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## HIV on the Inside

As the contributors to this issue of *ACRIA Update* make clear, the twin epidemics of HIV and HCV continue to seriously impact the health and well-being of prisoners across the U.S. For those who have never been incarcerated, it is all too easy to ignore the epidemic that is raging behind the bars of this country's prison system. But with a quarter of all people with HIV receiving their care while in prison, any attempt to address the HIV epidemic must look seriously at the quality of care, and the quality of life, of people living "on the inside."

Unlike any previous issue of *ACRIA Update*, we found when contacting writers that many felt constrained in their ability to

speak out against problems in the prison system. Whether they feared losing funding or were reluctant to criticize their employers, more than one author we approached did not feel they could write a piece that told the unvarnished truth about HIV in prison.

Likewise, many prisoners were unable to speak honestly, for fear of reprisals from both the correctional system and other inmates. We applauded those who did contribute and who even asked us to sign their name in spite of the consequences of such outspokenness. We can only hope their courage is met by an equal commitment from those of us "on the outside."

*Mark Milano*

## Prison Health = Public Health:

### HIV Care in New York State Prisons

*by Romeo Sánchez*

*"The degree of civilization in a society can be judged by entering its prisons." – Fyodor Dostoevsky*

There is a public health emergency in New York State prisons. Infection rates of HIV and hepatitis C virus (HCV) are 8 to 10 times higher in prison than in the general community. Women are disproportionately affected by both diseases. The most recent NYS Department of Health (DOH) blinded seroprevalence studies found HIV infection present in 5% of men and 14% of women. HCV infection rates are 14% for men and 23% for women. The NYS Department of Correctional Services (DOCS) estimates that there are approximately 10,000 prisoners with HCV – but this is very likely an underestimate. Published studies of pris-

oners in the correctional systems of California, Texas and Maryland have found that 30-40% of prisoners test positive for HCV. Since NYS DOCS currently houses about 65,000 prisoners, this indicates a probability of under-reporting.

There are 70 prisons in New York State, and the health care provided at each facility is subject to oversight only by DOCS, with no effective review by any outside agency. Whether a prisoner receives adequate care is dependent upon whether he or she is lucky enough to be at a facility where the generally understaffed and often poorly

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ACRIA is an independent, non-profit, community-based AIDS medical research and treatment education organization dedicated to rapidly improving the length and quality of life for people living with HIV/AIDS. Bulk copies of *ACRIA Update* are available free to agencies that provide services to people living with HIV/AIDS. For more information, call 212-924-3934 ext. 120.

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## Pregabalin for Peripheral Neuropathy

People with HIV who have peripheral neuropathy will take either pregabalin (Lyrica) or a placebo (dummy pill) for 3 months. Participants must be 18 or older and have had pain in their hands or feet for at least 3 months.

## TH9507 for Lipodystrophy

People who have excess abdominal fat and who are taking anti-HIV drugs will take either TH9507 (an experimental growth hormone releasing factor) or a placebo (dummy pill) for 26 weeks. Participants must be 18-65 years old, with a CD4 count over 100 and a viral load below 1,000.

## UK-427,857 for Drug-Resistant HIV

People who have taken anti-HIV drugs from three of the four classes of drugs will either take UK-427 (an experimental HIV CCR5 attachment inhibitor) with an optimized regimen of anti-HIV drugs, or take a placebo (dummy pill) with an optimized regimen, for 11 months. Participants must be 16 or older and have a viral load of at least 5,000.

**For the above trials, contact Dr. Douglas Mendez at 212-924-3934 ext. 126 or Dr. Yuriy Akulov at ext. 124.**

## Research on Older Adults with HIV: ROAH PROGRAM

People in this large study of older adults with HIV will fill out a survey about physical and behavioral health, social networks, quality of life and spirituality. Participants must be 50 or older and be able to read and complete a questionnaire. Study participants will be reimbursed \$25 for one visit. *Since the study is nearly completed, the only slots now available are for white men.*

**For the ROAH Program, contact Andrew Shippy at 212-924-3934 ext. 104.**

### Editor's Notes

- All material in *ACRIA Update* is presented for educational and informational purposes only, and is not intended as medical advice. All decisions regarding one's personal treatment and therapy choices should be made in consultation with a physician.
- *ACRIA Update* refers to most drugs by both their commercial and scientific names upon their first reference in an article. Thereafter in the article, they will be identified with the name by which we feel they are most commonly known, either commercial or scientific.

## Prison Health = Public Health *(continued from first page)*

trained medical personnel are both able and interested in providing services to the many sick prisoners under their charge. While prisoners are entitled to adequate healthcare under the Eighth Amendment to the United States Constitution, the reality is that they often do not receive it. In 1992, DOH performed a limited audit of DOCS healthcare at 12 prisons and found significant deficiencies in care. No follow-up to that review has occurred despite the assertions in a 1994 Memorandum of Understanding between DOH and DOCS that DOH would perform additional review of DOCS healthcare at the original 12 facilities and at other state prisons.

According to the Legislative Action Coalition on Prison Health and the NYS Assembly, most common deficiencies found in NYS prisons are: a) failure to provide inmates education about, and voluntary testing for, chronic diseases including HIV, HCV, etc.; b) the failure to have sufficient numbers of adequately trained health professionals who have the expertise to care for prisoners with chronic diseases; c) the failure to have access to specialists to treat these patients; d) the failure to prescribe needed therapy for patients with chronic diseases; e) the failure to have a chronic disease program to monitor and treat state inmates with these illnesses; f) the failure to have an adequate quality assurance program in DOCS to monitor the care being provided; and g) a failure to ensure continuity of care as patients are transferred from one prison to another or are released to the community.

Advocates agree that one of the major problems with health care in NYS prisons is a lack of uniformity of treatment and the overall substandard delivery of health care. Current bills in the NYS legislature, A. 3586 (Gottfried) and S. 2819 (Duane),

would amend the definition of “hospital” in Article 28 of the Public Health Law to include correctional health facilities. This would give the DOH oversight of all local and state health correctional facilities. It would ensure that all prisoners receive a uniform standard of care consistent with community standards as is required by the DOH in all other state health facilities.

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*“In 1992, DOH performed a limited audit of health care at 12 prisons and found significant deficiencies in care. No follow-up to that review has occurred...”*

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Another bill, A. 3544 (Gottfried), would require the Department of Health (DOH) to review the policies and practices concerning HIV and HCV care at state prisons and local jails annually. But some advocates have concerns regarding this legislation, and are not convinced that the outcome of DOH AIDS Institute reviews and recommendations will be sufficient to bring about the level of change required for serious improvement of healthcare for prisoners. Some question if one state agency will report negatively on another to the same governor.

People in prison need help and support in many areas. For example, while there are an estimated 10,000 Spanish-language-dominant speakers in NYS prisons, there are few Spanish-speaking health care providers within DOCS. Spanish-speaking prisoners must seek the help of a bilingual prisoner to translate their needs to a prison health care provider. In the process their privacy and confidentiality are breached, there are omissions of information, and a potential for misdiagnosis exists. Although prisoners try to help one another, they are not trained in medical terminology and it is difficult for them to provide accurate translations.

Advocates are also pressing for harm reduction techniques to be taught to prisoners, including safer sex and safer injecting drug use. Not everyone coming out of prison will remain drug free. In fact, there are prisoners who are released from prison with drug habits. In some prisons there is easy access to illegal drugs but a scarcity of syringes, leading to many prisoners sharing the same syringe. In addition, condoms are desperately needed to help stop the spread of HIV/HCV and sexually transmitted diseases. Sex occurs in prison on a daily basis, whether it is consensual, coerced, bartered, or involuntary. There is prostitution and there are same-sex marriages in prison. Sexual activity is not limited to prisoners – correctional staff also engage in unsafe sex with inmates. Another bill in the NYS legislature, A.3720 (Gottfried) and S.3048 (Duane), would require every correctional facility to implement STD/HIV education and prevention programs, including the distribution of condoms and latex barriers.

New York State continues to have the distinction of leading the nation in the number of prisoners with HIV and

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## Prison Health = Public Health *(continued from previous page)*

the number of prisoners in 24-hour lockdown cells. New York uses disciplinary confinement at a rate four times higher than any other prison system. Prisoners can be confined to these Special Housing Units (SHUs) for prolonged periods of time – months, or even years. During this time, they have no access to prison programs, are allowed limited family visitation, and can shower only three times a week, inside their cells. Many prisoners sentenced to SHUs have a prior history of mental illness, and those who don't often develop mental illness as a result of the isolation and oppressive conditions within the SHUs. Ironically, there is limited or no access to mental health professionals while they are confined in these units.

Each year, about 25,000 prisoners are released from New York State prisons, and most of them return to the most underserved and impoverished communities of New York City. All too often their health care and medical needs were neglected while incarcerated. There are scores of squandered opportunities by prison officials and their contracted health-care providers to educate prisoners about HIV/HCV, to provide testing, and to address their healthcare needs. The impact of inadequate, indifferent and neglectful health care delivery to prisoners is absorbed by the communities and the families that they return to. Many prisoners are released without adequate discharge planning, receive insufficient information about their health status, and often find that their parole officer has not received the training necessary to understand the connection between HIV, HCV, and substance abuse.

Transitional housing programs are also often lacking. People with HIV coming out of prison should never be

released to shelters, but they may choose to go to one rather than spend one more day in prison. When they do find a transitional housing program, it may not offer the appropriate infrastructure, such as substance abuse prevention services, medical care, and the other supportive services that are needed for a successful transition.

In New York State, the Legislative Action Coalition on Prison Health (LACPH) is working to organize

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*“The impact of inadequate, indifferent and neglectful health care delivery to prisoners is absorbed by the communities and the families that they return to.”*

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public forums, educate people about health care in prisons, and mobilize the community to support or oppose legislative bills that have an impact on the health of prisoners with HIV/HCV. LACPH is comprised of advocates and formerly incarcerated persons, and has the endorsement and support of over 50 community-based organizations, AIDS service organizations, activist groups, legal professionals, medical institutions, and policy groups. If

you would like to join or need additional information, please contact Michele Bonan at [micheleb@gmhc.org](mailto:micheleb@gmhc.org) or call (212) 367-1045.

Nationally, the AIDS Treatment Activist Coalition (ATAC) Access to Healthcare for the Incarcerated Working Group is designed to empower an HIV/HCV population that is the most marginalized in our nation. ATAC is working towards developing national prison health-care standards and seeks to work in unity with prisoners' activists across the United States to effect change. The mission of the Access to Healthcare for the Incarcerated Working Group is to improve the care provided to prisoners who are infected with HIV and/or hepatitis C virus and to enhance the prevention of these diseases through education, advocacy and building resources. If you would like to join or need additional information, please contact Christina Hurst at [hurstc@azdhs.gov](mailto:hurstc@azdhs.gov) or call (602) 364-3662.

Challenging the situation faced by people with HIV and HCV in our prisons requires consciousness and concerted actions from all members of our society. If we are to advance as a nation, we must ensure that all people have adequate opportunities to become self-sufficient and productive members of our society. We must demand that all people have decent and affordable housing and that all people are treated with respect and dignity.

*Romeo Sánchez is a formerly incarcerated person living with HCV and is a long-term advocate for prisoners with HIV/HCV and affected communities. He is Deputy Director of the New York City AIDS Housing Network.*

## DOH Oversight of Correctional Health Care

In early 2004, the NYS Assembly Standing Committees on Health and Corrections held public hearings to address the health care offered in NYS prisons. The following are excerpts from testimony by Lambert N. King, MD, PhD.

In his testimony to this committee, NYS Department of Corrections (DOCS) Commissioner Glenn Gourd testified: "I don't know of any other state health department responsible for prison medical care." Commissioner Gourd is apparently unaware that in California, where the prison system houses over 160,000 inmates in about 70 facilities, the California Department of Health Services has statutory and enforcement responsibility for specific standards, inspection and licensure of a range of hospital and correctional medical treatment facilities within the California prison system. Moreover, there are numerous major jail health care systems, including those in New York City and San Francisco, where the local city health departments are directly responsible for the oversight and quality of delivery of correctional health care services. Thus, such arrangements certainly do not lack precedent or prior experience.

But even if there were no such precedents, anyone familiar with the remarkable history of the NYS DOH knows that it has usually led the nation in unique health care and policy reforms. Two excellent examples are the creation and development of the AIDS Institute and the promulgation of standards for limitations on working hours and strengthened supervision of resident physicians in teaching hospitals. We should expect and must accept nothing less than similarly stellar leadership from the NYS DOH with respect to the vital responsibility of health care for the 65,000 men and women confined on any given day in New York's prisons.

Incarcerated persons are completely dependent upon DOCS for medical, mental health and oral health services. It is this total dependency, coupled with a long history of egregiously deficient health services and conditions in U. S. prisons, which converged to firmly establish that systematically inadequate health services in correctional institutions violate the Eighth Amendment prohibition against cruel and unusual punishment. 50 years ago, there was no firm legal basis to conclude that delivery of adequate health service was central to the mission of prisons and jails. Today, however, there can remain no doubt that our Constitution mandates provision of an ade-

quate health services program to be a *sine qua non* [absolute prerequisite] with respect to the very existence of jail and prisons.

In fact, multiple studies and publications have demonstrated that our major jail and prison systems are among our nation's largest institutional care providers for persons with serious mental illnesses, HIV and Hepatitis C infection, and the multiple sequelae [consequences] of cigarette smoking. Yet DOH continues to assert that DOCS is not "principally engaged in the provision of services by or under the direction of a physician." By doing so, DOH reminds us that denial isn't just a river in Egypt.

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***"By asserting that DOCS is not 'principally engaged in the provision of services under the direction of a physician,' DOH reminds us that denial isn't just a river in Egypt."***

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DOH surveillance of DOCS health services is not fundamentally a question of whether the current quality of DOCS health care is excellent, mediocre or awful. Article 28 [the public health law mandating DOH surveillance of hospitals and other health care facilities] exists because we all know that the quality of care in our hospitals can vary widely from place-to-place and from time-to-time. Not even our most prestigious health care institutions in New York State would assert, as does DOCS, that they should be exempt from DOH oversight under Article 28 because their quality of care is better than ever and, thereby, the checks and balances in place for all other major health care

providers do not apply.

It is irresponsible to continue to isolate correctional health care, including the DOCS program, from our entire health care system. Every day, many men and women leave our prisons and return to communities throughout the State. For those with serious health problems, we must have solid transitional medical care plans, continuity of care, and cost-effective use of the health care resources the State has already invested to care for them in prison. Left to its own devices, DOCS cannot and will not do this. DOH must not only accept its obligations to monitor and improve the quality of New York's prison health care system, it must embrace this extraordinary opportunity that exists to benefit the health of all of our citizens.

## *Personal Perspective: The HIV Merry-Go-Round*

*by Ismael Gonzalez*

My name is Ismael. I'm 44 years old and am incarcerated at the Marcy Correctional Facility in New York. When I was told that I was HIV-positive, at Rikers Island in 1990, I was in denial. It was like I was in a dream I couldn't wake up from. I kept it to myself, thinking about what I would say to my family and friends. It took me three years to finally tell my family, and they disowned me. They told me that they did not want to see me no more, and to this day they have not. In 1996 I was told that I had hepatitis C. This time I started blaming God and asking what I did in life to deserve this. I got HIV from shooting drugs, sharing needles and unprotected sex. I was selling my body for drugs to support my habit.

My experience in having HIV and hep C in prison has been a merry-go-round. When I was in Downstate Correctional Facility, the health care providers were very decent. They truly cared for inmates with HIV and had compassion toward me. But when I was transferred to Cayuga, things changed. The health care providers there were very nasty to inmates who were HIV-positive. The nurse always had an attitude toward inmates. Then, threatening letters were sent to the Deputy Superintendent of Security after an officer searching my cube found my antiretroviral medications. He questioned me about them and I told him it was confidential. That's when he figured out I had HIV and things began to get crazy. I eventually had to sign up for protective custody because inmates set my bed on fire when they found out I was HIV-positive.

In my current facility, the health care providers do not care about inmates. I go to sick call and right away they start using the kind of language that if I were to use, I would be issued a disciplinary ticket and be put in the box (solitary confinement). You ask the nurses questions about your CD4 and viral load and they get attitudes and tell you that you must see the doctor. But the doctors here, to be honest, do not know about HIV/AIDS. One doctor told me that I should stop taking my medication because it will kill me, and he always throws me out of his office when I ask him questions concerning my CD4 and viral load results. He just

informs me that they are good and says, "Have a nice day." I filed a grievance on this doctor and now am being retaliated against by medical staff and correction officers. I've been here for two years and I've never seen an HIV specialist, and I am being denied treatment for hep C. Our Constitutional rights are being violated by DOCS staff – the health services run by DOCS should be investigated.

Right now, I have to take my medication on the low-down: every morning and every night I go to the bathroom in one of the stalls to take my meds because I truly do not want nobody in this jail to know that I am HIV-positive. I'm concerned about my safety and I'm scared that one of the inmates may find out – I do not want to go through what I went through in Cayuga. It is bad enough that I am being discriminated against because I am a homosexual, but I feel that I am a monster because I have HIV. I hang out in the yard by myself when they have recreation. I sometimes feel like taking my own life. I wonder if this is a punishment from God for all the things I've done to people in society. But it's still a shame that we convicts with HIV and hep C are being treated like animals.

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***“One doctor told me that I should stop taking my medication because it will kill me . . .”***

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Once I get released next August, I will be homeless. I have to start my discharge planning and to be honest I do not know who to turn to – I'm kind of scared to go to a shelter when I get out. But I am a fighter. I've finished a program at this facility called PACE (Prisoners for AIDS Counseling and Education). I want to share and educate especially the young generations on how to protect themselves from getting the dreadful diseases that I've been carrying since 1990. I thank God for letting me live one day at a time, even though I would not wish this on my worst enemy. I am going to continue to struggle and fight this disease all the days of my life.

Thank you for letting me tell what I am going through being incarcerated and HIV-positive, and yes, you can use my name and the facility I am at. I truly want society to know how inmates who are HIV-positive are being treated by medical staff and correctional officers who work for NYS DOCS.

# HIV Care in U.S. Prisons: The Potential and Challenge

by Becky Stephenson, MD and Peter Leone, MD

Historically, HIV-positive individuals with mental health disorders or substance abuse problems, or who are members of racial and ethnic minorities, have experienced difficulties accessing HIV health care and treatment and achieving successful outcomes. Furthermore, the AIDS mortality and morbidity in these groups, especially in the south, continues to be higher than other groups. These populations that are at high risk for HIV are also those that are disproportionately at high risk of incarceration in our jails and prisons.

Correctional systems provide health care for approximately 25% of all people with HIV in the United States. In 2002, the prevalence of AIDS in state and federal prisons was greater than three times that in the general U.S. population. The prevalence of HIV infection was 2% of state and 1.1% of federal prison inmates, and was higher in women, 3%, than in men, 1.9%. Although prisons in the northeast had the highest rate of HIV infection, 4.6%, southern prisons had the highest number of HIV cases by geographical region. African-Americans had the highest prevalence of HIV reported in any racial group, 2.8%.

Although there is some evidence of intra-prison spread of the virus, most of the HIV among prisoners is thought to have been acquired outside of prison. The high prevalence of HIV in correctional facilities is mainly a consequence of the incarceration of substance abusers and at-risk minorities. In fact, correctional facilities are not only places where HIV-positive individuals are housed, but often where they are identified; prisons and jails may be the most important HIV testing sites in the U.S. In 1990 in Rhode Island, for example, over 40% of all newly diagnosed HIV-infected persons were first tested in a correctional setting.

The high-risk populations mentioned above, very often, are also those most likely to be underserved by the health care system. Indeed, the incarceration period may be the only time that they receive continuous access to health care.

Unfortunately, while correctional facilities are legally required to provide uniform access to care, the standard of that care (especially as it relates to HIV/AIDS) is anything but uniform and consistent both within

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*“The growing disparity of HIV for minorities and other marginalized populations in the United States is only further amplified within correctional facilities.”*

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and between states, even though incarcerated persons are the only Americans with the right to health care guaranteed by the Constitution. In fact, correctional facilities violate an inmate’s Constitutional rights if they are “deliberately indifferent” to an inmate’s “serious medical needs.”

While surveys and prison formularies support that antiretroviral therapy is widely available in correctional facilities, availability and access are not necessarily the same thing. Thus, the growing disparity of HIV for minori-

ties and other marginalized populations in the United States is only further amplified within correctional facilities.

Although there have been no prospective evaluations of HIV outcomes among inmates of correctional facilities, available data suggest that the outcomes in facilities that provide expert HIV care and open access to HIV therapy can be equivalent to or better than non-incarcerated populations. However, a standard of comparison to non-incarcerated populations that overwhelmingly lack access to any primary health care may hide the pressing need to address inadequacies that exist in many correctional systems.

The number of AIDS-related state prison deaths has mirrored the trend for all people with HIV since the introduction of HAART, decreasing by 72% from 1995 to 1999. The only systematic evaluation of HAART outcomes in correctional facilities examined the virological and immunological outcomes of 1,866 men and women treated with HAART for at least six months while incarcerated. The study found that 59% of the inmates achieved viral loads below 400 by the end of their incarceration, which is comparable to HAART outcomes in community cohorts. This study demonstrates that incarceration itself has no adverse impact on clinical outcome when inmates are given adequate clinical care and provided an opportunity to access HAART. But the testimonials of many incarcerated individuals speak to the fact that such care and such access are not always the rule. Prisoners can face many obstacles to controlling HIV disease, including transfers from one prison to another, leading to a lack of continuity of care, and difficulty in continuing medication during and after such moves.

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## *Personal Perspective: The Exception to the Rule*

by *Laura Whitehorn*

I spent the years from 1985 through 1999 in prison, being shipped from one facility to another. During that time, the AIDS epidemic unleashed its fury on my friends and neighbors in those prisons, in the community of women I knew.

Like many AIDS activists outside prison in those years, my grief at the deaths of too many friends propelled me into AIDS education and action. Because prison health care for people with AIDS was all but nonexistent – and administrators loathe to educate themselves, much less the prisoners, about HIV – I began participating in AIDS education, counseling and activist programs we prisoners organized for ourselves. Although I am not an expert on HIV treatment in prison, I am its intimate observer. From that standpoint, it has been all too clear to me for many years that medical care for people with HIV in prison in the U.S. does not meet the accepted standard of care.

To be sure, there are decent, intelligent and capable providers to be found in some prisons. But they are the exceptions who prove the rule. And in my experience, every provider who *was* decent, intelligent and capable was either fired or left prison practice due to severe burnout. And even some of these competent doctors found it hard to look at the HIV-positive woman across the desk as a patient rather than a convict.

For a person with HIV, prison is a crashout. The best-case scenario involves being lucky enough to be jailed in a state with real, board-certified doctors, with a minimum of prejudice and ignorance from guards, medical staff and other prisoners, and with a formulary that includes not only all the approved HIV meds but also the drugs needed to prevent or treat HIV-related infections. It also includes being fortunate enough to be locked up in a place where you can get a hepatitis C test – and treatment, if appropriate.

Some of the worst-case scenarios have been documented in news stories and court cases: deaths caused by callous

and incompetent providers; prisoners dying when guards were the ones to do triage; denial of the basic human right of health care. One of my first friends in jail to die of AIDS was not permitted to have her lover at her side as she died – both were prisoners. She hadn't been told anything about the infection ravaging her body. She died shackled to a bed in the prison wing of D.C. General Hospital. She was serving a two-year sentence for petty theft. At the same time, another positive friend was placed in an isolation cell by guards who would not call the medical staff when she developed a raging fever. Only clamor raised by a few prisoners who discovered the situation succeeded in summoning medical care – too late. Even in 1994, in a federal prison in Florida, we had to wage a year-long battle to obtain a basic GYN exam for a woman with AIDS. By the time we won, her infections were all but untreatable. She died soon after her release the next year.

Even more frightening than these cruel deaths is the fact that every day, all over the country, prisoners with no voice and no access to media or lawyers continue to suffer from routinely incompetent care and the stigmatization peculiar to AIDS. It makes harsh sense, too: Studies have shown the obvious – that people whose doctors have experience and knowledge about HIV live longer, healthier lives than do those whose doctors don't know much about HIV. How many prisoners do you think regularly see an HIV specialist?

It's not a mystery why people with HIV in prison suffer. I did my time in federal prison, where the medical care is generally better than in most state prisons. But there was no confidentiality, no say in the choice of your HIV combo, no regular monitoring of organ function and lipid levels, no participation in decisions about your treatment – and certainly no right to choose your doctor. The concept of patient empowerment – so basic to HIV care on the street – is non-existent in prison. In a federal women's prison near San Francisco, a friend, who had struggled to learn all she could about HIV meds, questioned the side effects of the combo she was given, only to

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be told by the prison doctor that she was “too smart for her own good.” The doctor even threatened to charge her with refusing to obey a direct order. Patient *disempowerment* – and that was in one of the better prisons.

There is a simple reason for this: Prisons are fundamentally about “security,” which means repression. Security concerns trump medical needs every time. This is, after all, a country in which pregnant women prisoners are still shackled to the bed while giving birth. In the federal prisons, women transported to an outside hospital were always handcuffed, waist chained and shackled – and strip searched. Being strip searched by a prison guard, an unpleasant enough procedure in any case, is even worse when you are recovering from surgery or delivery.

If the attention to “security” isn’t enough to make medical care a bad joke, budget will do it. There is a huge epidemic of hepatitis C and liver disease among prisoners. The percentage of those with HIV who also have hep C is higher than it is outside. Yet most states make it all but impossible for prisoners to receive appropriate testing and treatment for hep C – it’s just too expensive. Even Pennsylvania, which did respond to prisoner demands by initiating treatment a few years back, drastically cut the number of prisoners receiving treatment after a short period. Too costly. Yet liver disease tops the list of killers of people with HIV.

Both before and since my release, I’ve heard people say that prisoners with HIV get better medical care than they would on the street. I did, in fact, meet women who, when they’d been on the street, had rarely gone to doctors. Many of them were diagnosed with HIV only after they were locked up and were no longer doing drugs. But to say that prisoners get good care, or better care than they would outside the walls, is as inane as it is calous. All it tells you is that this very rich, very advanced country takes such poor care of its citizens – and charges them so much – that they can conceivably be better off in a jail cell than in an impoverished neighborhood. That is a comment on the corruption of human values in this society. But it is not a reliable opinion that health care in U.S. prisons is good – for people with HIV or for anyone else.

*Laura Whitehorn is a longtime prison activist and a Senior Editor at POZ Magazine.*

## HIV Care in U.S. Prisons

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Because of the high proportion of people with HIV who are incarcerated, it is important to investigate the factors that determine their health outcomes. Traditionally, these populations were underserved by the health care systems in their communities and experienced significant health care disparities before they were incarcerated. North Carolina, for example, has a waiting list for its AIDS Drug Assistance Program (ADAP). The population on the waiting list is no different demographically than the population of newly diagnosed HIV/AIDS cases in the state, being primarily of minority race/ethnicity, poor, and, increasingly, from rural areas. The structured health care of correctional facilities, with its presumed equal access, could therefore benefit these underserved non-incarcerated populations, who likewise suffer from unequal access to quality health care.

But, at the same time, prison health care may impede successful HIV outcomes. Directly observed therapy (DOT) is but one example of prison health care practices that can seriously impede HIV care. DOT was started in prisons and jails mainly to monitor inmate adherence to psychotropic and tuberculosis drugs. It was expanded to HIV medications because of the high costs of HAART and its unique resistance risks. Inmates who receive DOT must stand in line and wait to receive their medications, which a nurse or correctional officer dispenses and watches as they are taken. Many DOT programs in prisons are inflexible, involuntary, non-confidential, and non-individualized. The lack of confidentiality and long lines have been reported by many HIV-positive prisoners as barriers to taking medications. In one study involving directly observed therapy, HIV-infected individuals universally disliked the intervention. Given the stigma attached to HIV by both correctional facility staff and inmates, HIV cannot be treated like any other infection or disease.

It is unclear if DOT is an effective intervention for enhancing antiretroviral adherence in prisons. One study found DOT to be beneficial in a clinical trial of HAART: 95% of prisoners, who were on DOT, achieved viral loads below 400, compared to 75% of non-prisoners, who were not on DOT. But it remains unclear if the higher success rate was due to DOT or to the many other differences between those who are incarcerated and those who are not. Other observational studies in prisons have shown no difference in the adherence or viral loads of individuals on self-medications vs. DOT. DOT is also labor-intensive and costly for correctional facilities, most of which are chronically understaffed and over budget.

*(continued on page 11)*

## *Personal Perspective: Health Care for All?*

*by Name Withheld*

I found out I had HIV in 1999, the same year I was arrested and sent to Rikers Island. I was already on meds when I went in, but when I was arrested I missed a bunch of doses because you have to go through a process first – medical screening and all kinds of stuff. So I was denied my meds for two or three days. I told them it was dangerous for me to miss doses, but until I went through the court system, I was not allowed any meds.

There was a lot of ignorance about this disease at that time in Rikers. If guys found out you had HIV, they would isolate you – they were worried they might catch it. The only guys you could talk to about it were the guys in your support group. But people would find out because they would know which doctor you were going to see – they can put two and two together. The CO (correctional officer) would say, “Hey, you’ve got a appointment to see the infectious disease doctor,” and guys could figure out what that meant.

Some of the COs were very ignorant. One time they did a search and the CO asked me, “What are you doing with all these meds?” I said, “That’s my personal business.” He said, “When you’re in jail, nothing’s personal.” So I told him, and then he backed away and scowled, like he was going to catch it.

What was messed up at Rikers was that the medical center didn’t have private rooms, just low partitions. So when you talked to your doctor, you knew the guy in the next cubicle could hear everything you said. I knew I had to tell the doctor everything in order to take care of myself, but it was very uncomfortable knowing that someone was listening to every word you said.

I was then transferred to a federal prison in Louisiana because I’m Jamaican and they were starting deportation proceedings. My meds came with me, but when I saw the HIV doctor there, he wrote up a report saying that the treatment I was getting was very unprofessional. And then I started getting resistant to the meds because of missed doses. This was not my fault – sometimes the pharmacist

was just not there. We got our meds every Friday, but on the weekends they had only a skeleton crew, so if you didn’t get your meds on Friday, you had to wait until Monday to get a refill. That meant you often had no meds for the whole weekend.

Since the federal prison was a bigger jail, it was easier to keep your HIV status a secret. You had your own room and you were able to speak to the doctor in private. But then I was transferred to a county jail because of a lack of space. I was not allowed to bring my meds, so I had none for two and a half weeks while they ordered them from out of state. When they finally came, a CO gave them to me, not a nurse. I told him I had to take my meds twice a day, but he looked at the bottle and said, “No, you have to take them all right now.” I said, “Listen, I’ve been taking my meds for years and I know how to take them.” But I couldn’t convince him, so I would act like I took all my meds but palm the evening dose and save it for later. I had to do that every day for two months, until they finally straightened it out.

And then I was transferred to New Jersey, to Passaic County jail – the worst of the worst. That was the worst thing that ever happened to me in my whole life. I was not allowed to take my meds with me so again I missed doses, for about four days. When I got there, I was seen

by a nurse practitioner who told me to pick out my HIV meds from the pictures on a wall chart. I said, “This one, that one, and that one,” and she just gave me the meds I picked.

The jail was filthy, with 52 people crammed into each dorm room. And the bathrooms were nasty. We got half a bottle of bleach each day to clean them – that’s all. I was not allowed to keep my meds with me – we had to line up and go to the doctor to get them. I was taking meds twice a day, but they were giving them to me at 8 am and 4 pm. I said, “No, I can’t do it like that. That’s too short – one of the doses is four hours early.” I tried to palm the second dose once again, but I was busted and got a reprimand.

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***“The guard asked me, ‘What are you doing with all these meds?’ I said, ‘That’s my personal business.’ He said, ‘When you’re in jail, nothing’s personal.’ ”***

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## HIV Care in U.S. Prisons

*(continued from page 9)*

Luckily, the legal clinic at NYU took my immigration case, and they were very persistent. They pestered and pestered the warden to change when I got my meds. The warden said, “Mr. B. is not a trained physician – he can’t make decisions about when he should take his meds.” Well, they eventually changed it, but guess how! Now I had to get up at 4 in the morning to take my first dose! They do things for the convenience of the COs, because they change shifts at 4. It has nothing to do with the person with HIV.

And there was no confidentiality at all. When you met with the doctor, the door had to be open, and there was a line of other inmates waiting outside. So everyone heard everything you said to the doctor.

When I was released last May, my warden was specifically told I was going to need meds when I left, but I was kicked out the door with no meds, not anything. Luckily, when I was transferred from Louisiana, I had a few doses left over and I had hidden them in my bag. So I had a couple of days’ worth of meds to hold me over. That’s when I went to Exponents, and they referred me to St. Vincent’s Hospital where I got some emergency doses until my ADAP was approved.

People don’t know what it’s like to have HIV in prison – most of what they know about prison is what they see on TV. It’s not like that at all. A lot of guys have homosexual relationships in prison, but they don’t have condoms and they’re spreading disease. And many of those guys are going to be released, and they bring it back to their wives and girlfriends. They’re coming right back out into society. So they really need to start setting up education and prevention programs.

Having HIV in prison sucks, especially if you’re an immigrant who is in for committing a crime. We’re at the bottom of the pile. When I was in Louisiana, every time I would go see the doctor, he would ask me when I was leaving. I would say, “Why do you care when I’m leaving? You’re supposed to just treat me.” They’re supposed to treat everyone the same way. We’re not supposed to get substandard treatment because we’re immigrants. That’s one of the biggest problems I see – the difference in treatment, especially if you’re going through deportation proceedings. Their attitude is, “Why spend money on somebody who’s going to be kicked out of the country?” But we’re still human beings. Under the Constitution, we’re entitled to the same treatment as everyone else.

The history of health care within correctional systems in itself makes evaluation difficult. Until fairly recently, it was primarily correctional officers who attended to prisoners’ health care needs. With the advent of the modern prison health care system, that responsibility was reassigned to nurses, physicians, and physician-extenders such as nurse practitioners. But understaffing is such a chronic problem that prisons and jails are listed as “underserved areas” by the federal government. Staff turnover is high – especially among nurses – resulting in poor continuity of care. Often, prisons are once again relying on correctional officers to perform the many tasks more appropriately the responsibility of nurses. Treatment of HIV disease requires constant updates, education, and a high degree of expertise, and the use of those whose main responsibility is custody and control – and with whom prisoners not surprisingly tend to have adversarial relationships — can present substantial barriers to the delivery of quality care.

While adherence to HAART for inmates can be challenging, the barriers are not unique to prisons and can be overcome – given adequate access to expert care and open access to therapy. Issues such as confidentiality and the inflexibility of medication delivery are significant barriers to meaningful access, however, and thus may be greater determining factors for successful HIV outcomes than the mere presence of the latest medications. In addition, many opportunities for HIV testing and education around HIV prevention are missed in correctional institutions. The impact on inmates is great, and the impact on the communities these inmates are taken from and released into may be even greater.

The time has come to recognize the disparity of care that exists within the correctional system and to ensure that a consistent and equal standard of care is provided for all inmates with HIV, no matter the state or facility in which they are detained. The inadequacy of care that exists for people with HIV in the United States reflects a basic social injustice that must be addressed. The inadequacy of HIV care for many inmates may also pose a Constitutional rights issue.

*Becky Stephenson is an assistant professor of medicine at University of North Carolina School of Medicine at Chapel Hill, and is co-director for HIV services for the North Carolina Department of Corrections state prisons system.*

*Peter Leone is an associate professor of medicine at University of North Carolina School of Medicine at Chapel Hill.*

# It Takes A Community: The Challenges of Discharge Planning

by Dixon Valderruten

Meeting the needs of people with HIV released from state prisons is challenging to say the least, and becomes further complicated when they face other health complications such as chronic hepatitis C, mental illness, and chemical dependency.

An estimated 5,500\* men and women with HIV/AIDS are currently doing time in New York State prisons, and almost all of them will be released to their communities before the end of their sentences. Assuring a successful transition depends not only on close interaction among service agencies, but also on the role that released people play when trying to navigate various systems and services such as parole, drug treatment programs, hospitals, city and federal agencies, housing, child support, etc. Service agencies that successfully assist people with their discharge planning are those that collaborate with each other, empower their clients by educating them about their rights and responsibilities and, most importantly, work with clients on such issues as self-disclosure, accepting one's health status, and the other problems that released people often don't want to face.

Preparing for community re-entry is a process that includes several steps. Typically in New York State, the first step is performed by a transitional or discharge planner from a service agency funded under the Criminal Justice Initiative (CJI) of the AIDS Institute. One of the first steps that HIV-positive people in prison can take is to connect with the CJI provider agency in their facility, via the office of Transitional Services. They can do this by writing to the CJI provider directly, by contacting the facility's PACE office (Prisoners AIDS Counseling and Education), or by calling the NYS HIV Prison Hotline (see "Resources" on page 17).

*"It is a lot easier to admit that you have problems with alcohol or drugs than HIV or mental illness. I never told anyone that I had HIV and that I had been diagnosed as a schizophrenic when I was 14 years old. It was at Fishkill that I received treatment for the first time – I couldn't believe that those voices that haunted me for years could go away."*

Incarcerated men and women who participate in HIV activities while in prison (support groups, outreach, peer counseling, trainings, etc.), and who also confront any drug addiction or mental illness, may stand a better chance of implementing their release plan and succeeding in the community. They are often more likely to follow up with the transitional planning agreed to prior to their release, and they can carry their strong advocacy skills to their communities, where they can become powerful role models. On the other hand, most people in prison who have not disclosed their HIV status find themselves at a loss. Not only do they lack basic information about HIV/AIDS, but they are also not part of any supportive community. Upon release, a good number of them want to remain invisible. They attend only programs that are mandated, shy away from talking about personal issues (such as the fear of disclosing their HIV status), and have difficulty accepting their medical condition.

Once a prisoner contacts the CJI provider in his or her facility, the next step is to coordinate with the Facility Parole Officer (FPO) and the Office of Mental Health (OMH) in the facility before approaching the Medical Office. It is always good to know what each party is doing in order to avoid duplication of services. The FPO should ensure that all personal documents (birth certificates, Social Security cards) are in place before the release date. The OMH is responsible for documenting the diagnoses, treatments and services received during incarceration. Many outside providers may not fully understand that FPOs and OMH staff inside a correctional facility sometimes encounter the same obstacles and frustrations that outside agencies face when they try to obtain important documents like the Comprehensive Medical Summary (CMS) from an institution's medical office.

A CMS should include diagnoses (including opportunistic infections, or OIs), CD4 counts, viral load tests, and a list of prescribed medications. But getting a copy of it can be an ordeal. Obstacles include working with an understaffed Medical Office, having an incomplete "HIV Release of Confidential Information" form, or receiving a CMS that is not signed by the appropriate medical staff. And often when it is obtained it may lack key information, such as

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\* Blind seroprevalence tests of all incoming inmates between 2000-2001 found that 5% of men and 14% of women were HIV positive. But of the estimated 5,500 inmates with HIV, only about 3,000 are known to DOCS medical staff and are receiving care. Of all inmates, approximately 9,250 have HCV (23% of females and 14% of males), 73% have a history of substance abuse, and 11% have been diagnosed as "significantly, seriously, or persistently mentally ill." *The State of Prisons: 2002-2003: Conditions of Confinement in 14 NYS Correctional Facilities. The Correctional Association of New York, June 2002.*

OIs diagnosed prior to incarceration. One of the most challenging situations occurs when inmates are transferred from one facility to another and the medical records do not accompany them in a timely fashion. When this happens there are two options: contact the medical office from the prison where s/he was discharged, or wait until the Field Parole Officer (FPO), who supervises the person on parole after release, receives the person's chart.

***“Find me a decent place to live, not a shelter or a drug-infested SRO. Find me a place where I can lay my head, adhere to my HIV treatment, where I can start a new life and reunite with my family.”***

Housing is the single most important service in discharge planning. Not only does it increase the chances of succeeding in an often hostile environment, but it makes the transition smoother. It is well known among providers who serve ex-offenders that individuals released to shelters have a lower chance of succeeding than those who end up in more structured and private settings.

Another important part of transitional planning is to know, as early on as possible, the criminal background of the person being released and to make sure s/he understands all parole stipulations. For example, a person needs approval by the local parole office regarding where s/he plans to live. A discharge planner could have a “perfect” service plan but a parole officer may not agree to it if the client has a history of criminal activities in the proposed neighborhood. Parole officers can make concessions in certain cases, but when it comes to violent offenders or sex offenders they usually will not.

***“Women face problems that make family reunification a lot harder. Before we are approved to receive our children we must complete a parenting skills program that meets the court's stipulation. In addition, we are expected to find appropriate housing, which means separate bedrooms for your children. Sometimes finding a large family unit becomes a full-time job – it may not be so easy to find what you need for your children.”***

Service providers that work with ex-offenders know that women coming back from prison face a specific set of issues that are not necessarily addressed in traditional supportive settings. The interrelationship between domestic violence, sexual abuse, emotional abuse and chemical dependency is rarely addressed in a well-integrated fashion. While many programs offer groups that touch upon some of these issues, they often lack the clinical depth and qualified personnel who are sensitive to the issues of women returning to their families after several years of incarceration. Reuniting with their children is often one of their highest priorities, but many women have lost their parental rights while they were incarcerated. Finding an agency or a program that assists with child custody, court advocacy and parenting skills is paramount.

***“I was in and out of prison for years. I went to substance abuse programs every time I came out. I stayed clean for a while, but I guess I never realized the magnitude of my problems. It took me years to address and understand the real issues behind my addiction.”***

It is equally important to complete a thorough assessment of the person's history of drug use and mental health needs, to determine if the client will be able to attend programs that meet their needs and satisfy the conditions of release. Many people recently released are mentally ill and some services may not be suitable for them. Also, there are

some programs that may not meet parole qualifications – some parole officers buy into a harm reduction model, while others adhere strictly to law enforcement requirements of sobriety and a drug-free lifestyle. And if a PO does subscribe to a harm reduction model, the random drug testing often required of those on parole could negate any such program. In other words, transitional planning is not just making appointments for people – it is a process that prioritizes what is in their best interests. Many substance abuse programs offer groups that touch upon some of these issues in the form of counseling, support groups, etc.; however, they may lack clinical depth and more qualified personnel who are sensitive to issues of women reuniting with their families after several years of incarceration.

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## *Personal Perspective:*

# **If At First You Don't Succeed**

*by Michael Brown*

I was first told about my HIV status in 1985, when I was 30 years old. A few years later I was told that I'd gotten HCV in the same way: IV drug use. In January of 2003, I was arrested and sent to Rikers Island. I was taking methadone, but doing a lot of heroin as well – 3-4 grams a day. Plus, I was on psychiatric medications.

At Rikers, it seemed to me that the doctors were overworked and underpaid, because the kind of care I was given was poor. They took whatever information I told them without giving me any tests to see if I was telling them the truth or not. I ran into a lot of medical problems there, wound up with PCP pneumonia, and had to go into an isolation unit for intensive care. I was so sick I would just take the pills I was given, not knowing what they were for.

After recovering from the PCP, I was given a regimen for my HIV, but the doctor never explained it to me, so I never took it. Then my methadone was stopped without me being properly detoxed, and my psych meds were also stopped – somehow the medical staff messed up. I had to call Prisoners' Legal Services for help, and they wrote a letter on my behalf. I also sent a "Notice of Intent" to take legal action, but that didn't help, either – I still was denied treatment. This went on for about 15 months until I was transferred to the Beacon Correctional Facility, where I finally had an infectious disease doctor look at me.

The medical staff started doing tests and talking about a liver biopsy and HIV treatment, but there wasn't enough time for that at Beacon. I was ready to go upstate, and the medical staff felt it was best for me to wait – so I waited, for two more months.

Now I'm in the custody of DOCS, at the Altona Correctional Facility, and the treatment situation has

gotten a little better, but there are still a lot of loopholes in the way I am treated. For one, a lot of facilities' in-house infirmaries are closed due to cutbacks. And there are confidentiality problems, too. When I first came here I had some problems with a nurse. She was giving me a hard time approving my request for a bottom bunkbed, which I needed because of the neuropathy pain in my feet. So I wrote a letter to the head of Nursing Administration and he took care of the problem, but he showed the letter to a lieutenant who was dating the nurse!

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***"I had to have two liver biopsies because in the first one the doctor missed my liver completely and just hit muscle! So I had to go back and get another one."***

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The doctor here then sent me to the Coxsackie Correctional Facility to see an infectious disease specialist. This is where I was finally able to talk to medical staff about a treatment plan. But the medical trip is very uncomfortable. It takes three days just to get there, and I have to stay in isolation at another facility overnight on the way. The first time I went on this trip none of my medications came with me, because the correctional officer didn't tell me that I was going on a medical trip. Once I got there and was able to talk with an HIV doctor, things started to happen for the better. I asked the doctor if it was possible for us to have talks using his video hookup, but at that time my facility didn't offer that. Now it does, and my doctor is able to talk to me about getting all of my other medical problems under control before dealing with the HCV.

When it comes to treatment for HCV, there is a whole lot of time involved in even being approved for treatment, especially if you've had any mental problems. First, you have to wait to get into the facility's Residential Substance Abuse Treatment before you can ask for HCV treatment. Next, you have to get approval from Albany to have a liver biopsy, and then you have to go to an outside clinic to get it. Then you have to go back to Coxsackie to see the gastric specialist for the results, and even then you might not get approval.

## It Takes A Community

*(continued from page 13)*

***“This was life’s ultimate challenge for me – this was the moment I had dreamed of for years. But the weeks before my release were as stressful as the three parole boards I went through.”***

I had to have two liver biopsies because in the first one the doctor missed my liver completely and just hit muscle! So I had to wait another two months to go back and get another one done. I explained to my doctor what happened the first time, and he said I should go to Albany Medical Center instead, but they just sent me back to the same clinic that did the first biopsy. When I got the second liver biopsy, I told the doctor what had happened the first time, so he went in twice, with two separate needles, to make sure that he had a piece of my liver for testing!

The test came back genotype 1, stage 0 – no sign of liver damage. I asked the doctor at Coxsackie what that meant, and he just said, “Genotype 1,” and that he was going to put in a request to Albany for me to start HCV treatment – without even explaining it to me. It was like he was trying to force me to take the treatment even though I didn’t need it, after all the paperwork the medical staff did.

But thank God for my HIV doctor – he really explains things to me over the TV hookup, and he told me that I don’t need the HCV treatment right now due to the stage that my liver is in. He feels I should have another liver biopsy in two to three years, so if I’m not out by then I would have to go through all this again!

The medical staff here treats me okay, but where I really get help is at my self-help programs, AA and NA. I can let loose of whatever I’m going through with no problem. It’s sad not having an HIV support group at this facility. I’ve tried asking for one, and the response I get is, “We used to have one but nobody showed up, so we stopped it.”

I’ve been here close to 19 months. I took one HIV/HCV peer training run by the AIDS Council of Northeastern New York, five months ago. But now the only HIV support I get is when I call the Osborne Association’s AIDS in Prison Project hotline. Other than that, I feel alone. It is very hard to disclose to people who are still in denial about their addiction as well as their high-risk behavior, so I only talk to inmates that are close to me – and I can count them on one hand.

Returning to one’s community after doing five, ten, or more years in a state facility, having an HIV/AIDS diagnosis, perhaps with chronic hepatitis C and/or a mental disorder, is a very scary process for anyone coming out of prison. As one client said, even the best transitional service plan could fail overnight when someone ends up in the street without being emotionally prepared for the re-entry process.

***“When I first came out, I was intimidated by the services people offered me – I was not used to having so many people handling my business and asking me the same questions. To me, they all worked for the government; didn’t they all have access to the same information? I said, hold it, hold it, what do you want from me now?”***

One of the first problems parolees face is that service providers often don’t understand that prior to release, all services were provided at the same facility. Now they may need to access services from two or three different agencies, and traveling from one agency to another with a Metrocard may trigger old insecurities and frustrations. In some agencies, follow-up is done by a person other than the one who completed the discharge planning. In some cases, a person newly released from prison may not be ready to accept what service providers have to offer.

***“It wasn’t clear to me why my parole officer wanted me to complete another treatment program in the community when I had completed the Alcohol and Substance Abuse Treatment program in prison.”***

Another source of confusion is how to implement certain conditions of release, such as seeking and maintaining employment. Should a newly released person get a job and attend a substance abuse program after work, or put their health and sobriety first?

Often, people on parole do not want to admit that behind their HIV or HCV diagnoses are chronic substance abuse problems or mental illness. It is easy for people released from prison to focus on their parole stipulations rather than looking at substance abuse issues as part of their general health concerns.

*(continued on next page)*

## It Takes A Community *(continued from previous page)*

*"The reason I did not succeed the first time I came out was that I thought I could do it myself. I never trusted anybody inside or outside. The second time, my transitional planner insisted that I needed to develop a scenario with plan A and plan B. At the beginning this did not make much sense, but after my release the second time I realized that things never go perfect. I was glad that he had prepared me for the worst. I have been out for five years already; prison life is definitely in my past."*

Once all these unresolved issues, along with the economic needs of their families, begin to mount, people on parole may find themselves confronting their first crisis. Service providers must be proactive and address the emotional issues their clients face upon re-entry, and they must discuss a range of scenarios, helping them visualize and discuss the pros and cons of every action they may take.

Service agencies can take on additional key roles such as educating people on parole, as well as their parole officers, about living with double or triple diagnoses. One model, used at the Osborne Association, is to have staff regularly accompany clients to discuss medical issues with parole officers, who

receive first-hand education from the person on parole. Parole officers in turn educate their clients about the difficulties of supervising 40 to 50 people on parole at the same time. The most successful outcome of this interaction is the sensitivity that all parties are able to develop around issues of HIV/AIDS, substance use, and community supervision. For example, in the past many parole officers misinterpreted some of the behaviors associated with complicated medical issues such as AIDS-related dementia. Meetings between case managers and parole officers were instrumental in preventing clients from being sent back to prison for behaviors that parole officers could have interpreted as manipulation, rather than loss of memory or disorientation caused by HIV/AIDS.

In the end, transitional planning for people with HIV leaving prison is not limited to addressing material needs. It is also about assessing their emotional needs, and about going beyond traditional roles by taking on new challenges, such as educating parole officers about the facts of living with several chronic medical conditions. If we are to enable some of the sickest people in our society to obtain the services they need

to survive, *it takes a whole community.*

*Dixon Valderruten is the Senior Instructor at the Osborne Association's Peer Education and Empowerment Training Program. He has provided transitional planning and taught a wide range of HIV/AIDS training courses in prison and in the community for the past 15 years.*

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*"Service providers must be proactive and address the emotional issues their clients face upon re-entry, and they must discuss a range of scenarios ..."*

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### **ACRIA's Community Advisory Board Expanding**

ACRIA's CAB is expanding its role to include advising the agency's research efforts. The aim is to ensure that all of our activities retain their focus on their main purpose – extending and improving the lives of people with HIV and AIDS – and that they are informed by the insights of those they are intended to serve.

The CAB's new responsibilities will include reviewing selected clinical trials that are being offered to the agency. Interaction between research staff and the CAB will be a two-way street, with consumer input helping to inform ACRIA's choice of clinical trials and CAB members gaining insight into the process of selecting and conducting clinical trials. In addition, the CAB will enhance its participation in treatment education by reviewing and providing feedback on the content and presentation of workshops and printed materials.

The all-volunteer CAB is currently recruiting members interested in adding their voice to the services provided by ACRIA. Anyone interested should call Jack Denelsbeck at (212) 924-3934, ext. 120.



## HIV in Prison: Resources

### **ACT UP/NY (AIDS Coalition to Unleash Power) Prison Committee**

actupny.org/reports/prisons.html  
332 Bleecker St., Suite G5  
New York, NY 10014  
actupny@panix.com

Advocacy on HIV/AIDS and HCV in New York State Prisons; contains page to report substandard health care or denial of care in NYS Prisons

### **AIDS Treatment Activists Coalition (ATAC) Care for the Incarcerated**

atac-usa.org  
P.O. Box 1514  
Old Chelsea Station  
New York, NY 10113  
Contact: Rob Mealey at rmealey@critpath.org

Works to increase access to health care for prisoners through strategy coordination, information sharing, training and advocacy.

### **American Civil Liberties Union Prisoner Rights-Medical Care and HIV/AIDS**

aclu.org/HIVAIDS/HIVAIDSMain.cfm  
125 Broad St., 18th floor  
NY, NY 10004  
(212) 344-3005

Information on legal cases and fact sheets on prisoners with HIV/AIDS and their medical rights

### **The Body: Prisoners and HIV/AIDS**

thebody.com/whatis/prison.html  
Website offering info on various topics including: Personal Accounts, Women With HIV in Prison, Legal Issues for HIV-Positive Prisoners, HIV Treatment and Prisoners, and Prisoners and Hepatitis

### **Center for Community Alternatives**

communityalternatives.org  
39 West 19th St., 10th floor  
New York, NY 10011  
(212) 691-1911

HIV prevention education, HIV counseling, testing and supportive services, substance use programs

### **Exponents/ARRIVE**

exponents.org  
151 West 26th Street, 3rd Floor  
New York, NY 10001  
(212) 243-3434, (800) 673-7370  
info@exponents.org

Assists individuals and families through difficult transitions – from addiction to recovery, from incarceration to civilian life; from HIV-negative to HIV-positive, and from welfare to work. Two-month HIV/HCV training program available.

### **The Fortune Society**

fortunesociety.org  
53 West 23rd Street, 8th Floor  
New York, NY 10010  
(212) 691-7554

Provides HIV/AIDS-specific services to prisoners and former prisoners, including outreach, HIV-specific case management, supportive counseling and treatment adherence.

### **HIV/Hepatitis C in Prison Committee**

prisons.org/hivin.htm  
2940 16th Street, #B-5  
San Francisco, CA 94103  
(510) 665-1935  
email:hipcomm@excite.com

Advocates on behalf of prisoners in California for access to adequate medical care, ending segregation, access to harm reduction tools, compassionate care of seriously ill inmates, and ending discrimination based on sexual orientation.

### **HIV in Prisons, Bureau of Justice Statistics**

www.ojp.usdoj.gov/bjs  
Bureau of Justice Statistics  
810 Seventh Street, NW  
Washington, DC 20531  
(202) 307-0765  
askbjs@usdoj.gov

Detailed statistics on HIV and AIDS in State and Federal prisons. Click on "Publications" and scroll down for yearly reports.

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## HIV in Prison: Resources (continued from previous page)

### National Commission on Correctional Health Care

[ncchc.org](http://ncchc.org)

1145 W. Diversey Pkwy.  
Chicago, IL 60614  
(773) 880-1460  
[info@ncchc.org](mailto:info@ncchc.org)

Works to improve the quality of health care in prisons. Publishes *Standards for Health Services*, with recommendations for correctional health services.

### National HCV Prison Coalition

[hcvinprison.org](http://hcvinprison.org)

PO Box 41803  
Eugene, OR 97404  
(541) 607-5725 Phyllis Beck  
(541) 607-5725 Released Prisoner Hotline

Aims to help educate prisoners and advocate for better testing, treatment and prevention of hepatitis C.

### National Minority AIDS Council – Prison Initiative

[nmac.org](http://nmac.org)

(click on Programs & Services, then Treatment Education)

NMAC Treatment Division: (202) 483-6622.

Provides technical assistance and HIV education to service providers and the community; offers publications on HIV/HCV in prison, online or by mail.

### New York State Prison HIV Hotline

(716) 854-5469

Collect calls accepted from NYS inmates  
Mon-Fri, 12 noon - 8pm; Sat & Sun, 10am - 6pm

Basic information on HIV transmission, risk reduction, and treatment. Transitional planning help and referrals also available, and free HIV-related literature.

### The Osborne Association – AIDS in Prison Project

[osborneny.org/aids\\_in\\_prison\\_project.htm](http://osborneny.org/aids_in_prison_project.htm)

809 Westchester Avenue  
Bronx, NY 10455  
(718) 842-0500  
[info@osborneny.org](mailto:info@osborneny.org)

HIV education, counseling & testing, discharge planning offered on-site at Sing Sing, Fishkill, Downstate and Green Haven Correctional Facilities.

### The Parolee Human Rights Project

#### New York City AIDS Housing Network

[nycahn.org/parolee\\_human\\_rights.htm](http://nycahn.org/parolee_human_rights.htm)

(877) 615-2217  
or Romeo Sánchez (718) 802-9540 x10

Members advocate for the rights of persons with HIV or HCV who are on parole and their affected communities. Bi-weekly meetings.

### Positive Populations

[positivepopulations.org](http://positivepopulations.org)

(304) 262-2371  
[info@positivepopulations.org](mailto:info@positivepopulations.org)

Online publication on health care issues in prisons with a focus on chronic infectious diseases, including issues on HIV and HCV care

### Prisoners' HIV/AIDS Support Action Network

[pasan.org](http://pasan.org)

489 College St, Suite 500  
Toronto, Ontario M6G 1A5  
(416) 920-9567 [info@pasan.org](mailto:info@pasan.org)

Canadian organization with excellent discharge planning resources – much applicable in the U.S. *PROS & CONS: A Guide to Creating Successful Community-Based HIV/AIDS Programs for Prisoners* available online or free by mail.

### Rikers Island Transitional Consortium (RITC)

16-06 Hazen St.  
East Elmhurst, NY 11370  
(718) 546-6655  
George Strachan [strachgs@asgr.com](mailto:strachgs@asgr.com)

Provides transitional discharge planning services to inmates with HIV being released from Rikers Island.

### The Women's Prison Association

[wpaonline.org/services/targeted.htm](http://wpaonline.org/services/targeted.htm)

175 Remsen St.  
Brooklyn, NY 11201  
(718) 673-6800

110 Second Ave.  
New York NY 10003  
(212) 674-1163

Service and advocacy organization for women with criminal justice histories. Offers counseling, housing and employment assistance, mentoring, and HIV counseling & testing.

### **Treatment Education Targets Spanish-Speaking Communities**

With Spanish-speaking individuals accounting for almost one-third of New York City's HIV-positive population, ACRIA's Treatment Education Department has launched outreach to agencies that serve Spanish-language-dominant communities. Workshop series have begun at Manhattan's Alianza Dominicana and the Coalition of Hispanic Family Services in Brooklyn to provide health and treatment education directly to Latino and Hispanic communities.

The workshops deal with specific topics of importance to people with HIV and are conducted in Spanish by trained bilingual treatment educators. At the Coalition for Hispanic Family Services, each topic-specific workshop will be offered twice within the same month, scheduled to correspond to the Coalition's regularly scheduled support groups, one targeting Latino men who have sex with men and the other men and women at high risk. At Alianza Dominicana, we will begin a second cycle of workshops, three times a month for the next six months, as of November. The Treatment Education Department is continuing stepped-up outreach in Spanish-speaking communities in a search for new venues and partnerships to help reach this large and underserved population.

### **New Staff Welcomed**

ACRIA's Treatment Education Department has undergone several changes in staff over the last few months, as Treatment Education Director James Learned, Associate Director Donna Kaminski, and Treatment Educator Constance Chang have left the agency to pursue other professional and educational opportunities. *Luis Scaccabarozzi* has joined ACRIA as Treatment Education Director, bringing with him a decade of direct service, training, and administrative experience in both public and private HIV/AIDS programs. A native of Peru, Luis has worked at the

Center for Community Alternatives, PROCEED, Test Positive Aware Network, and the Chicago Department of Public Health.

He is joined by new Treatment Educator *Sarah Swofford*, who has worked in the United States and Latin America primarily on women's issues, including sexual violence and reproductive rights. Both Luis and Sarah are fluent in Spanish and English.

To ensure continuity in all of our services, program responsibilities have been reorganized somewhat, with Treatment Educators *Lisa Frederick* and *Carlos Santiago* taking primary responsibility for national and local technical assistance, respectively, while Publications Manager *Mark Milano*'s responsibilities have been expanded to include editorial duties for *ACRIA Update*. Finally, Education Administrative Coordinator *Jack Denelsbeck* has been promoted to the position of Treatment Educator. A new Administrative Coordinator will be appointed soon.

On the research side, recent Columbia MPH *David Ward* joins ACRIA as Research Outreach Coordinator following internships at the New York City Department of Health and Mental Hygiene, and *Perion Smith*, whose background includes several years of administrative experience in not-for-profit organizations, has taken over as Regulatory Affairs Coordinator.

In addition, this semester *Nicola DePietro, M.D.*, joins ACRIA in an internship sponsored by Hunter College as part of work toward his MPH. Nicola has almost 25 years experience as a clinical researcher and administrator for multiple clinical trials in Italy and throughout Europe and is an expert in the management and interpretation of large data sets. He will be involved in data entry and analysis for ROAH (Research on Older Adults with HIV).

### **Training Highlights**

As a follow-up to the four days of training and technical assistance we conducted in Charlotte, North Carolina, in June, ACRIA treatment educators will revisit the city for a one-day follow-up on November 7.

Our next four-day technical assistance course for New York City nonmedical services providers will take place October 17 through 20.

ACRIA has entered into an agreement with the International Association of Physicians in AIDS Care (IAPAC) to conduct community forums on HIV resistance and cross-resistance in New York City. The program kicks off with two forums during November, one at Housing Works and one at Exponents.

During the past three months, ACRIA has provided trainings under its National Viral Hepatitis Program in Vermont and Colorado. Another is being conducted in Pennsylvania as *ACRIA Update* goes to press.

### **ROAH Progress Report**

ACRIA's Research on Older Adults with HIV (ROAH) Program is nearing the completion of its initial phase. With its 1,000-person cohort and comprehensive study instruments that collect detailed data on social support, mental health, and sexual and drug-using behaviors, ROAH will be by far the largest study ever conducted on the overlooked population of HIV-positive people over the age of 50. As this is written, the data-collection phase of the study is almost complete, with information having been obtained from over 950 older people with HIV, and preliminary entry of the raw data has begun. The Research Advisory Group involved in the study, chaired by Dr. Marjorie Cantor, Professor Emerita and Brookdale Distinguished Scholar at the Fordham University Graduate School of Social Work, will meet in October to examine the larger data issues.

# generous contributions

*The following persons, corporations and organizations made major donations between July 1, 2005 and September 30, 2005 to support ACRIA's research and education efforts:*

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J Daniel Stricker



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