

MORE THAN A HOME

How Affordable Housing for New Yorkers Living With HIV/AIDS Will Prevent Homelessness, Improve Health and Reduce Costs



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ABOUT THE AUTHORS



VOCAL-NY builds power among low-income people affected by HIV/AIDS, mass incarceration and the war on drugs in order to create healthy and just communities. Through base building, leadership development, participatory research, civic engagement and direct action, we ensure that those who are directly affected by these issues have a say in programs and policies that affect their lives.



Community Development Project of the Urban Justice Center (CDP) strengthens the impact of grassroots organizations in New York City's low-income and other excluded communities. CDP partners with community organizations to win legal cases, publish community-driven research reports, assist with the formation of new organizations and cooperatives, and provide technical and transactional assistance in support of their work towards social justice.

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EXECUTIVE SUMMARY

The near-universal standard for affordable housing requires that tenants pay no more than 30 percent of their income towards rent. In New York State, only one low-income housing program denies tenants this standard affordable housing protection –the HIV/AIDS rental assistance program.

Low-income people living with HIV/AIDS and their families in New York City’s “independent living” rental assistance program are forced to pay upwards of 70 percent of their disability income towards rent, well above what is considered affordable housing or a sustainable rent share burden. As a result, hundreds of low-income New Yorkers living with HIV/AIDS are homeless and thousands more are on the brink of losing their homes. In addition, chronically ill people are forced to make difficult trade-offs between medical care, food and other essential needs in order to pay their rent each month.

Many are unable to continue this difficult balancing act and become homeless, with all the risks to their health – and to HIV prevention efforts – that homelessness entails. Homelessness can be a virtual a death sentence for a person living with HIV/AIDS. It jeopardizes the success of other interventions to fight the HIV/AIDS epidemic, making it harder for people living with HIV/AIDS to adhere to medication and medical appointments, adopt proper nutrition, and practice safer sex and other forms of HIV prevention.

A simple solution – and one that has broad bi-partisan support in the state legislature – is to ensure that homeless and formerly homeless people living with HIV/AIDS pay no more than 30 percent of their income towards their rent if they already qualify for rental assistance. This report outlines why this is not only humane and just, but also a highly effective public health intervention that will produce cost-savings for taxpayers.

Research Findings

VOCAL-NY and the Community Development Project (CDP) at the Urban Justice Center conducted this study in order to examine the impact that the high rent burden has on homelessness for people living with HIV/AIDS. The research findings in this report are based on 82 surveys and 3 focus groups with homeless and unstably housed people living with HIV/AIDS receiving housing assistance through the NYC HIV/AIDS Services Administration (HASA). VOCAL-NY and CDP utilized a participatory action research approach wherein low-income people living with HIV/AIDS were involved in designing, conducting and reviewing the research.

1. The severe rent burden causes loss of housing.

Although HASA’s rental assistance program is intended to promote stable housing and better health, it often causes the opposite. This is due to an unsustainable rent burden, which often leaves tenants in arrears and leads to recurring homelessness.

- » More than half of the respondents (56%) were behind on their rent when they lost their apartment. A majority (60%) of the respondents had fallen into arrears by more than \$1,000.
- » Overall, two-thirds of all respondents (63%) were in arrears for rent, utilities or both before losing their apartment.

2. Lack of affordable housing means sacrificing other basic needs.

Permanently disabled people living with HIV/AIDS (PLWHA) enrolled in HASA’s independent living rental assistance program are budgeted to live on a little more than \$12 per day for all other expenses after rent. This leads to nearly impossible trade-offs among clients in order to pay their rent each month.

Of the homeless PLWHA surveyed in emergency housing, in the six months before losing their apartment:

- » About two-thirds (65%) of respondents reported having to choose between paying rent and other basic necessities.
- » About half of respondents were not able to afford food (46%) or transportation (48%) (e.g. subway fare).
- » One in three (34%) respondents said they had trouble paying for healthcare expenses such as co-pays for medical appointments or prescription drugs that were not covered by their health insurance.

3. Homelessness and unstable housing adversely impact health.

The severe rent share burden in the rental assistance program forces many HASA clients into homelessness (including moving into HASA's often unsafe and substandard emergency shelters) or sacrificing basic needs to retain their housing. In both of these situations, the severe rent burden compromises the physical and mental health of those who are already permanently disabled.

- » Over two-thirds of survey respondents (67%) said that it has been harder to take care of their health since losing their apartment and entering the emergency housing system, with six in ten reporting that their health has deteriorated during that time.
- » More than half of respondents (54%) said it has been harder to keep medical appointments since becoming homeless, and slightly less than half (47%) said it had become harder to take their medication.
- » More than half (52%) had visited the emergency room and 38% had actually been admitted to hospitals since becoming homeless and entering the emergency housing system.

4. The Rent Burden Is A Barrier To Independent Living.

Due to the severe rent burden, many people living with HIV/AIDS who could otherwise live independently are instead forced to stay in substandard emergency housing or opt for costly supportive housing.

- » Nearly seven in ten homeless HASA clients surveyed in emergency housing said they worried they wouldn't be able to afford rent if they moved back into the independent living rental assistance program.
- » Four out of five respondents (78%) said they would be able to move into permanent housing sooner if they could rely on an affordable housing protection that limited their rent burden to 30 percent of income.

Policy Recommendations

As the research in this report indicates, the flawed policy in the HIV/AIDS rental assistance program that forces PLWHA to pay upwards of 70 percent of their income towards rent undermines health outcomes, increases avoidable healthcare expenses and is detrimental to overall wellbeing for PLWHA. A simple solution exists, however: in order to prevent homelessness and increase housing stability for over 10,000 PLWHA and their families, Governor Cuomo and state legislators can establish the same affordable housing protection in the HIV/AIDS rental assistance program that already exists in every other low-income housing program in New York, by capping rents at 30 percent of income.

An affordable housing protection that limits clients' share of rent to 30 percent of income will save the state a significant amount of money. It would more than pay for itself by reducing unnecessary shelter expenses, with additional indirect savings through reduced emergency and inpatient healthcare costs and minimizing new HIV infections by reducing risk behaviors. Most importantly, it would better enable low-income New Yorkers living with HIV/AIDS to attain a basic level of dignity.

This report recommends that elected officials in New York adopt the following steps to resolve the affordable housing crisis among homeless and low-income people living with HIV/AIDS who are permanently disabled and who qualify for rental assistance.

- Both the New York Senate and Assembly should swiftly pass the 30 percent rent cap affordable housing legislation that has already passed both houses by wide margins in the past.
- If the policy change is not passed as a stand-alone bill, Governor Cuomo should work with the Senate and Assembly to include the legislation in the budget in order to reflect the direct savings from the bill that would be achieved through: (1) reductions in emergency housing occupancy and rental arrears, which would fully offset the cost of implementing the new policy, and (2) indirect savings from improved health associated with increased housing stability.
- The Medicaid Redesign Team (MRT) should establish a “Moving On” initiative and advocate for passage of the legislation and/or inclusion of the policy change in the state budget. In their official MRT report, the Affordable Housing Work Group recognized that a 30 percent rent cap for the HIV/AIDS rental assistance program would improve health outcomes and reduce unnecessary expenses, both goals for Governor Cuomo’s Medicaid reform efforts. The Affordable Housing work group also concluded that the proposed policy would remove a barrier to greater independence for PLWHA currently residing in more costly settings and increase the availability of supportive housing, which is why it was framed as a “Moving On” initiative.
- Candidates for Mayor, Comptroller, Public Advocate and City Council in 2013 should endorse the state legislation and pledge to work towards its passage if elected.

This report also recommends that the NYC HIV/AIDS Services Administration (HASA) adopt the following steps to save money, improve the quality of emergency housing and address barriers to earned income.

- HASA should eliminate the use of commercial single room occupancies (SROs) for emergency shelter for homeless PLWHA based on the reduced occupancy that will occur after the affordable housing protection is enacted. Moreover, the remaining emergency shelter units that are needed for homeless PLWHA should be provided through contract-based non-profit transitional housing providers with onsite staff who can help clients obtain permanent housing.
- HASA should promote voluntary job training programs once the affordable housing protection is enacted, which will create a bridge-to-work for PLWHA in the rental assistance program by enabling them to keep a portion of any earned income while also contributing more towards their rent.



GLOSSARY OF TERMS

Emergency housing: According to HASA's Policies and Procedures manual, "Emergency housing is available to homeless single adult HASA clients in transitional supported housing and in commercial single room occupancy (SRO) hotels." The agency defines homeless clients as: "Newly accepted clients at ServiceLine (often discharged from correctional facilities) without a residence" and "active clients at service centers who have lost, left, been dispossessed, evicted or are in immediate danger of losing their housing."¹

HASA: HIV/AIDS Services Administration (HASA) is a specialized division within the New York City Human Resources Administration (HRA) established by Local Law 49 of 1997. HASA provides assistance to low-income people living with AIDS or symptomatic HIV (as defined by the New York State Department of Health). HASA works to ensure that "clients have adequate housing, financial security, medical care and other services necessary to allow them to manage their illness and to live their lives with the highest level of self-reliance and dignity."²

Homeless: This report uses the US Department of Housing & Urban Development's (HUD) definition of "literal homelessness," meaning a person who "has a primary nighttime residence that is a public or private place not meant for human habitation" or "is living in a publicly or privately operated shelter designated to provide temporary living arrangements (including congregate shelters, transitional housing, and hotels and motels paid for by charitable organizations or by federal, state and local government programs)."³ This does not include doubled-up or overcrowding situations.

Housing loss: The term "housing loss" in this report refers to the loss of housing by HASA clients as a result of not being able to afford their rent. HASA clients may lose their apartments due to rent arrears because they cannot afford to pay back a "one-shot" grant or no longer qualify after receiving previous assistance, or they may lose their housing after receiving an eviction notice from their landlord for non-payment of rent. In rare cases, a marshal may forcibly evict a tenant, although the vast majority of HASA clients in this situation vacate their apartments before that occurs. For most HASA clients who lose their apartments, the only viable option is to return to emergency housing.

One-shot deal: HASA clients may qualify for financial assistance to pay for rent or utility arrears through HRA's emergency grants program, colloquially called "one-shot deals," which are typically not approved more than once in a twelve-month period.⁴ One-shot payments are recouped from the client on an aggressive schedule so that this assistance often results in the client falling back into arrears again. Or, in other cases, clients realize the difficulty they would have in paying a one-shot grant back, so they decline to apply for it in the first place.

Permanently disabled: People living with HIV/AIDS who are unable to work may qualify for disability benefits under the Social Security Administration (SSA). According to the SSA, "The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."⁵

Rental assistance: HASA provides permanent housing assistance to most of their clients through rental subsidies that enable them to rent privately owned market-rate apartments. While the program is similar to Section 8 and other rental subsidy programs for low-income families, there is no cap on the portion of their income that HASA clients are required to pay towards rent.

Severe rent burden: According to HUD, tenants who pay more than 50 percent of their household income towards housing costs are considered to have a severe rent burden.⁶

Social security: HASA clients who are determined to be permanently disabled by the SSA may qualify for one of two forms of financial assistance. Social Security Disability Insurance (SSDI) is intended for people who worked for a requisite number of years and paid Social Security taxes before becoming disabled.⁷ Supplemental Security Income (SSI) pays benefits based on financial need to people with disabilities "who have little to no income...to meet basic needs for clothing, food and shelter."⁸

Unstably housed: For the purpose of this report, unstably housed individuals includes homeless individuals along with those who experience frequent moves, are doubled up, or are at risk of housing loss.

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I. INTRODUCTION

“A home is, you know, sort of like air and water; I think it’s just one of those things that you need to survive as a human being...the four walls that you can call your own that no one can take away from you...” – Independent Living Focus Group, Participant #1

Hundreds of low-income New Yorkers living with HIV/AIDS are homeless and thousands more are on the brink of losing their homes due to a loophole in state law that denies them affordable housing. New York’s tenant-based rental assistance program for homeless people living with HIV/AIDS, conceived as a medically appropriate alternative to the deadly options of the city’s shelter system or living on the streets, was created without factoring in rising housing costs or the overall increase in cost of living over time.

As a result of this increasingly ineffective program, low-income people living with HIV/AIDS, along with their families, who participate in New York City’s “independent living” rental assistance program are now forced to pay 70 percent or more of their disability income towards rent, well above what is considered to be the standard for affordable housing or a sustainable rent share burden. In short, state law allows New York City, by far the largest locality participating in the program and the focus of this report, to require that clients in the program spend down all of their disability income for rent so they are left with \$376 or less per month for all other expenses, including utilities, transportation, clothing, phone and unreimbursed medical expenses.

The near-universal standard for affordable housing, a standard that Governor Andrew Cuomo vigorously enforced as Secretary of the Department of Housing and Urban Development (HUD) in federally funded programs, requires tenants to pay no more than 30 percent of their income towards rent. In New York State, the HIV/AIDS rental assistance program is the only low-income housing program that fails to meet this standard for affordable housing.

As a consequence, New York City’s rental assistance program for people living with HIV/AIDS too often fails to achieve its ostensible goal of promoting stable housing and improving health outcomes. Instead, extremely low-income and chronically ill participants are forced into difficult trade-offs between medical care, food and other essential needs in order to pay their rent each month. Many are unable to continue this difficult balancing act and consequently become homeless again, with all the risks to their health – and to HIV prevention efforts – that homelessness entails.

Homelessness can be a virtual death sentence for persons living with HIV/AIDS. It jeopardizes the success of other interventions that are available to fight the HIV/AIDS epidemic, making it harder for people living with HIV/AIDS to adhere to medication and medical appointments, obtain proper nutrition, practice safer sex, and adopt other forms of HIV prevention.

A simple solution – one that has broad bi-partisan support in the state legislature – is to ensure that homeless and formerly homeless people living with HIV/AIDS pay no more than 30 percent of their income towards their rent if they already qualify for rental assistance. This report outlines why this is not only humane and fair, but also a highly effective public health intervention that will produce sizeable cost-savings for taxpayer.



Photo: David Y. Lee for Public Welfare Foundation

II. BACKGROUND

“Without stable housing, there are probably a lot of stupid things I would do and not just to myself but to other people. I would put myself at risk, I would put them at risk and, because why would I care? I would have no dignity left, I would be full of shame, I would be totally humiliated, and I would just probably do anything to get whatever I could get by doing whatever risky behavior.” – Independent Living Focus Group, Participant #1

In New York City, approximately 10,000 extremely poor and permanently disabled people living with HIV/AIDS (PLWHA) are at risk of becoming homeless because they pay half or more of fixed disability income toward their rent, even though they are enrolled in a rental assistance program through the HIV/AIDS Services Administration (HASA). Hundreds more homeless PLWHA languish in HASA’s shelter system because they have already lost their apartment or cannot afford to move out.

All disability-housing programs in New York, as well as all federally funded housing assistance programs, cap tenants’ rent contribution at 30 percent of income – with the exception of HASA’s rental assistance program. Those HASA clients who do maintain their housing face difficult trade-offs between paying rent and other essential needs like traveling to doctors, co-pays for medication, and groceries.

This report is concerned with the rent burden, or the rent-to-income ratio, of permanently disabled HASA clients and its impact on their housing stability, health, independence, and wellbeing. This report also addresses the persistently high rates of homelessness among PLWHA in New York City and the conditions they endure in HASA-funded emergency shelters.

Housing Is A Foundation For Healthcare & HIV Prevention

Stable housing produces dramatic and concrete benefits for the health of PLWHA. That is not surprising, given that housing is the necessary foundation, indeed a prerequisite, for effective treatment and care.

In fact, the housing status of a person living with HIV/AIDS is a stronger predictor of their health and adherence to medical care than are other factors such as demographic characteristics, drug and alcohol use, and use of social services.⁹ Compared to stably housed PLWHA, those who are homeless experience worse overall physical and mental health, including higher rates of hospitalization and emergency room use, lower CD4 counts (signaling a weaker immune system), higher viral loads, and poorer adherence to antiretroviral therapy.^{10,11}



According to a landmark randomized control trial known as the Housing & Health (H&H) Study, sponsored by the federal Centers for Disease Control & Prevention (CDC) and Department of Housing & Urban Development (HUD), stable housing among people living with HIV/AIDS reduced emergency room use by 35% and hospitalizations by 57% compared with those who remained homeless. The H&H Study also found that, in contrast, those who remained homeless were two and a half times more likely to use an emergency room and nearly three times as likely to have a detectable HIV viral load, which increases the risk of premature

death and HIV transmission. Those who were homeless were also much more likely to report perceived stress compared with those who received housing through the study.¹²

Analysis of the H&H Study indicates that provision of stable housing is a cost-effective healthcare intervention on par with HIV/AIDS medication or other widely accepted health care interventions like renal dialysis for people with kidney disease.¹³ In general, housing assistance for PLWHA generates savings in avoidable crisis

health services that more than offset the cost of housing interventions.¹⁴

Stable housing helps prevent new HIV infections as well. People living with HIV/AIDS who are homeless or unstably housed are “two to six times more likely [than those who have stable housing] to have recently used hard drugs, shared needles or engaged in high-risk sex,” according to NAHC.¹⁵ The emergence of treatment as prevention, a public health strategy that aims to increase the percentage of PLWHA with an undetectable viral load in order to reduce the risk of transmission, further underscores the importance of stable housing, which is strongly associated with low viral loads.

Affordable Housing For People With HIV/AIDS Saves Money

Studies have shown that helping low-income PLWHA maintain stable housing reduces spending on emergency shelter, healthcare and other PLWHA-related public expenses in multiple ways. First, cost analyses have shown that the amount the state spends on emergency shelter far surpasses the cost of increasing the monthly rental assistance contribution for non-emergency housing.¹⁶ Second, housing status is one of the strongest predictors of entry into HIV care, frequency of primary care visits, and remaining connected to care over time.¹⁷ In this way, PLWHA with stable housing incur lower medical costs as a result of significant reductions in emergency room visits, hospitalizations and opportunistic infections compared with those who are homeless.¹⁸

Early Beginnings of HIV/AIDS Housing Assistance in New York

Homelessness is deadly for people living with HIV/AIDS. The public health crisis created by homelessness and HIV/AIDS after the epidemic emerged combined with aggressive activism, forced government action to provide housing assistance for homeless PLWHA beginning in the mid-1980s.

New York City and State government responded by implementing policies that barred hospitals from placing homeless PLWHA into the general shelter system, where the risk for tuberculosis and other opportunistic infections was extremely high, or discharging them back into the street.¹⁹ As noted in the previous section, homelessness not only worsens health outcomes amongst PLWHA, it also increases the risk of HIV transmission.

Housing assistance for PLWHA who were homeless, or at risk of becoming homeless, was made available in the mid-1980s. New York City adopted a policy to “provide persons with AIDS and HIV-related illness access to enhanced rental assistance to maintain or secure housing,” while New York State established enhanced rental assistance for extremely low-income PLWHA, also limited to those with an AIDS diagnosis or HIV-related illness as defined by the New York State Department of Health.^{20, 21} The HIV/AIDS rental assistance program is now the most widely used form of housing assistance for PLWHA.

The success of providing housing assistance for PLWHA was dramatic in terms of reducing overall homelessness in NYC and improving health outcomes for PLWHA, especially after the introduction of better treatment opportunities for opportunistic infections and new drug combinations in the mid-1990s.

During the early 1980s and early 1990s, HIV prevalence in New York City was conservatively estimated at between 15 to 30 percent of the homeless shelter population. That high rate of PLWHA among the homeless population in New York City was reversed as housing assistance for homeless PLWHA was expanded.²² Similarly, the steep decline in tuberculosis cases in New York City, especially in the shelter system, from the early 1990s through today can also be attributed in part to expanding housing opportunities for homeless people living with HIV/AIDS.²³ HIV/AIDS-related mortality has also declined sharply over time, as stable housing has enabled PLWHA greater access to medical advances.²⁴

HIV/AIDS Housing Assistance in New York City Today

The early efforts to provide housing assistance to PLWHA led to the creation of the New York City HIV/AIDS Services Administration (HASA). NYC HASA, formerly known as the Division of AIDS Services and codified in local law in 1997, is a division within New York City's Human Resources Administration (HRA). HASA restricts eligibility for services to homeless and low-income people who have either "clinical/symptomatic HIV illness, as determined by the New York state department of health AIDS institute," or "AIDS, as defined by the federal centers for disease control and prevention."²⁵

HASA provides access to "medically appropriate transitional and permanent housing," such as "housing subsidies, including, but not limited to, enhanced rental assistance," along with other public benefits and services.²⁶

The agency now provides some form of housing assistance to more than 32,000 extremely low-income people living with HIV/AIDS, plus nearly 13,000 children whose parents qualify. Practically none of these individuals would be able to obtain private market housing if they relied solely on Social Security or public assistance income, given prevailing market rate rents in New York City and the extremely low rate of housing vacancies, which means that if not for the rental subsidy, a significant population within New York City would be homeless.

HASA offers clients three basic types of housing options: (1) emergency housing, in the form of either nonprofit transitional housing or commercial SRO hotels, (2) permanent supportive housing, either congregate or Scatter Site, where the client is placed in a private market apartment, and (3) tenant-based rental assistance, which the vast majority of the clients and their families rely on. More than 80% of HASA clients rely on rental assistance for housing, according to the agency's monthly fact sheets, while approximately 13% rely on supportive housing, 2% on NYCHA and 5% are homeless in the emergency housing system.

Emergency housing in commercial SRO hotels is the most costly option for taxpayers and the least healthy alternative for homeless people living with HIV/AIDS; elected officials, researchers and advocates have long called for the Bloomberg administration to reallocate HASA resources away from SRO housing towards permanent housing and more humane emergency housing options. The cost for most forms of housing is generally shared equally by the New York City and State governments. Many supportive housing units also receive federal funding through the Housing Opportunities for Persons With AIDS (HOPWA) and McKinney-Vento programs.

Legal mandates for Housing for People with HIV/AIDS in NYC

A New York City law passed in 1997, and sponsored by Thomas K. Duane, at the time a member of the City Council, requires that homeless people living with HIV/AIDS be transitioned into “medically appropriate” permanent housing on a timely basis. Nevertheless, HASA records indicate that the average length of stay in emergency housing is often unacceptably long. Our report data and other analyses suggest that this is related to the severe rent burden that clients in the rental assistance program face. During the 2011 fiscal year, the average length of stay in HASA emergency housing programs was over four months (123 days).²⁷

The laws of New York City include the following regulations regarding housing for homeless and low-income people living with HIV/AIDS.

“Benefits and services to be provided to persons with clinical/symptomatic HIV illness or with AIDS.”²⁸

Processing of applications for medically appropriate non-emergency housing.

(a) Unless the client shall decline, the division shall provide the following to every homeless client of the division on the day the client is determined to be eligible for services as a client of the division:

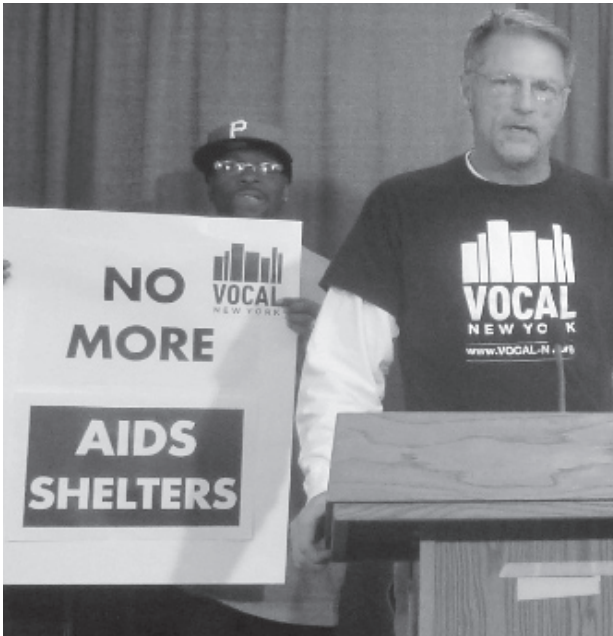
(i) an application for medically appropriate non-emergency housing; and (ii) information regarding financial assistance available to assist eligible clients in obtaining housing and regarding available housing options.

(b) The division shall ensure that every client receives any assistance needed to complete the application for medically appropriate non-emergency housing within 10 business days of the day on which the client is determined to be eligible for services as a client of the division.

(c) Within 90 days of initial placement in emergency housing or of completion of the physical documentation required from the client for the application for non-emergency housing, whichever is sooner, the division must provide every client who is eligible for non-emergency housing a referral to an available medically appropriate non-emergency housing option, which takes into consideration the medical, educational and familial needs and social circumstances of the client, to the extent such option is available.

(d) For any client who remains homeless or in emergency housing for over 45 days after the requirements of subparagraph (c) of this paragraph or the requirements of this subparagraph have been met, the division shall provide a referral to another medically appropriate non-emergency housing option, to the extent such option is available.”

Persistent Homelessness Among New Yorkers Living With HIV/AIDS



People living with HIV/AIDS are at greater risk of homelessness for a variety of reasons, including inability to work, loss of income, social discrimination, abandonment by family, and depletion of financial resources due to healthcare costs. Furthermore, the National AIDS Housing Coalition (NAHC) explains that “for many people with HIV, problems finding and keeping stable housing are exacerbated by discrimination related to HIV, sexual orientation, race, culture, mental health issues, substance use and/or involvement with the criminal justice system.”²⁹

People who are homeless are also at greater risk of contracting HIV, which further contributes to the disproportionate rate of homelessness among PLWHA. Again, NAHC explains: “People who are homeless or unstably housed have HIV infection rates as much as 16 times higher than people who have a stable place to live. The pressure of daily survival needs, exposure to violence,

substance use as a way to cope with stress or mental health issues, and other conditions of homelessness make homeless and unstably housed persons extremely vulnerable to HIV infection.”³⁰

Homelessness and unstable housing remain widespread among low-income New Yorkers living with HIV/AIDS, despite the promise of obtaining medically appropriate emergency and non-emergency housing assistance through HASA. In addition to a shortage of available supportive housing units, there are several policy and administrative barriers to promoting stable housing through the tenant-based rental assistance program: inadequate rental payment guidelines (more than 25% below the rental subsidy amounts defined by HUD’s Fair Market Rents for NYC), reduced broker’s fee payments, discrimination based on source of income, bureaucratic inefficiencies and a recently adopted policy of screening for substance use.

The foremost barrier to stable housing within HASA, and the focus of this report, is the severe rent share burden experienced by HASA clients in the tenant-based rental assistance program, upon which the vast majority of clients rely. The program has the distinction of being the only low-income housing program of its kind in New York that does not include an affordable housing protection.

New York’s HIV/AIDS Housing Assistance Denies Affordable Housing

As with other housing programs for low-income people, HASA clients receiving rental assistance are expected to contribute a portion of their income towards their rent. The problem is that there is no cap on what HASA clients are required to contribute. Instead, the agency relies on an outdated formula that denies affordable housing to clients.

HASA clients who are permanently disabled and qualify for SSDI, SSI and/or Veteran’s benefits end up paying upwards of 70 percent of their federal disability income towards their rent, with military veterans having the highest average rent contribution. HUD defines a “severe rent burden” as payment of more than half of one’s income towards rent. There are at least 10,000 clients in HASA’s rental assistance program who experience severe rent share burden as thus defined, according to a 2009 report from the agency.³¹

In fact, HASA’s rental assistance program is the only disability or low-income housing program in New York State, including supportive housing, public housing and the Section 8 program, that does not

cap tenants' rent contribution at 30 percent of income. HIV-positive Senator Tom Duane and others have characterized this inconsistency in policies as discriminatory.

The formula for calculating the rent contribution for HASA clients, which now requires clients to spend down all of their income for rent so that they are left with less than \$376 per month for all other expenses, regardless of how much disability income they receive, has been largely unchanged since the mid-1980s.³²

Given the rising cost of living and increased federal disability payments, which rises with inflation even as the spend-down level for HASA remains largely the same, this policy grows more problematic over time.

This rent budgeting policy forces tenants to literally choose between paying their rent and other essential needs like travel for medical appointments, co-payments and other unreimbursed medical care, utilities, phone service, toiletries, clothing and so on. These are difficult choices for any New Yorker to make, but can be a matter of life and death for PLWHA who are managing a complex and expensive chronic illness.

Unable to afford rent, utilities and other basic necessities, many HASA clients in the rental assistance program eventually lose their housing and end up in one of the costly emergency shelters funded by the agency, which can lead to major disruptions in medical care.

Not surprisingly, at least one in four rent-burdened HASA clients falls into arrears every year and one in nine becomes homeless.³³ Once a HASA client becomes homeless, she or he is placed into an expensive commercial SRO hotel or a non-profit transitional housing program; local law prohibits placement into the separate DHS shelter system due to the health risks posed for PLWHA by the system's housing conditions.

On average, over 1,700 HASA clients are homeless in these emergency shelters on any given day.³⁴ Many



of these clients are in HASA's shelter system because they were severely rent-burdened, fell into rent arrears and lost their apartments; others simply cannot afford to move out. According to an analysis by Shubert Botein Policy Associates, an estimated 36% of clients in HASA-funded emergency shelters, or nearly 2,500 clients annually, were previously in the rental assistance program but could not afford the rent share burden.

Not only do HASA's emergency shelters cost HASA two to three times as much as the rental assistance program, the rooms in these shelters generally provide barely enough space for a bed and do not provide cooking facilities, adequate storage or phones. Homeless clients in emergency shelters also have poorer linkage to healthcare and high rates of drug and alcohol misuse.

The severe rent burden in HASA's rental assistance program also acts as a powerful disincentive to independence in clients, as more stable residents opt to enter or remain in supportive housing in order to reduce their rent burden, or stay longer in emergency housing. As a result, there is very little turnover in the permanent supportive housing system, creating a shortage for people living with HIV/AIDS who have more complex health needs.

As this report and other research show, the lack of affordable housing and the severe rent burden in HASA's rental assistance program appear to be significant contributors to the high rates of homelessness among PLWHA in New York City.

Affordable Housing – A National Definition

The Department of Housing & Urban Development (HUD) defines a “severe rent burden” as payment of more than half of a household's income towards rent. Severe rent burdens can be especially difficult on households that rely on fixed disability income. Indeed, President Obama's *Opening Doors: The Federal Strategic Plan to Prevent and End Homelessness*, released in 2010, specifically calls for a 30% rent cap for all federal, state and local rental assistance programs for homeless persons or those at risk of homelessness.³⁵ Significantly, *Opening Doors* also notes the cost effectiveness of stable housing for people living with HIV/AIDS as an HIV prevention intervention and as a key component of HIV health care.³⁶

The concept of measuring rent burden by the percentage of a household's income spent on housing costs goes back to the 1930s.³⁷ After the National Housing Act of 1937 created the first public housing program for low-income Americans, a maximum rent standard was developed under which rent could not exceed 20 percent of income.³⁸ The 1968 Housing and Urban Development Act raised the rent threshold to 25 percent of one's household income. In 1981, this threshold was raised to 30 percent, which remains the rent standard for all federal and most local rental assistance programs today.³⁹ In New York, all low-income housing programs, with the notable exception of the HIV/AIDS rental assistance program, use the 30 percent standard to establish maximum rental payments for all types of supportive housing, public housing, Section 8, and other low-income housing programs.⁴⁰

New York's Medicaid Reform & Affordable Housing For People Living With HIV/AIDS

Governor Cuomo established a Medicaid Redesign Team (MRT) shortly after taking office. The goal of MRT was to find ways to improve health outcomes and reduce unnecessary healthcare expenses driven by uncoordinated care and broader social determinants of health, such as housing status and income level.⁴¹ Unstable housing and homelessness were identified early on as significant drivers of avoidable healthcare costs and poor health outcomes, and were prioritized as an essential cost containment strategy. According to the final MRT final report,

*There is strong and growing evidence in New York and around the country that a lack of stable housing results in unnecessary Medicaid spending – on individuals in nursing homes and hospitals who cannot be discharged only because they lack a place to live, and on repeated emergency department visits and inpatient admissions for individuals whose chronic conditions cannot be adequately managed on the streets or in shelters. The lack of appropriate affordable housing, especially in New York’s urban areas, may be a major driver of unnecessary Medicaid spending.*⁴²

The MRT process involved the creation of several work groups, including an Affordable Housing Work Group, which considered “the appropriateness of inclusion of specific proposals relative to special populations such as people living with HIV/AIDS and those at high risk of HIV infection.”⁴³



The Affordable Housing Work Group specifically addressed the need for a 30% cap in recommendations for a November 2011 report: “Supportive housing has been and must continue to be a successful intervention...there are certain groups who are not currently high-cost users of Medicaid, such as persons with HIV and persons at highest risk of HIV, who will become high-cost users in future years without appropriate interventions, which may include affordable or supportive housing.”⁴⁴

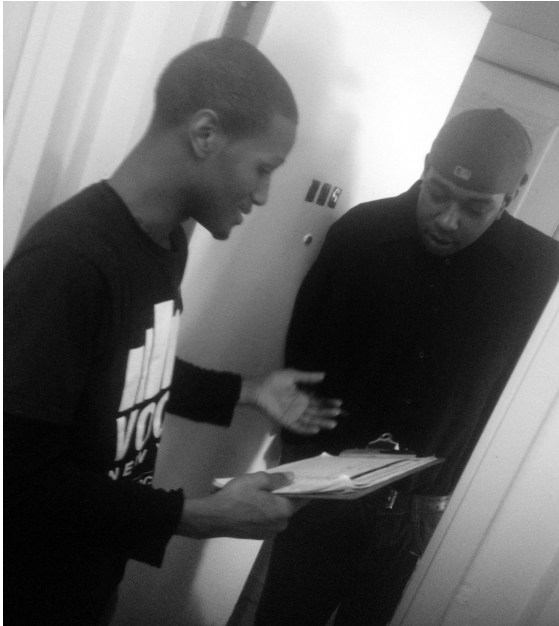
Furthermore, the final MRT Affordable Housing Work report concluded:

*This work group should also design a “Moving On” Initiative to incentivize and support tenants who are ready to or already live in independent housing. This group will identify resources as well as incentives and supports needed to support this effort including...evaluating mechanisms for supporting tenants whose chief barrier to independent living is a lack of a cap on the tenant contribution in subsidized rental programs such as the enhanced rental assistance program for people with HIV disease/AIDS.*⁴⁵

Notably, the rent cap was discussed not only as an intervention to improve health outcomes and reduce unnecessary healthcare costs, but also as a way to help PLWHA transition into more independent living settings and free up more intensive supportive housing for those most in need. That conclusion that the proposed rent cap would remove a barrier to independent living is based on the recognition that many low-income PLWHA are unable, or unwilling, to move out of supportive housing or emergency housing because they cannot afford the severe rent burden in the rental assistance program.

The final overall MRT report issued in December 2011 reiterated this goal in discussing the *Moving On* initiative: “The [Affordable Housing] workgroup made numerous other recommendations about how to improve access to housing and healthcare. Examples include but are not limited to...design[ing] a Moving On initiative to help move individuals to more independent settings thereby freeing up needed resources for those most in need.”⁴⁶

III. METHODOLOGY



The research findings in this report are based on surveys and focus groups with homeless and unstably housed people living with HIV/AIDS receiving housing assistance through the NYC HIV/AIDS Services Administration (HASA). The data collected is also supplemented with secondary research from public health journals. VOCAL-NY and CDP utilized a participatory action research approach wherein low-income people living with HIV/AIDS were involved in designing, conducting and reviewing the research. Surveys were administered by trained VOCAL staff and members to 82 residents of HASA-funded emergency housing programs, all of who were permanently disabled and formerly enrolled in HASA's rental assistance program. In addition, we conducted three focus groups with HASA clients residing in both emergency housing and tenant-based rental assistance programs to collect qualitative data about how they are impacted by high rent burdens.

Overall, the research found that HASA clients face tremendous challenges in their daily lives brought on by the severe rent share burden in the independent living program. The rent burden causes housing loss, leads clients into emergency housing where they endure poor conditions, forces trade-offs between essential needs for those who remain in independent living, and represents a major barrier for those stuck in emergency housing who would prefer to move into independent living but cannot afford to do so. All of these negatively impact the health of HASA clients. The following sections describe the research findings and provide a sensible, cost-effective solution.

IV. RESEARCH FINDINGS

1. Lack of Affordable Housing Causes Loss of Housing

Although HASA's rental assistance program is intended to promote stable housing and better health, it often causes the opposite. This is because of an unsustainable rent burden, which often leaves tenants in arrears and leads to recurring homelessness. Permanently disabled people living with HIV/AIDS in HASA's rental assistance program typically pay at least half or more of their disability income towards their rent, with many paying upwards of even 70 percent. HUD defines this as a severe rent share burden. This severe rent burden causes housing loss because many clients cannot afford to sacrifice basic needs in order to keep up with their rent or utilities payments.

For this report, we surveyed permanently disabled HASA clients who are homeless and living in the emergency housing system but who had been previously lived in independent housing through the agency's rental assistance program. Many survey respondents reported that a major factor leading to homelessness was their inability to afford their rent or utilities while in independent living.

- » **More than half of the respondents (56%) were behind on their rent when they lost their apartment. A majority (60%) fell into arrears by more than \$1,000.**
- » **About one-third fell behind on utilities, most of who reported having rent arrears as well.**
- » **Overall, two-thirds of all respondents (63%) were in arrears for rent, utilities or both before losing their apartment.**

Although HASA clients who fall behind on rent or utility payments can apply for a "one-shot deal," i.e. a one-time grant towards payment of rental or utility arrears that a client owes, this mechanism often does not prevent housing loss. In fact, one-shot deals, while temporarily solving the problem of rent arrears, ultimately fail to resolve the underlying problem of an unsustainable rent burden.

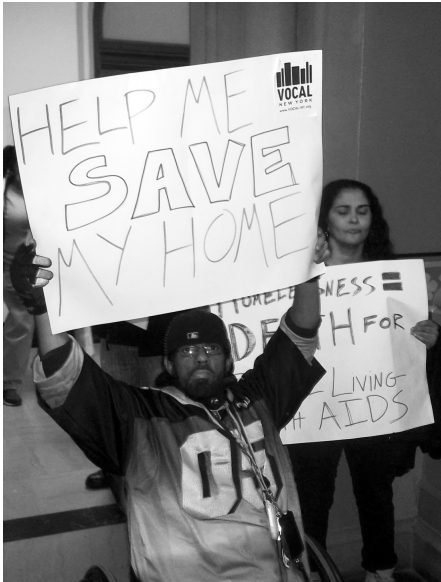
If a one-shot deal is approved, HASA recoups the grant on an aggressive schedule, leaving clients who already had difficulty paying their rent and utilities on time with even less income. Moreover, HASA often denies applications for one-shot deals, sometimes because the client has already received one. As a result, many HASA clients do not even bother to apply for one-shot deals, while those that do remain at high risk for homelessness.

- » **Nearly half of the HASA clients we surveyed in emergency housing, all of whom were previously in the HASA rental assistance program, had applied for a one-shot deal before losing their apartment and entering the shelter system.**
- » **43% of respondents had applied for a one-shot deal in the six months prior to losing their apartment. Of those who applied, 16% did not receive the one shot deal. Regardless of whether they received the one-shot deal, all of those we surveyed in emergency housing programs had become homeless after being unable to afford the independent living rental assistance program.**

Despite its cost and the harmful effects of the rental assistance program on the health of PLWHA, HASA refuses to release accurate and comprehensive data on housing loss among clients in the program, including the number of clients who lose their apartments each year and information about the causes of housing loss. Instead, HASA has released unsubstantiated figures that grossly underestimate the rate of housing loss through two invalid arguments.

First, HASA uses a narrow definition of what constitutes an eviction in order to minimize the scale of housing loss, defining an eviction as a forcible removal by a City Marshal or Sheriff, whereas most tenants

voluntarily leave before then. The data indicates that most people who fall into arrears leave their apartment before a physical eviction is carried out. Second, HASA argues that clients who receive a one-shot deal will not become homeless. Our data reveals that many clients who receive one-shot deals still lose their apartments, in part because the recoupment process leaves them in even deeper poverty than when they fell into arrears.



Many said they left after receiving an initial eviction notice, when they realized that they could not pay down the arrears or could not afford to pay back a one-shot deal.

“They gave me an eviction notice to get out so I got out before the time because somebody say once you get out before the time [of an eviction]... you ain’t gotta pay that money so, you ain’t gotta go to court or nothing, so I got out before.” – Emergency Housing Focus Group #2, Participant #2

“Yeah I just fell so behind and I did get an eviction notice, where they wanted me to go down and file a [order to] show cause... And I did that and it just gave me a court date to come back and tell them why I’m behind. I got so disturbed with the whole thing... I had to start with SROs all over again.” – Emergency Housing Focus Group #2, Participant #3

Another reason why HASA clients decide to vacate their apartments before they are forced out is that they are often denied one-shot deals. Focus group participants who received an eviction notice explained,

“I just got discouraged and I just walked away because I didn’t see no way out. I had already had a one shot deal and they made it clear I wasn’t getting another one. Why wait for somebody to knock on your door and say, ‘get out’... So I went.” Emergency Housing Focus Group #2, Participant #3

The same participant also talked about his frustration with being forced to quickly pay a one-shot deal for arrears after the one time he was approved,

“They did make me pay [the one-shot deal] back and that was the difference. You’re [HASA] gonna put it [one-shot deal] out for me so I can stay here but then you gonna take it back on the other end where I don’t have food for two weeks out of the month.” – Emergency Housing Focus Group #2, Participant #3

Summary

As already noted in the background section, at least one in four rent-burdened HASA clients falls into arrears every year, which suggests that a large percentage of clients are at immediate risk of homelessness.⁴⁷

Clients who fall into arrears can apply for “one-shot deals”; however, they are not always approved and the program is not structured to prevent housing loss. Moreover, many clients fall into arrears but do not apply for assistance because they no longer qualify for these grants or they cannot afford for the grant to be recouped in the future (which can leave them living on even less than \$12 per day).

Data from the “CHAIN” study, conducted by Columbia University and funded by the NYC Department of Health & Mental Hygiene (DOHMH), indicates an even bleaker picture for people who were recently homeless: according to the study, one in four formerly homeless New Yorkers living with HIV/AIDS who receive housing assistance lost their housing within 6-12 months.⁴⁸

Many HASA clients are in the emergency shelter system because they were severely burdened by rent,

fell into rent and/or utilities arrears and lost their apartments. The homelessness rate also remains high among HASA clients because many cannot afford to move out of the shelter system and cope with the severe rent burden again. On average, on any given day, 1,700 H H HASA clients are homeless and living in costly and unhealthy homeless shelters, including for-profit SROs.⁴⁹

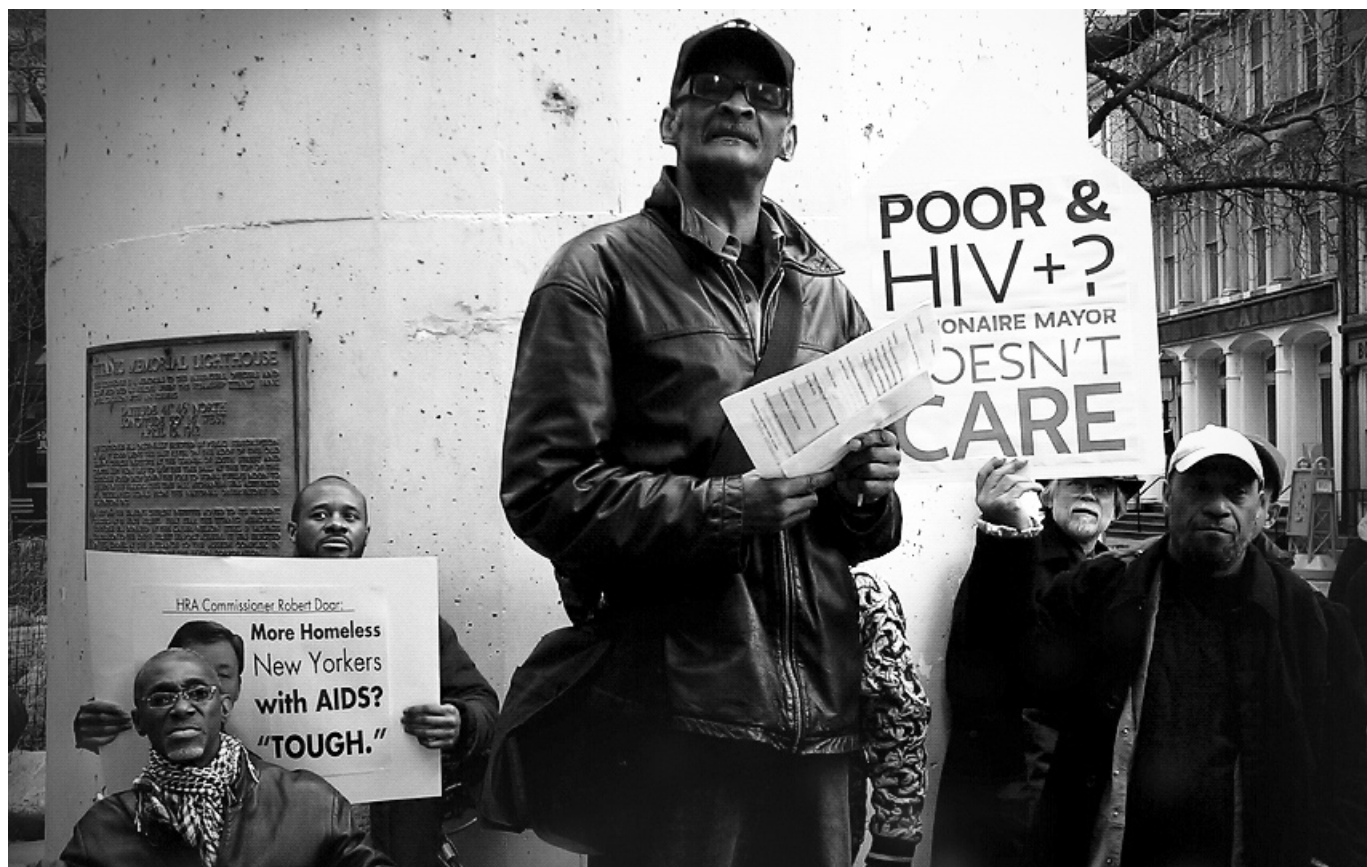
The severe rent burden is a major driver of homelessness and unstable housing among HASA clients in the rental assistance program.

2. Lack Of Affordable Housing Means Sacrificing Other Basic Needs

“My thing is, when it comes to the budget, some people may have to deal with a hardcore situation where it’s either I pay my phone bill or I pay my lights. Or my food stamps ran out so either I eat this month or I have the lights. So it’s either one or the other.” – Emergency Housing Focus Group #1, Participant #2

Permanently disabled PLWHA enrolled in HASA’s independent living rental assistance program are budgeted to live on less than \$12 per day for all other expenses after rent. This forces clients to make nearly impossible trade-offs among other necessities in order to pay their rent each month. Of the homeless PLWHA surveyed in emergency housing, in the six months before losing their apartment:

- » About two-thirds (65%) of respondents reported having to choose between paying rent and paying other basic necessities.
- » About half of respondents were not able to afford food (46%) or transportation (48%) (E.g. subway fare).
- » One in three (34%) respondents said they had trouble paying for healthcare expenses such as co-pays for medical appointments or prescription drugs that were not covered by their health insurance.
- » 40% of respondents said they could not afford toiletries, hygiene supplies or laundry expenses.



A focus group participant in emergency housing, who had previously been in the independent living program before losing his apartment due to the rent burden, described the day-to-day need for subway fare:

“I need MetroCards for going to the doctor, for going to my support groups so I could stay clean. I was trying to go to school at the time...the subway is a big part of my life.” – Emergency Housing Focus Group #2, Participant #3

While medical providers occasionally offer van service for appointments, focus group participants said they were often unreliable or had limited availability. All participant said they relied primarily on the subway for getting to and from appointments, which is also sometimes reimbursed by medical providers, but on an inconsistent basis and often only for one-way travel.

A participant in the independent living focus group described his frustration managing recent medical appointments:

“Last week I was scheduled for a sonogram and a dental appointment... I’ve been wearing dentures for ten years but all of a sudden they had left a piece of a root in my mouth so I had to have surgery and find out the HMO doesn’t pay for anesthesia. I had to get up money to pay for the anesthesia and then I missed that sonogram appointment. Even though I’m supposed to get a MetroCard for both of ‘em they told me, ‘Hey, you’re not entitled to a MetroCard because we didn’t do no work. You just came in here and filled out forms.’ [Chuckling] So I had to walk from Downstate Hospital. I had to walk 45 blocks back home because they wouldn’t give me a MetroCard to come back.” – Independent Living Focus Group, Participant #5

Participants in the independent living focus group talked about how HASA seemed to view daily necessities as “luxuries,” in the words of one participant, and described the indignities of trying to get by on \$12 per day in New York City:

“I don’t have any money and I will not give up my home of 13 years. I will not give up washing my clothes. I will not give up bathing. I will not give up washing my dishes so you just have to back out of it and deal with whatever’s left and the absolute necessities are paid for. It’s definitely a lifestyle choice but I think it’s a lifestyle that someone shouldn’t really have to live.” – Independent Living Focus Group, Participant #1

“You know, my apartment is first.... The food stamps, laundry that’s something you do without at the middle of the month. For instance, laundry I just had to do that, but I gotta pay that to eat.” – Emergency Housing Focus Group #2, Participant #1

Financial and other types of struggles included (from Focus Groups and Survey):

- » Difficulty in paying for gas heating during the winter
- » Struggling to pay for transportation can be a struggle, since medical appointments only sometimes provide fares
- » Often having to reschedule appointments
- » Having to wear hand-me-down clothes
- » Keeping up with the electric bill
- » Not being able to engage in social and entertainment activities, which can take a toll mentally
- » Doing laundry by hand

- » Purchasing toiletries, for shortage of cash
- » Facing great difficulty in making life insurance investments
- » Missing out on family events, and not being able to help one's family in emergencies
- » Accumulating arrears for electricity, phone and other such expensive utilities
- » Being compelled to trade-off between basic commodities and essentials
- » Not being able to keep up with ever-increasing food prices, and not being able to make food stamps last through the month.

Summary

Survey responses were similar to data collected by Columbia University's CHAIN project, which found that among people living with HIV/AIDS who were receiving rental assistance, 43% reported not having enough money for food, utilities, unreimbursed medical care or other health needs at least some time during the past 6 months.⁵⁰

Living on \$12 or less per day means that PLWHA in New York City cannot always afford basic needs ranging from transportation to medical or social service appointments to buying bath soap.

Not only does the severe rent burden in HASA's rental assistance program drive housing loss and instability, clients who manage to hang onto their apartments are also forced into choosing between essential needs such as healthcare and food in order to pay their rent. Aside from pushing people to the precipice of losing their homes when they can no longer manage their bills, these trade-offs have dire health consequences by forcing people to sacrifice proper nutrition, travel to medical appointments or paying for care that is not covered by their insurance.

3. Homelessness & Unstable Housing Adversely Impact Health



“My viral load went sky high, you know, and it’s not because of lack of taking medication. It’s because of the stress. It will kill you and you go through something being in these places [emergency shelters].” – Emergency Housing Focus Group #1, Participant # 7

The severe rent share burden in the rental assistance program, as explained in the two previous sections, forces many HASA clients into either homelessness (which includes moving into HASA's often unsafe and substandard emergency shelters) or sacrificing basic needs to keep their housing. In both these situations, the severe rent burden compromises the physical and mental health of those who are already permanently disabled.

Even for those who do retain their housing, the lack of affordable housing can mean missed healthcare appointments, unpaid unreimbursed medical expenses, poor nutrition, stress and anxiety. All these trade-offs can lead to unnecessary emergency and long-term medical expenses, along with measurably worse health outcomes, such as higher viral loads or lower CD4 counts. Unstable housing can also increase risk behaviors for people living with HIV/AIDS. Moreover, those who become homeless due to the lack of affordable housing may experience even more stress in emergency shelters and may be unable to cook or keep food.

According to survey respondents, the experience of becoming homeless and living in the emergency

housing system led to deterioration in health. They reported that it was harder to manage medical appointments and treatment, and that they also had high rates of emergency room visits and hospital admissions.

- » Nearly seven in ten survey respondents (67%) said that it has been harder to take care of their health since losing their apartment and entering the emergency housing system, with six in ten reporting that their health has become worse during that time.
- » More than half of respondents (54%) said it has been harder to keep doctors' appointments since they became homeless, and slightly less than half (47%) said it has become harder to take their medication regularly.
- » About half (52%) had visited the emergency room and 38% had actually been admitted to the hospital since they became homeless and entered the emergency housing system.

Focus group participants, in both emergency housing and the independent living rental assistance program, discussed the impact of homelessness and unstable housing on their treatment adherence, nutrition and mental health.

Treatment Adherence

Complex medical treatments offer the possibility of a near-normal lifespan for people living with HIV/AIDS. However, this possibility is limited to those who are able to take their medication as prescribed and live otherwise healthy lives – both of which are directly undermined by homelessness and unstable housing.

Speaking about what it would mean for his ability to manage treatment if he became homeless, a participant in the focus group for HASA clients in the independent living rental assistance program said:

“When I hear stories of people losing their homes and living out of suitcases or not even having a suitcase and just the clothes on their back, I cannot imagine managing my medication regime out of my pockets. I take around 30 pills a day—it’s a twice-a-day regime, thank God it’s not three or four or five.” He continued to imagine what becoming homeless would mean for his health: “And, so, um, and then it just sort of snowballs into then I’m unwell and I have to use the hospital or emergency room for my doctor because I’m not taking my medications so I am sick but I don’t have a home anymore so where do they call me to make the appointment or whatever?” – Independent Living Focus Group, Participant #1

Mental Health

In addition to speaking about the negative effects of a severe rent burden on their ability to keep medical appointments and adhere to treatment, participants in the focus group for clients in the independent living rental assistance program discussed the mental health impact:

“As far as the health impact, when you can’t make ends meet it keeps you in constant depression, you’re constantly stressed out.... So there is a sacrifice of quality of life and I know that I’m probably not taking care of myself as well as I could be if I did have some more money. There is a lot of issues like depression that probably could be lightened up a little bit if I could participate in some social activity,” – Independent Living Focus Group, Participant #1

Nutrition

Proper nutrition is an essential component of managing HIV/AIDS. Among other health benefits, proper nutrition helps prevent wasting syndrome, an AIDS-related condition where a person loses significant amount of weight and is vulnerable to other opportunistic infections; proper nutrition also minimizes the side effects of medication, as well as boosting the positive effects of treatment. PLWHA who have adequate food are, furthermore, less likely to engage in transactional sex or other risk behaviors in exchange for food or money to buy food. Malnutrition and hunger among New Yorkers living with HIV/AIDS may be increasing due to cutbacks for food programs.⁵¹

Food was the most common trade-off reported by focus group participants in the independent living rental assistance program.

“The nutritionist tells us that, living with HIV we have to have the high nutrition food... She tells you to eat 100% whole wheat bread, you can’t afford 100% whole wheat bread so you have to buy the cheaper brand... because that’s all you could afford.” – Independent Living Focus Group, Participant #5

While HASA clients in the independent living program reported sacrificing nutritious food to pay their rent, those in emergency housing described a different set of challenges because the shelters lack cooking facilities or food storage areas. While HASA clients do receive limited food stamps, they cannot use them to buy prepared or hot food. Since clients in emergency housing cannot cook, relying on food stamps also means they cannot purchase or prepare hot food. Focus group participants who were in emergency housing programs described this added difficulty:

“This is a non-cooking facility. They actually don’t serve meals here...and a lot of people have to have something to eat to go along with their medications. – Emergency Housing Focus Group #1, Participant, #7

“Over here, you can’t buy anything hot. You have to give ‘em cash, no food stamps. I gotta buy these things with my food stamps, not hot meals. ... [Before I lost my apartment] I cooked the rice then chicken, pork chop on the side in the ice box and I got food for the whole week. Over here I can’t do that.” – Emergency Housing Focus Group #2, Participant #1

“That’s another strange thing about this place too. We get food stamps, some of us. I get food stamps and you can’t buy hot food with the food stamps but here they don’t allow you to cook...it’s like you know, where are we supposed, to cook food at? You get tired of sandwiches all the time.” – Emergency Housing Focus Group #2, Participant #2

Summary

Stable and affordable housing is the foundation of effective HIV/AIDS treatment and care. After controlling for other factors that can impact HIV care and outcomes, it has been seen that housing assistance is independently associated with entry into appropriate HIV care, access and adherence to antiretroviral therapy, improved HIV health outcomes and reduced HIV risk behaviors.⁵²

PLWHA who have stable housing are also less likely than homeless or unstably housed PLWHA to transmit HIV to others, regardless of other determinants of risk.^{53 54 55} Even by a conservative estimate, each HIV infection prevented through more stable housing saves over \$300,000 in lifetime medical costs.⁵⁶ Compared with stably housed people living with HIV/AIDS, homeless and unstably housed PLWHA are up to six times as likely to engage in behaviors that can transmit HIV to others.^{57 58 59} According to one estimate, implementing a 30% rent cap on HASA’s rental assistance program would potentially prevent at least 54 new HIV infections annually, saving at least \$16,215,000 attributable to averted infections alone.⁶⁰



Data from surveys and focus groups indicate that the high rent share burden and the resultant incidence of homelessness severely impact the ability of persons living with HIV/AIDS to maintain their physical and mental health. High rent forces HASA clients in the independent living program to sacrifice essentials in order to retain their housing; such essentials include subway fare to doctors' appointments, over-the-counter medication, co-pays for prescriptions, nutritious food that is essential for individuals taking highly toxic medication. The stress and anxiety that accompany this situation further threaten the mental and physical health of HASA clients. We know these are just some of the ways the severe rent burden, and the recurring homelessness it triggers, undermine health.

Poor Conditions in Emergency Housing

"You're in this little room that you gotta call home." – Emergency Housing Focus Group #1, Participant, #2

Homeless people living with HIV/AIDS in New York City have a legal right to "medically-appropriate" emergency and permanent housing assistance. HASA's emergency housing system, while separate from the Department of Homeless Services (DHS) shelter system, still presents an unhealthy environment for people with fragile immune systems and often other co-occurring issues, including chronic illnesses and mental health and substance use issues. They are also often unsafe – a tragic murder at a HASA-funded commercial SRO this past summer drew rare attention to the safety issues at HASA emergency housing facilities.⁶¹

According to some focus group participants, poor conditions in emergency housing affected their health:

"For a while my room was ice cold and the heat wasn't coming up because they got no knob so you can't only on or off... I'm standing downstairs from it and I got shakes and chills...I got sick. I got pneumonia. I feel 100% if my heat was working they way it was supposed to, I wouldn't have gotten that sick." – Emergency Housing #1, Focus Group Participant #4

"I had an incident in October where I went in the bathroom one morning and I shut the door and the ceiling collapsed on me... I had to go to the hospital." – Emergency Housing Focus Group #2, Participant #3

Many described a lack of privacy, feeling unsafe and being disconnected from their families and friends in emergency housing:

"You have no privacy, you know? When you have your own place, it's different. You're the only one who's using it." – Emergency Housing Focus Group #1, Participant #5

"I have seen rooms being broken into, not in the act but I have seen instances of, you know, people losing things as a result of burglary and you can get some pretty unsanitary conditions in the bathrooms and things." – Emergency Housing Focus Group #2, Participant #3

"You can't be at peace because your mind's running all the time. You sleep and you don't know who's gonna come to the door and you're not safe here ...It's very difficult, sometimes I get real stressed." – Emergency Housing Focus Group #2, Focus Group Participant #1

Women living with HIV/AIDS in particular described feeling physically threatened in emergency housing:

"My life had been threatened...by the guy who lived next door to me. He wanted me to have sex with him and he threatened to stab me several times in this building with them standing there." – Emergency Housing Focus Group #1, Participant #2

4. Rent Burden Is A Barrier To Independent Living

“It’s hard to get a place when you got Social Security because a lot of people that used to be on Social Security wasn’t paying their rent.” – Emergency Housing Focus Group #1, Participant #4

Homeless people living with HIV/AIDS who are permanently disabled and receive Social Security or veterans’ benefits face added difficulties in finding permanent housing. Many became homeless because they could not afford to pay their rent in the independent living rental assistance program, and they fear moving back into that situation. Brokers and landlords are even less likely to rent to them compared with other HASA clients, who already face widespread housing discrimination, because they have a reputation for falling into arrears. This perception exists because permanently disabled clients in the program find that they cannot afford to both pay their rent and make other ends meet, which drives them into arrears or housing loss because of non-payment of rent.

Many people interviewed for this report described waiting long periods of time in emergency housing for an opening in one of the limited supportive housing programs; even though they felt they could live independently, they could not afford the severe rent burden in the independent living rental assistance program.

Governor Cuomo’s MRT Affordable Housing Work Group identified the severe rent burden as a barrier for homeless people living with HIV/AIDS in the emergency housing system and for clients who were living in supportive housing but no longer needed intensive case management in that setting. According to the final MRT report, “This work group should also design a “Moving On” Initiative to incentivize and support tenants who are ready to or already live in independent housing. This group will identify resources as well as incentives and supports needed to support this effort including...evaluating mechanisms for supporting tenants whose chief barrier to independent living is a lack of a cap on the tenant contribution in subsidized rental programs such as the enhanced rental assistance program for people with HIV/AIDS disease.”

Survey respondents identified the severe rent burden faced by HASA clients in independent living as a leading factor keeping them stuck in the emergency housing system,

- » Nearly seven in ten homeless (67%) HASA clients surveyed in emergency housing said they worried they wouldn’t be able to afford rent if they moved back into the independent living rental assistance program.
- » Four out of five respondents (78%) said they would be able to move into permanent housing sooner if they knew they had an affordable housing protection limiting their rent burden to 30 percent of income.

One challenge in particular is the perception that permanently disabled HASA clients in independent living do not pay their rent – a reputation that comes about due to the lack of affordable housing in the program. Brokers and landlords believe that HASA clients are more likely to fall into arrears because of their severe rent burden, so they are less likely to rent to them, despite laws protecting tenants from discrimination for source of income. Focus group participants in emergency housing described how they had a harder time finding permanent housing because brokers expect disabled HASA clients to fall into arrears and therefore avoid renting to them.

“[Brokers and landlords] ask you what type of program you’ve got. I always say HRA first and then I tell ‘em I also get Social Security. Once Social Security comes out of my mouth, oh we’ll call you back or they say things may come available or this and that. But I just spoke to you on the phone and I asked you if you had any apartments and you told me yeah but now because of Social Security.” – Emergency Housing Focus Group #1, Participant #4

“It’s the theory of that bad apple. I have landlords speak to me, confidentially...usually the matter is

like them being the landlords they say they have a lot of clients that have straight HASA and they were wonderful clients. Then they got a small amount who have straight HASA and Social Security and... they wouldn't pay. They're saying that once they dealt with that so many times, when they got HASA or Social Security it leaves a bad taste in their mouth.... I don't even get into the Social Security part. And then when you get to the Social Security part, they say no we want straight HASA.” – Emergency Housing Focus Group #1, Participant #2

Others participants in the emergency housing focus group talked about waiting for openings in the much more limited supportive housing programs because they cannot afford independent living. In discussing why they were waiting for a supportive housing placement even though they felt they did not need the additional case management, participants explained:

“For me, it would be the fact that it's more affordable. I mean, if I'm gonna stay for free, why would I move out? If you're gonna pay rent for me to stay in a hotel...and I'm gonna pay so much for my apartment? So what good would it be? I'll go to the Scatter Site or I'll go to a congregate.” – Emergency Housing Focus Group #1, Participant #6

“So - why would I go into independent and spend all my money...if you're in independent HASA wants you to spend up to about \$360 [on rent]... That's why I'm trying to get into Scatter Site or congregate. I really don't want [congregate] but I'll take it to get out of here... The rent is a whole lot cheaper.” – Emergency Housing Focus Group #1, Participant #4

Summary



The comprehensive NYC HIV/AIDS Housing Needs Assessment highlights the absence of an affordable housing protection in a section about barriers to independent living: “the most serious disincentive to more independent living for residents of supportive housing programs who receive income, typically SSI or SSDI disability benefits, is the large rent disparity between persons receiving rent supports and those in supportive programs.”

There is also strong evidence that HASA clients with an affordable housing protection are more likely to pay their rent. For example, a 2009 study by researchers at Harlem United compared rent payments among clients in two programs that were similar in most respects except that one program offered a 30 percent rent cap and the other did not. The study found that HASA clients in the housing program with the 30 percent rent cap were more than twice as likely to make timely rent payments than clients in the program with no affordable housing protection.

Most homeless people living with HIV/AIDS surveyed for this study said the severe rent burden faced by clients in the independent living rental assistance program was a major barrier keeping them from leaving the emergency housing system. The rent burden also increased the likelihood that brokers and landlords would believe that they were less likely to pay the rent and would therefore be less likely to rent to them. Most PLWHA also said they worried about how they would pay the rent once they did move into their own apartments again. Some said they would only move into supportive housing – not because they felt they needed onsite case management, but because it would come with an affordable housing protection.

As one would expect based on these experiences, most respondents also said that a 30 percent rent cap affordable housing protection would enable them to move out of the emergency housing system sooner.

V. CONCLUSION

Implementing the 30 percent rent cap on HASA's rental assistance program would prevent homelessness among people living with HIV/AIDS, improve health outcomes, reduce new HIV infections, save money by preventing unnecessary emergency housing placements and healthcare expenses, and establish basic fairness in New York's housing assistance programs; furthermore, adopting a law requiring the 30 percent rent cap affordable housing protection is an easy and affordable step to take. The reasons why a 30 percent rent cap should be mandated by law are summarized below.

First, the proposed law would pay for itself by reducing homelessness among HASA clients, which would produce a direct and immediate cost offset. HASA clients who are homeless would be able to afford to move into their own apartments while those who are constantly in arrears and at risk of losing their homes would become more stably housed. Housing assistance for New York City residents living with HIV/AIDS is uniquely structured in that both emergency and permanent housing assistance are drawn from the same budget. This means that reductions in emergency housing expenses can be immediately reinvested in permanent housing. It is a far more efficient use of limited housing resources to keep people with HIV/AIDS in independent housing instead of expensive, substandard emergency housing.

Second, an affordable housing protection would better allocate limited supportive housing resources to those most in need. Many residents who are able to live independently cannot afford to leave supportive housing assistance because their rent share would be double or more in the rental assistance program. The proposed policy change would remove a major barrier to independence for people living with HIV/AIDS.

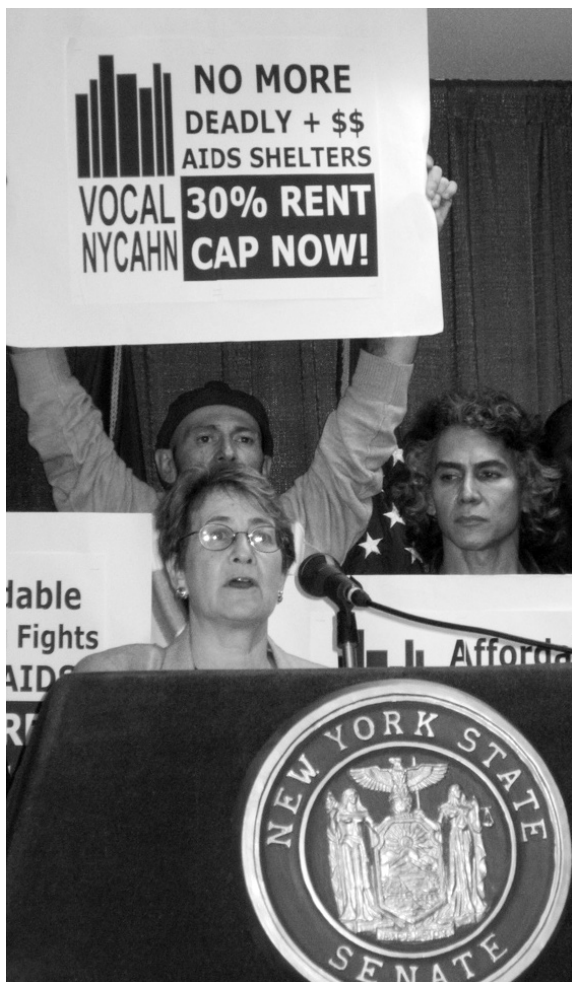
Third, housing is synonymous with healthcare for people living with HIV/AIDS, and there is a strong and undeniable relationship between stable and affordable housing for PLWHA and better health and HIV prevention outcomes. People are more likely to make doctors' appointments, take their medication, practice safer sex, reduce drug use and adopt other healthy steps if they have decent, safe and affordable housing.

Additional indirect cost savings would be realized by lowering the incidence of HIV infections and reducing unnecessary healthcare expenses, including Medicaid expenditures that result from homelessness and unstable housing.

Lastly, the proposed policy is about simple fairness. The HIV/AIDS rental assistance program is the only low-income or disability housing assistance program in New York State that does not cap a tenant's rent contribution at 30% of income, which is HUD's standard definition for affordable housing and a requirement for all federally funded housing programs. The rent share burden of tenants in other subsidized programs, such as supportive housing, NYCHA and Section 8, is calculated at 30% of their income. The time to align the HIV/AIDS rental assistance policy with other housing programs in the state is long overdue.

VI. POLITICAL CONTEXT

Legislative History of HIV/AIDS Affordable Housing Proposal



The proposal to implement a 30% rent cap on affordable housing has received widespread bi-partisan support in Albany. The bill has been sponsored by New York State Assembly member Deborah Glick and Senator Thomas K. Duane. Senator Duane, who is openly HIV-positive, left the Senate at the end of 2012 after two decades as an elected official and an extraordinary record of advocacy on behalf of people living with HIV. Senator Brad Hoylman, who now represents Senator Duane's former district, is now the primary Senate sponsor.

The bill first passed the Senate in 2009 (under Republican leadership) and again in 2010 (under Democratic leadership), both times by a wide margin and with bi-partisan support; the bill also passed the Assembly in 2010 as the first order of business that year. However, the bill was then inexplicably vetoed by Governor Paterson in September 2010, who referred to it as “my most difficult veto,” although he later said that he would consider the bill again if passed by the legislature during a special session that never materialized. The former governor's veto message referred to inaccurate information from Mayor Bloomberg's lobbyists that had been repeatedly proven false during legislative debate. After Governor Cuomo took office, his MRT process took up the proposal and discussed it, although the MRT postponed any action on it for a future “Moving On” initiative.

Most recently, the bill was on track to pass the Senate for a third time in June 2012, although it failed to secure enough votes after eight Senate Democrats were missing from the chamber, most of them absent with no explanation.

During the 2011–2012 session, the bill number was A.6275 / S.4098. The actual bill language is very brief:

AN ACT to amend the social services law, in relation to limiting the percentage of income payable towards shelter costs by persons with HIV or AIDS.

Section 1. Section 131-a of the social services law is amended by adding a new subdivision 14 to read as follows: 14. Notwithstanding any other provision of law, each person living with clinical/ symptomatic HIV illness or AIDS who is receiving shelter assistance or an emergency shelter allowance and who resides in a household that receives unearned and/or earned income shall not be required to pay more than thirty percent of the household's monthly unearned and/or earned income towards shelter costs including rent and utilities, with the remainder paid by public assistance, less any federal funds which are being used by the localities to pay for housing accommodations. § 2. This act shall take effect immediately.

Mayor Bloomberg was alone in his opposition to the bill among elected officials from New York City.

The New York City Council has adopted resolutions supporting the bill in 2009 and 2010, led by Speaker Christine Quinn and General Welfare Committee Chair Annabel Palma. Public Advocate Bill de Blasio has also spoken publicly in favor of the bill. More recently, all Democratic mayoral candidates pledged to support passage of the bill in Albany during an LGBT issues forum on March 25th, 2013.

How Much Will An Affordable Housing Protection Cost New York?

An affordable housing protection for low-income people living with HIV/AIDS who are eligible for rental assistance will more than pay for itself by reducing housing loss and unnecessary healthcare costs and by preventing new HIV infections. Most importantly, it would better enable low-income New Yorkers living with HIV/AIDS to attain a basic level of dignity.

An independent fiscal analysis by Shubert Botein Policy Associates (SBPA) concluded that the proposed affordable housing protection is a better utilization of an existing resource and would not result in a net increase in spending; rather, a direct and immediate cost offset would be created. The SBPA analysis found that the incremental annual rental assistance cost to the City and State of implementing the proposed policy, estimated at \$20.7 million, would be directly offset by at least \$21 million in averted rent arrears payments and emergency housing costs. Because emergency housing expenses for HASA clients are paid out of the same funding source as long-term rental assistance, there is an opportunity to immediately reinvest savings from reduced emergency housing placements into the rental assistance program within a single budget line, and to thus realize savings within the same fiscal year.

In addition, SBPA estimated additional indirect cost savings associated with preventable healthcare costs and new HIV infections. According to SBPA, “While it is more difficult to calculate the direct additional benefits in reduced Medicaid costs, we estimate annual savings conservatively at \$50million (\$22.5million in averted crisis health care and \$27.8million through prevention of new HIV infections).”

VII. RECOMMENDATIONS



As the research findings included in this report indicate, the primary source of housing assistance for low-income PLWHA in New York City fails to promote stable housing due to lack of affordability. The flawed policy in the rental assistance that forces PLWHA who qualify to pay upwards of 70 percent or more of their income towards rent undermines every possible goal from the program, improving health outcomes, reducing avoidable healthcare expenses and promoting overall wellbeing.

A simple solution exists to prevent homelessness and increasing housing stability for over 10,000 New Yorkers living with HIV/AIDS and their families. Governor Cuomo and state legislators can accomplish this by establishing the same affordable housing protection in the HIV/AIDS rental assistance program that already exists in every other low-income housing program in New York.

This report recommends the following steps among elected officials in New York to resolve the affordable housing crisis among homeless and low-income housing people living with HIV/AIDS who are permanently disabled and qualify for rental assistance.

- » Both the New York Senate and Assembly should swiftly pass the 30 percent rent cap affordable housing legislation that has already passed both houses by wide margins in the past.
- » If the policy change is not passed as a stand-alone bill, Governor Cuomo should work with the Senate and Assembly to include the legislation in the budget in order to reflect the direct savings from the bill that would be achieved through reductions in emergency housing occupancy and rental arrears, which would fully offset the cost of implementing the new policy, along with indirect savings from improved health associated with increased housing stability.

- » The Medicaid Redesign Team should move forward with establishing a “Moving On” initiative and advocate passage of the legislation and/or inclusion of the policy change in the state budget. The Affordable Housing Work Group recognized that the 30 percent rent cap for the HIV/AIDS would not only meet the goals for the MRT process around improving health outcomes and reducing unnecessary expenses, but also would also remove a barrier to greater independence for PLWHA currently residing in more costly settings and increase the availability of supportive housing.
- » Candidates for Mayor, Comptroller, Public Advocate and City Council in 2013 should endorse the legislation and pledge to work towards its passage if elected.
- » NYC HASA should eliminate the use of commercial SROs for emergency shelter for homeless PLWHA based on the reduced occupancy that will occur after the affordable housing protection is enacted. Moreover, the remaining emergency shelter units that are needed for homeless PLWHA should be provided through contract-based non-profit transitional housing providers with onsite staff who can help clients obtain permanent housing.
- » NYC HASA should promote *voluntary* job training programs once the affordable housing protection is enacted, which will create a bridge-to-work for PLWHA in the rental assistance program by enabling them to keep a portion of any earned income while also contributing more towards their rent.

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