ABSTRACT  The housing status of persons with HIV/AIDS is a central issue in their care and prognosis. We conducted eight focus groups to explore the housing needs of special populations of persons with HIV/AIDS in New York State; these populations included substance users, ex-offenders, persons with documented histories of homelessness, and rural dwellers/migrant workers. For the focus groups, 52 participants were recruited from the clientele of health and social service agencies. A major theme was the potent effect that housing situations had on participants' health. Participants frequently attributed lowered T-cell counts and increased lethargy to the stress associated with governmental rules and paperwork. Lack of money, inadequacy of entitlements, and high costs of housing were the major barriers to securing stable and appropriate housing. Furthermore, participants experienced housing discrimination based on HIV status and experience with the criminal justice system or drugs.

KEY WORDS  Housing, HIV/AIDS, Health, Discrimination, Health Services.

INTRODUCTION AND OVERVIEW

Adequate housing for persons with human immunodeficiency virus (HIV) disease greatly facilitates access to medical and social support services. Unstable housing situations undermine access to these services because they make it difficult to negotiate bureaucracies, file applications, and keep appointments. This may be why unstable housing and homelessness have been associated with higher rates of health care utilization among persons with HIV/AIDS (acquired immunodeficiency syndrome) (PWHAs). National estimates suggest that as many as one-third to one-half of persons with AIDS are homeless or in imminent danger of becoming so. Previous research about the housing needs of PWHAs in New York has not focused on talking to PWHAs who are most at risk for housing problems to ascertain the impact of these problems on them.

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As part of an evaluation of the housing needs of PWHAs in New York State, we conducted eight focus groups in April and May 1996. The groups were held to understand the housing problems of PWHAs at high risk for difficulties obtaining and maintaining suitable housing. Thus, while the groups were not selected to be an epidemiologic sample, they were chosen to represent populations identified by the New York State AIDS Housing Advisory Committee as having a great need for housing services, but for whom little housing information exists. The groups included substance users, ex-offenders, persons with a documented history of homelessness, and rural dwellers/migrant workers.

The focus groups explored the following topics:

- current housing status and issues associated with seeking housing assistance;
- the relationship among HIV/AIDS, health, and housing;
- housing needs, preferences, and obstacles.

METHODS

Recruitment and Selection of Participants

Recruitment began with a mailing to 400 statewide HIV/AIDS providers identified from the New York State Department of Health AIDS Institute mailing lists and regional HIV/AIDS organizations. The mailing explained the research project and asked agencies to serve as “hosts” from which participants might be recruited. The mailing also included a flyer to be posted or distributed to potential participants. The response was limited; accordingly, a telephone solicitation and/or follow-up call was done on a random basis to agencies located in areas of the state that did not respond to the mailing. Nine host agencies were secured, and participants were recruited for one pilot and eight focus group sessions.

Participants were recruited directly by agency staff or by self-referral to project staff from flyers posted in provider agencies. On being contacted, potential participants were screened to confirm that they were HIV positive and to assemble groups composed of the target populations. The number of participants per session was set at eight; random selection was exercised when a session had more than that number of interested participants. In all, 52 persons participated in eight focus groups, held in April and May 1996. The Appendix outlines how each group was recruited, when and where the groups convened, and characteristics of the participants. The composition of the focus groups included persons who, although self-selected, met the study’s goal of representing the target populations.

The focus groups were conducted under contract with a private nonprofit agency specializing in HIV/AIDS provider training. Two senior social work staff from the agency managed the groups, although only one of the social workers facilitated a group at any given time. At the beginning of each group meeting,