A STUDY OF HOW SUPPORTIVE AIDS HOUSING PROGRAMS IN SELECT U.S. CITIES ARE MEETING THE SPECIAL NEEDS HOUSING CHALLENGE

by

TERRI YVONNE MONTAGUE

B.A. Economics, University of Chicago (1987)

Submitted to the Department of Urban Studies and Planning in Partial Fulfillment of the Requirements for the Degrees of

MASTER OF CITY PLANNING

and

MASTER OF SCIENCE IN REAL ESTATE DEVELOPMENT

at the

MASSACHUSETTS INSTITUTE OF TECHNOLOGY

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ABSTRACT

This analysis addressed two primary questions: To what extent does AIDS housing fit within the traditional special needs housing paradigm? And, is the supportive AIDS housing model advocated by Schnitzer three years ago sufficiently meeting the demands of current practice, especially in light of the changing demographic profile of persons with AIDS (PWAs)? The study examined how Schnitzer’s model compares in practice to the experiences of twelve scattered site and congregate AIDS housing projects in select U.S. cities--Baltimore, Boston, Hartford, New York, San Francisco, and Seattle. It identified emerging implementation and policy challenges for future supportive AIDS housing initiatives.

Based on the experiences of the projects interviewed for this research, AIDS housing providers do not differ from other providers in the sense that they face the same challenges of NIMBYism, integrating housing and services, and managing problem people. Nevertheless, the author concludes that there are some unique characteristics of PWAs that set their housing needs outside of the conventional special needs housing paradigm, such as contagion and transmission risk, and the changing and unpredictable nature of the illness.

The findings from this research challenge the notion that each of Schnitzer’s housing options is applicable to every AIDS subpopulation. In fact, these findings suggest that a separate model for multi-diagnosed PWAs may need to be
developed. This research further revealed that the practice of allowing clients to "die in place" at nearly every level of the housing continuum is overstressing some projects, and is literally transforming the social setting of some others.

The author further concluded that Schnitzer’s planning criteria for meeting the housing needs of PWAs should be revised to include contagious disease protocols, eviction procedures, and a process for addressing morbidity and mortality issues—especially in scattered site and unsupervised congregate living settings. Balancing the rights of PWAs and the rights of their neighbors and fellow tenants, and balancing the interests of different political constituencies poses some difficult paradoxes and challenges for practitioners and policy-makers alike. Nevertheless, the author offers this research in hopes of promoting greater success among current and future supportive AIDS housing initiatives.

Thesis Supervisor: Langley Keyes
Title: Professor
# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>4</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>5</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>6</td>
</tr>
<tr>
<td>Research Context &amp; Question</td>
<td></td>
</tr>
<tr>
<td>Scope of Research</td>
<td></td>
</tr>
<tr>
<td>Methodology</td>
<td></td>
</tr>
<tr>
<td>I. CHAPTER ONE: Background and Nature of the Problem</td>
<td>13</td>
</tr>
<tr>
<td>HIV Infection and the AIDS Disease</td>
<td></td>
</tr>
<tr>
<td>Statistical Information on HIV/AIDS</td>
<td></td>
</tr>
<tr>
<td>Why AIDS Is A Housing Problem</td>
<td></td>
</tr>
<tr>
<td>Magnitude of the Problem</td>
<td></td>
</tr>
<tr>
<td>II. CHAPTER TWO: Literature Review</td>
<td>32</td>
</tr>
<tr>
<td>Synopsis of the Special Needs Housing Concept</td>
<td></td>
</tr>
<tr>
<td>The Debates</td>
<td></td>
</tr>
<tr>
<td>Other Common Problems Encountered</td>
<td></td>
</tr>
<tr>
<td>Schnitzer: An Ideal AIDS Housing Model</td>
<td></td>
</tr>
<tr>
<td>III. CHAPTER THREE: AIDS Housing Implementation</td>
<td>50</td>
</tr>
<tr>
<td>Overview</td>
<td></td>
</tr>
<tr>
<td>What The Literature Predicted</td>
<td></td>
</tr>
<tr>
<td>What The Literature Did Not Address</td>
<td></td>
</tr>
<tr>
<td>Implications for the Models</td>
<td></td>
</tr>
<tr>
<td>IV. CHAPTER FOUR: Conclusions, Policy Implications &amp; Further Question</td>
<td>85</td>
</tr>
<tr>
<td>Synopsis of Research</td>
<td></td>
</tr>
<tr>
<td>Findings</td>
<td></td>
</tr>
<tr>
<td>Conclusions &amp; Recommendations</td>
<td></td>
</tr>
<tr>
<td>Policy Paradoxes and Challenges</td>
<td></td>
</tr>
<tr>
<td>Further Research Questions</td>
<td></td>
</tr>
<tr>
<td>APPENDIX</td>
<td>101</td>
</tr>
<tr>
<td>A. Summary of Classification System for HIV Infection</td>
<td></td>
</tr>
<tr>
<td>B. Data from the CDC HIV/AIDS Surveillance Report (April 1992)</td>
<td></td>
</tr>
<tr>
<td>REFERENCES</td>
<td>105</td>
</tr>
</tbody>
</table>
This thesis represents a miraculous triumph. It was produced despite seemingly impossible circumstances, lively opposition and formidable obstacles. It was completed while I was struggling with a sense of deep personal loss, which resulted from the decease of two close friends and mentors since March 31st, difficult circumstances facing close family members, and my own deteriorating health and financial problems—all of which were exacerbated by several other simultaneous adverse, distracting and stress-inducing situations. Yet, my thesis experience was an immensely intriguing, challenging, and rewarding one—for which I am especially grateful.

The fact that I was able to remain in school, finish both the semester coursework and thesis—and finish well—is indeed a testament to the efficacy of prayer, the reality of serving a living God, and is a tribute to a few especially wonderful people who sometimes unknowingly provided invaluable support along the way.

First and foremost, I offer a special thanks to God, who fortunately, specializes in impossible situations. I also extend a hearty "Thank you" to my family, and my friends Maria Canales, Daniel Espitia, Chrystal McFadden and Denise Green who were ever willing to talk, pray, laugh and cry with me, whenever I needed to. I thank my course 11.433 study group, as well as members of the Community Fellows Class of '92 for their understanding and for just offering a word of encouragement from time to time, without needing to know all the details. I want to thank Bob Gehret for being so patient and flexible as I labored to fulfill so many simultaneous obligations. Lastly, I want to thank my advisor, Lang Keyes, who assisted me, expressed confidence in me and advocated unwaveringly on my behalf when few others were willing to.

In closing, I would also like to collectively acknowledge and thank the many AIDS housing providers and resource persons who gave so freely of their time to share their insights and experiences with me.
LIST OF TABLES

TABLE 1: Ten States Reporting The Highest Number of AIDS Cases (as of March 31, 1992)

TABLE 2: Ten Cities Reporting The Highest Number of AIDS Cases (as of March 31, 1992)

TABLE 3: Comparison of Cumulative Total AIDS Cases Reported By Age Group (as of March 31, 1992)

TABLE 4: Percentage Quartiles of TABLE 3. (as of March 31, 1992)

TABLE 5: Comparison of Distribution of Reported AIDS Cases By Transmission Category (as of March 31, 1992)
INTRODUCTION

Research Context & Question

Special needs housing is a longstanding phenomena on the housing landscape. Over time, health, social services and housing professionals have sought to develop a supportive housing model which was appropriate for the various special needs sub-populations--i.e., frail elderly, mentally retarded/chronic mentally ill, developmentally disabled, and otherwise physically-challenged. Conceptually, the traditional special needs housing paradigm seeks to maximize special needs clients' independence, flexibility and stability, and minimize the level of disruption they experience in their daily living. This model typically entails a multi-tiered residential system that provides alternative housing arrangements accompanied by varying levels of supportive services and supervision.

Within the field of special needs housing, some professionals have come to view persons with AIDS (PWAs) as just another (new) special needs sub-population. For them, AIDS housing is a subset of special needs housing and therefore falls within the existing continuum of care framework. For others, however, although PWAs share some commonalities with traditional special needs sub-populations, housing PWAs is in their view complicated by issues of race, class, substance abuse, and the unique nature of the disease.
These practitioners claim that, as such, PWAs require a housing continuum model that is tailored accordingly.

Three years ago (1989), in a thesis entitled *Planning To Meet The Housing And Social Service Needs of People With AIDS and HIV Infection In Boston*, Paula Schnitzer offered an AIDS-specific model of special needs housing, which at the time represented the collective wisdom and state of the art thinking about what an ideal supportive housing model for people with AIDS should include. Schnitzer predicted that as AIDS became more of a chronic illness affecting greater numbers of people, the current supportive AIDS housing system would become more inadequate.

Expanding on the rather limited body of research on providing supportive AIDS housing and building on Schnitzer’s AIDS housing model, this thesis revisits the traditional special needs housing paradigm to explore the ways in which the housing needs of PWAs do or do not fit the typical model, given what we now know about the AIDS phenomenon. I also examine how Schnitzer’s ideal AIDS housing model compares in practice to the experiences of the first generation of supportive AIDS housing providers, and present emerging implementation and policy challenges for future supportive AIDS housing efforts.
**Scope of Research**

This thesis addresses two primary questions: To what extent does AIDS housing fit within the traditional special needs housing paradigm? And, is Schnitzer’s supportive AIDS housing model adequately meeting the demands of current practice, especially in light of the changing demographic profile of PWAs? In Chapter One, I describe the AIDS phenomenon and discuss the dimensions and magnitude of the AIDS housing problem.

In Chapter Two, I present what the literature suggests are the critical factors and foremost challenges in providing special needs housing. I use this framework as a basis for comparing the housing needs of PWAs with those of other special needs populations. I also elaborate on the Schnitzer model as a precursor to Chapter Three’s analysis of whether practitioners at select project sites encounter the problems predicted in the literature and the degree to which the paradigm conceptualized by Schnitzer shifts when it becomes a paradigm of implementation.

Chapter Four contains a summary of my research findings and conclusions, and a discussion of future policy paradoxes and challenges. I conclude by suggesting future research questions.
**Relevance and Importance of Research**

In general, this research is important because it both highlights several successful AIDS housing efforts, and identifies burgeoning issues that will need to be addressed in the future. Learning about the experiences of AIDS housing providers can help influence policy-makers and funders to develop appropriately targeted program initiatives. Relatedly, researching this topic will further our knowledge of how currently available resources might be directed and leveraged to better support existing programs. And, articulating new challenges facing current practitioners might engage the support and resources of new non-traditional institutional players. This study also serves to assist prospective sponsors in program planning and development.

**Methodology**

In order to carry out this research, I combined two other concurrent projects and numerous resources. For the first project, in fulfillment of my Real Estate Management course (15.941) requirements, I analyzed the AIDS housing industry (specifically the sponsorship and product delivery arrangements) through the lens of strategic alliance theory in business management literature. The objective of this project was to investigate what management theory says about strategic alliances, and analyze whether those principles are present and practiced within the supportive AIDS housing field. I
focused specifically on what the literature suggests are the important decision areas and factors in selecting partners, managing the alliance relationships, and promoting inter-institutional learning, in order to recommend potential ways to improve these collaborations.

The second research project, conducted under the auspices of the City of Boston’s Public Facilities Department, was designed to identify the evolving models for providing supportive housing for person with AIDS (PWAs) and how they are funded, from both the local government and project sponsor perspectives. The Public Facilities Department initiated this project to identify key funding and implementation issues which Boston will need to anticipate and address as it implements Mayor Flynn’s "501 AIDS Housing Challenge".

This project afforded me tremendous access to unpublished research studies, supportive AIDS housing project summaries and funding proposals, minutes from AIDS Housing Task Force Subcommittee meetings, as well as access to local resource persons.

My primary sources to complete this work include reports and fact sheets developed by state and local housing and social services agencies, and AIDS advocacy groups, such as the Executive Office of Communities & Development, the Boston AIDS Consortium, and the AIDS Action Committee of Massachusetts, Inc. I also conducted interviews with several Public Health Nurses at Boston’s Department of Public Health.
The literature review is derived largely from custom library research, and from the readings compiled for use in a course entitled "Housing and Human Services", offered by the Department of Urban Studies & Planning at MIT. I also drew on academic and trade publications, how-to guides, unpublished foundation-commissioned studies, and newspaper articles for information on pertinent policy and practical issues concerning AIDS housing development and programming.

To guide the interviews, I devised a survey which focused on five main areas: project sponsorship, project description, target sub-populations and eligibility requirements, and management challenges. I relied on input and feedback from various practitioners and resource persons, such as

* Bob Gehret, Manager, Resources Unit, Policy and Program Development Division, Public Facilities Department (Boston, MA)

* Monroe Wright, Editor, Supportive Housing Newsletter (New Haven, CT)

* Ellen Alpert, Director, New York City Office of Special Needs Housing (New York, NY)

* Diane Randall, Executive Director, Connecticut AIDS Residence Program (New Haven, CT)

* Paul Lambrose, Northwest AIDS Foundation (Seattle, WA)

* Todd Summers, AIDS Housing Corporation (Boston, MA)

* Kurt Reynolds, VINFEN Corporation (Boston, MA)

to assist me with interpreting and drawing conclusions from the data gathered.

The research findings presented in Chapter Three are derived almost entirely from notes taken during telephone
interviews with practitioners. Despite my efforts to be conscientious and objective in collecting these data, the possibility of unintentional misstatements or misrepresentations remains. At the time of this writing, however, I am unaware of any such shortcomings in the research.
I. CHAPTER ONE: Background And Nature Of The Problem

To engage in meaningful discussion about AIDS housing issues, it is important to first understand the nature of the AIDS housing problem--specifically, for whom it is a "problem," in what ways and to what degree. In this chapter, I describe the phenomenon of AIDS in terms of its nature and manifestations as a disease, and present statistical information to indicate the magnitude of its incidence. This serves as a foundation to the subsequent discussion of the reasons, dimensions and magnitude of AIDS as a housing problem.

HIV Infection & the AIDS Disease

AIDS, Acquired Immunodeficiency Syndrome, is a clinical condition that is characterized by a breakdown in the body's natural defenses against disease. This immune system collapse leaves the individual vulnerable to a variety of serious illnesses--referred to as opportunistic infections--that are not usually found in people with healthy immune systems or that, if they are present under normal circumstances, have only relatively mild repercussions.¹ AIDS is caused by the HIV (Human immunodeficiency) virus. HIV infection begins

when the individual is inoculated with the virus. The HIV disease then progresses from latent HIV infection to severely damaged immunologic function in patients with AIDS.

The HIV virus does not immediately result in symptoms, but typically lies dormant for months or years before it begins the insidious process that leaves its victims susceptible to life-threatening infections, neurological disorders and malignancies—most notably, Kaposi’s Sarcoma, HIV Wasting Syndrome, Pneumocystis carinii Pneumonia,

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2Inoculation can occur either directly into the bloodstream (as during IV drug use with needle sharing, a needlestick injury, or receipt of HIV-contaminated blood products); or by exposure of the broken skin, an open wound or mucous membranes to HIV-contaminated fluids (as during sexual contact with an HIV-infected partner, or occupational exposure to HIV-contaminated body fluids); or by perinatal transmission from infected mother to infant. The AIDS Knowledge Base: A Textbook on HIV Disease from The University of California, San Francisco and the San Francisco General Hospital, by P.T. Cohen, MD, PhD, Merle A. Sande, MD, and Paul A. Volberding, MD, (eds.) Waltham, MA: The Medical Publishing Group, Massachusetts Medical Society, 1990, Section 4.1.1, p.1.

3Persons infected with HIV (Human immunodeficiency virus) may have a variety of manifestations, ranging from asymptomatic infection to severe immunodeficiency and life-threatening secondary infectious diseases or cancers. Ibid., Sections 1.1.1, p.1; 4.1.1, p.1.

4Current estimates suggest that an infected person who is without symptoms will probably develop detectable antibodies to the virus two to eight weeks after the initial exposure, but in some cases six or more months may pass before there is evidence of infection. The amount of time an infected individual remains asymptomatic seems to vary widely. The average length of the incubation period is now estimated at over 8 years, with a reported range of 4 months to 10 years. Langone, 1988, p.11; Ibid., 1.1.7, p.1.
Cytomeglovirus, Toxoplasmosis, Tuberculosis, and Encephalopathy (dementia).⁵

AIDS-related complex (ARC) is the more severe, intermediate stage of HIV infection. Typically, ARC is used to describe various conditions that are not diagnostic of AIDS but that clearly distinguished persons infected with HIV as having disease above and beyond that seen in asymptomatic HIV individuals.

Technically, the term "AIDS" is a clinical description of the end stage illness which results from the HIV virus infection. The acquired immune deficiency itself--i.e., the HIV virus--destroys the body’s capacity to fight bacterial and viral infections that would ordinarily be fought by a properly functioning immune system. Thus, it is the syndrome--i.e., the collection of invading opportunistic infections and diseases that result from a weakened immune system rather than the presence of the HIV virus per se--that actually precipitate the decline and eventual death of the infected individual.⁶

There is still much that medical professionals do not know about AIDS. However, it is generally understood that infection with the HIV virus does not guarantee that an individual has or will get AIDS.

⁵Appendix A provides detailed descriptions of the Center for Disease Control Surveillance Classification System for HIV infection.

Because of the long incubation period from HIV infection to AIDS, many more individuals are believed to be infected with the virus than are diagnosed with AIDS. Hence, the number of persons who are likely to be diagnosed with AIDS in the next few years is largely determined by the number of persons who are already infected.

**Statistical Information on HIV/AIDS**

The first diagnosed cases of AIDS in the U.S. were reported in June 1981.\textsuperscript{7} By June 1986, cases of AIDS had been reported from all fifty (50) states. The initial cases of AIDS were reported from New York and California, but these areas have accounted for a declining proportion as AIDS has become more common in other regions of the country.\textsuperscript{8} These initial cases were also predominantly found among gay men. Also in 1986, it was predicted that by the end of 1991, over 270,000 cases of AIDS would have been diagnosed, with over 179,000 deaths recorded.\textsuperscript{9}


\textsuperscript{8} Ibid., p.129.

\textsuperscript{9} Ibid., p.128.
TABLE 1: Ten States Reporting the Highest Number of AIDS Cases (as of March 31, 1992)

<table>
<thead>
<tr>
<th>Rank</th>
<th>State</th>
<th># Diagnosed AIDS Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>New York</td>
<td>44,176</td>
</tr>
<tr>
<td>2</td>
<td>California</td>
<td>41,042</td>
</tr>
<tr>
<td>3</td>
<td>Florida</td>
<td>20,810</td>
</tr>
<tr>
<td>4</td>
<td>Texas</td>
<td>15,236</td>
</tr>
<tr>
<td>5</td>
<td>New Jersey</td>
<td>13,274</td>
</tr>
<tr>
<td>6</td>
<td>Puerto Rico</td>
<td>6,849</td>
</tr>
<tr>
<td>7</td>
<td>Illinois</td>
<td>6,689</td>
</tr>
<tr>
<td>8</td>
<td>Georgia</td>
<td>6,046</td>
</tr>
<tr>
<td>9</td>
<td>Pennsylvania</td>
<td>5,975</td>
</tr>
<tr>
<td>10</td>
<td>Massachusetts</td>
<td>4,549</td>
</tr>
</tbody>
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TABLE 2: Ten Cities Reporting the Highest Number of AIDS Cases (as of March 31, 1992)

<table>
<thead>
<tr>
<th>Rank</th>
<th>MSA</th>
<th># Diagnosed AIDS Cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>New York City</td>
<td>38,326</td>
</tr>
<tr>
<td>2</td>
<td>Los Angeles</td>
<td>14,567</td>
</tr>
<tr>
<td>3</td>
<td>San Francisco</td>
<td>11,912</td>
</tr>
<tr>
<td>4</td>
<td>Miami</td>
<td>6,625</td>
</tr>
<tr>
<td>5</td>
<td>Houston</td>
<td>6,253</td>
</tr>
<tr>
<td>6</td>
<td>Washington, DC</td>
<td>6,226</td>
</tr>
<tr>
<td>7</td>
<td>Chicago</td>
<td>5,583</td>
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<tr>
<td>8</td>
<td>Newark</td>
<td>5,523</td>
</tr>
<tr>
<td>9</td>
<td>Atlanta</td>
<td>4,583</td>
</tr>
<tr>
<td>10</td>
<td>Philadelphia</td>
<td>4,521</td>
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</tbody>
</table>


Currently, the Centers for Disease Control report that the total cumulative number of AIDS cases reported as of March 31, 1992 was 218,301, with 141,223 total deaths reported. Approximately 75.4% and 47.7% of those cases were reported by the states and cities of highest AIDS incidence, respectively, that are depicted in the tables above.
Of the 218,301 AIDS cases reported to date, approximately 98% were among adults and adolescents over the age of thirteen. Approximately 2% of the cases were among children and youth under the age of twenty (20); 65.4% fell between the ages of twenty (20) and thirty-nine (39); while 29.6% were
adults between forty (40) and fifty-nine (59) years old. Persons over the age of sixty (60) accounted for the remaining 3.0% of reported cases.\(^\text{10}\)

Although the proportion of AIDS cases who were gay men has remained relatively constant over time nationwide there have been some significant changes in the proportion of cases in other population groups, and trends within these risk groups have also led to changes in the distribution of the AIDS cases by geographic area.\(^\text{11}\). As of January 30, 1989, 42% of total cases are reported from five SMSAs: New York (21%), San Francisco (8%), Los Angeles (7%), Houston (3%), and Newark (3%). And, the geographic distribution of cases by risk group is disproportionate. A preponderance of reported cases in IVDUs is from New York and New Jersey. In New York nearly 30 percent of reported cases are in IVDUs, whereas in San Francisco only 1% of cases are among heterosexual IVDUs. And, distribution of disease type by risk group is also disproportionate, with Kaposi’s Sarcoma reported primarily in homosexual men and infrequently in IVDUs.\(^\text{12}\)

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\(^\text{10}\)See Appendix C for distributions by gender, and ethnicity, and for comparisons for 1989 and 1992.

\(^\text{11}\)Gluckman and Vilers, 1986, p. 128-139.

cases by racial or ethnic group is also disproportionate: Blacks and Hispanics account for 43% of all AIDS cases, but make up only 18% of the U.S. population (See APPENDIX B).

These data reflect a burgeoning national trend of the changing demographic profile of the HIV/AIDS population: AIDS is quickly shifting from an epidemic primarily affecting the homosexual male community to one more closely associated with intravenous drug use, perinatal transmission and poverty.\(^\text{13}\)

This phenomenon is reportedly a function of an increasing incidence rate and changing mode of transmission risk in many cities in general. Thus, white gay and bisexual men continue to represent a significant percentage of people infected with HIV, however, a growing proportion are people of color, women, teenagers, children and active intravenous drug abusers.\(^\text{14}\)

In Boston, for example, there are currently over 12,000 individuals living with HIV infection, over 600 living with AIDS, and an estimated 1500 living with ARC. In 1981, homosexual contact accounted for 90% of the reported cases. In 1992, homosexual contact is responsible for only one half of newly diagnosed HIV/AIDS cases, with one third of all the cases linked to IVDUs, 10% attributed to heterosexual contact


and 4% to hemophilia/blood coagulation disorders. And, although most deaths have occurred among white, death rates are highest for Blacks and Hispanics. Black women have recently become the single most vulnerable group to HIV infection. Although the epidemic among homosexual men may be slowing down, the epidemic among IVDUs is reportedly still rapidly increasing, especially in the East Coast cities.

The Public Health Service projects that by the end of 1993, the cumulative number of diagnosed AIDS cases will total between 390,000 to 480,000, with cumulative deaths totalling between 285,000 and 340,000. In 1992 alone, there is expected to be between 151,000 and 225,000 newly diagnosed cases of AIDS, and deaths of between 53,000 and 76,000 primarily among those diagnosed in previous years. The Public Health Service estimates that approximately one million persons are infected with the HIV virus in the U.S.

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16Ibid., 1991.


18These figures were reported by the Centers for Disease Control in the "HIV/AIDS Quarterly Surveillance," First Quarter Edition, April 1992.
Why AIDS Is A Housing Problem

The HIV/AIDS disease becomes a critical housing problem for PWAs for six primary reasons. First, because of the debilitating, episodic and chronic nature of the illness, most PWAs are forced to worked sporadically or they become altogether unable to maintain employment as their illness progresses. Many therefore must rely on disability income (e.g., SSI/SSDI, Medicaid) to compensate for lack of income or decreased earning capacity. In most metropolitan areas, the standard disability allowance\(^{19}\) is far below standard market rents. Therefore, some PWAs are unable to remain in their current housing without additional subsidy.

Second, the uninsured or underinsured PWA is typically paying a large proportion of his income in rent, and is therefore forced to decide between paying for rent and paying for treatment and services--and as a result lives on the verge of homelessness.\(^ {20}\) Relatedly, PWAs can quickly become impoverished by the costs of medical care, especially if unable to maintain their private health insurance.\(^ {21}\)


\(^{20}\)"AIDS and Housing: Background and Need" AIDS Housing Corporation, pp. 1-6.

\(^{21}\)It has been reported that the costs of medical care for PWAs average $25,000 per year, until the final year when these costs may increase to $50,000 and perhaps exceed $75,000 in some instances. Excerpt from "AIDS Into The Nineties" 1990 Draft Report of the Boston AIDS Consortium, Harvard School of Public Health, March 1990.
Thirdly, many PWAs become homeless or are inadequately housed because as the disease progresses, it becomes impossible for them to afford their mortgages. It is estimated that between 30-60% of the adult homeless population is HIV infected.

Fourth, upon discharge from the hospital and in the absence of sufficient income and/or housing options, some PWAs are relegated to taking up residence in shelters, where they are especially vulnerable to substance abuse relapse and the stress and exposure of an host of illnesses and infectious diseases.

Fifth, because of the widespread fear, ignorance and stigma associated with HIV/AIDS, PWAs often experience discrimination by employers, and eviction by landlords and family members, when their illness becomes known.

Lastly, and most importantly, housing is the most crucial component in creating a comprehensive care system for PWAs, in that it provides the base from which the individual might


receive needed supportive services, medical attention, and care. The absence of housing is therefore, one of the greatest obstacles to providing PWAs with economic stability, social support and potentially life-prolonging treatment. And, limits on a PWA’s functional abilities restrict the individual’s ability to survive without some type of housing unit.

In essence, the AIDS housing problem is a multidimensional one which is partly a function of the rising incidence of HIV/AIDS and the transfiguring demographic profile discussed in the previous section. The complexity of the issue can also be partly attributed to the fact that the AIDS epidemic has struck at a time of severe and seemingly persistent economic recession, and limited availability of financial and housing resources.

One dimension of the AIDS housing problem has to do with accessing existing facilities. For instance, although subsidized housing is a potential option for PWAs, the long waiting lists for most public housing combined with a PWAs’ uncertain (short) life expectancy can be especially problematic.

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26 Ibid.

27 Ibid.
A second dimension to the problem is finding appropriate housing. That is, depending on the nature of the client's physical and functional limitations, the actual housing unit may need to be made physically adapted (e.g., wheelchair accessible) in order to be appropriate to the client's needs. And, with the advent of new treatments and technological and medical advancements, PWAs are beginning to live longer and live longer with AIDS. There is already evidence that AIDS is becoming a chronic condition which will make supportive services increasingly important. When a PWA's housing arrangement changes or the individual dies, this situation often impacts the housing need of family members as well.

In addition, part of the call for developing an array of housing options for PWAs derives from practitioners' desire to avoid over-servicing clients--which is regarded as both excessively restrictive and generally detrimental to the client, as well as a costly and inefficient use of resources.

Additionally, AIDS housing is not a problem exclusive to PWAs only--it potentially impacts the health care and medical services industry, the general population and other special needs populations as well. For example, the unwillingness of some acute care hospitals to release PWAs without adequate housing options means that these facilities are often

overutilized. This has two marked outcomes: (1) state health care budgets become overstressed, and (2) other patients (with perhaps more immediate needs) are denied admission or care.\textsuperscript{29}

Also, the rising incidence of AIDS will continue to impact federal Medicaid and SSI/SSDI budgets. There is a growing number of HIV infected persons who, on the one hand, are too sick to work, but, on the other hand, cannot access the benefits available to persons with full-blown AIDS, because they fail to meet Medicaid eligibility requirements.\textsuperscript{30} Furthermore, symptomatic HIV infected persons are also ineligible to benefit from many of the currently operational AIDS housing projects because they too require Medicaid-eligibility as the basis of housing placement or program participation.

**Magnitude of the Problem**

There are almost equally as many factors which might affect the magnitude of the problem. For instance, on the federal level, the housing and welfare policies of the federal government--namely, the general trend towards scaled down government, its retreat from affordable housing development

\textsuperscript{29}Medicaid reimbursements cost more for hospital stays than for other residential settings. Estimates for acute care stays for PWAs can range from $700 to $1400 per day.

\textsuperscript{30}In order to be Medicaid-eligible, an individual must qualify for specific disability or as an AFDC or General Relief recipient. McCormack, 1990.
arena, and the Department of Housing and Urban Development’s (HUD) resistance to expanding the "handicapped" classifications to enable PWAs to qualify for housing resources under existing programs\textsuperscript{31}--have combined to strongly impact the AIDS housing problem. And, the fact that the HIV epidemic is worsening during a time when the economy is also suffering makes mobilizing or reallocating resources difficult at best and (economically and politically) infeasible at worst.

The fact that until fairly recently, HIV/AIDS has been primarily viewed as a health issue has meant that public officials have neglected the housing-related issues and thus the housing needs of PWAs haven’t been fully addressed.\textsuperscript{32} More specifically, in the initial years of the epidemic, both policy-makers and funders tended to take the view that residential hospice and chronic care facilities would suffice in meeting the needs of PWAs. Housing provision for PWAs was also largely ignored by some AIDS advocacy organizations who were concentrating solely on the health-related needs of clients.\textsuperscript{33} Now, we witness the result: growing demand for a range of badly needed housing options that do not exist.

\begin{footnotes}
\item[33] Boston AIDS Consortium, 1990.
\end{footnotes}
Further, local affordable housing shortages place PWAs in the precarious position of having to compete with the general population and with other special needs populations (which also appear to be growing) for relatively few available housing units.

Based on informal telephone surveys I conducted with local city agencies in Atlanta, Baltimore, Miami, Washington, DC and Seattle, the number of people becoming infected with the HIV/AIDS disease is rising at a much faster rate than housing and social services resources are being made available. Recall from TABLE 2 (p.14) that Atlanta, Miami and Washington, DC were among the top ten metropolitan service areas with the highest AIDS cases reported to the Centers for Disease Control as of March 31, 1992. Yet neither Atlanta\textsuperscript{34} or Washington, DC\textsuperscript{35} have developed any sort of (comprehensive) public policy initiative around housing PWAs, to date. And, Miami, which claims to have the second highest rate of newly diagnosed AIDS cases in the U.S., is primarily focusing its efforts on providing short-term transitional housing and emergency rental assistance to enable PWAs to

\textsuperscript{34}Joseph Marenco, Director, Bureau of Housing Production, City of Atlanta, telephone interview, March 1992.

\textsuperscript{35}David Aschhiem, D.C. Department of Housing and Community Development, telephone interview, March 1992.
remain in their current units, as opposed to bringing new, or rehabbed units on line.\textsuperscript{36}

Even the cities with the highest AIDS incidence (i.e., New York and San Francisco), the most sophisticated service delivery networks, and the most ambitious AIDS housing initiatives, fall considerably short in terms of actual units compared to the level of need--750 and 447 dedicated units to meet the needs of an estimated 9500 and 3034 PWAs, who are said to be in need of housing, respectively.\textsuperscript{37}

To summarize, this chapter discussed the nature and incidence of the HIV/AIDS disease as a foundation for understanding the reasons, dimensions and magnitude of the housing need of PWAs. The discussion was intended to emphasize six key points. First, AIDS is a lethal and chronic condition about which scientists and supportive housing providers have much more to learn. Second, the AIDS disease is disproportionately represented among socially or economically marginalized subpopulations, such as the homosexual community, substance abusers, and increasingly heterosexuals--especially people of color, the chronic homeless and inner city youth.

\textsuperscript{36}Bill Lowrence, South Florida AIDS Network, telephone interview, April 1992.

Third, the HIV disease becomes a housing problem first and foremost because the episodic and increasingly debilitating nature of HIV-related illness causes fatigue, and periodic hospitalizations that leads to decreased earning capacity, loss of employment and eventually homelessness. Another dimension of the housing needs of PWAs has to do with the fact that the stigma associated with the illness or with particular subgroups impacted by it, often results in discrimination by insurance companies, employers, and eviction by family and members of the development community.

Fourth, there are different levels and types of housing need for people with AIDS, which cut across race, class and gender lines. Fifth, the magnitude of the AIDS housing problem is augmented by a decade of federal housing cutbacks, HUD’s resistance to extending the benefits of the handicapped designation to PWAs, and by the fact that the AIDS crisis comes at time of severe economic recession. The magnitude of the problem is exacerbated by the pre-existing affordable housing and homelessness crises, and by the fact that for too long, AIDS was only viewed as a health issue.

Lastly, this chapter established that even in the cities for which housing PWAs is a top priority, the level of need far exceeds the number of dedicated housing units. The following literature review offers some insights into the obstacle and challenges which the providers of these units typically encounter in project development and management.
II. CHAPTER TWO: Literature Review

This literature review serves several purposes. First, it provides a backdrop to, and justification and framework for this thesis research. It describes the special needs housing phenomenon and the subpopulations which are typically included under this designation. It identifies the rationale underlying the continuum of care concept, and serves as a departure point for comparing the supportive housing needs of these subpopulations. And, it provides a frame of reference for analyzing the experience of current AIDS housing programs.

In terms of approach, this chapter begins with a synopsis of literatures on the supportive housing concept. Next it highlights the foremost sets of debates in the special needs housing arena. This is followed by an enumeration of what the literature predicts to be the foremost obstacles which practitioners typically encounter in developing and managing special needs housing. Lastly, I overview the ideal AIDS housing model developed by Schnitzer. Underlying the discussions in this chapter are the questions of: (1) whether the housing needs of PWAS resemble those of other special needs populations, and (2) whether the current AIDS housing model is in need of revision, and if so, in what respects.

Synopsis of the Special Needs Housing Concept

31
In general, special needs or supportive housing is designed to serve residents whose physical and functional abilities differ from other tenants (EOCD 1988). The literature contains varying conceptions of special needs housing, including one view which says that special needs housing should be permanent housing with the capacity to meet the special needs of select tenants within it (Friedmutter 1989). Another view sees the goal of special needs housing as to provide alternative non-traditional living arrangements specifically adapted to tenants with special needs or limitations. And yet another view envisions special needs housing as facilities designed to serve the temporary and/or acute care needs of certain subpopulations.

Underlying the calls for special needs housing options are issues of affordability, accessibility and appropriateness. Finding and keeping a decent and affordable housing unit in a tight housing market which is characterized by rising rents, declining tenant income capacity and a generally poor economy is a problem for all special needs groups.

The literature indicates that for special needs groups, the accessibility issue has two primary dimensions. First, persons with special needs require access to and need to be accessed by a number of different systems: primary health care, mental health, child services, case management, substance abuse, pastoral care, meal providers, etc. (AIDS

Secondly, some project sponsors have encountered strong opposition by local residents and neighbors to siting residences, as well as regulatory barriers in the form of exclusionary or otherwise restrictive zoning ordinances that prevent high density and/or housing types specially adapted housing types.

More fundamentally, special needs housing has also been advocated for in order to address human and practical concerns about tenant isolation, health status, independence, risk of falling or injury, mental health problems, tenant ability to maintain the dwelling, and effects of tenants with problems on other tenants (Pascoe and Thompson 1979, Keyes 1982 1990, EOCD 1988, Lanspery 1989, Schnitzer 1989).

The underlying premise of special needs housing is that tenants’, housing managers and public interest are all served by the addition of supportive services because: (1) management may experience fewer problems; (2) costly high turnover rates and vacancies may decrease; (3) crises due to tenant injury, premature deterioration and traumatic relocations may be mitigated; (4) and the presence of a service provider may also help keep both management and service providers more accountable (EOCD 1988, Lanspery 1989).

Another important rationale for supportive (congregate) housing has been that it cuts down on the number and movements of outsiders; makes groups settings more home-like; provides
more intensive service quality monitoring; and economies of scale to providers (Lanspery and Callahan, Lanspery 1989).

The literature suggests that seven key elements or themes typically need to be addressed. First, special needs housing theory stresses that architecture and design effects should be an important part of the housing and services discussion based on the notion of environmental congruence, or the need to have a good match between the individual’s needs and capacities and the resources of their environment. The ideal environment is said to be one which is neither too challenging nor too protective, and the ideal design maximizes independence, is conducive to community formation, and provides services in a way that affords economies of scale benefits to provider (Schnitzer 1989, OECD 1990).

Secondly, another central idea in special needs housing theory is the desire to design supportive housing that will promote autonomy, flexibility and a decidedly non-institutional setting, in the interest of preserving the integrity of the individual’s lifestyle (Massachusetts Department of Mental Health 1985, Lanspery 1989, Schnitzer 1989, Boston AIDS Consortium 1990).

The third issue, locus of service provision, addresses whether services are to be provided on- or off-site and coordinated on- or off-site (Lanspery 1989, Schnitzer 1989). Tenant mix—that is, whether to consider a homogenous or
diverse community with respect to age, health and functional impairment--is a fourth theme (Lanspery 1989).

Fifth, the literature also suggests gathering information and assessing tenant needs should also be viewed as an important consideration in special needs housing provision (Lanspery 1989).

Community needs and resources is the sixth theme. That is, the surrounding community in which a special needs client or facility is located is an important consideration because of concerns of safety and the availability of professional services. And, even individuals who are highly functional require proximity to public transportation, laundry, groceries, and medical facilities, so that they might easily access off-site services and resources (Lanspery 1989). Lastly, there is the concept of tenant as partner, which entails treating the tenant as an equal partner with managers and service providers.

It is based on these element of themes that the continuum of care model rests. Conceptually, the continuum is a residential system that provides alternative housing and social and medical service arrangements which are attached to the housing unit. This model encompasses all types of formal and informal housing and services needed and used by those whose physical or mental conditions inhibit their ability to live independently (Lanspery 1989).
The Debates

Within the special needs housing arena there are four sets of debates. The first debate concerns this notion of continuum of care and whether it is preferable to move people or change the service packages offered in place, as the illness progresses—i.e., is it a continuum for services or for housing arrangement? Chief arguments contained in the literature in favor of a continuum of services include: (1) relocation is likely to be stressful; (2) the client’s preference is to remain in their community; (3) there are potential ill effects of institutionalization; (4) possible cost saving and flexibility which result from tailoring services to need; and (5) maximizing informal supports by encouraging continued involvement of family, friends, and community is preferable to depersonalized care (MA Department of Public Health 1985, APWA/COSCA 1989, Friedmutter 1989, Lanspery 1989, Schnitzer 1989, Newman and Struyk).

Services typically offered in the continuum of services framework include: homemaking; personal care; home health; social services; mental health; occupational therapy; meals; social participation opportunities; hospice; transportation; and nursing and physician care.

The premise underlying the continuum of housing concept is that available housing rarely provides an accommodating environment that allows the resident to remain in their current homes despite changing needs (Massachusetts Department

A second set of debates centers on integrating housing and social services provision--i.e., linkage. The essence of the linkage issue is that there are fundamental difference in attitudes, philosophies and concepts of housters and social service organizations. Rein (1986) says that these difference result from different "action frames"--where the former operates from a market orientation while the latter has a holistic or human need orientation. He further explains that each organization ‘sees’ the world differently; each operates from different organizational values, priorities and objectives (Rein 1986). Pascoe and Thompson (1978) likewise suggest that there is a fundamental conflict over primacy of mission. According to these authors, housing organizations are viewed as rigid and having poor human relations skills; and human service organizations are viewed as impractical.

Lanspery (1989) attributes the linkage problem to bureaucratic, functional and financing schisms that exist at all levels, as well as turf battles that derive from resentment over allocations of funds. For Pascoe and Thompson (1979). The problem results from lack of exposure to one another’s businesses.

EOCD (1988) cites misunderstandings over the level of the services and/or physical adaptions necessary as another reason. Relatedly, one writer points out that housters are
typically concerned that residents will be "hard", and they view social service organizations as mellow and unreliable, and generally insensitive to the fact that it is the house who must answer to other members of the community when the facility doesn't operate smoothly (EOCD 1988).

Another important aspect of this debate is that social services and tasks abstracted from them are extremely hard to define as a set of activities.38 This is partly because service providers must address a motley set of needs; and assessing those needs involves what people want as they define it and what others perceive they need--i.e., there may be difference between clients' perceived needs and professional assessments (Lanspery 1989).

There is also the perception that coordination is too vague to be a guiding principle for action (Rein 1986). On the one hand, case managers and service coordinators provide simple information and referral, on the other hand they exercise strict control over services allocation and financing sources (Lanspery 1989).

On a more practical level, the linkage problem often plays out around issues of how to respond to rent arrears; divergent expectations as to whether and how to intervene when anti-social behaviors and inter-neighbor disputes occur (Pascoe and Thompson 1979); how to weigh each partner's input

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38 "Social Services: Purpose and Form," From Policy To Practice. (photocopy).
in the tenant screening process; and tension over requests for special physical adaptations to the facility. And, blurred realms of responsibility often result in the emergence of service gaps (EOCD 1988).

A third set of debates revolves around NIBMY ("Not-In-My-Backyard") issues. The literature predicts difficulty in siting individuals or supportive housing facilities due to a stigma associated with the groups, which results in discrimination (Schnitzer 1989). For instance, the homeless are stigmatized based on negative perceptions about their behaviors (i.e., disruptive, unpredictable, sometimes criminal); in people’s minds homelessness is also increasingly associated with substance abuse and mental illness as well. Substance abusers are regarded in much the same way.

Arguments against elderly housing are usually made solely on economic grounds. And, CMI persons are stigmatized based on the mental and emotional limitations--i.e., people fear them and are embarrassed by their uncontrollable or sometimes vulgar behaviors.

Because the first cases of HIV infection and AIDS reported in the U.S. were among homosexual males, PWAs were initially stigmatized because of social attitudes toward homosexuality and moral judgements attached to this sexual conduct. The spread of HIV infection among IVDUs, and youth who engage in illicit and unprotected intercourse, has fed a perception of HIV disease as a sort of retribution for amoral
and deviant behavior. These groups are often blamed for their illness and are generally viewed by many as deserving of the illness. Thus, AIDS has generally become associated with socially marginalized groups, and deviant behaviors.

The social construct becomes more complicated. However, by the fact that many more individuals are contracting the illness through heterosexual contact (sometimes unknowingly) or through perinatal transmission (AIDS Housing Corporation, Boston AIDS Consortium 1990, Boston Task Force 1991).

Another aspect of the stigma associated with PWAs derives from the fact the AIDS—unlike mental illness or aging, or even homelessness and substance abuse—can be transmitted (sexually) and is attended by a multitude of contagious or infectious diseases (Langone 1988, Cohen et al. 1990, Public Facilities Department 1991a). And, until fairly recently, the fact that health professionals were unsure about how the HIV could be transmitted only catered to the fears of the general public (Cohen et al. 1990).

The fourth debate is about whether PWAs are just another special needs subgroup, and derives from three factors. First, there is a sense of urgency due to expectations about the life expectancy of PWAs after an AIDS diagnosis (AIDS Housing Corporation, Schnitzer 1989, Boston AIDS Consortium 1990). Another factor concerns disagreement within the AIDS
housing community about what PWAs' 'first need' is\textsuperscript{39}. The third factor concerns whether the needs of PWAs demand a different type or level of response than the other special needs groups (Lipsky and Smith 1987).

On the third point, it is important to note that many of the coalitions working on the AIDS issue are comprised of large contingents of homeless advocates. For them, the first need is remedying homelessness. They argue that many homeless persons have contracted HIV because of their transience, unstable and vulnerable living situation--which forces them to intermingle with others engaging in risky behaviors and creates a propensity to rely on illegal substance and narcotics in order to cope. Homeless advocates argue that these persons contracted AIDS as a result of factors created by their homelessness. These advocates would like additional resources targeted to the homelessness problem.

AIDS advocates see the HIV disease as the first need, and the reason that, because of the nature of the illness, PWAs become homelessness or suffer other debilitating situations. These advocates would therefore rather see AIDS-specific resources. They further argue that PWAs should at least be treated in the same manner as other special needs groups--i.e., the elderly, physically handicapped, mentally ill and homeless--all of whom are beneficiaries of specifically

\textsuperscript{39}Conversation with Ellen Alpert, Director, Office of Special Needs Housing, City of New York, telephone interview, February 1992.
targeted policy initiatives and resources on the federal, state and local levels.

Then there is the issue of on whether and on what basis PWAs should receive priority in obtaining housing and services, given that other special needs populations have to endure long waits, or are denied resources and facilities altogether due to shortages.

Other Common Problems Encountered

In addition to these debates, the literature predicts that supportive housing providers encounter three other common problems and challenges in practice. First, controlling or evicting "problem tenants" in order to keep the housing viable is viewed as a challenge because those tenants are equally needy of housing, and the special needs housing is often their last option (Rein and Schon; Keyes 1982, 1990).

Second, the human services industry is characterized by fragmented funding and service systems, such that an individual with multiple needs often receives services from multiple agencies, paid for through multiple sources. Lanspery (1989) views this as problematic because it often results in client confusion, and difficulty making good decisions. It also tends to create gaps in service provision which make clients vulnerable to premature functional deterioration and eventual institutionalization (Lanspery 1989).
Similarly, the literature reveals that supportive housing providers in in-home and scattered site living settings are not always able to meet service expectations due to staff shortages or capacity limitations. This can be especially problematic because it results in inadequate or infrequent client monitoring (Lanspery 1989).

The literature also suggests that assessing service need and risk, and evaluating outcomes are another longstanding challenge facing supportive housing providers (Lanspery 1989). For example, a major issue concerning CMI clients is that the illness tends to be untraumatic. It is therefore difficult to measure improvements in "quality of life", or to measure service utilization and needs (Lanspery 1989).

In terms of potential remedies for these problems, the literature predicts that approaching special needs housing with a view of the tenant as partner may be crucial to effective housing and service integration. Lanspery (1989) suggests that integrating housing and service providers will probably only succeed if both organizations see cooperation as being in their own, as well as their clients’ interest. One possible solution to the inadequacy of formal services is to rely on informal support, such as other members of the community. And, the fragmentation and cost challenge might be met by improved case management, service coordination and client targeting (Lanspery 1989).
Schnitzer: An Ideal AIDS Housing Model

Schnitzer, in her analysis of the housing and supportive service needs of persons with HIV/AIDS in Boston, argued that although there is much we can learn from planning models for affordable and special needs housing, there are some unique characteristics of AIDS that need to be taken into account, such as the unpredictable nature of the disease and the fact that different subpopulations have different housing needs.

Schnitzer’s model grew out of a sense that the projects that were operating and being developed at the time that she was writing, were not the product of any sort of comprehensive or coordinated planning effort.

She proposed a seven-option model with up to six options of housing types and supportive service types:

Option 1: Stay in current home
Option 2: Temporary, emergency, transitional housing
Option 3: Set-asides in unspecialized transitional housing
Option 4: Set-asides in special needs housing
Option 5: Specialized PWA residence
Option 6: Nursing home, chronic care hospital, skilled nursing facility, psychiatric skilled nursing facility
Option 7: Hospice residence

She viewed this model as a single model instead of many models, in that it was supposed to address all of the needs within the category of "persons with AIDS." Schnitzer’s
assumption about the continuum of care concept was that depending on the subpopulation, depending on their needs and depending very much on their preferences, clients may or may not advance through all of the options, because the illness manifests itself in different ways in different individuals at different times.

With PWAs beginning to live well and live longer with AIDS, Schnitzer predicted that as AIDS became a more chronic condition, planning would need to be approached in much the same way as for other groups suffering from chronic illness.

Schnitzer took the position that in many cases a continuum of services is preferable to a continuum of housing because it has greater potential to address the changing needs and changing demographic profile of PWAs.

Schnitzer offered seven implementation issues and obstacles to be considered in planning to meet the housing needs of PWAs: (1) neighborhood opposition to siting housing; (2) accessing existing housing resources; (3) integrating services into housing; (4) sensitivity to the needs of different subpopulations; (5) helping people negotiate the system; (6) coordination; (7) discrimination; (8) property management issues; (9) someone taking responsibility for developing needed resources.
In this chapter, I overviewed the special needs or supportive housing concept, highlighted common implementation challenges, and discussed the foremost debates within the special needs housing arena. This was done in order to analyze whether the housing needs of PWAs and the experiences of AIDS housing practitioners fall within the conventional special needs housing paradigm. Detailing the ideal AIDS housing model conceptualized by Schnitzer provides a frame of reference for analyzing the experiences of current practitioners.

Collectively, the literature established four points. First, special needs housing is made necessary because limitations on physical and functional abilities of some individuals inhibits their ability to find affordable, accessible, and appropriate housing options, or to remain in their current housing in the absence of supportive services. Relatedly, housing these individuals is special in that planners and providers must give particular attention to seven elements: architectural design features; promoting independence, flexibility and ‘normalcy’; locus of service provision; tenant mix; information gathering and tenant needs assessment; proximity to community based resources; and perceiving the tenant as a partner in their treatment decisions.

Second, there are four on-going primary sets of debates within the field which center around problems and issues
associated with: (1) whether a continuum of services or of housing is preferable; (2) effectively relating housing to service provision; (3) siting facilities; and (4) whether PWAs warrant special priority vis-à-vis other special needs populations.

Third, the literature also identified handling problem tenants, fragmented funding and service systems, and the capacity limitations of service providers as additional challenges that these providers characteristically encounter. Fourth, Schnitzer’s seven-option AIDS housing model attempts to tailor the conventional model to reflect the unique characteristics of the PWA group--that is, the nature of the illness and the diversity of housing needs within the AIDS subpopulations. Her implementation criteria suggest factors which AIDS housing planning should consider.

Ultimately, this chapter provided a framework for understanding and interpreting the data presented in Chapter Three.
III. CHAPTER THREE: AIDS Housing Implementation

This chapter provides glimpses into the world of AIDS housing implementation. The chapter begins with an overview of the projects interviewed. I then revisit the issues which the literature predicted would be problems in developing and managing the projects, discuss new implementation issues which were not foreseen in the literature, and reflect on implications for rethinking about the two models--i.e., the conventional model and Schnitzer’s ideal model.

This discussion is organized into three sections--What The Models Predicted; What The Models Did Not Predict; Implications For The Models--with subsections covering each implementation challenge separately. For each subsection, I state the main findings, elaborate on the key issues, and provide evidence to support or illustrate the issues raised. This evidence is necessarily anecdotal because it is based on interviews and there is presently no more formal means of collection and presenting this sort of data. And, as a practical matter, this format seemed to be the best way to give the reader a flavor of the many different ways the providers are addressing the various issues.

This chapter provides a foundation for the concluding chapter, in which I synthesize the research findings, state my overall conclusions, discuss important policy paradoxes and challenges, and suggest further research questions.
Overview

All of the project sites interviewed for this study were located in either Baltimore, Boston, Hartford, New York, San Francisco, or Seattle. Each of these cities was targeted either because of its high incidence of HIV infection/AIDS, or because it is known to have a proactive or unique approach to housing PWAs. This study also endeavored to encompass different geographic regions, as well as cities and project sponsors of varying sizes and profiles.

Taken together, the project sites all provide either scattered site or congregate (unsupervised and supervised) residential settings for persons with AIDS. Most of the projects were started within the last three or four years. And, with the exception of the two large SRO facilities (Bailey House and Peter Claver Community), each of the projects maintain residences which serve between four and twelve clients. Several of the projects--i.e., Shanti Project, Plymouth Congregational Church and Rose Hedge, operate multiple group residences.
What The Models Predicted

Based on the literature review, one might expect AIDS housing providers to have experienced difficulties around siting facilities or placing tenants, effectively linking housing and human service providers, handling problem tenants, and service provider capacity.

NIMBY (Not-In-My-Backyard).

The degree to which these project sponsors faced NIMBY issues varied considerably--as do their remedy approaches. Some project sponsors have managed to minimize placement controversy in private scattered site housing by combining a confidential placement strategy with the screening out of less than moderately functional clients. Thus, even though the clients are also "Class IV" (See APPENDIX A) AIDS-diagnosed cases, the illness does not always makes itself readily apparent to landlords and others in a way that jeopardized the "confidential placement" strategy employed by these programs.

In fact, all of the scattered site programs I interviewed had some specific screening criteria in addition to basic program eligibility requirements. One program in particular, the AIDS Resource Center in New York City, does not serve individuals who are "less than moderately functional; who have no history or have only limited capacity to tolerate independent living settings; who are in advanced stages of
dementia; who exhibit destructive behavior; or who have a high level of visual loss.40

Ellen Alpert, Director of the Office of Special Needs Housing for the City of New York, added that projects sponsor in New York’s new scattered site housing program do not seem to be having much difficulty placing tenants in private housing--especially non-profit housing for three key reasons: (1) the location of the buildings; (2) incentives for the landlord; and (3) practicality. First, Alpert point out that many of the buildings which program sponsors typically seek for client placements are ordinarily located in a low-income areas, and already house low-income people. Since these types of building owners already lease to potentially problematic tenants, they tend not to regard PWAs with any special disdain. In fact, according to Alpert, these landlords actually welcome the clients who will be provided with supportive service, because, in their view, the presence of the AIDS program sponsor offers some level of reassurance that the tenant is less likely (perhaps than other tenants) to misuse or damage the housing unit.

On the second point, these landlords also relish the prospect of having a city-sponsored project administrator sign a lease on behalf of a potentially problematic tenant because doing so effectively guarantees the landlord that the rent

40Marion Riedel, Deputy Director for Programs, AIDS Resource Center, New York, NY, telephone interview, April 1992.
will be paid, and gives him a more stable target for any liability claims that might need to be made. Thirdly, Alpert also reasoned that given the far-reaching impact of the HIV epidemic, particularly among the urban poor, it is highly likely that the landlord is unknowingly already housing AIDS/HIV infected tenants. Thus, bringing in a tenant who has health services and case management is preferable to a similar tenant without such supports.

Case Examples:

Plymouth Congregational Church, a Seattle-based cluster housing program for low income PWAs, leases entire buildings from private (for-profit) landlords under the guise of providing low-income housing, in order to house PWAs; the remainder of its buildings houses other low-income clients. Neither the property owner nor the other tenants are explicitly made aware that the project houses PWAs.

In San Francisco, Rita de Cascia House, a small (eight-bed) family residence targeting single women with children, did not encounter siting problems because project staff did not inform the community about it. According to Sarah Gillies\textsuperscript{41}, this is due to the fact that because there are a lot of substance abusers in the community, the neighbors seem

\textsuperscript{41}Sarah Gillies, Executive Director, Rita de Cascia House, San Francisco, CA, telephone interview, April 1992.
more receptive, and tend to view the program as an effort to address the problem constructively.

Similarly, because of the high level of drug-trafficking in its neighborhood, the Peter Claver Community, a 32-unit SRO housing facility with comprehensive 24-hour support services, was welcomed by the African American neighborhood in which the project is located. Recently, however, the area has started to gentrify, and some new neighbors have begun to express concern about the potential adverse impact which the facility might have on the value of their properties.

Serving people with AIDS was not only well received by members of the community in which the Fenway Community Development Corporation (Fenway CDC) operates, but it was a community person who prompted the Boston-based non-profit housing development corporation to get into the AIDS housing business in the first place. Fenway CDC is located in the Fenway, a largely gay and lesbian community. When the CDC was planning to do a 52-unit elderly housing project, the organization was approached by a prospective tenant with AIDS, who expressed interest in the residence. Following a series of informal discussions and contracting a local AIDS advocacy organization, the AIDS Action Committee, to provide supportive services, in January 1990, the project was operational, with four set-aside units for PWAs. According to Bob Van Meter, Acquisitions Director for the organization, as a member of the
community the CDC saw AIDS housing as "a need that they needed and wanted to address."

Linkage.

As indicated in the preceding chapter, the so-called linkage problem is really a problem of successfully integrating housing services and social services for the client or project. It is also about minimizing or mitigating against some of the classic difficulties associated with collaborating or interacting at the project level with an institutional partner who sees the world from a different "action frame" or point of view. In more practical terms this problem is often manifest at the project level by: (1) gaps in service provision that leaves the client underserved and at risk of unnecessary discomfort or premature functional deterioration; (2) inconvenience, threat or disturbance to other tenants; and (3) undue damage to the housing unit or the facility. The linkage problem can also result in: tension between housing manager and service provider; inter-neighbor disputes; or even client eviction.

The issue of integrating housing and human services has played out in a variety of scenarios in the programs interviewed for this study. In some cases, the common problems raised in the literature were mitigated against by

42Bob Van Meter, Acquisitions Director, Fenway Community Development Corporation, Boston, MA, telephone interview, May 1992.
one organization—usually an AIDS service or other non-profit service group, taking on both the housing and service components themselves. In other cases, programs involved more formal collaborations.

Case Examples:

Rita de Cascia House (San Francisco) does both the housing and service provision itself. As an affiliate of a large religious institution which possesses extensive internal social services and housing development resources and expertise on which to draw, doing both project components was clearly more feasible than if the program sponsor was smaller and less experienced.

The Plymouth Congregational Church’s (Seattle) Apartment Program, created both a housing subsidiary and social services unit in order to carry out its AIDS housing initiative. The housing subsidiary, Plymouth Housing Group, leases low-income buildings from private (for-profit) landlords on behalf of the church and provides a resident and an assistant manager who provide maintenance and tailor units in which PWAs reside, as necessary.\textsuperscript{44}

\textsuperscript{43}Rita de Cascia House is sponsored by the Catholic Charities of San Francisco, AIDS/ARC Program.

\textsuperscript{44}The service provider for the AIDS clients within the Plymouth buildings is actually the Northwest AIDS Foundation, a large secular AIDS advocacy and service organization which provides both housing and services throughout the Seattle area.
Plymouth's service unit endeavors to actually fill in the service gap that the literature predicts, by acting as what the program calls a "liaison" between the housing and the service provider (Plymouth Housing Group and Northwest Area Foundation, respectively).

The method is a buddy system in which a volunteer coordinator assigns each PWA to a buddy or "special friend". It is the buddy's task to develop a relationship with the client along whatever terms are appropriate or helpful to the client. Additional tasks typically involve making the case manager or other service providers aware of subtle changes in the client's status. Or it can involve mediating disputes and addressing behavioral problems which might arise. In the latter case, the buddy would intervene and seek to negotiate a resolution that is mutually agreeable to both landlord and client. According to Judy Pickens,45 Volunteer HIV/AIDS Coordinator, this is especially important with clients who have a history of substance abuse or other psycho-social problems. Pickens stressed that in the absence of the liaison, the project manager may be inclined to move to evict the tenant or otherwise remedy an adverse situation in a way that does not adequately take into account the details of the client's health and mental status.

For one Boston project, the linkage problem took the form of the housing provider having to intervene on behalf of the client for increased supportive services. From the houser’s viewpoint, the problem was that the service provider did not have the capacity or disposition to proactively follow-up the client in a way that allowed the agency to notice subtle changes in the client’s status. According to the housing provider, this resulted in frustration on client’s behalf by other tenants who began to ‘help out’. Fortunately, in this case, the housing and service organizations had built a strong enough relationship that they were able to address the issues to mutual satisfaction and still continue to work together.

Problem People.

Multi-diagnosed clients represent the PWA-equivalent of problem people described in the literature. Based on the interviews, several of the small congregate and scattered site projects seemed least equipped to handle and therefore generally overwhelmed by PWAs with "multiple diagnoses"--i.e., substance abusers, dementia or other psycho-social problems. Yet, it is exactly these PWAs that they are seeing more and more of.

In the case of individual with a substance abuse background, providers expressed concern about three primary issues: (1) relapse; (2) drug use on the premises; and (3) uncooperative or irresponsible behavior--specifically, child
neglect or abuse; destruction to themselves and/or the property; disruption of other residents; failure to pay rent; inviting strangers into the facility; and absences for unpredictable and often long periods of time.

The providers with licensed facilities were especially concerned that allowing active drug use on the premises might jeopardize their funding or put them in violation of their liability and licensing agreements. There was also the problem that substance abusing tenants typically spent rent money on drugs; this placed them in violation of their lease agreement and provided grounds for eviction. Program sponsors also expressed concern that disability and insurance reimbursements would be withheld unless the client was physically present or able to be accounted for--which was not always the case with these individuals since, given that the facilities are not "locked", clients are technically free to come and go at will.
Case Examples:

In San Francisco, Shanti Project, which operates 5-6 group homes, employs thorough and rigorous screening process to avoid admitting clients whose needs might exceed the program's capacity to meet them. For instance, the admissions process for prospective Shanti Project applicants begins with a group orientation, during which applicants are given an overview of the program. Applicants must then schedule an evaluation with the AIDS Substance Abuse Program at San Francisco General Hospital, and also go through an individual psycho-social interview with a Shanti Residence Advocate. Prior to admission, each applicant must demonstrate "the ability to live cooperatively in a group setting with no active alcohol, drug or psychiatric problems." In addition, Shanti provides each new client with detailed program policy information which specifies behavioral expectations and procedures for resolving any problems which may arise.

Similar to the Shanti Project, upon reviewing and signing detailed program and substance abuse contracts, Center City Churches (Hartford) applicants enter the program understanding that any violation is grounds for termination. According to Terence Donovan, Center City's Scattered Site Program Fact Sheet, "Residence Program Fact Sheet," The Shanti Project.

Terence Donovan, Housing Coordinator, Center City Churches Scattered Site Program, Hartford, CT, telephone interview, May 1992.
policy specifies that its clients are required to be either drug-free or in recovery. Nevertheless, during the program’s four-year history, the program has encountered some problems with clients over drug-related issues. The foremost challenges have been around: (1) time management, and (2) active drug use.

Concerning the former, Donovan explained that because most of their clients are on disability, employment is not an option for them; this leaves them with a lot of spare time. As a result, some clients suffer from depression and loneliness. Some take up with questionable companions, and ultimately relapse. He further points out that while some former substance abusing clients have done well, others have not only not done well, but have also become unwilling to accept assistance.

The second challenge has been that some clients have entered the program falsely claiming to be drug-free, but were later discovered to be using drugs privately. CCC has responded to this challenge by adding into the participation contract that clients will take periodic urine tests. Although, the Program has enlisted the assistance of the Hartford Dispensary Methadone Program, Donovan states that implementing this policy is "still difficult." Notwithstanding the Program’s efforts to be flexible when these problems have arisen, the Program can only report "varying degrees of success", according to Donovan.
Although Plymouth Congregational Church prefers that its clients remain drug-free as well, the program has responded to the relapse issue by relaxing its expectations somewhat. Judy Pickens recounted one instance in which the program negotiated with a client to allow minimal drug use. However, as a result of the growing demands that multi-diagnosed clients are placing on Program staff, the church's housing subsidiary has hired a full-time social worker, and the volunteer services unit has recently hired a case manager with mental health and AIDS experience. According to Pickens, the Program will soon be hiring a case manager who possesses substance abuse expertise as well. Pickens also notes that Program staff will feel better about the scattered site model with the upcoming opening of a local facility that will provide Plymouth clients with free transportation to adult day care programs.

With respect to encephalopathy (AIDS Dementia Complex), as PWAs are beginning to live longer, some practitioners have already begun to observe increasing numbers of clients suffering from dementia, and in worsening degrees. In fact, some medical experts and practitioners estimate that approximately 70% of HIV infected persons will develop some manifestations of psycho-social or dementia-related difficulty during the course of their disease.48 Without disputing these estimate, some other practitioners add that the level

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and particular manifestations are unique to each individual's experience, however—that is, some clients may not suffer from dementia at all.

Specific to scattered site housing, PWAs who suffer with dementia are prone to exhibit behaviors which may pose danger to themselves or the building—such as, leaving doors unlocked and stoves on, and forgetting to extinguish ignited cigarettes. The consequences for a facility manager could include fire hazards, increased maintenance expenses, insurance liability, or harm to and complaints from other tenants.

Case Examples:

The Peter Claver Community is the only facility in San Francisco that accepts individuals with AIDS who have additional diagnoses and are considered "problematic". According to Aiden McAleenan, Building Administrator for Peter Claver, the project is able to mitigate against the traditional concerns of housing managers by providing services that are "quite intensive."49 Peter Claver’s comprehensive 24-hour support services includes medical, substance abuse, social/psychological and emergency care. The project also

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provides intensive case management and mandatory money management services for clients.

For Kurt Reynolds, Executive Director of Amory Street Apartment Program, a cluster apartment program in Boston Public Housing, the challenge of providing residential programs for PWAs suffering from dementia is "a challenge to create "homes" where the physical safety of residents, as one priority, does not overshadow the importance of promoting independence and preserving both privacy and dignity in the least restrictive ways." Amory Street employs numerous approaches to mitigate against some of these concerns. First, the program conducts neuropsychiatric examinations early on to establish a baseline in order to evaluate changes more effectively over time. Second, the Program also recognizes the need to differentiate between AIDS dementia complex and reactive or depressive illness, which can be part of the experience of living with the HIV disease, and which often mimics HIV encephalopathy. Reynolds also stressed that with close collaboration with the client in developing a program-specific treatment plan, "many people can be successful living with AIDS dementia complex." In his view,

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50 In the money management program, clients agree to have their monthly rent deducted from their disability income upfront; the Program returns the remainder directly to the client.


52 Maximizing Independence" by Kurt Reynolds, Supportive Housing Newsletter, July 1991.
there are a lot of intervention strategies that can help people live well with less ability, including medical treatment (AZT), restricted use of appliances, and improved case management, etc.

Other providers, such as Rose Hedge and Rita de Cascia House, who are also grappling with how to adequately serve these types of clients, have opted to work with clients who have a certain level of functionality—e.g., cognitive slowness, decreased mobility, and withdrawal, beyond which they seek other accommodations or placements for them.

Eviction Issues.

Providers who serve multi-diagnosed HIV infected clients indicated that evictions were another challenge with which they are struggling with. This is true for several reasons. First, some sponsors felt that evicting problem clients might tarnish their image in the community and may damage an already fragile relationship. This is especially true of organizations which had to overcome resistance to siting their projects in the first place. Religious institutions in particular worried that evictions evoke an image of "the church throwing a dying person out on the street". Second, the housers have found that the conventional eviction process can be very lengthy (several months) and costly (some have

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53Aiden McAleenan, Building Administrator, the Peter Claver Community, telephone interview, May 1992.
spent up to $1000) in some cases. And during the process, the problem client’s presence continues to impose upon and intimidate fellow residents and maybe even jeopardize a program’s license because of drug use on the premises.

Apart from the eviction process itself, placing the clients in another facility has proven at time to be problematic because: (i) the client’s behavior is unlikely to be acceptable elsewhere either; (ii) there are not other appropriate facilities to which to send such ‘problem’ clients; (iii) and even if there were, other facilities are typically filled to capacity, with lengthy waiting lists.

Providers have begun to respond in several ways. Many providers with whom I discussed this issue have adopted some form of client participation agreement or contract, which serves as the basis for eviction if violated. One project sponsor has opted to avoid using leases with its clients in order to short-cut the eviction process. Two other programs seek alternative placements for clients’, while hoping that they will leave on their own volition. For all of the project sites interviewed, the eviction process was preceded by informal negotiations and opportunities for clients to modify their behavior.
What The Models Did Not Predict

There were also several implementation challenges which fell outside of the literatures predictions--i.e., dying in place effects; morbidity and mortality; contagious diseases, etc.

Dying In Place.

The continuum that was conceptualized by Schnitzer allowed for the fact that at almost each tier of the housing continuum there is a continuum of services to accommodate the fact that clients desire to die "in place." As a result, providers are finding that they are having to provide hospice-type care in non-hospice settings. Some are endeavoring to do so, with varied success. Others are instead having patients placed in an alternative facility that provides them with the additional care and supervision that is needed.

In general, Security has become an issue in some scattered site programs as the more sick an individual becomes, the more case managers and service providers will need to access the unit. If the program is being run confidentially in private housing, the landlord is under no obligation to provide access or duplicate keys.
Case Examples:

Don Miller House, a four-bed group home in Baltimore, seems better able to tailor its services to the preferences and needs of its clients by keeping the program small. It may also be significant that clients served by this program pay between $1200-2000 monthly to reside there—which is a much higher figure than is typical of most of the other projects with whom I spoke.

As a result of client preferences to die in place, Plymouth Congregational Church plans to use the client "buddies" to help provide the more intensive companionship and supervision that is sometimes required in this type of situation.

According to Sarah Gillies, although Rita de Cascia House (San Francisco) is currently a relatively minimally supervised congregate residence, she expects that the facility will eventually become a family hospice.

In New York, the Coalition for the Homeless has made arrangements to bring in around the clock health care, upon client request. Nevertheless, Lee Krieling⁵⁴, points out that ultimately "most of the clients die at the hospital."

Mortality and Morbidity.

Mortality and morbidity are an increasing concern for several of the providers with whom I spoke. The issue here is that the high and in some cases the increasing number of deaths in these facilities is starting to adversely social atmosphere of projects which they operate.

Case Examples:

Specifically, Fenway CDC’s Bob Van Meter described the West Fenway project’s nine (9) deaths in two and a half years as a "very high mortality rate". While this figure does not seem significant in comparison with Rose Hedge’s two or three deaths weekly, it has taken a toll on the tenants in the building.

Van Meter explained that what makes this phenomenon particularly problematic is the fact that the West Fenway project is a predominantly elderly housing project, and the fact that the individuals who died also happened to be very active participants in the developing the building’s sense of community. In response, Fenway’s remedy approach has been to work with both the project property manager and service provider to hold a series of workshops on grief issues. In one instance they even held a memorial service.

55A project of comparable size, Center City Churches Scattered Site Program (Hartford) reports experiencing the loss of only three (3) clients in two years, according to Terence Donovan, Housing Coordinator of the Program.
Marion Riedel, of Bailey House (New York), concurred on this issue. Although she believes people have a right to permanent housing, Riedel stressed that she would ideally limit resident tenure at Bailey to about six months because "it is extremely stressful to live in a place where people are frequently dying." Looking at the issue from another perspective, Riedel partly attributed the facility's recent 50% increase in the death rate to the fact that as more supportive AIDS housing models proliferate, the SRO facility is having sicker people referred there.

On the morbidity issue, one project sponsor suggested that the SRO living arrangement poses some real problems because as individuals become sicker they not only prefer not to leave their rooms to use the common restroom, they also prefer not to be seen and the other members of the house do not want to see them in that condition.

Tuberculosis (TB)/Infectious Diseases.

The AIDS-associated risk of developing tuberculosis has become a justified and growing concern among some specialists in the AIDS field.\(^5^6\) One discovery of this research was that few of the programs had any sort of process in place for detecting or treating PWAs who develop TB. This is especially disconcerting for several key reasons. First, tuberculosis is

highly contagious and easily transmitted. Relatedly, most AIDS housing programs are currently located in structures which currently lack isolation rooms, in which newly admitted clients suspected of TB exposure, might be segregated until TB test results confirm or rule out that prospect.

Second, TB can be fatal if untreated in an infected individual. Third, the very groups which have historically had the highest rates of TB infection--i.e., Haitians, African American and Hispanics, and intravenous drug users, are also becoming the groups most at risk of HIV infection. Jane Taylor, a Public Health Nurse with the Boston Public Health department, confirmed this point, saying that "TB is definitely a disease of poverty and crowded living conditions." 57

The elderly, the homeless, alcoholics, refugees and recent immigrants are other groups at high risk of TB, according to one study. 58 This writer goes on to say, "With the advent of HIV disease, TB is again on the rise. In areas such as New York City and New Jersey, total TB cases have increased markedly; the age distribution of cases has also changed, increasing in the young-adult age groups that are most heavily represented in reported AIDS cases...In San Francisco, where AIDS is predominantly seen in white gay and


58 Cohen et al. (eds), Section 6.2.2, p.1.
bisexual males, the majority of patients with TB and AIDS are non-IVDU white males. In fact, in December 1990, the first case of clinically active pulmonary TB was diagnosed at a residential facility for PWAs in San Francisco. In less than three months, eleven (11) other residents had developed active TB and four staff tested positive.

Fourth, although the disease can be readily detected and treated in persons with an intact immune systems so that they do not pose any risk to others, TB is more difficult to diagnose in PWAs and, if undetected, is virtually impossible to contain in communities where residents have compromised immune systems. For this reason, the Center for Disease Control stresses that the outbreak in San Francisco indicates the "urgency of immediate identification and medical evaluation of all HIV-infected contacts of persons with documented or suspected infectious TB. The rapid progression from clinical infection to clinically active disease in HIV infected persons makes early investigation...especially critical."

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59Ibid., p.1.


61Kate Matthews, Public Health Nurse, City of Boston, Department of Public Health.

Case Examples:

As part of its tenant selection process, the Peter Claver Community (San Francisco) requires individuals interested in the program to provide evidence that they have had a recent TB screening, or if they are actually TB infected, they must demonstrate that they are under treatment, in order to be admitted into the program.

The Amory Street Apartments Program (Boston) includes TB screening and treatment verification in its admissions criteria as well. Specifically, Amory program staff have worked closely with the Boston Public Health department’s TB Clinic to develop a model TB protocol which involves a PPD test plus two controls. Public Health Nurse, Jane Taylor explains that the "PPD" or, more correctly, the mantoux test, is a skin test to determine whether a person has been exposed and infected with TB anytime in their life. The test uses a Purified Protein Derivative (PPD) solution, and normally takes forty-eight (48) hours to show results. In Boston, the "controls" consist of solutions from one of three other illness--i.e., mumps, candida, or tetanus toxoid.

There are three common TB tests: the Tyne test, "PPD" test, and Sputum culture. The Tyne and PPD are skin tests, which take only a few days to show results. The Sputum test takes 12-14 days to show results, but is said to be the most reliable of the three tests.

The idea here is that most people have come in contact with at least one of these illness in their lifetime, and have therefore developed antibodies which will create a reaction when they come in contact with the virus via the control.
The idea underlying the use of controls is that when a person’s immune system is severely compromised, the individual may be "anergic" (due to lack of T-cells) or unable to mount a sufficient response to ensure that the skin test is reliable. Hence the Center for Disease Control recommends using the PPD on one arm plus the two controls on the opposite arm; a reaction to at least one of the controls is presumed indicative that the PPD result is reliable. The CDC also recommends that this procedure be followed by chest radiograph, clinical assessment, and treatment when necessary.

Rose Hedge has also adopted a TB protocol of sorts recently. Linda Chelotti points out however, that since ninety-five (95) percent of the projects admissions come from the hospital, program staff have the advantage of the discharge summaries to assist in TB screening. She also notes that Program staff have not seen many cases of TB among the formerly homeless PWAs whom they endeavor to serve. Rather, "substance abusers tend to be the ones with TB."

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Few of the remaining programs that were interviewed had any sort of TB protocol. One sponsor reasoned that since the apartments in which they house clients are self-contained (studios), it is reasonable to leave the matter the client to "handle it privately". Two other scattered site program sponsors indicated that although they do not currently have any protocol place, they have been recently informed on the TB issue at local AIDS networking and information-sharing meetings.

Additional Issues.

A few project sponsors found themselves addressing additional issues that they had not anticipated. For instance, during project planning, Bailey House (New York) staff had made a special point of ensuring that the facility had sufficient wheelchair equipment and accessibility. They found instead that, although some of their clients generally experience some motor and mobility limitations over the course of the illness, blindness has proven to be a much more serious problem for clients. As a result, the project has adapted the facility to include more grab bars and signage to help alleviate client’s difficult. Marion Riedel indicated that although many Bailey clients experience difficulty climbing stairs, fewer than five (5) percent ever need a wheelchair.

Two of the projects indicated that their programs are being virtually transformed as a result of their efforts to
accommodate client service needs. Bailey House expressed concern about becoming more and more 'institutional,' which is counter to the program's original intent but derives in part from improved treatments and the increasing availability of preliminary housing options. That is to say, because PWAs now have other independent living options and because they can reside in them for longer, clients who come to Bailey tend to be sicker and need more intensive supports.

Rose Hedge administrators were surprised to find themselves in the midst of a scabies outbreak. Scabies are parasites that burrow under the skin. They cause severe itching, and can live inside furniture and foam materials as long as they have oxygen—e.g., thus, merely sitting on an infected person's bed puts one at risk of contracting the infection. As an illness, scabies is highly contagious and tends to gravitate to closed moist areas on the victim's body, such as between fingers and in the groin area.

Fortunately, this affliction can be treated topically by applying either Quell lotion, or permetherin (a flour compound). Rose Hedge administrators responded to the scabies incident in three ways: (1) every member of the Rose Hedge community was treated in one of the two ways just mentioned; (2) all linens were re-laundered and furniture was 'bagged' (literally) to block off oxygen; and (3) the program

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69 This information was provided by Sarah Gillies, Director of Rose Hedge, Seattle, WA, April 1992.
implemented an in-depth screening and intake process to look at the history of the prospective clients to determine whether they have ever contracted or lived in environments conducive to contracting this illness. As a precaution, those with such a background are treated upon admission into the program.

Implications For The Models

These findings suggest several implications for both the conventional model and that conceived by Schnitzer. For instance, integrating housing and services in the scattered site setting in particular raises some serious questions about when and how information gets to the service provider. The experience of these providers suggests that the very nature of the illness and resulting multiplicity of needs warrants close monitoring by case managers and service providers. On the one hand, the ideological orientation (i.e., participation and empowerment) of some advocacy organizations makes them best suited to interact with the tenant in a manner which makes them feel like a partner in their care program. On the other hand, as one project sponsor pointed out, such organizations tend also to be non-interventionist (e.g., overly-respectful of what they perceive as client privacy and independence), which can create vulnerability for the client because declining functionality in PWAs is usually a gradual and subtle process. In this providers experience, some advocacy-oriented service providers tend to rely on client initiative.
to seek increased services; he contends that the client’s deteriorating condition may make doing so unlikely or impractical.

If in fact, certain types of service providers lack the capacity to carry out their end of the contract, this will create particular (and increasing) problems for housers. One obvious remedy approach would be to create capacity building forums in which advocacy organizations could receive additional training in conducting client needs assessment. However, service gaps may in fact be a symptom of a problem with the health care provider as well.

Scattered site programs had an isolating potential for multi-diagnosed PWAs. Based on the experience of the providers interviewed for this project, it appears that scattered site housing is not a feasible option for these clients (except maybe in the early stages of a dementia sufferer’s illness).

Most evictions involved multi-diagnosed clients whose behaviors became intolerable for providers or the communities of which they were a part. While evicting unmanageable clients is certainly reasonable, it does point to the dilemma of cutting off those most in need of supportive housing from the services they need the most. And, then there is the question of where else they will go, and whether the alternatives (streets, shelters) are in the interest of the
general public, given the issues of contagion and transmission risk.

When the model was originally conceptualized, it was intended that the range and level of services could be tailored in a such a way as to accommodate a client’s wishes to die ‘at home’ if they so desired. This practice raises issues of whether that is a desirable situation given the potential impact on the building in terms of a sense of morbidity it engenders, and the stress that it places on project staff and service providers. Particular to scattered site housing, there is also the issue that since some providers have placed HIV infected clients in apartments unbeknownst to the landlord, there is the risk that if the landlord finds out, they may be unable to lease space from that landlord in the future. For program’s such as New York City’s which place PWAs in scattered site apartment which house other special needs groups--such as the chronic mentally ill/mentally retarded, there is presumably the additional issue of how well these tenants would be able to cope with the frequent deaths of tenants who have AIDS. The findings on the mortality and morbidity issue further suggest that SRO clients should be given private bathrooms. However, the fact that most SRO programs share bathrooms.

Irrespective of whether the project is scattered site or congregate, project sponsors should anticipate the need to address mortality and grief issues as part of their
programming. In fact, most of the programs interviewed for this research already hold some sort of regular meetings in which clients come together to share experiences and coping strategies. These sessions might be used to hold workshops and seminars on grief issues as well. One project in particular, the Shanti Project (San Francisco), now offers a series of training manuals and videotapes on issues such as facing death and dying, emotional and practical support for volunteers, and how to effectively deal with depression among program staff and clients.

The experiences of these project sponsors also raises the issue of whether modifying the size of the project or number of AIDS units within a scattered site building might mitigate the morbidity affect. There is no guarantee, however, that having fewer units dedicated for PWAs will necessarily result in a lesser affect. And, perhaps as PWAs continue to live longer and remain relatively functional for longer periods, this problem might in a sense take care of itself.

Combining the facts that many of the projects interviewed are non-licensed providers who operate their programs on a confidential basis, with the absence of TB protocols makes for a very problematic situation. At the least, program sponsors should take the initiative to safeguard the clients, the general public and the reputation of their program by developing a TB protocol. At worst, they should avoid placing
clients at high risk of developing active TB in their facilities or scattered site units.

Jane Taylor offers some simple advice: "[prospective clients] coming into a program should confirm that they have not been infected before or are not now infected. If they don’t know, they you want to find out immediately—especially in congregate, group living settings in which you house other immune compromised people."

Another important point specific to scattered site projects is that follow-up of TB infected PWAs is critical for several reasons. New York and Florida are currently struggling to curtail the spread of a multidrug resistant strain of TB (MDR-TB) that developed among HIV infected individuals as a result of poor follow-up and inconsistent or sporadic application of treatments. Specifically, it was recently reported that in four hospitals in these two states seventy-seven (77) cases of MDR-TB were diagnosed between September 1989 and April 1991.70 Most of these patients were also PWAs, and many were also prisoners. This worsening situation should impress upon practitioners the urgency of this matter (although some are aware of this and yet have not begun to concretely address this issue in their own programs.)

Relatelly, for Rose Hedge, the scabies outbreak was inconvenient but manageable; but had the facility been larger, such an outbreak would have been much more problematic.

Providers should also develop screening procedures for other HIV-related contagious diseases.

Taken together, the analysis of the experiences of these providers achieved two objectives. First, it confirmed the conventional model’s predictions that NIMBYism, linking housing and human services, service provider capacity and serving problem tenants might present challenges. Second, this research confirmed Schnitzer’s assumptions that the continuum of services is generally preferable to a continuum of housing—especially for multi-diagnosed PWAs.

Nevertheless, these findings also challenged Schnitzer’s conception of one model for all AIDS subpopulations in that the experiences of these providers suggest that scattered site housing is inappropriate or infeasible for certain groups—such as the chronic homeless PWAs and clients suffering from at least moderate dementia. This is true because these clients tend to have no history of independent living, often do not possess the ability to convey their needs to supportive service providers and because they would benefit from a more structured setting, as indicated by the collective experiences of the project sponsor interviewed for this study.
IV. CHAPTER FOUR: Conclusions, Policy Implications & Further Questions

Synopsis of Research

This research began by asking two primary questions. The first question was whether AIDS housing fits within the traditional special needs housing paradigm. The second question this research addressed was whether the supportive AIDS housing model advanced by Schnitzer in 1989 is sufficiently meeting the demands of current practice, given the changing demographic profile of PWAs. When Schnitzer’s model was conceived, there was very little practical experience in the AIDS housing field against which to test the model’s assumptions. With three more years of practical experience on which to now draw, this thesis explored the degree to which the AIDS housing paradigm proposed by Schnitzer shifts when it becomes a paradigm of implementation.

This study began with a description of the AIDS phenomenon and discussion of the ways in which AIDS becomes a housing issue. Specifically, Chapter One highlighted the fact that AIDS is a lethal and growing epidemic that is expanding demographically from homosexuals to the heterosexual community and which does not discriminate on the basis of age, race or class; it is increasingly becoming associated with the homeless, substance abusers and the urban poor.
As a disease which is episodic, unpredictable and results in susceptibility to a multitude of opportunistic infections and diseases, persons with AIDS (PWAs) are typically unable to work regularly or at all, which results in declining or fixed income—and the consequent loss of their current housing. Because of the stigma associated with the disease and with certain subpopulations, PWAs often experience difficulty accessing new housing due to discrimination. In addition, the nature of the disease often affects a PWAs’ functional abilities in a way or to an extent that renders existing housing options inappropriate, in the absence of supervision, physical adaptability and proximity to community based treatment and care facilities. Although there have been some recent efforts to develop AIDS housing project, the combined number of available units falls far below the level of need.

Chapter Two overviewed the common themes, elements and challenges contained in the literature on special needs housing. And, it highlighted the foremost set of debates within the special needs housing arena. The literature indicated that the need for special needs housing derives chiefly from the fact that some individuals or groups have physical and/or functional limitations which require supportive housing options that: (1) reflect their changing physical and functional abilities over time; (2) promote independence, flexibility and stability, while minimizing disruptions; (3) provide close proximity to community based
services and facilities; (4) avoid, minimize or overcome the stigma and discrimination which these groups typically encounter. The proliferation of housing and service option which have been developed over time, come from changing perceptions about these subpopulations, and incorporates the changing demographics or increasing diversity within the subpopulations.

The literature I reviewed showed a clear bias in favor of independent living or community based housing options as opposed to institution-like facilities, for all of these special needs subgroups.

There are different assumptions made about each group in terms of the outcome of supportive housing. For instance, the presumption about the frail elderly is that due to their chronic condition, their level of physical and mental functionality will gradually decline over time. In the case of the homeless is expected that their condition and level of functionality will improve over time, to the point that they will need fewer services. The chronic mentally ill/mentally retarded are viewed as having a alternating periods of high functionality and brief periods of acute care needs. PWAs are presumed to initially have a high level of functionality that will decline progressively and relatively quickly, and be marked by unpredictable and periods of acute care needs.

In general, PWAs have in common with other special needs groups that they must survive on declining or fixed income,
and rely on subsidies in order to meet their basic needs. PWAs are said to be similar to the frail elderly in that they both experience progressively declining physical and sometimes mental health status due to a chronic condition.

The foremost debates within the special needs housing arena include: (1) whether to move the person to accommodate different stages of their illness, or to change the services in a single place to accommodate the clients changing needs; (2) whether and how best to integrate housing and social services; (3) how to address NIMBY (Not-In-My-Backyard) issues, such as siting and discrimination; and (4) whether PWAs are unique or just another special needs subgroup who deserves no special priority.

Comparing PWAs with the other special needs groups has led some advocates to conclude that PWAs are in fact a special case that not only requires priority, but a tailored continuum of supportive housing options. Schnitzer shares this point of view.

Schnitzer predicted that over time, because of earlier intervention and improved medical treatment, AIDS will become more of a chronic condition. Using the conventional special needs housing model (i.e., the conventional model) applied to these groups as a frame of reference, she argued that notwithstanding the similarities of other special needs groups with PWAs, the conventional model must be adapted--i.e., made more flexible--in order to adequately meet the needs of
persons with AIDS. As an alternative, she offered an AIDS-specific ("ideal") model which consists of seven options, with several alternatives at each option level. Although she described the model in terms of being a "continuum" of housing options, she emphasizes that each PWA need not necessarily advance through each stage or living setting. She also identifies implementation criteria which future project sponsors should incorporate in the planning.

Findings

Reflecting back on the two questions which this research set out to address, although AIDS housing providers do encounter many of the common challenges predicted by the special needs housing literature, the findings for this study indicate that the unique nature of HIV-related illness and the advent of multi-diagnosed PWAs combined to set the housing needs of PWAs apart from the conventional model. Although I conceptually agree with Schnitzer's premise that PWAs require a specially tailored model which reflects the unique and diverse housing need of PWAs, I conclude that even Schnitzer's model needs to be revised to incorporate the three years of in-practice experience that is now available.

Considered in comparison, Schnitzer's ideal model seems to differ from the conventional special needs housing model because of its emphasis on flexibility and sensitivity to the different housing needs of AIDS subpopulations. Also, within
the conventional special needs housing model, the SRO is regarded as a permanent housing alternative to emergency shelter and homelessness. However, within Schnitzer’s AIDS housing model, the SRO can be permanent housing for single adults, but seems to be more widely regarded as transitional housing as an interim measure, while a suitable permanent (independent) option is arranged.

In effect, the AIDS housing world is more problematic than Schnitzer originally thought. As such, this study suggests the need to expand Schnitzer’s planning criteria to include more AIDS-driven implementation considerations, such as contagious disease (TB) protocols, and to reflect the problem people issue.

To summarize the findings, in order to avoid siting problems and discrimination, many project sponsors placed their clients confidentially. The fact that the clients eligible for these units were highly functional made this practice feasible. Other sponsor only attempted to place client or site their facilities in low-income or troubled neighborhoods, in which they were unlikely to meet resistance from other tenants or from absentee landlord. Still other providers developed community support in advance of the project’s development, so as to avoid conflict latter down the line. One project sponsor essentially avoids the issue by
leasing entire buildings and reserving some of the units for PWAs.

Integrating housing and services continues to be a challenge for some of the project sponsors interviewed. This challenge has tended to be more pronounced in situations which involved an actual collaboration between the housing and human service organizations, as opposed to where the project was undertaken by a single sponsor—usually a large service or organization institution that had the in-house capacity to develop and service the project. These findings also suggest that there is a growing need for increased capacity among service providers, especially in the way of conducting client needs assessment.

One program used volunteer liaisons to ensure that vital information was being shared between the housing and service providers, and to monitor clients informally to ensure that changes in client service needs were not going unnoticed. The combined experience of these providers underscores the importance of clearly articulated roles and responsibilities, and building relationships that can withstand re-negotiation, as needed.

Taken together, the new implementation challenges presented in Chapter Three—especially, dying in place; tuberculosis; and difficulties associated with servicing multi-diagnosed clients (especially substance abusers and dementia clients)—played out at the project level in a way
that suggests that the continuum conceptualized by Schnitzer is both a continuum of housing and a continuum of services.

The multi-diagnosed clients are by far the most difficult clients for these providers to service, and have motivated several providers to adopt a variety of mechanisms in an effort to safeguard other tenants, preserve the integrity of the project, and minimize violation of liability insurance. Specific strategies include: (1) adopting formalized contracts and rigid participation policies as a basis for evicting problem clients if necessary; and (2) mandating the each client participate in a 'financial management' program. One program has even implemented routine urine testing as an incentive for former substance abusing clients to resist the inclination to relapse.

In addition to these issues and challenges, a few providers were surprised to find that wheelchair equipment and accessibility was far less of an issue for clients than visual loss. Two of the project staff also noted that their efforts to accommodate client preferences are effectively transforming their programs—e.g., making them more 'institutional'.

**Conclusions & Recommendations**

There are many implications which can be drawn from these findings. Multi-diagnosed PWAs are a growing phenomenon. Although there is no easy formula for managing projects which serve them, there is a growing cadre of providers who are
devising creative and practical strategies for meeting the needs of these clients without jeopardizing the programs’ viability or imposing on other clients and tenants. In most cases, this involves improved case management and drawing on the experience of supportive housing organizations which serve other special needs groups.

The practice of evicting problem tenants is a complicated one, which in all likelihood will continue to raise ethical and practical issues of tenant rights, and whether having these individuals reside in shelters or on the streets is a better alternative--given HIV related contagion and transmission risk.

These findings also raise the question of whether it is always feasible for project sponsors to encourage or allow clients to ‘die in place’. Relatedly, scattered site and unsupervised congregate programs in particular, should anticipate the need to develop processes and forums for other clients and tenant to address morbidity and mortality issues. Otherwise, they should work with clients early on to address the possibility of being relocated to a more suitable (i.e., more specialized) setting.

Relative to scattered site programs especially, in the absence of contagious disease protocols, the practice of confidential placements may put fellow tenants or neighbors, project personnel, and volunteers at risk of infection unnecessarily. This practice needs to be carefully re-
assessed, and all projects should develop the appropriate contagious disease protocols, irrespective of their placement or program admissions strategy. The latter action will require that health care providers play a larger role in program planning and perhaps even on an on-going basis.

There seems to be a dearth of information about how to do reliable tuberculosis screening, as well as a lack of urgency among those who are aware of this growing problem. Furthermore, none of the project sponsors with whom I discussed the issue seemed to be aware that by federal law, both the screening and treatment are free upon request.\(^{71}\) Instituting a TB protocol could begin with having local public health officials hold seminars for local and/or regional AIDS housing sponsors. Newly developed projects should also plan to utilize at least one portion of the facility as an isolation room, in which a new client might comfortably reside while awaiting TB test results. Treatment follow-up will be critical in all living settings in order to avoid further spread of TB in general, and of the multi-drug resistant form in particular.

As AIDS continues to spread throughout the homeless population, it will be interesting to see whether the homeless shelter providers find their projects essentially taken over

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by the AIDS-related challenges raised by this study—particularly the infectious disease and morbidity issues.

Policy Paradoxes & Challenges

This study underscored the fact that providing supportive housing for PWAs can be a complex task. This is true partly because we still know relatively little about the nature of the disease, and about the ways in which it is manifest in the different subpopulations, in particular. And, balancing the rights of PWAs with the rights of others poses some interesting paradoxes and difficult challenges for practitioners and policy-makers alike.

*On the one hand, practitioners want to provide PWAs with as much independence, flexibility and 'normalcy' as possible because clients are already experiencing trauma derived from their changing health and economic status; on the other hand, they need to balance that autonomy with properly safeguarding the health and general welfare of fellow tenants, and property management staff.

*On the one hand, multi-diagnosed client are difficult to service; on the other hand, they are therefore the ones most in need of the supportive housing and services.
*On the one hand, practitioners may need or want to maintain confidentiality of clients; on the other hand, service providers must also ensure that medical and supportive services personnel can regularly access clients in privately-owned buildings.

*Also for practitioners, on the one hand, TB is not new and should not necessarily become the basis for discriminating among AIDS subpopulations for placement in scattered site housing; on the other hand, the current spread of multidrug-resistant TB attests to the potential difficulty of monitoring TB treatment in this living setting.

*On the one hand, there is a potential that AIDS dementia complex becomes a proxy for all anti-social behavior; on the other hand the nature of the illness is such that these individuals are at some point likely to become a problem to themselves and to other people, and one ignores that fact at one’s peril, given that one is concerned with the other community members and with other dimensions of the housing market.

*Advocacy groups and policy-makers also face the dilemma of how to prioritize providing supportive housing and services among the various special needs groups--especially as more people living with AIDS continue to live longer and with
relatively high levels of functionality. It will be interesting to observe what happens among these different constituencies if or when AIDS stops being viewed as such an emergency. AIDS housing advocates in particular will face the challenge of sustaining the interest of coalition members and policy-makers.

*And, although it is important to continue to demand that additional resources be made available for supportive AIDS housing efforts, it is presently very difficult to estimate the real costs of programs and facility development because, until the more recent federal funding programs, providers ran their programs out of leased or donated facilities, and rarely separated out categories of costs. Furthermore, current delivery efforts continue to rely very heavily on volunteer manpower, which is always hard to valuate for budget purposes.

*Policy-makers find themselves caught between two political constituencies. Specifically, on the one hand, there are those who see the housing issue from the AIDS point of view; on the other hand are those who come at the issue from the McKinney and homelessness perspective. The two constituencies come together at some point but they are still different, and in a sense compete for resources and over how to frame the issue.
The urgency and magnitude of the need for supportive AIDS housing has motivated providers and policy-makers to mobilize resources rapidly, yet it is important to remain flexible enough to adapt to new technology, resources, and information about the illness which may enable them to innovate new housing and health care options for PWAs.

Further Research Questions

This research led to some logical, but potentially controversial conclusions. Some federal officials to attack the problem by providing vouchers rather than building new housing for PWAs. The findings from the study indicate that vouchers would not work for everyone. That is to say, some PWAs--e.g., multi-diagnosed clients, need more structure than scattered site programs can afford them. And, providers want more control over the living setting.

As a practical matter, the fact that the AIDS housing need intersects with the affordable housing and homelessness shortages almost guarantees that there will not be a sufficient number of affordable and appropriate units for those seeking them. One logical conclusion from the evidence then is that there clearly needs to be project based housing opportunities for PWAs with multiple diagnoses especially.

Another logical conclusion from my findings is that to house PWAs at high risk of developing TB among other special needs groups who are also at high risk of TB infection (e.g.,
the elderly) is not a prudent thing to do, in the absence of an effective protocol that includes screening, treatment follow-up and monitoring. Although this conclusion seems hard, and is based on a small sampling of projects, the consequence of it being true is sobering and suggests the need to consider these issues squarely and seriously.

The research also raises the question of how many specializations must policy-makers pursue. That is to say, it is unclear whether there are fundamental differences between AIDS dementia complex, and dementia suffered by the elderly or the chronic homeless. If so, are there any intrinsic reasons why PWAs needs separate facilities?

Relatedly, more investigation could also help clarify at what point a McKinney SRO becomes an AIDS-driven SRO just by virtue of the fact that increasing numbers of homeless people with AIDS are showing up. In other words, is there a fundamental difference in providing services to the two groups, and if so, around what issues?

Notwithstanding the fact that this data is only anecdotal, the serious implications of what it has brought to light underscore the need to know more about these issues than my observations. Further, what remains unclear is whether these challenges are common to most projects or simply representative of what is happening on the margin. In either case, these findings argue in favor of making additional
resources available in order to examine these important issues more closely.
### Appendix A: Summary of Classification System For HIV Infection

<table>
<thead>
<tr>
<th>Group</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group I.</td>
<td>Acute Infection</td>
</tr>
<tr>
<td>Group II.</td>
<td>Asymptomatic Infection</td>
</tr>
<tr>
<td>Group III.</td>
<td>Persistent Generalized Lymphadenopathy</td>
</tr>
</tbody>
</table>

Source: Cohen, P.T., MD, PhD, Merle A. Sande, MD and Paul A. Volberding, MD. *The AIDS Knowledge Base: A Textbook on HIV Disease from the University of California, San Francisco and the San Francisco General Hospital.* (1990).
### Appendix A: Summary of Classification System For HIV Infection (Cont'd)

<table>
<thead>
<tr>
<th>Group IV. Other HIV Disease</th>
<th>Clinical manifestations of patients designated by assignment to one or more of the following subgroups (independent of lymphadenopathy.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subgroup A. Constitutional disease</td>
<td>Fever persisting for &gt; one month, involuntary weight loss of &gt; 10% of baseline, or diarrhea persisting more than one month; and absence of concurrent illness or condition other than HIV infection to explain.</td>
</tr>
<tr>
<td>Subgroup B. Neurologic disease</td>
<td>Dementia, myelopathy, peripheral neuropathy; and absence of concurrent illness of condition other than HIV infection to explain.</td>
</tr>
<tr>
<td>Subgroup C. Secondary infectious diseases</td>
<td>Diagnosis of an infectious disease associated with HIV infection or at least moderately indicative of cell-mediated immunity in the two subgroups (next page).</td>
</tr>
<tr>
<td>Subgroup D. Secondary cancers</td>
<td>Kaposi's sarcome, non-Hodgeking's lymphoma, or primary lymphoma of the brain.</td>
</tr>
<tr>
<td>Subgroup E. Other conditions</td>
<td>Presence of other clinical findings or diseases, not classifiable above, that may be attributed to HIV infection or may be indicative of a defect in cell-mediated immunity.</td>
</tr>
</tbody>
</table>

Source: Cohen, P.T., MD, PhD, Merle A. Sande, MD and Paul A. Volberding, MD. The AIDS Knowledge Base: A Textbook on HIV Disease from the University of California, San Francisco and the San Francisco General Hospital. (1990).
<table>
<thead>
<tr>
<th>Subgroup C. Subcategories</th>
<th>Category C-1</th>
<th>Category C-2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Symptomatic or invasive disease due to one of twelve specified secondary infectious diseases listed in the CDC surveillance definition of AIDS: Pneumocystis carinii pneumonia, chronic cryptosporidiosis, toxoplasmosis, extrinintestinal strongyloidiasis, isisporiasis, candidiasis, cryptococcosis, histoplasmosis, mycobacterial infection, cytomegalovirus infection, chronic mucocutaneous or disseminated herpes simplex virus, or progressive multifocal leukoencephalopathy.</td>
<td>Symptomatic or invasive disease due to one of the six other specified secondary infectious diseases: oral hairy lukplakis, multidermatomal herpes zoster, recurrent salmonella bacteremia, nocardiosis, tuberculosis, or oral candidiasis (thrush).</td>
</tr>
</tbody>
</table>

Appendix B: Data from AIDS Quarterly Surveillance Report prepared by the CDC (through March 31, 1992)

### TABLE 6: Reported AIDS Cases By Ethnicity

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>1989* (%)</th>
<th>1992* (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White, not Hispanic</td>
<td>63,293 (56)</td>
<td>116,542 (53)</td>
</tr>
<tr>
<td>Black, not Hispanic</td>
<td>30,643 (27)</td>
<td>63,941 (29)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>17,199 (15)</td>
<td>35,582 (16)</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>687 (1)</td>
<td>1,365 (1)</td>
</tr>
<tr>
<td>India/Alaskan Native</td>
<td>150 (0)</td>
<td>352 (0)</td>
</tr>
<tr>
<td>Other/Unknown</td>
<td>269 (0)</td>
<td>519 (0)</td>
</tr>
</tbody>
</table>

### TABLE 7: Comparison of Distributions of Cases Among Adults By Gender (1989/1992)

<table>
<thead>
<tr>
<th>Gender</th>
<th>1989* (%)</th>
<th>1992* (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males:</td>
<td>100,325 (91)</td>
<td>192,002 (90)</td>
</tr>
<tr>
<td>Females:</td>
<td>10,008 (9)</td>
<td>22,607 (11)</td>
</tr>
<tr>
<td>Total:</td>
<td>110,333 (100)</td>
<td>214,609 (100)</td>
</tr>
</tbody>
</table>
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