

Threatened Change To HIV/AIDS Services

by Linda Ostreicher
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The drug regimen that has changed AIDS from a death sentence to a chronic disease for many New Yorkers requires patients to follow a complicated daily routine, which they do at a far higher rate than patients with other diagnoses comply with their medical instructions. AIDS and HIV patients do what they are supposed to 70 percent of the time, while other patients do so only about half the time. Unfortunately, to be effective, HIV treatment regimens require 95 percent compliance, a level nearly impossible to maintain without a clear mind, stable housing, adequate food and cooking facilities, and consistent coverage for medical care and prescriptions.

That is why AIDS activists see social and support services as a crucial factor in the health of people with AIDS, and why they so bitterly criticize Mayor Michael Bloomberg for his proposals to change Local Law 49, which governs the city agency known as the HIV/AIDS Services Administration.

WHO USES THE CITY'S HIV/AIDS SUPPORT SERVICES?

The city's HIV/AIDS Services Administration's 31,000 primary caseload includes the majority of New Yorkers with AIDS, plus a small number of those with HIV infection only. Over 14,000 family members of people diagnosed with HIV/AIDS also receive certain HIV/AIDS Services Administration services: counseling on daily living skills, housing if they live with the HIV-positive person and if their relative dies, bereavement counseling and help in finding non-AIDS-related housing.

Not all people with AIDS need HIV/AIDS Services Administration's help. With therapeutic drugs, some are able to continue working, maintaining insurance that covers their treatment, including medication. Others receive long-term disability payments through private insurance provided by former employers. However, all but the wealthiest people with AIDS face the possibility that they may eventually become too sick to work, and/or outlive their savings or other resources.

AIDS is most prevalent among people who are already poor, but it also makes middle-class people poor. It forces them to cut back on work or quit their jobs, pay extraordinarily high bills for prescription drugs which are rarely completely covered by health insurance and cope with unpredictable symptoms. The diagnosis alone creates emotional turmoil, sometimes

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requiring mental health treatment. Newly-diagnosed parents must decide whether or not to tell their children, who should care for the children if a parent dies, and how to juggle medical appointments, child care, and financial commitments.

A 1997 study by the national Centers for Disease Control found that people receiving care for HIV-related disease were twice as likely as others to be unemployed, to have household incomes below \$25,000 per year, and to have either public insurance, such as Medicaid, or no health insurance at all. For low-income HIV-positive New Yorkers, government benefits (not necessarily health care) can be the most crucial life support system.

BLOOMBERG'S PROPOSALS TARGET HIV/AIDS OFFICE AND SERVICES

Mayor Bloomberg has announced his intention to seek unspecified changes in Local Law 49, so that the city can provide more help for women and more job training for clients wanting to return to work. However, changing the law could also remove legal limits to the number of clients per caseworker, and to how long the administration can take to deliver benefits. Opponents of this proposal believe that the mayor's real goal is to weaken the law, so that his proposed budget actions would no longer violate it.

Under the mayor's executive budget for Fiscal 2004, 29 HIV/AIDS Services Administration case manager positions would be eliminated, case management services for all clients would be privatized, and city funds for HIV-prevention services for communities of color would be eliminated. Under the more drastic "doomsday" scenario, each contractor providing supportive housing for people with HIV/AIDS would take a 10 percent funding cut, affecting 4,000 residents with HIV/AIDS. Also, the city would eliminate all government benefits case management, public and private, for people with HIV/AIDS.

AIDS activists are vigorously protesting these policies. "People are disappointed that we have to do the same thing we were doing with Giuliani," said Terri Smith-Caronia of Housing Works, an AIDS service and advocacy organization. "At least Giuliani came out and said 'I hate poor people, I hate the disabled.' Bloomberg is far more disingenuous, more dangerous."

The executive budget also proposes that the Mayor's Office of AIDS Policy Coordination be

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folded into the health department.

"The implications are huge," explained Smith-Caronia. "Having this office affirms to the world that this city has a commitment to develop a coordinated policy on AIDS. The Mayor's Office is a hair's breadth above all the other agencies that deal with AIDS, so it can make sure the city doesn't waste federal dollars on duplicating services across departments."

THE NEED FOR MORE COORDINATION IN THE HIV/AIDS SERVICE SYSTEM

In February 2003, the Center for an Urban Future released a critique of the New York City HIV/AIDS service system, in which author Julie Hantman detailed how the lack of coordinated, objective planning has produced a glut of some social support services and a shortage of others, with a disproportionate share of nonprofit services being located in Manhattan. Of the 250-odd nonprofit organizations providing one or more HIV/AIDS-related services, only 15 offer a full selection at a single site. The rest advocate for "one-stop shopping" for public benefits at the HIV/AIDS Services Administration, but are themselves fragments in a labyrinth of community-based social services. It is just as difficult for a person with nausea, fever, and dementia to travel between multiple nonprofit agencies for mental health care, case management, substance abuse treatment, and food pantry bundles, as it is for them to travel between HRA offices to coordinate welfare benefits, Medicaid, and food stamps.

The term "case management" can refer to coordination of different kinds of services. Medical case managers coordinate health care services. Case managers at community-based organizations coordinate services ranging from housing and food to substance abuse and mental health treatment. For consumers who are poor enough, the HIV/AIDS Services Administration's staff performs government benefits case management, coordinating public assistance, Social Security Disability benefits, Supplemental Security Income, Medicaid, food stamps, and emergency food and housing assistance.

AIDS activists are critical of the city's use of federal housing funds to pay the salaries of HIV/AIDS Services Administration employees. "This is \$50 million that was meant to be used to build housing for people with AIDS," says Jennifer Flynn of the New York City AIDS Housing Network. However, she does not support privatizing or eliminating HIV/AIDS Services Administration case management in order to free up federal funds for AIDS housing. According to Flynn, the administration's case managers are unique, in that as city

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workers, they are authorized to decide whether applicants are eligible for government benefits and to issue checks, food stamp cards, and other concrete benefits.

□ State law requires that it be a state or local district employee that decides eligibility,□ she points out, noting that this function could not be performed by private agency employees, but would revert to regular welfare eligibility workers. Those workers lack expertise in AIDS issues, and carry far higher caseloads than the maximum of 34 allowed under Local Law 49 for HIV/AIDS Services Administration caseworkers.

THE MEDICAL IMPACT OF UNMET SOCIAL NEEDS

A diagnosis of symptomatic HIV illness or AIDS entitles HIV/AIDS Services Administration consumers to individualized service planning, financial counseling, support counseling, referrals to private service providers, and child custody planning. Staff can make home and hospital visits, and are mandated to try to find consumers who have dropped out of services -- although the administration does not claim to continue searching for them for the full 90 days required under Local Law 49. In theory, applicants with sufficient income are charged program fees and/or part of their rent.

The majority of people with AIDS in New York City rely on the HIV/AIDS Services Administration for financial assistance with their housing costs, often in the form of rent subsidies. The administration receives about 100 requests a day for emergency housing placement. This reflects the findings of a survey by New York City's HIV Planning Council, in which more than half of HIV-positive people surveyed named housing as their major need.

Researchers interviewed patients at a Bronx HIV Clinic about factors influencing compliance with antiretroviral treatment. In January 2003, Jane Simoni, lead investigator, noted that the most common reasons given for not taking medications were forgetting to do so and negative side effects. Depression and social isolation also made it less likely that patients would comply with treatment regimens.

At least 27 percent of New Yorkers diagnosed with HIV/AIDS as of March 2003 were intravenous drug users. A national study of HIV-positive patients found that over a 6-month period in 1996, over 60 percent used substance abuse treatment or mental health services.

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But there is a shortage of affordable mental health services and substance abuse treatment for New Yorkers who are HIV-positive, especially for those who need both.

Bloomberg has not announced any changes in his proposed cuts to HIV/AIDS services since the state legislature took action to pass a state budget more favorable to New York City than the governor's version. On April 30, protestors marched across the Brooklyn Bridge to demonstrate opposition to the HIV/AIDS cuts. Activists were arrested following a demonstration on May 8 just outside the mayor's bullpen office on the second floor of City Hall, and additional civil disobedience is planned.

Linda Ostreicher, a former budget analyst for the New York City Council, is a freelance writer and consultant to nonprofits. She is currently on the staff of Bronx Independent Living Services.