Use of Mental Health and Social Support Services by People with AIDS

Marilyn Cvitanic

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Marilyn Cvitanic

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1. INTRODUCTION

AIDS - A BRIEF OVERVIEW

AIDS (Acquired Immune Deficiency Syndrome) was first identified in 1981 when Michael Gottlieb, a UCLA physician, noticed several cases of an unusual strain of pneumonia occurring among gay men. Similar cases were reported in New York and San Francisco and within two years AIDS was recognized a major epidemic spreading throughout and beyond urban gay communities. Between 1981 and April 1990, over 125,000 cases have been diagnosed in the United States and approximately 80,000 Americans have died as a result of this new and formidable disease (CDC). The U.S. Public Health Service estimates that another 945,000 - 1,410,000 people were infected with human immunodeficiency virus (HIV), the primary causal factor of AIDS.

New York City and Los Angeles, the two cities discussed in this study, have the highest numbers of AIDS cases in the nation and illustrate the demographic range of the AIDS population affected by AIDS. While AIDS was initially discovered among gays, it also spread quickly among IV drug users (IVDUs), particularly in the north-eastern part of the United States. In New York City the AIDS population has changed dramatically from the from the early days of the epidemic when the caseload was almost entirely gay. As of August, 1990, New York City’s cumulative AIDS incidence of 28,391 is 46% gay and 42% IVDU (New York City Dept. of Health). IVDUs play a significant role in the heterosexual spread of AIDS leading to infection among women and children infected in utero. The Los Angeles case load, on the other
hand, is primarily gay. Of the 8576 persons diagnosed with AIDS in Los Angeles as of April, 1990, 81% are gay and another 4% have a history of IV drug use. The other 15% are hemophiliacs, blood transfusion recipients, children infected prenatally and cases of undetermined origin (Los Angeles County Health Dept.) By April 1990, 60% of AIDS cases in the U.S. have occurred among gay men and another 21% among IVDUs (CDC).

By 1984, HIV (Human Immunodeficiency Virus) was identified the causal factor of AIDS. Epidemiological investigation shows that the major modes of HIV transmission are sexual intercourse and contact with an infected person's blood. It appears HIV was first introduced to the United States through the gay community where it spread rapidly via sexual contact. It then made its way into the IV drug population through shared injection equipment. Because of its long incubation time, an average of ten years between infection and onset of opportunistic disease, many infected individuals unknowingly transmitted the virus before realizing they were infected. As a result, HIV infection was widespread throughout the gay and IVDU populations by the early eighties, leading to thousands of AIDS cases before the end of the decade.

HIV infection causes the gradual destruction of an individual's immune system leading to the series of opportunistic infections and malignancies characterizing AIDS. The progression from asymptomatic HIV infection to full-blown AIDS may occur within two years while the average incubation period appears to be ten years. In the future new antiviral drugs may extend this incubation period by further delaying
the onset of severe opportunistic infections. HIV infection leads to a loss of T4 cells which play an integral role in immune system functioning. As HIV infection progresses, an individual's T4 count drops from the normal level of between 800 and 1000 cells per cubic millimeter to below 100, thereby severely weakening the immune system. While an infected individual with a T4 count of 700 may develop KS, many of the other debilitating manifestations do not appear until the count drops below 400. For instance, PCP usually strikes those with T4 counts below 200.

Figure 1 illustrates the progression from exposure to HIV to death in a patient whose disease followed a typical course. As their T4 count gradually decreases, patients begin experiencing initial symptoms of HIV infection such as chronic swelling of lymph nodes and fatigue. As the T4 count drops below 400 impaired cell-mediated immunity is apparent, usually indicated through medical tests. By the time their T4 count goes below 200, many patients have developed persistent viral or fungal infections of the skin and mucous membranes. Finally, the onset of full-blown AIDS occurs with severe opportunistic infections and the patient's T4 count drops below 100 (Redfield). According to the Public Health Services estimates mentioned above, only about 125,000 of the between 945,000 and 1,410,000 people with HIV disease have been diagnosed with AIDS. Although this study focuses primarily on those with AIDS, many of the issues discussed also pertain to the many people in earlier stages of HIV infection.
Common manifestations of AIDS include Pneumocystis carinii pneumonia (PCP), tuberculosis and Kaposi's Sarcoma (KS). During the early days of the epidemic many PWAs presented with Kaposi's Sarcoma, a cancer which usually appears on the skin. In some patients KS is limited to several small lesions which respond to chemotherapy. However it can manifest itself internally, in lungs or the digestive tract, where it often becomes life threatening. KS is rarely found among IVDUs with AIDS and has been occurring with reduced frequency among gay PWAs. Presently, Pneumocystis carinii pneumonia (PCP) is the most common AIDS-defining manifestation, ultimately striking 80% of PWAs (Kovacs). PCP begins with shortness of breath and a dry cough progressing to a respiratory infection requiring hospitalization. Tuberculosis is also seen with increasing frequency among PWAs, particularly those with an history of IV drug use. While PCP and tuberculosis occur episodically, KS is a chronic disease which often progresses at a gradual pace. In addition to major opportunistic diseases, many PWAs experience constant fatigue, fevers, night sweats and persistent diarrhea.

While a cure continues to elude researchers, significant progress has been made. Over the past several years the treatment environment has evolved; a sense of frustration and helplessness has been substituted with the hope and promise of purposeful interventions. AZT emerged as the primary antiviral therapy effective in prolonging and increasing quality of life.
THE TWO MAJOR POPULATIONS AT RISK FOR HIV INFECTION

This study focuses on gay men and IVDUs, the two major populations with AIDS. In this section we discuss the spread of AIDS through these groups and the difficulty researchers face in measuring various characteristics of these populations. Representative samples are difficult to construct since many gays and IVDUs do not self identify and for a variety of reasons are reluctant or unlikely to participate in surveys or other research activities. Even the number of gays and IVDUs living in any given area is questionable.

Estimates of the number of gays or IVDUs living in a given areas are often based on guesswork and approximations. According to the Public Health Service, approximately 2.5 million men in the United States are exclusively gay and another 5 million have had homosexual contact. These are rough estimates as are the statistics on IVDUs. The Public Health Service estimates a total of 900,000 IVDUs nationwide, while Hahn uses 1.2 million.

By April 1990, 75,000 gay males have been diagnosed with AIDS. Another approximately 9,000 PWAs show a history of both homosexual contact and IV drug use. These 84,000 cases comprise 67% of the nation's AIDS caseload (CDC). The cities most heavily hit are New York, Los Angeles and San Francisco. Between 20 and 50% of the gay community in each of these cities is HIV infected (Wiley). The Public Health Service estimates 625,000-1,000,000 homosexual men were infected by 1987, comprising between 66-71% of the total HIV infected population (CDC). The racial breakdown of AIDS cases suggests seroprevalence is higher among certain ethnic groups. Blacks make up 12% of the US population
and 17% of the adult AIDS caseload. While many of these cases are among IVDUs, research suggests that seroprevalence among bisexual and homosexual blacks is also disproportionately high (Mays, Selik).

Clearly every segment of the gay community is affected, from middle class gays living in urban areas with a high concentration of gay men to those still in a suburban closet and others living in predominantly Black or Hispanic communities. Many studies focus on the white urban.

Clearly every segment of the gay community is affected, from middle class gays living in the so-called gay ghettos to those still in a suburban closet and others living in predominantly Black or Hispanic communities. Many studies focus on the white urban gay male who is out of the closet and active in gay organizations, uses STD clinics in gay neighborhoods or frequents well-known gay bars. This segment of the gay population is most accessible to researchers. Other gays, those who are less public about their homosexuality or do not live in major urban areas have a lesser chance of inclusion in research projects or even being counted as part of the gay population living in a given locale (Kotarba, Wiley).

Certain groups of Black and Hispanic gay or bisexual males are especially difficult to contact for research or even health education purposes. Language is the most obvious barrier for the Hispanic population, but the obstacles are more complex than that. Many nonwhite men, especially those who take the "penetrator" role in homosexual behavior do not consider themselves gay (Bakeman, Carrier). They do not identify with the gay community and are unlikely to join gay social organizations or the AIDS service organizations originating in the white
gay community. In geographically spread out cities such as Los Angeles, the distance between minority and white communities may be significant enough to limit interaction between the two. Given these obstacles, researchers cannot expect to recruit Black and Hispanic gays into studies without making a special effort to seek these groups out.

IVDUs are also difficult to study since they are often engaged in illegal activity and therefore do not self-identify. All statistics describing this population are based on estimates. The figures presented below represent the more commonly quoted figures.

There are approximately 900,000 IV drug users in the United States (CDC). IVDUs are most heavily concentrated in New York City; half of the country's 400,000 heroin addicts live there. Approximately another 200,000 New York IVDUs shoot up either heroin, cocaine, or amphetamines bringing the area's total up to 400,000 IVDUs (LA Times). Hahn, in a literature review of HIV prevalence among IVDUs, estimates seroprevalence among New York IVDUs at between 33-50%. Regional variation of seroprevalence among IVDUs is great even between urban centers. 52% of IVDUs with AIDS have been residents of New York or New Jersey (Hahn). Seroprevalence among IVDUs on the west coast and in the south is lower, estimated at 5% in Los Angeles, between 7-13% in San Francisco and 10% in Atlanta (Hahn). Using 1987 data, both the CDC and Hahn estimate 235,000 seropositive IVDUs nationwide, or 26% of the total IVDU population.

1 From discussion with Rev. Carl Bean, 5/22/90.
A disproportionately high number of IVDUs with AIDS are either Black or Hispanic. Out of the 26,883 IVDUs diagnosed with AIDS as of April, 1990, 13,424 are Black and 7,915 are Hispanic. Together these groups comprise approximately 80% of IVDUs with AIDS. In contrast, Blacks and Hispanics make up 12 and 8 percent of the general population, respectively (Mays, Perez-Stable). This extraordinarily high AIDS incidence implies higher rates of IV drug use in these populations as well as frequent needle sharing (Hahn). Selik et al.'s finding of significantly elevated relative risk \(^2\) among blacks and hispanics for AIDS transmission through needle sharing (20.7 for Blacks and 20.6 for Hispanics, indicating approximately 20 times higher rate of infection through needle use relative to whites) suggests these groups share needles and probably use shooting galleries more frequently than White IVDUs. Additionally, these risk ratios are even higher in the northeast section of the country (25.9 for Blacks and 30.7 for Hispanics), where shooting galleries are more prevalent (Lange).

As with the gay population, only certain IVDUs are accessible for study. Out of the 92 studies of IVDUs and HIV only three relied on data obtained outside of a medical setting or prison. By far the most frequent research setting is the methadone or drug detox clinic. Sixty-five (71%) of the studies reviewed by Hahn tested IVDUs in some form of detox program. The other studies recruited samples through STD clinics, hospitals and prisons.

\(^2\) Reference group is White, non-Hispanic
The number of IVDUs who have not used detox treatment or medical care is difficult to estimate. Their behavior, in terms of needle sharing as well as their HIV status is unknown. However, research suggests they tend to be younger, usually in their teens or early twenties and that non-whites tend to have less treatment experience than whites (Hunt). So, any generalizations about the IVDU population at large are tenuous. Research conclusions are subject to the caviat that they represent only the segment of the IVDU population accessible for study; results are not necessarily applicable to the addict on the street who is not in treatment.

In studies of gay males or IVDUS researchers must rely on members of both populations to self-identify, either in a confidential or public manner. Self-identifying may entail confidentially volunteering for a study of gay males or IVDUs conducted through a medical clinic or drug detox center or else openly attending support groups or social functions where one may be approached and recruited for study participation. In either case certain segments of both at-risk populations are unlikely to join the study sample. This includes those IVDUs or gays fearing an invasion of privacy or that their identities would not remain confidential if they participated.

Additionally, others may not be aware that studies are even being conducted; they do not frequent settings where recruitment is done or do not live in the urban locales where research is most often conducted. Finally, some potential study participants may not consider themselves eligible for studies of IVDUs or gay males. IVDUs who deny their addiction or view themselves as recreational or occasional users are
less inclined to end up in studies of IVDUs than those considering themselves regular users. Men having occasional homosexual relations but who do not consider themselves gay are less likely to join studies than self-acknowledged gays. With both IVDUs and gays, research results are of limited generalizability. They cannot be extended to the entire population, rather only to those subgroups (IVDUs in detox, gays belonging to certain support organizations, etc.) from which the study sample is drawn. While the problems discussed here also affect large-sample studies, they especially limit generalizability of smaller studies such as the one reported here.

THE NEED FOR MENTAL HEALTH AND SOCIAL SUPPORT SERVICES

Besides the physical consequences of AIDS, PWAs also experience emotional difficulties and practical problems which, if unaddressed, may impinge on the effectiveness of medical therapies. To maximize the effectiveness of these treatment improvements the existence of a well developed mental health and social support system is necessary for each patient. PWAs experience opportunistic infections, malignancies and general symptoms that often lead to periods of disability during which simple daily activities such as cooking, running errands or visiting friends can become difficult or even impossible tasks. The unpredictability and social stigma of this life-threatening illness can result in feelings of depression, isolation, and anxiety.

The specific nature of the support each PWA needs varies according to his or her circumstances. Generally the range of needs is great, especially considering the differences between the two major populations affected. Middle-class gay PWAs may have AIDS-oriented support
organizations to rely upon for services such as counseling, insurance advice and case management. Most IVDUs live in lower income communities where support organizations are less likely to exist. Additionally, many IVDUs face problems beyond AIDS including drug addiction, poverty and unemployment. Instead of looking to community organizations for support, IVDUs must rely on public programs and informal sources of care such as family and friends. The upcoming chapters will explore the provision of social support services for both gays and IVDUs by a variety of sources including family, friends, community organizations, mental health and social service professionals.

The need for a stable system of practical support and mental health care grows with increased prevalence of AIDS. Over 40,000 PWAs are living in the US today. While approximately 19% of these are in New York and another 7% and 6% in Los Angeles and San Francisco respectively, AIDS has spread well beyond these high caseload cities to virtually every part of the US.

The importance of a comprehensive system of mental health and social support is growing as PWAs spend less time in the hospital. The medical profession's better understanding of various manifestations of HIV disease have made out-of-hospital care increasingly possible. Once an option, outpatient and homecare prove a cheaper and often more comfortable alternative to prolonged hospital stays. A patient could be discharged from the hospital at an earlier date, perhaps with a visiting nurse to administer necessary services (IV drugs, wound care, oxygen adjustment) at a savings of hundreds of dollars per day. For example, in 1987 the average hospital cost per day at San Francisco General Hospital
was about $800 while the cost of a visiting nurse was approximately $100 per day (Jenna). But for home care to be viable, PWAs need nonmedical support as well, someone to clean house, cook and provide transportation until the patient is well enough to do it him or herself. A support network, made up either of family and friends, volunteers or paid assistants is necessary for home medical care to be an option for PWAs.

Besides the growing number of diagnosed cases, the prevalence of AIDS also increases with longer life expectancy after diagnosis. In 1984 the average life expectancy was only 11 months, by 1989 it reached 17.9 months for those with PCP only and 18 months for PWAs with Kaposi Sarcoma (KS) (Lemp). This increase in longevity implies an increase in the total need for medical and social support services.

Even though some PWAs are healthy enough to remain self-sufficient throughout much of their illness, all PWAs must constantly deal with the psychological ramifications of AIDS. Besides feelings of depression and helplessness which often accompany illness, PWAs must also cope with the prospect of death within the context of a disease whose course is highly unpredictable. To further complicate matters, between 30%-70% of PWAs experience some form of neuropsychiatric effects of either opportunistic infections such as toxoplasmosis or from HIV infection within the brain (Brew). These complications can lead to disorientation, short-term memory loss, depression and behavioral changes. Many PWAs and their loved ones will require emotional support from family and friends and counseling by mental health professionals to deal with this myriad of issues.
SOCIAL SUPPORT AND AIDS; A UNIQUE CHALLENGE

Models of mental health care and social support from other terminal or chronic illnesses are of limited use when studying AIDS. AIDS strikes a younger population which often does not have traditional family obligations, but also lacks the support system a family can provide. Since many gay men and IVDUs are estranged from their parents and siblings (Voller) they must become as self sufficient as possible. So, unlike leukemia patients who tend to become closer to their families of origin, PWAs' families are less available. As one oncologist who now treats PWAs put it, "A cancer patient comes in with his or her entire family while a PWA comes to my office alone."

While any diagnosis of serious illness can disrupt one's social support network, disclosing an AIDS diagnosis to family, friends and coworkers can be an especially traumatic experience. A gay PWA may have to simultaneously tell family members about his sexual orientation and AIDS diagnosis, risking alienating family members when he needs their support most. Problems also lie with the response of co-workers and the possibilities of job discrimination. PWAs often risk job loss by requesting a modified work schedule to accommodate medical appointments. Co-workers may begin avoiding the PWA, making the work environment highly unpleasant and possibly affecting his ability to do his job.

While all persons diagnosed with serious illnesses face new problems in dealing with family and friends, PWAs issues are unique in that they carry with them not only the stigma of disease, but also the stigma of homosexuality and drug addiction. The discrimination and stigma PWAs face can complicate coping with an AIDS diagnosis, thereby increasing
the need for emotional support from family, friends or through a formal counseling program.

AIDS strikes at a time in life when most people do not expect serious illness and are not prepared to deal with it on either a practical or emotional level. In the United States 90% of PWAs are male, 59% of PWAs fall into the 20-39 year age group and 79% are between 20 and 49 years old (CDC). By comparison, most cancer mortality occurs among people over the age of 65 (DHHS). As a result of the age differences alone, we can expect that emotional issues would differ significantly between the cancer populations and PWAs. The lifestyle changes which come with the chronic fatigue, loss of bodily control and memory lapses associated with AIDS are often extremely emotionally taxing for a previously active person.

Additionally, many PWAs have not had the opportunity to develop enough financial equity to support themselves during a prolonged period of illness. Many private health insurance policies do not cover outpatient and drug expenses encountered by PWAs. Financial assets are often quickly depleted after a few months of costly treatments. While Medicaid coverage is sometimes more comprehensive than private health plans, some PWAs find it psychologically difficult to accept Medicaid. Financial dependency on public programs, private charities and the goodwill of family and friends can be especially disturbing for a self-sufficient person. Finally, wills must be planned and decisions made as to what should be done in case the PWA becomes dependent on life-support systems. The stress and emotional trauma associated with such decisions can be extremely acute for a younger person who is used to planning for the future.
The clinical course of AIDS differs from that of cancer and most other diseases to the degree that unique coping strategies are required. Unlike certain cancers, AIDS does not progress in a predictable fashion. Rather than experiencing symptoms which gradually change or are treated in a systematic fashion, PWAs experience various opportunistic infections each having a different symptomatology and treatment. Until antiviral drugs make prolonged remission a possibility, PWAs must learn to cope with the unpredictability of AIDS, the constant threat of reinfection and chronic tiredness. They must devise means of coping without the signs of improvement which often help many persons with cancer deal with their illness.

In devising the best means of providing social support and mental health care to PWAs, we cannot rely too greatly on prior models of care. The AIDS epidemic's unique characteristics, the young age of PWAs, the unpredictable and varied course of the disease and the stigmatized history of the populations most heavily affected by it, demand a new and highly flexible system of care.

A BRIEF DESCRIPTION OF THIS STUDY

This study is based on face-to-face interviews with sixty-two PWAs. Forty of these are gay men living in the Los Angeles area and the other twenty-two are PWAs who have a history of IV drug use and reside in the Brooklyn area of New York City. The interviews covered each PWA's medical history, financial and employment background, health insurance history, living arrangements, use of medical services, mental health care and social support.
This study is unique because it encompasses both IVDUs and gays, the two major populations affected by AIDS in the United States. The groups interviewed also represent the largest risk group affected by AIDS in each city.

The groups interviewed for this project tend to be relatively well informed about the services available to them. The gay men in this study are all clients of AIDS Project Los Angeles (APLA) which means they are connected to one of the largest providers of mental health and social support services in the Los Angeles area. Many of these men also live within the vicinity of APLA’s offices and can easily use services. Most of the IVDU group regularly attend Kings County Hospital outpatient clinic, unlike many others who come in for service occasionally, often relying solely on the emergency room. The IVDU sample in this study probably have more contact with social workers and are also the most aware of support services offered through the hospital and local public agencies.

Because this study deals with a select group of PWAs, a relatively well informed group, our results probably represent higher than average utilization of services. While we cannot generalize to the AIDS population at large, these results show what utilization might look like were all PWAs put in an environment where information and actual services were accessible.

How PWAs meet their mental health and social support demands is complicated; there is no set protocol for how many or what type of services are needed and no established network of providers. Rather, individual PWAs are left to use whatever resources are available to
them. These resources vary from person to person, with some having a solid network of friends which can provide much of the support, both emotional and practical, that is necessary. Others may be much more isolated and find that AIDS-oriented community organizations are the only source of support available to them. Still others have sufficient financial resources to purchase the care they need.

In order to get a better understanding of how the two groups of FWAs in this study, IV drug users in Brooklyn and gay men in Los Angeles, get mental health care and other support services, I will examine the following research questions:

**How many services are used and in what quantity?**

Determining the volume of service utilization by FWAs is a first step in planning for the changes in demand that come with the growing and diversifying AIDS caseload. Utilization represents the result of the demand for a given service and the availability of that service. One can use the utilization estimates derived from the two small samples presented in this study and approximate the costs of providing this level of care to these and other groups of FWAs. The feasibility and appropriateness of providing these services to the broad population of FWAs is addressed in chapters focusing on need and availability of various services to groups within the Los Angeles and Brooklyn areas.

**Who provides services?**

In the case of social support and mental health we must look beyond conventional paid providers of services and towards AIDS-oriented community organizations and FWAs' friends and family. Three factors
determine where PWAs go for various services, availability of the service from a certain source, the cost of the service and its quality. Some PWAs are isolated from family and friends and must rely on community organizations. Others do not have the financial resources to cover the expense of services provided through paid professionals and are forced to seek help from either family, friends or services organizations. Other PWAs may have both family and money yet use free services provided through community organizations since they consider those services of a higher quality.

What is the cost or dollar value of each service?

Assigning a dollar value to each service used by the PWAs in this study allows for a unit of comparison of the relative amounts of care delivered by various providers. These values are based on the actual price paid for a service or the estimated market price for a service provided for free. By calculating the monetary value of all services used we can get a sense of the potential cost to society if these services were provided and paid for by the public sector. Additionally, should donated care become unavailable, the amount that would be paid out to maintain the current standard of care is approximately equal to the dollar value assigned to donated labor.

Are some segments of the AIDS population likely to have better access to donated services than others?

As mentioned above, some PWAs are socially isolated to the extent that they do not have family or friends to care for them. Others' social network may not consist of persons financially or psychologically capable of caring for a PWA. Such circumstances are likely to exist
among IVDUs with AIDS who are impoverished and socialize primarily with other IVDUs. Geography also influences the access to care. If the community organization that sponsors support groups is located in the opposite end of town from where most IVDUs live, then it is unlikely that IVDUs will be able use these support groups regularly. Also, if these organizations are primarily founded and organized from within a middle-class segment of the gay community, then they are less likely to have the expertise to serve lower income IVDUs.

The forthcoming chapters describe this study and its results along with detailed background material. Chapter two focuses on PWAs' psychosocial issues and support needs beginning with a discussion of the influence of coping styles on demand for care including PWAs' need for concrete services such as housekeeping and transportation assistance. Chapter three presents the study methodology including a detailed discussion of the development of the survey instrument and the actual interviewing process. It also discusses the limitations of the study in terms of the generalizability of the results to the PWA population at large. Chapter four provides background information pertaining to the various sources of care including family members, public programs and community organizations. Chapter five presents and discusses the study results with respect to the amount and types of services used, who provided care and the costs of care. Finally, chapter six is a brief discussion of policy implications of this project's results.
CONCLUSION

The population of gays and IVDUs at risk for AIDS is hard to define since certain segments of these populations are inaccessible to researchers. Especially difficult to reach are closeted gays, bisexuals who do not consider themselves gay and Black and Hispanics who are not in contact with the white gay community through which research participants are often recruited. IVDUs not in detox and not in regular contact with the health care system are also inaccessible. Because these groups are so elusive, any results concerning resource use cannot be blindly generalized to the entire AIDS population.

This study represents resource use among two subgroups of the AIDS population, urban gays affiliated with AIDS service organizations and PWAs with a history of IV drug use who are in regular contact with an AIDS outpatient clinic. It is difficult to determine what percentage of the AIDS population these two groups comprise. But clearly, they are not insignificant segments in terms of size or resource use. AIDS project Los Angeles serves approximately 70% of the PWAs in Los Angeles. At Kings County Hospital there were over 778 inpatient discharges of adult and pediatric AIDS cases, accounting for over 27% adult and 50% of pediatric AIDS discharges in Brooklyn. In 1988 there were 2712 visits to the Kings County AIDS outpatient clinic. As for resource use, both these groups are probably relatively high users of mental health and social support services compared to other members of the same risk group since study samples represent the gays and IVDUs with AIDS who are most directly affiliated with service providers.
II. PSYCHOSOCIAL ISSUES

Through a review of the literature this chapter presents some of the emotional and practical issues PWAs face soon after diagnosis and during their course of illness. Because of the unique populations affected by AIDS and the disease's erratic clinical course the literature review is almost entirely limited to articles and books pertaining directly to AIDS. This review illustrates the factors influencing demand for care including how one copes with an AIDS diagnosis and deals with other problems ranging from substance abuse to insufficient assistance at home. The review further reinforces the importance of understanding PWAs' support systems by describing the wide range of services they need. Finally, this chapter presents a context from which to view the study description and results presented in later chapters.

FACTORS INFLUENCING DEMAND FOR CARE

Factors influencing the need for mental health care and social support are complex, with each PWA having his or her own set of medical, practical and emotional needs. A standard for the amount of assistance a typical PWA needs would be difficult, if not impossible, to establish given the variety of clinical and emotional difficulties PWAs face. The symptomatology of AIDS varies substantially according to the type of infections, malignancies and symptoms a PWA experiences. A PWA with Kaposi's Sarcoma probably experiences much less disability early in illness than than someone with PCP or recurrent toxoplasmosis.
Additionally, each individual copes with illness in his or her own way, with some choosing to seek professional counseling, others relying on friends and family. Still others cope more privately and demand little outside help. Substance abuse problems also influence the psychosocial scenario, tending to increase needs for various services while often reducing the likelihood that the PWA will seek care. A typical set of needs, like the typical PWA are virtually impossible to define. Rather, a broad spectrum of services are required to help PWAs live with AIDS given their individual coping style, substance abuse needs and medical condition.

**Coping Styles**

Coping styles come into play when PWAs require either mental health care or practical assistance such as transportation, housekeeping or cooking. Some PWAs feel the need to be as self-sufficient as possible while others welcome assistance. Those with greater financial resources may want to pay for practical care rather than accepting "charity." To accept any sort of assistance, paid for or not, requires an acknowledgement of one's disability and needs. This is often extremely difficult for PWAs soon after diagnosis, a time when denial is often the most comfortable means of coping (Douglas). So while a PWA may benefit from counseling and practical assistance, the amount of care he or she actually accepts depends greatly on the individual's coping style.

While denial can temper depression and anger, it can also become part of a negative coping strategy, a state of avoidance so severe that medical advice is ignored to the point of life endangerment. Denial is a common "equilibrium-preserving" response to the initial AIDS diagnosis
and can be beneficial to the process of adjusting to AIDS (Nichols). While many PWAs experience some degree of denial, those diagnosed on the basis of Kaposi's sarcoma often deny their illness longest (Blaney). A PWA with minimal symptoms and for whom Kaposi's sarcoma is the only major manifestation of HIV infection can live a relatively normal life, without long hospitalizations or extensive periods of disability. PWAs who experience severe symptoms, such as extreme fatigue or constant diarrhea prior to diagnosis are less likely to deny their state, they may actually feel relief at the removal of uncertainty as to the cause of their symptoms (Blaney). Many of these PWAs are already depressed and have experienced the helplessness and anxiety associated with a diagnosis of serious illness (Nichols) making denial less likely. The extent to which denial occurs is also related to openness about one's homosexuality. Gay PWAs with positive attitudes towards their sexual orientation, with fewer feelings of guilt and blame, experience less fatigue, and depression (Wolcott, Namir, et.al.).

Three strategies of coping with serious illness have been defined, active-behavioral coping, active-cognitive coping, and avoidance coping (Billings and Moos). Namir et.al. summarize these strategies as follows:

Active-behavioral efforts deal directly with the problem and its events and relying on others for emotional, informational, and instrumental support.

Active-cognitive efforts deal with the appraisal of the stressfulness of the illness and includes one's beliefs, attitudes and thoughts about the illness.

Avoidance efforts are attempts to avoid thinking about or behaving in direct response to the illness and that includes self medication with alcohol and drugs.
In their study of fifty gay men recently diagnosed with AIDS, Namir et. al. found significant psychological correlates with coping strategy. Avoidance coping was correlated with higher anxiety, depression and lower self-esteem. Active-behavioral coping was positively correlated with self-esteem and inversely related to mood disturbance and depression, while active-cognitive coping failed to show significant correlations. So, PWAs openly seeking direct assistance in dealing with depression and anxiety do better than those who avoid acknowledging negative feelings associated with their illness.

Namir et. al.'s results imply that those with active behavioral coping styles, i.e., those who rely on others for assistance and deal directly with their illness, fare better psychologically than those who get stuck in a denial pattern. PWAs using avoidance coping showed fewer close friends and less satisfaction with their support network than those using active-behavioral coping.

Two factors could result in active copers' higher satisfaction with their support systems. First, PWAs report that emotionally sustaining help is more valuable than problem solving help soon after diagnosis (Zich). Active copers are more likely to receive emotionally sustaining help than those in denial since this support is difficult to provide to those who avoid acknowledging the existence of a problem. Second, coping styles can influence the availability of support. Wortman found that among cancer patients better copers are avoided by family and friends less frequently than are poor copers. This implies that the poor coper is caught in a cycle of denial of AIDS and dissatisfaction with his or her support system. To get out of this pattern a PWA will
have to acknowledge his diagnosis and his need for assistance, then he
can build up a support network he is satisfied with. Ironically, those
who use avoidance coping methods experience more severe depression and
anxiety and are the most socially isolated; they are the PWAs who most
need to seek out support from friends, family and community agencies.

Ultimately, the significance of coping style is its role in
determining whether a PWA seeks support services. If one is in denial,
he or she is less likely to seek mental healthcare or practical
assistance, even if these services were clearly beneficial. A more
active coper would seek out these services and, according to Namir's
findings, probably fare better psychologically than than those never
demanding such care. The economic consequences of active-coping are
difficult to pinpoint. Most likely, their costs of care are higher
since they use more services. However these extra costs should buy some
medical and quality-of-life benefits. Food banks or "meals-on-wheels"
services lead to healthier diets and volunteer transportation programs
help PWAs get to clinic appointments which they may miss otherwise.
Ultimately, these PWAs may experience fewer manifestations of HIV
infection and require shorter hospitalizations.

Chemical Dependency

IVDUs with AIDS have unique individual needs stemming from their
chemical dependencies, drug detox services and specialized counseling
being the most obvious. Frequently, because IVDUs feel disenfranchised
from mainstream society, they are disinclined to seek out care. The
following section discusses the association between IV drug use and
AIDS, some of the special needs of addicts with AIDS as well as the
obstacles they face in coping with AIDS.
1.3 million people use intravenous drugs in the United States and between 70 to 90% of these are thought to share equipment (Schuster). Communal works are a significant part of the drug culture and an efficient means of transmitting the AIDS virus. Shooting galleries, places where users can pay a small amount to use works and and shoot up in a relatively safe environment, are found in many urban areas but are most are common in parts of York City City, where 45% of AIDS cases are drug-related (New York City Dept. of Health). Additionally, Des Jarlis has documented the phenomenon of running partners, a small team of IVDUs who work together hustling money and drugs and share equipment. Both running partners and shooting galleries represent an oasis of security and familial relationships to the IVDU user, whose life is otherwise filled with mistrust and violence (Kleinman and Mockler).

Chemical dependency represents a significant danger to any HIV infected person as well as to those around him or her. Approximately 12% of women with AIDS in the US were infected through sexual contact with IVDUs (CDC). Almost all cases of AIDS among infants are traced to an HIV infected IV drug using parent. Sexual behavioral change necessary for reducing transmission is unlikely without treating drug and alcohol use. Faltz (1986) quotes a study for the San Francisco AIDS Foundation in which 61% of the gay men surveyed reported that they were "more likely to have unsafe sex when using alcohol or drugs."

IVDUs with AIDS face the double challenge of giving up drugs while also breaking off from their drug-oriented social network, often built around shooting galleries and running partners. This group of PWAs must find support elsewhere, often in formal support groups geared towards
staying off of drugs and maintaining a regimen of proper medical care and healthful living. Without accessing such groups, an IVDU with AIDS has little hope of going straight. Anecdotal evidence suggests that even those who have been clean for several years sometimes return to drug use after learning they are HIV positive. An IVDU with AIDS faces a short but grim future filled with the debilitating symptoms of AIDS that only make the constant struggles of life as an IVDU more difficult. Often these PWAs die alone in public hospitals, having alienated their families and friends and leaving social workers the task of burial and funeral arrangements.3

For those IVDUs who decide to quit using drugs, the detox process is difficult with uncertain results. The first problem is gaining access to a treatment program. A NIDA official estimates that there are currently 148,000 treatment slots and approximately 1.2 million users in need (Kleinman and Mockler). Some areas have more treatment programs than others. In New York City 1 in 7 heroin addicts are in treatment compared to only 1 in 20 in Boston (DesJarlis and Friedman 1987, Burack and Schuster). Many addicts choose methadone maintenance programs but have limited success. During the first year after treatment only 15-20% of clients stay off of both heroin and methadone (Kleinman and Mockler). Since methadone does not relieve cravings for other drugs, IV use of cocaine and amphetamines may continue through treatment (Landis).

Chaission's study of IVDUs in San Francisco shows 24% of study participants in methadone programs actually increased or began shooting up cocaine after joining the program. Another study estimates up to 50%  

3 From discussion with New York City social worker, 1/24/90.
of heroin users in methadone programs shoot up another drug (Kleinman and Mockler). Since no effective medical treatment for cocaine addiction exists, IVDUs must kick this part of their habit through drug-free detox, a process which is aided by regular support group meetings and counseling sessions.

Besides intravenous drugs, alcoholism and other illegal substances also pose an additional health problem for many PWAs. Approximately 30% of the clients at AIDS Project Los Angeles have problems with alcohol or other drugs most commonly marijuana or speed. Alcoholism is a particularly common problem among gay men for whom bars are a primary social gathering place. Like intravenous drugs, alcohol impairs judgement so unsafe sexual encounters are more likely to occur when under the influence (Schuster). Alcoholism may also lead to poorer self care. Fifteen percent of alcoholics attempt (or commit) suicide verses 1% of the general population (Flavin). Additionally, alcoholics often experience significant depression after detox which compounds the emotional difficulty of an AIDS diagnosis (Flavin) and implies the need for extensive support and counseling.

Clearly, PWAs with chemical dependencies require mental health and social support resources in excess of what most other PWAs need. They are dealing with two diseases simultaneously, diseases which exacerbate one another. However, not all chemically dependent PWAs seek out additional support services, many do not even maintain regular medical care. An IVDU with AIDS lacking a regular source of ambulatory care

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* From discussion with Rick Davis of AIDS Project Los Angeles, October 1, 1990.

From Discussion with Virrie Graham and Althena Kitchens, nurse educators at Kings County Hospital AIDS Program in Brooklyn.
and only visits the emergency room when absolutely necessary, is unlikely to maintain contact with counselors or support groups. Even those seeking help may not get it; long waiting lists for detox programs and lack of support programs close to home are formidable obstacles for those having the double burden of AIDS and chemical dependency. So while chemically dependent PWAs may require extra mental health and support services, they are not always likely to access these extra services.

Clinical Manifestations of HIV Disease

Individuals with HIV infection can experience a wide range of disorders causing varied degrees of disability, which in turn effect the amount of support and assistance they need. PCP and KS are often the most manifestations of HIV disease. However, a number of other infections also occur with significant frequency such as Toxoplasmosis (which often infects the brain leading to seizures and coma), cytomegalovirus (which can cause pneumonia, encephalitis, blindness and inflammation of the intestinal tract), and cryptococcus (often causing meningitis). Since all these diseases cannot be discussed in detail, the following paragraphs will use PCP and KS as examples of how specific manifestations of HIV disease can influence an individual's need for support.

Because the diseases (KS and PCP) differ so much, we can expect mental health and social service use by PWAs with these diseases to differ as well. Mobility is a major difference between KS and PCP patients. Often KS is primarily a cosmetic problem without any physically disabling effects. PCP patients are incapacitated for days
at a time and often require weeks for complete recuperation. PWAs with KS are less likely to require assistance with transportation, housekeeping or other daily activities. Those recovering from PCP usually need some form of home care for at least several days after leaving the hospital.

While little data exists on the subject, one can hypothesize that different physical manifestations of KS, and PCP probably have varied psychological impacts. Some PWAs with KS can deny their AIDS diagnosis by attributing their illness to cancer, not AIDS (Christ, 1988). However, a KS lesion is a constant visual reminder of AIDS which makes coping especially difficult if the lesion is on the PWA's face. PWAs with PCP face different coping challenges. Often they require long hospitalizations during which they are constantly reminded of their AIDS diagnosis through contacts with medical personnel. After discharge these PWAs often face longer periods of disability which in turn requires the PWA to begin coping actively by accessing AIDS service agencies. This act may reduce the PWA's denial but also lead to the painful process of acknowledging the diagnosis before the PWA is ready to do so.

RESOURCE NEEDS AND PSYCHOLOGICAL STAGES OF ILLNESS

PWAs, like people with cancer or other life-threatening illnesses, go through various psychological stages in coming to terms with their prognosis. Understanding these stages is useful in predicting which services a PWA is likely need and which services he or she is likely to seek out. Nichols (1985) has developed a 4-stage situational distress model of the various phases a PWA goes through during the course of
illness. The model suits the unpredictable course of AIDS by
acknowledging that a PWA does not necessarily experience the phases in a
neat linear fashion. Rather, a PWA can go back and forth between phases
in accordance with the symptoms of disease, the occurrence of serious
opportunistic infections and malignancies or other crisis such as job
loss of deaths of others with AIDS. At the time of diagnosis one enters
the initial crisis phase, then he can go into the transitional phase,
then the deficiency phase and finally preparation for death.

The initial crisis stage is the period immediately following
diagnosis during which a PWA fluctuates between denial and feelings of
great anxiety. While a diagnosis of life-threatening illness is
traumatic for anyone, PWAs face some uniquely difficult issues. Most
PWAs are diagnosed between the ages of 25 and 50, a time when careers
are being established and personal goals are made and carried out.
Dealing with AIDS requires a drastic change in thinking which usually
cannot be made over night. The initial crisis stage, while often
characterized by shock and emotional numbness, is the first step in
dealing with all the changes to come. PWAs face a loss in income, social
status and threats to relationships with family and friends (Macks).
Referrals to mental health specialists should begin at this time
(Christ, 1986). Though Nichols recommends no effort be made to move the
PWA past denial before he or she is ready. Denial or avoidance is
sometimes the only way to gain control over the onslaught of potential
hardships that come with an AIDS diagnosis (Christ, 1986).
During the transitional phase PWAs become increasingly open to counseling and other support services. Denial gives way to feelings of anger, guilt and anxiety. PWAs move away from the emotional numbness of the initial crisis phase into a state of greater sensitivity towards others' responses towards them, societal values and family reactions. Nichols finds that PWAs' anger can lead to dangerous sexual and drug using behavior including thoughts of suicide. During this phase, membership in support groups can help PWAs adjust to their own feelings and establish a new sense of self and new support network.

Acceptance and preparation for death are the third and fourth phases. Acceptance is characterized by coming to terms with AIDS and the effects of the disease on the PWA's life. More interest is taken in community activities and living each day to the fullest. During acceptance PWAs may embark on new efforts to restore health including taking on unconventional therapies and developing a determination to continue fighting in spite of declining health. This determination usually counterbalances worries about dependency on others and associated thoughts of suicide. Eventually, many PWAs become comfortable talking about death and begin preparations for it including specifics about where they would like to die, funeral arrangements and other plans to be carried out after death.

During the various phases PWAs are more or less likely to seek out certain services. If denial is particularly strong during the initial crisis phase then counseling may not be used and progression to the next phase is slow. If denial is brief, as might be the case for those diagnosed with ARC prior to developing full-blown AIDS, then use of
support groups probably begins earlier. PWAs in need of practical assistance including financial support, housing or food are more likely to go to community-based agencies for assistance once the initial crisis period is over, even though they might benefit from these services before then. Progression from phase to phase of Nichol's situational distress model is not always sequential since the progression of AIDS is unpredictable. PWAs are susceptible to a myriad of opportunistic infections and malignancies which do not occur in any prescribed pattern or frequency. Therefore, PWAs may go in and out of the phases of the situational distress model according to their health status.

A TYPOLOGY OF NEEDS

PWAs face a wide range of support needs upon diagnosis and throughout illness. Macks developed a typology of needs from which the following categorization is adapted:

Need for Concrete Services

At some period during their illness all PWAs experience severe disabilities which prevent them from going to work or carrying out daily activities such as cooking, shopping, cleaning house and visiting friends. Some PWAs are able to run their lives normally for over a year after diagnosis except for discrete bouts with various opportunistic infections. In other cases disability is a continuous state brought about by the constant fatigue, diarrhea and night sweats many PWAs experience (Volderbing).
PWAs have a variety of practical needs. These include having someone to help with household chores, transportation, housing, financial assistance, legal assistance and maintaining an adequate diet. In a recent study, 47% of PWAs surveyed reported difficulty in keeping up with household chores. Another 33% reported transportation needs were not met, 27% needed more housing assistance and 21% had problems obtaining proper food. Seventy-four percent responded that lethargy and fatigue limited their activities (Crystal). In the study mentioned above 47% of PWAs became unemployed due to physical limitations and another 26% lost their jobs due to fear or discrimination (Crystal). Unemployment often leads to problems keeping up with rent, mortgages, auto and health insurance payments, and in more extreme cases even proper food and shelter become unaffordable. In New York City, for example, 17 to 30% of hospitalized PWAs are homeless (Wright; Small, Laper and Ricci). This statistic may not be generalizable to the rest of the country since New York City has a large number of PWAs having a history of IV drug use and they may have a greater tendency towards homelessness than other PWAs. However, the high homelessness rate can be viewed as an indicator of the severity and types practical problems PWAs throughout the country face and the need for emergency support services.

PWAs must often look to a variety of providers for practical support. Since AIDS is linked to sexual behavior and drug use, a diagnosis can stir up feelings of guilt and anger disrupting familial and other supportive relationships, thereby limiting long-standing financial and emotional supports (Kelly). In a survey of 48 PWAs living
in New York City, Christ found that they are more dependent on friends than on family for assistance. Some PWAs live in a "family reconstitution" with close friends who provide assistance. However, about three-quarters of the surveyed lived alone and lacked a support network they could consistently rely on for help. While visiting nurse services are available, they often do not give 24-hour assistance or provide free care. "Buddy systems" developed by some AIDS service groups offer practical and emotional support services to PWAs at home but as with visiting nurses they cannot usually offer immediate assistance when needed. (Christ, 1986)

Community organizations serving HIV-infected persons can provide some care, yet these organizations are not always geographically accessible or have appropriate services for all PWAs. These organizations are often based in neighborhoods with a large predominately white, gay community and may not be convenient for minority PWAs living in other parts of town. For many blacks, the church is the main provider of practical assistance (Mays). For those who are unaffiliated with either a church group or any other community support agency, family and friends become the main source of care, particularly attendant care at home (Wolcott). When a PWA relies on community organizations, churches, friends and family, the degree to which needs are met depends on the resources available to the provider and the extent to which a PWA manages to piece together various types of assistance to meet his or her needs.
Addressing Neuropsychiatric Complications

Approximately 70% of PWAs show some sign of central nervous system disease by the time of death (Levy). Central nervous system disease may come from either lesions caused by opportunistic infections such as toxoplasmosis or cytomegalovirus or from HIV infection of brain tissue causing symptoms otherwise known as AIDS dementia or HIV encephalopathy. Usually signs of AIDS dementia do not appear until after a PWA's second major opportunistic infection, however symptoms have been seen even prior to an AIDS diagnosis (Siegal).

Because AIDS dementia often comes on slowly, mental health professionals and physicians must keep close watch for gradually developing symptoms including memory loss, unsteady gait, depression and confusion. These symptoms sometimes provoke sadness and anger which lead to difficulty coping with issues which were not problematic before (Christ, 1988). The challenge to health care providers is distinguishing CNS disease from effects of emotionally based health problems which counseling and stress reduction can alleviate. AIDS dementia associated with HIV brain infection requires pharmaceutical treatment, though it is impossible to completely relieve symptoms which can progress to significant leg and arm weakness, slow verbal response and incontinence.

Ideally, PWAs suffering from dementia should be kept as autonomous as possible (Tucker). However, AIDS dementia can lead to inability to drive, count money, cook or feed oneself. Calenders, appointment books and posted emergency phone numbers help PWAs maintain orientation. Since dementia can lead to paranoia and suicidal tendencies, all weapons
should be removed from the patient's home (Tucker). Patients must also decide who will be responsible for medical decisions should mental incapacitation occur (Christ, 1988). Caregivers need preparation for the possible development of advanced CNS symptoms so they can provide appropriate support (Christ, 1988). Eventually, some PWAs will need a round-the-clock caregiver or institutionalization.

**Substance Abuse Services**

At diagnosis PWAs face many immediate problems. Along with medical issues, PWAs face problems with finances and employment, emotions and reactions of family and friends to the diagnosis. Substance abuse may seem a low priority among these other emergencies. However, if chemical dependency is not dealt with, it gets in the way of solving these other problems (Faltz and Madover 1987). As mentioned earlier in this chapter, substance abusers have a more complex set of issues than non-abusing PWAs; chemical dependency is often related to other underlying personality problems. Mental health providers must sort out behavioral and emotional problems due to alcohol and drugs from those more fundamentally based (Caputo).

Additionally, some PWAs may feel little motivation for treatment. They may not consider the problem serious enough or feel it is worth dealing with in light of the high morbidity and mortality associated with AIDS (Faltz and Madover, 1988). In this case counselors must educate the PWA about the immunosuppressive effects of excessive alcohol and drug use (Brown) while presenting the standard educational message of the dangers of unsafe sex and needle sharing (Faltz and Madover, 1988). For those PWAs willing to go into treatment, social workers and
counselors should be aware of drug treatment programs which are sensitive to PWAs' needs (Macks). Unfortunately, the demand for treatment of IV drug use far exceeds capacity. During the summer of 1987 IVDUs in New York City typically had to wait between two to three months to get into drug treatment programs (DesJarlis and Friedman, 1988).

Social problems faced by IVDUs differ from those of many gay men with AIDS and require specific attention. Often IVDUs have families and worry about transmitting AIDS to their children or a non-using partner. Since there are approximately three times as many males shooting up drugs as females (Hanson), the sexual partners of IVDUs are often females who, if infected, can give birth to an infected child. In New York City, at least 80% of HIV-infected infants are born to at least one IVDU parent (New York City Dept. of Health). Additionally, many IVDUs turn to prostitution as a means of financing their drug habit. In New York City, approximately half the street prostitutes have histories of IV drug use (DesJarlis and Friedman, 1988). This has significant implications for the public health as well as for mental health workers faced with the task of educating HIV infected addicts into practicing safer sex.

Need For Information

AIDS is surrounded by myths and changing information. As a result, PWAs are constantly plagued by uncertainty as to their own prognosis, the unpredictability of friends', family and coworkers' reactions, and the mystery of what is appropriate medical and practical care. Supportive relationships reduce uncertainty by increasing perceived
control over events (Albrecht and Adelman). According to Lazarus, "Support occurs when information and resources from others in the environment ... minimize the perception of threat, maximize actual and perceived mastery and facilitate direct action and anticipatory modes of coping." So, providing information is a key part of support which in turn leads to uncertainty reduction and improved coping.

While new AIDS-related medical data is constantly coming out, there is still much that is not known about the disease's course and factors influencing it. Physicians often address basic medical questions such as the meaning of T-cell counts and other test results at the time of diagnosis when the PWA is in a state of crisis and retention is minimal (Macks). Nichols recommends having a friend come along for physician visits to help reiterate and clarify important information. This is a useful suggestion given Namir's report that 85% of PWAs end up seeking out additional information about their illness. Unfortunately many of the most asked questions about cofactors and prognosis have no answers. This emphasizes the importance of providing accurate information wherever possible in order to help PWAs gain greater control over their lives (Macks).

The decision of whether to take experimental drugs is another case where some information is available but a great deal of uncertainty still exists. PWAs ask, "Will it really help me?" while balancing out the possible unpleasant side effects and also structuring life around strict administration regimens (Dilley). Since the actual effects of the drugs are unknown, those on experimental protocols do not know whether they are improving their prognosis or simply putting themselves through a series of unpleasant side effects.
Other information needs include education about risk reduction for sexual activities and needle sharing and infection control. Macks recommends that both medical and mental health providers assess PWAs' level of knowledge in these areas and educate them accordingly. Some PWAs in the early crisis and denial stages of AIDS are not receptive to educational messages (Morin). Therefore providers must be willing to answer questions as they come up and act as educators continuously.

PWAs can use a variety of services including support groups, financial and housing assistance, food banks and alternative health therapies. Resource lists are another helpful piece of information, the importance of which is emphasized in the next section.

Managing Crisis and Distressing Feelings

From the point of diagnosis PWAs experience a wide range of emotions and mood fluctuations (Macks). Fifty-two percent of PWAs exhibit treatable emotional disturbance (Tross). Fear, anxiety, guilt and sometimes even thoughts of suicide plague PWAs.

While fear and anxiety are particularly obvious reaction to life threatening illness, the actual emotional reaction to AIDS can be quite complex. Fear is closely tied into the great uncertainty of AIDS (Cassens). Unlike many cancers, there is no established protocol for AIDS treatment. There are no real remissions, rather a series of opportunistic infections and malignancies, the onset of which is unpredictable (Christ, 1986). PWAs report feeling like "a walking time bomb," (Christ, 1988) wondering which infection will strike next and how to cope with it. Any physical change can trigger panic since it may
indicate onset of a new opportunistic infection. As a result, hypochondriacal behavior can occur along with anxiety and panic attacks (Holland and Tross, Blaney).

In addition to fear of pain, disfigurement and eventual death, PWAs often worry about abandonment from family and friends. Fear of abandonment by family is especially acute when a gay PWA is forced to disclose his sexual orientation; the AIDS diagnosis does not allow one’s sexuality to remain secret. In many cases, however, the family is not the major source of support. In a study of 42 New York City PWAs, 62% had minimal or no contact with their families (Christ) implying they must rely on friends or lovers for support. A British study of 192 PWAs shows rejection by 8/126 sexual partners and 19/164 close friends (King). While these numbers seem small, many PWAs still report not having been held or touched affectionately since diagnosis (Blaney).

The guilt attached to AIDS also comes in many forms. The notion of AIDS as punishment for promiscuity is well publicized (Morganthau) While few gays support this theory, guilt about past behavior including high risk sexual acts and drug use is well documented (Macks, Morganthau, Blaney, Wolcott). More so than most other diseases, societal blame for the AIDS epidemic tends to focus on its victims (Katz) and forces them into denial and hiding, perpetuating the rejection and isolation gay men have experienced throughout their lives (Stulberg and Cassens). Such feelings can evolve into homophobia among PWAs. In a study comparing attitudes among healthy gay men and those with AIDS, Wolcott, Namir, et al. show PWAs having more negative attitudes towards homosexuality than their healthy counterparts.
Particularly in the early stages of illness, some gay PWAs exhibit and hostility towards partners who may have "given" them the disease (Christ, 1988). Guilt frequently goes beyond oneself to worries about transmission to lovers, needle-sharing partners and family members, and particularly newborn children (Christ, 1988).

Suicidal ideations occur among PWAs with alarming frequency. Mazurk et al. found suicide rates among PWAs in New York City was 614 deaths per 100,000, that is approximately 66 times higher than the suicide rate of the general population. Suicide most commonly occurs close to time of diagnosis among PWAs who do not understand the resources available or the course of illness (Goldblum). It may also occur later in illness if the PWA becomes preoccupied with thoughts of death or at the final stages when the PWA is most debilitated and dependent (Goldblum, Wolcott). While PWAs often talk of suicide when anticipating periods of crisis, they are usually in a different frame of mind by the time the crisis occurs and do not attempt suicide (Macks and Turner,). Suicides are most likely among PWAs who have histories of depression and anxiety (Macks) or have experienced multiple losses related to AIDS (Goldblum). Whether a terminally ill person should be allowed to take his or her own life is an open ethical question (Goldblum, Glass). However, suicide prevention efforts give patients an opportunity to evaluate various means of dealing with both physical and emotional aspects of illness and often allows resolution of personal relationships (Marzuk).
Despite the frightening aspects of an AIDS diagnosis, many PWAs adjust without debilitating emotional side effects. A positive attitude develops, not based on denial but rather on the desire to make the best of life (Mandel). These personality changes may occur where one goes from self-orientation to emphasizing compassion and spirituality (Mandel). However, such positive adjustments often involve outside support. Wolcott et. al. (1986) estimate that between one third and one quarter of PWAs at UCLA Medical Center use some form of mental health service. In general, PWAs show high levels of interest in such services implying the importance of making mental health care available to PWAs (Wolcott, 1986).

All the above mentioned areas of need require attention, either from a professional care provider, family, friends or from community service organization volunteer. The emphasis on various sources of support can shift as illness progresses. As mentioned earlier in this chapter, Zich and Temoshock (1987) found that persons with AIDS or ARC considered emotionally-sustaining types of help more desirable and useful than problem-solving help. Emotionally-sustaining help is defined as "someone to talk to" while problem-solving help is "someone who offers suggestions" (Gottlieb). Emotionally-sustaining help can come from any member of the support system while problem solving help usually comes from an expert of some sort, physicians, lawyers, or even other PWAs. Often those with whom the FWA has informal relationships including family, friends and lovers provide the greatest amount of support early on. Once these immediate sources of support are worn out through an extended period of illness (Hammer) then the secondary
network (physicians, community based organizations) take on more significance (Zich and Temoshock).

PSYCHOSOCIAL SUPPORT: MORE THAN AN END IN ITSELF

Throughout history physicians and lay healers have debated the role of emotional states on illness. Over the past ten years a literature in the field of psychoimmunology has evolved around the connection between emotional and physical well-being. While few studies specifically dealing with AIDS have been published, the area still warrants attention. Research on cancer patients in particular implies the importance of coping style in the outcome of illness. Exploring the influence of coping and emotional state on the development of AIDS is worthwhile; unknown cofactors, some perhaps emotionally based, determine the onset of symptoms once an individual contracts HIV. If depression, anxiety or coping style influence disease progression then access to proper counseling and support are especially important for PWAs.

Studies of psychological influences on cancer progression share a common theme. They define a cancer prone personality based on the notion that how one copes with stress may have more immunological significance than how much objective stress is experienced (Locke). In his study of women with breast cancer, Greer found that poor copers, those who stoically accepted their illness and illustrated a helplessness against disease had poorer outcomes than patients exhibiting a "fighting spirit." Blumberg found faster progression of cancer among patients with higher levels of depression, and an "abnormal inability to decrease anxiety through outward channels." LeShan and Worthington came up with related findings in their study of 400 cancer
patients who showed histories of poor ability to express hostility and a sense of hopelessness and helplessness. The cancer prone personality, also called the type C personality, is characterized by patience, helplessness, unassertiveness and a cooperative nature. Individuals with the type C personality suppress negative emotions and have depressive tendencies (Temoshock). If these theories on cancer progression are applied to AIDS, then counseling geared towards helping FWA's maintain the fighting spirit which seems related to better outcomes.

Other studies focus directly on the immunological effects of stress. Locke found that natural killer cell activity decreased with poor coping (depression, anxiety) under stress. In a study of herpes virus latency Glaser et al. found significant changes in the antibody titers to herpes virus according to stress. Medical students had significantly lower titers immediately after summer vacation compared to the beginning of final exams, showing that stress-related immunosuppression influences herpes virus latency. If stress limits immune functioning in healthy persons, then its impact among those with HIV-infection or full-blown AIDS is devastating.

Work on the interactive effect of stress and coping style on the immune systems of persons with HIV infection is still in its early phases. In one of the few studies of this type Goodkin found that HIV-infected men with better support systems and "more confident coping styles" had not developed symptoms of AIDS or ARC. While these results sound extreme and Goodkin cautions that such research is still "at the descriptive level," it still clearly implies the importance of
psychological well-being in the progress of HIV-illness. Goodkin's results illustrate the connection between physical and emotional well-being and the importance of this relationship's influence upon the outcomes of HIV infection.

CONCLUSION

In this chapter many characteristics such as a PWA's medical condition, tendencies toward denial and substance abuse were discussed in terms of how they affect an individual's need for services and his or her likelihood of accessing care. One of the points coming across most clearly is that a variety of factors influence PWAs' need for support. Many of these same characteristics interact with one another and control one's tendency to access services. For instance, a PWA with a substance abuse problem may require special counseling, but if the abuse is severe enough, he or she may not be conscious of the need for help. Or a PWA may use alcohol or drugs as a means of denial and not begin using support services when they are needed. Since the existing research and literature sheds little light on the degree to which individuals' personal tendencies influence use of services, one is left to hypothesize on the role of coping style, substance abuse or medical condition on utilization. Because data is lacking, I have refrained from estimating how some of these factors may interact with one another. Instead, chapter three deals with the other half of the utilization equation, the services available to the two groups studied in this thesis, gay men in Los Angeles and IVDUs in Brooklyn.
III. METHODOLOGY

This chapter presents the methodological issues encountered in measuring the use of mental health and social support services among PWAs. The major methodological problems included deciding which services to measure and how to cost them out, defining the study population and sampling strategy and developing a data collection strategy. The following pages present these issues in detail and also discuss the generalizability of the study's results.

MEASUREMENT ISSUES

Defining The Scope of Service Use

Albrecht and Adelman define a social support network as "that set of personal contacts through which an individual maintains his or her social identity and receives emotional support, material aid and services and new social contacts." This definition encompasses the complexity of a PWA's actual social support network; that combination of both formal and informal contacts with friends, family and health professionals. This work focuses on two basic segments of this support network, formal provision of mental health care and the informal provision of practical support services and emotional support. The decision to limit my research to these areas is partially based on the difficulty of measuring informal support which is not associated with a tangible product. Food, a ride to the doctor or a gift of money are all measurable. Emotional support from friends, for example, is almost impossible to quantify since this form of support occurs intermittently
and under a wide range of circumstances. The definition and form it takes varies so considerably from person to person that any measurements would have limited meaning. Hours spent in a professional mental health treatment setting, on the other hand, is a measurable unit of service which is relevant for planning purposes and for the study of service delivery.

Specifically, the service use measured in this study includes the following:
- Mental health care defined as one-on-one or group therapy with a psychologist, psychiatrist or social worker.
- Shelter provided by a public or private service agency.
- Food provided by a food bank or charity meal delivery service.
- Legal aid provided free-of-charge or at reduced cost by a service organization.
- Financial assistance in the form of rent subsidies or other cash gifts from private sources.
- Household or practical assistance in the form of non-medical personal care and household chores performed by paid assistants, volunteers, friends or family members.
- Transportation in the form of rides or cash subsidies for taxi or public transportation.

Costing Out Dollar Values for Services Used

These estimates are based on charges for services used. No attempt was made to calculate marginal social costs. Since many of the services used by both Los Angeles and Brooklyn populations are provided free of charge, the dollar values finally assigned to these services are estimated in the following ways:
Mental Health Services:

- In Los Angeles the value of one-on-one therapy is $75 per hour if provided by a private therapist. This figure was arrived at through discussion with AIDS Project Los Angeles representatives familiar with therapists serving the AIDS population. If provided through AIDS Project Los Angeles one-on-one therapy is costed out at $29.50 per hour which was the MediCal reimbursement rate in 1988. Group therapy through AIDS Project Los Angeles is valued at $16 per hour, also based on the MediCal 1988 reimbursement rate.

- In Brooklyn the value of one-on-one therapy is $67 per visit which is the Medicaid reimbursement rate. This is applied to all cases since none had private insurance, all respondents relied on Medicaid. Group therapy was valued at $16 per hour since no New York Medicaid reimbursement rate was available.

Food Bank:

- In Los Angeles food bank services are valued at $70 per month based on ALPA's estimate of the wholesale cost of the groceries distributed.

- In Brooklyn the APLA figure is used since the church providing food could not be reached for an estimate of the monetary value of their service.
Attendant Care:

- In Los Angeles attendant care is valued at $11 per hour with each visit lasting three hours. Visits occur once per week unless otherwise noted. These figures are based on MediCal reimbursement rates and APLA's estimate of the duration and frequency of attendant visits.

- In Brooklyn the Los Angeles figures were applied.

Shelter:

- In Brooklyn shelter visits were valued at $480 per month which is the rate New York City pays for apartments for the homeless. This figure was divided by 30 to get a daily rate of $16.

- In Los Angeles daily shelter rates were not available. The figure for New York was applied since it approximated the average rent for an apartment in Los Angeles in 1988.

Transportation:

- In Brooklyn the value of each round-trip ride provided through the Medical Assistance program is estimated at $15. This figure was provided by social workers at Kings County Hospital.

- In Los Angeles none of the respondents used APLA’s transportation program.

Legal Assistance:

- In Los Angeles an hour of legal assistance provided through APLA is valued at 50$ per hour, a figure provided by APLA.
In Brooklyn legal assistance was not used.

Buddy Program:
- In Los Angeles a number of respondents used APLA's buddy program. This service was difficult to cost out since the amount of time buddies spent with APLA clients varies greatly, though at least five hours per week is encouraged. Since buddies are trained as counselors and attendants APLA estimates the dollar value at $11 per hour.
- In Brooklyn a comparable program does not exist.

Household Assistance from Family and Friends:
- In both Los Angeles and Brooklyn household assistance is valued equally to attendant care, $11 per hour, since family and friends often provide the same level of practical assistance as a paid attendant. For respondents reporting full-time help from live-in family, friends or lovers the dollar value is estimated according to eight hours of help five days per week. The method for valuing household assistance does not account for declining respondent health over time. We assume that patients use a constant amount of care throughout illness. This assumption, while convenient, may misrepresent the actual amount of care used. Respondents' use of services may increase over time with the onset of new infections or generally declining health. The validity of this assumption is discussed in detail below.

Surveys in both cities ask specifically about household help and financial assistance within the 30 days preceding the interview. In order to calculate one year's worth of care the thirty days worth is multiplied by twelve unless the respondent has been hospitalized with in
the six weeks prior to the interview. In these cases the 30 days estimate is reduced by one third and multiplied by twelve.

Imputing Values For One Year's Worth of Care

The results of this study are presented in terms of resource use during the first year after diagnosis. In both the Los Angeles and Brooklyn samples respondents were diagnosed between six months and two years prior to the interview. Estimates of resource use for the respondents with less than one year since diagnosis were calculated by assuming resource use was continuous for the remainder of the year. So if the interview yielded six months worth of resource use data, that amount would be doubled to approximate the respondent's first year of resource use. As mentioned in section H. of this chapter, resource use may change according to onset of opportunistic infections or declining general health and this assumption leads to general approximations of actual utilization.

Calculating Symptom Scores (Brooklyn sample only)

A symptom score was created to determine how sick or disabled a respondent had been during the three months prior to the interview. This scale was developed as a supplementary tool to describe the case studies presented in chapter 4.

During the interview each respondent answered a battery of questions regarding whether they had a certain symptom and if so, did it effect their ability to work or carry out regular activities. Each symptom was then given a score from one to three depending on whether it indicates progression of AIDS. For example, shortness of breath gets a
three since it is an early symptom of PCP. Trouble sleeping gets a one since insomnia has a variety of causes, many of which have nothing to do with the progression of physical disease. If the symptom was present but not severe enough to effect the respondent's functioning then it is given a zero. This system was developed with assistance from two physicians primarily serving PWAs. All the symptoms are added together to create a final symptom score for each respondent.

Attachment 1, found at the end of this chapter, is a copy of the survey items from which the symptom score is derived. They are from the Brooklyn survey. The Los Angeles survey did not contain a comparable section.

DATA COLLECTION
Survey Development

The data presented in this study comes from two surveys, one of gay male PWAs in Los Angeles and the other of PWAs with a history of IV drug use in Brooklyn. Each respondent was interviewed regarding his or her medical and demographic background, health insurance and employment history. The interview also covered resource use including medical (inpatient and outpatient), mental health and social support services.

The decision to use a personal interview format instead of a self-administered survey or a phone interview was based on the following reasoning. First, we wanted very detailed information on a wide range of areas. Some of the questions were complex, especially those regarding employment and health insurance history. Most likely, respondents would require clarification on items covering these areas. Because of the level of detail and the wide variety of respondents' experiences the
instrument had to accommodate it would be difficult to design a self-administered survey which did not appear overly complex and cumbersome, making its appearance a deterrence to respondents. Indeed, the final interview instrument was complex, and interviewers required training and practice before using it in the field. A phone survey was also inappropriate for this study. Besides the usual problems of finding respondents at home and getting accurate phone numbers, the survey had other potential complications. Some of our items, particularly in the areas of income and medical history, were personal and required a good rapport between the interviewer and respondent.

The Los Angeles survey was the first attempt at in-depth interviews covering PWAs' medical and support service utilization and health histories. While the survey was pretested prior to printing the final draft, it was not until the actual interviewing began in Los Angeles that parts of the instrument proved awkward. The Brooklyn instrument, designed after the Los Angeles study was completed, was tailored to the IVDU interviews, and included a simplified system to record chronological information on medical history and HIV related symptoms.

The Interviews

Los Angeles

The Los Angeles interviews were conducted at respondents' homes and took approximately one hour. Generally respondents were well prepared, having medical bills and health insurance documents available. Most respondents' recall was good, however a few had problems with details such as number of times and dates services were used. All respondents were cooperative and interviewers felt confident that the quality of the data was good.
Brooklyn

The interviews took place at the Kings County outpatient AIDS clinic. Respondents were cooperative and although they had a history of IV drug use, none were intoxicated during their interviews and all generally showed a good understanding of the interview questions. Recall problems were not significant, respondents could usually narrow dates down to month and year which were validated by comparison to medical records. The nurse-educators conducting the interviews had a good rapport with many respondents. They clarified questions about the use of the survey results and assured those concerned that confidentiality would be maintained. In general, respondents appeared to trust the interviewers enough to give truthful responses about sensitive issues such as use of drug treatment programs and sources of income which in some cases included burglary and other illegal activities. The Brooklyn interviews took approximately 35 minutes, 25 minutes less than the Los Angeles interviews. This difference was mostly due to general simplification of the survey and eliminating the private health insurance questions.

Validation

In both the Brooklyn and Los Angeles studies interviews are supplemented with a formal record of resource use. In Los Angeles billing records were collected and in Brooklyn medical records were abstracted. Some of the information from these records covers the same material as the interviews do, thereby providing a basis to validate the interview data. While the medical and billing record information do not
completely duplicate the interview material, this validation system does indicate whether, in general, that respondents' recall was good. Additionally, the results presented in this paper were intermittently reviewed by experienced staff at Kings County Hospital and AIDS Project Los Angeles for further validation. Finally, the cost-of-care estimates derived from the Los Angeles medical data were compared with other published estimates. The Los Angeles results were close to estimates by the experts and in the published literature, thereby validating the study's methodology.

DEFINING THE STUDY POPULATION AND GENERALIZABILITY OF RESULTS

As mentioned in Chapter 1, the AIDS caseload is primarily made up of gays and IVDUs. We could not develop samples representing a wide section of the gay and IVDU caseload because of budget constraints and limited sites for recruiting respondents. We defined our study population as those gay men with AIDS who are affiliated with an AIDS service organization (APLA in this case) and IVDUs who have regular contact with an outpatient clinic such as Kings County Hospital Clinic. This chapter presents the respondent recruitment strategy as well as the limited generalizability of the study results presented in the next chapter.

Recruiting Respondents

Los Angeles

The respondents for the Los Angeles portion of the study were recruited through AIDS Project Los Angeles (APLA). APLA is the largest private non-profit service organization providing mental health and
practical support services to PWAs in the Los Angeles area. APLA offers its clients support groups, one-on-one counseling, food bank, transportation, shelter, a buddy program and legal advice. Approximately 70% of PWAs in the Los Angeles area are APLA clients. Most clients come from the large predominately gay communities in West Hollywood and Silverlake which is in the vicinity of APLA's Hollywood office.

The recruitment effort focused on participants in another study conducted by the Palo Alto Medical Foundation/Research Institute (PAMF/RI) under a grant from California's Inter-University AIDS Task Force. This Project was designed to estimate the costs of medical treatment. PAMF/RI collected billing data on 100 APLA clients and shared their data with RAND for the thirty-six RAND interviewees. Initially PAMF/RI began recruitment by sending letters to all APLA clients inviting them to participate. Response to the mailing was very low. Since RAND was ready to begin interviews a phone recruitment effort was started and RAND offered respondents $75 for participating in both studies. APLA provided a volunteer to call clients and invite them to participate in the studies. APLA also provided a list of likely participants which included clients who either joined APLA within the last two years or had regular contact with a caseworker.

Recruiting via telephone was somewhat problematic. The major drawbacks included inaccurate phone numbers and clients who were not at home. We decided against leaving messages on answering machines since APLA guarantees its clients that their association with the agency remain private. However, once the clients were reached they generally
agreed to participate in the studies, often before hearing about the $75 payment.

Brooklyn

Recruitment was carried out in the Kings County Medical Center Outpatient AIDS Clinic. Prior to their clinic appointments, eligible patients were approached by nurse educators who invited them to participate in the study and offered them $30 upon completing the interview. Initially patients signed a consent form when they were approached and then set up an appointment to return for their interviews. This system proved unsuccessful since few patients actually returned for the interview. The procedure was changed so that interviews were conducted immediately prior to patients' clinic appointments.

The recruitment process was slow, beginning June 1989 and ending 10 months later in May 1990. The slow pace was due to low numbers of eligible patients coming to the outpatient clinic. While a large portion of the PWAs using Kings County Hospital have a history of IV drug use, relatively few use the outpatient clinic regularly. Many come to clinic only during the first weeks after hospitalization or do not use the outpatient facilities at all. Also, a significant portion of the patients at the clinic have ARC or asymptomatic HIV infection making them ineligible for the study. These two factors combined left the interviewers with fewer eligible patients than initially anticipated. To speed up recruitment the eligibility criteria were changed in November 1989 to include women. The final sample of 40 PWAs with IVDU histories was enrolled by May, 1990.
The sampling process was not carried out in a random manner, it would have been time consuming and costly to do so. Therefore both the Brooklyn and Los Angeles samples are biased. In both cases the more compliant and motivated PWAs were recruited. These were the people who came to the outpatient clinic in Brooklyn and kept in regular contact with APLA in Los Angeles. The sampling biases are discussed in more detail in the upcoming section on generalizability.

Because of dissertation funding considerations only the first 22 cases recruited in Brooklyn were included in this project.

**Respondent Eligibility**

The goal of the eligibility criteria was to create a sample which was homogeneous enough to illustrate some generalizable trends among the patients. This was a challenge given the wide variety of clients served at each recruiting site and the studies' limitations on sample size. The primary criteria was that all patients have an AIDS diagnosis. Persons with ARC and HIV infection were not eligible since their medical needs and resource use would vary significantly from those of persons diagnosed with AIDS. Additionally, patients had to have been diagnosed for at least six months so that a history of resource use could be picked up in the interview.

The Brooklyn sample had some additional eligibility criteria. Respondents had to have a history of IV drug use, which was an obvious but somewhat problematic criteria since IV drug users are difficult to recruit (see below). To avoid requirement and keep the interview as short as possible only men were initially recruited into the study. We
thought that women's medical and support needs might differ from men's significantly enough to require separate items in the interview. As recruitment slowed down and the research team realized that women could be interviewed using the current questionnaire, the "men only" criteria was dropped and women were recruited into the study. Additionally, Kings County Hospital had to be the primary source of care for all respondents so that data from the respondent's medical record could be abstracted to supplement the interview information. The final criterion in Brooklyn was that all respondents be on Medicaid. This did not exclude many prospective respondents since almost all the patients at the outpatient AIDS clinic were on Medicaid.

GENERALIZABILITY OF RESULTS

Generalizability is not an issue of precisely applying this study's results to the AIDS population at large. Rather, generalizability is the extent to which the resource use trends presented here apply to similar groups of PWAs. This study's results are put into context by identifying the differences between the study samples and the gay and IVDU segments of local AIDS populations. This chapter presents a basic overview of the two largest populations effected by the epidemic, gays in Los Angeles and IVDUs in Brooklyn. Then biases are discussed pertaining to the sampling methodology from the Brooklyn and Los Angeles studies. The study samples are also compared to other groups of PWAs from the same risk groups and similar geographic locations. The outcome of this exercise is to narrow down the segment of the AIDS population for whom these results are relevant and identify how other groups' resource use may vary.
Sampling Bias in Los Angeles and Brooklyn

Sampling biases limit the generalizability of this study's results. It is virtually impossible to systematically construct representative samples of gays in Los Angeles or IVDUs in Brooklyn. Rather, the studies are based on convenience sampling with respondents recruited through two organizations, APLA in Los Angeles and Kings County Hospital in Brooklyn. The samples in this study reflect certain sub-groups of both populations which are characterized in the brief discussion of sampling biases below.

In both cases the most significant bias is organizational, rooted in the sampling frames used at each site. The Los Angeles recruitment effort was limited to APLA clients and the Brooklyn sample was recruited through Kings County Hospital. Respondents' affiliation with these organizations influences this study's results, i.e., the amount and type of mental health and social support services used.

The Los Angeles respondents' affiliation with APLA affected the final resource use results; most likely the respondents used more services than PWAs not belonging to APLA. The respondents were all PWAs who decided to join an AIDS-oriented service organization. Unlike PWAs not joining APLA, the study respondents wanted access to APLA's wide variety of support services, most of which are provided free-of-charge. By virtue of this easy access to free care and their desire to use it, APLA clients are more likely to use mental health and support services than those who are not clients. Additionally, the respondents are more likely to use APLA services than services offered through other organizations. For example, only two respondents used mental health
services offered through other community-based service organizations. Since these other organizations are well known providers with waiting lists for counseling and support groups, our results probably underestimate the number of PWAs using these other providers relative to those using APLA.

The Brooklyn respondents' affiliation with Kings County Hospital's outpatient AIDS clinic biases their use of mental health and social support services upwards compared to other segments of the IVDU AIDS population. Since respondents were recruited when they came to clinic, those patients attending clinic more often had a greater chance of enrolling in the study than those rarely using the facility. All respondents attended the AIDS clinic on at least a semi-regular basis. That is, they went to clinic at least three times in the six months prior to their interview.

The study respondents are described by clinic personnel as the more compliant IVDU PWAs among the patient population. Noncompliant IVDU PWAs are totally unrepresented in this sample. By contrast, these are IVDUs with AIDS who come to the emergency room only when they are very sick. They are admitted yet do not attend the outpatient clinic after discharge.\footnote{Information from discussion with Virrie Graham and Althena Kitchens, nurse educators at Kings County Hospital AIDS Program.} Through their experiences working with IVDUs, clinic staff found that noncompliance is related to a poor support network and more frequent drug use. Patients often relied on friends and family to accompany them to the clinic. If they are still heavily using then obtaining drugs is their primary concern and attending clinic assumes a low priority.
Besides the upward bias due to the Brooklyn study recruiting the most compliant IVDUs with AIDS, an organizational bias also exists within the Brooklyn sample. All the respondents considered King County Hospital their regular source of medical care. Patient attitudes towards their illness, their support needs and the availability of medical and social support services are all influenced by the staff at Kings County. For example, if nurses, physicians or social workers encourage and help patients seek services then more patients are inclined to use care. Access to services is also determined by patients' hospital affiliation. Kings County provides a set of mental health services which may not be equivalent to mental health programs at other hospital programs. It is difficult to ascertain whether PWAs at Kings County tend to use more or fewer services than patients at other hospitals. However, the influence of the hospital staff and facility's location does effect use of services and limits the generalizability of this study's results.

Comparisons to PWA Populations

The extent to which the study samples represent local AIDS population can be expressed in quantitative terms by comparing the two groups. In the following section AIDS surveillance information is presented alongside data describing the Los Angeles and Brooklyn samples to illustrate how these samples differ from the AIDS population in their areas.
Los Angeles

As of January 1990, 8576 cases of AIDS have been diagnosed in Los Angeles (1). 6869 cases or 80% of the total caseload is comprised of men with homosexual contact as their only means of exposure. Another 686 or 8% of the cases occurred among men with a history of both IV drug use and homosexual contact. So, a total of 88% of all Los Angeles PWAs either consider themselves gay, bisexual or have had homosexual experiences. In terms of means of transmission, the Los Angeles sample of gay men is representative of the majority of cases in the area.

Racially, the Los Angeles study sample does not represent the local PWA population. Our sample is 100% white. While the cumulative population of gay males diagnosed in Los Angeles is 86% white, the proportion of newly diagnosed cases among whites is decreasing. 59% of the 1568 PWAs diagnosed in Los Angeles in 1989 are White, 23% are Hispanic and 17% are Black. This is up from a total of 27% minority cases diagnosed before 1985. Therefore, our data is not a good point from which to predict future trends in resource use for the AIDS population at large. This study's results describes resource use by white gay males which is probably higher and reflective of a different set of providers than among Blacks or Hispanics. Since few full-service community organizations are located in minority communities, Blacks and Hispanic PWAs are likely to depend on family and friends for support to even a greater degree than white PWAs (Mays).6

6 This was also mentioned in discussion with Rev. Carl Bean
A majority of Los Angeles PWAs present with PCP only. 72% or 26 members of the study sample presented with PCP and 28% or 10 members presented with KS. This compares to 51% presenting with PCP only and 15% with KS in the LA PWA population. The higher proportion of KS cases in the study sample is not surprising. The sample does not include IVDUs or Blacks, two groups rarely presenting with KS.

Brooklyn

By September 1989 4,359 AIDS cases were diagnosed in Brooklyn, 20% of New York City's total caseload of 22,108. Since the New York City health department reports statistics for the entire city rather than by borough, the Brooklyn IVDU study data must be compared to data representing all of New York City. The basis for discrepancies between our sample and the New York City data are difficult to discern. The differences may be due to peculiarities specific to our sample or to differences between Brooklyn and the rest of New York City. Also, some of the statistics presented are not broken down by risk group but represent traits such as opportunistic infections for the AIDS population as a whole. Since IVDUs with AIDS make up only 39% of the total caseload and are different from gay PWAs in terms of medical conditions and ethnicity, these population-wide statistics cannot be applied to the Brooklyn IVDU population. To compensate for this confusion, the study data will also be compared to data from other studies of IVDUs with AIDS, thereby providing a better sense of the generalizability of our data to other IVDU AIDS populations.

7 8% present with KS and PCP and 25% present with other opportunistic infections
Our sample includes proportionately fewer Whites, fewer Blacks and more Hispanics than the IVDU PWA population in New York City. Of the IVDUs diagnosed in New York City, 45% are Black, 17% are White and 38% are Hispanic. The study sample is 5% White, 26% Black and 68% Hispanic, making it comparable to New York in that the sample is primarily made up of minorities. However, the study results may be biased towards higher use of informally provided services because of the higher proportion of Hispanics. Traditionally, the Hispanic family is a close-knit group which offers support in times of illness and mediates all outside efforts at treatment (Schreiber). Therefore, the family is likely to provide services other ethnic groups may seek out through community organizations or public programs. A group of IVDUS with AIDS having a higher percentage of Blacks or Whites may show lower reliance on services provided by the family.

Table 1 compares the Brooklyn sample to IVDUs in other studies. All three comparison samples were from New York City. The Brown and Friedman samples were drawn from methadone maintenance clinics and included IVDUs who were not necessarily HIV infected. The Friedland sample was drawn from the population of IVDUs hospitalized with AIDS or ARC in the Bronx. All three groups were close in age and had a majority of Black and Hispanic members. Interestingly, the ethnic and income breakdowns between the Brooklyn and Friedland samples were quite close. By comparing these four study populations we see that the Brooklyn and

* The high number of Hispanics in our sample reflects Kings County Hospital's large Hispanic caseload. We searched hard for a hospital to collect data at; this is the one we could get.
Friedman samples may closely represent the population of PWAs with a history of IV drug use who are in contact with the health care system. IVDUs in methadone programs have a greater variation in income and ethnicity.

**STRENGTHS AND WEAKNESSES OF METHODOLOGY**

This project was the first of its kind; the first to comprehensively interview PWAs on their medical treatment, use of non-medical resources, health insurance, income and employment background. The studies were experiments from a methodological standpoint, both the Brooklyn and Los Angeles projects were pilots. The funding was sufficient to recruit and interview a small sample of PWAs at each site and test the methodology while illustrating trends in resource use among these populations. Unfortunately, the projects were not designed to collect a representative sample of PWAs from either city, nor to collect a sample large enough to draw statistically significant conclusions. So while these studies were among the first to interview PWAs on this issue, the results were not thoroughly generalizable.

Lack of generalizability is a limitation pertaining to both the Los Angeles and Brooklyn samples. In Los Angeles all respondents were recruited through APLA and were clients of that organization. They were connected to a service organization, which implies their use of mental health and social support services is higher than those PWAs not affiliated with such an organization. In Brooklyn, our sample was drawn from PWAs regularly attending an outpatient clinic. Those PWAs with a history of IV drug use who do not attend clinic but rely on the emergency room for care are not represented in this sample. Those not
attending clinic are probably less likely to avail themselves of support services which are offered through Kings County Hospital and promoted by outpatient clinic personnel.

It is difficult to determine what percentage of the AIDS population these two groups represented in this study comprise. It is likely they are not insignificant segments in terms of size or resource use. AIDS project Los Angeles serves approximately 70% of the FWAs in Los Angeles. At Kings County Hospital there were over 778 inpatient discharges of adult and pediatric AIDS cases, accounting for over 27% adult and 50% of pediatric AIDS discharges in Brooklyn. In 1988 there were 2712 visits to the Kings County AIDS outpatient clinic. As for resource use, both these groups are probably relatively high users of mental health and social support services compared to other members of the same risk group.

The small sample sizes led to difficulties imputing resource utilization for respondents with less than one year of data. While we assumed resource use is constant throughout the first year after diagnosis, this may not be the case. For example, respondents may use more resources after a hospitalization or those with a certain opportunistic infection may use more care or respondents may become sicker over time and need more assistance. Since our samples are small, we cannot detect such patterns. A larger sample in each site would provide information necessary for creating a more precise formula for imputing missing values. Currently, there is no evidence proving the constant resource use assumption wrong, but since there is no strong proof of the validity of this assumption it must be viewed as a weak link in the analysis.
While this study does not provide iron-clad conclusions, it has some very clear strengths. It proves that so-called "difficult" PWA groups can be cooperative in interviews. IVDUs were especially challenging. Since they are not part of mainstream society, one often assumes that IVDUs do not see the importance or value of participating in a study. While this project does not prove whether or not IVDUs agree to an interview out of a sense of social consciousness, it does show that IVDUs will participate if approached by a health worker they trust. The $30 cash payment for completing the interview provided extra incentive. Among the gay respondents the payment seemed unimportant since most agreed to participate before the recruiter mentioned payment.

Both groups answered personal questions, cooperation was high and respondents were able to answer detailed questions about income, employment and health history. Recall was usually good and all PWA respondents had sufficient stamina for a one hour interview. These positive qualities, however, may be an artifact of volunteering for the studies and not carry over to a broader segment of the PWA population.

The study also provided the first comprehensive view of both resource use and sociodemographic characteristics of the two major groups affected by the AIDS epidemic, gays and IVDUs. Prior studies only looked at a subsection of the variables covered in this survey, such as demographic characteristics, health insurance and medical factors. Even if the samples are too small to draw statistically significant conclusions, these results provide useful case studies on the course FWAs take through the health care system and some of the factors determining that course.
CONCLUSION

The population of gays and IVDUs at risk for AIDS is hard to define since certain segments of these populations are inaccessible to researchers. Especially difficult to reach are closeted gays, bisexuals who do not consider themselves gay and Black and Hispanics who are not in contact with the white gay community through which research participants are often recruited. IVDUs not in detox and not in regular contact with the health care system are also inaccessible. Because these groups are so elusive, any results concerning resource use cannot be blindly generalized to the entire AIDS population.

This study represents resource use among two subgroups of the AIDS population, urban gays affiliated with AIDS service organizations and PWAs with a history of IV drug use who are in regular contact with an AIDS outpatient clinic. It is difficult to determine what percentage of the AIDS population these two groups comprise. But clearly, they are not insignificant segments in terms of size or resource use. AIDS project Los Angeles serves approximately 70% of the PWAs in Los Angeles. At Kings County Hospital there were over 778 inpatient discharges of adult and pediatric AIDS cases, accounting for over 27% adult and 50% of pediatric AIDS discharges in Brooklyn. In 1988 there were 2712 visits to the Kings County AIDS outpatient clinic. As for resource use, both these groups are probably relatively high users of mental health and social support services compared to other members of the same risk group since study samples represent the gays and IVDUs with AIDS who are most directly affiliated with service providers.
IV. PROVISION AND FINANCING OF MENTAL HEALTH AND SOCIAL SUPPORT SERVICES

The responsibility for providing mental health and social support services for PWAs is spread across a number of organizations and individuals. Where a PWA gets care depends on his or her circumstances; whether he or she is covered through medicaid or private health insurance, whether family members are available to provide care and whether suitable community-based services exist. The importance of an integrated system of care is illustrated in San Francisco where community-based organizations and medical centers work together to coordinate support services for PWAs. As a result, San Francisco's hospital length-of-stay for PWAs is short, 11 days compared to a national average of 19 (Jenna). PWAs are discharged from the hospital earlier for care at home provided by friends, family or through a number of charitable and for-profit nursing and service organizations. Both Los Angeles and Brooklyn have support service infrastructures which facilitate low-cost home care and mental health services for PWAs. However, neither city has as comprehensive a community-based system as San Francisco's. As a result PWAs must turn to a combination of community organizations, public programs and paid providers in putting together the package of services they need. This chapter discusses the role providers and payers play in the delivery of mental health and social support services to PWAs in Los Angeles and Brooklyn.
MEDICAID

Medicaid eligibility criteria differ from state to state but in general, an individual must establish disability status as well as meet a low income criterion. PWAs meet the disability standard by virtue of their diagnosis; anyone with an AIDS diagnosis is automatically granted "presumptive eligibility". The income standard differs from state to state with criteria in more "liberal" states approximating the poverty level or even lying slightly above it. Medicaid eligibility income criteria lie below the poverty level in states with more restrictive programs (Pascal, 1989). These income criteria, along with a number of other factors, ultimately influence the number of PWAs qualifying for Medicaid.

Often PWAs are not on Medicaid at the time of diagnosis but become eligible during their illness. One may have private health insurance coverage through his or her employer at the time of diagnosis then lose the coverage upon leaving his or her job after diagnosis (see section Private Health Insurance). While continuation of group coverage is usually available, PWAs often cannot keep up premium payments once they've stopped working. To gain Medicaid eligibility the PWA must meet the income and asset criteria which usually requires a "spend down" phase. The PWA must spend any savings or other assets until he or she is sufficiently impoverished to meet the Medicaid income criteria. Upon going from private coverage to Medicaid many PWAs experience a discontinuity in care; their original providers (physicians, mental health professionals, home nursing services) may not accept Medicaid so they must find new sources of care. In August 1989 California enacted a
program to keep such individuals from having to go on MediCal. Once a
FWA with private insurance is no longer able to cover insurance premium
payments and has spent down to the MediCal income standard the MediCal
program will begin paying that FWA's private insurance premiums. This
allows the FWA to continue seeing the same providers and saves the
MediCal program approximately $20,000 per patient per year (Intergov.

Medicaid serves an ever growing portion of the AIDS population.
Nationally, between 30% - 60% of PWAs diagnosed from 1986 to 1991 will
be on Medicaid (Pascal, 1987). In California 42% of people who die from
AIDS by 1990 will be on MediCal. This is up from 28% in 1986
(California Department of Health Services) In 1985 approximately 45% of
AIDS related hospitalizations in New York state were covered by
Medicaid. This figure grew to 54% in 1988.9 Several factors
contribute to the high Medicaid caseload. The number of IVDUs with AIDS
is growing. This is a low income group relying almost exclusively on
Medicaid to cover medical expenses. Secondly, with PWAs living longer a
greater proportion are likely to exhaust private medical insurance
coverage and eventually turn to Medicaid. Thirdly, the 1987 broadening
of the CDC definition of AIDS allowed presumptive Medicaid eligibility
for all those additional PWAs meeting the new criteria.

Medicaid covers a portion of it's recipients' medical and support
services expenditures. Approximately 60-70% of inpatient costs are
reimbursed and about 15% of homecare expenditures are covered (Pascal,

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9 Discussion with Joan Cleary, New York State Office of Medicaid,
May 15, 1990
1987). Some mental health services are reimbursable, but at only half the rates commonly charged by psychiatrists and psychologists in private practice.\textsuperscript{10} In California, for instance, MediCal reimbursement is limited to only 24 psychiatric visits per year. There are additional limitations on home maker and home nursing services under New York's and California's general Medicaid programs (Health Care Financing Administration).

Both New York City and the state of California have additional public programs affiliated with Medicaid to cover supplementary services. In California the 1989 enactment of the AIDS-Specific 2176 Home and Community Based Services Waiver provides coverage for services PWAs require for earlier hospital discharge and subsequent home care. These include case management, home maker services and psychological counseling. New York City's Medical Assistance Program (MAP) is the city's locally administered Medicaid program which covers visiting nurse and home maker services as well as transportation. PWAs eligible for these can cover many of their mental health and support needs as long as providers in their locality accept Medicaid reimbursement rates. Since Medicaid often reimburses far below full costs, many providers do not accept Medicaid. PWAs relying on this coverage face a limited choice of providers and often end up using support services administered through public hospitals.

\textsuperscript{10} From discussion with Chuck Wolcott, California Dept. of Health Services, Medical Care Statistics, May 14th 1990.
PRIVATE HEALTH INSURANCE

Private health insurance is usually provided through one's employer although approximately 37% of Americans are uninsured. In 1986 38% of California's PWAs were covered by private insurance.\(^{11}\) With the growing proportion of IVDUs and lower income individuals with AIDS the percentage with private insurance is likely to decrease. Given the new California regulation using MediCal dollars to pay insurance premiums for PWAs otherwise forced to give up private coverage, the percent of PWAs in California with private health insurance is likely to at least remain constant if not increase.\(^{12}\) Elsewhere, the financing of AIDS is likely to shift over to the public sector since insurers are restricting eligibility to those with individual or small group policies by using HIV tests (Merritt). A national survey of private health insurers showed 99% of respondents consider individuals with ARC uninsurable and 91% consider those with HIV infection also uninsurable (Intergov. AIDS Report, Mar-Apr, 1990). Besides excluding those who test positive, those suspecting a seropositive status are discouraged from applying for fear of discrimination by employers (Merritt).

Once insured, PWAs do have some means of maintaining private coverage even after leaving their jobs. Nationally, PWAs covered by employer provided health insurance plans are protected by COBRA (Consolidated Omnibus Reconciliation Act of 1986). Under COBRA employers hiring more than 20 employees must extend health insurance

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\(^{11}\) From discussion with Chuck Wolcott, California Dept. of Health Services, Medical Care Statistics, May 14th 1990.

\(^{12}\) From discussion with Chuck Wolcott, California Dept. of Health Services, Medical Care Statistics, May 14th 1990.
coverage for 18 months at no more than 102% of the group premium to employees leaving leaving their jobs with organizations hiring more than 20 employees. PWAs with sufficient finances to pay premiums can maintain their private coverage, however after six months they may face significantly higher premiums and may be forced to turn to Medicaid.

While private insurers often pay the major portion of medical expenditures they usually do not provide complete coverage for mental health or home maker services. Data on the number of plans covering these services are not available, however frequently insurers place a limit on the number of mental health visits covered or the reimbursement rate per visit. While home health care and personal care are usually covered as an alternative to prolonged hospitalization, few insurers provide such coverage on a long-term basis. Insurers' response to paying high HIV-related expenditures is reflected in contradictory changes in benefits. Some insurers have expanded coverage of homecare services to encourage shorter hospitalizations thereby reducing costs. Others have limited coverage of services important for PWAs (Intergov. AIDS Reports, Mar-Apr, 1990) or capped AIDS benefits (Lambert).

COMMUNITY-BASED ORGANIZATIONS

As early as 1981, the gay community began responding to the AIDS epidemic by forming organizations to provide support for those affected by the disease. Basically, organizations such as APLA and Gay Men's Health Crisis (GMHC) evolved out of a need for services not consistently

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12 Bobbie Krusick, New York State Office of Medicaid, 5/15/90
provided through existing channels. As the sections above illustrate, neither Medicaid nor private insurers offer comprehensive coverage of mental health or practical support services. Additionally, since these AIDS service organizations originated from within the gay community, they provided culturally sensitive programs which many PWAs identify with. Community-based organizations are also often sole providers of unique services such as "buddy" programs, food banks, advocacy and specialized support groups for caretakers of PWAs and asymptomatic HIV infected individuals.

Community-based AIDS service organizations play an important role in reducing treatment costs. San Francisco's shorter length of stay is frequently attributed to the comprehensive network of services available through organizations such as Shanti and the San Francisco AIDS Foundation. Such organizations also reduce costs by relying heavily on volunteer labor, leading to higher production of services per dollar spent (Arno, 1986). According to one 1984 survey, approximately 80% of all community-based services were provided by volunteers (U.S. Conf. of Mayors). Arno (1986) calculated the value of donated labor provided by three San Francisco AIDS service organizations during fiscal year 1984-85. Assuming minimum wages, the dollar value comes to $455,997 for 131,046 hours of donated labor. Given hourly wages close to those of paid health care employees the value comes to $1,215,091. While current figures for the the value of donated labor in high incidence cities are unavailable, on can assume the value has risen substantially with the growth of community organizations and the increasing AIDS caseload.
Not every city has the extensive network of community services available in San Francisco. A number of factors, political, epidemiological and economic, determine these organizations' development. According to Arno, the city of San Francisco provided substantial funding to support community-based AIDS organizations during the early 80s. In both New York City and Los Angeles County AIDS service agencies received very little public support in the early days of the epidemic. Instead these organizations were built through private monetary contributions and individuals' donations of labor and other resources.

The gay community's political clout and organization influenced public funding as well as the effectiveness of the developing service organizations. San Francisco gays were an organized political force during the 70s making the development of effective AIDS service organizations a relatively natural and smooth process (Shilts). In New York, epidemiological factors influenced the evolution and effectiveness of the community-based approach. New York City's AIDS population includes substantially more minorities and IVDUs than San Francisco or Los Angeles (see Chapter 3). IVDUs are not a cohesive political force and are unlikely to self-organize around the AIDS issue. Additionally, IVDUs frequently do not associate themselves with gay-founded community organizations. Homophobia may be a factor, however more obvious reasons include geographic inaccessibility and a lack of culturally sensitive services for IVDUs, many of which are Black or Hispanic.\(^{14}\)

\(^{14}\) From discussion with Virrie Graham and Althena Kitchens, Nurse educators at Kings County Hospital in Brooklyn.
The Los Angeles and Brooklyn samples recruited for this study faced different options for community-based care. As previously mentioned, the Los Angeles group was recruited through APLA, implying they were aware of and had access to services provided through that organization. Additionally, most of the Los Angeles sample lived in the vicinity of other AIDS service organizations such as Shanti and the Edelman Health Center. The Brooklyn sample was recruited through a public hospital which provides or coordinates some of the same services a community-based organization would, such as mental healthcare and practical assistance. Unlike the Los Angeles sample, the Brooklyn group had few other options for care in their neighborhoods. The Brooklyn AIDS Task Force is the main AIDS service organization in the area yet it does not offer the comprehensive list of services that APLA does. Its primary role is that of case management, referrals, advocacy and short-term emotional support services. Other AIDS organizations serve special populations such as the Haitian Coalition on AIDS or The Women's AIDS Network which provide some direct services to PWAs but also devote resources to AIDS education. In order to get a comprehensive set of support services, Brooklyn PWAs must contact several organizations. Perhaps beginning with case management at Brooklyn AIDS task force and then getting referred to services offered through hospitals and other community-based organizations. In Los Angeles PWAs could turn to APLA for most of their support needs perhaps turning to one or two other organizations for special services not offered at APLA. Since community services are offered in such a diffuse manner in Brooklyn, it is not surprising that fewer services are used per patient, as illustrated in Chapter 5.
In spite of the larger number of AIDS service organizations in Los Angeles, some PWAs still have problems obtaining necessary care. The case of Josef, a Black PWA who spent his first months after diagnosis homeless in Venice Beach, California illustrates some of the obstacles PWAs face in getting care\textsuperscript{15}. After a two week hospitalization with PCP in August 1989, Josef returned to the Venice garage he lived in to find his belongings piled at the side of the building and a new lock on the door. His landlord evicted him for failing to pay the rent on time. Josef was diagnosed during that August hospitalization and applied for social security at that time. His only other income came from his small business of selling his hand-made wood carvings on the beach. Because of the lag between application and actual receipt of a social security check, Josef was not able to collect enough money to rent a new place and was forced to live on the beach. He tolerated this situation for about six weeks; Josef said all he wanted to do was lie in the sun until the weather cooled down.

By late October Joseph began feeling weaker and the beach was getting cold and windy. He phoned the Gay and Lesbian Service Center in hope of getting housing assistance. They told him to come to the West Hollywood Center to fill out papers but they could not promise him shelter. He was too weak to ride the bus to West Hollywood so he phoned APLA for help. Their response was similar so he decided to attempt the bus ride across town. He spent the night on the street in West Hollywood and phoned APLA in the morning. He needed housing immediately

\textsuperscript{15} Josef was interviewed March 23, 1990.
but was told the paperwork came first and then it might be several days before housing could be arranged. After getting angry at the APLA representative (he could not stand filling out papers, feeling as though he had filled out enough already) he was referred to Minority AIDS Project. They promised him shelter if he could take the bus to their offices in South Central Los Angeles. He was finally placed in an AIDS Hospice and filled out the necessary papers after spending a few days in the shelter.

Josef went on to Padua Hospice after becoming too ill for the shelter. He borrowed money from an AIDS service organization to cover the costs of the hospice. Apparently, an error was made in his Social Security paperwork, delaying the receipt of checks which would cover his hospice costs. Josef died in April 1990, seven months after diagnosis, without ever having received his social security.

Josef's story illustrates the problems a PWA completely without assistance faces. Not only was Josef without money or a solid support network, he also lacked the experience and the physical strength to deal with bureaucracies. As a result, he did not get the social security benefits owed him nor could he obtain housing until his situation became desperate. Most of the organizations he contacted were not prepared to deal with someone so completely without personal resources. Josef's experience shows that access to AIDS service agencies is difficult for those who are experiencing opportunistic infections, are without money or some minimal assistance from family and friends. The main problem is getting "into" these organizations, meeting with a caseworker and then getting shelter or whatever other services are needed. Once Josef
entered the "system," i.e., was housed in a shelter, he received comprehensive support. As seen in the next section, assistance from friends or family could have lessened his dependency on community-based organizations by providing him with temporary shelter or at least the transportation to meet with caseworkers and assistance with the paperwork he found so problematic.

FAMILY AND FRIENDS

Family and friends are often a valuable source of ongoing emotional and practical support for chronically ill persons. However, in the case of AIDS, families must often cope with more than the news of diagnosis. Along with diagnosis comes the question of transmission. In many cases parents and other family members were unaware of the PWA's gay lifestyle. While many gay men keep close familial ties, others do not maintain sustained family contact (Helquist, Altman) and would rather their parents not discover their sexual orientation. In some cases gay males marry and become parents, following through with a self-deception encouraged by society and their families (Voeller). When AIDS strikes a gay or bisexual male having a wife and children feelings of distrust and resentment are combined with the initial shock of diagnosis (FT). When homophobia is the overriding reaction, family members often reject the newly diagnosed PWA. However, in many cases parents and siblings come to terms with both the AIDS diagnosis and their son's or brother's homosexuality in time to provide support.

Coming to terms with the diagnosis also includes overcoming fear of contagion. Even in the early days of the AIDS epidemic casual transmission appeared unlikely given the spread of the disease. Once
the modes of transmission were clearly defined, those caring for PWAs both at home and in the hospital had little to worry about; they could take simple precautions to prevent infection. However, irrational fear of infection still persists. Often PWAs' families and friends require education. Friedland and Kahl found that family interactions increased once family members were counseled regarding their fears of transmission.

Besides the obvious shock to a family when one of its members is diagnosed with a serious illness, AIDS also often disrupts the family's life-cycle and developmental process. AIDS usually strikes at a time when the family is in a "centrifugal" state, a time when members are focusing on personal goals outside the family. The parents are making retirement plans and the children are starting careers and families of their own (Britton and Zarski). Family adjustment to a serious illness is particularly stressful as caretaking responsibilities interfere with personal needs (Kelly). The family's coping style may be very different from that of an earlier period when children were still dependent and the focus was on nurturing or when parents are older and illness is expected. The PWA may feel angry and guilty for asking for help while family members feel guilty about any resentment they feel having to provide care (Dilley, 1986). As a result families may require counseling to address and accommodate their personal needs while also supporting the member with AIDS. Without counseling, parents' and siblings' increased stress may limit their capabilities as caretakers.
The amount of care used depends on a number of factors. On average, eight people are directly affected by each AIDS diagnosis (Walker). These are the friends and family of the PWA, the individuals most likely to provide assistance. Their willingness to do so, along with the willingness of the PWA to accept assistance, determines the amount of care delivered. Some PWAs are so independent they do not accept help until they are bedridden. Others, feeling slighted and as though they never got their fair share of things become dependent quickly (Dilley, 1986). Generally, an individual's personality holds over through AIDS. Those having close friendships prior to diagnosis continue to maintain them and those with few friends are usually alone during illness (Dilley, 1986).

The family is an especially significant source of care in minority communities. Within both the Black and Hispanic communities family members are often the primary providers of information and support during periods of illness (Mays, Perez-Stable). In some cases outside help is not well received. Many Blacks maintain the Southern tradition of holding a fighting stance in the face of adversity. The independence associated with this fighting spirit can make acceptance of help outside the family difficult (Mays). Among Hispanics, showing illness or weakness to outsiders can be a humiliating experience, particularly for Hispanic men (Perez-Stable). Eugene McArthur, volunteer director of the Brooklyn AIDS Project which serves a minority population, finds that sending volunteers to unfamiliar neighborhoods often leads to suspicion among those living in the area. Therefore, Brooklyn AIDS Project has developed a program to train PWAs' families and friends to provide basic
emotional support and practical assistance. The majority of Brooklyn AIDS Task Force volunteers are directly associated with a client, illustrating how the organization has tapped into the family as a source of care for PWAs.

CONCLUSION

PWAs can receive support from a variety of sources ranging from publicly funded programs to community-based agencies to informally provided services through family and friends. However, a few depend only on one of these providers. For example, once a PWA loses his private health insurance he may quit seeing a private therapist and begin going to a support group provided free-of-charge through a community-based organization. Reliance upon volunteers and community organizations is common. Neither Medicaid nor private insurers offer comprehensive coverage of mental health and support services. Since community organizations may not meet all needs or be geographically accessible, some PWAs also rely heavily on family and friends.

Which services and providers a PWA uses depends on accessibility and the PWA's perceived need for care and degree of comfort with the provider. A PWA on Medicaid does not have access to the same private therapists and homecare providers that someone with private insurance has. A black or Hispanic PWA may not feel comfortable going to a support group offered by a community-based agency in a gay, predominately white neighborhood. Other PWAs are socially isolated, have few friends and are not used to dealing with public agencies. These individuals may contact a service agency. While a variety of factors determine the amount of care used, most PWAs must use more than one provider.
The process of obtaining care is often complicated by the provider's availability. Many community-based AIDS service organizations evolved from within the gay community and are located in gay neighborhoods. These organizations are often inaccessible for those FWAAs living in other parts of town. Additionally, many of these organizations are sparsely funded; they cannot meet demand so clients face discouraging waiting lists. At this point family and friends may be the only source of assistance. Unfortunately, some FWAAs face rejection when turning to family and friends for support, especially when the PWA has hidden his homosexuality or IV drug use.

While a variety of providers exist, the process of actually setting up a long-term support system is often complicated by changes in health insurance, support needs and access issues. Limits exist on the amount of care available from community organizations, public programs and family and friends. In the next chapter utilization figures are presented along with patterns of use over time which reflect some of the changes in need and access to various sources of support.
V. RESULTS AND DISCUSSION

This chapter presents the data three ways. In the first section average amounts of services used per respondent are presented along with breakdowns of the proportion of each service delivered by various providers. Both Los Angeles and Brooklyn samples are too small and diverse to yield statistically significant predictors of service use. So, the second portion of this chapter presents summaries of case studies to illustrate patterns of service use and indicate which variables tend to influence utilization. These summaries focus on high and low users of care. Finally, two representative cases are presented, one based on the Los Angeles sample comprised of gay men and the other of a PWA with a history of IV drug use derived from the Brooklyn data. These illustrate average utilization among respondents from each sample with a timeline showing how employment, insurance and medical factors influence use of mental health and other support services.

DEMOGRAPHIC CHARACTERISTICS

Table 2 shows the demographic and medical characteristics of the 36 gay men from Los Angeles and 22 IVDUs from Brooklyn who participated in the interviews. While the two groups were similar in age, they differed in most other respects. A comparison of income, race and employment characteristics indicate the socioeconomic differences between the samples.
Income and employment figures presented in Table 1 probably underestimate the true difference between the Los Angeles and Brooklyn samples. The mean incomes were $14,400 in Los Angeles and $9528 in Brooklyn. These figures represent income for the year prior to the interview for the Los Angeles sample and income one year prior to diagnosis for the Brooklyn sample. Since the Los Angeles figures combine income prior to diagnosis and income post diagnosis, the final figure minimizes the original (prediagnosis) socioeconomic standing of the Los Angeles sample thereby underestimating the difference between the two groups.

The employment figures represent whether the respondent was unemployed at diagnosis. The closeness of these figures, as with the income figures, underestimate the true socioeconomic differences between the Los Angeles and Brooklyn samples. The unemployment figures in Los Angeles are inflated because many of the respondents were diagnosed according to the old (pre-September 1987) diagnosis criteria. They were diagnosed later in their illness, after they had to quit working, thereby making unemployment appear higher than if all respondents were diagnosed according to the new CDC definition which includes debilitating symptoms such as wasting, severe fatigue and diarrhea.

In Los Angeles each respondent reported some employment within the year prior to diagnosis, though 42% quit working during this time. The high percentage leaving their jobs before, as opposed to after diagnosis is probably related to ARC symptoms. Permanent unemployment played a bigger role in Brooklyn. In the Brooklyn sample, 41% of the respondents were perpetually unemployed and one additional respondent quit working
immediately prior to diagnosis. So if we examined employment status a year prior to diagnosis we would probably find little change in the Brooklyn group (46% unemployed) while in Los Angeles close to 100% of the respondents would be employed.

Unlike the employment and income differences which were underestimated due to data limitations, the racial figures, combined with drug use history, clearly imply significant socioeconomic differences between the two samples. Ninety-five percent of the Brooklyn sample is either black or Hispanic and the Los Angeles sample is 100% white. Historically, minorities have been of the socioeconomically lower class (Harwood, Ethnicity and Medical Care) and those with a history of IV drug use are especially likely occupy a lower economic strata than the white gay male sample. Therefore, availability and use of resources is expected to differ dramatically between the two groups. As a result a strict comparison between the two small samples is not the best means of presenting the data. While comparisons will be presented, the remainder of the results section will also focus on the trends and factors influencing resource use among respondents within the two samples.

MEDICAL HISTORY

Table 3 shows the survey respondents' prior major opportunistic diseases. PCP (pneumocystis carinii pneumonia) is the most common diseases in both groups with KS (Kaposi's Sarcoma) occurring in the Los Angeles sample and Tuberculosis in the Brooklyn group. These two samples exemplify the medical differences between the IVDUs and gay men with AIDS; KS only occurs among gay PWAs and Tuberculosis occurs more
frequently among IVDUs. The reason for higher rates of KS among gay is not known for certain. The most prevalent theory suggests that KS is caused by a sexually transmitted cofactor. Respondents in both samples experienced other major infections. Bacterial pneumonia was more common among the IVDU group and members of both samples had toxoplasmosis and cytomegalovirus.

USE OF SERVICES

Mental Health

Table 4 illustrates mean use of services for each group. Mental health was the most heavily used service with 27% of the Brooklyn sample and 61% of the LA sample using some mental health care. However, the amount of care used and the sources of care differed between the two groups.

Among those in the LA sample using mental health services, approximately 40% went to community agency-sponsored support groups and one-on-one counseling. The rest received one-on-one counseling from private psychiatrists or psychologists. On average, the LA group used 42 hours of mental health care per year. This number indicates high utilization among the 61% who did obtain care. Typically, mental health care was used on a weekly basis for extended stretches of time. However, some respondents even went to both a support group and a private psychologist, thereby using double the amount of care and bringing up the group average.

Generally, the Brooklyn sample's use of mental health care was low. Respondents used an average of 2.23 hours of mental health services during the first year after diagnosis. IVDUs received counseling at
Kings County Hospital. Six of the 22 respondents (27%) used some mental health care. Four respondents went to one-on-one counseling sessions conducted by psychiatric staff at Kings County Hospital with only two relying only on the AIDS support group at the hospital. Utilization ranged from 2 respondents who made only one visit each and the heaviest user who went to one-on-one therapy fifteen times. The Brooklyn IVDU sample used care more sporadically and terminated counseling after fewer visits than the Los Angeles gay sample.

The data does not directly explain the why utilization of mental health care is so much higher among the Los Angeles sample than among the Brooklyn group. Two factors are worth considering as possible explanatory factors. First the social stigma associated with psychotherapy and counseling is a less significant obstacle to care in the gay community than among the Blacks and Hispanics comprising the Brooklyn sample (Mays). Additionally, the single main provider of mental health care for the Los Angeles sample was APLA, an organization which grew out of the gay community to serve those affected by AIDS. Presumably, gays could easily identify with APLA and found the organization's counseling program useful. Perhaps the Brooklyn respondents did not use much mental health care since they did not expect the service to meet their needs. The interview data does not explain why two out of the six Brooklyn users of mental health care went to the King County support group once and never returned. While access problems certainly affect support group attendance, the patients' perception of the usefulness of psychological counseling also determines whether a service is used.
Household Assistance

Household assistance is the most heavily used service in both samples. 77% of the Los Angeles sample and 64% of the Brooklyn sample used household assistance. This service made up 82% of the total value of services received in Brooklyn and 65% in Los Angeles. Household assistance was primarily delivered by unpaid sources such as family and friends. In Los Angeles less than one percent was provided through community organizations and in Brooklyn approximately 11% was delivered free-of-charge through the Medical Assistance Program. Paid attendants, such as those provided through the Medical Assistance Program are usually trained to give basic medical assistance and also do cooking and other household chores. Family and friends can also be trained by medical personnel to undertake simple responsibilities such as caring for a Hickman catheter and making sure medications are taken regularly.

The data only provide partial explanations for high and low use of household assistance. The interviews do show that PWAs with live-in helpers (family or friends who remain at home) receive the most care (see case 210 below). However, most PWAs need help at home during some point in their illness. The structure of the survey items for both Los Angeles and Brooklyn samples may have lead to an underestimation of the number of respondents receiving household assistance. Respondents were asked whether anyone provided this service over the past thirty days. Those receiving ongoing assistance were counted along with respondents temporarily using assistance. Other respondents in better health may not have requested care from friends or family recently, but may receive such assistance when necessary. This undercounting does not effect the
average hours used per respondent per year. Those temporarily using household assistance should cancel out those temporarily not using such care. However, on a case-by-case level, it is difficult to ascertain which respondents have not used any care at all during the months prior to the interview, which ones use assistance regularly and who receives assistance only when very ill. Additionally, one cannot determine which respondents are truly isolated from family and friends and do not get care for that reason.

Financial Assistance

A large portion of respondents in both samples received financial assistance. Families and friends provided all direct financial assistance to the Brooklyn respondents. The same was true in Los Angeles except for a very small fraction of the sample who received rent support from a community service organization. The mean support for one year came to $2892 in Los Angeles and $948 in Brooklyn. This amounts to 25% of the total value of all services used in Los Angeles and 15% in Brooklyn. The higher Los Angeles figure reflects the higher socioeconomic status of that respondent sample. Friends and family donating money are probably wealthier than those of the Brooklyn sample. Additionally, the Los Angeles respondents probably have a higher standard of living and require a higher more financial assistance to cover basic expenses such as rent, possibly car payments and insurance and in some cases health insurance premiums.
Food Bank Services

Food bank services were used primarily by the Los Angeles sample which had much easier access to this service than the Brooklyn group. AIDS Project Los Angeles runs a food bank while no comparable service is available to the Brooklyn sample. At least one local church offers a food service for needy persons, but has not targeted PWAs specifically, therefore few know about the service or use it.

Legal Services

Free legal services designed for PWAs are not available in the Brooklyn area and few PWAs travel to organizations such as Gay Men's Health Crisis (GMHC) in Manhattan for such assistance. Less perceived need or desire for legal advice may also contribute to the Brooklyn sample's low utilization. All respondents had a history of at least one illegal activity, IV drug use. As a result they may be less inclined, perhaps suspicious, of any contact with the legal system. Also, since many of them have little or no income and consequently, few possessions, they may not consider a will important. Twenty-five percent of the Los Angeles sample used legal services making for a group mean of 1.2 hours per year. Most respondents used one or two hours to arrange wills and other matters dealing with personal property.

Shelter

The Brooklyn sample used more shelter services than the Los Angeles group. In Los Angeles only one respondent received emergency shelter and that was provided by friends. In Brooklyn four respondents used shelter services, ranging from one to 21 nights. The number using
shelters might even be higher if not for two New York City laws. The first states that hospitals cannot discharge patients unless there is a home or appropriate shelter to discharge them to. If accommodations are not available then the patient must remain in the hospital. Secondly, PWAs cannot be discharged to public shelters. For health reasons, more stable housing must be found. If the PWA cannot afford to pay rent then the city will subsidize either a room in an SRO hotel (single room occupancy), discharge him or her to a special shelter for PWAs or cover up to $480 per month rent for an apartment in a public housing project. But since there is a shortage of such housing some PWAs remain in the hospital far longer than medically necessary. Those in the Brooklyn sample using shelter were either at a shelter especially for PWAs or went to a regular public shelter without disclosing their HIV status. One respondent could not find appropriate housing and remained at Kings County hospital for over 45 days, 30 days longer than medically necessary.

Transportation

Few respondents used transportation provided by service organizations. Since a large portion of both samples reported having friends or family to provide practical support including transportation, the need for these outside providers may be low. Additionally, none of the respondents was severely disabled, most could drive although the data doesn't indicate how many had cars. Presumably, few of the Brooklyn sample owned cars. However, the City of New York's Medical Assistance Program (MAP) has contracted with a car service to provide free transportation to and from clinic appointments. Staff at Kings
County Hospital suggest our survey methods may have led to an undercount of those using a publicly funded car service program for rides to and from clinic appointments. Since the respondents were never specifically asked whether they used that particular program, Kings County Staff suspect respondents neglected to report using it.

SERVICE PROVIDERS AND THE MONETARY VALUE OF CARE

Tables 5 and 6 illustrate the percentage of each service delivered by the various providers. One of the most significant differences lies in the amount of care provided by community-based organizations. Two heavily used services, mental health and legal advice were provided primarily by community organizations in Los Angeles. In Brooklyn respondents relied more on services provided through public programs and Kings County Hospital. A community-based organization, a church, provided the food bank service which was used by only one respondent. The difference in reliance on community based providers is based on two factors. First, the Los Angeles sample was recruited through AIDS Project Los Angeles (APLA), a community organization providing a wide range of services. As APLA clients, these respondents were familiar with the available services and had little need to look for other providers for care. In Brooklyn the situation is quite different. The respondents were recruited through an outpatient clinic and viewed Kings County Hospital as their main provider of not only medical care but also mental health and other types of support. The hospital social workers are often the main link to other services such as transportation and shelter which are provided through public programs. Additionally, the Brooklyn group has few community organizations serving them and often
these organizations do not provide comprehensive services. Rather they offer a specific service such as case management, housing or short-term psychological counseling.

In both Los Angeles and Brooklyn respondents' family and friends were the primary source of both household and financial assistance. Assistance from family and friends is preferred to assistance from other sources including professional services provided free-of-charge through community organizations or public programs. Members of both samples are eligible for free care yet tend not to use it. Only 11% of the Brooklyn sample used household assistance provided through a local public program and less than one percent of the Los Angeles sample used such services. That so few of the Los Angeles respondents used professional providers of household assistance reflects the solid personal support networks many of these PWAs have. The Brooklyn group relies more heavily on outside assistance which reflects IVDUs' isolation from family and friends.

The long-term availability of volunteer labor is questionable. Volunteers "burn-out" and families and friends often have limited resources. As the AIDS caseload increases, spreading to lower-income communities without a tradition of volunteerism, the shortage of donated resources may grow more acute. At this point public programs may step in, offering at least some of the care volunteers provide in other communities. As shown by the Brooklyn case, public programs such as MAP may begin to provide more of the non-medical support services used by many PWAs.
As mentioned above, however, PWAs seem to prefer being cared for by family and friends than by paid strangers. This leads to the difficulty of valuing donated care using commercial charge rates. The care donated by friends and family may be worth more to the PWA than that provided by strangers. Possibly, PWAs may not even use as much care were it offered by paid strangers. To further complicate matters, donating one's labor is a charitable act which is supposed to bring its own rewards. These are probably payment enough for most volunteers. So, it becomes impossible to determine a dollar value for donated services. By using charges one can at least predict the value of donated care given the assumptions that it would otherwise be purchased at the care at the going rate and that the amount used would remain the same.

Table 4 also shows the monetary value of the services provided, coming to $7484 in Brooklyn and $11465 in Los Angeles. As tables 4 and 5 illustrate, the majority of services were provided free-of-charge by family and friends and community organizations. The Brooklyn sample used $7259 (97% of total service use) worth of free care while the Los Angeles sample used $10,777 (94% of their total support service use). Were these services provided by paid professionals they would have raised the overall cost of care by 17%. Assuming the yearly costs of all medical services comes to approximately $46,000 (Pascal 1989), these additional services bring costs up to $55,000.

While the assumptions used to value mental health and social support services are based on sound propositions, actual Medicaid reimbursement rates and estimates from service providers, there is still the possibility that some of these services could be offered at other
prices. This is particularly true of household assistance which comprises the largest portion of the support used by both Brooklyn and Los Angeles samples. We have valued that service at $11 per hour, the California MediCal reimbursement rate for this type of care. However, some programs pay assistants much less. At the Los Angeles Veterans Administration Hospital a home assistance program for spinal injury patients pays minimum wage, $3.80 per hour. If home assistance for PWAs is valued at that rate the overall cost of support services would change greatly. In Los Angeles the value of home assistance changes from $7392 to $2553.60, bringing the total value of support services down 42% to $6,626 per year. In Brooklyn the change is just as significant with the value of home assistance changes from $5368 to $1854.40, reducing the total value of support services by 47% to $4334.40. These lower estimates are relevant in that programs in other areas may currently pay minimum wage or may do so in the future. This is especially true since this study costs out services currently provided free-of-charge. Should the supply of volunteer labor decrease, paid substitutes may be hired at rates ranging from minimum wage up to $11.00 per hour.

CASE STUDIES

Thus far the results of this project have been presented by service and mean utilization. A different perspective is provided using a series of case studies described in detail in the appendix. They illustrate the differences between high and low users and also show how utilization changes throughout the course of illness. High users are defined as those using the greatest variety and quantity of services. Low users, in most cases have not used any care besides an occasional legal
consultation or a small amount of assistance from family or friends. The section below presents summary findings of the case studies from each sample.

HIGH USERS - GAY MALE SAMPLE, LA

Cases 41, 22, 34

Frequently, PWAs initially obtain services or increase use during the second year after diagnosis. Sometimes this is due to the PWA’s deteriorating health, evinced through more frequent opportunistic infections or increasingly severe general symptoms. In other cases obvious health changes cannot explain increased use. Given the data in this study one can only speculate as to what causes increases during the second year. Some PWAs do not exhaust personal resources until the second year when they are forced to request assistance from friends and service organizations. Others are in a state of denial during the first year and are less likely to use care unless forced to. Still other PWAs may not be aware of available services immediately after diagnosis.

LOW USERS - GAY MALE SAMPLE, LA

Cases 13, 21, 10

The low utilization among these PWAs is difficult to explain. Cases 21 and 13 were diagnosed less than two years before the interview. Since case 21 was interviewed barely a year before diagnosis and has not had PCP, often the most devastating opportunistic infection, he may not be in great need of assistance now and may use access more care if he needs it later. Low utilization by case 13 is particularly surprising given his poor health. As stated above, he was probably aware of
available care since he was an APLA counselor. He was interviewed half way through his second year, a time when many other PWAs have already used some services. One can only speculate as to why this respondent reported using so few services; maybe he actually used more care but forgot to report it or misunderstood the interview question, he may be in a severe state of denial or have consciously chosen to cope with AIDS alone. Unfortunately our data does not shed much light on which of these theories is true. For case 10, on the other hand, low use is not surprising. This respondent appears fairly self-sufficient. His health relatively good with KS as his only opportunistic infection and a T-cell count of 600. He is well enough to continue working though his second year after diagnosis and probably does not require much practical assistance.

By examining high and low users of mental health and social support services in Los Angeles certain trends become apparent, but for each of these trends exceptions exist. First, use of services tends to increase with time since diagnosis. Often the increase is accompanied by declining health. However, a PWA having relatively good health, such as respondent 41, can get care more easily and may use more than one who is sick. The data also shows that high utilization seems to occur most often during the second year after diagnosis. But this isn't always the case, with respondent 21 using minimal services one and one half years after diagnosis.
LOW USERS - BROOKLYN IVDU SAMPLE

Cases 001, 104, 107, 108, 213

With the exception of case 213, the low-user respondents have been hospitalized no more than once and have symptom scores that fall below the median. Even respondent 213 showed good health until his second hospitalization when he finally quit working. Besides relatively good health, denial and poor awareness of available care can also contribute to minimal use of services. In the cases PWAs who have never been hospitalized at Kings County, awareness of services may be low since hospital social workers often educate patients and connect them with service agencies or in-house support groups.

HIGH USERS - BROOKLYN IVDU SAMPLE

Cases 216, 207, 210

Upon comparing the low users and high users in the Brooklyn sample an obvious difference emerges. The high users are sicker, all having symptom scores above the median. Additionally they have all been hospitalized more than once. The issues of denial and lack of awareness of available services are smaller obstacles to care in this group than amongst PWAs whose health is better. Denial is easier for those who have been hospitalized fewer times and are healthy enough to live fairly normal lives. Additionally, the healthier group has less exposure to hospital social workers who generally counsel inpatients. Therefore, they are less aware of services available to them.
Summary of Los Angeles and Brooklyn Cases

Among the IVDUs, higher users are sicker than average according to symptom scores. Additionally they have been hospitalized twice compared to once for low users. Besides being sicker than those IVDUs hospitalized only once, the high users also had more contact with Kings County Hospital hospital which is the main link to most support services.

Trends were not as clearly discernible among the Los Angeles respondents. Use of mental health and social support services increased during the second year after diagnosis, although clear explanations for the increase are not evident in the data. One can surmise, however, that since this group tends to go to community organizations (APLA primarily) for most services, a certain level of self-motivation is necessary to obtain support. These services are not linked to the hospital or any other medical care provider, rather the PWA must make a special effort to contact another agency and seek help. Perhaps this self-motivation is only partially related to how ill a PWA is, and then other unmeasured variables intervene such as personality factors or friends' encouragement to seek care.

REPRESENTATIVE CASES

While the cases describe some of the high and low use respondents, figures 2 and 3 illustrate representative case scenarios from each sample. These are not actual cases. They are constructed according to each sample's average utilization figures. The timelines show the interaction between medical, economic and support utilization variables.
during the first year after diagnosis. Additionally, they show the approximate timing of milestone events such as opportunistic infections, changes in insurance coverage and initial contacts with service organizations.

Figure 2 illustrates the case of a gay male with AIDS, a typical member of the Los Angeles sample. Financial, psychological, practical and medical variables determine when he uses various services. He quits working after diagnosis, retains his group health insurance for six months by virtue of COBRA (Consolidated Omnibus Budget Reconciliation Act of 1987) and then must "spend down," that is liquidate his assets so he becomes eligible for Medicaid. This usually does not take long since PWAs face extraordinary medical bills which can exhaust personal savings quickly. Once left without financial assets and on Medicaid, PWAs are more likely to use food banks and accept financial assistance as shown at months seven and eight in Figure 2.

Most respondents in the Los Angeles sample did not use support services immediately after diagnosis. They usually waited at least a month and often longer. Out of those 22 Los Angeles respondents using mental health services, only two used care immediately after diagnosis. Neither of them used APLA services, rather they joined support groups where they were hospitalized. Those using other mental health providers such as APLA did not begin counseling until between one month and one year after diagnosis. The possible reasons for the delay include lack of knowledge about available care, waiting lists for support groups and client denial regarding need for support. This latter reason is supported by the literature on coping with AIDS and other terminal
illness. Denial is often one of the earliest coping mechanisms. While useful in helping one come to terms with a difficult diagnosis, denial also leads to delays in contacting providers of support services.

The use of services depends on the PWA's practical needs and circumstances. This is illustrated by the household assistance column. If a PWA is recovering from a serious opportunistic infection then more assistance may be used. In this case assistance goes from thirty to fifty hours per month after a hospitalization and then settles at forty later in the year when the PWA is weaker. After the second hospitalization use of mental health care drops off. This may be due to the PWA's weaker physical condition. It becomes more difficult to get to support groups. In some cases, however, support group attendance may drop off simply because the PWA has moved or decides he or she is not benefiting from the service.

Figure 3 depicts the first year after diagnosis for a typical member of the Brooklyn sample, a PWA with a history of IV drug use. Service utilization is much more sporadic than the in the case of the gay male PWA in figure 2. Mental health care is used only immediately after hospitalizations. A church food bank is not used regularly either. Reasons for inconsistent use include access problems, perceived ineffectiveness of service, and in some cases, psychological barriers. Since many IVDU have a "tough-guy" outlook on life (Hanson), they may be less inclined to seek out assistance or admit to themselves that a support group is helpful. Additionally, if the PWA is still using drugs then getting the next fix, rather than attending a support group, is his or her primary concern (Friedland et al). The only service used
consistently is household assistance. The PWA is less likely to need to actively solicit this service since it is provided by friends and family members. These are people who the PWA is in regular contact with and who may have bailed him or her out of difficult situations before. Therefore, the PWA is more likely to accept and either passively or actively encourage this type of care.

SUMMARY

The data from interviews with 36 gay PWAs in Los Angeles and 22 Brooklyn PWAs having a history of IV drug use reveal the following points:

Gay male PWAs affiliated with support organizations such as APLA use more support services than inner-city PWAs having a history of IV drug use. While the IVDUs use a variety of services, utilization is sporadic. The lower-income IVDUs rely on support services offered by hospitals or programs provided through public agencies. The middle-class gay sample used some services offered by private providers and relied heavily on community based-organizations which grew out of the local gay community. Among IVDUs, those with more severe symptoms tend to use more support services. In the gay sample trends in support service use were difficult to ascertain, however utilization did increase during the second year after diagnosis.
VI. POLICY IMPLICATIONS AND CONCLUSIONS

This study was one of the first to examine the use and provision of mental health and social support services among PWAs and document the use of informally provided assistance through family and friends as well as community organizations. The study suggests that a large proportion of the labor for providing support services for persons with AIDS is donated free-of-charge. This labor is offered both formally, through community-based organizations employing volunteers and informally, by PWAs' families and friends. Additionally, this study also showed that PWAs tend to receive support from a variety of sources. There were few indications that a long-term plan for care exists for most PWAs. Rather utilization depends on fluctuating factors such as the individual's financial situation, availability of family and friends and accessibility of community-based AIDS service organizations. Finally, the study illustrates the difference in utilization of mental health and social support services by gay PWAs and those with a history of IV drug use. Gays tend to use approximately 65% more services than IVDU. This study's findings illustrate trends which warrant attention and lead to new policy questions focusing on meeting the mental health care and social support support needs of increasing numbers of HIV-infected persons.
CAN A COMPREHENSIVE SOCIAL SUPPORT SYSTEM REDUCE HOSPITAL STAYS?

A statistically significant relationship between use of support services and hospitalizations is difficult to discern. Many variables affect this relationship. A wide range of factors, many of them unknown, influence the progression of AIDS and the quality of support services varies greatly. Additionally, the relationship between support service use and hospital stays may be subtle, requiring a huge sample size to identify it. While this project could not detect a correlation between length or frequency of hospitalizations and use of support services it does provide some insights. In some extreme cases a shortage of support services can clearly influence PWAs' length-of-stay. Social workers at Kings County Hospital frequently must search for appropriate housing for homeless PWAs who are ready for discharge. These PWAs, who may have been ready for discharge after a week or two may remain hospitalized for up to six months until housing is found.

The effect of a good support support system on the frequency and length of hospitalizations can also be more subtle. For example, PWAs must maintain a nutritionally sound diet to help prevent the opportunistic infections requiring hospitalization. During periods of severe fatigue, grocery shopping and cooking become difficult or even impossible chores. At these times PWAs must rely on family, friends and volunteers for meals. Similarly, PWAs may have to depend on others for transportation to clinics and money for rent and other necessities including medication. Assistance in these areas may prevent opportunistic infections in some PWAs thereby reducing hospitalizations and overall treatment costs. Perhaps the PWAs in our sample who were
heavy users of such care would have spent more time in the hospital if practical assistance were not available.

WILL THERE BE ENOUGH VOLUNTEERS TO SERVE PWAS IN THE FUTURE?

The high monetary value of donated labor indicates the significant contribution of volunteers and family and friends of PWAs. Both IVDUs and gay males relied heavily on their families and friends for practical support while gays also turned to community-based organizations. The absence of a comprehensive community-based support network for IVDUs places additional emphasis on informally provided support as seen in the results of this study. Family and friends provided 97% of the care used by IVDUs as compared to 77% for gays who received another 17% from community organizations.

This dependence upon volunteer labor and the growing AIDS caseload leads to the question of whether there will be enough volunteers to serve PWAs in the future. This is a particularly acute question within minority communities where fewer AIDS service organizations exist and family-oriented caretaking is substituted for organizationally based volunteerism.

WILL PUBLIC PROGRAMS BE ABLE TO MEET THE NEEDS OF A GROWING PWA CASELOAD?

While mental health and social support services are available through a variety of sources, many PWAs must rely on public programs for care. This study indicates that lower-income IVDUs used more services provided by hospitals or public agencies than did the gay sample. As mentioned above, this is due to a combination of two factors, a shortage of community organizations offering services for IVDUs with AIDS and
IVDUs' lack of private health insurance. Even a solid support network of family and friends cannot substitute for care offered by formal organizations and professional caregivers. In some instances community organizations offer limited services. For example mental health care, particularly long-term psychological counseling, is not available through community service organizations in Brooklyn. Since the family cannot provide a substitute for professional counseling and private therapists are expensive, the Brooklyn IVDUs turned to the Kings County Hospital where individual sessions are covered by Medicaid and support groups are available.

By comparison, the Los Angeles gay sample did not use many public programs. Instead, some of those with private health insurance used private psychologists and psychiatrists while others turned to support groups and individual counseling programs sponsored by community organizations. However, middle class gay males may turn to public programs more often in the future. As mentioned above, the ability of these organizations to meet future needs is not guaranteed since these groups rely on donated labor and funds. Private health insurers are unlikely to make up for what community organizations cannot do. Insurers usually do not provide comprehensive coverage for mental health care and coverage for other support services is scanty.

Unless more options for mental health care and social support services arise from within the community, IVDUs with AIDS will continue to depend on public hospitals and other public programs. The importance of these programs grows with the expanding IVDU and lower income caseload, especially in urban areas of the United States. Whether the
current system can support the needs of HIV infected population is questionable. Pressing policy issues include the funding and organization of public systems to house, clothe and feed and otherwise support those PWAs having minimal personal and financial resources.

HOW WILL DEMAND FOR SERVICES CHANGE WITH INCREASING LONGEVITY OF PWAS?

Among IVDUs, those with more severe symptoms tend to use more support services. In the gay sample trends associated with symptoms were difficult to determine, however these PWAs did tend to use more care during their second year of illness. These findings seem to correlate with the expectation that the sicker one is, the more support services he or she needs and uses. Additionally, the longer one is sick, the more likely he or she is to have passed the denial-based psychological obstacles to asking for support.

The influence of increased use of services with duration of illness and increased severity of symptoms has questionable bearing on future demand for services. If life expectancy of PWAs increases along with improved quality of life the need for support services may actually decrease. However, if life expectancy grows with quality of life remaining constant or decreasing in later months the need for support services will grow even more quickly than caseload. To plan for this possible scenario, policy makers must consider the possible needs of PWAs in their later months of illness, the stability of the volunteer labor force and the role of public programs in meeting upcoming demand.
The results of this study, presented in Chapter 6, do not represent the need for mental health and social support services. Instead, they represent the use of services, a compromise between need for care and the accessibility of specific services by a segment of the PWA population. As Josef's case clearly illustrates, many individuals' needs go unmet for extended periods of time. Often, these are the people who have the fewest personal resources and would benefit most from the services of a community-based or public program. But since these individuals are not adept at dealing with bureaucracy they are most likely to find themselves homeless and without a support network, as Josef did, soon after their AIDS diagnosis. This study's results do not represent service utilization by PWAs like Josef. Instead it shows service use by a small group of relatively well-connected and compliant PWAs in two very different communities. However, these results do provide insight to the system by which care is delivered and a baseline from which to roughly estimate utilization, and even more roughly estimate need for other segments of the PWA population.

This study is an early step in developing a system to better meet the mental health and social support needs of all PWAs. The role of projects such as this one is to draw attention to the importance and problems of providing nonmedical support services to PWAs, to illustrate the need for additional policy research and finally to help in meeting the practical and emotional needs of the expanding PWA population.
Fig. 1 -- Declining T-Cell Count in Typical HIV Infected Patients

From: "HIV" Infection: The Clinical Picture
By: Robert R. Redfield and Donald S. Burke
In: Scientific American
October 1988, Vol. 259, No. 4
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Fig. 2 – Gay Male PWA, Representative Case
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<td>Financial Asst.</td>
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<td>Church Food bank 5 days</td>
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<td>8</td>
<td></td>
<td>TB</td>
<td>11 Days</td>
<td>1 Visit Psychologist</td>
<td>Church food</td>
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<td>5 days Food bank</td>
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<td>9</td>
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<td>Transportation To Clinic 1 Ride</td>
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Fig. 3 – IVDU PWA, Representative Case
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<tr>
<th></th>
<th>RAND 1989 n=22</th>
<th>BROWN 1985 n=454</th>
<th>FRIEDLAND 1981-83 n=40</th>
<th>FRIEDLAND 1984 n=59</th>
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<td>Age</td>
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<td>68</td>
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<tr>
<td>&lt;$5,000</td>
<td>64</td>
<td>78</td>
<td>(&lt;10000) 73</td>
<td>2</td>
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<td>$5,000-$10,000</td>
<td>18</td>
<td>10</td>
<td>(≥10000) 27</td>
<td>34</td>
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<tr>
<td>&gt;$10,000</td>
<td>24</td>
<td>12</td>
<td></td>
<td>64</td>
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<tr>
<td></td>
<td>Los Angeles</td>
<td>Brooklyn</td>
<td></td>
<td></td>
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<tr>
<td>---------------</td>
<td>-------------</td>
<td>----------</td>
<td></td>
<td></td>
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<tr>
<td>Mean Age</td>
<td>36</td>
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<tr>
<td>Race</td>
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<td>5%</td>
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<tr>
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<td>26%</td>
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<tr>
<td>Hispanic</td>
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<td>68%</td>
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<tr>
<td>Mean Income*</td>
<td>$14,400</td>
<td>$9528</td>
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<tr>
<td>Unemployed at Diagnosis</td>
<td>42%</td>
<td>46%</td>
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<td>Insurance</td>
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<tr>
<td>Medicaid</td>
<td>42%</td>
<td>100%</td>
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<tr>
<td>Private</td>
<td>58%</td>
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* Year prior to diagnosis
<table>
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<tr>
<th></th>
<th>PCP</th>
<th>KS</th>
<th>Other *</th>
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<tr>
<td>Los Angeles</td>
<td>26 (72%)</td>
<td>10 (28%)</td>
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</tr>
<tr>
<td>Brooklyn</td>
<td>17 (77%)</td>
<td>0 (0%)</td>
<td>5 (23%)</td>
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*(CMV, Meningitis)*
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<th>Service</th>
<th>Los Angeles n=36</th>
<th>Brooklyn n=22</th>
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<tr>
<td>Mental Health</td>
<td>42 hours</td>
<td>2.32 hours</td>
</tr>
<tr>
<td>Household Assistance</td>
<td>84 days</td>
<td>61 days</td>
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<tr>
<td>Transportation</td>
<td>0</td>
<td>&lt;1 trip</td>
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<tr>
<td>Shelter</td>
<td>1 day</td>
<td>3.5 days</td>
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<tr>
<td>Food Bank</td>
<td>2.4 months</td>
<td>.46 months</td>
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<tr>
<td>Legal Assistance</td>
<td>1.2 hours</td>
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<tr>
<td>Financial Assistance</td>
<td>$2,892</td>
<td>$9.48</td>
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<tr>
<td>Buddy</td>
<td>32.5 days</td>
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<tr>
<td>Total Monetary Value</td>
<td>$11,465</td>
<td>$7,484</td>
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* Per patient per year
## TABLE 5

**Services by Provider Matrix**

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<tr>
<td>41%</td>
<td>99%</td>
<td>100%</td>
<td>&lt;1%</td>
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</table>

* APLA Buddy not included

** Percentages represent portion of dollar value of mean utilization

- Ins.
- Self Pay

None used
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<td>Comm. Orgs.</td>
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<td>100%</td>
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<tr>
<td>Friends &amp; Family</td>
<td>89%</td>
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<td>100%</td>
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<td>100%</td>
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<tr>
<td>Medicaid (Public)</td>
<td>100%</td>
<td>11%</td>
<td>100%</td>
<td>100%</td>
<td>none used</td>
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<tr>
<td>Ins.</td>
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</tr>
<tr>
<td>Self Pay</td>
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</table>
HIGH USERS - GAY MALE SAMPLE, LA

Case 41

Respondent 41 was diagnosed in April 1986 and has never been hospitalized, his only major infection being KS and his main symptom, fatigue. This PWA used resources from a number of providers including APLA, Christ Chapel and the AIDS Services Foundation and AID for AIDS. He also received assistance in the form of cash and practical help from family and friends. He used multiple sources for similar services; APLA and the AIDS Services Foundation provided mental health, food was provided by both APLA and Christ Chapel, APLA provided insurance counseling. Vitamins were paid for by Christ Chapel and AID for AIDS. He was unemployed for almost the entire duration of his illness and made only $9600 per year before being diagnosed, so his need for financial and food assistance is expected. His exceptionally high use of services from a number of different providers signifies his ability to access providers. PWAs with poorer health may have similar needs but lack the strength to research providers and access services.

Case 22

This respondent used more services as he got sicker. He used a variety of services during his second year after diagnosis. Medical covered attendant care and transportation, APLA provided food bank services and family and friends provided significant financial and practical support. Opportunistic infections include CMV, herpes and two bouts of PCP. The respondent also experienced fatigue, weight loss and
constant eye irritation. He left his job immediately upon diagnosis and has remained unemployed since. Not until his second year did the second bout of PCP, the CMV and herpes occur. This explains the increased use of services at that time, particularly the use of attendant care.

Case 34

As in case 22, this respondent used most services after his first year of illness. While he was hospitalized three times in the first year, he did not leave his job until the second year. During the second year he began consuming most of his mental health services. He used a private psychiatrist, a Shanti buddy, APLA support groups, therapists at Hollywood Hospital and his minister as sources of emotional support. He also received $4000 of support from his family during his second year after diagnosis. The increased use of services in the second year can relate to his increase in general symptoms. Weight loss and neuropathy began to set in during this time, so while major opportunistic infections did not occur, the respondent did seem to get sicker and accessed more assistance.

LOW USERS - GAY MALE SAMPLE, LA

Case 13

This respondent used surprisingly few services given his medical condition. We have just over one and a half years of data on him and throughout this time he used one hour of insurance counseling and two days of inpatient mental healthcare at VA Wadsworth. He was hospitalized four times with CMV and KS. His symptoms, ongoing since diagnosis included fever, weight loss, diarrhea and headaches. He left
his job as an APLA counselor when he was first diagnosed with AIDS and has only used insurance counseling services since. He also indicated no support received from friends or family. While it seems he would benefit substantially from some support services he has failed to access them. He was once an APLA counselor, so it appears this has been a conscious decision since he must be aware of available services.

Case 21

This respondent has been hospitalized twice, once with CMV and once with toxoplasmosis. He experienced ongoing diarrhea and weight loss beginning shortly before diagnosis. We have slightly over one year of data on him, during which he did not use any formal support services and did not report recent assistance from family and friends. His reasons for not accessing formal care are probably not financial. He left his job soon after diagnosis but maintained private health insurance which frequently covers the costs of some mental health consultation and some homemaker assistance.

Case 10

This PWA was diagnosed two years prior to the interview, KS is his only opportunistic infection and he reports no major symptoms with his latest T4 count at 600. He has remained employed full-time since diagnosis and actually moved up to a higher paying job during this time. He used APLA's insurance counseling service once and reported receiving some assistance from friends and family but not recently. This respondent's health is relatively good, implying his need for support services, particularly practical assistance, is lower than that of most other PWAs.
BROOKLYN IVDU SAMPLE - LOW USERS

Case 001

We have seven months of data on this patient. He was never hospitalized, his only opportunistic infection being isoporiasis. His symptom score was 14, which puts him in the 42nd percentile and well under the average symptom score of 22. His was never formally employed with burglary as his source of income. Since this patient never needed hospitalization he probably never met with hospital the social workers who would inform him about available services. Also he may not be as much in need of services as PWAs who have been hospitalized and come home to recuperate.

Case 104

This PWA's health is relatively good. We have four months of data on him and know he was hospitalized once for PCP but is doing well with a symptom score of 7 which puts him in the 23rd percentile. He has a history of unemployment and now lives in a residential hotel which represents his only use of a support service. We have not seen much service use since this patient is fairly healthy and was diagnosed only four months prior to the interview.

Case 108

We have 14 months of data on this patient. He was hospitalized once but had two opportunistic infections, TB and PCP. His symptom score of only 11 puts him in the 32nd percentile. He was diagnosed while in jail (7/88) and remained there for five more months. He was not employed for the two years prior to the interview. This patient's low service use
can be explained by his relative good health and that he spent the first five months after diagnosis in jail, where he probably did not have access to support services. The data does not indicate that he was hospitalized since leaving jail. Since patients receive information on support services from social workers in the hospital, it is possible he was never informed about services available to him.

**Case 107**

This PWA was diagnosed in January, 1989 and we have eight months of data on him. He was hospitalized once for meningitis and has a symptom score of 5 which is in the 22nd percentile. He was unemployed five months prior to his AIDS diagnosis but there is no indication of ARC symptoms or a positive HIV test which could cause job loss. This patient seems fairly healthy, he was hospitalized only once, has never had PCP and has a low symptom score. Therefore, his low use of support services may be related to generally better health than most of the other patients in the sample.

**Case 213**

Unlike the other four low-user patients, this PWA was hospitalized twice, once with PCP and once with meningitis. While his symptom score is fairly high, 28 and 59th percentile, this PWA's employment record shows that he remained functional for much of his illness. He was first hospitalized in November of 1988 but kept a full-time job until his second hospitalization in May of 1989, three months before his interview. His low utilization is probably based on a minimal need for services throughout most of his illness. However since his second
hospitalization his health has declined and needs have probably increased. His family has given him $600 since that hospitalization and perhaps he will go on to use more services in the future.

HIGH USERS, IVDU SAMPLE

Case 216

This PWA's high use was centered around $3663 worth of days of in-home attendant care provided through MAP and 32 rides to and from clinic covered by Medicaid. While she was not recently hospitalized, her symptom score was 31. She is in the sickest fourth of the sample, is somewhat debilitated and probably in need of household assistance. Her employment history does not show a change in health status since she was perpetually unemployed. Unlike some of the other patients in the sample, this PWA tapped into the public services she was eligible for. She also attended Kings County Methadone maintenance program where she may have received the extra counseling leading to other support service providers.

Case 207

This PWA was diagnosed one and a half years prior to the interview. He had a symptom score of 30, which puts him in the sickest quarter of the sample. He had two opportunistic infections, PCP and TB. He has tapped resources available to him using $2504 worth of days of attendant care, $31 worth of visits to a church food bank and $104 worth of rides to and from the clinic. He also reported receiving counseling from a MAP worker regarding Medicaid eligibility. Possibly this counselor connected him with the resources he ended up using. Otherwise
his counselor at the methadone program he belonged to provided these connections.

Case 210

As with the previous two cases, respondent 210 was in the sickest quartile of the sample. His symptom score was 31, he was diagnosed in July of 1986 with his interview taking place approximately one year later. This case represents a different type of high user than those described above. Unlike cases 207 and 216, respondent 210 did not use formally provided services. Instead he relied on his common-law wife for support. When the number of hours of support she provided gets costed out the total is higher than that of most respondents using extensive formally provided care. Case 210 is one of four respondents using extensive services provided by live-in family or friends.
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