PLANNING TO MEET THE HOUSING AND SOCIAL SERVICE NEEDS OF PEOPLE WITH AIDS AND HIV INFECTION IN BOSTON

by

PAULA SCHNITZER

B.A. Brown University (1982)

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

MASTER OF CITY PLANNING

at the

MASSACHUSETTS INSTITUTE OF TECHNOLOGY

June 1989

© Paula Schnitzer 1989. All rights reserved.

The author hereby grants to M.I.T. permission to reproduce and to distribute copies of this thesis document in whole or in part.

Signature of the Author..................................
Department of Urban Studies and Planning, May 12, 1989

Certified by..................................................
Frank S. Jones
Ford Professor of Urban Affairs

Accepted by..................................................
Donald A. Schon
Chair, Master of City Planning Committee
DISCLAIMER OF QUALITY

Due to the condition of the original material, there are unavoidable flaws in this reproduction. We have made every effort possible to provide you with the best copy available. If you are dissatisfied with this product and find it unusable, please contact Document Services as soon as possible.

Thank you.

Some pages in the original document contain text that runs off the edge of the page.
PLANNING TO MEET THE HOUSING AND SOCIAL SERVICE NEEDS OF
PEOPLE WITH AIDS AND HIV INFECTION IN BOSTON

by

Paula Schnitzer

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

MASTER OF CITY PLANNING

ABSTRACT

An analysis of the housing and social service needs of people with Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) infection in Boston was completed. The study identified a number of factors which must be considered in planning housing and social services for people with AIDS, developed a model for an ideal system of housing and service options and described current efforts in Boston to meet the need.

The study concluded that as AIDS becomes more of a chronic illness affecting greater numbers of people, the current system of housing and social services for people with AIDS in Boston will become more inadequate. It recommends a number of steps the City of Boston should take to effectively meet the need for a comprehensive, coordinated system of housing and social services for people with AIDS.

Thesis Supervisor: Frank S. Jones

Title: Ford Professor of Urban Affairs
# TABLE OF CONTENTS

INTRODUCTION................................................1

CHAPTER 1: THE SOCIAL CONTEXT OF THE AIDS EPIDEMIC...........8

CHAPTER 2: HOUSING PEOPLE WITH AIDS........................16

CHAPTER 3: AN IDEAL SYSTEM OF HOUSING OPTIONS FOR PEOPLE...35
WITH AIDS

CHAPTER 4: CURRENT HOUSING OPTIONS FOR PEOPLE WITH AIDS....55
IN BOSTON

CHAPTER 5: RECOMMENDATIONS: RECONCILING THE IDEAL WITH.....68
THE POSSIBLE
"[T]he extreme nature of AIDS so stresses the system that cracks appear that are normally obscured."\(^1\)

INTRODUCTION

It is difficult not to feel a sense of urgency about the disastrous consequences of the convergence of two of our worst urban crises--the shortage of affordable housing in many cities in the United States and the Acquired Immune Deficiency Syndrome (AIDS) epidemic. But, perhaps for the vast majority, the connection is not intuitively clear. This thesis addresses these important questions: What kind of housing do people with AIDS (PWAs) need and why is it so difficult to provide it? What is an appropriate planning process to coordinate housing and social service needs? What is currently being done in the city of Boston, and what more is needed?

The crisis of housing and homelessness and its impact on people with AIDS

A growing crisis of housing and homelessness has been developing in this country for a number of years, particularly in this decade. In the city of Boston, both inadequate supply and lack of affordability are critical problems. The City lost approximately 20,000 units of rental housing between 1980 and 1988, primarily due to conversion to condominiums. Less than

5500 new subsidized units were created to replace them.\(^2\) This occurred at a time when Boston's population increased for the first time in forty years, a trend which is expected to continue well into the 1990s.\(^3\) As population increased, vacancy rates decreased and the cost of both rental housing and homeownership skyrocketed.\(^4\)

In a tightening housing market, affordability of homeownership and rental housing has worsened. A study of twenty-nine metropolitan areas done by the National Association of Realtors found that Boston had the worst housing affordability ratio, measured by the ratio of housing prices to median annual wages.\(^5\) The percentage of households paying more than fifty percent of income for rent increased from eleven percent in 1980 to twenty percent in 1985.\(^6\) One study of housing affordability in Boston concluded that more than 76,000 families were paying


\(^4\)Ibid., p. 2.


more than they can afford for rental housing or homeownership.  

Homelessness in Boston has also been on the rise. A census of homeless people in shelters or on the street in the winter of 1988-89 counted almost 3500 men, women and children. This was a twenty-two percent increase from the number of homeless people counted in a similar census the previous winter. The census data does not count the "invisible" homeless who are living in overcrowded or substandard housing, or who are uncounted for other reasons. 

Finding and keeping decent and affordable housing in a tight housing market like Boston's presents a unique challenge to people with AIDS, because all of the problems of affordability and accessibility which other Boston residents face are exacerbated for people with AIDS. Affordability becomes more of a problem as many people with AIDS become too sick to work and can no longer afford their current housing without subsidies. As their illnesses progress, some people will need more intensive services and supports, which may mean accessing in-home care or specialized residential programs. To allow people to remain independent as long as possible, it is critical that housing be linked with important services, such as assistance with meals,


transportation, homemaking and case management.

There are also people who are either being discharged from hospitals with no place to go, or in many cases not being discharged because they have no place to go. Prolonged, unnecessary hospitalization is not only inappropriate, but at an average cost of $700\textsuperscript{10} per day, is the most costly way to "house" someone.

Displacement of people with AIDS from their housing due to discrimination is also a big problem. Unfortunately, fear and ignorance often result in PWAs' forced eviction from their homes by landlords, roommates and families.\textsuperscript{11}

Some PWAs are homeless for other reasons before getting sick. Among the chronically homeless population, the increasing incidence of human immunodeficiency virus (HIV) infection and AIDS is presenting new problems in sheltering and housing this group, particularly as many of the HIV infected homeless people are intravenous drug users.

A glimpse of the future offers us a picture of growing numbers of people living with HIV infection and AIDS for longer

\textsuperscript{10}George R. Seage, et al, "Cost of Medical Care for Patients with Acquired Immunodeficiency Syndrome (AIDS)," prepared for publication in the Journal of the American Medical Association. The authors found that a sample of AIDS patients in Massachusetts Hospitals stayed an average of 33.2 days/year in the hospital at an average cost/year of $22,097.

\textsuperscript{11}Ann Arata, Leasing and Occupancy Director, Cambridge Housing Authority, presentation at "AIDS and Housing" conference, March 20, 1989; Ann Sanders, Mayor's Liaison to the Gay and Lesbian community, City of Boston, personal interview, April 18, 1989.
periods of time. As new treatment and care of people with AIDS continues to prolong lives, AIDS is becoming a chronic condition. While episodes of acute illness may require hospitalization, during non-acute phases, many people are able to live at home if appropriate social or medical support services are available. First and foremost, therefore, people need a place to live, with coordination and integration of whatever support services are necessary. This is imperative to keeping them out of hospitals, shelters, inappropriate living situations and off the streets.

Scope of this thesis

In this thesis, I address the need for a comprehensive system of housing and social services for people with AIDS and HIV infection in Boston. First, I lay out the social context of the AIDS epidemic and how this has affected caring for people with AIDS, including providing housing. This epidemic, like many others, has been characterized by stigmatization and discrimination. In this case it is due mainly to existing stigmatization of the groups most affected by the different "waves" of the epidemic. The first wave was (and continues to be) among gay men, a group already stigmatized for its lifestyle. The second and third waves of the epidemic are affecting intravenous drug users and women and children. There is disproportionate representation of communities of color and poor women and children, members of the so-called urban "underclass."

Second, I look at a number of important criteria which must
be considered in determining what an appropriate housing and service system might be. This includes projecting the number of people who will be living with AIDS, and the different factors which determine their housing needs. A person with AIDS' housing needs vary based on physical health, mental health, economic status, existing housing, support systems and personal preference. Intravenous drug users and women and children will have particular needs in addition to these. In order to develop an ideal housing and service system, the need to overcome stigmatization and to effectively coordinate housing and service systems is as important as identifying personal factors affecting an individual's housing needs. There are particularly troublesome questions about serving the intravenous drug using population.

In Chapter 3 I lay out an ideal model of housing and social service options for people with AIDS. The model is designed to account for the complexities of the problem and the need for a wide range of solutions.

Chapter 4 is a "case study," of sorts, of efforts in the Boston area to meet the housing and social service needs of PWAs, and where they fit into the conception of an ideal model of housing and services. I identify who is currently doing development and planning at the community, city and state level and some of the obstacles they face.

A vision of an ideal system must always be tempered with consideration of what currently exists and the realistic
assessment of financial and political constraints. Chapter 5 provides some recommendations about ways to strengthen existing communication and cooperation as keys to developing an integrated housing and services system.

Methodology

Because it is only recently that planners have begun to focus on the housing needs of people with AIDS, there is not a lot of written material on the subject. My research, therefore, relies heavily on personal interviews with planners and providers at the community, city and state level, and provide the bulk of my references for chapters 3 and 4. There is a growing body of literature about the AIDS epidemic in general, and I draw on this for the background information presented in chapter 1. The statistics and numerical data in chapter 2 are from the national Centers for Disease Control, the Massachusetts Department of Public Health and Center for Communicable Diseases, and the City of Boston Department of Health and Hospitals.
CHAPTER 1: THE SOCIAL CONTEXT OF THE AIDS EPIDEMIC

Every minute, someone in the world becomes infected with HIV, the human immunodeficiency virus which causes AIDS and a host of other HIV-related illnesses. The virus attacks the human immune system, leaving it vulnerable to a wide range of opportunistic infections. The United States currently has the dubious distinction of reporting the majority of the world's cases. As of the end of March, more than 90,000 people in the United States have been diagnosed with full-blown AIDS, and approximately half of them have died. In addition, the federal Centers for Disease Control (CDC) estimates that there are currently one to two million people infected with HIV, most of whom will probably develop AIDS within ten years of infection.

AIDS is a perplexing issue which engenders a great deal of denial, fear, prejudice and hysteria. Since 1983, we have


13 The New England Journal of Public Policy Special Issue on AIDS (Winter/Spring 1988, p. 9) offers the following definitions: "AIDS is a disease caused by a virus known as HIV, in which the body's immune system is seriously damaged, leaving it vulnerable to infections and some rare cancers that ultimately result in death. AIDS-related complex (ARC) patients have some symptoms of AIDS, but not the "full-blown" disease.


16 Ibid., p. 18.
known that AIDS is caused by a virus (HIV) which is transmitted through exchange of infected bodily fluids, predominantly blood and semen. Nevertheless, irrational fears of contracting the virus through casual contact remain, and stigmatization of and discrimination against people who are infected with HIV or have AIDS has not abated. The consequence has been that we as a society have been slow to take the appropriate action necessary to prevent the spread of the virus, to find a cure for HIV-related illnesses and to provide humane care for people with AIDS (PWAs). It is precisely because of this that as we approach the second decade of the AIDS epidemic we have very few of the necessary structures in place.

A common and dangerous mistake in this epidemic has been to erroneously equate the disease and risk for contracting the virus with certain groups, as opposed to certain behaviors. The waves of the epidemic to date have disproportionately affected groups which our society already considers marginal, undesirable and threatening and whose lives are expendable. Since the epidemic has been most closely associated with gay or bisexual men (who still make up the majority of current AIDS cases) and intravenous drug users (one of the fastest growing rates of infection is among intravenous drug users, their sex partners and children), there are people who still think this is strictly a gay or needle-users disease.

There are several consequences to this way of thinking. By ignoring the fact that it is through certain behaviors that
someone is at risk, rather than affiliation with a certain group, many people may put themselves at risk of contracting the virus. But equally as problematic is the social context in which this epidemic arose, which prohibits us from addressing the epidemic appropriately. As social historian Alan Brandt writes:

>We need to perform a difficult task; that of separating deeply irrational fears from scientific understanding. Only when we recognize the ways in which social and cultural values shape this disease will we be able to begin to deal effectively and humanely with a problem as serious and complex as AIDS. 17

However, this is no small task. We live in a society that views both homosexuality and drug use as deviant—even criminal—behavior. Obviously there are differences in the stigmatization of these two groups. While sodomy is illegal in many states, homosexuality is not judged on the same level of criminal activity as drug use. In addition, members of the gay community have much more access to community and personal support systems, and in many ways are less marginalized. There are very real differences in perceptions of the two groups, yet they both fall prey to similar misconceptions.

There are lingering moral judgments that people who contract the disease are in some way culpable and deserving; if they did not engage in certain behaviors, they would not have contracted the virus. This argument has become less common as the virus has begun to spread more widely through heterosexual contact; yet,

still the stigmatization of gay/bisexual men and intravenous drug users (IVDUs) persists. Recently, Dr. Mervyn Silverman, president of the American Foundation for AIDS Research and past Commissioner of Public Health in San Francisco, observed that even after eight years of the AIDS epidemic in this country, social and political attitudes toward people with AIDS remain characterized by "enormous denial, apathy, ignorance and bigotry."\^1^8

Hemophiliacs or transfusion recipients who received infected blood products and children who contracted the virus from their mothers are often portrayed as "innocent" victims. This reinforces the idea that there are those who are not innocent, but in some way deserving, i.e. gay men and intravenous drug users. Historically, this is not a new phenomenon. In the early twentieth century, for example, there were similar attitudes about blameless versus "deserving" syphilis sufferers.\^1^9 This has also happened during other epidemics. As Mervyn Silverman points out, "Society is managing no better than what we did with the plague and the cholera epidemic in the 1830s."\^2^0

The AIDS epidemic cannot be viewed as merely a medical or a public health issue, due to the social construction of disease and the fact that we place social and moral meanings onto

\^1^8^"After 8 years, AIDS attitudes are stubborn, specialist says," Boston Globe, April 7, 1989, p. 32.

\^1^9^Brandt, p. 201.

\^2^0^Boston Globe, April 7, 1989.
illness. As Brandt suggests:

AIDS is an unfinished chapter in our medical and social history. It reveals the contemporary nature of biomedical science and research; our beliefs about health, disease, and contagion; our ideas about sexuality and social responsibility. AIDS demonstrates how economics and politics cannot be separated from disease; indeed, these forces shape our response in powerful ways. In the years ahead we will, no doubt, learn a great deal about the nature of our society from the manner in which we address the disease. AIDS will be a measure upon which we may calibrate not only our medical and scientific skill but our capacity for justice and compassion.

What makes AIDS particularly challenging is the fact that it is not just a medical or public health problem, but rather it is weaving itself throughout our social structure in some very complex ways. A recurrent theme in the literature about the impact of AIDS on our society is exemplified by Mary Catherine Bateson and Richard Goldsby's observation in Thinking AIDS that, "AIDS moves along the fault lines of our society, and becomes a metaphor for understanding that society."  

There is no better place to observe the consequences of the AIDS epidemic's movement along our society's "fault lines" than in our inner cities. AIDS in the United States has been concentrated in cities--increasingly in cities already torn by race and class divisions, facing the problems of poverty and

---


22 Brandt, pp. 203-4.

economic injustice, widespread use and sale of drugs, lack of affordable housing, discrimination and violence against people of color, gay men, lesbians and women, and the whole gamut of urban problems which city dwellers and planners confront on a daily basis. On top of this we lay the AIDS crisis, a new and overwhelming burden to systems which are already underfunded, stressed and disintegrating.

AIDS is a complex issue. The epidemic forces us to look at race, class, and gender inequality, to face squarely the causes and consequences of drug use, and to discuss the taboo subjects of sexuality and death. It is no wonder that many people get overwhelmed when they think about the implications of this epidemic on our society and our social and economic future; it is overwhelming. An effective response to this epidemic requires an ability to see beyond its enormity and understand it as a challenge and an opportunity to creatively address society's fault lines and cracks:

The AIDS crisis represents an immense tragedy for many persons and a danger for many more. It also represents an opportunity for changes in our understanding of human biology and social life and the ways in which we use knowledge. From this point of view, the epidemic is a moment of opportunity for discovering the full potential of humanness. If we can use the impetus of AIDS to expand and apply knowledge cooperatively and humanely, we may also learn to control the dangers of the arms race and of world hunger and environmental degradation, for the imagination of AIDS is the imagination of human unity, intimately held in the interdependent web of life.24

24Ibid., pp. 10-11.
There are no known preventive vaccines or cures for AIDS, and it is unclear when, if ever, researchers will be able to develop them. Consequently, education and prevention are our only tools to stop the spread of the virus. Efforts to do so have had mixed results. Education and prevention efforts in urban gay male communities have contributed to very low rates of new infection with the virus in those communities. But, education efforts among intravenous drug users, women, and among communities of color have been much less effective.²⁵

Even if we could prevent the spread of the virus, there are still tens of thousands of people living with AIDS and millions already infected with the virus. And, realistically, people are and will continue to get infected in the years to come. It is projected that by 1991, there will be 270,000 cumulative AIDS cases in the U.S.²⁶ While it is important to work on education, prevention and cures for AIDS, we also have to address the reality that there will be many people living with AIDS for many years to come. Meeting their needs for care is just as difficult and just as important as preventing further spread of the virus.

Looking at the complex needs of PWAs and the different systems which must be called upon to meet those needs provides another example of the fault lines in our society and the cracks


in our systems. PWAs need access to a number of different systems: medical care, mental health care, social services, drug treatment, housing, etc.; systems that have not been well coordinated historically and which have not met people's needs in an integrated way.²⁷ The AIDS crisis is further stressing these systems and exacerbating the problems caused by lack of communication, coordination and planning.

²⁷Laurie Novick, Coordinator of Social Service Advocacy, AIDS ACTION Committee, personal interview, April 2, 1989.
CHAPTER 2: HOUSING PEOPLE WITH AIDS

We need to consider several central issues in planning to meet the housing needs of people with AIDS (PWAs). First, we must have projections of the numbers of people who will need housing units. Second, we need to consider that there are different groups of people with different needs and complicating factors due to their race, gender, economic status or drug addiction. We have to take into consideration the growing proportion of PWAs who are intravenous drug users (IVDUs), the growing proportion of low-income women and their children, and the rising incidence of AIDS among chronically homeless people. Third, there are many different kinds of opportunistic infections which PWAs get as a result of having suppressed immune systems. These opportunistic infections have different physical and neurological manifestations which may change over time and may be unpredictable. Fourth, we need to address the need for housing and services planning and coordination at many levels. Finally, we need to deal with the issue of stigmatization and the consequent discrimination.

Numbers of AIDS cases in Massachusetts and in Boston

As of March 31, 1989, there were 2205 reported AIDS cases in Massachusetts. Forty-two percent (928) were Boston residents. Table 1 shows cumulative AIDS case data for Massachusetts and the United States by transmission category, primary diagnosis, sex,
### AIDS SURVEILLANCE SUMMARY: STATE AND NATIONAL COMPARISONS

<table>
<thead>
<tr>
<th>Residence</th>
<th>Massachusetts (2,205)*</th>
<th>United States (87,188)**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. (%)</td>
<td>No. (%)</td>
</tr>
<tr>
<td>City of Boston</td>
<td>928 (42)</td>
<td>85,756</td>
</tr>
<tr>
<td>Remainder SMSA</td>
<td>516 (23)</td>
<td></td>
</tr>
<tr>
<td>Remainder State</td>
<td>553 (25)</td>
<td></td>
</tr>
<tr>
<td>Out-of-State</td>
<td>208 (9)</td>
<td>2,873 (3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transmission Categories (Adults)</th>
<th>Massachusetts (2,164)</th>
<th>United States (85,756)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homosexual/Bisexual Male</td>
<td>1,341 (62)</td>
<td>52,758 (62)</td>
</tr>
<tr>
<td>I.V. Drug User</td>
<td>376 (17)</td>
<td>17,226 (20)</td>
</tr>
<tr>
<td>Homosexual Male/I.V. Drug User</td>
<td>93 (4)</td>
<td>6,140 (7)</td>
</tr>
<tr>
<td>Hemophilia</td>
<td>32 (1)</td>
<td>831 (1)</td>
</tr>
<tr>
<td>Heterosexual Cases***</td>
<td>187 (9)</td>
<td>3,792 (4)</td>
</tr>
<tr>
<td>Transfusion Blood/Components</td>
<td>70 (3)</td>
<td>2,136 (2)</td>
</tr>
<tr>
<td>None of the Above</td>
<td>65 (3)</td>
<td>2,873 (3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transmission Categories (&lt;13 yrs)</th>
<th>Massachusetts (41)</th>
<th>United States (1,432)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent with AIDS/at risk for AIDS</td>
<td>33 (80)</td>
<td>1,119 (78)</td>
</tr>
<tr>
<td>Hemophilia</td>
<td>2 (5)</td>
<td>85 (6)</td>
</tr>
<tr>
<td>Transfusion, Blood/Components</td>
<td>6 (15)</td>
<td>176 (12)</td>
</tr>
<tr>
<td>None of the above</td>
<td>0 (0)</td>
<td>52 (4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Primary Diagnosis (hierarchical order)</th>
<th>Massachusetts (1,323)</th>
<th>United States (51,960)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumocystis carinii Pneumonia</td>
<td>1,323 (60)</td>
<td>51,960 (60)</td>
</tr>
<tr>
<td>Other Opportunistic Diseases</td>
<td>644 (29)</td>
<td>27,719 (32)</td>
</tr>
<tr>
<td>Kaposi's Sarcoma</td>
<td>238 (11)</td>
<td>7,509 (9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sex</th>
<th>Massachusetts (1,968)</th>
<th>United States (79,091)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1,968 (89)</td>
<td>79,091 (91)</td>
</tr>
<tr>
<td>Female</td>
<td>237 (11)</td>
<td>8,097 (9)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Condition</th>
<th>Massachusetts (1160)</th>
<th>United States (37,212)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alive</td>
<td>1160 (53)</td>
<td>37,212 (43)</td>
</tr>
<tr>
<td>Dead</td>
<td>1045 (47)</td>
<td>49,976 (57)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>Massachusetts (1,544)</th>
<th>United States (49,945)</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>1,544 (70)</td>
<td>49,945 (57)</td>
</tr>
<tr>
<td>Black</td>
<td>442 (20)</td>
<td>23,290 (27)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>204 (9)</td>
<td>13,154 (15)</td>
</tr>
<tr>
<td>Other/Unknown</td>
<td>15 (1)</td>
<td>799 (1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Massachusetts (41)</th>
<th>United States (1,432)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 13</td>
<td>41 (2)</td>
<td>1,432 (1)</td>
</tr>
<tr>
<td>13-19</td>
<td>12 (1)</td>
<td>350 (0)</td>
</tr>
<tr>
<td>20-29</td>
<td>480 (22)</td>
<td>18,006 (21)</td>
</tr>
<tr>
<td>30-39</td>
<td>1051 (48)</td>
<td>40,290 (46)</td>
</tr>
<tr>
<td>40-49</td>
<td>444 (20)</td>
<td>18,245 (21)</td>
</tr>
<tr>
<td>over 49</td>
<td>177 (8)</td>
<td>8,865 (10)</td>
</tr>
</tbody>
</table>

*Includes 285 cases meeting the revised case definition.

**U.S. data as of 2/28/89.

***Includes 70 persons who have had heterosexual contact with high risk individuals and 117 persons born in countries in which heterosexual
mortality status, race and age.

The Boston Department of Health and Hospitals projects that by 1992 there will be 5688 cumulative AIDS cases in the city, with 1268 of them diagnosed in 1992. (See Figure 1) Of the 5688 cumulative cases projected through 1992, approximately 3601 will be gay men and 2467 will be IVDUs. Of the new cases expected to be diagnosed in 1992, approximately 734 will be gay men, 711 will be IVDUs and 490 will be "others" (See Figures 2, 3, 4).

Currently, approximately half of the people diagnosed with AIDS are living at any one time. Therefore, based on the projection of 5688 cumulative AIDS cases in Boston in 1992, at least 2844 PWAs will be living in 1992. New advances in research and treatment of PWAs may expand the number living with AIDS by 1992. In addition, estimates are that for every reported case that meets the Centers for Disease Control (CDC) definition of full-blown AIDS, there are an additional 10-20 people who are asymptomatic but infected with HIV, or who are ill with symptoms which do not meet the clinical definition of AIDS. Assuming this continues to be true in 1992, in addition to the minimum of 2844 people living with AIDS in Boston, there may also be an additional 28,000 to 56,000 HIV infected people who may or may not have developed symptoms.

Obviously, not everyone who has AIDS or HIV infection is going to need assistance with housing. Many people will have access to informal support networks of friends and family so that they can either stay in their current housing situation or move
Actual and Projected AIDS Cases

Number of Cases

Year of Diagnosis

Gay Men
IV Drug Users
Other
AI
Figure 2

Actual and Projected AIDS Cases

GAY MEN

![Graph showing actual and projected AIDS cases for gay men from 1984 to 1992. The graph includes actual cases, projected cases, and 95% confidence intervals.]
Figure 3

Actual andProjected Cases
IVDUs (Sqrt Model)

<table>
<thead>
<tr>
<th>Year of Diagnosis</th>
<th>Actual</th>
<th>Projected</th>
<th>Low95%</th>
<th>Up95%</th>
</tr>
</thead>
<tbody>
<tr>
<td>84</td>
<td>35</td>
<td>35</td>
<td>35</td>
<td>35</td>
</tr>
<tr>
<td>85</td>
<td>47</td>
<td>47</td>
<td>47</td>
<td>47</td>
</tr>
<tr>
<td>86</td>
<td>74</td>
<td>74</td>
<td>74</td>
<td>74</td>
</tr>
<tr>
<td>87</td>
<td>127</td>
<td>127</td>
<td>127</td>
<td>127</td>
</tr>
<tr>
<td>88</td>
<td>203</td>
<td>203</td>
<td>203</td>
<td>203</td>
</tr>
<tr>
<td>89</td>
<td>417</td>
<td>417</td>
<td>417</td>
<td>417</td>
</tr>
<tr>
<td>90</td>
<td>299</td>
<td>299</td>
<td>299</td>
<td>299</td>
</tr>
<tr>
<td>91</td>
<td>554</td>
<td>554</td>
<td>554</td>
<td>554</td>
</tr>
<tr>
<td>92</td>
<td>711</td>
<td>711</td>
<td>711</td>
<td>711</td>
</tr>
</tbody>
</table>

Number of Cases

Year of Diagnosis
Figure 4

Actual and Projected Cases

OTHERS (Sqrt Model)

![Graph showing actual and projected cases over years with squared model predictions.](image)
in with someone else. Others will be able to purchase whatever housing and service resources they need in the "private" market and will not need access to publicly-subsidized housing and services. A rough approximation of the percentage of people who will need publicly-subsidized special needs resources is thirty percent of the total of that special needs population. Applying this percentage to the numbers of people with AIDS, we can project that by 1992 at least 853 PWAs will need access to publicly-subsidized housing. This calculation includes only those who are projected to have full-blown AIDS, and does not include any of the estimated 28,000+ HIV-infected people.

While the rough approximation of thirty percent in need of publicly-subsidized resources may be a good place to start in planning numbers of housing units, it doesn't tell the whole story. As the first wave of the epidemic gives way to the second and third waves, we can safely assume that there will not be an even distribution of people who do and do not need access to publicly-subsidized resources on the basis of race, gender and drug use.

The effect of changing demographics of PWAs on need for housing

The demographics of the AIDS epidemic are clearly shifting. While the majority of PWAs today are gay white men (even though rates of new infection are decreasing), AIDS is

---

disproportionately affecting communities of color and women. According to the 1980 census in Boston, black people ages 15-49 represented 22% of the population, but as of September 1988 were 32% of the reported AIDS cases for that age group.\textsuperscript{29} Table 2 shows the number of reported AIDS cases per 100,000 of population for Boston and Massachusetts, broken down by race. Stated another way, the table shows that for Boston residents ages 15-49, a white person has a 1 in 548 chance of having AIDS, a hispanic person has a 1 in 418 chance and a black person has a 1 in 333 chance.

Black females made up 23% of the female population in the 1980 census, but represented 78% of female AIDS cases in Boston as of September 1988.\textsuperscript{30} Table 3, AIDS incidence per 100,000 population disaggregated by race and sex, shows that a white female Boston resident has a 1 in 11,494 chance of having AIDS, a hispanic female has a 1 in 2710 chance, and a black female has a 1 in 775 chance.

Between 1983 and 1988, the proportion of total AIDS cases in the state who were women increased from 2.2% to 10.6%. Seventy-nine percent of the women with AIDS were of childbearing age (between 13 and 39 years old).\textsuperscript{31} Since approximately forty

\textsuperscript{29}The Boston AIDS Consortium Task Force Reports and Preliminary Recommendations, November 1988, p. 83.

\textsuperscript{30}Ibid., p. 84.

\textsuperscript{31}"Epidemiology of AIDS in Massachusetts: An Update," AIDS Surveillance Program, Massachusetts Center for Disease Control, February 1989.
Table 2: AIDS Incidence per 100,000 population by race*

<table>
<thead>
<tr>
<th></th>
<th>Males and Females Age 15-49</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boston residents</td>
<td>MA residents</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>182.5</td>
<td>35.9</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>300.7</td>
<td>247.8</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>239.3</td>
<td>175.7</td>
<td></td>
</tr>
</tbody>
</table>

* Based on 1980 population figures and September 1, 1988 AIDS case data.
(Source: Boston AIDS Consortium, p. 83A)

Table 3: AIDS Incidence per 100,000 population by race and sex*

<table>
<thead>
<tr>
<th></th>
<th>Males Age 15-49</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boston residents</td>
<td>MA residents</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>361.4</td>
<td>69.6</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>505.8</td>
<td>411.4</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>467.6</td>
<td>327.4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Females Age 15-49</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Boston residents</td>
<td>MA residents</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>8.7</td>
<td>3.5</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>129.1</td>
<td>101.2</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>36.9</td>
<td>37.8</td>
<td></td>
</tr>
</tbody>
</table>

* Based on 1980 population figures and September 1, 1988 AIDS case data.
(Source: Boston AIDS Consortium, p. 84A)
percent of babies born to infected mothers end up HIV infected also, there is clear evidence that an increasing proportion of infected women and their children will require housing options which are appropriate for families where parents and/or children may have AIDS or be infected with HIV.

In addition to an increasing proportion of women with AIDS, there is also a trend to a higher proportion of intravenous drug users (IVDUs). Between 1985 and 1988, the proportion of AIDS cases of IVDUs in the state increased from 14% to 23%. There are currently an estimated 40,000 IVDUs in the state; approximately twenty-five percent, or 10,000 of them are probably HIV infected. In fact, these two trends are related, as intravenous drug use remains the main transmission category for women, followed by heterosexual contact with a person at risk for AIDS, often as the result of iv drug use.

Planners are faced with some difficult dilemmas about meeting the housing needs of PWAs who are active drug users. While a compassionate response may be that any sick person deserves care and shelter, the precedent in housing programs has always been to exclude active illegal drug users, with the exception of residential drug treatment programs. Meeting this

---


34 "Epidemiology of AIDS in Massachusetts: An Update."
challenge will mean figuring out a way for every willing addict
to receive treatment on demand, providing ongoing support for
recovering addicts and addressing squarely the fact that some
addicts will not be willing to enter treatment, even if it is
available.

The effect of the nature of the illness on housing needs

One of the greatest challenges in planning for housing needs
of PWAs results from the nature of HIV-related diseases. People
suffer from different combinations of opportunistic infections
which their bodies' suppressed immune systems are unable to
fight. In addition to physical manifestations of illness which
may affect an individual's ability to live independently and need
for support services, sixty-three percent of PWAs also have some
type of neurological symptoms during the course of their
illness.\(^3^5\) The most common neurological impairment is HIV
encephalopathy, also known as AIDS dementia. It can cause memory
loss, disruptive and hard to manage behavior and motor
impairment.\(^3^6\) People with AIDS dementia often need twenty-four
hour supervision.

People with AIDS do not necessarily experience the
progression of the disease in a linear fashion. While some

\(^3^5\) Alexandra Beckett and Theo Manschreck, "Neuropsychiatric
Complications of HIV Infection: Public Policy Implications," New
England Journal of Public Policy, Special Issue on AIDS,
Winter/Spring 1988, p. 112.

\(^3^6\) Ibid., p. 111.
people do become sick and steadily deteriorate until they die, others may live relatively well for periods of time which may be interrupted by episodes of acute illness.

One model of a continuum of housing needs to meet the housing needs of PWAs depending on their health status, was developed by the Housing Resource Developer at the AIDS ACTION Committee (AAC), a Boston-based AIDS service organization. (See figure 5) This model provides a useful basis for thinking about what housing and services options are appropriate for what populations, and some possible funding sources for developing each type of resource.

Coordination

A person with AIDS needs access to a number of different resources and systems during his/her lifetime, often needing many at the same time. For example, a person may need housing, medical care, mental health care, home health care, meals, transportation and homemaker services all at once. Drug addicts may need all of the above and drug treatment at the same time. Families may need child care, respite care, and/or foster care along with everything else. The key to meeting all of these needs is two-fold. First, strong individual case management is necessary so people receive information about their rights and options, as well as assistance and advocacy so they are able to access a range of appropriate resources. Second, providers and planners of different systems must communicate better and
### CONTINUUM OF HOUSING NEEDS FOR PEOPLE LIVING WITH AIDS

#### Appropriate Client

| Client diagnosed with AIDS or ARC. Living well | Client diagnosed with AIDS or ARC. Living well but in need or desiring support of communal setting. | Client diagnosed with AIDS or ARC. Client in need of 24 hour supervision due to physical or mental limitations, etc. | Client diagnosed with AIDS or ARC. Client in last stages of illness and in need of complex medical services. |

#### Goal

- To keep client in his or her own apartment if possible. If not, to access a subsidized housing unit.
- To allow clients to maintain a large degree of independence while providing some support systems.
- To allow clients to live in a homelike setting while providing extensive support services.
- To provide for the physical, psycho-social and spiritual needs of people living with AIDS as they get closer to death. To avoid hospitalization.

#### Type of Housing Resources

- Private rental housing or unit in public housing
- Congregate housing - a large single family.
- Multi-unit housing - either a number of units within a building or scattered sites. (Some units should be wheelchair accessible.)
- Hospice.

#### Services

- AIDS ACTION staff-based client advocacy, supported by volunteer services.
- Provide group living environment with emphasis on mutual support. No medical, psychological or addiction counseling services provided but strong advocacy system in place to access services.
- 24-hour supervision. Medical and nursing care and other services, including protective services, support services, community programs, information and referral, and case management.

#### Funding Sources

- Rental assistance available through set aside of Section 8.
- Rental assistance available through Chapter 707 programs administered by local housing authorities.
- Housing Innovations Fund: deferred payment loans for capital costs.
- 659 Program for development of special needs housing.
- 667/705 Programs - AIDS patients eligible for handicapped units within public housing.
coordinate and integrate services to facilitate access, fill in gaps and eliminate duplication.

Another important consideration is to look at the needs of an entire household, not just at the individual with AIDS. This means considering support services for caregivers, including respite care and emotional support. It also means developing adult day care programs for people who can stay in their current living situation due to existing support systems, but who cannot be alone during the day when the caregiver is not home. Considering the needs of the entire household also means addressing the question of how other members' housing needs change when the PWA needs to move or dies.

Stigmatization

Stigmatization of PWAs and the ensuing discrimination have implications for meeting the housing needs of PWAs. Community fear and resistance often contribute to the displacement of PWAs from their homes when their HIV status becomes known and provide major obstacles to siting new programs in residential neighborhoods. This is a particular problem for siting programs for active drug users, as neighbors frequently have legitimate fears about the presence of drug users in their community.

The need for a system of housing for PWAs

Looking at AIDS as a chronic illness which affects individuals in varying ways and affects populations with
different needs presents a unique challenge to planning a housing system which will be able to meet those diverse needs. On one level, planning housing for PWAs is very much like planning affordable housing in general, and we can draw on that experience. On another level, it is very much like planning special needs housing for any other special needs group, and we can learn, for example, from the experience of planning housing for the chronically mentally ill or the frail elderly. Yet, housing for PWAs is also different from both of these.

Developing housing for PWAs is like developing other affordable housing programs because it involves a high level of subsidy at a time when there are scarce resources, particularly as federal dollars have shrunk to near nonexistence, and state dollars are insufficient to fill the gap. Coordination and partnership efforts among the state, municipalities, non-profit and for-profit developers is both a challenge and a necessity for affordable housing development in this decade, and equally true for affordable housing for PWAs.

AIDS is like chronic mental illness in some respects, in that they are both chronic conditions with possible episodes of acute illness. They are also similar because they affect mainly younger people who could remain in the system for a long time (although the current life expectancy of a PWA is only a couple of years, this may change with earlier diagnosis and more effective medical interventions).

A model for providing housing for chronically mentally ill
(CMI) was laid out in the governor's 1985 special message on mental illness, and included a five-level residential system, based on a changing level of services and supervision needs to go along with the physical residence. The model is based on an assumption that individuals will move through the levels of the model from level 1, which is the most restrictive and service-intensive, to level 5, which is the least restrictive and closest to "normalized" housing in the community. There is some debate over whether this type of model makes sense, at it implies that an individual must physically move as s/he moves through different levels of service need. A model for housing options for people with AIDS which has different levels of service attached to different levels of housing will create a similar problem for PWAs whose service needs may change over time.

An alternative model is to have fewer levels--perhaps two--where level 1 is very restrictive and service intensive and level 2 is a flexible model which allows for changes in the service level to accommodate the individual's needs without requiring him/her to physically move. The argument against this alternative is that it is much less cost effective to have a plan based on changing to meet individual needs and is much more difficult to plan residential programs. Because there are such varied needs among different groups of PWAs, a multi-level option


38 Ibid.
is needed. However, to avoid the trauma and disruption of physically moving, each option should have as much flexibility to change service levels to keep an individual in that location as long as possible.

Housing for PWAs is like frail elderly housing because both are for populations with a chronic condition, which may be stable for periods of time, but is eventually fatal (again, this may change for PWAs as research continues). The likely presence of dementia or other neuropsychological impairments is also a similarity. Housing programs for frail elderly often combine social and medical services in a residential setting, often with the expectation that service needs will increase rather than decrease over time.\textsuperscript{39}

Although there is much we can learn from planning models for affordable and special needs housing, AIDS requires a new model which accounts for the diversity and complexity of needs of people with AIDS, both now and in the future. While it may be tempting to develop different models for different populations, it is preferable to have one model of housing and services which can incorporate all of the different needs. Chapter 3 lays out an ideal system for a range of options to meet the housing needs of PWAs. While differentiating the options into categories

provides a framework for the overall system, within each option there must be flexibility to account for a variety of factors based on physical health, neuropsychological health, drug use, and the presence of dependent children.
CHAPTER 3: AN IDEAL SYSTEM OF HOUSING OPTIONS FOR PEOPLE WITH AIDS

There is growing recognition of a need for a range of housing options and service packages available for people with AIDS (PWAs) and people with HIV infection, i.e. the need for a "continuum" of housing options. The continuum can be looked at in two ways. One is following the progression of an individual throughout the course of his/her disease, recognizing how needs will change over the individual's lifetime with AIDS. An alternative approach is to look at a variety of needs that different groups or individuals may have due to certain characteristics including the stage of disease. An ideal system should be set up based on the latter, that at any one time different groups will need different options. Within that framework, every effort should be made for levels of service to be flexible to allow an individual to stay where s/he is as long as possible by varying the services available. Obviously, at some point it may be impossible to provide the necessary level of services and an individual may have to move to another location.

In general, people who are in the early stages or in non-acute stages of illness can live relatively independently. They will need access to subsidized, emergency and transitional housing, with few, if any, on-site services. As the disease progresses, people may need housing options with more services available on-site. In many cases this may include long-term congregate housing, but there are other options which should be
considered. Persons in the end stages of chronic illness, who do not need acute in-patient hospital care, may need palliative care in the form of in-home or residential hospice care. People will not necessarily need every type of housing during the course of illness. However, for many people the progression of disease is non-linear and unpredictable, so their housing and/or service needs may change several times. Although many people will only need access to one or two housing options during their lifetime, there will always be some individuals or households requiring any given option at any given time. Therefore, the goal of the system should be to provide as wide a range of options as possible, but to allow individuals as much stability and as little disruption as possible.

A system of options must be responsive to the various factors that determine an individual or household's housing and service needs which include health status, financial status, personal support system, community support services and personal preference, with special consideration for families, drug addicts and the chronically homeless. The system also needs to respond to the fact that in some cases, PWAs just need access to existing affordable housing resources, in some cases access to existing special needs resources, and sometimes resources specifically for PWAs. The needed options can be defined in the

---

*Andy Kruzich, Project Coordinator, AIDS Prevention Project, Seattle-King County Department of Public Health, presentation at "AIDS and Housing" conference, March 29, 1989.*
following way:*1

Option 1: Stay in current home

Option 2: Temporary, emergency, transitional housing

Option 3: Set-asides in unspecialized residence, i.e. public housing, Mass. Housing Finance Agency subsidized; Section 8 or 707 leased

Option 4: Set-asides in special needs housing, i.e. elderly, disabled, chronically mentally ill, etc.

Option 5: Specialized PWA residence, unsupervised and supervised

Option 6: Nursing home, chronic care hospital, skilled nursing facility; psychiatric skilled nursing facility

Option 7: Hospice residence

The goals of each option and who they may be appropriate for is as follows:

Option 1: Stay in current home

The goal of this level is to keep people who are currently adequately housed in their current situation as long as they want to and are able. Keeping someone in his/her home may require subsidies to maintain affordability and possibly some level of home-care services, including medical home care and/or homemaker services such as cooking and cleaning. The home-care system is currently inadequately reimbursed by insurance programs and many needed services may be unavailable, such as in-home mental health services or methadone treatment for drug addicts who are too sick

*1 The development of these options is based on the work of AIDS and housing work done by a variety of organizations in Boston, San Francisco and Seattle.
to go to clinics." Home-care support is often supplemented by or replaced with informal support systems or friends, partners and families. The AIDS ACTION Committee also offers staff- and volunteer-provided services to clients who request it. While informal support systems and volunteer efforts have met a large part of the need to date, as the numbers of PWAs increase, these sectors will be unable to keep up with the demand. Also, many IVDUs lack these kind of support systems. The reimbursement issues in home-care, as well as the staffing shortage, could be major obstacles to allowing PWAs to live independently in their own homes.

This option is important because it prevents isolation and segregation of PWAs, and allows people to stay in communities. It provides them with the opportunity to maintain their lifestyles and as much control over their lives as possible.

Option 2: Temporary, emergency, transitional housing

There is a need for short-term housing options for people who need a place to stay while they look for a more permanent arrangement. People may be coming out of hospitals, shelters, or other locations and may need housing search support to evaluate their needs and options. There is a particularly large need for

---

*2 Laurie Novick.

*3 AIDS ACTION Committee "Support and Services" brochure.

this option for chronically homeless people and for children with pediatric AIDS. For the chronically homeless, a viable short-term model is a single room occupancy (SRO) arrangement. For children with AIDS it may involve congregate living for their families or some type of foster care arrangement.

Option 3: Set-asides in unspecialized residence

People whose primary need is an affordable place to live would benefit from special set-aside programs or improved access to existing subsidized, but unspecialized residences, such as public housing units, leased units participating in the section 8 or chapter 707 programs, or Massachusetts Housing Finance Agency (MHFA) financed developments. Home-care and other needed services could be accessed if needed. In the short-term, expanded access to existing affordable housing is critical. Unfortunately, however, the shortage of units, long waiting lists, and competition from other groups are formidable barriers.

Option 4: Set-asides in special needs housing

PWAs should qualify for housing for disabled and handicapped individuals, and could gain access through set-aside programs or through the general application process. More attention needs to be given to PWAs' eligibility to existing special needs housing resources for disabled, handicapped, mentally ill and other populations. This option allows some level of normalization,
because people are not isolated with only PWAs; however, there may be some isolation of special needs housing from the rest of the community.

**Option 5: Specialized PWA residences**

Some people will prefer or need both unsupervised and supervised residences specifically for PWAs. The advantages of specialized housing are the opportunity for mutual support and shared experience with other PWAs and the ability to provide specialized services to PWAs, if needed and desired. Residences may range in design from very independent living along the lines of a single-room occupancy (SRO) model to a congregate, group home model, with room for a lot of variation in between.

There is the need for a range of resources in this category. Twenty-four hour supervised housing is necessary for people affected by AIDS dementia to ensure their safety. Recovering drug addicts may need a structured, supervised environment separate from other PWAs. Chronically homeless people may need support in making a transition from shelters or the streets to living in a residence. Families with children will have particular space, care and service needs.

While there is the danger of isolating and segregating PWAs in specialized residences, there is also the opportunity to provide specialized support and services in a group setting, if needed and desired.
Option 6: Nursing home, chronic care hospital, skilled nursing facility, psychiatric skilled nursing facility

People who cannot live independently in a community setting due to neuropsychological impairment or other factors, but who do not need acute in-patient care, will need access to other options.

Option 7: Hospice residence

In the end-stages of illness, many PWAs will opt for an environment which stresses palliative, rather than curative care. While home-based hospice care is an option for some, there is also a need for residential hospice programs.

IMPLEMENTATION ISSUES AND OBSTACLES

An ideal housing system, therefore, is one that provides as much "normalization" and as little disruption in people's lives as possible. It does not "overservice" people, but it offers specialized programs for PWAs who want and need them. There are many difficult issues to address and conflicting factors to balance in effectively implementing such a broad community-based system.

Siting housing: neighborhood opposition and education

Siting any type of housing for PWAs, be it specialized or integrated into existing housing, must address the issue of stigmatization and the not-in-my-backyard (NIMBY) syndrome. Unfortunately, there is still a sizable minority of people in
this country who believe that PWAs should not be allowed to live in their neighborhood. The NIMBY syndrome is certainly an obstacle to siting many kinds of affordable housing or special needs housing where people fear outsiders or those whom they perceive as a threat to them or their property values, but it is particularly problematic in siting housing for PWAs.

In January of this year, the opening of a group home in New York City for ten HIV-infected children under the age of seven had to be carried out with 24-hour police protection due to bomb threats. Neighbors claimed that they feared for the medical safety of themselves and their families and the effect the house would have on their property values. The majority of children expected to live in the house are black and latino and it is located in a middle-class black neighborhood. Clearly the opposition is based on fear of AIDS as opposed to racism. Neighbors had a similar reaction eight years ago when a program for retarded teen-agers opened in the same house, so perhaps there is cause for hope.

Last summer, residents in a neighborhood of Portland, Maine initially opposed the siting of a 4-unit residence for PWAs by AIDS Lodging House, Inc. The site was chosen specifically because it was near hospitals, social service agencies and downtown. Neighbors reacted out of ignorance, afraid their


children could somehow "catch" AIDS. They organized a petition drive and a demonstration and appeared on local television. AIDS Lodging House held an informational meeting attended by more than 100 people to educate people about AIDS. Through this and other efforts, neighborhood sentiments have been turned around and most people are supportive of the house.47

Clearly, then, siting specialized PWA housing can cause isolation and trigger further stigmatization and fear, but it can also be an opportunity to raise community awareness and dispel myths about AIDS. As many groups have learned, community education efforts are very time-consuming, but an integral part of creating an effective housing system.

Accessing existing housing resources

People with AIDS should be eligible for existing special needs housing by virtue of their handicapped or disabled status and for public housing due to their financial status. But, there have been obstacles to access due to failure to recognize their eligibility and the competition for scarce resources. The federal department of Housing and Urban Development (HUD) recently denied a $1 million low-interest loan to Housing for Independent People (HIP), a non-profit organization in San Jose, California. HIP was going to rehabilitate four residences for homeless PWAs. The HUD money was from a program for subsidized

housing for disabled people. A HUD official argued that PWAs do not qualify for federal benefits because their condition is "not expected to be of long-continued and indefinite duration."

National Gay Rights Advocates is bringing a lawsuit, charging that HUD is violating the Federal Rehabilitation Act which defines AIDS as a "physical handicap."48

An advantage to PWAs moving into existing special needs housing is that many are already barrier-free for the physically handicapped and may have service components available. The disadvantage is that it increases the competition among groups for access to a scarce resource.

Integrating services into housing

People's needs for home-based services will vary widely and may change over time. Consequently, a very difficult question to answer is whether services should be attached to the housing unit or the individual. Some people will be able to stay in one unit for most of their lives, provided that the appropriate services and support are available. In addition to the obstacles discussed above, there are other policy considerations. While home-care services are clearly cheaper than acute hospitalization, providing in-home services to geographically dispersed people can be expensive. Individual needs and preferences will constantly be played off of the rules of

economies of scale and fiscal constraints. However, while it may be cheaper to concentrate people with similar service needs in one location, attaching a certain level of services to a unit may limit the ability to be flexible to meet people's changing needs. Consequently, there is the problem of people having to physically move as their service needs change, and the effect of this disruption on their lives. The goal should always be to keep an individual as independent as possible and maintain as little disruption as possible. The key to this is good case management to allow for as flexible a use of services as possible.

Sensitivity to needs of different populations

We need to respect people's preferences to live in their communities of origin with others with similar backgrounds, yet not perpetuate racist, sexist and homophobic segregation. We need to recognize that PWAs may share some commonalities, but have many differences. Particular differences which must be acknowledged and planned for are the needs of drug users who may or may not want drug treatment and the needs of non-drug users not to live with active users. There is a shortage of both residential and day treatment programs for people who suffer from addiction, and many existing programs do not have the capacity to take people who are sick. The lack of coordination between drug treatment, health and housing planners, and inadequate funding levels are obstacles which must be addressed.

As people are living longer with AIDS, the incidence of AIDS
dementia and other neurological impairments is rising. Therefore, this is another subgroup of PWAs who may need specialized programs ranging from 24-hour supervised housing to adult day programs, home-care and support for their informal network of caregivers.

The majority of HIV-infected babies are born to mothers who are infected. Most of the mothers contracted the virus either through sharing needles or through sex with an infected partner. Therefore, many sick children also have sick parents. Families may need services which include child care, respite care, drug treatment and support in dealing with parenting and guardianship issues when there is a sick parent.

**Helping people negotiate the system**

A system which is based on providing a number of options and is strongly grounded in an individual's right to choose housing and services can be as difficult for an individual to maneuver as it is for planners to conceptualize and implement. Advocacy and case management are a vital part of any system, so individuals are aware of their options and entitlements and are assisted in gaining access to resources to meet their needs. This is especially important because of the occurrence of housing discrimination against PWAs and people's lack of knowledge of and resources to fight for their rights.
Coordination

Because of the complexities of meeting the disparate needs of PWAs, the current fragmentation of housing and services planning and provision will be a major obstacle. People working within different systems have different views of the world and ways of "doing business"; these differences must be bridged as participants in each system have something valuable to contribute to an overall more integrated approach.

Discrimination

Stronger federal antidiscrimination laws are sorely needed. At a press conference on June 2, 1988, Retired Admiral James D. Watkins, chair of the President's Commission on AIDS, said that threat of discrimination is "the most significant obstacle to progress. If the nation does not address this issue squarely it will be very difficult to solve most other HIV-related problems. People will simply not come forward to be tested, nor supply names of sexual contacts... if they feel they will lose their jobs and homes." Watkins proposed that there be a federal law which would prohibit discrimination against those with HIV infection. He suggested expanding current federal statutes which protect the rights of disabled and handicapped people to include people with HIV infection.*9

The Commission stated in its final report that the following are obstacles to progress in combating discrimination against

persons with HIV infection:

There is not a societal standard or national policy statement clearly and unequivocally stating that discrimination against persons with HIV infection is wrong; there is no comprehensive, national legislation clearly prohibiting discrimination against persons with HIV infection as a handicapping condition; there is a lack of coordinated leadership from our public and private institutions on the issue of discrimination against persons with HIV infection; a patchwork of federal, state, and local laws is both confusing and, ultimately, ineffective in preventing discrimination or providing remedies; enforcement of existing anti-discrimination laws is slow and ineffective; education about transmission of the virus and about the laws banning HIV-related discrimination is insufficient. This results in ignorance, misinformation, acts of discrimination, and, in some persons, an irrational fear of association with those who are HIV-infected.  

In its final report, the Commission recommended as a first step that:

The President should issue an executive order banning discrimination on the basis of handicap, with HIV infection included as a handicapping condition. This executive order would reinforce existing Section 504 regulations and clarify that all persons with HIV infection are covered by Section 504. Such an executive order would reaffirm existing federal anti-discrimination law which prohibits discrimination on the basis of handicap and would be a powerful message from the leadership of the nation.  

The report went on to note that only federally-funded programs are covered by Section 504's prohibition against discrimination and "there is no anti-discrimination protection for persons with disabilities facing discrimination in the workplace, housing, or public accommodations which do not receive federal funds."

---

50 "Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic," June 1988, p. 120.

51 Ibid., p. 121.
Because there is some question whether asymptomatic HIV-infected people are considered disabled, the Commission recommended:

Comprehensive federal anti-discrimination legislation which prohibits discrimination against persons with disabilities in the public and private sectors, including employment, housing, public accommodations, and participation in government programs, should be enacted. All persons with symptomatic or asymptomatic HIV infection should be clearly included as persons with disabilities who are covered by the anti-discrimination protections of this legislation.²

In a recent development, an amendment to Title VIII of the federal Fair Housing Act went into effect. This law, which bars discrimination in private housing on the basis of disability or handicap was amended to include PWAs. There is some concern, however, over the fact that HUD is the enforcement agency for this legislation.³

Property management issues

Balancing PWAs' right to privacy and property management and maintenance staff's need for information is a difficult question. The best policy is for staff to be educated and trained about AIDS and to adopt "universal precautions" for infection control regardless of whether there are known HIV-carriers in the building. Because it is impossible to tell who is and is not HIV infected, appropriate infection control procedures should be followed as a rule. Some property management companies are

²Ibid., p. 123.

³Boston AIDS Consortium Housing Task Force meeting minutes, March 16, 1989.
beginning to train their staff about AIDS and develop policies and guidelines.

Developing needed resources: who is responsible?

Because such a comprehensive system is needed, there is a role for many different organizations to get involved at different levels of policy, coordination and development. The role of AIDS service organizations, PWAs and advocates is to articulate needs and hold public agencies accountable by working with them and sometimes, when necessary, opposing them. AIDS service organizations need to continue their valuable role of providing support services, advocacy and case management.

Service organizations have also historically played a role in developing and operating residences for their client populations due to their extensive knowledge about and interest in meeting their clients' needs. Because many service organizations do not have housing development expertise per se, training and technical assistance will be important. Another option is for service organizations to work cooperatively with housing development organizations, such as non-profit community development corporations, local housing authorities and for-profit developers, who know a great deal about housing development but may not know much about the needs of PWAs. There is a particular need for housing and service organizations

54 Boston AIDS Consortium Housing Task Force meeting minutes, February 16, 1989.
working in communities of color to work to develop more housing resources for PWAs in their communities. Coalitions such as the Boston AIDS Consortium also can play an important role in getting people together to network and share information, identify service gaps and plan and advocate for change.

The city of Boston also has a responsibility to be a major player in addressing the housing issue. It is instructive to look at the responses of other city governments to meeting the housing needs of people with AIDS and HIV infection. A prime example of the consequences of the failure of a city to respond in an appropriate and timely manner is New York City.

The Coalition for the Homeless recently won a lawsuit filed against the city of New York to force it to address the growing problem of homeless PWAs. The trial court ordered the city to provide adequate housing for the estimated 5000 homeless PWAs. In addition, the city also must address the needs of homeless people who have HIV-related illness but not full-blown AIDS. Ten to fifteen percent of the city's estimated 250,000 homeless people are believed to be in this category. The city currently provides 58 apartments for PWAs and Bailey House, a city-funded residence for 44 homeless PWAs.55

A more positive example of a city's response can be found in San Francisco, whose planning process is often hailed as a model of both comprehensive and participatory planning. One important factor in San Francisco's success is that PWAs in that city are

55Gay Community News.
very homogenous demographically. PWAs in that city are 85% white and 85% gay, and there are very small proportions of IVDUs, women and children, and people of color. Nevertheless, there are still a number of important lessons other cities can learn about planning from San Francisco. The San Francisco Department of Public Health has put together a written plan which has gone through many rounds of community input and review; the most recent edition of the plan came out in April of 1988. The section on Chronic Care, Housing, and Related Support Services lays out a system of housing and service resources provided by public and private, non-profit agencies. The report also includes rough projections of numbers of people expected to be living with AIDS through 1993, housing needs in terms of resident days per year, and ranges of estimated costs of different categories of services. While the authors of the report state explicitly that the projections of service needs are purely speculative and a number of factors could alter what the actual numbers are, it is a helpful place to start to plan for future needs and costs.

The city of Seattle has also done an impressive job responding to housing needs of PWAs, who are also currently a homogeneous population of gay white men and whose numbers are still relatively few. All of the funding is funnelled through the Seattle-King County Department of Public Health; eighty

percent of it then gets sub-contracted out to community-based organizations. The collaborative effort relies heavily on a community planning process with input from public agencies, community-based agencies and PWAs. There is currently a continuum of eight different housing and service types available; the Health Department has also done projections of numbers of clients who will need each type of housing, the numbers of units needed and the estimated cost for each year through 1991.

Problems and issues which the city has faced in developing housing resources include: a shortage of staff time and expertise, difficulty in projecting and substantiating the need, difficulty in developing a strategy and following through on it, limitations and needs of existing long-term care providers, problems with planning and siting facilities, lack of capital and operating funds, debates about whether clients should move as they require different levels of services, addressing the economies of scale problem for small facilities, debates about whether additional long-term care beds should be added and whether or not there should be AIDS-specific facilities. 5 7

Because siting is a major obstacle to housing development and there is a shortage of affordable, vacant land and buildings, the city can play an important role in identifying or donating sites and/or buildings, assisting with zoning and permitting problems, working with community groups on public education efforts and providing technical assistance and development

5 7 Andy Kruzich.
expertise. In addition, city agencies should continue networking and communicating to facilitate coordination and cooperation among many different agencies to meet the diverse needs of PWAs. The city can also play a leadership role in instigating a broad, participatory planning process and the development of a working document to guide future policy.

Coordination and cooperation at the state level is also important, as developing housing resources for PWAs demands the resources and skills of many different agencies. Historically, different state agencies have had conflicting policies and procedures. These conflicts must be resolved and communication must be strengthened.

The federal government must also be held accountable to meeting housing needs, particularly in the area of financing. Restrictive eligibility guidelines for federal programs such as disallowing PWAs to qualify as handicapped or disabled, must be changed. In addition to expanding existing housing programs to include housing for PWAs, the possibility of new funding sources must be explored.
A number of organizations in the Boston area are currently involved in providing or planning housing options for people with AIDS (PWAs). They include both housing-focused and social services-focused organizations, as well as public government agencies at the city and state level, and community-based coalitions. The following includes a description of "who is doing what" and identification of some of the obstacles they face. Since every day more and more individuals and organizations are recognizing the need to get involved in developing housing options for PWAs, it would be impossible to report on every initiative currently underway. Instead, this is a report on a sample of projects to give a sense of what is currently happening and the issues and obstacles which need to be addressed in order to make more of these options available in the future.

PLANNING AT THE COMMUNITY, CITY AND STATE LEVEL

There is a growing realization of the need for coordination, networking and planning at the community, city and state level. A federally-funded housing resource developer, based at the AIDS ACTION Committee, works with organizations in the Boston area on a number of development and policy issues. The Boston AIDS Consortium, a coalition of organizations and individuals, recently formed a Housing Task force to bring people together to
share information and develop policies and planning recommendations. City Life, a neighborhood organization in Jamaica Plain, recently formed the Jamaica Plain AIDS Housing Task Force and began a community education campaign about housing for people with AIDS.

On the city level, the Mayor's AIDS Task Force, an interagency group, recently set up an advisory committee to focus on what concrete action the city could take on some AIDS policy issue. The task force includes members from a number of city agencies; among them are the Department of Health and Hospitals, the Mayor's Office, the Office of Neighborhood Services and the Public Facilities Department. The advisory committee identified housing as its first priority and will be developing strategies for how the City can play a role in providing housing for PWAs. The committee is currently working with the city's Public Facilities Department to encourage private developers and community development corporations to convert old single room occupancy (SRO) buildings into transitional housing for PWAs.58

The state Executive Office of Communities and Development has recently gotten involved in providing capital funds for housing for PWAs through its Housing Innovations Fund (HIF) program, which is providing support for the Fenway Community Development Corporation and Hospice West projects. In addition, an internal working group on public housing issues is addressing

58 Julie Marston, AIDS Coordinator, Department of Health and Hospitals, City of Boston, telephone interview, March 29, 1989; Ann Sanders.
the AIDS and housing issue, as is the Governor's Interagency AIDS Task Force." The AIDS Policy Analyst in the Governor's Office of Human Resources is currently writing a report titled "Massachusetts AIDS Initiatives: Policy, Research, Education, Services Progress Report and Plans," which includes a section on Residential and Day Care Services.

In March, several state agencies (Office of the Governor, Executive Office of Human Services, Executive Office of Communities and Development, Department of Public Health) worked in cooperation with the AIDS ACTION Committee to sponsor a conference on AIDS and housing. The conference planning committee, which is now the Governor's Intersecretarial AIDS and Housing Committee, will be coordinating resources of different state agencies focused on housing for PWAs.

HOW CURRENT OPTIONS IN BOSTON FIT INTO THE MODEL SYSTEM

Option 3: Set-asides in unspecialized subsidized residence

The barriers to accessing public rental subsidies or subsidized units for PWAs have been multi-faceted. Until recently, a PWA's access to rental subsidy programs such as federally-funded Section 8 and state-funded 707 certificates or


[60] Cynthia Gilles.

public housing units was limited to getting on waiting lists the duration of which often exceeded his/her lifetime.

The federal Department of Housing and Urban Development (HUD) guidelines require local housing authorities (LHAs) to use preference categories in issuing rental subsidies. Many LHAs give first preference to households who are homeless through "no fault of their own." This can exclude from eligibility many people who have moved out due to inability to pay rents that were more than 50% of income. Many PWAs, not knowing their rights, move out rather than waiting for an eviction notice which can be used to help them qualify for "no fault" status.62

Another barrier has been an additional requirement that to qualify as homeless, an individual must be out on the street or living in a shelter. This requirement poses a major life threat to people with HIV infection. A recent change in regulations allows a waiver of this requirement with a letter from a doctor documenting that living in a shelter would provide imminent danger to a person's life due to his/her HIV status.63 In addition to this regulation change, EOCD and the Cambridge Housing Authority (CHA) applied to HUD for approval of set-aside programs for rental certificates which would allow PWAs to access them without going through the usual preference categories. HUD


has granted permission for a similar program in Seattle, Washington. While they are awaiting approval, both CHA and EOCD are going ahead with the programs, which are for 10 and 20 set-aside certificates, respectively.

The set-aside certificates are not specifically for PWAs, but for people with terminal illnesses and a life expectancy of less than three years. Tenants pay 30% of their income to private landlords who receive a subsidy for the difference between the tenant's contribution and market rent.

Since many PWAs have been evicted or discriminated against by private landlords in the past, recruiting landlords to participate in the program is a problem.\(^4\) There is tension between informing and educating landlords about HIV infection and AIDS and protecting tenants' rights to privacy and confidentiality.

The current structure of set-aside programs raises other implementation issues. Requiring a doctor's certification that someone has less than three years to live is difficult to do in a sensitive way. Also, as people with AIDS live longer, there is some question whether they would be eligible in the future if life expectancy increases beyond three years. Further, if certificates are issued based on one household member being terminally ill, it is unclear what happens to the rest of the household when that person dies or needs to move into some other type of residence.

\(^4\) Ann Arata.
Finally, there are difficult political implications of set-aside programs in areas such as Boston that have very tight rental markets with a lot of competition for scarce affordable housing resources. Although there may be some sympathy for persons with terminal illness getting first priority for some housing units, there is still undeniable discrimination against PWAs and may be resentment among other groups also seeking more access to existing units. Nevertheless, this is a key factor in allowing PWAs to remain independent in their communities and is a program which needs to be expanded to meet the growing need.

Option 4: Set-asides in special needs (elderly) housing development

The Fenway Community Development Corporation (CDC) is planning to set aside four units for PWAs in a 52-unit development for elderly residents which is scheduled to open in September of 1989. The program includes an agreement with the AIDS ACTION Committee (AAC) to screen tenants and provide appropriate support services. Because a PWA’s health status is so unpredictable and it is unclear exactly what services tenants will need to allow them to remain in their units, Fenway CDC believe that the services agreement with AAC is essential, and they would not have entered into the project without it.65 At least one AAC staffperson believes, however, that people should not be forced to accept services they do not want. She believes

65 Sandra Brandt, Project Manager, Fenway Community Development Corporation, telephone interview, April 4, 1989.
that services should be available for PWAs, but they should be able to choose which ones they want to use.\textsuperscript{66} The issue of tenant or client choice is further complicated by the fact that some AIDS service organizations may not be able to provide culturally-relevant services to different tenant populations in a development.

Working on community education and acceptance is an important component of this project. Fenway CDC staff targeted supportive people in the neighborhood who were trained by AAC staff to go out and do community education. Applicants to the development will be informed of the tenant mix and the set-aside units. Maloney Properties, the management company, has also participated in training and developing policies for maintenance staff.\textsuperscript{67}

Option 5: Specialized PWA residences (unsupervised)

The AIDS ACTION Committee (AAC) operates two residences with a total of eleven beds. One of the residences is a leased building with three two-bedroom units; the other is a five-bedroom group house which AAC owns. The goal of the residential program is to provide a safe, predictable environment; the underlying philosophy is to preserve the integrity of residents' lifestyles and create a minimal amount of change in their lives.

\textsuperscript{66}Laurie Novick.

\textsuperscript{67}Matt Thall, Director, Fenway Community Development Corporation at Boston AIDS Consortium Housing Task Force meeting, February 16, 1989.
While there is no on-site supervision of the residences, AAC's housing manager maintains regular phone contact, supervises volunteers, and conducts weekly house meetings. Residents are referred through AAC client advocates who provide ongoing case management. To be eligible to live in one of the residences, an individual must have AIDS or ARC, be well enough to care for him/herself, demonstrate financial need, and agree to program guidelines. Approximately eighty-percent of residents have been gay men, the rest heterosexual men and women; approximately one-third have been people of color. One of the units is currently occupied by a man and his two children. Every effort is made to allow someone to remain in the residences as long as possible. When a person is no longer able to do so, the AAC client advocate and the residence manager assist him/her to find an appropriate living situation.  

Option 5: Specialized PWA resident (supervised) 

There are currently no long-term residences with 24-hour supervision in Boston specifically for PWAs. In Westfield, Jewish Family Services of Springfield operates Chesed House, a five-bedroom house on the campus of Western Massachusetts Hospital. Almost 20 people have lived in the house since it opened in May of 1987. Although there is 24-hour staff supervision, residents must be able to live independently, 

68 Kurt Reynolds, Housing Program Coordinator, AIDS ACTION Committee, personal interview, April 12, 1989.
including being able to cook and clean and do laundry. Residents use their social security or disability payments to pay into a food pool, but do not pay rent.

Referrals to Chesed House are from the Department of Public Health (which funds the program), AAC, drug treatment programs and hospital discharge staff. The majority of residents have been women in their twenties and thirties, and most contracted the virus through IV drug use.

The biggest problems Chesed House has faced is mixing people of different backgrounds in a group living situation and dealing with the issue of drug use. As one resident put it, oftentimes residents "have nothing in common except for a virus." While active drug use is not permitted, and residents must submit to urine testing, drug issues are still a problem. It is very difficult for people who have never used drugs or are recovering users to live with people who may be currently using and have no desire to stop using. One resident reported that she had never used drugs, but had contracted the virus from her boyfriend whom she had not known was an IVDU. She was very angry about living with people with a history of drug use.

Community response to the program has generally been pretty positive, although it may not be generally known that the residence exists, and it is physically isolated from neighbors. Despite attempts at education among emergency response personnel, there are some ambulance companies which have reacted negatively
or inappropriately to calls from the house."  

The Catholic Archdiocese of Boston is currently renovating a former residence on the campus of Saint John of God Hospital in Brighton which Catholic Charities will operate as a 24-hour staffed residence for twenty-four homeless PWAs. The Archdiocese Task Force on AIDS began working two years ago to develop a smaller (ten bed) residence for PWAs, but was unable to locate an appropriate site due to problems with physical structure, inaccessibility to transportation and neighborhood resistance. The Archdiocese is donating the Saint John of God site and providing matching funds to a federal Hill-Burton fund grant for renovations, which are expected to be completed in the fall.

Project staff are assuming that approximately half of the residents will have a history of substance use, but there will be a policy against active drug use. Residents must be diagnosed with AIDS or ARC to be eligible, and will be referred by hospital discharge planners and other service providers. Only ambulatory residents will be accepted, but the hope is that there can be enough flexibility to allow people to either use the residence as a transition to another option or to stay as long as they like, provided enough home care supports can be accessed.  

---

69 Chesed House staff and residents, personal interviews, February 22, 1989.

70 Sister Gretchen Guilroy, Director, AIDS Ministry, Catholic Charities, Archdiocese of Boston, personal interview, April 6, 1989.
Option 7: Hospice residence

Hospice West will be opening a specialized hospice facility for 18 PWAs in the Mission Hill neighborhood later this year; this is the first hospice residence in the state and will be specifically for PWAs. The siting criteria was that it be in a residential area in the city and close to public transportation; zoning regulations were a concern. Grassroots community education was of key importance in gaining acceptance for the residence. Hospice West staff called friends in the area, who talked with their friends and neighbors, so that the information moved out in concentric circles. The strategy was based on the belief that it would be best for people to hear about the development plans under controlled circumstances and not as rumor from neighbors.

Hospice philosophy is based on a premise that residents are living in a home, not an institution. Hospice West did, however, have to meet certain requirements for licensing and Medicare reimbursement, including physical design and staffing. 71

Special populations: children and families, homeless IVDUs

Children and families:

At least two of the residences for PWAs can accommodate children, if they are living with an adult caregiver. Chesed

House in Westfield has had well children living with a sick mother.\textsuperscript{72} One of the AIDS ACTION Committee apartments is currently occupied by a man and his two children.\textsuperscript{73}

The Children's AIDS Project (CAP) at Boston City Hospital is a residence run by the City's Department of Health and Hospitals for five HIV infected children whose parents are unable to care for them. CAP is planning to expand its program to care for twelve children and meet more of the needs of their families.\textsuperscript{74} Siting the residence in a residential community has been a major problem, and staff of the City's Public Facilities Department have been working with Health and Hospitals staff on securing a site and working on community education and acceptance issues.\textsuperscript{75}

Homeless IV drug users:

Staff at the Pine Street Inn homeless adult shelter and its affiliated development entity, the Paul Sullivan Trust, have been working with city and state officials for several years to site a residence for homeless IV drug users with HIV infection. Shelter staff estimate that more than 90 percent of the AIDS cases they

---

\textsuperscript{72} Staff interviews.

\textsuperscript{73} Kurt Reynolds.

\textsuperscript{74} Boston AIDS Consortium Housing Task Force meeting minutes, February 16, 1989.

\textsuperscript{75} Janet Van Zandt and Steve Gag, Public Facilities Department, City of Boston, personal interview, March 28, 1989.
have seen have been needle users." Of the estimated 3500 homeless people in Boston, approximately 300 are HIV infected IVDUs."

It has become apparent to Pine St. Inn staff that siting and funding issues make it impossible to develop a residence for HIV-infected IV drug users. Despite the fact that this may be the most needy group of HIV infected homeless people, it is also the hardest to serve. Consequently, current plans are to develop a residence for 12-14 formerly homeless people who are willing to commit to living drug and alcohol free. The residence, which hopefully can be sited near hospitals and transportation, will be an independent, congregate living arrangement (probably an SRO-type model) with services provided by Pine St. Inn, supplemented by home-care agency services.

---


78Bob Johansen.
In her latest book, *AIDS and Its Metaphors*, Susan Sontag reflects on why she had written an earlier book, *Illness as Metaphor*, while she was being treated for cancer. "The metaphors and the myths, I was convinced, kill." She wrote it as an exhortation "to regard cancer as if it were just a disease--a very serious one, but just a disease."79 Hence, in the beginning of her new book, she argues:

Of course, one cannot think without metaphors. But that does not mean there aren't some metaphors we might well abstain from or try to retire. As, of course, all thinking is interpretation. But that does not mean it isn't sometimes correct to be "against" interpretation.80

It is helpful to look at the metaphors which have been used to understand AIDS, and how they relate to how we plan. Kenneth Kenniston suggests that the four most common types of metaphors for AIDS are war--the struggle or fight against an invading enemy virus, crisis, epidemic or plague, and disease.81 Kenniston argues that one of the reasons why the first three metaphors are particularly dangerous and misleading is that images of war, crisis and epidemic all imply a phenomena of a particular duration--ending perhaps with a victory--but at least ending.


80 Sontag, *AIDS*, p. 5.

Kenniston, echoing Sontag, concludes that despite the limitations of the disease model, it is the best metaphor for understanding and approaching AIDS, particularly if we apply a chronic disease model of a growing number of people living with illness for longer periods of time. The people who currently have AIDS are only the "tip of the iceberg" of a much larger infected population, and there is no clear end to AIDS in sight. In fact, we expect things to get much worse for an indefinite period of time, before they get better. Planning, therefore, has to take a very long-term view, despite the uncertainty of what the future looks like.

Planning housing for people with AIDS (PWAs) needs to occur in the context of thinking about AIDS as a long-term chronic illness and with the recognition that there will be growing numbers of people living with chronic illness for longer periods of time. The experience of the city of New York should serve as a warning to the city of Boston. Now is the time to do comprehensive planning, or in a matter of a few short years, we too could have 5000 homeless people with AIDS out on the streets and in homeless shelters.

How we got to where we are and where we go from here

The current housing options available to people with AIDS in Boston have been developed not out of any elaborate planning process, but because individuals and agencies have recognized a

\textsuperscript{82} Ibid., pp. 22-23.
need and done what they could to meet it. They did not have a lot of experience to go on, and probably many people shared the sentiments of one program planner, who said he wished there had been someone who had done it before him who could tell him how to do it. Now there are a number of people who "know how to do it" and the challenge is to build on their knowledge and experience to fill in the gaps which still exist in the system.

The way to accomplish this is to "go where the energy is." Many of the housing initiatives have come from social service agencies. Their efforts need to be supported by linking them up with other organizations, particularly those with housing development expertise. Local housing authorities and private, non-profit or for-profit developers should also be encouraged to get involved, and need to hook up with service organizations to integrate appropriate services with their housing programs. A proposal to create a new non-profit community development corporation specifically to develop housing for people with AIDS should be explored further. This type of networking and information sharing is already beginning to happen through the housing task force of the Boston AIDS Consortium and as a result of the efforts of AIDS ACTION Committee's housing resource developer.

---

83 Jason Schneider, Boston AIDS Consortium Housing Task Force meeting, February 16, 1989.

The city of Boston has been very slow in getting involved in housing for PWAs, and its role has been minimal. Clearly, this needs to change and needs to change soon. The City should face its responsibility now, before the crisis becomes completely unmanageable and before a lawsuit forces it to play "catch up."

Specifically, the City administration should implement the following recommendations:

1. The Mayor should immediately make a public statement stating that housing for people with AIDS is a top priority for his administration. Mayor Flynn should assign a visible and influential member of his staff to direct the City's response.

2. The City should develop a written plan which includes projections of numbers and cost of units and/or residence days needed for the next five years, including an analysis of housing needs in different neighborhoods.

3. The City should commit existing resources, including vacant land through the Public Facilities Department's 747 buildable lots program and vacant city-owned buildings.

4. The City should work with the Boston Housing Authority and the state Executive Office of Communities and Development to allocate more chapter 707 and section 8 rental certificates and public housing units for people with AIDS.

5. The City should continue and expand its current efforts working with developers of single room occupancy dwellings and expanding the options for families through the Children's AIDS Project.

6. The City should play a more active role in siting residential drug treatment programs which serve people with AIDS, particularly those which serve families and linguistic minorities.

7. The City should establish better systems of communication and coordination among city agencies and between city and state agencies.
The seriousness of the growing need for housing for people with AIDS and the political sensitivity of the issue demand that the Mayor play a strong and visible role in placing it high on the public agenda. The history of the Flynn Administration shows us that action on an issue occurs when the Mayor appoints one of his key aides to develop policy on an issue, build public support for it, and coordinate the City's response. The time for the Mayor to take this step is long overdue.

The City's policy and planning for housing for PWAs should be explicitly stated in a written plan, most likely as a section of a larger city plan for addressing the wide range of planning issues related to AIDS. Following the model of San Francisco, the housing plan needs to include projections of units needed for the next five years, an estimation of the expected need in terms of residence days per year, and the costs to meet the need. In addition to planning for the different options which have been laid out in this paper, particular attention should be paid to an analysis of housing needs by neighborhood of the city.

The City's Public Facilities Department is currently working on housing development on city-owned land, through the 747 buildable lots program. In a city where the supply of developable land is limited and costly, the City should designate some of the lots for development of housing for people with AIDS, or require that some of the units created be designated for PWAs. In addition, vacant city-owned buildings which could be renovated for housing for PWAs should be identified.
Because it is desirable for many PWAs to remain in their current homes or communities as long as possible, accessing more rental subsidies and subsidized units is critical. The City should advocate for more set-asides of rental certificates and units from the Boston Housing Authority and the state Executive Office of Communities and Development to keep PWAs in their neighborhoods.

The flexibility of the SRO model to accommodate many different levels of service need and different populations, makes it an attractive option. Yet, there are fewer and fewer SROs left in the city. The current efforts of the advisory committee to the Mayor's AIDS Task Force to increase SRO development should be expanded. Likewise, the expansion of the Children's AIDS Project into a larger, neighborhood-based program is critical. The City should continue work on siting this program and developing others to meet the needs of families. In addition, city officials should continue and increase their community education efforts to facilitate siting housing for people with AIDS in residential neighborhoods.

While a discussion of residential drug treatment facilities is beyond the scope of this thesis, it is important to note that siting programs is incredibly difficult. The City needs to be more involved in supporting agencies which serve drug-addicted PWAs, particularly programs which could accommodate children and which serve linguistic minority populations. These are two chronically underserved populations whose needs are growing.
Because AIDS in general, and housing for people with AIDS in particular, demands the expertise and coordination of so many different individuals, agencies and system, a clear mechanism for communication and coordination is necessary. The advisory committee to the Mayor's AIDS Task Force should continue its efforts to make housing for people with AIDS a top priority for more city agencies and to coordinate the efforts of different agencies. The committee should also develop better lines of communication with state agencies and participate in statewide planning efforts.

While the city of Boston clearly has an important role to play by itself, it also should be lobbying for more resources from the federal government and better coordination on the part of the state government. Because the cost of AIDS care threatens to bankrupt many cities, including Boston, the city administration has a responsibility to not only think of creative financing strategies, but to hold the state, and particularly the federal government, accountable to meeting their respective financial responsibilities.

Conclusion

The city of Boston needs an integrated model of housing and services for people with AIDS and HIV infection which takes into account a number of different needs of both individuals with AIDS and different populations of people with AIDS. An ideal model consists of many different options with different levels of
services to meet the needs of different groups of PWAs. While many different options need to be available, every effort should be made to maintain enough service flexibility in every option to allow an individual to stay in one place as long as possible, with a minimal amount of disruptions in his/her life.

The city of Boston currently has the basis of such a model in place, but much more needs to be done to fill in the existing gaps and to meet the growing need for housing units as more people get sick with AIDS and live longer with chronic conditions. The key to future planning is to recognize the energy that exists to develop housing options among community-based agencies, to encourage more such involvement, and to commit more city resources to support such efforts, as well as encouraging the state and federal governments to play more active roles.