AIDS Law Project of Pennsylvania

a non-profit,
public interest
law firm

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Nan Feyler, Esq.
Executive Director
AIDS Law Project of Pennsylvania

Good afternoon. Thank you for this opportunity to address several concerns regarding the medical treatment of HIV infected inmates in our state prisons.

The AIDS Law Project of Pennsylvania is a non profit public interest law firm which has been serving the legal needs of people with HIV and AIDS from throughout the Commonwealth since 1988. Last year we provided free legal information, advocacy, and representation to more than 1800 people.

In 1997, in response to the growing number of HIV infected inmates writing us for help, we created a project devoted to assisting them. Our goal is to ensure that the community standard of care is reflected in medical treatment for HIV infected inmates while incarcerated and to ensure continuity of care throughout their incarceration - from arraignment through release.

There are four concerns I would like to briefly address today. They are: 1) the problem of medication interruptions for HIV infected inmates; 2) the need for Keep on Person delivery of medications; 3) the need for systematic and effective discharge planning and linkages to community clinicians upon release; 4) education and prevention measures for all inmates in Pennsylvania. These issues are not only of key importance to inmates and their families, but they are important public health concerns.

1211 Chestnut Street • Suite 1200 • Philadelphia, PA 19107
(215) 587-9377 (215) 587-9902 FAX

HIV Infection Effects Inmates at Staggering Rates

The growing changes in sentencing laws and the increasing incarceration of individuals for drug use have contributed to the exponential growth in the number of HIV infected individuals in prisons. The people at greatest risk of being infected with HIV reflect the same communities hardest hit by high rates of incarceration. While the exact number of incarcerated men and women living with HIV is not known, we do know that the prevalence of HIV and AIDS within correctional facilities is substantially higher than in the general population. As of 1998, the US Department of Justice reported that HIV/AIDS occurred in the corrections population nationwide at up to 5.5 times the rate of the general population. While women are substantially under represented in prisons, they are disproportionately affected by the HIV epidemic. In New York State prisons, for example, 20% of female inmates are known to be infected with HIV. The prevalence of HIV and AIDS is higher among Hispanic and black inmates than among white inmates.

According to the Pennsylvania Department of Corrections, as of December 1997 there were 697 inmates confirmed with HIV infection, of these 44 were women. This is a total of 2% of the inmate population. Looking at the rate of infection in similar states, we suspect these numbers do not accurately reflect the real numbers of infected inmates. More aggressive HIV education and voluntary testing would no doubt increase these numbers.

The Medical Concerns of HIV Infected Inmates

Protease inhibitors and combination therapies have brought dramatic

improvement in the medical condition and survival of people infected with HIV both within and outside prison. The US Health and Human Services guidelines on treatment provide a detailed standard of care which is regularly updated as new medications are approved, and more experience is gained.

These regimes are complicated, however, and pose special challenges in the corrections system.

1) Medication interruptions for HIV infected inmates

One of the major limitations of HIV antiretroviral treatment is that medications must be taken exactly as a physician prescribes to avoid a patient developing a drug resistant strain of HIV. HIV medications are "unforgiving." When treatment is interrupted or dosages are incomplete or missed, even only a few times, an inmate may become resistant to the medications they are currently taking, as well as other similar HIV medications, permanently eliminating a class of potential life-sustaining medications for that inmate. When an inmate's medications fail, opportunistic infections develop, serious side effects occur and treatment problems multiply. Drug resistance can lead to disease progression and the onset of life-threatening illnesses which, at the very least, can be very expensive to treat. In addition, upon release, an individual who has developed a drug resistance strain of HIV could potentially transmit it to others. Indeed, studies are beginning to show that newly infected people are already infected with a strain of HIV resistant to some or all current therapies.

Unfortunately, interruptions in medication is a real problem in our state prisons. We routinely hear from inmates whose medications have been interrupted for a variety of

reasons. Since 1999 we have been mailing a brief medical survey to infected inmates on our mailing list to better understand their care. The numbers are small –we have received completed surveys from 46 inmates (out of 74 inmates). However, their experiences is troubling: More than 76% of the inmates responding to the survey indicated that they had experienced interruptions in their HIV medications. This is an overwhelming percentage of inmates who now have an increased risk of developing drug resistance and declining health.

Specifically, inmates report that interruptions seem to occur for a variety of reasons, including refills were late, the inmate was too sick to wait on line, the inmate was newly arrived to the prison, medications were given at the wrong time or the person was in the RHU.

Recommendations: Develop quality assurance programs to ensure that all HIV related medications are provided without interruption or delay.

2. The need for increased use of self-medication (or "Keep on Person")

Directly observed therapy (DOT) refers to the process of requiring inmates to go to medication lines in order to receive each dose of their medication. Until recently, HIV infected inmates have been allowed to keep their medications in their cells and were only required to go to the medical department for refills (called "Keep on Person" or KOP). Inmates took their medications in the privacy of their cells. This method provided greater assurance that other inmates were not aware of their medications, the frequency of dosages or the number of pills that they are required to take. Many states continue to permit HIV infected inmates to take their medications to their cells in daily or weekly

bubble packs, with great success.

We believe that it is a mistake to eliminate KOP for all HIV infected inmates as has been the recent trend. It is our fear that if HIV infected inmates are required to take part in directly observed therapy, they may refuse to take HIV medications for fear of others learning their HIV status. This is a very real concern of many inmates, particularly women, who tell us that they live in overwhelming fear that their HIV status will be made public, and reported at home, for example to their children who are unaware of their mother's illness.

Many inmates on directly observed therapy report they have trouble making the long walk in some institutions to get to the medication. Many facilities continue to require inmates to walk outside year round in all kinds of whether to get to the med line, thus exposing the inmates to varying weather conditions. With immune systems that are already compromised, HIV inmates will be much more susceptible to disease.

Above all else, inmates infected with HIV should have the opportunity to learn their medication regimens, the protocol for taking the medication, the dosages and the timing of medications. Directly observed therapy does not give inmates this opportunity. They are not afforded the benefits of learning their complicated medication regimen under the supervision of the medical staff.

Recommendation: Institute "Keep on Person" program for inmates who demonstrate an ability to adhere to medications regimes. Alternatively, at the least, begin self-medications during the months before the inmate will be released. Provide ongoing education and support (including peer education) to HIV infected patients on the

importance of adherence to their medications.

3. Discharge Planning and Linkages to Community Clinicians

My third point is necessary to underscore the need for well developed and well-funded services for HIV infected inmates who are released from one of the state correctional facilities. The good news is that all HIV infected inmates are currently released with a 30 days supply of HIV medications. However, there is no systemic program to ensure that inmates are linked to physicians experienced in treating people with HIV, and not every inmate is released with a medical discharge summary needed for their new treating physician. Obviously, losing a person to medical care can result in the person become sicker as their health deteriorates from interrupted medical care. Conversely, studies show that released inmates involved in comprehensive HIV related programs have a reduced rate of re-arrest and drug relapse.

Inmates tell us that the transition back to the community after years in a state prison can be very difficult and confusing. For many inmates, the first HIV related medical care they receive is in prison, either because they first learned their diagnosis in prison or did not have access to adequate health care on the street.

In a recent survey of 79 inmates requesting case management assistance from BEBASHI to help them when they get out, almost 87% reported not having a doctor to go to when they are released. They simply don't know where to go for medical care. It is common for a person who has been treated for HIV in prison to arrive at a community clinic (usually because he or she has started to get sick) many months since last on HIV medications in prison. Physicians tell us it is extremely difficult to properly treat

someone with this history of interrupted health care. Also, if rearrested, these same inmates are more costly and difficult to treat.

The public health consequences, the increased cost of treatment, and the human suffering that interruptions in HIV care cause can be avoided through careful discharge planning. Careful planning includes linking inmates to AIDS service organizations in their areas, giving them an adequate supply of HIV medications, and ensuring that they have a complete medical discharge summarily upon release. Ensuring continuity of treatment, beginning with an inmate's intake in prison through his or her release to the community, is of critical concern.

Recommendation: As other states are beginning to recognize, coordination and board participation of all segments of the public health, criminal justice and community-based organizations is required. We recommend that a statewide task force of key decision makers within DOC, DOH, DPW, ADAP, community corrections and community based medical and social services agencies begin more systematic planning so that inmates are linked to care and support prior to release. Specifically, all HIV infected inmates should continue to be released with a 30 day supply of medications. They should also receive a medical discharge summary, appointment with HIV experienced physician and have an established relationship with am HIV transitional case manager.

4 Education and Prevention Measures for All Inmates in Pennsylvania

As I noted earlier, a high percentage of HIV infected inmates are first diagnosed in prison. Of the inmates who reported a place of diagnosis to BEBASHI, more than

57% answered prison. This statistic illustrates the great need for education, medical care and other programs for inmates living with HIV. The prison system has the unique opportunity to introduce educational information and supportive programs to inmates when they are first diagnosed with HIV. While incarcerated, inmates infected with HIV can be given information on health care and treatment options.

In addition, HIV prevention efforts should be enhanced. The DOC has instituted peer education programs, which is reportedly very successful for inmates involved. It should not doubt be expanded.

We believe that the Pennsylvania should join the other two states and eleven cities, including Philadelphia, and provide condom distribution within the prison setting. It is incumbent of the Department to recognize that, while such activity is prohibited, sex continues to occur within prison. Studies show that condom access does not result in increased sexual activity and does not threaten prison security. Availability does, however, help reduce the spread of HIV within prison, and reinforces behavior to reduce the spread of HIV upon an inmates release.

Recommendation: Begin distribution of condoms within the state prison. Alternatively begin a pilot project in one of two prisons to evaluate the programs success.

There is no doubt that strides have been made in the treatment of inmates with HIV. For many, prison is the first opportunity to learn their HIV status and receive HIV treatment. We hope that these problems can be addressed to ensure that incarcerated people at risk or living with HIV will return to their community, healthy and ready to continue good care.