Consumer Input: Focus Group Summaries

Focus group meetings of people living with HIV/AIDS were a vital component of this needs assessment process. Because not everyone was interested in or able to complete a survey, focus groups offered another means for consumers to communicate their needs, preferences, and opinions about issues affecting the HIV/AIDS housing system. The focus groups provided a safe setting in which consumers could discuss their housing histories and current issues.

Four focus group meetings were held during August and September 2000. Focus group meetings were hosted by agencies represented on the Housing Committee of the Service Provider’s Council. The host agencies were selected based on the populations that they serve, including the homeless and formerly homeless (Chicago Connections/Rafael Center), Hispanic, Latino/as (CALOR), women (Chicago Women’s AIDS Project), and people recently released from incarceration (the CORE Center). These populations were identified by the Housing and Steering Committees as target focus group participants based on their status as emerging HIV-impacted groups.

The four host agencies invited people living with HIV/AIDS to attend, arranged a meeting space, and provided refreshments; AIDS Housing of Washington staff facilitated the discussions and AIDS Foundation of Chicago staff attended. Focus group participants were paid $35 each for a one-hour meeting. Translation services were available for the focus group meeting at CALOR.

Summaries of the four focus group meeting discussions follow.

Chicago Connections/Rafael Center

This focus group meeting was held on August 8, 2000, and included 10 participants—2 women, 8 men, 5 African American/Blacks, 2 Hispanic/Latino/as, and 3 White/Caucasians. Participants were asked to discuss their current housing situation, their housing histories, and housing-related issues.

Focus group participants indicated that they had experienced significant problems finding safe, appropriate, available, and decent housing units, as rents are increasing and affordable units are becoming scarce.

Many of the participants indicated that they work, but some others indicated that they did not feel healthy enough to work and that their SSI payments did not provide enough income to cover their expenses.

Many participants noted that the housing that they currently lived in was substandard, including participants who lived in units with rats, bugs, or no air conditioning. It was also noted that affordable units are located in bad neighborhoods populated with “bad neighbors.”
Participants felt that there were barriers limiting their ability to find a stable housing situation, including the expenses and logistics involved in moving; landlords that conduct credit, criminal history, and rental history checks; and landlords that conduct drug screening. Participants felt that, in particular, it was difficult for people with criminal histories and substance use problems to find a place to live.

Participants indicated they had difficulty accessing housing-related assistance and that all rental subsidy programs, including the HOPWA and Section 8 programs, have very long waiting lists. Participants felt that they need to have an income and to be very ill to get housing assistance and other benefits, yet their health either did not allow them to work at all or limited their ability to work more than part-time.

Participants also said that they did not know enough about the housing options available in the EMA. Many participants indicated that in order to get housing assistance they had to call every day to remain on housing lists, complete multiple forms, and live on the same side of town where the housing program was located. In addition, participants indicated that their case managers had referred them to buildings that are home to drug dealers, despite knowledge of their substance use problems.

One participant indicated that agencies notify residents of changes in housing programs via mail, which is not a reliable way to convey important information. For example, a low-literacy consumer with Section 8 received what he thought was an eviction notice and as a result was homeless for three months. Another participant, living in CHA senior housing, was told that he would have to move out because he was younger than 60, even though CHA had placed him there the year prior. Another participant lost housing due to a landlord terminating his contract with Rafael Center (the landlord no longer accepts Shelter Plus Care).

Participants said that finding a landlord who will accept them and saving enough money for moving, move-in costs, deposits, etc. made it very difficult to leave substandard or otherwise inadequate housing. In addition, one participant noted that even when he had a stable housing situation, he did not feel stable—he worried about what would happen when he needed to look again. Another participant noted that moving is stressful, and she gets sick very easily.

Many participants indicated that they wanted case managers to work with them on a housing plan so that they could feel more in control of their future.

Participants indicated that they felt the AIDS housing system needed more permanent independent housing and treatment programs and fewer group homes or AIDS-dedicated buildings.

**CALOR**

*This focus group meeting was held on September 20, 2000, and included seven participants — four women, three men, all seven Hispanic/Latino/as. Each participant in this focus group lived on the West Side of Chicago. Each of the women lived with families, including children, parents, and/or grandparents. AIDS Foundation of Chicago staff provided translation services for the three to four*
people that were monolingual. Participants were asked to discuss their current housing situation, their housing histories, and housing-related issues.

Each focus group participant lived in rented housing, mostly one-bedroom apartments, despite their families’ size (four participants had families of four or more). Participants noted that rents are increasing, causing people to pay more for small, substandard places.

One participant indicated that he was receiving housing assistance through the HOPWA program but his subsidy amount had been decreased and he will receive assistance for only 2 more months. Some participants were on waiting lists for housing programs, including for Casa Contreras (new CALOR facility), Section 8, and HOPWA.

One participant’s daughter applied for Section 8, but because the participant’s income exceeds the maximum amount to qualify for the program, and she does not want to leave her job, she is thinking about not moving with her daughter. However, they do not want to separate because they depend on each other for support, income, childcare, etc. Another participant’s family had to move out of their substandard housing unit because their landlord did not want the five-person family living in a studio apartment. The $325 per month unit was all the family could afford.

Participants did not know about many of the housing programs available in the EMA, including the HOPWA rental program, and said that the focus group was actually very educational for them.

Participants were asked if they had the means, would they move away from their current neighborhood to an area where they could pay less for a better place. Some participants who have lived in their neighborhood for their entire life said that they would not move. Other participants, all of whom were monolingual, said they would welcome an opportunity to relocate and pay less for a better place.

Three of the participants were working at the time of the meeting, two of them full-time. Many participants felt that their health problems limited their ability to work. All of the participants seemed to be documented and were receiving benefits.

Participants said that their financial problems were rooted not just in HIV, but in discrimination by employers, landlords, and neighbors based on HIV, race, language, family size, and children’s age (teenagers). Many participants had confidentiality concerns and had not told anyone of their illness. Participants indicated that they often lie about their illness, such as telling people they have cancer, or don’t allow family and friends to visit them if they are placed in an AIDS section of the hospital.

Participants were asked how they would feel about living in an HIV-specific facility. Every participant indicated that they did not like the idea due to confidentiality concerns. One participant said it was hard enough to have to lie about where they were going when they went to hospital, CALOR, etc. This participant noted, “I go days without thinking about HIV, and I couldn’t do that at an AIDS place.” Others felt that an HIV facility could maintain confidentiality, but still others in the group said the word about the building was a home for people living with AIDS would eventually get out.
Participants said that, despite their unwillingness to live in an AIDS-specific building, support from other persons living with AIDS is very important. One participant noted that support groups for people living with HIV/AIDS are like fiestas because you never want to miss them.
Chicago Women’s AIDS Project

This focus group meeting was held on September 20, 2000, and included six participants, all African American/Black women. Participants were asked to discuss their current housing situation, their housing histories, and housing-related issues.

Participants lived in a variety of housing situations, including a house in the southern suburbs, Vision House, a two-bedroom apartment, with children, and with parents. Others had lived in AIDS housing programs in the past, including Chicago House. One participant was an immigrant mother who was homeless. Three participants had been homeless in the past.

Participants were asked how they would feel about living in an HIV-specific facility. Some participants said that they were not interested in living in an AIDS housing program because they felt it would stigmatize them. One participant indicated that many AIDS housing programs don’t accept kids, and that subsidized housing for families was needed. One participant said that AFC should build a big building for people living with HIV/AIDS, without staff but with security. Some participants would rather have a non-HIV rent subsidy than live in an HIV-housing program because HIV subsidies only pay a percentage of the rent and provide limited privacy. One participant did acknowledge that there is a give and take situation between having privacy and being part of a community.

One participant said it is demeaning to have to go somewhere for help if you want to take care of yourself. Another said that to apply for programs, you need to do a ton of paperwork and are asked the same questions 50 times.

One participant indicated she had to make choices between paying the phone or the light bill, and all participants admitted to juggling their bills, paying one month and not the next. Another participant indicated that they paid nearly all of their SSI income on rent.

When asked about what their barriers to housing had been, participants indicated that they had faced barriers due to poor credit, health status, lack of availability of housing programs to all people, and discrimination by landlords based on source of subsidy.

One participant noted that if you get a Section 8 voucher, you have only 120 days to find a housing unit, which does not give them enough time to get an inspection.

Participants said that the Housing Advocate Program works better on the North Side than on the South Side, because the concern and money is on the North Side.

Participants were asked to suggest improvements to the HIV/AIDS housing system. Participants felt that relationships with landlords needed to be developed throughout the city. Other participants suggested eliminating the difference between HIV and AIDS in eligibility decisions.
The CORE Center

This focus group meeting was held on September 20, 2000, and included four participants—three men and one woman, all African American/Black. Participants were asked to discuss their current housing situation, their housing histories, and housing-related issues.

Participants were asked where they live and whether the situation was working for them.

J. I prefer a 2-bedroom house because I have a child and 3 grandchildren; but I’m in a safe and clean apartment building, in a one-bedroom unit, where neighbors don’t know about you, which is preferable. The apartment is subsidized by Community Supportive Living Systems (CSLS).

C. I’m from Texas and was in jail for over 10 years; now I live in subsidized housing (CSLS). I have kids and grandkids here and like the privacy and independence I have. I pay 30 percent of income for rent. I like being mixed in with regular community. It doesn’t seem like there’s a lot of AIDS services for homeless people.

J. I agree. I was homeless and couldn’t find any AIDS-specific services.

C. My only income is SSI, and I’m worried they will pull it. I have medical problems but still get letters from SSA asking when I can go back to work. I tried to work a while back but got sick. I’m also worried about medications. I’m not living, I’m surviving. I’m not contributing to my family…I’m in limbo…If I make one wrong turn, I’ll end up in the ditch. If SSI is cut off, then I’ll lose my apartment.

E. My situation is similar to J. and C. (also living in a CSLS unit). I used to be on my own and have a problem depending on someone else. I’m concerned about how my living situation is not permanent. I could move, but my problem is affordability. Maybe an SRO would be possible, but if you need to refrigerate meals, then what? I’m scared. I have health issues—I’d live on the street and take care of myself if I had to. I don’t think it’s right when I see healthy people getting by, but having AIDS, people think bad of you, like you’re on drugs or something. I don’t feel comfortable because I’m not on my own.

Participants had many comments about not liking their dependent situation.

J. Forget social services, period. I want to be on my own. When I got sicker, I moved to New Orleans because it was cheaper, but then moved back home when I got too sick.

C. As much as I need the system, I hate it.

E. People in public housing are treated with more respect than us.

Participants were asked where they lived prior to CSLS.

C. It didn’t take me long to find CSLS once I moved from Texas but if I had gone by the book, I’d still be waiting.

E. I was in the hospital for 18 months and once I got better, I went home with my mother. I was persistent in finding housing so it didn’t take too long to get my subsidized apartment.

N. I was incarcerated for 15 months prior and was released a month ago. I went to New Beginnings and there was too much stress there and I didn’t like it. At CSLS, I feel isolated from family and have major transportation issues. I’m comfortable with my case manager.
and my health isn’t great but OK. I look at my situation as temporary because I want to be on my own; however I realize if I get sicker, I’ll need something else.

If you didn’t have CSLS, would you have housing?

J. No.
N. No.
E. Yes. I chose CSLS because they don’t push religion.
N. That’s what they did at New Beginnings! When I first heard I had AIDS, I though it was a death sentence. But it gave me a wake-up call. I started looking for opportunities. Without CSLS, doors would be closed in my face.
C. I would have found housing. I’ve got my family. I’m worried about the country—the Republican party, Congress. With Bush, I see Armageddon.
N. When I was in jail, a brother told me how to take my meds and about programs. I’m from the West Side, and I didn’t know about anything. It’s like a secret.
C. That’s the problem with the Black community. They don’t want to talk about it. I had to go to the Whites on the North Side. I had to educate my case manager. She would write down the information. I case managed her!
N. When I found out, I didn’t want to hear it. Nobody wants to hear it or talk about it.
E. Yeah, others act like they’re sick.
C. My biggest thing is what’s going to happen next? Nobody’s sitting with me, planning the next steps.
E. I ask for it, but they will not do it. I don’t know why.
N. I’m not prepared. I’ll be homeless. With a felony, if you can’t get Section 8, where are you going to go?