention and treatment services, the New York State AIDS Advisory Council determined that renewed and intensified commitment to this issue was required. The Council had previously addressed this issue extensively in a 1989 report titled “Management of HIV Infection in New York State Prisons.”
In late 1996 the Council constituted a new Criminal Justice Subcommittee in part to examine the state’s record in implementing the recommendations of the 1989 report and in part because of the advent of new combination therapies and their potential for increased quality and length of life for people with HIV. The Subcommittee was to review inmate HIV services in New York State prison facilities and publish its own report with specific recommendations addressing each area of concern.

The Criminal Justice Subcommittee to date has consisted of 13 members, including physicians, lawyers, service providers, former inmates, activists, and AIDS Advisory Council members. (They are listed at the end of this report.) The group met nearly monthly from October 1996 through November 1997 and periodically thereafter, together with AIDS Institute staff members, observers, and invited guests. The Subcommittee was chaired initially by Lambert King, M.D., Medical Director and Senior Vice President for Medical and Academic Affairs at St. Vincent’s Hospital and Medical Center in New York City, and, following his resignation, from April 30, 1997 to the present has been chaired by Victoria Sharp, M.D., Director, AIDS Center Program, St. Luke’s-Roosevelt Hospital Center in New York City.

**Methods**

The Subcommittee pursued a number of routes for gathering information:

a) The Subcommittee wrote letters requesting specific information from the Department of Correctional Services in New York and from HIV service providers and organizations who work with inmates. Inmates were also encouraged to contribute statements.

b) The Subcommittee requested information from New York State Department of Health divisions, including the Bureau of HIV/AIDS Epidemiology and the AIDS Institute’s Criminal Justice Initiative and Quality of Care Program.

c) A survey of Department of Health HIV Directors regarding HIV care in prisons in selected states was conducted by the AIDS Institute through NASTAD (the National Association of State and Territorial AIDS Directors). In addition, the Subcommittee conducted its own survey of State Corrections Medical Directors, soliciting responses from all fifty states.

d) A number of speakers, including officials from the New York State and City Corrections and Health Departments, were invited to make presentations to the Subcommittee and participate in its work on an ongoing basis.

e) Subcommittee and staff members made site visits to Sing Sing Correctional Facility for men and Taconic Correctional Facility for women, the Albany Medical Center HIV Care Unit for inmates, and Coxsackie Regional Medical Unit.
f) Focus groups on prison service issues were conducted as part of a Criminal Justice Providers Conference in Albany, NY.

g) The Subcommittee reviewed in detail a number of state documents concerning HIV services in prisons, including the AIDS Advisory Council’s 1989 report, a 1988 Commission of Corrections report, 1988 and 1990 Department of Health audits of prison health services, and a 1993 Memorandum of Understanding between the State Departments of Health and Correctional Services. The work of the AIDS Advisory Council’s Ethical Issues in Access to Treatment Workgroup, which convened from June to September 1997, was reported regularly to the Subcommittee.

h) The Subcommittee examined proposed and existing legislation pertaining to prisons, including the mandate of the Commission on Correction, health law and regulations pertaining to various types of facilities and services, and proposed legislation, including New York State Senate bills S3906, which would transfer responsibility for health care in prisons from DOCS to DOH, and S3429, which would require inmate co-payments of $7 per health service.

i) A literature and on-line review was undertaken. Data, letters, articles, statistics, reports, and other written and electronic documents were also submitted by Subcommittee members.

j) Members of the Subcommittee related their own experience examining this issue, caring for inmates, and visiting DOCS facilities.

Results of all information gathering processes were shared with Subcommittee members. Meetings were recorded, and minutes were written and reviewed. Drafts of the principles and recommendations, as well as the body of this report, were circulated and discussed extensively.

The Principles and Recommendations of the Subcommittee were submitted to the full Council in December of 1997 and approved unanimously at the Council’s January 1998 meeting. This report details the information and discussions from which the recommendations were formulated. Supporting data have been updated through December 1998.

The Subcommittee has attempted to inventory the entire range of HIV services appropriate to inmates — from education, counseling, and testing through support groups, treatment, medical parole, and transitional planning — to assess what services are available and where there are gaps or barriers that should be addressed. It was not within the scope of this review to undertake a sophisticated analysis of program effectiveness, although it was the Subcommittee’s intent whenever possible to highlight programs that appear to be functioning well and could serve as models and to point out clear deficiencies. The Subcommittee did not undertake to survey mental health or drug treatment services, although it recognizes the close association of these issues with HIV/AIDS care. It is hoped that information in this report will prompt more extensive analysis of ways in which exemplary inmate health
services can be delivered.

HIV/AIDS SERVICES IN NEW YORK STATE PRISONS

I. ADMINISTRATION OF HIV AND HEALTH CARE SERVICES

SUBCOMMITTEE CONCERNS:
Uneven, uncoordinated services
Lack of a single standard of care
Lack of oversight
Inadequate health care staff and training

In New York State, the correctional system includes the New York State Department of Correctional Services, the New York State Division for Youth, the New York City Department of Corrections, and county jails. The New York State Department of Correctional Services (DOCS) has responsibility for all health care services for state inmates, including those for people with HIV and AIDS. HIV services in New York City facilities and in other county and youth detention facilities are not within the purview of this report.

New York has one of the largest prison systems in the nation. As of November 16, 1998, there were more than 105,000 people incarcerated in New York’s state, city, and county corrections facilities, of whom 70,341 were under the jurisdiction of the New York State Department of Correctional Services (DOCS).^2^ Inmates in state prisons are housed in 73 correctional facilities, counting medical, drug treatment, and shock centers (See Appendix A). They range from minimum to maximum security and are arranged in 9 clusters, or regional hubs, each administered by a Senior Superintendent.

As of January 1, 1998, 95% of state inmates were male. More than 50% were black, 33% Hispanic, and 16% white. The average age was 33. About 68% of state inmates were from New York City; 13% were foreign-born; almost 10% spoke Spanish as their primary language; more than 25% were designated as alcoholic; and 59% reported past drug use. About 52% were incarcerated for a violent felony and 53% for a second felony. Nearly 65% reported never having been married, but 59% had children. Under 43% had a high school diploma.^1^ Minimum sentences for the January 1, 1998 inmate population are as follows: 12.6% to serve less than two years; 53%, two to six years; and 34.2%, six years or more. The median minimum sentence is 48 months.^4^
New York has more inmates with HIV than any other state. Although estimates have ranged up to 9,500, a commonly cited conservative figure is about 8,000. (Information on the number of inmates with HIV or AIDS by facility was not provided to the Subcommittee). As of June 30, 1998, there were a total of 6,417 New York State inmates diagnosed with AIDS while incarcerated since the 1981 start of data collection, of whom 3,611 (3,223 males and 388 females) were presumed alive (but may or may not still be incarcerated).

HIV services in New York State prisons are provided by personnel employed by DOCS, by the New York State Department of Health AIDS Institute (AI), or by outside organizations under contract to DOCS or AI. In addition, other state agencies provide limited services to inmates, including those with HIV. The Office of Mental Health provides all mental health services for inmates with AIDS, including short term residential psychiatric units. Drug treatment services are provided by the Office of Alcohol and Substance Abuse Services.

Health services in DOCS facilities are directed by the Chief Medical Officer, who reports to the Commissioner of Correctional Services. Five Regional Medical Directors and five Regional Health Service Administrators nominally oversee inmate health services, although health care is primarily directed at the facility level. There are medical directors at each facility, but some are employed only part time. While facilities provide widely varying levels of health care, almost all have some medical personnel who are responsible for primary care and are expected to provide basic HIV care. Approximately 1,000 DOCS staff members provide health services statewide. All inmates receive a medical examination at intake, and most are treated for routine health problems in on site medical clinics and infirmaries. Nutritional services are not provided by DOCS health services, but by a separate DOCS division. Medications are provided through a DOCS formulary and, in about 20% of prisons, through outside contractors.

With the 11-bed Special Needs Unit (SNU) established at Sing Sing Correctional Facility in 1983, New York became the first state in the country to establish a prison nursing care unit for AIDS care. The Unit was intended to provide care closer to inmates' families (most inmates with HIV are from New York City). However, this unit has recently been closed. Inmates with HIV have been moved into infirmaries or reintegrated into the general inmate population.

New York was also the first to institute an AIDS treatment program in an outside hospital. Since the need for inpatient AIDS care for inmates could not be met by the eight medical centers providing inmate hospital services, DOCS contracted in 1987 for a 25-bed secured unit at St. Clare’s Hospital in Manhattan to provide inmate AIDS care. St. Clare’s also provided some outpatient care to inmates. The inpatient unit was closed in mid-1998, and most outpatient care has been discontinued. New York was also the first to offer bilingual HIV education to inmates and staff.

Coordinated specialty care contracts
Currently, all acute and specialty care is provided by outside contractors under the “coordinated
specialty care contracts.” Access to acute hospital care is determined by prison personnel. Since there are often no subspecialists near prisons, DOCS has divided the State into four contractual regions for acute hospital and specialty care, including HIV.

Under the contract terms, prison physicians request an outside specialty consultation for an inmate through the contractor. The contractor determines whether and how the request will be filled, finds the specialist, and arranges care.\textsuperscript{12} Specialty clinics are also held regularly according to schedules that vary by region and specialty. At Coxsackie Regional Medical Unit, for example, at the end of 1997, there were fifteen outpatient clinics, including one for HIV held six days per month serving 22 DOCS facilities. Clinics are staffed by physicians from a nearby acute care facility, Albany Medical Center.\textsuperscript{13}

DOCS has experienced substantial difficulties maintaining consistent contractor services. The first contractor, United Correctional Managed Care, began with responsibility for the central region of the State in September 1994 and added the eastern (Albany) region in February 1996. Correctional Physician Services (CPS) started in the western region in September 1997 and added the southern region in June 1998. Administrative and quality of care difficulties resulted in the termination of the United contract for the central region in March 1998. DOCS is now handling services in that area until Wexford, the new contractor, can begin. Correctional Medical Services (CMS) took over United’s contract for the eastern region in April 1998.

There is now some evidence of difficulties in both the western and southern regions, particularly concerning access to specialty care.\textsuperscript{14} CPS declined to renew its contract for the western region after one year. DOCS is now also handling that region until the contract can be rebid. Performance problems in the southern region forced the recent firing of all staff and relocation of the contract administration to Buffalo.\textsuperscript{15} (See also the treatment and quality assurance sections of this report.)

\textbf{Regional Medical Units}

DOCS has built and opened three Regional Medical Units (RMUs), with another under construction and a fifth planned. Designed for long term care, RMUs are now defined as subacute care facilities with provision for hospice and chronic care. The RMU at Walsh Correctional Facility has been operating since March 1991. The Coxsackie RMU was opened in February 1996. An RMU at Wende opened in August 1998. One for women will be opened at Bedford Hills, and, in two to three years, the fifth at Fishkill will be operational. The contract with CMS includes the operation of the Coxsackie RMU, for which DOCS pays on a per bed basis whether the bed is occupied or not. The Walsh and Wende RMUs are staffed by DOCS. Inmates are admitted to an RMU from a hospital or a prison. Admission is determined with input from the RMU staff, the referring facility, and DOCS Senior Utilization Review staff.\textsuperscript{16}

\textbf{Telemedicine}

Telemedicine (interactive television consultation) was initiated in 1997. DOCS has installed units in several prisons to be used for emergency triage and to expand access to specialty care. Inmates in
prisons are accompanied by a physician or registered nurse (no guard is present in the room) and interviewed by physicians in another location via the televised system.

At Albany Medical Center, the equipment has also been used for staff training, and reports of other use by DOCS indicate that the method has been well received by inmates. The intent is to expedite hospital admissions and avoid unnecessary hospitalization. The plan is to link the entire northern part of the State to provide interactive education and improved clinical care. Teleconferenced clinics, including those for HIV, could avoid inmate inconvenience and prison expenses for transportation. Telemedicine can be used for pre-anesthesia reviews and testing prior to surgery to avoid extra trips to the hospital. A pilot program in teleradiology is underway, whereby x-rays can be read immediately at distant sites to provide rapid feedback. Individual doctors must be trained to use the system, and patient selection is important.17

However, reports of actual utilization indicate significant start up problems. Telemedicine clinics for pre-emergency room triage, pre-anesthesia, infectious diseases, and dermatology have been initiated, but use of pre-ER triage was low compared to the number of ER visits for the first half of 1998. The one infectious disease physician providing telemedicine consultation ended this service in mid-1998, and there has been no replacement. A high rate of missed infectious disease appointments includes those for telemedicine consults.18

**AIDS Institute Initiatives**

In January 1990, a collaborative agreement between the New York State Departments of Health and Correctional Services resulted in the institution of the Criminal Justice Initiative (CJI) at the Department of Health’s AIDS Institute. The program does not provide medical services. It was initially funded to provide HIV training for staff, voluntary and anonymous counseling and testing for inmates, development of staff and peer counselors as in-house HIV resources for inmates, and links for discharged inmates to community-based organizations. Three AIDS Institute (AI) staff teams of several counselors each were organized to serve the following sites: the Ulster Reception Center (one of three DOCS intake centers), western region facilities (on a rotating basis), and Sing Sing (the latter team assembled in 1996).

Contracts with community organizations were added to provide confidential counseling and testing, peer education, and support services. HIV education, support services, case management for parolees, HIV education for women, a train-the-trainer component, and a hotline were initiated at different times from 1991 to 1995.19 (See Timeline in Appendix B.) AIDS Institute staff now directly provide only anonymous counseling and testing at 15 facilities under a Memorandum of Understanding initiated with DOCS in 1989.20 All other services are provided by community organizations under contract to the Institute.

AIDS Institute review of the Criminal Justice Initiative in 1996 resulted in a number of structural and strategic changes. A revised service model designed a continuum of HIV care from intake through
release, using contracted community providers. In the current CJI plan, the State is divided into five regions, and services fall into the following categories: HIV prevention education; training of inmate peer educators; anonymous counseling and testing; support services for inmates with HIV and those at risk; transitional planning; and case management, education, and support services for parolees. Curricula have been developed and training sessions have been provided to all contractors. A document detailing contractual standards has been distributed. The intent is that each CJI contractor will provide many types of service, so that each facility will have a single contractor that maintains a regular presence.

There are a number of funding sources and programs currently providing services to New York state inmates, including the Women’s Prison Initiative, the Peer Initiative, the Ryan White Title II and Centers for Disease Control and Prevention service contracts, and the HIV Continuum Initiative. Twelve community organizations are currently under contract for prison services. (See provider list in Appendix B.)

Interagency collaboration
While DOCS and DOH have established a certain degree of cooperation for the administration of education, HIV testing, support services, and transitional planning, subsequent sections of this report will detail the degree to which this relationship falls short of the close liaison necessary to provide acceptable health services for inmates. AIDS Institute staff and contractor services are not available in all facilities and do not reach adequate numbers of inmates in facilities where programs exist. Health services provided by DOCS are highly variable by facility, are uncoordinated, and are not regularly monitored by the Department of Health or any other agency. Deficiencies in staffing, training, and quality assurance have been recognized by a number of external reviews over the past decade. Outside of very recent discussions of inmate health services by the Governor’s Interagency Task Force on HIV/AIDS, which was established in 1998, there is no regular interagency collaboration and no mechanism for insuring that health services are consistent throughout the prison system and meet current standards of medical care. (See the treatment and quality assurance sections of this report.)

It is the Subcommittee’s central argument that the Department of Health is responsible for ensuring a single standard of health care in all settings and that the state has a special obligation to see that inmates are receiving care in accordance with that standard, since inmates cannot choose their health care providers, have no sources of information other than those provided by the state, and have no recourse to medical decisions made by others. DOH has twice audited health care services provided by DOCS, but the resulting modest momentum for improvement has not been sustained or expanded.

The Subcommittee has thus enumerated nine principles of HIV care in correctional facilities that it hopes will serve as a guide to instituting consistent, appropriate health services in all prisons. These principles include universal HIV education, encouragement of voluntary HIV testing, confidentiality of medical information, access to current medical therapies, continuity of care and maintenance of treatment regimens, and effective health care administration and review.
These principles cannot become the basis for improved services unless the Departments of Health and Correctional Services establish an intensely collaborative working partnership. At issue is the need to integrate correctional services’ legitimate concern for control and security and the Department of Health’s legitimate emphasis on appropriate health care. DOH staff does not have the expertise necessary to maintain security in prison health settings, just as DOCS staff does not have the expertise in specialized HIV services necessary to maintain rapidly changing standards of medical care. It is thus essential that these agencies work together to administer health services.

Since DOCS has had great difficulty assuring access to these services, the Subcommittee proposes that the Department of Health assume overall responsibility for health services in correctional facilities as a logical extension of its current mandate. Since this will require legislative action, DOH should, until that is accomplished, assume an oversight role in ensuring appropriate health care in prisons. Both of these roles will require the good faith and strong commitment of the two agencies to agree on division of responsibilities, a specific system-wide plan for change, and a time frame for implementing it.

See Principles of HIV Care in Correctional Facilities at the conclusion of this report; the recommendation number 1 on DOH roles, numbers 2, 3, and 4 on staffing and training; number 10 on standards; number 20 on data collection and analysis; number 21 on quality of care and accountability; and number 24 on funding.
II. HIV EDUCATION AND PREVENTION

SUBCOMMITTEE CONCERNS:
Lack of universal HIV education
Contractor difficulties gaining access to facilities
Insufficient use of peer educators
Lack of condoms and other prevention methods

HIV education encompasses information about HIV transmission, prevention, and treatment options and is critical for all inmates, whether infected or not. It is important for every inmate to know how to prevent infection in prison and upon release and to understand that new treatment methods may significantly improve quality of life for people with HIV but are not a cure. (Training of medical and security personnel is addressed in the treatment section of this report.)

HIV education is offered to all inmates at intake by DOCS medical personnel, and it is provided thereafter by AIDS Institute counselors and contractors in about 40 facilities in New York State and in 25 facilities by inmate peer educators as well.23 (See Appendix B.) DOCS is considering the use of treatment education videotapes for inmates, funded by pharmaceutical companies.24 An HIV self-care manual was prepared in the summer of 1997 by DOCS staff, but it has not yet been distributed.25

HIV education is voluntary, although providers have urged that it be made mandatory in order to avoid confidentiality concerns for those who wish to receive information. In prison, even interest in HIV information can cause suspicion and attract attention.

HIV education specialists emphasize that repeated exposure to prevention information is often necessary to begin to effect behavior change and that trust in the provider increases attention and responsiveness. For these reasons, different sources of HIV information and regular access to educational materials and providers are recommended. Educational strategies must also take into account the limited reading ability of some inmates and should, therefore, include oral, video, and other types of presentations.

Providers and inmates have also requested that curricula be translated into Spanish and other languages.26 This is fundamental, but it is important to recognize that simple translation is often insufficient. Awareness of cultural differences among Spanish speaking groups, for example, is essential if materials are to be effective.

Information on the number of inmates receiving HIV education by DOCS personnel was not made available to the Subcommittee. In the first six months of 1998, 22,006 New York State inmates received HIV/AIDS prevention education through AIDS Institute community providers.27 (See Appendix B.) These are not unduplicated figures and thus may include more than one educational
The following figures are for HIV education programs provided by CJI (AI) contracted providers:

<table>
<thead>
<tr>
<th>Hubs</th>
<th># Facilities Served by CJI Contractors</th>
<th># Inmates Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Oneida</td>
<td>6</td>
<td>2,717</td>
</tr>
<tr>
<td>2 Watertown</td>
<td>5</td>
<td>644</td>
</tr>
<tr>
<td>3 Clinton</td>
<td>8</td>
<td>84 (5 facilities with no education services)</td>
</tr>
<tr>
<td>4 Sullivan</td>
<td>7</td>
<td>2,050</td>
</tr>
<tr>
<td>5 Green Haven</td>
<td>6</td>
<td>12,067 (4 facilities with no education services)</td>
</tr>
<tr>
<td>6 Great Meadow</td>
<td>7</td>
<td>2,179 (1 facility with no education services)</td>
</tr>
<tr>
<td>7 Wende</td>
<td>9</td>
<td>602 (4 facilities with no education services)</td>
</tr>
<tr>
<td>8 Elmira</td>
<td>5</td>
<td>1,413 (3 facilities with no education services)</td>
</tr>
<tr>
<td>9 New York City</td>
<td>6</td>
<td>250 (4 facilities with no education services)</td>
</tr>
<tr>
<td>Total</td>
<td>59</td>
<td>22,006 (21 facilities with no education services)</td>
</tr>
</tbody>
</table>

It is evident that HIV education services are absent or inadequate at many prisons. Twenty-one DOCS facilities served by CJI contractors had no CJI education programs in the first half of 1998, and 14 other facilities (73 total - 59 above) are not served by any CJI contractor for any service. Thus, nearly half of state prisons have no CJI education programs. Besides wide variation in availability of education services among hubs, the number receiving education services per facility ranges from 8 to 10 at Franklin, Sullivan Annex, and Bare Hill to 3,897 at Bedford Hills and 8,170 at Taconic (both women’s facilities). The highest numbers served at men’s facilities are 1,427 at Ulster and 1,181 at Willard.28 (See Appendix B.)

Regarding these inconsistencies and lack of services in many facilities, CJI staff noted that it was difficult for contractors to gain entry to some prisons and difficult to reach inmates in prisons because of scheduling or other administrative obstacles. This constitutes a major barrier to service in that each contractor essentially must negotiate access, work space, and the terms under which programs will operate with the administrators of each facility. Several contractors enumerated some of the details of this problem to the Subcommittee:

- Persistence and diplomacy are required to establish and maintain workable relationships with prison officials, who often only reluctantly grant access to contractors. In one case, the facility administrator was supportive, but the facility medical director and nurse administrator were not.

- Depending on who is in charge, prison officials may delay assigning a liaison (a DOCS employee responsible for arranging space and time for the contractor’s program and escorting contractor staff inside the facility), may limit time and space available for the program, may impede access to medical records, may be cautious about allowing inmates to lead
presentations, and may discourage the gathering of large groups of inmates (which are preferable to maintain confidentiality). Officials do not censor program content.
• There is greater resistance to contractor access in maximum security facilities.

• In some cases, prison officials may see the need for HIV education but wish to conduct it themselves. Contractors note that HIV education administered by DOCS is not effective, since instructors may not be specifically trained to provide it and may not use standard curricula. Further, DOCS instructors represent the corrections system and, therefore, lack credibility to inmates as health care educators.
• The status of contractor staff is unclear. Some officials consider them volunteers subject to standard restrictions, while others have a broader definition of their role.
• Finally, prison environments and the needs of each group of inmates vary enormously. Contractors need the flexibility to respond appropriately in each facility.29

Peer education also shows wide variation in availability and in number and size of sessions. CJI staff note that peer educator training generally requires 16 sessions, plus two follow-ups. In the first half of 1998, 564 peer training sessions were conducted by CJI contractors in 25 facilities, but only ten prisons had sufficient sessions to allow completion of the 18 session course.30

Contractors are responsible for monitoring how peer educators actually function, but have no authority to determine how peer educators are used in the prisons. Some prison administrators do not support peer education, and this can compromise both the implementation and the effectiveness of programs.31 A contractor reports that the DOCS liaison in each facility selects inmates to be trained by contractors as peer educators, based on criteria submitted by the contractor (no security violations, diverse ethnicity, unlikely to be discharged soon). Although inmates trained as peer educators are expected to accept the role for one year, a frequent problem is the untimely transfer of peer educators to other facilities. It is difficult to train and update a consistent group of inmate educators. There is a need for Spanish speaking peer educators.32

It is the Subcommittee’s view that every inmate is at risk for HIV and should be required to participate at intake and annually thereafter in an HIV education program conducted by a trained instructor. Every inmate should have access to regular sources for HIV information and should be encouraged by all health providers to be tested for HIV. The CJI program should be expanded so that full HIV services, including education, are available in every facility. While the actual role of peer educators may vary, the Subcommittee supports the view that in general peer education appears to be highly effective and should be widely used.33

An important additional barrier to HIV prevention in prisons is the fact that prison officials do not acknowledge high risk behavior by inmates. Maintaining that inmates do not engage in sex or drug use, prison officials do not, therefore, condone the provision of condoms or harm reduction materials to
prevent HIV transmission through needle sharing. The Subcommittee believes that HIV prevention education should include instruction on the use of condoms and harm reduction materials, and that condoms should be available to inmates on request from medical providers.

Inmates who are HIV positive should have prompt and clear explanations of current treatment options. The Subcommittee concurs with the AIDS Advisory Council’s Ethical Issues in Access to HIV Treatment Workgroup, which stressed the importance of obtaining treatment information from a trusted provider who involves the patient in treatment decisions. A commitment to begin complicated treatment regimens must be done with full knowledge of nutritional and dosage requirements and the potential clinical danger of interrupting or stopping medications. (See the discussion of HIV specialty care in this report’s section on HIV treatment services.)

See Recommendations number 5, 6, and 7 on prevention and treatment education.
III. HIV COUNSELING, TESTING, AND SEROPREVALENCE

SUBCOMMITTEE CONCERNS:
Large discrepancy between seroprevalence rates in voluntary and blinded tests
Lack of confidentiality and other barriers to counseling and testing

All HIV testing in New York facilities is on a voluntary basis. The State has never instituted mandatory testing for inmates, a policy which the Subcommittee strongly supports.

Testing for HIV is initiated at the request of an inmate or can be offered by DOCS medical staff, AIDS Institute staff, or AIDS Institute contractor personnel. Peer educators also encourage inmates to learn their HIV status. DOCS staff and AIDS Institute contractor staff provide voluntary, confidential HIV testing in which pre- and post test counseling is to be conducted consistent with the New York State HIV Confidentiality Law, Article 27-F, and test results are to be known only by the inmate and his/her medical providers.

AIDS Institute staff provide anonymous HIV testing (results are not revealed to DOCS, although Institute staff can link tests to inmates for counseling follow-up). Inmates using the anonymous testing service have the option of converting to confidential status and are encouraged to do so to enable treatment for those testing positive. From January to June 1998, 68% of inmates testing positive in anonymous prison testing settings converted to confidential status. Although AIDS Institute staff provided follow-up counseling to those who did not convert in attempts to encourage them to seek treatment, many inmates continue to refuse because they fear that DOCS’ knowledge of their HIV status will impede an imminent transfer or release, they do not want DOCS to know their HIV status for other reasons, or they fear information about their status will become known to other inmates.35

Within the population of approximately 70,000 inmates in 73 DOCS facilities, from January 1, 1998 to June 30, 1998, 2,658 inmates in 15 facilities were tested anonymously by AIDS Institute staff, and 1,199 in 18 facilities were tested by AIDS Institute contractors. (Testing was conducted in a total of 25 facilities by AI staff and/or AI contractors.) In addition, 8,781 inmates were tested by DOCS staff, bringing the total to 12,638 inmates tested in this six month period.36 This total may include some inmates tested more than once. (See Appendix B.) No information was provided to the Subcommittee on the number of inmates tested by DOCS by facility.

Counseling and testing is now offered by AIDS Institute staff at only one intake facility (Ulster) since inmates have indicated that they prefer not to be tested at intake when there are so many other adjustments to make. AIDS Institute staff have also found that reporting results is difficult since inmates only stay in intake facilities from three to five days.37 In contrast, some states have voluntary testing rates of 68 to 80% at intake. (See chart of state responses to the Subcommittee’s survey, Appendix
Although recent testing rates exceed those of past years (DOCS reports that in the entire year of 1996 only 17,500 testing and/or counseling “encounters” occurred\(^{38}\)), and although many long term inmates may know their status, counselors agree that insufficient numbers of inmates at risk for HIV elect testing. This is confirmed by the large discrepancy between seroprevalence rates in inmates electing voluntary or anonymous testing and those in inmates tested through blinded testing studies. (See below.)

### Voluntary (Confidential) and Anonymous Testing Programs:

<table>
<thead>
<tr>
<th>Program</th>
<th>Period</th>
<th>Population</th>
<th>HIV Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOCS-DOH(^{39})</td>
<td>1996</td>
<td>3,416 males</td>
<td>2.1%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1,016 females</td>
<td>5.6%</td>
</tr>
<tr>
<td>AIDS Institute anonymous(^{40})</td>
<td>1997</td>
<td>3,098 inmates</td>
<td>2.16%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1,016 females</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Range: Albany- 2144</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Southern- 67)</td>
<td></td>
</tr>
<tr>
<td>AIDS Institute anonymous(^{41})</td>
<td>July 97-June 98</td>
<td>5,099 inmates</td>
<td>1.6%</td>
</tr>
<tr>
<td>AI staff and contractors(^{42})</td>
<td>Jan. 98 - June 98</td>
<td>3,857 inmates</td>
<td>1.6%</td>
</tr>
<tr>
<td>DOCS staff(^{43})</td>
<td>Jan. 98 - June 98</td>
<td>8,781 inmates</td>
<td>3%</td>
</tr>
</tbody>
</table>

Since 1987, the Department of Health has periodically conducted blinded HIV tests on incoming inmates at one state facility for male inmates, and since 1988 at one facility for female inmates. (The rates in incoming inmates may not reflect those in the inmate population as a whole.)

### Blinded HIV Seroprevalence Studies:

<table>
<thead>
<tr>
<th>Study</th>
<th>Period</th>
<th>Population</th>
<th>HIV Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>male facility(^{44})</td>
<td>1987</td>
<td>incoming males</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>1997</td>
<td></td>
<td>9%</td>
</tr>
<tr>
<td></td>
<td>1987-1997</td>
<td></td>
<td>average 11%</td>
</tr>
<tr>
<td>female facility(^{45})</td>
<td>1988</td>
<td>incoming females</td>
<td>19%</td>
</tr>
<tr>
<td></td>
<td>1997</td>
<td></td>
<td>18%</td>
</tr>
<tr>
<td></td>
<td>1988-1997</td>
<td></td>
<td>average 18%</td>
</tr>
</tbody>
</table>
Rates are highest for residents of New York City, people of color, injecting drug users, and those who currently have or had syphilis. The decreasing seroprevalence for men and constant rates for women are consistent with trends in the non-incarcerated population. However, it is hypothesized that decreasing rates for men reflect the decline in high risk injection drug behavior, including needle sharing, reported by inmates in blinded studies (from 28% admitting to injection drug use and 11% to needle sharing in 1987 to 11% and 5%, respectively, in 1996). While women also report decreased injection drug use (28% in 1988 and 12% in 1996), a sharp increase in high risk sex among women (9% exchanged sex for drugs or money in 1988, compared to 29% in 1997), together with an aging female inmate population, may explain the lack of decrease in female inmate HIV rates.

The large difference between HIV rates in blinded studies and those in voluntary testing programs by the AIDS Institute and DOCS was of serious concern to the Subcommittee. This issue was also part of the focus of a 1994 AIDS Institute study, in which no demographic differences were found between the two tested groups. Refusal to test voluntarily for HIV was not due to knowledge of HIV status, but rather to an inmate’s fear of learning his status, belief that he was negative, or desire to avoid the issue. A later study found that those declining the test had higher HIV rates than those electing voluntary testing.

This is consonant with information from HIV counselors working in the prisons. One program noted that it wasn’t until the third year of the voluntary testing program that any inmates tested positive. Counselors speculated that many of those testing were not at high risk. Acknowledging this issue, the AIDS Institute is continuing discussion with DOCS staff on strategies to increase voluntary testing rates and intends to explore mechanisms to address this through the Criminal Justice Initiative.

Lack of confidentiality surrounding an HIV diagnosis in prisons undoubtedly prevents many inmates from seeking testing. A contractor noted that inmates do not trust the confidentiality of drop boxes that contain requests for HIV testing. There have been reports of groups of inmates brought together for viral load testing, call-outs specifically for HIV treatment, discussions of inmates’ HIV status by medical staff in front of other inmates, and security personnel who reveal information about inmates’ HIV status.

No data have been collected on seroconversions within prisons, despite the fact that inmates regularly report that substantial numbers of inmates engage in HIV risk behavior. It is also not known whether there has been any decline in seroprevalence rates at facilities where prevention education, counseling, and testing programs are in effect and what sort of outreach would be most effective in overcoming the reluctance of inmates to be tested. However, the Subcommittee strongly supports regular access to both anonymous and voluntary HIV testing programs.

To encourage testing, the Subcommittee believes that more extensive HIV education and testing programs are needed. Expansion of AI staff and contractor education and testing programs to all prisons and much greater use of peer educators may persuade more reluctant inmates to learn their
HIV status and enter treatment if positive.

While encouraging all inmates to learn their HIV status, prisons should make every effort to protect inmate confidentiality by training staff and interpreters in confidentiality principles, avoiding HIV-specific call-outs or locations for information and treatment, distributing medications in ways that do not reveal HIV status, and guarding against other types of confidentiality breaches.

See Recommendation number 8 on confidentiality and number 9 on counseling and testing.
IV. HIV TREATMENT SERVICES

SUBCOMMITTEE CONCERNS:
Inadequate identification of HIV-positive inmates
Inadequate HIV training of primary care providers
Uneven inmate access to HIV therapies
Insufficient access to HIV specialty care
Inadequate treatment education and attention to continuity of care
Lack of coordination of primary and specialty care

Most general health and HIV care is provided on site in prisons by DOCS medical staff. Inmates with acute problems beyond the capacity of prison sick call, clinics, and infirmaries are transferred to local hospitals or to DOCS Regional Medical Units.

Dr. Lester Wright, Associate Commissioner and Chief Medical Officer for DOCS, Division of Health Services, reports that the correctional system is aware of one third to one half of the estimated total of 8,000 inmates with HIV. Many inmates do not know their HIV status, and many who are positive but not symptomatic may protect their confidentiality by not revealing their status to DOCS and not seeking treatment. Although no documents were submitted to the Subcommittee detailing the number of known HIV-positive inmates by facility, there are indications of large and unexplained variation among facilities with the same types of medical services. Nevertheless, the known need for HIV care is substantial. One facility reports that HIV-related visits account for about 50% of daily call-outs.

In November 1997, 2,525 DOCS inmates were receiving antiretroviral therapy for HIV/AIDS, 60% taking three or more medications. While the availability of these treatments is commendable, there are substantial differences in access to medications by facility. In September of 1997, based on a sample of about 70% of prisons, inmates with HIV using three or more drugs ranged from 33.6% at Gowanda, Collins, and Lakeview, 40% at Orleans, and 56.5% at Bedford Hills (women), to 76% at Taconic (women), and 76.3% at Riverview and Ogdensburg.

Budgetary projections are also illuminating. The DOCS fiscal year 1998-99 budget request estimated that half of 8,000 inmates with HIV would be receiving antiretroviral therapy, and 90% of these would take at least three drugs. Nearly $53 million was budgeted for all inmate medications, including about $37 million for HIV drugs. However, as of June 1998, the total projection for medications was reduced by $11 million (most for HIV medications) because of lower than expected utilization. (See also the section of this report on funding.)

Standards of care
Quality health care begins with treatment protocols for consistent care that meets current medical
While DOCS has provided care for inmates with HIV since the first cases were identified, there have never been system-wide guidelines for comprehensive HIV/AIDS care. However, since 1995 DOCS has issued annually updated HIV Primary Care Practice Guidelines for the administration of antiretroviral therapy. In at least one instance when they differed from federal HIV guidelines (on criteria for initiation of treatment), DOCS worked with the AIDS Institute to make medically appropriate revisions.

The Subcommittee believes that the standard of HIV care for inmates should be the same as that for non-incarcerated people with HIV. That involves a full range of HIV services that allow inmates to learn their status, prevent HIV infection to themselves and others, and receive prompt, medically appropriate treatment. This applies to inmates housed in general population, as well as in protective custody, isolation, or other special units. Inferior medical care is not a condition of punishment.

Therefore, the Subcommittee strongly recommends that the Department of Health take measures to ensure that statewide standards of health and HIV care are maintained in prison settings. The AIDS Institute issues regularly updated practice guidelines for HIV care that should serve as the basis for prison HIV services. AIDS Institute standards of care should also be established in prisons for all special populations, including women, pregnant women, adolescents, substance users, and the mentally ill. Special care should be exercised not to compromise the immigration status of foreign-born inmates. DOCS has recently begun review of AI protocols for HIV care.

**Staffing and training**

Under present circumstances, it will be difficult for DOH and DOCS to assure HIV care consistent with statewide standards, since DOCS has suffered from a lack of adequate medical staffing for the past decade. For fiscal year 1990-91, DOCS requested a health care staffing increase of more than 30%. In 1993, DOCS recommended that, “The existing ratios of professional and support staff should be enhanced,” and noted the need to increase professional salaries, citing especially “Glaring examples of large competitive differences...for physician assistants, pharmacists,...physical therapists,...and [nurses].” In fiscal year 1994-95, the requested staff increase for nurses alone was more than 40%. These requests for major increases in health care staff, each following a DOH audit (see the quality assurance section of this report), were not reflected in the Governor’s budgets and failed to result in financial or personnel changes. No effort was made to reassess or redeploy health staff at prisons when these proposals were not implemented.

Since 1993 there has been little change in prison staffing, except at Regional Medical Units. Long term medical staff vacancies intensify the problem. Physician and nursing positions may be unfulfilled for months, and physician assistant positions for years. Insufficient medical staff has resulted in overworked nurses at sick call and unacceptable delays in inmate access to physicians and physician assistants in the prison clinics.
Staff in corrections facilities, local hospitals, and RMUs may or may not have expertise in HIV care. Two DOH reports have documented inadequate HIV training of DOCS health staff. In 1988, DOH auditors concluded that there were clear deficiencies in HIV care and recommended physician training in programs during which they would be supervised by specialists at an AIDS Designated Center (hospital centers for HIV diagnosis, treatment, and clinical education). In 1992, the need for improvement in HIV skills was again stressed for DOCS staff.

These recommendations have not been implemented. There are no standard HIV training requirements for DOCS health care providers treating inmates with HIV. The Subcommittee saw no evidence of any other mechanism to ensure that all prison medical staff providing HIV care are qualified and adequately trained or that new treatment information is made available in a consistent and timely fashion. This is particularly disturbing considering the complexity of current HIV therapies.

**Treatment education**

Access to care by appropriately trained physicians is a concern for all inmates with HIV but particularly those taking HIV medications. Since interruption or cessation of HIV drugs can have long term clinical consequences, possibly increasing the chance of resistance in individual patients and in entire populations, careful patient education about treatment options and about the requirements of drug therapy and careful monitoring of those taking HIV drugs are critical. Clinical monitoring is also important because drug treatment may not be effective for some patients and because side effects are common and frequently intolerable. Studies show that mortality is reduced when patients with HIV have access to providers with substantial experience treating HIV. Inmates, like other people taking HIV medications, should have regular access to medical personnel trained to provide current HIV care.

Reports from inmates suggest that medications are in fact sometimes prescribed by DOCS medical personnel with little information to the inmate about nutritional requirements, possible side effects, treatment options, or the importance of treatment maintenance. In some cases inmates have used medications for a year or more in the absence of any specific treatment education session. There is no uniform program for patient education about treatment options, although one was proposed by DOCS staff.

There is also a great need for treatment education materials in Spanish and other languages and for confidential interpreters for sensitive health information. Interruptions in medication schedules at intake, transfer, and prison discharges without adequate transitional planning further compromise effective treatment. (See the section on transitional planning in this report.)

DOCS informed the Subcommittee that it is aware of the importance of maintaining treatment regimens and has made efforts to teach inmates, with the use of printed instructions and pictures, to take responsibility for a day’s worth of medications at a time on their own. However, no documents were provided by DOCS to substantiate efforts at continuity of treatment or accommodation of nutritional requirements for inmates on HIV medications. In practice, most medications are provided at 30-day
intervals with very little, if any, monitoring of patient adherence to regimens. There is no evidence of a system-wide program to ensure treatment maintenance.\textsuperscript{65}

\textbf{Infectious disease specialty care}

DOCS HIV Primary Care Practice Guidelines assume that HIV care is provided by primary care physicians, and DOCS policies do not encourage use of infectious disease specialists for inmates with HIV. While the December 1996 guidelines “strongly” recommended referral to a specialist when triple combination HIV therapy was being considered, this was changed in the 1997 and 1998 guidelines to state that an infectious disease referral “may be indicated” with the use of triple therapy or two protease inhibitors. A specialist on the guideline committee actively disagreed with this change and noted that DOCS prison staff were not following the recommendations of specialists regarding infectious disease clinic appointments. Many inmates with HIV are never seen by infectious disease specialists and few, if any, are routinely monitored by them. Delays in access to specialty care have been a chronic problem under DOCS coordinated specialty care contracts.\textsuperscript{66}

In many cases, prison physicians insufficiently trained in HIV specialty care provide on site HIV treatment services either as a matter of policy or to avoid the time, expense, and inconvenience of scheduling a long trip to the specialty clinic. While some HIV care can and should be provided by primary care staff in prisons, appropriate training in HIV care, triage skills, and consistent coordination with specialists are essential.

\textbf{Chronic care}

HIV is a chronic disease and requires a system for chronic care management that ensures continuity of care. To date this does not exist in individual corrections facilities or at the statewide DOCS level. There is no standard tracking system, manual or computerized, that can be used to schedule routine follow-up care, order and report laboratory and diagnostic tests, and monitor specialty care appointments and timely implementation of medical recommendations. Neither are any health staff designated to accomplish this.

HIV-infected inmates are often not assigned to a specific provider who regularly schedules and monitors the patient’s care. Although the DOCS HIV Guidelines include forms to assist in the management of care and routine laboratory testing, they have not been consistently used by the prisons. Further, the Guidelines concern only antiretroviral therapy and blood work. The result is that each provider must develop an independent system to monitor patients. Since few providers have the time, skill, or resources to do this effectively, patients may receive fragmented, delayed, or inadequate care.

\textbf{Coordination of care}

The difficulties of providing and coordinating hospital and specialty care under the “coordinated specialty care contracts” were illustrated in the Subcommittee’s site visit to Albany Medical Center (AMC), a subcontractor that provides a twenty-bed secured inpatient unit for inmates under these
contracts and staffs specialty clinics at the Coxsackie Regional Medical Unit. AMC is reimbursed using per service Medicaid rates for acute specialty, subspecialty, and ancillary care, including HIV. Length of stay in the AMC unit serving inmates is shorter than for patients in other AMC hospital units, and the unit is rarely full.

Since primary care is not part of the managed care provided under the contracts, one of the most important issues, according to AMC staff, is the disconnection between primary and specialty services.67

- AMC physicians function as consultants with no control over care once the inmate leaves the unit. Prison primary care medical staff also do post-operative care following surgery at AMC.
- Coxsackie provides sub-acute care and should, according to AMC staff, function as a step-down unit. However, beds do not turn over rapidly at Coxsackie, and it is usually full. When AMC and Coxsackie staff disagree about discharge, negotiation must take place.
- The HIV clinic run by AMC physicians at Coxsackie was initially expected to meet for ten sessions per month, which dropped to four for lack of referrals from DOCS health staff (and has now been restored to six). Physicians at each inmate’s prison are responsible for implementing the clinic recommendations, so again AMC physicians have no control over follow-up.
- Upon admission to AMC, inmates, like other patients, are accompanied by medical summaries, not their medical records, although AMC keeps its own patient records. If AMC physicians see an inmate whose prescribed treatment plan is not being followed they must initiate a complaint to the principal contractor, which often results in the administration of prescribed medication at the prison. However, some inmates refuse to take prescribed medication. There is no coordination between AMC and DOCS physicians regarding this issue. DOCS officials state that they have begun to track when inmates do not appear at prison pharmacies to fill or refill prescriptions, but the Subcommittee received no documentation of this effort.
- An estimated 10% of inmates arrive at AMC with medically inappropriate regimens, compared to about 5% of AMC patients from the regular community. The principal contractor is responsible for investigating these cases.
- AMC physicians also note missed appointments. A scheduled one-month follow-up appointment for inmates sometimes does not take place for six months; an estimated 25% of appointments are not kept.
- AMC physicians report that inmate knowledge about treatments varies widely. There has been greatly increased inmate access to protease inhibitors, but understanding of their use and the need for adherence is often poor.

To improve coordination between Albany Medical Center and Coxsackie, United, prior to the termination of their contracts, had asked that the Coxsackie Medical Director become an AMC employee. It is unclear how this is being handled under the new contracts and what is being done to improve coordination among DOCS staff and contracted medical personnel.
Regional Medical Units
The Subcommittee’s site visit to the 60-bed Regional Medical Unit at Coxsackie Correctional Facility provided some insight into the use of the Regional Medical Units. Coxsackie is a prison housing more than 1,000 inmates (80% under 24 years old). The modern RMU contains single and double rooms, as well as isolation units with negative air pressure capability. RMU staff consist of a full-time physician and three full time nurse practitioners, plus back up staff including a physician on-call at all times. Physicians from Albany Medical Center initially made rounds and visited inmates in cells at Coxsackie, in addition to staffing the outpatient clinics, although this has now ended.

The RMU receives from 2 to 12 admissions per month from prisons and hospitals, about 50% of which are HIV-related. Admission and discharge are determined by DOCS and RMU staff. Inmates can be returned to general population in their facilities, can remain in the RMU, or can be released on medical parole. No data on average length of stay is available, but patient turnover is slow. Most RMU residents with HIV are terminal patients who die in the unit.

Although the RMUs are not under state health regulatory authority, DOCS officials asserted that they follow state health care standards and that hospice care is based on national standards.68 (See additional discussion of hospice care and medical parole in the terminal care section of this report.)

RMU officials acknowledged problems with coordination of care, medical follow-up, and lab work. An inmate cited a complete lack of confidentiality for patients with HIV. One official commented that there was less need for HIV clinics, because more HIV care was being done routinely by RMU physicians.69 However, Subcommittee members voiced concerns about the HIV expertise of RMU staff. Further, given that nearly 70% of inmates are from New York City, transfer of sick inmates to RMUs, which are all upstate, places most patients far from their families and friends.

All inmates with HIV who need acute hospital care fear that any episode could become life threatening, and, if they are transferred, they could die alone in a remote hospital. The Subcommittee noted that decreasing hospital occupancy rates in New York City have made many empty beds available that could be used to care for inmates. This would be more efficient and economical in view of construction costs for new inmate medical facilities and would place sick or dying inmates closer to their families.

The Subcommittee clearly believes that substantial work must be done to improve treatment services for all inmates with HIV. Uniform, comprehensive, universally implemented standards for HIV care, adequate numbers of trained health care staff, appropriate access to infectious disease specialists, chronic care management, coordination of primary and specialty care, treatment education for English and non-English-speaking inmates (including the use of interpreters trained in confidentiality principles), mechanisms to ensure treatment maintenance and confidentiality, and more efficient use of medical facilities would be dramatic steps toward effective, even exemplary, health care.
See Recommendations number 2, 3, and 4 on staffing and training; number 7 on treatment education; number 8 on confidentiality; number 10 on standards; numbers 11 through 17 on acute, chronic, inpatient, specialty, and hospice care; and number 25 on utilization of existing empty hospital beds.
V. TRANSITIONAL AND SUPPORT SERVICES

SUBCOMMITTEE CONCERNS:
Insufficient inmate access to transitional planning
Inadequate provisions for follow-up
Uneven provision of support services

Transitional planning is essential to ensure continuity of medical care for any inmate scheduled to be transferred, discharged, or released on parole. Ideally, it is a process that begins six months prior to transfer or release and includes an assessment of needed services, the preparation of documents necessary to apply for those services, and a written plan of action and referral information for the inmate prepared by a trained provider. The written discharge plan includes appointments for specific services, such as housing, drug treatment, and medical care. From January 1 through June 30, 1998, CJI contractors provided transitional planning services to 719 inmates in 48 facilities.70 (See Appendix B.)

Support services for HIV-positive inmates, funded through the AIDS Institute’s Criminal Justice Initiative, consist of groups led by staff or inmates with staff supervision, as well as individual counseling, and buddy programs which escort newly discharged inmates to their initial residence and to medical, housing, and parole appointments for up to one month. Individual counseling and support groups provide emotional support, reinforce sexual and risk reduction behavior, and address issues such as partner notification, nutrition, and living with HIV/AIDS. They may include case management, crisis intervention, and referrals. From January 1 to June 30, 1998, CJI recorded 2,103 inmates who participated in support groups and 2,345 who received one-on-one counseling.71 (These are not unduplicated counts.) Again, service provision is uneven. There are no support services in Hub 4 (Sullivan) and all other hubs show gaps in services.

Although DOCS officials have stated that all discharged inmates receive referrals for follow-up services, there was no information available to confirm DOCS procedures for or utilization of transitional planning. Further, there is no evidence of a mechanism to ensure that all inmates designated for discharge from a facility served by AIDS Institute Criminal Justice Initiative providers are in fact referred to them for transitional planning. While DOCS may provide referrals for continuity of care upon discharge, there is no standard mechanism for seeing that inmates make or keep appointments or obtain new prescriptions. (In the case of parolees, the Division of Parole is responsible for follow-up.72)

CJI contractors noted difficulty gaining access to inmate medical records, documents, and DOCS cooperation for timely transitional planning. They must individually and carefully cultivate relationships with officials at each prison and with agencies to which they wish to refer inmates. An inventory of organizations, including Designated AIDS Centers, with which CJI providers can establish referral networks does not exist and would be extremely useful.73 Providers emphasize that housing is the number one need for discharged inmates and is the most difficult to arrange. Maintenance of treatment regimes is also critical.74
See Recommendation 19 on transitional planning.
VI. TERMINAL CARE AND COMPASSIONATE RELEASE

SUBCOMMITTEE CONCERNS:
Inadequate access to hospice care
Inadequate access to compassionate release
Terminal care far from inmates’ families

Many inmates who have HIV do not meet the Centers for Disease Control and Prevention (CDC) definition of AIDS and die without an AIDS diagnosis. However, looking only at CDC-defined AIDS, this diagnosis has been a leading cause of death in New York State prisons for some time. The 181 AIDS deaths in 1996 represented a rate of 26 per 1,000 inmates, down from a high of 38 per 1,000 in 1995, a decrease of 17%, compared to the 30% decrease in AIDS mortality in New York City in that time period.75

Since 1996, earlier diagnosis and better treatments continue to be reflected in reduced AIDS deaths in prisons as well as in the general population. AIDS deaths in prisons have continued to decrease both in absolute numbers and as a percent of all inmate deaths. (See chart on the next page.)

Although officially hospice care exists in only two DOCS facilities, the Coxsackie and Walsh Regional Medical Units, inmates terminally ill with HIV/AIDS reside in all DOCS facilities and most often die there or in local acute care hospitals. The hospice program at the Coxsackie RMU was opened in September 1997. Through November 1998, there have been 32 patients in the program (18 died; 4 were paroled; 5 were discharged from the hospice program; and 5 are currently in care), with an average census of 5 to 6.76

Compassionate release
Under New York State law,77 inmates who are terminally ill, except those convicted of certain violent crimes,78 may apply for compassionate release in order to die with family and friends outside of prison.

To apply for medical parole, inmates must first know about the program, not be past their normal parole eligibility date, be in the final stages of illness, and, according to New York State statutory provisions, be severely restricted in the ability to walk and to care for themselves.79 The application undergoes a multi-stage evaluation involving medical and security criteria. Inmates who have not yet served their minimum sentences can write to DOCS, where a doctor and the Associate Commissioner/Chief Medical Officer medically evaluate the case and send candidates to the Commissioner of Correctional Services, who determines whether a recommendation for medical parole and discharge plan will be sent to the Division of Parole. A parole hearing, involving a judge and district attorney, is held to make a final security risk determination. Medical parole is granted for six months and then reevaluated. Inmates who have exceeded their minimum sentences may be granted a
compassionate release though a full Board case review.

From June 1992, immediately after the law took effect, through June 1998, 1,253 inmate requests for medical parole were made, the great majority HIV-related, 412 of which resulted in a completed application to the Associate Commissioner/Chief Medical Officer (currently Dr. Lester Wright). Of these, 271 were approved by DOCS, and 199 of these were then approved by the Division of Parole. This has resulted in 186 medical parole releases, plus 22 full Board case review releases, for a total of 208 inmates who have been granted compassionate release since the start of the program. There have been 424 inmate deaths prior to successful completion of the application process. 80

Despite the lower number of deaths from AIDS in prisons in recent years, inmates are not benefitting from compassionate release in adequate numbers. Not counting applicants who were ineligible for the program, the rate of compassionate release in 1998 is substantially below that in 1995.

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Deaths in NYS Prisons 81</th>
<th>AIDS Deaths (% of total deaths) 82</th>
<th>Compassionate Releases (% of total deaths) 83</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>396</td>
<td>258 (65%)</td>
<td>63 (15.9%)</td>
</tr>
<tr>
<td>1996</td>
<td>330</td>
<td>181 (55%)</td>
<td>43 (13%)</td>
</tr>
<tr>
<td>1997</td>
<td>221</td>
<td>60 (27%)</td>
<td>20 (9%)</td>
</tr>
<tr>
<td>1998 (1st half)</td>
<td>92</td>
<td>18 (20%)</td>
<td>7 (7.6%)</td>
</tr>
</tbody>
</table>

Many terminally ill inmates are not aware of the program, and many close to death can still walk and thus are generally deemed ineligible. Physicians have also expressed reluctance to make recommendations for medical parole for fear of liability following release of a potentially dangerous inmate. However, the decreasing rate of compassionate releases relative to prison deaths may also reflect increasing reluctance of prison authorities to approve applications.

Inmates with advanced AIDS therefore most often die far from their families. Although the use of RMUs as hospice facilities has been limited to date, the Subcommittee has expressed concern that they will be used as a substitute for compassionate release.

See Recommendations number 17 on hospice care and 18 on medical parole.
VII. QUALITY ASSURANCE

SUBCOMMITTEE CONCERNS:
Inadequate oversight of correctional health services
Lack of statewide quality assurance mechanisms
Lack of information about inmate health services

State Correction Law on health services\(^\text{84}\) provides 18 pages of specifics about inmate health care, requiring the institution of defined levels of health care for all inmates,\(^\text{85}\) a utilization review plan,\(^\text{86}\) “a formal, coordinated program which periodically evaluates the health care delivery activities of each facility,”\(^\text{87}\) and, regarding HIV/AIDS, “uniform policies, procedures, and protocols for the early detection and diagnosis of HIV illness” consistent with Public Health Law, article 27-F, in addition to a full range of timely inpatient and outpatient services.\(^\text{88}\)

According to its mission statement, the New York State “Commission of Correction oversees the operation of all State and local correctional facilities......It also inspects these facilities to ensure adherence to standards.”\(^\text{89}\)

The Department of Health has no direct oversight role for health services in prisons, but is responsible for standards and monitoring of all health services provided in New York State in Article 28 facilities, which do not include prison health units. State agencies are in general exempt from state law related to health facilities. Thus, even though Regional Medical Units, for example, are similar to skilled nursing facilities, they do not fall under state regulatory authority for health facilities. The Department of Health has, however, undertaken two audits of health services in corrections facilities and has entered into Memoranda of Understanding with the Department of Correctional Services in attempts to work collaboratively to improve prison health care.

This report has noted that the Department of Correctional Services, aware of HIV/AIDS from the earliest years of the epidemic, has made some innovative efforts to provide HIV services, such as the establishment of the Special Needs Unit at Sing Sing and the use of an HIV care unit at St. Clare’s in Manhattan. The Subcommittee acknowledges and commends that in recent years, DOCS has appropriated funds and moved to offer current therapies, including triple combination therapies and protease inhibitors, to inmates. Administrators at some facilities have worked effectively in partnership with community based organizations to incorporate HIV education, testing, and support services into prison environments.

Despite these legislative and statutory mandates and ad hoc initiatives, there has been little or no regular oversight of DOCS health services for inmates. However, there have been numerous critical reports over many years and inadequate curative responses by DOCS. A chronology of these efforts may help
to support the strong and detailed recommendations of the Subcommittee and provide the basis for its vigorous endorsement of a primary oversight role for the Department of Health.

Reviews of prison health services have been conducted by a number of agencies and will be summarized here in roughly chronological order.

**Commission of Correction Report**
A New York State Commission of Corrections report in June 1988 on the Special Needs Unit at Sing Sing concluded that the unit “does not address the identified needs of AIDS patients or approach the current generally accepted state-of-the-art in management of AIDS.” Although the Commission noted that corrections officials had been responsive to the AIDS crisis, it offered 36 recommendations to improve services to inmates in the SNU.

**Five-Year Interagency Plan for AIDS Services**
In 1989, New York’s five-year Interagency Plan for AIDS Services recognized that “The prison health care delivery system was designed to provide primary care, not to meet the complex needs of inmates with HIV disease. At present, DOCS manages inmates with HIV-related illness in facility-based infirmaries in 33 maximum and medium security facilities. These are capable of only the most rudimentary diagnostic services and are not staffed or equipped to deliver advanced levels of care; many have only part-time medical directors and/or physician staff.”

The Interagency Plan detailed 18 additional HIV/AIDS initiatives to be undertaken for inmates and 10 for parolees with AIDS. They included regional teams and peer counselors to provide HIV education to inmates and staff, enforcement of anti-discrimination policies, counseling and testing services, memoranda of understanding with other state agencies, development of standards for medical discharge, additional Special Needs Units, and access to HIV medications.

**AIDS Advisory Council 1989 Report**
In 1989, increasing numbers of inmates with HIV/AIDS prompted the New York State AIDS Advisory Council to examine HIV care available to inmates, with inevitable attention to prison health services in general. In its report, “Management of HIV Infection in New York State Prisons,” the Council concluded that there were serious deficiencies in prison health services, particularly for inmates with HIV, and that substantial improvements should be undertaken immediately. If sufficient improvement did not occur promptly, authority for health care in prisons should be transferred to the Department of Health.

Among other recommendations, the report called for a strong quality assurance program; extensive use of outside contractors and community providers, with careful contract monitoring and strict accountability; a clear and comprehensive medical records system; reliance for acute
care on the Designated AIDS Center hospitals and others with specific HIV expertise; creation of both skilled nursing and health-related facilities; close collaboration with Departments of Health and Mental Health; drug treatment centers in all prisons; special health services for women and their children; inmate access to condoms if HIV is transmitted in prisons; treatment education and informed consent; culturally and linguistically appropriate HIV education for all staff and inmates, including confidentiality requirements; both confidential and anonymous testing; and encouragement of voluntary testing.

Most of these recommendations were not implemented or were only partially implemented. (A list at the end of this report notes the degree of implementation.)

**DOH Audits**

Two DOH audits were undertaken, in 1988 and 1992. For the 1988 audit, several teams of medical providers reviewed eleven prisons. The report concluded that “the most severe deficits were associated with medical care of HIV-infected inmates.” Reviewers found that the “quality of health provided to patients with AIDS is associated with deficits in diagnosis and evaluation, treatment, consultation and provider training.” Although the audit recommended that prisons respond with remediation plans, there were no specific follow-up requirements and none was undertaken by DOCS or DOH.

Following negative publicity, a second audit was performed on 12 facilities (11 of the same ones from 1988) in 1992 by a team that included many of the same providers, plus a team of Island Peer Review Organization (IPRO) chart reviewers. The report cited a number of improvements since the previous audit, including recruitment of a Medical Director, expansion of Central Office health staffing, development of a capital expenditure plan, implementation with DOH of HIV education, counseling, and testing programs, use of a pilot quality assurance protocol in 20 facilities, expansion of inmate access to AZT, and upgrading of pharmacy operations and health care guidelines. However, critical improvements were still needed to improve HIV care guidelines, TB diagnosis and treatment, inmate access to on site and outside acute and specialty services, documentation and follow-up, and quality assurance.

Again, the report failed to call for a required DOCS response or remediation plan, although DOCS issued a response in April 1993 listing 11 of its own recommendations to correct deficiencies. To “develop and implement a comprehensive quality management program,” DOCS suggested a Memorandum of Understanding with DOH, which would contribute to the design and “provide periodic review to ascertain compliance.”

**Memoranda of Understanding**

A Memorandum of Understanding (MOU) to cover the period October 1993 to October 1995 was signed by the Commissioner of Health and the Commissioner of Correctional Services. It provided $200,000 for staff to execute the agreement in which the two agencies
would “cooperatively plan, develop, implement, monitor, and evaluate a quality management program for DOCS health care.” The program was to identify the following components: DOCS oversight staff and DOH consultative staff, types of services to be maintained, review indicators, standards of performance that would trigger greater scrutiny, data collection methods, corrective processes, reassessment procedures, feedback mechanisms, and resources. A contractor was to implement the plan, although reports had to be approved by DOCS. An annual quality management report was to be issued by the two agencies. Apart from DOH participation in the selection of an outside contractor, William M. Mercer, Inc., and in some DOCS Hub meetings, this MOU was never implemented.

The AIDS Institute currently receives $821,000 in state funds under a Memorandum of Understanding initiated with DOCS in 1989 for the provision of anonymous counseling and testing at selected correctional facilities.

Mercer contract

After initiating halting and intermittent quality assurance efforts during the 1980s and early 1990s, DOCS negotiated, primarily as a result of the DOH audits, a three year contract with William M. Mercer, Inc., to develop a quality management program. As nearly as the Subcommittee could determine, the quality management activity undertaken by Mercer in 1994-1997 consisted mainly of data collection, regional meetings for staff instruction in data collection, and tabulations returned to the facilities. Facilities were required to report to a central office monthly on 18 indicators of health service utilization (such as the number of inmates appearing at sick call), but there is no indication that the Mercer data were ever analyzed, deficiencies discussed, or remedial plans or recommendations developed. In addition, although data collection continues, there is no mechanism in place for monitoring actual practice. There have been no plans for other quality management contracts since the conclusion of those with Mercer.

HIV Practice Guidelines

Mercer did encourage the development of DOCS’ HIV Primary Care Practice Guidelines. They were first issued in July 1995, and revised in December 1996, July 1997, and February 1998. While they are presumably being used, they have not become the basis for any quality assessment tool that could be used to monitor practice. The guidelines address few issues other than antiretroviral therapy.

United Correctional Managed Care, a former DOCS contractor, assured the Subcommittee in a site visit to Coxsackie Regional Medical Unit that both internal (by facility) and external (statewide) quality of care mechanisms are in place, but it was unclear how they operated. The Subcommittee was told that data were being collected, but data were not available to the Subcommittee. There was, for example, no accessible record of the total number of inmates who had received care to date in the Coxsackie RMU.
Control of access to specialists through the coordinated specialty care contracts would allow for utilization review. Since a Uniform Billing Form gives information on admission to and discharge from local hospitals, it could also be used to track use of acute care facilities.

However, even without assessment tools, the Subcommittee noted problems, many of which have been discussed in previous sections of this report. Anecdotal reports suggest that correctional staff wait so long to authorize hospitalization that inmates are generally too sick to be transferred any distance and are instead treated by local hospitals inexperienced in treating complex HIV cases. Despite the fact that primary care is done in prisons and specialty care by other organizations, there is no effective system for establishing collaboration between specialists and primary care prison doctors or to ensure that follow-up appointments at the hospital or RMU are made or kept. There is as yet no central, comprehensive, computerized medical records system. Records maintained by managed care contractors do not include primary care administered in the prisons. A new records system under development is expected to be completed in five years.101

In short, there seem to be no uniform standards or statewide quality assurance program for HIV/AIDS services. On the other hand, DOCS has recently expressed strong interest in the Quality of Care program developed by the AIDS Institute, which uses federally funded HIVQUAL continuous quality improvement software, state designed algorithms (step by step procedures for HIV care, including performance indicators), practice guidelines, on site reviews, and consultations to establish facility capacity to meet statewide standards of care. This program would require adaptation for use in DOCS facilities, but DOCS is working with the AIDS Institute to make this possible. DOCS has received copies of the AIDS Institute protocols for HIV/AIDS care, which DOCS is adapting to integrate into its HIV services.

Quality assurance regarding the AIDS Institute Criminal Justice Initiative contracts could also be improved. As noted previously, there are service gaps in all regions. Subcommittee members were critical of the reliance on inmate self-referrals and the lack of evaluation data to date, noting that there was no mechanism for monitoring adherence to contractual standards for service delivery and no confirmation of numbers of inmates served.

Although the CJI Initiative was revised in 1996, many contractors did not begin services until mid-1997. CJI staff acknowledged that some programs may be too new for impact to be properly assessed. The Subcommittee noted providers’ complaints about the difficulty of training staff to work in prisons and the logistical difficulties of reaching prisons and monitoring staff. They also concluded that AI staff and resources allotted to the Initiative seem inadequate to meet a goal of providing a full range of HIV services in each prison. Needs assessment, evaluation of peer educators and, especially, centralized coordination with DOCS officials to enable access to all facilities were other principal quality assurance issues.

The Subcommittee felt strongly that mechanisms for continuous quality improvement, regular auditing,
and public accountability should be established. These might include independent quality assurance assessments, annual data analysis and reporting, and incorporation of components of the AIDS Institute’s Quality of Care Program, and/or other strategies for ensuring quality inmate health services. It is essential that the Department of Health assume an active role in partnership with DOCS, forming working relationships with other agencies as appropriate. Finally, the lack of information noted throughout this report is undoubtedly as great an impediment to quality assurance as it was to the work of this Subcommittee. It is critical that modern methods for data collection and analysis be instituted.

See Recommendation 1 on DOH, 20 on data collection, and 21-23 on quality of care.
FUNDING

In fiscal year 1986-87, with 53 facilities and approximately 40,000 inmates, it was estimated that DOCS spent about $50 million for all direct medical services for inmates, excluding related security costs ($10 million), benefits, equipment, and costs incurred by the Office of Mental Health. DOCS officials estimated they would spend “$10.8 million for direct AIDS medical services and $7.6 million in associated security costs in fiscal year 1988-89.”

In fiscal year 1996-97, with 73 facilities and 70,000 inmates, the DOCS total health care budget was $146.2 million. The capital budget included $150 million for health care facility construction. The State spent $45.8 million on AIDS programs for inmates. It is unclear whether this includes HIV-related security costs, but it is evident that AIDS program costs include expenses for non-AIDS care. The Walsh RMU, for example, included below as an AIDS expense, serves non-HIV-infected inmates as well. It is uncertain whether costs for “outside hospitals,” listed below, include care for non-HIV-infected inmates.

Slightly over $10 million of this $45.8 million came from the Family Benefit Fund, which consists of commissions paid to the state by long distance phone carriers on collect phone calls made by inmates. The Fund was expected to total about $15 million in that fiscal year. It is the opinion of the Subcommittee that this use of the Fund constitutes an unfair and hidden mechanism by which inmates’ families are made to pay for HIV services.

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<tbody>
<tr>
<td>General Fund</td>
<td>$24,458,200</td>
<td>24,933,100</td>
<td>33,037,600</td>
<td>36,840,600</td>
<td>35,692,100</td>
</tr>
<tr>
<td>Benefit Fund</td>
<td>6,775,700</td>
<td>8,542,800</td>
<td>5,083,400</td>
<td>3,480,200</td>
<td>10,180,200</td>
</tr>
<tr>
<td>Total</td>
<td>31,233,900</td>
<td>33,475,900</td>
<td>38,121,000</td>
<td>40,320,800</td>
<td>45,872,300</td>
</tr>
</tbody>
</table>

In fiscal year 1996-97, DOCS spent the $45.8 million in the following way:

- AIDS Drugs: $13,866,400
- St. Clare’s: $8,071,500
- Outside Hospitals: $13,099,900
- Special Needs: $1,459,600
- Training: $910,200
- Screening: $987,900
- Walsh RMU: $7,476,800

Funding for the AIDS Institute’s Criminal Justice Initiative components currently totals nearly $3 million.
from state and federal sources. In addition, the Institute receives $821,000 for anonymous counseling and testing under a Memorandum of Understanding with DOCS. CJI funding seems insufficient to provide comprehensive contractor services.

The Subcommittee was unable to determine whether DOCS funding is adequate. The Subcommittee anticipates that some of its recommendations will require additional financial resources, although some could be implemented at no cost. No charges to inmates or their families of any kind, including co-payments, should be exacted for HIV or other health services.

See Recommendations 24 and 25 on funding.
INTERSTATE SURVEYS

NASTAD
In May 1997, the AIDS Institute surveyed selected state Department of Health HIV Directors who are members of NASTAD (the National Association of State and Territorial AIDS Directors). Questionnaires asking about the relationship between the departments of health and correctional services were distributed to 19 states:

Arkansas (AR), California (CA), Connecticut (CT), Florida (FL), Illinois (IL), Maryland (MD), Massachusetts (MA), Michigan (MI), Minnesota (MN), Mississippi (MS), Missouri (MO), New Jersey (NJ), North Carolina (NC), Oregon (OR), Pennsylvania (PA), Texas (TX), Vermont (VT), Washington (WA), and Wyoming (WY).

Of these, 17 (all but Mississippi and Pennsylvania) responded.

Results were as follows:
- DOH was not responsible for medical care in prisons in any responding state. In 15, the state correctional system was responsible.
- In 12 states, DOH had no role in developing standards for prison medical care. In 4 others (AR, MA, MO, NJ), DOH had a consultative or advisory role.
- Only 2 states (AR, MA) indicated that DOH had an advisory role in developing or monitoring prison health quality assurance standards.
- However, even without direct responsibility for medical care, standards, or quality assurance, 8 states (FL, MA, MD, NC, NJ, VT, WA, WY) described types of collaborative and advisory relationships between DOH and their corrections system, ranging from advice on request about specific issues, such as HIV and substance abuse (MD, NC, VT), to sharing of medical protocols and guidelines (NJ), to joint development of the prison health care plan (WA). DOH clinicians are on the corrections advisory board in one state (MA), and the medical administrator of corrections is on the Governor’s AIDS advisory committee in another (WA).
- Three states (MD, NJ, WY) contract for medical care; in one (CT), HIV care is under a long-term consent decree and is monitored by the courts; and in one state (TX) the corrections medical division cooperates with a university medical branch to provide most outpatient and all inpatient care.

Medical directors
In addition to the NASTAD survey, in June 1997, the Subcommittee sent letters to the medical directors of all state prison facilities outside of New York requesting information on the relationship between the departments of corrections and health, prison health care budgets, the inmate population, deaths attributed to AIDS in 1996, seroprevalence rates, and HIV counseling, testing, and treatment services. The Subcommittee received responses from 22 states:

California (CA), Delaware (DE), Florida (FL), Hawaii (HI), Illinois (IL), Indiana (IN), Kansas (KS), Maine (ME), Maryland (MD), Massachusetts (MA), Michigan (MI), Minnesota (MN), Missouri (MO), Nebraska (NE), Nevada (NV), Ohio (OH), Pennsylvania (PA), South Carolina (SC), Texas (TX), Virginia (VA), West Virginia (WV), and Wisconsin (WI).
addition, the Subcommittee gathered information on Rhode Island (RI).

Fourteen of the 23 states included in this survey of Department of Corrections medical directors of state prison facilities did not respond to the NASTAD survey of Department of Health HIV directors. Nine states were the same and eight responded to NASTAD survey but not the survey of DOC medical directors. Thus, a total of 31 states provided some information to the Subcommittee. Subcommittee members also called DOH officials in at least nine states to pursue discussion of DOH-DOC interactions and inmate HIV services. (See Appendix C for survey results by state.)

- **DOH-DOC relationships:**
  Interestingly, although DOC medical director respondents were asked about DOH direct or oversight responsibility for prison health services and not specifically about other types of collaborative or advisory relationships, 14 of these 23 responding states indicated some degree of DOH involvement in health care in corrections facilities (DE, FL, IL, IN, KS, MA, MI, MN, MO, NV, RI, SC, TX, and VA), including joint work groups (MA, VT). When these are added to the unduplicated six (AR, NC, NJ, VT, WA, and WY) from the NASTAD survey that reported a DOH role, and an additional state (MD) that described one in a phone interview, 21 of 31 states noted DOH-DOC working relationships.

- **Use of contractors:**
  Fourteen of 23 states in the DOC medical directors survey (DE, FL, IL, IN, KS, ME, MD, MI, MN, MO, NV, SC, TX, WI) and two unduplicated states in the NASTAD survey (NJ, WY), for a total of 16 of 31 states, contract for some or all health services in prisons.

- **Health services budgets:**
  In the 17 states for which it was possible to determine the proportion of the corrections budget spent on health care, the figures ranged from 3.6% (WI) to 25% (NV) with a mean of 11.3%.

- **AIDS deaths:**
  In two states (FL, MD) AIDS accounted for at least 50% of prison deaths.

- **Seroprevalence:**
  In all states responding to this question, HIV seroprevalence in prison facilities was substantially higher than in the general population and higher for women than men.

- **Testing:**
  Ten states reported mandatory testing of inmates under some circumstances.

- **Treatment:**
  Nearly all states described some combination of on-site and off-site care with varying degrees of access to specialists. It is unclear from some responses whether HIV care was considered a specialty. While most responses stated that inmates have access to all medically appropriate therapies and that treatment conforms to medical standards for the non-incarcerated population, a number noted that some inmates, particularly those who are non-symptomatic, refuse medications. In NV, for example, 15 of 25 women and 32 of 72 males with HIV (not AIDS) refuse medication. There is no indication of
what relationship this may have to treatment education.

• Quality assurance:
  Few states described a formal, detailed quality assurance program. In some cases, the
  state infection control supervisor, usually an RN, was responsible for reviewing care; in
  others quality assurance was left to the contractor responsible for providing care. Only
  one state (SC) mentioned a process complete with corrective action requirements and
  repeat audits.

It should be noted that these surveys conducted and reviewed by the Subcommittee were not
scientifically designed research instruments. Further, although Subcommittee members were able to
interview a number of state officials by phone, there were insufficient Subcommittee resources to
follow-up on or clarify survey responses, and often reported data represent different time periods or
data collection methodologies. Seroprevalence rates, for example, are in some cases reports from
voluntary testing, in others from blinded samples, and in still others from universal mandatory testing.

It was neither the mandate nor intention of the Subcommittee to carefully delineate the quality of HIV
care in state prisons across the nation, but rather its hope that this cursory look at other states would
give at least rough indications of topics for further investigation.
In view of this report’s detailed recommendations and delineation of the principles on which they are based, the Subcommittee’s conclusions will be summarized here only in broad categories. This document is intended to prompt further investigation and frequent monitoring of HIV/AIDS and all health services for inmates in New York State.

It is not possible to adequately address HIV in the prison system without acknowledging the interdependence of many aspects of the problem. A great many inmates with HIV are not receiving care because they don’t know their HIV status. They don’t know their status because they don’t believe they are at risk, fear loss of confidentiality, are not informed about the benefits of treatment, or don’t think they will get adequate care if they are positive. Effective treatment therefore starts with education and testing.

Regardless of the quality of the educational and support programs, inmates and the sex partners of inmates (inside and outside of prison) will continue to be at high risk if there are inadequate substance abuse and mental health services, if there is no admission that sex and HIV transmission occur in prisons, if there are inadequately trained or inaccessible staff, and if there is little or no discharge planning. Prevention is thus dependent on realistic assessments of risk and need and the availability of a continuum of services.

Further, inmates with HIV will not receive a medically acceptable standard of care if there is no emphasis on coordination and continuity of care and no acknowledgment that new treatments require extensive education about the regimen prior to beginning therapy and understanding by both staff and inmate of the importance of treatment maintenance, facilitated by sustained physician-patient relationships. Inmates must be convinced of the value of treatment decisions that affect their lives.

Similarly, there can be no real improvement in health services without a strong quality assurance program, an adequate medical records system, current epidemiologic data, and a commitment to improved HIV education and treatment. No goal can be achieved without the proper tools and a sense of purpose.

This report recognizes that HIV care in prisons is difficult and, in some respects, unlike care for non-incarcerated people. Confidentiality in a prison requires creative and determined strategies. Arranging effective treatment education, medication schedules, and other aspects of HIV care may be more complex. On the other hand, prevention, prevention education, and record keeping should be easier.

The Subcommittee firmly believes that it is possible to design and administer quality HIV services in a correctional setting.
It should be noted that the Subcommittee had considerable difficulty obtaining not only precise epidemiological data, but information on many important parameters of care in the DOCS system, frequently because the data has not been gathered or centralized. No specific information was provided to the Subcommittee on the utilization of health services by facility, rates of access to specialty care or follow-up, medical staff and training by facility, the number of inmates receiving non-retroviral treatments for HIV-related illness, nutritional and scheduling accommodations for those taking HIV medications, staff skill in providing treatment education, the number of inmates refusing or discontinuing treatment, procedures for and the number receiving discharge planning, or many other issues. Further, although the Subcommittee was not able to investigate mental health or substance abuse services for inmates, it was apparent that there is little or no coordination between these health areas and HIV care.

This report has organized its recommendations around the following key issues:

1) effective universal HIV education  
2) inmate knowledge of HIV status  
3) confidentiality of medical information  
4) training and commitment of staff  
5) uniform standards of care  
6) inmate access to a continuum of medically appropriate treatment  
7) coordination and continuity of care  
8) oversight and quality assurance  
9) documentation and public dissemination of data  
10) funding

These issues all work together. Some are the same as those that have been cited in critical reports for the past ten years. Many of the Subcommittee’s recommendations echo national guidelines, such as the 1996 “Standards for HIV-AIDS Care in Prisons and Jails” of the American Public Health Association, which expand upon previous standards for health services in prisons dating from 1976. The 1996 standards stress the need for culturally appropriate AIDS education at entry into the prison system and prior to release, peer programs, staff training, access to anonymous and confidential HIV testing with pre- and post-test counseling, confidentiality, extension of community standards of care to inmates, condom availability, timely access to hospital care and new treatments, discharge planning, and release of terminally ill patients.

While HIV continues to threaten the lives of New Yorkers, despite the advent of effective new therapies, prevention of HIV infection continues to be the best strategy and should be one of the highest public health goals. Yet in 1998 in New York, rates of HIV infection continue to be substantially higher in inmates than in the general population, access to the most current therapies is uneven, counseling and testing programs fail to identify large numbers of inmates with HIV infection, condoms are unavailable, data is woefully lacking, and there is little oversight or enforcement of existing regulations.

Although it was not within the scope of this report to analyze and comment on recent legislative initiatives regarding prison health, the Subcommittee did consider them. One State Senate bill (S-3906) called for the transfer of authority for prison health services to the Department of Health. Without
necessarily supporting the particulars or the reasoning of this bill, this transfer of authority, a contingency of the AIDS Advisory Council’s 1989 report, is one of the major recommendations of this report.

Finally, a single overriding premise should illuminate future discussion. Substandard medical care is not a legally, medically, or morally acceptable condition of incarceration.
Principles and Recommendations

of the

AIDS Advisory Council
Subcommittee on Criminal Justice
PRINCIPLES OF HIV CARE IN CORRECTIONAL FACILITIES

1. The state has an obligation to provide a single standard of health care to all people within its boundaries, that is, the same standard of health care for inmates as well as for other New York residents.

HIV protocols and treatment guidelines should apply equally to prison settings. An interactive physician-patient relationship in which treatment options are discussed and medical decisions are jointly determined and based on knowledge should be the uniform state standard. Recommendations of the AIDS Advisory Council’s Ethical Issues in Access to HIV Treatment Workgroup should apply no less in prisons than in other settings.

2. In a prison setting, where inmates cannot choose their health care providers and have few sources of information and little recourse about decisions made in their behalf, the state has particularly rigorous ethical obligations regarding access to health services.

Specifically, they include obligations to ensure that:

- all inmates are informed of their rights regarding health care services and have access to impartial mechanisms for redress of grievances;

- general health and HIV prevention and treatment information is not simply available but offered to every inmate in a manner in which it can be understood;

- prison health care staff are adequate in number, carefully selected, well distributed, accessible, appropriately trained, and monitored;

- every inmate with HIV or any other medical problem receives appropriate care consistent with the most current medical knowledge; and

- inmates are never charged for health education, HIV testing, or any other health care services.

3. While security is of paramount concern in correctional facilities, security should not be used to deny health services or to refuse to make reasonable
accommodations that would allow inmates to benefit from new medical
treatments in accordance with evolving standards of care. Access to health
services should never be used as a privilege or a punishment.

4. Every inmate should be considered to be at risk for HIV. Prevention of HIV
transmission, which is the responsibility of both inmates and prison officials,
requires the acknowledgment of high risk activities and the initiation of active
measures to reduce the risk of infection.

5. An HIV test is the first step toward HIV care. Prison health care providers
have an obligation to strongly encourage every inmate to learn his/her HIV
status.

6. The state has an obligation to ensure continuity of care and maintenance of
treatment regimens both while an inmate is confined to a specific correctional
facility and in the event of inmate transfer, discharge, parole, hospitalization,
work release, or any other permanent or temporary change in confinement
location or status.

7. Prison inmates have the same right to confidentiality of their medical
information as patients in any other setting. Recognizing that the preservation
of complete confidentiality about HIV status in prison settings is extremely
difficult, it is nevertheless incumbent upon all staff to avoid unnecessary
disclosure of medical information in general and to observe existing state
statutes regarding HIV information.

8. State departments and agencies have an obligation to work closely together to
design effective and efficient programs that minimize duplication of effort and
maximize use of existing resources such as community HIV providers, federal
and state HIV treatment guidelines and protocols, and trained HIV clinical
specialists.

9. The state has a public health responsibility to monitor the quality of health care
in prisons as it does in other settings and, specifically, to collect and make
available data on HIV testing and infection rates among inmates, use of HIV
therapies, and all HIV programs and services in prisons or administered
through the prisons. Effective administration of health services in prisons
benefits inmates, conserves resources, and protects the public health.
RECOMMENDATIONS FOR HIV CARE IN NEW YORK STATE CORRECTIONAL FACILITIES

RELATIONSHIP OF DOCS-DOH

1. The Department of Health should assume overall responsibility for health services in correctional facilities. The New York State Legislature should take action to mandate DOH responsibility. Until that time, DOH should assume an oversight role in assuring quality health care in prisons.

This means, specifically, establishing protocols for HIV care in correctional settings consistent with statewide standards and determining how they should best be implemented, using some combination of Department of Health (DOH), Department of Correctional Services (DOCS), and outside contractor staffing and expertise.

   a. DOH should establish a partnership with the Department of Correctional Services (DOCS) to structure health services consistent with security requirements and to implement the plan in each prison.

   b. A memo of understanding should specify the responsibilities of DOH and DOCS in the coordination of health care for inmates and a time frame for accomplishing the transition of responsibility and implementing the plan.

   c. DOH and DOCS should fully utilize the expertise of the DOH AIDS Institute in the formulation of HIV care standards and quality assessment and improvement programs, in selecting contractors and specialty care providers, and in integrating HIV with other health care services, such as management of tuberculosis and sexually transmitted diseases.

   d. The Interagency Task Force on HIV should consider and make recommendations regarding the role of DOH in providing health services in prisons, should monitor any working relationship established between DOCS and DOH, and should help to ensure the establishment of a uniform standard of HIV care throughout the state. Consistent with its mission, the Task Force should, on an ongoing basis, coordinate health and HIV services for inmates with services provided by other state agencies, such as the Office of Alcohol and Substance Abuse Services, the Office of Mental Health, the Division of
Parole, and should assure that adequate levels of quality care are provided by all agencies serving inmates.

**STAFFING AND TRAINING**

2. **The Department of Health should have oversight or direct responsibility for determining qualifications and duties and for training all personnel providing health services in correctional facilities.**

   a. Training should reinforce to all staff the need for prompt inmate access to medical providers, and should provide basic information about HIV prevention and transmission, the importance of HIV testing and early treatment, and the types of accommodations necessary to the maintenance of inmate treatment regimens.

   b. The Department of Health should be responsible for insuring that HIV providers receive regular clinical updates of HIV information and should ensure the ability of HIV care providers to fully explain the requirements, potential benefits, and possible side effects of new treatments.

   c. The state should undertake efforts to recruit and retain more minority health care providers for correctional facilities.

3. **Each prison should have a full-time Medical Director who has basic knowledge of HIV.**

   a. In addition to clinical duties, the Medical Director should be responsible for regular staff meetings, arranging continuing medical education for staff, and ensuring continuous quality improvement in health services.

   b. Regularly updated written protocols for HIV care in prisons, following practice guidelines developed and revised by the AIDS Institute, should be distributed to the Medical Director of each correctional facility.

4. **Sufficient staff should be engaged to permit timely access by any inmate with a medical problem to a physician, nurse, physician’s assistant, or nurse practitioner.**

   a. Medical staff vacancies should be promptly filled and alternative coverage arranged immediately whenever a vacancy exists.

   c. Staffing should include provision for interpreters knowledgeable about medical
terms who are not inmates or DOCS security staff and who can be called upon for translation of HIV education programs or medical interactions between HIV care providers and non-English speaking inmates.

d. Staffing should include sufficient pharmacists to ensure that medications and prescription renewals are provided in a medically appropriate manner.

HIV EDUCATION

5. Every inmate should be given HIV information and should have access to regular sources for continuing HIV education.

a. All staff and inmates should be advised that every person should seek HIV information and that obtaining it does not identify a person as positive, merely informed.

b. All inmates at entry into the prison system and at least annually thereafter should be encouraged to have an HIV test and required to participate in an HIV/AIDS education program conducted by trained AIDS educators.

c. Written educational materials on HIV/AIDS should be readily available in all DOCS prisons.

d. In addition to annual HIV programs and written materials, inmates should be allowed access to a specific location with regular hours and programs that provide general health as well as HIV information so that inmate questions can be answered promptly by knowledgeable personnel. Contracted or designated HIV service providers should seek to establish an ongoing regular presence in each prison. Ideally, a single organization, group of personnel, and location should be established.

e. Inmate visits to health care providers should routinely incorporate a recommendation to learn one's HIV status.

f. Provisions should be made for translations of basic materials and for non-English HIV and health presentations. The need for interpreters should be determined during each inmate's intake process and noted in the record. Interpreters and medical care providers should be sensitive to cultural issues, disabilities, and other factors that affect receptivity to and understanding of health and HIV information. Interpreters should not be inmates or security staff.

g. The fullest possible use should be made of trained peer educators in all HIV education programs for inmates.
6. Comprehensive HIV education programs for all inmates should include information about HIV prevention, the availability and advisability of HIV testing, the benefits of early identification and treatment, and the availability of drug treatment, mental health, and other services.

   a. HIV prevention education should specify methods of harm reduction for activities both in and outside the correctional system, including the use of barrier protections and methods to reduce the risk of infection when using injectable drugs.

   b. Latex condoms should be available to any inmate requesting them from a medical provider and should be distributed along with information about proper use for maximum risk reduction.

7. Providers of medical care for HIV-infected inmates are responsible for the education of their patients about HIV treatment options and should carefully explain and discuss all medically appropriate treatments so that inmates understand the requirements of drug regimens, possible side effects, and the importance of continuing treatment once begun.

   a. Adequate time for patient education during medical visits and other arrangements should be made to allow the implementation in prison settings of the 1997 recommendations of the AIDS Advisory Council’s Ethical Issues in Access to HIV Treatment Workgroup.

CONFIDENTIALITY

8. While confidentiality in prison settings is admittedly difficult, the state should nevertheless develop a plan to ensure the highest degree of confidentiality possible about each inmate’s HIV status and medical condition. The plan should pertain to every aspect of HIV training, education, counseling, testing, and treatment, should assure rigorous enforcement of Public Health Law 27-F in prison settings, and, in addition, should include the following provisions:

   a. Staff training should emphasize the need for confidentiality of medical information and should devise ways to limit access to health records to only those individuals and under those circumstances deemed essential for the health of the inmate. Giving information to staff about an inmate’s disabilities so that proper care can be administered does not require revelation of a diagnosis.
b. Means should be devised to prevent the interpretation of visits to the location where HIV information is regularly provided as an admission of positive status. For example, this location could be used to dispense general health information as well as that about HIV, and all inmates and staff could be encouraged to visit there.

c. Written HIV prevention and treatment information should be distributed to all inmates, not just those considered high risk or known to be infected.

d. Condoms, medications, and other products for HIV prevention and treatment should be dispensed and stored in ways that do not reveal HIV status.

e. Call-outs for health education or treatment should be for unspecified medical appointments, not HIV-specific reasons.

f. Interpreters, staff who participate in telemedicine sessions, and others who have access to inmate health information should be trained in confidentiality principles.

h. When an inmate or staff member has been exposed to HIV, care should be taken to protect the confidentiality of the index patient.

HIV COUNSELING AND TESTING

9. Every inmate should be strongly encouraged to learn his/her current HIV status. Both anonymous and confidential HIV testing using the most current testing technology should be available to all inmates on a voluntary basis in every facility housing DOCS inmates.

a. Requests for HIV testing should result in the prompt administration of the test, preceded by pre-test counseling by a trained counselor and followed by post-test counseling as soon as results become available. Inmates who test positive should be encouraged to enter treatment and offered assistance with partner notification.

b. Inmates who request an anonymous test should have the option of converting to confidential status and making the results known to medical providers.
c. Inmates who may have been exposed to HIV through high risk behavior or accidental exposure to blood or body fluids should be individually counseled to have an HIV test. State standards for post exposure HIV prophylactic care should be made known and available to inmates.
d. The state should review HIV testing rates in each correctional facility. If data indicate a disparity between HIV seroprevalence rates in blinded studies and those in anonymous and confidential prison testing programs, more aggressive efforts should be made to encourage voluntary HIV testing among inmates.
e. Similarly, if data indicate disparities between the number testing positive in anonymous and confidential prison HIV testing programs and the number receiving HIV care, specific efforts should be undertaken to bring HIV-positive inmates into treatment.
f. Inmates who have known risk behaviors and do not know their HIV status prior to discharge should again be encouraged to take an HIV test and offered counseling. If positive, they should be given referrals for treatment and offered help with partner notification.

HEALTH CARE SERVICES

Standards

10. The state should assure that statewide standards of health and HIV care prevailing now and those in the future are maintained in prison settings.

a. If the Department of Health does not assume direct responsibility for prison health services, then health units in corrections facilities should meet the requirements of those licensed by New York State under Article 28.

b. Implementation of AIDS Institute HIV practice guidelines should be undertaken immediately throughout the DOCS system, and a mechanism to review their implementation should be established.

c. AIDS Institute standards of HIV care for all special populations (i.e., women, pregnant women, adolescents, substance users, the mentally ill) should be implemented throughout the DOCS system. Specifically, inmates in need of substance abuse, mental health, and other specialized services should have appropriate access to treatment, on site OB-GYN clinics should be established in all women’s correctional facilities, and other services should be instituted as needed to enable implementation of the standards.
d. While telemedicine has significant potential to improve access of inmates to regular and specialty care, to monitor implementation of medical recommendations, and to train staff, its use should also be reviewed to ensure implementation of appropriate protocols and safeguarding of inmate confidentiality.

e. Inmates in protective custody, disciplinary segregation, or other special units should have access to the same standards of emergency, acute, and chronic care services as other inmates.

Acute and Chronic Care

11. In order for inmates to receive timely access to medical services for acute problems, determination of the level of care needed should be made by an on site staff person trained in medical triage with knowledge of HIV care.

12. The state should establish an effective system for care of inmates with chronic conditions, including HIV. The system should include but not be limited to regular providers, specialized housing, coordinators of chronic health care services, access to permanency planning services, and a statewide computer system to maintain and easily transfer essential inmate medical information.

a. Every inmate with a chronic illness, which includes all inmates with HIV, should be assigned a regular primary health care provider responsible for coordinating care, treatment education, and monitoring the patient’s clinical condition and response to therapy.

b. Every inmate with HIV should have regular access to a physician with HIV/AIDS expertise consistent with AIDS Institute standards for HIV specialists (currently defined in the AIDS Institute manual “Criteria for the Medical Care of Adults with HIV Infection,” published July 1, 1997). The HIV specialist should either be or work closely with the primary care provider.

c. Specialized housing units should be established for chronic care patients, who would include but not be limited to those with HIV. Voluntary residence in these units would be based on medical condition or treatment requirements, not diagnosis. These units would provide a level of care less intensive than that available in hospitals, regional medical units, infirmaries, or hospices, but with support services not available in general inmate housing.
d. A chronic health care services coordinator should be designated for each facility, responsible for insuring that services are scheduled and completed in a timely manner.

e. Permanency planning services should be made available to any inmate with a potentially fatal illness who wishes to plan future care for family members.

13. The state should establish a system to ensure that all new HIV treatment options are made available to inmates in a manner consistent with the 1997 recommendations of the AIDS Advisory Council’s Ethical Issues in Access to HIV Treatment Workgroup, whose report on universal access to HIV treatment should apply equally to prison settings.

a. Since cessation of a current HIV medication regimen can compromise the individual's potential for future benefit from these drugs, the state should do everything possible to ensure that HIV treatment regimens can be successfully maintained. This includes providing access to medications at appropriate hours, accommodations in diet, feeding, and work schedules, monitoring of side effects, and other considerations to encourage maintenance of therapy.

Specialty Care

14. Inmates should have timely access to specialty health services, including specialized HIV care, whenever needed diagnostic expertise and/or treatment services are not available from the inmate’s primary care physician. The primary care provider should be responsible for coordinating specialty consultations, monitoring, and follow-up care.

a. Mechanisms should ensure that consultations and follow-up care are arranged promptly, that impediments to keeping appointments are removed, that results of specialty care visits are reported to the primary care physician, and that recommendations are implemented or reasons for a failure to do so are documented in the inmate’s medical chart.

Inpatient Care

15. Regional Medical Units (RMUs) and all infirmaries housing HIV-positive inmates should meet statewide standards for skilled nursing facilities and should utilize medical personnel with HIV expertise.

a. RMUs should establish cooperative written agreements with Designated AIDS Centers for the provision of complicated HIV care.
16. Standard procedures should be developed and implemented that will ensure coordination of care with an inmate’s regular primary and specialty care providers during a hospitalization and upon the inmate’s return to the prison.

   a. The procedure should be written and distributed to prisons and any RMUs or hospitals to which prisons transfer inmates for inpatient or emergency services.

Terminal Care

17. The use of hospice care should be offered whenever medically appropriate and be consistent with national hospice care standards.

18. Medical parole, which is infrequently granted, should be permitted for any inmate meeting legal criteria who is near death and wishes to die among family and friends.

   a. Current practice based on ambulatory ability excludes many likely candidates and should be reviewed. A broader interpretation of eligibility that does not compromise community safety should be adopted.

   b. Provisions of the medical parole program should be made known to all providers of prison health care and to all inmates who may become candidates.

Transitional Planning

19. HIV-infected inmates should begin participation in a transitional planning program at least six months prior to the expected release date or as early as possible when the length of stay will be shorter. This standard should apply whether release is for discharge, parole, medical parole, probation, work release, or transfer to other facilities.

   a. Transitional planning should be coordinated by trained designated personnel in each correctional facility and should include a follow-up system to prevent disruption of medical care.

   b. Essential medical information and all appropriate documentation should be made available to discharge planners to permit the successful development and implementation of the plan.

   c. HIV-infected inmates released from DOCS custody should have at least a four
week supply of medications, a written schedule of medications and associated nutritional requirements, and specific referrals to community health and social service providers. Discharged or transferred inmates should have received careful instruction about the consequences of discontinuing treatment and the importance of follow-up care.

d. Written agreements among DOH, DOCS, the Division of Parole, and other involved agencies and organizations should specify the roles and responsibilities of each in implementing the discharge plan.

DATA COLLECTION AND ANALYSIS

20. The state should monitor and publicly report by facility at least annually on a variety of indices.

a. These should include but not be limited to:
   - the number of inmates and DOCS staff participating in scheduled HIV educational programs;
   - the number of inmates tested anonymously and confidentially;
   - the HIV infection rate among inmates at intake and the number of inmates known to be HIV-infected;
   - the number of inmates with HIV in treatment and, specifically, the number receiving various forms of HIV treatment (including particular regimens such as combination antiretroviral therapy with and without protease inhibitors), the number of inpatients at RMUs and hospitals, and the number receiving hospice care;
   - the number granted medical parole;
   - the number of inmates receiving transitional planning and referrals for continuation of care;
   - the number of deaths attributable to HIV/AIDS.

b. Blinded seroprevalence studies should be continued on a two year schedule.

c. Records on numbers of HIV-positive inmates should be maintained with demographic data and attributable risk factors but without any information that identifies individual patients. If HIV named reporting is instituted, positive test results by name should not be reported to corrections facilities, preserving an inmate’s right to confidentiality of HIV status.

d. Personnel from DOCS, DOH, and outside contractors should compile information in a standard format and channel all data to the entity responsible for health care in DOCS facilities. There should be a designee at each
correctional facility responsible for monitoring chronic care services.

QUALITY OF CARE/ACCOUNTABILITY

21. Data collection should not substitute for quality of care assessment. DOH and DOCS should work together to implement a continuous quality improvement program for health care in DOCS facilities, adopting the components of the Quality of Care Program developed at the AIDS Institute.

   a. Any continuous quality improvement program for health care in prisons should use both quantitative and qualitative indicators, should document results, should include a plan for action to correct deficiencies, and should build in specified times for audits to ensure that deficiencies are remedied. The goal should be to develop the capability of each facility to maintain its own continuous quality improvement program.

   b. There should be an annual assessment both system-wide and by facility of the quality of health services provided to inmates, including care provided at RMUs and by contractors, including those funded by the AIDS Institute, and specialty care provided under the Coordinated Specialty Care contracts. Written results should be made available to DOCS facilities, government agencies, legislative bodies, and the public.

22. The state should strengthen the Commission on Corrections and/or establish an independent body to monitor the delivery of health services to inmates.

   a. Existing statutory mandates of the Commission regarding HIV education, training, care, staffing, medical records, and other HIV-related provisions should be enforced. Sufficient staff and funding should be provided to accomplish this.

   b. An independent monitoring body should be given a clear and specific mandate and sufficient resources to regularly evaluate health services in prisons and make the results known publicly.

   c. Monitoring bodies should solicit and incorporate input from inmates, former inmates, advocates, and health care providers.

23. The state should monitor funds spent on health services for inmates, tracking specifically the sources and use of all DOCS budgetary allocations for health
care, including resources derived from the inmate phone fund.

FUNDING

24. DOH should be provided with specific budget lines and sufficient funding to provide health care services in prisons that meet statewide standards.

a. Sufficient funding should be allocated to ensure that fully qualified health service providers are hired for DOCS facilities, that contractors and other personnel are supported for comprehensive HIV services, and that continuous quality improvement programs can be undertaken.

b. Savings on inpatient costs resulting from the use of new HIV therapies should not result in a reduced health care budget but should be used to improve HIV and general health services for inmates.

c. Inmates should not pay, through co-payments, indirect charges, or in any other way for health services. Funds now collected through the inmate phone program should be directed toward enhancement of state-sponsored services, for example, broadening HIV prevention efforts at inmate discharge to include family members, or expanding HIV support services in specialized housing units.

25. The state should strive for economic efficiency, utilizing existing empty hospital beds, particularly in New York City, where many inmates have families, instead of building additional costly inpatient units specifically for inmates.

a. Transportation and security measures should be reviewed with a view toward public safety, cost efficiency, and prompt access to inpatient services.

REPORT IMPLEMENTATION

26. A mechanism should be established to review the implementation of recommendations within this report, to remove barriers to implementation, and to address default. A review should occur within one year of public dissemination of these recommendations by the AIDS Advisory Council.
Notes

1. The U.S. currently has about 1.8 million incarcerated people, of whom 1.1 million are in state custody. Although the incarceration rate was 110 inmates per 100,000 people for most of this century, the rate began to increase rapidly in the mid-70s and is now 445 per 100,000 people and 1,100 per 100,000 adult men. Schlosser, Eric., “The Prison-Industrial Complex,” *The Atlantic Monthly*, December 1998, p. 51.


5. Wright, LN, oral presentation, Coxsackie Regional Medical Unit, Oct. 15, 1997.


7. Wright, LN, presentation to the Subcommittee, November 15, 1996.


12. Subcommittee site visit to Coxsackie Regional Medical Unit and Albany Medical Center HIV Care Unit, October 15, 1997.

13. Ibid.


15. Oral communication to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, November 5, 1998.

17. Officials at Albany Medical Center HIV Care Unit, site visit of October 15, 1997.


22. New York State Department of Health Criminal Justice Initiative program charts, provided to the Subcommittee, November 15, 1998.


29. McLave, Michelle, Deputy Executive Director of the AIDS Council of Northeastern New York, in phone conversation with Subcommittee members, December 2, 1998; and Criminal Justice Providers Conference, Albany, New York, June 24, 1997; and reports by members of the Subcommittee.


41. Ibid.

42. AIDS Institute Criminal Justice Initiative materials provided to the Subcommittee, November 5, 1998.

43. Ibid.

44. AIDS in New York State 1997, p. 3 and p. 39.

45. Ibid.

46. AIDS in New York State 1997, p. 38.

47. Correspondence from the New York State Department of Health Bureau of HIV/AIDS Epidemiology to the Legal Aid Society, January 22, 1998, p. 3-5.


49. AIDS-Related Community Services, correspondence to the AIDS Advisory Council Criminal Justice Subcommittee, July 11, 1997.


52. Oral communication to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, September 22, 1998.


54. Wright, LN, phone conversation providing information to the Subcommittee, reported Nov. 12, 1997.

55. Information provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, September 22, 1998.

56. Information provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, September 22, 1998.

57. Correctional Health Services in Transition, New York State Department of Correctional Services, April 5, 1993, p. 5-6.

58. Materials provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, December 22, 1998.

59. Ibid.

60. Prison Health Services Assessment, December 23, 1988, p. 16 and 18.

61. 1992 Prison Health Services Assessment, "Major Findings and Recommendations."


63. Oral information provided to Subcommittee members by inmates at Sing Sing Correctional Facility, site visit of May 1, 1997, and by providers’ focus groups, June 24, 1997.

64. Wright, LN, presentation at Coxsackie Correctional Facility, Oct. 15, 1997.

65. Materials provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, December 15, 1998.

66. Materials provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, September 22, 1998.

67. Officials at Albany Medical Center HIV Care Unit, site visit of October 15, 1997.


70. AIDS Institute Criminal Justice Initiative program summary charts provided to the Subcommittee, November 5, 1998.

71. Ibid.


73. Criminal Justice Providers’ Conference forum, June 24, 1997; and McLave, Michelle, Deputy Executive Director, AIDS Council of Northeastern New York, oral communication, December 2, 1998.


75. Goord, GS, Commissioner of Correctional Services, correspondence to the Honorable Catherine M Abate, New York State Senator, Jan. 29, 1997, p. 3.

76. Materials provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, December 22 and 28, 1998.

77. McKinney’s Executive Law §259-r.

78. Murder in the first or second degree, manslaughter in the first degree, sexual offenses defined under Article 130 or penal law or any attempt to commit any of these offenses.

79. McKinney’s, op cit.


82. Ibid.

83. Oral information provided to the Subcommittee by the Prisoners’ Rights Project of the Legal Aid Society, November 5, 1998.

84. Statutory authority: Correction Law, section 45[6], [15], Part 7651.1- 7651.33 (effective January 1, 1993).

85. Ibid, §7651.4.

86. Ibid.
87. Ibid.

88. Ibid, §7651.18.


91. Ibid, p. xiii-xxiv.


100. United Correctional Managed Care officials, presentation at Coxsackie Correctional Facility, Oct. 15, 1997.


103. Wright, LN, presentation to the Subcommittee, Nov. 15, 1996.


Following is a check list of specific recommendations and their degree of implementation since 1989. (“Partial implementation” means inconsistent availability or available at only some facilities.) The report called for:

1) a special DOCS medical authority, administering care monitored by DOH through a strong quality assurance program, and transfer of health care authority to DOH in 18 months if changes were ineffective; implemented

   not implemented

2) extensive use of outside contractors and community providers, with careful contract monitoring and strict accountability based on needs assessment and funding reviews, little or no use of DOCS staff for direct health care; and a clear and comprehensive medical records system; recent implementation for acute and chronic care just now being implemented not clear

3) sufficient funding for appropriate HIV care; not clear

4) expansion of the acute care hospital network providing inmate services, implemented
emphasizing the Designated AIDS Center hospitals and others with specific HIV expertise, partially implemented
including two secure hospital wards (NYC and upstate); implemented

5) creation of both skilled nursing and health-related facilities not clear

6) close collaboration with Departments of Health and Mental Health; not implemented

7) HIV+ inmates in general population unless acutely ill, implemented
   with HIV education for inmates and staff
   and HIV training for primary care medical staff; partially implemented

8) DOH and DOCS facilitation of inmate participation in clinical trials; not implemented

9) medical release of all non-dangerous terminally ill inmates implemented
   after counseling and discharge planning;
   hospice care; partially implemented

10) drug treatment centers in all prisons; not implemented

11) psychiatric consults for HIV-related dementia, partially implemented
    psychological counseling for inmates and staff,
    staff education about HIV stress,
    inmate support groups,
    counseling for families and friends
    of inmates with HIV; partially implemented

12) special health services for women and their children; partially implemented

13) determination by the Commissioner of Health of whether HIV is transmitted in prison, not implemented
    and, if so, inmate access to condoms; not implemented

14) inmate autonomy in health decisions, not implemented
    including treatment education and informed consent
    and living wills executed by non-prison providers; partially implemented

15) culturally and linguistically appropriate HIV education for all staff and inmates, partially implemented
    including confidentiality requirements;

16) peer educators and counselors; partially implemented
17) DOCS-DOH mandatory HIV education for corrections officers, including confidentiality, and voluntary counseling and testing for officers and their families; not implemented

18) encouragement of voluntary counseling and testing of inmates, providing both confidential and anonymous tests, prevention of discriminatory staff behavior; just now being implemented partially implemented not clear

19) conjugal visits. implemented

Members of the
New York State AIDS Advisory Council
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