Free At Last?

A drug bust, a prison sentence and an HIV diagnosis could easily derail anyone's life. But HIV-positive ex-prisoners Waheedah Shabazz-El and Cathy Olufs let their diagnoses and time in prison fuel their work as HIV educators and advocates. They may never escape the virus or their criminal records, but that doesn't keep them from breaking out from behind stigma and discrimination to help others rebuild their lives behind bars—and connect to health and happiness on the outside. Meet two impressive members of the HIV-positive prisoner population's new guard.

November 1, 2008 By Glenn Townes

Waheedah Shabazz-El, a loyal and devoted employee of the U.S. Postal Service for more than 20 years, made decent money and lived an exciting life that included a big house in the West Oak Lane section of Philadelphia. She drove a Nissan Elantra, dressed in only designer clothes, vacationed in the Bahamas and enjoyed plenty of male companionship. She also did drugs, mostly marijuana and crack cocaine—and she was no stranger to the more expensive powdered stuff.

"Back in the day, my house was the party place," Shabazz-El says. "There were always a lot of people, music, drugs and alcohol at any time of the day or night." One day in 2003 an army of Philadelphia police officers raided her house, rounded up everyone and took them to jail. Shabazz-El was sentenced to six months at the Cambria Correctional Center (CCC) in Philadelphia for drug possession with intent to distribute a controlled substance. She was placed on five years probation. Shabazz-El, whom POZ profiled briefly in 2004, discovered that she was HIV positive during a routine examination at the correctional facility.

"The tester blurted out that I was HIV positive in an open room with a large window and no curtains," she recalls. "Everyone walking by could see me. I sobbed and wanted to kill myself." Uneducated about HIV/AIDS, Shabazz-El never thought that the disease could directly affect her.

Some might have written off Shabazz-El, a 55-year-old, Muslim, HIV-positive mother of three and grandmother of four. But she did more than survive prison and HIV—she fully integrated into society after doing her time. Perhaps that's why her story of survival resonates so deeply. But it's an important story because it illuminates the link between incarceration and the spread of AIDS.

According to the Centers for Disease Control and Prevention (CDC), nearly one in every four Americans living with HIV passes through a state or federal correctional facility each year. A disproportionate number of those individuals are people of color. Many never recover from the trauma of prison life and its destabilizing effect on all areas of their lives.

African Americans represent 45 percent of all new HIV infections in the United States. HIV is the No. 1 killer of African-American women ages 25 to 44. And the United States incarcerates more people than any other nation on earth (more than 2.3 million)—the majority of them black. These facts translate to an escalating number of HIV-positive black Americans behind bars.

But like the mugshot number that identifies a prisoner, startling statistics tell only part of the story. The soaring incarceration rates for African-American women (they are the fastest rising group to be imprisoned; proportionally, the number of HIV-positive women in prison is higher than that for men) and an increase in HIV infection rates in general in the black community hint at a connection between the two disturbing trends. But it has been hard to explain the exact relationship between being HIV positive and being incarcerated. Too many people wrongly believe that skyrocketing HIV rates among black people result from drug-addled inmates engaging in indiscriminate sexual activity behind bars, acquiring HIV in prison or jail then taking it home and spreading it through an unsuspecting community. The fact is, most people don't contract HIV in prison; they enter the system already positive then, like Shabazz-El, discover their status behind bars.

A 2006 CDC study noted that about 90 percent of people with HIV in the state of Georgia's male prison population were HIV positive before they were incarcerated. The statistics were similar for women.

In fact, Shabazz-El was never tested for the virus—until she was in jail. "Discovering that I was HIV positive and being in jail at the same time was almost too much to bear," she says.

Laura McTighe, project coordinator of Project Unshackle and author of a study titled "Confronting Overlapping Epidemics: HIV and Mass Imprisonment" commissioned by the Community HIV/AIDS Mobilization Project (CHAMP), a grassroots advocacy group based in Philadelphia, says the relationship between HIV and imprisonment is about much more than what happens while people are imprisoned. "The notion that prisons are hotbeds for HIV transmission is inaccurate," she says. "The intertwining of HIV and imprisonment points to a deeper community level crisis." McTighe notes that although HIV is transmitted by specific behaviors, recent research indicates that the risk of HIV and vulnerability are more closely related to socioeconomic inequities. "These injustices often make it more difficult for people to protect their health [both inside and outside of prison]," she says. Translation: If you are hungry and have nowhere to live or your kids need new clothes and you're broke, you may get involved in something you might not do (selling drugs, stealing, prostituting yourself) if your bank account were flush.

McTighe's study discovered that people with HIV in prison often leave sicker than when they were first locked up. This is because prisons fall short of addressing essential HIV needs. Prisoners lack meds. They lack knowledgeable docs who can prescribe effective regimens. They lack regular delivery of meds (interruptions can lead to drug resistance). When they do take their meds, prisoners often lack proper food, and that can amplify side effects. They lack drug resistance testing, which can cause them to take an ineffective HIV regimen. And they lack viral load and CD4 tests, which can show the meds are working and therefore provide incentives for patients to

adhere to meds.

Another common dilemma is that coinfection with hepatitis C—a common killer of HIV-positive people behind bars—may go untreated because prisons don't want to pay for expensive hep C meds.

In addition, inmates with HIV/AIDS are often segregated, abused and stigmatized. And, denied access to the Internet and abandoned by families who could provide info, many HIV-positive prisoners are in the dark about what HIV/AIDS is, how to treat it and how to avoid getting, or spreading, it. "The lack of knowledge, condoms, clean needles and other HIV-prevention tools can increase a person's risk of contracting [and inadvertently spreading] HIV while imprisoned," McTighe notes.

While consensual and non-consensual sex in prison (and a lack of condoms) contributes to the spread of HIV, another key factor influences the escalating rates among African Americans: the mass incarceration of the black community. In a Stanford Law Review article titled "The Social and Moral Cost of Mass Incarceration in African-American Communities," Dorothy E. Roberts discusses how incarceration disrupts the family structure and saddles women with crushing financial and emotional burdens. Roberts says that locking up mothers in particular disrupts family life because these mothers are often the primary caretakers of their children before entering prison. With more African-American women behind bars, more black children are placed in foster care or state institutions.

Incarcerated African-American mothers may also disempower the next generation. If so many black mothers are behind bars, who is raising the kids—let alone teaching them to negotiate sex safely during adolescence?

The mass incarceration of men creates a domino effect that further disorders women's lives and destroys their power in sexual relationships with men. For one thing, with so many black men behind bars, the women have fewer potential male partners—and that may create a competitive environment in which women are less likely to demand the use of condoms. To further complicate things, some of those men are ex-inmates themselves—some unknowingly carry the virus or are unwilling to reveal their status.

The continued stigmatization of prisoners with HIV makes inmates less likely to get tested while inside, or, if they do, to disclose their HIV status upon release. Fear of stigma may also prevent people from seeking treatment. When people don't seek treatment, they're more likely to have higher viral loads and are therefore more sexually infectious.

Prison is a dehumanizing experience that erodes people's self-esteem and taxes their resilience. When one group controls another, the unbalanced social structure makes things volatile. Add to that the perception of prisoners as "bad guys" who deserve whatever they get, and it's easy to imagine how prisons can become a fertile breeding ground for both physical and mental abuse. One woman we spoke to recounted how, when she asked a male guard for a sanitary napkin, he

replied he'd already given her one earlier; it didn't matter that she needed another one.

A daily diet of indignities such as this, coupled with the added pressures of being HIV positive, can trigger a slew of emotional and health care issues that prisoners often carry with them when they go home to their communities.

Another critical factor that leads to the spread of HIV is the lack of sex education both inside—and outside—prison walls.

"African-American women moving through the penal system are among those at greatest risk of HIV infection because prevention efforts fail to address a number of issues when it comes to making informed sexual choices," says Jessica Fields, an assistant professor of sociology at the University of California at San Francisco and the principal investigator of an ongoing study of sex education and HIV prevention among incarcerated women in San Francisco.

Indeed, after learning her status, Shabazz-El was handed some literature about HIV/AIDS, given brief counseling and prescribed some HIV medication—some of which made her ill. She contemplated whether she would disclose her diagnosis to her family and close friends. For a while, she chose to keep the news a closely guarded secret. She hid the handouts and pamphlets about HIV/AIDS in her Koran.

While incarcerated, Shabazz-El experienced a multitude of emotions ranging from mania and anxiety to melancholia and depression. She also wondered how she would survive living in such a controlled and nondescript environment for an extended period, battling an illness she knew very little about. "My family came to visit me a few times," she says. "There were periods when I lost hope and thought that my life was over."

Shabazz-El says prison nurses would dispense medications in a cumbersome and lengthy process—and in some instances, HIV-positive inmates were often the last to receive meds.

"On numerous occasions, I received my HIV medications late," she says. "I would have to wait until the nurse went to all of the other cell blocs, before returning with my HIV meds." Shabazz-El says she believes the delay was intentional, because HIV-positive prisoners were often isolated and stigmatized by prison staff and HIV-negative inmates. Also, Shabazz-El says her relationship with a general practitioner doctor in prison changed once the doctor discovered she was HIV positive.

"He was an older white doctor who I would see for other ailments I had besides HIV when I was incarcerated," she says. "We would laugh and talk about books and current events during my exams." Once the physician received her full medical charts and records that highlighted her status, however, the friendly demeanor and warm bedside manner abruptly changed. "Exams were now quick, cold and impersonal once he discovered that I was positive."

Looking beyond these hardships, Shabazz-El anticipated the time when she'd be released and would be able to return to her family. "When I was released from jail, I went to live with my middle son, Salim, and his girlfriend at their small house in the city," she says.

Once she settled in, Shabazz-El had to make regular visits to her physician and various clinics in order to get medication. Some of her meds had to be refrigerated—something she obviously couldn't do without revealing her HIV status to her son.

She lived with him for 15 months in close quarters. Hiding her meds and lying about where she was going became her biggest stressors.

"My son and I were very close, and we talked all the time," she says. "I continuously put myself at great risk by not adhering to the prescribed drug regimen. I eventually got tired of lying." After a few months, she told her son that she was HIV positive.

"We both cried and hugged each other," she says. "I assured him that even though I was living with the virus, I was taking care of myself."

Shabazz-El told her son not to share the news of her illness with his siblings. She wanted to disclose the information in her own time and way to her eldest son, Fahmee, and daughter, Salwa. However, one day, while discussing details about an upcoming local fashion show, Shabazz-El says, her daughter became agitated regarding a small aspect of the show. "I was shocked at how angry and upset she became about a minor detail, and she was rambling on and on about it," she says. "I finally just told her that I was HIV positive." Shabazz-El says her daughter immediately stopped her tirade and told her that she already knew about it from her brother. "Her frustration about the fashion show was just a substitute for the anger and resentment she had toward me for not telling her about my status."

Shabazz-El shared the news with her eldest son shortly after. "He began researching HIV and telling me about all of the new drugs and clinical trials that were being done. There were some tears, some anger and a lot of love and hugs," she says. "I was relieved that I no longer had to hide my condition from the people I loved the most."

The tale of another woman who ended up HIV positive and in jail tells another side of the same story. When she was in her late teens and early 20s, Cathy Olufs was a self-labeled troublemaker. She lied, cheated and stole to support a serious drug habit.

All of it—the rambunctious behavior, drug use and thievery—led her to frequent stays at various jails throughout California. In 1995, Olufs tested positive for HIV, and less than a year later she was sentenced to serve 16 months at the California Institution for Women (CIW).

Olufs says the worst period in her life was just before being sentenced to CIW. "I didn't have a life before being sentenced to prison," she says. "I was homeless and did what I had to do in order to support my drug habit." Once incarcerated, she vowed to turn her life around and never return to

the confines of a prison cell.

While in prison, Olufs's family rarely contacted her. "Once in a while, they would send me letters, but they never came to visit," she says. "They were afraid of me and the person I had become." Olufs received a 30-day supply of HIV meds throughout her prison term and maintained the prescribed drug regimen when she was released less than a year later.

Today, Olufs, 44, is the education director for the Center for Health Justice in West Hollywood.* Among other things, the organization offers counseling and other services to people living with HIV.

"For HIV-positive people, especially women, a number of critical needs must be met in order [for them] to be successful and healthy upon release from prison," she says. "[For many women] just finding a place to live, medical care and social and emotional support are difficult." To the American public, prisoners rank at the bottom of the sympathy scale, Olufs says. For prisoners facing poverty, single parenthood, HIV and difficulty accessing health care, the chance for successful re-entry to society is all but non-existent. "There are fewer and fewer programs to prepare people for release in a meaningful way," she observes.

Shabazz-El agrees.

"Rehabilitation and dealing with the reality of HIV has to start before the offender is released," Shabazz-El says. If the tools for coping with HIV and re-entry to society are in place before prisoners are released, she adds, they'll have a better chance of making it on the outside and less chance of doing something that will send them back to jail.

José Martin Garcia Orduná, executive director of the Manhattan HIV CARE Network, says many professionals fail to give prisoners the necessary tools to stay well in prison so that they may successfully re-enter society. "This starts with providing HIV-positive men and women with adequate health care and support systems," he says. Many clients who seek assistance from organizations such as the Manhattan HIV CARE Network are recently released inmates infected with HIV.

Outwardly, Shabazz-El and Olufs are vastly different, yet they are in many ways similar. Thousands of miles apart and from different backgrounds, the two women still share a bond—the bond of surviving the indignities and humiliation of being incarcerated and HIV positive.

The reason these two HIV-positive women have become stellar role models is that they were able to navigate the system and turn their lives around. Plus, both Shabazz-El and Olufs left prison with their physical well-being and mental health intact. Now, they offer hope and inspiration to thousands of others.

Today, Shabazz-El is an active and vocal crusader for the rights of the disenfranchised and HIV-positive men and women. She is an activist and panelist for numerous local and national

organizations including ACT UP Philadelphia, Positive Women's Network: Women of Color United Against Violence and HIV, CHAMP, and the Prison Re-Entry Health Care Network in Philadelphia. In addition, she regularly gives speeches and teaches HIV/AIDS awareness classes throughout the Philadelphia metro area. At one time, she also penned a self-help and advice column called "Dear Waheedah" for a prison health newsletter.

"Offenders would send me letters asking for my opinion about various issues including prisoner re-entry and HIV," she recalls. "Some of the letters would be so heart-wrenching and painful to read. I answered every letter I got." When asked if all of her advocacy work and community activism becomes emotionally draining or is a strain on her health, Shabazz-El responds: "Absolutely not. It's vital that we provide all the accurate and current information about HIV to not only those with the virus, but to everyone."

Advocates for better health care for prisoners agree that until prison officials, politicians and others firmly commit to a strategy to address the issue of HIV in prison, minimal progress will be made. While efforts to combat the spread of HIV behind bars have improved somewhat in recent years—various states launched pilot programs and prison outreach initiatives—much more needs to be done. Warriors like Shabazz-El and Olufs are determined to foster further changes.

"Expanding HIV prevention and awareness programs and [allowing for] the distribution of condoms to inmates nationwide will decrease the spread of HIV in prison," Shabazz-El says. "Until these two elements are widely practiced in prisons, HIV and other STIs will remain a problem." Olufs adds that legislators and officials are in a state of denial when it comes to illicit activities behind bars. "Unfortunately, some entities [refuse] to acknowledge that sex and drug use happen in prison and jails," Olufs says. "And for the few that do, they fear the political ramifications of actually doing something about it."

Both Olufs and Shabazz-El offer hard-won expert advice on how to stop the flow of HIV from the outside to the inside and back out again. They also offer another defense against the rising tide of HIV: the personal examples of their lives, which encourage others to talk freely about HIV (and HIV prevention) and to get tested and treated. Standing up as they have—freeing themselves from the double burden of being ex-prisoners and HIV-positive women—Olufs and Shabazz-El offer what may be the key to freeing us all from the epidemic's continuing spread: positive role-modeling that makes people change their behavior to protect their health.

* Correction: The asterisked sentence above has been updated from the original version, which incorrectly stated the name of the organization of the person cited.

The following are excerpts from letters that POZ has received during the past year from HIV-positive inmates from around the country.

"I'm writing from the Salt Lake City jail where I await placement in my second in-patient drug treatment program. My addiction to crystal meth changed my life. Three years ago, before experimenting with meth at a New Year's Eve party, I was a practicing licensed clinical social

worker. My recreational drug use quickly progressed to compulsive use and dependency. I received two felony charges; addiction destroyed the affection between my partner and me, and my ex-wife sued for custody of our three children. In July of 2004, I was told I was infected with HIV. Disclosures in jail have created an incredible variety of experiences; rejection within such confined quarters provides unique opportunities for personal growth and public education. Conversely, it can create enough anxiety and isolation to break one's spirit. Without support, HIV-positive men and women in correctional institutions are very vulnerable. My support comes from my friends at the Health Department, my friends who have understood
the addiction, and my children."

Salt Lake County Adult Detention Complex,
Salt Lake City, Utah

"I sit here in this prison on a charge of aggravated assault because I didn't have the backbone to tell my partner that I was HIV+. My partner never became infected, which I am very grateful for. This all happened about one year after I found out I was HIV+. I was not dealing with any issues relating to HIV/AIDS. I was not reading any material to help me figure out what was going on. Why is it so hard to disclose to somebody that you really care for? I think being rejected is a part of it. I was given a sentence of 8–16 years for this. I did put my partner in danger so I had no choice but to take the charge. The sentence is a little harsh, but I am dealing with it. I am trying to get involved with HIV/AIDS peer education here in the prison, but I keep meeting a lot of roadblocks from administration."

State Correctional Insitution, Frackville, Pennsylvania

"I'm 42 years old, and I'm HIV positive. I've been incarcerated for 24 years during which time I've lost five brothers and six sisters as well as my mother and father. I have no family. No outlet beyond these prison walls. At 17, I had unprotected sex, and while in prison later I turned up HIV positive during a routine checkup. For 13 years…I've felt ashamed and felt like an outcast and all alone. The support groups here are a joke. I'm segregated in one of two HIV-positive units. I may be out 10.01.08. I need help in getting a doctor, housing, essentially my life back in order. I need a real support group. The South Carolina Department of Corrections will only give me a 30-day supply of my medication. The state will not help you obtain your [medical] benefits. I feel I have a chance at life to regain my dignity to be able to be a functioning positive person within society without feeling that I'm dead."

Broad River Correctional Institution, Columbia, South Carolina

"I was probably with HIV in 1995, [but I had an] AIDS diagnosis in 2004. I'll have you know that living with AIDS is like living in one grand dysfunctional family. I'm living in a subculture at this time that offers no primary AIDS physician, no information, etc. Doctors in here view themselves as authority figures. They believe they're smarter than patients so they expect patients to be compliant; unfortunately, all too many patients agree-—that's why they're falling through the cracks. We as patients have more time and motivation to research stuff that might keep us alive longer. I'll be honest with you: I'm not afraid of dying of AIDS. I'm afraid someone will kill me before I die of AIDS. I know that if I would have listened to all my doctors' advice I would have

been dead a long time ago. Remember that nobody asked for AIDS. It threatens your income, destroys your health, shatters your family and then demands that you spend time managing it. [In prison] when you ask for information, you get misinformation. Heck, the moral around here is, 'You'll be dying soon.' It really is."

Taylor Correctional Institute, Perry, Florida

"I am a 31-year-old male from Lafayette, Indiana. For me, HIV was a blessing and a curse. When I found out, it saved my life. It gave me answers about myself that most people will never have. (Why am I here? Do I have a purpose?) I have the words "HIV positive" tattoo'd across my shoulders and a red AIDS ribbon on my shoulder. I want people to know—that's why I got the tattoo. There is no medical care, and having this tattoo here does me no favors. I try to talk to people [about HIV], and a lot of times I can bring them around, erase their fears and educate them. But there are some who would rather use violence toward me. Last week, I was in a cell and a new guy came in and decided he wanted my bunk and thought he could intimidate me out of it. There was some raised voice and when the guards came in he told them I threatened to spit on him. Which is total B.S., but he played on their fears and it worked. They took me out and placed me in segregation. I am locked in a cell by myself for 23 hours a day. I have no interaction with anyone else. Since no report was made I am left to conclude that I am being put here due to my HIV status. I feel like I am getting sick again and that they will leave me to die. I don't want special treatment—I just want equal treatment. I am not in here for some crazy crime, I just got sick and fell behind on my child support."

Tippecanoe County Jail, Lafayette, Indiana

"I am an inmate at the Georgia Department of Corrections. I was positive before I was incarcerated in 1998. When I was arrested, I had known for a year. I wanted to end my life and tried to make the police end my life because I could not do it myself. I was arrested and sentenced to 15 years in prison. I have been in now for 10 years and I have finally come to my senses that I need to be strong if I want to live a normal life. I am still by myself; my family does not want anything to do with me. I have made a lot of changes in my life, and I have disclosed my HIV status to the inmates and staff here at this prison as a step in an area that I want others to know everything about HIV/AIDS that I know. I have gotten stigmatized but not as much as I thought I would get…

I am not a bad person, I just chose wrong. I was scared at the time and had no one to turn to. I am willing to share my experiences with everyone. I am not scared anymore.

Scott State Prison, Hardwick, Georgia

"I've been positive since '98. Being in prison, information is limited. Broad River is basically an HIV/AIDS camp with about 400+ with the virus. There's so much negative things going on I can tell you about. With just one doctor for so many HIV/AIDS it's not a good situation. Don't get me wrong, we do have street social workers with different programs. The thing is, none of these social workers are HIV positive. I'm in the process of starting group counseling for those getting release within a month or two. I need your help to get this program off the ground. Computers are not available here for me to use. I have seen too many guys pass away when education is lacking. Also

hearing about guys dying after a few months on the streets. I'm sending an SOS to you!!!"

Broad River Correctional Institute, Columbia, South Carolina

"I am writing from South Bay Correctional Facility. I am currently involved in a volunteer STD facilitator training course offered by the Palm Beach Health Department. I am requesting that you print this letter and allow me to make all my brothers aware that they can be HIV tested, know their status and be treated during their incarceration. We will all receive a test upon expiration of our sentences; however, there are numerous benefits to early diagnosis. All we have to do to be tested is submit a request to the medical department and wait for a call out. No co-payment required."

South Bay Correctional Facility, South Bay, Florida

RESOURCES

American Civil Liberties Union
AIDS Project
125 Broad Street, 18th floor
New York, NY 10004
212.344.3005
aclu.org/hiv/crimjustice
Provides information on legal cases and medical rights for HIV-positive prisoners. Also provides downloadable fact sheets.

Buddhist Peace Fellowship
Transformative Justice Program
P.O. Box 3470
Berkeley, CA 94703
510.655.6169
bpf.org/html/home.html
Provides a comprehensive listing of post-release resources by state.

Community HIV/AIDS Mobilization Project (CHAMP)
Project Unshackle
32 Broadway, Suite 1801
New York, NY 10004
212.937.7955
champnetwork.org/unshackle
Advocates for prisoner rights and offers links to organizations that provide support and resources.

National Minority AIDS Council
Prison Initiative
1931 13th Street NW

Washington, DC 20009
202.483.6622.
nmac.org
Offers numerous publications on HIV/AIDS programs and policy.

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http://beta.docker.poz.com/article/hiv-prisoners-feature-15439-2986