

Examining the Housing Situation for
People Living with HIV in Philadelphia: A Qualitative Study

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1. INTRODUCTION

In 2001, Culhane¹ found that among people living with AIDS in Philadelphia, 9% had had been admitted to a shelter in the three years prior to the study, a rate that was triple that of the general population for the same time-period. In another section of this current study, Metreaux² finds that between 2007 and 2014, 6.9% of people with AIDS in Philadelphia had at least one shelter stay, a rate that is more than double that of the general population. These results indicate that people living with HIV (PWH) are at considerable risk of experiencing homelessness. This report presents the results of a qualitative study examining the housing-related challenges confronting PWH in Philadelphia, and the manner in which The Housing Opportunities for People with AIDS (HOPWA), a federal housing program for low-income people living with AIDS, is addressing these challenges.

2. METHODS

We conducted 47 in-depth semi-structured qualitative interviews with service providers (n=32) and clients (n=15). We also conducted five focus groups (n=5 in each) with PWH in vulnerable communities.

¹ Culhane DP, Gollub EE, Kuhn RR, Shpaner M. (2001). The co-occurrence of AIDS and homelessness: Results from the integration of administrative data for AIDS surveillance and public shelter utilization in Philadelphia. *Journal of Epidemiology and Community Health* 55(7): 515–520.

² Metreaux, S. (2016). *Assessing the Intersection Between HIV/AIDS and Shelter Use in Philadelphia*. Office of Housing and Community Development. Philadelphia.

2.1. Sample

Our sample included 32 providers, and 40 PWH. Of the 32 providers, 22 were in Philadelphia County, and 10 in Montgomery, Bucks, Delaware and Chester counties. Of the 40 PWH included in our study, 15 completed individual semi-structured interviews, and 25 participated in 5 focus groups (of 5 participants each).

2.2 Recruitment

For the first group (managers and providers), all facilities were selected from the City's Office of Housing and Community Development (OHCD) HIV service provider list. All facilities were approached to take part in the study, and study investigators contacted at least one or multiple staff members from each facility. Of all providers contacted, 9 refused or did not respond to requests for interviews. The final sample includes a total of 32 providers.

For the second group, investigators used snowball sampling methods to recruit 15 HOPWA clients through referrals and word-of-mouth.

For the third group, focus group members were recruited through fliers put up in agencies across the city. The sample for this group included 25 HOPWA clients doing 5 focus groups of 5 clients each.

2.3 Analysis

A grounded theory approach was utilized to code the interviews (Glaser & Strauss,

1967³). Data collection was terminated when theoretical saturation was reached and new analytical concepts ceased to emerge (Guest, Bunce & Johnston, 2009). Primary codes were identified by the lead author and verified by the other authors. Axial codes were then identified by each of the authors and verified by the team. Institutional review board clearance was obtained from a U.S. university.

3. RESULTS

Our results indicate that participants faced significant barriers to adherence while homeless, and that the HOPWA program was successful in helping them negotiate many of these hurdles. The results also indicate that the program faced significant challenges itself.

3.1. Challenges with homelessness

Participants described significant struggles with homelessness, and the barriers it posed to adherence. Two participants describe the challenges to accessing their medication while homeless:

I didn't even know what day it was when I was homeless, man. Didn't keep appointments, didn't get my pills. Keeping alive on the streets seemed more important than taking pills. I know that isn't true when you have the time to think about it, but ain't no thinking been done on the streets, you know what I mean?

I didn't even have my pills when I was on the streets. I mean, I wasn't going to get a refill when I didn't even know where I was going to get food.

³ Glaser, B.G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Chicago, Aldine Publishing Company.

Describing his struggles with keeping his pills secure while homeless, one participant noted:

In my situation, I lost a lot of medication when I was homeless. [In the shelter, on the street], everywhere people take your bag and then you lost everything and then you're medication is in the bag. And then people take your bag, or it's stolen or something, like they take your property, they take my bag...That's why housing, it affects the medication because they steal it or you get lost. Last week I lost all my medication they gave me for this month. In the 4 days that I've been on the street, they took my coat, my hoodie, my phone, my coat, everything. I was sleeping and when I wake up everything was gone.

The same participant described how he would hoard his pills in order to have enough medication to last:

I [went to the doctor to get] more medication or saved medication, like take no doses one day and then save that, so at the end of the month you've got like a couple medication extra and you could put it somewhere to save it in case you lost your medication, like you know, until you see your doctor. That's what I'm doing, I don't know about other people.

Describing the way homelessness undermined his motivation to take his medication, one participant notes:

I'd get thrown out of a housing situation and it was back to square one, you know? I mean, if you can't keep yourself safe with a roof over your head, what's the point of taking pills, right? So I'd go through this cycle of becoming homeless and not caring about my meds.

Several participants described the challenges of being adherent to HIV medication while staying in shelters. One states:

It's not easy in the shelter. They do everything to you in the shelter. At 5 in the morning, you have to go out to the street. At 3 they do something, they sound an alarm. They were giving me all the pills together and...it can't be like that. They want you to take them in the morning and at night, the 5 pills that I was taking - two of each and one other.

Several participants noted the barrier posed by the practice of shelters separating participants from their pills and meting them out at set times:

If you're not there [at the shelter] at the time that they give it, then they don't give you the medication. You can't go late or they won't give it to you.

I had problems when I was in the shelter because they didn't give me my medicine on time. I had to ask for it because they weren't going to give it to me. In the shelters, you get robbed, food gets taken, and nobody steps in to defend you, then they kick you out for defending yourself. You have to go through it all again, apply again, go from here to there. It's all unfair. 6 or 7 months for one application. I've been in this country for years looking for assistance.

I bounced from shelter to shelter for about a month. That in and of itself is ridiculous because you don't get to keep your meds. Which means that you have to get in this line every single day. They don't give it to you with food or anything. They just hand them out at 7am and 7pm. And you're expected to take it right there in front of their face. So if you're not getting food, your stomach is going to get upset. I take a pill to help with nausea, but I didn't have that then. And you know, you're embarrassed. Because you have to get in this line and you gotta get these pills. But people are watching. And after awhile they start talking. And you know, I'm not embarrassed about my status, but at the same time it's not everybody's business.

At my shelter it takes half an hour just to take my medication in the morning. I have to wait in line, and then inch up closer and closer. Then take the pills right in front of them. When I had a home, it took 5 seconds to take my medications. Now it takes over half an hour just to take five pills. It makes it a hassle.

Homelessness thus exacerbated the barriers to staying adherent, exposing participants to chaotic environments, preventing them from accessing medication and keeping it safe, and subjecting them to cumbersome shelter protocols.

3.2 Addressing homelessness through HOPWA

Our results indicate that HOPWA enjoys widespread support from providers in the community, especially given the challenges to adherence that homelessness constitutes. One

agency provider notes the way in which HOPWA circumvents the traditional barriers to housing encountered by vulnerable communities:

Our HIV clients who have been incarcerated are difficult to find stable housing for because the federal bans on housing restrict where someone with a criminal record can reside. For clients with an AIDs diagnosis HOPWA has actually removed those barriers. For example, if an HIV positive client has a felony, then under section 8 or public housing, that person is potentially ineligible. If you are a registered sex offender than there is a lifetime ban from both housing programs. However, under the HOPWA guidelines for that ex-felon or sexual offender who has an AIDs diagnosis there is no restrictions for housing. So we really were able to help some of our most vulnerable clients who might not have been able to get housing had they not gone through the program.

Another provider notes the crucial role HOPWA plays in housing clients in her agency:

The HOPWA program is essential. I mean, without it, the city of Philadelphia would probably have thousands of people with HIV/AIDS living on the street. The unfortunate thing in recent years is that the HOPWA funding has been either capped or cut ... But the HOPWA funds, as I said, are very essential. It helps to pay the rent in our agency for about 276 clients. It also helps to pay the utilities... I think the HOPWA program is a vital program, and it helps a number of constituents around the city to ensure they're not living in a cardboard box.

Describing the way HOPWA improved the chances of survival for his clients, one provider states:

The HOPWA program improves the [clients'] quality of life. Being with [name of agency] for the past 9 years, I've noticed that the consumers that are in the HOPWA program, because they're not living on the street, they tend to have a longer lifespan because they do have that housing, which is to me that main component. And if the housing wasn't there, I could see that we would have more folks unfortunately out there dying on the street.

HOPWA clients were equally effusive in their praise of the program. Noting the way the housing has helped him keep adherent, one participant notes:

This housing has saved my life. It has kept me off the street. Kept me safe. I take my meds and that is only because I have a safe space to call my own and can remember to take them.

Another participant describes the way the housing has improved his hope for the future, and consequently, increased his motivation to stay adherent:

I waited a long time for this [housing]. As soon as I got it my whole view changed. I feel like I can look forward to something now. I'm not going to just die on the streets. I have a place of my own. I take my meds now and am full of hope.

3.3. HOPWA waitlist challenges

Static waitlists for HOPWA housing constitute the most significant challenge to the effectiveness of the program. Several providers commented on how the increasing life expectancy of PWH was adversely affecting time on waitlists:

Today you see the improvements in medical treatment and people with AIDS are not only surviving, but thriving. People who get a subsidy are retaining them. The result, is that there are 230 people on the waiting list in Philadelphia for HOPWA subsidized housing and that wait can be up to two years.

People are on the waitlist for a long time because many of the clients who are in HOPWA housing are long term, long time clients. They've been in those houses for a long time. We have older clients who have been in the HOPWA program for many years. So it's not a program that turns over rapidly at all.

They are living longer. We have clients who probably have been on HOPWA for 10 or 15 years. And as long as they maintain their health and that their medication is accessible, you know they're medically adherent, they're not going anywhere.

Longer waits for HOPWA slots were experienced keenly by participants. Two of them note:

I am [currently on] the AACO waiting list. It's been maybe two or three years, but I'm also on the Housing Authority waiting list and I'm also the Section 8 waiting list. I've been on that forever and ever, forever, I mean for a long time. A long time. [I don't get updates or] nothing. I even call down there just to make sure that, am I, should I update, should

I...that's how you have to do it because if not, they're not going to contact you, they're not going to call you at all. PHA no.

I've been on housing [lists] since 5 years and I've been on section 8 [lists] 10 years and I still haven't gotten nothing. I'm on the lists, not in the housing. I've been homeless, 5 years homeless, because I didn't have nowhere to go, so I was in shelter and there they steal my clothes, everything, so I had to get out of there. But I'm still searching for housing. Yeah. And when every year comes a letter to me updating housing Section 8, I fill it out, I call, but still.

Many providers described the reluctance on the part of housing providers to keep the waitlist moving. One notes:

I don't think housing providers have a real incentive to encourage clients that are ready for independent living to move out of supportive housing programs. I think providers see these clients to be stabilizing and low-maintenance to the housing community, and don't really require a lot of support services. But when our clients in supportive housing don't have exit opportunities, the system becomes backed up, and then we have new consumers facing additional barriers to entering the system.

Study participants described their frustration with the logic dictating the position of a person on the waitlist. Three participants, all of them providers, describe the effects of creating a hierarchy of priorities:

They have it broken down into priorities. It's priority 1, 2, and 3. Priority 1 would be homeless individuals, and they take precedence over everyone else on the waitlist. There's people that have applied at least 8 years ago and have been a priority 2, and they didn't move anywhere on the list because there's always gonna be that homeless client that is put in front of them. When a spot does open up, that homeless client is referred.

People can have HOPWA, get terminated, and reapply in 6 months. But what we've encountered over the past two years is at least 4 separate occasions I can think of right now – people have had housing, they've been terminated, two years later, they become homeless, and they're placed at the front of the list again. So they've had it twice. One person had it three times within like a span of five years while people were still on the waitlist waiting for their opportunity.

This is 2015 – of the last 9 housing referrals we received from AACO, all of which were priority 1 individuals, 6 have reported previously receiving a subsidy, 5 of those were HOPWA subsidies. So those were all duplicate – 6 duplicate out of 9, and again there's

people that are priority 2 and 3 who have never had an opportunity to participate in this program.

Participants who lose their place on the list for some reason, find themselves at the back of the line when they return. Describing this phenomenon, one states:

I wound up staying with a friend. And when I was with that friend they put me at the bottom of the list on AACO because I had a roof over my head. But it's not my residence. So I went from being at the top of the list to being at the bottom, just because I was staying with a friend. And now they tell me I have to wait 7 years to get housing. I said, "What am I supposed to do for 7 years?"

One provider expressed concern with the way the logic of the waitlist intersected with the manner in which HOPWA clients were placed by the city, noting that some clients were being disadvantaged by the process:

There's a shorter list, for emergency housing and for the homeless. With regards to AACO and OSH, they're always putting people into transitional housing. They like transitional housing, it can be a quick referral. if you're in transitional that you're no longer considered homeless. You are now housed. And that's just ridiculous because someone who is on an AACO list... we don't put them in transitional, we don't even bother with it. Because it's a total setup. You would go into transitional housing, you'd lose your AACO status for being in line on either list, and then you're screwed. You'd end up being homeless again. So, what I would like to see is a more liberal approach to transitional housing to where someone could remain on the AACO list if they were put into transitional housing. In other words, if it's defined as transitional, make it transitional. Don't pretend that it's permanent.

Expanding life expectancies, the reluctance of providers to serve new clients, and the logic of how the waitlist was managed thus emerged as the primary factors exacerbating the challenge of static waitlists.

3.4. Challenges with securing and maintaining housing

For those lucky enough to get off the list, several barriers threatened to derail their placement into housing. Economic barriers, challenges associated with documentation protocol, and substance use emerged as challenges to maintaining housing for PWH, and for HOPWA clients specifically.

3.4.1. Economic barriers: Several providers commented on the barriers that rising rental rates posed for clients. One notes, “Those with HIV who seek access to the city’s housing programs are unable to afford rents that average \$1,400 a month for a one-bedroom apartment.” Describing the way gentrification has limited the number of neighborhoods clients can live in, two providers note:

The affordability is kind of the biggest thing. And also areas, unfortunately, because units can’t exceed a certain amount – they have to fall within the fair market rent – clients are kind of forced to live in areas that are not so good or in unhealthy environments. People with substance abuse history end up living in a drug-infested neighborhood. It’s definitely difficult to find places that kind of meet their needs or meet what they want.

With the gentrification areas – once, where rents were very cheap in certain areas, they skyrocketed like, unbelievable, so that kind of took a toll on desired areas that the clients wanted to move into. Now they can’t because the rents are so high, and we just can no longer afford to cover rents in those particular areas.

Voicing his frustration at the low quality of housing that the program secured for him, one participant notes:

The city has a different standard for human beings and for homeless people. It’s like, everybody has a nice place to live, but the homeless?...big [sic] deal. You can carve out a space this big and give them nothing. I mean, you have to be a total desperado to want to go and live there. You know, there’s supposed to be a lottery. So you’ve got a certain number of people on a list, you throw the dice – what’s up next? Oh, single room occupancy, okay that person will go there. Knowing full well that you’re going to get a single room occupancy in a terrible place, with a half-inch cable wrapped around the fridge

with a lock on it. You know, something's not right there. And so some of the places, you know the wind was blowing through in the winter.

Several participants described city and federal policies that made it difficult to secure housing for clients. Providers note the difficulty clients had negotiating utilities:

We are using these section 8 utility scales that haven't been updated since 2003. There have been a significant increases in utility costs since that time, both gas and electric. I think everyone in Philadelphia has kind of been complaining to HUD about this for quite some time to update your utility scale. What HUD is saying is that the person may spend \$48 heating their home when we know that's not the case, so it's kind of unfair to the client. What happens is they're actually paying more in rent than what they should be, because that utility scale is calculated in their 30% - 30% of their income is used toward rent and utilities, so you look at 30%, you deduct what HUD says is gonna be used on utilities, and the remaining balance is the tenant's rent. So if that utility scale was higher, their rental portion would be lower, and we'd actually be considering what they're really paying as opposed to these fake numbers that HUD hasn't updated in 10 years.

Recently, what we've encountered with PECO – unfortunately, they are not really flexible. We've had clients have their services terminated, and PECO refuses to restore services. If you set up a couple payment plans with them and you've deferred from those plans, they'll demand large amounts of money and threaten to shut off services... Often, people end up having to bite the bullet and pay large amounts of money, get their check of \$700 and make a \$500 payment to PECO. Their rent, utilities, they have a few hundred dollars left after that, so it's difficult to budget. It's difficult to be responsible and consistently pay bills.... There have been times when termination of utilities has threatened the client's participation in the subsidy program. We try our best, but if someone doesn't have lights and there's no clear plan to get electric restored, there's kind of nothing we can do.

Several providers also described unethical actions that landlords engaged in, that increased the economic barriers for clients. Hidden costs and out-of-compliance status put clients in deeper financial stress:

The city of course continues to raise property taxes, there's trash fees now, and of course the landlords pass that cost on to tenants. So we have encountered times where the units are now – where the landlords are requesting rent that exceeds the FMR or just too much of a rent increase for one year.

Another [barrier] is if they don't have income, they can't pay the rental insurance...and the landlords are now requiring that they have rental insurance and for some of them it's quite

expensive because they want them to hold such huge, like \$100,000, coverage. Our clients don't have \$100,000 in their units. That's not realistic.

Last year, the city decided to link the rental licenses with every other account that that landlord possesses in the city, so if you have a license to do business in the city, if you owe property taxes on another property – what happened was, when it was time to renew these clients, which we do on an annual basis, landlords were unable to get rental licenses from the city because they owed taxes on a property that they no longer even owned or the city hadn't cleared their record, or they hadn't paid their business taxes. So these people could not get rental licenses from the city, which caused us, unfortunately, to withhold rent because they couldn't apply with our program in the requirements of being a landlord. We did have to relocate two individuals when it was all said and done.

Economic barriers were therefore, a crucial barrier to placing helping to maintain clients in housing.

3.4.2. Documentation and logistical barriers: Our results indicate that documentation and other program-related protocols proved to be a challenge to participants securing HOPWA housing. Calling attention to the lengthy wait times associated with program protocols, one staff member notes, “The process is slowed down because of delays in the process for approving rental subsidies.” Another provider notes:

It's common for clients who have experienced homeless for a long time to not have documentation because they're coming from all over and looking for us to help. So clients who are HIV positive we have to prove they are disabled due to AIDS. So we those are people we can't even provide those options to.

A provider echoes this level of frustration with the AACO protocols involved in placing people in housing, stating:

We actually try to bypass AACO/HOPWA because if the person has other issues, we can go other routes and find them housing quicker. If they have mental health we can get them into [name of an agency]. If they're a vet, we can go through the VA. Honestly, it's just quicker and more streamlined than AACO and HOPWA. And there's a better housing stock. The AACO housing options are terrible.

3.4.3. Substance use and lack of housing first as a barrier: Substance use proved to be a significant barrier to keeping clients in HOPWA housing. One provider notes his own bias against users because of the challenge posed by AACO rules to maintaining housing:

You have to have paperwork saying that they're sober. And if you get them into AACO housing and they relapse within 5 days, it's only going to take 2-3 months of them not paying their rent and they're back on the street. I get into arguments with case managers sometimes because I won't take the addicts.

Another provider discusses the reluctance on the part of landlords to rent to users:

Many landlords are unwilling to rent apartments to those struggling with substance abuse and mental health issues. We're talking about people who are not only HIV-positive, we're talking about people who have socio-economic issues. People with addiction problems don't stand a chance – they are kicked out before they even start.

The extent of the problem emerged in the story of one participant who we had an opportunity to follow after his release from incarceration. A young, African American, HIV-positive man, he was released from custody by a judge into a treatment program because of his struggles with substance use. The release was facilitated by the fact that he had a housing slot allocated to him. While in treatment, he reduced his use, and became virally suppressed by being adherent to his medication regimen. However, he lost his HOPWA housing slot one month after moving in because he failed to become abstinent in his use. Despite the fact that his case manager pleaded his case by pointing out that he had attended treatment regularly, significantly reduced his substance use, remained adherent to his medication, and achieved viral suppression, the manager of the housing program insisted that housing was contingent on abstinence. The participant then found a slot in a shelter that served people in the lesbian, gay, bisexual and transgender community. However, after not being able to attend two meditation sessions at five in the morning in the first week, he lost that slot. At the time of the last interview, the participant

was homeless, not adherent to his medication, and is facing a fresh stint in prison since his release was contingent on being able to maintain housing. Describing his level of frustration, he notes:

I wish I hadn't been released. At least inside I had food, shelter and my meds. It's worse when you get housing and then lose it even when you're trying your best. You build up hope, and then bam! You're back to square one. Even worse.

The resistance to the idea of housing first – i.e. housing that is not contingent on factors such as substance use – was widely prevalent among many providers. One argued, “you can't reward users with housing,” a sentiment that is inconsistent with the tenets of harm reduction practice. There appeared to be a general lack of understanding about the evidence demonstrating the crucial role housing first played in reducing risk for HIV-positive communities.

Demonstrating an abstinence-first orientation, one provider notes:

Some referrals come to me when the client only had 3 weeks clean. Their last usage was three weeks ago. That's not enough time to be ready for housing.

Another argues for removing clients who use illegal drugs from HOPWA housing and finding higher levels of care for them:

Finding them an inpatient facility is obviously what we need to do. I wish they would screen these folks out, because they will use sooner or later and lose their slot anyway. They need to have more in-patient treatment before transitioning them out into independent transitional living or housing.

The situation is exacerbated by staff and providers putting onerous demands on clients, like the way our participant was asked to attend meditation sessions early in the morning. Some housing

program rules, driven by the orientation to ensure sobriety and compliance, appeared to undermine the agency and rights of participants routinely. One landlord noted:

We do unit inspections - one is scheduled one is not - to ensure that the unit is very clean, disinfected, and orderly. This allows us to see if drugs or any other activities are taking place.

3.4.4. Case management challenges: Participants often complained about the challenges they faced with receiving case management services that helped them negotiate the opaque bureaucracies associated with receiving housing. Two participants describe the lack of communication between their case managers and housing staff:

[I've been on the waiting list for] years. My case managers never call me back. When they do work with you, the housing office folks don't call me back. My case manager was checking the computer and everything, but they never called me back. Nothing. So I'm still waiting.

I always make sure that somebody comes with me who speaks more English than I do and understands better. But they tell you they'll call you, they'll call you, and nothing. You call and they say no. I haven't gotten a call since last year. I went and they told me that the list and the application I had completed expired and that I had to complete a new one. My case manager doesn't help at all. They are so busy.

Another participant notes, "I haven't seen my case manager in months. They never have any good news for me anyway and don't reach out to me."

Providers on the housing end note the difficulty they have experienced in working with case managers:

Unfortunately, a lot of the times what we encounter is that case managers aren't really responsive or doing everything they necessarily could be doing with the clients. Often, housing counselors have to take on that case management role as well. So kind of all of the things I've mentioned: referring clients to treatment, assisting with food bank

referrals, budgeting, and all of that – those are more roles that are defined toward a case manager as opposed to a housing counselor.

Like, we're sending a termination letter saying, "Listen, we've been working with this person, their subsidy is in jeopardy, this has happened, we've tried to help them to the best of our ability, and this person could possibly lose their housing." And we don't get a response. It's ignored. Or they'll call and say, "Well, I haven't seen that person for six months. I didn't know this was going on."

Another provider describes the structural challenge confronting case management services in an era of shrinking resources:

Case management has been cut in the last several years. I think that, while people are living longer and they're able to manage, there comes times when things may become overwhelming, medications get changed, life events happen to all of us, so I think that there is a need for someone to look at case management. I hear from some of my case management friends that they have caseloads that went from like 20 to 50.

The lack of adequate case management therefore, emerged as a significant barrier for participants seeking HOPWA housing.

4. DISCUSSION AND RECOMMENDATIONS

Our results indicate that the HOPWA housing program, remains crucial to the health of PWH, and faces some challenges in the way it is engaging with participants currently.

4.1. Successfully improving adherence in Philadelphia through HOPWA

Participants in our research faced significant challenges to adherence to their HIV medication regimen when they were homeless. An inability to store medication safely, challenges to remembering to take their pills on time, violence, and a chaotic environment undermined participants' ability to stay on their regimen. Protocols in shelters around storing and

meting out medication at set times emerged as a significant barrier to adherence for our participants. PWH were often unable to access their medication and were given medication in public, non-confidential settings when they were in shelters. In fact, many of the challenges confronting homeless PWH that led to the inception of the HOPWA program continued to exacerbate the risk environment that participants found themselves in.

Given these challenges confronting homeless PWH, the HOPWA program continues to receive support and backing from the community and providers. Our results indicate that it was a crucial bulwark against homelessness for PWH and served the housing needs of the most vulnerable section of that population (Table 1). By reducing chaos, improving motivation and stabilizing the living environments of PWH, HOPWA continues to play a crucial role in improving adherence to HIV medication among participants.

Table 1: HOPWA and its successes in boosting adherence among previously PWH^a

Medication Adherence Challenges (3.1)	HOPWA successfully addressing challenges (3.2)
chaotic environment leading to lost pills, hoarding, and failure to remember to take medication	providing hope and order
no safe place to store medication in shelters	addressing the housing needs of vulnerable clients like prisoners and substance users, who face challenges securing housing utilizing normal channels
cumbersome shelter rules regarding taking medication that violate confidentiality	linking to services

^a numbers in brackets refer to the numbered sections with the results associated with themes

4.2. Addressing the challenges confronting the HOPWA program

The program in Philadelphia faced two types of challenges : a stable waitlist, and barriers to placing participants in housing, and helping them maintain it (Table 2).

Table 2: Challenges Confronting HOPWA Clients^b

Waitlist Challenges (3.4)	Securing & maintaining housing challenges (3.5)
<p>static waitlist due to longer lifespans</p> <p>landlords resisting turnover in renters</p>	<p>economic barriers (3.5.1)</p> <ul style="list-style-type: none"> - gentrification pressures - rental rules and utilities-associated barriers <p>documentation and protocol barriers (3.5.2)</p> <ul style="list-style-type: none"> - complicated bureaucracy - complicated paperwork requirements <p>substance use barriers (3.5.3)</p> <ul style="list-style-type: none"> - lack of housing first orientation <p>case management barriers (3.5.4)</p> <ul style="list-style-type: none"> - lack of engagement of case managers - cuts in case management budget

^b numbers in brackets refer to the numbered sections with the results associated with themes

4.2.1. A stable waitlist: PWH are living longer, resulting in a low turnaround in the HOPWA program. This has led to a stable waitlist that has become a significant barrier for PWH seeking housing through HOPWA. Protocols to manage the waitlist that prioritize some people over others has exacerbated the problem for PWH who may not be able to demonstrate certain needs.

The only way to reduce the waitlist is to expand the number of housing slots available to the HOPWA program. As one provider puts it:

I just think that there's a greater need for housing, honestly. When HOPWA was first designed, it was designed for like a short-term, like six-month, temporary housing. That's no longer the case. Like you mentioned, people weren't living as long, so it was kind of like temporary housing, and that's no longer the case. We have people who have been on our program for like 13 years.

Federal algorithms that determine HOPWA funding need to take into account the fact that longer life spans for people living with AIDS, and stable waitlists are putting PWH at risk in Philadelphia. Moreover, the city offices administering the HOPWA program need to work closely with the community to bring focus to the housing needs of PWH. HOPWA as a program, was born out of social movements that shone light on the shelter needs of PWH. Large cities like Philadelphia bear the responsibility of maintaining the political and social pressure mobilized by these movements in order for the program to be expanded in the future.

4.2.2. *Securing and maintaining housing:* Our results indicate that economic barriers, complicated bureaucratic protocols, the lack of an adequate approach to address substance use challenges, and inadequate case management services pose significant challenges to HOPWA clients finding and maintaining housing.

4.2.2.1. *Addressing economic barriers:* The economic challenges documented above can be addressed by the program closely monitoring and resisting burdensome rental rules, as well as segregationary impulses dictated by gentrification. Addressing these issues, some providers advise:

We need to have a better check-in system to make sure our clients are not falling prey to predatory landlords or being asked to comply with unfair utility rates. Those slots that do not meet standards of fairness for our clients should be prevented from getting HOPWA funding.

I would like to see some efforts, some creative thinking. Not just you know, throw them into these little back hole rooms. You know? Get some real developers involved, get some architects involved. Why don't we care at all where these homeless guys with AIDS are being housed? So yes, I want to see a paradigm shift that is preparing for the future and addressing the fact that we're going to have hundreds of thousands of peoples that are reaching a certain age in the county that have HIV/AIDS and they're going to be elderly. And they're not going to be able to climb stairs. They're not going to be able to go out and do the grocery shopping.

I would like to see that the community create a task force to look toward the future to address these housing needs. Stop only offering apartments on the second floor. Stop offering crappy studios. Because why? Because you've got dialysis, you've got people on Hep C, which luckily there is a cure for now. But still, every single one of these guys has medical issues. Diabetes, obesity, feet problems. These issues need to be kept in mind in the type of housing offered.

Our results therefore indicate that the economic challenges confronting clients need to be taken into account in the way the program identifies housing slots, and monitors their condition. Program administrators also need to continue to monitor the rules and processes linked to renting, such as the payment of utilities and the relationship between renter and landlord.

4.2.2.2. Addressing complicated bureaucratic protocols: As documented above, several participants discussed their challenges with the paperwork and protocols involved in securing and maintaining HOPWA housing. Suggesting the need to integrate, centralize and synchronize services, one provider notes:

Honestly, I think there's a lot of confusing bureaucracy right now with different agencies getting and overseeing funding and then you have multiple providers. I think we need one place where people can go and say they need housing and what do they have to do to get it and then they have those needs met right there.

Another recommends better monitoring processes to ensure clients are linked with the proper level of care:

There's no uniformed assessment or a centralized system tracking placement. I think the result has resulted in an inefficient use of the existing supportive housing system which has been marked by countless inappropriate referrals and placements and create clients who are both underserviced and over serviced.

The current system of de-centralized services where care provision and follow-up are the responsibility of individual agencies creates impediments to the wrap-around care that the Affordable Care Act (ACA) is designed to provide. In the new era of ACA health homes, Philadelphia and its neighboring counties might consider reconfiguring its current system by studying the examples of cities like New York, where housing has become integrated with, and central to a comprehensive HIV care model.

4.2.2.3. Addressing substance use challenges: Substance use remains an enduring challenge for securing and retaining housing for participants. The lack of a comprehensive housing first orientation in the HOPWA program in Philadelphia facilitates the process of clients being kicked out of HOPWA housing because of their use. It is instructive to examine the evidence-based housing first models that New York's and Seattle's HOPWA programs⁴ have adopted across the board, in efforts to stop the revolving door of substance using HIV clients securing housing and promptly losing it. As previous studies have shown, a HOPWA program that operates all of its housing as housing first programs will experience success in reducing the prevalence of homelessness among PWH, thereby increasing rates of survival and reducing the spread of the disease.

⁴ Victory Programs Inc., U.S. Department of Housing and Urban Development's Office of Community Planning and Development. (2010). Targeting homeless households: DESC, Seattle. *HOPWA 20: Housing Innovations in HIV Care*. pg 7.
<https://portal.hud.gov/hudportal/documents/huddoc?id=hopwa20.pdf>

4.2.2.4. *Addressing case management challenges:* Ballooning caseloads, cuts in case management budgets, and the lack of follow-up on the part of case managers on behalf of their HOPWA clients present barriers to housing. The undermining of case management is most acutely felt by the most vulnerable clients who need services, such as substance users and those released from incarceration. Calling for better pre-release planning for clients coming out of incarceration, one provider notes:

There needs to be an improvement in the pre-release discharge planning for inmates with HIV/AIDS. Because what happens is that people are leaving prison and do not have a current driver's license or a social security card, and no copy of their birth certificates which are necessary to obtain their state ID required for job applications, to establish eligibility for public benefits, or to rent an apartment. There's this huge emphasis being put on bettering our reentry of ex-offenders back into the community, but still discharge planning and other transitional supports remain unavailable to many inmates facing release from prison. And not many places offer assistance to secure stable housing prior to release.

It is instructive once again, to note the model of case management used by the city of New York to manage its HOPWA clients. Centrally located in the city's HIV/AIDS Services Administration (HASA), active and targeted case management coordinates services for HOPWA clients across the city's agencies. Any case management that clients receive from individual agencies is in addition to HASA case management⁵. So successful and cost-effective has this centralized model of comprehensive case management been in managing the epidemic, that the city of New York this year extended these services to all people living with HIV, even when they have not been diagnosed with AIDS. Philadelphia would be well served to integrate this model

⁵ Isett, K. R, Sparer, M., Glied, S. A. M., Brown, L. D. (2011). Aligning ideologies and institutions: Reorganization in the HIV/AIDS Services Administration of New York City. *Public Administration Review*, March/April, 243-252.

into its own case management apparatus, thus ensuring a uniform level of case management coverage that will counteract any weaknesses in services at the level of the agency.

Table 3 summarizes the recommendations emerging out of the results of this study. The results of this assessment indicate that HOPWA is crucial to PLWA living longer and healthier lives. With some reconfiguration of the program it will continue to be a frontline intervention for people living with AIDS in the Philadelphia area.

Table 3: Recommendations and Suggestions

Waitlist recommendations

- expand housing slots by demonstrating need
- work with community activists and social movements to preserve the HOPWA program

Challenges to securing and maintaining housing

Economic recommendations

- identify better and more appropriate housing stock for clients with increasing levels of disabilities
- monitor housing conditions and rental rules to prevent predatory and discriminatory practices

Addressing complicated bureaucratic protocols

- centralize and simplify protocol
- make housing a central part of the cascade of care, utilizing ACA guidelines

Addressing substance use challenges

- implement housing first in all HOPWA housing

Addressing case management challenges

- centralize HOPWA case management, locating it in a city office
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