Re-entry Issues for Offenders Living with HIV

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Reentry for offenders living with HIV/AIDS is a complex process. The stigma and physical challenges associated with HIV/AIDS create barriers to employment, housing and reunification with family and friends. The need for assistance with health care and social services is integral to an offender's ability to remain healthy and productive. This paper will discuss HIV/AIDS among offenders, care, treatment and education in correctional systems generally and in New Jersey, and the particular needs of offenders returning to the community.

Background

According to the Bureau of Justice Statistics, the rate of AIDS has been higher among prison inmates than in the general population since 1991. New Jersey followed Florida with the largest number of reported AIDS-related deaths in state prisons. (Bureau of Justice Statistics Bulletin, October 2002, NCJ 196023). The introduction of protease inhibitors in 1996 and the other anti-retroviral therapies that followed has improved quality and extended life for many people with HIV. However, there continue to be new infections among inmates because prevention efforts have failed to reach and/or change the behavior of those at highest risk.

Inmates in the northeast had the highest rates of HIV infection. In 2000, New York had the highest percentage of inmates known to be HIV positive (8.5%) and New Jersey reported 3.2% in the general prison population and 6.8% of the female population. (Bureau of Justice Statistics Bulletin, October 2002, NCJ 196023)

The most recent study conducted by the Department of Health in 1999 found a rate of 4.1 sero-prevalence and 8.4% sero-prevalence rate among females. This was an anonymous unlinked survey that tested the blood of offenders entering the prison system over a three month period. The results of this study only demonstrate the sero-prevalence rates among the newly incarcerated. It also confirms that there is a significant number of inmates infected with HIV who need care. (Interview with Helene Cross, PhD, DOHSS) According to the State Department of Corrections, as of December 2002 a total of 601 inmates had HIV and 160 were diagnosed with AIDS. Of these numbers, 66 women tested positive for HIV and 19 are diagnosed with AIDS.

Recent research confirms the importance of correctional settings for HIV prevention and treatment interventions. There has been tremendous growth in the incarcerated population. There is an over-representation of people of color and a disproportionately heavy burden of infectious diseases and other health problems among inmates who have had poor prior access to health care. Correctional facilities have an opportunity to provide prevention and treatment services in a high risk "captive" population that could result in future savings in health care, law enforcement and incarceration costs. ("A National Perspective on the Correctional Response to HIV/AIDS, 1985-1999", Connections to Care Conference May 30, 2002, Theodore Hammett, Ph.D., Abt Associates Inc.)

Services provided within correctional settings also better prepare the offender for re-entry. Assuming that correctional health services are prepared to treat offenders with HIV/AIDS, testing and treatment in prison may be the first opportunity to assess the extent of their HIV infection and their ability to tolerate complex drug therapies. Coupled with shelter, food and a greater likelihood of sobriety while incarcerated, inmates are often healthier than they were prior to incarceration. If they are able to re-enter the community healthier than when they left and connect with health care resources in the community, they have a greater chance of success.

During the early years of the epidemic, advocacy and service efforts were directed toward the gay community while ignoring the rising epidemic among injection drug users. New Jersey has always had the distinction of having the majority of cases of HIV/AIDS caused by injection drug use. Prevention efforts did not target injection drug users or correctional facilities with a high percentage of inmates with injection drug use histories. There were a few programs around the country as early as 1984. In that same year in New Jersey, there were limited educational efforts in a few of the county correctional facilities. There were no formal education, treatment or prevention programs in the state institutions.

Offenders with chronic or terminal illnesses face the challenge of managing their health care upon return to the community. Offenders living with HIV/AIDS also have the additional burden of the stigma of HIV. In addition to complex health management issues, positive HIV status may affect their access to housing and employment. Fear of disclosure of HIV status may interfere with reconnecting to family and friends, an important source of support in the reentry process. Infection with other blood-borne pathogens, in particular Hepatitis C, is an increasing problem because of the associated treatment concerns and the possibility that one condition may exacerbate the other.

Health concerns for incarcerated women are complex and require a particular response from correctional health care systems. “The rate of HIV infection is generally higher for women than for men within the same state or county correctional system, and incarcerated women usually face an array of difficulties and risk, including a history of drug use, high risk sex work, and sexual abuse”. (Harm Reduction Inside and Out: Controlling HIV In and Out of Correctional Institutions, Hollibaugh, AIDS Read 10(1):45-52, 2000, c. 2000 Cliggot Publishing, Division of SCP Communications)

Incarcerated women with HIV require regular gynecological services to screen for HPV and other STIs. Pap smears are recommended every six months. An initial exam should include a pelvic exam, pap smear, pregnancy and STI screening. Health care staff should ask detailed questions about menstruation, gynecological symptoms, pregnancies and abortions, history of physical, sexual, and emotional abuse. Substance abuse and history of sex work and mental health history must be determined as they affect HIV care. (“Pushing for Progress: HIV/AIDS in Prisons”, National Minority AIDS Council, June 2002)

Roe v. Fauver

This class action lawsuit was initiated by inmates challenging the segregation of inmates with AIDS, the denial of programming and services, and the adequacy of medical care. A Consent Decree was entered into in March of 1992 and still serves as a blueprint for the Department of Corrections as to the care, treatment, education and housing of inmates with HIV/AIDS in the correctional system.

The terms of the decree provide for the desegregation of inmates with AIDS from special housing units and ensures that housing assignments are not made on the basis of HIV status. The Consent Decree also states that access to programs, services, jobs, work release and furloughs must be given to inmates with HIV. Medical care shall be provided in conformity with US Public Health Service recommendations and an HIV risk assessment taken by trained medical staff must be included in the health screening for each inmate upon entering the system. The document outlines in detail the medical care expected and the training of health care professionals involved in the care of inmates. It also outlines the process by which inmates should be informed of their medical care, have access to staff to respond to inmate questions and medical records. Details about access and information about drug therapies is also included. Education and training is required for all staff and inmates.

Current State and County Services

In 1999, the State Department of Health and Senior Services (DOHSS-DOA) received funding from the CDC to implement, with the State Department of Corrections (DOC), comprehensive HIV/AIDS programming in three of the adult facilities. Two other facilities, one county correctional facility in Monmouth County and the juvenile secure facility at Jamesburg, were included in the program. With additional funding from Ryan White Title II, the DOHSS expanded the programming to seven other state and contract facilities. In addition, the State Department of Corrections allows inmates access to an 800 warm-line for HIV/AIDS information and discharge planning assistance operated by a non-profit AIDS services agency. This service allows all inmates, even if they are incarcerated in facilities not included in the state program, access to information and assistance. It is also a vehicle for correctional staff to gain information about community services.

The state sponsored programs offer counseling and testing, basic health education and risk reduction sessions, treatment education, STI and Hepatitis information and resources, discharge planning and follow-up in the community upon and after release. The prevention aspects of the program are targeted to high-risk inmates and are intended to continue after release. The goal is to keep those at high risk HIV negative and help to remove barriers to positive behavior change.

The success of the projects depends largely on the cooperation of institutional staff and the expertise of the project staff. Project staff must work closely with the

medical services contractor, Correctional Medical Services. The program staff must gain the trust of the inmate population, custody and medical staff. Effective programming also relies upon the availability of appropriate space for counseling and group sessions and the ability of staff to operate independently between inmate movements. Some projects hold activities two and three times during the day and in the evening to maximize access to the inmate population.

To effectively assist inmates in discharge planning, project staff need access to medical records, parole and/or release plans and individual meetings with inmates anticipating release. New Jersey state institutions are located throughout the state with a large percentage of inmates housed one and one half to two and a half hours from their cities of origin and the home of family and friends. This creates a barrier for the projects. To secure medical and social service appointments for inmates in communities outside of the project's operating area is more difficult. To act as a liaison and advocate when a client is released is more time consuming as a result of the travel. Public transportation is limited in the southern part of the state and can be a huge barrier for inmates in poor health without resources.

Services in the county correctional facilities vary. Apart from the State sponsored program in Monmouth County Correctional Facility, other counties rely on community-based organizations to provide services with funding from the Ryan White Care Act or other sources. Some counties provide testing inside the facilities but there is no uniform system of service delivery. Responses to an informal survey find that Atlantic, Burlington, Camden, Cape May, Gloucester, Hudson, Hunterdon, Morris and Union County Correctional Facilities provide HIV services, counseling and testing and discharge planning. In Bergen, Passaic, Somerset, Salem and Warren County Correctional Facilities staff report that HIV services and counseling and testing are provided. Information was not obtained from Ocean, Sussex, Middlesex, Essex and Mercer Counties. Services are not uniform and may include discharge planning, prevention/education, health education and risk reduction sessions and case management and counseling and testing. HIV services may refer to health care services only.

Guiding Principles of the Re-entry Roundtable and the intersection of HIV/AIDS

The following session lays out a series of recommendations on how New Jersey could improve outcomes for individuals living with HIV who are leaving incarceration, using as a starting point the guiding principles of the New Jersey Reentry Roundtable.

1. *A reentry strategy for New Jersey should ensure that adults and juveniles returning to their communities from incarceration or detention are sufficiently prepared so as to maximize their chances for successful reintegration.*

Custody, Administrative and Medical Staff require HIV/AIDS Training

The challenges created by HIV/AIDS require particular responses from the correctional community. Custody, administrative and medical staffs must receive

training to understand HIV transmission and pathogenesis with the goal to minimize fear and maximize the use of universal precautions, protect the confidentiality of medical records and HIV status and ensure that disease management and prevention messages are appropriate. Only then will correctional facilities be prepared to provide the medical and social services needed by inmates with HIV/AIDS. This is basic to preparing inmates with HIV for discharge to the community.

Testing Must Be Offered and Conducted Prior To Release and Drug Therapy Initiated and Provided

Preparing inmates for release should include education about HIV testing and provide testing upon request so that inmates can find out their HIV status before they get sick. Inmates who are positive must be evaluated and a determination made with the inmate if drug therapy should be initiated. If the inmate is on drug therapy upon release, he/she needs enough medication on hand until the next scheduled medical appointment, as well as a prescription in the event the medical appointment is cancelled.

Drug Therapy Must Be Appropriate - Supporting Adherence is Critical to Future Health

During incarceration it is critical for inmates to maintain their health, decrease harm and preserve the immune system before becoming vulnerable to opportunistic infections. This means they must have access to antiretroviral medications to suppress the amount of HIV produced. Adherence to drug therapy is key - no missed doses or failure to receive medications for any period of time. The health care staff must create a sequenced treatment plan. Optimize, maintain and extend the use of currently available anti-HIV therapies and avoid development of drug resistance. This means health care staff must think long-term even if an inmate will be with them for a relatively short period of time. Each choice in drug therapy affects later options. Starting with the wrong drug combination can eliminate other treatment options in the future. Health care management includes minimizing toxicity, and managing side effects and drug interactions.

An assessment of the Department of Corrections current adherence to the Roe v. Fauver Consent Decree should be undertaken with particular attention to the education and training of inmates and staff and the medical management of inmates.

2. A reentry strategy for New Jersey should seek to eliminate the structural and legal barriers to reintegration that are unnecessary to preserve public safety.

Prior to release, correctional facilities must provide inmates with copies of medical records regardless of the inmates ability to pay. **Applications for the AIDS Drug Distribution Program, Medicaid and Social Security should be completed during incarceration so that the process can be initiated immediately upon release.**

Securing access to benefit programs prior to release is key to connecting offenders to care quickly without barriers. All people living with HIV/AIDS may qualify for disability benefits provided by the Social Security Administration but the application and appeal process established by Social Security can be long, tedious and taxing with particular challenges for ex-offenders. There is a need to document the medical care received while incarcerated and/or in the community. Documents must be made available for review by Social Security staff. Benefits received prior to incarceration and payments made during incarceration may impact an inmates ability to receive benefits upon release.

All programs, including SSDI and SSI require medical records, such as blood tests, laboratory work, and physicals which are often difficult to obtain and evaluate by social service providers assisting ex- offenders with the application process. Inmates are often discharged without copies of medical records and other documents. There can be costs associated with obtaining these records and the inmate does not have the required funds. Additionally, all applicants for entitlement programs need a social security card, birth certificate, names and address of all doctors, hospitals and clinics that have provided medical treatment as well as a thorough explanation of how HIV/AIDS has affected the applicants activities of daily living.

Often inmates do not have the required documents for these applications. Many ex-offenders must locate, or in some cases obtain for the first time, their birth certificates and social security cards. This slows down the application process. Institutional staff could order birth certificates and copies of social security cards, copy medical records and ensure that the records reflect the condition of the inmate prior to release.

Correctional facilities must make appointments with health, social or AIDS services providers in an effort to link offenders to care thus establishing a connection with community agencies prior to discharge.

The most difficult hurdle faced by applicants is meeting the strict definition of disability outlined by the Social Security Administration. Social Security usually defines HIV as a disability based on severe impairments like pulmonary tuberculosis, carcinoma of the cervix, lymphatic cancers and neurosyphilis. Therefore, all applicants, including ex-offenders, are challenged to explain and document the day to day symptoms and the general malaise associated with chronic HIV infection. Although some symptoms and general malaise are not recognized as a severe impairment by Social Security, they clearly contribute to the client's overall disability and inability to sustain gainful employment. The medical records from correctional facilities are not enough to prove the applicant's inability to work. It is critical for the ex-offender to continue care and treatment once they are in the community. Social Security requires an applicant to be under medical supervision while they are applying for benefits. Therefore, the continuation of care for ex-offenders must start in the institution - develop a discharge plan and link offenders to care with community agencies prior to discharge.

If the inmate does not have a permanent address, arrangements with social or health care agencies must be made to receive the inmate's mail.

The first few months of the application process for Social Security are important because any unobtainable or missing information for the application and file will significantly slow down the claim process. When an applicant with HIV first applies for Social Security they are often denied. This can be a particularly difficult time for ex-offenders who have little resources and support. Ex-offenders often become frustrated, lose contact with community agencies, and drop out of the application process. Often it is at this point in the process that ex-offenders lose contact with community agencies and do not follow through with the application process.

Applying for benefits is a lengthy and tedious process. It requires patience, organization and perseverance on the part of the social service provider and applicant. It also requires the applicant to have a stable living arrangement and permanent address. The volume of mail received and returned to Social Security during the application process is enormous. The consequences of any delay results in delayed decisions or even termination of the case.

Inmates receiving Social Security prior to incarceration should be advised to inform Social Security that they have been incarcerated.

Individuals convicted of a felony and incarcerated are not entitled to benefit payments while incarcerated. If payments were mailed and cashed during an inmate's incarceration, Social Security will demand a refund. This will affect the former inmate's new application and payment amount. Applicants must prove that they were not responsible for or gained from any illegally cashed checks. They may apply for a waiver of overpayment or make retribution while receiving payments under a new claim.

3. A reentry strategy for New Jersey should acknowledge the roles that families and communities play in the reentry process and ensure that they are sufficiently prepared to take on those responsibilities.

HIV Education for Families Should Be Incorporated Into Institutional Programs

Every effort should be made to reach the families of inmates living with HIV. For inmates who consent, a discussion with family members may make the difference between those who are able to maintain their physical and mental health and those who are not. Education about HIV transmission, care and treatment are essential. Many families do not understand the disease and are fearful of the returning family member, especially when there are children in the home. If HIV programs within an institution already exist, seminars for families should be offered. Seminars could, for example, be provided during the period immediately preceding a visit session or as part of a children's program. Materials and staff to provide information should be on hand. Families should

be encouraged to support the treatment plan and be aware of food or drink that may interfere with drug efficacy or exacerbate adverse effects.

Family Reunification for Women with HIV Requires Additional Support and Education for Families and Division of Youth and Family Services (DYFS) Training

For women reuniting with children, the educational process is critical for supporting family members, as it is not unusual for women to ignore their own health while caring for their children. Children need to be prepared for the return of a parent, especially one who is disabled. For families who will be reunited under the supervision of DYFS, it is essential that DYFS staff have a thorough understanding of HIV disease, transmission and related psychosocial issues to support the reunification process.

4. A reentry strategy for New Jersey should recognize that financial resources are limited and should be used wisely and creatively, with firm accountability.

The fact that current federal levels of funding available for HIV treatment and services are insufficient to the needs outlined by the HIV advocacy community poses very serious problems for people living with HIV in New Jersey. The struggle to secure and maintain additional federal funding remains a tremendous challenge. Many of the programs vital to our ability to address the epidemic, such as HOPWA (Housing Opportunities for People with AIDS) have been cut or face an uncertain future in the new administration. ADAP, AIDS Drug Distribution Program is the only source of medication for many people living with HIV/AIDS. Although New Jersey is meeting current demand, federal funding has been cut. Some states have already adopted waiting lists and cuts in the drug formulary, limiting access to life saving treatments.

The State must consider matching existing federal dollars and implement cost effective early identification programs.

Additionally, we face cuts and programmatic changes in our health care programs for the poor and needy, particularly Medicaid, which is the only source of health care and treatment for many ex-offenders. The State must consider matching existing federal dollars and implement cost effective early identification programs which prioritize the medical management of HIV to avoid enormous health care costs associated with treating AIDS.

To invest in medical care for inmates while they are incarcerated and ensure that funding is directed toward continued care in the community is a cost saving measure. Given that studies have shown that quality medical/social discharge planning and community support impact recidivism, it will save money in the long run by reducing the cost of incarceration.

5. *A reentry strategy for New Jersey should include policy goals that reflect solid research and a plan for broad public education around these goals geared toward public officials, the media, and the public at large.*

Public education for public officials and the community at large to support changes in the law to allow access to sterile syringes is necessary for successful HIV prevention.

Syringe exchange, condom distribution and harm reduction strategies are critical to slowing the spread of the epidemic. For inmates with HIV returning to the community and likely to recidivate and return to drug use, syringe exchange may be the only means to limit the transmission of HIV.

Syringe exchange is illegal in New Jersey. As already stated, we owe the majority of our HIV epidemic to transmission through injection drug use. Research demonstrates that the use of sterile syringes stops the transmission of HIV. We don't need to conduct additional research. What is needed is public education for pubic officials and the community at large to support the necessary changes in the law, and implement syringe exchange.

A study should be conducted to assess the rate of recidivism in general and how chronic and acute health care conditions contribute to the problem.

There is very little data collection and information with regard to the health conditions of incarcerated inmates and those supervised by Parole. Information about access, quality of care and adherence to treatment regimens for parolees would assist with program planning and interventions.

A study should be conducted to determine the prevalence rate of the currently incarcerated.

This will provide important information about health care, treatment and prevention which can better inform the discharge planning process.