The Chicago Area AIDS Housing Plan *2008–2012*

A Place to Call Home

Section IV Consumer Input

AIDS Foundation
OF CHICAGO

RxChicago
Department of Public Health
"Providing the Prescription for a Healthy City"

A Place to Call Home

"For persons battling HIV/AIDS, a stable place to live may decide the length and quality of life itself. It is nearly impossible for a person on the streets to engage in a needed continuous AIDS treatment regimen when the very basic question of where that person will rest his or her head when darkness comes in just a few hours is unresolved. When danger lurks on the streets, when cold numbs the limbs, when tiredness overwhelms the mind, when fear breaks the spirit, a place to call home would make all the difference."

Henry Cisneros
U.S. Secretary of the Department of Housing and Urban Development
1993 - 1997

Quote from: "AIDS and Behavior"
Special Edition on AIDS Housing Research – November 2007

A Place to Call Home

CONSUMER INPUT

Section IV

This section describes the input solicited and received from consumers of AIDS housing services, which helped shape the Plan and its recommendations. Consumer input was especially important for questions regarding consumer needs and preferences.

The Chicago Department of Public Health (CDPH), the AIDS Foundation of Chicago (AFC), and other stakeholders collaborated to prepare the Chicago Area AIDS Housing Plan, 2008–2012: *A Place to Call Home*. The Plan describes critical issues, recommendations, strategies, and benchmarks to address the housing needs of people with HIV/AIDS in the context of the region's affordable housing crisis.

Upon its release in 2001, the Five-Year Chicago Area AIDS Housing Plan noted the importance of considering consumer preferences in determining the types of housing resources needed to address unmet need. Consumer preferences identified in the 2001-2006 Plan included greater options for scattered-site independent housing with supportive services available offsite, and an increase in harm-reduction housing for people living with HIV/AIDS. Since that time, AIDS housing providers in the Chicago region have made great strides in addressing these preferences, significantly increasing the amount and availability of scattered-site housing and harm-reduction units.

In preparing *A Place to Call Home*, AIDS Foundation of Chicago (AFC)—in collaboration with the SPC Housing Committee and AIDS Housing Advisory Council—conducted four consumer focus groups to gain feedback on key issues related to AIDS housing. These focus groups were developed and facilitated by an external consultant. As requested by the committees, sites were chosen with the aim of fostering representation from the major areas of the Chicago metropolitan region: central city/downtown, hosted by AFC; South Side, hosted by Heartland Alliance; West Side, hosted by Pilsen Little Village; and North Side, hosted by Test Positive Aware Network (TPAN). Participants were recruited by members of the AIDS Housing Advisory Council (AHAC) and through AFC's coordinated system of housing advocates. Participants received notice of the focus groups via flyers from their housing advocates, case managers, or by word of mouth. As an incentive for participation, participants were offered dinner and $25 honorarium.

In total, 39 individuals participated in the focus groups. Of these participants, 12 identified as female, 26 as male, and one as transgender; 26 identified as Black (including African American, African Caribbean, and others), 1 as Asian or Pacific Islander, 4 as Hispanic (including Latino or Latina), 2 as multiracial, 5 as White, Non-Hispanic, and 1 as Other. The largest represented age bracket was 41–50 years of age. Monthly income levels ranged from $0 to $1,820, with $1,820 being a significant outlier. Additionally, 33 were receiving case-management services, 4 were not, and 2 were unsure if they were receiving such services; 29 were currently working with housing advocates, 6 were not, and 4 were unsure.

Download the entire report, entitled the *Chicago Area AIDS Housing Plan, 2008-2012: A Place to Call Home*, at the AIDS Foundation of Chicago's website, aidschicago.org.

Each focus group opened with an opportunity for participants to share their perceptions of the ideal landlord. Participants were then asked to discuss issues facing AIDS housing in the Chicago area, including preferred types of AIDS housing, the need for supportive housing, and funding choices.

PART I: THE IDEAL LANDLORD

Participants were asked to share what type of AIDS housing they use, if any; how they would define the ideal landlord; and what they would change about AIDS housing in Chicago. Participants used a variety of AIDS housing and services including housing advocacy, rental assistance, supportive housing and services (both scattered-site and project-based), transitional housing, and shelters. Some participants were not using any AIDS housing, either by choice or lack of availability, but many were still seeking assistance.

When asked their opinions about an ideal landlord, responses included:

- a landlord who offers an affordable rent that is within the tenant's financial means;
- someone who keeps the building safe and secure;
- someone who relates with tenants and strives to reach common ground;
- someone who is respectful and considerate—not a source of stress—and who does not get into the tenant's business.

The ideal landlord is professional and respects a tenant's right to confidentiality, especially if the tenant's HIV status is known. Also, the ideal landlord cares about tenants and not just collecting the rent. He or she is someone who will work with the tenant and cares about the tenant's situation.

> ***Focus group participant:***
>
> *"It should be 50/50 when it comes to tenants and landlords. Landlords have to understand but tenants need to be respectful, too. Both must follow the rules. If you want respect you have to give respect. A landlord must be reliable and deal with individual situations, but in the realm of reality. A landlord should be fair, confidential, and professional—mutual respect. I want a landlord who understands my need for a clean place. When you ask them to fix a leak, they fix it, or anything else that is broken. They do something about traffic of strangers and bugs."*

When asked the one thing they would change about AIDS housing in the Chicago area, responses included:

- having more say in unit location and size;
- increased utility assistance;

- safer scattered-site placements with less gang and drug activity in the buildings and neighborhoods;
- increased resources to house the newly diagnosed;
- increased assistance and support for those looking to transition into their own unsubsidized units.

Others felt that providers of both medical and social services needed increased education and training regarding the availability of AIDS housing programs. Increased confidentiality and discretion were also mentioned. Some participants felt their housing was stigmatized because it was labeled as AIDS housing. Many participants also mentioned the need to remove barriers to housing such as restrictions due to past convictions, drug use, or lack of dual diagnosis or an acute illness.

> ***Focus group participant:***
> *"The only availability for help is if you are dually eligible. You have to have HIV and be a drug addict to get any help. I don't want to lie to get housing. There are a lot of people out there who don't do drugs but can't find affordable housing. If you are clean and sober, you can't get housing. I make a little too much money to get help with rent but it is not enough to live on."*

PART II: PREFERRED AIDS HOUSING TYPES

Participants were asked to review the 2007 Chicago Area AIDS Housing Inventory and supplemental definitions to help guide a discussion on preferred types of AIDS housing. They were then asked to write down some of their thoughts on the advantages and disadvantages of abstinence-based housing and harm-reduction housing.

Feedback on the advantages of abstinence-based housing included:

- living in a drug-free environment;
- learned responsibility through consequences for drug or alcohol use;
- better community health and state of mind;
- better living conditions;
- an overall sense of safety.

Disadvantages of abstinence-based housing included:

- the feeling of being monitored;
- fear of losing housing over drug or alcohol use;
- the feeling of increased stress based on the need to remain abstinent;
- forced sobriety, regardless of an individual's readiness or desire for sobriety.

Feedback on the advantages of harm-reduction housing included:

- support for a gradual shift toward sobriety;
- available shelter/housing regardless of an individual's willingness to maintain a sober lifestyle;
- an option for people who are homeless and using;
- a sense of acceptance;
- exposure to different treatment options.

Disadvantages of harm-reduction housing included:

- possible lack of boundaries or limits for one's actions;
- potential gang and drug activity;
- possible reckless living with no consequences;
- increased legal problems due to drug or alcohol use;
- in some cases, unaddressed drug- and alcohol-use problems.

> ***Focus group participant:***
>
> *"Harm-reduction housing can be tricky. In one way, it offers the individual the opportunity to get off the streets. But in another way, it could promote bad behavior. It could have a negative affect on the community. It's hard. People need the supportive services. Some need them in the building. Some need them in the community. It depends on the person."*

Participants were also asked to write down their thoughts on the advantages and disadvantages of project-based units and scattered-site apartments. Feedback on the advantages of project-based units included:

- the familiarity of living with others who are in similar situations, alleviating feelings of isolation;
- less discrimination in one's environment;
- more conducive to interactions with friendly people;
- a stronger sense of community and commitment to health;
- a chance to improve one's health in a supportive environment.

Disadvantages of project-based units included:

- the potential stigma of being recognized as someone who lives in an AIDS housing unit;
- the building being labeled;
- less freedom to make choices;
- greater chance for peers to feed off each other's negativity and bad behaviors;
- increased depression brought on by the environment.

Some of the advantages of scattered-site apartments included:

- privacy;
- freedom to choose unit and community;
- the chance for better social development in the community;
- a sense of normalcy;
- no constant reminder of one's HIV/AIDS status by the environment;
- a better sense of confidentiality.

The disadvantages of scattered-site apartments included:

- less support in one's immediate environment;
- too much freedom;
- unreliable landlords or building managers;
- lack of quality housing;
- the time it takes to find an appropriate unit;
- not knowing one's neighbors;
- the element of the unknown.

At the beginning of this section of the focus groups, when descriptions of harm-reduction and abstinence-based housing were presented, some focus group participants clearly understood the concepts and were able to participate in this portion of the discussion. Many were less vocal during this portion. Increased consumer education in these concepts, which may significantly influence housing choices, will benefit consumers and increase awareness of the type of resources available to them.

PART III: NEED FOR SUPPORTIVE HOUSING

Participants were given the opportunity to review two stories of individuals seeking AIDS housing. Participants were then asked to define the most important considerations for appropriate AIDS housing placement for each individual. Responses included the individual's medical condition, mental heath, drug or alcohol use, homelessness, immediate needs, and the level of service needed.

In addition to identifying the most important considerations for appropriate AIDS housing placement, participants discussed the need to equip the AIDS housing system to handle the needs of all consumers, and to keep consumers abreast of changes as they occur.

Focus group participants:

"Total wraparound case management is needed. Medical needs should be the number-one consideration. All other issues affecting clients' lives must also be addressed."

"The system and programs are consistently changing. Clients need to be kept updated in whatever program they are in. Clients have to be willing to learn and educate themselves. Please keep clients informed of changes—the system is constantly changing."

PART IV: FUNDING CHOICES

Participants were asked to review a funding scenario in which they were charged with distributing an additional $2-million award to the Chicago-area AIDS housing continuum. Participants were asked to work together to make a decision with the following consideration in mind: all $2 million had to be allocated to either project-based or scattered-site units.

Participants discussed the funding scenario and posed insightful questions to each other in an effort to determine the appropriate distribution. Those who supported allocating the $2 million toward project-based units argued that the funding would go further, and that the city would be able to get more units out of the award. They also argued that project-based housing offers more support and structure to the individual and has a built-in sense of community. Those who supported allocating the funding to scattered-site housing argued that increased funding was needed to accommodate the growing number of people entering scattered-site units. They argued that scattered-site housing often fosters independence and motivates the individual. By increasing the number of scattered-site units, they would be fostering increased independence among people living with HIV/AIDS.

Focus group participant:

"I can't make a decision for one or the other. I mean, it's like you're asking me to decide who gets housing and who doesn't. Everyone needs housing. No one should not get funding."

A significant number of participants refused to allocate all the funding to one type of housing. They maintained that each type of housing has its benefits, and that to allocate all the funding to one type would not be fair. A final tally of all votes from focus group participants was equally divided: one-third for project-based units; one-third for scattered-site units; and one-third for dividing the $2 million between both types of housing.