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Health Resources and Services Administration
HIV/AIDS Bureau
Division of Science and Policy
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The following comments regard HRSA HAB Policy Notice-99-02, Amendment 1, published in the December 6, 2006 (Volume 71, Number 234) edition of the *Federal Register*.

In 1990, Congress passed the Ryan White CARE Act to provide for the unmet needs of persons living with HIV. At that time, AIDS was essentially a death sentence and few therapies existed to effectively treat this disease. The CARE Act primarily provided social services and end of life care for those with HIV/AIDS.

Since that time, medical breakthroughs have contributed to a great transformation in the lives of those with HIV. AIDS deaths have dropped significantly and for many, HIV has become a chronic rather than a terminal disease. As a result, more Americans are living with HIV than ever before and the cost of life saving drugs is considerable. A drug combination including Fuzeon, for example, can cost between \$30,000 and \$35,000 a year to treat a single patient.

While the face of AIDS has changed, our federal response has been slow to adapt to those changes.

The great promise and incredible cost of AIDS drugs underscores the need to prioritize core medical services. While social services can compliment treatment, such programs are not essential and should not come at the expense of life saving medicine.

Funding for the CARE Act has increased dramatically from \$257 million in 1991 to over \$2 billion in 2006, yet hundreds of Americans with HIV are on waiting lists for access for life saving AIDS medications and many others face formulary restrictions. Tragic headlines have reported the deaths of patients on waiting lists for treatment

provided by the CARE Act's AIDS Drug Assistance Program (ADAP) in Kentucky, South Carolina and West Virginia.

The U.S. federal government is expected to spend more than \$20 billion on HIV/AIDS related programs this year alone and we as a nation have committed ourselves to providing billions of dollars worth of medication and care services to those living with HIV in Africa and elsewhere. Clearly, there is no acceptable reason why with such a large financial investment that any American living with HIV can not access medically necessary care or for patients to be dying on waiting lists for AIDS drugs.

In December, Congress passed and the President signed a bill to reauthorize the CARE Act, directing a greater focus on primary medical care and treatment. The bill sets a treatment funding "floor" requiring that not less than 75 percent of funds be spent to provide core medical services to eligible patients.

"Core medical services" means the following services:

- Outpatient and ambulatory health services;
- AIDS Drug Assistance Program treatments;
- AIDS pharmaceutical assistance;
- Oral health care;
- Early intervention services;
- Health insurance premium and cost sharing assistance;
- Home health care;
- Medical nutrition therapy;
- Hospice services;
- Home and community-based health services;
- Mental health services;
- Substance abuse outpatient care; and
- Medical case management, including treatment adherence services.

This new legal requirement will essentially update the CARE Act by establishing medical care and treatment as the program's primary focus. This prioritization means that other less essential CARE Act services, such as housing, must take a secondary role to ensure that first and foremost every eligible patient has access to these life saving core medical services.

In line with this new directive, the Health Resources and Services Administration (HRSA) has recently proposed placing a cumulative lifetime period of 24 months on CARE Act funded short-term and emergency housing assistance. There currently is no time limit for those receiving housing assistance under the CARE Act.

HRSA's proposal results from an Office of Inspector General audit encouraging clarification of the definition of short-term housing and emergency housing assistance. This proposed change will align the HRSA definition of short-term housing with the widely accepted program standard used by the U.S. Department of Housing and Urban

Development (HUD), Continuum of Care Homeless Assistance Programs and the Housing Opportunities for Persons with AIDS (HOPWA) program.

The change would free up additional resources to provide life saving AIDS drugs and primary medical care to patients living with HIV/AIDS. This is particularly important because as of November 15, 2006, a total of 340 individuals were on ADAP waiting lists. Tragically, four patients on ADAP waiting lists in South Carolina died in recent months.

Those living with HIV without stable housing would still have access to federally subsidized AIDS housing. HUD, for example, has an Office of HIV/AIDS Housing. One of the primary functions of the Office of HIV/AIDS is to manage the HOPWA program, which is specifically designed to address the housing needs of persons living with HIV/AIDS and their families. In addition to HOPWA, HUD has other programs designated to serve persons with a variety of needs that can be used to serve persons living with HIV/AIDS. HUD programs such as HUD's Homeless Assistance Programs, Programs for Persons with Disabilities, and HOME Initiatives can be directed to persons living with HIV/AIDS and their families.

To ensure that sufficient funds are available under HOPWA to assist those receiving housing under the CARE Act, HUD could control the amount being spent on bureaucratic and administrative costs.

According to a Government Accountability Office (GAO) investigation, in Fiscal Year (FY) 2003 only 57 percent of HOPWA funding was spent on housing financial assistance. The remainder was spent on case management (35 percent) and administration (8 percent). According to GAO, the proportion of HOPWA money actually spent on housing for persons with HIV/AIDS is declining. Between 1994 and 1998, 64 percent of HOPWA funds spent on financial rent assistance.

These excessive overhead costs siphon away funding from the very population the program is intended to serve.

HOPWA is expected to be funded at \$286,110,000 in FY 2007. By requiring 75 percent of this amount to be spent on housing assistance, HUD could provide nearly \$52 million more to eligible individuals. According to the U.S. Census Bureau American Housing Survey, the median monthly housing costs (rent, utilities, etc.) for renter occupied homes is nearly \$650, or \$7,800 for a year. That means that roughly 6,600 more Americans with HIV/AIDS and their families could be provided housing assistance next year by simply restraining HOPWA overhead costs.

HUD could also ensure additional resources by implementing better outcome measures and combating fraud and abuse.

A recent Office of Management and Budget (OMB) program assessment found HOPWA "not performing" because results had not been demonstrated. Specifically

OMB stated that “no data has been collected from grantees on stated outcome measures.” OMB also found that “The current [HOPWA] formula is flawed because it allocates funds based on the cumulative number of AIDS cases over time which does not reflect the current housing needs of the eligible population in that area.” OMB’s recommended improvement plan to address these deficiencies includes “requiring grantees to report their progress toward achieving the program’s long-term outcome measures” and “completing a statutory update to the formula to use local housing costs and Center for Disease Control [and Prevention] estimates of persons living with AIDS to better allocate resources based on current need.”

There have been a number of reports of waste, fraud and abuse—adding up to millions of dollars-- involving HOPWA that indicates AIDS housing dollars should be better monitored.

A HUD report issued in March 2006 found that Hope House, a West Palm Beach, Florida, service agency with 55 patient leases — which provide housing to patients and about 100 family members — had a number of serious problems. Over \$1 million of Hope House’s \$1.3 million budget is derived from federal money. In 2004, Hope House sold a property called King’s Court that had been improved with city-dispensed federal money. But the sale violated an agreement that said the property couldn’t be sold for 10 years. The city could be fined more than \$100,000 for the violation. The city didn’t keep a complete list of Hope House’s equipment, a violation of federal guidelines. Some residents were paying more in rent than federal limits allow. Hope House has a history of problems. Another investigation found that a former executive director stole \$313,870 of Hope House money in 1995. In May 2000, the Quantum Foundation sued Hope House, saying it made “vast unapproved expenditures” totaling \$403,500 from a Quantum grant that was supposed to be used to build cottages for children whose parents are sick. And past audits have found proper documentation for expenses was lacking. In August, the city ended its long-running financial support of Hope House, saying it has lost confidence in the ability of the nonprofit organization to follow federal guidelines in carrying out its mission to house needy AIDS patients.

New York City provided \$2.2 million in questionable payments over 2 ½ years, partly to rent rooms listed to people who had died, the city comptroller charged in an audit released in July 2005. The city’s Human Resources Administration paid \$182,391 for rooms listed to 26 people up to two years after their deaths, with one housing provider receiving 76 percent of the money, \$137,920, said the report from Comptroller William Thompson Jr. Auditors said many of the problems stemmed from the agency’s failure to review its own data and client files before making payments to housing providers. Among the findings, auditors said, \$1 million went to housing providers for residents who did not sign registration logs; \$456,292 was paid for overnight stays on or after clients’ last days of occupancy; \$417,463 in payments for people not in the agency’s new database; \$118,185 in double billing; and a \$20,030 check to one vendor who submitted a \$2,030 bill, an overpayment the agency said it will correct.

In 2004, the Arkansas Department of Health was forced to launch an investigation

of its AIDS division to determine whether some of the \$8.2 million it receives in federal funding was misspent. The division received \$4.9 million from HRSA, \$741,000 from HUD, and \$2.6 million from the U.S. Centers for Disease Control and Prevention. The Health Department terminated the contract of one organization, finding that \$53,592.85 of its program expenses could not be adequately documented. Some groups received increasing amounts of funding without documenting their work, leaving the Health Department unsure of what services were provided. Agency officials also never questioned why so many of the grants were awarded without a competitive bid process. The husband of a program administrator received more than \$8,000 from a program that did not employ him. Department spokesman Bob Alvey said most of her grants were a type of agreement that didn't require bids. But, in fact, the state's plan for HUD grants requires a bid process. One of the three HUD grants she coordinated didn't go through a bid process until the federal agency requested it.

A Washington, DC AIDS organization spent thousands of dollars of federal grant money on cigarettes, movie tickets and bingo games, according to a 2004 HUD Office of Inspector General (OIG) audit. The group, Safe Haven Outreach Ministry Inc., also could not account for how it spent more than \$1.1 million in federal grant money since 1997, according to the report. Safe Haven received more than \$1.9 million from HUD through three housing grants, including a \$1.2 million grant awarded in 2000 to provide housing for people with AIDS. Under that grant, Safe Haven officials charged more than \$3,800 for movie tickets, cigarettes, decorations and weekly bingo games, HUD investigators found. HUD also criticized the group's accounting practices, saying Safe Haven officials failed to maintain documentation supporting hundreds of thousands of dollars drawn on its three HUD grants.

Another HUD OIG audit found that the Peninsula AIDS Foundation of Newport News, Virginia may have misused some of the grant money it received. The federal funds were intended for programs that help those with HIV/AIDS and their families to pay for housing, transportation and other services. In the report given to HUD on May 17, 2004, the auditors concluded that Peninsula AIDS Foundation officials had no records to show how the organization used nearly \$340,000 -- or 96 percent -- of a \$353,562 grant. It is unclear how the money was used.

Over a period of years, HUD funneled more than \$3 million into a housing project in New Orleans through the non-profit Desire Community Housing Corp. Desire had received federal funding to rehabilitate one of the two buildings on the site to house AIDS patients. The original grant of about \$600,000 mushroomed to \$1.2 million in 2000 and to \$1.7 million in 2001, even while progress never picked up beyond a "snail's pace" according to city memo. By June 2001, Anthony Faciane, the city's construction administrator, warned his bosses in an email: "The buildings are being vandalized, water is entering the units and work that was previously paid for is being destroyed. We must move to take over this project." A July 2002 memo by affordable-housing bureau chief Lynn Ashley explains that the Desire group spent \$2.3 million in federal grant money to build 17 homes, an average cost of about \$133,000 apiece. Federal rules limit subsidies to \$96,697 per home. Nonetheless, Desire was given an additional \$500,000 in 2001 to

finish the job, in what Ashley's memo called "a puzzling finale." The new grant worsened the problem of oversubsidy that bureaucrats already had diagnosed. Available records do not provide a full accounting of where the \$1.1 million dedicated to the Bayou Apartments complex went. A 2002 memo from Desire shows that \$130,884 in expenses were incurred on the project in the previous year, less than half of it attributable to construction. Most of the money listed was earmarked for hefty salaries. In 2001, two employees were receiving six figure salaries, according to Desire's federal tax forms. A few months after the grant for AIDS patients was announced, city officials were shocked when they heard from a prospective buyer offering to pay \$275,000 for the two buildings. City officials, fearing that the nonprofit was going to sell the buildings and keep the money, sued in early 2003, asking that the civil sheriff's office seize the building for the city. The request was granted. The suit said the building that was supposed to be renovated first is worth less than \$113,000- less than Desire paid for it in 1996 and only 10 percent of the \$1.1 million that supposedly went into its rehabilitation. The housing agency "failed miserably to perform its obligations," the lawsuit says. According to the *Times-Picayune*, "Looking at the site today, it's hard to believe that such a sum was poured into the complex's two squat, beige brick buildings. The place has a ghostly feel, like an old mining camp left to decay after the ore ran out. Nearly every window is broken, leaving the units completely open to the elements. Many doors are missing, and some are lying around the site, ruined. Foot-tall weeds and grass sprout in the driveway and parking area. Graffiti mars the outside of the buildings. There's evidence that squatters have taken over some units, while weeds inhabit others. Signs of waste are everywhere. Hundreds of sheets of damp, unused drywall are stacked inside the units, and once-new insulation is being damaged by exposure."

New York City spent as much as \$329 per person per night to house AIDS patients in "glitzy" four-star hotels, according to an April 2001 *New York Post* report. The city's Division of AIDS Services and Income Support finds shelter for about 200 homeless AIDS patients each day in locales ranging from "crack-infested brothels to four-star hotels." As the agency has "failed to find permanent housing" for some of their clients and has "ruined" relationships with less expensive hotels by failing to pay them in time, DASIS is "forced" to turn to four-star luxury hotels. Jennifer Flynn, director of the New York City AIDS Housing Network, estimated that the city spends about \$180,000 per week on hotel rooms, or more than \$9 million per year. "They have the money to house these people, and they're wasting it," she said, adding, "Putting them in these hotels shows that the city has no plan to provide these people with permanent housing." Some DASIS clients report facing "scorn" when entering the "swank" hotels in which they are placed, according to the *New York Post* report.

Clearly, implementing better controls on overhead spending, establishing outcome measures, and curtailing waste, fraud and abuse in federal AIDS housing programs could ensure that as the CARE Act transitions to a primary health care program as intended by Congress, those who still may require additional housing assistance can access such services from HOPWA. HOPWA is the more appropriate source of such assistance, after all, while the CARE Act should be the appropriate source of medical care assistance.