

## Chapter 16

### Housing for Women with AIDS

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AIDS in the U.S. has been stereotyped as a "gay man's disease." Despite the best efforts of many people, American society as a whole still is not adequately prepared to respond to the housing needs of women with AIDS. In fact, the provision of appropriate housing facilities for the AIDS patients in general, and for women with AIDS (WWA) in particular, has long been ignored. The purposes of this study are to provide evidence to support the hypothesis that WWA have housing needs that are different from those of men with AIDS (MWA), and to suggest means for designing housing facilities for WWA. Ten current AIDS housing facilities across the U.S. are analyzed for such purposes.

Housing needs for WWA do not seem to present any major problems at this point. According to the Center for Disease Control, in 1991, women in the United States who were tested HIV-positive made up 9.8% of the total AIDS population in this country. The relatively small number of WWA at this point might well be the reason why most residential care facilities in the U.S. have been developed primarily for single men. However, some researchers believe that women constitute the fastest growing group among people with AIDS (Shayne and Kaplan, 1991, p. 21). The increasing seriousness of AIDS for women is abundantly illustrated by the following statistics. In New York City, AIDS was the leading cause of death for women between 25 to 34 in 1987 (Koonin *et al.*, 1989, p. 1306). In the U.S., the number of cases of AIDS diagnosed in women of color 18 to 44 years old increased 29% from 1988 to 1989, as compared to an increase of 18% in men in the same age group (Kent, 1991, p. 1442). Furthermore, AIDS was one of the five leading causes of death among women in 1990 (Chu *et al.*, 1990, pp. 225-229). Therefore, it seems reasonable to expect that housing needs for WWA will soon become critical and even unmanageable.

In developing appropriate housing facilities for WWA, it would be beneficial to understand the nature of care for AIDS patients. A number of problems can be readily identified regarding the provision of care (Cameron, 1992, pp. 9-14). The first problem relates to the fact that many current and former IV drug users who have AIDS are often difficult to manage medically. They frequently miss medical appointments, do not always take medication as prescribed, and fail to follow through with social service appointments for government benefits. It is difficult to keep these people stable in their homes and therefore they present a tremendous challenge to health care providers.

The second problem is the objection of communities to AIDS facilities. Many people are still afraid of AIDS patients. Indeed, the "Not In My Back Yard" mentality is widespread, and people in general react negatively when housing for AIDS patients is proposed in their neighborhoods. A specific concern is that this type of residential care facility may decrease the value of their property. Also, some communities believe that crime, noise, and traffic in the neighborhood will increase significantly.

Another problem regarding the provision of care for AIDS patients involves its cost. The reliability and consistency of information about the costs of treatment of AIDS patients is limited. For example, on the average, hospital costs per day in New York City in 1987 were \$500. Intensive care or care for a patient with AIDS can drive the costs to \$1,500 (Smith, 1987, p. 28). It has been estimated that the costs of health care for an AIDS patient from diagnosis to death are about \$50,000 (Bartlett, 1987, p. 3). On the other hand, researchers at New England Deaconess Hospital in 1986 suggested that the cost for hospital care alone is around \$147,000 per patient. The prevailing view regarding AIDS health care costs is that "nobody knows what private insurers are paying," because these companies do not always disclose what they are paying for hospital care (Brunetta, 1988, p. 7). The few estimates available do not include ancillary or community-based home care services. Also, these figures are just for inpatient medical care and do not reflect the estimated cost of outpatient visits and prescription drugs that almost all AIDS patients require.

### **Barriers in Housing Women with AIDS**

A number of problems are readily identifiable regarding housing WWA. A major problem is that many of these women are incapable of taking proper care of themselves. Many of these women are drug users and often have severed their ties with their families. Furthermore, a disproportionately higher number of WWA are from Black and Hispanic families. In 1991, Black and Hispanic women made up a disproportionately high percentage of WWA, accounting for 52.4% and 20.4%, respectively (HIV/AIDS Surveillance Report, 1991). However, according to recent U.S. population statistics, Black women accounted for only approximately 14.7% of the U.S. female population, while Hispanic women were only 7% (Shayne and Kaplan, 1991, p. 22). Also, many WWA are of childbearing age, many are single heads of their households or families with children,

many are poor and some are engaged in prostitution (Shayne and Kaplan, 1991).

At least three groups of characteristics set WWA apart from their male counterparts. The differences might help to explain why WWA have housing needs different from those of male AIDS patients. These are biological, socioeconomic, and epidemiological characteristics. First, according to one study, between 80% of the AIDS cases reported among adult women have been diagnosed among women of reproductive age, 15 to 44 years old (Koonin *et al.*, 1989, p. 1306), and obviously only women can bear children.

Second, as mentioned earlier, a disproportionately high number of women with AIDS are poor and are ethnic minorities. According to Shayne and Kaplan, about 73% of mothers with children who have AIDS are recipients of public assistance. The few that were employed were earning an average annual income of about \$10,000 (no specific dates were provided for these statistics in the study but the implication was that these statistics were prior to 1987) (Shayne and Kaplan, 1991, p. 29). Although these characteristics may not distinguish female from male AIDS patients, they are associated with such distinctions. WWA are often subject to abandonment and discrimination by friends and family (Shayne and Kaplan, 1991, p. 28), and a higher proportion of women contracted the AIDS virus through intravenous drug use than their male counterparts. Between August, 1990, and July, 1991, 48% of WWA had contracted the disease as the result of IV drug use, in contrast to only 21% of the MWA (HIV/AIDS Surveillance Report, 1991).

Third, a major epidemiological characteristic that sets WWA apart from their male counterparts is that women function as the receptacle of the spread of AIDS. By citing statistics from the Center for Disease Control and several other studies, Shayne and Kaplan point out that about 30% of WWA have been infected through heterosexual sex, in contrast to only 2% of male AIDS patients. This is probably because there are many more men infected with HIV than women (Shayne and Kaplan, 1991, p. 25). Therefore women are more likely to encounter an infected man than the reverse. Another epidemiological characteristic is that WWA can pass the virus on to unborn children. Many HIV-infected women often remain undiagnosed until the onset of AIDS or until a prenatally infected child becomes ill (Kent, 1991, p. 1442). In fact, women infected with the HIV have been the major source of infection of infants with

AIDS (Shayne and Kaplan, 1991, p. 28). Finally, women with AIDS typically are sicker than their male counterparts, and as a result, WWA do not live as long as MWA (Bakeman *et al.*, 1986; Shaw, 1987). In fact, the average life span for WWA is seven months; for MWA it is two years (Kent, 1991, p. 1442).

## Methodology

A list of housing services for women with AIDS has been obtained from the National AIDS clearinghouse through the U.S. Department of Health and Human Services. It contains information about services offered to persons with AIDS in over 100 facilities throughout the United States. Ten of these residential care facilities were identified for this study, chosen as providing long-term care for WWA, in operation for over 18 months, and offering comprehensive services.

To obtain information regarding WWA from these facilities, a questionnaire was developed and sent to the selected AIDS residential care facilities. Telephone interviews with the administrators of these facilities would be conducted several days later. The questions were designed to obtain information regarding the age distribution, ethnic mix, and length of stay of the patients, the building design, type of medical facilities, nature of over-night accommodation for family members and "significant others,"<sup>1</sup> type of social and medical services offered, reasons for patients' stay in facility, and differences in caring for women with AIDS and men with AIDS. We report here on two of the ten facilities, Bailey House in New York City and Shanti Project in San Francisco.

## Case Study Analysis

### Bailey House, New York City

According to the documents provided by AIDS Resource Center, Inc., Bailey House opened in December, 1986, to provide supportive housing for approximately 44 homeless persons with AIDS (PWA). It is operated by AIDS Resource Center Inc., and is located in Greenwich Village, New York City. The geographic area served by Bailey House includes the five NYC boroughs. Bailey House is not a medical care facility, nursing home, hospice, nor a care giver of the last resort. It is a supportive residence for persons with AIDS. It provides referrals for medical, mental health, and substance abuse care. Also, Bailey House provides for its residents medical monitoring, counsels residents

about issues related to having AIDS, works with families, provides recreation, and offers pastoral care and housekeeping services.

Every resident has his or her own room, private bath, television, telephone, and small refrigerator. Three meals a day are served in the dining room, and snacks are available between meals. Residents are allowed to come and go as they wish, and are permitted to receive guests. Each bedroom has a lock, and residents are encouraged to decorate and personalize their rooms. Overnight guests for both women and men are allowed at Bailey House. Children may stay overnight with their parents, with a limit of two per parent per night. All visitors must pay for their meals. However, no more than four children are allowed in the building on any one night. Each child may visit up to two nights each week. Cots are placed in a resident's room for overnight guests.

All Bailey House residents are referred to the facility by the Case Management Unit of the city's Division of AIDS Services (DAS). Most are referred to DAS by hospital discharge units while others may come through such other channels as the YMCA and YWCA. For admission to Bailey House, applicants must be diagnosed with AIDS. Also, they must be homeless, eligible for public assistance and Social Security Insurance or disability, and be ambulatory.

Bailey House's operations are primarily funded by New York City, which receives about 50% reimbursement from the state Department of Social Services. Other funding sources include the federal Ryan White Act, the residents' entitlement checks, the state Division of Substance Abuse, and private fund-raising activities. Each resident of Bailey House is required to pay \$364 per month for rent, food, and care.

When Bailey House was first opened, a few residents came from mainstream backgrounds, such as gay artists or waiters, who became impoverished once they became sick. The majority, however, have lived on the streets or in unstable environments for a number of years. Many of the women residents have children. Fourteen percent of the Bailey House resident AIDS patients since 1986 have been female. Of the female population, 65% has been Black, 19% Hispanic, and 15% White. Furthermore, most of the women have been substance users (i.e., intravenous drug users) and some have been the sexual partners of men at risk. At the time the questionnaire was administered (March 31, 1992), 49 AIDS



patients resided at Bailey House, including four women (two Hispanic and two Black). All four females were over 30 but had not reached their fortieth birthdays.

The major reasons for the care of WWA in Bailey House are that many of its women residents have medical, mental health, economic, prostitution, and substance abuse problems that preceded their diagnosis with AIDS. As for the length of stay for AIDS patients, Bailey House does not keep separate statistics for men and women residents. In general, residents have lived at Bailey House from eleven days to more than two and one-half years as of March, 1992. Ten of the residents have lived there for more than two years. Twelve residents died within their first month at Bailey House. Currently, the WWA and MWA at Bailey House have been there from 3 to 9 months and from 4 to 36 months, respectively. Many residents chose Bailey House because its social services and housing are affordable and comprehensive. Other male residents are street people who do not have any housing options other than Bailey House.

Eighty-six percent of the Bailey House resident AIDS patients since 1986 have been male. Of the male population, 55% have been Black, 25% Hispanic, and 20% White. The male population has been evenly divided between one-time intravenous drug users and gay men, with about 5% overlap of the two. At the time of our study, there were 24 male residents between 30 and 39 years of age; 15 between 40 and 49 years of age; and 6 over 49. There are 16 Black, 14 Hispanic, and 15 White residents.

Responding to the important questions of whether caring for MWA differs from caring for WWA and whether WWA actually have different housing needs, the Bailey House administration points out that gay men may have different housing needs from those of their female counterparts, especially if WWA were heterosexual or IV drug users. Gay men may simply want to associate with other gay men. On the other hand, the administration also points out that WWA might have housing needs different from those of their male counterparts.

As previously indicated, women are usually sicker than their male counterparts. This would lead to a need for more medical services. If more medical equipment is required, more storage and bedroom space would be needed to house the additional equipment. Women with AIDS who have children or who are pregnant may require additional living quarters for themselves and their children. Women with AIDS often feel uncomfort-

able living with homosexual men with AIDS. House staff suggest that because the majority of the residents are gay males, it may be difficult for a woman resident to personalize the space she shares with other residents.

#### **Shanti Project, San Francisco**

Prior to caring for persons with AIDS, the Shanti Project was a facility for seriously ill patients. In 1984, the Shanti Project started offering residential care solely to persons with AIDS. Currently, Shanti Project leases 17 apartments, two 24-hour hospice care facilities, and one single-family residence. These facilities are located throughout the City and County of San Francisco. Among them is a single-family residence specifically for WWA, opened in September, 1990. It is a two-story building located in Noe Valley. The geographic area served by Shanti Project includes the entire Bay area.

Similar to Bailey House, the Shanti Project's congregate living program is a supportive residence for persons with AIDS, and does not provide medical care or nursing care services. Case management and visiting nurse services are provided on a contract-out basis. Each flat is assigned a case manager. Residents can receive referrals for medical, mental health, and substance abuse care. In the two 24-hour care facilities, medical monitoring by a nurse is also provided on the premises. Residents in all the Project facilities are counseled on issues related to AIDS.

In the single-family residence every woman has her own room but shares such other facilities as bathroom, television, telephone, and refrigerator. Residents buy their own food. Meals can be shared or prepared separately by residents. Also, residents are allowed to come and go as they wish, and are permitted to entertain guests. WWA in the single-family residence are encouraged to decorate and personalize their bedrooms. Overnight guests of WWA are allowed at the Noe Valley residence. "Significant others" may stay overnight with their partners, with a limit of five overnight stays per month. Children cannot stay overnight in the building, but are not limited in the number of visits. Overnight guests must sleep in a resident's room. All visitors must pay for their meals.

Potential residents for Shanti Project are identified through city and county social service agencies. Some are referred by hospital discharge units while others may come through other channels. For example, WWA living in a family setting no longer comfortable may be encouraged by the social worker to seek placement in

Shanti Project. For admission to Shanti Project, applicants must be HIV-positive or diagnosed with AIDS. Also, they must be eligible for public assistance and Social Security Insurance or disability payments, and be ambulatory. Ellen Hardtke, Residence Program Director, notes that potential residents must also be cooperating in their care for medical, mental health, and substance abuse needs at the time of admission. Furthermore, residents must be amenable to a culturally diverse setting.

Shanti Project's operation is primarily funded by the City and County of San Francisco, which receives about 40% reimbursement and donations. Other funding sources include the federal Ryan White Act, the residents' entitlement checks, and private fund-raising activities. Each resident is charged 25% of her or his income for rent and other services.

According to the information provided by the Shanti Project administration, since 1984, the Project has served over 10,000 AIDS patients. Among them, less than 5% of the resident AIDS patients has been female. Of the female population, 70% has been Black, 15% Hispanic, 5% White, and less than 1% Asian/Pacific Islander. Some of the women have been substance users, and some have been the sexual partners of men at risk. At the time the questionnaire was administered (April 1, 1992), three WWA lived at the single-family house in Noe Valley: one Black, one White, and one Asian/Pacific Islander. The women came from middle-class backgrounds: they became poor once they became sick. None of the women has children. Two are under 30 and one is over 40.

In general, WWA have lived at the Noe Valley residence from six months to more than two years, averaging one year. On the other hand, MWA in Shanti Project stay an average of 14 months. The longest stay for MWA is approximately three years and the shortest, one month. A number of male residents died during their first month at Shanti Project's congregate living program. The length of stay has been increasing for both men and women because of proactive medical treatments, early HIV testing, and outreach counseling.

Like the WWA in New York's Bailey House, many women residents in Shanti have medical, mental health, economic, and substance abuse problems that preceded their diagnosis with AIDS. The Shanti administration points out that, because there are considerably fewer women with AIDS, most facilities in the U.S., and in San Francisco, are for MWA; only a few are for both

WWA and MWA. There is a significant lack of affordable housing in the San Francisco Bay Area. Therefore WWA who are unemployed have few housing options. Additionally, these women often lack emotional and financial support from family members and, as a result, do not have family members or friends willing to provide housing for them.

Among the MWA in Shanti, a number have medical, mental health, economic, and substance abuse problems that preceded their diagnosis with AIDS. Although there are considerably more residential care facilities for MWA, only a few of them have the experience and level of social services provided by Shanti Project's congregate living program to persons with AIDS. Like the WWA, many of these men also lack emotional and financial support from family members and "significant others." Thus MWA do not have family or friends willing or able to provide the level of support that would be necessary to keep them at home.

The same perception also exists among the Shanti Project administration that gay men might have housing needs different from those of their female counterparts, especially if the women are heterosexual and/or IV drug users. Furthermore, staff at the Noe Valley residence believe that WWA have housing needs different from those of their male counterparts. Not surprisingly, though, the same reasons are cited by the Noe Valley staff. These include the fact that WWA are usually sicker than MWA and, therefore, need more medical services and more space; WWA often have children or are pregnant; and that WWA might not feel comfortable with homosexual men with AIDS.

## Recommendations

The essential questions posed by this study are: Do women with AIDS have housing needs that differ from those of their male counterparts? And if so, how can we provide housing facilities that are more conducive to caring for them? It would be inappropriate to provide a definitive answer to these questions on the basis of only two of the ten selected facilities, i.e., results at this writing are too preliminary to justify conclusions. However, some of the differences between WWA and MWA identified in this study are established biological and medical facts. Furthermore, we have found that, with the majority of WWA being heterosexual, they in general feel uncomfortable and some have even expressed a concern for safety (for their children, relatives, and themselves) in being housed in the same facility with mostly gay men with AIDS. Similar perceptions

regarding housing needs for WWA have been expressed by the personnel of Bailey House and Shanti Project, two of the largest AIDS care organizations in the U.S. The hypothesis that WWA have different housing needs thus seems reasonable at this point.

We recommend a range of housing options for WWA and their families. These housing options, each equipped with different social and medical services, must be able to address the needs of single WWA as well as WWA with families. We advocate a continuum of housing options for WWA in different stages of the illness.

WWA in the early or in non-acute stages of the illness can live relatively independently. As the illness progresses, the women may need housing options with more services that can best be provided in a residential care facility which has a stronger medical component. WWA in the later stages of the illness may need palliative care in the form of in-home or residential hospice care. To meet the housing needs of WWA, two different design options emerged from the information obtained. In one option, a woman would be moved to the facility that could best address her medical, social, and daily living needs. In other words, WWA in different stages of the disease should be cared for in a separate housing and health care facility. As noted earlier, WWA are generally sicker than their male counterparts; thus they may need to reside in a residential care facility located in a one-story building. Because they are much sicker when they seek medical intervention, they may need larger bedrooms to accommodate the medical equipment used to sustain their lives.

In the second housing option, comprehensive health care and social service programs are to be provided within one single facility. In a single residence all WWA's daily needs could be cared for in the same structure. Thus, services would be delivered to WWA and their children regardless of their HIV status. The structure could contain several floors. Every floor could be geared for single WWA or for WWA with families. These residential care facilities could also be divided according to medical status or a combination of the two. All activities would be accommodated on the premises: offices would be provided for the unit for such services as counseling, medical, physical therapy, housekeeping, day care, and legal services. There could be communal areas centrally located throughout the building for recreational space, reading, and an outdoor area. Communal space could be used by any family.

In summary, information from two major AIDS care organizations lends support to the argument that WWA have housing needs different from those of their male counterparts. Two housing options are posed in the study to meet the specific needs. Clearly, a more definitive answer and appropriate housing designs for WWA would require the analysis of more AIDS care facilities.

#### Note

<sup>1</sup> This term is used to describe arrangement between two individuals who are not legally married but as a practice maintain a living arrangement very similar to married couples. In San Francisco and Seattle the arrangement is recognized by law.

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