



The Crisis in AIDS Care

A Call To Action

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Introduction

The Citizens Commission on AIDS for New York City and Northern New Jersey began its work more than a year and a half ago with a mission of stimulating private sector leadership in response to AIDS. The care and service needs of people with AIDS and HIV infection was identified by the Commission as an urgent item on its agenda. Like other groups that have examined this issue, the Commission found that AIDS is a beacon that focuses attention on gaps in health and social services. What began as an examination of the problems of people with AIDS and HIV infection has thus turned into an increasing awareness that health care for all is endangered.

As a result, the Commission's recommendations have been drafted with the goal of improving health care and social services for all citizens. A growing sense of urgency has framed our work. Words like "crisis," "emergency," and "catastrophe" came to be commonplace in our discussions. That sense of urgency is, we hope, conveyed in our Action Plans for New York City and New Jersey.

This background report was prepared for the Commission by its Work Group on Care and Service Needs, co-chaired by Peter Arno, assistant professor of health economics at Montefiore Medical Center/Albert Einstein College of Medicine; and Jesse Green, director of health policy research at New York University Medical Center. The Commission staff also contributed to the report. It opens with sections on hospitals and long-term care facilities. Then it explores the complex questions surrounding community-based organizations; housing and homelessness; women, children, and adolescents; discrimination in the care of AIDS/HIV patients; and the impact of early diagnosis and intervention.

In the course of its study, the Commission met with persons with AIDS and heard moving testimony about their difficulties in obtaining care. Five interviews are included here to bring to life the kinds of problems people with AIDS face as they seek health care and supportive services.

Having produced this report, the Commission now moves to its next stage: advocacy. There can be no satisfaction in adding yet another report to the growing body of documentation of the health care crisis unless it leads to greater public awareness and action. An informed and aroused citizenry must mobilize to meet the emergency.

John E. Jacob
John E. Zuccotti
March 1989

Chapter 1

AIDS and the Future of Hospital Care

AIDS appeared on the health care horizon ten years ago, suddenly and without warning. Although the entirely new and phenomenally complex disease did not even have a name, hospitals immediately became involved in its diagnosis and treatment, as well as in research. A whole new field of therapeutics had to be invented to deal with its myriad manifestations. Whole hospital wards became AIDS units. AIDS teams were formed. Physicians learned about a new disease from scratch. Thousands of nurses, residents, social workers, technicians, dieticians, and orderlies dealt with personal fears and -- in the vast majority of cases -- overcame them and kept on working.

Ten years later, New York City's hospitals are still at the forefront of the provision and development of AIDS treatment. They too have responded, by and large, by doing their job -- providing care and treatment to those with AIDS. As Bruce Vladeck, president of the United Hospital Fund, has said, "We need to begin by taking note of the extraordinary response of this city's hospital community...to the extraordinary challenges with which the epidemic has confronted it."

The impact of AIDS on New York City hospitals is far out of proportion to its impact on any other city. Presently, the AIDS census in New York City's hospitals grows by more than one bed every day. There are more AIDS patients hospitalized every day at Bellevue Hospital in New York City than in the entire city of San Francisco. New York City hospitals admit more than four times as many AIDS patients and devote more than eight times as many beds to AIDS treatment as San Francisco hospitals. And while San Francisco's one public hospital has an AIDS caseload composed almost entirely (97 percent) of gay men, New York City's 11 public hospitals have an AIDS caseload that is more than two-thirds IV drug users -- individuals with a host of special problems including homelessness, histories of poor health and poor nutrition, responsibilities for young children without other caretakers, lack of insurance, poor access to primary care physicians, and detoxification needs.

As a result of AIDS and other health care crises, New York City's hospitals are stretched to the breaking point. Occupancy levels are dangerously high; emergency rooms are backed up; staffing shortages are critical; revenues are not covering costs. New York may be the only American city with fewer hospital beds than it needs and this gap is likely to widen significantly. The result will be a serious loss of access to hospital care for all New Yorkers and a constant state of crisis in these facilities. Despite the danger, there is no sign that major efforts are underway to find systemwide solutions.

New York City's Hospitals at the Breaking Point

New York City's hospitals are operating at occupancy levels higher than at any time in recent history and higher than in any other city in the country. The average hospital occupancy rate in the United States is 60 percent. In many parts of the country, hospitals aggressively attract patients through marketing efforts. In New York City, by contrast, most hospitals have occupancy rates above 90 percent and many exceed 100 percent.

Like any service delivery system, hospitals require a buffer between average occupancy level and maximum capacity in order to deal with peak times and with crises. There are large daily fluctuations in hospital census totals due primarily to the ebb and flow of unscheduled admissions. If the average day brings a hospital to 90-100 percent of capacity, what happens on a busy day? On a very busy day? What happens during a catastrophe, such as an explosion, a plane crash, a riot, or a terrorist incident? How can the system cope with the outbreak of another epidemic illness, such as Legionnaire's disease, a virulent strain of flu, or something else that we can't even predict?

In a report entitled "New York City's Hospital Occupancy Crisis: Caring For a Changing Patient Population," the Bigel Institute and the United Hospital Fund describe the factors that created the current crisis. During the early 1980s, hospital utilization in New York City declined, reaching a ten-year low in 1986. A similar trend occurred throughout the United States. Forecasters and planners expected the trend to continue, but instead it reversed dramatically, with hospital occupancy levels soaring from 82 percent to above 90 percent. According to the report, "the annual cycle of winter highs and summer lows disappeared, replaced by relentless increases in utilization."²

A number of factors combined to cause the occupancy crisis: planned downsizing of the hospital plant in New York City, resulting in a 9 percent decrease in beds; additional bed reductions due to staff shortages and the need to isolate some patients; increased demand for services among New York City's growing population of the poor; dramatic increases in the use of emergency rooms as points of entry; and the large numbers of newborns requiring very long hospital stays. City hospitals may well have been able to absorb these shocks were it not for the simultaneous pressure placed on acute services by three interrelated epidemics: psychiatric disorders, substance abuse, and AIDS. Although AIDS has actually contributed the smallest share of bed need to date, it is by far the fastest growing epidemic and its full impact is yet to be felt.

Along with the occupancy crisis, New York City hospitals face a severe financial crunch. The 1988 deficit for New York City hospitals is estimated to be \$120 million.³ Hospitals anticipate an additional \$169 million loss statewide (\$100 million in New York City) as a result of recent changes in Medicare payment policy for patients whose

hospitalizations are much longer than expected. A large reduction is also expected in Medicare payments to teaching hospitals, where many New York City AIDS patients are hospitalized. In addition, Governor Mario Cuomo has announced substantial cuts in Medicaid. Coupled with the large budget deficits at both the federal and state levels, these cutbacks create pressure to reduce rather than expand health care resources.

Current Bed Needs in New York City

In its most recent survey (September, 1988) of New York City hospitals, the Greater New York Hospital Association found that 1,679 beds -- more than 6 percent of the City's total medical/surgical beds -- were occupied by patients with confirmed AIDS or suspected AIDS. This is up sharply from 1,071 in March, 1987 when the survey was first conducted. In February 1989, the New York City AIDS Task Force reported 1,800 beds used for HIV illness and AIDS.

Why does New York City have so many AIDS patients in the hospital? First, because the epidemic has hit the region hard. One in four U.S. AIDS cases has occurred in New York City. There have been more AIDS cases reported here than in the next four highest-incidence cities (San Francisco, Los Angeles, Houston, and Newark) combined. If the City Department of Health's estimate of 200,000 New Yorkers infected with HIV is accurate, it is four times higher than similar estimates for San Francisco. And, if the estimate is accurate, 90 percent of those infected in New York City have not yet developed AIDS.

In addition, AIDS patients typically require hospitalization for acute illness twice between diagnosis and death. A majority of the hospital admissions occur within six months of diagnosis and lengths of stay vary greatly. Some AIDS-related hospitalizations (about 10 percent) are for just one day. More than one-third are for one week or less. But a significant number of hospitalizations last a very long time, skewing the average stay to just under 20 days. In particular, long stays characterize the one in five hospital admissions for AIDS that end in the patient's death.

Comparisons of utilization data across cities indicate that AIDS patients in New York City are hospitalized about as often as in San Francisco but for longer periods of time. This difference is due in part to the greater availability of sub-acute services in San Francisco and to the extensive support by a network of volunteers. Other likely reasons include differences in patient mix, and the fact that IV drug users have a more complex set of medical problems.

Some observers have suggested that a relatively large subgroup of the 1,800 AIDS and HIV patients currently hospitalized can be cared for outside the hospital in order to ease the strain on services and possibly reduce the cost of care. However,

there is little hard evidence that many hospitalized AIDS patients do not actually need acute care. Although there has been little systematic study of the question, some estimates do exist for New York City. These range from a low of 5 percent, based on alternate level of care days, to highs of about 20 percent⁴ or 25 percent.⁵ Even the State's projections assume only a 10 percent reduction in bed need when alternate care settings become available. And a national survey of public hospitals found that 10 percent of hospitalized AIDS patients do not need acute care. Thus, it appears that sub-acute services, even if they could be made available quickly, would reduce by a relatively small degree the need for acute care beds.

Further, it is not clear that alternatives to hospitalization for AIDS patients actually save money. Comparing the average cost of a day in the hospital with a day in long-term care, for example, oversimplifies the cost tradeoffs involved. The hospitalization costs for an AIDS patient who is ready to be discharged is less per day than for the typical and sicker hospital patient, whereas once admitted to long-term care that patient is likely to generate higher costs than the average patient in a hospital. There are also costs involved in creating alternative beds and in coordinating the efficient transfer of patients to alternative sites (case management). And we cannot guarantee that additional beds outside the hospital will be used exclusively as substitutes for hospital days.

Forecasts of Hospital Bed Needs for AIDS in New York City

Projections of future bed needs have been made separately by the New York City AIDS Task Force and the New York State Department of Health (see Table). The State's projections are somewhat lower because they are based on reported HIV-related hospitalizations whereas the City AIDS Task Force adjusted to account for substantial underreporting.

PROJECTIONS OF AIDS-RELATED HOSPITAL BEDS NEEDED IN NEW YORK CITY

<u>End of Year</u>	<u>NY State DOH*</u>	<u>NYC AIDS Task Force**</u>
1989	2,071	2,420
90	2,477	3,020
91	2,909	***2,940
92	3,351	3,470
93	3,792	4,020

Sources:

* B. Pasley and P. Vernon, "Health Care Resource Requirements for AIDS Patients in New York State: Acute Care 1987-1994." Paper presented at the American Public Health Association Annual Meeting, Boston, MA. November 14, 1988. The authors applied the official New York State bed need methodology to New York City.

** New York City AIDS Task Force, presentation of Needs Assessment Work Group, February 22, 1989.

*** The task force's methodology involves a downward adjustment beginning in 1991 for the addition of non-hospital options to the system.

Either of these projections suggest a citywide acute care crisis of major proportions by 1991. Even the lowest estimate shows that an additional 1,100 beds will be needed. By 1993, 2,100 more AIDS beds will be called for. If these projections are accurate and if other factors stay constant, all of New York City's hospitals could be operating above 100 percent capacity. Clearly this could create serious access problems for any New Yorker seeking hospital care. And if other problems, including drug abuse, homelessness, psychiatric disorders and nursing shortages worsen as well, the strain on hospital care in New York City in the next decade will be almost unimaginable.

How Accurate are the Projections?

Both State and City forecasts of hospital bed need depend on the so-called linear extrapolation method to project future need from past trends. The method makes two critical assumptions: (1) the rate at which AIDS incidence has been growing will continue at a constant rate; and (2) the average length of a hospital stay by AIDS patients will continue to decline.

The assumption that AIDS cases will grow at a constant rate may be unsound because HIV did not spread at a constant rate. The best epidemiologic data available shows that among gay men in San Francisco the spread of infection took place very

rapidly about four or five years ago and slowed substantially after that.⁶ There is evidence of a similar history among New York City IVDUs.⁷ If the pattern does prove to be similar, the State's projections -- which show the incidence of AIDS levelling off among gay men but growing sharply among IVDUs -- will be inaccurate. Further, our ability to estimate the rate of infection in other populations, such as female partners of IVDUs, other heterosexuals, and infants, is even more imprecise.

The second questionable assumption is that the average length of hospital stay by AIDS patients will continue to drop. This is based solely on data from 1983 through 1986, when average length of stay decreased, and ignores a more recent upward trend in New York City (from 19.2 days in 1986 to 19.7 days in 1987). Nationally, the length of stay for AIDS cases has increased from 19 days to 20.29 days.⁸ The State's estimate also fails to take into account the trend toward increasing proportions of AIDS cases among IVDUs, whose lengths of stay in the hospital are generally longer than average. Finally, the State assumes that lengths of stay will decline 10 percent when alternate facilities are available and the New York City AIDS Task Force has said that sub-acute facilities may lower average length of stay to 16 days by 1991, but, as the studies cited earlier suggest, these may be optimistic assessments.

Given the high degree of uncertainty surrounding the projections, the only thing that can be forecast with confidence is that estimates will change. This past year the New York City Commissioner of Health changed the City's best estimate of HIV-infected gay men in New York City from about 200,000 to between 60,000 and 90,000. An expert panel has reviewed the new estimates and found them justifiable. Recent data about seroprevalence among gay men, IVDUs, infants and women, which have not been incorporated into the projections, will also need to be considered. Although fluctuations in data often make policymakers feel they are aiming at a moving target, it obviously remains critical to plan on the basis of the best available information and then revise when necessary.

Why Poor Neighborhoods and Public Hospitals Bear a Heavy Burden

Because of its link to drug abuse, AIDS has become especially prevalent in the poorest neighborhoods, among a population with very limited resources and very few medical services. Staten Island, for example, has barely been affected at all while certain Manhattan, Bronx, and Brooklyn neighborhoods have been devastated. Ernest Drucker of Montefiore Medical Center has estimated that 10 to 20 percent of young men (17-34 years old) in the South Bronx are seropositive.⁹ The impact of this level of infection (and future disease) on an impoverished neighborhood is immense. And if 20 percent of sexually active young men are infected, the implications for the young women in the South Bronx and their babies are equally ominous.

In poor neighborhoods the local hospital emergency room (ER) often provides the only available access to a physician. A systemic problem that transcends the AIDS epidemic is highlighted here: Like other residents of impoverished neighborhoods, HIV-infected patients make inappropriate use of the ER simply because no other health care is available. For the same reason, a disproportionate share of AIDS patients is being handled by public Health and Hospitals Corporation hospitals, which account for 16 percent of New York City medical/surgical beds but 36 percent of the AIDS census. The New York City Strategic Plan for AIDS cites the readjustment of this share between public and voluntary hospitals as one of the City's most important AIDS policy objectives. Realistically, however, this cannot be achieved without a major change in the way the poor receive their health care. And in any event, the redistribution of patients will not solve the need for more beds.

Current Plans and Programs to Meet the Acute Care Needs of PWAs

The State has sent out mixed signals in response to the hospital crisis in general and specifically to AIDS-related hospital needs. Some State initiatives have helped hospitals cope with AIDS, most notably the supplemental reimbursement for AIDS care that is provided through the Designated AIDS Center program, and the adoption of AIDS-specific Diagnosis Related Groups (DRG), which are unique to New York State. (DRGs are rates of reimbursement established for various illnesses based on typical resource requirements.) The Designated AIDS Center program was modeled on San Francisco General Hospital's combination of a dedicated unit, an interdisciplinary team, case management, and community-based alternative care. The program has since evolved to fit the realities of New York State's health care environment and has developed standards of care that are constantly monitored. The New York State Department of Health has announced a goal to provide 60 percent of AIDS hospital beds through Designated Centers. So far, however, there are only 14 centers statewide, 9 of which are in New York City. None of the City's public hospitals has become a center.

The City has long recognized the need for additional beds but has little power to create them. The State, which does have the power, has had a more restrained response to anticipated need. Early in the crisis, Dr. David Axelrod, the State health commissioner, announced that the AIDS epidemic could not be used to allow New York City to enlarge its hospital system. Since the State has labored for ten years to contract that system, a reluctance to see its effort reversed is natural. As a result, even when State health planners began to project expanded needs as a consequence of AIDS, the hope was that most of this capacity would be created by shorter stays among non-AIDS patients. The thinking here was that implementing an all-payor DRG system in New York State would reduce lengths of stay across the board thus freeing up many

beds. Unfortunately, the opposite has occurred. The average length-of-stay has increased in the State since DRGs were implemented.¹⁰

The State's recently released five-year plan continues to acknowledge the huge increase in AIDS cases and the need for new beds. Given the ongoing interest in downsizing hospitals, however, it is safe to anticipate that the State will attempt to reallocate existing beds rather than add new ones. A number of revealing actions in this direction have already been taken. First, the New York State Department of Health has issued emergency regulations to allow for the temporary certification of 500 "mothballed" beds in New York City. But the fate of these 500 beds remains much in doubt. To date only about 10 percent have actually been brought on line, with the others apparently stymied by staffing shortages. There are also some beds in the under construction.

Second, the State has begun to look at Veterans Administration (VA) hospitals around the City, which have relatively low occupancy levels. The New York State Department of Health recently drafted a memo instructing hospitals to check on the veteran status of in-patients and, where feasible, to transfer veterans to VA hospitals. The VA has responded by demanding Medicaid funds to handle the extra cases. The outcome of this struggle is unclear. However, if the State is successful, the federal share of the burden would increase somewhat.

Third, the State will continue and perhaps step up its efforts to reduce hospital utilization through regulatory and reimbursement mechanisms; such a reduction was the major purpose of the all-payor DRG system. Undoubtedly, hospitals will also continue to be pressured to discharge patients sooner, to perform more surgery on an outpatient basis, and to reduce or delay admissions for discretionary procedures.

Finally, a certain number of beds can be effectively returned to service by providing more staff. About 4 percent of New York City's medical/surgical beds are out of service due to a critical shortage of nurses and other health care workers.¹¹ Despite the demand, some hospitals have had to reduce admission levels because of the acute shortages. In addition, recent regulations have reduced the long hours interns and residents work, a measure which was designed to enhance quality of care but which also reduces available staff in the hospital.

The shortage of health care workers has its roots in some fundamental demographic and societal changes.¹² Solving the problem will require major initiatives including economic incentives, redefinition of functions, and scholarship programs. It may also require an overhaul of the City educational system in order to increase the number and quality of high school graduates.

The State faces some very tough choices. Given the great uncertainty about future resource needs, it must decide whether to stay the course on downsizing New York City's hospital system or accept the need to change in response to recent ominous trends. Any decision is a gamble because we don't know for sure whether the upward trends in utilization are an aberration or a reflection of protracted need in New York City. Faced with such uncertainty, there will be a strong temptation to take a wait-and-see approach. Given the lead time required to increase the capacity of New York City's health care system, however, this would be unwise. Instead, the State should intervene now to assure that adequate hospital beds are available to meet projected need.

Hospitals in New Jersey

New York's hospital crisis may appear to overshadow the problem in New Jersey where there is no comparable bed shortage. However, AIDS has created a serious strain on New Jersey's hospital system.

In New Jersey, where inner-city hospitals in Newark, Paterson, and Jersey City provide services to a disproportionate number of AIDS patients, AIDS has added a layer of unexpected cost. According to the Community AIDS Needs Assessment, 72% of these cases are found in the five most densely populated counties--Essex, Hudson, Bergen, Passaic, and Union, though Middlesex and Monmouth Counties are now reporting well over 200 cases each.¹³ The New Jersey Hospital Association has stated that some inner-city hospitals regularly have a daily census of over fifty patients with AIDS, in addition to the hundreds of outpatients who are also receiving care.¹⁴

This problem is compounded by the fact that roughly 80% of these AIDS patients are indigent drug users and their sexual partners. These patients generally do not enter the health care system until they are too sick to be placed in units with ordinary levels of nursing care and they often require more hours of nursing care than the average medical-surgical patients. Care for these indigent AIDS patients not only requires extra financial resources, but also affects the recruitment and retention of practitioners and health care workers who are already in short supply. In addition, absent equitable reimbursement mechanisms, a lack of long-term health care facilities and other support services, and the care needs of these indigent patients limit the ability of these hospitals to provide adequate services to other patients.

The "all-payer system" for hospital reimbursement in New Jersey has effectively reduced the "dumping" of patients, that is, referring them to other hospitals. In this system, the New Jersey Department of Health administers an Uncompensated Care Trust Fund that is financed by a uniform, state-wide add-on to all hospital bills. Public and private hospitals are reimbursed for care provided to all patients regardless of their

ability to pay. Nevertheless, AIDS-specific dumping, characterized by subtle discrimination practices and inappropriate referrals, does occur. Moreover, the Trust Fund does not cover the cost of physician's fees or the costs of subacute care.

Therefore, hospitals in Hudson and Essex counties are still struggling with the extraordinarily high cost of treatment. And although the "all-payer system" will be continued at least until 1990, it is possible that the rising costs of hospital uncompensated care (linked to an increase in AIDS-related care) may lead the legislature to replace it with a system that provides less certain access to hospital care.

Regulatory changes which place enormous burdens on the hospitals have already been instituted. For example, hospitals are now required to document a patient's financial status and to prove indigent status; they are required to provide social services that include efforts to insure that the patient has applied to Medicaid and that every effort has been made to obtain payment from the patient for any amount that is deemed appropriate. These procedures are burdensome for inner-city hospitals. Although it is ultimately to the advantage of the hospitals to help their patients obtain access to Medicaid, more often than not these hospitals cannot provide the required documentation because the patients being served are frequently impoverished, homeless, and difficult to locate.

Although New Jersey has no AIDS-specific diagnosis-related groups (DRGs), the Department of Health has approved a surcharge of \$600 per AIDS admission. However, these rates of reimbursement still do not take into account the particular characteristics of HIV-infected persons. Because the system operates on the basis of prospective hospital payments that are determined by a patient's admitting diagnosis (increased by \$600), they cannot take into account variables resulting from the clinical course of HIV infection. Some hospital officials claim that DRG rates of reimbursement are \$150-\$300 less than the actual costs per day incurred by a PWA. The episodic nature of HIV-infection requires more specific DRGs that accurately reflect the nature of the illness and the population being served. More specifically, DRGs, as they now exist, underestimate the cost of caring for HIV-infected individuals who are IV drug users, often homeless, and without recourse to any significant network of community support services.

The financial impact of AIDS on urban hospitals in New Jersey is exacerbated by the relative lack of long-term care facilities for persons with AIDS (see section on Long-Term Care). There are currently many patients in the system who meet normal discharge criteria but remain in acute care settings simply because there are no subacute facilities available.

Although there are currently a significant number of beds available in residential health care facilities (boarding homes with a minor nursing component), many of these

institutions are reluctant to admit HIV-positive individuals. Moreover, there are no reimbursement mechanisms that adequately fund these facilities.

The financial burden resulting from uncompensated care, linked to the increase in costs of AIDS-related care, combined with a reduction in Federal Medicare participation in the program, and the lack of long-term facilities, have created a cash-flow problem for hospitals that is expected to worsen as more individuals become hospitalized HIV-related illnesses.

- NOTES -

1. B. Vladeck, United Hospital Fund, "Social Morbidity and the Transformation of New York's Hospital System," President's Letter (July 1988): 1.
2. L. P. Myers, B. Spitz, B. C. Vladeck et al., New York City's Hospital Occupancy Crisis: Caring for a Changing Patient Population, Bigel Institute for Health Policy, United Hospital Fund (August 1988).
3. K. Raske, "AIDS Takes Its Toll on New York Hospitals," Health Week, 27 December, 1988.
4. B. Pasley and P. Vernon, "Health Care Resource Requirements for AIDS Patients in New York State: Acute Care 1987-1994," Paper presented at the American Public Health Association Annual Meeting, Boston, MA. 14 November, 1988.
5. Nassau-Suffolk Health Systems Agency, "Plan for a Comprehensive Response to HIV Infection and Related Diseases in Nassau and Suffolk Counties," Executive Summary (November 1988).
6. W. Winkelstein, M. Samuel, N. S. Padian et al., "The San Francisco Men's Health Study: III. Reduction in Human Immunodeficiency Virus Transmission among Homosexual/Bisexual Men, 1982-86," American Journal of Public Health 76 (1987): 685-689.
7. D. C. Des Jarlais, S. R. Friedman, D. M. Novick et al., "HIV-1 Infection among Intravenous Drug Users in Manhattan, New York City, 1988-1987," Journal of the American Medical Association 261 (1989): 1008-1012.
8. D. P. Andrulis et al., "Medical Care for AIDS Patients in U.S. Hospitals: 1987 Preliminary Report," Medical Benefits 5 (1988): 2-3.
9. E. Drucker and S. H. Vermund, "Estimating Prevalence of Human Immunodeficiency Virus Infection in Urban Areas with High Rates of Intravenous Drug Abuse: A Model of the Bronx in 1987," American Journal of Epidemiology (In press).
10. New York Business Group on Health, Inc, "Experience with DRGS in NYS," NYBGH Newsletter 8, no. 6: 1, 8.
11. New York State Department of Health, Bureau of Health Facility Planning, Recent Trends in New York City Hospital Utilization (January 1988).
12. New York State Department of Health, New York State Labor-Health Industry Task Force on Health Personnel, Report to the Commissioner of Health (Draft: January 1988).
13. The Community AIDS Assessment was prepared by the New Jersey Community AIDS Partnership Advisory Committee of the Community Foundation of New Jersey, January 1989.
14. New Jersey Hospital Association Statement on AIDS presented to The Assembly Health and Human Resources Committee of the New Jersey State Legislature, February 9, 1989.

Interview: "Robert"

"I went back to using drugs again because I didn't have no alternative. And it's sad man cause you're telling people, you know, I need help, I'm sick, and nobody wants to hear nothing."

Robert,* a 38-year-old man with AIDS, is a former IV drug user now living at Bailey House, a residence for homeless people with AIDS in New York City. For a bleak 13 months before moving to Bailey House, the former plumber lived on the streets or in a shelter on Wards Island, relying on soup kitchen meals to survive. Family support has been minimal: he is separated from his wife and while his brother and his aunt have each taken care of him at various stages of illness, his brother has his own family to support, and his aunt is elderly and unable to provide additional help.

The saga of Robert's illness began late in 1986, while he was enrolled in a methadone maintenance program. He learned that he was HIV positive while participating in a federally funded research project. Soon afterwards, he began to feel sick and was hospitalized with Pneumocystis carinii pneumonia.

Around that time, Robert was forced to drop out of the methadone program. The reason? The weekly charge of \$25 had simply become unaffordable. Robert found his way to the Human Resources Administration where he applied for Medicaid. With proof of application, he was permitted to re-enter methadone maintenance. But as months dragged on with no action on his Medicaid application, one program administrator after another explained that without the promised coverage, Robert would have to go in search of a new program. Ultimately, he was forced to leave methadone maintenance altogether. -- and return to using IV drugs.

I constantly went from program to program and spent 2 or 3 months at a time until they found out I didn't have any Medicaid and they kicked me off again. I went back to using drugs again because I didn't have no alternative. And it's sad man cause you're telling people, you know, I need help, I'm sick, and nobody wants to hear nothing.

Much has been written about the health and social service bureaucracy and the difficulties that disenfranchised persons have in accessing care. The problem takes on a human face when a patient like Robert describes his 13-month wait for a Medicaid card:

* The name in this and all the other patient interviews have been changed to protect confidentiality.

The problem was this. Some kind of way in the computer it said that I had a [Medicaid] card. But I never had a card; I never had Medicaid. So what happened was that then they found out that it was true I didn't have a card, didn't have Medicaid. But there was no way for them to get my number out of the computer to give me a permanent card.

So listen to this. This is good. So in turn they couldn't even give me a temporary card because by giving me a temporary card then every time they applied for a permanent card the permanent card would be no good because the temporary card overrides the permanent card. So I went in this circle for a long time. I couldn't get a card. I was sick; I needed hospitalization and couldn't get it. I needed a doctor's appointment and couldn't get it. I needed an operation-- I still need it--haven't got it. I just got glasses I needed. I need my dentures fixed. I mean I got a hundred things wrong with me because of this AIDS and I couldn't get anything. All I kept getting was the run around. I got kicked off the methadone program because I didn't have Medicaid.

People work hard, get themselves on a program, getting their lives together and then the program says we gotta kick you off for no payment. [The program] tells you you are entitled to Medicaid. You go to Medicaid and then they tell you you already have Medicaid and they give you a run around for this, for that, for this. And in the meantime you say I've been on this [methadone] program for five years drinking methadone every day; these people are talking about putting me off in two weeks. No help. Nobody to go to. I had to stay out of the program until I got a Medicaid card.

Today, life has brightened somewhat for Robert. He is back on methadone maintenance and appears to be healthy. Since July 1988, he has been living at Bailey House, where he was referred by one of his counsellors. His 14-year-old daughter and his estranged wife have both tested negative for HIV infection. Still, other hassles loom ahead: currently, Robert is trying to use his Medicaid coverage to pay for the dentures he needs. Although Medicaid will cover them, he was told that "special permission" is required and he is understandably anxious about maneuvering through the bureaucracy once again.

Much needs to be done to meet the health and social service needs of persons with AIDS, according to Robert, who says:

Right now I think the main thing we have to do is speed up the whole process people have to go through to get help. When you tell people to come to you for help but you run them back and forth, the person gets disgusted and refuses the help.

Chapter 2

Long-term Care: A Long-term Commitment

"Long-term care concerns the details of the life and death of people in this country...long-term care is not about placements, cases, and target groups but about people, their families, their communities, and their lives."

(Kane and Kane, 1987)¹

"We pray our way in and we pray our way out."

(Plight of the Home Care Workers, 1988)²

A person with AIDS (PWA) suffers from a chronic illness characterized by progressive deterioration of the immune system, likely neurological impairment including dementia, a bewildering variety of opportunistic infections, and malignancies. From the time AIDS diagnosis occurs, generally after an individual has a significant bout of illness, median survival is about one year.³ However, new therapies are rapidly improving survival rates,⁴ leading to growing need for long-term, chronic care. When they are not hospitalized, AIDS patients often remain fairly ill with a number of medical problems.⁵ These problems can be met by a range of services that can be delivered at home (if there is a suitable home) or in non-acute facilities.

It is easy to misunderstand long-term care, since even the language we use to describe it is murky. The phrase "long-term care," with its emphasis on duration, tells us little. "Nursing home" is a misleading term, since most facilities have few nurses and are not much like home. Nor do any of the technical terms, such as "skilled nursing facility (SNF)," "intermediate care facility (ICF)," "health-related facility (HRF)," or even "home care" tell us much.

Though the demographic characteristics of AIDS patients (mostly young, mostly male, often minority) are 180 degrees opposite from the usual recipients of long-term care (mostly elderly females over 75 years of age), there are some striking similarities in long-term care needs.⁶ Most such care (whether in the patient's home or in an organized facility) emphasizes assistance with the basics of daily life, including eating, cleaning, cooking, and going to the bathroom. Symptoms such as fatigue, weight loss, diarrhea, fever, shortness of breath, and difficulties with mental functioning often make it difficult to perform these tasks. Many people with AIDS, like many of the elderly,

receive help from friends, relatives, or neighbors and never enter the health care system at all. Others are cared for by specially trained paraprofessionals.

Another dimension of long-term care reflects the development of sophisticated medical technology over the past decade. Many patients can now receive relatively intensive medical services at home, including 24-hour nursing care, intravenous therapy, and oxygen therapy,⁷ thus avoiding hospitalization while receiving the care they need. AIDS patients and the elderly also both have medical needs, such as nutritional support, guidance in taking medication, and monitoring that can be provided outside the hospital environment.

PWAs entering long-term care must choose between two basic philosophies of care: rehabilitative and palliative.⁸ Unlike rehabilitative care, which involves active treatment to restore strength and functional capacity, palliative or hospice-like care emphasizes the relief of pain, physical discomfort, and mental anguish. If palliative care is elected, the goal of therapy is only to "provide relief from pain, depression, agitation, or psychosis."⁹ For PWAs, who are generally young men or women in the prime of life, the desire to continue living is very strong. Therefore it is very difficult for young people to embrace the hospice philosophy. Many PWAs also hold out great hope that one of the many avenues of research underway will lead to a breakthrough, and so they don't want to "give up." The choice between rehabilitative and palliative care is therefore only appropriate as part of a spectrum of choices.¹⁰ No patient or care partner should ever be pressured into opting for hospice, a decision that involves a human being's most basic rights.

Whatever long-term care services PWAs select are generally provided by homecare attendants or nursing home aides. A study of home care services in Los Angeles found that the average PWA used nearly 50 hours of attendant services for every hour of professional nursing.¹¹

How are AIDS Patients Receiving Long-term Care Now?

The three basic approaches to long-term care are care in the home, care in residential health care facilities, mainly nursing homes, and supported housing, although day care and adult foster care also need to be developed as part of the family of available services. Despite the demand, and despite some exemplary models, most of the need for long-term care is not being met. The table gives an indication of just how great the gap is between need and availability in long-term care services in New York City.

LONG-TERM CARE FOR PERSONS WITH AIDS IN NEW YORK CITY: NEED VS. ACTUAL SERVICES

	<u>Nursing Home Beds*</u>	<u>Supported Housing Units*</u>	<u>Home Care Average Daily Clients**</u>
<u>Currently provided:</u>	126	66	400
<u>Projected need:</u>			
End of 1989	600	1,280	1,370
1990	740	1,590	1,638
1991	910	1,930	1,922
1992	1,060	2,280	2,219
1993	1,220	2,640	2,517

Sources:

* Projections are from the New York City AIDS Task Force.

** Projections are based on AIDS: New York's Response (The 5-year Interagency Plan).

Without even considering future projections, the State's estimates of the current need for nursing home beds (600) exceeds what is now available by 474 beds. The State's estimate of 1,370 PWAs currently needing home care exceeds by nearly 1,000 the number being served by formal programs. While 1,280 PWAs need supported housing now, only 66 units are actually provided (about 5 percent of need). Some long-term care needs are currently being met by hospitals because of the lack of alternatives. At a time when overcrowding has reached critical levels in New York City, any unnecessary use of beds is a serious problem. Some of the gaps in formal care are also being met informally by friends, relatives, neighbors, and other volunteers. By the end of 1993, the situation will be worse: to meet expected needs we must increase the availability of nursing home beds tenfold, housing units fortyfold, and home care services sixfold.

Services that are available to PWAs today come from a handful of sources. Only two of New York City's 147 nursing homes -- Coler Memorial and Goldwater Hospitals, which are part of the City's Health and Hospitals Corporation -- currently

have beds for PWAs. With a total of 52 dedicated skilled nursing facility beds, this is by far the largest such undertaking in the country. At Coler, 89 percent of the PWAs are male, 43 percent are black, and 32 percent are Hispanic. More than 80 percent have a history of intravenous drug use.

The Coler/Goldwater experience in providing long-term care services to AIDS patients since 1985 was recently described in the first published account of nursing home services to PWAs.¹² The authors address the issues of which patients are most appropriate for placement in a long-term care facility; the special training and staffing that is required to care for these patients; and the differences between caring for AIDS patients and other chronic care patients.

A one-day survey of 17 PWAs at Coler illustrates the broad range of care needs that a residential health care facility is asked to meet. The survey found five patients requiring isolation, four on tube feeding, five with herpes simplex, five with disseminated mycobacteria, four with pulmonary tuberculosis, four with pneumocystis pneumonia, one with Kaposi's sarcoma, one with meningitis, one with disseminated candidiasis, two with toxoplasmosis, two with cryptococcoses, and two with cytomegalovirus. Fifteen of the 17 patients suffered from some form of dementia, seven were on psychotropic drugs, nine were receiving psychiatric treatment, and 12 were being treated by neurology.¹³ Clearly, service demands go beyond what is available in most nursing homes.

In New Jersey, as in New York City, long-term care has been the most difficult part of the continuum of care to establish.¹⁴ Several programs and/or facilities designed to address this need are in various stages of planning.

The Wanaque Convalescent Center in Wanaque, New Jersey, will provide 120 skilled nursing beds for PWAs in the near future. Ten to 21 beds are currently being occupied by PWAs and the remainder will slowly be filled at a rate of about 8 beds per month. When the plan was first announced in April 1988, it was challenged by local residents and officials from Wanaque as well from neighboring Bloomingdale, Pompton Lakes, and Ringwood.¹⁵ However, the challenges failed. The facility is being reimbursed (through Medicaid) at a rate of approximately \$350 per day, about three times the normal skilled nursing home rate, and almost twice the normal rate for "heavy duty" rehabilitative skilled nursing. However, at the end of April 1989 there will be an audit. If the rate of reimbursement is found to be too high, it will be cut to reflect more costs more accurately.

Other attempts to place PWAs in nursing homes have not been successful. Plans for a Newark Nursing home run by Continental Affiliates of Englewood Cliffs were dropped because of opposition from both the Mayor's Office and the City Council.¹⁶

The Department of Health is also attempting to encourage nonprofit and private entities to provide residences for people with AIDS. The Jersey City Medical Center in Jersey City, has already announced its intention to open a 40 bed sub-acute facility for Hudson County residents within its current building. While the medical center does not preclude taking AIDS patients from outside Hudson County, the emphasis will be on taking care of local need, with priority going to the medical center's patients.¹⁷ This project was initiated jointly by the hospital and a private firm, Stopwatch, headed by former state health commissioner Dr. J. Richard Goldstein. Anthony Cucci, the Jersey City Mayor, supports the plan. The project has received a certificate of approval from the New Jersey Department of Health and is ready to be implemented.

Five hospitals in Newark including University Hospital, United Hospitals, St. Michael's Hospital, Beth Israel Hospital, and Columbus Hospital, have formed a consortium to create a series of facilities for PWAs. The first step is intended to be a sub-acute facility located in or near one of the hospitals. Also on the drawing board are outpatient clinics, congregate and scatter-site housing, and respite and hospice facilities.

The facilities will be managed by a new incorporated entity under the direction of Marc Lory, current Chair of the consortium and Vice President and CEO of University Hospital in Newark. It is intended to serve all Newark, and it apparently has the backing of the Newark city government which includes the Mayor and the City Council. Discussions have begun with the New Jersey Department of Health, which is being supportive but as yet nonspecific in discussions of licensing and funding. No discussions have taken place with Medicaid officials.

Although the programs mentioned above are beginning to provide long-term care in New Jersey, the number of PWAs in need of long-term care continues to rise at an alarming rate. Many more programs and facilities will have to be designed to address this need.

Home care to PWAs in New York City is primarily provided by the Visiting Nurse Service (VNS), which has a contract with New York City's Human Resources Administration (HRA) to serve Medicaid patients. As of December 1988, the caseload of Medicaid clients with AIDS was 367. The VNS/HRA AIDS Home Care Program provides a wide range of services, including home attendants, home health aides, rehabilitation therapists, and nursing visits. The program is designed to accommodate the level of service to fluctuations in a client's condition. Some patients with private insurance also receive services from HRA/VNS but many insurance policies either fail to cover or severely limit coverage for home care.

In addition to VNS, a number of Certified Home Health Agencies (CHHA) provide some home care services to PWAs, although not in large volume. One CHHA

serving Manhattan, Brooklyn, and Queens provided services to 19 cases in 1987. Another CHHA in New York City provided services to 54 cases in 1988.

The issue of how to care for PWAs who lack appropriate housing is a controversial one. In projecting future needs, the State's methodology prioritizes the lowest level of care, meaning that if home care is possible, the patient is assigned to home care even if there is no home. In so doing, the State makes the assumption that housing for homeless PWAs will be provided so that they can be served by home care. In practice, however, nursing home construction seems likely to proceed more rapidly than the development of housing for PWAs. Currently, the AIDS Resource Center's Bailey House with 44 beds and about 22 scatter-site apartments in New York City provide the only available supported housing units. As a result, the State may end up placing homeless PWAs projected to be served by home care in nursing home beds instead. This could double or triple the volume of such beds anticipated by the State's plan and deny PWAs access to more appropriate care through supported housing.

Hospices represent a final long-term care option. The Ritter Scheuer Hospice in New York City has been providing care to PWAs since 1986. As of January, 1988 this hospice had served 62 PWAs whose average stay lasted 35 days. Unlike the traditional mix of hospice care which (according to federal reimbursement rules) consists of 80 percent home care and 20 percent institutional care, Ritter Scheuer found the AIDS hospice care was 91 percent institutional care and only 9 percent home care.¹⁸

Home and Community-Based Services Waiver in New Jersey

Beginning in March 1987, New Jersey received a federal waiver from Medicaid regulations that permitted the Department of Human Services to provide, in addition to the usual Medicaid services, community-based case management, skilled nursing in the home, personal health care assistance in the home, medical day care, provision of drug use treatment in the home, residential placement for treatment, and increased reimbursement for family-based foster care. The program is available to persons who have diagnoses of AIDS or advanced ARC, who have a maximum monthly income of about \$1,050, and who are qualified for nursing home level of care under Medicaid principles as well as for HIV-infected children up to the age of two. It is a three-year waiver program with 350 slots in year 1, 650 in year 2, and 1,000 in year 3. All these slots have not been filled. As of March 17, 1989, there were 349 participants in the program; 713 persons had participated in the program to that date.

Although the home and community based waiver program can potentially provide badly needed care to PWAs in their homes, there are several problems: (1) The program has had difficulty recruiting and training personnel, primarily nurses and home health aides; the program has resisted efforts, thus far, to provide enhanced reimbursement for these services. (2) Many of the individuals who could benefit from

the program cannot participate because they have no housing. The services can only be provided in a home. (3) The program requires that a participant who receives private duty nursing also have a primary care giver who lives with the patient (private duty nursing is provided for a maximum of 16 hours per day). Some potential recipients of services are ineligible for this reason. (4) Many individuals who are IV drug users are difficult to locate and follow because they have no permanent housing. (5) Although the program has made some significant improvements to expedite the process to determine eligibility, some hospital personnel and program officials are still concerned about the excessive paperwork required to establish eligibility.

The components of the Home and Community-Based Services waiver can help individuals with AIDS remain in their communities for a longer period of time. Because the goal of the program is both compassionate and pragmatic (hospital care is much more expensive), the Department of Human Services should conduct a formal evaluation of the program. This evaluation would help to identify and resolve programmatic problems, and might be a guide to other states considering the waiver.

The Quality of Long-term Care

As we began to write this section, The New York Times reported that a sad chapter in New York State history ended with the payment of the last \$1.4 million installment by Bernard Bergman's estate of the fines he incurred in the nursing home scandals that were first reported 15 years ago.¹⁹ The article was an important reminder of how bad things can get but also a recognition of how far we have come. The same article pointed out that federal auditors recently found the quality of New York State's nursing homes better than that of most other states. Still, as we gear up to construct hundreds of nursing home beds for PWAs, many of whom are very poor and politically powerless, we must remember the lessons of the Bergman era and build in the standards and enforcement mechanisms that will assure excellence.

The difference between good and poor quality nursing home care is based on many factors, both tangible and intangible. The physical environment should be comfortable, unrestricted, and pleasant.²⁰ Access to a physician is vitally important for all nursing home patients but perhaps especially for PWAs. Yet as Linda Aiken states, "physicians participate very little in nursing home care."²¹ According to her research, only 8.3 percent of all doctors make any nursing home visits at all and those who do average only 1.5 hours per month.

Even access to a nurse can be a problem since most skilled nursing facilities (SNFs) lack 24-hour-a-day RN coverage. The average SNF has a ratio of one nurse to 49 patients, which amounts to 15 minutes of nursing care per patient per day.²² Misuse and over-use of medications remain serious problems in nursing homes.²³ Over-use of psychoactive drugs for behavior control, the use of inappropriate drugs, and the administration of medicines by inadequately trained nurses' aides are the most

commonly noted problems.²⁴ Since PWAs often have multiple prescriptions, some for new, experimental drugs, the need to monitor this component of care is crucial. It should also be stressed that in any nursing home (or home care) program that is not exclusively a hospice, PWAs must have access to clinical trials and experimental therapies.

Careful monitoring of quality is also important in providing home care. In our haste to discharge AIDS patients from the hospital we must be careful not to swing too far in the direction of "quicker and sicker."^{25, 26} A thorough clinical assessment should be part of any decision to discharge a patient to home care. With 60,000 New Yorkers receiving care at home,²⁷ it is difficult to monitor or regulate quality of care, but the establishment of AIDS-specific standards, surveillance, and follow-up of complaints are a minimal part of any effort to expand home care.

New York State's Initiative for AIDS Nursing Homes

In July, 1988, New York State issued new regulations intended to "encourage development of high quality services and facilities for PWAs who need institutional alternatives to the hospital."²⁸ These may be skilled nursing facility beds or less intensive health-related facility beds and can be part of an existing facility or a separate AIDS nursing home.

The regulations specify that enhanced reimbursement rates will be available for care of persons with AIDS, ARC, or other symptomatic HIV illnesses. The enhanced reimbursement is quite generous since it first assigns PWAs to a high-paying Resource Utilization Group (RUG) and then adds to that payment a sum equal to the amount paid for the average nursing home patient. Thus payment is two or three times the average rate. This approach appears to be attracting nursing home operators. Terence Cardinal Cooke Health Care Center will soon open an AIDS HRF on the Upper East Side of Manhattan. The Village Nursing Home, Bronx-Lebanon Hospital, Samaritan House, and Brookdale Institute have reportedly applied to license nursing home beds for PWAs.²⁹

In addition, capital financing is being developed. The State of New York Mortgage Association will insure bonds to raise \$8.5 million to construct a five-story nursing home in New York City. Shearson Lehman Hutton is managing the issue, and the New York State Medical Care Fair Financing Agency (MCFFA) is issuing the bonds. The MCFFA is also trying to add 800 to 1,000 beds by raising \$80 to \$100 million through tax-exempt bonds.³⁰

The National Council of Health Facilities Finance Authority has called New York State's efforts to obtain capital financing for AIDS exemplary, but New York's efforts have been frustrated by federal intransigence, specifically the refusal to raise the

\$150 million ceiling on tax-exempt debt, which precludes many of New York City's teaching hospitals from financing needed AIDS non-acute care. The federal government has also refused to allow the State to pool the bond issues for 12 AIDS facilities. Presently, HUD approves mortgages one by one, which creates unconscionable delays.³¹

In the field of home care, the State has developed enhanced Medicaid reimbursement rates (30 percent above average) for CHHAs providing home nursing to PWAs. But there is no special rate for attendants' visits, which are reimbursed on an hourly basis and make up the vast majority of AIDS care. The suggestion that higher reimbursement rates be paid to home care workers for visiting AIDS patients has received no City or State response. Whether or not differential wages (a kind of combat pay) for AIDS care is supported, the broader issue of low wages for home care workers needs to be addressed. Ninety-three percent of these workers are black women, and their average salary does not even raise them above the poverty line. Every day these women care for 60,000 disabled New Yorkers, often under extremely difficult circumstances, yet they are among the most undervalued workers in our society. Not surprisingly, turnover is very high; a job in a fast-food restaurant often pays more and is more dependable.

With the emphasis now being placed on the need for home care for PWAs, we must remember the burdens that fall on workers who cannot earn enough to make ends meet in their own homes. A statement by David Gould of the United Hospital Fund made the point very well: "We can no longer call for and design a system of high quality home care services and ground it on a foundation of minimum wages, marginal benefits and dead-end jobs."³²

Will Providing Long-term Care be Cost Effective?

On the surface, long-term care saves money. One day in a nursing home costs \$100, while a single day of hospitalization costs \$800. In fact, though, studies of care for the elderly have shown that long-term care fails to decrease costs significantly and sometimes actually increases them. Similar findings have resulted when nursing home services were substituted for hospital services, and when home care services were substituted for either nursing home or hospital services.^{33, 34, 35} After reviewing a number of such studies W. G. Weissert concluded that long-term care is "a complement not a substitute" for hospitalization³⁶ because it is very difficult to channel services only to those currently receiving acute care. Inevitably, people in the community with unmet needs also find their way to the new services.³⁷ Studies have also found that hospitalized patients ready for discharge incur costs much below the average for hospital care. Such patients use only about 24 percent to 30 percent of average daily hospital resources.³⁸

Though a substantial body of research indicates that long-term care does not reduce hospital use or lower costs, the belief that it would do so for AIDS patients has long been almost an article of faith. Probably the major reason for this has been the shorter lengths of stay in San Francisco hospitals, where community care is more prevalent. But as A. E. Benjamin points out, "It is one thing to show that San Francisco has more AIDS community care and shorter hospital stays but quite another to demonstrate empirically that there is a cause and effect relationship."³⁹ Moreover, though there may initially have been more out-of-hospital AIDS care in San Francisco than in New York City,⁴⁰ it is not clear that this remains true today. In 1988, New York City served considerably more AIDS patients in nursing home beds than San Francisco. In home care, San Francisco had an average daily census of 80 clients in 1988; New York City's HRA/VNS program served more than 300 per day.⁴¹ And the Shanti project's 48 supported housing units in San Francisco are fewer than the 66 units of the AIDS Resource Center in New York City. But as New York City moves ahead of San Francisco in providing long-term care for AIDS patients we should not expect hospital stays and costs to drop to anything like San Francisco levels.

Both the City and State are depending on the notion that providing long-term care to PWAs will substantially reduce the per-patient use of the hospital and thereby decrease costs. Though there may be such an effect on a small scale, it is not something we can depend on in our planning.

What Should Be Done?

On any given day, 186,000 New Yorkers are served by long-term care programs of one kind or another. But the existing system has absolutely no slack. Nursing homes in New York are full. Waiting lists are long. The availability of supported housing is minimal. Formal home care programs do not meet current needs, let alone needs projected for the future. And even if there were no AIDS epidemic, projected growth in the elderly population would create a need for 11,000 new long-term care slots in the next few years.⁴²

PWAs are not an easy client population to serve. Few have private insurance. Care needs are complex. Many have a history of IV drug use. Some, despite their illness, continue to use and engage in drug trafficking. To a nursing home operator or a home care administrator with a clientele consisting mainly of elderly women, the prospect of adding all these difficulties to their daily list of problems may be a considerable deterrent. Even the promise of increased reimbursement for nursing home care to PWAs has only brought in nursing home operators like the Archdiocese and some hospitals that are already familiar with AIDS. Most existing nursing home operators have decided not to open their doors to PWAs, even at reimbursement rates two to three times average rates.

To generate the needed home care capacity will require financial investment, but dollars alone are not sufficient. Leadership and innovation are also needed. For example, to provide home care to PWAs, home care workers will need more support -- not just financial, but also added security from escorts, better supervision, and help with management of the case. To increase availability of nursing home care for PWAs, government regulations should be made flexible, with an eye toward encouraging participation and innovation while setting high standards of quality. Construction of long-term care facilities which had been planned primarily for the elderly should be expedited if we are to avoid a crisis in home care analogous to the one we are experiencing in acute care today.

Nursing home operators and home care agencies should do their share, but they must be provided with technical assistance to handle the special problems of this population. They also need to be assured that the State and City are making a long-term commitment and will not lose interest in the issue after the beds are built. New York has accomplished a great deal in long-term care over the years. We came through the nursing home scandals and greatly improved industry standards. We have led the nation in the provision of home care services to the elderly. We now have an opportunity to set an example for the nation in providing home care to PWAs.

- NOTES -

1. R. L. Kane and R. A. Kane, Long-Term Care: Principles, Programs and Policies (New York: Springer Publishing Co., 1987).
2. New York City Office of the President of the Borough of Manhattan, Plight of the Home Care Worker: Report of the Manhattan Borough President's Hearing on April 29, 1987. (New York: January 1988).
3. R. Rothenberg, M. Woelfel, R. Stoneburner et al., "Survival with Acquired Immunodeficiency Syndrome: Experience with 5833 Cases in New York City," The New England Journal of Medicine 317 (1987): 1297-1302.
4. T. Creagh-Kirk, P. Doi, E. Andrews et al., "Survival Experience Among Patients with AIDS Receiving Zidovudine," Journal of the American Medical Association 260 (1988): 3009-3015.
5. D. Werdegard and J. Amory, AIDS in San Francisco: Status Report for Fiscal Year 1987-88 and Projections of Service Needs and Costs for 1988-93 (San Francisco: San Francisco Department of Public Health, 22 April, 1988).
6. A. E. Benjamin, "Long Term Care and AIDS: Perspective from Experience with the Elderly," Milbank Quarterly 67 (1989).
7. J. Fuller and G. Gordon, "Home Health Care Takes on a New Role," Business and Health (November 1988): 34-35.
8. N. Rango, "Nursing Home Care for Persons with AIDS," in David E. Rogers and Eli Ginzberg eds., The AIDS Patient: An Action Agenda (Boulder and London: Westview Press, 1988): 35-41.
9. Ibid.
10. New York City Interagency Task Force on AIDS, New York City Strategic Plan for AIDS, (New York: New York City Department of Health, May 1988).
11. J. Little, S. Daley, A. Long, and H. Fortson, AIDS Home Health, Attendant or Hospice Care Pilot Study -- April 1, 1986 to May 31, 1987 (Los Angeles, CA: AIDS Project Los Angeles (prepared for the Office of AIDS, California Department of Health Services), January 1988).
12. N. Afzal and A. Wyatt, "Long Term Care of AIDS Patients," Quality Review Bulletin 15 (1989): 20-25.
13. New York City Interagency Task Force on AIDS, New York City Strategic Plan for AIDS. (New York: New York City Department of Health, May 1988).
14. Richard Conviser, Stephen Young, "Providing and Funding a Continuum of Care for People with AIDS: An Update," prepared for the Public Health Plenary Session, Southern Health Association and Virginia Public Health Association Meetings, Richmond, May 5, 1988.
15. "Wanaque Says it has Legal Grounds to Bar AIDS Care at Nursing Home," The Star Ledger, April 7, 1988.
16. "40-Bed AIDS Facility Planned in New Jersey," The Star-Ledger, April 11, 1988.

17. Ibid.
18. W. Bulkin, L. Brown, D. Fraioli et al., "Hospice Care of the Intravenous Drug User AIDS Patient in a Skilled Nurse Facility," Journal of Acquired Immune Deficiency Syndrome 1 (1988): 375-380.
19. S. Roberts, "Bergman Legacy: \$1,376,032 Check and 110 Auditors," The New York Times, 13 February, 1989: B1.
20. N. Rango, "Nursing Home Care in the United States," The New England Journal of Medicine 307 (1982): 883-889.
21. L. H. Aiken, M. D. Mezey, J. E. Lynaugh, and C. R. Buck, Jr., "Teaching Nursing Homes: Prospects for Improving Long-Term Care," Journal of the American Geriatrics Society 33 (1985): 196-201.
22. Ibid.
23. R. L. Kane and R. A. Kane, Long-Term Care: Principles, Programs and Policies (New York: Springer Publishing Co., 1987).
24. M. Beers, J. Avron, S. B. Soumerai et al., "Psychoactive Medication Used in Intermediate-Care Facility Residents," Journal of the American Medical Association 260 (1988): 3016-3020.
25. A. M. Smith, "Alternatives in AIDS Homecare," AIDS Patient Care 1 (1987): 28-32.
26. A. E. Benjamin, "Long Term Care and AIDS: Perspective from Experience with the Elderly," Milbank Quarterly 67 (1989).
27. United Hospital Fund, Home Care in New York City, Providers, Payors and Clients.
28. New York State Department of Health, Memo #88-63, and New York State Code of Rules and Regulations, Amendments to Subpart 86-2 of Title 10.
29. Greater New York Hospital Association, Status of Plans for Long-Term Care Beds for AIDS (1988).
30. J. Nemes, "Agency To Insure Bonds For AIDS Facilities," Modern Healthcare 46 (23 December, 1988).
31. S. P. Palm, "Bond Pool Would Help Build AIDS Facilities," Modern Healthcare 56 (24 June, 1988).
32. New York City Office of the President of the Borough of Manhattan, Plight of the Home Care Worker: Report of the Manhattan Borough President's Hearing on April 29, 1987 (New York, January 1988).
33. S. C. Hedrick and T. S. Inui, "The Effectiveness and Cost of Home Care: An Information Synthesis," HSR: Health Services Research 20 (1986): 852-880.
34. C. J. Newschaffer, "The Future Demand for RNs in Home Care: An Examination of Issues and Projections," in U.S. Department of Health and Human Services, Secretary's Commission on Nursing: Support Studies & Background Information, Volume II (III-1 to III-5) (Washington, DC: U.S. Government Printing Office, December 1988).
35. W. G. Weissert, C. M. Cready, and Pawelak, "The Past and Future of Home-and Community-based Long-term Care," The Milbank Quarterly 66 (1988): 309-389.

36. W. G. Weissert, "Seven Reasons Why It is so Difficult to Make Community-Based Long-Term Care Cost-Effective," Health Services Research 20 (1985): 423-433.
37. P. Kemper, R. Applebaum, and M. Harrigan, "Community Care Demonstrations: What Have We Learned?" Health Care Financing Review 8 (1987): 87-100.
38. A. Hochstein, "Treating Long-Stay Patients in Acute Hospital Beds: An Economic Diagnosis," The Gerontologist 25 (1985): 161-165.
39. A. E. Benjamin, "Long Term Care and AIDS: Perspective from Experience with the Elderly," Milbank Quarterly 67 (1989).
40. P. S. Arno and R. G. Hughes, "Local Policy Responses to the AIDS epidemic: New York and San Francisco," NY State Journal of Medicine 87 (May 1987): 264-272.
41. AIDS in San Francisco: Status Report for Fiscal Year 1987-88, HRA/VNS Homecare data (Unpublished: 1988).
42. New York State Department of Health, Office of Health Systems Management, New York State Long Term Care Need Methodology (Draft: November 1988).

Interview: "Noni"

"The bathroom in front of my door was piled up with human feces and it smelled terrible. Kids would be running around playing in all this stuff. I wasn't raised in filth like this."

Noni, a 34-year-old woman from Brooklyn, is not sure how she got AIDS. Perhaps, she says, it came from the time several years ago, when she was regularly sharing needles to shoot cocaine. Or, she may have become infected as a result of her sexual relationship with a bisexual man.

Regardless of the origins of her illness, Noni was diagnosed with AIDS in June 1988 and spent four months in the hospital receiving treatment for cryptococcal meningitis. Fortunately, she came under the wing of a trusted and helpful social worker who intervened on her behalf in the hospital and referred her to needed services when she was released.

Until her diagnosis, Noni had lived with her mother, but afterwards, the older woman was afraid to allow her daughter back home. Noni's social worker directed her to the Division of AIDS Services of the Human Resources Administration [HRA] in New York City, which provided assistance in her search for housing. But the HRA's weekly subsidy of \$86 enabled her to afford only a series of squalid, drug-infested hotels. Weakened by AIDS and desperately trying to control her occasional crack use, she was constantly exposed to drugs in an environment she describes as "filthy," "unsanitary," and filled with "sickness." She describes one of these hotels as follows:

The hotel should be reported 'cause it's a health hazard. It had big rats running around. It had roaches. It had bathrooms that were filthy. The elevators looked like a dungeon. They give you old, rusty mattresses which look like they had bugs. The bathroom in front of my door was piled up with human feces and it smelled terrible. Kids would be running around playing in all this stuff. I wasn't raised in filth like this.

Most recently, Noni has moved to another hotel, which is less squalid than some of the others but still "a dirty, dirty place," where she must contend with drugs and violence. While she dreams of her own clean apartment, she has found a cheerful and secure environment at the Day Care Program of the Village Nursing Home, which is specifically designed to meet the needs of persons with AIDS. Meanwhile, of course, the ravages of illness come and go. Prior to her most recent hospitalization, Noni was forced to wait in an emergency room for ten hours before receiving treatment. But she is not a complainer by nature -- it is only the sub-human housing conditions to which she has been exposed that spark great anger.

Chapter 3

An Expanded Role for Community-Based Organizations

In the early days of the AIDS epidemic, there was an enormous and unanticipated need for medical, public health, social, and educational resources. Local governments were unwilling or unable to provide this broad range of human and social services and in New York and New Jersey, as elsewhere in the country, an array of community-based organizations (CBOs) arose to fill the gap. CBOs -- generally defined as nonprofit, grassroots agencies that emerge to serve a particular and well-defined constituency -- have served persons with AIDS and their families in a number of vital ways, including:

- * Public health education
- * Psychosocial counseling
- * Practical support, particularly help with day-to-day activities such as cooking, cleaning, laundry, shopping and transportation
- * Home health care services
- * Housing
- * Government benefits advocacy
- * Legal protection, such as fighting employment and housing discrimination
- * Access to health care, including provider referrals, and access to clinical trials and experimental drugs

By providing a broad array of social services, CBOs play a pivotal role in promoting continuity of care and case management for large numbers of AIDS patients. The availability of community-based services allows many patients to remain outside hospitals or reduce their length of stay when medically appropriate. In addition, these services facilitate the care of patients at home by friends, family members, and health care personnel. The economic contributions of CBOs, as well as their impact on service provision, are thus critically important to patients, local health care systems and municipal governments. AIDS service organizations have relied heavily on volunteer labor since the inception of the epidemic. This approach has thus far worked relatively well in the gay community, although there are concerns about burnout, availability of volunteers, and long-term viability. In poor, minority neighborhoods, however, the use of volunteer labor in community-based organizations is significantly more problematic. Those CBOs which do provide services in these neighborhoods must rely primarily on paid staff, supplemented by a limited number of volunteers.

As AIDS spreads increasingly into poor communities, it will be important either to expand the funding of CBOs so that paid staff can be hired or to develop new models of care. In this section, we review the potential of community-based organizations as a means of delivering services in both the gay and the minority communities and probe the limitations of voluntarism.

The Role of Community-Based Initiatives

With the recognition that AIDS was disproportionately affecting gay men, the gay community galvanized its resources to create self-help voluntary organizations such as the Gay Men's Health Crisis in New York and the Hyacinth Foundation in New Jersey. Building upon human rights movements of the 1960s and 1970s, gay men were able to organize politically and financially in a way that less cohesive groups at risk, such as intravenous drugs users (IVDUs), were not.

The need for and success of these voluntary organizations have been demonstrated repeatedly. In San Francisco, for example, the extensive development of outpatient services, which rely on volunteer-supported CBOs, has helped reduce unnecessary use of the hospital by AIDS patients.^{1,2,3} The gay communities of New York City and northern New Jersey have helped build effective educational, advocacy, and service organizations that annually provide hundreds of thousands of hours of direct services to persons with AIDS.⁴

However, the organization and administration of large volunteer networks require substantial financial support from public and private sources and significant commitments from a pool of volunteers, neither of which is assured in the future. It remains unclear whether current levels of voluntarism in the gay community can be maintained. Emotional burnout among paid and unpaid staff is an important operational issue in any volunteer organization but it is intensified among AIDS groups, whose staff members continually bear witness to the suffering and death of their colleagues and the people they serve.

Also threatening future provision of services is the fact that many of the first AIDS-specific organizations have functioned successfully only within their constituent group, which is mainly white, middle class, gay men. With a few notable exceptions, they have not been able to meet the needs of patients in minority communities. In 1987, for example, the Gay Men's Health Crisis added to its caseload an estimated 47 percent, 15 percent and 17 percent of New York City's newly diagnosed AIDS cases among white, blacks and Hispanics, respectively.⁵

As the epidemic shifts increasingly toward poor, inner-city communities, the demand for health and social services mounts. In neighborhoods already suffering from a host of other debilitating social problems, including poverty, unemployment, racism,

lack of adequate housing, educational opportunities, substance abuse and teenage pregnancy, AIDS does not always receive priority. The increasing numbers of women, children and IVDUs diagnosed with AIDS is creating complex new pressures on fragile family support systems, such as child care and foster care, which will intensify during the next few years. (For more information on this topic, see Chapter 5: "The Special Needs of Women, Children, and Adolescents.")

Housing is the most critical non-medical need of people with AIDS or HIV illness. The most common reason for inappropriate hospitalization of AIDS patients is the lack of adequate housing where outpatient care can be delivered. The extent of homelessness or precarious living arrangements is estimated to affect between 2,000 and 5,000 persons in New York City alone.⁶ A recent study of 174 hospitalized AIDS patients who are also IVDUs indicated that 40 percent are either homeless or precariously housed at the time of diagnosis and hospitalization.⁷ As more IVDUs become ill over the next few years, this will translate into thousands of individuals in need of housing. (For more information on this topic, see Chapter 4: "Housing, Homelessness, and the Impact of HIV Disease.")

Poverty and unemployment place severe restraints on the development of new community-based organizations or the expansion of existing CBOs in many minority neighborhoods. Volunteers in inner-city neighborhoods have traditionally donated their services mainly through their churches or political organizations; efforts to combat teenage pregnancy and juvenile crack use have recently received the greatest attention.

A few community-based groups, relying primarily on volunteer labor, have emerged to deal with AIDS in poor communities but the level of organizational development among these groups has not been on a scale necessary to meet the rising service needs. Self-help efforts among IVDUs and their sexual partners have also been slow to emerge. In addition to the health and social problems stemming from drug addiction, a number of other obstacles to internal mobilization exist. There is no tradition of collective self-organization and the very behaviors around which people might organize are illegal. Moreover, there is internal competition and conflict within the drug subculture.^{8,9}

One positive sign of change is that City, State, Federal and private dollars are increasingly available for AIDS, enabling a number of established organizations to broaden their programs to include AIDS-related services. Emmaus House, which works with minority homeless, and Covenant House, which helps adolescents, are two notable examples; other well-established social service agencies, including Lighthouse for the Blind and Cancer Care, now include individuals with AIDS or HIV-disease among their constituents and have begun to plan for the services they need. Human Service Agency Executives Concerned about AIDS, a coalition of mainstream and AIDS-specific groups, is facilitating this process.

Until the political and church leadership of the minority communities speak out forcefully on AIDS, however, the work of both established and fledgling CBOs is likely to be hampered. Political leaders have been fearful -- with some justification -- that representing AIDS as a minority issue will diminish the current level of public support for all AIDS programs. The stigma of homosexuality among blacks and Hispanics and the conservative values that permeate many of the churches in minority communities has also stifled indigenous support for AIDS work by CBOs.¹⁰

Although many black and Hispanic churches are active in the community, providing foster care programs, adult education, food, and shelter to impoverished individuals and their families, the leadership has failed to respond collectively to the AIDS crisis. According to Reverend John Vaughn, executive director of East Harlem Interfaith, "In Spanish Harlem we are at a point where the gay community was five years ago."¹¹ Although there is a growing willingness in Spanish Harlem to talk about homosexuality, cultural and theological traditions foster resistance, fear, and denial within the community as a whole. The refusal of many pastors to take an active role can often be directly linked to their fear of accusations that they are advocates for gays or gay themselves. Reverend Lee Wesley, executive director of the Minority Task Force on AIDS, has suggested that "homophobia" is the principal reason most church leaders are reluctant to take a more active stance in the AIDS crisis.¹² In addition, churches face an overwhelming number of other social problems on a daily basis and their modest resources are already stretched to meet the myriad other needs of their congregations.

The willingness of many churches to foster the work of AIDS-focused CBOs is thus contingent upon individual pastors and their particular theological and ideological beliefs. Some activists have played important roles in helping to build community-based AIDS initiatives and there are already some vital church-sponsored programs in place. Of particular note are the Lunch for Life Program at the Yorkville Pantry, the Upper Room AIDS Ministry, God's Love We Deliver, AIDS Interfaith, St. Peter's Momentum Outreach and Project Brave.

St. Peter's Momentum Outreach Program, serving approximately 400 persons with AIDS and their families, is the largest of these church-sponsored programs. It is primarily maintained by volunteers from St. Peter's Lutheran Church. With private sector support, mainly from the Robert Wood Johnson Foundation, this model program is being replicated at seven sites throughout the New York metropolitan area to provide food and supportive services to people with AIDS.^{13, 14} Another church-sponsored CBO, God's Love We Deliver, has grown significantly since it was founded in the summer of 1985; currently it delivers free gourmet meals daily to approximately 130 homebound persons with AIDS.¹⁵

Unmet Needs

One rough gauge of the need for additional AIDS-related health and social services was recently demonstrated by the national request for proposals issued by the Robert Wood Johnson (RWJ) Foundation's AIDS Prevention and Service Project Initiative.¹⁶ In the largest response in the Foundation's history, 1,026 grant proposals totalling \$537 million were received in July 1988. More than half the proposals were from CBOs. According to Dr. Leighton E. Cluff, RWJ Foundation president:

The response reveals what is, in effect, a national assessment of community needs in the fight against AIDS. We were not surprised by this enormous response but we are sobered by it. The proposals represent the voice of people who are actually fighting this epidemic.¹⁷

Nationally, 54 projects were selected by the Foundation and \$16.7 million dollars in awards were recently announced. New York and New Jersey alone submitted 140 and 48 proposals totalling \$87.5 million and \$22.3 million dollars, respectively. These figures far exceed the level of state-only expenditures for AIDS (exclusive of Medicaid) for fiscal year 1988, which are estimated at \$39.9 million in New York and \$7.9 million in New Jersey.¹⁸

Two other calls for substantial increases in funding AIDS-related health care and social service needs have recently been issued in New York, one focused on city agencies,¹⁹ the other on state programs.²⁰ The Committee for AIDS Funding, a diverse coalition of 22 community-based AIDS service providers in New York City, recommended an additional budget allocation of \$41,321,713 for New York City alone. The New York AIDS Coalition, comprised of more than 70 individuals representing different communities affected by AIDS around the state, has called for \$139,707,785 in additional state funding (for budget summaries see Appendix). These funding requests are for the coming fiscal year, focus on non-mandated spending, and are geared mainly toward improving community-based ambulatory care services and programs.

Community-based AIDS organizations were surveyed in New York City and northern New Jersey by the Citizens Commission on AIDS in the Spring of 1988. The following problems, ranked in order of importance, were identified. In New York: 1) lack of funding; 2) staff shortages; 3) discrimination against gays and minorities; 4) lack of adequate housing; and 5) insufficient drug treatment slots. In New Jersey: 1) lack of funding; 2) lack of public education; 3) lack of adequate housing; 4) lack of psychosocial support for patients and their families; and 5) lack of adequate home health care. CBOs from both states serving primarily ethnic minorities were more likely to identify inadequate funding as a major problem than CBOs serving other groups.

Conclusion

Community-based organizations have played a crucial role in responding to the needs of the AIDS epidemic but their potential is far from being realized. Although there has been much discussion of the value of CBOs in promoting the continuity of care and case management of large numbers of AIDS patients, there has been no systematic planning with public agencies or the private sector.

Beyond the issue of unrealized potential lies the reality that voluntarism has inherent limitations. Efforts to impose on minority communities models that have worked so effectively among gay groups are unlikely to succeed. Thus, it is imperative that the model of CBOs using paid labor be expanded and that other innovative approaches be adequately supported. One promising development is that recent government contracting and funding from the private sector are beginning to push established community groups toward incorporating AIDS services in their mission. But greater efforts to foster a more proactive role in response to AIDS must be made by black and Hispanic church and political leaders and by the private sector if the complex needs of minority communities are to be met.

Appendix A

Funding Agenda for Community Based AIDS Programs and Services in New York State: New York AIDS Coalition. November 1988.

Comprehensive Services

Primary Care	\$10,000,000
Drug Therapies	7,260,000
Continuum of Care	4,280,000
Housing	52,550,000
Mental Health	1,300,000
Discrimination	331,700
Community Service Programs	6,897,335

Populations with Special Needs

Adolescents	5,740,000
Blood Transfused	75,000
Children and Families	1,195,000
Ethnic Minorities	8,000,000
Gay and Bisexuals	2,500,000
Immigrants	180,000
Substance Abusers	17,850,000
Mentally Retarded	525,000
Physically Disabled	658,750
Prisoners	2,500,000
Suburban and Rural	10,830,000
Women	<u>7,035,000</u>

TOTAL	\$139,707,785
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Appendix B

**Funding Agenda for Community-based HIV/AIDS Service
Programs in New York City FY 1989-90
Committee for AIDS Funding, December 1988**

Total Request:	\$41,321,713
A. Steps Towards Comprehensive Services	
Health Care Services	\$18,467,950
Supportive Housing	\$3,087,743
Community-based Social Service Organizations	\$6,439,270
AIDS Training Centers	\$3,075,400
Mental Health Services	\$1,565,600
Discrimination: HIV Infection and Human Rights	\$300,000
B. Populations with Special Needs	
Youth	\$2,614,000
Children	\$1,225,000
Ethnic Minorities	\$800,000
Gay/Bisexual Men	\$600,000
Substance Users	\$1,990,550
Women	\$1,156,200
C. CAF Request from City Agencies: CAF'S Response to the NYC Strategic Plan for AIDS	
Department of Health (DOH)	\$9,554,650
Health and Hospitals Corporation (HHC)	\$10,495,685
Human Resources Administration (HRA)	\$16,877,778
Department of Mental Health (DMHMRAS)	\$3,265,600
Board of Education (BOE)	\$800,000
Commission of Human Rights (CCHR)	\$300,000

Summary Descriptions

Section A: Steps towards Comprehensive Services

Page	Description	
26	HEALTH CARE SERVICES	\$18,467,950
27	Primary Care HIV/AIDS Community Based Clinics	
	- Five adult clinics (HHC)	\$3,018,475
	- Two adolescent clinics (HHC)	\$1,220,060
31	Mobile Units: Providing Assessment Services in the Community	
	- Four mobile units: one for the Bronx, Brooklyn, Queens and Manhattan (HHC)	\$1,685,400
32	AIDS-Specific Outpatient Services in Public Hospitals	
	- Five AIDS-specific outpatient clinics on-site in 5 facilities (HHC)	\$4,039,800
33	Grants to Free Standing Primary Care Clinics	
	- Four grants, \$95,000 each (HHC)	\$380,000
34	Pilot Grant: Weekend Staffing of Primary Care Clinic (HHC)	\$109,450
35	Community Assistance to People with AIDS	
	- Two adult day care programs to serve 40 clients per day, total enrollment of 100 (HRA)	\$500,000
	- Home health care for the medically indigent, serves 105 clients (HRA)	\$3,402,000
	- Worker demonstration/Home health care Request for Proposal (RFP), (HRA)	\$250,000
39	Community-based Research/Clinical Trail Information	
	- Community-based research	\$529,000
	- Clinical trail information	\$260,000
42	Expand AIDS Case Management Unit (CMU)	
	- Case management unit: add 66 workers to serve 1,980 new clients (HRA)	\$3,073,765

43 SUPPORTIVE HOUSING * \$3,087,743

- Supportive Housing Apartment Program:
Four programs serving 60 single and 20 families =
180 annual residences (HRA) \$1,172,198
 - Large group residence: 44 single adults
= 66 annually (HRA) \$794,539
 - Two small apartment houses: 70 people
(40 singles, 10 families) = 105 annual residents (HRA) \$1,121,006
- * Must be matched by the State

48 COMMUNITY-BASED SOCIAL SERVICE ORGANIZATIONS \$6,439,270

- Flexible Grants: Small Community-based Organizations
- Churches, synagogues, neighborhood collaboratives, associations and
collectives, etc., to provide concrete social service delivery in the form of
food, clothing, support groups, etc., to persons affected and infected by
HIV/AIDS in the five boroughs (HRA, DMHMRAS) \$4,500,000

- 51 State AIDS Community Service Program (CSP) Assistance
- \$200,000 to CSPs in the Bronx, Brooklyn, Queens,
Upper Manhattan and Staten Island (DOH) \$1,000,000

- 52 Emergency Resource Networks
- Consultant group to serve community based organizations
in the five boroughs (financial advocacy, ombudspersons,
legal services, substance abuse services, etc.) (HRA) \$723,610
 - Clearinghouse for donated/bulk purchased goods (HRA) \$215,000

55 AIDS TRAINING CENTERS \$3,075,400

- Five Centers and coordinating staff to serve 4,000
people each year. Includes training programs for
health and social service providers; career requirement
program for students, family members of AIDS patients,
recipients of public assistance. (DOH) \$3,075,400

57	MENTAL HEALTH SERVICES	\$1,565,600
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|---|--|-----------|
| - | Expand DMHMRAS mental health centers in each borough. (DMHMRAS) | \$500,000 |
| - | Outpatient services for HIV-positive children in Harlem, the Bronx and Brooklyn. Initiatives for HIV-positive children in foster care established in five boroughs (DMHMRAS) | \$300,000 |
| - | Expand mental health AIDS professional training and education to mental health agencies. (DMHMRAS) | \$100,000 |
| - | Community-based HIV/AIDS peer support groups, Four (DMHMRAS) | \$665,600 |

61	DISCRIMINATION: HIV INFECTION AND HUMAN RIGHTS	\$300,000
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|---|-----------------------------------|-----------|
| - | Training manuals and staff (CCHR) | \$200,000 |
| - | Community mediation teams (CCHR) | \$100,000 |

Section B: Populations with Special Needs

63	YOUTH, EDUCATION AND OUTREACH	\$2,614,000
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- | | | |
|---|---|-----------|
| - | Street youth outreach (HRA-SSC) | 1,000,000 |
| - | After school AIDS education network (Youth Bureau) | \$689,000 |
| - | Needs survey of school personnel (BOE) | \$139,000 |
| - | Training film for professionals working with youth (DOH) | \$150,000 |
| - | New youth AIDS education film (DOH) | \$150,000 |
| - | Development of youth-oriented PSAs for TV and radio (DOH) | \$50,000 |
| - | Subway/bus poster campaign (DOH) | \$250,000 |
| - | Alternative health care delivery system for youth (HHC/DOH) | \$85,000 |
| - | Teen AIDS hotline | \$101,000 |

71	CHILDREN	\$1,225,000
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|---|---|-----------|
| - | In-Home Respite Care, serves 75 children and their families (HRA) | \$625,000 |
| - | Counseling services for families and children; 300 persons, 3 sites (DMHMRAS) | \$600,000 |

73	ETHNIC MINORITIES	\$800,000
	<ul style="list-style-type: none"> - Citywide education and outreach programs (DOH) \$200,000 - Psychosocial assessments and psychological support communities of color (DMHMRAS) \$200,000 - Mental health care in communities of color (DMHMRAS) \$200,000 - Community-based organizations to develop case management outreach programs in communities of color (DOH) \$200,000 	
75	GAY/BISEXUAL MEN	\$600,000
	<ul style="list-style-type: none"> - Education and services (DOH) \$200,000 - Psychosocial support systems (DMHMRAS) \$200,000 - Outreach to Gay/Bisexual men of color (DOH) \$200,000 	
77	SUBSTANCE USERS	\$1,990,550
80	Substance User Outreach and Education Programs <ul style="list-style-type: none"> - Five new centers (one in each borough) to serve substance users and their families/partners, and the community at large. (DOH) 	\$1,057,200
82	Recovering Substance Users Peer Support Groups <ul style="list-style-type: none"> - Two centers to serve a variety of recovering substance users, with support groups, drop-in centers, outreach and recruitment, therapeutic child care (DOH) 	\$933,350
84	WOMEN	\$1,156,200
	<ul style="list-style-type: none"> - Preventive education and outreach (DOH) \$200,00 - Two family care aides and counseling programs (DOH) \$456,200 - Female adolescence peer support groups program (DOH) \$200,000 - Provider education on multi-cultural characteristics and concerns of women (DOH) \$300,000 	

CAF Total Request from the City of New York	\$41,321,713
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- NOTES -

1. R. T. Chen, et al. "Use of hospitals by patients with AIDS in San Francisco," New England Journal of Medicine 319 (1988): 1671-2.
2. P. S. Arno and R. G. Hughes, "Local policy responses to the AIDS epidemic: New York and San Francisco" New York State Journal of Medicine 87 (1987): 264-72.
3. P. S. Arno, "The nonprofit sector's response to the AIDS epidemic: community-based services in San Francisco," American Journal of Public Health 76 (1986): 1325-30.
4. P. S. Arno, "The future of voluntarism and the AIDS epidemic," in D. E. Rogers and E. Ginzberg, eds., The AIDS Patient: An Action Agenda (Boulder and London: Westview Press, 1988), 56-70.
5. Ibid.
6. P. Smith. Testimony before the President of the New York City Council, City Hall, New York. 1 November, 1988.
7. E. Drucker et al., "IV drug users with AIDS in New York City: A study of dependent children, housing and drug addiction treatment," (Unpublished paper: July 1988).
8. S. R. Friedman et al., "AIDS and self-organization among intravenous drug users," The International Journal of Addiction 22 (1987): 201-19.
9. D. C. Des Jarlais et al., "AIDS among intravenous drug users: a sociocultural perspective," in D. Felman and T. Johnson, eds., The Social Dimensions of AIDS (New York: Praeger, 1986).
10. E. Hammonds, "Race, Sex, AIDS: The construction of other," Radical America 20 (1987): 28-36.
11. Interview by Nelson Fernandez from the Citizens Commission on AIDS with John Vaughn, Executive Director of East Harlem Interfaith, a religious-based community organization whose goals include the development of a network of religious and secular organizations which work together to create structural social change. 28 October, 1988.
12. Interview by Peter Arno from the Citizens Commission on AIDS with Reverend Lee Wesley, Executive Director of the Minority Task Force on AIDS, 25 April, 1988. The Task Force advocates for more effective AIDS prevention and treatment modalities in minority communities and provides limited services to minority persons with AIDS and their families, including a telephone information and referral service, a volunteer "buddy" program and free weekly meals.
13. L. E. Cluff, "Grants awarded under the Robert Wood Johnson Foundation's AIDS prevention and service projects initiative," (Special memorandum to members of Congress, governors, selected federal officials, foundation executives and corporate executives: 12 December, 1988).
14. Interview by Nelson Fernandez from the Citizens Commission on AIDS with Peter Avitable, founder and executive director, St. Peter's Momentum Outreach Program, 27 December, 1988.
15. Interview by Nelson Fernandez from the Citizens Commission on AIDS with James Kirkpatrick, Business Manager, God's Love We Deliver, 28 December, 1988.

16. L. E. Cluff, "Grants awarded under the Robert Wood Johnson Foundation's AIDS prevention and service projects initiative," (Special memorandum to members of Congress, governors, selected federal officials, foundation executives and corporate executives: 12 December, 1988).
17. L. E. Cluff, cited in AIDS/HIV Record (August 1988).
18. M. J. Rowe and C. C. Ryan, "Comparing State-only expenditures for AIDS," American Journal of Public Health 78 (1988): 424-9.
19. Committee for AIDS Funding, Funding agenda for community-based HIV/AIDS service programs in New York City FY 1989-1990 (December 1988).
20. New York AIDS Coalition, Funding agenda for community-based AIDS programs and services in New York State (November 1988).

Interview: "Jeff"

"I have had to become almost totally destitute in order to qualify for some of the services I have received. I'm not supposed to have anything."

For two years, Jeff made the rounds of the medical experts trying to pinpoint the source of intermittent fevers and a severe infection in his right leg. The 48-year-old gay man was repeatedly misdiagnosed until 1985, when doctors finally realized the bone infection that sometimes prevented him from walking was actually an AIDS-related opportunistic infection.

A freelance writer living in Manhattan, Jeff paid his own living expenses and even maintained a modest savings account until his health deteriorated. In order to qualify for subsidies that would enable him to obtain the treatment he needed, however, Jeff was forced to "spend down" almost every cent he had socked away.

I don't think it's fair to have to divest yourself of your assets in order to qualify for public assistance. I have had to become almost totally destitute in order to qualify for some of the services I have received. I'm not supposed to have anything. I find this extremely distressing.

After adjusting to the shock of his diagnosis, Jeff's next great challenge was to learn about the treatments and services available to people with AIDS. Like many PWAs, he found that acquaintances were often a better source of information than health care providers. For example, it was an informed friend who told him he could obtain a nebulizer, a machine for inhaling pentamidine, for use in his own home.

Jeff has become acutely aware of the inadequacy of health care for AIDS patients. He is currently hospitalized in an institution that is depressing and badly in need of renovations. It is also inefficiently managed: By his third day at the hospital, Jeff had already been moved into four different rooms. And he has complaints about physicians who are inaccessible and incommunicative:

There's a tendency [among physicians who treat PWAs] to be less than fair with people in terms of giving them time to make decisions. I was not given either the information or the time I deserved in order to make a proper decision concerning treatment of my leg. My decision to proceed with radiation therapy as opposed to chemotherapy was made with blissful ignorance. I regret that now. Radiation has been destructive. It interferes with the body in a permanent way.

The point is that I was permitted to make this decision in ignorance without having been given the information or the time I needed to have made a truly informed decision. Just yesterday, the doctor spoke to me once again about wanting to inject me with some radioactive substance to identify and locate the infection. I always get the feeling that the doctors are all wanting to do something quickly.

Thanks to Social Security Disability payments, Jeff is able to maintain his own apartment, which is relatively cheap by New York standards. Allowing PWAs to remain in their own homes is critical, he says, noting that the availability of home attendant care is an important tool for making this possible. As a patient who depends on an attendant for both logistical help, such as cooking, cleaning and shopping, and for companionship and emotional support, Jeff pleads for their right to a living wage. Asked how he could have managed without his home attendant, Jeff shudders and refuses even to speculate about it.

Chapter 4

Housing, Homelessness, and the Impact of HIV Disease

Homelessness is a great tragedy. AIDS is another. No words are sufficient to describe the plight of those facing both afflictions, strewn amidst the gleaming towers of our greatest of cities in this land of plenty.

Justice Edward H. Lehner, in his New York State Supreme Court preliminary injunction of January 11, 1989, urged New York City and State into action with these words. Unless local and state governments, as well as the private sector, step in to alleviate the tragedy of those with HIV-related illness who have no homes, we may soon witness an unravelling of the social fabric in our city. A plan of action for dealing with AIDS and homelessness is clearly vital.

The numbers of men, women, adolescents and children suffering from AIDS and other HIV-related illnesses who lack adequate housing are growing, while the importance of permanent supportive homes for them and their families is becoming ever more clear. As the epidemic shifts increasingly toward intravenous drug users, their sexual partners and children, many of the assumptions regarding patterns of care developed for gay men may be inappropriate for a patient population who a) have different HIV-related clinical syndromes; b) are 30-40% female; c) are primarily low income blacks or Hispanics; and d) often lack insurance, and material resources, including access to stable housing.^{1, 2, 3, 4}

The crisis in housing for HIV-infected persons is part of the nationwide homeless tragedy. Much of the blame rests directly on the policies of the Reagan Administration, which slashed annual Federal housing subsidies from \$30 billion to \$8 billion over the past decade. The typical poor family is now forced to spend an unheard-of 78 percent of its income on housing.

The City and State's reliance on the out-dated AIDS surveillance definition used by the Centers for Disease Control (CDC) also contributes to the tragedy of homelessness. It has been official government policy to house or provide rental subsidies only to those persons with a CDC-defined AIDS diagnosis. Those with HIV-related illnesses, which can be as debilitating as AIDS itself, have not been eligible for any special housing benefits. The New York City Department of Health is reconsidering this policy; both the City and State should act quickly to bring housing eligibility criteria in line with medical knowledge about the spectrum of HIV illness.

The number of homeless people with HIV-disease cannot easily be determined. Estimation problems include uncertainty over both the total numbers of homeless and

the number of people infected with HIV, as well as confusion over the arbitrary distinctions along the clinical spectrum of illness. The Partnership for the Homeless estimates that there are 5,000 homeless with AIDS or ARC now in the City and that the number will rise to 30,000 over the next three to four years. Andrew Stein, president of the City Council, adopted that estimate as the sub-title for his hearings of December 1988, "Sick and No Place to Go: 5,000 Homeless People with AIDS and AIDS-related Illness." The AIDS Resource Center puts the number slightly lower -- citing a rough estimate of 2,000-5,000 with projections for a large increase by 1991.⁵ The Coalition for the Homeless, which has filed a class action suit to force New York City and State to house HIV-infected persons who do not meet the criteria for CDC-defined AIDS, estimates that population group at 10,000.⁶

In New Jersey, the State Health Department has been collecting data from its AIDS Health Services Program, which provides case management services to persons with HIV disease in hospitals in Newark and Jersey City. Of the program's 1,903 clients, 197 are in need of "housing assistance" (approximately 10 percent). These clients include those with "CDC-defined" AIDS, ARC, and mildly symptomatic HIV infection. Applying that same 10 percent figure to the 2,300 people living with AIDS in New Jersey, one can estimate there are about 230 homeless PWAs in the State.⁷

In New Jersey, the majority of AIDS cases are related to intravenous drug use. Those affected are generally residents of poor, minority communities. Most of the drug abusers had housing problems even before the AIDS crisis. Although the major urban areas of Newark, Jersey City, and Paterson are especially affected, recent trends show growing problems in coastal areas including Asbury Park and Atlantic City.

The increasing number of homeless PWAs in New Jersey is the result of several factors: (1) an increase in the number of AIDS-related evictions; (2) eviction by family members who are either unwilling or unable to provide care for the individual; (3) loss of employment and income; and (4) the impoverishment that many PWAs were already struggling with prior to their illness; and (5) loss of eligibility for Assistance to Families with Dependent Children [AFDC] when a mother with AIDS loses custody of her children because they have been placed in foster care.

In addition, the rate of HIV infection among homeless adolescents is high and rising according to a New York State Department of Health study of youths tested at Covenant House between October 1987 and October 1988. That study concluded that 10 percent of adolescents then resident at Covenant House and almost 7 percent of all homeless adolescents in the street survey were HIV-seropositive -- a statistic that must challenge any optimistic predictions for a drop in the rate of HIV infection in the future.⁸

Although all New Yorkers recognize the existence of homelessness on our streets, the problem is not limited to the most visible homeless, those on the streets, on

subways, and in bus stations. For HIV-infected IV-drug users, precarious housing has become almost the norm.⁹ The city agencies also place men and women in Single Room Occupancies (SROs) unsuitable for those who are HIV-infected and, despite official denials, hundreds (and perhaps thousands) are also "housed" in city-owned or operated shelters. Here again, the distinction among HIV-related illnesses is used to excuse inappropriate housing. Many persons, particularly those in the shelters, have not received a "full-blown" diagnosis of AIDS or are afraid to pursue medical attention for fear of social or economic repercussions, according to Dr. Stephen C. Joseph, New York City Commissioner of Health.¹⁰

A report prepared by the New York State Division of Substance Abuse Services (The DSAS Report) states clearly that it is impossible to determine the number of homeless AIDS or ARC patients in the shelters because they fear intimidation and violence and are afraid to come forward.¹¹

Appearing before the Assembly Committee on Health, New York State Department of Social Services Division of Adult Services deputy commissioner Judith Berek described a joint City/State study of the post-discharge needs of 269 clinically stable patients with HIV-related illness or AIDS in 20 New York City hospitals. She testified that:

Just over 50 percent of these patients had no home to which they could return. Of that 50 percent, 36 percent had been undomiciled prior to admission; 48 percent had had houses or apartments but couldn't return for reasons such as eviction, failure to pay the rent, increased clinical needs, or the exhaustion or rejection of essential support persons.¹²

Jo Ivey Boufford, president of New York City's Health and Hospital Corporation, has a lower estimate. She reports that 15 percent of patients in public hospitals are homeless.¹³ Many of those homeless patients are otherwise self-directing and functionally independent and could be helped by rent subsidies and visiting home care in scattered-site apartments -- if more such housing were available.

The lack of appropriate, affordable housing -- a tragedy in any circumstance -- multiplies astronomically as HIV disease progresses. All treatments, whether medicinal, nutritional, or holistic, assume the availability of basic necessities, including access to a clean kitchen, bathroom, bed, and heat. Most obvious, but worth emphasizing: a patient cannot receive home health care without a home. Visiting nurse services and home-care practitioners cannot provide medical care without, at a minimum, hot running water and sanitary facilities. The control over one's life that is vital for wellness becomes virtually impossible without stable housing.¹⁴

Ginny Shubert of the Coalition for the Homeless has stated:

Infection with HIV is becoming a primary cause of homelessness in New York City. Persistent and recurring illness and episodic hospitalizations result in the loss of jobs and housing and leave HIV-infected persons without the resources to fight their way back into the housing market. For those HIV-infected persons already homeless, progression to serious illness and death will likely be hastened by life on the streets or in City barrack shelters, where infectious disease is rampant and violence towards HIV-infected persons is common.¹⁵

The DSAS Report identifies not only medical but managerial problems of the homeless AIDS patient: they are unable to complete diagnostic tests, they lose prescriptions, and they break outpatient appointments. Many of these problems are clearly due to living conditions in shelters, SROs, or on the streets.¹⁶

At the Assembly Health Committee hearing, Manhattan borough president David Dinkins provided a consensus report detailing the criteria for supported housing for HIV-infected persons that specified a minimum of 120 square feet per person, single rooms with private bathrooms, cots for health aides and care providers, staff and support services and adaptive physical access (see Appendix A).¹⁷ Advocacy groups serving the homeless and the AIDS community have demanded housing that is not only sanitary and physically adequate but also "supportive." Douglas Dornan, Executive Director of the AIDS Resource Center, defined supported housing as subsidized housing and support services (such as case management, mental health and substance abuse counseling, home health care services, recreational therapy, transportation, etc.) provided on-site or through agreement and affiliation with other community agencies.¹⁸

The lack of adequate housing with these or lesser standards is also affecting the hospitalization patterns of AIDS patients, adding to the length of their stay in acute care beds and, therefore, increasing the cost of providing care. Based on a survey of 174 hospitalized IV drug users with HIV disease, Ernest Drucker and his colleagues report that an estimated 40 percent of patients are homeless (living on the streets or in shelters) or are precariously housed (i.e., living doubled-up or at some place where they are unlikely to return following a hospital stay) at the onset of their illness.¹⁹ Borrowing a term previously reserved for infants with no place to go, Drucker described 10-20 percent of the hospitalized IV drug-using AIDS patients as "boarder adults." In August, 1988, Emmaus House, a community organization based in Harlem, which has provided a range of services to the homeless for more than 20 years, cited even more alarming statistics for Harlem Hospital. Emmaus House reported that "50 percent to 60 percent of that daily flow of [AIDS and ARC] patients have no home or have very tenuous living situations."²⁰

Government Response: New York City

A summary of AIDS services available in New York City published in The New York Times on January 3, 1989, cited a 1985 memorandum by then-Mayoral Assistant Victor Botnick recommending that the City "work to develop viable housing options" and "offer community and voluntary groups assistance in locating and finding congregate facilities and rehabilitating in-rem housing" (tax delinquent housing taken over by the City). In the last four years, the City cannot reasonably claim to have fulfilled either of these goals.

At legislative hearings held by City Council President Andrew Stein and State Assemblyman Richard Gottfried, representatives of government, AIDS advocacy groups, the medical community and the homeless have all decried the lack of speed in the City's response. New York's two leading advocacy groups for the homeless -- the Coalition for the Homeless and the Partnership for the Homeless -- have reported on housing problems for the HIV-infected population in the context of a citywide shortage of affordable housing. All sides emphasize that the City's response has been inadequate, that funds have been improperly targeted and in short supply, and that the reliance on the CDC definition of AIDS for determining housing assistance eligibility criteria has misdirected efforts to solve the dual tragedies of AIDS and homelessness. The City has recently begun to work with some community and voluntary groups but its progress has been limited by two major factors: First, these small community-based groups are ill-equipped to deal with governmental bureaucracies; and second, these groups have been denied funds if they overstep the arbitrary boundary between HIV illness and CDC-defined AIDS.

In a class action suit brought against the City and State by the Coalition for the Homeless, Dr. Stanley R. Yancovitz, Director of Clinical AIDS Activities for Beth Israel Medical Center in Manhattan, testified that:

The known prevalence of infectious disease in the municipal shelters poses a substantial health risk to...anyone infected with HIV. Persons who are HIV infected are highly susceptible to the types of infectious disease rampant in shelters, and the crowded conditions and shared use of sanitary facilities further increase the risk of infection. Once an infectious disease is contracted, one who is HIV-infected is more likely to become seriously ill than a non-infected person. Moreover, a weakened immune system, coupled with the stress of living in an environment such as that found on the streets or in the municipal shelters ... makes recovery from infection difficult or impossible.²¹

Government Response: New York State

New York State's response to AIDS and homelessness has focused on the creation of a two-pronged plan for the future -- the building or rehabilitation of facilities to provide supportive care and the use of federal funds to establish and finance them. Judith Berek outlined the state's plan at the Gottfried Hearings, where she stated that AIDS not only "compounds" the problems of homelessness, but prevents progress in "developing housing models that will improve, or at least maintain, the quality of life of a person or family with HIV-infection."²² The State's initial effort has been to maintain self-directed people with AIDS and ARC and their families in their own homes by providing home relief, Social Security Disability insurance, Aid for Families with Dependent Children, Food Stamps, Homemaker Services and Housekeeper/Chore Services, Personal Care Services and Home Health Care Services. Emergency shelter allowances of up to \$480 per month for a single adult and up to \$333 for each additional person living in the house or apartment can serve as a supplement to rent. This money can be used for scattered-site housing as available. Berek testified that, as of July 1988, "1,080 clients in New York City were receiving that assistance and that, according to the City's Human Resources Agency, about 52 percent of the cases served by their management unit were getting the rental supplement."²³ She added that Tier II family shelter programs, developed for the general population and funded by various government programs, may eventually be made available to HIV-affected families.

The population of single adults with AIDS and HIV-related diseases form the core of the housing problem in New York State as it does in New York City. The State, however, has focused its attention on AIDS-specific health-related facilities. The State appears to endorse residential health care for the future, based on two factors: First, its demographic analysis of AIDS patients who are most often fairly young (average age 35), with a history of drug use, without a suitable home support system or home, and second, its perception of the progress of medical care, specifically "chemotherapeutic advances for HIV infection."²⁴ Berek praised this approach for its efficient physical plant and for its funding capabilities. Medicaid will reimburse the State for each patient's care under existing legislation.

Berek specified four models of adult care that the State considered both appropriate and economically feasible under current SSI (Supplemental Security Income) levels: 1) family-type homes for one to four residents; 2) enriched housing programs operated by not-for-profit corporations or public agencies for five or more residents; 3) adult homes for five to 200 residents; and 4) multi-licensed facilities.²⁵ The latter, called the most preferable congregate care option, presents a way to provide the different levels of care required by the episodic nature of the disease and at the same time bring in Medicaid dollars. Given the extent of the problem, all of these models may be adopted by the State but it is highly unlikely that any of them will be

operational until the end of 1991. (For more on the State's plan to build residential care beds, see Chapter 2: "Long-term Care: A Long-term Commitment.")

Although New York State has based its housing plan on the availability of federal Medicaid funds, state planners may have overlooked another grant source. Catholic Charities in San Francisco recently received a \$2 million federal grant under the Stewart B. McKinney Homeless Assistance Act of 1987 (PL10-77) to provide Section 8 rent subsidy vouchers for up to 35 HIV-infected residents in a supported housing program over a 10-year period. The funds are funneled through the Departments of Public Health of the City and County of San Francisco.²⁶ We know of no attempt on the State or City level to utilize federal funds in a similar manner.

Government Response: New Jersey

Although the New Jersey Department of Health has made some efforts to create some medically-related housing for PWAs, there are no programs that provide supported housing. (See Chapter 2 on long-term care.)

At present, a PWA can apply to the county or municipal welfare office for emergency assistance and shelter; this is normally provided in congregate shelters, which are a less expensive option but are often inappropriate for PWAs. Such settings are closed during the day, and PWAs need a place to stay round the clock. Proper diet, rest, and administration of medication are practically impossible in such settings. Overcrowding also places individuals at serious risk of infections such as tuberculosis.

Advocates are often needed to insure that the welfare office provides a separate room in a sanitary facility for the individual. Furthermore, municipal shelter has been available for a 5 month period only. However, a recent Appellate Court decision found that this time limit violated state law because homeless individuals, some of whom are PWAs, were being evicted at 5 months without being provided with any alternatives.²⁷

The Response of Community-based Organizations

AIDS advocacy groups in New York have developed financial, legal, pastoral and medical support networks since the onset of the epidemic. They have been joined by religious and community-based organizations, and by advocates for the homeless in the fight to provide housing for all. A number of housing programs have been established, and while limited in scope, they show that solutions are possible. On December 27, 1988, the City's Human Resources Administration solicited proposals from qualified community-based organizations to manage supportive, scattered-site housing for homeless persons with AIDS. The Request for Proposals required each agency to secure, furnish, operate, and maintain a total of at least 100 scattered-site apartments with counseling, referral services, and advocacy specified as contracted services.

Community-based, religious, and advocacy organizations have developed or proposed a number of other projects. Emmaus House now includes men, women and infants with AIDS within its continuing programs. Currently, 55 homeless men and women live at Emmaus House on a long-term basis and 16 additional men can be housed in an emergency shelter. Emmaus House has applied to the City for title to 20 City-owned apartments in clustered sites, preferably in East Harlem, in order to expand its programs. Its AIDS housing proposal includes orientation, counseling, advocacy for those dealing with entitlement applications, and participation in community meals programs.

The AIDS Resource Center maintains both the only supported residence for AIDS patients, Bailey House, a 44-bed residential facility, and a group of 20 scattered-site apartments that have served more than 100 persons through the end of 1988. Bailey House will be enlarged to a capacity of 52 beds and will be made wheelchair-accessible through a \$600,000 grant from the United States Public Health Service and a \$1 million award from the State's Homeless Housing Assistance Program. The Task Force on Homeless PWAs has endorsed the scattered-site model and is proposing to establish small group homes for no more than 10 people, each with an entitlements advocacy program, visiting nurses, and City-funded home health aides. The Task Force's proposal emphasizes that with the scattered-site program no community would be asked to carry a disproportionate burden of housing homeless PWAs/ARC. By renovating available housing stock, such a project could expand with a relatively small infusion of capital funds and could be completed far more quickly than the time required to construct new facilities.

New Jersey, unlike New York City, does not have community based organizations focused on housing comparable to the AIDS Resource Center in New York City. Since hospital social workers are often unwilling to discharge homeless patients, and since the cost of a hospital bed can reach up to \$700 per day, the failure to develop housing for PWAs continues to be a financially devastating problem. Moreover, although New Jersey does have a Medicaid community care waiver program in place, the lack of housing at the time of discharge results in ineligibility for community-based services.

Conclusions

Any solution to the overlapping problems of homelessness and AIDS will require commitments from the City, State and Federal governments that recognize the continuum of HIV disease. Unless HIV disease is redefined in light of medical realities, immunocompromised people are destined for death in shelters or on the streets. Advocacy, whether from AIDS activist groups, religious institutions, or community-based institutions, is vital to guiding the HIV-infected through the maze of bureaucratic entitlement programs. Appropriate treatment and concomitant social

services must be provided to patients struggling with the burdens of illness, many of whom are substance abusers.

Scattered-site, supported housing, which generally does not alarm the residential communities in which it is placed or ghettoize the HIV infected, is one cost-efficient and humane way to provide care. The Partnership for the Homeless has recommended a "one percent" program in which one percent of the currently habitable 225,000 apartments owned, subsidized or controlled by New York City would be set aside to provide supported housing for homeless and near-homeless people with HIV illness. These apartments would be passed into scattered-site programs operated by nonprofit sponsors over three years at the rate of about 750 units per year from the normal annual vacancies of over 10,000 apartments.²⁸ The AIDS Resource Center has created an important model for supported housing that provides a full range of counseling, food, medical care, and other services. Adequate public funding will enable other non-profit sponsors to duplicate that model and ensure that genuinely supported housing -- not barracks -- are actually constructed. Health-Related Facilities clearly have some drawbacks, notably the fact that they create an institutional, rather than a home-like environment, and traditionally require residents to be discharged when their health status changes. Further, the State will not be able to complete construction on them for several years. However, an HRF solution has the advantage of not requiring a change in existing regulations and allowing the state to access federal funds through the Medicaid program.

In order to meet the needs of homeless HIV-infected individuals or PWAs in New Jersey, leadership is essential. Local resistance to the siting of residential facilities and the lack of technical assistance available to non-profit organizations attempting to develop housing alternatives are also serious problems.

Rather than attempting to squeeze solutions into existing funding streams, however, we should be looking closely at what the actual problems are and what it will take to solve them. As a nation, we have been painstakingly slow to develop appropriate responses to the triple tragedies of AIDS, homelessness, and drug abuse. Increasingly, these issues are intertwined. We can not afford to allow fear, indifference, or even budget deficits to shape our response to an epidemic that poses a real danger to the social fabric of our communities.

Appendix A

Criteria for Supported Housing for People with AIDS Prepared by Manhattan Borough President's Office

Size and Configuration

- Facilities should house no more than 50 people
- Minimum of 120 square feet per person in sleeping area
- No more than one person per room
- Private bathroom for each person
- Physical access issues unique to this population must be adequately addressed
- Common lounge space
- Common kitchenette on every floor
- Refrigerator in each room
- Three meals a day as individually necessary
- Capacity to open a cot for an additional person, to accommodate a health aide or other care provider

Support Services

- Bilingual staff capacity in the delivery of services
- Case manager/client ratio of 1:15 maximum should be maintained
- Mental health/counseling staff should include: psychiatrist, social worker, substance abuse counselor, case manager
- Recreational therapist
- Home health care services (aides) attached to facility or personal care assistants (2 per shift)
- 24-hour nursing
- 24-hour security
- 24-hour transportation available according to need
- Elevator service in building at all times

CVR/ST.PWA/GROUP

- NOTES -

1. A. R. Moss, "AIDS and intravenous drug use: the real heterosexual epidemic," British Medical Journal 294 (1987): 389-90.
2. D. C. Des Jarlais and S. R. Friedman, "HIV Infection among intravenous drug users: epidemiology and risk reduction," AIDS 1 (1987): 67-76.
3. P. S. Arno, "The Future of Voluntarism and the AIDS Epidemic," in D. E. Rogers and E. Ginzberg, eds., The AIDS Patient: An Action Agenda (Boulder and London: Westview Press, 1988): 65-70.
4. P. S. Arno and R. G. Hughes, "Local Policy Responses to the AIDS Epidemic: New York and San Francisco," New York State Journal of Medicine 87 (1987): 264-272.
5. D. Dornan, "Supportive housing for homeless people with AIDS and AIDS-related illnesses," Testimony before the New York State Assembly Committee on Health, 5 December, 1988.
6. Mixon v. Grinker, Index No. 14932/88 (Sup Ct NY Cty) (Opinion granting preliminary injunction Lehner, J.) (1989).
7. Personal communication with Stephen Young of the New Jersey Department of Health, January 26, 1989.
8. Covenant House. A blind seroprevalence study done at Covenant House in conjunction with New York City and New York State Departments of Health. Presented at the Annual Meeting of the American Public Health Association, Boston, November 14-16, 1988.
9. E. Drucker et al., IV Drug Users with AIDS in New York City: A Study of Dependent Children, Housing and Drug Addiction Treatment (The AIDS Service Delivery Consortium/NYC: July 1988), 15.
10. G. Kolata, "Many with AIDS Said to Live in Shelters in New York City," The New York Times, 4 April, 1988: B1.
11. New York State Division of Substance Abuse Services, The Homeless Intravenous Substance Abuser and the AIDS Epidemic (May 1988): 11.
12. J. Berek, "Residential Care and Housing Services for Persons with AIDS," Testimony before the New York State Assembly Committee on Health (5 December, 1988).
13. Jo Ivey Boufford, "What Needs to Be Done on the Hospital Front" in D. E. Rogers and E. Ginzberg, eds., The AIDS Patient: An Action Agenda (Boulder and London: Westview Press, 1988): 20.
14. AIDS Resource Center. "More than Just a Place to Live," News from the AIDS Resource Center, (November/December 1988): 1.
15. G. Shubert, Coalition for the Homeless (Press Release: 12 January, 1989).
16. DSAS Report, Op cit.: 13.
17. D. Dinkins, Testimony before the New York State Assembly Committee on Health (5 December, 1988).

18. D. Dornan, "Supportive Housing for Homeless People with AIDS and AIDS-related Illnesses," AIDS Resource Center, 29 September, 1988: 1.
19. Drucker et al., Op cit.
20. Emmaus House, "A Proposal for Housing Homeless Persons with AIDS," August 1988.
21. S. R. Yancovitz, Medical Affidavit in Mixon v. Grinker (September 1988).
22. Berek, Op cit.
23. Ibid: 6-7.
24. New York State, AIDS, New York's Response: A 5-Year Interagency Plan (January 1989): 71-77.
25. Berek, Op cit.: 12-13.
26. D. Werdegarr et al., AIDS in San Francisco: Status Report for Fiscal Year 1987-1988 and Projections of Service Needs and Costs for 1988-93. (San Francisco: San Francisco Department of Public Health, 15 March, 1988), 5.117.
27. Williams vs. New Jersey Department of Human Services, _____ N.J. Super. _____, (App. Div. 15 November, 1988) dkt. A-4317-87T1F. Companion case was Jimperson vs. New Jersey Department of Human Services.
28. The Partnership for the Homeless, AIDS -- The Cutting Edge of Homelessness in New York City (January 1989): 23-26.

Interview: "Paco"

"If you got AIDS, sometimes you gotta wait to get treated 'cause everybody is scared to get it."

Until he became too weak to work, Paco, 32, was employed as a salesperson in Newark. An IV drug user, he spent much of his spare time injecting a potent mixture of heroin and cocaine into his veins, a drug ritual known as "speedballing." Sharing needles with friends was the most likely source of Paco's infection:

Paco learned that he carried the HIV virus in 1984, after agreeing to take the antibody test while hospitalized with pneumonia. He was diagnosed with AIDS-Related Complex (ARC) shortly thereafter and has since travelled through the revolving door of hospital services at least ten times. He needs constant treatment for HIV-related sicknesses, requires psychiatric services and has few personal resources to rely on. Paco was forced to move back into his parents' home after his wife, an antibody-positive drug user, left him.

Although he has now managed to free himself from drug addiction, Paco has found the health care and social service systems appallingly unresponsive. Initially, City Welfare granted him presumptive disability. Then his case was reviewed in detail and it was decided that because he did not meet the CDC criteria for an AIDS diagnosis, he could not qualify for Social Security Disability status after all. Eligibility criteria may ultimately be changed to accommodate the debilitating effects of ARC, but until then Paco is unlikely to get the treatment that could stabilize his weakening health.

Speaking about his experiences in dealing with the bureaucracy, Paco says:

Right now I get my medication paid for by Welfare [He is referring to a Medicaid voucher issued by City Welfare]. They give me a letter so I could get my medication. When I was in the hospital, the social worker told me that Welfare would pay for my bills. They also pay for my medication. But the doctors tell me they can't help me [obtain SSI] because they say they need more medical records. Then they sent me a letter telling me my records were closed.

Anyway, it's been a hassle living here because you hardly get any treatment. They don't have the different kind of treatments you can get in New York. My friends are doing really bad; they're very sick and they're not being helped. I got a brother-in-law who has AIDS in New York and he gets help that we don't get here. Here I see my doctor once a month. Here if you got AIDS sometimes you gotta wait to get treated 'cause everybody is scared to get it.

Paco's prospects have brightened somewhat since he was referred to the Hyacinth Foundation, a nonprofit organization established to meet the health care and social service needs of persons with AIDS in New Jersey. His case worker is serving as an advocate, completing the paperwork that Paco needs to access additional resources. But grave problems remain:

To me the problem is that I'm not getting any help from anybody else. My parents are doing everything and they can't do it all. And Social Security opens my case and they close it and they open it again. It's been hard trying to get Social Security Disability. They gave it to me but then they took it away when I got better. And I'm not the only one they're doing it to. I don't know what more proof they want that I'm sick. I wish they would do more here in Jersey for other people like me.

Chapter 5

The Special Needs of Women, Children, and Adolescents

Although media attention and celebrity visits have drawn the public eye to the plight of hospitalized "AIDS babies," the concrete services that children and their families need are still inadequate in New York City and Northern New Jersey. Other sections of this report have outlined shortcomings in the health care and social service systems that affect all persons with HIV disease. This section will focus on the increasingly urgent needs of the young, which include access to primary medical care, housing, a wide range of social services, foster care, day care, and support services for natural and foster families.

The special needs of women are often neglected in systems designed for a disease that began largely in the male population. While increasing attention is being focused on women as potential vectors of HIV infection to their fetuses, women's needs should not be seen solely in that context. Women who have AIDS or HIV illness need care that is attentive to their individual situations, whether or not they have children or husbands.

Still, most women who need services do have children and face enormous obstacles in providing appropriate care for them. Services for children are in that sense services for their mothers and other family members as well.

How Many Children and Youth Are Affected?

Three main categories of children and youth are affected by HIV/AIDS: (1) those who are HIV-infected or already have AIDS; (2) infants whose HIV status is indeterminate because they are born with their mother's antibodies but may not be truly infected; and (3) those who are not infected but who are deprived of emotional and financial support because a parent or other family member has HIV-related illness or has died of AIDS.

Pediatric Cases. With 1,432 pediatric cases of AIDS, defined as children under 13 years of age, reported to the Centers for Disease Control as of February 20, 1989, New York City leads the nation with 432, or about a third of the cases. New Jersey is second with 187. Florida and California are the only other states reporting significant numbers of children with AIDS. "Half of the reported cases have died.¹ The surveillance statistics probably underestimate the number of cases of full-blown AIDS and do not count children with other HIV-related diseases. A recent study of New York City hospitals identified 828 children with CDC-defined AIDS or clinically

apparent HIV infection who had received care in 1988; by contrast, the New York City Department of Health Surveillance report of November 1988 listed 134 CDC-defined pediatric AIDS cases in the city.²

AIDS now ranks as the ninth leading cause of death nationwide among children aged 1 to 4 years, and the seventh among young people aged 15 to 24, according to Dr. Antonia Novello, deputy director of the National Institute of Child Health and Human Development. She predicts that if present trends continue, in the next three or four years AIDS will move to fifth place as a killer of Americans from birth to their 24th birthday.³ The U.S. Public Health Service estimates that by 1991 there will be a cumulative total of between 10,000 and 20,000 children infected with HIV. Based on the current percentage distribution, this means that between 4,500 and 9,000 of these children will be in New York and New Jersey.⁴

The New York State Department of Health predicts that 700 HIV-infected infants will be born in 1988. Most of these births will occur in New York City, one-third in the Bronx, and the vast majority will be black or Hispanic. The New York City Department of Health now estimates that from 1,600 to 4,400 children are HIV-infected. Many of these children will go on to develop AIDS.⁵

Some evidence about transmission comes from a New York State Department of Health HIV seroprevalence study of newborn infants. As of June 30, 1988, more than 158,000 newborn infants in the state had been tested for HIV antibodies. The confirmed presence of antibodies in the infant is a reliable predictor of infection in the mother; an estimated 25 to 40 percent of these infants will themselves be infected. The rest will lose their maternal antibodies, usually within the first year of life. This serosurvey found that one in every 150 women who gave birth in New York State during the previous six months was infected; 87 percent of them were from New York City. The ZIP code breakdown of HIV-positive births in New York City correlates with areas known to have a high prevalence of IV drug use.⁶ Selected studies in some hospitals in Brooklyn, Manhattan, and the Bronx indicate rates of infection among pregnant women of ranging from one in 50 to one in 20.

A similar statewide seroprevalence study conducted over a three-month period by the Department of Health in New Jersey found that of 30,000 newborns tested, one in 200 was seropositive (indicating true infection in their mothers). The highest rates were found in Essex and Hudson counties, but only six of New Jersey's 21 counties had no antibody-positive infants at all. On the basis of this survey, Commissioner Molly Joel Coye estimates that 200 to 300 babies born each year will be truly HIV-infected.⁷ Newark is particularly hard hit: A sample test conducted in University Hospital in Newark in the fall of 1988 showed an extremely high rate of infection -- one in 20 births, or ten times higher than the state as a whole.⁸

In addition to the infants who are found to be antibody positive at birth, increasing numbers of HIV infection are diagnosed only when the child becomes symptomatic. A recent study of newborns in New York City concluded that the incubation periods between HIV infection and AIDS is longer than previously reported.⁹ Therefore, children may not show signs of HIV infection until they reach the age of four or five.

Adolescents. Although the numbers of cases are still low, indications are that AIDS and HIV infection are growing among adolescents in the region. The spread of HIV is linked to drug use and sexual behavior, and young women are affected in almost the same numbers as young men.

If data about newborns and young children are sparse, information about adolescents is almost nonexistent. The CDC has only recently begun to count AIDS among adolescents as a separate category. Relatively few cases (350 through February 1989) have been reported among young people aged 13 to 19. However, it is misleading to look only at AIDS cases. Because of the long latency period between HIV infection and the onset of symptoms, many of the cases of AIDS now being seen in people in their 20s undoubtedly reflect infection in their adolescent years.

Although nationwide the ratio of male to female adolescents with AIDS is seven to one, in New York City it is three to one. That ratio approaches the statistics in Africa, where AIDS is predominantly a disease of heterosexual men and women and equal numbers of men and women are infected.

Nationwide, 22 percent of adolescent cases are linked to hemophilia or transfusions with contaminated blood, whereas in New York City these risk factors account for just 11 percent. Twenty-three percent of the adolescents with AIDS in New York City are more likely to report drug use as a risk factor, a much higher figure than elsewhere in the country. Among young women, heterosexual transmission (usually as a result of sex with a drug-using partner) accounts for 52 percent of the adolescent AIDS cases.¹⁰

IV infection rates among New York City military recruits are higher than the national average. A study of HIV seroprevalence rates among military applicants in four New York counties (New York, Kings, Queens, and the Bronx) showed that "rates for any specified age group were four to ten times greater in these counties than in the rest of the United States." Furthermore, HIV seroprevalence rates among men and women in these four counties were "surprisingly similar, suggesting that infection is occurring in the male and female populations at comparable rates."¹¹

Although proportionately fewer adolescents have acquired AIDS through homosexual behaviors, young gay men are clearly at special risk. Homeless youth, many of whom turn to homosexual or heterosexual prostitution and drug use, are

another category of adolescents at high risk. (See Chapter 4: "Housing, Homelessness, and the Impact of HIV Disease.")

HIV is already spreading among adolescents; it will be facilitated by high rates of other sexually transmitted diseases in this population, and by a reluctance to change risky behavior. In the light of these facts, the inadequacy of AIDS education and services especially designed for adolescents is particularly alarming.

Healthy children in HIV-infected families. An estimated 10,000 children in New York City will lose both parents to AIDS within the next few years. Another 60,000 to 70,000 will lose one parent.¹² In addition to the growing numbers of children and adolescents who are HIV-infected or who have AIDS there are healthy children who have special needs because their family structure has been disrupted by HIV-related disease. Such children include the healthy siblings of HIV-infected babies. Their mothers, themselves infected and likely to become ill, are often unable to provide appropriate care for either sick or healthy children. Without supervision, nurturing, and emotional support, these healthy children may turn to risky sexual and drug-using behavior. At the very least, they are vulnerable to problems at school and must deal with the stigma associated with AIDS and drug use in their families.

The New York City AIDS Task Force has concluded that "over the next few years a minimum of 60,000 to 70,000 children in New York City will lose at least one parent to AIDS. Of these, maybe 10,000 will lose both parents to the disease."¹³ Ernest Drucker and his colleagues at Montefiore Medical Center agree that 10,000 children will be orphaned; they place the number of children who will lose at least one parent at over 100,000, "and in the case of 35,000 children, it will be the parent with whom that child lives."¹⁴

Another study conducted by the National Women's Health Network estimates that there are between 32,000 and 45,000 infected mothers in New York City (a much higher figure than official New York City Department of Health estimates). If 80 percent of these women develop AIDS or a lethal HIV-related illness, between 26,000 and 36,000 will die. If on the average these women have two uninfected children, a total of 52,272 and 72,000 children will motherless. Since in many cases the child's father has either died of AIDS, is not present, or is unable to take over the care, the child will be in effect orphaned. Although these figures are based on many still-unproven assumptions, they suggest at the very least a serious problem that has not been addressed at all.¹⁵

The Economic Impact

Current estimates of the costs of care for HIV-related disease and AIDS vary considerably, depending on the population served, the region of the country, and the

services provided. But these estimates generally share one feature: they are based on the care of adults, not children.

A recent study conducted at Harlem Hospital Center suggests that hospital costs for children are different in some respects and probably higher.¹⁶ James D. Hegarty and his colleagues note that the incubation period for pediatric HIV disease is shorter and the cumulative mortality rate higher. Infected children are particularly vulnerable to recurrent episodes of bacteremia, meningitis, and other bacterial infections, as well as to many of the same opportunistic infections that strike adults. Most of these children also experience developmental and growth delays and the social and medical problems associated with poverty and drug use in their families.

The Harlem Hospital study found that the total cost of caring for 37 HIV-infected children from 1981 to 1986 was \$3,362,597, or an average lifetime cost of \$90,347 per child. One third of the total inpatient days and more than 20 percent of the cost resulted from social factors. "Boarder babies" had a mean length of stay nearly four times longer than those with homes (339 days versus 89 days), although their daily costs were lower (\$466) than for babies with opportunistic infections (\$705 per day) who required intensive medical interventions. By comparison, the average daily costs at St. Clare's Home for Children, a transitional residence in Elizabeth, New Jersey, for children with AIDS or HIV infection, are \$260.¹⁷ The key factors predicting length of stay were not medical but social: maternal intravenous drug use and the lack of a suitable home.

In reviewing 1986 data, the New York State Department of Health found that more than one third of the pediatric AIDS cases had an average length of stay per hospitalization of more than 50 days; the longest length of stay was 129.5 days. In 1987, nearly one third of the hospital stays was 40 or more days. Because large numbers of children have not historically needed home care or long-term care, virtually no such services exist.¹⁸

A study conducted at Yale-New Haven Hospital found that 54 percent of the days spent in the hospital by 34 HIV-infected children were "medically unnecessary."¹⁹ Nearly all of the unnecessary stays over three weeks resulted from difficulties in placing the child after discharge. The proportion of medically unnecessary days was actually lower than those reported in 1983 and 1984, due to improved outpatient services offered by the hospital.

These studies conclude that improved outpatient medical and social services could substantially reduce the costs of care. However, they do not consider the indirect costs to society that will result from premature mortality and morbidity, or the social and human costs of inappropriate hospitalization of children.

Any assessment of indirect costs should also account for the long-term impact on the economy of the future loss of productivity among HIV-infected young people. In her report to Dr. Bowen, Dr. Novello pointed out that the current population of young people aged 11 to 24 is unusually small to begin with. "If AIDS were to make serious inroads in this group, the long-term consequences could be disastrous for the nation's economy."²⁰ Since adolescents in the New York City-Northern New Jersey region are most at risk, this region's economy may be the hardest hit in the nation.

The Major Needs

Several groups have already issued reports on the major needs of children and adolescents affected by HIV/AIDS, and have proposed remedies. Although some encouraging individual projects are underway or planned, none of these reports has resulted in dramatically increased services.

In April 1987 the Citizens' Committee for Children of New York issued a report entitled "The Invisible Emergency: Children and AIDS in New York." The Citizens Committee found that "[HIV-infected] children and their families have intense medical and social support needs that are not being adequately met by the network of services available in New York City."²¹ Services most difficult to obtain, the report concluded, are safe and decent housing, foster home placement, adequate stimulation and recreational services for the children, and counseling services for their parents.

New York City's Strategic Plan for AIDS, issued in May 1988, which covers only City agencies, included a section on pediatric AIDS prepared by the Health and Hospitals Corporation. The plan contains some specific goals and timetables but so far no reports have been issued to document progress or lack of it in meeting these goals.²²

The New York City AIDS Task Force, a public-private collaboration organized by the New York City Department of Health, has addressed the problems of providing care for adolescents and children. Its report, entitled "Models of Care," outlines several constraints in providing care for adolescents. Specifically, the report notes that health care facilities are usually organized to provide care for adults or young children, and that the few existing adolescent health services do not have staff to accommodate new HIV-related services. Adolescents living on their own do not have access to public or private health insurance. Even when they are able to obtain medical care, they often cannot afford drugs and other medical supplies. Existing drug treatment facilities usually exclude minors, and housing for homeless youth and HIV-positive adolescents is difficult to obtain.²³

The Task Force recommended that New York State and New York City "establish special funding for purposes of providing medical care and psychosocial support services to HIV-positive youth." It also recommended, among other things, the

development of group homes for homeless youth under 18 years of age with multiple problems, and residences and shelters for homeless youth 18 to 21 years of age.

The Task Force noted that long-term care and respite services for children are severely limited, that there are tremendous difficulties in recruiting foster parents for HIV-infected children, and that there is community resistance to group homes for HIV-infected children. Among its recommendations were the provision of mental health services for children to lessen the psychological impact of AIDS, and the continuation of financial incentives to attract more foster care parents. "The aim," the Task Force said, "should be to place every abandoned or orphaned HIV-infected child who cannot be placed with relatives in a foster home." However, it stressed that natural families should be given assistance in cash and services to maintain their children at home if at all possible.²⁴

The New York State 5-Year Interagency Plan calls for a broad array of services for women, children, and families, and reports that "a major Department of Health initiative is underway to augment services within the AIDS center system for children, adolescents, pregnant women and their families."²⁵ These initiatives, if implemented, would make an enormous difference. However, since the five-year plan does not contain any funding sources, the program goals may never be reached.

The New York City AIDS Fund issued its "Needs Assessment" in October 1988. The Fund is a private sector collaboration of the National Community AIDS Partnership, a project of the Ford Foundation, and grantmaking organizations in New York City. It found that the outstanding needs for adolescents and pre-adolescents are: primary prevention/education programs for those youngsters not yet sexually active and/or abusing drugs; and behavior change strategies tailored to adolescent subpopulations at especially high risk. For infants and children the priority needs are: expanded and improved family supports and foster care resources, services for uninfected children of parents and/or siblings with HIV infection or AIDS, and family-oriented prevention and care services.²⁶

In a comparable effort in New Jersey, the New Jersey AIDS Fund recently completed its needs assessment. It found that private funds are particularly needed to support the recruitment of foster parents for children with AIDS and to underwrite a new transitional residence in Monmouth County and at least two more additional homes in southern and northern New Jersey. The Fund also identified day care for adults and children as pressing needs.

Existing Models of Care

While existing facilities and services are inadequate to meet future needs, they do provide some replicable models if the necessary funding and support were provided:

1. Acute Care Units. Children with AIDS and some with HIV infection need the specialized care that is available on an inpatient basis. Some hospitals have established special units offering comprehensive medical care and access to experimental drugs for pediatric patients. Such units have been established at Harlem Hospital, Albert Einstein College of Medicine, and the Newark Children's Hospital.

2. Transitional Pediatric Residences. St. Clare's Home in Elizabeth, New Jersey serves as a transitional facility for children with AIDS who do not need to be hospitalized and are awaiting placement with a foster family or return to their natural family.²⁷ The home, located near the grounds of St. Elizabeth's Hospital, was opened with the support of the community, including volunteer labor for remodeling. St. Clare's can accommodate five babies at a time and provides a comprehensive set of services. Operated by a nonprofit organization called AIDS Resource Foundation for Children (ARFC), St. Clare's is funded by a grant from the New Jersey Department of Health, the State's Division of Youth and Family Services, Medicaid payments, and private contributions. ARFC has opened a second home in Jersey City and is planning a third in Monmouth County. It also operates Haller House in Newark, which provides housing as well as a variety of services for children with AIDS.

In New York City, the Association to Benefit Children is planning to open a Child Center in Yorkville. It will be the primary home for six abandoned, homeless infants diagnosed with AIDS or non-HIV-related handicapping conditions, until they can be placed in families. There are also plans to provide on-site day care for ten other babies with similar problems. An extensive volunteer program is planned to supplement the staff efforts. Funding will come from Medicaid and the New York City Human Resources Administration.

The Children's Center, a pediatric residence has opened in Brooklyn (after considerable community protest), and the Archdiocese of New York is also planning to open a residential facility for children.

3. Day Care Facilities. Many children with AIDS and HIV infection are able to attend regular day care and educational programs. However, some are too ill or too developmentally delayed to participate in these mainstream programs and need special services. The Bronx Municipal Hospital and the Albert Einstein College of Medicine operate a day care program for children with AIDS and ARC that can accommodate 25 children per day, ranging in age from infancy to age 7. Medical support is provided by a nurse on site and by the Bronx Municipal Hospital Center pediatric staff.

The Parent/Child Extension Center, a day care center that incorporates a Head Start program, broke ground in October in Newark, and is expected to begin operations shortly. Operated by the Babyland Nursery of the New Community Corporation, it will eventually care for 30 children and will receive state and federal support to provide day care, preschool programs, and medical care in a previously vacant building.²⁸

4. Adolescent Services. Special health care services for adolescents are provided at Montefiore Medical Center in the Bronx and at The Door, an adolescent health program in Manhattan. The Hetrick-Martin Institute provides services to gay and lesbian youth. Covenant House provides temporary housing for homeless youth and has just opened a special section of their Manhattan facility for adolescents with HIV infection or AIDS.

5. Foster Care. Financial incentives -- a monthly rate of \$1,177 a month, which is at least double the standard rate -- are provided in New York City to foster care families who take children with AIDS, and the problem of "boarder babies" has been somewhat ameliorated. The Leake and Watts Home in Yonkers has been a leader in providing foster care for New York City children. In New Jersey, the Children's Hospital AIDS Program of Newark has been providing comprehensive services to children and their families; by the end of 1987, 55 percent of the children receiving care at Children's Hospital were in some type of foster care setting (an increase of 20 percent over the previous year).²⁹ However, foster care systems have many problems of their own, and placing a child in foster care does not end the need for special services. Many of the developmental problems associated with HIV infection are discovered only when the child has been placed in a family setting.³⁰

What Must Be Done

The studies and surveys so far have reached many of the same conclusions: AIDS and HIV infection present special problems among newborns, children, and adolescents. The major needs are:

1. Access to primary medical care, with an emphasis on early diagnosis and intervention and continuity of comprehensive care.
2. Housing appropriate for the child's age, family status, and health. Especially urgent is the need for transitional residences for HIV-infected children who do not need to be hospitalized but who do not have biological or foster families able to care for them. Another urgent need is for housing for homeless HIV-infected adolescents.
3. Social services that include case management, mental health services, recreational opportunities, legal advocacy, and special educational services for developmental problems.
4. Day care for children who are too ill to be able to attend regular day care facilities.
5. Family supports (whether for natural or foster families) that enable children to be raised in a nurturing environment.
6. Special services for uninfected children whose parents or siblings are ill with AIDS or HIV infection.

While the costs of providing the services and programs that meet these needs will be significant, the costs of not doing so will be even greater. A society that claims to support "family values" cannot ignore the most needy of its children.

- NOTES -

1. Centers for Disease Control, AIDS Weekly Surveillance Report (5 December, 1988).
2. Citizens' Committee for Children, United Hospital Fund, and Gay Men's Health Crisis, The Invisible Emergency Continues: The Problem of Unreported Cases of HIV-Infected Children in New York City (24 February, 1989): 3.
3. Antonia Novello, report to Dr. Otis R. Bowen, Secretary of Health and Human Services, reported in The New York Times, 20 December, 1988.
4. U.S. Public Health Service, "Report of the Second Public Health Service AIDS Prevention and Control Conference," Public Health Reports 103, supplement no. 1 (1988): 94.
5. New York City Department of Health, Report of the Expert Panel on HIV Seroprevalence Estimates and AIDS Case Projection Methodologies (New York: February 1989), 5.
6. State of New York, AIDS: New York's Response: A 5-Year Intragency Plan (Albany, NY: February 1989): 18.
7. Robert Schwaneberg, "One in 200 Jersey Newborns Tests Positive for AIDS Virus," The Star-Ledger, 10 February, 1989: 1, 38.
8. P. L. Wyckoff, "Babies Born in Newark Will Be Tested Anonymously for AIDS Antibodies," The Star-Ledger, 15 March, 1988: 26.
9. I. Auger et al., "Incubation Periods for Paediatric AIDS Patients," Nature 336, no. 8 (December 1988): 575-577.
10. Sten H. Vermund, Karen Hein, Helene D. Gayle et al., "Acquired Immunodeficiency Syndrome among Adolescents in New York" (in press).
11. Donald S. Burke et al., "Demography of HIV Infections among Civilian Applicants for Military Service in Four Counties in New York City," New York State Journal of Medicine (May 1987): 262-64.
12. New York City AIDS Task Force, Models of Care Report (December 1988), 42.
13. New York City AIDS Task Force, Service Model for Persons Infected with the Human Immunodeficiency Virus (December 1988), 42.
14. Ernest Drucker et al., "IV Drug Users with AIDS in New York City: A Study of Dependent Children, Housing and Drug Addiction Treatment," Montefiore Medical Center, Albert Einstein College of Medicine, Department of Epidemiology and Social Medicine, 20 July, 1988: 19.
15. Chris Norwood, "AIDS Orphans in New York City: Projected Numbers and Policy Demands," National Women's Health Network (September 1988).
16. James D. Hegarty et al., "The Medical Care Costs of Human Immunodeficiency Virus--Infected Children in Harlem," Journal of the American Medical Association 260, no. 13 (8 October, 1988): 1901-05.

17. Terrence P. Zealand, "St. Clare's Home for Children: A Transitional Residence for Children with AIDS," QRB (January 1989): 18.
18. New York State, AIDS: New York's Response: 88.
19. Kathi Kemper and Brian Forsyth, "Medically Unnecessary Hospital Use in Children Seropositive for Human Immunodeficiency Virus," Journal of the American Medical Association 260, no. 13 (8 October, 1988): 1906-09.
20. Novello, pp. 84-85.
21. Citizens Committee for Children of New York, Inc., The Invisible Emergency: Children and AIDS in New York (New York: April 1987), 50.
22. Interagency Task Force on AIDS, New York City Strategic Plan for AIDS, section E.2 (May 1988): 16-18.
23. New York City AIDS Task Force, Service Model for Persons Infected with the Human Immunodeficiency Virus (December 1988), 29-31.
24. Ibid., 42-44.
25. AIDS: New York's Response: 86-89.
26. New York City AIDS Fund, AIDS, Community Needs and Private Funding: A Needs Assessment for New York City (October 1988), 30.
27. Terrence P. Zealand, "St. Clare's Home for Children: A Transitional Foster Home for Children with AIDS," QRB (January 1989): 17-20.
28. Joan Whitlow, "A Caring Place," The Star-Ledger, 5 October 1988: 1, 53.
29. Mary G. Boland, Patricia Evans, Edward M. O'Connor, and James M. Oleske, "Foster Care Needs of Children with HIV Infection," AIDS & Public Policy Journal 3, no. 1 (Winter 1988): 8-9.
30. Suzanne Daley, "Study of Foster Infants Finds New York City Failed Them," The New York Times, 1 February, 1989: A1, B5.

Interview: "James"

"The most difficult thing is fighting the system for what you are entitled to . . . I get threatening notes from ambulance services. Can you imagine?"

James, a 37-year-old man, is a former IV drug user from Manhattan who has been living in Bailey House since January 1988. Raised in a family where drug use was common, James worked sporadically as a shipping clerk in the garment industry until he fell ill late in 1985. He agreed to discuss his illness in the hopes that his experiences will help sensitize others to the problems of people with AIDS.

Three years ago, a recurrent fever, body aches, and chills made him too weak even to negotiate a set of stairs. His condition quickly deteriorated and he had to be hospitalized for 30 days, where he was treated for Pneumocystis carinii pneumonia or PCP. He did not receive an AIDS diagnosis at this time and was eventually able to return to his job in the garment industry -- and to pick up his old drug habit as well.

But within a few months, he was back in the same hospital with another case of PCP. When he was released a grueling 60 days later, he still did not know that he had AIDS. By then unable to work, and threatened with the prospect of homelessness, James turned to the social service system for assistance. It was another 10 months before Medicaid processed his application and declared him eligible for subsidized care.

Not until the winter of 1987-88, when James suffered his most severe physical collapse, was he diagnosed as having AIDS --at the same hospital that had first treated him in 1985. James is certain that the hospital's initial failure to recognize the nature of his health problem meant he did not receive appropriate care. As his physical condition deteriorated, his elderly mother was no longer able to care for him and with his third hospitalization, James joined the ranks of the homeless.

Along with the physical and psychological consequences of AIDS and homelessness, James found the machinery of the health care and social service systems in New York City overwhelming. Although his social worker was able to help him move to Bailey House after his third hospitalization, he still recalls his dependency on impersonal bureaucracy with dread:

The most difficult thing is fighting the system for what you are entitled to. You go and apply for Food Stamps and you're pulled through a rigmarole. Case in point: I speak to the doctor and he schedules a bronchoscopy for me. The finance department has the nerve to call me here and tells me don't come to the hospital because our computer has

no record of your receiving Medicaid. They say I don't have Medicaid, which I did. I get threatening notes from ambulance services -- can you imagine?

Chapter 6

Preventing Discrimination in the Care of AIDS/HIV Patients

Discrimination by direct care providers is legally, professionally, and ethically prohibited. Despite this categorical statement, some health professionals are refusing to treat people with AIDS. The conduct of this small but growing population of physicians, dentists, and nurses "threaten[s] the very fabric of health care in this country, which is based on the assumption that everyone will be cared for and no one will be turned away," declared U.S. Surgeon General C. Everett Koop in the fall of 1987.¹

This chapter looks at the reality of discrimination against AIDS and HIV-seropositive individuals, discusses the legal and moral proscriptions against such behavior, and describes the rational ways in which health providers can protect themselves without denying care to those who need it.

The Extent of the Problem

In the greater New York-New Jersey region and across the United States, reports of discrimination by health and social service providers have increased since the inception of the HIV epidemic. A noted heart surgeon from Milwaukee, Wisconsin, Dr. Dudley Johnson, publicly declared his refusal to operate on patients infected with the virus.² An orthopedic surgeon, Dr. Robert Spicer, is reported to have refused emergency medical care to a Washington, D.C. man simply because he was assumed to be gay.³ Officials at Newark's University Hospital have complained of patient dumping because too many physicians simply don't want to deal with AIDS patients.⁴ The East Rutherford (New Jersey) Ambulance Squad refused to transport a man to a hospital in spite of pleas from his physician.⁵ A renowned private children's hospital, the Alfred I. du Pont Institute in Wilmington, Delaware, announced a policy to test all patients, hospital employees, and job applicants; patients testing positive would be refused treatment and HIV positive employees would be subject to adverse personnel actions.⁶ This policy was subsequently "postponed" following the enactment of a new state law prohibiting employment discrimination against the handicapped and threats of a legal challenge by the Delaware Attorney General.⁷ Finally, the New York City Commission on Human Rights has been investigating several reports of dentists refusing to care for infected patients.⁸

Studies of physician attitudes are equally disturbing. In a recent survey⁹ of medical and pediatric interns and residents affiliated with New York City hospitals, two-thirds of respondents stated that any personal concerns about acquiring AIDS did not affect patient care, but 25 percent would not continue to care for AIDS patients if

given a choice. A remarkable 36 percent of medical and 19 percent of pediatric residents reported that their on-the-job experiences made them less likely to care for AIDS patients in their future practices. Moreover, 11 percent were moderately or extremely resentful about being required to treat persons with AIDS. A study among physicians and nurses working at the New York Hospital-Cornell Medical Center in New York City revealed that "almost one-third of the physicians and nurses said that hospitalized AIDS patients received 'inferior care' compared with patients of other illnesses -- as many gay people had asserted -- and that they had felt 'more negatively' about homosexuality since the AIDS crisis emerged."¹⁰ Even more alarming, 60 percent of the physicians responding to a British survey reported feeling "hostile" to individuals with AIDS and did not desire to provide them medical care.¹¹

Surveys of public attitudes regarding discrimination by health care providers reveal conflicting views. In a recent New England Journal of Medicine analysis of public opinion surveys which examined AIDS-related discrimination, 87 percent of Americans were "very supportive of the government's banning discrimination" by hospitals against patients with AIDS.¹² Almost one-third (32 percent), however, "would allow physicians to make their own choices about whether to treat patients with the disease."¹³

Legal Protections

People with or perceived as having AIDS or HIV infection are protected from discrimination by health and social service providers by several sources. A number of legal decisions have affirmed that persons with AIDS are covered under the Federal Rehabilitation Act of 1973, which bars discrimination against handicapped individuals in all federal agencies or in federally-funded programs.¹⁴ The U.S. Supreme Court recently held that contagious diseases fall within the purview of the Rehabilitation Act's nondiscrimination provisions.¹⁵ In the Civil Rights Restoration Act of 1987, the United States Congress has also reaffirmed this interpretation by extending the Rehabilitation Act's employment protections to include individuals with contagious conditions who pose no threat to the health of coworkers and who are able to perform their job duties.¹⁶ Finally, in a reversal of an often-criticized 1986 interpretation, the United States Justice Department recently announced that the anti-discrimination protections of the Rehabilitation Act extended to people infected with HIV.¹⁷ Therefore, all federally funded health and social services programs, including Veterans Administration hospitals and hospitals and nursing homes accepting Medicare and Medicaid, are included under this act.¹⁸

Two recent court decisions confirm that the Rehabilitation Act protects the right of people with AIDS and HIV infection to appropriate health care. In Doe v. Centinela Hospital,¹⁹ a federal district court in California held that an asymptomatic, HIV-positive individual who was barred from a drug treatment program could sue

under the Act for discriminatory exclusion. Likewise, in a Texas case, Dallas Gay Alliance, Inc. et al. v. Dallas County Hospital District,²⁰ a state court used the Rehabilitation Act, as well as other statutes, to prevent a public hospital from discriminating against patients with AIDS and ARC. The hospital had limited the number of hospital beds allocated to HIV-positive patients, established waiting lists for AZT treatment, and denied medically prescribed aerosolized pentamidine treatment.

The civil rights laws of New Jersey,²¹ New York State,²² and New York City²³ protect individuals with or perceived as having AIDS and HIV infection from discrimination in places of "public accommodation," which generally include public and private hospitals, dispensaries, clinics, and social service agencies. While the States of New York and New Jersey have not yet determined whether the offices of individual physicians and dentists are included within their laws, New York City law has been explicitly interpreted to cover all health care practitioners.²⁴ To remedy this legislative gap, New York State, in its recently issued 5-year Interagency Plan, recommended that the State Division on Human Rights propose legislation to amend the State Human Rights Law "to include explicitly professional offices that treat or serve patients or clients within the definition of places of public accommodation."²⁵

State and City enforcement agencies must be appropriately funded and staffed to permit prompt and thorough investigations and prosecutions of discrimination complaints. While New York State concedes that "existing protections may be enhanced by increased funding for enforcement activities," it has not allocated additional funds to do so.²⁶

Until the legal issues are resolved, the right of physicians or other independent health care practitioners to refuse treatment to individuals with AIDS or HIV-antibodies will continue to be vigorously debated. Meanwhile, other avenues to redress discrimination may be considered, including those created by express or implied contract and by ethical standards developed by medical associations and state licensing boards.

The application of federal and state disability discrimination statutes to nursing homes has also been a controversial issue. While nursing home facilities are hardly ideal settings in which to provide care and are often inappropriate for people with AIDS who are usually years younger than the typical long-term care patient,²⁷ such skilled nursing care may be medically indicated for some individuals who do not require medical care, but need round-the-clock support services. However, relatively few nursing homes in the bistate region, and nationwide, are willing to provide care to people with AIDS.²⁸ Despite legal mandates, few state regulators are challenging these discriminatory acts.

One exception is the Minnesota Department of Human Rights, which filed a successful complaint in 1987 under the State Human Rights Act against 16 nursing homes that refused to admit people with AIDS.²⁹ Although the facilities claimed that

treating persons with AIDS was too costly, that proper safety precautions had not yet been taken, and that admitting such individuals would result in losses of other patients, the Human Rights Department determined that "not one of those reasons [was] a valid cause for discriminating against someone with a disability."³⁰ The Department further reported that extensive staff evaluations of the costs of care for AIDS patients

found no basis for the belief that their care cost more than traditional nursing home patients...AIDS patients, like heart patients or other patients, do have varying needs, so some AIDS patients may cost more. But generically, AIDS patients don't cost more...[Likewise,] nursing homes have had several years to advise their staffs of the [necessary] safety precautions...[While] losing other patients by admitting AIDS patients may be a possibility...it still is not a valid legal excuse.³¹

Subsequently, all facilities agreed to accept HIV infected patients.³² Similar litigation, filed under the auspices of federal and state law, is currently pending in Texas.³³

The Impact of Common Law and Professional Ethics

In an article in the Hastings Center Report, George J. Annas describes the traditional common law bases of the "duty-to-treat" concept.³⁴ Under common law, physicians have not been obligated to attend to a patient in the absence of a consensual doctor-patient relationship, but medical care has become mandated in specific situations. First, physicians working in emergency rooms are required to treat all patients with medical emergencies. Second, once a voluntary relationship with a physician is established, the doctor may not abandon the patient. More specifically, Annas writes that "once a doctor-patient relationship is established, it continues until:

1. It is terminated by mutual consent;
2. It is terminated by the patient;
3. The physician's services are no longer needed; or
4. The physician withdraws after reasonable notice to the patient."³⁵

Moreover, under the public interest business doctrine, which has generally been displaced by the public accommodations statutes, businesses claiming to serve the public may be bound to provide services.³⁶ Finally, individuals participating in specific health provider agreements, such as those maintained by health maintenance organizations, will benefit from a broader duty to treat than that existing with the individual practitioner.

Professional associations are responsible for setting the ethical ideals for individual practice. While these codes of behavior do not have the force of law, they are useful for establishing a "standard of care" that courts may find persuasive in

establishing liability in discrimination or malpractice cases. Regarding the ethical obligations of physicians, the American Medical Association has stated:

Those persons who are afflicted with [AIDS] or are seropositive have the right to be free from discrimination. A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive. . . . Neither those who have the disease nor those who have been infected with the virus should be subjected to discrimination based on fear or prejudice, least of all by members of the health care community.³⁷

While the A.M.A. has no plans to enforce this policy actively, doctors found to violate these norms could theoretically be expelled from the association should a patient file a successful complaint.³⁸

State licensing boards also set guidelines and regulations for their practitioners. Unlike the ideals established by the A.M.A., licensing boards set the legal minimum requirements for practice in their state; these guidelines are enforceable in disciplinary proceedings that can lead to the suspension or revocation of an offending practitioner's license. The State Boards of Medical Examiners and of Dentistry in New Jersey have both issued policy guidelines on patient care.³⁹ The Medical Examiners AIDS policy states:

A licensee of this Board may not categorically refuse to treat a patient who has AIDS or AIDS related complex, or an HIV positive blood test, when he or she possesses the skill and experience to treat the condition presented. . . . Even where . . . extenuating circumstances may exist, the Board would hold that the licensee retains the responsibility to make alternative arrangements for the proper care of a patient.⁴⁰

Unfortunately, the medical and dental licensing boards in New York State have not adopted any guidelines on care for people with HIV-related conditions. However, the Associated Medical Schools of New York, which represents the state's 13 private and public medical schools, has stated that physicians have a "most fundamental responsibility to treat AIDS, regardless of risk"; faculty members, hospital residents, or medical students refusing to treat persons with AIDS are subject to dismissal.⁴¹ Furthermore, New York State, in its 5-Year Interagency Plan, authorized the State Education Department to "modify New York professional codes and accompanying regulations to prohibit discrimination based on disability by licensed professionals."⁴²

The fear of HIV transmission lies at the root of most discrimination. To address that issue, the Centers for Disease Control has developed detailed guidelines, commonly known as "universal precautions," to prevent occupational HIV exposure among health care workers and allied professionals.⁴³ It is widely accepted, and has been

epidemiologically demonstrated, that the potential of work-related transmission among most health care workers following CDC guidelines is minimal.⁴⁴ Staff education is essential in preventing fear-related discrimination. Unfortunately, however, it must be noted that discrimination by care providers is also linked to outright prejudice based on sexual orientation, race, ethnic origin, and drug-using status.⁴⁵

Unlike most health care providers, surgeons may in fact be at higher risk of occupational transmission. In an article in the New England Journal of Medicine, Ezekiel J. Emanuel delineates those factors, such as the number of patients with AIDS and the frequency of unavoidable punctures, which increase or reduce the risk of transmission to surgeons.⁴⁶ While Emanuel suggests that excessive risk may limit a surgeon's obligation to operate on individuals with AIDS, it does not eliminate all obligations, such as the performance of emergency procedures. The author recommends adopting universal precautions, forgoing elective surgical interventions, and "reducing the number of patients with AIDS treated by a single physician by requiring other competent physicians to treat them."⁴⁷

Ultimately, mandating all surgeons to treat a few AIDS patients -- thereby reducing the risk to practitioners who treat many of them -- requires effective action by the appropriate medical societies and state licensing boards. This, in turn, provides the autonomy for the profession to define its own ethical standards. However, as suggested by Annas, "Should the profession fail to respond adequately to the needs of patients in an unprecedented epidemic, the law will rightfully continue to set a standard of minimum conduct below which no physician may fall without confronting the possibility of losing a malpractice or discrimination suit or even his license to practice."⁴⁸

Conclusion

Although federal, state, and local statutes already provide an important measure of protection to people with disabilities, additional legislative and regulatory action is needed to ensure against discrimination in the care of people with AIDS or HIV illness. New Jersey and New York State have been dilatory in determining whether private medical practices should be subjected to the civil rights laws that ordinarily protect individuals from discrimination. State and City enforcement agencies have not been funded or staffed at levels that permit prompt and thorough investigation and prosecution of discrimination complaints. States have been lax in challenging the discriminatory policies of many nursing homes.

Professional associations can and must also do more to see that their members respect the basic human and civil rights of individuals with AIDS. In New Jersey, the State Board of Medical Examiners and the State Board of Dentistry have issued policy guidelines that obligate physicians and dentists to provide a reasonable level of care.

The fact that comparable boards in New York State have not taken similar action is simply inexcusable.

Our society has come a long way in the struggle to overcome prejudice and discrimination, but AIDS poses new ethical and legal challenges of great magnitude. Health care providers should extend their services to persons with AIDS; with detailed precautions now available, fear of HIV transmission is not an acceptable excuse for turning from people in need.

- NOTES -

1. "Doctors Who Shun AIDS Patients Are Assailed by Surgeon General," The New York Times, 10 September, 1987.
2. "Surgeon Won't Operate on Victims of AIDS," The New York Times, 13 March, 1987.
3. "AIDS Suspicion Bars Surgery," The New York Times, 9 July, 1987.
4. "A dump for AIDS patients," The [Bergen] Record, 30 October, 1987.
5. "AIDS man is denied ambulance," The [Bergen] Record, 15 October, 1987.
6. "Private Hospital to Bar Patients With AIDS Virus," The New York Times, 25 June, 1988.
7. "Delaware Hospital to Revise Controversial Testing Policy," AIDS Policy & Law 3, no. 13 (Bureau of National Affairs, 13 July, 1988).
8. See "AIDS Patient Wins Decision In Rights Case," The New York Times, 23 February, 1988; "Barton v. New York City Human Rights Commission," New York Law Journal, 13 July, 1988; and "A Dental Clinic Is Fined \$47,000 For Refusing to Treat AIDS Cases," The New York Times, 29 September, 1988.
9. R. Nathan Link, Anat R. Feingold, Mitchell H. Charap, Katherine Freeman, and Steven P. Shelov, "Concerns of Medical and Pediatric House Officers About Acquiring AIDS from Their Patients," American Journal of Public Health 78 (April 1988): 455, 457.
10. "Health care workers' homophobia affects care of AIDS patients: study," American Medical News, 14 June 1985.
11. "Big Proportion of Doctors Said to Be Unsympathetic," AIDS Policy & Law 2, no. 5 (25 March, 1987): 7.
12. "Occasional Notes--Discrimination Against People With AIDS: The Public's Perspective," The New England Journal of Medicine 319 (13 October, 1988): 1022, 1025.
13. Ibid.
14. 29 U.S.C. §§ 706(8)(B), 794.
15. School Board of Nassau County, Florida v. Arline, 480 U.S. ___, 107 S.Ct. 1123 (1987).
16. P.L. 100-259, 22 March, 1988.
17. "Protection for U.S. Workers With AIDS Is Widened," The New York Times, 7 October, 1988. For a discussion of the Justice Department's initial opinion see "Rights Laws Offer Only Limited Help on AIDS, U.S. Rules," The New York Times, 23 June, 1986.
18. U.S. v. Baylor University Medical Center, 736 F.2d 1039 (5th Cir. 1984), cert. denied, 469 U.S. 1189, 105 S.Ct. 958 (1985).
19. John Doe v. Centinela Hospital, et al., unpublished opinion, No. CV 87-2514 PAR (PX) (Central Dist. Cal., 30 June, 1988).

20. Dallas Gay Alliance, Inc., et al. v. Dallas County Hospital District D/B/A Parkland Memorial Hospital, unpublished opinion, No. 88-6346-A (14th Dist. Dallas Co., Texas, 20 May, 1988). This case has been removed to the United States District Court for the Northern District of Texas, Dallas Division.
21. N.J.S.A. 10:5-1 et seq.
22. N.Y. Executive Law §290 et seq.
23. N.Y.C. Admin. Code, Chap. 1, Title 8.
24. See note 8 above. The state civil rights agencies of New Jersey and New York State are accepting discrimination complaints involving health care practitioners. However, also see Elstein v. State Division on Human Rights, New York Law Journal, 18 August, 1988 (The New York State Supreme Court held that the office of an independent practicing physician is not a public accommodation under the state human rights law; this case has been set for reargument on procedural grounds, in addition to being appealed to the State Appellate Division.)
25. State of New York, AIDS: New York's Response, A 5-Year Interagency Plan (January 1989): 116.
26. State of New York, AIDS: New York's Response, A 5-Year Interagency Plan (January 1989): 116.
27. "Nursing Homes: Experts Say Problems of Younger Patients are Being Overlooked," The New York Times, 28 January, 1988.
28. See e.g., "Study Reports Inadequacies in Illinois Nursing Homes," AIDS Policy and Law (Bureau of National Affairs, 5 October, 1988): 2-3.
29. "Nursing Homes Are Charged In Refusal to Take Patients," AIDS Policy & Law 2, no. 18 (Bureau of National Affairs, 23 September, 1987): 3.
30. *Ibid.*
31. *Ibid.*
32. "Minnesota Nursing Homes Agree to Accept Patients," AIDS Policy & Law 2, no. 21 (Bureau of National Affairs, November 4, 1987): 6; Conversation with Elaine Hanson, Intake Supervisor at the Minnesota Department of Human Rights, on October 11, 1988.
33. See David Piontkowsky and Michael J. Kowal, "The Right to Nursing Home Care for Persons with AIDS," in Paul Albert, Leonard Graff, and Benjamin Schatz, eds., AIDS Practice Manual: A Legal and Educational Guide (National Gay Rights Advocates and the National Lawyers Guild AIDS Network 1988): X2. This article provides one of the few analyses of discrimination claims against nursing homes.
34. George J. Annas, "Legal Risks and Responsibilities of Physicians in the AIDS Epidemic," Hastings Center Report 18 (April/May supplement 1988): 26-28.
35. *Ibid.*, p. 27.
36. See James M. Campbell, "Access to Health-Related Services," in Abby R. Rubinfeld, ed., AIDS Legal Guide (Lambda Legal Defense and Education Fund, Inc., 1987), 3-2.

37. American Medical Association, "Report of the Council on Ethical and Judicial Affairs," released 12 November, 1987.
38. "A.M.A. Rules That Doctors Are Obligated to Treat AIDS," The New York Times, 13 November, 1987.
39. New Jersey State Board of Medical Examiners, AIDS Policy, adopted 18 November, 1987; New Jersey State Board of Dentistry, AIDS Policy Statement, adopted 3 February, 1988.
40. New Jersey State Board of Medical Examiners, AIDS Policy, adopted 18 November, 1987.
41. "13 Medical Colleges Say Staffs Must Treat AIDS," The New York Times, 9 December, 1987.
42. State of New York, AIDS: New York's Response, A 5-Year Interagency Plan (January 1989): 117.
43. Centers for Disease Control, "Recommendations for Prevention of HIV Transmission in Health-Care Settings," Morbidity and Mortality Weekly Report 36 (21 August, 1987): 2S, 3S-18S. Also see Centers for Disease Control, "Update: Universal Precautions for Prevention of Transmission of Human Immunodeficiency Virus, Hepatitis B Virus, and Other Bloodborne Pathogens in Health-Care Settings," Morbidity and Mortality Weekly Report 37 (24 June, 1988): 377-382, 387-388.
44. See James R. Allen, "Health Care Workers and the Risk of HIV Transmission," Hastings Center Report 18 (April/May supplement 1988): 2-4.
45. See John D. Arras, "The Fragile Web of Responsibility: AIDS and the Duty to Treat," Hastings Center Report 18 (April/May supplement 1988): 10, 17-18.
46. Ezekiel J. Emanuel, "Do Physicians Have an Obligation to Treat Patients With AIDS?" The New England Journal of Medicine 318 (23 June, 1988): 1686, 1688-89.
47. *Ibid.*, p. 1688.
48. George J. Annas, note 34 above: 26.

Chapter 7

Planning for Early Intervention in HIV Disease

Impending breakthroughs in the early treatment of HIV-seropositive individuals will soon pose tremendous new challenges to the health care system in the New York region and throughout the United States. If it becomes feasible to halt or reverse the progression to AIDS, the way in which we think about the disease and plan for care is certain to change markedly. Huge numbers of chronically ill people will demand extensive -- and traditionally difficult-to-fund -- ambulatory services, possibly for many years. With the expanded need for appropriate testing, counseling, treatment and follow-up services, innovative organizational and financing mechanisms will have to be found.

Although the medical justification for early intervention is not yet firmly in place, a number of key clinical studies suggest the day is not far off. Scientists are beginning to understand the serological markers that signal the progression of infection; they believe that the timely administration of AZT or other anti-viral and immune-boosting medications may be effective in staving off full-blown AIDS; and they are learning to prevent Pneumocystis carinii pneumonia, the most common presenting opportunistic infection.

In New York City alone, more than 100,000 of the estimated 200,000 asymptomatic seropositive individuals may benefit from early intervention, based on their clinical status. This is five to ten times the number who have actually been diagnosed with AIDS.^{1,2} In New Jersey, an estimated 70,000 to 105,000 individuals are HIV infected; half of them might also benefit from early intervention. Providing accessible care to them will become both a measure of our humanity and a potential tool for stemming the tide of the epidemic. But time is short. In the absence of intervention, current epidemiological data suggests that most HIV-infected individuals will ultimately develop end-stage AIDS.^{3,4,5,6,7} With appropriate treatment, however, viral replication may be controllable.⁸ Combined with counselling and known methods of risk reduction, treatment may help curb future transmission and slow the spread of disease. Potent anti-viral agents may also help contain the growing incidence of non-opportunistic disease, including syphilis, tuberculosis and bacterial pneumonia, which has been an overlooked concomitant of the AIDS epidemic, particularly among IV drug users.^{9, 10, 11, 12}

Alert to the imminent development of early intervention strategies, policymakers should be planning now for their impact. Instead, this potentially explosive issue has been virtually ignored. No government agency in New York or New Jersey has developed even the most preliminary contingency plans for addressing it. The recent

reports issued about the AIDS crisis in New York omit any in-depth discussion of new treatment modalities and their potential impact. This chapter describes current research into early intervention, examines the potential impact on the provision and financing of health care, and presents a dramatic case for the importance of immediate planning.

Medical Breakthroughs and the Potential of Early Intervention

Three key medical developments have greatly enhanced the likelihood that early medical intervention for HIV-positive individuals will be available soon.

First, researchers are beginning to understand the changes in immunological markers that signal disease progression, notably shifts in T-helper lymphocytes (CD4), beta-2 microglobulin, HIV p24 antigen levels and other specific antibody and immune cell levels.^{13, 14, 15, 16, 17, 18, 19, 20, 21, 22} While the prognostic value of any particular marker has not been established, there is evidence that the simultaneous shifting of several markers is highly significant. As scientists learn more about the significance of these markers, the propitious timing of early treatment and the monitoring of its efficacy will become viable.

Second, preliminary studies suggest that early treatment with AZT and other anti-viral pharmaceuticals can suppress replication of the HIV virus, as indicated by marker changes, and thus retard, halt, or conceivably reverse the progression of disease.^{23, 24} Other drugs have also displayed some promise for early intervention, such as Imuthiol, an immune system modulator.²⁵ National clinical trials are underway to test the efficacy of such therapies; once efficacy is determined, the demand for services will surge far beyond anything presently envisioned.

Third, great strides have been made in the prevention of Pneumocystis carinii pneumonia (PCP), the opportunistic infection that affects 80 percent of patients with AIDS.²⁶ Until recently, most studies have focused on averting relapses^{27, 28, 29} but attention is now being turned towards primary prophylaxis during the asymptomatic period. Ongoing research will determine what role aerosolized pentamidine and other drugs that have proven so vital to secondary prophylaxis of PCP will ultimately play in early intervention strategies.

Although the prospect of early medical intervention is enticing, the time frame in which to reverse the course of infection -- and perhaps prolong the lives of many thousands of HIV-infected individuals -- is alarmingly limited. Epidemiological data in San Francisco suggest that the overwhelming majority of gay men who have been infected with the HIV virus are fast approaching the late stages of asymptomatic infection. Within a few years, early intervention strategies will be of no practical value to this population. While there is insufficient data to know exactly when infection

spread in New York and New Jersey, the timing is not likely to differ markedly from that of the infected gay population in San Francisco.^{30, 31, 32}

How Early Intervention Challenges the Provision of Health Care

As early intervention becomes medical reality, the organization and financing of health care is likely to be further strained. New patients will enter the health care system in record numbers. Many will be intravenous drug users, a group with a poor record of participation in programs that offer long-term structured care. Most will be members of minority groups who live in impoverished neighborhoods with a tradition of inadequate and severely understaffed medical services.

And they will require a host of expanded ambulatory care programs. With meaningful treatment available to antibody-positive individuals, HIV testing will offer the potential of benefits beyond merely providing information that may be helpful in reducing risk to themselves or others. Large numbers of individuals in high-risk groups can be expected to seek antibody testing. Although legitimate concerns about confidentiality will remain -- and measures to guard against unauthorized disclosure of the results must be kept in place -- testing will come to be viewed as an important first step in identifying a serious but treatable medical condition.^{33, 34, 35} It should remain, nonetheless, voluntary; informed consent must be obtained.

Counseling patients before and after HIV testing, as the Public Health Service recommends, will assume paramount importance once medical intervention keeps infected individuals asymptomatic for longer periods of time. By bringing seropositive individuals into the health care system at an early stage, we have the opportunity to stem further transmission by providing appropriate counseling in risk-reduction strategies.

The need for serological monitoring to track immunological markers and to determine when medical intervention is appropriate will place further demands on outpatient services. Once treatment begins, serologic monitoring and other follow-up medical care will have to be provided continually -- perhaps for many years -- in order to assess immune function and to guard against side-effects from potent medications.

Today, the demand for antibody testing is met, albeit insufficiently, in a variety of settings, including freestanding clinics, hospital-affiliated outpatient departments, drug treatment facilities, STD clinics, and anonymous HIV testing sites, as well as in the offices of private physicians. But tomorrow, if early intervention becomes standard medical practice, these facilities will be totally inadequate to care for asymptomatic, seropositive individuals. How, then, will their plethora of needs be handled?

The answers demand creative thinking and a cautious -- but prompt -- evaluation of social and economic realities. Questions of equity and accessibility pose grave concerns. Already, middle-class gay men avail themselves of preventive treatment with AZT and aerosolized pentamidine. Because AZT is not approved for use in asymptomatic individuals, it is not covered by insurance and is therefore unaffordable to those who are infected but impoverished. These are primarily members of the minority communities.

An expanded and enriched ambulatory system will certainly be needed. The heightened stress on the health care system is illustrated in Table 1, where the number of physician/clinic visits required by patients seeking early intervention treatment are estimated. The availability of adequate funds is clearly a key issue but it is not the only one; the acute personnel shortages that already plague the health care system must also be addressed immediately. We must also consider whether patients should be mainstreamed into existing primary care facilities or steered towards specialty clinics. The peril of the latter approach is that it will allow health care practitioners to abdicate their responsibility for providing care to HIV-infected individuals by referring them to specialized centers.

Table 1
Estimated Number of Physician/Clinic Visits Required to
Provide Early Intervention Treatment Services in
New York City Beginning Each Year 1988-91
(Thousands of Visits per year)

	<u>1988</u>	<u>1989</u>	<u>1990</u>	<u>1991</u>
Low	492	471	445	417
Medium	945	941	891	834
High	1,970	1,882	1,782	1,669

Based on 12 physician/clinic visits per year for 25%, 50%, and 100% of all estimated HIV seropositives prior to an AIDS diagnosis.

The roles of primary care physicians, nurses, social workers, and other health care providers must be redefined and broadened. A team approach to care, which is already being used successfully to treat some hospitalized AIDS patients, has promising application in outpatient practice but funding constraints and personnel shortages have impeded efforts to develop this model.

In California, two early intervention programs are already in operation. Each provides immunological monitoring, psychological support, risk-reduction programs, and treatment referrals to seropositive, asymptomatic persons. Initially funded through Federal grants as a demonstration project, the California legislature recently appropriated \$1.5 million from general revenue funds to continue the existing programs and to develop six more prevention and follow-up centers this year. A commitment to this sort of innovation has thus far been sorely lacking in New York.

What Treatment Might Cost

Providing comprehensive medical intervention to HIV-infected individuals is an enormous undertaking. Although numerous variables make it impossible to provide firm estimates, the following scenario illustrates the magnitude of the costs in New York City alone.

Costs begin to mount well before pharmaceutical treatment begins. Apart from initial serotesting for the presence of HIV infection, we can envision a pre-treatment phase that would include a thorough, annual baseline examination; quarterly serologic monitoring (to measure such markers as CD4 cell count, beta-2 microglobulin and p24 antigen levels) and regular counseling, appointments. The costs of these services conservatively total approximately \$1,000 per year.

Once treatment begins, the figures soar. Serologic monitoring, counseling and physician visits become bi-monthly, or even monthly, occurrences. Assuming AZT is the anti-viral drug of choice and is administered at between one-half and 100 percent of the full dosage currently prescribed for AIDS patients, total annual treatment costs are estimated at between \$4,891 and \$10,382.*

Multiply these figures by the estimated number of HIV-infected individuals in New York (see Table 2) who have not yet been diagnosed with AIDS (in 1989, that figure is 158,846) and the burden is staggering, even if only 25 percent of potential candidates actually receive treatment (see Table 3). Add in potential costs for adverse side effects, additional drugs and ultimately, perhaps, end-stage treatment costs, and that burden may become far greater.

Table 2
Estimated Number of HIV-Infected New Yorkers
1988-1991
(Pre-AIDS Diagnosis)

<u>1988</u>	<u>1989</u>	<u>1990</u>	<u>1991</u>
164,136	158,846	148,483	139,047

Based on the mean estimated number of HIV-infected New Yorkers adjusted for cumulative and projected diagnosed AIDS cases and adjusted for the underreporting of IV drug users reported by Stoneburner.³⁷

Table 3
Estimated Costs of Early Intervention,
Treatment Beginning Each Year 1988-1991:
New York City
(expenditures in millions of dollars)

	<u>1988</u>	<u>1989</u>	<u>1990</u>	<u>1991</u>
Low	\$313	\$299	\$283	\$265
Medium	627	599	567	531
High	\$1,253	1,198	1,134	1,062

Low, medium and high estimates reflect treating 25%, 50%, and 100% of all estimated HIV seropositives prior to an AIDS diagnosis.

Although there are many unknowns in this scenario -- notably, how many years an individual will require care -- the large numbers of HIV-infected persons, the high cost of drug regimens and the inadequacy of current financing mechanisms make it clear that new ways to pay for treatment must be found. Unlike end-stage costs, which are mostly for inpatient care,^{38, 39} early intervention is provided largely in an ambulatory setting, where care has historically been poorly reimbursed.

The costs of obtaining prescription medications illustrate the flaws in current reimbursement policies. Early medical intervention depends heavily on drug efficacy, as indicated by the fact that AZT represents nearly 80 percent of the early intervention

treatment costs just described. Prices are very high -- half the normal dose of AZT runs \$4,000 a year. Since three-quarters of all prescription drug costs in the United States are paid out-of-pocket,⁴⁰ AZT and most other new drugs become unaffordable for all but a very privileged few unless special subsidies are provided. For the moment, the federal government does underwrite the cost of AZT for persons who lack adequate insurance as long as they have full-blown AIDS, but even that limited policy will expire in 1989, unless statutory changes are made. Even if the subsidies are maintained, they are unlikely to be expanded to include all asymptomatic seropositive individuals.

One option for bringing down the cost of early intervention is to reduce the price of pharmacological agents such as AZT. Under the Orphan Drug Act, the federal government has provided manufacturers with incentives to produce drugs for rare diseases by granting exclusive monopoly contracts without price constraints. The price of AZT does not represent actual production costs but rather windfall profits allowable under the Act. Political pressure may ultimately force the federal government to substitute non-exclusive licensing, accompanied by price controls, on all HIV-related products.

Regardless of that outcome, financing indigent AIDS care remains a burden that now falls on state-funded Medicaid programs. As early intervention enables HIV-positive individuals to live longer, some observers have suggested that costs may shift to the federal government via the Medicare program. Unfortunately, this is unlikely to happen. The presumption of disability, which entitles individuals to receive Social Security and, after a two-year qualifying period, Medicare, is granted only to those diagnosed with full-blown AIDS, not to all seropositive persons. Even if the rules are relaxed, eligibility for federal entitlements will continue to be determined by level of disability, thus restricting participation only to the severely ill.

Conclusion

Scientific research is rapidly advancing toward the time when it will be feasible to provide early medical intervention for individuals infected with the HIV virus. As we await the results of the large clinical trials now taking place in the United States and abroad, policymakers should be considering the ramifications of early intervention carefully and making plans to cope with the changes it will bring to our health care system.

We need to plan for expanded ambulatory care, which lies at the heart of effective early intervention and for the range of psychological and social services that will be needed. Early intervention may provide an opportunity to save thousands of lives. But we must act quickly, or the opportunity will be lost.

- NOTES -

1. New York City Department of Health, AIDS Surveillance Update (28 December, 1988).
2. New York City Department of Health, Estimate of HIV-infected New Yorkers (Working paper: July 1988).
3. N. A. Hessol et al. "The natural history of HIV infection in a cohort of homosexual and bisexual men: a decade of follow-up." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
4. A. R. Moss et al, "Seropositivity for HIV and the development of AIDS or AIDS related condition: three year follow-up of the San Francisco General Hospital cohort," British Medical Journal 296 (1988): 745-50.
5. M. E. Eyster et al., "Natural history of human immunodeficiency virus infections in hemophiliacs: effects of T-Cell subsets, platelet counts, and age," Annals of Internal Medicine 107 (1987): 1-6.
6. B. F. Polk et al., "Predictors of the acquired immunodeficiency syndrome developing in a cohort of seropositive homosexual men," New England Journal of Medicine 316 (1987): 61-6.
7. J. Goedert et al., "Three year incidence of AIDS in five cohorts of HTLV-III infected risk group members," Science 231 (1986): 992-5.
8. D. Osmond et al., "Time of exposure and risk of HIV infection in homosexual partners of men with AIDS," American Journal of Public Health 78 (1988): 944-8.
9. R. L. Stoneburner et al., "A larger spectrum of severe HIV-1-related disease in intravenous drug users in New York City," Science 242 (1988): 916-19.
10. P. A. Selwyn et al, "Increased risk of bacterial pneumonia in HIV-infected intravenous drug users without AIDS," AIDS 2 (1988): 267-72.
11. A. R. Kristal, "The impact of the acquired immunodeficiency syndrome on patterns of premature death in New York City," Journal of the American Medical Association 255 (1986): 2306-10.
12. Centers for Disease Control, "Increase in pneumonia mortality among young adults and the HIV epidemic," Morbidity and Mortality Weekly Reports 37 (1988): 593-6.
13. A. R. Moss et al., "Seropositivity for HIV and the development of AIDS or AIDS related condition: three year follow-up of the San Francisco General Hospital cohort," British Medical Journal 296 (1988): 745-50.
14. M.E. Eyster et al, "Natural history of human immunodeficiency virus infections in hemophiliacs: effects of T-Cell subsets, platelet counts, and age," Annals of Internal Medicine 107 (1987): 1-6.
15. B. F. Polk et al., "Predictors of the acquired immunodeficiency syndrome developing in a cohort of seropositive homosexual men," New England Journal of Medicine 316 (1987): 61-6.
16. J. P. Allain et al, "Long-term evaluation of HIV antigen and antibodies to p24 and gp41 in patients with hemophilia," New England Journal of Medicine 317 (1987): 1114-20.

17. W. Lang et al., "Clinical, immunologic, and serologic finding in men at risk for acquired immunodeficiency syndrome: The San Francisco men's health study," Journal of the American Medical Association 257 (1987): 326-30.
18. J. J. Goedert et al., "Effect of T4 count and cofactors on the incidence of AIDS in homosexual men infected with human immunodeficiency virus," Journal of the American Medical Association 257 (1987): 331-4.
19. R. E. Anderson et al., "Beta-2-microglobulin level predict AIDS." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
20. J. Gold et al., "Elevation of serum beta-2-microglobulin associated with decreased CD4 lymphocyte count in HIV infection. Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
21. B. Clotet et al., "T4/T8, T4 and lymphocyte count in patients with antibodies to HIV: a 3 year follow-up study." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
22. P. Lambin et al., "Neopterin and beta 2 microglobulin in sera of HIV seropositive subjects during a two year follow-up." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
23. J. M. A. Lange et al., "Markers for progression to acquired immunodeficiency with zidovudine treatment of asymptomatic subjects," Journal of Infectious Diseases 18 (1989): in press.
24. F. D. Wolf et al., "Effect of zidovudine on serum human immunodeficiency virus antigen levels in symptom-free subjects," Lancet 1 (1988): 373-6.
25. J. M. Lang, et al., "Randomised, double-blind, placebo-controlled trial of ditiocarb sodium ('Imuthiol') in human immunodeficiency virus infection," Lancet 2 (1988): 702-5.
26. A. E. Glatt, "Treatment of infections associated with human immunodeficiency virus," New England Journal of Medicine 318 (1988): 1439-46).
27. M. A. Fischl, G. M. Dickinson, and L. La Voie, "Safety and efficacy of sulfamethoxazole and trimethoprim chemoprophylaxis for pneumocystis carinii pneumonia in AIDS," Journal of the American Medical Association 259 (1988): 1185-9.
28. F. R. Sattler et al., "Trimethoprim-sulfamethoxazole compared with pentamidine for treatment of pneumocystis carinii pneumonia in the acquired immunodeficiency syndrome: A prospective, noncrossover study," Annals of Internal Medicine 109 (1988): 280-7.
29. E. M. Bernard et al., "Prevention of pneumocystis carinii pneumonia with aerosol pentamidine." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
30. G. S. Leoung et al., "Aerosol pentamidine for pneumocystis carinii pneumonia (PCP): A randomized trial of 439 patients." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
31. W. Winkelstein et al., "The San Francisco men's health study: continued decline in HIV seroconversion rates among homosexual/bisexual men," American Journal of Public Health 78 (1988): 1472-4.

32. D. Werdegarr, J. Amory, and G. Rutherford, AIDS in San Francisco: status report for fiscal year 1987-1988 and projections of service needs and costs for 1988-93. San Francisco Department of Public Health, March 15, 1988.
33. T. J. Coates et al., "AIDS antibody testing: Will it stop the AIDS Epidemic? Will it help infected people with HIV?" American Psychologist 43 (1989): 859-64.
34. W. D. Johnson, F. S. Sy, and K. L. Jackson, "The impact of mandatory reporting of HIV seropositive persons in South Carolina." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
35. L. J. Fehrs et al., "Anonymous vs. confidential human immunodeficiency virus (HIV) testing: Results of a trial in Oregon." Presented at the Fourth International Conference on AIDS, Stockholm, June 13-16, 1988.
36. These figures are based on a sensitivity analysis where, for example, AZT is used as a prototypical drug for early intervention costed at one-half to a full dosage level for the Medicaid program in New York State; 6 to 12 physician/clinic visits per year at \$60 to \$66 per visit; 6 to 12 serologic panels (CD4 cell count, Beta-2-Microglobulin and p24 antigen level) per year at \$75-\$109 per panel; and 6 to 12 counseling sessions at \$10 to \$20 per visit. The annual midrange estimate for treatment costs, used for subsequent calculations, is \$7,637 per year.
37. R. L. Stoneburner et al., "A larger spectrum of severe HIV-1-related disease in intravenous drug users in New York City," Science 242 (1988): 916-19.
38. A. A. Scitovsky and D. P. Rice, "Estimates of the direct and indirect costs of acquired immunodeficiency syndrome," Public Health Report 102 (1987): 1-17.
39. K. W. Kizer, J. Rodriguez and G. F. McHolland, An updated quantitative analysis of AIDS in California. California Department of Health Services, April 1987.
40. Health Care Financing Administration, Office of the Actuary, Division of National Cost Estimates, June 1987.

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