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The AIDS Law Project of Pennsylvania is a non profit public interest law firm which, since 1988, has been serving the legal needs of people with HIV and AIDS from throughout the Commonwealth. Last year we provided free legal information, advocacy, and representation to over 1700 people.

Two years ago, in response to the growing number of HIV infected inmates writing us for help, we created a project devoted to assisting them. We see our primary responsibility to advocate 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 back to their community. There are three issues I would like to briefly address today. I welcome, of course, further discussion on any of these or other related issues. They are: 1) the need for inmates to receive care from an HIV-experienced clinician; 2) the need for adequate nutritional expertise and support for inmates with HIV; 3) the need for systematic and effective discharge planning and linkages to community clinicians upon release. These issues are not only of key importance to inmates and their families; they are important public heath concerns.

HIV Infection Effects Inmates in Staggering Rates

The growing changes in sentencing laws and the increasing incarceration of individuals

with drug use have led to the exponential growth in the number of HIV infected individuals in prisons. People at greatest risk of being infected with HIV reflect the same community hardest hit by high rates of incarceration. While the exact numbers 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. According to the World Health Organization, in 1998 HIV/AIDS occurred in the correctional population at up to 14 times the rate of the general population. While prisoners represent .34% of this country's total population, they account for 4.6% of all AIDS cases (U.S.D.J., 1994). While women are substantially under represented in prisons, they are disproportionately affected by the HIV epidemic.

In the Commonwealth, according to the Department of Corrections, in January 1998 there were two hundred and twenty once inmates confirmed with AIDS. It was not reported how many are infected with HIV or how many are being treated for HIV disease, although 113 inmates learned they were infected with HIV when tested in prison in 1998. According to the DOC, in 1992 there were 13 deaths from AIDS and in 1997, 19 inmates died from AIDS.

The Medical Concerns of HIV Infected Inmates

Beginning in October 1998, the AIDS Law Project began mailing surveys to inmates with HIV/AIDS in Pennsylvania State Correctional Facilities. By the end of February 1999, 47 (out of 190 inmates) responded from over nineteen state prisons. While this is a relatively small sample, the responses are instructive.

The good news is that in most institutions the majority of HIV infected inmates appear to be receiving what approaches the minimum standard of medical care. Inmates report that,

consistent with community medical standards, 90% had CD4 and viral load testing within the last three months. 72% were on one or more protease inhibitors and 84% were on one or more other antiretroviral medication. Viral load and CD4 numbers were generally good in these respondents.

Several concerns, however, are reflected in these survey results, in our investigation of inmate concerns, and in communications with Corrections nurses and physicians.

1) Access to physicians experienced in treating people with HIV disease

Medical literature abounds with data which confirms that HIV is a complicated and ever-changing field where experienced physicians are needed to adequately treat the patient. Increasing amount of data shows that survival of patients with HIV is prolonged if patients are cared for by physicians who are experienced in the management of HIV infection. At the Johns Hopkins HIV care programs for example there was a 12% reduction in cost and 20% increase in survival for AIDS patients who were treated by experienced physicians. According to the Infectious Disease Society of America "generalists who provide primary care for small numbers of individuals with HIV cannot be expected to provide the best and most timely care considering the rates of change and growth of knowledge regarding care and the high complexity of [disease] management."

In our survey, only 41% were seen by physicians experienced in treating individuals infected with HIV. The Department of Corrections policy to rely on general practitioners who attend seminars is not cost effective, can endanger lives, and enhances suffering of HIV infected inmates. When an inmate's medications fail, opportunistic infections develop or serious side occur, problems multiply. More than once I have reviewed an inmate's protocol with a community based clinician who advises more aggressive and more immediate changes in

medications or other strategies.

Recommendation: a standard of care utilizing the expertise of experienced clinicians must be developed, enforced and funded, using telemedicine or other technology where necessary.

2) Adequate nutritional expertise and support for HIV infected inmates

Early intervention to prevent significant weight loss and wasting syndrome of inmates with HIV is another serious issue threatening the lives of inmates with HIV. Side effects of medications, mouth lesions, altered sense of taste, malabsorption and endocrine dysfunction are all medical conditions common to people living with HIV. Medical literature is replete with studies which show that avoiding weight loss and nutritional complications saves money and lives.

The majority of HIV inmates complain of some of these problems. Many report unexplained weight loss of more than 10% of their base line weight while in prison. Of special concern, is a recent trend where inmates complain that what extra nutritional support they had -- for example extra meal portions or food supplements such as "Ensure" has been cut back or eliminated in the last few months. Short term cost saving will result in longer term and greater expenses without more aggressive DOC standards.

Recommendation: Consistent with community standards, a uniform standard of care for nutritional evaluation and support be developed for HIV infected inmates with access to experienced nutritionists when needed.

3) Discharge Planning and Linkages to Community Clinicians Upon Release

My third and final point is 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 advent new treatment regimes, along with lengthening the survival and quality of life of people with HIV, has created unique challenges, particularly in Corrections. One of the major limitations of HIV antiretroviral treatment is the development of drug resistant strains of HIV if treatment is interrupted or dosages are missed. Drug resistance can lead to disease progression and the onset of life-threatening illnesses which can be very expensive to treat. Inmates released to the street without medications and linkages to physicians experienced in treating people with HIV often become sicker as their health deteriorates from interrupted medical care. Ensuring continuity of treatment, beginning with an inmate's intake in prison, and up through his or her release to the community, is of critical concern.

For many inmates, the first HIV-related medical care they've had is in prison, either because they first learned their diagnosis in prison, or did not have access to adequate health care on the street. They don't have doctors to go back to and they don't know where to turn. Many leave prison not even knowing how important uninterrupted medical treatment is to their health. It is not uncommon 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 antiviral medications in prison. In the meantime, the patient's HIV infection has worsened, and he or she may have developed increased resistance to lifesaving HIV medications. Physicians tell us it is extremely difficult to properly treat someone with this history of interrupted health care.

If rearrested, these same inmates are more costly and difficult to treat in prison and jail. Advanced AIDS, and opportunistic infections are far more expensive and complicated to treat, often requiring hospitalization which can be avoided with effective, potent and continuous antiretroviral treatment. In addition, resistance to one antiretroviral medication can mean cross

resistance to other antiretroviral medications reducing treatment options. Cross-resistance among all the protease inhibitors seems likely, making it difficult to regain HIV suppression once a regimen fails and limiting future treatment options. This means that the consequences can be life threatening and, at least until new therapies are developed, lifelong. "Salvage therapy" for people who have resistant strains of HIV very often fails.

In addition, all HIV infected inmates released from prison must be given a medical summary of all their medical history, lab tests or medications. Otherwise, unnecessary and expensive tests must be ordered in clinics, wasting money and valuable time once an inmate is released.

The public health consequences, the associated increased medical costs and human suffering attendant to interrupted HIV care must be avoided through careful planning and the expenditure of resources to ensure every HIV infected inmates who is released to his or her community is linked to AIDS services and has an adequate supply of HIV medications and a complete medical discharge summary.

In the past year the AIDS Law Project and the Medical Director's office of the Department of Corrections have begun working together to developing discharge planning guidelines and programs. Despite lack of funding, since last summer one case manager at BEBASHI a Philadelphia-based case management agency has been assigned to this project. He now has over 75 HIV infected inmates seeking his help who are to be released in the next six months back to Philadelphia. Many are without housing, family support and most have no idea where to get medical care upon release. This one case manager is overwhelmed. Funding to support adequate linkage programs is nonexistent

Recommendation: Funding be established to provide a statewide case management and medical linkage program to ensure that HIV infected inmates are linked to HIV experienced clinicians and other support upon release back to their community.

Thank you for your consideration of these issues. Please do not hesitate to contact me for further information and discussion of these concerns.

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